

# Family Guardian Survey

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Final Report – May 2009  
2007-2008 Data



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

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# Table of Contents

## List of Tables & Figures

## Organization of Report

<b>I. Introduction .....</b>	<b>3</b>
Overview of National Core Indicators .....	3
Family Indicators .....	4
<b>II. Family Guardian Survey .....</b>	<b>6</b>
Background .....	6
State Participation .....	6
Survey Instrument .....	7
<b>III. Methods .....</b>	<b>7</b>
Sampling & Administration .....	7
Data Analysis .....	8
<b>IV. Results .....</b>	<b>9</b>
Participating States .....	9
Characteristics of Family Members with Disabilities .....	10
Characteristics of Respondents.....	16
Services and Supports Received.....	19
National Core Indicators .....	20
Information and Planning .....	21
Access to and Delivery of Services and Supports .....	28
Choice and Control .....	36
Community Connections .....	44
Outcomes and Satisfaction with Services and Supports .....	49
Aggregate Results & State Comparisons .....	55

## Appendix A – Analysis of Open-Ended Comments

## List of Tables & Figures

### Tables

Table 1	State Participation in National Core Indicators .....	4
Table 2	Family Indicators.....	5
Table 3	State Participation in NCI Family Guardian Survey.....	6
Table 4	Family Guardian Survey – State Response Rates.....	8
Table 5	Type of Residence.....	11
Table 6	Gender of Family Member .....	12
Table 7	Age of Family Member .....	12
Table 8	Race/Ethnicity of Family Member .....	13
Table 9	Level of Mental Retardation of Family Member.....	14
Tables 10A-B	Other Disabilities of Family Member .....	15
Table 11	Age of Respondent.....	16
Table 12	Relationship of Respondent to Individual with Disabilities.....	17
Table 13	Frequency of Visits .....	17
Table 14	Respondent is Legal Guardian/Conservator .....	18
Table 15	Services and Supports Received .....	19
Tables Q1-6	Information and Planning.....	22-27
Tables Q7-13	Access and Delivery of Supports.....	29-35
Tables Q14-20	Choices and Control .....	37-43
Tables Q21-24	Community Connections .....	45-48
Tables Q25-29	Outcomes and Satisfaction.....	50-54
Tables 16-21	State Comparisons in Responses Above & Below State Average .....	56-61

### Charts

Chart 1	States Participating in NCI Family Guardian Survey .....	9
Chart 2	Type of Residence of Family Member.....	11
Chart 3	Gender of Family Member.....	12
Chart 4	Level of Mental Retardation of Family Member.....	14
Charts Q1-Q6	Information and Planning.....	22-27
Charts Q7-Q13	Access and Delivery of Supports.....	29-35
Charts Q14-Q20	Choices and Control .....	37-43
Charts Q21-Q24	Community Connections .....	45-48
Charts Q25-Q29	Outcomes and Satisfaction.....	50-54

## Organization of Report

Eleven states conducted the National Core Indicators (NCI) Family Guardian Survey during the 2007-2008 project year and submitted their data. The Family Guardian Survey was administered to individuals having an adult family member with disabilities living outside of the family's home. This Final Report provides a summary of results, based on the data submitted by June 2008.

This report is organized as follows:

### I. INTRODUCTION

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

### II. FAMILY GUARDIAN 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 (HSRI) 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 an overall view of the aggregate survey results and takes a look at state trends, comparing individual state results against the state averages.

## I. Introduction

### Overview of National Core Indicators

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

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

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

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

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	Phase X 2007-2008
AZ	AZ	AZ	AL	AL	AL	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	AR	AR	AR
MO	KY	DE	CA - RCOC	CA - RCOC	CA - RCOC	CA-RCOC	AZ	AZ	AZ
NE	MA	IA	CT	CT	CT	CT	CA-RCOC	CA-RCOC	CA-RCOC
PA	MN	KY	DE	DE	DE	DE	CT	CT	CT
VT	NE	MA	HI	HI	DC	DC	DE	DE	DE
VA	NC	MN	IL	IN	HI	HI	DC	GA	GA
	PA	MT	IN	IA	IN	KY	GA	HI	HI
	RI	NE	IA	KY	KY	MA	HI	IN	IN
	VT	NC	KY	MA	MA	ME	KY	KY	KY
	VA	PA	MA	ME	ME	NC	MA	MA	LA
	WA	RI	NE	NE	NE	OK	ME	ME	MA
		UT	NC	NC	NC	PA	NM	NM	ME
		VT	OK	OK	ND	RI	NC	NC	MO
		WA	PA	PA	OK	SC	OK	OK	NC
			RI	RI	PA	VT	PA	PA	NJ
			UT	SC	RI	WA	RI	RI	NM
			VT	SD	SC	WV	SC	SC	NY
			WA	VT	SD	WY	SD	TX	OK
			WV	WA	VT		TX	VT	PA
			WY	WV	WA		VT	WA	RI
				WY	WV		WA	WV	SC
					WY		WV	WY	TX
							WY		VT
									WA
									WV
									WY

Denotes first year of participation in NCI.

## Family Indicators

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

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

Table 2 Family Indicators			
DOMAIN	<b>FAMILY INDICATORS</b> 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. Family Guardian Survey

### Background

This report focuses on the Family Guardian Survey.

The Family Guardian Survey was developed and first utilized during Phase II of the Core Indicators Project (1999-2000), in response to various states' interest in finding out whether family members of individuals with disabilities were involved in their family members' lives, whether they were supported in their efforts to be involved, and their level of satisfaction with how the service system was meeting the needs of their family member with disabilities. In this effort, seven states administered the Family Guardian 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 outside of the family household and (2) the individual received at least one service or support besides case management. If fewer than 1,000 families met these criteria, the state was instructed to mail the questionnaire to all qualified families. The requirement that questionnaires be mailed to 1,000 families was based on an expected return rate of 40%, which in turn would yield 400 completed questionnaires in hand for each state.

Between 2001 and 2008, seven to eleven states have participated each year. Response rates within states have varied greatly, between 12% - 81%, yet each year, NCI has had between 2,800 – 5,000 completed surveys available for analysis.

### State Participation

Below is a chart indicating participation in the Family Guardian Survey since its inception.

<b>Table 3</b> <b>State Participation in NCI Family Guardian Survey</b> <b>(Adults Living Out-of-Home)</b>									
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	Phase X 2007-2008
NA	CT KY MN NE PA VA WA	AZ DE MA MN NC PA RI	CA-RCOC HI NE NC PA UT WA	AZ CA-RCOC HI IN MA NC PA SC SD WY	AZ CA-RCOC CT ME NC ND PA SC WA WY	AZ CA-RCOC CT CT HI PA SC WY	CA-RCOC CT GA ME NC PA SC SD WA WY	AZ CT DE GA HI ME NM PA WY	GA LA ME MO NC NJ PA CA-RCOC SC WA WY



## Survey Instrument

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

The Family Guardian Survey used in 2007-2008 not only asks families to express their overall level of satisfaction with services and supports their family member receives, 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; satisfaction 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, relationship to individual, level of involvement with family member).

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

**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 to and delivery of services, choice and control, community connections, satisfaction and outcomes). Each question is constructed so that the respondent can select from three possible responses ("always or usually", "sometimes", and "seldom or never"). Respondents also have the option to indicate that they don't know the answer to a question, or that the question is not applicable.

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

## III. Methods

### Sampling & Administration

States were asked to administer the Family Guardian Survey by selecting a random sample of 1,000 families who: a) have an adult family member with developmental disabilities living outside of the family 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 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 this person 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 at home with the family, yet received the Family Guardian Survey, their responses were dropped.
- ♦ If the respondent indicated that the family member was under the age of 18, the 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 2007-08, eleven states administered the Family Guardian 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. The desired response rate (the percentage of surveys returned versus the number mailed) is 40%.

Table 4 Family Guardian Survey - State Response Rates				
State	Surveys Mailed	Surveys Returned	Response Rate	Usable Surveys
Georgia	2,000	551	28%	509
Louisiana	1,218	422	35%	408
Maine	1,500	601	40%	578
Missouri	1,000	417	42%	410
New Jersey	1,000	336	34%	325
North Carolina	365	224	61%	220
Pennsylvania	4,070	1,206	29%	1,113
RC Orange County, CA	880	251	29%	250
South Carolina	3,000	352	12%	325
Washington	1,250	464	37%	443
Wyoming	850	342	40%	247
<b>Overall</b>	<b>17,133</b>	<b>5,166</b>	<b>30%</b>	<b>4,828</b>

## Data Analysis

NCI data management and analysis is coordinated by 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 charts below provide the findings from the Family Guardian Survey. Findings are presented in aggregate, as well as by state.

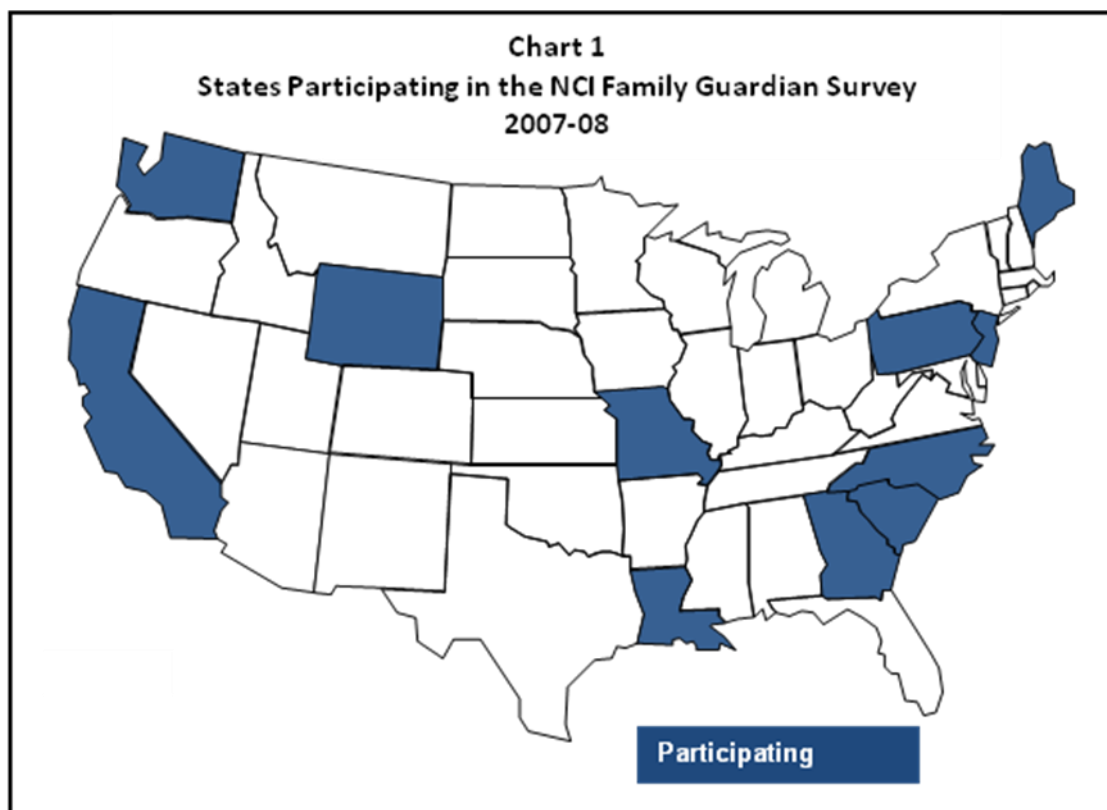
Please note that the TABLES provide individuals state results and result averages that are calculated through two separate methods:

1. Total % indicates the percentage across all individual respondents.
2. State Average % indicates the average percentage across the eleven states that conducted this survey.

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

### Participating States

- ♦ Eleven states provided data sets to be included in the Final Report. They include Georgia, Louisiana, Maine, Missouri, New Jersey, North Carolina, Pennsylvania, Regional Center of Orange County (CA), South Carolina, Washington, and Wyoming.



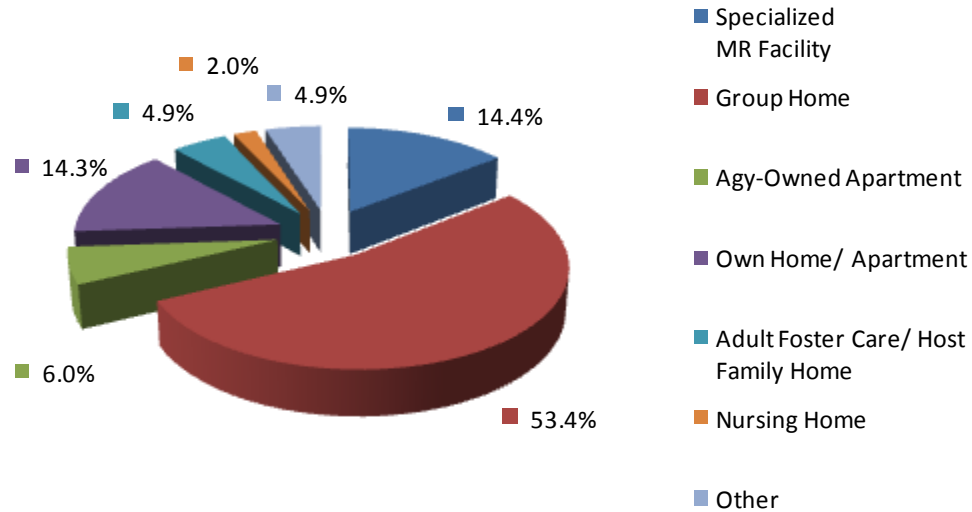
## Characteristics of Family Members with Disabilities

This section provides information about the individual with disabilities living outside of the family's home.

- On average, across the states, over half (53%) of the family members with disabilities lived in group home settings. Fourteen percent (14%) lived in their own homes or apartments, 14% lived in specialized facilities, 6% lived in agency-owned apartments, 5% lived in adult foster care or host family homes, 5% in a variety of other settings, and 2% in nursing homes.
- On average, 55% of family members were male across the participating states. The remaining 45% were female.
- Across states, the average age of family members with disabilities was 45, with a range in age from 18 to 94.
- On average, 86% of the family members were White, 10% were Black/African American, 1% were Asian, 1% were Hispanic, 1% were American Indian/Alaska Native, 1% were Mixed Races, less than 1% were Native Hawaiian/Pacific Islander, and less than 1% marked Other or Unknown. (In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.)
- On average, almost one-third (32%) of the family members with disabilities had a diagnosis of severe or profound mental retardation. Additionally, 31% were individuals with moderate mental retardation, 18% had mild mental retardation, and 4% had no mental retardation diagnosis. Additionally, 17% of respondents were unsure of their family member's diagnosis.
- In addition to mental retardation, many family members experience other disabilities as well (e.g., seizure disorder, cerebral palsy, physical disability, communication disorder). The most prevalent additional disabilities included: seizure disorders/neurological problems (28%), physical disabilities (27%), mental illness (22%), vision or hearing impairments (22%), communication disorders (20%), and cerebral palsy (17%).

## Type of Residence

**Chart 2. Type of Residence**



**Table 5**  
**Type of Residence in Which Family Member Lives (%)**

State	Specialized MR Facility	Group Home	Agy-Owned Apartment	Own Home/ Apartment	Adult Foster Care/ Host Family Home	Nursing Home	Other
CA-RCOC	4.9	72.9	1.2	12.6	1.2	4.9	2.4
GA	5.4	50.9	7.2	19.4	10.6	1.0	5.4
LA	24.7	40.6	3.0	27.7	0.3	0.3	3.5
ME	11.6	52.8	6.8	9.9	11.0	4.0	3.9
MO	22.5	43.0	5.8	18.3	0.5	2.8	7.3
NC	34.4	44.8	2.4	7.1	1.4	0.9	9.0
NJ	2.5	72.5	9.8	5.7	6.3	0.0	3.2
PA	16.9	52.9	3.5	10.7	4.8	6.1	5.0
SC	11.1	69.5	10.2	5.1	1.6	0.3	2.2
WA	17.2	30.5	4.7	29.5	8.1	1.2	8.8
WY	7.7	57.1	11.3	11.3	8.5	0.8	3.2
<b>Total N</b>	<b>682</b>	<b>2,442</b>	<b>265</b>	<b>685</b>	<b>255</b>	<b>127</b>	<b>233</b>
<b>Total %</b>	<b>14.5</b>	<b>52.1</b>	<b>5.7</b>	<b>14.6</b>	<b>5.4</b>	<b>2.7</b>	<b>5.0</b>
<b>State Avg %</b>	<b>14.4</b>	<b>53.4</b>	<b>6.0</b>	<b>14.3</b>	<b>4.9</b>	<b>2.0</b>	<b>4.9</b>

## Gender of Family Member

Table 6 Gender (%)		
State	Male	Female
<b>CA-RCOC</b>	58.4	41.6
<b>GA</b>	58.5	41.5
<b>LA</b>	51.8	48.2
<b>MO</b>	60.3	39.7
<b>NC</b>	54.5	45.5
<b>NJ</b>	54.7	45.3
<b>PA</b>	54.0	46.0
<b>SC</b>	55.1	44.9
<b>WA</b>	54.9	45.1
<b>WY</b>	50.4	49.6
<b>Total N</b>	<b>2,261</b>	<b>1,831</b>
<b>Total %</b>	<b>55.3</b>	<b>44.7</b>
<b>State Avg %</b>	<b>55.3</b>	<b>44.7</b>

## Age of Family Member

Table 7 Age of Family Member (%)		
State	Average Age	Range
<b>CA-RCOC</b>	43.7	18-74
<b>GA</b>	43.3	18-89
<b>LA</b>	46.6	19-79
<b>ME</b>	47.2	18-91
<b>MO</b>	42.4	18-88
<b>NC</b>	45.1	18-82
<b>NJ</b>	46.3	19-89
<b>PA</b>	47.1	18-87
<b>SC</b>	47.2	19-94
<b>WA</b>	46.3	19-89
<b>WY</b>	40.7	21-83
<b>Total N</b>	<b>4,693</b>	
<b>Total Avg</b>	<b>45.5</b>	<b>18-94</b>
<b>State Avg %</b>	<b>45.1</b>	

## Race/Ethnicity of Family Member

**Table 8**  
**Race/Ethnicity of Family Member (%)**

State	White	Black/ African American	Asian	Amer. Indian/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
<b>CA-RCOC</b>	85.2	1.2	5.6	1.2	0.0	3.6	0.0	3.2
<b>GA</b>	75.2	22.8	0.4	0.4	0.0	1.0	0.4	0.6
<b>LA</b>	83.4	14.1	0.5	0.3	0.0	1.5	0.0	1.0
<b>ME</b>	98.6	0.2	0.2	0.7	0.0	0.2	0.7	0.0
<b>MO</b>	89.9	7.2	0.7	1.0	0.5	0.5	0.0	0.0
<b>NC</b>	70.8	26.9	0.9	0.5	0.5	0.0	0.0	0.5
<b>NJ</b>	80.6	8.3	0.9	0.6	0.6	1.2	2.5	0.0
<b>PA</b>	94.0	3.5	0.0	1.4	0.2	0.6	0.1	0.7
<b>SC</b>	77.2	20.8	0.3	0.6	0.0	0.3	0.0	0.6
<b>WA</b>	92.9	1.4	1.4	3.0	0.7	1.6	0.9	0.9
<b>WY</b>	93.8	0.8	0.8	2.9	0.0	2.5	0.4	1.7
<b>Total N</b>	<b>4,147</b>	<b>402</b>	<b>36</b>	<b>54</b>	<b>10</b>	<b>48</b>	<b>20</b>	<b>34</b>
<b>Total %</b>	<b>87.6</b>	<b>8.5</b>	<b>0.8</b>	<b>1.1</b>	<b>0.2</b>	<b>1.0</b>	<b>0.4</b>	<b>0.7</b>
<b>State Avg %</b>	<b>85.6</b>	<b>9.7</b>	<b>1.1</b>	<b>1.1</b>	<b>0.2</b>	<b>1.2</b>	<b>0.5</b>	<b>0.8</b>

## Level of Mental Retardation of Family Member

**Chart 4. Level of MR**

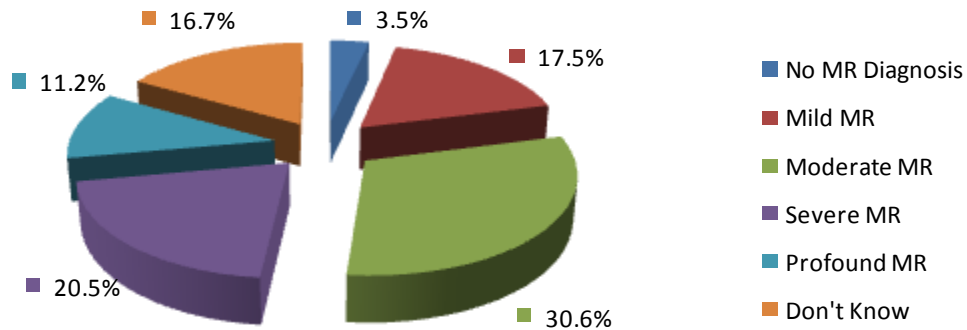


Table 9 Level of Mental Retardation of Family Member (%)						
State	No MR Diagnosis	Mild MR	Moderate MR	Severe MR	Profound MR	Don't Know
CA-RCOC	3.6	18.1	34.3	20.2	11.3	12.5
GA	3.3	17.7	33.1	19.7	11.0	15.2
LA	3.6	15.8	23.0	26.0	16.6	15.1
ME	1.8	12.7	31.8	24.4	14.9	14.3
MO	7.7	20.9	29.1	16.6	6.9	18.9
NC	1.4	15.3	23.9	24.9	15.3	19.1
NJ	5.9	17.7	30.9	18.1	4.9	22.6
PA	1.1	16.5	25.1	20.7	15.3	21.3
SC	4.5	18.9	32.7	20.2	7.4	16.3
WA	3.6	13.8	30.5	19.5	12.4	20.2
WY	1.7	25.5	41.8	15.5	7.1	8.4
<b>Total N</b>	<b>144</b>	<b>781</b>	<b>1,360</b>	<b>953</b>	<b>555</b>	<b>804</b>
<b>Total %</b>	<b>3.1</b>	<b>17.0</b>	<b>29.6</b>	<b>20.7</b>	<b>12.1</b>	<b>17.5</b>
<b>State Avg %</b>	<b>3.5</b>	<b>17.5</b>	<b>30.6</b>	<b>20.5</b>	<b>11.2</b>	<b>16.7</b>



## Other Disabilities of Family Member

Table 10A Other Disabilities of Family Member (%)						
State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
<b>CA-RCOC</b>	14.0	18.0	21.2	12.0	24.8	0.4
<b>GA</b>	21.8	14.7	15.7	9.4	23.8	0.4
<b>LA</b>	23.5	8.6	17.5	13.3	30.7	1.1
<b>ME</b>	23.9	12.6	18.1	8.2	32.9	0.4
<b>MO</b>	27.2	13.5	15.9	10.5	26.0	2.0
<b>NC</b>	24.7	14.6	13.7	7.3	28.8	0.9
<b>NJ</b>	12.1	16.9	18.2	8.0	19.4	0.0
<b>PA</b>	24.2	11.5	18.0	9.5	32.3	1.3
<b>SC</b>	20.9	11.6	14.7	12.3	30.5	1.7
<b>WA</b>	26.8	13.6	18.1	14.1	25.8	0.5
<b>WY</b>	24.8	5.9	17.2	13.0	28.6	1.7
<b>Total N</b>	<b>1,046</b>	<b>583</b>	<b>792</b>	<b>478</b>	<b>1,303</b>	<b>44</b>
<b>Total %</b>	<b>22.8</b>	<b>12.7</b>	<b>17.3</b>	<b>10.4</b>	<b>28.4</b>	<b>1.0</b>
<b>State Avg %</b>	<b>22.2</b>	<b>12.9</b>	<b>17.1</b>	<b>10.7</b>	<b>27.6</b>	<b>0.9</b>

Table 10B Other Disabilities of Family Member (%)						
State	Vision/ Hearing Impairment	Physical Disability	Communi- cation Disorder	Alzheimer's Disease	Down Syndrome	Other Disability
<b>CA-RCOC</b>	18.8	21.6	20.4	0.4	11.6	14.0
<b>GA</b>	18.3	22.6	19.4	0.8	11.4	13.8
<b>LA</b>	27.1	32.1	22.4	1.7	13.6	19.1
<b>ME</b>	25.0	33.4	24.3	1.8	13.3	16.2
<b>MO</b>	20.8	26.5	22.3	2.9	10.5	19.6
<b>NC</b>	22.8	24.2	18.3	1.4	8.7	17.4
<b>NJ</b>	15.3	16.9	13.7	0.6	11.5	10.8
<b>PA</b>	22.3	27.7	20.6	1.6	11.5	13.1
<b>SC</b>	19.5	28.4	18.8	1.4	11.3	11.3
<b>WA</b>	24.3	31.5	20.8	1.5	14.9	19.1
<b>WY</b>	27.7	26.2	17.6	0.4	13.4	16.8
<b>Total N</b>	<b>1,012</b>	<b>1,243</b>	<b>934</b>	<b>66</b>	<b>552</b>	<b>702</b>
<b>Total %</b>	<b>22.1</b>	<b>27.1</b>	<b>20.4</b>	<b>1.4</b>	<b>12.0</b>	<b>15.3</b>
<b>State Avg %</b>	<b>22.0</b>	<b>26.5</b>	<b>19.9</b>	<b>1.3</b>	<b>12.0</b>	<b>15.6</b>

## 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 outside of the household.

- Across states, most respondents (57%) fell between the ages of 55 and 74. Just over one-fifth (21%) of respondents were 35 to 54, and the same amount (21%) were 75 years old or over.
- Just over three-fifths of respondents were parents of adult children with disabilities (62%). Twenty-four percent (24%) were siblings, less than 1% were spouses, and the remaining 14% had other relationships to the individual.
- On average, almost three-fifths (59%) of respondents indicated they saw their family member more than twelve times per year (e.g., once a month or more). Others visited with their family members less frequently: 14% saw their family member 7 to 12 times per year, 12% visited their family member four to six times per year, 11% saw their family member one to three times per year, and the remaining 4% less than once per year.
- On average, 72% of respondents indicated that they were their family member's legal guardian or conservator. In Maine and Wyoming, nearly all respondents served as their family member's guardian, while in Georgia and South Carolina, fewer than half of respondents held this role.

### Age of Respondent

Table 11 Age of Respondent (%)				
State	Under 35	35-54	55-74	75 or Older
<b>CA-RCOC</b>	0.8	11.4	56.3	31.4
<b>GA</b>	1.6	21.1	60.0	17.4
<b>LA</b>	2.2	18.4	57.8	21.6
<b>ME</b>	1.2	20.6	59.2	19.0
<b>MO</b>	2.3	23.6	53.9	20.3
<b>NC</b>	1.8	33.5	51.8	12.8
<b>NJ</b>	0.3	12.1	54.1	33.4
<b>PA</b>	1.2	23.0	55.0	20.8
<b>SC</b>	1.6	20.1	54.2	24.1
<b>WA</b>	2.1	18.4	57.0	22.6
<b>WY</b>	1.6	23.4	65.2	9.8
<b>Total N</b>	<b>71</b>	<b>983</b>	<b>2,686</b>	<b>998</b>
<b>Total %</b>	<b>1.5</b>	<b>20.7</b>	<b>56.7</b>	<b>21.1</b>
<b>State Avg %</b>	<b>1.5</b>	<b>20.5</b>	<b>56.8</b>	<b>21.2</b>

## Relationship of Respondent to Individual with Disabilities

Table 12 Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
CA-RCOC	84.5	14.3	0.0	1.2
GA	64.4	24.5	0.2	10.8
LA	57.9	28.0	0.0	14.1
ME	59.7	27.3	0.0	13.0
MO	63.8	17.7	0.0	18.5
NC	49.3	26.3	0.0	24.4
NJ	74.6	21.3	0.0	4.1
PA	54.4	37.9	0.0	7.7
SC	50.8	28.7	0.0	20.6
WA	56.4	22.7	0.2	20.6
WY	63.7	17.6	0.4	18.4
Total N	2,810	1,251	3	603
Total %	60.2	26.8	0.1	12.9
State Avg %	61.8	24.2	0.1	13.9

## Frequency of Visits between Respondent and Individual with Disabilities

Table 13 Frequency of Visits with Family Member (%)					
State	Less than once/year	1-3 times/year	4-6 times/year	7-12 times/year	More than 12x/year
CA-RCOC	4.1	12.6	10.2	15.4	57.7
GA	2.2	5.3	10.6	14.3	67.6
LA	5.9	13.9	10.6	14.6	55.0
ME	2.8	9.9	11.8	17.8	57.7
MO	3.7	14.2	14.0	12.2	55.9
NC	2.8	7.9	15.0	14.5	59.8
NJ	4.2	7.8	9.8	14.0	64.2
PA	4.2	13.5	12.9	12.9	56.4
SC	2.2	6.4	10.8	11.1	69.4
WA	6.5	14.5	14.3	14.3	50.5
WY	2.8	13.0	13.0	17.8	53.4
Total N	183	530	576	676	2,768
Total %	3.9	11.2	12.2	14.3	58.5
State Avg %	3.8	10.8	12.1	14.4	58.9

## Respondent's Role as Guardian or Conservator

Table 14 Respondent is Legal Guardian or Conservator (%)		
State	Yes	No
CA-RCOC	64.7	35.3
GA	48.0	52.0
LA	67.6	32.4
ME	98.2	1.8
MO	87.4	12.6
NC	85.6	14.4
NJ	76.5	23.5
PA	52.0	48.0
SC	45.7	54.3
WA	68.5	31.5
WY	98.4	1.6
Total N	3,158	1,397
Total %	69.3	30.7
State Avg %	72.1	27.9

## Services and Supports Received

- ♦ Overall, residential supports, transportation services, and day/employment supports were all very highly utilized.

Table 15 Services and Supports Received (%)				
State	Residential supports	Day/ Employment supports	Transportation	Other
<b>CA-RCOC</b>	96.0	84.7	86.7	45.9
<b>GA</b>	91.5	77.1	91.2	44.4
<b>LA</b>	93.7	65.4	88.0	55.3
<b>ME</b>	97.4	80.8	95.0	71.4
<b>MO</b>	98.8	66.4	87.2	59.7
<b>NC</b>	93.5	67.3	86.5	74.9
<b>NJ</b>	98.0	90.0	91.0	57.0
<b>PA</b>	92.0	70.0	85.0	60.7
<b>SC</b>	97.8	87.3	98.7	58.0
<b>WA</b>	92.6	56.1	82.4	58.2
<b>WY</b>	98.4	88.0	94.6	82.6
<b>Total N</b>	<b>4,449</b>	<b>3,413</b>	<b>4,091</b>	<b>2,732</b>
<b>Total Avg %</b>	<b>94.8</b>	<b>74.3</b>	<b>89.1</b>	<b>60.1</b>
<b>State Avg %</b>	<b>95.4</b>	<b>75.7</b>	<b>89.7</b>	<b>60.7</b>

## National Core Indicators

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

For each question, a Figure and Table is provided.

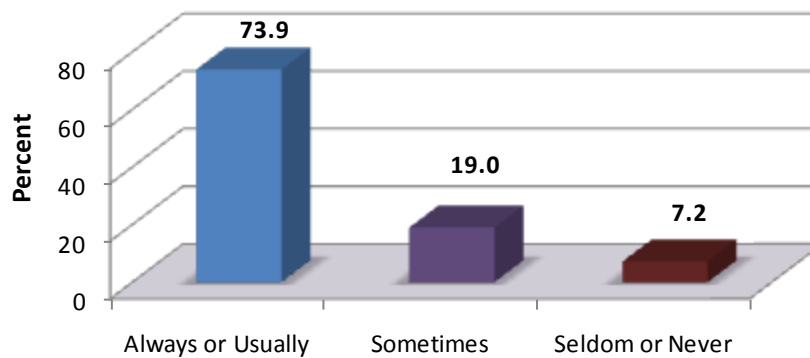
- ♦ The Figure illustrates the State Average results (i.e., the average percentage across the eleven states that conducted this survey).
- ♦ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state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

- On average, almost three-fourths of respondents (74%) stated that they got enough information to help them participate in planning.
- About two-thirds of respondents (63%), on average, indicated that they typically helped to develop their family member's service plan.
- On average across states, about three-fourths (77%) of respondents surveyed indicated that their family member's service plan included things that were important to them. Twenty percent (20%) stated this was only true some of the time, while the remaining 4% stated the service plan seldom included things important to the respondent.
- Across states, nearly all respondents (92%) felt that planning staff were generally respectful and courteous.
- Across states, approximately three-fourths (76%) felt that planning staff were generally effective.
- Across states, 85% felt they were able to contact planning staff when needed.

**Chart Q1** Do you get enough information to help you participate in planning services for your family member?

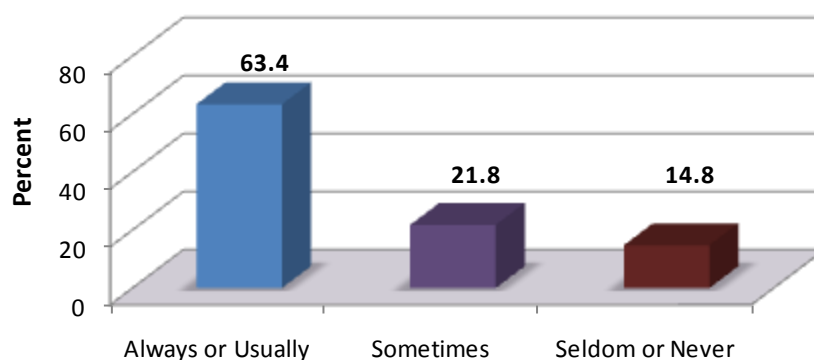


**2007-08 Average for 11 States**

<b>Table Q1</b> Do you get enough information to help you participate in planning services for your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		72.2	19.4	8.4	237
GA	↓↓↓	56.9	29.0	14.2	480
LA		71.2	18.9	10.0	371
ME	↑↑↑	90.1	8.7	1.2	565
MO		76.1	19.0	4.9	385
NC	↑	83.7	12.0	4.3	208
NJ	↓↓↓	62.0	27.2	10.8	287
PA		73.1	18.5	8.4	999
SC		71.5	22.0	6.6	305
WA		74.2	18.7	7.1	395
WY	↑	81.6	15.6	2.9	244
Total %		73.8	18.9	7.4	4,476
State Avg %		73.9	19.0	7.2	



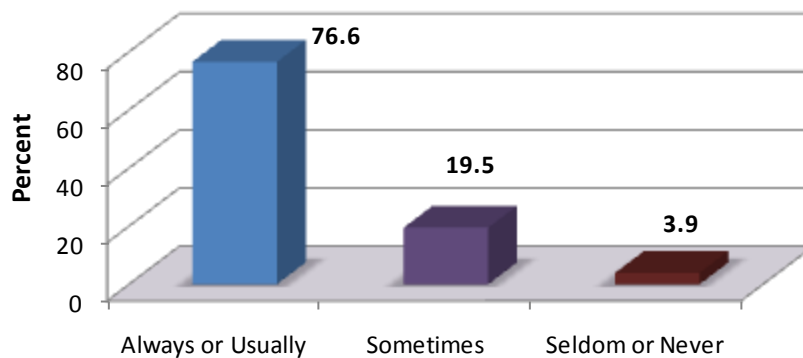
**Chart Q2** If your family member has a service plan, did you help develop the plan?



**2007-08 Average for 11 States**

Table Q2					
If your family member has a service plan, did you help develop the plan? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		58.7	22.9	18.3	218
GA	↓↓	52.1	28.9	19.0	436
LA	↓	56.2	23.3	20.4	313
ME	↑↑	77.2	15.7	7.1	534
MO		68.3	22.5	9.3	356
NC	↑↑	73.5	16.9	9.5	189
NJ	↓	56.1	24.6	19.3	228
PA	↓↓	48.2	27.0	24.9	868
SC		59.5	24.4	16.0	262
WA		64.2	21.1	14.7	360
WY	↑↑	83.3	13.0	3.8	239
Total %		61.4	22.6	16.0	4,003
State Avg %		63.4	21.8	14.8	

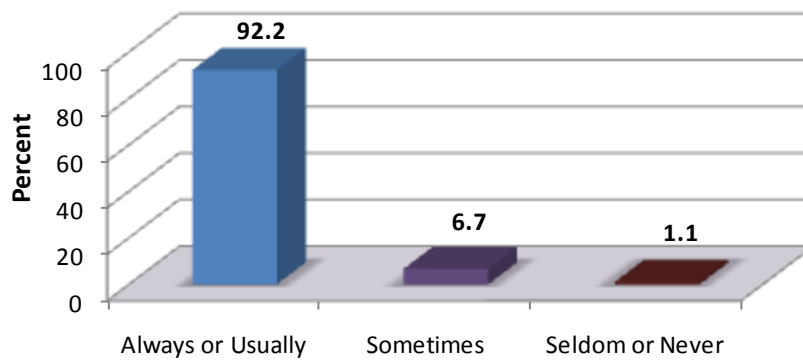
**Chart Q3** If your family member has a service plan, does the plan include things that are important to you?



**2007-08 Average for 11 States**

Table Q3					
If your family member has a service plan, does the plan include things that are important to you? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		74.8	23.4	1.9	214
GA	↓↓↓	64.4	29.3	6.3	413
LA		76.3	17.7	6.0	317
ME	↑↑↑	88.0	11.1	0.9	548
MO		78.2	19.3	2.5	363
NC	↑	84.4	13.5	2.1	192
NJ	↓	68.1	25.5	6.4	235
PA		73.0	21.2	5.7	857
SC		74.3	20.9	4.9	268
WA		74.1	21.0	4.8	352
WY	↑↑↑	86.6	12.1	1.3	239
Total %		76.3	19.6	4.1	3,998
State Avg %		76.6	19.5	3.9	

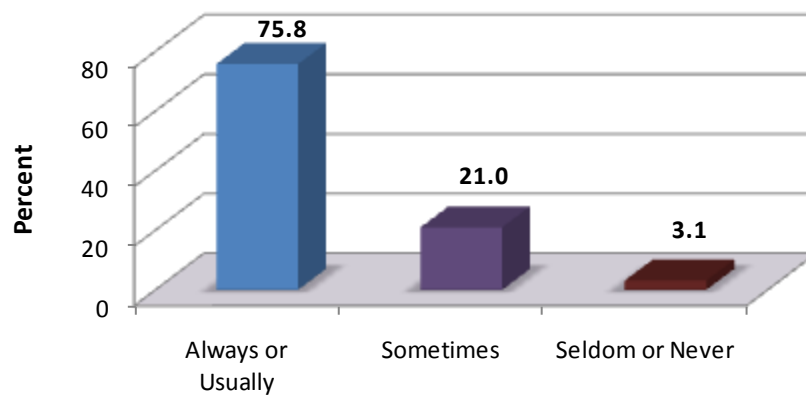
**Chart Q4** Are the staff who assist you with planning generally respectful and courteous?



**2007-08 Average for 11 States**

<b>Table Q4</b> Are the staff who assist you with planning generally respectful and courteous? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		94.3	5.2	0.4	230
GA	↓	84.9	13.2	2.0	456
LA		90.4	7.9	1.7	353
ME		96.8	3.2	0.0	560
MO		91.5	7.9	0.5	378
NC		94.5	5.5	0.0	200
NJ		92.1	5.6	2.3	266
PA		92.6	5.9	1.5	933
SC		92.9	4.7	2.4	295
WA		94.4	5.0	0.5	377
WY		90.1	9.5	0.4	242
Total %		92.2	6.6	1.1	4,290
State Avg %		92.2	6.7	1.1	

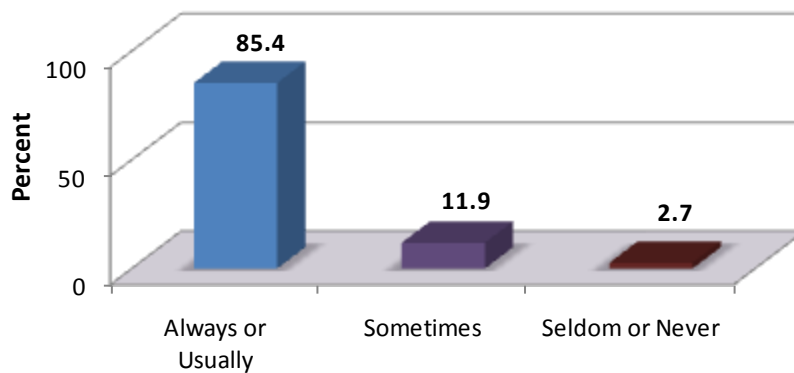
**Chart Q5** Are the staff who assist you with planning generally effective?



**2007-08 Average for 11 States**

Table Q5 Are the staff who assist you with planning generally effective? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		75.8	21.1	3.1	223
GA	↓↓	60.6	35.0	4.5	426
LA		78.4	17.5	4.1	342
ME	↑↑	86.6	12.3	1.1	553
MO		73.9	23.1	3.0	368
NC	↑	81.3	16.7	2.0	198
NJ		70.8	24.5	4.7	253
PA		78.0	19.3	2.7	902
SC		75.1	20.7	4.2	285
WA		77.3	19.9	2.7	366
WY		76.3	21.3	2.5	240
Total %		76.3	20.7	3.0	4,156
State Avg %		75.8	21.0	3.1	

**Chart Q6** Can you contact the staff who assist you with planning whenever you want to?



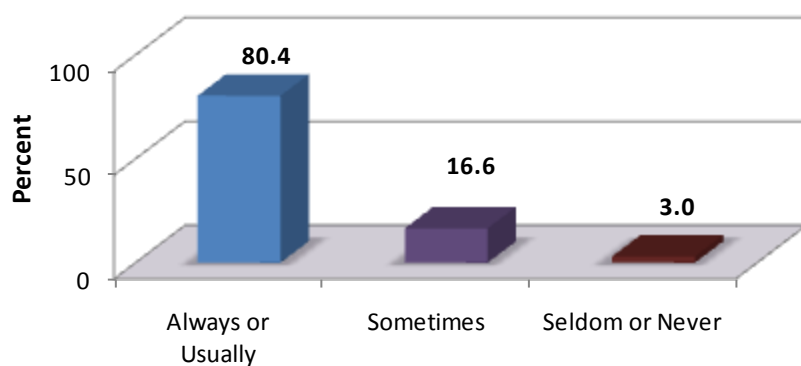
**2007-08 Average for 11 States**

Table Q6					
Can you contact the staff who assist you with planning whenever you want to? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		82.4	14.9	2.7	221
GA	↓	75.5	18.9	5.5	470
LA		83.3	12.0	4.7	359
ME	↑	93.4	6.3	0.4	560
MO		87.2	9.9	2.9	382
NC		88.7	9.8	1.5	204
NJ		81.8	15.0	3.2	253
PA		87.0	11.0	2.0	939
SC		86.1	10.8	3.1	295
WA		84.0	13.6	2.4	374
WY	↑	90.4	8.8	0.8	239
Total %		85.7	11.7	2.6	4,296
State Avg %		85.4	11.9	2.7	

## Access to and Delivery of Services and Supports

- On average, most respondents (80%) stated that their service coordinator helped them get needed supports when they asked. Seventeen percent (17%) said this only happened some of the time, and 3% indicated that their service coordinator was seldom or never helpful in getting their family member the assistance needed.
- Eighty percent (80%) of respondents, on average, indicated that their family member always or usually gets the services and supports they need.
- Among those respondents whose family member with disabilities did not speak English, or who used different ways to communicate, the majority (77%) indicated there were enough staff to communicate with their family member. Eighteen percent (18%) stated that these staff were available some of the time, and another 5% did not have staff available to communicate with their family members in their preferred means of communication/ languages.
- On average, 87% of respondents indicated that their family member had access to the special equipment or accommodations that s/he needs.
- Almost two-thirds of respondents (64%) indicated that frequent changes in support staff were a problem for their family at least some of the time. The remaining 36% stated that this was not an issue for them.
- Among those receiving residential supports, nearly all (88%) felt their family member's residential setting was a safe and healthy environment, however 12% felt their family member's residence was only sometimes or seldom safe.
- Among those receiving day/employment supports, nearly all (89%) felt their family member's day/employment setting was a safe and healthy environment. The remaining 11% felt their family member's day setting was sometimes or seldom safe.

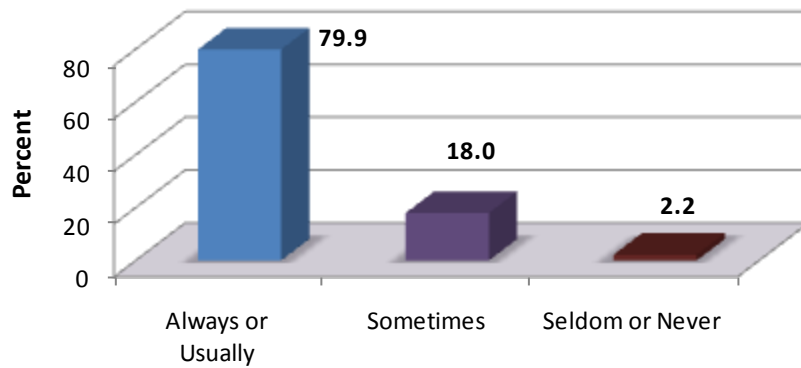
**Chart Q7** When you ask the service coord./case manager for assistance, does he/she help you get what you need?



**2007-08 Average for 11 States**

<b>Table Q7</b> When you ask the service coordinator/case manager for assistance, does he/she help you get what you need? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		79.1	18.9	1.9	206
GA	↓ ↓	67.5	25.6	6.8	468
LA		83.2	13.6	3.2	375
ME		84.5	14.4	1.2	515
MO		81.6	15.8	2.6	385
NC		85.3	13.3	1.4	211
NJ	↓	72.7	22.1	5.2	271
PA		82.7	14.7	2.6	936
SC		82.7	15.0	2.3	307
WA		78.6	16.6	4.8	373
WY	↑	86.4	12.8	0.8	242
Total %		80.4	16.6	3.1	4,289
State Avg %		80.4	16.6	3.0	

**Chart Q8 Does your family member get the services and supports he/she needs?**

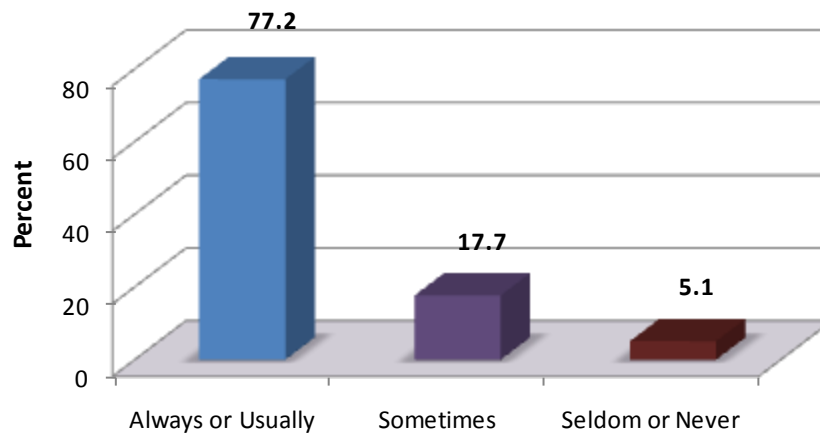


**2007-08 Average for 11 States**

Table Q8					
Does your family member get the services and supports he/she needs? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		79.0	19.3	1.7	233
GA	↓	70.6	25.8	3.6	476
LA		82.7	15.0	2.4	381
ME	↑	86.5	12.6	0.9	554
MO		79.7	18.8	1.5	389
NC		82.0	15.6	2.4	211
NJ	↓↓	69.8	27.4	2.8	281
PA	↑	85.4	12.9	1.8	1019
SC		83.6	15.5	1.0	304
WA		77.1	19.8	3.2	410
WY		82.7	14.8	2.5	243
Total %		80.7	17.2	2.1	4,501
State Avg %		79.9	18.0	2.2	



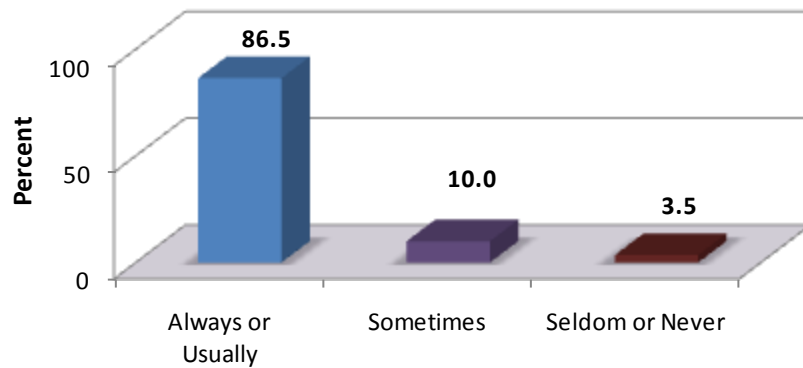
**Chart Q9** If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?



**2007-08 Average for 11 States**

Table Q9					
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? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓↓↓	66.7	24.4	8.9	45
GA	↓	67.3	22.2	10.5	153
LA	↑	84.3	11.4	4.3	140
ME	↑	82.5	13.6	3.9	228
MO	↑	83.6	15.1	1.4	146
NC		80.8	17.9	1.3	78
NJ	↓	71.3	18.4	10.3	87
PA	↑	82.3	15.3	2.4	379
SC	↑	82.7	15.3	2.0	98
WA	↓	72.1	21.7	6.2	129
WY		75.8	19.4	4.8	62
Total %		78.9	16.6	4.5	1,545
State Avg %		77.2	17.7	5.1	

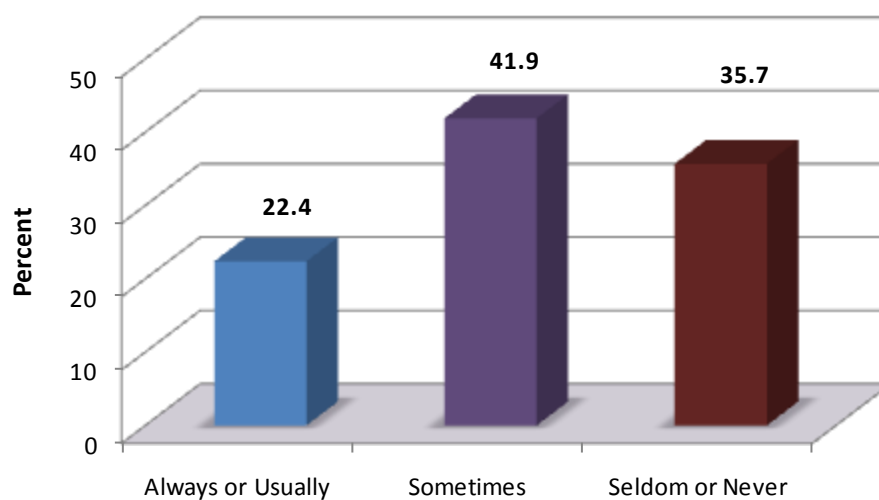
**Chart Q10** Does your family member have access to the special equipment or accommodations that he/she needs?



**2007-08 Average for 11 States**

<b>Table Q10</b> 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
CA-RCOC	↓	79.8	17.4	2.8	109
GA	↓↓	76.4	16.5	7.1	212
LA		89.7	6.3	4.0	224
ME		91.0	6.3	2.7	366
MO		88.8	9.0	2.2	223
NC		88.7	9.0	2.3	133
NJ	↓	80.7	14.0	5.3	114
PA		90.4	7.2	2.4	615
SC		84.8	9.8	5.5	164
WA		89.5	7.9	2.6	229
WY	↑	91.9	6.5	1.6	123
Total %		87.7	9.0	3.3	2,512
State Avg %		86.5	10.0	3.5	

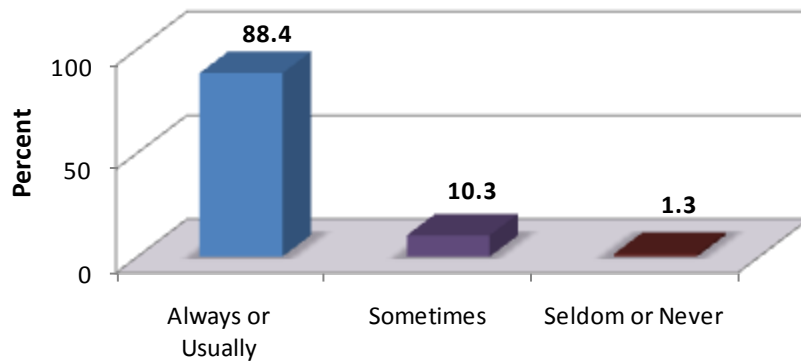
**Chart Q11 Are frequent changes in support staff a problem for your family member?**



**2007-08 Average for 11 States**

Table Q11					
Are frequent changes in support staff a problem for your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	28.5	0.0	71.5	137
GA		24.7	45.1	30.2	437
LA		19.3	42.9	37.8	331
ME	↓	27.8	45.3	26.9	490
MO		25.1	49.7	25.1	354
NC	↑↑	12.0	37.2	50.8	183
NJ		20.0	53.5	26.5	245
PA		22.5	44.6	32.9	861
SC		21.9	47.2	30.9	269
WA		17.6	42.3	40.1	324
WY		26.9	53.0	20.1	234
Total %		22.8	44.2	33.0	3,865
State Avg %		22.4	41.9	35.7	

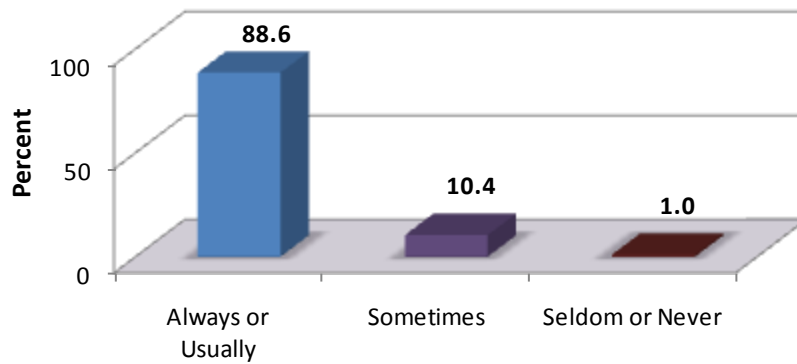
**Chart Q12** Do you feel that your family member's residential setting is a healthy and safe environment?



**2007-08 Average for 11 States**

Table Q12 Do you feel that your family member's residential setting is a healthy and safe environment? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↑	94.1	4.6	1.3	239
GA		84.0	13.9	2.1	482
LA		88.5	9.7	1.8	390
ME		91.3	7.8	0.9	562
MO		89.8	9.7	0.5	392
NC		89.6	9.4	0.9	212
NJ		84.9	13.4	1.7	292
PA		88.1	9.6	2.2	1070
SC		90.0	7.7	2.3	311
WA		87.6	11.7	0.7	419
WY		84.1	15.4	0.4	246
Total %		88.3	10.2	1.5	4,615
State Avg %		88.4	10.3	1.3	

**Chart Q13** Do you feel that your family member's day/employment setting is a healthy and safe environment?



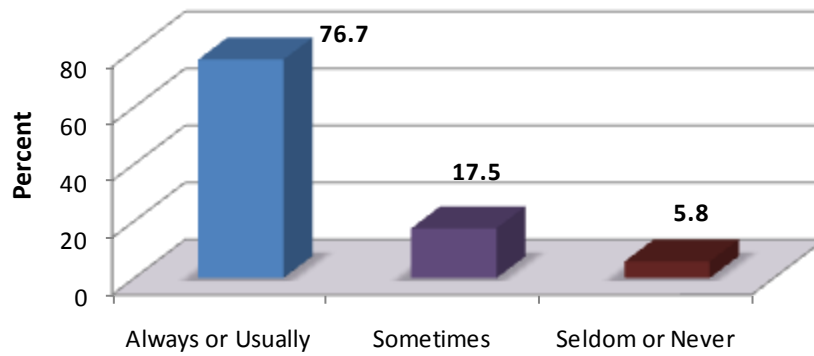
**2007-08 Average for 11 States**

Table Q13					
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
CA-RCOC		89.9	9.1	1.0	208
GA		83.9	14.4	1.7	410
LA		89.0	10.7	0.3	299
ME		89.2	9.5	1.3	473
MO		90.3	9.0	0.7	300
NC		88.5	10.9	0.5	183
NJ		86.4	12.4	1.2	250
PA		90.4	8.4	1.1	806
SC		87.9	11.0	1.1	282
WA		90.7	8.5	0.8	258
WY		88.4	10.7	0.9	224
Total %		88.7	10.2	1.0	3,693
State Avg %		88.6	10.4	1.0	

## Choices and Control

- Among families where the individual with disabilities received residential services, 77% of respondents stated that the agency involved them in important decisions. Another 18% stated that this happens some of the time, and 6% said the agency seldom or never involved them in important decisions.
- Among families where the individual with disabilities received day or employment services, 62% of respondents stated that the agency involves them in important decisions. Another 21% stated that this happens sometimes, and 17% said the agency seldom or never involves them in important decisions.
- On average across states, over two-thirds of respondents (70%) seldom or never chose the support staff who work with their family members.
- Across states, only 11% of respondents said that they had control or input over the hiring and management of their support staff, with an additional 10% indicated they had this type of control sometimes. Eighty percent (80%), however, had little or no input or control over the hiring or management of their family's support staff.
- While only 21% of respondents said they had any amount of control over the hiring or management of their support workers, here 63% of respondents indicate that they want some control over the hiring and management of their support staff.
- Forty percent (40%) of respondents, on average, knew how much money was spent on behalf of their family member. Forty-one percent (41%), however, had no idea. In Wyoming, a far greater percentage of families (83%) knew the amount of money spent.
- On average across states, almost half of the families surveyed (44%) had at least some decision-making authority over how the money allocated to their family member with disabilities by the MR/DD agency was spent. The majority (56%), however, did not.

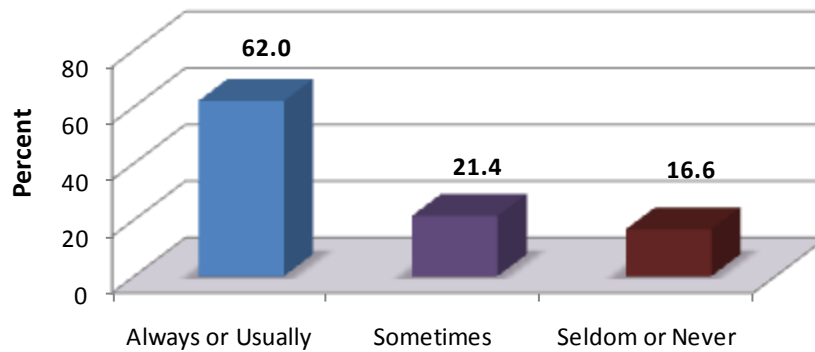
**Chart Q14** Does the agency providing residential services to your family member involve you in important decisions?



**2007-08 Average for 11 States**

<b>Table Q14</b> Does the agency providing residential services to your family member involve you in important decisions? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		71.9	18.6	9.5	231
GA	↓ ↓	64.1	24.6	11.3	468
LA		77.8	14.3	7.9	378
ME	↑ ↑	90.4	8.9	0.7	551
MO		77.4	18.1	4.5	398
NC	↑	86.3	12.3	1.5	204
NJ		71.7	21.7	6.6	286
PA		73.8	19.5	6.7	997
SC		75.3	18.3	6.3	300
WA		73.3	19.6	7.1	393
WY	↑	82.2	16.6	1.2	241
Total %		76.3	17.7	6.0	4,216
State Avg %		76.7	17.5	5.8	

**Chart Q15** If your family member gets day or employment services, does the agency providing these services involve you in important decisions?

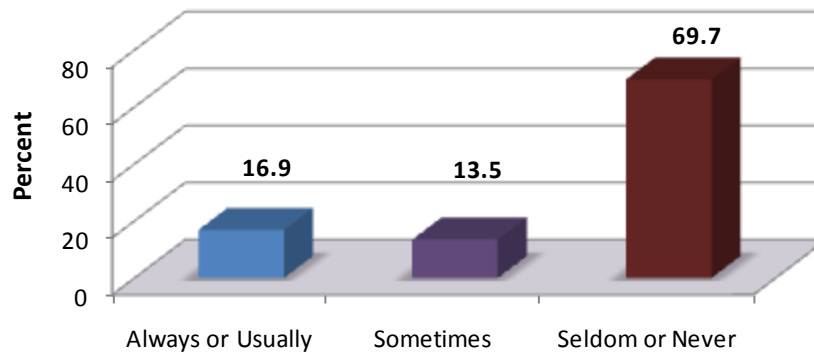


**2007-08 Average for 11 States**

Table Q15					
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
CA-RCOC	↓↓	51.0	22.2	26.8	194
GA	↓	53.0	26.4	20.6	383
LA		64.9	17.5	17.5	268
ME	↑↑	79.6	14.7	5.7	436
MO		60.7	20.0	19.3	270
NC	↑	69.3	19.3	11.3	150
NJ	↓	55.1	23.7	21.2	236
PA		59.7	23.2	17.1	730
SC		57.9	23.9	18.2	247
WA		58.6	23.8	17.6	261
WY	↑↑	72.5	20.8	6.8	207
Total %		62.2	21.5	16.3	3,382
State Avg %		62.0	21.4	16.6	



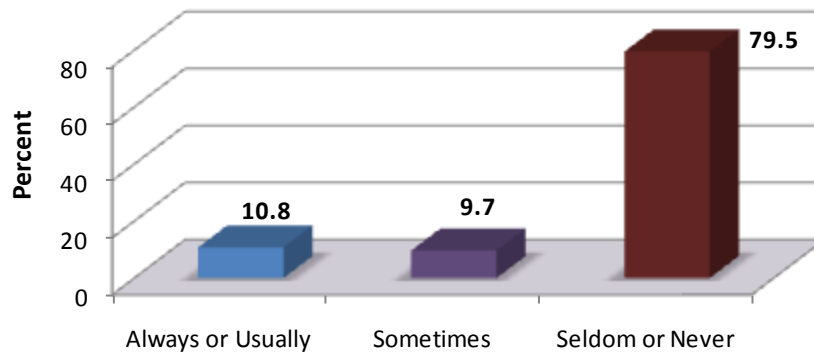
**Chart Q16 Do you or your family member choose the support workers who work with your family member?**



**2007-08 Average for 11 States**

<b>Table Q16</b> <b>Do you or your family member choose the support workers who work with your family member? (%)</b>					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		18.7	14.6	66.7	198
GA		14.6	15.3	70.1	418
LA		20.4	13.5	66.1	289
ME		17.9	18.4	63.6	429
MO	↓	11.4	13.6	75.1	317
NC	↑	22.0	9.8	68.3	164
NJ	↓	9.0	6.8	84.2	221
PA	↓	10.9	11.0	78.2	774
SC		17.4	9.4	73.2	235
WA		16.5	11.0	72.5	255
WY	↑	26.6	24.8	48.6	222
Total %		15.7	13.5	70.8	3,522
State Avg %		16.9	13.5	69.7	

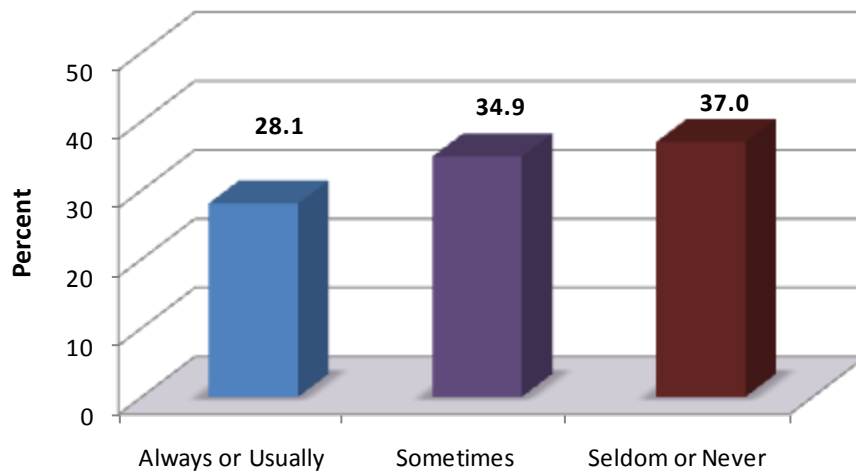
**Chart Q17** Do you or your family member have control and/or input over the hiring and management of your support workers?



**2007-08 Average for 11 States**

Table Q17					
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
CA-RCOC		12.4	7.5	80.1	186
GA	↑	8.5	10.5	81.0	400
LA		20.0	10.0	70.0	280
ME		12.2	15.7	72.2	395
MO		8.7	10.0	81.2	309
NC	↓	13.6	8.0	78.4	162
NJ		2.9	4.8	92.4	210
PA		8.9	5.4	85.7	722
SC		9.6	7.2	83.2	208
WA		10.6	13.0	76.5	293
WY		11.9	14.3	73.8	210
Total %		10.5	9.5	79.9	3,375
State Avg %		10.8	9.7	79.5	

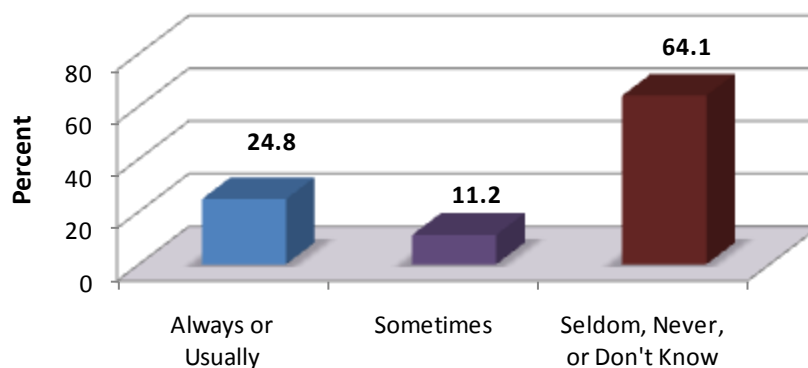
**Chart Q18** Do you or your family member want to have control and/or input over the hiring and management of your support workers?



**2007-08 Average for 11 States**

Table Q18					
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
CA-RCOC		25.9	30.7	43.4	166
GA		32.7	37.8	29.5	376
LA	↑	34.8	33.0	32.2	270
ME		29.6	32.5	37.9	375
MO		30.5	32.5	36.9	295
NC		26.4	29.9	43.8	144
NJ		28.8	38.8	32.4	170
PA		26.3	32.7	41.0	661
SC		26.9	38.0	35.1	208
WA	↓	23.0	37.8	39.2	283
WY		24.2	39.9	35.9	198
Total %		28.3	34.6	37.0	3,146
State Avg %		28.1	34.9	37.0	

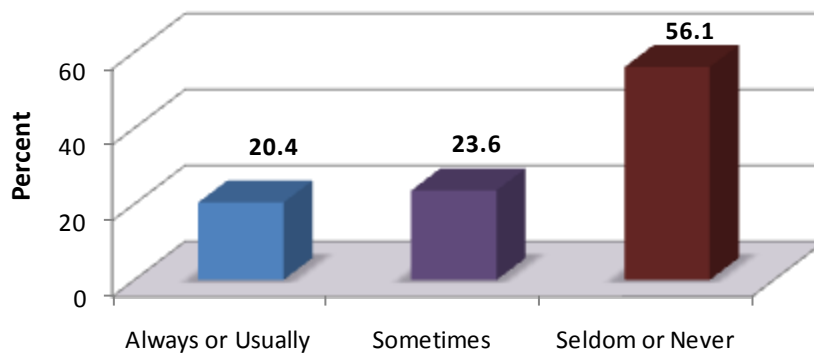
**Chart Q19** Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?



**2007-08 Average for 11 States**

Table Q19					
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
CA-RCOC	↓	19.2	10.7	70.1	234
GA	↓↓↓	12.4	8.9	78.7	474
LA	↓	16.9	6.3	76.8	367
ME		21.7	15.7	62.6	508
MO		22.2	13.4	64.4	374
NC		26.0	7.8	66.2	204
NJ	↓	16.5	12.0	71.5	267
PA	↓	18.7	11.0	70.4	975
SC		20.6	13.3	66.1	286
WA		21.2	12.6	66.2	405
WY	↑↑↑	76.9	11.2	12.0	242
Total %		22.3	11.3	66.3	4,336
State Avg %		24.8	11.2	64.1	

**Chart Q20** Do you or your family member get to decide how this money is spent?



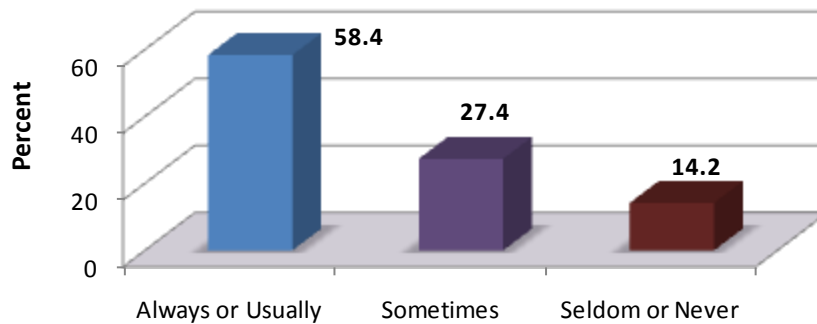
**2007-08 Average for 11 States**

Table Q20					
Do you or your family member get to decide how this money is spent? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	15.4	26.6	58.0	169
GA	↓	12.7	16.0	71.3	394
LA		16.5	19.4	64.0	278
ME	↑	29.7	27.3	43.0	370
MO	↓	13.0	22.2	64.8	315
NC		20.7	24.3	55.0	169
NJ	↓	12.3	26.5	61.1	211
PA		17.6	22.2	60.2	733
SC		17.3	26.4	56.4	220
WA		19.0	19.4	61.6	294
WY	↑↑	50.0	28.8	21.2	212
Total %		19.7	22.9	57.4	3,365
State Avg %		20.4	23.6	56.1	

## Community Connections

- Fifty-eight percent (58%) of respondents remarked that staff were usually able to help them connect with typical supports in their community (e.g., recreation programs, church activities) if they desired to do so. Twenty-seven percent (27%) indicated that staff could sometimes help in this way, while 14% stated that staff rarely or never provided this type of assistance.
- Of families interested in using family or friends to provide some of the supports needed, 60% stated that planning or support staff were helpful in making this happen. The remaining 40% indicated that staff were only sometimes, seldom, or never capable of helping families utilize friends, neighbors, etc. as supports.
- Almost two-thirds (62%) of respondents felt that their family member typically had access to community activities.
- While 62% of families felt their family member had regular access to community activities, only 40% stated that their family member usually participated in these activities, although another 42% indicated that their family member sometimes took part in community events/activities.

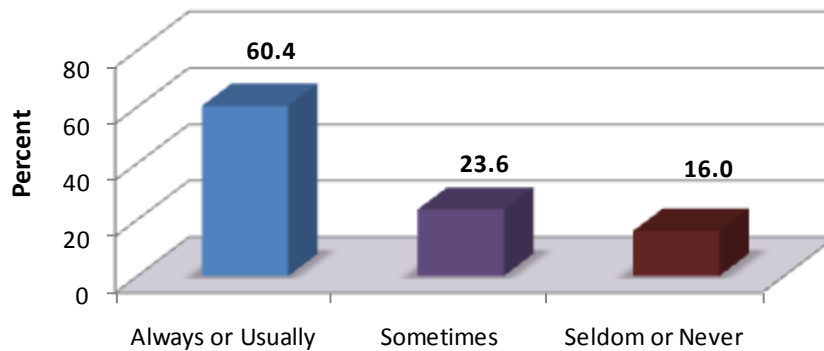
**Chart Q21** If your family member wants to use typical supports in your community, do the staff who help you plan or who provide support help connect you to these supports?



**2007-08 Average for 11 States**

<b>Table Q21</b> If your family member wants to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓↓	47.2	30.9	22.0	123
GA	↓↓	45.7	30.4	23.9	352
LA		56.9	25.4	17.7	248
ME	↑↑	78.6	17.6	3.7	459
MO		62.7	26.1	11.2	303
NC	↑↑	69.6	23.2	7.2	138
NJ	↓	48.7	33.5	17.8	191
PA		62.7	25.9	11.3	663
SC		59.4	29.2	11.3	212
WA		54.5	29.5	16.0	288
WY		56.4	29.9	13.7	204
Total %		60.2	26.5	13.3	3,181
State Avg %		58.4	27.4	14.2	

**Chart Q22** If your family member would like to use family, friends, or neighbors to provide , do staff who help you plan or who provide support help him/her do this?

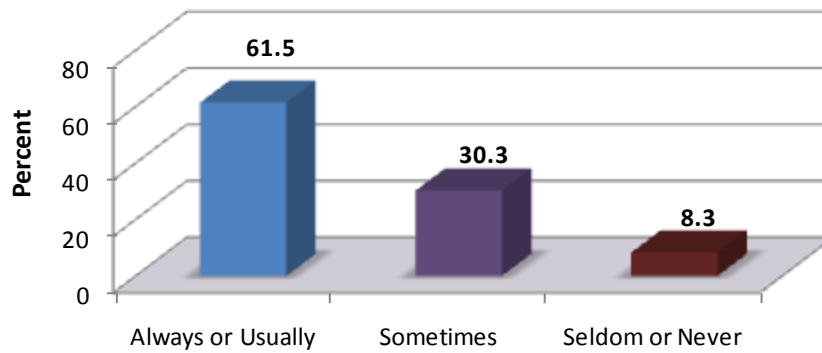


**2007-08 Average for 11 States**

<b>Table Q22</b> If your family member would like to use family, friends, or neighbors to provide some of the supports he/she needs, do either the staff who help you plan or who provide support help him/her do this? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
<b>CA-RCOC</b>	↓↓↓	48.0	23.5	28.6	98
<b>GA</b>	↓↓↓	49.1	28.6	22.3	318
<b>LA</b>		63.9	23.5	12.6	230
<b>ME</b>	↑↑↑	80.4	15.0	4.7	428
<b>MO</b>		60.4	22.3	17.3	260
<b>NC</b>	↑	68.0	21.1	10.9	128
<b>NJ</b>		56.6	26.6	16.8	173
<b>PA</b>	↑	65.6	22.3	12.1	587
<b>SC</b>		59.1	26.4	14.4	208
<b>WA</b>	↓	54.2	24.7	21.1	251
<b>WY</b>		59.2	25.3	15.5	174
<b>Total %</b>		<b>62.5</b>	<b>22.9</b>	<b>14.6</b>	<b>2,855</b>
<b>State Avg %</b>		<b>60.4</b>	<b>23.6</b>	<b>16.0</b>	



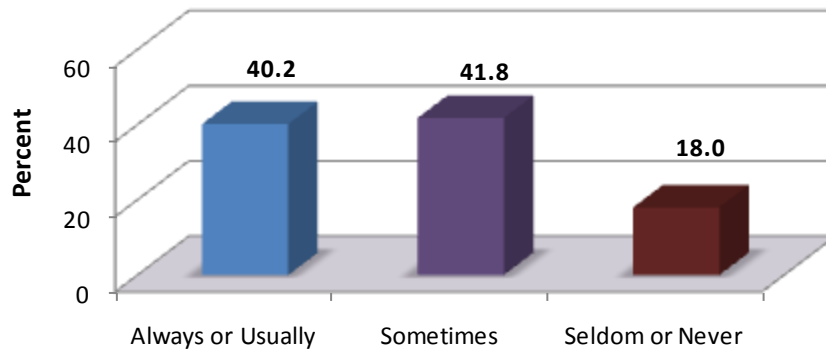
**Chart Q23** Do you feel that your family member has access to community activities?



**2007-08 Average for 11 States**

Table Q23 Do you feel that your family member has access to community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓↓	50.5	36.2	13.3	196
GA	↓↓	48.9	37.5	13.6	448
LA		60.5	28.7	10.8	342
ME	↑↑	80.0	18.0	2.0	549
MO		66.3	27.6	6.1	359
NC	↑	69.4	25.4	5.2	193
NJ	↓	53.4	35.9	10.7	234
PA		65.2	28.0	6.8	923
SC		56.7	35.2	8.0	261
WA		59.2	31.6	9.1	373
WY		65.9	28.9	5.2	232
Total %		62.9	29.3	7.8	4,110
State Avg %		61.5	30.3	8.3	

**Chart Q24** Does your family member participate in community activities?



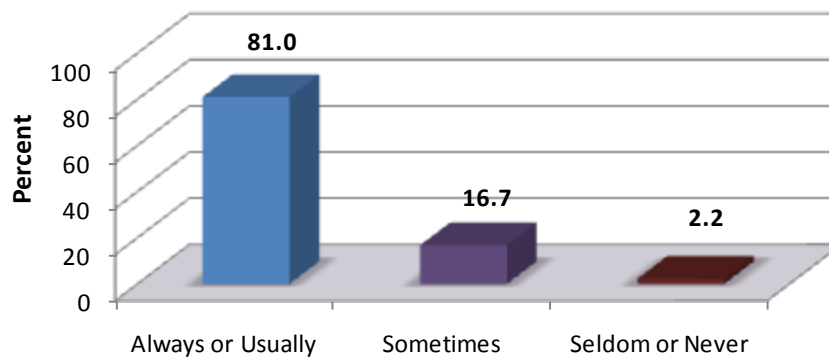
**2007-08 Average for 11 States**

Table Q24 Does your family member participate in community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC	↓	33.5	37.6	28.9	197
GA	↓	34.3	43.2	22.5	431
LA		39.4	41.2	19.4	340
ME	↑↑	56.9	33.5	9.7	517
MO		42.6	41.8	15.6	340
NC	↑	46.0	44.4	9.6	187
NJ	↓↓	29.0	48.1	22.9	231
PA		42.9	40.2	16.9	881
SC		40.3	39.9	19.8	248
WA	↓	35.2	44.0	20.9	364
WY		41.8	46.1	12.1	232
Total %		41.4	41.1	17.5	3,968
State Avg %		40.2	41.8	18.0	

## Outcomes and Satisfaction with Services and Supports

- On average, most respondents (81%) were satisfied with the services and supports their family member received. Seventeen percent (17%) were only somewhat satisfied, and 2% were seldom or not satisfied.
- On average, 75% of respondents knew about their agency's grievance process, 12% knew something about it, and 14% had no knowledge of the process for lodging a complaint.
- The majority of respondents (69%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 32%, however, were either not satisfied, or satisfied only some of the time with how these matters were resolved.
- The majority of respondents (84%) felt that services and supports had a positive impact on their family's life. Fourteen percent (14%) stated that services sometime made a positive difference, and the remaining 2% indicated that supports seldom or never had a positive impact.
- Eighty percent (80%) of respondents felt that their family member was happy. Two percent (2%) indicated that their family member was seldom or never happy.

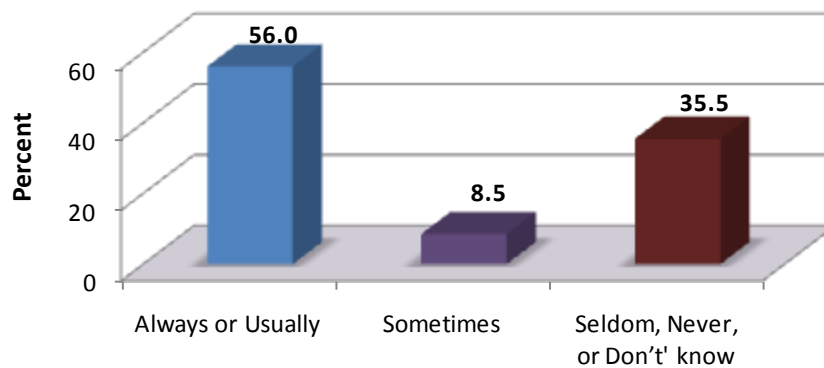
**Chart Q25** Overall, are you satisfied with the services and supports your family member currently receives?



**2007-08 Average for 11 States**

<b>Table Q25</b> Overall, are you satisfied with the services and supports your family member currently receives? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		84.0	14.7	1.3	238
GA	↓	73.6	22.9	3.4	497
LA		79.3	16.9	3.8	396
ME	↑↑	91.6	7.7	0.7	571
MO		81.4	16.8	1.8	392
NC		82.2	16.4	1.4	213
NJ	↓	76.0	20.5	3.5	283
PA		83.1	15.5	1.4	1054
SC		80.5	16.2	3.3	303
WA		79.4	18.2	2.3	428
WY		80.0	18.4	1.6	245
Total %		81.6	16.3	2.1	4,620
State Avg %		81.0	16.7	2.2	

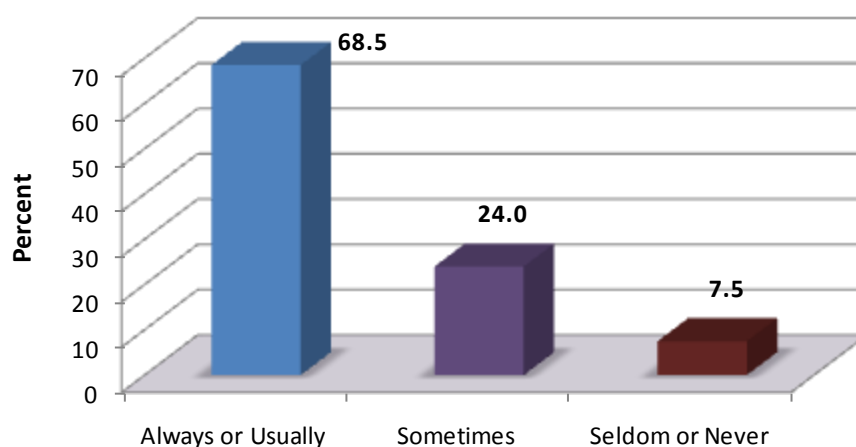
**Chart Q26** Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?



**2007-08 Average for 11 States**

<b>Table Q26</b> <b>Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them? (%)</b>					
State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	N
CA-RCOC		56.8	12.7	30.5	213
GA	↓↓	38.9	10.1	50.9	475
LA		56.8	8.0	35.3	377
ME	↑↑	73.2	6.7	20.1	538
MO		57.4	7.0	35.6	371
NC	↑↑	67.7	6.1	26.3	198
NJ	↓↓	43.4	8.9	47.7	258
PA		51.8	8.3	39.9	967
SC	↓	48.2	8.3	43.5	278
WA		50.1	8.7	41.1	389
WY	↑↑	71.7	8.4	19.8	237
Total %		55.2	8.3	36.5	4,301
State Avg %		56.0	8.5	35.5	

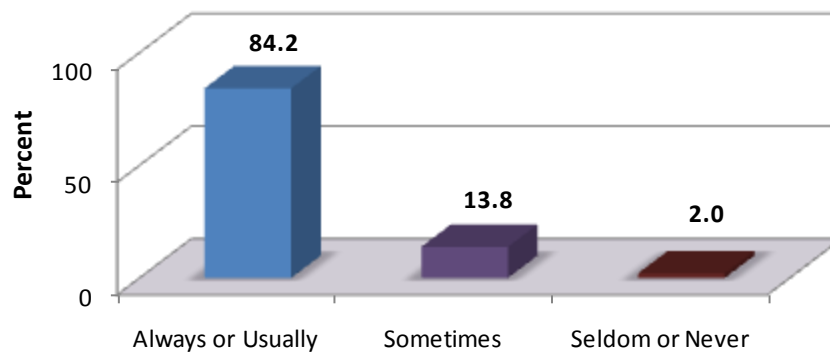
**Chart Q27** Are you satisfied with the way complaints/grievances are handled and resolved?



**2007-08 Average for 11 States**

Table Q27 Are you satisfied with the way complaints/grievances are handled and resolved? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		70.2	25.4	4.4	114
GA	↓	58.6	27.3	14.1	297
LA		70.8	18.8	10.5	277
ME	↑↑	79.6	16.8	3.5	398
MO		63.9	28.7	7.4	244
NC	↑	74.5	21.5	4.0	149
NJ	↓	59.6	30.7	9.6	166
PA		70.6	23.5	5.9	656
SC		68.3	23.6	8.2	208
WA		67.6	24.8	7.6	210
WY		69.3	23.3	7.4	176
Total %		69.2	23.4	7.4	2,895
State Avg %		68.5	24.0	7.5	

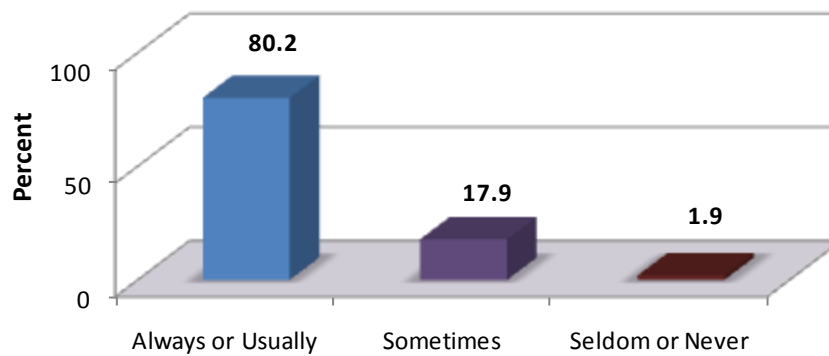
**Chart Q28** Do you feel that services and supports have made a positive difference in the life of your family?



**2007-08 Average for 11 States**

Table Q28 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
CA-RCOC		88.2	10.1	1.8	228
GA	↓	78.5	17.8	3.7	483
LA		82.9	15.3	1.8	380
ME	↑	90.3	9.0	0.7	566
MO		82.3	15.7	2.1	389
NC		87.2	11.4	1.4	211
NJ	↓	78.5	17.9	3.6	274
PA		82.4	15.8	1.8	1019
SC		85.9	11.8	2.3	306
WA		83.4	15.4	1.2	410
WY		86.8	11.6	1.7	242
Total %		83.9	14.2	2.0	4,508
State Avg %		84.2	13.8	2.0	

**Chart Q29** Overall, do you feel that your family member is happy?



**2007-08 Average for 11 States**

Table Q29					
Overall, do you feel that your family member is happy? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
CA-RCOC		83.6	15.1	1.3	238
GA	↓	74.2	23.5	2.2	489
LA		80.4	17.8	1.8	387
ME	↑↑	90.3	8.3	1.4	568
MO		77.5	19.9	2.5	396
NC		80.8	17.8	1.4	214
NJ		76.7	20.5	2.8	283
PA		79.6	18.6	1.8	1052
SC		81.2	16.9	1.9	308
WA		78.4	19.8	1.9	425
WY		79.3	18.7	2.1	241
Total %		80.3	17.8	1.9	4,601
State Avg %		80.2	17.9	1.9	



## Aggregate Results & State Comparisons

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

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

For each category, there is also a TABLE that looks at the arrows (i.e.,  $\uparrow$  and  $\downarrow$ ) of the 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 Maine, North Carolina, and Wyoming, responses to information and planning questions were generally above the overall state average. In Georgia and New Jersey, overall results were generally below the state average.

**Chart 5: Information & Planning (N= 11)**

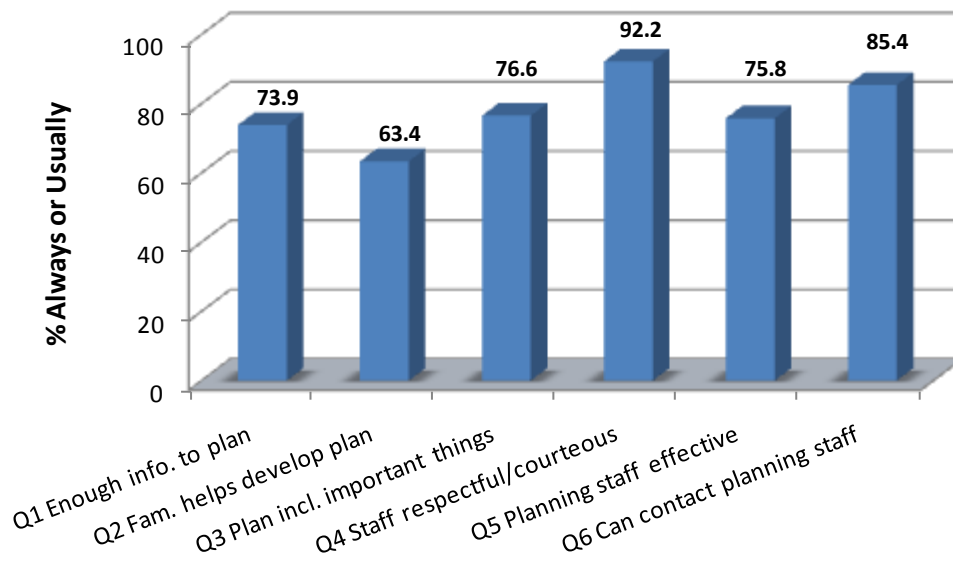
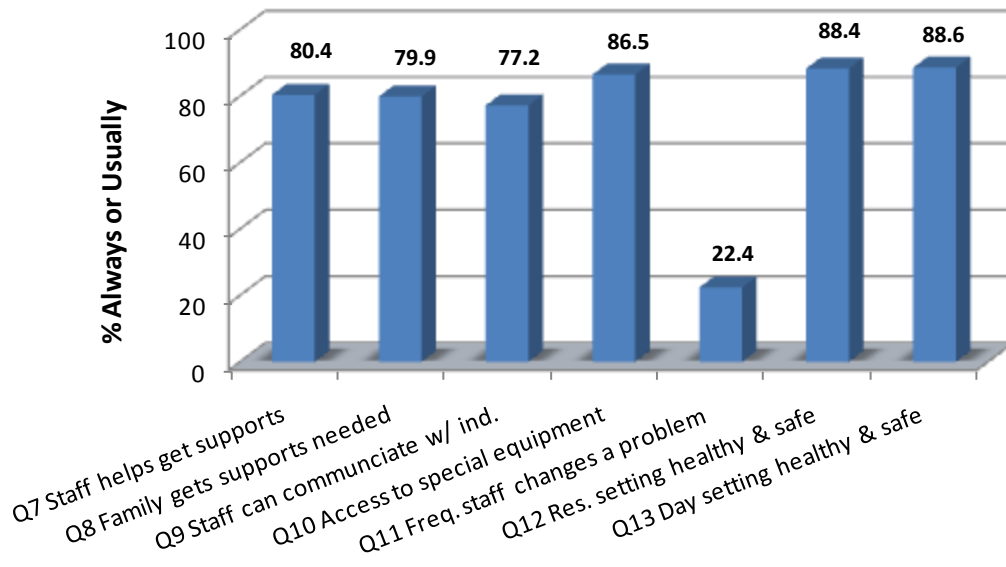


Table 16 Deviation in Responses Above & Below State Average: Information & Planning							
State	Q1	Q2	Q3	Q4	Q5	Q6	Net Sum
CA-RCOC							0
GA	↓↓	↓↓	↓↓	↓	↓↓	↓	-10
LA		↓					1
ME	↑↑	↑↑	↑↑		↑↑	↑	9
MO							0
NC	↑	↑↑	↑		↑		5
NJ	↓↓	↓	↓				-4
PA		↓↓					-2
SC							0
WA							0
WY	↑	↑↑	↑↑			↑	6

## Access and Delivery of Services

- ♦ In this series of questions, responses were generally consistent across states. However, Georgia and New Jersey tended to score somewhat lower than the state average.

**Chart 6: Access to Services (N= 11)**

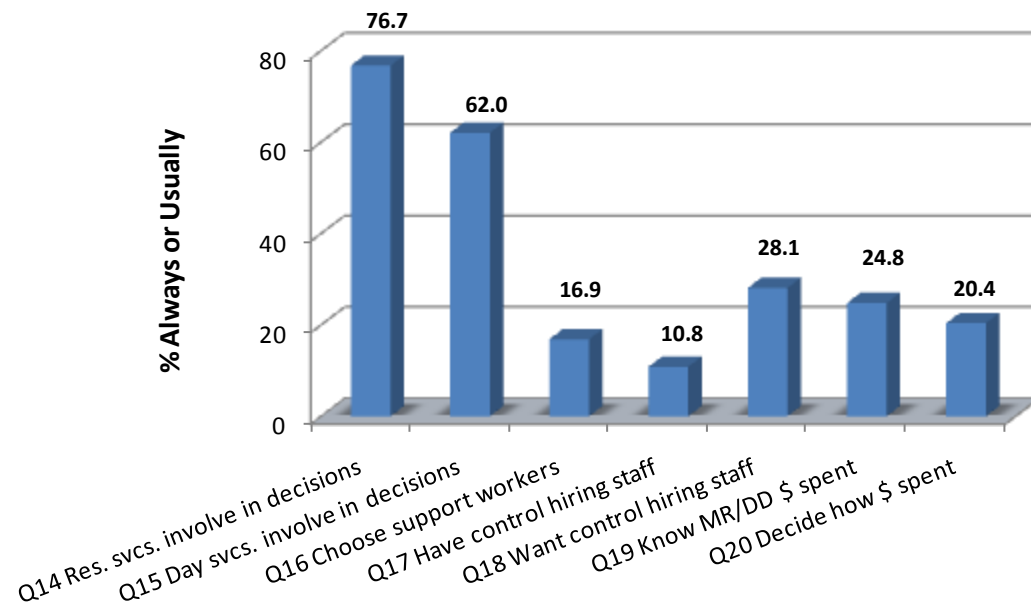


<b>Table 17</b> <b>Deviation in Responses Above &amp; Below State Average</b> <b>Access to Services &amp; Supports</b>								
State	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
CA-RCOC			↓↓	↓	↓	↑		-3
GA	↓↓	↓	↓	↓↓				-6
LA			↑					1
ME		↑	↑		↓			1
MO			↑					1
NC					↑↑			2
NJ	↓	↓↓	↓	↓				-5
PA		↑	↑					2
SC			↑					1
WA			↓					-1
WY	↑			↑				2

## Choice and Control

- ♦ In Wyoming, Maine, and North Carolina, responses to choice and control questions were generally above the overall state average. In Georgia and New Jersey, results were generally below the state average.

**Chart 7: Choice & Control (N= 11)**



**Table 18**  
Deviation in Responses Above & Below State Average  
Choice & Control

State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Net Sum
CA-RCOC		↓↓				↓	↓	-4
GA	↓↓	↓				↓↓	↓	-6
LA				↑	↑	↓		1
ME	↑↑	↑↑					↑	5
MO			↓				↓	-2
NC	↑	↑	↑					3
NJ		↓	↓	↓		↓	↓	-5
PA			↓			↓		-2
SC								0
WA					↓			-1
WY	↑	↑↑	↑			↑↑	↑↑	8

## Community Connections

- ♦ In Maine and North Carolina, responses to community connections questions were above the overall state average. In Georgia and Orange County, results were below the state average.

**Chart 8: Community Connections (N= 11)**

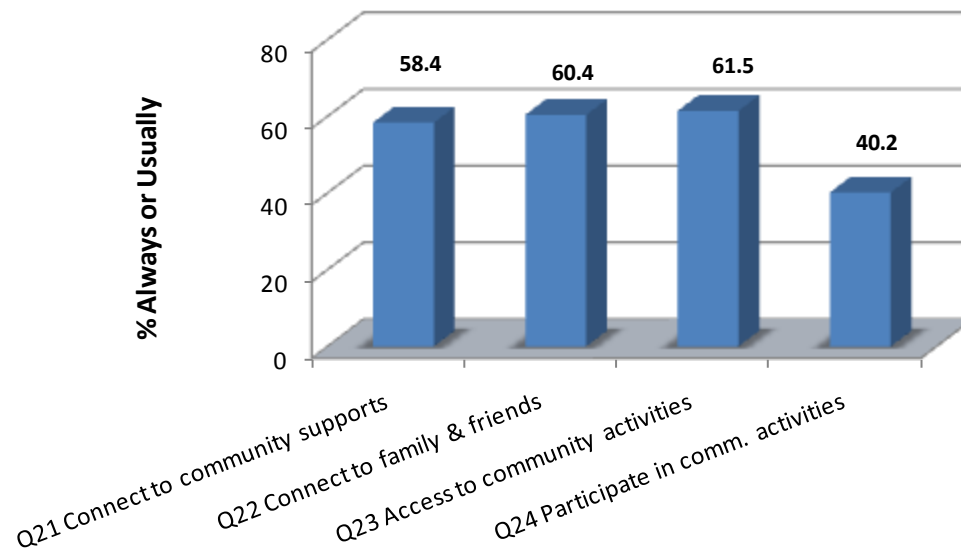


Table 19 Deviation in Responses Above & Below State Average Community Connections					
State	Q21	Q22	Q23	Q24	Net Sum
CA-RCOC	↓↓↓	↓↓↓	↓↓↓	↓	-7
GA	↓↓↓	↓↓↓	↓↓↓	↓	-7
LA					0
ME	↑↑↑	↑↑↑	↑↑↑	↑↑↑	8
MO					0
NC	↑↑↑	↑	↑	↑	5
NJ	↓		↓	↓↓↓	-4
PA		↑			1
SC					0
WA		↓		↓	-2
WY					0

## Satisfactions with Services and Supports & Outcomes for Families

- ♦ In Maine and North Carolina, responses to satisfaction with services and outcomes for families questions were generally above the overall state average. In Georgia and New Jersey, results were generally below the state average.

**Chart 9: Satisfaction (N= 11)**

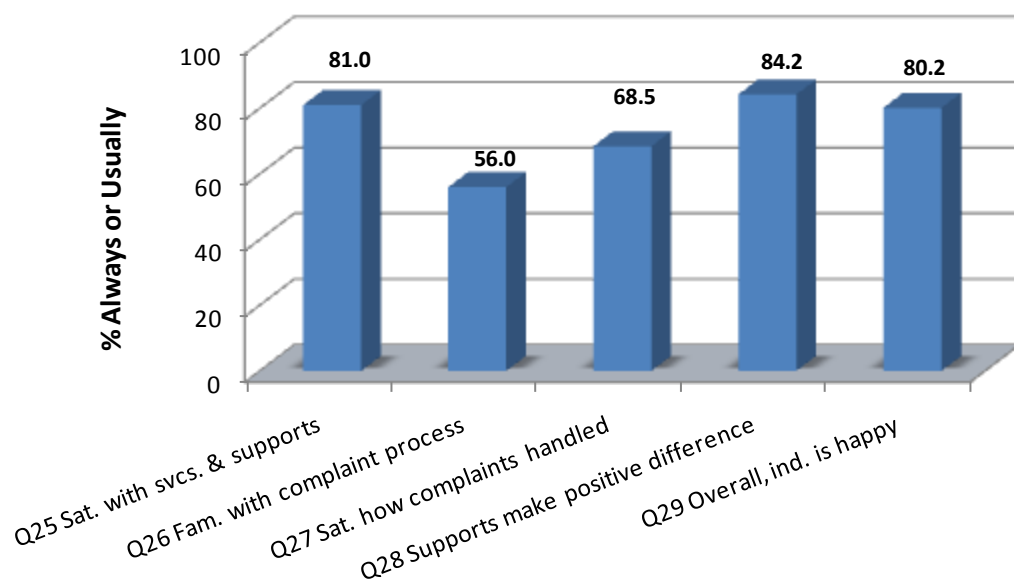


Table 20 Deviation in Responses Above & Below State Average Satisfaction & Outcomes						
State	Q25	Q26	Q27	Q28	Q29	Net Sum
CA-RCOC						0
GA	↓	↓↓	↓	↓	↓	-6
LA						0
ME	↑↑	↑↑	↑↑	↑	↑↑	9
MO						0
NC		↑↑	↑			3
NJ	↓	↓↓	↓	↓		-5
PA						0
SC		↓				-1
WA						0
WY		↑↑				2

## Overall State Results

- ♦ Looking at results across all categories, Maine, North Carolina, and Wyoming consistently received results that were above the overall state average. In Georgia, New Jersey, and Orange County, results were generally below the overall state average.

<b>Table 21</b> <b>Aggregate Deviation in Responses</b> <b>Above &amp; Below State Average</b>						
<b>State</b>	<b>Information &amp; Planning</b>	<b>Access &amp; Delivery</b>	<b>Choice &amp; Control</b>	<b>Community Connections</b>	<b>Satisfaction &amp; Outcomes</b>	<b>Total Sum</b>
<b>CA-RCOC</b>	0	-3	-4	-7	0	<b>-14</b>
<b>GA</b>	-10	-6	-6	-7	-6	<b>-35</b>
<b>LA</b>	1	1	1	0	0	<b>3</b>
<b>ME</b>	9	1	5	8	9	<b>32</b>
<b>MO</b>	0	1	-2	0	0	<b>-1</b>
<b>NC</b>	5	2	3	5	3	<b>18</b>
<b>NJ</b>	-4	-5	-5	-4	-5	<b>-23</b>
<b>PA</b>	-2	2	-2	1	0	<b>-1</b>
<b>SC</b>	0	1	0	0	-1	<b>0</b>
<b>WA</b>	0	-1	-1	-2	0	<b>-4</b>
<b>WY</b>	6	2	8	0	2	<b>18</b>

# **APPENDIX A**

## Analysis of Open-Ended Comments



## Additional Open-Ended Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record open-ended 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

## GEORGIA

Georgia had more than three times more comments indicating general satisfaction with services and supports than comments indicating general dissatisfaction.

More specifically, families reported most often on their Satisfaction with Home. Many report that the group home or host home provides excellent care. These families have peace of mind, as expressed in this comment:

The home that my son is in is wonderful. The staff is very loving and my son's care is great. However, it took me months to find this great place. Some that I looked at were very sub-standard and I would not have ever put my son in them.

There were also many comments from families who were satisfied with staff members. Here is a representative example:

My son's aid that helps him with things is wonderful. We think a lot of him, and hope we can have him forever. My son's gets really upset if they send anyone else to take care of him. Thank you.

Although families were satisfied with staff members, many also expressed the hardships resulting from Staff Turnover. For a number of families, their principal concern is that Turnover is too high for assuring continuity of care – even when the staff is perceived as doing a good job. One comment noted that in one year, five home managers turned over. Families may not be notified of the changes, which exacerbate challenges when their family member has health problems, as with this family guardian's experience:

Most people at the (Provider) try to do their job. The turnover rate makes continuity of care impossible. My son has several health problems that have not been addressed, though we have pointed out to the staff repeatedly.

## MISSOURI

There were very many more comments (50) indicating general satisfaction with services and supports by Missouri families than comments stating dissatisfaction.

Satisfaction with Home in Missouri, as with most of the family guardian surveys this year across the states, was the area most often commented upon. This satisfaction includes those whose family members have more recent residential placements to those who have been residing in a supported home for over 30 years. With long term residential supports the concept of aging in place arises. This comment illustrates the experiences of one family/guardian who is favorably impressed with a provider's changing level of support as their family member ages:

My sister's group home has made many changes over the past 19 years to accommodate my sister. She is practically bedridden now and they are helping to do everything to keep her at home.

Another frequent comment area was Staff Turnover. Families/guardians are appreciative when there is a good fit between staff and their family members. However, their experience is that turnover is an entrenched chronic problem that is hard on the individual supported and that negatively impacts the quality of care:

There is too much staff change and not enough communication with them. The IHP plans are not always carried out, such as recreation and healthy meals. People are hired before we give the permission.

However, many families also indicated that they were satisfied with the staff members who were working with their family members.

The care and concern for my family member by staff exceeds my expectations. He is clean, safe and well fed. The care has always met all of his needs and comfort.

## **NORTH CAROLINA**

North Carolina families had more than 10 times the comments indicating general satisfaction with services and supports than those who stated general dissatisfaction.

The top comment area in North Carolina this year mirrored those in other states – Satisfaction with Home. Comments related to Satisfaction with Home note the family's gratitude and peace of mind when their family member has this type of support:

I am very pleased with the difference the (Provider) has made in (Name's) life. She is very happy there. I know she is well taken care of, and I don't have to worry about her getting proper care. I am very thankful that (Name) is where she is.

The second most frequently commented upon area in North Carolina is Satisfaction with Staff. Many families expressed gratitude for the good care their family members receive and the wish that they could reward the staff:

I only wish I could reward all of the staff as they deserve and I am very thankful my sister will be well taken care of as I age and can do less and less for her!

Families in North Carolina also had some negative things to say, specifically referring to Day/Employment Programs. The families were frustrated with the overall situation, not just the particular program:

He does pretty much the same things every week. He needs a job and more to do. Staff has taken him to look for jobs but no luck. We couldn't even find volunteer work. I don't want to give up. A lot of companies will not hire him. It may have to do with his disability. He refuses to go to V.R.

## **NEW JERSEY**

The majority of New Jersey's "general" comments indicated that families were satisfied with services and supports; at a more than three to one ratio than comments expressing general dissatisfaction.

Families in New Jersey also provided feedback most often in the categories of Satisfaction with Home. As with other states, Satisfaction with Home comments tell stories of how happy individuals are in their homes and the peace of mind this affords families/guardians:

My daughter has been in her present location for approximately three years. I am amazed at the confidence she displays. She loves her staff and her program. I,

as both parent and guardian, visit the facility frequently and have always seen a positive and caring atmosphere. Holidays and special days are always made special. I sleep at night knowing my loved one is well cared for and also treated with dignity and respect.

After satisfaction with home were comments related to Satisfaction with Staff. Some families took the opportunity to praise the staff:

The entire staff at (Provider) Group Home is amazing. The staff is loyal, generous, kind, patient and giving. My aunt is so lucky to be in that home. Special kudos to the manager (Name) + Assistant (Name). They are both gems – and certainly assets to the home and community. They and all the staff make it a very warm, happy, safe, and secure place for my aunt to live her life. We couldn't ask more for her. I hope you acknowledge their contributions to (Provider) and its residents!

Following satisfaction with staff are comments noting Dissatisfaction with Communication. New Jersey is unique in that this area did not rise to the top three comment areas in any of the other participating NCI states. Families/guardians note problems with communication along many fronts -- from calls to case managers that are not returned, to never having been advised what budget an individual has available for services, to being invited to participate in development of a service plan. This comment expresses the fundamental frustration:

How do I find out how to get them to keep me more informed?

## **PENNSYLVANIA**

Pennsylvania families tended to express much more general satisfaction towards services and supports than dissatisfaction. There was more than a nine to one ratio of positive to negative comments.

Concerning the more specific comments, Satisfaction with Home far and away topped the comments from families/guardians in this state. The ratio between comments reporting satisfaction with home and those reporting dissatisfaction were 7 to 1. Typical is this comment:

I am very happy with my son's care at his residence. The staff there is professional, get very affectionate and considerate of (Name) and his feelings, personality, and his needs. He is very happy in this setting, as well as safe...

The next most commented upon area in Pennsylvania was Satisfaction with Staff. Many families/guardians understand that their family member may be challenging to support and appreciate the efforts of staff to provide good care and to communicate regularly with them. In some cases, guardians expressed amazement at the positive changes observed, such as this guardian's comment:

(Provider) workers are so good and communication is excellent with my brother and myself. My brother (Name) has become an "adult" since he has been at (address) the past two years... More polite, caring, mature, giving and expressing love. I am amazed!

In spite of, or maybe because of, the many positive comments families had about staff members, there were also many comments from families stating their concern regarding staff turnover:

For the most part, my family and I are satisfied with our sister's care in her group home. However, as is the case in almost every area of social services, there seems to always be a high turnover in staff. Caregivers are overworked and underpaid...

## **REGIONAL CENTER- ORANGE COUNTY**

There were far more comments (32) indicating general satisfaction with services and supports than those comments which stated general dissatisfaction (only 1).

Families/guardians receiving services through the Regional Center commented most often on their Satisfaction with Home services. A number of these comments relay that prior placements were not satisfactory but the current one is. Below is one such comment:

I believe RCOC had my brother in the wrong place for over 12 years. This situation was unsatisfactory! Thanks to his new coordinator (Name), he is now in the proper and safe place. His new home in (City) is a 100% improvement...

In second place were comments expressing Satisfaction with Service Coordination. As was evidenced from the comment above where the service coordinator made the difference in an appropriate home placement, these guardians too believe the right service coordinator makes all the difference:

(Name) is priceless! She makes sure all of her clients are well taken care of and raised/live in a family atmosphere. I'm truly blessed to have her involved in my son's care.

The category with the third most comments from Orange County families was General Well Being- Social. Families indicated that they want their family members to have more social interaction. Here is a representative example:

I feel social recreation for clients would be a benefit for all involved. Interaction with different people and situation would allow for a better rounded experience for client.

## **SOUTH CAROLINA**

Concerning general comments, families were more satisfied than dissatisfied with services and supports by a 15 to one ratio.

Fewer comments were received from South Carolina than most of the other participating states. Families/guardians that did comment most often noted their Satisfaction with Staff. These respondents perceived staff to be caring and competent and were most appreciative:

My daughter is very well cared for and I thank the people who do care for her.

Tied for the next most frequent comments in South Carolina are three categories where guardians believe services to be under par: Dissatisfaction with Home, Dissatisfaction with

Staff, and Staff Turnover. Guardians Dissatisfied with Home services noted a variety of issues including poor matching with other housemates, and using toxic materials in a home renovation. A couple of the comments made reference to placements very distant from the guardian. This is one such comment:

Daughter was placed in a group home. We feel we were mistreated. Rather than our local DDSN helping to locate her closer to home, we had no choice but to accept the group home 200 miles away.

Dissatisfaction with Staff comments note caregivers that have poor attitudes while at work and those that display little emphasis on the quality of their work. This comment represents those guardians noting the poor attitudes:

The majority of staff members at (Provider) are uncaring, rude and incompetent.

Comments pertaining to Staff Turnover all remark on the turnover as constant with no end in sight as this comment depicts:

Constant turnover in some areas is not good for the house or the consumer. Just how long does it take to see the light?

## **WASHINGTON**

Washington families wrote more comments stating general satisfaction with services and supports than comments stating general dissatisfaction at more than a 15 to one ratio.

Families most specific comments focused on Satisfaction with Home services. Families/guardians in Washington report that their family members are happy where they live, and are living full and satisfying lives. This comment typifies others in this area:

I feel the (Provider) Home Program is a godsend for my son (Name). Part of being Autistic is the tendency to not deal well with change. How perfect is the same provider and same home, morning, noon and night?

Being satisfied with staff members was also a topic widely discussed:

(Name) has always received good quality care and the staff members are great at calling to let us know when a problem arises. They are very patient with her and we try to work together to solve any problem that arises

Another area frequently commented upon is the Need for Information. Uppermost in these comments were those regarding the Case Managers and the infrequency of contact. Several guardians noted that they had no contact information for the current Case Manager and had never been contacted. The following comment exemplifies several of the comments in this category:

I have only spoken to her State case manager once, I believe, over the years she's been in place, and never to her predecessor...

## **WYOMING**

Wyoming families wrote more comments stating general satisfaction with services and supports than comments stating general dissatisfaction at more than a 12 to one ratio.

Family guardians in Wyoming commented most often about their Satisfaction with Home Services. Their comments reflect trust and comfort with service providers and the typical lives their family members are living. This comment is representative:

My son is a resident of (Provider) services in (City). My daughter (co-guardian) and I consider this an exemplary program and we are very satisfied with all aspects of it. My son is very happy there and is always willing to return to “his home” after visiting either of us.

The next most commented upon area is Staff Turnover. With respect to Staff Turnover, families/guardians in Wyoming, like those across all the participating states, are dismayed at the high rate of turnover and the impact this has on their family members. This comment well articulates the relationship between staff turnover and individuals’ quality of life:

Our daughter has had two mental health hospitalizations since August and we are likely facing a third. There has been so many changes in staff. It’s hard to know who will answer the phone when you call. Lots of inconsistencies across her day with staff changes. It’s definitely affecting her behaviorally and emotionally.

The category with the third most comments is Dissatisfied with Staff. The following comment captures several areas of concern:

Inconsistency of staff is always an issue and large turnover of staff continues to be an unstable influence on our daughter. Most recently shortness of staff has become a large issue. They saw no one even is applying. Don’t pay enough for such a demanding job!