

# Child Family Survey

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Final Report – August 2010  
2008-2009 Data



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

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**August 2010**

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## Organization of Report

Six states conducted the National Core Indicators (NCI) Child Family Survey during the 2008-2009 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 2009.

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 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 2009, the NCI effort continued to expand. The following figure summarizes state participation in the National Core Indicators since its inception through the 2008-2009 data collection cycle. States are listed if they participate in one or more of the NCI activities (e.g., consumer survey, family surveys, etc.).

**TABLE 1: NCI State Participation**

Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003	Phase VI 2003-2004	Phase VII 2004-2005	Phase VIII 2005-2006	Phase IX 2006-07	Phase X 2007-2008	Phase XI 2008-2009
AZ	AZ	AZ	AL	AL	AL	AL	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	AR	AR	AR	AR
MO	KY	DE	CA-RCOC	CA-RCOC	CA-RCOC	CA-RCOC	AZ	AZ	AZ	AZ
NE	MA	IA	CT	CT	CT	CT	CA-RCOC	CA-RCOC	CA-RCOC	CT
PA	MN	KY	DE	DE	DE	DE	CT	CT	CT	DE
VT	NE	MA	HI	HI	DC	DC	DE	DE	DE	GA
VA	NC	MN	IL	IN	HI	HI	DC	GA	GA	HI
	PA	MT	IN	IA	IN	KY	GA	HI	HI	IL
	RI	NE	IA	KY	KY	MA	HI	IN	IN	IN
	VT	NC	KY	MA	MA	ME	KY	KY	KY	KY
	VA	PA	MA	ME	ME	NC	MA	MA	LA	LA
	WA	RI	NE	NE	NE	OK	ME	ME	MA	MA
		UT	NC	NC	NC	PA	NC	NM	ME	ME
		VT	OK	OK	ND	RI	OK	NC	MO	MO
		WA	PA	PA	OK	SC	PA	OK	NC	NC
			RI	RI	PA	VT	RI	PA	NJ	NJ
			UT	SC	RI	WA	SC	RI	NM	NM
			VT	SD	SC	WV	SD	SC	NY	NY
			WA	VT	SD	WY	TX	TX	OK	OH
			WV	WA	VT		VT	VT	PA	OH- HC
			WY	WV	WA		WA	WA	RI	OH- MC
				WY	WV		WV	WV	SC	OH-MEORC
					WY		WY	WY	TX	OK
									VT	PA
									WA	SC
									WV	TX
									WY	WA
										WY

Denotes first year 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 living 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 2009, five to eight states have participated each year. Response rates within states have varied greatly, between 11% - 65%, 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.

Table 3 State Participation in NCI Children Family Survey (Children Living at Home)									
Phase I & II Field Test	Phase III 2000-01 Data	Phase IV 2001-02 Data	Phase V 2002-03 Data	Phase VI 2003-04 Data	Phase VII 2004-05 Data	Phase VIII 2005-06 Data	Phase IX 2006-07 Data	Phase X 2007-08 Data	Phase XI 2008-09 Data
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	AZ LA MO SC TX WA



## 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 2008-2009 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 the services that families receive 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** – Lastly, 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 18, or under age 22 if still receiving child services. 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. Final sample size of 400 would provide a 95% confidence level and a 5% margin of error when interpreting the results. Where there were fewer than 1,000 potential respondent families, states were asked to send surveys 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 four 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 22, their responses were dropped.
- ◆ If the respondent indicated that no services were being received, 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 2008-2009 data year, six 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.

<b>Table 4 Child Family Survey - State Response Rates</b>				
<b>State</b>	<b>Surveys Mailed</b>	<b>Surveys Returned</b>	<b>Response Rate</b>	<b>Usable Surveys</b>
Arizona	1,000	243	24%	235
Louisiana	1,600	320	20%	302
Missouri	1,100	406	37%	368
South Carolina	1,300	324	25%	273
Texas	2,000*	887	44%	825
Washington	1,246	415	33%	404
<b>Overall</b>	<b>8,246</b>	<b>2,595</b>	<b>31%</b>	<b>2,407</b>

\*Estimate

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 are 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.

## IV. Results

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

The TABLES provide individual state results and result averages that are calculated through two separate methods:

1. **Total Percentages** indicate the average percentage across all individual respondents.
2. **State Averages** indicate the average percentage across the six states that conducted this survey.

### Important note about how the results are displayed:

Response rates varied by state, and some states were more successful than others in obtaining the recommended sample size of 400 returned surveys. In order to include as many states as possible but still maintain acceptable research standards, we made the decision to exclude states with final samples of less than 200 returned surveys. States that submitted a final sample that resulted in a margin of error of between 5% and 7% were included in the analysis, but are listed separately in the tables because they do not meet the accepted minimum standard. States that met the minimum standard of a 5% margin of error are grouped together at the top of the tables.

The term “margin of error” is also known as the “confidence interval.” A margin of error of 5% means that the true percentage for the population is within plus or minus 5% of the estimate from the sample. A higher margin of error indicates a less precise estimate of the population, and these results should be interpreted with greater caution. A confidence interval of 95% combined with margin of error of 5% means that we can be 95% certain that the true percentage for the population is within 5% of the estimate.

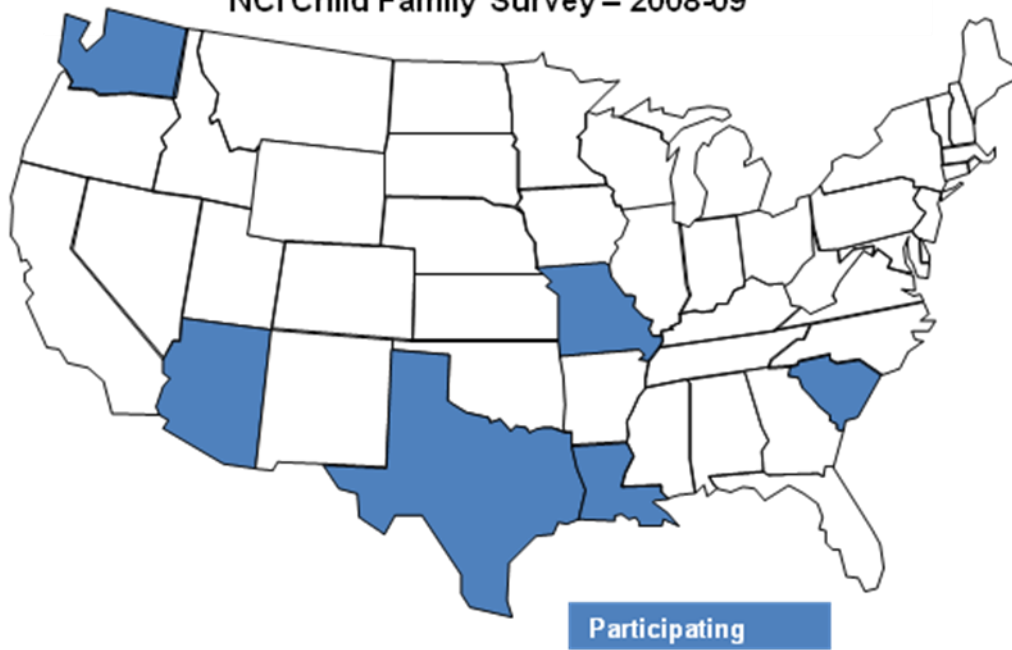
All of the states listed in the tables are included in the total percentage and state average displayed at the bottom of each table.

The CHARTS and text in this section illustrate the state average results.

### Participating States

- ◆ Six states (Arizona, Louisiana, Missouri, South Carolina, Texas, and Washington) provided data for this Report.

**Chart 1**  
States Participating in the  
NCI Child Family Survey – 2008-09



## Characteristics of Children with Disabilities

This section provides information about the children with disabilities living in the household (using the State Average percentages).

- On average, across the states, 64% of children with disabilities were male and 36% were female.
- Across all participating states, the average age of children with disabilities was 10 years old, with a range in age from 0 to 22.
- Across all states, 64% of the children with disabilities were White, 17% were Black/African-American, 13% were Hispanic/Latino, 5% were Mixed Races, 3% were American Indian/Alaska Native, 3% were Asian-American, and 1% were Native Hawaiian/Pacific Islander. In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.
- On average, 19% of households include more than one individual with a developmental disability.
- On average, 79% of children with disabilities required moderate to complete levels of assistance with activities of daily living. Twenty-one percent (21%) of children required little or no assistance with these activities.
- Many families indicated that their children have mental retardation (35%) and/or other developmental disabilities (36%). Additionally, many children experience other disabilities, such as physical disabilities (28%), autism (30%), seizure disorders (27%), communication disorders (26%), vision or hearing impairments (23%), and/or cerebral palsy (20%).

## Gender of Family Member

<b>Table 5 Gender (%)</b>		
<b>State</b>	<b>Male</b>	<b>Female</b>
<b>Margin of error ≤ 5%</b>		
<b>MO</b>	60.9	39.1
<b>TX</b>	63.2	36.8
<b>WA</b>	64.8	35.2
<b>Margin of error &gt; 5%</b>		
<b>AZ</b>	64.8	35.2
<b>LA</b>	62.0	38.0
<b>SC</b>	66.0	34.0
<b>Total N</b>	<b>1,485</b>	<b>855</b>
<b>Total %</b>	<b>63.5</b>	<b>36.5</b>
<b>State Avg %</b>	<b>63.6</b>	<b>36.4</b>

## Age of Family Member

<b>Table 6 Age of Child</b>		
<b>State</b>	<b>Average Age</b>	<b>Range</b>
<b>Margin of error ≤ 5%</b>		
<b>MO</b>	11.5	0-18
<b>TX</b>	13.7	5-22
<b>WA</b>	11.8	3-18
<b>Margin of error &gt; 5%</b>		
<b>AZ</b>	7.4	1-17
<b>LA</b>	7.8	1-18
<b>SC</b>	6.3	1-21
<b>Total N</b>	<b>2,309</b>	
<b>Total Avg</b>	<b>10.8</b>	
<b>State Avg %</b>	<b>9.7</b>	<b>0-22</b>

## Race/Ethnicity of Family Member

<b>Table 7</b> Race/Ethnicity of Child (%)								
State	White	Black/ African- American	Asian	Am. Indian/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
<b>Margin of error ≤ 5%</b>								
MO	88.3	5.3	0.8	3.9	0.8	2.2	0.8	0.3
TX	48.8	15.2	1.5	1.0	0.6	4.3	0.4	32.4
WA	72.3	6.0	9.3	3.8	1.3	7.1	1.0	10.3
<b>Margin of error &gt; 5%</b>								
AZ	57.5	8.0	0.9	6.2	0.9	9.3	0.4	31.0
LA	60.9	35.1	1.4	0.7	0.0	1.8	0.0	0.4
SC	57.2	33.0	1.9	1.5	0.4	5.7	1.1	3.0
<b>Total N</b>	<b>1,438</b>	<b>365</b>	<b>63</b>	<b>57</b>	<b>16</b>	<b>111</b>	<b>14</b>	<b>374</b>
<b>Total %</b>	<b>62.3</b>	<b>15.8</b>	<b>2.7</b>	<b>2.5</b>	<b>0.7</b>	<b>4.8</b>	<b>0.6</b>	<b>16.2</b>
<b>State Avg %</b>	<b>64.2</b>	<b>17.1</b>	<b>2.6</b>	<b>2.9</b>	<b>0.7</b>	<b>5.1</b>	<b>0.6</b>	<b>12.9</b>

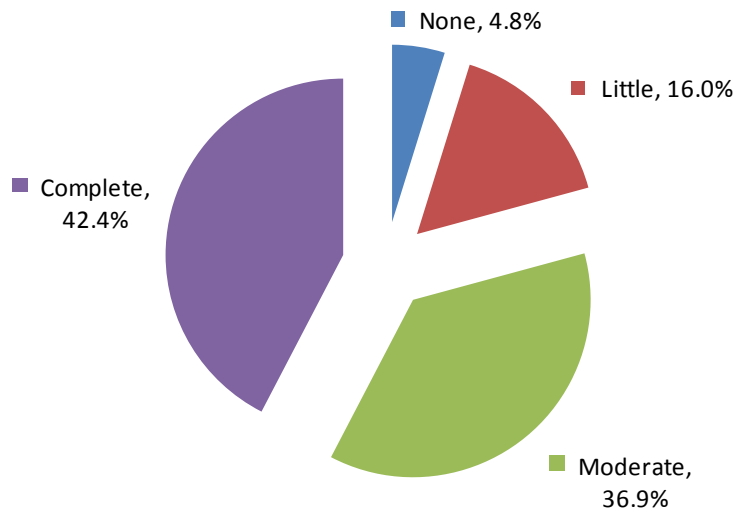
## More Than One Person with Disabilities Living in Household

<b>Table 8</b> More Than One Person in Household with a Dev. Disability (%)		
State	Yes	No
<b>Margin of error ≤ 5%</b>		
MO	26.0	74.0
TX	14.6	85.4
WA	22.4	77.6
<b>Margin of error &gt; 5%</b>		
AZ	18.1	81.9
LA	13.9	86.1
SC	17.3	82.7
<b>Total N</b>	<b>432</b>	<b>1,936</b>
<b>Total %</b>	<b>18.2</b>	<b>81.8</b>
<b>State Avg %</b>	<b>18.7</b>	<b>81.3</b>

## Level of Help with Daily Activities

<b>Table 9</b>				
<b>Level of Help with Daily Activities (%)</b>				
<b>State</b>	<b>None</b>	<b>Little</b>	<b>Moderate</b>	<b>Complete</b>
<b>Margin of error ≤ 5%</b>				
<b>MO</b>	10.8	17.8	33.9	37.5
<b>TX</b>	3.3	9.3	32.7	54.7
<b>WA</b>	1.0	9.5	44.0	45.5
<b>Margin of error &gt; 5%</b>				
<b>AZ</b>	3.5	18.0	39.9	38.6
<b>LA</b>	3.8	17.5	31.3	47.4
<b>SC</b>	6.1	23.7	39.7	30.5
<b>Total N</b>	<b>104</b>	<b>329</b>	<b>842</b>	<b>1,054</b>
<b>Total %</b>	<b>4.5</b>	<b>14.1</b>	<b>36.2</b>	<b>45.3</b>
<b>State Avg %</b>	<b>4.8</b>	<b>16.0</b>	<b>36.9</b>	<b>42.4</b>

**Chart 2. Level of Help with Daily Activities**





## Family Member's Disabilities

<b>Table 10A</b> Disabilities of Child (%)						
State	Mental Retardation	Other Dev. Disability	Mental Illness	Autism	Cerebral Palsy	Brain Injury
<b>Margin of error ≤ 5%</b>						
<b>MO</b>	32.9	35.4	9.9	37.0	14.1	9.7
<b>TX</b>	58.0	35.2	6.3	25.2	37.7	14.3
<b>WA</b>	46.4	37.7	7.2	36.2	17.7	8.5
<b>Margin of error &gt; 5%</b>						
<b>AZ</b>	31.3	32.1	3.6	34.8	17.4	9.8
<b>LA</b>	20.4	42.2	4.1	20.0	21.1	6.7
<b>SC</b>	17.8	33.6	7.1	25.7	11.5	5.9
<b>Total N</b>	<b>929</b>	<b>826</b>	<b>151</b>	<b>673</b>	<b>542</b>	<b>236</b>
<b>Total %</b>	<b>40.5</b>	<b>36.0</b>	<b>6.6</b>	<b>29.4</b>	<b>23.6</b>	<b>10.3</b>
<b>State Avg %</b>	<b>34.5</b>	<b>36.0</b>	<b>6.4</b>	<b>29.8</b>	<b>19.9</b>	<b>9.2</b>

<b>Table 10B</b> Disabilities of Child (%)							
State	Seizure Disorder/ Neurological Problem	Chemical Dependency	Vision/Hearing Impairments	Physical Disability	Communication Disorder	Down Syndrome	Other Disability
<b>Margin of error ≤ 5%</b>							
<b>MO</b>	25.4	0.0	21.3	28.2	29.8	6.9	33.4
<b>TX</b>	45.3	0.6	39.5	46.0	38.4	8.7	33.5
<b>WA</b>	27.4	0.0	23.9	24.9	26.9	10.7	25.9
<b>Margin of error &gt; 5%</b>							
<b>AZ</b>	19.2	1.3	20.5	23.2	20.1	15.2	19.2
<b>LA</b>	27.0	0.7	21.9	27.4	17.8	9.6	24.8
<b>SC</b>	14.6	0.8	13.4	17.4	22.9	8.3	31.2
<b>Total N</b>	<b>710</b>	<b>12</b>	<b>621</b>	<b>732</b>	<b>668</b>	<b>217</b>	<b>676</b>
<b>Total %</b>	<b>31.0</b>	<b>0.5</b>	<b>27.1</b>	<b>31.9</b>	<b>29.1</b>	<b>9.5</b>	<b>29.5</b>
<b>State Avg %</b>	<b>26.5</b>	<b>0.6</b>	<b>23.4</b>	<b>27.9</b>	<b>26.0</b>	<b>9.9</b>	<b>28.0</b>

## Characteristics of Respondents

This section provides information about survey respondents (using the State Average percentages). Respondents are the individuals who completed the survey forms, not the individual with disabilities living in the household.

- ◆ Across all states, nearly all (91%) of respondents were under 55 years old, with most respondents (63%) falling in the 35 to 54 year old age category.
- ◆ The vast majority of respondents were parents of children with disabilities (92%). The remaining respondents were grandparents (6%), siblings (1%), or others (2%).
- ◆ 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 (52%) or excellent (24%) health. Twenty-three percent (23%), however, categorized their health as being fair or poor.
- ◆ Forty-six percent (46%) of respondents had an annual household income (including all wage earners within the household) of \$25,000 or less. Twenty-one percent (21%) had a household income between \$25,001 and \$50,000 and 33% 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>Margin of error ≤ 5%</b>				
<b>MO</b>	19.7	70.5	9.0	0.8
<b>TX</b>	15.3	74.6	9.5	0.6
<b>WA</b>	17.0	69.7	13.0	0.3
<b>Margin of error &gt; 5%</b>				
<b>AZ</b>	32.3	59.1	8.1	0.4
<b>LA</b>	41.2	53.2	5.6	0.0
<b>SC</b>	43.4	51.1	5.5	0.0
<b>Total N</b>	<b>582</b>	<b>1,579</b>	<b>213</b>	<b>10</b>
<b>Total %</b>	<b>24.4</b>	<b>66.2</b>	<b>8.9</b>	<b>0.4</b>
<b>State Avg %</b>	<b>28.2</b>	<b>63.0</b>	<b>8.5</b>	<b>0.4</b>

## Relationship of Respondent to Child with Disabilities

<b>Table 12</b> Relationship to Child with Disabilities (%)				
<b>State</b>	<b>Parent</b>	<b>Sibling</b>	<b>Grand-parent</b>	<b>Other</b>
<b>Margin of error <math>\leq</math> 5%</b>				
<b>MO</b>	94.5	0.0	4.4	1.1
<b>TX</b>	90.6	0.1	6.9	2.3
<b>WA</b>	92.3	0.2	5.2	2.2
<b>Margin of error <math>&gt;</math> 5%</b>				
<b>AZ</b>	93.2	0.0	4.3	2.6
<b>LA</b>	91.9	0.7	6.1	1.4
<b>SC</b>	89.7	1.8	6.3	2.2
<b>Total N</b>	<b>2,185</b>	<b>9</b>	<b>138</b>	<b>48</b>
<b>Total %</b>	<b>91.8</b>	<b>0.4</b>	<b>5.8</b>	<b>2.0</b>
<b>State Avg %</b>	<b>92.0</b>	<b>0.7</b>	<b>5.5</b>	<b>2.0</b>

## Respondent's Role as Primary Caregiver

<b>Table 13</b> Respondent is Primary Caregiver (%)		
<b>State</b>	<b>Yes</b>	<b>No</b>
<b>Margin of error <math>\leq</math> 5%</b>		
<b>MO</b>	98.9	1.1
<b>TX</b>	98.4	1.6
<b>WA</b>	94.7	5.3
<b>Margin of error <math>&gt;</math> 5%</b>		
<b>AZ</b>	99.1	0.9
<b>LA</b>	97.3	2.7
<b>SC</b>	96.7	3.3
<b>Total N</b>	<b>2,310</b>	<b>57</b>
<b>Total %</b>	<b>97.6</b>	<b>2.4</b>
<b>State Avg %</b>	<b>97.5</b>	<b>2.5</b>

## Health of Respondent

<b>Table 14</b> <b>Health of Respondent (%)</b>				
<b>State</b>	<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>
<b>Margin of error ≤ 5%</b>				
<b>MO</b>	20.1	54.7	20.3	4.9
<b>TX</b>	18.0	60.2	17.7	4.1
<b>WA</b>	23.4	47.6	24.4	4.5
<b>Margin of error &gt; 5%</b>				
<b>AZ</b>	28.4	52.2	16.8	2.6
<b>LA</b>	27.9	49.8	17.6	4.7
<b>SC</b>	27.7	49.4	20.7	2.2
<b>Total N</b>	<b>538</b>	<b>1,282</b>	<b>463</b>	<b>95</b>
<b>Total %</b>	<b>22.6</b>	<b>53.9</b>	<b>19.5</b>	<b>4.0</b>
<b>State Avg %</b>	<b>24.3</b>	<b>52.3</b>	<b>19.6</b>	<b>3.8</b>

## Household Income

<b>Table 15</b> <b>Household Income (%)</b>					
<b>State</b>	<b>Below \$15,000</b>	<b>\$15,001 - \$25,000</b>	<b>\$25,001 - \$50,000</b>	<b>\$50,001 - \$75,000</b>	<b>Over \$75,000</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>	23.2	14.2	28.2	20.4	13.9
<b>TX*</b>					
<b>WA</b>	23.6	15.4	20.1	24.5	16.5
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>	24.5	19.0	23.1	16.7	16.7
<b>LA</b>	39.1	16.1	15.1	13.3	16.5
<b>SC</b>	39.5	17.2	18.8	11.9	12.6
<b>Total N</b>	<b>426</b>	<b>233</b>	<b>305</b>	<b>259</b>	<b>220</b>
<b>Total %</b>	<b>29.5</b>	<b>16.1</b>	<b>21.1</b>	<b>17.9</b>	<b>15.2</b>
<b>State Avg %</b>	<b>30.0</b>	<b>16.4</b>	<b>21.1</b>	<b>17.4</b>	<b>15.2</b>

\*TX did not collect household income information

## Services and Supports Received

- ◆ Across participating states, on average, specialized services and supports were most often utilized (75%) by families having a child with disabilities.
- ◆ Additionally, 57% obtained in-home supports, 31% used out-of-home respite, 45% received SSI financial support, and 23% 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>Margin of error ≤ 5%</b>							
<b>MO</b>	37.3	26.1	43.9	22.5	12.9	9.2	76.2
<b>TX</b>	61.6	19.2	82.1	36.8	6.0	18.4	67.5
<b>WA</b>	41.0	32.0	60.4	69.2 <sup>1</sup>	3.6 <sup>2</sup>	16.4	63.0
<b>Margin of error &gt; 5%</b>							
<b>AZ</b>	37.6	8.4	53.6	27.2	31.9	13.0	88.6
<b>LA</b>	45.7	33.0	60.7	16.4	27.1	12.1	72.2
<b>SC</b>	44.4	20.2	41.9	16.5	46.5	10.0	81.3
<b>Total N</b>	<b>1,122</b>	<b>510</b>	<b>1,441</b>	<b>790</b>	<b>360</b>	<b>332</b>	<b>1,672</b>
<b>Total %</b>	<b>48.2</b>	<b>23.1</b>	<b>62.6</b>	<b>34.4</b>	<b>16.8</b>	<b>14.4</b>	<b>72.3</b>
<b>State Avg %</b>	<b>44.6</b>	<b>23.2</b>	<b>57.1</b>	<b>31.4</b>	<b>21.3</b>	<b>13.2</b>	<b>74.8</b>

<sup>1</sup> WA uses a slightly different definition of “Out of Home Respite Care”- someone takes care of your child with a disability either at your home or elsewhere to give your family a break

<sup>2</sup> WA uses a slightly different definition of “Early Intervention”- your child is under age 3 and receives services to enhance his/her development

## 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.

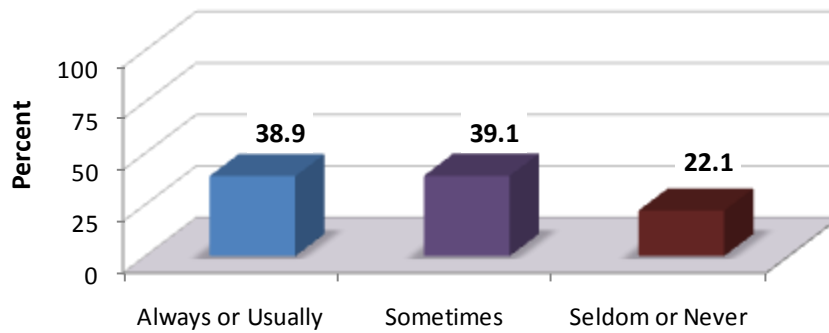
- ◆ The Figure illustrates the State Average results (i.e., the average percentage across the seven states that conducted this survey).
- ◆ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state 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, 39% of respondents indicated they regularly receive information about the services and supports available to them.
- Among those who receive information, 57% found the information easy to understand, while the remaining 44% 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, 62% found it easy to understand.
- Forty-eight percent (48%) of respondents stated they got enough information to help them participate in planning. A larger percentage (52%) indicated they only sometimes, seldom, or never had enough information.
- Three-quarters (75%) of respondents, on average across states, indicated that they typically help in developing their family member's service plan. These results varied from 69% in Texas to 85% in Missouri.
- Of those families with a service plan, 73% stated that the plan included things important to the respondent. Twenty-seven percent (27%) of respondents indicated that the plan sometimes, seldom or never included things important to them.
- Across states, over half (59%) indicated that planning staff would help them figure out the supports they needed. However, a large percentage (41%) stated that this was only sometimes, seldom, or never the case.
- Across states, over three-quarters (78%) of respondents felt that their choices and opinions were respected by staff.
- Only 38% of respondents indicated that planning staff discussed with them the public benefits that may or may not be available to them. Another 23% sometimes received this information, while 40% indicated that planning staff seldom or never relayed this information to them.
- Among all respondents, 85% felt that agency staff were generally respectful and courteous.
- Among all respondents, 65% felt that agency staff were generally effective.
- Across all states, 73% 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?

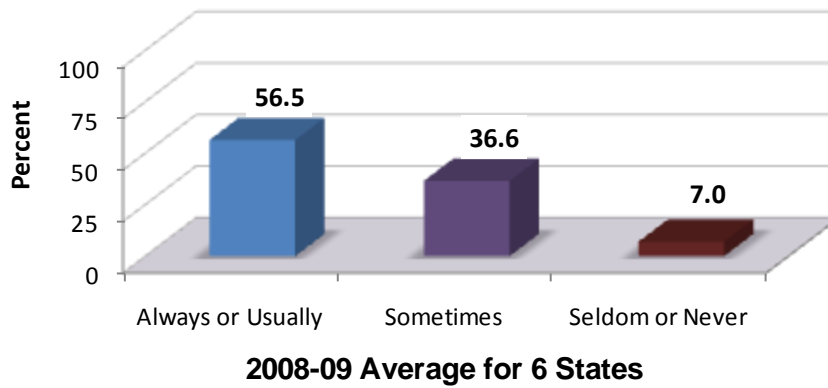


**2008-09 Average for 6 States**

<b>Table Q1</b>					
<b>Do you receive information about the services and supports that are available to your child and family? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		39.3	38.2	22.5	356
<b>TX</b>		34.8	39.4	25.9	800
<b>WA</b>		37.1	37.1	25.7	385
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		34.5	47.6	17.9	229
<b>LA</b>	↑	44.6	37.4	18.0	289
<b>SC</b>		42.8	34.6	22.6	257
<b>Total %</b>		<b>38.0</b>	<b>38.9</b>	<b>23.2</b>	<b>2,316</b>
<b>State Avg %</b>		<b>38.9</b>	<b>39.1</b>	<b>22.1</b>	



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



<b>Table Q2</b>					
<b>If you receive information, is it easy to understand? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		56.1	36.5	7.4	326
TX	↓↓	45.0	46.1	9.0	723
WA		55.1	38.9	6.0	350
<b>Margin of error &gt; 5%</b>					
AZ		55.7	38.1	6.2	210
LA	↑	61.9	30.0	8.1	270
SC	↑	64.9	29.9	5.2	231
<b>Total %</b>		<b>53.8</b>	<b>38.8</b>	<b>7.4</b>	<b>2,110</b>
<b>State Avg %</b>		<b>56.5</b>	<b>36.6</b>	<b>7.0</b>	

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

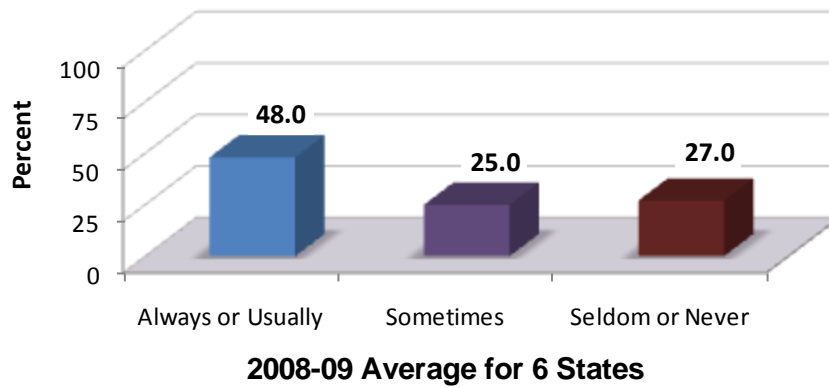
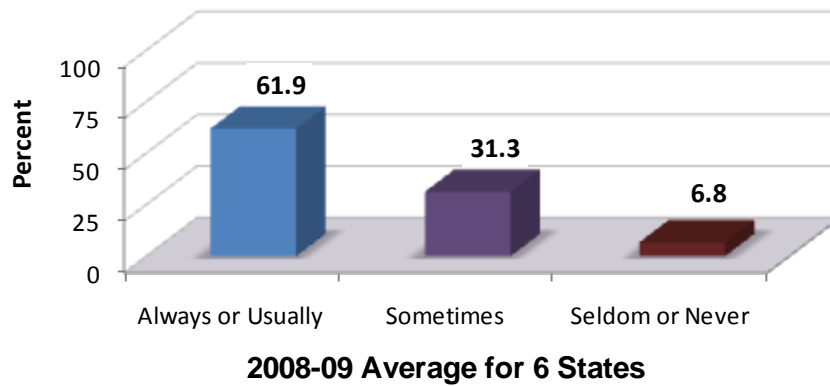


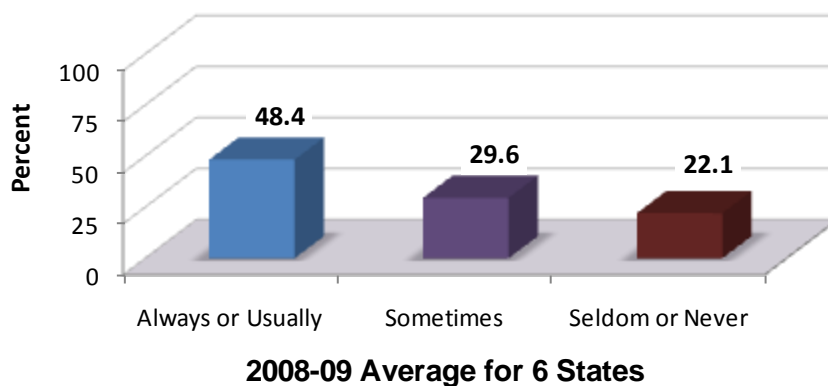
Table Q3 Do you receive information about the status of your child's development? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		48.1	24.2	27.6	322
TX	↓	40.6	26.7	32.7	741
WA	↓↓	35.9	25.1	39.1	343
<b>Margin of error &gt; 5%</b>					
AZ		45.4	29.5	25.1	227
LA	↑↑	59.2	20.2	20.6	277
SC	↑↑	58.9	24.1	17.0	253
<b>Total %</b>		<b>46.0</b>	<b>25.2</b>	<b>28.8</b>	<b>2,163</b>
<b>State Avg %</b>		<b>48.0</b>	<b>25.0</b>	<b>27.0</b>	

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



<b>Table Q4</b>					
<b>If yes, is this information easy to understand? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		66.4	27.4	6.2	259
<b>TX</b>	↓	54.0	37.5	8.5	568
<b>WA</b>	↓	55.5	34.3	10.2	254
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		59.2	34.2	6.5	184
<b>LA</b>	↑	70.0	26.6	3.4	233
<b>SC</b>		66.5	27.8	5.7	227
<b>Total %</b>		<b>60.5</b>	<b>32.4</b>	<b>7.1</b>	<b>1,725</b>
<b>State Avg %</b>		<b>61.9</b>	<b>31.3</b>	<b>6.8</b>	

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



<b>Table Q5</b>					
<b>Do you get enough information to help you participate in planning services for your family? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO	↑	55.8	25.7	18.6	339
TX	↓	39.7	35.0	25.3	760
WA	↓	41.1	33.0	25.9	348
<b>Margin of error &gt; 5%</b>					
AZ	↓	42.3	34.7	23.0	213
LA	↑	55.0	24.4	20.7	271
SC	↑	56.2	24.9	18.9	249
<b>Total %</b>		<b>46.5</b>	<b>30.7</b>	<b>22.8</b>	<b>2,180</b>
<b>State Avg %</b>		<b>48.4</b>	<b>29.6</b>	<b>22.1</b>	

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

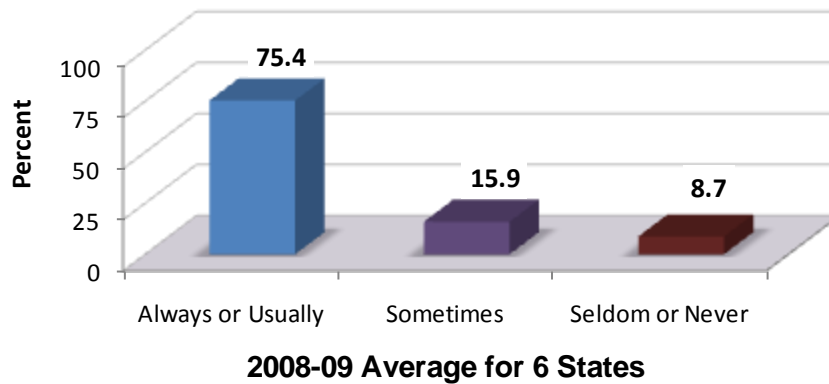
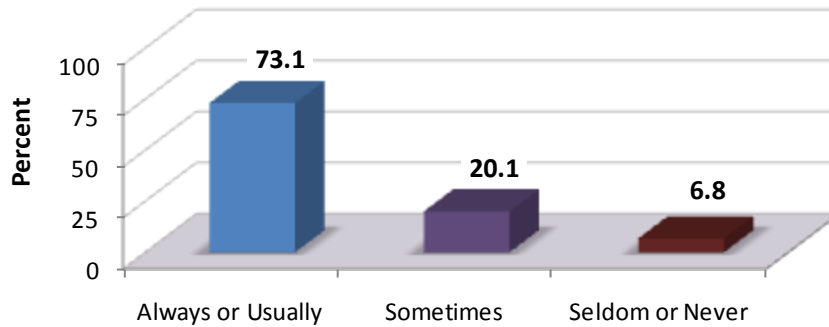


Table Q6 If your family member has a service plan, did you help develop the plan? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO	↑↑	85.4	10.9	3.6	329
TX	↓	69.4	20.2	10.4	644
WA	↓	68.6	20.3	11.1	261
<b>Margin of error &gt; 5%</b>					
AZ		73.8	17.3	8.9	191
LA		77.0	13.5	9.6	230
SC		77.9	13.4	8.8	217
<b>Total %</b>		<b>74.5</b>	<b>16.7</b>	<b>8.9</b>	<b>1,872</b>
<b>State Avg %</b>		<b>75.4</b>	<b>15.9</b>	<b>8.7</b>	

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



**2008-09 Average for 6 States**

<b>Table Q7</b>					
<b>If your family member has a service plan, does the plan include things that are important to you? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO	↑	79.9	16.7	3.3	329
TX		69.5	23.3	7.1	630
WA	↓	63.2	26.3	10.5	266
<b>Margin of error &gt; 5%</b>					
AZ		72.5	21.7	5.8	189
LA	↑	79.7	14.7	5.6	231
SC		73.8	17.6	8.6	221
<b>Total %</b>		<b>72.5</b>	<b>20.7</b>	<b>6.8</b>	<b>1,866</b>
<b>State Avg %</b>		<b>73.1</b>	<b>20.1</b>	<b>6.8</b>	

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

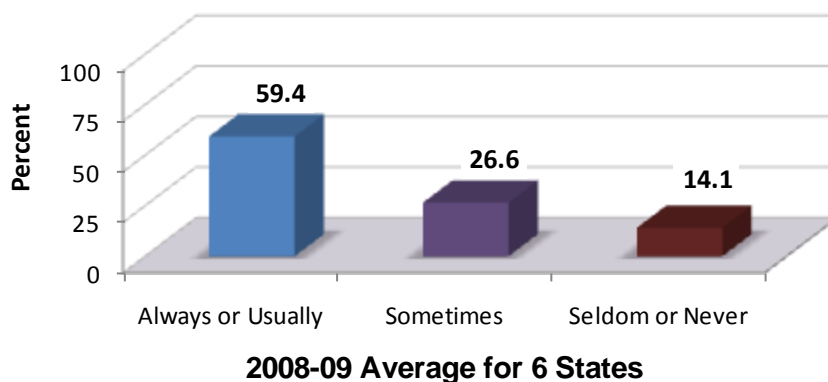
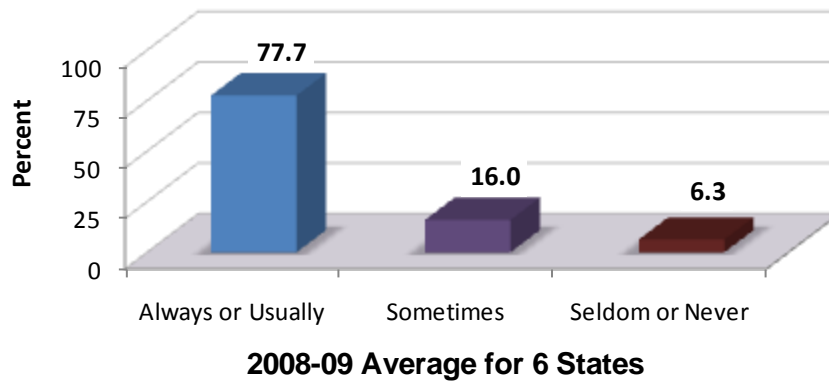


Table Q8 Do the staff who assist you with planning help you figure out what you need as a family to support your child? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		62.3	25.5	12.2	337
TX	↓	52.0	33.0	15.0	687
WA	↓	54.0	26.8	19.2	302
<b>Margin of error &gt; 5%</b>					
AZ	↓	50.0	32.9	17.1	210
LA	↑	68.1	22.3	9.6	260
SC	↑↑	69.7	18.8	11.5	234
<b>Total %</b>		<b>57.9</b>	<b>27.8</b>	<b>14.3</b>	<b>2,030</b>
<b>State Avg %</b>		<b>59.4</b>	<b>26.6</b>	<b>14.1</b>	

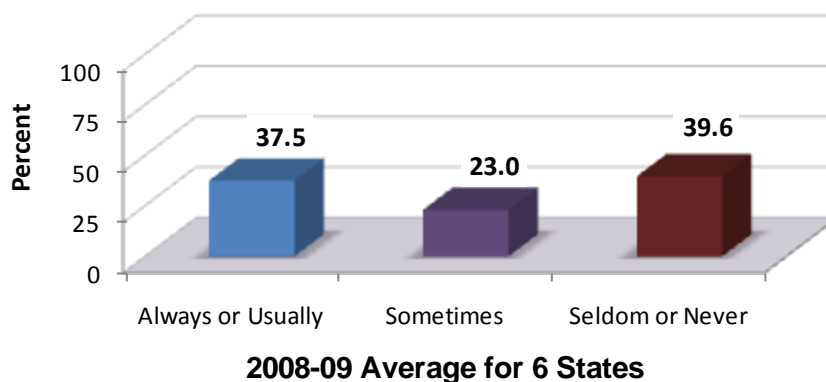
**Chart Q9 Do the staff who assist you with planning respect your choices and opinions?**



<b>Table Q9</b>					
<b>Do the staff who assist you with planning respect your choices and opinions? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		79.7	15.3	5.0	340
TX		74.5	17.9	7.6	671
WA		76.8	13.4	9.7	298
<b>Margin of error &gt; 5%</b>					
AZ	↓	72.7	21.0	6.3	205
LA		81.8	14.0	4.3	258
SC		80.4	14.6	5.0	240
<b>Total %</b>		<b>77.2</b>	<b>16.2</b>	<b>6.6</b>	<b>2,012</b>
<b>State Avg %</b>		<b>77.7</b>	<b>16.0</b>	<b>6.3</b>	

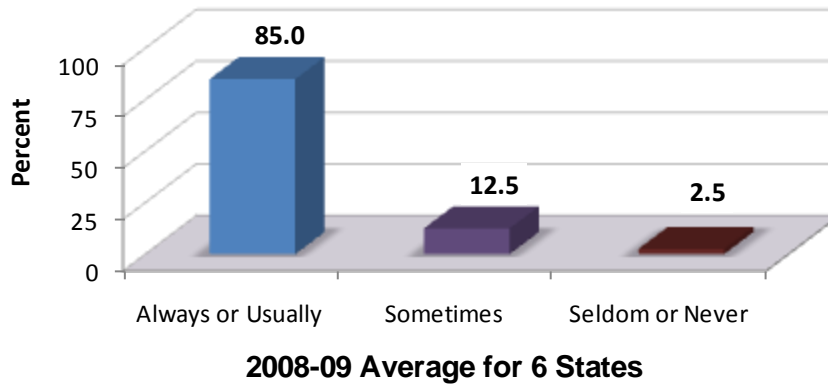


**Chart Q10** Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)?



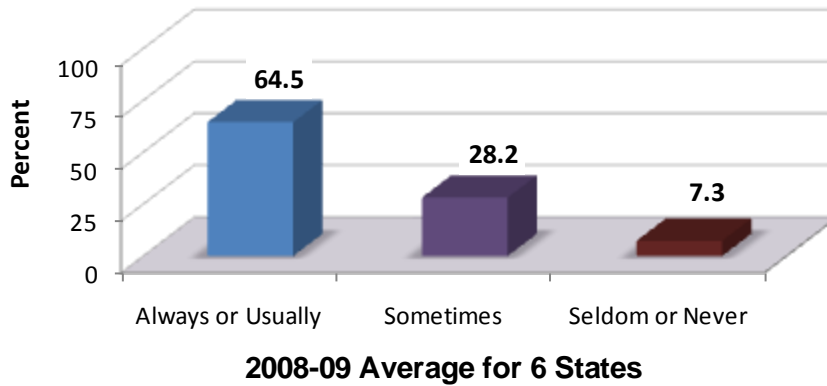
<b>Table Q10</b>					
Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		39.9	23.7	36.4	308
TX		37.2	24.3	38.5	732
WA	↓	31.2	26.0	42.8	327
<b>Margin of error &gt; 5%</b>					
AZ	↓↓	26.4	22.4	51.2	201
LA		42.2	20.9	36.9	263
SC	↑↑	47.9	20.5	31.6	234
<b>Total %</b>		<b>37.4</b>	<b>23.4</b>	<b>39.1</b>	<b>2,065</b>
<b>State Avg %</b>		<b>37.5</b>	<b>23.0</b>	<b>39.6</b>	

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



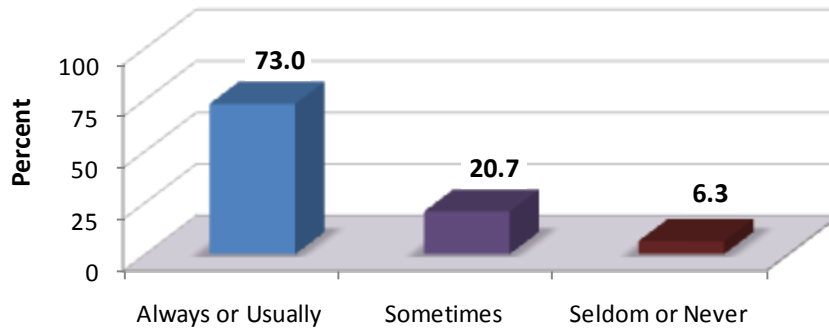
<b>Table Q11</b>					
<b>Are the staff who assist you with planning generally respectful and courteous? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		87.3	11.3	1.4	346
<b>TX</b>		80.8	16.1	3.1	741
<b>WA</b>		86.3	11.4	2.3	351
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		83.0	15.1	1.9	212
<b>LA</b>		86.0	11.0	2.9	272
<b>SC</b>		86.5	10.2	3.3	245
<b>Total %</b>		<b>84.3</b>	<b>13.2</b>	<b>2.6</b>	<b>2,167</b>
<b>State Avg %</b>		<b>85.0</b>	<b>12.5</b>	<b>2.5</b>	

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



<b>Table Q12</b>					
<b>Are the staff who assist you with planning generally effective? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		65.1	28.2	6.7	344
<b>TX</b>	↓	58.2	32.7	9.1	725
<b>WA</b>		63.3	28.3	8.4	332
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>	↓	58.3	33.0	8.7	206
<b>LA</b>	↑	69.6	24.1	6.3	270
<b>SC</b>	↑	72.7	22.7	4.5	242
<b>Total %</b>		<b>63.2</b>	<b>29.1</b>	<b>7.7</b>	<b>2,119</b>
<b>State Avg %</b>		<b>64.5</b>	<b>28.2</b>	<b>7.3</b>	

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



**2008-09 Average for 6 States**

<b>Table Q13</b>					
<b>Can you contact the staff who assist you with planning whenever you want to? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		77.2	17.5	5.3	342
<b>TX</b>	↓	67.7	23.5	8.8	731
<b>WA</b>		71.0	21.5	7.6	331
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>	↓	63.8	29.1	7.0	213
<b>LA</b>	↑	80.7	15.2	4.1	270
<b>SC</b>		77.6	17.4	5.0	241
<b>Total %</b>		<b>72.1</b>	<b>21.1</b>	<b>6.8</b>	<b>2,128</b>
<b>State Avg %</b>		<b>73.0</b>	<b>20.7</b>	<b>6.3</b>	

## Access to and Delivery of Services and Supports

- Overall, 70% of families stated their service coordinator helped them get needed supports when asked. Twenty-four percent (24%) said this happened sometimes, and 6% indicated that their service coordinator was rarely helpful in getting the assistance needed.
- Just over half of families (55%) said they always or usually get the services and supports needed. Thirty-five percent (35%) got needed supports some of the time, and the remaining 10% seldom or never received needed supports.
- Fifty-three percent (53%) of respondents said that the supports received met their families' needs, although this varied from state to state. Another 36% said that the supports sometimes met their needs, while the remaining 11% seldom or never felt the supports offered met their family's needs.
- For less than half of families (48%), supports were always or usually available when needed. More families indicated that supports were only sometimes available (38%), or seldom/never available (15%) when needed.
- Forty-five percent (45%) 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 35% indicated that the state agency or provider agency was usually or always responsive to these requests.
- Over half (54%) 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 (67%) indicated that staff or translators were available to speak with them in their preferred languages. Nineteen percent (19%) indicated that staff/translators were sometimes available, and the remaining 13% 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), 44% of families said there were enough support staff regularly available who could communicate with their child. The remaining 56%, however, said capable staff were only sometimes, seldom or never available.
- Fifty-seven percent (57%) of respondents felt their child had access to the special equipment or accommodations needed.
- The vast majority of respondents (91%) felt that they had access to health services for their child.
- Slightly fewer families (86%) 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 (86%) 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?

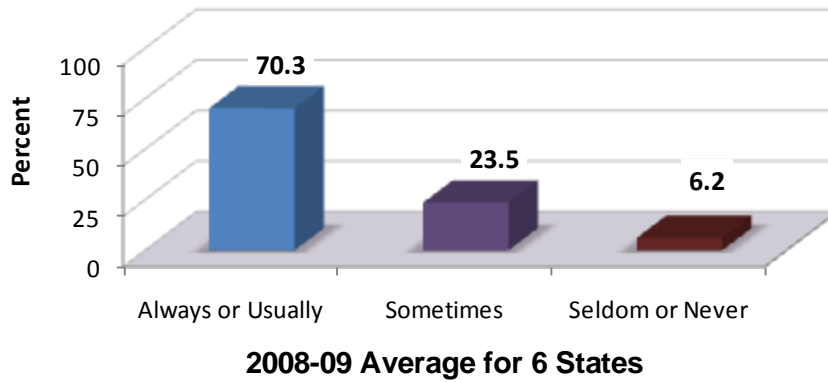


Table Q14					
When you ask the service/support coordinator for assistance, does he/she help you get what you need? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		71.7	22.0	6.3	350
TX	↓	64.4	29.2	6.4	767
WA		71.6	23.4	5.0	380
<b>Margin of error &gt; 5%</b>					
AZ	↓	63.0	28.2	8.8	227
LA	↑	75.5	19.3	5.1	274
SC	↑	75.5	19.1	5.4	241
<b>Total %</b>		<b>69.2</b>	<b>24.7</b>	<b>6.1</b>	<b>2,239</b>
<b>State Avg %</b>		<b>70.3</b>	<b>23.5</b>	<b>6.2</b>	

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

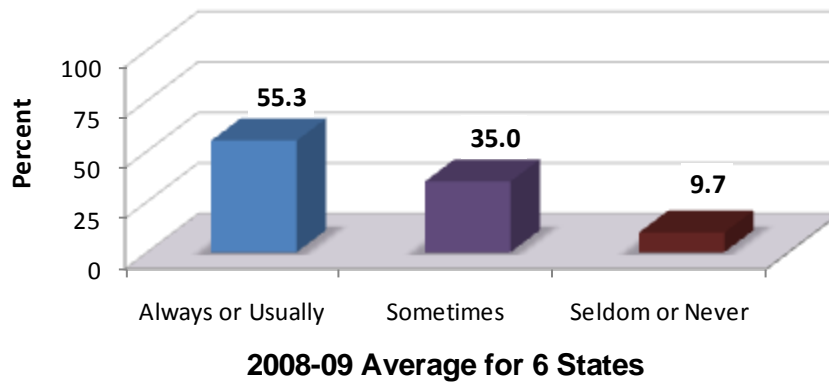
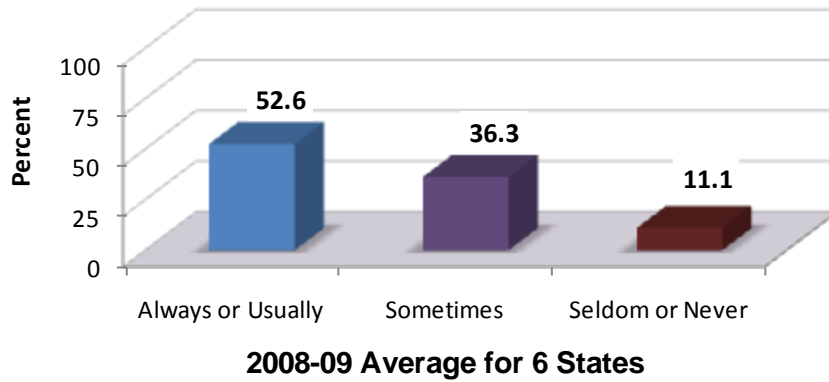


Table Q15 Does your family get the services and supports you need? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		55.0	34.5	10.5	342
TX		51.5	37.4	11.1	778
WA	↓↓	43.9	47.8	8.3	387
<b>Margin of error &gt; 5%</b>					
AZ		51.1	39.5	9.4	223
LA	↑↑	65.6	25.8	8.6	279
SC	↑	64.4	25.2	10.4	250
<b>Total %</b>		<b>53.9</b>	<b>36.2</b>	<b>10.0</b>	<b>2,259</b>
<b>State Avg %</b>		<b>55.3</b>	<b>35.0</b>	<b>9.7</b>	

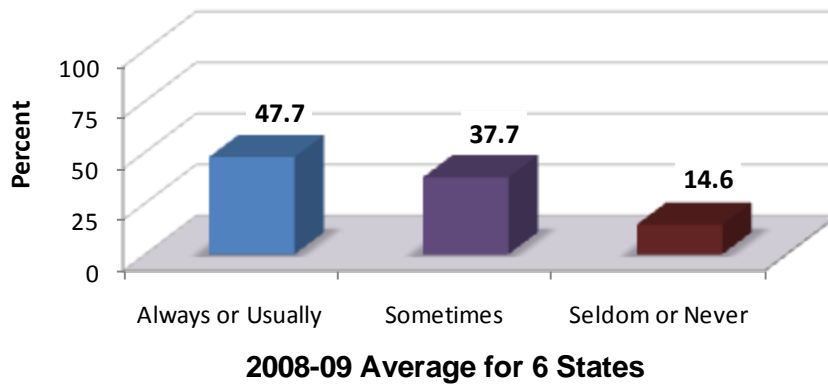
**Chart Q16 Do the services and supports offered meet your family's needs?**



<b>Table Q16</b>					
<b>Do the services and supports offered meet your family's needs? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		52.6	36.9	10.5	352
<b>TX</b>		49.4	40.0	10.6	777
<b>WA</b>	↓↓	38.4	46.5	15.1	385
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		49.3	38.8	11.9	219
<b>LA</b>	↑↑	63.6	27.6	8.7	286
<b>SC</b>	↑	62.4	28.0	9.6	250
<b>Total %</b>		<b>51.3</b>	<b>37.6</b>	<b>11.1</b>	<b>2,269</b>
<b>State Avg %</b>		<b>52.6</b>	<b>36.3</b>	<b>11.1</b>	

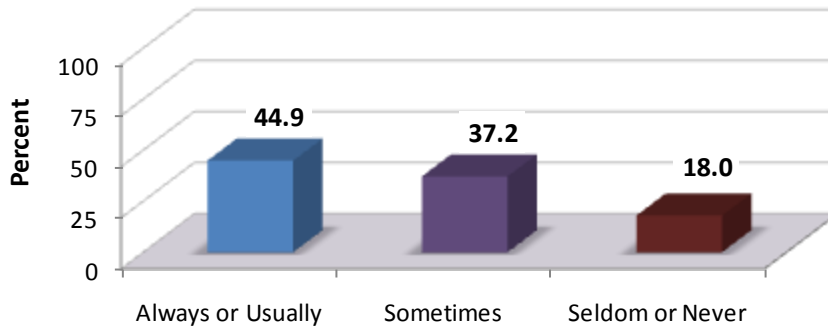


**Chart Q17 Are supports available when your family needs them?**



<b>Table Q17</b>					
<b>Are supports available when your family needs them? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		46.9	38.2	14.9	343
<b>TX</b>		43.8	40.8	15.3	764
<b>WA</b>	↓↓	37.6	46.7	15.7	364
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>	↓	39.8	42.2	18.0	211
<b>LA</b>	↑↑	58.1	31.6	10.3	272
<b>SC</b>	↑↑	59.9	26.9	13.2	242
<b>Total %</b>		<b>46.4</b>	<b>38.8</b>	<b>14.7</b>	<b>2,196</b>
<b>State Avg %</b>		<b>47.7</b>	<b>37.7</b>	<b>14.6</b>	

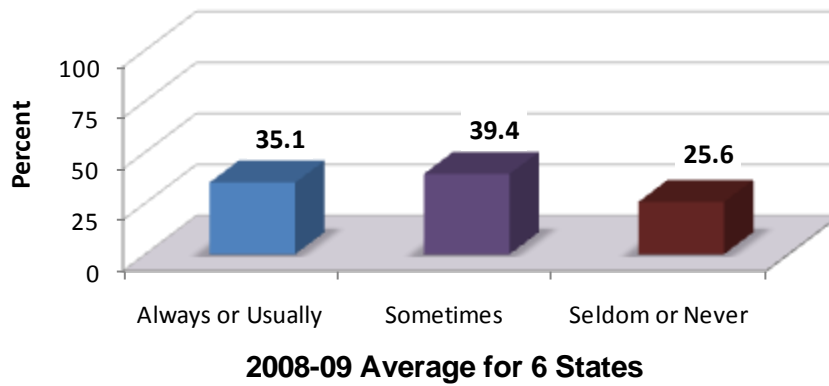
**Chart Q18 Do families in your area request that different types of services and supports be made available in your area?**



**2008-09 Average for 6 States**

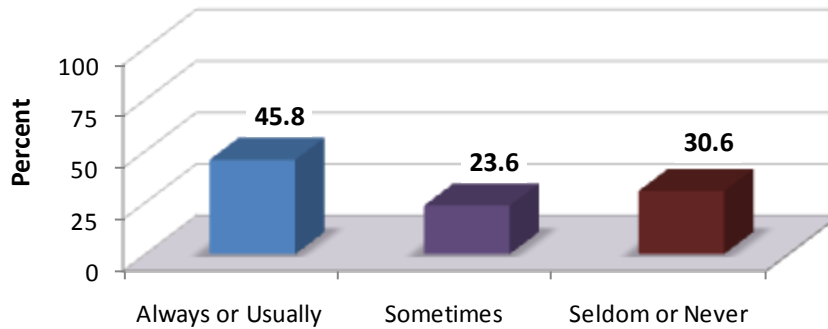
<b>Table Q18</b>					
<b>Do families in your area request that different types of services and supports be made available in your area? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		40.0	47.1	12.9	155
<b>TX</b>		43.5	36.6	19.9	361
<b>WA</b>		40.1	43.3	16.6	157
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		47.7	35.5	16.8	107
<b>LA</b>		45.7	32.6	21.7	129
<b>SC</b>		52.3	27.9	19.8	111
<b>Total %</b>		<b>44.1</b>	<b>37.6</b>	<b>18.2</b>	<b>1,020</b>
<b>State Avg %</b>		<b>44.9</b>	<b>37.2</b>	<b>18.0</b>	

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



<b>Table Q19</b>					
<b>If yes, does either the state agency or provider agency respond to their requests? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>	↓↓	23.3	48.1	28.7	129
<b>TX</b>		34.2	40.1	25.7	292
<b>WA</b>	↓↓	23.5	40.9	35.7	115
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>	↓	27.5	46.3	26.3	80
<b>LA</b>	↑↑	52.0	34.3	13.7	102
<b>SC</b>	↑↑	50.0	26.5	23.5	98
<b>Total %</b>		<b>34.4</b>	<b>39.7</b>	<b>25.9</b>	<b>816</b>
<b>State Avg %</b>		<b>35.1</b>	<b>39.4</b>	<b>25.6</b>	

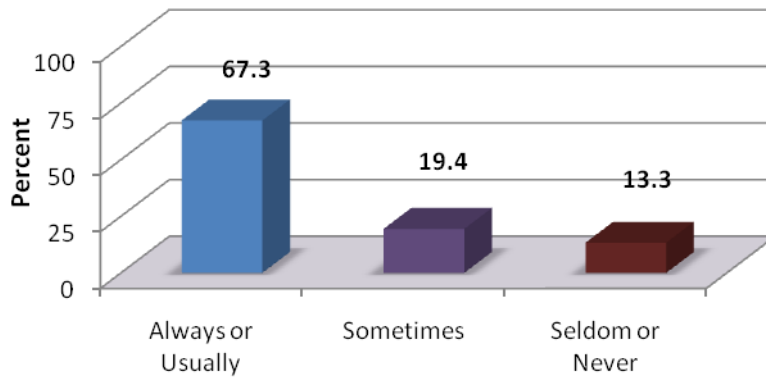
**Chart Q20** If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?



**2008-09 Average for 6 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
<b>Margin of error ≤ 5%</b>					
MO	↑	53.4	21.5	25.2	163
TX	↓	37.3	23.4	39.3	389
WA		42.0	26.0	32.0	181
<b>Margin of error &gt; 5%</b>					
AZ	↓	38.9	27.8	33.3	90
LA		50.0	21.1	28.9	142
SC	↑	53.4	21.6	25.0	116
<b>Total %</b>		<b>44.0</b>	<b>23.4</b>	<b>32.6</b>	<b>1,081</b>
<b>State Avg %</b>		<b>45.8</b>	<b>23.6</b>	<b>30.6</b>	

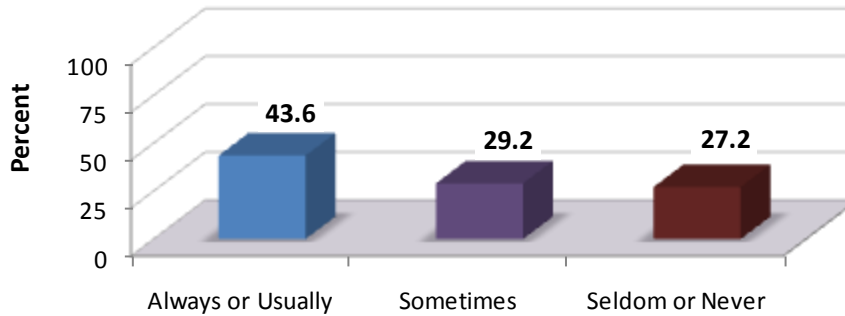
**Chart Q21 If English is not your first language, are there support workers or translators available to speak with you in your preferred language?**



**2008-09 Average for 6 States**

<b>Table Q21</b>					
<b>If English is not your first language, are there support workers or translators available to speak with you in your preferred language? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>	↓↓	54.5	22.7	22.7	22
<b>TX</b>		69.4	21.4	9.2	206
<b>WA</b>		67.2	19.0	13.8	58
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		66.7	29.6	3.7	54
<b>LA</b>		70.6	17.6	11.8	34
<b>SC</b>	↑	75.5	6.1	18.4	49
<b>Total %</b>		<b>68.8</b>	<b>20.1</b>	<b>11.1</b>	<b>423</b>
<b>State Avg %</b>		<b>67.3</b>	<b>19.4</b>	<b>13.3</b>	

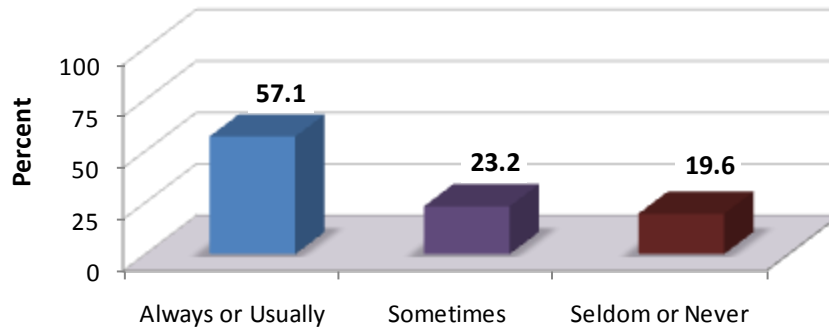
**Chart Q22** If your child does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?



**2008-09 Average for 6 States**

<b>Table Q22</b>					
<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? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>	↓↓	31.1	29.5	39.3	61
<b>TX</b>		40.5	28.2	31.3	227
<b>WA</b>	↓	36.0	33.3	30.7	75
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>	↓↓	31.4	48.6	20.0	70
<b>LA</b>	↑↑	58.1	17.7	24.2	62
<b>SC</b>	↑↑	64.7	17.6	17.6	68
<b>Total %</b>		<b>42.6</b>	<b>29.1</b>	<b>28.2</b>	<b>563</b>
<b>State Avg %</b>		<b>43.6</b>	<b>29.2</b>	<b>27.2</b>	

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



**2008-09 Average for 6 States**

<b>Table Q23</b>					
<b>Does your child have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		59.0	25.7	15.2	210
TX		58.1	26.3	15.6	589
WA	↓↓	45.2	31.6	23.2	228
<b>Margin of error &gt; 5%</b>					
AZ		54.8	25.0	20.2	104
LA	↑	64.2	12.4	23.4	137
SC		61.4	18.4	20.2	114
<b>Total %</b>		<b>56.7</b>	<b>25.0</b>	<b>18.3</b>	<b>1,382</b>
<b>State Avg %</b>		<b>57.1</b>	<b>23.2</b>	<b>19.6</b>	

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

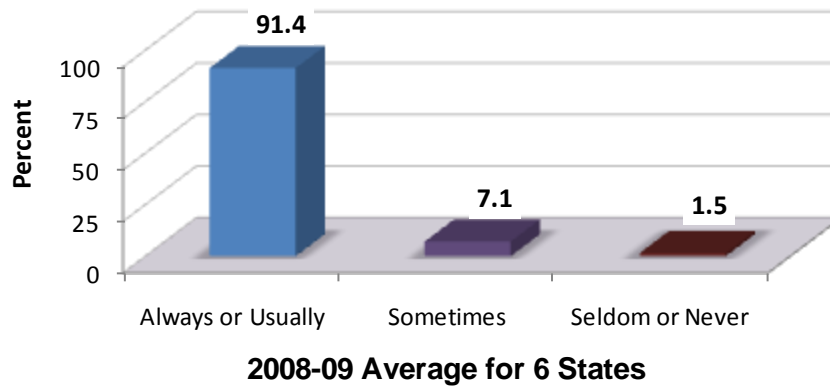
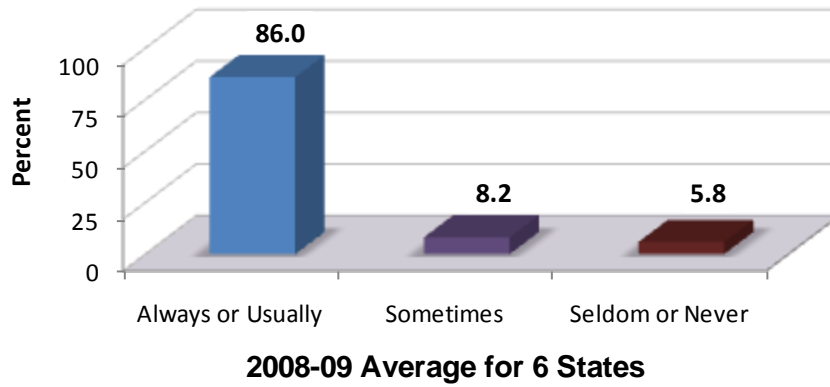


Table Q24 Do you have access to health services for your child? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of error $\leq$ 5%					
MO		90.8	7.0	2.2	357
TX		91.1	7.2	1.7	806
WA		91.1	7.6	1.3	384
Margin of error > 5%					
AZ		92.1	7.0	0.9	229
LA		92.4	6.9	0.7	290
SC		90.7	7.0	2.3	258
<b>Total %</b>		<b>91.3</b>	<b>7.1</b>	<b>1.6</b>	<b>2,324</b>
<b>State Avg %</b>		<b>91.4</b>	<b>7.1</b>	<b>1.5</b>	

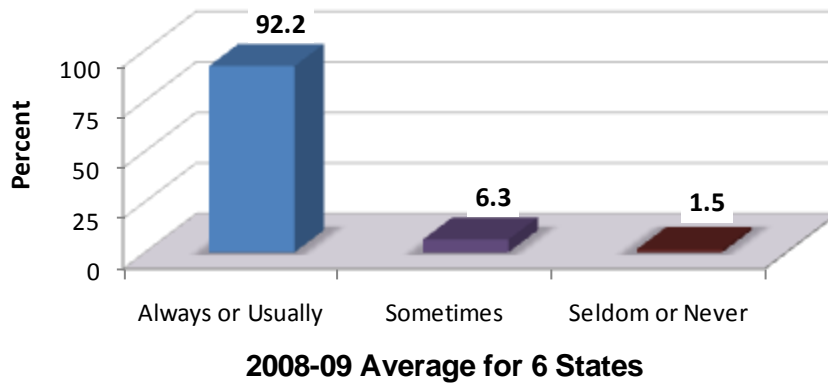


**Chart Q25 Do you have access to dental services for your child?**



<b>Table Q25</b>					
<b>Do you have access to dental services for your child? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>	↓	76.3	14.0	9.7	350
<b>TX</b>		89.6	6.7	3.6	801
<b>WA</b>		88.1	8.1	3.8	396
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		86.4	7.0	6.5	214
<b>LA</b>		86.2	6.5	7.3	275
<b>SC</b>		89.2	6.8	4.0	250
<b>Total %</b>		<b>86.6</b>	<b>8.1</b>	<b>5.3</b>	<b>2,286</b>
<b>State Avg %</b>		<b>86.0</b>	<b>8.2</b>	<b>5.8</b>	

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



<b>Table Q26</b>					
<b>Do you have access to necessary medications for your child?</b>					
<b>(%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		93.4	5.2	1.4	347
<b>TX</b>		94.4	5.1	0.5	801
<b>WA</b>		90.2	7.0	2.8	387
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		90.4	8.2	1.4	208
<b>LA</b>		95.4	3.9	0.7	284
<b>SC</b>		89.5	8.5	2.0	248
<b>Total %</b>		<b>92.7</b>	<b>5.9</b>	<b>1.3</b>	<b>2,275</b>
<b>State Avg %</b>		<b>92.2</b>	<b>6.3</b>	<b>1.5</b>	

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

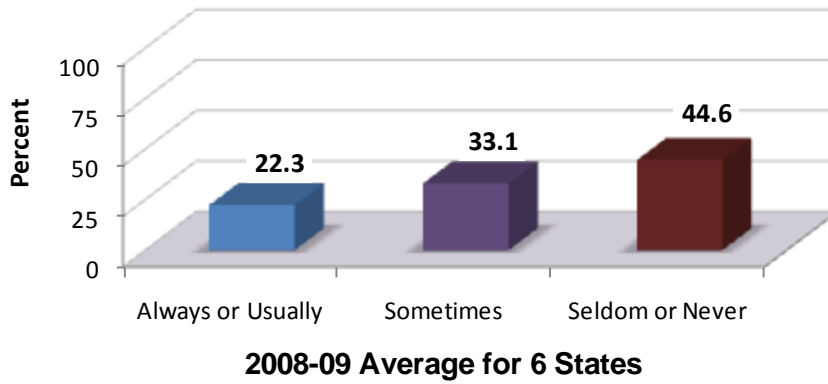
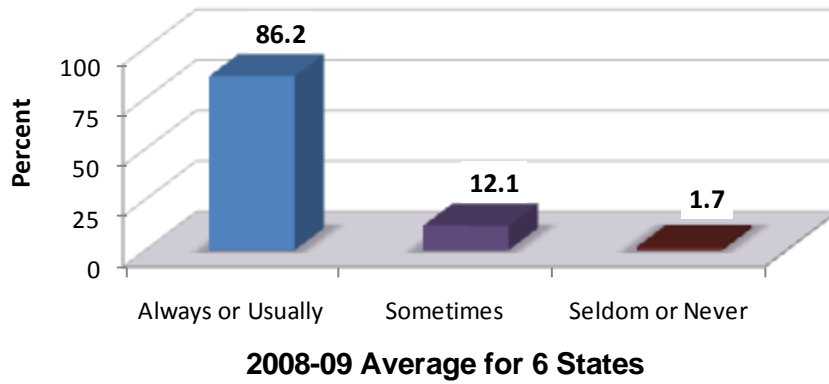


Table Q27					
Are frequent changes in support staff a problem for your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of error $\leq$ 5%					
MO	↑	17.2	39.6	43.2	285
TX	↓	28.8	36.0	35.2	677
WA		21.1	35.5	43.4	265
Margin of error > 5%					
AZ		21.3	38.3	40.4	188
LA		19.9	28.0	52.1	236
SC		25.7	21.0	53.3	214
<b>Total %</b>		<b>23.7</b>	<b>34.0</b>	<b>42.3</b>	<b>1,865</b>
<b>State Avg %</b>		<b>22.3</b>	<b>33.1</b>	<b>44.6</b>	

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



<b>Table Q28</b>					
<b>Are support staff generally respectful and courteous? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		84.7	14.0	1.3	314
<b>TX</b>		81.4	17.5	1.0	765
<b>WA</b>		90.9	7.8	1.3	319
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		85.2	13.9	0.9	223
<b>LA</b>		90.5	8.4	1.1	275
<b>SC</b>		84.3	11.2	4.4	249
<b>Total %</b>		<b>85.2</b>	<b>13.3</b>	<b>1.5</b>	<b>2,145</b>
<b>State Avg %</b>		<b>86.2</b>	<b>12.1</b>	<b>1.7</b>	

## Choice and Control

- Across the states, on average, 66% of respondents chose the agencies or providers who work with their families. There was great variation between the states.
- While 66% 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 (47%) had control or input over the hiring and management of their support staff, and an additional 17% 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 64% of respondents had at least some control over the hiring or management of their support workers, 86% wanted this type of control at least some of the time.
- Only 22% of respondents always or usually knew how much money was spent by the MR/DD agency on behalf of their family member. Sixty-eight percent (68%), 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, half of the families surveyed (50%), 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. Once again, results varied considerably from state to state.

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

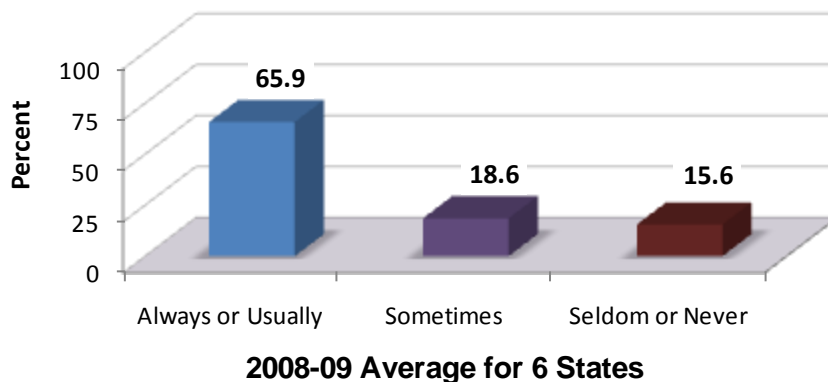


Table Q29 Do you choose the agencies or providers who work with your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO	↓	57.0	22.8	20.3	316
TX	↑↑	80.0	14.9	5.1	779
WA		69.7	18.2	12.1	346
<b>Margin of error &gt; 5%</b>					
AZ	↓↓	54.9	23.9	21.1	213
LA	↑↑	77.4	11.7	10.9	257
SC	↓	56.1	20.1	23.8	239
<b>Total %</b>		<b>69.5</b>	<b>17.7</b>	<b>12.8</b>	<b>2,150</b>
<b>State Avg %</b>		<b>65.9</b>	<b>18.6</b>	<b>15.6</b>	

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

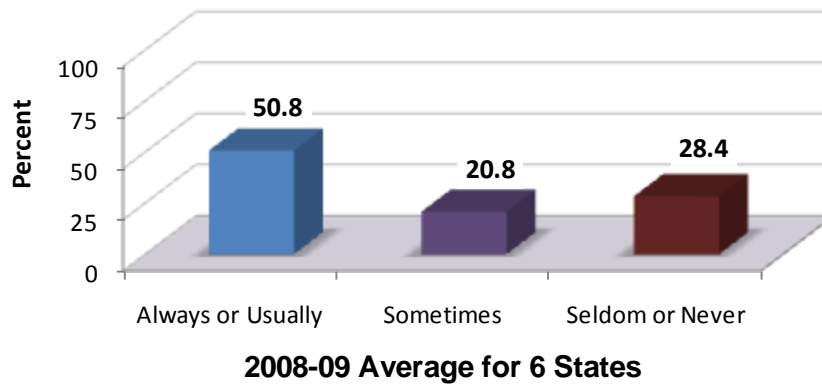


Table Q30 Do you choose the support workers who work with your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO	↓	40.9	23.0	36.1	291
TX	↑↑	65.6	20.8	13.6	744
WA		49.5	23.6	26.9	301
<b>Margin of error &gt; 5%</b>					
AZ	↓↓	40.1	22.2	37.7	212
LA	↑↑	66.7	13.0	20.3	246
SC	↓	41.7	22.4	36.0	228
<b>Total %</b>		<b>54.4</b>	<b>20.9</b>	<b>24.7</b>	<b>2,022</b>
<b>State Avg %</b>		<b>50.8</b>	<b>20.8</b>	<b>28.4</b>	

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

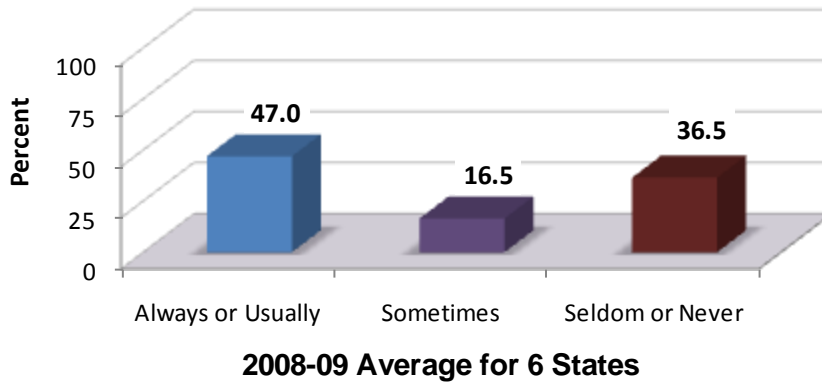
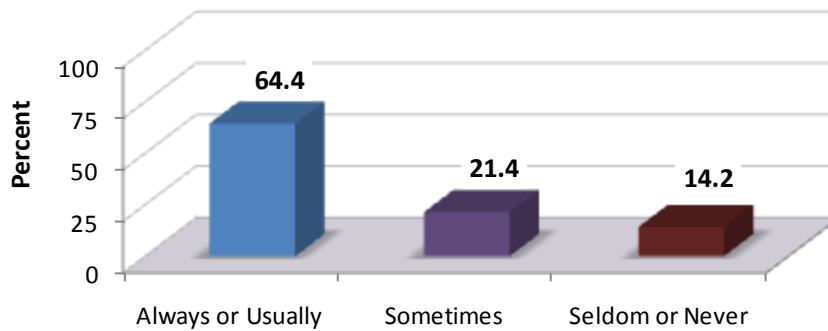


Table Q31 Do you have control and/or input over the hiring and management of your support workers? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO	↓	37.8	16.9	45.3	267
TX	↑↑	64.1	18.6	17.3	694
WA	↑↑	70.2	16.6	13.2	302
<b>Margin of error &gt; 5%</b>					
AZ	↓↓	32.0	17.7	50.3	181
LA		50.0	13.2	36.8	204
SC	↓↓	27.8	16.0	56.2	169
<b>Total %</b>		<b>53.1</b>	<b>17.1</b>	<b>29.8</b>	<b>1,817</b>
<b>State Avg %</b>		<b>47.0</b>	<b>16.5</b>	<b>36.5</b>	



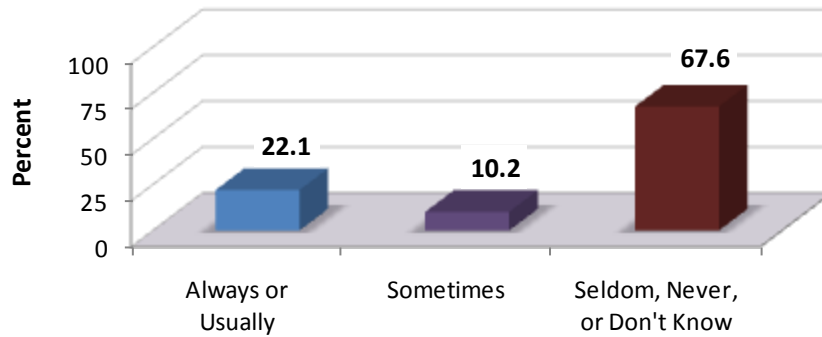
**Chart Q32 Do you want to have control and/or input over the hiring and management of your support workers?**



**2008-09 Average for 6 States**

<b>Table Q32</b>					
<b>Do you want to have control and/or input over the hiring and management of your support workers? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO	↓	56.6	24.5	18.9	249
TX	↑↑↑	77.2	17.7	5.1	662
WA	↑↑	79.9	16.1	4.0	299
<b>Margin of error &gt; 5%</b>					
AZ	↓	56.1	28.9	15.0	173
LA		68.4	16.7	14.9	215
SC	↓↓↓	48.3	24.4	27.2	180
<b>Total %</b>		<b>68.7</b>	<b>20.0</b>	<b>11.2</b>	<b>1,778</b>
<b>State Avg %</b>		<b>64.4</b>	<b>21.4</b>	<b>14.2</b>	

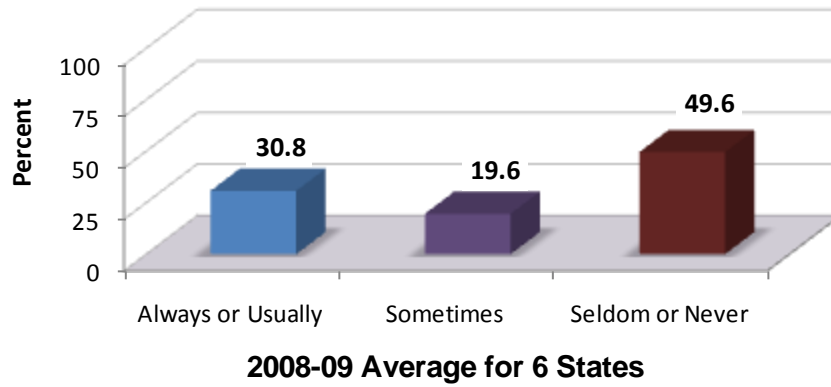
**Chart Q33 Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?**



**2008-09 Average for 6 States**

<b>Table Q33</b>					
<b>Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability? (%)</b>					
State		Always or Usually	Sometimes	Seldom, Never, or Don't Know	N
<b>Margin of error ≤ 5%</b>					
MO		19.5	8.8	71.7	328
TX	↑↑	35.2	14.4	50.3	772
WA	↑	28.0	13.5	58.5	378
<b>Margin of error &gt; 5%</b>					
AZ	↓↓	5.0	8.6	86.4	221
LA	↑	30.0	9.0	61.0	277
SC	↓	15.0	7.1	77.9	253
<b>Total %</b>		<b>25.8</b>	<b>11.4</b>	<b>62.9</b>	<b>2,229</b>
<b>State Avg %</b>		<b>22.1</b>	<b>10.2</b>	<b>67.6</b>	

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



<b>Table Q34</b>					
<b>Do you get to decide how this money is spent? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO	↑	35.8	23.1	41.0	229
TX	↑↑	47.4	27.7	24.8	584
WA	↑	39.4	26.5	34.1	264
<b>Margin of error &gt; 5%</b>					
AZ	↓↓	12.3	13.8	73.8	130
LA		34.7	10.4	54.9	173
SC	↓↓	15.0	16.3	68.7	147
<b>Total %</b>		<b>36.7</b>	<b>22.6</b>	<b>40.7</b>	<b>1,527</b>
<b>State Avg %</b>		<b>30.8</b>	<b>19.6</b>	<b>49.6</b>	

## Community Connections

- On average, only 27% 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 25% 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, 38% of respondents indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports, 23% said they sometimes received help in this area, and the 39% said it seldom or never happens.
- Only 38% 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 38% had regular access to community activities, only 21% of children regularly participated in them. Forty-three percent (43%) of respondents said that their child seldom or never participated in community activities or events.
- Just over half (57%) of respondents' children regularly spend time with children who do not have disabilities ~ which leaves 43% who only spend some or little to no time with children without disabilities.

**Chart Q35** If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?

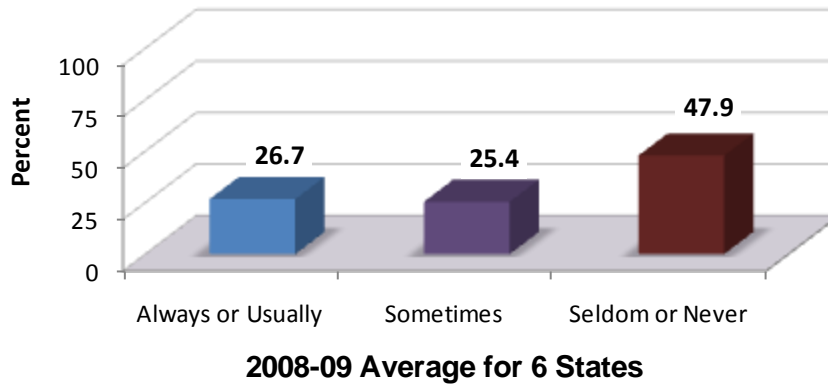
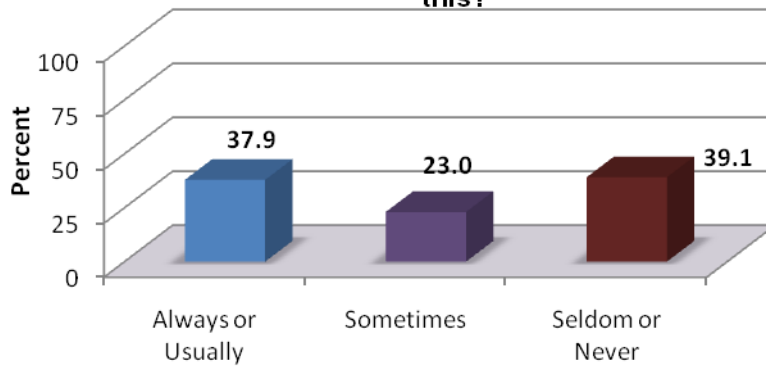


Table Q35					
If you want to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		30.1	27.0	43.0	256
TX		24.3	28.0	47.7	514
WA	↓	21.3	26.0	52.7	277
<b>Margin of error &gt; 5%</b>					
AZ		25.0	25.0	50.0	148
LA		27.2	23.7	49.1	169
SC	↑	32.5	22.9	44.6	166
<b>Total %</b>		<b>26.0</b>	<b>26.1</b>	<b>47.8</b>	<b>1,530</b>
<b>State Avg %</b>		<b>26.7</b>	<b>25.4</b>	<b>47.9</b>	

**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?



**2008-09 Average for 6 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
<b>Margin of error ≤ 5%</b>					
MO		35.4	20.9	43.7	254
TX		42.3	27.0	30.7	567
WA	↑	44.7	21.7	33.6	295
<b>Margin of error &gt; 5%</b>					
AZ		34.4	22.5	43.1	160
LA		34.3	23.3	42.4	172
SC		36.5	22.6	40.9	159
<b>Total %</b>		<b>39.5</b>	<b>23.8</b>	<b>36.8</b>	<b>1,607</b>
<b>State Avg %</b>		<b>37.9</b>	<b>23.0</b>	<b>39.1</b>	

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

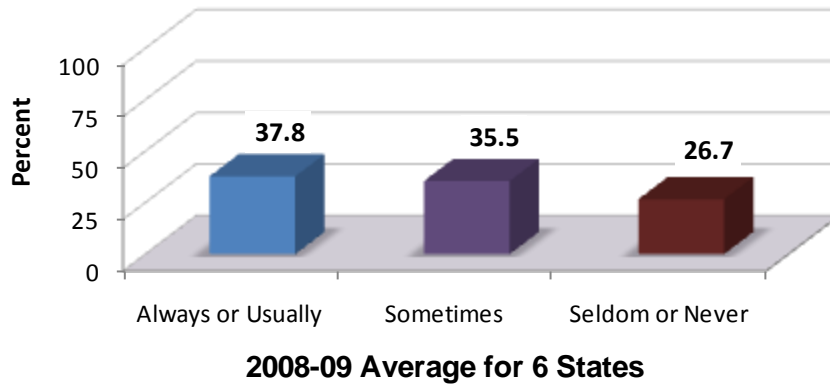


Table Q37 Do you feel that your child has access to community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		41.4	38.6	20.0	345
TX		34.0	36.4	29.7	698
WA	↓	30.6	42.8	26.7	360
<b>Margin of error &gt; 5%</b>					
AZ		34.6	38.8	26.6	188
LA	↑	43.3	29.2	27.5	240
SC	↑	42.9	27.4	29.6	226
<b>Total %</b>		<b>36.8</b>	<b>36.3</b>	<b>27.0</b>	<b>2,057</b>
<b>State Avg %</b>		<b>37.8</b>	<b>35.5</b>	<b>26.7</b>	

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

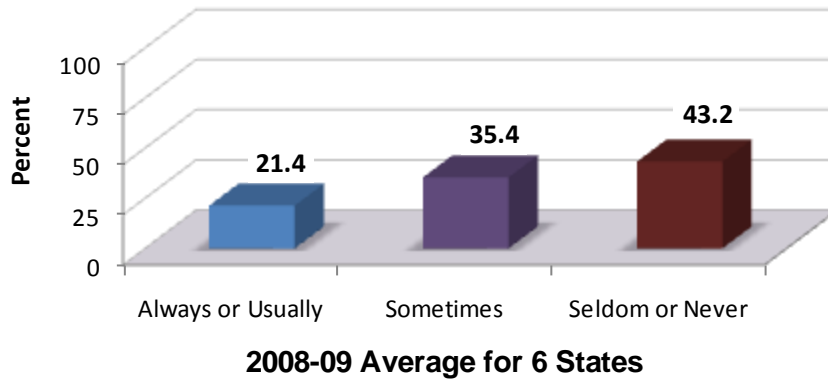


Table Q38					
Does your child participate in community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		22.7	38.2	39.1	353
TX		19.7	36.8	43.5	715
WA		16.7	38.9	44.4	360
<b>Margin of error &gt; 5%</b>					
AZ		17.1	39.2	43.7	199
LA		25.2	30.2	44.6	258
SC	↑	26.7	29.2	44.1	236
<b>Total %</b>		<b>20.9</b>	<b>36.0</b>	<b>43.1</b>	<b>2,121</b>
<b>State Avg %</b>		<b>21.4</b>	<b>35.4</b>	<b>43.2</b>	



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

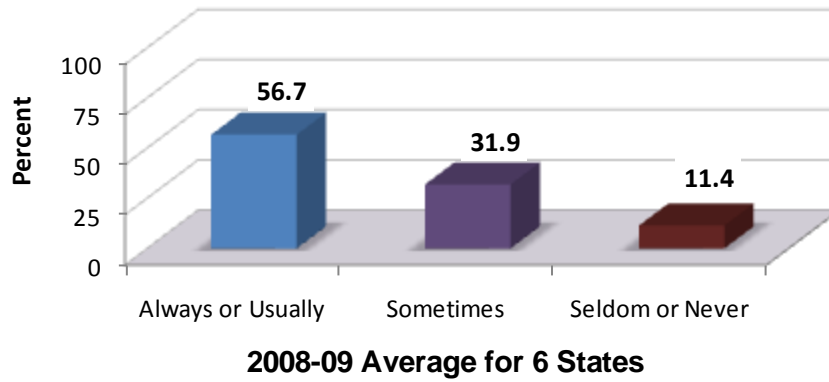
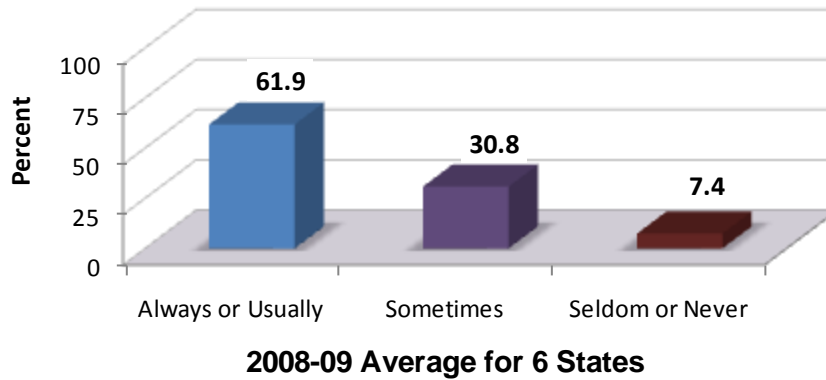


Table Q39 Does your child spend time with children who do not have developmental disabilities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		57.8	30.0	12.2	360
TX	↓	50.6	34.4	15.0	791
WA	↓	48.3	35.3	16.4	391
<b>Margin of error &gt; 5%</b>					
AZ		58.1	35.8	6.1	229
LA	↑	61.7	29.0	9.3	290
SC	↑	63.8	26.8	9.3	257
<b>Total %</b>		<b>54.9</b>	<b>32.5</b>	<b>12.6</b>	<b>2,318</b>
<b>State Avg %</b>		<b>56.7</b>	<b>31.9</b>	<b>11.4</b>	

## Outcomes and Satisfaction with Services and Supports

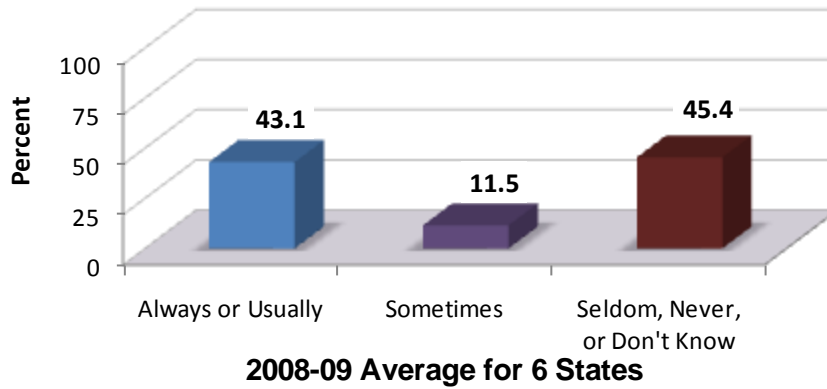
- Overall, 62% were always or usually satisfied with the services and supports they received. Thirty-one percent (31%) were somewhat satisfied, and 7% were seldom or never satisfied.
- On average, only 43% of respondents knew about their agency's grievance process, while another 45% had little or no 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 (56%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 44%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.
- Seventy percent (70%) of families felt that services and supports have made a positive difference in their lives. Six percent (6%) stated that they seldom or never felt this way.
- Nearly all families (93%) felt that family supports improved, sometimes or more often, their ability to care for their child.
- Three-fourths (75%) of respondents indicated that services have made a difference in helping them keep their child at home.
- Eighty-four percent (84%) 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?**



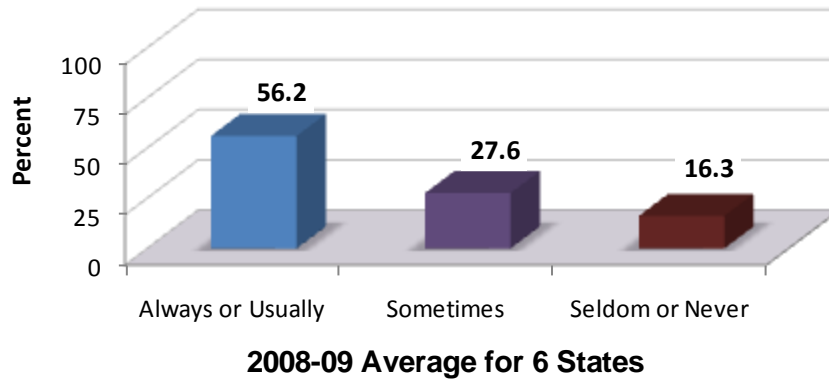
<b>Table Q40</b>					
<b>Overall, are you satisfied with the services and supports your child and family currently receives? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		65.1	27.6	7.4	352
TX		59.2	33.3	7.4	795
WA	↓	55.6	38.0	6.4	392
<b>Margin of error &gt; 5%</b>					
AZ	↓	55.1	36.6	8.4	227
LA	↑	69.2	26.2	4.5	286
SC	↑	66.9	23.1	10.0	251
<b>Total %</b>		<b>61.2</b>	<b>31.6</b>	<b>7.3</b>	<b>2,303</b>
<b>State Avg %</b>		<b>61.9</b>	<b>30.8</b>	<b>7.4</b>	

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



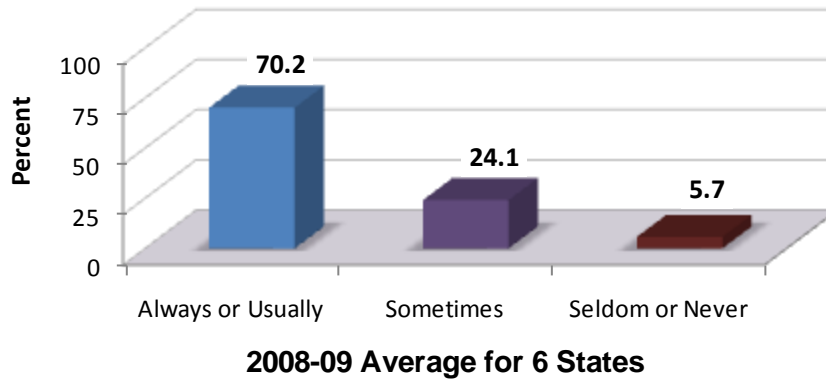
<b>Table Q41</b>					
<b>Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them? (%)</b>					
State		Always or Usually	Sometimes	Seldom, Never, or Don't Know	N
<b>Margin of error ≤ 5%</b>					
MO		41.1	12.5	46.3	343
TX	↑	51.3	14.7	34.0	756
WA		40.1	11.5	48.5	347
<b>Margin of error &gt; 5%</b>					
AZ	↓	33.6	12.6	53.8	214
LA	↑	51.9	10.0	38.1	270
SC		40.5	7.9	51.7	242
<b>Total %</b>		<b>45.0</b>	<b>12.3</b>	<b>42.7</b>	<b>2,172</b>
<b>State Avg %</b>		<b>43.1</b>	<b>11.5</b>	<b>45.4</b>	

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



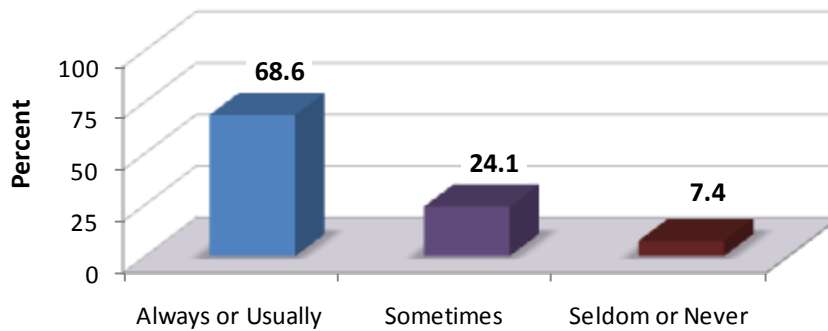
<b>Table Q42</b>					
<b>Are you satisfied with the way complaints/grievances are handled and resolved? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>Margin of error ≤ 5%</b>					
MO		55.9	22.9	21.2	118
TX		54.7	29.4	15.9	391
WA		56.7	27.5	15.8	120
<b>Margin of error &gt; 5%</b>					
AZ	↓↓	36.7	41.1	22.2	90
LA	↑↑	67.2	22.4	10.4	134
SC	↑	65.8	22.2	12.0	117
<b>Total %</b>		<b>56.5</b>	<b>27.6</b>	<b>15.9</b>	<b>970</b>
<b>State Avg %</b>		<b>56.2</b>	<b>27.6</b>	<b>16.3</b>	

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



<b>Table Q43</b>					
<b>Do you feel that family supports have made a positive difference in the life of your family? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		70.9	20.9	8.2	340
<b>TX</b>		71.0	24.5	4.5	758
<b>WA</b>		70.9	23.9	5.2	364
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		65.7	30.0	4.3	207
<b>LA</b>		73.4	22.5	4.1	271
<b>SC</b>		69.3	22.8	7.9	241
<b>Total %</b>		<b>70.6</b>	<b>23.9</b>	<b>5.5</b>	<b>2,181</b>
<b>State Avg %</b>		<b>70.2</b>	<b>24.1</b>	<b>5.7</b>	

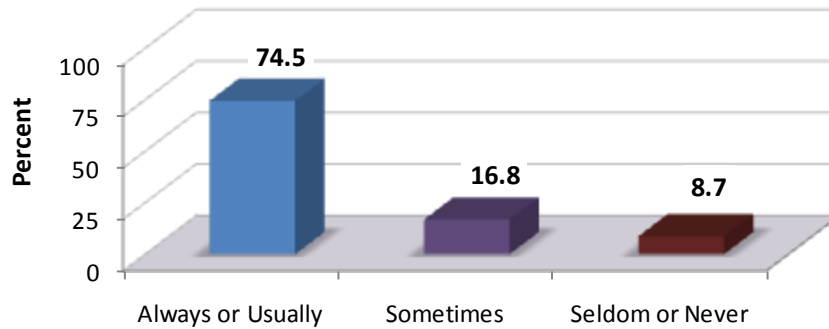
**Chart Q44 Do you feel that family supports have improved your ability to care for your child?**



**2008-09 Average for 6 States**

<b>Table Q44</b>					
<b>Do you feel that family supports have improved your ability to care for your child? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		69.9	21.7	8.3	336
<b>TX</b>		71.9	22.1	6.1	757
<b>WA</b>		70.4	23.6	6.0	368
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>	↓	60.6	30.8	8.7	208
<b>LA</b>		70.3	23.7	6.0	266
<b>SC</b>		68.2	22.5	9.3	236
<b>Total %</b>		<b>69.6</b>	<b>23.4</b>	<b>7.0</b>	<b>2,171</b>
<b>State Avg %</b>		<b>68.6</b>	<b>24.1</b>	<b>7.4</b>	

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

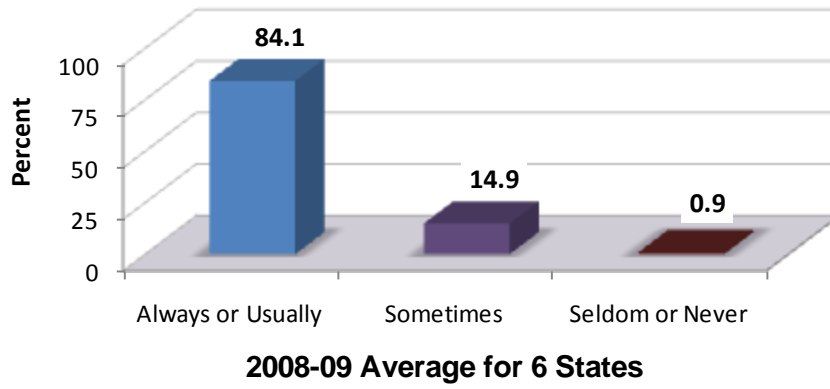


**2008-09 Average for 6 States**

<b>Table Q45</b>					
<b>Do you feel that family supports have helped you to keep your child at home? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		76.9	13.2	9.9	303
<b>TX</b>		78.7	14.6	6.6	724
<b>WA</b>		74.0	16.3	9.7	319
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>	↓	65.5	24.3	10.2	177
<b>LA</b>		77.3	15.6	7.1	225
<b>SC</b>		74.4	16.9	8.7	207
<b>Total %</b>		<b>75.9</b>	<b>15.9</b>	<b>8.2</b>	<b>1,955</b>
<b>State Avg %</b>		<b>74.5</b>	<b>16.8</b>	<b>8.7</b>	



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



<b>Table Q46</b>					
<b>Overall, do you feel that your child is happy? (%)</b>					
<b>State</b>		<b>Always or Usually</b>	<b>Sometimes</b>	<b>Seldom or Never</b>	<b>N</b>
<b>Margin of error ≤ 5%</b>					
<b>MO</b>		83.4	15.2	1.4	361
<b>TX</b>		85.1	13.9	1.0	801
<b>WA</b>	↓	78.7	20.1	1.3	389
<b>Margin of error &gt; 5%</b>					
<b>AZ</b>		82.5	17.0	0.4	223
<b>LA</b>		87.5	11.8	0.7	297
<b>SC</b>		87.6	11.6	0.7	267
<b>Total %</b>		<b>84.1</b>	<b>14.9</b>	<b>1.0</b>	<b>2,338</b>
<b>State Avg %</b>		<b>84.1</b>	<b>14.9</b>	<b>0.9</b>	

## 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.

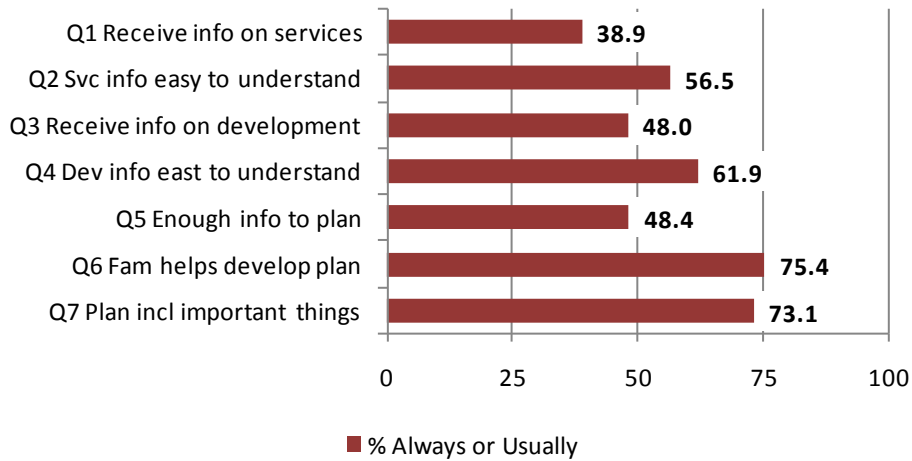
This compilation of results (up arrows minus down arrows) provides a crude overview of results, across states and within topic groupings (e.g., information and planning, choice and control), illustrating how states measured up, overall, against the state averages.

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

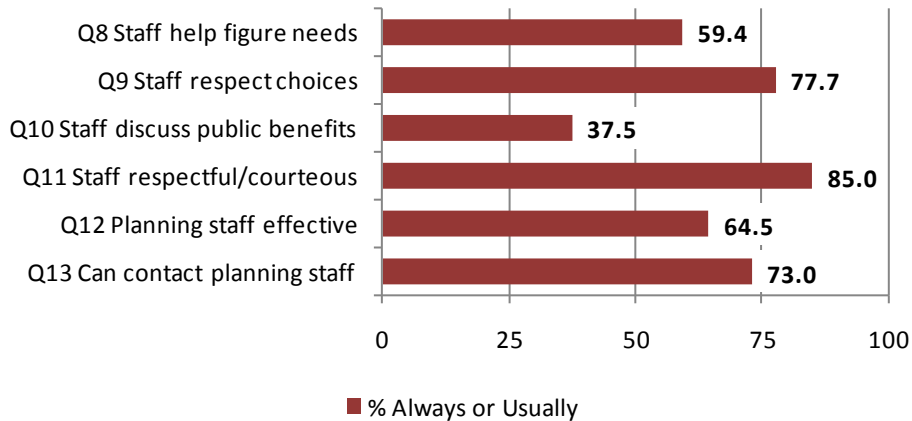
## Information and Planning

- In LA, SC, and MO, responses to information and planning questions were generally above the state average. In TX, WA, and AZ, results were generally below the state average.

**Chart 4. Information and Planning (I)**



**Chart 5. Information and Planning (II)**



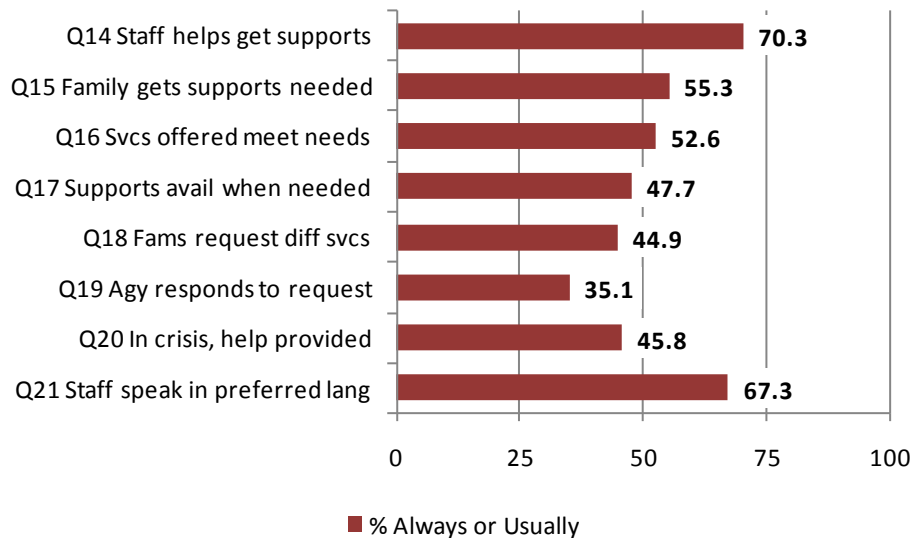
**Table 17  
Deviation in Responses Above & Below State Average  
Information & Planning**

State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
MO					↑	↑↑	↑							4
TX		↓↓	↓	↓	↓	↓		↓				↓	↓	-9
WA			↓↓	↓	↓	↓	↓	↓		↓				-8
AZ					↓			↓	↓	↓↓		↓	↓	-7
LA	↑	↑	↑↑	↑	↑		↑	↑				↑	↑	10
SC		↑	↑↑		↑			↑↑		↑↑		↑		9

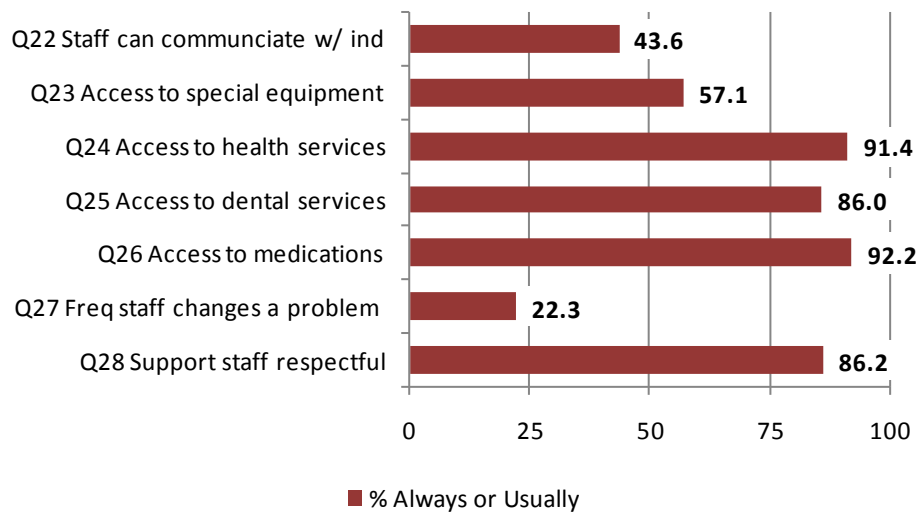
## Access and Delivery of Services

- In Louisiana and South Carolina, responses to access and delivery of services questions were generally above the state average. Note that Question 18 is considered a “neutral question”. Therefore, up and down arrows for this question were not used in the calculation of state trends.

### Chart 6. Access to Services & Supports (I)



### Chart 7. Access to Services & Supports (II)



**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
MO						↓↓	↑	↓↓	↓↓			↓		↑		-5
TX	↓						↓							↓		-3
WA		↓↓	↓↓	↓↓		↓↓			↓	↓↓						-11
AZ	↓			↓		↓	↓		↓↓							-6
LA	↑	↑↑	↑↑	↑↑		↑			↑↑	↑						11
SC	↑	↑	↑	↑↑		↑	↑	↑	↑↑							10

## Choice and Control

- In this category, Texas scored considerably above the state average. In Arizona and South Carolina, results were generally below the state average.

**Chart 8. Choice & Control**

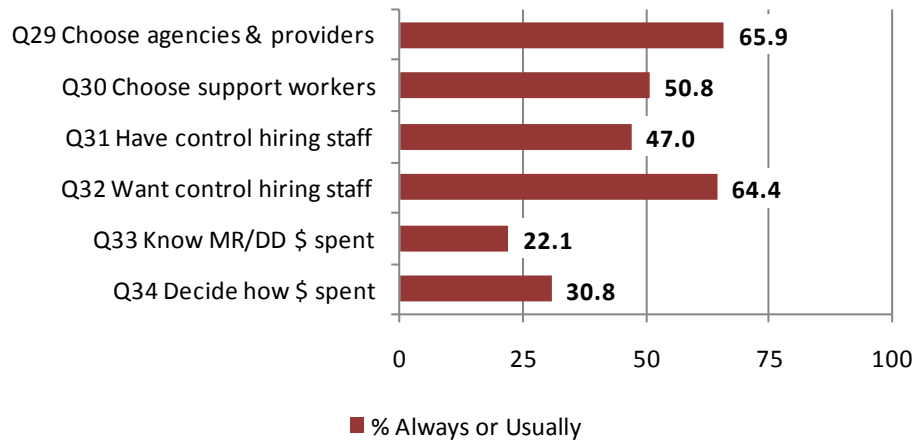


Table 19 Deviation in Responses Above & Below State Average Choice & Control							
State	Q29	Q30	Q31	Q32	Q33	Q34	Net Sum
MO	↓	↓	↓	↓		↑	-3
TX	↑↑	↑↑	↑↑	↑↑	↑↑	↑↑	12
WA			↑↑	↑↑	↑	↑	6
AZ	↓↓	↓↓	↓↓	↓	↓↓	↓↓	-11
LA	↑↑	↑↑			↑		5
SC	↓	↓	↓↓	↓↓	↓	↓↓	-9

## Community Connections

- In South Carolina and Louisiana, responses to community connections questions were generally above the overall state average.

### Chart 9. Community Connections

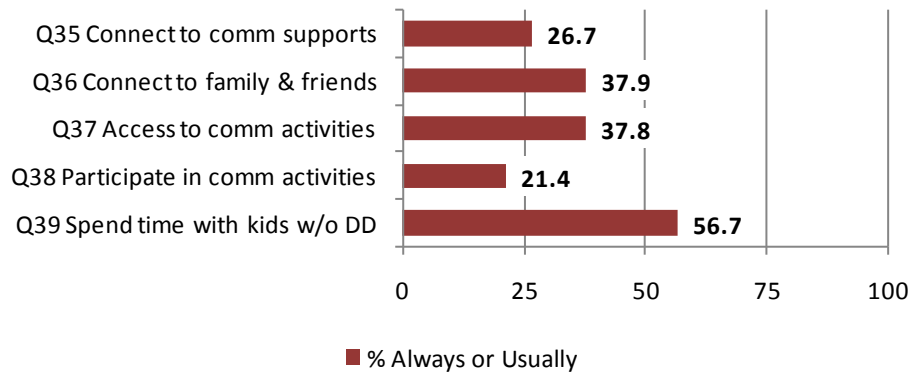


Table 20 Deviation in Responses Above & Below State Average Community Connections						
State	Q35	Q36	Q37	Q38	Q39	Net Sum
MO						0
TX					↓	-1
WA	↓	↑	↓		↓	-2
AZ						0
LA			↑		↑	2
SC	↑		↑	↑	↑	4



## Satisfactions with Services and Supports & Outcomes for Families

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

**Chart 10. Satisfaction & Outcomes**

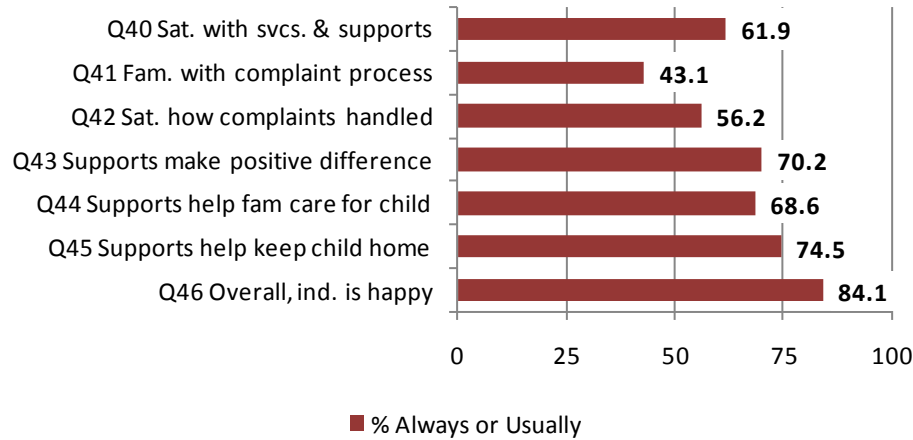


Table 21 Deviation in Responses Above & Below State Average Satisfaction & Outcomes								
State	Q40	Q41	Q42	Q43	Q44	Q45	Q46	Net Sum
MO								0
TX		↑						1
WA	↓						↓	-2
AZ	↓	↓	↓↓		↓	↓		-6
LA	↑	↑	↑↑					4
SC	↑		↑					2

## Overall State Results

- Looking at results across all categories, Louisiana and South Carolina had results that were well above the overall state average. In Arizona and Washington, results were generally below the overall state average.

Table 22 Overall Deviation in Responses Above & Below State Average						
State	Information & Planning	Access & Delivery	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
MO	4	-5	-3	0	0	-4
TX	-9	-3	12	-1	1	0
WA	-8	-11	6	-2	-2	-17
AZ	-7	-6	-11	0	-6	-30
LA	10	11	5	2	4	32
SC	9	10	-9	4	2	16

# **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. The themes identified are detailed here, and the main results of this analysis are presented below.

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. Access to Services/Supports
  - b. Info Regarding Services/Supports
  - c. Need More Services/Supports
  - d. General Satisfaction with Service Management
  - e. General Dissatisfaction with Service Management
  - f. Waiting List
18. Not Analyzed
19. General Concerns

Families across the six states who conducted the Child Family Survey in 2008-09 wrote a wide array of comments. The following three areas were commented on the most:

### Need More Services/Supports

*“There should be more services for people with developmental disabilities past age 2. It’s like once they make 21, they are totally forgotten. It’s hard to find providers and I don’t understand why.”*

*“Even though we have the choice of which agencies we can use to help our child, we really have no choice because there are very few providers who serve the [area]. The staff that helps us develop our plan did not help us to figure out what support we need.”*

*“There are many needs for children with physical and mental (developmental) disabilities in rural areas-many services are located in bigger cities and transportation and daycare is limited.”*

*“I believe there is a need for child care before and after school 13-18 year olds for disabilities. There is no help in this area for families. It is a need.”*

*“I often feel that we are substantially neglected in terms of services/opportunities because we live in a rural area.”*

*“I have used the grievance process before and was not successful. I cannot seem to get supports that are needed. I feel that there is no one to turn to help me! I don’t understand why there is nothing for my child.”*

*“We are still trying to get help for our son. We have no qualified for any help - but my son needs tons of help. (He can’t dress himself, wipe himself, bathe himself, brush his own teeth, he falls more than he walks, and he talks like he has a mouth full of marbles) He wants to spend most of his time chewing and licking metal but according to state agencies he’s fine! This is not fine for a 7 year old. He has trouble figuring out when and where to go potty, but he’s normal. I am very dissatisfied. He needs help - and he’s falling through the cracks of state systems.”*

*“This state is severely lacking in aide for those with disabilities. Being placed on years long waiting lists does nothing for the here and now. If nothing else, the Federal diaper program would help greatly but I’m told this state does not have that.”*

*“I would just like to comment that Early Intervention service that my child receives works well for our family. But the support that I am supposed to receive just does not seem to be available or no one has informed me/us about it. A lot of the services and supports I did not know were available. It makes it very hard for me to stay home with my child because I am faced with deciding on whether I should go back to work because I don’t have enough support to continue to maintain the functions of living in a home and keeping my utilities paid. So I am faced with putting my child in day care and risk him catching RSV because I am not aware of what services and support that is available for him/us.”*

*“I think the services that my child receives are very good. There are some services that they used to offer such as buying diapers and pull ups, I thought this was wonderful. It helps those families that have a hard time getting these things a great deal. I really did appreciate that. It would be nice to see more services that will help the families financially.”*

### Information Regarding Services/Supports

*"We appreciate any and all services that are "out there" but learning of them and getting access to those opportunities is often a mystery which we solve via word of mouth and networking versus program notices."*

*"[State] is a right to know state. If you don't know what to ask for you don't get it. My children are lucky because I am determined to get them the help they need. It's a shame seeing similar children that don't get the service to survive-much less thrive."*

*"We have two children at home with physical disabilities, but only one receives any kind of services. We have asked how to go about getting our other child on services, such as the waiver program to help with medical supplies, but have not gotten any answers."*

*"The system is set up for people who know what is out there to help their families and for those who don't know are left in the cold. There should be an easier way for people to have this info from the moment their child is born and discovered he/she has a disability."*

*"I know there a more services that are out there but I don't know where to start looking. He only gets cash sub, but my friends who have disabled children get more services than us. I don't know where to begin. It is very overwhelming."*

*"Services and support funds are not laid out; they must be discovered and pursued by the parents. All available help should be told in writing in plain English so people aren't left in a rut or running in circles."*

*"My son has so many different disabilities that I'm in the dark on many aspects. He gets [service], which helps provide him insurance and respite services. But as far as community support, programs and/or anything else that would help him, I know nothing."*

*"Without these programs, our family would not exist. Without these programs, our child would not exist. The programs are wrought with very little "availability" of information and flexibility for the caregivers."*

*"I found the process of my son starting in the [name] program very difficult and confusing. I think there is minimal information given to families about additional services available."*

*"There is a huge "lack" of advertising of resources for families of children with special needs. It is so hard to find out what community or state resources or programs are available."*

### Satisfied with Support Staff

*"I never had any problems and always had my questions answered promptly. The staff was always friendly and happy to help. I regret having to leave because I assure you I do not receive near the help where we are now."*

*"For years we had no one to provide services, or if they did get hired they left for better paying positions. We now have a great caregiver who we knew from our church. Our schedule and hers fits perfectly. We lost some hours only because we had no caregiver for so long. Overall we are pleased and happy now."*

*"The therapists that work with my son are amazing and have made such a large difference in his life. The amount of progress that he's made since his therapists began working with him is unbelievable."*

*"Just want to say that [Program] has been the best thing that has happened for my child. We cannot give enough praise to the staff that my child sees. This is truly a great program that makes a positive impact on the patient and the families."*

*"I am very blessed to have the therapist I do. They are very passionate and emotionally connected with my child and his needs. They go above and beyond to service my child's needs and are very supportive of what I am going through."*

*"Everyone who has helped my son during his time participating in the [name] program has been wonderful. I feel like they all are part of our family and that they genuinely care about my son's success. We are very lucky to have such a great team."*

*"I believe that my son is receiving an adequate amount of help for his disability. He remains to be a content child and shows progress daily of breaking through the barriers that his disability supplies. Life for my son and I has become easier now that help for him has been easily accessible. His Early Interventionist, and therapists are outstanding professionals that I would, and have already, recommended to families who are seeking out similar care/therapy for their child in need. My son has made outstanding progress over the last year and my family and I are greatly appreciative to even have the opportunity to receive these means of help."*

*"Thanks to everyone for the help and support concerning my son's speech delay. He has really improved during the months he has been receiving aide. The therapist and the other helper are really flexible concerning our schedule and other obligations. Thank you all once more! I am very grateful for them coming to our home because the closest therapy center to us is forty-five minutes to an hour away."*

*"We have been a part of this program [Name] for many years and have always been very happy with everyone we have had the pleasure of working with. We could only imagine what life would be like without its support."*

*"Management has always considered my daughter's well being and if I ever have questions or problems they will assist in any matter in which we need help with. My daughter loves her caregivers and does not want to change companies."*