

Child Family Survey

Final Report – April 2008
2006-2007 Data



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

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Organization of Report

Seven states conducted the National Core Indicators (NCI) Child Family Survey during the 2006-2007 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 September 2007.

This report is organized as follows:

I. INTRODUCTION

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

II. CHILD FAMILY SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

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

IV. RESULTS

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

V. DISCUSSION OF RESULTS

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

I. Introduction

Overview of National Core Indicators

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

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

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

In 2002, the Core Indicators Project changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. And between 2002 and 2007, the NCI effort continued to expand. The following figure summarizes state participation in the National Core Indicators since its inception through the 2006-2007 data collection cycles. States are listed if they participate in one or more of the NCI activities (e.g., consumer survey, family surveys, expenditure/utilization data, etc.).

Table 1
State Participation in National Core Indicators

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 2006-2007
AZ	AZ	AZ	AL	AL	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	AR	AR
MO	KY	DE	CA - RCOC	CA - RCOC	CA - RCOC	CA-RCOC	AZ	AZ
NE	MA	IA	CT	CT	CT	CT	CA-RCOC	CA-RCOC
PA	MN	KY	DE	DE	DE	DE	CT	CT
VT	NE	MA	HI	HI	DC	DC	DE	DE
VA	NC	MN	IL	IN	HI	HI	DC	GA
	PA	MT	IN	IA	IN	KY	GA	HI
	RI	NE	IA	KY	KY	MA	HI	IN
	VT	NC	KY	MA	MA	ME	KY	KY
	VA	PA	MA	ME	ME	NC	MA	MA
	WA	RI	NE	NE	NE	OK	ME	ME
		UT	NC	NC	NC	PA	NM	NM
		VT	OK	OK	ND	RI	NC	NC
		WA	PA	PA	OK	SC	OK	OK
			RI	RI	PA	VT	PA	PA
			UT	SC	RI	WA	RI	RI
			VT	SD	SC	WV	SC	SC
			WA	VT	SD	WY	SD	TX
			WV	WA	VT		TX	VT
			WY	WV	WA		VT	WA
				WY	WV		WA	WV
					WY		WV	WY
							WY	

Denotes first year of participation in NCI.

Family Indicators

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

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

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

II. Child Family Survey

Background

This report focuses on the Child Family Survey.

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

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

Between 2001 and 2007, five to seven states have participated each year. Response rates within states have varied greatly, between 21% - 57%, yet each year, NCI has had between 1,800 – 2,400 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
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

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 2006-2007 not only asks families to express their overall level of satisfaction with services and supports, it also probes specific aspects of the service system's capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; and outcomes. Combined, this information provides an overall picture of family satisfaction within and across states.

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

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

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

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

III. Methods

Sampling & Administration

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

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

- ◆ The question "Does your child live at home with you?" was used to screen out respondents who received a survey by mistake. For instance, if a respondent indicated that their child with disabilities lived outside of the family home, yet received the Child Family Survey, their responses were dropped.
- ◆ If the respondent indicated that their family member was over the age of 21, their responses were dropped.

- ♦ If demographic information was entered into the file, but no survey questions were answered, these responses were also dropped.

Response Rates

During the 2006-2007 data year, seven states administered the Child Family Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis.

Table 4 Child Family Survey - State Response Rates				
State	Surveys Mailed	Surveys Returned	Response Rate	Usable Surveys
Arizona	1,000	269	27%	258
Connecticut	1,200	301	25%	268
Oklahoma	636	257	40%	251
Texas	2,047	801	39%	781
Washington	1,240	427	34%	408
West Virginia	*	294	*	287
Wyoming	412	176	43%	146
Overall	6,535	2,525	35%	2,399

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

Data Analysis

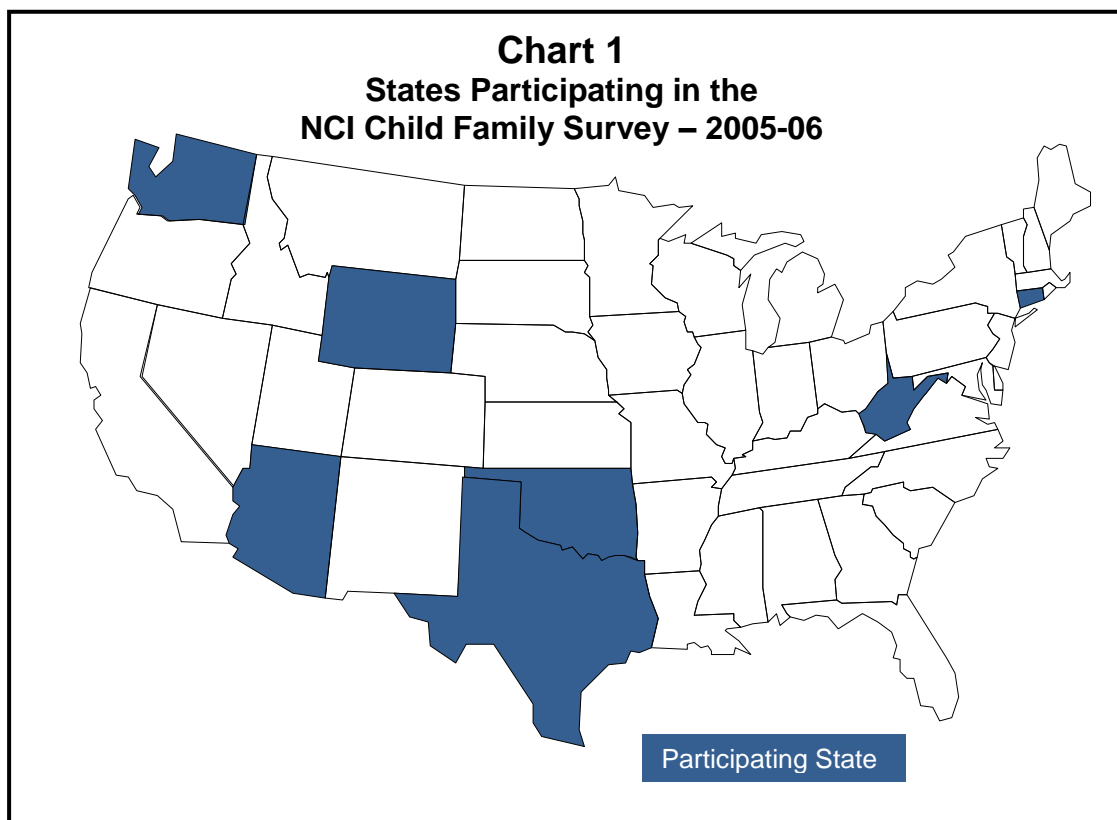
NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid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

IV. Results

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

Participating States

- ◆ Seven states (Arizona, Connecticut, Oklahoma, Texas, Washington, West Virginia and Wyoming) provided data for this Report.



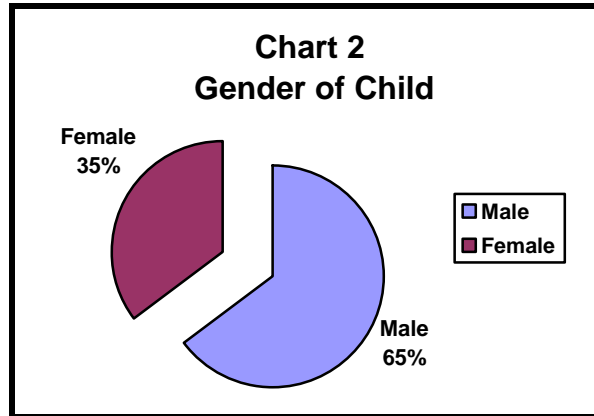
Characteristics of Children with Disabilities

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

- On average, across the states, 65% of children with disabilities were male, 35% were female.
- Across all participating states, the average age of children with disabilities was 11.2, with a range in age from 1 to 21.
- Across all states, 74% of the children with disabilities were White, 7% were Black/African-American, 6% were American Indian/Alaska Native, 2% were Asian-American, less than 1% were Native Hawaiian/Pacific Islander, 5% were Mixed Races, and 14% were Hispanic/Latino. In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.)
- On average, 17% of households include more than one individual with a developmental disability.
- On average, 81% of children with disabilities required moderate to complete levels of assistance with activities of daily living. Nineteen percent of children required little or no assistance with these activities.
- Many families indicated that their children have mental retardation (54%) and/or other developmental disabilities (35%). Additionally, many children experience other disabilities, such as physical disabilities (33%), autism (31%), seizure disorders (31%), communication disorders (30%), vision or hearing impairments (29%), and/or cerebral palsy (25%).

Gender of Family Member

Table 5 Gender		
State	% Male	% Female
AZ	64.9	35.1
CT	68.4	31.6
OK	60.8	39.2
TX	58.7	41.3
WA	65.0	35.0
WV	67.7	32.3
WY	67.4	32.6
Total n	1,464	846
Total %	63.4	36.6
State Avg. %	64.7	35.3



Age of Family Member

Table 6 Age of Child		
State	Average Age	Range
AZ	7.9	1-21
CT	11.5	3-18
OK	12.4	1-19
TX	12.6	1-21
WA	11.7	2-18
WV	10.8	1-18
WY	11.6	1-20
Total n	2,292	
Total Avg.	11.5	1-21
State Avg.	11.2	

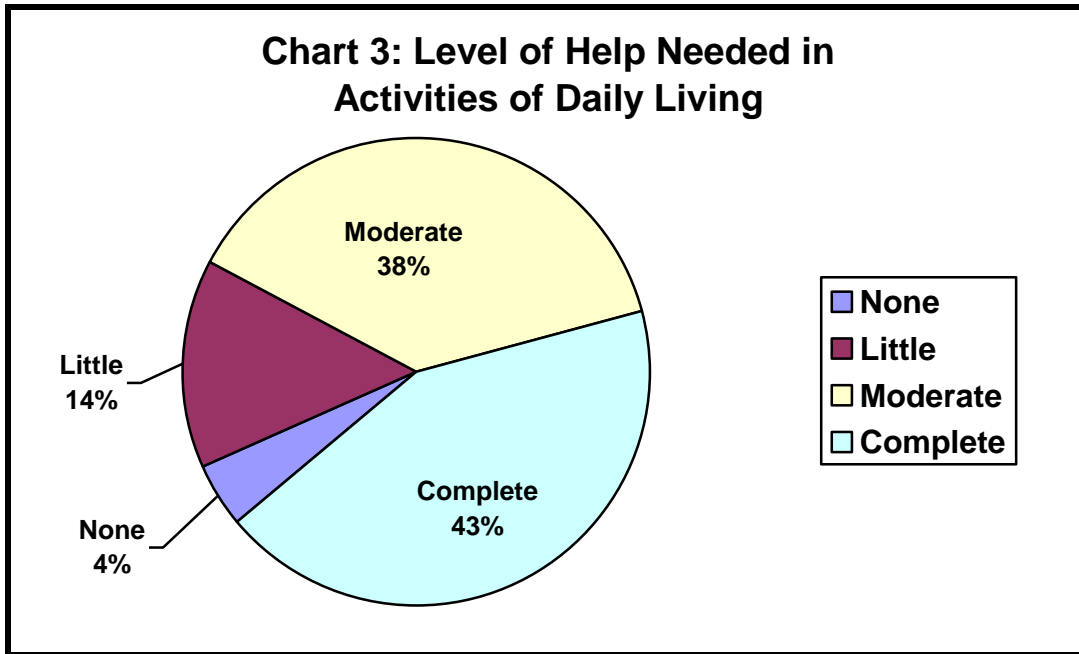
Race/Ethnicity of Family Member

Table 7 Race/Ethnicity of Child (%)								
State	White	Black/ African-American	Asian	Am. Indian/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
AZ	56.8	4.9	2.1	6.2	0.8	9.5	0.0	32.9
CT	73.4	8.9	1.5	1.9	0.8	3.5	0.8	15.4
OK	71.9	13.6	1.2	17.4	0.8	4.1	1.7	5.0
TX	58.2	11.3	1.7	1.3	0.4	3.6	0.8	27.2
WA	73.9	7.8	6.0	5.5	0.8	6.5	1.3	10.3
WV	91.8	4.6	2.1	3.6	1.4	5.0	1.8	2.1
WY	93.6	1.4	0.7	3.5	0.0	2.8	0.0	5.0
Total n	1,621	199	56	109	16	113	22	390
Total %	70.1	8.6	2.4	4.7	0.7	4.9	1.0	16.9
State Avg. %	74.2	7.5	2.2	5.6	0.7	5.0	0.9	14.0

More Than One Person with Disabilities Living in Household

Table 8 More Than One Person in Household with a Dev. Disability		
State	% Yes	% No
AZ	21.1	78.9
CT	21.6	78.4
OK	17.7	82.3
TX	12.6	87.4
WA	21.9	78.1
WV	12.0	88.0
WY	14.4	85.6
Total n	391	1,963
Total %	16.6	83.4
State Avg. %	17.3	82.7

Level of Mental Retardation of Family Member



**Table 9
Level of Help with Daily Activities**

State	None	Little	Moderate	Complete
AZ	2.8	15.7	42.5	39.0
CT	6.3	20.1	35.0	38.6
OK	7.3	18.5	34.7	39.5
TX	4.2	6.9	29.2	59.8
WA	2.5	11.5	44.5	41.5
WV	0.7	8.2	40.1	51.1
WY	6.9	20.1	41.7	31.3
Total n	95	287	855	1,103
Total %	4.1	12.3	36.5	47.1
State Avg. %	4.4	14.4	38.2	43.0

Family Member's Disabilities

Table 10A Disabilities of Child						
State	Mental Retardation	Other Dev. Disability	Mental Illness	Autism	Cerebral Palsy	Brain Injury
AZ	34.8	30.4	5.7	35.2	17.4	7.7
CT	56.2	30.8	6.9	31.2	21.5	7.7
OK	71.0	39.2	10.2	25.4	30.2	16.8
TX	55.1	42.3	6.7	19.8	41.7	16.6
WA	42.4	38.2	6.5	31.8	23.8	10.7
WV	56.2	36.0	8.1	43.3	23.0	10.6
WY	61.0	27.5	8.5	31.7	20.4	5.6
Total n	1241	868	169	676	680	287
Total %	53.0	37.1	7.2	28.9	29.1	12.3
State Avg. %	53.8	34.9	7.5	31.2	25.4	10.8

Table 10B Disabilities of Child							
State	Seizure Disorder/	Chemical Dependency	Vision/Hearing Impairments	Physical Disability	Commun. Disorder	Down Syndrome	Other Disability
AZ	18.2	0.8	24.3	23.5	22.7	11.3	25.1
CT	32.3	0.8	23.1	29.2	28.1	18.8	21.2
OK	34.3	0.8	34.3	38.1	31.4	17.6	22.9
TX	47.0	1.2	42.7	53.7	43.6	5.5	39.8
WA	26.8	0.2	25.8	30.5	24.1	11.7	28.0
WV	37.9	1.8	35.5	36.2	35.8	12.1	27.7
WY	21.1	0.0	20.4	23.2	23.2	18.3	19.7
Total n	816	21	762	894	769	269	695
Total %	34.9	0.9	32.6	38.2	32.9	11.5	29.7
State Avg. %	31.1	0.8	29.4	33.5	29.8	13.6	26.3

Characteristics of Respondents

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

- ◆ Across all states, nearly all (89%) of respondents were under 55 years old, with most respondents (71%) falling in the 35 to 54 year old age category.
- ◆ The vast majority of respondents were parents of children with disabilities (93%). The remaining respondents were grandparents (5%), or others(1%).
- ◆ In total, 99% 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 (25%) health. Twenty-three percent, however, categorized their health as being fair or poor.
- ◆ Thirty-nine percent of respondents (39%) had an annual household income (including all wage earners within the household) of \$25,000 or less. 26% had a household income between \$25,001 and \$50,000 and 36% had an income over \$50,000.

Age of Respondent

Table 11 Age of Respondent (%)				
State	Under 35	35-54	55-74	75 or Older
AZ	28.4	63.8	7.8	0.0
CT	10.0	81.2	8.8	0.0
OK	13.2	73.2	13.6	0.0
TX	15.0	75.6	8.9	0.5
WA	15.5	72.1	11.2	1.2
WV	24.7	65.9	9.4	0.0
WY	21.9	65.1	13.0	0.0
Total n	413	1,716	237	9
Total %	17.4	72.3	10.0	0.4
State Avg. %	18.4	71.0	10.4	0.2

Relationship of Respondent to Individual with Disabilities

Table 12 Relationship to Child with Disabilities (%)				
State	Parent	Sibling	Grand-parent	Other
AZ	92.2	0.0	5.8	1.9
CT	95.0	0.4	3.5	1.2
OK	91.6	0.0	6.4	2.0
TX	93.4	0.1	5.0	1.4
WA	90.1	0.0	8.1	1.7
WV	94.1	0.0	4.5	1.4
WY	96.6	0.0	2.7	0.7
Total n	2,210	2	129	36
Total %	93.0	0.1	5.4	1.5
State Avg. %	93.3	0.1	5.1	1.5

Respondent's Role as Primary Caregiver

Table 13 Respondent is Primary Caregiver		
State	% Yes	% No
AZ	98.8	1.2
CT	99.6	0.4
OK	99.2	0.8
TX	98.7	1.3
WA	97.5	2.5
WV	99.3	0.7
WY	99.3	0.7
Total n	2,330	29
Total %	98.8	1.2
State Avg. %	98.9	1.1

Health of Respondent

Table 14 Health of Respondent (%)				
State	Excellent	Good	Fair	Poor
AZ	28.4	48.6	20.6	2.3
CT	25.5	52.9	18.3	3.4
OK	30.2	47.6	19.8	2.4
TX	19.0	55.4	22.9	2.6
WA	21.3	49.1	24.8	4.7
WV	24.5	55.9	16.1	3.5
WY	27.6	54.5	16.6	1.4
Total n	558	1,247	497	72
Total %	23.5	52.5	20.9	3.0
State Avg. %	25.2	52.0	19.9	2.9

Household Income

Table 15 Household Income					
State	Below \$15,000	\$15,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	Over \$75,000
AZ	23.9	20.2	24.8	15.1	16.0
CT	19.8	10.9	23.8	19.4	26.2
OK	20.4	21.7	25.3	16.7	15.8
TX	Question not asked				
WA	25.6	18.2	27.0	14.0	15.2
WV	24.2	20.0	27.5	18.1	10.2
WY	12.5	14.0	26.5	24.3	22.8
Total n	325	261	381	253	251
Total %	22.1	17.7	25.9	17.2	17.1
State Avg. %	21.1	17.5	25.8	17.9	17.7

Services and Supports Received

- ◆ Across participating states, on average, specialized services and supports were most often utilized (77%) by families having a child with disabilities.
- ◆ Additionally, 57% obtained in-home supports, 42% used out-of-home respite, 41% received SSI financial support, and 30% received other types of financial support.

Table 16 Services and Supports Received (%)							
State	SSI financial support	Other financial support	In-home support	Out-of-home respite care	Early intervention	Transportation	Specialized services/ supports
AZ	41.4	10.1	46.1	26.7	17.9	12.8	84.0
CT	33.3	31.2	30.3	33.2	11.0	8.6	69.9
OK	42.9	24.7	80.4	17.4	6.9	7.9	71.2
TX	44.0	22.1	87.1	35.5	8.5	16.2	73.1
WA	46.1	30.6	61.3	69.5	5.5	15.4	66.6
WV	42.2	45.6	49.8	38.6	7.2	12.6	89.0
WY	35.2	43.7	46.0	73.1	20.0	12.4	87.1
Total n	970	607	1,460	928	204	303	1,730
Total Avg. %	42.0	27.5	64.4	40.9	9.7	13.3	75.4
State Avg. %	40.7	29.7	57.3	42.0	11.0	12.3	77.3

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, 33% of respondents indicated they regularly receive information about the services and supports available to them. Individual state results varied considerably, ranging from 24% in Connecticut to 44% in Wyoming.
- Among those who receive information, about half (48%) found the information easy to understand, while the remaining 52% found the information, at least sometimes, difficult to understand.
- Across states, less than half (44%) of respondents indicated they regularly receive information about their child's disability or development.
- Among those who receive this information, 56% found it easy to understand, and the remaining 44% found the information, at least sometimes, difficult to understand.
- Only 41% of respondents stated they got enough information to help them participate in planning. A larger percentage (59%) indicated they only sometimes or seldom 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 62% in Connecticut to 89% in Wyoming.
- Of those families with a service plan, 69% stated that the plan included things important to the respondent. Almost one-third of respondents (31%) indicated that the plan only sometimes, seldom or never included things important to them.
- Across states, about half (54%) indicated that planning staff would help them figure out the supports they needed. However, a large percentage (46%) stated that this was only sometimes or even seldom the case.
- Across states, three-quarters (75%) of respondents felt that their choices and opinions were respected by staff.
- Only 32% of respondents indicated that planning staff discussed with them the public benefits that may or may not be available to them. Another quarter sometimes received this information, while 44% indicated that planning staff did not relay this information to them. Results were fairly consistent across states.
- Among all respondents, 84% felt that agency staff were generally respectful and courteous. Across all states, these results were fairly consistent.
- Among all respondents, 59% felt that agency staff were generally effective.
- Across all states, 69% of respondents indicated they could typically contact staff when desired.

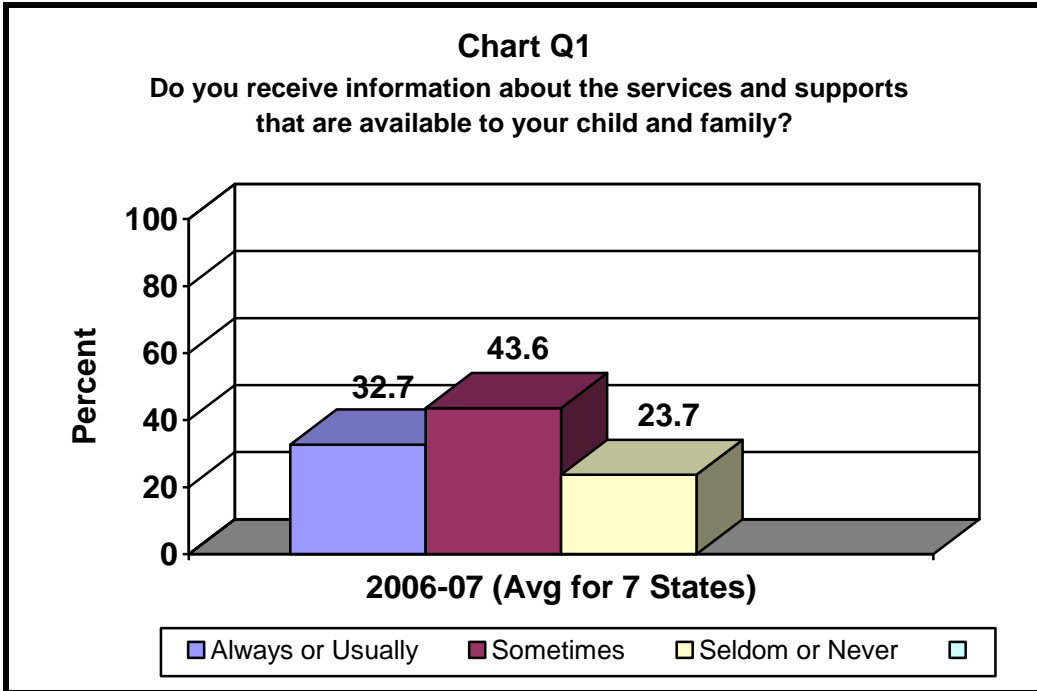


Table Q1
Do you receive information about the services and supports that are available to your child and family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		34.5	43.4	22.1	249
CT	↓	23.7	42.7	33.6	253
OK		29.6	45.7	24.7	247
TX		31.4	43.6	25.0	755
WA		30.8	37.4	31.8	390
WV		34.5	45.7	19.8	278
WY	↑↑	44.4	46.5	9.0	144
Total %		31.8	43.1	25.1	2,316
State Average		32.7	43.6	23.7	7

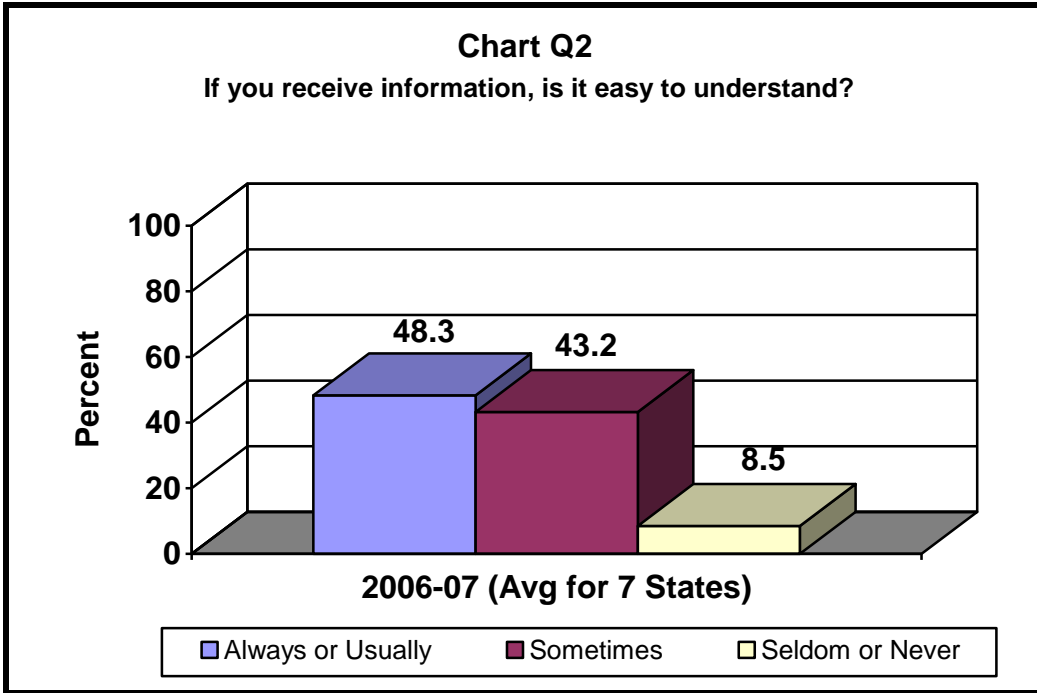


Table Q2
If you receive information, is it easy to understand?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	50.0	42.1	7.9	240
CT	45.4	47.3	7.3	205
OK	46.8	44.6	8.6	222
TX	47.2	44.9	7.9	680
WA	46.9	38.9	14.2	337
WV	43.6	47.9	8.5	259
WY	58.4	36.5	5.1	137
Total %	47.5	43.6	8.8	2,080
State Average	48.3	43.2	8.5	7

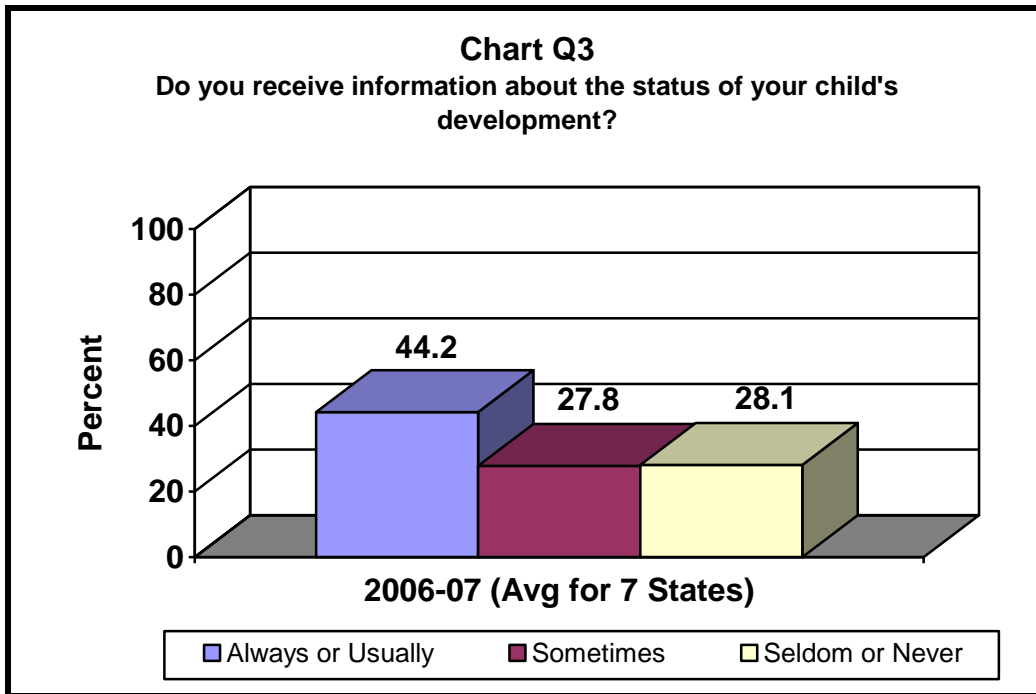


Table Q3
Do you receive information about the status of your child's development?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		48.8	25.2	26.0	242
CT	↓	36.2	24.3	39.4	218
OK		39.3	35.5	25.2	234
TX		42.9	23.5	33.6	693
WA	↓	37.3	24.6	38.1	354
WV	↑	53.6	27.9	18.6	280
WY	↑	51.1	33.3	15.6	141
Total %		43.5	26.5	30.1	2,162
State Average		44.2	27.8	28.1	7

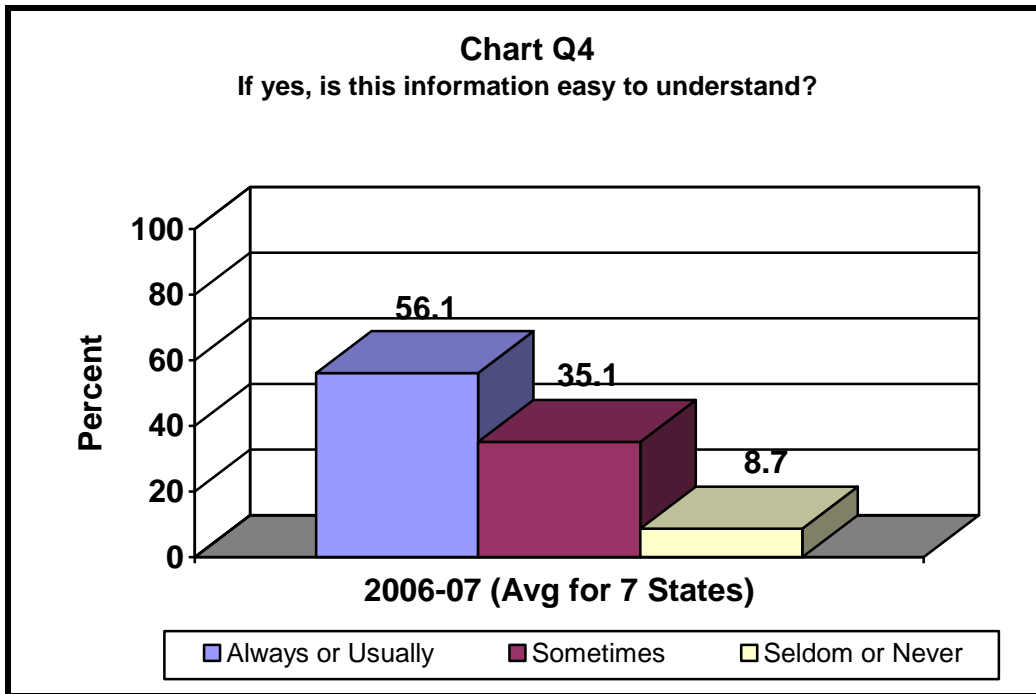


Table Q4
If yes, is this information easy to understand?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		58.5	31.7	9.8	205
CT	↓↓↓	46.1	41.7	12.2	180
OK		54.7	36.8	8.4	190
TX		57.8	34.8	7.4	529
WA		52.8	34.1	13.1	252
WV		56.4	35.8	7.8	243
WY	↑↑	66.7	30.9	2.4	123
Total %		56.0	35.1	8.8	1,722
State Average		56.1	35.1	8.7	7

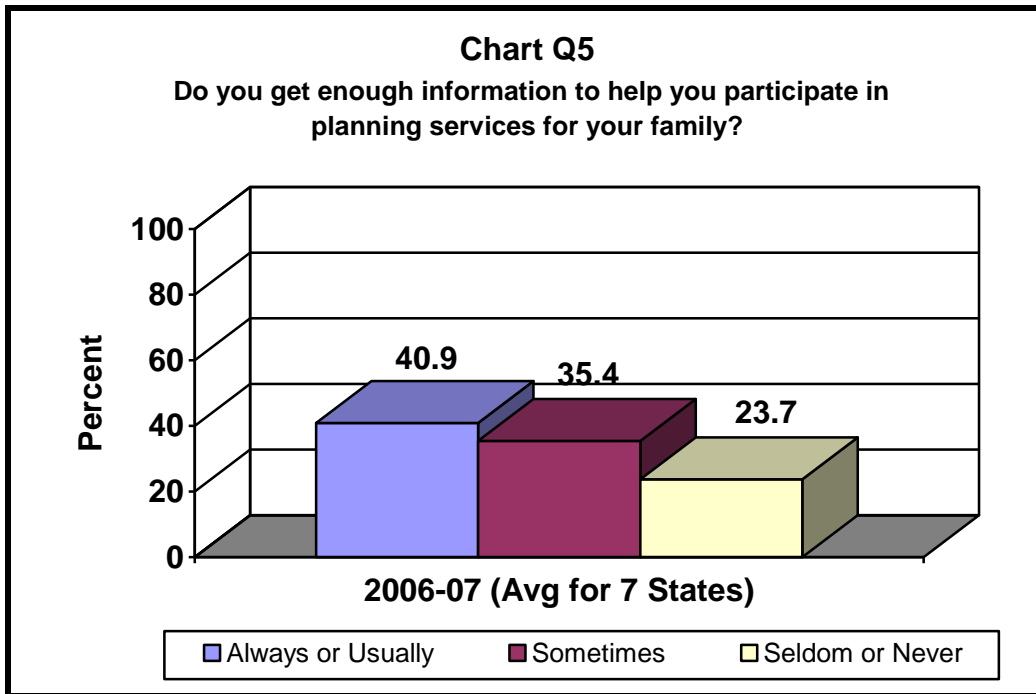


Table Q5
Do you get enough information to help you participate in planning services for your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		44.4	34.3	21.3	239
CT	↓↓↓	22.7	38.0	39.3	229
OK		39.7	32.8	27.6	232
TX		41.5	35.5	23.0	708
WA	↓	33.6	33.6	32.7	342
WV		44.4	38.9	16.7	275
WY	↑↑↑	60.3	34.8	5.0	141
Total %		40.0	35.4	24.6	2,166
State Average		40.9	35.4	23.7	7

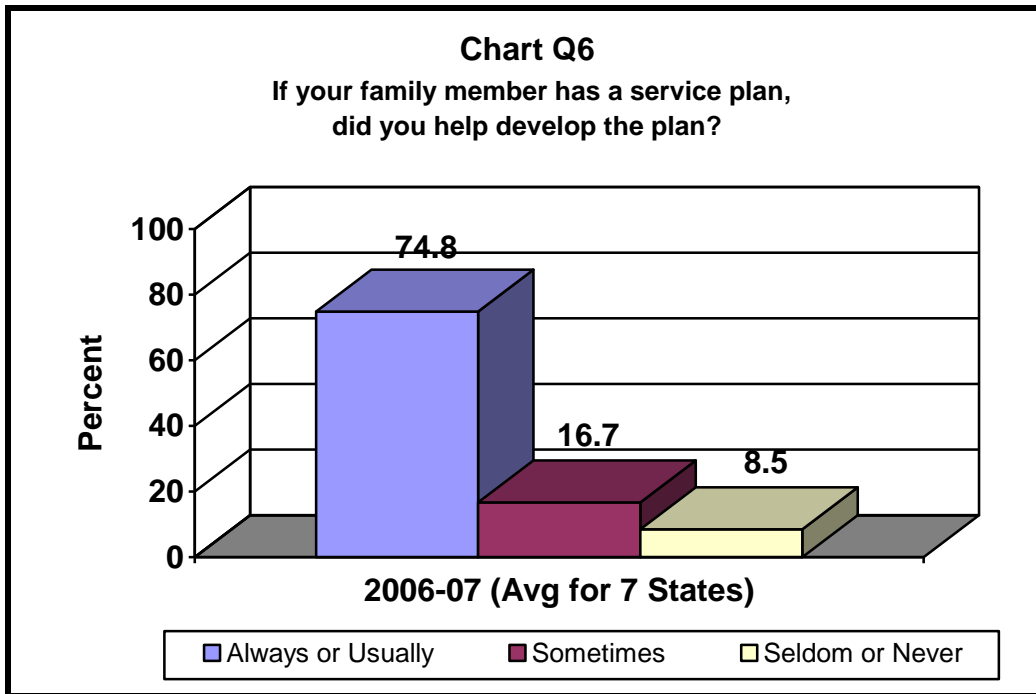


Table Q6
If your family member has a service plan, did you help develop the plan?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		73.7	18.2	8.1	198
CT	↓↓↓	61.7	20.3	18.0	133
OK	↑	79.9	14.9	5.2	194
TX		74.4	17.7	7.9	606
WA	↓	66.3	19.0	14.7	252
WV		78.4	16.9	4.7	255
WY	↑↑↑	89.1	10.1	0.7	138
Total %		74.5	17.1	8.3	1,776
State Average		74.8	16.7	8.5	7

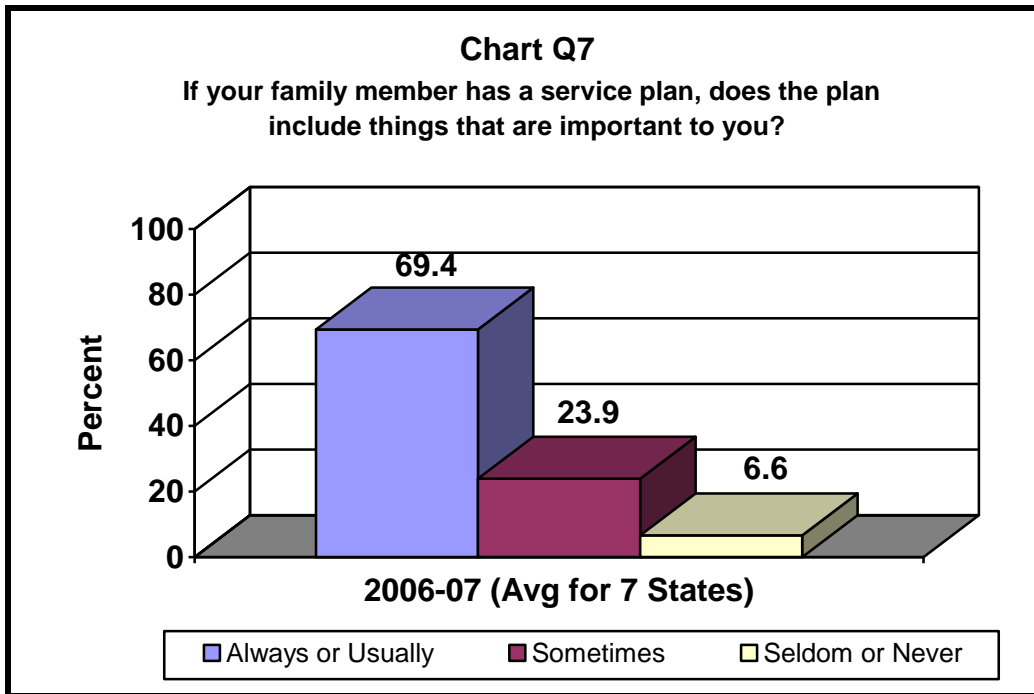


Table Q7
If your family member has a service plan, does the plan include things that are important to you?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		69.7	24.2	6.1	198
CT	↓↓	52.4	32.3	15.3	124
OK		71.7	25.1	3.1	191
TX		70.7	23.6	5.6	605
WA	↓	63.0	26.4	10.6	246
WV	↑	76.0	19.7	4.3	254
WY	↑↑	82.5	16.1	1.5	137
Total %		70.0	23.7	6.3	1,755
State Average		69.4	23.9	6.6	7

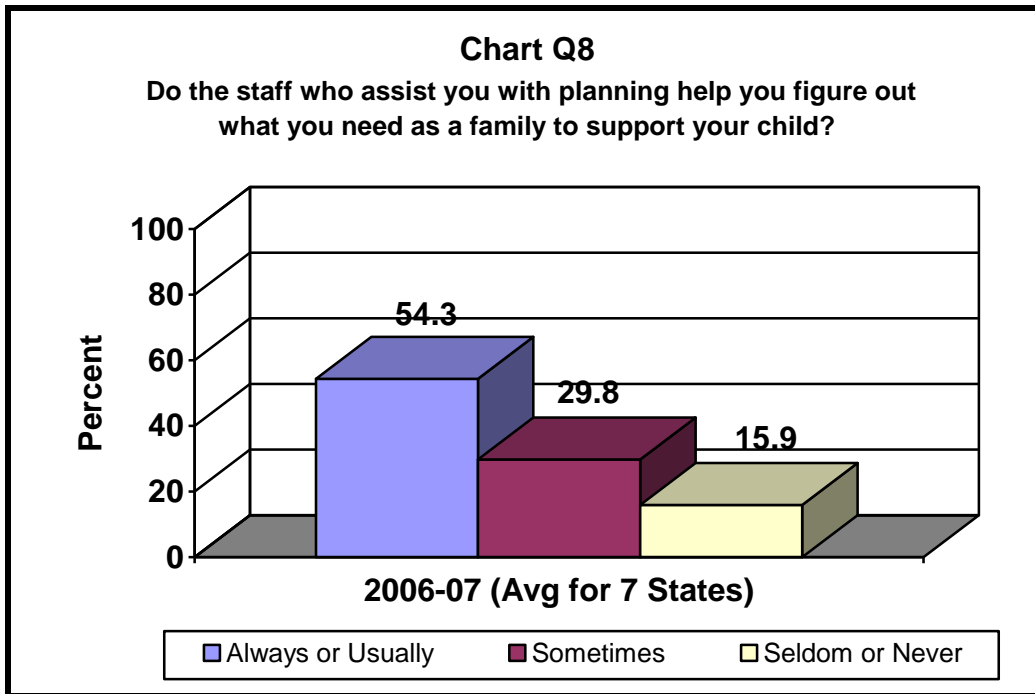


Table Q8
Do the staff who assist you with planning help you figure out what you need as a family to support your child?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		49.5	33.3	17.1	216
CT	↓↓	42.7	33.3	24.0	171
OK		54.6	31.9	13.4	216
TX		54.1	30.5	15.4	663
WA	↓	46.7	28.6	24.7	304
WV	↑	62.1	26.4	11.5	269
WY	↑↑	70.5	24.5	5.0	139
Total %		53.8	29.9	16.3	1,978
State Average		54.3	29.8	15.9	7

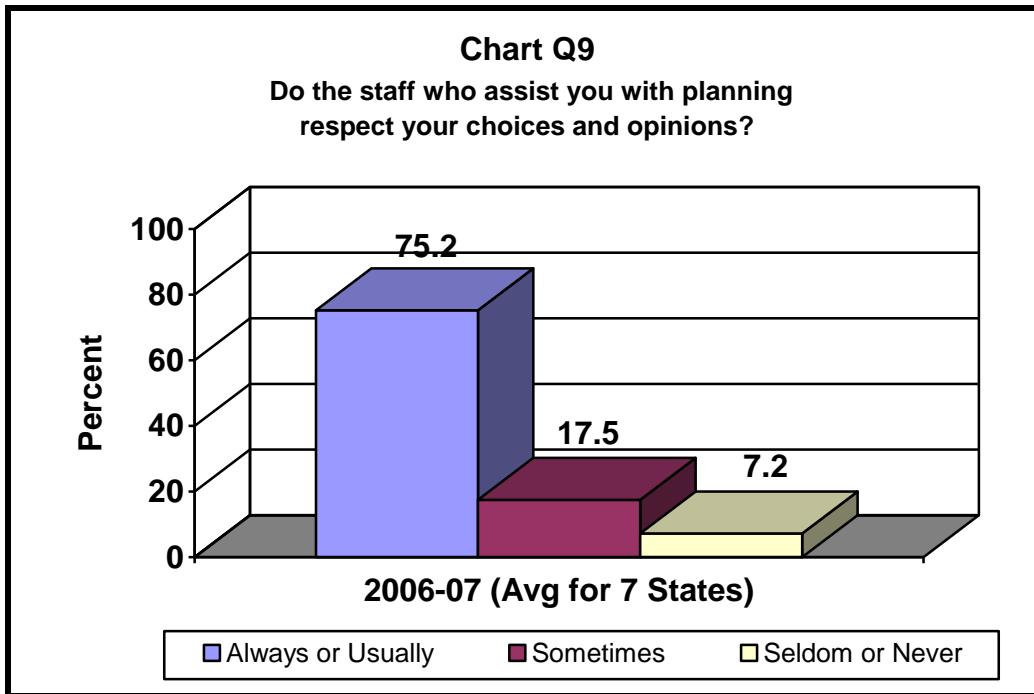


Table Q9
Do the staff who assist you with planning respect your choices and opinions?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		74.5	17.7	7.7	220
CT	↓	68.8	21.4	9.7	154
OK		75.3	17.7	7.0	215
TX		74.5	19.5	5.9	656
WA		72.0	16.7	11.3	300
WV		75.1	18.3	6.6	273
WY	↑↑	86.5	11.3	2.1	141
Total %		74.7	18.1	7.2	1,959
State Average		75.2	17.5	7.2	7

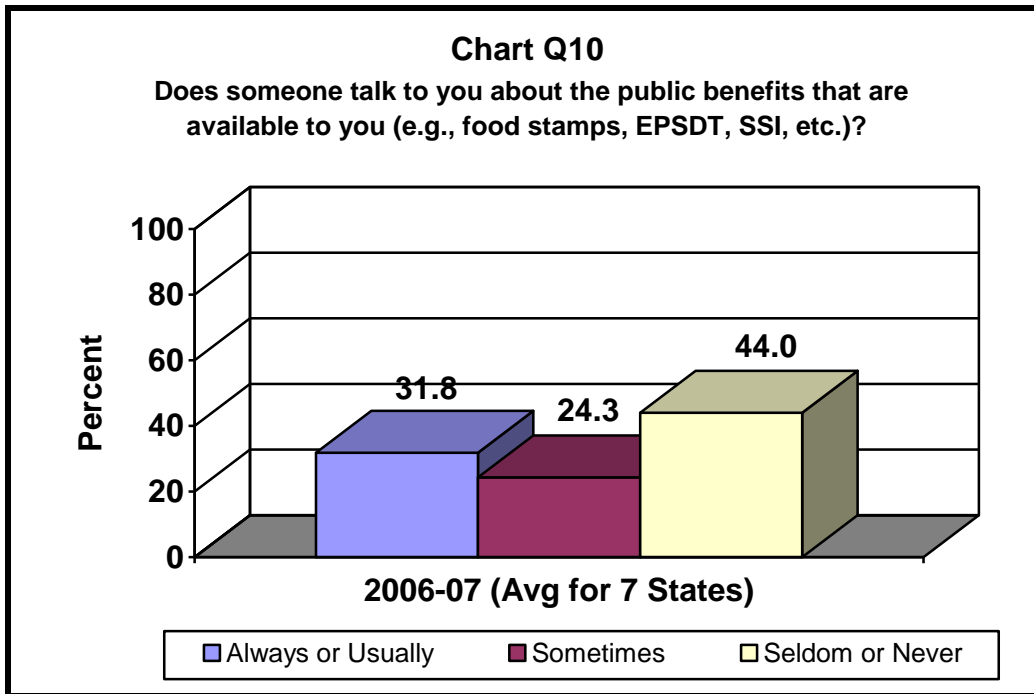


Table Q10
Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	26.4	23.6	50.0	220
CT	↓	25.8	22.2	52.0	198
OK	↑	41.6	23.9	34.5	226
TX		32.9	25.6	41.5	696
WA		29.6	23.7	46.7	334
WV		33.9	26.8	39.3	257
WY		32.2	24.0	43.8	121
Total %		32.0	24.6	43.4	2,052
State Average		31.8	24.3	44.0	7

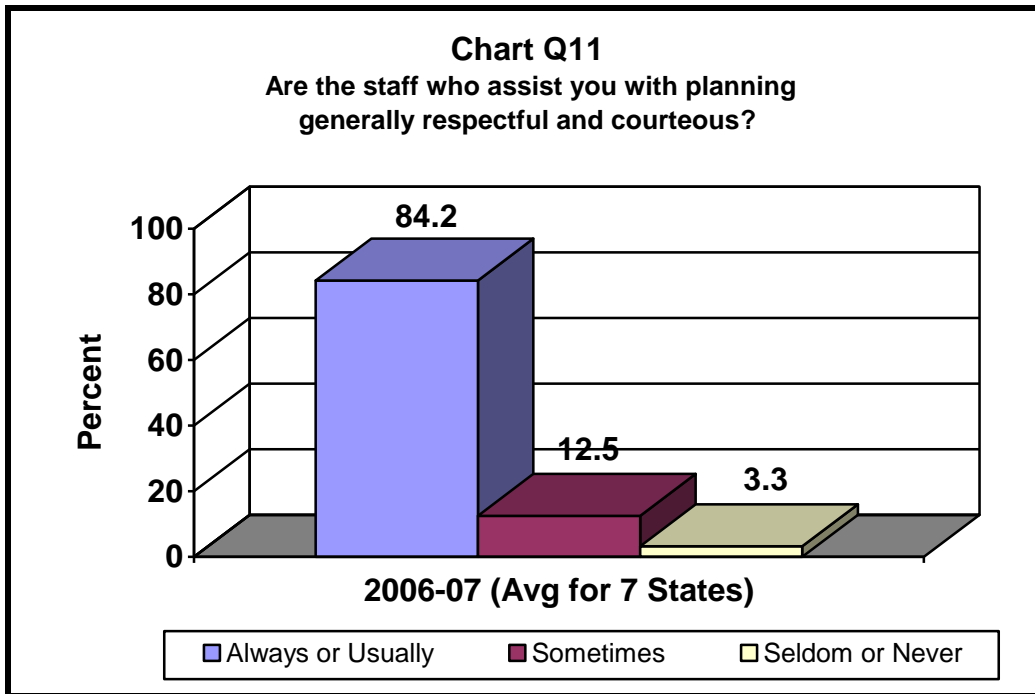


Table Q11
Are the staff who assist you with planning generally respectful and courteous?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	84.9	11.6	3.4	232
CT	81.6	14.1	4.3	185
OK	85.2	11.3	3.5	230
TX	82.7	14.7	2.6	687
WA	84.6	9.8	5.6	337
WV	79.4	17.3	3.2	277
WY	90.9	8.4	0.7	143
Total %	83.5	13.1	3.4	2,091
State Average	84.2	12.5	3.3	7

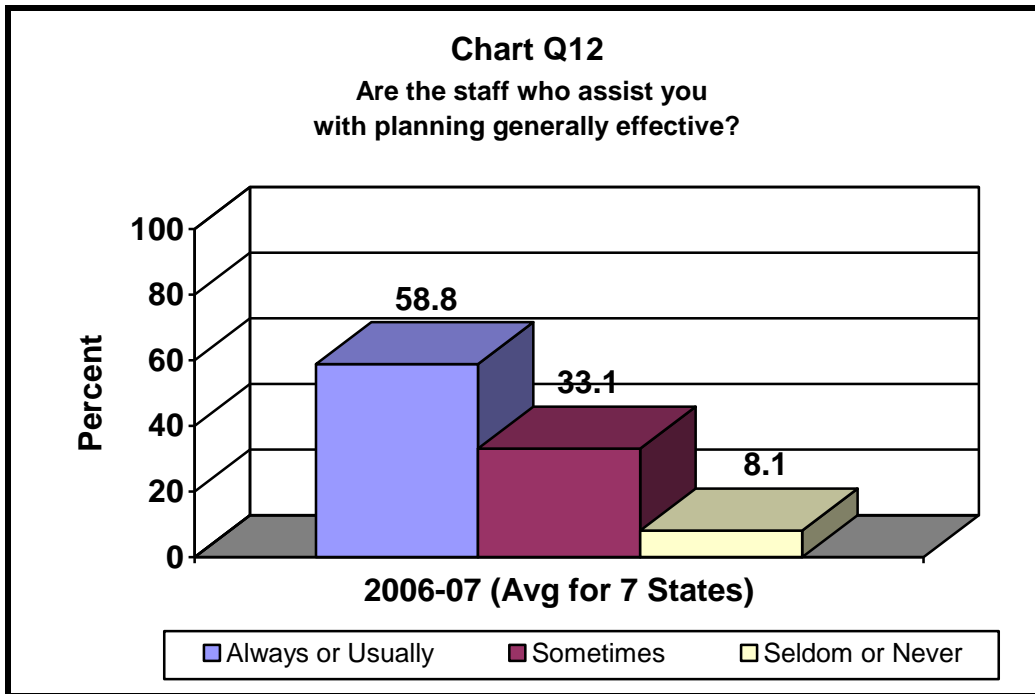


Table Q12
Are the staff who assist you with planning generally effective?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	52.6	36.8	10.5	228
CT		54.5	33.0	12.5	176
OK		57.0	36.8	6.1	228
TX		59.5	33.0	7.5	679
WA		59.9	30.7	9.3	322
WV		58.5	33.1	8.4	275
WY	↑↑	69.5	28.4	2.1	141
Total %		58.7	33.2	8.2	2,049
State Average		58.8	33.1	8.1	7

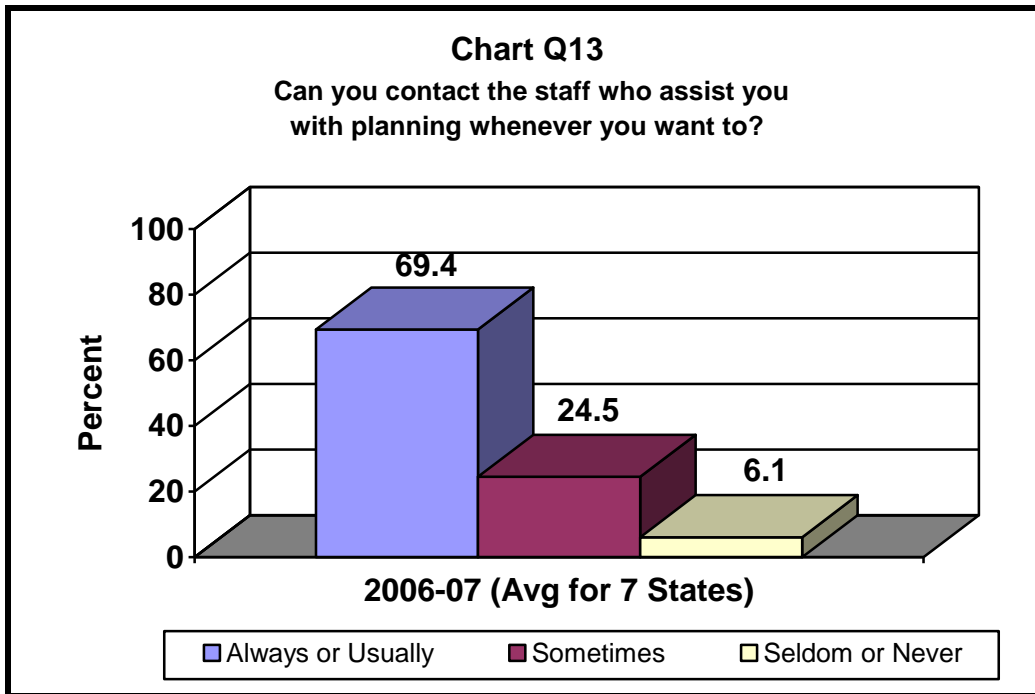


Table Q13
Can you contact the staff who assist you with planning whenever you want to?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		66.2	27.8	6.0	234
CT	↓	63.8	26.6	9.6	188
OK		64.7	28.0	7.3	232
TX		71.8	22.2	6.1	677
WA	↓	64.1	26.6	9.3	334
WV		72.7	23.6	3.6	275
WY	↑↑	82.5	16.8	0.7	143
Total %		69.3	24.4	6.3	2,083
State Average		69.4	24.5	6.1	7

Access to and Delivery of Services and Supports

- Overall, 67% of families stated their service coordinator helped them get needed supports when asked. Twenty-seven percent said this happened sometimes, and 6% indicated that their service coordinator was rarely helpful in getting the assistance needed.
- About half of families (48%) said they always or usually get the services and supports needed. Forty percent got needed supports some of the time, and the remaining 12% seldom or never received needed supports.
- Almost half (45%) of respondents said that the supports received met their families' needs, although this varied from state to state. Another 42% said that the supports sometimes met their needs, while the remaining 13% seldom or never felt the supports offered met their family's needs.
- For less than half of families (40%), supports were always or usually available when needed. However, even more families indicated that supports were only sometimes available (44%), or seldom/never available (15%) when needed.
- Eighty percent 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 26% indicated that the state agency or provider agency was usually or always responsive to these requests.
- Over half (59%) 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 (62%) indicated that staff or translators were available to speak with them in their preferred languages. Twenty-three percent indicated that staff/translators were sometimes available, and the remaining 15% 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), 36% of families said there were enough support staff regularly available who could communicate with their child. The remaining 64%, however, said capable staff were only sometimes, seldom or never available.
- Half of respondents (51%) 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 (88%) felt they had access to appropriate dental services for their child.
- Nearly all respondents (93%) felt they had access to necessary medications for their child.
- A majority of respondents (62%) indicated that frequent changes in support staff were a problem for their family at least some of the time.
- A large majority of families (84%) felt that support staff were respectful and courteous.

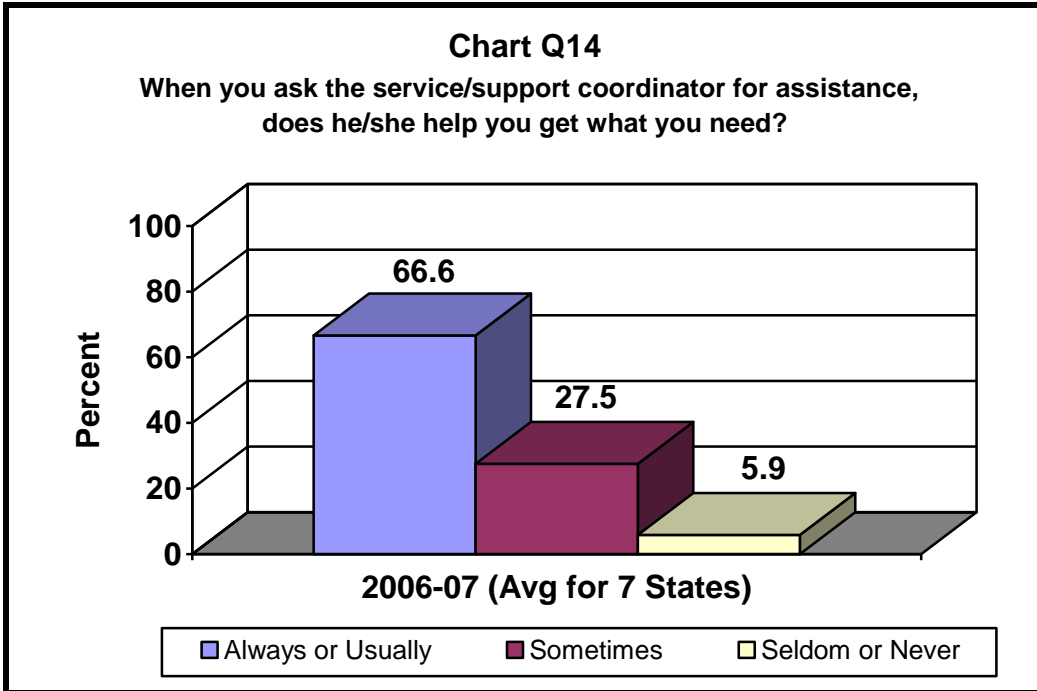


Table Q14
When you ask the service/support coordinator for assistance, does he/she help you get what you need?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		62.7	29.9	7.4	244
CT	↓↓↓	52.5	36.8	10.8	204
OK		68.4	25.8	5.7	244
TX		67.6	27.5	4.9	714
WA		65.4	28.6	6.0	384
WV		68.0	27.2	4.8	272
WY	↑↑↑	81.9	16.7	1.4	144
Total %		66.4	27.9	5.8	2,206
State Average		66.6	27.5	5.9	7

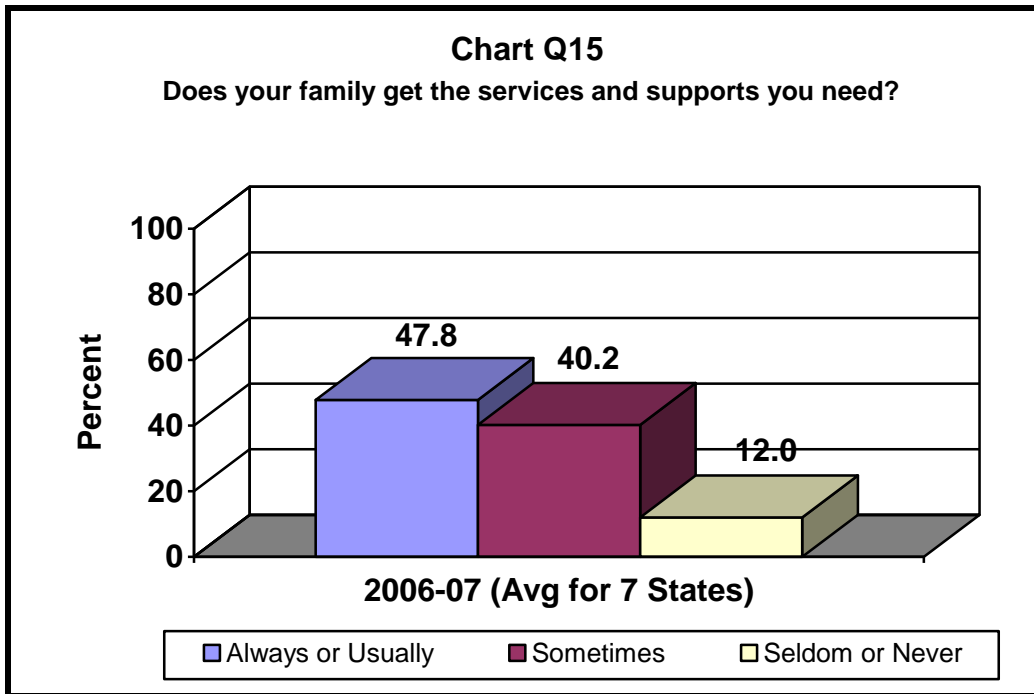


Table Q15
Does your family get the services and supports you need?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		43.9	43.1	13.0	239
CT	↓↓↓	25.7	51.4	22.9	218
OK		52.5	36.9	10.7	244
TX		50.4	41.7	7.9	748
WA		43.1	43.3	13.6	383
WV	↑	54.2	39.3	6.5	275
WY	↑↑↑	64.6	25.7	9.7	144
Total %		47.7	41.2	11.1	2,251
State Average		47.8	40.2	12.0	7

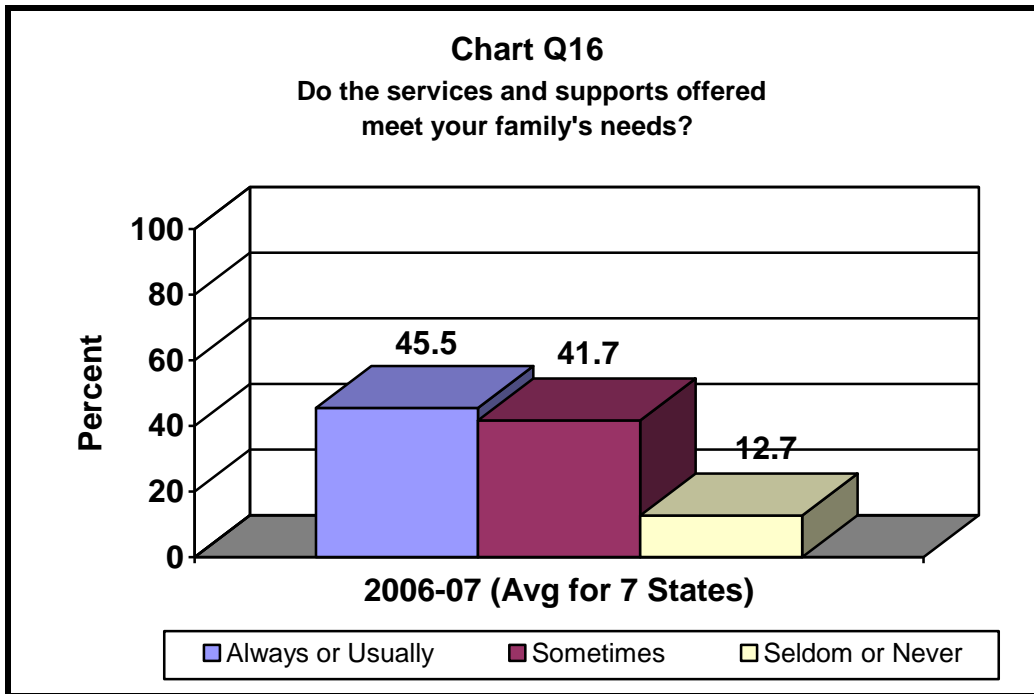


Table Q16
Do the services and supports offered meet your family's needs?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		42.8	44.1	13.1	236
CT	↓↓↓	25.1	49.2	25.6	199
OK	↑	51.0	38.0	11.0	245
TX		49.9	41.1	8.9	749
WA	↓	38.5	45.1	16.4	379
WV	↑↑↑	56.6	36.9	6.6	274
WY	↑	54.9	37.5	7.6	144
Total %		46.3	41.7	12.0	2,226
State Average		45.5	41.7	12.7	7

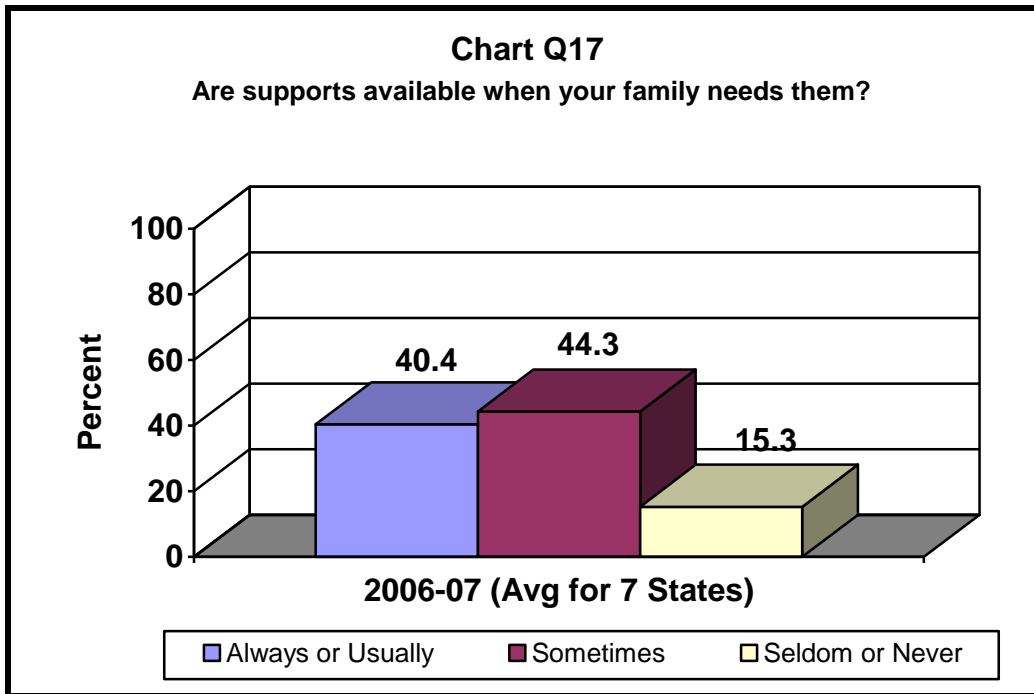


Table Q17
Are supports available when your family needs them?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		36.7	45.1	18.1	226
CT	↓↓↓	23.7	48.5	27.8	194
OK		43.2	42.7	14.1	234
TX		43.7	45.8	10.5	732
WA		36.1	47.5	16.4	366
WV	↑	45.6	43.0	11.5	270
WY	↑↑↑	53.8	37.8	8.4	143
Total %		40.7	45.0	14.2	2,165
State Average		40.4	44.3	15.3	7

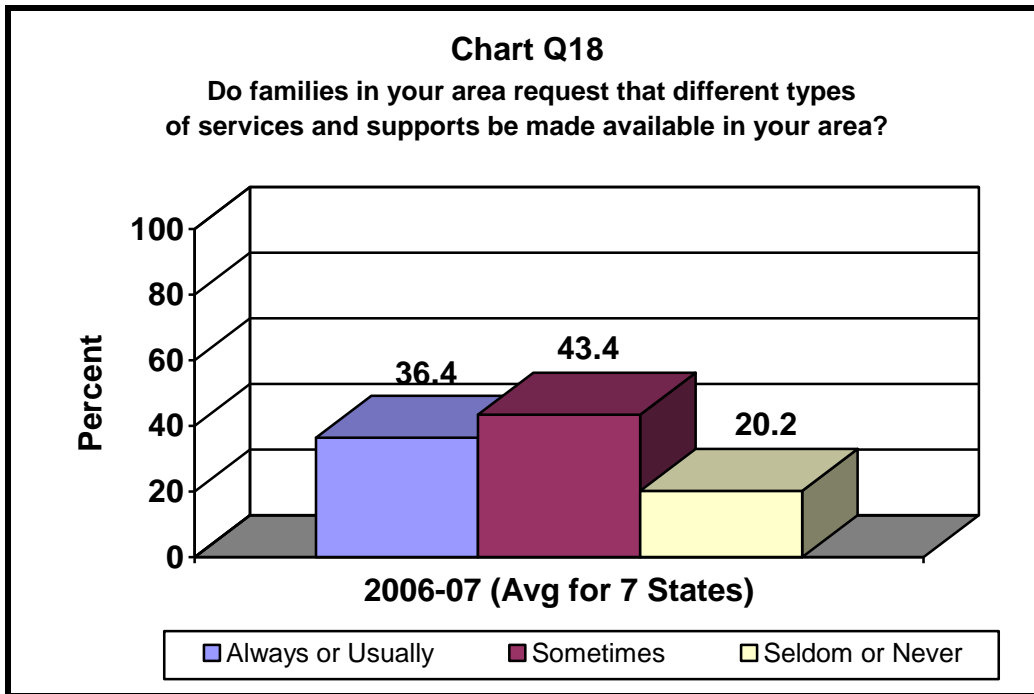


Table Q18
Do families in your area request that different types of services and supports be made available in your area?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	33.6	46.0	20.4	113
CT	33.8	40.0	26.3	80
OK	35.8	40.6	23.6	106
TX	33.2	44.0	22.8	334
WA	41.6	44.5	13.9	137
WV	34.8	46.4	18.8	138
WY	42.3	42.3	15.5	71
Total %	35.6	43.8	20.5	979
State Average	36.4	43.4	20.2	7

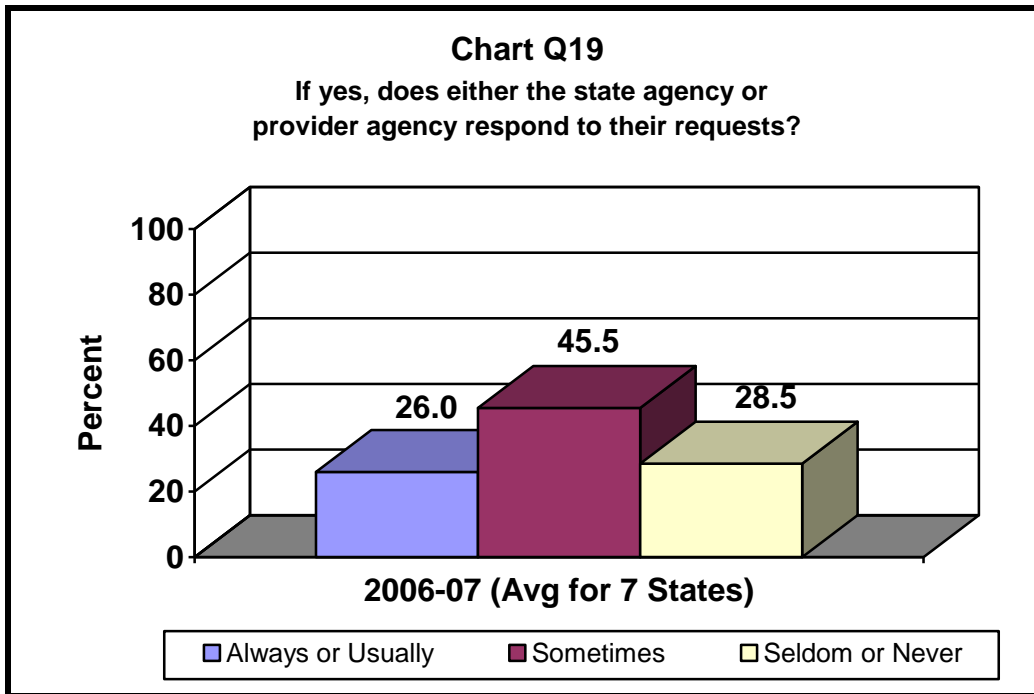


Table Q19
If yes, does either the state agency or provider agency respond to their requests?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		21.4	48.0	30.6	98
CT	↓	21.0	40.3	38.7	62
OK		29.5	43.2	27.3	88
TX		28.0	47.2	24.8	254
WA		30.9	40.9	28.2	110
WV		25.9	52.6	21.6	116
WY		25.0	46.4	28.6	56
Total %		26.7	46.2	27.2	784
State Average		26.0	45.5	28.5	7

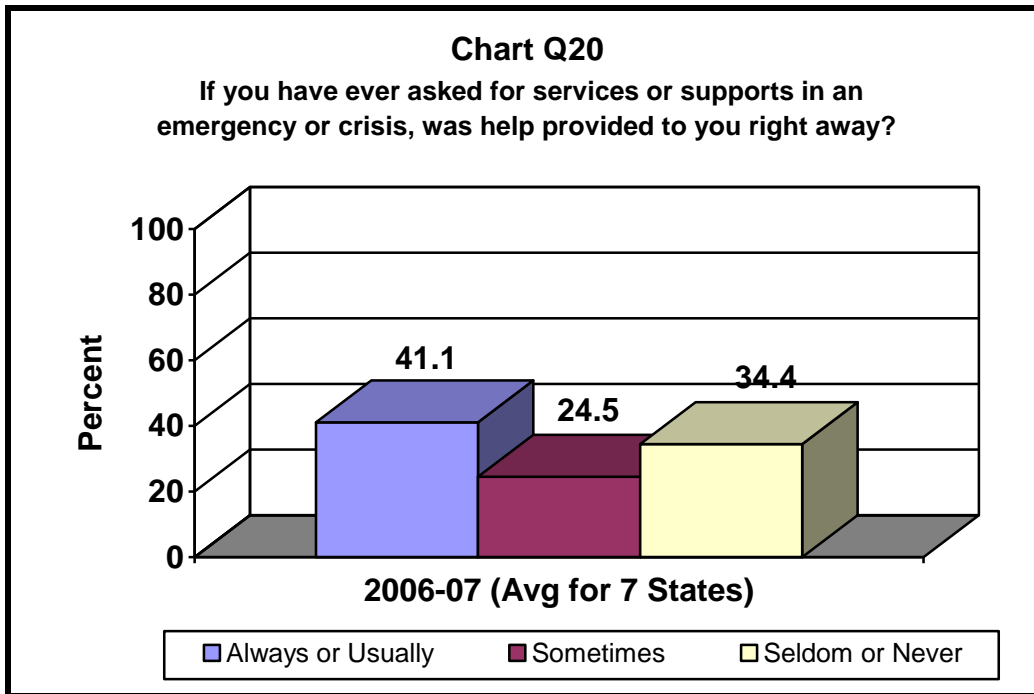


Table Q20
If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		38.7	22.7	38.7	119
CT	↓↓↓	26.1	28.3	45.7	92
OK		35.3	23.5	41.2	102
TX		44.5	26.1	29.4	398
WA		43.4	18.5	38.2	173
WV		45.5	28.8	25.8	132
WY	↑↑↑	54.2	23.7	22.0	59
Total %		41.9	24.7	33.5	1,075
State Average		41.1	24.5	34.4	7

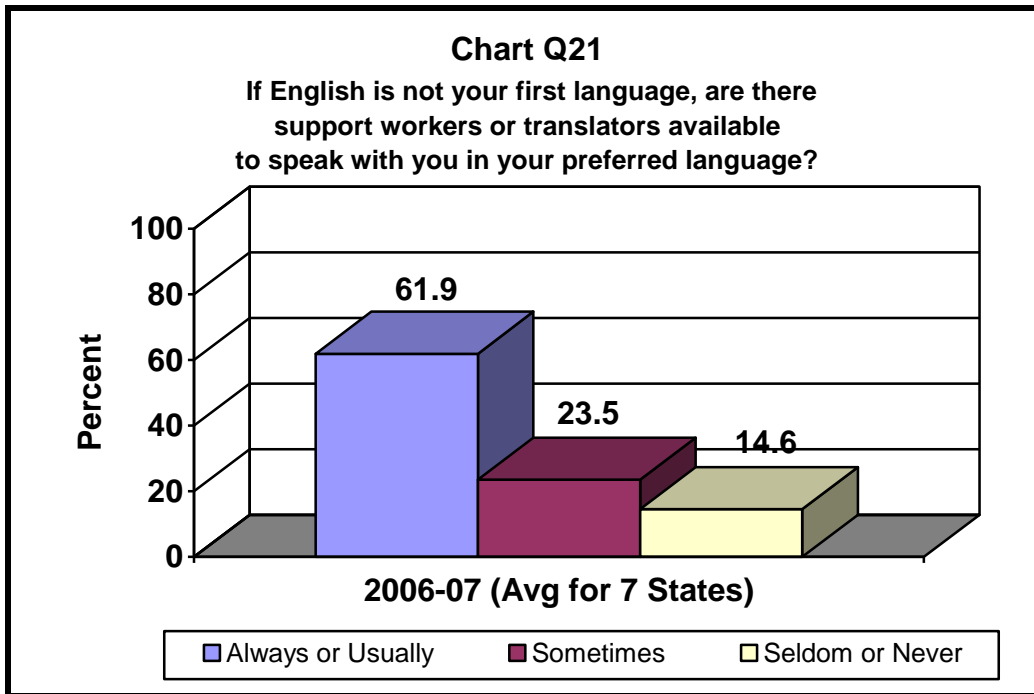


Table Q21
If English is not your first language, are there support workers or translators available to speak with you in your preferred language?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	67.7	27.7	4.6	65
CT	↓↓↓	51.3	28.2	20.5	39
OK	↑↑↑	73.3	0.0	26.7	15
TX	↑↑↑	72.8	15.9	11.3	151
WA	↑	71.4	22.4	6.1	49
WV	↓↓↓	46.7	20.0	33.3	15
WY	↓↓↓	50.0	50.0	0.0	4
Total %		67.8	20.4	11.8	338
State Average		61.9	23.5	14.6	7

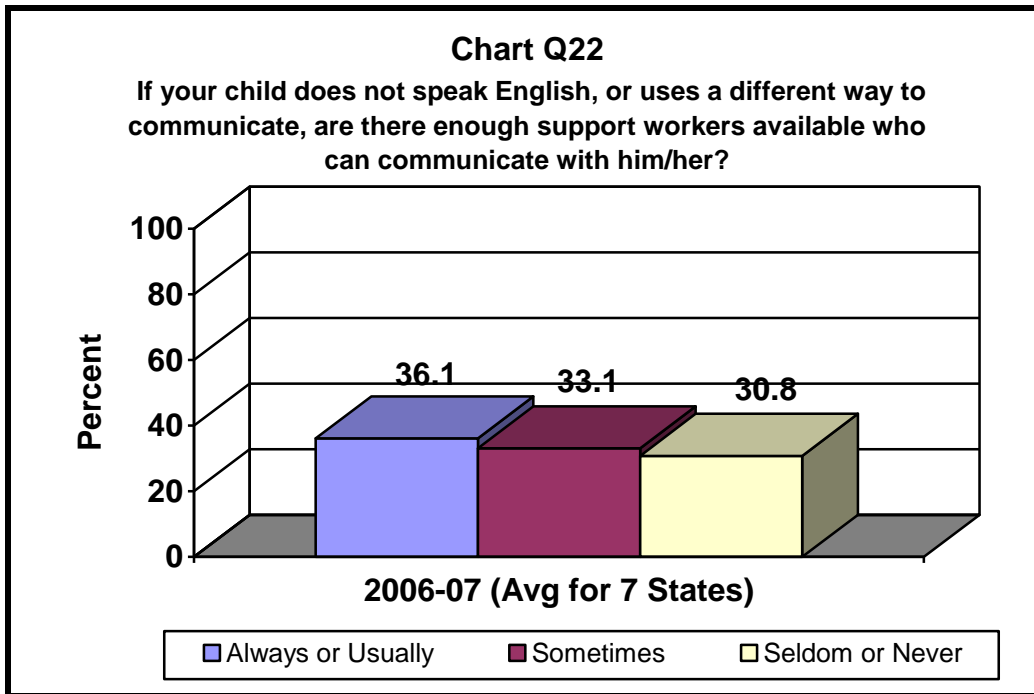


Table Q22
If your child does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		40.3	28.4	31.3	67
CT	↓↓↓	25.5	29.1	45.5	55
OK		32.7	30.8	36.5	52
TX		38.3	33.6	28.0	214
WA	↑↑↑	46.7	31.7	21.7	60
WV		31.2	31.2	37.7	77
WY		38.2	47.1	14.7	34
Total %		36.7	32.6	30.8	559
State Average		36.1	33.1	30.8	7

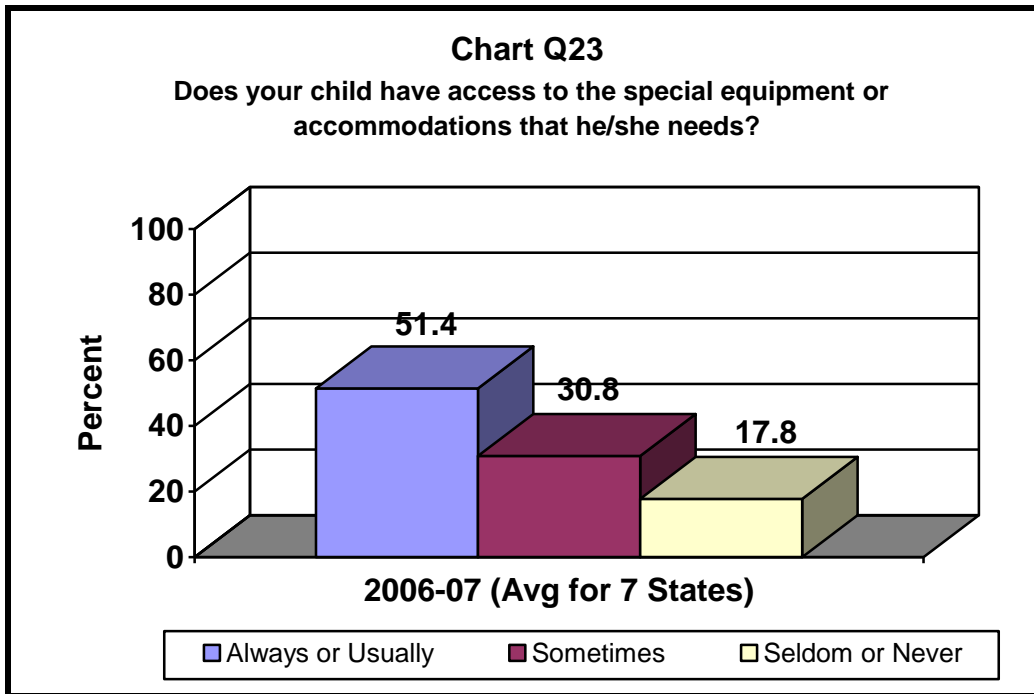


Table Q23
Does your child have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		50.4	30.1	19.5	113
CT	↓	42.9	35.7	21.4	112
OK	↓	45.9	29.6	24.5	159
TX	↑	58.7	28.0	13.3	615
WA		49.5	27.3	23.1	216
WV		50.0	32.3	17.7	186
WY	↑↑	62.1	32.6	5.3	95
Total %		53.3	29.6	17.0	1,496
State Average		51.4	30.8	17.8	7

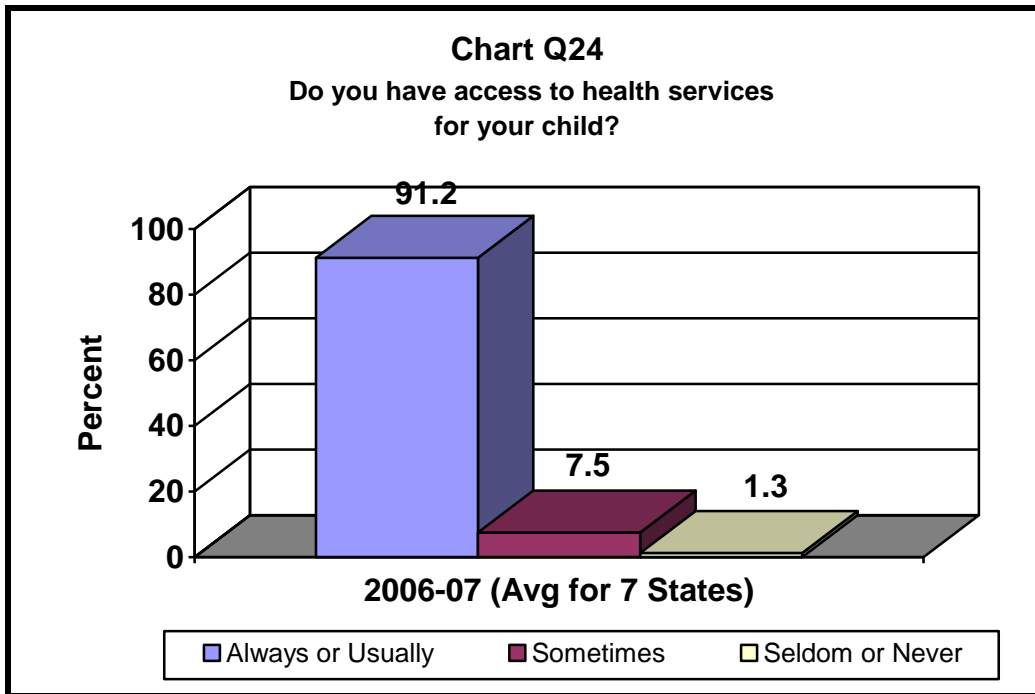


Table Q24
Do you have access to health services for your child?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	90.6	8.6	0.8	244
CT	86.6	12.1	1.3	231
OK	93.9	4.5	1.6	247
TX	90.8	7.3	1.8	762
WA	91.8	6.9	1.3	389
WV	95.3	3.9	0.7	279
WY	89.6	9.0	1.4	144
Total %	91.3	7.3	1.4	2,296
State Average	91.2	7.5	1.3	7

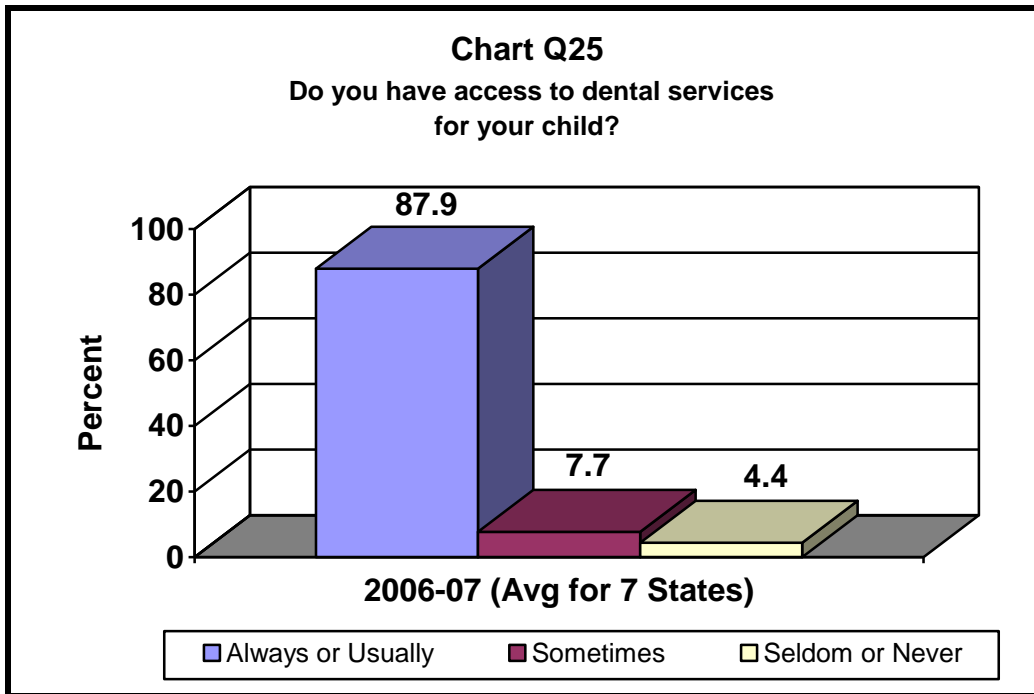


Table Q25
Do you have access to dental services for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		89.6	5.2	5.2	231
CT	↓	82.7	10.2	7.1	226
OK		90.9	4.9	4.1	243
TX		88.4	7.5	4.1	759
WA		89.1	6.8	4.0	396
WV		90.0	7.1	2.9	280
WY		84.5	12.0	3.5	142
Total %		88.3	7.4	4.3	2,277
State Average		87.9	7.7	4.4	7

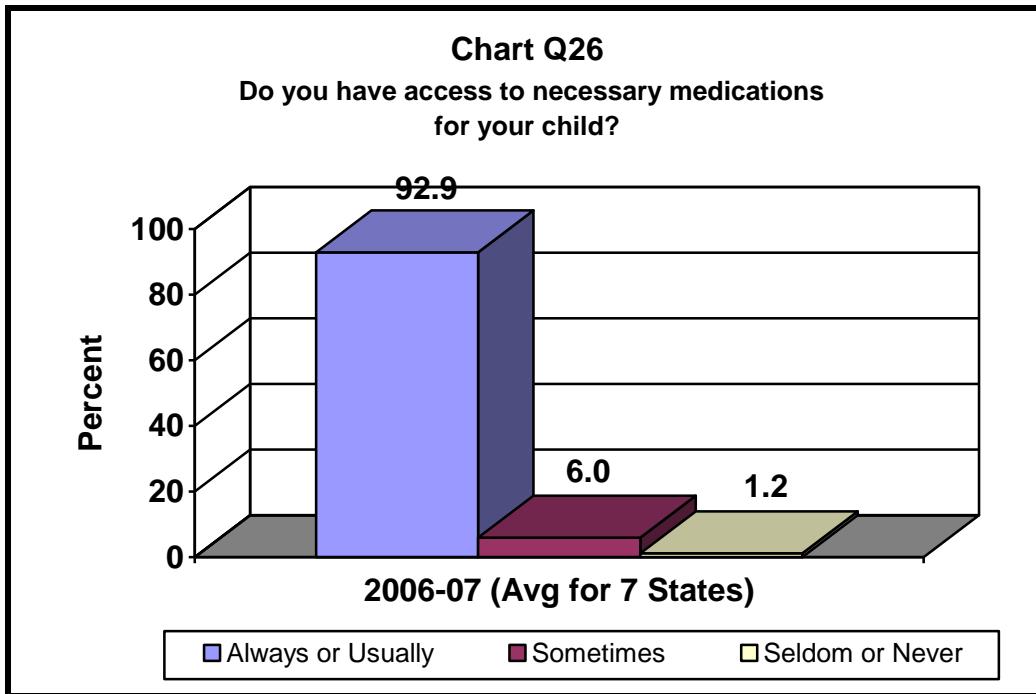


Table Q26
Do you have access to necessary medications for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		91.5	6.0	2.6	235
CT	↓	86.4	11.3	2.3	221
OK		94.6	5.0	0.4	241
TX		94.6	4.9	0.5	761
WA		94.0	4.7	1.3	385
WV		95.7	4.0	0.4	278
WY		93.5	5.8	0.7	138
Total %		93.4	5.5	1.0	2,259
State Average		92.9	6.0	1.2	7

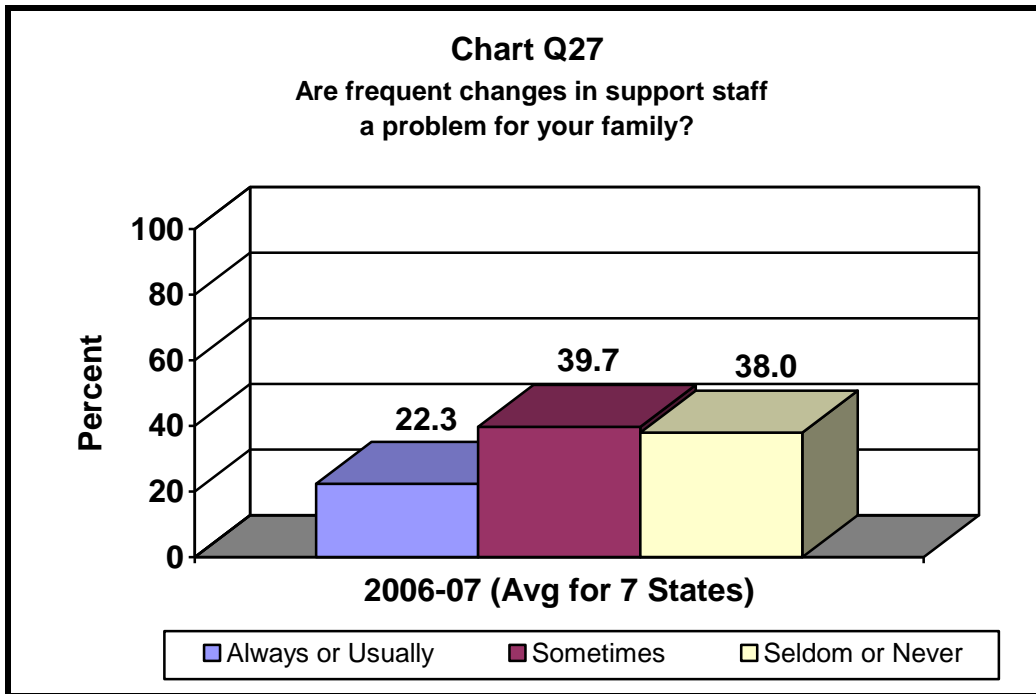


Table Q27
Are frequent changes in support staff a problem for your family?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	22.3	48.3	29.4	211
CT	19.4	44.8	35.8	165
OK	25.5	35.2	39.4	216
TX	22.0	42.1	35.9	665
WA	21.0	34.7	44.3	262
WV	26.7	45.5	27.8	255
WY	19.5	27.3	53.1	128
Total %	22.5	40.7	36.8	1,902
State Average	22.3	39.7	38.0	7

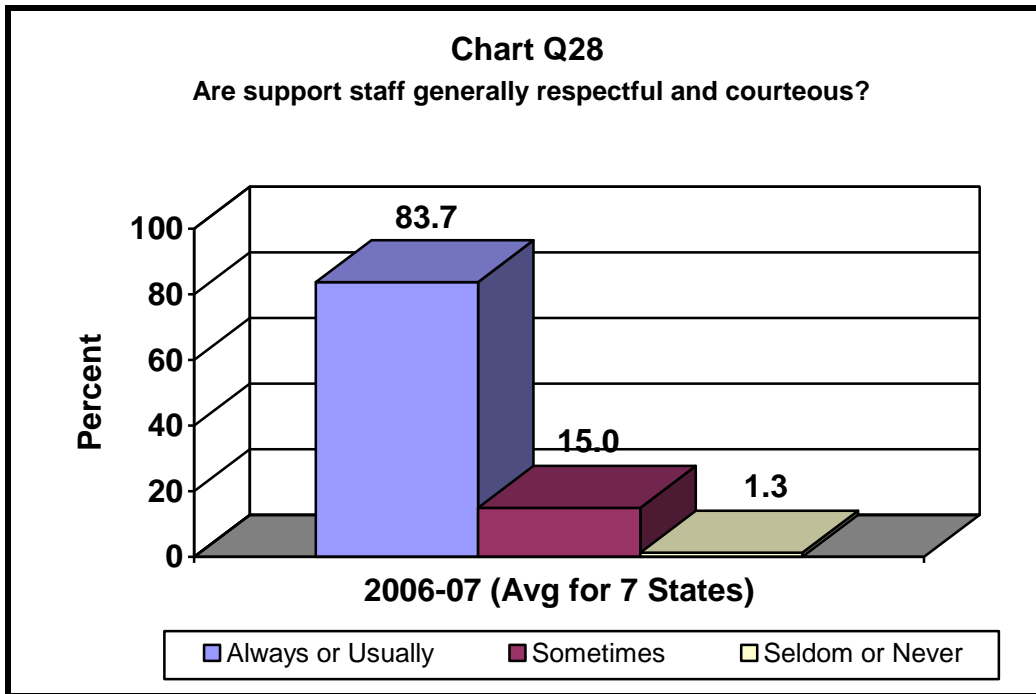


Table Q28
Are support staff generally respectful and courteous?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		86.3	12.9	0.8	240
CT		80.8	18.7	0.5	182
OK		81.8	16.1	2.1	236
TX		79.6	18.8	1.6	736
WA	↑	90.3	6.7	3.0	299
WV		81.0	18.6	0.4	274
WY		86.4	12.9	0.7	140
Total %		82.9	15.7	1.5	2,107
State Average		83.7	15.0	1.3	7

Choice and Control

- Across the states, on average, 67% of respondents chose the agencies or providers who work with their families. In Texas and Wyoming, this percentage was considerably higher, with 76%-85% of families choosing their service providers. In Connecticut and Arizona, considerably fewer families chose their providers/agencies (45%-49%).
- While 67% of respondents typically chose their family's provider agency, only 51% (on average) typically chose the support workers who worked directly with their family. Once again, the results were considerably higher in Wyoming.
- Among all respondents, nearly half (48%) had control or input over the hiring and management of their support staff, and an additional 19% indicated they had this control sometimes. Thirty-three percent, however, had little or no input/control over the hiring or management of their family's support staff.
- While 67% of respondents had at least some control over the hiring or management of their support workers, 91% wanted this type of control at least some of the time.
- Only 29% of respondents knew how much money was spent by the MR/DD agency on behalf of their family member. Over two-thirds (71%), however, had little or no idea. These results vary significantly from state to state.
- Overall, more than half of the families surveyed (57%), had at least some decision-making authority over how the money available to their family member with disabilities by the MR/DD agency was spent. Forty-three percent, however, did not. Once again, results varied considerably from state to state.

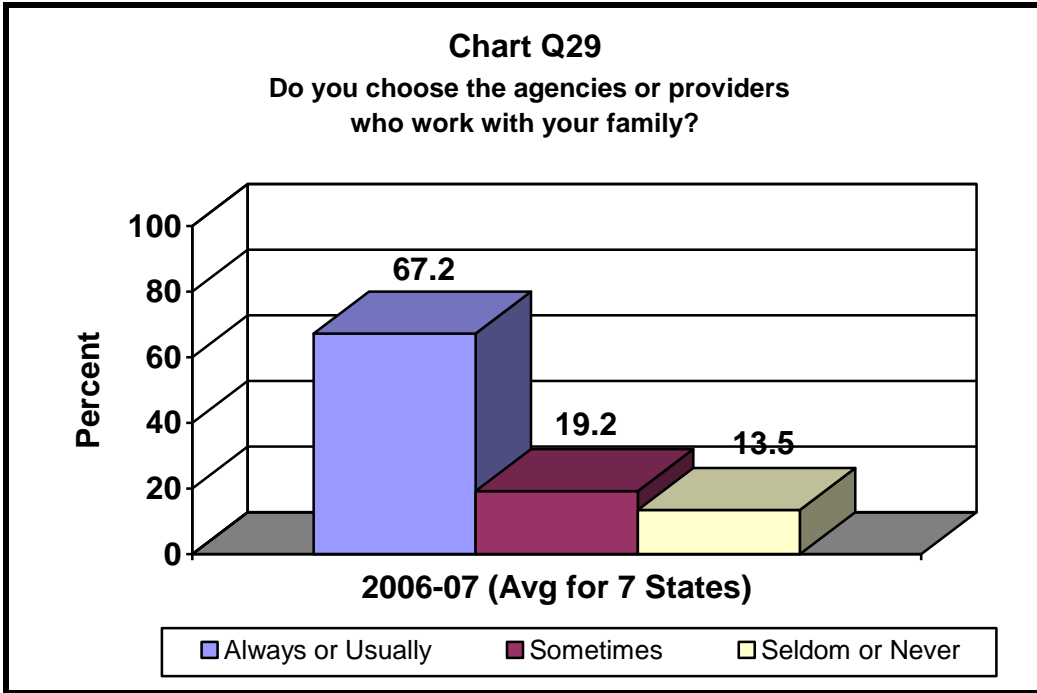


Table Q29
Do you choose the agencies or providers who work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	49.3	23.1	27.5	229
CT	↓↓↓	45.0	31.7	23.3	180
OK	↑	75.7	16.3	7.9	239
TX	↑↑	78.4	15.0	6.6	747
WA		66.0	17.6	16.4	347
WV		71.8	17.2	11.0	273
WY	↑↑	84.5	13.4	2.1	142
Total %		69.8	18.0	12.2	2,157
State Average		67.2	19.2	13.5	7

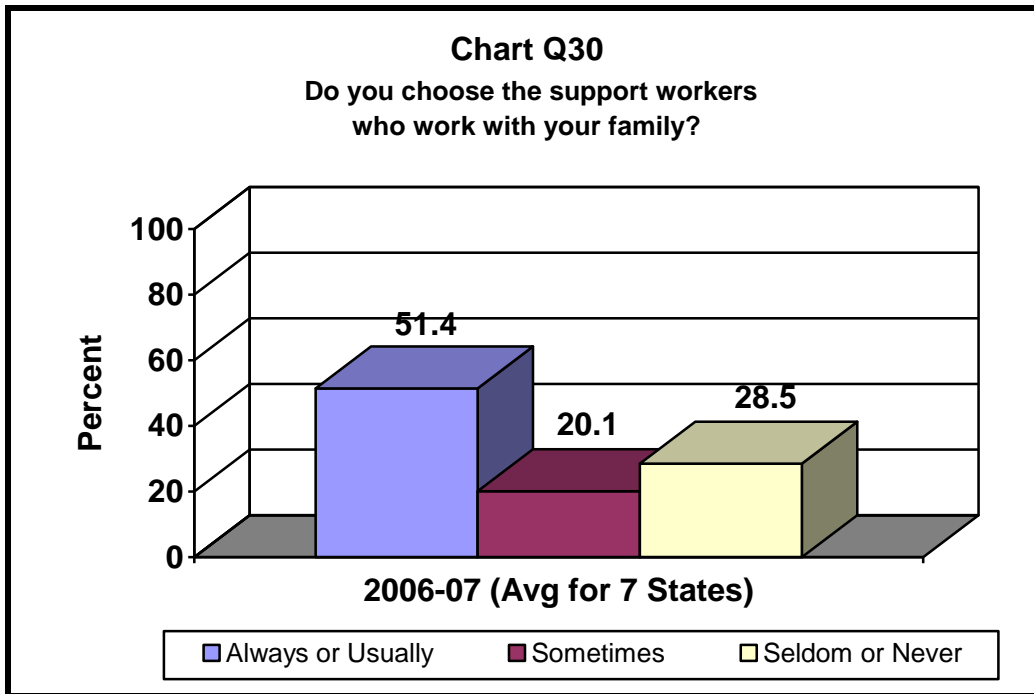


Table Q30
Do you choose the support workers who work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	30.0	19.2	50.7	213
CT	↓↓↓	28.2	23.6	48.3	174
OK	↑↑↑	67.2	19.4	13.4	232
TX	↑	61.3	23.5	15.2	715
WA	↓	43.6	21.5	34.9	307
WV		47.5	20.8	31.7	265
WY	↑↑↑	81.9	13.0	5.1	138
Total %		52.8	21.2	25.9	2,044
State Average		51.4	20.1	28.5	7

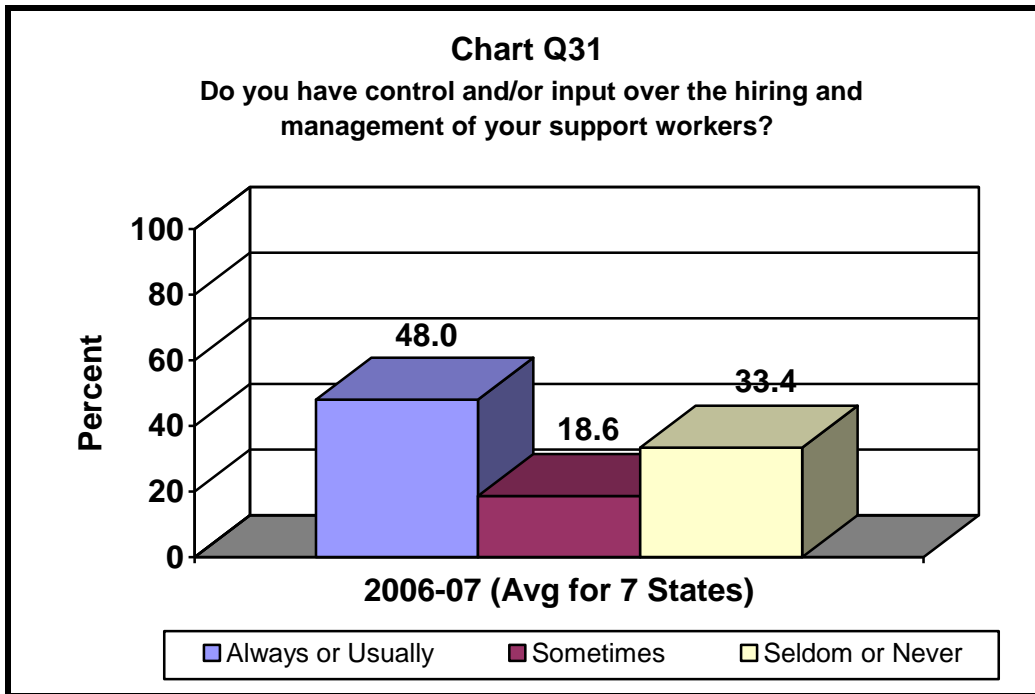


Table Q31
Do you have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	29.6	18.3	52.2	186
CT	↓↓↓	24.8	19.1	56.0	141
OK	↑↑↑	66.8	17.3	15.9	220
TX	↑↑↑	59.4	20.9	19.6	683
WA	↑	56.5	18.8	24.7	308
WV	↓↓↓	36.1	19.3	44.6	233
WY	↑↑↑	63.1	16.2	20.8	130
Total %		51.7	19.3	29.0	1,901
State Average		48.0	18.6	33.4	7

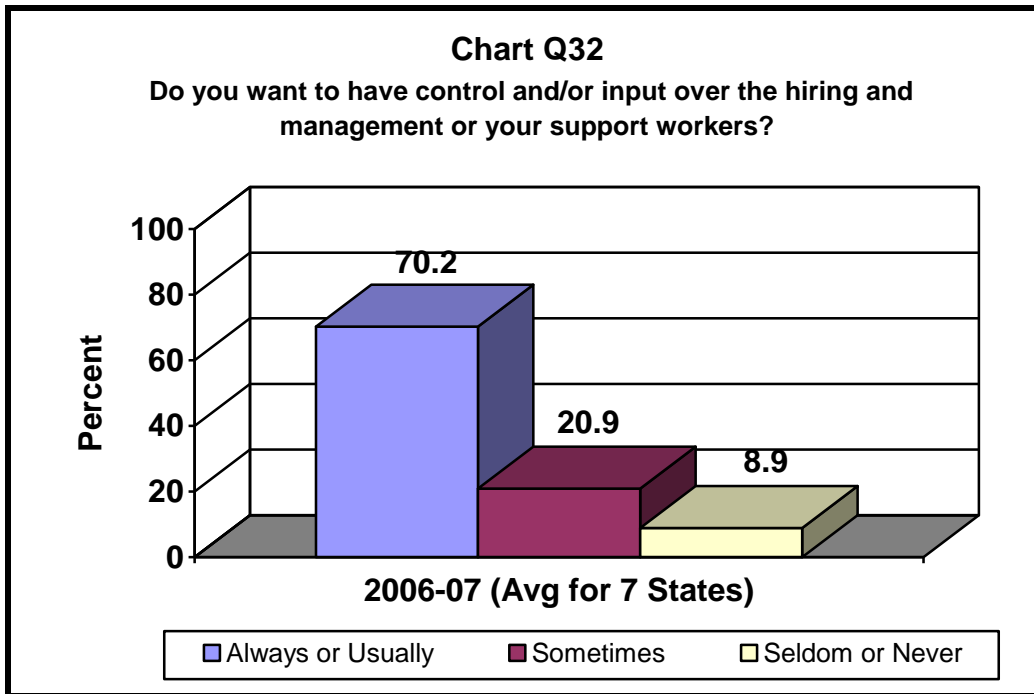


Table Q32
Do you want to have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	59.0	26.1	14.9	188
CT	↓	64.5	27.6	7.9	152
OK	↑	78.6	18.3	3.1	224
TX	↑	79.1	15.0	5.9	646
WA		72.1	16.7	11.1	287
WV		68.8	21.0	10.3	224
WY		69.6	21.6	8.8	125
Total %		72.8	19.0	8.2	1,846
State Average		70.2	20.9	8.9	7

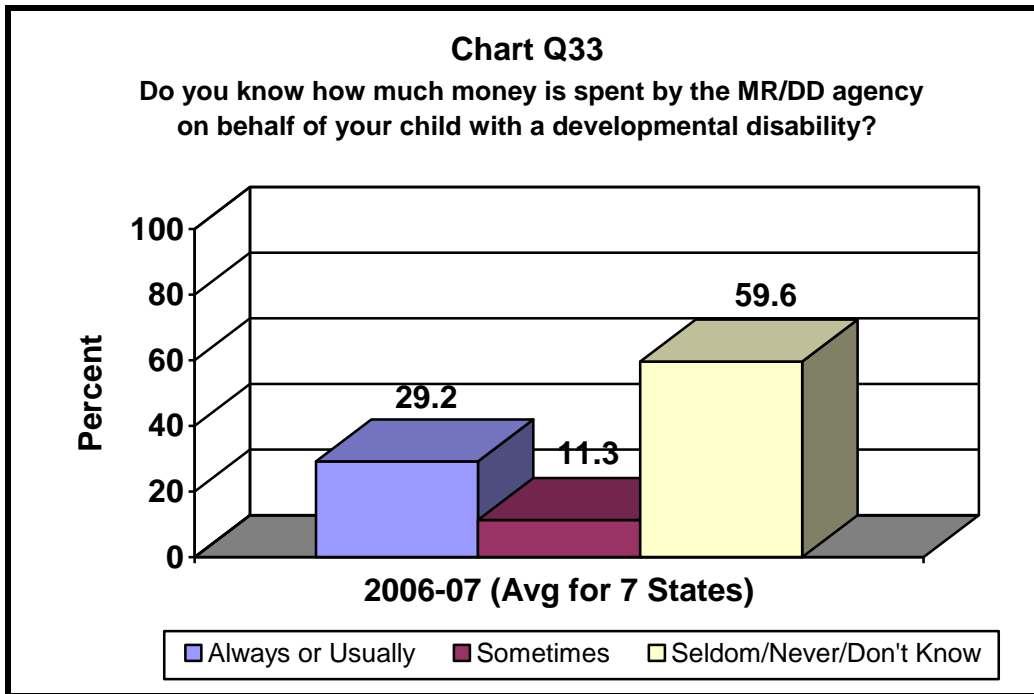


Table Q33
Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ	↓↓↓	5.0	6.6	88.4	241
CT	↓↓↓	15.1	6.0	78.9	218
OK	↑	35.7	13.3	51.0	249
TX	↑	38.2	12.6	49.2	752
WA	↓	20.7	10.7	68.6	382
WV	↓	23.6	15.2	61.2	276
WY	↑↑↑	65.8	14.4	19.9	146
Total %		29.2	11.5	59.3	2,264
State Average		29.2	11.3	59.6	7

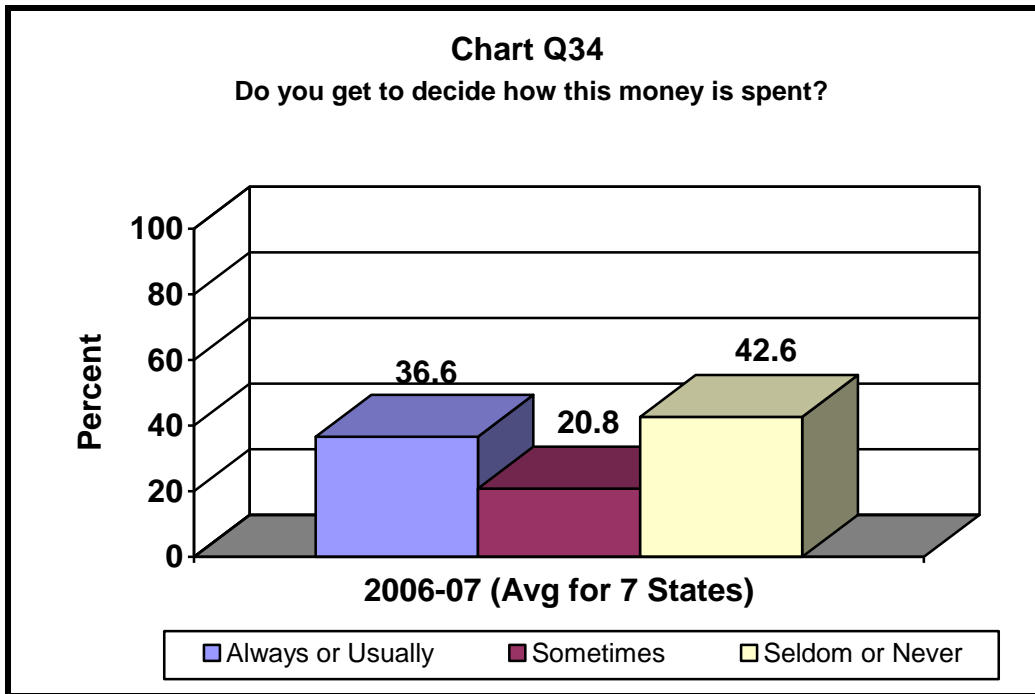


Table Q34
Do you get to decide how this money is spent?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	8.1	8.7	83.2	149
CT		38.1	14.2	47.8	134
OK	↑	44.1	26.7	29.2	195
TX	↑↑↑	47.7	24.9	27.5	579
WA		32.9	21.4	45.7	280
WV	↓↓↓	20.6	22.2	57.2	194
WY	↑↑↑	64.9	27.6	7.5	134
Total %		38.7	22.1	39.2	1,665
State Average		36.6	20.8	42.6	7

Community Connections

- On average, only 21% 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 28% said that staff were sometimes helpful, but 51% stated that planning and support staff were seldom or never helpful in connecting their family members to typical community supports or resources.
- Overall, one-third of respondents (33%) indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (40% said they received little or no help in this area, and the remaining 27% said it occasionally happens).
- Only 35% of families felt their family member always or usually had access to community activities. Twenty-eight percent stated their family member seldom or never had access to the community.
- While 35% had regular access to community activities, only 23% of children regularly participated in them. Forty percent of respondents said that their child seldom or never participated in community activities or events.
- About half (53%) of respondents' children regularly spend time with children who do not have disabilities ~ which leaves the other half (47%) who only spend some or little time with children without disabilities.

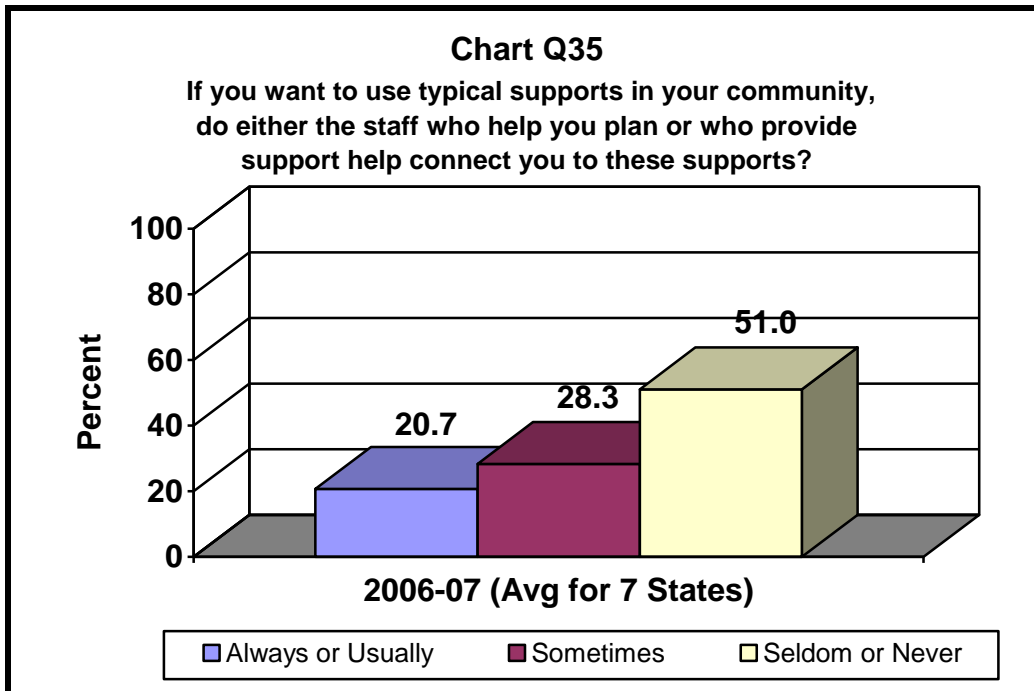


Table Q35
If you want to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	14.6	25.5	59.9	157
CT	↓↓	10.1	27.2	62.7	158
OK		22.5	27.8	49.7	169
TX		22.0	23.0	55.1	501
WA		20.8	27.7	51.5	264
WV	↑	28.0	29.0	43.0	214
WY	↑	27.2	37.9	35.0	103
Total %		21.1	26.8	52.2	1,566
State Average		20.7	28.3	51.0	7

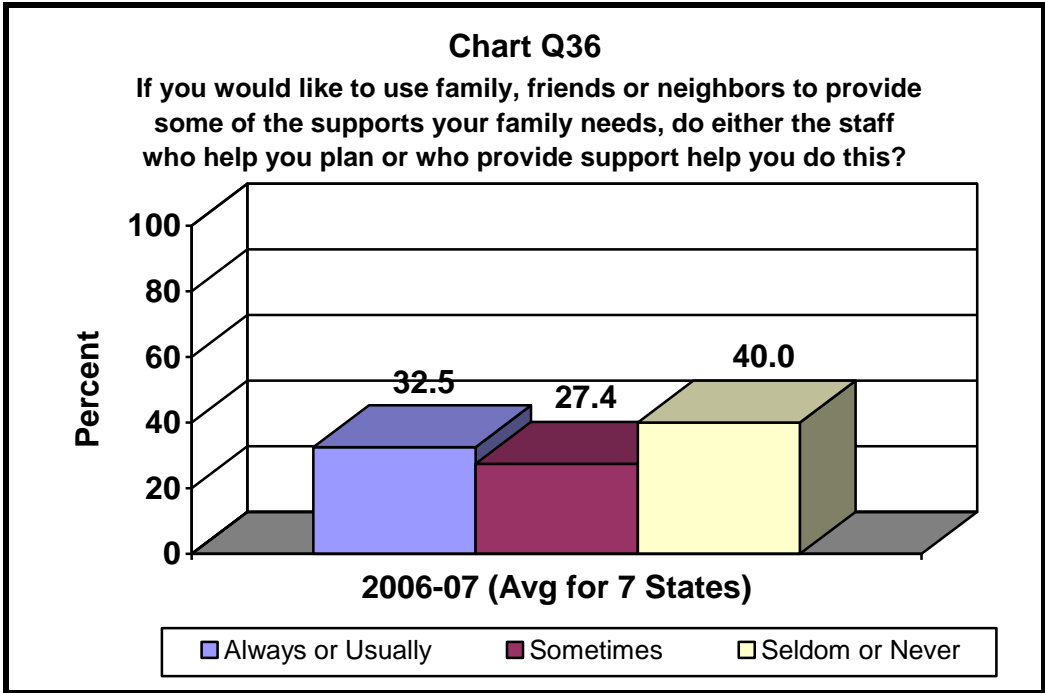


Table Q36

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
AZ	21.0	19.1	59.9	162
CT	10.3	27.1	62.6	155
OK	44.3	27.8	27.8	194
TX	38.6	28.2	33.2	546
WA	39.5	23.4	37.1	286
WV	34.5	33.2	32.3	220
WY	39.6	33.3	27.0	111
Total %	34.6	27.4	38.0	1,674
State Average	32.5	27.4	40.0	7

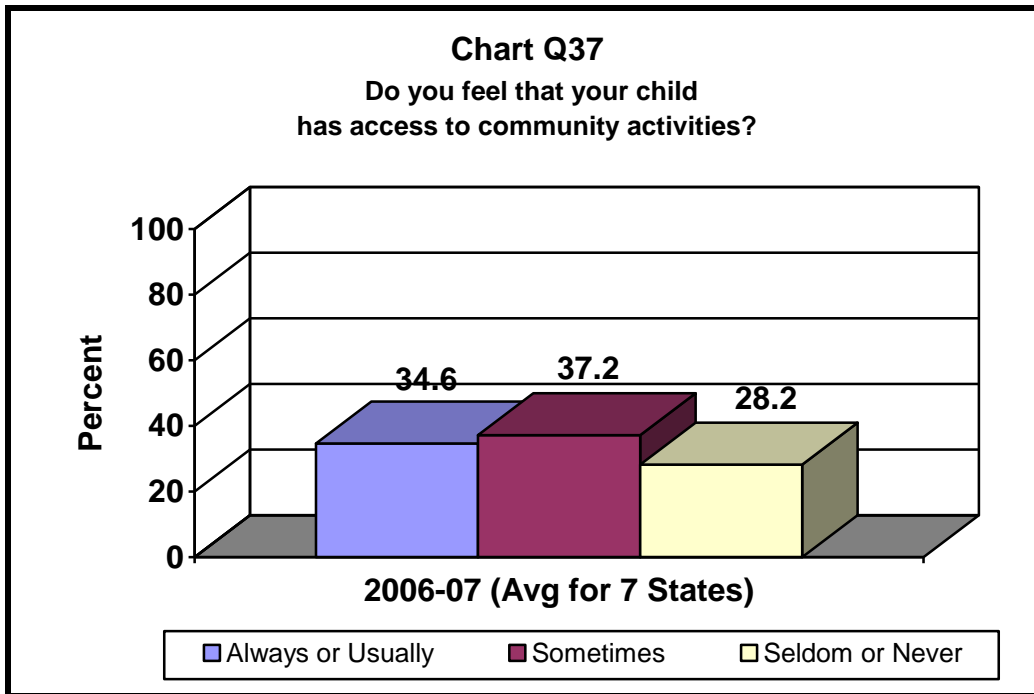


Table Q37
Do you feel that your child has access to community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		34.1	34.1	31.7	208
CT	↓↓↓	16.7	39.1	44.2	215
OK		38.2	37.8	23.9	238
TX		34.4	35.3	30.2	688
WA		31.5	37.3	31.2	362
WV	↑↑	49.3	33.5	17.3	278
WY		37.7	43.5	18.8	138
Total %		34.7	36.5	28.8	2,127
State Average		34.6	37.2	28.2	7

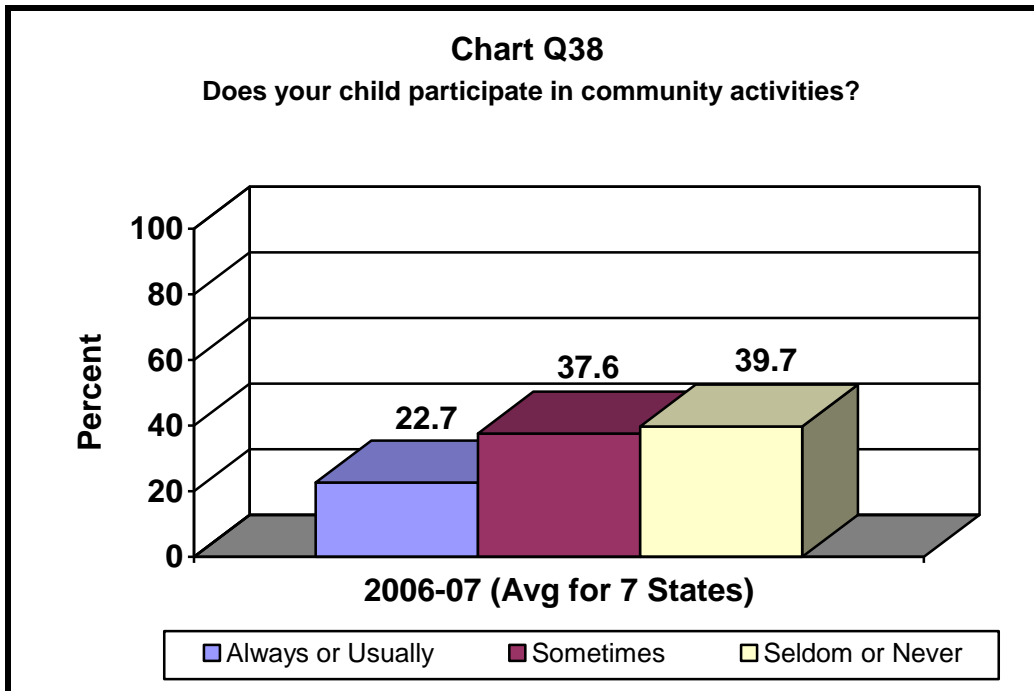


Table Q38
Does your child participate in community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		18.3	33.9	47.7	218
CT	↓	13.9	34.6	51.5	231
OK		23.5	40.3	36.2	243
TX		21.6	34.4	44.0	700
WA		19.8	32.3	47.9	378
WV	↑↑	39.0	42.9	18.1	282
WY		23.1	44.8	32.2	143
Total %		22.7	36.4	40.9	2,195
State Average		22.7	37.6	39.7	7

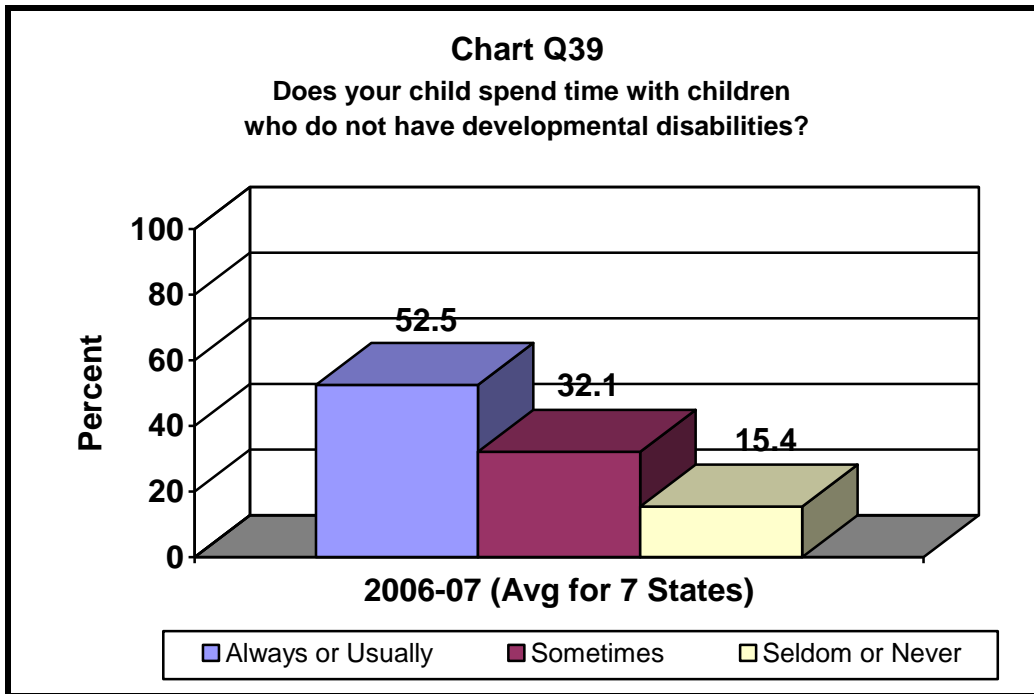


Table Q39
Does your child spend time with children who do not have developmental disabilities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		55.5	28.6	15.9	245
CT	↓	45.6	36.0	18.4	239
OK		53.8	34.1	12.0	249
TX		50.5	32.2	17.4	749
WA		48.6	35.6	15.8	393
WV	↑	61.1	30.2	8.8	285
WY		52.4	28.0	19.6	143
Total %		52.0	32.5	15.5	2,303
State Average		52.5	32.1	15.4	7

Outcomes and Satisfaction with Services and Supports

- Overall, 53% were always or usually satisfied with the services and supports they received. 38% were somewhat satisfied, and 8% were seldom or never satisfied.
- On average, only 44% of respondents knew about their agency's grievance process, while 44% had little or no familiarity with the process for lodging a complaint.
- Half of respondents (50%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 50%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.
- Sixty-six percent of families felt that services and supports have made a positive difference in their lives. Six percent stated that they seldom or never felt this way.
- Nearly all families (92%) felt that family supports improved, sometimes or more often, their ability to care for their child.
- Over two-thirds (71%) of respondents indicated that services have made a difference in helping them keep their child at home.
- Eighty-four percent of respondents felt that their family member was usually happy.

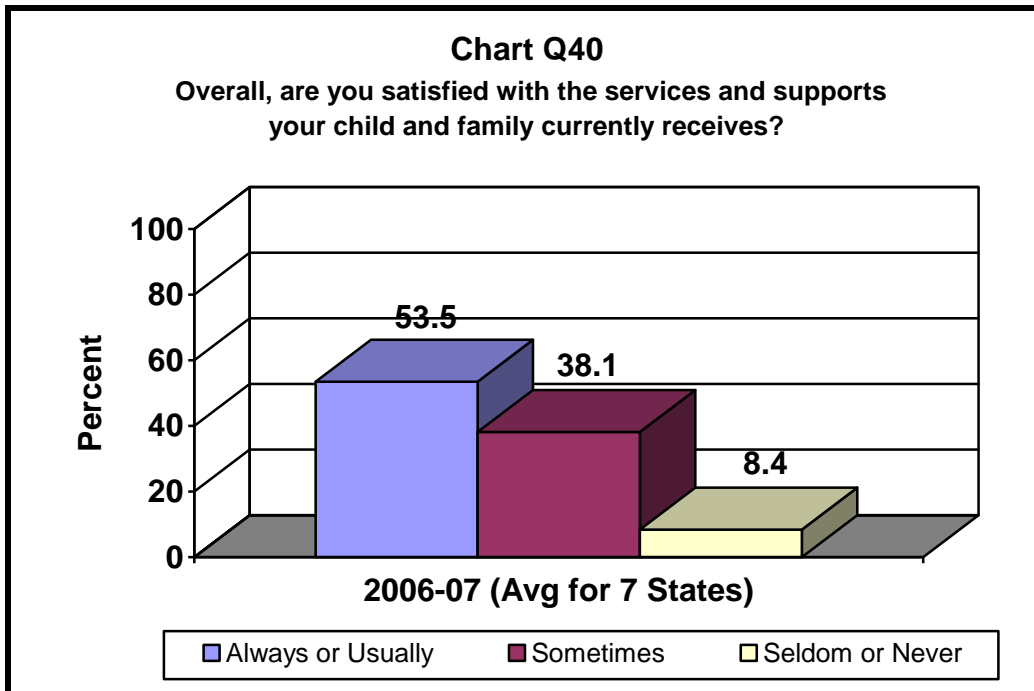


Table Q40
Overall, are you satisfied with the services and supports your child and family currently receives?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	48.4	43.0	8.6	244
CT	↓↓	34.1	46.2	19.7	223
OK		57.3	36.6	6.1	246
TX	↑	59.2	36.2	4.6	754
WA	↓	47.7	41.9	10.4	396
WV	↑	59.4	35.3	5.3	283
WY	↑↑	68.1	27.8	4.2	144
Total %		54.0	38.3	7.7	2,290
State Average		53.5	38.1	8.4	7

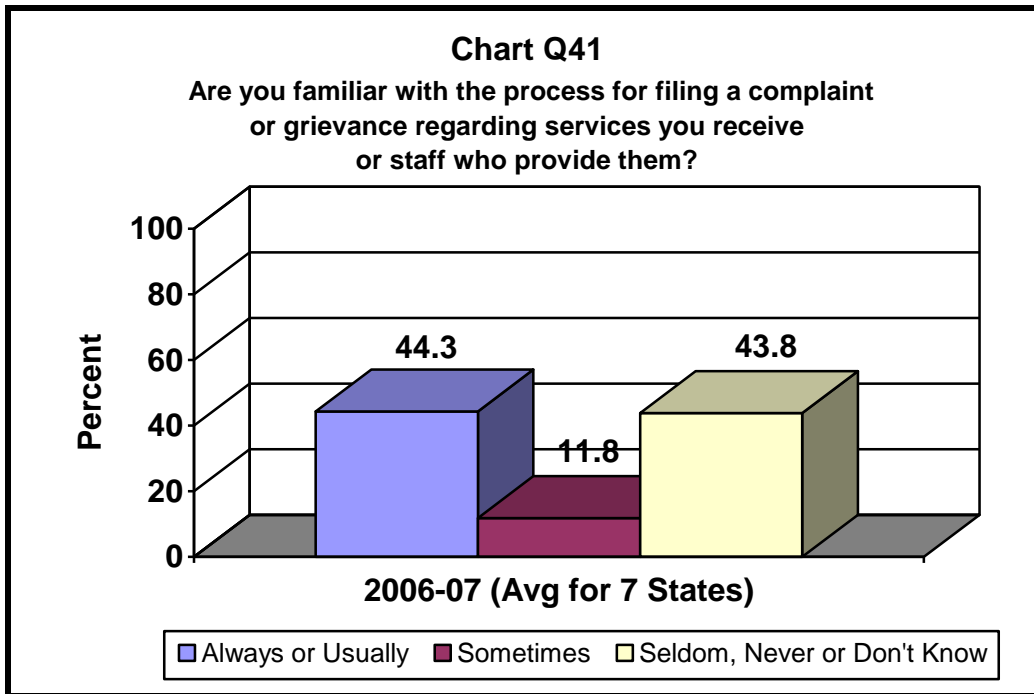


Table Q41
 Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ	↓	36.8	11.8	51.3	228
CT	↓↓	21.2	8.9	70.0	203
OK	↑	54.1	12.0	33.9	233
TX	↑	51.9	13.0	35.0	722
WA	↓	39.1	12.1	48.8	371
WV	↑	49.8	12.8	37.4	265
WY	↑↑	57.4	12.1	30.5	141
Total %		45.6	12.2	42.3	2,163
State Average		44.3	11.8	43.8	7

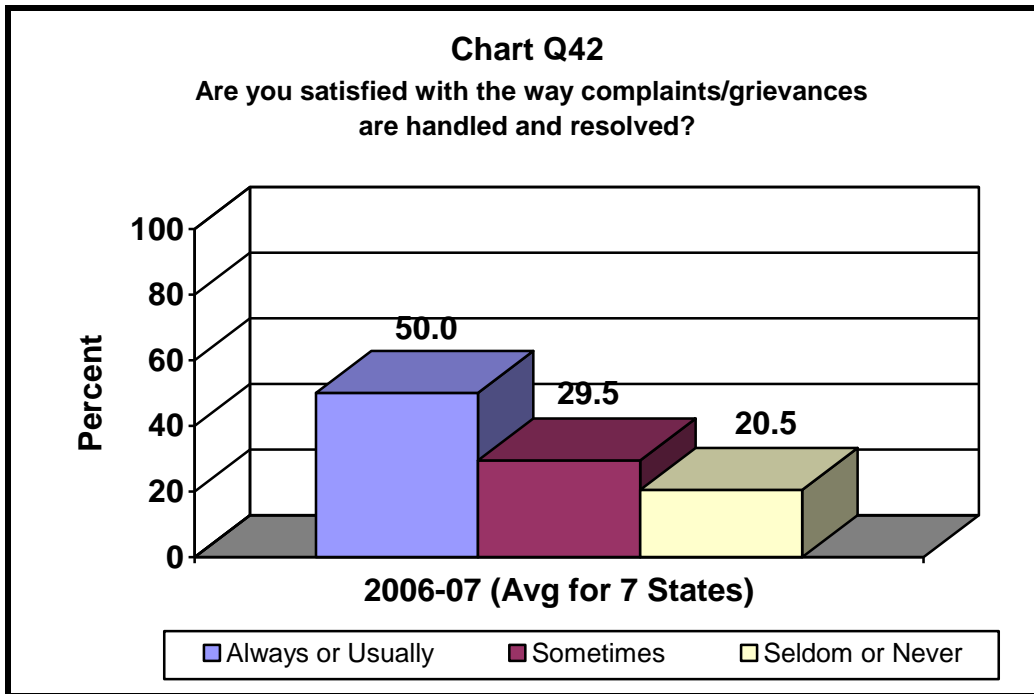


Table Q42
Are you satisfied with the way complaints/grievances are handled and resolved?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	39.4	35.1	25.5	94
CT	↓	41.7	28.3	30.0	60
OK	↑	56.6	27.4	15.9	113
TX		53.3	28.3	18.4	375
WA		49.3	31.3	19.4	144
WV	↑	55.7	20.9	23.5	115
WY		53.8	35.4	10.8	65
Total %		51.3	28.9	19.8	966
State Average		50.0	29.5	20.5	7

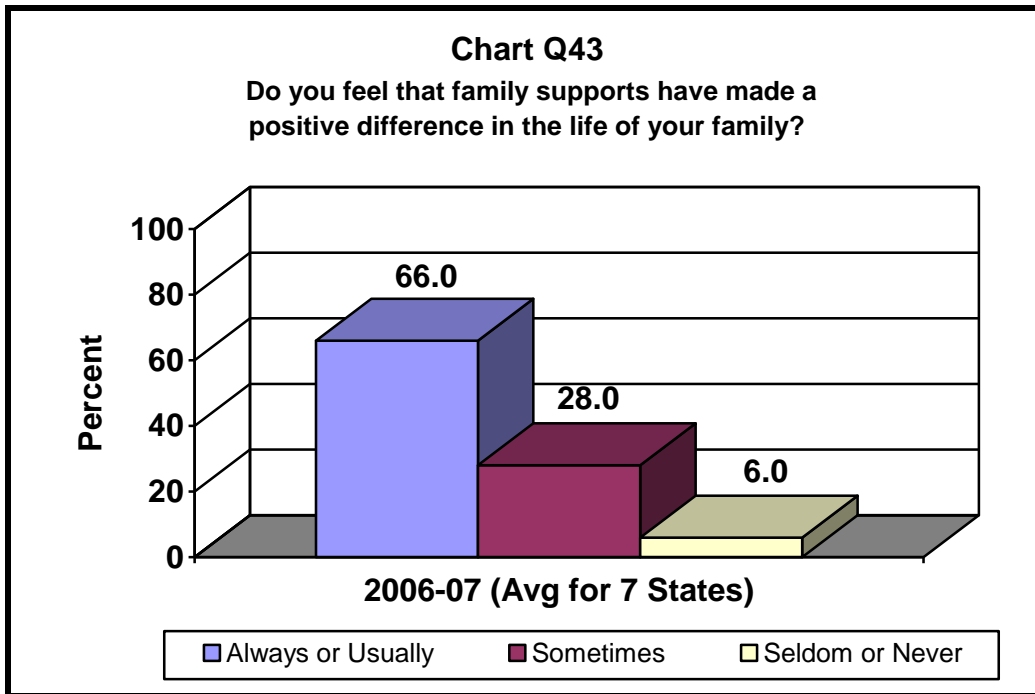


Table Q43
Do you feel that family supports have made a positive difference in the life of your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	58.1	37.2	4.7	215
CT	↓↓	50.3	35.2	14.5	193
OK		70.0	25.7	4.3	230
TX	↑	74.4	21.0	4.6	733
WA		64.7	28.0	7.3	371
WV		65.2	31.2	3.6	276
WY	↑↑	79.1	18.0	2.9	139
Total %		67.6	26.7	5.7	2,157
State Average		66.0	28.0	6.0	7

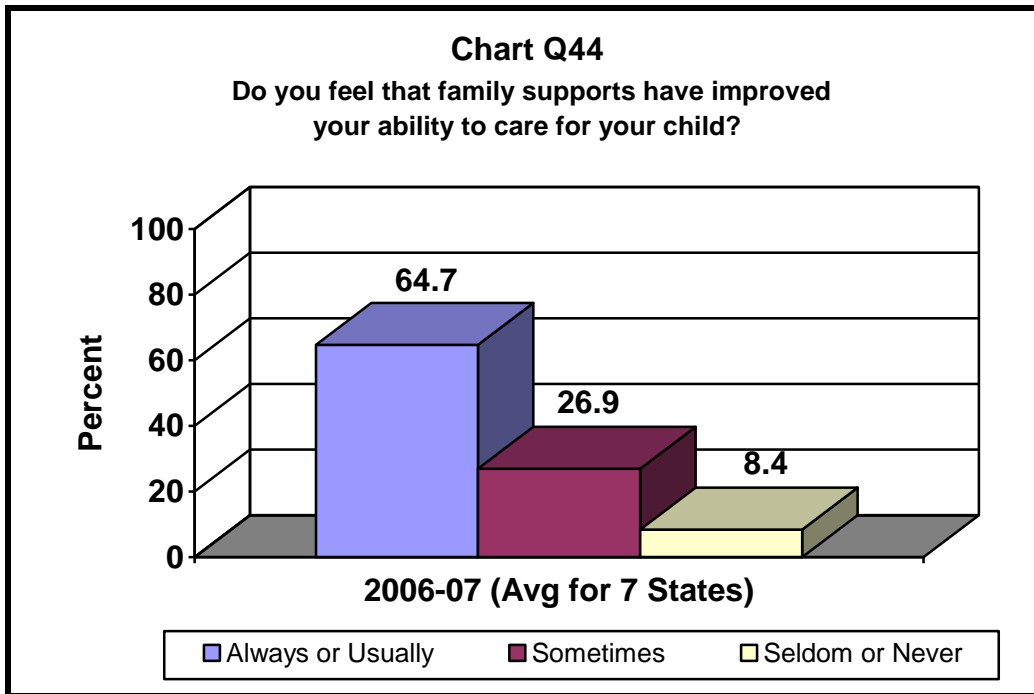


Table Q44
Do you feel that family supports have improved your ability to care for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	58.1	32.4	9.5	222
CT	↓↓	45.2	35.2	19.6	199
OK		66.1	28.7	5.2	230
TX	↑	74.6	20.2	5.2	737
WA		64.2	29.0	6.7	372
WV		66.1	26.9	7.0	271
WY	↑↑	78.3	15.9	5.8	138
Total %		66.7	25.8	7.5	2,169
State Average		64.7	26.9	8.4	7

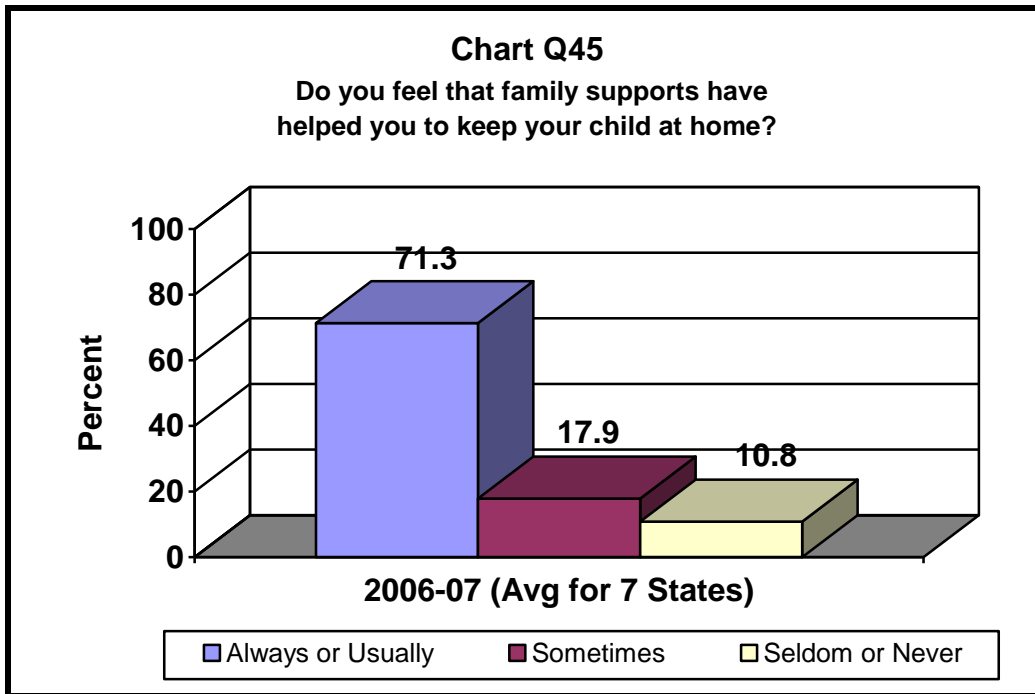


Table Q45
Do you feel that family supports have helped you to keep your child at home?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		67.7	21.2	11.1	198
CT	↓↓↓	50.9	24.0	25.1	167
OK		74.3	18.9	6.8	206
TX	↑↑↑	81.7	13.3	5.0	716
WA		68.7	21.3	9.9	342
WV		71.4	18.0	10.6	255
WY	↑↑↑	84.4	8.6	7.0	128
Total %		73.7	17.2	9.1	2,012
State Average		71.3	17.9	10.8	7

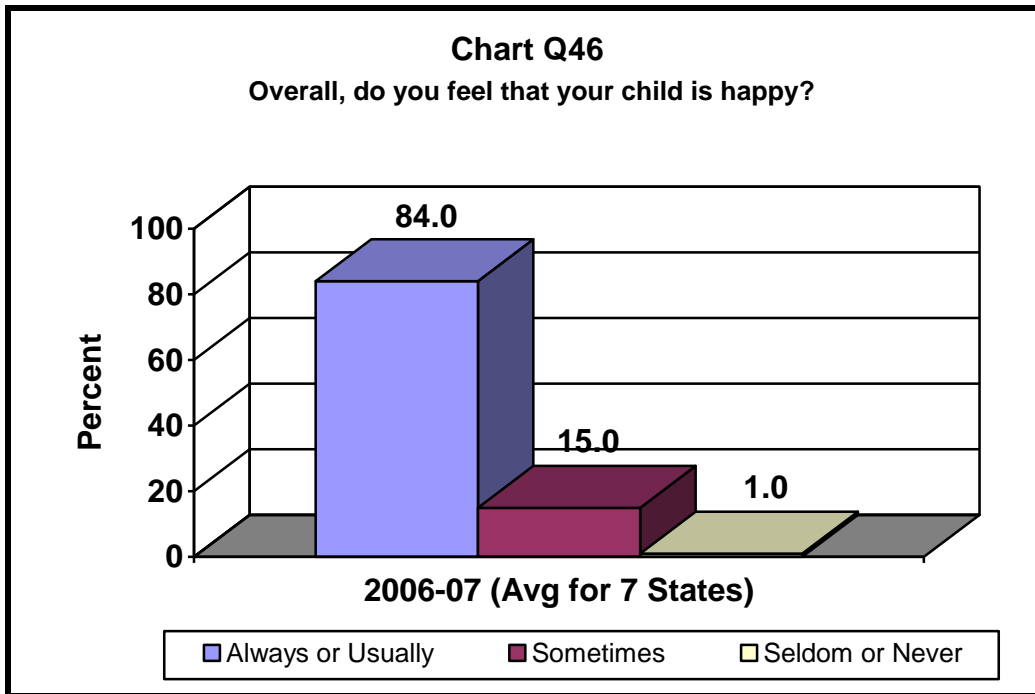


Table Q46
Overall, do you feel that your child is happy?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	83.9	14.5	1.6	249
CT	76.8	22.7	0.4	233
OK	87.2	12.3	0.4	243
TX	87.8	10.9	1.3	762
WA	81.1	17.4	1.5	396
WV	86.9	13.1	0.0	282
WY	84.1	13.8	2.1	145
Total %	84.7	14.2	1.1	2,310
State Average	84.0	15.0	1.0	7

Aggregate Results & State Comparisons

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

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

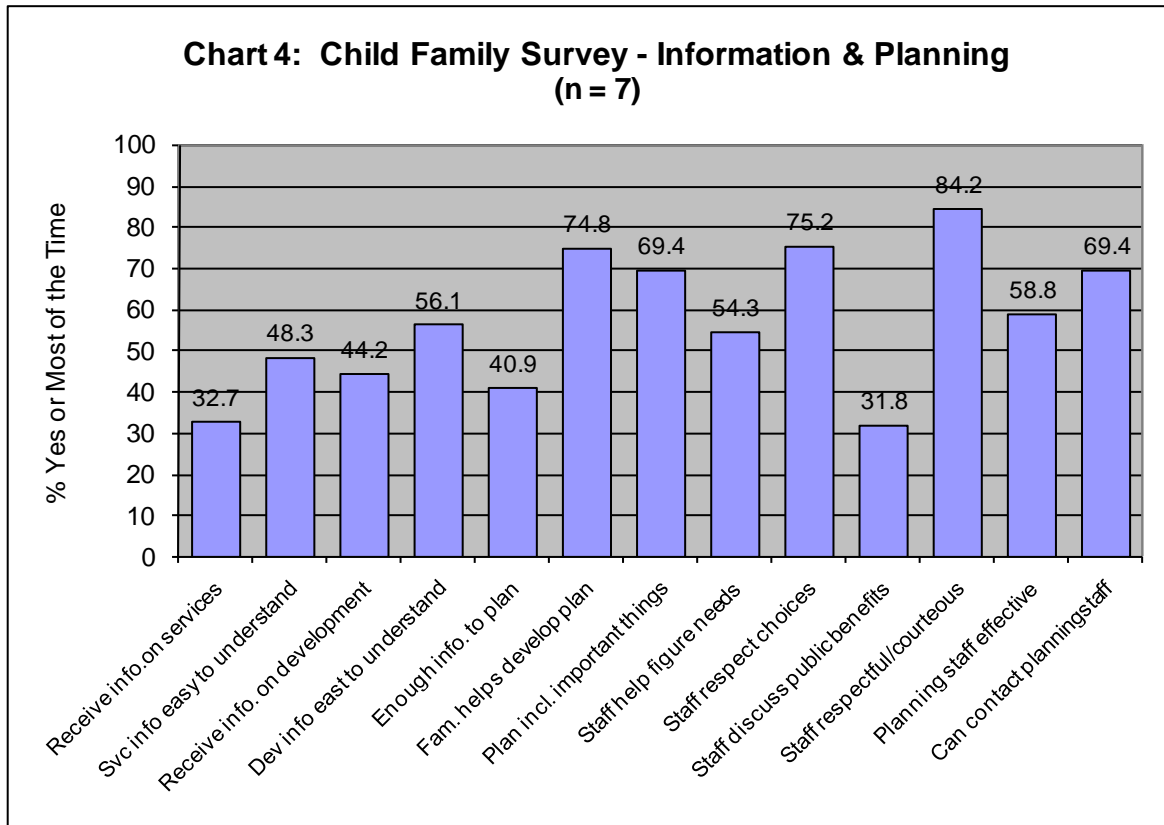
For each category, there is also a TABLE that looks at the arrows (i.e., \uparrow and \downarrow) of the previous Tables, with single arrows representing state results $\pm 5\%$ from the state average, and double arrows ($\uparrow\uparrow$ and $\downarrow\downarrow$) representing $\pm 10\%$ from the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

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

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

Information and Planning

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



**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
AZ										↓		↓		-2
CT	↓		↓	↓↓	↓↓	↓↓	↓↓	↓↓	↓	↓			↓	-15
OK						↑				↑				2
TX														0
WA			↓		↓	↓	↓	↓					↓	-6
WV			↑				↑	↑						3
WY	↑↑	↑↑	↑	↑↑	↑↑	↑↑	↑↑	↑↑	↑↑		↑	↑↑	↑↑	22

Access and Delivery of Services

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

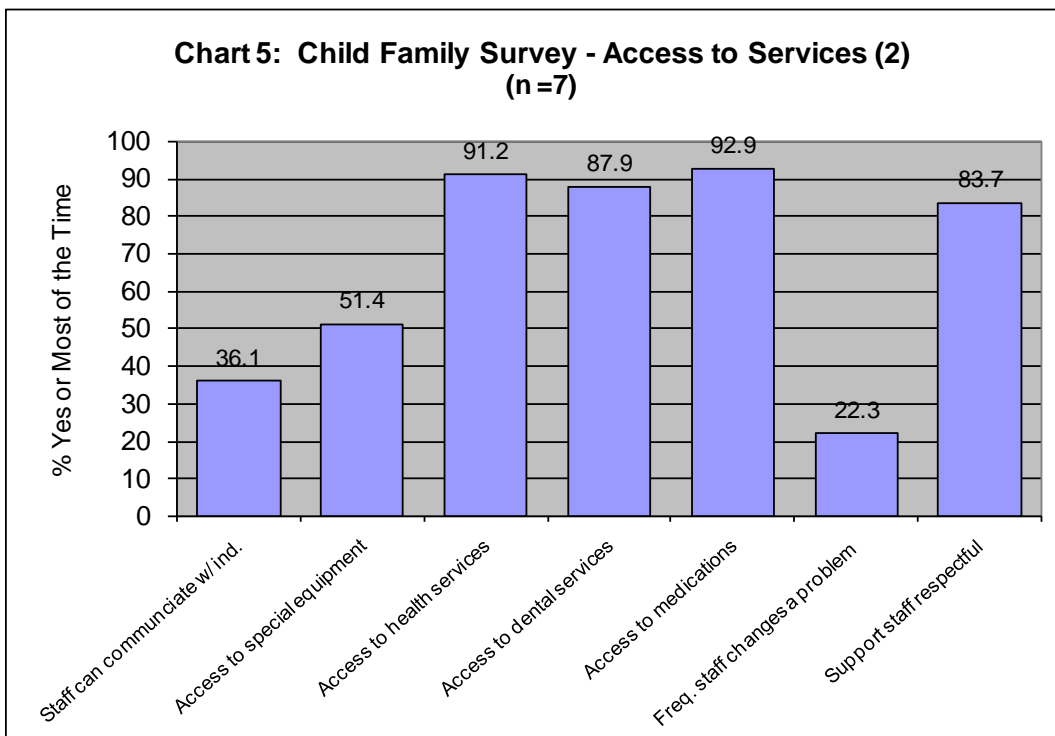
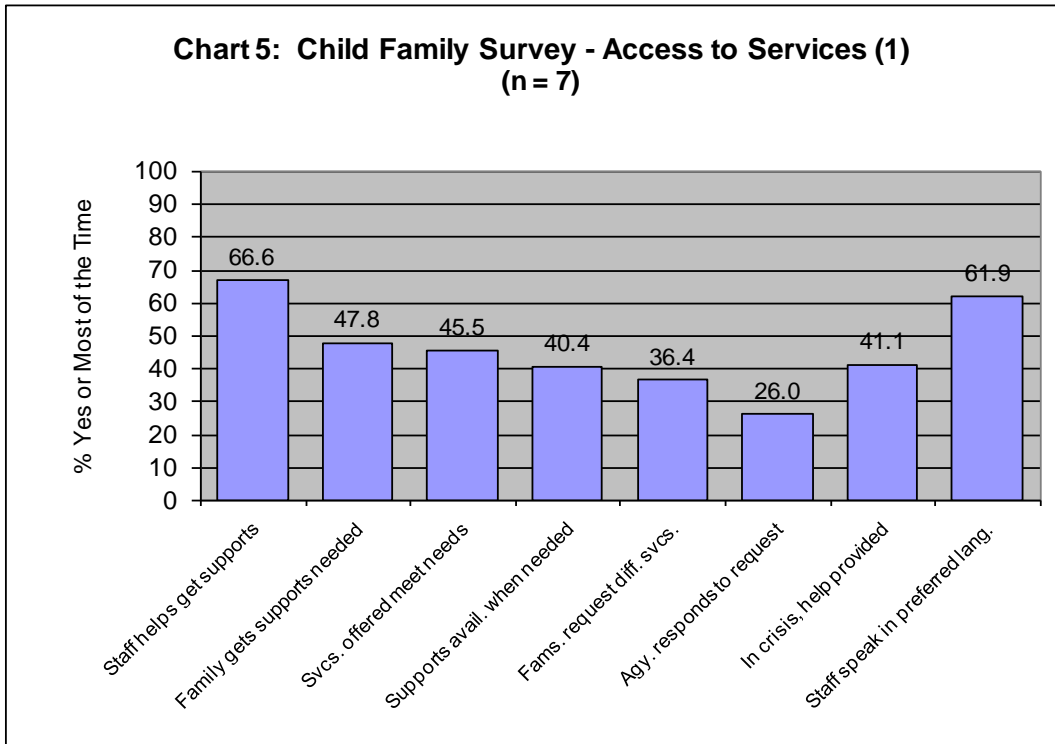
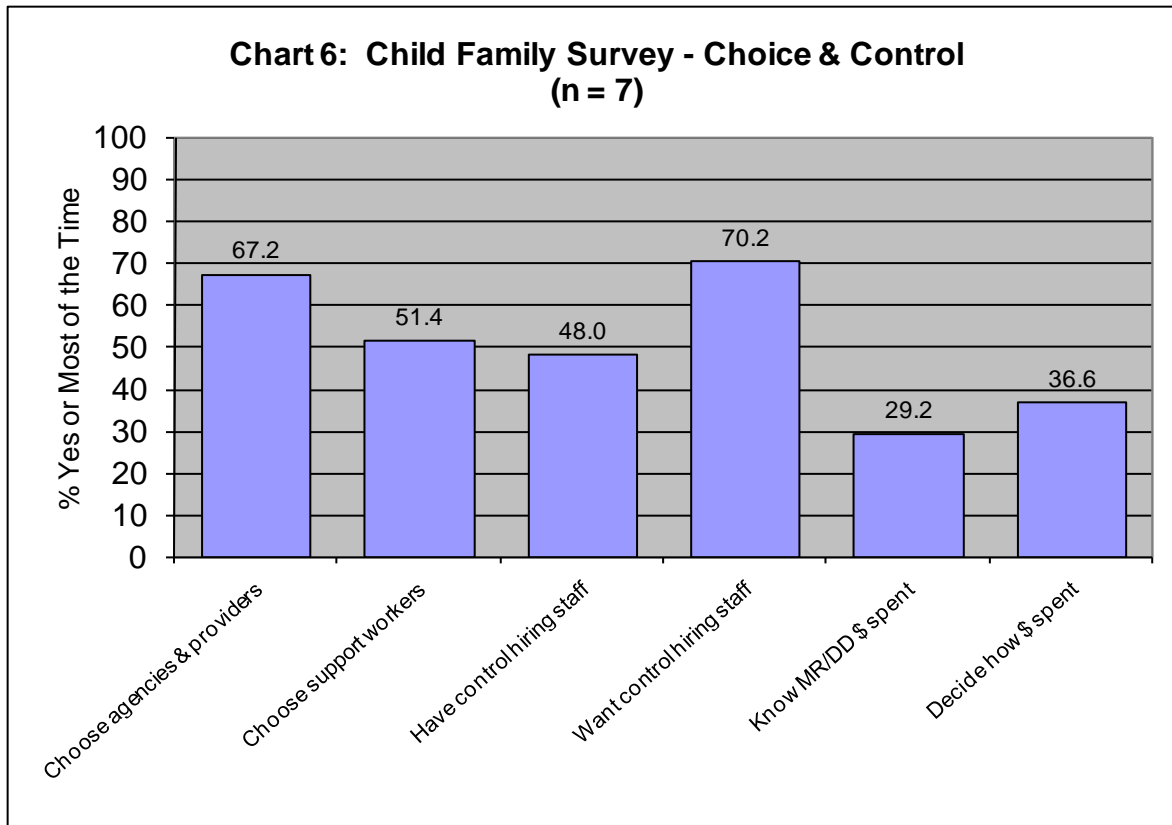


Table 18
Deviation in Responses Above & Below State Average
Access to Services & Supports

State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Q27	Q28	Net Sum
AZ								↑								1
CT	↓↓	↓↓	↓↓	↓↓		↓	↓↓	↓↓	↓↓	↓		↓	↓			-18
OK			↑					↑↑		↓						2
TX								↑↑		↑						3
WA			↓					↑	↑↑						↑	3
WV		↑	↑↑	↑				↓↓								2
WY	↑↑	↑↑	↑	↑↑			↑↑	↓↓		↑↑						9

Choice and Control

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

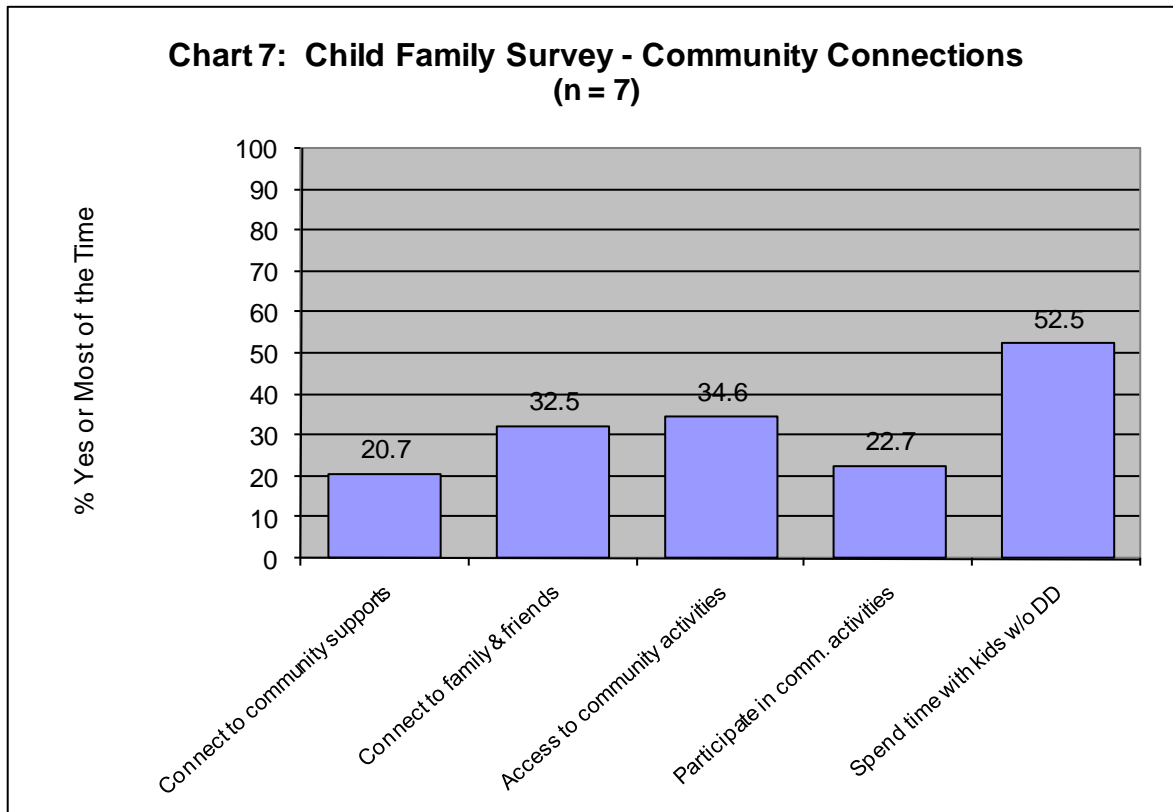


**Table 19
Deviation in Responses
Above & Below State Average
Choice & Control**

State	Q29	Q30	Q31	Q32	Q33	Q34	Net Sum
AZ	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	-12
CT	↓↓	↓↓	↓↓	↓	↓↓		-9
OK	↑	↑↑	↑↑	↑	↑	↑	8
TX	↑↑	↑	↑↑	↑	↑	↑↑	9
WA		↓	↑		↓		-1
WV			↓↓		↓	↓↓	-5
WY	↑↑	↑↑	↑↑		↑↑	↑↑	10

Community Connections

- In Wyoming, responses to community connections questions were generally above the overall state average. In Arizona and Connecticut, results were generally below the state average.

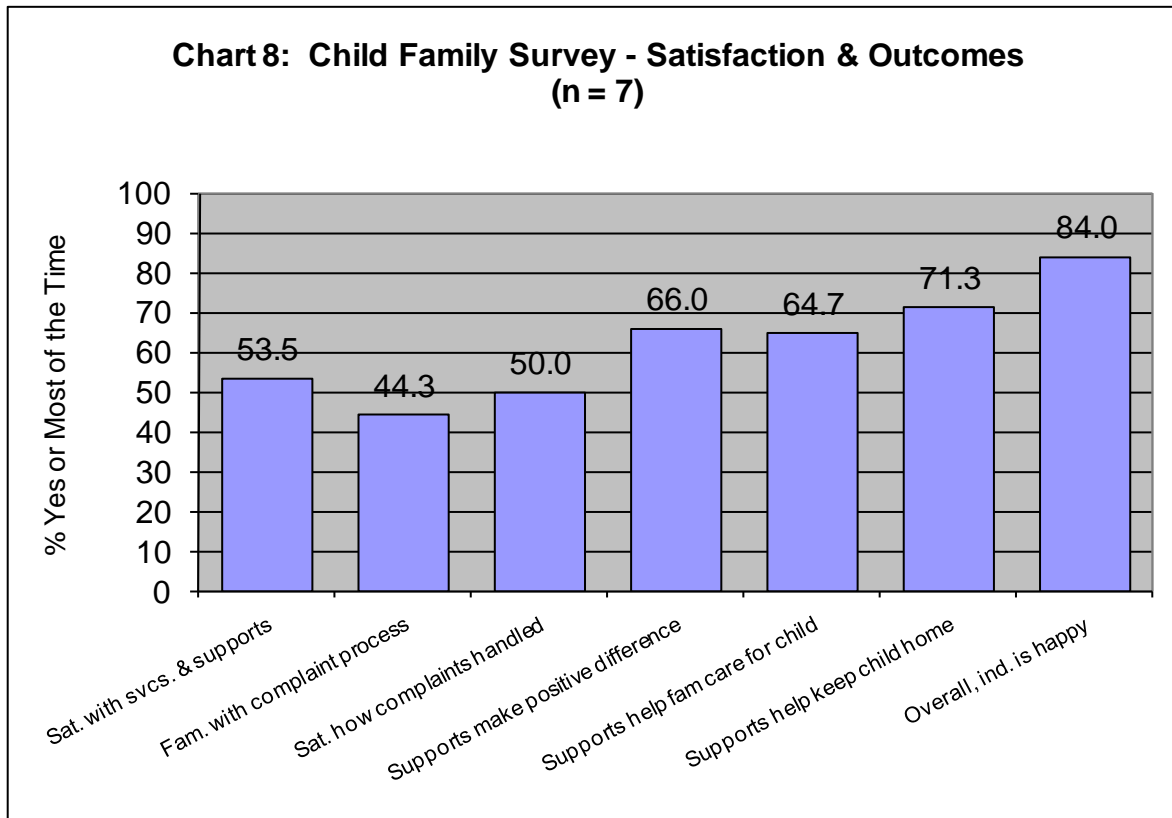


**Table 20
Deviation in Responses
Above & Below State Average
Community Connections**

State	Q35	Q36	Q37	Q38	Q39	Net Sum
AZ	↓	↓↓				-3
CT	↓↓	↓↓	↓↓	↓	↓	-8
OK		↑↑				2
TX		↑				1
WA		↑				1
WV	↑		↑↑	↑↑	↑	7
WY	↑	↑				2

Satisfactions with Services and Supports & Outcomes for Families

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



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

State	Q40	Q41	Q42	Q43	Q44	Q45	Q46	Net Sum
AZ	↓	↓	↓↓	↓	↓			-6
CT	↓↓	↓↓	↓	↓↓	↓↓	↓↓	↓	-12
OK		↑	↑					2
TX	↑	↑		↑	↑	↑↑		6
WA	↓	↓						-2
WV	↑	↑	↑					3
WY	↑↑	↑↑		↑↑	↑↑	↑↑		10

Overall State Results

- Looking at results across all categories, Wyoming had results that were well above the overall state average. In Connecticut, 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
AZ	-2	1	-12	-3	-6	-22
CT	-15	-18	-9	-8	-12	-62
OK	2	2	8	2	2	16
TX	0	3	9	1	6	19
WA	-6	3	-1	1	-2	-5
WV	3	2	-5	7	3	10
WY	22	9	10	2	10	53

APPENDIX A

Summary Tables of Survey Responses

Table A - Characteristics of Child with a Disability: 2006-07 Data											
STATES	Total %		State Avg.	AZ	CT	OK	TX	WA	WV	WY	
Number of surveys	2,399		n = 7	258	268	251	781	408	287	146	
	n	%	%	n	%	n	%	n	%	n	%
Gender:											
Male	1,464	63.4	64.7	163 64.9	171 68.4	149 60.8	437.0 58.7	258.0 65.0	191 67.7	95 67.4	
Female	846	36.6	35.3	88 35.1	79 31.6	96 39.2	307.0 41.3	139.0 35.0	91 32.3	46 32.6	
Age:											
Mean	11.5		11.2	7.9	11.5	12.4	12.6	11.7	10.8	11.6	
Range	1-21			1-21	3-18	1-19	1-21	2-18	1-18	1-20	
Race/Ethnicity* (duplicated counts):											
White	1,621	73.4	74.2	138 56.8	190 73.4	174 71.9	436 58.2	295 73.9	257 91.8	131 93.6	
Black	199	10.2	7.5	12 4.9	23 8.9	33 13.6	85 11.3	31 7.8	13 4.6	2 1.4	
Asian	56	2.9	2.2	5 2.1	4 1.5	3 1.2	13 1.7	24 6.0	6 2.1	1 0.7	
Amer. Indian/Alaska Native	109	5.6	5.6	15 6.2	5 1.9	42 17.4	10 1.3	22 5.5	10 3.6	5 3.5	
Hawaiian/ Pacific Islander	16	0.8	0.7	2 0.8	2 0.8	2 0.8	3 0.4	3 0.8	4 1.4	0 0.0	
Hispanic	390	19.9	14.0	80 32.9	40 15.4	12 5.0	204 27.2	41 10.3	6 2.1	7 5.0	
Two or More Races	113	5.8	5.0	23 9.5	9 3.5	10 4.1	27 3.6	26 6.5	14 5.0	4 2.8	
Other/Unknown	22	1.1	0.9	0 0.0	2 0.8	4 1.7	6 0.8	5.0 1.3	5 1.8	0 0.0	
More than 1 person with DD in household:											
Yes	391	16.6	17.3	54 21.1	53 21.6	44 17.7	97 12.6	88 21.9	34 12.0	21 14.4	
No	1,963	83.4	82.7	202 78.9	192 78.4	205 82.3	675 87.4	314 78.1	250 88.0	125 85.6	
	2,354			256	245	249	772	402	284	146	
Level of Help with Daily Activities											
None	95	4.1	4.4	7 2.8	16 6.3	18 7.3	32 4.2	10 2.5	2 0.7	10 6.9	
Little	287	12.3	14.4	40 15.7	51 20.1	46 18.5	52 6.9	46 11.5	23 8.2	29 20.1	
Moderate	855	36.5	38.2	108 42.5	89 35.0	86 34.7	221 29.2	178 44.5	113 40.1	60 41.7	
Complete	1,103	47.1	43.0	99 39.0	98 38.6	98 39.5	453 59.8	166 41.5	144 51.1	45 31.3	
	2,340			254	254	248	758	400	282	144	
Other disabilities* (duplicated counts):											
Mental retardation	1,241	53.0	53.8	86 34.8	146 56.2	174 71.0	419 55.1	171 42.4	159 56.2	86 61.0	
Other developmental disability	868	37.1	34.9	75 30.4	80 30.8	96 39.2	322 42.3	154 38.2	102 36.0	39 27.5	
Mental illness	169	7.2	7.5	14 5.7	18 6.9	25 10.2	51 6.7	26 6.5	23 8.1	12 8.5	
Autism	676	28.9	31.2	87 35.2	81 31.2	62 25.4	151 19.8	128 31.8	122 43.3	45 31.7	
Cerebral Palsy	680	29.1	25.4	43 17.4	56 21.5	74 30.2	317 41.7	96 23.8	65 23.0	29 20.4	
Brain injury	287	12.3	10.8	19 7.7	20 7.7	41 16.8	126 16.6	43 10.7	30 10.6	8 5.6	
Seizure/neurological problem	816	34.9	31.1	45 18.2	84 32.3	84 34.3	358 47.0	108 26.8	107 37.9	30 21.1	
Chemical dependency	21	0.9	0.8	2 0.8	2 0.8	2 0.8	9 1.2	1 0.2	5 1.8	0 0.0	
Vision or hearing impairments	762	32.6	29.4	60 24.3	60 23.1	84 34.3	325 42.7	104 25.8	100 35.5	29 20.4	
Physical disability	894	38.2	33.5	58 23.5	76 29.2	93 38.1	409 53.7	123 30.5	102 36.2	33 23.2	
Communication disorder	769	32.9	29.8	56 22.7	73 28.1	77 31.4	332 43.6	97 24.1	101 35.8	33 23.2	
Down Syndrome	269	11.5	13.6	28 11.3	49 18.8	43 17.6	42 5.5	47 11.7	34 12.1	26 18.3	
Other disability	695	29.7	26.3	62 25.1	55 21.2	56 22.9	303 39.8	113 28.0	78 27.7	28 19.7	

Table B - Characteristics of Respondents: 2006-07 Data

STATES	Total %	State Avg.	AZ	CT	OK	TX	WA	WV	WY								
Number of surveys	2,399	n = 7	258	268	251	781	408	287	146								
Age:																	
	n	%	%	n	%	n	%	n	%	n	%						
Under 35	413	17.4	18.4	73	28.4	26	10.0	33	13.2	116	15.0	62	15.5	71	24.7	32	21.9
35 to 54	1,716	72.3	71.0	164	63.8	211	81.2	183	73.2	585	75.6	289	72.1	189	65.9	95	65.1
55 to 74	237	10.0	10.4	20	7.8	23	8.8	34	13.6	69	8.9	45	11.2	27	9.4	19	13.0
75 or Over	9	0.4	0.2	0	0.0	0	0.0	0	0.0	4	0.5	5	1.2	0	0.0	0	0.0
	2,375			257		260		250		774		401		287		146	
Relationship to consumer:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Parent	2,210	93.0	93.3	237	92.2	245	95.0	228	91.6	724	93.4	365	90.1	270	94.1	141	96.6
Sibling	2	0.1	0.1	0	0.0	1	0.4	0	0.0	1	0.1	0	0.0	0	0.0	0	0.0
Grandparent	129	5.4	5.1	15	5.8	9	3.5	16	6.4	39	5.0	33	8.1	13	4.5	4	2.7
Other	36	1.5	1.5	5	1.9	3	1.2	5	2.0	11	1.4	7	1.7	4	1.4	1	0.7
	2,377			257		258		249		775		405		287		146	
Respondent is primary caregiver:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	2,330	98.8	98.9	253	98.8	251	99.6	248	99.2	761	98.7	389	97.5	285	99.3	143	99.3
Household Income:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Below \$15,000	325	22.1	21.1	57	23.9	49	19.8	45	20.4			93	25.6	64	24.2	17	12.5
\$15,001-\$25,000	261	17.7	17.5	48	20.2	27	10.9	48	21.7			66	18.2	53	20.0	19	14.0
\$25,001-\$50,000	381	25.9	25.8	59	24.8	59	23.8	56	25.3			98	27.0	73	27.5	36	26.5
\$50,001-\$75,000	253	17.2	17.9	36	15.1	48	19.4	37	16.7			51	14.0	48	18.1	33	24.3
Over \$75,000	251	17.1	17.7	38	16.0	65	26.2	35	15.8			55	15.2	27	10.2	31	22.8
	1,471			238		248		221		0		363		265		136	
Health of respondent:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Excellent	558	23.5	25.2	73	28.4	67	25.5	75	30.2	147	19.0	86	21.3	70	24.5	40	27.6
Good	1,247	52.5	52.0	125	48.6	139	52.9	118	47.6	428	55.4	198	49.1	160	55.9	79	54.5
Fair	497	20.9	19.9	53	20.6	48	18.3	49	19.8	177	22.9	100	24.8	46	16.1	24	16.6
Poor	72	3.0	2.9	6	2.3	9	3.4	6	2.4	20	2.6	19	4.7	10	3.5	2	1.4
	2,374			257		263		248		772		403		286		145	

Table C - Services and Support Received: 2006-07 Data																	
STATES	Total %		State Avg.	AZ		CT		OK		TX		WA		WV		WY	
	n	%	n = 7	n	%	n	%	n	%	n	%	n	%	n	%	n	%
SSI financial support	864	39.3	37.8	104	41.4	83.0	33.3	105.0	42.9	334	44.0	71	25.5	117	42.2	50	35.2
Other financial support	560	25.9	28.2	25	10.1	77.0	31.2	57.0	24.7	160	22.1	63	20.2	119	45.6	59	43.7
In-home support	1,347	62.5	54.9	113	46.1	76.0	30.3	193.0	80.4	648	87.1	118	44.7	135	49.8	64	46.0
Out-of-home respite care	798	37.3	39.8	66	26.7	80.0	33.2	42.0	17.4	263	35.5	136	53.8	105	38.6	106	73.1
Early intervention	197	9.4	10.7	44	17.9	25	11	16	6.9	58	8.5	11	3.4	18	7.2	25	20.0
Transportation	285	11.9	11.7	32	12.8	21.0	8.6	19.0	7.9	120	16.2	41	11.2	35	12.6	17	12.4
Specialized services/supports	1,608	74.1	75.1	210	84.0	167.0	69.9	173.0	71.2	551	73.1	135	51.1	250	89.0	122	87.1

Table D - Information and Planning: 2006-07 Data									
STATES	TOTAL %	STATE AVG.	AZ	CT	OK	TX	WA	WV	WY
Q1 - Do you receive information about the services and supports that are available to your child and family?									
Number of surveys	2,316	n = 7	249	253	247	755	390	278	144
% always or usually	31.8	32.7	34.5	23.7	29.6	31.4	30.8	34.5	44.4
% sometimes	43.1	43.6	43.4	42.7	45.7	43.6	37.4	45.7	46.5
% seldom or never	25.1	23.7	22.1	33.6	24.7	25.0	31.8	19.8	9.0
Q2 - If you receive information, is it easy to understand?									
Number of surveys	2,080	n = 7	240	205	222	680	337	259	137
% always or usually	47.5	48.3	50.0	45.4	46.8	47.2	46.9	43.6	58.4
% sometimes	43.6	43.2	42.1	47.3	44.6	44.9	38.9	47.9	36.5
% seldom or never	8.8	8.5	7.9	7.3	8.6	7.9	14.2	8.5	5.1
Q3 - Do you receive information about the status of your child's development?									
Number of surveys	2,162	n = 7	242	218	234	693	354	280	141
% always or usually	43.5	44.2	48.8	36.2	39.3	42.9	37.3	53.6	51.1
% sometimes	26.5	27.8	25.2	24.3	35.5	23.5	24.6	27.9	33.3
% seldom or never	30.1	28.1	26.0	39.4	25.2	33.6	38.1	18.6	15.6
Q4 - If yes, is this information easy to understand?									
Number of surveys	1,722	n = 7	205	180	190	529	252	243	123
% always or usually	56.0	56.1	58.5	46.1	54.7	57.8	52.8	56.4	66.7
% sometimes	35.1	35.1	31.7	41.7	36.8	34.8	34.1	35.8	30.9
% seldom or never	8.8	8.7	9.8	12.2	8.4	7.4	13.1	7.8	2.4
Q5 - Do you get enough information to help you participate in planning services for your family?									
Number of surveys	2,166	n = 7	239	229	232	708	342	275	141
% always or usually	40.0	40.9	44.4	22.7	39.7	41.5	33.6	44.4	60.3
% sometimes	35.4	35.4	34.3	38.0	32.8	35.5	33.6	38.9	34.8
% seldom or never	24.6	23.7	21.3	39.3	27.6	23.0	32.7	16.7	5.0
Q6 - If your family has a service plan, did you help develop the plan?									
Number of surveys	1,776	n = 7	198	133	194	606	252	255	138
% always or usually	74.5	74.8	73.7	61.7	79.9	74.4	66.3	78.4	89.1
% sometimes	17.1	16.7	18.2	20.3	14.9	17.7	19.0	16.9	10.1
% seldom or never	8.3	8.5	8.1	18.0	5.2	7.9	14.7	4.7	0.7
Q7 - If your family has a service plan, does the plan include things that are important to you?									
Number of surveys	1,755	n = 7	198	124	191	605	246	254	137
% always or usually	70.0	69.4	69.7	52.4	71.7	70.7	63.0	76.0	82.5
% sometimes	23.7	23.9	24.2	32.3	25.1	23.6	26.4	19.7	16.1
% seldom or never	6.3	6.6	6.1	15.3	3.1	5.6	10.6	4.3	1.5

Table E - Information and Planning: 2006-07 Data (cont'd)

STATES	TOTAL %	STATE AVG.	AZ	CT	OK	TX	WA	WV	WY
Q8 - Do the staff who assist you with planning help you figure out what you need as a family to support your child?									
Number of surveys	1,978	n = 7	216	171	216	663	304	269	139
% always or usually	53.8	54.3	49.5	42.7	54.6	54.1	46.7	62.1	70.5
% sometimes	29.9	29.8	33.3	33.3	31.9	30.5	28.6	26.4	24.5
% seldom or never	16.3	15.9	17.1	24.0	13.4	15.4	24.7	11.5	5.0
Q9 - Do the staff who assist you with planning respect your choices and opinions?									
Number of surveys	1,959	n = 7	220	154	215	656	300	273	141
% always or usually	74.7	75.2	74.5	68.8	75.3	74.5	72.0	75.1	86.5
% sometimes	18.1	17.5	17.7	21.4	17.7	19.5	16.7	18.3	11.3
% seldom or never	7.2	7.2	7.7	9.7	7.0	5.9	11.3	6.6	2.1
Q10 - Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI)?									
Number of surveys	2,052	n = 7	220	198	226	696	334	257	121
% always or usually	32.0	31.8	26.4	25.8	41.6	32.9	29.6	33.9	32.2
% sometimes	24.6	24.3	23.6	22.2	23.9	25.6	23.7	26.8	24.0
% seldom or never	43.4	44.0	50.0	52.0	34.5	41.5	46.7	39.3	43.8
Q11 - Are the staff who help you with planning generally respectful and courteous?									
Number of surveys	2,091	n = 7	232	185	230	687	337	277	143
% always or usually	83.5	84.2	84.9	81.6	85.2	82.7	84.6	79.4	90.9
% sometimes	13.1	12.5	11.6	14.1	11.3	14.7	9.8	17.3	8.4
% seldom or never	3.4	3.3	3.4	4.3	3.5	2.6	5.6	3.2	0.7
Q12 - Are the staff who assist you with planning generally effective?									
Number of surveys	2,049	n = 7	228	176	228	679	322	275	141
% always or usually	58.7	58.8	52.6	54.5	57.0	59.5	59.9	58.5	69.5
% sometimes	33.2	33.1	36.8	33.0	36.8	33.0	30.7	33.1	28.4
% seldom or never	8.2	8.1	10.5	12.5	6.1	7.5	9.3	8.4	2.1
Q13 - Can you contact the staff who assist you with planning whenever you want to?									
Number of surveys	2,083	n = 7	234	188	232	677	334	275	143
% always or usually	69.3	69.4	66.2	63.8	64.7	71.8	64.1	72.7	82.5
% sometimes	24.4	24.5	27.8	26.6	28.0	22.2	26.6	23.6	16.8
% seldom or never	6.3	6.1	6.0	9.6	7.3	6.1	9.3	3.6	0.7

Table F - Access & Delivery of Services & Supports: 2006-07 Data									
STATES	TOTAL	STATE	AZ	CT	OK	TX	WA	WV	WY
	%	AVG.							
Q14 - When you ask your service/support coordinator for assistance, does he/she help you get what you need?									
Number of surveys	2,206	n = 7	244	204	244	714	384	272	144
% always or usually	66.4	66.6	62.7	52.5	68.4	67.6	65.4	68.0	81.9
% sometimes	27.9	27.5	29.9	36.8	25.8	27.5	28.6	27.2	16.7
% seldom or never	5.8	5.9	7.4	10.8	5.7	4.9	6.0	4.8	1.4
Q15 - Does your family get the services and supports you need?									
Number of surveys	2,251	n = 7	239	218	244	748	383	275	144
% always or usually	47.7	47.8	43.9	25.7	52.5	50.4	43.1	54.2	64.6
% sometimes	41.2	40.2	43.1	51.4	36.9	41.7	43.3	39.3	25.7
% seldom or never	11.1	12.0	13.0	22.9	10.7	7.9	13.6	6.5	9.7
Q16 - Do the services and supports offered meet your family's needs?									
Number of surveys	2,226	n = 7	236	199	245	749	379	274	144
% always or usually	46.3	45.5	42.8	25.1	51.0	49.9	38.5	56.6	54.9
% sometimes	41.7	41.7	44.1	49.2	38.0	41.1	45.1	36.9	37.5
% seldom or never	12.0	12.7	13.1	25.6	11.0	8.9	16.4	6.6	7.6
Q17 - Are supports available when your family needs them?									
Number of surveys	2,165	n = 7	226	194	234	732	366	270	143
% always or usually	40.7	40.4	36.7	23.7	43.2	43.7	36.1	45.6	53.8
% sometimes	45.0	44.3	45.1	48.5	42.7	45.8	47.5	43.0	37.8
% seldom or never	14.2	15.3	18.1	27.8	14.1	10.5	16.4	11.5	8.4
Q18 - Do families in your area request that different types of services and supports be made available in your area?									
Number of surveys	979	n = 7	113	80	106	334	137	138	71
% always or usually	35.6	36.4	33.6	33.8	35.8	33.2	41.6	34.8	42.3
% sometimes	43.8	43.4	46.0	40.0	40.6	44.0	44.5	46.4	42.3
% seldom or never	20.5	20.2	20.4	26.3	23.6	22.8	13.9	18.8	15.5
Q19 - If yes, does either the state agency or provider agency respond to their requests?									
Number of surveys	784	n = 7	98	62	88	254	110	116	56
% always or usually	26.7	26.0	21.4	21.0	29.5	28.0	30.9	25.9	25.0
% sometimes	46.2	45.5	48.0	40.3	43.2	47.2	40.9	52.6	46.4
% seldom or never	27.2	28.5	30.6	38.7	27.3	24.8	28.2	21.6	28.6
Q20 - If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?									
Number of surveys	1,075	n = 7	119	92	102	398	173	132	59
% always or usually	41.9	41.1	38.7	26.1	35.3	44.5	43.4	45.5	54.2
% sometimes	24.7	24.5	22.7	28.3	23.5	26.1	18.5	28.8	23.7
% seldom or never	33.5	34.4	38.7	45.7	41.2	29.4	38.2	25.8	22.0
Q21 - If English is not your first language, are there support workers or translators available to speak with you in your preferred language?									
Number of surveys	338	n = 7	65	39	15	151	49	15	4
% always or usually	67.8	61.9	67.7	51.3	73.3	72.8	71.4	46.7	50.0
% sometimes	20.4	23.5	27.7	28.2	0.0	15.9	22.4	20.0	50.0
% seldom or never	11.8	14.6	4.6	20.5	26.7	11.3	6.1	33.3	0.0

Table G - Access & Delivery of Services & Supports: 2006-07 Data (cont'd)

STATES	TOTAL AVG.	STATE AVG.	AZ	CT	OK	TX	WA	WV	WY
Q22 - If your child does not speak English or uses a different way to communicate (e.g., sign language), are there enough support workers available who can communicate with him/her?									
Number of surveys	559	n = 7	67	55	52	214	60	77	34
% always or usually	36.7	36.1	40.3	25.5	32.7	38.3	46.7	31.2	38.2
% sometimes	32.6	33.1	28.4	29.1	30.8	33.6	31.7	31.2	47.1
% seldom or never	30.8	30.8	31.3	45.5	36.5	28.0	21.7	37.7	14.7
Q23 - Does your child have access to the special equipment or accommodations that he/she needs (e.g., wheelchair, ramp, communication board)?									
Number of surveys	1,496	n = 7	113	112	159	615	216	186	95
% always or usually	53.3	51.4	50.4	42.9	45.9	58.7	49.5	50.0	62.1
% sometimes	29.6	30.8	30.1	35.7	29.6	28.0	27.3	32.3	32.6
% seldom or never	17.0	17.8	19.5	21.4	24.5	13.3	23.1	17.7	5.3
Q24 - Do you have access to health services for your child?									
Number of surveys	2,296	n = 7	244	231	247	762	389	279	144
% always or usually	91.3	91.2	90.6	86.6	93.9	90.8	91.8	95.3	89.6
% sometimes	7.3	7.5	8.6	12.1	4.5	7.3	6.9	3.9	9.0
% seldom or never	1.4	1.3	0.8	1.3	1.6	1.8	1.3	0.7	1.4
Q25 - Do you have access to dental services for your child?									
Number of surveys	2,277	n = 7	231	226	243	759	396	280	142
% always or usually	88.3	87.9	89.6	82.7	90.9	88.4	89.1	90.0	84.5
% sometimes	7.4	7.7	5.2	10.2	4.9	7.5	6.8	7.1	12.0
% seldom or never	4.3	4.4	5.2	7.1	4.1	4.1	4.0	2.9	3.5
Q26 - Do you have access to necessary medications for your child?									
Number of surveys	2,259	n = 7	235	221	241	761	385	278	138
% always or usually	93.4	92.9	91.5	86.4	94.6	94.6	94.0	95.7	93.5
% sometimes	5.5	6.0	6.0	11.3	5.0	4.9	4.7	4.0	5.8
% seldom or never	1.0	1.2	2.6	2.3	0.4	0.5	1.3	0.4	0.7
Q27 - Are frequent changes in support staff a problem for your family?									
Number of surveys	1,902	n = 7	211	165	216	665	262	255	128
% always or usually	22.5	22.3	22.3	19.4	25.5	22.0	21.0	26.7	19.5
% sometimes	40.7	39.7	48.3	44.8	35.2	42.1	34.7	45.5	27.3
% seldom or never	36.8	38.0	29.4	35.8	39.4	35.9	44.3	27.8	53.1
Q28 - Are support staff generally respectful and courteous?									
Number of surveys	2,107	n = 7	240	182	236	736	299	274	140
% always or usually	82.9	83.7	86.3	80.8	81.8	79.6	90.3	81.0	86.4
% sometimes	15.7	15.0	12.9	18.7	16.1	18.8	6.7	18.6	12.9
% seldom or never	1.5	1.3	0.8	0.5	2.1	1.6	3.0	0.4	0.7

Table H - Choices and Control: 2006-07 Data

STATES	TOTAL %	STATE AVG.	AZ	CT	OK	TX	WA	WV	WY
Q29 - Do you choose the agencies or providers that work with your family?									
Number of surveys	2,157	n = 7	229	180	239	747	347	273	142
% always or usually	69.8	67.2	49.3	45.0	75.7	78.4	66.0	71.8	84.5
% sometimes	18.0	19.2	23.1	31.7	16.3	15.0	17.6	17.2	13.4
% seldom or never	12.2	13.5	27.5	23.3	7.9	6.6	16.4	11.0	2.1
Q30 - Do you choose the support workers who work with your family?									
Number of surveys	2,044	n = 7	213	174	232	715	307	265	138
% always or usually	52.8	51.4	30.0	28.2	67.2	61.3	43.6	47.5	81.9
% sometimes	21.2	20.1	19.2	23.6	19.4	23.5	21.5	20.8	13.0
% seldom or never	25.9	28.5	50.7	48.3	13.4	15.2	34.9	31.7	5.1
Q31 - Do you have control and/or input over the hiring and management of your support workers?									
Number of surveys	1,901	n = 7	186	141	220	683	308	233	130
% always or usually	51.7	48.0	29.6	24.8	66.8	59.4	56.5	36.1	63.1
% sometimes	19.3	18.6	18.3	19.1	17.3	20.9	18.8	19.3	16.2
% seldom or never	29.0	33.4	52.2	56.0	15.9	19.6	24.7	44.6	20.8
Q32 - Do you want to have control and/or input over the hiring and management of your support workers?									
Number of surveys	1,846	n = 7	188	152	224	646	287	224	125
% always or usually	72.8	70.2	59.0	64.5	78.6	79.1	72.1	68.8	69.6
% sometimes	19.0	20.9	26.1	27.6	18.3	15.0	16.7	21.0	21.6
% seldom or never	8.2	8.9	14.9	7.9	3.1	5.9	11.1	10.3	8.8
Q33 - Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?									
Number of surveys	2,264	n = 7	241	218	249	752	382	276	146
% always or usually	29.2	29.2	5.0	15.1	35.7	38.2	20.7	23.6	65.8
% sometimes	11.5	11.3	6.6	6.0	13.3	12.6	10.7	15.2	14.4
% seldom/never/don't know	59.3	59.6	88.4	78.9	51.0	49.2	68.6	61.2	19.9
Q34 - Do you get to decide how this money is spent?									
Number of surveys	1,665	n = 7	149	134	195	579	280	194	134
% always or usually	38.7	36.6	8.1	38.1	44.1	47.7	32.9	20.6	64.9
% sometimes	22.1	20.8	8.7	14.2	26.7	24.9	21.4	22.2	27.6
% seldom or never	39.2	42.6	83.2	47.8	29.2	27.5	45.7	57.2	7.5

Table I - Community Connections: 2006-07 Data

STATES	TOTAL %	STATE AVG.	AZ	CT	OK	TX	WA	WV	WY
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?									
Number of surveys	1,566	n = 7	157	158	169	501	264	214	103
% always or usually	21.1	20.7	14.6	10.1	22.5	22.0	20.8	28.0	27.2
% sometimes	26.8	28.3	25.5	27.2	27.8	23.0	27.7	29.0	37.9
% seldom or never	52.2	51.0	59.9	62.7	49.7	55.1	51.5	43.0	35.0
Q36 - 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?									
Number of surveys	1,674	n = 7	162	155	194	546	286	220	111
% always or usually	34.6	32.5	21.0	10.3	44.3	38.6	39.5	34.5	39.6
% sometimes	27.4	27.4	19.1	27.1	27.8	28.2	23.4	33.2	33.3
% seldom or never	38.0	40.0	59.9	62.6	27.8	33.2	37.1	32.3	27.0
Q37 - Do you feel that your child has access to community activities?									
Number of surveys	2,127	n = 7	208	215	238	688	362	278	138
% always or usually	34.7	34.6	34.1	16.7	38.2	34.4	31.5	49.3	37.7
% sometimes	36.5	37.2	34.1	39.1	37.8	35.3	37.3	33.5	43.5
% seldom or never	28.8	28.2	31.7	44.2	23.9	30.2	31.2	17.3	18.8
Q38 - Does your child participate in community activities?									
Number of surveys	2,195	n = 7	218	231	243	700	378	282	143
% always or usually	22.7	22.7	18.3	13.9	23.5	21.6	19.8	39.0	23.1
% sometimes	36.4	37.6	33.9	34.6	40.3	34.4	32.3	42.9	44.8
% seldom or never	40.9	39.7	47.7	51.5	36.2	44.0	47.9	18.1	32.2
Q39 - Does your child spend time with children who do not have developmental disabilities?									
Number of surveys	2,303	n = 7	245	239	249	749	393	285	143
% always or usually	52.0	52.5	55.5	45.6	53.8	50.5	48.6	61.1	52.4
% sometimes	32.5	32.1	28.6	36.0	34.1	32.2	35.6	30.2	28.0
% seldom or never	15.5	15.4	15.9	18.4	12.0	17.4	15.8	8.8	19.6

Table J - Satisfaction with Services and Outcomes: 2006-07 Data

STATES	TOTAL %	STATE AVG.	AZ	CT	OK	TX	WA	WV	WY
Q40 - Overall, are you satisfied with the services and supports your child and family currently receive?									
Number of surveys	2,290	n = 7	244	223	246	754	396	283	144
% always or usually	54.0	53.5	48.4	34.1	57.3	59.2	47.7	59.4	68.1
% sometimes	38.3	38.1	43.0	46.2	36.6	36.2	41.9	35.3	27.8
% seldom or never	7.7	8.4	8.6	19.7	6.1	4.6	10.4	5.3	4.2
Q41 - Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?									
Number of surveys	2,163	n = 7	228	203	233	722	371	265	141
% always or usually	45.6	44.3	36.8	21.2	54.1	51.9	39.1	49.8	57.4
% sometimes	12.2	11.8	11.8	8.9	12.0	13.0	12.1	12.8	12.1
% seldom/never/don't know	42.3	43.8	51.3	70.0	33.9	35.0	48.8	37.4	30.5
Q42 - Are you satisfied with the way complaints/grievances are handled and resolved?									
Number of surveys	966	n = 7	94	60	113	375	144	115	65
% always or usually	51.3	50.0	39.4	41.7	56.6	53.3	49.3	55.7	53.8
% sometimes	28.9	29.5	35.1	28.3	27.4	28.3	31.3	20.9	35.4
% seldom or never	19.8	20.5	25.5	30.0	15.9	18.4	19.4	23.5	10.8
Q43 - Do you feel that family supports have made a positive difference in the life of your family?									
Number of surveys	2,157	n = 7	215	193	230	733	371	276	139
% always or usually	67.6	66.0	58.1	50.3	70.0	74.4	64.7	65.2	79.1
% sometimes	26.7	28.0	37.2	35.2	25.7	21.0	28.0	31.2	18.0
% seldom or never	5.7	6.0	4.7	14.5	4.3	4.6	7.3	3.6	2.9
Q44 - Do you feel that family supports have improved your ability to care for your child?									
Number of surveys	2,169	n = 7	222	199	230	737	372	271	138
% always or usually	67	64.7	58.1	45.2	66.1	74.6	64.2	66.1	78.3
% sometimes	25.8	26.9	32.4	35.2	28.7	20.2	29.0	26.9	15.9
% seldom or never	7.5	8.4	9.5	19.6	5.2	5.2	6.7	7.0	5.8
Q45 - Do you feel that family supports have helped you to keep your child at home?									
Number of surveys	2,012	n = 7	198	167	206	716	342	255	128
% always or usually	73.7	71.3	67.7	50.9	74.3	81.7	68.7	71.4	84.4
% sometimes	17.2	17.9	21.2	24.0	18.9	13.3	21.3	18.0	8.6
% seldom or never	9.1	10.8	11.1	25.1	6.8	5.0	9.9	10.6	7.0
Q46 - Overall, do you feel that your child is happy?									
Number of surveys	2,310	n = 7	249	233	243	762	396	282	145
% always or usually	84.7	84.0	83.9	76.8	87.2	87.8	81.1	86.9	84.1
% sometimes	14.2	15.0	14.5	22.7	12.3	10.9	17.4	13.1	13.8
% seldom or never	1.1	1.0	1.6	0.4	0.4	1.3	1.5	0.0	2.1

APPENDIX B

Analysis of Open-Ended Comments

Analysis of Open-Ended Comments

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

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

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

ARIZONA

Overall, there was a two to one ratio of positive to negative comments regarding general satisfaction with services and supports.

More specifically, many of the comments focused on the lack of occupational, physical, and/or speech therapies:

My only concern with support services is that we need speech therapy and we haven't been able to get it in-home or outside the home for more than a year. It's one of the most important therapies a child with Ds can have, and we really need it! It would be helpful to our family to have more therapists available to help meet our needs. Thanks.

Many families were concerned about the lack of information that they were receiving regarding services and supports:

I don't know everything that is available for my child. It would be nice to know ALL my options. I am new at all of this & feel I only receive what I ask for; which I don't even know what to ask for. A development specialist comes to my home once a week & I can't figure out what she does besides sit there & watch me do all the work. Is this what they do or should I expect more? I need more help than what she's doing & honestly it's almost a waste of my time.

Although Arizona families wished they had more information, overall they were satisfied with the jobs the case managers/service coordinators were doing:

(Name) is my son's case manager. He attends IEP meetings and his participation in the IEP meetings and support he gives my son that his IEP is implemented has been a god send. (Name) is very involved in letting me know services available to meet my son's needs. I cannot say enough good things about (Name) and the support he provides for our family during any problem that occurs and (Name) makes service that will help my son available to him. Thank you!

CONNECTICUT

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

However, they also stated that more of the services and supports were needed:

I believe the majority of families of children with special needs who attend public schools would love to have after-school programs for their children through high school just to enable the parents to hold full-time jobs. It would be terrific if daily living skills & recreation were incorporated into this type of programs and if the program would be held locally or transportation provided (at least from school). There is also a need for community based programming so our children could spend time with their "regular ed" peers. Maybe a community Ctr. for families? Most leisure programming keeps our kids segregated. Thank you.

Home accommodations were the service most needed:

Assistance to help with home modifications seems almost non-existent. Each Agency we tried to contact referred us to the Corporation for Independent Living and they could not

even offer a name of a contractor to help with Handicap Renovations. If possible, more assistance should be available to help modify a home as a child grows. Our family is very thankful to have the support of DMR services. Thank you.

In addition to needing more services, Connecticut families indicated that they needed more information on services as well:

I wish you could mail listing of all different services to DMR recipients because my child is 4 and very capable. It does not seem that she qualifies for many supports – or I have not heard about supports that she does qualify for.

OKLAHOMA

Like Arizona and Connecticut, Oklahoma had a two to one ratio of positive comments regarding general satisfaction of services and supports.

Oklahoman families wrote many comments indicating their need for more services...

I need help taking care of my child or I will have to look into putting him outside my home. He is very difficult to lift and take care of.

...and their need for more information regarding services:

Overall I am happy with the support (Name) gets. But sometimes I don't understand all that's available to him as far as services go. I'm told its left up to me to find qualified people to help my son and I have no idea how to do that.

Similarly to Arizona, although families stated there was a lack of information, they were mostly satisfied with the case managers/service coordinators:

Our case worker is very positive & personal. She goes way & beyond to help us in anyway. She's very well informed & keeps up on any changes or policies that might affect our child. She is very dedicated to her job!

TEXAS

The vast majority of comments indicated that families were generally satisfied with services and supports.

Interestingly, many of the specific comments had to do with service coordination, and the majority of those pertaining to dissatisfaction with paperwork as well as families wanting more control over the services:

The paper process is too much. The timeframe to complete and set services up takes to long. The process to get equipment takes to long even if you know it's not medicaid approved. 6 to 8 months to long.

I would like to be in charge of hiring/training/paying support staff. I use (provider) and I feel that they do not do enough to earn their reimbursement since I find my own support staff.

Families wanted more information regarding services/supports:

My only concern about services is I do not know what is out there. I have no guidance on what services she can get or what all she need for her future.

Many comments indicated that it was difficult to get health care equipment for their children:

My only issue is that I am having a very hard time getting the medical supplies that are classified as durable medical equipment that my child needs. I have been working for 3 months to get these items so far and still have not been able to coordinate

WASHINGTON

The amount of comments from families stating general satisfaction of services and supports was substantially higher than the amount of comments that indicated general dissatisfaction of services and supports.

Specifically, like many other States in this survey, families indicated that they needed more services and needed more information regarding services:

Over the last few years my child has the need of more support do to her severe behavior & physical aggressions. We do not receive the support that our family needs. Over the last 3 years hrs have been taken away.

It would be helpful if the case manager could offer information on what types of services are available. I personally would probably use more services but I don't know what is available to my child.

Also, like other States, there were many comments about how great the case managers/service coordinators are:

Our DDD case worker, has been a coach and a cheerleader for our family. She has always provided us with top of line service and professionalism. Without her and DDD services our family would be lost. The services that have been provided to us are invaluable

WEST VIRGINIA

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

More specific comments than any other had to do with families needing more services:

I feel that in our county there should be more help for children with disabilities. Also for adults.

There were several comments that had to do with staff, mainly that families were dissatisfied with staff turnover and the staff members themselves:

I feel there are too many turnovers with the staff in the MR/DD agencies. This causes a lot of confusion and repetitiveness.

Most of the people I deal with are nice and listen, but those that don't deal with people with disabilities. Like only some people in DHHR are nice to me and some doctors, they just act like they don't have time or care.

WYOMING

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

Many commented on how much they liked the case managers/service coordinators:

I am very happy with the services my child receives. We love everyone who works with him they are like family-my son's case manager is fabulous. She is so involved and helpful. I don't believe she could even improve. She is the BEST! We are very thankful for everyone and everything that has been a positive influence in my son's life. I believe he is better today because of the services he has received. Thanks and feel free to contact me if needed (Name; Phone#; Email Address)

Families were dissatisfied, however, when it came to respite services...

The individual we had chosen to provide respite care has been unable to find out the status of her application. The case mgr. has called and complained, the individual has called numerous times. Meanwhile, we have been without services. Quality respite and other (homemaking, res-hab) providers are very difficult to find in central Wyoming.

...as well as getting overall services that they need:

We should have had services years ago when my son was in second grade that's when we moved here from SLC Ut. I think that if he would have had them then he would be better off now...