

# Child Family Survey

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Final Report – May 2009  
2007-2008 Data



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

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## Organization of Report

Eight states conducted the National Core Indicators (NCI) Child Family Survey during the 2007-2008 project year and submitted data. The Child Family Survey was administered to families having a child with disabilities living in the family's home. This Final Report provides a summary of results, based on the data submitted by June 2008.

This report is organized as follows:

### **I. INTRODUCTION**

This section provides an overview of the National Core Indicators, and a brief history of the development, administration, and participation of states in the NCI Child Family Survey.

### **II. CHILD FAMILY SURVEY**

This section briefly describes the structure of the survey instrument.

### **III. METHODS**

This section illustrates the protocol used by states to sample participating families, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by Human Services Research Institute staff to aggregate and analyze the data.

### **IV. RESULTS**

This section provides aggregate and state-by-state results for demographic, service utilization, service access and delivery, satisfaction and outcome data.

### **V. DISCUSSION OF RESULTS**

This section provides aggregate and state-by-state results for demographic, service utilization, service planning, access and delivery, choice and control, community connections, satisfaction and outcome data. It also provides an overall view of the aggregate survey results.

## **I. Introduction**

### **Overview of National Core Indicators**

In 1996, the NASDDDS Board of Directors launched the Core Indicators Project (CIP). The project's aim is to support state developmental disabilities authorities (SDDAs) in developing and implementing performance/outcome indicators and related data collection strategies that will enable them to measure service delivery system performance. The project strives to provide SDDAs with sound tools in support of their efforts to improve system performance and thereby to better serve people with developmental disabilities and their families. NASDDDS' active sponsorship of CIP facilitates states pooling their knowledge, expertise and resources in this endeavor.

Phase I of CIP began in 1997 when the CIP Steering Committee selected a “candidate” set of 61 performance/outcome indicators (focusing on the adult service system), in order to test their utility/feasibility. Seven states conducted a field test of these indicators, including administering the project’s consumer and family surveys and compiling other data. The results were compiled, analyzed and reported back to participating states.

During Phase II (1999-2000), the original indicators were revised and data collection tools and methods were improved. The new (Version 2.0) indicator set consisted of 60 performance and outcome indicators. Twelve states (see below) participated in Phase II, and this data is considered baseline project data. In Phase III (2000-2001), additional states joined the effort and the project expanded its scope to include services for children with developmental disabilities and their families.

In 2002, the Core Indicators Project changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. And between 2002 and 2008, the NCI effort continued to expand. The following figure summarizes state participation in the National Core Indicators since its inception through the 2007-2008 data collection cycles. States are listed if they participate in one or more of the NCI activities (e.g., consumer survey, family surveys, expenditure/utilization data, etc.).

<b>Phase I Field Test</b>	<b>Phase II 1999-2000</b>	<b>Phase III 2000-2001</b>	<b>Phase IV 2001-2002</b>	<b>Phase V 2002-2003</b>	<b>Phase VI 2003-2004</b>	<b>Phase VII 2004-2005</b>	<b>Phase VIII 2005-2006</b>	<b>Phase IX 2006-2007</b>	<b>Phase X 2007-2008</b>
AZ	AZ	AZ	AL	AL	AL	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	AR	AR	AR
MO	KY	DE	CA - RCOC	CA - RCOC	CA - RCOC	CA-RCOC	AZ	AZ	AZ
NE	MA	IA	CT	CT	CT	CT	CA-RCOC	CA-RCOC	CA-RCOC
PA	MN	KY	DE	DE	DE	DE	CT	CT	CT
VT	NE	MA	HI	HI	DC	DC	DE	DE	DE
VA	NC	MN	IL	IN	HI	HI	DC	GA	GA
	PA	MT	IN	IA	IN	KY	GA	HI	HI
	RI	NE	IA	KY	KY	MA	HI	IN	IN
	VT	NC	KY	MA	MA	ME	KY	KY	KY
	VA	PA	MA	ME	ME	NC	MA	MA	LA
	WA	RI	NE	NE	NE	OK	ME	ME	MA
		UT	NC	NC	NC	PA	NM	NM	ME
		VT	OK	OK	ND	RI	NC	NC	MO
		WA	PA	PA	OK	SC	OK	OK	NC
			RI	RI	PA	VT	PA	PA	NJ
			UT	SC	RI	WA	RI	RI	NM
			VT	SD	SC	WV	SC	SC	NY
			WA	VT	SD	WY	SD	TX	OK
			WV	WA	VT		TX	VT	PA
			WY	WV	WA		VT	WA	RI
				WY	WV		WA	WV	SC
					WY		WV	WY	TX
							WY		VT
									WA
									WV
									WY

Denotes first year of participation in NCI.

## Family Indicators

Getting direct feedback from families is an important way for states to gauge service and support satisfaction, as well as pinpoint areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to compare changes in performance over time, as well as compare its own performance against that of other states.

The Family Indicators were developed and approved by the NCI Steering Committee in 2002. The table below details the Family Sub-Domains, Concerns, and Indicators, and identifies the surveys in which the indicators are explored. The Sub-Domains include: **Information and Planning, Choice and Control, Access and Support Delivery, Community Connections, Family Involvement, Satisfaction and Outcomes.** The structure of each family survey follows this framework.

Table 2 Family Indicators			
DOMAIN	FAMILY INDICATORS The project's family indicators concern how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.		
SUB-DOMAIN	CONCERN	INDICATOR	DATA SOURCE
Information & Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.	The proportion of families who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	All Surveys
		The proportion of families who report they have the information needed to skillfully plan for their services and supports.	All Surveys
		The proportion of families reporting that their support plan includes or reflects things that are important to them.	All Surveys
		The proportion of families who report that staff who assist with planning are knowledgeable and respectful.	All Surveys
Choice & Control	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.	The proportion of families reporting that they control their own budgets/supports (i.e. they choose what supports/goods to purchase).	Children & Adult Family Surveys
		The proportion of families who report they choose, hire and manage their service/support providers.	All Surveys
		The proportion of families who report that staff are respectful of their choices and decisions.	All Surveys
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.	The proportion of eligible families who report having access to an adequate array of services and supports.	All Surveys
		The proportion of families who report that services/supports are available when needed, even in a crisis.	All Surveys
		The proportion of families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication .	All Surveys
		The proportion of families who report that service and support staff/providers are available and capable of meeting family needs.	All Surveys
		The proportion of families who report that services/supports are flexible to meet their changing needs.	All Surveys
		The proportion of families who indicate that services/supports provided outside of the home (e.g., day/employment, residential services) are done so in a safe and healthy environment.	Both Adult Surveys
Community Connections	Families/family members use integrated community services and participate in everyday community activities.	The proportion of families/family members who participate in integrated activities in their communities.	All Surveys
		The proportion of families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	All Surveys
Family Involvement	Families maintain connections with family members not living at home.	The proportion of families/guardians of individuals not living at home who report the extent to which the system supports continuing family involvement.	Family/Guardian Survey
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	All Surveys
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Children & Adult Family Surveys

## II. Child Family Survey

### Background

This report focuses on the Child Family Survey.

The Child Family Survey was developed and first utilized during Phase III of the Core Indicators Project (2000-2001), in response to state interest in determining the level of satisfaction with services and supports among families of children with disabilities living at home. In this effort, five states administered the Child Family Survey.

States were instructed to mail the survey to 1,000 randomly-selected families who met two criteria: (1) a child family member with a developmental disability lived in the household and (2) either the individual or the family received at least one service or support besides case management. If fewer than 1,000 families met these criteria, the state was instructed to mail the questionnaire to all qualified families. The requirement that questionnaires be mailed to 1,000 families was based on an expected return rate of 40%, which in turn would yield 400 completed questionnaires in hand for each state.

Between 2001 and 2008, five to eight states have participated each year. Response rates within states have varied greatly, between 11% - 57%, yet each year, NCI has had between 1,800 – 2,700 completed surveys available for analysis.

### State Participation

Below is a figure indicating state participation in the Child Family Survey since its inception.

<b>Table 3</b> <b>State Participation in NCI Children Family Survey</b> <b>(Children Living at Home)</b>								
<b>Phase I &amp; II Field Test</b>	<b>Phase III 2000-01 Data</b>	<b>Phase IV 2001-02 Data</b>	<b>Phase V 2002-03 Data</b>	<b>Phase VI 2003-04 Data</b>	<b>Phase VII 2004-05 Data</b>	<b>Phase VIII 2005-06 Data</b>	<b>Phase IX 2006-07 Data</b>	<b>Phase X 2007-08 Data</b>
NA	AZ MN NC UT WA	CA-RCOC NE NC UT VT	AZ CA-RCOC MA SC SD WA WY	CA-RCOC CT HI ND SC WY	AZ CA-RCOC CT WA WY	CA-RCOC CT HI SC SD TX WY	AZ CT OK TX WA WV WY	CA-RCOC HI LA NJ OK SC WV WY



## Survey Instrument

States that administer the Child Family Survey agree to employ the NCI's base instrument and questions. If it wishes, a state may include additional questions to address topics not dealt with in the base instrument. Since all states use the standard questionnaire, the results are comparable state-to-state. Here, we describe the Child Family Survey development. Further on in the report, we discuss how the surveys were administered and how the results were analyzed.

The Child Family Survey used in 2007-2008 not only asks families to express their overall level of satisfaction with services and supports, it also probes specific aspects of the service system's capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; and outcomes. Combined, this information provides an overall picture of family satisfaction within and across states.

**Demographics** – The survey instrument begins with a series of questions tied to characteristics of the child with disabilities (e.g., child's age, race, type of disability). It is then followed by a series of demographic questions pertaining to the respondent (e.g., respondent's age, health status, relationship to individual).

**Services Received** – A brief section of the survey asks respondents to identify the services and supports their family/child receives.

**Service Planning, Delivery & Outcomes** – The survey then contains several categories of questions that probe to specific areas of quality service provision (e.g., information and planning, access and delivery of services, community connections). Each question is constructed so that the respondent can select from three possible responses ("always or usually", "sometimes", and "seldom or never"). Respondents also have the option to indicate that they don't know the answer to a question, or that the question is not applicable for their family/family member.

**Additional Comments** – Finally, the survey provides an opportunity for respondents to make additional open-ended comments concerning their family's participation in the service system.

## III. Methods

### Sampling & Administration

States were asked to administer the Child Family Survey by selecting a random sample of 1,000 families who: a) have a child with developmental disabilities living at home, and b) receive service coordination and at least one additional service or support. Children were defined as individuals with disabilities under age 22. A sample size of 1,000 was selected in anticipation that states would obtain at least a 40% return rate, yielding 400 or more usable responses per state. With 400 usable responses per state, the results may be compared across states within a confidence level of  $\pm 10\%$ . In states where there were fewer than 1,000 potential respondent families, surveys were sent to all eligible families.

Each state entered survey responses into a standard file format and sent the data file to HSRI for analysis. As necessary, HSRI personnel “cleaned” (i.e., excluded invalid responses) based on three criteria:

- ♦ The question "Does your child live at home with you?" was used to screen out respondents who received a survey by mistake. For instance, if a respondent indicated that their child with disabilities lived outside of the family home, yet received the Child Family Survey, their responses were dropped.
- ♦ If the respondent indicated that their family member was over the age of 21, their responses were dropped.
- ♦ If demographic information was entered into the file, but no survey questions were answered, these responses were also dropped.

### Response Rates

During the 2007-2008 data year, eight states administered the Child Family Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis.

Table 4 Child Family Survey - State Response Rates				
State	Surveys Mailed	Surveys Returned	Response Rate	Usable Surveys
CA- RCOC	4,637	941	20%	940
Hawaii	624	202	32%	186
Louisiana	1,541	342	22%	328
New Jersey	1,000	372	37%	332
Oklahoma	606	185	30%	176
South Carolina	3,000	317	11%	292
West Virginia	1,000	278	28%	272
Wyoming	752	202	27%	185
<b>Overall</b>	<b>13,160</b>	<b>2,839</b>	<b>22%</b>	<b>2,711</b>

The desired response rate (the percentage of surveys returned versus the number mailed) to these surveys is 40%. Table 4 indicates the response rates by state, based on the number of returned surveys entered into the database and submitted for analysis, compared to the total number mailed out.

### Data Analysis

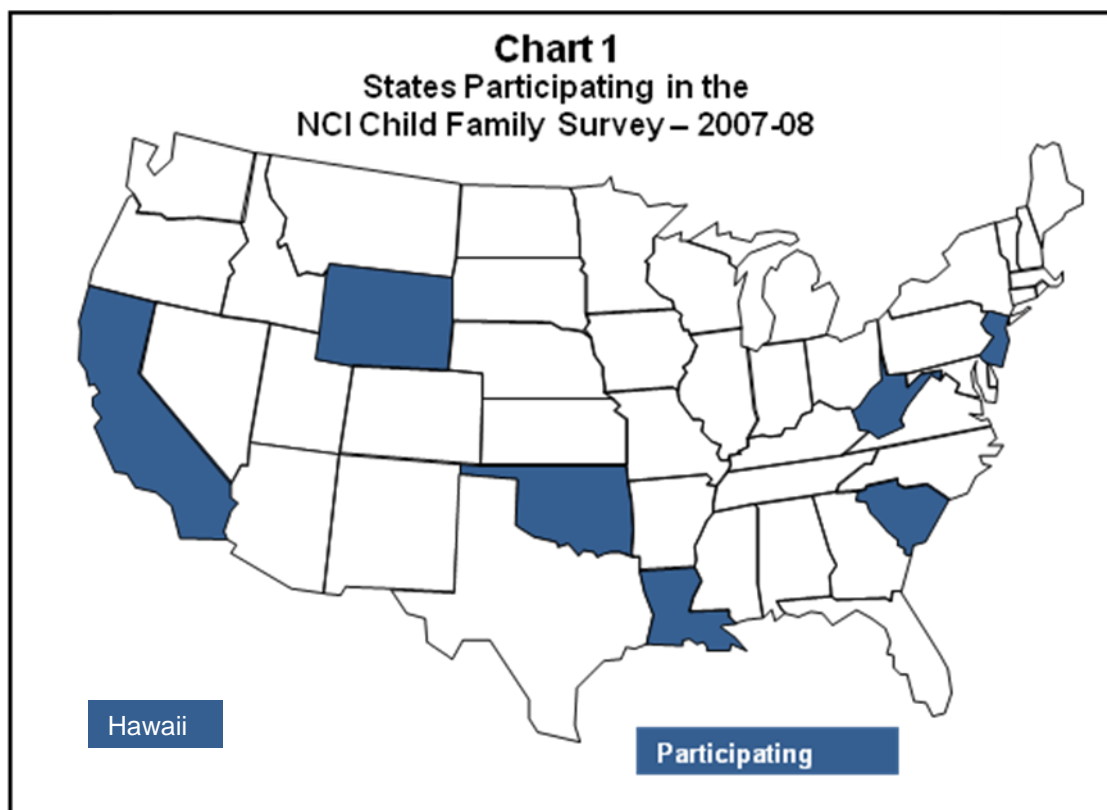
NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. HSRI utilizes SPSS (v. 15) software for statistical analysis and N6 software for support in analysis of open-ended comments.

## IV. Results

The figures below provide the findings from the Child Family Survey. Findings are presented in aggregate, as well as by state.

### Participating States

- ♦ Eight states (California- Regional Center of Orange County, Hawaii, Louisiana, New Jersey, Oklahoma, South Carolina, West Virginia and Wyoming) provided data for this Report.



## Characteristics of Children with Disabilities

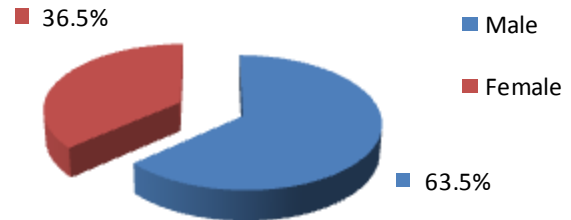
This section provides information about the child with disabilities living in the household.

- On average, across the states, 64% of children with disabilities were male and 37% were female.
- Across all participating states, the average age of children with disabilities was 11, with a range in age from 1 to 21.
- Across all states, 66% of the children with disabilities were White, 13% were Black/African-American, 5% were American Indian/Alaska Native, 11% were Asian-American, 4% were Native Hawaiian/Pacific Islander, 8% were Mixed Races, and 9% were Hispanic/Latino. In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.
- On average, 17% of households include more than one individual with a developmental disability.
- On average, 77% of children with disabilities required moderate to complete levels of assistance with activities of daily living. Twenty-four percent (24%) of children required little or no assistance with these activities.
- Many families indicated that their children have mental retardation (42%) and/or other developmental disabilities (32%). Additionally, many children experience other disabilities, such as physical disabilities (25%), autism (37%), seizure disorders (27%), communication disorders (26%), vision or hearing impairments (25%), and/or cerebral palsy (20%).

## Gender of Family Member

Table 5 Gender (%)		
State	Male	Female
CA-RCOC	65.5	34.5
HI	64.0	36.0
LA	60.8	39.2
NJ	66.8	33.2
OK	51.5	48.5
SC	70.4	29.6
WV	66.3	33.7
WY	63.0	37.0
Total N	1,686	928
Total %	64.5	35.5
State Avg %	63.5	36.5

Chart 2. Gender



## Age of Family Member

Table 6 Age of Child		
State	Average Age	Range
CA-RCOC	9.8	3-18
HI	11.1	3-18
LA	10.8	1-18
NJ	10.9	2-19
OK	12.7	5-18
SC	7.8	1-18
WV	11.3	1-19
WY	11.7	2-21
Total N	2,643	
Total Avg	10.4	1-21
State Avg	10.8	2-19

## Race/Ethnicity of Family Member

**Table 7**  
**Race/Ethnicity of Child (%)**

State	White	Black/ African- American	Asian	Am. Ind/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
<b>CA-RCOC</b>	42.2	2.4	19.3	1.4	1.7	8.5	1.7	37.4
<b>HI</b>	33.3	5.6	50.8	6.2	28.2	23.7	2.8	6.2
<b>LA</b>	67.0	31.1	1.3	0.3	0.3	10.0	0.0	0.0
<b>NJ</b>	59.6	15.8	6.1	2.7	0.3	4.0	1.3	13.5
<b>OK</b>	77.8	9.6	0.6	18.6	0.0	4.2	2.4	3.0
<b>SC</b>	63.6	29.6	1.1	1.4	0.0	4.3	4.0	4.6
<b>WV</b>	91.8	6.0	3.4	4.5	2.2	3.4	3.4	3.4
<b>WY</b>	95.0	1.1	1.7	1.1	0.6	3.3	0.0	3.9
<b>Total N</b>	<b>1,564</b>	<b>293</b>	<b>309</b>	<b>82</b>	<b>75</b>	<b>171</b>	<b>39</b>	<b>437</b>
<b>Total %</b>	<b>59.8</b>	<b>11.2</b>	<b>11.8</b>	<b>3.1</b>	<b>2.9</b>	<b>6.5</b>	<b>1.5</b>	<b>16.7</b>
<b>State Avg %</b>	<b>66.3</b>	<b>12.7</b>	<b>10.5</b>	<b>4.5</b>	<b>4.2</b>	<b>7.7</b>	<b>2.0</b>	<b>9.0</b>

## More Than One Person with Disabilities Living in Household

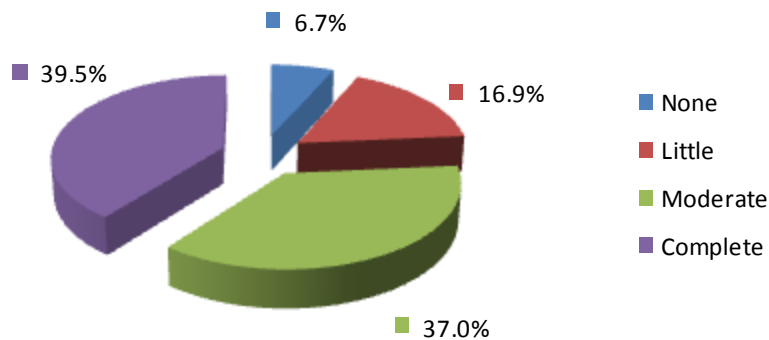
**Table 8**  
**More Than One Person in  
Household with a Dev. Disability (%)**

State	Yes	No
<b>CA-RCOC</b>	15.6	84.4
<b>HI</b>	18.8	81.2
<b>LA</b>	16.0	84.0
<b>NJ</b>	19.9	80.1
<b>OK</b>	19.5	80.5
<b>SC</b>	14.4	85.6
<b>WV</b>	14.2	85.8
<b>WY</b>	16.4	83.6
<b>Total N</b>	<b>429</b>	<b>2,193</b>
<b>Total %</b>	<b>16.4</b>	<b>83.6</b>
<b>State Avg %</b>	<b>16.9</b>	<b>83.2</b>

## Level of Help with Daily Activities

Table 9 Level of Help with Daily Activities (%)				
State	None	Little	Moderate	Complete
CA-RCOC	4.0	19.5	38.9	37.6
HI	11.9	15.3	31.3	41.5
LA	5.3	13.1	36.4	45.2
NJ	6.5	19.5	40.3	33.8
OK	4.7	15.4	35.5	44.4
SC	9.6	18.9	33.6	37.9
WV	1.1	8.2	43.5	47.2
WY	10.3	25.0	36.4	28.3
<b>Total N</b>	<b>151</b>	<b>455</b>	<b>992</b>	<b>1,029</b>
<b>Total %</b>	<b>5.7</b>	<b>17.3</b>	<b>37.8</b>	<b>39.2</b>
<b>State Avg. %</b>	<b>6.7</b>	<b>16.9</b>	<b>37.0</b>	<b>39.5</b>

**Chart 3. Level of Help with Daily Activities**



## Family Member's Disabilities

Table 10A Disabilities of Child (%)						
State	Mental Retardation	Other Dev. Disability	Mental Illness	Autism	Cerebral Palsy	Brain Injury
CA-RCOC	37.0	13.0	3.1	49.0	11.6	4.3
HI	38.3	38.9	3.4	44.6	21.7	9.7
LA	35.2	43.2	4.1	19.0	32.4	12.1
NJ	20.7	28.9	6.3	51.3	13.2	3.6
OK	75.4	38.6	9.9	24.6	27.5	17.5
SC	23.2	31.3	4.4	31.3	16.2	6.6
WV	61.3	34.2	7.4	44.6	19.3	11.5
WY	44.8	24.0	6.0	33.3	18.0	9.8
Total N	1028	701	127	1063	465	203
Total %	39.1	26.7	4.8	40.4	17.7	7.7
State Avg %	42.0	31.5	5.6	37.2	20.0	9.4

Table 10B Disabilities of Child (%)							
State	Seizure Disorder/ Neurological Problem	Chemical Dependency	Vision/Hearing Impairments	Physical Disability	Commun. Disorder	Down Syndrome	Other Disability
CA-RCOC	17.2	0.3	12.1	11.1	18.7	13.4	12.8
HI	32.0	1.1	20.6	22.9	24.1	8.0	25.3
LA	34.6	1.0	30.8	31.4	23.2	15.2	20.6
NJ	16.4	0.3	17.1	19.1	21.1	11.2	21.1
OK	38.0	1.2	37.4	36.3	45.0	19.3	24.6
SC	19.9	0.7	20.2	22.1	23.2	9.2	29.8
WV	33.8	3.7	37.5	29.7	35.3	17.1	28.3
WY	24.0	1.6	21.3	24.0	20.2	16.9	22.4
Total N	631	26	558	547	627	357	533
Total %	24.0	1.0	21.2	20.8	23.9	13.6	20.3
State Avg %	27.0	1.2	24.6	24.6	26.4	13.8	23.1



## Characteristics of Respondents

This section provides information about survey respondents. Respondents are the individuals who completed the survey forms, not the individual with disabilities living in the household.

- ♦ Across all states, nearly all (90%) of respondents were under 55 years old, with most respondents (71%) falling in the 35 to 54 year old age category.
- ♦ The vast majority of respondents were parents of children with disabilities (94%). The remaining respondents were grandparents (5%) or others(1%).
- ♦ In total, 98% of all respondents were the primary caregiver for their child with disabilities. This was consistent across all of the states.
- ♦ Most respondents indicated that they were in good (54%) or excellent (25%) health. Twenty-one percent (21%), however, categorized their health as being fair or poor.
- ♦ Thirty-six percent (36%) of respondents had an annual household income (including all wage earners within the household) of \$25,000 or less. Twenty-eight percent (28%) had a household income between \$25,001 and \$50,000 and 36% had an income over \$50,000.

### Age of Respondent

<b>Table 11</b> <b>Age of Respondent (%)</b>				
<b>State</b>	<b>Under 35</b>	<b>35-54</b>	<b>55-74</b>	<b>75 or Older</b>
<b>CA-RCOC</b>	16.9	76.6	6.4	0.0
<b>HI</b>	18.9	70.6	10.6	0.0
<b>LA</b>	19.1	70.5	10.2	0.3
<b>NJ</b>	11.3	81.0	6.0	1.7
<b>OK</b>	12.6	70.1	17.2	0.0
<b>SC</b>	36.0	57.3	6.3	0.3
<b>WV</b>	21.0	71.0	7.7	0.4
<b>WY</b>	21.2	69.6	9.2	0.0
<b>Total N</b>	<b>509</b>	<b>1,921</b>	<b>216</b>	<b>8</b>
<b>Total %</b>	<b>19.2</b>	<b>72.4</b>	<b>8.1</b>	<b>0.3</b>
<b>State Avg %</b>	<b>19.6</b>	<b>70.8</b>	<b>9.2</b>	<b>0.3</b>

## Relationship of Respondent to Individual with Disabilities

Table 12 Relationship to Child with Disabilities (%)				
State	Parent	Sibling	Grand-parent	Other
CA-RCOC	97.7	0.2	1.4	0.6
HI	93.9	0.0	3.3	2.8
LA	90.4	0.6	7.4	1.5
NJ	93.3	0.3	5.7	0.7
OK	92.0	0.0	5.2	2.9
SC	94.0	0.4	4.9	0.7
WV	93.0	0.0	6.6	0.4
WY	95.1	0.0	3.3	1.6
Total N	2,503	6	107	29
Total %	94.6	0.2	4.0	1.1
State Avg %	93.7	0.2	4.7	1.4

## Respondent's Role as Primary Caregiver

Table 13 Respondent is Primary Caregiver (%)		
State	Yes	No
CA-RCOC	97.7	2.3
HI	95.5	4.5
LA	98.1	1.9
NJ	98.3	1.7
OK	99.4	0.6
SC	98.2	1.8
WV	98.9	1.1
WY	98.4	1.6
Total N	2,540	52
Total %	98.0	2.0
State Avg %	98.1	1.9

## Health of Respondent

Table 14 Health of Respondent (%)				
State	Excellent	Good	Fair	Poor
CA-RCOC	27.0	51.5	18.8	2.7
HI	28.3	53.9	15.6	2.2
LA	26.9	50.3	19.1	3.7
NJ	18.8	57.7	20.1	3.4
OK	25.3	49.4	20.7	4.6
SC	26.9	50.7	19.9	2.4
WV	23.2	56.6	17.3	2.9
WY	26.6	60.3	10.9	2.2
Total N	678	1,406	485	78
Total %	25.6	53.1	18.3	2.9
State Avg %	25.4	53.8	17.8	3.0

## Household Income

Table 15 Household Income (%)					
State	Below \$15,000	\$15,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	Over \$75,000
CA-RCOC	15.0	16.7	20.7	15.1	32.4
HI	21.3	12.1	25.3	24.7	16.7
LA	32.0	14.3	25.0	13.7	15.0
NJ	16.8	14.7	18.3	50.2	0.0
OK	18.9	9.4	31.4	22.6	17.6
SC	33.0	17.6	26.7	10.6	12.1
WV	24.8	17.6	32.8	13.6	11.2
WY	13.1	9.1	34.1	22.2	21.6
Total N	516	374	616	492	486
Total %	20.8	15.1	24.8	19.8	19.6
State Avg %	22.8	13.5	27.7	22.5	13.5

## Services and Supports Received

- ♦ Across participating states, on average, specialized services and supports were most often utilized (72%) by families having a child with disabilities.
- ♦ Additionally, 47% obtained in-home supports, 32% used out-of-home respite, 39% received SSI financial support, and 29% received other types of financial support.

<b>Table 16</b> <b>Services and Supports Received (%)</b>							
<b>State</b>	<b>SSI financial support</b>	<b>Other financial support</b>	<b>In-home support</b>	<b>Out-of-home respite care</b>	<b>Early intervention</b>	<b>Transportation</b>	<b>Specialized services/ supports</b>
<b>CA-RCOC</b>	29.3	7.7	40.7	27.7	38.5	6.6	55.6
<b>HI</b>	29.0	26.6	42.0	41.2	10.1	20.1	67.9
<b>LA</b>	46.9	33.2	70.7	18.8	19.3	14.3	68.1
<b>NJ</b>	30.3	49.8	25.9	13.1	11.2	8.0	61.1
<b>OK</b>	43.1	25.1	79.8	20.8	7.1	8.2	72.3
<b>SC</b>	48.6	14.4	34.0	18.4	7.0	9.5	80.4
<b>WV</b>	47.7	42.9	49.2	42.1	16.9	15.2	86.9
<b>WY</b>	35.3	33.0	36.5	74.2	16.8	9.8	81.8
<b>Total N</b>	<b>971</b>	<b>614</b>	<b>1,179</b>	<b>753</b>	<b>264</b>	<b>261</b>	<b>1,761</b>
<b>Total %</b>	<b>36.8</b>	<b>23.9</b>	<b>45.2</b>	<b>29.3</b>	<b>16.8</b>	<b>10.1</b>	<b>67.4</b>
<b>State Avg %</b>	<b>38.8</b>	<b>29.1</b>	<b>47.4</b>	<b>32.0</b>	<b>15.9</b>	<b>11.5</b>	<b>71.8</b>

## National Core Indicators

In these next several sections, the questions and results are discussed that tie directly to the National Core Indicator domains for assessing service and support quality. These questions are grouped as they pertain to 1) information and planning; 2) access and delivery of services and supports; 3) choice and control; 4) community connections; and 5) overall satisfaction and outcomes.

For each question, a Figure and Table is provided.

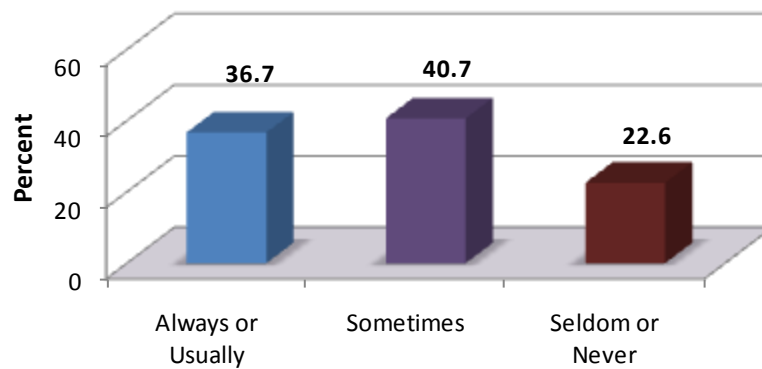
- ♦ The Figure illustrates the State Average results (i.e., the average percentage across the seven states that conducted this survey).
- ♦ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state results).
- ♦ In the Tables, a (↑) next to a state name indicates, that its results are **5% or more ABOVE** the state average among respondents who answered “Always or Usually” to each question.
- ♦ In the Tables, a (↑↑) next to a state name indicates, that its results are **10% or more ABOVE** the state average among respondents who answered “Always or Usually” to each question.
- ♦ A (↓) next to a state name indicates that its results are **5% or more BELOW** the state average among respondents who answered “Always or Usually” to each question.
- ♦ A (↓↓) next to a state name indicates that its results are **10% or more BELOW** the state average among respondents who answered “Always or Usually” to each question.
- ♦ In general, when a Table has many arrows (up and down), it indicates that there is considerable variance in results among states. When there are few arrows, responses across states are more uniform.

Following all of the individual question results, an overview of results by topic grouping (e.g., information and planning, choice and control) is offered, providing a crude overview of how states measured up, overall, against the state averages.

## Information and Planning

- Across states, 37% of respondents indicated they regularly receive information about the services and supports available to them. Individual state results varied considerably, ranging from 12% in New Jersey to 48% in Wyoming.
- Among those who receive information, just over half (52%) found the information easy to understand, while the remaining 48% found the information, at least sometimes, difficult to understand.
- Across states, less than half (48%) of respondents indicated they regularly receive information about their child's disability or development.
- Among those who receive this information, 63% found it easy to understand, and the remaining 37% found the information, at least sometimes, difficult to understand.
- Only 45% of respondents stated they got enough information to help them participate in planning. A larger percentage (56%) indicated they only sometimes, seldom, or never had enough information.
- Just shy of three-quarters (74%) of respondents, on average across states, indicated that they typically help in developing their family member's service plan. These results varied from 38% in New Jersey to 88% in Wyoming.
- Of those families with a service plan, 72% stated that the plan included things important to the respondent. Almost one-third of respondents (28%) indicated that the plan only sometimes, seldom or never included things important to them.
- Across states, just over half (55%) indicated that planning staff would help them figure out the supports they needed. However, a large percentage (45%) stated that this was only sometimes, seldom, or never the case.
- Across states, almost three-quarters (73%) of respondents felt that their choices and opinions were respected by staff.
- Only 33% of respondents indicated that planning staff discussed with them the public benefits that may or may not be available to them. Another 24% sometimes received this information, while 43% indicated that planning staff seldom or never relayed this information to them.
- Among all respondents, 84% felt that agency staff were generally respectful and courteous.
- Among all respondents, 61% felt that agency staff were generally effective.
- Across all states, 70% of respondents indicated they could typically contact staff when desired.

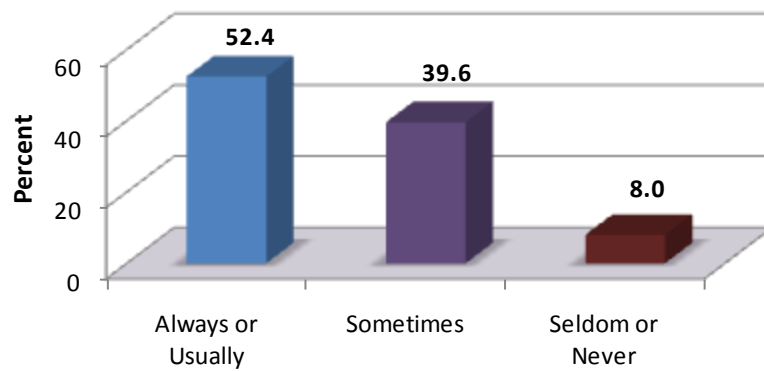
**Chart Q1** Do you receive information about the services and supports that are available to your child and family?



**2007-08 Average for 8 States**

<b>Table Q1</b> Do you receive information about the services and supports that are available to your child and family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↑	46.6	38.9	14.5	908
HI		36.3	46.7	17.0	182
LA	↑	46.0	37.4	16.6	313
NJ	↓ ↓	11.9	38.3	49.8	303
OK	↓	30.8	44.2	25.0	172
SC		37.7	38.8	23.4	273
WV		36.5	45.8	17.7	271
WY	↑ ↑	47.8	35.2	17.0	182
Total %		38.8	40.0	21.2	2,604
State Avg %		36.7	40.7	22.6	

**Chart Q2** If you receive information, is it easy to understand?

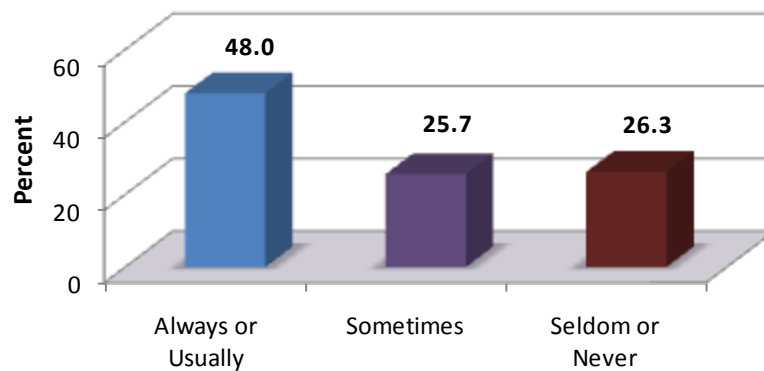


**2007-08 Average for 8 States**

Table Q2					
If you receive information, is it easy to understand? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↑	59.8	35.2	5.0	853
HI		53.0	38.7	8.3	168
LA		51.7	42.4	5.9	288
NJ	↓	43.8	38.9	17.3	226
OK		48.7	44.2	7.1	156
SC	↑	60.6	34.0	5.4	259
WV		47.8	45.0	7.2	251
WY		54.1	38.4	7.6	172
Total %		54.5	38.4	7.1	2,373
State Avg %		52.4	39.6	8.0	



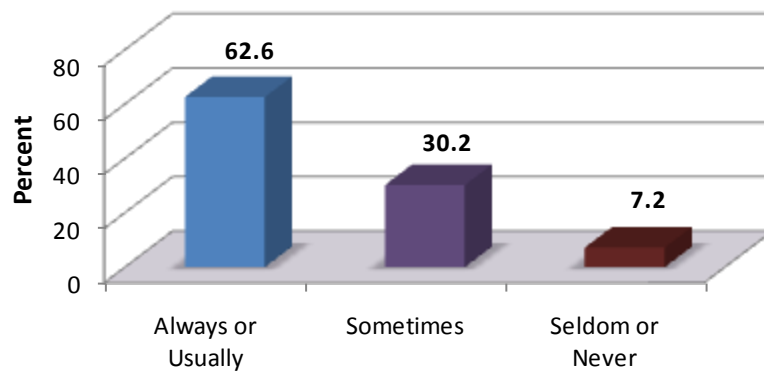
**Chart Q3** Do you receive information about the status of your child's development?



**2007-08 Average for 8 States**

Table Q3					
Do you receive information about the status of your child's development? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	40.9	31.4	27.7	845
HI		52.6	22.5	24.9	173
LA		51.6	20.3	28.1	281
NJ	↓ ↓	33.2	20.2	46.6	253
OK	↓	41.8	32.7	25.5	165
SC	↑	54.8	23.0	22.2	270
WV	↑	53.2	30.3	16.5	267
WY	↑	55.6	25.4	18.9	169
Total %		46.2	26.9	26.9	2,423
State Avg %		48.0	25.7	26.3	

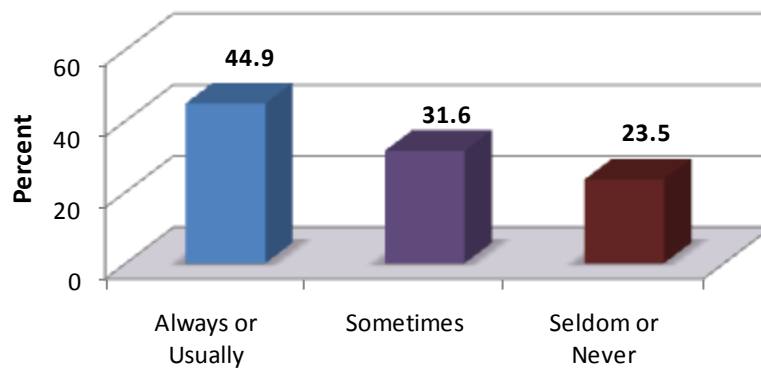
**Chart Q4** If yes, is this information easy to understand?



**2007-08 Average for 8 States**

Table Q4 If yes, is this information easy to understand? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		62.3	30.8	6.9	668
HI		66.7	27.7	5.7	141
LA		67.3	26.1	6.6	226
NJ	↓ ↓	49.7	36.1	14.2	169
OK		62.7	31.0	6.3	142
SC	↑	71.1	21.6	7.3	232
WV		58.9	35.2	5.9	236
WY		62.4	32.9	4.7	149
Total %		62.8	30.1	7.1	1,963
State Avg %		62.6	30.2	7.2	

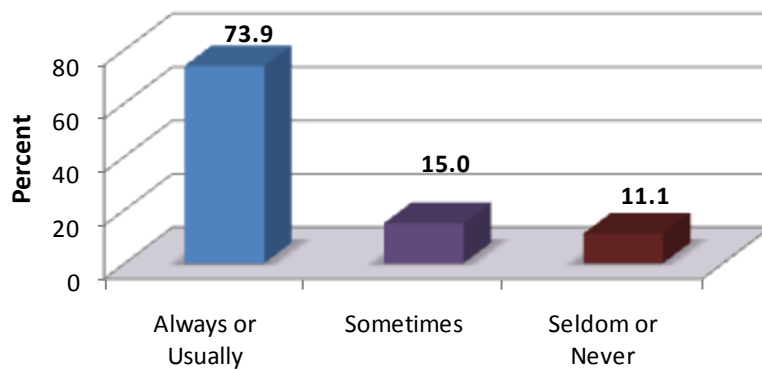
**Chart Q5** Do you get enough information to help you participate in planning services for your family?



**2007-08 Average for 8 States**

<b>Table Q5</b> Do you get enough information to help you participate in planning services for your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		40.1	38.9	20.9	855
HI		44.9	30.3	24.7	178
LA	↑	53.7	26.9	19.4	294
NJ	↓ ↓	15.6	31.6	52.7	256
OK		46.7	29.1	24.2	165
SC		48.0	27.9	24.2	269
WV	↑	51.9	35.4	12.7	260
WY	↑ ↑	58.3	32.6	9.1	175
Total %		43.4	33.4	23.2	2,452
State Avg %		44.9	31.6	23.5	

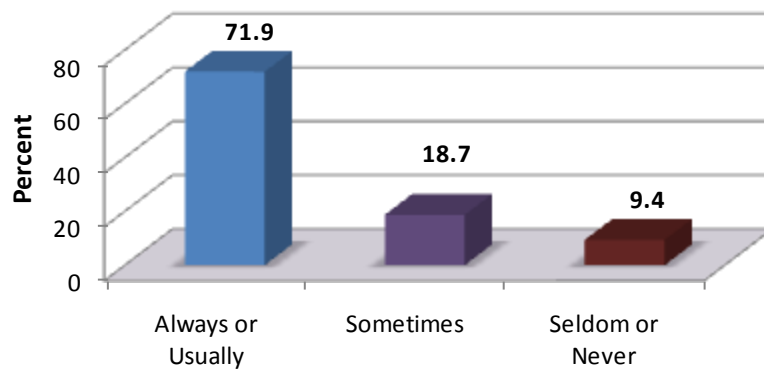
**Chart Q6** If your family member has a service plan, did you help develop the plan?



**2007-08 Average for 8 States**

Table Q6					
If your family member has a service plan, did you help develop the plan? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		74.9	14.7	10.4	702
HI	↑	79.9	15.4	4.7	169
LA	↑	80.5	13.9	5.6	267
NJ	↓↓	38.4	16.8	44.8	125
OK		71.7	21.1	7.2	152
SC		75.2	14.6	10.2	226
WV	↑	83.4	13.0	3.6	253
WY	↑↑	87.3	10.3	2.4	165
Total %		75.7	14.7	9.7	2,059
State Avg %		73.9	15.0	11.1	

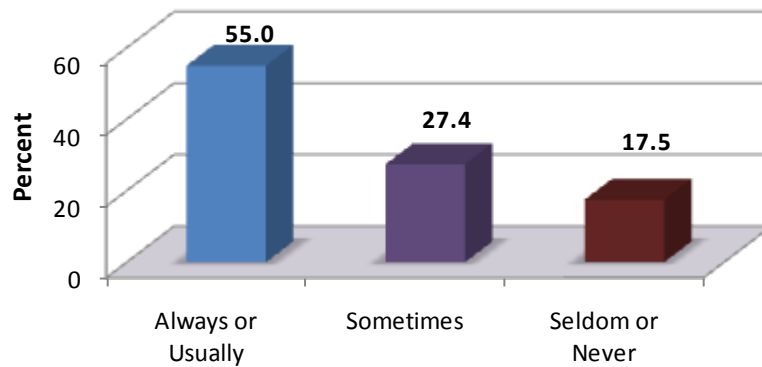
**Chart Q7** If your family member has a service plan, does the plan include things that are important to you?



**2007-08 Average for 8 States**

<b>Table Q7</b> If your family member has a service plan, does the plan include things that are important to you? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		69.0	21.3	9.7	670
HI		74.4	19.8	5.8	172
LA	↑↑	81.9	13.7	4.4	270
NJ	↓↓	39.8	22.2	38.0	108
OK		76.6	16.9	6.5	154
SC		74.1	19.3	6.6	228
WV	↑	78.7	18.1	3.1	254
WY	↑	80.5	18.3	1.2	164
Total %		72.9	19.0	8.1	2,020
State Avg %		71.9	18.7	9.4	

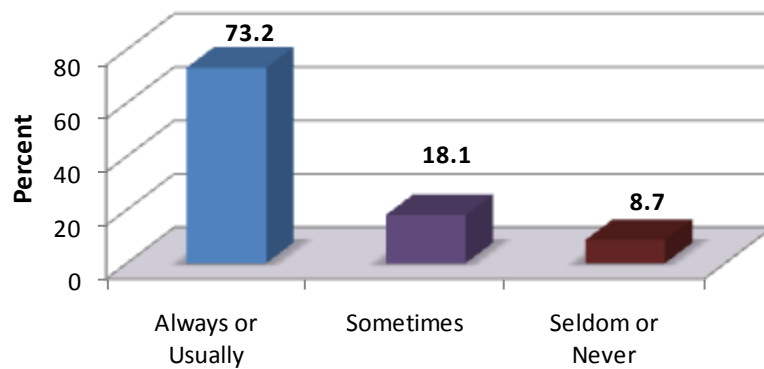
**Chart Q8** Do the staff who assist you with planning help you figure out what you need as a family to support your child?



**2007-08 Average for 8 States**

<b>Table Q8</b> Do the staff who assist you with planning help you figure out what you need as a family to support your child? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	46.7	34.6	18.6	869
HI		57.5	32.4	10.1	179
LA	↑↑	65.6	24.2	10.2	285
NJ	↓↓	22.6	20.8	56.5	168
OK		54.7	31.4	13.8	159
SC	↑	61.5	23.5	15.0	247
WV	↑	64.2	26.2	9.6	260
WY	↑↑	67.4	26.2	6.4	172
Total %		53.7	29.2	17.1	2,339
State Avg %		55.0	27.4	17.5	

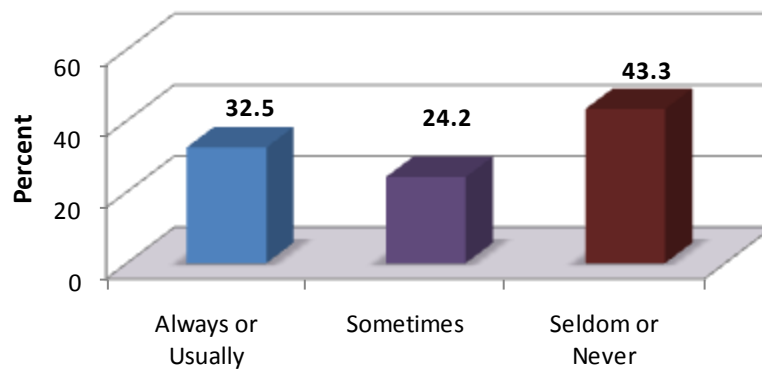
**Chart Q9** Do the staff who assist you with planning respect your choices and opinions?



**2007-08 Average for 8 States**

<b>Table Q9</b> Do the staff who assist you with planning respect your choices and opinions? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↑	78.7	17.1	4.2	840
HI		71.6	22.7	5.7	176
LA	↑↑	83.2	12.5	4.3	279
NJ	↓↓	40.2	23.5	36.4	132
OK		76.3	16.9	6.9	160
SC		76.4	16.7	6.9	246
WV		77.6	19.3	3.1	259
WY	↑	81.9	15.8	2.3	171
Total %		76.1	17.5	6.4	2,263
State Avg %		73.2	18.1	8.7	

**Chart Q10** Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)?

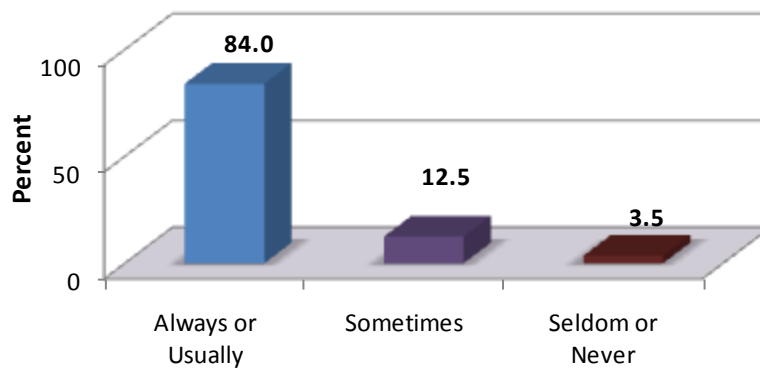


**2007-08 Average for 8 States**

<b>Table Q10</b> Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		36.8	32.0	31.2	840
HI		30.7	24.5	44.8	176
LA	↑	41.3	21.4	37.4	279
NJ	↓ ↓	15.7	15.2	69.1	132
OK	↑	38.8	28.1	33.1	160
SC		31.8	20.8	47.5	246
WV		36.0	23.1	40.9	259
WY		29.0	28.4	42.6	171
Total %		33.9	25.9	40.3	2,263
State Avg %		32.5	24.2	43.3	



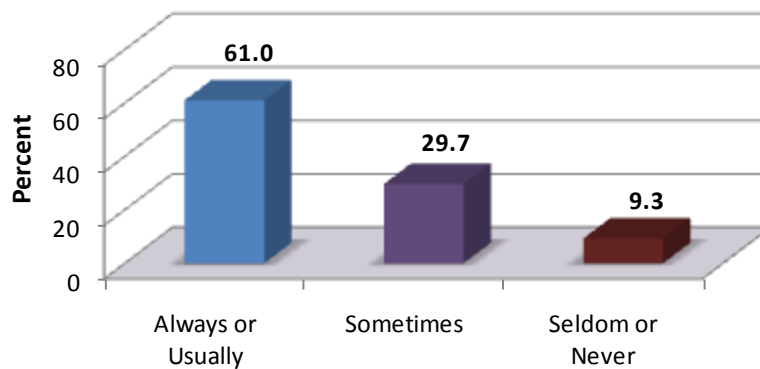
**Chart Q11** Are the staff who assist you with planning generally respectful and courteous?



**2007-08 Average for 8 States**

<b>Table Q11</b> Are the staff who assist you with planning generally respectful and courteous? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		88.5	9.8	1.7	907
HI		83.0	13.1	4.0	176
LA	↑	90.1	8.2	1.7	293
NJ	↓ ↓	59.8	27.4	12.8	179
OK		87.7	9.2	3.1	163
SC		86.0	10.9	3.1	258
WV		85.9	13.7	0.4	263
WY	↑	90.9	8.0	1.1	175
Total %		85.7	11.5	2.7	2,414
State Avg %		84.0	12.5	3.5	

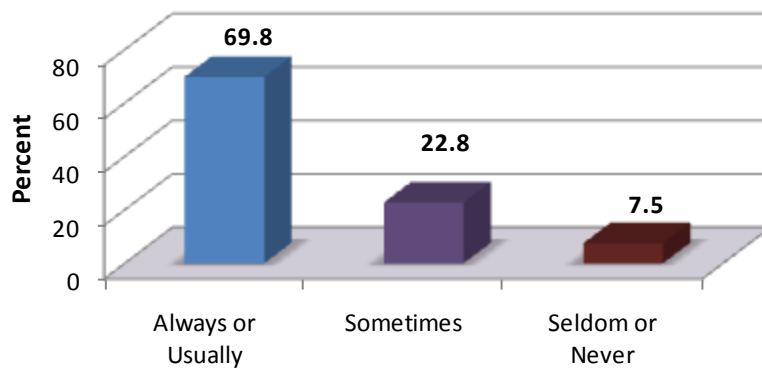
**Chart Q12** Are the staff who assist you with planning generally effective?



**2007-08 Average for 8 States**

Table Q12					
Are the staff who assist you with planning generally effective? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		62.9	29.1	8.0	879
HI		57.6	33.9	8.5	177
LA	↑	70.4	25.1	4.5	291
NJ	↓ ↓	36.2	33.9	29.9	174
OK		60.0	34.4	5.6	160
SC	↑	66.7	24.5	8.8	249
WV		64.1	32.4	3.4	262
WY	↑	69.7	24.6	5.7	175
Total %		62.3	29.2	8.4	2,367
State Avg %		61.0	29.7	9.3	

**Chart Q13** Can you contact the staff who assist you with planning whenever you want to?



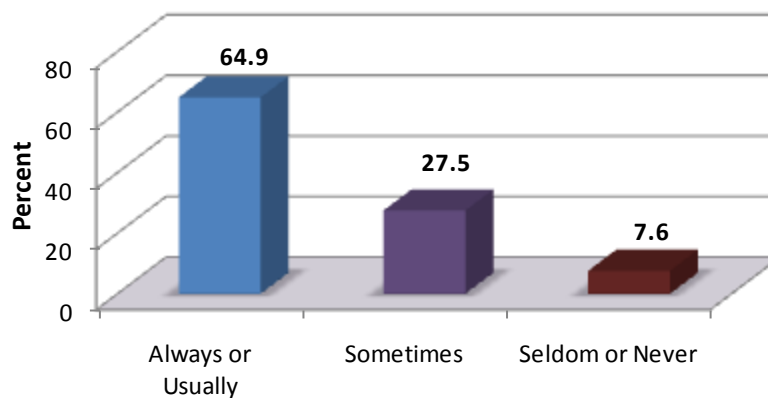
**2007-08 Average for 8 States**

<b>Table Q13</b> Can you contact the staff who assist you with planning whenever you want to? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		72.7	22.8	4.5	890
HI		66.3	25.8	7.9	178
LA	↑	79.3	17.0	3.7	294
NJ	↓ ↓	38.0	34.0	28.0	200
OK	↑	75.2	18.8	6.1	165
SC		74.3	20.5	5.2	249
WV		74.2	23.5	2.3	260
WY	↑	78.0	19.8	2.3	177
Total %		71.0	22.6	6.4	2,413
State Avg %		69.8	22.8	7.5	

## Access to and Delivery of Services and Supports

- Overall, 65% of families stated their service coordinator helped them get needed supports when asked. Twenty-seven percent (28%) said this happened sometimes, and 8% indicated that their service coordinator was rarely helpful in getting the assistance needed.
- About half of families (49%) said they always or usually get the services and supports needed. Thirty-eight percent (38%) got needed supports some of the time, and the remaining 13% seldom or never received needed supports.
- Almost half (48%) of respondents said that the supports received met their families' needs, although this varied from state to state. Another 38% said that the supports sometimes met their needs, while the remaining 14% seldom or never felt the supports offered met their family's needs.
- For less than half of families (44%), supports were always or usually available when needed. However, even more families indicated that supports were only sometimes available (40%), or seldom/never available (16%) when needed.
- Seventy-nine percent (79%) of respondents stated that families in their area at least sometimes asked for different types of supports than the ones that were currently being offered.
- On the occasions when families did request different types of supports, only 32% indicated that the state agency or provider agency was usually or always responsive to these requests.
- Over half (58%) of families who asked for assistance in an emergency or crisis did not consistently receive help right away.
- Among respondents whose first language was not English, a majority (66%) indicated that staff or translators were available to speak with them in their preferred languages. Sixteen percent (16%) indicated that staff/translators were sometimes available, and the remaining 18% stated that staff/translators who spoke in the families' preferred languages were not available.
- Among respondents who had children who did not speak English, or who used a different means to communicate (e.g., sign language, communication board), 45% of families said there were enough support staff regularly available who could communicate with their child. The remaining 55%, however, said capable staff were only sometimes, seldom or never available.
- Just over half of respondents (52%) felt their child had access to the special equipment or accommodations needed.
- The vast majority of respondents (89%) felt that they had access to health services for their child.
- Slightly fewer families (87%) felt they had access to appropriate dental services for their child.
- Nearly all respondents (92%) felt they had access to necessary medications for their child.
- A majority of respondents (55%) indicated that frequent changes in support staff were a problem for their family at least some of the time.
- A large majority of families (83%) felt that support staff were respectful and courteous.

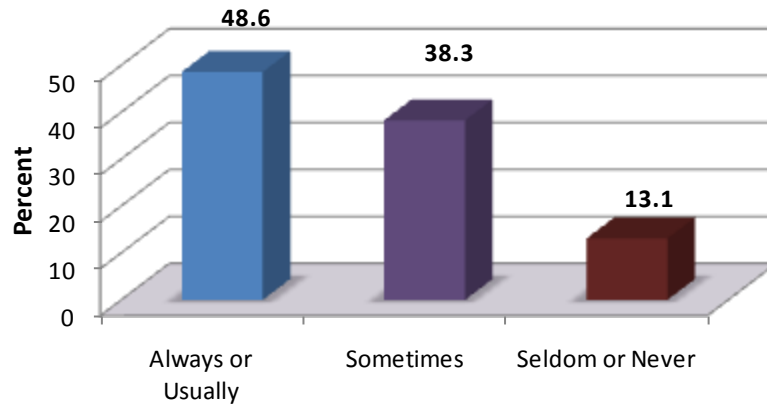
**Chart Q14** When you ask the service/support coordinator for assistance, does he/she help you get what you need?



**2007-08 Average for 8 States**

<b>Table Q14</b> When you ask the service/support coordinator for assistance, does he/she help you get what you need? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		63.0	28.5	8.5	874
HI	↓	57.5	34.5	8.0	174
LA	↑	72.1	22.9	5.0	301
NJ	↓ ↓	41.0	39.6	19.4	278
OK	↑	73.4	22.5	4.0	173
SC		69.1	22.0	8.9	259
WV		68.8	27.0	4.2	263
WY	↑	74.2	23.0	2.8	178
Total %		64.0	27.8	8.1	2,500
State Avg %		64.9	27.5	7.6	

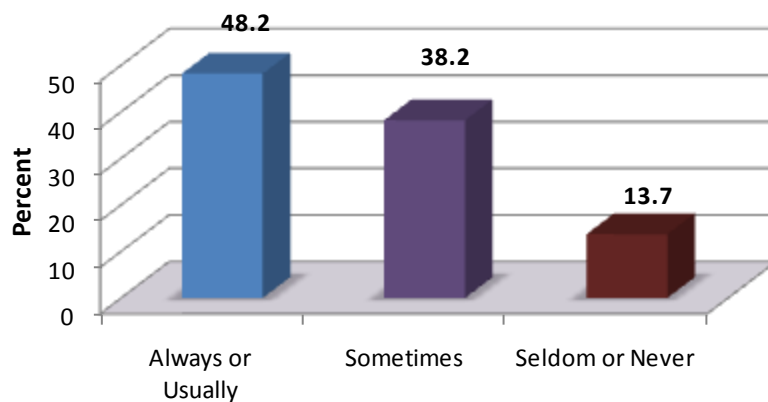
**Chart Q15** Does your family get the services and supports you need?



**2007-08 Average for 8 States**

Table Q15 Does your family get the services and supports you need? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		45.5	39.4	15.1	855
HI		47.1	37.9	14.9	174
LA	↑↑	65.4	26.1	8.5	306
NJ	↓↓	20.2	49.2	30.6	258
OK		52.1	40.7	7.2	167
SC		48.5	36.8	14.7	266
WV		52.6	41.4	6.0	268
WY	↑	57.0	35.2	7.8	179
Total %		47.8	38.4	13.8	2,473
State Avg %		48.6	38.3	13.1	

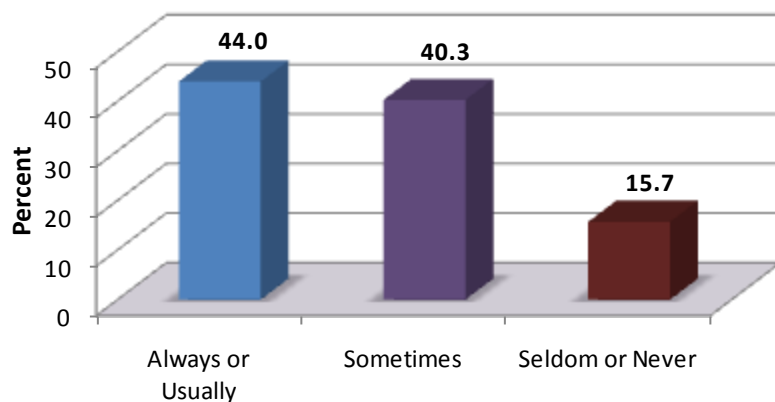
**Chart Q16** Do the services and supports offered meet your family's needs?



**2007-08 Average for 8 States**

Table Q16 Do the services and supports offered meet your family's needs? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		44.5	41.9	13.6	840
HI		47.5	37.9	14.7	177
LA	↑↑	62.8	27.0	10.2	304
NJ	↓↓	19.5	48.2	32.3	251
OK	↑	53.8	35.1	11.1	171
SC		49.8	35.7	14.4	263
WV	↑	55.1	39.2	5.7	265
WY		52.5	40.2	7.3	179
Total %		47.4	38.9	13.8	2,450
State Avg %		48.2	38.2	13.7	

**Chart Q17** Are supports available when your family needs them?

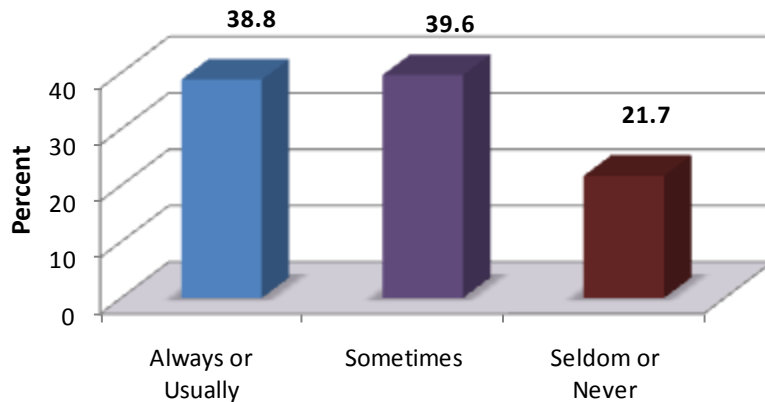


**2007-08 Average for 8 States**

Table Q17 Are supports available when your family needs them? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		41.9	40.8	17.3	802
HI		40.2	44.3	15.5	174
LA	↑↑	58.1	31.8	10.0	289
NJ	↓↓	17.4	48.3	34.3	236
OK		44.6	40.5	14.9	168
SC	↑	50.8	31.8	17.4	258
WV		44.9	47.2	7.9	265
WY	↑	53.7	37.9	8.5	177
Total %		43.7	40.2	16.1	2,369
State Avg %		44.0	40.3	15.7	



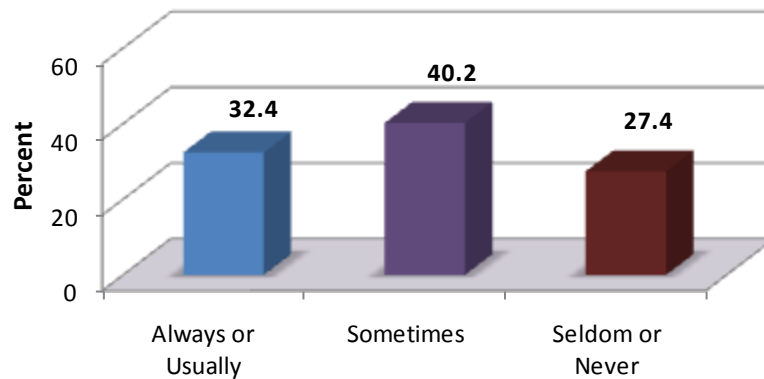
**Chart Q18** Do families in your area request that different types of services & supports be made available in your area?



**2007-08 Average for 8 States**

<b>Table Q18</b> Do families in your area request that different types of services and supports be made available in your area? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		33.5	39.5	27.1	266
HI		29.9	46.8	23.4	77
LA		51.4	31.1	17.6	148
NJ		27.5	36.3	36.3	102
OK		40.0	41.4	18.6	70
SC		39.5	37.2	23.3	129
WV		43.5	42.0	14.5	138
WY		44.9	42.3	12.8	78
Total %		38.7	38.9	22.4	1,008
State Avg %		38.8	39.6	21.7	

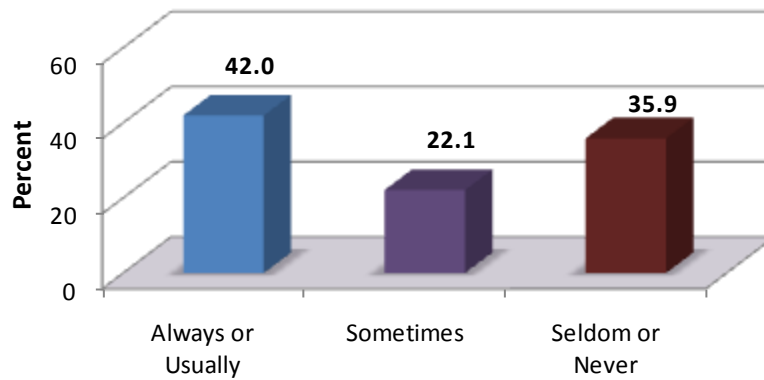
**Chart Q19** If yes, does either the state agency or provider agency respond to their requests?



**2007-08 Average for 8 States**

<b>Table Q19</b> If yes, does either the state agency or provider agency respond to their requests? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		36.9	37.4	25.8	198
HI		35.4	41.5	23.1	65
LA	↑↑	43.8	33.0	23.2	112
NJ	↓↓	12.0	40.0	48.0	75
OK	↑	41.8	40.0	18.2	55
SC		31.9	39.6	28.6	91
WV	↓	26.6	53.2	20.2	109
WY		31.0	36.6	32.4	71
Total %		33.1	39.9	26.9	776
State Avg %		32.4	40.2	27.4	

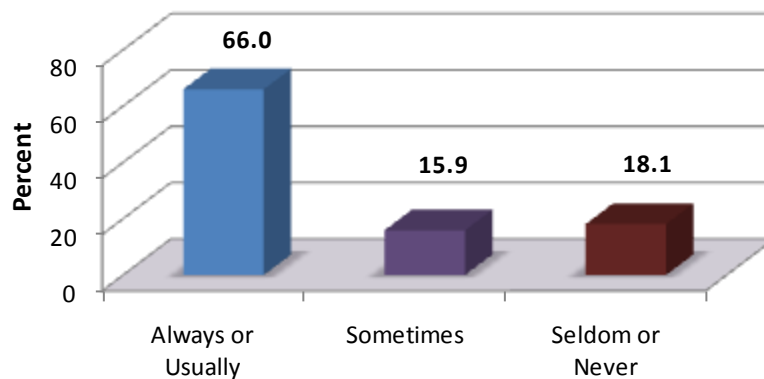
**Chart Q20** If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?



**2007-08 Average for 8 States**

<b>Table Q20</b> If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		41.5	20.0	38.5	330
HI	↓	33.7	33.7	32.6	86
LA	↑	51.3	18.0	30.7	150
NJ	↓ ↓	19.5	20.4	60.2	113
OK		46.7	26.7	26.7	75
SC		41.0	20.9	38.1	139
WV		41.3	26.6	32.1	109
WY	↑ ↑	61.2	10.4	28.4	67
Total %		41.4	21.5	37.0	1,069
State Avg %		42.0	22.1	35.9	

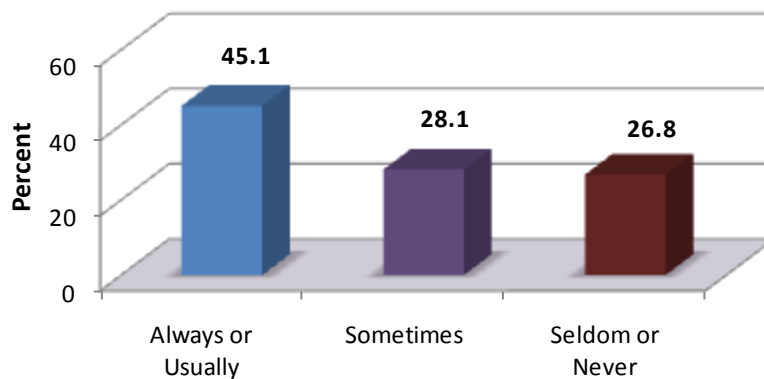
**Chart Q21** If English is not your first language, are there support workers or translators available to speak with you in your preferred language?



**2007-08 Average for 8 States**

<b>Table Q21</b> If English is not your first language, are there support workers or translators available to speak with you in your preferred language? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↑↑	81.4	15.4	3.1	350
HI	↓↓	50.0	30.8	19.2	26
LA	↑	72.2	2.8	25.0	36
NJ	↓↓	42.9	19.0	38.1	42
OK	↑↑	80.0	13.3	6.7	15
SC		70.0	20.0	10.0	30
WV	↑↑	88.2	11.8	0.0	17
WY	↓↓	42.9	14.3	42.9	7
Total %		75.1	15.7	9.2	523
State Avg %		66.0	15.9	18.1	

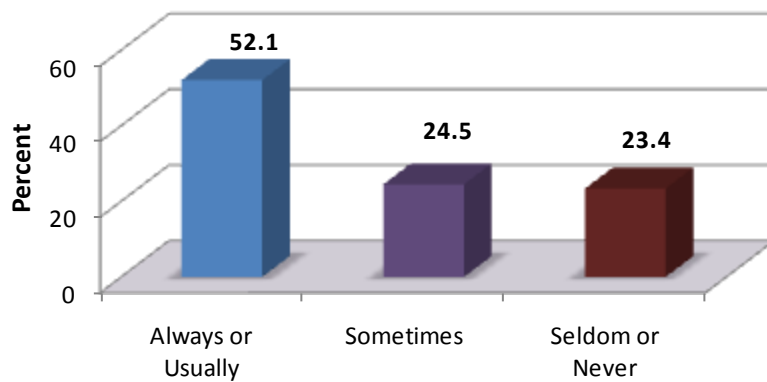
**Chart Q22** If your child does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?



**2007-08 Average for 8 States**

<b>Table Q22</b> If your child does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↑↑	56.7	24.0	19.2	208
HI	↓	37.3	35.3	27.5	51
LA	↑↑	62.2	20.7	17.1	82
NJ	↓↓	23.5	23.5	52.9	51
OK	↑↑	57.1	22.9	20.0	35
SC	↑	52.9	21.6	25.5	51
WV	↓	38.8	22.4	38.8	67
WY	↓↓	32.4	54.1	13.5	37
Total %		49.0	25.9	25.1	582
State Avg %		45.1	28.1	26.8	

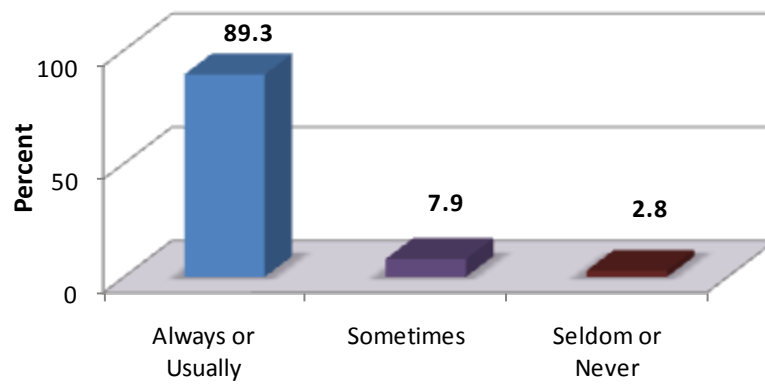
**Chart Q23** Does your child have access to the special equipment or accommodations that he/she needs?



**2007-08 Average for 8 States**

<b>Table Q23</b> Does your child have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	44.5	18.6	36.9	290
HI	↓	45.4	32.0	22.7	97
LA	↑↑	65.3	18.9	15.8	190
NJ	↓↓	32.8	25.9	41.4	116
OK		55.2	21.6	23.3	116
SC		57.0	20.0	23.0	135
WV		55.4	28.8	15.8	184
WY	↑	61.0	30.5	8.6	105
Total %		52.1	23.4	24.6	1,233
State Avg %		52.1	24.5	23.4	

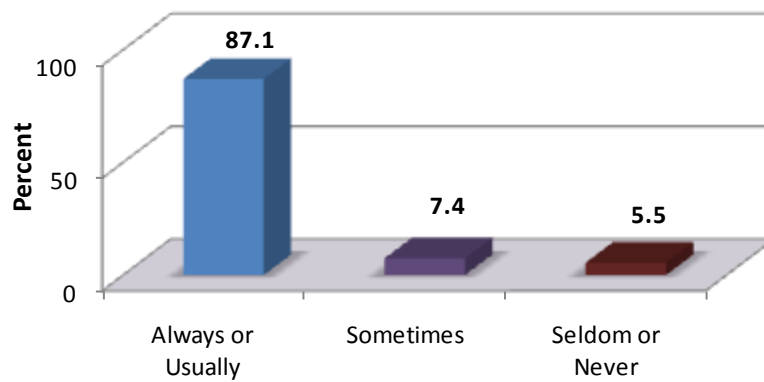
**Chart Q24** Do you have access to health services for your child?



**2007-08 Average for 8 States**

Table Q24 Do you have access to health services for your child? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		91.7	5.8	2.5	895
HI	↓	83.7	12.2	4.1	172
LA		90.4	7.1	2.6	312
NJ	↓	79.8	12.1	8.2	257
OK		94.2	4.6	1.2	173
SC		90.8	7.0	2.2	271
WV		92.7	7.3	0.0	262
WY		91.2	7.2	1.7	181
Total %		89.9	7.3	2.7	2,523
State Avg %		89.3	7.9	2.8	

**Chart Q25** Do you have access to dental services for your child?

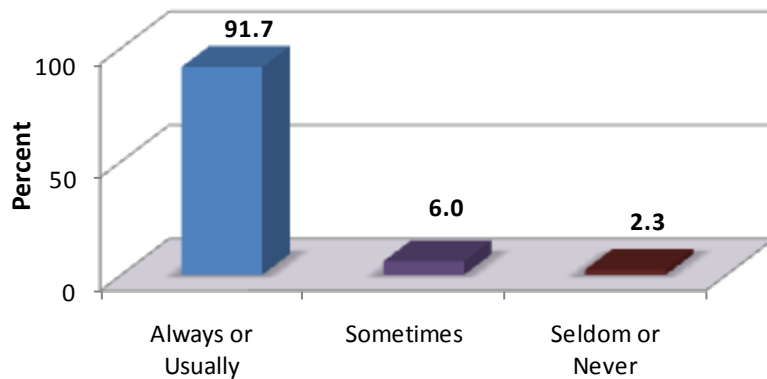


**2007-08 Average for 8 States**

Table Q25					
Do you have access to dental services for your child? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	86.4	7.2	6.3	885
HI		83.4	8.6	8.0	175
LA		87.5	7.1	5.4	297
NJ		77.2	11.8	11.0	254
OK		90.8	5.8	3.5	173
SC		91.6	5.8	2.6	274
WV		91.8	5.6	2.6	269
WY		88.2	7.3	4.5	178
Total %		87.0	7.3	5.7	2,505
State Avg %		87.1	7.4	5.5	



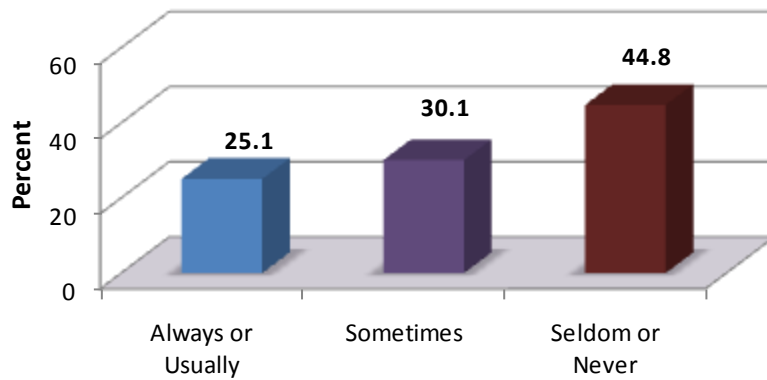
**Chart Q26** Do you have access to necessary medications for your child?



**2007-08 Average for 8 States**

Table Q26					
Do you have access to necessary medications for your child? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		89.1	7.4	3.5	857
HI		89.8	8.4	1.8	167
LA		91.3	4.8	3.9	310
NJ	↓	84.1	10.8	5.2	251
OK	↑	97.7	2.3	0.0	172
SC		92.3	5.9	1.8	272
WV		94.0	5.2	0.7	268
WY		95.3	2.9	1.8	170
Total %		90.8	6.4	2.8	2,467
State Avg %		91.7	6.0	2.3	

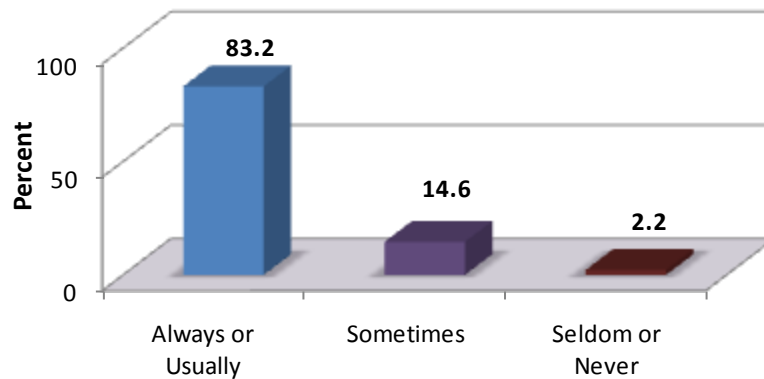
**Chart Q27** Are frequent changes in support staff a problem for your family?



**2007-08 Average for 8 States**

Table Q27 Are frequent changes in support staff a problem for your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		25.6	0.0	74.4	900
HI		26.0	42.2	31.8	154
LA	↑	30.6	27.2	42.3	265
NJ		22.0	38.7	39.3	168
OK		29.1	27.8	43.0	151
SC		21.7	29.6	48.7	230
WV		29.9	44.2	25.9	251
WY	↓	15.6	31.3	53.1	147
Total %		25.6	20.7	53.7	2,266
State Avg %		25.1	30.1	44.8	

**Chart Q28** Are support staff generally respectful and courteous?



**2007-08 Average for 8 States**

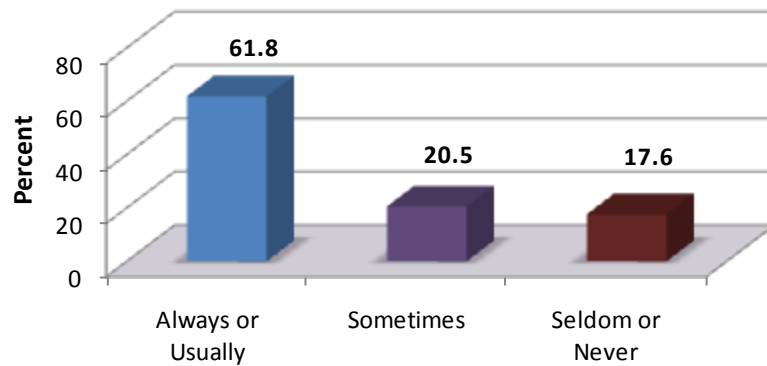
**Table Q28**  
Are support staff generally respectful and courteous? (%)

State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↑	88.1	10.6	1.3	680
HI		84.1	14.8	1.1	164
LA	↑	88.8	10.2	1.0	301
NJ	↓ ↓	65.7	28.1	6.2	194
OK		81.0	17.3	1.8	169
SC		86.5	10.9	2.6	257
WV		84.4	13.0	2.6	263
WY		87.2	11.7	1.1	179
Total %		84.7	13.3	2.0	2,207
State Avg %		83.2	14.6	2.2	

## Choice and Control

- Across the states, on average, 62% of respondents chose the agencies or providers who work with their families. There was great variation between the states.
- While 62% of respondents typically chose their family's provider agency, only 51% (on average) typically chose the support workers who worked directly with their family.
- Among all respondents, nearly half (45%) had control or input over the hiring and management of their support staff, and an additional 18% indicated they had this control sometimes. Thirty-seven percent (37%), however, had little or no input/control over the hiring or management of their family's support staff.
- While 63% of respondents had at least some control over the hiring or management of their support workers, 90% wanted this type of control at least some of the time.
- Only 28% of respondents knew how much money was spent by the MR/DD agency on behalf of their family member. Sixty-one percent (61%), however, had little or no idea. These results vary significantly from state to state. The "Don't Know" responses were included in the data table, grouped with "Seldom or Never."
- Overall, more than half of the families surveyed (55%), had at least some decision-making authority over how the money available to their family member with disabilities by the MR/DD agency was spent. Forty-five percent (45%), however, did not. Once again, results varied considerably from state to state.

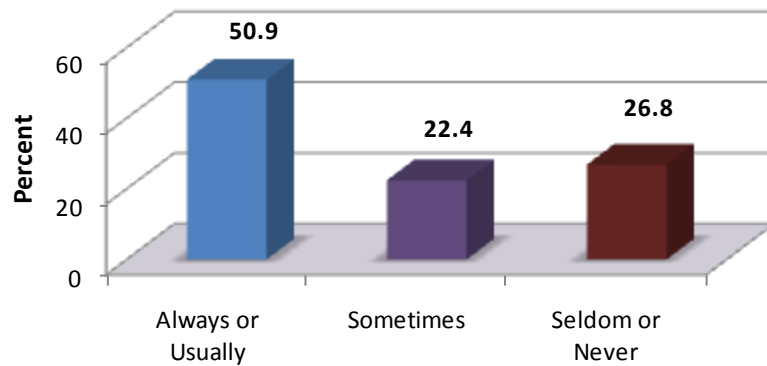
**Chart Q29** Do you choose the agencies or providers who work with your family?



**2007-08 Average for 8 States**

Table Q29					
Do you choose the agencies or providers who work with your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓↓↓	45.1	29.0	25.9	680
HI		59.1	20.1	20.7	164
LA	↑↑↑	82.7	13.3	4.0	301
NJ	↓↓↓	32.5	25.8	41.8	194
OK	↑↑↑	74.6	17.8	7.7	169
SC	↓↓↓	49.8	25.3	24.9	257
WV		66.5	20.2	13.3	263
WY	↑↑↑	84.4	12.8	2.8	179
Total %		58.7	22.2	19.0	2,207
State Avg %		61.8	20.5	17.6	

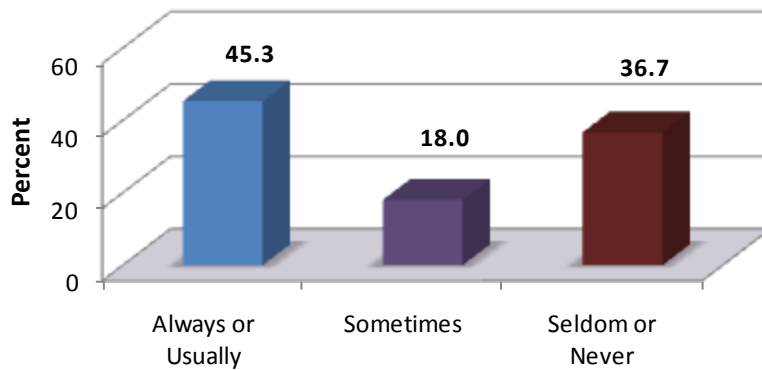
**Chart Q30** Do you choose the support workers who work with your family?



**2007-08 Average for 8 States**

Table Q30					
Do you choose the support workers who work with your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	42.7	28.1	29.3	670
HI		46.9	25.6	27.5	160
LA	↑↑	69.6	14.9	15.6	289
NJ	↓↓	29.0	19.9	51.1	176
OK	↑↑	70.2	19.9	9.9	161
SC	↓↓	33.6	22.5	43.9	244
WV	↓↓	39.7	26.8	33.5	257
WY	↑↑	75.4	21.1	3.4	175
Total %		48.9	23.5	27.7	2,132
State Avg %		50.9	22.4	26.8	

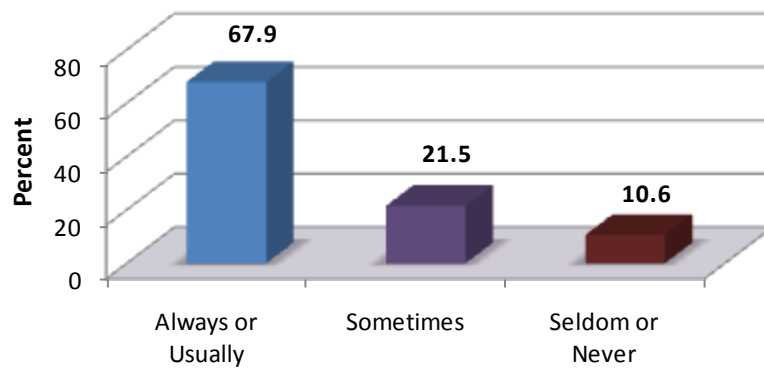
**Chart Q31** Do you have control and/or input over the hiring and management of your support workers?



**2007-08 Average for 8 States**

Table Q31 Do you have control and/or input over the hiring and management of your support workers? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓↓↓	35.0	19.6	45.4	535
HI		48.3	24.5	27.3	143
LA	↑↑↑	64.5	13.7	21.8	248
NJ	↓↓↓	26.5	14.2	59.4	155
OK	↑↑↑	66.7	17.0	16.3	153
SC	↓↓↓	26.6	16.5	56.9	188
WV	↓↓↓	34.9	16.5	48.6	212
WY	↑↑↑	60.1	22.2	17.6	153
Total %		43.4	18.0	38.6	1,787
State Avg %		45.3	18.0	36.7	

**Chart Q32** Do you want to have control and/or input over the hiring and management of your support workers?

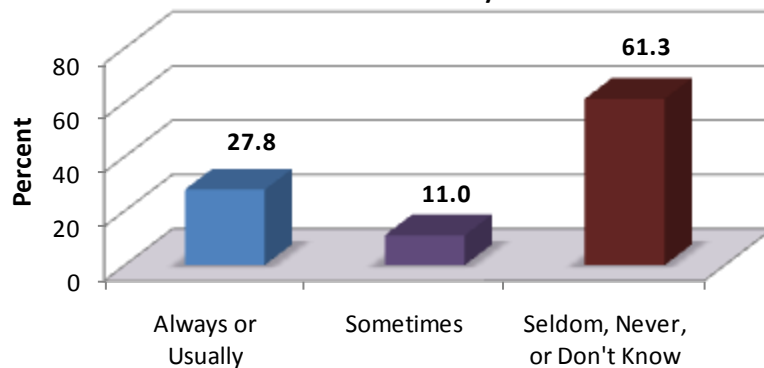


**2007-08 Average for 8 States**

Table Q32 Do you want to have control and/or input over the hiring and management of your support workers? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓↓↓	56.1	27.6	16.4	544
HI	↑	74.1	18.0	7.9	139
LA	↑	75.4	15.5	9.1	252
NJ	↓	61.9	28.1	10.0	160
OK	↑↑	84.4	12.3	3.2	154
SC	↓↓↓	50.7	30.2	19.0	205
WV	↓	62.6	25.1	12.3	227
WY	↑↑	78.1	15.2	6.6	151
Total %		65.0	22.9	12.1	1,832
State Avg %		67.9	21.5	10.6	



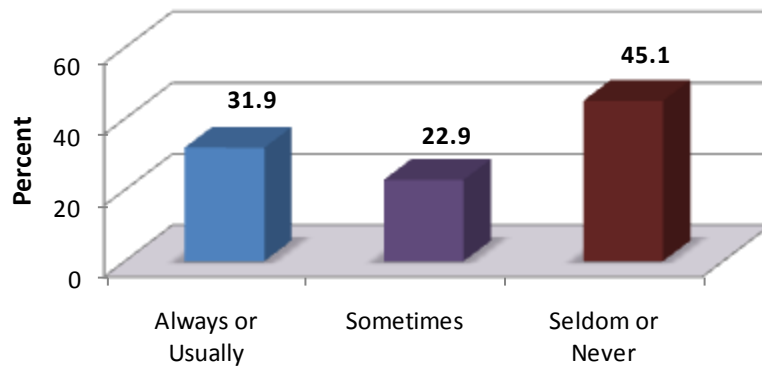
**Chart Q33** Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?



**2007-08 Average for 8 States**

<b>Table Q33</b> Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability? (%)					
State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	N
CA-RCOC	↓↓↓	9.5	5.8	84.7	852
HI	↓	21.4	10.7	67.9	168
LA	↑	36.3	9.9	53.8	303
NJ	↓↓↓	7.7	2.0	90.2	246
OK	↑	36.3	13.1	50.6	168
SC	↓↓↓	12.7	7.5	79.8	267
WV	↑	35.8	24.2	40.0	265
WY	↑↑↑	62.3	14.8	23.0	183
Total %		22.4	9.6	68.0	2,452
State Avg %		27.8	11.0	61.3	

**Chart Q34** Do you get to decide how this money is spent?



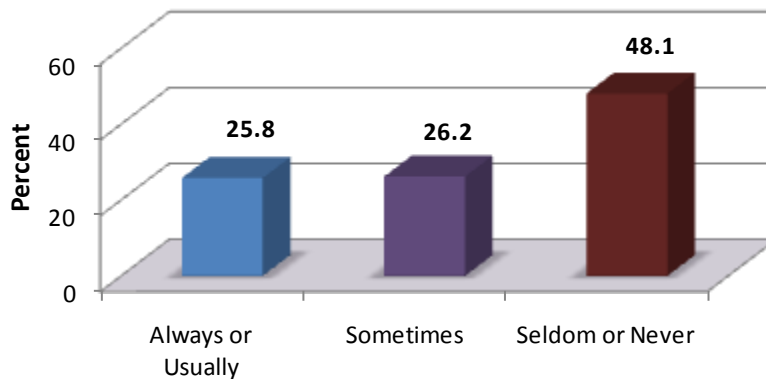
**2007-08 Average for 8 States**

Table Q34					
Do you get to decide how this money is spent? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	22.1	12.8	65.1	438
HI	↓↓	17.3	26.5	56.1	98
LA	↑	39.0	18.2	42.8	187
NJ		35.8	15.7	48.4	159
OK	↑	39.4	32.1	28.5	137
SC	↓↓	15.9	13.6	70.5	176
WV		27.2	31.9	40.8	213
WY	↑↑	58.5	32.7	8.8	159
Total %		30.4	21.0	48.6	1,567
State Avg %		31.9	22.9	45.1	

## Community Connections

- On average, only 26% of respondents felt that planning or support staff were regularly available to help them use typical community supports (e.g., from a local health club, church or recreation activities) if desired. Another 26% said that staff were sometimes helpful, but 48% stated that planning and support staff were seldom or never helpful in connecting their family members to typical community supports or resources.
- Overall, over one-third of respondents (37%) indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (39% said they received little or no help in this area, and the remaining 24% said it occasionally happens).
- Only 39% of families felt their family member always or usually had access to community activities. Twenty-seven percent (27%) stated their family member seldom or never had access to the community.
- While 39% had regular access to community activities, only 24% of children regularly participated in them. Thirty-nine percent (39%) of respondents said that their child seldom or never participated in community activities or events.
- About half (51%) of respondents' children regularly spend time with children who do not have disabilities ~ which leaves the other half (49%) who only spend some or little time with children without disabilities.

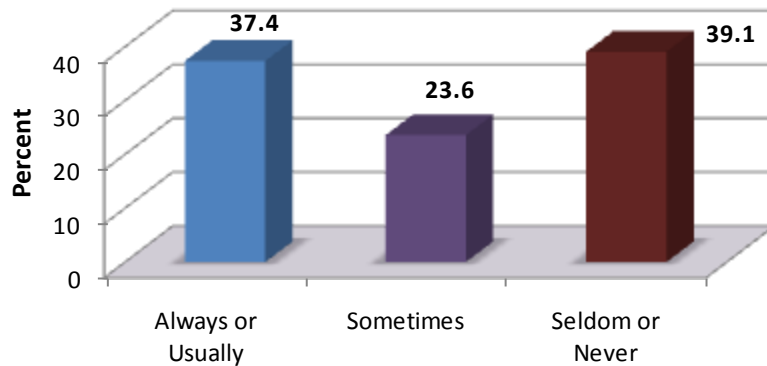
**Chart Q35** If you want to use typical supports in your community, do support or planning staff help connect you to these supports?



**2007-08 Average for 8 States**

<b>Table Q35</b> If you want to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		24.9	24.2	50.9	546
HI		23.4	27.0	49.5	111
LA	↑	32.1	20.7	47.3	184
NJ	↓ ↓	10.2	23.5	66.3	166
OK		27.7	29.2	43.1	130
SC		26.1	28.0	45.9	157
WV		29.8	29.3	40.9	198
WY	↑	31.9	27.5	40.6	138
Total %		25.6	25.6	48.8	1,630
State Avg %		25.8	26.2	48.1	

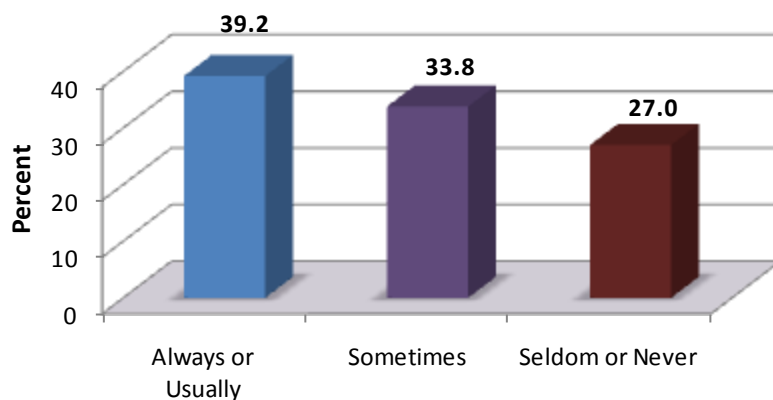
**Chart Q36** If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do support or planning staff help you do this?



**2007-08 Average for 8 States**

<b>Table Q36</b> If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	32.4	24.1	43.6	553
HI		38.9	30.5	30.5	131
LA	↑↑	48.2	22.1	29.7	222
NJ	↓↓	17.0	14.5	68.6	159
OK	↑	45.5	26.1	28.4	134
SC	↓	32.4	23.5	44.1	179
WV		41.7	26.6	31.7	218
WY	↑	42.8	21.0	36.2	138
Total %		36.5	23.6	39.9	1,734
State Avg %		37.4	23.6	39.1	

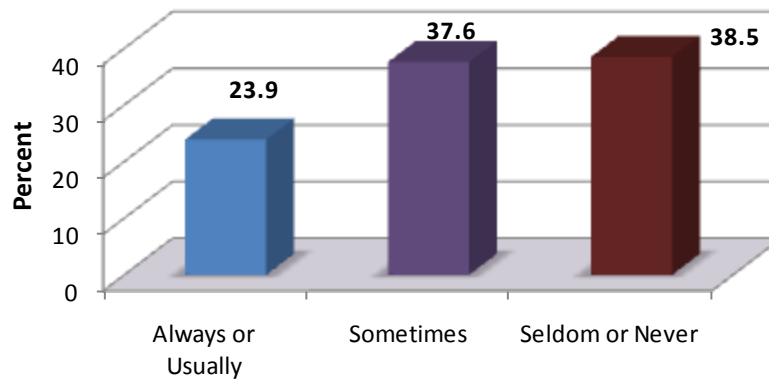
**Chart Q37** Do you feel that your child has access to community activities?



**2007-08 Average for 8 States**

Table Q37 Do you feel that your child has access to community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓↓	28.9	36.8	34.3	761
HI		38.2	36.9	24.8	157
LA	↑	47.1	30.4	22.5	280
NJ	↓↓	19.9	33.2	46.9	241
OK		43.4	34.6	22.0	159
SC	↑	45.1	24.9	30.0	237
WV	↑↑	50.4	34.7	14.9	262
WY		40.7	39.0	20.3	172
Total %		36.9	34.2	28.9	2,269
State Avg %		39.2	33.8	27.0	

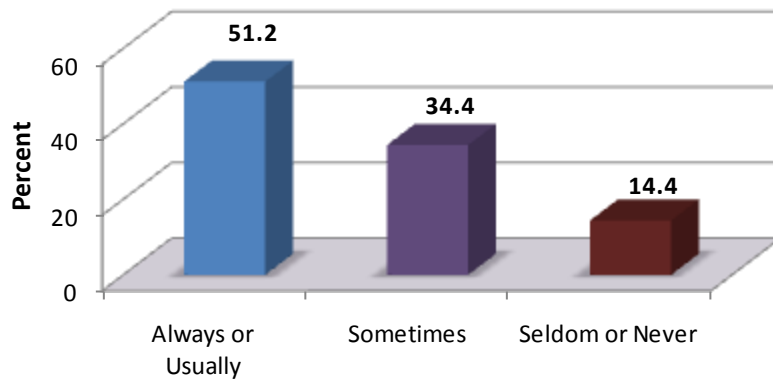
**Chart Q38** Does your child participate in community activities?



**2007-08 Average for 8 States**

Table Q38 Does your child participate in community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	16.3	33.7	50.1	799
HI		22.3	41.0	36.7	166
LA	↑	30.0	32.9	37.1	280
NJ	↓ ↓	11.6	33.3	55.0	249
OK		27.7	41.0	31.3	166
SC		20.2	31.1	48.6	257
WV	↑ ↑	40.2	42.5	17.3	266
WY		22.6	45.2	32.2	177
Total %		22.2	36.1	41.6	2,360
State Avg %		23.9	37.6	38.5	

**Chart Q39** Does your child spend time with children who do not have developmental disabilities?



**2007-08 Average for 8 States**

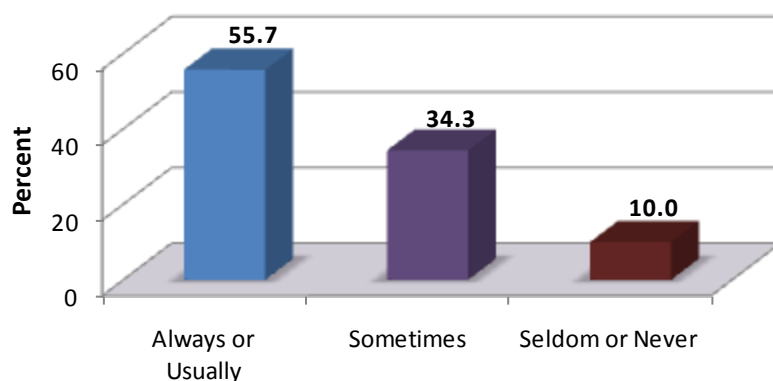
<b>Table Q39</b> <b>Does your child spend time with children who do not have developmental disabilities? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	44.6	37.1	18.3	911
HI		51.7	33.9	14.4	180
LA	↑	56.9	31.3	11.8	313
NJ	↓ ↓	32.7	43.9	23.4	278
OK		51.2	35.5	13.4	172
SC	↑	58.6	30.0	11.4	280
WV	↑ ↑	62.8	31.2	5.9	269
WY		51.4	32.2	16.4	183
Total %		49.6	35.1	15.3	2,586
State Avg %		51.2	34.4	14.4	



## Outcomes and Satisfaction with Services and Supports

- Overall, 56% were always or usually satisfied with the services and supports they received. 34% were somewhat satisfied, and 10% were seldom or never satisfied.
- On average, only 44% of respondents knew about their agency's grievance process, while another 44% had little or no familiarity with the process for lodging a complaint. The "Don't Know" responses were included in the data table, grouped with "Seldom or Never."
- Just over half of respondents (53%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 47%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.
- Sixty-six percent (66%) of families felt that services and supports have made a positive difference in their lives. Eight percent (8%) stated that they seldom or never felt this way.
- Nearly all families (89%) felt that family supports improved, sometimes or more often, their ability to care for their child.
- Over two-thirds (69%) of respondents indicated that services have made a difference in helping them keep their child at home.
- Eighty-five percent (85%) of respondents felt that their family member was usually happy.

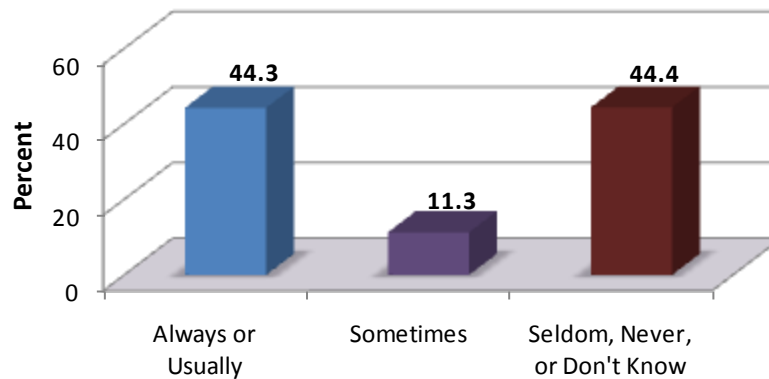
**Chart Q40** Overall, are you satisfied with the services and supports your child and family currently receives?



**2007-08 Average for 8 States**

<b>Table Q40</b> Overall, are you satisfied with the services and supports your child and family currently receives? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		56.7	34.1	9.2	880
HI	↓	49.7	40.3	9.9	181
LA	↑↑	72.1	23.4	4.5	312
NJ	↓↓	28.1	39.4	32.5	249
OK		59.1	32.7	8.2	171
SC		57.2	34.1	8.7	276
WV		58.8	37.8	3.4	267
WY	↑	64.1	32.6	3.3	181
Total %		56.3	33.9	9.8	2,517
State Avg. %		55.7	34.3	10.0	

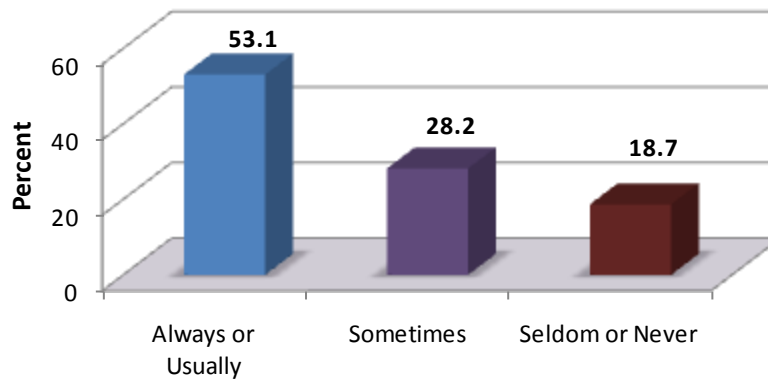
**Chart Q41** Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?



**2007-08 Average for 8 States**

<b>Table Q41</b> Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them? (%)					
State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	N
CA-RCOC		45.2	16.2	38.6	850
HI		43.2	15.3	41.5	176
LA	↑↑	64.1	6.6	29.3	287
NJ	↓↓	12.3	5.9	81.8	236
OK	↑↑	59.7	8.2	32.1	159
SC	↓↓	32.6	9.7	57.8	258
WV		48.1	14.7	37.2	258
WY	↑	49.4	13.7	36.9	168
Total %		44.3	12.4	43.3	2,392
State Avg. %		44.3	11.3	44.4	

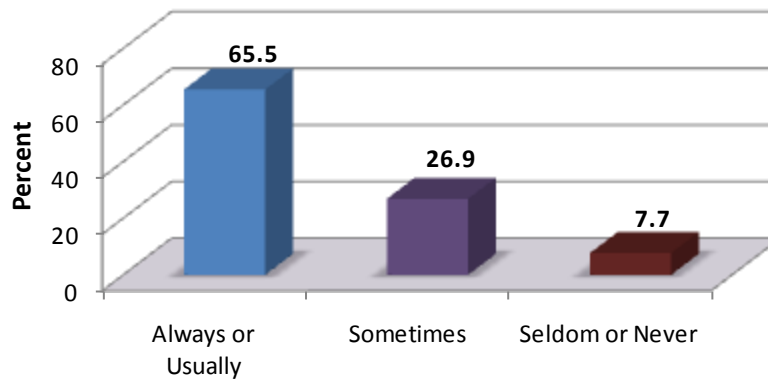
**Chart Q42** Are you satisfied with the way complaints/grievances are handled and resolved?



**2007-08 Average for 8 States**

<b>Table Q42</b> Are you satisfied with the way complaints/grievances are handled and resolved? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↑	58.4	29.4	12.2	385
HI	↓↓	42.0	35.8	22.2	81
LA	↑↑	72.7	16.8	10.6	161
NJ	↓↓	30.2	23.8	46.0	63
OK	↑	60.8	25.7	13.5	74
SC		56.9	25.0	18.1	116
WV		54.0	33.9	12.1	124
WY		50.0	35.0	15.0	60
Total %		56.7	27.7	15.6	1,064
State Avg %		53.1	28.2	18.7	

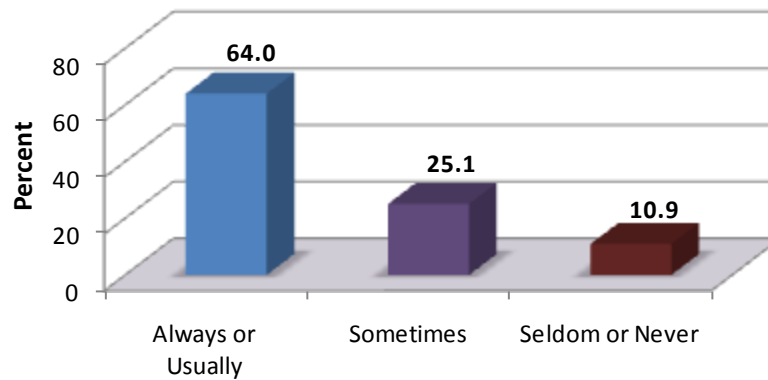
**Chart Q43** Do you feel that family supports have made a positive difference in the life of your family?



**2007-08 Average for 8 States**

<b>Table Q43</b> Do you feel that family supports have made a positive difference in the life of your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		63.6	29.0	7.4	761
HI		62.2	28.5	9.3	172
LA	↑↑	75.7	21.3	3.0	296
NJ	↓↓	39.8	38.1	22.1	226
OK	↑↑	77.1	18.2	4.7	170
SC		62.1	29.5	8.4	261
WV		69.2	27.8	3.0	263
WY	↑	73.9	22.8	3.3	180
Total %		65.0	27.5	7.5	2,329
State Avg %		65.5	26.9	7.7	

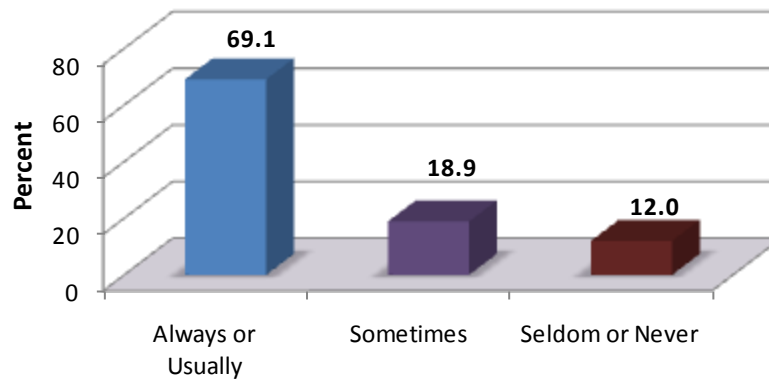
**Chart Q44** Do you feel that family supports have improved your ability to care for your child?



**2007-08 Average for 8 States**

<b>Table Q44</b> Do you feel that family supports have improved your ability to care for your child? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	56.8	31.6	11.5	730
HI		61.0	28.5	10.5	172
LA	↑↑	75.1	18.3	6.6	289
NJ	↓↓	41.9	30.7	27.4	215
OK	↑	73.4	18.3	8.3	169
SC		63.7	25.6	10.7	262
WV		67.7	27.0	5.3	263
WY	↑	72.6	20.7	6.7	179
Total %		62.6	26.5	10.9	2,279
State Avg %		64.0	25.1	10.9	

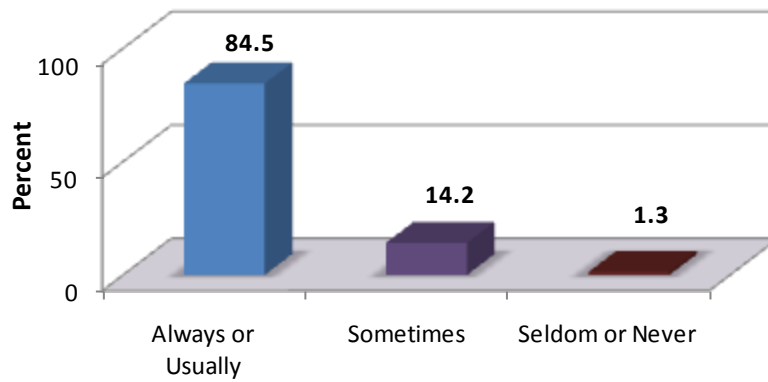
**Chart Q45** Do you feel that family supports have helped you to keep your child at home?



**2007-08 Average for 8 States**

<b>Table Q45</b> Do you feel that family supports have helped you to keep your child at home? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		68.3	19.2	12.5	688
HI		71.2	22.2	6.5	153
LA	↑↑	80.4	11.9	7.7	260
NJ	↓↓	43.8	24.2	32.0	178
OK	↑	75.2	15.9	8.9	157
SC	↓	63.9	23.1	13.0	216
WV	↑	74.2	18.5	7.3	248
WY	↑	75.8	16.1	8.1	161
Total %		69.3	18.8	11.9	2,061
State Avg %		69.1	18.9	12.0	

**Chart Q46** Overall, do you feel that your child is happy?



**2007-08 Average for 8 States**

Table Q46 Overall, do you feel that your child is happy? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	77.2	21.3	1.5	886
HI		85.5	13.4	1.1	179
LA		89.4	9.6	1.0	312
NJ	↓ ↓	72.6	23.7	3.6	274
OK		87.6	10.6	1.8	170
SC		84.7	15.3	0.0	288
WV	↑	89.8	10.2	0.0	266
WY		89.0	9.3	1.6	182
Total %		82.5	16.2	1.3	2,557
State Avg %		84.5	14.2	1.3	



## Aggregate Results & State Comparisons

Above, the findings are displayed question by question. In this section, we look at survey findings by each categorical area of questioning (i.e., information and planning, access and delivery of services, choice and control, community connections, and overall satisfaction).

For each of these categories, there is a CHART that displays the State Average ~ indicating the average percentage, across states, of respondents who answered each question with an “always or usually” response. In nearly all cases, the higher this response, the more satisfied the respondents were with their supports.

For each category, there is also a TABLE that looks at the arrows (i.e.,  $\uparrow$  and  $\downarrow$ ) of the previous Tables, with single arrows representing state results  $\pm 5\%$  from the state average, and double arrows ( $\uparrow\uparrow$  and  $\downarrow\downarrow$ ) representing  $\pm 10\%$  from the state average.

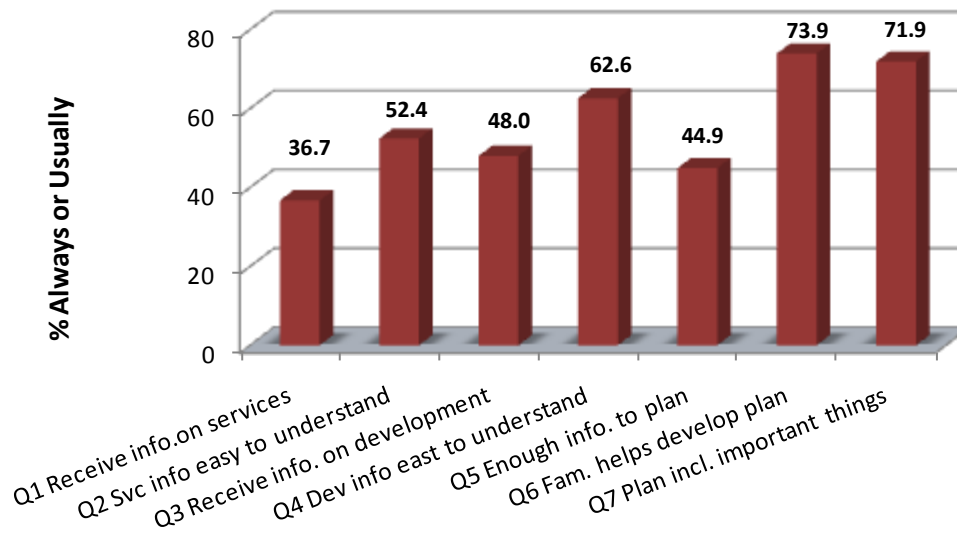
This compilation of results (up arrows minus down arrows) provides a crude overview of results, across states and within topic groupings (e.g., information and planning, choice and control), illustrating how states measured up, overall, against the state averages.

As a review, the first chart illustrates state averages, and the table that follows illustrates how states compared to these state averages.

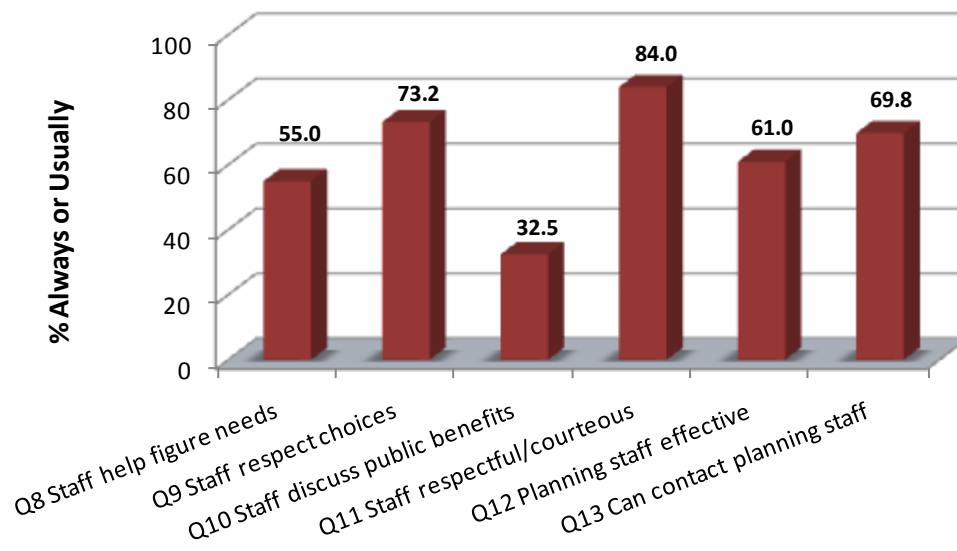
## Information and Planning

- In Wyoming, responses to information and planning questions were generally above the overall state average. In New Jersey, results were generally below the state average.

**Chart 4. Information & Planning (I) (N=8)**



**Chart 4. Information & Planning (II) (N=8)**



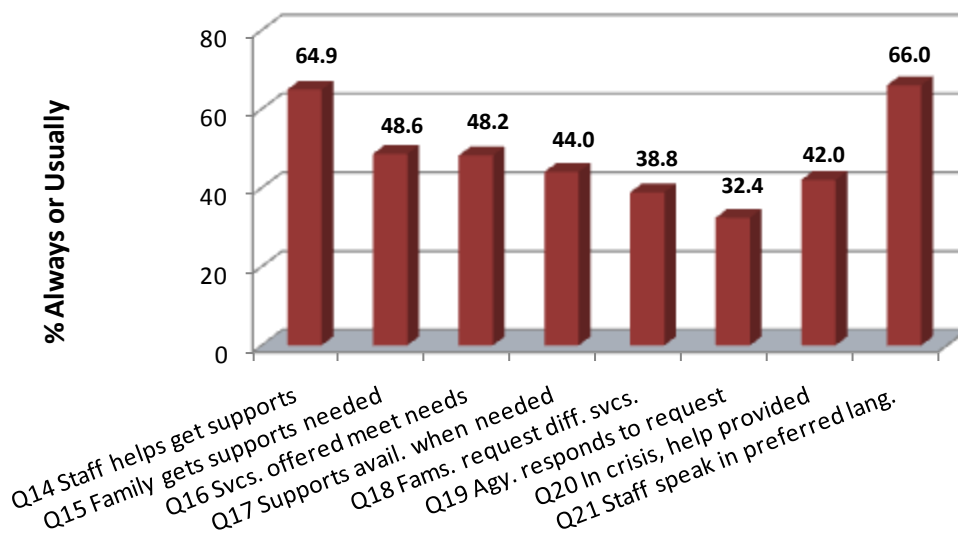
**Table 17**  
**Deviation in Responses Above & Below State Average**  
**Information & Planning**

State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
CA-RCOC	↑	↑	↓					↓	↑					1
HI						↑								1
LA	↑				↑	↑	↑↑	↑↑	↑↑	↑	↑	↑	↑	13
NJ	↓↓	↓	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	-25
OK	↓		↓							↑			↑	0
SC		↑	↑	↑				↑				↑		5
WV			↑		↑	↑	↑	↑						5
WY	↑↑		↑		↑↑	↑↑	↑	↑↑	↑		↑	↑	↑	14

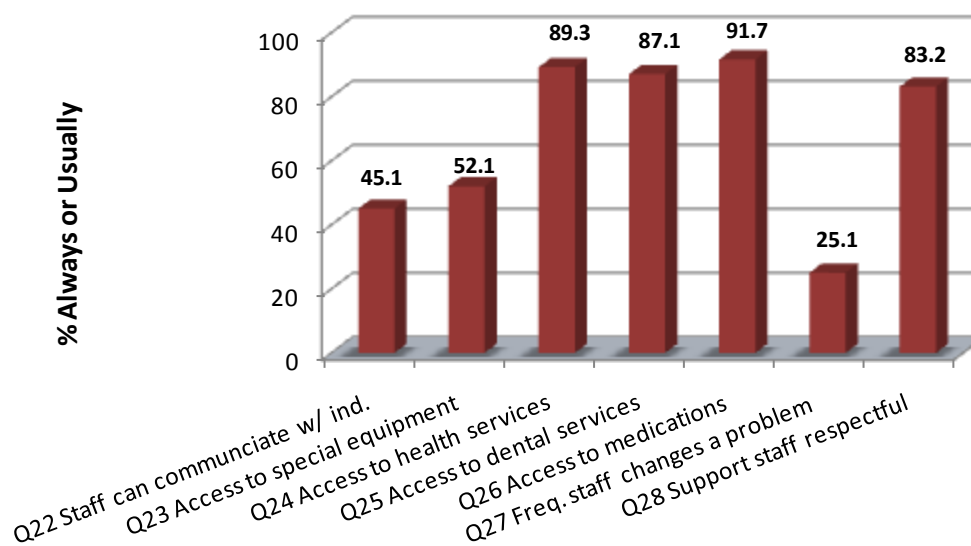
## Access and Delivery of Services

- In Louisiana and Oklahoma, responses to access and delivery of services questions were generally above the state average. In New Jersey and Hawaii, results were generally below the state average. Note that Question 18 is considered a “neutral question”. Therefore, up and down arrows were not used in the calculation of state trends.

**Chart 5. Access to Services (I) (N=8)**



**Chart 5. Access to Services (II) (N=8)**



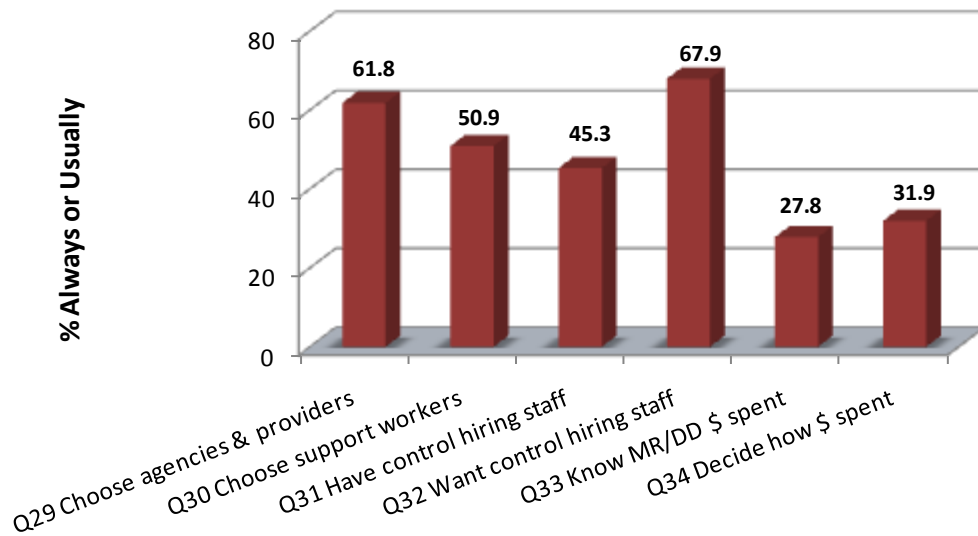
**Table 18**  
**Deviation in Responses Above & Below State Average**  
**Access to Services & Supports**

State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Q27	Q28	Net Sum
CA-RCOC								↑↑	↑↑	↓					↑	4
HI	↓						↓	↓↓	↓	↓	↓					-7
LA	↑	↑↑	↑↑	↑↑		↑↑	↑	↑	↑↑	↑↑				↑	↑	17
NJ	↓↓	↓↓	↓↓	↓↓		↓↓	↓↓	↓↓	↓↓	↓↓	↓	↓	↓		↓↓	-23
OK	↑		↑			↑		↑↑	↑↑				↑			8
SC				↑					↑							2
WV			↑			↓		↑↑	↓							1
WY	↑	↑		↑			↑↑	↓↓	↓↓	↑				↓		1

## Choice and Control

- In this category, nearly all states scored considerably above or below the state average, indicating that there was very little middle ground when it came to choice and control. In Oklahoma, Louisiana and Wyoming, responses to choice and control questions were well above the overall state average. In most other states, results were generally below the state average.

**Chart 6. Choice and Control (N=8)**



**Table 19**  
Deviation in Responses  
Above & Below State Average  
Choice & Control

State	Q29	Q30	Q31	Q32	Q33	Q34	Net Sum
CA-RCOC	↓↓↓	↓	↓↓↓	↓↓↓	↓↓↓	↓	-10
HI				↑	↓	↓↓↓	-2
LA	↑↑↑	↑↑↑	↑↑↑	↑	↑	↑	9
NJ	↓↓↓	↓↓↓	↓↓↓	↓	↓↓↓		-9
OK	↑↑↑	↑↑↑	↑↑↑	↑↑↑	↑	↑	10
SC	↓↓↓	↓↓↓	↓↓↓	↓↓↓	↓↓↓	↓↓↓	-12
WV		↓↓↓	↓↓↓	↓	↑		-4
WY	↑↑↑	↑↑↑	↑↑↑	↑↑↑	↑↑↑	↑↑↑	12

## Community Connections

- In West Virginia and Louisiana, responses to community connections questions were generally above the overall state average. In Orange County, CA and New Jersey, results were generally below the state average.

**Chart 7. Community Connections (N=8)**

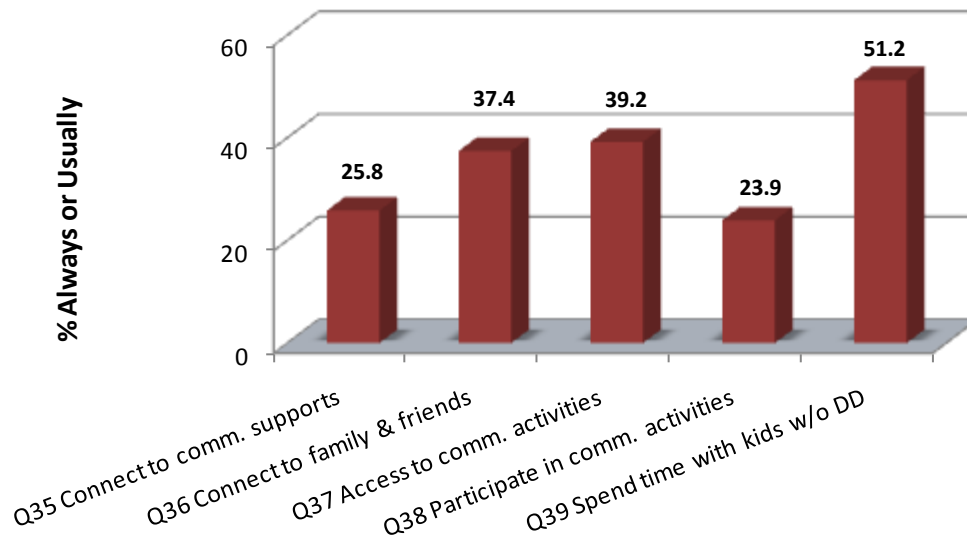
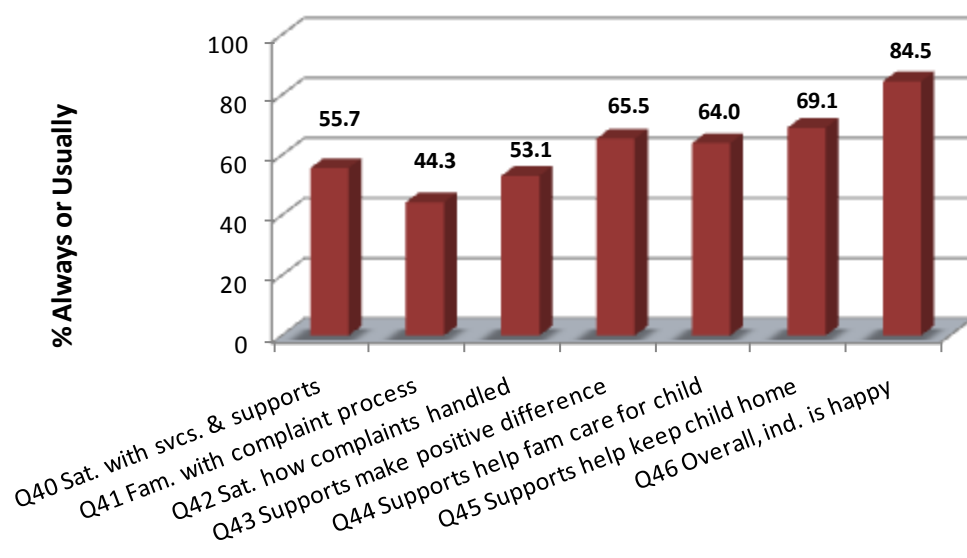


Table 20 Deviation in Responses Above & Below State Average Community Connections						
State	Q35	Q36	Q37	Q38	Q39	Net Sum
CA-RCOC		↓	↓↓	↓	↓	-5
HI						0
LA	↑	↑↑	↑	↑	↑	6
NJ	↓↓	↓↓	↓↓	↓↓	↓↓	-10
OK		↑				1
SC		↓	↑		↑	1
WV			↑↑	↑↑	↑↑	6
WY	↑	↑				2

## Satisfactions with Services and Supports & Outcomes for Families

- In Oklahoma, Louisiana, and Wyoming, responses to satisfaction with services and outcomes for families questions were generally above the overall state average. In New Jersey, results were generally below the state average.

**Chart 8. Satisfaction & Outcomes (N=8)**



**Table 21**  
Deviation in Responses  
Above & Below State Average  
Satisfaction & Outcomes

State	Q40	Q41	Q42	Q43	Q44	Q45	Q46	Net Sum
CA-RCOC			↑		↓		↓	-1
HI	↓		↓↓					-3
LA	↑↑	↑↑	↑↑	↑↑	↑↑	↑↑		12
NJ	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	-14
OK		↑↑	↑	↑↑	↑	↑		7
SC		↓↓				↓		-3
WV						↑	↑	2
WY	↑	↑		↑	↑	↑		5



## Overall State Results

- Looking at results across all categories, Louisiana had results that were well above the overall state average. In New Jersey, results were generally below the overall state average.

<b>Table 22</b> <b>Overall Deviation in Responses</b> <b>Above &amp; Below State Average</b>						
<b>State</b>	Information & Planning	Access & Delivery	Choice & Control	Community Connections	Satisfaction & Outcomes	<b>Total Sum</b>
<b>CA- RCOC</b>	1	4	-10	-5	-1	<b>-11</b>
<b>HI</b>	1	-7	-2	0	-3	<b>-11</b>
<b>LA</b>	13	17	9	6	12	<b>57</b>
<b>NJ</b>	-25	-23	-9	-10	-14	<b>-81</b>
<b>OK</b>	0	8	10	1	7	<b>26</b>
<b>SC</b>	5	2	-12	1	-3	<b>-7</b>
<b>WV</b>	5	1	-4	6	2	<b>10</b>
<b>WY</b>	14	1	12	2	5	<b>34</b>

# **APPENDIX A**

## Analysis of Open-Ended Comments

## Analysis of Open-Ended Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. QSR N6 was used to code and to sort the qualitative comments by theme. The themes identified are detailed here, and the main results of this analysis are presented by state below. States have many family comments coded into the “General Satisfaction” and “General Dissatisfaction” themes, with all states having more positive general comments about services and supports than negative comments. However, there was great variation from state to state. Therefore, the analysis below will begin by describing how each state did on the “general” themes, and then will highlight specific themes that were commented upon with the greatest frequency and provide examples of typical comments.

1. Home
  - a. Satisfied with Home
  - b. Dissatisfied with Home
  - c. Accommodations with Home
  - d. Furnishings/Cleanliness of Homes
  - e. Waiting List
2. Employment and Day Programs
  - a. Satisfied with Employment
  - b. Dissatisfied with Employment
3. Health Care
  - a. Health Care Equipment
  - b. Health Care Insurance
  - c. Dental
  - d. Medical
  - e. OT/PT/ST
  - f. Vision
  - g. Psychological
4. Education and Training
  - a. Satisfied with Education/Training
  - b. Dissatisfied with Education/Training
5. Transportation
  - a. Satisfied with Transportation
  - b. Dissatisfied with Transportation
  - c. No Transportation
6. Recreation Activities
  - a. Satisfied with Recreation Activities
  - b. Dissatisfied with Recreation Activities
7. Communication
  - a. Satisfied with Communication
  - b. Dissatisfied with Communication
  - c. Information
  - d. Language Barrier
  - e. Non-communicative
  - f. Planning Meetings
  - g. Interagency
8. Aging Caregiver Issues
9. Transition Issues
10. Service Coordination
  - a. Satisfied with CM
  - b. Dissatisfied with CM
  - c. CM Turnover
  - d. Shortage of CM Workers
  - e. CM Not Qualified
  - f. Pay CM More
  - g. Service Plan
11. Staff
  - a. Satisfied with Staff
  - b. Dissatisfied with Staff
  - c. Staff Turnover
  - d. Shortage of Staff
  - e. Staff Not Qualified
  - f. Pay Staff More
  - g. Substitutes
12. Family Issues
  - a. Parents as Paid Staff or Case Manager
  - b. Family Support Group
13. General Well Being
  - a. Health
  - b. Safety
  - c. Abuse/Neglect/Mistreatment
  - d. Social
14. Respite
  - a. Satisfied with Respite
  - b. Dissatisfied with Respite
15. Crisis
16. Funding and Budget Cuts
17. Services and Supports
  - a. General Satisfaction with Services
  - b. General Dissatisfaction with Services
  - c. Access to Services/Supports
  - d. Info Regarding Services/Supports
  - e. Need More Services/Supports
  - f. General Satisfaction with Service Management

- g. General Dissatisfaction with Service Management
- h. Waiting List
- 18. Support Groups
- 19. General Concerns

## HAWAII

Hawaii families did not make as many comments as most of the other States. With this in mind, there was almost a two to one ratio of positive to negative comments regarding general satisfaction with services and supports.

More specifically, families indicated their satisfaction with case management/service coordination:

We love all the helpful services that is given to our son (Name) with DDD branch. Case manager has been truly helpful & understanding in every way! We truly love her and she's been so understand & inspirational for us & our little boy (Name).

Families were concerned about funding and budget issues, with half of these families frustrated that they “made too much money” to be considered for some types of funding or services:

To me it seems like the people who make decent money don't get services as easily as low income families. We have to fight for services or grumble to get a little help. It's really tiring & stressful caring for a total care special needs child

Although Hawaii families made positive comments about case management, some expressed a desire for more information regarding services and supports. One family offered a suggestion to improve the information flow:

It would be very helpful to be presented all the services, assistance, support in writing regular basis with how to access those services in easy to understand format. Thank you.

## OKLAHOMA

Of those who provided comments, about three times more Oklahoma families tended to have more general satisfaction towards services and supports than dissatisfaction.

Like Hawaii, families in Oklahoma had the most to say about their satisfaction with the case managers/service coordinators:

(Name) is (Name's) case manager. She does an excellent job and always involves him with decisions that affect him. We appreciate supportive attitude so very much.

The category that received the second highest amount of comments was Health Care- OT/PT/ST. The common theme in these comments was the inability of families to obtain therapy for their children:

I do believe that the Health Care Authority takes too long to approve either adaptive equipment or therapy sessions. By the time it is approved the child is outgrowing the equipment or has missed therapy sessions that is needed to continue to rehabilitation

Some Oklahoma families also expressed frustration with the lack of communication concerning the status of their children's services:

No one offers information. We have to dig for every piece of info regarding our child. We have to have all purchases approved by people whose only interest in our child has to do with them getting a pay check.

## REGIONAL CENTER OF ORANGE COUNTY, CA

Similar to Oklahoma, Orange County had an approximately three to one ratio of positive comments regarding general satisfaction of services and supports.

Like most of the other States, many families commented on their satisfaction with the case managers/service coordinators:

I'm very happy with my service coordinator. There's plenty of communication with her and she has helped me resolved many worries.

And, also like many other States, although Orange County families were satisfied with the case management, they are concerned about the lack of information they receive regarding services and supports:

I feel like the RC hides programs and parents are left in the dark. By talking with other parents is how I find out about programs. There is all of information that parents need to help their kids, so make the info accessible. Thank you

Families were also frustrated with the lack of therapy services provided by Orange County:

My neurologist has recommended supplemental speech/OT. I'm being told that RC will not offer any services for my son. RC just passes the buck to the school district. My private insurance won't pay for any speech or OT either!

## SOUTH CAROLINA

Just a few more families in South Carolina commented that they were generally satisfied with services and supports compared with those who indicated they were generally dissatisfied.

More specifically, South Carolina families' main concerns were the lack of therapy services:

I strongly believe that ABA/ABT, being the most effective form of therapy for autistic kids should be readily available to support the child as much as he needs it. It makes no sense to let these kids wait for such therapy to be approved for them when we are in a race for time to pull these kids back before the window of opportunity to heal closes on them.

Families were also frustrated with the lack of funding for services:

\$ requested seems to be selective in distribution. I am terribly unhappy that as a PDD Waiver recipient my child no longer qualifies for other funding available! Waiver recipients depending on service providers cannot leave their home or allow their child to be transported to any activity.

Many comments indicated that it was difficult to get information regarding services and supports:

I think too that information to families regarding services should be readily available upon diagnosis instead of having to get limited, sporadic, information from people we just happen to meet.

## WEST VIRGINIA

Overall, there was just over a four to one ratio of positive to negative comments regarding general satisfaction of state services and supports.

More specific comments than any other had to do with the lack of respite services available to families:

It is imperative that services such as respite and child care be provided to parents. I am a single mother. My parents are too old to help out. There are no programs for my daughter to attend after school. I need help with day care.

There were several comments that had to do with the lack of information provided to families:

I have always been concerned that families with disabled children do not get educated on possible programs or help. No agency points out our child could have this or that.

The two categories tied with the third most comments were both related to health care: equipment and psychological services:

The only thing that gets hard to do is to get money to put in special equipment for our son. We wanted to put in a handicapped shower and the tub. We got \$1,000 which not much, but I knew other people who got like \$3,000 for a play-yard that isn't used

My son needs ABA Applied Behavioral Analysis or behavioral therapy. We have insurance through my husband's work, but they only provide 10 therapies a year. It will not help cover the cost of this therapy.

## WYOMING

Wyoming families tended to have much more general satisfaction towards services and supports than dissatisfaction.

However, many specifically commented on how they wished they had more flexibility with the budget provided for their children:

I am completely satisfied with our case manager and all of his efforts and support. Our respite had been good, though we rarely need it. My dissatisfaction comes into play with the limitations on the budget for equipment. Our daughter is severely autistic and truly needs equipment that has been deemed “household”, “toys” or is on the “no list.” I get so frustrated that families can spend \$30,000 a year on respite (essentially allowing someone else to raise their child) but we can't get an adaptive tricycle for our daughters so that she can go riding with her family. Ironical isn't it?? “The family that plays together stays together”—yet we are not financially supported for our efforts. In order for us to afford the special diet and all the researched interventions, we spend thousands out of our own pocket and are not able to buy the “toys” and “household” items she so desperately needs. It seems to me that the good and honest families are being punished and the non-attentive uninvolved families have no problems. Please look at the list on the back for the truly useful skill building or disability specific items we need instead of respite.

Along the same lines, Wyoming families also stated that they needed more services and supports:

Some help need to be addressed in regards to our lack of providers and the providers that are on the wavier are not accepting clients.

Unique to any other State, many Wyoming families commented on their dissatisfaction with the service management:

Great program but flawed because of paper work. As usual the comment is simple. I have the funds for my child but the paper work and the incompetence of the Division makes it difficult to get providers, also the lack of providers available. If you find someone to help with your child-it is no help if it takes 3-4 months to get them qualified. Case management is great- but dealing with the Division is difficult. The Division staff is less than helpful getting providers through the maze of paperwork. The paper work may come from the Feds but every provider has a horror story.