

2019-20 Family/Guardian Survey (FGS)

Regional Center Report

Frank D. Lanterman Regional Center



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Quality Assessment Project and National Core Indicators®

This report contains regional center level results from California's statewide National Core Indicators Family/Guardian 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 Family/Guardian Survey findings from Frank D. Lanterman Regional Center (FDLRC) 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 Family/Guardian Survey?

The NCI Family/Guardian Survey is used to gather data on family outcomes. It is mailed to families who have an adult family member who <u>does not live with</u> 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 Family/Guardian Survey (FGS). All NCI averages are weighted.² This report includes this regional center's Family/Guardian Survey data compared to California and NCI averages.

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 Family/Guardian Survey, data analysis and state samples, check out the National Family/Guardian Survey: <u>https://www.nationalcoreindicators.org/resources/reports/#reports-family-survey-final-reports.</u>

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

² NCI averages are comprised of 9,435 valid surveys collected across 11 states: AZ, CA, FL, GA, MD, MN, NH, NC, PA, SD, and UT.

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 began 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. Family Member's Residence

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses, and personal characteristics. Specialized Facility for People With ID includes ICFs, state-run or other institutional settings.

RC v CA v NCI	Specialized Facility for People With ID	Group Home or Agency- Operated Apartment	Independent Home or Apartment	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	Ν
FDLRC	22%	49%	22%	1%	2%	0%	5%	88
CA Average	14%	43%	35%	2%	1%	0%	6%	5,198
Weighted NCI Average	12%	59%	19%	8%	1%	0%	2%	9,233

Table 2. Family Member's Residential Designation

RC v CA v NCI	Urban or Suburban	Rural	N
FDLRC	100%	0%	86
CA Average	94%	6%	5,120
Weighted NCI Average	84%	16%	9,121

Table 3. Family Member's Age

RC v CA v NCI	Average Age	Ν
FDLRC	45.6	88
CA Average	42.8	5,146
Weighted NCI Average	45.4	9,163

Table 4. Family Member's Gender

Standard NCI response options include "Male" and "Female"

RC v CA v NCI	Male	Female	Other	N
FDLRC	69%	31%	0%	90
CA Average	61%	39%	0%	5,269
Weighted NCI Average	60%	40%	n/a	9,353

Table 5. 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	Hawaiian or Pacific Islander	White	Hispanic or Latino	Other
FDLRC	2%	13%	3%	1%	70%	19%	3%
CA Average	2%	8%	7%	1%	76%	12%	3%
Weighted NCI Average	2%	3%	11%	0%	80%	6%	2%

Table 6. 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
FDLRC	62%	31%	36%	14%	5%	5%
CA Average	67%	28%	33%	17%	7%	6%
Weighted NCI Average	75%	36%	28%	16%	8%	6%

Table 7. 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
FDLRC	9%	30%	1%	6%	1%	1%	14%
CA Average	10%	25%	1%	8%	1%	1%	13%
Weighted NCI Average	10%	27%	1%	10%	1%	2%	13%

Table 8. 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
FDLRC	2%	12%	8%	35%	27%
CA Average	8%	18%	6%	29%	28%
Weighted NCI Average	10%	19%	6%	31%	31%

Table 9. 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	Other
FDLRC	8%	2%	4%	27%	8%	24%
CA Average	8%	1%	3%	16%	14%	27%
Weighted NCI Average	11%	2%	5%	16%	14%	23%

Table 10. 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	Ν
FDLRC	74%	17%	1%	2%	6%	84
CA Average	79%	13%	2%	1%	5%	5,179
Weighted NCI Average	77%	16%	2%	2%	4%	9,221

Table 11. Family Member's Preferred Language

CA specific question

RC v CA v NCI	English	Spanish	Mandarin	Tagalog	Vietnamese	Ν
FDLRC	89%	5%	0%	0%	0%	88
CA Average	94%	2%	0%	0%	0%	5,221
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	Korean	Arabic	Armenian	Farsi	Hmong	N
FDLRC	2%	0%	1%	0%	0%	88
CA Average	0%	0%	0%	0%	0%	5,221
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

Table 13. Family Member's Preferred Language (Continued)

CA specific question

RC v CA v NCI	Khmer	Laos	Russian	ASL	Other	N
FDLRC	0%	0%	0%	0%	3%	88
CA Average	0%	0%	0%	1%	3%	5,221
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

Table 14. 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	None	Limited	Full	Has Guardianship but Level Is Unknown	N
FDLRC	31%	69%	n/a	n/a	78
CA Average	45%	55%	n/a	n/a	4,754
Weighted NCI Average	26%	25%	44%	4%	8,649

Table 15. Guardian or Conservator Relationship to Family Member

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	Family	Friend	Regional Center Employee or Guardianship Agency	Other	N
FDLRC	87%	0%	9%	4%	53
CA Average	91%	1%	5%	3%	2,483
Weighted NCI Average	86%	2%	9%	4%	5,449

Table 16. 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
FDLRC	42%	1%	22%	13%	6%	9%	8%	79
CA Average	28%	1%	31%	21%	3%	9%	7%	4,913
Weighted NCI Average	33%	1%	32%	23%	3%	4%	5%	8,722

Table 17. 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. Job is part of the typical labor market (for example, competitive employment).

RC v CA v NCI	Yes	No	N
FDLRC	12%	88%	84
CA Average	16%	84%	4,833
Weighted NCI Average	12%	88%	8,713

Table 18. 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
FDLRC	8%	93%	80
CA Average	14%	86%	4,669
Weighted NCI Average	12%	88%	8,467

Table 19. 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 nondisabled population; this is NOT in a traditional sheltered workshop and NOT enclave.

RC v CA v NCI	Yes	No	N
FDLRC	4%	96%	79
CA Average	9%	91%	4,736
Weighted NCI Average	6%	94%	8,567

Table 20. 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	Ν
FDLRC	17%	83%	77
CA Average	28%	72%	4,554
Weighted NCI Average	27%	73%	8,247

Table 21. 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
FDLRC	5%	95%	80
CA Average	13%	87%	4,700
Weighted NCI Average	21%	79%	8,538

Table 22. 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
FDLRC	24%	76%	75
CA Average	27%	73%	4,542
Weighted NCI Average	33%	67%	8,251

Table 23. Family Member's Activities in the Past Two Weeks Included School

RC v CA v NCI	Yes	No	N
FDLRC	12%	88%	82
CA Average	10%	90%	4,790
Weighted NCI Average	6%	94%	8,627

Table 24. Family Member's Activities in the Past Two Weeks Included Stays at Home

RC v CA v NCI	Yes	No	N
FDLRC	33%	67%	73
CA Average	27%	73%	4,646
Weighted NCI Average	27%	73%	8,376

Table 25. Family Member's Activities in the Past Two Weeks Included Other Activities

RC v CA v NCI	Yes	No	N
FDLRC	31%	69%	26
CA Average	48%	52%	1,726
Weighted NCI Average	42%	58%	2,991

Table 26. 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	None	Some	Extensive	N
FDLRC	39%	30%	30%	89
CA Average	40%	37%	23%	5,127
Weighted NCI Average	33%	39%	28%	9,135

Table 27. 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	None	Some	Extensive	N
FDLRC	27%	32%	41%	90
CA Average	33%	35%	32%	5,180
Weighted NCI Average	24%	37%	39%	9,235

Table 28. 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	None	Some	Extensive	N
FDLRC	2%	30%	68%	90
CA Average	5%	30%	64%	5,165
Weighted NCI Average	3%	21%	76%	9,229

Demographics of Respondents

This section provides demographic information about the respondent.

Table 29. Language Usually Spoken at Home

Standard NCI response options include "English", "Spanish", and "Other"

RC v CA v NCI	English	Spanish	Mandarin	Tagalog	Vietnamese	Ν
FDLRC	84%	4%	0%	0%	1%	90
CA Average	93%	3%	1%	0%	0%	5,212
Weighted NCI Average	97%	1%	n/a	n/a	n/a	9,284

Table 30. 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
FDLRC	2%	1%	3%	0%	0%	90
CA Average	0%	0%	0%	0%	0%	5,212
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	9,284

Table 31. 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
FDLRC	0%	0%	0%	0%	3%	90
CA Average	0%	0%	0%	0%	3%	5,212
Weighted NCI Average	n/a	n/a	n/a	n/a	1%	9,284

Table 32. Respondent's Age

RC v CA v NCI	Under 35	35-54	55-74	75 and Older	Ν
FDLRC	0%	6%	52%	43%	89
CA Average	1%	8%	59%	32%	5,214
Weighted NCI Average	2%	13%	62%	24%	9,270

Table 33. Respondent's Health

RC v CA v NCI	Excellent	Very Good	Fairly Good	Poor	Ν
FDLRC	16%	46%	29%	9%	89
CA Average	18%	44%	32%	6%	5,213
Weighted NCI Average	18%	46%	32%	5%	9,280

Table 34. Respondent's Relationship to Family Member

RC v CA v NCI	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	Ν
FDLRC	85%	10%	0%	0%	0%	1%	3%	89
CA Average	89%	7%	0%	0%	0%	0%	4%	5,218
Weighted NCI Average	66%	19%	0%	1%	3%	3%	7%	9,280

Table 35. Respondent's Frequency of Visits With Family Member in the Past Year

RC v CA v NCI	Did Not Visit	1 - 3 Times	4 - 6 Times	7 - 12 Times	More Than 12 Times	N
FDLRC	3%	9%	6%	12%	70%	89
CA Average	5%	9%	8%	10%	68%	5,194
Weighted NCI Average	3%	9%	11%	12%	65%	9,242

Table 36. 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	Ν
FDLRC	9%	10%	3%	27%	50%	88
CA Average	4%	12%	4%	26%	53%	5,180
Weighted NCI Average	4%	17%	7%	23%	50%	9,218

Table 37. 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
FDLRC	12%	7%	5%	13%	11%	17%	35%	75
CA Average	10%	5%	6%	14%	11%	24%	29%	4,588
Weighted NCI Average	9%	6%	7%	16%	13%	21%	28%	8,234

Table 38. 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
FDLRC	48%	5%	27%	13%	7%	83
CA Average	49%	7%	21%	19%	4%	4,991
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

Table 39. 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
FDLRC	3%	11%	3%	6%	14%	44%
CA Average	4%	4%	1%	9%	4%	41%
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 (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
FDLRC	0%	6%	58%	0%	39%	31%
CA Average	1%	5%	59%	1%	34%	27%
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

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 41. 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	In-home Support	Residential Support	Day or Employment Supports	Transportation	Other	Self-direction or Fiscal Intermediary Services
FDLRC	41%	42%	80%	49%	59%	49%	22%
CA Average	36%	44%	79%	67%	67%	41%	21%
Weighted NCI Average	32%	45%	88%	69%	86%	54%	26%

Table 42. Additional Services and Supports Received

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
FDLRC	92%	32%
CA Average	91%	30%
Weighted NCI Average	95%	29%

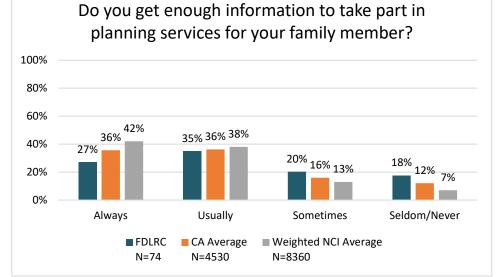
⁴ Some NCI states provide services through a statewide ID/DD agency

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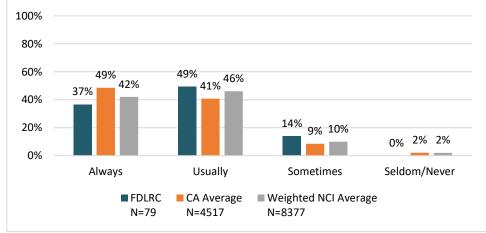
Information and Planning Charts

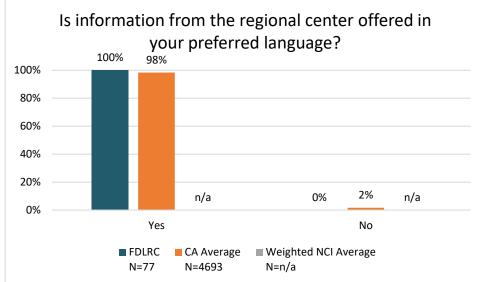
Families and family members with disabilities have the information and support necessary to plan for their services and supports.

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

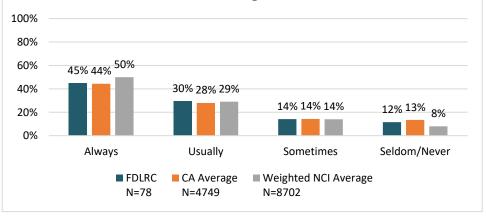


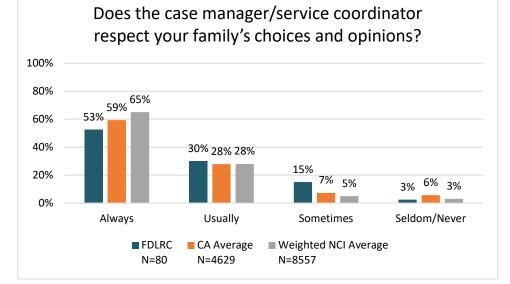
Is the information you get about services and supports easy to understand?



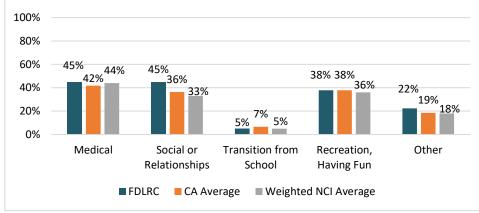


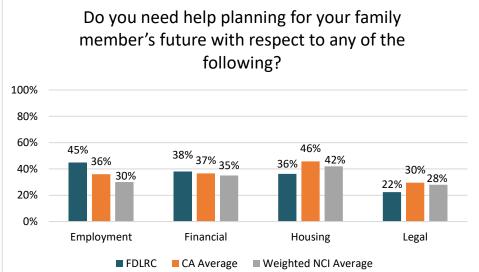
Do staff or the residential agency keep you informed about how your family member is doing?



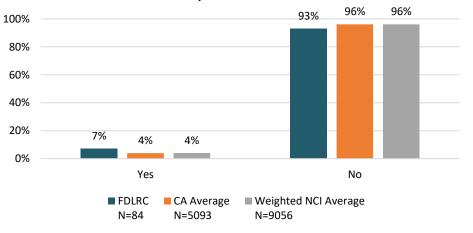


Do you need help planning for your family member's future with respect to any of the following?



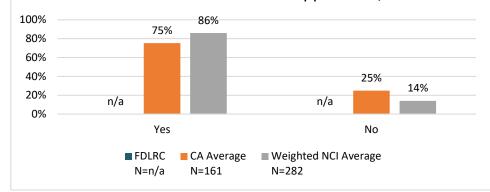


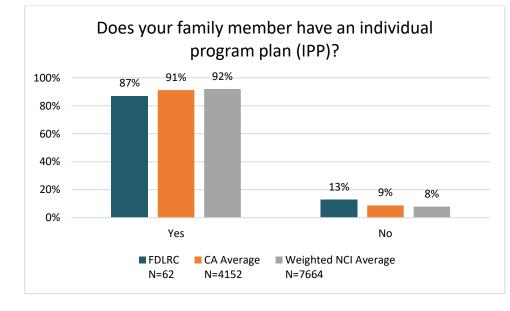
In the past year, did your family member move out of the family home for the first time?



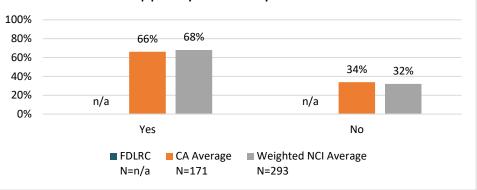
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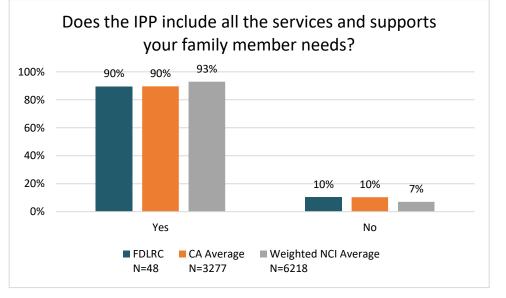
If your family member moved out of the family home for the first time in the past year, did your family member receive enough information about services available to support him/her?

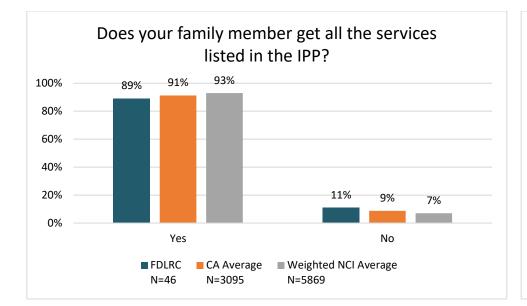


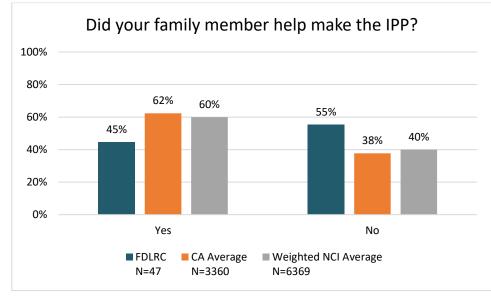


If your family member moved out of the family home for the first time in the past year, did you have enough choices of service providers to support your family member?

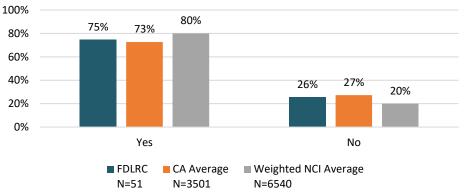




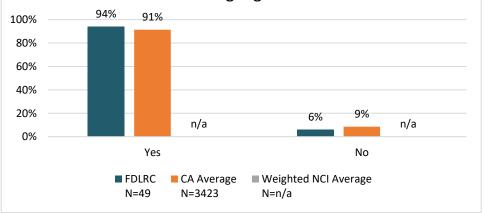




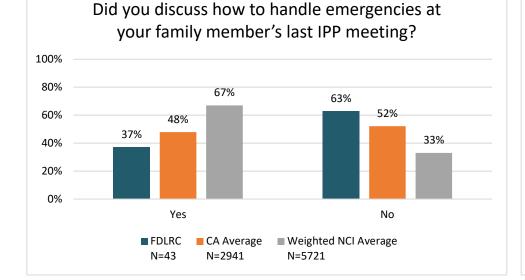
Did you or someone else in your family (besides your family member with a disability) help make the IPP?



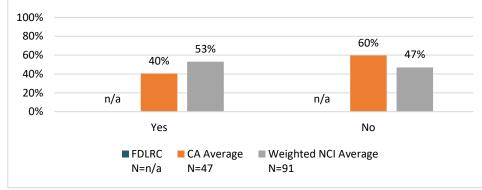
Did you or your family member get a copy of the IPP in your or your family member's preferred language?

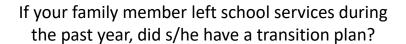


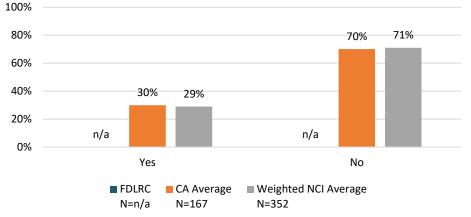
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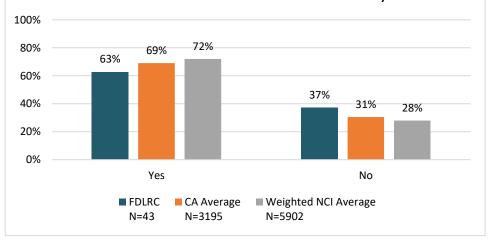
If your family member left school services during the past year and had a transition plan, did the plan include getting or continuing work in a community job?

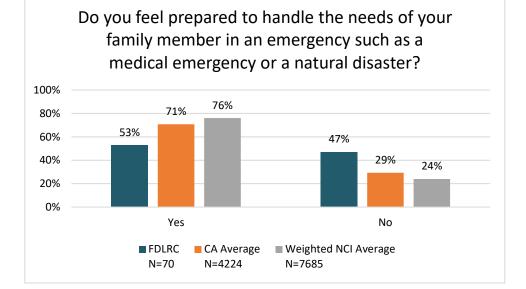






Does your family member have enough supports to work or volunteer in the community?





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	Ν
FDLRC	27%	35%	20%	18%	74
CA Average	36%	36%	16%	12%	4,530
Weighted NCI Average	42%	38%	13%	7%	8,360

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

CA specific question

RC v CA v NCI	Yes	No	Ν
FDLRC	100%	0%	77
CA Average	98%	2%	4,693
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
FDLRC	37%	49%	14%	0%	79
CA Average	49%	41%	9%	2%	4,517
Weighted NCI Average	42%	46%	10%	2%	8,377

Table Q4. Do staff or the residential agency keep you informed about how your family member is doing?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
FDLRC	45%	30%	14%	12%	78
CA Average	44%	28%	14%	13%	4,749
Weighted NCI Average	50%	29%	14%	8%	8,702

Table Q5. Does the case manager/service coordinator respect your family's choices and opinions?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	Ν
FDLRC	53%	30%	15%	3%	80
CA Average	59%	28%	7%	6%	4,629
Weighted NCI Average	65%	28%	5%	3%	8,557

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

Future planning needs…	FDLRC	CA Average	Weighted NCI Average
Employment	45%	36%	30%
Financial	38%	37%	35%
Housing	36%	46%	42%
Legal	22%	30%	28%
Medical	45%	42%	44%
Social or Relationships	45%	36%	33%
Transition from School	5%	7%	5%
Recreation, Having Fun	38%	38%	36%
Other	22%	19%	18%

Table Q7. In the past year, did your family member move out of the family home for the first time?

RC v CA v NCI	Yes	No	Ν
FDLRC	7%	93%	84
CA Average	4%	96%	5,093
Weighted NCI Average	4%	96%	9,056

Table Q8. If your family member moved out of the family home for the first time in the past year, did your family member receive enough information about services available to support him/her?

RC v CA v NCI	Yes	No	Ν
FDLRC	n/a	n/a	n/a
CA Average	75%	25%	161
Weighted NCI Average	86%	14%	282

Table Q9. If your family member moved out of the family home for the first time in the past year, did you have enough choices of service providers to support your family member?

RC v CA v NCI	Yes	No	N
FDLRC	n/a	n/a	n/a
CA Average	66%	34%	171
Weighted NCI Average	68%	32%	293

Table Q10. Does your family member have an individual program plan (IPP)?

RC v CA v NCI	Yes	No	Ν
FDLRC	87%	13%	62
CA Average	91%	9%	4,152
Weighted NCI Average	92%	8%	7,664

Table Q11. Does the IPP include all the services and supports your family member needs?

RC v CA v NCI	Yes	No	Ν
FDLRC	90%	10%	48
CA Average	90%	10%	3,277
Weighted NCI Average	93%	7%	6,218

Table Q12. Does your family member get all the services listed in the IPP?

RC v CA v NCI	Yes	No	Ν
FDLRC	89%	11%	46
CA Average	91%	9%	3,095
Weighted NCI Average	93%	7%	5,869

Table Q13. 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	Ν
FDLRC	75%	26%	51
CA Average	73%	27%	3,501
Weighted NCI Average	80%	20%	6,540

Table Q14. Did your family member help make the IPP?

RC v CA v NCI	Yes	No	Ν
FDLRC	45%	55%	47
CA Average	62%	38%	3,360
Weighted NCI Average	60%	40%	6,369

Table Q15. 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	Ν
FDLRC	94%	6%	49
CA Average	91%	9%	3,423
Weighted NCI Average	n/a	n/a	n/a

Table Q16. 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	Ν
FDLRC	37%	63%	43
CA Average	48%	52%	2,941
Weighted NCI Average	67%	33%	5,721

Table Q17. 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
FDLRC	n/a	n/a	n/a
CA Average	30%	70%	167
Weighted NCI Average	29%	71%	352

Table Q18. If your family member left school services during the past year and had a transition plan, did the plan include getting or continuing work in a community job?

RC v CA v NCI	Yes	No	N
FDLRC	n/a	n/a	n/a
CA Average	40%	60%	47
Weighted NCI Average	53%	47%	91

Table Q19. 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	Ν
FDLRC	63%	37%	43
CA Average	69%	31%	3,195
Weighted NCI Average	72%	28%	5,902

Table Q20. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

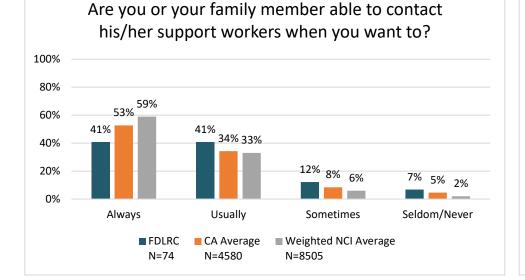
Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Yes	No	Ν
FDLRC	53%	47%	70
CA Average	71%	29%	4,224
Weighted NCI Average	76%	24%	7,685

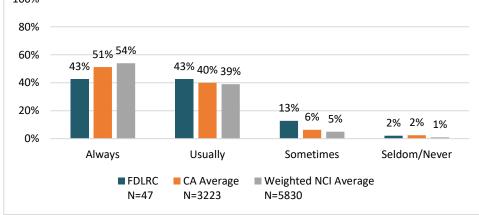
Access and Delivery of Services and Supports Charts

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

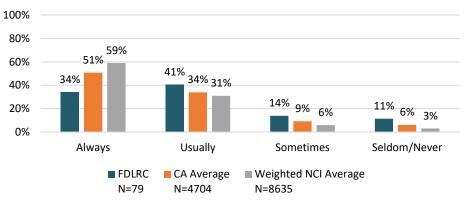
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.

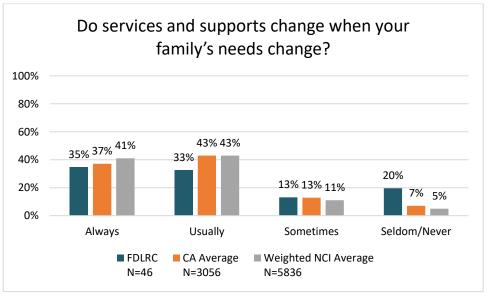


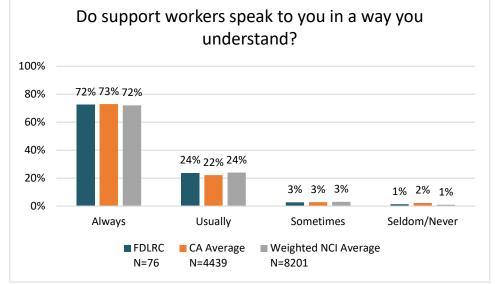
Do support workers come and go when they are supposed to?

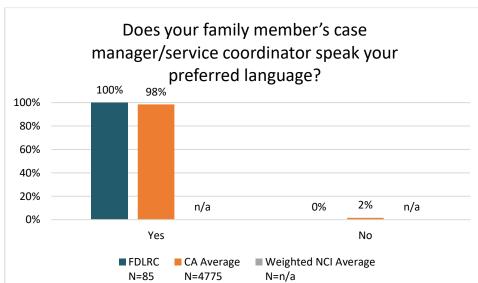


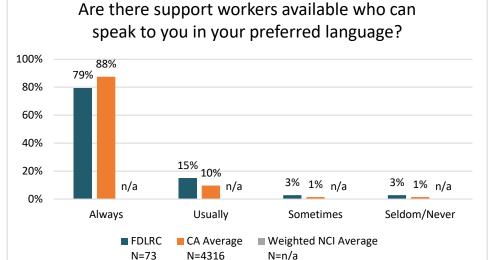
Are you or your family member able to contact his/her case manager/service coordinator when you want to?



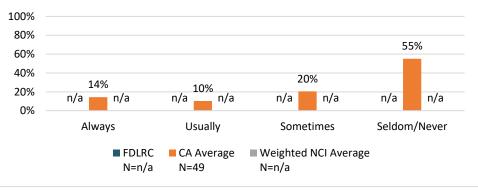




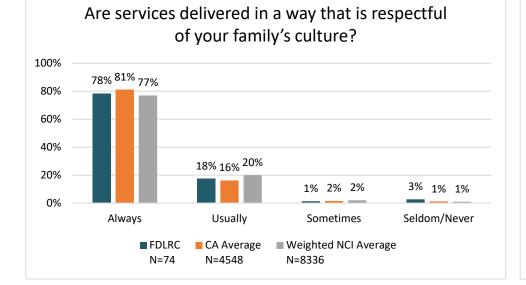




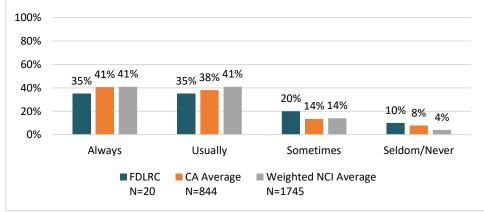
If your case manager/service coordinator does not speak your preferred language, is a translator provided when you speak with the case manager/service coordinator?



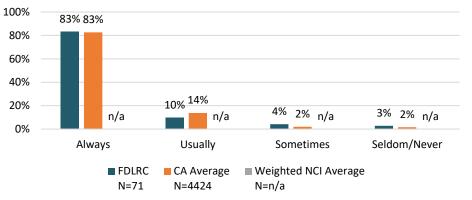
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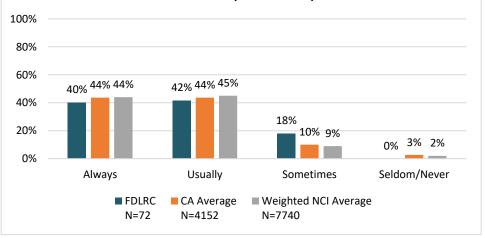
If your family member does not communicate verbally, are there support workers who can communicate with him/her?



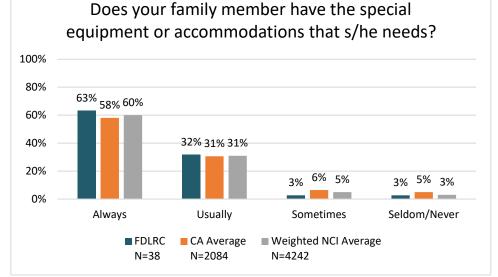
Does your family member's case manager/service coordinator support you in a way that is respectful of your culture?



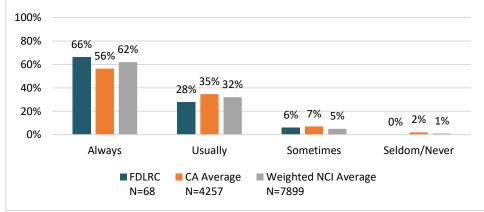
Do support workers have the right information and skills to meet your family's needs?

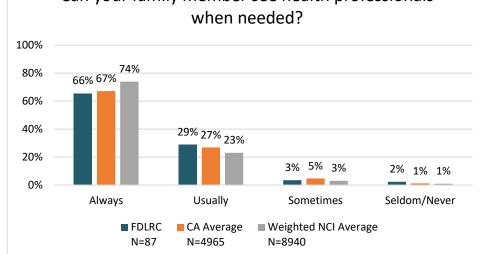


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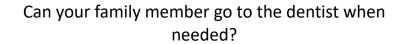


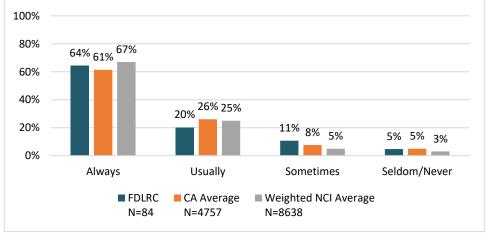
Does your family member's primary care doctor understand your family member's needs related to his/her disability?

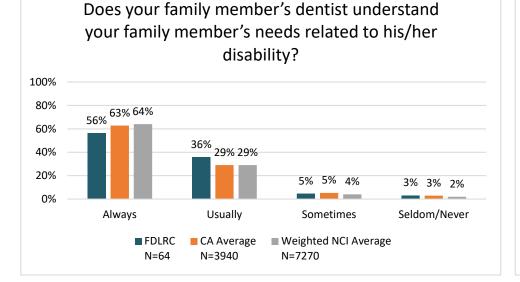




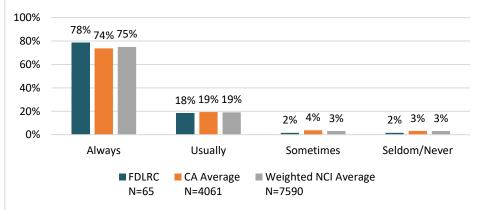
Can your family member see health professionals

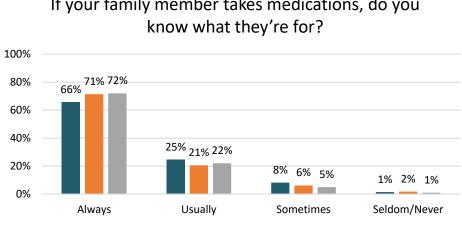






Do you, your family member, or someone else in your family know what is needed to safely take the medications?





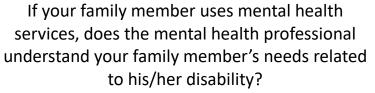
CA Average

N=4353

FDLRC

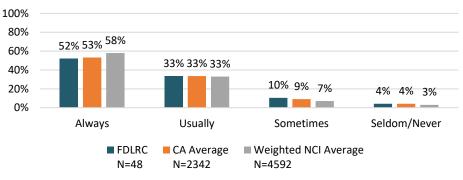
N=73

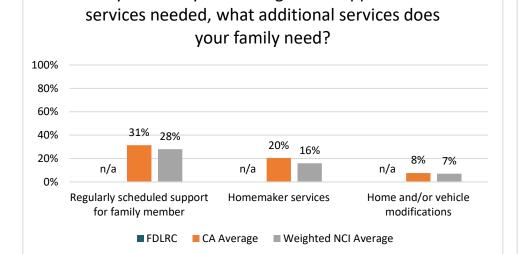
If your family member takes medications, do you



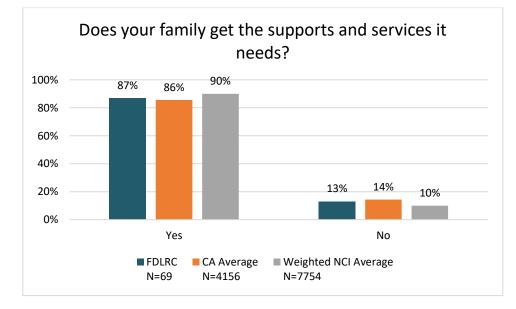
Weighted NCI Average

N=8098

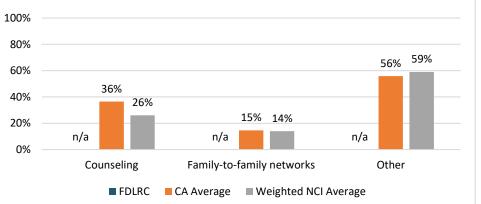




If your family does not get the support and



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



Access and Delivery of Services and Supports Tables

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

Table Q21. Are you or your family member able to contact his/her support workers when you want to?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	Ν
FDLRC	41%	41%	12%	7%	74
CA Average	53%	34%	8%	5%	4,580
Weighted NCI Average	59%	33%	6%	2%	8,505

Table Q22. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	Ν
FDLRC	34%	41%	14%	11%	79
CA Average	51%	34%	9%	6%	4,704
Weighted NCI Average	59%	31%	6%	3%	8,635

Table Q23. 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	Ν
FDLRC	43%	43%	13%	2%	47
CA Average	51%	40%	6%	2%	3,223
Weighted NCI Average	54%	39%	5%	1%	5,830

Table Q24. 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	Ν
FDLRC	35%	33%	13%	20%	46
CA Average	37%	43%	13%	7%	3,056
Weighted NCI Average	41%	43%	11%	5%	5,836

Table Q25. Do support workers speak to you in a way you understand?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	Ν
FDLRC	72%	24%	3%	1%	76
CA Average	73%	22%	3%	2%	4,439
Weighted NCI Average	72%	24%	3%	1%	8,201

Table Q26. 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	Ν
FDLRC	79%	15%	3%	3%	73
CA Average	88%	10%	1%	1%	4,316
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a

Table Q27. Does your family member's case manager/service coordinator speak your preferred language?

CA specific question

RC v CA v NCI	Yes	No	Ν
FDLRC	100%	0%	85
CA Average	98%	2%	4,775
Weighted NCI Average	n/a	n/a	n/a

Table Q28. If your case manager/service coordinator does not speak 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	Ν
FDLRC	n/a	n/a	n/a	n/a	n/a
CA Average	14%	10%	20%	55%	49
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a

Table Q29. Are services delivered in a way that is respectful of your family's culture?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	Ν
FDLRC	78%	18%	1%	3%	74
CA Average	81%	16%	2%	1%	4,548
Weighted NCI Average	77%	20%	2%	1%	8,336

Table Q30. Does your family member's case manager/service coordinator support you in a way that is respectful of your culture?

CA specific question

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
FDLRC	83%	10%	4%	3%	71
CA Average	83%	14%	2%	2%	4,424
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a

Table Q31. 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	Ν
FDLRC	35%	35%	20%	10%	20
CA Average	41%	38%	14%	8%	844
Weighted NCI Average	41%	41%	14%	4%	1,745

Table Q32. 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	Ν
FDLRC	40%	42%	18%	0%	72
CA Average	44%	44%	10%	3%	4,152
Weighted NCI Average	44%	45%	9%	2%	7,740

Table Q33. Does your family member have the special equipment or accommodations that s/he needs?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	Ν
FDLRC	63%	32%	3%	3%	38
CA Average	58%	31%	6%	5%	2,084
Weighted NCI Average	60%	31%	5%	3%	4,242

Table Q34. 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	Ν
FDLRC	66%	29%	3%	2%	87
CA Average	67%	27%	5%	1%	4,965
Weighted NCI Average	74%	23%	3%	1%	8,940

Table Q35. Does your family member's primary care doctor understand your family member's needs related to his/her disability?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
FDLRC	66%	28%	6%	0%	68
CA Average	56%	35%	7%	2%	4,257
Weighted NCI Average	62%	32%	5%	1%	7,899

Table Q36. 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	Ν
FDLRC	64%	20%	11%	5%	84
CA Average	61%	26%	8%	5%	4,757
Weighted NCI Average	67%	25%	5%	3%	8,638

Table Q37. 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	Ν
FDLRC	56%	36%	5%	3%	64
CA Average	63%	29%	5%	3%	3,940
Weighted NCI Average	64%	29%	4%	2%	7,270

Table Q38. If your family member takes medications, do you know what they're for?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	Ν
FDLRC	66%	25%	8%	1%	73
CA Average	71%	21%	6%	2%	4,353
Weighted NCI Average	72%	22%	5%	1%	8,098

Table Q39. 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
FDLRC	78%	18%	2%	2%	65
CA Average	74%	19%	4%	3%	4,061
Weighted NCI Average	75%	19%	3%	3%	7,590

Table Q40. 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	Ν
FDLRC	52%	33%	10%	4%	48
CA Average	53%	33%	9%	4%	2,342
Weighted NCI Average	58%	33%	7%	3%	4,592

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	Ν
FDLRC	87%	13%	69
CA Average	86%	14%	4,156
Weighted NCI Average	90%	10%	7,754

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

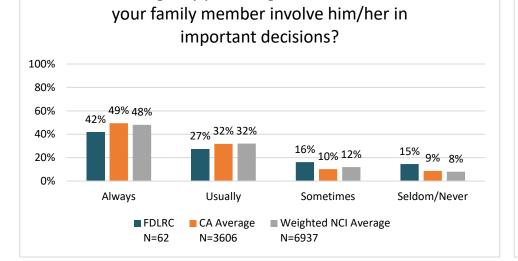
Categories are not mutually exclusive; therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

Additional Services Needed	FDLRC	CA Average	Weighted NCI Average
Regularly scheduled support for family member	n/a	31%	28%
Homemaker service	n/a	20%	16%
Home or vehicle modifications	n/a	8%	7%
Counseling	n/a	36%	26%
Family-to-Family networks	n/a	15%	14%
Other	n/a	56%	59%

Choice, Decision Making and Control Charts

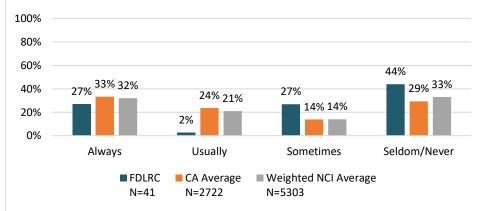
Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.

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

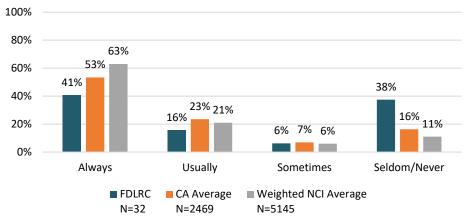


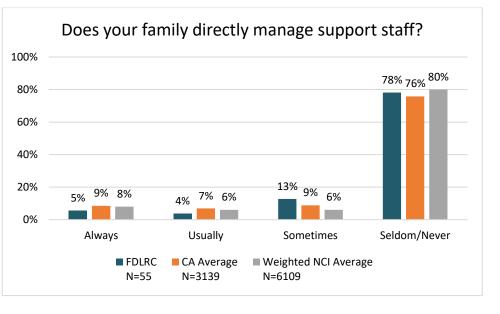
Does the agency providing residential services to

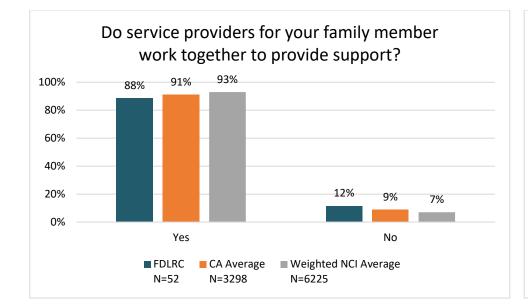
Can your family choose or change the individual staff that provide the services for your family member?

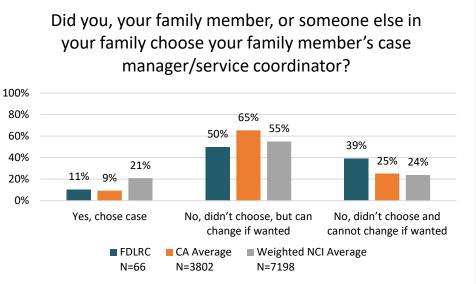


Can your family choose or change the agency that provides your family member's services?









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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. Does the agency providing residential services to your family member involve him/her in important decisions?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	Ν
FDLRC	42%	27%	16%	15%	62
CA Average	49%	32%	10%	9%	3,606
Weighted NCI Average	48%	32%	12%	8%	6,937

Table Q44. 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	Ν
FDLRC	41%	16%	6%	38%	32
CA Average	53%	23%	7%	16%	2,469
Weighted NCI Average	63%	21%	6%	11%	5,145

Table Q45. Can your family choose or change the individual staff that provide the services for your family member?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
FDLRC	27%	2%	27%	44%	41
CA Average	33%	24%	14%	29%	2,722
Weighted NCI Average	32%	21%	14%	33%	5,303

Table Q46. Does your family directly manage support staff?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	Ν
FDLRC	5%	4%	13%	78%	55
CA Average	9%	7%	9%	76%	3,139
Weighted NCI Average	8%	6%	6%	80%	6,109

Table Q47. 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	Ν
FDLRC	88%	12%	52
CA Average	91%	9%	3,298
Weighted NCI Average	93%	7%	6,225

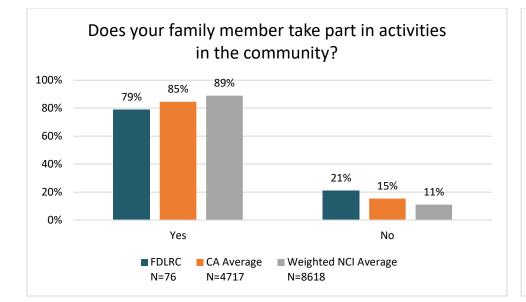
Table Q48. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?	FDLRC	CA Average	Weighted NCI Average
Yes, chose	11%	9%	21%
No, didn't choose, but can change if wanted	50%	65%	55%
No, didn't choose and cannot change if wanted	39%	25%	24%
Ν	66	3,802	7,198

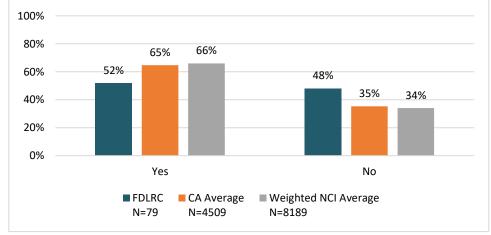
Involvement in the Community Charts

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

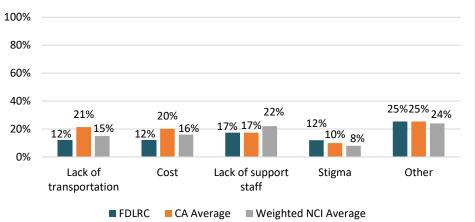
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.



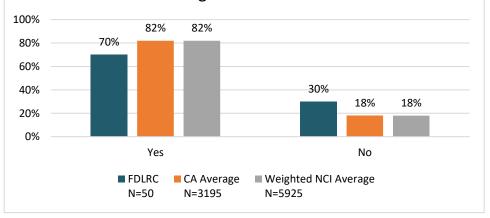
Does your family member have friends other than paid support workers or family?



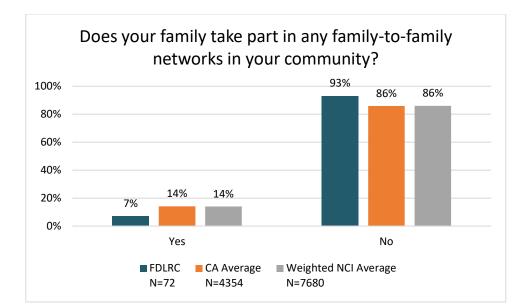
For your family member, what makes it hard to take part in activities in the community?



In your community, are there resources that your family can use that are not provided by the regional center?



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Involvement in the Community Tables

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

Table Q49. 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
FDLRC	79%	21%	76
CA Average	85%	15%	4,717
Weighted NCI Average	89%	11%	8,618

Table Q50. 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.

RC v CA v NCI	Lack of transportation	Cost	Lack of support staff	Stigma	Other
FDLRC	12%	12%	17%	12%	25%
CA Average	21%	20%	17%	10%	25%
Weighted NCI Average	15%	16%	22%	8%	24%

Table Q51. Does your family member have friends other than paid support workers or family?

RC v CA v NCI	Yes	Νο	Ν
FDLRC	52%	48%	79
CA Average	65%	35%	4,509
Weighted NCI Average	66%	34%	8,189

Table Q52. In your community, are there resources that your family can use that are not provided by the regional center⁵ (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
FDLRC	70%	30%	50
CA Average	82%	18%	3,195
Weighted NCI Average	82%	18%	5,925

Table Q53. 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.

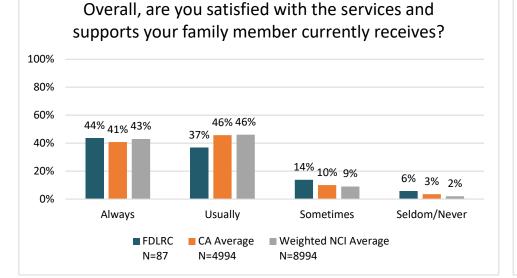
RC v CA v NCI	Yes	No	Ν
FDLRC	7%	93%	72
CA Average	14%	86%	4,354
Weighted NCI Average	14%	86%	7,680

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

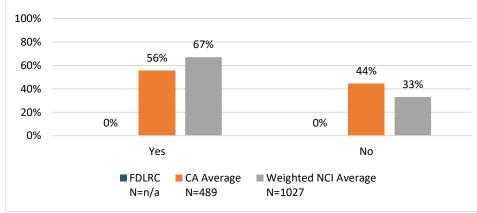
Satisfaction With Services and Supports Charts

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

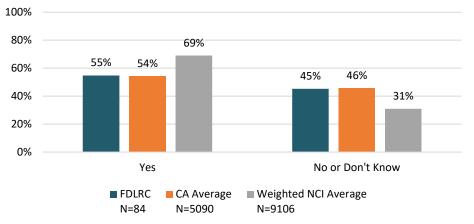
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.



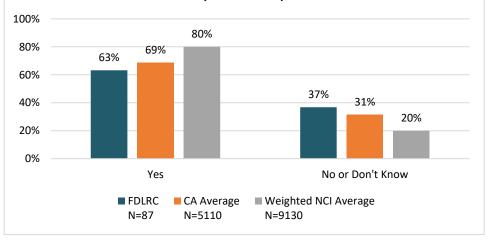
If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?

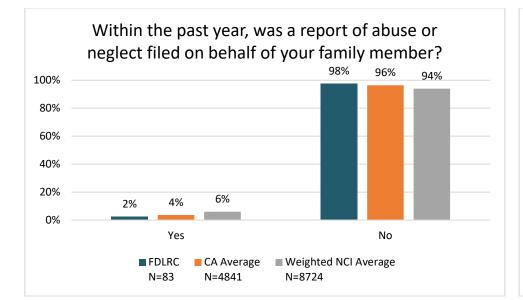


Do you know how to file a complaint or grievance about provider agencies or staff?

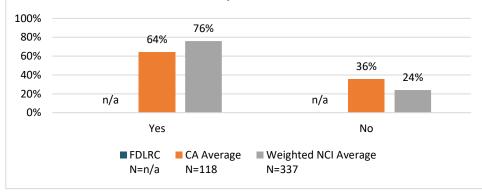


Do you know how to report abuse or neglect related to your family member?

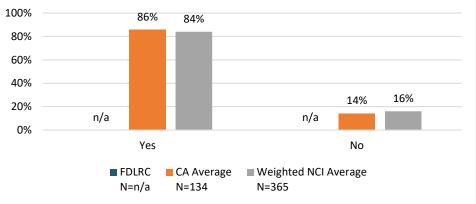




If someone outside of your family reported abuse or neglect on behalf of your family member in the past year, were you notified of the report in a timely manner?



If a report of abuse or neglect was filed on behalf of your family member in the past year, did the appropriate people respond to the report?



Do you feel that services and supports have made a positive difference in the life of your family member? 96% 95% 93% 100% 80% 60% 40% 20%

Yes

CA Average

N=4693

FDLRC

N=76

0%

7%

Weighted NCI Average

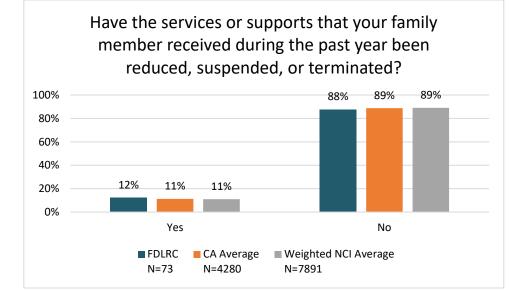
N=8500

5%

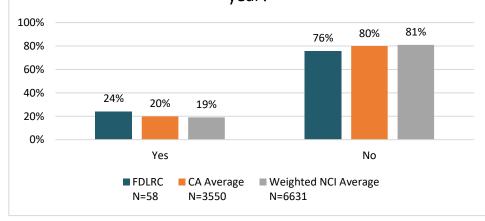
No

4%

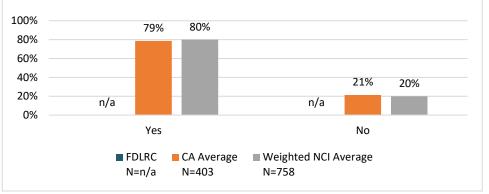


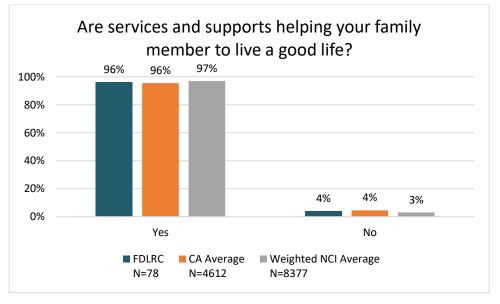


Have the services or supports that your family member received been increased in the past year?

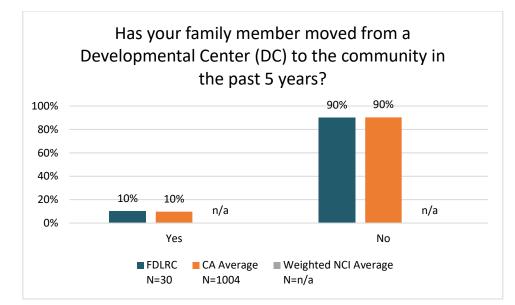


If services or supports were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?

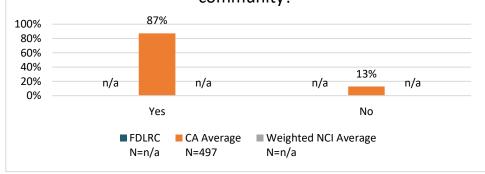


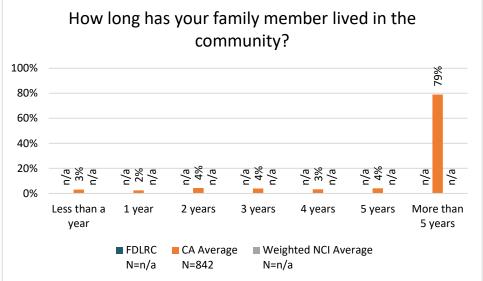


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Are the services that were decided upon in the Individual Development Team (IDT) meeting (community transition planning meeting) being delivered to your family member in the community?





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Satisfaction With Services and Supports Tables

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

Table Q54. 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	Ν
FDLRC	44%	37%	14%	6%	87
CA Average	41%	46%	10%	3%	4,994
Weighted NCI Average	43%	46%	9%	2%	8,994

Table Q55. Do you know how to file a complaint or grievance about provider agencies or staff?⁶

RC v CA v NCI	Yes	No or Don't Know	Ν
FDLRC	55%	45%	84
CA Average	54%	46%	5,090
Weighted NCI Average	69%	31%	9,106

Table Q56. 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	Ν
FDLRC	n/a	n/a	n/a
CA Average	56%	44%	489
Weighted NCI Average	67%	33%	1,027

Table Q57. Do you know how to report abuse or neglect related to your family member?⁷

RC v CA v NCI	Yes	No or Don't Know	Ν
FDLRC	63%	37%	87
CA Average	69%	31%	5,110
Weighted NCI Average	80%	20%	9,130

⁶ Don't Know' responses were included in 'No' responses for this question.

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

Table Q58. Within the past year, was a report of abuse or neglect filed on behalf	of your family member?
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RC v CA v NCI	Yes	No	Ν
FDLRC	2%	98%	83
CA Average	4%	96%	4,841
Weighted NCI Average	6%	94%	8,724

Table Q59. If a report of abuse or neglect was filed on behalf of your family member in the past year, did the appropriate people respond to the report?

RC v CA v NCI	Yes	No	Ν
FDLRC	n/a	n/a	n/a
CA Average	86%	14%	134
Weighted NCI Average	84%	16%	365

Table Q60. If someone outside of your family reported abuse or neglect on behalf of your family member in the past year, were you notified of the report in a timely manner?

RC v CA v NCI	Yes	No	Ν
FDLRC	n/a	n/a	n/a
CA Average	64%	36%	118
Weighted NCI Average	76%	24%	337

Table Q61. 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	Ν
FDLRC	93%	7%	76
CA Average	95%	5%	4,693
Weighted NCI Average	96%	4%	8,500

Table Q62. 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
FDLRC	12%	88%	73
CA Average	11%	89%	4,280
Weighted NCI Average	11%	89%	7,891

Table Q63. If services or supports 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	Ν
FDLRC	n/a	n/a	n/a
CA Average	79%	21%	403
Weighted NCI Average	80%	20%	758

Table Q64. 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	Ν
FDLRC	24%	76%	58
CA Average	20%	80%	3,550
Weighted NCI Average	19%	81%	6,631

Table Q65. 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	Ν
FDLRC	96%	4%	78
CA Average	96%	4%	4,612
Weighted NCI Average	97%	3%	8,377

Table Q66. Has your family member moved from a Developmental Center (DC) to the community in the past 5 years?

CA specific question

RC v CA v NCI	Yes	No	Ν
FDLRC	10%	90%	30
CA Average	10%	90%	1,004
Weighted NCI Average	n/a	n/a	n/a

Table Q67. 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	Ν
FDLRC	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
CA Average	3%	2%	4%	4%	3%	4%	79%	842
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a

Table Q68. Are the services that were decided upon in the Individual Development Team (IDT) meeting (community transition planning meeting) being delivered to your family member in the community?

CA specific question

RC v CA v NCI	Yes	No	N
FDLRC	n/a	n/a	n/a
CA Average	87%	13%	497
Weighted NCI Average	n/a	n/a	n/a