

# Family Guardian Survey

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Final Report – February 2005  
2003-2004 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

Nine states and one local developmental disability authority conducted the National Core Indicators (NCI) Family Guardian Survey during the 2003-2004 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 September 2004.

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** – Phase I of CIP Phase 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 agreed to conduct a field test of these indicators, including administering the project's consumer and family surveys and compiling other data. Field test data were transmitted to project staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

**1999 - 2000** – Phase II of CIP was launched in 1999, with a deadline for collection of 1999 data set in June 2000. During Phase II, 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 (Arizona, Connecticut, Kentucky, Massachusetts, Minnesota, Nebraska, North Carolina, Pennsylvania, Rhode Island, Virginia, Vermont, Washington) participated in Phase II, and this data is considered baseline project data. .

**2000 - 2001 (Phase III)** – In the spring and summer of 2001, data from the year 2000 was collected. Moving forward, four additional states joined the project (Delaware, Iowa, Montana, Utah) and the project expanded its scope to include services for children with developmental disabilities and their families. Also during this time, the CIP staff and participants continued to develop and refine the indicators, and recruit additional states to participate in the project.

**2001 - 2002 (Phase IV)** – The Core Indicators Project (CIP) officially changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. Participation in the National Core Indicators is entirely voluntary. For this year's round of data collection, seven new states and one local DD authority joined NCI (Alabama, Orange County in California, Hawaii, Illinois, Indiana, Oklahoma, West Virginia, Wyoming). During 2001-2002, 20 states and one local authority were active in NCI.

**2002 – 2003 (Phase V)** - Maine, South Carolina and South Dakota joined the National Core Indicators effort.

**2003 – 2004 (Phase VI)** – Project participation continues to grow. During this past year, North Dakota and the District of Columbia have joined the National Core Indicators effort, raising participation to 21 states, one local DD authority, and the District of Columbia.

The figure on the following page summarizes state participation in the National Core Indicators since its inception through the 2003-2004 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
AZ	AZ	AZ	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ
MO	KY	DE	CA - RCOC	CA - RCOC	CA - RCOC
NE	MA	IA	CT	CT	CT
PA	MN	KY	DE	DE	DE
VT	NE	MA	HI	HI	DC
VA	NC	MN	IL	IN	HI
	PA	MT	IN	IA	IN
	RI	NE	IA	KY	KY
	VT	NC	KY	MA	MA
	VA	PA	MA	ME	ME
	WA	RI	NE	NE	NE
		UT	NC	NC	NC
		VT	OK	OK	ND
		WA	PA	PA	OK
			RI	RI	PA
			UT	SC	RI
			VT	SD	SC
			WA	VT	SD
			WV	WA	VT
			WY	WV	WA
				WY	WV
					WY

Denotes first year of participation in NCI.

## Family Indicators

Obtaining direct feedback from families is an important means for states to gauge satisfaction with services and supports as well as to pinpoint potential areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to gauge changes in performance over time. In addition, these results permit a state to compare its own performance against other states.

Previously, there were two family-related indicators under the **Consumer Outcomes** domain of the Phase II Core Indicators. The two sub-domains were **Supporting Families** and **Family Involvement**. From these sub-domains, three family surveys had been designed: the Adult Family Survey; the Children Family Survey; and the Family/Guardian Survey.

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

**Table 2  
Family Indicators**

<b>DOMAIN</b>	<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.		
<b>SUB-DOMAIN</b>	<b>CONCERN</b>	<b>INDICATOR</b>	<b>DATA SOURCE</b>
<b>Information &amp; Planning</b>	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
<b>Choice &amp; Control</b>	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
<b>Access &amp; Support Delivery</b>	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
<b>Community Connections</b>	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
<b>Family Involvement</b>	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
<b>Satisfaction</b>	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
<b>Family Outcomes</b>	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.

**1999-2000** – The Family Guardian Survey was developed and first utilized during Phase II, 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. Over 13,600 surveys were mailed out, and the overall return rate was 39.4%.

**2000-2001** – In the year 2000, seven states participated and mailed out over 10,000 Family Guardian Surveys. Response rates among states ranged from 40% to 53%, with approximately 4,600 completed surveys returned.

**2001-2002** – Seven states participated, mailing out approximately 6,400 Family Guardian Surveys. Response rates among states ranged from 33% to 64%, with approximately 3,800 completed surveys returned.

**2002-2003** – Ten states participated and mailed out over 10,000 Family Guardian Surveys. Response rates ranged from 23% to 63%, and approximately 4,600 completed surveys were utilized for analysis.

**2003-2004** - The results from this year’s survey are explored in this report. Ten states participated. Response rates range from 33% to 48%, and over 4,800 completed surveys were analyzed.

### State Participation

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

Table 3 State Participation in NCI Family Guardian Survey (Adults Living Out-of-Home)					
Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003	Phase VI 2003-2004
NA	CT	AZ	CA-RCOC	AZ	AZ
	KY	DE	HI	CA - RCOC	CA - RCOC
	MN	MA	NE	HI	CT
	NE	MN	NC	IN	ME
	PA	NC	PA	MA	NC
	VA	PA	UT	NC	ND
	WA	RI	WA	PA	PA
				SC	SC
				SD	WA
				WY	WY

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## 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 2002-2003 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 administered 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 2003-2004, nine states and one local developmental disability authority 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%.

<b>Table 4 Family Guardian Survey - State Response Rates</b>				
<b>State</b>	<b>Surveys Mailed</b>	<b>Surveys Returned</b>	<b>Response Rate</b>	<b>Usable Surveys</b>
Arizona	1,000	372	37%	341
CA-Orange Co.	907	301	33%	301
Connecticut	1,200	578	48%	559
Maine	1,198	684	57%	672
North Carolina	1,090	380	35%	364
North Dakota	732	346	47%	328
Pennsylvania	2,760	1,214	44%	1,170
South Carolina	1,000	184	18%	164
Washington	1,368	662	48%	640
Wyoming	596	289	48%	287
<b>Overall</b>	<b>11,851</b>	<b>5,010</b>	<b>42%</b>	<b>4,826</b>
* denotes data missing				

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. Unless noted, the “surveys mailed” figures include some number of “undeliverable” surveys (e.g. those returned due to incorrect addresses) or surveys that were returned but were excluded from the database for other reasons (e.g. did not meet the state's inclusion criteria). Response rates ranged from 18% to 57%.

## 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. 10) 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.

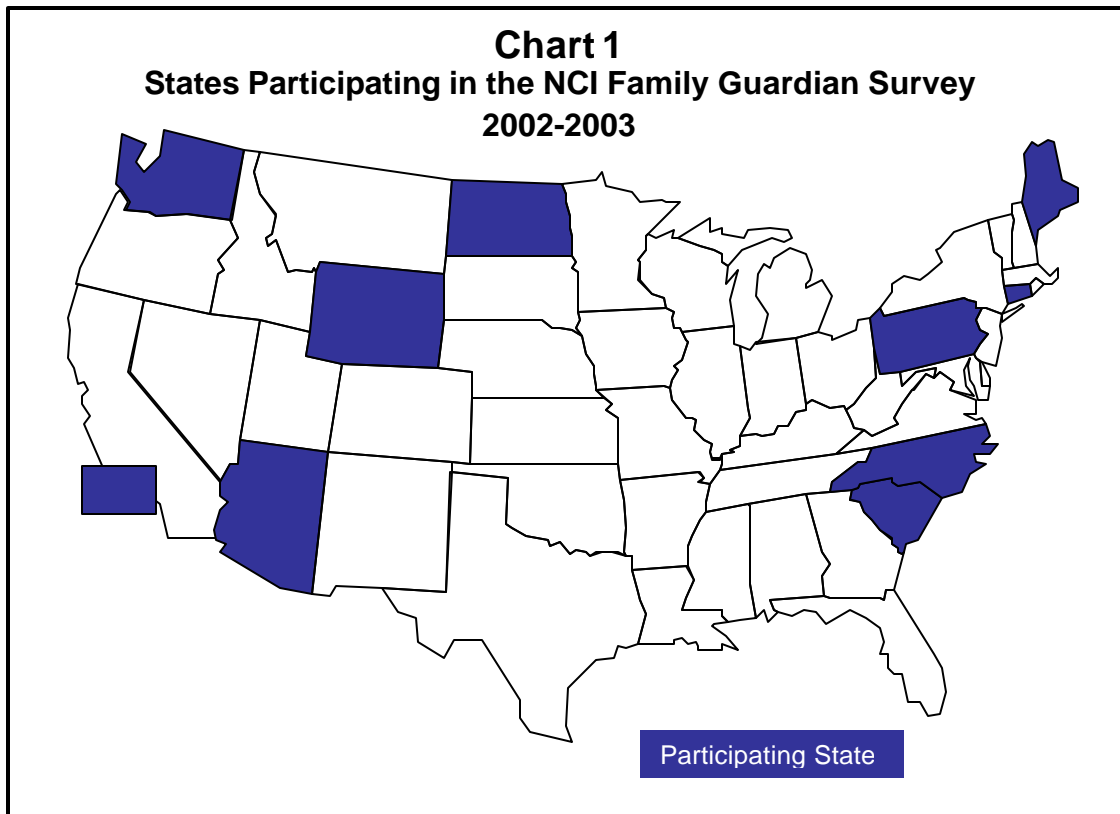
Please note that the TABLES provide individuals state results and result averages that are calculated through two separate methods:

1. Total % indicates the percentage across all individual respondents.
2. State Average % indicates the average percentage across the nine states and one local DD authority that conducted this survey.

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

### Participating States

- ♦ Nine states and one local DD authority provided data sets to be included in the Final Report. They include Arizona, Connecticut, Maine, North Carolina, North Dakota, Pennsylvania, South Carolina, Washington, Wyoming, and Orange County Regional Center in California.

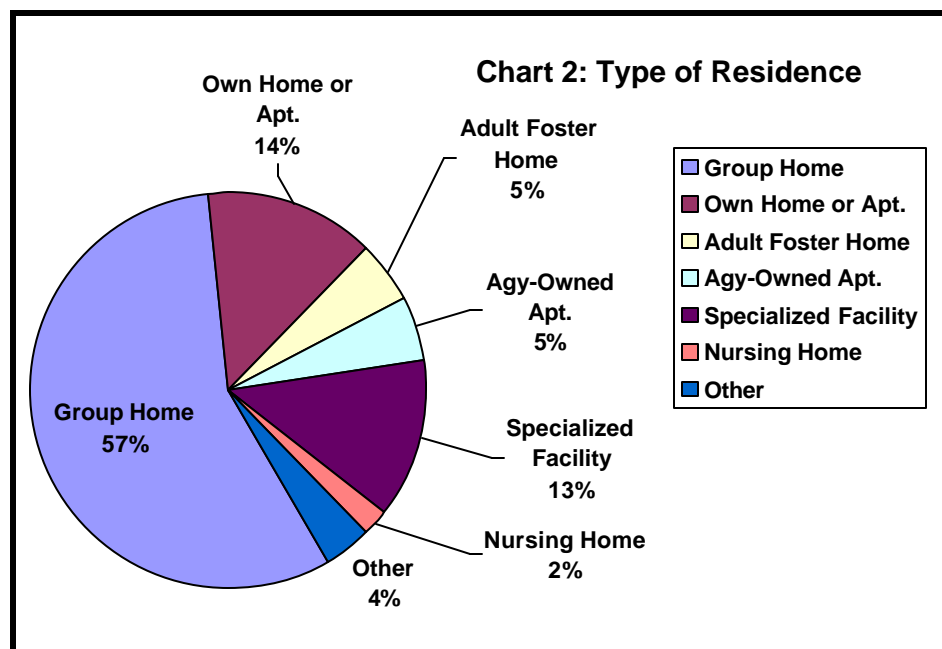


## Characteristics of Family Members with Disabilities

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

- ◆ On average, across the states, over half (57%) of the family members with disabilities lived in group home settings. 14% lived in their own homes or apartments, 13% in specialized facilities, 5% lived in adult foster care or host family homes, 5% lived in agency-owned apartments, 2% in nursing homes, and 4% in a variety of other settings.
- ◆ 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 43.7, with a range in age from 18 to 97.
- ◆ On average, 87% of the family members were White, 6% were Black/ African American, 2% were American Indian/Alaska Native, 1% were Asian, 1% were Mixed Races, 3% were Hispanic, 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, one-third (35%) of the family members with disabilities had a diagnosis of severe or profound mental retardation. Additionally, 31% were individuals with moderate mental retardation, 15% had mild mental retardation, and 2% had no mental retardation diagnosis. Additionally, 16% 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 (29%), physical disabilities (26%), vision or hearing impairments (22%), communication disorders (22%), mental illness (19%), and cerebral palsy (17%).

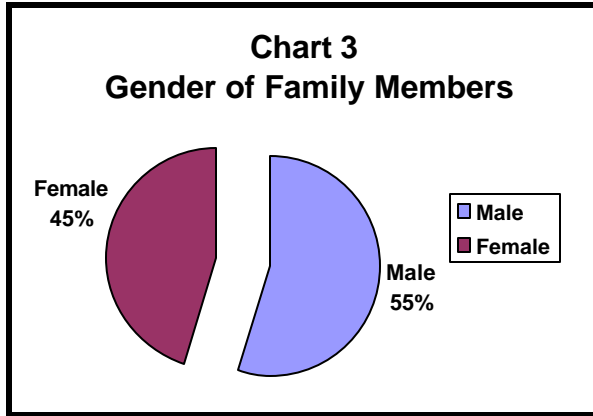
## Type of Residence



**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	Nursing Home	Other
AZ	5.4	74.4	4.8	3.6	6.3	2.1	3.3
CA-RCOC	6.8	68.7	1.4	15.6	2.4	2.4	2.7
CT	5.0	75.3	4.3	11.9	1.3	0.2	2.0
ME	11.1	49.7	4.5	10.6	11.7	6.9	5.5
NC	27.0	52.8	2.3	5.3	3.2	2.1	7.3
ND	4.9	56.8	6.2	28.4	2.8	0.0	0.9
PA	17.9	56.6	2.6	9.8	4.7	3.3	5.0
SC	11.6	61.9	14.8	5.2	4.5	0.0	1.9
WA	20.9	26.7	6.6	28.2	6.4	3.0	8.2
WY	12.6	62.6	5.8	9.7	7.2	0.0	2.2
<b>Total n</b>	630	2,619	209	619	250	122	210
<b>Total %</b>	13.5	56.2	4.5	13.3	5.4	2.6	4.5
<b>State Avg. %</b>	13.1	56.8	5.4	13.9	4.9	2.0	4.0

## Gender of Family Member



<b>Table 6</b> <b>Gender</b>		
<b>State</b>	<b>% Male</b>	<b>% Female</b>
AZ	54.4	45.6
CA-RCOC	56.4	43.6
CT	54.6	45.4
ME	52.3	47.7
NC	54.7	45.3
ND	56.5	43.5
PA	55.9	44.1
SC	58.0	42.0
WA	53.5	46.5
WY	50.9	49.1
<b>Total n</b>	<b>2,502</b>	<b>2,082</b>
<b>Total %</b>	<b>54.6</b>	<b>45.4</b>
<b>State Avg. %</b>	<b>54.7</b>	<b>45.3</b>

## Age of Family Member

<b>Table 7</b> <b>Age of Family Member</b>		
<b>State</b>	<b>Average Age</b>	<b>Range</b>
AZ	42.5	18-81
CA-RCOC	42.1	19-78
CT	45.0	20-97
ME	44.5	19-86
NC	45.2	18-83
ND	42.8	18-86
PA	45.5	18-89
SC	46.5	19-81
WA	43.9	18-85
WY	39.4	18-81
<b>Total n</b>	<b>4,628</b>	
<b>Total Avg.</b>	<b>44.1</b>	<b>18-97</b>
<b>State Avg.</b>	<b>43.7</b>	

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## Race 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
AZ	72.1	2.1	0.3	5.7	0.3	3.9	0.0	14.7
CA-RCOC	89.0	1.7	3.3	1.7	0.7	1.7	0.3	2.7
CT	90.9	4.8	0.4	0.7	0.0	1.3	0.2	3.0
ME	97.0	0.2	0.8	1.1	0.0	0.6	0.8	0.6
NC	68.4	25.3	0.0	1.4	0.0	0.0	0.0	0.8
ND	95.7	0.3	0.0	3.1	0.0	0.6	0.0	0.3
PA	96.6	2.4	0.1	0.3	0.1	0.4	0.0	0.3
SC	79.6	20.4	0.0	0.0	0.0	0.0	0.0	0.0
WA	92.2	2.5	2.2	1.9	0.3	1.6	0.5	1.6
WY	89.4	0.0	0.4	3.2	0.7	4.3	0.0	2.8
<b>Total n</b>	4,258	207	34	74	8	58	10	103
<b>Total %</b>	90.0	4.4	0.7	1.6	0.2	1.2	0.2	2.2
<b>State Avg. %</b>	87.1	6.0	0.8	1.9	0.2	1.4	0.2	2.7

Level of Mental Retardation of Family Member

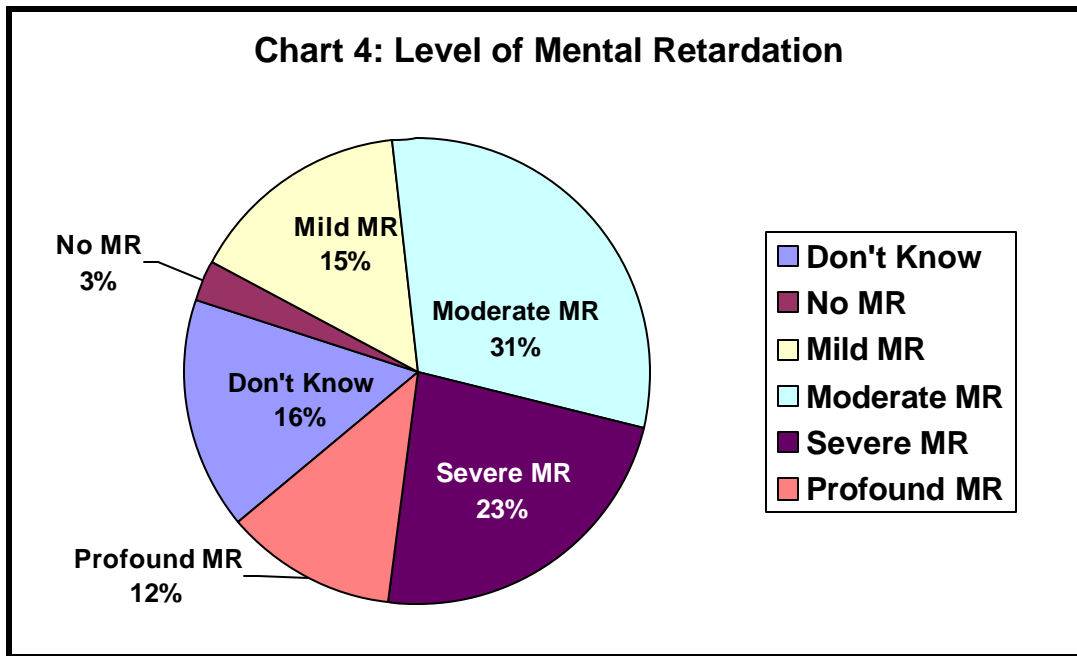


Table 9 Level of Mental Retardation of Family Member						
State	No MR Diagnosis	Mild MR	Moderate MR	Severe MR	Profound MR	Don't Know
AZ	4.0	15.2	31.1	24.2	8.7	16.8
CA-RCOC	4.1	16.9	37.8	20.6	8.4	12.2
CT	0.6	16.3	26.3	23.8	13.1	20.0
ME	2.3	12.9	28.3	25.7	15.1	15.7
NC	1.8	15.6	25.3	25.3	13.8	18.2
ND	1.9	13.0	33.2	30.4	7.5	14.0
PA	0.7	14.7	26.5	24.7	17.9	15.5
SC	1.3	21.3	34.8	18.7	4.5	19.4
WA	6.4	11.7	28.7	19.5	17.1	16.6
WY	1.5	17.3	34.6	18.8	15.1	12.9
<b>Total n</b>	107	676	1,339	1,083	639	739
<b>Total %</b>	2.3	14.8	29.2	23.6	13.9	16.1
<b>State Avg. %</b>	2.5	15.5	30.7	23.2	12.1	16.1

## Other Disabilities of Family Member

Table 10A Other Disabilities of Family Member						
State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
AZ	17.0	10.4	18.5	11.0	28.3	1.2
CA-RCOC	14.3	11.6	20.9	15.0	26.2	0.7
CT	20.2	13.4	16.5	9.8	27.7	0.8
ME	21.8	13.1	16.5	9.5	29.8	0.5
NC	23.9	8.2	12.1	6.0	22.0	0.5
ND	16.2	8.8	15.9	9.8	30.5	0.3
PA	20.4	8.4	20.3	11.8	30.6	0.8
SC	17.8	7.5	13.7	11.0	24.0	1.4
WA	19.5	9.7	17.1	11.3	31.7	0.5
WY	21.2	5.3	17.0	11.7	35.0	1.4
<b>Total n</b>	916	460	810	497	1,354	34
<b>Total %</b>	19.8	9.9	17.5	10.7	29.2	0.7
<b>State Avg. %</b>	19.2	9.6	16.9	10.7	28.6	0.8

Table 10B Other Disabilities of Family Member						
State	Vision/ Hearing Impairment	Physical Disability	Communi- cation Disorder	Alzheimer's Disease	Down Syndrome	Other Disability
AZ	21.7	22.9	17.3	0.9	13.7	15.2
CA-RCOC	18.9	24.9	19.6	0.0	13.0	16.9
CT	27.1	23.6	21.0	2.0	15.5	11.8
ME	25.7	27.5	22.9	1.4	14.8	16.1
NC	17.0	18.7	18.1	1.1	11.0	13.5
ND	23.8	27.7	29.6	1.8	18.9	13.1
PA	21.1	25.7	20.2	0.8	10.6	13.3
SC	17.8	22.6	20.5	0.7	15.8	17.8
WA	27.3	31.4	29.7	0.8	13.0	22.2
WY	23.7	31.8	24.7	1.1	13.1	19.1
<b>Total n</b>	1,068	1,208	1,040	50	618	720
<b>Total %</b>	23.1	26.1	22.4	1.1	13.3	15.5
<b>State Avg. %</b>	22.4	25.7	22.4	1.1	13.9	15.9

## 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 outside of the household.

- ◆ Across states, most respondents (55%) fell between the ages of 55 and 74. Nearly one-fifth of respondents, in addition, were 75 years old or over.
- ◆ Three-fifths of respondents were parents of adult children with disabilities (62%). Another 23% were siblings, less than 1% were spouses, and the remaining 15% had other relationships to the individual.
- ◆ On average, over half (56%) 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: 16% saw their family member 7 to 12 times per year, 13% visited their family member four to six times per year, 12% saw their family member one to three times per year, and the remaining 4% less than once per year.
- ◆ On average, 77% of respondents indicated that they were their family member's legal guardian or conservator. In North Dakota, Wyoming and Maine, nearly all respondents served as their family member's guardian, while in Pennsylvania and South Carolina, approximately half of respondents held this role.

### Age of Respondent

Table 11 Age of Respondent				
State	Under 35	35-54	55-74	75 or Older
AZ	2.3	16.0	55.3	16.4
CA-RCOC	0.7	17.2	57.4	24.7
CT	2.8	19.7	55.0	22.5
ME	0.8	26.9	56.6	15.8
NC	4.4	32.7	50.7	12.2
ND	1.3	34.7	49.7	14.4
PA	1.3	22.0	55.9	20.7
SC	1.9	17.1	60.1	20.9
WA	0.8	25.8	52.1	21.2
WY	3.2	32.9	53.7	10.2
<b>Total n</b>	80	1,175	2,563	872
<b>Total %</b>	1.7	25.1	54.6	18.6
<b>State Avg. %</b>	2.0	24.5	54.7	17.9

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## Relationship of Respondent to Individual with Disabilities

Table 12 Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
AZ	67.7	14.2	0.0	18.0
CA-RCOC	79.7	16.2	0.0	4.1
CT	64.9	23.7	0.0	11.4
ME	59.9	28.3	0.0	11.8
NC	49.1	20.8	0.6	29.5
ND	58.0	31.8	0.0	10.2
PA	58.6	34.0	0.2	7.2
SC	55.7	24.1	0.0	20.3
WA	64.5	18.2	0.0	17.3
WY	57.8	19.1	0.4	22.7
<b>Total n</b>	<b>2,857</b>	<b>1,172</b>	<b>5</b>	<b>623</b>
<b>Total %</b>	<b>61.3</b>	<b>25.2</b>	<b>0.1</b>	<b>13.4</b>
<b>State Avg. %</b>	<b>61.6</b>	<b>23.0</b>	<b>0.1</b>	<b>15.3</b>

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## 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
AZ	1.5	12.9	13.5	18.3	53.8
CA-RCOC	1.7	10.2	9.2	17.6	61.4
CT	6.4	11.1	10.2	14.5	57.7
ME	2.0	8.4	11.5	14.5	63.7
NC	2.9	11.1	15.5	17.8	52.6
ND	4.9	12.6	14.4	18.7	49.4
PA	6.3	10.9	15.5	15.7	51.6
SC	1.9	12.0	12.0	13.3	60.8
WA	5.1	8.6	10.9	12.8	62.6
WY	7.7	18.0	13.4	13.7	47.2
<b>Total n</b>	<b>212</b>	<b>516</b>	<b>605</b>	<b>728</b>	<b>2,643</b>
<b>Total %</b>	<b>4.5</b>	<b>11.0</b>	<b>12.9</b>	<b>15.5</b>	<b>56.2</b>
<b>State Avg. %</b>	<b>4.0</b>	<b>11.6</b>	<b>12.6</b>	<b>15.7</b>	<b>56.1</b>

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## Respondent's Role as Guardian or Conservator

<b>Table 14</b>		
<b>Respondent is Legal Guardian or Conservator</b>		
<b>State</b>	<b>% Yes</b>	<b>% No</b>
AZ	77.3	22.7
CA-RCOC	65.7	34.3
CT	86.9	13.1
ME	96.2	3.8
NC	75.7	24.3
ND	99.1	0.9
PA	48.3	51.7
SC	50.3	49.7
WA	71.6	28.4
WY	97.9	2.1
<b>Total n</b>	<b>3,435</b>	<b>1,164</b>
<b>Total %</b>	<b>74.7</b>	<b>25.3</b>
<b>State Avg. %</b>	<b>76.9</b>	<b>23.1</b>

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## Services and Supports Received

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

<b>Table 15 Services and Supports Received (%)</b>				
<b>State</b>	Residential supports	Day/ Employment supports	Transportation	Other
AZ	96.4	85.7	92.7	66.7
CA-RCOC	95.9	88.1	86.8	57.0
CT	98.3	90.7	96.7	74.6
ME	97.2	82.4	94.4	77.0
NC	93.5	73.8	88.8	73.4
ND	97.9	89.3	96.3	76.8
PA	95.5	74.4	89.0	74.9
SC	96.9	87.7	96.1	63.1
WA	92.7	65.7	82.4	62.1
WY	99.3	93.2	97.2	87.5
<b>Total n</b>	4,430	3,612	4,126	2,991
<b>Total Avg. %</b>	96.1	80.6	91.2	72.3
<b>State Avg. %</b>	96.4	83.1	92.0	71.3

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## 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.

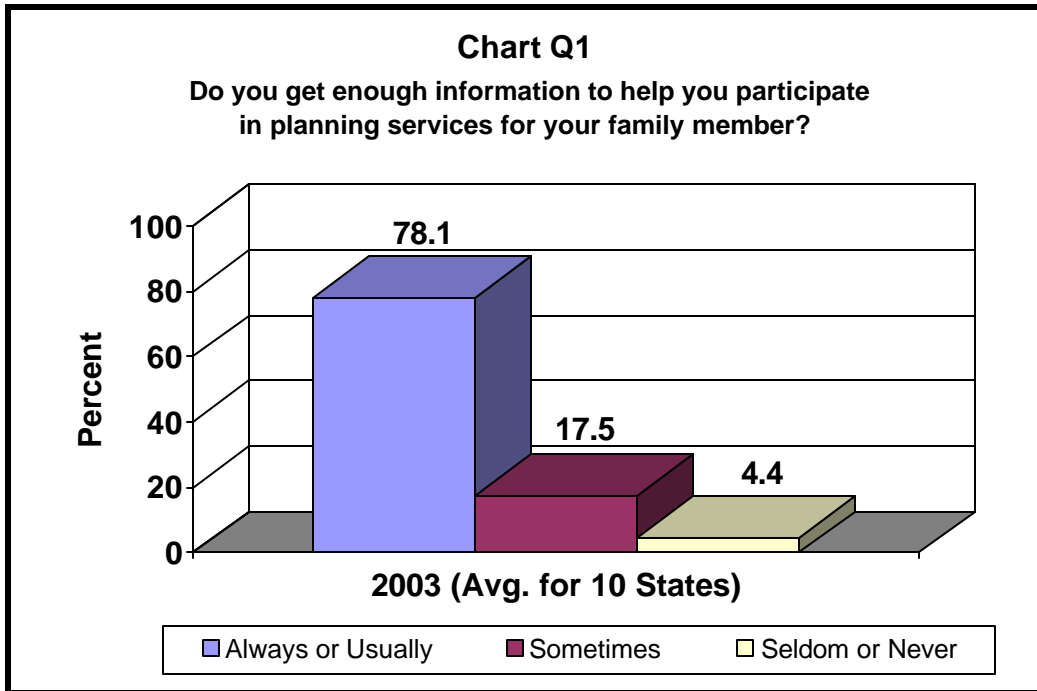
- ◆ The Figure illustrates the State Average results (i.e., the average percentage across the nine states and one local DD authority that conducted this survey).
- ◆ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average 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 “Yes or Most of the Time” 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 “Yes or Most of the Time” 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 “Yes or Most of the Time” 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 “Yes or Most of the Time” 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.

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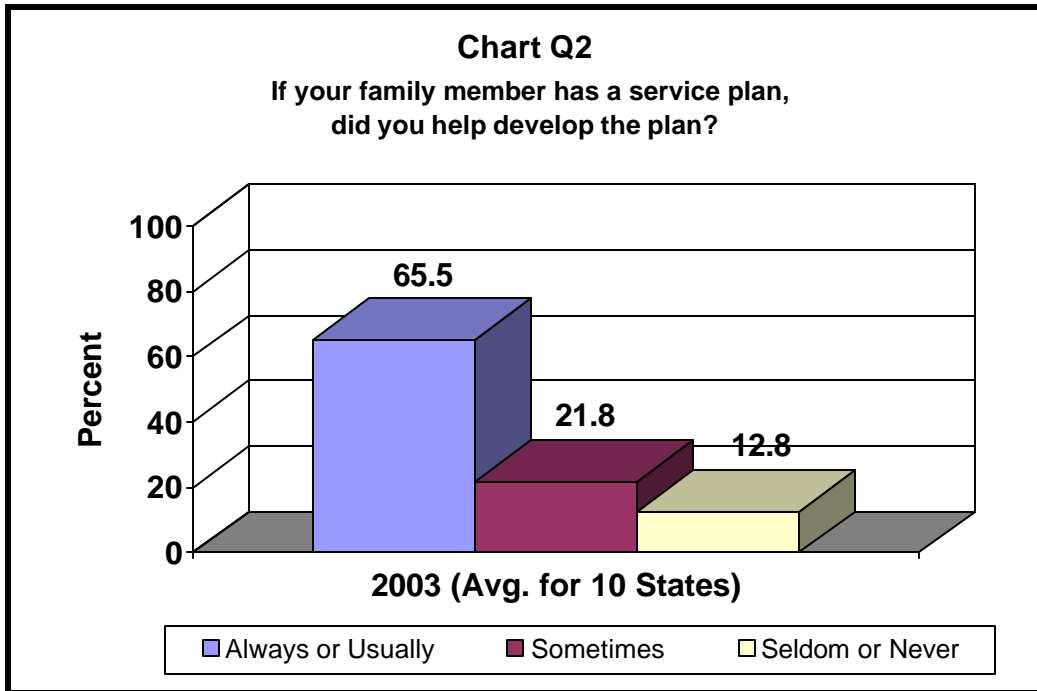
## Information and Planning

- ◆ On average, three-fourths of respondents (78%) stated that they got enough information to help them participate in planning.
- ◆ About two-thirds of respondents (65%), on average, indicated that they typically helped to develop their family member's service plan.
- ◆ On average across states, four-fifths (80%) of respondents surveyed indicated that their family member's service plan included things that were important to them. 17% stated this was only true some of the time, while the remaining 3% stated the service plan seldom included things important to the respondent.
- ◆ Across states, nearly all felt that planning staff were generally respectful and courteous.
- ◆ Across states, approximately three-fourths (77%) felt that planning staff were generally effective.
- ◆ Across states, 88% felt they were able to contact planning staff when needed.



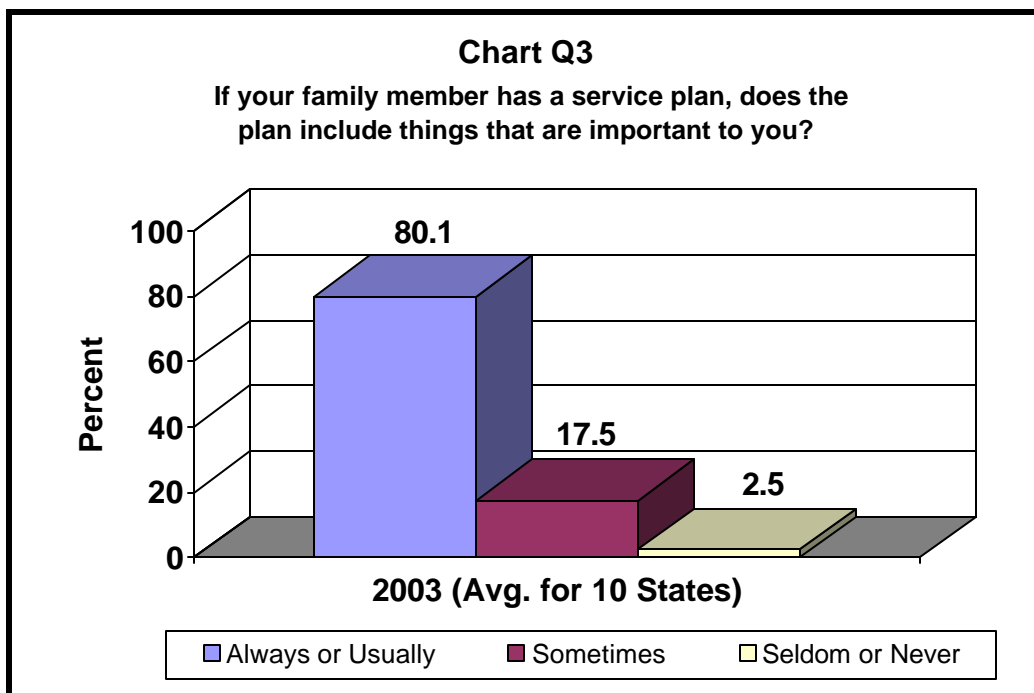
**Table Q1**  
Do you get enough information to help you participate in planning services for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		79.1	17.5	3.4	325
CA-RCOC	↓	72.3	23.0	4.7	274
CT		80.9	14.5	4.6	503
ME	↑	86.2	11.1	2.7	639
NC		79.7	16.6	3.7	325
ND	↑	83.3	16.4	0.3	317
PA		73.6	20.5	5.8	1,043
SC		74.1	19.7	6.1	147
WA	↓↓	65.9	22.7	11.4	560
WY	↑	86.2	12.7	1.1	283
<b>Total %</b>		<b>77.6</b>	<b>17.6</b>	<b>4.8</b>	<b>4,416</b>
<b>State Average %</b>		<b>78.1</b>	<b>17.5</b>	<b>4.4</b>	<b>n = 10</b>



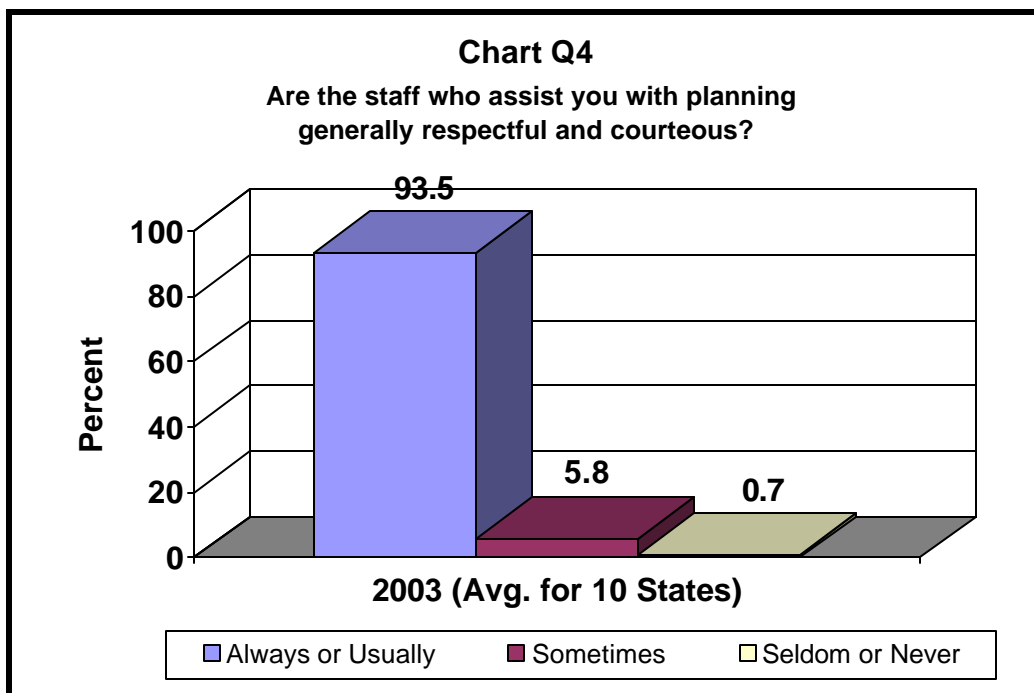
**Table Q2**  
If your family member has a service plan, did you help develop the plan?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		70.4	20.9	8.8	297
CA-RCOC	↓	58.0	26.8	15.2	250
CT		64.2	24.1	11.6	439
ME	↑	72.7	19.4	7.9	583
NC		65.1	20.8	14.1	284
ND	↑	74.5	19.9	5.6	306
PA	↓↓	47.5	24.8	27.7	874
SC		63.0	21.3	15.7	127
WA		61.9	23.8	14.4	480
WY	↑↑	77.7	15.7	6.6	274
<b>Total %</b>		<b>63.3</b>	<b>22.2</b>	<b>14.5</b>	<b>3,914</b>
<b>State Average %</b>		<b>65.5</b>	<b>21.8</b>	<b>12.8</b>	<b>n = 10</b>



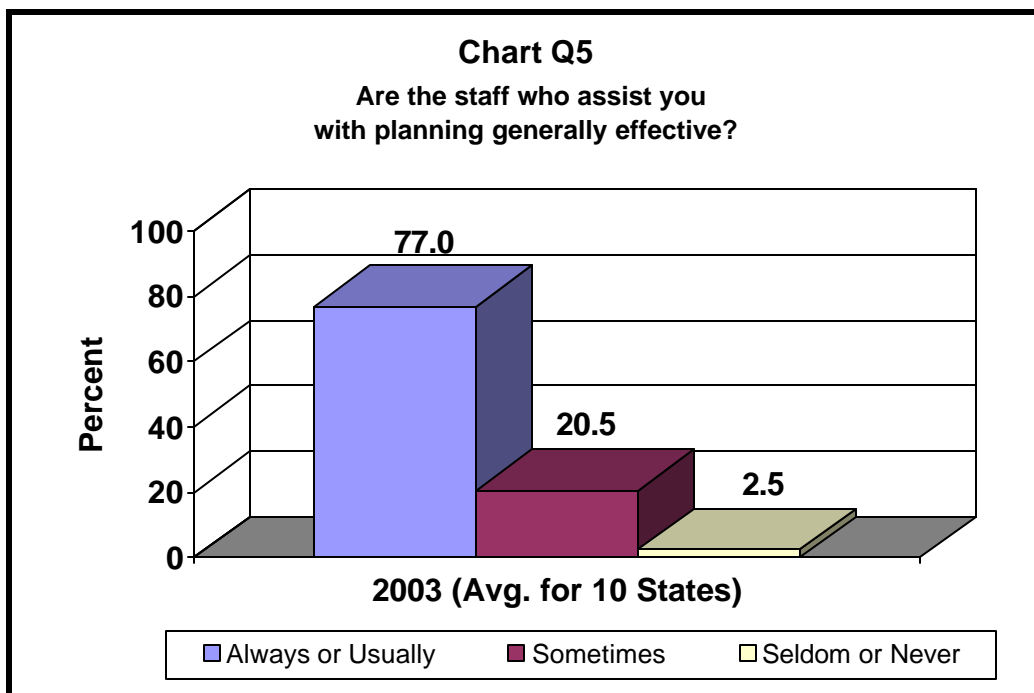
**Table Q3**  
If your family member has a service plan, does the plan include things that are important to you?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		84.1	14.0	2.0	301
CA-RCOC		76.0	22.8	1.2	250
CT		81.5	16.7	1.8	448
ME	↑	86.2	12.8	1.0	603
NC		81.1	13.9	5.1	296
ND		84.7	14.6	0.6	308
PA	↓	74.5	20.9	4.6	872
SC	↓↓	69.8	27.9	2.3	129
WA		78.2	16.7	5.1	468
WY		84.7	14.2	1.1	275
<b>Total %</b>		<b>80.2</b>	<b>17.0</b>	<b>2.8</b>	<b>3,950</b>
<b>State Average %</b>		<b>80.1</b>	<b>17.5</b>	<b>2.5</b>	<b>n = 10</b>



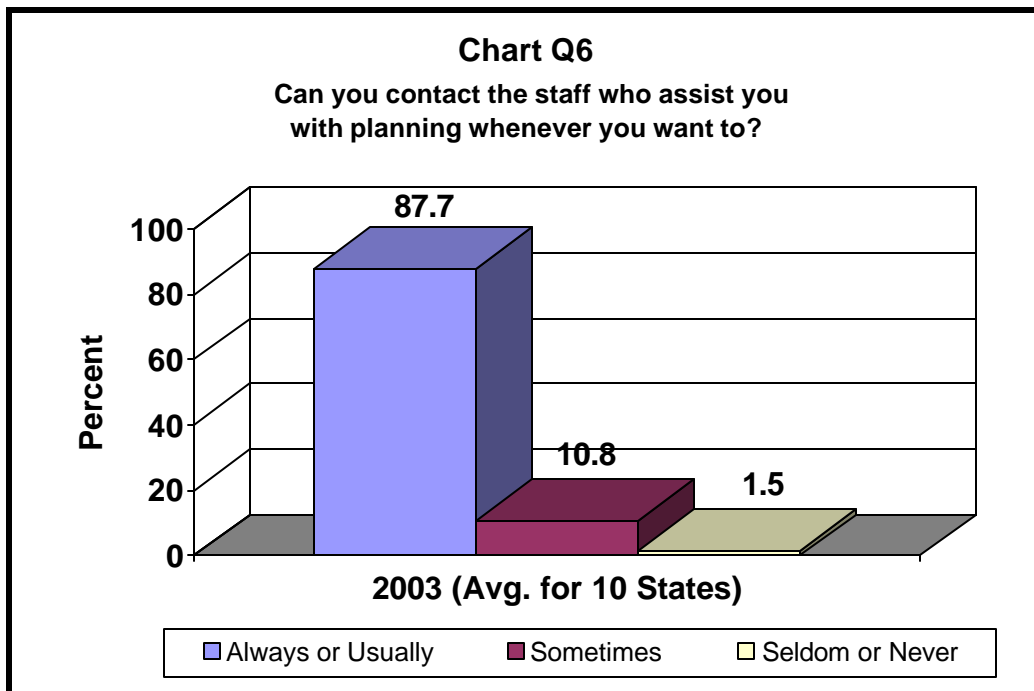
**Table Q4**  
Are the staff who assist you with planning generally respectful and courteous?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	92.2	6.5	1.2	321
CA-RCOC	92.4	6.8	0.7	278
CT	95.1	4.3	0.6	490
ME	96.7	3.3	0.0	632
NC	93.0	6.1	1.0	313
ND	94.6	5.0	0.3	317
PA	93.5	6.2	0.3	982
SC	91.0	8.3	0.7	144
WA	93.1	5.2	1.7	535
WY	93.7	6.0	0.4	285
<b>Total %</b>	<b>93.9</b>	<b>5.5</b>	<b>0.6</b>	<b>4,297</b>
<b>State Average %</b>	<b>93.5</b>	<b>5.8</b>	<b>0.7</b>	<b>n = 10</b>



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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		74.9	22.2	2.9	315
CA-RCOC		75.2	20.3	4.5	266
CT	↑	83.2	15.1	1.7	476
ME	↑	84.6	14.9	0.5	623
NC		81.0	16.3	2.7	300
ND		78.2	21.4	0.3	308
PA		77.0	20.2	2.8	940
SC	↓↓	65.9	31.2	2.9	138
WA		73.6	21.8	4.6	518
WY		76.5	21.7	1.8	281
<b>Total %</b>		<b>78.1</b>	<b>19.5</b>	<b>2.4</b>	<b>4,165</b>
<b>State Average %</b>		<b>77.0</b>	<b>20.5</b>	<b>2.5</b>	<b>n = 10</b>

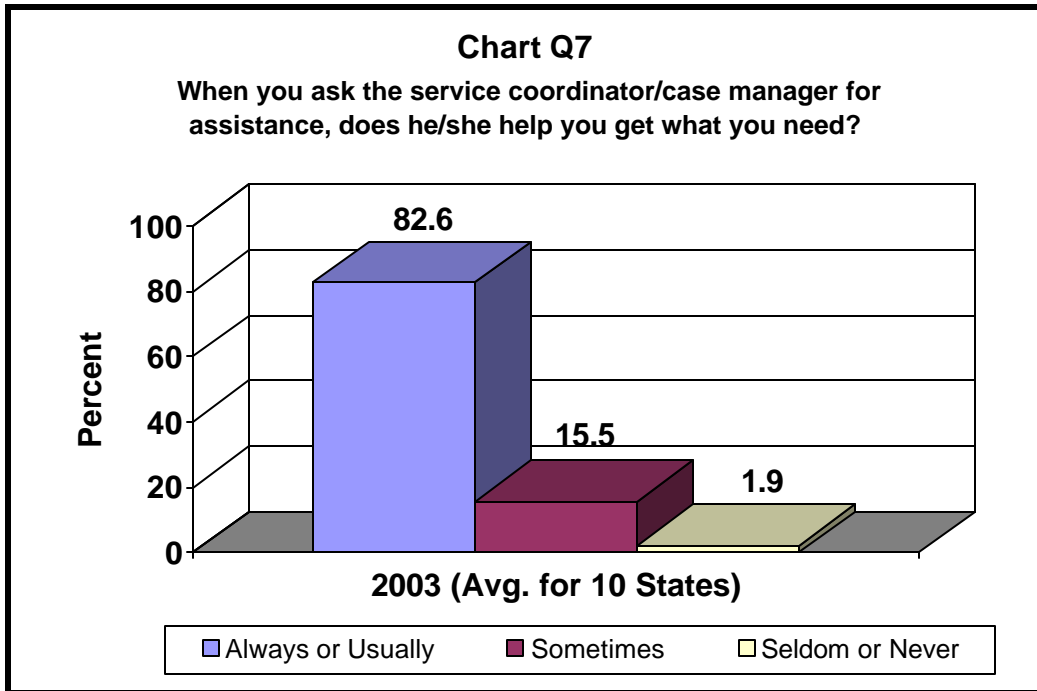


**Table Q6**  
Can you contact the staff who assist you with planning whenever you want to?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	87.9	10.9	1.2	321
CA-RCOC	83.1	15.4	1.5	267
CT	90.6	7.8	1.6	490
ME	92.6	6.6	0.8	625
NC	87.5	11.0	1.5	328
ND	↑ 94.4	5.3	0.3	320
PA	87.1	11.3	1.6	989
SC	↓ 80.4	17.4	2.2	138
WA	↓ 81.8	13.9	4.3	539
WY	91.9	8.1	0.0	284
<b>Total %</b>	<b>88.1</b>	<b>10.3</b>	<b>1.6</b>	<b>4,301</b>
<b>State Average %</b>	<b>87.7</b>	<b>10.8</b>	<b>1.5</b>	<b>n = 10</b>

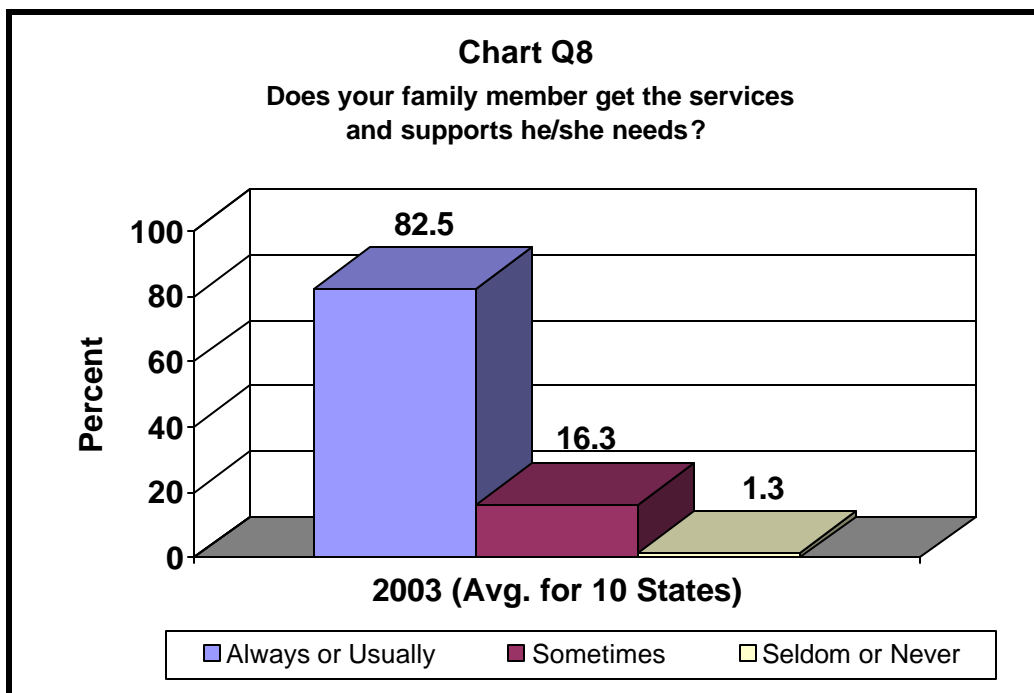
## Access to and Delivery of Services and Supports

- ◆ On average, most respondents (83%) stated that their service coordinator helped them get needed supports when they asked. Fifteen percent said this only happened some of the time, and 2% indicated that their service coordinator was seldom or never helpful in getting their family member the assistance needed.
- ◆ Eighty-three percent 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 (78%) indicated there were enough staff to communicate with their family member. Nineteen percent stated that these staff were available some of the time, and another 3% did not have staff available to communicate with their family members in their preferred means of communication/ languages.
- ◆ On average, 89% of respondents indicated that their family member had access to the special equipment or accommodations that s/he needs. Eleven percent stated that equipment was only seldom or sometimes available.
- ◆ Two-thirds of respondents (67%) indicated that frequent changes in support staff were a problem for their family at least some of the time. The remaining third stated that this was not an issue for them.
- ◆ Among those receiving residential supports, nearly all (90%) felt their family member's residential setting was a safe and healthy environment, however 10% 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 residence was sometimes or seldom safe.



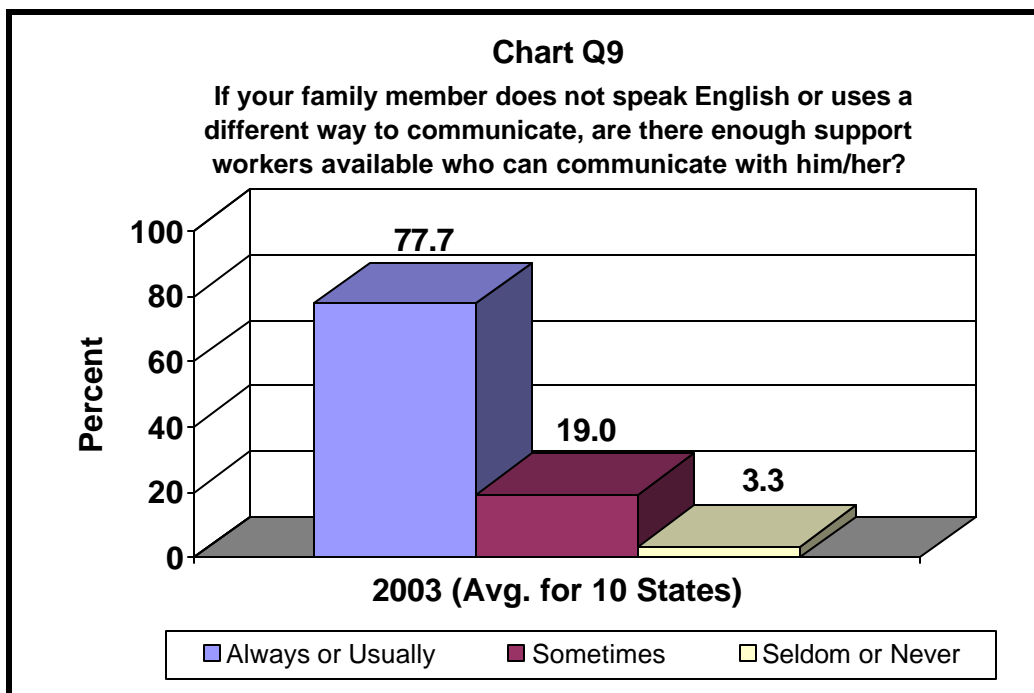
**Table Q7**  
When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		85.5	13.8	0.6	311
CA-RCOC		78.0	19.6	2.4	250
CT		86.3	12.2	1.5	476
ME		83.9	14.3	1.8	559
NC		83.3	14.8	1.9	311
ND	↑	90.7	8.7	0.6	322
PA		82.4	14.8	2.8	999
SC	↓↓	72.5	24.2	3.4	149
WA	↓	75.2	21.8	3.0	505
WY	↑	88.3	10.3	1.4	281
<b>Total %</b>		<b>82.9</b>	<b>15.1</b>	<b>2.0</b>	<b>4,163</b>
<b>State Average %</b>		<b>82.6</b>	<b>15.5</b>	<b>1.9</b>	<b>n = 10</b>



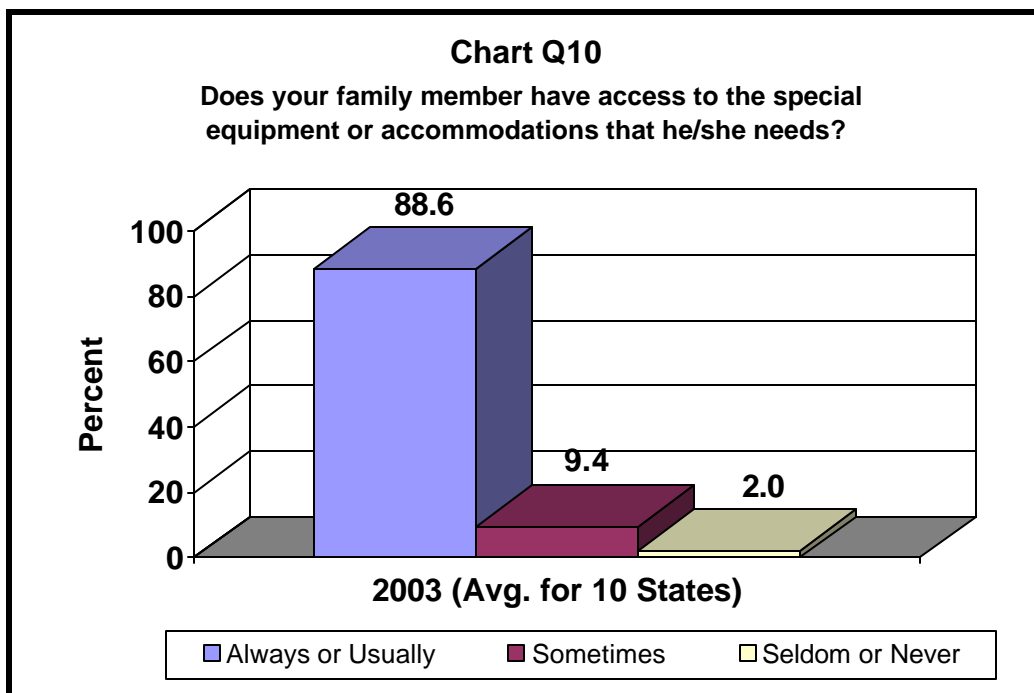
**Table Q8**  
Does your family member get the services and supports he/she needs?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		83.8	15.9	0.3	320
CA-RCOC	↓	74.4	24.9	0.7	277
CT	↑	89.1	10.1	0.8	505
ME		85.5	13.9	0.6	640
NC		83.2	15.6	1.2	333
ND		86.6	12.5	0.9	320
PA		84.4	14.0	1.7	1,080
SC	↓	74.7	23.3	2.1	146
WA	↓	77.5	19.4	3.1	578
WY		85.6	13.4	1.1	284
<b>Total %</b>		<b>83.3</b>	<b>15.3</b>	<b>1.3</b>	<b>4,483</b>
<b>State Average %</b>		<b>82.5</b>	<b>16.3</b>	<b>1.3</b>	<b>n = 10</b>



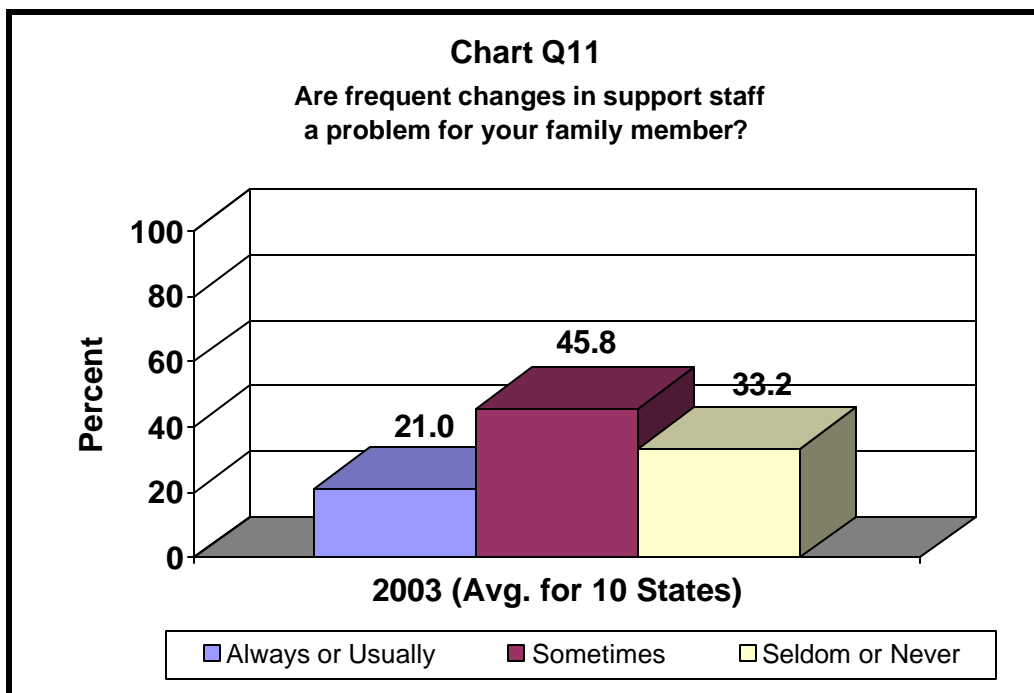
**Table Q9**  
If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	74.5	18.4	7.1	141
CA-RCOC	79.2	15.8	5.0	101
CT	72.9	24.1	3.0	166
ME	81.6	15.4	2.9	272
NC	79.7	16.3	4.1	123
ND	78.2	21.2	0.6	156
PA	82.6	15.3	2.1	386
SC	80.0	20.0	0.0	35
WA	73.1	21.0	5.9	186
WY	75.5	22.5	2.0	102
<b>Total %</b>	<b>78.4</b>	<b>18.3</b>	<b>3.3</b>	<b>1,668</b>
<b>State Average %</b>	<b>77.7</b>	<b>19.0</b>	<b>3.3</b>	<b>n = 10</b>



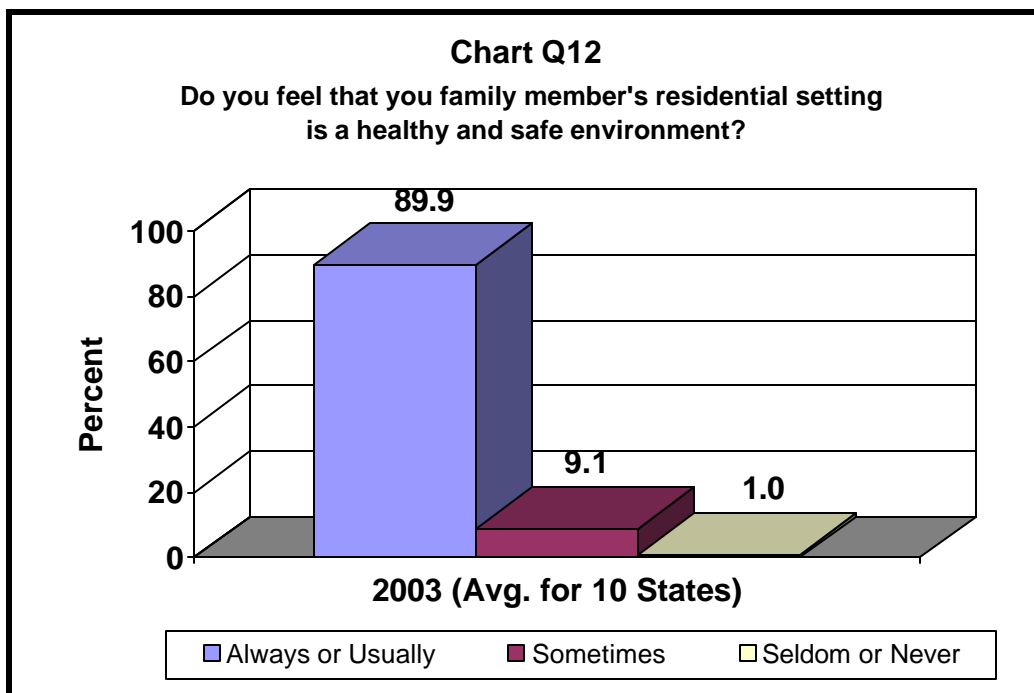
**Table Q10**  
Does your family member have access to the special equipment or accommodations that he/she needs?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	88.0	12.0	0.0	191
CA-RCOC	84.4	11.5	4.1	122
CT	93.2	5.8	1.1	278
ME	89.4	8.0	2.6	387
NC	89.6	8.7	1.6	183
ND	88.5	10.1	1.4	208
PA	90.2	6.6	3.2	621
SC	85.5	13.0	1.4	69
WA	87.5	7.9	4.6	303
WY	89.2	10.8	0.0	167
<b>Total %</b>	<b>89.2</b>	<b>8.4</b>	<b>2.3</b>	<b>2,529</b>
<b>State Average %</b>	<b>88.6</b>	<b>9.4</b>	<b>2.0</b>	<b>n = 10</b>



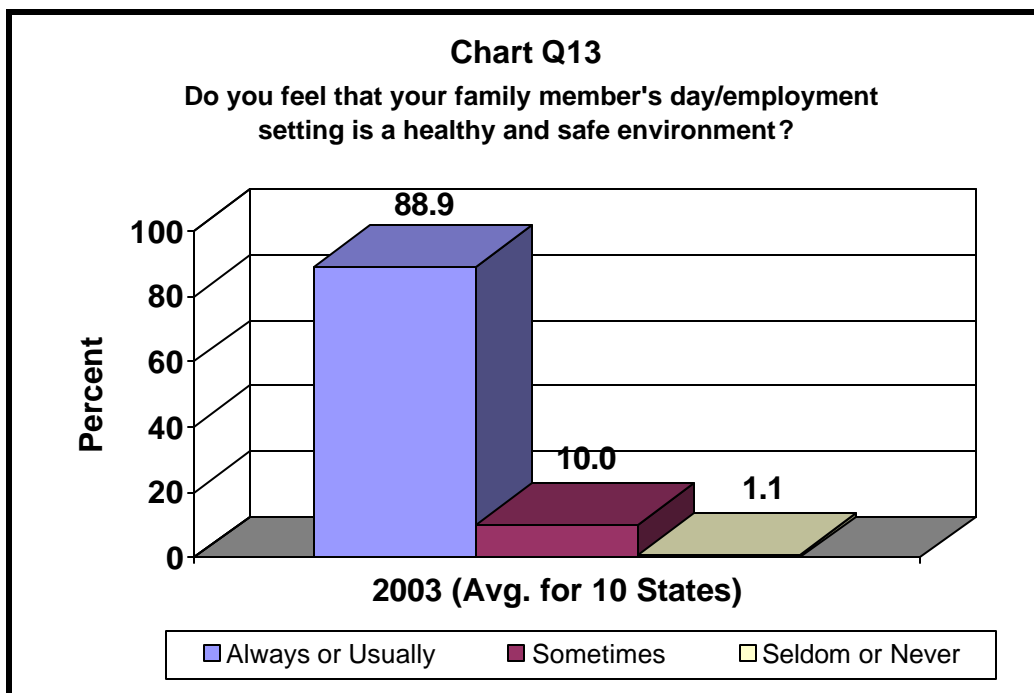
**Table Q11**  
Are frequent changes in support staff a problem for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	26.8	48.8	24.4	291
CA-RCOC		20.0	43.9	36.1	230
CT		17.2	47.2	35.5	453
ME		18.5	48.0	33.5	579
NC		17.2	35.1	47.8	268
ND		19.9	51.5	28.5	291
PA		22.1	44.2	33.7	903
SC		21.8	48.1	30.1	133
WA		18.2	40.3	41.5	467
WY	↓	28.2	51.2	20.6	248
<b>Total %</b>		<b>20.6</b>	<b>45.5</b>	<b>33.9</b>	<b>3,863</b>
<b>State Average %</b>		<b>21.0</b>	<b>45.8</b>	<b>33.2</b>	<b>n = 10</b>



**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
AZ	87.2	11.6	1.2	328
CA-RCOC	89.5	9.8	0.7	285
CT	90.3	8.4	1.4	514
ME	↑ 95.3	4.6	0.2	653
NC	92.7	6.7	0.6	341
ND	91.0	8.4	0.6	321
PA	90.6	8.2	1.2	1,122
SC	↓ 84.7	13.4	1.9	157
WA	90.3	8.3	1.3	599
WY	87.3	12.0	0.7	283
<b>Total %</b>	<b>90.7</b>	<b>8.4</b>	<b>1.0</b>	<b>4,603</b>
<b>State Average %</b>	<b>89.9</b>	<b>9.1</b>	<b>1.0</b>	<b>n = 10</b>

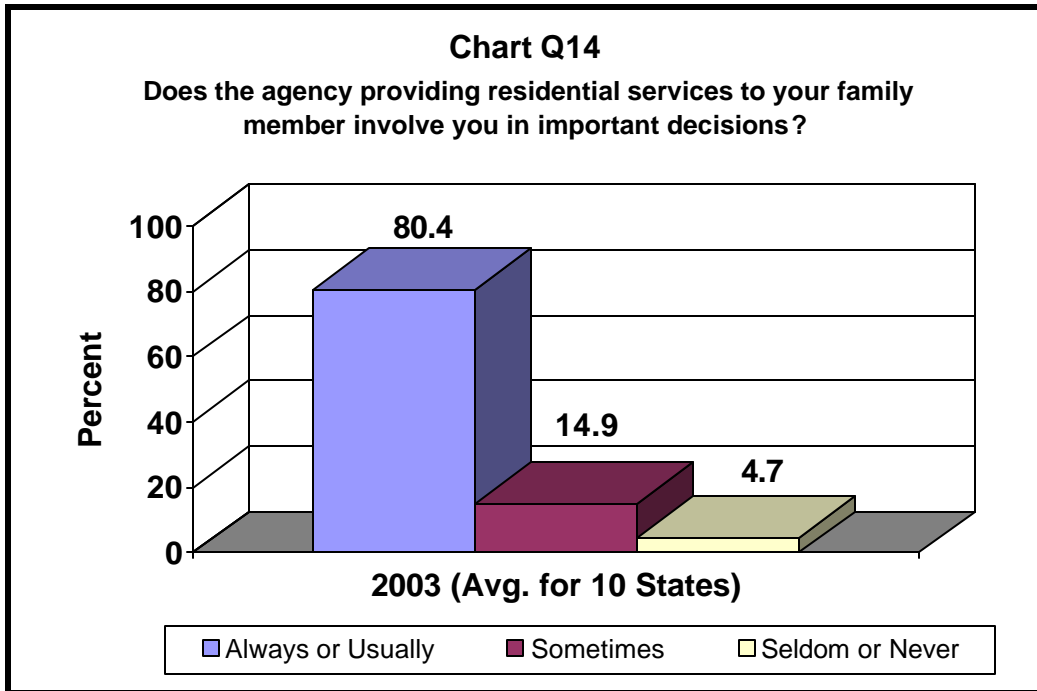


**Table Q13**  
Do you feel that your family member's day/employment setting is a healthy and safe environment?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	87.4	12.2	0.3	286
CA-RCOC	86.0	14.0	0.0	243
CT	90.9	8.4	0.7	451
ME	93.8	5.7	0.6	544
NC	90.5	8.8	0.7	294
ND	87.8	10.5	1.7	295
PA	88.9	9.4	1.8	853
SC ↓	82.5	14.6	2.9	137
WA	92.6	6.2	1.2	433
WY	88.6	10.6	0.8	264
<b>Total %</b>	<b>89.7</b>	<b>9.2</b>	<b>1.1</b>	<b>3,800</b>
<b>State Average %</b>	<b>88.9</b>	<b>10.0</b>	<b>1.1</b>	<b>n = 10</b>

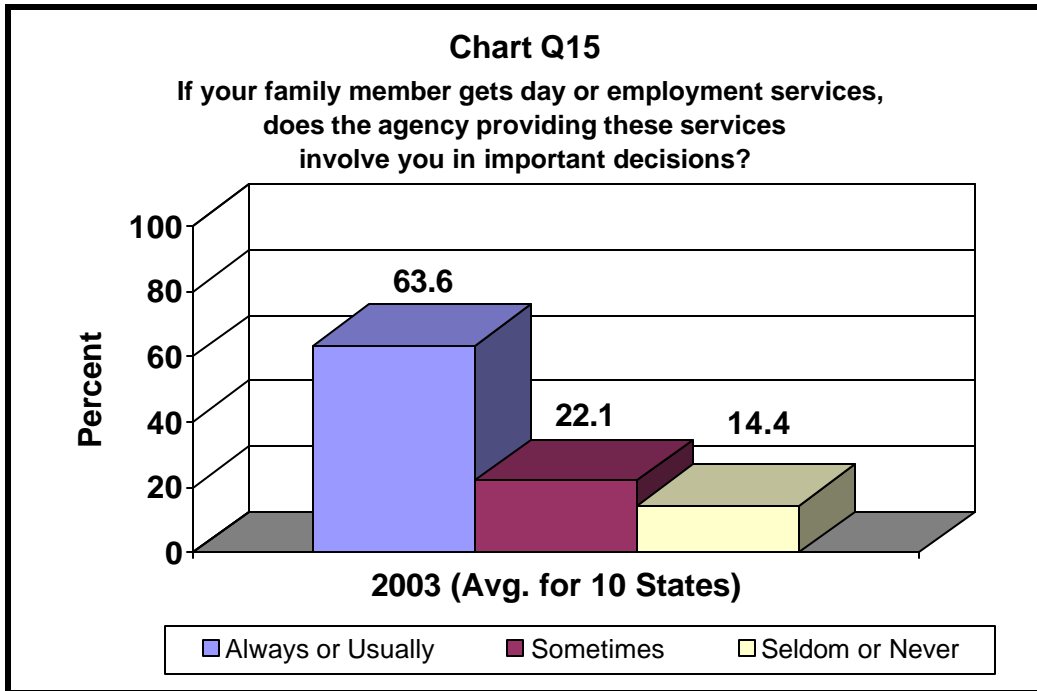
## Choices and Control

- ◆ Among families where the individual with disabilities received residential services, 80% of respondents stated that the agency involved them in important decisions. Another 15% stated that this happens some of the time, and 5% said the agency seldom or never involve them in important decisions.
- ◆ Among families where the individual with disabilities received day or employment services, 64% of respondents stated that the agency involves them in important decisions. Another 22% stated that this happens sometimes, and 14% said the agency seldom or never involves them in important decisions.
- ◆ On average across states, approximately two-thirds of respondents (71%) seldom or never chose the support staff who work with their family members. In Orange County, Maine, North Carolina, South Carolina and Wyoming, more individuals or families did typically choose their support workers, however even there, it amounted to fewer than one-quarter of the families surveyed.
- ◆ Across states, only 9% of respondents said that they had control or input over the hiring and management of their support staff, with an additional 11% indicated they had this type of control sometimes. Eighty percent, however, had little or no input or control over the hiring or management of their family's support staff.
- ◆ While only 20% 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 fo their support staff.
- ◆ Twenty-five percent of respondents, on average, knew how much money was spent on behalf of their family member. Over half (64%), however, had no idea. In Arizona and Wyoming, a far greater percentage of families (38% and 57%) knew the amount of money spent.
- ◆ On average across states, almost half of the families surveyed (47%) 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 other half (53%), however, did not.



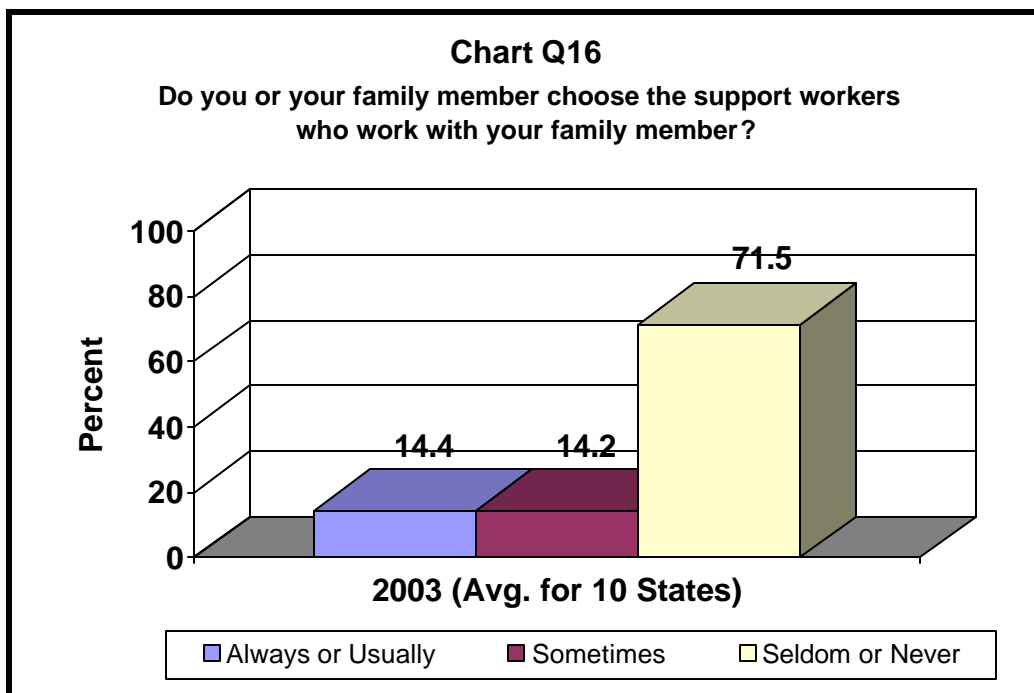
**Table Q14**  
Does the agency providing residential services to your family member involve you in important decisions?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		81.9	13.5	4.6	326
CA-RCOC	↓	71.3	21.5	7.2	265
CT	↑	85.7	11.0	3.3	516
ME	↑↑	91.2	7.5	1.3	639
NC		82.9	12.7	4.3	322
ND	↑	87.5	11.9	0.6	319
PA	↓	73.2	19.3	7.6	1,058
SC	↓↓	70.1	22.1	7.8	154
WA		77.5	14.1	8.4	560
WY		82.3	15.5	2.1	283
<b>Total %</b>		<b>80.5</b>	<b>14.5</b>	<b>5.0</b>	<b>4,442</b>
<b>State Average %</b>		<b>80.4</b>	<b>14.9</b>	<b>4.7</b>	<b>n = 10</b>



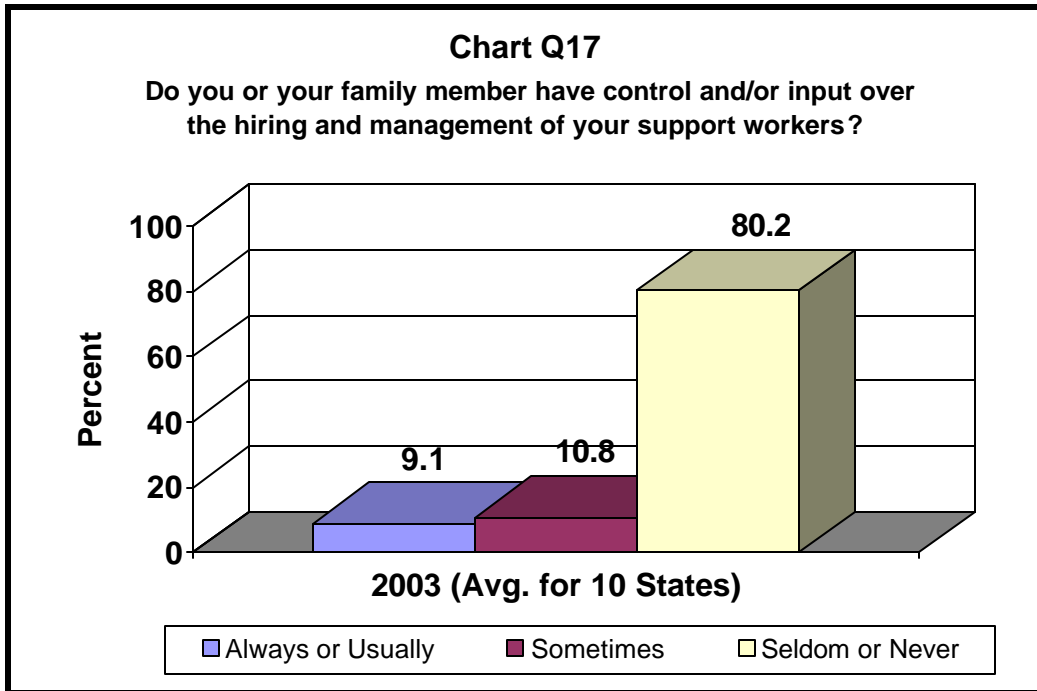
**Table Q15**  
**If your family member gets day or employment services, does the agency providing  
 these services involve you in important decisions?**

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		68.1	22.6	9.3	270
CA-RCOC	↓↓↓	43.1	28.0	28.9	225
CT	↑	68.8	18.9	13.3	435
ME	↑↑	77.8	16.8	5.4	518
NC		66.3	18.9	14.8	243
ND	↑	68.6	24.9	6.5	277
PA	↓	55.8	24.2	20.0	770
SC	↓↓↓	52.9	22.3	24.8	121
WA		65.5	20.5	14.0	385
WY	↑	69.4	23.4	7.3	248
<b>Total %</b>		<b>64.4</b>	<b>21.7</b>	<b>13.9</b>	<b>3,492</b>
<b>State Average %</b>		<b>63.6</b>	<b>22.1</b>	<b>14.4</b>	<b>n = 10</b>



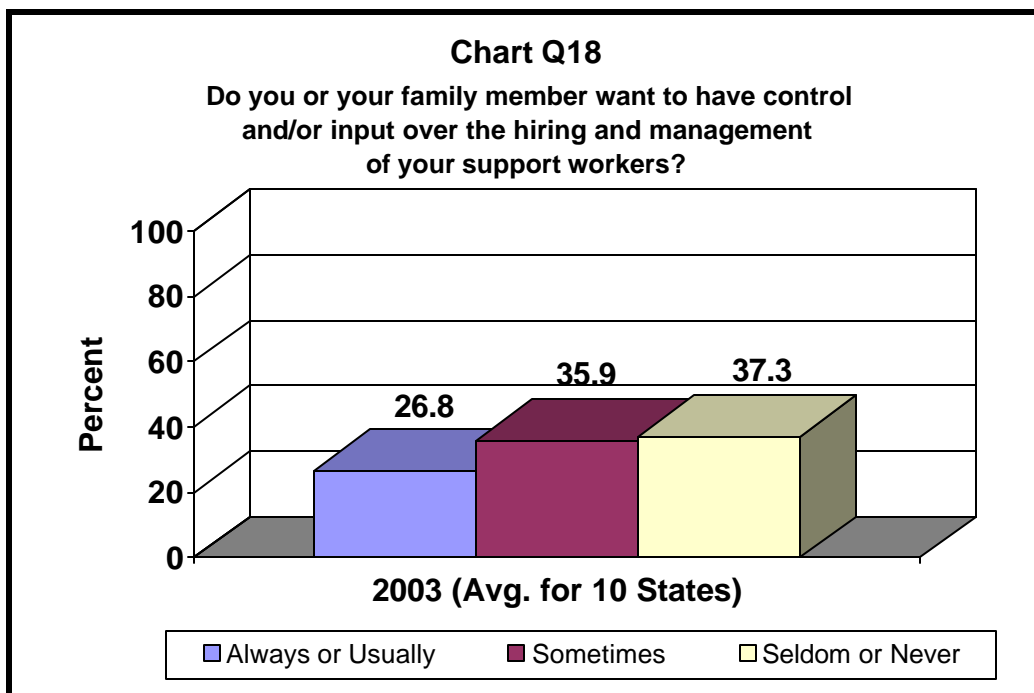
**Table Q16**  
Do you or your family member choose the support workers who work with your family member?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	10.9	12.3	76.8	276
CA-RCOC	17.5	6.6	76.0	229
CT	↓ 8.7	11.7	79.7	403
ME	16.3	13.3	70.5	351
NC	16.5	17.0	66.5	230
ND	11.3	12.5	76.2	265
PA	10.1	9.5	80.4	820
SC	18.9	13.9	67.2	122
WA	13.0	14.6	72.4	369
WY	↑ 20.5	30.1	49.4	259
<b>Total %</b>	<b>13.3</b>	<b>13.3</b>	<b>73.4</b>	<b>3,324</b>
<b>State Average %</b>	<b>14.4</b>	<b>14.2</b>	<b>71.5</b>	<b>n = 10</b>



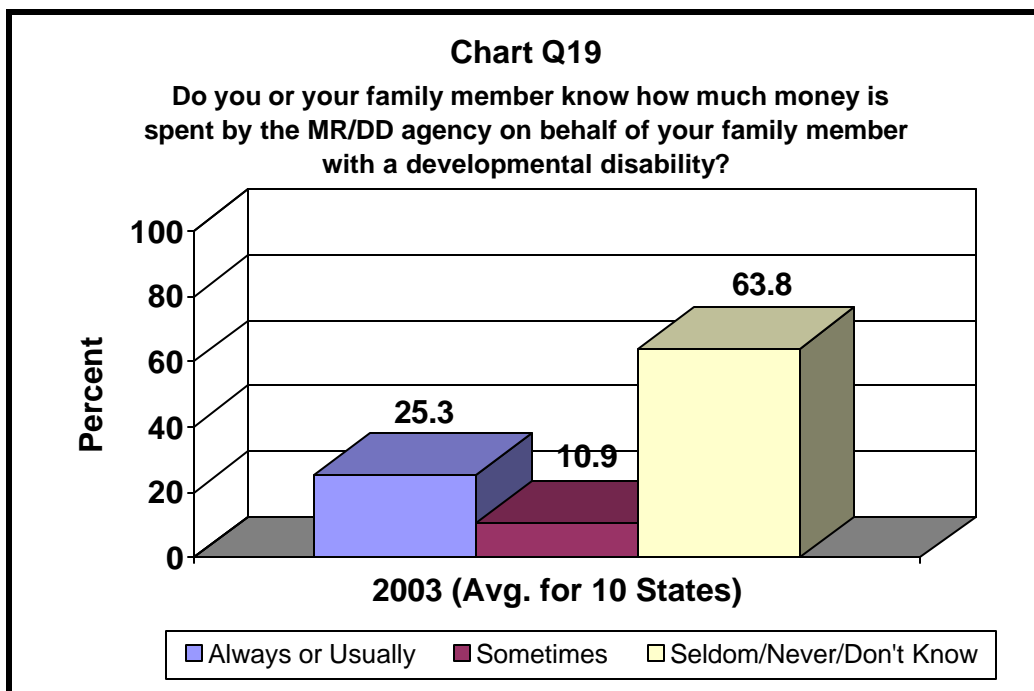
**Table Q17**  
Do you or your family member have control and/or input over the hiring and management of your support workers?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	7.0	11.4	81.6	272
CA-RCOC	10.9	8.1	81.0	211
CT	6.8	6.8	86.4	397
ME	9.9	10.7	79.3	484
NC	11.4	12.9	75.7	210
ND	6.3	7.5	86.2	254
PA	5.5	6.3	88.2	765
SC	7.8	14.8	77.4	115
WA	13.7	12.2	74.1	402
WY	11.3	16.8	71.8	238
<b>Total %</b>	<b>8.7</b>	<b>9.8</b>	<b>81.6</b>	<b>3,348</b>
<b>State Average %</b>	<b>9.1</b>	<b>10.8</b>	<b>80.2</b>	<b>n = 10</b>



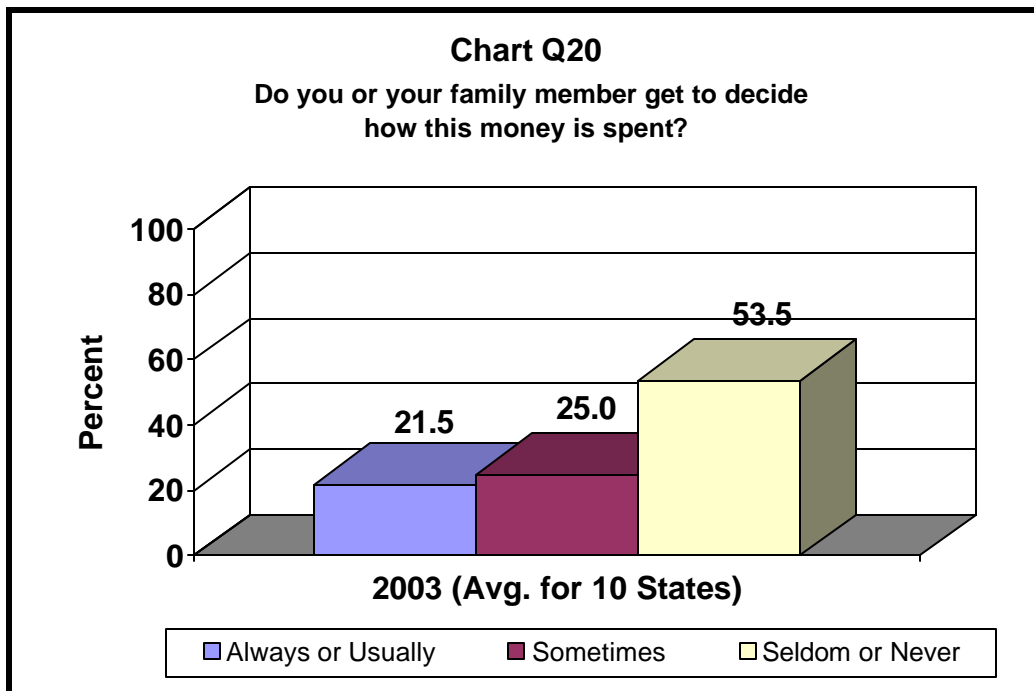
**Table Q18**  
Do you or your family member want to have control and/or input over the hiring and management of your support workers?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	29.2	42.5	28.3	233
CA-RCOC	26.5	36.8	36.8	185
CT	23.2	35.0	41.7	257
ME	25.9	34.2	39.9	436
NC	27.6	34.6	37.8	185
ND	↓ 21.6	35.2	43.2	236
PA	23.3	32.4	44.4	658
SC	31.2	33.0	35.8	109
WA	29.7	34.5	35.8	394
WY	30.0	40.4	29.6	230
<b>Total %</b>	<b>26.1</b>	<b>35.3</b>	<b>38.7</b>	<b>2,923</b>
<b>State Average %</b>	<b>26.8</b>	<b>35.9</b>	<b>37.3</b>	<b>n = 10</b>



**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
AZ	↑↑	38.5	12.7	48.8	322
CA-RCOC	↓	15.6	14.9	69.5	269
CT	↓↓	14.7	9.9	75.4	476
ME	↓↓	14.3	10.6	75.0	601
NC		25.9	7.5	66.6	305
ND	↑	32.6	11.5	55.9	313
PA	↓↓	15.0	9.8	75.2	1,022
SC	↓↓	14.0	10.7	75.3	150
WA		25.8	5.8	68.4	570
WY	↑↑	57.0	15.4	27.6	279
<b>Total %</b>		<b>22.8</b>	<b>10.3</b>	<b>66.9</b>	<b>4,307</b>
<b>State Average %</b>		<b>25.3</b>	<b>10.9</b>	<b>63.8</b>	<b>n = 10</b>

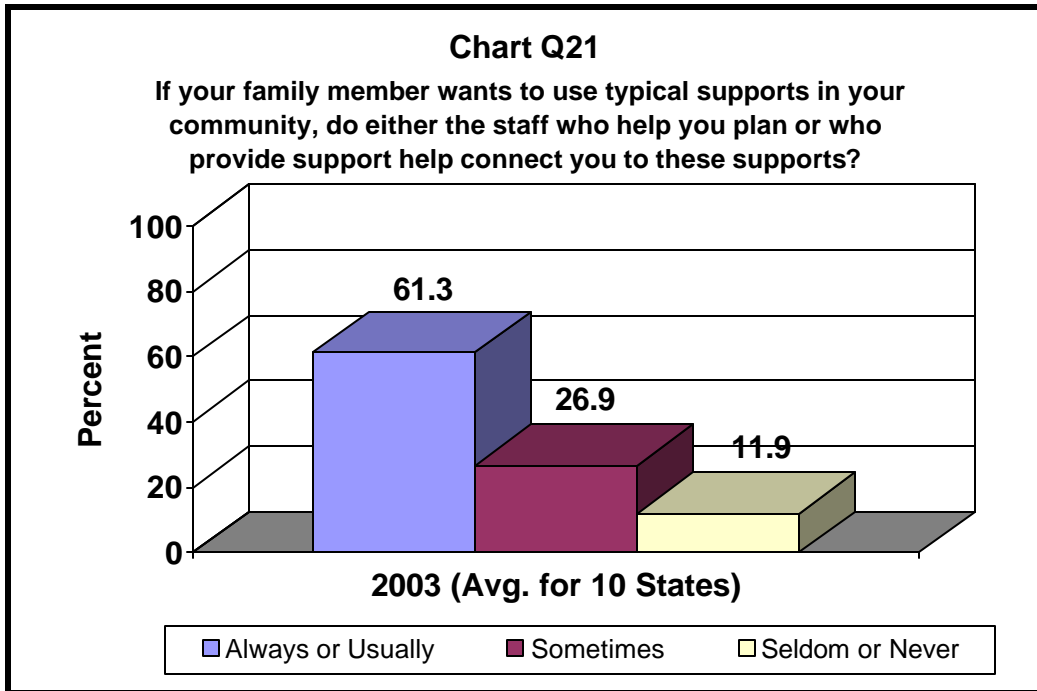


**Table Q20**  
Do you or your family member get to decide how this money is spent?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	30.7	26.6	42.7	274
CA-RCOC		17.5	20.6	61.9	194
CT	↓	12.3	26.2	61.5	408
ME		20.9	26.3	52.8	449
NC		23.3	17.8	58.9	219
ND		24.6	34.5	40.9	264
PA	↓	14.3	21.9	63.7	753
SC	↓	15.6	23.4	60.9	128
WA		24.8	19.7	55.6	412
WY	↑	30.8	32.9	36.3	240
<b>Total %</b>		<b>20.4</b>	<b>24.6</b>	<b>55.0</b>	<b>3,341</b>
<b>State Average %</b>		<b>21.5</b>	<b>25.0</b>	<b>53.5</b>	<b>n = 10</b>

## Community Connections

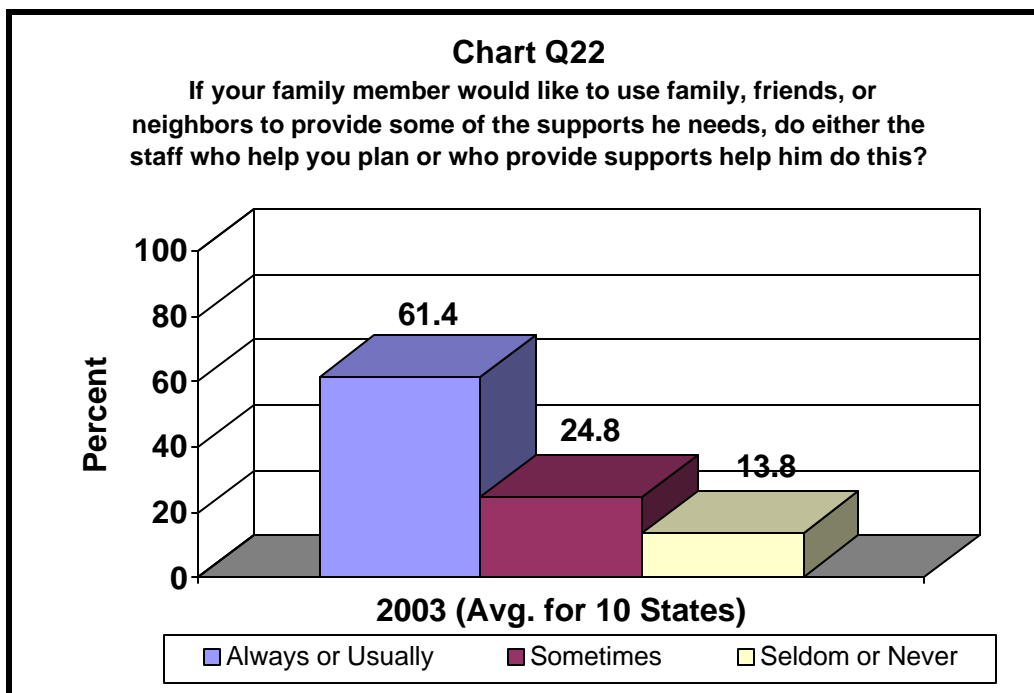
- ◆ Sixty-one percent of respondents remarked that staff were usually able to help them connect with typical supports in their community (e.g., recreation programs, church activities) if they desired to do so. 27% indicated that staff could sometimes help in this way, while 12% stated that staff rarely or never provided this type of assistance.
- ◆ Of families interested in using family or friends to provide some of the supports needed, 61% stated that planning or support staff were helpful in making this happen. The remaining 39% indicated that staff were only sometimes or seldom capable of helping families utilize friends, neighbors, etc. as supports.
- ◆ Only 64% of respondents felt that their family member typically had access to community activities.
- ◆ While 64% of families felt their family member had regular access to community activities, only 43% 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.



**Table Q21**

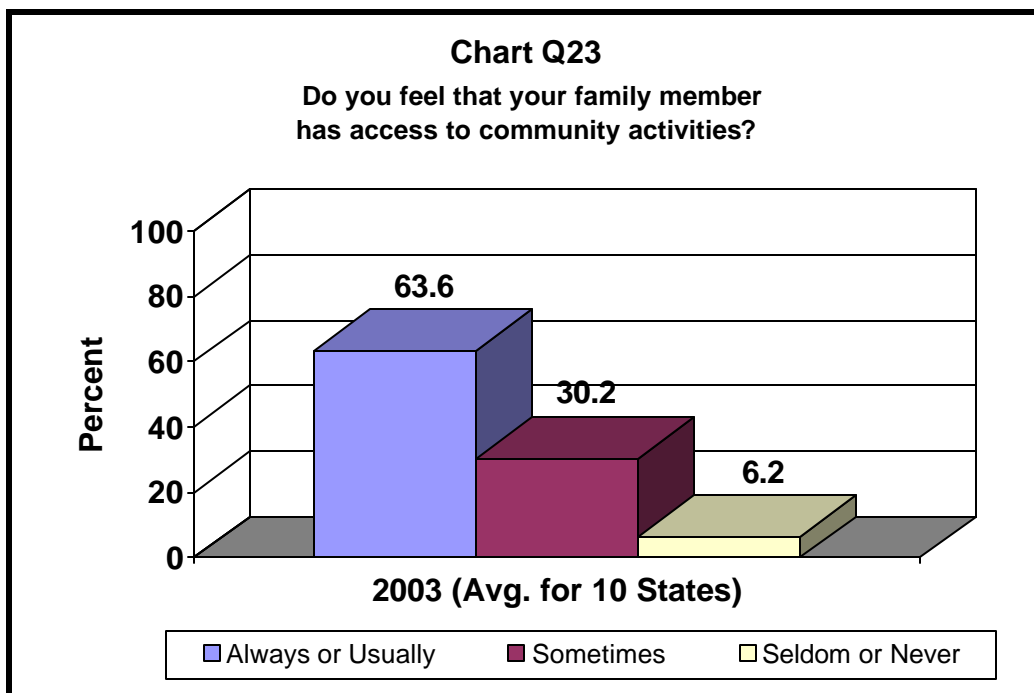
If your family member wants to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		59.2	28.3	12.5	240
CA-RCOC	↓↓↓	43.6	30.8	25.6	133
CT		64.8	23.0	12.2	352
ME	↑↑↑	76.4	19.1	4.5	512
NC	↑↑↑	71.4	23.5	5.1	217
ND	↑	68.1	25.7	6.2	276
PA		59.9	26.9	13.3	670
SC	↓	52.9	30.6	16.5	121
WA		58.0	24.6	17.4	414
WY		58.6	36.1	5.3	227
<b>Total %</b>		<b>63.3</b>	<b>25.6</b>	<b>11.1</b>	<b>3,162</b>
<b>State Average %</b>		<b>61.3</b>	<b>26.9</b>	<b>11.9</b>	<b>n = 10</b>



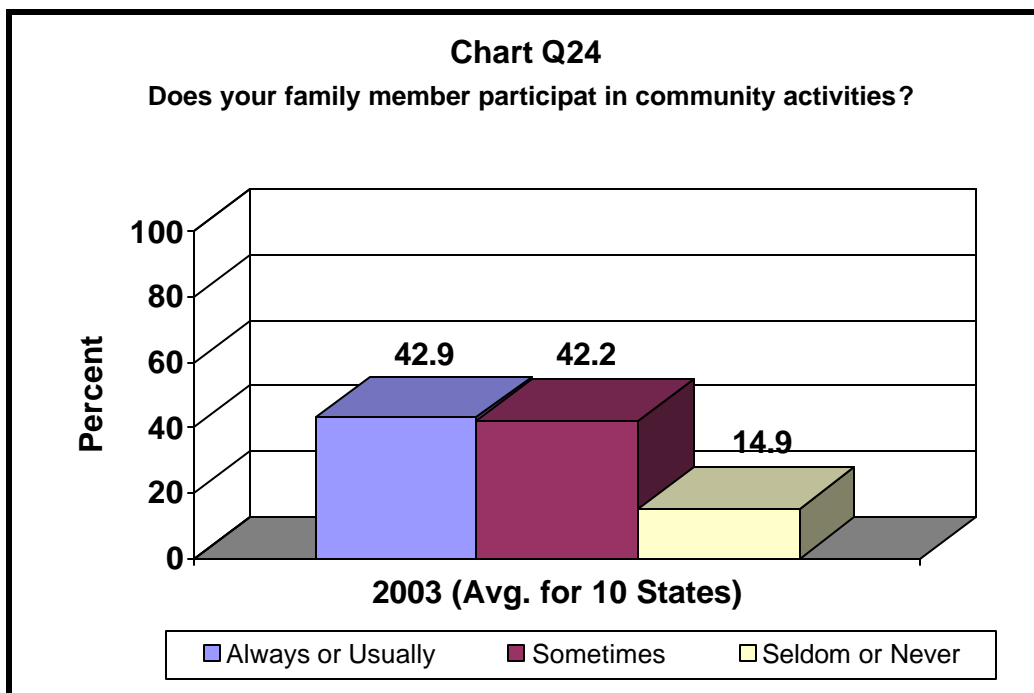
**Table Q22**  
 If your family member would like to use family, friends, or neighbors to provide some of the supports he/she needs, do either the staff who help you plan or who provide support help him/her do this?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		65.3	21.8	13.0	216
CA-RCOC	↓↓↓	41.7	28.3	30.0	120
CT		66.1	22.3	11.6	310
ME	↑↑	76.3	17.8	5.9	472
NC		65.2	21.9	12.9	178
ND		62.3	27.9	9.7	247
PA		62.5	23.4	14.1	581
SC	↓	53.9	31.8	14.5	110
WA		59.2	23.8	17.0	353
WY		61.6	29.3	9.1	198
<b>Total %</b>		<b>63.9</b>	<b>23.5</b>	<b>12.6</b>	<b>2,785</b>
<b>State Average %</b>		<b>61.4</b>	<b>24.8</b>	<b>13.8</b>	<b>n = 10</b>



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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		60.9	32.5	6.6	302
CA-RCOC	↓↓↓	48.5	40.2	11.3	239
CT	↑	69.6	26.3	4.1	460
ME	↑	72.7	23.4	3.9	608
NC		66.9	30.0	3.1	290
ND	↑	72.8	23.4	3.8	312
PA		64.6	29.1	6.3	948
SC	↓↓↓	48.9	40.6	10.5	133
WA		58.8	32.1	9.1	529
WY	↑	72.5	24.5	2.9	273
<b>Total %</b>		<b>65.2</b>	<b>28.9</b>	<b>5.9</b>	<b>4,094</b>
<b>State Average %</b>		<b>63.6</b>	<b>30.2</b>	<b>6.2</b>	<b>n = 10</b>

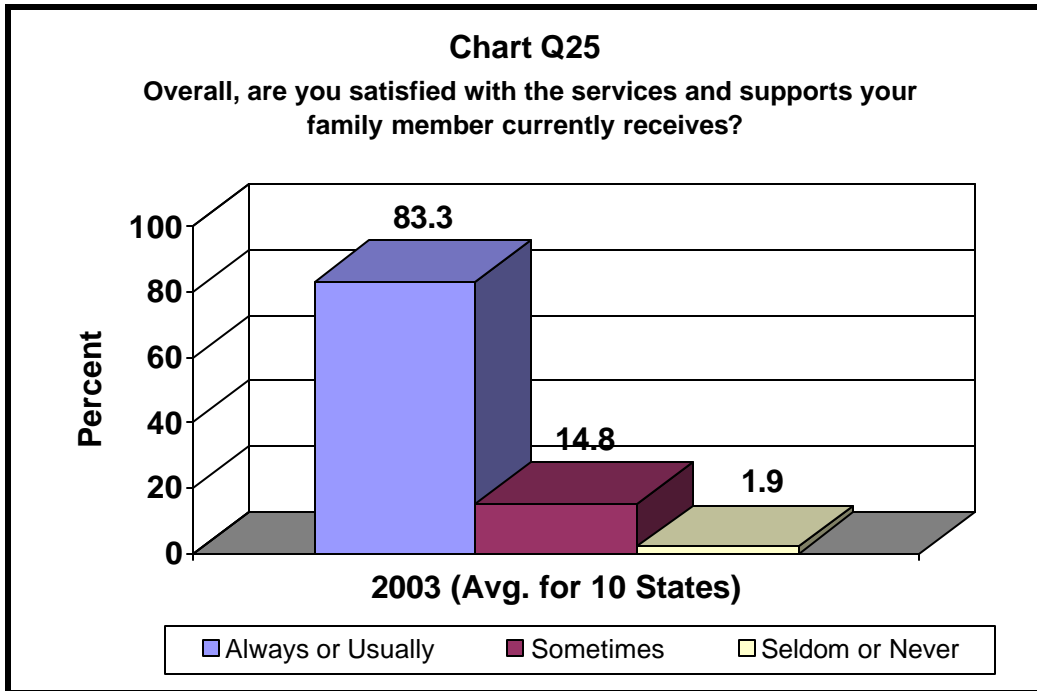


**Table Q24**  
Does your family member participate in community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		47.0	40.3	12.7	283
CA-RCOC	↓↓↓	26.0	44.6	29.4	231
CT	↑	49.2	39.6	11.2	437
ME	↑	48.0	39.8	12.2	581
NC	↑↑	52.9	35.5	11.6	276
ND		43.8	44.1	12.1	306
PA		39.3	43.3	17.4	896
SC	↓	34.4	51.2	14.4	125
WA		39.1	38.5	22.4	522
WY	↑	48.9	45.5	5.6	268
<b>Total %</b>		<b>43.2</b>	<b>41.5</b>	<b>15.3</b>	<b>3,925</b>
<b>State Average %</b>		<b>42.9</b>	<b>42.2</b>	<b>14.9</b>	<b>n = 10</b>

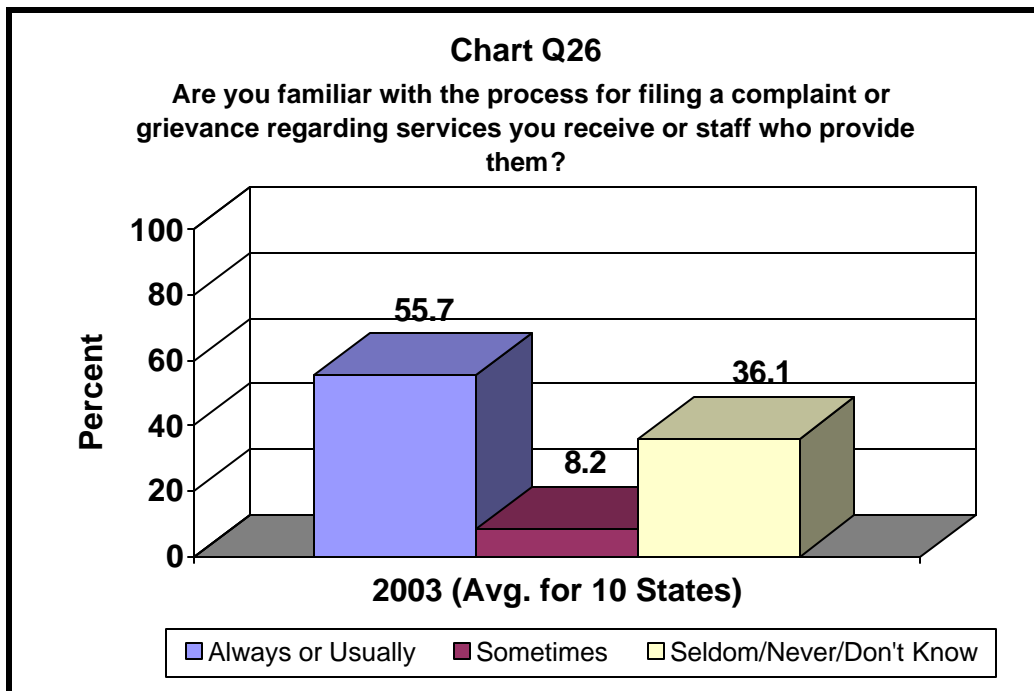
## Outcomes and Satisfaction with Services and Supports

- ◆ On average, most respondents (83%) were satisfied with the services and supports their family member received. 15% were only somewhat satisfied, and 2% were seldom or not satisfied.
- ◆ On average, 56% of respondents knew about their agency's grievance process, 8% knew something about it, and 36% had no knowledge of the process for lodging a complaint.
- ◆ The majority of respondents (68%) 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 (85%) felt that services and supports had a positive impact on their family's life. 13% stated that services sometime made a positive difference, and the remaining 2% indicated that supports seldom or never had a positive impact.
- ◆ Eighty-two percent of respondents felt that their family member was usually happy. One percent indicated that their family member was not happy.



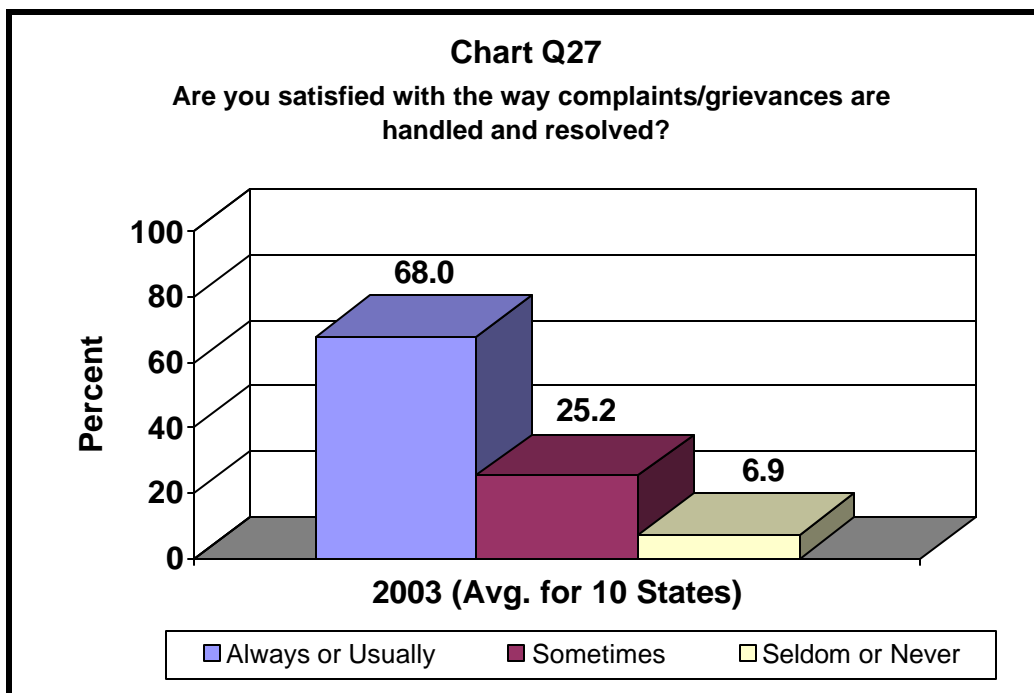
**Table Q25**  
Overall, are you satisfied with the services and supports your family member currently receives?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		81.9	16.6	1.5	332
CA-RCOC		79.4	17.7	2.8	282
CT		87.7	10.7	1.6	513
ME	↑	88.8	10.4	0.8	654
NC		83.8	15.3	0.9	346
ND	↑	88.6	10.4	0.9	317
PA		83.5	14.3	2.3	1,106
SC	↓	74.4	22.4	3.2	156
WA		79.0	17.5	3.4	610
WY		86.2	12.4	1.4	283
<b>Total %</b>		<b>84.0</b>	<b>14.1</b>	<b>1.9</b>	<b>4,599</b>
<b>State Average %</b>		<b>83.3</b>	<b>14.8</b>	<b>1.9</b>	<b>n = 10</b>



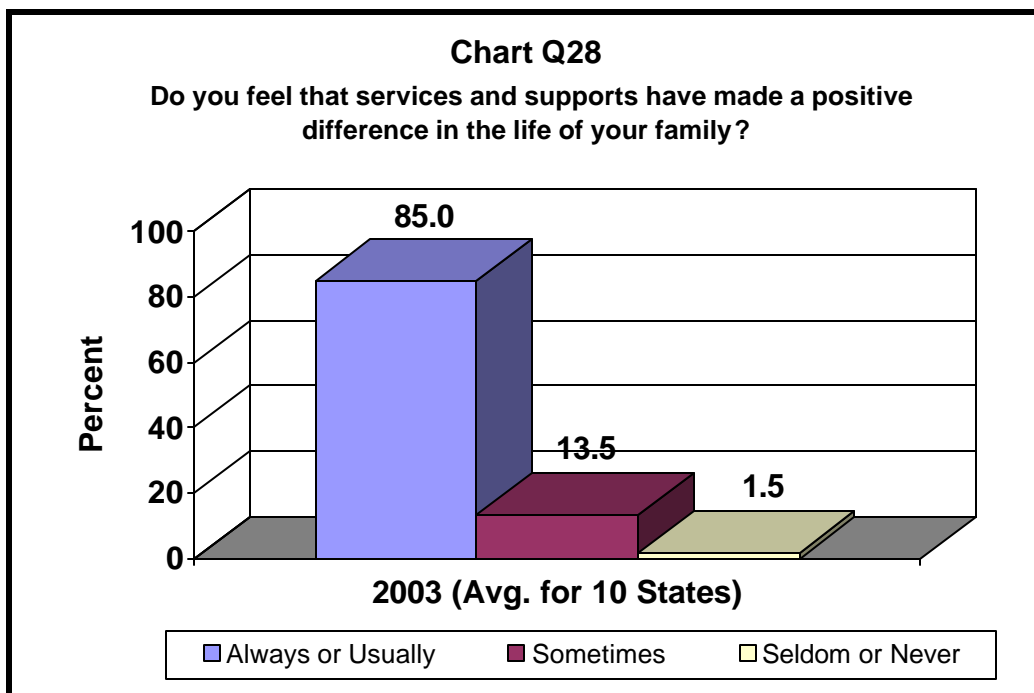
**Table Q26**  
**Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?**

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ		56.0	9.1	34.9	318
CA-RCOC	↓	50.2	8.7	41.1	263
CT		50.8	8.6	40.6	463
ME		60.0	7.9	32.0	593
NC	↑	64.1	6.4	29.4	326
ND	↑↑	67.0	7.4	25.6	309
PA	↓	49.6	7.0	43.4	1,028
SC	↓	48.3	10.9	40.8	147
WA	↓↓	42.6	8.0	49.4	585
WY	↑↑	68.5	8.0	23.6	276
<b>Total %</b>		<b>54.2</b>	<b>7.9</b>	<b>37.9</b>	<b>4,308</b>
<b>State Average %</b>		<b>55.7</b>	<b>8.2</b>	<b>36.1</b>	<b>n = 10</b>



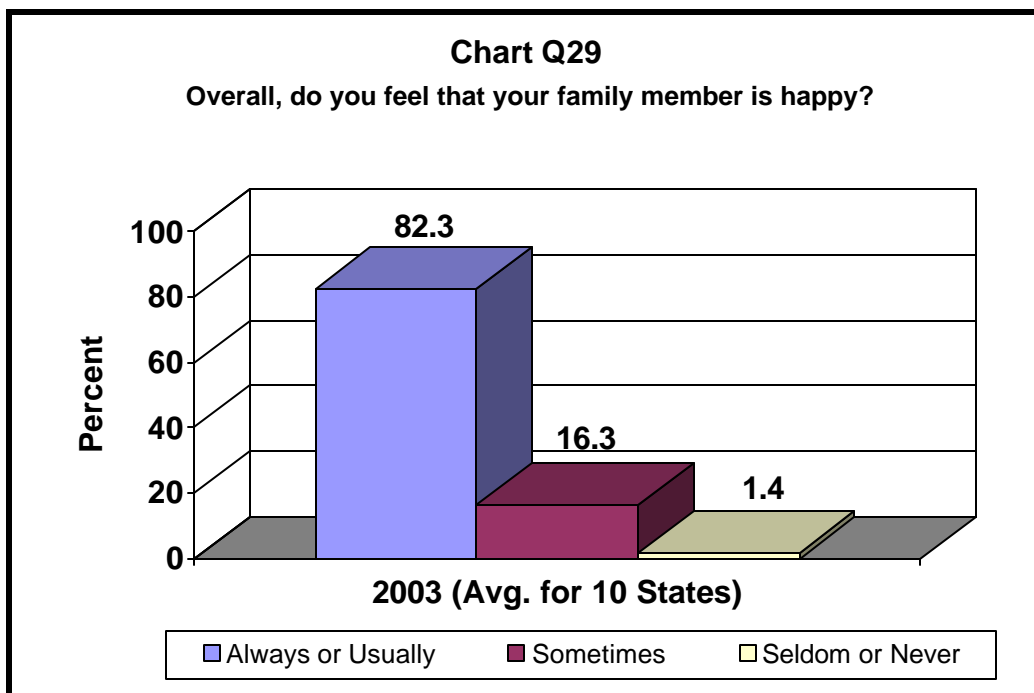
**Table Q27**  
Are you satisfied with the way complaints/grievances are handled and resolved?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		64.2	29.8	6.0	215
CA-RCOC	↓	60.6	32.3	7.1	127
CT		67.4	24.8	7.8	307
ME	↑↑	78.1	19.6	2.4	424
NC	↑	74.4	20.2	5.4	258
ND		71.1	24.5	4.4	249
PA		68.9	24.5	6.5	657
SC	↓	58.6	29.7	11.7	111
WA		67.2	22.5	10.3	329
WY		69.0	23.6	7.4	203
<b>Total %</b>		<b>69.5</b>	<b>24.1</b>	<b>6.5</b>	<b>2,880</b>
<b>State Average %</b>		<b>68.0</b>	<b>25.2</b>	<b>6.9</b>	<b>n = 10</b>



**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
AZ	82.0	15.5	2.5	323
CA-RCOC	80.9	18.1	1.1	282
CT	88.2	10.5	1.4	507
ME	89.1	10.6	0.3	624
NC	86.7	12.4	0.9	339
ND	87.4	12.3	0.3	309
PA	85.0	12.9	2.1	1,060
SC	↓ 79.4	18.1	2.6	155
WA	81.6	15.0	3.5	575
WY	89.4	9.9	0.7	273
<b>Total %</b>	<b>85.4</b>	<b>13.0</b>	<b>1.6</b>	<b>4,447</b>
<b>State Average %</b>	<b>85.0</b>	<b>13.5</b>	<b>1.5</b>	<b>n = 10</b>



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

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	79.1	17.8	3.1	326
CA-RCOC	84.8	13.8	1.4	283
CT	85.2	13.5	1.4	512
ME <span style="font-size: small;">↑</span>	87.3	11.7	0.9	647
NC	83.4	16.3	0.3	343
ND	84.0	15.4	0.6	319
PA	82.7	15.8	1.5	1,102
SC <span style="font-size: small;">↓↓</span>	72.3	25.2	2.5	159
WA	79.6	19.0	1.3	609
WY	84.6	14.6	0.7	280
<b>Total %</b>	<b>83.0</b>	<b>15.7</b>	<b>1.3</b>	<b>4,580</b>
<b>State Average %</b>	<b>82.3</b>	<b>16.3</b>	<b>1.4</b>	<b>n = 10</b>

## Aggregate Results & State Trends

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

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

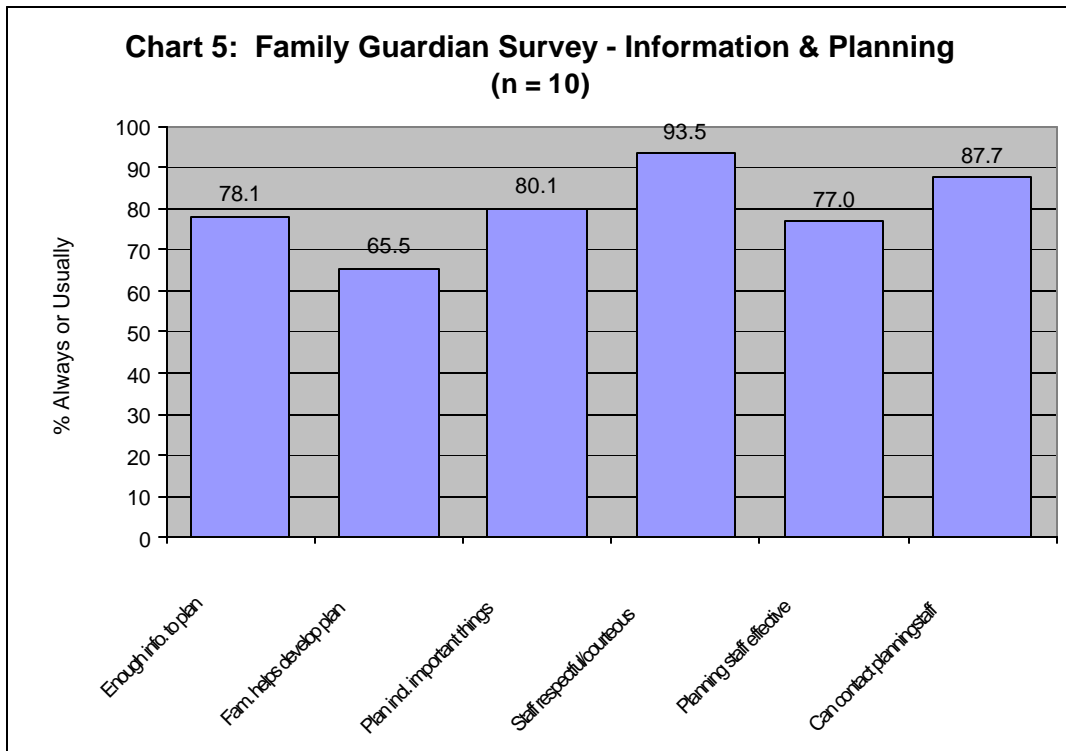
For each category, there is also a TABLE that looks at the arrows (i.e.,  $\uparrow$  and  $\downarrow$ ) of the previous Tables, with single arrows representing state results  $\pm 5\%$  from the state average, and double arrows ( $\uparrow\uparrow$  and  $\downarrow\downarrow$ ) representing  $\pm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

This compilation of results (up arrows minus down arrows) provides a crude overview of trends, 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, responses to information and planning questions were generally above the overall state average. In South Carolina, results were generally below the state average.

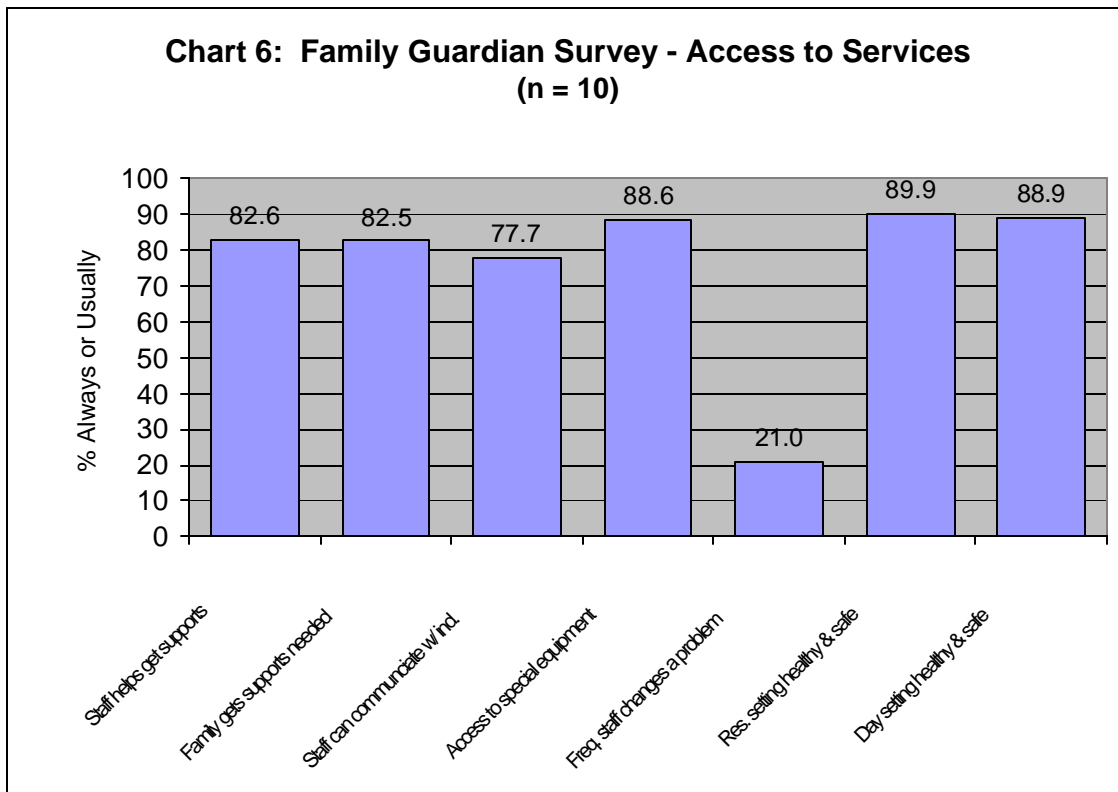


**Table 16**  
**Trends in Responses**  
**Above & Below State Average**  
**Information & Planning**

State	Q1	Q2	Q3	Q4	Q5	Q6	Net Sum
AZ							0
CA-RCOC	↓	↓					-2
CT					↑		1
ME	↑	↑	↑		↑		4
NC							0
ND	↑	↑				↑	3
PA		↓↓	↓				-3
SC			↓↓		↓↓	↓	-5
WA	↓↓					↓	-3
WY	↑	↑↑					3

## Access and Delivery of Services

- ◆ In this series of questions, responses were generally consistent across states. However, South Carolina did score considerably lower than the state average.

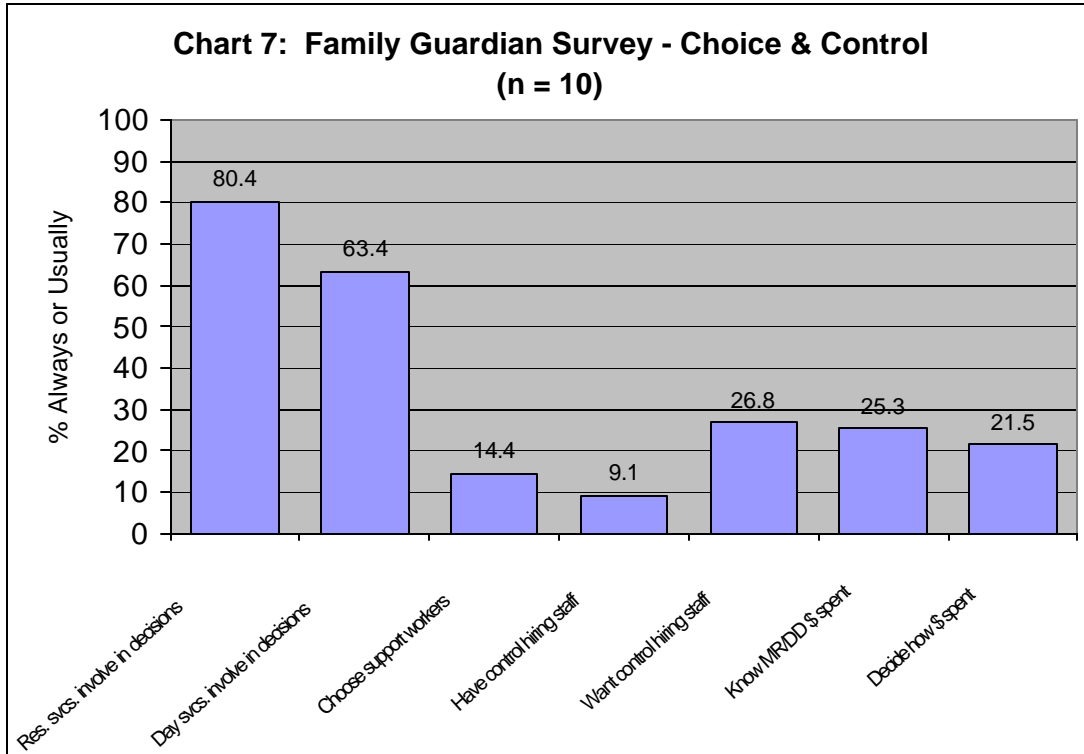


**Table 17**  
Trends in Responses Above & Below State Average  
Access to Services & Supports

State	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
AZ					↓			-1
CA-RCOC		↓						-1
CT		↑						1
ME						↑		1
NC								0
ND	↑							1
PA								0
SC	↓↓	↓				↓	↓	-5
WA	↓	↓						-2
WY	↑				↓			0

## Choice and Control

- ◆ In Wyoming, responses to choice and control questions were generally above the overall state average. In Orange County, California, Pennsylvania and South Carolina, results were generally below the state average.

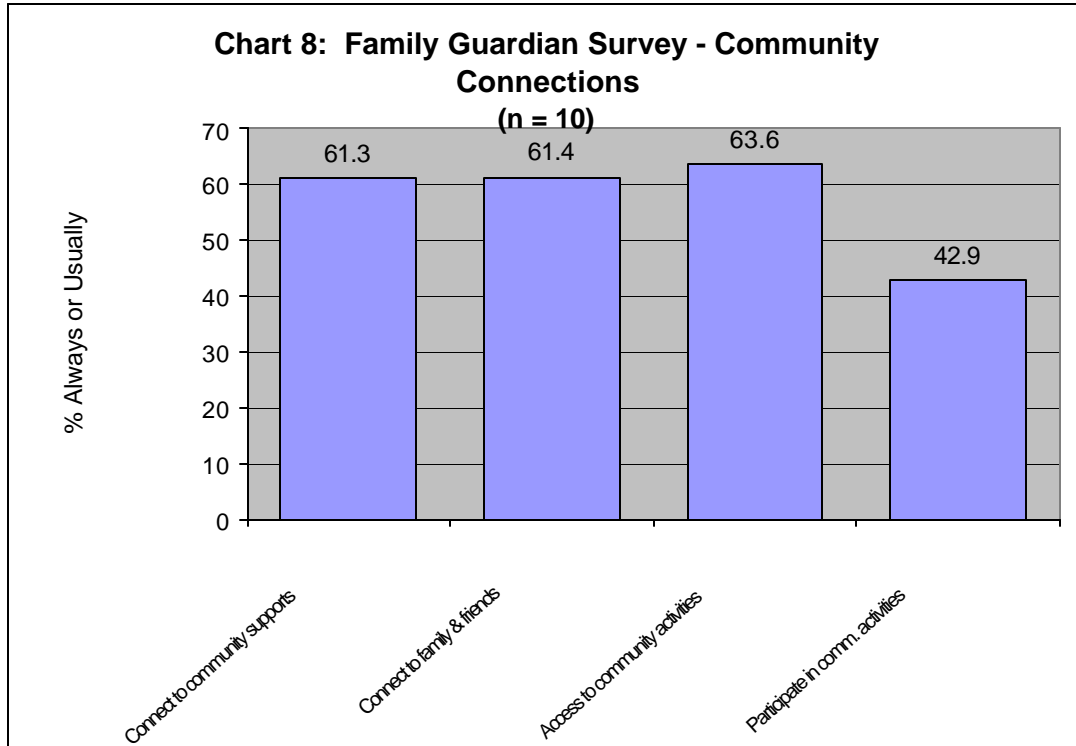


**Table 18**  
**Trends in Responses**  
**Above & Below State Average**  
**Choice & Control**

State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Net Sum
AZ						↑↑	↑	3
CA-RCOC	↓	↓↓				↓		-4
CT	↑	↑	↓			↓↓	↓	-2
ME	↑↑	↑↑				↓↓		2
NC								0
ND	↑	↑			↓	↑		2
PA	↓	↓				↓↓	↓	-5
SC	↓↓	↓↓				↓↓	↓	-7
WA								0
WY		↑	↑			↑↑	↑	5

## Community Connections

- ◆ In Maine and North Carolina, responses to community connections questions were generally above the overall state average. In Orange County, California and South Carolina, results were consistently below the state average.

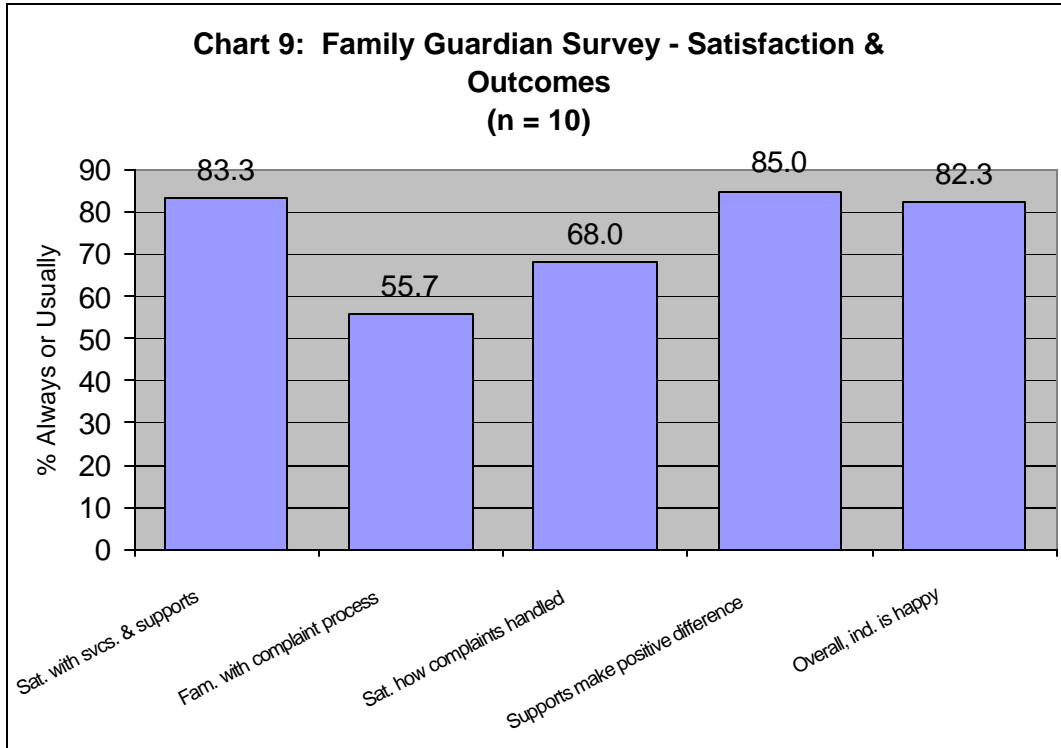


**Table 19**  
**Trends in Responses**  
**Above & Below State Average**  
**Community Connections**

State	Q21	Q22	Q23	Q24	Net Sum
AZ					0
CA-RCOC	↓↓	↓↓	↓↓	↓↓	-8
CT			↑	↑	2
ME	↑↑	↑↑	↑	↑	6
NC	↑↑			↑↑	4
ND	↑		↑		2
PA					0
SC	↓	↓	↓↓	↓	-5
WA					0
WY			↑	↑	2

### Satisfactions with Services and Supports & Outcomes for Families

- ◆ In Maine and North Dakota, responses to satisfaction with services and outcomes for families questions were generally above the overall state average. In South Carolina, results were generally below the state average.



**Table 20**  
**Trends in Responses**  
**Above & Below State Average**  
**Satisfaction & Outcomes**

State	Q25	Q26	Q27	Q28	Q29	Net Sum
AZ						0
CA-RCOC		↓	↓			-2
CT						0
ME	↑		↑↑		↑	4
NC		↑	↑			2
ND	↑	↑↑				3
PA		↓				-1
SC	↓	↓	↓	↓	↓↓	-6
WA		↓↓				-2
WY		↑↑				2

## Overall State Trends

- Looking at results across all categories, Maine received results that were generally above the overall state average. In Orange County, California and South Carolina, results were generally below the overall state average.

Table 21 Overall Trends in Responses Above & Below State Average						
State	Information & Planning	Access & Delivery	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
AZ	0	-1	3	0	0	2
CA-RCOC	-2	-1	-4	-8	-2	-17
CT	1	1	-2	2	0	2
ME	4	1	2	6	4	17
NC	0	0	0	4	2	6
ND	3	1	2	2	3	11
PA	-3	0	-5	0	-1	-9
SC	-5	-5	-7	-5	-6	-28
WA	-3	-2	0	0	-2	-7
WY	3	0	5	2	2	12

## 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 comments. QSR NUD\*IST (v.6) was utilized to code and sort the qualitative comments by theme. Themes included home, employment and day programs, education and training, health services and equipment, transportation, recreational activities, communication, aging caregiver issues, transition issues, service coordination, staff, funding and budget cuts, and overall satisfaction with services. The results of this analysis are presented by state below. Note the qualitative comments were not available for Connecticut and North Carolina.

The analysis of qualitative comments varied substantially by the number of responses from each state. In states where the sample size was large, such as Pennsylvania, a clearer understanding of the data begins to emerge. Regardless of the number of responses, these comments provide insight and supplement the quantitative results presented earlier.

### ARIZONA

Thirty-four percent of respondents wrote qualitative comments for this survey. The comments are summarized by theme below. The most frequently mentioned topic was staff, followed by home and satisfaction with services.

#### Staff

Staff was the most frequently mentioned issue. Slightly more respondents reported being satisfied with staff than dissatisfied. What follows is a sampling of comments regarding satisfaction with staff. In sum, respondents described good staff as cooperative, caring, loving, wonderful, aware of needs, helpful, and supportive.

“She is happy in the group home and the staff is very cooperative. Since I am unable to care for her, I see her every weekend. We both go to church and she is so good, always happy. The staff takes good care of her socially.”

“My son has a beautiful home at [provider] with caring people to care for him. We had a wonderful house manager...”

“The staff that takes care of my son is very good. They love him, take care of him and take him places. You name it they do it. He has a wonderful staff at home and at work.”

“All I can say is thank you for taking care of my brother all these years. The staff at [city] has been great. They have always been inclusive and I get the feeling that they, for the most part, genuinely care about the folks under their watch. It’s a difficult business and anyone can get lost in the bureaucratic maze.”

“The people we work with for our family member’s care seem to be very aware of his needs, are very protective of his space and needs, are attentive to our desires and wishes and are willing to put forth our desire for his care to other care professionals who see him on and off basis. We have been well pleased with his care on the most part since we’ve been guardians.”

"I am very happy with our family member's environment, her friends and the exceptional caring, able staff! I am deeply grateful."

"[Provider] has provided a home and living situation for my daughter [name] which I consider very good to excellent. I am not fully aware of the nature of her activities during the days spent at the [provider] Center. The home manager or supervisors do an excellent job in trying to take their 'charges' on interesting excursions into the community and commercial establishments."

"I feel that [provider] has been doing a very good job of taking care of [name]. I appreciate and trust the house supervisor, she keeps me informed, and I can call her anytime. If I have a question she can't answer, she finds out and calls me back. I am well satisfied with his care."

Slightly fewer respondents indicated that they were dissatisfied with staff due to inappropriate behavior or activities, communication issues, turnover, shortage of workers, and lack of training.

"This issue is very important to us. Every time or every once in a while money disappears. We know it is the employees. They need to be screened a lot better. We do not want 'employees' to bring all their kids and friends to the group home for Christmas or birthday parties. Young people are too loud and sometimes careless. We feel that young girls employed by [provider] should not bring their boyfriends to the group home. Let's try to stop that, they have no business there."

"I would like to see more communication between revolving staff at the group apartment on daily schedules (i.e. laundry, need for wearing apparel, help with bed making). My family member needs help with those things which aren't done sometimes..."

"The change of staff has really affected my daughter's moods and behavior. I'm hoping there will be less change of staff."

"Frequent changes in staff in group home and not enough training for new hires in group home."

"Dear Sir It seems to be that the biggest problem for MR people, who can't care for themselves, is the people who care for them. When I call or go to see my son, I usually find someone different caring for him. They know little or nothing about him and often it seems they care even less. I think staff that does direct care of our helpless ones need to be paid a lot more. Then maybe you could attract more stable people. Maybe have some incentive to stay there."

"Staff turnover is a definite problem - our family has been fortunate in that our service provider works very hard to minimize the issues that high turnover rates cause, but I think the burn-out rate is a major worry for parents."

"[Provider] have faithful and caring employees, however I am sure, they are understaffed, not only [provider] but other companies that provide services to DDD. I think these companies should offer to their employees better wages, good health benefits as well as a good retirement plan..."

## Home

The home environment was the second most frequently mentioned issue. More respondents discussed being satisfied with their family member's placement than dissatisfied.

"Overall I think that a group home for my daughter has had a very positive effective for her and our family. Through the group home they are able to provide for many more activities and community involvement than I could ever do on my own. Because my child is in a group home I have been able to work not just stay at home to care for my child. I feel I'm always informed on what is going on with my child and the burden of arranging for all of her service needs are taken care of by a professional."

"My son has a beautiful home at [provider] with caring people to care for him. We have a wonderful house manager..."

"The family member has lived in the institution most of his life. We are pleased with the relationship the institution has created and maintained!"

"My family member has resided most of her life at the [provider]. She began in a dorm setting which was not the greatest and now in a group home at the same location. What a marvelous place at her group home and she is very happy and very well cared for."

"My daughter has wonderful care since moving to [provider] Schools. She lives in a very clean group home. She is always clean and treated so kindly although she cannot talk she can make the people caring for her understand her needs. I am very pleased she is under the care of the [provider] School. Wish she could have been there from the beginning. She and they have learned so much about and with her. It is a wonderful home."

"Our family member is very fortunate to have the group home and the present supervisor is very good."

"I feel that the [provider] has provided very good services to my son, throughout his 14 year stay at one of their group homes. I have had very few problems which have been quickly resolved to my satisfaction."

Several respondents reported being dissatisfied with their family member's placement. Most indicated that they have placement needs or would like their family member to continue residing in a particular placement.

"The agency that has been providing living arrangements for my brother has not always been attentive to the living conditions within the home. The home has often been dirty and in need of repair. It is my hope the new company will work at maintaining."

"...the [provider] needs to set limits on how many clients can be served at one apartment setting."

"If this is a survey related to [provider] closure, the [provider] should not be closed. Staff are not only caretakers but friends and only family for the majority of residents. [Provider] is home to them."

"We have noted our family member's depression and senility. If these conditions worsen and make it too difficult for his home manager and day care center, would it be possible and appropriate to place him in the [provider]? This question does not mean that we are dissatisfied with [provider]. We are very appreciative of all they are doing."

"We are looking to contact [provider] and the other two agencies for a new psychiatrist and a new residential situation. We are very unhappy with staff at the group home and the severe Downs Syndrome guy who is an irritant to our family member and us when we come over."

"My son has been away for almost one year and he is in a family home. We want him back but they won't let us have him back. We are good parents and have never mistreated him at all. My son wants to come home and they won't let him. We're only allowed to see him once a month for 2 hours."

"Our family member is a 51 year old man who has totally fallen through the cracks of the system. Had it not been for what we've done ourselves it would all be for naught. He now is confined to a nursing home due to a caregiver allowing him to fall. However, now his health has improved and he needs more stimulation, which he does not receive. My wish for the new year is that something change and just one person could see how much he understands and allow him more personal attention and love."

"Regarding his day program, we would much prefer that [name] be placed in a less urban setting where he would have more freedom to be more active physically and would be allowed a greater choice of activities as well as different learning experiences."

### **Overall Satisfaction with Services**

Satisfaction with services was a frequently mentioned issue. More respondents reported that they were satisfied with services than dissatisfied.

"I am very happy with the care my brother is getting."

"My wife and I are well satisfied with the care and support afforded to our daughter. We wish to thank all who have a part in her care and life."

"My daughter is profoundly retarded and needs constant care. Her needs are beyond my financial means. For sometime now, she has been cared for by the non-profit organization, [provider]. I feel these people do a remarkable job caring for my daughter. They furnish her with those needs that I consider to be important. I would encourage DES/DDD to work hand in hand with not only this organization but any organization of this kind."

"Our son is very challenging and difficult to work with. We know that a lot of state money is being spent on his care and we are very grateful for everything that is being done to care for him."

"My son is his own guardian and is intelligent enough to make decisions with his support group. I have a disability that prevents my attending all or most of his meetings. I totally approve of the programs they have set up to help him."

"I'm very thankful there is DDD assistance for my daughter."

Our family member has been with [provider] since 1984. He has had excellent care. He is well known and almost independent. He takes the bus to visit me each year. He takes the city bus to work each A.M. I can not make any decisions for him, while living out of state. He has done so well, why change anything.”

“Overall, her placement and support has been excellent.”

“We are extremely pleased with the services and support that this program provides.”

A couple respondents reported being dissatisfied with services.

“Decisions are made re: the use of funds in a poor way. Communication conflict resolution is poor. There is way too much middle management. The quality of service gets lost. People say the right words but frequently do not know how to implement quality service. Very little financial support for quality of life in Arizona. People say they want family involvement but do not know how to utilize it.”

“My biggest concern is how the individuals' accounts are being managed. Financial decisions are made without consultation with parents or guardians and they are not in line with the ISPs.”

“I believe that he doesn't receive as many available services because of him still being registered with the school system. I fear when he reaches 22 years old and he no longer has that available to him. That there will not be any program in place for him.”

“Presently I have verbally submitted valid concerns against any visitation inside my brother's residence! [Provider] informed me Oct 2, 2002 stay out--no previous warning? After 25 years of being involved with my brothers needs, concerns etc. This experience has been the most disgraceful, irresponsible act and decision any organization has attempted without proper cause! I have requested thorough investigation.

## **Case Management**

A few respondents noted that case management is an important issue. More respondents reported being satisfied with case management than dissatisfied.

“Our family member has a very involved case manager and group home monitor that have been involved with her long-term. They keep me advised on all issues and I trust them and their judgment regarding all aspects of her care.”

“The support coordinator has always been supportive and stays in contact with us when the needed.”

“Our family member's case manager has been an extraordinary help with our family member's care and with coordinating necessary support and collateral services.”

“My sister's support coordinator is wonderful. She is thorough and helpful and extremely competent.”

A couple respondents reported being dissatisfied with case management.

"I do wish his state caseworker was a little more on the ball. She never seems to be prepared for our meeting nor does she keep her files in order."

"There are continuous changes in staff of the provider, so we never know who will be with our family member. In the 16 years since he left the school system, and even before, the State caseworkers or as now called Support Coordinators have changed numerous as much as two or three in one month. Occasionally we have found one who keeps in touch with our son, looks in on him, and is always available to me. That has been rare, although right now I am able to reach her when I feel it necessary. "

## **Communication**

A few respondents wrote comments regarding communication. In particular, respondents wrote comments about communication problems, language barriers, and needing information about services and supports.

"We would appreciate quicker communication between the group home, day program and our home as far as incidents are concerned. We get written reports but would appreciate a call as soon as an incident occurs. We care and are concerned about how she is doing. We want our input quickly about how and best resolve the problem whatever it may be."

"There should be better and more prompt contact when there is a problem - physical, doctor appointments, hospitalization. The doctor contacted me when she was taken to the hospital (2 days later) instead of the counselors."

"On page 5, my answer is due to your not having staff that speak Spanish. They are very nice but we can't communicate. I ask, why do you not have Spanish speaking personnel so that we can better communicate? There are things that I do not understand in the group my daughter is in."

"Staff that cannot speak the English language clearly it is hard to understand when they telephone me with a problem."

"Would like information on filing a complaint should the need arise."

"DDD needs to have a reliable list of support specialize services, re: OT, PT... that can provide required services or else be willing to pay those that can! Parents/guardians do not have such information at hand."

"I would like to know how his [provider] is being used toward his cares, activities and how it is spread out for his care. I would also like to know the monthly amount of his [provider] check. I have not seen any paper work on this for over a couple of years."

## **Employment and Day Programs**

A few respondents wrote comments about employment and day programs.

"His day program is the most positive part of his life. Without that he would regress and have and create problems."

"I must say that the [provider] which manages our family member's group home and is as well his employer at the day program where he works (and loves it) has done exemplary work in both instances. Their concern and care is pretty evident in their daily actions in dealing with my son and his many problems."

"His job is a fine fit for his limited talents. He loves his apartment and work."

## **Health Care**

Health care issues were mentioned by a few respondents.

"A complaint was filed regarding a motorized wheelchair and even went to court to no avail. Our family member was denied the proper cushion for her wheelchair even though it was requested by three different therapists and a doctor."

"I would appreciate dental care. The cost is so expensive when the patient must be sedated."

"I think more dental services should be available for handicap. Without dental insurance, it is very expensive for families."

"Is it possible for my son to go to a Physical Therapist to work on his legs at least to have him bend his legs? Are there other places he can go to rehabilitate the usage of his legs?"

## **General Well-Being and Safety**

A few respondents wrote comments regarding well-being and safety.

"I am basically happy with [provider]. One thing that constantly falls through the cracks is making [name] exercise. It's always on her IPP, but not followed through on. She has very bad knees and is heading for a wheelchair. She has gained 60 to 70 lbs!"

"My daughter gets hit regularly by one of the other two residents at her three resident group homes."

"My family member's health has been put in danger due to [provider]!"

## **Funding and Budget Cuts**

A couple respondents mentioned funding and budget cuts as areas of concern.

"Overall my son has received quality care. I worry that this won't always be so with the cutbacks that are coming."

"Continuing budget cuts make it very difficult to provide a good and happy living arrangement for these people. His day program is the most positive part of his life. Without that he would regress and have and create problems."

Thirty-four percent of respondents from California wrote qualitative comments for this survey. The comments are summarized by theme below. The most frequently mentioned topic was satisfaction with services, followed by home, and health care.

### **Overall Satisfaction with Services**

Satisfaction with services was the most frequently mentioned topic. Over one fifth of respondents wrote comments regarding satisfaction with services. Most indicated that they were satisfied with services.

“Thank you for all you all do to support the needs of the developmentally disabled in Orange County. My sister's quality of life is excellent because of services your organization provides.”

“Thank you for your services rendered to this consumer. Deeply appreciated.”

“RCOC has been very patient in handling my son's case which is very difficult. His worker has always been responsive to all his demands, which at most times are unreasonable. I feel you are all doing a fabulous job.”

“We are very satisfied in the services given to our family member and hope for continuation of this program.”

“I have used RCOC for the entire 31 years my son has needed them. It has mostly been great and am forever grateful they are available. The group home he is in currently has been one of the best experiences ever, for him and I both.”

“My daughter is quite self-sufficient now due to all the fine support she has received since she was small. She lives in her own HUD apartment works as a bagger for a large market and loves her job! Her last job was a 9 year commitment and she loved it. She is able to get all over Orange County by city bus transferring when necessary and is rather unflappable and capable. I must say, she is a lovely lady, very happy, responsive and eager to be helpful. Everyone seems to like her and she likes everyone she meets. She rather begrudgingly allows her day program to work with her on any issues she has 1 hour a week. She belongs to several groups of handicapped young people and has a nice social life . I truly think she is a great success story and I'm always happy and proud of her. She's the youngest of 5 adult children. Over the many years we have been so happy to have wonderful support from RCOC.”

“We are deeply grateful for the services provided by the Regional Center of Orange. Our son's life could never have been so full and independent without their help!”

“You all have done a wonderful job with meeting our disabled family member's needs. I thank you so very much. It is very satisfying to know those of us, who are not perfect are cared for and can have dignity and respect.”

“Thank you, Regional Center for being there, and for your much needed services.”

A few respondents reported being dissatisfied with services.

“Regional Center does not follow through with their recommendations. When problems in group homes are brought to RCOC's attention, they say there is nothing they can do. Always say other agencies are responsible. Everything seems to be a problem when you call. Resolution is never easy and the family has to push constantly if something needs to be done.”

“You should also be asking how much work the family/guardian does in getting supports and services - if we really need something. I know the RCOC is not the place to turn to get it. I'll do it myself (e.g. get what I need myself). RCOC is generally ineffective. I'm the one who gets wheelchair repairs, communication devices fixed, etc. They do nothing!”

## Home

The home environment was the second most frequently mentioned topic. Families wrote comments about satisfaction with their loved one's placement, needing placement options, and dissatisfaction with the placement.

“My daughter has lived at the same placement for many years. I am pleased with her care there, she is a happy, well adjusted adult. I am a widow, 84 years old and it is a godsend that she lives at this place. I am pleased, she happy and productive.”

“We are happy with the group home, school setting/job training for our child.”

“I have used RCOC for the entire 31 years my son has needed them. It has mostly been great and I am forever grateful they are available. The group home he is in currently has been one of the best experiences ever, for him and I both.”

“I am extremely happy with my son's placement and the support of RCOC in his well being.”

“My family member loves and expresses the fact that he want to stay in the group home where he now lives.”

“My son has lived in many other homes and this is the best he has resided in, the staff are very loving and caring people. He also has said he likes living there.”

A few respondents indicated that they were dissatisfied with the home environment or placement decisions.

“They do not call when he is sick and ends up in the hospital. I feel my son is being taken advantage of. I am so far away. His father put him in a home. Now his father is not around and didn't visit when he was. I have bought my son so many things. They seem to disappear. Also, now my calls are not accepted. He told me before that he was sad and lonely not having family members around. I used to call everyday. I stopped trying. Also, I believe he is being manipulated by the house owner. He told my son I only want him with me for the benefits but I do believe it is the other way around. The service coordinator is no help.”

“I am very unhappy with the process that RCOC decided that my brother was a candidate for a move to an outside residence despite my repeated input that I think such a move is detrimental. Just because the state says MR individuals should be moved out of a place if there are no problems with the person doesn't necessarily mean that it's an appropriate move. Disruption in a person's normal routine can cause setbacks which then take a long

time to overcome once again. I strongly disagree with this policy and the fact that I will have to fight this in court to prevent such a move.”

“I would encourage Regional to use whatever means available to conduct ‘quality of care and inspection visits’ to client “home” facilities on an unannounced basis and adapt a grading system and report to encourage Group Home to maintain care and quality.”

“I would like to see our Regional Center develop more homes where the adult residents can have their own bedrooms. I think we need more quality assurance personnel checking on residential programs occasionally: pillows, blankets, soap and towels in bathrooms, clean carpets and bedspreads, activities and recreation, clothes mended, pressed, correct size, etc. These should be unannounced visits.”

## **Health Care**

Health care was a frequently mentioned area of concern. Families wrote comments about health insurance, dental care, and medical care.

“The only concern I have regarding my daughter's care is her medical and dental benefits. So many physicians won't take medical because of the extremely low reimbursement that it is hard to find doctors that provide good care. She had surgery for a fractured femur last year. I was very satisfied with the hospital and surgeon. However, her dental care has been inadequate. She suffers from peritoneal disease and needs treatment every 3 months. It is difficult to get her teeth cleaned every 6 months. She has already lost teeth and she is only 34 years old.”

“I need help in finding a provider of dental services for my son who will pay for anesthesia. He needs to go under for dental work. Currently, I have dental insurance that pays for it, but it will cease very soon when I go to Medicare.”

“I feel that RCOC or the care providers should have lists of doctors, psychiatrists, psychologists, dentists, etc. to provide to consumers, parents or guardians. It is very difficult to find which ones accept medical and other forms of insurance that's provided to the clients.”

“I think more mental health assistance should be provided to people with developmental disabilities. It is very difficult to find professionals who are qualified to competently help DD individuals who have mental illness (dual diagnosis). Mental health assistance is not available from RCOC to a client who has medical insurance coverage from parent's employment, even though that assistance is desperately needed.”

## **Staff**

Several respondents wrote comments about staff issues. A majority of respondents reported that they were satisfied with respondents describing good staff as: friendly, helpful, caring, empathetic, loving, and supportive.

“The personnel are friendly and helpful. I realize that the staff have a difficult job to do and that they work hard. It would be nice if staff stayed longer; but I realize the job must be exhausting. The people working with my son presently, are extremely helpful and caring.”

“As a parent, I am extremely grateful to Regional Center. The support and advocacy, guidance and direction, connections and the very personalities have all made dealing with handicaps more bearable. We appreciate all you do. Thank you! I've also been amazed at the higher quality and genuine empathy and care at Regional Center workers have exhibited.”

“On every survey I complete I feel the need to mention the wonderful work of this facility and her staff. They have provided my son with love, care and support. He has never been so content in any other environment and that of course enhances my well being.”

A couple respondents reported being dissatisfied with staff.

“Regional Center staff have limited knowledge about my adult child and his disability. I have no support from RC staff -- the quality of staff at RCOC has decreased over the past years. Staff are less trained and less interested in the consumers they serve.”

“Also, group home rates increase so staff can be paid more would lesson turnover rate. More lobbying should be done on this aspect.”

## **Case Management**

Several respondents mentioned case management issues. Approximately the same number of respondents indicated that they were satisfied with case management as those who reported being dissatisfied.

“As always, our entire family is most grateful for the services, counselors and service coordinators of Regional Center of Orange County. The home where my son lives is the best thing that could have happened to him. He is very happy there and loves the people who tend to him. My RCOC worker right now is the best!”

“We are especially grateful for the help and kindness from our service coordinator.”

“I am very satisfied and grateful for the support my son receives from RCOC. I am very glad that he has the service coordinator that he does.”

About half of the respondents reported being dissatisfied with case management.

“I can contact the service coordinator but she doesn't always contact me back. Service coordinator is respectful but treats the consumer like a baby - he is 32! Talks down to him, speaks loudly to him (he is not hearing impaired).”

“It would be helpful if the RCOC service coordinator was not changed so frequently. It seems we just get to know the person and establish a working relationship and that person has to leave for some reason or other. Also clients who are disabled do not adapt willingly to some changes so it would be better if the RCOC service coordinator could serve for a longer period. When it is necessary for the service coordinator to change it would be helpful if she or he could introduce the person taking their place.”

“RCOC's inability to keep services coordinators should be addressed. Probably low pay and large case load are factors. Hopefully it won't get worse with new state budget.”

## Communication

A few respondents wrote comments about communication. Most reported being dissatisfied with communication.

“My son lives at a facility and one person handles most of his program but I am well informed and am in contact with her on a weekly basis. Most of the time.”

“Although conversations take place via telephone, seldom do the words become action! Calls are not always returned nor do I receive feedback or updates without being the one to make contact. Too much talk to placate my concerns but seldom has action been initiated. Had reason to contact on duty day person (because current case worker had quit). Day person took my inquiry, but never called back. I was told they would call back within 24 hours. I was disappointed. Meanwhile, I was able to resolve problem yet could have done so sooner if the on-call worker had gotten back to me.”

“Nobody gets in touch with me about my daughter. I don't go to visit because it makes me very sad to see my daughter like this. That's why I stay away and also she is 9 to 10 hours away. Would like to know how she is doing, even though I don't go down to Southern California.”

“At this time, the lady in charge of her home speaks little English. She is kind and warm but we worry about a serious emergency. Could she communicate--we hope so. In my experience group home staff (a large percentage of them) have very limited English speaking skills. It can be an issue.”

“If I had my way, the staff at the group home could speak English. Can't understand a word any of them say, they don't understand me, it's a big problem to me. But no one cares.”

## Employment and Day Programs

A few respondents wrote comments about employment and day programs. Slightly more respondents indicated that they were dissatisfied than satisfied with these services.

“She would like more hours of paid work, or meaningful volunteer activity like a library.”

“I believe my disabled family member should return to a sheltered workshop experience like the long-term relationship he had before.”

“Adults need more opportunities for meaningful work.”

“My major concern was regarding my brother being removed from a work setting that was a good fit, and being ‘promoted’ to an enclave setting after I had expressed more than once that this had been tried 2 or 3 times in the past without success. I strongly object to my brother being pushed into inappropriate settings, to provide work for trainers, and then to suffer feelings of failure because he doesn't meet the required expectations. He has no wife, no children, no hobbies - his place of work is very important to him. More care should be exercised before that routine is changed. How much ‘support’ did he receive when he was initially fired from his new job and demoted back to the old one? Job counselors appear to overrule experienced family members.”

“Thank you for caring for my son. He loves working at his job. He has been working there for 13 years.”

### **Recreational Activities**

A couple respondents wrote comments about recreational activities.

“We keep busy, shopping, visiting, bowling, camping, etc. When at the group home very little activities other than sending him to his day program, takes place. I think the group homes should be mandated to provide social activities for clients who want them.”

“It would be helpful to receive information on athletic events such as Special Olympics. RCOC coordinators never follow through on getting my brother involved so I would love to see that information readily available. Especially to those consumers who are out of school and need to be a part of the a team to participate.”

### **Aging Care Giver Issues**

Aging caregiver issues were mentioned by a couple respondents.

“I have concerns but have no clue as to who to contact. Not much I can do anymore since getting up in age myself. When I think of her, I worry and get upset. So I am doing my best to convince myself not to even think about her because I have no rights on her behalf anymore.”

“My concern is my aging and not being able physically to see my son as often as I would like. I do call once a week and see him four times a year. I hope to be able to do this. I am kept informed of his activities. For financial and health reasons I live several hours away. And am not able to drive freeways at this time. I pray that the work of the Regional Center will continue to be as wonderful as it as been. And that group home where my son lives is always available to him.”

### **General Well-Being**

A couple respondents wrote comments about general well-being, such as safety issues, hygiene, and consumer abuse.

“Sometimes I do not feel what I think needs to be taken care of ‘NOW’...is done soon enough. Example: ‘Broken or lost glasses’. Can take up to 3-4 weeks to replace or refit. ‘Cracked Helmet’ (for seizures) up to a month ‘podiatrist’ over 3 months. His toe nails have been growing over and around toes (he won't complain I understand that's a problem). Regular scheduling of appointments might solve that.”

“The more serious problems have been a lack of response when consumers report abuse. A lack of advocacy for the consumer and more support for the group homes. Quality Assurance has even been in meetings and said things like: ‘shut up’, ‘the group homes have to run a business, ‘wait until you move out’. The consumer called a liar by area supervisor when she says they need to get me out. Service coordinator great but RCOC as a system needs to be white sheeted and revamped and started over from scratch.”

## Transportation

One respondent wrote a comment about transportation.

“Although [provider] provides a very important and good quality service, it would be so nice if my son could have transportation without having to call a day in advance. He could, and has ridden the city bus, but it makes him feel vulnerable and uneasy.”

Approximately 34% of respondents from Maine wrote qualitative comments for this survey. The comments are summarized by theme below. The most frequently mentioned topic was home, followed by satisfaction with services and staff.

## **Home**

Home was the most frequently mentioned topic. Most respondents reported that they were satisfied with the home situation, while only a few were dissatisfied. Some respondents also commented on placement issues. Respondents who were satisfied made comments such as “my daughter is in a safe and healthy environment” and “I no longer have to worry about her care and comfort.” The following are examples of positive comments.

“[Name] is the agency caring for my daughter. I no longer have to worry about her care and comfort. The administrative staff and personal care providers are the very best. I am very thankful for their service.”

“My daughter is in a safe and healthy environment she seems happy the staff are doing a good job and all are very caring for all their clients.”

“[Name] is very happy at the group home. Please do not disrupt his life.”

“I strongly feel that my daughter needs to continue being cared for in a single home with full staff. She has done better in a setting like this than any other. The setting she has been in the past few years has worked much better than any other.”

“My sister is living in a group home. [Name] could not be a better care person. She goes way above the call with her girls. We could not find a better place for her to live.”

“I feel this home that he is in and the staff that he has have been wonderful to my brother and when I get a chance to see him you can tell he is content I thank all the people that has been in my brother's life.”

“My daughter is happy in the home that she is living in.”

“She gets the best care around. Always looks well dressed and clothes all match. Hair also combed well and clean hair. She could not get better care anywhere.”

“At the present time my son is in a very nice home and has been there for 9 years. Been a lot of help changes which upsets him but he does seem to overcome them.”

“Were he is now he loves to be there, he has friends, a nice room, and likes to play records.”

“My brother is very happy. It is a wonderful caring facility and we hope [Name] will be able to stay there permanently. They have all helped [Name] unbelievably since living there.”

“Our son [Name] has been a resident at [location] since 1978. He has been the happiest there and we are so pleased to have him there. I just can't say enough good things about them.”

"We have nothing but praise for [location]. The staff is a group of extremely dedicated people who have the residents' best interests at heart. We are most grateful to them and the workshop personnel."

"I am very happy with the care and love she receives from [location]. It is very special to [name] and all the staff are very good with her."

"We have noticed how happy [name] has become since he moved into [location]. He has much more freedom to do the things he loves. He goes everywhere with staff. They are very compassionate with all of their clients. They always keep us informed."

"My daughter lives in a group home. She is well taken care of and staff is wonderful. She is taken on outings and your horse back riding."

"The man for whom I am guardian resides in an [organization] home and I must commend them on their excellence in philosophy of care of PIR -training of their staff-and doing their best of maintain a steady staffing patterns."

"The wonderful place where she is now has been a blessing and provided my sister with a life changing dream fulfilling world."

"The only thing I want and say is I hope in the future my sister is not moved. She is so happy there. The staff is so good her. She's done so well there. It would be a hardship on me because I could not get to her."

"The staff at [Name]'s group home have always been supportive to him and me. I feel he gets the best of care and I am very happy with them."

"She lives with a roommate. She has very good staffing. They keep us well informed."

Some respondents wrote that they were dissatisfied with an aspect of the home situation. The following comments are examples of this dissatisfaction.

"I am not completely satisfied with my sons living conditions. He is in a low income apartment crowded with many small children around. Children make him very uneasy and he sometimes gets quite upset. We would like very much to find an affordable small home."

"The closing of [center] in [city] was the worst thing that could happen to my daughter's well being that was the only place she did really well for a very long period of time. I only hope she can adjust to her new place."

"The staff turnover at the group home makes it difficult sometimes to get problems taken of!"

"As guardians/parents -we sometimes feel the house manager and staff do not make any effort to schedule activities that our daughter wants to do. Many times she has asked them to do something only to be told staff was not available."

"Although I was impressed with the pre-placement visit I have been somewhat disappointed with the way things have turned out over time. I feel the department paid way too much for the services [name] has been receiving. There is no recreational activity program."

“Recently there was a management change made at the group home and we were notified by phone days after the event. Then this week the team leader moved out and another co-worker notified us after a few days.”

“Since he is having so unnatural behavior changes at this time I have some concerns about how well he is adjusting to his new provider home.”

Some respondents wrote comments about home placement issues.

“My older brother receives adequate care and we are working to find him a more suitable placement through his case worker.”

“Been trying for 4 years to get [name] a place to live but for some reason the worker is out to lunch or doesn't return calls.”

“This was a hard survey for me because I just removed my daughter from a house and she is in respite till a new home is found.”

“It took help from several people to get my sister out of a nursing home and back into an [agency] home.”

“Our family member has had difficulties at times with finding appropriate housing when one situation ends and there are no other openings available. Stressful on everyone!”

“My family member is in the process of finding a new home due to the closing of his. The process has been extremely difficult and frustrating with the current system set up due to the state of the State of Maine.”

“Right now I am quite upset and have spent many sleepless nights over the changes in my daughter's home services.”

“My family member has the best life he has ever had. His transition to his own apartment was smoother than I'd ever dreamed it could be.”

“My son recently moved into a two client home and the transition went very well. I'm very pleased with the final arrangement. It took about 2 years to complete all arrangements for this move.”

### **Satisfaction with Services or Agencies**

Satisfaction with services was the second most frequently mentioned topic. Most respondents were satisfied with services, while only a few respondents wrote comments expressing dissatisfaction with services. Respondents who were satisfied with services used words like gratitude, appreciation, satisfied, happy, excellent, helpful and courteous to describe their satisfaction.

“No complaints. I have gratitude and appreciation for the care and services he receives on a regular basis.”

“[Agency] is very good with my son. I am very much satisfied with everything that they do.”

“I am satisfied with his group members.”

“Our son is very happy w/his services and life.”

“My younger brother receives excellent care.”

“In his present program with [organization] he is far better off in all ways. I sincerely hope that his future will maintain this great level of care. I only wish that our parents could see how he is cared for.”

“My family and I are more than satisfied with the service our family member is receiving. It has taken years of dedication of many people in our community area to develop the services that are available to our loved ones.”

“I believe my son receives the best care and services that can be provided due to the severity of his condition. His support staff are always helpful and courteous. They keep me informed and involved in his treatment and condition.”

“I feel that the overall program is very efficient and fair to the client.”

“We are very happy with the services our family member receives. We believe these services are very important in order for our family member to have the highest quality of life possible. These services have helped him mature and gain a high self esteem.”

“The agency that deals with my brother is exceptional in the services they give and the way they care for clients.”

“The [agency] program to include all employers and administration who are responsible for the care and well-being of [Name] have performed in a most satisfactory manner in his care.”

“We are grateful for the funding that enables our daughter to live independently-a true gift. Thank you and bless you.”

“As indicated we are pleased with our son's services. Hopefully there will be no charge in the future.”

“My son has been with the [organization] adult program for about 18 years. I have been very pleased with the care he has received. I can't think of a better situation for him.”

“I fell that [the program] is helpful and we could not function as a family and maintain our own jobs without your supports.”

“The care given my brother has been a god send. Providing for him in ways I and my family would never be able to-either physically or financially. Thank you.”

A few respondents commented that they were dissatisfied with services.

“I realize this way seems callous but I feel more of the resources which are devoted to people such as my sisters could be devoted instead to the healthy-non-impaired children of this country. But this would also go to diverting resources from the military.”

“[Name] should spend her time and money on data management and invest more time in human interaction.”

“Our disabled child daughter is a 3 to 6 year old in a 48 year old body. Because she is 48 the agency thinks she should be treated as an adult and consequently has made a few errors in judgment.”

## Staff

Staff was the third most frequently mentioned topic. Most respondents were satisfied with staff, and only a few were dissatisfied. Many respondents commented on staff turnover, a shortage of workers, and pay. The following are examples of positive comments.

“Staff at [location] are very good at what they do. If more homes in Maine were as good as this one-no one would have any complaints.”

“Always satisfied with the care givers we couldn't ask more.”

“Most of the support people she has had through the years have been excellent!”

“I live on an island off [city]. Staff are always willing to help with plans to get my daughter back and forth. They call-write and e-mail me whenever the need comes up.”

“His support staff are always helpful and courteous. They keep me informed and involved in his treatment and condition.”

“In [city] the staff should be a role model for the rest of the homes in Maine. Due to their lack of staff changes. They have a knowledgeable-helpful-understanding staff that is the envy of any other home in Maine.”

“Generally the care received by our family member has greatly enhanced both his life and ours. He gets the best of care by a loving caring compassionate group of people who are very capable in all they do.”

“The staff that work with my sister have always been helpful and any information I need is supplied. Phone calls are always made to me when important decisions in her daily life are needed. Otherwise I trust them to make the best decisions in her everyday life.”

“He is very well supervised and the supervisors and staff communicate very well with mom and dad.”

“I would offer my gratitude and appreciation to the Resident Director and staff at the [agency] group home. They are extremely caring and sensitive to the needs of the residents and are excellent in communicating to me.”

“His staff are caring and compassionate. He wants for nothing.”

“[Name] is very happy with the staff some of whom she has known for 25 years. She likes the house and is a very happy little girl.”

A few respondents reported dissatisfaction with staff.

“It has been very difficult for staff to sustain a program for diet and weight control. A difficult task altogether, her but stakes are high for mobility and general health.”

“Recently one full-time staff and one floater staff communicated to me they did not know how to operate a nebulizer. I reported this to the house director. Staff should have knowledge of all equipment used by their consumers.”

Several respondents commented on staff turnover, a shortage of workers and worker pay.

“I think the constant turnover in staff is a problem for everybody.”

“One concern I have is that there is usually a high turnover rate for staff personnel. I understand that this is a difficult area to improve on since the reasons for high turnover are Medicare pay and burnout.”

“My niece doesn't do well when new staff come on board. Her needs are everyday and with the same routine. Thank you.”

“Changing staff is an on going problem. Maybe if the state could provide a better wage for them there wouldn't be such a big turnover.”

“The turnover of the hands-on workers in the group home is constant. Some of [Name]'s very favorite people have been replaced without our knowledge or without our understanding the reason. Every turnover is upsetting to [name].”

“The only problem I have with the agency that takes care of my family member is staffing. I am pretty sure my family member is at a level of care needed for one on one during working hours. I believe that is what you are paying for.”

“If only the wages could be raised and benefits included.”

“Also the low pay of the wonderful staff is abominable and contributes to frequent staff turnover.”

“There is a large turnover of staff members- I believe this is partially to do with low incomes and too long a time span between pay raises.”

“Support staff are underpaid and under-supervised.”

## **Case Management**

Several respondents wrote comments about case management. Most respondents were satisfied with case management, while only a few were dissatisfied. Additionally, two respondents commented on case manager turnover. The following highlight the positive comments.

“Since our family member has been under the care and supervision of [name] his life has taken on a much fuller happier quality. He feels secure with her and has come to trust her for the support and consistency that have alleviated so many of his fears.”

“[Case worker] is the best person we could ever have to take care of [Name]. We know that as long as [case worker] is with [name] that she is being well cared for. We trust [case worker] thoroughly with any decisions that need to be made regarding [name].”

"I have been very satisfied with the case manager who always returned calls and problem solved these past years."

"Our case manager has been doing a wonderful job."

"My sister's caseworker has been very helpful over the years. Sometimes, however, it is necessary to go to a higher authority to get things done."

"I feel that we are so blessed to have a warm and caring social worker. She has enabled us to keep our family intact."

"[Case manager] is a crucial part of the care that my son gets. She is on top of everything no matter how difficult the things seem to be. I would be lost with out her."

"[Name] has been in crisis for several months and I am truly thankful for the way her case worker has helped her."

"My son is very well served by [case worker]. She returns [Name]'s phone calls(which can be numerous), and has coffee with him from time to time."

A few respondents were dissatisfied with case management. This comment is an example of this dissatisfaction.

"My son is a high profile consumer and has a huge budget yearly. I could do a better job of managing his services."

Two respondents commented on case manager turnover.

"I understand why it happens but if at all possible it would make it easier for client and family to have the same caseworker as long as possible. Otherwise this family has been very happy with all services and people we have had to meet."

"There has been such a turnover in case workers my son does not have one right now."

## **Employment**

Several respondents commented on employment. All respondents were satisfied with employment services.

"We also are very happy with her employment."

"My daughter enjoys going to her day program very much."

"My daughter is happy in the home that she is living in and the workshop or day services she receives are excellent."

"She goes to a day program in [city] and they do remarkable work with her."

"[Employer] is doing a great outstanding job, they should be congratulated."

"My son is happy and he loves to go to work. Even if he can only do minor amounts of work- he is very proud to be able to go to work."

“Thank God for [employer] and the devoted employees.”

“My daughter has been in the same home and job as a hostess at [employer] for 14 years. She leads a full and satisfying life and is very content. She takes part in many community events- knows many people-has many friends.”

“My son has Down Syndrome and has just turned 40. He volunteers at the Bath Soup Kitchen and delivers Meals on Wheels 1 day a week. He is really proud to do this and likes the praise he gets.”

## **Communication**

Several respondents wrote comments about communication. While a few respondents were satisfied with communication, most were dissatisfied. Communication topics mentioned include interagency communication and the communication of information. The following are examples of positive comments about communication.

“Communication is a top priority. We like the one on one phone calls with staff and our daughter.”

“The facility my son is in is great. Communication between the facility and me about my son is excellent. I would never want him anywhere else.”

The next comments highlight many respondents’ dissatisfaction with communication.

“The problem I have most of the time is getting the answer to my questions from the State.”

“I wish those in charge of trying to help him would listen to my comments. They set him up for failure time after time and those who really know him on a daily basis agree with me and have for 35 years.”

“It’s sometimes difficult to know who to contact when there are questions. A general chart or fact sheet showing who’s responsible for what would be helpful. I am very pleased with the care my ward receives at his RCF.”

“I have both a daughter and a son. My son I get a lot of information but I get no information about my daughter.”

“It’s very important to keep active parents involved with all aspects of their disabled family member. Many of us don’t know who is being hired as client and family members’ needs.”

“I think it would be wonderful to be asked if I wanted to or could attend interviews. Not always possible but when it is I would love to attend and have some input.”

“I am very concerned with [name]’s unemployment status and the lack of communication (in American Sign Language) between group home staff and [name]. As a result of both factors [name]’s behavior has drastically deteriorated.”

“I am very concerned with the merger between two very over-worked agencies. I don’t want my ward’s programming or service to change with the merger. It has taken me several years to get him to a place where he is stable and happy most of the time.”

## **Funding and Budget Cuts**

Several respondents wrote comments about funding and budget cuts.

“I would like to say that I am very concerned with my budget cuts that will undoubtedly affect my friend and his services he currently needs. Cuts have already affected his health and well being regarding Medicare.”

“We are satisfied with the services she receives now and hope the state will maintain enough money so these same services will be available in the future. We cannot see any area of her services that should be cut including the number of people that work with her.”

“Our daughter has matured into a wonderful young woman. Our only concern is the problem with the state and funding.”

“The Governor and his staff have to step back and think hard about curtailing services for these people. In our case our sister has outlived our parents and my sister and I are now co-guardians. So to cut any services would put a financial burden on us.”

“My concern is going forward if my sister will have access to the programs to fulfill her needs. What happens if the funds are not available? She is happy where she is and I wonder if she will be able to continue in the program if the funds are cut.”

“There is a constant concern about diminishing financial resources for group home activities.”

“I am concerned that perhaps the cuts will affect him and his population. I have a problem with cutting funds for our population that can't support themselves.”

“Lack of funding often prevents my son from receiving services that he sometimes requires.”

## **Aging Caregiver Issues/Health Problems**

A few respondents commented on aging caregiver issues and caregiver health problems.

“Her parents aren't going to live forever-then what will happen to him?”

“I was unsure of the appropriate way to answer some of these questions since we are currently in a state of flux. My brother has always lived in his own home with our parents. Our father died 5 years ago and our mother recently went into a nursing home.”

“Chuck is in a Therapeutic Foster Home (with one other 40's male) with Autism. I feel it is appropriate at this time, but what happens after death? I don't want his siblings taking on my responsibility.”

“My mother has been the active guardian until now. But she is in a nursing home so as the co-guardian I'm just starting to be involved.”

## **Health Care**

A few respondents commented on the topic of health care. These respondents focused on dental and medical care.

“My only disappointment is that my brother’s dental needs are not being attended to.”

“I would like for someone to help [Name] control his violent behavior to find out if his conduct is caused by the combinations of the drugs that he is taking.”

“Family member with disability has feet with deformity extremely wide and has to have special shoes made for her.”

### **General Well Being**

Two respondents wrote comments about the consumer’s general well being. These comments on health and safety.

“[Name] seems to be very happy with the way his life is going right now. He sees us when he wants to and we see him whenever we want to. He also enjoys the provided care more now than in the past.”

“We believe some of the safety issues should be reviewed and evaluated. Our son had his small finger broken twice in one month and nobody seemed to know how it happened.”

### **Transportation**

One respondent commented on transportation.

“My daughter can exhibit aggressive behavior. The agency does not allow her to travel unless it is in a van. They do not provide the van so unless the worker owns a van she does not get out unless she walks.”

### **Recreation Activities**

One respondent wrote a comment about recreation activities.

“There are certain activities like camp that my family member enjoys. He went one year and the following year he wasn’t able to go. We were told there wasn’t enough money /or he wasn’t on the list.”

### **Advocacy/Choice/Self-Determination**

One respondent commented on advocacy, choice, and self-determination.

“As a family member ages and has lived out of the home environment for a number of years it would be ludicrous for another family member to decide how support money should be spent.”

## NORTH DAKOTA

Approximately 31% of respondents from North Dakota wrote qualitative comments for this survey. These comments are summarized by theme below. The most frequently mentioned issue was concerning staff followed by home issues, satisfaction with services, and dissatisfaction with services.

### Staff

Staff was the most frequently mentioned issues for this survey. Approximately the same number of respondents wrote comments stating that they were satisfied with staff as were dissatisfied. Respondents who were satisfied described staff as: willing to meet, does a great job, well informed, warm, respectful, caring, supportive, treated my family member like family, competent, devoted, top-notch, reliable, dedicated, and respectful.

"I appreciate all that is done for my daughter. Anytime I have concerns or questions or want to meet all or most of the team; willing to meet. When the staff has issues they need or want to discuss they call."

"We have always had great respect for the workers in the area of disabilities. They do a great job. And always seem well informed on their jobs."

"We are very satisfied with the services and care provided at our local group home. The workers all seem to be cut out with the same "cookie cutter"- warm, caring, respectful and supportive. They help the eight men fit into the community beautifully."

"I have always been very impressed by my sister's care in a group home. The staff have treated her like family and always been professional in keeping me informed regarding her health and progress. Good job!"

"Our daughter has been in a group home in [city] for 6 years. She seems happy there and sometimes is brought to [city] as our health is not great. Always so good to see her and caregivers are very good to her. The service providers are thorough, caring, and respectful of the needs, desires of my family member!"

Approximately half of respondents were dissatisfied with staff services, specifically noting staff turnover, lack of education or training, lack of communication, or low pay as problems.

"I would like the staff hired to help my child to be screened more carefully. He has been abused in the past. My child has had a great turnover of staff that were his primary contact person. I get confused at times to whom I should call about my concerns, etc."

"I have also noted that staff doesn't take resident's physical complaints seriously and also are not often informed about various medical illnesses. In regards to: the personal care assistance-needs improvements; the turnover of staff in group home- highly needs improvement; the quality of care of client's personal items- needs improvement (i.e., personal items inventory kept up to date and an honest search through each client's room for 'lost or missing' items including clothing)."

"We see our brother out in public with dirty clothes, unshaven, and in clothes that don't fit. One of his caretakers was a convicted felon and he was arrested in front of him. Checks

were written for fast food signed by him but used by others on weekends that he was home with his family. A staff member wrote checks out to CASH, signed them and endorsed the back to receive cash. Not at all proper! Tremendous amounts of groceries were purchased (over \$300.00 at Sam's Club) and the cupboards were empty. His bedding is very seldom changed and actually filthy sometimes. Checks were written to the barber shop (he's bald) for haircuts. He complains (for years to date) that one caretaker hits him. Caretaker's wife is the one who wrote check to CASH. Her brother also works there. It makes for a dangerous situation."

"There is a fairly high turnover of staff who do direct care at the home. We suspect their wages are modest and probably do not commensurate with the hard work they do."

"Our main concern for our son is quality staff-caregivers at his apartment. There's such a large turnover and too many that are not trustworthy. Another concern is lack of affordable physical therapy."

"We feel that if staff in these programs were paid better, they may be able to keep staff and not have such a high turnover. The staff has a very hard job, with all the needs that need to be met for the individuals. We feel they need more training working with the individuals before they are allowed to do services for them."

"We are so grateful for the support of so many good caregivers. Our family could not survive without them. But we worry that we are losing a lot of good people because the "pay" is not always that good. Would like to see that increased because it is such a valuable service."

## Home

The majority of respondents who wrote comments about the home environment were satisfied. Most of these respondents specifically noted that they were satisfied with the group home their family member resided in.

"I had her home a lot till we moved to ND, then we dropped down to every 6 weeks. In the past year, our daughter has become happy at her group home, that she doesn't want to come to our house, which is what a parent works for."

"I think that these people who are working with my son are doing a great job. My son has been at this place for 40 years. He was taught to read, write, control his temper! He is now at work doing janitor work, goes to recycle places. He goes to dances, movies and many other things in the community. They are very good to my son! Thank you for helping my son and other people like him! Keep up the good work!"

"My son is placed in a group home [city], ND. In my estimation he could not get better care anywhere."

"I feel the group home in [city] has very caring staff and give my uncle a very nice home. I feel that they go above and beyond the call of duty to make my family member very happy. When we ask if he wants to live some place other then the group home, he says he wants to stay there forever."

A few respondents mentioned that they were dissatisfied with the home environment.

"I feel the group home my daughter is in should be cleaned by adult cleaning people- not clients who are on a job outing, as things aren't done. The floors are terrible and entrances are never cleaned unless it rains. Supervision needs to be on the weekends also- this is not the case for my daughter. Unsupervised workers sit and watch TV. Very limited monitoring for adult services- bothers me!"

"The state of ND lacks group home settings geared to the folks with mild MR that require supervision of medication, assistance with medical appointments and supports, and general coaching in making safe choices and staying out of trouble. They would benefit from living with others at their level. It is alarming to know that many of those former [provider] consumers are now on their own- to SINK or SWIM!! Why is it that government insists on taking needed services from those that often can't stand up and engage in defending their right to services?"

### **Overall Satisfaction with Services**

Several respondents reported that they were satisfied with services, specifically with staff and group homes.

"The family services are excellent in every way!"

"We are happy with the care our daughter is receiving. [Provider] and [Provider] does a very good job. My brother lives approximately 90 miles from where I live. And where he is, we are 100% satisfied with the services he receives."

"We appreciate the staff of our family member's Group Home and all the provisions of [provider]. Our family has high regards for services provided for my brother."

"I am very happy with [provider]. They do a great job in meeting my son's needs. They keep me involved with what they are doing and goals they hope to meet."

"I am happy with my family member's care and I am informed of her care. Overall, I'm very satisfied with the care she receives from [provider] in [city]. She is in a wonderful environment with dedicated and caring staff from group home worker on up to top management."

"We are very happy and satisfied, where our child is. She has made her parents and siblings very proud of her and she has taught us all a lot about life."

"I am very satisfied with the care my son gets. They have done so much more for him than I could (I raised him the first 12 years). There are some very dedicated people working in that field, and I am amazed at the patience they have with those less fortunate, their charges."

"I am very pleased with the services offered/available to my cousin. I am included as necessary and my input is always considered and accepted."

"As guardian, I am completely satisfied with the care and services that are provided to my elderly brother. He is getting outstanding care, something I could've never given him, as I worked outside the home and have, in my retirement years, health problems myself. My thanks goes out to all who provide this kind of care to our loved ones who are incapable of caring for themselves! He has it so good where he is, everyone is so good to him."

## Overall Dissatisfaction with Services

A few respondents reported that they were dissatisfied with services. In particular, they tended to mention dissatisfaction with the home environment, limited services options, or inappropriate placement.

“This community independent living buildings are not working out. The clients are either scared or bored when it gets dark. So they go out in the community looking for companionship. The only kind out there are the no good. So they get In trouble or get into bad habits. There needs to be more housing with 24 hour staff. I am thinking of a building with apartments and community living room. Doors locked every night at the same time so no one can leave or get in. The clients need to feel safe and know that staff is there for them any time. Just because a client can prove that he or she is capable of the domestics for apartment living does not qualify them to act responsible to community social functions. Also I do not like your guidelines for your programs. You do not consider all the functions when going by the guidelines to qualify for the programs. For instance, the capability of being able to do the function disqualifies you to participate in the program. But the capability of not being able to do it on your own isn't considered. Why does it take so long to get anything done? It is always the same thing over and over. It's almost like it gets passed from one person to the next and no one seems to know why.”

“I think having a choice of service providers would make life better for my son. At this time we have only one agency providing SEP services. Only one provider that does attendant care. If you have a problem with the one provider that serves your community and there is no where else to get the service, you are stuck between a rock and a hard place. On several occasions, we have made the decision to not receive any services vs. inadequate or sub-standard services. The biggest concern with this type of situation is we (his family) must make up for the missing service which we will do. But what about when we are gone? Or what about people without active family support?”

“Yes I would like to see my sister doing more for herself. She has to learn to do more for herself, to cook not just to microwave. She needs to know everything doesn't come out of a box. And to clean her messes up everyday, not just when she feels like it. It would be nice if she could find more people at her level, not the real handicapped. She has been hit and scared of some of these people. Sometimes I think it brings her down because I think she feels sometimes she is crazy. She needs to go to more dances. She loves to dance. And do more art and other things.”

## Health Care

A few respondents reported that they were dissatisfied with health care, specifically, with health care equipment, insurance, dental care, and physical therapy.

“As a guardian, I feel that people with disabilities needing a wheelchair that use ND programs should not be limited to one chair. I feel that the program should provide repairs on the manual and the electric chair. I feel that residents who have wheelchairs are treated unfairly. My child that I am guardian for gets \$30 dollars a month for fun activities, supplies, clothes, eat out etc. and is expected to pay for her expenses on a manual chair because the system will only pay for 1 chair. Put yourself in her place, where do you get the funds to pay for a new chair and expenses?”

“Family member is on Medicare and Medicaid. I have concerns about some of the restrictions and limitations of medical services and special needs that impact individuals with disabilities.”

“Another concern is lack of affordable physical therapy. There is not enough funding for regular therapy. Presently, our son receives none.”

## **Case Management**

A few respondents wrote comments regarding case management services. Slightly more respondents commented that they were satisfied with case management.

“Our family's/child's needs have always been met wonderfully through the DHS case management services. When hard decisions have had to be made case management has been there to guide and implement available supports. The services have met our son's needs as far as IHP/Respite/Residential/ ISLA, wherever the need be presented! We have felt well supported!”

“As a mother of a 55 year old daughter (MR and Bipolar), I am very satisfied with the services she receives at [providers] in [city]. Human Service case workers have always been very caring and helpful.”

“I feel the DDS Case Managers withhold information and services that are available.”

“...the communication from his caseworker is basically nil. I just left her a message, I was my son's mother in case she had forgotten. She did call last week to tell me they have an IPP meeting- didn't let me know before hand.”

## **Transportation**

A few respondents noted that they were dissatisfied with transportation services.

“I also find the transportation system ineffective for those who work in a area where the bus routes don't go. And the system must think that the world stops on Sunday or later in the evenings, as it is not available to those who can't drive and have no other means to get around.”

“A concern of ours is the high cost it is for these people to ride the [city] Para transit to and from their work. 24 cost them \$4.00 a day which gets to be \$80.00 a month. It's a very good way for them to go from work but at times they can't afford it. At times, the staff has to give them a ride to and from work to save money. Still costs, but cheaper, would be better for him to ride the Para transit.”

“Another need that our family cannot afford is transportation for our son if we would like to go on a short trip to visit friends or relatives. We have inquired about renting a van with a wheelchair lift, but in our area that is only available for medical needs. Our son is not able to join us on family outings because we do not have a van and lift. We can get assistance for getting a lift, but not the van.”

## **Employment and Education**

A few respondents reported that they were dissatisfied with employment or educational services.

“Overall, [city] limits the opportunities for the handicapped by keeping most handicapped working with each other- not with non handicapped. [City] isn't making adaptations for some I'm sure due to cost.”

“My son just went to a new facility 30 days ago. His new place is meeting more of his needs. When he was in our community, the workplace was not right for him. He needed gross motor activities-he got stuffing envelopes. He became more and more unhappy and agitated until he started having serious behaviors. Where my son is now he is very happy. So I know he's not just sitting in one spot day after day. I don't think the day program in [city] looks after the needs of the people- they try to make the people with handicaps meet their needs.”

“The person I am guardian to has lived in a community setting for about 2 1/2 years. Community providers have not provided vocational (work) services which has result in a lot of problems. When living at the [provider] in [city], all needs were met and the person I'm guardian to had a much better quality of life!”

“Would like to see more work put into helping them to continue with reading skills that they had stressed in school-also writing. Feel this should be continued right after graduating at 21 and when they first get into the programs such as this. Each individual would be treated as to what they can accomplish as a person and more individual attention on this matter.”

## **Recreational Activities**

A couple respondents reported that they were dissatisfied with the recreational opportunities available for their family member.

“Fitness, sporting activities, group activities are not available for the lower functioning people- swimming, fitness.”

“...not a lot of follow through with planned programming, such as getting people to church, getting to certain activities that may be interesting. Everything seems to be rallied around group functions and little room for independent choices on the part of the individual.”

## **Funding and Budget Cuts**

Funding and budge cuts were mentioned by a couple respondents.

“We have made great strides in providing services and integrating people with disabilities into the community setting. I am concerned about proposed budget cuts or inadequate revenue to continue providing these essential services and opportunities. I cannot begin to express the appreciation I have for the opportunities provided for my brother. His life has changed dramatically from merely existing in [provider] to where he is living in an apartment with friends, has a job, has access to transportation and community activities and can communicate and relate to family and friends on a daily basis. He is happy and feels like he is contributing to society.”

“In comparison of other states, ND should be very proud of the quality of service to persons with disabilities. It is very unfortunate however that budget deficit cuts continue to erode current programming. Unfortunately, the state of ND learned through a lawsuit in the 80's that ND families demand and expect quality services for their loved ones, so they may have a quality of life and can achieve independence. The state needs to improve service continually and nurture and protect our loved ones.”

### **Aging Caregiver Issues**

One respondent expressed concerns regarding guardianship and caring for their daughter as they age.

“We are very pleased with our daughter's care and support overall. We have a concern for our daughter as we grow older. Our grown children can become more involved? Will they need to be legal guardian?”

Thirty-nine percent of respondents from Pennsylvania wrote qualitative comments for this survey. The comments are summarized by theme below. The most frequently mentioned topic was home, followed by staff and communication.

## **Home**

The home environment was the most frequently mentioned issue. A significant majority of the respondents reported being satisfied with their family member's home environment. Most respondents reported that family members live in group homes, while the remainder live in an institution. What follows is a summary of respondent's comments who were satisfied.

"Group homes are a plus for MR people. The group situation that he is in is best for him. He has adjusted well."

"My daughter lives at [name] center. She is very well taken care of and seems to be very happy there. I visit almost every night. Staff is very nice."

"Individual seems to be very happy and comfortable in the group home. The staff treats him well and he always seems to be well taken care of."

"Group home has been a godsend to our family. We appreciate the love and support they have given to our son."

"We are very pleased that our family member lives with [caretaker] and her family. She always seems happy to see [name] when we return her and that shows us that she is happy. She has been away since she was 3 years old and we feel she has done very well."

"Our loved one is so happy and content in the group home. Our loved one has come to life and is able to talk more and even in sentences. Our loved one enjoys going to day program and enjoys going to church. All of our loved one's needs are being taken care of by the staff and this gives us piece of mind. Our loved one is eating better than ever before. Everyone works together for the good of this home and the residents who live there. This comment comes from a mother who initially wanted nothing to do with group homes and I am now so happy I changed my mind."

"I am very please with the services our family member is receiving at the group home. My loved one receives excellent care at the group home and because I have problems getting in and out of the group home's driveway, they bring my loved one home to my house once each month for a visit. I usually tell them how long I would like my loved one to stay and this is satisfactory for both of us. This group home is doing a much better job that the previous one. They take my loved one to visit the older brother, who lives in a nursing facility. The group home is making plans for my loved one to help visit with the younger brother as well, who is about 30 miles away in another facility. I think that this group home gives outstanding care to all who live there."

"My loved one is well taken care of and lives in a very clean environment. My loved one enjoys the bedroom and exercise/recreation activities. My loved one is able to have a dignified life and I am so glad that my loved one attends church every Sunday."

"When you make the important decision to place a loved one outside your home, you hope the environment will be much like your own home. I feel our placement is!"

"In February 2002, our family member was moved to a smaller facility in [city]. It has been a very good move for him and we are very thankful."

"The girls at the home are so willing to bring our family member home to visit me. I can't say enough good things about the care he is receiving at the group home. These girls are super fine and I thank God everyday for them. He is always well groomed and the house is super clean and neat at all times."

"Anything I have to say about my child's living situation is totally positive. This child is a changed person. The agency and staff are able to aid my child in ways I was unable to achieve. This placement has been a lifesaver for this person...for our whole family."

"We found a place for him where he would be watched 24 hours a day. He was pleased at several group homes, but they had a problem about his temper and eloping often. So, they placed him at his present group home. At my amazement, he has no problem with eloping. They watch him 24x7. He loves his staff workers, he goes fishing, camping and many other activities. I feel very satisfied with his progress at this group home and staff. He is well taken care of all the time. I trust them very much. If there are any problems, they call me at my home."

"Our family member lives with [name] and [name] and when asked if she is happy she responds with "yes" very much so. We would like [name] to stay with [name] and [name] as long as they want to keep her. She is always within reach for them when ever they might need him."

"My daughter has been institutionalized since the age of 18 months. She has been at the [provider] center, [city, state]. I cannot ask for better care than what she receives there. She does not walk, talk, etc. But her care is outstanding. The staff is wonderful and caring. I have no complaints."

"I feel my daughter is very well taken care of at [provider] center. She is very happy, healthy, and well adjusted. The staff takes excellent care of her at all times day and night. I can't think of a better place for her to be. Physically, emotionally and mentally, she is very satisfied and so am I. I can't praise the staff enough for all the care and kindness she receives from them on a daily basis. They are all to be commended for all their patience, kindness and understanding at all times!"

"Our family member has been at [provider] for over 40 years and has received wonderful care since he entered. They taught him to walk, feed himself and did it all lovingly."

"We are very pleased with the care. The staff is compassionate where my sister is. We are not advocates of a group home as she has had wonderful care with the state run facility."

"It was one of the best as she was very happy there. She has been kept very clean and neat. She has a beautiful bedroom at the pine apartments on the grounds with two other ladies. From the administration down to the cleaning ladies, all are very good and kind to her."

“Her family (myself, my mother, my husband) have always been thrilled with having her at [provider] center. The place, surroundings, and employees are outstanding!”

“I am very pleased where our family member is living. He is very well taken care of. They are always in touch with my husband and me, his mother. He could not be in a better place, then [provider] state and hospital. The staff is always nice and ready to answer any questions that I have and they keep me informed, on what is going on with my son.”

“I think this is a very good place for family member to live. They have helped him do a lot of things he wouldn't have done otherwise. The home has done almost everything available to make a safe and secure environment for my son. I am very thankful for the service they provide. If there is a problem with a staff member, I can write letters or make telephone calls and there is usually positive results. My son is, for the most part, contented at his residence.”

“From what I see during my brief visits is favorable. He has done so many more things while in the group home as compared to an institution. I would never want him to go back into that situation.”

“I would have to give the group home 100%. She never had a life at [group home] and would not be here today had she not been removed. The girls are excellent. In five years I have had no complaints.”

“I would say overall this past year has been great for our family member. The foster care family he lives with are great with him. He really seems happy. “

“I have a very positive attitude about the quality of services my son receives. He is well taken care of at the group home and goes to an activity center daily. He is more active, happy, and alert now than he was when he lived at home.”

“Our family member has adjusted so well, I could not be more pleased. Her home adjustment and care is so excellent. She works successfully at [provider] and is kept involved with activities with the blind association. Her house parents are exceptional. She is dressed beautifully for all occasions. She enjoys her religious contact. Her staff assists me in keeping her aware of her [religious] heritage. We enjoy many social and family experiences together.”

“My daughter has been in a group home operated by [provider] for almost 6 years. I have nothing but the highest praise to offer for the care she has been given in this time. The staff is kind, caring, and very cooperative. It is wonderful to know she has such wonderful care, after having been at home with me for 68 years, I couldn't be more pleased and happy with the care she is given at [provider].”

“We are very pleased with the group home. We think our son is getting the best care and opportunities. He is very happy in his working and living environment. The staff is knowledgeable and supportive and caring.”

“In all, I am very happy with my son's group home. The staff is just great. The house coordinator tries to take care of all my worries and house staff is the best ever.”

"My sister has lived at this group home for over 10 years. Most of that time she has been quite happy and content. She has been involved in many, many activities and truly enjoys them. This is only limited by her physical health problems. She has been given guidance with some of her behaviors that could result in problems for her (money management for one). I greatly appreciate this. I'm also very impressed with the kindness and caring shown here by the staff, and by the variety of activities offered. In my opinion this group home should be given very high marks."

"We were pleased that our autistic son has adjusted to a small group home after many years in institutions."

"My daughter is in residence at the group home. It is a beautiful home and she is lovingly cared for by a dedicated and committed staff. We are always welcome to drop by and we feel reassured that she is in a safe, happy environment. We are delighted with the personnel and the program."

A few respondents reported that they were dissatisfied with their family member's home environment.

"My son's housemate is often intrusive and his moving into the house has limited activities my son can go to and participate. Management staff is not always responsive to concerns. Home supervisor is not familiar enough with my son to adequately meet his needs. She does not spend enough time directly supervising in his house."

"Nursing home does not get son out of bed everyday, much less outside to the patio or social events. Concerns have been passed to the county and addressed with support coordinator. Concerned that son is unhappy at the home, but knows he needs the care he receives there."

"I have a wonderful relationship with my sister's day staff. I wish some of her home staff was as great as they are. My sister has bad problems at her home and still those problems remain for her and the other ladies. I feel that the group home staff needs more training for cooking, and caring for the people that have severe behavioral problems. I also feel she shouldn't be put into a home where is a lot of unrest due to other clients and staff not behaving maturely. I don't expect perfection just love, patience and motherly caring for people. At times I don't feel that upper management really listen or care when parents talk to them about problems. Some group home staff are great but if they do their job well they are picked on by other staff that don't care or just there for the benefits or money. I have to be the one asking the questions in order to get answers."

"I think our family member would get along better with higher functioning people in a group home. She needs someone she can talk to on her level and where she is. She can't and often times is told not to talk at all. I know sometimes at home she can't keep quiet very long. Sometimes some of the staff scream and yell at the whole group and get them all hyper and someone gets hurt. I know it's not an easy job and I think some of the staff need more training for a group of 4 or 5 in a group home. I know of 1 or 2 that shouldn't be working at my daughter's house. "

"Our family is currently in the process of changing procedures for my brother. As you can tell from this questionnaire, we are not happy with the current procedure/group home. My brother is not getting the services that were promised by the provider; living conditions are

poor, staff are not properly trained, he does not receive day programming on a consistent basis, and he is not able to live a more independent and happy life.”

“If time and money were not problems I would like my family member to have more supervision with cleaning his apartment. Actually he needs a maid service! It is difficult for [name] to accept me (his mother) coming in and making suggestions. I try to be low key but he quickly becomes agitated. The staff does work with him and helps him clean, but he can not seem to carry out their examples.”

Several respondents wrote comments about potential changes with their family member’s placement or indicated that they need a new placement. In particular, several respondents reported that they do not want their family member moved from an institution into a group home.

“We are very satisfied with our son's living program at [provider] center. We do not want him in a community group home! He is very happy where he is - the staff is very caring and involved with all his activities and programs. He has excellent medical care, is well clothed, and enjoys the workshop and recreational activities - plus a daily reading tutor.”

“It is my opinion that our family member, due to her profound retardation, would not possibly be a candidate for community living. Therefore, the [provider] center offers she the required services and supports she needs - all due to a highly competent, caring staff who are dedicated and committed to the success of the center and bettering the quality of life for its residents. The state of [state] should be commended and be proud to offer such excellent care to its deserving constituents. I feel sure that the state recognizes the high quality of work of employees like those at [provider] center.”

“Just a note to let you know my sister has been at [name] center since she was 7 years old. This is her home, her family and friends and it appears they are taking excellent care of her. My family and I would be outraged if they wanted to place her elsewhere. We know that many institutions are scaling back or closing down completely and we are hopeful that never happens to the center. It's a lovely place where we feel all patients are treated with dignity and respect.”

“We have been very pleased with the care my brother has received. We are totally against him being moved to any group homes or any other place. His MR is severe and he needs the care he receives currently.”

“Residential support in our area is needed for moderately retarded individuals.”

“I think our family member does better in a family environment rather than a group home setting. I would like to discuss this at your convenience.”

“When daughter was relocated to a group home in [county] it was a nice suburban neighborhood. Since then she has been moved twice to inter city area not to our liking. Why couldn't she have stayed in the original group home? Seems like this was only for show to get her out of the state institution.”

“Family member was told there would be a placement for him where he would have more freedom by staff there. She built his hopes up only to find out funding was not available for a group home for him. I feel nothing should have been said to him about the group home until

I was contacted, talked about it and discussed it with him if not now you can move. He is in an excellent facility.”

“He would never be able to live on his own or share an apartment in a supervised area (that was attempted in his 2nd placement) and we are very concerned about possible legislation to disband group homes.”

“My daughter would like to just sit in the wheelchair and fade away. She has always needed encouragement. She needs training or schooling to get out of the house and not just sit in a wheelchair. She doesn't have someone to help her with her personal care. She should be attending social activities of some sort. She wants to live in the community alone but I don't see any support.”

## **Staff**

Staff was the second most frequently mentioned issue. The majority of respondents reported being satisfied with staff, in fact, many examples of staff satisfaction can also be seen in the Home topic area.

“[Provider] is a professional provider and their staff including [name] and [name] and others share a genuine concern for him. He keeps me informed of his doctor appointments and behavior. I have a professional relationship with [name] which means I can reach him by cell phone at any time. He makes himself available to our family.”

“Staff person has been with my daughter from the beginning. I've met her and trust her implicitly. She treats my daughter as her own. She is a very special person.”

“In general, the staff and support has been excellent in what can be a trying job. I applaud their work and commitment.”

“My sisters and I feel the case manager and the staff do everything they can to support our family member mentally and physically. She always is happy, clean and healthy. They do an excellent job in caring for her. I thank God that there are such programs to take care of people like her and such caring staff.”

“My son is very happy with his staff. They treat him with respect and dignity. I appreciate the care he is receiving.”

“I am very pleased and satisfied with services provided for my brother. I live 700 miles from his residence and frequent visits are not possible. However, any time I call with a question, the manager and staff are always courteous, cooperative, and responsive.”

“I am mostly satisfied with the staff. They are always very nice and helpful. County MH/MR staff do an excellent job supporting their clients especially ones with communication handicaps.”

“I feel our family member is doing as well as he can. He really likes his staff now, [name] and [name]. He is very happy with them and they are very good at keeping in touch with me about my brother.”

"I feel that our family member's support staff really care about him and want the best for him."

"There is wonderful staff at [name] - run by [provider]. My brother really feels as if that is his true home."

"My family is extremely happy with our family member's care. The staff is caring, attentive, and even protective of our loved one. This appears to be both true at the group home as well as the day program. Our loved one has blossomed over the past three years in their care. We will forever be grateful. We know that this is a very expensive gift, not just financially, but in the caring hearts of those who patiently and lovingly care for someone who is so completely dependent. I cannot say enough, I cannot thank enough for all you do."

"I am extremely pleased with the care my brother receives. I feel I am included when it is necessary and appropriate. He lives in [provider] and his staff goes above and beyond for him."

"The two most consistent caregivers, [name] and [name], are truly angels from heaven. My brother's well-being would be greatly compromised if they were not a part of his life. We are pleased with the rest of the staff, too, but [name] and [name] are most important in his life. I have no idea how well group home staff are compensated but I'm willing to bet it is not enough. They are truly dedicated individuals."

"All of our loved one's needs are being taken care of by the staff and this gives us piece of mind. Our loved one is eating better than ever before. Everyone works together for the good of this home and the residents who live there."

"Our son is very happy where he is. The staff are all so very good to him. He loves all of them and looks forward each day to seeing them. We are happy with his care."

"I can be updated on happenings or express concerns. At times they are short staffed, but I feel they do their very best to support all my brothers needs. When concerns arise, the staff contacts me, which I truly appreciate. There was one time I wasn't informed or something and I thought I should have been. I made them 'aware of my concerns' and we were able to reach a solution. I feel free to communicate my concerns."

"Our family member has been at [provider] for over 40 years and has received wonderful care since he entered. They taught him to walk, feed himself and did it all lovingly. He is 49 now, he has a feeding tube and during the past year has been in hospital in the intensive care unit. On two different occasions upon his return to [provider], he can do nothing for himself and his eyes are closed, but the care he gets is remarkable. They talk to him, try to stimulate him and are always so kind when I call to inquire about him. He is truly loved by his caretakers at [provider]. I feel grateful for all the staff on his unit."

"The staff is extremely cooperative and they are highly competent in the work they do, they are truly professional. Their work is difficult, but they work unceasingly to better the lives of their residents. I can't think of a better place for her to reside than [provider] center. There she receives total care in every facet of her life, all due to the staff."

"I am and will be eternally grateful to the staff of [provider] center. I feel my daughter is in good, caring hands. I have come to know many of the people over the years and am always impressed with their dedication and sincere approach to helping my daughter."

Several respondents indicated that they were dissatisfied with staff. Key problems include staff turnover, management of staff, underpaid staff, lack of staff training, and a shortage of staff.

"Staff turnover is a problem and I think part of the problem is that there is too much paperwork for staff to do. The system places too much emphasis on paper compliance rather than on things that are important like staff longevity. The agency and staff do try and they do a pretty good job all things considered."

"Service provider stretches staff too thin and burn-out occurs quickly - followed by new staff- a vicious circle that keeps our son from making gains in his goal to live truly independently."

"My only complaint is the consistent and constant turnover of employees. I know this situation is a universal one in the field. I have no remedy for this as does anyone else. This impacts not only the house in general, but the members and their families in particular."

"The constant change in staff makes it very difficult to establish an on-going relationship. It could be nice to know ahead of time when support staff is going to be changed. It is often difficult to know who to contact."

"Management staff is not always responsive to concerns. Home supervisor is not familiar enough with my son to adequately meet his needs. She does not spend enough time directly supervising in his house. I am not given information about my son's funding amounts and options on spending choices. "

"The supervisor in my son's group home is not trust worthy and I object to her attitude. The staff in general, do not help my son in the way I would like."

"I think staff turnover is the hardest thing for my family member."

"We are very satisfied with our daughter's care but are disturbed by so many staff turnover. This upsets her and us."

"It's extremely frustrating having such a high turnover of support staff in group homes. Not only is my child physically and mentally handicapped, she cannot communicate fully her needs, wants, feelings, etc, except by using her and our own adapted sign language. Each time staff changes, she goes through increased turmoil and frustration. Maybe if our government valued each person for the smallest contribution they can make, they'd pay these special support people more so they didn't opt to work at restaurants where the level of responsibility cannot compare to what these people are asked to do."

"I am most unhappy regarding an incident where money was removed from my family member's account by a staff person. When I found out about it was most unhappy that it was covered up and that person was moved to another house and the opportunity to do it again. I would welcome the opportunity to talk about this. This person should not be given the opportunity to do this again!"

“Nothing in life can be perfect for anyone. Concerns for my son's safety and well being are always addressed/not always to my satisfaction. In part, I blame the state for not making more sufficient funding available to MH/MR agencies. Salaries are not adequate for staff people to support their families. Because of the lack of adequate funding, agencies lack resources and sufficient staff to care for the clients, thereby putting the client and sometimes a staff member at risk for their safety and well being. Depending on the circumstances, health, behavior problems, or inclement weather endanger clients and staff members. There isn't always someone available to keep a sick person at home and a person is required to transport clients to day program and other places because of lack of sufficient funds rather than allowing them to remain in the group home. We need more group homes and also better paid, increased staffing.”

“However some of the workers that have been with our family member for a long time take it upon themselves to make decisions based upon their observations and limited knowledge. They have most recently overridden decisions for additional medications without consulting me. I have found out after the fact. Most recently they decided to have our family member additionally medicated to try to control outbursts of crying or aggression.”

“I wish we lived in [city] or [city] county where residential help is paid more and are interested in the client's needs and wants. [Provider] staff only does the bare necessities. They don't show any care and feelings for the clients. I hope to change this soon by the help of the county commissioners and lay people.”

“There should be staff training on "common sense". Sometimes my family member comes home not shaved clean, dirty nose, not wiped clean on rear end, too tight clothing, sneakers stained with food. There should be staff training on how to use an electric shaver. Pick out clothing that is torn and with buttons missing.”

“There were difficulties in the apartment program because they are not trained enough to handle a person with both mental illness and retardation.”

“In light of what happened, the terrible incident that took place at site 2 in July 2003, when a staff member injured our family member. We would be happier to have more of a secure feeling that his current situation will not change. He had to undergo surgery to repair a broken femur and subsequent physical therapy. A meeting had taken place shortly after the incident where we were assured that all medical bills would be handled with no cost to him or myself. I feel that [company] should take another look into the hiring and training practices of their staff. The support staff that was involved should have had better training. He tried to give my son the incorrect medication and when he refused to take it, he tried to push it on him and at this point he shoved my family member, which fell over the couch and broke his leg. The worker should have known that he would know his medication and upon refusal, the worker should have called the office for instructions. With all of his prior problems, he is now in constant pain and much slower than he was before the incident, this has affected not only our family member, but also my whole family.”

“After 5 years of having self determination as a part of my son's life, the provider is still not operating with self determination principles as their guide. New staff is brought in without knowing self-determination and are not in training to learn self-determination unless parent makes it an issue. Even one full time staff who has been working in the home for over one year is not able to type with my son.... At the last quarterly, this has been made an issue and they are to be re-trained immediately. Provider encourages staff not to share with me

what is really going on with in the home - if they do, they are reprimanded. People without invitation show up at quarterly meeting who are not one of the circle members - self determination is not the way of doing business nor is it honored when the person is trying so hard to be truly self determining.”

“My brother has medical issues which are currently not being well addressed. He has had to be taken to the local emergency room twice in the last week. I don't think enough attention is being paid to his medical difficulties. The staff needs more training to reduce the salt in his diet which is contributing to his congestive heart failure. The staff is generally well but not competent enough to care for him. Staff turnover is also a problem at the group home. That is probably a widespread problem in this industry, since salary levels for direct care staff are low.”

“I feel my son gets to be around wonderful people and who are so very much underpaid, I'm sure. Special needs people require special people to give them lots of love and attention. He seems happy so I feel confident with all who are involved with him.”

## **Communication**

Several respondents mentioned that communication was an important topic. More respondents noted that they were dissatisfied with communication than satisfied. Specifically, respondents noted a lack of communication, getting the run around, and needing information about what services their family member is receiving.

“When I call the office I only get a message machine. Would like to talk to a person when I have a concern about my daughter.”

“I don't remember the last time someone from this agency contacted me just to see how things are going. I work for the federal government and I realize we all wear many hats but at least I try my best to provide good quality customer service.”

“They don't inform me when my family member is having health problems, they didn't ask me about moving her.”

“I have asked the agency to let me know dates and times of all doctor/dental appointments. They never did. The reason is because I would like to be there for my daughter. I called the agency 3 months ago to ask them a question. They said they would look into it and get back to me. They never did. My daughter was taken to the emergency room for an abraded cornea. I never would have known about this if the physician himself had not called me and told me. He said he thought I should know. None of the staff at her group home ever called me, nor did they intend to. They told me, ‘we never thought of it’. I expressed my displeasure with this. But I usually don't bother these people with the indignant complaints. I don't want my child to suffer the consequences.”

“All in all, everything is okay, but it would be nice to know when our family member needs medical treatments for anything other than her routine check-ups. Would be nice to know about her finances such as her income, how much goes to the family provider, how much goes to the family member, how much goes to the agency and what goes into savings. Just would be nice to know how she is being provided for and what she has for her own recreation, and such.”

“Since my family member has lived with [provider], I have had very little input or communication as to plans, programs or whatever influences his life.”

“I would like to know what monies and services are available.”

“More information on health is desired and on the employment - as to how he is doing on the job, are there problems, etc.?”

“What I’d like most to be able to find out is how my family member’s money is being used. In all the years she has been at [name] school, I have never been sent any kind of report. I don’t even know how much she has put aside for expense if ever something happens to her. I could not get an insurance policy on her. So I’m in dark about anything in her state of her money. I have signed her [provider] and [provider] fund over to the school.”

A few respondents indicated that they were satisfied with communication.

“I feel family member is doing as well as he can. He really likes his staff now. He is very happy with them and they are very good at keeping in touch with me.”

“I’m glad for the quarterly meetings held at the group home. It’s one way of knowing how things are coming along with our loved one.”

“...when I have a concern of any kind regarding my family member, I just pick up the phone and contact [staff person] at [provider].”

“I have been very happy with the support staff/program that is in place for my brother. I attend almost all of his monthly meetings where I can be updated on happenings or express concerns. At times they are short staffed, but I feel they do their very best to support all my brother’s needs. When concerns arise, the staff contacts me, which I truly appreciate. There was one time I wasn’t informed or something and I thought I should have been. I made them ‘aware of my concerns’ and we were able to reach a solution. I feel free to communicate my concerns.”

“Any problems, I am the first to know and I voice my opinion. I have been notified immediately of any problems.”

### **Overall Satisfaction with Services**

Several respondents reported that they are satisfied with the services and supports their family member receives.

“These support services have been a blessing for my son and family. We would not have survived without them. They generally rapidly deal with any substandard caregivers or unsafe practices.”

“Overall, I am very pleased with the care being provided for my brother.”

“My sister and I are grateful for the support system in place to help our family member. He is quite fond of his ‘helpers.’ It would be difficult on a day to day basis to cope with his needs as we are aging and dealing with our own problems. From our perspective, the county’s MH/MR program is a success.”

"Thank goodness they have these services for the MR because both of the patient's parents are deceased. My husband and I work and could not give 24/7 to the client, which is what he needs and gets with your services."

"Thanks for your support. MH/MR has always been helpful, agreeable, sympathetic and entertaining!"

"Having been an advocate for more than 48 years, I am happy to say that my daughter is being cared for in a most professional, loving and caring manner."

"The care and support received for my sister are excellent and she is happier that at any point in her life since she was at home with mother when she was very young."

"We are extremely pleased with his care. He has progressed far beyond our expectations which we feel can be contributed to the care he receives from [provider]."

"I am very satisfied with the services received by my son and with the high quality of services which are provided to him."

"My relative is in the [provider] program-without it relative would be institutionalized. This program is of great blessing to my relative as well as the family. They do a great job, enriching my relative's life..."

"Very satisfied with support given to my family members. 100% better quality of life now that she has the services needed."

"I am a friend of [person]'s and have known her for 24 years, since she was in the [provider] home. For the most part, I think that the services rendered by human services has been a great help to her. It has allowed her to "live on her own," and given her a sense of independence. There has been a helping hand for her when she has tried to work in the community. When she has needed help for physical or emotional problems, these needs seem to always be met. Thanks to your services, people like [name] can be given opportunities to make them walk a little taller and feel good about themselves."

## **General Well-Being**

Several respondents wrote comments about general well-being, including hygiene and grooming, health, and safety issues.

"There could be more movies and activity that the group home could plan for him and he needs more guidelines on properly fitting clothing and a neater appearance from his apartment staff."

"Realistic [provider] goals are set but it takes forever to get them started. One such goal (an exercise program) has been talked about for months (years?) But no one does anything about it. Also appointments with the podiatrist are not kept and his toenails are dangerously long. I know that he is a handful and sometimes difficult to manage (especially when at the foot doctor's and dentist) but the reason he is living in a group home and not with me is because I can't handle him and the staff at the group home is supposed to be made up of qualified professional caregivers who know how to handle him."

"Haircuts, fingernail and toenails clipped and shaving, but that is only a suggestion we could make."

"We feel that staff support should have more instruction on how to buy and prepare more healthful meals."

"There are major problems in the plans that are made for my loved one and they are seldom followed through for the long term. Staff gives up too easily. I am having a major problem with my loved one's diet and exercise program, both in the home and at day program.....with the fact that there is none. My loved one is eating a very unhealthy and there is no patience for exercise. I have tried to express my concerns on these matters, but no one does anything about it."

"Our family member has a tube for nutrition, but does sometimes try solid food. I would like to see them try a larger variety of solid food to encourage her to eat."

"Another reason my son is un-happy where he is now is because the other man who lives there gets violent at times. He has attacked my son."

"I don't want any men supervisors at the group home attending my daughter. Women only. I won't stand for it. They wanted to hire a male supervisor for my daughter's group home a while back and I totally refused. I don't want any males dressing or bathing my daughter. I'm speaking on my daughters behalf."

"My son lives in a [provider] facility - in an apartment alone. This has always been his dream. However, a few years ago he was sexually abused by another tenant. This tenant still lives in another apartment in the same building. My son goes to the office -about a block away and across the street - at 8 a.m. to get his meds and at 7 p.m. to get evening meds (he has diabetes and also to have his elastic stockings put on and taken off in p.m. so they can be washed.) Lately, he has been avoiding this trip. There is something bothering him about this and he can't explain what it is."

"My family member has been injured in accidents that never seem to be well explained. For example, his most recent injury has been a cut over his left eye from a fall. I am told he wears a helmet when up and around. The fall seems suspicious. Last spring his ankle or lower leg was broken. My brother is a gentle man who doesn't give anyone a problem. I have never filed a grievance because I didn't know the procedure and didn't think it would make a difference."

## **Employment and Day Programs**

Several respondents wrote comments about employment and day programs. Approximately the same number of respondents indicated that they were satisfied with these services as dissatisfied.

"Family member also goes to work thanks to this wonderful organization and his supervisors seem to work with him and are always trying to accommodate him. We are very, very pleased with the whole program."

"She works in [name] workshop - not always cooperative- but lately, she loves it and was given the "employee of the month" award (July 03), with her picture - talk about proud!"

“He likes his job at the workshop. I am happy with your service in [name] county. My brother does a lot of things himself, but the workers help him when he needs help. I am so glad that the services have the work program. My brother is a very hard worker and he gets bored very easily, so he looks forward in going to work.”

“Our family feels [provider] offers a good day program and a wonderful clean house. Staff at day program and house seem to like their jobs.”

The following respondents indicated that they were dissatisfied with employment and day programs for their family member.

“I do wish there were other day programs available in the [name] county area since the one my daughter attends does not seem to meet her needs.”

“The workshop does not let us know what outside jobs she is working at. We should know being her legal guardian. The last time the workshop didn't let her group home know. This comes up every year at her planning services meetings.”

“Would like family member to be placed in a sheltered workshop and go to church. Have been trying for a day program since 5/02 or longer to no avail. Have found a provider but no action by county or group home provider.”

“We are disappointed with the day workshop for many reasons. Our family member received second degree burns and choked and received the Heimlich. Meanwhile, the report that was sent home said, ‘she was fine and didn't need to see the nurse.’ Wow! Supervision and safety are always a concern at her day program. It only takes three years of meetings at this workshop to make positive changes after the events, such as above, happen.”

“I don't think [name] is getting the best possible care at the workshop. I really do think adequate staff isn't available. I don't think the workshop is run properly for the clients.”

“There are not many resources for work. There are no agencies that will train or take a client with a mental illness/mental retardation who cannot be at work every day or who may need to take off work because they mentally cannot handle being at work that day. This leaves clients sitting at home with no meaningful work.”

One respondent wrote a comment about caregiver employment issues.

“With my husband's and my work schedule it is nearly impossible to attend daytime meetings. It is not that we are not interested in planning goals or programs. We just aren't able to attend a meeting during the day. We have a son who is very much interested in learning more about planning for our family member. He also finds it very hard to attend meetings due to his job. We feel very bad that we are unable to participate more.”

## **Case Management**

Several respondents wrote comments about case management services. Approximately the same number of respondents indicated that they were satisfied with case management as those who reported that they were dissatisfied. In sum, good case managers were described as available, caring, helpful, knowledgeable, wise, nice, kind, and supporting.

“I feel that our MR coordinator does an excellent job working on behalf of disabled individuals. You can contact her anytime. She makes herself available and genuinely cares about the individuals and their families. “

“The county case managers have also been extraordinarily helpful, knowledgeable and wise. In general, I can only say that the services provided to us have helped us to survive some serious situations. I wish there were an adequate way to express the profound gratitude and appreciation for the flexibility, receptiveness, and commitment of the professionals involved.”

“I feel that my family member is doing extremely well with the help of her coordinator and caseworker. She has come a long way and I’m so proud of her. Her independence is important to her and I feel she has been able to achieve that with the agency’s help.”

“Our case management has always been supporting and helpful.”

The following summarizes respondents’ comments who reported that they were dissatisfied with case management services.

“Sometimes I call our family member on her day off and she tells me her case manager is coming so she can’t go with us. By day’s end, she calls and says she never came. Very upsetting. I do not know what the requirements are for our family member since she lives independently in her home (rented) but usually her case manager comes only one time a month, if that. Then she picks up our family member and takes her to the mall while she shops for herself or her family. She spends no time other than that with her.”

“My loved one’s supports coordinator does not do the job and follow through on important matters, and never calls you back. The supports coordinator constantly places the blame onto someone else and has many excuses. I have requested repeatedly to have my loved one’s supports coordinator changed and it has not.”

“Although I would like more contact with our family member’s caseworker. She doesn’t return my calls.”

“My concerns are whenever a case worker is replaced my daughter receives no preparation for the new person.”

“The only problem is that county supports coordinators change so often, that they don’t get a chance to establish a long term relationship with their clients. It’s like starting over every time a new person takes over and this is very frustrating on families.”

## **Health Care**

Several respondents commented on health care issues, including medical equipment, dental care, insurance, and medical care. In particular, a number of respondents were concerned about the amount or type of medication their family member is taking.

“My sister doesn’t get any help at all. I have asked for help getting her a hearing aid. I have not heard anything back. It has been several months.”

"I am also concerned about medical coverage and payments. She recently had to be put under for a dental procedure and most of the surgeon's costs were not covered under my husband's plan."

"Our family member's residential providers are not taking care of her braces. They take care of all her other medical needs, but have made no arrangements to get new braces. We have asked repeatedly about it, but we aren't getting any response."

"I do hope county MH/MR is taking some measures/lobbying to pursue dental services/orthopedic services or whatever services are needed to ensure good health since we are aware no dental/orthopedic services do not accept our [insurance]. This county should be caring, interested in preventative care. Why should we have to go out of county for services?"

"I am not happy that my son's medications are either increased or decreased without my being told about the reason for it."

"Mental health care: behavioral plan could help but none is in place. Not enough time for finding help for my son to control his challenging behaviors -- medication does not help very much, and is constantly being changed."

"Family would like more input with regard to medical decisions made, i.e. the amount of [medicine] and/or [medicine] he takes. Updates regarding new diabetes medications."

"Time will tell. I believe they should find a behavior specialist to work with family member instead of applying medications they believe would help. He is already heavily medicated on Phenobarbital which helps control his seizure disorder. Additionally he takes medication for his thyroid. When it comes to medicines more may not be better. Can we get him a behavior specialist?"

## **Recreational Activities**

A few respondents wrote comments regarding recreational activities for their family member. The majority of respondents reported that they were dissatisfied with these services. Some respondents noted that staff shortages prohibited community outings or other recreational activities.

"The staff at the homes have been very good to family member but I feel they should have extra staff for times he needs to participate in community activities, especially on weekends."

"My son is involved in community activities, but primarily because I take him. The agency could be much more proactive in that regard."

"I definitely would like to hear he has more pleasures in his life on weekends. There could be more movies and activity that the group home could plan for him..."

"There is a constant hassle over not having enough staff. I would like to see my family member do things in the community, but because he shares the house with another client who can't be taken to these 'outings', it's the same old excuse, 'we only have one staff on', and therefore, he won't be able to go. Maybe these complaints seem small to you people,

but overall, these little things contribute to the overall appearance and comfort to these consumers.

“The community does not have enough places and people for socialization.”

A couple respondents indicated that they were satisfied with recreational activities.

“We are also very pleased with the [provider] and other recreational activities including travel arrangements being provided for our son.”

### **Advocacy, Choice, and Self-Determination**

A few respondents wrote comments about advocacy, choice and self-determination. A couple respondents noted that their family member did not want services, while others talked about not having enough input into their family members care. Three respondents mentioned that their family member needed services to help them be more independent.

“My brother has made it known that he does not wish to attend meetings or even have the meetings held for his plan of care. He further claims he does not want to be told what to do. He has refused to have me present at these meetings in the past. I do not feel he is competent to make these decisions or any decision regarding his welfare and care. There is no one other than myself to advocate for him.”

“They have suggested and tried many approaches to this situation with no success. I was told early this year that my family member would be dropped from the books because [name] does not even want the minimum of 6 hours. We all know that my family does need to be checked on and that he needs services, so I hope that he won't be dropped. Eventually, he will realize he needs outside help.”

“There is not enough consideration from the higher ups in charge who make the decisions regarding my daughter. They make and let you know that they have made a decision pertaining to many assorted things then they contact you and want to arrange a meeting to have a discussion pertaining to a certain decision or change that they deem necessary for my daughter. But the frustrating thing in the whole situation is for the most part they have already decided.”

“After 5 years of having self determination as a part of my son's life, the provider is still not operating with self determination principles as their guide.”

“The services my daughter receives are good, but unfortunately not comprehensive enough to allow her to develop her independent skills. Due to finances she has to choose to have either a worker to help her with daily living skills and finances or getting supported employment or workshop employment and transportation. She needs assistance in both areas to become a truly independent adult. Until she becomes independent, she will be a continual drain on the MR budget for services. I foresee that she could someday function well on her own with only minimal support.”

“I feel too much emphasis is placed on ‘job training’ in lieu of pleasure, rest and relaxation, personal choice, etc. The state centers are touted as being their home, home-like surroundings are emphasized, residents should not be made to participate in certain training

if they are not interested and/or are not capable of concentrating on it (or don't like it) they should be given vacations, time-off for holiday weeks, etc.”

“I have no input into my sister's care and service due to state regulations that supersede family wishes or what we believe to be in her best interest.”

## **Education and Training**

A few respondents indicated that they were dissatisfied with education and training services for their family member.

“I’m still hoping he will get a reading program addressing his perceptual or problems a person with psychomotor learning problems.”

“She could however benefit from basic academics classes.”

“Schools do not know how to deal with MH/MR students. They have no programs to address MH problems. There is only one training program so if you do not like it you have nothing.”

“I think more vocational training is needed.”

“She needs training or schooling to get out of the house and not just sit in a wheelchair.”

## **Guardianship**

A couple respondents wrote comments about guardianship or power of attorney issues.

“I just feel that they should help more with guardianships of our family member. The costs of guardianship are too expensive and some families can't afford them.”

“I would like to have power of attorney for my brother if he is incapable of making a decision for his admission in the hospital.”

“The question was asked if we were legal guardians by the courts. No, but we feel right now we would like to have that. In the past we have always been asked and informed about our son, but now it is different. We are living on social security and have expenses with our healthcare and medicine. We would like to know if there is a way to get legal guardianship that wouldn't cost as much. “

## **Transportation**

A couple respondents wrote comments about transportation.

“We are also very pleased with the [provider] and other recreational activities including travel arrangements being provided for our son.”

“Transportation support is needed for recreation.”

“Have not seen him in two years. Need a van to get to center from [city]. Need help with transportation to see him.”

## SOUTH CAROLINA

Approximately 43% of respondents from South Carolina wrote qualitative comments for this survey. The comments are summarized by theme below. The most frequently mentioned topic was satisfaction with services, followed by staff and health care.

### Satisfaction with Services

Satisfaction with services was the most frequently mentioned topic. Most respondents reported that they were satisfied with services, while some said they were dissatisfied. Respondents who were satisfied with services mentioned good communication and professionalism as two key strengths of service providers.

“The [county] DSN Board and staff do a very good job with providing services to our son. The entire staff seems to desire and respect our input and comments in providing services. They tell us when the services can’t be provided. It is important to us and to our son that his needs be met. Thank you.”

“We are very happy.”

“My family member receives the best care. We could never be more satisfied than we are. She gets the best care. She goes to workshop everyday and church on Sundays. They go out to eat and shopping at Wal-Mart. She gets the best medical attention. We are truly thankful.”

“[Program] has and continues to do excellent work with a limited budget. The board has my gratitude.”

“I think the services that my family member receives are very good. Without them my family member wouldn’t be as happy and healthy as they are. Services are really needed here. I would like more input on everything that concerns my family member.”

“I do appreciate all of the care and concern my family member receives.”

“My family member who has a DD is my sister but after my mom’s death, my late husband and I adopted her in order to place her in a facility who could help her. I am happy with the care and support she has received.”

“We have received effective, prompt, and satisfactory services since 2002 when [provider] became our SC. Prior to that, services were very good to very poor because of changes in SC. There were times we didn’t hear from anyone in over a year. We have been pleased with the residential services that [program] gives.”

“[Provider] is the best! Staff is friendly and professional. I have no worries about the care she gets. My family member loves it there.”

“I am in bad health myself and do not see my family member very much, but when I do see him, he seems happy and well taken care of. For this I am thankful and I thank you for taking care of him.”

"I am so happy that my son has a place to stay, that can watch over him 24-7. We as parents cannot do this. Thank you very much."

"My son is not able to make any decisions as to what he wants or needs. I appreciate everything the agency does for him. He requires individual attention. He is in a CTH

"Thank God for [provider] at [program], I don't know what I would have done without her and the staffing at [program], on [street]. I would like the state to thank her. She is good!"

"Our son is in a [program] and we are extremely happy and satisfied with their services. Our son has been at [program] and [program] before coming to [program]. [Program] is the best of the three."

"We believe [program] is in excellent hands. [Provider], is we believe the best thing that has happened there in 20 years. We have high hopes that [program] will continue to improve under the staff that now have been employed. Thank you for giving me this opportunity."

"I have 2 daughters in [program]. I have been pleased with the staff in both of these homes. I feel they try very hard to do what is in my daughter's best interest. There have been problems in one of these homes that one of my daughter's lives in. One of the clients can be violent and dangerous. I had a meeting with Dr. [name] about my concerns 1 month ago. We discussed some things that could help the client do better. Dr. [name] has done what she said she would do. The client is improving and I am thankful that Dr. [name] would do what she said she would. She is doing a great job."

"Our family has been very pleased with the people and services of [program]. We have had a long time association with this organization and appreciate their effectiveness."

"We sincerely appreciate all that is done in our family member's behalf."

"The services my family member receives is very satisfactory. Our family member is happy so that makes us happy too."

"Thank you for providing housing and community supports for our family member."

"Thank you all for the things you have done for me and my family member these years. He has become a well adjusted young man. He is now someone who respects others. Good attitude and manners. Thanks!"

"My husband and I became guardians of our family member last year after his mother's death. We have visited several times. We feel that his counselors have been very helpful."

Some respondents expressed dissatisfaction with services received.

"We have had to go through [program] to get this problem solved in the past. There are times our son doesn't get a hair cut because funds are late. He has been outside unsupervised and is profoundly retarded and should have 24/7 supervision min by min. Too many workers laid off."

"My family member just moved to a new facility. In the previous home, run by the same agency the staff turnover is ridiculous. The house manager was a tyrant that bullied staff."

She was involved in illegal things on and off the clock. She would harass staff. One person snapped and was fired. There are staff that would like to come forward but are too afraid.”

“I feel that when a parent suggests things that are not unreasonable that it should be taken seriously and given consideration. The parent is not told something just to satisfy them. When I visit the facility everyday and see and hear things that are wrong, I make suggestions to the appropriate people and I am not just brushed off. There is a lot of good but a lot of bad in the system. Things get shuffled person to person and then don’t get done. Decision makers should visit the programs so they can see each house is different. Decisions are not made for each person.”

“I would lie for my family member to have more assistance with meals and shopping lists. Also I would like for other clients at her facility not to tease her and try to attend to her business. This harassment has gone on for a long time.”

“My cousin seems very happy at her group home. She does not like to leave. One of us usually picks her up for Thanksgiving and takes her home a couple of days. She is very uncomfortable out of her group home. We talked about moving her to [city] but strongly advised by [county] staff not to do this. My parents called to make arrangements to take her out but when they arrived she was still at the workshop. Staff failed to communicate. Staff did help to get her from the workshop. She did not want to go so they got take out pizza and took it to the home to eat. My parents travel 2 hours for this. We would like to see her involved in more activities but it is her choice to stay in her room. I don’t see her enough to make an accurate assessment.”

## **Staff**

Staff was the second most frequently mentioned topic. Approximately the same number of respondents reported that they were satisfied with staff as dissatisfied. Some respondents also felt staff should be paid more and that staff turnover was a problem. Respondents described good staff as courteous, considerate and well trained. The following are positive comments about staff.

“The [county] DSN Board and staff do a very good job with providing services to our son. The entire staff seems to desire and respect our input and comments in providing services. They tell us when the services can’t be provided. It is important to us and to our son that his needs be met. Thank you.”

“My son is at [provider]. The staff have been great! I cannot imagine that transitioning into a group home from home would have been easier. He has received top care since living there the last 21 months. I am very involved in all activities. He comes home every weekend and we go to dinner next week. They take care of all my concerns immediately.”

“I feel my brother is well cared for. I am very satisfied with the staff at his home. They are wonderful people, well trained and sincerely care about my family member. He also seems satisfied and speaks favorably about them. Please give them acknowledgement and a RAISE! This is very important that my family member get good care. Thank you.”

“I feel that my family member is well cared for, well adjusted, and happy. The staff is courteous and considerate of my wishes and my family member likes them.”

"[Provider] is the best! Staff is friendly and professional. I have no worries about the care she gets. My family member loves it there." "I have been very satisfied with my sister's care and supervision. I am always involved in planning activities for her and provide as much personal involvement as possible. The staff in her group home are excellent, and show a caring concern for each resident."

"The staff at [provider] are wonderful. I have no problem with them."

"Thank God for [provider] at [program], I don't know what I would have done without her and the staffing at [program], on [street]. I would like the state to thank her. She is good!"

"I have 2 daughters in [program]. I have been pleased with the staff in both of these homes. I feel they try very hard to do what is in my daughter's best interest."

On the other hand, many respondents were dissatisfied with staff. Respondents mentioned inappropriate hiring and lack of competence as problems.

"There have been a lot of employee changes, some good, some bad. I have complained about some of the staff coming to my son's apt and watching TV and making themselves at home."

"Staff at my son's home are not always honest i.e. they tell me my son has been taken to a doctor for an injury when he hasn't."

"Caregivers need more support in matters of importance with the clients and cleanliness of the home."

"I believe hiring of capable staff should be done by the executive director. They should be put on temporary duty until we know they get along with the clients and other staff. There are many changes because staff have financial problems."

"Support staff are not always appropriately hired in this group home. Severely obese females are members of the staff. All 4 occupants are confined to wheelchairs and require lifting. Staff have back problems. Even though transportation is provided staff refuse to transport sometimes because they don't feel like it or it's too far. They can hardly get off the sofa, so bending down to a wheelchair is difficult. We visit our son 3-4 times week. We are aware of his residential environment. Unclean floor in his room, rubber gloves, and soiled linens and wheelchair is dirty. Staff are proficient in telephone usage and TV viewing."

"I would like to see more training of the household staff who have hands on contact with the clients. Training that is applicable to the clients they are working with. I would like the staff paid according to their experience and how well they do their job."

"There is not much follow up as to if the house staff is working on the plans as they need to. Most of the time they are just making that the person refused to do the objective or just writing something down so it looks as if it was worked on. The staff at the house do not keep up with personal grooming unless they know someone is going to show up. Objectives should be written to help the person gain independence. They don't even bother to see if the person can do it before they implement it. Objectives should be tailored to help the person grow."

A few respondents mentioned staff turnover and staff pay as concerns.

“Services can be improved but my main complaint is the turnover. Consistency is very important to us and the lives of the consumers”

“Direct support staff should be paid enough that they will be able to earn enough to discourage so much matriculation.”

“At the pay scale the staff normally gets, I think they do a good job. Like all government agencies, the hands on people are the lowest paid. Overall they do a great job. We thank you.”

## **Health Care**

Health care was the third most frequently mentioned topic. Respondents commented on health care equipment and medical issues.

“No special training has been afforded to her. Early last year she was taken for a hearing test and a hearing aid was recommended. She went for a mold for her ears but still no hearing aid. I hope this could be provided without further ado.”

“She was unhappy and gained weight. In 11/2003 she started work at [company] and she is a changed person. She loves her job, acted in a play and is managing her free time. She volunteers at [program] and [program] helps her with the transportation. We are very pleased. My family member works with a psychologist and this is beneficial.”

“I have repeatedly requested counseling to be provided for my son but it has never been done. This is because of his Autism diagnosis. He is high functioning and even 15 minutes would benefit him.”

“The state should encourage more MD’s who could work with the nonverbal autistic.”

“My daughter needs to see a ENTDR that takes Medicaid.”

“I have no problem with them. Dr. [name] is a great person at [program]. She is very helpful. I go to Dr’s appointments with my daughter. All in all I am satisfied.”

“My sister resides in [program] but has just returned after a long illness that kept her in the hospital for 3 weeks. She then was sent to a nursing home, which was TERRIBLE, for therapy. She had a blood vessel burst in the brain and received little therapy in the hospital. Her Dr told me she would never be the same again. She made a remarkable recovery. She had a good therapist in the nursing home, a good nurse, and is walking today. She did not handle these changes well. She did not understand what was happening. The hospital was a traumatic experience. The nursing home had patients screaming and she was put into a room with three other patients. She was not accustomed to the noise. She is still a little insecure but is happy to be back at [program]. With the people she loves. All of the caregivers seem to love her and she loves them. She has a very nice bedroom and there is a sitting room. She likes the quiet. I am concerned about the elimination of caregivers and her supervision especially with a resident that can be violent. She did not attend the day care program this week because she seemed weak. She seemed fine on Wednesday. I hope she gets a regular routine. Thank you for allow me to express my feelings.”

“My family member’s health issues are not address timely (eye, dental).”

## Home

Several respondents mentioned home issues. All respondents reported satisfaction with these issues.

“My son is at [provider]. The staff have been great! I cannot imagine that transitioning into a group home from home would have been easier. He has received top care since living there the last 21 months. I am very involved in all activities. He comes home every weekend and we go to dinner next week. They take care of all my concerns immediately.”

“I feel my brother is well cared for. I am very satisfied with the staff at his home. They are wonderful people, well trained and sincerely care about my family member. He also seems satisfied and speaks favorably about them. Please give them acknowledgement and a RAISE! This is very important that my family member get good care. Thank you.”

“We have been pleased with the residential services that [program] gives.”

“I am so happy that my son has a place to stay, that can watch over him 24-7. We as parents cannot do this. Thank you very much.”

“My brother has been a part of the [program] for 2 years. During this time, I have observed a very positive change in him. He thoroughly enjoys his group home staff and other residents. He has had the opportunity of bowling, movies, activities and shopping. His vocabulary has improved tremendously and he is learning to interact with others. He told me 3 days ago, I am happy. And I am doing good at the workshop. I can’t say enough good things about the [program] and I am so grateful it exists.”

“My family member’s parents died in 1960. She lived with her sister and me for 13 years when her sister died in 1973. I put her in [program] since I couldn’t take care of her. Then she was sent to [program] in [city] and now to [city] where I live. Knowing that she is living with three other ladies and living in a nice home and being taken care of by wonderful people Thanks and God Bless.”

## Communication

Some respondents commented on communication. Most respondents were dissatisfied with communication and felt they did not receive enough information from staff and agencies. A positive comment about communication follows below.

“[Program] has been lots of help buy telling me things like where I could get help. Also disability from [city] referred me to a lot of things I didn’t know about, such as transportation.”

The remaining comments highlight dissatisfaction with communication.

“Move Communication between 1, 2 and 3rd shift workers and the work center so that when a family has questions at either place the staff will know the answer.”

“That employee is still employed by [program]. I want to know how his money is spent, and for what.”

“Other services should be more visible and easily accessed.”

### **General Well-Being**

A few respondents wrote comments about the general well-being of the consumer. These comments address hygiene and health issues.

“Some areas such as manners might help. Overall appearance such as baths, oral hygiene, shaving, could be better.”

“The staff at the house do not keep up with personal grooming unless they know someone is going to show up.”

“My only concern is that my relative needs more physical activity. Thank you.”

“I am the sister of my family member. She is not doing too well over all, but I am not sure what could help her other than an exercise program and better supervision over what she eats. She is a diabetic and has allergies and presently may need tubes in her ears! She is overweight and has recently been shaky. Is it the medicine?”

### **Recreational Activities**

A few respondents wrote comments about recreational activities. Respondents were both satisfied and dissatisfied with these activities.

“My family member is severely retarded. He enjoys and benefits from outings and social activities offered to him through his home. He lives there because he needs supervision and is unable to make decisions and choices about daily activities.”

“He thoroughly enjoys his group home staff and other residents. He has had the opportunity of bowling, movies, activities and shopping.”

“The only problem is a lack of social activity outside of family visits. They don't have the staffing or take to go out to the mall, movies etc. Overall we are pleased with services.”

### **Employment**

Two respondents commented on employment issues. One respondent was satisfied, one respondent was dissatisfied.

“She loves her job, acted in a play and is managing her free time. She volunteers at [program] and [program] helps her with the transportation. We are very pleased. My family member works with a psychologist and this is beneficial.”

“I have also asked he work and sometimes he does but many days he sleeps all day and stays up all night.”

### **Case Management**

Two respondents wrote comments about case management. Both were dissatisfied with case management services.

“The SC make a plan that the individual is suppose to be on to follow. There is never any follow up on the plan except for the reviews that they have to do. They don’t tend to even know the person they are writing the plan for. They seem to copy the plan from the previous year and never update personal information except for the objectives.”

“We have received effective, prompt, and satisfactory services since 2002 when [provider] became our SC. Prior to that, services were very good to very poor because of changes in SC. There were times we didn’t hear from anyone in over a year.”

### **Transportation**

One respondent commented on transportation.

“Can’t get [provider] drive to bring home my family member when we can’t pick her up.”

### **Respite**

One respondent wrote a comment about respite care.

“There should be respite facilities that are only for respite for families so they can have less stress.”

### **Visits**

One respondent commented on visitation.

“I would like to see my nephew once every weekend because I don’t have anyway to see him. I don’t have transportation of my own and I don’t have anyway to see him. He is all the way in [city], SC so I wish they could get him over to [city] to visit me every weekend or every other weekend.”

## WASHINGTON

Approximately 47% of respondents from Washington wrote qualitative comments for this survey. The comments are summarized by theme below. The most frequently mentioned topic was home, followed by satisfaction with services and case management.

### Home

Home was the most frequently mentioned topic. Most respondents reported that they were satisfied with home situations. A small proportion reported dissatisfaction with home situations. Respondents also wrote comments about accommodations, furnishings/cleanliness, and placement. In commenting about the home situation, satisfied respondents used words such as happy, safe, satisfied, caring and loving to describe the home setting. Positive comments about home situations are summarized below.

"I am very happy with the adult home and care giver my sister lives with."

"My son is in the SOLA program and is very happy where he lives. I bring him home on Saturdays and Sundays - we have lunch together, but after approximately, 2 hours he wants to go home - so I think he is very content where he stays."

"My son has been at [location] for 39 years and it is the only home he knows. And he is HAPPY there. I am very much against the closure of this facility and can not understand why a simple downsizing of the grounds to a smaller area, keeping a few halls and certain other buildings would not be better than the uprooting of at risk residents."

"My daughter has been at [location] for 49 years. This is her home and she seems happy there. She is profoundly retarded and needs more care than I can give her. [Location] is a safe country environment, especially for those who are profoundly retarded and would not be safe in the community."

"[Location] and the 2035 staff do an excellent job with [Name]'s care and needs--he is very happy--that is his home and we feel blessed that he has such a good safe place to live out his years."

"We are very satisfied with the care and love [location] offers our son. We feel blessed that [name] is able to live in an environment that he is happy in. Nothing in life is 100% but we are very satisfied with this situation."

"We are happy with [Name]'s care and well being. She is very happy in her home situation."

"[Name] is brain damaged and requires supervision. She is happy with her life in a group home."

"I am satisfied that he is being well cared for in the family where he lives."

"[Name], my son, is doing very well- largely due to his residential home, [employment program], and the effort of me, his mother."

"Our son [name] likes the group home he is in - he has a good sized room which he shares."

"We are grateful for her living situation and the affectionate way the care giver relate to her."

"We are contacted quite often and attend office visits at her Drs. We are invited to her home often and can visit at any time."

"We are very thankful that [name] has progressed the way he has. The day we left him at [location] when he was 8 1/2 years old he has been taken very good care of. When we moved from [city] to [city], [name] was moved to [city]. He lived at a private place with good discipline."

"I am satisfied with the quality of care my ward receives at [location]. I do monitor it. The staff members are skilled and I am always impressed at how kind and caring they are. The professional doctors and dentist have specialized skills not obtainable outside [location] for dealing with the mentally disabled. I feel the environment is safe with much oversight. I do not feel comfortable that such a high degree of quality of care could be obtained outside [location]. She had been seen once in the community and it did not go well for her. I fear that any changes at her age would be detrimental for her outcome."

"He is very happy about having his own place. [name] cannot handle money so getting someone to help him with finances was part of what made it possible for him to have his own apartment."

"The program that supervises our daughter has been a vital part of her ability to live in her own home, with their help on a normal life. With their help and caring I know that she is shopping, cooking, keeping her home clean, making and keeping doctor appointments, following up on treatments and being involved in the community. They help as much as she needs, then monitor her progress, stepping in to intervene at appropriate times."

"[Location] is an excellent place for mental retarded people. I couldn't ask for more."

"[Name] seems genuinely happy in the adult family home where he resides. The people there seem so sweet, kind and caring."

"Our son is in a Companion Home. This model works well for him, however there is little or no communication with other Companion Homes. A systematic organization for support to care givers would enhance service delivery. They could help each other with respite and join each other for community activities. Problem solving could be shared. Please provide support to companion home. Thank you."

"My brother is very happy at [location]. It is 'home' to him. He gets all the support he needs and relies on the staff as though they are parents. He would not be able to receive adequate support in any other setting."

"[Name] has received good care so far at [location]. All his needs have been met. Hope things don't have to change too much. As [name] doesn't adapt to change well."

"I feel we have had our need met very well and my daughter is now in a very good adult group home that is providing excellent service to her."

"Our daughter rents an apartment and receives services from [organization]. This has allowed her to live semi-independently and we are very grateful."

"Thank you for helping [name] live a quality, happy life. [Location] is absolutely fantastic. The care and love [name] receives is of the highest quality. We are richly blessed."

"The management of our cousin's daily needs are always fulfilled by the professionals at [location]. We are always informed of illnesses and incidents, financial states and we assist in planning our cousins IHP. Our cousin feels [location] is his "home," we feel. We would vehemently oppose moving him to a different environment."

"She lives in a home for community living, a group of four in a newly built home, and she is very happy there."

"[Name] is doing great at [location] and gets great care so all is well."

"Our son is very happy in his group home and so are we. We talk to him daily from [city]."

"[Location] has been her home for more than 40 years. She has received very good care! She doesn't adjust to change very well at all. We expect that she will be able to live her life out at [Location]!"

"My daughter is profoundly disabled. Is at [location], and receives excellent care. The staff is great."

"[Name] has been at [location] since 1965. Generally, his stay has been very pleasant, and uneventful. He has had some medical problems that have been addressed promptly and thoroughly. We are very happy with the care he receives. The staff and management at [location] are excellent and cooperate with us always. Couldn't ask for more."

"I feel [location] staff and support personnel are doing a fine job."

"[Name] receives exceptional services and care from [location]. They are an extremely well-managed program. I am on the board of directors and have two charges with disabilities in the program."

"We are pleased with the care provided at [location]."

"My family and I have been very pleased with the care my brother receives at [location]. The staff (and peers) are his 'family,' but unlike family, they are much more tolerant of his behavioral challenges that appear to be age related. I have a great deal of personal respect and admiration for the staff and case manager(s)."

"We believe our family member receives the best care available at [location]. We are very satisfied with the staff and services provided. I would consider any move detrimental to our family member."

"My husband, now deceased, and I have been pleased with the care our daughter receives at [location]. They provide her with the care we were not able to give and we are most grateful. Since my husband's death, the staff has worked well with me to lessen the impact on [Name] and I have as I continue to age, she will be well cared for there."

"[Location] is very good at keeping us informed and we feel [Name] is getting excellent care."

Some respondents reported dissatisfaction with the home situation. These comments are summarized below.

"[Location] has been [name]'s home for thirty five years. The staff and residents are his extended family. He does not understand the changes going on around him. If and when he had to go to [location] he will no longer be able to come home for the afternoon."

"The man for whom I am a Volunteer Community member-guardian moved from [location] to his community 2.5 years ago. While some changes have been positive for him i.e. 1) transitioning from pureed food to typical food, 2) elimination of helmet, 3) generally more appropriate clothing, it is disappointing to me that in other significant ways community living has not been an improvement over institutional life. No headway has been made on toilet training, basic skills such as personal hygiene, dressing himself, in-home leisure time activities, communication, basic home management skills."

"There seems to be no quality control or specific criteria for adult family homes regarding the care to be provided. There should be minimum requirements for physical activities, mental stimulation, nutritional guidelines/real prep and quality, and weight management. It shouldn't be acceptable for care providers to let residents sit in front of the TV all day while serving high fat meals and snacks."

"I don't like where she lives but decent places that she would agree to are hard to find."

"I don't think the [location] is the right place for him. They don't know how to handle people with cerebral palsy. [name] is completely dependent on help. He can not eat alone, drink alone, brush his teeth, or use the bathroom. He cannot talk. He uses a lightwriter communicator. He can use the power wheelchair. But the chair is broken and can not be repaired. He has been waiting for a new chair for 2 years."

"Our son lives in an intensive support house in the community. The vendors or agency that serves these supports does have problems with keeping program managers in particular. The Transitions from one program manager to another has not been smooth. We have to start over in the planning process each time. The agency doesn't seem to be proactive in providing the stability that is needed in the house, the parents like to have more input in the services and what is expected of the staff. We'd like to see some creativity in the day to day activities in the house."

"The mannerism of [Name]'s living companion are very erratic and disruptive to the peaceful environment. Whenever [Name] has company or when I come over he frequently becomes disruptive. His personality changes dramatically from one minute to the next. Very unsettling."

"We would hope in the future residential providers would see the value of the parents' years of experiences with their family member as a valued resource and take advantage and learn from them rather than think that a few months of supporting the person they know it all. Sadly to say it's the person who is being served that suffers."

"I believe I'm considered to be an annoyance rather than a 'member of the team.'"

Several respondents wrote comments about home placement.

“It will soon be 2 years that the process was started to find housing and care for Tom. Up to that time he lived with his dad at home with a DD brother. Dad was 80 years old and experienced a major medical problem. It was known that Dad would not be capable of future care of sons. The process of arranging for housing and care was cumbersome and dismaying. It is not possible to tell the entire story/process here.”

“[Name] currently lives at home. He has lived independently with a roommate but needs almost daily supports for hygiene, money management, meal planning and prep. He would be a good candidate for group home or with a roommate and weekly support staff.”

“Because of our sons disabilities and some of his current behavior, we believe that the 24/7 program would be the very best place for him to live. We are desperately seeking placement in this setting at the present time through [organization]. They of course are fighting my request. They have gotten him on the waiver list but need to get Sec. 8 housing approval also. We want him in this and what as it would be best for him with his current behaviors to be in the 24/7 program.”

“Right now, I'm concerned about the closing of [location], and possible moving of [name]. She has had a hard time fitting in, because of her blindness and other disabilities. The staff at [location] have been kind to her. It is difficult for her to accept new surroundings.”

“I have requested that [name] be put on a list to be moved to a smaller group home. No response has been made.”

“However, it took two years trying to find the right placement, and I had very good support and assistance in finding this. They were supportive emotionally for me, as well. They helped me through the paperwork process and were really wonderful.”

“Unfortunately it took many years to find this team and she suffered as her family struggled to find an appropriate placement. It's strange that so many years were lost despite good intentions and serious effort.”

“Robert will be transitioning to an apt. w/assisted living. I think this will be a positive stop for him.”

A few respondents wrote comments about home accommodations and furnishings/cleanliness.

“She needs a phone that is very simple to use, so numbers that are programmed are EASY for her to remember and reach.”

“[Location], where my son lives, needs the plumbing altered.”

“My concern with regard to a ‘safe and healthy’ environment is attributed to the kitchen carpeting in the home where my daughter is a tenant. The kitchen floor appears to have black mold surfacing from beneath the carpeting. The carpet has been cleaned several times; however, this apparent mold continues to resurface. I have voiced my concerns about this problem to my daughter's caregivers and case managers on numerous occasions over the past several years. The previous property owner had the carpeting professionally cleaned which failed to eliminate the recurring black stains. I was advised several weeks ago that the new owner has agreed to clean and treat the carpet, but has refused to replace the kitchen carpet with a floor covering more suitable for tenants with developmental

disabilities. It is virtually impossible to effectively clean and sanitize kitchen carpeting that has been in place for many years.”

### **Satisfaction with Services or Agencies**

Satisfaction with services was the second most frequent topic. Approximately two-thirds of respondents who wrote comments about this topic reported satisfaction with services, while the other one-third reported dissatisfaction with services. Positive comments are summarized below.

“I’m very satisfied with [name] in [city] who operates the group home where my son resides.”

“Our latest experience with Developmental Disabilities Support Services has been the most positive ever. Perhaps this is because my son has matured and is better able to express himself, but I also think that the Choices Program gives him that opportunity. He does not get so frustrated with services that do not fit so that he gives up and opts out.”

“I am very pleased with [Name]’s care where he is. He is happy, well cared for, and has as much freedom as he is capable of handling! All the staff have been cooperative and do as much for him as they can! I dearly love my son and I consider that he has a very good home.”

“Although I have little contact with the case manager, I am very satisfied with the services DDD provides for my daughter. I can’t imagine how difficult life would be without these services. Thank you.”

“Over all I am very happy with my sister’s care. She has not been this happy for several years.”

“I am especially grateful for the service provided and level of care. Thank you for your good work and support. On behalf of the family, we are most pleased.”

“In our situation the disabilities are not severe, but any help requests have always been openly discussed and dealt with promptly. The client himself should be as dependable and helpful as our service providers are.”

“At this time we are completely satisfied with the service [name] is receiving.”

“Over all we are pleased with the services for our daughter.”

“We are thankful for all the services received - thank you! Whenever a crisis has arrived and we really need special help from DSHS, it has been there for us, and your people have been helpful in resolving the problems.”

“My family is grateful for the services and support given to our son.”

“DDD has been the best agency we have worked with. They seem to be the most knowledgeable and the most willing to help.”

“I’m very pleased with the care my daughter is receiving.”

“Overall we think DD does a good job even though you have so many cases to work on.”

"I would just like to thank everyone for doing such a wonderful job with my sister. I could never, on my own do all that needs to be done to help her live a good life. She has had many a trial, but bounces back with a smile because she has such a good support system. Thanks to the programs that are available and the WONDERFUL case workers, staff, etc. I'm SO glad we live in America! Thanks again."

"We are close to his staff and case worker at all times so that we always know what's going on all the time. At this point we don't have any complaints about [name]'s care and needs."

"[Name] seems to be happy so this makes us happy. Everything is fine."

"Excellent service for [Name]. Couldn't be more pleased!"

"I don't know what we'd do without the DDD!"

"I can't thank all the people enough for all the care they have given [Name] and the protection she has had all these years. We have been kept informed on the problems and good things at all times. Thank you all again."

"I am totally satisfied with my brother's care, the caregivers and his case manager at [organization]."

Some respondents wrote comments expressing dissatisfaction with services.

"The residential vendor has been very slow to follow up on tasks discussed at team meetings. If we weren't actively advocating for our member very little would happen. It takes a long time for our concerns to be acknowledged and respected both by the residential vendor and the medical providers."

"With the exception of the caregiver and facility my sister lives in, other people do not seem to follow through with plans in a timely manner."

"There is a dishonest lack of accountability within the administration of DDD and DSHS."

"There seemed to be no help our here. I was also told finally that - they DSHS couldn't help me while he was home. (I needed more through help with monitoring of the needs. Behavioral help (I would not call the police, that was not the way)"

"I kept asking for was help. This was my feelings not DSHS. See, I believe in family and I didn't want my son to have to leave home. I certainly didn't want him to ever go to an institution - but it finally had to happen because of his violence. He is happy there and I am hoping for more help for him. He is on respite there. I still can't help feeling things wouldn't have been this way if we had had more professional help."

"She is excellent. Our only complaint is with the new assessment tool, which seems geared toward people who are elderly, rather than equally serving those with disabilities."

"We would like more contact with his case manager and more help with employment service as [employment vendor] is not doing the job. His job coach does not come out to his work and see how well he is doing."

"We desperately needed services. I cannot tell you how horrible life was for all of us in the late teen years. At times, I really felt I'd have no choice but to drop my son off as the mission -in fact- our case manager recommended that one time! How pathetic is it when desperately needed services are unavailable and force people to even consider such radical choices. Just writing this reminds me of the pain to the point of tears."

"Very difficult to deal with the state in past experiences."

## **Case Management**

Case management was the third most frequently mentioned topic. More respondents were satisfied than dissatisfied with case management. However, many respondents identified staff turnover and a shortage of workers as case management problems. Satisfied respondents described case managers as fabulous, informed, pleasant, responsive and thorough. Positive comments are summarized below.

"The case worker is a nice person and a good listener."

"The DDD case manager provides excellent 'moral support' (i.e. talk)."

"I hope that he can stay with his current case manager as they have a good rapport."

"Our current case manager with DDD is fabulous. She keeps us updated and informed. We can always get answers to our questions and concerns. She is the only case manager who has contacted us and kept us informed in the 10 years we have been guardians."

"The current case manager has been very pleasant and responsive to my sister's concerns and needs and seems genuinely caring and committed to her job."

"[Name] is capable of communicating with her case workers, so my involvement there had been minimal. She thinks DSHS has done a good job and has no complaints."

"I would like to state that her case worker, though she has only been a case worker since Jan. of 2004, is very helpful and thorough, pleasant and approachable."

"The case workers have always been encouraging, listening, and helpful."

"Again- our case manager is very special."

"Our case manager was very understanding and helpful at all times."

"Our daughter's case worker has worked very hard on our daughter's behalf. She is excellent."

"I had a real nice care manager, the best one [name] had."

"When I call I get good response but I rarely hear from her. This is fine for our situation right now."

"Case workers are a lot more attentive than years ago."

"[Name] is an excellent case manager and provides the daily support my daughter needs."

"I have enjoyed working with [case manager]. She is always cheerful and pleasant. There to help where she can. She does a great job juggling everything considering she has a large, needy population she deals with. I have called her with questions and if she doesn't know the answer, she will research it and call me back with the information she found. [Case manager] does a great job and I look forward to working with her in the future."

On the other hand, many respondents were dissatisfied with case management. Dissatisfied respondents used phrases such as: less available, not knowledgeable and reluctant to request adequate support. These comments are summarized below.

"Case management either doesn't care or are reluctant to request adequate support and consultation/training. I have the feeling they are directed to discharge requests that may require additional funding."

"Case managers rarely contact us and client gets a new one without being told for awhile. I am usually satisfied with their help when I do have to call them. In the past it has been years before we have even seen a case manager. Some rarely even call."

"At this time we don't know who her case worker is!"

"I have only been contacted 1 time by the case manager in relation to [name] getting a job. I have tried to contact by telephone 5-6 times and have never had a returned call. I have never had a face to face meeting."

"Group home states current case manager is not knowledgeable and gives incorrect answers!"

"The 2003 Annual Client Report lists [Name]'s DD Counselor as [Name]. I assume this is his case manager. We have NEVER met this person, never talked personally nor by phone with this person, never known her to visit [Name] or review and evaluate his living situation. In short, we have had no contact with her. We feel this is a serious deficiency in service."

"I usually never hear from [Name]'s case workers. I never hear when they are going to do the service plans each year. In the past [Name] has had a case worker that didn't even know that she had a guardian. I received a letter saying [Name] had a new case worker, then I found out from the AFH where she lives she still has the old one??"

"Beginning around 6 years ago, DDD caseworkers were less available."

"I have little or no contact with the case manager, sometimes he/she shows up when my son has his yearly review and sometimes not. I haven't had good luck in the past, but things are going as well as can be expected considering the lack of money so I can't complain. If I need something I know how to find out about it and hopefully get results".

Many respondents also wrote comments about case management staff turnover and a shortage of case management workers.

"Our case manager was just recently changed. We haven't met him. It is too bad for the clients who like routine, that things have to change."

"[Name]'s case manager has changed 3 times during the past year and this makes it more difficult to stay current and informed. It's also difficult to keep rebuilding that trust."

"There has been a change in the case managers and we have had not contact yet."

"The only thing I would add is that between Jan 2003 and Dec 2003 [name] was assigned to FOUR different case workers."

"I wish there wasn't as much turnover in case managers and personnel as there has been."

"[Name]'s manager has changed several times since I have been his legal guardian. I meet the new case manager each year at his ISP and there is usually a new one by the next year. I am not typically notified of the change in case managers. I am not necessarily unhappy with the frequent changing, because [name] is happy in his home and always receives the services he needs. Case managers always seem competent when they take over [name]'s case."

"Case managers seldom last longer than a month or 2. It seems that they move to other positions before I get to know them."

"Working this past year with the case manager has been a joke. At present I do not know who that person is, nor have I been notified of my son's case manager for the last 3 years. It's really a nightmare to call and get a different person each time."

"The case managers I know really try. But they don't have the time to give to you unless you call them and ask. You have to keep on top of them."

"My biggest frustration is getting in contact with her case manager. He's always so busy. It would be nice if more case managers could be hired."

"Less case work time has been available from DDD workers in the last few years than previously. I rely much more on [residential program] staff for all support and information."

"Case worker time available was reduced drastically several years ago. Assigned worker formally met at all staffings (twice yearly) and was more in touch."

"These improvements would include more frequent contact with the case manager. Because of the case load the case manager sees each client once a year."

"The case manager(s) have been distant. They appear over burdened."

## **Staff**

Several respondents wrote comments about staff. Approximately the same number of respondents reported that they were satisfied with staff as dissatisfied. Respondents also reported that staff turnover and staff qualifications were a concern. Positive comments about staff are summarized below.

"I very much appreciate his efforts, and certainly those of all staff members, to make [name]'s necessarily restricted life as pleasant as possible. My thanks to you all."

"[Name] seems to be happy with her care giver and is cared for very well."

"[Name] is the greatest care giver now. She has done wonders for [name]. Medically she sees about his eyes, hearing and all other needs. Keeps in touch with us. Makes preparation for him to come home. Makes his apartment very nice and he is very happy."

"I sincerely appreciate what [name] does for him as my plate is full working full-time, caring for my children, husband and caring for my parents in the evening. I usually see [name] on holidays or if our nursing home visits coincide or if [name] is in some sort of financial crisis."

"Group home staff has and continues to provide excellent caring support."

"I know that my daughter likes and respects all who work for and with her. I have met most of those who assist her and feel they have her best interests at heart."

"We have been extremely happy having [name] as [name]'s weekly helper, as he goes above and beyond in working with [name]. We trust him completely in the decisions he and [name] make."

"The people working with our daughter and on her behalf seem to be of the highest caliber and dedication. They seem to really know and understand her and have her welfare and best interests in their plans for her. We could not ask for better people working with her. Thank you."

"I feel staff does an excellent job. I am contacted often, but not too often. They handle challenges on their own"

"We are very pleased with [Name]'s help, it isn't easy taking care of her as she gets older."

Many respondents were dissatisfied with staff. These comments are summarized below.

"However, the service provider (who usually says 'yes they can do this,') usually does not follow thru with the commitments. It is a constant struggle on our part to see that our family member gets the service agreed to at the annual reviews, and we only have limited success."

"Management and Residential Staff: Both have a very narrow understanding of how to increase the quality of life in the community for this man and others. They seem not to be the least bit disturbed by the fact that other than in ways previously mentioned his life in his community is not too different from institutionalization. I have requested and twice received DD consultant services: 1) Staff training on how to deal with behaviors and teach skills. It was not enough to really help and there was no follow-up to ascertain how or if it was working. 2) A positive behavior support plan was developed. A few of the suggestions made were implemented with good results. It just didn't go far enough and again there was no follow-up."

"More monitoring of care givers - they come late to relieve night shift. More interaction of care givers with clients - They just let them sit and they do the housework but would be nice if they sat and talked to clients more."

"We strongly feel the staff has taken the wrong approach ('he is an adult now') considering that mentally handicapped are capable at making decisions that affect their and family

members live in particular with proper diet (he's gained 30 # since leaving our 24 hr care) exercise, education and training.”

“We wish [name]'s care takers were more conscientious about looking out for his needs, especially since he does not communicate verbally.”

“I found these questions very confusing and hard to answer. Staff at the home are not encouraged to tell parents what's going on. Several have been fired for doing that.”

“I am not at all happy with [organization] that is supposed to be giving [Name] support in her apartment. She shows up about half of the time. When she doesn't show up she doesn't bother to call and explain. This has been reported to the case manager.”

Respondents also identified staff turnover and staff training as problematic.

“Just recently met new case manager. There seems to be lots of staff changes taking place. Parents rarely notified of changes or reasons for why staff being replaced. Very disruptive for residents. The yearly planning session is always filled with good ideas and goals, however, much is never accomplished, and the next year the same rhetoric.”

“[Organization] is giving very good services and care to my son. There is frequent turn over in staff.”

“[Name]'s residential support is very good, but I am concerned about the high rate of turnover among the residential staff. However, thankfully the management staff IS consistent and does an excellent job overseeing her care and safety.”

“[Name]'s care provider that he had for over 10 years was suddenly dismissed. We have never been told why. He now has a new care provider who seems to be doing an adequate job but does not have as much expertise with the system as the previous person. We were not happy with the way this whole process was handled.”

“The only complaint we have is the high rate of care giver turnover and the sometimes inadequate training of the new employee.”

“More in-depth training for the care givers to enable them to learn more about the situations of persons with disabilities, nutrition and more sensitive to the needs of cultural minorities.”

“Over the past years I've been shocked to find the lack of skill in care givers provided by the state. They don't want to work or even show up for work, but always want to collect the pay. The state has not checked their references and has allowed disabled people to become victims of prey. A much better referral and screening service must be established by the state to protect the disabled.”

## **Communication**

Several respondents wrote comments about communication. Nearly all the comments about communication were from dissatisfied respondents. Respondents identified the communication of information, interagency communication and language barriers as areas of concern. The comment below summarizes positive comments about communication.

“Our son is more independent of us now than he used to be. He can communicate with his case manager and let his needs be known. We do like to know what is going on if there is a change or a problem.”

The following comments reflect the dissatisfaction with communication expressed by most respondents who commented on this topic.

“I would like to meet his case worker to know what is going on with [name]. I receive no information on his current situation.”

“Communication with agency that provides service is very poor. Response to our concerns and questions is very poor. The office staff and floor staff do not communicate participants’ needs and/or concerns. Medication and program changes are made without our knowledge or approval. Consultant NEVER coordinates care or keeps us informed. Agency does not let consultants know of our concerns as per consultants. As guardians, we want our concerns and questions addressed in a timely manner.”

“However, communication is limited to the yearly evaluation and changes of residence. We initiate any other communication.”

“We felt that the shared parenting plan where we were supposed to work with foster parent to make decisions didn't really work. The foster parents did not include us in decision making or keep us informed. We would find out what was going on in team meetings or not at all. We decided not to complain because we knew our son had a good living situation. This did make us disinclined to want to have contact. There were hard to reach and almost never home. We would have to call after 10 PM. We feel more included by the adult facility.”

“Our son is in a Companion Home. This model works well for him, however there is little or no communication with other Companion Homes. A systematic organization for support to care givers would enhance service community activities. Problem solving could be shared. Please provide support to companion home.”

“I am not satisfied with management with the services provided. Doesn't seem to get any communication with the program he is in. I have written to DDD about a manager who assists with his care and whom I don't want working with him and she continues to do so. We would like to file a grievance with the court because of my lack of involvement in his goal planning and particular people who work with him.”

“The case manager from DDD had never contacted me or my wife other than to sent letter or IHP: for signatures. I only know what DDD provided through the agency that takes care of her.”

“A pamphlet with other government assistance would be a nice hand out.”

“UGH!! After 5 1/2 years I am still trying to find out which person is responsible to see that her annual/quarterly visits to her different doctors is accomplished. Right now I have concerns that I've spoken to the team leader about, but haven't received an answer.”

“Also, sometimes if there's a problem (example: transport) it's hard to find information. One person may tell you one thing and another will tell you something else. Or I'm not even sure

which agency I should contact about some things. Is there a guidebook for what agencies do what?"

"I would like more input on [name]'s care and also who to contact and numbers for case manager, care giver."

"I would like to be more involved in [Name]'s activities or at the least know what he does each day, his menu and needs. I need a break down of monies actually spent on [Name] since we pay this, etc."

"I would like to be provided with information as to what I should expect from the services being provided for my son and how to best monitor these services and assist my son. I also want to be appointed medical guardian."

"In the future, I would like to be notified when my son receives a new caseworker and given his or her name and phone number. I also want to be notified of my son's ISP meetings every year and any other meeting(s) (between DD & my son's group home) concerning my son."

"It would be helpful if the care providers were proficient in English."

"I do not know who my son's case manager is, or has been for several years."

"Coordination and communication between those who provide support seems non-existent to my knowledge, (i.e. doctors, psychiatrists, case managers, community access, physical therapist, etc.). It would be beneficial."

"I know that DSHS has a difficult job. I would like to see DSHS and social security, etc., work together better."

## **Employment**

Several respondents commented on employment issues. Most respondents expressed dissatisfaction with employment, while a few expressed satisfaction. Positive comments are summarized below.

"He has a solid job with the city and owns and insures a car he drives. He uses public transportation to work downtown."

"[Organization] has been very helpful in getting family member into a job."

"She is in a work shop and appears to be happy with her job."

Comments showing dissatisfaction with employment are listed below.

"Employment: He has been involved in an employment program for most of the 2.5 years he has lived in the community. He had one assessment which was terminated by the business because his noises frightened the customers. DVR deems him unemployable and last week a second employment agency notified us that they have made no progress and will no longer serve him. The upshot of that is that further services while being called employment services will look more like community access—which is not a totally bad thing if the provider

will work on increasing his comfort level in community environments and help him and community members to get to know each other.”

“My most important concern is regarding day programs. I feel that it is VITAL that community access programs be available for whatever activities the participant desires to attend. These programs must NOT be seen as only vocational or pre-vocational programs. They should instead be seen as valuable programs for integrating persons with developmental disabilities into the community in many social ways. They need to be available for any activity from going to the public library, the pool, concerts, or just out to lunch at a local restaurant. They are too important to be reduced to only vocational training.”

“[Name] wants more than anything to have a job. He NEEDS to work. He has (on his own) applied for 2 jobs. One at [company], one at [company]. He has been a ‘greeter’ in the past, and LOVES people.”

“DVR is slow in my opinion, in helping [Name] get a job. Nothing has developed since DVR contacted her in January 2004. Today is 6/7/04.”

“I am VERY disappointed that [Name]’s employer is choosing to terminate her program. [Name] is very proud of her job and I hope another program will be available or that [company] will reconsider this closure. [Name] should NOT have to be confined to her residential setting all day.”

“I would like lots more help in finding employment for [Name].”

“My son seems very happy where he is. I wish there was a way we could figure out how to get him to go to work.”

“I don’t understand what takes so long for my disabled daughter to actually get a job. She goes through the whole process for months and is still waiting for a job. Something is wrong somewhere! It seems like a game to me.”

“My comment is about the \$5 an hour the clients make. It’s not right that they let a staff member take the LEARNING STEP and if he can do it in an hour, the disabled will get the hourly wage. But if THEY can’t, it’s \$5 no matter what. That barely gets them a tube of toothpaste or some other necessity. I and other parents think it is very cheap labor, when most of the workers have been there 30 years or more (at work!) Thank you.”

## **General Well Being**

Some respondents commented on the consumer’s general well being. These comments centered on the consumer’s health and safety.

“My son has suffered several family deaths in the last two years. He is not going to counseling for grief, and he is angry and hurting. He has spoken on the phone to me daily and is overwhelmed. He is also upset over a friend’s child having Leukemia (not doing well). He is angry because his family is dying and wants to come home and cannot until he is done w/DOC and probation. He hurts and doesn’t know how or who to talk to. Nor for that matter do I. He is a bit overwhelmed.”

“Most of the time he is not happy unless he has his way. Therefore his support staff have little patience at times and he feels like no one cares. It is very hard for us.”

“[Name] is married, lives with wife in independent living, with help with money by mother in law. He works for [company] and is assisted by at arms length, by [company]. He has suffered an on the job injury and was off the job for one year, however he is now back on the job full time. “

“Safety is the main reason that MR people like [name] -- who are too social and have a behavior to running away and no sense of direction -- need a home setting with much acreage, to walk and visit their peers and familiar staff with no fear of the harm the general public must face.”

“[Name] has broken a shoulder 2 months ago and now is in a re-hab/nursing home. She and her group, drs., family, case-workers, therapists, etc., are concerned about her safety living by herself and are questioning if she should perhaps be looking into an assisted living environment?”

“[Name] sleeps soundly BUT for safety reasons, (such as fire,) must have staff 24 hours.”

“[Name] was hurt before and I have asked the care provider to closely monitor on this matter, as [name] is not capable to protect or defend himself. The matter was resolved. The care givers did a good job on this matter, like they always did in other issues in the past.”

“Our child (female) is non-verbal. Our main concern is for her safety and that she is not abused. She is not capable of reporting any violations because of her inability to communicate. Despite the fact that she is in the safest environment for her condition at [location], we still have a concern with regard to night staffing of her residence.”

## **Funding and Budget Cuts**

Some respondents wrote comments about funding and budget cuts.

“The downsizing/closure process (dishonestly blamed on the legislature,) threatens [name]’s welfare.”

“For the past five years I have been trying to open the temp part of my house for sure for two other disabled persons who would be suitable to live with my daughter and convert daily help into a 24 hours daily assistance with sleep in personnel. The main reason for objecting is funding and lack of clients. Both of these reasons seem to be weak excuses. Perhaps DSHS could be more progressive and sensitive toward the disabled in this respect?”

“Caregiver hours have been cut from 99 hours per month to 37 hours per month. I feel my nephew needs more than 37 hours per month care. I most likely will be quitting soon and the state can figure out what to do with this developmentally disabled 29 year old. I have helped him for close to 9 years. My sister gave him up because she could not handle him. Maybe another group home when I quit?”

“Personal care hours were cut drastically from 144 hours to 53.35. Lost care giver due to cuts.”

“DSHS is cutting services. [Name] lives at [location] and staffing cuts and overcrowding have affected her greatly.”

“I'm concerned that services to people with developmental disabilities keep getting cut. My daughters mental capabilities don't improve yet her personal care hours have been cut and will probably be cut some more. The new assessment seemed to be more focused on physical disabilities i.e. getting in/out of bed; showering, cutting nails, etc. and less on the mental and safety issues of good judgment; letting time, shopping/cooking, etc. These changes along with cuts in Sec 8 housing are very troublesome to me!”

“With all the taxes that we pay in to the government, one would think that someone could or would be available to her on an as needed basis to assist her in job coaching, and to encourage her to keep a cleaner more organized house. Thank you.”

### **Aging Caregiver Issues/Health Problems**

A few respondents commented on aging caregiver issues or health problems.

“Our mother died 3 years ago. Our father became unable to supervise [Name]'s care, so I have been handling it for him. I am still learning.”

“I wish there was more help available for her in her living situation. I'm close by and help her often. But I wonder what will happen when I'm gone?”

“My husband passed away July 2001, so [name] and I are alone. I moved in a retirement home May 15 2004. My age is 86. I need help. [Name] lives at [location] right now. I would like him to be moved closer to [city] so I can keep visiting him. I still drive.”

“I would worry about his needs being met should something happen to us.”

I'm getting older and worry that [Name] will need help when I am gone or can't help her. I would like more involvement with this.”

“I have health problems and my husband broke his hip this winter.”

“I am 87 and my wife is 88. Our health is not very good. We are only able to see [Name] when some one in the family takes us!”

### **Health Care**

A few respondents commented on the topic of health care. These commented focused on medical and dental care.

“At our last appointment I was notified that [doctor] was not accepting Med. Coupons. This was due I gather from a much too intrusive paper work from DSHS. I would never consider another dentist, even when it puts the financial burden on me, and I am sure there are many who are deprived of his services for this reason, I have contacted DSHS in Olympia and get no answers. It would be a help to me and I'm sure to others to look into this matter.”

“My son sees the [location] dentist once a month. When that facility closes, I'm concerned about back of resources for dental care.”

“My sister has been well cared for. I would like to see her dental needs cared for and also some mental health counseling.”

“Not all medical facilities accept medical coupons or Dedicare and this presents a burden on us as parents as [name] does not earn high wages.”

“My son has been dealing with enormous changes in his health. This has been very challenging for us and his support agency.”

“We need better access to medical professionals such as psychologists.”

## **Recreation Activities**

A few respondents commented on recreation activities. Most were dissatisfied with these activities.

“He goes to church 2 times a month - they take him out to movies, dinner, shopping and [name] cuts his hair.”

“He has extremely limited opportunities to meet people due to his staff's lack of skills and motivation to help him get involved with others. Their reluctance seems to stem from their inability to foster acceptance, due to behaviors that are different, and at time I'm sure are embarrassing to them. Therefore outings are mostly limited to little frequented locations.”

“Recreational Supports: Much is needed. Everything I have suggested that she liked to do while she was with me is ‘oh yes, sounds good,’ but goes nowhere.”

“Most of his free time (now wasted) could be used to better his reading, physical condition (walking) as well as task performance speed.”

“It would help family member a great deal if she could be involved in more activities. She likes to be kept busy, and she gets really bored when there is nothing for her to do.”

“There definitely is not adequate staff time (from funding) to provide community or social skills/activities. He sits around at his house way too much.”

## **Transportation**

Five respondents wrote comments about transportation. All respondents were dissatisfied with transportation services.

“I -- as his guardian -- can no longer endure the I5 Corridor Traffic in an older auto, (yes, I've arranged for other relatives, neighbors and even [school] staff to transport him to our home in [city],) BUT these options are no longer available to me.”

“More van accessible so clients can come and go more. Ours has an outing once or twice a week - otherwise she sits in a chair and watches to with 2 other residents.”

“My biggest frustration at present is transportation as dial-a-lift has denied services under their present budget constraints.”

“A HUGE issue with our family is that the agency providing for our daughter does not have any van for the clients use. Public transportation is very difficult/impossible for her. She misses out on activities or experiences that she might enjoy.”

“A concern I have is that my brother is consistently kicked off the shuttle for taking off his seat belt. This restricts him from going to his JOB. It seems to me that lives or shuttle drivers should know how to work with people with disabilities. So far he's been off work for one a month because of not fastening his seat belt! This is the second or third time.”

### **Advocacy/Choice/Self-Determination**

Three respondents wrote comments about advocacy, choice and self-determination.

“At this time, my sister is doing a great job advocating for herself with the assistance of the adult family home provider. [Name] has an excellent understanding of my sister's needs and has been an outstanding advocate for her as well.”

“What happened to Choice/Individualized programs based on the needs of the client? Funding might be limited, but it is also not monitored for expenses paid out to the agencies. Are the clients really getting their needs met? Having to share the ISH with other clients often leaves the client sitting in their apartment or having to tag along. My experience as a family member and a court guardian with the DDD system has been frustrating.”

“Family member feels (or seems to) acknowledge his freedom and rejects help because he has been told that he can make his own choice. My concern is that some of these choices are not safe and he won't accept any other changes.”

## WYOMING

Approximately 30% of respondents from Wyoming wrote qualitative comments for this survey. These comments are summarized by theme below. The most frequently mentioned issue was staff followed by satisfaction with services and case management.

### Staff

Staffing issues was the most frequently reported topic. More respondents reported that they were dissatisfied with staff, in particular, noting staff turnover, under trained and under qualified staff, and staff pay as problems.

“I sometimes wonder if staff members are overwhelmed by job responsibilities. I sometimes wonder who staff members are serving – the client or the program. Everyone is always respectful acting but seems like program is first – person second at times. Is there too much paperwork for staff members to complete?”

“The worst problems are with the constant change of employers, it seems we get everything on a smooth roll and then they leave. It is harder on the client. My brother has been 13 years with Agency and I have to constantly remind them of his diet or other important matters.”

“My concern and the concern of Agency is the turnover problem. We need to pay home trainers and most other staff better, so they can stay on the job long enough to develop a long history of personal success.”

“I am concerned about the turnover rate of the employees of Agency that provide the group home services to my aunt. The reason for them leaving seems to be rate of pay and lack of affordable health care...”

“I would like to see consistent support staff that are properly trained to understand Prader-Willis Syndrome. When staff change and young summer help are assigned, they do not understand or are not trained to work with my sister.”

“I believe that higher level staff when short of care for clients need to roll up their sleeves and help. I feel workers need higher pay and appreciation and incentives and reasons to stay. Our society is judged on how we care for our weakest and most vulnerable citizens and it is failing. I am sincerely grateful that my daughter has a home and a sense of life because of Agency. I only wish for consistency of care and lengthy employment of staff.”

A few respondents commented that they were satisfied with staff.

“The staff at Person’s group home are very caring of Person and other residents. I am well pleased.”

“I feel that the case manager and the people at the group home do an excellent job. A lot of the success for my son is because of the caring nature of the case manager, in particular, and the staff at the organization. I am handicapped by the fact that my daughter does not talk. All I know comes through her caretakers – for whom I have great admiration and appreciation.”

“I feel that Agency does a good job and that my sister, Person, is well cared for and that the staff are kind and patient on the whole.”

“Person would not be alive without the outstanding care she receives from the staff that take care of her.”

### **Satisfaction with Services**

The second most frequently mentioned topic was satisfaction with services. Respondents specifically mentioned their satisfaction with providers, staff, and overall satisfaction.

“Parent loves the Agency! Agency is a wonderful place to have a child with disabilities, they do wonders for their members.”

“I am highly impressed with the services and the caliber of the care that Person receives. It really couldn't be any better, in my opinion! I am very satisfied that my son Person is at Agency in City. They really care about their clients as people, not just paychecks like other agencies he has been at.”

“I think my brother has received excellent care.”

“Generally, the services our son, Person is receiving have been satisfactory. Our other son and daughter-in-law, who live close to Person are excellent advocates for Person and keep us fully informed on everything. Thanks for the many services Person is receiving. We are very appreciative.”

“I am thoroughly satisfied with the services I have received for my son since 3/89. Those services rendered by the Agency services organization are both professional and understanding and I know that my natural son receives the best care available and helped with warmth and honesty. I highly recommend Agency.”

### **Case Management**

Several respondents commented on case management. Approximately half of those who wrote comments reported being satisfied with case management services.

“My son's manager is a caring professional person who has gone beyond this stated job description to help my son and family through some difficult times for which I will always be grateful!”

“The first time we have had a case manager that tries to make a difference. She is very wonderful for our daughter. It is very hard to find somebody to work with our daughter. She does need very special care and her seizures are bad sometimes. She now has one very good caretaker and a very good case manager.”

“I feel that the case manager and the people at the group home do an excellent job. A lot of the success for my son is because of the caring nature of the case manager, in particular, and the staff at the organization.”

About half of the respondents reported being dissatisfied with case management.

“Case manager does not always get back to me when I ask her questions.”

“Case manager says he will do something and does not follow through.”

“Our biggest concern has been turnover in case management over the last 3 years. Continuity of services can suffer greatly with instability in case management. Staff and care providers have done a great job weathering the changes.”

“Please understand that it is not case manager’s fault but how thinly she is stretched and stressed. The case manager is spread so thin consistency of care is lacking.”

## **Home**

Several respondents reported that they were dissatisfied with the home environment, specifically, group or other residential placements for their family member.

“My biggest question I have for DDD is why don’t the parents that keep their children at home with them get some financial support to? Why do we have to put our child or young adult in an institution or special hab home to get respite? If a child or young adult costs the staff \$100,000 per year in an institution or special hab home, why can’t the parents be even a little financially supported while their child or young adult live with them? The other question I have is why does this survey not apply to clients living at home with their parents? Just because they live at home does not or should not mean their needs need not to be known as well as those living with someone else.”

“The services at Agency in City1 are very poor. My two sons are there have lost so many home and school that were taught. My sons are so confused as to want to move home here to City2. They call me and tell me they want to move home and by the time I see them Agency has them in their grasps and won’t let me see them. If I do see them without Agency staff they are my loving sons who are happy and glad to see me.”

“It has taken 4 years to get accessible bathroom.”

“He was living alone and very happy. One year ago they moved him into a group home as they needed the space for someone else due to construction changes. He remains in the group home and is unhappy. He much prefers to live alone but Agency has not accommodated him yet.”

A few respondents also commented that they were satisfied with the home environment.

“Agency of City has provided a home for my aunt for 10 years. She was 18 before that. Agency has become her home. They are exceptional!”

“I am very satisfied at this time with Person’s group home and his day program. I believe that he is surrounded by professionals in this field and is doing 100% better than the day I put him in the program.”

## **Health Care**

A few respondents wrote comments regarding health care. All respondents who wrote comments were dissatisfied with access to health care, dental care, or mental health care.

“The one complaint I have is I can’t get dental insurance for my daughter. If you tell an insurance company she has MR or DD they don’t want nothing to do with insuring her. I did apply for her to get free dental care, which I can do once a year. I just think it would be better if she had regular 6 months check ups. I think it is terrible that because she is over 21 she does not get the same services as young children. Medicaid should give equal care.”

“The PT, OT and Speech Therapies are real lacking.”

“There doesn’t seem to be the professional expertise to really deal with his psychological problems – we have to go to Utah for his doctor.”

## **Communications**

A few respondents mentioned that they were dissatisfied with communications with, case managers, providers, or between agencies.

“New case manager has only made 1 contact in 2 months since she took over, I have been satisfied with CM in the past.”

“I feel with adult services we as guardians are less aware of decisions and what is going on. We feel left out at times. Never sure what our rights or involvement can, should be.”

“My concerns for the moment now are those of miscommunication between the group home staff and day hab staff for planning purposes, the lack of updated information on a regular basis, i.e., - calendar schedule, regular meetings of guardians with staff to get our input (there are meetings, but they are scheduled for their staff convenience instead of guardian convenience) staff changes.”

## **Employment and Training**

A few respondents wrote comments about employment and day programs.

“City business’s do not support people with DD. There is a big lack of job coaches, so there are very few jobs.”

“Agency seems to need help with their vocational training program this area/program doesn’t seem as strong as other programs/community.”

## **Suggestions for Improvement**

A couple respondents noted suggestions for program improvement for their loved ones.

“I wish the division and government were more geared toward the individual on a real level rather than ‘statistically’. I feel sometimes rules and regulations over power what is satisfactory and acceptable to my family member’s needs and our needs as a family for our setting and her individually.”

“We are very active in our son’s activities both respite and day hab, however there have been times when things happen with no explanation. It would be good to know the actual process for filing a formal process of grievance as long as the child has no repercussions from this.”

“I feel the State should make unannounced visits to the places that provide services to the disabled so that they can check on how the places run daily.”

# APPENDIX A

Summary Tables of Survey Responses

**Table A - Characteristics of Family Member with a Disability: 2003 Data**

<b>STATES</b>	<b>Total %</b>		<b>State Avg.</b>		<b>AZ</b>		<b>CA-RCOC</b>		<b>CT</b>		<b>ME</b>		<b>NC</b>		<b>ND</b>		<b>PA</b>		<b>SC</b>		<b>WA</b>		<b>WY</b>	
Number of surveys	<b>4,826</b>		<b>n = 10</b>		<b>341</b>		<b>301</b>		<b>559</b>		<b>672</b>		<b>364</b>		<b>328</b>		<b>1,170</b>		<b>164</b>		<b>640</b>		<b>287</b>	
	n	%			n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
<b>Gender:</b>																								
Male	2,502	<b>54.6</b>	<b>54.7</b>		174	<b>54.4</b>	163	<b>56.4</b>	286	<b>54.6</b>	331	<b>52.3</b>	187	<b>54.7</b>	179	<b>56.5</b>	636	<b>55.9</b>	87	<b>58.0</b>	320	<b>53.5</b>	139	<b>50.9</b>
Female	2,082	<b>45.4</b>	<b>45.3</b>		146	<b>45.6</b>	126	<b>43.6</b>	238	<b>45.4</b>	302	<b>47.7</b>	155	<b>45.3</b>	138	<b>43.5</b>	502	<b>44.1</b>	63	<b>42.0</b>	278	<b>46.5</b>	134	<b>49.1</b>
<b>Age:</b>																								
Mean	<b>44.1</b>		<b>43.7</b>		42.5		42.1		45		45		45.2		42.8		45.5		46.5		43.9		39.4	
Range	<b>18-97</b>				18-81		19-78		20-97		19-86		18-83		18-86		18-89		19-81		18-85		18-81	
<b>Type of Residence</b>																								
Specialized MR Facility	630	<b>13.5</b>	<b>12.3</b>		18	<b>5.4</b>	20	<b>6.8</b>	27	<b>5.0</b>	71	<b>11.1</b>	92	<b>27.0</b>	16	<b>4.9</b>	206	<b>17.9</b>	18	<b>11.6</b>	127	<b>20.9</b>	35	<b>12.6</b>
Group Home	2,619	<b>56.2</b>	<b>58.6</b>		247	<b>74.4</b>	202	<b>68.7</b>	406	<b>75.3</b>	318	<b>49.7</b>	180	<b>52.8</b>	184	<b>56.8</b>	650	<b>56.6</b>	96	<b>61.9</b>	162	<b>26.7</b>	174	<b>62.6</b>
Agency-Owned Apartment	209	<b>4.5</b>	<b>5.3</b>		16	<b>4.8</b>	4	<b>1.4</b>	23	<b>4.3</b>	29	<b>4.5</b>	8	<b>2.3</b>	20	<b>6.2</b>	30	<b>2.6</b>	23	<b>14.8</b>	40	<b>6.6</b>	16	<b>5.8</b>
Own Home/Apartment	619	<b>13.3</b>	<b>12.8</b>		12	<b>3.6</b>	46	<b>15.6</b>	64	<b>11.9</b>	68	<b>10.6</b>	18	<b>5.3</b>	92	<b>28.4</b>	113	<b>9.8</b>	8	<b>5.2</b>	171	<b>28.2</b>	27	<b>9.7</b>
Adult Foster Care/ Host Family Home	250	<b>5.4</b>	<b>5.1</b>		21	<b>6.3</b>	7	<b>2.4</b>	7	<b>1.3</b>	75	<b>11.7</b>	11	<b>3.2</b>	9	<b>2.8</b>	54	<b>4.7</b>	7	<b>4.5</b>	39	<b>6.4</b>	20	<b>7.2</b>
Nursing Home	122	<b>2.6</b>	<b>2.0</b>		7	<b>2.1</b>	7	<b>2.4</b>	1	<b>0.2</b>	44	<b>6.9</b>	7	<b>2.1</b>	0	<b>0.0</b>	38	<b>3.3</b>	0	<b>0.0</b>	18	<b>3.0</b>	0	<b>0.0</b>
Other	210	<b>4.5</b>	<b>3.9</b>		11	<b>3.3</b>	8	<b>2.7</b>	11	<b>2.0</b>	35	<b>5.5</b>	25	<b>7.3</b>	3	<b>0.9</b>	58	<b>5.0</b>	3	<b>1.9</b>	50	<b>8.2</b>	6	<b>2.2</b>
	4,659				332		294		539		640		341		324		1149		155		607		278	
<b>Race/Ethnicity* (duplicated counts):</b>																								
White	4,258	<b>90.0</b>	<b>87.1</b>		240	<b>72.1</b>	268	<b>89.0</b>	490	<b>90.9</b>	640	<b>97.0</b>	249	<b>68.4</b>	309	<b>95.7</b>	1110	<b>96.6</b>	121	<b>79.6</b>	579	<b>92.2</b>	252	<b>89.4</b>
Black/ African-American	207	<b>4.4</b>	<b>6.0</b>		7	<b>2.1</b>	5	<b>1.7</b>	26	<b>4.8</b>	1	<b>0.2</b>	92	<b>25.3</b>	1	<b>0.3</b>	28	<b>2.4</b>	31	<b>20.4</b>	16	<b>2.5</b>	0	<b>0.0</b>
Asian	34	<b>0.7</b>	<b>0.8</b>		1	<b>0.3</b>	10	<b>3.3</b>	2	<b>0.4</b>	5	<b>0.8</b>	0	<b>0.0</b>	0	<b>0.0</b>	1	<b>0.1</b>	0	<b>0.0</b>	14	<b>2.2</b>	1	<b>0.4</b>
American Indian/ Alaska Native	74	<b>1.6</b>	<b>1.9</b>		19	<b>5.7</b>	5	<b>1.7</b>	4	<b>0.7</b>	7	<b>1.1</b>	5	<b>1.4</b>	10	<b>3.1</b>	3	<b>0.3</b>	0	<b>0.0</b>	12	<b>1.9</b>	9	<b>3.2</b>
Hawaiian/ Pacific Islander	8	<b>0.2</b>	<b>0.2</b>		1	<b>0.3</b>	2	<b>0.7</b>	0	<b>0.0</b>	0	<b>0.0</b>	0	<b>0.0</b>	0	<b>0.0</b>	1	<b>0.1</b>	0	<b>0.0</b>	2	<b>0.3</b>	2	<b>0.7</b>
Hispanic	103	<b>2.2</b>	<b>2.7</b>		49	<b>14.7</b>	8	<b>2.7</b>	16	<b>3.0</b>	4	<b>0.6</b>	3	<b>0.8</b>	1	<b>0.3</b>	4	<b>0.3</b>	0	<b>0.0</b>	10	<b>1.6</b>	8	<b>2.8</b>
Mixed Races	58	<b>1.2</b>	<b>1.4</b>		13	<b>3.9</b>	5	<b>1.7</b>	7	<b>1.3</b>	4	<b>0.6</b>	0	<b>0.0</b>	2	<b>0.6</b>	5	<b>0.4</b>	0	<b>0.0</b>	10	<b>1.6</b>	12	<b>4.3</b>
Other/Unknown	10	<b>0.2</b>	<b>0.2</b>		0	<b>0.0</b>	1	<b>0.3</b>	1	<b>0.2</b>	5	<b>0.8</b>	0	<b>0.0</b>	0	<b>0.0</b>	0	<b>0.0</b>	0	<b>0.0</b>	3	<b>0.5</b>	0	<b>0.0</b>

**Table B - Characteristics of Family Member with a Disability: 2003 Data**

	Total %		State Avg.	AZ	CA-RCOC	CT	ME	NC	ND	PA	SC	WA	WY										
Number of surveys	4,826		n = 10	341	301	559	672	364	328	1,170	164	640	287										
	n	%		n	%	n	%	n	%	n	%	n	%										
<b>Level of MR:</b>																							
No MR label	107	2.3	2.5	13	4.0	12	4.1	3	0.6	14	2.3	6	1.8	6	1.9	8	0.7	2	1.3	39	6.4	4	1.5
Mild	676	14.8	15.5	49	15.2	50	16.9	85	16.3	79	12.9	53	15.6	42	13.0	166	14.7	33	21.3	72	11.7	47	17.3
Moderate	1,339	29.2	30.7	100	31.1	112	37.8	137	26.3	173	28.3	86	25.3	107	33.2	300	26.5	54	34.8	176	28.7	94	34.6
Severe	1,083	23.6	23.2	78	24.2	61	20.6	124	23.8	157	25.7	86	25.3	98	30.4	279	24.7	29	18.7	120	19.5	51	18.8
Profound	639	13.9	12.1	28	8.7	25	8.4	68	13.1	92	15.1	47	13.8	24	7.5	202	17.9	7	4.5	105	17.1	41	15.1
Don't know	739	16.1	16.1	54	16.8	36	12.2	104	20.0	96	15.7	62	18.2	45	14.0	175	15.5	30	19.4	102	16.6	35	12.9
	4,583			322		296		521		611		340		322		1130		155		614		272	
<b>Other disabilities* (duplicated counts):</b>																							
Mental illness	916	19.8	19.2	57	17.0	43	14.3	103	20.2	140	21.8	87	23.9	53	16.2	228	20.4	26	17.8	119	19.5	60	21.2
Autism	460	9.9	9.6	35	10.4	35	11.6	68	13.4	84	13.1	30	8.2	29	8.8	94	8.4	11	7.5	59	9.7	15	5.3
Cerebral Palsy	810	17.5	16.9	62	18.5	63	20.9	84	16.5	106	16.5	44	12.1	52	15.9	227	20.3	20	13.7	104	17.1	48	17.0
Brain injury	497	10.7	10.7	37	11.0	45	15.0	50	9.8	61	9.5	22	6.0	32	9.8	132	11.8	16	11.0	69	11.3	33	11.7
Seizure disorder/ neurological problem	1,354	29.2	28.6	95	28.3	79	26.2	141	27.7	191	29.8	80	22.0	100	30.5	341	30.6	35	24.0	193	31.7	99	35.0
Chemical dependency	34	0.7	0.8	4	1.2	2	0.7	4	0.8	3	0.5	2	0.5	1	0.3	9	0.8	2	1.4	3	0.5	4	1.4
Vision or hearing impairments	1068	23.1	22.4	79	21.7	57	18.9	138	27.1	165	25.7	62	17.0	78	23.8	236	21.1	26	17.8	166	27.3	67	23.7
Physical disability	1208	26.1	25.7	77	22.9	75	24.9	120	23.6	176	27.5	68	18.7	91	27.7	287	25.7	33	22.6	191	31.4	90	31.8
Communication disorder	1040	22.4	22.4	58	17.3	59	19.6	107	21.0	147	22.9	66	18.1	97	29.6	225	20.2	30	20.5	181	29.7	70	24.7
Alzheimer's disease	50	1.1	1.1	3	0.9	0	0.0	10	2.0	9	1.4	4	1.1	6	1.8	9	0.8	1	0.7	5	0.8	3	1.1
Down Syndrome	618	13.3	13.9	46	13.7	39	13.0	79	15.5	95	14.8	40	11.0	62	18.9	118	10.6	23	15.8	79	13.0	37	13.1
Other disability	720	15.5	15.9	51	15.2	51	16.9	60	11.8	103	16.1	49	13.5	43	13.1	148	13.3	26	17.8	135	22.2	54	19.1

**Table C - Characteristics of Respondents: 2003 Data**

<b>STATES</b>	<b>Total %</b>	<b>State Avg.</b>	<b>AZ</b>	<b>CA-RCOC</b>	<b>CT</b>	<b>ME</b>	<b>NC</b>	<b>ND</b>	<b>PA</b>	<b>SC</b>	<b>WA</b>	<b>WY</b>											
Number of surveys	<b>4,826</b>	<b>n = 10</b>	<b>341</b>	<b>301</b>	<b>559</b>	<b>672</b>	<b>364</b>	<b>328</b>	<b>1,170</b>	<b>164</b>	<b>640</b>	<b>287</b>											
<b>Age of Respondent:</b>																							
	<b>n</b>	<b>%</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>										
Under 35	80	1.7	2.0	7	2.3	2	0.7	15	2.8	5	0.8	15	4.4	4	1.3	15	1.3	3	1.9	5	0.8	9	3.2
35 - 54	1,175	25.1	25.5	79	26.0	50	17.2	107	19.7	179	26.9	112	32.7	111	34.7	254	22.0	27	17.1	163	25.8	93	32.9
55 - 74	2,563	54.6	54.7	168	55.3	167	57.4	298	55.0	377	56.6	174	50.7	159	49.7	644	55.9	95	60.1	329	52.1	152	53.7
75 and Over	872	18.6	17.9	50	16.4	72	24.7	122	22.5	105	15.8	42	12.2	46	14.4	239	20.7	33	20.9	134	21.2	29	10.2
	4,690			304		291		542		666		343		320		1,152		158		631		283	
<b>Relationship to Family Member:</b>																							
	<b>n</b>	<b>%</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>										
Parent	2,857	61.3	61.6	214	67.7	231	79.7	337	64.9	387	59.9	163	49.1	188	58.0	682	58.6	88	55.7	404	64.5	163	57.8
Sibling	1,172	25.2	23.0	45	14.2	47	16.2	123	23.7	183	28.3	69	20.8	103	31.8	369	34.0	38	24.1	114	18.2	54	19.1
Spouse	5	0.1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	2	0.6	0	0.0	2	0.2	0	0.0	0	0.0	1	0.4
Other	623	13.4	15.3	57	18.0	12	4.1	59	11.4	76	11.8	98	29.5	33	10.2	84	7.2	32	20.3	108	17.3	64	22.7
	4,657			316		290		519		646		332		324		1,137		158		626		282	
<b>Respondent is guardian or conservator:</b>																							
Yes	3,435	74.7	76.9	255	77.3	190	65.7	465	86.9	638	96.2	258	75.7	318	99.1	519	48.3	72	50.3	446	71.6	274	97.9
<b>Frequency of Visits with Family Member:</b>																							
Less than once/year	212	4.5	4.0	5	1.5	5	1.7	34	6.4	13	2.0	10	2.9	16	4.9	72	6.3	3	1.9	32	5.1	22	7.7
1-3 times/year	516	11.0	11.6	43	12.9	30	10.2	59	11.1	56	8.4	38	11.1	41	12.6	125	10.9	19	12.0	54	8.6	51	18.0
4-6 times/year	605	12.9	12.6	45	13.5	27	9.2	54	10.2	76	11.5	53	15.5	47	14.4	178	15.5	19	12.0	68	10.9	38	13.4
7-12 times/year	728	15.5	15.7	61	18.3	52	17.6	77	14.5	96	14.5	61	17.8	61	18.7	180	15.7	21	13.3	80	12.8	39	13.7
More than 12 times/year	2,643	56.2	56.1	179	53.8	181	61.4	306	57.7	422	63.7	180	52.6	161	49.4	592	51.6	96	60.8	392	62.6	134	47.2
	4,704			333		295		530		663		342		326		1,147		158		626		284	

**Table D - Services and Support Received: 2003 Data**

STATES	Total %		State Avg.	AZ		CA-RCOC		CT		NC		ND		PA		SC		WA		WY			
	n	%	n = 9	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%		
<b>Residential Supports</b>	4,430	<b>96.1</b>	<b>96.4</b>	317	<b>96.4</b>	279	<b>95.9</b>	514	<b>98.3</b>	631	<b>97.2</b>	314	<b>93.5</b>	320	<b>97.9</b>	1070	<b>95.5</b>	156	<b>96.9</b>	550	<b>92.7</b>	279	<b>99.3</b>
<b>Day/Employment Supports</b>	3,612	<b>80.6</b>	<b>83.1</b>	275	<b>85.7</b>	260	<b>88.1</b>	458	<b>90.7</b>	515	<b>82.4</b>	239	<b>73.8</b>	285	<b>89.3</b>	804	<b>74.4</b>	136	<b>87.7</b>	380	<b>65.7</b>	260	<b>93.2</b>
<b>Transportation</b>	4,126	<b>91.2</b>	<b>92.0</b>	306	<b>92.7</b>	250	<b>86.8</b>	498	<b>96.7</b>	603	<b>94.4</b>	286	<b>88.8</b>	310	<b>96.3</b>	971	<b>89.0</b>	147	<b>96.1</b>	482	<b>82.4</b>	273	<b>97.2</b>
<b>Other Services/ Supports</b>	2,991	<b>72.3</b>	<b>71.3</b>	204	<b>66.7</b>	143	<b>57.0</b>	343	<b>74.6</b>	468	<b>77.0</b>	224	<b>73.4</b>	228	<b>76.8</b>	728	<b>74.9</b>	77	<b>63.1</b>	339	<b>62.1</b>	237	<b>87.5</b>

**Table E - Information and Planning: 2003 Data**

STATES	TOTAL	STATE										
	%	AVG.	AZ	CA	CT	ME	NC	ND	PA	SC	WA	WY
<b>Q1 - Do you get enough information to help you participate in planning services for your family member?</b>												
Number of surveys	4,416	n = 10	325	274	503	639	325	317	1,043	147	560	283
% always or usually	<b>77.6</b>	<b>78.1</b>	79.1	72.3	80.9	86.2	79.7	83.3	73.6	74.1	65.9	86.2
% sometimes	<b>17.6</b>	<b>17.5</b>	17.5	23.0	14.5	11.1	16.6	16.4	20.5	19.7	22.7	12.7
% seldom or never	<b>4.8</b>	<b>4.4</b>	3.4	4.7	4.6	2.7	3.7	0.3	5.8	6.1	11.4	1.1
<b>Q2 - If your family member has a service plan, did you help develop the plan?</b>												
Number of surveys	3,914	n = 10	297	250	439	583	284	306	874	127	480	274
% always or usually	<b>63.3</b>	<b>65.5</b>	70.4	58.0	64.2	72.7	65.1	74.5	47.5	63.0	61.9	77.7
% sometimes	<b>22.2</b>	<b>21.8</b>	20.9	26.8	24.1	19.4	20.8	19.9	24.8	21.3	23.8	15.7
% seldom or never	<b>14.5</b>	<b>12.8</b>	8.8	15.2	11.6	7.9	14.1	5.6	27.7	15.7	14.4	6.6
<b>Q3 - If your family member has a service plan, does the plan include things that are important to you?</b>												
Number of surveys	3,950	n = 10	301	250	448	603	296	308	872	129	468	275
% always or usually	<b>80.2</b>	<b>80.1</b>	84.1	76.0	81.5	86.2	81.1	84.7	74.5	69.8	78.2	84.7
% sometimes	<b>17.0</b>	<b>17.5</b>	14.0	22.8	16.7	12.8	13.9	14.6	20.9	27.9	16.7	14.2
% seldom or never	<b>2.8</b>	<b>2.5</b>	2.0	1.2	1.8	1.0	5.1	0.6	4.6	2.3	5.1	1.1
<b>Q4 - Are the staff who assist you with planning generally respectful and courteous?</b>												
Number of surveys	4,297	n = 10	321	278	490	632	313	317	982	144	535	285
% always or usually	<b>93.9</b>	<b>93.5</b>	92.2	92.4	95.1	96.7	93.0	94.6	93.5	91.0	93.1	93.7
% sometimes	<b>5.5</b>	<b>5.8</b>	6.5	6.8	4.3	3.3	6.1	5.0	6.2	8.3	5.2	6.0
% seldom or never	<b>0.6</b>	<b>0.7</b>	1.2	0.7	0.6	0.0	1.0	0.3	0.3	0.7	1.7	0.4
<b>Q5 - Are the staff who assist you with planning generally effective?</b>												
Number of surveys	4,165	n = 10	315	266	476	623	300	308	940	138	518	281
% always or usually	<b>78.1</b>	<b>77.0</b>	74.9	75.2	83.2	84.6	81.0	78.2	77.0	65.9	73.6	76.5
% sometimes	<b>19.5</b>	<b>20.5</b>	22.2	20.3	15.1	14.9	16.3	21.4	20.2	31.2	21.8	21.7
% seldom or never	<b>2.4</b>	<b>2.5</b>	2.9	4.5	1.7	0.5	2.7	0.3	2.8	2.9	4.6	1.8
<b>Q6 - Can you contact the staff who assist you with planning whenever you want to?</b>												
Number of surveys	4,301	n = 10	321	267	490	625	328	320	989	138	539	284
% always or usually	<b>88.1</b>	<b>87.7</b>	87.9	83.1	90.6	92.6	87.5	94.4	87.1	80.4	81.8	91.9
% sometimes	<b>10.3</b>	<b>10.8</b>	10.9	15.4	7.8	6.6	11.0	5.3	11.3	17.4	13.9	8.1
% seldom or never	<b>1.6</b>	<b>1.5</b>	1.2	1.5	1.6	0.8	1.5	0.3	1.6	2.2	4.3	0.0

**Table F - Access and Delivery of Services and Supports: 2003 Data**

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	ME	NC	ND	PA	SC	WA	WY
<b>Q7 - When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?</b>												
Number of surveys	4,163	n = 10	311	250	476	559	311	322	999	149	505	281
% always or usually	<b>82.9</b>	<b>82.6</b>	85.5	78.0	86.3	83.9	83.3	90.7	82.4	72.5	75.2	88.3
% sometimes	<b>15.1</b>	<b>15.5</b>	13.8	19.6	12.2	14.3	14.8	8.7	14.8	24.2	21.8	10.3
% seldom or never	<b>2.0</b>	<b>1.9</b>	0.6	2.4	1.5	1.8	1.9	0.6	2.8	3.4	3.0	1.4
<b>Q8 - Does your family member get the services and supports he/she needs?</b>												
Number of surveys	4,483	n = 10	320	277	505	640	333	320	1,080	146	578	284
% always or usually	<b>83.3</b>	<b>82.5</b>	83.8	74.4	89.1	85.5	83.2	86.6	84.4	74.7	77.5	85.6
% sometimes	<b>15.3</b>	<b>16.3</b>	15.9	24.9	10.1	13.9	15.6	12.5	14.0	23.3	19.4	13.4
% seldom or never	<b>1.3</b>	<b>1.3</b>	0.3	0.7	0.8	0.6	1.2	0.9	1.7	2.1	3.1	1.1
<b>Q9 - If your family member does not speak English or uses a different way to communicate (e.g., sign language), are there enough support workers available who can communicate with him/her?</b>												
Number of surveys	1,668	n = 10	141	101	166	272	123	156	386	35	186	102
% always or usually	<b>78.4</b>	<b>77.7</b>	74.5	79.2	72.9	81.6	79.7	78.2	82.6	80.0	73.1	75.5
% sometimes	<b>18.3</b>	<b>19.0</b>	18.4	15.8	24.1	15.4	16.3	21.2	15.3	20.0	21.0	22.5
% seldom or never	<b>3.3</b>	<b>3.3</b>	7.1	5.0	3.0	2.9	4.1	0.6	2.1	0.0	5.9	2.0
<b>Q10 - Does your family member have access to the special equipment or accommodations that he/she needs (e.g., wheelchairs, ramps, communication boards)?</b>												
Number of surveys	2,529	n = 10	191	122	278	387	183	208	621	69	303	167
% always or usually	<b>89.2</b>	<b>88.6</b>	88.0	84.4	93.2	89.4	89.6	88.5	90.2	85.5	87.5	89.2
% sometimes	<b>8.4</b>	<b>9.4</b>	12.0	11.5	5.8	8.0	8.7	10.1	6.6	13.0	7.9	10.8
% seldom or never	<b>2.3</b>	<b>2.0</b>	0.0	4.1	1.1	2.6	1.6	1.4	3.2	1.4	4.6	0.0
<b>Q11 - Are frequent changes in support staff a problem for your family member?</b>												
Number of surveys	3,863	n = 10	291	230	453	579	268	291	903	133	467	248
% always or usually	<b>20.6</b>	<b>21.0</b>	26.8	20.0	17.2	18.5	17.2	19.9	22.1	21.8	18.2	28.2
% sometimes	<b>45.5</b>	<b>45.8</b>	48.8	43.9	47.2	48.0	35.1	51.5	44.2	48.1	40.3	51.2
% seldom or never	<b>33.9</b>	<b>33.2</b>	24.4	36.1	35.5	33.5	47.8	28.5	33.7	30.1	41.5	20.6
<b>Q12 - Do you feel that your family member's residential setting is a healthy and safe environment?</b>												
Number of surveys	4,603	n = 10	328	285	514	653	341	321	1,122	157	599	283
% always or usually	<b>90.7</b>	<b>89.9</b>	87.2	89.5	90.3	95.3	92.7	91.0	90.6	84.7	90.3	87.3
% sometimes	<b>8.4</b>	<b>9.1</b>	11.6	9.8	8.4	4.6	6.7	8.4	8.2	13.4	8.3	12.0
% seldom or never	<b>1.0</b>	<b>1.0</b>	1.2	0.7	1.4	0.2	0.6	0.6	1.2	1.9	1.3	0.7
<b>Q13 - Do you feel that your family member's day/employment setting is a healthy and safe environment?</b>												
Number of surveys	3,800	n = 10	286	243	451	544	294	295	853	137	433	264
% always or usually	<b>89.7</b>	<b>88.9</b>	87.4	86.0	90.9	93.8	90.5	87.8	88.9	82.5	92.6	88.6
% sometimes	<b>9.2</b>	<b>10.0</b>	12.2	14.0	8.4	5.7	8.8	10.5	9.4	14.6	6.2	10.6
% seldom or never	<b>1.1</b>	<b>1.1</b>	0.3	0.0	0.7	0.6	0.7	1.7	1.8	2.9	1.2	0.8

Table G - Choices and Control: 2003 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	ME	NC	ND	PA	SC	WA	WY
<b>Q14 - Does the agency providing residential services to your family member involve you in important decisions?</b>												
Number of surveys	4,442	n = 10	326	265	516	639	322	319	1,058	154	560	283
% always or usually	<b>80.5</b>	<b>80.4</b>	81.9	71.3	85.7	91.2	82.9	87.5	73.2	70.1	77.5	82.3
% sometimes	<b>14.5</b>	<b>14.9</b>	13.5	21.5	11.0	7.5	12.7	11.9	19.3	22.1	14.1	15.5
% seldom or never	<b>5.0</b>	<b>4.7</b>	4.6	7.2	3.3	1.3	4.3	0.6	7.6	7.8	8.4	2.1
<b>Q15 - If your family member gets day or employment services, does the agency providing these services involve you in important decisions?</b>												
Number of surveys	3,492	n = 10	270	225	435	518	243	277	770	121	385	248
% always or usually	<b>64.4</b>	<b>63.4</b>	68.1	43.1	67.8	77.8	66.3	68.6	55.8	52.9	65.5	68.4
% sometimes	<b>21.7</b>	<b>22.0</b>	22.6	28.0	18.9	16.8	18.3	24.9	24.2	22.3	20.5	23.4
% seldom or never	<b>13.9</b>	<b>14.4</b>	9.3	28.9	13.3	5.4	14.8	6.5	20.0	24.8	14.0	7.3
<b>Q16 - Do you or your family member choose the support workers that work with your family?</b>												
Number of surveys	3,471	n = 10	276	229	403	498	230	265	820	122	369	259
% always or usually	<b>13.3</b>	<b>14.4</b>	10.9	17.5	8.7	16.3	16.5	11.3	10.1	18.9	13.0	20.5
% sometimes	<b>13.3</b>	<b>14.2</b>	12.3	6.6	11.7	13.3	17.0	12.5	9.5	13.9	14.6	30.1
% seldom or never	<b>73.4</b>	<b>71.5</b>	76.8	76.0	79.7	70.5	66.5	76.2	80.4	67.2	72.4	49.4
<b>Q17 - Do you or your family member have control and/or input over the hiring and management of your family member's support workers?</b>												
Number of surveys	3,348	n = 10	272	211	397	484	210	254	765	115	402	238
% always or usually	<b>8.7</b>	<b>9.1</b>	7.0	10.9	6.8	9.9	11.4	6.3	5.5	7.8	13.7	11.3
% sometimes	<b>9.8</b>	<b>10.8</b>	11.4	8.1	6.8	10.7	12.9	7.5	6.3	14.8	12.2	16.8
% seldom or never	<b>81.6</b>	<b>80.2</b>	81.6	81.0	86.4	79.3	75.7	86.2	88.2	77.4	74.1	71.8
<b>Q18 - 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	3,023	n = 10	233	185	357	436	185	236	658	109	394	230
% always or usually	<b>26.1</b>	<b>26.8</b>	29.2	26.5	23.2	25.9	27.6	21.6	23.3	31.2	29.7	30.0
% sometimes	<b>35.3</b>	<b>35.9</b>	42.5	36.8	35.0	34.2	34.6	35.2	32.4	33.0	34.5	40.4
% seldom or never	<b>38.7</b>	<b>37.3</b>	28.3	36.8	41.7	39.9	37.8	43.2	44.4	35.8	35.8	29.6
<b>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?</b>												
Number of surveys	4,307	n = 10	322	269	476	601	305	313	1,022	150	570	279
% always or usually	<b>22.8</b>	<b>25.3</b>	38.5	15.6	14.7	14.3	25.9	32.6	15.0	14.0	25.8	57.0
% sometimes	<b>10.3</b>	<b>10.9</b>	12.7	14.9	9.9	10.6	7.5	11.5	9.8	10.7	5.8	15.4
% seldom or never	<b>66.9</b>	<b>63.8</b>	48.8	69.5	75.4	75.0	66.6	55.9	75.2	75.3	68.4	27.6
<b>Q20 - Do you or your family member get to decide how this money is spent?</b>												
Number of surveys	3,341	n = 10	274	194	408	449	219	264	753	128	412	240
% always or usually	<b>20.4</b>	<b>21.5</b>	30.7	17.5	12.3	20.9	23.3	24.6	14.3	15.6	24.8	30.8
% sometimes	<b>24.6</b>	<b>25.0</b>	26.6	20.6	26.2	26.3	17.8	34.5	21.9	23.4	19.7	32.9
% seldom or never	<b>55.0</b>	<b>53.5</b>	42.7	61.9	61.5	52.8	58.9	40.9	63.7	60.9	55.6	36.3

Table H - Community Connections: 2003 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	ME	NC	ND	PA	SC	WA	WY
<b>Q21 - 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 plan or who provide support help connect him/her to these supports?</b>												
Number of surveys	3,162	n = 10	240	133	352	512	217	276	670	121	414	227
% always or usually	<b>63.3</b>	<b>61.3</b>	59.2	43.6	64.8	76.4	71.4	68.1	59.9	52.9	58.0	58.6
% sometimes	<b>25.6</b>	<b>26.9</b>	28.3	30.8	23.0	19.1	23.5	25.7	26.9	30.6	24.6	36.1
% seldom or never	<b>11.1</b>	<b>11.9</b>	12.5	25.6	12.2	4.5	5.1	6.2	13.3	16.5	17.4	5.3
<b>Q22 - If your family member would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help plan or who provide support help him/her do this?</b>												
Number of surveys	2,785	n = 10	216	120	310	472	178	247	581	110	353	198
% always or usually	<b>63.9</b>	<b>61.4</b>	65.3	41.7	66.1	76.3	65.2	62.3	62.5	53.6	59.2	61.6
% sometimes	<b>23.5</b>	<b>24.8</b>	21.8	28.3	22.3	17.8	21.9	27.9	23.4	31.8	23.8	29.3
% seldom or never	<b>12.6</b>	<b>13.8</b>	13.0	30.0	11.6	5.9	12.9	9.7	14.1	14.5	17.0	9.1
<b>Q23 - Do you feel that your family member has access to community activities?</b>												
Number of surveys	4,094	n = 10	302	239	460	608	290	312	948	133	529	273
% always or usually	<b>65.2</b>	<b>63.6</b>	60.9	48.5	69.6	72.7	66.9	72.8	64.6	48.9	58.8	72.5
% sometimes	<b>28.9</b>	<b>30.2</b>	32.5	40.2	26.3	23.4	30.0	23.4	29.1	40.6	32.1	24.5
% seldom or never	<b>5.9</b>	<b>6.2</b>	6.6	11.3	4.1	3.9	3.1	3.8	6.3	10.5	9.1	2.9
<b>Q24 - Does your family member participate in community activities?</b>												
Number of surveys	3,925	n = 10	283	231	437	581	276	306	896	125	522	268
% always or usually	<b>43.2</b>	<b>42.9</b>	47.0	26.0	49.2	48.0	52.9	43.8	39.3	34.4	39.1	48.9
% sometimes	<b>41.5</b>	<b>42.2</b>	40.3	44.6	39.6	39.8	35.5	44.1	43.3	51.2	38.5	45.5
% seldom or never	<b>15.3</b>	<b>14.9</b>	12.7	29.4	11.2	12.2	11.6	12.1	17.4	14.4	22.4	5.6

**Table I - Satisfaction with Services and Outcomes: 2003 Data**

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	ME	NC	ND	PA	SC	WA	WY
<b>Q25 - Overall, are you satisfied with the services and supports your family member currently receives?</b>												
Number of surveys	4,599	n = 10	332	282	513	654	346	317	1,106	156	610	283
% yes or most of the time	<b>84.0</b>	<b>83.3</b>	81.9	79.4	87.7	88.8	83.8	88.6	83.5	74.4	79.0	86.2
% some of the time	<b>14.1</b>	<b>14.8</b>	16.6	17.7	10.7	10.4	15.3	10.4	14.3	22.4	17.5	12.4
% no or not at all	<b>1.9</b>	<b>1.9</b>	1.5	2.8	1.6	0.8	0.9	0.9	2.3	3.2	3.4	1.4
<b>Q26 - 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	4,308	n = 10	318	263	463	593	326	309	1,028	147	585	276
% yes or most of the time	<b>54.2</b>	<b>55.7</b>	56.0	50.2	50.8	60.0	64.1	67.0	49.6	48.3	42.6	68.5
% some of the time	<b>7.9</b>	<b>8.2</b>	9.1	8.7	8.6	7.9	6.4	7.4	7.0	10.9	8.0	8.0
% no or not at all	<b>37.9</b>	<b>36.1</b>	34.9	41.1	40.6	32.0	29.4	25.6	43.4	40.8	49.4	23.6
<b>Q27 - Are you satisfied with the way complaints/grievances are handled and resolved?</b>												
Number of surveys	2,880	n = 10	215	127	307	424	258	249	657	111	329	203
% yes or most of the time	<b>69.5</b>	<b>68.0</b>	64.2	60.6	67.4	78.1	74.4	71.1	68.9	58.6	67.2	69.0
% some of the time	<b>24.1</b>	<b>25.2</b>	29.8	32.3	24.8	19.6	20.2	24.5	24.5	29.7	22.5	23.6
% no or not at all	<b>6.5</b>	<b>6.9</b>	6.0	7.1	7.8	2.4	5.4	4.4	6.5	11.7	10.3	7.4
<b>Q28 - Do you feel that services and supports have made a positive difference in the life of your family?</b>												
Number of surveys	4,447	n = 10	323	282	507	624	339	309	1,060	155	575	273
% yes or most of the time	<b>85.4</b>	<b>85.0</b>	82.0	80.9	88.2	89.1	86.7	87.4	85.0	79.4	81.6	89.4
% some of the time	<b>13.0</b>	<b>13.5</b>	15.5	18.1	10.5	10.6	12.4	12.3	12.9	18.1	15.0	9.9
% no or not at all	<b>1.6</b>	<b>1.5</b>	2.5	1.1	1.4	0.3	0.9	0.3	2.1	2.6	3.5	0.7
<b>Q29 - Overall, do you feel that your family member is happy?</b>												
Number of surveys	4,580	n = 10	326	283	512	647	343	319	1,102	159	609	280
% yes or most of the time	<b>83.0</b>	<b>82.3</b>	79.1	84.8	85.2	87.3	83.4	84.0	82.7	72.3	79.6	84.6
% some of the time	<b>15.7</b>	<b>16.3</b>	17.8	13.8	13.5	11.7	16.3	15.4	15.8	25.2	19.0	14.6
% no or not at all	<b>1.3</b>	<b>1.4</b>	3.1	1.4	1.4	0.9	0.3	0.6	1.5	2.5	1.3	0.7