

# Adult Family Survey

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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**

Eleven states conducted the National Core Indicators (NCI) Adult Family Survey during the 2006-2007 project year and submitted their data. The Adult Family Survey was administered to individuals having an adult family member with disabilities living at 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 Adult Family Survey.

### **II. ADULT FAMILY SURVEY**

This section briefly describes the structure of the survey instrument.

### **III. METHODS**

This section illustrates the protocol used by states to select families to participate in the survey, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by 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 planning, access and delivery, choice and control, community connections, satisfaction and outcome data. It also provides a look at state trends, comparing individual state results against the average of all state results, and an analysis of open-ended comments offered by respondents.

# 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

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. Adult Family Survey

### Background

This report focuses on the Adult Family Survey.

During Phase I, all seven field test states conducted this survey. States were instructed to mail the survey to 1,000 randomly-selected families who met two criteria: (1) an adult 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. Phase I demonstrated that the survey was relatively straightforward to administer, yielded good response rates, and provided sound feedback to SDDAs. Based on feedback from the states, the Phase I instrument was slightly modified and reissued for administration during Phase II.

During Phase II, twelve states administered the revised survey. Only minor changes were made following Phase II. Some graphics were added to make the survey more visually interesting, easier to follow, and more appealing to answer; and some of the demographic questions were reworded and clarified based on feedback from participating states. In addition, a few questions were added to gauge the level of interest in self-management of supports and services.

Between 2001 and 2007, eight to fifteen states have participated each year. Response rates within states have varied greatly, between 24% - 80%, yet each year, NCI has had between 4,000 – 6,500 completed surveys available for analysis.

### State Participation

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

Table 3 State Participation in NCI Adult Family Survey (Adults Living at Home with Family)								
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	CT	AZ	CA-RCOC	AZ	CA-RCOC	AZ	CT
CT	CT	DE	CA-RCOC	CT	CA-RCOC	CT	CA-RCOC	DE
MO	KY	IA	HI	DE	CT	HI	CT	GA
NE	NE	KY	IL	HI	ME	OK	GA	HI
PA	NC	MA	IA	IN	NC	PA	KY	ME
VT	PA	MN	NE	IA	ND	SC	ME	NM
VA	VT	MT	NC	ME	OK	WV	NC	OK
	WA	NE	OK	MA	PA	WY	OK	PA
		NC	PA	NC	SC		PA	VT
		PA	UT	OK	WA		SC	WV
		RI	VT	PA	WV		SD	WY
		UT	WA	SC	WY		WA	
			WV	SD			WV	
			WY	WV			WY	
				WY				



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## Survey Instrument

States that administer the Adult Family Survey agree to employ 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 Adult Family Survey developed by the project. Later, we discuss how the surveys were administered and how the results were analyzed.

The Adult 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 family member with disabilities (e.g., individual'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 that they and/or their family member with a disability receive.

**Service Planning, Delivery & Outcomes** – The survey contains several groupings of questions that probe specific areas of quality service provision (e.g., information and planning, access and delivery of services, choice and control, community connections). Each question is constructed so that they 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.

**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 Adult Family Survey by selecting a random sample of 1,000 families who: a) have an adult family member with developmental disabilities living at home, and b) receive service coordination and at least one additional "direct" service or support. Adults were defined as individuals with disabilities age 18 or older. 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 family member 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 family member with disabilities lived outside of the family home, yet received the Adult Family Survey, their responses were dropped.
- ◆ If the respondent indicated that their family member with disabilities was under the age of 18, 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 2006-2007, eleven states administered the Adult Family Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis.

<b>Table 4 Adult Family Survey - State Response Rates</b>				
<b>State</b>	<b>Surveys Mailed</b>	<b>Surveys Returned</b>	<b>Response Rate (%)</b>	<b>Usable Surveys</b>
Connecticut	1,200	378	32%	355
Delaware	1,339	360	27%	297
Georgia	1,862	694	37%	658
Hawaii	670	409	61%	344
Maine	881	364	41%	339
New Mexico	1,023	450	44%	437
Oklahoma	1,043	527	51%	476
Pennsylvania	2,760	1238	45%	1,029
Vermont	465	226	49%	217
West Virginia	*	164	*	157
Wyoming	330	71	22%	59
<b>Overall</b>	<b>10,373</b>	<b>4,881</b>	<b>42%</b>	<b>4,368</b>
* denotes data missing				

The desired response rate (the percentage of surveys returned versus the number mailed) to these surveys is 40%. Table 4 shows 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 Adult Family Survey. Findings are presented in aggregate, as well as by state.

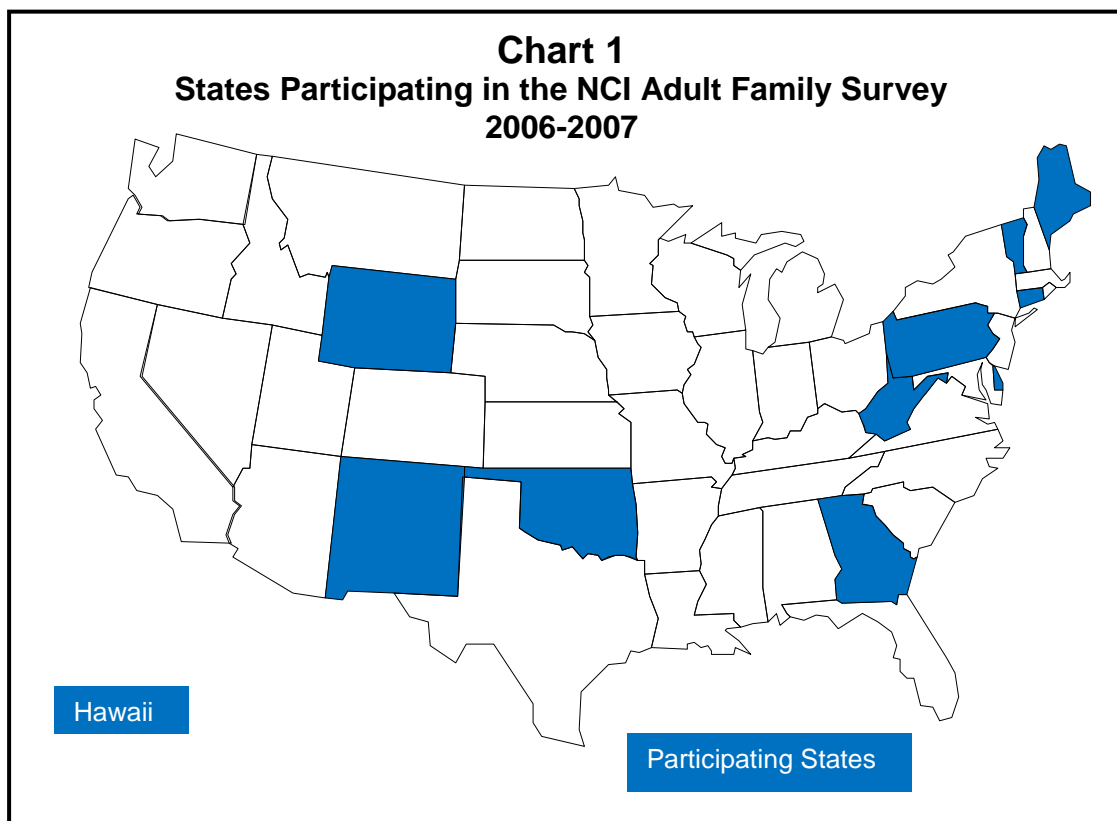
It is important to note that the TABLES provide individual state results and result averages that are calculated through two separate methods:

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

The CHARTS in this section illustrate the state average results, as do the COMMENTS (unless otherwise noted).

### Participating States

- ◆ Eleven states provided data for this Report. They include Connecticut, Delaware, Georgia, Hawaii, Maine, New Mexico, Oklahoma, Pennsylvania, Vermont, West Virginia and Wyoming.



## Characteristics of Family Members with Disabilities

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

- ◆ On average, across participating sites, 54% of family members with disabilities were male, 46% were female.
- ◆ The average age of family members with disabilities was 33.5, with a range in age from 18 to 87.
- ◆ Seventy-six percent (76%) of the family members were White, 8% were Black/African-American, 7% were Hispanic/Latino, 6% were Asian-American, 3% were American Indian/Alaska Native, 3% were Native Hawaiian/Pacific Islander, and 4% were Mixed Races.
- ◆ Thirteen percent of households include more than one individual with a developmental disability.
- ◆ Over one-third (37%) of the family members with disabilities had a diagnosis of moderate mental retardation. Additionally, 22% were individuals with severe/profound mental retardation, 20% had mild mental retardation, and 4% had no mental retardation diagnosis. 17% of respondents were unsure of their family member's diagnosis.
- ◆ Many family members experience disabilities in addition to mental retardation. The most prevalent "other" disabilities include: seizure disorders/neurological problems (31%), physical disabilities (28%), vision/hearing impairments (25%), and communication disorders (23%).

### Gender of Family Member

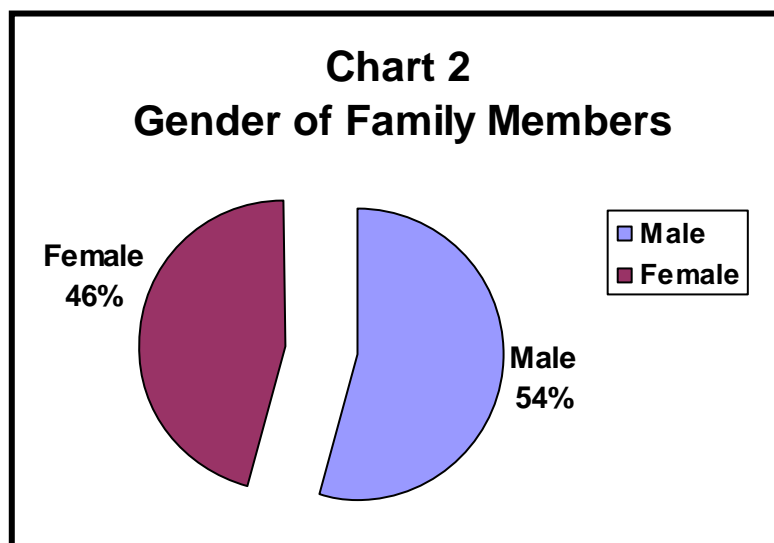


Table 5 Gender		
State	% Male	% Female
CT	53.1	46.9
DE	55.6	44.4
GA	57.5	42.5
HI	56.9	43.1
ME	54.8	45.2
NM	52.6	47.4
OK	52.7	47.3
PA	54.9	45.1
VT	52.7	47.3
WV	55.5	44.5
WY	44.8	55.2
<b>Total n</b>	2,292	1,902
<b>Total %</b>	54.6	45.4
<b>State Avg. %</b>	53.7	46.3

## Age of Family Member

Table 6 Age of Family Member		
State	Average Age	Range
CT	34.9	18-73
DE	33.7	18-83
GA	38.3	18-82
HI	31.2	18-87
ME	34.0	18-64
NM	33.0	18-73
OK	30.7	18-72
PA	34.6	18-79
VT	33.6	18-71
WV	32.8	18-73
WY	31.9	21-77
<b>Total n</b>	4,271	
<b>Total Avg.</b>	34.0	
<b>State Avg.</b>	33.5	18-87

## Race/Ethnicity of Family Member

In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.

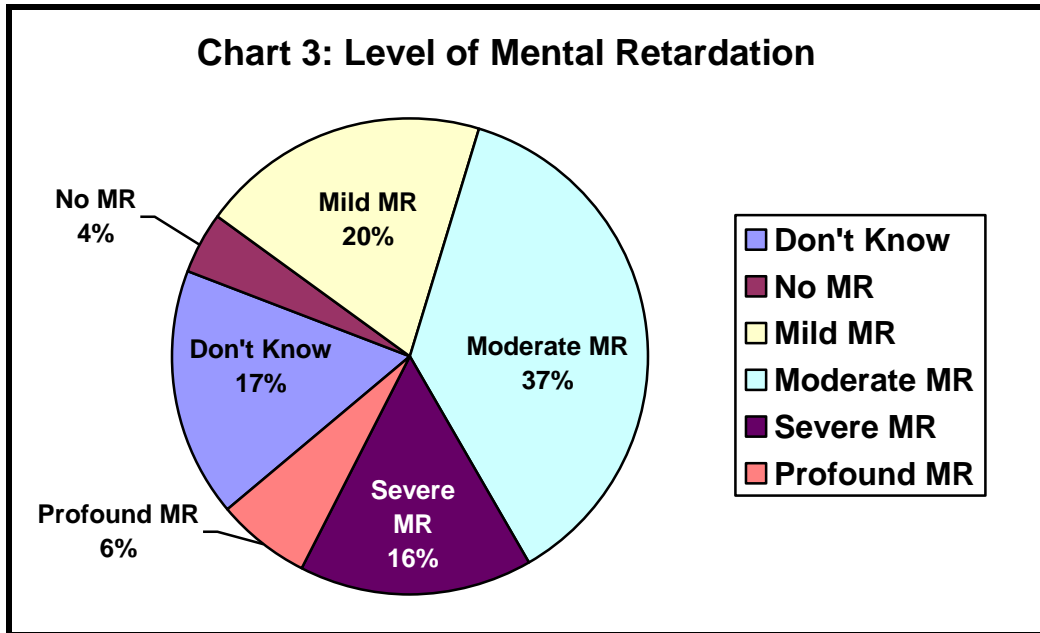
Table 7 Race/Ethnicity of Family Member (%)								
State	White	Black/ Af. American	Asian	Amer. Indian/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
CT	83.0	8.8	2.3	1.2	0.3	0.3	0.6	6.2
DE	70.5	24.7	1.8	0.7	0.4	1.8	0.0	1.1
GA	62.9	33.7	1.2	0.5	0.0	0.8	0.2	1.9
HI	25.7	1.6	49.8	2.5	27.0	21.6	2.8	4.7
ME	96.4	0.3	0.6	3.6	0.0	0.9	0.0	0.6
NM	43.6	1.2	0.7	7.9	0.2	4.7	0.5	47.0
OK	77.9	9.7	1.5	13.7	0.9	4.7	0.4	2.4
PA	91.8	4.1	1.0	1.5	0.2	0.5	0.3	1.3
VT	97.2	0.0	0.5	2.3	0.0	0.5	0.0	0.5
WV	89.6	6.5	3.2	2.6	2.6	3.9	1.9	3.2
WY	93.0	0.0	0.0	1.8	0.0	3.5	0.0	7.0
<b>Total n</b>	3,145	427	208	150	99	138	22	278
<b>Total %</b>	74.6	10.1	4.9	3.6	2.3	3.3	0.5	6.6
<b>State Avg. %</b>	75.6	8.2	5.7	3.5	2.9	3.9	0.6	6.9

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**More Than One Person with Disabilities Living in Household**

<b>Table 8 More Than One Person in Household with a Developmental Disability</b>		
<b>State</b>	<b>% Yes</b>	<b>% No</b>
CT	11.0	89.0
DE	14.8	85.2
GA	13.0	87.0
HI	12.1	87.9
ME	11.7	88.3
NM	10.5	89.5
OK	7.8	92.2
PA	13.7	86.3
VT	10.8	89.2
WV	19.7	80.3
WY	11.9	88.1
<b>Total n</b>	519	3,714
<b>Total %</b>	12.3	87.7
<b>State Avg. %</b>	12.5	87.5

Level of Mental Retardation of Family Member



**Table 9  
Level of Mental Retardation of Family Member**

State	No MR Diagnosis	Mild MR	Moderate MR	Severe MR	Profound MR	Don't Know
CT	2.6	25.0	35.9	11.5	4.1	20.9
DE	7.3	16.9	34.2	17.7	3.8	20.0
GA	3.4	18.6	33.7	18.8	8.4	17.0
HI	6.0	14.4	31.3	19.7	5.6	22.9
ME	3.2	26.5	38.7	13.1	4.8	13.7
NM	7.8	19.7	37.9	15.9	6.3	12.4
OK	3.3	17.9	31.6	20.7	12.2	14.4
PA	1.8	22.9	35.5	12.6	5.9	21.2
VT	Question not asked in Vermont					
WV	5.3	12.5	41.4	21.1	9.9	9.9
WY	0.0	25.0	50.0	7.1	1.8	16.1
<b>Total n</b>	150	794	1,379	624	265	694
<b>Total %</b>	3.8	20.3	35.3	16.0	6.8	17.8
<b>State Avg. %</b>	4.1	19.9	37.0	15.8	6.3	16.9



**Family Member's Disabilities – Other than Mental Retardation**

<b>Table 10A Other Disabilities of Family Member</b>						
<b>State</b>	<b>Mental Illness</b>	<b>Autism</b>	<b>Cerebral Palsy</b>	<b>Brain Injury</b>	<b>Seizure Disorder</b>	<b>Chemical Dependency</b>
CT	12.7	15.9	17.1	6.7	26.0	0.6
DE	12.3	15.9	16.3	6.0	27.4	0.0
GA	17.0	9.9	16.7	10.2	30.4	0.9
HI	11.6	12.6	20.0	8.4	33.2	1.0
ME	10.8	16.3	15.4	6.5	23.2	0.3
NM	15.1	11.7	21.1	10.3	28.4	0.9
OK	13.5	10.9	31.4	13.3	39.7	2.0
PA	15.0	9.5	15.7	8.1	26.9	1.0
VT	18.0	19.5	13.7	10.2	25.9	0.0
WV	18.9	20.9	29.1	10.1	43.9	4.1
WY	14.5	20.0	23.6	16.4	30.9	1.8
<b>Total n</b>	594	516	781	376	1,219	41
<b>Total %</b>	14.5	12.6	19.1	9.2	29.8	1.0
<b>State Avg. %</b>	14.5	14.8	20.0	9.7	30.5	1.1

<b>Table 10B Other Disabilities of Family Member</b>						
<b>State</b>	<b>Vision/ Hearing Impairment</b>	<b>Physical Disability</b>	<b>Communi- cation Disorder</b>	<b>Alzheimer's Disease</b>	<b>Down Syndrome</b>	<b>Other Disability</b>
CT	24.8	20.6	16.2	1.3	26.0	13.7
DE	17.9	20.6	17.1	1.6	20.2	13.5
GA	21.7	22.9	21.1	0.2	17.0	12.3
HI	25.5	28.7	20.6	1.3	21.6	19.0
ME	23.9	20.9	20.3	0.7	27.5	12.7
NM	25.6	26.5	25.4	0.9	17.4	23.8
OK	33.2	40.7	31.8	1.5	19.0	16.8
PA	24.1	25.1	15.8	0.6	24.5	15.5
VT	19.5	26.3	24.9	1.0	24.9	24.9
WV	37.8	45.9	34.5	4.1	12.2	22.3
WY	25.5	27.3	20.0	1.8	18.2	10.9
<b>Total n</b>	1,018	1,097	877	41	868	673
<b>Total %</b>	24.9	26.9	21.5	1.0	21.3	16.5
<b>State Avg. %</b>	25.4	27.8	22.5	1.4	20.8	16.9

## 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, 50% of respondents (individuals who completed the surveys) fell into the age category of 55 to 74 years old. Eleven percent of respondents were over age 75, and the remaining 38% were under 55.
- ◆ The vast majority of respondents were parents of adult children with disabilities (86%). The remaining respondents included siblings (7%), spouses (1%), and others(6%).
- ◆ Ninety-seven percent of all respondents considered themselves to be the primary caregiver for their family member with disabilities. This was consistent across all of the states.
- ◆ Two-thirds (70%) of respondents indicated that they were their family member’s legal guardian or conservator. Across the states, results varied from 51% in Pennsylvania to 82% in Connecticut, Hawaii and Vermont.
- ◆ Most respondents (76%) indicated that they were in good or excellent health, however nearly one-quarter of respondents (24%) categorized their health as being fair or poor.
- ◆ About half (48%) of respondents had an annual household income (including all wage earners within the household) of \$25,000 or less. 27% had a household income between \$25,001 and \$50,000, and 25% had an income over \$50,000.

### Age of Respondent

Table 11 Age of Respondent				
State	Under 35	35-54	55-74	75 or Older
CT	3.8	25.7	52.6	17.8
DE	3.2	32.6	52.3	11.8
GA	2.8	26.2	58.9	12.1
HI	6.7	36.7	47.3	9.4
ME	1.8	35.8	48.5	13.9
NM	5.1	37.1	48.2	9.6
OK	4.6	40.8	46.6	8.0
PA	3.3	34.1	48.8	13.8
VT	1.9	33.6	49.1	15.4
WV	1.9	45.8	45.8	6.5
WY	1.7	33.9	55.9	8.5
<b>Total n</b>	152	1,448	2,154	517
<b>Total %</b>	3.6	33.9	50.4	12.1
<b>State Avg. %</b>	3.3	34.8	50.4	11.5

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## Relationship of Respondent to Individual with Disabilities

Table 12 Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
CT	89.4	7.1	0.3	3.2
DE	76.3	9.5	0.4	13.8
GA	79.8	10.0	1.6	8.6
HI	82.8	7.1	1.2	8.9
ME	92.2	4.8	0.3	2.7
NM	84.7	8.9	0.0	6.5
OK	86.5	5.1	0.2	8.2
PA	85.4	9.0	1.1	4.5
VT	91.0	5.2	0.0	3.8
WV	86.8	7.2	0.0	5.9
WY	91.5	3.4	1.7	3.4
<b>Total n</b>	3,607	329	30	273
<b>Total %</b>	85.1	7.8	0.7	6.4
<b>State Avg. %</b>	86.0	7.0	0.6	6.3

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## Respondent's Role as Primary Caregiver

Table 13 Respondent is Primary Caregiver		
State	% Yes	% No
CT	96.5	3.5
DE	96.1	3.9
GA	97.5	2.5
HI	95.1	4.9
ME	98.8	1.2
NM	98.3	1.7
OK	96.0	4.0
PA	94.7	5.3
VT	97.2	2.8
WV	95.5	4.5
WY	96.6	3.4
<b>Total n</b>	4,115	153
<b>Total %</b>	96.4	3.6
<b>State Avg. %</b>	96.6	3.4

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## Respondent's Role as Guardian or Conservator

<b>Table 14 Respondent is Legal Guardian or Conservator</b>		
<b>State</b>	<b>% Yes</b>	<b>% No</b>
CT	82.0	18.0
DE	55.3	44.7
GA	52.3	47.7
HI	82.0	18.0
ME	78.2	21.8
NM	74.2	25.8
OK	66.2	33.8
PA	51.4	48.6
VT	82.1	17.9
WV	72.5	27.5
WY	78.0	22.0
<b>Total n</b>	<b>2,688</b>	<b>1,411</b>
<b>Total %</b>	<b>65.6</b>	<b>34.4</b>
<b>State Avg. %</b>	<b>70.4</b>	<b>29.6</b>

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## Health of Respondent

<b>Table 15 Health of Respondent (%)</b>				
<b>State</b>	<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>
CT	20.8	52.3	24.0	2.9
DE	15.8	63.0	19.7	1.4
GA	12.7	53.5	30.4	3.4
HI	24.9	54.8	19.1	1.2
ME	20.9	55.2	22.1	1.8
NM	31.0	55.8	12.0	1.2
OK	23.4	55.1	17.8	3.7
PA	14.1	55.6	26.3	3.9
VT	25.2	55.1	16.8	2.8
WV	14.1	54.5	27.6	3.8
WY	18.6	61.0	18.6	1.7
<b>Total n</b>	<b>820</b>	<b>2,364</b>	<b>964</b>	<b>121</b>
<b>Total %</b>	<b>19.2</b>	<b>55.4</b>	<b>22.6</b>	<b>2.8</b>
<b>State Avg. %</b>	<b>20.1</b>	<b>56.0</b>	<b>21.3</b>	<b>2.5</b>

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## Household Income

<b>Table 16 Household Income</b>					
<b>State</b>	<b>Below \$15,000</b>	<b>\$15,001 - \$25,000</b>	<b>\$25,001 - \$50,000</b>	<b>\$50,001 - \$75,000</b>	<b>Over \$75,000</b>
CT	20.6	21.0	22.1	17.3	19.1
DE	23.9	23.1	21.4	16.8	14.7
GA	29.5	24.3	25.1	10.5	10.5
HI	18.9	17.6	34.8	14.5	14.2
ME	<b>Question not asked in Maine</b>				
NM	28.2	25.7	26.8	10.5	8.8
OK	24.9	19.6	29.1	14.4	12.0
PA	30.0	21.0	27.6	13.5	7.9
VT	<b>Question not asked in Vermont</b>				
WV	34.3	23.6	27.1	8.6	6.4
WY	21.8	20.0	32.7	16.4	9.1
<b>Total n</b>	867	707	874	427	355
<b>Total %</b>	26.8	21.9	27.1	13.2	11.0
<b>State Avg. %</b>	25.8	21.8	27.4	13.6	11.4

## Services and Supports Received

- ◆ Across participating states, on average, day/employment and transportation services were the supports most often provided (72% and 64% respectively) to the family member with disabilities.
- ◆ Additionally, 41% received financial support, 37% utilized out-of-home respite care, 34% obtained in-home supports, and 32% received other needed supports.

<b>Table 17 Services and Supports Received (%)</b>						
<b>State</b>	<b>Financial support</b>	<b>In-home support</b>	<b>Out-of-home respite care</b>	<b>Day / employment supports</b>	<b>Transportation</b>	<b>Other</b>
CT	35.2	20.8	29.8	87.9	73.6	10.7
DE	29.9	9.0	17.8	72.0	70.2	15.5
GA	32.2	14.0	20.3	86.9	76.6	18.7
HI	51.7	34.3	38.9	63.4	60.4	24.2
ME	48.6	19.2	23.7	84.8	80.2	24.1
NM	41.7	40.7	70.4	67.2	43.1	80.1
OK	37.8	69.6	15.0	42.9	40.0	37.2
PA	45.8	24.9	29.9	70.3	58.9	22.3
VT	30.1	25.3	58.5	80.1		
WV	49.3	65.4	45.6	65.4	64.7	46.3
WY	43.6	46.6	56.1	74.6	69.0	43.9
<b>Total n</b>	1,580	1,271	1,348	3,023	2,482	1,166
<b>Total Avg. %</b>	40.5	30.5	32.7	72.0	62.2	29.8
<b>State Avg. %</b>	40.5	33.6	36.9	72.3	63.7	32.3

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## National Core Indicators

In the 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.

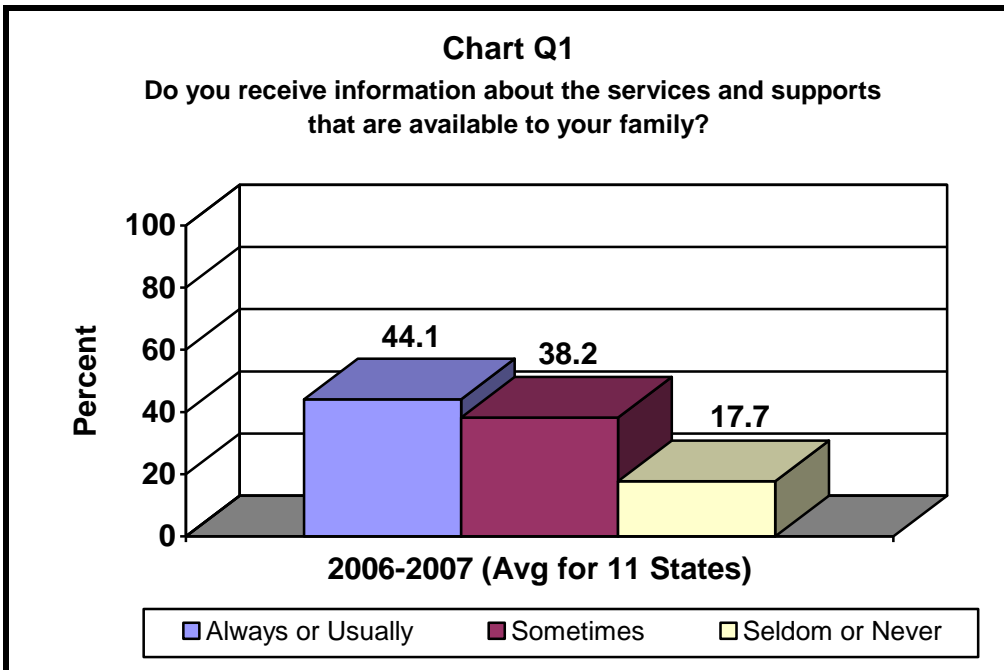
- ◆ The Figure illustrates the State Average results (i.e., the average percentage across the eleven states that conducted this survey).
- ◆ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state 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

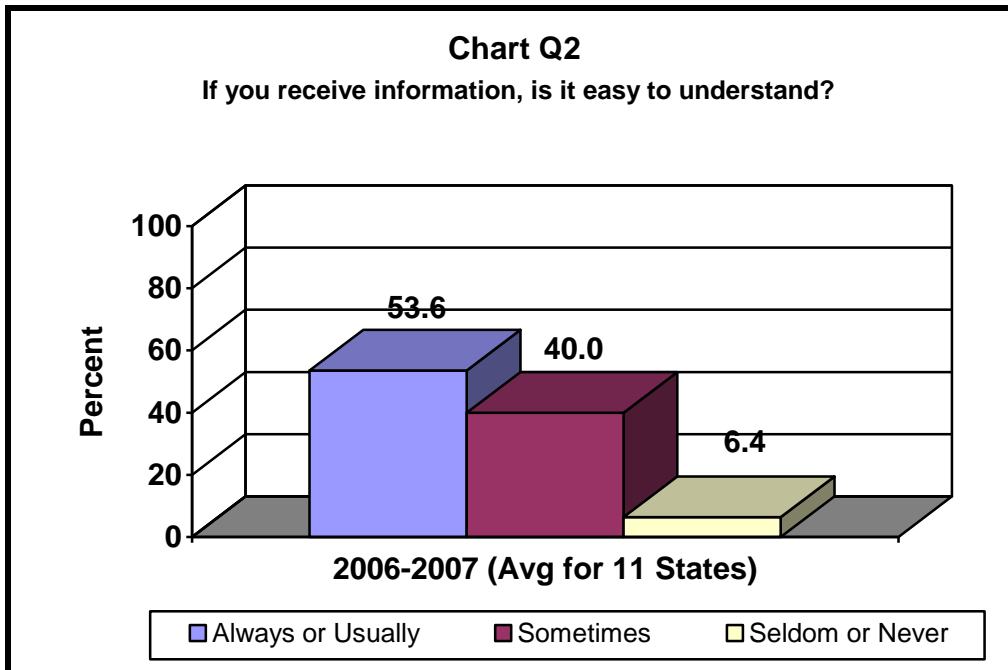
- Across all participating states, fewer than half (44%) of respondents indicated they receive information about the services and supports available to them. Individual state results varied considerably, ranging from 28% in Georgia to 61% in New Mexico.
- Among those who receive information, over half (54%) found the information easy to understand, while the remaining 46% found the information, at least sometimes, difficult to understand.
- Half of respondents (53%) stated that they got enough information to help them participate in planning, while the other half indicated they only sometimes or seldom had enough information.
- Three-fourths (77%) of respondents indicated that they helped in developing their family member's service plan.
- Of those families with a service plan, 72% stated that the plan included things important to the respondent. Twenty-eight percent of respondents indicated that the plan only sometimes, seldom or never included things important to them.
- Over half (61%) of respondents indicated that planning staff would help them figure out the supports they needed. However, a large percentage (39%) stated that this was only sometimes or even seldom the case.
- Three-fourths (78%) of respondents felt that staff respect their choices and opinions.
- Nine of ten (89%) felt that agency staff were generally respectful and courteous.
- Sixty-seven percent of all respondents felt that agency staff were generally effective.
- Seventy-seven percent of respondents indicated they could typically contact staff when desired.





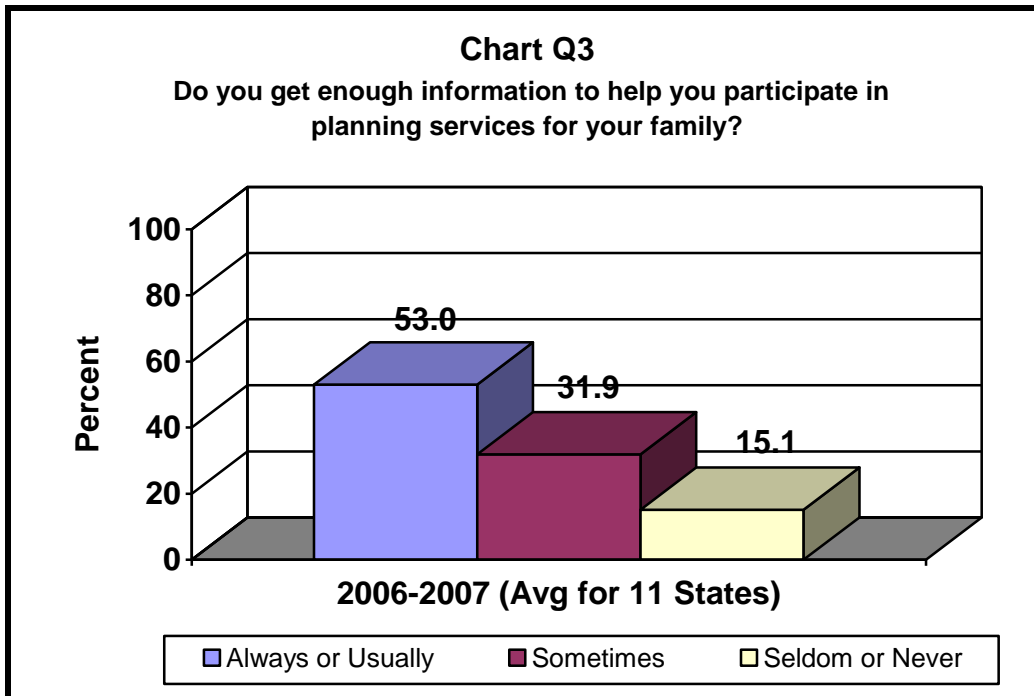
**Table Q1**  
Do you receive information about the services and supports that are available to your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		39.4	43.1	17.5	325
DE	↓↓↓	33.0	40.5	26.5	279
GA	↓↓↓	28.4	38.8	32.8	613
HI	↑	53.9	38.5	7.6	330
ME	↓	35.0	44.0	21.1	323
NM	↑↑↑	60.6	28.5	10.8	424
OK	↓	37.4	40.7	21.9	457
PA		46.0	37.7	16.3	980
VT	↑	50.7	36.5	12.8	203
WV		46.3	34.9	18.8	149
WY	↑↑↑	54.4	36.8	8.8	57
<b>Total %</b>		<b>42.7</b>	<b>38.2</b>	<b>19.1</b>	<b>4,140</b>
<b>State Average %</b>		<b>44.1</b>	<b>38.2</b>	<b>17.7</b>	<b>11</b>



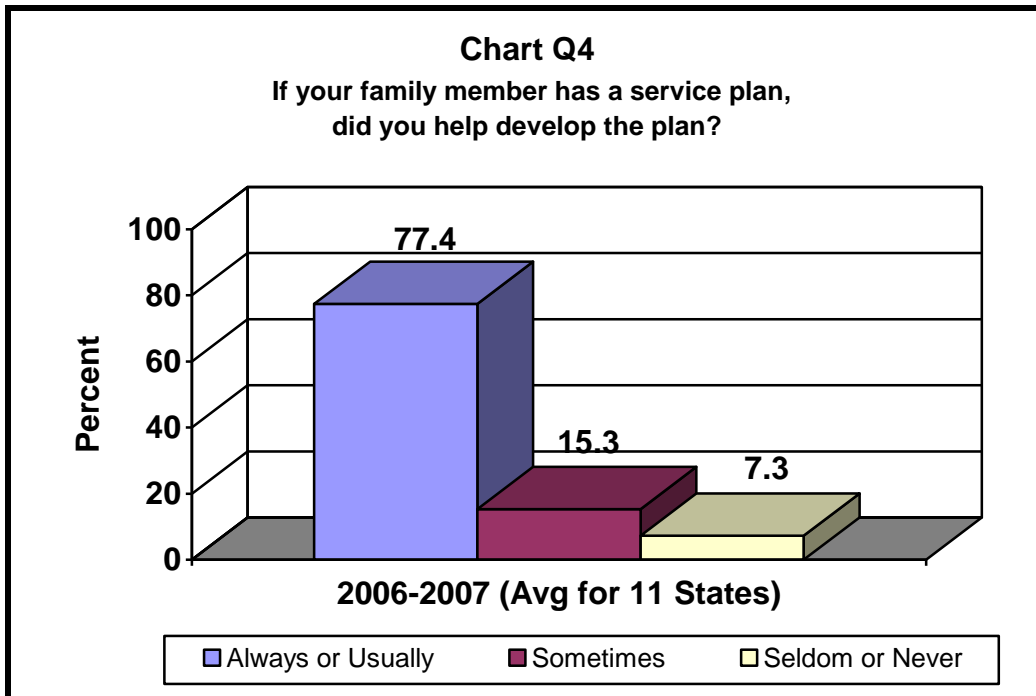
**Table Q2**  
If you receive information, is it easy to understand?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		50.9	42.8	6.4	283
DE		58.5	34.2	7.0	243
GA	↓	47.0	40.5	12.5	538
HI	↑	59.3	36.4	4.3	324
ME		50.9	43.4	5.7	281
NM		53.9	40.4	5.7	406
OK		50.8	41.3	7.9	419
PA	↑	59.7	35.0	5.3	908
VT		58.3	34.4	7.3	192
WV	↓	48.6	45.0	6.4	140
WY		51.8	46.4	1.8	56
<b>Total %</b>		<b>54.3</b>	<b>38.8</b>	<b>6.9</b>	<b>3,790</b>
<b>State Average %</b>		<b>53.6</b>	<b>40.0</b>	<b>6.4</b>	<b>11</b>



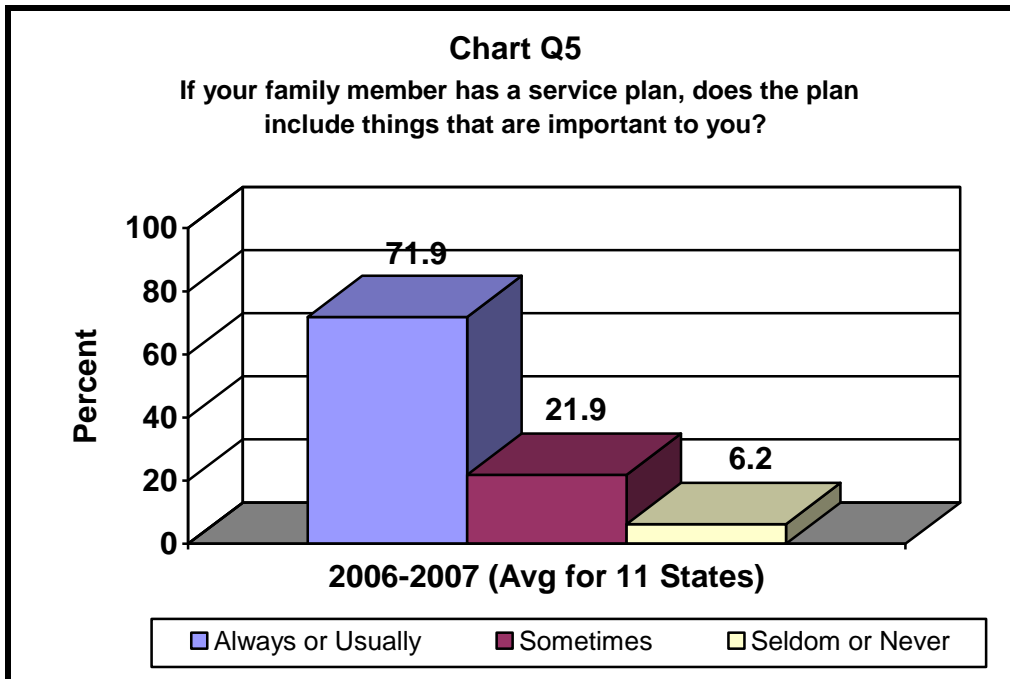
**Table Q3**  
Do you get enough information to help you participate in planning services for your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	47.8	31.9	20.3	301
DE	↓↓	39.6	34.2	26.3	240
GA	↓↓	40.6	30.5	28.9	577
HI	↑	59.8	33.6	6.5	321
ME	↑	58.9	29.0	12.1	297
NM	↑	61.3	31.0	7.7	416
OK	↓	47.4	34.2	18.5	439
PA		53.5	31.2	15.4	911
VT	↑	61.9	29.9	8.1	197
WV		51.0	32.0	17.0	147
WY	↑	60.7	33.9	5.4	56
<b>Total %</b>		<b>51.8</b>	<b>31.7</b>	<b>16.5</b>	<b>3,902</b>
<b>State Average %</b>		<b>53.0</b>	<b>31.9</b>	<b>15.1</b>	<b>11</b>



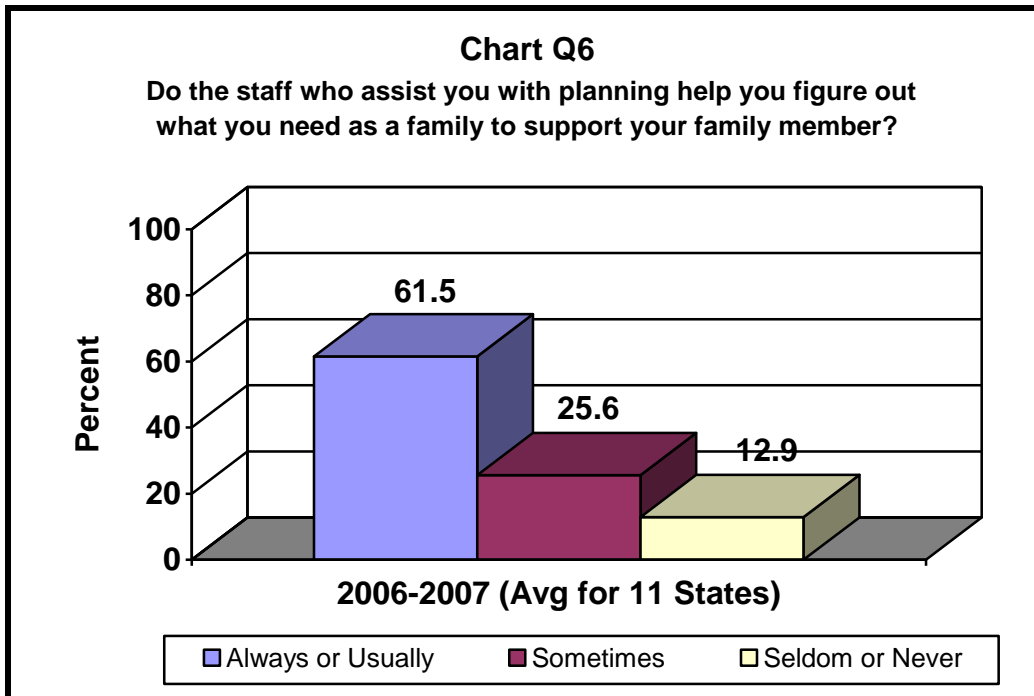
**Table Q4**  
If your family member has a service plan, did you help develop the plan?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		73.7	18.2	8.1	236
DE	↓↓↓	58.6	25.7	15.7	140
GA	↓↓↓	66.8	20.4	12.8	494
HI	↑	83.1	12.4	4.6	307
ME	↓	68.3	20.9	10.8	287
NM	↑↑↑	91.5	7.0	1.5	402
OK	↑	84.0	11.7	4.3	418
PA		75.4	15.4	9.2	768
VT	↑	86.7	9.7	3.6	195
WV		73.8	17.9	8.3	145
WY	↑↑↑	89.3	8.9	1.8	56
<b>Total %</b>		<b>77.2</b>	<b>15.2</b>	<b>7.7</b>	<b>3,448</b>
<b>State Average %</b>		<b>77.4</b>	<b>15.3</b>	<b>7.3</b>	<b>11</b>



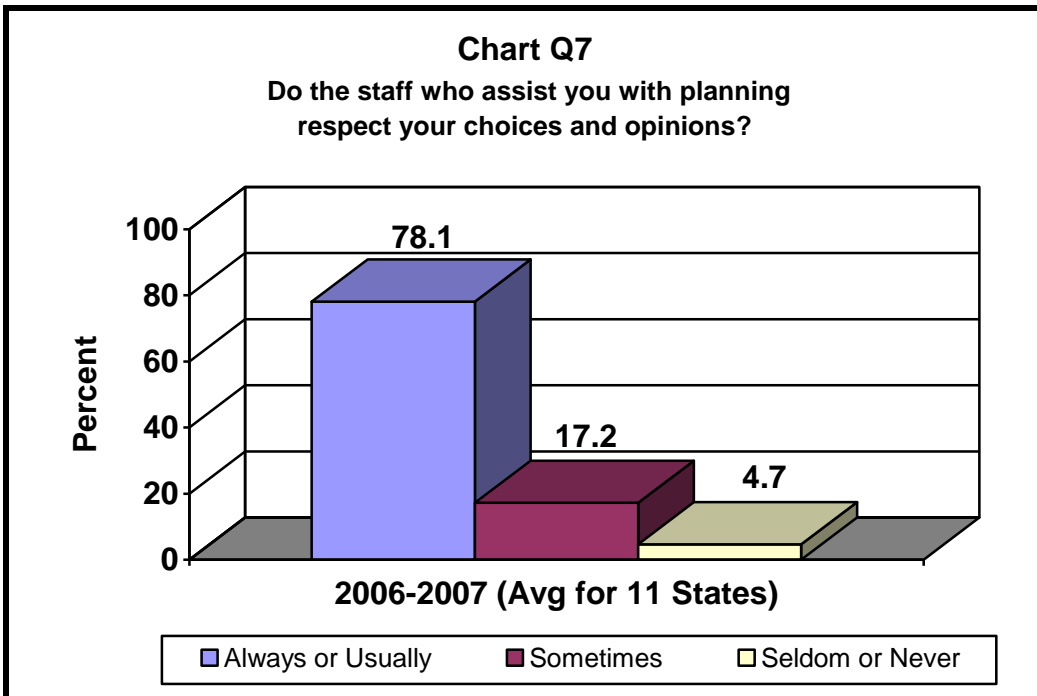
**Table Q5**  
If your family member has a service plan, does the plan include things that are important to you?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	61.8	28.6	9.5	241
DE	↓↓↓	60.4	24.3	15.3	144
GA	↓↓↓	57.7	31.4	10.9	513
HI	↑↑↑	82.3	14.8	2.9	311
ME		75.7	19.9	4.5	292
NM	↑	78.5	17.3	4.2	405
OK		74.9	20.0	5.0	419
PA		72.6	21.7	5.7	766
VT	↑↑↑	82.7	15.7	1.5	197
WV		67.6	26.9	5.5	145
WY		76.4	20.0	3.6	55
<b>Total %</b>		<b>71.7</b>	<b>22.1</b>	<b>6.3</b>	<b>3,488</b>
<b>State Average %</b>		<b>71.9</b>	<b>21.9</b>	<b>6.2</b>	<b>11</b>



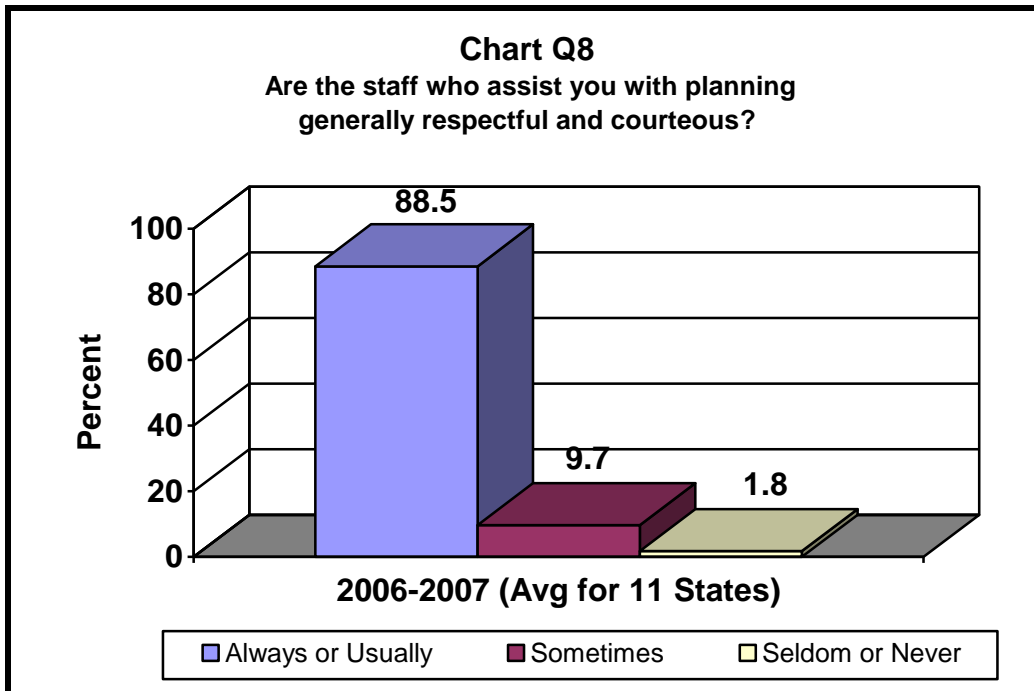
**Table Q6**  
Do the staff who assist you with planning help you figure out what you need as a family to support your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		60.9	26.0	13.2	258
DE	↓↓↓	48.3	26.7	25.0	180
GA	↓↓↓	50.1	29.0	20.9	545
HI	↑	68.0	26.6	5.3	319
ME	↓	56.5	30.3	13.3	294
NM	↑↑↑	75.4	18.8	5.8	414
OK		64.2	25.8	10.0	422
PA		62.5	24.4	13.1	824
VT		61.2	25.9	12.9	201
WV		59.5	25.7	14.9	148
WY	↑	70.2	22.8	7.0	57
<b>Total %</b>		<b>61.4</b>	<b>25.6</b>	<b>13.0</b>	<b>3,662</b>
<b>State Average %</b>		<b>61.5</b>	<b>25.6</b>	<b>12.9</b>	<b>11</b>



**Table Q7**  
Do the staff who assist you with planning respect your choices and opinions?

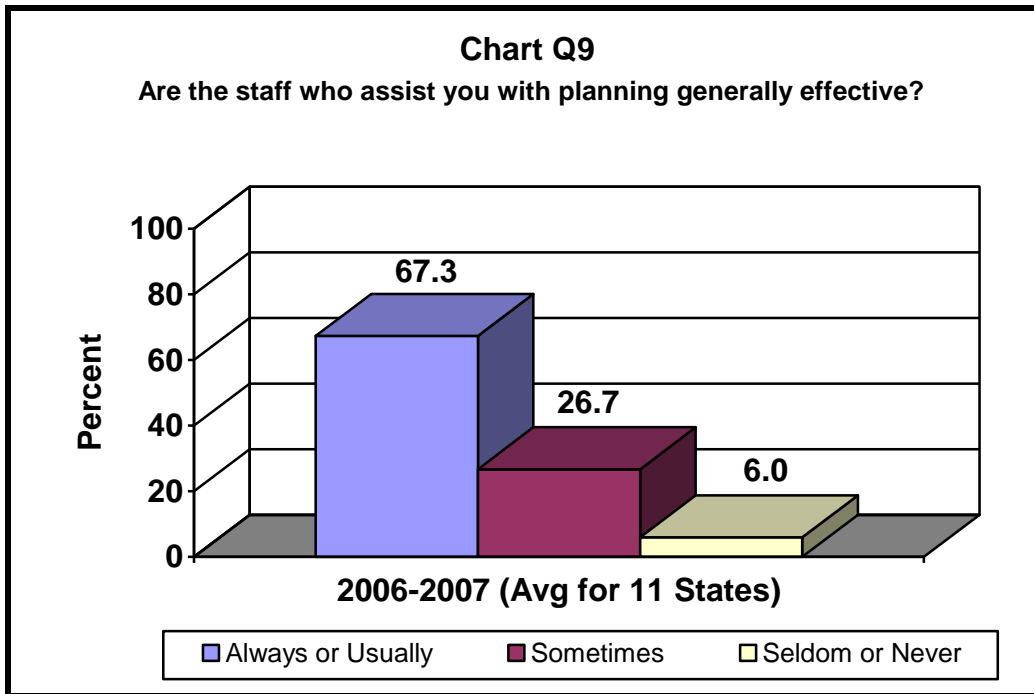
State		Always or Usually	Sometimes	Seldom or Never	n
CT		76.7	18.2	5.0	258
DE		73.4	14.7	11.9	177
GA	↓	71.7	18.6	9.7	554
HI	↑	85.2	13.9	0.9	324
ME		76.6	18.7	4.7	299
NM	↑	86.1	12.0	1.9	417
OK		81.4	16.3	2.3	429
PA		81.8	13.3	4.9	836
VT		80.8	16.7	2.5	203
WV	↓	69.9	24.0	6.2	146
WY		75.4	22.8	1.8	57
<b>Total %</b>		<b>79.2</b>	<b>15.9</b>	<b>4.8</b>	<b>3,700</b>
<b>State Average %</b>		<b>78.1</b>	<b>17.2</b>	<b>4.7</b>	<b>11</b>



**Table Q8**  
Are the staff who assist you with planning generally respectful and courteous?

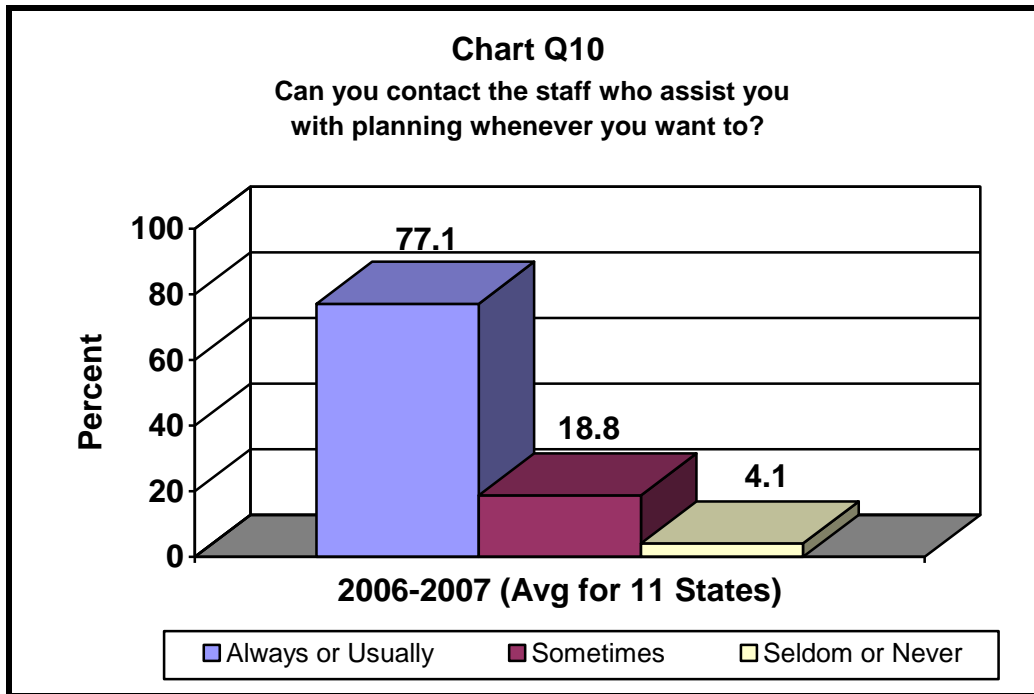
State		Always or Usually	Sometimes	Seldom or Never	n
CT		92.6	6.7	0.7	269
DE		84.2	10.4	5.5	183
GA	↓	82.5	14.7	2.8	566
HI		91.0	8.1	0.9	332
ME		92.0	6.6	1.3	301
NM		91.9	7.2	1.0	419
OK		91.2	7.9	0.9	431
PA		92.6	5.2	2.2	866
VT		88.9	10.6	0.5	207
WV		85.9	12.1	2.0	149
WY	↓	80.7	17.5	1.8	57
<b>Total %</b>		<b>89.6</b>	<b>8.6</b>	<b>1.8</b>	<b>3,780</b>
<b>State Average %</b>		<b>88.5</b>	<b>9.7</b>	<b>1.8</b>	<b>11</b>





**Table Q9**  
Are the staff who assist you with planning generally effective?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		64.4	28.1	7.5	267
DE	↓	60.2	26.7	13.1	176
GA	↓	60.3	31.4	8.3	554
HI	↑	75.1	23.7	1.2	329
ME		68.2	26.7	5.1	296
NM	↑	75.8	20.9	3.3	422
OK		70.6	25.2	4.2	425
PA		70.4	23.9	5.7	849
VT		67.3	29.3	3.4	205
WV	↓	62.3	28.8	8.9	146
WY		65.5	29.3	5.2	58
<b>Total %</b>		<b>68.3</b>	<b>26.0</b>	<b>5.7</b>	<b>3,727</b>
<b>State Average %</b>		<b>67.3</b>	<b>26.7</b>	<b>6.0</b>	<b>11</b>

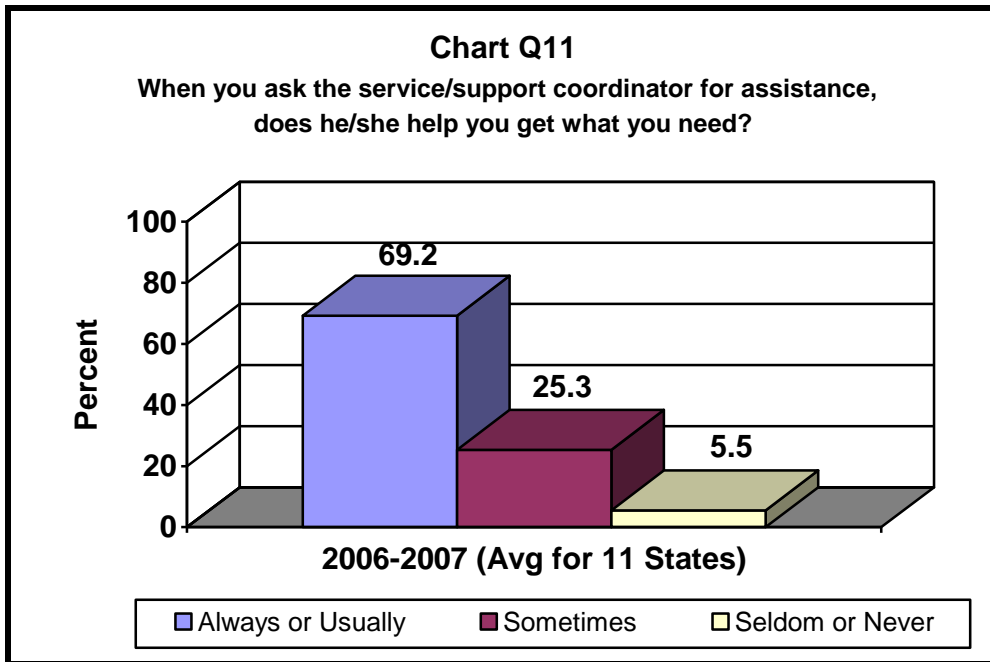


**Table Q10**  
Can you contact the staff who assist you with planning whenever you want to?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		75.7	21.7	2.6	267
DE	↓↓	62.6	25.7	11.8	187
GA		75.4	18.7	5.9	557
HI		82.0	15.9	2.1	333
ME	↑	82.9	14.4	2.7	299
NM		81.2	15.7	3.1	420
OK		76.9	18.2	4.9	429
PA		79.2	16.7	4.0	872
VT		72.8	24.9	2.3	213
WV		73.3	22.7	4.0	150
WY	↑	86.2	12.1	1.7	58
<b>Total %</b>		<b>77.6</b>	<b>18.2</b>	<b>4.2</b>	<b>3,785</b>
<b>State Average %</b>		<b>77.1</b>	<b>18.8</b>	<b>4.1</b>	<b>11</b>

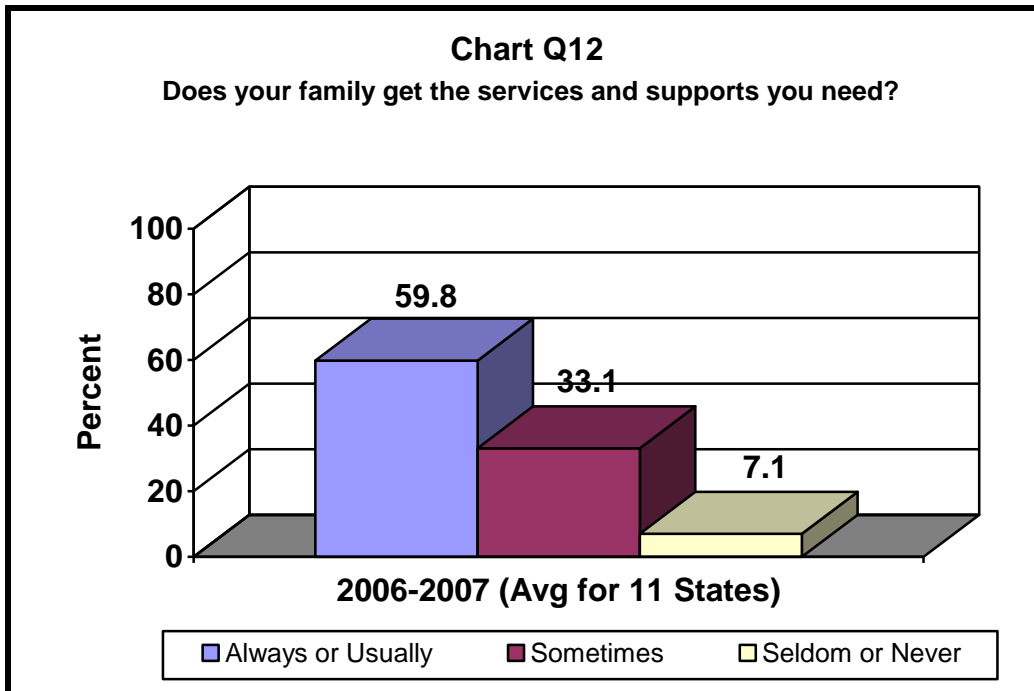
## Access to and Delivery of Services and Supports

- Overall, 69% of families indicated their service coordinator helped them get needed supports when asked. Twenty-five percent said this happened sometimes, and the remaining 5% indicated their service coordinator was rarely helpful in getting the assistance needed.
- Over half (60%) of respondents always or usually received the services/supports needed. Thirty-three percent got them sometimes, while 7% seldom or never received needed supports.
- The majority (56%) said the supports received met their families' needs. 36% stated that supports sometimes met their needs, while 8% felt supports seldom/never met their needs.
- For one-half of families (54%), supports were always or usually available when needed. However, almost as many families indicated that supports were only sometimes available (37%), or not available (9%) when needed.
- Forty-three percent of respondents stated that families in their area 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, 40% indicated that the state agency or provider agency was usually or always responsive to these requests.
- Slightly more than half (54%) of families who asked for assistance in an emergency or crisis received help right away.
- Among respondents whose first language was not English, 67% indicated that staff or translators were available to speak with them in their preferred languages. Fourteen percent indicated that staff/translators were sometimes available, and 20% stated that staff/translators who spoke in the families' preferred languages were not available.
- Among respondents with family members who did not speak English, or used a different means to communicate (e.g., sign language), about half (54%) of families said there were enough support staff regularly available who could communicate with their family member.
- About two-thirds of respondents (65%) felt their family member had access to the special equipment or accommodations needed.
- Most respondents (90%) felt they had access to health services for their family member.
- Compared to access to health care, slightly fewer families (77%) felt they had access to appropriate dental services for their family member. Fourteen percent had significant difficulty accessing dental services.
- Nearly all respondents (93%) felt they had access to necessary medications for their family member with a disability.
- Three-fourths of respondents (78%) indicated that frequent changes in support staff were a problem for their family at least some of the time.
- When the family member with a disability received day/employment supports, the vast majority of respondents (84%) felt that day/employment setting was a safe and healthy environment.
- Nine out of ten families (89%) felt that support staff were respectful and courteous.



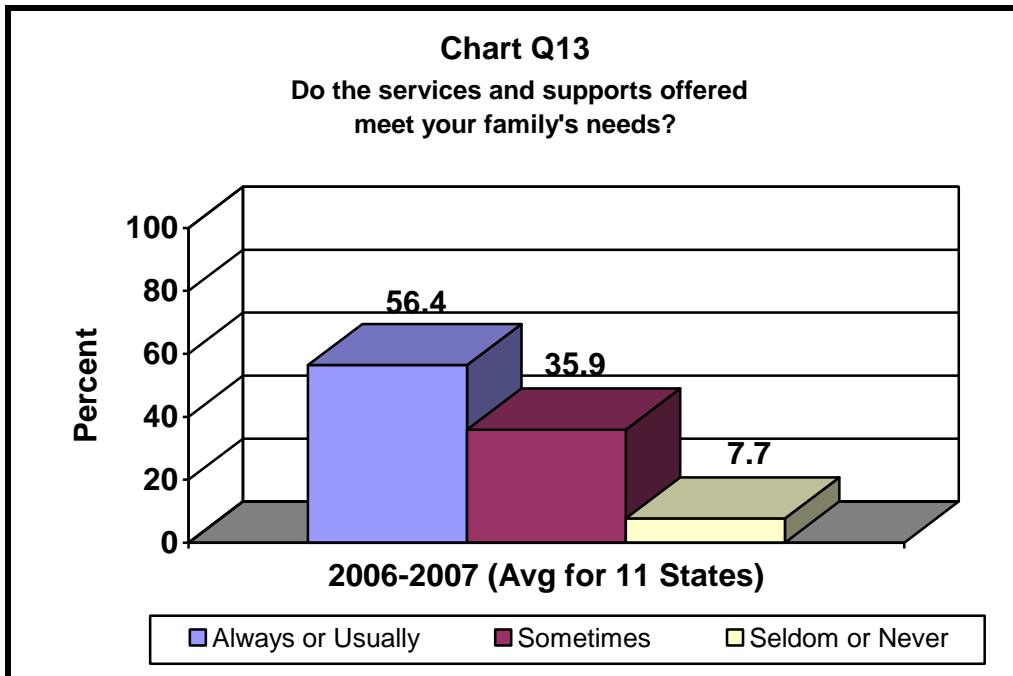
**Table Q11**  
When you ask the service/support coordinator for assistance, does he/she help you get what you need?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		68.2	24.5	7.2	277
DE	↓↓	55.7	32.3	12.0	192
GA	↓	61.5	29.6	8.9	564
HI		72.1	26.3	1.5	323
ME		68.8	25.7	5.5	292
NM	↑↑	80.4	17.3	2.4	423
OK	↑	74.2	20.5	5.3	453
PA		71.8	23.3	4.9	896
VT	↑	76.0	21.2	2.9	208
WV	↓	61.0	31.2	7.8	154
WY		71.9	26.3	1.8	57
<b>Total %</b>		<b>70.0</b>	<b>24.5</b>	<b>5.5</b>	<b>3,839</b>
<b>State Average %</b>		<b>69.2</b>	<b>25.3</b>	<b>5.5</b>	<b>11</b>



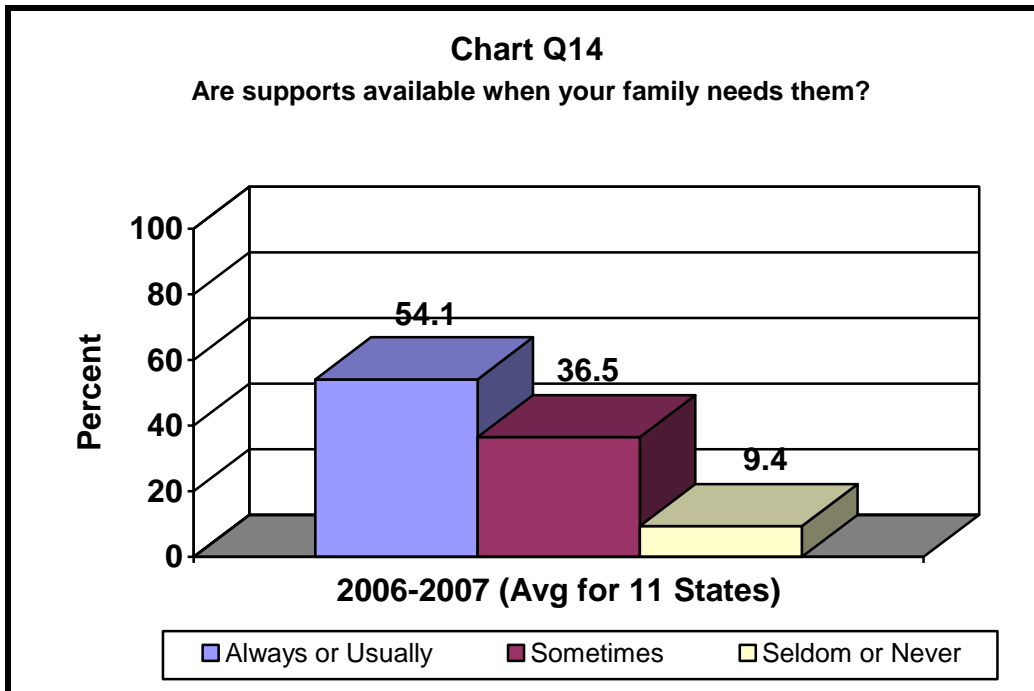
**Table Q12**  
Does your family get the services and supports you need?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	51.8	39.1	9.1	276
DE	↓	51.9	31.0	17.1	216
GA	↓	51.7	36.6	11.7	582
HI	↑	69.3	28.9	1.8	329
ME		57.3	36.5	6.2	307
NM	↑↑	71.1	25.9	3.1	425
OK		58.8	35.1	6.0	447
PA		62.3	27.8	9.9	921
VT		63.1	33.0	3.9	206
WV		55.7	34.9	9.4	149
WY	↑	64.9	35.1	0.0	57
<b>Total %</b>		<b>60.0</b>	<b>32.1</b>	<b>7.9</b>	<b>3,915</b>
<b>State Average %</b>		<b>59.8</b>	<b>33.1</b>	<b>7.1</b>	<b>11</b>



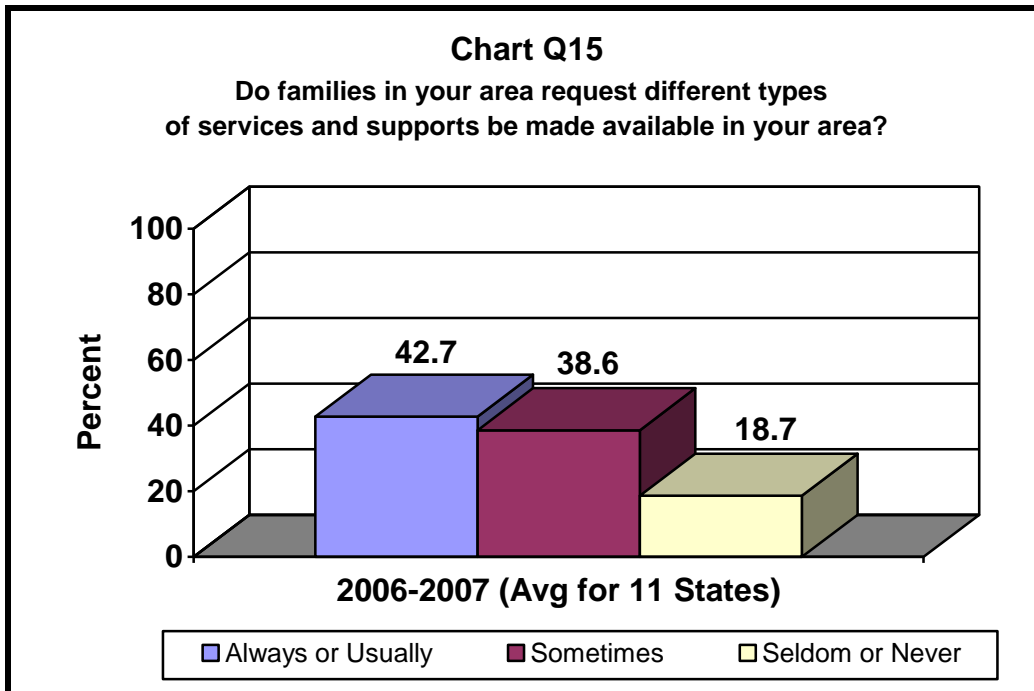
**Table Q13**  
Do the services and supports offered meet your family's needs?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	48.6	41.8	9.6	282
DE	↓↓	42.8	43.8	13.5	208
GA		52.2	36.3	11.5	567
HI	↑↑	66.5	31.3	2.2	316
ME		57.0	36.6	6.4	298
NM	↑	65.3	29.3	5.4	427
OK		57.2	36.7	6.1	444
PA		58.0	33.7	8.2	910
VT	↑	62.7	32.1	5.3	209
WV		54.5	34.4	11.0	154
WY		56.1	38.6	5.3	57
<b>Total %</b>		<b>57.1</b>	<b>35.1</b>	<b>7.8</b>	<b>3,872</b>
<b>State Average %</b>		<b>56.4</b>	<b>35.9</b>	<b>7.7</b>	<b>11</b>



**Table Q14**  
Are supports available when your family needs them?

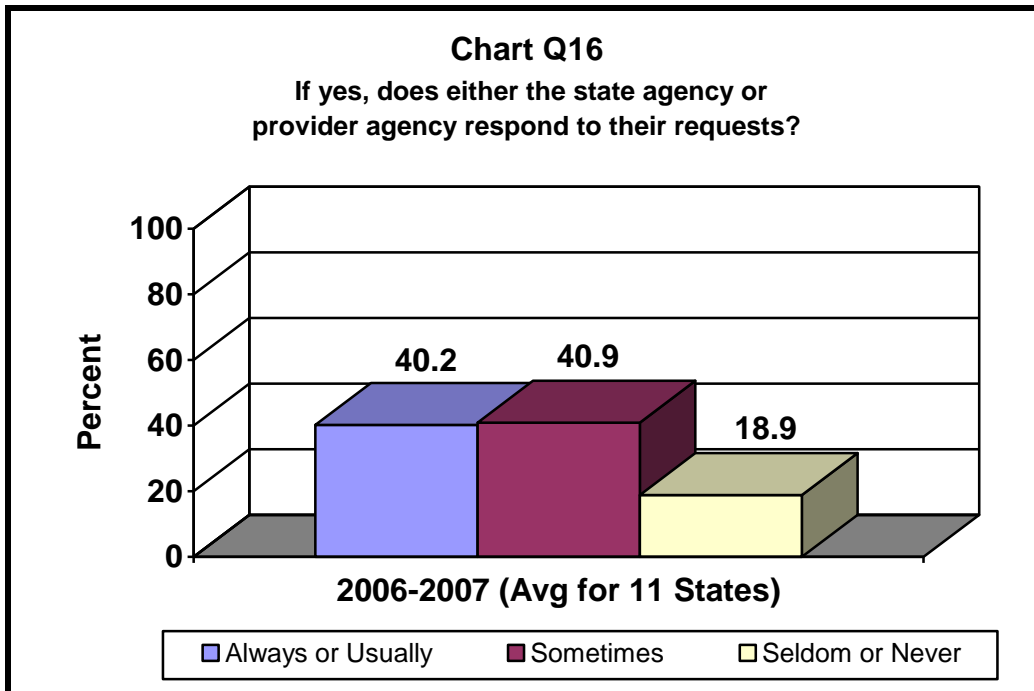
State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	43.1	43.5	13.4	262
DE	↓	45.5	34.7	19.8	202
GA	↓	47.1	37.2	15.8	546
HI	↑	59.7	37.4	2.9	310
ME		53.6	37.3	9.2	295
NM	↑↑	64.7	30.1	5.3	419
OK		52.7	39.1	8.2	427
PA		56.4	34.0	9.6	863
VT	↑	62.4	33.2	4.4	205
WV		50.0	38.7	11.3	150
WY	↑	59.6	36.8	3.5	57
<b>Total %</b>		<b>54.2</b>	<b>36.0</b>	<b>9.8</b>	<b>3,736</b>
<b>State Average %</b>		<b>54.1</b>	<b>36.5</b>	<b>9.4</b>	<b>11</b>



**Table Q15**  
Do families in your area request that different types of services and supports be made available in your area?

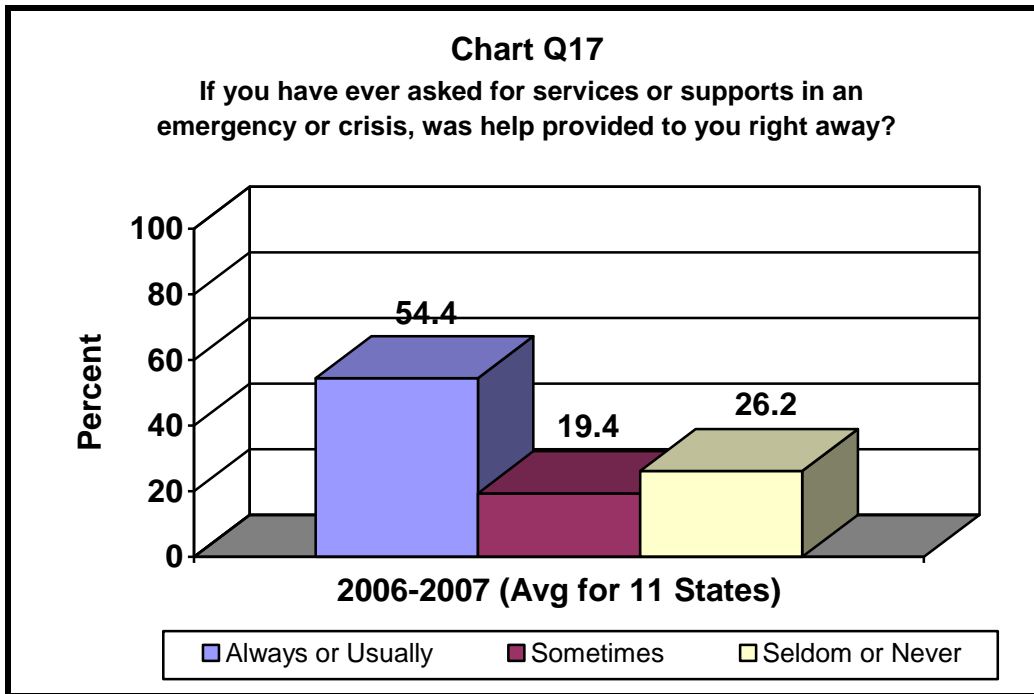
State	Always or Usually	Sometimes	Seldom or Never	n
CT	45.5	39.1	15.5	110
DE	39.3	31.0	29.8	84
GA	39.2	40.0	20.8	265
HI	44.9	40.9	14.2	127
ME	36.7	44.0	19.3	109
NM	50.4	38.3	11.3	230
OK	40.3	37.4	22.3	139
PA	40.6	40.3	19.1	335
VT				
WV	42.4	41.2	16.5	85
WY	48.1	33.3	18.5	27
<b>Total %</b>	<b>42.4</b>	<b>39.3</b>	<b>18.3</b>	<b>1,511</b>
<b>State Average %</b>	<b>42.7</b>	<b>38.6</b>	<b>18.7</b>	<b>11</b>





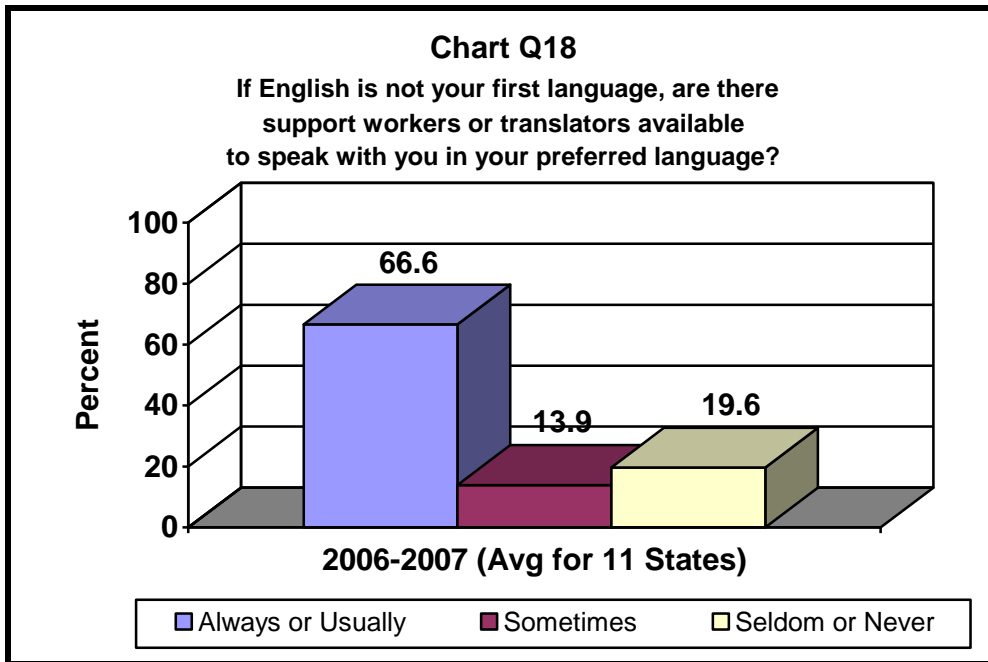
**Table Q16**  
If yes, does either the state agency or provider agency respond to their requests?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↑	45.5	38.8	15.7	121
DE	↑	46.7	32.0	21.3	75
GA	↓	30.9	37.7	31.4	207
HI	↑	46.2	40.6	13.2	106
ME		38.1	48.8	13.1	84
NM		44.3	41.4	14.3	203
OK		39.5	41.9	18.5	124
PA		36.9	42.9	20.1	268
VT					
WV		38.8	41.8	19.4	67
WY	↓	34.8	43.5	21.7	23
<b>Total %</b>		<b>39.7</b>	<b>40.8</b>	<b>19.5</b>	<b>1,278</b>
<b>State Average %</b>		<b>40.2</b>	<b>40.9</b>	<b>18.9</b>	<b>11</b>



**Table Q17**  
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
CT	↓	47.9	15.7	36.4	121
DE	↓	48.5	13.6	37.9	103
GA	↓	45.0	26.3	28.7	331
HI		50.3	29.0	20.6	155
ME	↑	59.5	14.5	26.0	131
NM	↑↑	66.5	16.3	17.1	245
OK		50.0	19.9	30.1	216
PA		55.5	20.2	24.3	391
VT	↑↑	67.0	20.8	12.3	106
WV	↑	60.2	12.9	26.9	93
WY	↓	48.0	24.0	28.0	25
<b>Total %</b>		<b>54.3</b>	<b>20.1</b>	<b>25.6</b>	<b>1,917</b>
<b>State Average %</b>		<b>54.4</b>	<b>19.4</b>	<b>26.2</b>	<b>11</b>

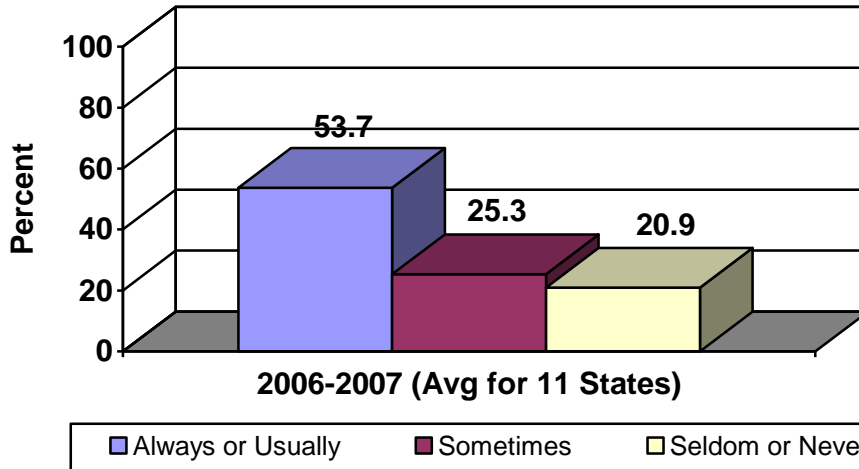


**Table Q18**  
If English is not your first language, are there support workers or translators available to speak with you in your preferred language?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	43.8	28.1	28.1	32
DE		64.3	10.7	25.0	28
GA		66.2	15.5	18.3	71
HI	↓↓↓	53.0	25.8	21.2	66
ME		71.4	22.9	5.7	35
NM	↑	75.6	17.1	7.3	82
OK	↑	73.5	2.9	23.5	34
PA		64.8	11.1	24.1	54
VT	↑↑↑	81.3	12.5	6.3	16
WV	↑↑↑	88.2	5.9	5.9	17
WY	↓↓↓	50.0	0.0	50.0	2
<b>Total %</b>		<b>66.4</b>	<b>16.5</b>	<b>17.2</b>	<b>437</b>
<b>State Average %</b>		<b>66.6</b>	<b>13.9</b>	<b>19.6</b>	<b>11</b>

**Chart Q19**

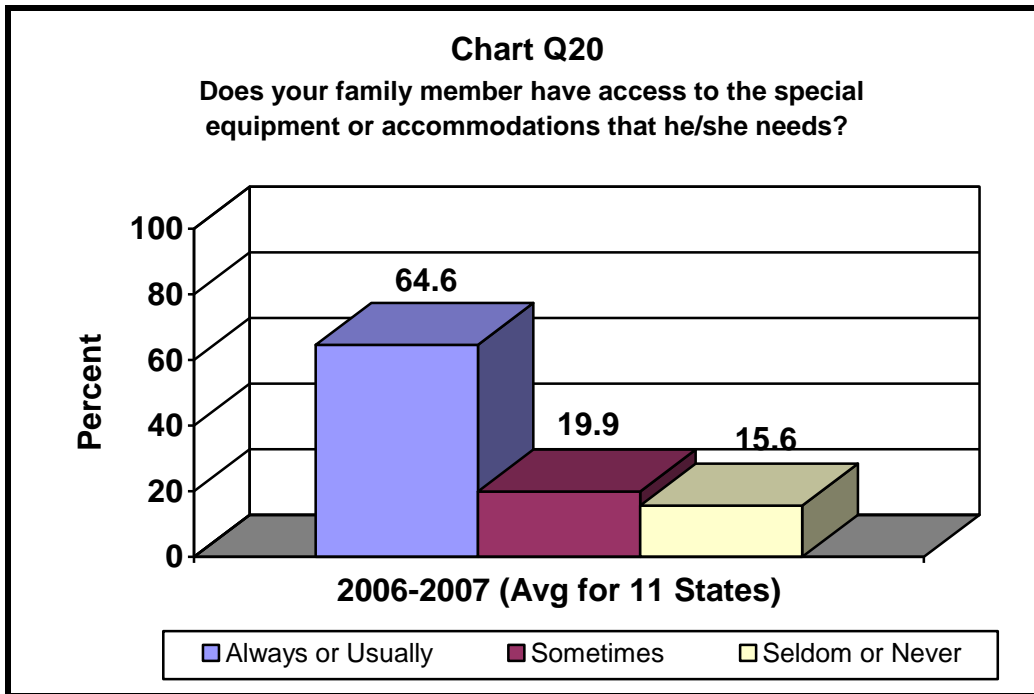
If your family member does not speak English, or uses a different way to communicate, are there enough support workers available who can communicate with him/her?



**Table Q19**

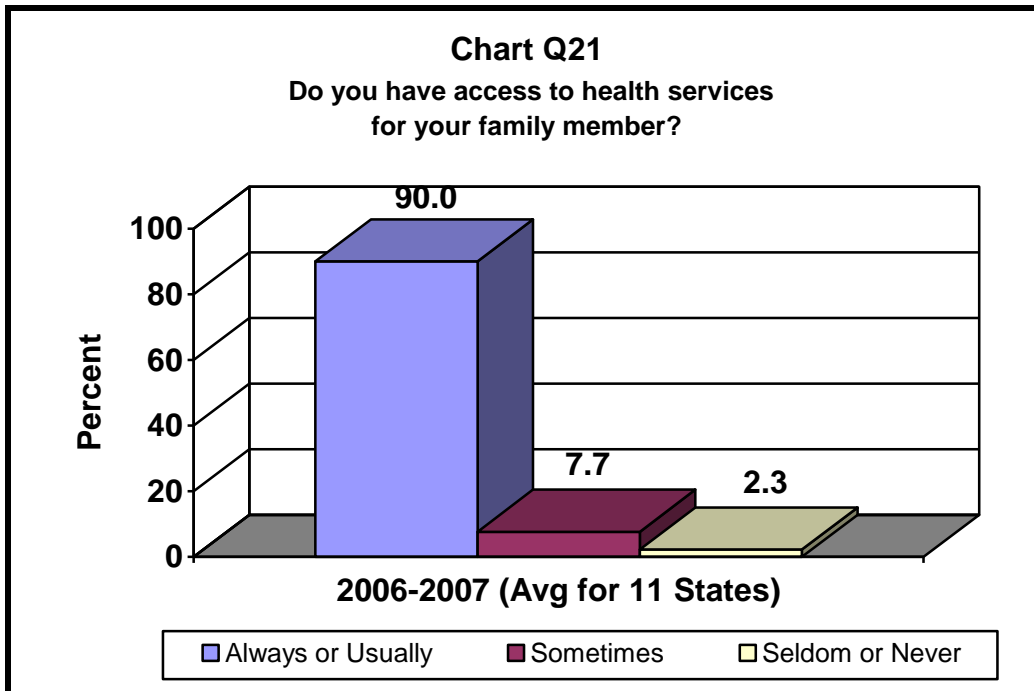
If your family member does not speak English or uses a different way to communicate (for example, sign language), are there enough support workers available who can communicate with him/her?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	39.5	30.2	30.2	43
DE	↑↑↑	64.3	14.3	21.4	28
GA	↓	46.4	27.7	25.9	112
HI		51.9	29.1	19.0	79
ME		54.0	26.0	20.0	50
NM	↑	60.6	24.8	14.7	109
OK		50.6	24.7	24.7	77
PA		54.7	17.9	27.4	106
VT	↑↑↑	64.7	29.4	5.9	34
WV		57.6	21.2	21.2	33
WY	↓	46.7	33.3	20.0	15
<b>Total %</b>		<b>53.4</b>	<b>24.9</b>	<b>21.7</b>	<b>686</b>
<b>State Average %</b>		<b>53.7</b>	<b>25.3</b>	<b>20.9</b>	<b>11</b>



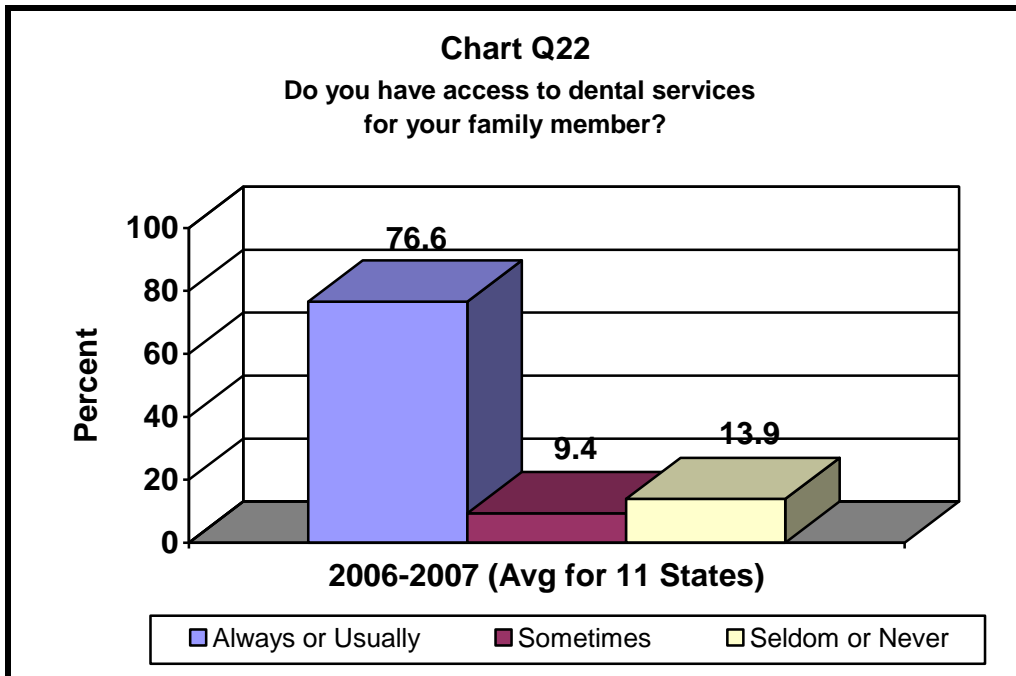
**Table Q20**  
Does your family member have access to the special equipment or accommodations that he/she needs?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	59.0	21.7	19.3	83
DE	↓	55.6	21.0	23.5	81
GA		60.7	18.7	20.6	267
HI	↓	59.1	19.7	21.2	132
ME	↑	69.8	18.8	11.5	96
NM	↑	74.0	16.5	9.5	200
OK		66.8	19.2	14.0	250
PA		68.3	17.6	14.1	341
VT		62.9	15.7	21.4	70
WV		68.8	22.6	8.6	93
WY		65.4	26.9	7.7	26
<b>Total %</b>		<b>65.5</b>	<b>18.9</b>	<b>15.6</b>	<b>1,639</b>
<b>State Average %</b>		<b>64.6</b>	<b>19.9</b>	<b>15.6</b>	<b>11</b>



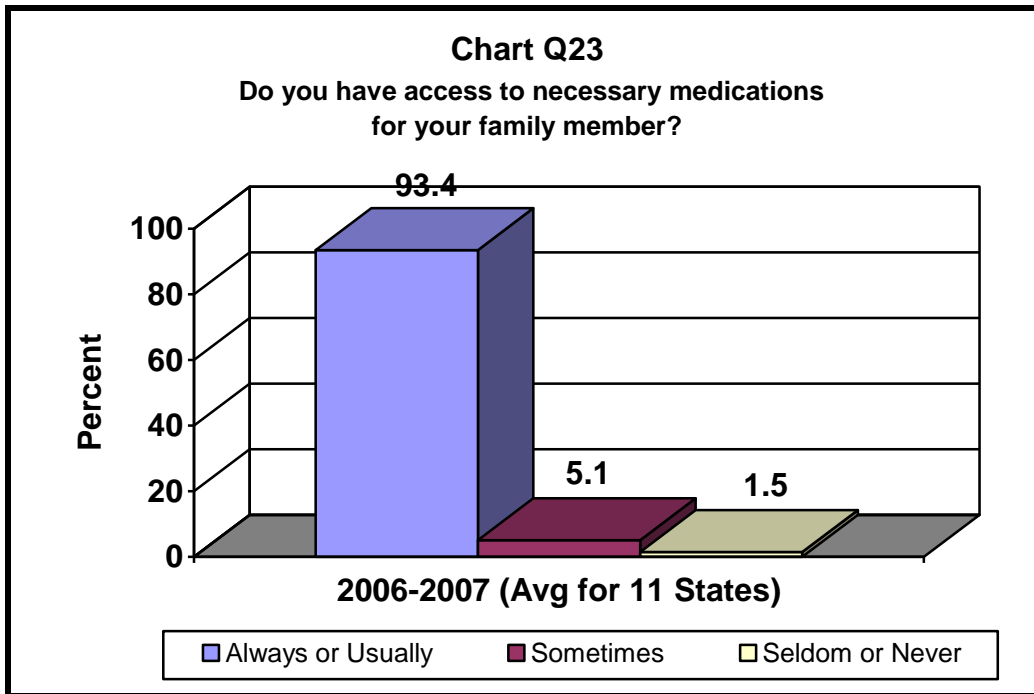
**Table Q21**  
Do you have access to health services for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	84.6	11.6	3.8	293
DE		89.1	7.3	3.6	247
GA		86.0	10.7	3.3	614
HI		88.0	10.0	1.9	309
ME	↑	95.4	4.0	0.6	329
NM		94.6	4.2	1.2	427
OK		88.9	8.9	2.2	450
PA		91.6	6.6	1.8	953
VT		93.2	4.9	1.9	206
WV		91.0	5.8	3.2	155
WY		87.9	10.3	1.7	58
<b>Total %</b>		<b>90.2</b>	<b>7.6</b>	<b>2.2</b>	<b>4,041</b>
<b>State Average %</b>		<b>90.0</b>	<b>7.7</b>	<b>2.3</b>	<b>11</b>



**Table Q22**  
Do you have access to dental services for your family member?

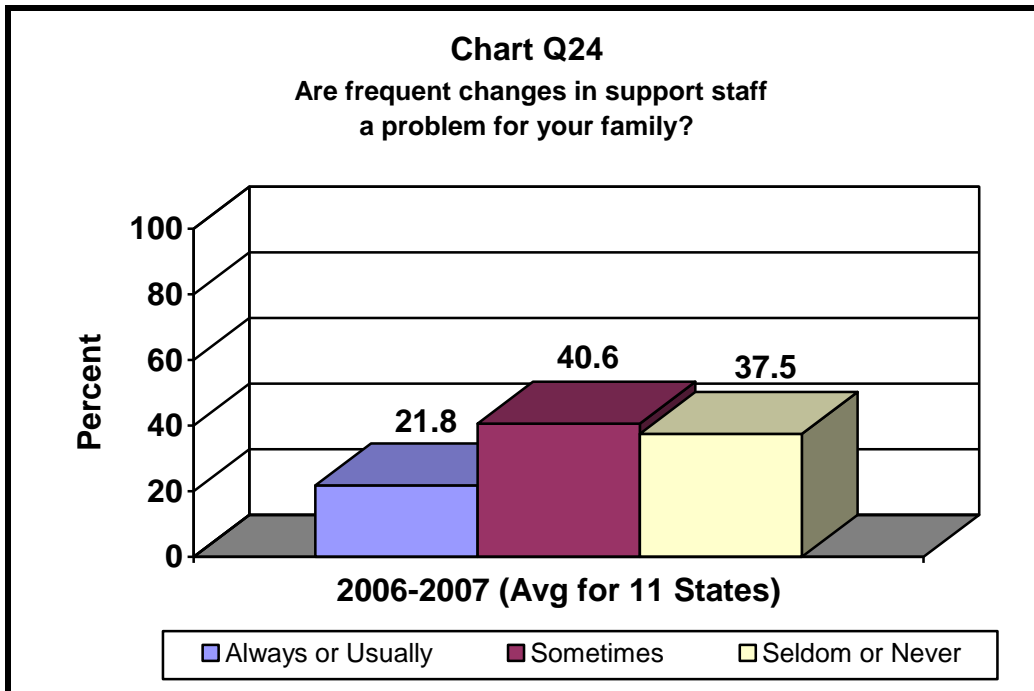
State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	71.1	11.8	17.1	287
DE	↓↓	64.7	7.6	27.7	224
GA	↓	70.2	11.2	18.6	587
HI		74.4	11.8	13.7	313
ME		79.8	9.5	10.7	317
NM	↑↑	89.7	5.8	4.6	417
OK	↓	69.6	7.9	22.5	405
PA		81.5	7.3	11.2	914
VT	↑↑	89.1	6.0	5.0	201
WV		77.3	9.2	13.5	141
WY		75.4	15.8	8.8	57
<b>Total %</b>		<b>77.1</b>	<b>8.8</b>	<b>14.1</b>	<b>3,863</b>
<b>State Average %</b>		<b>76.6</b>	<b>9.4</b>	<b>13.9</b>	<b>11</b>



**Table Q23**  
Do you have access to necessary medications for your family member?

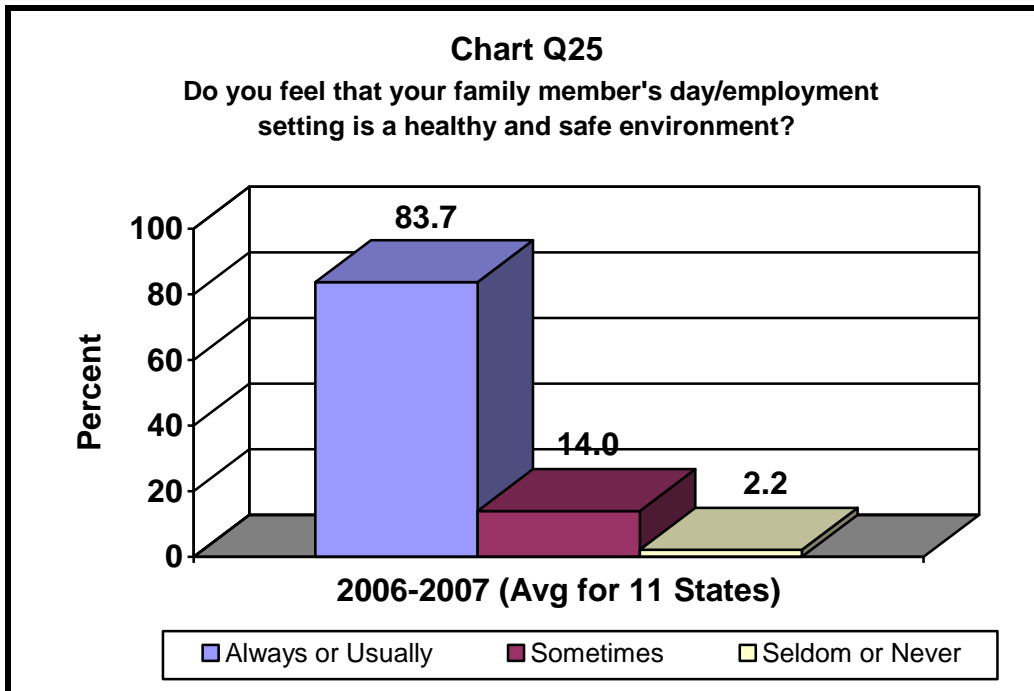
State	Always or Usually	Sometimes	Seldom or Never	n
CT	93.1	4.5	2.4	290
DE	89.9	7.3	2.8	248
GA	91.7	6.8	1.5	602
HI	89.8	6.4	3.8	313
ME	97.5	2.2	0.3	323
NM	94.5	4.8	0.7	421
OK	93.3	5.8	0.9	445
PA	94.9	3.4	1.7	940
VT	96.5	2.0	1.5	200
WV	95.3	4.0	0.7	150
WY	91.1	8.9	0.0	56
<b>Total %</b>	<b>93.6</b>	<b>4.8</b>	<b>1.6</b>	<b>3,988</b>
<b>State Average %</b>	<b>93.4</b>	<b>5.1</b>	<b>1.5</b>	<b>11</b>





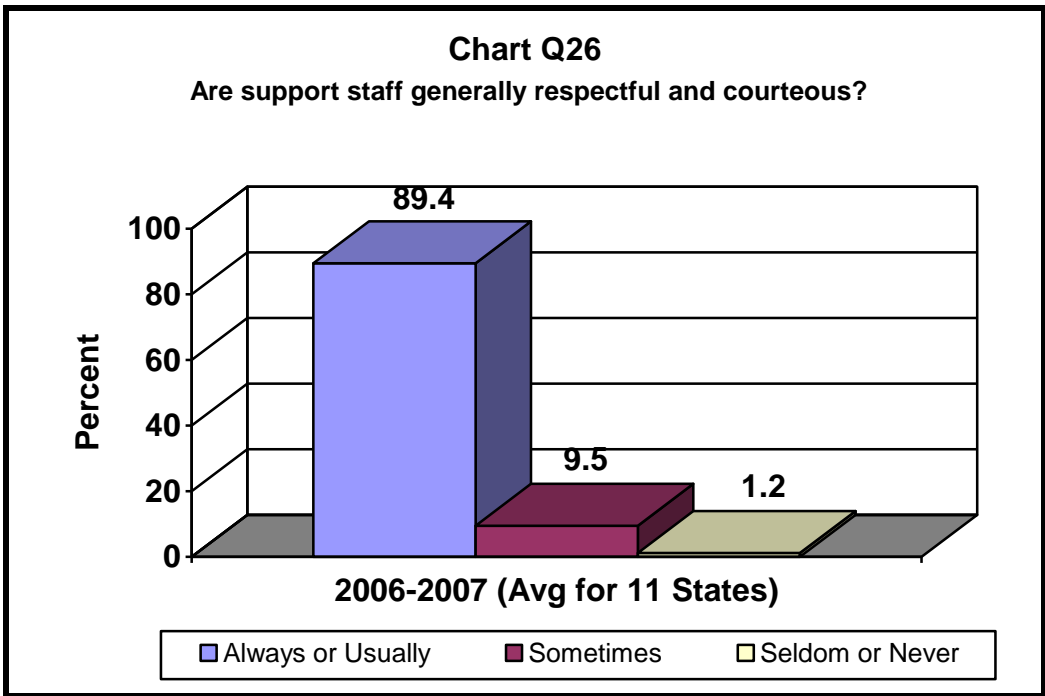
**Table Q24**  
Are frequent changes in support staff a problem for your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		21.5	46.9	31.6	228
DE		21.2	39.7	39.1	179
GA	↑	16.1	37.6	46.3	497
HI		23.1	41.4	35.4	268
ME		16.9	42.6	40.6	249
NM		21.3	40.3	38.4	380
OK		25.4	33.1	41.5	366
PA		21.6	34.9	43.5	754
VT		26.2	41.0	32.8	183
WV		24.6	40.1	35.2	142
WY		22.4	49.0	28.6	49
<b>Total %</b>		<b>21.3</b>	<b>38.7</b>	<b>40.0</b>	<b>3,295</b>
<b>State Average %</b>		<b>21.8</b>	<b>40.6</b>	<b>37.5</b>	<b>11</b>



**Table Q25**  
Do you feel that your family member's day/employment setting is a healthy and safe environment?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		85.3	14.4	0.3	299
DE		81.6	16.7	1.8	228
GA		83.9	13.6	2.5	558
HI		84.5	11.9	3.6	278
ME		87.2	11.4	1.4	281
NM		81.2	15.4	3.4	324
OK		88.2	10.5	1.2	323
PA		86.1	11.9	2.0	812
VT	↑	92.1	7.3	0.5	191
WV	↓↓	68.8	27.2	4.0	125
WY		82.0	14.0	4.0	50
<b>Total %</b>		<b>84.7</b>	<b>13.2</b>	<b>2.1</b>	<b>3,469</b>
<b>State Average %</b>		<b>83.7</b>	<b>14.0</b>	<b>2.2</b>	<b>11</b>

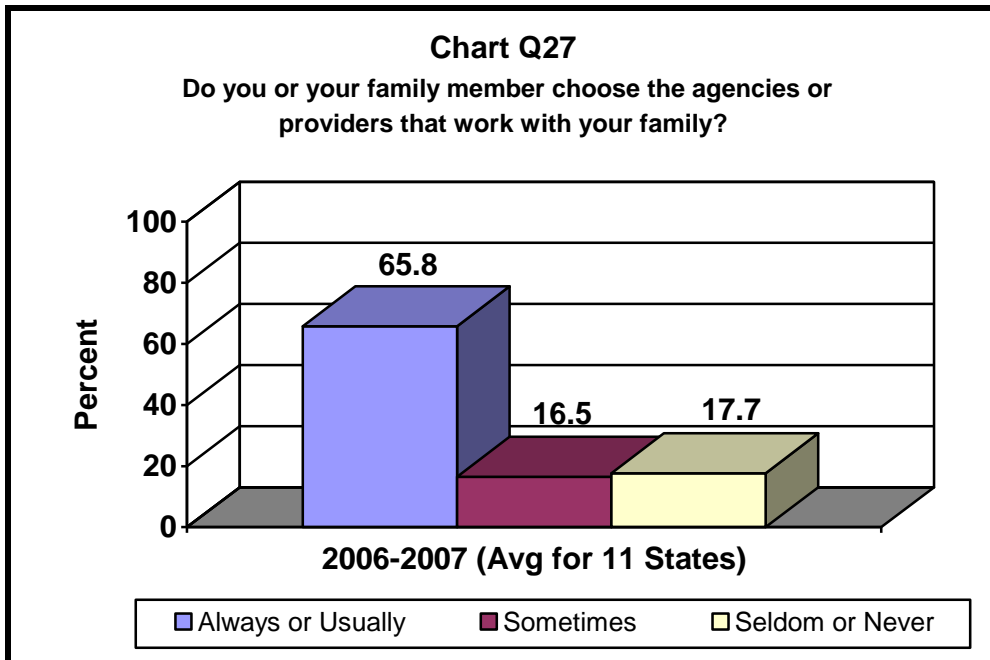


**Table Q26**  
Are support staff generally respectful and courteous?

State	Always or Usually	Sometimes	Seldom or Never	n
CT	92.7	6.7	0.7	300
DE	87.0	10.9	2.1	239
GA	90.0	8.8	1.1	613
HI	89.4	10.3	0.3	329
ME	91.9	7.4	0.6	310
NM	89.0	10.0	1.0	418
OK	89.8	9.7	0.5	422
PA	92.7	6.7	0.6	927
VT	93.4	6.1	0.5	212
WV	84.6	13.4	2.0	149
WY	↓ 82.5	14.0	3.5	57
<b>Total %</b>	<b>90.5</b>	<b>8.6</b>	<b>0.9</b>	<b>3,976</b>
<b>State Average %</b>	<b>89.4</b>	<b>9.5</b>	<b>1.2</b>	<b>11</b>

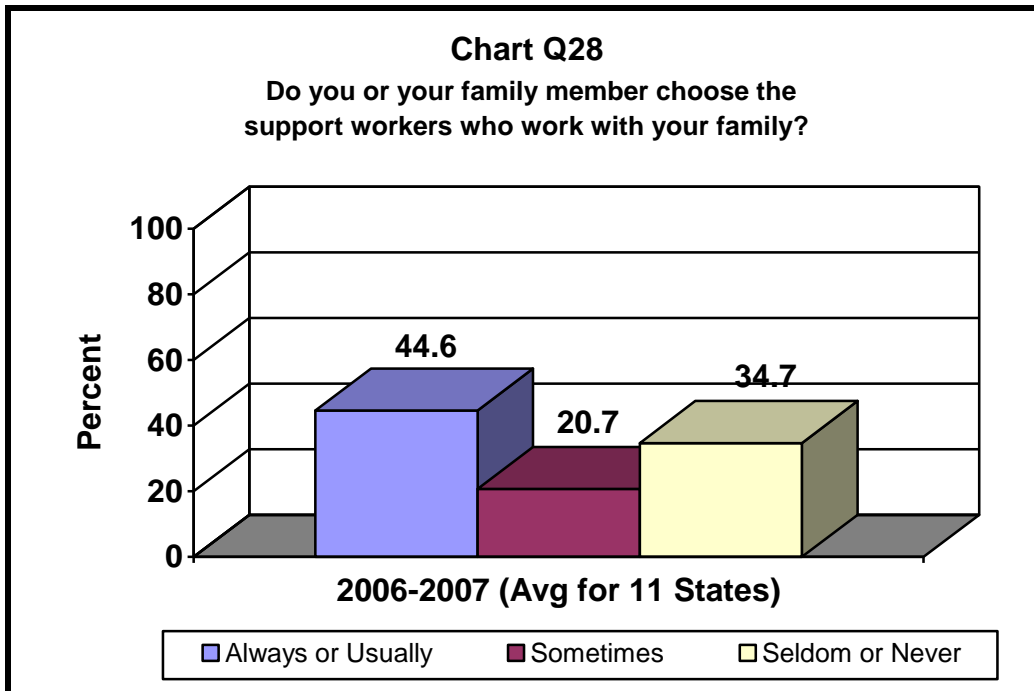
## Choices and Control

- Across the states, on average, 66% of respondents chose the agencies or providers who work with their families. In New Mexico, Oklahoma and Wyoming, this percentage was considerably higher, with 80% or more of families choosing their service providers.
- While 66% of respondents typically chose their family's provider agency, only 45% typically chose the support workers who worked directly with their family. Here again, the results were considerably higher in New Mexico and Oklahoma.
- Across the states, 72% of families who received day/employment supports felt the provider agency regularly involved them in important decisions.
- Among all respondents, 40% had control or input over the hiring and management of their support staff, and 17% indicated they had this control sometimes. Forty-three percent, however, did not have any input or control over the hiring or management of their family's support staff.
- While only 57% of respondents had at least some control over the hiring or management of their support workers, 84% wanted this type of control at least sometimes.
- Twenty-nine percent of respondents or their family members knew how much money was spent by the MR/DD agency on behalf of their family member. Fifty-eight percent, however, had little or no idea. (Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses.)
- Overall, three-fifths of the families surveyed (63%) 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. Thirty-seven percent (37%), however, did not.



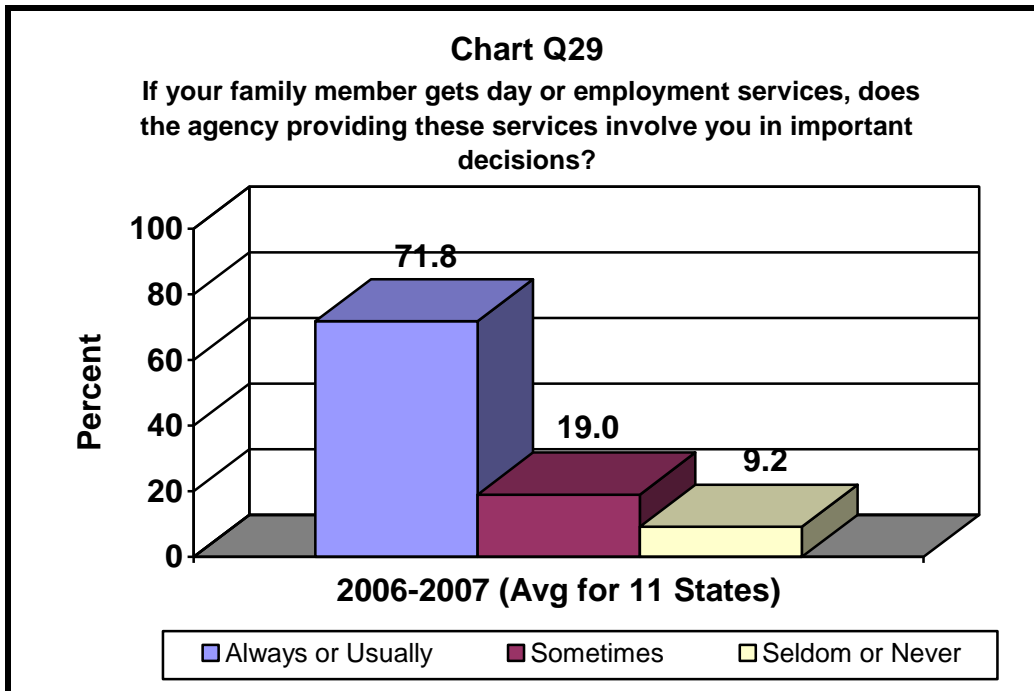
**Table Q27**  
Do you or your family member choose the agencies or providers that work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	57.9	18.3	23.8	252
DE	↓↓	53.5	21.1	25.4	213
GA	↓↓	47.9	17.7	34.4	509
HI	↑	73.7	15.1	11.2	312
ME	↓↓	55.8	24.0	20.1	283
NM	↑↑	88.9	6.8	4.2	425
OK	↑↑	80.2	12.8	7.0	445
PA	↓↓	53.1	19.9	27.0	800
VT	↓	58.1	19.9	22.0	191
WV		68.5	15.8	15.8	146
WY	↑↑	86.0	10.5	3.5	57
<b>Total %</b>		<b>63.6</b>	<b>16.7</b>	<b>19.6</b>	<b>3,633</b>
<b>State Average %</b>		<b>65.8</b>	<b>16.5</b>	<b>17.7</b>	<b>11</b>



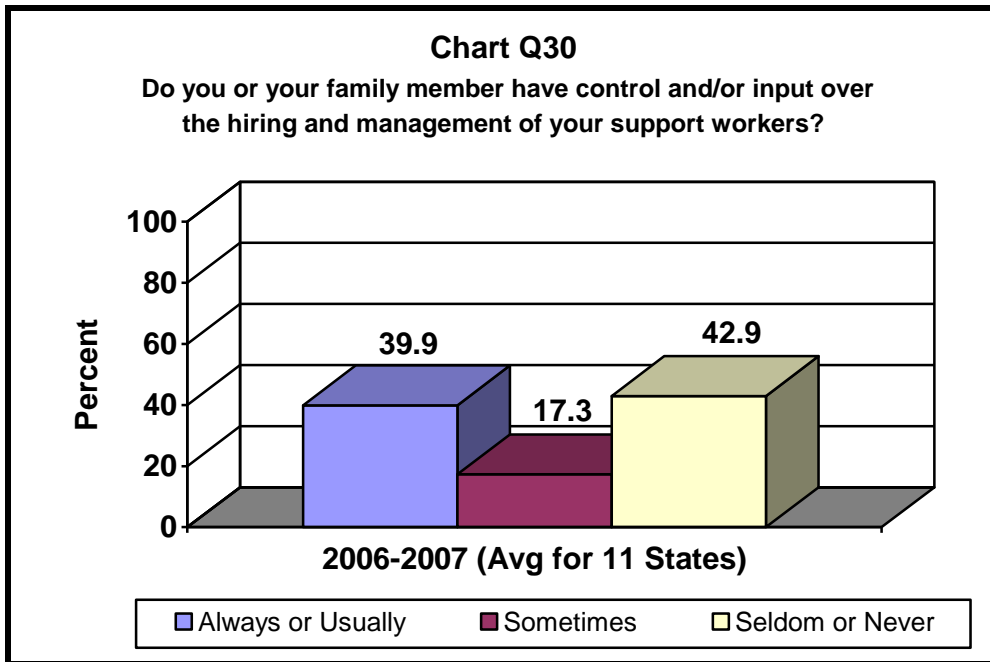
**Table Q28**  
Do you or your family member choose the support workers who work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	28.3	18.8	52.9	240
DE	↓↓↓	27.3	15.5	57.2	194
GA	↓↓↓	23.5	15.7	60.8	497
HI	↑	49.8	26.4	23.7	295
ME	↓	35.9	24.5	39.6	273
NM	↑↑↑	65.7	18.7	15.6	411
OK	↑↑↑	69.0	15.8	15.1	423
PA	↓↓↓	34.5	19.0	46.6	775
VT	↑↑↑	56.3	18.2	25.5	192
WV		44.7	26.2	29.1	141
WY	↑↑↑	55.4	28.6	16.1	56
<b>Total %</b>		<b>43.3</b>	<b>19.4</b>	<b>37.3</b>	<b>3,497</b>
<b>State Average %</b>		<b>44.6</b>	<b>20.7</b>	<b>34.7</b>	<b>11</b>



**Table Q29**  
If your family member gets day or employment services, does the agency providing these services involve you in important decisions?

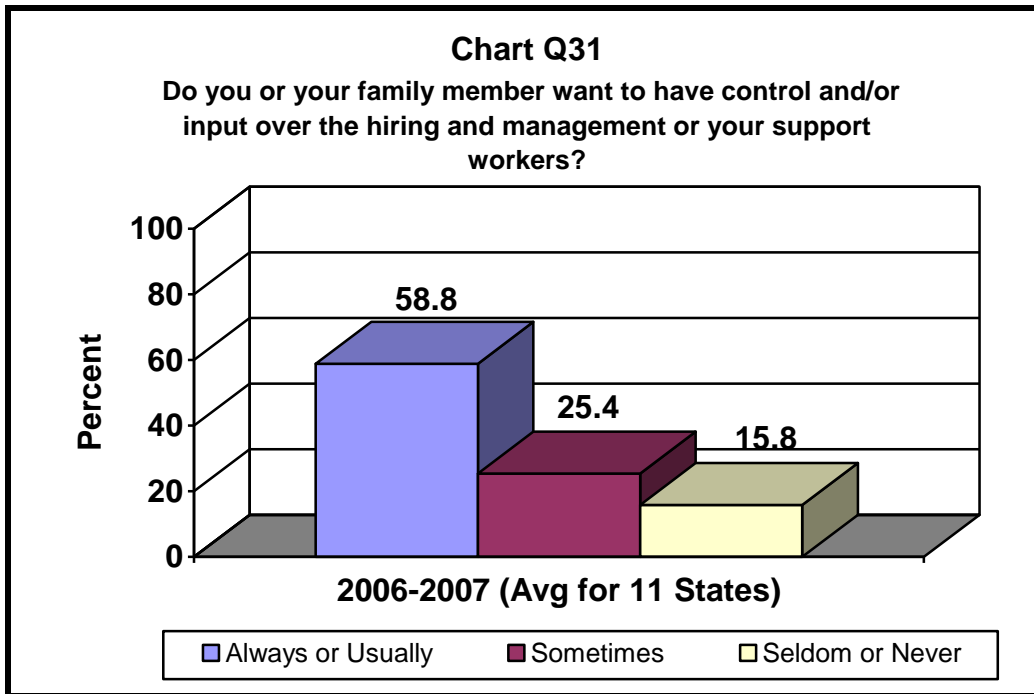
State		Always or Usually	Sometimes	Seldom or Never	n
CT		73.2	19.3	7.4	269
DE		70.8	18.5	10.8	195
GA	↓	64.6	23.6	11.8	492
HI		76.4	15.9	7.7	233
ME		76.4	17.2	6.4	267
NM		71.0	20.8	8.1	307
OK		74.0	17.1	8.9	246
PA		70.6	19.7	9.7	681
VT		76.1	18.9	5.0	159
WV		67.3	23.8	8.9	101
WY		69.8	14.0	16.3	43
<b>Total %</b>		<b>71.3</b>	<b>19.6</b>	<b>9.1</b>	<b>2,993</b>
<b>State Average %</b>		<b>71.8</b>	<b>19.0</b>	<b>9.2</b>	<b>11</b>



**Table Q30**  
Do you or your family member have control and/or input over the hiring and management of your support workers?

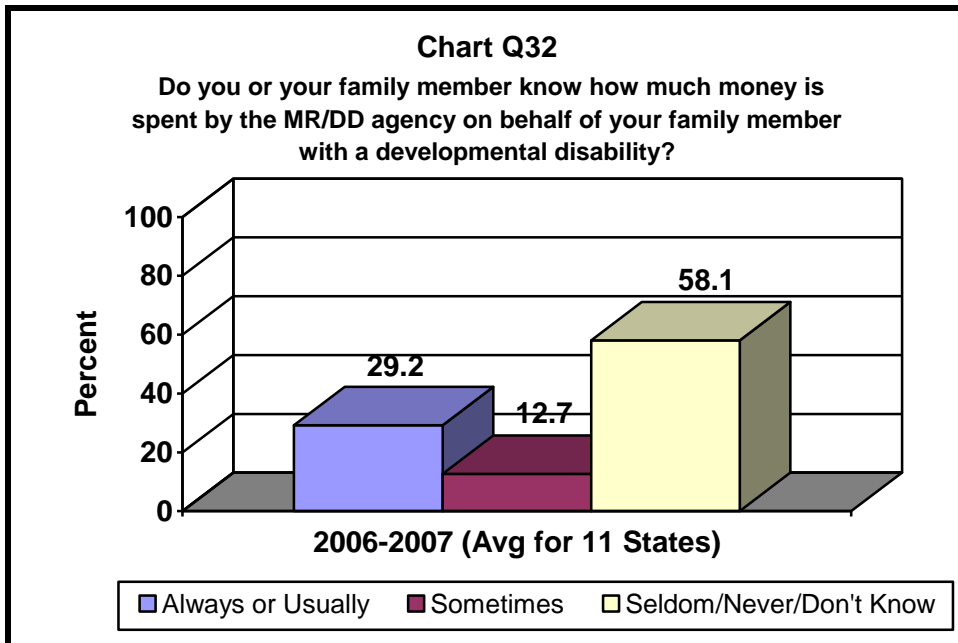
State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	28.0	20.3	51.7	207
DE	↓↓↓	28.5	11.8	59.7	144
GA	↓↓↓	11.2	12.0	76.8	409
HI	↑↑↑	55.2	19.3	25.6	223
ME	↓↓↓	21.3	20.4	58.3	211
NM	↑↑↑	53.9	14.9	31.2	369
OK	↑↑↑	68.5	15.8	15.8	368
PA	↓	31.0	11.5	57.5	590
VT	↑↑↑	58.6	17.7	23.7	186
WV		41.3	16.7	42.1	126
WY		40.9	29.5	29.5	44
<b>Total %</b>		<b>39.1</b>	<b>15.4</b>	<b>45.5</b>	<b>2,877</b>
<b>State Average %</b>		<b>39.9</b>	<b>17.3</b>	<b>42.9</b>	<b>11</b>





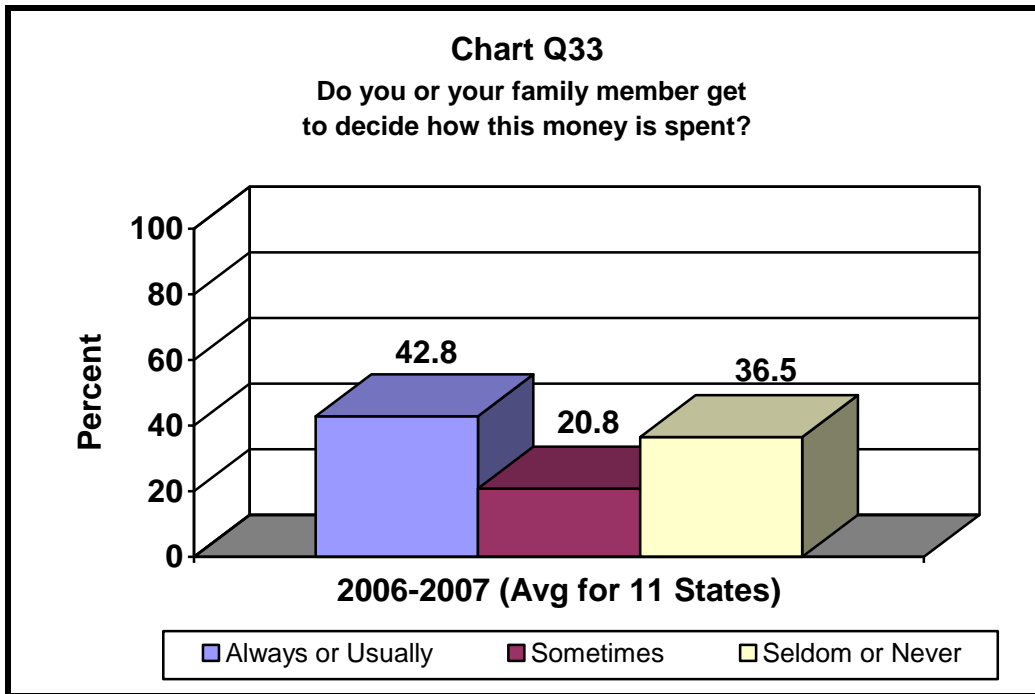
**Table Q31**  
Do you or your family member want to have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	48.2	40.8	11.0	191
DE	↓↓↓	48.1	27.8	24.1	162
GA	↓↓↓	38.8	27.7	33.5	397
HI	↑	63.8	22.9	13.3	210
ME	↓↓↓	47.1	30.1	22.8	206
NM	↑	68.3	21.5	10.2	344
OK	↑↑↑	81.0	14.4	4.5	374
PA	↓	49.7	23.1	27.3	572
VT	↑↑↑	71.9	19.2	9.0	167
WV	↑↑↑	69.0	22.4	8.6	116
WY		61.0	29.3	9.8	41
<b>Total %</b>		<b>57.6</b>	<b>24.2</b>	<b>18.2</b>	<b>2,780</b>
<b>State Average %</b>		<b>58.8</b>	<b>25.4</b>	<b>15.8</b>	<b>11</b>



**Table Q32**  
Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
CT		32.1	11.7	56.2	308
DE	↓↓↓	8.9	4.0	87.1	248
GA	↓↓↓	6.4	4.5	89.1	578
HI	↓↓↓	13.6	12.3	74.1	309
ME	↓↓↓	10.4	6.4	83.2	298
NM	↑	38.3	15.1	46.7	418
OK	↑↑↑	45.7	17.1	37.1	455
PA		32.1	14.3	53.7	911
VT	↑↑↑	51.2	14.4	34.4	209
WV		25.5	16.8	57.7	149
WY	↑↑↑	57.1	23.2	19.6	56
<b>Total %</b>		<b>27.1</b>	<b>11.9</b>	<b>61.0</b>	<b>3,939</b>
<b>State Average %</b>		<b>29.2</b>	<b>12.7</b>	<b>58.1</b>	<b>11</b>

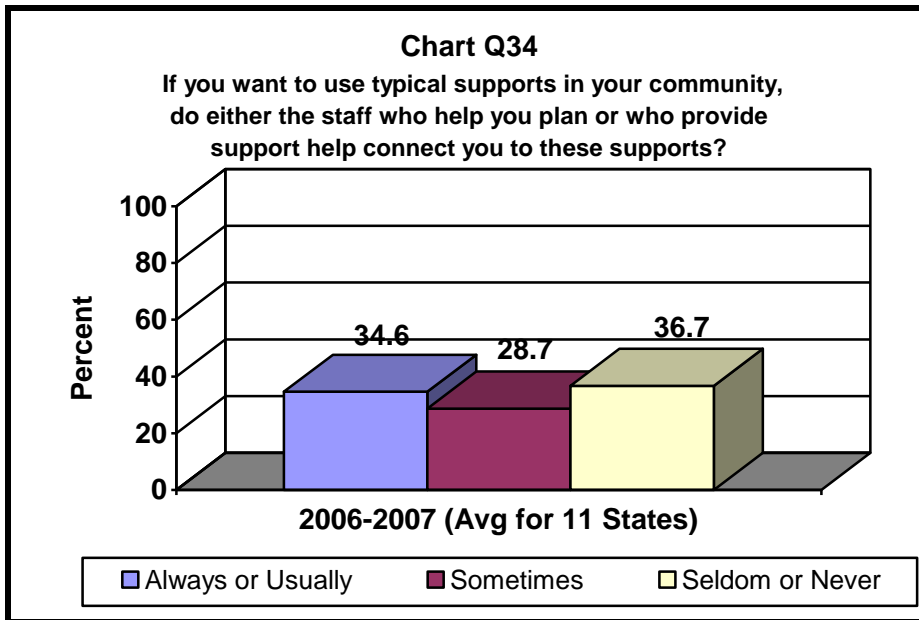


**Table Q33**  
Do you or your family member get to decide how this money is spent?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		41.1	20.8	38.2	207
DE	↓↓↓	28.8	7.5	63.7	146
GA	↓↓↓	29.7	11.8	58.5	448
HI		42.6	19.3	38.1	176
ME	↓↓↓	27.7	16.9	55.4	195
NM	↑↑↑	55.1	25.2	19.7	365
OK	↑↑↑	57.3	25.5	17.2	372
PA		45.2	20.4	34.4	677
VT	↑	47.8	27.0	25.3	178
WV	↓↓↓	28.5	26.8	44.7	123
WY	↑↑↑	66.7	27.1	6.3	48
<b>Total %</b>		<b>43.0</b>	<b>20.2</b>	<b>36.8</b>	<b>2,935</b>
<b>State Average %</b>		<b>42.8</b>	<b>20.8</b>	<b>36.5</b>	<b>11</b>

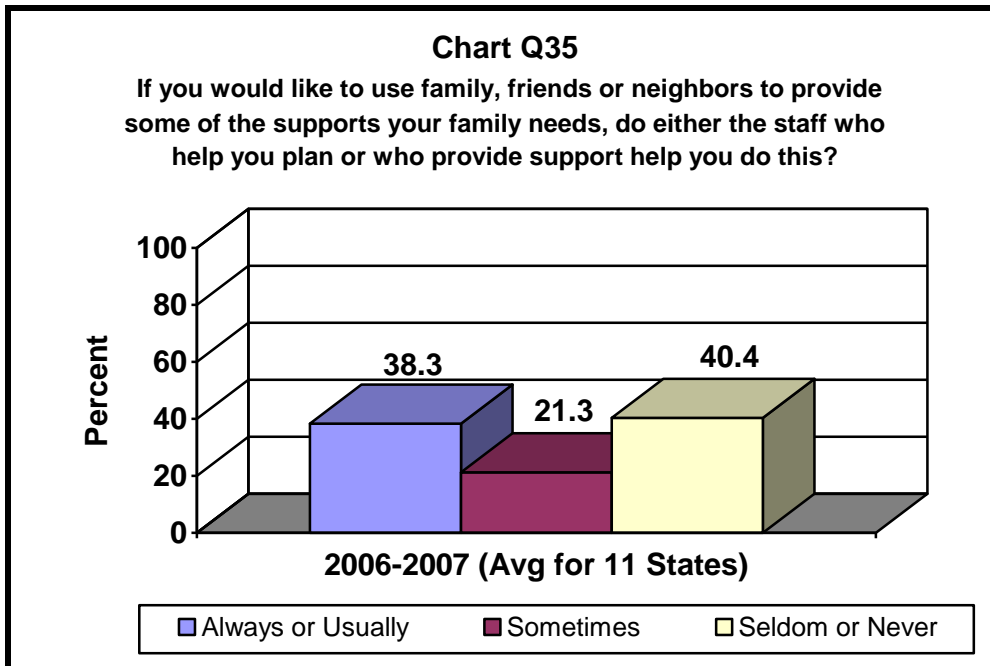
## Community Connections

- On average, one-third of respondents (35%) 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 29% said that staff were sometimes helpful, but 37% stated that planning and support staff were seldom or never helpful in connecting their family members to typical community supports or resources.
- Overall, there was a split between respondents who indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (60% say always, usually or sometimes, 40% say seldom or never).
- Only 55% of families felt their family member always or usually had access to community activities. 14% stated their family member seldom or never had access to the community.
- While 55% had regular access to community activities, only 37% of family members regularly participated in them. Twenty-five percent of respondents said that their family member seldom or never participated in community activities or events.



**Table Q34**  
If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?

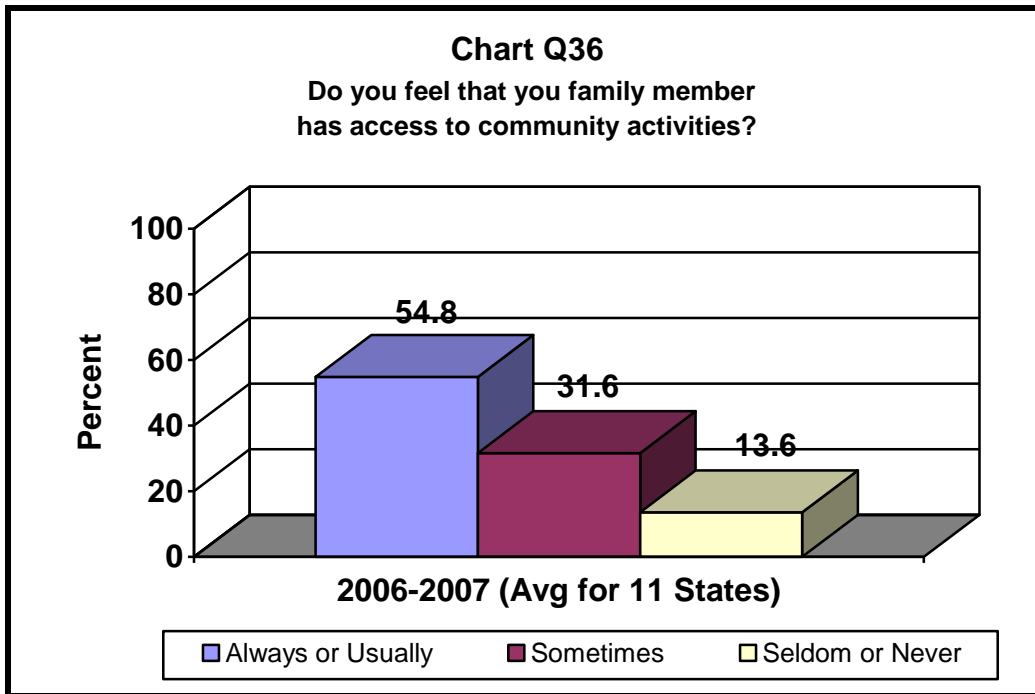
State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	27.1	30.9	42.0	181
DE	↓↓	20.7	30.7	48.7	150
GA	↓↓	24.4	24.7	50.9	401
HI		37.4	27.6	35.0	203
ME		38.6	26.7	34.8	210
NM	↑↑	45.4	28.4	26.1	348
OK	↑	39.9	27.4	32.6	288
PA		34.7	24.8	40.5	568
VT	↑	44.4	29.2	26.4	144
WV		35.1	20.7	44.1	111
WY		33.3	44.4	22.2	45
<b>Total %</b>		<b>34.8</b>	<b>27.1</b>	<b>38.1</b>	<b>2,649</b>
<b>State Average %</b>		<b>34.6</b>	<b>28.7</b>	<b>36.7</b>	<b>11</b>



**Table Q35**

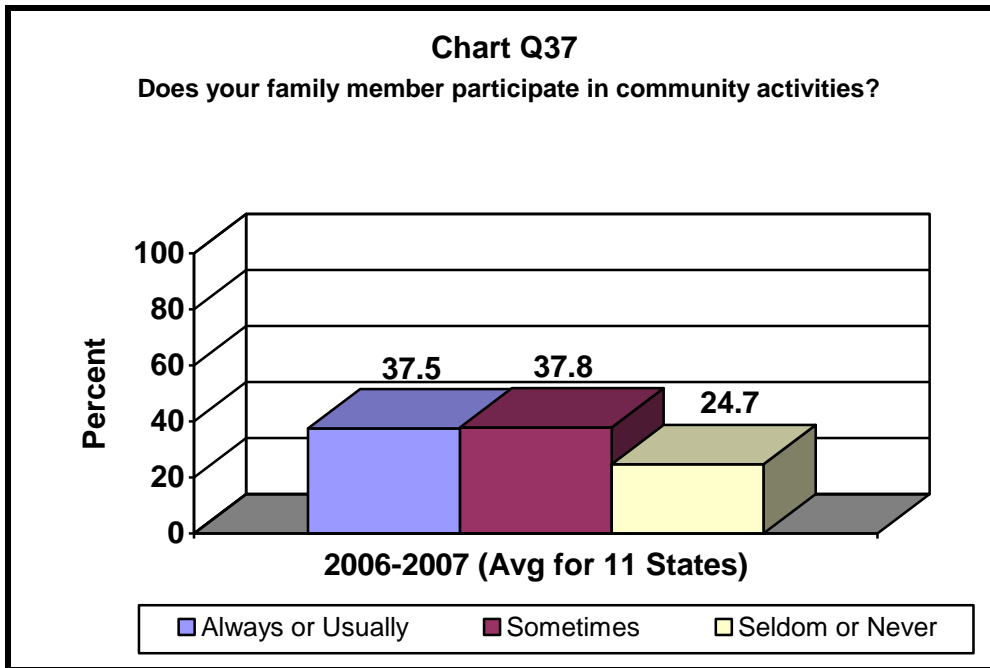
If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	26.8	21.3	51.8	164
DE	↓↓↓	27.4	20.5	52.1	146
GA	↓↓↓	19.6	19.1	61.3	362
HI	↑↑↑	50.0	25.7	24.3	206
ME	↓	29.4	22.8	47.8	180
NM	↑↑↑	52.9	23.4	23.7	333
OK	↑	47.8	20.4	31.8	318
PA		37.7	19.9	42.4	549
VT	↑	46.5	25.7	27.8	144
WV	↑↑↑	49.1	17.2	33.6	116
WY		34.2	18.4	47.4	38
<b>Total %</b>		<b>38.5</b>	<b>21.3</b>	<b>40.3</b>	<b>2,556</b>
<b>State Average %</b>		<b>38.3</b>	<b>21.3</b>	<b>40.4</b>	<b>11</b>



**Table Q36**  
Do you feel that your family member has access to community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	40.8	33.9	25.3	277
DE	↓	45.7	31.2	23.1	221
GA	↓↓↓	44.2	38.7	17.1	556
HI		56.1	34.8	9.1	287
ME		54.0	33.9	12.1	289
NM	↑↑↑	69.7	23.2	7.2	419
OK		52.6	34.1	13.3	428
PA		52.4	33.0	14.6	863
VT	↑	61.7	30.8	7.5	201
WV		59.4	31.5	9.1	143
WY	↑↑↑	66.7	22.2	11.1	54
<b>Total %</b>		<b>53.3</b>	<b>32.7</b>	<b>14.0</b>	<b>3,738</b>
<b>State Average %</b>		<b>54.8</b>	<b>31.6</b>	<b>13.6</b>	<b>11</b>



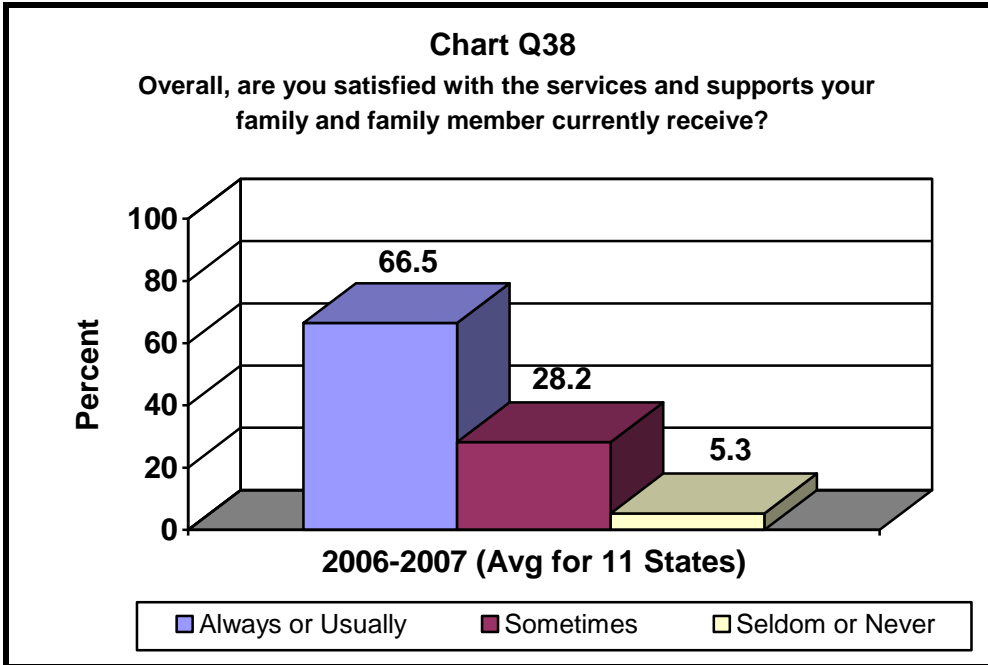
**Table Q37**  
Does your family member participate in community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	23.4	40.3	36.2	290
DE	↓↓↓	25.1	34.0	40.9	247
GA	↓	30.6	45.0	24.4	578
HI		40.1	31.8	28.1	299
ME		36.2	39.7	24.1	307
NM	↑↑	56.8	29.9	13.3	421
OK		35.4	39.3	25.3	438
PA		33.6	37.0	29.5	906
VT	↑	42.7	39.8	17.5	206
WV	↑↑↑	48.0	37.8	14.2	148
WY		41.1	41.1	17.9	56
<b>Total %</b>		<b>36.4</b>	<b>37.8</b>	<b>25.8</b>	<b>3,896</b>
<b>State Average %</b>		<b>37.5</b>	<b>37.8</b>	<b>24.7</b>	<b>11</b>



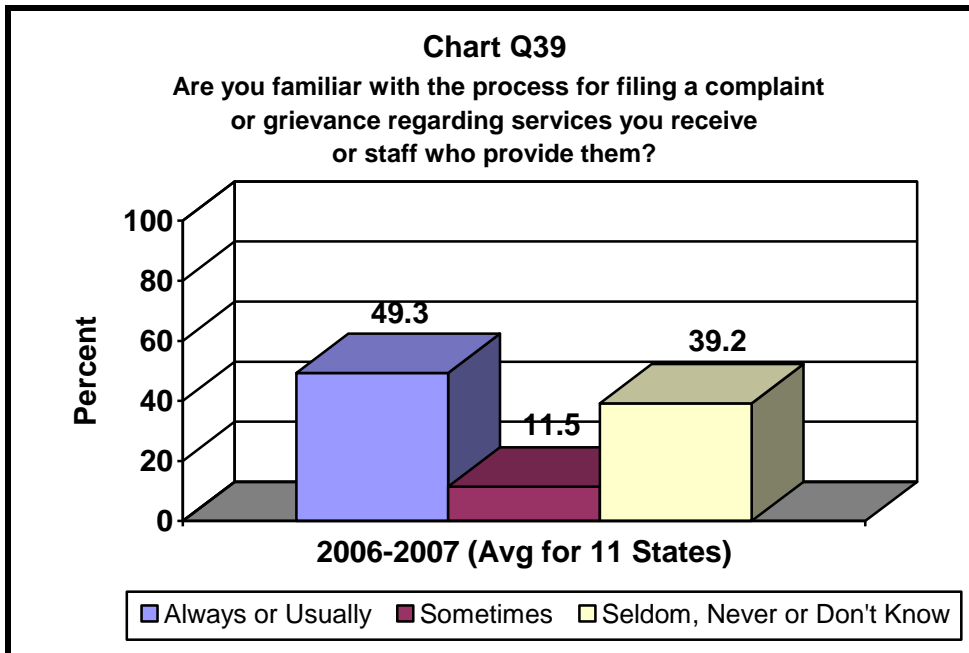
## Outcomes and Satisfaction with Services and Supports

- Overall, two-thirds of families (67%) were always or usually satisfied with the services and supports they received. 28% were somewhat satisfied, and 5% were seldom or never satisfied.
- On average, only 49% of respondents knew about their agency's grievance process, while 39% had little or no familiarity with the process for lodging a complaint. (Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses.)
- The majority of respondents (59%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 41%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.
- Seventy-two percent (72%) of families felt that services and supports have made a positive difference in their lives. Only 4% stated that they seldom felt this way.
- Three-fourths (78%) of respondents indicated that services have made a difference in helping them keep their family members at home.
- Most families (83%) indicated that their family member would still be living at home, even without services. Eleven percent of respondents, however, stated their family member would not be at home without needed services.
- Eighty-six percent (86%) of respondents felt that their family member was usually happy.



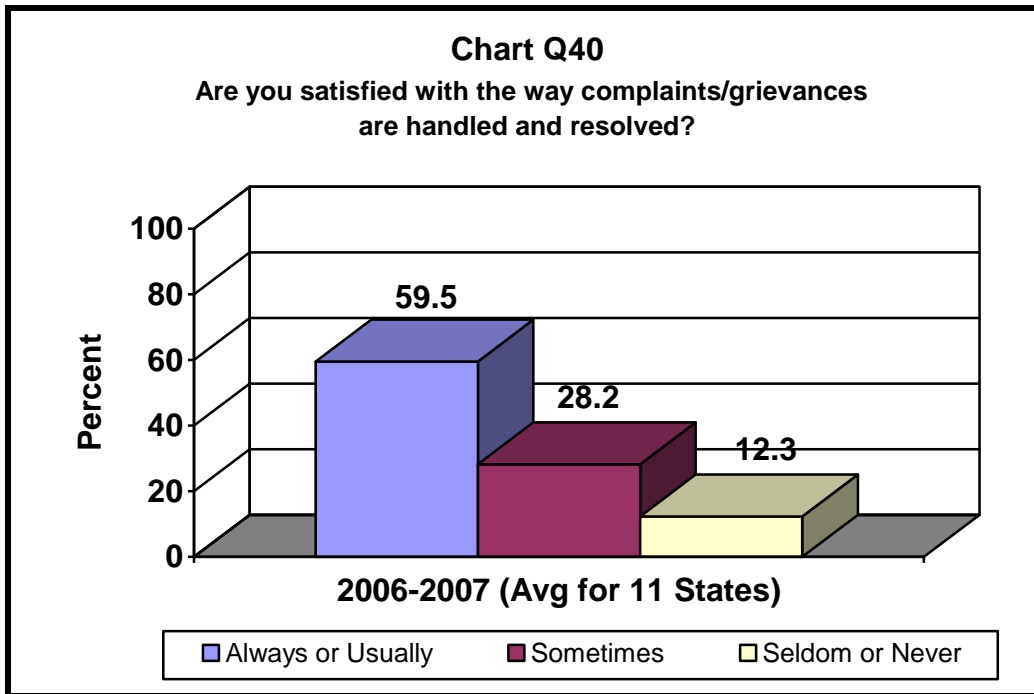
**Table Q38**  
Overall, are you satisfied with the services and supports your family and family member currently receive?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓↓↓	54.1	38.0	7.9	305
DE	↓↓↓	54.4	37.1	8.5	259
GA	↓↓↓	55.6	35.6	8.7	620
HI	↑	76.1	21.7	2.1	327
ME		69.7	26.0	4.3	323
NM	↑	74.6	22.8	2.6	429
OK		67.1	27.7	5.2	459
PA		68.3	26.0	5.7	954
VT	↑	72.4	23.2	4.4	203
WV	↓	57.1	34.4	8.4	154
WY	↑↑	82.5	17.5	0.0	57
<b>Total %</b>		<b>65.7</b>	<b>28.6</b>	<b>5.7</b>	<b>4,090</b>
<b>State Average %</b>		<b>66.5</b>	<b>28.2</b>	<b>5.3</b>	<b>11</b>



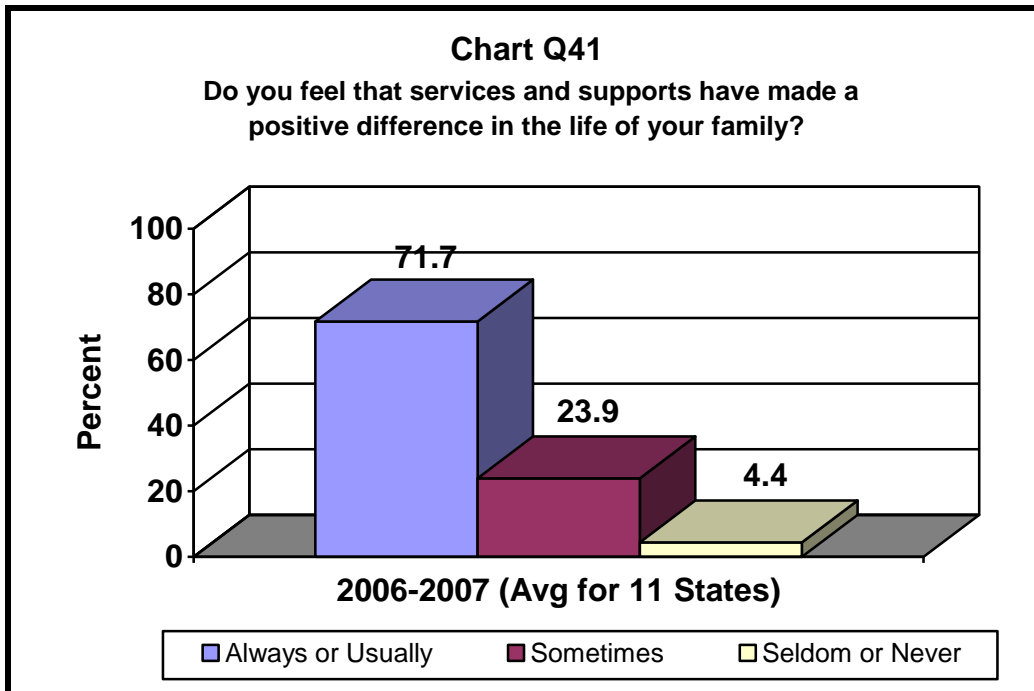
**Table Q39**  
Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
CT	↓↓↓	38.6	10.8	50.5	277
DE	↓↓↓	29.2	7.9	62.9	240
GA	↓↓↓	36.5	9.3	54.1	567
HI		44.7	15.5	39.8	304
ME		46.2	10.0	43.8	290
NM	↑↑↑	72.6	8.6	18.9	419
OK	↑↑↑	65.4	9.0	25.6	434
PA		48.2	9.2	42.6	855
VT	↑↑↑	65.6	4.1	30.3	195
WV		48.6	12.3	39.1	138
WY		46.3	29.6	24.1	54
<b>Total %</b>		<b>49.7</b>	<b>9.9</b>	<b>40.4</b>	<b>3,773</b>
<b>State Average %</b>		<b>49.3</b>	<b>11.5</b>	<b>39.2</b>	<b>11</b>



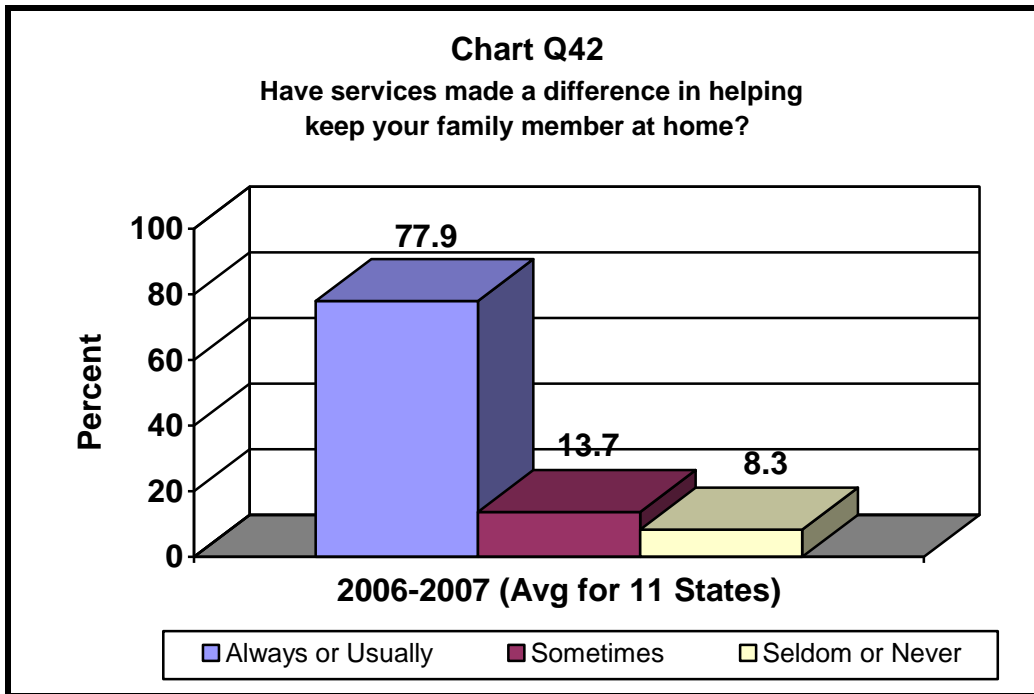
**Table Q40**  
Are you satisfied with the way complaints/grievances are handled and resolved?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	52.5	31.4	16.1	118
DE		55.1	29.6	15.3	98
GA	↓	53.3	31.5	15.3	321
HI	↑	65.8	26.0	8.2	146
ME		56.6	30.8	12.6	143
NM	↑	67.2	22.1	10.7	271
OK	↑	67.7	21.7	10.6	226
PA		62.3	29.8	7.9	416
VT	↑↑	71.7	19.5	8.8	113
WV	↓↓	45.9	30.6	23.5	85
WY		56.3	37.5	6.3	32
<b>Total %</b>		<b>60.7</b>	<b>27.5</b>	<b>11.7</b>	<b>1,969</b>
<b>State Average %</b>		<b>59.5</b>	<b>28.2</b>	<b>12.3</b>	<b>11</b>



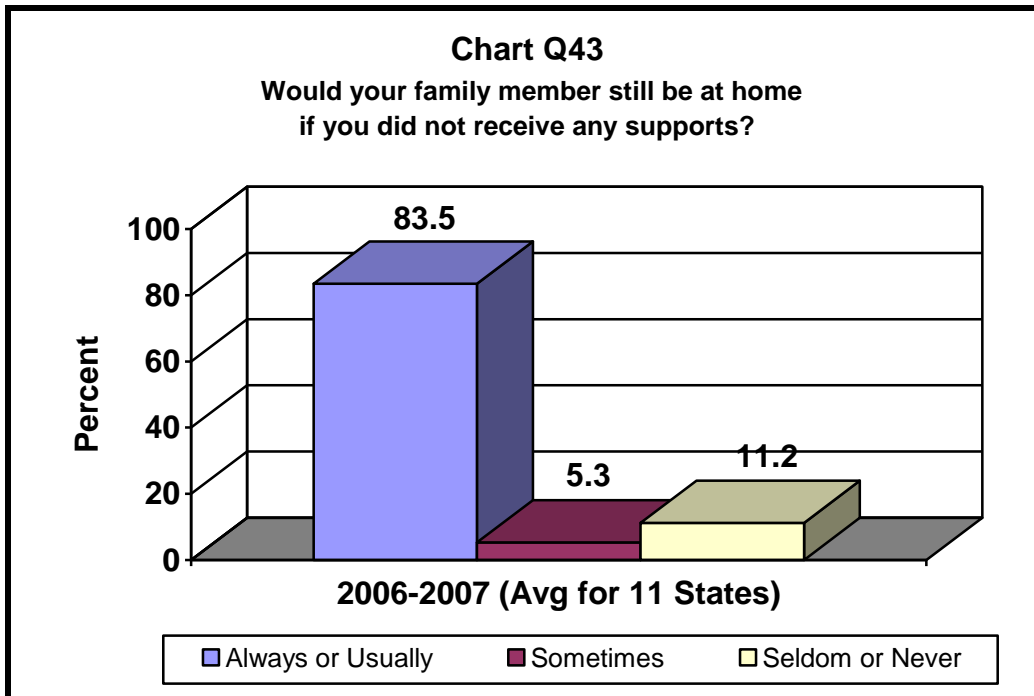
**Table Q41**  
Do you feel that services and supports have made a positive difference in the life of your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CT		68.2	24.2	7.6	289
DE	⇓⇓	58.2	32.5	9.3	237
GA	⇓	66.1	29.5	4.5	584
HI	⇑	80.4	18.1	1.6	321
ME		68.7	25.4	5.9	307
NM	⇑	80.8	17.5	1.6	428
OK	⇑	79.3	19.1	1.6	445
PA		71.6	23.0	5.3	917
VT	⇑	76.8	19.7	3.4	203
WV		70.4	25.7	3.9	152
WY		67.9	28.6	3.6	56
<b>Total %</b>		<b>72.3</b>	<b>23.4</b>	<b>4.3</b>	<b>3,939</b>
<b>State Average %</b>		<b>71.7</b>	<b>23.9</b>	<b>4.4</b>	<b>11</b>



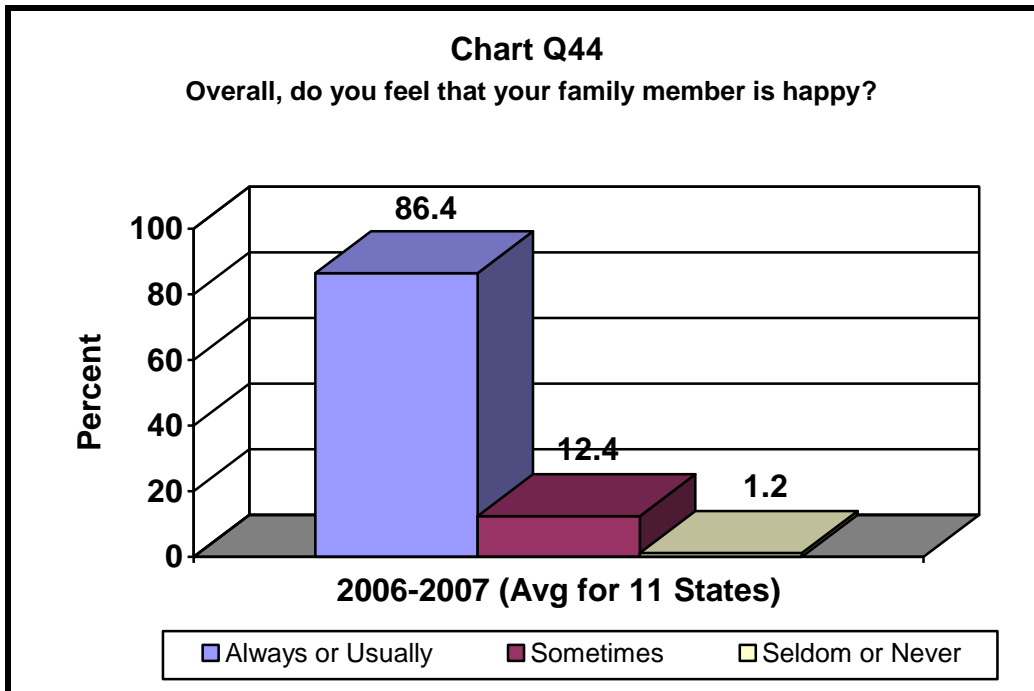
**Table Q42**  
Have services made a difference in helping keep your family member at home?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	68.3	20.2	11.5	262
DE	↓↓	62.9	21.0	16.2	210
GA	↓	71.6	17.3	11.1	532
HI	↑	84.3	12.3	3.4	293
ME		74.9	11.6	13.5	267
NM	↑	86.6	9.0	4.4	409
OK	↑	84.7	10.8	4.5	426
PA		74.4	13.1	12.6	804
VT	↑	84.5	12.7	2.8	181
WV		81.5	11.0	7.5	146
WY	↑	83.7	12.2	4.1	49
<b>Total %</b>		<b>77.3</b>	<b>13.7</b>	<b>9.1</b>	<b>3,579</b>
<b>State Average %</b>		<b>77.9</b>	<b>13.7</b>	<b>8.3</b>	<b>11</b>



**Table Q43**  
Would your family member still be at home if you did not receive any supports?

State	Always or Usually	Sometimes	Seldom or Never	n
CT	84.5	4.6	11.0	219
DE	88.9	1.6	9.5	189
GA	85.8	4.8	9.4	479
HI	84.9	6.1	9.0	245
ME	85.9	3.4	10.7	234
NM	81.2	7.1	11.7	324
OK	84.7	3.7	11.6	353
PA	87.1	4.7	8.3	751
VT	84.9	6.5	8.6	139
WV	76.6	5.4	18.0	111
WY	73.9	10.9	15.2	46
<b>Total %</b>	<b>85.0</b>	<b>4.9</b>	<b>10.2</b>	<b>3,090</b>
<b>State Average %</b>	<b>83.5</b>	<b>5.3</b>	<b>11.2</b>	<b>11</b>



**Table Q44**  
Overall, do you feel that your family member is happy?

State		Always or Usually	Sometimes	Seldom or Never	n
CT	↓	81.4	17.3	1.3	318
DE		83.8	15.1	1.1	271
GA		81.5	17.1	1.4	642
HI		90.3	9.7	0.0	330
ME		86.8	11.6	1.6	319
NM		90.1	9.4	0.5	434
OK		90.2	9.4	0.4	468
PA		87.0	11.3	1.7	998
VT		82.5	15.5	1.9	206
WV		90.9	9.1	0.0	154
WY		86.0	10.5	3.5	57
<b>Total %</b>		<b>86.3</b>	<b>12.5</b>	<b>1.1</b>	<b>4,197</b>
<b>State Average %</b>		<b>86.4</b>	<b>12.4</b>	<b>1.2</b>	<b>11</b>



## Aggregate Results & State Comparisons

In the previous section, 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/sites, 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.

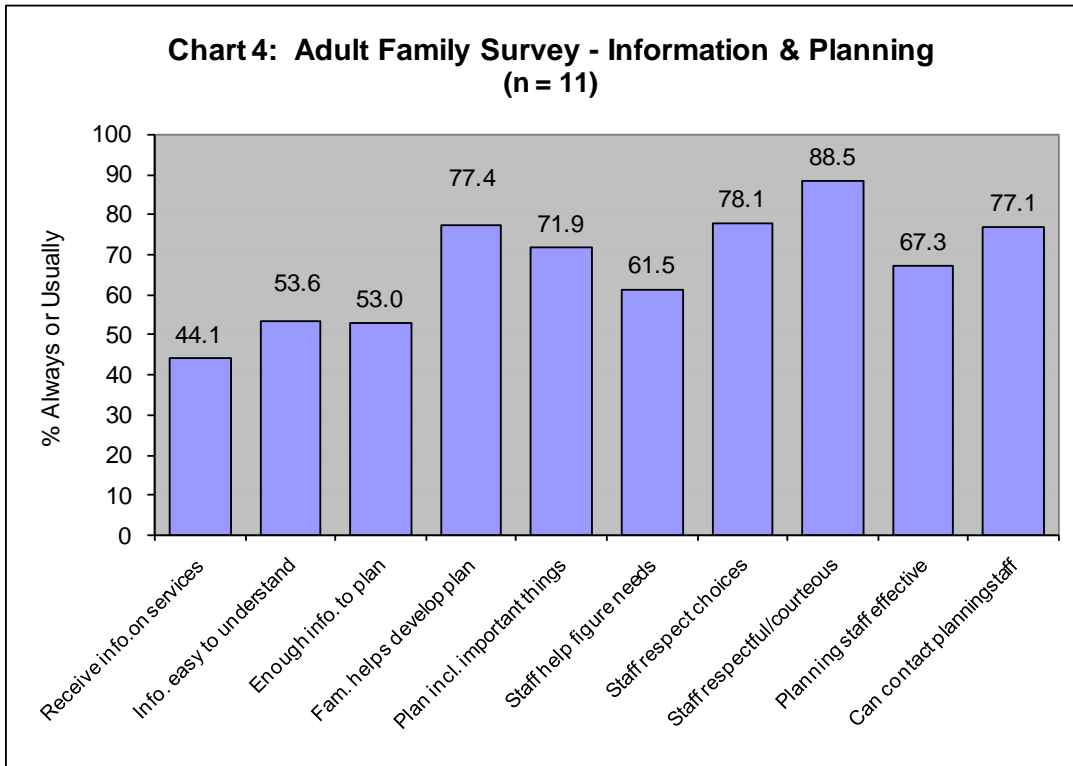
For each category, there is also a TABLE that looks at the arrows (i.e.,  $\uparrow$  and  $\downarrow$ ) of the Tables displayed earlier in this report, with single arrows representing state results  $\pm 5\%$  from the state average, and double arrows ( $\uparrow\uparrow$  and  $\downarrow\downarrow$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

This compilation of results (up arrows minus down arrows) provides a crude overview of deviations, 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 Hawaii, New Mexico and Wyoming, responses to information and planning questions were generally above the overall state average. In Delaware and Georgia, results fell noticeably below the state average.

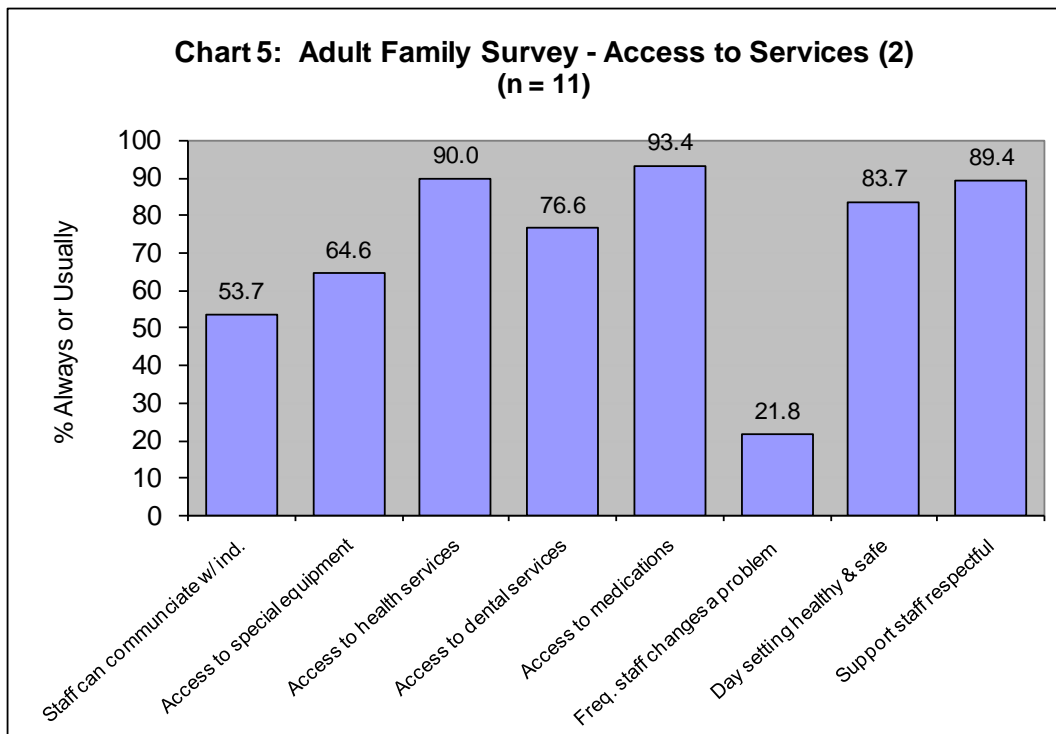
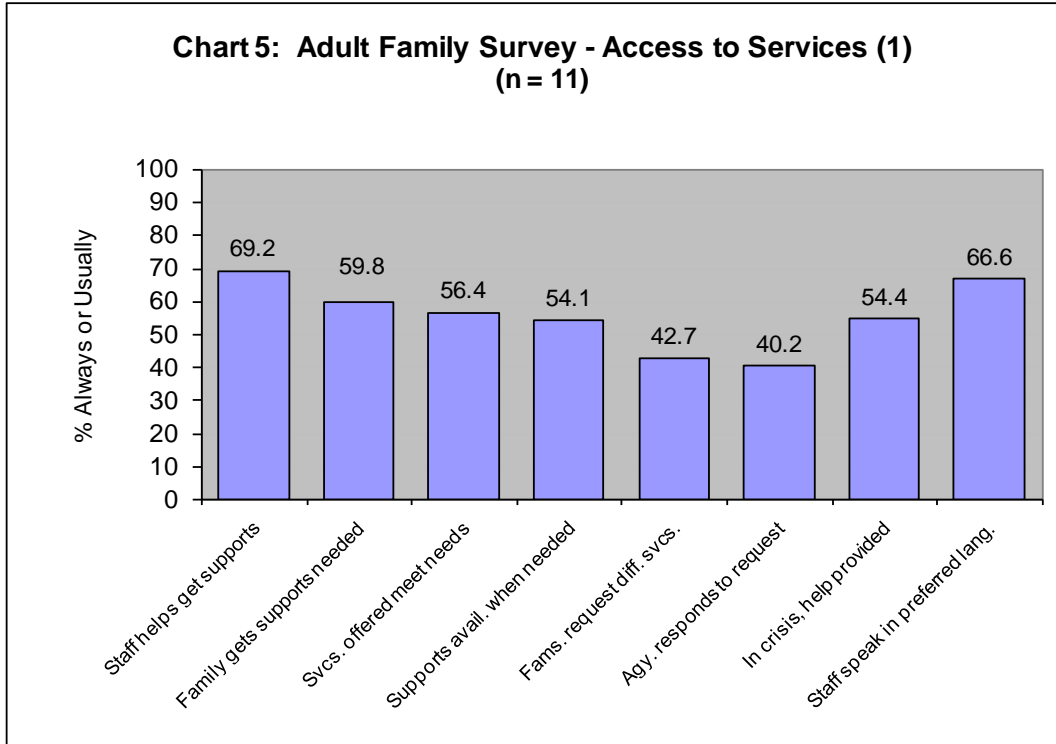


**Table 18**  
**Deviation in Responses Above & Below State Average**  
**Information & Planning**

State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Net Sum
CT			↓		↓↓						-3
DE	↓↓		↓↓	↓↓	↓↓	↓↓			↓	↓↓	-13
GA	↓↓	↓	↓↓	↓↓	↓↓	↓↓	↓	↓	↓		-14
HI	↑	↑	↑	↑	↑↑	↑	↑		↑		9
ME	↓		↑	↓		↓				↑	-1
NM	↑↑		↑	↑↑	↑	↑↑	↑		↑		10
OK	↓		↓	↑							-1
PA		↑									1
VT	↑		↑	↑	↑↑						5
WV		↓					↓		↓		-3
WY	↑↑		↑	↑↑		↑		↓		↑	6

## Access and Delivery of Services

- ◆ In New Mexico and Vermont, responses to access and delivery of services questions were generally above the overall state average. In Connecticut, results were generally below the state average. Please note that Question 15 is considered a “neutral question”, and therefore was not used in the calculation of state deviations from the average.

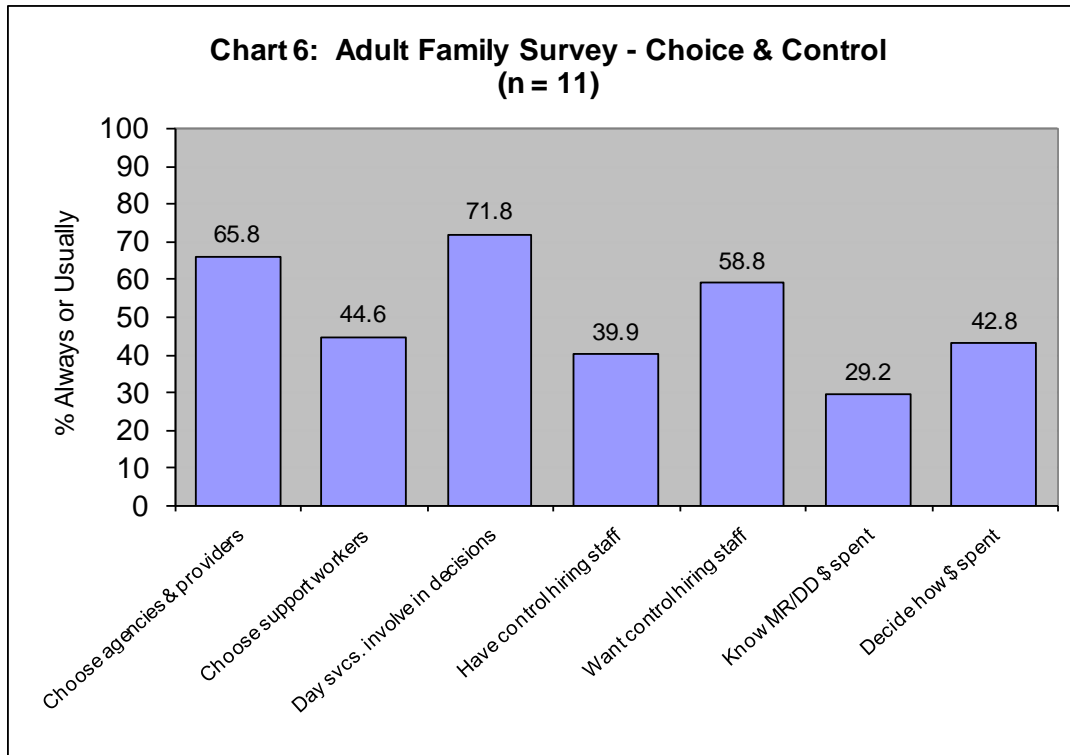


**Table 19**  
**Deviation in Responses Above & Below State Average**  
**Access to Services & Supports**

<b>State</b>	<b>Q11</b>	<b>Q12</b>	<b>Q13</b>	<b>Q14</b>	<b>Q15</b>	<b>Q16</b>	<b>Q17</b>	<b>Q18</b>	<b>Q19</b>	<b>Q20</b>	<b>Q21</b>	<b>Q22</b>	<b>Q23</b>	<b>Q24</b>	<b>Q25</b>	<b>Q26</b>	<b>Net Sum</b>
CT		↓	↓	↓↓		↑	↓	↓↓	↓↓	↓	↓	↓					-11
DE	↓↓	↓	↓↓	↓		↑	↓		↑↑	↓		↓↓					-7
GA	↓	↓		↓		↓	↓		↓			↓		↑			-6
HI		↑	↑↑	↑		↑		↓↓		↓							2
ME							↑			↑	↑						3
NM	↑↑	↑↑	↑	↑↑			↑↑	↑	↑	↑		↑↑					14
OK	↑							↑				↓					1
PA																	0
VT	↑		↑	↑			↑↑	↑↑	↑↑			↑↑			↑		12
WV	↓						↑	↑↑							↓↓		0
WY		↑		↑		↓	↓	↓↓	↓							↓	-4

## Choice and Control

- ♦ New Mexico, Oklahoma, Vermont and Wyoming's responses to choice and control questions were generally above the overall state average. Connecticut, Delaware, Maine and Pennsylvania's results were below the state average.

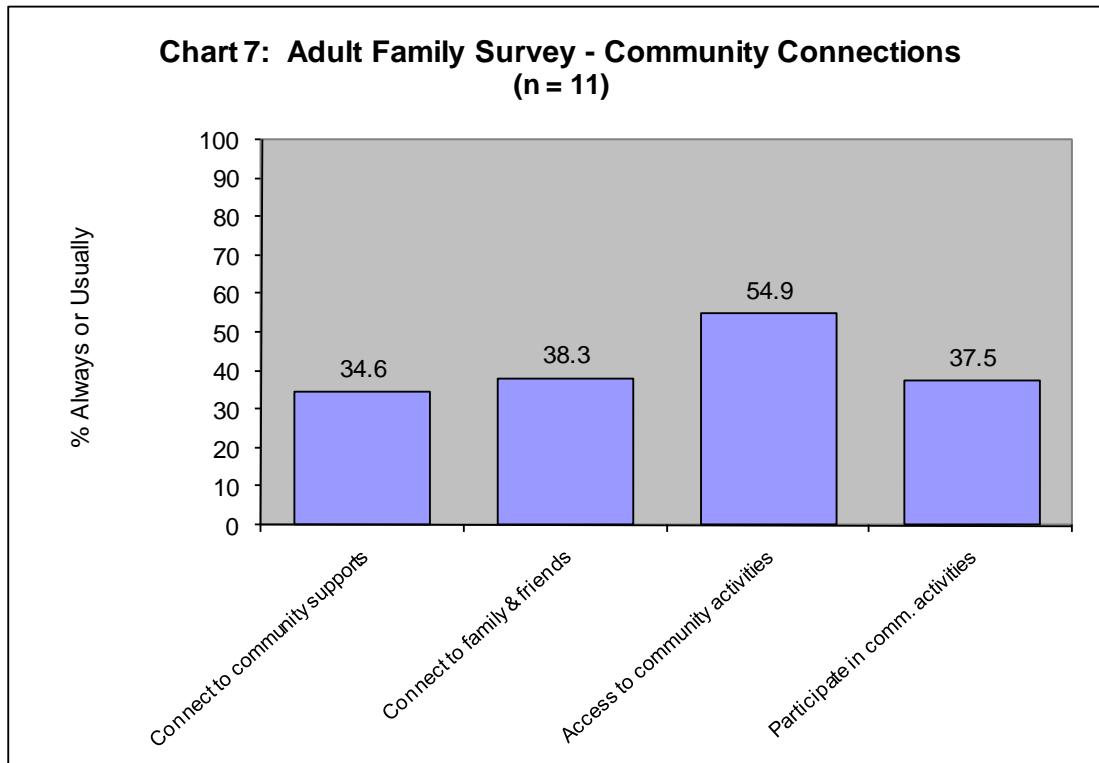


**Table 20**  
**Deviation in Responses**  
**Above & Below State Average**  
**Choice & Control**

State	Q27	Q28	Q29	Q30	Q31	Q32	Q33	Net Sum
CT	↓	↓↓		↓↓	↓↓			-7
DE	↓↓	↓↓		↓↓	↓↓	↓↓	↓↓	-12
GA	↓↓	↓↓	↓	↓↓	↓↓	↓↓	↓↓	-13
HI	↑	↑		↑↑	↑	↓↓		3
ME	↓↓	↓		↓↓	↓↓	↓↓	↓↓	-11
NM	↑↑	↑↑		↑↑	↑	↑	↑↑	10
OK	↑↑	↑↑		↑↑	↑↑	↑↑	↑↑	12
PA	↓↓	↓↓		↓	↓			-6
VT	↓	↑↑		↑↑	↑↑	↑↑	↑	8
WV					↑↑		↓↓	0
WY	↑↑	↑↑				↑↑	↑↑	8

## Community Connections

- ◆ In New Mexico, Vermont and West Virginia, responses to community connections questions were generally above the overall state average. In Connecticut, Delaware and Georgia, results were generally below the state average.

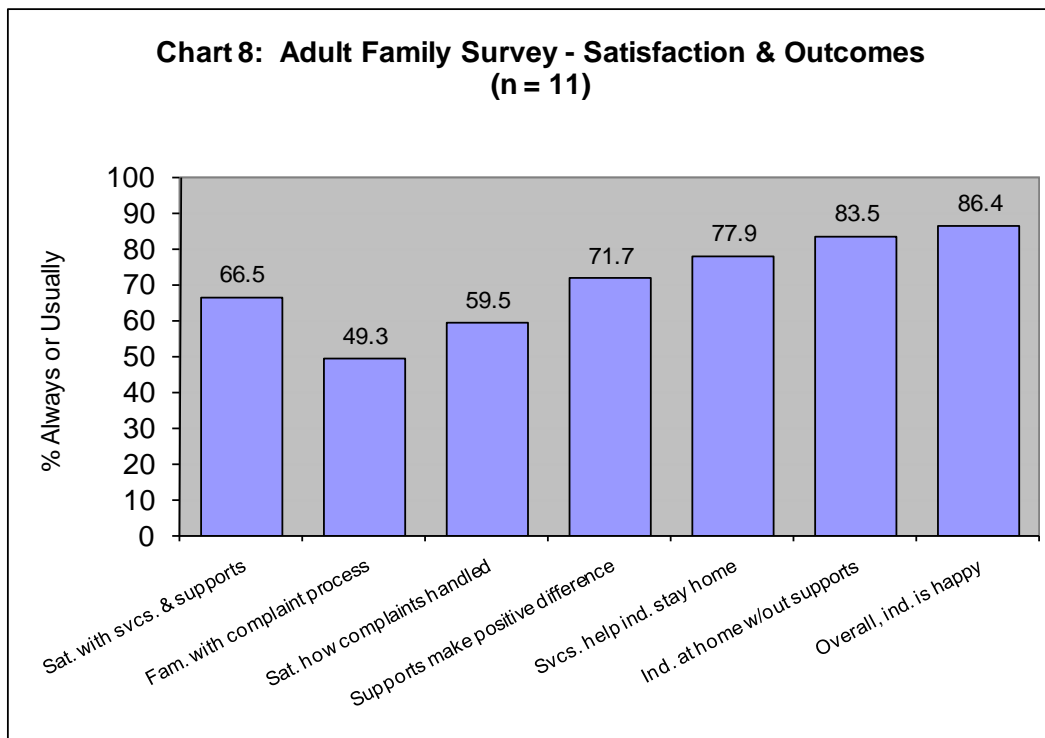


**Table 21  
Deviation in Responses  
Above & Below State Average  
Community Connections**

State	Q34	Q35	Q36	Q37	Net Sum
CT	↓	↓↓	↓↓	↓↓	-7
DE	↓↓	↓↓	↓	↓↓	-7
GA	↓↓	↓↓	↓↓	↓	-7
HI		↑↑			2
ME		↓			-1
NM	↑↑	↑↑	↑↑	↑↑	8
OK	↑	↑			2
PA					0
VT	↑	↑	↑	↑	4
WV		↑↑		↑↑	4
WY			↑↑		2

## Satisfactions with Services and Supports & Outcomes for Families

- ◆ In Hawaii, New Mexico, Oklahoma, and Vermont, responses were generally above the overall state average. In Connecticut, Delaware and Georgia, results were generally below the state average. Note that Question 43 is considered a “neutral question”, and was not used in the calculation of deviation from the average.



**Table 22  
Deviation in Responses  
Above & Below State Average  
Satisfaction & Outcomes**

State	Q38	Q39	Q40	Q41	Q42	Q43	Q44	Net Sum
CT	↓↓↓	↓↓↓	↓		↓		↓	-7
DE	↓↓↓	↓↓↓		↓↓↓	↓↓↓			-8
GA	↓↓↓	↓↓↓	↓	↓	↓			-7
HI	↑		↑	↑	↑			4
ME								0
NM	↑	↑↑	↑	↑	↑			6
OK		↑↑	↑	↑	↑			5
PA								0
VT	↑	↑↑	↑↑	↑	↑			7
WV	↓		↓↓↓					-3
WY	↑↑				↑			3

## Overall State Results

- ♦ Looking at results across all categories, New Mexico and Vermont received results that were generally above the overall state average. In Connecticut, Delaware and Georgia, results were substantially below the overall state average.

Table 23 Overall Deviation in Responses Above & Below State Average						
State	Information & Planning	Access & Delivery	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
CT	-3	-11	-7	-7	-7	-35
DE	-13	-7	-12	-7	-8	-47
GA	-14	-6	-13	-7	-7	-47
HI	9	2	3	2	4	20
ME	-1	3	-11	-1	0	-10
NM	10	14	10	8	6	48
OK	-1	1	12	2	5	19
PA	1	0	-6	0	0	-5
VT	5	12	8	4	7	36
WV	-3	0	0	4	-3	-2
WY	6	-4	8	2	3	15



# **APPENDIX A**

Summary Tables of Survey Responses

**Table A - Characteristics of Family Member with a Disability: 2006-07 Data**

STATES	Total %		State Avg.		CT		DE		GA		HI		ME		NM		OK		PA		VT		WV		WY		
Number of surveys	4,368		n = 11		355		297		658		344		339		437		476		1,029		217		157		59		
	n	%	%		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	
<b>Gender:</b>																											
Male	2,292	54.6	53.7		178	53.1	155	55.6	375	57.5	182	56.9	181	54.8	214	52.6	246	52.7	541	54.9	108	52.7	86	55.5	26	44.8	
Female	1,902	45.4	46.3		157	46.9	124	44.4	277	42.5	138	43.1	149	45.2	193	47.4	221	47.3	445	45.1	97	47.3	69	44.5	32	55.2	
<b>Age:</b>																											
Mean	34.0		33.5		34.9		33.7		38.3		31.2		34.0		33.0		30.7		34.6		33.6		32.8		31.9		
Range	18-87		4,271		18-73		18-83		18-82		18-87		18-64		18-73		18-72		18-79		18-71		18-73		21-77		
<b>Race/Ethnicity* (duplicated counts):</b>																											
White	3,145	74.6	75.6		283	83.0	194	70.5	414	62.9	82	25.7	321	96.4	177	43.6	363	77.9	912	91.8	208	97.2	138	89.6	53	93.0	
Black	427	10.1	8.2		30	8.8	68	24.7	222	33.7	5	1.6	1	0.3	5	1.2	45	9.7	41	4.1	0	0.0	10	6.5	0	0.0	
Asian	208	4.9	5.7		8	2.3	5	1.8	8	1.2	159	49.8	2	0.6	3	0.7	7	1.5	10	1.0	1	0.5	5	3.2	0	0.0	
American Indian/ Eskimo/Aleut	150	3.6	3.5		4	1.2	2	0.7	3	0.5	8	2.5	12	3.6	32	7.9	64	13.7	15	1.5	5	2.3	4	2.6	1	1.8	
Hawaiian/Pacific Islander	99	2.3	2.9		1	0.3	1	0.4	0	0.0	86	27.0	0	0.0	1	0.2	4	0.9	2	0.2	0	0.0	4	2.6	0	0.0	
Hispanic	278	6.6	6.9		21	6.2	3	1.1	12	1.9	15	4.7	2	0.6	191	47.0	11	2.4	13	1.3	1	0.5	5	3.2	4	7.0	
Mixed Races	138	3.3	3.9		1	0.3	5	1.8	5	0.8	69	21.6	3	0.9	19	4.7	22	4.7	5	0.5	1	0.5	6	3.9	2	3.5	
Other/Unknown	22	0.5	0.6		2	0.6	0	0.0	1	0.2	9	2.8	0	0.0	2	0.5	2	0.4	3	0.3	0	0.0	3	1.9	0	0.0	
<b>More than 1 person with DD in household:</b>																											
Yes	519	12.3	12.5		37	11.0	42	14.8	84	13.0	40	12.1	39	11.7	42	10.5	37	7.8	138	13.7	23	10.8	30	19.7	7	11.9	
No	3,714	87.7	87.5		299	89.0	241	85.2	560	87.0	290	87.9	295	88.3	359	89.5	437	92.2	869	86.3	190	89.2	122	80.3	52	88.1	
	4,233				336		283		644		330		334		401		474		1,007		213		152		59		

**Table B - Characteristics of Family Member with a Disability: 2006-07 Data**

	Total %		State Avg.		CT		DE		GA		HI		ME		NM		OK		PA		VT		WV		WY		
Number of surveys	4,368		n = 11		355		297		658		344		339		437		476		1,029		217		157		59		
	n	%	%		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	
<b>Level of MR:</b>																											
No MR label	150	3.8	4.1	9	2.6	19	7.3	21	3.4	19	6.0	10	3.2	31	7.8	15	3.3	18	1.8					8	5.3	0	0.0
Mild	794	20.3	19.9	85	25	44	16.9	115	18.6	46	14.4	83	26.5	78	19.7	82	17.9	228	22.9					19	12.5	14	25.0
Moderate	1,379	35.3	37.0	122	35.9	89	34.2	208	33.7	100	31.3	121	38.7	150	37.9	145	31.6	353	35.5					63	41.4	28	50.0
Severe	624	16.0	15.8	39	11.5	46	17.7	116	18.8	63	19.7	41	13.1	63	15.9	95	20.7	125	12.6					32	21.1	4	7.1
Profound	265	6.8	6.3	14	4.1	10	3.8	52	8.4	18	5.6	15	4.8	25	6.3	56	12.2	59	5.9					15	9.9	1	1.8
Don't know	694	17.8	16.9	71	20.9	52	20.0	105	17.0	73	22.9	43	13.7	49	12.4	66	14.4	211	21.2					15	9.9	9	16.1
	3,906			340		260		617		319		313		396		459		994		0				152		56	
<b>Other disabilities* (duplicated counts):</b>																											
Mental illness	594	14.5	14.5	40	12.7	31	12.3	112	17.0	36	11.6	33	10.8	66	15.1	62	13.5	141	15.0	37	18.0	28	18.9	8	14.5		
Autism	516	12.6	14.8	50	15.9	40	15.9	65	9.9	39	12.6	50	16.3	51	11.7	50	10.9	89	9.5	40	19.5	31	20.9	11	20.0		
Cerebral Palsy	781	19.1	20.0	54	17.1	41	16.3	110	16.7	62	20.0	47	15.4	92	21.1	144	31.4	147	15.7	28	13.7	43	29.1	13	23.6		
Brain injury	376	9.2	9.7	21	6.7	15	6.0	67	10.2	26	8.4	20	6.5	45	10.3	61	13.3	76	8.1	21	10.2	15	10.1	9	16.4		
Seizure Disorder/ Neurological Disorder	1,219	29.8	30.5	82	26	69	27.4	200	30.4	103	33.2	71	23.2	124	28.4	182	39.7	253	26.9	53	25.9	65	43.9	17	30.9		
Chemical dependency	41	1.0	1.1	2	0.6	0	0.0	6	0.9	3	1.0	1	0.3	4	0.9	9	2.0	9	1.0	0	0.0	6	4.1	1	1.8		
Vision or hearing impairments	1018	24.9	25.4	78	24.8	45	17.9	143	21.7	79	25.5	73	23.9	112	25.6	152	33.2	226	24.1	40	19.5	56	37.8	14	25.5		
Physical disability	1097	26.9	27.8	65	20.6	52	20.6	151	22.9	89	28.7	64	20.9	116	26.5	187	40.7	236	25.1	54	26.3	68	45.9	15	27.3		
Communication disorder	877	21.5	22.5	51	16.2	43	17.1	139	21.1	64	20.6	62	20.3	111	25.4	146	31.8	148	15.8	51	24.9	51	34.5	11	20.0		
Alzheimer's disease	41	1.0	1.4	4	1.3	4	1.6	1	0.2	4	1.3	2	0.7	4	0.9	7	1.5	6	0.6	2	1.0	6	4.1	1	1.8		
Down Syndrome	868	21.3	20.8	82	26	51	20.2	112	17.0	67	21.6	84	27.5	76	17.4	87	19.0	230	24.5	51	24.9	18	12.2	10	18.2		
Other disability	673	16.5	16.9	43	13.7	34	13.5	81	12.3	59	19.0	39	12.7	104	23.8	77	16.8	146	15.5	51	24.9	33	22.3	6	10.9		

**Table C - Characteristics of Respondents: 2006-07 Data**

STATES	Total %	State Avg.	CT	DE	GA	HI	ME	NM	OK	PA	VT	WV	WY												
Number of surveys	<b>4,368</b>	<b>n = 11</b>	<b>355</b>	<b>297</b>	<b>658</b>	<b>344</b>	<b>339</b>	<b>437</b>	<b>476</b>	<b>1,029</b>	<b>217</b>	<b>157</b>	<b>59</b>												
<b>Age:</b>																									
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%										
Under 35	152	<b>3.6</b>	<b>3.3</b>	13	3.8	9	3.2	18	2.8	22	6.7	6	1.8	21	5.1	22	4.6	33	3.3	4	1.9	3	1.9	1	1.7
35 to 54	1,448	<b>33.9</b>	<b>34.8</b>	88	25.7	91	32.6	171	26.2	121	36.7	121	35.8	154	37.1	194	40.8	345	34.1	72	33.6	71	45.8	20	33.9
55 to 74	2,154	<b>50.4</b>	<b>50.4</b>	180	52.6	146	52.3	384	58.9	156	47.3	164	48.5	200	48.2	222	46.6	493	48.8	105	49.1	71	45.8	33	55.9
75 and Over	517	<b>12.1</b>	<b>11.5</b>	61	17.8	33	11.8	79	12.1	31	9.4	47	13.9	40	9.6	38	8.0	140	13.8	33	15.4	10	6.5	5	8.5
	4,271			342		279		652		330		338		415		476		1,011		214		155		59	
<b>Relationship to consumer:</b>																									
Parent	3,607	<b>85.1</b>	<b>86.0</b>	303	89.4	216	76.3	502	79.8	270	82.8	308	92.2	354	84.7	411	86.5	866	85.4	191	91.0	132	86.8	54	91.5
Sibling	329	<b>7.8</b>	<b>7.0</b>	24	7.1	27	9.5	63	10.0	23	7.1	16	4.8	37	8.9	24	5.1	91	9.0	11	5.2	11	7.2	2	3.4
Spouse	30	<b>0.7</b>	<b>0.6</b>	1	0.3	1	0.4	10	1.6	4	1.2	1	0.3	0	0.0	1	0.2	11	1.1	0	0.0	0	0.0	1	1.7
Other	273	<b>6.4</b>	<b>6.3</b>	11	3.2	39	13.8	54	8.6	29	8.9	9	2.7	27	6.5	39	8.2	46	4.5	8	3.8	9	5.9	2	3.4
	4,239			339		283		629		326		334		418		475		1,014		210		152		59	
<b>Respondent is primary caregiver:</b>																									
Yes	4,115	<b>96.4</b>	<b>96.6</b>	335	96.5	271	96.1	637	97.5	310	95.1	332	98.8	408	98.3	455	96.0	956	94.7	206	97.2	149	95.5	56	96.6
<b>Respondent is guardian or conservator:</b>																									
Yes	2,688	<b>65.6</b>	<b>70.4</b>	278	82.0	145	55.3	324	52.3	264	82.0	258	78.2	305	74.2	302	66.2	481	51.4	174	82.1	111	72.5	46	78.0
<b>Health of respondent:</b>																									
Excellent	820	<b>19.2</b>	<b>20.1</b>	72	20.8	45	15.8	83	12.7	81	24.9	71	20.9	129	31.0	109	23.4	143	14.1	54	25.2	22	14.1	11	18.6
Good	2,364	<b>55.4</b>	<b>56.0</b>	181	52.3	179	63.0	348	53.5	178	54.8	187	55.2	232	55.8	256	55.1	564	55.6	118	55.1	85	54.5	36	61.0
Fair	964	<b>22.6</b>	<b>21.3</b>	83	24.0	56	19.7	198	30.4	62	19.1	75	22.1	50	12.0	83	17.8	267	26.3	36	16.8	43	27.6	11	18.6
Poor	121	<b>2.8</b>	<b>2.5</b>	10	2.9	4	1.4	22	3.4	4	1.2	6	1.8	5	1.2	17	3.7	40	3.9	6	2.8	6	3.8	1	1.7
	4,269			346		284		651		325		339		416		465		1,014		214		156		59	
<b>Household Income</b>																									
Below \$15,000	867	<b>26.8</b>	<b>25.8</b>	56	20.6	57	23.9	174	29.5	56	18.9			105	28.2	102	24.9	257	30			48	34.3	12	21.8
\$15,001-\$25,000	707	<b>21.9</b>	<b>21.8</b>	57	21.0	55	23.1	143	24.3	52	17.6			96	25.7	80	19.6	180	21.0			33	23.6	11	20.0
\$25,001-\$50,000	874	<b>27.1</b>	<b>27.4</b>	60	22.1	51	21.4	148	25.1	103	34.8			100	26.8	119	29.1	237	27.6			38	27.1	18	32.7
\$50,001-\$75,000	427	<b>13.2</b>	<b>13.6</b>	47	17.3	40	16.8	62	10.5	43	14.5			39	10.5	59	14.4	116	13.5			12	8.6	9	16.4
Over \$75,000	355	<b>11.0</b>	<b>11.4</b>	52	19.1	35	14.7	62	10.5	42	14.2			33	8.8	49	12	68	7.9			9	6.4	5	9.1
	3,230			272		238		589		296		0		373		409		858		0		140		55	

**Table D - Services and Support Received: 2006-07 Data**

STATES	Total %		State Avg.	CT		DE		GA		HI		ME		NM		OK		PA		VT		WV		WY	
	n	%	n = 11	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
<b>Financial support</b>	1,580	<b>40.5</b>	<b>40.5</b>	111	35.2	79	29.9	193	32.2	166	51.7	137	48.6	166	41.7	160	37.8	416	45.8	56	30.1	72	49.3	24	43.6
<b>In-home support</b>	1,271	<b>30.5</b>	<b>33.6</b>	68	20.8	26	9.0	88	14.0	115	34.3	62	19.2	169	40.7	321	69.6	245	24.9	48	25.3	102	65.4	27	46.6
<b>Out-of-home respite care</b>	1,348	<b>32.7</b>	<b>36.9</b>	96	29.8	51	17.8	124	20.3	128	38.9	75	23.7	298	70.4	67	15.0	292	29.9	117	58.5	68	45.6	32	56.1
<b>Day/employment supports</b>	3,023	<b>72.0</b>	<b>72.3</b>	290	87.9	206	72.0	559	86.9	211	63.4	280	84.8	285	67.2	194	42.9	697	70.3	157	80.1	100	65.4	44	74.6
<b>Transportation</b>	2,482	<b>62.2</b>	<b>63.7</b>	237	73.6	203	70.2	495	76.6	204	60.4	260	80.2	180	43.1	179	40.0	583	58.9			101	64.7	40	69.0
<b>Other</b>	1,166	<b>29.8</b>	<b>32.3</b>	35	10.7	45	15.5	116	18.7	78	24.2	75	24.1	339	80.1	169	37.2	215	22.3			69	46.3	25	43.9

**Table E1 - Information and Planning: 2006-07 Data**

STATES	TOTAL	STATE	CT	DE	GA	HI	ME	NM	OK	PA	VT	WV	WY
	%	AVG.											
<b>Q1 - Do you receive information about the services and supports that are available to your family?</b>													
Number of surveys	4,140	n = 11	325	279	613	330	323	424	457	980	203	149	57
% always or usually	42.7	44.1	39.4	33.0	28.4	53.9	35.0	60.6	37.4	46.0	50.7	46.3	54.4
% sometimes	38.2	38.2	43.1	40.5	38.8	38.5	44.0	28.5	40.7	37.7	36.5	34.9	36.8
% seldom or never	19.1	17.7	17.5	26.5	32.8	7.6	21.1	10.8	21.9	16.3	12.8	18.8	8.8
<b>Q2 - If you receive information, is it easy to understand?</b>													
Number of surveys	3,790	n = 11	283	243	538	324	281	406	419	908	192	140	56
% always or usually	54.3	53.6	50.9	58.8	47.0	59.3	50.9	53.9	50.8	59.7	58.3	48.6	51.8
% sometimes	38.8	40.0	42.8	34.2	40.5	36.4	43.4	40.4	41.3	35.0	34.4	45.0	46.4
% seldom or never	6.9	6.4	6.4	7.0	12.5	4.3	5.7	5.7	7.9	5.3	7.3	6.4	1.8
<b>Q3 - Do you get enough information to help you participate in planning services for your family?</b>													
Number of surveys	3,902	n = 11	301	240	577	321	297	416	439	911	197	147	56
% always or usually	51.8	53.0	47.8	39.6	40.6	59.8	58.9	61.3	47.4	53.5	61.9	51.0	60.7
% sometimes	31.7	31.9	31.9	34.2	30.5	33.6	29.0	31.0	34.2	31.2	29.9	32.0	33.9
% seldom or never	16.5	15.1	20.3	26.3	28.9	6.5	12.1	7.7	18.5	15.4	8.1	17.0	5.4
<b>Q4 - If your family member has a service plan, did you help develop the plan?</b>													
Number of surveys	3,448	n = 11	236	140	494	307	287	402	418	768	195	145	56
% always or usually	77.2	77.4	73.7	58.6	66.8	83.1	68.3	91.5	84.0	75.4	86.7	73.8	89.3
% sometimes	15.2	15.3	18.2	25.7	20.4	12.4	20.9	7.0	11.7	15.4	9.7	17.9	8.9
% seldom or never	7.7	7.3	8.1	15.7	12.8	4.6	10.8	1.5	4.3	9.2	3.6	8.3	1.8
<b>Q5 - If your family member has a service plan, does the plan include things that are important to you?</b>													
Number of surveys	3,488	n = 11	241	144	513	311	292	405	419	766	197	145	55
% always or usually	71.7	71.9	61.8	60.4	57.7	82.3	75.7	78.5	74.9	72.6	82.7	67.6	76.4
% sometimes	22.1	21.9	28.6	24.3	31.4	14.8	19.9	17.3	20.0	21.7	15.7	26.9	20.0
% seldom or never	6.3	6.2	9.5	15.3	10.9	2.9	4.5	4.2	5.0	5.7	1.5	5.5	3.6

**Table E2 - Information and Planning: 2006-07 Data**

STATES	TOTAL	STATE	CT	DE	GA	HI	ME	NM	OK	PA	VT	WV	WY
	%	AVG.											
<b>Q6 - Do the staff who assist you with planning help you figure out what you need as a family to support your family member?</b>													
Number of surveys	3,662	n = 11	258	180	545	319	294	414	422	824	201	148	57
% always or usually	61.4	61.5	60.9	48.3	50.1	68.0	56.5	75.4	64.2	62.5	61.2	59.5	70.2
% sometimes	25.6	25.6	26.0	26.7	29.0	26.6	30.3	18.8	25.8	24.4	25.9	25.7	22.8
% seldom or never	13.0	12.9	13.2	25.0	20.9	5.3	13.3	5.8	10.0	13.1	12.9	14.9	7.0
<b>Q7 - Do the staff who assist you with planning respect your choices and opinions?</b>													
Number of surveys	3,700	n = 11	258	177	554	324	299	417	429	836	203	146	57
% always or usually	79.2	78.1	76.7	73.4	71.7	85.2	76.6	86.1	81.4	81.8	80.8	69.9	75.4
% sometimes	15.9	17.2	18.2	14.7	18.6	13.9	18.7	12.0	16.3	13.3	16.7	24.0	22.8
% seldom or never	4.8	4.7	5.0	11.9	9.7	0.9	4.7	1.9	2.3	4.9	2.5	6.2	1.8
<b>Q8 - Are the staff who help you with planning generally respectful and courteous?</b>													
Number of surveys	3,780	n = 11	269	183	566	332	301	419	431	866	207	149	57
% always or usually	89.6	88.5	92.6	84.2	82.5	91.0	92.0	91.9	91.2	92.6	88.9	85.9	80.7
% sometimes	8.6	9.7	6.7	10.4	14.7	8.1	6.6	7.2	7.9	5.2	10.6	12.1	17.5
% seldom or never	1.8	1.8	0.7	5.5	2.8	0.9	1.3	1.0	0.9	2.2	0.5	2.0	1.8
<b>Q9 - Are the staff who assist you with planning generally effective?</b>													
Number of surveys	3,727	n = 11	267	176	554	329	296	422	425	849	205	146	58
% always or usually	68.3	67.3	64.4	60.2	60.3	75.1	68.2	75.8	70.6	70.4	67.3	62.3	65.5
% sometimes	26.0	26.7	28.1	26.7	31.4	23.7	26.7	20.9	25.2	23.9	29.3	28.8	29.3
% seldom or never	5.7	6.0	7.5	13.1	8.3	1.2	5.1	3.3	4.2	5.7	3.4	8.9	5.2
<b>Q10 - Can you contact the staff who assist you with planning whenever you want to?</b>													
Number of surveys	3,785	n = 11	267	187	557	333	299	420	429	872	213	150	58
% always or usually	77.6	77.1	75.7	62.6	75.4	82.0	82.9	81.2	76.9	79.2	72.8	73.3	86.2
% sometimes	18.2	18.8	21.7	25.7	18.7	15.9	14.4	15.7	18.2	16.7	24.9	22.7	12.1
% seldom or never	4.2	4.1	2.6	11.8	5.9	2.1	2.7	3.1	4.9	4.0	2.3	4.0	1.7



**Table F1 - Access and Delivery of Services and Supports: 2006-07 Data**

STATES	TOTAL %	STATE AVG.	CT	DE	GA	HI	ME	NM	OK	PA	VT	WV	WY
<b>Q11 - When you ask the service/support coordinator for assistance, does he/she help you get what you need?</b>													
Number of surveys	3,839	n = 11	277	192	564	323	292	423	453	896	208	154	57
% always or usually	70.0	69.2	68.2	55.7	61.5	72.1	68.8	80.4	74.2	71.8	76.0	61.0	71.9
% sometimes	24.5	25.3	24.5	32.3	29.6	26.3	25.7	17.3	20.5	23.3	21.2	31.2	26.3
% seldom or never	5.5	5.5	7.2	12.0	8.9	1.5	5.5	2.4	5.3	4.9	2.9	7.8	1.8
<b>Q12 - Does your family get the services and supports you need?</b>													
Number of surveys	3,915	n = 11	276	216	582	329	307	425	447	921	206	149	57
% always or usually	60.0	59.8	51.8	51.9	51.7	69.3	57.3	71.1	58.8	62.3	63.1	55.7	64.9
% sometimes	32.1	33.1	39.1	31.0	36.6	28.9	36.5	25.9	35.1	27.8	33.0	34.9	35.1
% seldom or never	7.9	7.1	9.1	17.1	11.7	1.8	6.2	3.1	6.0	9.9	3.9	9.4	0.0
<b>Q13 - Do the services and supports offered meet your family's needs?</b>													
Number of surveys	3,872	n = 11	282	208	567	316	298	427	444	910	209	154	57
% always or usually	57.1	56.4	48.6	42.8	52.2	66.5	57.0	65.3	57.2	58.0	62.7	54.5	56.1
% sometimes	35.1	35.9	41.8	43.8	36.3	31.3	36.6	29.3	36.7	33.7	32.1	34.4	38.6
% seldom or never	7.8	7.7	9.6	13.5	11.5	2.2	6.4	5.4	6.1	8.2	5.3	11.0	5.3
<b>Q14 - Are supports available when your family needs them?</b>													
Number of surveys	3,736	n = 11	262	202	546	310	295	419	427	863	205	150	57
% always or usually	54.2	54.1	43.1	45.5	47.1	59.7	53.6	64.7	52.7	56.4	62.4	50.0	59.6
% sometimes	36.0	36.5	43.5	34.7	37.2	37.4	37.3	30.1	39.1	34.0	33.2	38.7	36.8
% seldom or never	9.8	9.4	13.4	19.8	15.8	2.9	9.2	5.3	8.2	9.6	4.4	11.3	3.5
<b>Q15 - Do families in your area request that different types of services and supports be made available in your area?</b>													
Number of surveys	1,511	n = 10	110	84	265	127	109	230	139	335		85	27
% always or usually	42.4	42.7	45.5	39.3	39.2	44.9	36.7	50.4	40.3	40.6		42.4	48.1
% sometimes	39.3	38.6	39.1	31.0	40.0	40.9	44.0	38.3	37.4	40.3		41.2	33.3
% seldom or never	18.3	18.7	15.5	29.8	20.8	14.2	19.3	11.3	22.3	19.1		16.5	18.5
<b>Q16 - If yes, does either the state agency or provider agency respond to their requests?</b>													
Number of surveys	1,278	n = 10	121	75	207	106	84	203	124	268		67	23
% always or usually	39.7	40.2	45.5	46.7	30.9	46.2	38.1	44.3	39.5	36.9		38.8	34.8
% sometimes	40.8	40.9	38.8	32.0	37.7	40.6	48.8	41.4	41.9	42.9		41.8	43.5
% seldom or never	19.5	18.9	15.7	21.3	31.4	13.2	13.1	14.3	18.5	20.1		19.4	21.7
<b>Q17 - If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?</b>													
Number of surveys	1,917	n = 11	121	103	331	155	131	245	216	391	106	93	25
% always or usually	54.3	54.4	47.9	48.5	45.0	50.3	59.5	66.5	50.0	55.5	67.0	60.2	48.0
% sometimes	20.1	19.4	15.7	13.6	26.3	29.0	14.5	16.3	19.9	20.2	20.8	12.9	24.0
% seldom or never	25.6	26.2	36.4	37.9	28.7	20.6	26.0	17.1	30.1	24.3	12.3	26.9	28.0
<b>Q18 - If English is not your first language, are there support workers or translators available to speak with you in your preferred language?</b>													
Number of surveys	437	n = 11	32	28	71	66	35	82	34	54	16	17	2
% always or usually	66.4	66.6	43.8	64.3	66.2	53.0	71.4	75.6	73.5	64.8	81.3	88.2	50.0
% sometimes	16.5	13.9	28.1	10.7	15.5	25.8	22.9	17.1	2.9	11.1	12.5	5.9	0.0
% seldom or never	17.2	19.6	28.1	25.0	18.3	21.2	5.7	7.3	23.5	24.1	6.3	5.9	50.0



**Table F2 - Access and Delivery of Services and Supports: 2006-07 Data (Cont'd)**

STATES	TOTAL AVG.	STATE AVG.	CT	DE	GA	HI	ME	NM	OK	PA	VT	WV	WY
<b>Q19 - If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?</b>													
Number of surveys	686	n = 11	43	28	112	79	50	109	77	106	34	33	15
% always or usually	53.4	53.7	39.5	64.3	46.4	51.9	54.0	60.6	50.6	54.7	64.7	57.6	46.7
% sometimes	24.9	25.3	30.2	14.3	27.7	29.1	26.0	24.8	24.7	17.9	29.4	21.2	33.3
% seldom or never	21.7	20.9	30.2	21.4	25.9	19.0	20.0	14.7	24.7	27.4	5.9	21.2	20.0
<b>Q20 - Does your family member have access to the special equipment or accommodations that he/she needs?</b>													
Number of surveys	1,639	n = 11	83	81	267	132	96	200	250	341	70	93	26
% always or usually	65.5	64.6	59.0	55.6	60.7	59.1	69.8	74.0	66.8	68.3	62.9	68.8	65.4
% sometimes	18.9	19.9	21.7	21.0	18.7	19.7	18.8	16.5	19.2	17.6	15.7	22.6	26.9
% seldom or never	15.6	15.6	19.3	23.5	20.6	21.2	11.5	9.5	14.0	14.1	21.4	8.6	7.7
<b>Q21 - Do you have access to health services for your family member?</b>													
Number of surveys	4,041	n = 11	293	247	614	309	329	427	450	953	206	155	58
% always or usually	90.2	90.0	84.6	89.1	86.0	88.0	95.4	94.6	88.9	91.6	93.2	91.0	87.9
% sometimes	7.6	7.7	11.6	7.3	10.7	10.0	4.0	4.2	8.9	6.6	4.9	5.8	10.3
% seldom or never	2.2	2.3	3.8	3.6	3.3	1.9	0.6	1.2	2.2	1.8	1.9	3.2	1.7
<b>Q22 - Do you have access to dental services for your family member?</b>													
Number of surveys	3,863	n = 11	287	224	587	313	317	417	405	914	201	141	57
% always or usually	77.1	76.6	71.1	64.7	70.2	74.4	79.8	89.7	69.6	81.5	89.1	77.3	75.4
% sometimes	8.8	9.4	11.8	7.6	11.2	11.8	9.5	5.8	7.9	7.3	6.0	9.2	15.8
% seldom or never	14.1	13.9	17.1	27.7	18.6	13.7	10.7	4.6	22.5	11.2	5.0	13.5	8.8
<b>Q23 - Do you have access to necessary medications for your family member?</b>													
Number of surveys	3,988	n = 11	290	248	602	313	323	421	445	940	200	150	56
% always or usually	93.6	93.4	93.1	89.9	91.7	89.8	97.5	94.5	93.3	94.9	96.5	95.3	91.1
% sometimes	4.8	5.1	4.5	7.3	6.8	6.4	2.2	4.8	5.8	3.4	2.0	4.0	8.9
% seldom or never	1.6	1.5	2.4	2.8	1.5	3.8	0.3	0.7	0.9	1.7	1.5	0.7	0.0
<b>Q24 - Are frequent changes in support staff a problem for your family?</b>													
Number of surveys	3,295	n = 11	228	179	497	268	249	380	366	754	183	142	49
% always or usually	21.3	21.8	21.5	21.2	16.1	23.1	16.9	21.3	25.4	21.6	26.2	24.6	22.4
% sometimes	38.7	40.6	46.9	39.7	37.6	41.4	42.6	40.3	33.1	34.9	41.0	40.1	49.0
% seldom or never	40.0	37.5	31.6	39.1	46.3	35.4	40.6	38.4	41.5	43.5	32.8	35.2	28.6
<b>Q25 - Do you feel that your family member's day/employment setting is a healthy and safe environment?</b>													
Number of surveys	3,469	n = 11	299	228	558	278	281	324	323	812	191	125	50
% always or usually	84.7	83.7	85.3	81.6	83.9	84.5	87.2	81.2	88.2	86.1	92.1	68.8	82.0
% sometimes	13.2	14.0	14.4	16.7	13.6	11.9	11.4	15.4	10.5	11.9	7.3	27.2	14.0
% seldom or never	2.1	2.2	0.3	1.8	2.5	3.6	1.4	3.4	1.2	2.0	0.5	4.0	4.0
<b>Q26 - Are support staff generally respectful and courteous?</b>													
Number of surveys	3,976	n = 11	300	239	613	329	310	418	422	927	212	149	57
% always or usually	90.5	89.4	92.7	87.0	90.0	89.4	91.9	89.0	89.8	92.7	93.4	84.6	82.5
% sometimes	8.6	9.5	6.7	10.9	8.8	10.3	7.4	10.0	9.7	6.7	6.1	13.4	14.0
% seldom or never	0.9	1.2	0.7	2.1	1.1	0.3	0.6	1.0	0.5	0.6	0.5	2.0	3.5

**Table G - Choices and Control: 2006-07 Data**

STATES	TOTAL %	STATE AVG.	CT	DE	GA	HI	ME	NM	OK	PA	VT	WV	WY
<b>Q27 - Do you or your family member choose the agencies or providers that work with your family?</b>													
Number of surveys	3,633	n = 11	252	213	509	312	283	425	445	800	191	146	57
% always or usually	<b>63.6</b>	<b>65.8</b>	57.9	53.5	47.9	73.7	55.8	88.9	80.2	53.1	58.1	68.5	86.0
% sometimes	<b>16.7</b>	<b>16.5</b>	18.3	21.1	17.7	15.1	24.0	6.8	12.8	19.9	19.9	15.8	10.5
% seldom or never	<b>19.6</b>	<b>17.7</b>	23.8	25.4	34.4	11.2	20.1	4.2	7.0	27.0	22.0	15.8	3.5
<b>Q28 - Do you or your family member choose the support workers that work with your family?</b>													
Number of surveys	3,497	n = 11	240	194	497	295	273	411	423	775	192	141	56
% always or usually	<b>43.3</b>	<b>44.6</b>	28.3	27.3	23.5	49.8	35.9	65.7	69.0	34.5	56.3	44.7	55.4
% sometimes	<b>19.4</b>	<b>20.7</b>	18.8	15.5	15.7	26.4	24.5	18.7	15.8	19.0	18.2	26.2	28.6
% seldom or never	<b>37.3</b>	<b>34.7</b>	52.9	57.2	60.8	23.7	39.6	15.6	15.1	46.6	25.5	29.1	16.1
<b>Q29 - If your family member gets day or employment services, does the agency providing these services involve you in important decisions?</b>													
Number of surveys	2,993	n = 11	269	195	492	233	267	307	246	681	159	101	43
% always or usually	<b>71.3</b>	<b>71.8</b>	73.2	70.8	64.6	76.4	76.4	71.0	74.0	70.6	76.1	67.3	69.8
% sometimes	<b>19.6</b>	<b>19.0</b>	19.3	18.5	23.6	15.9	17.2	20.8	17.1	19.7	18.9	23.8	14.0
% seldom or never	<b>9.1</b>	<b>9.2</b>	7.4	10.8	11.8	7.7	6.4	8.1	8.9	9.7	5.0	8.9	16.3
<b>Q30 - Do you or your family member have control and/or input over the hiring and management of your support workers?</b>													
Number of surveys	2,877	n = 11	207	144	409	223	211	369	368	590	186	126	44
% always or usually	<b>39.1</b>	<b>39.9</b>	28.0	28.5	11.2	55.2	21.3	53.9	68.5	31.0	58.6	41.3	40.9
% sometimes	<b>15.4</b>	<b>17.3</b>	20.3	11.8	12.0	19.3	20.4	14.9	15.8	11.5	17.7	16.7	29.5
% seldom or never	<b>45.5</b>	<b>42.9</b>	51.7	59.7	76.8	25.6	58.3	31.2	15.8	57.5	23.7	42.1	29.5
<b>Q31 - Do you or your family member want to have control and/or input over the hiring and management of your support workers?</b>													
Number of surveys	2,780	n = 11	191	162	397	210	206	344	374	572	167	116	41
% always or usually	<b>57.6</b>	<b>58.8</b>	48.2	48.1	38.8	63.8	47.1	68.3	81.0	49.7	71.9	69.0	61.0
% sometimes	<b>24.2</b>	<b>25.4</b>	40.8	27.8	27.7	22.9	30.1	21.5	14.4	23.1	19.2	22.4	29.3
% seldom or never	<b>18.2</b>	<b>15.8</b>	11.0	24.1	33.5	13.3	22.8	10.2	4.5	27.3	9.0	8.6	9.8
<b>Q32 - Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?</b>													
Number of surveys	3,939	n = 11	308	248	578	309	298	418	455	911	209	149	56
% always or usually	<b>27.1</b>	<b>29.2</b>	32.1	8.9	6.4	13.6	10.4	38.3	45.7	32.1	51.2	25.5	57.1
% sometimes	<b>11.9</b>	<b>12.7</b>	11.7	4.0	4.5	12.3	6.4	15.1	17.1	14.3	14.4	16.8	23.2
% seldom/never/don't know	<b>61.0</b>	<b>58.1</b>	56.2	87.1	89.1	74.1	83.2	46.7	37.1	53.7	34.4	57.7	19.6
<b>Q33 - Do you or your family member get to decide how this money is spent?</b>													
Number of surveys	2,935	n = 11	207	146	448	176	195	365	372	677	178	123	48
% always or usually	<b>43.0</b>	<b>42.8</b>	41.1	28.8	29.7	42.6	27.7	55.1	57.3	45.2	47.8	28.5	66.7
% sometimes	<b>20.2</b>	<b>20.8</b>	20.8	7.5	11.8	19.3	16.9	25.2	25.5	20.4	27.0	26.8	27.1
% seldom or never	<b>36.8</b>	<b>36.5</b>	38.2	63.7	58.5	38.1	55.4	19.7	17.2	34.4	25.3	44.7	6.3

**Table H - Community Connections: 2006-07 Data**

STATES	TOTAL	STATE	CT	DE	GA	HI	ME	NM	OK	PA	VT	WV	WY
	%	AVG.											
<b>Q34 - If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?</b>													
Number of surveys	2,649	n = 11	181	150	401	203	210	348	288	568	144	111	45
% always or usually	<b>34.8</b>	<b>34.6</b>	27.1	20.7	24.4	37.4	38.6	45.4	39.9	34.7	44.4	35.1	33.3
% sometimes	<b>27.1</b>	<b>28.7</b>	30.9	30.7	24.7	27.6	26.7	28.4	27.4	24.8	29.2	20.7	44.4
% seldom or never	<b>38.1</b>	<b>36.7</b>	42.0	48.7	50.9	35.0	34.8	26.1	32.6	40.5	26.4	44.1	22.2
<b>Q35 - 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?</b>													
Number of surveys	2,556	n = 11	164	146	362	206	180	333	318	549	144	116	38
% always or usually	<b>38.5</b>	<b>38.3</b>	26.8	27.4	19.6	50.0	29.4	52.9	47.8	37.7	46.5	49.1	34.2
% sometimes	<b>21.3</b>	<b>21.3</b>	21.3	20.5	19.1	25.7	22.8	23.4	20.4	19.9	25.7	17.2	18.4
% seldom or never	<b>40.3</b>	<b>40.4</b>	51.8	52.1	61.3	24.3	47.8	23.7	31.8	42.4	27.8	33.6	47.4
<b>Q36 - Do you feel that your family member has access to community activities?</b>													
Number of surveys	3,738	n = 11	277	221	556	287	289	419	428	863	201	143	54
% always or usually	<b>53.3</b>	<b>54.9</b>	40.8	45.7	44.2	56.1	54.0	69.7	52.9	52.4	61.7	59.4	66.7
% sometimes	<b>32.7</b>	<b>31.6</b>	33.9	31.2	38.7	34.8	33.9	23.2	34.1	33.0	30.8	31.5	22.2
% seldom or never	<b>14.0</b>	<b>13.6</b>	25.3	23.1	17.1	9.1	12.1	7.2	13.3	14.6	7.5	9.1	11.1
<b>Q37 - Does your family member participate in community activities?</b>													
Number of surveys	3,896	n = 11	290	247	578	299	307	421	438	906	206	148	56
% always or usually	<b>36.4</b>	<b>37.5</b>	23.4	25.1	30.6	40.1	36.2	56.8	35.4	33.6	42.7	48.0	41.1
% sometimes	<b>37.8</b>	<b>37.8</b>	40.3	34.0	45.0	31.8	39.7	29.9	39.3	37.0	39.8	37.8	41.1
% seldom or never	<b>25.8</b>	<b>24.7</b>	36.2	40.9	24.4	28.1	24.1	13.3	25.3	29.5	17.5	14.2	17.9

**Table I - Satisfaction with Services and Outcomes: 2006-07 Data**

STATES	TOTAL %	STATE AVG.	CT	DE	GA	HI	ME	NM	OK	PA	VT	WV	WY
<b>Q38 - Overall, are you satisfied with the services and supports your family member currently receives?</b>													
Number of surveys	4,090	n = 11	305	259	620	327	323	429	459	954	203	154	57
% always or usually	65.7	66.5	54.1	54.4	55.6	76.1	69.7	74.6	67.1	68.3	72.4	57.1	82.5
% sometimes	28.6	28.2	38.0	37.1	35.6	21.7	26.0	22.8	27.7	26.0	23.2	34.4	17.5
% seldom or never	5.7	5.3	7.9	8.5	8.7	2.1	4.3	2.6	5.2	5.7	4.4	8.4	0.0
<b>Q39 - Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?</b>													
Number of surveys	3,773	n = 11	277	240	567	304	290	419	434	855	195	138	54
% always or usually	49.7	49.3	38.6	29.2	36.5	44.7	46.2	72.6	65.4	48.2	65.6	48.6	46.3
% sometimes	9.9	11.5	10.8	7.9	9.3	15.5	10.0	8.6	9.0	9.2	4.1	12.3	29.6
% seldom/never/don't know	40.4	39.2	50.5	62.9	54.1	39.8	43.8	18.9	25.6	42.6	30.3	39.1	24.1
<b>Q40 - Are you satisfied with the way complaints/grievances are handled and resolved?</b>													
Number of surveys	1,969	n = 11	118	98	321	146	143	271	226	416	113	85	32
% always or usually	60.7	59.5	52.5	55.1	53.3	65.8	56.6	67.2	67.7	62.3	71.7	45.9	56.3
% sometimes	27.5	28.2	31.4	29.6	31.5	26.0	30.8	22.1	21.7	29.8	19.5	30.6	37.5
% seldom or never	11.7	12.3	16.1	15.3	15.3	8.2	12.6	10.7	10.6	7.9	8.8	23.5	6.3
<b>Q41 - Do you feel that services and supports have made a positive difference in the life of your family?</b>													
Number of surveys	3,939	n = 11	289	237	584	321	307	428	445	917	203	152	56
% always or usually	72.3	71.7	68.2	58.2	66.1	80.4	68.7	80.8	79.3	71.6	76.8	70.4	67.9
% sometimes	23.4	23.9	24.2	32.5	29.5	18.1	25.4	17.5	19.1	23.0	19.7	25.7	28.6
% seldom or never	4.3	4.4	7.6	9.3	4.5	1.6	5.9	1.6	1.6	5.3	3.4	3.9	3.6
<b>Q42 - Have services made a difference in helping keep your family member at home?</b>													
Number of surveys	3,579	n = 11	262	210	532	293	267	409	426	804	181	146	49
% always or usually	77.3	77.9	68.3	62.9	71.6	84.3	74.9	86.6	84.7	74.4	84.5	81.5	83.7
% sometimes	13.7	13.7	20.2	21.0	17.3	12.3	11.6	9.0	10.8	13.1	12.7	11.0	12.2
% seldom or never	9.1	8.3	11.5	16.2	11.1	3.4	13.5	4.4	4.5	12.6	2.8	7.5	4.1
<b>Q43 - Would your family member still be at home if you did not receive any services?</b>													
Number of surveys	3,090	n = 11	219	189	479	245	234	324	353	751	139	111	46
% always or usually	85.0	83.5	84.5	88.9	85.8	84.9	85.9	81.2	84.7	87.1	84.9	76.6	73.9
% sometimes	4.9	5.3	4.6	1.6	4.8	6.1	3.4	7.1	3.7	4.7	6.5	5.4	10.9
% seldom or never	10.2	11.2	11.0	9.5	9.4	9.0	10.7	11.7	11.6	8.3	8.6	18.0	15.2
<b>Q44 - Overall, do you feel that your family member is happy?</b>													
Number of surveys	4,197	n = 11	318	271	642	330	319	434	468	998	206	154	57
% always or usually	86.3	86.4	81.4	83.8	81.5	90.3	86.8	90.1	90.2	87.0	82.5	90.9	86.0
% sometimes	12.5	12.4	17.3	15.1	17.1	9.7	11.6	9.4	9.4	11.3	15.5	9.1	10.5
% seldom or never	1.1	1.2	1.3	1.1	1.4	0.0	1.6	0.5	0.4	1.7	1.9	0.0	3.5

# **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. Most states had a majority of 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

## CONNECTICUT

Overall, there was a 2 to 1 ratio of positive to negative comments regarding general satisfaction of state services and supports. More specifically, Case Managers/Service Coordinators received many positive comments from the families. An example:

All in all, I am pleased with DMR's help and I strongly recommend my son's case manager Ms. (Name) to you in the Highest regard. A wonderful and caring person, competent and a tribute to her profession. I think she should be publicly commended by DMR for the excellent case manager she is, and I would like to thank her for her unflagging attention to my son's needs and care despite her obviously heavy, perhaps over whelming caseload.

Despite the appreciation of the case managers/service coordinators, many families stated that they still needed more services and supports. There was great variety in the type of services and supports that families needed. One family member described many services that needed to be restored:

DMR recreational services should be restored to more frequency, approx 1 event every 7-10 days. (2) Also restoring transportation to and from rec events like dances would certainly help. (3) Restoring Independent Living skills -- Adult Ed courses in localities would give these adults a place to continue education beyond home and gain social skills with peers.

A primary service that families in Connecticut needed more of was respite:

The need for more respite, whether in or out of home is essential to the caregivers. As the mother of a 26 year old with profound mental retardation who requires TOTAL care., I find myself falling into more severe depression every day. Since the likelihood of her entering a group home in the near future is doubtful the future seems bleak at best. 2 or 3 times a year for respite is simply not enough!

## DELAWARE

The amount of comments from families stating general satisfaction of services and supports was only just higher than the amount of comments that indicated general dissatisfaction of services and supports. Family members specifically indicated that they needed more information regarding what services and supports were available:

I was never told about any of the services that my daughter need or can help her - nothing about money, a support person, nothing -that's not right I was never sent any information of any kind. Thank you (Name)

Like Connecticut, Delaware families stated that they needed more services and supports than what they are currently getting:

We just moved to (Town). Son has no job. He wants to take a trade, wants to do whatever he can as far as a job goes. He has no hobbies. Has no friends. Needs to get out and do things and meet people. Please help me. (Name), mother

Dental care was a prevalent topic in the comments; mostly pertaining to the lack of it:



(Name) is very happy. The most desired help would be dental care. She has problems w/ her teeth that stem from birth defects, abuse and lack of proper dental services. She is cute and deserves her teeth to be straight & white. Thank you

## GEORGIA

Like Delaware, Georgia had only slightly more comments indicating general satisfaction with services and supports than comments indicating dissatisfaction.

Funding and budget issues were a major concern for Georgian families. Although the comments varied, most stated that more money was needed and funding cuts were not appreciated:

Our daughter's NSE waiver has been paying for her to go to an out of state camp for the past 3 years. Now, we have been told that the waiver won't pay for it anymore. It states that if there is an established pattern that it would pay for it. When we keep asking about it, we are told no. We were led to believe that the money for her waiver was for her and help make her life a little easier and to make her happy. We feel that this is wrong to take things away from them that they enjoy doing and helping them at the same time.

In connection with more funding needed for services, families indicated that more services were needed as well:

My son desires to learn more so he can be more independent. I spoke with his advisors about this. Transportation when needed, if requested. My son participates in our church. No agency has anything to do with this. My son received supportive employment from this agency. We can't seem to get anything else done that would really help him and help me with him. However, I'm very thankful for the help received to assist him with his past and present job. Presently, I'm waiting for a response.

There were many comments related to day and employment programs; a slight majority of which had positive things to say...

The services we receive from the training center are vital for our child. This service allows me to continue to work and gives our child friendships, social outings, and teaches skills she needs. Reducing this service would be a devastating loss.

...but others stated dissatisfaction with the programs, for various reasons:

The employment services coordinator needs to put her priorities in line. They receive money for my son who seldom gets any services rendered. He is very much employable and it has taken her 1.5 years to find him a job and he is still looking.

There are not enough job opportunities or vocational support to learn real job skills. My daughter has had one job in the past 10+ years-She worked at (Employer) assembling pizza boxes-she loved it! She worked for one year-never missed a day; she got laid off and has never worked again!

Current services delivered to our family member are limited to a day program under contract with the (Program) Training Center. While their services are adequate, they are not optimum.

## HAWAII

Hawaii had fewer comments than most any other state who conducted this survey. Families were overwhelmingly more generally satisfied with services and supports than dissatisfied.

Like Delaware, dental care was a an issue for Hawaiian families:

I wished we can do something for dental. My daughter has a very hard time finding a dentist

We are paying our own dental service.

Families indicated that they were satisfied with staff:

I have always been more than satisfied with all the support helpers, in fact I truly adore them all - thank you so very much for all, you all, have done for us.

## NEW MEXICO

New Mexico's responses contained many, many more comments indicating general satisfaction of services and supports than those indicating general dissatisfaction.

Concerning specifics, by far the theme most commented on was dissatisfaction of respite services. Families made some fairly strong comments concerning cutbacks in services:

Unless things have changed since I spoke w/ my case manager, I find it a fallacy to cut back on the respite hours allotted to my daughter. If my husband and I can't have time away from our home, sometimes I wonder what the waiver program is for. My daughter is severely handicapped and total care. Although we love her to pieces, we do need a break from her - and her from us!!

Again, families indicated that more servicers were needed:

The current proposed changes to the DD Waiver cause hardship for our daughter, xxxxx because we will not access adult hab due to her vulnerable status and the lack of choice as to activities in the community. I would hope that DDS would consider increasing the hours of substitute care available to Family Living Providers or provide for another viable option to least meet the needs of our individuals. An affordable community access program for those individuals that cannot program for those individuals that cannot spend time in the community due to health and safety issues. Please help us care for our children in the least "institution-like" environment available a loving home environment.

New Mexico families were also vociferous pertaining to service coordination- mainly about paperwork and choice:

As a parent and guardian of my 20 yr/old daughter, I would like to see less paperwork to fill out. Sometimes we spend more time logging in goals- daily monthly and yearly that we forget what we are here for- "the child" less "quality" time is spent with the child because we are too worried about filling out monthly reports. I can see surrogate families or even adopted parents having to monitor daily activities and goals, but as for biological parents such as myself, 1 we have weathered all the challenges that God has given us w/ our daughter, 2 I have given up and sacrificed my adult life to care for her

24-7 and still I have to document every activity daily instead of just loving her and caring for her as it should be!

They need to give families more choices on child's care and the state should be more involved with outside services to families and agencies shouldn't be able to control what happen to your child- like on me

## **OKLAHOMA**

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

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

It has been difficult getting the services we need. It was very difficult getting DDSD Services to begin with. The staff has been very helpful both with (provider) and DDSD, however for families trying to get services it is very frustrating.

Dental care was once again a topic of interest:

Definitely need to improve dental services! This has always been a problem and a big expense for us to provide the dental care our son needs. Thanks for caring.

Families were also dissatisfied with communication with the state, particularly case managers and staff:

The primary problem with services is in caseworkers not returning phone calls. I only call if there is a specific need or question regarding services, I'll leave several phone messages and rarely are phone calls returned.

## **PENNSYLVANIA**

Pennsylvania families were more likely to express comments stating their general satisfaction to services and supports provided than general dissatisfaction.

Like Georgia, there were many comments pertaining to funding and budget issues

The funding provided to (county), Pennsylvania by the Commonwealth of Pennsylvania is woefully inadequate to meet our needs and the needs of the population of (county) which is increasing rapidly. Our family moved to Pennsylvania from Minnesota.

Families had good things to say about the jobs the case managers/service coordinators were doing:

Our supports coordinator is excellent. She constantly asks to make sure we are satisfied with services. If we have any concerns she follows up immediately and checks with us on the outcome.

Interestingly, there were many comments related to transitional issues, mainly parents worried what will happen when their child graduates from high school:

My son is still in school but my biggest concerns are when he is finished, that there are no programs for him to go to, he is on a long waiting list, as are many other young adults (18-21). We need more day programs, more respite (money/time) for family.

## VERMONT

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

Many of the specific comments from Vermont families had to do with day/employment support. Many comments indicated dissatisfaction with these supports; mainly dissatisfaction with the amount of hours the person gets:

My daughter gets 5 hrs weekly, unless there is a holiday, to do all she needs and wants to do. It is not enough. My daughter is slow and there is never enough hours a week to meet her demands let alone wants. We keep trying to get just 2 hours more weekly or 3 and can't seem to get them so my daughter comes home periodically having to leave out something and she does have to juggle a lot in such a short amount of time. 2-3 hrs weekly increase I feel is not a lot extra to ask for.

However, there were some comments from families expressing satisfaction of the day/employment supports:

The fact that my daughter is in a day program makes all the difference in the world to our family. She needs and enjoys the social outlet. And she and I (her mother) need time apart. I am sure that without this break, we would not be able to cope as well, especially as we get older.

Dissatisfaction with respite services was another topic commented on by Vermont families:

I am a working parent/guardian and I need respite care at home. I have never been able to find enough staff to fill the whole position, thus I have to rely on my aging mother to watch my son. Many times I am about to leave to go to work and my respite worker calls in sick. It is very stressful for me to have to find a place for my son to go. I have asked the agency for some respite help on the weekend so I can have some time with my other children. The agency said they would look into this in July and it is now September. I will have to call them to see why they haven't done anything about this and this is stressful for me. This weekend respite was talked about at his annual ISA meeting and was well received, so I don't understand why it wasn't pursued. It would help me if the agency was responsible for hiring the respite help (and finding the help) and covering if the help called in sick.

## WEST VIRGINIA

There were just a few more comments indicating general satisfaction with services than comments indicating general dissatisfaction with services.

Specifically, the most comments had to do with families needing more services:

My family member receives services at (Provider) on Aging. His hours are 8:00 am until 3:00 pm, Monday and Friday. The rest of his care is done by mother and father 24 hours 7 days a week. More help would be nice

Service coordination issues were also a topic for West Virginian families:

I think the parents have too much paper work to do, it adds to the stress. Check it out, look at what paperwork the respites do. The stress always ends up in the parents' lap. You don't realize it. It's always repetitive too

Families are also stating that staff members should be paid more money:

We are & have been dissatisfied with the pay our workers (receive)

## WYOMING

Like Hawaii, Wyoming had very few comments compared to the other states. There were a few that stated general satisfaction with services and supports received

Families need more services:

The (Provider) in (Town) is always helpful. Services in our town are hard to come by or non-existent. No day hab, no hippo therapy, no emergency care for overnight respite, etc.

They are satisfied with day/employment programs:

The day care he attends between jobs gives him the exposure to others and the community.

And there were several comments concerning families' satisfaction with the case manager/service coordinator...

We are very happy with our case manager.

...and dissatisfaction:

I'm seeing case managers more and more who need to realize they should be facilitators, not dictators. Too many case managers are pushing what they want, with little or no regard to person served or guardian input. It's becoming a matter of looking good on paper.

