Child Family Survey

2014-15 Final Report



A Collaboration of the National Association of State Directors of Developmental Disabilities Services and the 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

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Executive Summary

Direct feedback from families is an important means for states to gauge service and support satisfaction and to pinpoint areas for quality improvement. The National Core Indicators (NCI) project uses standard measures (or indicators) collected across states to assess the outcomes of services provided to individuals with intellectual/developmental disabilities and their families. Indicators address key areas of concern such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that result from NCI surveys are often used to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Many states also share the data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction.

The NCI Child Family Survey is administered to families who have a child with a developmental disability¹ who lives in the family's home and receives at least one service other than case management. Not all states that participate in NCI administer the Child Family Survey on an annual basis. Of the 41 states, District of Columbia and 22 sub-state entities who participated in NCI during the 2014-15 data collection cycle, nine (9) states submitted a valid sample of Child Family Survey data to be included in this report. This Final Report provides a summary of results.

The following are NCI national averages for a selection of survey items. Complete breakouts by state for each item in the Child Family Survey can be found in the Results section of this report.

Demographics and Characteristics of Children for Whom the Survey Was Completed

The average age of the child receiving services in the household was 12 years old, and males accounted for a higher percentage than females (67% versus 33%). Two-thirds of children were identified as white (66%) and 13% were black/African American; 10% were Hispanic. Most children were reported to communicate using spoken language (58%), while 28% used gestures or body language, 3% sign language or finger spelling, 5% used a communication aid or device and 6% communicated in another way. Most children required complete or moderate support for daily

¹ Some states include individuals up to 22 years old, if they are continuing to receive "child" services.

activities (40% and 39% respectively) while17% needed little help and 5% did not need help to complete daily activities.

Demographics and Characteristics of Respondents

The majority of respondents were under 55 years old (68% were 35-54 and 17% were under 35); nearly all were the child's parent (93%). Most families surveyed had one (23%) or two (63%) adults in the home. Nearly half of respondents had a college degree (46%). Household incomes were reported as: 20% below \$15,000; 14% between \$15,001 and \$25,000; 24% at \$25,001 to \$50,000; 19% earned \$50,001 to \$75,000; and 23% over \$75,000. Nationally, out of pocket expenses spent on the child's care were: 22% nothing; 13% spent \$1 to \$100; 31% from \$101 to \$1,000; 30% between \$1,001 and \$10,000; and 4% over \$10,000.

Services and Supports Received

Among the services and supports specified in the survey, 60% of respondents used in-home support, 41% received social security benefits were the most commonly utilized; 66% utilized services not specified in the survey.

Information and Planning

One-quarter (25%) of respondents reported they always receive information about available services and supports available to the family and that the information they received was always easy to understand; about one-third indicated the information they get always comes from their case manager/service coordinator (34%). The majority of respondents, 69%, felt the case manager/service coordinator always respected the family's choices and opinions.

Across states, the majority of respondents reported they helped develop the child's service plan (97%). Most felt the plan includes all services and supports the family wants (79%) and needs (73%). Eighty-five percent (85%) reported the family receives all services listed in the plan.

Access and Delivery of Services and Supports

Slightly more than half of all respondents reported that they can always contact support workers and case managers/service coordinators when needed (both 57%); slightly more than one-third reported that services and supports are always available when needed (34%).

Just over half of respondents whose primary language is not English reported that there are always support workers or translators available to speak in their preferred language (53%) and three-quarters of all respondents whose primary language is English reported similarly. Fewer than one-third of respondents who completed the survey about a child who is non-verbal indicated that support workers could always communicate with the child (29%). Seventy-percent (72%) reported that services are always delivered in a manner that is respectful to their family's culture.

The majority of respondents reported having access to various healthcare services for the child including: health services (98%), dental services (95%), needed medications (98%), and mental health services (89%); slightly fewer had access to respite services (80%).

Choice and Control

The majority of respondents always determined the provider agencies and support workers who work with their family (60% and 53% respectively).

Fifteen percent (15%) of respondents reported they chose the case manager/service coordinator. Most reported they have control or input over hiring and managing the family's support workers (63%). Thirty percent (30%) reported that they know how much money the ID/DD agency spends on behalf of the child. Of the 44% of respondents indicated that they have a say in how ID/DD agency money is spent, 88% had all the information needed to decide how to spend ID/DD money.

Community Connections

More than four-fifths of respondents reported that the child participates in community activities (81%) and that the child spends time with children who do not have DD (86%).

Satisfaction With Services and Supports

More than one-third of all respondents indicated they are always satisfied with the services and supports their family receives (37%).

About half indicated they know how to file a complaint or grievance against provider agencies or staff (52%) and nearly three-quarters reported they know how to report abuse or neglect (73%).

Family Outcomes

Nearly all respondents reported that services and supports have made a positive difference in their family's life (94%). Most also indicated that services and supports have: reduced the family's out-of-pocket expenses for the child's care (88%) and improved the family's ability to care for the child (91%).

Of the 23% of respondents who reported that services or supports were reduced, suspended or terminated in the past year, 80% felt that this change impacted their family negatively.

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 Family Surveys

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 relating to characteristics of the child with a developmental disability (e.g., age, race, type of disability) followed by a series of demographic questions pertaining to 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.

Additional Comments

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

Presentation of Data

All demographic and individual outcome results from the Adult Family Survey are presented in this report. Outcome results are presented in six subsections that correspond with the sections of the Child Family Survey.

For each question, outcome results are first shown in a graph with the NCI Average and then in a table that shows a breakout of each state's percentage.

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, and significantly below the NCI Average. Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI Average Range, their 'always' or 'yes' response was not statistically different from the NCI Average.

States receive an 'N/A' designation for a survey item if fewer than 20 people responded. The NCI Average is the average of all individual state percentages.

Note on Significance: in some cases, a state (let's call it state A) with a lower (or higher) proportion than another state (let's call it state B) may be significantly above (or below) NCI Average even though the other state that is further away from the NCI Average is not. This may happen because statistical significance depends on both the difference between the average and the state's proportion and the sample size of the state. So, for example, when state A has a larger valid sample for the indicator than state B, state A may be significantly different from the average when state B is not, even though state B's difference from that average is larger than state A's. The larger the sample size of a state, the smaller the difference needs to be to be statistically significant.

Demographics

Child

This section provides demographic information about the child receiving services.

State	Age	Ν
AZ	9.4	212
HI	11.7	121
LA	11.4	508
MN	11.4	455
NC	12.5	190
SD	11.9	246
VA	15.0	145
WA	11.4	373
WI	11.2	1,030
NCI Average	11.8	3,280

Table 1. Child's Age

Table 2. Child's Gender

State	Male	Female	Ν
AZ	70%	30%	211
н	60%	40%	121
LA	63%	37%	504
MN	67%	33%	454
NC	69%	31%	191
SD	68%	32%	246
VA	67%	33%	144
WA	65%	35%	371
WI	70%	30%	1,030
NCI Average	67%	33%	3,272

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
AZ	5%	4%	4%	0%	51%	1%	12%	38%
HI	6%	54%	5%	34%	45%	5%	28%	8%
LA	2%	1%	35%	0%	57%	0%	5%	2%
MN	4%	7%	8%	0%	76%	1%	4%	7%
NC	6%	3%	27%	1%	58%	1%	9%	8%
SD	6%	0%	3%	0%	89%	0%	2%	2%
VA	1%	3%	21%	1%	71%	1%	6%	2%
WA	6%	8%	7%	1%	66%	1%	7%	15%
WI	2%	3%	6%	0%	85%	1%	5%	6%
NCI Average	4%	9%	13%	4%	66%	1%	9%	10%

Table 3. Child's Race

Table 4. More Than One Child in the Home Has a Disability

State	Yes	No	Ν
AZ	19%	81%	208
HI	18%	82%	123
LA	15%	85%	498
MN	28%	72%	450
NC	28%	72%	189
SD	16%	84%	244
VA	19%	81%	144
WA	21%	79%	375
WI	18%	82%	1,020
NCI Average	20%	80%	3,251

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AZ	59%	23%	5%	10%	3%	212
HI	43%	40%	6%	2%	9%	100
LA	57%	32%	2%	3%	6%	500
MN	67%	20%	1%	6%	5%	416
NC	63%	27%	4%	4%	3%	193
SD	69%	22%	4%	3%	2%	228
VA	52%	30%	3%	7%	7%	145
WA	50%	32%	4%	5%	9%	371
WI	57%	27%	1%	8%	7%	1,024
NCI Average	58%	28%	3%	5%	6%	3,189

Table 5. Child's Primary Means of Expression

Table 6. Child's Primary Language

State	English	Spanish	Other	N
AZ	74%	23%	4%	213
Н	82%	0%	18%	108
LA	95%	0%	5%	503
MN	92%	2%	6%	454
NC	95%	3%	3%	195
SD	97%	1%	2%	246
VA	95%	0%	5%	145
WA	80%	8%	12%	373
WI	94%	1%	5%	1,027
NCI Average	89%	4%	7%	3,264

Table 7. Frequency of Medical Care Needed for Child

State	Less Frequently Than Once a Month	At Least Once a Month, Less Than Once a Week	At Least Once a Week	N
AZ	69%	19%	12%	206
HI	68%	20%	12%	105
LA	61%	23%	16%	493
MN	72%	19%	9%	451
NC	71%	22%	7%	188
SD	80%	15%	5%	246
VA	63%	20%	16%	142
WA	65%	21%	14%	369
WI	74%	19%	7%	1,012
NCI Average	69%	20%	11%	3,212

Table 8. Amount of Behavioral Support Needed for Child

State	None	Some	Extensive	N
AZ	43%	42%	15%	211
н	35%	43%	22%	111
LA	42%	38%	20%	499
MN	26%	43%	31%	454
NC	31%	46%	24%	195
SD	56%	34%	10%	247
VA	30%	44%	27%	147
WA	30%	43%	26%	371
WI	36%	44%	21%	1,025
NCI Average	37%	42%	22%	3,260

Table 9. Amount of Help Needed for Child's Daily Activities

State	None	Little	Moderate	Complete	N
AZ	2%	19%	45%	34%	215
HI	5%	9%	33%	52%	111
LA	3%	17%	40%	40%	507
MN	2%	14%	44%	40%	455
NC	10%	16%	40%	34%	194
SD	9%	29%	32%	30%	245
VA	3%	14%	39%	45%	146
WA	5%	15%	35%	45%	375
WI	5%	20%	39%	36%	1,027
NCI Average	5%	17%	39%	40%	3,275

Respondents

This section provides demographic information about the respondent.

Table 10	Respondent's	Age
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State	Under 35	35-54	55-74	75 or Older	N
AZ	29%	48%	22%	0%	214
н	20%	65%	14%	1%	108
LA	19%	66%	14%	1%	508
MN	17%	74%	9%	0%	456
NC	8%	80%	10%	2%	195
SD	22%	66%	13%	0%	247
VA	9%	65%	22%	4%	148
WA	13%	72%	15%	0%	377
WI	17%	75%	8%	0%	1,024
NCI Average	17%	68%	14%	1%	3,277

Table 11. Respondent's Health

State	Excellent	Good	Fair	Poor	Ν
AZ	26%	52%	20%	2%	212
н	20%	57%	22%	1%	122
LA	25%	49%	22%	4%	508
MN	23%	58%	17%	2%	451
NC	17%	53%	27%	3%	192
SD	34%	49%	16%	1%	241
VA	16%	53%	27%	4%	146
WA	22%	55%	20%	3%	381
WI	25%	59%	14%	2%	1,033
NCI Average	23%	54%	21%	3%	3,286

State	Parent	Sibling	Grandparent	Other	N
AZ	96%	1%	2%	1%	214
HI	92%	1%	3%	4%	123
LA	88%	0%	10%	2%	506
MN	96%	0%	3%	1%	457
NC	90%	0%	6%	4%	194
SD	97%	0%	2%	0%	244
VA	90%	0%	7%	3%	148
WA	93%	0%	6%	1%	379
WI	97%	0%	2%	0%	1,034
NCI Average	93%	0%	5%	2%	3,299

Table 12. Respondent's Relationship to Child

Table 13. Respondent Is Child's Primary Caregiver

State	Yes	No	Ν
AZ	98%	2%	213
HI	98%	2%	121
LA	98%	2%	504
MN	99%	1%	454
NC	99%	1%	193
SD	100%	0%	243
VA	97%	3%	146
WA	93%	7%	379
WI	99%	1%	1,028
NCI Average	98%	2%	3,281

State	One	Two	Three	Four or More	N
AZ	14%	65%	14%	7%	213
HI	20%	54%	13%	13%	123
LA	35%	55%	7%	3%	506
MN	21%	69%	7%	3%	456
NC	30%	59%	5%	5%	192
SD	19%	72%	8%	2%	245
VA	28%	57%	9%	5%	148
WA	19%	63%	10%	7%	378
WI	20%	71%	7%	3%	1,030
NCI Average	23%	63%	9%	5%	3,291

Table 14. Number of Adults in the Household

Table 15. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree	Ν
AZ	19%	12%	5%	25%	39%	210
н	4%	23%	3%	29%	42%	120
LA	11%	22%	8%	21%	38%	503
MN	6%	18%	7%	19%	50%	453
NC	9%	13%	5%	22%	50%	193
SD	4%	21%	12%	17%	47%	241
VA	5%	23%	2%	16%	54%	147
WA	11%	16%	6%	23%	44%	374
WI	4%	19%	9%	19%	48%	1,032
NCI Average	8%	19%	6%	21%	46%	3,273

State	Below \$15,000	\$15,001- \$25,000	\$25,001- \$50,000	\$50,001- \$75,000	Over \$75,000	N
AZ	23%	16%	22%	19%	20%	198
HI	16%	16%	26%	22%	19%	117
LA	30%	16%	18%	14%	21%	478
MN	15%	13%	24%	24%	24%	445
NC	27%	18%	22%	14%	19%	173
SD	13%	10%	32%	21%	24%	238
VA	20%	10%	18%	20%	31%	127
WA	16%	16%	28%	18%	21%	368
WI	17%	11%	23%	19%	30%	997
NCI Average	20%	14%	24%	19%	23%	3,141

Table 16. Total Taxable Family Income of Wage Earners in the Household in the Past Year

Table 17. Out-of-Pocket Expenses for Child in the Past Year

State	Nothing	\$1- \$100	\$101- \$1,000	\$1,001- \$10,000	Over \$10,000	N
AZ	30%	10%	35%	25%	0%	208
Н	16%	11%	35%	32%	6%	118
LA	23%	11%	28%	35%	4%	492
MN	19%	13%	29%	33%	6%	447
NC	23%	20%	28%	26%	3%	187
SD	27%	17%	32%	20%	3%	235
VA	26%	7%	33%	28%	7%	141
WA	17%	11%	28%	37%	6%	372
WI	15%	14%	34%	32%	5%	1,019
NCI Average	22%	13%	31%	30%	4%	3,219

Services and Supports Received

This section provides information about the services and supports received by the family from the state ID/DD agency (social security benefits being the exception).

State	Financial Support	In-Home Support	Out-of- Home Respite Care	Early Intervention	Transportati on	Other	Social Security Benefits
AZ	6%	69%	46%	22%	25%	85%	44%
HI	18%	44%	38%	9%	40%	58%	32%
LA	43%	61%	19%	15%	14%	54%	50%
MN	51%	64%	26%	12%	27%	72%	35%
NC	13%	65%	42%	1%	18%	62%	49%
SD	63%	29%	43%	14%	20%	69%	42%
VA	26%	86%	45%	4%	34%	71%	45%
WA	42%	52%	19%	8%	16%	53%	42%
WI	37%	67%	38%	9%	17%	68%	33%
NCI Average	33%	60%	35%	10%	23%	66%	41%

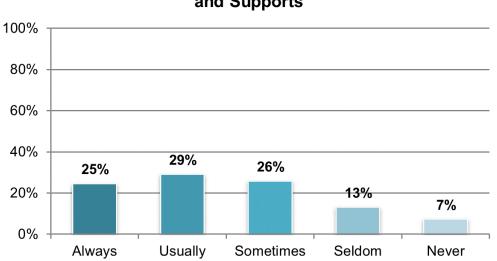
Table 21. Services and Supports Received From ID/DD Agency²

² All services and supports are provided by the state with the exception of social security benefits.

Child Family Survey Results

Information and Planning

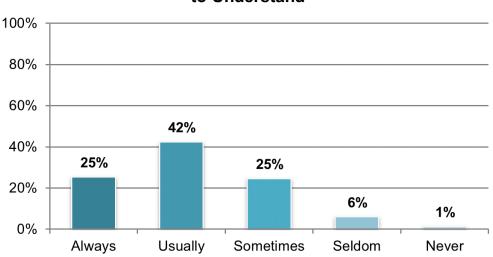
Families and family members with disabilities have the information and support necessary to plan for their services and supports.



Receives Information About Available Services and Supports

Table Q1. Do you receive information about the services and supports that are available to your child and fa	amily?
Tuble Q1. Do you receive information about the services and supports that are available to your enna and the	····· .

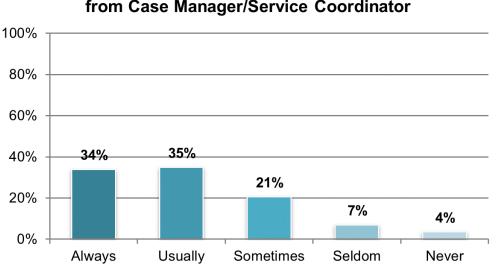
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly A	bove Average					
SD	46%	33%	14%	6%	2%	246
Within Average	Range					
AZ	31%	38%	19%	11%	2%	208
LA	26%	26%	27%	13%	9%	488
VA	26%	29%	27%	12%	6%	146
WI	21%	33%	30%	11%	5%	1,016
WA	20%	23%	31%	17%	8%	372
NC	18%	24%	31%	15%	13%	190
HI	17%	25%	28%	17%	13%	118
Significantly B	elow Average					
MN	16%	31%	28%	17%	8%	442
NCI Average	25%	29%	26%	13%	7%	3,226



Information About Services and Supports Is Easy to Understand

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

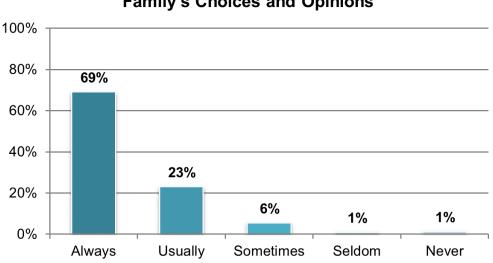
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly A	bove Average					
SD	40%	43%	15%	3%	0%	240
Within Average	Range					
AZ	33%	43%	19%	5%	0%	206
VA	31%	41%	23%	4%	1%	135
LA	28%	38%	28%	5%	1%	440
WI	23%	45%	26%	6%	1%	956
HI	22%	45%	22%	8%	2%	99
NC	18%	46%	27%	7%	1%	163
Significantly B	elow Average					
WA	19%	38%	31%	9%	3%	333
MN	15%	44%	31%	9%	2%	409
NCI Average	25%	42%	25%	6%	1%	2,981



Information About Services and Supports Comes from Case Manager/Service Coordinator

Table Q3. Does the information you receive primarily come from your case manager/service coordinator (as opposed to family, friends, and others outside of state services)?

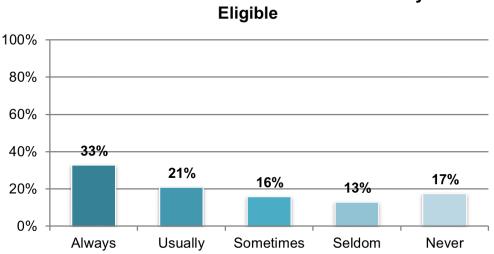
State	Always	Usually	Sometimes	Seldom	Never	N		
Significantly A	Significantly Above Average							
SD	53%	32%	10%	3%	1%	229		
Within Average	Range							
AZ	40%	32%	22%	5%	3%	200		
LA	39%	34%	18%	7%	2%	407		
WI	35%	38%	21%	5%	1%	948		
н	32%	32%	24%	5%	7%	97		
VA	31%	38%	23%	7%	1%	137		
WA	30%	34%	21%	10%	6%	319		
NC	27%	36%	20%	12%	5%	152		
Significantly B	elow Average							
MN	20%	38%	27%	10%	5%	383		
NCI Average	34%	35%	21%	7%	4%	2,872		



Case Manager/Service Coordinator Respects Family's Choices and Opinions

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

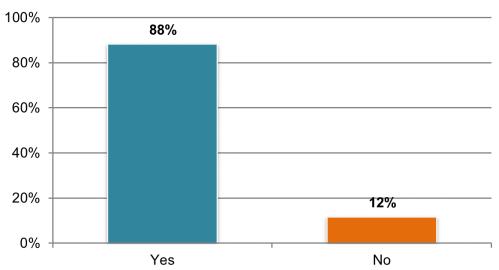
State	Always	Usually	Sometimes	Seldom	Never	Ν
Significantly A	bove Average				·	
AZ	79%	15%	5%	0%	0%	207
Within Average	Range					
SD	76%	18%	5%	0%	0%	235
LA	72%	21%	4%	1%	2%	440
WI	72%	22%	4%	1%	1%	1,001
WA	69%	22%	6%	2%	1%	351
VA	69%	24%	7%	0%	0%	144
NC	66%	23%	6%	1%	4%	163
MN	63%	27%	6%	1%	3%	390
HI	57%	34%	6%	2%	1%	109
NCI Average	69%	23%	6%	1%	1%	3,040



Case Manager/Service Coordinator Tells Family About Other Public Services for Which Family Is Eligible

Table Q5. Does your case manager/service coordinator tell you about other public services that you are eligible for (e.g., food stamps, Early Period Screening Diagnosis and Treatment [EPSDT], Supplemental Security Income [SSI], housing subsidies, etc.)?

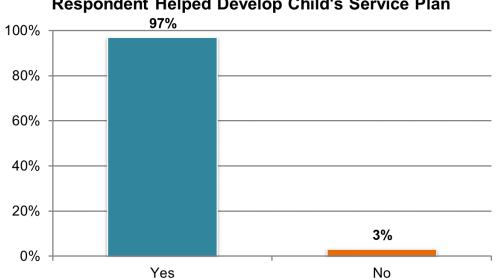
State	Always	Usually	Sometimes	Seldom	Never	N	
Significantly A	bove Average						
SD	59%	22%	11%	5%	3%	217	
Within Average	Range						
LA	35%	19%	14%	12%	20%	443	
AZ	34%	14%	17%	11%	24%	194	
VA	32%	21%	19%	16%	12%	134	
WI	31%	27%	17%	13%	13%	920	
WA	29%	23%	15%	13%	19%	326	
н	27%	19%	13%	17%	24%	104	
Significantly B	Significantly Below Average						
MN	24%	26%	16%	17%	17%	397	
NC	24%	17%	22%	13%	24%	164	
NCI Average	33%	21%	16%	13%	17%	2,899	



Child Has a Service Plan

Table Q6. Does your child have a service plan?

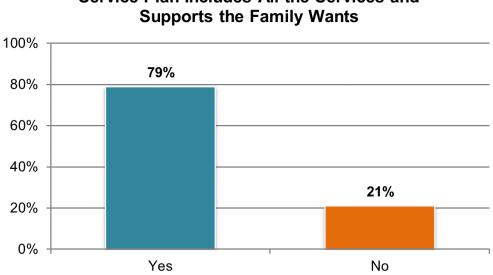
State	Yes	No	N		
Significantly Al	bove Average				
SD	97%	3%	216		
AZ	94%	6%	194		
WI	93%	7%	868		
Within Average	Range				
VA	92%	8%	130		
HI	90%	10%	105		
MN	88%	12%	351		
NC	84%	16%	177		
Significantly Below Average					
LA	83%	17%	362		
WA	73%	27%	253		
NCI Average	88%	12%	2,656		



Respondent Helped Develop Child's Service Plan



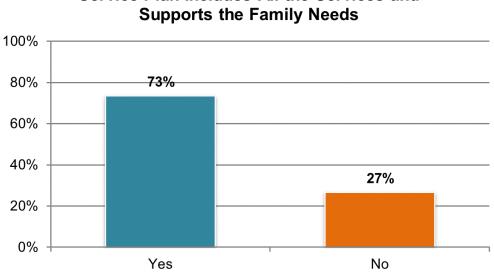
State	Yes	No	N				
Significantly Al	Significantly Above Average						
VA	100%	0%	117				
Within Average	Range						
SD	99%	1%	203				
AZ	98%	2%	174				
WI	98%	2%	784				
HI	97%	3%	89				
NC	96%	4%	141				
MN	96%	4%	300				
LA	96%	4%	284				
WA	93%	7%	170				
NCI Average	97%	3%	2,262				



Service Plan Includes All the Services and



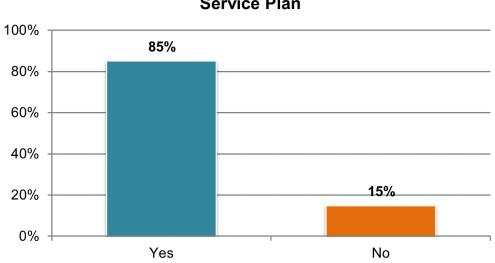
State	Yes	No	Ν				
Significantly A	Significantly Above Average						
SD	91%	9%	191				
AZ	88%	12%	162				
LA	85%	15%	268				
Within Average	Range						
VA	87%	13%	107				
MN	79%	21%	273				
HI	75%	25%	67				
NC	72%	28%	141				
Significantly B	elow Average						
WI	71%	29%	710				
WA	62%	38%	156				
NCI Average	79%	21%	2,075				



Service Plan Includes All the Services and

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

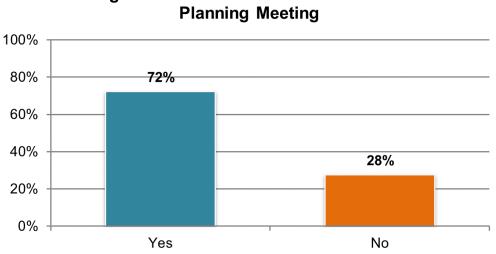
State	Yes	No	Ν				
Significantly Al	Significantly Above Average						
SD	87%	13%	186				
AZ	82%	18%	153				
Within Average	Range						
VA	81%	19%	108				
LA	77%	23%	260				
MN	71%	29%	266				
WI	69%	31%	703				
NC	69%	31%	132				
НІ	64%	36%	66				
Significantly Below Average							
WA	61%	39%	150				
NCI Average	73%	27%	2,024				



Family Receives All Services Listed in the Service Plan

Table Q10. Does your family receive all of the services listed in the plan?

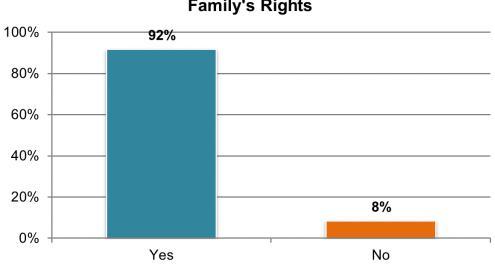
State	Yes	No	Ν				
Significantly A	Significantly Above Average						
SD	94%	6%	195				
WI	91%	9%	742				
Within Average	Range						
VA	92%	8%	107				
MN	88%	12%	282				
LA	86%	14%	263				
NC	86%	14%	138				
HI	84%	16%	67				
WA	78%	22%	155				
Significantly Below Average							
AZ	68%	32%	163				
NCI Average	85%	15%	2,112				



Respondent Discussed How to Handle Emergencies Related to Child at Last Service Planning Meeting

Table Q11. Did you discuss how to handle emergencies related to your child at the last service planning meeting?

State	Yes	No	Ν			
Significantly Above Average						
LA	86%	14%	277			
Within Average	Range					
HI	83%	17%	77			
SD	79%	21%	182			
AZ	77%	23%	158			
NC	77%	23%	131			
WA	68%	32%	161			
MN	66%	34%	268			
VA	63%	38%	104			
Significantly Below Average						
WI	52%	48%	696			
NCI Average	72%	28%	2,054			



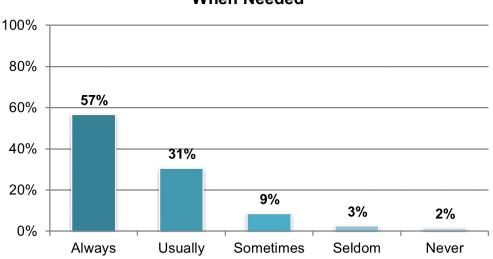
Respondent Received Information About Family's Rights

Table Q12. Have you received information about your family's rights?

State	Yes	No	Ν				
Significantly A	Significantly Above Average						
SD	99%	1%	227				
WI	96%	4%	912				
AZ	96%	4%	193				
Within Average	Range						
HI	95%	5%	92				
VA	92%	8%	125				
MN	91%	9%	364				
LA	88%	12%	405				
WA	87%	13%	252				
Significantly B	Significantly Below Average						
NC	82%	18%	160				
NCI Average	92%	8%	2,730				

Access and Delivery of Services and Supports

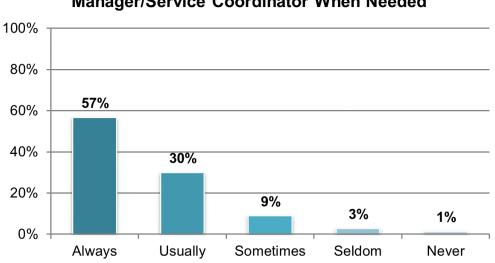
Families and children with disabilities get the services and supports they need.



Respondent Is Able to Contact Support Workers When Needed

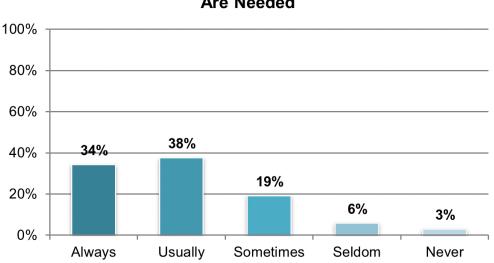


State	Always	Usually	Sometimes	Seldom	Never	N	
Significantly A	Significantly Above Average						
SD	76%	20%	4%	0%	0%	225	
WI	63%	30%	6%	1%	0%	984	
Within Average	Range						
AZ	63%	27%	7%	2%	0%	209	
LA	62%	28%	7%	1%	2%	455	
VA	61%	31%	6%	1%	1%	145	
NC	50%	35%	8%	2%	4%	165	
HI	48%	34%	9%	6%	2%	97	
Significantly B	elow Average						
WA	47%	33%	15%	3%	1%	317	
MN	40%	36%	15%	6%	3%	417	
NCI Average	57%	31%	9%	3%	2%	3,014	



Respondent Is Able to Contact Case Manager/Service Coordinator When Needed

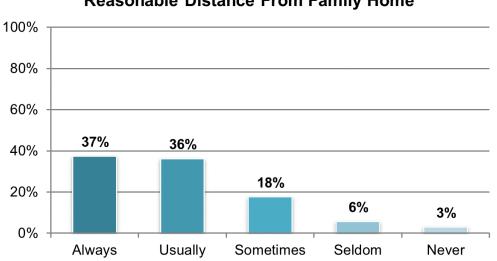
State	Always	Usually	Sometimes	Seldom	Never	N	
Significantly A	Significantly Above Average						
SD	76%	18%	6%	0%	0%	236	
WI	63%	29%	6%	1%	0%	1,015	
Within Average	Range						
LA	60%	31%	6%	1%	2%	453	
VA	58%	32%	6%	3%	1%	148	
AZ	57%	28%	10%	3%	1%	211	
WA	52%	32%	12%	2%	2%	359	
HI	50%	35%	8%	6%	1%	103	
NC	48%	32%	13%	4%	3%	160	
Significantly B	Significantly Below Average						
MN	46%	32%	13%	5%	3%	427	
NCI Average	57%	30%	9%	3%	1%	3,112	



Service and Supports Are Available When They Are Needed

Table Q15. Are services and supports available when you need them?

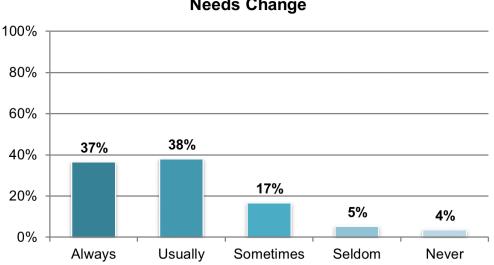
State	Always	Usually	Sometimes	Seldom	Never	N		
Significantly A	Significantly Above Average							
SD	58%	32%	8%	1%	0%	233		
LA	43%	32%	16%	6%	3%	444		
Within Average	Range							
AZ	40%	35%	17%	7%	1%	211		
WI	33%	40%	22%	4%	1%	987		
VA	28%	50%	17%	4%	1%	145		
HI	28%	36%	23%	5%	8%	97		
NC	26%	45%	16%	7%	6%	171		
Significantly B	elow Average							
WA	27%	36%	23%	10%	4%	331		
MN	25%	34%	30%	7%	4%	417		
NCI Average	34%	38%	19%	6%	3%	3,036		



Services and Supports Are Available a Reasonable Distance From Family Home

Table 016	Are services and supports available within a reasonable distance fro	m your home?
Table Q10.	Are services and supports available within a reasonable distance in	in your nome:

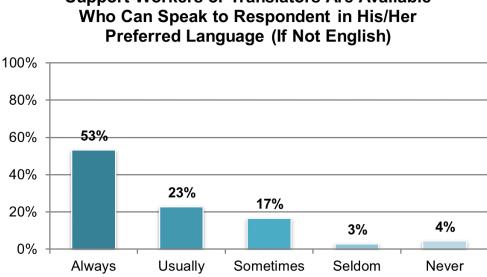
State	Always	Usually	Sometimes	Seldom	Never	N		
Significantly Al	Significantly Above Average							
SD	55%	31%	12%	2%	1%	232		
LA	45%	31%	18%	4%	2%	409		
Within Average	Range							
HI	38%	30%	23%	5%	5%	84		
WI	37%	39%	16%	7%	1%	951		
AZ	35%	33%	22%	8%	1%	203		
NC	35%	38%	16%	5%	5%	165		
VA	34%	45%	12%	7%	2%	141		
Significantly Bo	elow Average							
MN	29%	40%	21%	6%	4%	403		
WA	29%	40%	18%	8%	5%	304		
NCI Average	37%	36%	18%	6%	3%	2,892		



Services and Supports Change When Child's Needs Change

Table Q17. Do the services and supports change when your child's needs change?

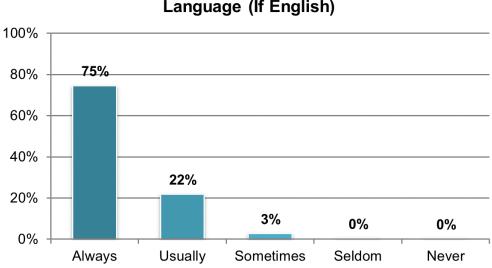
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly A	bove Average					
SD	57%	33%	6%	2%	2%	229
LA	45%	31%	16%	4%	5%	383
Within Average	Range					
AZ	44%	30%	19%	4%	3%	192
WI	36%	40%	18%	5%	2%	881
NC	35%	40%	14%	5%	7%	162
VA	31%	47%	15%	3%	4%	138
HI	27%	46%	18%	8%	1%	74
Significantly B	elow Average					
MN	28%	37%	24%	6%	5%	379
WA	27%	39%	21%	9%	4%	266
NCI Average	37%	38%	17%	5%	4%	2,704



Support Workers or Translators Are Available

Table Q18. If English is not your primary language, are there support workers or translators who can speak with you in your language?

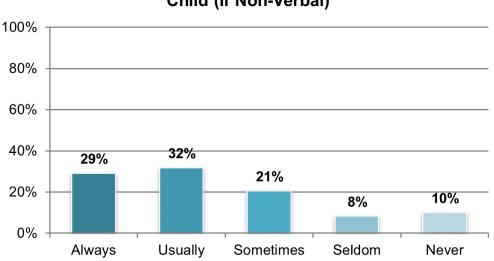
State	Always	Usually	Sometimes	Seldom	Never	Ν
Within Average	Range				· · · · ·	
AZ	63%	18%	12%	6%	0%	49
WA	57%	21%	16%	1%	4%	68
WI	48%	12%	30%	0%	9%	33
MN	44%	40%	8%	4%	4%	25
НІ	NA	NA	NA	NA	NA	NA
LA	NA	NA	NA	NA	NA	NA
NC	NA	NA	NA	NA	NA	NA
SD	NA	NA	NA	NA	NA	NA
VA	NA	NA	NA	NA	NA	NA
NCI Average	53%	23%	17%	3%	4%	175



Support Workers Speak Effectively in Primary Language (If English)

		C	1 .1 .		
Table Q19.	If English is v	your first language	e, do the support we	orkers speak to y	ou effectively?

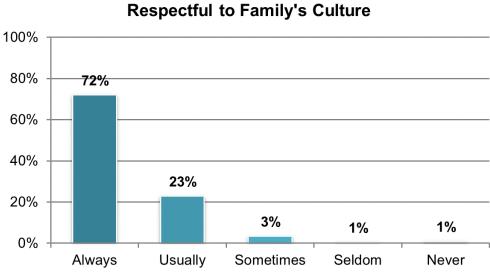
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly A	bove Average			·		
SD	90%	9%	1%	0%	0%	209
LA	81%	17%	2%	1%	0%	348
Within Average	Range					
AZ	82%	13%	5%	0%	0%	130
WI	77%	21%	1%	0%	0%	847
NC	73%	20%	6%	0%	1%	138
VA	68%	29%	2%	1%	0%	114
HI	68%	30%	0%	2%	0%	60
Significantly B	elow Average					
MN	68%	26%	5%	0%	1%	351
WA	64%	32%	3%	0%	0%	232
NCI Average	75%	22%	3%	0%	0%	2,429



Support Workers Can Communicate With the Child (If Non-Verbal)

Table 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?

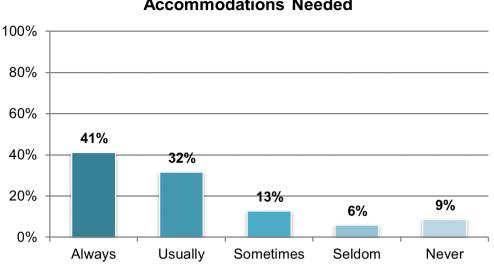
State	Always	Usually	Sometimes	Seldom	Never	N
Within Average	Range					
NC	43%	32%	14%	5%	6%	63
SD	40%	28%	24%	4%	3%	67
LA	35%	27%	20%	5%	12%	164
AZ	29%	36%	17%	9%	9%	76
VA	27%	38%	24%	6%	5%	63
WI	24%	34%	23%	9%	9%	357
HI	24%	36%	12%	14%	14%	50
WA	23%	29%	23%	12%	12%	137
Significantly B	elow Average					
MN	17%	26%	28%	9%	20%	127
NCI Average	29%	32%	21%	8%	10%	1,104



Services Are Delivered in a Manner That Is Respectful to Family's Culture

Table 021		م منام محمد بنام ام	way that is not		un formilu de quiture 2
Table QZ1.	Are services	uenvereu ma	way that is res	pectiul to you	ur family's culture?

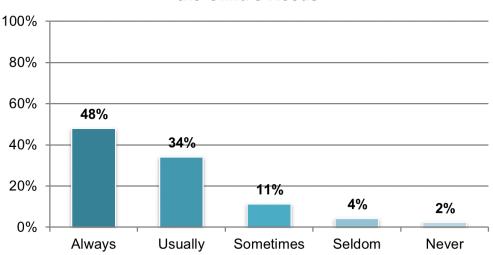
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly A	bove Average					
SD	87%	11%	2%	0%	0%	219
Within Average	Range					
AZ	79%	15%	5%	0%	0%	203
WI	75%	22%	2%	0%	0%	937
VA	74%	24%	1%	0%	1%	136
NC	73%	20%	5%	1%	1%	157
LA	72%	25%	3%	0%	0%	427
MN	66%	28%	4%	0%	1%	390
Significantly B	elow Average					
WA	64%	28%	5%	2%	2%	309
HI	58%	34%	4%	1%	3%	99
NCI Average	72%	23%	3%	1%	1%	2,877



Child Has Access to Special Equipment or Accommodations Needed

Table Q22. Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

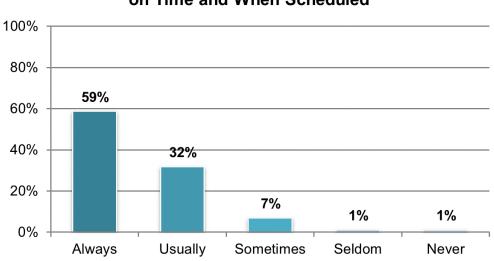
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly A	bove Average					
SD	57%	30%	8%	1%	4%	152
Within Average	Range					
LA	48%	25%	11%	4%	11%	264
WI	44%	37%	12%	4%	4%	641
AZ	44%	25%	15%	6%	10%	126
VA	42%	37%	8%	8%	6%	90
MN	37%	39%	14%	4%	6%	276
HI	34%	29%	13%	11%	13%	62
NC	32%	35%	15%	7%	11%	98
Significantly B	elow Average					
WA	33%	29%	18%	7%	13%	230
NCI Average	41%	32%	13%	6%	9%	1,939



Support Workers Have the Right Training to Meet the Child's Needs

Table Q23. Do the support workers have the right training to meet your child's needs?

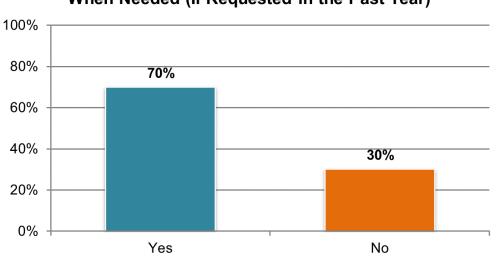
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly A	bove Average					
SD	67%	25%	7%	1%	0%	212
LA	57%	30%	8%	3%	2%	396
Within Average	Range					
AZ	53%	34%	7%	6%	1%	200
WI	48%	35%	15%	2%	1%	910
WA	45%	35%	10%	6%	3%	278
VA	44%	35%	17%	4%	0%	141
HI	42%	34%	12%	6%	7%	86
Significantly B	elow Average					
MN	39%	40%	16%	3%	2%	360
NC	37%	41%	11%	6%	4%	158
NCI Average	48%	34%	11%	4%	2%	2,741



Support Workers Who Come to the Home Arrive on Time and When Scheduled

Table Q24. Do the support workers who come to your home arrive on time and whe	n scheduled?
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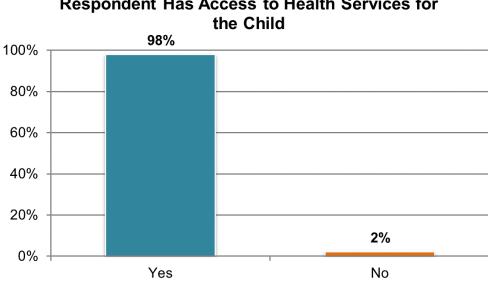
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly A	bove Average			·		
SD	84%	14%	2%	0%	0%	174
LA	66%	24%	8%	1%	1%	398
Within Average	Range					
AZ	65%	27%	7%	1%	0%	209
WI	62%	31%	6%	1%	0%	901
WA	58%	33%	5%	2%	2%	285
MN	53%	38%	6%	2%	2%	363
НІ	52%	36%	6%	2%	3%	88
Significantly B	elow Average					
VA	46%	42%	9%	1%	1%	142
NC	41%	43%	14%	1%	2%	157
NCI Average	59%	32%	7%	1%	1%	2,717



Crisis or Emergency Services Were Provided When Needed (If Requested in the Past Year)

Table Q25. If you asked for crisis/emergency services during the past year, were services provided when needed?

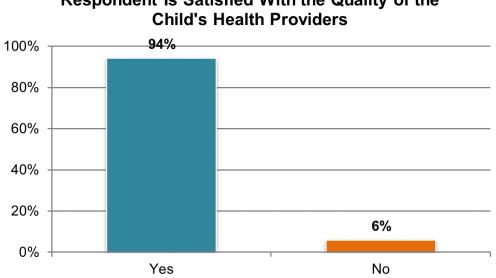
State	Yes	No	Ν
Significantly Al	bove Average		
SD	88%	12%	49
Within Average	Range		
AZ	81%	19%	47
LA	75%	25%	114
VA	70%	30%	37
WI	70%	31%	200
HI	69%	31%	32
WA	66%	34%	87
NC	59%	41%	58
Significantly Bo	elow Average		
MN	53%	47%	79
NCI Average	70%	30%	703



Respondent Has Access to Health Services for

Table Q26. Do you have access to health services for your child?

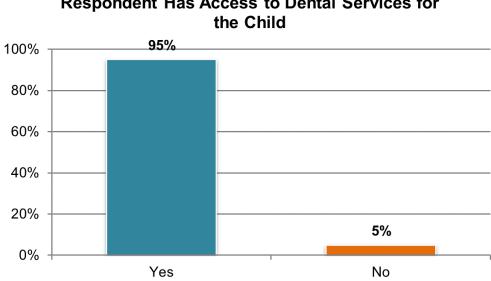
State	Yes	No	N
Significantly Al	oove Average		
MN	100%	0%	445
WI	100%	0%	1,006
Within Average	Range		
NC	98%	2%	185
SD	98%	2%	236
AZ	98%	2%	208
VA	98%	2%	146
LA	97%	3%	462
Н	96%	4%	104
WA	96%	4%	359
NCI Average	98%	2%	3,151



Respondent Is Satisfied With the Quality of the Child's Health Providers

Table 26a. If you have access to health services for your child, are you satisfied with the quality of these providers?

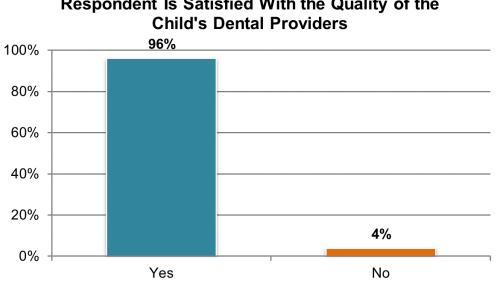
State	Yes	No	N
Significantly Al	oove Average		
WI	96%	4%	975
Within Average	Range		
LA	96%	4%	428
SD	96%	4%	227
VA	95%	5%	142
MN	95%	5%	435
AZ	94%	6%	191
NC	94%	6%	172
WA	94%	6%	320
н	86%	14%	95
NCI Average	94%	6%	2,985



Respondent Has Access to Dental Services for

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

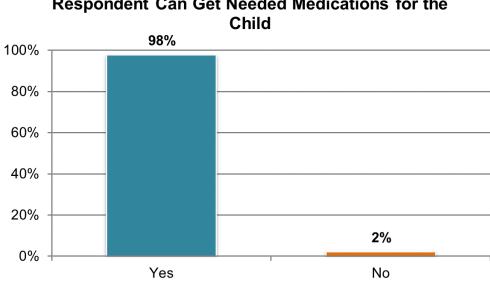
State	Yes	No	Ν
Significantly Al	oove Average		
WA	98%	2%	360
Within Average	Range		
SD	97%	3%	239
MN	97%	3%	441
AZ	97%	3%	205
NC	96%	4%	184
WI	94%	6%	1,003
LA	94%	6%	464
HI	93%	7%	108
VA	92%	8%	142
NCI Average	95%	5%	3,146



Respondent Is Satisfied With the Quality of the Child's Dental Providers



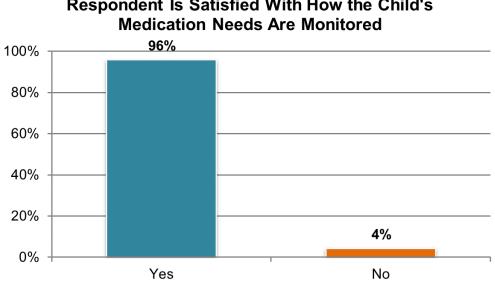
State	Yes	No	Ν
Within Average	e Range		
VA	98%	2%	129
WA	98%	2%	333
LA	97%	3%	400
SD	97%	3%	219
MN	97%	3%	415
WI	96%	4%	913
н	95%	5%	94
AZ	94%	6%	191
NC	94%	6%	170
NCI Average	96%	4%	2,864



Respondent Can Get Needed Medications for the

Table Q28. Are you able to get medications needed for your child?

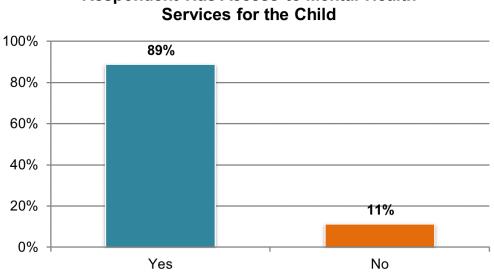
State	Yes	No	Ν
Significantly Al	oove Average		
WI	99%	1%	962
Within Average	Range		
VA	99%	1%	141
NC	98%	2%	182
SD	98%	2%	232
MN	98%	2%	436
AZ	97%	3%	195
LA	97%	3%	467
WA	97%	3%	346
н	96%	4%	108
NCI Average	98%	2%	3,069



Respondent Is Satisfied With How the Child's

Table 28a. If you have access to needed medications for your child, are you satisfied with how your child's medication needs are monitored?

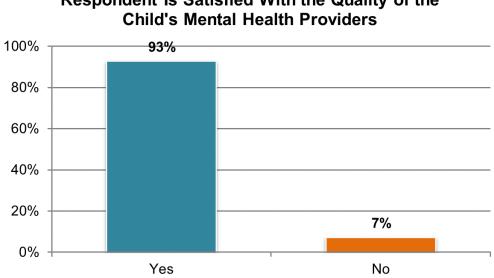
State	Yes	No	Ν
Within Average	Range		
SD	97%	3%	213
LA	97%	3%	423
VA	96%	4%	136
WI	96%	4%	914
WA	96%	4%	321
AZ	96%	4%	184
MN	95%	5%	413
NC	95%	5%	168
HI	95%	5%	93
NCI Average	96%	4%	2,865



Respondent Has Access to Mental Health

Table Q29. If needed, do you have access to mental health services for your child?

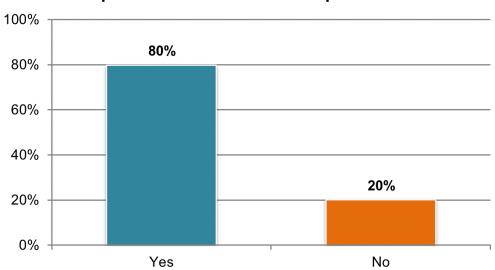
State	Yes	No	Ν
Significantly A	bove Average		
MN	94%	6%	301
Within Average	Range		
AZ	94%	6%	121
VA	94%	6%	96
SD	93%	7%	135
NC	93%	7%	134
WI	92%	8%	601
LA	86%	14%	295
HI	73%	27%	55
Significantly Below Average			
WA	80%	20%	212
NCI Average	89%	11%	1,950



Respondent Is Satisfied With the Quality of the Child's Mental Health Providers

Table 29a.	If you have access to mental health services for your child, are you satisfied with the quality of these
providers?	

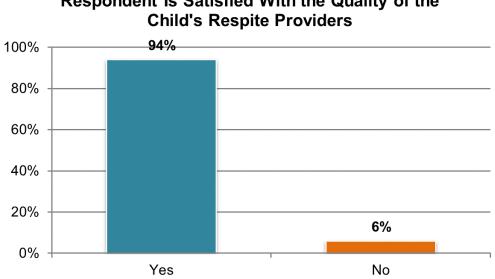
State	Yes	No	N
Within Average	Range		
SD	97%	3%	101
VA	96%	4%	75
LA	95%	5%	218
HI	94%	6%	32
MN	93%	7%	243
WA	92%	8%	126
WI	92%	8%	428
NC	90%	10%	100
AZ	87%	13%	99
NCI Average	93%	7%	1,422



Respondent Has Access to Respite Services

Table Q30. If you need respite services, do you have access to them?

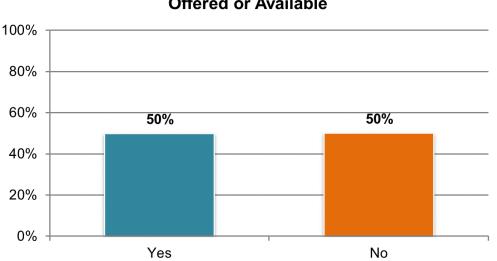
State	Yes	No	N
Significantly A	bove Average		
AZ	93%	7%	183
SD	89%	11%	206
VA	89%	11%	140
WI	85%	15%	830
Within Average	Range		
NC	85%	15%	160
LA	83%	17%	286
Significantly B	elow Average		
MN	69%	31%	309
WA	65%	35%	240
HI	62%	38%	78
NCI Average	80%	20%	2,432



Respondent Is Satisfied With the Quality of the Child's Respite Providers

Table 30a. If you have access to needed respite services, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Al	bove Average		
SD	98%	2%	159
MN	97%	3%	184
WI	96%	4%	639
Within Average	Range		
VA	96%	4%	114
HI	95%	5%	42
AZ	95%	5%	151
LA	95%	5%	202
WA	87%	13%	133
NC	87%	13%	113
NCI Average	94%	6%	1,737



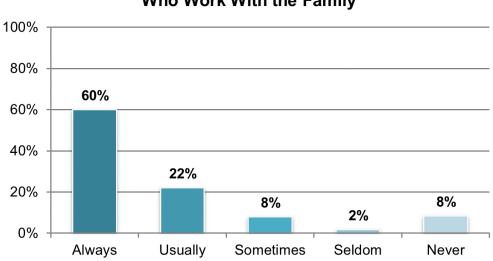
Services Are Needed That Are Not Currently Offered or Available

Table Q31. Are there other services that your family needs that are not currently offered or available?

State	Yes	No	Ν
Significantly Al	bove Average		
WA	67%	33%	198
Within Average	Range		
НІ	65%	35%	54
NC	55%	45%	123
VA	52%	48%	108
WI	50%	50%	612
MN	47%	53%	285
AZ	44%	56%	144
LA	42%	58%	288
Significantly Below Average			
SD	26%	74%	159
NCI Average	50%	50%	1,971

Choice and Control

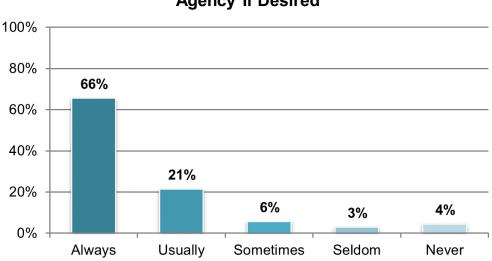
Families and children with disabilities determine the services and supports they receive and the individuals or agencies who provide them.



Respondent Chooses the Provider Agencies Who Work With the Family

Table O32.	Do you choos	e the provider	agencies who	work with v	our family?
	D 0 y 00 chi00.		ageneics wite		our further.

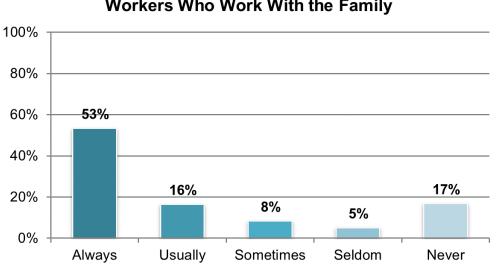
State	Always	Usually	Sometimes	Seldom	Never	N		
Significantly Above Average								
LA	75%	15%	4%	1%	5%	411		
Within Average	Within Average Range							
AZ	62%	20%	10%	0%	7%	203		
NC	62%	22%	8%	1%	7%	166		
VA	61%	25%	6%	1%	6%	141		
MN	59%	28%	6%	2%	5%	410		
HI	59%	18%	8%	0%	14%	83		
WA	57%	20%	10%	3%	9%	294		
SD	55%	25%	7%	2%	11%	197		
Significantly Below Average								
VVI	49%	26%	11%	4%	10%	899		
NCI Average	60%	22%	8%	2%	8%	2,804		



Respondent Can Choose a Different Provider Agency If Desired

Table Q33. Can you choose a different provider agency if you want to?

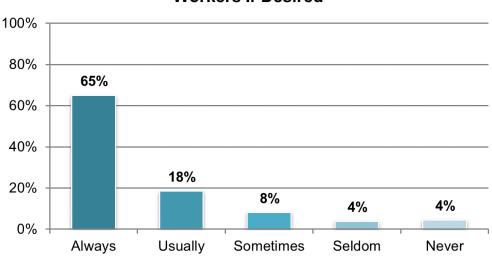
State	Always	Usually	Sometimes	Seldom	Never	N		
Significantly Above Average								
LA	77%	18%	1%	1%	3%	368		
Within Average	Within Average Range							
VA	73%	18%	3%	3%	3%	118		
NC	72%	19%	5%	1%	3%	154		
AZ	69%	18%	7%	3%	3%	181		
SD	67%	21%	4%	1%	7%	158		
MN	62%	28%	5%	3%	2%	356		
HI	58%	28%	6%	2%	6%	64		
WA	58%	21%	9%	6%	6%	237		
Significantly Below Average								
WI	55%	23%	10%	5%	7%	648		
NCI Average	66%	21%	6%	3%	4%	2,284		



Respondent Chooses Individual Support Workers Who Work With the Family

Table O24	Do you choose the	individual cunnor	t workers who we	rk directly with	vour family?
Table Q54.	Do you choose the	: muiviuuai suppor	t workers who wo	rk unectly with	your family:

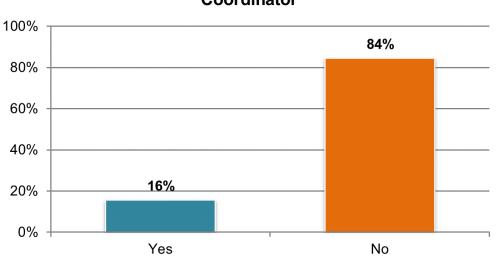
State	Always	Usually	Sometimes	Seldom	Never	N		
Significantly Above Average								
VA	67%	13%	4%	6%	10%	141		
LA	65%	14%	3%	3%	14%	401		
Within Average	Range							
NC	59%	20%	7%	4%	10%	157		
AZ	54%	16%	11%	3%	16%	196		
WA	53%	10%	12%	6%	19%	267		
MN	51%	17%	10%	6%	16%	381		
HI	46%	18%	8%	7%	20%	83		
SD	45%	21%	9%	3%	22%	179		
Significantly Below Average								
VVI	41%	18%	10%	7%	23%	880		
NCI Average	53%	16%	8%	5%	17%	2,685		



Respondent Can Choose Different Support Workers If Desired

Table Q35. Can you choose different support workers if you want to?

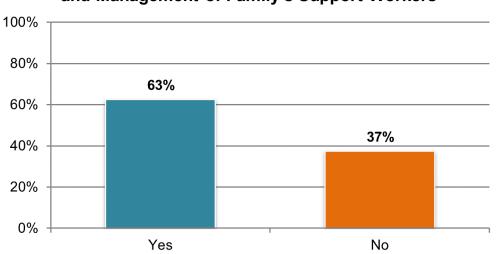
State	Always	Usually	Sometimes	Seldom	Never	N		
Significantly Above Average								
LA	76%	17%	3%	1%	3%	356		
Within Average	Within Average Range							
SD	71%	15%	7%	2%	5%	149		
VA	71%	17%	5%	5%	2%	126		
NC	66%	19%	4%	7%	5%	151		
AZ	65%	16%	9%	3%	6%	171		
WA	61%	13%	10%	7%	8%	231		
MN	61%	22%	10%	3%	5%	313		
HI	59%	22%	14%	3%	2%	58		
Significantly Below Average								
VVI	55%	25%	10%	4%	6%	672		
NCI Average	65%	18%	8%	4%	4%	2,227		



Respondent Chose Case Manager/Service Coordinator

Table Q36. Did you choose your case manager/service coordinator?

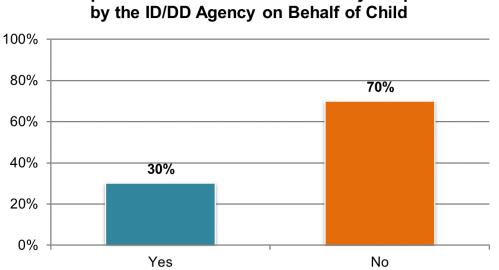
State	Yes	No	N
Significantly Al	bove Average		
LA	37%	63%	418
VA	27%	73%	142
NC	26%	74%	155
Within Average	Range		
SD	21%	79%	214
Significantly B	elow Average		
AZ	9%	91%	209
WI	6%	94%	975
MN	5%	95%	424
WA	4%	96%	348
HI	4%	96%	103
NCI Average	16%	84%	2,988



Respondent Has Control or Input Over the Hiring and Management of Family's Support Workers

Table Q37. Do you have control and/or input over the hiring and management of your family's support workers?

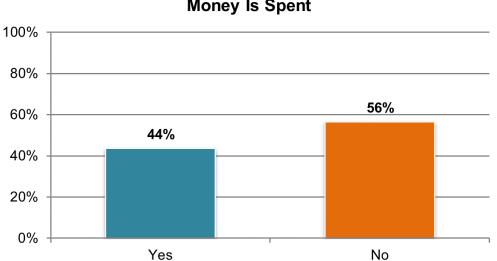
State	Yes	No	Ν			
Significantly A	bove Average					
VA	74%	26%	151			
Within Average	Range					
MN	69%	31%	70			
LA	67%	33%	347			
NC	66%	34%	328			
н	63%	37%	144			
SD	62%	38%	159			
AZ	54%	46%	123			
Significantly B	Significantly Below Average					
WI	54%	46%	242			
WA	54%	46%	761			
NCI Average	63%	37%	2,325			



Respondent Knows How Much Money Is Spent by the ID/DD Agency on Behalf of Child

Table Q38. Do you know how much money is spent by the ID/DD agency on behalf of your child?

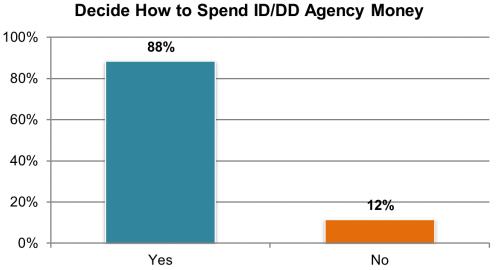
State	Yes	No	N
Significantly A	bove Average		
SD	65%	35%	236
MN	50%	50%	444
LA	39%	61%	470
Within Average	Range		
WI	33%	67%	1,024
WA	31%	69%	366
NC	23%	77%	172
Significantly B	elow Average		
VA	16%	84%	141
н	10%	90%	105
AZ	4%	96%	210
NCI Average	30%	70%	3,168



Respondent Has Say in How ID/DD Agency Money Is Spent

Table Q39. Do you have a say in how this money is spent?

State	Yes	No	Ν
Significantly A	bove Average		
SD	88%	12%	190
WI	66%	34%	695
MN	63%	37%	325
LA	52%	48%	288
Within Average	Range		
WA	48%	52%	246
Significantly B	elow Average		
NC	29%	71%	123
VA	23%	77%	86
AZ	12%	88%	132
н	10%	90%	59
NCI Average	44%	56%	2,144



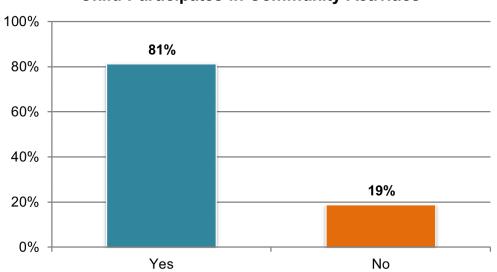
Respondent Has All Information Needed to Decide How to Spend ID/DD Agency Money

Table 39a. If you have a say in how this money is spent, do you have all the information you need to make decisions about how to spend this money?

State	Yes	No	N			
Significantly A	bove Average					
SD	95%	5%	152			
Within Average	Range					
LA	90%	10%	132			
MN	90%	10%	176			
NC	88%	12%	33			
WA	85%	15%	95			
Significantly B	elow Average					
WI	83%	17%	371			
NCI Average	88%	12%	959			
N < 20	N < 20					
VA	N/A	N/A	N/A			
н	N/A	N/A	N/A			
AZ	N/A	N/A	N/A			

Community Connections

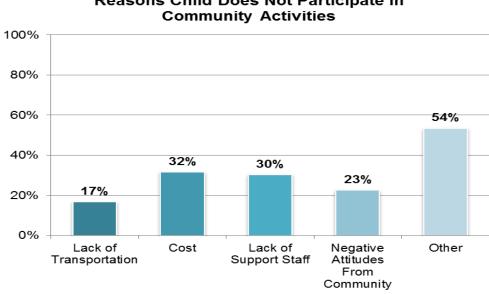
Family members with disabilities use integrated community services and participate in everyday community activities.



Child Participates in Community Activities

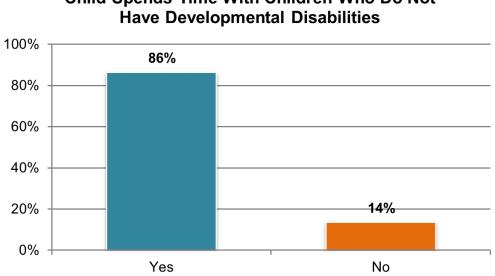
Table Q40. Does your child participate in community activities (such as going out to a restaurant, movie, or sporting event)?

State	Yes	No	N		
Significantly Al	oove Average				
SD	92%	8%	239		
Within Average	Range				
LA	85%	15%	493		
MN	83%	17%	449		
VA	82%	18%	147		
NC	81%	19%	187		
WI	80%	20%	1,016		
AZ	77%	23%	206		
HI	75%	25%	117		
Significantly Below Average					
WA	75%	25%	372		
NCI Average	81%	19%	3,226		



Reasons Child Does Not Participate in Community Activities

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes From Community Members	Other
AZ	20%	32%	14%	23%	48%
HI	18%	43%	36%	21%	46%
LA	26%	21%	18%	9%	58%
MN	11%	37%	30%	34%	63%
NC	18%	29%	47%	18%	47%
VA	16%	28%	44%	16%	48%
WA	13%	28%	21%	26%	63%
WI	13%	35%	33%	34%	55%
NCI Average	17%	32%	30%	23%	54%
N < 20					
SD	N/A	N/A	N/A	N/A	N/A



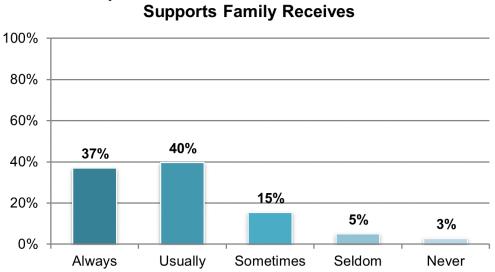
Child Spends Time With Children Who Do Not



State	Yes	No	Ν	
Significantly A	bove Average			
SD	92%	8%	237	
LA	91%	9%	487	
Within Average	Range			
AZ	91%	9%	211	
NC	90%	10%	182	
WI	86%	14%	995	
MN	86%	14%	447	
VA	82%	18%	145	
н	79%	21%	116	
Significantly Below Average				
WA	80%	20%	364	
NCI Average	86%	14%	3,184	

Satisfaction With Services and Supports

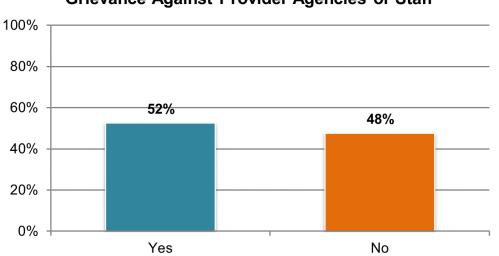
Families and family members with disabilities receive adequate and satisfactory supports.



Respondent Is Satisfied With Services and Supports Family Receives

Table Q42. Overall, are you satisfied with the services and supports your family currently receives?

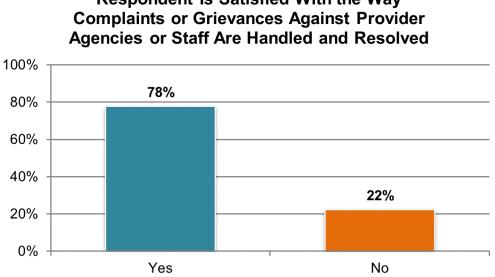
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly A	bove Average					
SD	60%	32%	7%	1%	0%	239
LA	47%	32%	15%	5%	2%	479
Within Average	Range					
AZ	46%	40%	8%	5%	1%	213
WA	39%	30%	19%	8%	3%	355
VA	30%	48%	18%	1%	2%	145
HI	27%	37%	18%	11%	7%	111
Significantly B	elow Average					
WI	29%	51%	16%	3%	0%	1,014
NC	27%	41%	18%	6%	8%	175
MN	27%	46%	21%	5%	2%	442
NCI Average	37%	40%	15%	5%	3%	3,173



Respondent Knows How to File a Complaint or Grievance Against Provider Agencies or Staff

Table 043. Do you	know the process for	filing a complaint or g	rievance against n	rovider agencies or staff?
	KIIUW LITE PLOCESS IUI	ming a complaint of g	inevance against p	I OVIGET AGENCIES OF STATE

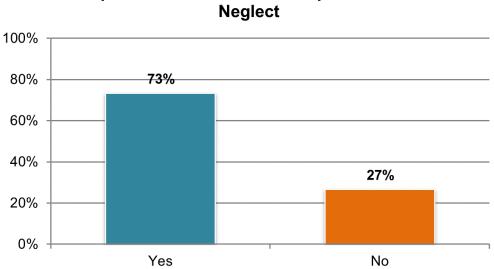
State	Yes	No	Ν			
Significantly A	bove Average					
SD	78%	22%	233			
WI	61%	39%	1,019			
LA	61%	39%	479			
Within Average	Range					
MN	53%	47%	448			
NC	51%	49%	177			
VA	49%	51%	142			
НІ	44%	56%	116			
Significantly B	Significantly Below Average					
AZ	38%	62%	209			
WA	37%	63%	360			
NCI Average	52%	48%	3,183			



Respondent Is Satisfied With the Way Complaints or Grievances Against Provider

Table Q44. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and
resolved?

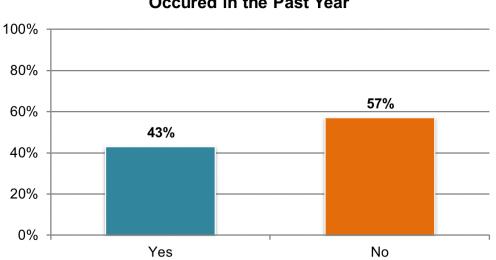
State	Yes	No	N
Significantly Al	oove Average		
SD	92%	8%	76
LA	87%	13%	207
Within Average	Range		
WI	82%	18%	295
VA	77%	23%	57
MN	76%	24%	137
WA	73%	27%	96
н	72%	28%	36
NC	70%	30%	67
AZ	70%	30%	60
NCI Average	78%	22%	1,031



Respondent Knows How to Report Abuse or Neglect

Table Q45. Do you know how to report abuse or neglect?

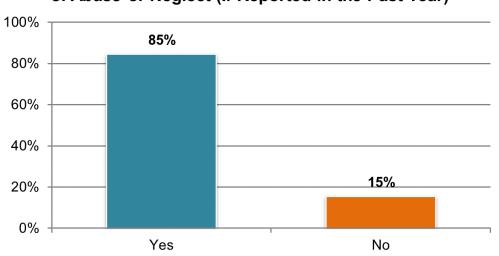
State	Yes	No	N		
Significantly Al	bove Average				
SD	93%	7%	237		
LA	80%	20%	467		
Within Average	Range				
VA	81%	19%	139		
MN	78%	22%	441		
WI	76%	24%	998		
NC	71%	29%	180		
н	63%	37%	109		
Significantly B	Significantly Below Average				
WA	63%	37%	344		
AZ	54%	46%	205		
NCI Average	73%	27%	3,120		



Respondent Reported Abuse or Neglect If it Occured in the Past Year

Table Q46. Within the past year, if abuse or neglect occurred, did you report it?

State	Yes	No	Ν
Within Average	Range		
NC	59%	41%	27
VA	56%	44%	25
LA	50%	50%	70
SD	50%	50%	28
MN	44%	56%	63
WI	39%	61%	122
HI	32%	68%	22
AZ	31%	69%	42
Significantly Below Average			
WA	26%	74%	62
NCI Average	43%	57%	461



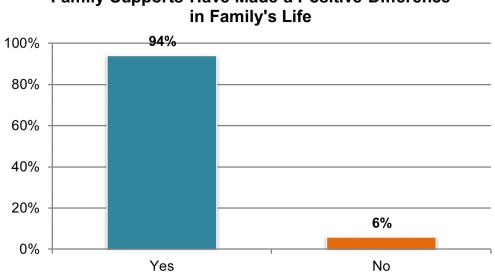
Appropriate People Were Responsive to Report of Abuse or Neglect (If Reported in the Past Year)

Table 46a. If you reported abuse or neglect within the past year, were the appropriate people responsive to your report?

State	Yes	No	Ν
Within Average	Range		
WI	88%	12%	43
LA	87%	13%	23
MN	78%	22%	23
NCI Average	85%	15%	89
N < 20			
WA	N/A	N/A	N/A
н	N/A	N/A	N/A
AZ	N/A	N/A	N/A
SD	N/A	N/A	N/A
NC	N/A	N/A	N/A
VA	N/A	N/A	N/A

Family Outcomes

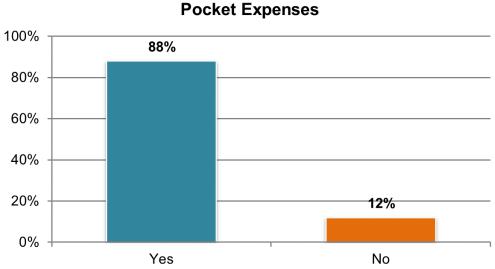
Individual and family supports make a positive difference in the lives of families.



Family Supports Have Made a Positive Difference

Table Q47. Do you feel that family supports have made a positive difference in the life of your family?

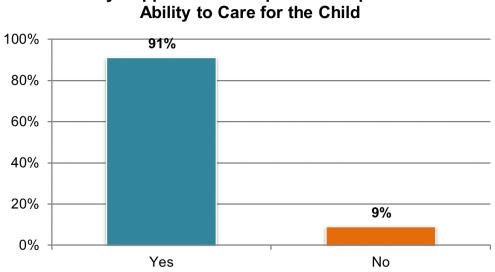
State	Yes	No	N
Significantly Al	oove Average		
SD	99%	1%	238
LA	97%	3%	448
Within Average	Range		
VA	97%	3%	137
AZ	96%	4%	197
WI	96%	4%	960
MN	95%	5%	416
NC	92%	8%	159
WA	91%	9%	327
HI	84%	16%	88
NCI Average	94%	6%	2,970



Services and Supports Have Reduced Out-of-Pocket Expenses

Table Q48. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your child's care?

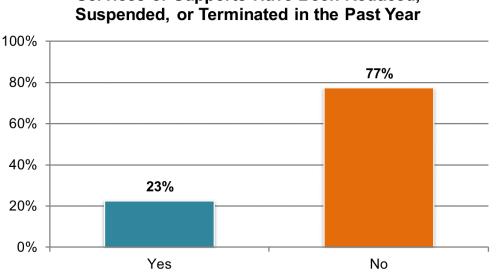
State	Yes	No	N
Significantly Al	oove Average		
SD	98%	2%	233
WI	91%	9%	955
Within Average	Range		
LA	91%	9%	447
VA	90%	10%	138
AZ	89%	11%	195
MN	88%	12%	411
NC	85%	15%	155
WA	84%	16%	340
HI	76%	24%	83
NCI Average	88%	12%	2,957



Family Supports Have Improved Respondent's Ability to Care for the Child

Table Q49. Do you feel that family supports have improved your ability to care for your child?

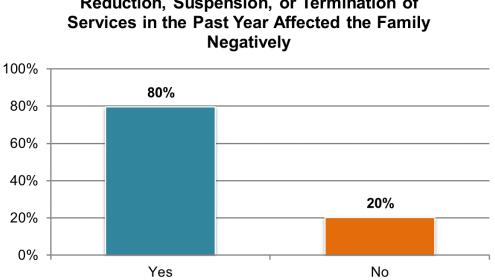
State	Yes	No	Ν
Significantly A	bove Average		
SD	98%	2%	236
LA	94%	6%	448
WI	93%	7%	956
Within Average	Range		
AZ	93%	7%	205
VA	93%	7%	139
MN	93%	7%	424
NC	90%	10%	165
WA	87%	13%	332
Significantly Below Average			
н	79%	21%	89
NCI Average	91%	9%	2,994



Services or Supports Have Been Reduced,

Table Q50. Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?

State	Yes	No	N		
Significantly Al	oove Average				
WA	29%	71%	312		
Within Average	Range				
NC	32%	68%	154		
WI	26%	74%	919		
VA	23%	77%	132		
HI	23%	77%	78		
MN	23%	77%	412		
AZ	18%	82%	199		
Significantly Be	Significantly Below Average				
LA	17%	83%	426		
SD	12%	88%	210		
NCI Average	23%	77%	2,842		



Reduction, Suspension, or Termination of

Table 50a. If services or supports received by your family were reduced, suspended, or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family negatively?

State	Yes	No	N	
Within Average	Range			
VA	90%	10%	29	
WI	80%	20%	203	
WA	80%	20%	81	
NC	80%	20%	45	
AZ	78%	22%	32	
MN	77%	23%	79	
LA	72%	28%	65	
NCI Average	80%	20%	534	
N < 20				
HI	NA	NA	NA	
SD	NA	NA	NA	

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 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

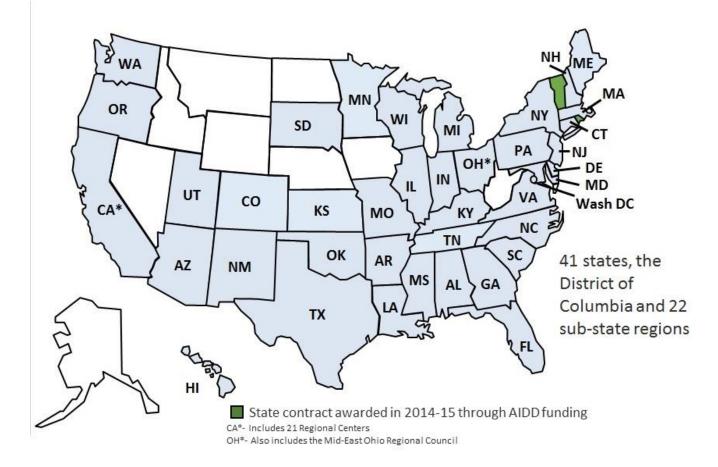
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

Since the initial field test, NCI has 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 <u>http://www.nationalcoreindicators.org</u>.

State Participation

During the 2014-15 data collection cycle, 41 states, the District of Columbia and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and the participating states are shown in the chart below.

Chart 1. NCI State Participation 2014-15



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 Table 1 on the following page). Three data sources are used to assess outcomes: the Adult Consumer Survey, three Family Surveys, a Provider 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.

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 & 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.
Community Connections	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.
Family Outcomes	Individual and family supports make a positive difference in the lives of families.

Family Survey Sub-Domains and Concern Statements

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.

NCI data are not intended to be used at the provider level. 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, policy-makers, 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 child³ 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%.⁴

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.

³ "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.

⁴ See "Response Rates" section for information on total surveys mailed and received by states as well as each state's margin of error.

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

- 1. The respondent indicated the child lived outside the family home; or
- 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 average⁵; 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.

Response Rates

During 2014-15, nine 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. Table R1 shows the number of surveys each state mailed, surveys returned, response rates, and the number of valid surveys accepted for inclusion in data analysis.

State	Usable Surveys Returned	Surveys Mailed	Response Rate
AZ	215	1300	16.5%
Н	123	361	34.1%
LA	512	3000	17.1%
MN	458	1919	23.9%
NC	195	1200	16.3%
SD	249	935	26.6%
VA	148	778	19.0%
WA	382	1900	20.1%
WI	1037	1200	86.4%
NCI Average	3319	12593	26.4%

Table R1. Child Family Survey: State Response Rates

⁵ The NCI Average is the sum of all state averages divided by the total number of states.