

Family Guardian Survey

Final Report – January 2004
2002-2003 Data



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

HUMAN SERVICES RESEARCH INSTITUTE

2336 Massachusetts Avenue
Cambridge, MA 02140

8100 SW Nyberg Road, Suite 205
Tualatin, OR 97062

**NATIONAL ASSOCIATION OF STATE DIRECTORS
OF DEVELOPMENTAL DISABILITIES SERVICES**

113 Oronoco Street
Alexandria, VA 22314

January 2004

Table of Contents

List of Tables & Figures

Organization of Report

I. Introduction	1
Overview of National Core Indicators	1
Family Indicators	2
II. Family Guardian Survey	4
Background	4
State Participation	4
Survey Instrument	5
III. Methods	5
Sampling & Administration	5
Data Analysis	6
IV. Results	7
Participating States	7
Characteristics of Family Members with Disabilities	8
Characteristics of Respondents	13
Services and Supports Received	17
Information and Planning	18
Access to and Delivery of Services and Supports	24
Choice and Control	31
Community Connections	38
Outcomes and Satisfaction with Services and Supports	42
Aggregate Results & State Trends	47
Additional Open-Ended Comments	54

Appendix A – Summary Tables of Survey Responses

List of Tables & Figures

Tables

Table 1	State Participation in National Core Indicators.....	2
Table 2	Family Indicators	3
Table 3	State Participation in NCI Family Guardian Survey	4
Table 4	Family Guardian Survey – State Response Rates	6
Table 5	Type of Residence.....	8
Table 6	Gender of Family Member.....	9
Table 7	Age of Family Member	9
Table 8	Race/Ethnicity of Family Member	10
Table 9	Level of Mental Retardation of Family Member	11
Tables 10A-B	Other Disabilities of Family Member	12
Table 11	Age of Respondent.....	13
Table 12	Relationship of Respondent to Individual with Disabilities.....	14
Table 13	Frequency of Visits	15
Table 14	Respondent is Legal Guardian/Conservator	16
Table 15	Services and Supports Received.....	17
Tables Q1-6	Information and Planning.....	18-23
Tables Q7-13	Access and Delivery of Supports	24-30
Tables Q14-20	Choices and Control.....	31-37
Tables Q21-24	Community Connections	38-41
Tables Q25-29	Outcomes and Satisfaction.....	42-46
Tables 16-21	State Trends in Responses Above & Below State Average.....	48-53

Charts

Chart 1	States Participating in NCI Family Guardian Survey.....	7
Chart 2	Type of Residence of Family Member.....	8
Chart 3	Gender of Family Member.....	9
Chart 4	Level of Mental Retardation of Family Member	11
Charts Q1-Q6	Information and Planning.....	18-23
Charts Q7-Q13	Access and Delivery of Supports	24-30
Charts Q14-Q20	Choices and Control.....	31-37
Charts Q21-Q24	Community Connections	38-41
Charts Q25-Q29	Outcomes and Satisfaction.....	42-46
Chart 5	Overview: Information and Planning	48
Chart 6	Overview: Access and Delivery of Supports.....	49
Chart 7	Overview: Choices and Control	50
Chart 8	Overview: Community Connections	51
Chart 9	Overview: Outcomes and Satisfaction	52

Organization of Report

Nine states and one local developmental disability authority conducted the National Core Indicators (NCI) Family Guardian Survey during the 2002-2003 project year and submitted their data. The Family Guardian Survey was administered to individuals having an adult family member with disabilities living outside of the family's home. This Final Report provides a summary of results, based on the data submitted by June 2003.

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. At this time, it was decided to switch from describing the data sets as “phases” of the project to describing them by year in which the data was collected. Therefore, Phase III was now 2000 Data. 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. Technical reports for Phase II (1999 Data) and 2000 Data, along with other selected documents are available online at www.hsri.org/cip/core.html

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) - Project participation continues to grow. During this past year, Maine, South Carolina and South Dakota have joined the National Core Indicators effort.

The figure on the following page summarizes state participation in the National Core Indicators since its inception through the 2002-2003 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
AZ	AZ	AZ	AL	AL
CT	CT	CT	AZ	AZ
MO	KY	DE	CA - Orange Co.	CA - Orange Co.
NE	MA	IA	CT	CT
PA	MN	KY	DE	DE
VT	NE	MA	HI	HI
VA	NC	MN	IL	IN
	PA	MT	IN	IA
	RI	NE	IA	KY
	VT	NC	KY	MA
	VA	PA	MA	ME
	WA	RI	NE	NE
		UT	NC	NC
		VT	OK	OK
		WA	PA	PA
			RI	RI
			UT	SC
			VT	SD
			WA	VT
			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**

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

II. 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 endeavor, seven states administered the Family Guardian Survey. During Phase II, 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 – The results from the first cycle of this survey are explored in this report.

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
NA	CT KY MN NE PA VA WA	AZ DE MA MN NC PA RI	HI NE NC PA UT WA CA - Orange Co.	AZ CA - Orange Co. HI IN MA NC PA SC SD WY
Denotes anticipated participation in 2nd Cycle of Phase V.				

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 2002-2003, 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%.

Table 4			
Family Guardian Survey - State Response Rates			
State	Surveys Mailed	Surveys Returned (%)	Usable Surveys
Arizona	1,100	365 (33%)	343
CA-Orange Co.	927	210 (23%)	210
Hawaii	234	147 (63%)	143
Indiana	*	546 (*)	530
Massachusetts	2,000	784 (39%)	744
North Carolina	916	451 (49%)	438
Pennsylvania	2,760	1182 (43%)	1,150
South Carolina	*	81 (*)	72
South Dakota	1,692	812 (48%)	772
Wyoming	540	237 (44%)	236
Overall	*	2953 (*)	4,638
* 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 23% to 63%.

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.

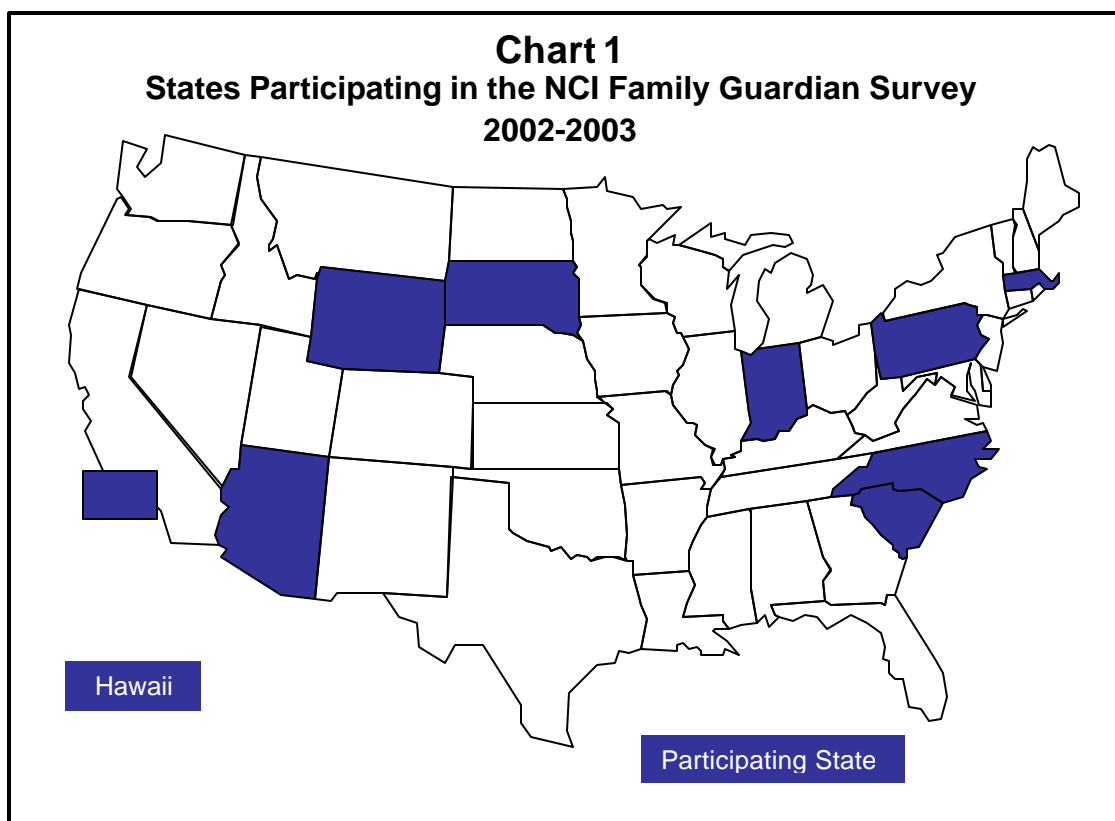
Please note that the TABLES provide individuals state results and result averages that are calculated through two separate methods:

1. Total % indicates the percentage across all individual respondents.
2. State Average % indicates the average percentage across the five 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

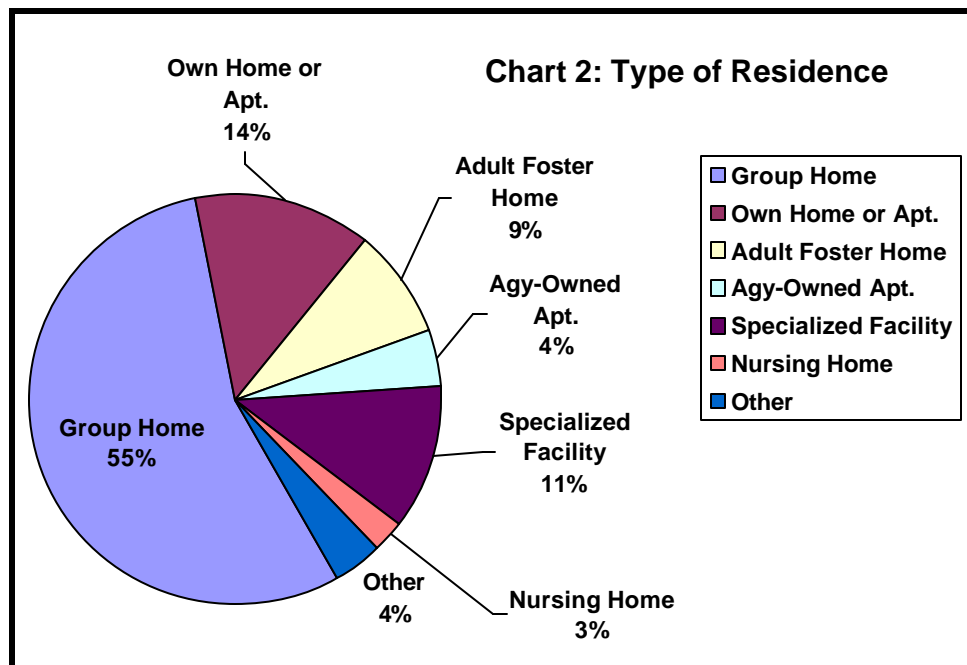
- ◆ Nine states and one local DD authority provided data sets to be included in the Preliminary Report. They include Arizona, Hawaii, Indiana, Massachusetts, North Carolina, Pennsylvania, South Carolina, South Dakota, Wyoming, and Orange County Regional Center in California.



Characteristics of Family Members with Disabilities

Type of Residence

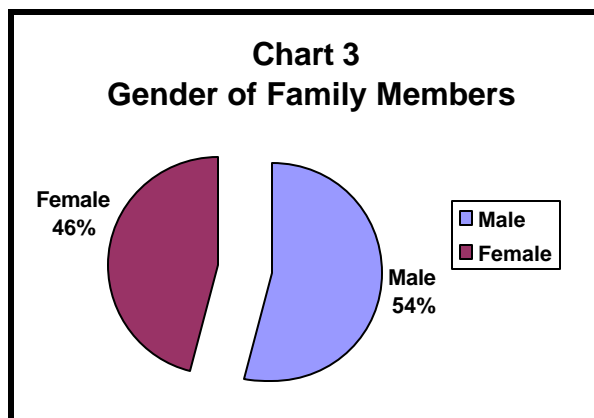
- ♦ On average, across the states, over half (56%) of the family members with disabilities lived in group home settings. 14% lived in their own homes or apartments, 12% lived in adult foster care or host family homes, 5% lived in agency-owned apartments, 8% in specialized facilities, 1% in nursing homes, and 4% in a variety of other settings.



State	Specialized MR Facility	Group Home	Agy-Owned Apartment	Own Home/ Apartment	Adult Foster Care/ Host Family	Nursing Home	Other
AZ	5.4	74.3	4.8	3.6	6.3	2.1	3.6
CA-RCOC	8.3	65.9	0.5	18.0	2.0	1.0	4.4
HI	3.1	26.7	0.8	12.2	51.1	0.8	5.3
IN	10.0	42.7	5.4	22.0	1.7	13.9	4.2
MA	20.2	58.9	3.6	4.9	6.6	3.9	2.0
NC	22.1	47.8	3.8	10.6	6.4	1.4	8.0
PA	11.4	58.5	3.6	12.3	6.1	2.7	5.4
SC	12.5	62.5	1.4	18.1	2.8	0.0	2.8
SD	7.6	46.7	14.2	28.8	0.4	0.5	1.7
WY	11.2	69.2	6.7	7.1	4.5	0.0	1.3
Total n	545	2,458	249	640	257	149	177
Total %	12.2	54.9	5.6	14.3	5.7	3.3	4.0
State Avg. %	11.2	55.3	4.5	13.8	8.8	2.6	3.9

Gender of Family Member

- ◆ On average, 54% of family members were male across the participating states. The remaining 46% were female.



State	% Male	% Female
AZ	54.3	45.7
CA-RCOC	53.4	46.6
HI	56.2	43.8
IN	55.5	44.5
MA	52.6	47.4
NC	56.1	43.9
PA	55.4	44.6
SC	53.6	46.4
SD	51.4	48.6
WY	53.0	47.0
Total n	2,412	2,048
Total %	54.1	45.9
State Avg. %	54.2	45.9

Age of Family Member

- ◆ Across states, the average age of family members with disabilities was 42.8, with a range in age from 18 to 95.

State	Average Age	Range
AZ	42.6	18-81
CA-RCOC	41.7	19-81
HI	42.6	18-92
IN	45.0	18-93
MA	44.7	18-88
NC	42.4	18-95
PA	43.7	18-88
SC	44.6	18-75
SD	42.1	18-90
WY	38.8	20-76
Total n	4,378	18-95
Total Avg.	43.2	
State Avg.	42.8	

Race of Family Member

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

- ◆ On average, 78% of the family members were White, 8% were Black/ African American, 7% were Asian, 2% were Native Hawaiian/Pacific Islander, 3% were Mixed Races, 3% were Hispanic, 2% were American Indian/Alaska Native, and 0.3% marked Other or Unknown.
- ◆ The majority of family members were White/Caucasian in all states except Hawaii. In Hawaii, the majority population was Asian (60%).

Table 8 Race/Ethnicity of Family Member (%)								
State	White	Black/ African American	Asian	American Indian/ Alaska Native	Native Hawaiian/ Pacific Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
AZ	71.9	2.1	0.3	5.7	0.3	3.9	0.0	14.9
CA-RCOC	88.1	0.0	3.3	1.0	1.0	0.5	1.0	5.7
HI	23.5	2.9	60.3	2.9	16.2	16.9	0.7	2.2
IN	91.8	6.9	0.6	0.8	0.0	0.6	0.0	0.4
MA	95.0	2.1	1.0	1.1	0.0	0.6	0.3	1.0
NC	68.3	27.6	0.0	1.8	0.0	0.9	0.0	0.5
PA	95.4	2.9	0.2	0.8	0.1	0.5	0.4	0.4
SC	66.7	33.3	0.0	0.0	0.0	0.0	0.0	0.0
SD	91.2	0.0	0.1	5.6	0.0	1.2	0.0	0.0
WY	92.1	1.8	0.9	3.5	0.4	2.2	0.9	3.9
Total n	3,940	244	105	105	27	68	12	90
Total %	86.7	5.4	2.3	2.3	0.6	1.5	0.3	2.0
State Avg. %	78.4	8.0	6.7	2.3	1.8	2.7	0.3	2.9

Level of Mental Retardation of Family Member

- ◆ On average, one-third (34%) of the family members with disabilities had a diagnosis of severe or profound mental retardation. Additionally, 28% were individuals with moderate mental retardation, 16% had mild mental retardation, and 3% had no mental retardation diagnosis. Additionally, one in five (19%) respondents were unsure of their family member's diagnosis.

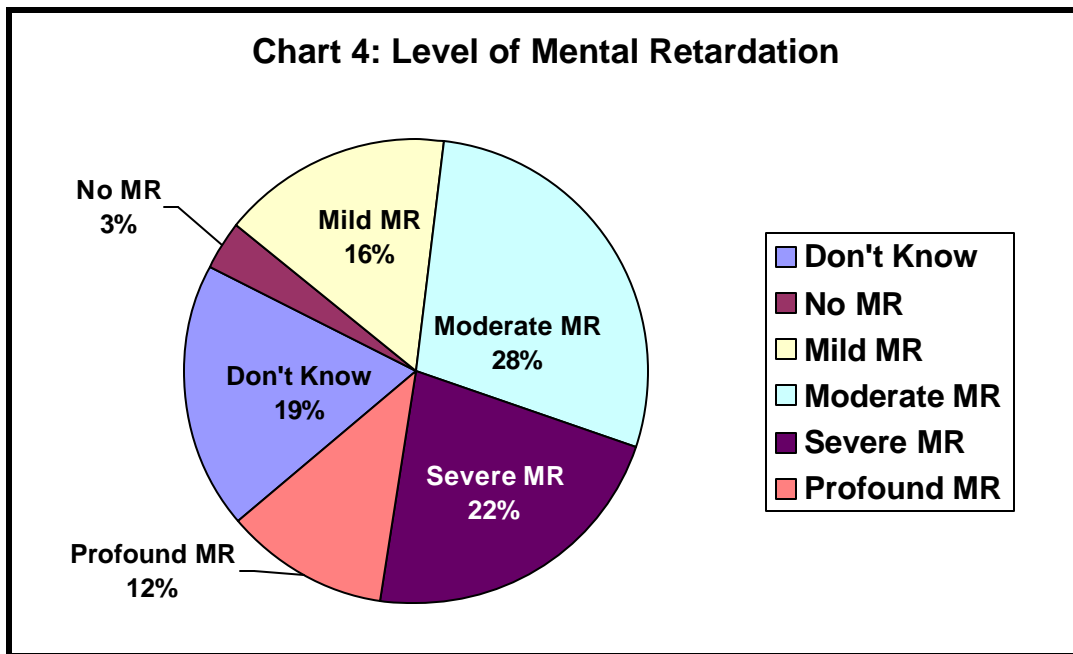


Table 9 Level of Mental Retardation of Family Member						
State	No MR Diagnosis	Mild MR	Moderate MR	Severe MR	Profound MR	Don't Know
AZ	4.0	15.1	31.2	24.4	8.6	16.7
CA-RCOC	5.5	21.9	40.3	17.4	8.0	7.0
HI	2.3	6.1	26.5	23.5	12.1	29.5
IN	3.8	14.6	25.1	21.9	16.0	18.6
MA	2.1	9.4	27.1	28.0	16.2	17.1
NC	2.9	21.2	24.4	23.2	10.2	18.0
PA	1.3	17.6	23.9	20.8	15.5	20.9
SC	5.7	17.1	24.3	17.1	10.0	25.7
SD	4.0	22.7	27.2	19.9	7.8	18.4
WY	1.8	15.1	33.8	24.9	10.7	13.8
Total n	123	730	1,181	982	551	803
Total %	2.8	16.7	27.0	22.5	12.6	18.4
State Avg. %	3.3	16.1	28.4	22.1	11.5	18.6

Other Disabilities of Family Member

- ◆ In addition to mental retardation, many family members experience other disabilities as well (e.g., seizure disorder, cerebral palsy, physical disability, communication disorder).
- ◆ The most prevalent additional disabilities included: seizure disorders/neurological problems (28%), physical disabilities (26%), mental illness (20%), vision or hearing impairments (20%), communication disorders (20%), and cerebral palsy (16%).

Table 10A Other Disabilities of Family Member						
State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
AZ	16.9	10.4	18.6	10.9	28.4	1.2
CA-RCOC	14.1	12.1	22.3	16.0	30.6	1.9
HI	14.6	7.7	14.6	13.1	26.9	0.8
IN	22.9	10.4	16.8	10.7	29.1	2.0
MA	18.5	12.5	19.0	12.6	35.1	1.3
NC	29.9	6.6	12.6	10.0	20.8	2.3
PA	20.3	8.4	18.2	10.7	29.5	1.3
SC	26.9	3.0	7.5	7.5	22.4	1.5
SD	14.1	7.6	16.2	8.4	27.5	0.9
WY	23.2	8.4	16.9	12.9	33.8	0.0
Total n	878	409	765	487	1,297	60
Total %	19.7	9.2	17.2	10.9	29.1	1.3
State Avg. %	20.1	8.7	16.3	11.3	28.4	1.3

Table 10B Other Disabilities of Family Member						
State	Vision/ Hearing Impairment	Physical Disability	Communi- cation Disorder	Alzheimer's Disease	Down Syndrome	Other Disability
AZ	21.6	23.1	17.5	0.9	13.6	15.1
CA-RCOC	17.0	23.3	19.9	0.0	11.7	14.6
HI	25.4	26.9	25.4	0.8	14.6	16.2
IN	19.3	29.4	21.2	0.8	9.2	15.1
MA	26.6	30.0	28.4	2.2	15.0	16.0
NC	16.7	20.5	13.9	0.5	8.7	13.7
PA	22.0	24.0	16.0	0.6	11.3	14.8
SC	11.9	29.9	10.4	1.5	17.9	19.4
SD	21.5	25.3	20.2	0.6	*	12.0
WY	23.1	28.0	26.7	0.9	16.4	13.8
Total n	960	1,145	894	39	449	647
Total %	21.5	25.7	20.1	0.9	12.2	14.5
State Avg. %	20.5	26.0	20.0	0.9	13.2	15.1

* Question not asked in South Dakota

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.

Age of Respondent

- ◆ Across states, most respondents (53%) fell between the ages of 55 and 74. One-fifth of respondents, however, were 75 years old or over.

State	Under 35	35-54	55-74	75 or Older
AZ	2.3	26.1	55.0	16.6
CA-RCOC	0.5	12.4	57.9	29.2
HI	3.6	20.4	48.2	27.7
IN	2.3	28.8	52.0	16.8
MA	1.4	20.6	57.3	20.7
NC	6.0	35.3	46.8	11.9
PA	2.0	26.0	53.0	19.0
SC	12.5	15.3	36.1	36.1
SD	1.2	12.3	72.1	14.4
WY	1.3	37.7	53.5	7.5
Total n	104	1,066	2,531	805
Total %	2.3	23.7	56.2	17.9
State Avg. %	3.3	23.5	53.2	20.0

Relationship of Respondent to Individual with Disabilities

- ◆ Three-fifths of respondents were parents of adult children with disabilities (59%). Another 22% were siblings, less than 1% were spouses, and the remaining 19% had other relationships to the individual.

Table 12				
Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
AZ	67.4	14.4	0.0	18.2
CA-RCOC	83.6	13.0	0.0	3.4
HI	63.5	27.7	0.7	8.0
IN	51.7	22.2	0.4	25.8
MA	60.6	28.3	0.1	10.9
NC	48.7	19.8	0.2	31.3
PA	59.3	28.5	0.3	12.0
SC	35.7	18.6	0.0	45.7
SD	58.7	25.9	0.3	15.1
WY	59.2	21.9	0.0	18.9
Total n	2,676	1,102	10	750
Total %	59.0	24.3	0.2	16.5
State Avg. %	58.8	22.0	0.2	18.9

Frequency of Visits between Respondent and Individual with Disabilities

- ♦ On average, over one-third (40%) 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: 29% saw their family member 7 to 12 times per year, 14% visited their family member four to six times per year, 13% saw their family member one to three times per year, and the remaining 4% less than once per year.

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	53.9
CA-RCOC	2.4	8.6	7.7	12.9	68.4
HI	4.5	23.3	13.5	58.6	0.0
IN	5.1	14.1	15.2	12.9	52.7
MA	5.3	11.0	12.7	11.0	60.0
NC	3.8	11.5	12.7	13.6	58.4
PA	4.6	11.6	11.8	13.2	58.7
SC	7.1	7.1	10.0	75.7	0.0
SD	3.5	13.4	26.6	56.6	0.0
WY	7.4	16.2	13.1	14.8	48.5
Total n	198	568	675	1,033	2,054
Total %	4.4	12.5	14.9	22.8	45.4
State Avg. %	4.5	13.0	13.7	28.8	40.1

Respondent's Role as Guardian or Conservator

- ◆ On average, 72% of respondents indicated that they were their family member's legal guardian or conservator.
- ◆ In Wyoming, nearly all respondents served as their family member's guardian, while in Pennsylvania and South Carolina, fewer than half of respondents held this role.

State	% Yes	% No
AZ	76.8	23.2
CA-RCOC	60.9	39.1
HI	94.0	6.0
IN	63.3	26.7
MA	87.0	13.0
NC	75.5	24.5
PA	49.7	50.3
SC	35.3	64.7
SD	75.3	24.7
WY	97.8	2.2
Total n	3,103	1,315
Total %	70.2	29.8
State Avg. %	71.6	27.4

Services and Supports Received

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

Table 15 Services and Supports Received (%)				
State	Residential supports	Day/ Employment supports	Transportation	Other
AZ	96.1	85.8	92.8	66.6
CA-RCOC	96.6	88.7	85.6	54.3
HI	96.3	84.1	94.1	71.1
IN	96.1	68.0	89.2	78.8
MA	98.5	88.5	93.8	81.6
NC	94.3	72.9	87.8	76.6
PA	95.3	79.8	88.4	69.3
SC	86.8	82.9	89.9	92.4
SD	97.1	92.9	91.5	77.7
WY	99.1	91.4	97.3	87.3
Total n	4,313	3,600	3,981	2,976
Total Avg. %	96.3	83.1	90.7	75.1
State Avg. %	95.6	83.5	91.0	75.6

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 Chart and Table are provided.

- ◆ The Chart 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).

Information and Planning

- ◆ On average, three-fourths of respondents (73%) stated that they got enough information to help them participate in planning. However, these results ranged from only 63% in Orange County, California and South Carolina to 82% in Wyoming.

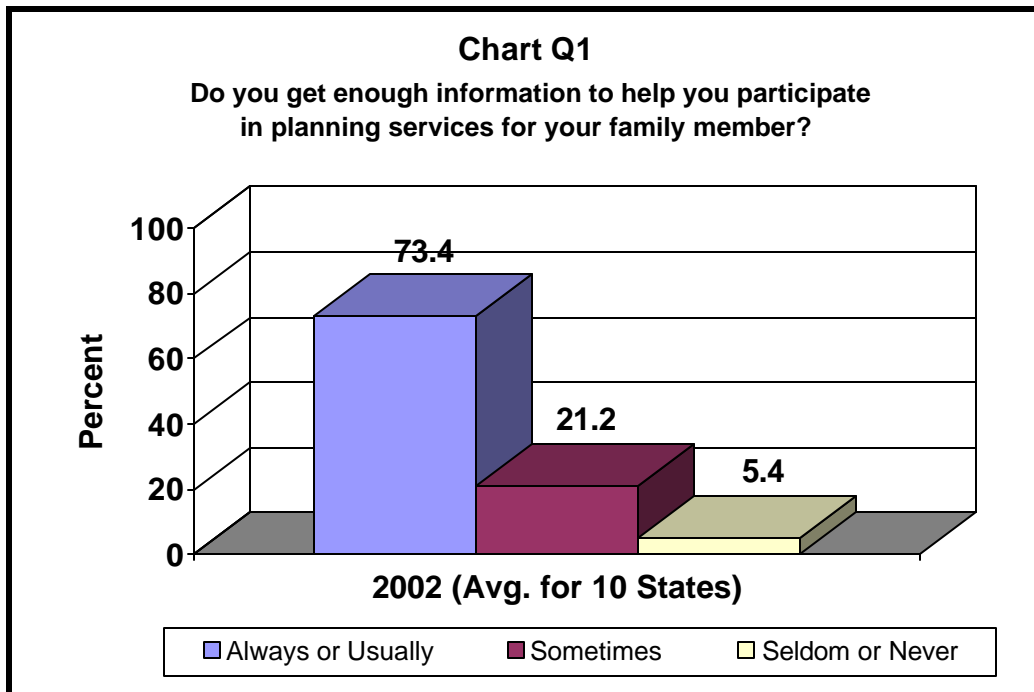


Table Q1
Do you get enough information to help you participate in planning services for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	79.1	17.5	3.4	326
CA-RCOC	↓↓	63.2	28.4	8.5	201
HI		68.5	25.2	6.3	127
IN		70.8	21.5	7.7	466
MA	↑	78.4	17.2	4.4	698
NC		75.6	19.5	4.9	405
PA		71.7	20.4	7.9	1,012
SC	↓↓	63.4	29.6	7.0	71
SD	↑	81.4	16.0	2.6	733
WY	↑	82.1	16.5	1.4	218
Total %		75.2	19.4	5.4	Total n = 3202
State Average %		73.4	21.2	5.4	Total n = 10

- ◆ Less than two-thirds of respondents (62%), on average, indicated that they typically helped to develop their family member's service plan.

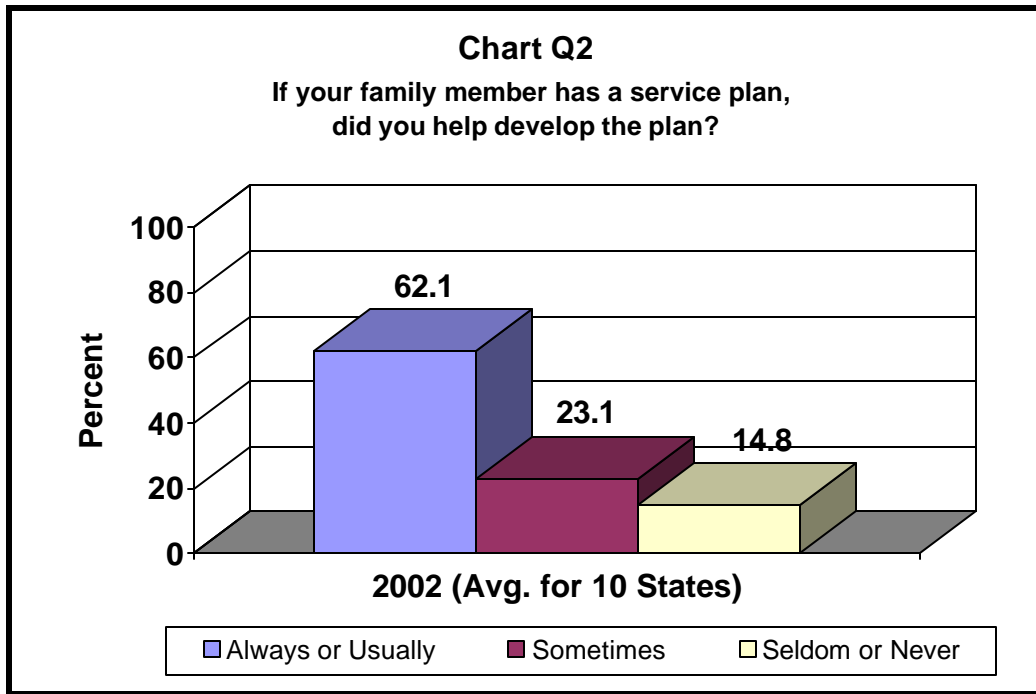


Table Q2
If your family member has a service plan, did you help develop the plan?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	70.4	20.9	8.8	297
CA-RCOC		58.8	23.2	18.1	177
HI		61.1	23.9	15.0	113
IN	↓	52.3	23.2	24.4	409
MA		65.0	20.2	14.9	645
NC		62.0	20.0	18.0	345
PA	↓↓↓	48.0	25.5	26.5	858
SC		59.1	31.8	9.1	66
SD	↑	71.1	21.1	7.9	660
WY	↑↑	72.9	21.4	5.7	210
Total %		60.9	22.4	16.7	Total n = 3780
State Average %		62.1	23.1	14.8	Total n = 10

- ◆ On average across states, four-fifths (78%) of respondents surveyed indicated that their family member's service plan included things that were important to them. 19% stated this was only true some of the time, while the remaining 3% stated the service plan seldom included things important to the respondent.

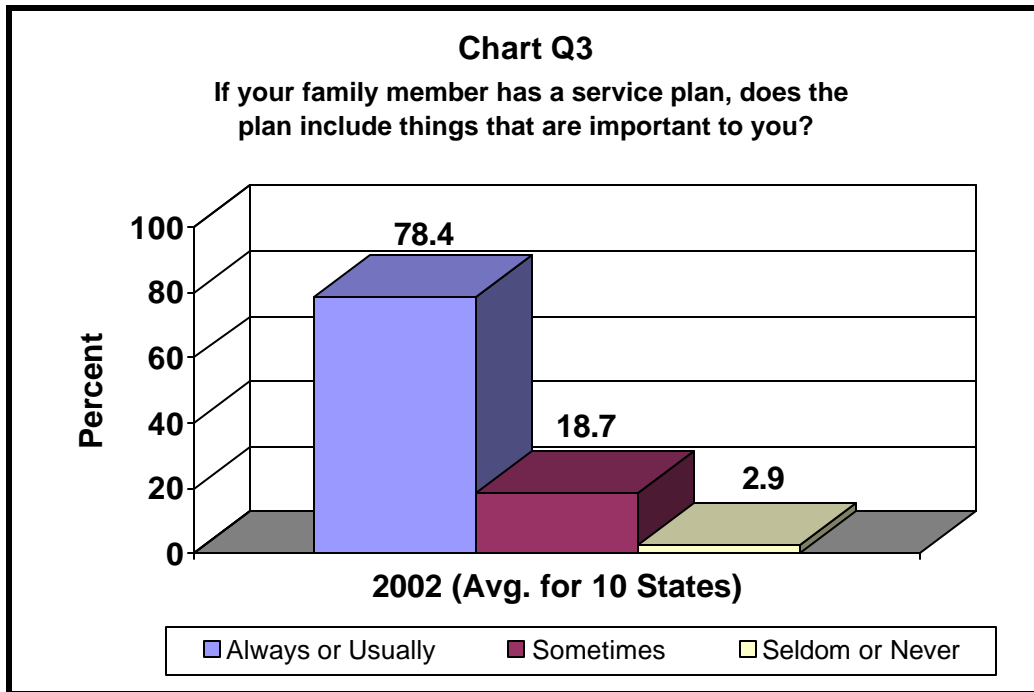


Table Q3
If your family member has a service plan, does the plan include things that are important to you?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	84.1	14.0	2.0	301
CA-RCOC	↓	73.3	25.0	1.7	176
HI		80.4	17.0	2.7	112
IN		74.4	21.4	4.2	407
MA		80.8	16.1	3.2	665
NC		75.9	19.3	4.8	352
PA	↓	71.8	22.4	5.8	866
SC		78.3	20.0	1.7	60
SD		79.7	18.7	1.7	664
WY	↑	85.6	13.0	1.4	215
Total %		77.6	19.0	3.5	Total n = 3818
State Average %		78.4	18.7	2.9	Total n = 10

- ◆ Across states, nearly all felt that planning staff were generally respectful and courteous.

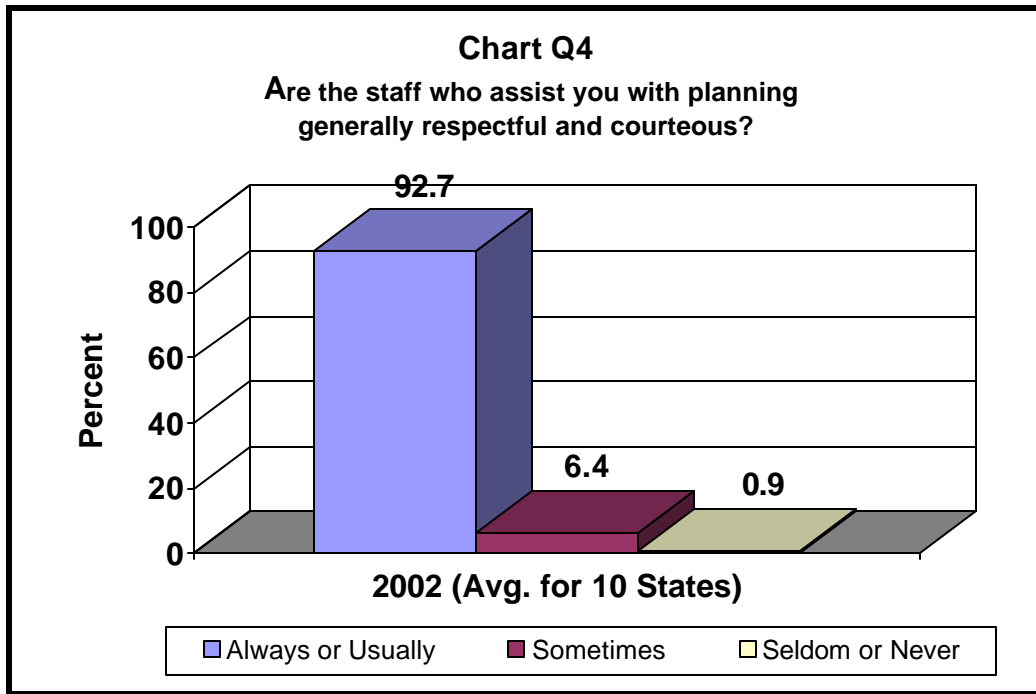


Table Q4
Are the staff who assist you with planning generally respectful and courteous?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	92.2	6.5	1.2	321
CA-RCOC	95.5	3.0	1.5	201
HI	92.7	6.5	0.8	124
IN	89.2	9.4	1.3	446
MA	94.5	4.5	1.0	694
NC	92.4	6.6	1.0	395
PA	93.6	5.2	1.2	963
SC	90.0	10.0	0.0	70
SD	94.8	4.8	0.4	730
WY	91.8	7.7	0.5	220
Total %	93.2	5.8	1.0	Total n = 4164
State Average %	92.7	6.4	0.9	Total n = 10

- ◆ Across states, approximately three-fourths (76%) felt that planning staff were generally effective.

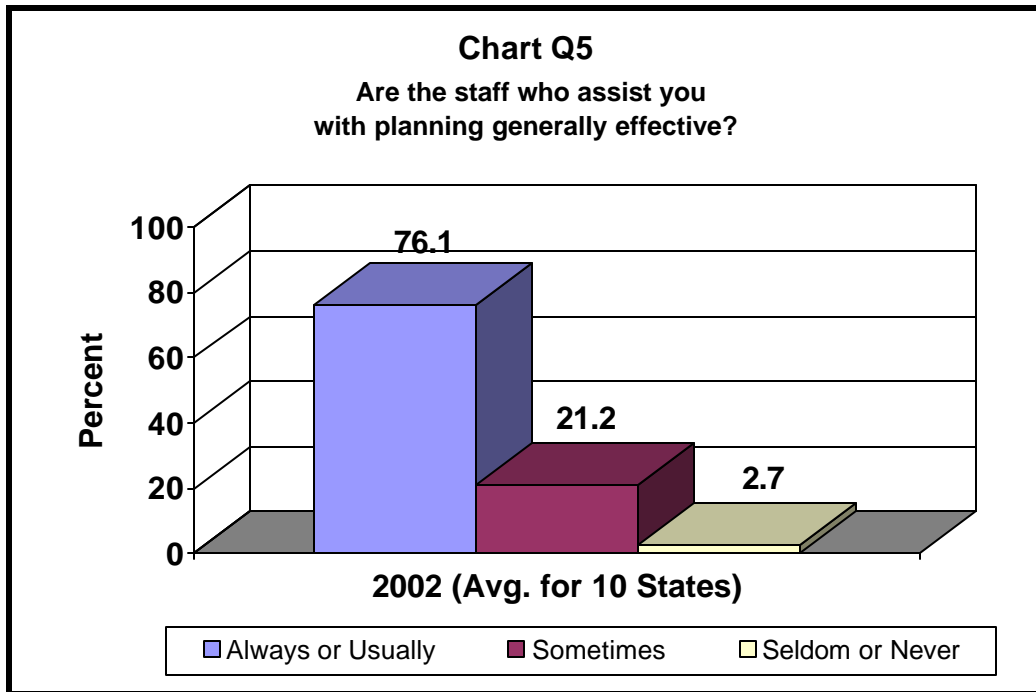


Table Q5					
Are the staff who assist you with planning generally effective?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		74.9	22.2	2.9	315
CA-RCOC		74.7	23.7	1.5	194
HI		72.6	23.4	4.0	124
IN		71.5	25.4	3.1	425
MA		75.3	22.6	2.1	677
NC		80.6	17.1	2.3	386
PA		78.9	18.3	2.8	897
SC		75.0	20.6	4.4	68
SD	↑	85.8	13.3	1.0	723
WY		71.7	25.6	2.7	223
Total %		77.8	19.9	2.3	Total n = 4032
State Average %		76.1	21.2	2.7	Total n = 10

- ◆ Across states, 87% felt they were able to contact planning staff when needed.

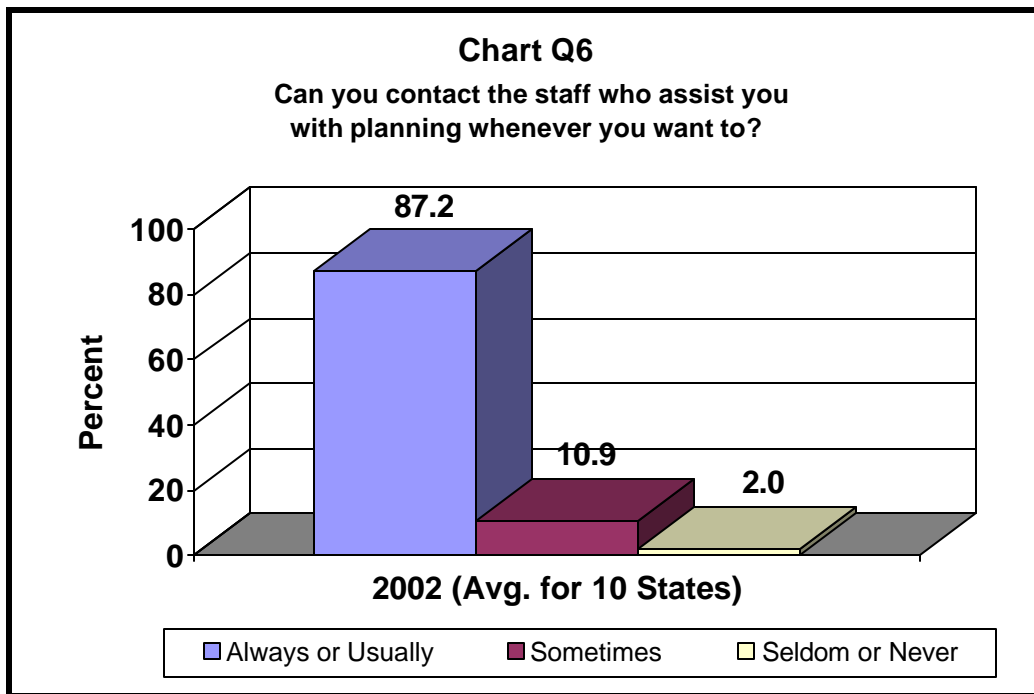


Table Q6
Can you contact the staff who assist you with planning whenever you want to?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	87.9	10.9	1.2	321
CA-RCOC	87.2	9.7	3.1	195
HI	84.0	12.8	3.2	125
IN	84.3	13.2	2.4	453
MA	88.2	10.5	1.3	687
NC	88.3	10.2	1.5	410
PA	88.1	9.6	2.3	951
SC	82.9	14.3	2.9	70
SD	92.0	7.2	0.8	725
WY	88.9	10.2	0.9	226
Total %	88.2	10.1	1.7	Total n = 4163
State Average %	87.2	10.9	2.0	Total n = 10

Access to and Delivery of Services and Supports

- ♦ On average, most respondents (82%) stated that their service coordinator helped them get needed supports when they asked. Sixteen 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.

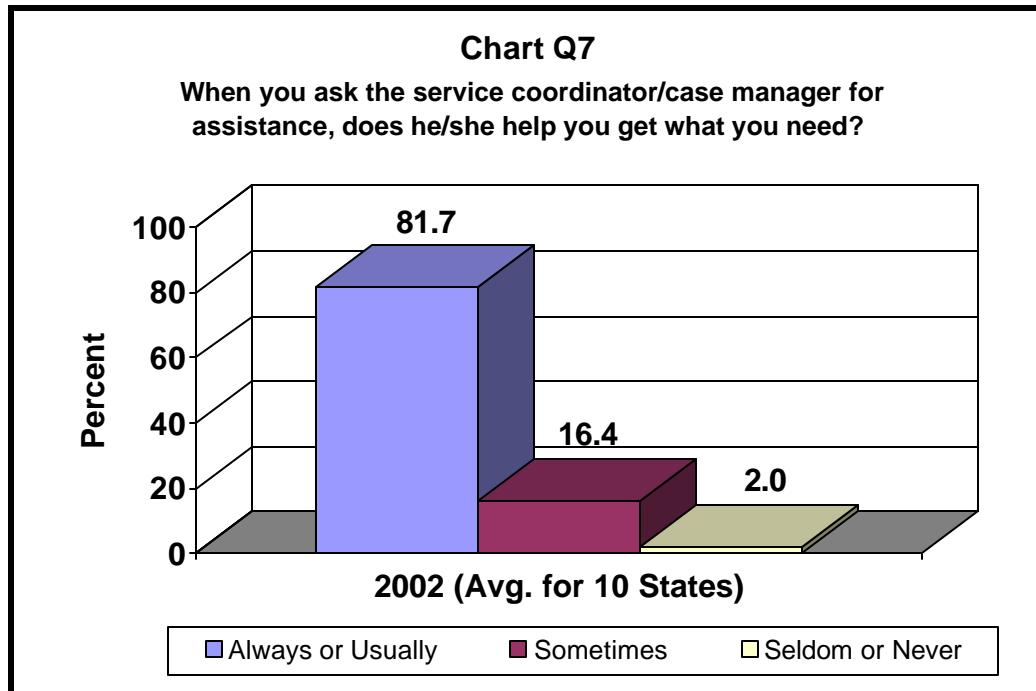


Table Q7					
When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		85.5	13.8	0.6	311
CA-RCOC	↓	75.1	22.1	2.8	181
HI	↓	75.4	20.6	4.0	126
IN		80.8	16.8	2.4	463
MA		80.2	17.4	2.4	677
NC		81.8	15.0	3.2	401
PA		82.0	14.9	3.1	961
SC		82.3	17.7	0.0	62
SD	↑	89.4	9.6	1.0	728
WY		84.2	15.8	0.0	222
Total %		82.7	15.1	2.2	Total n = 4132
State Average %		81.7	16.4	2.0	Total n = 10

- ◆ Eighty percent of respondents, on average, indicated that their family member always or usually gets the services and supports they need.

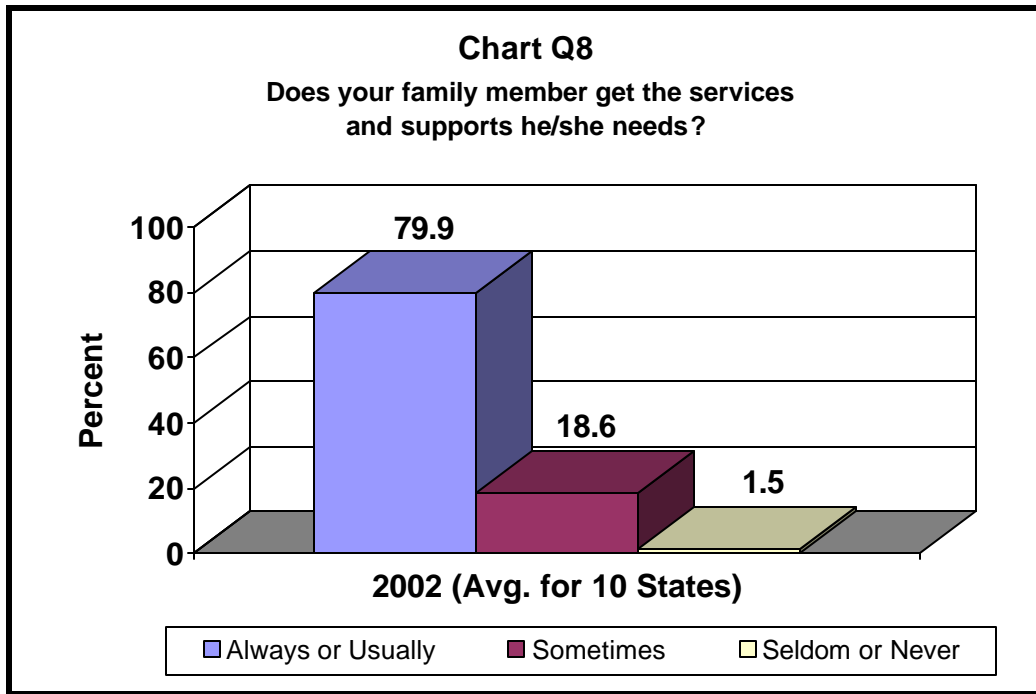


Table Q8
Does your family member get the services and supports he/she needs?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	83.8	15.9	0.3	321
CA-RCOC	75.4	23.1	1.5	199
HI	75.4	21.5	3.1	130
IN	81.4	17.6	1.0	490
MA	79.8	19.4	0.8	718
NC	83.1	15.5	1.4	419
PA	81.5	16.4	2.1	1,032
SC	75.8	21.2	3.0	66
SD	83.6	15.5	0.9	749
WY	78.8	19.9	1.3	226
Total %	81.2	17.4	1.4	Total n = 4350
State Average %	79.9	18.6	1.5	Total n = 10

- ◆ Among those respondents whose family member with disabilities did not speak English, or who used different ways to communicate, the majority (75%) 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 6% did not have staff available to communicate with their family members in their preferred means of communication/ languages.

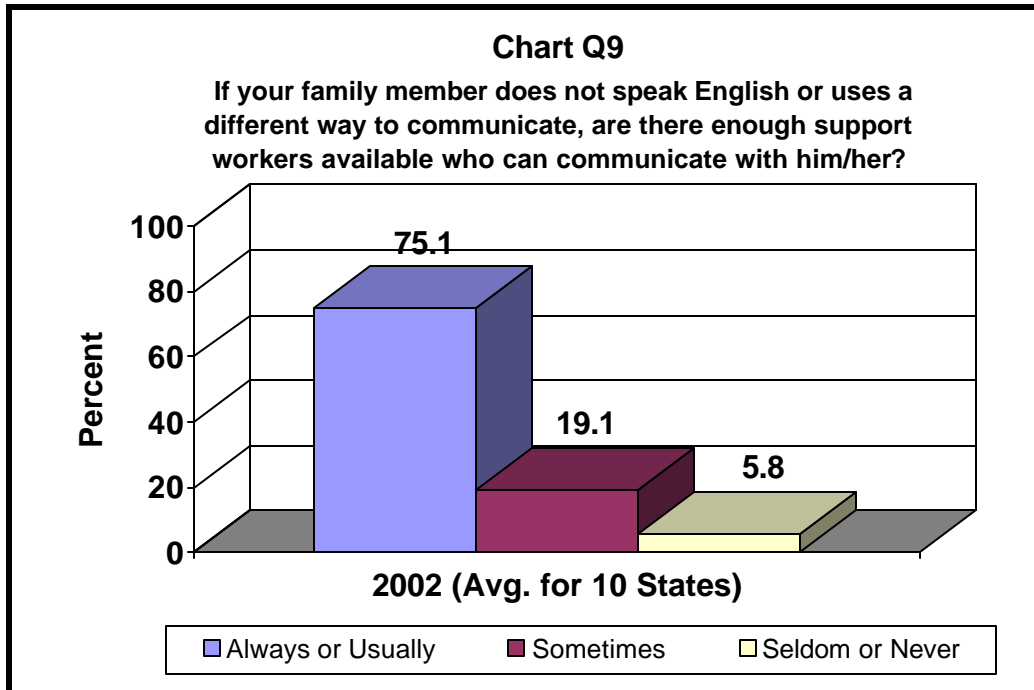


Table Q9

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	↓	67.6	19.1	13.2	68
HI	↓	67.8	28.8	3.4	59
IN		76.4	21.1	2.5	161
MA		73.6	22.0	4.3	322
NC	↑↑	87.6	11.1	1.3	153
PA		79.7	14.8	5.5	384
SC		76.2	14.3	9.5	21
SD		79.4	18.6	2.0	296
WY	↓	67.9	23.1	9.0	78
Total %		76.9	18.5	4.6	Total n = 1683
State Average %		75.1	19.1	5.8	Total n = 10

- ◆ On average, 87% of respondents indicated that their family member had access to the special equipment or accommodations that s/he needs. Thirteen percent stated that equipment was only seldom or sometimes available.

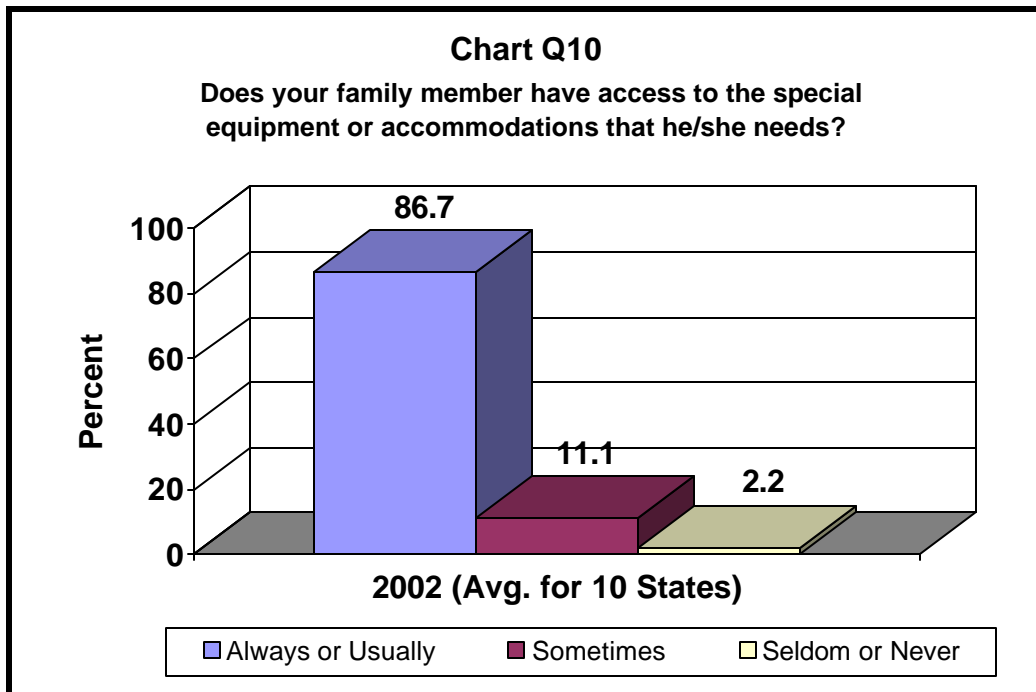


Table Q10
Does your family member have access to the special equipment or accommodations that he/she needs?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		88.0	12.0	0.0	192
CA-RCOC	↓	78.3	18.1	3.6	83
HI	↓	78.1	15.6	6.3	64
IN		86.4	12.0	1.6	309
MA		86.3	11.7	2.0	454
NC		91.1	6.6	2.3	213
PA		89.7	6.5	3.8	556
SC	↑	92.3	7.7	0.0	26
SD		91.0	8.1	0.9	443
WY		85.6	12.9	1.5	132
Total %		88.0	9.8	2.1	Total n = 2472
State Average %		86.7	11.1	2.2	Total n = 10

- ◆ Nearly three-fourths of respondents (71%) indicated that frequent changes in support staff were a problem for their family at least some of the time. The remaining quarter stated that this was not an issue for them.

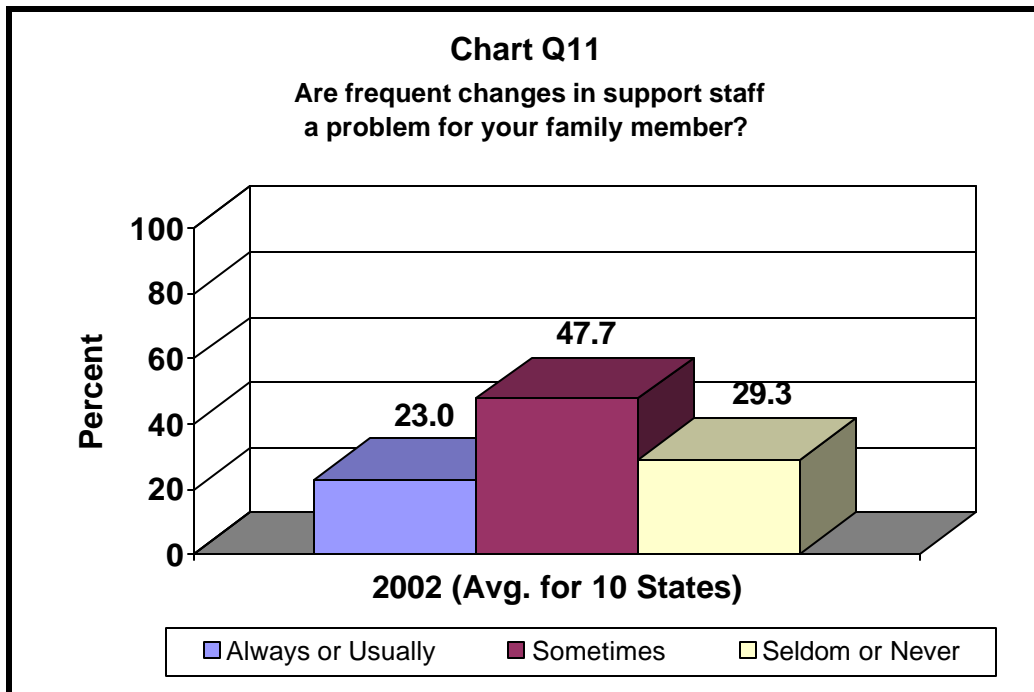


Table Q11
Are frequent changes in support staff a problem for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		26.8	48.8	24.4	291
CA-RCOC		19.1	48.3	32.6	178
HI		22.1	47.4	30.5	95
IN		22.8	43.1	34.1	413
MA		25.5	45.6	28.9	627
NC	↓↓	19.0	32.1	48.8	336
PA		23.2	44.1	32.7	866
SC	↑↑	25.9	63.0	11.1	54
SD		18.7	50.2	31.1	657
WY	↑↑	27.1	54.6	18.4	207
Total %		22.7	45.8	31.6	Total n = 3724
State Average %		23.0	47.7	29.3	Total n = 10

- ◆ Among those receiving residential supports, nearly all (89%) felt their family member's residential setting was a safe and healthy environment, however 11% felt their family member's residence was only sometimes or seldom safe.

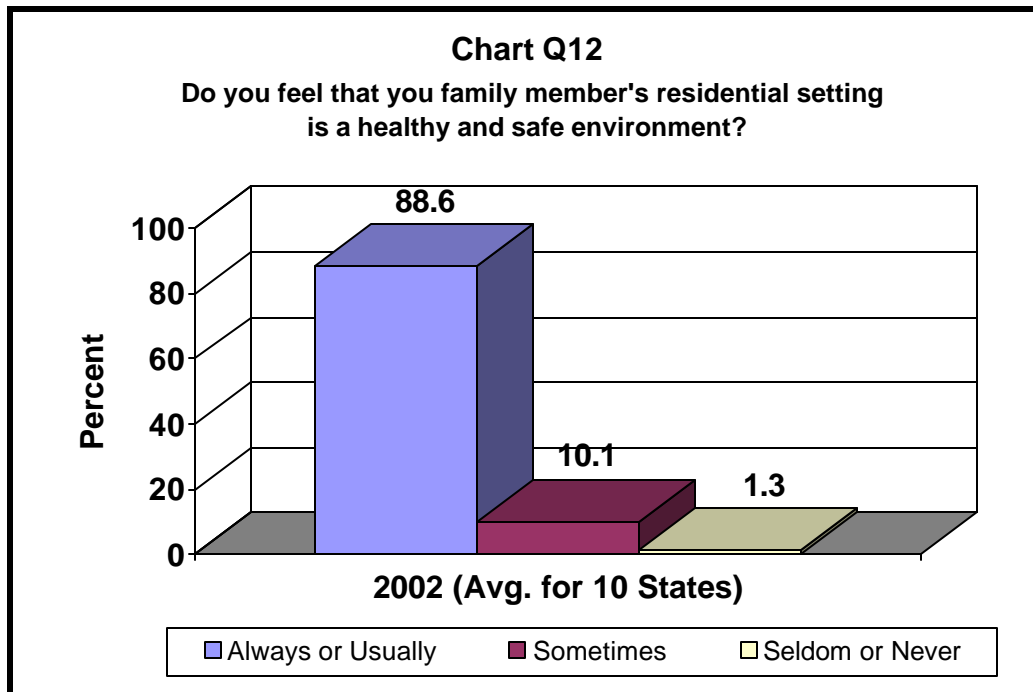


Table Q12
Do you feel that your family member's residential setting is a healthy and safe environment?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	87.2	11.6	1.2	329
CA-RCOC	89.2	10.3	0.5	204
HI	89.3	9.9	0.8	131
IN	88.1	10.5	1.4	513
MA	89.5	9.2	1.2	725
NC	90.6	7.8	1.7	424
PA	89.6	8.8	1.6	1,070
SC	88.9	7.9	3.2	63
SD	88.9	10.8	0.3	748
WY	84.4	14.3	1.3	231
Total %	88.9	9.9	1.2	Total n = 4438
State Average %	88.6	10.1	1.3	Total n = 10

- ◆ Among those receiving day/employment supports, nearly all (88%) felt their family member's day/employment setting was a safe and healthy environment. The remaining 12% felt their family member's residence was sometimes or seldom safe.

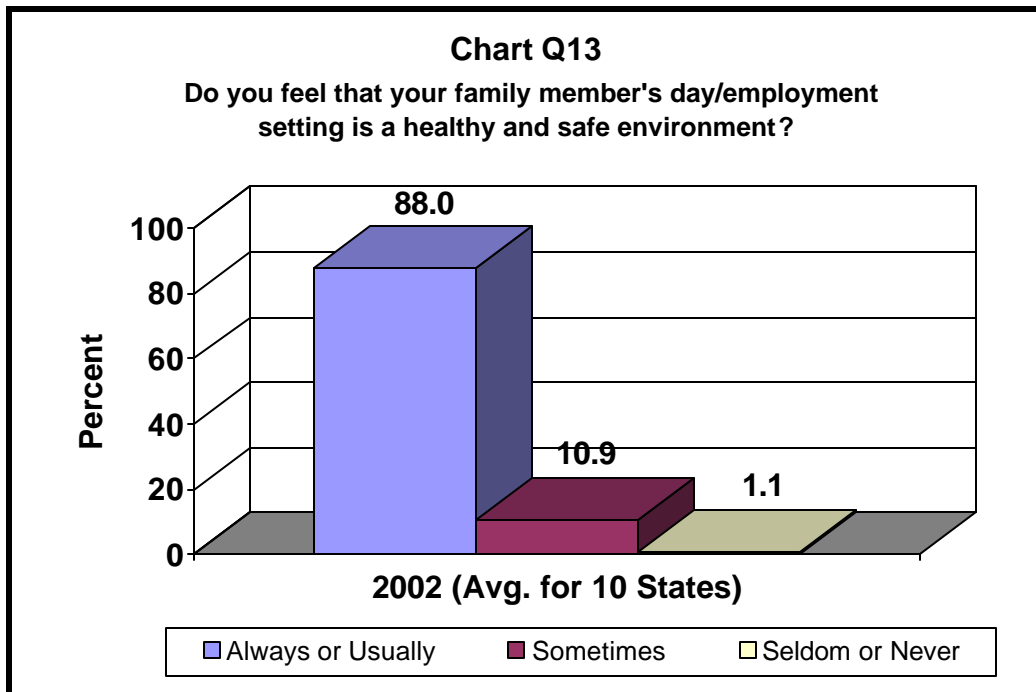


Table Q13
Do you feel that your family member's day/employment setting is a healthy and safe environment?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	87.5	12.2	0.3	287
CA-RCOC	85.1	13.7	1.1	175
HI	89.9	8.3	1.8	109
IN	87.2	11.2	1.6	383
MA	90.0	9.5	0.5	629
NC	90.3	9.1	0.6	340
PA	91.8	7.2	0.9	870
SC	↓ 79.7	17.2	3.1	64
SD	92.9	6.5	0.6	705
WY	85.4	14.1	0.5	213
Total %	89.8	9.3	0.8	Total n = 3775
State Average %	88.0	10.9	1.1	Total n = 10

Choices and Control

- ◆ Among families where the individual with disabilities received residential services, 78% of respondents stated that the agency involved them in important decisions. Another 17% stated that this happens some of the time, and 5% said the agency seldom or never involve them in important decisions.

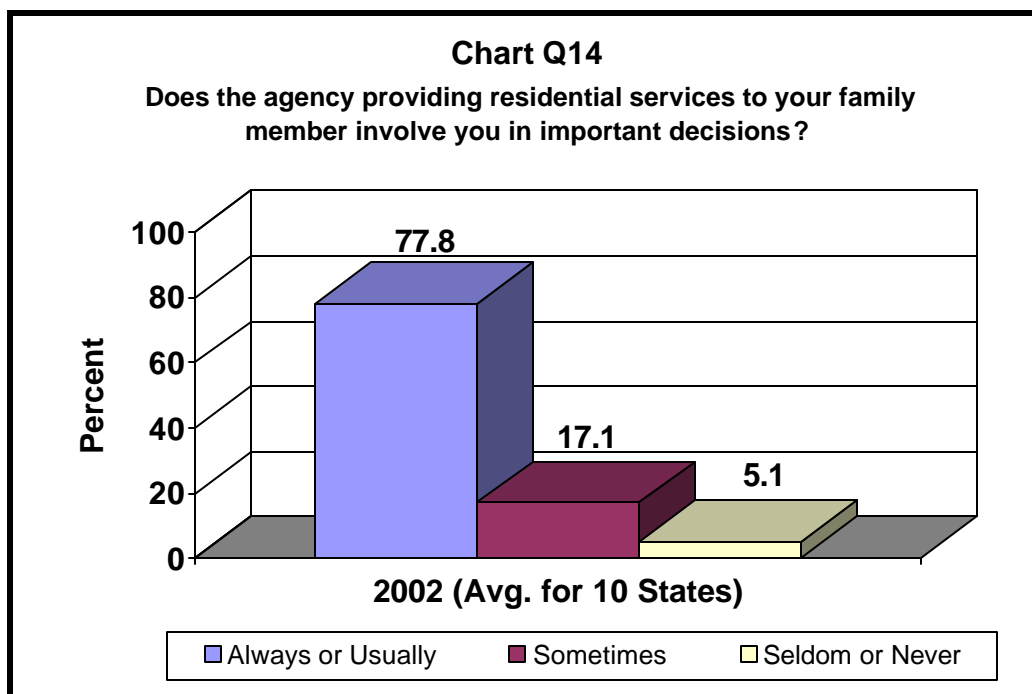


Table Q14

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	82.0	13.5	4.6	327
CA-RCOC	74.2	19.2	6.6	198
HI	80.5	17.2	2.3	128
IN	75.9	16.9	7.2	486
MA	78.9	17.1	4.0	703
NC	78.2	14.5	7.3	399
PA	↓	19.9	8.6	995
SC	74.2	19.7	6.1	66
SD	81.1	16.2	2.7	734
WY	81.7	16.5	1.8	224
Total %	77.3	17.2	5.6	Total n = 4260
State Average %	77.8	17.1	5.1	Total n = 10

- ◆ Among families where the individual with disabilities received day or employment services, 61% of respondents stated that the agency involves them in important decisions. Another 24% stated that this happens sometimes, and 15% said the agency seldom or never involves them in important decisions.

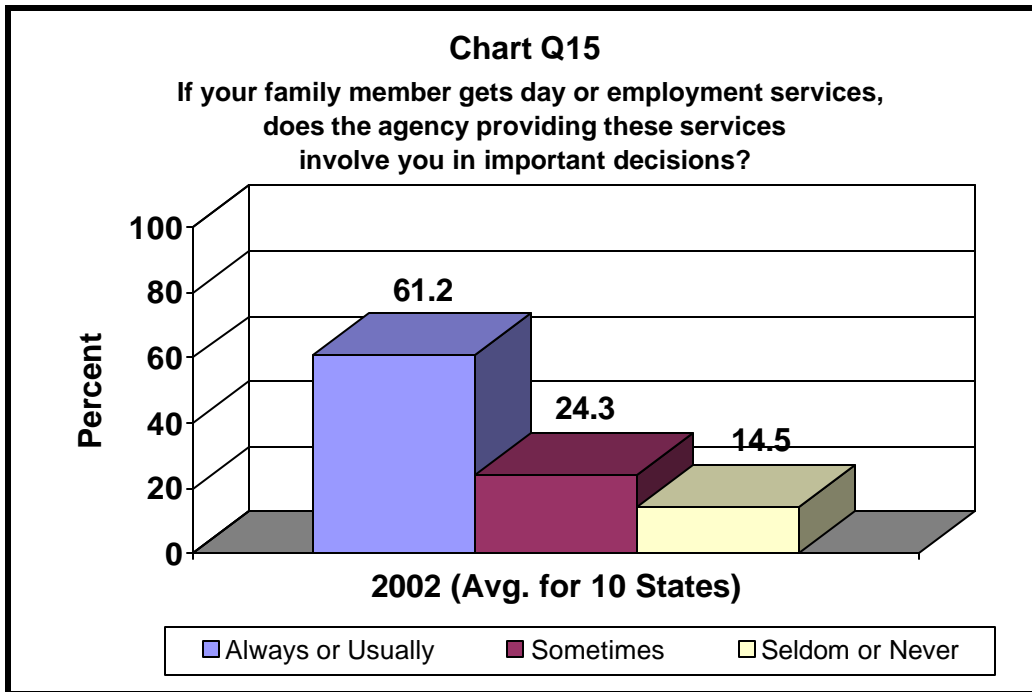


Table Q15
If your family member gets day or employment services, does the agency providing these services involve you in important decisions?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	68.3	22.5	9.2	271
CA-RCOC	43.4	30.1	26.5	166
HI	62.6	28.3	9.1	99
IN	55.8	24.6	19.7	346
MA	57.4	27.7	14.8	573
NC	64.8	23.0	12.2	287
PA	59.4	23.3	17.3	776
SC	65.5	12.1	22.4	58
SD	69.6	22.1	8.3	639
WY	65.5	29.0	5.5	200
Total %	61.6	24.5	14.0	Total n = 3415
State Average %	61.2	24.3	14.5	Total n = 10

- ♦ On average across states, approximately two-thirds of respondents (68%) seldom or never chose the support staff who work with their family members. In Hawaii, North Carolina, South Carolina and Wyoming, more individuals or families did choose their support workers, however even there, it amounted to fewer than half of the families surveyed.

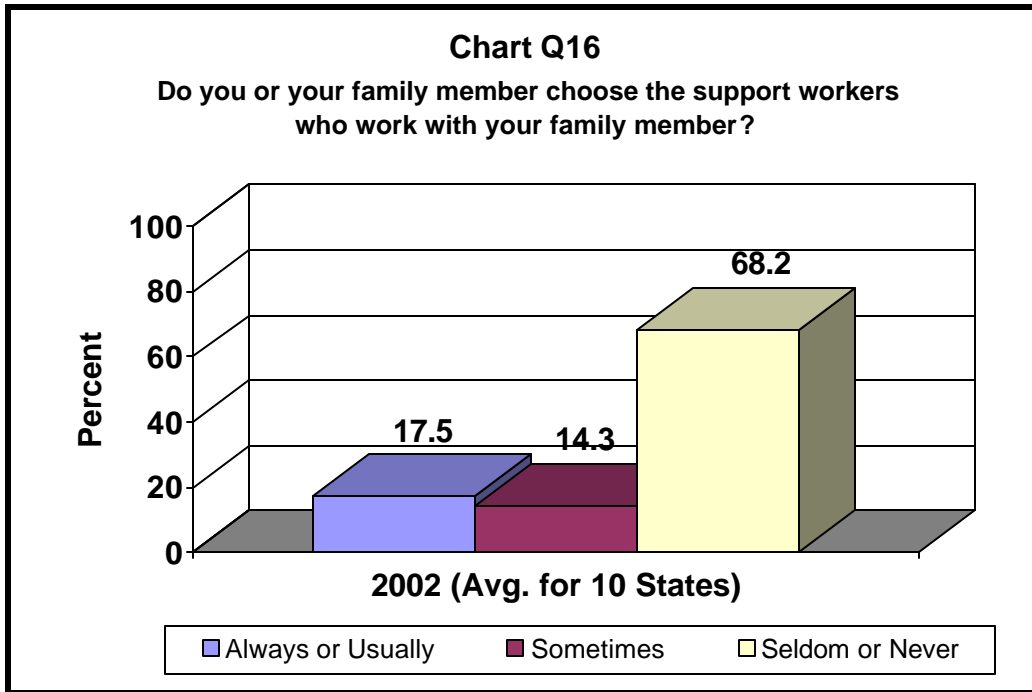


Table Q16
Do you or your family member choose the support workers who work with your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	11.2	12.3	76.5	277
CA-RCOC	↓	11.0	9.8	79.3	164
HI	↑↑	32.7	12.2	55.1	98
IN	↓	12.3	13.3	74.4	399
MA		13.0	12.8	74.2	593
NC	↑	24.8	13.1	62.1	298
PA	↓	11.4	9.6	79.0	814
SC		19.7	26.2	54.1	61
SD		13.2	10.0	76.8	608
WY	↑	25.5	24.1	50.5	212
Total %		14.8	12.4	72.9	Total n = 3524
State Average %		17.5	14.3	68.2	Total n = 10

- ◆ Across states, only 10% 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. Seventy-nine percent, however, had little or no input or control over the hiring or management of their family's support staff.

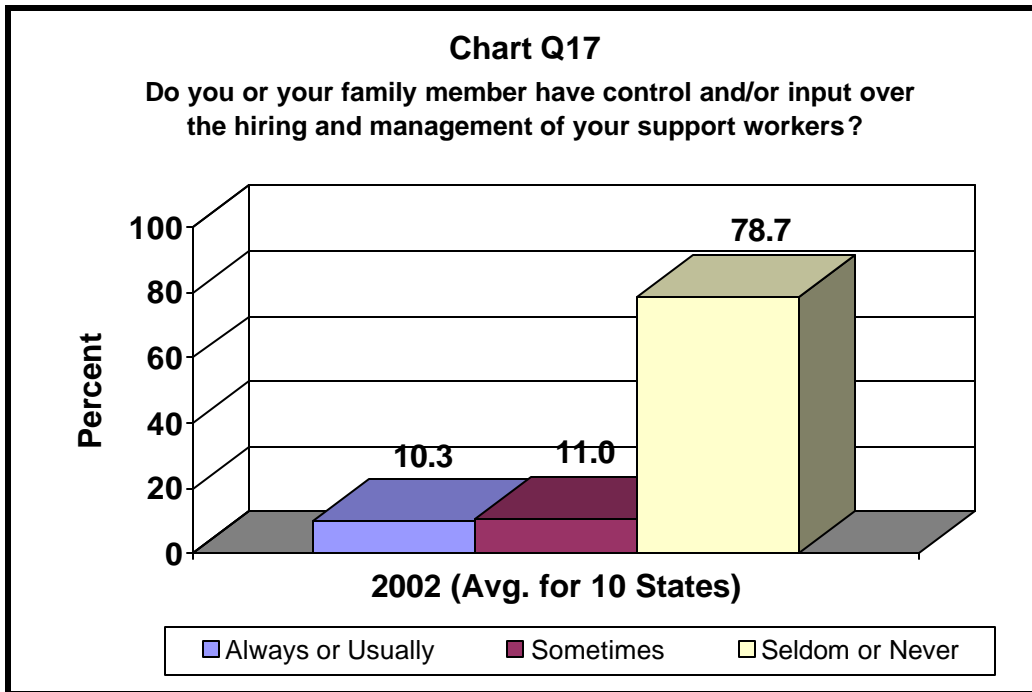


Table Q17

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	81.7	273
CA-RCOC		7.8	9.7	82.5	154
HI	↑↑	23.8	13.1	63.1	84
IN		8.6	11.0	80.5	374
MA		6.3	11.8	81.9	552
NC	↑	15.6	12.6	71.9	270
PA		6.6	6.9	86.4	767
SC		14.3	14.3	71.4	49
SD	↓	4.7	7.9	87.4	572
WY		8.2	11.3	80.5	195
Total %		7.9	9.8	82.2	Total n = 3290
State Average %		10.3	11.0	78.7	Total n = 10

- ◆ While only 21% of respondents said they had any amount of control over the hiring or management of their support workers (see previous question), here 66% of respondents indicate that they want this type of control.

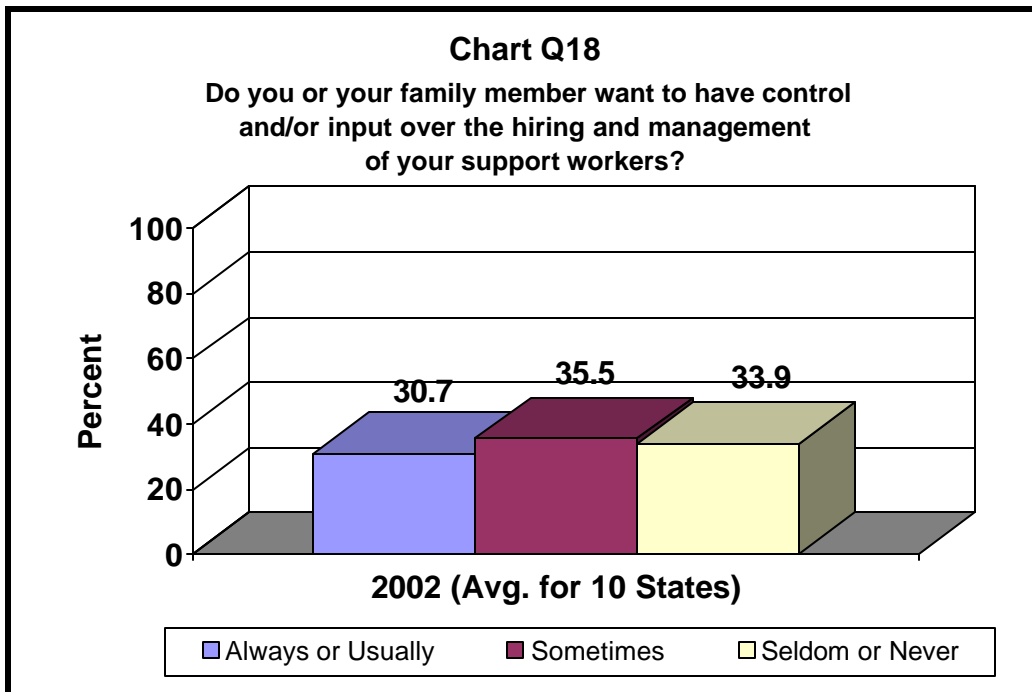


Table Q18

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		29.5	42.3	28.2	234
CA-RCOC		28.7	34.3	37.1	143
HI	↑↑	42.7	31.7	25.6	82
IN		30.1	31.3	38.6	342
MA		30.3	39.6	30.1	512
NC		31.9	36.9	31.2	260
PA	↓	25.5	31.3	43.1	686
SC	↑↑	43.8	31.3	25.0	48
SD	↓↓	15.3	32.7	52.0	496
WY		29.0	43.2	27.8	176
Total %		27.2	35.2	37.7	Total n = 2979
State Average %		30.7	35.5	33.9	Total n = 10

- ◆ Twenty-nine percent of respondents, on average, knew how much money was spent on behalf of their family member. Over half (59%), however, had no idea.
- ◆ In Hawaii and Wyoming, a far greater percentage of families (44% and 63%) knew the amount of money spent. In Orange County, California and Pennsylvania, a much smaller percentage of respondents (14% and 13% respectively) knew this information.

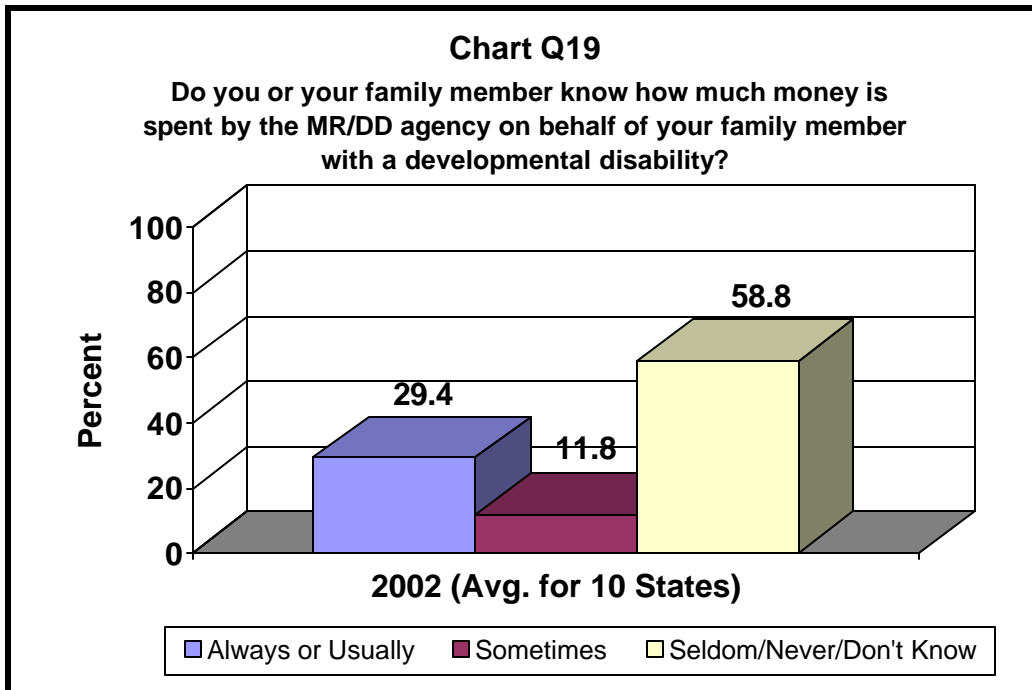


Table Q19

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	↑	38.4	12.7	48.9	323
CA-RCOC	↓↓	13.6	8.6	77.8	198
HI	↑↑	43.5	14.5	41.9	124
IN	↓	21.9	11.8	66.3	475
MA		26.0	11.9	62.1	678
NC	↓	23.2	9.0	67.8	388
PA	↓↓	13.3	7.1	79.6	1,004
SC	↓↓	17.2	14.1	68.8	64
SD		33.6	12.1	54.2	708
WY	↑↑	63.1	16.4	20.4	225
Total %		26.3	10.8	63.0	Total n = 4187
State Average %		29.4	11.8	58.8	Total n = 10

- ◆ On average across states, half of the families surveyed (49%) 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 (51%), however, did not.

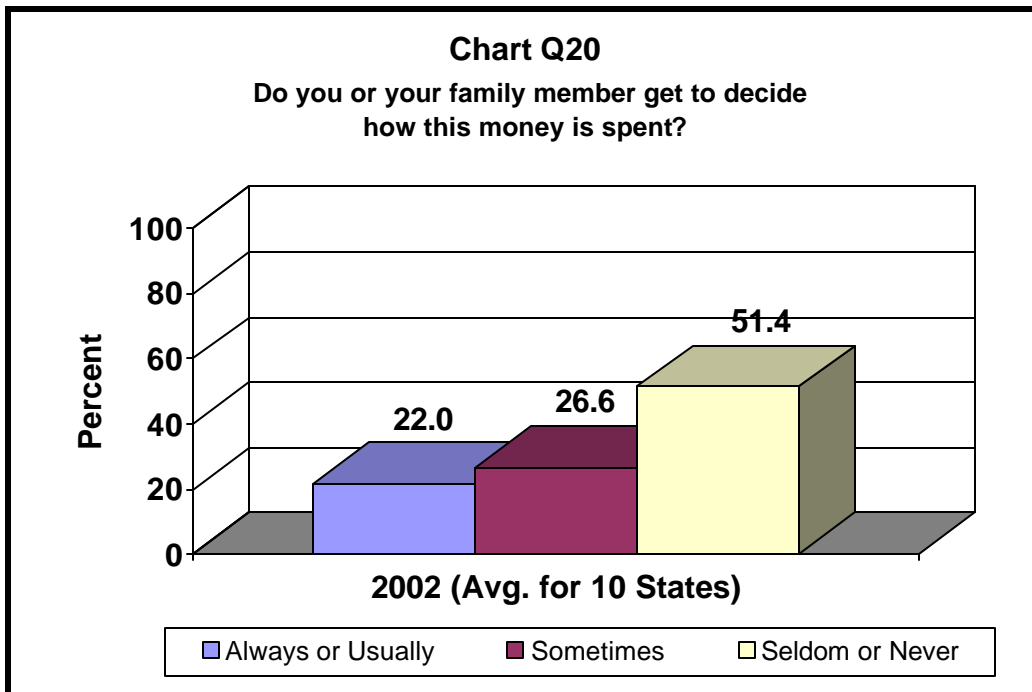


Table Q20
Do you or your family member get to decide how this money is spent?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	30.7	26.6	42.7	274
CA-RCOC	↓	14.3	14.3	71.4	154
HI	↑	27.8	28.9	43.3	90
IN	↓	15.4	26.8	57.7	369
MA		23.7	24.3	52.0	535
NC		18.2	23.7	58.0	274
PA		17.9	17.2	64.9	737
SC		18.4	36.7	44.9	49
SD		26.0	29.4	44.6	588
WY	↑	27.7	37.9	34.5	206
Total %		21.9	24.8	53.4	Total n = 3276
State Average %		22.0	26.6	51.4	Total n = 10

Community Connections

- ♦ Slightly over half (58%) of respondents remarked that staff were usually able to help them connect with typical supports in their community (e.g., recreation programs, church activities) if they desired to do so. 28% indicated that staff could sometimes help in this way, while 14% stated that staff rarely or never provided this type of assistance.

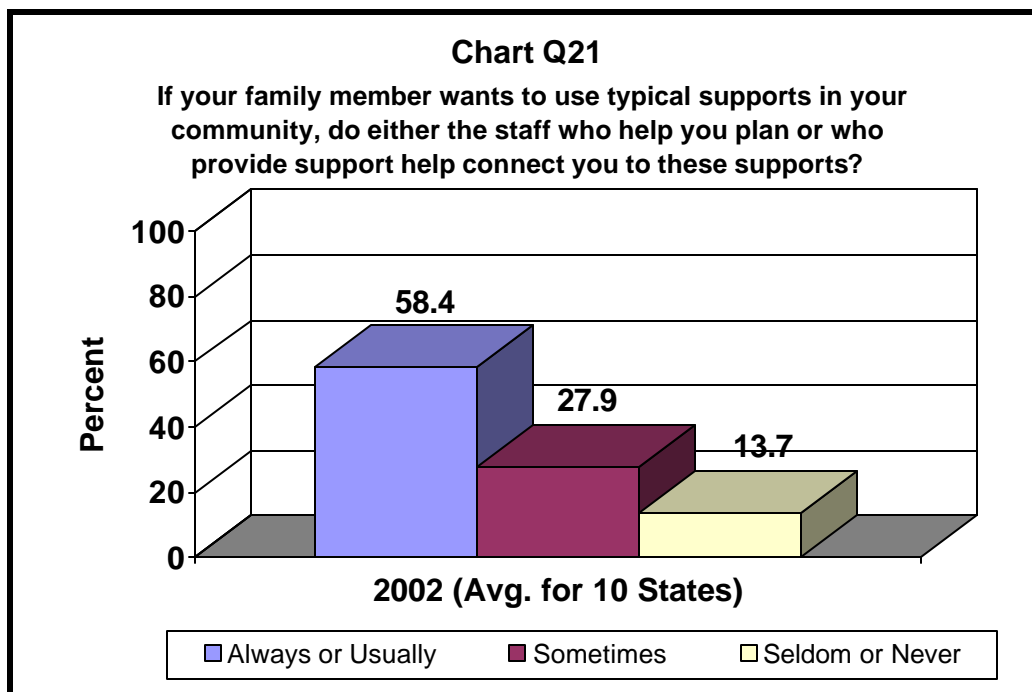


Table Q21

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		58.9	28.2	12.9	241
CA-RCOC	⇓⇓	37.0	31.0	32.0	100
HI		56.2	24.7	19.2	73
IN		60.2	31.5	8.2	352
MA		59.7	30.9	9.4	489
NC	↑	65.1	23.9	10.9	284
PA	↑	64.7	22.8	12.5	728
SC		60.0	26.7	13.3	45
SD	↑	67.4	25.3	7.3	628
WY		54.8	34.0	11.2	188
Total %		61.8	27.1	11.1	Total n = 3128
State Average %		58.4	27.9	13.7	Total n = 10

- ♦ Of families interested in using family or friends to provide some of the supports needed, 59% stated that planning or support staff were helpful in making this happen. The remaining 41% indicated that staff were only sometimes or seldom capable of helping families utilize friends, neighbors, etc. as supports.

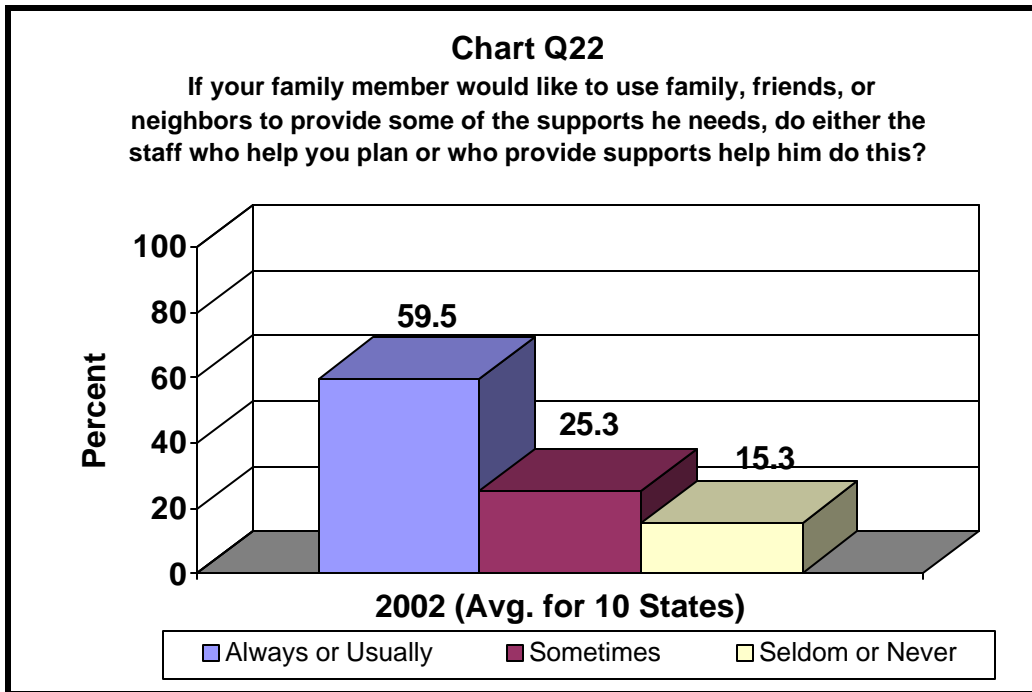


Table Q22

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	↑	65.0	21.7	13.4	217
CA-RCOC	↓↓	43.8	20.8	35.4	96
HI	↓↓	49.3	28.4	22.4	67
IN		62.3	27.5	10.2	313
MA		58.8	30.0	11.3	444
NC		62.3	23.0	14.8	257
PA		62.6	24.8	12.6	634
SC		59.1	25.0	15.9	44
SD	↑	68.8	23.6	7.6	555
WY		62.7	28.4	8.9	169
Total %		62.3	25.4	12.2	Total n = 2796
State Average %		59.5	25.3	15.3	Total n = 10

- ◆ Only 62% of respondents felt that their family member typically had access to community activities.

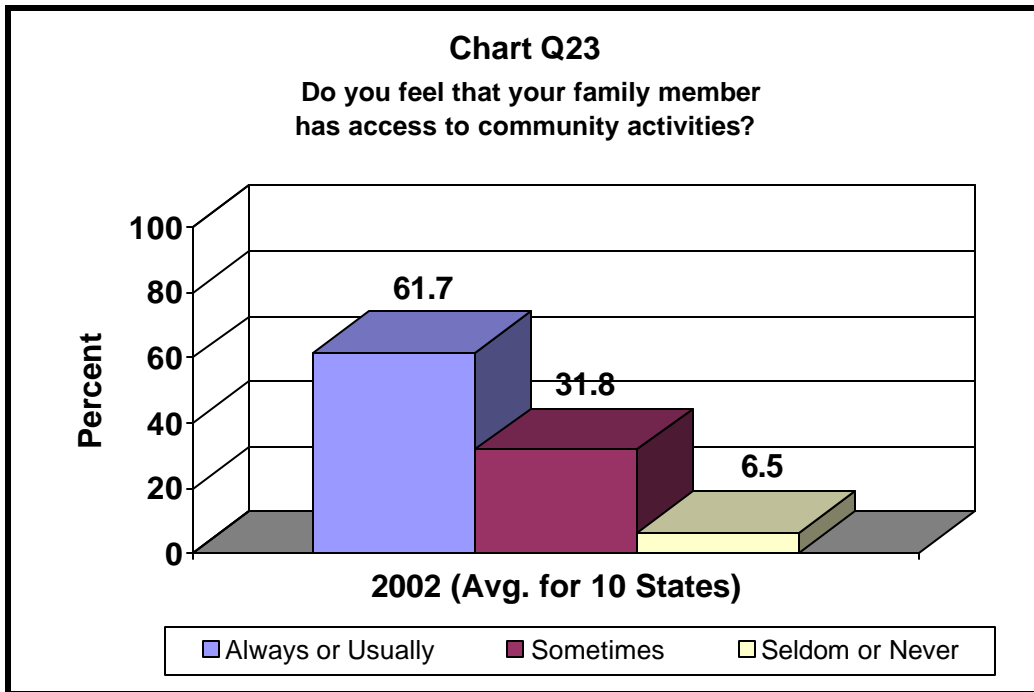


Table Q23
Do you feel that your family member has access to community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		61.1	32.3	6.6	303
CA-RCOC	↓↓	45.3	43.0	11.6	172
HI	↓	53.9	39.3	6.7	89
IN		64.6	29.6	5.8	432
MA		60.8	33.4	5.8	622
NC		64.5	29.4	6.1	361
PA		64.9	27.7	7.4	950
SC		64.8	25.9	9.3	54
SD	↑↑	73.1	24.3	2.6	736
WY		63.7	33.2	3.1	223
Total %		64.3	29.9	5.8	Total n = 3942
State Average %		61.7	31.8	6.5	Total n = 10

- ◆ While 62% of families felt their family member had regular access to community activities, only 40% stated that their family member usually participated in these activities, although another 42% indicated that their family member sometimes took part in community events/activities.

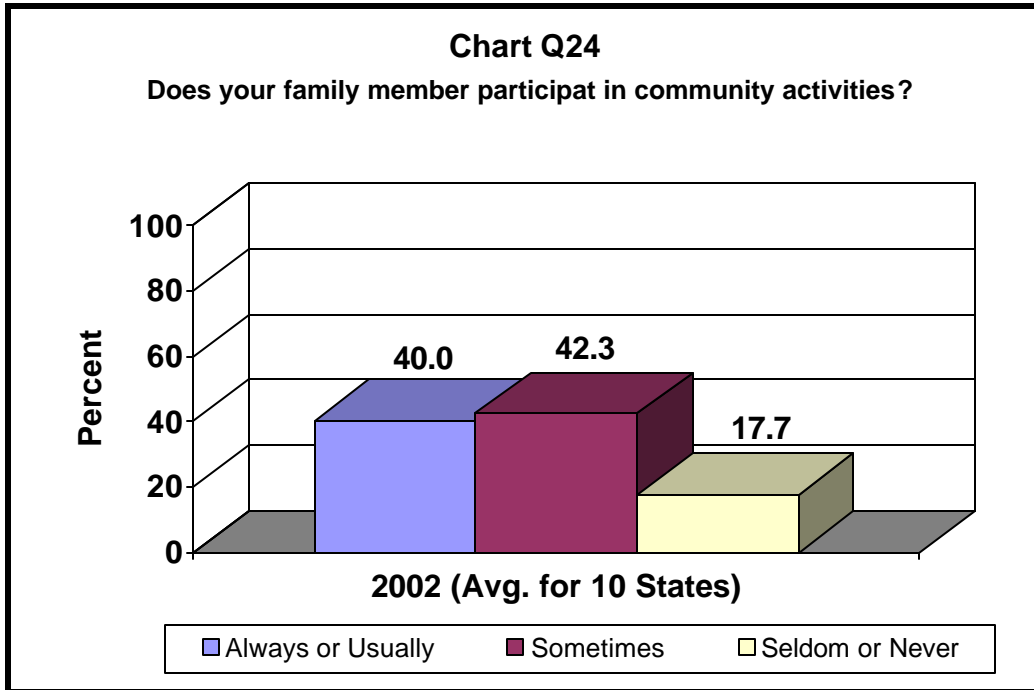


Table Q24
Does your family member participate in community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	46.8	40.1	13.0	284
CA-RCOC	↓↓	22.4	42.4	35.3	170
HI		35.6	40.0	24.4	90
IN		40.8	43.8	15.4	409
MA		40.2	43.5	16.3	607
NC	↑	45.4	41.0	13.6	346
PA		42.1	37.7	20.2	888
SC		43.6	40.0	16.4	55
SD		42.9	44.9	12.3	700
WY		40.4	50.0	9.6	218
Total %		41.3	42.1	16.5	Total n = 3767
State Average %		40.0	42.3	17.7	Total n = 10

Outcomes and Satisfaction with Services and Supports

- ♦ On average, most respondents (82%) were satisfied with the services and supports their family member received. 16% were only somewhat satisfied, and 2% were seldom or not satisfied.

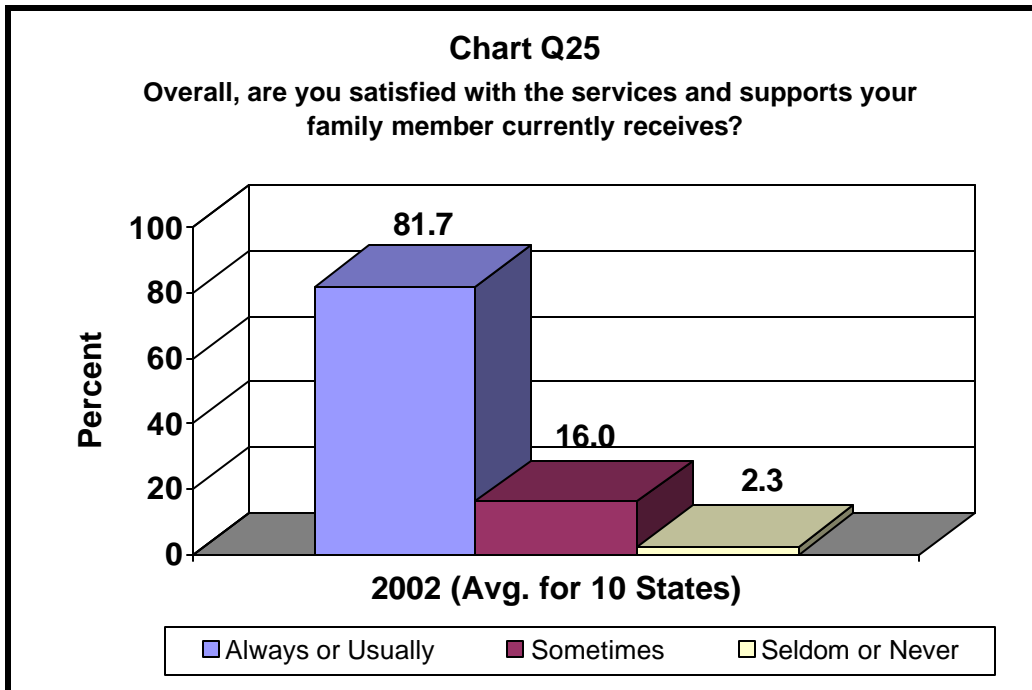


Table Q25
Overall, are you satisfied with the services and supports your family member currently receives?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	82.0	16.5	1.5	333
CA-RCOC	85.0	13.5	1.5	200
HI	↓ 76.5	20.5	3.0	132
IN	80.7	16.3	3.0	498
MA	80.9	17.4	1.7	718
NC	80.1	18.7	1.2	423
PA	81.1	16.8	2.0	1,081
SC	86.4	7.6	6.1	66
SD	85.6	13.4	0.9	752
WY	78.4	19.5	2.2	231
Total %	81.8	16.4	1.8	Total n = 4434
State Average %	81.7	16.0	2.3	Total n = 10

- ♦ On average, 54% of respondents knew about their agency's grievance process, 8% knew something about it, and 38% had no knowledge of the process for lodging a complaint.

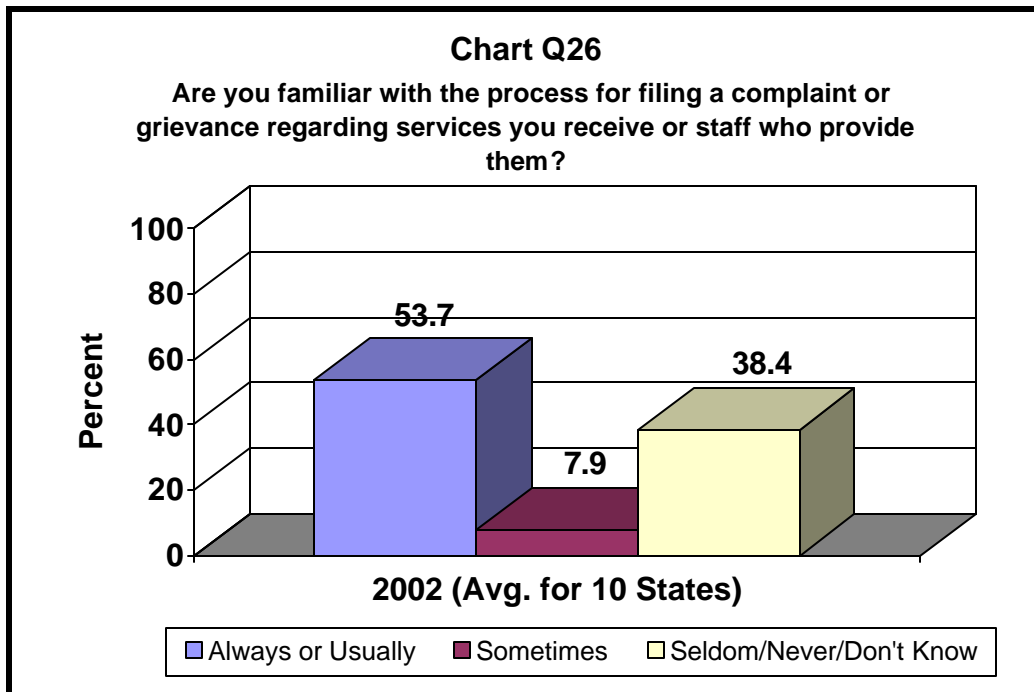


Table Q26

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		56.1	9.1	34.8	319
CA-RCOC	↓↓	41.9	9.4	48.7	191
HI	↓↓	41.7	10.0	48.3	120
IN		54.0	7.0	38.9	483
MA	↑	59.6	8.3	32.1	683
NC		56.3	7.7	36.0	405
PA	↓	45.7	6.0	48.2	997
SC		50.0	8.8	41.2	68
SD	↑↑	64.2	8.3	27.5	709
WY	↑↑	67.6	4.5	27.9	222
Total %		54.8	7.5	37.7	Total n = 4197
State Average %		53.7	7.9	38.4	Total n = 10

- ♦ The majority of respondents (65%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 35%, however, were either not satisfied, or satisfied only some of the time with how these matters were resolved.

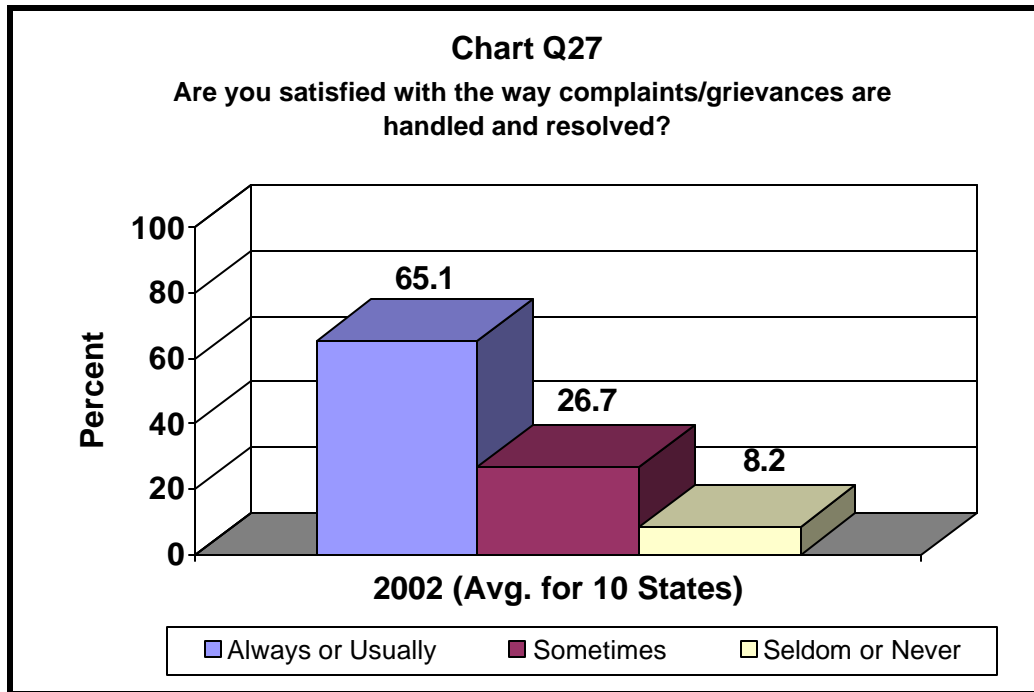


Table Q27
Are you satisfied with the way complaints/grievances are handled and resolved?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		64.4	29.6	6.0	216
CA-RCOC	↓	56.0	39.4	4.6	109
HI		65.7	23.9	10.4	67
IN		64.2	25.4	10.4	338
MA		65.0	26.9	8.1	532
NC	↑↑	77.0	16.7	6.3	287
PA		65.8	25.5	8.7	644
SC	↓	57.1	26.2	16.7	42
SD	↑	72.6	23.1	4.3	540
WY		63.2	30.1	6.7	163
Total %		67.1	25.5	7.4	Total n = 2938
State Average %		65.1	26.7	8.2	Total n = 10

- ◆ The majority of respondents (82%) felt that services and supports had a positive impact on their family's life. 16% stated that services sometime made a positive difference, and the remaining 2% indicated that supports seldom or never had a positive impact.

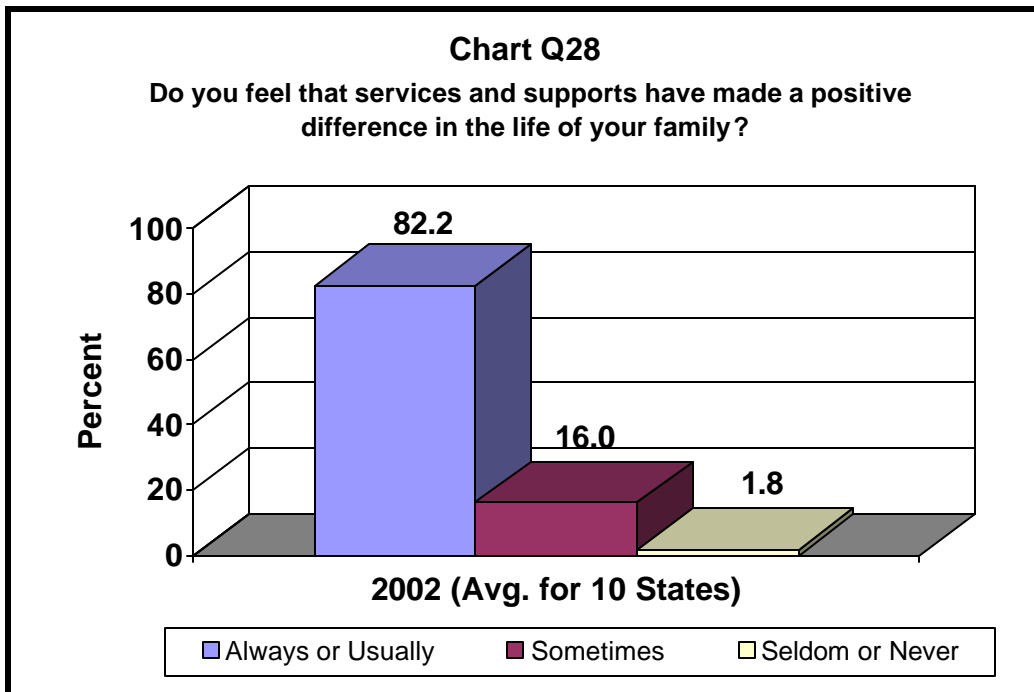


Table Q28
Do you feel that services and supports have made a positive difference in the life of your family?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	82.1	15.4	2.5	324
CA-RCOC	80.0	18.4	1.6	190
HI	75.2	22.3	2.5	121
IN	80.7	17.0	2.3	477
MA	85.0	13.8	1.2	685
NC	85.1	13.7	1.2	409
PA	82.8	15.0	2.2	1,008
SC	84.3	12.9	2.9	70
SD	85.3	13.3	1.4	729
WY	81.6	18.0	0.4	228
Total %	83.2	15.1	1.7	Total n = 4251
State Average %	82.2	16.0	1.8	Total n = 10

- ♦ Eighty percent of respondents felt that their family member was usually happy. Two percent indicated that their family member was not happy.

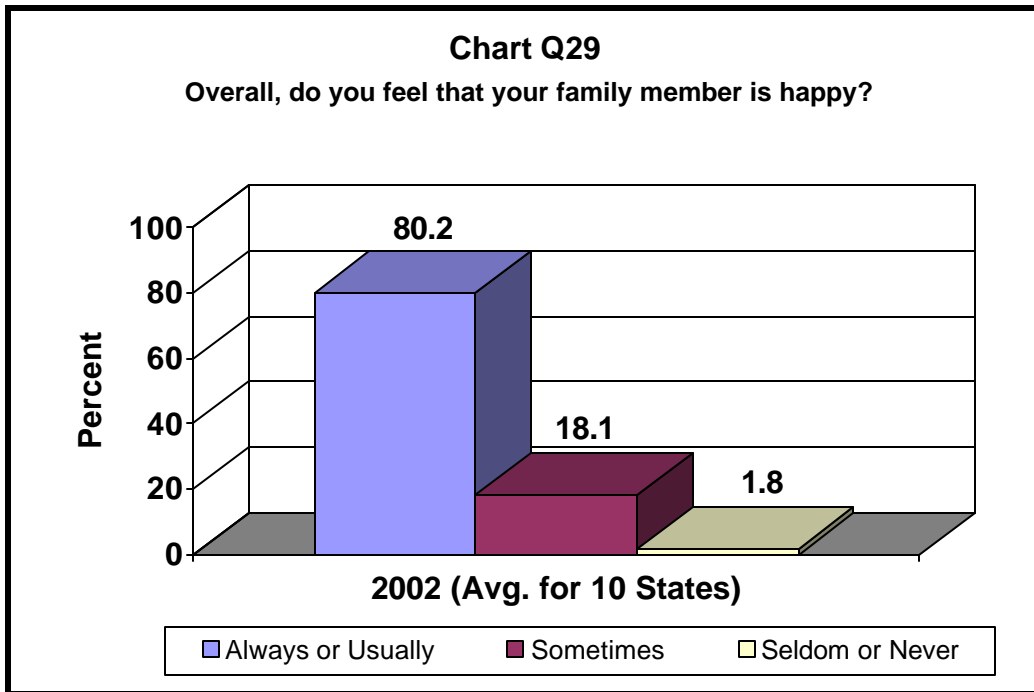


Table Q29
Overall, do you feel that your family member is happy?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	79.2	17.7	3.1	327
CA-RCOC	82.8	16.3	1.0	203
HI	76.7	20.2	3.1	129
IN	76.5	21.9	1.6	493
MA	81.1	17.6	1.3	705
NC	80.3	18.5	1.2	422
PA	81.1	17.2	1.7	1,064
SC	80.3	16.9	2.8	71
SD	83.3	15.9	0.8	749
WY	80.7	18.4	0.9	228
Total %	80.7	17.8	1.5	Total n = 4391
State Average %	80.2	18.1	1.8	Total n = 10

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 Arizona, South Dakota and Wyoming, responses to information and planning questions were generally above the overall state average. In Orange County, California and Pennsylvania, results were generally below the state average.

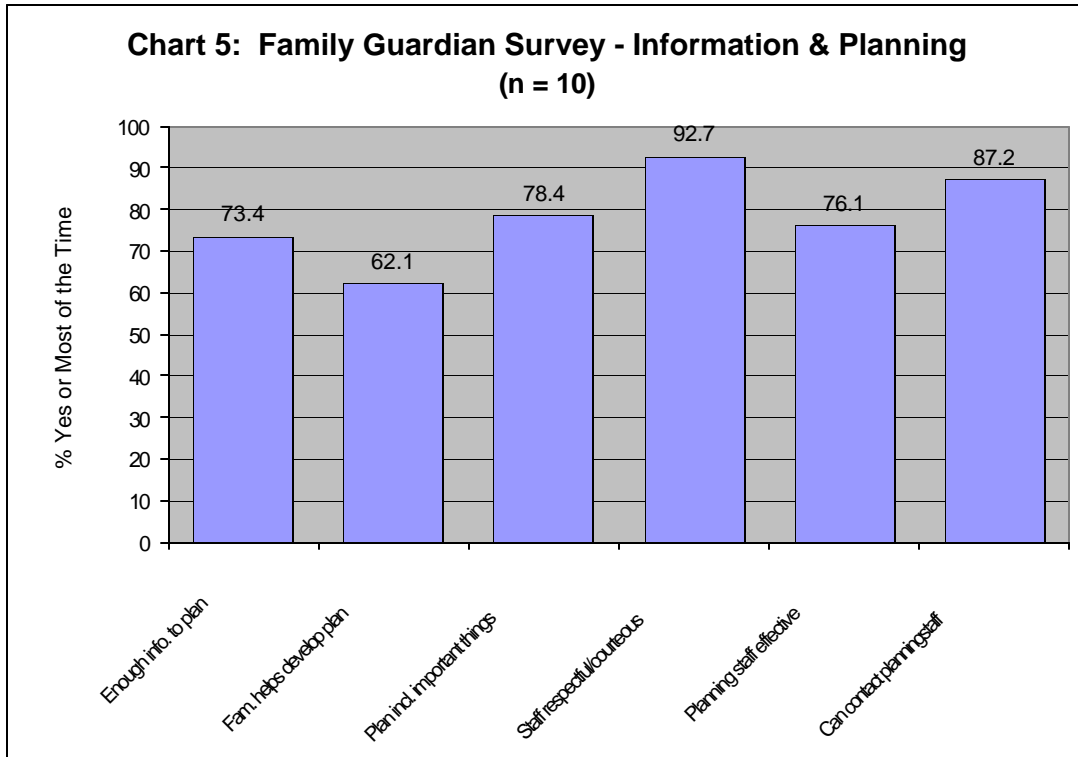


Table 16
Trends in Responses
Above & Below State Average
Information & Planning

State	Q1	Q2	Q3	Q4	Q5	Q6	Net Sum
AZ	↑	↑	↑				3
CA-RCOC	↓↓		↓				-3
HI							0
IN		↓					-1
MA	↑						1
NC							0
PA		↓↓	↓				-3
SC	↓↓						-2
SD	↑	↑			↑		3
WY	↑	↑↑	↑				4

Access and Delivery of Services

- ◆ In this series of questions, responses were generally consistent across states.

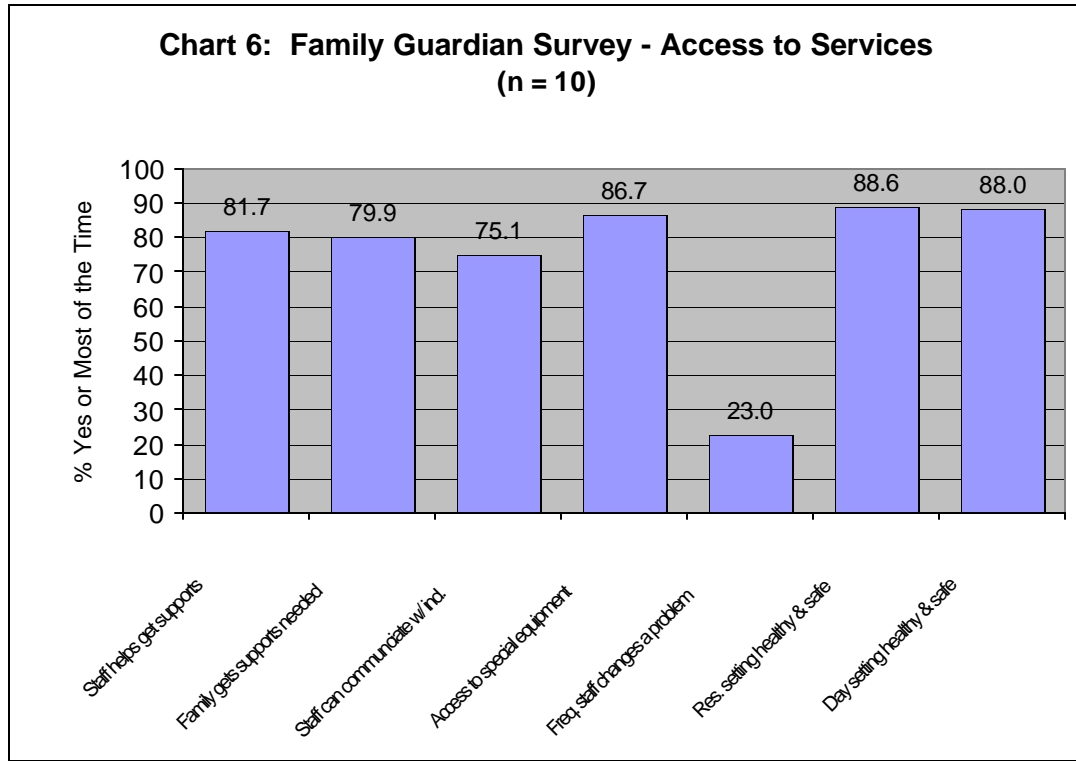


Table 17
Trends in Responses Above & Below State Average
Access to Services & Supports

State	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
AZ								0
CA-RCOC	↓		↓	↓				-3
HI	↓		↓	↓				-3
IN								0
MA								0
NC			↑↑		↓↓			0
PA								0
SC				↑	↑↑		↓	2
SD	↑							1
WY			↓		↑↑			1

Choice and Control

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

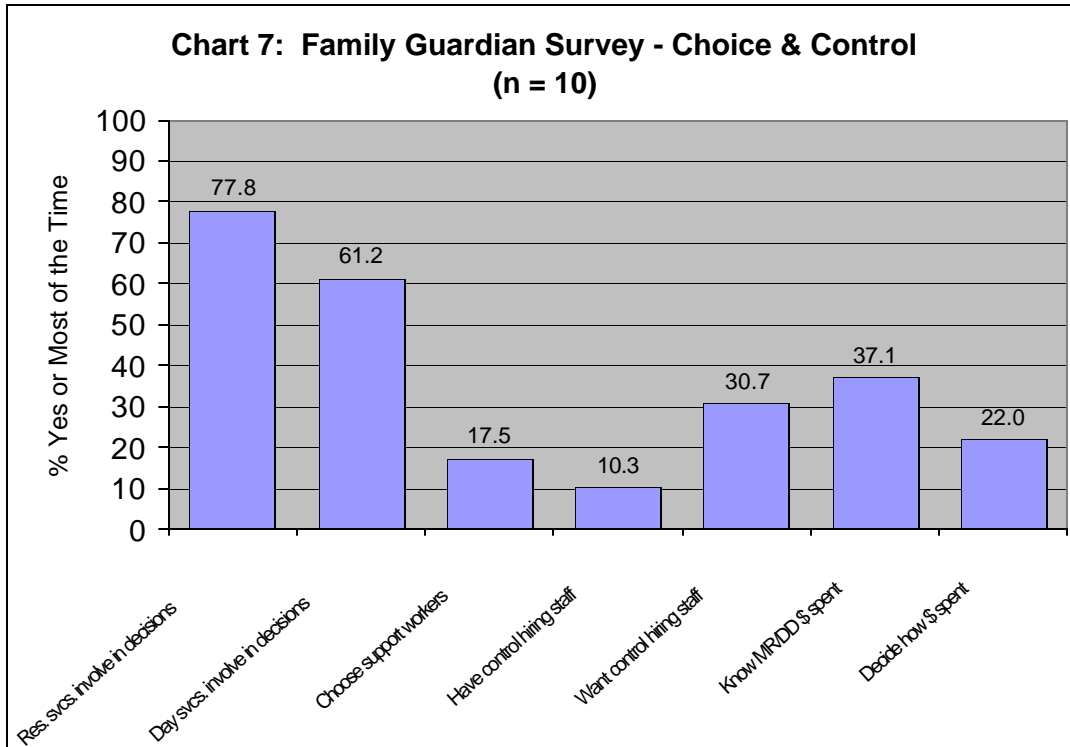


Table 18
Trends in Responses
Above & Below State Average
Choice & Control

State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Net Sum
AZ			↓			↑	↑	1
CA-RCOC		↓↓	↓			↓↓	↓	-6
HI			↑↑	↑↑	↑↑	↑↑	↑	9
IN		↓	↓			↓	↓	-4
MA								0
NC			↑	↑		↓		1
PA	↓		↓		↓	↓↓		-5
SC					↑↑	↓↓		0
SD				↓	↓↓			-3
WY			↑			↑↑	↑	4

Community Connections

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

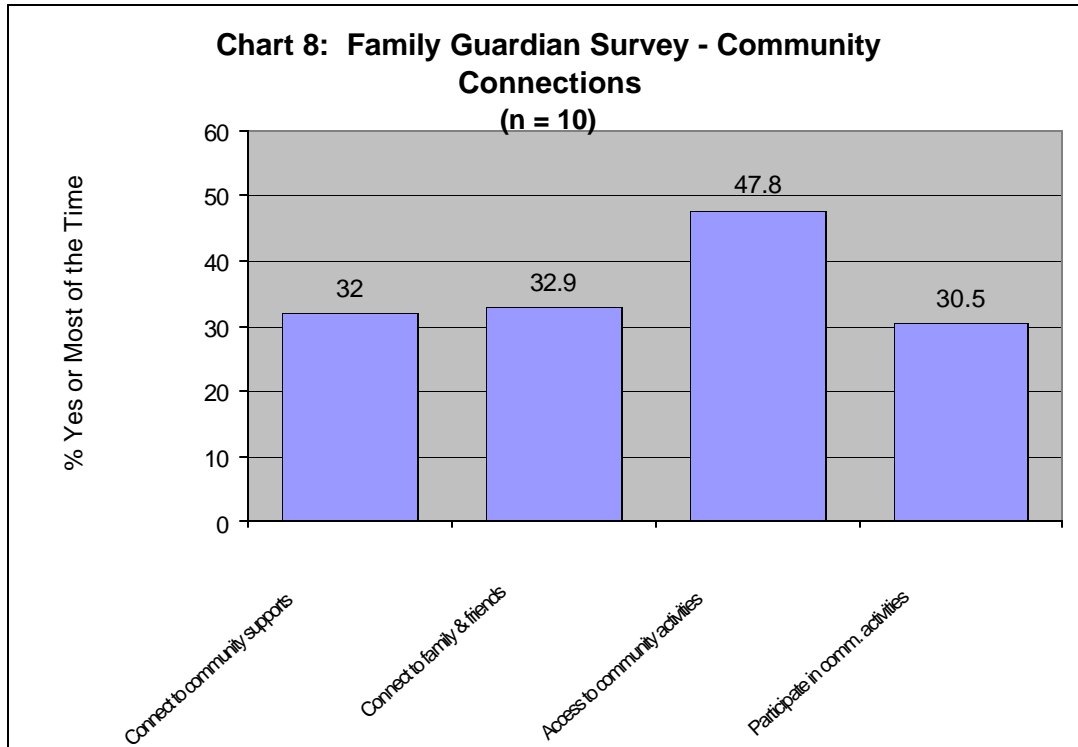


Table 19
Trends in Responses
Above & Below State Average
Community Connections

State	Q21	Q22	Q23	Q24	Net Sum
AZ		↑		↑	2
CA-RCOC	↓↓	↓↓	↓↓	↓↓	-8
HI		↓↓	↓		-3
IN					0
MA					0
NC	↑			↑	2
PA	↑				1
SC					0
SD	↑	↑	↑↑		4
WY					0

Satisfactions with Services and Supports & Outcomes for Families

- ◆ In South Dakota, responses to satisfaction with services and outcomes for families questions were generally above the overall state average. In Orange County, California and Hawaii, results were generally below the state average.

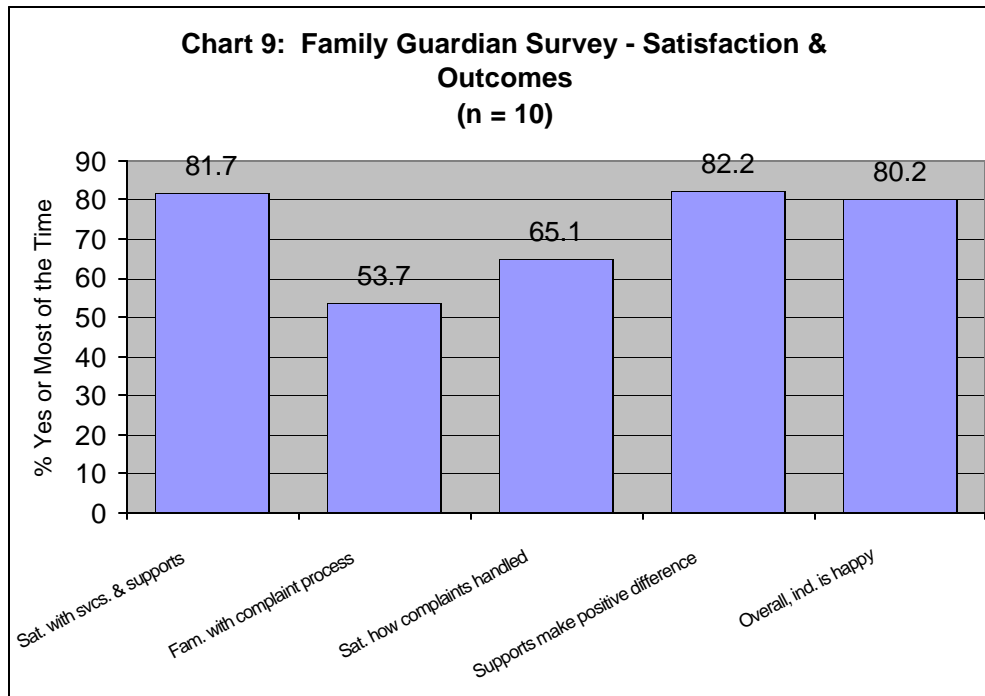


Table 20
Trends in Responses
Above & Below State Average
Satisfaction & Outcomes

State	Q25	Q26	Q27	Q28	Q29	Net Sum
AZ						0
CA-RCOC		↓↓	↓			-3
HI	↓	↓↓		↓		-4
IN						0
MA		↑				1
NC			↑↑			2
PA		↓				-1
SC			↓			-1
SD		↑↑	↑			3
WY		↑↑				2

Overall State Trends

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

Table 21 Overall Trends in Responses Above & Below State Average	
State	Total Sum
AZ	6
CA-RCOC	-23
HI	-1
IN	-5
MA	2
NC	5
PA	-8
SC	-1
SD	8
WY	11

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 Orange County California and some comments from Maine were incomplete – specifically, comments were cut off due to the nature of their database.

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 North Carolina, 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

Approximately 33% of survey respondents from Arizona wrote qualitative comments. These comments are summarized by theme below. Residential setting was the most frequently mentioned issue, followed by staff, and communication.

Residential Setting

The majority of people were satisfied with their family member's residential setting. Reasons for satisfaction included caring staff and good services.

"[Provider] has provided a home and living situation for my daughter J. which I consider very good to excellent."

"My brother has been in this home for approximately 6 months and his health has improved and [staff] is working with D. to accomplish tasks I believe are very important."

I feel that the [provider] has provided very good services to my son, throughout his 14 years stay at one of their group homes.

"The [provider] have faithful and caring I have been very pleased with the care and concern all the years that my cousin has been so well supervised by the many that have are in charge of him at home and at his work area."

"My daughter has wonderful care since moving to [school]. 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."

"The 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 training center at [city]. 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."

“Overall my daughter is doing better. There have been bad times during the times she has lived in a group home. Some of those could have been avoided if administration had listened to my objections. Presently it is better.”

A few people expressed dissatisfaction with their family member’s residential setting. Specific reasons included over-crowded settings, safety, and living conditions.

“The Division of Developmental Disabilities needs to set limits on how many clients can be served at one apartment setting.”

“My daughter gets hit regularly by one of the other two residents at her group home.”

“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.”

One concern mentioned by a few respondents was placement. People reported that their family member wanted to live in a different setting, but it was difficult to accommodate those needs.

“As of late she has demanded to come home to live. I let her come home quite often but I just can't hold up for an all time stay. I am 80 years old and tire out real fast.”

“My son has been away for almost 1 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 miss treated him at all. My son wants to come home and they won't let him.”

“The state tried to place my son in a foster home before I placed him at [provider]. The social worker apologized to me after he was placed there from the hospital. I kept him home for 6 years. He needed more care than I could give him medically.”

Staff

Several people were satisfied with staff. Specifically, they mentioned that staff were supportive, receptive to needs, and go out of their way to help their family member.

“The staff at the day program and the group home are very helpful and support her as much as possible.”

“I think the staff and home helpers are doing a good-even better than good for D. She is easy to live and work with if she has love and concern for her desires. She doesn't like people that push her to hard.”

“We had a wonderful house manager for years. She has moved to a new position at [center] but still takes an interest in my son.”

“Everyone turns themselves inside out to make life good for him. He has a 1:1 day staff because he has trouble in a group day setting.”

“The people we work with for C.'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 C.'s care to other care professionals who see him.”

"The staff that takes care of my son are very good. They love him take care of him take him places. You name it they do it. He has a wonderful staff at home and at work. Thank you all a whole lot!"

Many people were dissatisfied with the high amount of turnover. Turnover led to inconsistent care for their family members and also resulted in poorly trained and inexperienced staff. A few other respondents were dissatisfied with staff for reasons other than turnover.

"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."

"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."

"There are continuous changes in staff of the provider, so we never know who will be with our family member."

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

"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."

"Group home should hire people that have some knowledge of cooking."

Communication

Communication was a frequently mentioned issue. Multiple people stated that they were kept well informed and had good communication with staff and support coordinators.

"I stay in touch with the people at [provider] by telephone for any decisions."

"I am very satisfied with [provider]. They are always responsive to my concerns and complaints. We were involved for the first time with my son's plan last year. However this only occurred because we requested it."

"I appreciate and trust [name], 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."

"The support coordinator has always been supportive and stays in contact with us when the need arises, also the nurse for our family member does the same."

Some people were dissatisfied with communication, mainly because communication was not timely. A few people mentioned language barriers, one person mentioned poor communication between staff, and others sited a general lack of knowledge about services.

"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."

"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."

"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?"

"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)."

"I am not fully aware of the nature of her activities during the days spent at the [provider]."

"I would like to know how his Social Security 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 SS check. I have not seen any paper work on this for over a couple of years."

Overall Satisfaction with Services

In general, numerous people were satisfied with the services and supports that their family member received.

"I am very thankful to the [provider]. My son is happy, which takes tremendous worries off my mind."

"I would not change anything in the care of my son. I just pray it will always be there for him as well as the outstanding staff!"

"My daughter has been in the 'system' for approximately 15 years and even though the road she's traveled has had hills and valleys over-all the services that have been provided have been excellent."

"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. God bless you all."

"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."

"Overall the services received by my daughter meet her needs for her every day life. Overall, her placement and support has been excellent."

"This program has been wonderful at every level."

Although many people were satisfied with services overall, some people were not.

“There is way too much middle management. The quality of service gets lost. People say the right works but frequently do not know how to implement quality.”

“G. is a 51 year old young 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.”

“People with developmental disabilities need to have more choices given to them.”

Employment Services and Day Program

Several people were satisfied with their family member's employment/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 B.'s group home and is as well his employer at the day program where he works (and love's it) has done exemplary work in both instances. Their concern and care is pretty evident in their daily actions.”

“The day care program is top-notch.”

Health Services and Equipment

Health services were mentioned by a few individuals. Some people mentioned the need for dental care, while others needed physical therapy or medical equipment.

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

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

“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? Is there other places he can go to rehabilitate the usage of his legs?”

“A complaint was filed re: a motorized wheelchair and even went to court to no avail. D. was denied the proper cushion for her wheelchair even though it was requested by three different therapists and a doctor.”

“Wheelchair support is often slipshod or ineffective.”

Recreational Activities

Several people reported satisfaction with recreational and social activities.

“They take her to restaurants, swap meets and other outings.”

“We both go to church and she is so good, always happy. The staff takes good care of her socially.”

“Through the group home they are able to provide for many more activities and community involvement than I could ever do on my own.”

Support Coordination

For the most part, people were satisfied with their service coordinators. Specifically, they mentioned that their service coordinators were helpful, receptive, and supportive. A few people mentioned issues with turnover.

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

“G.'s supporter has only recently been assigned to his case. On the one occasion when we met with her, she was very helpful and receptive to our comments and concerns.”

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

“Case managers change a lot! They should make every effort to meet their client and legal guardian.”

“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 times.”

Funding and Budget Cuts

Several people had concerns about the way funds were spent. In addition, some people had concerns over budget cuts.

“Decisions are made for the use of funds in a poor way.”

“Continuing budget cuts make it very difficult to provide a good and happy living arrangement for these people.”

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

Approximately one-fourth of survey respondents from Hawaii wrote qualitative comments. These comments are summarized by theme below. The most frequently mentioned issues were case management, satisfaction with services, and dissatisfaction with services.

Case Management

Over half of all comments written were related to case management. Words respondents used to describe good case workers included: professional, helpful, experienced, concerned, understanding, goes out of her way, pay attention to family's needs, and dependable.

"We are very pleased with case manager's professional help and concern of/for health and development of our daughter."

"Case manager is always concerned and understanding. Easy to deal with."

"Our case manager is a special person. She goes out of her way to offer to pick me up when I don't have a way to the meetings (ISP). I feel very comfortable with her."

"Great program and great cooperation and assistance from case manager. Case management is doing a very good job!"

"We've been assigned several different case managers over the years but 2 of them really stand out. One was [name of case manager] and the current one is [name of case manager]. They both show us the true meaning of 'social worker' in that they really 'pay attention' to the family's needs and can be counted on to connect us with the services needed. I am extremely satisfied and grateful."

Several respondents were dissatisfied with case management services. Specifically, respondents commented on case manager turnover, large case loads, and lack of follow through.

"Our only complaint is that the turn over of case managers are so often. They just begin to know the person and family's needs and they're gone. I feel it is unfair to us as well as the case manager."

"Family member has been in a foster home for 1 year and within 2 year period – he had 3 case managers and a fourth one was going to be assigned to him until I requested that we do not want another one. We were just about getting acquainted and then we have to start all over again. We felt we were being shifted too many times. To date, manager needed to inform us of their decision."

"The case manager keeps changing – usually before I can even meet them – they don't know and don't care about their clients!"

"Changes in the staffing of case managers disrupts the relationship with the family members and the parent/guardian because it takes time for the case manager to get to know the family member's problems. Also the caseloads carried by the case managers also make it difficult to get together to resolve problems. However, my daughter and I have had excellent relations and results with the present case manager."

“Some ideas presented or suggested by the case manager are not followed up by her. Informed by case manager that funds can assist with various items but not told when or how long before money is available. Did not receive copy of annual ISP.”

Satisfaction with Services

Several Respondents indicated that they were satisfied with services.

“Our annual review is well done and complete. We appreciate everyone’s support and care.”

“After seeing him abused as a child by my father, I’m so pleased with the caring way that the State has handled my brother’s care. To me, you care about him more than all 11 members of our family have done recently.”

Dissatisfaction with Services

Several respondents indicated that they were dissatisfied with services.

“The ISP is great if everyone followed it. I am very dissatisfied with making a plan every year than having to argue each month to have it implemented. Frustrating! On paper it’s great, in practice it isn’t worth the paper it’s written on. Sorry but that’s the way it is. I still have to say that the State spends double the money caring for my grandson (and others) than it would cost if half that amount was given to help the client stay with the family.”

“The agency providing services would not allow certain goal, i.e. a specific diet and P.A. responsibility in keeping my son’s apartment in a clean and safe setting to maximize my son’s independence in living on his own.”

“One incident stands out. My brother was in the van coming home. He fell forward and bruised his face and leg. We tried to find out who was the driver. Was he driving fast? Was he strapped in? Or did they forget to strap him in? All they told my daughter and I was that they moved the driver to another location. No one gives us a good answer. It seems very frustrating.”

Home

A couple respondents indicated that they were dissatisfied with placement options for their family member.

“The past couple of months have been very difficult for my child. I’ve learned that there is NOT ENOUGH homes for a child with disability to be placed with a caregiver. There seems to be many homes for the elderly – why aren’t there enough homes for the disabled child or young adult?”

“I believe the group home manager needs more help – she has 5 residents to care for.”

Employment and Day Programs

A couple of respondents noted that they were dissatisfied with employment or day programs, or that annual reviews conflict with their work schedules.

“Need day program. My sister has been on waiting list for [agency].”

“Would like updates by phone once a quarter (every 3 months). Annual reviews are conducted at a time when it is not possible for guardians to attend. My occupation requires that I work during these hours.”

INDIANA

Approximately 47% of survey respondents from Indiana wrote qualitative comments. These comments are summarized by theme below. Respondents mentioned staff the most frequently, followed by home, satisfaction with services, and dissatisfaction with services.

Staff – Satisfied

Staff was the most frequently mentioned issue. Approximately the same number of respondents wrote that they were satisfied with staff as those who wrote that they were dissatisfied with staff. Respondents typically described good staff as: informative, helpful, caring, compassionate, going the extra mile, polite, professional, and competent.

“My brother is not social and does not converse as such. He uses grunts and sign language with a minimum of words. He has learned much from his care givers and is comfortable with them; I feel he is happy in his environment and I'm ever so grateful for the very special people who care for him.”

“The support staff are extremely helpful and caring. They (staff in group home) have made such a difference in D.'s life and in ours.”

“We are extremely pleased with the care and services provided by the staff at [provider]. They have always kept me informed and have provided our son with excellent care beyond what their job description expects.”

“I know I probably am going into more detail than I should but I just wanted special recognition for the staff person who assisted, and guided me in getting my brother placed in the group home. I spoke with [staff person] on the phone and he had such compassion and caring for these children with disabilities. I felt as I could see inside of this mans heart, and I haven't even met him. Maybe he has a love one with a disability, but his feelings and concern for these children is truly genuine and I could see that. It not very often you find a person with such integrity and devotion, and he does deserve a special thanks.”

“To date neither I, nor my brother-in-law have had any complaints with any of his staff. They always seem to be willing to go the extra mile to make sure he is comfortable and satisfied. And they keep me updated on a regular basis as to what is going on, and they always notify me when there are meetings or evaluations. The staff has always been very helpful. They genuinely care about my brother-in-law.”

“E. has improved a great deal at Group Home. He's more outgoing, communicates more via phone calls and loves his home. The caregivers always go above and beyond the call of duty for E. I am very thankful that he is able to live his life to the fullest capacity.”

“All the staff that has been in contact with my wife and myself have always been very polite and positive in their information to us about our daughter. [Staff] has always been a person to contact with any questions and has always been very knowledgeable, caring and professional. We really appreciate her information and her always keeping us informed about all aspect of our daughter's care and health.”

About half of the respondents were dissatisfied with staff. Common problems included: turnover, shortage of workers, inadequate training, and insufficient pay.

“Some staff think that they baby sit and don't need to do anything else. Staff needs to get people with disabilities to live as independent as they can. Sometimes state and federal dollars are wasted on people who don't and won't do their jobs. All these providers need to be checked out to make sure that they are doing their jobs and following through with the people.”

“At the few case planning meetings I have been invited too the staff always ask him, ‘What would make you happy?’ He has commented ‘having a house, getting married, etc.’ Staff then take these goals but in the real world those things don't just happen because we want them too. I worked long and hard and got college education (only one in my family to attend) before I earned the opportunity and responsibility to have a house. Staff often make it sound like You want it, you get it! They do not keep family informed.”

“A. is always in clothes that aren't hers, don't fit, or backward or just plain dirty. I have talked to staff many times about this, to no avail. Have also spoken to worker about this but nothing is ever done.”

“The younger newer staff are not mixed with older seasoned staff on some days and that is when I have concerns that some of the clients are not interacted with and the girls [staff] are friends and tend to chat among themselves and clients are left on their own.”

“The biggest problem seems to be finding competent help.”

“The residential staff has had many changes in the last 8 months and program structure and consistency has been a problem.”

“It seems there is a rapid turnover of support staff. This creates confusion for our daughter not knowing who to ask for help when dealing with health issues, apartment problems, transportation, job, money, etc. It takes time to build trust and an open line of communication, and then the support staff is changed.”

“In general services and plans for my sister have been impressive in the waiver program situation. Support staff for her 24 hr. supervision have really been the only headache/worry.”

“I feel that 8 people in a group home are too many. All their needs are not met. The group home is always short on staff. Many times on week-ends they are not staffed adequately and therefore unable to go anywhere.”

“I feel like there needs to be more training in Waiver Services. Staff have no idea what their role is to be. It seems to be more of a babysitting service.”

“Things are going fairly well for S. I still think that they key work in all of these homes is training, and more money as the staff proves themselves.”

“J. receives very good care most of the time but there needs to be more caregivers and higher pay for the caregivers. Some of the management people do very little work, don't

help the staff with the clients and don't spend any time with the clients. Most of the caregivers and aids are very wonderful, dedicated, hard working people.”

Home

Many respondents indicated that they were satisfied with the home environment including group homes, independent living, and residential. Specifically, several respondents indicated that their family member was happier in a group home, and had more independence.

“We are very satisfied with the Group Home.”

“My daughter has been at the [facility] for 36 years. I have been thankful for the changes in that time and I do thank the state for their interest and maintenance. She is in the [name] complex, is very clean and organized, the attendants are just like family, I call them my in-laws.”

“There is a wonderful organization in [town] where my sister resides, who takes her for outings, lunches, gatherings. I am so thankful for them!”

“[His] father and I are very pleased with his placement in his own apartment with staff support. We feel that he is much happier now and enjoys his support staff. [His] apartment is neat and clean. And his appearance is always clean and well coordinated. We are happy that some of his medications have been stopped or dosages lowered. Some bad behaviors have stopped and some greatly improved.”

“I realize [residential hospital] is a blessing for my sister to be in. They do the best they can and work on problems that are pointed out to them.”

“We feel the group home our daughter is in does a good job of providing a home like situation for her. She enjoys being in a group situation. My daughter M. is severely and profoundly developmentally disabled and non-verbal. She is happy most of the time. The group home where she is located is immaculate. It seems to me the staff works well with the residents.”

“My sister is in the best placement she has ever had; therefore she has a new normal life environment since she is in a group home. This placement has enhanced her life greatly.”

“By given the opportunity to live in a group home, my brother has been given a chance to live as independently as possible. This has been a great change in his life. We are thankful to all those who make this possible. At our age it would be very difficult to have B. return home. He's well and happy in his placement and it's a real blessing for us. “

“My aunt seems to be very satisfied and happy in her group home. It is the best thing that could have happened to her (over the state facility) she was in past years.”

Although a majority of respondents were satisfied with the home environment, several were dissatisfied. Specifically, respondents noted they were dissatisfied with the placement, the placement was unclean or needed repairs, and safety.

“My daughter has had several problems with support services since she moved out into community living. Such things as abandonment, living in a filthy environment. Not eating were planned meals. Not receiving assistance for ADL's. She has had agencies who have infringed upon her rights. Her Case manager and behavior manager are kind and very helpful. However the agencies who have provided in home supportive services have been terrible.”

“I'd like K. to be able to move out of her group home and their poor, [provider], day program, but she's on the waiting list for other wheelchair accessible group homes and the Medicaid Waiver.”

“There has been a decided diminution in the quality of care for my son, J., is receiving in some respects to health care. His group home in [city], IN is very carelessly run. My complaints are met with courtesy and then ignored.”

“Actually, I would like for D. too be in a home with maybe two or three others if that was possible. I wish he had a lot more freedom to go outside and shoot baskets, take walks, etc. He does not have that at all now. They say he must be supervised constantly and someone has to take him out if he goes out to get fresh air. Usually, there is not enough staff to be able to take him out-or if there is not enough staff there on duty they just don't take the time to take him out-unless they want to go out and sit for a while or smoke.

“We feel it's a money making service. Sometimes the decisions that are made are not to the clients benefit. We feel like the clients are not in a happy, clean environment, especially at this home [group home] there seems to be more lip service than action. Sometimes we feel we're told what they want us to hear, not always the facts. The house it's self needs repair.”

“My daughter is at [provider]. I feel she gets very good care. I am unhappy about her going to a group home, as I feel there won't be enough care givers to know if they are competent for caring for her in private, without others seeing how she is being cared for. But I have no choice.”

“My ward has had no other options for residential placement. Since the age of 12 he has lived in large institutional settings or nursing homes. The State of Indiana has violated the spirit of ADA and OBRA by ignoring individuals such as my ward. Now faced with the closing of the ICF-MR we are faced with a crisis. Where do these individuals go and how well has the state planned for such situations?”

“(She) has been on the Medicaid Waiver list for approximately 5 years or more. She is very appropriate for a DD Waiver slot. Her skills far exceed a group home environment.”

Satisfaction with Services

Several respondents indicated that they were satisfied with services.

“Your intervention in our son's life has made a very positive difference. We appreciate the services made available to him because they allow him to take control of his own life - he can function as a young man rather than just as a son. He doesn't need to depend on parents for validation of his choices - and that's important.”

“As recipients of services provided by [agency], our family feels very fortunate to have such a facility available to us. We have been involved with the services since its beginning in 1966 and have been very pleased with most all of the programs initiated by them. We are hopeful these sincere concerns and well-planned programs for the disabled will continue in the future.”

“I'm so appreciative of all the help! Thank you all.”

“All of the services provided for our daughter come from [provider] in Indiana. In all the years our daughter has received public funded services (since she was 18) none have approached our provider. Our seven years of association with [provider] have been outstanding. “

“I'm well pleased with the care my brother L. is receiving.”

“We deeply appreciate the services and attention that J. receives from the [provider]. We have no fault to find with the staff or administration. This is a great program and hope that these fine services continue.”

“I'm very happy and grateful with the services provided for my son. He is very independent and happy.”

Dissatisfaction with Services

Several respondents reported that they are dissatisfied with services.

“If they would keep [provider] open and use the money they're wasting on transition to fund [provider] everyone would be happy. We are satisfied with [provider]. Our daughter could not be in a better place and would not survive anywhere else. We would appreciate it if they would leave things alone.”

“I have several people at [provider]. I feel that the Medicaid waiver program will fall thru the cracks and these people who are being placed out will fall thru the systems' racks. There needs to be an institution that will provide 24 hour care for these people.”

“No, I am not happy with [provider] and the way they have handled some things concerning my uncle. I feel all they see is dollar signs.”

“The state of Indiana has had too little, too late. Programs for the severely handicapped have been dismal and reactive to crisis rather than proactive planning. There are extremely limited choices and even poorer communication from the local FSSA office on what choice might be available.”

“I am unhappy to hear that she'll no longer be able to stay at her present location due to changes in her waiver services from DD to foster care. This will have a tremendous negative impact on her. She had been living alone in an apartment. To reduce costs, she wanted to move in with her staff which is more cost effective. During the time she's lived with staff, her maladaptive behaviors have been zero. If she must leave her present situation due to budget costs, I can almost guarantee her behaviors will increase causing the state to pay an even greater amount than before due to her potential hospitalization.”

"It is important in these times of reduced budgets that priority are made to keep the group homes staffed to provide safety, meals, sanitary and assistance with living. The current program is not perfect, but it is providing a most valuable service to the community as a whole and to our family. The group home concept is a most valuable asset to our family member. Let's not lose it!"

Employment

Several respondents wrote comments about employment issues. A couple respondents were generally satisfied with employment.

"We are very pleased with the agency that provides day employment. The staff there seem to know how to deal with and work with our daughter."

A few respondents indicated that they were dissatisfied with employment.

"Family Member's personal and physical needs are mostly taken care of at the group home. He only has the use of one arm and no use of his legs, so he is confined to a wheel chair. He needs something to do during the day, because he gets very bored. It is very hard to find a job for him because of his limitations, and he could only work for about three hours before getting tired. J. is very nice looking and has a great sense of humor. Everyone likes him. He loves to be around people and have a good time. He volunteers at a Hospice delivering mail for 2-3 hrs. a week. He would make a good greeter. He is able to make cassettes from CD's and records and program a VCR. He has also run paper through a shredder. He doesn't need a job to earn money. He would gladly volunteer."

"B. would like to do something other than push carts at Wal-Mart, but no other position seems to be open right now (or over) when he can get to work. He probably won't complain to anyone about this. He may need a job coach again for help."

"The only thing I am unhappy with is [agencies] decision to discontinue trying to get outside work for those clients in the workshop who are able to do piece work. It makes a very long boring day for the clients and I feel could lead to other problems."

"Mom would like for T. to get a job-there hasn't been much done with this. He is getting very bored and depressed."

"She is being asked to find employment within the community. She does not have the social skills necessary for most employment situations. She is also very set in her ways and doesn't want to change. This situation doesn't make good sense to me. I am also not sure all accommodations for disabled persons were made for her in her job situation."

Health Care

A few respondents wrote comments about health care issues, including insurance, dental care, and medical care.

"S. would have died if he hadn't been placed in [provider]. He went without medical care for many years because he seemed to always fall through the cracks of one agency to

another. In 12 years of having him at home we only left him twice and both times were a disaster, because of medical bills being placed on our credit record we cannot get conventional bank loans. We had to pay 21% interest rate not because of anything else but the medical bills, when everyone else gets a rate of 5.5% Its not fair that we have been penalized time and time again for trying to keep him home as long as we did. Not only was it difficult to be a normal family but it seems were still being punished for trying our best. I've seen many children get the help only because they have divorced parents. If a child has a Dad at home he gets no help. It's wrong that he is the one who suffered because his family was intact. The main reason he went to [provider] was so he could receive medical care, he wasn't entitled to if he remained at home. I think it should be against the law to put bills on our credit report because it makes the family pay more for a home or an auto and then can't put that money to feed or cloth, and take care of the family much less pay the medical bills on the rest of the family. We dropped the medical insurance from my husband's employer this year in order to pay on our medical bills. Yet we know they will still keep coming. We hope they will stop when he is 18 or will they?"

"I was very angry about my sister's dental work. I presumed her dental work would be cleaning and filling, only to find they have pulled out most of her teeth and the front ones in particular - with out consulting me. I found out the reasoning when I went to a Care Plan Meeting, never having complained of a toothache - I can't help but wonder if such drastic work was really necessary - or was it because no one was there to object - and it meant a larger payment."

"Family member's family MD sometimes doesn't seem as concerned as he should - since she can't tell us how she feels."

"I would like to know why [provider] could not call 911 when S. fell at the nursing home, and hit his head hard. It took 1and 1/2 hours for the ambulance to get to him, causing so much damage I thought he was going to die four times. He also tells me they do not wash him up on days he doesn't get a shower. They never brush his teeth. I always took him to the dentist, and he had good teeth."

Recreation Activities

A few respondents wrote comments about recreational activities, most indicated that their family member needed more recreational and socialization activities.

"I would like to see him go to more functions with people like himself so he can get more friends besides family. He needs this."

"She really needs some activities in community in during thing to help herself."

"So far M. hasn't received to OK too start finding community activities or other groups due to lack of funding."

Communication

Several respondents wrote comments about communication. Important aspects of communication included: informing guardians about health or other problems of their family member, providing information about services, and a lack of communication.

“One area of improvement I feel is helping parents of newly diagnosed individuals seek out services for them. It's the most common concern I hear expressed from parents- it's a very frustrating and lonely process.”

“The staff has been generally working together, as much as possible. If and when I have concerns, they are ready to hear me out, and we usually work through them together.”

“The staff is very efficient in helping her with the things she needs. I get information about her on a regular basis. They keep me informed of what is happening with her.”

“Because I live out of town I am rarely contacted. The only contacts are extreme emergencies.”

“They used to call me and ask me if things will be all right to do. The people at the group home used to call me and now they don't. I have to call them.”

“My number one complaint is that my phone calls are not returned.”

“There needs to be more communicating between staff and staff and advocates.”

“Usually decisions are made by staff and they are faithful to inform me when invited to a planning meeting. It was obvious the Real Meeting had already taken place.”

Case Management – Satisfied

A few respondents wrote comments pertaining to case management. Some indicated that they were satisfied with case management services. Respondents described good case managers as concerned, takes hands-on approach, effective, cooperative, and receptive to input from guardian.

“Our daughter's independent case manager is excellent! She has a true concern for her consumers and takes a hands-on approach for their care and support. Without her help and knowledge, we would be in trouble.”

“His case worker and home manager are effective and cooperative in helping him to live a productive happy life in the new Medicaid waiver home.”

“Over the years I have found the caseworkers willing to work with and for my son. They have been receptive to all my suggestions and complaints.”

In contrast a couple respondents indicated that they were dissatisfied with case management services. Specific problems included: turnover and lack of communication.

“She did have a case worker that contacted me always, but now there is a new one I seldom hear from.”

That we can have her home every other Sunday - all day. (Client's) first 3 years at the home - had the same manager, which was good. Since that time it has been constant change.”

General Well-Being – Hygiene

Several respondents indicated that general well-being was an area of concern. In particular, respondents noted hygiene, poor nutrition, and lack of exercise, and safety as problems.

“A. is always in clothes that aren't hers, don't fit, or backward or just plain dirty. I have talked to staff many times about this, to no avail.”

“Often when I have picked up M., she has had wet pants. She has a problem with wetting her pants during the day and with bed wetting. She needs to be reminded to use the restroom often. The last time I picked her up, her pants were soaked, no one seemed to notice, when I went to her room to help her change, and she had no diapers.”

“Our main concern for our son is the continual permission for him to smoke. Second-hand smoke is also made available by his room-mate; an incessant pipe smoker.”

“If the family member is already thin more attention should be given to their dietary needs and they should be offered food they like and that is nourishing.”

“I would like to see more physical exercise to strengthen her legs.”

“I had intended on sending this out 3 weeks ago but events in my person's life have changed my opinion of the day services he receives. There have been 3 incidents in the last 2 weeks. One involving him finding and consuming a potentially life threatening item. The next is an unexplained broken digit and recently being hit by another consumer. There have also been reports of his undergarments not being changed in a reasonable amount of time. Our case manager and our residential services provider are looking into providing safe programming in his residential setting than the day programs.”

“It seems that my daughter gets injured often these past few months. I have asked the facility to change her program room so that she's with residents with fewer behavioral problems. In over a week's time, they still have not put her in a different room. I'm very unhappy about the delay. My daughter's safety and happiness is very important to me. It's hard enough that she must live some place other than her home and having to constantly worry about her safety makes it harder.”

“[She] has been hurt many times while in [large ICF-MR facility] we request being notified each time this happens. Our daughter is a resident of [large ICF-MR].”

“When my family member was injured by another resident, I wasn't happy with the outcome. The one who kicked my member wasn't moved. She was given medication to control her. It didn't happen again, thank God. I think she has been moved now.”

MASSACHUSETTS

Approximately half of survey respondents from Massachusetts wrote qualitative comments. These comments are summarized by theme below. Home environment was the most frequently mentioned issue followed by staff, case management, satisfaction with services and dissatisfaction with services.

Home

The home environment was mentioned by the greatest number of respondents. Approximately the same number of respondents were satisfied with the home environment as were dissatisfied. Respondents frequently mentioned that their family member is placed in a residential or group home. A couple respondents indicated that they needed more support for their family member—in an institution instead of a group home. Also, family members who were satisfied often mentioned that the atmosphere is “family like” or “home like” or that staff are good, house is neat, clean, quality staff, several respondents mentioned that their family member is in a family environment, not a group home, and a few respondents mentioned a court decision that impacted quality of care in a state institution.

“My daughter is very happy where she is and the residential setting is ideal for her. They are quick to respond to her medical needs. The open door policy is wonderful as you can get an ideal picture of what is happening. The care for her in the same manner I would if I were with her.”

“J. lives in a homelike setting and seems to be happy with the staff, and roommates. As far as I can tell she is getting all the services she needs at this time.”

“He has been at the residence since he was 37 years old. Until then he lived at home; where we traveled many miles to get help for him. He is very well and contented and we can visit him at any time.”

“My sister is in a group home. It is the best possible environment for her. She is among her peers and has a supportive staff.”

“C. has been at [agency] since she was 14 months old. In all the time that she has been there we have never been dissatisfied with the way she was cared for. She is always very clean, well dressed and very happy. We are very satisfied with the care and love that C. receives there. We hope to be able to keep her at [agency] because we feel she would never get such good care anywhere else.”

“The state school is a very good school. My daughter would not be good in a support home.”

“Since M. has been at [agency] he has improved measurable from over what he was at another agency. He is better able to take care of his personal needs and to enjoy his surroundings.”

“My daughter has been in a group home for almost two years. She has adjusted well and seems happy and seems to be more grown-up and independent. It’s a great home and the 3 other girls with her are great they all get along well.”

“Speaking for our daughter’s welfare, happiness and living in a group home. Her family is most happy and grateful for all that is done to make her life as normal as possible. In appreciation for all past and present services to our daughter and her family.”

“The facility is always spotless and the care providers go out of their way to make it a happy well organized home. Everyone there is compassionate and take special care with the residents. I am completely satisfied with my son’s care and services and feel the providers are exceptional people.”

“I am fully satisfied with the care and attention my sister is getting at the house and I do not worry about her not being happy and content with the way she is living. I usually go once a week to visit her and I am pleased with the way she is dressed and fed and I see as improvement in her since she has been at the house and with all who are there to take care of her.”

“D. has been in a group home setting for about 8 years. I am very pleased with her continued progress. She seems happier with environment and people that support her.”

“My family member is doing much better in the smaller setting as she does get individual care, maybe not the best all the time, but more than I can do for her. She seems happy where she is ‘comfortable surroundings’ and that is what matters most. The [agency] is a very well run, clean and important part of our life. I hope and pray Gov. Romney keeps it open and well financed.

“My daughter gets very good service in the house she is in. I see her whenever I need to, just a phone call is all I need. I could not have found a better person to care for her than the people who take care of my daughter. Thank you for a fine placement and care for her. No regrets, keep up the fine work.”

“I am the legal guardian of a 40+ year old woman with severe physical and mental disabilities. She lives in a group home where her quality of life is maximized by the staff and environment she resides in.... I am very pleased and confident in the care received.”

“My daughter lives in her own home with the primary caregiver people and is doing very well. She is extremely happy and close to her family.”

“Since my brother has relocated from a state-run school/hospital into a group home, he has blossomed and thrived like no other period in his life. His group home is a beautiful home.

I am impressed with the care my son receives at the facility where he lives. The staff are caring, compassionate individuals. The quality of medical and therapeutic services are, in my opinion, superior. My son seems very happy. Because of his severe mental and physical disabilities, he is limited in the area of community involvement. However, the facility makes an outstanding effort to provide him with opportunities to go out on trips to the community within his ability. Despite his severe limitations, I believe my son has a good quality of life.”

“My daughter is very happy in the home she resides in.”

“Since I am now a single parent with no relatives, this program has been a godsend. I know that when I go she will continue to be cared for in an environment in which she is very happy.”

“My brother has been a resident of the [institution] for most of his life. Since the completion of the Federal Case and Judge Tauro’s intervention, under the guidance of Superintendent Nick D’Alusio, the patients remaining at that institution have received wonderful care. The staff is very caring. Now at 75 years, and having been in the same environment for most of his life, I would not like to see him, or others who have spend a lifetime there, removed to unfamiliar surroundings,. A building at the institution should be designated to elderly DMR patients. There is a hospital on the premises that gives immediate and good care. I know that if the patients there were to be sent to the communities, they would not survive or be happy. I think it has been a big mistake to send mentally retarded patients to halfway houses. They are not happy there and do not get care as they do at [the institution].”

“My son is very lucky to be in his group home which is 20 minutes away from his real home. I can see him every other day or every second day. He looks good, he eats good, his behavior is great and we’re starting to wean off the helmet which is a dream for us. He loves to go out and always seems happy.”

“We are very happy with the placement of our daughter in a group home. We would never want her in a vendor operated home.”

“Our son has been in a local group home for 7 years after being transferred from the [school]. We are just so glad that the transfer happened. Our son gets wonderful care by a caring staff and a great administrative staff. My wife and I cannot say enough good things about the house our son resides in. We go to the group home about 2 or 3 times a week. “

“Knowing that life is not perfect (understatement) overall, my husband and I are quite pleased in the way our daughter has been cared for and monitored. The fact that we can walk into her facility at any time, with no prior announcement, says a lot!”

“Our son is happy in the residential group home he’s in and without all his extremely needful services, he would definitely not have developed into a positive and productive adult that he is now.”

Other respondents reported that they were dissatisfied with the home environment. Frequently mentioned issues were inappropriate placement, dissatisfaction with placement, lack of placements, cleanliness issues, problems with vendor homes, safety concerns, and staff who do not speak English.

“I feel P. is very inappropriately placed. He has been diagnosed with Autism. For years, I have been trying to place him in a group home with fewer clients. He is currently living with seven more adults. I as his mother and guardian feel P. is regressing in his current environment. He has had many falls and injuries that sometimes no one seems to know what happened. P. had done so well at [agency] before moving to Lexington. He was hiking, swimming, roller-blading, bowling. He was doing great. All of this he has lost. He is now very aggressive. He uses language that I know he has been spoken to in

rough terms. It is a constant source of worry to me for the last five or six years. With the proper setting P. would do very well.”

“My child has cerebral palsy and I think that some of your group homes should also be geared towards that group of the population and not just the mentally retarded. Even though he is with your agency, I feel that he is somewhat left out. I don’t think that the group home that he is in is fully equipped with items that may be helpful to him (other seating besides wheelchair etc.). And also that the other clients are not as mentally aware as he is, and to me that seems to be a problem. If not for the staff there would be no one to talk to him.”

“After years of not being on medicine, it was recommended T. be put on Celexa. Shortly thereafter, when we spoke with in, he would be crying or angry or fixated on some injustice in his life. Through his own undoing/verbal threats, he was removed from an excellent family situation and placed in a group home with somewhat violent, non-verbal adults. Things went downhill with T. The service provider had T. evaluated to see if he was just verbalizing his threats or was actually dangerous. When things got beyond endurable, we insisted his medication stop. Within days, T. was happy and able to handle his day-to-day frustrations. Six months have gone by and the evaluations have never been completed. We don’t know what to do. Our son is in a living limbo. Does DMR have any course of action we should follow? Is there something more we could do to help T.? His ‘temporary’ living/placement is unacceptable.”

“Not all people with MR can live in the community and the trend in Massachusetts is for community placement. The success of mildly retarded people placed in the community has been used to justify moves of more severely retarded that have multiple disabilities and who need a higher level of care. The situation is quite different for one who has the mental age of a six month old or requires around the clock medical care because of seizures or other disabilities. Distinctions must be acknowledged and caution taken when dealing with the lives of these medically fragile people. Please support and save our state schools for the severely retarded.”

“Sometimes I feel that the [provider] is very unrealistic in that they feel that people who need nurturing environments/family should be independent and this puts their clients at risk for injury. After dealing with DMR for 24 years, I don’t understand why some providers offer med-certified personnel to those clients who are otherwise fairly self-sufficient enough to live alone, and other absolutely will not offer this service. This forces some high-functioning clients into group homes (or similar settings) which is a definite step backward for them and promotes even more dependency.”

“My main problem with the group homes is that they have become a babysitting service. They do not participate in any activities in the community. They are not even given a vacation away from the home supposedly due to funds – even though we are willing to pay for them. The turnover is outrageous and they all they do is watch TV. There is not positive support from the staff in the group home. There is not training of staff. Many are from other countries and are not familiar with activities out there. The group home provider does not want to spend a dime on these young adults. There are not enough penalties given to help correct the situation. When looking for a group home they promise you the world. Only to later turn away when you think of changing group homes you are told there is nothing available out there. I could go on and on but nothing will change so why bother.”

"In our situation we believe providers through DMR cannot provide the services needed for our family member, because they are restricting services under the umbrella of 'privacy' or least restrictive environment'. Our son needs day-to-day, hour to hour structure but DMR is not committed to that level of care or at least they have not advised us, if that level of care is available in the community we believe our son is bored in his current program, due to lack of structure, unbelievable turnover in staff and management (20 changes in house manager and 18 changes in direct care staff in 3 years). Can't fault the staff who are in perpetual training mode. Do you think 3 plus years is long enough for a provider, who continues to open new residences, to motivate folks to stay? The agency provides a safe and healthy environment for my brother, where he can express himself and be assured of support. It has had a profound impact on my brother's quality of life."

"Our family member has been placed in jeopardy numerous times by being in under supervised situations with dangerous residents. The care provided is custodial at best, with caretakers who are insufficiently trained and managed. The quality of services has degraded continually over the past 35 years. The independent vendor system needs to be completely re-evaluated and perhaps scrapped altogether. State-run community homes have a much better reputation for quality of care and stability of staff."

"The program has deteriorated greatly over the 25 years that D. has received community residential services. In my opinion, he is no longer treated as a valued human being at his residence."

"My son was placed in a behavioral unit in 1996, supposedly for a short-term stay. He is still there and the DMR support for return to the community setting has been lacking. They constantly refer to fiscal constraints when the state is paying a much larger fee for his present placement. His unit has recommended his release for many years all to no avail. Initially our DMR coordinator was very involved but over the past two years we have had very little contact with the department unless we initiate it. We have recently contacted the commissioner who has been helpful in evaluating the present situation. We hope it will result in a positive conclusion to my son's present placement."

"J. always received good service – but it's becoming difficult to care for him at home – but a regular nursing home isn't the answer either. It's so overwhelming at times."

"It's been a hard year for us as there have been many changes in S.'s life. He's now with the [provider] and it seems hard for them to get good managers and to get answers and plans for visits at our home and going to church to seem really hard to get done because of staffing problems. It can be very aggravating and at times you feel like you're hitting your head against a brick wall as you have to keep addressing the same things."

"The residential part of his life at times has a lot to be desired i.e. – safety – house environment too often having plumbing problems. Safety – snow removal is not properly done (should be pulled away from doors, house, gates); changing staff due to people leaving for higher paying jobs; change of staff is leaning toward non-English speaking people – this is harmful to the individuals in that what little communication they have (verbal) is being lost; middle and upper management do not address the needs of the staff as much as they should."

"I think overall my daughter lives in a safe place, however, the house is in critical need of repair, it isn't clean and my comments about this to the staff of the house are overlooked. They say the landlord will not co-operate in the repairs that need to be done. The front stairs are broken and dangerous! At my age, (65) I need to know that my daughter has everything she needs to be safe and happy."

"The other major complaint is the appearances of some of these residential home looks and smells. Why can't there be a crackdown of some of these homes. I think you will find a lot of waste. The individuals that are forced to live away from home deserve the best possible care that we can provide. Let them keep some of their dignity."

My experience with DMR is that is way to restrictive in its thinking there are several young adults with my daughter's syndrome who could live in a group home together. To benefit these people it would seem that caring for the clients from across various agencies/regions could be helpful. I am also applaud by the current status of many families who have had their children were at home and how as young adults they are not eligible for residential placements at age 22 and over. Raising a child with multiple handicaps and MR is at best tiring for a family. It is the states responsibility to provide residential support for those who choose it so that parents and their adult children continue to live independent healthy lives.

Staff

Staff issues were a frequently mentioned topic. Approximately the same number of respondents indicated that they were satisfied with staff as those who reported that they were dissatisfied. Words used to describe staff included: caring, friendly, attentive, dedicated, concerned, excellent caregivers, well trained, responsible, helpful, respectful, supportive, outstanding, excellent, and compassionate.

"The staff is friendly kind and attentive to her needs. Overall I am very pleased with the staff and their courteous and dedicated service."

"I feel her caretakers are part of my family. I love them all."

"The service is great and so are the workers. I have been able to revisit my sister the last 2 years and have always found the staff to be helpful and kind to us and it was an unexpected visit and m sister was well taken care of. I am very pleased with the services she is receiving."

"I would not want my daughter to be moved to any other facility. She gets excellent care and appropriate programs provided by dedicated, well-trained, under-paid staff."

"My brother is very happy in his group home and his staff is stable and very caring. We're grateful for all the state has done for him and us."

"My daughter lives in a group home where her quality of life is maximized by the staff and environment she resides in.... I am very pleased and confident in the care received."

"The staff at the home have always been supportive and kind and we enjoy meeting these people."

“The staff at [agency] that also work with D. are very good and are always trying to teach him new things to do. They’re always very helpful when I go and see D.”

“I can not say enough positive things regarding the staff at where E. resides. They treat E. and the other residents as if they were their own family members. The group home is always clean and everyone there seems to be very happy. E. has made tremendous progress in many areas, such as organizational skills, maintaining his weight, and showing his maturity.”

Some respondents were dissatisfied with staff. Common problems included: staff substitutes, staff who speak little or no English, staff turnover, shortage of staff, inadequate training, and low pay.

“Also there is a problem with floats. Some don’t have enough experience with clients in that apartment, which has left clients vulnerable—bruises and not properly feed—they are sent there when some one is off work out on vacation or they send some worker out of their own apt. to go to another apartment. It would be better for familiar workers to remain in their own apartment where they are familiar with their own clients.”

“Staff changes are very different for our daughter – wages are usually a factor along with benefits. When there is a decrease in staff, safety and behavioral factors are a concern. I would like to see professional nurses giving medications rather than regular staff. Through the community have services available—the lack of staff to support the needs—prevent the residents from getting them.”

“Also, we need American born workers (direct care) in our community residences and this will happen only when direct care wages are increase as to attract more college education people in this field. I have found in many residences the staff doesn’t speak understandable English and I wonder how the disabled (who have speech difficulty) understand the staff. I am a parent and I have great difficulty communicating and understanding staff at times.”

“DMR has been completely ineffective in monitoring and correcting the poor (unacceptable) performance of the independent vendors in charge of the residential programs. The turnover is so frequent that most visits who new faces as direct care providers. There appears to be no organization within the residence and no training. Staff members do not know the schedules of the residents, and are not familiar with their individual needs.”

“Staff are not always attentive to daily log books, with the result that lots of problems go unnoticed and one is always dealing with the issue of staff not always being able to communicate with us.”

“His house staff is wonderful. The big problem is that direct care salaries are not nearly adequate for the responsibilities. Good workers who leave are so hard to replace. Staff turnover is a big problem for our son.”

“Our biggest concern in the constant change in staff which leads to much anxiety frustration and fear for the disabled person. Never sure who is going to be there. One other concern is the lack of understanding and therefore treatment of the individual needs especially emotionally. More training I believe would help.”

"I feel the biggest problem in DMR service is the frequent turnover of staff and lack of properly trained staff who have an understanding of persons with MR. This is probably due to the very low pay scale which prevents recruiting qualified personnel."

"Generally speaking, staff have been great! Due to cutbacks they can only do as much and when staff are cut. Safety issues become a big concern. Why do the most vulnerable among us have to suffer?"

"Adequate staffing is essential to providing services. Our daughter did not have adequate staff and was frequently left in her room. With more staff, comes more incentive to interact."

Case Management

Case management was a frequently mentioned topic. More respondents who mentioned case management were satisfied with services than dissatisfied. Respondents described good case managers as: available when needed, listens, compassionate, attentive, helpful, professionalism, patience, supportive, and informative.

"We have only great things to say about our case manager. He is always there when needed. When something is needed or there seems to be a problem, my daughter calls him and they talk about it. It is either worked out on the phone, and he talks to mgr of the home as he sets up a meeting with my daughter."

"I am very happy with my sister's service coordinator. She is always on top of things and is quick to return my calls. She always answers my questions and makes me feel that my sister is in very good hands."

"My family member's service coordinator makes herself available and is always willing to consider and investigate new ideas. Above all, she listens. Your agency is indeed fortunate to have H. as an employee."

"K. was our service coordinator for several years. He was always compassionate, attentive and helpful."

"DMR is lucky to have the dedicated, knowledgeable and most of all effective A. who has always been able to guide our family member through the system, especially with regard to the maze of social security, court, and everyday issues that are such a road block to obtaining and maintaining the services that are even basic to care for someone with developmental disability. Without this caring dedication our family member would be lost in the 'maze'."

"I feel that the program that my sister is in is the best one for her. Her service coordinator seems to always work for the best's interests of my sister."

"K. has been our service coordinator for years. She has always shown complete professionalism as well as patience and complete helpfulness regarding K,. She has always been available to our family regarding any questions or needs we had to address for this we are very grateful."

"We currently have an outstanding social worker, named [case manager's name], who is our service coordinator. He knows my family member (my brother) and helps my mother see him on a regular basis. She does not drive and would need to wait for family members to take her to see my brother otherwise."

"The service coordinator has been especially helpful in getting programs and housing for our family member, I would like to congratulate our service coordinator, for the outstanding services she has provided and for her constant availability to us whenever we have called."

Some respondents were dissatisfied with case management services. Problems included: turnover, shortage of workers, and lack of availability, and infrequent contact with family.

"I only wish that she could have a caseworker that will be with her for a longer period of time because change confuses and disappoints her. I hope these comments will help to remedy this ongoing problem."

"Service coordinators need to pay more attention to the individuals needs. Need to resist more often and get involved with community functions that their individuals are involved in. Cut some of the paper work at the ISP's are so repetitive every year it's almost the same. Goals are not met and objectives are not worked on. The ISP system is a big farce what I mean is a lot of it is not the truth."

"In all honesty, I filled this out with the agency providing the services. They are fabulous but the DMR coordinators is so scarce we only see or speak to him once a year at the evaluation. All arrangements and decisions are coordinated with the agency directly. Takes months to forward proper paperwork and callbacks are weeks. The coordinator at DMR is nice but rather useless!"

"Because of DMR cutbacks in service coordinators, my son's coordinator only works part time and is not always available. If I leave a message, she usually gets back to me in a few days, or the following week."

"The service coordinator assigned to my brother, T., is never available to reach by phone. When I leave messages, she seldom returns my calls. It takes forever to receive T.'s ISP in the mail. Last one took 8 months to get. Am I happy? NO!"

"Service Coordinator has changed for the second or third time in the past year. I don't know who it is at this time. I usually hear from our service coordinator about once a year at ISP meeting. The issue I have had with DMR service coordination involves the revolving CSC that my individual has in any given year. It changes so often, I never get to know the person before another person comes on board."

Satisfaction with Services

Several respondents mentioned that they were satisfied with services.

"The service administered by [agency] (my sister's support group) for the past ten years has been excellent, and, in time, the Department of Mental Retardation of the Commonwealth, has also been wonderful. Not only in the material necessary needs that

my sister's condition demands, but also, in the compassionate and human way they respond."

"We feel very comfortable with the services we have received over the years, and are grateful for the committed DMR Team. The DMR Commissioner's Reports, and his dedication to helping people, in our Commonwealth, who have special needs."

"We are very please with the services provide to D. Never has there been a problem that has not been taken care of immediately, and done lovingly for the greatest good for D. and her family."

"Very happy with everything in general!"

"I am very happy with all the services and people who have been involved in supporting and helping with my son. It is very comforting knowing that he is getting all the care that he does and that he's happy. It is obvious that he enjoys his surroundings and all the folks that care for him."

"I am very satisfied with my grandson's care. I never worry about him because I know, personally, how well he is provided for."

"I am so grateful for the wonderful services provided for my daughter. Fifteen months ago my husband, her father, left our family—a devastating situation for all. Everyone has gone over and above to help my whole family. I couldn't have done it without them."

Dissatisfaction with Services

A number of respondents reported that they were dissatisfied with services.

"Have had many problems with DMR Legal Service Department for over 2 years no action has been taken for my family member due to paralegal's initial mistake. Finally a lawyer was assigned and he has not returned phone calls or paperwork to us since January 2002. Unbelievable incompetence!"

"I'm disturbed with reports that serious employee discipline problems are overturned by arbitrators, costing the Commonwealth thousands and ten's of thousands of dollars. Those should be used to pay other providers and/or benefit of the clients! This must be stopped, otherwise other cuts in budget should be looked upon with a jaundiced eye! The relationship between DMR and ARC are too cozy. My family member was subjected to sexual abuse, with police intervention, and DMR swept the matter under the rug. DMR acts to defend "The System" and clients like my brother pay the price. The ISP process is a joke. DMR willingly accepts ARC's excuses, there is no accountability for the tax dollars flowing from DMR to provider agencies."

"The downfall or deficiencies in the system are generally related to policy, regulations of decisions made by the people you never meet, which this survey does not address, for example, agencies providing services must do more and more paperwork, etc. with the same dollars allocated to individuals and yet continue to provide the direct care necessary."

"I would like to see services – such as speech therapy, physical therapy, occupational and recreational therapy available. Again, they have been discontinued for some time."

"Agency supports and encourages family members, friends and guardians to participate in the design of care and support of loved ones who reside at [agency]. Were not clear, and are concerned about advocacy for our loved one, after were gone, because we initiate most contacts. This issue needs your attention.

"How can they close centers for the retarded when there are over two thousand people in the community waiting and, very old parents who may not be around long? Are we to take them with us when we go? Group homes are staffed with people who have training to work at Burger King! Services does not take care of foster children who can speak. What is going to happen to those who cannot even speak?"

"[Agency] – very, very, very rarely informs any of the family members/legal guardian of changes in staff/policies, etc. Very, Very disappointed in [agency].

"We are going through a difficult period with my daughter at this time. I am feeling very frustrated and helpless in trying to get support services."

"There seems to be great stress on 'human rights' in DMR – so much so that safety and common sense take a back seat. It may be our son's right to choose what he wears, but no hat or boots in cold weather puts him in a situation where he will be uncomfortable, also, it is his right to decide not to go on an outing with his group, but to be home alone is not safe. These 'rights' (and there are many more examples) need to be tempered with a little more intelligence on the part of staff. It is okay to say no. Limits and guidelines are useful and necessary. There are a lot of times when our living situation for our son is more of a custodial situation than a real home. The guys spend too much time alone in their rooms watching TV than being together and doing things and learning. There have been many staff people who are horribly lazy and the good ones seem to leave quickly because people with ideas are deemed to be trouble."

"The system is layered with too many chiefs doing very little. A disproportionate percentage of DMR resources are directed to an over bloated bureaucracy and not enough trickles down to the people that the system is in place to serve. Why are consumers and families not aware of the access to Flexible Funding. Is it available for consumers who may need financial assistance. The consumer who resides with myself and family could use some assistance if Flexible Funding is available."

"My family member could receive better serviced if 'Vendor Agencies' were given the same \$\$ as 'State Operated' agencies."

Funding and Budget Cuts

Several respondents mentioned funding and budget cuts. Specifically, respondents reported that they were concerned the quality and/or quantity of services would be reduced due to funding and budget cuts.

"His world is about to change yet again, as our governor cuts budgets and closes institutions and facilities that provide good quality care and programs for a huge number of people with a broad range of disabilities. [Agency] provides many services for our

loved ones—from the dental care thru therapeutic pool which is a wonderful place for all people with disabilities and families. This is where my son ‘works’ in his day program. When this complex closes, many people with disabilities will be left with little or no services. The severely disabled residents have no where else to go---there are no nursing facilities available to care for them. When the closes, there is no therapeutic pool in existence for the disabled and their families. When the pool closes, my son will lose his day program---his job and his expanded world filled with people and friends. Where does the governor propose he go? Where does the governor propose any of this population go for services? Do we lose the funding for day programs because the programs and facilities were axed?”

“My fear is that budget cuts will start to directly affect him and all the other people who so desperately need this level of services.”

“The biggest concern is the cutbacks of money each year.”

“I believe budget cuts have impacted some of his staff needs, i.e., changes, staff fill-ins from one house to another, etc.”

“Services particularly recreational have been cut severely in the past, and I suppose more cuts will happen now.”

“Obviously, our biggest concern regarding our daughter’s well-being is funding. With constant cuts in the budget and Human Services always being one of the departments to be cut, I can’t help but feel the right people are not informed and aware of what is needed for this segment of our society. It continues to be a major issues...one in which has not been addressed correctly! As parents and advocates for our daughter, we have continually gone the extra mile to impress upon the legislature how great the need is. It seems to fall on deaf ears!”

“With the budget cuts taking place in the state, my mother and I are concerned with P.’s quality of care.”

“My daughter is in a wonderfully supportive family environment. As my husband and I age and have health issues, we worry that cutbacks may disrupt her life (and ours) and that our daughter will find herself moved away from the family she has bonded with.”

“The quality of services has improved dramatically over the years (especially since the implementation if Judge Tauro’s order). My family and I are apprehensive that under present Gov. (Mitt Romney) that the quality of services to these residents will diminish because of his overly ambitious plans to cut.”

General Well Being

A few respondents reported that they had concerns about the hygiene, health of their family member, or safety. In particular, poor eating habits and lack of exercise were mentioned by several respondents.

“General appearance, general grooming , sharing haircuts long toenails which sometime curled in, skin not clean, ed sheets might not seem change for a while. Light bulbs not replaced even after requested. Has gained approx 30 lbs or so since 22 years of age

from lack of activities and exercise. There doesn't seem to be an effort to get him involved in healthy community outing or day trips other than occasional monies, Dunkin Donuts, McDonalds, van rides into Boston and food shopping."

"New personnel mostly seem nonplussed by the task. Where B. likes to remain in the background and remain solitary. His overall appearance may lack a hair cut, and nails trimmed. Brushing without prompts. Putting on clean clothes each day. He has the ability to do these things he just needs the prompts. I feel he fades into the background and therefore he is overlooked. He requires prompts, especially in the hygiene area."

"However, I feel that there should be more active recreation, more walking."

"One issue that I've been a bit frustrated with is my sister's significant weight gain (20 lbs. And she's 4'7") since she moved to a new group home in 2001 and trying to get her new residential program to provide less caloric foods for her and get her involved in some kind of exercise program."

Employment and Day Programs

A few respondents wrote comments about employment and day program issues.

"Overall, in regards to my son, I have been very pleased and happy with the support system my son receives. From his residence (there is stunning progress) to his workshop where he is in a valuable and satisfied employee."

"We are very satisfied with the day habilitation program."

"He has been out of a workshop situation for over 10 years and because the Agency hired by DMR 3 years ago to find him a job did nothing. He was put back a workshop below his functioning ability and became overly agressed. Now I am told there is no way to find a job for him and coach him for a few weeks (no funding). And so we are back at square one once again."

"Also, it was recommended T. have a job coach but there was no funding for one. The fiscal constraints are tough and getting tougher for social services. We finally intervened and got T. a job at an exclusive golf club. While seasonally employed, T. was very happy. The prospects for rehire in the spring look good...but couldn't DMR or the service provider have helped T. secure employment?"

Health Care

A few respondents reported that health issues, such as lack of dental care, lack of providers, were a problem.

"I would like to see something done with S.'s top teeth. She had beautiful teeth and all of a sudden they were gone. Something needs to be done about her weight."

"Our member was supposed to receive at least 16 hours of nursing a day, however this is not the case and at time this is of great concern to us. At the present time, I am having great difficulty in working with my present program director and this makes all discussions that much more frustrating. We do, however, feel that in spite of staffing

and nursing problems our loved one receives very good care and we are very active in his life so we would see if things are not well. Our concern is that our member has a G-tube and if he should need just aspirin he would be sent to E.R. if there is no nurse on site. Often times he is sent alone to the E.R.”

“My son’s health needs are not always addressed in a timely manner. Re: appointments; blood work ups which are essential given the level o medication he takes; dental appointments not made.”

Recreational Activities

A few respondents mentioned recreational activities.

“Although money for programs appear to be threatened---I believe more money for more recreation and staff for 1 on 1 coverage on an outside activity would be a good thing.”

“Very severely handicapped individuals live in this home and without enough staff it is difficult for any individuals to get out in the community. Thank heavens an excellent physical therapist is there once a week and has achieved unbelievable results with almost all 8 clients. She is also an excellent resource for parents and staff.”

“The other complaint that we always hear is lack of recreation. Some staff just don’t seem to be motivated enough to have this population interact with the rest of the world.”

“Okay, regarding community activities, but activities in the group home need to be more innovative and creative. The television set seems to be the main activity filled with uninteresting programs, on at least interest.”

Communication

In general, most respondents appear to be dissatisfied with communication.

“Our overall experience in the last 5 years has been a good one. Our only concern comes with some communication issues and the ever-present problem of retaining quality staff.”

“There was a recent change in service providers. Currently I’m very satisfied, but have little communication. Would like a little more input to things that are happening in my son’s life. Prior to this change, I had a very non-supportive service provider that I would have to continuously call and not get called back, and not follow thru on stuff.”

“My father and I don’t even know who our DMR service coordinator is at this time. The only contact we’ve ever had, has been at an annual meeting at my brother Rene’s group home to discuss his ISP.... But, both my dad and I feel we’d like to be better informed about what’s happening.”

“My grandmother and father died in December. At no time was there any communication from my brother’s service coordinator. I pick up my brother once a month and he is taken care of very well. I would appreciate some communication from DMH. We have an ISP once a year and I still haven’t receive a copy from last year. “

"I appreciate receiving the annual review and would like very much to attend his annual review every year. However, I haven't been notified ahead of time, so have not been attending the review. Would appreciate being notified ahead of time about date, time, place of annual review and, as guardian, I think I should be."

"Communication is the biggest drawback in system. Letting guardians know how client is being helped and how we can better help and provide services that may be needed. More communication from direct care persons to inform us about extra activities."

"My family member is profoundly deaf and legally blind in addition to her mental retardation. She has received services from DMR for many years. She has never had a service coordinator who could communicate with her through sign language, which is her primary means of communication. I find this to be a serious flaw in the DMR system. Sign language proficiency seems to be viewed as (nice, but not necessary) for service coordinators. I disagree. If a service coordinator is assigned to a deaf consumer they should be given the time and resources to learn sign languages and it should be a requirement."

"Situation is okay for my son now, however I had a difficult time getting DMR and DMG to work effectively for my son who also has a mental illness."

A couple respondents indicated that they were satisfied with communication.

"Whenever I have any questions his caregivers keep in touch with me."

"The service coordinator has always been available for me, so it would be difficult for me to say how many times we have had contact. All I can say is, he is always available."

Transition Issues

A couple respondents reported that they were concerned about transition issues.

"I am currently in the process of transition from school to a group home. It's been about five months since he's turned 22. The biggest problem has been being able to find homes and day programs that match his needs. I feel that the department regional offices do not coordinate well together. The service coordinator is not very familiar with options available outside their area office. Also, I have not been able to do any of the leg work (research) myself since I haven't been able to find out who the vendors are. We're almost to point of transition. The home has been selected and we've narrowed down the day program. Should be finished in a month. This transition process has taken longer than anticipated. Better coordination among area offices may have expedited the process."

"We have been unable to obtain any list or directory of statewide services, programs or options. All services are only thought of as "local," without any context of statewide best programs for particular disabilities. We are approaching the "turning 22" age for our son. We would like to pick the best program in the state for his particular disabilities, regardless of location or service provider. This mystifies DMR. We have been told to pick a service company (provider) and then work within a location to find the program fit, which is silly. Why can't we access statewide lists, access quality assessment measure

and find the best program for his needs? Why are DMR reps only familiar with resources in a geographic location?"

NORTH CAROLINA

Approximately half of survey respondents from North Carolina wrote qualitative comments. These comments are summarized by theme below. Respondents most frequently mentioned home issues, followed by satisfaction with services, staff issues, and dissatisfaction with services.

Home – Satisfied

Respondents noted several issues related to the home environment. Several people mentioned that their family member was satisfied with their home setting. In contrast, several people also indicated that they were dissatisfied with their home setting, or were seeking residential or community placement outside of the home.

“I am very pleased with the group home that M. is staying at. He is taken to work, everyday. He gets to go on trips (to the beach etc.) to the stores, shopping. He is feed well. I think he is very pleased with the support he gets and the family type home he is in. He also looks forward everyday going to work. I really believe M. would not be able to make it if he were not in the position to go to work everyday, or his routine were to be changed. The group home, his work and friends gives him a will to exist, to live to be the great person that he is.”

“I would like to comment on the wonderful home my daughter lives in. She has grown so much in the four years she has been there. This group home is most definitely an asset to our community and is an outstanding model for other group homes. Its staff is the best I’ve ever had contact with and their dedication and support are constant.”

“I feel that our ward gets the care he needs with the [agency]. Staff has been courteous, helpful. The home is always clean, neat, orderly. It is a safe environment. Staff does good job with input, communication and the nursing service is good.”

“I am so thankful for the care H. gets in this home. I have very few complaints. The care is so much better than I could give her, and she seems to be happy most of the time.”

“I feel very fortunate to have my son in a group home where the primary goal of all the personnel employed is the well being of my son and the other guys in the home. They consistently demonstrate a caring, compassionate, professional attitude, and go to great lengths to insure that the guys are happy, healthy, and integrated into the larger community at every opportunity.”

“My husband and I have always been completely happy with the care and progress our son has made since he has been at [agency]. I don’t know of another environment that could possibly give our son the same care and structure that has enabled him to learn more than I or anything in the community (we did try a group home in our home town and were completely dissatisfied with care and there was absolutely no structure) could give him as [agency]. He is happy and so are we.”

“Better attention needs to be given to my son’s personal appearance (grooming, shaving daily, hair, etc.) and care of his clothing. Clothing is often wrinkled (not ironed) and inappropriate for the weather. His room needs to be kept cleaner. Bedding appropriate for the season. At the present time there is not a blanket on his bed or a top sheet- only

a thin bedspread for cover (February). I personally provided flannel sheets and blankets but they are not being used. Staff should be trained on how to make a bed, especially when client wets the bed. TV programs selected by staff are not appropriate. At least, we don't want our son to watch them (Example: Jerry Springer). We included in our son's treatment plan that he is not to watch programs with sex scenes, violence, bad language, etc. We want our son to live in a healthy, safe environment. Are there any guidelines for group homes to follow? My son is the only one of his race in the home (consumers and staff). We are for integration, but we don't think a consumer should be isolated from their race completely (5 consumers in home). It appears to us that the staff is not adequately monitored and supervised."

"I would like to see my daughter have more therapy and movable activity in this facility, and have more screening by caseworker. In order to get back to group home where she stayed 11 years. She had brain surgery's for seizures."

"My son was only supposed to be in the nursing home until they found an apartment or group home. He has now been in the home almost 3 years. He now has taken in the behavior of the other residence who are all elderly and most have Alzheimer's. This is my number one complaint. My son is 34 years old TBI patient who used to be very motivated now all he wants to do is stay in bed."

"J. is a head injury-has short term memory- also disabilities with walking I have tried to find a suitable environment in the area but there doesn't seem to be any for female TBI's J. is receiving help from Section 8 but I could not find any housing in a safe neighborhood so I purchased a house near mine."

"There are not nearly enough places in North Carolina for people like our daughter to live as independently as they can. Institutions are not the answer, but we can find answers by looking at other states. Virginia and Kentucky, for example, have university-like settings where the residents can live in dormitory or clustered home settings, attend classes, go to work, and participate in gardening for the residents. Many states have apartment with a roommate. They can cook and dine in the apartment or eat together in the common dining room. There are endless possibilities but North Carolina must begin to think outside the box."

"When another group home is build please let me know so my family member can get into it close to my house."

Overall Satisfaction with Services

Satisfaction with services was a frequently mentioned topic. In particular, respondents mentioned satisfaction with group homes, residential facilities, satisfaction with staff or case managers, employment, or satisfied with services in general.

"The most important thing to me is that my sister is happy and well cared for. She is! I am thankful for the prompt assistance you have given to me whenever I needed it."

"I am quite happy with the way my daughter is being cared for. She is happy and that satisfies me. I can talk to those in charge make suggestions at any time. There is compliance as long as something I want doesn't interfere with rules and regulation of the state."

"We are very pleased with the care and support given our brother. His progress is good. The support/residential staffs are great in working with him and in communicating with him and the family regarding day-to-day activities, employment and family/community activities."

"As a rule, I am satisfied with the service my son receives. On occasion, little things do come up that I'm not happy about, but usually these are resolved to my satisfaction "

"I am very satisfied with the services that my child receives. I know she is getting the best of help I thank God every for that because of ours family don't have that kind of help to help some that is different from all the rest of us. I see that she learns more every day from them I can truly say she is getting the best of help from them."

"Our county is one of the fortunate counties to establish a workshop for its citizens with developmental disabilities. This is a program that is a plus for this area, without it we would be at a disadvantage as it is key to improving the life of our DD residents. My prayers are that our government will continue to support our communities with DD. This is what communities are all about supporting each other and not building more institution to place our DD family members in. With day help like the workshop this gives the caretaker a break, and family member are able to live at home."

"My son is a high functioning autistic adult who works full time and lives in a townhouse owned by [provider] with another high functioning autistic adult. They both pay rent and participate in social and developmental activities sponsored by [agencies] and other organizations. We are educated consumers of support services in this community. We have sought out and we receive excellent services."

"I feel that my family member receives all the support from services that she currently needs. I am satisfied with the support and overall assistance she receives."

"I feel that my family member is well taken care of."

"I am very grateful as a parent to be able to work with my special daughter. It makes my life and the life of my daughter so much better. I hope and pray that we will never loose this opportunity."

Staff

Staff was a frequently mentioned issue. Approximately half of respondents who wrote about this topic were satisfied. Respondents described good staff as: dedicated, supportive, caring, courteous, helpful, compassionate, professional, friendly, helpful, attentive, kind, and skilled.

"The group home's staff is the best I've ever had contact with and their dedication and support are constant."

"My stepson lost his father in December. The overall support of staff and management was wonderful. They continue to give him extra emotional support and understanding. They also helped the rest of the family during a very difficult time. Most of the staff that I have observed really seems to have special feelings for the clients in the home. So to most of them it is not just a job."

“The support/residential staffs are great in working with him and in communicating with him and the family re: day-to-day activities, employment and family/community activities.”

“The facility is always clean, the staff friendly and helpful, the staff attentive to her needs.”

The staff who serve our B. have always been so kind and skilled in working with him.”

Some respondents indicated that they are dissatisfied with staff services. Specific problems noted included: turnover, shortage of workers, insufficient training, and under paid.

“We have found that the goals that are chosen not followed through with by staff daily care in group home setting.”

“Some caregivers fail to properly respect the resident as an adult, thinking person. Resident is ‘talk down’ to and disciplined; is not accepted as that person really is.”

“I am very concerned about the changing the staff. They are almost always good and caring, but not paid enough and over worked or part time (CBI-CISS) and therefore not on call for questions/problems. The service system is frightening in its unreliability.”

“Staff turnover in the group home and in CAP services periodically presents a problem to my cousin. Sometimes staff seem more concerned about freedom to choose (especially related to food) than my cousin’s overall health (particularly related to weight gain).”

“One of the problems we’ve encountered is the turnover of staff in her group home. We’ve had problems with staff not doing the job, stealing from the clients and dissatisfied with salaries/benefits and leaving.”

“Staff (and supervisors) are in general poorly trained and lacking in motivation to provide more than ‘just adequate’ services. State funding for services has remained static or actually been reduced for several years. If North Carolina aims to provide quality services to DD people, it will have to get more realistic about providing funds.”

“Not enough training of staff in developmental disabilities- characteristics, needs, and methods of working with this population. Need a better education!”

Dissatisfaction with Services or Agencies

Several respondents indicated that they were dissatisfied with services or had inadequate services. Issues included: a lack of transportation to services, problems with the provider network, overall dissatisfaction, lack of placement options, service eligibility restrictions,

“This is a comment on the provider network: Providers have too much political lobby! They are able to generally control rates for services and this often holds the local area programs financially hostage. The state has not supported area programs when providers are of poor quality. The state is hesitant to pull license of providers who violate regulations and standards of care all too often the local area program is left to deal with these providers without support from the state who has issued the license. This allows poor providers to continue to operate. Providers are also being allowed to reduce

the number of licensed beds in community group homes. This does two things: It allows the provide to charge higher rates for placements and reduces the number of available beds for disable persons seeking community placement. In a time of growing waitlist this is unfair and the situations, which create, class action lawsuits!”

“Moreover, I do not believe that DSS has provided quality assistance for my son for any extended period of time during the 10 plus years of his association with your organization. He has been neglected, directed into inappropriate programs (both residential and community based), placed in footer arrangements operated by unqualified and unsupervised persons, used by providers to accumulate paid hours without rendering services, and DSS has failed to assist in and supervise attainment of employment or job skills. Pleas for action, complaints, and requests for involvement have been ignored, dismissed, or declined.”

“In general, I am very satisfied with my daughter’s service plan. The problem lies in a major disconnect between it and reality. She is placed in a group home run by a for-profit agency with a nearly constant staff turnover. Little effort is made to connect with community services –transportation problems? There is I suppose, a contract the agency has to guarantee services. I am in regular touch with the situation and have discovered major lapses in adequate meals, medication, transportation, and etc. from time to time. I have filed a formal grievance in the past-not at all easy to carry through!”

“I am totally unhappy with services from Division for Blind and would like my sister served by Voc. Rehab. Anytime I make inquiries I’m told she has to stay with Division for Blind because of her poor eyesight. I would also like our group home and workshop to be person centered rather than manager or instructor centered.”

“There are so many services out there, but none that will help him or us. Either it is because he works or I have too much income. That stinks. J. made a total of \$11,630.00 last year. If you all think you can survive on your own then please try it!! It’s as though, because J. is self sufficient, no one cares, or wants to help to improve his life. We wish that we were knowledgeable enough to teach J. what he needs to get his license. But we have run into obstacles with that also. For J. to get his license would render him to become more independent. That would be awesome for him. Then maybe he could get a job that would help him to survive on his own. We have come so close to getting services from you only to have it and quicker than it got started to have to go through all this again makes us very leaky. All we want is to help to get him a driver’s license, but we know that will most likely never happen. These are battles that I have fought since his birth and I will continue, with or without your help.”

“Whenever I have asked for support services for my daughter, I am always told ‘there’s no money’. Since she graduated from school in 1994 she has become a hermit and agoraphobic.”

“Service providers in the community are inconsistent, difficult to find PT, OT, ST on a regular basis. C. has had four different ST in two years. Community medical services are poor with regard to no knowledge of needs or how to work with DD consumers.”

“We, as guardians, believe that the family and disabled family members should have flexibility to select and or create programs that best serve the disabled individual and

that the money should follow the client. The family should therefore be told what money is available for the clients' assistance."

Case Management

Several respondents mentioned case management as an issue. Approximately half of the respondents who wrote comments on this issue were satisfied.

"We have a very good case manager. I am involved in all writing of treatment plans and she reports pertinent information to me."

"My family member's social worker is very helpful."

A few respondents were dissatisfied with case management services.

"We are pleased with the current support staff worker, but displeased with the case manager. She is unprepared, unprofessional, and unavailable. Our disabled family member's job status is a big concern. She was unrealistically enticed into leaving her job with no plan for another job. It has been almost two years."

"I am particularly disappointed in the way my family was treated by the Single-Portal Coordinator from our County. We were ignored, put off, and lied to by her. She expressed a 'don't care' attitude when my family was in a huge crisis and my mother was dying."

"It would be very helpful to have the same case manager for longer than 3 months! They change too much."

Funding and Budget Cuts

Several respondents wrote comments regarding funding and budget cuts.

"I am satisfied with the group home my son K. is in, however we are desperately in need of funding. I have sent letters and called many of my 'elected officials' in Washington, D.C. pleading for help."

"Families are concerned about services-funding changes or limitations. My daughter will require on going, long-term services-supports, supervision, training- how will the system provide services for an aging population?"

"Service system is frightening in its unreliability. Good agencies are disappearing because of funding follies. Someone in Ral./Wash. needs to wakeup and take hold of this teetering system before it implodes."

"We are aging parents (69) and concerned about the decrease in CAP waiver funding. I was just told today that supportive employment may be deleted. Our daughter has had a two- hour one day a week job that has meant so very much to her. She has missed one time, due to illness, in the 16-17 months she's worked on this job. I despair to think of the blow not being able to go to the job would mean to her."

Employment

A few respondents wrote comments about employment issues. Most respondents were dissatisfied with these services.

“He also looks forward everyday going to work. I really believe M. would not be able to make it if he were not in the position to go to work everyday, or his routine were to be changed.”

“I have a complaint about my son. He was taken from his job at the workshop in where he worked, for no reason at all, and the job were given to another I just don’t think this is fair and I haven’t rested with this since it was done.”

“I know the workshop is not perfect but it serves a purpose. So until something better is created –some folks are introduced to employment in the community through the workshop. Some folks will never have employment in the community. So beef up the workshop and keep a program available for these folks. “

“Another problem we’ve had is securing meaningful employment for her. When the local workshop was managed by the county she made a decent wage and worked to achieve her goal. She wanted to work in one of the enclaves that left the workshop each day to work for a large hotel/convention center. She got the job and made decent wages. The workshop was taken over by a private firm out of [city] who immediately asked local employers for more money-not to cover the clients but to cover their own expenses. As a result, our daughter lost her job and was stuck in the workshop for the next two years with her wages going from \$200-400 per month to \$30-70 per month. It was only with the help of the Association for Retarded Citizens that she secured the good job she has now. North Carolina needs to get into the business of helping the disabled and the mentally challenged become successful. They can be productive members of the community if we just provide the opportunities.”

Health Care

A few respondents mentioned health care issues. Specifically, respondents mentioned issues related to insurance, dental care, and medical care.

“Lack of dental care for Medicaid.”

“We worry about him being on a lot of medication.”

“When D. was in MH group homes, they didn’t seem to know how to deal with mental health episodes. This I found strange. These homes wanted a couch potato who went nowhere or did anything. Very interesting and frustrating. D.is in a DD home now but the mental health problems are still an issue.”

“It is my opinion as well as my other siblings’ that the Mental Health Services have caused deterioration to my mother’s physical health. Due to the drugs they feel are necessary for her mental health. They drugs they insist she takes are the types of drugs you would give to a violent mentally retarded individual. She is not violent nor is she mentally retarded. She had a brain injury at 15 years old. This causes her to be slower mentally. She doesn’t look to the future, only at the present day. I do not think that

these things warrant the type of drugs the Mental Health is insisting that she takes every day of her life.”.

“These mental health services have been helpful and supportive to us as a family.”

“Community medical services are poor with regard to no knowledge of needs or how to work with DD consumers.”

Recreation Activities

A few respondents wrote comments regarding recreational activities for their family member. A few respondents indicated that they were satisfied with these services.

“M. gets to go on trips (to the beach etc.) to the stores, shopping. He is feed well. I think he is very pleased with the support he gets and the family type home he is in.”

“Our case manager has increased recreation by swimming at the local pool, she has made friends.”

Some respondents indicated that they were dissatisfied with recreational services.

“I would like to see my family member more involved in community activities. Most of the activities he is involved in are what staff wants to do. Example: running personal errors.”

“Weekends and free evenings usually are filled with some unnecessary, and frequently undesirable, (walk again through WalMart again) or some similar tiring chore. My daughter wants and needs rest and hobby time just to be at home.”

“My son is now moving to another county. Their Parks and Recreation Department does not provide any programs. I see this as a need. All communities need to provide activities for their citizens with special needs.”

Communication – Satisfied

Several respondents commented on communication issues.

“If anything happens they always call to let us know the problem.”

“We do not know what a case manager is, or if we have one.”

“It would be helpful if there was a class or forum describing services available, who is eligible, and how to go about implementing them into the lives of the DD consumer. I am upset because of the lack of information that is present due to the state’s way of handling services.”

“Occasionally trying to get information is like interviewing the Keystone Cops, but with a large organization I guess that is to be expected.”

“My family member receiving services is deaf, cannot read lips, and communicates totally using sign language. My major issue is with staff support workers having very minimum, or no, skill or knowledge of any basic language sign language. It is very unpleasant feeling knowing that my family member has to go thru daily living of

communicating by having to try to understand. The gestures or made up signs of each of the support workers.”

General Well Being

A few respondents wrote comments related to general well being, such as hygiene, health, and safety.

“Group homes should be smoke free. We do not feel smoking is a healthy environment.”

“The group home is not providing as healthy a food choice as it could. Many of the men are overweight. The opportunity to provide healthy, low fat meals is there it’s just not done.”

“Also, my daughter’s weight has become a health issue. She has gained approximately 100 pounds.”

“Sometimes staff seem more concerned about freedom to choose (especially related to food) than my cousin’s overall health (particularly related to weight gain).”

“Somehow or some way he was abused. They don’t know how it happen. It happen on Sunday, and I was not called until Wednesday at 4:00. We went up there drove all night got a room, went over a got J. for the day. The staff was told not to talk to us about this. We went to Social Service, Police Department, two ER Rooms, but we got no answer. After the investigation, they told us there was no abuse, or exploited, but you don’t get bruises as big as a hard ball from your knees to up all around your private parts, not one but many, and not blue but some black. They moved him out of that unit.”

Crisis Services

A couple respondents noted issues pertaining to crisis services.

“In certain counties they do not have all night agencies that needs to be available in case of an emergency.”

“Our major worry is D. is only 1 year mentally and nonverbal. If he needs to go to the hospital they will send him in an ambulance alone. A worker does not go with him and stay until we (father and mother) arrive. Someone should be on call for this kind of emergency. D. is not the only one who should be accompanied to the hospital. The only other thing is when visiting D. there are times I would like to speak to someone before I leave and usually there is no one at the desk. They are busy in other rooms. We understand it would be too costly to have someone at the desk all the time but there should be some way of getting their attention.”

Transportation – Dissatisfied

A couple respondents mentioned that they were dissatisfied with transportation services.

“Unable to get transportation for day program in [city] NC.”

"The only complaint or dissatisfaction we have is his ride to the workshop. He has to pay a transportation fee and sometimes it is more than he makes at the workshop. A year ago we were told that he should get enough money for his ride to the workshop but so far we have not seen that happen."

Transition Issues

One respondent noted transition issues.

"My daughter will be graduating in June 2003. For the very first time in her life, she is in a very good class and living in a very good home. Before either the class has been good or the home has been good but never both. I really do not know what the future will be like come June but I am hopeful that she will go to another good program. Change is difficult to everyone especially when one has been under the protection of the school system for so long. However, my daughter is now an adult entering this big world. I believe with continued support and services from you and me she will be able to make the best out of life."

PENNSYLVANIA

Approximately 35% of survey respondents from Pennsylvania wrote qualitative comments. These comments are summarized by theme below. Residential setting was the most frequently mentioned issue, followed by staff, and communication.

Residential Setting

Multiple people mentioned that they were satisfied with their family member's residential setting. Numerous people mentioned that their family member was happy with his or her residential setting. Several people specifically mentioned positive transitions from institutions to the community. Other reasons for satisfaction included location, caring staff, and cleanliness of the environment.

"We are very satisfied with the care our daughter is receiving in her current placement. She is nearby and we can see her often. She seems happy."

"I just wanted to say how happy we are to have P. moved to the new home. I know he was excited about it so were we to have him right around the corner."

"We could not ask for anything more – he's so happy where he is living."

"Our daughter lives in a home where she is the only client. She gets all of the attention from the staff which makes her very happy."

"S.'s improvement since leaving [center] and going into community placement has been nothing short of miraculous!"

"Life has changed dramatically since living in his own home with supports chosen and monitored by his family."

"Basically, his life is much better in the setting rather than in the institution setting, that can only be a positive."

"My sister is very happy at her home with the [Name] family. She is well taken care of and the [Name]'s is her family you can see that when you visit them."

"My son is very happy in his new group home. He loves his housemates and the staff. He is very well taken care of and is always clean."

"R. is very happy with his home style of life and gets along with his aides and they are very good to him. His home is very beautiful and real clean."

While many comments about residential settings were positive, some people were not satisfied. Reasons for dissatisfaction included over-crowded settings, poor care, and environmental issues.

"For one thing there are too many in the house, there are four. My daughter and another lady have to share a bedroom, which is too small."

"J.'s bedroom is too small for him. He doesn't have enough room for his clothes or TV or music, etc. His roommate has the largest room but he has less things."

"I do not feel my son is getting the care he needs at the group home. He is not always clean and dressed the way he should be."

"I am unhappy with the management of J.'s group home. I hope to have certain issues resolved in the near future. If not, what's my next step?"

"I feel that the living area that my daughter lives in could be a little more colorful and nicer, just by brightening the paint and nicer rugs."

"The back porch at [group home] could use a roof over it so that it could be used when it rains or snows."

One issue mentioned by several people was placement. Several people reported their family member would like to be placed in a different residential setting; however, due to a lack of settings, this is not possible. Other people mentioned they did not want placement to change

"Would love to see J. be placed in a group home where she would be with others."

"T. seems happy with work, and seems to like the home, but he says he would still like to go to family living."

"Each year I ask for my son to be moved to [city], where I live."

"I would like to see my son living in a MR home in my community. He would have more family contacts and visits. My community now has three such homes."

"We do not wish to have our daughter moved from her present location at the [Center]."

"We did not want S. to leave the institution, mostly because of its uncertain permanence."

"I was against S. being put in a group home. He was happy at the [Center] and against my and my husband's wishes he was relocated."

Staff

Numerous people reported satisfaction with staff. Specifically, staff were noted as caring, knowledgeable, courteous, and accommodating. In addition, long-term staff were appreciated.

"All staff who actually provide hands-on care are generally great and most helpful."

"The nurses know how to take care of my sister and they do a great job."

"We are extremely pleased with both the program that has been developed for A. and the talent, professionalism, and genuine caring shown by his caring staff."

"The staff has been extremely helpful, courteous and polite. They are very accommodating to my loved one's needs."

“The staff and specialists get together and try to make plans for T. which will help him improve.”

“My sister’s staff are so good. I am really happy to have them. They understand her and try to make her as happy as they can.”

“[Name] is wonderful as my sister’s family care provider. She is my sister’s number one advocate.”

“We are pleased with the care that J. receives. If there is a problem, the staff usually finds an answer.”

“We think our son has benefited from his placement in the group home. It is a stable environment with little change in staff or clients.”

“There has been minimal staff turnover in the group home which has affected stability and a feeling of ‘home.’”

Although most people reported satisfaction with staff, numerous people were dissatisfied. The major reasons for dissatisfaction were turnover and a shortage of workers, but other reasons such as discourteous behavior and a lack of training were also cited. Turnover was linked to low pay.

“I would like to see the support workers have better training. Better pay for them would probably help.”

“Group home staff turnover – changes in support staff affect my son and all the group home residents. It takes time for new support staff to get to know them.”

“There is a turnover in staff and sometimes that is traumatic.”

“My daughter has been a client for many years. The biggest problem is continuous staff changes within the group home she lives.”

“The agency is constantly under-staffed and seeking new employees. This impacts on the feeling of security of my family member.”

“Not enough help to care for my son. They hire anyone regardless of size of person to handle 6 wheelchair boy-girls. Some get better attention.”

“Direct care staff deserves to be paid a respectable wage as opposed to the pittance they currently receive. Then maybe we could retain competent staff.”

“The staff in the group homes should receive a much higher rate of pay.”

“Some of house parents treating client in an overly disciplinary way as in giving orders loudly and phrasing them improperly.”

“More training for workers. Make a point of different culture and outlook concerning a more beneficial relationship with the client and their parents.”

“Some of the people working for the services my daughter needs are very incompetent.”

“Need staff with driver’s license all the time. There should be somebody in the house with a license, maybe not all the people.”

Communication

Communication was a frequently mentioned issue. Respondents who were satisfied stated that they were kept informed and their questions were answered promptly.

“[Provider] has always been great in keeping touch thru letters, etc. to us regarding our daughter. We appreciate this, especially in our later years now.”

“Pleased with how things are handled and the reports received.”

“When I have a problem they listen to me and address it. They may not be able to solve the problem but, they do address it.”

“We are generally happy with C.’s care and the communication between the staff.”

“My son’s MH/MR caseworker is thorough and available and checks out all concerns.”

Many people reported dissatisfaction with communication. Reasons for dissatisfaction included not being kept informed and a lack of involvement in meetings. In addition, a few people reported poor communication regarding financial issues and grievance procedures.

“I would like to be more informed of doctor’s appointments, events, etc. that go on in my daughter’s life. I no longer receive that in this group home.”

“I wish I was more involved. Families should have more control. But more information is needed.”

“Case manager never calls me to fill me in on changes or other matters. I call once a month, talk to staff.”

“Communication between staff and parents needs improvement.”

“I think more staff members should be present at meetings to give family members more input.”

“Several years ago when I was employed I was contacted about service meetings for my brother on a very impromptu basis. Sometimes it was difficult for me to attend.”

“We had found it is very difficult to obtain any information pertaining to our family member’s financial situation from his residential provider.”

“Family wants to know the money income the state pays shared support for B.’s care per year. For example how much for staff, food, insurance, lighting, etc.”

“We would like to have informative statements sent to us on what our loved one’s financial account activity is, so this way we may help keep track of it.”

“Lack of information about grievance procedures.”

One final issue mentioned was communication with the individual with a disability. A few people reported that because of non-communicative behavior it is difficult to know what their family member liked or disliked. One person mentioned the need for interpreters with doctors.

“The family member does not talk, so making some of these answers are just guessing.”

“Since L. does not live in our residence, and is non-verbal, assumptions about her happiness are just that.”

“Getting doctors to provide interpreters.”

Overall Satisfaction with Services

In general, numerous people were satisfied with the services and supports their family member received.

“My sister is receiving better care than what I could give her. They give her positive reinforcement and the results are overwhelming.”

“Thank you for making these services available. I don’t know what I would do without them.”

“I am delighted with my brother’s care and treatment.”

“I feel that she would be further advanced if she had been involved in this agency at an earlier age. I am satisfied with services at the agency.”

“We are very grateful for the wonderful care that D. receives. She has been given many opportunities in life that she probably would never had been.”

“Since my sister has gone into the [program], she has a happy and fulfilled life.”

“The program my sister is in is excellent. She has shown improvement especially with interacting with others.”

“We are very happy with the support and services T. has been receiving. These have enabled him to live a life we never dreamed possible.”

“L. is the happiest I have ever seen her.”

“The staff of [group home] does a terrific job caring for my brother. He has had more opportunities to do things in the seven years he has been there.”

Some people reported overall dissatisfaction with services. Specifically, people noted poor follow through on plans, lack of choice or availability of services, and ineffective interagency collaboration.

“Sometimes complaints fall on deaf ears.”

“Even though his plan is given and or structured, it is rare that it is either followed through to any fraction.”

"There seems to be no recourse when provider doesn't follow person centered plan."

"Most of my dissatisfaction is due to the lack of choices for programs which are suitable for M."

"There aren't support services available for family members and clients living in [county] area."

"Self-determination concepts and implementation are slow to be embraced by [county] MH/MR."

"The integrated 'system' (state, county, provider) seems to have too much insensitive inertia. It rolls over the client without consideration or consultation."

"The biggest problem for my loved one is the lack of cohesion between agencies that help her."

Employment Services and Day Programs

Some people reported satisfaction with their family member's employment and/or day programs.

"I am very happy with the excellent care my son receives at the group home and the sheltered workshops."

"He also lives to attend his work place."

"M. is happy going to day care."

"She loves the workshop."

Several people cited dissatisfaction with employment/day programs. The main reason for dissatisfaction was lack of appropriate employment.

"At this point I think what S. needs most is 10-15 hours of weekly work. If you could help us that would be greatly appreciated."

"T. needs daily activities to keep him busy and happy. A job would be good."

"D.'s greatest need is to find work that is appropriate and enjoyable."

"Wish there was a better daytime programming option for my brother. Because of budget constraints his only choice is skills which is not the best option."

"He does not appear to like his day program."

"My only complaint is about the amount of work available where my sister-in-law works. Some days she just sits and writes her name."

"Workshop has P. sign paper that I don't know what she signs. Also, I'm not told where she is working when she goes out of the workshop."

Education and Training

The need for education or training was mentioned by a few people.

“Needs speech therapy.”

“My loved one need to learn to communicate better, perhaps learning some sign language. In addition, I would like to see more one-on-one opportunities.”

Health Services and Equipment

Several individuals mentioned issues regarding dental services, medical care, and equipment. Two people specifically noted the need for dental care. Some people reported that their family member received good medical care, while other people expressed specific medical needs. In addition, one person reported the need for medical equipment.

“My daughter had a front tooth removed about 2 years ago and it hasn’t been replaced yet. It spoils her appearance.”

“D. needs assistance in getting to the dentist to have her teeth removed. His father and I are physically unable to do this. Is there any assistance?”

“I’m pleased at the response to my sister’s medical needs.”

“Her medicine control seems the best ever.”

“I would like to see T.’s knee problem taken care of.”

“Needs physical therapy but will not follow directions. Needs to try creative strategies to get her to move.”

“My loved one needs a new wheelchair.”

Transportation

Several people were satisfied with their family member’s access to transportation. However, some people expressed the need for transportation.

“He is very well cared for and seems to be happy with the daily rides.”

“My child is in a group home. I was forced to move 60+ miles away. Since I do not drive the home brings my child here for the weekend once a month.”

“He is happy with activities [provider] affords him and also the personal car.”

“Transportation cost through the county are too high.”

“We would like S. to have transportation to doctor’s appointments.”

Recreational Activities

Comments about recreational activities – such as sports, church, dances, and outings - were split between those who thought there were enough recreational activities and those who felt there was a need for more.

“My son is very happy where he resides and they take him out whenever possible.”

“He enjoys all the outings.”

“He is happy with activities [provider] affords him.”

“I would like to see her going out doing things such as: bowling, G movies, craft shows, etc. There is too much going out to eat at fast food places.”

“J. needs to go on more outings such as wrestling matches, ball games, concerts, Special Olympics, bowling, etc.”

“Few scheduled activities – mainly custodial care leading to boredom and unhappiness.”

Aging Caregivers

Aging caregiver issues were mentioned by several respondents. A few people expressed concern over the future, while others felt their loved one would be cared for if they passed away. Some individuals mentioned it was difficult to be involved with the care of their family member because of age and medical condition.

“Each year I ask for my son to be moved to [city], where I live. As I am getting older, 67, and my eyesight is deteriorating, I am not able to see him.”

“As I face my senior years, my concern remains that my son continues to receive all the services he currently has, in order to assure him the best quality.”

“I am almost 86 years old. I am so grateful that my dear son is safely with the group homes.”

“I had to place V. in the [group home], as my health wasn’t good enough to keep taking care of her and without my husband’s help, as he passed away.”

Case Workers

Many people reported satisfaction with their case manager. Specifically, case managers were cited as being helpful, concerned, and supportive.

“Also the county caseworkers have been helpful and professional.”

“I know J., my brother, likes his social worker. Would like to spend more time with him.”

“I appreciate having [case worker], I feel she really shares my concerns, knows D., and understands him. She is willing to help and guide me.”

"[Name], who was my brother's coordinator for many years, always called me about my brother's condition. The one now doesn't return my calls."

"The services received from our support coordinator has been outstanding. She is always available and has been a wonderful support."

"Our son's case worker, [name], has been very cooperative in helping us find and implement programs for our son."

Some people were dissatisfied with case workers due to unfamiliarity with them and their family member.

"I have never met her case worker."

"I feel the case worker should be more familiar with the family. The worker should meet with the family when they first take on the family member's case."

"We wish we had a permanent case manager assigned."

General Well Being

Issues about general well-being included hygiene, health and safety. Respondents were satisfied with personal hygiene issues. The major concerns about health related to diet and exercise. For the most part, people cited dissatisfaction regarding nutrition and exercise regimens. While several people noted their family member resided in a safe environment, other people had concerns.

"Every time we or my family have stopped at D.'s residence, after without notice, we have found her well-dressed and groomed."

"They are on top of most situations and he is very clean."

"Healthy preparations and making fresh fruit and vegetables sliced and prepared for easy access instead of junk food would be appreciated."

"Not enough control of weight. Too much junk food!"

"I am concerned about his weight loss and how regular and proper food diet he is receiving. As when he visits his family's home, he seems so anxious for food."

"We worry about our daughter not gaining her weight back. What are the aides cooking for the girls to eat?"

"He looks good and has gained weight."

"I have always felt that [group home] needed an aide on every shift."

"She should not be left alone so much. If she falls asleep and can't get up, what will happen then?"

Funding Issues

A few people mentioned concerns about funding issues.

“It appears as if many agencies are simply driven by their bottom-line profits.”

“I have noticed discrimination when monies are contributed to the provider by parents. Those parents’ individuals are given priority over the others.”

SOUTH CAROLINA

Approximately 6% of survey respondents from South Carolina wrote qualitative comments. Due to the relatively small number of comments, all comments are shown below.

Home

One respondent noted that she is satisfied with her daughter's placement.

"Our daughter is in a nice group home. We feel a little better to know that when our day comes, our daughter is hopefully in good hands."

Communication

One respondent reported that her family member needs sign language.

"Parents want consumer to get sign language in the program."

Staff

A couple of respondents wrote comments about staff.

"The group that works with my daughter is very supportive. I do not feel that the system is perfect, however I do see extensive effort by the staff and management. We are thankful for the care our family member receives."

"The people at [agency] are doing a very good job. I just wish there were ways for them to be compensated more equitably so that the changes in the support services would not be so frequent."

SOUTH DAKOTA

Approximately one third of survey respondents from South Dakota wrote qualitative comments. These comments are summarized by theme below. Overall, satisfaction with services was the most frequently mentioned topic followed by staff, home environment, and communication.

Overall Satisfaction with Services

Nearly a third of respondents who wrote comments mentioned that they were satisfied with services. In particular, several respondents wrote about satisfaction with a specific vocational services agency, satisfaction with their group homes or other placement, caring, and competent staff.

“I am happy with my daughter’s life with [agency]. Her day parallels that of her siblings—up in the morning, breakfast at home, work at 8 AM until 3 PM—Home to do necessary chores around the house she lives in. Responsible for making her bed and keeping the room tidy. Do assigned chores—shower or bath. Dinner. Some evenings she goes shopping for her needs—or to some planned outing. She is a happy lady...”

“We would like to thank vocational services and staff on their positive help and reinforcement on the co-workers. My brother has changed for the better and we are very happy and so is he. His staff is very outgoing and we feel they are doing a great job.”

“Our family member is at vocational services. It is a great plan for him. He is happy there and doing so well. He has a job he likes which entitles him to earn a little money. Staff takes good care of him – even takes him on vacations – which he loves. Medical care is adequate. We are happy we have such a great place for him.”

“I am very happy with the care my son gets they are always willing to help in whatever his needs are – this takes such a burden off his father and me because I know he is getting excellent care.. “

“I think the care and service working are absolutely excellent! My family member is very happy – and, thus, we are also.”

“I am delighted for the most part with the care and support that our family member receives.”

“My daughter is supported by [agency]. Without their help she would not be able to live the independent life she now enjoys. They help her with her budget, shopping and meal planning so that I can be assured that she is living well. They provide excellent care and guidance for her and have helped her work through some difficult decisions. The staff are just wonderful! They contribute to my sister’s quality of life in so many ways. They listen to us and to my sister and are so accommodating and supportive. You couldn’t find a better organization to work with!”

“I am very impressed with the service and level of competence of the staff at [agency]. They are very committed and are always looking for ways to improve the level of service to their clients.”

"I feel very confident that my brother is well taken care of. If there are concerns I am usually contacted. The staff are very caring and concerned for my brother's happiness and well being."

"I am completely happy with the service and care my son receives at [agency] in South Dakota."

"I am very satisfied with the staff and service being received in behalf of my family member. The staff at the center do a great job and we are very happy to have our family member there."

"My sister makes most of her own decisions with help of support staff or advocate! We are generally very satisfied with her treatment and life."

"We feel fortunate to have such an excellent facility and services for our daughter."

Home

Several respondents commented on the home environment. Most respondents who mentioned this topic were satisfied. In particular, a few respondents noted that their family member is more independent due to services.

"I feel that our son has become very independent and is very happy where he is living. He has supervision most of the time, so it eases my mind, and know he is being taken care of. I think [agency] has made a significant difference in my son's happiness and ability to live pretty much of an independent life. I hope he can continue to use their services."

"I feel that my sister is very happy in the group home that she lives at. They have a great staff and it's a good place for her to be at."

"Our Son has matured and developed beyond what we had hoped for since living at [agency]. He is happy now and we are also."

"My son has progressed so much more since he has been at [agency]. Much more than I ever dreamt he would. He enjoys his work. He and his friend live in an apartment and have to make their breakfast and supper. They are very well supervised. My other son wrote a paper for college and said "that taking him to [agency] was the best thing my parents did."

"The staff at [agency] has been very supportive of my daughter. Because of the training and help she received when she first became a client, she is now able to live on her own with very little help from friends or family. Friends from her church help with transportation to their activities. She is able to use taxi and bus for other transportation to her volunteer jobs."

"I am quite pleased with the services my son is getting. His overseer's at the group home take very good care of him and see that he is content and happy."

"My daughter is very happy in her apartment. She is getting the best of care and is getting so many opportunities that she would not have otherwise."

“Our family member is very happy with his new apartment. The service he received from [agency] is excellent. He has some health problems and is monitored on his diet and medications. [Agency] is a very good program, I am grateful for the service they provide for him.”

“Family member lives in an apartment at [provider]. We are well satisfied with the care and support he is given. They do their best for him.”

“[Agency] has provided a safe, nurturing environment for our family member to grow. He has had the opportunity to work and live in the community, travel across the US, and become involved in his church and community.”

“I feel very fortunate to have this kind of facility, compared to the old institution type. We have come out of the ‘dark ages’. The group home setting is so much better for these people who cannot function on their own and need 24-hour supervision. We are truly blessed!”

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

“Our main complaint is with residential services. We have no input as to where he will live. Last time he moved we didn’t know where until the lease was signed. We had no address and had to call on a weekend to get his new address. It took 3 weeks for him to get a phone. He is now living quite a distance from all his friends and can’t go to see them because he has to be home for meds for his acne at 8:00 pm. The move before we weren’t told that he needed to stay there a year to continue to qualify for housing assistance and they moved him at six months so now he doesn’t qualify for at least a few more months so he is spending a lot on rent.”

“Where can I get information on money assistance to fix my bathroom for disabled persons. Is there a government assist program (for money) to help handicapped or disabled people to fix their homes. My sister comes home on weekends but can’t give her a shower for I need a lift and a new shower where she can wheel a chair in the shower part to take a shower the shower in the bathroom isn’t fixed for a handicapped (disabled person on a wheel chair or shower chair.)”

“I feel as though the staff could do a much better job in keeping the home cleaner. Washing windows, floors, painting, etc.”

Needs to be more thought on what will be done for these clients the older they become – such as housing where they can receive more care than in apartments.”

“My daughter has been waiting since August 2001 for residential assistance so she can live in Sioux Falls. “

“I hate the fact that the supervised living apts. have become more of a group home. Our daughter is on a higher functionality level but due to uncontrolled seizures she needs the care of supervised living – thus we are between a rock and a hard place – she really has no one to talk to or communicate except the staff and they do not have the time for her individually.”

"We are satisfied with the services for our son. We realize that the agency is burdened by the poor state/federal funding. We feel that the state could allocate more money to the disabled community if it spent less on corrections. Redfield has a beautiful campus that was built by our state founders for the disabled. It should continue to be an option for us. It should not be a prison. Many of the prisoners we have met do not need to be there, they should be home with their families and working at a job, paying taxes. We do not see any sort of rehabilitation there for them. If this location was funded with the same amount of money, but only for handicapped individuals who chose it, our state would be better served. There are people who would choose a segregated option. You need to focus on giving people choices rather than being politically correct."

"Better housing needs to be available to the disabled. More grants to training centers for the building of new group homes and apartments."

Staff

Staff issues were a frequently mentioned topic. Most respondents who wrote about this issue were dissatisfied with staff. Common problems included: turnover, low staff pay, inadequate training, and shortage of workers.

"I would like to see more mature staff in my daughters, group home not so much, short term people. Someone who isn't going to school. My reason, for this, is I've found its just a job, money, to help them go on to more money jobs. We have or had some, who, are in medical school, that are exceptions."

"Staff turn over a big problem and staff sometimes more interested in their pay than work. We are wearing out!"

"Our concern regards the medical care of the clients. – Staff doesn't seem to be properly trained. Also information doesn't seem to be "passed on" to the next shift."

"Staff who work in the residential setting for this individual are rarely around. The setting was set up to be a supervised apartment setting. When contact is made with the staff they are unaware of concerns (i.e. wetting by the individual, poor/unhealthy living accommodations, dirty bathrooms, clothing, etc.). Messages are left when wanting to take individual out for the day/evening. These messages are not being relayed to on coming staff, who frantically locate me that the individual is out of the facility. My opinion is that they are either way understaffed, poorly trained and/or just don't care."

"The staff that often work with client do not know him; thus this affects the consistence of this ISP. I have found that staff who are working there 6 months and are the primary staff who do not even know his ISP and history, thus they do not follow the learning methods rather they "do" for the individual versus teach and maintain a skill."

"...most of the staff at the house are not good right now. Communication between staff and between staff and family has been terrible lately. Changing staff and staff shortage is always a problem."

"I've been disappointed with staff care, at times, when he tells me how rough people talk to him if he's sick or sad at the group home. It is an atrocity to me, that some of his

expensive and/or sentimental toys have been stolen by a staff member, with no restitution offered.”

“The high turn over in the residential facilities is very disruptive though – we wished they could do more to keep good people.”

“A frequent turnover of staff is upsetting, just get acclimated to the situation and they leave. It would be beneficial to pay your workers more. As each time a new one comes we have to start over in the process of what is important and any hint of new help she’s getting is stopped or slowed down.”

“Employee turnover is probably our biggest concern over the years.”

“Because of lower pay/staff turnover, the people that work directly with our daughter are less satisfactory. They are usually kind + meet immediate needs but have little concept for the future – the way to motivate or to train.”

“Good, caring staff is always a challenge to employ and keep on a long term basis. Staff turn over is hard for our family member to adjust to.”

“We feel very comfortable with our daughter at [provider]. The only thing we wished there was more staff because we’ve been there when they are so busy and short staffed.”

“My main concern is that the group home and Training Center are not fully staffed at all times. Some day they are very understaffed, I do not always feel that my relative is safe because of lack of staff.”

Some respondents indicated that they were satisfied with staff. Words respondents used to describe staff included: caring, concerned, keep informed, capable, competent, considerate, kind, communicates well, understanding, and patient.

“I can’t begin to express my admiration and appreciation for all the people at [agency] who work to make life comfortable for my family member. It is very obvious that his life is enriched on a regular basis by their care and concern for all aspects of his life. They are tops!”

“I’m Very Impressed with the Staff I talk with. They seem to care about my brother’s concerns and I really appreciate that.”

“Staff always keeps me informed of what’s going on. I’m very satisfied with them. They are a caring group of people and keep me informed.”

“I am pleased w/the quality of care my consumer receives. The staff is very capable and competent.”

“We feel our family member is doing very well and the staff that work with her all are doing a great job – She is content and happy with all her care workers. They are kind and considerate while working with her. This has been a great program for her.”

"I am most please with the individual attention and personal concern showed by the staff at the [provider] and group home to my sister. They take a very active role in her personal, social and occupational life. All involved seem to go out of their way to make her life meaningful and happy."

"Appreciate all the staff who extend the loving care, patience, concern and understanding they provide to my son. I'm grateful for the guidance and direction they provide in planning and developing a program for my son."

"The staff have been great to work with and have been very helpful in improving the life of our disabled family member. We are very thankful for all the assistance they provide."

Communication – Satisfied

Several respondents wrote comments about communication issues. Most of these comments reflected dissatisfaction with communication.

"My family is almost never able to get a hold of staff where he lives and messages are frequently left on the phone there and cell phone. Sometimes no return call ever received or if it is, it will be 2-3 days later. We are able to reach his job supervisor without difficulty."

"We live nearly 400 miles away from our son so it is hard to know, what is going on in his life. It would nice to be updated occasionally."

"I wish there was better communication between office and staff. If I have word with the staff it never gets sent on."

"I do feel I could be more closely informed by fax or phone about her health condition, money, etc."

"Sometimes I feel they don't inform us about situations, such as moving to a new place or some problem until it's already been decided on what should be done."

"I am not always satisfied with the communication between my sister's case worker and myself. I feel she'd rather not have to talk to me."

"Wish the doctors were in better communication."

"Lack of communication between staff and family."

"...there are/have been times when I should have been notified of Medical services + wasn't for 24/48 hrs later. Or wasn't notified when he had some skin break down till I noticed or found it once I brought him home. I'm never told his schedule for community events so visits sometimes mean he misses an outing. Or misses coming home for weekend."

"We'd have to say we've been generally Very pleased with his care. Since our family member doesn't talk, sometimes I'd appreciate his teachers trying to anticipate what he needs more, such as a drink or help going to a bathroom."

“Communication between facilities and staff is a definite problem. The concern regarding protection of records often hinders the appropriate care.”

A couple respondents indicated that they were satisfied with communication.

“I am informed continually even though I have moved far away. I am always being called or emailed and feel confident that her quality of care continues without me “being there” everyday.”

“The staff at the group home are very good and they are very good to communicate with us to keep us informed about him.”

“Even though I live far away I am kept informed of everything. Appreciate service coordinator’s frequent calls, often just to tell positive stories (not just concerns).”

Employment

Employment issues were mentioned by a few respondents and most of these comments were negative.

“Even though my son suffers from Schizophrenia/Paranoia in addition to quadriplegia, he is in a job that has no challenge or interest to him mentally, yet is difficult for him to handle physically. Most of the people he works with are very mentally retarded, and sociability is very difficult. My son also has ADHD, so he definitely has very special needs, and as a family we do not feel his needs are being fully met.”

“My brother needs to have variety in the work that he does – there previously was two jobs he could work on – one job was eliminated and now he must do the same job for his full work day – he needs to have a change.”

“R. loves people and loves his work. He is employed as a dishwasher at a university. Because of this, he is not employed during the summer months. This causes a little problem because, ‘what can he do to occupy his time?’”

“I believe that there are many times that [agency] makes the people with developmental disabilities that they serve more dependent on them and systems like them, rather than helping to develop independence. It’s even in their name ‘training centers’, but what are we training for? Many times there is not enough work to do back in the workshop so the people using the day program have nothing to do but sit and sleep. I’ve walked in unannounced, and there have been many times no one has had any work to do!”

“The workplace environment he attends each day does not fit his needs. He needs more physical outlets...”

“I feel that our family member is doing very well and is happy with her job and apartment.”

“I’m glad he likes where he works...”

Health Care

A few respondents mentioned health care issues such as medical or dental issues or insurance problems.

“The only real complaint that I have is their care of his teeth. He cannot do it himself. The care they give is minimal and his gums are deteriorating. I had him home for a week and in that short time they improved greatly with my care. I brushed them thoroughly, flossed them, then used a special brush and carefully went around the gum lines. I also brushed them at bedtime. I understand this is a problem in all institutions.”

“My son would not have a ‘normal’ life without services. I wish he could have more support. I also wish the mandatory see the psychiatrist, every 3 months, had a little more information. I feel there should be some kind of information sheet made available to support staff and family if relevant that could be completed and go to the psychiatrist. So pertinent problems could be addressed by the appointment.”

“Because most of the clients have medical problems, it would be beneficial to have more RN’s on staff. Since the Center cut back their nursing staff we have seen a deterioration in the care. I suggest the Center could benefit by having a ‘nurse practitioner’ on staff to help with medical decision making which would eliminate unnecessary frequent trips to the doctor’s and emergency room. I question the availability of the ‘nurse on call’. Either the staff doesn’t call or the nurse is not available.”

“Our family member comes home almost every weekend. Her med. box has enough meds for 1 ½ months in it. We are talking 2 controlled substances. This is a lot of medication to be responsible for. If we take her on an outing and one medication has to be given during the time we have her, the whole med box has to be checked out. We are not allowed to take just that one pill, we are required to check out all the meds just to spend 3-4 hours at the mall or a birthday party etc. This stops us from taking her on outings sometimes because we don’t feel comfortable carrying all those meds around.”

Education and Training

A few respondents noted that they were dissatisfied with education and training opportunities.

“Also the Special Ed program was drastically changed from a certified Special Ed teacher working with small groups to the workshop staff showing videos, and group home staff doing some training. Reading site words or ‘survival words’ does not get reinforced! At least as far as I can tell! My son seems like he’s becoming harder to understand. He used to have some pretty understandable speech.”

“Our son goes home on weekends and therefore misses visits to the library. He is not encouraged to read and develop skills in recreational reading at his group home. His schedule is not accommodated to providing for this need.”

“I believe the hometown school has a ‘push out’ the unfit child and let someone else deal with them. If the parents want to be closer, make them move to where the child is. (There is one spec ed director telling me to do this.) She shows no compassion for disabled children or parents, but since she saves the school money if she stays in the program. Is this right? Set up another center or two midstate so parents can really see

what's going on with their child in their training centers or group home setting. Let us be assured our child is doing fine."

Recreational Activities

Several respondents indicated that they were dissatisfied with recreational activities.

"My son has no involvement in activities if we the parents do not take him with us. He has many friends at work, but sees none of them socially as we work nights and it is hard to get him from place to place."

"There doesn't appear to be enough staff members who are able to do things with the disabled people after work from 3 pm on. Most of the disabled people have to entertain themselves. They need more activity programs."

"I would like my daughter more involved in going to community functions. Would like for her to be more involved with clients that are more like her. I feel that they could do more things."

Case Management

A few respondents wrote comments about case management issues.

"Our caseworker is always so conscience of us being comfortable with the way things are going and also with good staff which is the most important factor."

"For months now I have felt very discouraged because there is almost no contact of the case manager with my son, they want him to come to them and he is not consistent with this (he has no phone much of the time and communication with the facility is impaired due to this, also transportation sometimes is not available)."

"Her case worker since she went into a group home doesn't contact me on anything – the one she had before let me no what was going on at all times, also she let me no when she had a spell and what have you. I get nothing from the one she has now."

General Well Being – Health

Some respondents commented about health and well being issues.

"Her diet is very poor/unhealthy, she needs help in planning a menu for each week as she is diabetic. I feel that she needs a reference book w/pictures on how to cook meals. I feel she has become withdrawn over the past 5-7 years. She is not as talkative as she use to be. When communicating w/her she now can give a word answer or just nods her head. Although she has hearing aids she sometimes pretends not to hear you and will ignore you. She needs therapy for emotional and physical and sexual abuse."

"His diet seems to lack vegetables and fruits – a high fat low fiber high salt diet is offered. He refuses to eat many healthy foods now as a result. As a dietitian who works with adults with MR I see how serious a problem it is when poor habits are allowed – children who are institutionalized – once they are adults the problems are serious."

"I have concern over cutbacks on night time supervision. I feel there needs to be round the clock supervision at our daughter's group home."

"Also very hard, as a mother, to have my child attacked by the same resident several times. I do know they put a plan in place, that did help reduce the other client's stress level and improved the situation, but it did occur again recently."

Advocacy and Choice

A few respondents mentioned issues related to family or personal choice regarding services.

"The residential unit where my daughter lives usually includes me in their plans however the agency does not ask for my input. I just get a letter saying they are making changes – everything is already decided without my input."

"I feel we have little control on choosing personnel who work with our youth."

"Feel at times that too much support is provided and client is not encouraged to independence. Has lost many skills since entering the program and does not feel free to set own schedule."

"Families need to feel more welcomed and invited to attend more things."

Dissatisfaction with Services

Some respondents noted that they were dissatisfied with services or lived too far from services.

"My daughter can function with minimal support. I feel that, for that reason, she doesn't always receive the services that she should have, i.e., job placement, housekeeping assistance."

"The disabilities system in South Dakota has taken on a life of its own, the goal of which seems to be serving and meeting the needs and wants of the people running the program, rather than the disabled. The disabled and their families have become victims of an insidious bureaucracy."

"There is absolutely no religious input at the group home and the morality of staff and the example they set has been a problem in the past. The kids are allowed to have too much access to the opposite sex, dating/going out/going steady is not discouraged; kids (or my son) does not seem to have any moral socially responsible values reinforced by home or school. Kids may have too much of a possibility to get involved with pornography at school. Our son has access to websites that our filtering device (at home) would not allow."

"We, as the parents, are very satisfied with the services provided to our family member. Our only problem is that it is so far away from us. It is 265 miles, one way, from our place and the family member enjoys coming home on holidays and we love to have him, but we don't have much money or a dependable vehicle and driving is very stressful for me because I have MS."

WYOMING

Approximately 41% of survey respondents from Wyoming wrote qualitative comments. These comments are summarized by theme below. Staff issues were the most frequently cited, followed by case managers, communication, and employment.

Staff

In contrast to case management, most respondents reported that they were dissatisfied with staff and services. Staff turnover was the most frequently noted problem followed by low staff pay. Other problems included: difficulties working with managers of agencies, staff who are not well trained, low staff pay, and a shortage of staff.

“Activities within the program appear to run smoothly. However if family member plans outside activity with family or friends, there have been problems from the paid support services due to what we are told—‘lack of staff,’ ‘communication problems,’ i.e. wasn’t told of an overnight outing and her meds were not ready. Frustration is felt when transportation is provided from paid support services and transportation provided by family or friends. This shouldn’t be. It appears that paid supports have problems functioning ‘out of the box’ of their own structured program security.”

“There have been numerous changes in the staffing which has resulted in behavior problems. The staff has made mistakes overlooking plan requirements and over all relaxed in the quality of care. The staff (some) are very young and their attitudes are immature.”

“I have more problems with the CEO than the staff. He is difficult to talk to and reluctant to be co-operative to resolve situations or conditions concerning the client. Example—both the case manager and myself repeatedly request/instruct that our ward is not to do mindless copying text on the computer but the staff repeatedly set him at this babysitting type task and management repeatedly tries to excuse/ignore this problem. Stricter controls and monitoring of the money is crucial to serve the best interest of our DD population.”

“Many times the case manager brings certain requests to the C.E.O. and nothing gets done past them - the case manager can do no more. Sometimes the C.E.O. doesn’t ‘hear’ or fix things and sometimes I understand they can’t either. It’s all in maybe too much paper work where the money goes and not to the clients direct. Although I am very thankful for what we have and know it’s so much better than other places. But could still be better if they were not such an overturn in staff - and everyone worked as a ‘team’ for the betterment of the clients. Sometimes their silent voice gets overlooked!”

“Changes in support staff is the biggest problem for my family member. He needs to trust caregivers and with frequent turnover of staff he’s learned not to trust them because they’ll be leaving soon anyway. As a result medications are used to help reduce behavior problems when preferred staff are not available.”

“Another concern we have is the turn over of employees. I don’t know if the turn over is due to low wages paid or what the problems are. It seem like they walk in the front and out the back door.”

“You need to pay staff more. (We) would like to have her in a town home. Again, [staff name] is awesome, so is [staff name]. Please appreciate those who not only work but do it from the heart. How can [provider] give appreciation and thanks to staff, encouragement and higher pay. We are fortunate to still have this skilled women, lower trainer turn over is notorious. “

“My biggest problem is why we keep losing qualified people who are doing a good job in management in the last 3 years we've lost 2 very great people who were always on top of the problems. One of them in last month. Is it because of internal problems? Maybe it's because they aren't getting paid a living wage.”

“Our biggest concern is the constant change in personnel-most likely due to low wages paid for stressful work.”

“We feel at times there isn't enough training time spent with trainers before they are given total responsibilities. More time should be spent with these employees so they understand the needs of lack client in the group home and also at day lab.”

Case Management

Overall, people noted that they were satisfied with their case manager while some people mentioned problems related to case management. Case managers who were informative, caring, knowledgeable, and cooperative were noted. A couple of respondents mentioned that case manager turnover was problematic.

“The case manager is very cooperative with me and my daughter. She keeps in contact with me at all times and also in contact with all the doctors of my daughter. She also sends in seizure reports to her doctors.”

“We have a very compassionate and knowledgeable case manager-he has gone beyond his job description to help when his client was having a difficult time last year.”

“My daughter's case manager—she is excellent and has gone an above and beyond the requirements of her job as far as seeing to it we have what we need and yet isn't overboard on special equipment etc. When I've said 'I don't think this is called for,' she has always taken my point of view. I'm talking about special equip etc that some group home help or day lab help thinks they need.”

“The case manager has changed a few times. Some have been more concerned and more active in helping our family member that others have. The ability to change case managers is very important and helpful.”

“Case managers are only here for about two months. Consequently we don't have much faith in case managers and as a rule they are pleasant, nice people but only know them briefly. What is wrong?”

Communication and Information

Several people reported encountering communication problems, most specifically a lack of communication between the family and case managers and insufficient information about

services, providers, and relaying information about a family's loved one activities, behavior, or changes.

"I do not get the input from the new case manager(s) as I did from [the former case manager]. My case manager doesn't ask about my family. I didn't know that that was part of her job. Also they could do more communicating with me on what's happening with my son with a developmental disability."

"We are very happy with overall services, we would like case manager to keep me better informed. Example reports very 6-8 weeks on my daughter's activities, behaviors, changes in house staff, daughter's responses and problems."

"My greatest complaint is lack of information regarding providers who are actually available to serve. It would help tremendously if the list had available hours, i.e. (work evening only, not available on weekends) etc."

"There needs to be better communication between provider - parent- state. Where all are receiving the same info as it becomes available. Many times parent is unaware of what and where the state policies etc. are developing or have been changed. This needs to be a 3 way situation as providers often have an overload of responsibilities as it is."

Employment and Day Programs

Respondents noted several issues pertaining to employment and day programs. Several people mentioned that they were dissatisfied with employment and day program options, services, and supports. Only one person responded that they son/daughter had adequate opportunities for employment and the city supported the agency and clients with building projects and jobs for those who have disabilities. Specifically people reported a lack of opportunities, lack of training of staff or insufficient staff, lack of follow through of program/goals for loved one, and insufficient funding for services.

"We took our son, has talents that aren't being used for his employment. He is currently not working and this upsets me more should be done to find him employment."

"My family member attends a day program. I would like to see her involved in more activities, and be able to have a more one on one time with trainers. Also in the group home she lives in there are six clients living there. When they opened the group home we were told there would be 4 clients. I feel with two staff members it would be easier for the clients and trainers, too. It can be a chore to get goals done; they don't have a lot of time to spend with each client. We feel at times there isn't enough training time spent with trainers before they are given total responsibilities. More time should be spent with these employees so they understand the needs of lack client in the group home and also at day lab."

"An ongoing problem no matter which day hab we use is that the trainers do as little as possible, opposed to running goals as written, oppose detailed documentation, falsifying documentation, etc. Unfortunately day hab management, although sometimes giving lip service, seldom enforces goal running as written, makes excuses, tries to deflect problems and requests, etc."

"I feel that the program is often driven by money they can make as opposed to the actual needs of clients- especially true in area of employment."

Overall Satisfaction with Services

Many family guardians noted that they were satisfied with services or agencies, often noting that staff are attentive and understanding and problems are addressed.

"[Provider] is an outstanding organization. They have served my sister for over 14 years. They have a true understanding of my sisters needs and apply these insights in a proactive approach."

"My brother's service provider has been doing a very good job in providing care and providing meaningful daily activity fulfillment. I am very pleased."

"I feel my sister gets good care and is happy at [provider] in [city]. The staff overall has been very receptive to our need and concerns."

"I feel my son is receiving the services he needs and is well taken care of. If there are problems with the staff, they are immediately taking care of it. They do not look the other way. Overall I could not ask for a better place for my son to live."

"If we have concerns they are always taken out and followed up with a report. As aging parents we feel fortunate she is in their care. Our other children have their lives to live but they are on top of what her life is about generally. We as a family are happy with the dramatic change since she has been in [provider's] care. We have been happy with our son's services so far."

"Since moving back to the U.S. we are blessed a thousand fold, for the caring staff and brilliant system. All of our fears for our son's well being have gone and are gratitude to Wyoming/[provider] is indescribable. He has all his social and health issues dealt with at once. How grateful we are."

"He has been enrolled in [program] since March of '89. I am satisfied with this organization and have served on the board of directors for the past 12 years. [Provider] is a fine professional organization and has adequate expertise, understanding and compassion for its clients their parents/family and legal guardians. There is always room for improvement in any company but very little at [provider]!"

Many people reported being satisfied with services overall. About half as many people indicated that they were not satisfied with services. A couple of respondents reported that the ability to visit family member was difficult due to distance.

"We are very frustrated with constant staff changes and their training or lack of I should say. Also, PT, OT and Speech Therapies are non-existent and shouldn't be!"

"I think house supervisors have too much say. I have had this experience in two programs. Both are and were difficult to work with. Programs/Instructions not always up to date in books. Medical instructions not always followed, at either day lab or residential. Person had temp and low blood pressure. Several times, and dehydration, because medical instructions not followed. Person has had same residential staff since

moving to [provider]. She seems to care for them a lot. Program a lot more willing to use out of house services than [program]. I was surprised that is the team thought person needed service, they receive it without arguments. How does a person (parent-guardian) know how much they can be involved? L. receives a tremendous amount of money. I do not think any program outreach (social workers) not much help. We have a lot of work to do. Progress has been made but is slow—we can't just place persons in community and think everything is okay. We need a lot of follow up and training to provide better services.”

“Most agencies only want to take the ‘cream of the crop’ or the medically fragile. The ones that bring in the most money and require the least amount of effort. You can spend your whole life raising and caring for your child in your community, only to have him sent far away and out of the community as an adult. Unless your disabled person is in the community where you live and you can monitor things all the time, your disabled loved one is at risk! The system only works for some and not for others.”

“My disability lives in [city], WY while I live in [city], the long distance makes it impractical to go visit him. We do occasionally talk to him on the phone but his speech impediment doesn't allow for a good conversation.”

Health Care

A few people reported that they were dissatisfied with health care, particularly access to affordable dental care.

“My comment on Medicaid is shame on them. After a person turn 21 they don't cover anything for dental. Oh, I forgot they pay for extractions and gum disease so unless I get my daughter some kind of dental care, she will end up toothless. My daughter receives \$465 a month and \$400 goes for living expenses and the rest for personal care. That leaves little for insurance. I could go on and on but what's the point.”

“The disabled people need insurance for teeth, health etc. We find most dentists will not work in hospitals or surgical centers. There is no one to pay the dentists. Family either pays in advance or there is no service.”

Education, Training, and Recreational Activities

A few people reported that they are unhappy with the education, training, and recreation services and programs. This ranged from conflicts over taking a family member to church, finding recreation programs, and educating a child who has multiple handicaps.

“The real problem now appears to be in my child's education. My impression is that the Department of Education will go to any extreme to avoid having to educate this child.”

“At this time, we take our son to church services on Friday. But if we are not in town, he does not attend. He is in a wheelchair and cannot go himself. He is part of the church community. The facilities do not address this issue and perhaps feels it is the church's responsibility to provide someone to take him to services. I think it is the faculties' responsibility.”

What happens when we are no longer living? Is this part of his life that disappoints, too?”

"I feel they all could use a free pass card to the recreation department for physical exercises because they really don't receive any money after paying the rent."

Home

A couple of people noted concerns about where their family member lives and the condition and cleanliness of the home environment.

"People have few choices regarding who they live with in a group home. Family member has to witness other's outbursts from mental illness when he has no outburst behavior. This does not give a person safe feelings in the home they live. I sometimes wonder if the 'program' is really there for each person or is each person there for the 'program'. Although the program is certainly not a large impersonal institution, the program does resemble a small, personal, mini-institution. People should not feel like they are in trouble when they've done nothing wrong and just because they have a disability or disabilities. Choices should be available and should be determined by each person or by those people who are family, guardians, or friends."

"When dealing with less critical medical or cleanliness issues, the house personnel seems to be less than attentive. It may be written but not paid attention too."

"I know disabled people have rights but if they didn't need help, they would these people clean their homes, apartments, and in their personal care. There should be a way they take care of these matters without interfering with their rights."

APPENDIX A

Summary Tables of Survey Responses

Table A - Characteristics of Family Member with a Disability: 2002 Data

STATES	Total %		State Avg.		AZ		CA-RCOC		HI		IN		MA		NC		PA		SC		SD		WY	
Number of surveys	4,638		n = 10		343		210		143		530		744		438		1,150		72		772		236	
	n	%			n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Gender:																								
Male	2,412	54.1	54.2		175	54.3	110	53.4	77	56.2	289	55.5	360	52.6	240	56.1	625	55.4	37	53.6	383	51.4	116	53.0
Female	2,048	45.9	45.9		147	45.7	96	46.6	60	43.8	232	44.5	325	47.4	188	43.9	503	44.6	32	46.4	362	48.6	103	47.0
Age:																								
Mean	43.2		42.8		42.6		41.7		42.6		45		44.7		42.4		43.7		44.6		42.1		38.8	
Range	18-95				18-81		19-81		18-92		18-93		18-88		18-95		18-88		18-75		18-90		20-76	
Type of Residence																								
Specialized MR Facility	545	12.2	11.2		18	5.4	17	8.3	4	3.1	52	10.0	141	20.2	94	22.1	128	11.4	9	12.5	57	7.6	25	11.2
Group Home	2,458	54.9	55.3		248	74.3	135	65.9	35	26.7	221	42.7	412	58.9	203	47.8	655	58.5	45	62.5	349	46.7	155	69.2
Agency-Owned Apartment	249	5.6	4.5		16	4.8	1	0.5	1	0.8	28	5.4	25	3.6	16	3.8	40	3.6	1	1.4	106	14.2	15	6.7
Own Home/Apartment	640	14.3	13.8		12	3.6	37	18.0	16	12.2	114	22.0	34	4.9	45	10.6	138	12.3	13	18.1	215	28.8	16	7.1
Adult Foster Care/ Host Family Home	257	5.7	8.8		21	6.3	4	2.0	67	51.1	9	1.7	46	6.6	27	6.4	68	6.1	2	2.8	3	0.4	10	4.5
Nursing Home	149	3.3	2.6		7	2.1	2	1.0	1	0.8	72	13.9	27	3.9	6	1.4	30	2.7	0	0.0	4	0.5	0	0.0
Other	177	4.0	3.9		12	3.6	9	4.4	7	5.3	22	4.2	14	2.0	34	8.0	61	5.4	2	2.8	13	1.7	3	1.3
	4,475				334		205		131		518		699		425		1120		72		747		224	
Race/Ethnicity* (duplicated counts):																								
White	3,940	86.7	78.4		241	71.9	185	88.1	32	23.5	480	91.8	667	95.0	299	68.3	1074	95.4	48	66.7	704	91.2	210	92.1
Black/ African-American	244	5.4	8.0		7	2.1	0	0.0	4	2.9	36	6.9	15	2.1	121	27.6	33	2.9	24	33.3	0	0.0	4	1.8
Asian	105	2.3	6.7		1	0.3	7	3.3	82	60.3	3	0.6	7	1.0	0	0.0	2	0.2	0	0.0	1	0.1	2	0.9
American Indian/ Alaska Native	105	2.3	2.3		19	5.7	2	1.0	4	2.9	4	0.8	8	1.1	8	1.8	9	0.8	0	0.0	43	5.6	8	3.5
Hawaiian/ Pacific Islander	27	0.6	1.8		1	0.3	2	1.0	22	16.2	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	0	0.0	1	0.4
Hispanic	90	2.0	2.9		50	14.9	12	5.7	3	2.2	2	0.4	7	1.0	2	0.5	5	0.4	0	0.0	0	0.0	9	3.9
Mixed Races	68	1.5	2.7		13	3.9	1	0.5	23	16.9	3	0.6	4	0.6	4	0.9	6	0.5	0	0.0	9	1.2	5	2.2
Other/Unknown	12	0.3	0.3		0	0.0	2	1.0	1	0.7	0	0.0	2	0.3	0	0.0	5	0.4	0	0.0	0	0.0	2	0.9

Table B - Characteristics of Family Member with a Disability: 2002 Data

	Total %		State Avg.	AZ	CA-RCOC	HI	IN	MA	NC	PA	SC	SD	WY										
Number of surveys	4,638		n = 10	343	210	143	530	744	438	1,150	72	772	236										
	n	%		n	%	n	%	n	%	n	%	n	%										
Level of MR:																							
No MR label	123	2.8	3.2	13	4.0	11	5.5	3	2.3	19	3.8	14	2.1	12	2.9	14	1.3	4	5.7	29	4.0	4	1.8
Mild	730	16.7	16.4	49	15.1	44	21.9	8	6.1	74	14.6	64	9.4	87	21.2	193	17.6	12	17.1	165	22.7	34	15.1
Moderate	1,181	27.0	30.5	101	31.2	81	40.3	35	26.5	127	25.1	184	27.1	100	24.4	262	23.9	17	24.3	198	27.2	76	33.8
Severe	982	22.5	21.8	79	24.4	35	17.4	31	23.5	111	21.9	190	28.0	95	23.2	228	20.8	12	17.1	145	19.9	56	24.9
Profound	551	12.6	10.5	28	8.6	16	8.0	16	12.1	81	16.0	110	16.2	42	10.2	170	15.5	7	10.0	57	7.8	24	10.7
Don't know	803	18.4	17.7	54	16.7	14	7.0	39	29.5	94	18.6	116	17.1	74	18.0	229	20.9	18	25.7	134	18.4	31	13.8
	4,370			324		201		132		506		678		410		1096		70		728		225	
Other disabilities* (duplicated counts):																							
Mental illness	878	19.7	17.2	57	16.9	29	14.1	19	14.6	115	22.9	128	18.5	131	29.9	220	20.3	18	26.9	109	14.1	52	23.2
Autism	409	9.2	9.1	35	10.4	25	12.1	10	7.7	52	10.4	87	12.5	29	6.6	91	8.4	2	3.0	59	7.6	19	8.4
Cerebral Palsy	765	17.2	17.8	63	18.6	46	22.3	19	14.6	84	16.8	132	19.0	55	12.6	198	18.2	5	7.5	125	16.2	38	16.9
Brain injury	487	10.9	12.0	37	10.9	33	16.0	17	13.1	54	10.7	87	12.6	44	10.0	116	10.7	5	7.5	65	8.4	29	12.9
Seizure disorder/ neurological problem	1,297	29.1	29.5	96	28.4	63	30.6	35	26.9	146	29.1	243	35.1	91	20.8	320	29.5	15	22.4	212	27.5	76	33.8
Chemical dependency	60	1.3	1.0	4	1.2	4	1.9	1	0.8	10	2.0	9	1.3	10	2.3	14	1.3	1	1.5	7	0.9	0	0.0
Vision or hearing impairments	960	21.5	21.8	73	21.6	35	17.0	33	25.4	97	19.3	184	26.6	73	16.7	239	22.0	8	11.9	166	21.5	52	23.1
Physical disability	1145	25.7	25.1	78	23.1	48	23.3	35	26.9	148	29.4	208	30.0	90	20.5	260	24.0	20	29.9	195	25.3	63	28.0
Communication disorder	894	20.1	21.0	59	17.5	41	19.9	33	25.4	106	21.2	197	28.4	61	13.9	174	16.0	7	10.4	156	20.2	60	26.7
Alzheimer's disease	39	0.9	0.6	3	0.9	0	0.0	1	0.8	4	0.8	15	2.2	2	0.5	6	0.6	1	1.5	5	0.6	2	0.9
Down Syndrome	449	12.2	13.5	46	13.6	24	11.7	19	14.6	46	9.2	104	15.0	38	8.7	123	11.3	12	17.9	*	*	37	16.4
Other disability	647	14.5	14.4	51	15.1	30	14.6	21	16.2	76	15.1	111	16.0	60	13.7	161	14.8	13	19.4	93	12.0	31	13.8

Table C - Characteristics of Respondents: 2002 Data

STATES	Total %	State Avg.	AZ	CA-RCOC	HI	IN	MA	NC	PA	SC	SD	WY											
Number of surveys	4,638	n = 10	343	210	143	530	744	438	1,150	72	772	236											
Age of Respondent:																							
	n	%	%	n	%	n	%	n	%	n	%	n	%										
Under 35	104	2.3	1.8	7	2.3	1	0.5	5	3.6	12	2.3	10	1.4	25	6.0	23	2.0	9	12.5	9	1.2	3	1.3
35 - 54	1,066	23.7	22.5	80	26.1	26	12.4	28	20.4	149	28.8	151	20.6	148	35.3	295	26.0	11	15.3	92	12.3	86	37.7
55 - 74	2,531	56.2	56.6	169	55.0	121	57.9	66	48.2	269	52.0	420	57.3	196	46.8	601	53.0	26	36.1	541	72.1	122	53.5
75 and Over	805	17.9	19.1	51	16.6	61	29.2	38	27.7	87	16.8	152	20.7	50	11.9	215	19.0	26	36.1	108	14.4	17	7.5
	4,506			307		209		137		517		733		419		1,134		72		750		228	
Relationship to Family Member:																							
	n	%	%	n	%	n	%	n	%	n	%	n	%										
Parent	2,676	59.0	65.3	215	67.4	173	83.6	87	63.5	273	51.7	445	60.6	207	48.7	674	59.3	25	35.7	442	58.7	135	59.2
Sibling	1,102	24.3	21.9	46	14.4	27	13.0	38	27.7	117	22.2	208	28.3	84	19.8	324	28.5	13	18.6	195	25.9	50	21.9
Spouse	10	0.2	0.2	0	0.0	0	0.0	1	0.7	2	0.4	1	0.1	1	0.2	3	0.3	0	0.0	2	0.3	0	0.0
Other	750	16.5	12.6	58	18.2	7	3.4	11	8.0	136	25.8	80	10.9	133	31.3	136	12.0	32	45.7	114	15.1	43	18.9
	4,538			319		207		137		528		734		425		1,137		70		753		228	
Respondent is guardian or conservator:																							
Yes	3,103	70.2	75.8	255	76.8	123	60.9	125	94.0	324	63.3	627	87.0	314	75.5	528	49.7	24	35.3	561	75.3	222	97.8
Frequency of Visits with Family Member:																							
Less than once/year	198	4.4	4.0	5	1.5	5	2.4	6	4.5	27	5.1	39	5.3	16	3.8	52	4.6	5	7.1	26	3.5	17	7.4
1-3 times/year	568	12.5	14.3	43	12.9	18	8.6	31	23.3	74	14.1	80	11.0	48	11.5	131	11.6	5	7.1	101	13.4	37	16.2
4-6 times/year	675	14.9	14.4	45	13.5	16	7.7	18	13.5	80	15.2	93	12.7	53	12.7	133	11.8	7	10.0	200	26.6	30	13.1
7-12 times/year	1,033	22.8	29.1	61	18.3	27	12.9	78	58.6	68	12.9	80	11.0	57	13.6	149	13.2	53	75.7	426	56.6	34	14.8
More than 12 times/year	2,054	45.4	38.3	180	53.9	143	68.4	0	0.0	277	52.7	438	60.0	244	58.4	661	58.7	0	0.0	0	0.0	111	48.5
	4,528			334		209		133		526		730		418		1,126		70		753		229	

Table D - Services and Support Received: 2002 Data

STATES	Total %		State Avg.	AZ		CA-RCOC		HI		IN		MA		NC		PA		SC		SD		WY	
	n	%	n = 6	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Residential Supports	4,313	96.3	96.8	318	96.1	200	96.6	130	96.3	492	96.1	719	98.5	395	94.3	1044	95.3	59	86.8	732	97.1	224	99.1
Day/Employment Supports	3,600	83.1	87.1	277	85.8	181	88.7	111	84.1	327	68.0	618	88.5	293	72.9	850	79.8	58	82.9	684	92.9	201	91.4
Transportation	3,981	90.7	91.6	308	92.8	173	85.6	128	94.1	440	89.2	662	93.8	361	87.8	952	88.4	62	89.9	679	91.5	216	97.3
Other Services/ Supports	2,976	75.1	71.1	205	66.6	95	54.3	86	71.1	345	78.8	533	81.6	288	76.6	643	69.3	61	92.4	527	77.7	193	87.3

Table E - Information and Planning: 2002 Data

STATES	TOTAL	STATE										
	%	AVG.	AZ	CA	HI	IN	MA	NC	PA	SC	SD	WY
Q1 - Do you get enough information to help you participate in planning services for your family member?												
Number of surveys	3,202	n = 10	326	201	127	466	698	405	1,012	71	733	218
% always or usually	75.2	73.4	79.1	63.2	68.5	70.8	78.4	75.6	71.7	63.4	81.4	82.1
% sometimes	19.4	21.2	17.5	28.4	25.2	21.5	17.2	19.5	20.4	29.6	16.0	16.5
% seldom or never	5.4	5.4	3.4	8.5	6.3	7.7	4.4	4.9	7.9	7.0	2.6	1.4
Q2 - If your family member has a service plan, did you help develop the plan?												
Number of surveys	3,780	n = 10	297	177	113	409	645	345	858	66	660	210
% always or usually	60.9	62.1	70.4	58.8	61.1	52.3	65.0	62.0	48.0	59.1	71.1	72.9
% sometimes	22.4	23.1	20.9	23.2	23.9	23.2	20.2	20.0	25.5	31.8	21.1	21.4
% seldom or never	16.7	14.8	8.8	18.1	15.0	24.4	14.9	18.0	26.5	9.1	7.9	5.7
Q3 - If your family member has a service plan, does the plan include things that are important to you?												
Number of surveys	3,818	n = 10	301	176	112	407	665	352	866	60	664	215
% always or usually	77.6	78.4	84.1	73.3	80.4	74.4	80.8	75.9	71.8	78.3	79.7	85.6
% sometimes	19.0	18.7	14.0	25.0	17.0	21.4	16.1	19.3	22.4	20.0	18.7	13.0
% seldom or never	3.5	2.9	2.0	1.7	2.7	4.2	3.2	4.8	5.8	1.7	1.7	1.4
Q4 - Are the staff who assist you with planning generally respectful and courteous?												
Number of surveys	4,164	n = 10	321	201	124	446	694	395	963	70	730	220
% always or usually	93.2	92.7	92.2	95.5	92.7	89.2	94.5	92.4	93.6	90.0	94.8	91.8
% sometimes	5.8	6.4	6.5	3.0	6.5	9.4	4.5	6.6	5.2	10.0	4.8	7.7
% seldom or never	1.0	0.9	1.2	1.5	0.8	1.3	1.0	1.0	1.2	0.0	0.4	0.5
Q5 - Are the staff who assist you with planning generally effective?												
Number of surveys	4,032	n = 10	315	194	124	425	677	386	897	68	723	223
% always or usually	77.8	76.1	74.9	74.7	72.6	71.5	75.3	80.6	78.9	75.0	85.8	71.7
% sometimes	19.9	21.2	22.2	23.7	23.4	25.4	22.6	17.1	18.3	20.6	13.3	25.6
% seldom or never	2.3	2.7	2.9	1.5	4.0	3.1	2.1	2.3	2.8	4.4	1.0	2.7
Q6 - Can you contact the staff who assist you with planning whenever you want to?												
Number of surveys	4,163	n = 10	321	195	125	453	687	410	951	70	725	226
% always or usually	88.2	87.2	87.9	87.2	84.0	84.3	88.2	88.3	88.1	82.9	92.0	88.9
% sometimes	10.1	10.9	10.9	9.7	12.8	13.2	10.5	10.2	9.6	14.3	7.2	10.2
% seldom or never	1.7	2.0	1.2	3.1	3.2	2.4	1.3	1.5	2.3	2.9	0.8	0.9

Table F - Access and Delivery of Services and Supports: 2002 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	HI	IN	MA	NC	PA	SC	SD	WY
Q7 - When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?												
Number of surveys	4,132	n = 10	311	181	126	463	677	401	961	62	728	222
% always or usually	82.7	81.7	85.5	75.1	75.4	80.8	80.2	81.8	82.0	82.3	89.4	84.2
% sometimes	15.1	16.4	13.8	22.1	20.6	16.8	17.4	15.0	14.9	17.7	9.6	15.8
% seldom or never	2.2	2.0	0.6	2.8	4.0	2.4	2.4	3.2	3.1	0.0	1.0	0.0
Q8 - Does your family member get the services and supports he/she needs?												
Number of surveys	4,350	n = 10	321	199	130	490	718	419	1,032	66	749	226
% always or usually	81.2	79.9	83.8	75.4	75.4	81.4	79.8	83.1	81.5	75.8	83.6	78.8
% sometimes	17.4	18.6	15.9	23.1	21.5	17.6	19.4	15.5	16.4	21.2	15.5	19.9
% seldom or never	1.4	1.5	0.3	1.5	3.1	1.0	0.8	1.4	2.1	3.0	0.9	1.3
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?												
Number of surveys	1,683	n = 10	141	68	59	161	322	153	384	21	296	78
% always or usually	76.9	75.1	74.5	67.6	67.8	76.4	73.6	87.6	79.7	76.2	79.4	67.9
% sometimes	18.5	19.1	18.4	19.1	28.8	21.1	22.0	11.1	14.8	14.3	18.6	23.1
% seldom or never	4.6	5.8	7.1	13.2	3.4	2.5	4.3	1.3	5.5	9.5	2.0	9.0
Q10 - Does your family member have access to the special equipment or accommodations that he/she needs (e.g., wheelchairs, ramps, communication boards)?												
Number of surveys	2,472	n = 10	192	83	64	309	454	213	556	26	443	132
% always or usually	88.0	86.7	88.0	78.3	78.1	86.4	86.3	91.1	89.7	92.3	91.0	85.6
% sometimes	9.8	11.1	12.0	18.1	15.6	12.0	11.7	6.6	6.5	7.7	8.1	12.9
% seldom or never	2.1	2.2	0.0	3.6	6.3	1.6	2.0	2.3	3.8	0.0	0.9	1.5
Q11 - Are frequent changes in support staff a problem for your family member?												
Number of surveys	3,724	n = 10	291	178	95	413	627	336	866	54	657	207
% always or usually	22.7	23.0	26.8	19.1	22.1	22.8	25.5	19.0	23.2	25.9	18.7	27.1
% sometimes	45.8	47.7	48.8	48.3	47.4	43.1	45.6	32.1	44.1	63.0	50.2	54.6
% seldom or never	31.6	29.3	24.4	32.6	30.5	34.1	28.9	48.8	32.7	11.1	31.1	18.4
Q12 - Do you feel that your family member's residential setting is a healthy and safe environment?												
Number of surveys	4,438	n = 10	329	204	131	513	725	424	1,070	63	748	231
% always or usually	88.9	88.6	87.2	89.2	89.3	88.1	89.5	90.6	89.6	88.9	88.9	84.4
% sometimes	9.9	10.1	11.6	10.3	9.9	10.5	9.2	7.8	8.8	7.9	10.8	14.3
% seldom or never	1.2	1.3	1.2	0.5	0.8	1.4	1.2	1.7	1.6	3.2	0.3	1.3
Q13 - Do you feel that your family member's day/employment setting is a healthy and safe environment?												
Number of surveys	3,775	n = 10	287	175	109	383	629	340	870	64	705	213
% always or usually	89.8	88.0	87.5	85.1	89.9	87.2	90.0	90.3	91.8	79.7	92.9	85.4
% sometimes	9.3	10.9	12.2	13.7	8.3	11.2	9.5	9.1	7.2	17.2	6.5	14.1
% seldom or never	0.8	1.1	0.3	1.1	1.8	1.6	0.5	0.6	0.9	3.1	0.6	0.5

Table G - Choices and Control: 2002 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	HI	IN	MA	NC	PA	SC	SD	WY
Q14 - Does the agency providing residential services to your family member involve you in important decisions?												
Number of surveys	4,260	n = 10	327	198	128	486	703	399	995	66	734	224
% always or usually	77.3	77.8	82.0	74.2	80.5	75.9	78.9	78.2	71.5	74.2	81.1	81.7
% sometimes	17.2	17.1	13.5	19.2	17.2	16.9	17.1	14.5	19.9	19.7	16.2	16.5
% seldom or never	5.6	5.1	4.6	6.6	2.3	7.2	4.0	7.3	8.6	6.1	2.7	1.8
Q15 - If your family member gets day or employment services, does the agency providing these services involve you in important decisions?												
Number of surveys	3,415	n = 10	271	166	99	346	573	287	776	58	639	200
% always or usually	61.6	61.2	68.3	43.4	62.6	55.8	57.4	64.8	59.4	65.5	69.6	65.5
% sometimes	24.5	24.3	22.5	30.1	28.3	24.6	27.7	23.0	23.3	12.1	22.1	29.0
% seldom or never	14.0	14.5	9.2	26.5	9.1	19.7	14.8	12.2	17.3	22.4	8.3	5.5
Q16 - Do you or your family member choose the support workers that work with your family?												
Number of surveys	3,524	n = 10	277	164	98	399	593	298	814	61	608	212
% always or usually	14.8	17.5	11.2	11.0	32.7	12.3	13.0	24.8	11.4	19.7	13.2	25.5
% sometimes	12.4	14.3	12.3	9.8	12.2	13.3	12.8	13.1	9.6	26.2	10.0	24.1
% seldom or never	72.9	68.2	76.5	79.3	55.1	74.4	74.2	62.1	79.0	54.1	76.8	50.5
Q17 - Do you or your family member have control and/or input over the hiring and management of your family member's support workers?												
Number of surveys	3,290	n = 10	273	154	84	374	552	270	767	49	572	195
% always or usually	7.9	10.3	7.0	7.8	23.8	8.6	6.3	15.6	6.6	14.3	4.7	8.2
% sometimes	9.8	11.0	11.4	9.7	13.1	11.0	11.8	12.6	6.9	14.3	7.9	11.3
% seldom or never	82.2	78.7	81.7	82.5	63.1	80.5	81.9	71.9	86.4	71.4	87.4	80.5
Q18 - Do you or your family member want to have control and/or input over the hiring and management of your support workers?												
Number of surveys	2,979	n = 10	234	143	82	342	512	260	686	48	496	176
% always or usually	27.2	30.7	29.5	28.7	42.7	30.1	30.3	31.9	25.5	43.8	15.3	29.0
% sometimes	35.2	35.5	42.3	34.3	31.7	31.3	39.6	36.9	31.3	31.3	32.7	43.2
% seldom or never	37.7	33.9	28.2	37.1	25.6	38.6	30.1	31.2	43.1	25.0	52.0	27.8
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?												
Number of surveys	2,372	n = 10	323	198	124	278	367	181	1,004	36	708	225
% always or usually	46.4	37.1	38.4	13.6	43.5	37.4	48.0	49.7	13.3	30.6	33.6	63.1
% sometimes	19.0	15.8	12.7	8.6	14.5	20.1	22.1	19.3	7.1	25.0	12.1	16.4
% seldom or never	34.6	47.1	48.9	77.8	41.9	42.4	30.0	30.9	79.6	44.4	54.2	20.4
Q20 - Do you or your family member get to decide how this money is spent?												
Number of surveys	3,276	n = 10	274	154	90	369	535	274	737	49	588	206
% always or usually	21.9	22.0	30.7	14.3	27.8	15.4	23.7	18.2	17.9	18.4	26.0	27.7
% sometimes	24.8	26.6	26.6	14.3	28.9	26.8	24.3	23.7	17.2	36.7	29.4	37.9
% seldom or never	53.4	51.4	42.7	71.4	43.3	57.7	52.0	58.0	64.9	44.9	44.6	34.5

Table H - Community Connections: 2002 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	HI	IN	MA	NC	PA	SC	SD	WY
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?												
Number of surveys	3,128	n = 10	241	100	73	352	489	284	728	45	628	188
% always or usually	61.8	58.4	58.9	37.0	56.2	60.2	59.7	65.1	64.7	60.0	67.4	54.8
% sometimes	27.1	27.9	28.2	31.0	24.7	31.5	30.9	23.9	22.8	26.7	25.3	34.0
% seldom or never	11.1	13.7	12.9	32.0	19.2	8.2	9.4	10.9	12.5	13.3	7.3	11.2
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?												
Number of surveys	2,796	n = 10	217	96	67	313	444	257	634	44	555	169
% always or usually	62.3	59.5	65.0	43.8	49.3	62.3	58.8	62.3	62.6	59.1	68.8	62.7
% sometimes	25.4	25.3	21.7	20.8	28.4	27.5	30.0	23.0	24.8	25.0	23.6	28.4
% seldom or never	12.2	15.3	13.4	35.4	22.4	10.2	11.3	14.8	12.6	15.9	7.6	8.9
Q23 - Do you feel that your family member has access to community activities?												
Number of surveys	3,942	n = 10	303	172	89	432	622	361	950	54	736	223
% always or usually	64.3	61.7	61.1	45.3	53.9	64.6	60.8	64.5	64.9	64.8	73.1	63.7
% sometimes	29.9	31.8	32.3	43.0	39.3	29.6	33.4	29.4	27.7	25.9	24.3	33.2
% seldom or never	5.8	6.5	6.6	11.6	6.7	5.8	5.8	6.1	7.4	9.3	2.6	3.1
Q24 - Does your family member participate in community activities?												
Number of surveys	3,767	n = 10	284	170	90	409	607	346	888	55	700	218
% always or usually	41.3	40.0	46.8	22.4	35.6	40.8	40.2	45.4	42.1	43.6	42.9	40.4
% sometimes	42.1	42.3	40.1	42.4	40.0	43.8	43.5	41.0	37.7	40.0	44.9	50.0
% seldom or never	16.5	17.7	13.0	35.3	24.4	15.4	16.3	13.6	20.2	16.4	12.3	9.6

Table I - Satisfaction with Services and Outcomes: 2002 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	HI	IN	MA	NC	PA	SC	SD	WY
Q25 - Overall, are you satisfied with the services and supports your family member currently receives?												
Number of surveys	4,434	n = 10	333	200	132	498	718	423	1,081	66	752	231
% yes or most of the time	81.8	81.7	82.0	85.0	76.5	80.7	80.9	80.1	81.1	86.4	85.6	78.4
% some of the time	16.4	16.0	16.5	13.5	20.5	16.3	17.4	18.7	16.8	7.6	13.4	19.5
% no or not at all	1.8	2.3	1.5	1.5	3.0	3.0	1.7	1.2	2.0	6.1	0.9	2.2
Q26 - Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?												
Number of surveys	4,197	n = 10	319	191	120	483	683	405	997	68	709	222
% yes or most of the time	54.8	53.7	56.1	41.9	41.7	54.0	59.6	56.3	45.7	50.0	64.2	67.6
% some of the time	7.5	7.9	9.1	9.4	10.0	7.0	8.3	7.7	6.0	8.8	8.3	4.5
% no or not at all	37.7	38.4	34.8	48.7	48.3	38.9	32.1	36.0	48.2	41.2	27.5	27.9
Q27 - Are you satisfied with the way complaints/grievances are handled and resolved?												
Number of surveys	2,938	n = 10	216	109	67	338	532	287	644	42	540	163
% yes or most of the time	67.1	65.1	64.4	56.0	65.7	64.2	65.0	77.0	65.8	57.1	72.6	63.2
% some of the time	25.5	26.7	29.6	39.4	23.9	25.4	26.9	16.7	25.5	26.2	23.1	30.1
% no or not at all	7.4	8.2	6.0	4.6	10.4	10.4	8.1	6.3	8.7	16.7	4.3	6.7
Q28 - Do you feel that services and supports have made a positive difference in the life of your family?												
Number of surveys	4,251	n = 10	324	190	121	477	695	409	1,008	70	729	228
% yes or most of the time	83.2	82.2	82.1	80.0	75.2	80.7	85.0	85.1	82.8	84.3	85.3	81.6
% some of the time	15.1	16.0	15.4	18.4	22.3	17.0	13.8	13.7	15.0	12.9	13.3	18.0
% no or not at all	1.7	1.8	2.5	1.6	2.5	2.3	1.2	1.2	2.2	2.9	1.4	0.4
Q29 - Overall, do you feel that your family member is happy?												
Number of surveys	4,391	n = 10	327	203	129	493	705	422	1,064	71	749	228
% yes or most of the time	80.7	80.2	79.2	82.8	76.7	76.5	81.1	80.3	81.1	80.3	83.3	80.7
% some of the time	17.8	18.1	17.7	16.3	20.2	21.9	17.6	18.5	17.2	16.9	15.9	18.4
% no or not at all	1.5	1.8	3.1	1.0	3.1	1.6	1.3	1.2	1.7	2.8	0.8	0.9