Child Family Survey

2015-16 Final Report

A Collaboration of

The National Association of State Directors of Developmental Disabilities Services
and
Human Services Research Institute

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List of Abbreviations Used in This Report

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

Table of Contents

Child Family Survey Highlights **1**
I. Results **5**
Survey Development **6**
Organization of the Child Family Survey 6

Important Notes on Analysis **8**
California 8
Texas 8

Demographics **9**
Child 10
Table 1. More Than One Child Living in the Home Has ID/DD 10
Table 1. Child's Age 10
Table 2. Child's Gender 10
Table 6. Child's Race and Ethnicity 11
Table 4. Child's Disabilities 12
Table 5. Child's Health Conditions 13
Table 7. Child's Preferred Means of Communication 14
Table 8. Child's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors 14
Table 9. Child's Level of Help Needed With Personal Care Activities 14
Respondents 15
Table 11. Respondent's Age 16
Table 12. Respondent's Health 16
Table 13. Respondent's Relationship to Child 16
Table 14. Respondent or Other Family Member Provides Paid Support to Child 17
Table 15. Number of Adults in Household 17
Table 16. Number of Children in Household 17
Table 17. Respondent's Highest Level of Education 18
Table 18. Total Taxable Household Income of Wage Earners in the Past Year 18
Table 19. Residential Designation (Urban/Suburban or Rural) 18

Services and Supports Received 19
Table 19. Services and Supports Received From ID/DD Agency 20
Table 20. Other Services or Supports Received 20

Child Family Survey Results 21
Information and Planning 22
Table Q1. Do you get enough information to help you participate in planning services for your family? 23
Table Q2. Is the information you receive easy to understand? 24
Table Q3. Does the case manager/service coordinator respect your family's choices and opinions? 25
Table Q4. Do you get enough information about other public services for which your family is eligible? 26
Table Q5. Do you need help planning for your child's future with respect to any of the following? 27
Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed? 28
Table Q7. Does your child have a service plan? 29
Table Q8. Does the plan include all the services and supports your child needs? 30
Table Q9. Does your child receive all of the services listed in the plan? 31
Table Q10. Did you or another family member help develop the plan? 32
Table Q11. Did your child help develop the plan? 33
Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your child's last service planning meeting? 34
Table Q13. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster? 35
Table Q14. Does your child have a transition plan (as part of an IEP or Section 504 plan through his/her high school, usually starting at age 14)? 36
Table Q15. If yes to Q14, did you help make the transition plan? 37
Access and Delivery of Services and Supports 38
Table Q16. Are you or your child able to contact his/her support workers when you want to? 39
Table Q17. Are you or your child able to contact his/her case manager or service coordinator when you want to? 40
Table Q18. Do support workers come and leave when they are supposed to? 41
Table Q19. Do services and supports change when your family's needs change? 42
Table Q20. Do support workers speak to you in a way that you understand? 43
Table Q21. Are services delivered in a way that is respectful of your family's culture? 44

Table Q22. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her? 45

Table Q23. Do support workers have the right information and skills to meet your family's needs? 46

Table Q24. Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)? 47

Table Q25. Can your child see health professionals when needed (for example, doctor, dentist, psychologist)? 48

Table Q26. Does your child's primary care doctor understand your child's needs related to his/her disability? 49

Table Q27. Do you have access to dental services for your child? 50

Table Q28. If yes to Q27, does your child's dentist understand your child's needs related to his/her disability? 51

Table Q29. If your child takes medications, do you know what they're for? 52

Table Q30. If your child takes medications, do you, your child, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)? 53

Table Q31. If your child uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your child's needs related to his/her disability? 54

Table Q32. If you need respite services, do you have access to them? 55

Table Q33. If Yes to Q32, are you satisfied with the quality of the respite services? 56

Table Q34. Does your family get the support needed? 57

Table Q35. If no to Q34, what additional services are needed? 58

Choice, Decision Making and Control 59

Table Q36. Can your family choose or change the agency that provides your child's services? 60

Table Q37. Can your family choose or change your child's support workers? 61

Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)? .. 62

Table Q39. Do service providers for your child work together to provide support? 63

Table Q40. Did you, your child, or someone else in your family choose your child's case manager/service coordinator? 64

Involvement in the Community 65

Table Q41. Does your child take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)? 66

Table Q42. If no to Q41, why did the child not take part in community activities? 67

Table Q43. Does your child spend time with children who do not have developmental disabilities? 68

Table Q44. In your community, are there resources that your family can use that are not provided by the I/DD agency? 69

Table Q45. Does your family take part in any family-to-family networks in your community? 70

Satisfaction With Services and Supports 71
Table Q46. Overall, are you satisfied with the services and supports your family currently receives? 72

Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff? 73

Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved? 74

Table Q49. Do you know how to report abuse or neglect related to your child? 75

Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child? 76

Table Q51. If yes to Q50, did the appropriate people respond to the report? 77

Table Q52. If Yes to Q50, if someone other than you reported abuse or neglect in the past year, were you notified of the report in a timely manner? 78

Family Outcomes 79
Table Q53. Do you feel that services and supports have made a positive difference in the life of your family? 80

Table Q54. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your child's care? 81

Table Q55. Do you feel that family supports have improved your ability to care for your child? 82

Table Q56. Have the services or supports that you or your child received during the past year been reduced, suspended, or terminated? 83

Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your child negatively? 84

Table Q58. Have the services or supports that your child received been increased in the past year? 85

Table Q59. Are services and supports helping your child to live a good life? 86

II. NCI History and Activities 87

Overview of National Core Indicators 88

State Participation 89
Figure 1. NCI State Participation 89

The Core Indicators 89
Sub-Domains and Concern Statements 90

Figure 2. Family Survey Sub-Domains and Concern Statements 90

How NCI Data Are Used 91
Caution and Limitations 91

III. Methodology 93

Sampling & Administration **94**
TEXAS 94

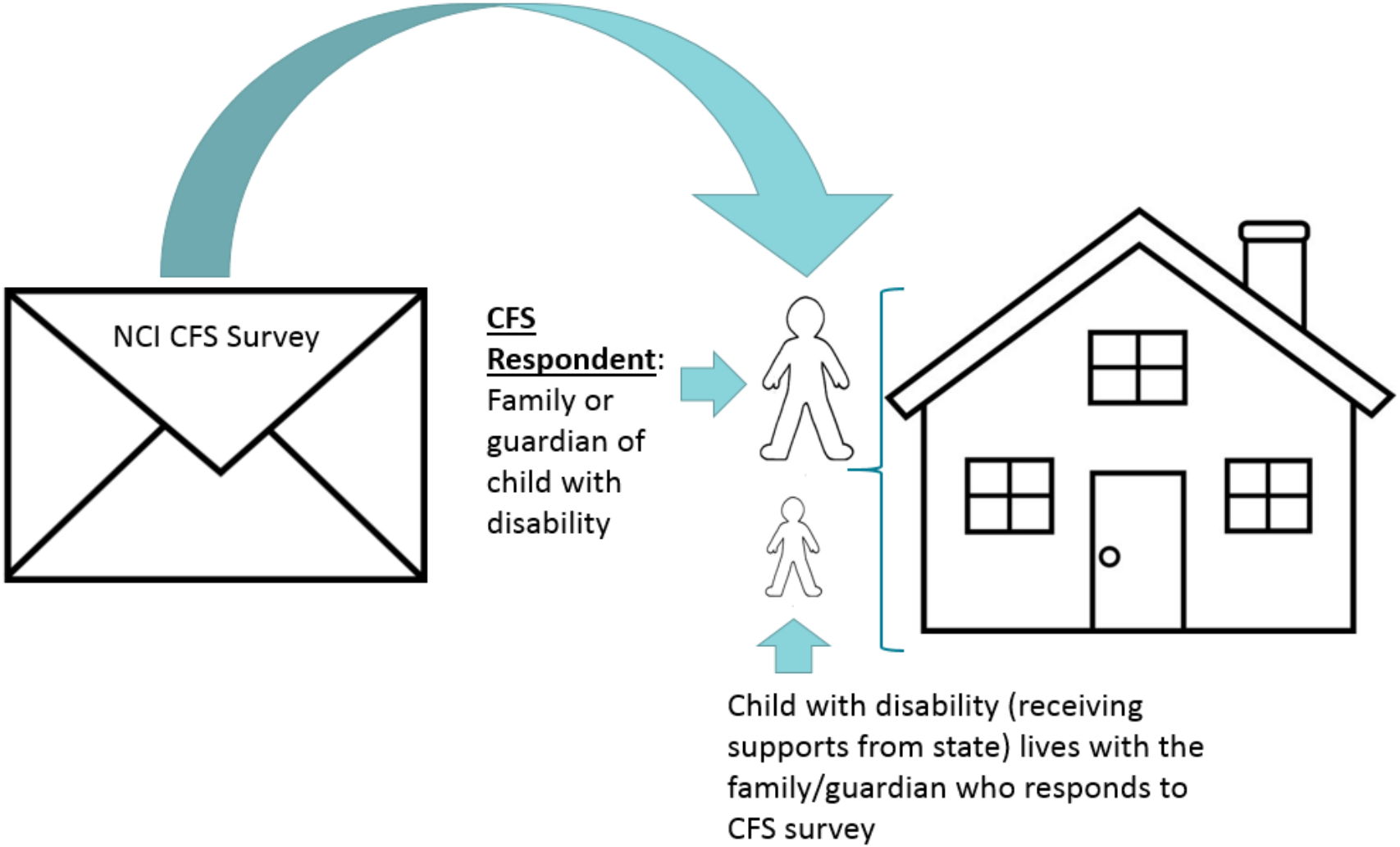
Data Entry and Analysis 95
Response Rates 97
Figure 3. Child Family Survey: State Response Rates 97

IV. Appendix A **98**

Child Family Survey Highlights

LOOKING AT THE 2015-16 CHILD FAMILY SURVEY (CFS)

Respondents: families or guardians of a child with an intellectual/developmental disability. The child with the disability lives in the family home (with the respondent) and receives at least one service funded by the state developmental disability agency in addition to case management.
8 states*: Total sample: 16,999



*CFS: CA, ID, NC, OR, SD, TX, UT, VA

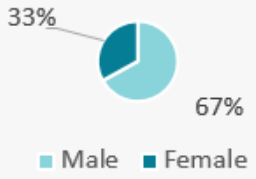
Demographics of sample of children with disabilities receiving supports from the state

Average Age
Of the sample of children with disabilities receiving supports from the state

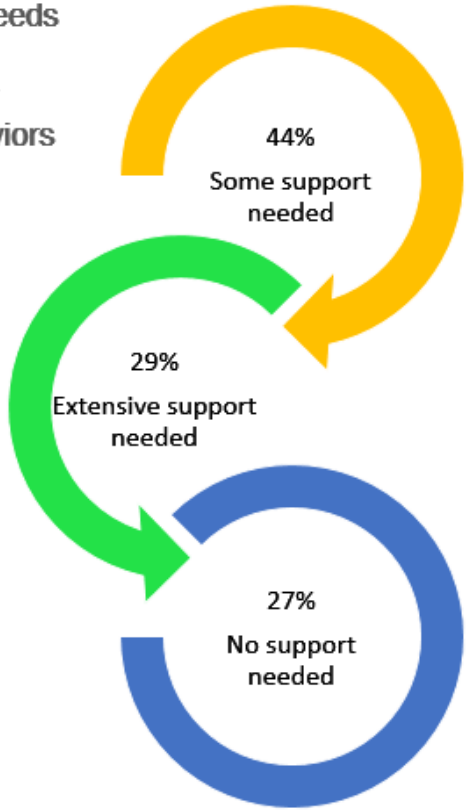
12 years old

***

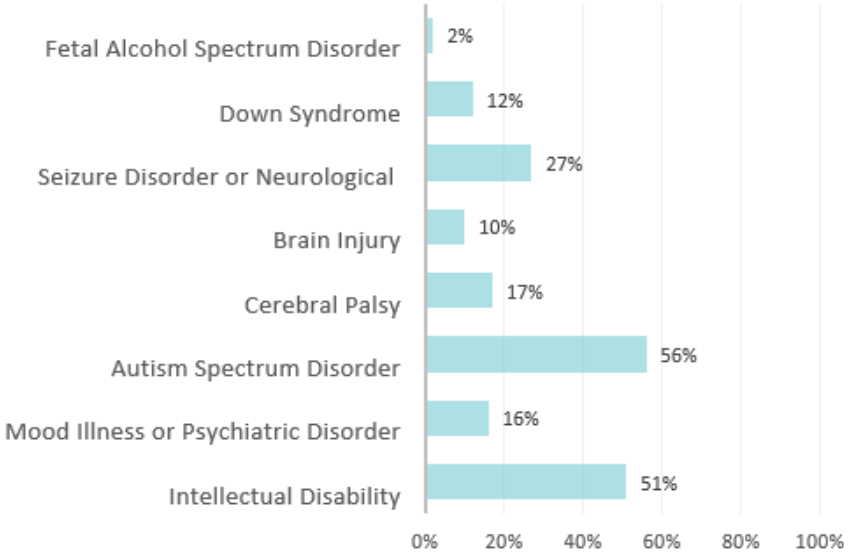
Gender Breakdown
Of the sample of children with disabilities receiving supports from the state



Child's support needs for self-injurious, disruptive and/or destructive behaviors

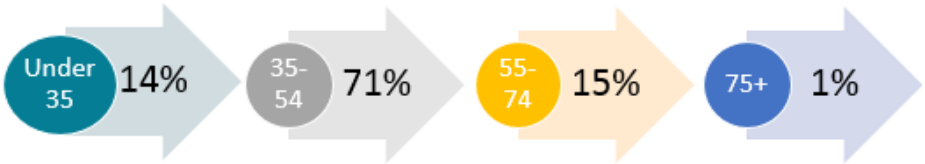


Diagnoses of children with disabilities



Characteristics of respondents
(family or guardian of the child with disability)

Respondent's Age



NATIONAL CORE INDICATORS™

Information and Planning

Respondents reported…

35%

- Always receive enough information to help plan services for child with disability

27%

- Information received to help plan services is always easy to understand

Access and Delivery of Supports and Services

Respondents reported…

73% Family gets needed supports

51% Support workers always have the right information and skills to meet family's needs

63% Support workers always come and leave when they are supposed to

56% Always able to contact support workers when wanted

Choice, Decision-making and Control

Respondents reported…	
Family can always choose or change the agency that provides supports	66%

Involvement in the Community

Respondents reported…

84% – Child with disability takes part in community activities

84% – Child with disability spends time with children without I/DD

Satisfaction with Services and Supports

Respondent is always satisfied with services and supports family receives	36%

I. Results

This section provides state-by-state and national results for demographic and survey outcomes data.

Survey Development

The Child Family Survey was developed and first utilized during Phase III of CIP (2000-2001) in response to state interest in determining the level of satisfaction with services and supports among families of children with developmental disabilities living at home.

Many questions were drawn from survey instruments already in use in the field; others were developed specifically for NCI. NCI staff routinely refine the instrument based on feedback from families and state staff.

Most participating states use the basic survey tool developed by the project. However, some states opt to incorporate additional survey questions to look more deeply at specific issues. The addition of supplementary questions is typically done after a state participates in NCI for at least a year and establishes baseline results.

Organization of the Child Family Survey

The Child Family Survey is composed of three sections described below. There is also an opportunity for families to write open-ended comments concerning their family's participation in the service system.

Demographics

The survey instrument begins with a series of questions on the characteristics of the child with a developmental disability (e.g., age, race, type of disability) followed by a series of demographic questions on the survey respondent (e.g., age, health status, relationship to the child with the developmental disability).

Services and Supports Received

A brief section of the survey asks the respondent to identify the services and supports that they and/or their child with a developmental disability receive.

Questions Regarding Services and Supports

The survey contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes.

Each question is constructed so the respondent selects from either five possible responses ("always," “usually,” "sometimes," "seldom,” or “never") or two responses (“yes” or “no”). Respondents also have the option to indicate that they don't know the answer to a question or that the question is not applicable.

***Please note: In the 2015-16 CFS survey tool, the “Seldom” and “Never” response options, which were separate in previous years, were combined into a “Seldom/Never” response option. This may affect comparisons from year to year.**

Additional Comments

The end of each section provides an opportunity for the respondent to make additional open-ended comments concerning their family’s participation in the service system.

Important Notes on Analysis

Two states' data were treated differently than others due to differences in sample strategies.

California

The size of the state's sample influences statistical significance. Therefore, it is possible that a state with a lower percentage but a larger sample will be classified as significantly above average while a state with a somewhat higher percentage but a smaller sample will not. California's sample size is much larger than other states. In the tables in this section that show the results of statistical testing, California's data are marked with a double asterisk (**) if the data were significant only due to the size of the sample in the state.

Texas

Weighting was performed for one state's estimates – TX. Texas selected a representative sample of the programs in their state so that each program could be examined individually. Applying statistical weights adjusted for the fact that some programs were over-represented in the sample and some were under-represented. Weights were developed using the sample proportions and the true population proportions of each program. The programs in question are:

a.) CLASS
b.) HCS
c.) MDCP
d.) TXHML

Texas' estimates throughout the report are thus weighted estimates. The counts (Ns) are unweighted.

For more information on Texas' mode of survey administration, see section entitled: "Sampling & Administration" in this report.

Demographics

Child

Table 1. More Than One Child Living in the Home Has ID/DD

State	Yes	No	N
CA	23%	77%	12,837
ID	32%	68%	906
NC	22%	78%	253
OR	15%	85%	459
SD	13%	87%	212
TX	20%	80%	1,316
UT	31%	69%	295
VA	21%	79%	145
NCI Average	**22%**	**78%**	**16,423**

Table 2. Child's Age

State	Age	N
CA	10.6	11,455
ID	10.5	865
NC	13.9	235
OR	11.3	426
SD	10.8	201
TX	13.9	1,313
UT	11.6	279
VA	15.2	143
NCI Average	**12.2**	**14,917**

Table 3. Child's Gender

State	Male	Female	N
CA	73%	27%	12,105
ID	69%	31%	887
NC	69%	31%	248
OR	64%	36%	449
SD	67%	33%	213
TX	60%	40%	1,314
UT	69%	31%	292
VA	63%	37%	145
NCI Average	**67%**	**33%**	**15,653**

Table 4. Child's Race and Ethnicity

State	American Indian or Alaska Native	Asian	Black or African-American	Hawaiian or Pacific Islander	White	Other or Unknown	Two or More Races	Hispanic or Latino
CA	2%	17%	8%	1%	35%	2%	14%	50%
ID	5%	3%	3%	0%	84%	1%	12%	18%
NC	2%	2%	26%	0%	69%	2%	6%	5%
OR	4%	5%	4%	0%	81%	4%	14%	16%
SD	7%	2%	4%	0%	88%	0%	5%	4%
TX	2%	6%	13%	1%	59%	4%	19%	38%
UT	3%	3%	2%	1%	88%	1%	10%	14%
VA	1%	2%	19%	1%	82%	4%	11%	4%
NCI Average	**4%**	**5%**	**10%**	**1%**	**73%**	**2%**	**11%**	**19%**

Table 5. Child's Disabilities

State	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
CA	33%	n/a*	67%	11%	7%	4%	5%	15%	1%	10%	0%	1%	17%
ID	41%	24%	67%	8%	4%	4%	6%	16%	0%	8%	0%	3%	33%
NC	51%	16%	62%	19%	9%	4%	8%	26%	0%	12%	1%	3%	33%
OR	49%	13%	51%	16%	10%	5%	8%	24%	0%	13%	1%	4%	33%
SD	43%	9%	40%	15%	8%	5%	8%	26%	0%	22%	0%	2%	19%
TX	72%	18%	36%	27%	28%	13%	22%	46%	4%	14%	1%	1%	50%
UT	58%	17%	71%	15%	8%	5%	12%	27%	0%	7%	2%	2%	28%
VA	62%	16%	56%	25%	11%	8%	11%	32%	1%	10%	0%	1%	27%
NCI Average	**51%**	**16%**	**56%**	**17%**	**11%**	**6%**	**10%**	**27%**	**1%**	**12%**	**1%**	**2%**	**30%**

***CA IS NOT INCLUDED DUE TO A DISCREPANCY IN DATA COLLECTION.**

Table 6. Child's Health Conditions

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol	Dysphagia	Pressure Ulcers	Other
CA	14%	4%	3%	5%	8%	14%	1%	66%
ID	10%	5%	2%	4%	4%	17%	0%	74%
NC	9%	10%	3%	6%	10%	13%	4%	70%
OR	11%	2%	2%	6%	4%	36%	3%	66%
SD	21%	5%	8%	3%	3%	22%	3%	56%
TX	19%	3%	3%	9%	7%	40%	6%	71%
UT	10%	3%	3%	4%	7%	19%	3%	71%
VA	9%	11%	0%	5%	13%	17%	5%	70%
NCI Average	**13%**	**5%**	**3%**	**5%**	**7%**	**22%**	**3%**	**68%**

Table 7. Child's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
CA	71%	18%	4%	2%	4%	12,985
ID	80%	12%	3%	3%	3%	853
NC	65%	24%	1%	4%	6%	251
OR	59%	25%	3%	5%	7%	464
SD	71%	21%	3%	3%	3%	187
TX	51%	25%	3%	3%	17%	1,299
UT	52%	25%	2%	1%	20%	301
VA	57%	29%	3%	7%	4%	147
NCI Average	**63%**	**22%**	**3%**	**4%**	**8%**	**16,487**

Table 8. Child's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

State	None	Some	Extensive	N
CA	23%	48%	30%	12,747
ID	18%	49%	33%	914
NC	27%	45%	27%	251
OR	26%	39%	35%	455
SD	39%	46%	15%	216
TX	41%	32%	27%	1,298
UT	18%	46%	36%	298
VA	24%	45%	32%	148
NCI Average	**27%**	**44%**	**29%**	**16,327**

Table 9. Child's Level of Help Needed With Personal Care Activities

State	None	Some	Extensive	N
CA	8%	42%	50%	13,111
ID	7%	45%	48%	926
NC	9%	37%	54%	254
OR	2%	35%	63%	460
SD	9%	47%	44%	216
TX	4%	29%	67%	1,328
UT	2%	32%	65%	300
VA	5%	29%	66%	149
NCI Average	**6%**	**37%**	**57%**	**16,744**

Respondents

This section provides demographic information about the respondent.

Table 10. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
CA	18%	72%	10%	0%	13,182
ID	22%	66%	11%	0%	948
NC	8%	72%	20%	1%	257
OR	12%	73%	14%	0%	467
SD	20%	69%	11%	0%	216
TX	10%	70%	19%	1%	1,332
UT	18%	72%	10%	0%	303
VA	3%	70%	23%	3%	149
NCI Average	**14%**	**71%**	**15%**	**1%**	**16,854**

Table 11. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
CA	18%	47%	31%	5%	13,069
ID	19%	46%	30%	4%	942
NC	16%	50%	30%	4%	255
OR	16%	49%	31%	4%	467
SD	19%	51%	28%	2%	216
TX	19%	44%	31%	6%	1,323
UT	20%	40%	32%	8%	300
VA	13%	41%	37%	10%	147
NCI Average	**17%**	**46%**	**31%**	**5%**	**16,719**

Table 12. Respondent's Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
CA	96%	0%	2%	1%	13,231
ID	94%	0%	4%	1%	936
NC	91%	0%	7%	2%	255
OR	95%	1%	4%	0%	468
SD	96%	0%	4%	0%	217
TX	92%	0%	6%	1%	1,335
UT	99%	0%	0%	1%	302
VA	90%	1%	6%	3%	149
NCI Average	**94%**	**0%**	**4%**	**1%**	**16,893**

Table 13. Respondent or Other Family Member Provides Paid Support to Child

State	Respondent	Other Family	No	N
CA	28%	11%	61%	12,876
ID	4%	8%	88%	945
NC	5%	5%	91%	255
OR	6%	29%	66%	464
SD	5%	6%	89%	215
TX	14%	25%	63%	1,296
UT	2%	30%	68%	300
VA	5%	28%	68%	145
NCI Average	**8%**	**18%**	**74%**	**16,496**

Table 14. Number of Adults in Household

State	One	Two	Three	Four or More	N
CA	17%	59%	17%	8%	13,020
ID	21%	66%	10%	3%	944
NC	29%	56%	11%	4%	257
OR	20%	61%	13%	6%	462
SD	20%	66%	9%	5%	215
TX	18%	54%	18%	9%	1,323
UT	11%	69%	15%	5%	303
VA	23%	51%	20%	6%	142
NCI Average	**20%**	**60%**	**14%**	**6%**	**16,666**

Table 15. Number of Children in Household

State	One	Two	Three	Four or More	N
CA	33%	39%	19%	9%	12,639
ID	27%	35%	18%	20%	937
NC	43%	37%	15%	5%	239
OR	38%	40%	14%	8%	454
SD	32%	39%	16%	14%	207
TX	39%	35%	17%	9%	1,043
UT	21%	32%	26%	22%	297
VA	48%	32%	16%	4%	123
NCI Average	**35%**	**36%**	**18%**	**11%**	**15,939**

Table 16. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree or Higher	N
CA	19%	16%	8%	19%	38%	12,517
ID	7%	21%	6%	24%	42%	894
NC	10%	12%	5%	20%	54%	256
OR	5%	15%	6%	23%	51%	465
SD	4%	17%	12%	13%	53%	210
TX	11%	14%	6%	21%	47%	1,293
UT	4%	14%	8%	29%	45%	302
VA	5%	12%	5%	20%	58%	146
NCI Average	**8%**	**15%**	**7%**	**21%**	**49%**	**16,083**

Table 17. Total Taxable Household Income of Wage Earners in the Past Year

State	Below $15,000	$15,001-$25,000	$25,001-$50,000	$50,001-$75,000	Over $75,000	No Earned Income	N
CA	17%	19%	24%	12%	23%	5%	11,525
ID	13%	16%	28%	16%	19%	8%	845
NC	20%	9%	16%	14%	30%	11%	231
OR	12%	12%	22%	18%	30%	6%	431
SD	11%	12%	24%	22%	27%	4%	195
TX	18%	14%	22%	15%	26%	6%	1,067
UT	6%	12%	26%	27%	27%	2%	270
VA	11%	7%	20%	24%	33%	6%	128
NCI Average	**13%**	**13%**	**23%**	**19%**	**27%**	**6%**	**14,692**

Table 18. Residential Designation (Urban/Suburban or Rural)

State	Urban or Suburban	Rural	N
CA	92%	8%	11,813
ID	72%	28%	919
NC	60%	40%	247
OR	79%	21%	463
SD	70%	30%	213
TX	80%	20%	1,299
UT	80%	20%	298
VA	62%	38%	143
NCI Average	**74%**	**26%**	**15,395**

Services and Supports Received

This section provides information about the services and supports received by the family.

Table 19. Services and Supports Received From ID/DD Agency

State	Financial Support	In-home Support	Out-of-home Respite	Early Intervention	Transportation	Other	Self-direction or Fiscal Intermediary Services
CA	11%	38%	30%	N/A*	5%	38%	5%
ID	21%	43%	30%	13%	22%	86%	43%
NC	12%	78%	49%	5%	22%	65%	18%
OR	20%	75%	48%	11%	21%	52%	33%
SD	57%	9%	43%	17%	20%	72%	23%
TX	13%	67%	33%	6%	21%	63%	36%
UT	7%	65%	57%	5%	24%	49%	58%
VA	26%	86%	48%	3%	29%	69%	67%
NCI Average	**21%**	**58%**	**42%**	**9%**	**20%**	**62%**	**35%**

***CA** IS NOT INCLUDED DUE TO A DISCREPANCY IN DATA COLLECTION.

Table 20. Other Services or Supports Received

State	SSI/SSB	Services or Supports From Other Agencies
CA	42%	49%
ID	46%	66%
NC	44%	65%
OR	40%	67%
SD	35%	74%
TX	54%	44%
UT	27%	65%
VA	46%	64%
NCI Average	**42%**	**62%**

Child Family Survey Results

Important note on results: a double asterisk (**) on CA means that with a sample size of 400 there would be NO significant difference.

Information and Planning

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

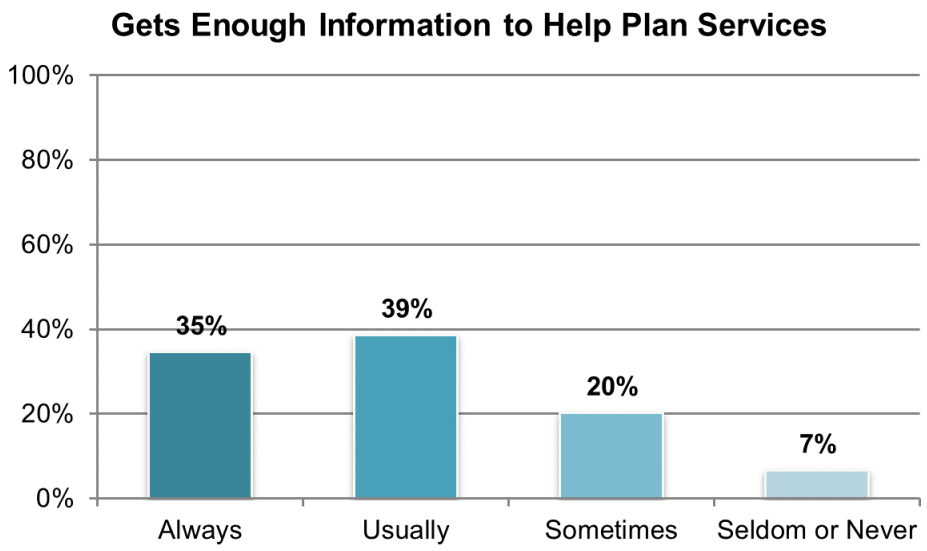


Table Q1. Do you get enough information to help you participate in planning services for your family?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	48%	40%	11%	1%	203
Within Average Range					
NC	37%	38%	21%	3%	247
UT	36%	45%	16%	3%	292
OR	33%	41%	20%	6%	454
ID	33%	43%	19%	5%	900
TX	32%	31%	23%	13%	1,271
VA	28%	40%	26%	6%	144
Significantly Below Average					
CA**	29%	30%	25%	15%	12,162
NCI Average	**35%**	**39%**	**20%**	**7%**	**15,673**

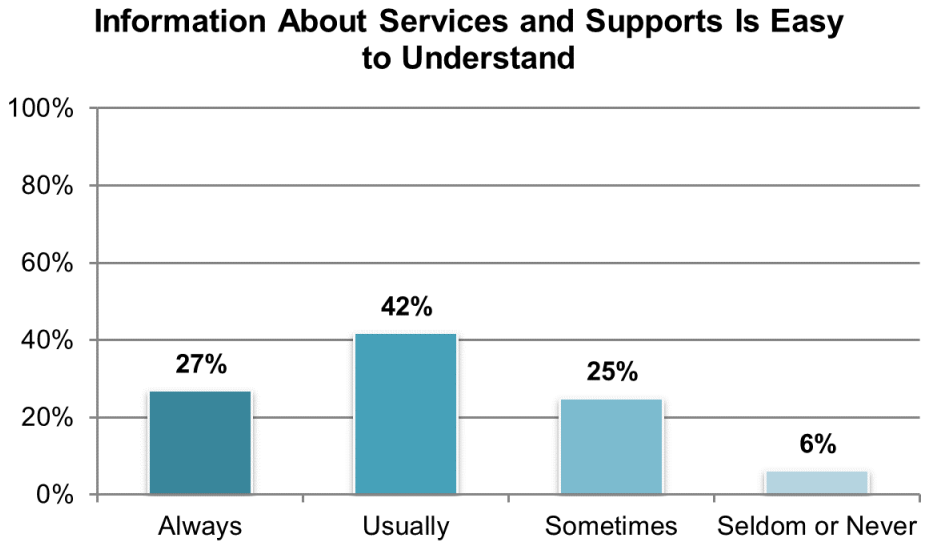


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	45%	42%	12%	1%	205
CA**	30%	35%	26%	8%	12,238
Within Average Range					
UT	27%	43%	26%	4%	292
TX	24%	34%	32%	9%	1,285
OR	24%	45%	24%	8%	450
NC	23%	46%	24%	6%	245
VA	21%	45%	28%	6%	143
Significantly Below Average					
ID	20%	44%	28%	8%	905
NCI Average	**27%**	**42%**	**25%**	**6%**	**15,763**

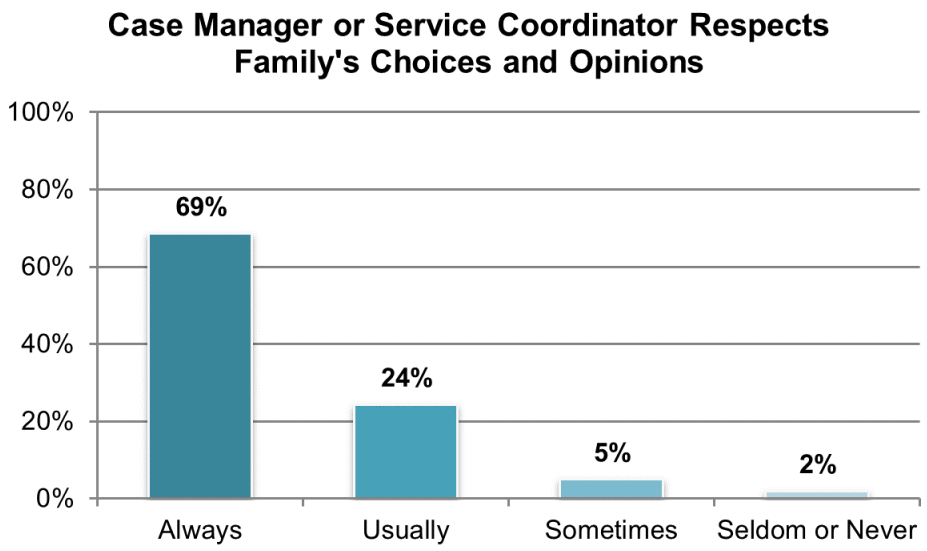


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
UT	82%	14%	3%	1%	293
SD	78%	19%	2%	0%	201
Within Average Range					
TX	69%	22%	6%	3%	1,257
OR	67%	27%	4%	2%	448
NC	65%	28%	6%	2%	236
VA	62%	30%	5%	3%	145
Significantly Below Average					
CA**	63%	25%	8%	4%	12,342
ID	63%	29%	6%	2%	837
NCI Average	**69%**	**24%**	**5%**	**2%**	**15,759**

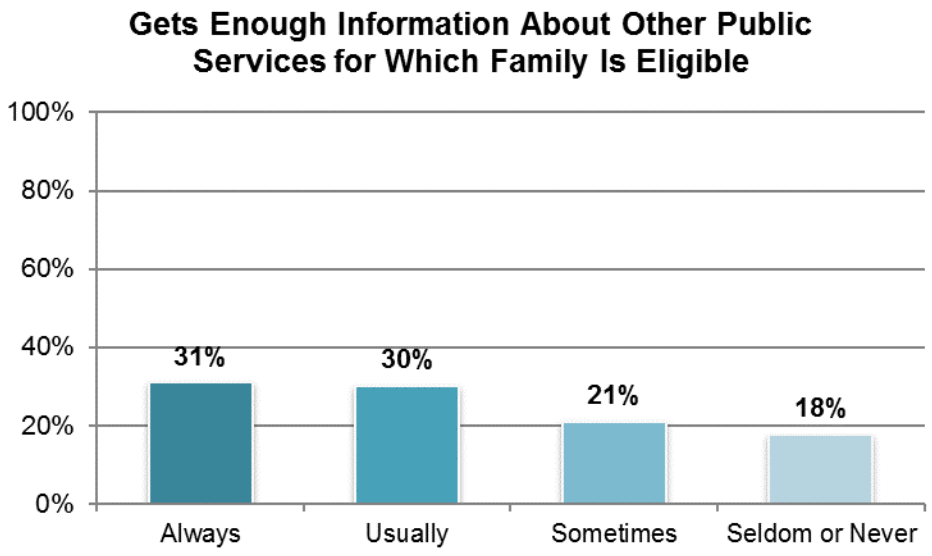


Table Q4. Do you get enough information about other public services for which your family is eligible?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	51%	34%	12%	3%	189
Within Average Range					
OR	32%	32%	20%	16%	403
VA	30%	31%	21%	18%	128
UT	27%	30%	27%	17%	260
NC	26%	31%	20%	23%	222
Significantly Below Average					
CA**	30%	24%	21%	25%	11,121
TX	27%	29%	25%	19%	1,211
ID	26%	30%	23%	21%	785
NCI Average	**31%**	**30%**	**21%**	**18%**	**14,319**

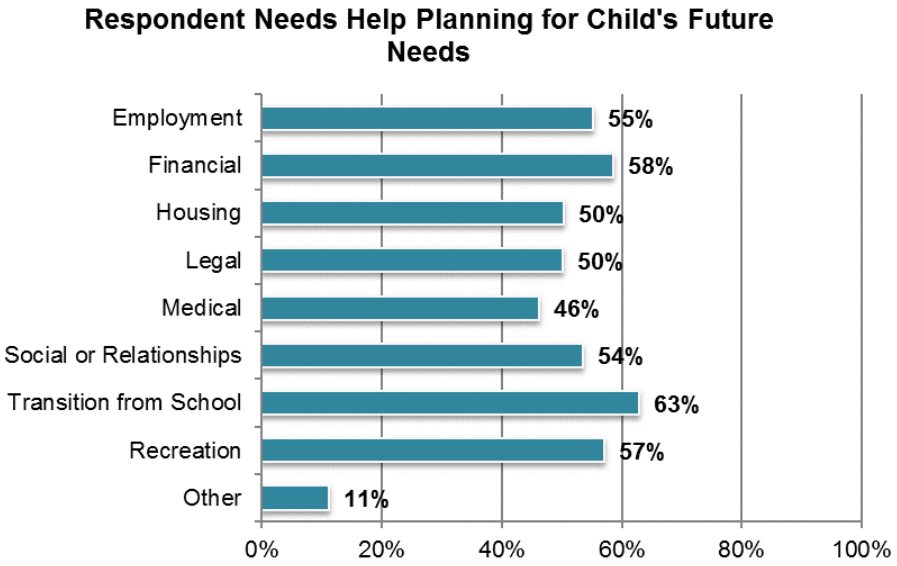


Table Q5. Do you need help planning for your child's future with respect to any of the following?

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition from School	Recreation	Other
CA	52%	51%	48%	43%	46%	60%	57%	63%	8%
ID	55%	57%	45%	43%	45%	63%	61%	52%	15%
NC	60%	63%	47%	50%	39%	53%	67%	54%	13%
OR	60%	63%	57%	50%	51%	59%	63%	64%	12%
SD	57%	52%	54%	43%	36%	45%	58%	49%	11%
TX*	47%	60%	50%	59%	59%	51%	59%	61%	16%
UT	56%	64%	46%	60%	51%	50%	68%	60%	9%
VA	53%	58%	55%	54%	42%	47%	69%	54%	7%
NCI Average	**55%**	**58%**	**50%**	**50%**	**46%**	**54%**	**63%**	**57%**	**11%**

*The modes by which TX administered this survey may have affected the percentages of people who replied "yes" to each of these options. Results for those who replied using the paper mode demonstrated lower proportions of "yes" than for all three modes combined. See section "Sampling & Administration" for more information.

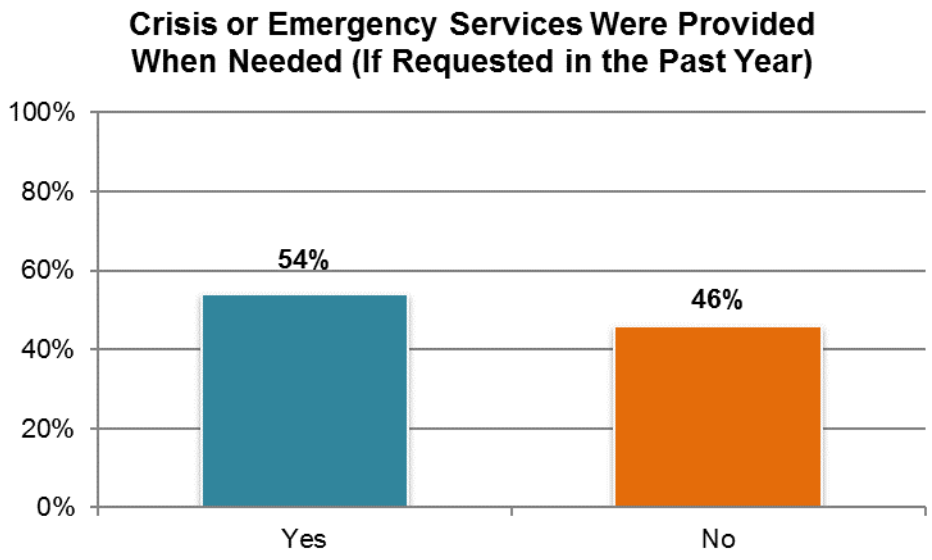


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

State	Yes	No	N
Significantly Above Average			
TX	69%	31%	378
Within Average Range			
SD	67%	33%	36
UT	62%	38%	55
OR	56%	44%	108
NC	49%	51%	68
VA	47%	53%	38
Significantly Below Average			
ID	45%	55%	213
CA	40%	60%	3,994
NCI Average	**54%**	**46%**	**4,890**

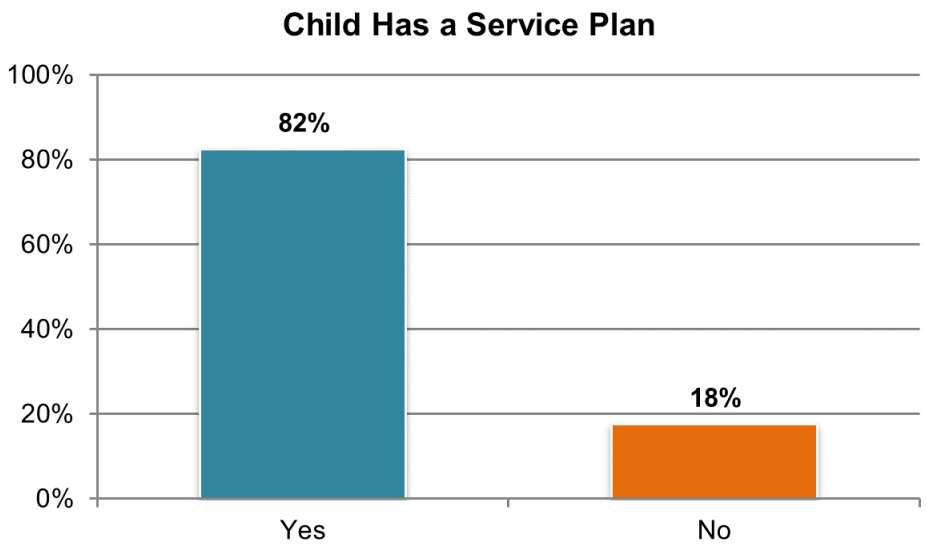


Table Q7. Does your child have a service plan?

State	Yes	No	N
Significantly Above Average			
OR	89%	11%	401
Within Average Range			
SD	88%	12%	174
NC	88%	12%	234
VA	83%	17%	132
ID	83%	17%	825
UT	82%	18%	234
Significantly Below Average			
CA**	80%	20%	10,533
TX	68%	32%	1,090
NCI Average	**82%**	**18%**	**13,623**

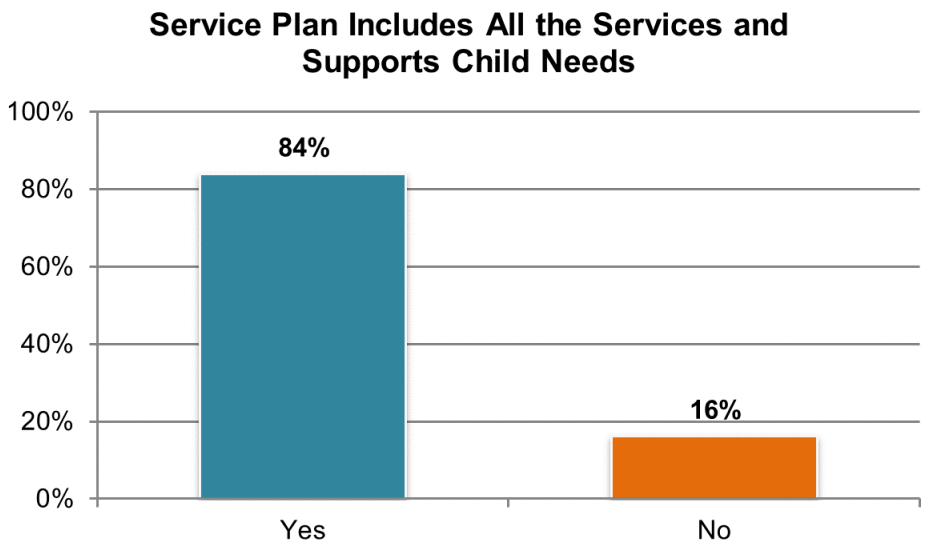


Table Q8. Does the plan include all the services and supports your child needs?

State	Yes	No	N
Significantly Above Average			
SD	91%	9%	137
Within Average Range			
VA	89%	11%	100
TX	85%	15%	738
ID	85%	15%	624
NC	84%	16%	192
UT	81%	19%	174
OR	79%	21%	315
Significantly Below Average			
CA	78%	22%	7,065
NCI Average	**84%**	**16%**	**9,345**

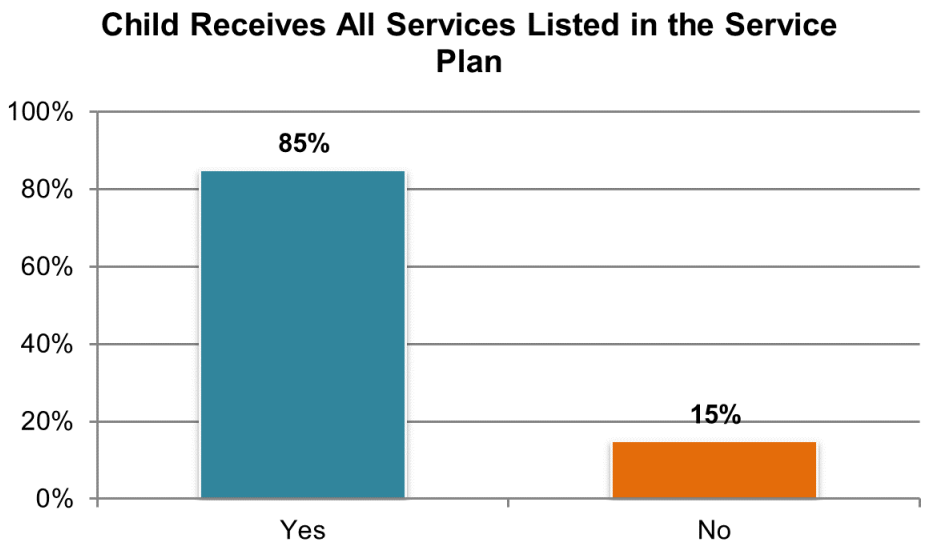


Table Q9. Does your child receive all of the services listed in the plan?

State	Yes	No	N
Significantly Above Average			
SD	92%	8%	143
CA**	87%	13%	7,135
Within Average Range			
UT	88%	12%	172
OR	85%	15%	312
VA	84%	16%	102
NC	84%	16%	198
ID	81%	19%	637
Significantly Below Average			
TX	79%	21%	733
NCI Average	**85%**	**15%**	**9,432**

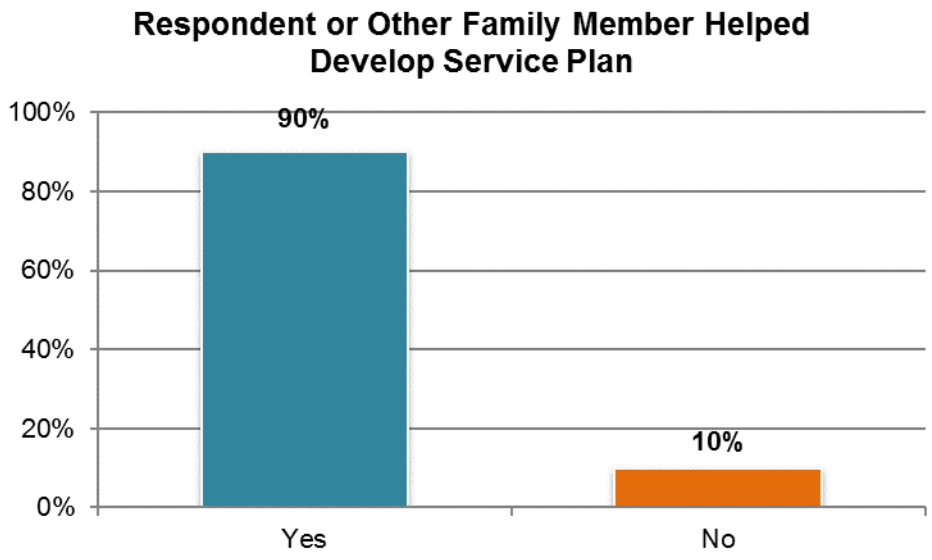


Table Q10. Did you or another family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
UT	95%	5%	183
Within Average Range			
NC	93%	7%	201
VA	92%	8%	106
SD	92%	8%	152
ID	90%	10%	668
OR	90%	10%	339
TX*	87%	13%	758
Significantly Below Average			
CA	79%	21%	7,588
NCI Average	**90%**	**10%**	**9,995**

*The modes by which TX administered this survey may have affected the percentages of people who replied "yes" to this question. Results for those who replied using the paper mode demonstrated lower proportions of "yes" than for all three modes combined. See section "Sampling & Administration" for more information.

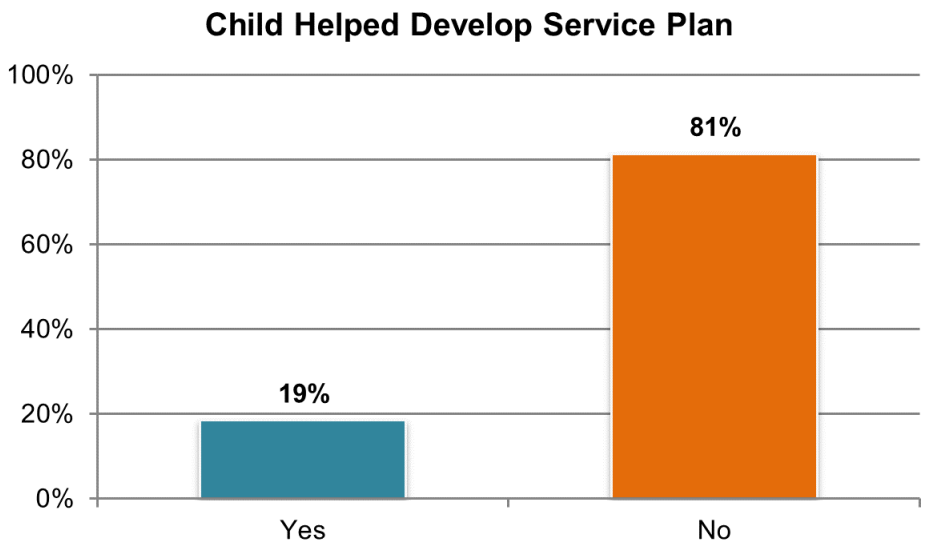


Table Q11. Did your child help develop the plan?

State	Yes	No	N
Within Average Range			
VA	24%	76%	107
SD	24%	76%	149
NC	19%	81%	205
UT	19%	81%	186
OR	16%	84%	337
Significantly Below Average			
CA**	17%	83%	7,560
ID	15%	85%	664
TX	14%	86%	772
NCI Average	**19%**	**81%**	**9,980**

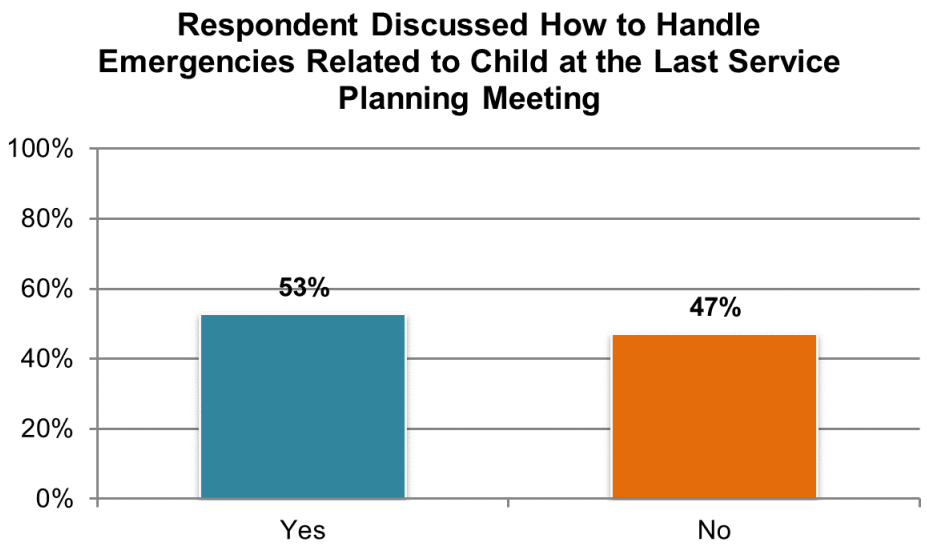


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your child's last service planning meeting?

State	Yes	No	N
Significantly Above Average			
TX	72%	28%	726
NC	67%	33%	191
SD	67%	33%	139
Within Average Range			
OR	50%	50%	305
UT	46%	54%	171
Significantly Below Average			
ID	42%	58%	601
CA	41%	59%	7,186
VA	38%	62%	102
NCI Average	**53%**	**47%**	**9,421**

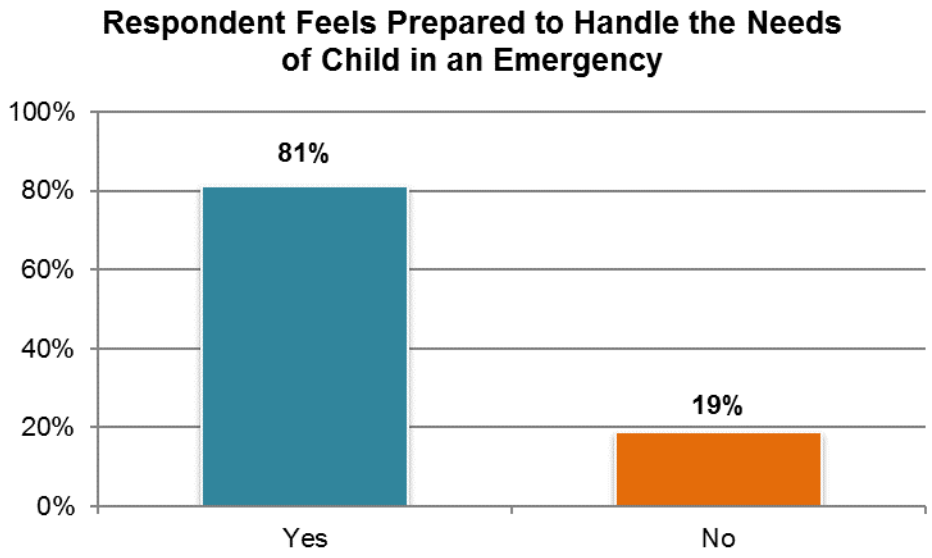


Table Q13. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster?

State	Yes	No	N
Significantly Above Average			
TX	93%	7%	760
SD	92%	8%	143
Within Average Range			
ID	83%	17%	593
NC	83%	17%	189
VA	80%	20%	105
Significantly Below Average			
OR	72%	28%	296
CA	72%	28%	7,230
UT	69%	31%	171
NCI Average	**81%**	**19%**	**9,487**

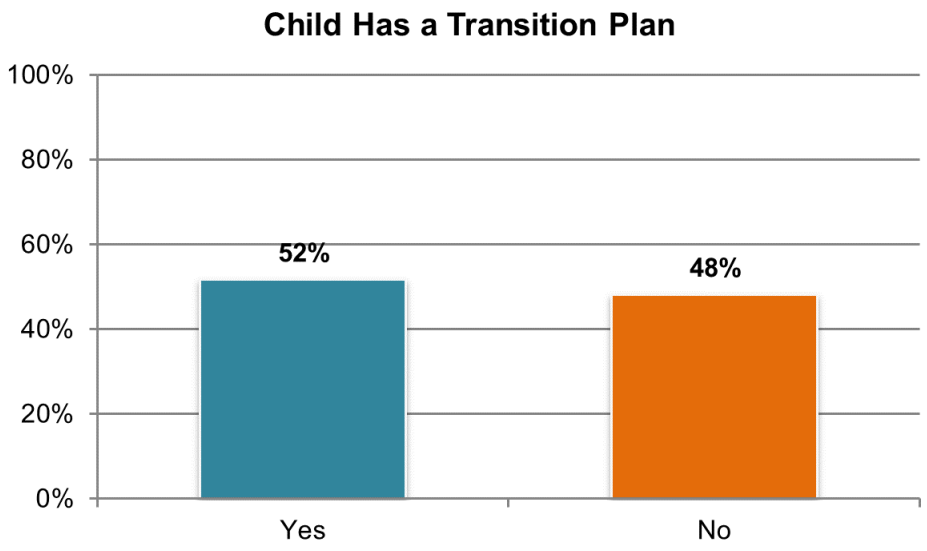


Table Q14. Does your child have a transition plan (as part of an IEP or Section 504 plan through his/her high school, usually starting at age 14)?

State	Yes	No	N
Significantly Above Average			
NC	73%	27%	139
VA	65%	35%	113
Within Average Range			
SD	67%	33%	66
UT	61%	39%	102
Significantly Below Average			
TX	39%	61%	965
ID	38%	62%	384
OR	35%	65%	206
CA	35%	65%	5,979
NCI Average	**52%**	**48%**	**7,954**

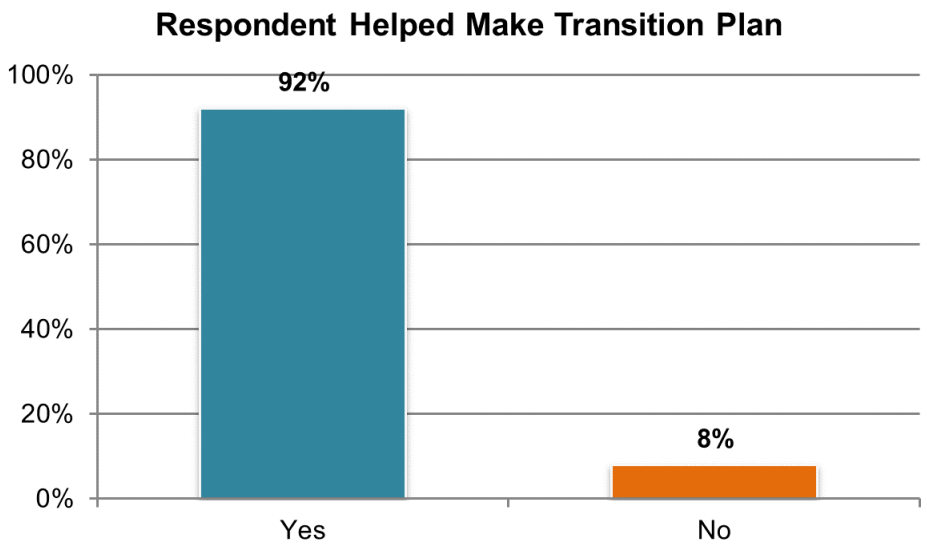


Table Q15. If yes to Q14, did you help make the transition plan?

State	Yes	No	N
Within Average Range			
SD	98%	2%	44
VA	96%	4%	69
NC	95%	5%	99
ID	94%	6%	140
OR	93%	7%	68
TX	91%	9%	443
UT	85%	15%	60
Significantly Below Average			
CA	86%	14%	1,915
NCI Average	**92%**	**8%**	**2,838**

Access and Delivery of Services and Supports

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

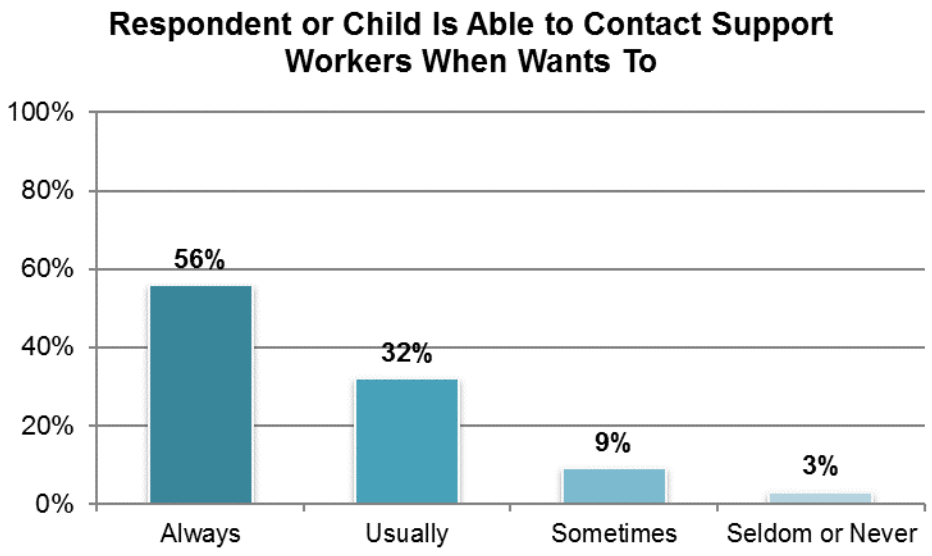


Table Q16. Are you or your child able to contact his/her support workers when you want to?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	68%	27%	4%	1%	195
UT	65%	29%	5%	1%	285
Within Average Range					
OR	56%	31%	10%	3%	462
TX	55%	28%	12%	5%	1,236
VA	53%	37%	10%	0%	146
NC	53%	36%	8%	3%	234
ID	52%	36%	10%	2%	840
Significantly Below Average					
CA	49%	31%	14%	6%	11,127
NCI Average	**56%**	**32%**	**9%**	**3%**	**14,525**

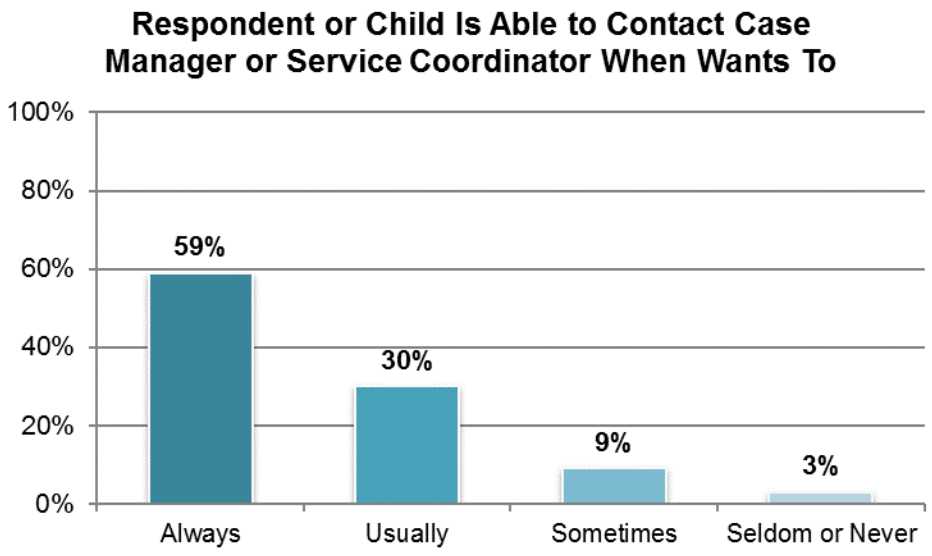


Table Q17. Are you or your child able to contact his/her case manager or service coordinator when you want to?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	76%	21%	3%	0%	199
UT	72%	24%	4%	0%	292
Within Average Range					
VA	57%	32%	9%	1%	149
TX	56%	28%	11%	5%	1,265
OR	55%	31%	11%	3%	460
NC	52%	36%	10%	2%	231
Significantly Below Average					
CA	52%	29%	14%	6%	12,474
ID	51%	37%	9%	3%	826
NCI Average	**59%**	**30%**	**9%**	**3%**	**15,896**

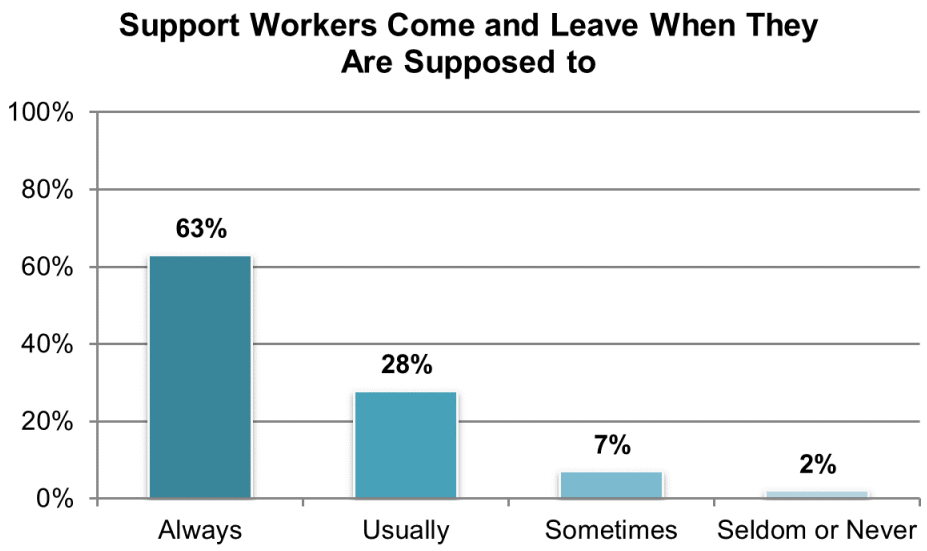


Table Q18. Do support workers come and leave when they are supposed to?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	79%	17%	3%	1%	158
Within Average Range					
UT	68%	26%	5%	1%	287
TX	64%	25%	8%	3%	1,207
OR	64%	28%	6%	2%	447
CA	64%	26%	7%	3%	10,704
VA	56%	29%	13%	2%	144
Significantly Below Average					
ID	56%	37%	6%	1%	800
NC	54%	34%	10%	3%	229
NCI Average	**63%**	**28%**	**7%**	**2%**	**13,976**

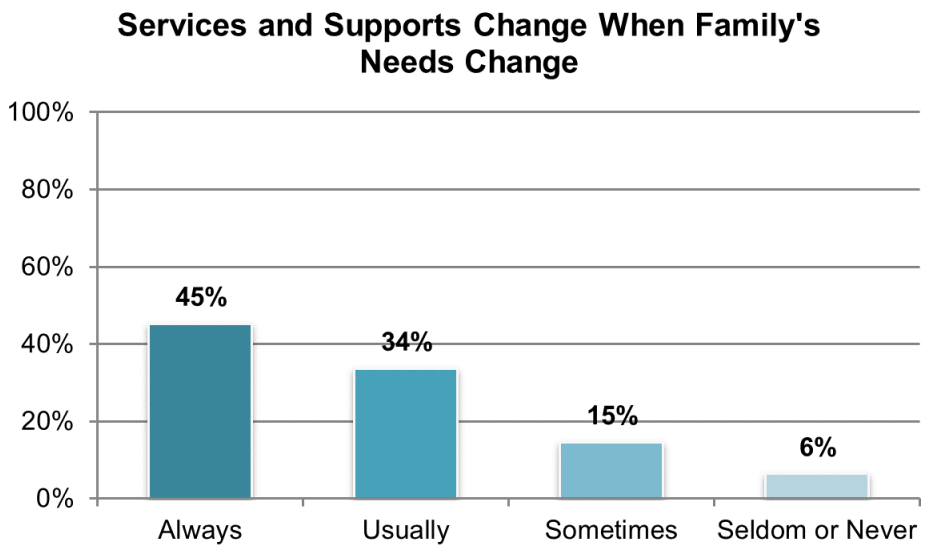


Table Q19. Do services and supports change when your family's needs change?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	64%	27%	6%	3%	156
Within Average Range					
UT	51%	33%	10%	5%	243
ID	44%	39%	13%	5%	765
VA	42%	31%	21%	7%	134
TX	42%	30%	19%	9%	1,098
OR	40%	38%	15%	7%	383
NC	37%	42%	16%	6%	218
Significantly Below Average					
CA**	42%	30%	16%	11%	9,584
NCI Average	**45%**	**34%**	**15%**	**6%**	**12,581**

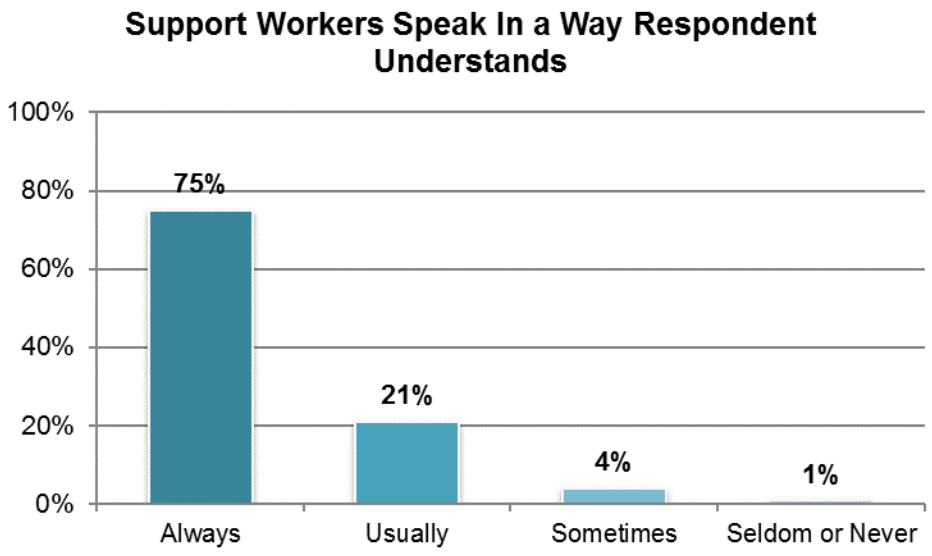


Table Q20. Do support workers speak to you in a way that you understand?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	84%	15%	1%	0%	176
Within Average Range					
OR	77%	19%	4%	1%	450
NC	77%	19%	3%	1%	236
UT	75%	23%	2%	0%	288
ID	74%	22%	4%	1%	834
TX	72%	20%	6%	1%	1,243
VA	65%	30%	5%	0%	144
NCI Average	**75%**	**21%**	**4%**	**1%**	**3,371**

DUE TO LOW RESPONSE RATE (<20), CA WAS NOT INCLUDED IN THIS ANALYSIS.

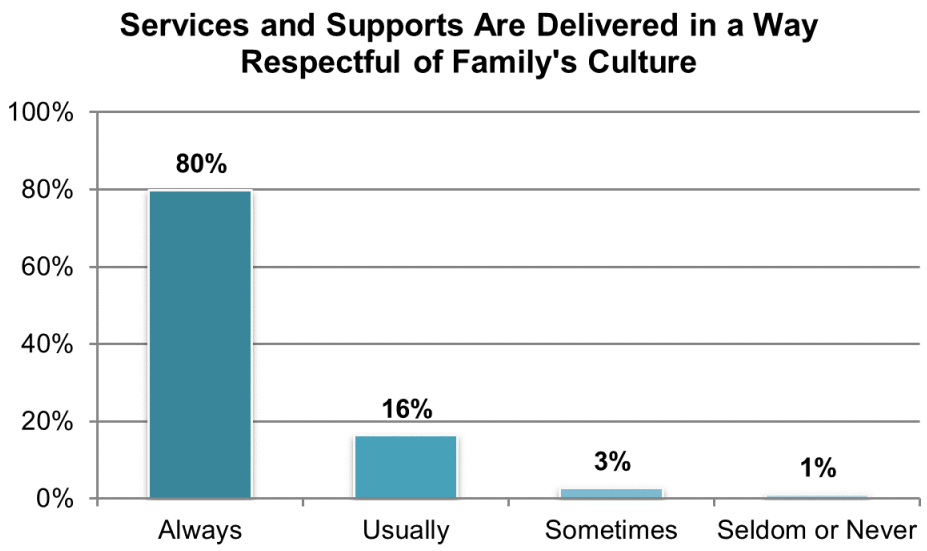


Table Q21. Are services delivered in a way that is respectful of your family's culture?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	89%	10%	1%	0%	198
UT	86%	12%	2%	0%	292
Within Average Range					
OR	83%	15%	2%	0%	447
TX	80%	15%	3%	2%	1,280
ID	76%	19%	4%	1%	890
NC	75%	19%	3%	3%	240
VA	73%	23%	4%	0%	146
Significantly Below Average					
CA**	77%	18%	3%	2%	11,964
NCI Average	**80%**	**16%**	**3%**	**1%**	**15,457**

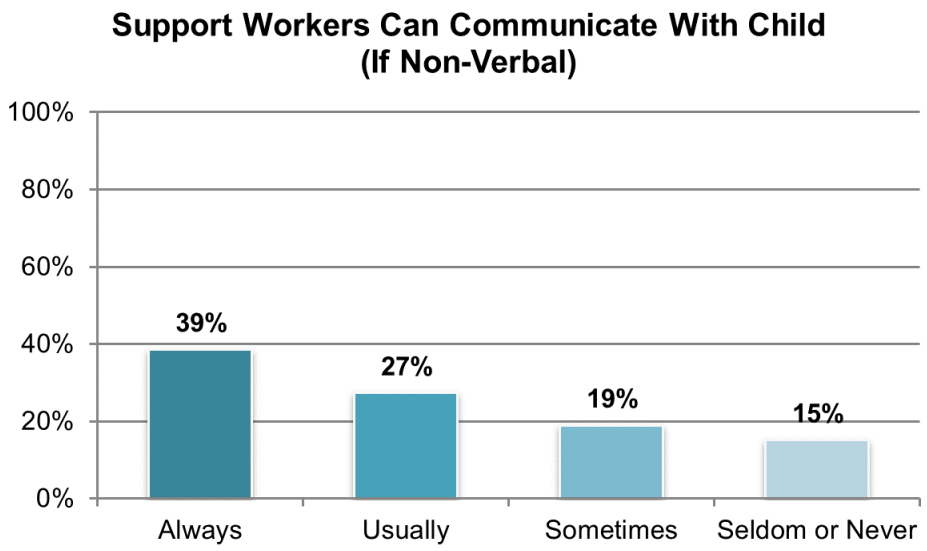


Table Q22. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom or Never	N
Within Average Range					
NC	52%	30%	19%	0%	54
SD	45%	20%	22%	14%	65
OR	44%	15%	24%	17%	54
CA	36%	22%	18%	24%	1,109
UT	35%	31%	23%	10%	124
ID	35%	38%	12%	15%	66
TX	35%	24%	21%	21%	363
VA	27%	39%	14%	20%	44
NCI Average	**39%**	**27%**	**19%**	**15%**	**1,879**

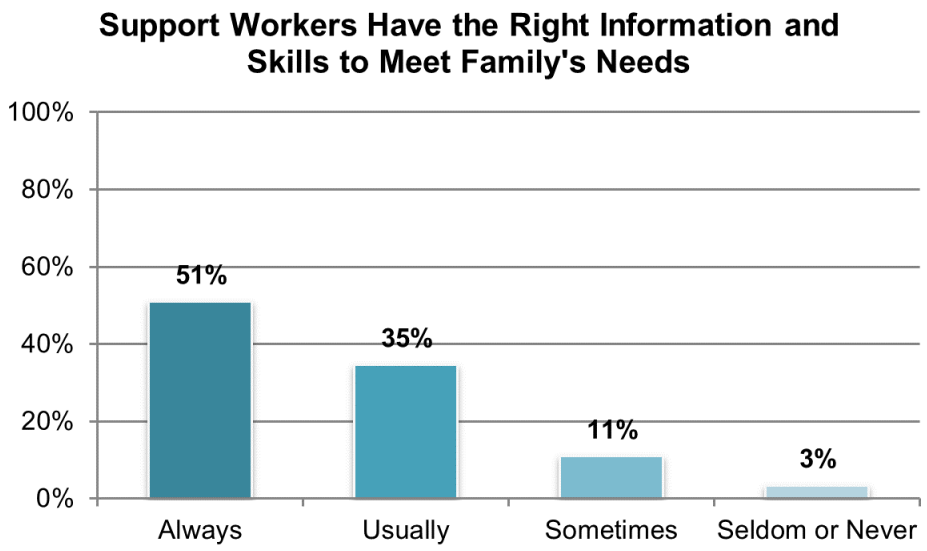


Table Q23. Do support workers have the right information and skills to meet your family's needs?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	67%	24%	9%	1%	174
Within Average Range					
UT	57%	33%	8%	2%	288
TX	53%	34%	10%	3%	1,226
OR	51%	35%	11%	3%	442
CA	50%	32%	13%	4%	10,361
ID	48%	39%	11%	3%	820
NC	43%	41%	11%	4%	229
Significantly Below Average					
VA	39%	40%	14%	7%	144
NCI Average	**51%**	**35%**	**11%**	**3%**	**13,684**

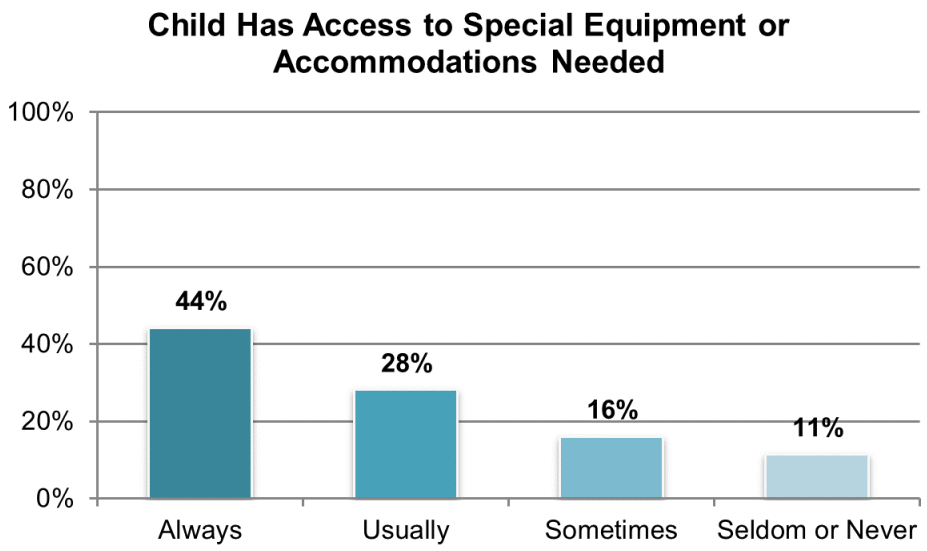


Table Q24. Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	63%	28%	7%	2%	126
TX	50%	29%	14%	8%	930
Within Average Range					
NC	50%	27%	12%	11%	124
UT	40%	28%	22%	10%	162
OR	40%	27%	20%	14%	275
VA	36%	35%	20%	9%	98
Significantly Below Average					
CA**	38%	24%	14%	24%	4,770
ID	37%	28%	20%	15%	397
NCI Average	**44%**	**28%**	**16%**	**11%**	**6,882**

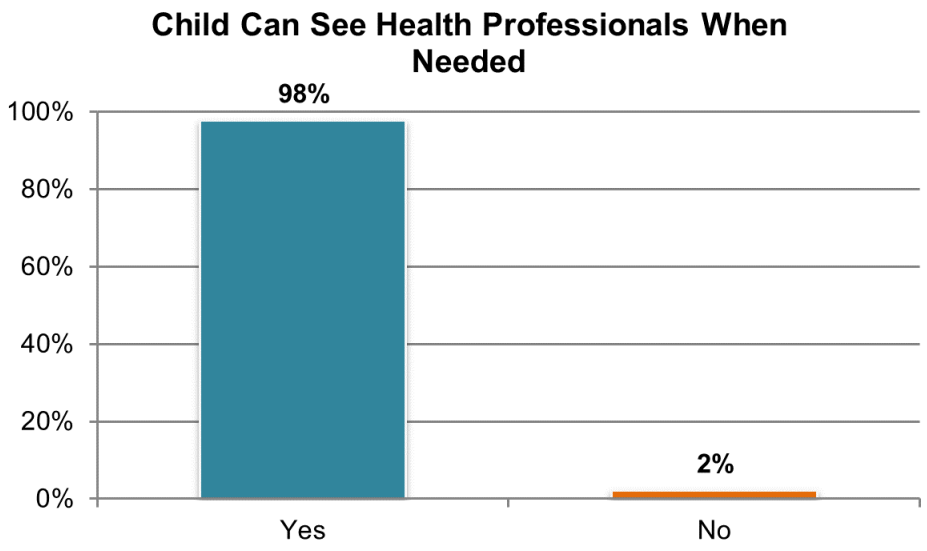


Table Q25. Can your child see health professionals when needed (for example, doctor, dentist, psychologist)?

State	Yes	No	N
Significantly Above Average			
UT	99%	1%	301
Within Average Range			
NC	99%	1%	257
SD	99%	1%	215
ID	98%	2%	948
VA	97%	3%	146
OR	97%	3%	463
Significantly Below Average			
CA**	96%	4%	12,889
TX	96%	4%	1,320
NCI Average	**98%**	**2%**	**16,539**

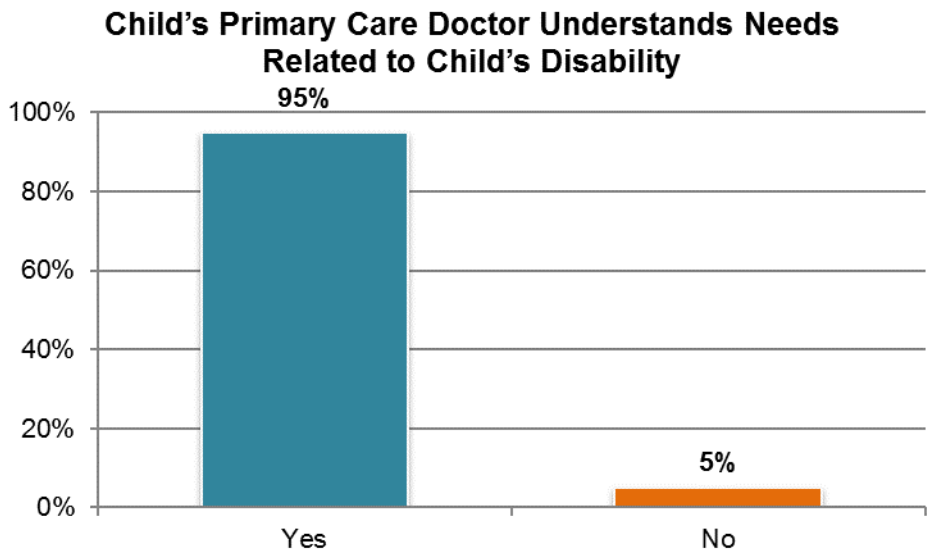


Table Q26. Does your child's primary care doctor understand your child's needs related to his/her disability?

State	Yes	No	N
Significantly Above Average			
UT	97%	3%	290
Within Average Range			
SD	96%	4%	209
NC	95%	5%	244
TX	95%	5%	1,292
ID	94%	6%	888
VA	94%	6%	140
OR	93%	7%	431
Significantly Below Average			
CA**	92%	8%	12,239
NCI Average	**95%**	**5%**	**15,733**

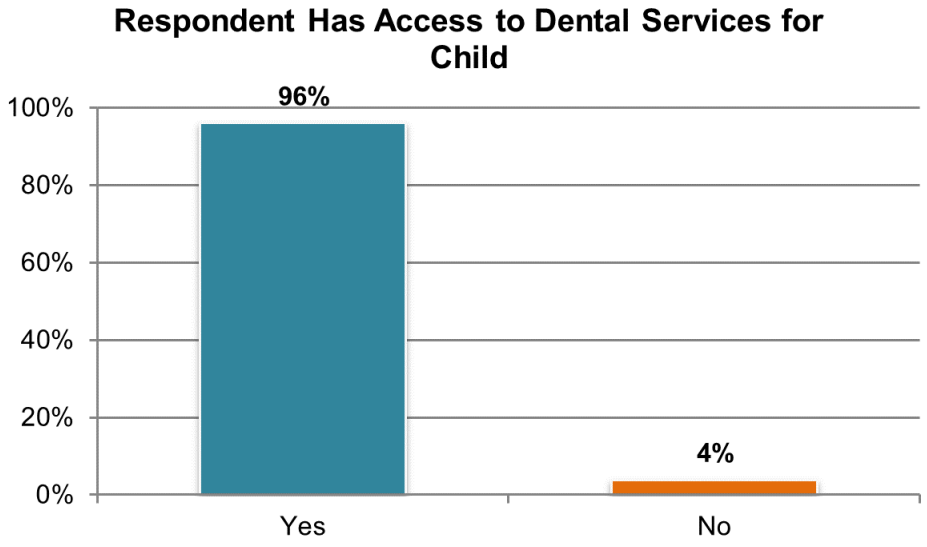


Table Q27. Do you have access to dental services for your child?

State	Yes	No	N
Significantly Above Average			
SD	100%	0%	216
UT	99%	1%	297
Within Average Range			
ID	97%	3%	930
OR	96%	4%	461
VA	95%	5%	144
NC	95%	5%	254
TX	95%	5%	1,302
Significantly Below Average			
CA	92%	8%	12,442
NCI Average	**96%**	**4%**	**16,046**

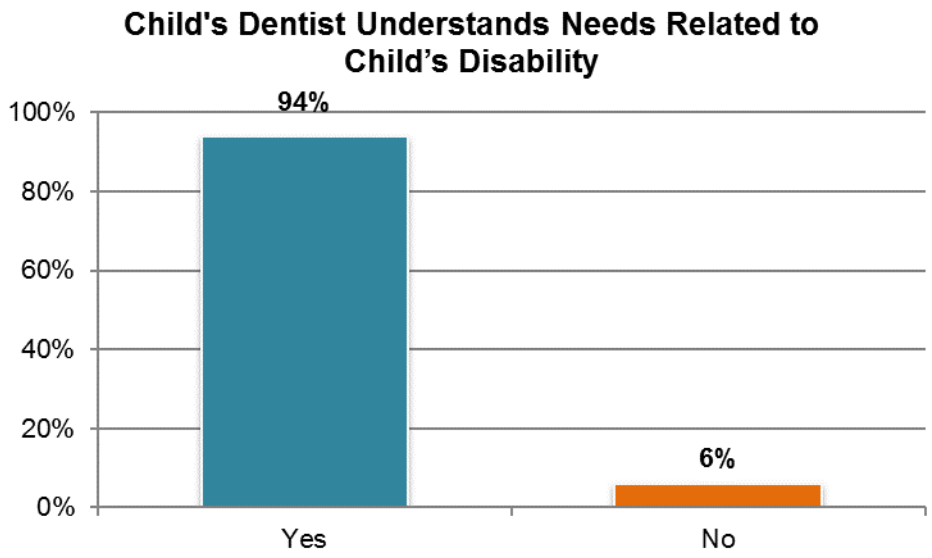


Table Q28. If yes to Q27, does your child's dentist understand your child's needs related to his/her disability?

State	Yes	No	N
Significantly Above Average			
TX	96%	4%	1,179
Within Average Range			
SD	95%	5%	188
UT	95%	5%	275
ID	94%	6%	815
NC	94%	6%	228
OR	93%	7%	400
VA	92%	8%	126
Significantly Below Average			
CA**	92%	8%	10,249
NCI Average	**94%**	**6%**	**13,460**

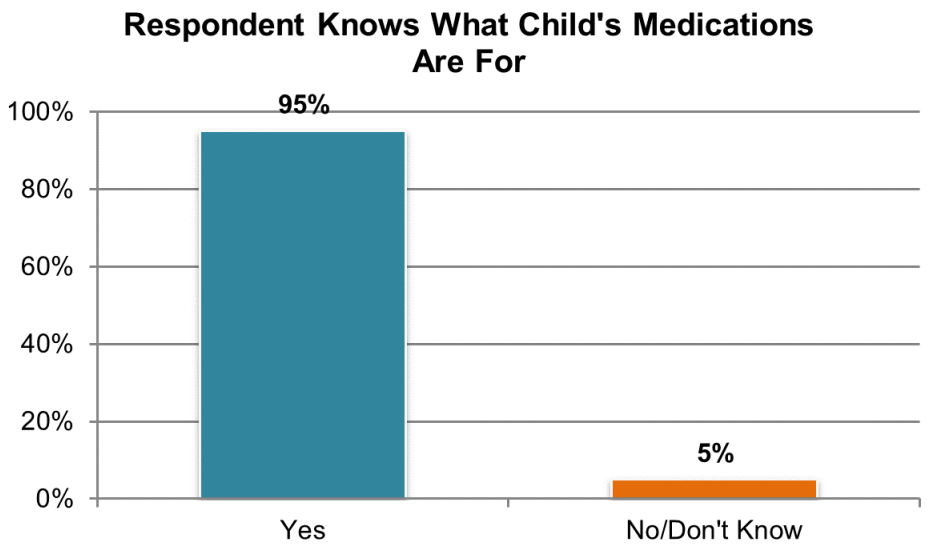


Table Q29. If your child takes medications, do you know what they're for?[1]

State	Yes	No/Don't Know	N
Significantly Above Average			
TX	99%	1%	1,201
Within Average Range			
VA	98%	2%	137
NC	97%	3%	226
UT	97%	3%	235
OR	95%	5%	366
ID	95%	5%	675
SD	93%	7%	176
Significantly Below Average			
CA	86%	14%	8,597
NCI Average	**95%**	**5%**	**11,613**

[1] For this question, 'no' and 'don't know' responses were combined.

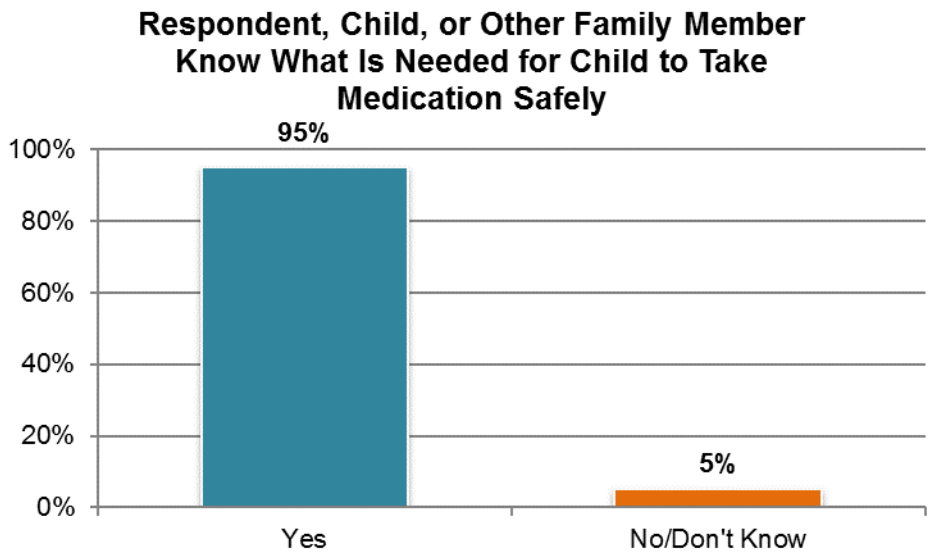


Table Q30. If your child takes medications, do you, your child, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?[2]

State	Yes	No/Don't Know	N
Significantly Above Average			
TX	98%	2%	1,183
Within Average Range			
VA	97%	3%	132
OR	96%	4%	350
ID	96%	4%	648
UT	96%	4%	229
SD	95%	5%	169
NC	93%	7%	219
Significantly Below Average			
CA	92%	8%	7,533
NCI Average	**95%**	**5%**	**10,463**

[2] For this question, 'no' and 'don't know' responses were combined.

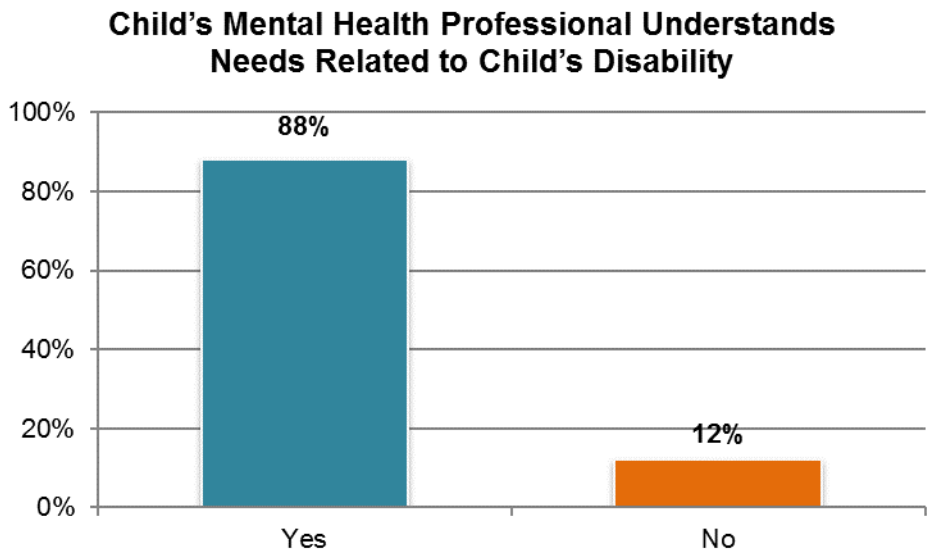


Table Q31. If your child uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your child's needs related to his/her disability?

State	Yes	No	N
Significantly Above Average			
ID	92%	8%	443
Within Average Range			
UT	93%	7%	110
TX*	91%	9%	625
NC	91%	9%	121
VA	90%	10%	72
SD	88%	12%	73
OR	86%	14%	182
Significantly Below Average			
CA	75%	25%	5,211
NCI Average	**88%**	**12%**	**6,837**

*The modes by which TX administered this survey may have affected the percentages of people who replied "yes" to this question. Results for those who replied using the paper mode demonstrated lower proportions of "yes" than for all three modes combined. See section "Sampling & Administration" for more information.

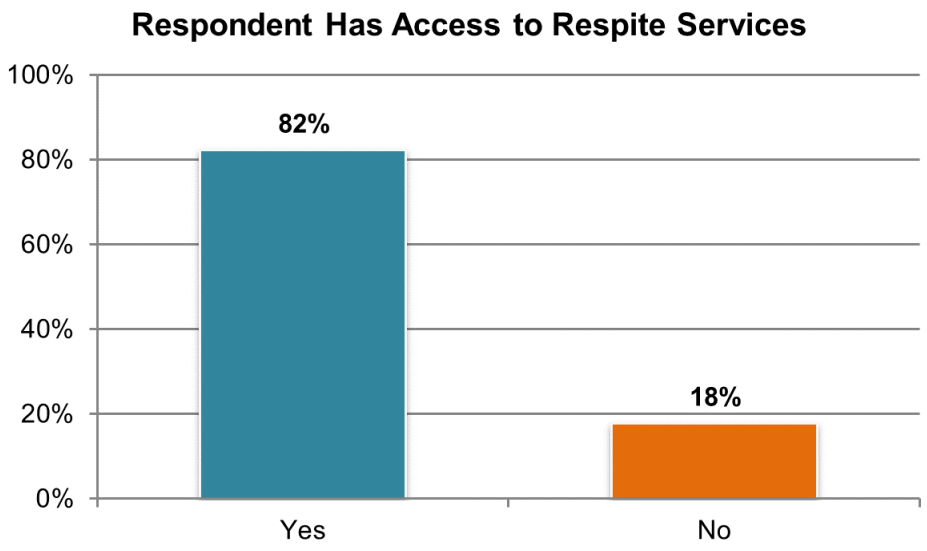


Table Q32. If you need respite services, do you have access to them?

State	Yes	No	N
Significantly Above Average			
UT	89%	11%	276
OR	88%	12%	390
Within Average Range			
SD	85%	15%	155
TX	84%	16%	1,198
NC	83%	17%	233
CA	82%	18%	9,957
VA	82%	18%	136
Significantly Below Average			
ID	65%	35%	603
NCI Average	**82%**	**18%**	**12,948**

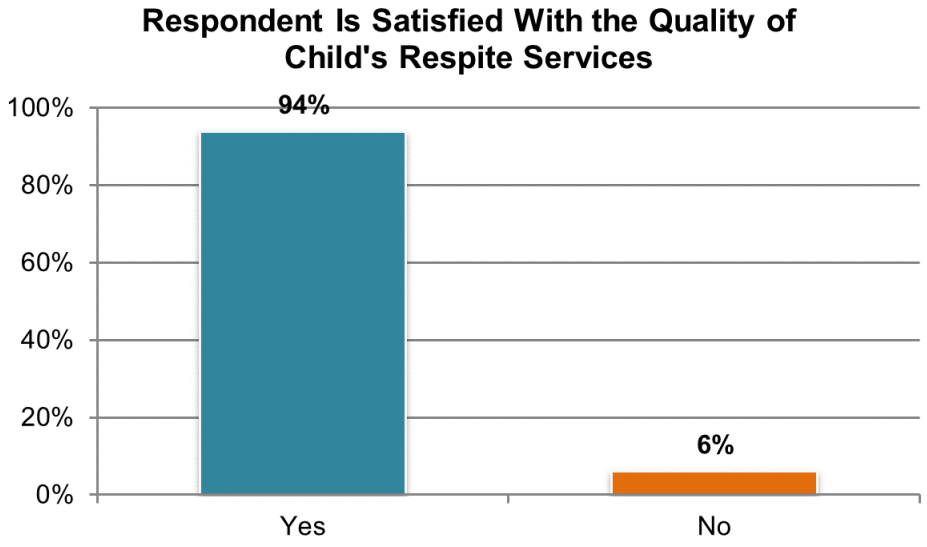


Table Q33. If Yes to Q32, are you satisfied with the quality of the respite services?

State	Yes	No	N
Significantly Above Average			
TX	97%	3%	932
Within Average Range			
SD	96%	4%	121
VA	95%	5%	106
UT	95%	5%	238
ID	94%	6%	332
OR	94%	6%	325
NC	91%	9%	185
Significantly Below Average			
CA	90%	10%	7,457
NCI Average	**94%**	**6%**	**9,696**

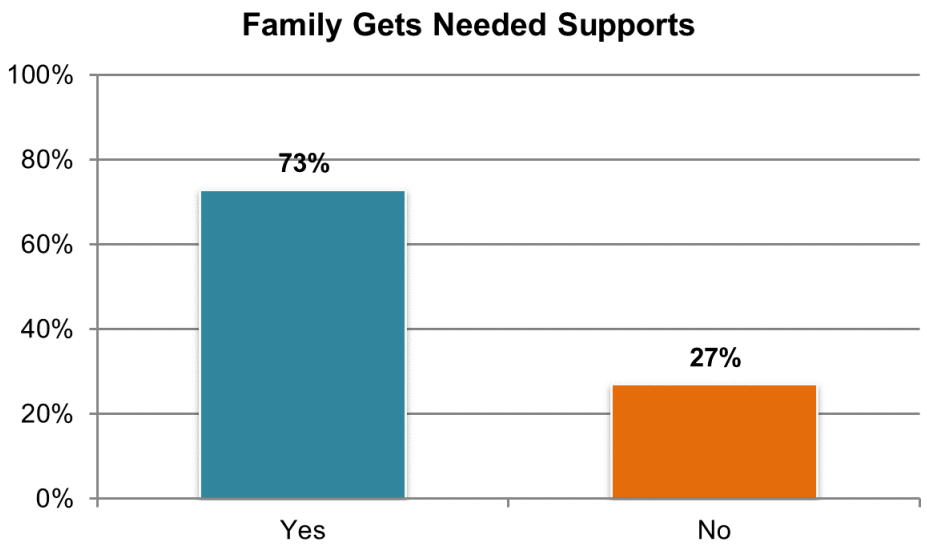


Table Q34. Does your family get the support needed?

State	Yes	No	N
Significantly Above Average			
SD	88%	12%	201
TX*	82%	18%	1,266
Within Average Range			
OR	74%	26%	439
ID	73%	27%	836
VA	71%	29%	139
UT	68%	32%	290
Significantly Below Average			
CA	64%	36%	11,400
NC	63%	37%	249
NCI Average	**73%**	**27%**	**14,820**

*The modes by which TX administered this survey may have affected the percentages of people who replied "yes" to this question. Results for those who replied using the paper mode demonstrated lower proportions of "yes" than for all three modes combined. See section "Sampling & Administration" for more information.

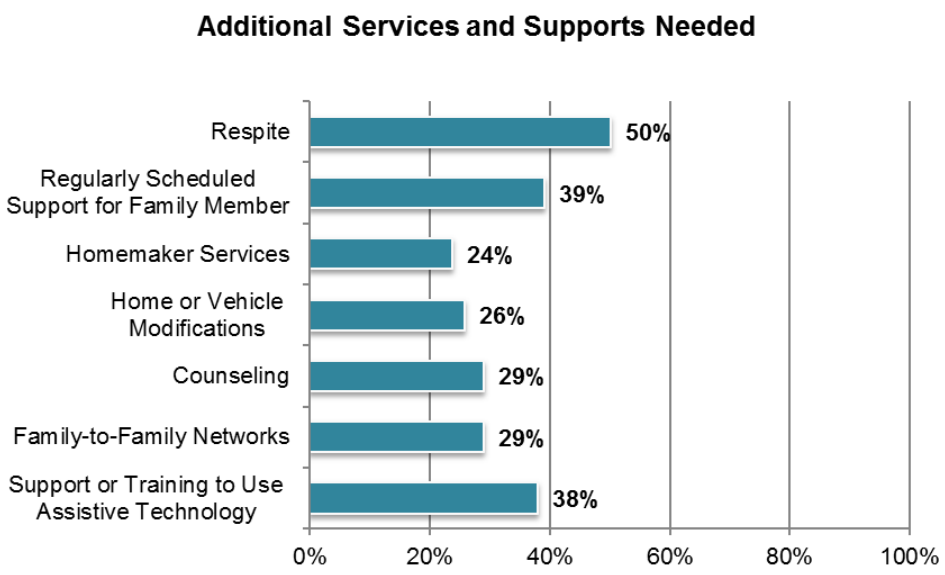


Table Q35. If no to Q34, what additional services are needed?

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-Family Networks	Support or Training to Use Assistive Technology	N
CA	46%	39%	24%	16%	36%	29%	31%	3,725
ID	67%	30%	20%	17%	23%	33%	41%	218
NC	46%	43%	16%	19%	30%	26%	36%	90
OR	52%	40%	32%	28%	35%	35%	42%	112
SD	36%	41%	27%	27%	23%	27%	45%	22
TX	57%	51%	35%	42%	40%	38%	39%	216
UT	55%	35%	25%	26%	24%	29%	24%	91
VA	44%	33%	10%	31%	21%	15%	49%	39
NCI Average	**50%**	**39%**	**24%**	**26%**	**29%**	**29%**	**38%**	**4,513**

Choice, Decision Making and Control

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

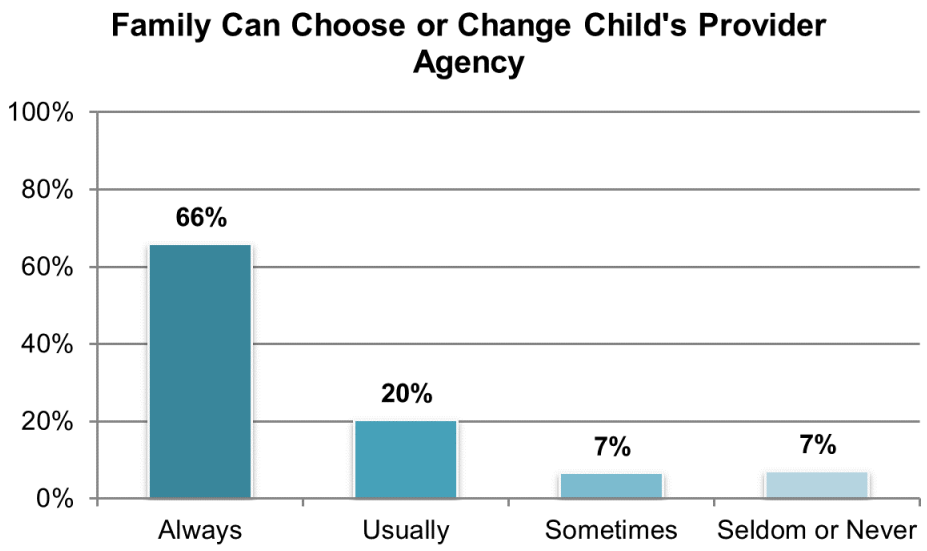


Table Q36. Can your family choose or change the agency that provides your child's services?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
UT	75%	19%	4%	2%	238
TX	74%	14%	6%	6%	1,221
NC	74%	17%	7%	2%	218
ID	74%	18%	4%	5%	751
Within Average Range					
SD	69%	24%	4%	3%	124
VA	68%	20%	6%	7%	105
Significantly Below Average					
CA	48%	27%	11%	14%	7,170
OR	46%	24%	11%	19%	210
NCI Average	**66%**	**20%**	**7%**	**7%**	**10,037**

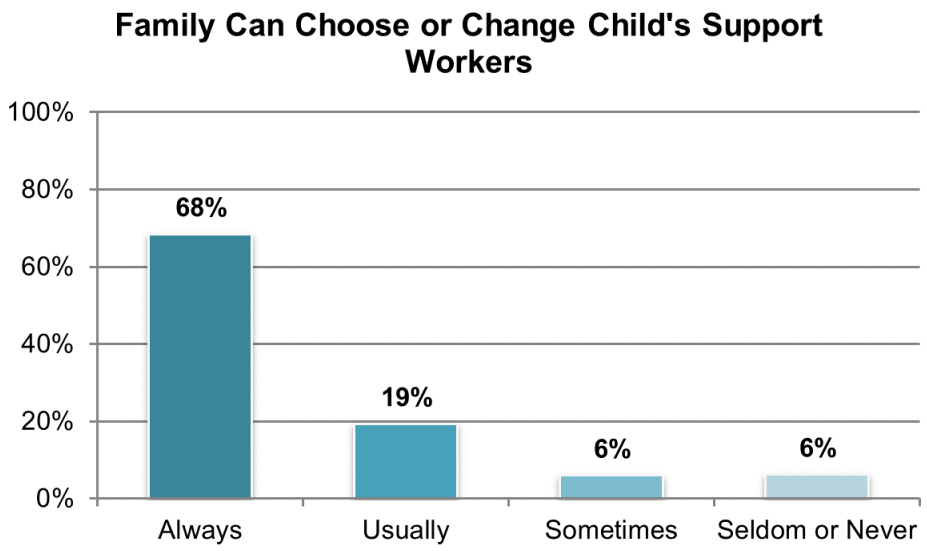


Table Q37. Can your family choose or change your child's support workers?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
UT	80%	14%	3%	3%	266
Within Average Range					
SD	73%	19%	2%	6%	124
OR	72%	18%	4%	7%	334
NC	72%	18%	4%	5%	223
TX	69%	17%	6%	8%	1,154
ID	66%	22%	6%	5%	755
VA	64%	22%	10%	4%	124
Significantly Below Average					
CA	53%	25%	11%	11%	7,230
NCI Average	**68%**	**19%**	**6%**	**6%**	**10,210**

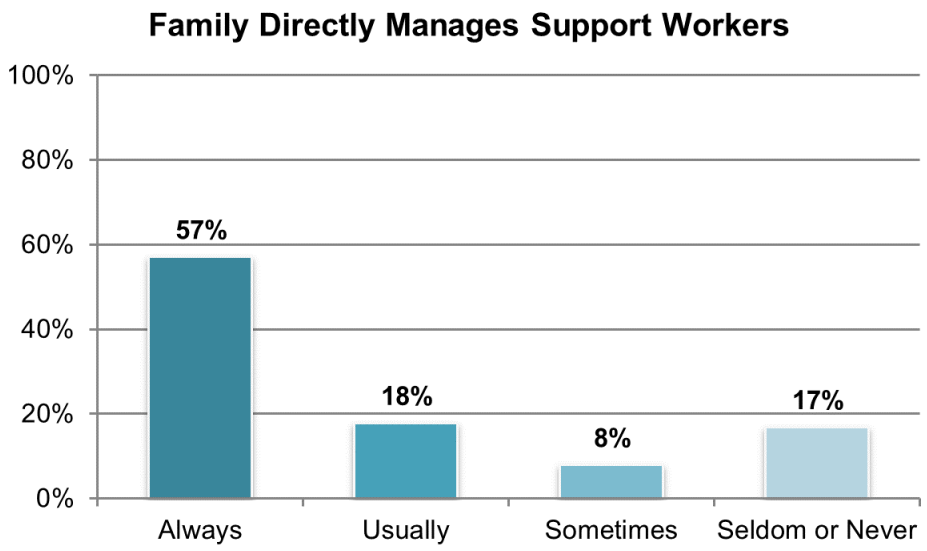


Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
OR	77%	11%	5%	8%	400
UT	69%	12%	5%	13%	275
VA	69%	15%	7%	9%	137
Within Average Range					
TX	61%	13%	9%	17%	1,155
SD	49%	28%	7%	17%	107
Significantly Below Average					
NC	47%	27%	9%	17%	223
CA	43%	20%	12%	24%	7,373
ID	43%	16%	11%	29%	717
NCI Average	**57%**	**18%**	**8%**	**17%**	**10,387**

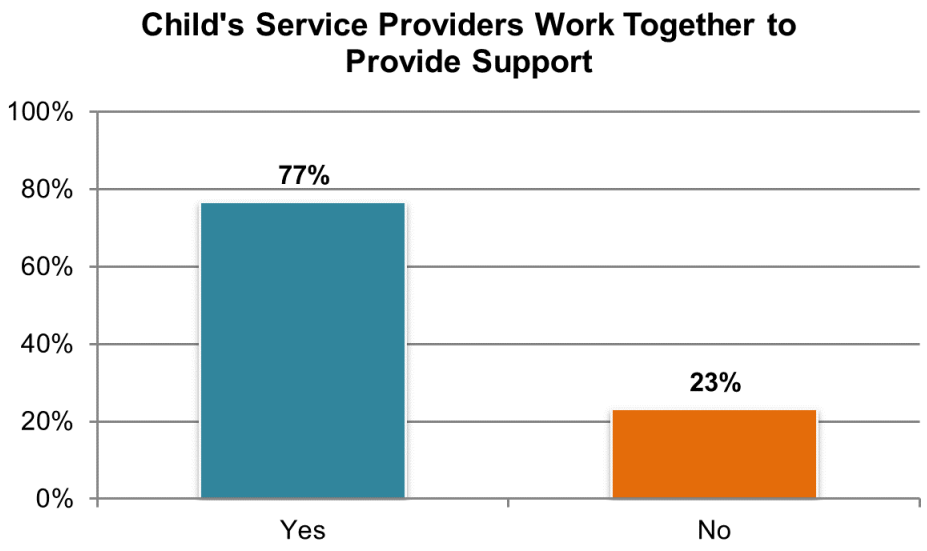


Table Q39. Do service providers for your child work together to provide support?

State	Yes	No	N
Significantly Above Average			
TX	85%	15%	939
UT	85%	15%	148
Within Average Range			
SD	85%	15%	82
ID	81%	19%	506
NC	78%	22%	133
VA	71%	29%	86
Significantly Below Average			
OR	66%	34%	210
CA	62%	38%	5,062
NCI Average	**77%**	**23%**	**7,166**

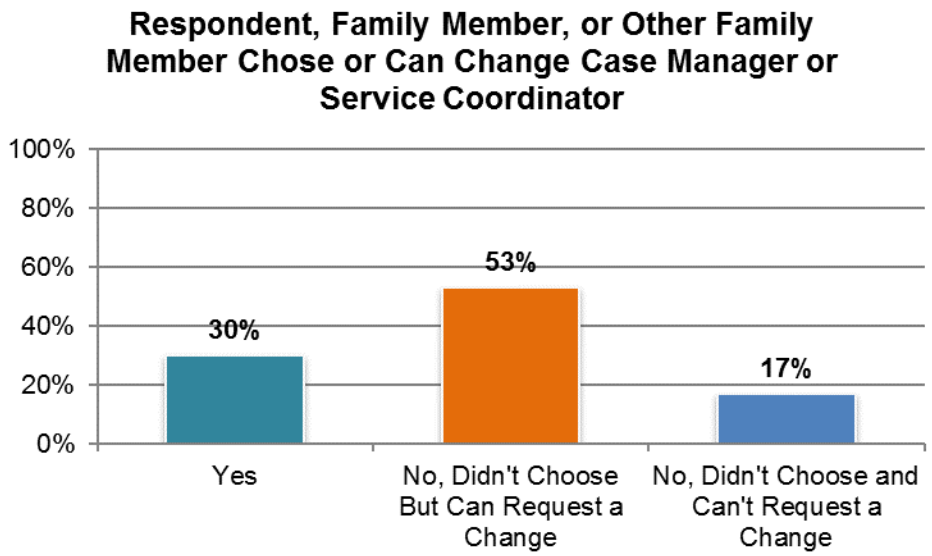


Table Q40. Did you, your child, or someone else in your family choose your child's case manager/service coordinator?

State	Yes	No, Didn't Choose But Can Request a Change	No, Didn't Choose and Can't Request a Change	N
Significantly Above Average				
UT	68%	25%	6%	280
ID	36%	48%	16%	648
Within Average Range				
VA	35%	46%	19%	129
Significantly Below Average				
NC	26%	60%	14%	208
SD	20%	74%	6%	154
TX	19%	55%	26%	1,068
OR	8%	65%	27%	341
NCI Average	**30%**	**53%**	**17%**	**2,828**

***CA IS NOT INCLUDED DUE TO A DISCREPANCY IN DATA COLLECTION.**

Involvement in the Community

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

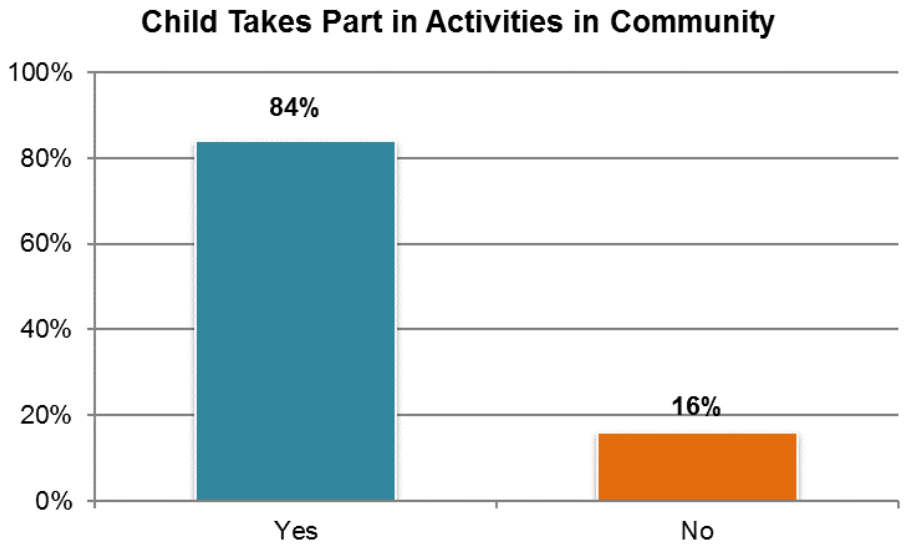


Table Q41. Does your child take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

State	Yes	No	N
Significantly Above Average			
SD	92%	8%	213
Within Average Range			
VA	88%	12%	147
ID	86%	14%	921
OR	84%	16%	462
NC	83%	17%	253
UT	79%	21%	302
Significantly Below Average			
TX	80%	20%	1,321
CA	78%	22%	12,920
NCI Average	**84%**	**16%**	**16,539**

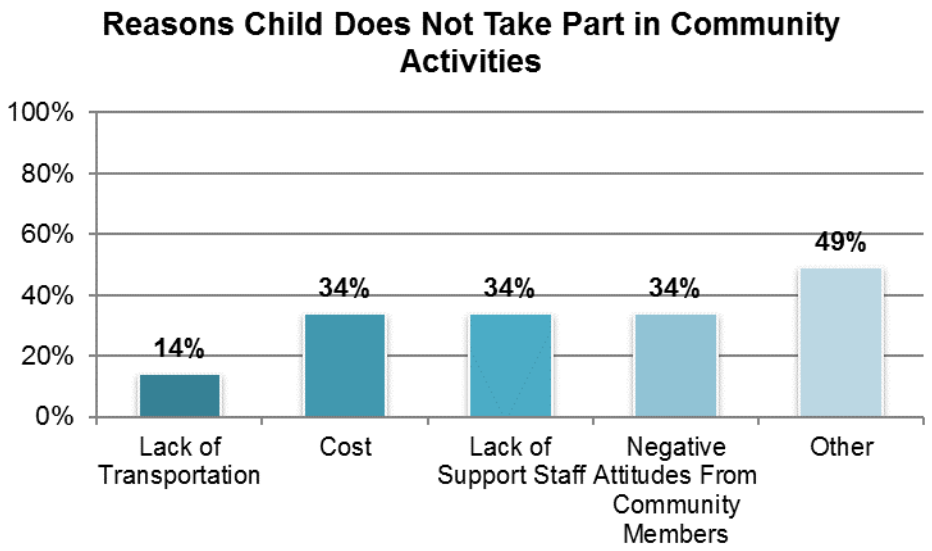


Table Q42. If no to Q41, why did the child not take part in community activities?

State	Lack of transportation	Cost	Lack of Support Staff	Negative Attitudes from Community Members	Other	N
CA	20%	38%	35%	34%	34%	2,561
ID	12%	44%	35%	40%	41%	124
NC	15%	43%	38%	35%	40%	40
OR	14%	33%	30%	33%	63%	70
TX	15%	17%*	32%**	23%	69%	205
UT	9%	30%	31%	39%	47%	64
NCI Average	**14%**	**34%**	**34%**	**34%**	**49%**	**3,064**

Due to low response rate (<20), the following states were not included in this analysis: SD, VA.

*The modes by which TX administered this survey may have affected the percentages of people who replied "yes" to this question. Results for those who replied using the paper mode demonstrated higher proportions of "yes" than for all three modes combined. See section "Sampling & Administration" for more information.

**The modes by which TX administered this survey may have affected the percentages of people who replied "yes" to this question. Results for those who replied using the paper mode demonstrated lower proportions of "yes" than for all three modes combined. See section "Sampling & Administration" for more information.

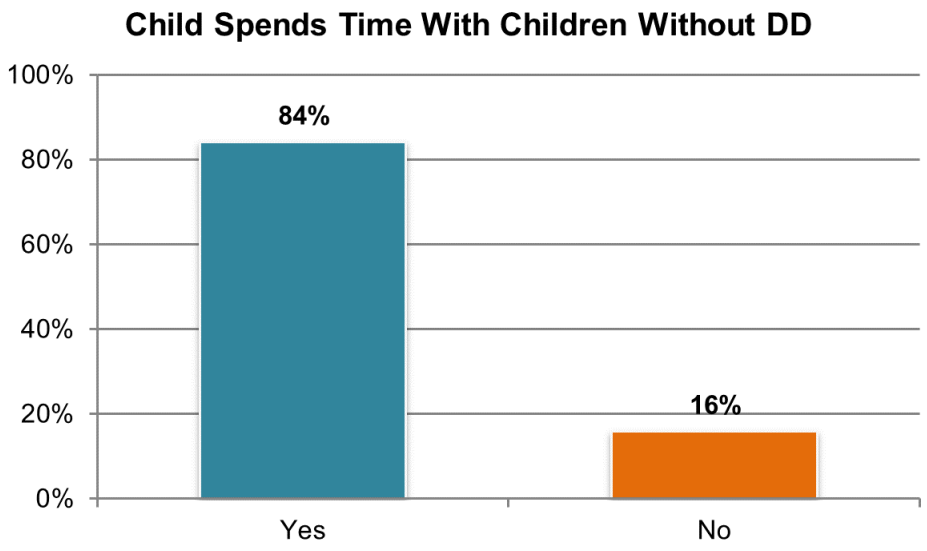


Table Q43. Does your child spend time with children who do not have developmental disabilities?

State	Yes	No	N
Significantly Above Average			
ID	92%	8%	927
SD	91%	9%	212
CA**	85%	15%	12,921
Within Average Range			
TX	83%	17%	1,315
OR	82%	18%	463
UT	81%	19%	294
VA	81%	19%	144
NC	79%	21%	255
NCI Average	**84%**	**16%**	**16,531**

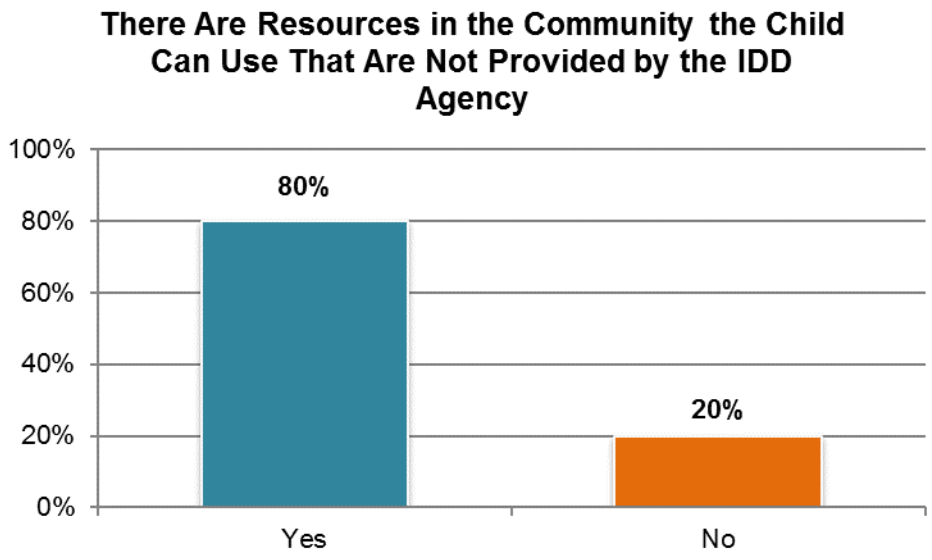


Table Q44. In your community, are there resources that your family can use that are not provided by the IDD agency?

State	Yes	No	N
Significantly Above Average			
ID	88%	12%	771
OR	86%	14%	353
Within Average Range			
NC	84%	16%	218
SD	82%	18%	190
UT	77%	23%	237
VA	75%	25%	122
Significantly Below Average			
CA**	77%	23%	9,955
TX	73%	27%	1,057
NCI Average	**80%**	**20%**	**12,903**

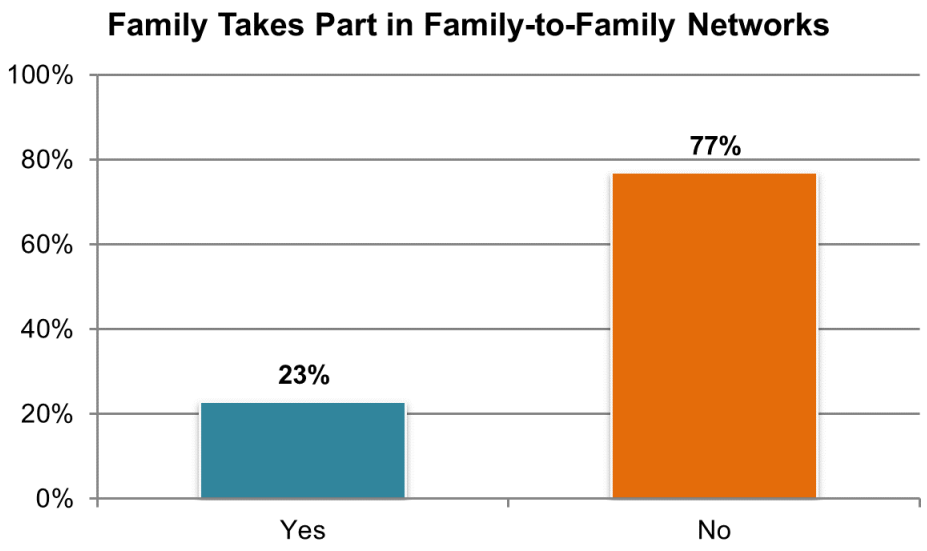


Table Q45. Does your family take part in any family-to-family networks in your community?

State	Yes	No	N
Significantly Above Average			
TX	31%	69%	1,211
CA	29%	71%	11,319
Within Average Range			
OR	26%	74%	419
NC	24%	76%	221
SD	23%	77%	181
UT	18%	82%	285
Significantly Below Average			
ID	19%	81%	803
VA	14%	86%	125
NCI Average	**23%**	**77%**	**14,564**

Satisfaction With Services and Supports

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

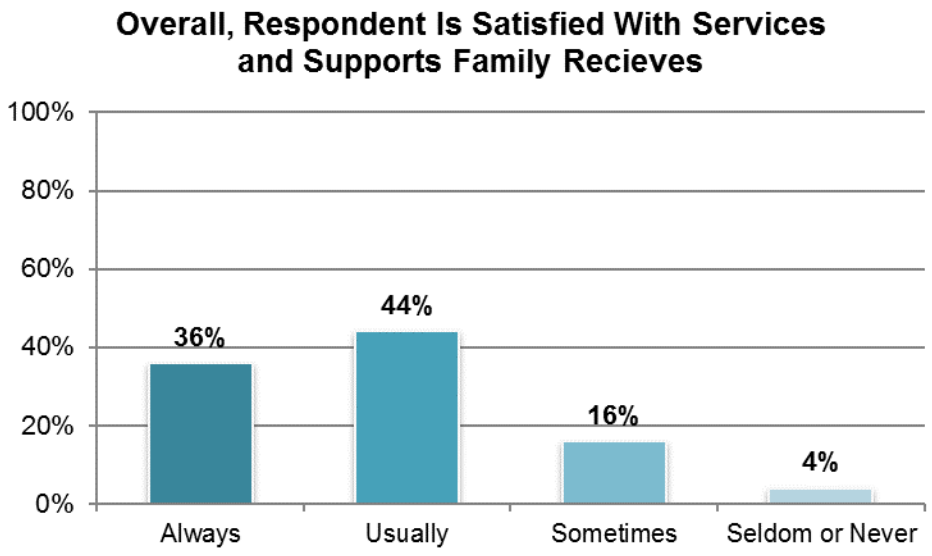


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
SD	53%	37%	9%	1%	213
TX	42%	40%	13%	5%	1,313
Within Average Range					
UT	42%	45%	10%	3%	295
VA	30%	44%	22%	4%	147
Significantly Below Average					
CA**	35%	36%	22%	8%	12,696
OR	30%	50%	17%	3%	456
ID	29%	47%	19%	4%	930
NC	27%	52%	15%	7%	248
NCI Average	**36%**	**44%**	**16%**	**4%**	**16,298**

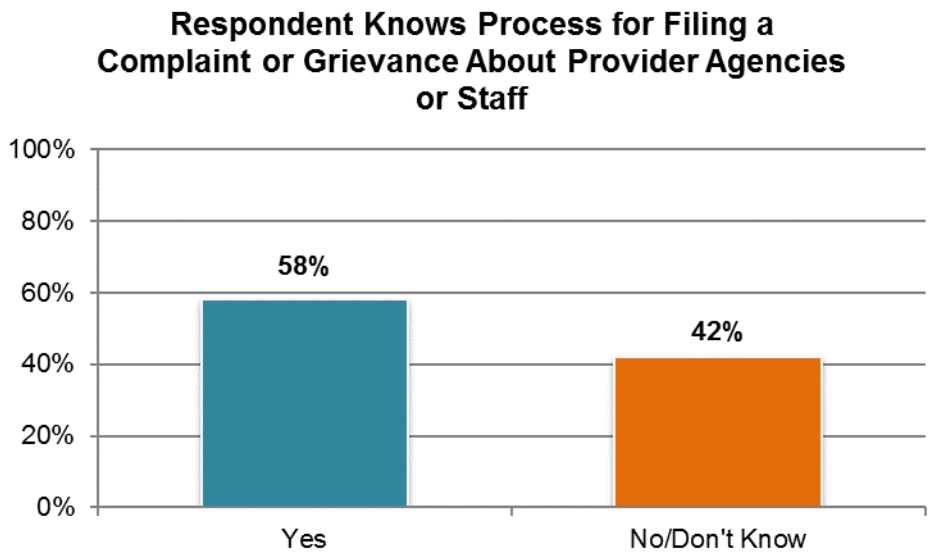


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?[3]

State	Yes	No/Don't Know	N
Significantly Above Average			
SD	74%	26%	214
TX	70%	30%	1,326
Within Average Range			
OR	58%	42%	464
UT	58%	42%	298
NC	57%	43%	251
VA	53%	47%	146
Significantly Below Average			
ID	52%	48%	944
CA	43%	57%	12,963
NCI Average	**58%**	**42%**	**16,606**

[3] For this question 'No' and Don't Know' responses were combine.

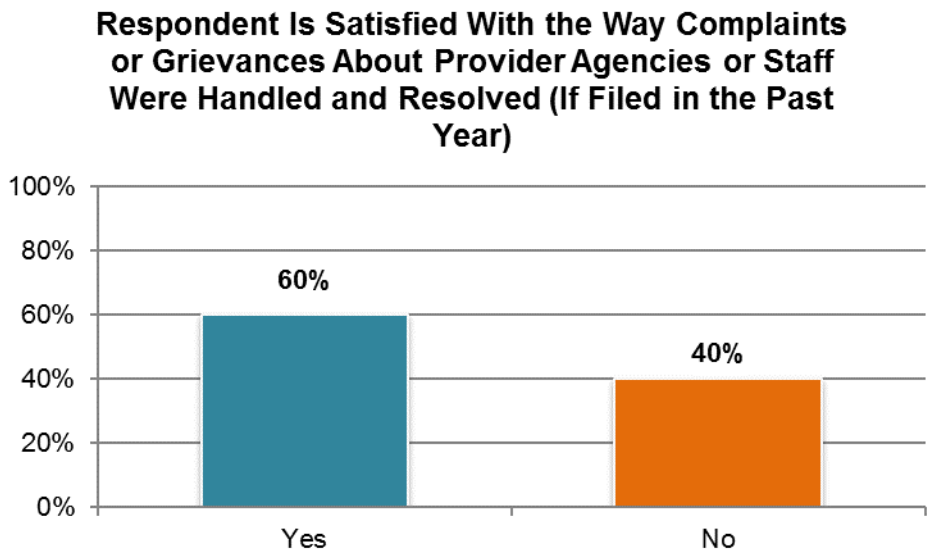


Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

State	Yes	No	N
Significantly Above Average			
TX*	74%	26%	253
Within Average Range			
NC	67%	33%	48
OR	59%	41%	39
ID	57%	43%	105
UT	55%	45%	20
Significantly Below Average			
CA	50%	50%	2,287
NCI Average	**60%**	**40%**	**2,752**

Due to low response rate (<20), the following states were not included in this analysis: SD and VA.

*The modes by which TX administered this survey may have affected the percentages of people who replied "yes" to this question. Results for those who replied using the paper mode demonstrated lower proportions of "yes" than for all three modes combined. See section "Sampling & Administration" for more information.

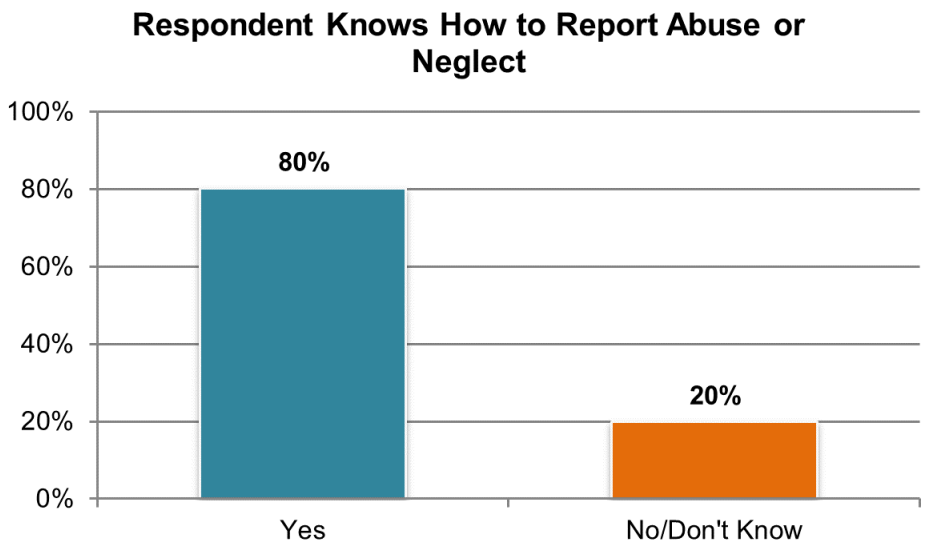


Table Q49. Do you know how to report abuse or neglect related to your child?[4]

State	Yes	No/Don't Know	N
Significantly Above Average			
SD	93%	7%	214
TX	84%	16%	1,327
Within Average Range			
OR	84%	16%	465
VA	83%	17%	145
NC	82%	18%	253
UT	77%	23%	300
Significantly Below Average			
ID	75%	25%	946
CA	61%	39%	12,963
NCI Average	**80%**	**20%**	**16,613**

[4] For this question, 'No' and Don't Know' responses were combined.

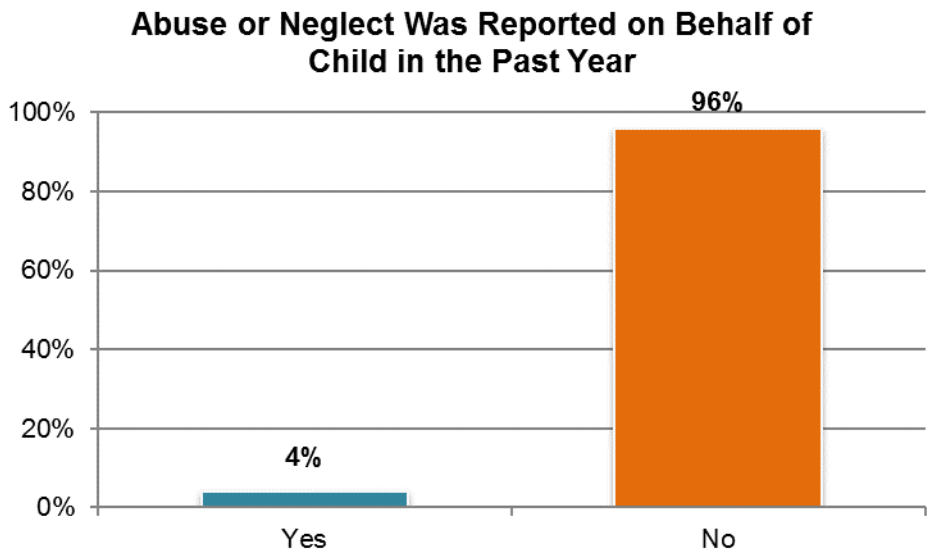


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child?

State	Yes	No	N
Within Average Range			
NC	7%	93%	249
UT	5%	95%	288
CA	4%	96%	12,245
TX	4%	96%	1,312
OR	4%	96%	432
ID	4%	96%	883
VA	3%	97%	145
SD	2%	98%	204
NCI Average	**4%**	**96%**	**15,758**

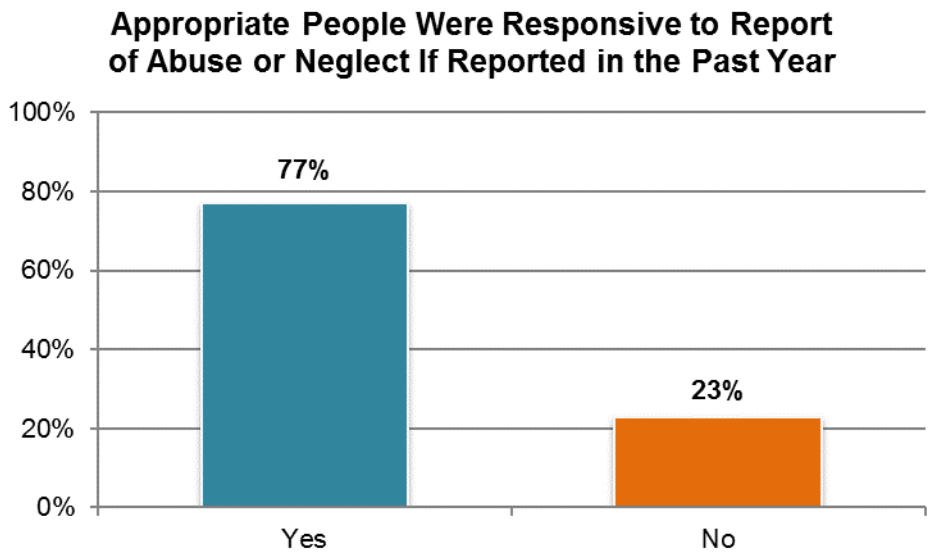


Table Q51. If yes to Q50, did the appropriate people respond to the report?

State	Yes	No	N
Within Average Range			
ID	86%	14%	28
TX	78%	22%	47
Significantly Below Average			
CA	69%	31%	363
NCI Average	**77%**	**23%**	**438**

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: NC, OR, SD, UT, AND VA.

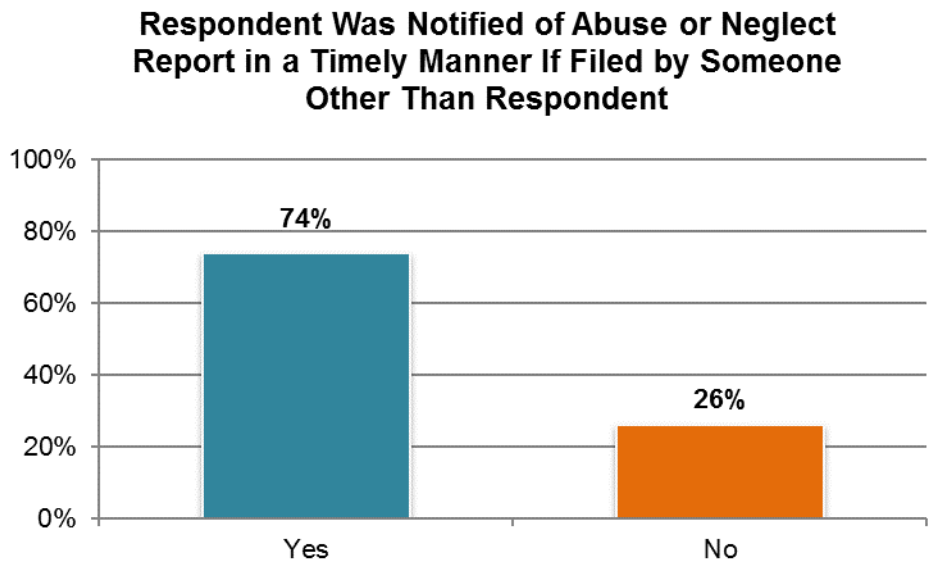


Table Q52. If Yes to Q50, if someone other than you reported abuse or neglect in the past year, were you notified of the report in a timely manner?

State	Yes	No	N
Within Average Range			
ID	86%	14%	22
TX	68%	32%	36
CA	67%	33%	311
NCI Average	**74%**	**26%**	**369**

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: NC, OR, SD, UT, AND VA.

Family Outcomes

Individual and family supports make a positive difference in the lives of families.

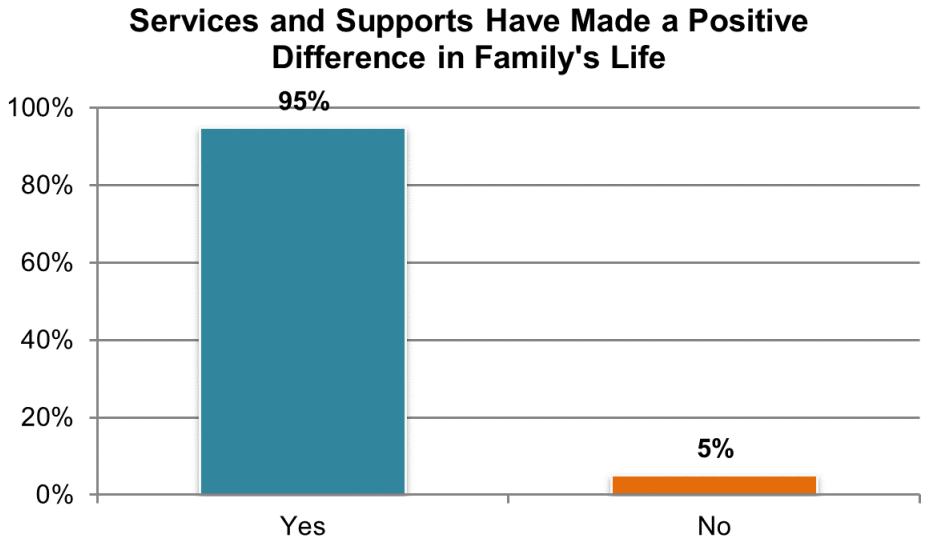


Table Q53. Do you feel that services and supports have made a positive difference in the life of your family?

State	Yes	No	N
Significantly Above Average			
SD	99%	1%	206
UT	98%	2%	291
Within Average Range			
OR	97%	3%	432
VA	96%	4%	135
NC	95%	5%	231
Significantly Below Average			
TX	93%	7%	1,247
ID	93%	7%	827
CA	90%	10%	11,070
NCI Average	**95%**	**5%**	**14,439**

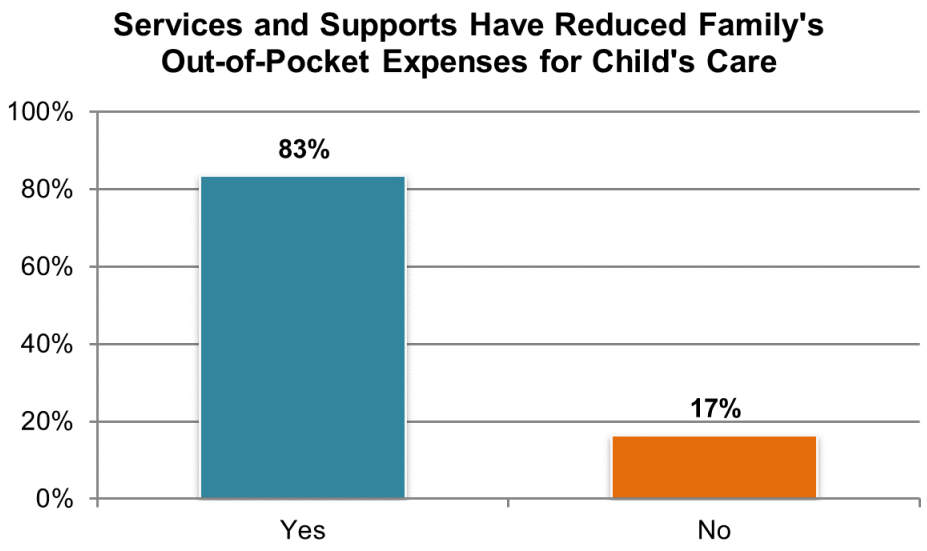


Table Q54. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your child's care?

State	Yes	No	N
Significantly Above Average			
SD	97%	3%	203
UT	89%	11%	287
Within Average Range			
OR	87%	13%	437
VA	86%	14%	139
TX	84%	16%	1,259
NC	77%	23%	235
Significantly Below Average			
ID	77%	23%	836
CA	72%	28%	11,122
NCI Average	**83%**	**17%**	**14,518**

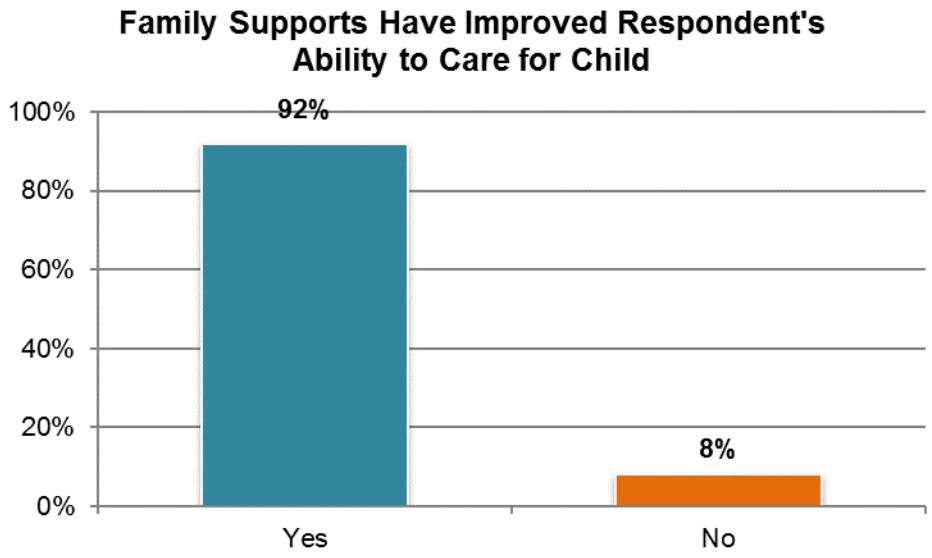


Table Q55. Do you feel that family supports have improved your ability to care for your child?

State	Yes	No	N
Significantly Above Average			
UT	96%	4%	291
Within Average Range			
SD	96%	4%	202
VA	95%	5%	138
OR	93%	7%	445
TX	93%	7%	1,259
NC	91%	9%	229
Significantly Below Average			
ID	89%	11%	859
CA	87%	13%	11,223
NCI Average	**92%**	**8%**	**14,646**

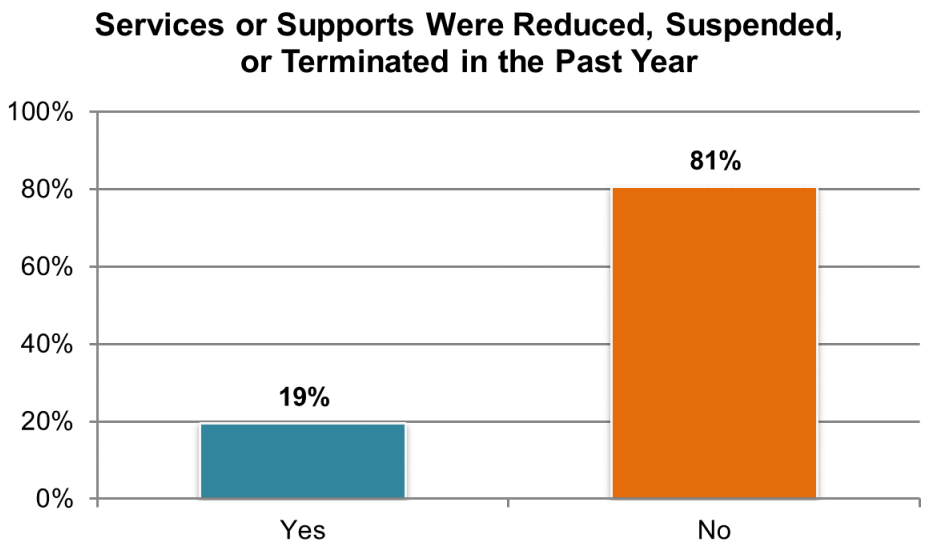


Table Q56. Have the services or supports that you or your child received during the past year been reduced, suspended, or terminated?

State	Yes	No	N
Significantly Above Average			
CA	28%	72%	11,406
Within Average Range			
OR	25%	75%	442
NC	23%	77%	231
ID	21%	79%	883
TX	20%	80%	1,249
VA	18%	82%	142
Significantly Below Average			
UT	11%	89%	284
SD	10%	91%	200
NCI Average	**19%**	**81%**	**14,837**

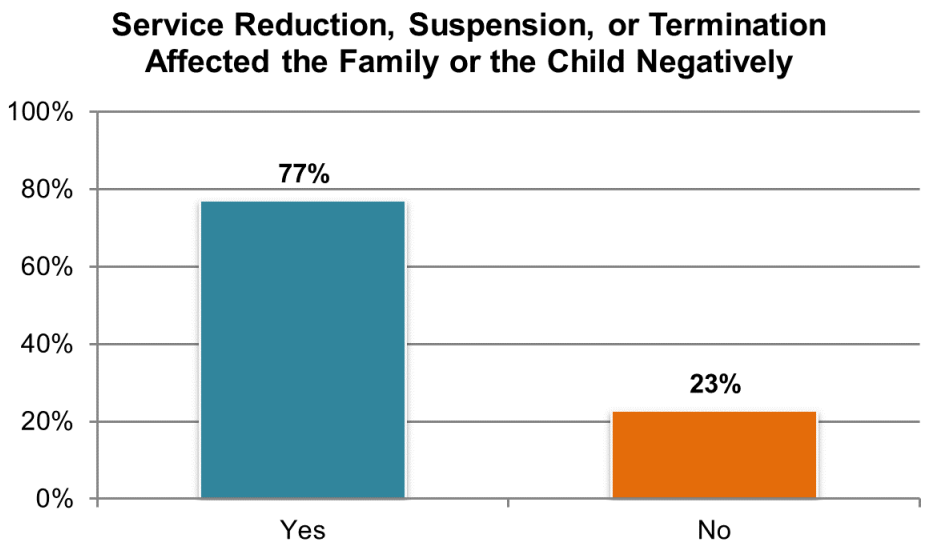


Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your child negatively?

State	Yes	No	N
Significantly Above Average			
VA	96%	4%	24
Within Average Range			
NC	86%	14%	51
ID	84%	16%	162
TX	73%	27%	216
OR	72%	28%	95
UT	64%	36%	25
Significantly Below Average			
CA	65%	35%	2,203
NCI Average	**77%**	**23%**	**2,776**

DUE TO LOW RESPONSE RATE (<20), SD WAS NOT INCLUDED IN THIS ANALYSIS.

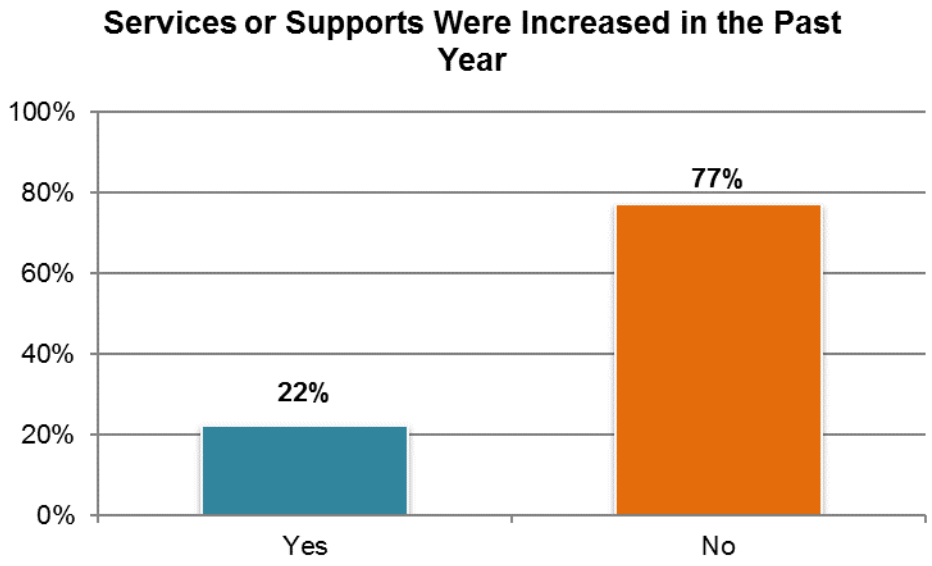


Table Q58. Have the services or supports that your child received been increased in the past year?

State	Yes	No	N
Significantly Above Average			
OR	41%	59%	427
Within Average Range			
UT	28%	72%	258
NC	21%	79%	232
TX	20%	80%	1,256
SD	18%	82%	172
VA	17%	83%	138
Significantly Below Average			
CA**	18%	82%	11,686
ID	17%	83%	876
NCI Average	**22%**	**78%**	**15,045**

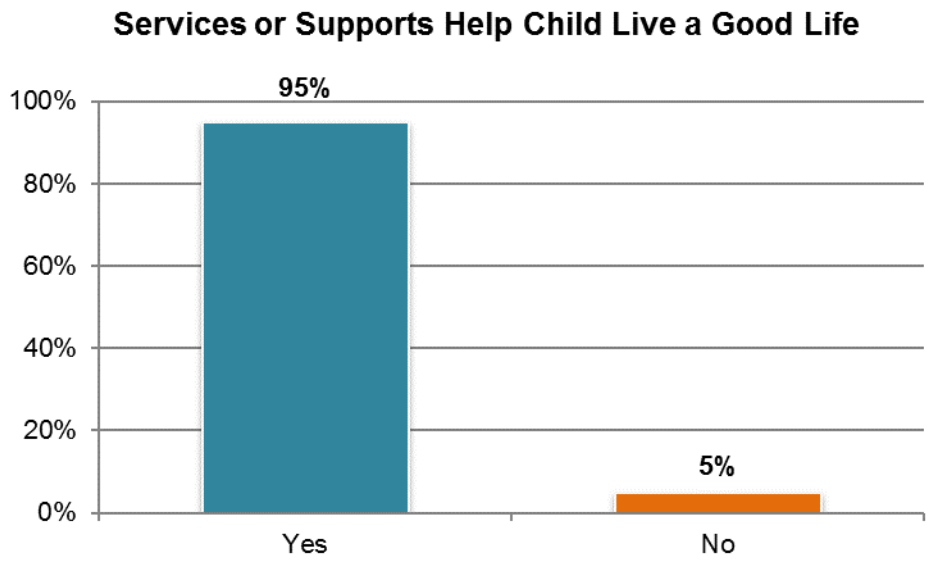


Table Q59. Are services and supports helping your child to live a good life?

State	Yes	No	N
Significantly Above Average			
SD	99%	1%	199
UT	98%	2%	285
Within Average Range			
OR	96%	4%	435
TX	96%	4%	1,278
ID	95%	5%	843
VA	94%	6%	135
NC	92%	8%	231
Significantly Below Average			
CA	91%	9%	11,243
NCI Average	**95%**	**5%**	**14,649**

II. NCI History and Activities

This section briefly describes the history of the National Core Indicators and NCI surveys.

Overview of National Core Indicators

In December 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI), launched the Core Indicators Project (CIP). The aim of the project was to support state developmental disabilities authorities in the development and implementation of performance and outcome indicators—and related data collection strategies—so that they could measure service delivery system performance. This effort, now called National Core Indicators (NCI), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI facilitates pooled knowledge, expertise, and resources among the states.

In 1997, 15 states convened to discuss the scope and content of a potential performance measurement framework. Directors and staff from these 15 states worked to identify the major domains and sub-domains of performance, indicators, measures, and data sources. The original 61 indicators, developed through a consensus process, were intended to provide a system-level "snapshot" of how well each state was performing. The states were guided by a set of criteria that was designed to select indicators that were:

1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of disability or residential setting

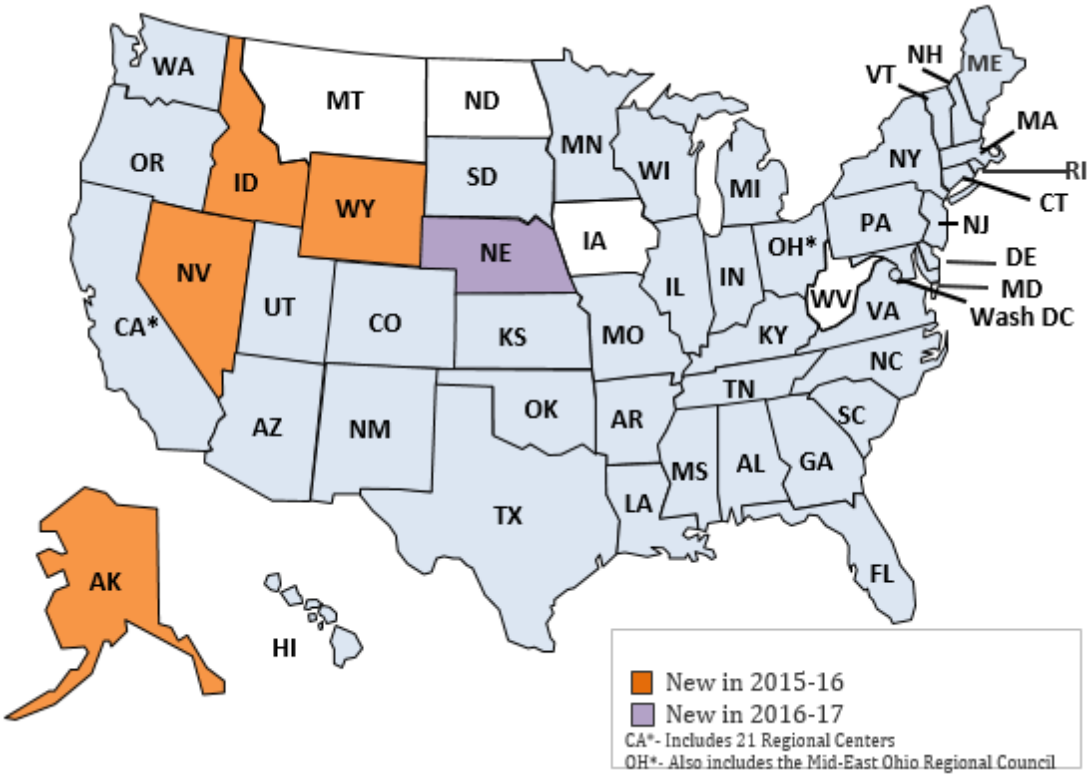
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states volunteered to pilot test the indicators. Eight additional states served on the Steering Committee.

Since the initial field test, NCI expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI continues to develop and refine the indicators and expand state participation. For more information about NCI states, technical reports, and other resources, please visit http://www.nationalcoreindicators.org.

State Participation

During the 2015-16 data collection cycle, 45 states and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and participating states are shown in the chart below.

Figure 1. NCI State Participation



The Core Indicators

The Core Indicators are the standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern, including employment, respect/rights, service planning, community inclusion, choice, and health and safety. An example of a Core Indicator would be, "The proportion of people who have a paid job in the community." To see the entire list of Core Indicators, please visit http://www.nationalcoreindicators.org/indicators.

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly

participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

The current set of performance indicators includes approximately 100 consumer, family, system, and health and safety outcomes—outcomes that are important to understanding the overall health of public developmental disabilities agencies. Indicators are organized across five broad domains: Individual Outcomes; Health, Welfare and Rights; Staff Stability and Competency; Family Outcomes; and System Performance. Each domain is broken down into sub-domains (please see Figure 2, below). Four data sources are used to assess outcomes: the Adult Consumer Survey, three Family Surveys, a Staff Stability Survey (e.g., staff turnover).

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI program is a dynamic effort that allows for measures to be added, dropped, or changed to reflect current and future priorities of participating states.

The data collection tools used to gather indicator data are regularly refined and tested to ensure they remain valid, reliable, and applicable to current issues within the field. Details on the design and testing of this tool are provided in the next section of this report.

Sub-Domains and Concern Statements

The following table lists the sub-domains under the "Family Outcomes" domain.

Figure 2. Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI as a data source for supplemental performance measures in their home and community-based services (HCBS) waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

Caution and Limitations

This report does not provide benchmarks for acceptable or unacceptable levels of performance. Rather, it is up to each state to decide whether its score or percentage is an acceptable performance level. States that fall into the "below average" tier on any scale or indicator are not necessarily underperforming; instead, this placement indicates only that the state's scale score or indicator percentage is significantly lower than the average of all states—where "significantly" means "not due to chance." The results tables throughout this report display states' scores relative to one another and show which states tend to have similar results. Notably, the difference between a "below average" state and the average across the other states may be very small, and it is up to public managers, policymakers, and other stakeholders to decide whether a state's result relative to the NCI Average suggests that changes or further investigation are necessary.

Moreover, the NCI Average should not be interpreted as defining "acceptable" levels of performance or satisfaction. Instead, it represents a multi-state "norm" that describes average levels of performance or satisfaction across the participating states. In some instances there are few significant differences among states; this denotes that the majority of states are performing similarly. Instances in which several states' results are especially high (considerably above the average level) indicate the levels of performance or satisfaction achieved in those states might define a level of performance that may serve as a guidepost for other states.

Data from previous years are not presented in this report. Comparisons of results from year to year should be made with caution: even slight changes in wording or response options of certain questions may affect comparability of results from one year to the next; the mix of participating states differs slightly each year and may affect the NCI Averages; and states draw new samples each year rather than following the same group of individuals.

III. Methodology

This section describes the protocol used by states to select families to participate in the survey, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by NCI Program staff to aggregate and analyze the data.

Sampling & Administration

States were asked to administer the Child Family Survey by selecting a random sample of at least 1,000 families who:

1. Had a child[5] with a developmental disability living at home; and
2. Received at least one direct service or support other than service coordination.

All states mailed out a paper survey to families selected in their sample. A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error no greater than +/- 7%.[6]

TEXAS:

We employed sensitivity analysis in order to aid our decision on whether to include all of Texas' data in the analysis and reporting in the Child Family Survey 2015-16 National Report. Sensitivity analysis, broadly speaking, is an analysis method that is used to identify how much a change in an input (independent) variable will impact the results for a mathematical model. In other words, the aim of sensitivity analysis is to gauge the effect that changing the assumptions or values of predictive variables will have on the conclusions or values of the dependent variable.

While the prescribed mode of administration for CFS is mail-in paper surveys, Texas sought to increase the response rate to the CFS surveys by allowing for three modes of administration: paper, web, and phone. TX mailed out invitation letters to program participants asking them to participate and providing them with a telephone number and web link so that they could complete the survey by phone or web. Both options were available in both English and Spanish. After a month, TX sent out paper surveys (available in Spanish and English) to everyone on the sampling frame who had not responded by phone or web.

[5] "Child" is defined as an individual age 18 or younger with a disability; however, a Child Family Survey could be completed for an individual up to 22 years if still receiving "child" services.

[6] See "Response Rates" section for information on total surveys mailed and received by states as well as each state's margin of error.

The resulting frequencies for the three modes of administration in Texas were as follows:

TX Mode	Frequency	Percent
Paper	274	20.5%
Web	286	21.4%
Phone	778	58.1%
TOTAL	1338	100%

While allowing for different modes of administration likely results in increased response rates, it presents a potential complication for being able to compare data collected through the three modes in Texas to data collected through mail-in paper surveys only in other states. We considered two potential approaches: including only surveys collected through mail when analyzing and presenting Texas's data, or including all three modes. We conducted item-by-item sensitivity analysis to determine the effect of including all three modes of administration vs. only paper surveys on Texas's estimates and overall conclusions.

Sensitivity analysis included comparing Texas's aggregate percentage/proportion under two scenarios: 1) including only paper surveys, and 2) including all surveys. The comparisons were conducted for each survey outcome item and any significant differences in resulting proportions and associated conclusions were noted.

Conducting this basic type of sensitivity analysis allowed us to conclude that, apart from a few items (noted in the report), including all three modes of administration when calculating Texas's proportions does not significantly change TX's aggregate results. That is, overall conclusions for Texas's data do not change appreciably if only mail-in paper surveys are included versus all three modes. For that reason, we elected to include all available TX's data throughout the report and note any items where including only mail-in surveys makes a substantial difference.

For more information on TX mode of CFS survey implementation will please contact dhiersteiner@hsri.org.

Data Entry and Analysis

Each state entered its survey responses into the Online Data Entry Survey Application (ODESA). All raw data files were reviewed for completeness, invalid responses were eliminated, and quality

checks were performed. The data files were then cleaned and merged to create the national dataset.

Data were considered invalid, and therefore excluded, based on the following two criteria:

1. The respondent indicated the child lived outside the family home.
2. Demographic information was entered into the file but no survey questions were answered.

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the NCI average[7]; significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

[7] The NCI Average is the sum of all state averages divided by the total number of states.

Response Rates

In 2015-16, eight states administered the Child Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% margin of error. Their data are included in this report. Figure 3 shows the number of surveys each state mailed, surveys returned, response rates, and the number of valid surveys accepted for inclusion in data analysis.

Figure 3. Child Family Survey: State Response Rates

State	Number Eligible to Be Drawn into the Sample	Surveys Mailed	Usable Surveys Returned	Response Rate	Margin of Error
CA	63901	63901	13300	21%	0.76%
ID	3262	3190	961	30%	2.66%
NC	12000	1200	259	22%	6.02%
OR	2253	1991	471	24%	4.02%
SD	903	903	218	24%	5.78%
TX	10356	5545[8]	1337	24%	2.50%
UT	1000	1000	304	30%	4.69%
VA	854	854	149	17%	7.30%
Total			16,999		

[8] For Texas, this figure represents the number of survey invitations sent.

IV. Appendix A

Child Family Survey Changes from 2014-15 to 2015-16

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
Information About Family Member								
A	Does your child with a disability live at home with you?	A	Does your child with a disability live at home with you?	No change	NA	x	x	x
B	Is there more than one child with a disability in your household?	B	Is there more than one child with a disability in your household?	No change	NA	x	-	x
C	How old is your child?	C	How old is this child?	No change	NA	x	x	x
D	What is the gender of your child?	D	What is the gender of this child?	No change	NA	x	x	x
E	Has your child been diagnosed with any of the conditions listed below?	E	Has this child been diagnosed with any of the following disabilities listed below?	Modified Changed response options from "yes", "no", "don't know" to check all that apply Added vision and hearing response options Added fetal alcohol syndrome Added explanations to some response options	Beginning 2015-16, conditions can be compared to years prior to 2013-14.	x	x	x
F	Has your child been diagnosed with any of the health conditions listed below?			New question Aligns with question in AFS and FGS	NA	x	x	x
G	What is your child's race and ethnicity?	F	What is this child's race?	Modified Added "and ethnicity"	NA (question always captured race and ethnicity)	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
H	What is your child's preferred means of communication?	G	What is this child's primary means of expression?	Modified Added open text for "other" response	NA	x	x	x
I	If your child needs support to manage self-injurious, disruptive, or destructive behavior, how much support is needed?	J	Does this child need support to manage any of the following behaviors: self-injurious behavior, disruptive behavior, destructive behavior?	Modified Added explanation to response options	Comparisons to previous years' data should be made with caution.	x	x	x
J	About how much help (support) does your child need with daily personal care activities (for example, bathing, dressing, eating)?	K	About how much help does this child need with daily activities (such as bathing, dressing, eating)?	Modified Changed response options	Comparisons to previous years' data should be made with caution.	x	x	x
Deleted or Rephrased Questions- Information About Family Member **H. What is this child's primary language? (*this question will be re-added in future years)** **I. How often does this child require medical care by a trained medical provider (e.g., nurse or physician)?**								

Information About Respondent								
K	What is your age?	L	What is your age?	No change	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
L	How would you describe your health?	M	How would you describe your health?	Modified Changed response options "good" and "fair" to "very good" and "fairly good"	Comparisons to previous years' data should be made with caution.	x	x	x
M	How are you related to this child?	N	What is your relationship to this child?	No change	NA	x	x	x
N	Is anyone in your family paid to provide support to your child with a disability?			New question Provide additional context to data, possible begin to look into caregiver burden	NA	x	-	x
O	How many adults (over age 18) live in the household?	P	How many adults live in your household?	Modified Added this parenthetical	NA	x	x	x
P	How many children under age 18 live in the household?			New question Gives better overall picture of home	NA	x	-	x
Q	What is <u>your</u> highest education level?	Q	What is your highest education level?	Added response options: "Vocational school to "vocational school **or certificate program"** "College degree" to "college degree ***or higher***"	Comparisons to previous years' data should be made with caution.	x	x	x
R	What was the total income last year of all wage earners in your household?	R	What was the total taxable income last year of the primary wage earners in your household?	Deleted "taxable" Added additional explanatory text Added response option "prefer not to say"	Comparisons to previous years' data should be made with caution.	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
S	What county do you currently live in?	T	What County do you currently live in?	No change	NA	x	x	x
T	Do you live in an urban or rural area?			New question This could be important for states to drill down by outcomes based on the person's setting	NA	x	x	x
Deleted or Rephrased Questions- Information About Family Member **O. Are you a primary caregiver for this child?** **S. Approximately how much out-of-pocket money did you spend last year on your child's medical services, equipment, supplies, therapies, and other supports/services?**								
Services and Supports Received								
i-vii	Services received	i-vi	Services received	Added "self-direction/fiscal intermediary services"	NA	x	x	x
viii	Does your family/family member receive Social Security benefits (SSI, survivor benefits, etc.)?	vii	Does your family member receive Social Security payments (SSI or SSDI, survivor benefits, etc.)?	Modified	Comparisons to previous years' data should be made with caution.	x	x	x
ix	Does your family member receive services or supports from other agencies or organizations (school services, vocational rehab, etc.)?			New question Determine additional non-state funded supports the person receives	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
Part 2: Questions about services and supports **Overall changes:** **Combined Seldom and Never responses** **Included explanatory text for NA responses where applicable**								
Information and Planning								
1	Do you get enough information to take part in planning services for your child?			New question Replaces former Q1	Parallel comparisons to previous years' data cannot be made.	x	x	x
2	Is the information you get about services and supports easy to understand?	2	Is the information you receive easy to understand?	Modified	Comparisons to previous years' data should be made with caution.	x	x	x
3	Does the case manager/service coordinator respect your family's choices and opinions?	4	Does the case manager/service coordinator respect your family's choices and opinions?	No change	NA	x	x	x
4	Do you have enough information about other public services for which your family is eligible (food stamps, SSI, or housing subsidies, for example)?	5	Does your case manager/service coordinator tell you about other public services that you are eligible for?	Modified	Parallel comparisons to previous years' data cannot be made.	x	-	x
5	Do you need help planning for your child's future with respect to any of the following?			New question Adds information about future planning; all other questions are about current services/needs	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
6	If you asked for crisis or emergency services during the past year, were services provided when needed?	25	If you asked for crisis/emergency services during the past year, were services provided when needed?	Question moved from Access and Delivery of Services	NA	x	-	x
7	Does your child have a service plan?	6	Does your child have a service plan?	Modified Added additional explanatory text	Comparisons to previous years' data should be made with caution.	x	x	x
8	Does the plan include all the services and supports your child needs?	9	Does the plan include all the services and supports your family needs?	Changed order of questions	NA	x	x	x
9	Does your child get all the services listed in the plan?	10	Does your family receive all of the services listed in the plan?	Changed order of questions	NA	x	x	x
10	Did you or another family member help make the plan?	7	Did you help develop the plan?	Changed order of questions Added "or another family member"	Comparisons to previous years' data should be made with caution.	x	x	x
11	Did your child help make the plan?			New question Aligns with question in AFS and FGS, determines child's level of involvement in service planning	NA	x	x	x
12	Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your child's last service planning meeting?	11	Did you discuss how to handle emergencies related to your child at the last service planning meeting?	Rephrased with additional explanatory text	Comparisons to previous years' data should be made with caution.	x	x	x

2015-2016		2014-2015	Change Made	Note	AFS	FGS	CFS
13	Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster?		New question Builds on emergency preparedness and adequacy of ER plans from Q12	NA	x	x	x
14	Does your child have a transition plan (as part of an IEP or Section 504 plan through his/her high school, usually starting at age 14)?		New question Provides information about transition process for families	NA	-	-	x
15	If yes to Q14, did you help make the transition plan?		New question Provides information on families level of involvement in transition planning	NA	-	-	x

Deleted or Rephrased Questions- Information and Planning

1. Do you receive information about the services and supports that are available to your child and family?

3. Does the information you receive come from your case manager/service coordinator

8. Does the plan include all the services and supports your family wants?

12. Have you received information about your family's rights?

Access and Delivery of Services and Supports								
16	Are you able to contact your child's support workers when you want to?	13	Are you able to contact your support workers when you need to?	Modified Changed "need" to "want"	Comparisons to previous years' data should be made with caution.	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
17	Are you able to contact your child's case manager/service coordinator when you want to?	14	Are you able to contact your case manager/service coordinator when you need to?	Modified Added additional explanatory text Changed "need" to "want"	Comparisons to previous years' data should be made with caution.	x	x	x
18	Do support workers come and leave when they are supposed to?	24	Do the support workers who come to your home arrive on time and when scheduled?	Modified Added additional explanatory text Changed order of questions	Comparisons to previous years' data should be made with caution.	x	x	x
19	Do services and supports change when your family's needs change?	17	Do the services and supports change when your child's needs change?	Modified Changed "child" to "family"	Parallel comparisons to previous years' data cannot be made.	x	x	x
20	Do support workers speak to you in a way that you understand?			New question Replaces former Q18-Q19	In future years, this question will be able to be analyzed by primary language.	x	x	x
21	Are services delivered in a way that is respectful of your family's culture?	21	Are services delivered in a way that is respectful to your family's culture?	Changed order of questions	NA	x	x	x
22	If your child does not communicate verbally (for example, uses gestures or sign language, uses communication aid), are there support workers who can communicate with him/her?	20	If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?	Changed order of questions	NA	x	x	x
23	Do support workers have the right information and skills to meet your family's needs?			New question Replaces former Q23	Replaces former Q23	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
24	Does your child have the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?	22	Does your child have access to the special equipment or accommodations that s/he needs (e.g., wheelchair, ramp, communication board)?	No change	NA	x	x	x
25	Can your child see health professionals (for example, doctor, dentist, psychologist) when needed?	26	Do you have access to health services for your child?	Modified	Parallel comparisons to previous years' data cannot be made.	x	x	x
26	Does your child's primary care doctor understand his/her needs related to his/her disability?			New question Better gets at quality of care	NA	x	x	x
27	Do you have access to dental services for your child?			No change	NA	x	x	x
28	If yes to Q27, does your child's dentist understand his/her needs related to his/her disability?			New question Better gets at quality of care	NA	x	x	x
29	If your child takes medications, do you know what they're for?			New question Gets at family understanding of medication use	NA	x	x	x
30	If yes to Q29, do you, your child, or someone else in your family know when your child should take the medication, how much to take, and the potential side effects?			New question Better get at family understanding of using medication safely	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
31	If your child uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your child's needs related to his/her disability?			New question Gets at quality of care	NA	x	x	x
32	If you need respite services, do you have access to them?	30	If you need respite services, do you have access to them?	Modified Added additional explanatory text	Comparisons to previous years' data should be made with caution.	x	-	x
33	If yes to Q32, are you satisfied with the quality of the respite providers?	30a	If Yes to Q30, are you satisfied with the quality of these providers?	No change	NA	x	-	x
34	Does your family get the support it needs?	31	Are there other services that your family needs that are not currently offered or available?	Modified	Comparisons to previous years' data should be made with caution.	x	x	x
35	If no to Q34, what additional services are needed?	31a	If Yes to Q31, what services are needed (list here):	Modified	Comparisons to previous years' data should be made with caution.	x	x	x

2015-2016	2014-2015	Change Made	Note	AFS	FGS	CFS
Deleted or Rephrased Questions- Access and Delivery of Services and Supports						
15. Are services and supports available when you need them?						
16. Are services and supports available within a reasonable distance from your home?						
18. If English is not your primary language, are there support workers or translators who can speak with you in your language?						
19. If English is your first language, do the support workers speak to you effectively?						
23. Do the support workers have the right training to meet your child's needs?						
26a. If Yes to Q26, are you satisfied with the quality of these providers?						
27a. If Yes to Q27, are you satisfied with the quality of these providers?						
28. Are you able to get medications needed for your child?						
28a. If Yes to Q28, are you satisfied with how your child's medication needs are monitored?						
29. If needed, do you have access to mental health services for your child?						
29a. If needed, do you have access to mental health services for your child?						

Choice, Decision-Making, and Control							
36	Can your family choose or change the agency that provides your child's services?		New question Replaces former Q32 and Q33, now includes all family and whether family chose or can change agencies.	Parallel comparisons to previous years' data cannot be made.	x	x	x

2015-2016		2014-2015	Change Made	Note	AFS	FGS	CFS
37	Can your family choose or change your child's support workers?		New question Replaces old Q34 and Q35, now includes all family and whether family can chose or can change workers.	Parallel comparisons to previous years' data cannot be made.	x	x	x
38	Does your family directly manage support workers (for example, hiring and deciding schedule)?		New question Replaces former Q37	Parallel comparisons to previous years' data cannot be made.	x	x	x
39	Do service providers for your child work together to provide support?		New question Determines whether multiple providers work together to support families	NA	x	x	x
40	Did you, your child, or someone else in your family choose your child's case manager/service coordinator?		New question Replaces former Q36, now includes all family and whether family chose or can request a change to case manager.	Parallel comparisons to previous years' data cannot be made.	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
Deleted or Rephrased Questions- Choice and Decision-Making								
32. Did you choose the provider agencies who work with your family?								
33. Can you choose a different provider agency if you want to?								
34. Did you choose the individual support workers who work directly with your family?								
35. Can you choose different support workers if you want to?								
36. Did you choose your case manager/service coordinator?								
37. Do you have control and/or input over the hiring and management of your family's support workers?								
38. Do you know how much money is spent by the ID/DD agency on behalf of your child?								
39. Do you have a say in how this money is spent?								
39a. If Yes to Q39, do you have all the information you need to make decisions about how to spend this money?								
Involvement in the Community								
41	Does your child take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?	40	Does your child participate in community activities (such as going out to a restaurant, movie, or sporting event)?	No change	NA	x	x	x
42	If no to Q41, why not?	40a	If No to Q40, then why?	No change	NA	x	x	x
43	Does your child spend time with children who do not have developmental disabilities?	41	Does your child spend time with children who do not have developmental disabilities?	No change	NA	-	-	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
44	In your community, are there resources that your family can use that are not provided by the I/DD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?			New question Determines whether families have access to non-traditional supports	NA	x	x	x
45	Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?			New question Determines whether families have access to support networks	NA	x	x	x
Satisfaction								
46	Overall, are you satisfied with the services and supports your family currently receives?	42	Overall, are you satisfied with the services and supports your family currently receives?	No change	NA	x	x	x
47	Do you know how to file a complaint or grievance about provider agencies or staff?	43	Do you know the process for filing a complaint or grievance against provider agencies or staff?	Modified	NA	x	x	x
48	If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?			New question Replaces former Q44	Parallel comparisons to previous years' data cannot be made.	x	x	x
49	Do you know how to report abuse or neglect?	45	Do you know how to report abuse or neglect?	No change	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
50	Within the past year, was a report of abuse or neglect filed on behalf of your child?	46	Within the past year, if abuse or neglect occurred, did you report it?	Modified	Parallel comparisons to previous years' data cannot be made.	x	x	x
51	If yes to Q50, did the appropriate people respond to the report?	46a	If Yes to Q46, were the appropriate people responsive to your report?	Modified	Due to rephrasing of Q50, parallel comparisons to previous years' data cannot be made.	x	x	x
52	If yes to Q50, if someone other than you or another family member reported abuse or neglect, were you notified of the report in a timely manner?			New question Follow-up to assess whether family is kept apprised of abuse/neglect reports	NA	x	x	x
Deleted or Rephrased Questions- Satisfaction **44. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?**								
Outcomes								
53	Do you feel that family supports have made a positive difference in the life of your family?	47	Do you feel that family supports have made a positive difference in the life of your family?	No change	NA	x	x	x
54	Have services and supports reduced your family's out-of-pocket expenses for your child's care?	48	Do you feel that services and supports have reduced your family's out-of-pocket expenses for your child's care?	No change	NA	x	-	x
55	Do you feel that family supports have improved your ability to care for your child?	49	Do you feel that family supports have improved your ability to care for your child?	No change	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
56	Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?	50	Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?	No change	NA	x	x	x
57	If Yes to Q56, did the reduction, suspension, or termination of these services or supports affect your family negatively?	50a	If Yes to Q50, did the reduction, suspension, or termination of these services or supports affect your family negatively?	No change	NA	x	x	x
58	Have the services or supports that your child received been increased in the past year?			New question This gets at the reverse of previous question (whether services were reduced); may give some insight to other outcomes	NA	x	x	x
59	Are services and supports helping your child to live a good life?			New question Helps determine overall satisfaction with service delivery	NA	x	x	x