

Adult Family Survey

Preliminary Report – January 2004
2002-2003 Data



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

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Organization of Report

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

This report is organized as follows:

I. INTRODUCTION

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

II. ADULT FAMILY SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

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

IV. RESULTS

This section provides aggregate and state-by-state results for demographic, service utilization, service planning, access and delivery, choice and control, community connections, satisfaction and outcome data. It also provides a look at state trends, comparing individual state results against the average of all state results, and an analysis of open-ended comments offered by respondents.

I. Introduction

Overview of National Core Indicators

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

Phase I – 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. Adult Family Survey

Background

This report focuses on the Adult Family Survey, formerly called the Family Support Survey.

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

Nearly 3,300 survey questionnaires were returned, with the return rates (number of questionnaires returned divided by the total number mailed) ranging from 37 to 48 percent. These were relatively good return rates for this type of mail survey. Phase I demonstrated that the survey was relatively straightforward to administer, yielded good response rates, and provided sound feedback to SDDAs. Based on feedback from the states, the Phase I instrument was slightly modified and reissued for administration during Phase II.

1999 - 2000 – During Phase II, twelve states administered the revised “Family Support Survey.” Over 10,800 surveys were mailed out, and the overall return rate was 39.6%. Only minor changes were made following Phase II. Some graphics were added to make the survey more visually interesting, easier to follow, and more appealing to answer, and some of the demographic questions were reworded and clarified based on feedback from participating states. Also, the title of the survey form was changed to “Family Survey.” In addition, a few questions were added to gauge the level of interest in self-management of supports and services.

2000 - 2001 – In the year 2000, twelve states participated and mailed out over 15,000 Family Surveys. Response rates among states ranged from 31% to 58%, with approximately 6,300 completed surveys returned.

2001-2002 – Fourteen states participated, mailing out over 15,000 Adult Family Surveys. Response rates among states ranged from 27% to 72% (averaging 38%), with approximately 6,000 completed surveys returned.

2002-2003 – The results from this year’s survey are explored in this report. Fifteen states participated. Over 15,000 surveys were sent out, with response rates ranging from 24% to 53%, and approximately 5,200 completed surveys utilized for analysis.

State Participation

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

Table 3 State Participation in NCI Adult Family Survey (Adults Living at Home with Family)				
Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003
AZ	AZ	CT	AZ	CA - Orange Co.
CT	CT	DE	HI	CT
MO	KY	IA	IL	DE
NE	NE	KY	IA	HI
PA	NC	MA	NE	IN
VT	PA	MN	NC	IA
VA	VT	MT	OK	ME
	WA	NE	PA	MA
		NC	UT	NC
		PA	VT	OK
		RI	WA	PA
		UT	WV	SC
			WY	SD
			CA - Orange Co.	WV
				WY

Survey Instrument

States that administer the Adult Family Survey agree to employ NCI's base instrument and questions. If it wishes, a state may include additional questions to address topics not dealt with in the base instrument. Since all states use the standard questionnaire, the results are comparable state-to-state. Here, we describe the Adult Family Survey developed by the project. Later, we discuss how the surveys were administered and how the results were analyzed.

The Adult Family Survey used in 2002-2003 not only asks families to express their overall level of satisfaction with services and supports, it also probes specific aspects of the service system's capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; and outcomes. Combined, this information provides an overall picture of family satisfaction within and across states.

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

Services Received – A brief section of the survey asks respondents to identify the services and supports that they and/or their family member with a disability receive.

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

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

III. Methods

Sampling & Administration

States administered the Adult Family Survey by selecting a random sample of 1,000 families who: a) have an adult family member with developmental disabilities living at home, and b) receive service coordination and at least one additional "direct" service or support. Adults were defined as individuals with disabilities age 18 or older. A sample size of 1,000 was selected in anticipation that states would obtain at least a 40% return rate, yielding 400 or more usable responses per state. With 400 usable responses per state, the results may be compared across states within a confidence level of $\pm 10\%$. In states where there were fewer than 1,000 potential respondent families, surveys were sent to all eligible families.

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

- ◆ The question "Does your family member live at home with you?" was used to screen out respondents who received a survey by mistake. For instance, if a respondent indicated that their family member with disabilities lived outside of the family home, yet received the Adult Family Survey, their responses were dropped.
- ◆ If the respondent indicated that their family member with disabilities was under the age of 18, their responses were dropped.
- ◆ If demographic information was entered into the file, but no survey questions were answered, these responses were also dropped.

Response Rates

During 2002-2003, fourteen states and one local developmental disability authority administered the Adult Family Survey. Table 3 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis.

Table 4
Adult Family Survey - State Response Rates

State	Surveys Mailed	Surveys Returned (%)	Response Rate (%)	Usable Surveys
CA-Orange Co.	2,915	726	25%	724
Connecticut	1,200	328	27%	315
Delaware	800	261	33%	261
Hawaii	486	237	49%	220
Indiana		62	#DIV/0!	26
Iowa	1,367	332	24%	317
Maine	713	377	53%	353
Massachusetts	2,000	497	25%	448
North Carolina	1,100	430	39%	390
Oklahoma	1,051	496	47%	483
Pennsylvania	2,760	1,132	41%	1,076
South Carolina		226	#DIV/0!	193
South Dakota	153	79	52%	53
West Virginia	800	272	34%	253
Wyoming	203	79	39%	78
Overall	15,548	5,534	37%	5,190

* denotes data missing

The desired response rate (the percentage of surveys returned versus the number mailed) to these surveys is 40%. Table 3 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. 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 24% to 53%. Of all Adult Family Surveys returned, 94% were accepted and included in the data analysis.

Data Analysis

NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. HSRI utilizes SPSS (v. 10) software for statistical analysis and N6 software for support in analysis of open-ended comments.

IV. Results

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

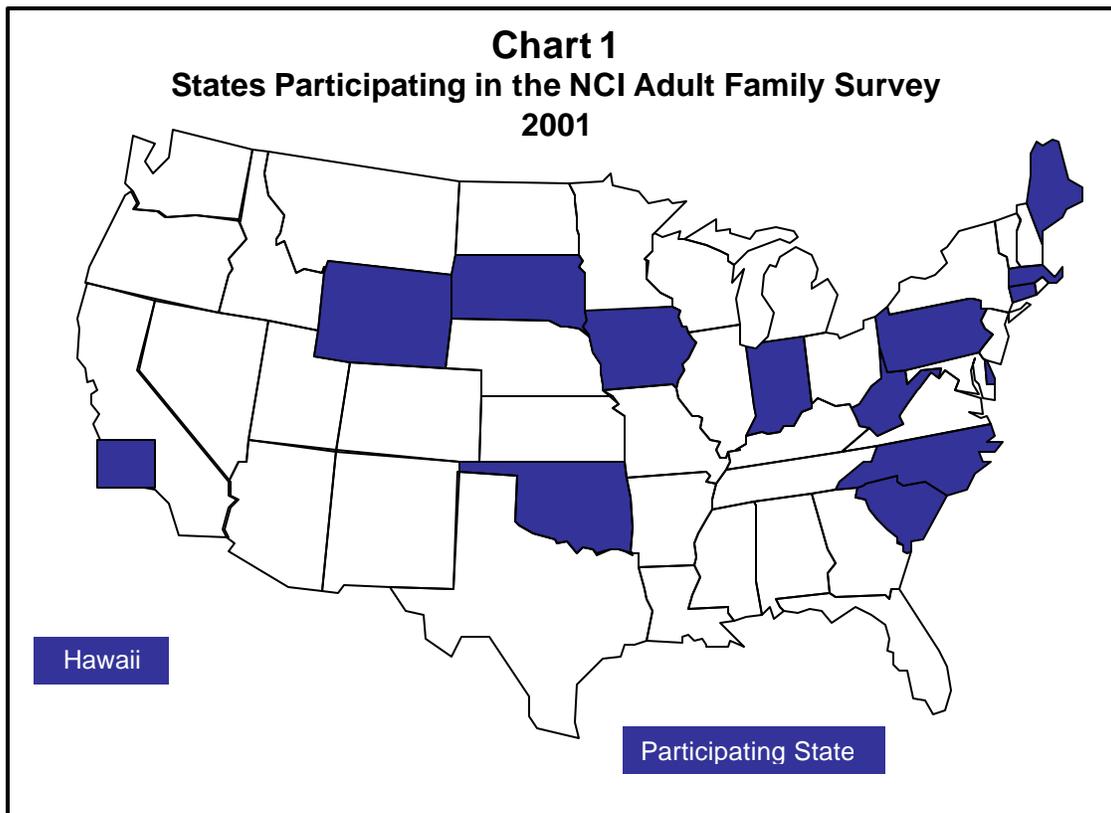
It is important to note that the TABLES provide individual state results and result averages that are calculated through two separate methods:

1. Total Percentages indicate the average percentage across all individual respondents.
2. State Averages indicate the average percentage across the fourteen 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

- ◆ Fourteen states and one local DD authority provided data for this Report. They include California's Orange County Regional Center, Connecticut, Delaware, Hawaii, Indiana, Iowa, Maine, Massachusetts, North Carolina, Oklahoma, Pennsylvania, South Carolina, South Dakota, West Virginia and Wyoming.

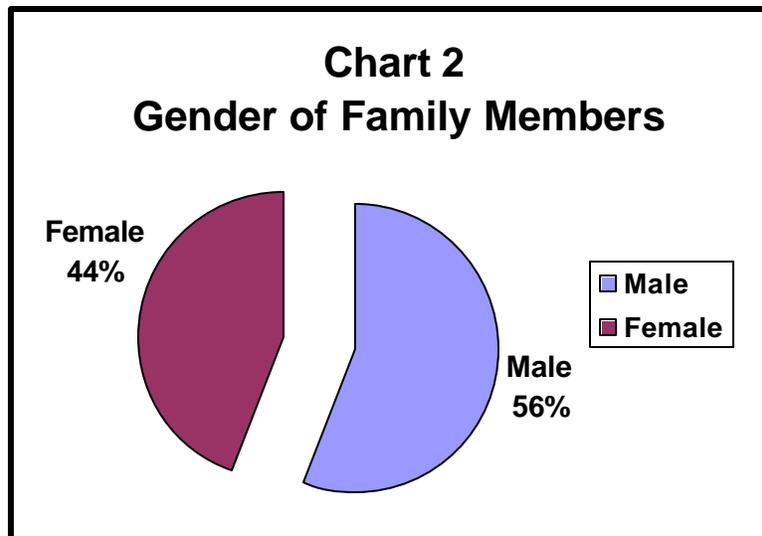


Characteristics of Family Members with Disabilities

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

Gender of Family Member

- ◆ On average, across the states, 56% of family members with disabilities were male, 44% were female.



State	% Male	% Female
CA-RCOC	53.7	46.3
CT	51.7	48.3
DE	57.0	43.0
HI	56.7	43.3
IA	52.7	47.3
IN	69.2	30.8
MA	56.8	43.2
ME	54.0	46.0
NC	59.0	41.0
OK	54.7	45.3
PA	57.1	42.9
SC	57.5	42.5
SD	53.2	46.8
WV	50.2	49.8
WY	53.9	46.1
Total n	2,780	2,241
Total %	55.4	44.6
State Avg. %	55.8	44.2

Age of Family Member

- ◆ Across all participating states, the average age of family members with disabilities was 33.7, with a range in age from 18 to 97.

State	Average Age	Range
CA-RCOC	32.6	18-96
CT	32.9	18-84
DE	34.3	18-75
HI	29.3	18-78
IA	32.7	18-73
IN	38.1	18-67
MA	37.1	18-89
ME	33.6	18-79
NC	35.3	18-97
OK	30.0	18-83
PA	34.7	18-77
SC	34.1	18-74
SD	32.5	19-63
WV	33.9	18-87
WY	34.5	21-55
Total n	5,061	
Total Avg.	33.6	18-97
State Avg.	33.7	

Race of Family Member

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

- ◆ Across all states, 77% of the family members were White, 10% were Black/African-American, 5% were Asian-American, 3% were Hispanic/Latino, 3% were Native Hawaiian/Pacific Islander, 2.5% were Mixed Races, and 2% were American Indian/Alaska Native.

Table 7 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
CA-RCOC	51.7	1.4	19.9	1.4	1.1	3.6	1.1	23.3
CT	80.1	7.8	1.7	2.0	0.3	1.7	0.3	7.8
DE	73.8	19.8	1.2	0.8	0.0	1.6	0.0	2.4
HI	23.9	0.5	49.2	1.5	24.4	17.8	4.1	2.5
IA	84.1	2.5	0.6	1.9	0.0	0.0	5.7	0.0
IN	92.0	11.5	0.0	3.8	0.0	0.0	0.0	0.0
MA	92.3	3.5	0.7	3.0	0.2	0.7	0.5	2.3
ME	97.3	0.6	0.3	1.8	0.0	1.5	0.0	0.0
NC	62.8	33.1	0.0	1.8	0.0	0.8	0.0	0.8
OK	78.7	6.9	1.5	12.1	0.2	4.5	0.9	3.0
PA	93.8	3.5	0.4	1.5	0.0	0.5	0.5	0.8
SC	41.3	56.0	0.5	1.1	0.5	1.6	0.5	0.5
SD	90.6	0.0	0.0	5.7	0.0	0.0	0.0	1.9
WV	93.9	4.1	0.4	4.9	0.8	1.2	0.4	0.4
WY	92.2	1.3	1.3	2.6	0.0	2.6	0.0	3.9
Total n	3,871	423	269	145	62	115	48	244
Total %	76.9	8.4	5.3	2.9	1.2	2.3	1.0	4.8
State Avg. %	76.6	10.2	5.2	3.1	1.8	2.5	0.9	3.3

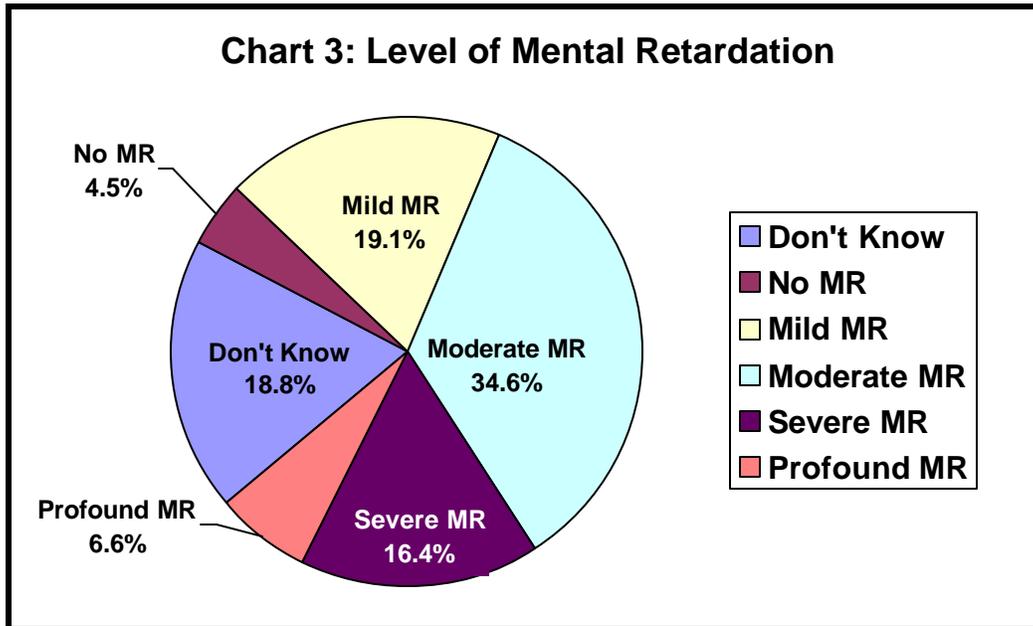
More Than One Person with Disabilities Living in Household

- ◆ Overall, 12% of households include more than one individual with a developmental disability.

Table 8 More Than One Person in Household with a Developmental Disability		
State	% Yes	% No
CA-RCOC	10.2	89.8
CT	14.1	85.9
DE	14.1	85.9
HI	9.0	91.0
IA	21.1	78.9
IN	29.2	70.8
MA	11.0	89.0
ME	11.0	89.0
NC	16.8	83.2
OK	10.2	89.8
PA	10.4	89.6
SC	7.4	92.6
SD	1.9	98.1
WV	10.4	89.6
WY	9.1	90.9
Total n	593	4,433
Total %	11.8	88.2
State Avg. %	12.4	87.6

Level of Mental Retardation of Family Member

- ◆ On average, over one-third (35%) of the family members with disabilities had a diagnosis of moderate mental retardation. Additionally, 23% were individuals with severe/profound mental retardation, 19% had mild mental retardation, and 5% had no mental retardation diagnosis. 19% of 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
CA-RCOC	8.2	18.8	31.1	20.2	5.3	16.4
CT	1.7	19.4	36.7	16.6	4.2	21.5
DE	4.9	19.8	33.7	11.9	3.3	26.3
HI	5.4	16.7	37.9	19.7	4.9	15.3
IA	14.9	19.0	33.0	12.7	5.1	15.2
IN	0.0	12.5	50.0	12.5	12.5	12.5
MA	2.2	15.7	45.1	14.2	4.8	18.1
ME	3.1	27.5	35.2	14.2	2.5	17.6
NC	6.5	14.1	25.0	23.4	14.4	16.6
OK	2.7	14.9	31.1	22.7	11.1	17.6
PA	1.5	20.3	33.5	14.5	6.0	24.2
SC	10.4	16.2	19.1	11.6	6.9	35.8
SD	2.0	30.6	36.7	14.3	6.1	10.2
WV	4.0	19.4	25.1	21.1	8.8	21.6
WY	0.0	21.9	45.2	16.4	2.7	13.7
Total n	231	918	1,619	831	316	971
Total %	4.7	18.8	33.1	17.0	6.5	19.9
State Avg. %	4.5	19.1	34.6	16.4	6.6	18.8

Family Member's Disabilities – Other than Mental Retardation

- ♦ Many family members experience disabilities in addition to mental retardation. The most prevalent “other” disabilities include: seizure disorders/neurological problems (28%), vision/hearing impairments (25%), and physical disabilities.

Table 10A Other Disabilities of Family Member						
State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
CA-RCOC	14.0	11.6	13.6	10.8	24.2	1.1
CT	10.2	11.6	15.4	7.4	23.2	0.4
DE	13.5	10.1	12.7	7.2	26.2	1.3
HI	14.1	12.0	19.4	13.6	34.6	3.1
IA	5.8	5.7	14.0	12.7	25.4	0.0
IN	16.0	24.0	24.0	20.0	28.0	8.0
MA	16.5	7.0	15.6	4.9	22.4	1.0
ME	13.8	8.2	13.2	8.2	21.0	0.6
NC	19.7	10.3	20.3	12.1	28.2	1.0
OK	12.3	8.2	31.7	14.7	38.8	1.5
PA	15.7	6.3	17.9	10.5	26.2	1.0
SC	16.3	7.3	19.7	11.2	27.0	1.7
SD	5.7	9.4	24.5	15.1	26.4	0.0
WV	32.2	10.7	29.5	15.8	40.6	1.7
WY	7.8	6.5	22.1	10.4	26.0	1.3
Total n	728	432	905	527	1,346	55
Total %	14.8	8.8	18.4	10.7	27.4	1.1
State Avg. %	14.2	9.9	19.6	11.6	27.9	1.6

Table 10B Other Disabilities of Family Member						
State	Vision/ Hearing Impairment	Physical Disability	Communi- cation Disorder	Alzheimer's Disease	Down Syndrome	Other Disability
CA-RCOC	17.0	20.2	16.2	0.8	18.0	12.6
CT	21.1	21.1	22.1	0.0	23.9	13.7
DE	20.7	19.0	13.1	0.4	20.3	12.2
HI	27.2	31.9	18.3	0.5	22.5	19.4
IA	16.2	19.4	14.0	0.0	11.4	14.9
IN	28.0	20.0	32.0	4.0	12.0	20.0
MA	25.5	21.4	15.6	0.7	28.2	15.1
ME	21.0	22.9	18.2	1.3	25.1	14.4
NC	25.4	27.9	24.4	0.5	11.8	13.1
OK	32.1	40.5	31.0	0.4	15.3	18.8
PA	21.2	21.5	16.6	0.3	22.9	13.5
SC	27.1	32.2	29.9	0.6	11.9	11.9
SD	32.1	20.8	18.9	0.0	*	17.0
WV	29.9	41.7	36.8	3.0	10.3	14.6
WY	33.8	19.5	27.3	0.0	27.3	10.5
Total n	1,136	1,234	996	31	938	702
Total %	23.1	25.1	20.3	0.6	19.3	14.3
State Avg. %	25.2	25.3	22.3	0.8	18.6	14.8

* 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 in the household.

Age of Respondent

- ◆ Across all states, nearly half (46%) of respondents fell into the age category of 55 to 74 years old. Eleven percent of respondents were over age 75, and the remaining 41% were under 55.

State	Under 35	35-54	55-74	75 or Older
CA-RCOC	5.4	29.9	45.6	19.0
CT	4.2	37.3	43.8	14.6
DE	0.8	35.9	51.6	11.7
HI	6.6	41.7	43.6	8.1
IA	8.4	45.3	37.3	9.0
IN	0.0	40.0	56.0	4.0
MA	4.5	25.9	52.0	17.5
ME	7.1	39.1	44.0	9.7
NC	3.9	46.8	40.8	8.5
OK	2.0	48.8	41.2	8.0
PA	3.7	33.4	48.8	14.2
SC	9.8	28.0	35.8	26.4
SD	0.0	19.6	76.5	3.9
WV	5.4	42.7	46.9	5.0
WY	3.9	29.9	29.9	10.4
Total n	235	1,851	2,313	656
Total %	4.6	36.6	45.8	13.0
State Avg. %	4.4	36.3	46.3	11.3

Relationship of Respondent to Individual with Disabilities

- ♦ The vast majority of respondents were parents of adult children with disabilities (85%). The remaining respondents included siblings (9%), spouses (less than 1%), and others(6%).

Table 12				
Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
CA-RCOC	89.1	7.9	0.1	2.9
CT	90.4	5.9	0.0	3.6
DE	81.9	6.5	0.4	11.2
HI	84.8	11.4	0.0	3.8
IA	83.9	5.1	5.1	5.8
IN	80.8	7.7	0.0	11.5
MA	79.8	12.2	3.0	5.1
ME	84.6	9.6	0.9	4.9
NC	82.1	7.3	1.6	9.1
OK	89.9	3.2	0.0	6.9
PA	85.2	9.6	0.8	4.3
SC	75.4	10.7	0.0	13.9
SD	86.5	13.6	0.0	0.0
WV	89.1	6.1	0.4	4.3
WY	84.4	11.7	0.0	3.9
Total n	4,298	413	50	280
Total %	85.3	8.2	1.0	5.6
State Avg. %	84.5	8.6	0.8	6.1

Respondent's Role as Primary Caregiver

- ◆ In total, 96% of all respondents considered themselves to be the primary caregiver for their family member with disabilities. This was consistent across all of the states.

Table 13 Respondent is Primary Caregiver		
State	% Yes	% No
CA-RCOC	95.3	4.7
CT	96.0	4.0
DE	94.1	5.9
HI	97.6	2.4
IA	95.4	4.6
IN	96.2	3.8
MA	91.2	8.8
ME	94.5	5.5
NC	97.1	2.9
OK	97.6	2.4
PA	96.6	3.4
SC	92.9	7.1
SD	96.2	3.8
WV	97.1	2.9
WY	97.3	2.7
Total n	4,770	218
Total %	95.6	4.4
State Avg. %	95.7	4.3

Respondent's Role as Guardian or Conservator

- ◆ Overall, nearly two-thirds (63%) of respondents indicated that they were their family member's legal guardian or conservator. Across the states, results varied from 46% (in Orange County, California and Indiana) to 80% or more in Hawaii and Connecticut).

State	% Yes	% No
CA-RCOC	45.7	54.3
CT	82.6	17.4
DE	51.7	48.3
HI	79.7	20.3
IA	61.5	38.5
IN	46.2	53.8
MA	60.5	39.5
ME	70.3	29.7
NC	66.9	33.1
OK	58.1	41.9
PA	56.0	44.0
SC	60.6	39.4
SD	72.5	27.5
WV	61.2	38.8
WY	72.7	27.3
Total n	2,930	
Total %	60.6	39.4
State Avg. %	63.1	36.9

Health of Respondent

- ♦ Most respondents (individuals who completed the surveys) indicated that they were in good (52%) or excellent (22%) health, however one-fourth of respondents (26%) categorized their health as being fair or poor.

State	Excellent	Good	Fair	Poor
CA-RCOC	23.6	54.8	18.7	2.9
CT	19.1	59.2	19.1	2.6
DE	15.4	58.7	21.6	4.2
HI	22.6	54.8	19.7	2.9
IA	27.9	52.1	18.7	1.3
IN	38.5	53.8	3.8	3.8
MA	22.4	52.5	21.5	3.7
ME	25.6	48.1	22.5	3.7
NC	15.8	49.1	28.3	6.8
OK	21.8	46.2	25.7	6.3
PA	18.1	52.7	25.1	4.1
SC	17.6	41.5	35.6	5.3
SD	27.5	54.9	11.8	5.9
WV	13.4	50.8	29.7	6.1
WY	22.7	54.7	20.0	2.7
Total n	1,045	2,636	1,173	207
Total %	20.6	52.1	23.2	4.1
State Avg. %	22.1	52.3	21.5	4.2

Household Income

- ◆ Over half (52%) of respondents had an annual household income (including all wage earners within the household) of \$25,000 or less. 29% had a household income between \$25,001 and \$50,00, and only 19% had an income over \$50,000.

Table 16 Household Income					
State	Below \$15,000	\$15,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	Over \$75,000
CA-RCOC	26.4	21.5	23.8	15.4	12.9
CT	27.9	19.7	24.6	15.6	12.3
DE	23.8	26.7	27.1	14.3	8.1
HI	19.8	20.3	33.5	16.2	10.2
IA	33.0	19.8	22.3	15.4	9.5
IN	20.0	10.0	50.0	20.0	0.0
MA	20.5	25.4	29.0	15.0	10.1
ME	* Question not asked				
NC	39.0	25.7	23.0	10.0	2.4
OK	28.2	23.6	31.9	10.6	5.7
PA	31.8	23.3	27.5	7.9	4.3
SC	56.7	21.3	18.9	2.4	0.6
SD	23.3	23.2	27.9	20.9	4.7
WV	34.0	31.0	26.6	5.4	3.0
WY	16.9	29.2	35.4	13.8	4.6
Total n	1,158	954	1,039	453	273
Total %	29.9	24.6	26.8	11.7	7.0
State Avg. %	28.7	22.9	28.7	13.1	6.3

Services and Supports Received

- ◆ Across participating states, on average, day/employment and transportation services were the supports most often provided (68% and 60% respectively) to the family member with disabilities.
- ◆ Additionally, 37% received financial support, 31% obtained in-home supports, 30% utilized out-of-home respite care, and 28% received other needed supports.

Table 17 Services and Supports Received (%)						
State	Financial support	In-home support	Out-of-home respite care	Day / employment supports	Transportation	Other
CA-RCOC	32.7	22.4	26.1	62.7	57.4	13.6
CT	37.3	16.2	27.8	78.8	66.0	17.1
DE	31.4	8.0	23.4	75.8	73.5	14.9
HI	40.5	26.9	34.4	64.4	56.7	24.1
IA	35.7	56.6	39.5	67.1	59.0	29.5
IN	35.0	41.7	56.0	65.4	57.7	26.9
MA	42.2	19.6	31.9	79.2	71.7	28.5
ME	50.0	24.7	23.0	70.5	63.5	23.7
NC	32.6	44.2	36.5	62.7	53.7	29.9
OK	43.2	66.2	18.8	42.5	49.5	46.2
PA	42.5	22.6	27.0	67.5	55.0	19.4
SC	20.2	28.3	19.1	54.5	58.5	32.6
SD	40.4	9.6	17.0	88.7	64.2	29.4
WV	39.9	34.6	25.6	64.3	60.9	40.5
WY	35.6	38.5	46.8	71.4	58.4	40.3
Total n	1,772	1,493	1,366	3,292	2,950	1,239
Total Avg. %	38.4	30.4	27.9	66.0	59.2	25.5
State Avg. %	37.3	30.7	30.2	67.7	60.4	27.8

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 is provided.

- ◆ The Chart illustrates the State Average results (i.e., the average percentage across the fourteen 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

- ◆ Across states, fewer than half (42%) of respondents indicated they receive information about the services and supports available to them. Individual state results varied considerably, ranging from 28% in Delaware, Maine and North Carolina to 71% in Orange County, CA.

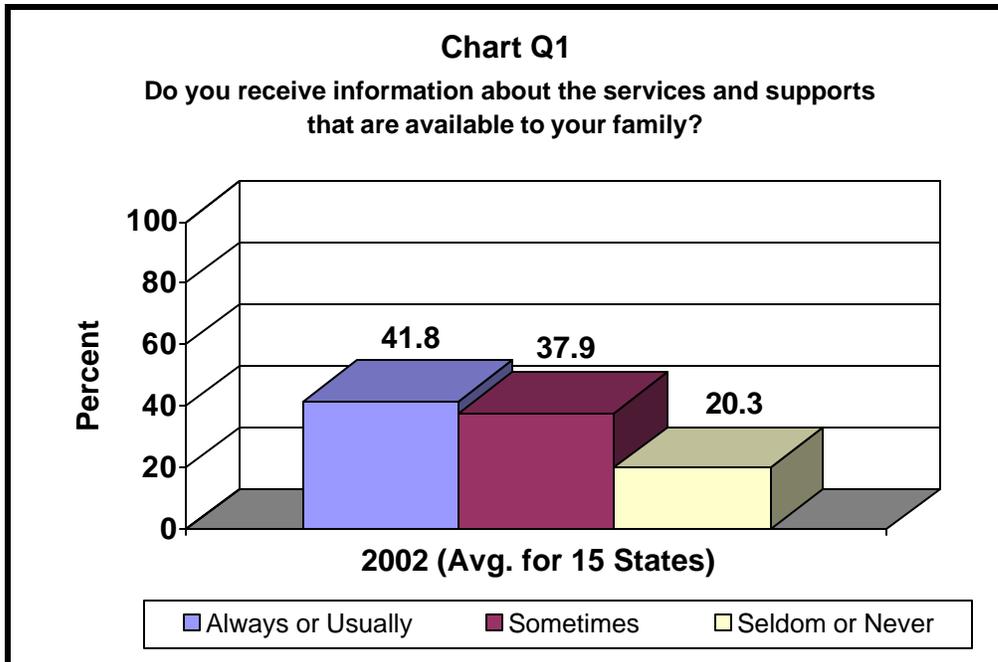


Table Q1

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑↑	71.1	22.3	6.6	678
CT	↓	34.4	47.6	18.0	294
DE	↓↓	28.5	44.8	26.7	221
HI	↑↑	51.9	38.7	9.4	212
IA	↑	47.7	39.1	13.2	302
IN		42.3	46.2	11.5	26
MA		37.5	38.2	24.2	421
ME	↓↓	28.2	38.1	33.7	323
NC	↓↓	28.8	39.4	31.8	368
OK	↓	36.1	44.2	19.7	468
PA		46.0	38.5	15.6	1,003
SC		45.3	33.0	21.8	179
SD		39.2	31.4	29.4	51
WV		37.4	36.9	25.7	222
WY	↑↑	52.0	30.7	17.3	75
Total %		43.8	37.2	19.0	4,843
State Average %		41.8	37.9	20.3	15

- ◆ Among those who receive information, over half (56%) found the information easy to understand, while the remaining 44% found the information, at least sometimes, difficult to understand.

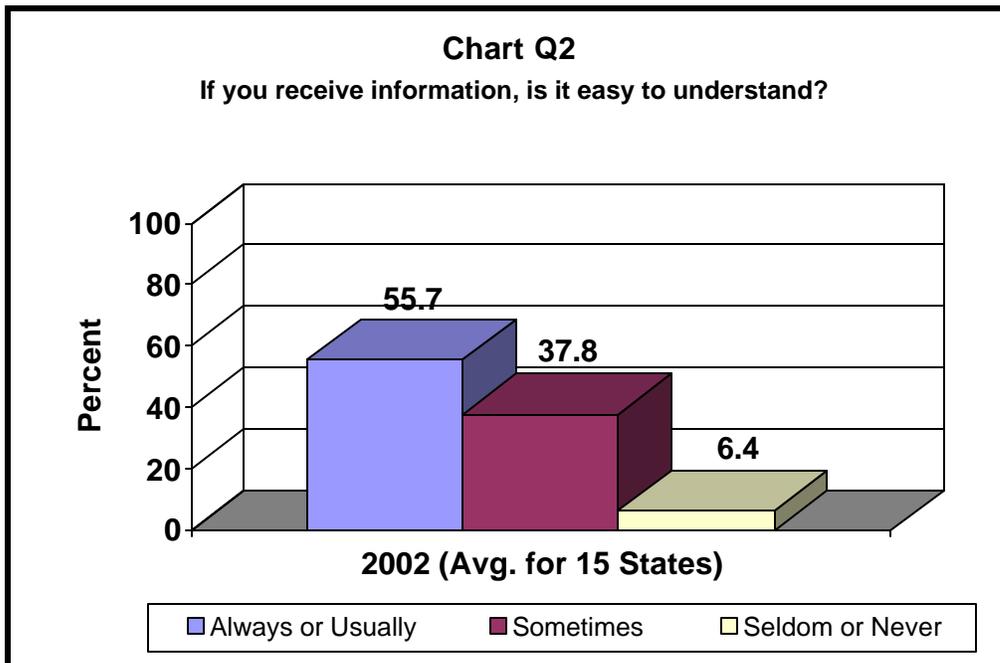


Table Q2
If you receive information, is it easy to understand?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑↑	72.3	24.3	3.3	658
CT		55.7	38.8	5.5	255
DE		54.4	36.9	8.7	195
HI		63.9	31.7	4.5	202
IA		54.5	41.3	4.2	286
IN	↓	50.0	45.8	4.2	24
MA		57.9	36.5	5.6	373
ME	↓	49.2	43.2	7.5	266
NC	↓	47.8	39.4	12.8	312
OK	↓	48.8	44.8	6.4	424
PA	↑	63.6	31.7	4.7	928
SC		52.4	36.1	11.4	166
SD	↑↑	67.5	30.0	2.5	40
WV	↓↓	41.6	51.8	6.6	197
WY		56.3	35.2	8.5	71
Total %		58.0	36.0	6.0	4,397
State Average %		55.7	37.8	6.4	15

- ◆ Half of respondents stated they got enough information to help them participate in planning, however the other half indicated they only sometimes or seldom had enough information.

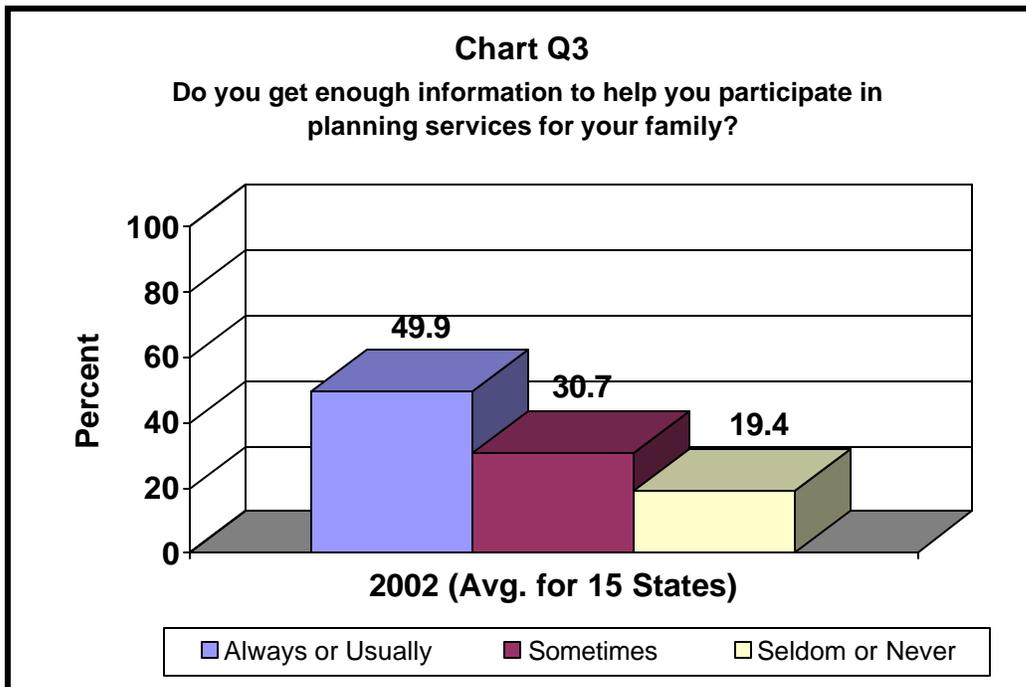


Table Q3
Do you get enough information to help you participate in planning services for your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑↑	65.7	23.7	10.5	636
CT	↓↓	39.0	34.1	26.9	249
DE	↓↓	37.9	34.1	28.0	211
HI	↑	57.0	30.9	12.1	207
IA	↑	58.0	30.8	11.2	286
IN		52.0	32.0	16.0	25
MA		45.7	32.3	22.0	396
ME	↓↓	38.7	31.3	29.9	284
NC		49.9	27.6	22.6	341
OK		47.3	32.3	20.4	446
PA		52.5	30.2	17.4	922
SC	↑	55.9	24.7	19.4	170
SD		52.9	29.4	17.6	51
WV		45.1	31.6	23.3	215
WY		50.7	35.2	14.1	71
Total %		51.1	30.0	19.0	4,510
State Average %		49.9	30.7	19.4	15

- ◆ About three-quarters (73%) of respondents, on average across states, indicated that they helped in developing their family member's service plan.

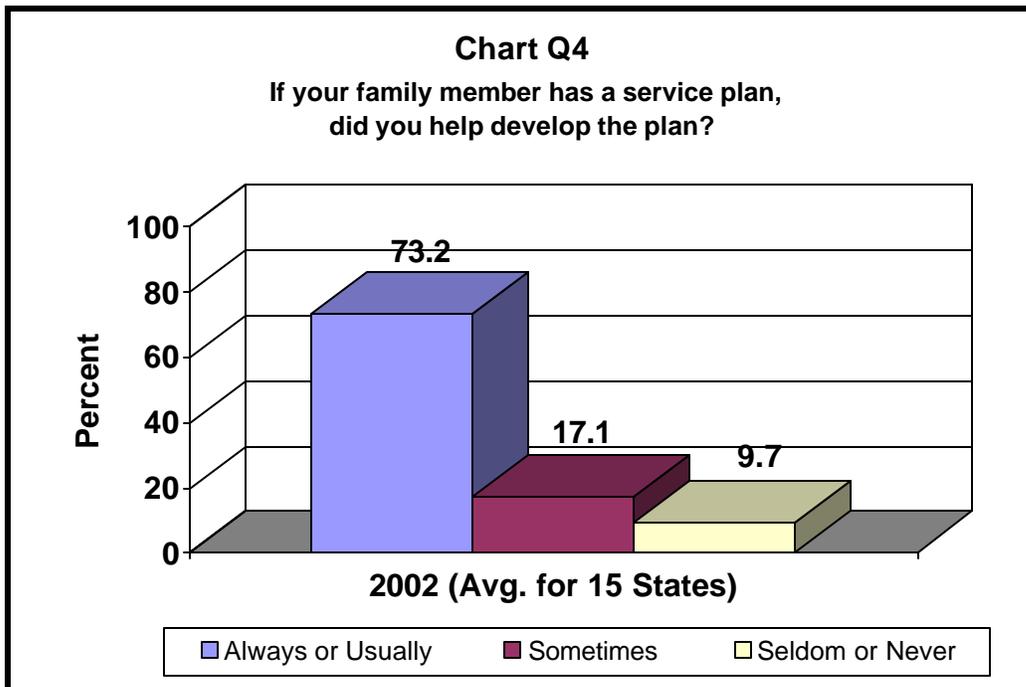


Table Q4
If your family member has a service plan, did you help develop the plan?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		69.1	18.0	12.9	511
CT		69.3	18.4	12.3	163
DE	↓↓	62.8	18.2	18.9	148
HI	↑↑	83.2	10.5	6.3	191
IA		76.4	18.9	4.7	254
IN	↑↑	87.0	13.0	0.0	23
MA		71.1	17.0	11.9	336
ME	↓	65.8	16.6	17.6	199
NC		71.0	16.6	12.4	307
OK	↑	81.5	12.6	5.9	406
PA		69.7	18.3	12.0	700
SC		69.8	20.8	9.4	159
SD		70.8	25.0	4.2	48
WV		69.0	18.5	12.5	184
WY	↑	82.1	13.4	4.5	67
Total %		72.1	17.0	10.9	3,696
State Average %		73.2	17.1	9.7	15

- ◆ Of those families with a service plan, 71% stated that the plan included things important to the respondent. Over one quarter of respondents (29%) indicated that the plan only sometimes, seldom or never included things important to them. Indiana had notably higher results, with 87% of respondents stating the plan reflected goals important to them

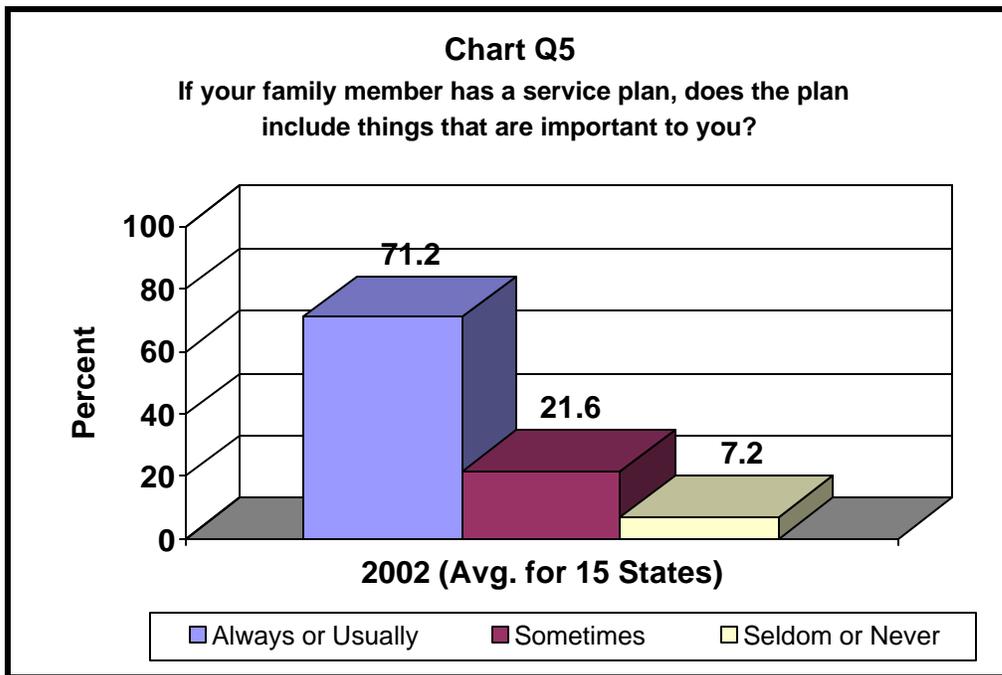


Table Q5
If your family member has a service plan, does the plan include things that are important to you?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		69.0	23.4	7.7	496
CT	↓↓	58.1	31.7	10.2	167
DE	↓	65.5	18.6	15.9	145
HI		76.1	19.7	4.3	188
IA		72.9	22.5	4.7	258
IN	↑↑	87.5	12.5	0.0	24
MA		68.6	23.7	7.7	338
ME	↓	65.2	22.1	12.7	204
NC		70.7	20.7	8.6	304
OK		73.0	21.1	6.0	403
PA		68.3	24.2	7.5	706
SC		72.4	21.2	6.4	156
SD	↑	76.6	21.3	2.1	47
WV		66.9	27.4	5.7	175
WY	↑	77.9	13.2	8.8	68
Total %		69.6	22.8	7.6	3,679
State Average %		71.2	21.6	7.2	15

- ◆ Across states, over half (58%) indicated that planning staff would help them figure out the supports they needed. However, a large percentage (42%) stated that this was only sometimes or even seldom the case.

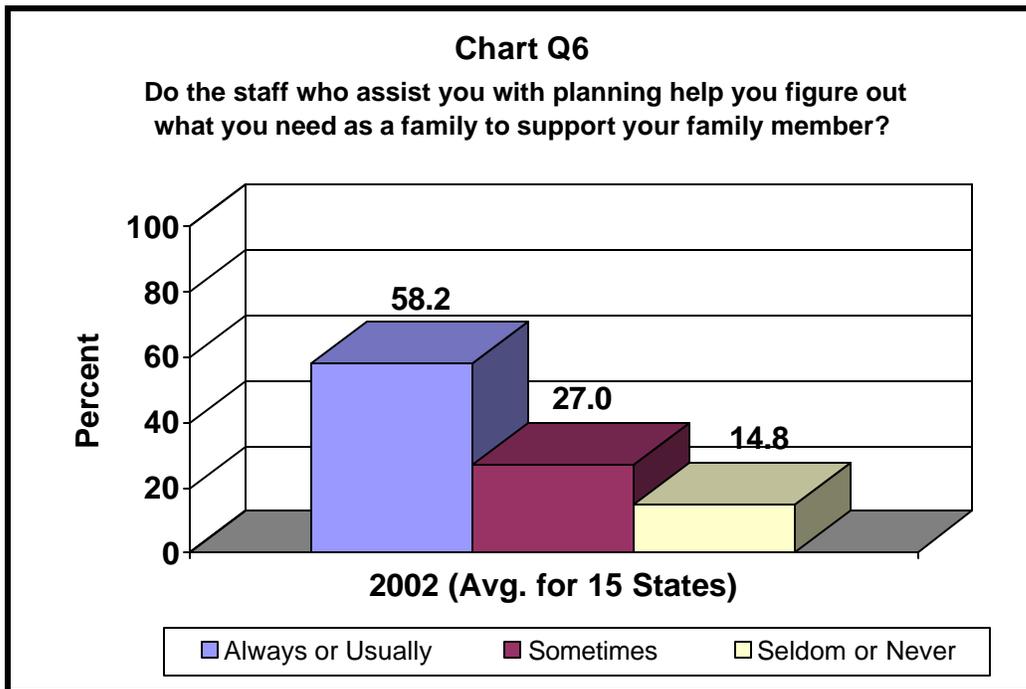


Table Q6					
Do the staff who assist you with planning help you figure out what you need as a family to support your family member?					
State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		59.0	27.0	14.1	619
CT		54.6	28.6	16.8	196
DE	↓	50.3	30.1	19.6	163
HI	↑	63.3	25.5	11.2	196
IA	↑	64.8	25.4	9.9	284
IN	↑↑	72.0	16.0	12.0	25
MA		53.4	29.8	16.9	356
ME	↓	50.6	29.0	20.4	245
NC		59.5	24.5	16.0	326
OK		59.3	27.3	13.3	428
PA		57.1	27.6	15.3	765
SC		55.6	30.8	13.6	169
SD		57.4	34.0	8.5	47
WV		55.3	26.3	18.4	190
WY		61.2	22.4	16.4	67
Total %		57.6	27.4	15.1	4,076
State Average %		58.2	27.0	14.8	15

- ◆ Across states, approximately three-quarters (77%) of respondents felt that staff respect their choices and opinions.

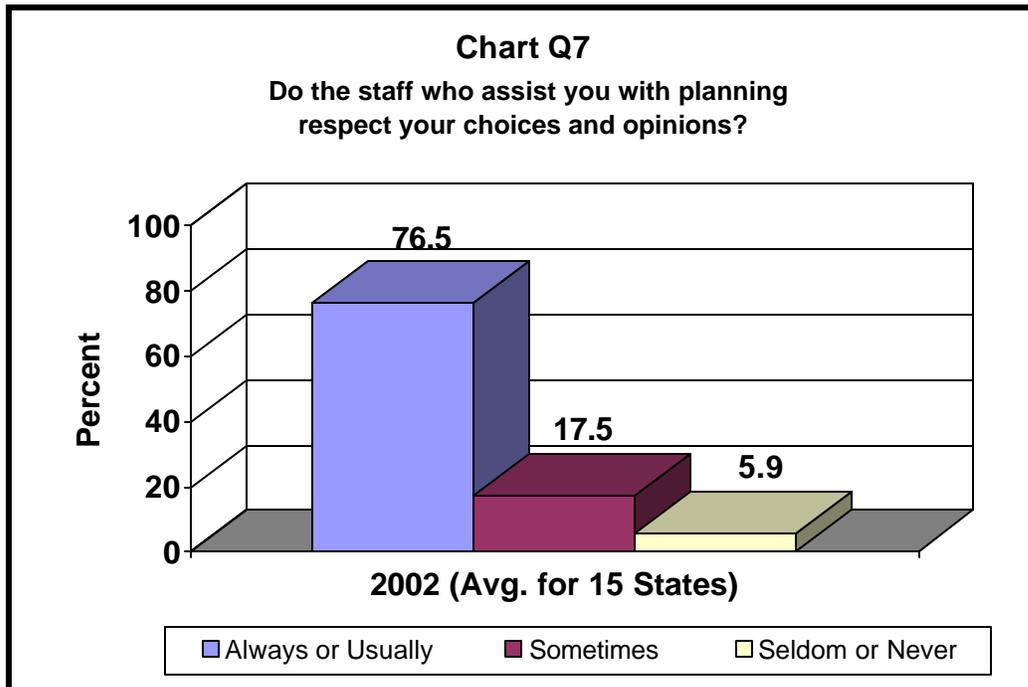


Table Q7
Do the staff who assist you with planning respect your choices and opinions?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑	83.9	12.9	3.3	644
CT		74.3	19.4	6.3	206
DE		78.1	14.4	7.5	160
HI	↑	82.4	14.7	2.9	204
IA		79.5	14.4	6.2	292
IN		76.9	19.2	3.8	26
MA		76.1	18.9	5.1	355
ME	↓	70.8	19.1	10.1	257
NC		77.7	13.9	8.4	323
OK		76.8	17.4	5.7	436
PA		78.0	16.2	5.8	778
SC		79.1	18.4	2.5	163
SD		72.9	22.9	4.2	48
WV	↓	68.1	25.7	6.3	191
WY		73.6	15.3	11.1	72
Total %		77.7	16.5	5.7	4,155
State Average %		76.5	17.5	5.9	15

- ◆ Among all respondents, nine of ten (89%) felt that agency staff were generally respectful and courteous.

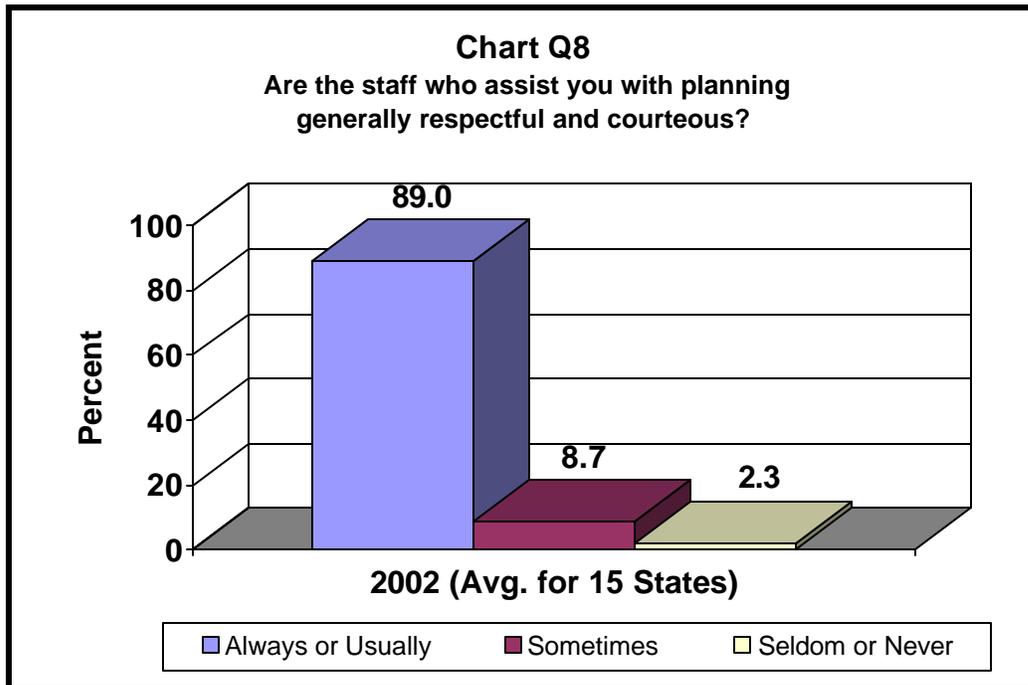


Table Q8
Are the staff who assist you with planning generally respectful and courteous?

State	Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	93.2	5.8	1.0	675
CT	86.3	11.7	2.0	205
DE	89.8	5.4	4.8	166
HI	89.7	9.8	0.5	204
IA	88.2	10.5	1.3	304
IN	96.2	3.8	0.0	26
MA	87.5	10.1	2.4	368
ME	86.6	10.3	3.1	261
NC	86.3	9.8	4.0	328
OK	86.2	11.1	2.7	443
PA	89.8	8.3	1.9	824
SC	90.8	6.9	2.3	173
SD	91.7	8.3	0.0	48
WV	86.3	10.2	3.6	197
WY	86.7	8.0	5.3	75
Total %	88.9	8.8	2.3	4,297
State Average %	89.0	8.7	2.3	15

- ◆ Among all respondents, 67% felt that agency staff were generally effective.

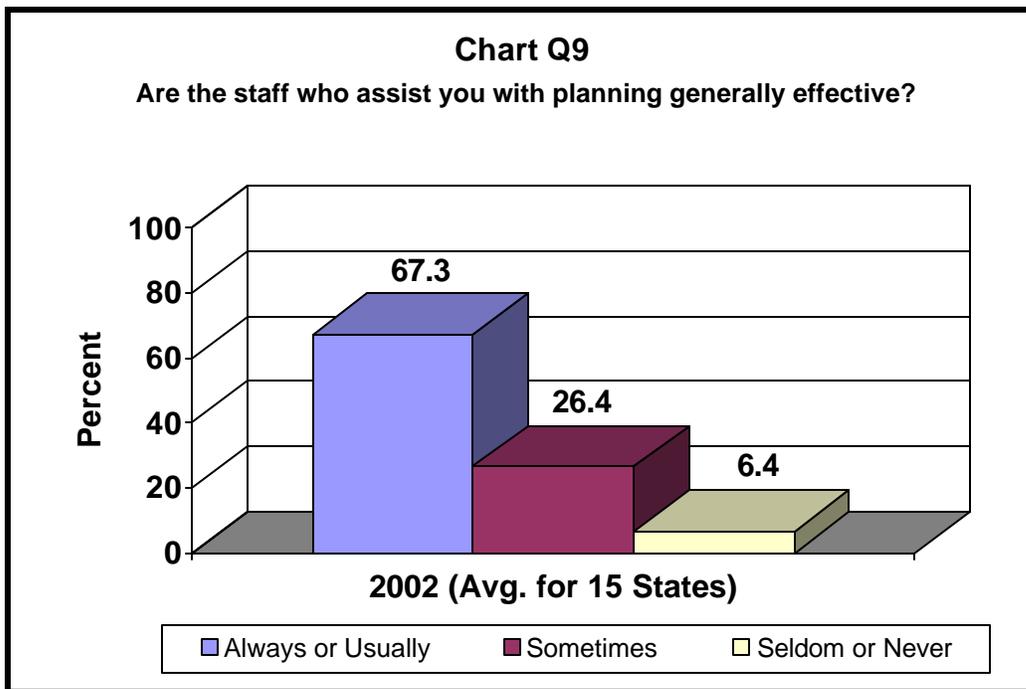


Table Q9
Are the staff who assist you with planning generally effective?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑	74.0	21.6	4.4	657
CT	↓	60.5	33.8	5.7	210
DE	↓	60.6	28.5	10.9	165
HI		69.0	25.5	5.5	200
IA	↑	78.9	16.3	4.8	294
IN	↑↑	80.8	15.4	3.8	26
MA		63.1	29.3	7.6	355
ME	↓	60.3	30.7	8.9	257
NC		66.0	26.8	7.2	321
OK	↓	60.7	32.0	7.3	440
PA		67.3	26.0	6.7	796
SC		63.3	30.2	6.5	169
SD	↑↑	79.2	20.8	0.0	48
WV		63.5	25.9	10.6	189
WY	↓	61.6	32.9	5.5	73
Total %		66.9	26.5	6.6	4,200
State Average %		67.3	26.4	6.4	15

- ◆ Across all states, 78% of respondents indicated they could typically contact staff when desired.

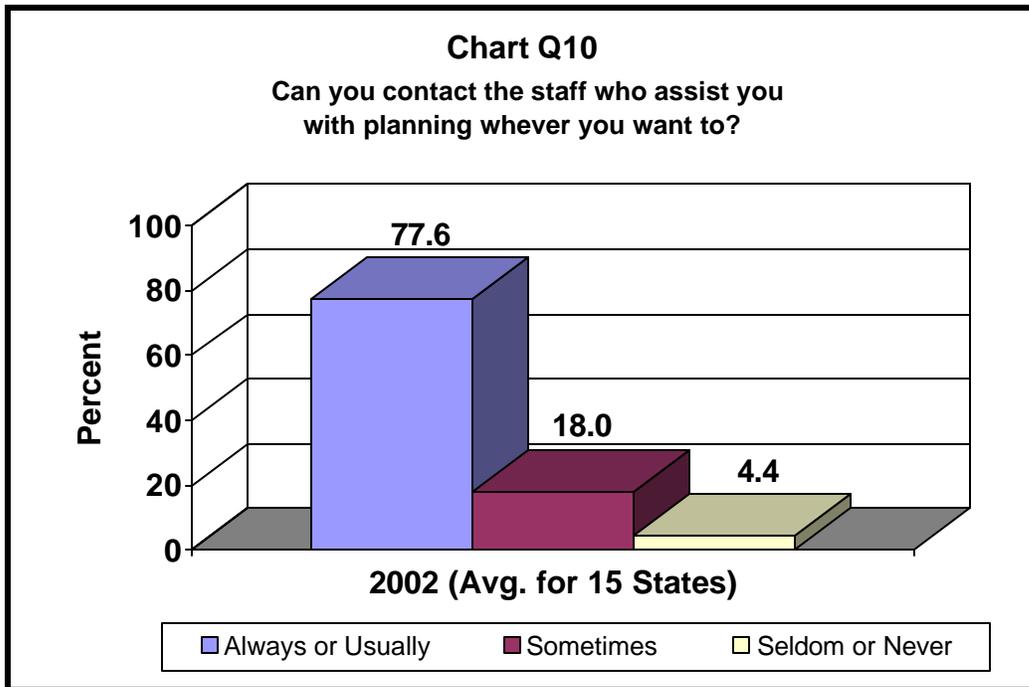


Table Q10
Can you contact the staff who assist you with planning whenever you want to?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		77.0	18.3	4.8	652
CT	↓	72.4	22.4	5.1	214
DE	↓	71.8	22.4	5.9	170
HI		77.6	18.9	3.5	201
IA		82.1	15.2	2.6	302
IN	↓	72.0	28.0	0.0	25
MA		75.9	19.2	4.9	369
ME		78.4	14.8	6.8	264
NC		76.0	16.6	7.4	325
OK		73.8	21.5	4.8	442
PA		80.4	14.5	5.1	827
SC		81.2	15.9	2.9	170
SD	↑↑	93.6	4.3	2.1	47
WV		73.8	21.9	4.3	187
WY		78.4	16.2	5.4	74
Total %		77.4	17.7	4.9	4,269
State Average %		77.6	18.0	4.4	15

Access to and Delivery of Services and Supports

- Overall, 70% of families stated their service coordinator helped them get needed supports when asked. Twenty-four percent said this happened sometimes, and 6% indicated that their service coordinator was rarely helpful in getting the assistance needed.

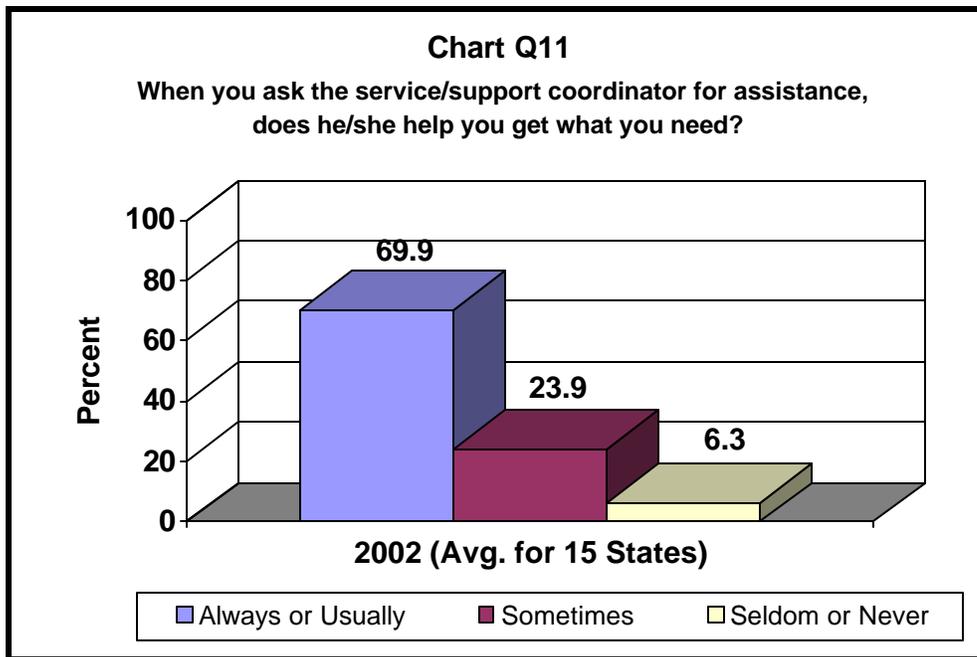


Table Q11
When you ask the service/support coordinator for assistance, does he/she help you get what you need?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		74.4	21.8	3.7	618
CT	↓	61.1	32.9	6.0	234
DE	↓	63.1	24.6	12.3	179
HI	↓	62.6	31.8	5.6	198
IA	↑↑	81.3	16.0	2.8	288
IN		72.0	28.0	0.0	25
MA		66.7	27.2	6.1	375
ME		68.7	25.4	5.8	291
NC		70.3	21.8	7.9	330
OK		70.0	24.3	5.7	474
PA		70.9	23.0	6.2	844
SC		72.7	20.3	7.0	172
SD	↑	78.0	18.0	4.0	50
WV		66.7	24.0	9.3	204
WY		69.6	18.8	11.6	69
Total %		70.1	23.8	6.1	4,351
State Average %		69.9	23.9	6.3	15

- ◆ Fifty-eight percent of respondents said they always or usually get the services and supports needed. Thirty-two percent got needed supports some of the time, and the remaining 10% seldom or never received needed supports.

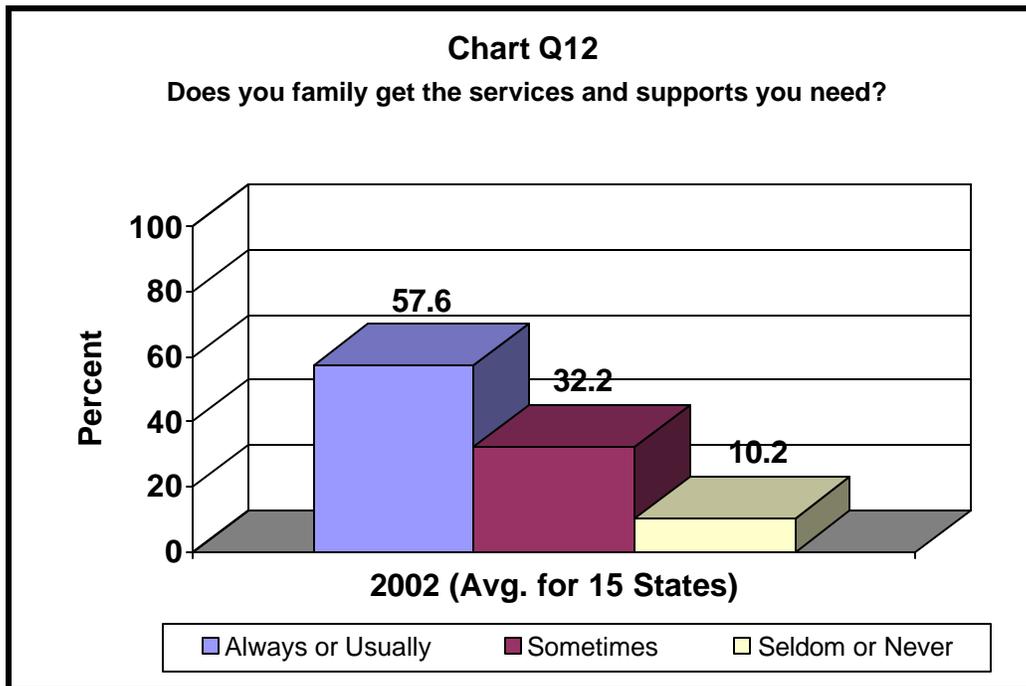


Table Q12
Does your family get the services and supports you need?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑	65.6	27.9	6.5	619
CT	↓ ↓ ↓	41.2	43.6	15.2	243
DE	↓	50.8	31.4	17.8	191
HI		58.5	34.5	7.0	200
IA	↑ ↑	72.8	22.4	4.8	294
IN		60.0	32.0	8.0	25
MA		53.5	35.8	10.6	385
ME		57.7	31.4	10.9	293
NC		54.0	33.7	12.3	350
OK		53.9	36.5	9.6	471
PA		60.9	29.7	9.4	895
SC	↑	63.7	24.6	11.7	171
SD	↑	66.0	30.0	4.0	50
WV	↓ ↓ ↓	45.4	41.3	13.3	196
WY		60.0	28.6	11.4	70
Total %		58.1	32.0	9.9	4,453
State Average %		57.6	32.2	10.2	15

- ◆ Among all respondents, the majority (55%) said that the supports received met their families' needs. Another 36% said that the supports sometimes met their needs, while the remaining 9% seldom or never felt the supports offered met their family's needs.

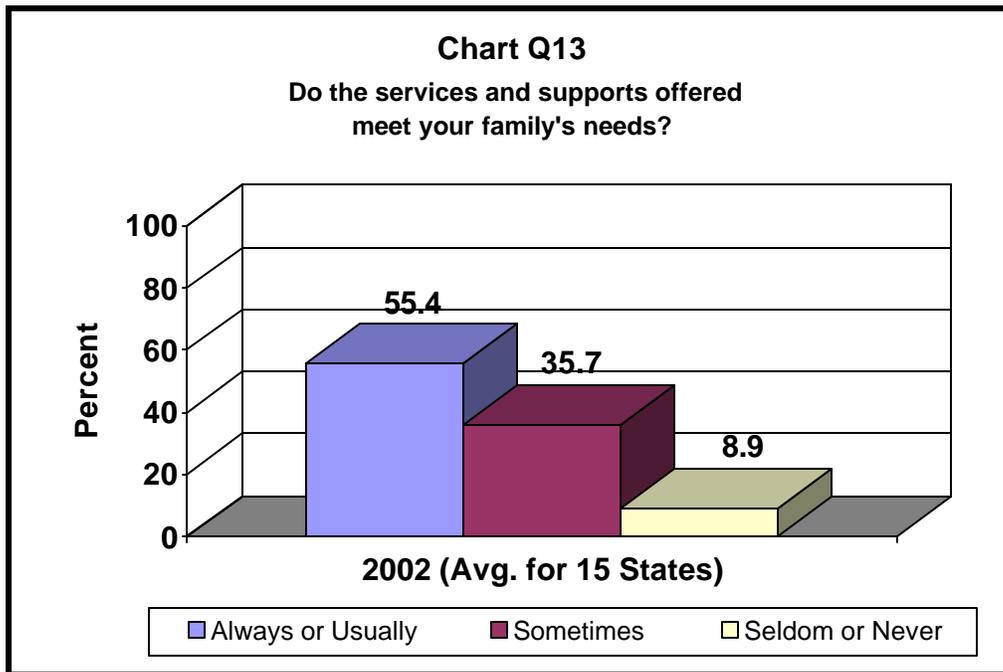


Table Q13
Do the services and supports offered meet your family's needs?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑	64.9	29.6	5.5	615
CT	↓ ↓ ↓	36.5	48.1	15.4	241
DE	↓	49.2	35.4	15.5	181
HI		54.6	38.2	7.2	207
IA	↑	60.8	36.5	2.7	296
IN	↑	63.6	31.8	4.5	22
MA	↓	49.7	41.1	9.2	380
ME		53.4	36.1	10.5	277
NC		57.0	30.7	12.3	342
OK		50.9	38.7	10.4	462
PA		55.2	37.2	7.6	877
SC		59.4	33.1	7.4	175
SD	↑ ↑ ↑	66.0	29.8	4.3	47
WV		54.0	36.1	9.9	202
WY		56.3	32.4	11.3	71
Total %		55.0	36.2	8.8	4,395
State Average %		55.4	35.7	8.9	15

- ♦ For slightly more than one-half of families (52%), supports were always or usually available when needed. However, almost as many families indicated that supports were only sometimes available (37%), or not available (11%) when needed.

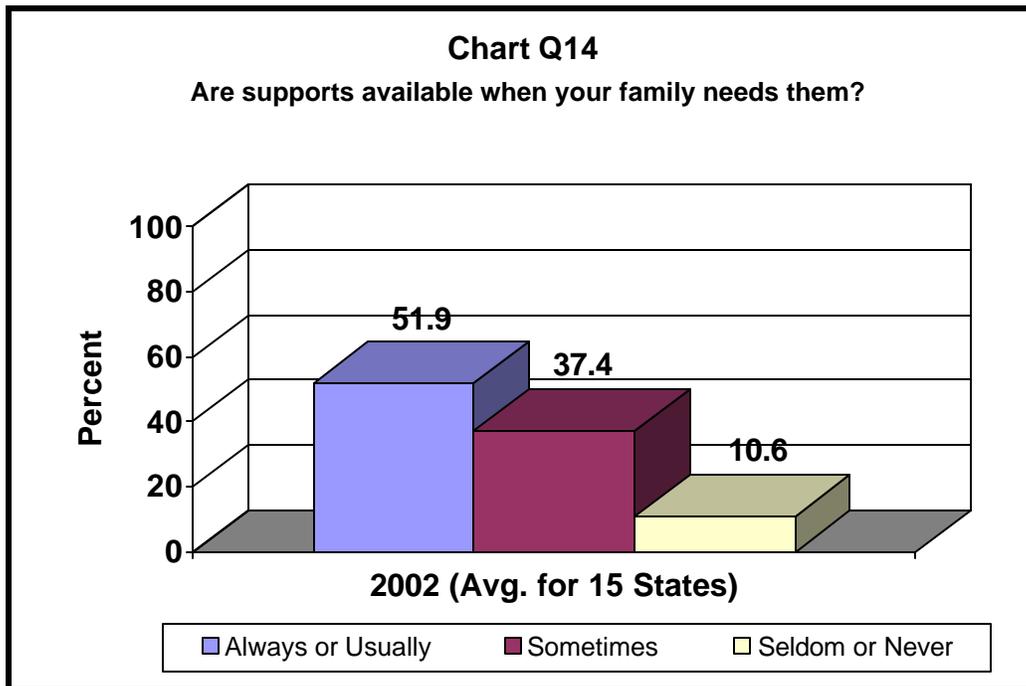


Table Q14
Are supports available when your family needs them?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑↑↑	63.1	30.7	6.2	566
CT	↓↓↓	35.8	47.3	16.8	226
DE		48.0	34.3	17.7	175
HI		51.3	38.6	10.2	197
IA	↑↑	65.0	31.4	3.6	280
IN		56.5	39.1	4.3	23
MA	↓	45.5	42.7	11.7	358
ME	↓	46.9	40.3	12.8	273
NC		50.6	35.3	14.1	340
OK	↓	46.1	41.8	12.1	445
PA		55.2	36.1	8.8	821
SC	↑↑	62.0	30.1	7.8	166
SD		52.2	41.3	6.5	46
WV		47.9	36.8	15.3	190
WY		52.9	35.7	11.4	70
Total %		52.5	36.9	10.5	4,176
State Average %		51.9	37.4	10.6	15

- Seventy-six percent of respondents stated that families in their area occasionally asked for different types of supports than the ones that were currently being offered.

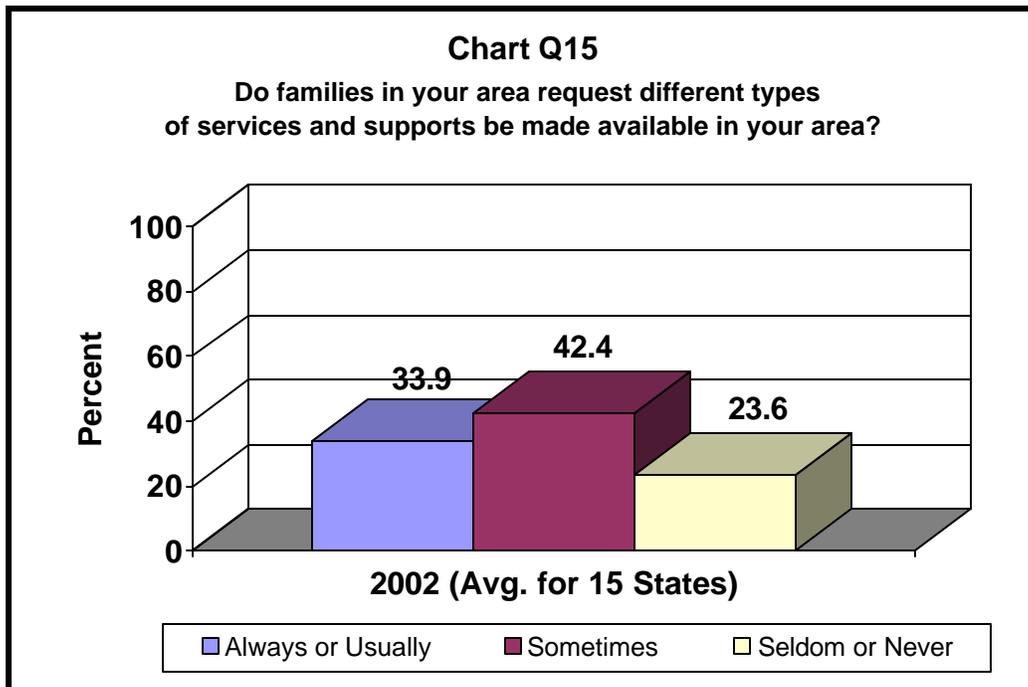


Table Q15
Do families in your area request that different types of services and supports be made available in your area?

State	Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	35.4	36.5	28.1	192
CT	36.2	43.6	20.2	94
DE	40.9	33.3	25.8	66
HI	36.6	39.0	24.4	82
IA	27.9	52.5	19.7	122
IN	15.4	61.5	23.1	13
MA	35.9	37.4	26.7	131
ME	27.9	50.5	21.6	111
NC	41.4	33.1	25.4	169
OK	36.6	38.5	24.8	161
PA	38.9	42.0	19.1	288
SC	31.7	32.9	35.4	82
SD	35.7	50.0	14.3	14
WV	36.2	37.2	26.6	94
WY	32.3	48.4	19.4	31
Total %	35.7	40.3	24.0	1,650
State Average %	33.9	42.4	23.6	15

- ◆ On the occasions when families did request different types of supports, 37% indicated that the state agency or provider agency was usually or always responsive to these requests.

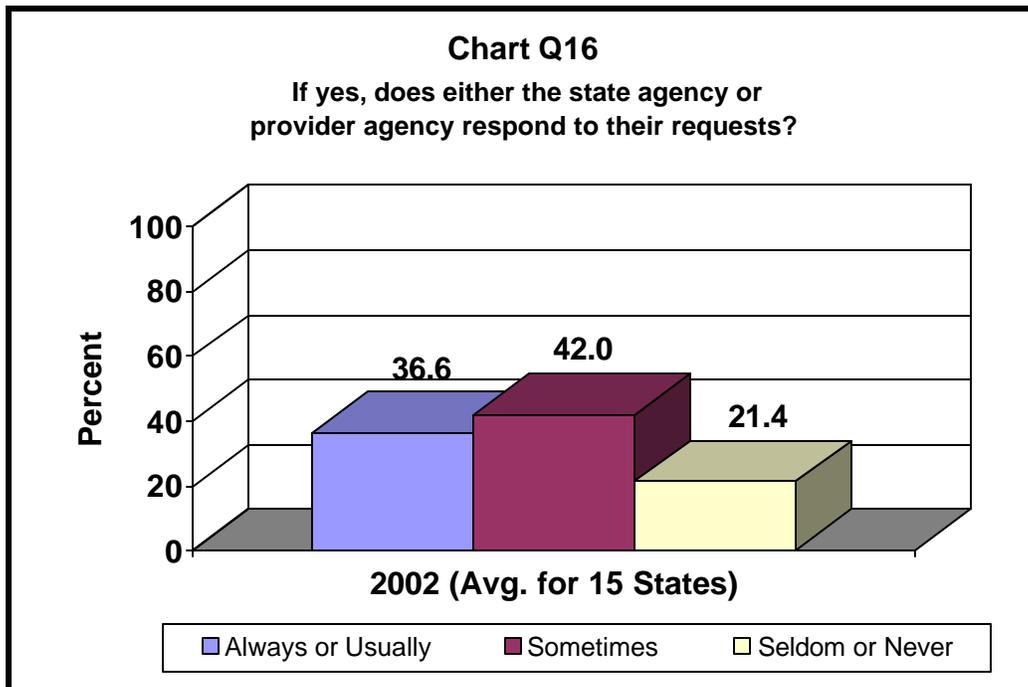


Table Q16
If yes, does either the state agency or provider agency respond to their requests?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑↑	60.8	25.9	13.2	189
CT		40.9	40.9	18.3	115
DE		33.3	41.7	25.0	60
HI	↑↑	49.2	35.4	15.4	65
IA		36.0	54.0	10.0	100
IN		38.5	38.5	23.1	13
MA		34.2	43.2	22.5	11
ME	↓	29.2	48.3	22.5	89
NC		39.1	34.4	26.5	151
OK	↓↓	23.9	45.5	30.6	134
PA	↓	31.6	48.5	19.8	237
SC		39.4	39.4	21.1	71
SD	↓	28.6	50.0	21.4	14
WV		32.5	43.4	24.1	83
WY		31.8	40.9	27.3	22
Total %		37.9	41.4	20.7	1,354
State Average %		36.6	42.0	21.4	15

- ♦ Slightly less than half (44%) of families who asked for assistance in an emergency or crisis did not consistently receive help right away.

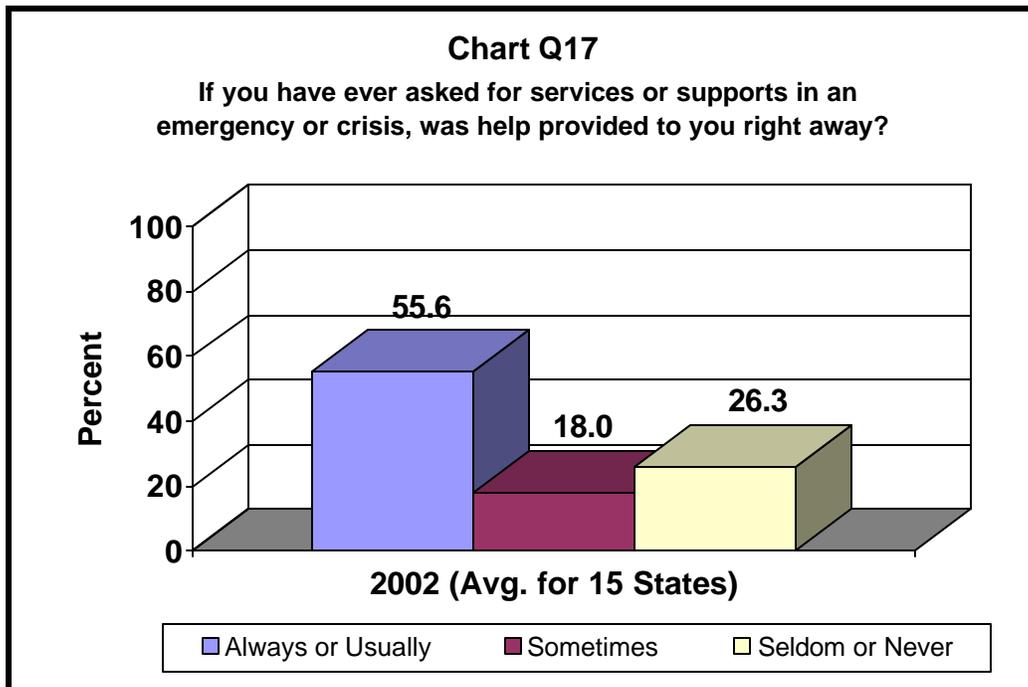


Table Q17
If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		54.8	18.0	27.2	283
CT		52.7	15.2	32.1	112
DE	↓↓↓	44.2	22.1	33.7	95
HI	↓	46.8	20.2	33.0	94
IA		59.2	19.7	21.1	152
IN	↑↑↑	73.3	6.7	20.0	15
MA		58.3	15.1	26.6	192
ME		53.5	21.3	25.2	155
NC		56.3	24.7	19.0	247
OK		52.0	23.8	24.2	223
PA		56.7	20.3	23.0	413
SC	↑↑	66.7	11.7	21.6	111
SD		53.1	9.4	37.5	32
WV	↓	50.0	20.7	29.3	116
WY		56.8	21.6	21.6	37
Total %		55.1	19.6	25.3	2,277
State Average %		55.6	18.0	26.3	15

- ◆ Among respondents whose first language was not English, about two-thirds (64%) indicated that staff or translators were available to speak with them in their preferred languages. Thirteen percent indicated that staff/translators were sometimes available, and one-fourth (23%) stated that staff/translators who spoke in the families' preferred languages were not available.

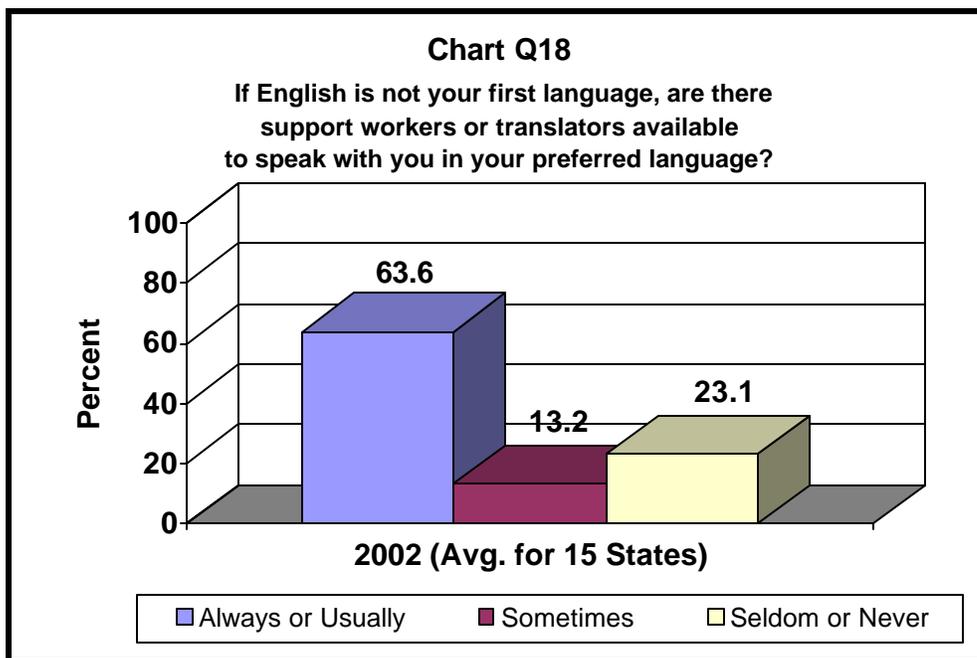


Table Q18
If English is not your first language, are there support workers or translators available to speak with you in your preferred language?

State	Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	85.1	10.2	4.7	235
CT	63.9	16.7	19.4	36
DE	59.1	9.1	31.8	22
HI	48.4	22.6	29.0	31
IA	77.8	11.1	11.1	18
IN	100.0	0.0	0.0	1
MA	61.0	24.4	14.6	41
ME	56.7	20.0	23.3	30
NC	75.6	15.6	8.9	45
OK	74.2	12.9	12.9	31
PA	62.0	20.0	18.0	50
SC	76.2	4.8	19.0	21
SD	0.0	0.0	100.0	1
WV	64.7	5.9	29.4	17
WY	50.0	25.0	25.0	4
Total %	72.9	13.9	13.9	583
State Average %	63.6	13.2	23.1	15

- ◆ Among respondents who had family members who did not speak English, or who used a different means to communicate (e.g., sign language, communication board), about half (51%) of families said there were enough support staff regularly available who could communicate with their family member.

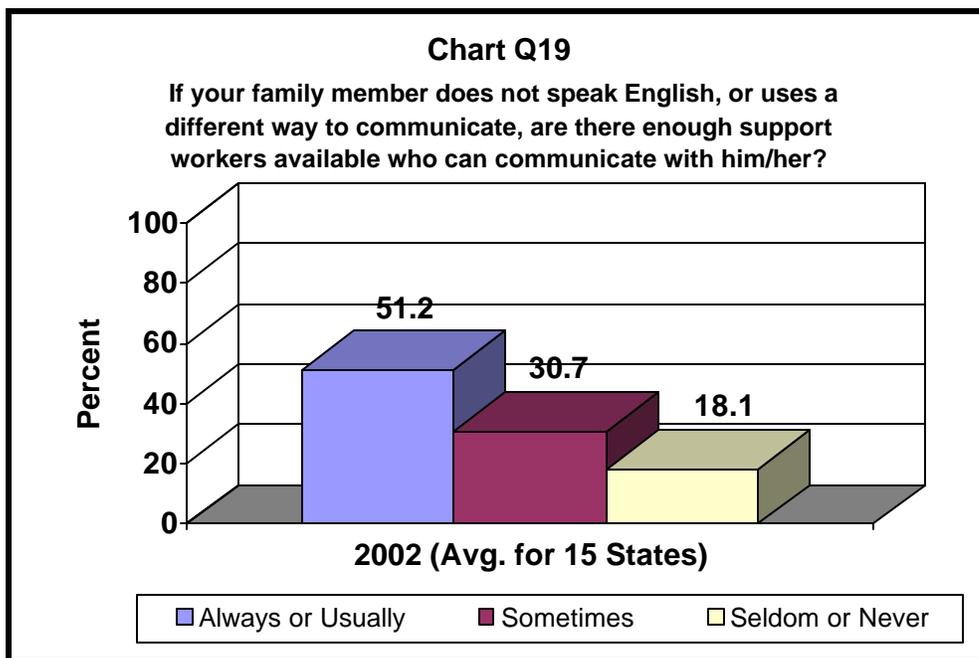


Table Q19

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑↑	72.8	15.0	12.1	173
CT		54.8	26.2	19.0	42
DE	↑	57.7	15.4	26.9	26
HI	↓↓	31.1	37.8	31.1	45
IA	↑↑	61.9	38.1	0.0	42
IN		50.0	50.0	0.0	2
MA		50.0	35.3	14.7	68
ME	↓	44.9	32.7	22.4	49
NC		47.4	36.8	15.8	76
OK		53.8	26.4	19.8	91
PA	↓	44.8	28.6	26.7	105
SC	↑	58.1	19.4	22.6	31
SD		50.0	50.0	0.0	2
WV	↓	43.9	34.1	22.0	41
WY	↓	46.2	15.4	38.5	13
Total %		54.1	27.3	18.6	806
State Average %		51.2	30.7	18.1	15

- ◆ About two-thirds of respondents (64%) felt their family member had access to the special equipment or accommodations needed.

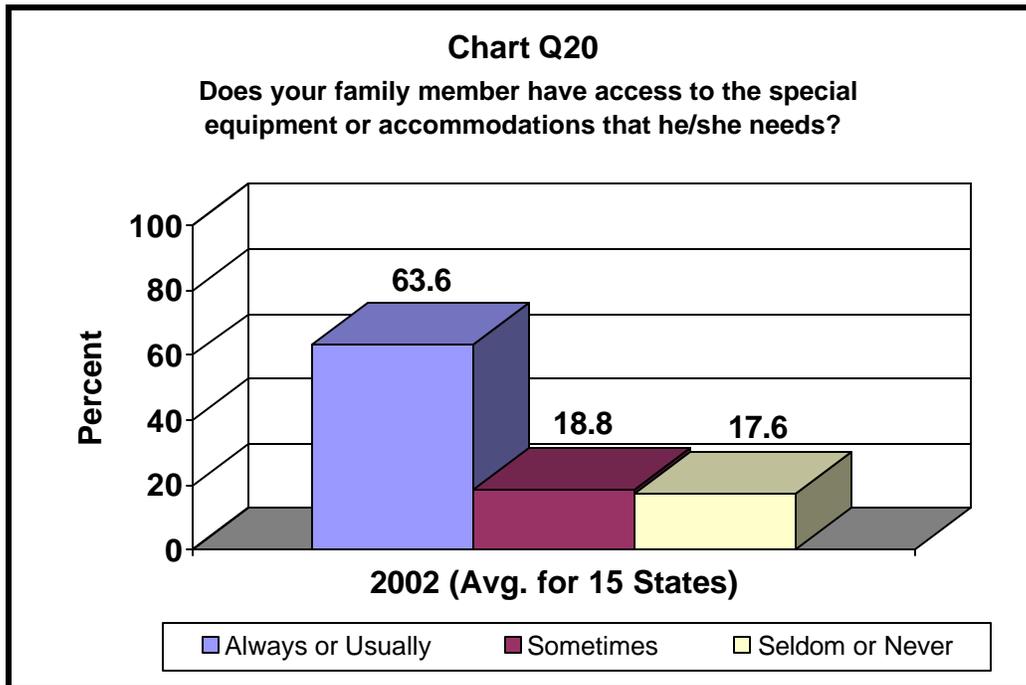


Table Q20

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↓	55.1	19.3	25.6	207
CT		61.3	12.9	25.8	62
DE		65.6	21.3	13.1	61
HI	↓	55.6	26.4	18.1	72
IA		63.2	26.3	10.5	114
IN	↑↑	75.0	8.3	16.7	12
MA		64.9	20.1	14.9	134
ME		60.2	18.5	21.3	108
NC		62.2	20.6	17.2	180
OK		64.3	21.7	14.1	263
PA		65.3	21.3	13.4	314
SC		65.9	23.5	10.6	85
SD	↑↑	77.3	4.5	18.2	22
WV	↓	56.6	23.0	20.4	113
WY		62.1	13.8	24.1	29
Total %		62.3	20.8	16.9	1,776
State Average %		63.6	18.8	17.6	15

- ◆ The vast majority of respondents (89%) felt that they had access to health services for their family member.

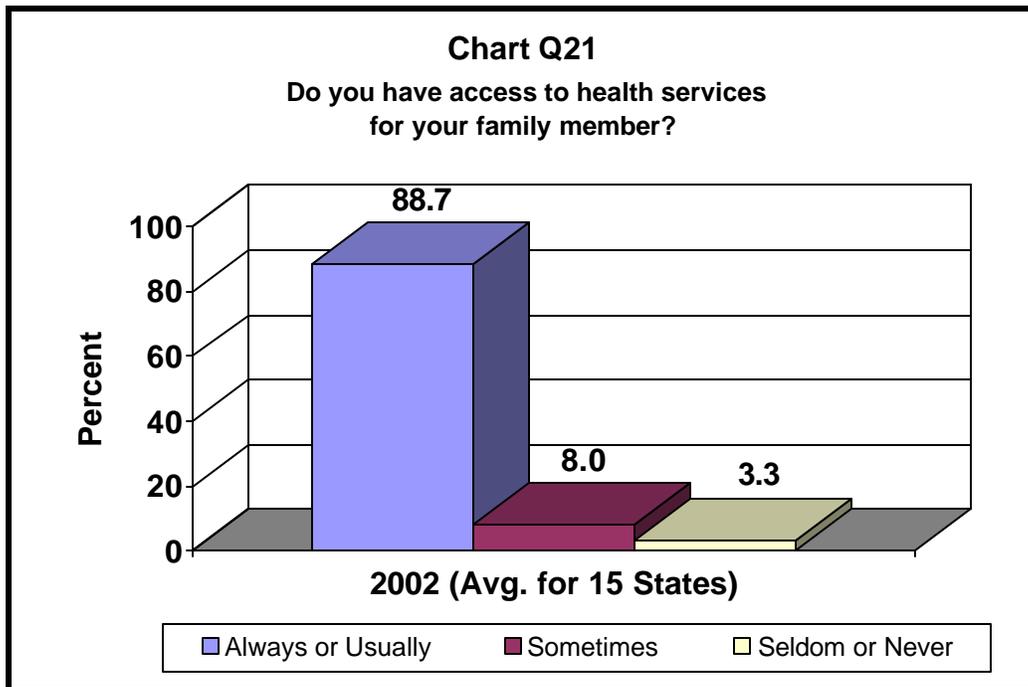


Table Q21
Do you have access to health services for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		86.1	8.4	5.4	606
CT	↓	83.1	11.8	5.1	254
DE		85.8	8.0	6.1	212
HI		84.3	12.7	3.0	197
IA	↑	95.3	4.7	0.0	296
IN		92.0	8.0	0.0	25
MA		87.9	8.3	3.8	397
ME		91.0	5.8	3.2	311
NC		85.3	11.4	3.3	368
OK		84.1	13.9	2.0	459
PA		91.0	6.8	2.3	930
SC		83.9	9.2	6.9	174
SD	↑↑	100.0	0.0	0.0	51
WV		87.5	6.0	6.5	216
WY		93.2	5.4	1.4	74
Total %		87.9	8.6	3.5	4,570
State Average %		88.7	8.0	3.3	15

- ♦ Slightly fewer families (77%) felt they had access to appropriate dental services for their family member. Fourteen percent of families had significant difficulty accessing dental services. In Delaware and Oklahoma, results show this number substantially higher with approximately one-fourth of all families having a difficult time accessing dental care.

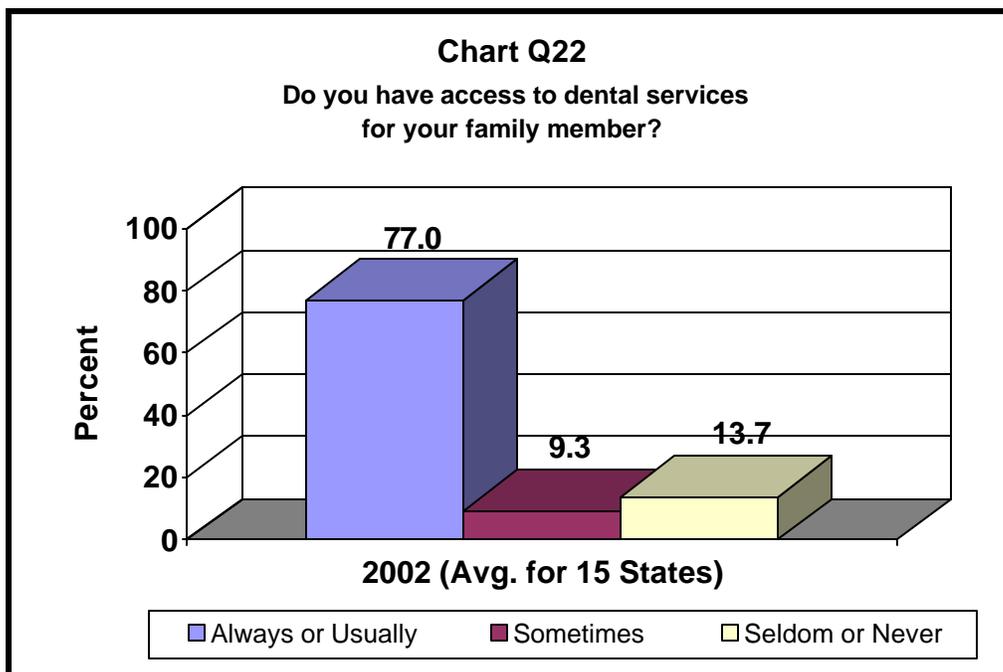


Table Q22
Do you have access to dental services for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		80.1	9.0	10.9	579
CT		72.8	12.8	14.5	235
DE	↓↓↓	63.9	11.5	24.6	183
HI	↓↓↓	68.2	15.1	16.7	192
IA	↑↑↑	93.8	3.4	2.7	292
IN	↑↑↑	91.7	8.3	0.0	24
MA		75.5	7.9	16.6	379
ME		77.0	8.0	15.0	300
NC		75.1	14.3	10.6	357
OK	↓↓↓	60.8	12.0	27.2	426
PA		79.4	8.7	11.9	892
SC		79.9	7.7	12.4	169
SD	↑↑↑	98.1	0.0	1.9	52
WV	↓↓↓	68.0	11.2	20.8	197
WY	↓↓↓	70.3	9.4	20.3	64
Total %		75.9	9.7	14.4	4,341
State Average %		77.0	9.3	13.7	15

- ◆ Nearly all respondents (92%) felt they had access to necessary medications for their family member with a disability.

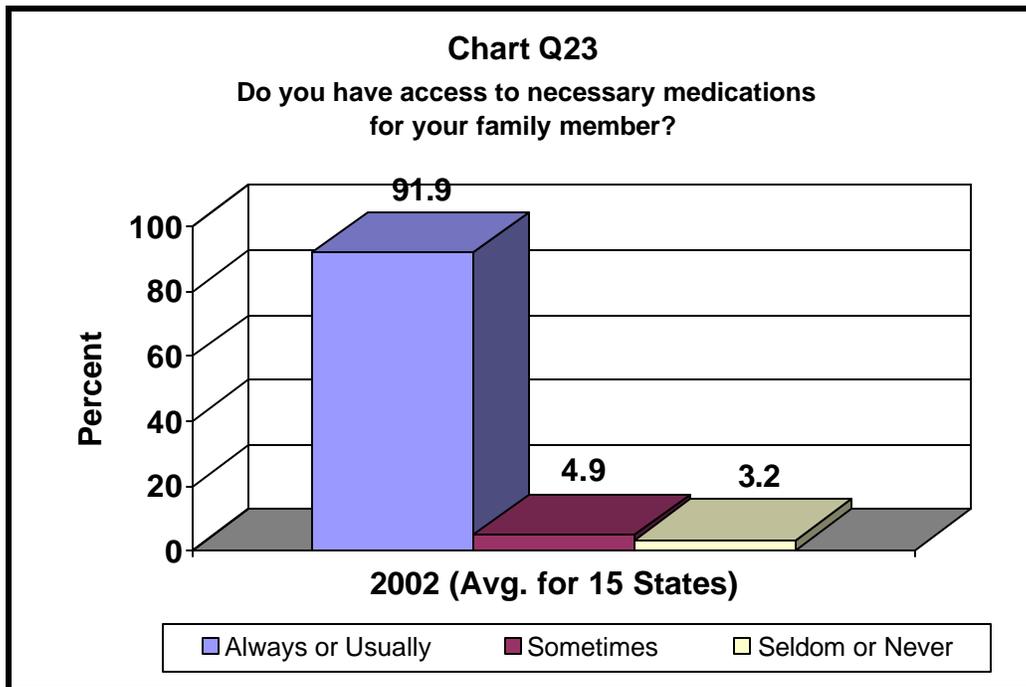


Table Q23
Do you have access to necessary medications for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↓	84.7	7.8	7.6	593
CT		92.9	3.7	3.3	241
DE	↓	86.5	6.5	7.0	215
HI		92.0	5.5	2.5	201
IA		96.6	2.8	0.7	290
IN		95.0	5.0	0.0	20
MA		90.2	6.1	3.8	396
ME		95.2	2.3	2.6	311
NC		90.0	7.2	2.8	359
OK		87.3	9.2	3.5	455
PA		94.7	3.5	1.8	911
SC		88.3	3.7	8.0	163
SD	↑	100.0	0.0	0.0	49
WV		93.1	3.7	3.2	216
WY		92.5	6.0	1.5	67
Total %		91.1	5.3	3.6	4,487
State Average %		91.9	4.9	3.2	15

- ◆ Over three-quarters of respondents (78%) indicated that frequent changes in support staff were a problem for their family at least some of the time.

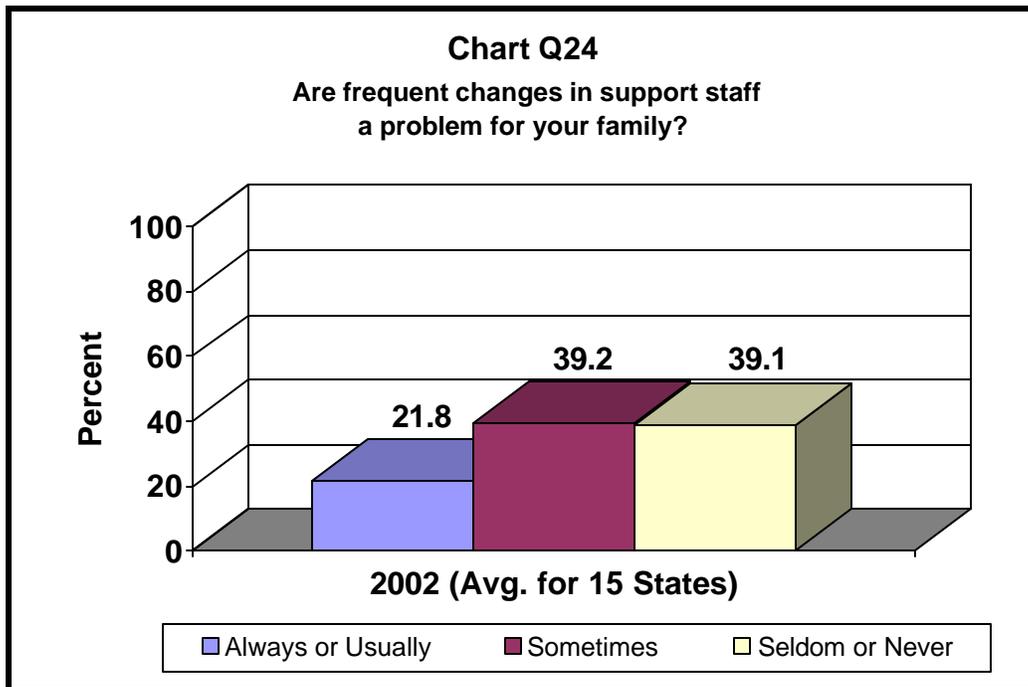


Table Q24
Are frequent changes in support staff a problem for your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		23.4	32.7	43.8	495
CT	↑	13.8	42.9	43.4	189
DE		25.5	37.2	37.2	145
HI		20.5	42.6	36.9	176
IA	↑↑	8.5	35.9	55.6	234
IN		40.0	24.0	36.0	25
MA		18.3	41.7	40.0	300
ME		18.8	44.4	36.8	234
NC		20.6	41.9	37.5	272
OK		25.1	33.9	41.1	375
PA		18.6	39.4	42.1	749
SC	↓	26.9	29.1	44.0	134
SD	↑	14.9	46.8	38.3	47
WV	↓	26.8	44.6	28.6	168
WY		24.6	50.8	24.6	61
Total %		20.4	38.7	40.9	3,604
State Average %		21.8	39.2	39.1	15

- ◆ When the family member with a disability received day/employment supports, the vast majority of respondents (82%) felt that day/employment setting was a safe and healthy environment.

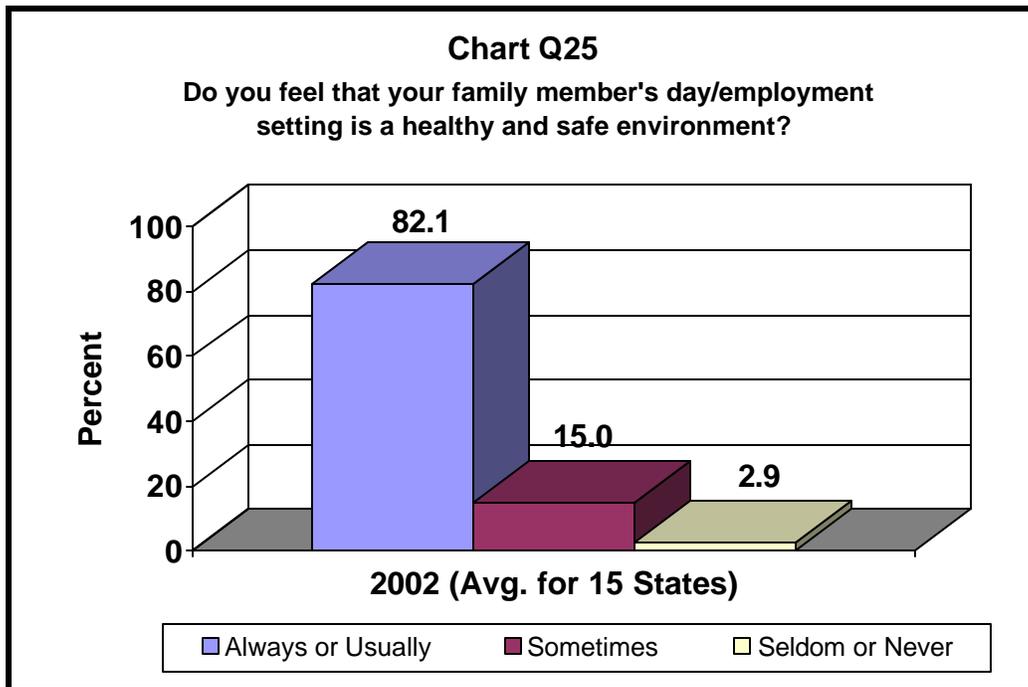


Table Q25
Do you feel that your family member's day/employment setting is a healthy and safe environment?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		84.1	13.3	2.6	541
CT		80.4	17.0	2.6	235
DE		82.9	13.3	3.8	210
HI		82.4	14.8	2.8	176
IA		84.1	14.4	1.5	264
IN	↑	90.0	10.0	0.0	20
MA		83.3	13.2	3.4	378
ME		85.4	12.9	1.8	280
NC		80.5	17.2	2.3	302
OK		82.1	15.4	2.6	312
PA		84.3	12.8	2.9	782
SC	↓	72.8	22.8	4.4	136
SD	↓	76.9	21.2	1.9	52
WV	↓	77.6	18.6	3.7	161
WY		84.1	7.9	7.9	63
Total %		82.6	14.5	2.8	3,912
State Average %		82.1	15.0	2.9	15

- ◆ Nine out of ten families felt that support staff, in general, were respectful and courteous.

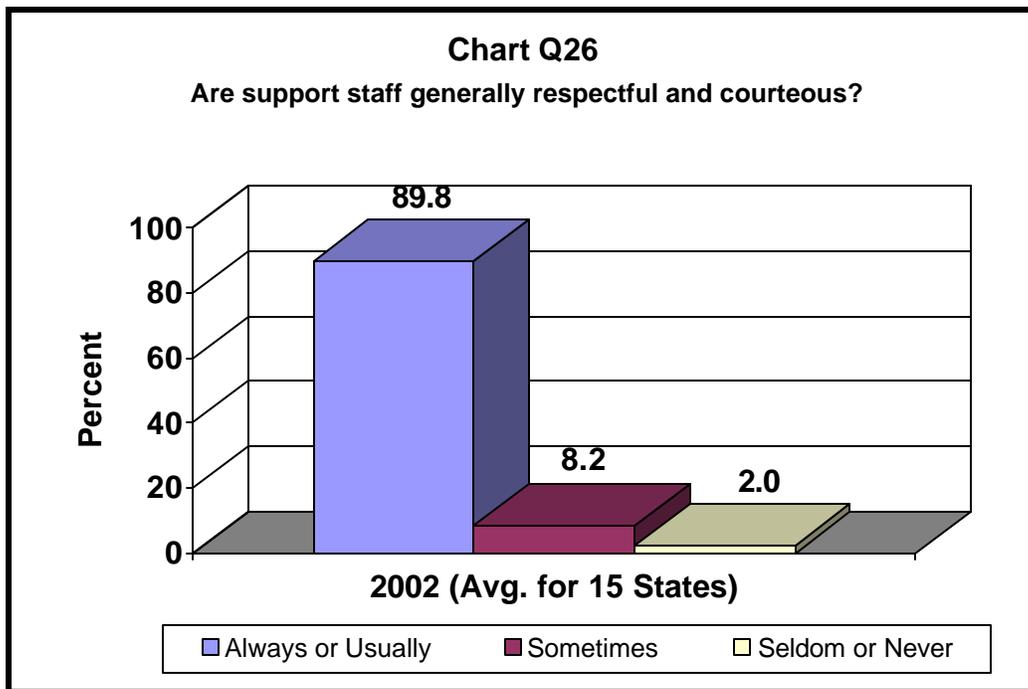


Table Q26
Are support staff generally respectful and courteous?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		93.8	5.2	0.9	632
CT		90.5	8.2	1.2	243
DE		90.7	8.3	1.0	205
HI		86.4	10.7	2.9	206
IA		92.2	5.9	2.0	306
IN	↑	95.8	0.0	4.2	24
MA		87.9	9.0	3.1	390
ME		87.9	10.7	1.3	298
NC		86.9	11.1	2.0	343
OK		85.5	12.4	2.0	442
PA		91.4	7.6	1.0	919
SC		91.7	6.0	2.4	168
SD		90.4	9.6	0.0	52
WV	↓	84.8	12.1	3.0	198
WY		91.4	5.7	2.9	70
Total %		89.8	8.5	1.7	4,496
State Average %		89.8	8.2	2.0	15

Choices and Control

- ◆ Across the states, on average, 57% of respondents chose the agencies or providers who work with their families. In Indiana, Oklahoma and Wyoming, this percentage was considerably higher, with 73% or more of families choosing their service providers.

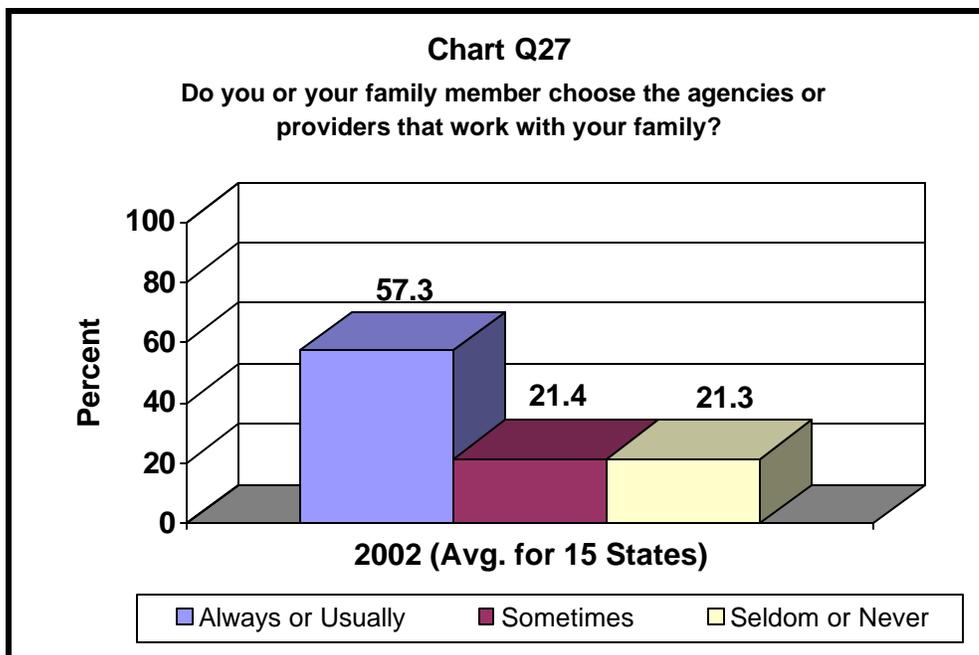


Table Q27
Do you or your family member choose the agencies or providers that work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		56.2	21.1	22.7	493
CT	↓	51.7	21.7	26.6	207
DE	↓	48.5	22.8	28.7	171
HI		60.3	22.3	17.4	184
IA		62.0	20.4	17.5	274
IN	↑↑	79.2	12.5	8.3	24
MA	↓↓	41.6	22.0	36.4	327
ME		54.7	21.9	23.4	265
NC	↑	66.4	17.3	16.4	330
OK	↑↑	73.6	16.1	10.2	440
PA	↓	51.1	21.4	27.5	734
SC	↓↓	40.7	31.3	28.0	150
SD	↓↓	44.7	25.5	29.8	47
WV		56.9	25.4	17.7	181
WY	↑↑	72.6	19.2	8.2	73
Total %		56.5	21.1	22.4	3,900
State Average %		57.3	21.4	21.3	15

- ◆ While 57% of respondents typically chose their family's provider agency, only 39% (on average) typically chose the support workers who worked directly with their family. Here, however, the results were considerably higher in North Carolina, Oklahoma and Wyoming.

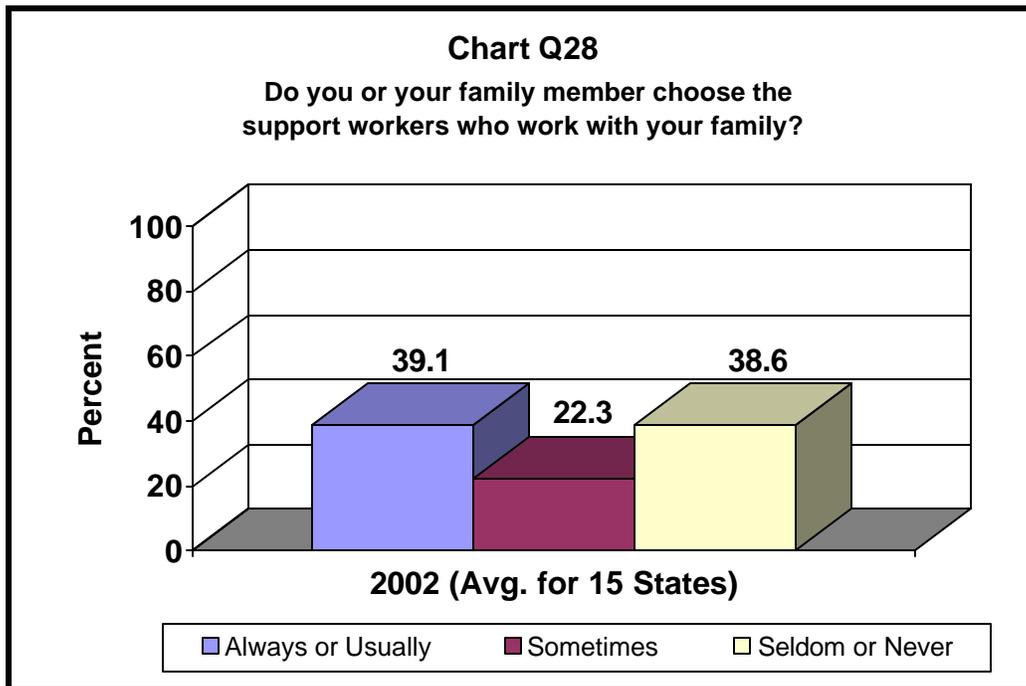


Table Q28
Do you or your family member choose the support workers who work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		37.4	18.9	43.7	460
CT	↓	30.7	18.2	51.0	192
DE	↓	25.8	18.2	56.0	159
HI		39.5	25.6	34.9	172
IA		40.1	25.5	34.3	274
IN	↑	45.8	41.7	12.5	24
MA	↓	29.4	22.0	48.6	313
ME	↓	29.7	20.9	49.4	249
NC	↑↑	55.2	19.7	25.1	315
OK	↑↑	68.1	17.9	14.0	420
PA	↓	33.4	18.3	48.3	716
SC		35.6	19.2	45.2	146
SD	↓↓	17.0	27.7	55.3	47
WV		39.1	23.7	37.3	169
WY	↑↑	59.7	16.7	23.6	72
Total %		40.1	20.3	39.6	3,728
State Average %		39.1	22.3	38.6	15

- ◆ Across the states, 69% of families who received day/employment supports felt the provider agency regularly involved them in important decisions.

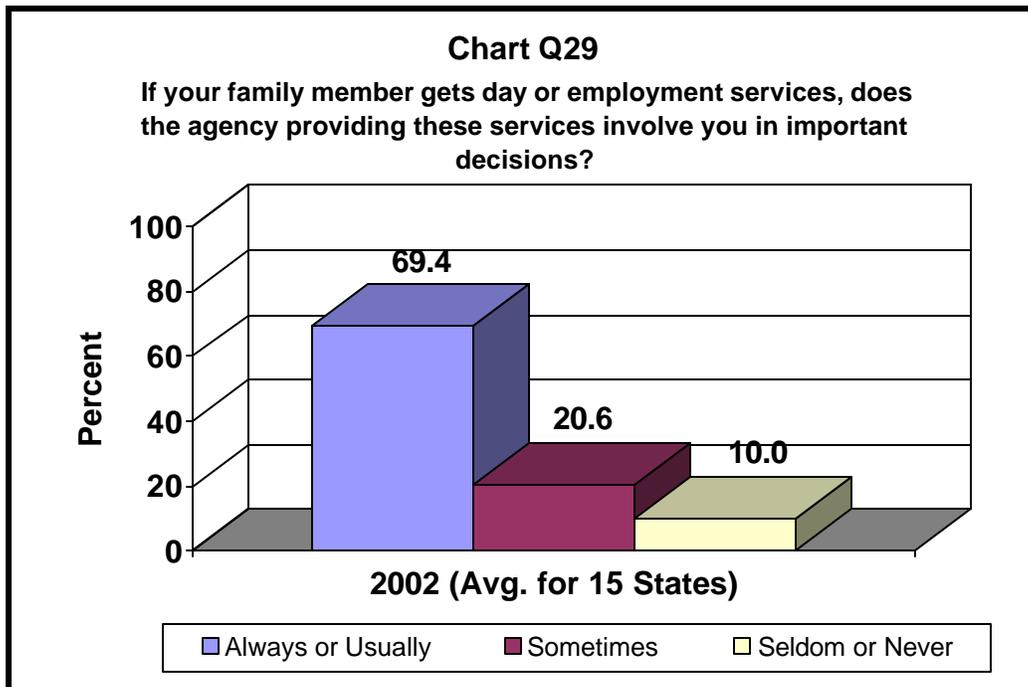


Table Q29

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↓	60.3	24.4	15.3	418
CT	↓	62.7	27.5	9.8	204
DE		74.1	18.1	7.8	166
HI	↑	76.4	16.4	7.1	140
IA		72.5	17.4	10.1	218
IN	↑↑	84.2	10.5	5.3	19
MA		66.4	25.9	7.8	321
ME		66.7	25.6	7.7	234
NC		71.1	18.6	10.3	253
OK		68.5	19.1	12.4	267
PA		69.3	20.5	10.2	616
SC	↓	60.2	22.1	17.7	113
SD		68.0	26.0	6.0	50
WV		65.4	23.5	11.1	153
WY		75.0	13.5	11.5	52
Total %		67.7	21.7	10.6	3,224
State Average %		69.4	20.6	10.0	15

- ◆ Among all respondents, about one-third (36%) had control or input over the hiring and management of their support staff, and an additional 15% indicated they had this control sometimes. Forty-nine percent, however, did not have any input or control over the hiring or management of their family's support staff.

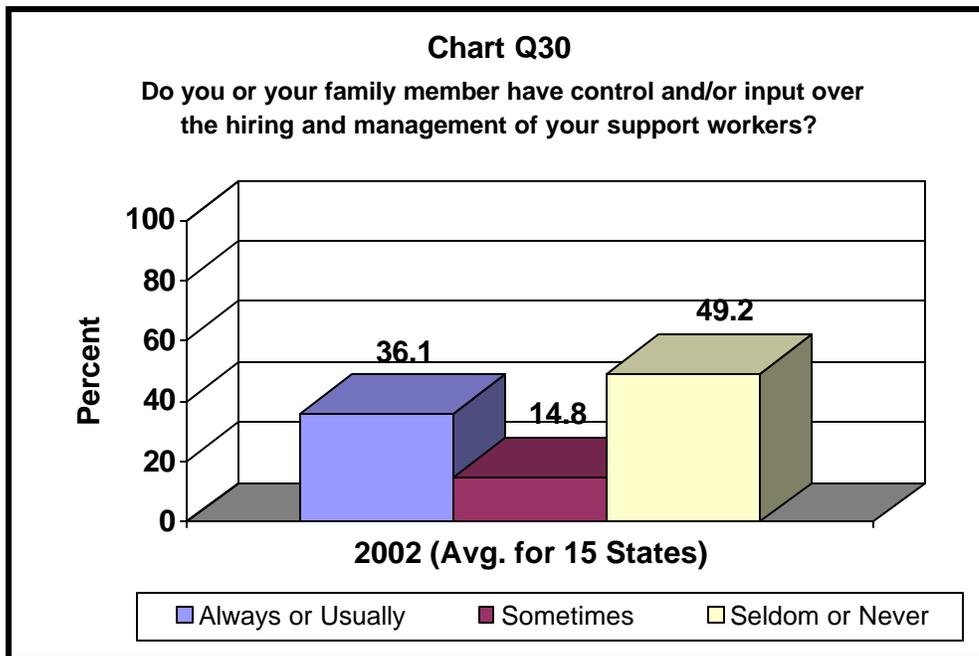


Table Q30

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		36.1	15.4	48.5	324
CT	↓↓↓	26.0	9.5	64.5	169
DE	↓↓↓	19.8	11.6	68.6	121
HI		39.3	17.9	42.9	140
IA		31.7	26.0	42.3	208
IN	↑↑↑	50.0	13.6	36.4	22
MA	↓	28.9	14.8	56.3	263
ME	↓	22.2	17.9	59.9	212
NC	↑↑↑	53.8	17.0	29.2	253
OK	↑↑↑	65.4	15.6	19.0	384
PA		31.7	14.0	54.3	578
SC		35.8	5.3	58.9	95
SD	↓↓↓	16.7	16.7	66.7	42
WV	↑	42.4	12.9	44.7	132
WY	↑	41.2	13.7	45.1	51
Total %		37.7	15.3	47.0	2,994
State Average %		36.1	14.8	49.2	15

- ◆ While only 51% of respondents had at least some control over the hiring or management of their support workers, 81% wanted this type of control.

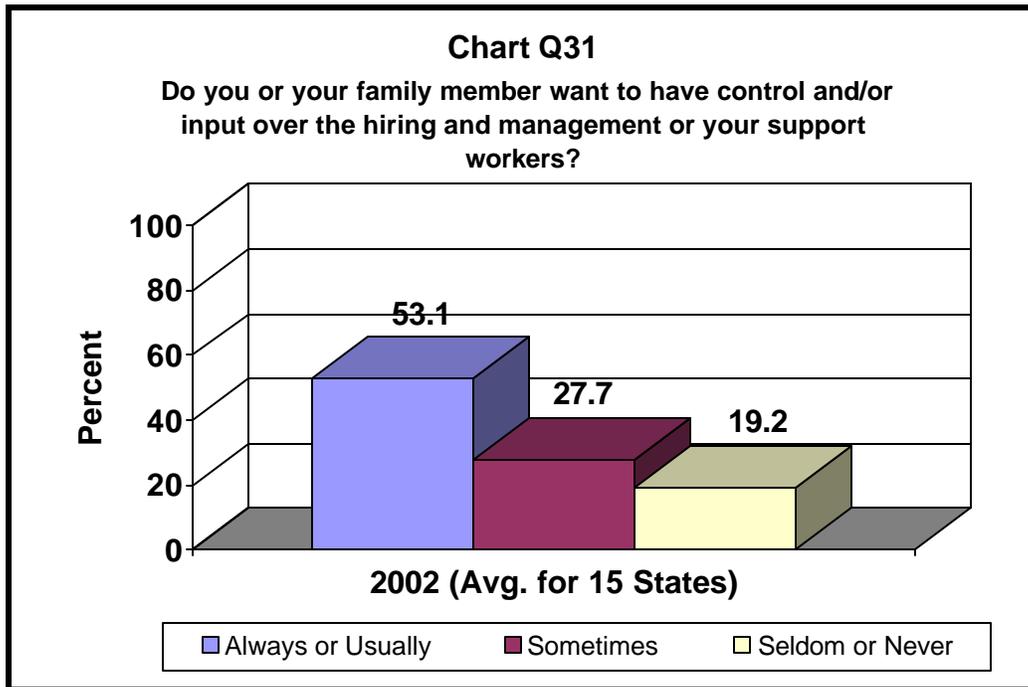


Table Q31
Do you or your family member want to have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑	58.6	19.9	21.5	321
CT		50.6	29.7	19.6	158
DE	↓	46.5	24.6	28.9	114
HI		54.5	22.4	23.1	134
IA	↓	47.0	32.5	20.5	234
IN	↑↑	63.6	36.4	0.0	22
MA	↓	45.9	32.1	22.0	268
ME		50.2	26.8	22.9	205
NC	↑↑	67.0	22.1	10.9	267
OK	↑↑	83.8	12.8	3.4	382
PA		49.2	28.2	22.6	553
SC	↓	44.6	26.7	28.7	101
SD	↓↓	27.0	45.9	27.0	37
WV	↑↑	64.5	23.4	12.1	141
WY	↓	43.4	32.1	24.5	53
Total %		56.3	25.2	18.5	2,990
State Average %		53.1	27.7	19.2	15

- ◆ Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses. For this reason, states may notice higher responses in this category than in previous years.
- ◆ Less than one-quarter (20%) of respondents or their family members knew how much money was spent by the MR/DD agency on behalf of their family member. Over two-thirds (71%), however, had little or no idea.

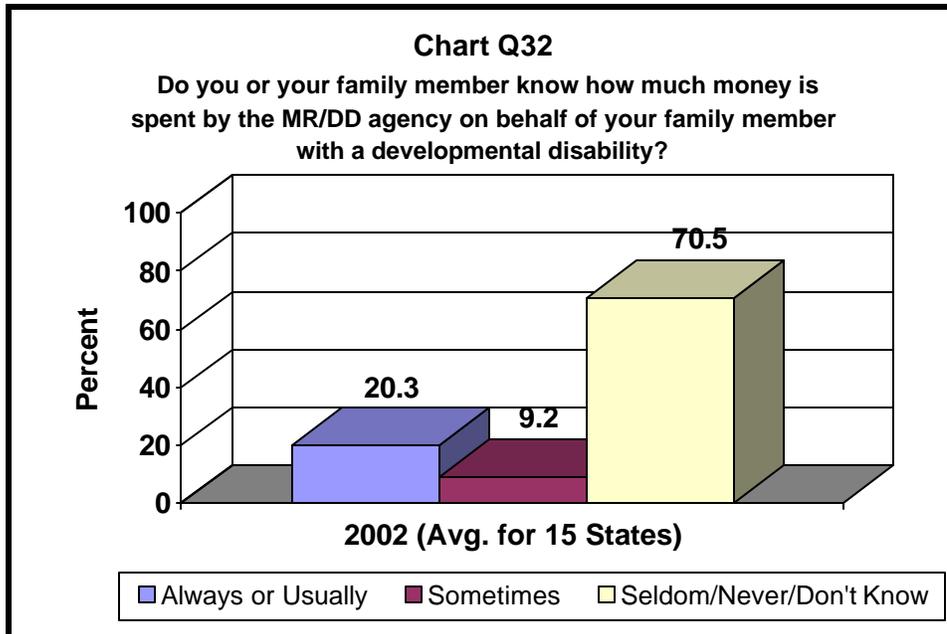


Table Q32

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

State	Always or Usually	Sometimes	* Seldom, Never or Don't Know	n	
CA-RCOC	↓	12.6	6.2	81.2	628
CT	↓	15.3	9.1	75.6	275
DE	↓↓	7.3	5.8	86.9	206
HI	↑↑	32.2	13.4	54.5	202
IA		22.7	15.3	62.0	300
IN		16.7	8.3	75.0	24
MA	↓	11.2	7.9	80.9	392
ME	↓	12.9	9.2	78.0	295
NC		21.1	9.0	69.9	356
OK	↑↑	45.1	14.8	40.1	466
PA		24.4	8.7	66.9	930
SC		18.6	10.2	70.9	21
SD	↓↓	10.2	4.1	85.7	49
WV	↓	10.9	5.7	83.3	192
WY	↑↑	43.8	9.6	46.6	73
Total %		21.0	9.3	69.7	4,409
State Average %		20.3	9.2	70.5	15

- ◆ Overall, approximately half of the families surveyed (52%) had at least some decision-making authority over how the money available to their family member with disabilities by the MR/DD agency was spent. Forty-eight percent, however, did not.

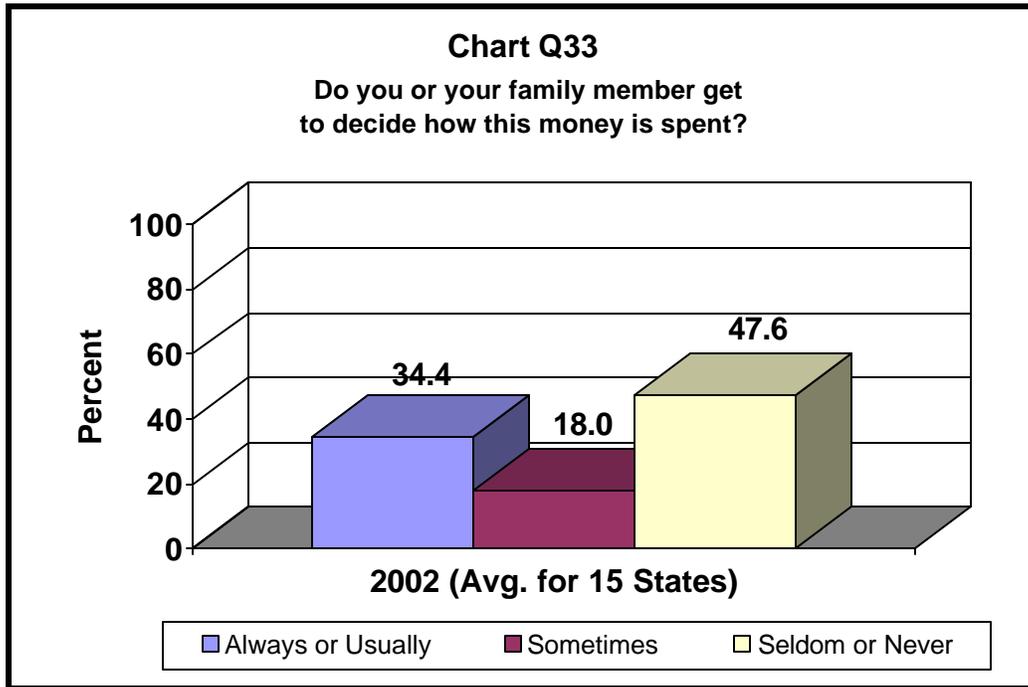


Table Q33
Do you or your family member get to decide how this money is spent?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		39.3	14.3	46.4	336
CT	↓	27.3	17.6	55.1	187
DE	↓↓	21.9	10.5	67.5	114
HI		41.0	16.4	42.5	134
IA		34.9	20.2	45.0	218
IN		38.9	22.2	38.9	18
MA	↓	28.3	20.9	50.8	258
ME		32.1	17.6	50.2	221
NC		34.9	18.5	46.6	232
OK	↑↑	58.2	21.2	20.7	397
PA	↑	43.2	23.1	33.7	641
SC	↓	28.7	11.9	59.4	101
SD	↓↓	11.4	20.0	68.6	35
WV		31.3	12.5	56.3	112
WY	↑	44.3	23.0	32.8	61
Total %		38.3	18.9	42.8	3,065
State Average %		34.4	18.0	47.6	15

Community Connections

- ♦ On average, one-third of respondents (32%) felt that planning or support staff were regularly available to help them use typical community supports (e.g., from a local health club, church or recreation activities) if desired. Another 27% said that staff were sometimes helpful, but 41% stated that planning and support staff were seldom or never helpful in connecting their family members to typical community supports or resources.

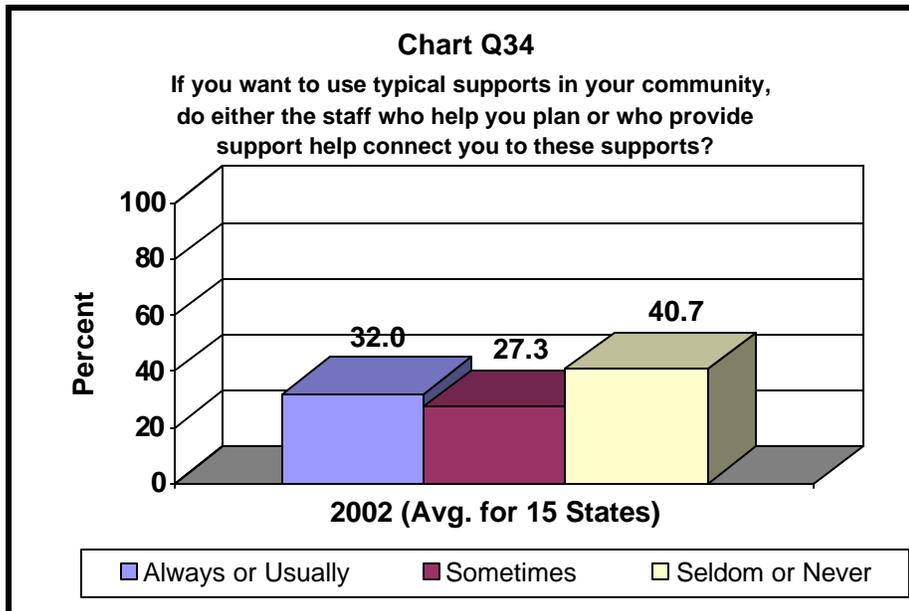


Table Q34
If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑	37.2	24.2	38.6	355
CT		27.5	26.3	46.1	167
DE	↓↓	19.8	25.7	54.5	101
HI		29.8	28.1	42.1	121
IA	↑	38.6	32.7	28.7	202
IN	↑↑	52.4	33.3	14.3	21
MA	↓	24.3	32.3	43.4	251
ME		27.9	28.4	43.7	197
NC		33.5	30.6	35.9	245
OK		34.0	29.9	36.2	318
PA		31.7	26.1	42.2	533
SC		33.3	17.2	49.5	93
SD	↓	23.1	33.3	43.6	39
WV		28.4	22.4	49.1	116
WY	↑	38.9	18.5	42.6	54
Total %		31.7	27.5	40.8	2,813
State Average %		32.0	27.3	40.7	15

- ◆ Overall, there was a split between respondents who indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (56% say yes or sometimes, 44% say no).

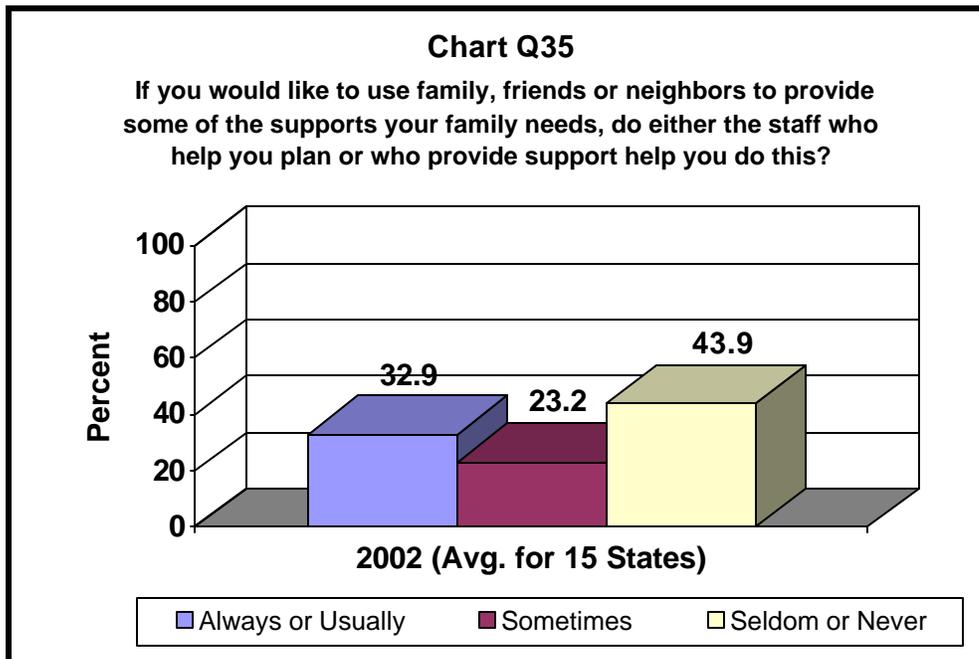


Table Q35

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑	42.7	20.7	36.6	328
CT	↓	23.3	18.7	58.0	150
DE	↓	24.3	27.0	48.6	111
HI		34.4	21.6	44.0	125
IA		32.6	26.3	41.1	190
IN		30.4	26.1	43.5	23
MA	↓	26.9	25.6	47.5	242
ME	↓	23.1	26.3	50.5	186
NC		33.3	23.3	43.4	219
OK	↑↑	46.3	19.4	34.3	324
PA		37.2	22.3	40.5	546
SC	↑	40.4	22.8	36.8	114
SD	↓↓↓	22.9	25.7	51.4	35
WV	↑↑	44.4	19.5	36.1	133
WY		31.8	22.7	45.5	44
Total %		35.2	22.6	42.2	2,770
State Average %		32.9	23.2	43.9	15

- ◆ Only 48% of families felt their family member always or usually had access to community activities. 19% stated their family member seldom or never had access to the community.

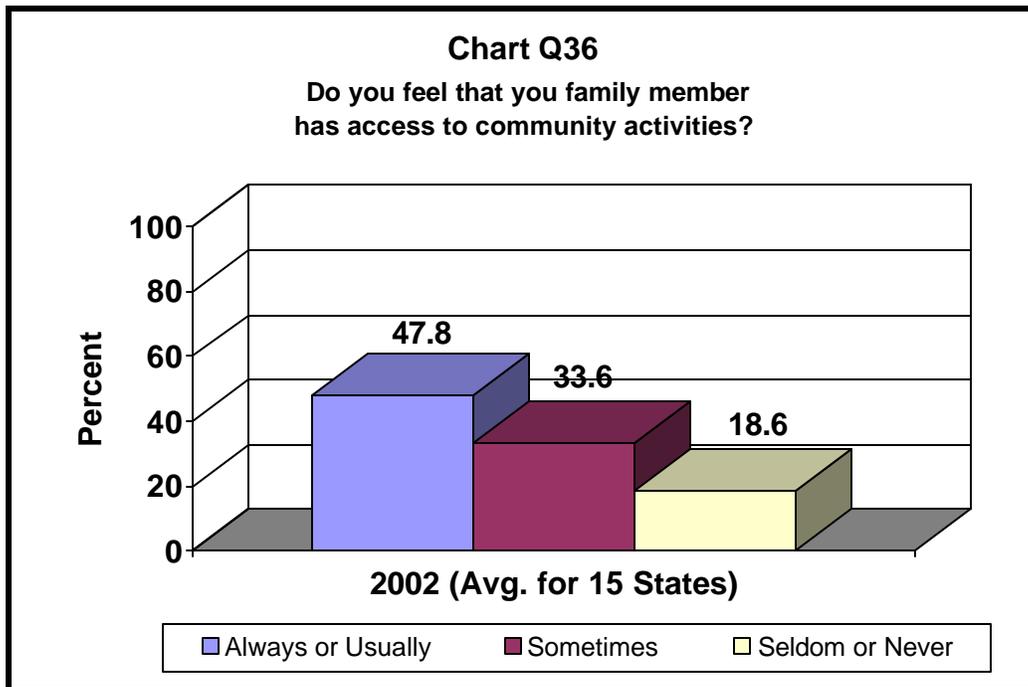


Table Q36
Do you feel that your family member has access to community activities?

State	Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	45.7	33.9	20.4	534
CT	↓	42.4	34.5	238
DE	↓↓	36.3	32.6	190
HI		48.5	35.7	171
IA	↑	57.7	30.3	284
IN	↑↑	70.8	20.8	24
MA		43.8	35.1	356
ME	↓↓	37.8	41.1	299
NC	↓	41.9	34.7	329
OK		50.8	33.0	433
PA		47.9	32.8	833
SC	↓	40.9	31.8	154
SD		44.2	44.2	52
WV		52.1	32.5	194
WY	↑	56.3	31.0	71
Total %	46.4	33.9	19.7	4,162
State Average %	47.8	33.6	18.6	15

- ◆ While 48% had regular access to community activities, only 31% of family members regularly participated in them. Nearly one-third (31%) of respondents said that their family member seldom or never participated in community activities or events.

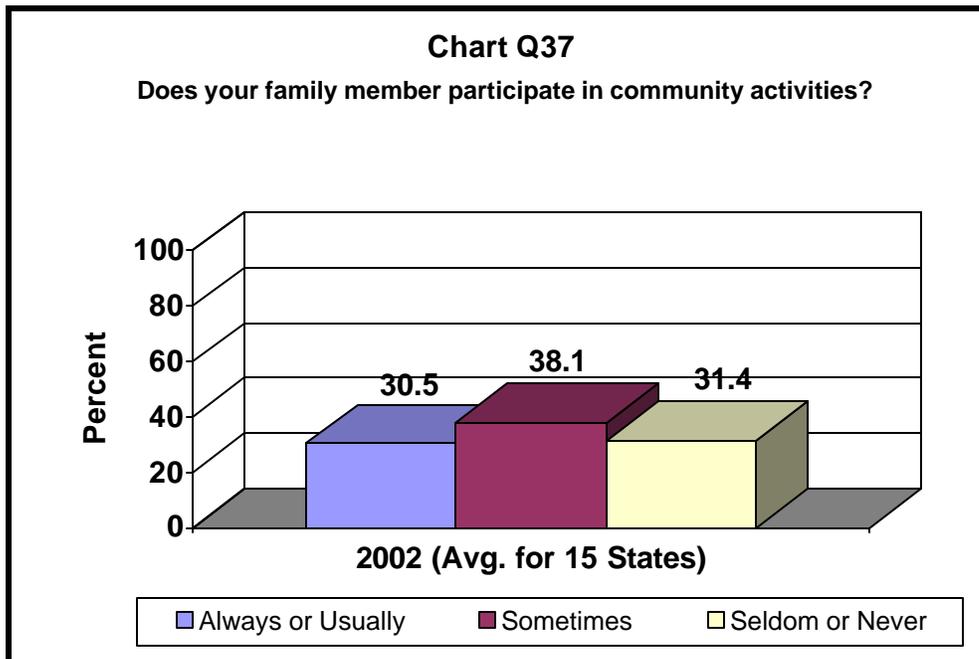


Table Q37
Does your family member participate in community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↓	22.7	33.6	43.7	586
CT		29.1	37.5	33.3	261
DE	↓	21.1	34.4	44.5	209
HI		29.4	42.2	28.3	187
IA	↑	37.5	38.2	24.3	288
IN	↑↑	60.0	20.0	20.0	25
MA		25.9	35.8	38.3	386
ME		28.5	37.9	33.7	309
NC	↓	24.8	42.1	33.1	335
OK		32.1	34.8	33.0	448
PA	↓	24.3	36.2	39.4	883
SC	↓	21.7	38.9	39.5	157
SD	↓	24.0	56.0	20.0	50
WV		32.5	40.7	26.8	194
WY	↑↑	43.8	42.5	13.7	73
Total %		27.4	37.2	35.5	4,391
State Average %		30.5	38.1	31.4	15

Outcomes and Satisfaction with Services and Supports

- Overall, two-thirds of families (67%) were always or usually satisfied with the services and supports they received. 26% were somewhat satisfied, and 7% were seldom or never satisfied.

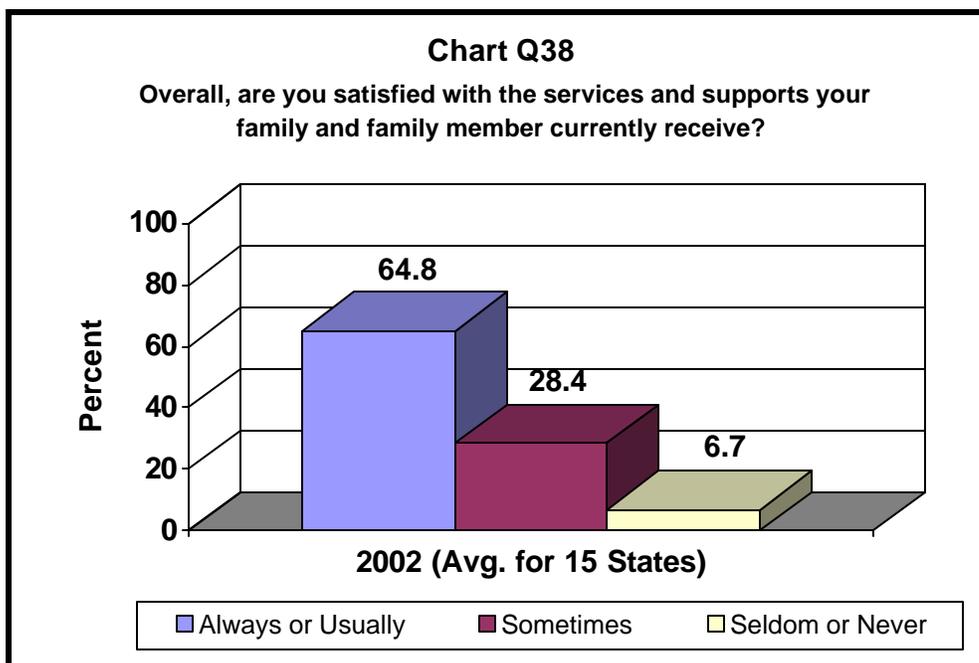


Table Q38
Overall, are you satisfied with the services and supports your family and family member currently receive?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑↑	76.6	19.0	4.4	653
CT	↓↓	47.6	41.9	10.5	267
DE	↓↓	51.6	39.0	9.4	213
HI		69.1	23.7	7.2	207
IA	↑↑	77.4	20.6	1.9	310
IN	↑↑	77.3	22.7	0.0	22
MA		60.3	30.9	8.7	401
ME		59.9	33.1	6.9	317
NC		61.5	28.6	9.9	364
OK		62.7	29.7	7.5	464
PA		66.4	28.1	5.5	961
SC		69.3	26.1	4.5	176
SD		69.2	25.0	5.8	52
WV		63.0	30.3	6.7	208
WY		60.3	27.4	12.3	73
Total %		65.2	28.2	6.7	4,688
State Average %		64.8	28.4	6.7	15

- ◆ Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses. For this reason, states may notice higher responses in this category than in previous years.
- ◆ On average, only 43% of respondents knew about their agency's grievance process, while 47% had little or no familiarity with the process for lodging a complaint.

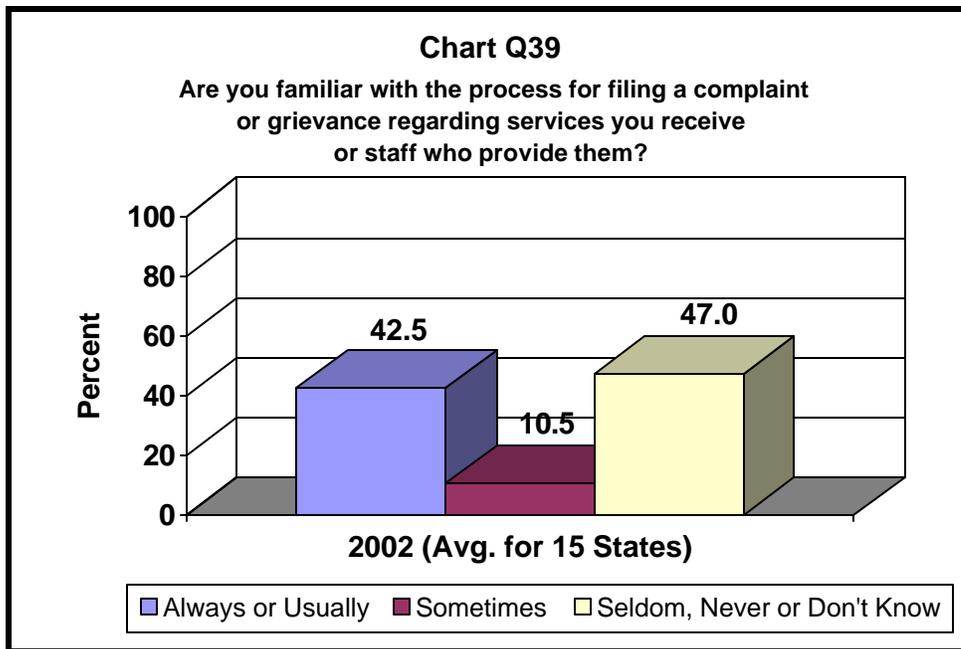


Table Q39
Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?

State	Always or Usually	Sometimes	* Seldom, Never or Don't Know	n	
CA-RCOC	44.0	9.0	47.0	589	
CT	↓↓	29.8	10.3	59.9	242
DE	↓↓	30.9	9.7	59.4	207
HI	↓	34.5	10.2	55.3	197
IA		45.8	15.3	38.9	288
IN		44.0	8.0	48.0	25
MA		39.1	9.8	51.0	386
ME	↓↓	31.1	12.2	56.8	296
NC		44.9	9.9	45.2	352
OK	↑↑	59.2	10.9	29.9	441
PA		41.3	10.4	48.3	895
SC		45.5	11.7	42.9	154
SD	↑↑	64.7	9.8	25.5	51
WV		38.9	9.4	51.7	203
WY		43.7	11.3	45.1	71
Total %	42.1	10.6	47.4	4,397	
State Average %	42.5	10.5	47.0	15	

- ◆ The majority of respondents (58%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 42%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.

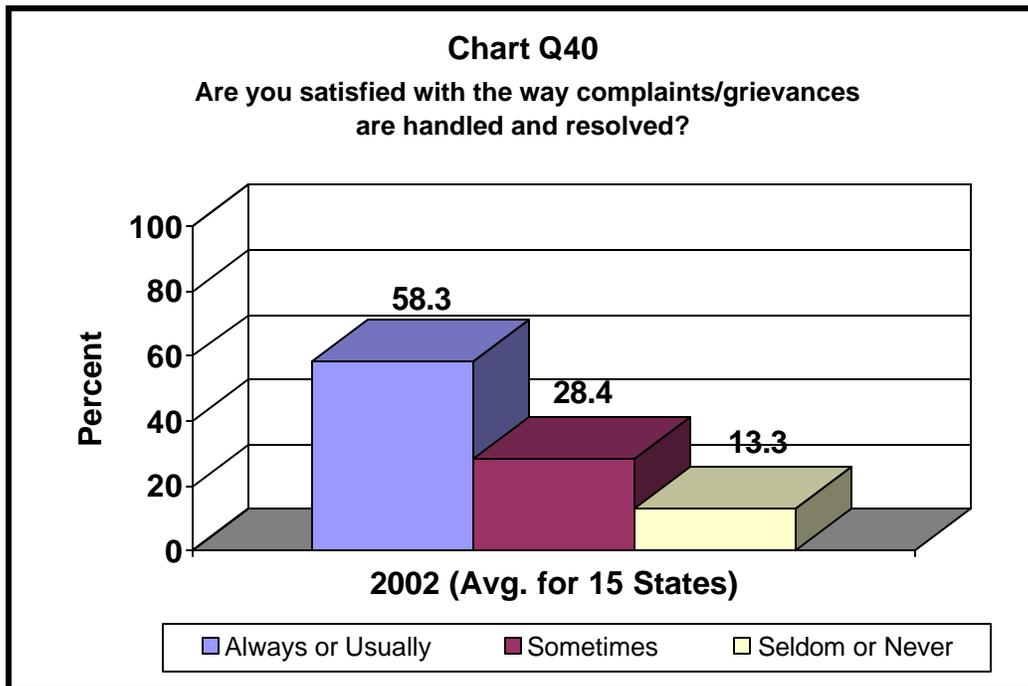


Table Q40
Are you satisfied with the way complaints/grievances are handled and resolved?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑↑↑	71.1	17.8	11.1	270
CT	↓	49.0	34.7	16.3	98
DE	↓↓↓	46.5	33.7	19.8	101
HI		55.8	33.8	10.4	77
IA		62.3	27.5	10.1	138
IN	↑↑	70.0	20.0	10.0	10
MA		56.1	32.1	11.8	212
ME	↓	51.7	33.8	14.5	145
NC		55.0	27.5	17.6	222
OK	↑	66.7	23.6	9.7	195
PA		61.4	27.3	11.4	396
SC		62.4	26.9	10.8	93
SD		61.1	27.8	11.1	36
WV	↓	52.4	27.6	20.0	105
WY		53.7	31.7	14.6	14
Total %		59.3	27.6	13.0	2,112
State Average %		58.3	28.4	13.3	15

Sixty-eight percent of families felt that services and supports have made a positive difference in their lives. Only 6% stated that they seldom felt this way.

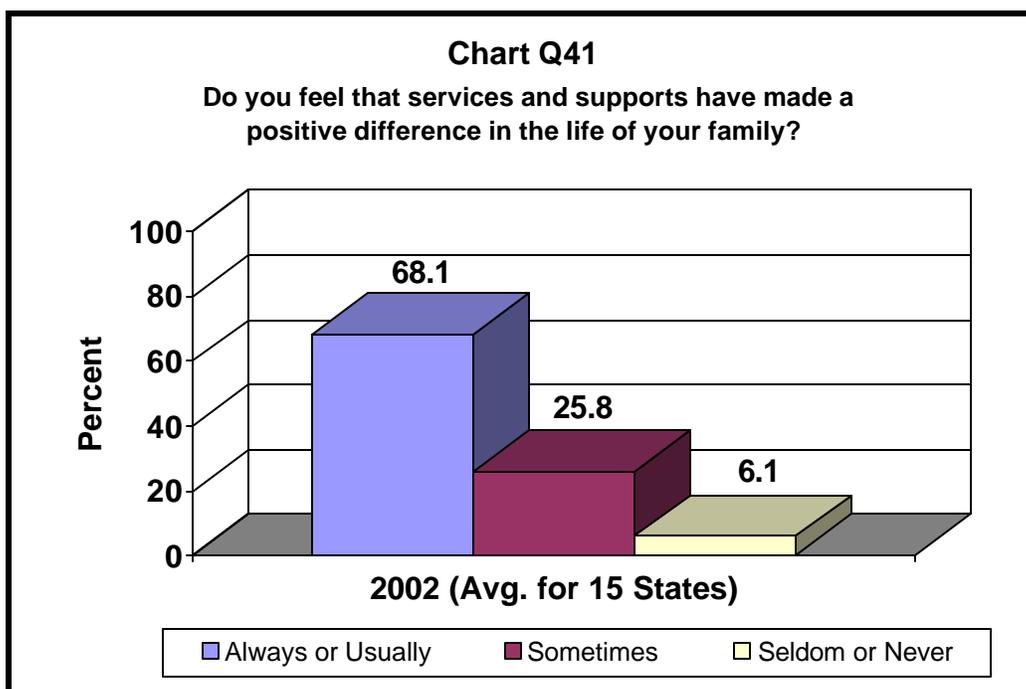


Table Q41
Do you feel that services and supports have made a positive difference in the life of your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	↑	75.4	17.8	6.8	606
CT	↓↓	56.8	32.2	11.0	236
DE	↓↓	54.8	35.1	10.1	188
HI		72.7	21.0	6.3	205
IA	↑↑	80.0	17.4	2.6	310
IN	↓↓	54.2	41.7	4.2	24
MA		65.8	26.9	7.3	386
ME		67.2	26.2	6.6	305
NC	↑	73.3	21.0	5.7	352
OK		72.8	23.1	4.1	459
PA		67.2	26.9	5.9	895
SC		72.6	24.0	3.4	175
SD		72.5	23.5	3.9	51
WV		68.0	26.9	5.1	197
WY		68.9	23.0	8.1	74
Total %		69.6	24.3	6.1	4,463
State Average %		68.1	25.8	6.1	15

- ◆ Three-fourths (73%) of respondents indicated that services have made a difference in helping them keep their family members at home.

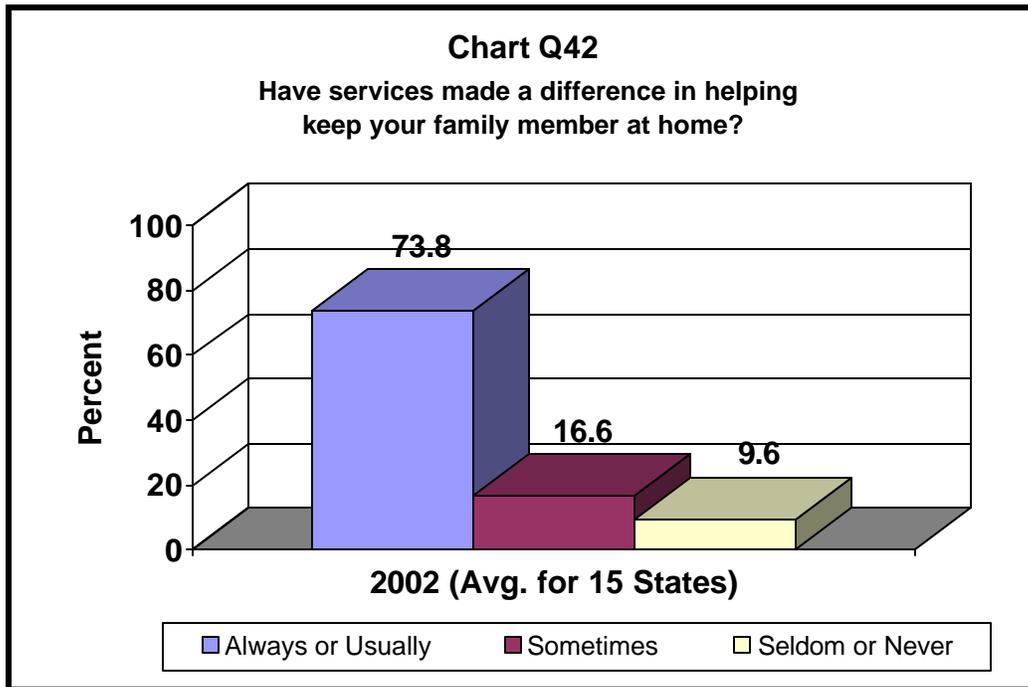


Table Q42
Have services made a difference in helping keep your family member at home?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		76.4	14.1	9.5	495
CT	↓ ↓ ↓	62.0	24.0	13.9	208
DE	↓	66.9	20.6	12.5	160
HI		73.4	20.1	6.5	184
IA	↑	81.6	12.8	5.7	282
IN	↓ ↓ ↓	61.1	33.3	5.6	18
MA		74.9	14.4	10.8	334
ME		71.5	15.7	12.7	267
NC	↑	79.3	13.9	6.8	324
OK		77.3	14.4	8.3	436
PA		72.0	14.3	13.7	790
SC	↑	79.7	11.5	8.8	148
SD		74.5	17.0	8.5	47
WV		74.5	14.7	10.9	184
WY	↑	81.2	8.7	10.1	69
Total %		74.5	15.2	10.3	3,946
State Average %		73.8	16.6	9.6	15

- ◆ Most families (86%) indicated that their family member would still be living at home, even without services. 9% of respondents, however, stated their family member would not be at home without needed services.

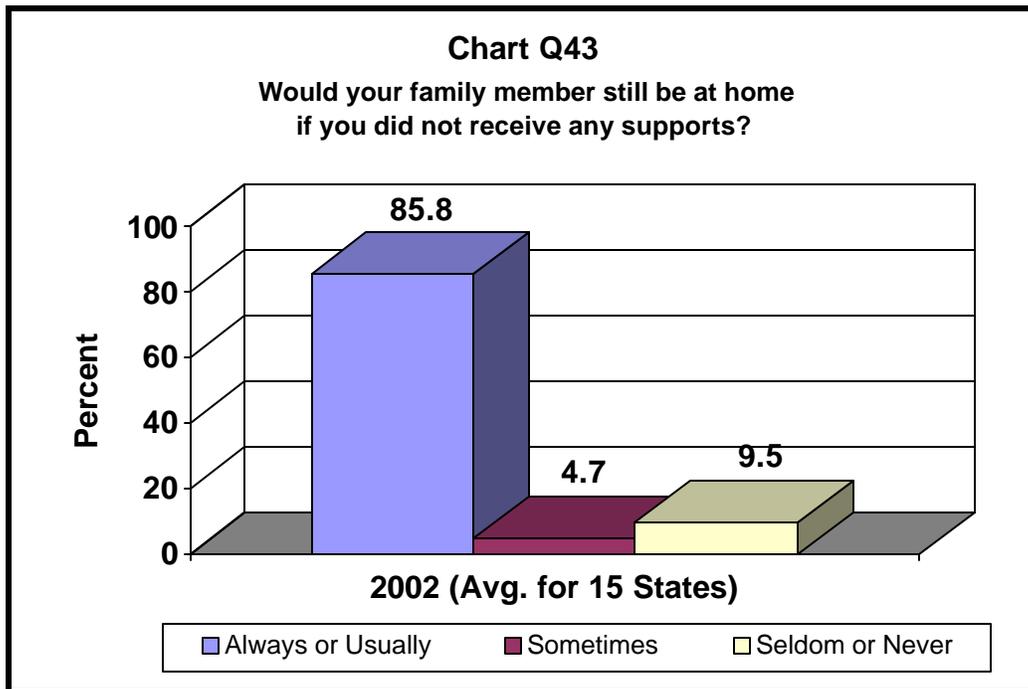


Table Q43
Would your family member still be at home if you did not receive any supports?

State	Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	83.7	5.0	11.3	443
CT	79.8	5.5	14.8	183
DE	90.4	3.2	6.4	156
HI	85.2	3.9	11.0	155
IA	79.2	7.3	13.5	192
IN	100.0	0.0	0.0	13
MA	81.3	4.1	14.6	294
ME	86.2	5.3	8.5	247
NC	79.5	7.9	12.6	254
OK	83.5	5.3	11.2	340
PA	90.5	3.5	6.0	770
SC	84.4	6.3	9.4	128
SD	88.9	5.6	5.6	36
WV	87.0	5.9	7.1	169
WY	88.1	1.5	10.4	67
Total %	85.2	4.9	10.0	3,447
State Average %	85.8	4.7	9.5	15

- ◆ Eighty-four percent of respondents felt that their family member was usually happy.

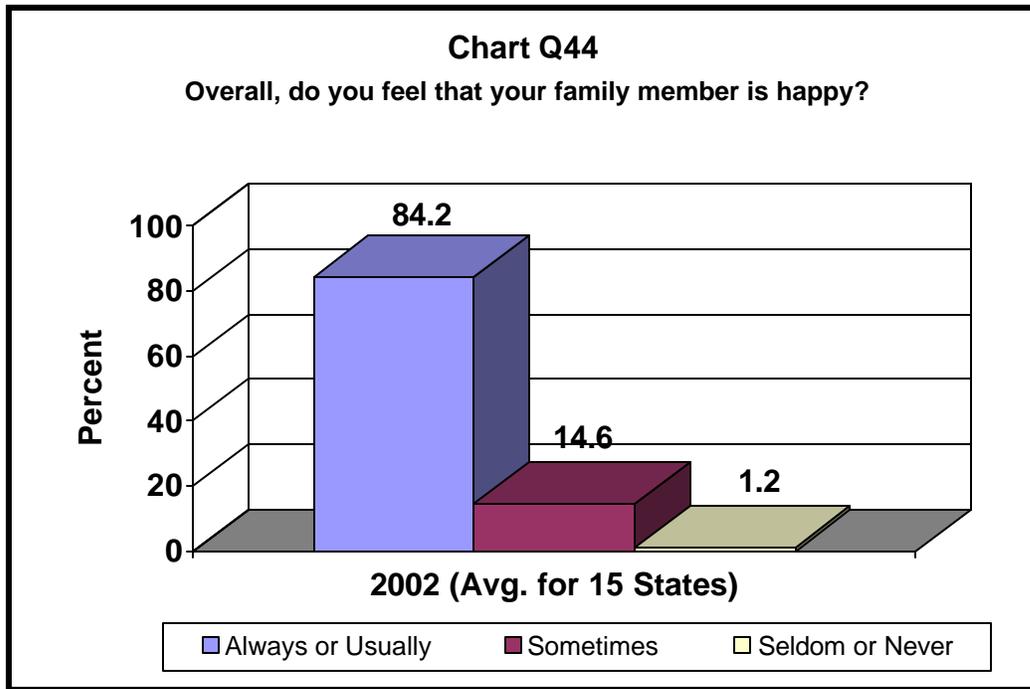


Table Q44
Overall, do you feel that your family member is happy?

State	Always or Usually	Sometimes	Seldom or Never	n	
CA-RCOC	83.6	14.1	2.3	640	
CT	80.3	19.0	0.7	274	
DE	82.0	15.5	2.5	239	
HI	87.1	12.0	1.0	209	
IA	86.5	12.2	1.3	312	
IN	88.0	12.0	0.0	25	
MA	82.6	15.8	1.7	419	
ME	84.3	15.1	0.6	332	
NC	81.6	16.0	2.4	374	
OK	87.9	11.8	0.2	473	
PA	84.6	14.1	1.3	1,005	
SC	83.0	15.3	1.7	176	
SD	↓	78.8	21.2	0.0	52
WV	81.0	16.4	2.6	232	
WY	↑	92.2	7.8	0.0	77
Total %	84.1	14.5	1.4	4,839	
State Average %	84.2	14.6	1.2	15	

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., ↑ and ↓) of the previous Tables, with single arrows representing state results $\pm 5\%$ from the state average, and double arrows (↑↑ and ↓↓) 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 Orange County, California, Hawaii, Indiana and South Dakota, responses to information and planning questions were generally above the overall state average. In Connecticut, Delaware and Maine, results were generally below the state average.

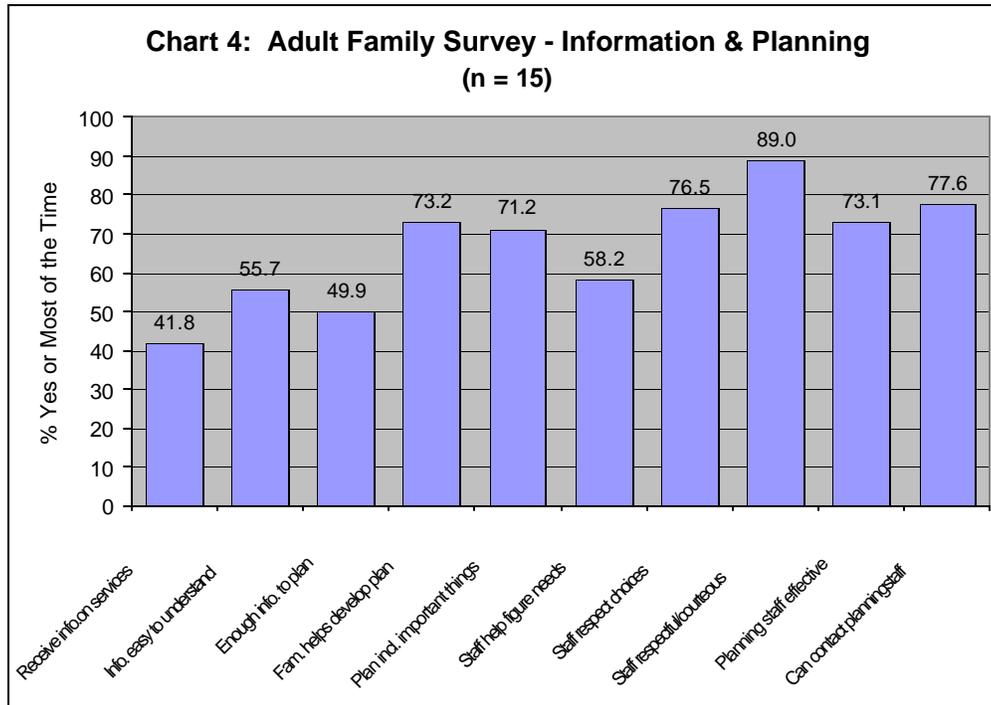


Table 18
Trends in Responses Above & Below State Average
Information & Planning

State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Net Sum
CA-RCOC	↑↑	↑↑	↑↑				↑		↑		8
CT	↓		↓↓		↓↓				↓	↓	-7
DE	↓↓		↓↓	↓↓	↓	↓			↓	↓	-10
HI	↑↑		↑	↑↑		↑	↑				7
IA	↑		↑			↑			↑		4
IN		↓		↑↑	↑↑	↑↑		↑	↑↑	↓	7
MA											0
ME	↓↓	↓	↓↓	↓	↓	↓	↓		↓		-10
NC	↓↓	↓									-3
OK	↓	↓		↑					↓		-2
PA		↑									1
SC			↑								1
SD		↑↑			↑				↑↑	↑↑	7
WV		↓↓					↓				-3
WY	↑↑			↑	↑				↓		3

Access and Delivery of Services

- ◆ In Iowa and Indiana, responses to access and delivery of services questions were generally above the overall state average. In Connecticut and West Virginia, results were generally below the state average. Please note that Question 15 is considered a “neutral question”, and therefore, up and down arrows were not used in the calculation of state trends.

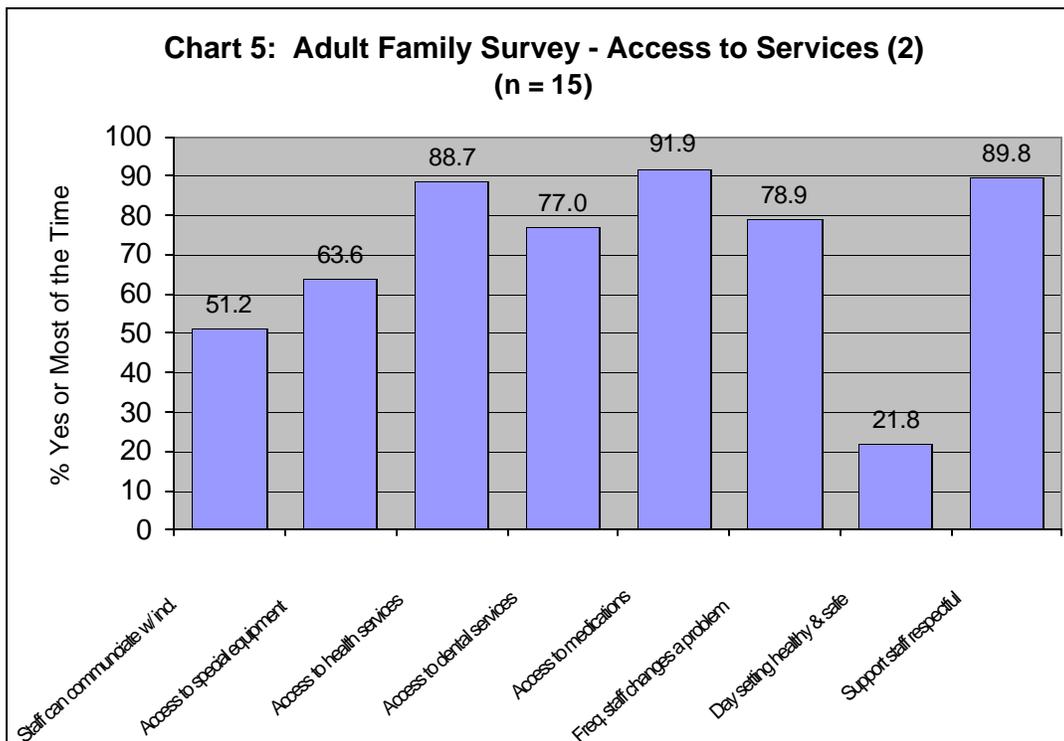
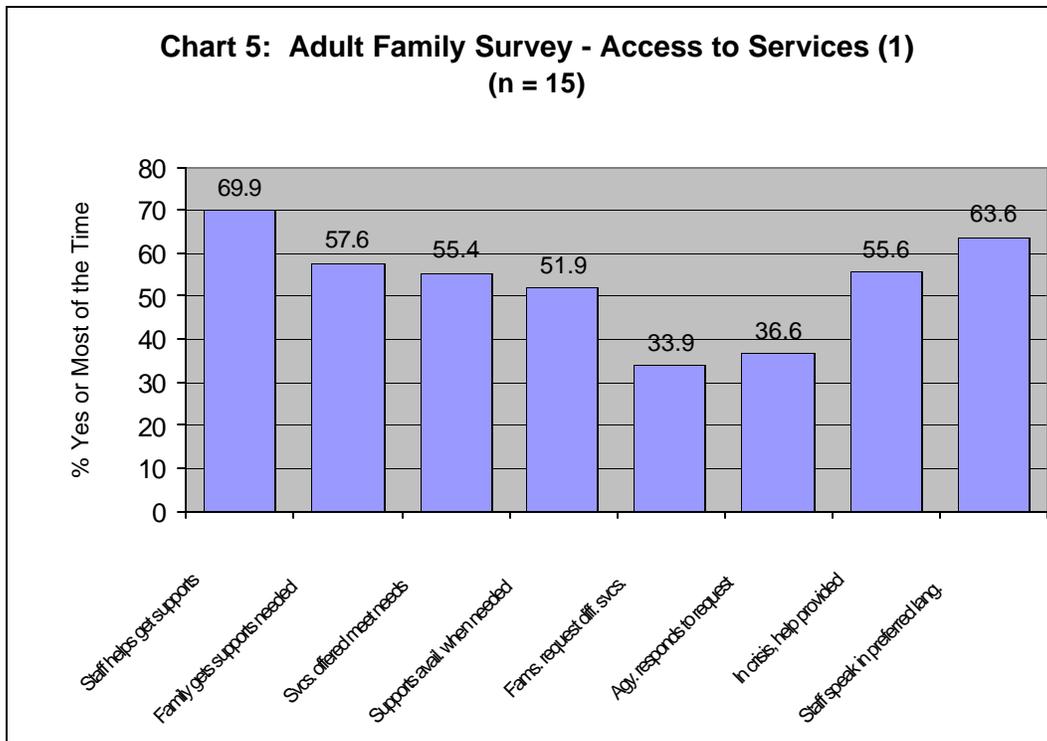


Table 19
Trends in Responses Above & Below State Average
Access to Services & Supports

State	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Net Sum
CA-RCOC		↑	↑	↑↑		↑↑		↑↑	↑↑	↓			↓				8
CT	↓	↓↓	↓↓	↓↓							↓			↑			-9
DE	↓	↓	↓				↓↓		↑			↓↓	↓				-7
HI	↓					↑↑	↓	↓↓	↓↓	↓		↓↓					-7
IA	↑↑	↑↑	↑	↑↑				↑↑	↑↑		↑	↑↑		↑↑			16
IN			↑				↑↑	↑↑		↑↑		↑↑			↑	↑	11
MA			↓	↓													-2
ME				↓		↓		↓	↓								-4
NC								↑↑									2
OK				↓		↓↓		↑↑				↓↓					-3
PA						↓			↓								-2
SC		↑		↑↑			↑↑	↑↑	↑					↓	↓		6
SD	↑	↑	↑↑			↓		↓↓		↑↑	↑↑	↑↑	↑	↑	↓		8
WV		↓↓					↓		↓	↓		↓↓		↓	↓	↓	-10
WY								↓↓	↓			↓↓					-5

Choice and Control

- ♦ In Indiana, North Carolina, Oklahoma and Wyoming, responses to choice and control questions were generally above the overall state average. In Connecticut, Delaware, Massachusetts and South Dakota, results were generally below the state average.

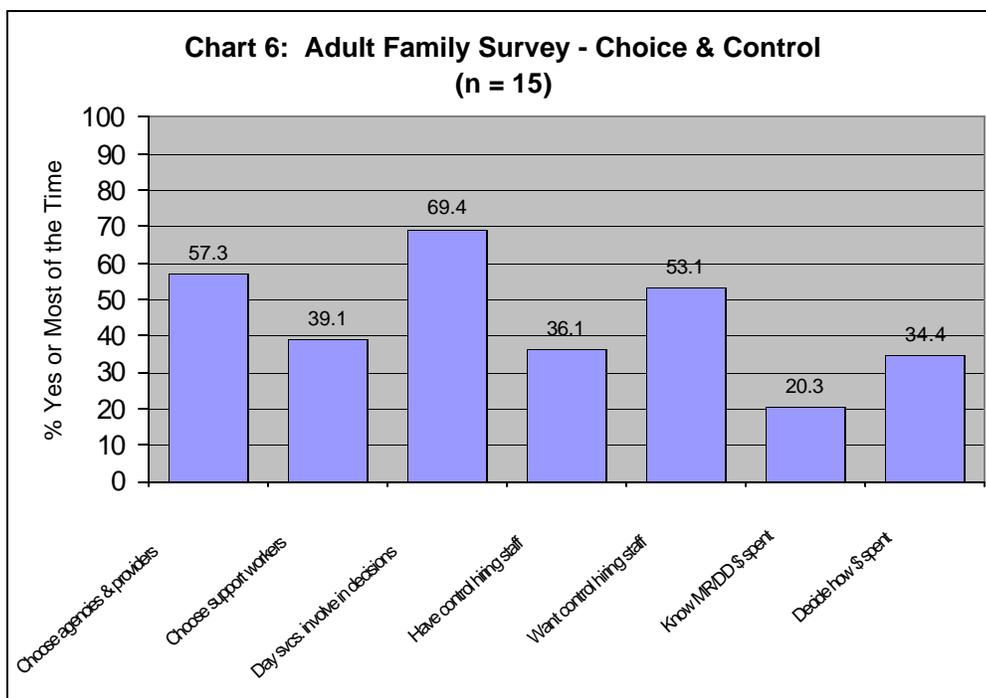


Table 20
Trends in Responses
Above & Below State Average
Choice & Control

State	Q27	Q28	Q29	Q30	Q31	Q32	Q33	Net Sum
CA-RCOC			↓		↑	↓		-1
CT	↓	↓	↓	↓↓↓		↓	↓	-7
DE	↓	↓		↓↓↓	↓	↓↓↓	↓↓↓	-9
HI			↑			↑↑		3
IA					↓			-1
IN	↑↑	↑	↑↑	↑↑	↑↑			9
MA	↓↓↓	↓		↓	↓	↓	↓	-7
ME		↓		↓		↓		-3
NC	↑	↑↑		↑↑	↑↑			7
OK	↑↑	↑↑		↑↑	↑↑	↑↑	↑↑	12
PA	↓	↓					↑	-1
SC	↓↓↓		↓		↓		↓	-5
SD	↓↓↓	↓↓↓		↓↓↓	↓↓↓	↓↓↓	↓↓↓	-12
WV				↑	↑↑	↓		2
WY	↑↑	↑↑		↑	↓	↑↑	↑	7

Community Connections

- ◆ In Indiana and Wyoming, responses to community connections questions were generally above the overall state average. In Delaware and South Dakota, results were generally below the state average.

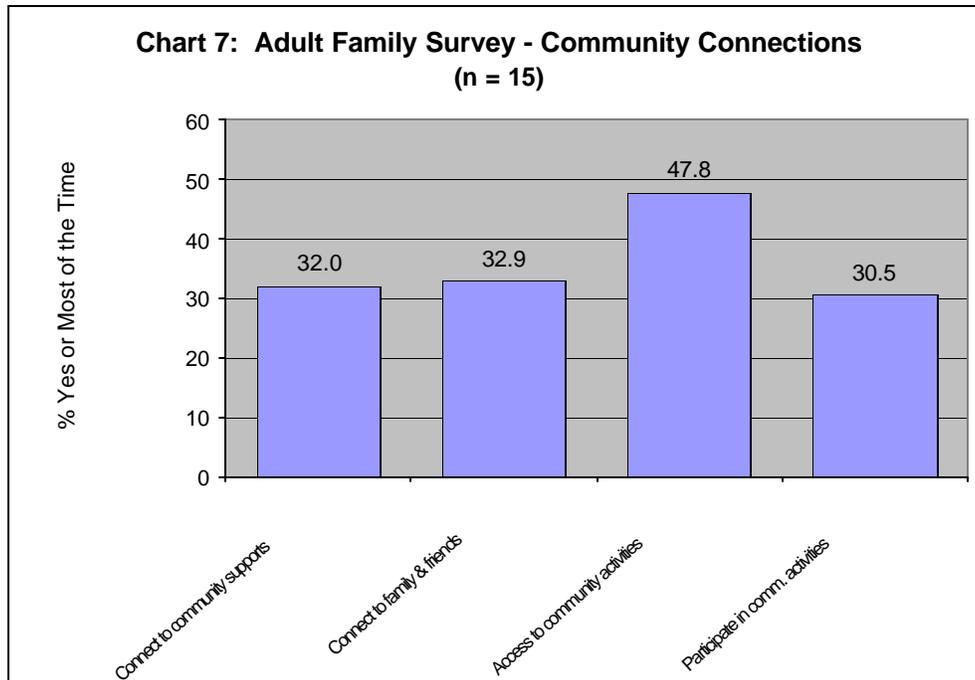
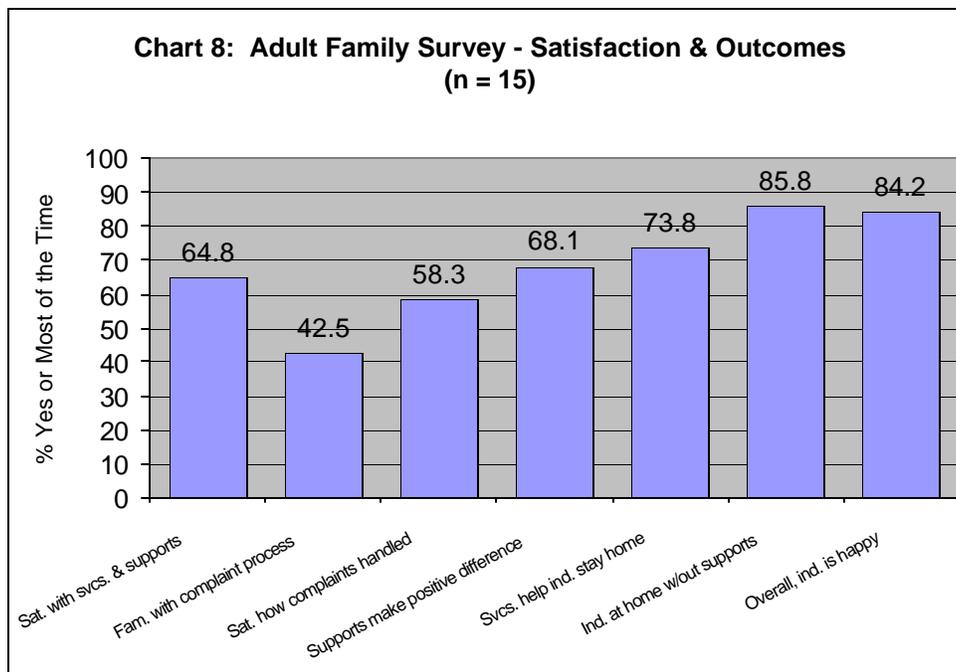


Table 21
Trends in Responses
Above & Below State Average
Community Connections

State	Q34	Q35	Q36	Q37	Net Sum
CA-RCOC	↑	↑		↓	2
CT		↓	↓		-2
DE	↓↓	↓	↓↓	↓	-6
HI					0
IA	↑		↑	↑	3
IN	↑↑		↑↑	↑↑	6
MA	↓	↓			-2
ME		↓	↓↓		-3
NC			↓	↓	-2
OK		↑↑			2
PA				↓	-1
SC		↑	↓	↓	-1
SD	↓	↓↓		↓	-4
WV		↑↑			2
WY	↑		↑	↑↑	4

Satisfactions with Services and Supports & Outcomes for Families

- ◆ In Orange County, California and Iowa, responses to satisfaction with services and outcomes for families questions were generally above the overall state average. In Connecticut and Delaware, results were generally below the state average. Note that Question 43 is considered a “neutral question”, and therefore, up and down arrows were not used in the calculation of state trends.



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

State	Q38	Q39	Q40	Q41	Q42	Q43	Q44	Net Sum
CA-RCOC	↑↑		↑↑	↑				5
CT	↓↓	↓↓	↓	↓↓	↓↓			-9
DE	↓↓	↓↓	↓↓	↓↓	↓			-9
HI		↓						-1
IA	↑↑			↑↑	↑			5
IN	↑↑		↑↑	↓↓	↓↓			0
MA								0
ME		↓↓	↓					-3
NC				↑	↑			2
OK		↑↑	↑					3
PA								0
SC					↑			1
SD		↑↑					↓	1
WV			↓					-1
WY					↑		↑	2

Overall State Trends

- ♦ Looking at results across all categories, Orange County, California, Iowa and Indiana received results that were generally above the overall state average. In Connecticut, Delaware and Maine, results were generally below the overall state average.

Table 23 Overall Trends in Responses Above & Below State Average	
State	Total Sum
CA-RCOC	22
CT	-34
DE	-41
HI	2
IA	27
IN	33
MA	-11
ME	-23
NC	6
OK	12
PA	-3
SC	2
SD	0
WV	-10
WY	11

Analysis of Open-Ended Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. QSR 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, Pennsylvania, and West Virginia 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 Pennsylvania, a clearer understanding of the data begins to emerge. Regardless of the number of responses, these comments provide insight and supplement the quantitative results presented earlier.

CONNECTICUT

Twenty-six percent of survey respondents from Connecticut wrote qualitative comments for this survey. These comments are summarized by theme below. The most frequently mentioned issues were: home issues, respite concerns, and funding and budget cuts, followed by aging caregiver issues, cuts in services, and overall dissatisfaction with services or agencies.

Home

The largest proportion of respondents noted that they had issues or problems related to the family, group, or residential home. Most respondents noted that they were unhappy with the home environment for their family member or reported that they were on waiting lists for supported living placements, group home, or other placement facilities.

“There seems to be a need for increased group home services for mildly impaired persons who could benefit from a more independent living situation.”

“My son is 20 years old. He wants to move out of our house and have his own life. He will need 24 hour support so a group home would have to be his placement but when we talk to his case manager she tells us it could take a long time for this to happen. She said the lists are long (would take years) and no more group homes are being built, and there’s no funding. Isn’t it sad that he has to stay home, when he wants to be like every other young adult and move out on their own? Hopefully you show these surveys to Gov. Rowland and let him see what he’s doing to our children.”

“We have three areas of deep concern relative to DMR, especially in the context of the movable aftermath of our inevitable deaths: (1) Nothing is being done to serve the growing waiting list for housing for persons with developmental disabilities who cannot or should not live on their own. No viable alternatives have been developed that work. (2) Despite repeated attempts going through the channels, parents such as we are unable to get their adult child’s priority raised to Priority I, despite our ages and health issues. (3) There is a pervasive lack of sense of advocacy for its own program at DMR. We see these at all levels, most especially at the top levels (regional and state).”

“My family’s biggest concern is, of course, a group home. She is now 28, and has been priority number one since she was 17. We have had one group home offering in 11 years and she

was turned down. A. is a Down's syndrome, hearing and speech impaired 35 years old. I do not feel he should be allowed outdoors without supervision. That is why his father and I both feel he should be placed in a group home."

A couple of respondents reported that they are happy with their family member living at home.

"We are starting to think about future living arrangements for S., but at this point we feel her quality of life living with us is far superior to what she could have outside our home."

"The only thing I want best is for my daughter to be happy. Don't want her to go to any group homes. She's very happy where she is. We take good care of her ."

Respite

Most respondents were dissatisfied with respite services. Major concerns include: a lack of providers, needed respite homes for short overnight stays, and reductions in respite hours. One respondent noted that she was happy with respite services.

"I wrote to Dr. [name], telling him I need respite, as all of it was taken from me. I had two nights from 3-7pm or 9pm, twice a week then once a week; then once a month, now zilch – nothing. I am under a lot of stress and I asked for at least one day a week from 3-7pm or 9pm. I guess that is too much to ask because I still don't have anything."

"My husband is retired – I will be in a few years. Our opportunities to spend time together as a couple have been very limited. Sometimes we take our son with us but it is not always possible because of occasional loud behavior when least expected in public places. We have no relatives who are capable of caring for him. The most we get is you two ought to get out and go someplace – there must be someplace you can have him put! You must not be working hard enough to make it happen. An area respite center has opened. Offerings has been few and far between and when they come, have not gone well. So far I have been refused for two anniversary weekends, a graduation and anticipated short-term trip for which a deposit was paid. "

"For those of us who are caregivers for our children at home and opted not to place our children in a state or private facility, I truly believe that the state should provide more options for the families. Perhaps a list of competent caregivers who could provide companionship or respite to the disabled at a minimum cost to the families, i.e., in order to go out to a movie on a weekend night, can cost us \$40-50 for a caregiver to come to our home. Transportation with Title XIX providers very difficult to arrange. There are too many rules and restrictions in order to get rides for my child from a respite facility to her day program. Legislature makes life very difficult."

"We need more respite services out of our house, more qualifying people; better communication between parents and staff 211 line – not helpful."

"Although I have respite care within my home, it is not consistent, and it would make it easier for me if my son had a consistent place to go to when I'm working."

Funding and Budget Cuts

Funding and budget cuts were a frequently cited issue. Families reported a variety of problems due to the cuts and a couple of respondents noted that they deferred looking for services because they anticipated the services would not be available.

"To make up for your budget cuts and less activities, we now pick up her friends and do activities more. A. and one friend at a time, but it would be nice to have more respite as it gives my husband and a very needed break."

"Since the cut in DMR budget, A. misses the respite time she had once a week going out to the movies, mini golf, out to dinner, etc."

"If we did need help, it would not be available due to cutbacks in spending and services by the state of Connecticut."

"I am concerned because we are being told there is no funding for day programs, transportation, and placement once my daughter reaches age 21. Right now her school program and vocational program are part of her IEP. What happens when she reaches age 21? I am very concerned about her future."

"M. likes to go on outings with DMR, but now that Gov. Rowland cut back a lot of things, M. just plays his Playstation or watches TV. He rarely gets out of the house. He used to like bowling and going on day trips during vacation. He is always looking for activities a place to go evenings and weekends. He doesn't always want to go out with us, his parents. Respite service is greatly needed. He would also like to live on his own in a supported living apartment. It would enable him to be more independent. We realize with all the budget cuts how difficult it is to provide services to people with disabilities, but we hope something can be done soon to increase monies for DMR services."

Again Caregiver Issues or Health Problems

Aging caregivers or caregiver health problems was a frequently mentioned topic often focusing on the need for placement for family members.

"Our most pressing need is full-time placement for our son. As we get older, it becomes more difficult to provide for his needs."

"Dad is 93 and P. is 60 with dislocated hips. What services are available if she is in a wheelchair? Bathing, toilet help, getting in and out of bed. Will we be able to keep her at home? When dad dies she will live with her sister. Sister works, who will be there for her when she comes from daycare or if there is no daycare? What services will be available in the area? Will there be help available for P. when sister is at work? P. cannot stay alone. In winter she will not go out in snow or ice as she is afraid of falling. What will happen? Will there be help out there for P. while sister is working? Is there any assistance to help out with this problem? I want to keep her in a home environment and save the state expensive cost of putting her in a home or institution but still keep my job. Is there help out there for me?"

Overall Dissatisfaction with Services or Agency

Several Respondents reported that they were overall dissatisfied with services or agencies. Especially noted were eligibility restrictions, lack of needed services, or the poor quality of services.

"The State of Connecticut should spend a fair amount of money on each handicapped person no matter where the person is living. So much money is used for those who live in sheltered apartments or group homes, but realistically very little money is spent on improving the lifestyle for the handicapped person and his family if they are still at home. Respite homes should be made available on a regular basis and for up to a two-week period of time so the parents can get away and relax. DMR should change its focus on helping us (the parents with adult handicapped children living at home) by providing more services. I have not seen my

child's social worker for two years. We are just a case in a large caseload. We should also be receiving financial help on a monthly basis to spend as we see fit in enriching our lives."

"They need to help more with people who have income level because when you have someone with a lot of health problems it is very costly. I think they should look at that – how much it cost to take care of a person with a lot of health problems."

"Generally speaking we receive no services from DMR. At one time our daughter was in a supported living arrangement in her own apartment. She received almost no support – 1-2 hours/week for marketing, the support person didn't even know how to balance a checkbook. Recreational activities offered are to go to a group meeting where we'll all make brownies and put on two more pounds making everyone more obese. As a consequence, our daughter came home and is relatively happy but has limited activity – works a couple months a year.

Recreational Activities – Dissatisfied

Several respondents reported that they were dissatisfied with the availability of recreational activities.

"DMR have dropped all recreation for my son. I feel this is not necessary. The government in Connecticut STINKS."

"We've lived in the area and was a great change in DMR moving to [city] where there was a lot less. Now recreation is terrible. I think this has affected C.'s behavior (has helped worsen it). I have to look for places for her to go for recreation."

"I have a job in the community, but this is a real challenge to develop for her because of her physical, mental and visual disabilities. This is also what makes recreational activities difficult. Our daughter uses a wheelchair and needs some assistance in the bathroom, especially if it is not handicapped accessible, or only somewhat accessible (they vary greatly, you know!). These two obstacles, combined with her mild to moderate MR, really make it difficult for her to participate in a group staffed only by one person and impossible if the staff person is a man and the activity will take her out for more than two hours and she will need to go to the bathroom."

"We need more recreation/leisure services. There is no connection of community through city recreation department or staff who help connect us to these supports."

Transportation – Dissatisfied

A few respondents noted that they were dissatisfied with transportation services for their family member.

"I need transportation; he has a one mile walk to work."

"S. does not understand working parents – and punctuality is vital. Staff doesn't seem to recognize this. During a recent problem I had to pull her out, as the new driver couldn't arrive within a 15 minute period – a 45 min-1hour which is not acceptable. My overall impression of [provider] – we are the only game in town. It's our way or the highway."

"It would be extremely helpful for parents like myself to have transportation for our disabled adults living at home."

Employment

A couple of respondents identified employment issues as an area of concern. A couple of respondents noted that their own employment has been impacted by their child's disability.

"Our main dissatisfactions are her assembly room job – on the days there is no work, there is not much else for her to do. But this is partly because she does not enjoy driving out to the stores, etc. which is a pleasant alternative offered. We would like for her to have a job in the community, but this is a real challenge to develop for her because of her physical, mental, and visual disabilities."

"J. loves school and I am very concerned about the availability and quality of a day program when he graduates from school."

"I would like to have programs that would enable me to work by providing before and after car for my son because his day program hours are only from 9-2:30. Although I have respite care within my home, it is not consistent, and it would make it easier for me if my son had a consistent place to go to when I'm working."

Overall Satisfaction with Services or Agency

A few respondents noted that they were overall satisfied with agencies or services.

"The services we have received from DMR have been wonderful. Mr. C. has always helped us and guided us. We are very appreciative."

"Thank you and god bless all of you. R. is very happy and his overall quality of life is so much better since he receives services through [provider], DMR, day care, Nursing Staff and daily aides, which are loving, caring and regarding to him. He enjoys the attention and contact with everyone involved in his general overall care plan and general care on a day to day basis. Thank you again, you're all so special, and our family is very grateful to you all, for you make it possible to keep him in his home with his family."

Health Care – Insurance

A few respondents reported that there are problems with health care. A couple reported that insurance was a problem, a couple mentioned that access to dental care was problematic, and one respondent reported that they needed access to gynecological care and one respondent noted that their family member is in need of alternative health care.

"Doctor and dental care for her because everywhere I go, doesn't take Title XIX insurance card."

"Our dentist just retired and I'm having a problem finding one who takes Title XIX. Will find one and pay full price – no choice. I feel like I am being ignored."

"Client needs help in funding medical needs and ob/gyn for her menstrual months."

"A. will also see a naturologist who deals with homeopathic remedies and nutritional support. All these are not covered by her medical insurance or Title XIX. This is disappointing because this model of health care has been more beneficial than the medical model. Is there any help in this area?"

Communication – Dissatisfied

A few respondents noted that they had problems related to communication, including lack of information, or poor communication with DMR or caseworkers.

“I have never asked for help or have been asked if I needed help. Every once in a while I get a letter from DMR, but that is the extent of communication. I know nothing of what they have to offer.”

“Any kind of help is not forthcoming. We don’t even hear from our DMR caseworker – when we have expressed a need for our son, you either can’t find help or you will see what you can and get back to you. We have grown apathetic with your response and think DMR in CT is a joke and not helping some very needy individuals. Maybe you can do better.”

Transition Issues

A few respondents reported that they were concerned about transition issues. A couple respondents noted that they were satisfied with transition services or planning. Other respondents were concerned about the availability of transition services for their children.

“Overall, my son’s caseworker has been very helpful and supportive – especially during transition from school to work. I am disappointed with Social Security (even though that is not your department). The agency servicing his employment has been wonderful – he is very happy with his job. I would like to eventually have him live outside our home for the following reasons – 1) he needs to have his own life; 2) would like to have this transition done before it becomes a forced issue.”

“My son has two more full school years left and the rest of this one. I am concerned about what happens next and how to plan for him this year so that it is successful when it happens.”

“I am concerned because we are being told there is no funding for day programs, transportation, and placement once my daughter reaches age 21. Right now her school program and vocational program are part of her IEP. What happens when she reaches age 21? I am very concerned about her future.”

Case Management

A couple of respondents reported that they were satisfied with their case management services.

“My son’s case manager for DMR is the most caring helpful individual. She has been a great support to us. I don’t know how to thank her. She is always ready to help. God bless her.”

Staff

A couple of respondents noted that they were dissatisfied with staff.

“One of our needs at this time is contact with responsible caretakers...”

“My support worker came one day and told me when it is good for her, then she would come. She is always happy because her family loves and cares for her! No thanks to DMR.”

Approximately 40% of respondents wrote qualitative comments for this survey. Employment was the most frequently mentioned concern followed by respite, health issues, and home issues.

Employment and Day Programs

Employment was the most frequently cited issue. Most respondents who mentioned this issue were dissatisfied with employment or day program services or opportunities.

“Our son's job placement has not been completed after in excess of a year in process due to his psychological problems. We were told that this job just be long term, but we are afraid that his psychological problems will interfere with long term employment as in the past.”

“It took almost a year to get him into a employment program at [provider]. We called a lot.”

“Workshop program – [provider] has been very good, but is very far from home. There is also a lot of "Down Time" recently - need more contracts.”

“After meeting with J. I'm trying to give [provider] another chance. But I haven't been happy cause I don't think they challenge my son to his ability when it comes to his job.”

“I would like to see MUCH better coordination between all agencies and programs to offer ALL participants job opportunities.”

“My daughter was approved for DDDS services in February 2003 and has not been placed in a day program yet. She has had her physical and I call her counselor weekly to find out what's steps are being taking by the agency to get her placement. T. is home everyday with me, she is bored, has nothing to do daily and hates just sitting around, I have tried everything, far as to getting her some type of placement for the day time and I have not been able to get DDDS to place her.”

“She loves her job and the staff are like family to her. The money is lousy! From \$11.00 or so for 2 weeks up to \$40.00 or more sometimes. Staff there tell me she is a great worker and fast! Some workers make much more than that—so how come they can't move her around once in a while where she can do a project that will net her more money? That is the question? But it seems there is no answer!”

A few respondents stated that they were satisfied with employment. Respondents frequently noted that they were happy with the staff.

“My adult son attends the [day program] daily. What a blessing to him as well as to us. He loves it and eagerly waits for the para-transit to pick him up. He is ready an hour early. The staff at are great. Thank you DDDS for providing this opportunity for him to go to there.

“Only support our L. receives is day program (rehab center) and transportation for it, which we highly appreciate and are happy with.”

“Good program (day care). Without staff and program we don't know what life would be like for J. He has come a long way and looks forward to going to the workshop everyday.”

"I would like to say that our son, K., is currently employed at [provider] and loves the staff and his job. Our goal is to eventually have him hired on at [company]. [Provider] is providing excellent training for him."

A couple of respondents noted that as caregivers, they had employment concerns.

"With the restrictions that the governor has made through budget cuts P. and I never get to talk with our worker from DMR. Her hours were so drastically cut.... My husband passed away two years ago and I have no family that can help w/ care on days I need to be at an appt. or work. Usually, I don't plan anything for those times. I have requested a yearly calendar of events however sometimes it is difficult to plan that far in advance."

"My son receives a home health aide after school. Occasionally, there is no one available, so I have to leave work and come home. This is very hard some days."

Respite

Respite was another frequently mentioned issue for respondents. Most respondents stated that they were dissatisfied with respite services.

"We were not at all pleased with the respite provider that was assigned for J.'s case."

"I am waiting for a call from respite - It is supposedly approved but I still haven't gotten a check to pay the sitters. They have to be someone I feel can handle Sue's problems."

"I feel that as a parent of a child w/ disabilities I am really on my own. I would like to see it be easier for respite care so parents like myself could keep their family member at home with them but still get time away. This to me is MY BIGGEST PROBLEM! I never get a break except when I am at work and that's not a break. I have been seriously thinking about placing my son because of that reason and just recently called his case worker about this."

"I would like to see an out-of-home respite. There is no one that DDD can recommend to me."

"I feel changes in respite have made it more difficult to receive and to get on short notice especially. Feel social worker has been of no benefit to our child/family up to this point."

"The last time was last summer and I requested 3 months of weekends (off and on). But the question was asked what I needed it for. Just my asking should have been enough as I do not abuse the request and was told to ask for more than my 14 days."

A couple of respondents noted that they were satisfied with respite services.

"We have used respite services by having friends and/or family take care of client while we are on vacation."

"We have just used the Respite Care in Jan. '03 to go away for 1 week vacation. We haven't had a break in 18 years! It was wonderful - our son, L. was in a car accident 18 years ago and we are his only caregivers. We had to find someone to come to the house. The money provided, even the small amount \$440.00, was a motivator to get someone to take care of him (day and night) for the week. We did this again in May for 3 days to get some ministry and counseling for ourselves. We had someone come in to watch L. for 3 days."

Health Care – Insurance

Respondents frequently mentioned health care issues, such as unaffordable insurance, or doctors who do not accept Medicare, medical problems, or lack of dental insurance.

“My biggest problem and concern is finding dental help for my son; and help with medications when needed. He receives Medicare but when needed we can't get prescription meds. I have yet to find a dentist to care for a 21 yr. Old autistic man's teeth. We don't have dental insurance.”

“We have always been able to care for our child but money was always a problem. He has no insurance. Medical expenses are what is needed most. Because a person works they should not be penalized and health insurance taken away. They still have other expenses to use their income on. Why should they and their family be penalized for taking care of their member because the family income is a few dollars too much?”

“I don't think it's right once a disabled person turns 21 years of age that they have to pay for dental and glasses themselves.”

“The biggest problem our family member has is to find health insurance that he can afford. He has only Medicare. He has no help with paying for medications or with dental care. If he were to be hospitalized, the costs above what Medicare pays would be really hard for us to come up with. Affordable health insurance is just impossible to find. Case workers have told me for several years that they would try to help us find health insurance for D., but so far I have not been informed of any that is affordable.”

“Dental was a very big problem. Dentist refusing to even see disabled son as soon as they heard he had Down Syndrome. I finally had a friend of sibling to see him for his dental needs/ dad dental at A.I. Until 18 and then had to find help. I am at the same spot with medical doctor since he has gotten older. Praying he doesn't get sick. Don't know where I could take him.”

“My sister is P. is blind and retardation and has seizures. She goes to [provider] every day, her has no dental. She has about 10 teeth and we don't have money to have them removed.”

“Needs preventative care - OT, PT, vision therapies, body work massage, chiropractic, myofascial, cranial - sacral, polarity therapy at reduced prices. Need dental clinic.”

Case Management

Several respondents reported that they were either satisfied or dissatisfied with case management services.

“J.'s case worker is very helpful and very nice to us. She always answer my phone calls. J. and I really enjoy talking to her. She is very helpful”

“The only reason (I have) such a positive response on this survey is because my son's case worker is [name]. He should receive an award for his caring, organization and rapid response to any question. He has called and visited J., attended an emergency school meeting and his IEP meeting. He has toured a day program and would have taken us to others. I can't say enough about what a great case worker he has been. Sadly, he is leaving very shortly (or maybe has already). We will really miss him.”

The majority of respondents mentioned that they were dissatisfied with case management.

"I know 'case workers' for DDS are spread pretty thin. Sometimes it is so thin that in our son's case worker she only sees our son or contacts us once a year. It should not be that way. Also at our 'yearly' meeting she had information on our son's medical insurance and medical info that was five to six years old and had change several times since. Again, I stress it should not be that way. They should also be knowledgeable on all the up to date information on what services are provided for each case."

"DDDS I know have very good programs. I had a very good worker but she moved and now I have seen our new case worker two times. He is lazy and offer no help to me when asked questions. I find that I'm told DDDS won't help I should take other steps. This case worker never visits my child or help with anything needed. I must call DDDS myself to see what is available for me to use."

"Generally, I believe our DDDS case worker is genuinely interested and tries to help in any way possible. I believe governmental and financial restraints severely restrict services that could be available to all families who have a family member who needs such services. The burden of care and financial, social and work-related supports rests almost completely on the family itself."

"I have not seen my son's case manager for over 4 years."

"The worker case loads are to big. There are not enough workers. Sometimes it is hard to get a hold of them. Sometimes the process of getting things done takes too long."

Home

Several respondents reported that they needed placement for their child with disabilities. Two respondents noted that more services are needed to help families keep their children at home as opposed to a group home or other placement.

"Family support needs more money to keep our children home, not placed in a nursing home."

"A voucher system would be useful. Not everyone who wants to live outside of their family's home wants to live in an institution or group homes."

"The only problem we are having is getting our daughter into a group home."

"B.'s life has been changed greatly in the past year that he has moved back home with us, his parents. He was being over medicated, and not treated to kindly in the group home that he was living in New Jersey. Since starting his program in February, 2003, he is a much happier person, and is learning to be kind to everyone. Hopefully he will continue doing well, and soon be part-time employed and move into a well managed group home."

"I would like to know how to go about getting my son in a group home when he turns 21? I also would like to know if the low cost housing apartments could be used as group homes? They are state owned. It makes a lot of sense to me."

"My son is 36 year old male with Down Syndrome and OCD. He volunteers at a local hospital. I am very pleased with his case manager at DDDS and his Job Coach. I am a 70 year old widow who has requested group home placement for him through DDDS and [provider] an am extremely frustrated that this is being denied at this time. I believe this placement (appropriate location and other clients) would be a positive event in his life."

"The group home situation is dire. My son needs to be placed where he can enjoy other people his age. He has no outlet to social activities and it is increasingly difficult for me to care for him at home."

Education and Training

One respondent reported that she is dissatisfied with education and training for her family member.

"I would like to see more support with the reading and math in special ed, teacher to take time with each student. Reading session - math counting money and all. My son is confused with time. My son can hardly read and comprehend what is read. My son cannot do math well, eh can't count change for money when sent to the store. I have to have him bring me the receipt. Right now I don't think he wants his so-called friend know that he has a disability problem."

Transportation

A few respondents noted that they were dissatisfied with transportation services, especially transportation to recreational activities.

"It would be nice to have some sort of transportation for extra activities. He likes Special Olympics. It's difficult to get him to practices. Practices are on weekends when your time is valuable when you work. Four hours spent traveling and practicing is a huge part of a Saturday or Sunday"

Recreational Activities

A few respondents noted that they are unhappy with the availability of recreational or socialization activities for their family member.

"Socializing or mentors young adults in their teens need a social life. They need friends so they can do things together. They are dependent on their parents 24 x 7 and this wears us out. My daughter always wants to do something every weekend. My husband and I are getting older. They need peers their own age to socialize. Also, a bus to pick them up and take them to different places. After school-recreation activity, learning a craft, skating, learning a dance, cooking class, tennis, bowling, and walking."

"Recreational - This seems very lacking. Would like to have opportunity for socialization - particularly dances (monthly or quarterly) and bowling."

"I feel that there should be more recreational activities made available to those with mental/physical disabilities. There is a program in [name of County], MD, run by the Department of Parks and Recreation, that is especially geared for those with disabilities. I feel something similar should be offered in our county where most of the participants are older adults or whose parents are older and could use a break."

"H. needs to be involved in activities with individuals like herself lately she has been very lonely and regresses with doing nothing. She is going to camp and is very excited."

Communication – Dissatisfied

A few respondents noted that communication was a concern, in particular, respondents mentioned a lack of information.

"While we have been connected to a social worker in the past, we have not heard nor seen her in years. Calls made to her and/or the Department have not been returned. We have had no success dealing with the Department. We have given up!"

"I do not even know who on your staff is in charge of my daughter's case. We haven't had any contact from DMR for quite some time. The previous representative was quite good."

"We are very satisfied with Vocational Rehabilitation; however, the provider rarely communicates with us and we have no input at all regarding job coach decisions."

"It would be nice to have a booklet of the service departments available and what services they provide example (wheelchair, lifts for vans, ramps, etc.) so that you can contact that agency when needed."

"We need more Spanish speaking case manager and support personnel."

"The services offered are good, but they could be much better if the group supervisors had more support from the agency staff to accomplish the goals set up in the service plan. I would like to see MUCH better coordination between all agencies and programs to offer ALL participants job opportunities."

Aging Caregiver or Health Problems

Aging caregiver or caregiver health problems was mentioned by a couple of respondents.

"I am 82 and my wife is 81—we have cared for our daughter for 44 years. It is debatable how long we can continue. She goes to [provider] and is a work support group which has been very good for her and for us. We thought she would go to [provider] they have declined to take her though she has been there for respite. It is suggested she go to a group home and presently is in category 2 with a shift to category one if the need arises. Will she get in when either one or both of us wishes?"

Transition Issues

A couple respondents mentioned that they have concerns regarding transition issues.

"From what I've experienced and observed, schools do fair to good job, but transitioning and adult needs are sorely lacking."

"Our 20 yr. Old son is still in school but this year we have visited 4 agencies around vocational planning for next year. Our son is ready to work but the economics of today have us concerned about eventually employment. As I understand, a road block we have is that he has to be either funded through the school or through DDS/DVR and there is no transitional services where he could do both. In other words, if he is employed this year for 2 months, loses his job, etc., we cannot place him back in school."

Staff

Overall, respondents reported that they were satisfied with staff.

“We are very pleased with the people who have come to the house to help our daughter. The aide is wonderful. The physical therapist was great and helped S. to be able to do more to help herself.”

“Our provider give our child gives him personal attention. She shows that she cares like a friend. We are glad we have her as a support person.”

One respondent noted that relatives should have the opportunity to get paid to provide care for their family member.

“I feel as a State care provider I should get paid like other people for taking care of my niece but I don't. I think this unfair to me just because I'm her aunt. If someone else had her they would get paid. I take very good care of her. For the year I had her has been the best year of her life. She has grown to do things they said she couldn't do with my help and love I give her.”

Advocacy and Choice

A couple of respondents noted the need for more choice in services, providers, etc.

“The Division of DDS needs to be more flexible in services delivered; what type, who provides, and who gets services. A voucher system would be useful.”

“Need more control over how funding for support in the home is spent; need more choices for employment for participants who need higher level of care; need community living choices; and need more complimentary therapies (OT, PT, SLP, etc).”

Funding and Budget Cuts

A couple respondents mentioned that funding and budget cuts were a big concern.

“With the restrictions that the governor has made through budget cuts I never get to talk with our worker from DMR. Her hours were so drastically cut. Also, P. was endanger of losing her home health care aide to two hours instead of 4. This lady has been P.'s home health care person for approx. 13 years. Since I worked on a PT basis this is the only other adult I have to depend on to care for P.. However, due to holidays and in-service workshops that cost 6 or 8 hrs. I do not have any assistance to care for P. This is something that needs to be addressed. My husband passed away two years ago and I have no family that can help with care on days I need to be at an appt. or work. Usually, I don't plan anything for those times. I have requested a yearly calendar of events however sometimes it is difficult to plan that far in advance. More respite should be provided. This is one service I don't feel we get enough of.”

“The Federal and State Governments should stop cutting and start refunding monies for more programs it is a disgrace. I work hard and pay plenty of tax dollars.”

“My daughter lives with me. We need food stamps, someone around to talk to me about getting them.”

Overall Satisfaction with Programs and Services

A few respondents noted that they were overall satisfied with available programs and services.

“My daughter has really progressed and able to do a lot of things I never thought she could do. My help from the services have really helped. How glad I am as I have been struggling with my daughter since the age of 7. Thanks.”

“Thank you for the opportunity to share my comments. My daughter has been helped tremendously through your program.”

Overall Dissatisfaction with Programs and Services

A couple of respondents stated that they are overall dissatisfied with the available programs and services for their family member.

“I am extremely disappointed with your organization. We were assigned to [case manager]. I am the caretaker to C., and I myself is a disabled adult suffering an incurable disease. I have a total of 10 major operations, and we never receive the help of all your questions from you agency. She at first try at the beginning, but after a while her answers to me where that she had to help others more than us. And was extremely to busy to help me. Even as when I had my last surgery, and I needed the support from your services. I don't know what services you provide as to everything she said is the money situation. I have spoken to her supervisor about this. And, she referd me to a Spanish agency that wasn't able to help us. I believe there is no help for us in Delaware. We are alone here.”

“Delaware needs to take a more proactive role in the adult handicapped population. Support services, social activities and group support for care givers are all needing attention. The program I found and C. attends is the best of the best, but it was a long, difficult struggle for Delaware to fund this program at that time. The policy of ‘Person Centered Plan’ is lagging in Delaware - the individual needs a place based on their needs.”

Approximately 30% of survey respondents from Hawaii wrote qualitative comments. These comments are summarized by theme below. Case management was the most frequently cited issue, followed by lack of services, and overall satisfaction with services.

Case Management

Case management was by far the most frequently mentioned issue. Approximately half of all comments referred to case management services. Most respondents who wrote on this topic were satisfied with services. Words to describe good case managers included: caring, responsive, efficient, personable, reliable, compassionate, supportive, resourceful, informative, helpful, good listener, planful, and quick to respond.

“Case manager has done a terrific job! My son’s services through DDSB and [provider] have been excellent! Our case manager has been my son’s social worker for many years now (we truly appreciate the continuity). She is exceptionally caring and responsive to my son’s needs, efficient, personable and reliable. I can’t say enough about her positive can-do attitude and the personal interest she takes in our son. Mahalo!”

“Very satisfied with my case manger, currently. Very compassionate, concerned and so very easy to talk to. Willing to help out and answer questions without “beating around the bush”.

“There are times when our family has to make decisions and have support, he has been the only person I could turn to help with the daily on going living expectations. For all the years, I have not been able to reach this point with any other case manager/social worker. Being he is finding the placement for each individual on a personal base, the others seem more involved with all paper processing. With much gratification, I wish to have my case manager on going for the years to come with my daughter.”

“Our case manager is great, helpful, resourceful, and informative.”

“Case manager is very helpful and caring. Really explains things as you understand what is going to happen to the person.”

“We are completely satisfied with our case manager. She understands all our needs and is on top of everything requested of her. We feel very fortunate and grateful to have her as our case manager. “

“Case manager is terrific and a great help to my son and I. Case manager is very good with communication and program planning. Through the help of our case worker, life has been wonderful.”

“ My son’s case manager is on top of what is needed to help enhance son’s life. We were in a crisis in February because I fell and broke my ankle. Her quick response allowed us to get temporary increase in hours to have help available in caring for my son. (it took me 4 months to heal). In any event, I /we will always be grateful and thankful that we had our case manager to help us in our time of need. Please keep her in mind is you have special recognition and/or awards available to your employees.”

Although most respondents were satisfied with case management services, some were dissatisfied. Common problems included: turnover, lack of professionalism, lack of communication skills,

unqualified, failure to follow-up, failure to visit family member or understand family member's needs, too much paper work, large caseloads, or scheduling meetings when parents work and cannot attend.

"My daughter just graduated from high school in June. She has Downs Syndrome. Her case manager changed about 3 times. Her case manager is NEW, therefore. He doesn't know many things, for instance, always calling me back, forgot to go over something, forgetting deadlines I gave him to stop personal assistant services, mailing me wrong forms, etc. In fact, [name of agency] where my daughter attends day program taught me more about the ISP meeting than the case manager. I realize he's new at this nut I have found myself very frustrated, especially when I need a supportive, informative and helpful case manager during a time of transition. I feel more importantly, he does not know how to show true compassion for my daughter. Bottom line is he doesn't know his job and he doesn't truly care!"

"They do not follow-up on ISP."

"Really difficult to work with this case manager. Never even requested to visit this disabled member and his family at home. When I speak to him, he rushed especially by phone and doesn't really ask about disabled member's needs, our family's needs, respite needs, etc. I had a hard time with him and need to change with someone who will really help our disabled family member."

"Last year's ISP review was scheduled at my family member's residence. Unfortunately, no one perceived it a problem that another client was home sick and would be there as well, listening. The location was changed to across the street from the home. When 2 members of the agency were unavailable, I suggested that the review be rescheduled. Both persons were scheduled to attend the review in the first place. Both showed up about half an hour late- each with her own logical excuse. None the less, it did alter my impression of the professionalism of the gathering. If it were a baseball game with me up to bat, I'd call the fact that I was the only one who was bothered by their strike 3 and yes, I came away feeling anything but a winner. What message was sent to my family member?"

"ISP is a process to determine hourly needs and access dollars. ELP is attached. It is the 'plan' which tell caregivers how to support what is important and addresses health and safety issues. Case management fills out paperwork. They do not assist in creating a 'plan' which what supports the individual's quality of life. Case management simply does not have the time or knowledge to help plan the personal details, changes and action needed in contributing to an individual's quality of life. In fact, they can interfere with this process since the ultimate responsibility is paperwork – not the individual they represent."

"Because of the frequent changes in case manager, it's difficult to answer the survey questions. Turnover of case manager is a concern, but feel that people generally do the best they can."

"The only comment I have is that the DOH turnover is killing you. [Name of case manager], for the short time she has been our assigned case worker has made every effort to learn about her clients, makes unsolicited follow-up calls and follows through on all requests. My only regret is if we lose her – it seems like your efficient workers get burnt out. But I have no complaints about our case manager. Wish you had more like her on a consistent basis! Excellent case worker."

"Case workers changes all the time. Most of them are good. Some I've only met once. Currently, I've only met with case worker one time."

“Meeting of ISP are held during the day and I work so I cannot attend.”

Lack of Services or Dissatisfaction with Services

Lack of services was a frequently mentioned issue. Respondents reported problems with eligibility guidelines, long waits for services, or needing services that they are not receiving.

“Our problem is with services is that our daughter’s income fluctuates and she has a small trust. She cannot qualify for Medicaid and Waiver services. This is a problem as we consider Independent Living and future health needs. We feel there should be some way for people with DD to access basic services on a sliding scale option. They should not be denied access because they are employed or have other income which makes them more not less like typical people in society. They have achieved yet in this waiver system they are excluded. Our daughter’s disability is such that she will never be completely independent or self supporting. How is she to access services?”

“We have to wait months for services. It is so frustrating – that we are considering putting our son into a home.”

“If at all possible, my family feels a day-care plan or service is necessary. The challenge of a disabled family member, day to day, is not easy.”

“Services has been overwhelmingly denied or they just plain don’t understand what families can or can’t have based on the no knowledge of what the waiver encompasses. Maui seems only interested in saving money and denying services. Well it seems fitting to file suit for denied access to services. It also seems the more disabled a client is the less the services are. This is discrimination within an agency that seems to do just that but tells the public differently. Medicaid just denied my son’s entrance to ICF/MR and said to try the waiver program. No luck to me. I am not happy.”

“But not satisfied with limited array of options for individuals with DD who need supports for independent living and employment and not day services. Medicaid waiver programs need to be more flexible.”

“Because we are in need of dental services. No service is provided here on Maui although we have dental plan.”

Overall Satisfaction with Services

Several respondents indicated that overall they were satisfied with services.

“My brother’s spirits are better and he looks forward to aides who provide daily care and socialization. The family is happier and can only attribute this marked change to your agency’s concerns, expertise and support.”

“A job well done. Keep up the good work!”

“I appreciate all that is done for my grandson – supports that was needed. I’m thankful and appreciative.”

“Although we have only been receiving services for the past 6 months, it has been a very positive experience!”

Staff

A few respondents reported that they were satisfied with staff. Words respondents used to describe staff included: caring, friendly, and ready to listen.

“We are grateful to the center staff at our son’s center. He is happy and shows small but positive growth in behavioral and social skills. Staff shows the caring attitude towards the clients that give us peace of mind”

“My sister is very happy attending [agency name]. All the workers are very friendly and always ready to listen to what she has to say.”

Transition Issues

A couple respondents mention transition issues. Respondents reported that they need information about transition services and talked about gaps in services between the educational system and the adult system.

“Believe another ISP is due – my daughter turned 18 years old and therefore her needs are changing. I am working towards trying to get legal guardianship for her – which is expensive. Help would be good in this. She stays in school till she is 20 years old. How is [provider] monitoring what type of job she is going to?”

“I’m just weary, in the transition that is a lurch and a lull both after leaving [provider], there is not any structure anymore.”

Communication – Dissatisfied

A couple of respondents noted that they were dissatisfied with communication. Specifically, they were dissatisfied with communication with their case manager, information about services, or interagency communication.

“We have not had any contact with a case manager for over 5 months. I don’t know if we still have one?”

“I would like to see a ‘complete handout’ of what support services are out there in the community. I’m not aware of what’s available so it’s frustrating to decide what’s ‘best’ for my sister.”

“Will this information be made available to all agencies?. Wouldn’t it be advantageous for agencies to be in direct communication with one another in regards to the welfare of all Downs Syndrome individuals?”

Fifty-five percent of respondents from Indiana wrote comments for this survey. These comments are summarized by theme below. Staff concerns were the most frequently mentioned issues followed by transition, parents or relatives as paid staff or case managers, and employment issues.

Staff

The largest number of respondents mentioned staff concerns. Most respondents were concerned about turnover, a shortage of staff, unqualified workers, or low pay. One respondent noted that she was satisfied with the staff who works with her family member.

“They keep tear my family apart. Because they do not want to do and her work. They want to eat and watch T.V. and knit blanket and read book to there self. While the kids are tearing up the house up. All I ask for is them to learn bathe kids clean and pick up after them self and for the aids to pick up after there self but all I get is this and they don't know to cook. Need someone who cares about they job.”

“My complaint has always been that there is not enough staff. The staff I have is excellent and I am greatly appreciative of them. Without the Autism Waiver I would be extremely frustrated. I could not have my son at home if not for the services and staff we have. It seems the staff all the way from the case manager to home staff, have tremendous amount of paperwork to do. I would like to see better training for staff in the field of Autism. The turnover is great, due to pay I would assume. I have had one staff person a long time and I am fortunate and grateful.”

“Most workers are careless and irresponsible! In past 4 yrs., 3 new sweepers have been destroyed! My money, new clothes, unpaid bills thrown in trash. A new jacket disappeared. A towel rack ripped off a wall. Washing machine drain pipes pulled apart. This list could go on and ON and ON! “

“In small communities it is hard to get good respite and personal assistants. They are usually unreliable and there is no back up supports. Also the community involvement is tough. If I don't go with my daughter, there are no community activities that she will be to participate in.”

“Staffing has been a continual problem - I find my staff. [Provider] has a problem with supplying me with staff. They say they interview them and will send them out but I never hear from them.”

“I feel that our son has made a lot of progress because of the services he receives. Through the waiver, we have been very fortunate to have good staff to work with him. But we have also lost good staff because of the pay they receive.”

Overall Satisfaction with Services or Agencies

Several respondents reported that they are satisfied overall with services or agencies.

We are so thankful for the services provided for our daughter. We now have a sense of 'normal' in our home. Family member has come so far with all the help that your service has provided for her—we just can't tell you how much it means to us and our baby. Thank you from the bottom of our hearts!”

"When we were first introduced to Medicaid Waiver - Area IV wasn't real helpful - not too good but that was 6-7 years ago. We are much better off with individual care plan coordinator – Provider, they are very informative."

"I'm very happy with services I am receiving at this time."

Transition Issues

A few respondents mentioned that they had concerns about transition issues.

"I also feel more services need to be available to my son to help him be more independent. How to run a household, laundry, grocery store etc. This needs to be continually addressed as the children get to be young adults, not wait until they are adults. I home school my son and have since age 11. FWCS - just doesn't kick it. For these families who do the same or will do more programs need to be out there for young adults. I feel this age is overlooked. They wait till they're adults and then start to address the issues."

There needs to be more services for those severely involved in wheelchairs with mental deficits. I have not yet found any place for my son to go once he "graduates" from school that would be stimulating and fun for him to spend his day. I have found places where he could just SIT for the day. There is not much for those with feeding, communication, physical...disabilities to do."

"Our son needs something like school that is structured and provides water therapy and activities and learning possibilities to keep him busy also therapy for P.T., O.T. and speech. Please consider this because he will not be able to work or hold down a job, but he needs a routine to get out of the house and keep busy and see people and do different things. He enjoys school so much and going on the bus or van. We are really concerned about this when he is too old to go to high school, but are really happy with his high school and the activities they provide. He needs something like school to continue beyond 22 years and there are several children like him that will need this also."

Parents as Paid Staff or Case Managers

A few parents mentioned that it would be beneficial if parents or relatives could serve as paid staff or case managers.

"I have a sister who could watch my son if she would get paid for it instead of trusting his care to strangers. I am extremely grateful for the in-home care when provided."

"I wondered if there will be a guardianship program here in IN? They have a program in N.M. that pays the caregiver to stay home with the family member. Family member is a very family oriented person, and I'm thinking about moving back out to New Mexico now, because we are barely getting by."

"I would like to know how I could be responsible for my daughter's money. Make a monthly report of where her SSI money is spent? Two years ago, I helped her each Friday and took her check to the bank and had her checking acct. up to \$2,200. When she lived on Franklin St., then she moved her boyfriend in, and he spent all of her money. Please check with the bank. There is a person who is being paid by the state that is supposed to see that her bills are paid, that her apt. is clean, (which she never did), I cleaned the apt. myself and moved her out, at my expense."

Employment

A few respondents noted that they were concerned about employment opportunities for their family member or caregiver employment issues.

“Am a little dissatisfied with the workshop because of lack of work sometimes and not the right job for a legally blind client.”

“...we need to work out something that is consistent because I can't even work because he isn't in a program everyday.”

“I work very odd hrs and it's not easy. I struggle money wise so I have to work and can't afford not to work and leaving work to do this kind of things, it would be helpful if we had this.”

“We are very thankful for the program. It helps us [both parents] to continue to work and support our family. But most of all family member has the support she needs from being as safe w/her caregivers, support to get out in the community, learning to be independent as much as she can[self-confidence]. She is so happy w/ the new company we are with now. Working together (physical therapy) has improved. The change in my daughter is wonderful. Enjoys working. Job Coach does a great job.”

Home

A couple of respondents noted that they had issues related to the home environment.

“I do not like my home regarded as a group home. It seems more and more that it's going that way. All the paperwork for myself and respite workers takes time away from the boys. I believe once a year for any training would be sufficient. Changes are very disruptive to our family life. Once again this is a HOME not a group home!”

“Four yrs. ago applied for new bathroom modifications and 6 mos. Ago mentioned new kitchen cabinets—nothing done yet!”

Recreational Activities

A couple of respondents noted that they were dissatisfied with available recreational activities for their family member.

“There are no services I've found to take my son and his wheelchair and his physical body out into the community. He is stuck at home unless I transport him.”

“Also the community involvement is tough. If I don't go with my daughter, there are no community activities that she will be able to participate in.”

Respite – Dissatisfied

A couple of respondents noted that they were dissatisfied with respite services, usually needing more hours of care or difficulty finding providers.

“Am a little dissatisfied with the workshop because of lack of work sometimes and not the right job for a legally blind client. Finding respite care is nearly impossible but using my older daughter and paying her has helped. Biggest problem is change of people working with our daughter. Autistic people need uniformity and little change and this is not happening.”

"I appreciate the lady who comes to help with Robin every weekday until 1:00 , Monday through Friday. I have had help on Monday, Wednesday and Friday 1:00 PM until 6:00 PM, also 9:00 AM Saturday until 6:00 PM, Sunday 8:00 AM until 10:30 to get Robin ready for church. Now I don't have this help either. I am getting so tired but I have been trying to keep up. I am a diabetic on cholesterol meds, take insulin shots, 79 years old, had cancer 7 years ago of lung and liver. I need more help but can't seem to get it. Thanks for reading this, hope I am not complaining too much. I do want him at home with me. I love him very much but I do need more help."

Case Management

Dissatisfaction with case management services and caseworker turnover was reported by a couple of respondents.

"Our current case worker, who is an independent case worker is NOT very good as far as I'm concerned. She promises to do things, send things, fax things, etc., and it never seems to happen. I am afraid to change caseworkers though because I don't know if my son's status is really current due to the lack of information provided by the caseworker."

Overall Dissatisfaction with Agency or Services

One respondent reported that she were overall dissatisfied with the agency or provided services.

"Satisfied with the waiver and how it provides money for service. Not satisfied with the POWER the agencies have over the money and the consumer. Families should bill direct to the state; it would save the state much money in the future."

Approximately 27% of respondents from Iowa wrote qualitative comments. These comments are summarized by there below. The most frequently mentioned issues were employment, overall dissatisfaction with services, and home.

Employment and Volunteering

The most commonly cited issue was employment or volunteer opportunities. Most respondents who commented on this topic were dissatisfied with employment. Two respondents reported that they were satisfied.

“When my son graduated from high school I was under the impression that he would be able to go to work. I requested a one on one aide for him and was denied that by the county board of supervisions. So I took it upon myself for him to volunteer at the school he had attended which was working out fine because that is one of his goals to be out in the community. Well a few weeks ago our case manager told us he could no longer do that because it wasn't one of his goals so now he just sits home.”

“Our family member is 18 years old and has mild to moderate disabilities. His program no longer includes volunteer work in the community. Dollars go outside our country and big corporations instead of assisting something that is very much needed for him right now.”

“In regards to employment services, these seems to be a need for jobs for the mentally/physically handicapped in businesses other than food service, janitorial or cleaning hotels. Perhaps looking towards government agencies, insurance companies, US Postal Service, attorneys offices, banks etc. Jobs such as, sorting, filing, mail delivery in office buildings, copying etc.”

“Working has helped and daycare is good.”

“My son really loves his job.”

Overall Satisfaction with Programs or Services

Overall satisfaction with programs or services was a frequently mentioned topic.

“Services and supports have been real good to us so far.”

“My son and I are very happy with the services we receive from state agencies. It helps make a big difference in our lifestyle.”

“Thank you for all of your wonderful assistance!”

Home – Satisfied

A few respondents mentioned home issues such as satisfaction with home environment and placement needs.

“I feel without the help of Human Services I wouldn't be able to keep my daughter at home. They have been a god send for our family. They have always been very caring and helpful. I think I would have been lost without there help.”

"H. seems to be ready to move to a group home but there seem to be no opinions and no good prospects locally. The state and county budget crunch is part of the reason for that."

Case Management

Case management was noted by a few respondents as an area of concern. About the same number of respondents indicated that they were satisfied with case management as who were dissatisfied.

"We are very happy with our case manager and the wonderful variety of services that have been made available to our son. Thank you."

"Case manager have been most helpful and kind in planning for my son. We are grateful for the concerns and needs of M."

A couple respondents indicated that they were dissatisfied with case management services.

"I am very with my agency which is in [city]. They are very good at trying to get what we need. I am not happy with the case management in the county. They are rude and very hard to get a hold of or questions answered or any kind of information."

"A continual changing of case managers is not helpful to an autistic individual. We had 4 in less than a 2 year span."

Respite

Respite services were mentioned by several respondents. Most respondents were dissatisfied with respite, while one respondent indicated that she was satisfied.

"Overall we are satisfied with services in the area. An area I think still needs to be addressed is as parent/guardian/and care provider for an adult there is nothing available that I'm aware to give provider a break from family member to have an evening out with spouse once in awhile. Not eligible for respite as I am a CDAC provider."

"The entire family would have appreciated respite when our son was younger. This has created a huge burden on the younger siblings. No one wants to baby-sit a handicapped teen. We have an extremely difficult time locating individuals to provide in home respite. My wife and I are only able to be out together maybe once or twice a year."

"The current budget has had a definite negative effect on our family and our child's care. Unfortunately, due to health and other reasons she wasn't able to access respite and SCL services for a year or more and therefore her services were cut severely. Now that her health has improved and she is able to be in the community, having some SCL and respite services she can not. We feel very fortunate we have some hours for SCL and respite and hope they will not be further cuts as we really depend on these services."

"I really doubt that our daughter would still be living at home if we didn't have respite help."

Health Care

A few respondents noted that they were concerned about health care like needed equipment, dental insurance, or mental health care.

"He understands other but due to difficulty with speech others often can't understand him, He can read and write. A communication device would be useful but we were never able to get one for him."

"L. has at present dental work being done for him here in [city]. The charges are excessive and title 19 doesn't pay for his entire work. It's a problem as cost of 1 tooth is \$550. It would take him months to pay such outlandish costs. Is there anything that can be done to lessen this burden on him?"

"His doctor through mental Health. I am not always happy with him. He always wants to take medicine away from him that he needs for his mental illness. He had a bad incident last year and I don't want him to have to go through that again, so I believe that the medicine he's on is doing real good for him at this."

Education and Training

Education and Training was mentioned by a couple respondents.

"I have B. was fully included mainstreamed into his high school class. He graduated with special ed classes and by auditory some regular classes. Even though he is under 21 because he went through the ceremony of graduation, he is not eligible to receive further special education schooling. If her were in a city, or non-rural setting, there are programs to go into. I feel it discriminates against rural disabled people to exclude them from education services simply because they went through the graduation ceremony. What is the point of working if they don't graduate with the class? My suggestion is to allow students to go through graduation ceremony then if they want to come back the next year for day, a vocational class, a reading and a math class, let them in one district. He could be surveyed by the HS SCI classroom. He was really making reading and math progress, especially his last couple years in school. Right now the only adult basic ed classes available less than ½ hour to 45 minutes away that are appropriate small groups with 1 on 1 help are at elderly having independence. It's close, good teacher but of little social value as the other clients are all 50 years. If you have any insight into a possible grant I could get for to establish study program for kids not able to take GED but needing to practice skills, please let me know who should I contact to get the graduation rules changed? It seems that since B. is retarded, no one thinks it's worth practicing reading and math skills. Aren't those basics everyone needs? All of his regular friends have education options but he does not. I feel he's being discriminated against because he is retarded."

"Why in the state of Iowa are there not place to help kids/people read or write to get a job to help pay their bills. Why do schools just pass the children and not help them read or write before they graduate?"

Parents as Paid Staff or Case Managers

Allowing parents or other relatives to provide care or be case managers was noted by a couple respondents.

"Would like to use family members for respite care but the rules state that family members must become licensed as respite providers for this to happen. Have other children and to provide in home respite care we would need two providers the family member for the other children and respite provider for child with disability. This is not in the best interests of the child or family. This side should be change."

Overall Dissatisfaction with Programs or Services

A couple respondents reported that they were dissatisfied with programs or services for their family member.

“In the last 6 months there have been some problems with communications with my daughters [provider] administrators and I. One of her workers I specifically asked for and was granted 6 hours a month was taken off of our roster for supposedly 2 weeks and I am still trying to get the worker back. I am told basically if I don't like not having her on my roster take my child elsewhere. This came from the head of [provider] head man. I felt betrayed as they are suppose to work with what best for my child and their client. I am disappointed in their attitude and lying.”

“At 18 years of age the school (to get rid of her) gave her a signed diploma and left her for us to take care of. Upon the prodding of our daughter who just graduated as an RN, she insisted we find her a place for rehab. The only one came to our aid was the case manager and placed her in [city] for 6 months. They assured us she would be 100% supervised and not to worry about her as she is in good hands. How come she came home pregnant? When this happened she ran away. Our RN daughter took her off our hands until time of delivery. This boy, N., turned 18 Nov of 2002 and a senior to graduate May of 2003.”

Fourteen percent of survey respondents from Maine wrote qualitative comments. These comments are summarized by theme below. The most frequently mentioned issue was dissatisfaction with communication followed by case management, staff, employment, and the home environment.

Communication

Dissatisfaction with communication was the most frequently cited topic. Problems include poor communication, lack of communication, and inadequate information about services.

“As I stated-this year 2002 is when I've seen some real improvement in support for my son, T. Although, if I don't ask about supports, agencies don't readily give you information.”

“Communication is very bad at the program between bosses, staff and parents.”

“To date no one has addressed any of our concerns.”

“I find all of the different agencies all blur into one confusing group of helper. Initial intake is thorough in all cases but seldom leads to much unless I initiate it. No one check in, no one seems to be proactive. I am a strong advocate and go after what's needed for my daughter, however, having professionals approach and work with me in a proactive way would be of tremendous value. I cannot imagine what parents with few skills do to get their needs met.”

“No one is even contacting us regarding our case to see if anything at all is being done to help.”

“Everything is fine except case workers could work a little more on getting back to clients a little faster after leaving a voice mail.”

“Case workers do not know of everything available out there. Any information we have found has been through the experiences of other parents. Case workers did not know of certain group boarding homes or the program my daughter is currently in.”

“My son is on his own. He has a part time job. He receives Social Security. He barely makes enough money. He'd like to further his education, but we have reached dead ends there. I feel services are hard to track down and not familiar to us at all. Maybe a mailing listing what services are available would help.”

Case Management

Several respondents mentioned case management. A few respondents reported that they were satisfied with case management, while slightly more indicated that they were dissatisfied with services.

“M.'s coordinator has done a lot for my daughter and more. If M. didn't have him I don't know what we would do.”

“We do have an excellent case worker now who keeps in touch regularly and who provides information and makes suggestions.”

“I am very satisfied with my sons social worker, teachers. They are a great help and I truly appreciate what they have done for my family.”

"My case worker is very good. She helps us as much as she can."

"Case worker has been a great support for the past ten years to this family."

Several respondents reported that they are dissatisfied with case management services such as turnover, poor communication, and large case loads.

"I feel that her worker doesn't always listen to how we feel. This has been a sudden change to our family and we would like help. I don not understand my sister and I try and try to support her. We have a big family. We have 5 children of our own and we have custody of her daughter and we also have her. So this is very hard. I would love all the help that we could get for her.

"I think our case worker don't take enough time to fulfill our needs."

"C. is also handicapped with one hand and one foot not right. She is getting a brace which the podiatrist arranged. She will be starting math and reading lessons. My literacy volunteer will be teaching her. These were arranged by my senior companion. C.'s social worker visited at least 2 months ago. At that time, he promised to take her to see if she liked sunrise workshop and said he would stay with if I get sick. Also said he would be back in two weeks. Needless to say none of this has happened."

"My son has had too many changes in case workers too much time has been wasted with talking and no results of getting a job or being kept busy, idle time , 24 hours a day."

"I think the staff and councilors are stretched very thin, so more needs to be done, to lighten their caseload. Everyone would benefit especially the clients

Staff

Respondents frequently wrote comments regarding staff issues. Most respondents reported that they were dissatisfied with staff due to turnover, shortage of workers, and low pay. A couple of respondents noted that they were happy with staff.

"I have to say that my daughter and our family was very blessed when we got hooked up with our agency. We have had the same in home support worker for a little over 2 years. I have never seen anyone more dedicated to my daughters needs as she is. It makes me frustrated with my other child's program."

"He participates in group home activities to a great extent and their staff is exceptional."

"My daughter goes to [provider] and the program has a lot of staff problems but that the best there is here for here The directors is half the problem them the other is the staff some them don't respect the clients or themselves. A lot of verbal abuse going on and degrading behavior. My child speaks up so I know when something going on. But not always. The program should be looked into."

"I think direct service workers need a better rate of pay to encourage them to continue working in the field. Consistency of staffing is vital to the person with a disability. Their quality of life is enhanced and their chances of leading the most productive life with the least amount of assistance is greatly improved with consistent staffing."

"It takes them too long to make the necessary changes in staff. She was suppose to get 1 on 1 in June but can't because not enough staff. Takes them too long to hire someone. It's been 5 months still no one has been hired."

"Currently there are insufficient employees at community services. This staffing shortage cause family member/staff ration to be ineffective."

"Some of these answers may seem rather conflicting but I answered them the way I thought best. The day care agency needs more help, it seems. Seldom is the help replace dif they call in sick."

Employment

Employment was a frequently cited issue. More respondents indicated that they were dissatisfied with employment.

"P. is doing well, especially since he began his part-time hob at the store. Prior to that time he was at home most of the time.

"My son goes to [employer] everyday. This is a very positive experience for J."

We feel very lucky to have found such a great fit for our son at [provider]. He's very happy there and is very enthusiastic about going off to work each day. The difference between a school and the center's client centered meeting was striking. Instead of looking at deficits the focus was I making our son's life more comfortable and productive."

"My son is 23 years old, has potential and doesn't want to bag groceries all his life."

"It is impossible and unrealistic to find work in [city] and [city] area under the current regulations for the mentally handicapped. No one wants to hire for minimum wage with very limited job coaching, when there are individuals waiting in line with no disabilities and can be more productive and quite content with minimum wage. Not to even mention the influx of Somalians in the area. The whole system is not working and needs to change if we really wan these people to be able to contribute and feel useful and needed in our community.

"The client served is attending the workshop I feel that a huge staff turnaround and the lack of caring that management has pertaining this issue the staff that has stayed are not happy they are treat with a great deal of disrespect from supervisors and the clients can sense the tensions I also feel that the service provided are more of a babysitting nature than an actual getting the clients out in the community to teach them to be able to lead a productive life. The purpose of the workshop was to teach the clients how to work in the community. I feel it has lost its mission."

Home

The home environment was a frequently cited topic. Respondents tended to write on satisfaction and dissatisfaction with home, accommodation, and placement.

"B. had been going to a day program for over 20 years. He decided he didn't want to go anymore. He has been staying home for over 1 year. He helps cleaning, meal on wheels and enjoys it also helping me and his brother and seems happy and contented."

The respite he goes to a respite home he loves it but I only have him go 2 times a year because he is happy at home too My son loves at home and will as long as I and his dad and

his CNA and others who help me. He would be lost if he went into a home. He's loved here immensely. We give him what he needs and if I can't I try to get his case worker to help me

"Our family member enjoys living in our home with her family members."

"My child would always stay at home because we love her and always will be there for her. Regardless of respite care or other services that she would get."

"My son does receive SSY and the medical his Maine card which are both a great help. Other services are lacking. Housing for him will soon be a very real problem."

"N. wants to build a apartment onto our home so she can be on her own. I can't afford this and have been asking her case worker to see if there was anyway we could get his for her. N. is very impressionable, she will agree to whatever someone says at that time, she changes like the weather. I would like to have better help for N. N. couldn't be on her own. We look after her and let her spend what money she gets on herself. We have and intend to continue providing for her. She needs to stay here and be apart of her family."

"My family member would like to have an apartment and be alone and on her own. She is 20 years old now with medical problems and needs this is impossible at this time because there is no place right now that funds this with medical staff, staff available. I would like to see this maybe in the near future for the higher functioning people. It would be a great opportunity for them to be on their own but not without supervision."

"Our final step and our greatest challenge will be independent living. Mitch will outlive us. It is a necessity to provide safe, clean environments for our dev. disabled adult to live and work."

Education and Training

Dissatisfaction with education and training was mentioned by several respondents.

"Need of dental care more job specific voc training."

"Educational activities would be welcomed, i.e. math and vocabulary exercises. In our families case communication and speech enunciation are top priorities that are currently not well served."

"My son is on his own. He has a part time job. He receives Social Security. He barely makes enough money. He'd like to further his education, but we have reached dead ends there. I feel services are hard to track down and not familiar to us at all. Maybe a mailing listing what services are available would help."

"I do not understand why a child who turns 20 years old on May 31st is denied the privileges of attending school to her 21st birthday. Is there legal council available?"

Transportation and Rural Issues

The majority of respondents were dissatisfied with transportation services or lived outside the city and therefore had limited access to services.

"We live in a rural area with very limited state money. The worker I deal with are dedicated and make every effort to provide services. My daughter needs to be moved on to group housing but it is not available any closer than a 4 hour drive from our home. State money is a big problem."

"We live 1.5 miles out of the city and it is limiting her re employment. She does not drive. Both my husband and I transport her but are not always available to agree with her schedule. We've tried city transportation which we found to be inadequate and taxis are too expensive. Safety is of utmost importance. "

"Another thing that made employment difficult was transportation. I was not willing to drive my daughter 10-12 miles one way so she could work 2 hours then return to pick her up. I was also not willing to put her in a taxi and depend on god knows who to drive her. Again I was difficult. Transportation by [provider] for example should be provided along with the employment for the handicapped."

"Our biggest challenge in helping him stay involved and able to participate in activities such as bowling, and swimming is transportation. My husband and I both work 20 miles from our home. Getting F. to day activities and even a ride to town for doctor appointments is difficult. His driver from his job will sometimes schedule other trips for us and I pay him 2.00/mile but he isn't always available to do these trips. Transportation remains our biggest obstacle to getting him around."

Recreational and Social Activities

A few respondents mentioned that they were dissatisfied with recreational opportunities.

"M. needs more social activities in the community to attend with other special needs young adults. The co-coordinator at camp has left and the position has not been filled for a long time. He used to go monthly or bimonthly dances and periodically other occasions. This has not happened for about 8 months. He misses this as he got to be with some of his friends he graduated from high school with."

"In addition, the people w/ MR in the community are so fragmented that it is very difficult for them to meet new people and develop relationships."

"I really like the question you asked because it really opens what is really out there for these young adults to do to have fun beside school or work. There should be places for fun things. Doing things like swimming, planting flowers. He has no place to go to do anything. We don't go to the movie in our area because it too long to get and out and other people just look at him like he is numb D. is a very happy young man who loves people. "

One respondent reported that she is satisfied with activities.

"My daughter attends many activities connected to [provider]. Baking, dances, classes, YMCA swimming, etc social activities at different times through the year."

Aging Caregiver Issues or Health Problems

A few respondents reported that aging caregiver or health problems was a concern.

"Hardest problem we have ever faced, having our 42 year old son living with us, we are in our 70's and caring for him also physical problems."

"Are most urgent needs are help in the house. Someone to work with S. with housekeeping his area of our house. I'm 76 and have arthritis in my left leg and can spend minimal time working in our family room because of the cement floor and that is where S. spends a lot of time."

"T. can not talk, can not walk by herself needs help, still in diapers, need help with all things. She need 24 hour care. When she gets help, I her mother have to be with her. My health is arthritic and pacemaker."

Transition Issues

A couple of responded reported that transition issue were a concern.

"She than went in transition program at voc rehab, did not see any advances. She was placed at [provider] where she received some job coaching. Continued with counseling as she had done since junior high school. Only once did we have contact with a case worker or individual. She was lost in the system after she left high school and voc rehab.

"So much money is spent on children for special ed all through their school years and once they are out there is nothing. So it has been a waste of state money only to set them a drift in a life boat for their adult life."

Advocacy and Choice

Choice in service providers, advocates, or other staff or advocacy efforts were noted by a few respondents.

"Other times staff from the agency has not listened to our voice such as raise in PCA hours stop cutting our hours and letting us have a voice in who is our advocate."

"My son has a great support system because his mom is a strong and determined man who won't accept no as an answer. I often her very sad stories about kids and adults who are not well cared for and planned for. I wish all the special needs society could be given the same opportunities not just the kids that have family who is willing to fight to make sure their needs are met."

"I am a strong advocate and go after what's needed for my daughter, however, having professionals approach and work with me in a proactive way would be of tremendous value. I cannot imagine what parents with few skills do to get their needs met."

Respite

Several respondents reported that they were dissatisfied with respite services.

"Respite money is okay but we also have 2 other children so we don't have in home services because they won't pay to watch the other 2. So we have to hire someone to watch all 3 and pay out of our own pockets, or ask family to watch, which we don't pay but respite should. We have no in home medical services at all. Our state supplied person we may see once a year There are very few options on day programs, he currently gets bused to Fairfield. Would like to have him closer but finding a program to suit both his physical problems and his needs to learn is all but impossible."

"Services for a person with developmental disabilities are not to good in State Maine. We need more respite services for parents with children with disability."

"Respite care has always been a problem. We need for our daughter to stay overnight some place or someone to come to our home and stay with her. We receive respite money each year. This year it was cut in half which was a big upset for us."

"My biggest problem is being alone with my daughter and never being able to get respite care. My husband is in the veteran's home and I have no family member close enough to help. I never get away from it. I have to be home at all time except when she is in school."

Funding and Budget Cuts

Several respondents noted that they were concerned about funding and budget cuts.

"The family support funds are a wonderful thing and do help out but there is not enough money to cover all necessities needed in a year for those with disabilities and their families."

"We know there is a financial crisis in Maine at this time but to withhold services from a handicapped person that have been provided in the past is cruel. They do not understand why things have changed. A shortage of money cannot be explained to them. Do not offer services that cannot be continued."

Overall Satisfaction with Programs or Services

Several respondents noted that they satisfied overall with programs or services.

"I have been very satisfied with the services she has received. Recently I have started looking into independent living for her and have found the person helping with this to be very helpful and knowledgeable."

"Our family deeply appreciates all the help and support we receive from government agencies and his provider. Their involvement has helped us cope with the needs of our child. Beyond that, however, his life is meaningful and he is making a contribution to the community."

"Your services helped are son a lot."

"We can not say in words, what a wonderful program S. is receiving at Landmark. Everyone is so kind, acing and courteous. We are blessed to have such a wonderful program for S. to attend. S.s' quality of life has improved so very much."

"I am very pleased with the services my daughter receives. All the staff and C.'s workers have been very helpful. I am very thankful for these services and they have made a big difference in my life and my daughter's. Thank you."

Overall Dissatisfaction with Programs or Services

A few respondents reported that they were dissatisfied overall with programs or services.

"We have lived in three states, MA, FL and now Maine and by far Maine's services for the mentally retarded are of the poorest quality in both delivery and substance of the service. Services are difficult to uncover and then access. In addition, the people w/ MR in the community are so fragmented that it is very difficult for them to meet new people and develop relationships. I suppose overall what our family would say to you is that the current system stinks and provides the mentally retarded with a terrible quality of life. We find the system just awful for our family member that we love dearly. "

"Services for a person with developmental disabilities are not to good in State Maine. We need more respite services for parents with children with disability."

“After 20 years of seeking help for our son, I have become quite cynical. I believe services for people with special needs exist primarily to provide employment. People with special needs are the fuel for the bureaucracy.”

“The closing of [provider] was lauded but it seems to me we just have a little [provider] in many communities across the state. Someday I hope to be surprised by a plan to meet my son's needs and not a plan that fits with the needs and convenience of an agency. I would change the way service providers think of their services they provide. For example what percentage of your time is spent in direct service to people with disabilities?”

Crisis

A couple respondents indicated that crisis services are inadequate.

“My only complaint for our family is our local crisis team. If my son who just turned 26 is in crisis especially evening or night time. By the time we get a response from someone on the crisis team someone gets hurt at home. Sometimes when I contact the crisis team help line and they try to reach crisis worker 30 minutes has past before we get a response. A lot of damage can happen in that time.”

Parents as Paid Staff or Case Managers

A few respondents wrote comments about parents as paid staff or case managers.

“It is difficult to respond to this survey because I developed a business for my son to provide for his needs. I have 3 employees and I control who they are and what they do with him. I do very much appreciate the financial support provided so I can continue to do this.”

“As biological parent and caregiver I feel there is a discrimination against us. As the state departments do not encourage biological families particularly in the funding sources such as cash to pay living cost. Historically the children services has not provided support in acquiring funding for our child but pushed for us to relinquish custody in order to get funding for agencies who care for disabled children.”

Health Care – Dental

A couple of respondents reported that dental care is insufficient.

“Dental care could be a problem as he doesn't have dental insurance and is self pay for work that is done.”

“There should be dental care for retarded adults. We see that R. sees a dentist every 6 months. Necessary dental work is done in order to get a dentist for R.. I had to agree not to use Medicaid support. Even with that I had to call many dentists before I found one that would see R.”

Approximately 36% of survey respondents from Massachusetts wrote qualitative comments. These comments are summarized by theme below. The most frequently mentioned issue was case management followed by employment, communication, and home issues.

Case Management – Satisfied

Case management was the commonly mentioned issue. A majority of respondents who wrote comments on this topic were satisfied with case management services. Words respondents used to describe good case management services include: accommodating, helpful, understanding, supportive, kind, respectful, informative, and attentive. In addition a couple respondents stated that their case manager made it possible to keep their child at home.

“We have been extremely pleased with our coordinator and the services that are provided to our daughter.”

“My wife and I wish to thank our coordinator, the staff of [provider], who have helped us over the years. Without them I don’t think my wife and I would have made it.”

“Our service coordinator is great. The only time I call is when I need weekend babysitting. He always accommodates. I just found out last year I have more weekends than I thought.”

“A few years ago my daughter was sexually assaulted by a bus driver. Our coordinator was helpful but I’m the kind of person who handles things on my own. He also is always concerned that my daughter has good employment.

“Our job coordinator gives 110%. She has gotten my daughter a better job. She works hard and checks in on my daughter often. She is a great go-between my daughter and employer. She has saved my daughter’s job from little incidents. I thank God for her.”

“My sister’s DMR worker has been a wonderful asset for us. He has helped my family with services, [agency] services, guardianship, etc. He understands our family situation and has been extremely supportive in helping us.”

“I am overall very happy with our coordinator and the services my daughter receives. She is treated with kindness and most importantly with respect. Her needs and programs are met with a degree that allows her as much independence as she wants. She enjoys the friends she makes at the day program and social program. Allowing her to experience a very happy and fulfilling life. Thank you for your support.”

“J. is my daughter’s service coordinator. He is the only coordinator from the DMR that has contact us or shown any interest. He has been very helpful and caring.”

“I, as L.’s mother, feel blessed that we have [name] as our service coordinator. She has been informative and tries to get L. the services she needs. I know there are many families in need of services and I also know there have been more budget cuts over the years, which makes it harder for the service coordinator to grant all that is asked of them. Their hands are tied, which is frustrating to all parties concerned.”

“My daughter is a 23 year old wonderful child with severe mental retardation. She has multiple needs and I have been blessed with caring people to guide one through the maze of DMR. [Case manager] was wonderful and when M. turned 22, she changed to the adult world or

DMR and has been cared for by [case manager]. Without these services, we would not be able to have M. live with us in our home.”

“Our service coordinator has been a great source of support for us. She has been very kind and has assisted us on many different occasions. She has been very helpful as well as knowledgeable regarding sources available to us. She has done a wonderful job. We enjoy working with her.”

“It would be very difficult to carry on without our service coordinator’s commitment.”

Although most respondents were satisfied with case management services, some were dissatisfied. Commonly cited problems include: poor communication, failure to follow through, and large case loads.

“Out of five service coordinators only one was fully supportive and had the qualities one should expect. Present coordinator is terrible! He does not answer queries, cannot be reached by phone or e-mail if he doesn’t choose to respond. I have made 10 calls without response from him at times. He often ignores (by not responding) my requests via e-mail. He has worked for the department some 15 or 20 years. How is it that someone can be so poor in performance and remain in his job?”

I do realize that each coordinator has many clients but I do wish that they could do more. I have pushed for two years to get my daughter out working because of her skill levels. Nothing for two years. I sometimes feel like I get lip service. I want action and I realize that it is the job of the day care center to get the job but it is the coordinator who should be checking to make sure that the educational plan is followed.”

“We should be switching “coordinators” as our child will be turning 22. Hopefully, we will actually have a service coordinator who will do something. At least get back to us when we have left a message.”

“The 10 hour, four day work week makes it much more difficult to get in touch with service coordinators especially when there is a holiday in that week. Service coordinators are assigned too many clients to deal with in just four days.”

Employment, Training, and Day Programs

Employment, training, and day programs were commonly mentioned areas of concern. Approximately the same number of respondents reported that they were satisfied with employment, training, and day program services and opportunities as those who reported that they were dissatisfied.

“My brother has lived with me since June 2000. He is a very easy to please person and is a lot of fun to be with. He is employed through [agency] and loves it.”

“Our son attends a wonderful program in [city] Day Rehab. The staff are wonderful, caring people who work very hard at their jobs in caring for disabled adults.”

“Our disabled person attends an EXCELLENT DAY HAB. Program.”

“M.’s time at his workshop is great and the instructors are wonderful. He is very happy there.”

“J. participates in the Sheltered Workshop in [city] She likes the supervisors/staff and employees. She gets to the program via [agency] transportation. These programs are essential to J.’s happiness and self-esteem.”

Some respondents reported that they are dissatisfied with employment and day programs. Common concerns included: placement in a sheltered workshop verses a job in the community and lack of job coaching or training services.

"I wish I could see my son in a life career training in systems that help hands on abilities. To me, my son has a strong retention (memory) problem. I feel he has visual capacity. He does not seem to forget what he sees. But forgets what he reads (poor in reading) and what he is told or hears. A slow practical training to do things would help him train for a career."

"My daughter, with a disability, has been receiving SSDI but she also has worked in the community for the past fourteen years. Last June she was laid off at the nursing home she was working as they needed someone on a full time basis and because of her physical disabilities she was unable to do this – she was an 'aide'. She now has returned to the agency she attended before working in the community and is not really happy there, as she puts it, 'I'm not like them.' This is only temporary until they can find her a job in the community which I understand is difficult these days. The staff is trying but I would like to know if there wouldn't be a place that would offer jobs to people with disabilities as she is used to being in this type of atmosphere. She has the ability of getting along well with people, that has been a plus. At the moment, this is our biggest concern."

"There is never enough resources to provide adequate training or job coaching for our daughter. Lack of funding has caused our very capable daughter to sit home four days a week and only work one day for three hours!"

"Thank you for giving me a chance to let you know just how unpleased I am. I actually feel that he has lost skill that he had learned while he was in the school system. The DMR staff person has very little to offer. The program he is in [agency], almost never does any actual job skills or placement. If feel my son is just being baby sat and even that they are not doing a good job at. I am sick of trying to get somewhere with them and I am considering legal actions. My wife and I have worked for 23 years to make him a better person only to bring us to this point, for what! He's getting nowhere. I hope something can be done before it is too late. I will not stand for this too much longer."

"My daughter attended public school in a substantially separate class, though she was very much integrated in social/recreational activities of the school at large. It didn't seem an appropriate adult placement would be an isolated, non-integrated day hab program but that is where she is placed and has been for the past 11 years. She is very sociable, has no behavior issues and is very much integrated in the community through family activities as well as her family support services which are excellent. It is my personal belief that many individuals placed in day hubs would greatly benefit from a more integrated setting with typical peer models. I have always envisioned a program placed in a college or community college since that's where typical people continue their education post-secondary. Although they may be unable to participate academically, they would certainly be able to participate socially and/or in recreational activities. This would also provide a natural setting for recruiting and training human service workers for which there is a desperate need. For many people served in day hubs, the model is institutional and a thing of the past. Conversely, my daughter participates in a superb family support program and goes out every Saturday for hours with long tern friend (4-6 girls) and attend a variety of community events and sports activities. Families have significant input into the program as do the individuals who participate. Unfortunately, we have not seen much change or innovation in day and training programs over recent years and the choices remain limited primarily due to funding issues."

Communication

Dissatisfaction with communication was a frequently mentioned issue. Frequently cited problems included: failure to respond to phone calls or e-mails, no response to requests for services, lack of information about services, and language barriers.

"I volunteer in my community over six years. I think the one big issue is the communication with DMR. In our group, some families don't know who is the service coordinator for their member? What kind of service they can get and can use? Where can get the support to help the disabled member, etc. Also, English is not our first language, it is so difficult to find the same language people in DMR and having the better understanding the needs for us."

"We never receive calls concerning anything, get information by making request calls. No concern for our needs, no individualization for our family member's needs, no support. We are not in crisis, it feels as if we are held up to a standard of waiting for a crisis to develop to have needs answered. We hat to be reduced to nagging, begging and badgering, but is seems necessary to receive services. No a fair thing for a support agency to do to a family."

"Very poor communication from state agencies. Will not give list of possible ways to help person with disability. There are no alternatives given. You never know what is available. You are just at mercy of those who work for system. You know what you want which is to give best possible treatment for disabled. However, you really don't know or where to get it."

"I don't know bout my service coordinator. I don't know what services are available. Paperwork with names and actual services available would be helpful."

Home

Several respondents mentioned home issues, most frequently noting placement concerns and noting that more services are needed for families to keep their children at home. A couple of respondents mentioned that they are aging and will soon need placements for their family member.

"My son, J., having been recently discharged from [rehabilitation agency]. Has made me feel that he will never go to another one due to neglect of and infected toe and verbal abuse. At this time of my life and good health, I will continue to take care of him and use my own judgment for his needs. Something needs to be done about these places. Unfortunately, there's not enough supervision!"

"The need of financial help when the person lives at home needs to be increased. Those funds she received does not meet the cost of her living at home. The cost to put her in a home away from home is much larger."

Our daughter L., lost her residential slot because we were told that the vendor did not want to accommodate her any longer, due to her medical needs. Her medical needs are diet and exercise to control her diabetic condition, so ordered by her primary care doctor. We were under the impression that these needs were part of her human rights. She has been back home with us for the past three years. With our failing health, it is getting to be a hardship for us to have our daughter living at home with us. We feel L.'s slot in the residential program should be restored. It was not our fault that the vendor did not want to fore fill their responsibilities."

"There could be more residences for the handicapped people. Some of us parents are getting worn out."

"I am now looking at group homes which have been not satisfactory for him. I continue to look as I am widowed and we are both getting older. I hope more group homes are built on one level with on some of the state land so available in our area. Some homes old, lots of stairs, not too clean and short staffed."

"I am 72 years old and my husband is 77 years old and our daughter is 37 years old. We would like to have another safe and appropriate living situation for our daughter in our area. She has lived her all of her life. I've been told that it will be another five years before she can be put on a residential list again. She was dropped from the original one before the lawsuit against the DMR. We enjoy having her at home but would like to know that she has a place to go and be happy when we can no longer care for her."

Overall Satisfaction with Services

Several respondents indicated that they were overall satisfied with services.

"Overall, the services are good. The 'service' givers are excellent and very caring."

"The services we receive are a tremendous help in the care of our son."

"We are quite happy with overall services."

"Don't know what we'd do without the services DMR provides. You have helped make 'all' our lives more livable and very 'happy'. We are very grateful to all of you."

"It's hard for me to express how very grateful I am for all the services my son has been given for his entire life (24 years). I have raised him alone since he was 2 and the quality of all our lives has been immeasurably better due to all the help we have received. I never take the help for granted, but I know that my life would have been very difficult, different and joyless if I'd had to do this alone."

"P. is a foster child 22 years of age profoundly retarded with medical issues. Without respite money and nursing we could never care for him. Thank you for your continuing support!"

Overall Dissatisfaction with Services

Several respondents reported that they were overall dissatisfied with services.

I seem to get little help at all from DMR. Even complaining to its director and asking for a new coordinator (which was granted) I get no where. I lost my husband a year and a half ago. It is my brother and myself. I requested funds for help to purchase a bedroom set for him. Was given the paperwork to request it. Completed the paperwork myself and sent it in. NO response. I requested respite care to occasionally get a break. No response. If his transportation isn't re-instated how can I work? I asked if DMR could help defray the cost and was told no. I take time off from work and take him to all his doctor, dentist, eye appointments. I ask for very little help. I can never seem to get services I request. The only good thing the agency did for me was help in obtaining guardianship and that was almost a year long battle. The [agency] seems to provide the least.... Whenever we have spoken to DMR regarding our need for supports at home, we have not been offered any additional assistance. It appears to us that those developmental disabled individuals who were abandoned by their families to state care have received the bulk of service provided and unless in crisis, we will be given no help. We seemed to have an extremely hard time getting services when and since we moved to Massachusetts."

"It seems difficult to access the DMR from a long term point of view. From my observations since July 2002, I would say that I have been disappointed in the services. Only lately have things seemed to have come around. S. is still home. We still need more help. We will continue to work with DMR, case manager and provider to try to give S. more service to help him lead a more normal life."

"We reintroduced ourselves to the system last January after 10 years of no communication. Our son never had a transitional plan as DMR did not come to meetings planned originally before he turned 22. They came to second meeting and had no contact after that. Our son has had part time employment in the private sector since he was 22 and fell through the cracks at DMR. Our fault for not pursuing an ISP! But have recently hooked up again and are taking stabs for a future with some support for him."

Respite

Dissatisfaction with respite services was a frequently mentioned issue.

"I would appreciate if at all possible, to receive respite services from the Department to have a weekend off at a time would be of service, both to G. and myself."

"The major area for improvement is overnight respite care. Although the services have greatly improved, I would like to see more availability (summers are very difficult to schedule) and a warmer home environment. What I mean by that is more home cook meals with people who love to cook, e.g., widowed grandmothers."

"We would really like to be able to get funding for in-home respite care."

"Would like more respite care in or out of home, no respite houses in area, badly needed, area needs group homes that can handle multiple disabilities not just MR. Some folks have more than one disability and no or little help and services out there to assist us."

Funding and Budget Cuts

Several respondents reported that their family members have been affected by funding and budget cuts.

"I have met with my DMR service provider for my child up to age 22. Basically have been told there is no money in the budget so no services for my child. I don't understand this as when the budget is cut it seems every person should lose services, and spread the money around to all who need services. Instead, it seems like depending on when you turn 22 you either get everything or nothing and if its nothing you have no recourse. I do not have a service coordinator for E. and was told that I don't have one because she is not getting services – which comes first? How to I get services without a service coordinator?"

"Because K. is married, she doesn't get many services from DRM. The few times that I have asked for services for K., we were told there was no money."

"I am very pleased with the services that the DMR provides. I am, however, greatly concerned with the cutbacks in social services. I am unable to work since I need to care for my daughter at home, and have been notified that my Mass Health insurance will end in February. Also, our flexible funding has been cut by 20%, and more cuts are upcoming. I fear that I will not be able to give my daughter the care she needs at home without these support systems. I need help."

“When I have asked for extra respite, I have been told about budget cuts. I am made to feel like I am begging and it is not important.”

“We are very concerned about funding due to governor’s cut. Hopefully we will be able to continue with the very good service and attention to our needs.”

Health Care and Other Services

A few respondents mentioned needing services like speech and physical therapy, and insurance issues, mental health care, and dental care as areas of concern.

“Also, he needs physical therapy to be able to function at his level. Never mind the ‘maintenance level.’ How can he keep and retain what he has if he does not get physical therapy? He is multi-handicapped (C.P. – M.R. – Seizure Disorder, Spastic Quad, Speech Impediment).

“I would like to see psychological help available through the DMR for help through times of anxiety and stress in their lives. Private help is too expensive for most families.”

“As documented by teachers and doctors, my son is in need of speech therapy in order to communicate. Because my son’s work schedule does not match the one and only speech therapist in [cities], no services are provided or sought. Why are there no services? Why are there no alternatives? Intelligible speech communication is essential!”

“I would like to know why, people like K., are the first to lost benefits whenever cuts need to be made. Her health benefits went from Mass Health to Medicare because my ex-husbands on disability, how that affects her is still a mystery to me. Her physical exam is going to cost \$400.00 – Medicare pays for nothing. They are generous enough to waive the \$50.00 a month deductible, how big hearted of them!”

“I have tried to get speech therapy evaluation and lessons for my son for 10 years. My doctor approves it and BCBS will not provide it because Mass Health refuses it! “

“Better dental, mental health and medical coverage needed.”

“I think it was a gross error to cut out dental benefits like cleaning teeth. That’s preventive care which is important. I paid \$80.00 for my daughter to have her teeth cleaned.”

“Why would you pull out a special needs teeth and not provide them with dentures. Dental/Vision, etc. leaves a lot to be desired.”

Transportation

Transportation was mentioned by a few respondents. Most respondents who wrote comments about transportation were dissatisfied with services.

“The vans (for a day treatment program) should be new and updated. My neighbors complain to me about them and are surprised that D. is allowed to travel on them. The neighbors have complained to me about fast driving on their streets. I do not want D. driven up Fulton Street from November through May or any other steep hill. The vans are always cluttered and dirty inside and out. There has been no supervision in the area of vans that I can see and no response to my complaints for years.”

“Transportation to and from work and recreation on evenings and weekends are critical services needed to keep my child in the home.”

“There is not sufficient transportation to programs provided.”

Recreational Activities- Satisfied

A few respondents mentioned recreational activities. Most respondents who noted this issue were dissatisfied.

“My son belongs to the Friday night recreation group. It would be nice to do something other than visiting malls.”

“I have been very unhappy with [agency] the only local provider for social activities. Very unorganized and also let go a wonderful worker with 18 years of service. After several parent meetings, we all come to the same conclusion. It was made up charges to rid themselves of a higher paid worker to save on budgets. New coordinator is a terrible coordinator of services.”

Transition Issues

A few respondents indicated that they had concerns about transition.

“I feel that I need more help with planning for my son’s life after I’m gone or not able to do all that I do for him. I still work and provide all that my son needs as for health care with my insurance and much more what will happen when he needs to be on his own. I have seen other people that has happened to and it was not good. I don’t want that to happen to him.”

“Exiting the school system and entering the Adult Service Support System of DMR was horrible for our daughter and for us. While school systems have improved greatly for students with disabilities, DMR has NOT kept up with the times. Our daughter has been out of school for a year and a half and still does not have an appropriate JOB. Everyone worked so hard to educate her, but the DMR agencies have jobs that do no utilize her potential nor her wonderful skills.”

“I don’t feel there is enough input from the parents and it seems that after a consumer turns 22 years old DMR leaves a lot to be desired. There is little support.”

Staff

A few respondents mentioned staff issues.

“... we are pleased with our son’s support staff, case counselor and employment counselor. Our son connects well with them and that’s the main thing.”

“I feel very strong, the salary paid to the people directly involved with client are not paid a fair salary. Over the last 25 years I’ve seen a big turnover in help, all the same reason SALARY. Yet the administration gets bigger salary. It’s not an easy job. Some staff should get combat pay.”

Crisis

A couple of respondents wrote comments about crisis services.

“The people from DMR have saved our family. We were in crisis last year at this time and are doing so much better today with their continued support. I cannot praise these people enough.”

“I feel that DMR should work closer with the family in need/crisis to help make sure that the family has what they need to help the person with the disabilities. Also, it may help the household. DMR worker should stop and think how they would feel if they were the family that need the services. Actions speak louder than words. DMR should step up to the plate and help families in crisis.”

Advocacy and Choice

A couple of respondents mentioned that they had concerns about choice of services, providers, or advocacy for their family member.

“I feel the need to volunteer at most of my daughter’s activities, it seems if you’re a low level handicap and can’t speak up for yourself, you’re more likely to be overlooked and not be included in the same way as someone who can make known what they want or need.”

“My experiences with DMR support services have been fairly positive partly because over the past 28 years I have learned to be a staunch advocate for my daughter in regard to her needs and services. I have been part of a strong support network and I’ve become proactive over the years, as well. This has been a team effort. I/we have studied my/our daughter’s educational, medical and vocational needs and wherever needed we have (fought for) advocated for those things she needed to live a rich, full life and reach her greatest potential. DMR has helped us in our efforts but it is always wise to understand the system and the individual’s rights.”

NORTH CAROLINA

Approximately 38% of respondents in North Carolina wrote comments for this survey. The home environment was the most frequently mentioned issue, followed by health issues, respite, staff, employment, communication, and transportation.

Home

The highest proportion of respondents mentioned home issues. Specifically, respondents noted satisfaction and dissatisfaction with the home environment, particularly services that are needed to keep the family member home and out of placement, the need for accommodations, and placement needs or concerns.

“E.’s Dad and I have always treated her the same as her brothers. But it has not always been easy, since she is retarded and has a swallowing problem. We prefer to have her live with us. We hope to be able care for her as long as possible. If we reach a time that we can’t, we would like to be able to have someone help us here at home, so she will not have to leave her home.”

“Our case managers have been exceptional. Our son and family have greatly benefited from the program. Our family situation would be very compromised without it and I’m not sure our son could remain at home.”

“Our family member is much happier at home. She loves the worker and she is able to get her to do more then the family. Thank you.”

“We have a very hard time trying to find a group home or AFL home that is willing to take S. He doesn’t seem to fit the criteria they are working for. We tried [provider] but he was too high functioning for them. He needs 24-hour supervision and sometimes can get mean and hard o redirect. He has no interest in anything inside the home. He loves to ride a bicycle but would go to the road. It is getting very frustrated not being able to find a place for him as we are getting older and want him taken care of in case something happens to myself or my husband.”

“North Carolina has done about the same as long as I have paid attention. I kept and keep mine at home. Can’t be much longer –I am 81 now. I wish there was an answer before I die and hoped something could be better with this administration. Any thing would be an improvement at the group homes. Assisted living won’t work again because not enough people and good quality. People for caregivers. Thank you for your interest. There is a great need. I suppose it’s all about money. We use a lot of money far this group of people but little gets to them. (People with disabilities especially).”

“I would like someone to contact me and explain why there cannot be more group homes in N.C. for Prader-Willi syndrome? There is a large wait list for these homes. I would like to assist in getting them started especially in the County. Group homes are available for single people I think such homes should be available for married clients.”

“Why, if I have him committed, monies will be there for a group home, but if I keep him at home, doing the same things as a group home, no part of that money can he ever have do better his life?”

“North Carolina needs supported living apartments for young disabled adults. Like we have for older adults.”

"My daughter wants to live in a deaf group home. Where are they? If we find one she has to be on a waiting list. After waiting, then the state comes in and closes homes. There are no deaf people in our community..."

Health Care

Health care issues were a frequently mentioned topic. Respondents indicated that they have the following problems regarding health care: a lack of providers who accept Medicaid, services or health care equipment that insurance does not cover, and a lack of providers who accept patients with disabilities. In addition, a few respondents reported that they had difficulty accessing mental health care.

"My daughter goes to kidney dialysis 3 days weekly-she goes to Gaston skills 2 day weekly. 1- Not on Medicaid 2-Needs to beHas serious bowel syndrome. My family member has fallen through the cracks of the system. Her case manager has not done what she should have done for her. She lost her Medicaid benefits when she reached the age of 21 after the agency was told she was approaching the age of 21."

"Also he has no medical coverage except for Medicare, which doesn't cover basic medical such as (check ups, medications, etc.)."

"There is also not a good working network to get info to families about health providers who accept Medicaid. I have talked with local service providers' offices in Raleigh and Charlotte, and though everyone tried to be helpful, it took months to find doctors."

"Our main concern is health insurance. We can't by private insurance at a reasonable rate. Best we got quoted was \$985 per month from BC/BS-no mental health care included. His insurance through work -he pays for it- provides some coverage. We spent a year and went in circles with OPC trying to get A. Medicaid coverage. Autism is a long-term disability. We were denied twice by SS."

"However, we have had problems with finding doctors and dentists who accept special needs clients/ patients. That is a HUGE concern! My daughter is in dire need of a complete physical as well as dental care."

"I would hope that he would receive a wheel chair to accommodate his needs in the future."

"We have had issues with health care. She is unable to find a supplier for her colostomy items and we have been unable to find anyone at Carolina Access Medicaid who can help."

"Recently another psychiatrist was added to the staff [clinic]. The earliest appointment we were able to schedule was March 28. T.'s medication needs to be changed and he needs to see the doctor earlier. It would be good to have another doctor added to the staff."

"We have been asking for counseling for our daughter for 1 year and we are still waiting due to the demand and only one counselor for the county."

"My family is extremely concerned by recent actions taken to consolidate our local mental health services with other counties. Families were given little or no prior warning, explanation or opportunity for input into decisions, which may profoundly affect our children with disabilities. We personally feel close to our case manager and have an excellent rapport with her, but no one has been able to reassure us that she will be allowed to continue to work with our family. Mental Health Services has made no apparent effort to inform consumers directly

of our options or warp our family member will be affected by the changes in its operation, a fact we find to be very disappointing and disturbing.”

Respite

Respite services was a frequently mentioned problem, specifically cuts in services, inadequate respite hours, and difficulty finding providers. In addition, a couple respondents reported that they needed respite due to their own health problems.

“It would have been nice if his respite time had not been cut back. He seems to really enjoy being with this respite person.”

“There needs to be more respite options for families to use. Since [agency] is no longer taking admittances, my son has no other option except to go to places not properly staffed for someone with his multiple medical needs.”

“I feel family members should be able to get respite when they need it. Respite is limited for my family we get a few hours a year, at this time we haven’t had respite since last year in October and it didn’t start until maybe 3 or 4 months into the year.”

“I have two adult children, severe/profound-C.P., and an average of 13 hours per week help is close to no help! I give one afternoon to my 88 year old mother, lunch and shopping. I have Saturday to myself for pleasure- whatever I want. There is no time for doctor, dentist, car repairs/service, funerals, weddings, and baby showers, hospital visits to any friends, never any vacation!, no dinner out at night, no every other weekends for first for me, no overnights, no date time, no beauty shop, never a manicure, massage, or pedicure!, no parties at holidays, wedding showers, birthday parties, dance recitals, soccer games for grand children, CPR-First Aid courses, T.B. testing. And this is just off the top of my head. I take these two adults to my dentist and OB/GYN once a year. Can we upset a waiting room at the OB/GYN office! My mammogram doctor does not allow children, so I do not get once a year. Can you understand pushing two wheelchairs at a time? I have done it! Be a part of my world!”

“I am happy that D. has a place to go during the day but would like to see a day program open earlier and stay open later to accommodate people who work. I take care of D. by myself and receive no help with him at all. I get SSI, and Social Security off of my deceased father of \$543, total a month. I drop D. off at a family and pick him up at another family from our church to whom I pay for his adult day care before and after his day program until I get off of work. I never have any time to myself as soon as I leave work I pick him up. We do everything together.... I was told I had ovarian cancer in May and went through two major surgeries on December 10th I was told I was cancer free and I am excellent in health. I went through six chemo treatments, and coming home from the surgeries and took care of D. alone, cooked, cleaned and provided for D. with some help from our church family on day 4,5 after treatment. I do get tired and have learned to slow down and take naps and to get a lot of rest but some help with D. and free time to myself would be nice.”

Staff

Several respondents wrote comments about staff issues including, satisfaction with staff, dissatisfaction with staff, staff turnover, under trained staff, and higher pay rates to attract or keep quality staff. Approximately the same number of respondents reported that they were satisfied with staff as those who reported that they were dissatisfied.

“We are very grateful for the services our son receives! In general, all the staff we work with are competent and caring-a joy to work with.”

"I would like to take the time to tell you, that everyone at [provider] are very special people, I don't know what I would do without them."

"We are very lucky to have all the support services we usually need and great staff who are committed to making sure she (our disabled family member) is healthy, happy, and doing the most with her life she is able to."

"The difference between providers is going the extra mile. Being able to speak openly and candidly about matters, and knowing that they have your best interest at heart. The attitude about management and leadership is one of warmth and concern. I honestly feel that the care of my son is always the foremost important objective."

"The [provider] in [city] NC is a wonderful place. The staff are great. They are very supportive and spend many hours at night and on weekends to provide extra activities for the clients."

The following respondents reported that they were dissatisfied with staff services.

"The provider agency for our workers provides excellent workers who are well trained. However, it is difficult to get full coverage for the hours in our son's plan. He has 3hrs/day after school in his plan, but usually is staffed for about 3 days. Also, there is respite care in his plan, but no one to provide it. Workers are hard to find in our area and everywhere."

"Quality staff is utmost. Staffing patterns encourage burnout. I could write all day but that would not be productive. All the issues with my son's care could have been remedied and weren't. Good leadership was lacking."

"The providers do not seem to be trained on how to carry out anything. R. has worked with 2 different providers and it seems that each one can only do one thing with him and not progress and try anything different. Providers do not know how to motivate and stimulate new activities with him or are just lazy. And I also honestly feel just to give up is easy; the first time there is any resistance it's like well we just won't try that any more. Plans can be very well written and look great on paper but unfortunately are seldom carried out. I feel like this is a problem of organization and lack of supervision. The tools are there to help many people live a more productive and rewarding life but are being misused and abused by the very people who are being paid to provide this service."

"Throughout the years the workers seem to have been short termed (guess big turnover in agency). Because she needs consistency this sometimes is not very good."

"Many agency staff personnel lack real experience and education to adequately perform their functions."

"I am very fortunate for the services and hours and have great case managers. Dependent is too severe to participate in much quad can't talk. Lots of work (better pay) for home health workers may help. It's hard to get great home health workers. It's a very hard job."

Employment

Most respondents who wrote comments about employment were dissatisfied.

"I would like for my girl to get a job."

“C. is currently on the waiting list for supported employment services. He has been waiting for two years and still no job. This is due in part to the economy and to no transportation, and scarcity of jobs suitable for him.”

“My main concern at this time is the lack of employment opportunities for people with disabilities. There are not enough day programs nor do they meet the special population’s needs. I have also tried to keep my daughter very active in the community, but due to lack of recreational resources this has been very difficult. Any assistance with employment opportunities other than [provider] would be greatly appreciated.”

“My son does cleaning chores- he lost his second job due to an unfortunate incident. Now he only goes to one job site. This is frustrating to M. Neither the CAP Coordinator nor the Provider Agency are trying to help M. get more work to do. I have to go ‘door to door’ seeking productive work (volunteer) cleaning type chores.”

A couple of respondents wrote comments regarding employment difficulties they face as they work and care for their child with a disability.

“I had a job but I had to quick it because my handicap son take bad off sick. And I had to quit work and stay home with him. But in the meantime I ask for help but they turn me down. I need Medicare because I been to the doctor but now they turn me down because I don’t have any money.”

“Well I am writing this letter because my daughter J. has been on the CAP waiting list for over 7 years. J. is 21 years old, visually impaired, and has developmental disabilities. I am a single parent with no child support from her father. Each month I receive some kind of shut off notice or final notice bill from [providers]. What can I say to these companies? 1) I have a disabled daughter who can not work. 2) I have not one to care for J. at home and these are critical needs for my family. I am struggling to pay my rent on a part-time salary. Do you have a clear understanding of why J. needs a CAP slot?”

Communication

Several respondents reported that they were dissatisfied with communication, lacked needed information on services or programs, or inefficient interagency communication.

“Because our Mental Health worker treats myself and my spouse like we are idiots. Her name is [name] and works for County Mental Health. She also never listens to our input as to the way we want things to be done for our 18-year-old grandson. Instead she tells us, we have to do what she says or she’ll take him from us. Thank you. I can’t seem to get anyone to return my calls.”

“When a family complains about services (i.e. Wheelchair vendors) there needs to be a follow up done to make sure things are handled properly. I have complained locally and to Raleigh and have not received satisfaction. I will continue but most families would not. I don’t feel that because these are tax dollars losing spent (Medicare or Medicaid) that vendors should be allowed to overcharge and get away with it.”

“We applied for disability money several months ago. M. had to go to a psychiatrist. We never received a copy of his report or any other information. I have been very disappointed in the follow up on this matter. The same lack of responsibility applies to Social Security. We follow the rules and nothing is done.”

"We do not know what is available. He goes to a workshop during the day. He has Medicaid for medical and independent living helps out sometimes. That is all we know anything about. We would like to know what is available."

"I have been contacted by phone approximately one time regarding services and there has never been any follow-up. I feel my daughter deserves services that would enhance her independence and involvement in the community. I feel that your agency did not explain the process to me so that I understood what was available for my daughter."

"I need more information on how to better care for my brother in addition what services are available to him. I need assistance in getting guardianship of my brother. The problem is it costs too much to have the legal procedure done."

"There are a number of agencies in the Raleigh, NC area that have as their charter the assisting of individuals in need of support services, but they do not seem to communicate with each other resulting in most information on assistance being 'word of mouth' from one parent to another. It is suggested that a central clearing house for information be established in order to better communicate to individuals seeking support as well as save precious dollars by reducing duplication from one agency to another."

Transportation or Rural Issues

Several respondents reported that they have insufficient transportation or live in rural area that lack adequate services or transportation to services.

"Our main concern as a family with a young adult with DD is the lack of services (living arrangements, jobs, transportation to those jobs in the community) for those seeking independent living skills. While he is very comfortable living at home, he still desires to be able to live on his own (or with a roommate) in the future. We understand that the coordinator of these types of services is complex, but it needs to be addressed. It seems to be especially weak in the rural areas."

"It is so hard to sent your child off to a school where you can't see them daily unless you move. You don't know what is happening to your child, but you trust the system. There are so many things that are wrong with the system."

"J. needs transportation to work because I have to drive 40 miles a day to my job plus take him to work and return to pick him up; adding 28 additional miles."

"Also, transportation is nil. I have to transport our son every day to the [agency] in Burlington. We did pay for his transportation previously until 2002. We have lived in Pennsylvania, Delaware, South Carolina and Southern Pines NC, but since coming to this city, 14 years ago, this is the only location that we have found transportation and services to be inadequate."

"The fee to ride the van per month is \$50- that I can't understand, why these handicap people have to pay to ride the van service. The public school buses are free? But if I could afford to pay with out a supreme sacrifice, I wouldn't complain."

Case Management

Several respondents indicated that they were satisfied with case management services. Words used to describe case managers include: helpful, hard worker, informative, prompt, kind, and compassionate.

"We appreciate the services of [provider] its case manager is excellent and the services at [provider] and the excellent providers they furnish."

"My son has one the best case managers, she helps every way she can to get what he needs."

"The county through our case manager has been wonderful to work with, as well as the case manager at [provider]."

"Years ago I had a bad caseworker but complained and changed and mine always helps me find information and products I need. She is a hard worker."

"Our caseworkers are excellent, meet our needs in good time frame are prompt to return calls and assist when necessary."

"Our family would not make it through many days if she were not our case manager. She is very thorough, kind, compassionate to our daily struggles, well schooled in policies and procedures available, and will go out of her way to assist is with any of our needs, no matter if they are great or small. If I can help her, I would like to recommend to you that she be given an outstanding employer award, which I would proudly present her if I could."

Slightly fewer respondents indicated that they were dissatisfied with case management services.

"My family member has fallen through the cracks of the system. Her case manager has not done what she should have done for her."

"Three years ago [name] became A.'s case manager when she first received him on her caseload she came out to the house and met me, my wife and A. That is the only time we have met with her. She called one time and had me stop by there to sign a paper. I don't even know what it was for. We have no contact with her we ran out of forms (progress notes and provider forms) and one of her caseworkers got the forms for us. There are lots of things that we could use. If other people in her caseload receive the same service she is unworthy of the title 'case manager'. Thank you for this opportunity to voice our concerns."

Recreational Activities

A few respondents indicated that they were dissatisfied with recreational or social activities for their children with disabilities.

"My daughter definitely needs services and would benefit from community involvement."

"There are no deaf people in our community, the only social life she has is with me her mother and a few family members and her job. Her workers takes her out when she can, but that's not often. I take her out, but I do not sign like an interpreter so she still misses a lot. She needs people her age and other deaf people."

"The one thing I think R. would benefit from is programs to provide socialization for him. He has a hard time meeting people his age with similar interests because of his autism. I think R. would benefit if the case manager could find another person that R. could socialize with on planning outings. Or even group settings of people with similar disabilities.

"I want to know why there's no van or transportation is not provided to take the clients out with the staff that's care for them. On either shift for an hour or so they can take them out to the mall, parks during the summer, to get fresh air, instead of sitting in all the time or the whole weekend."

Would like to see programs where family member and support person can meet and play basketball, watch TV, etc. with other people in same situation without having to worry with privacy. Such as a 'recreation' room at mental health center or some other site so that family members can mingle if they want to with others in their situations. Support persons would know after working with family members if they could, walk, fish, do something together."

Education and Training – Satisfied

A few respondents mentioned education and training issues. Approximately the same number of respondent reported that they were satisfied as those who reported that they were dissatisfied.

"We feel that [provider] does an excellent job helping and training clients for jobs in the workshop and in the community. We are proud of the facility and think that the staff is great! "

"The program runs smoothly with a competent staff. Parents are always welcome to participate in activities. R. looks forward to going to 'school' everyday and I feel assured that she will be safe and happy while she is there."

"There is a great need for real job training in and for the real world, since the school system does not do an adequate job, if any at all. Any training organization should also provide follow-up and support and again be accountable for the results, if public money is used. Most agencies seem more interested in seeking funding than providing services. Accountability and results should eliminate some of this non-performance. Many agency staff personnel lack real experience and education to adequately perform their functions."

"I think there should be more educational services for adults with disabilities."

"The only thing I wish to be different is that [provider] could provide an academic reading program, but I don't know how many more of their clients could benefit from such a program. When she was in the public school K. had a reading program and she was doing well. "

Aging Caregiver or Health Problems

A few respondents commented on problems providing care for their children due to age- related health problems or other health problems.

"I have tried everything to get J. some help since his Daddy passed away two years ago. But I hit a brick wall every way I turn. J. is 37 years old but he is like a baby. He cannot do anything for his self. He does not walk or talk. You have to bath, shave, and diaper and feed him, pick him up and carry him everywhere he goes. And for a mother that is 69 years old and had surgery on her shoulder, that is hard. I have tried to get him on CAP but no luck. The only income we have is my social security and J.'s social security. His Daddy and myself made a promise to each other many years ago we would never put him in a home. And I will keep that promise as long as the Lord sees fit."

"Regarding services in this area of North Carolina, we have been very dissatisfied Example I had a heart by-pass surgery in 1999 and could not get anyone to help with looking after our Downs-Syndrome son while my wife came to the UNC hospital during surgery. The same thing happened in 2002 when my wife had a hip replacement."

Parents as Paid Staff or Case Managers

A couple of respondents mentioned that being paid staff or case managers is very helpful.

“I take care of my son. It’s hard to work and not be able to depend on a worker to come so I quit my job and work with him full time. It is the best of both worlds. I can depend on myself and still provide income to the family. It was the best thing that happened to our family allowing Mom to be CAP workers.”

Mom is currently our child’s CAP worker. We were not satisfied with outside personnel that were offered by agencies. CAP support has enabled my wife to discontinue outside employment so that she can take care of our child. We had to have a second income to meet our financial obligations especially with two brothers in college.”

General Well Being

A couple of respondents reported problems accessing crisis services and safety concerns.

“Most of the time I am happy with the services, but there are times like when she is in crisis and needs help there are just so many things that she has to go through. She was in crisis on 2-16-03, we went to the crisis center., which also is the only one near us. We stayed there from 12 noon until 345, at that time we were sent to the hospital so that she could be placed. That visit lasted until 1130 for her. Why when you go to the crisis center first, all the information is taken. She is totally deaf- she is MR and she is having a breakdown, did she have to endure that. The people at the crisis center knew her history they knew she needed help and where she needed to be, but the state law says she has to go to the hospital with commitment papers, go through all the changes of an uncaring ER staff and then wait for a hospital in Pitt Co. to say we can take her. She then waits for the County (police) to come get her to take her in handcuffs to a hospital that does not have an interpreter that knows nothing about her, and to top all of this off the family can’t get information because they couldn’t take her. Why? I think and feel very strongly that that the deaf should not have to be put through this. The state has a hospital that has a unit just for the deaf, so why put them and their families through this. The services help, but they can be better. We need more interpreters. We need more people that understand the deaf and people with disabilities. Most of the things for the deaf are in other counties.”

“The workshop has no security personnel to monitor clients ‘outside’ the facility. For instance, my son once wandered off and walked miles through heavy traffic (I.Q.-40!) and no one noticed he was gone. It took hours to find him-parents, police and workshop personnel looking until 9.30 pm! His dad and I were terrified! I asked for a security person to monitor clients’ outside the building but they will NEVER be done.”

Advocacy and Choice

A few respondents wrote comments about advocacy and choice of services, providers, etc.

“The biggest problem we have with my sons services is that Mental Health caseworkers constantly try to dictate what he should or not love. If you fight for your child’s rights then you are sort of black listed and made to wait and made to wait a long time on receiving services. I have to constantly “do battle” with caseworkers. Items that we should have no problem getting are constantly held up because of Mental Health writing total control. I worked for our local Mental Health System for over six years and I am totally for client. It still bothers me that many people working in this field should not be. They want total control of the client and many do not have the clients’ best interest at heart.”

“I would like to receive a voucher for respite care through the CAP program so that I can spend my respite dollars to pay for a caretaker I know and trust rather than through a provider agency’s employee that I don’t know. Plus, if I had the dollars I could hire someone for less per hour. Than the provider agency pays for the employee-more value for my (the State’s) dollar.”

“My son’s services are handled thru the [agency]. We are 100% in favor of self-determination! His ‘supported living’ services are making his live productive and keeping his and my attitude very positive.”

Funding and Budget Cuts

A few respondents indicated that they lost services due to funding and budget cuts.

“The major problem confronting your agency is, and will continue to be budgetary. Every year the governor proposes cuts to your programs and the legislature continues to cut funding.”

“T. has been on the CAP MR waiting list now for over 6 years. Instead of the state always cutting mental health services, that if very needed, they need to cut somewhere else. “

“I would like to say that cutting benefits for the disabled was a grave mistake. If anyone needs more funds it is this population.”

“As a family member, sometimes the changes and how they affect us can be a little overwhelming. I know with the budgets being cut you can’t help it. I wish the changes could be more subtle. One day what you have been doing or the names you use for different things for the last few years are fine then you can’t call it that or do it the same the next. I know myself changes are hard- and we all live with a lot of stress and sometimes it’s just not easy to be flexible overnight.”

Overall Satisfaction with Services or Providers

Several respondents indicated that overall, they were satisfied with services or providers.

“Out of a scale of 1-5 stars I could rate the services my son receive now 4 ½ stars. I have no complaints.”

“We appreciate the CAP Program. Our 27-year-old daughter benefits greatly from this service. She is still learning and making progress as a result of this great program. I will be happy to sing praises for this program!”

“The services that my family member receives have made a positive influence in his life and other family members. We are thankful and appreciate the services we receive from the agencies for people with developmental disabilities.”

“We are very lucky to have all the support services we usually need and great staff who are committed to making sure she (our disabled family member) is healthy, happy, and doing the most with her life she is able to. If we did not receive support services, I do not know how we would be able to manage our son.”

“The past two years have been wonderful for me and my family. I have a great agency and a wonderful worker. My daughter is much happier and my life has been so much better.”

“I am very well pleased with the services L. is receiving. She does enjoy going to school. I have seen great improvement.”

Approximately 30% of survey respondents from Oklahoma wrote qualitative comments for this report. Staff was the most frequently mentioned issue followed by home, health care, needed services, and case management.

Staff

Respondents most frequently mentioned staff issues for this survey. Some respondents reported that they were satisfied with staff. Frequently mentioned words to describe good staff were: listened, patient, dependable, and caring.

“S. has 2 great workers. They have been great. They have listened and believed me. They have helped when things have gone wrong. They were even patient with me while I worked through the anger of the first 2 1/2 years there for HTS caregivers.”

“The first HTS my daughter had was very good but did not last long enough. We have gone through three HTS workers and this third one I think has been the best. I think it has been good for my daughter to have a non-related person to help her in everyday dealings. This is a great program and all who can benefit from it should take advantage for those who are eligible.”

“All in all I am happy that this service is for B., she enjoys her lady that comes in two days a week and relates to her very well. The worker comes in and she is the best one we have ever had, she is kin to us but she has that love for any she has ever worked for.”

“As a widow with two adult developmentally delayed children living at home and full-time employment necessary, the current services I receive are absolutely necessary. I am appreciative of staff and case management, they are excellent.”

“I have two independent HTS workers. They are wonderful and very dependable.”

Most respondents who commented on this issue were dissatisfied with staff. Problems with staff included: staff turnover, shortage of workers, inadequately trained workers, or higher pay needed to attract and keep qualified workers.

“We have been unable to get-keep a reliable HTS.”

“The problem with the In-Home Support Waiver is that none of the HTS's want to work for only 4 hours, they want full-time employment so finding someone to work has been extremely difficult, they are underpaid, and as a result mostly unskilled, they are lazy, and one more than four occasions they didn't show up for work at all with no advance call to the provider company. In addition, I don't particularly like some strange person in my home while I'm not there. My mother has been assisting me with care for my daughter while I work for her whole life, but she is 70 years old now. I had hoped to relieve her of the responsibility in caring for my daughter, but the HTS's were so undependable, my mom had to become her HTS and take over her care again.”

“The situation with HTS being paid only \$7.00/hour has left a void for many people. There are no persons available to assist with being an HTS or for a backup in case we need one at our home with my daughter. We have been very happy with the HTS that has been provided for the most part. We have had two excellent helpers but in between we have had some not so dependable. The problem is not enough good helpers on the list.”

“Our son’s regular HTS’s are over worked, underpaid and don’t wish to take on weekends and no person in their right mind would go to 15 classes to work for 8 hours a week.”

“We are continually faced with turnover at every state from DHS Case Managers, Program Coordinators and HTS staff. It is a constant point of stress on our family from day to day wondering if we have help to care for J.”

“We live in a rural area with few choices for provider agencies. Only two have survived the past few years but they do not train staff adequately, nor are they screened well before hiring.”

“It is very difficult to find good help. The agencies do not pay enough. The pay should be much higher for this type of work.”

“Have complained to case manager about HTS reporting excess charges with no results. Have no way of knowing what is being charged. Do not get to see what is turned in. I think that time and miles charged to client should be signed off, such as a time card.”

Overall Dissatisfaction with Services/Needed Services

Dissatisfaction with services or needed services was a frequently mentioned issue.

Several respondents reported that services were insufficient at their current level. In particular, respondents talked about: inadequate mental health services, groups homes for special population, eligibility restrictions, long wait times, or inequitable provision of services.

“We don’t have enough services for the second member of our family, a 14-year old in a wheelchair with C.P. and also does not speak. Nor is he able to feed or dress himself. Both boys are in diapers.”

“My son is on psychotropic medication and needs monitoring by a specialist but is not receiving it. My son is self-abusive and I have no support system for this problem. I have asked the case manager and her supervisor for help to no avail. All they can talk about are the cuts and there is no money.”

“I feel a group home for women only is needed in this area with qualified workers to run and maintain it. Safety being top priority and one on one care provided. Proper screening of help would be a must. A place I would feel secure in leaving P. if I needed to be away for any length of time or became ill and needed a place for her to go. I have tried for two years to get help and to this day, I have not got the help he needs. This family member needs the help but can’t get it, I applied for DDS Services over two years ago. All I ever get was a promise and no one has got the services through and I have been very disappointed that it takes so long to get help.”

“It is getting much harder to receive needed services. It takes too long. Too much is denied. We continue to lose services, medical access, no dental and less needed prescriptions. People will die and become more disabled and sick from this neglect from the state! These people (even the ones who can afford it) are uninsurable! They are not treated with the respect and courtesy for them or their lives that these state decision makers would afford their own family members!”

“While I am aware that the system of care for developmentally disabled individuals has evolved over time, starting with the Homeward Bound lawsuit, it has evolved unfairly. While I am grateful for the In-Home Support Waiver, which has enabled me to be a parent HTS and which has relieved me of working part-time, being able to spend time with my son after his

graduation from high school, I feel services should be provided as follows: 1. Hissom Class Members 2. Clients whose parents and responsible family members are deceased. 3. Severely disabled individuals-those who are in wheelchairs and need help with most activities. 4. Single parents who need to work and have developmentally and physically disabled children. Also families who suffer from financial stress. You have too many clients who do not need the assistance they are getting, i.e. those who are well connected with the top echelon of DDS, those who have parents who are attorneys, etc., those who work for DDS and have children as clients. Everybody knows this and they are resentful. You have no idea.”

Home

The home environment was a frequently mentioned issue. Most respondents indicated that services have allowed them to keep their child at home, needed accommodations to the home or vehicle, and differences in service need for families who choose to keep their children at home as opposed to an institution.

“I appreciate the support that has been provided that has enabled my son, K., to stay in our home and allowed other family members to live as normal as possible a life. Thanks to your program, I've been able to teach 27 years. Thanks to your program I was able to attend my 22 year old son's sport activities. Thanks to your program, my son was able to get out in the community and learn to depend on others. My son's heart condition has slowed him down, but has wonderful memories of activities he has attended, through your program's help. I hope this program can continue touching and supporting lives of families with disabilities.”

“I appreciate everything that is being done and has been done to support our family. With the help of DHS it has been possible to keep my 25 year old developmentally disabled son at home.”

“We are very pleased as how this group home helps my son, M. and they are always there to help us when we need them.”

“Thank you so much for your help. Without it life would be very hard on me and Jeremy. Because of your services I can keep and care for him at home.”

“We are having a very hard time getting K. in and out of our vehicle. We have to lift K. into the van and he weighs 200 lbs. It's getting to be impossible for us to take Kevin to the doctor for his blood level checks much less anywhere else. We need a van with a wheelchair lift. There are other things we need but this would make the greatest difference in us being able to continue caring for Kevin at home.”

“I believe that many services are provided to clients who live in assisted living, such as recreation, transportation, trips, etc. which are not provided to those who live with their family. I believe that you should encourage clients to live with their families when possible. I think this would be less costly than group homes.... I choose to take care of my son (which I have always done and will do). But us who has a family who loves theirs one very much pays a price because of our choice. We don't ask for anything that C. doesn't need. All we want is things that are helpful to him and his needs.”

If we did not have this program we could not live in the home we live in. We could not buy tires for his wheelchair and extra medical equipment he needs. I'm able to do extra things for him that I could never do before, eat out at McDonald's, extra snacks, gas to take him places we never could before do anything because we never had the money.”

“Need more HTS workers when a child lives at home with parents. Rules should be different than people in group homes or on their own. Such as meds in the home (how they are locked in home), the parents telling HTS workers what needs to be done for child such as food, clothes, cleaning, meds, not agency.”

Health Care

Respondents frequently mentioned health care issues, including equipment, health insurance, medical care, and dental care. Specifically, several respondents talked about delays in getting medical equipment, Medicaid's prescription drug benefit limitations, needed dental and eye care insurance, and providers for dental care.

“Equipment etc. authorizations are very slow.”

“We have been trying for 11 months to get a shower chair-everywhere the request is turned in-it's not done here. No one person seems to know how to do something in the DD system.”

“We wish services would provide for hearing aids and eyeglasses.”

“Current service level is good but am concerned about health care and therapies in the future. The policies of the insurance companies and the Health Care Authority are confusing and hard to make work for us. I wish they would talk to each other! I fear that some clients are going to be squeezed out of having private insurance and will be receiving sub-standard health care on Medicaid.”

“Our son is now on 8 costly daily medications and is allowed only 5 by current Medicaid standards. All are necessary. Our son is indigent and handicapped. How is he to survive?”

“My son was on 17 prescription medications and when the state changed people over 21 could only get 5 prescriptions per month it is really a financial hardship on us and we can not continue to purchase them!”

“It is getting very hard to find a physician or dentist or optometrist that will take Medicaid clients. Help!”

“We need dental insurance. It's not right to only be able to have \$2,000 to receive services. Then will not provide for them when they need something. They should be able to receive nice glasses-dental work-along with health care.”

“Since C. is allowed only five prescriptions a month anymore when she uses up five, it's up to me to decide which ones she has to do without. It's very frustrating to have to see her do without something that she desperately needs to be on by doctor's orders. I am not financially able to pay for her prescriptions especially since my cost of living increase was almost nil.”

“Dental services, providers, where are they? Who provides these services for hyperactive, mentally handicapped 26 years old?”

“I think people with disabilities would benefit more if they could receive more and proper dental care.”

Case Management

Case management was a frequently mentioned topic. For respondents who wrote about this issue, more were dissatisfied than satisfied with case management services. Respondents described good

case managers as: friendly, concerned, excellent, “does what needs to be done”, patient, efficient, and helpful.

“My experience with B.’s case workers have all been excellent.

“Really like our case manager. He is always prompt in doing whatever needs to be done. If doesn't know the answer to a question, finds out ASAP. Always friendly and concerned while being business like. Have confidence in him.”

“Case manager has been patient, very courteous and wonderful to work with us!”

“His case workers have all been efficient and helpful.”

Several respondents indicated that they were dissatisfied with case management services. Problems included: large case loads, poor communication, missed appointments, turnover, and unqualified workers.

“Our biggest issue has been with my daughter's case manager. She gave us wrong information on almost everything we asked her for two years. Finally I asked for a new case manager. I've had a new one for almost a year and she's never ever met my daughter. Basically non-existent. Anything I get for my daughter is like pulling teeth. Need more case managers or something!”

“Please do not have such a big case load on the case manager. It can keep them from being as effective if they are overloaded with clients. Thank you.”

“Our manager does not keep appointments, period. For 7 months (since June 2002) we have tried to meet with her to help us gain guardianship of our son. We met once in June. Since that time she has not kept a single appointment, the latest being two in December not kept.”

“It was hard answering these questions. It's been hard keeping a case worker and I have never really understood the program-what's available, how to use it, and so on.”

My daughter has had many different case managers from DHS this past year, 2002. This seems so inefficient.”

“Case Worker is new to position and does not have appropriate training.”

“We loved our previous case manager and without any notice at all we were assigned a new person. We had no say in the matter and had a negative experience previously with the case manager. She does not respect other people's schedules or working arrangements.”

Transportation and Rural Issues

Several respondents noted that they were dissatisfied with transportation services or lived in rural areas with few services.

“Finding transportation for work was the biggest problem we have encountered to this point.”

“Transportation and/or lifts needed in area. Not just Tulsa.”

“She isn't in any job training at this time because there's not much out there. It's all out of town stuff and no transportation.”

"I would love to know why it would be possible for my child to be transported by metro cab (the cost) and it be paid for and not be able to ride on the transportation provided by the center and that not be paid for."

"Also, I don't think it's fair that people with physical disabilities receive help with the purchase of a modified vehicle and people that can't drive because of mental and physical disabilities can only receive modifications to a vehicle if they have one but cannot get help getting a vehicle if needed. Even people with mental as well as physical handicaps deserve to get to appointments and go places for recreation."

"Living in [city], it is impossible for DDSD family members to receive the support and training in his IEP. Such as speech therapy, occupational therapy and physical therapy. No professional in these fields will drive to [city] from Tulsa for free for the two hours it takes for the round trip. There are no above professionals practicing in our area."

"We live in a rural area with few choices for provider agencies."

"I understand about the cuts but I wish we could receive help enough to get G. a life. It seems out here in far western Oklahoma we are forgotten."

Cuts in Services

Several respondents indicated that they were concerned about cuts in services.

"We are concerned that PT services are being cut. Respite services were discontinued for my daughter and have created a major problem since I have to commute to Oklahoma City for doctor's visits weekly since I have a debilitating disease myself. I don't think we should be forced to go to only doctors or dentists of the States choice. If our choice of doctor or dentist charges more than the state would pay then we would pay the difference. We should not be penalized by receiving no help for choosing a doctor or dentist close to home and one we trust."

"I am concerned about being able to keep my grandson at home due to the cuts in DDSD programs. I need the help. I cannot do it alone. I am so thankful for the assistance I have received. His HTS has been with us for 14 years. She is well qualified and very dependable. His case workers have all been efficient and helpful."

"Reduction in therapy units has been harmful. Effectiveness of grievance process has not been determined."

Overall Satisfaction with Services

Several respondents mentioned that they were satisfied with services or programs overall.

"HTS is a great program and all who can benefit from it should take advantage for those who are eligible."

"Although my son, G., will always have a home here, with us, the extra support provided by the State through a habilitation aide has proved to be a true God send. I didn't realize how hard it had been until we received the extra help! I actually have a somewhat 'normal' life again."

"I'm very pleased with the DDS program. My son feels like he is important and has grown as a person and is treated as such. He is very proud of himself."

"I am very pleased with the program for D. He has developed many skills and improved others. He is becoming more self-confident."

"Without the services T. receives, her development in all areas would not be what they are now. Also, I would not be able to work without the aide coming to our house to help her get ready for work. Her work at [provider] means so much to her. She loves going to work and the people there are wonderful to her. She has a good life to look forward to. The two nights each month give me some relaxation when she is away over night. She enjoys being away and having fun and I certainly enjoy the peace and quiet. T. enjoys her activities and leads a full life and the services she receives helps make this possible. We both feel lucky. Thank you for making our lives happier and easier!"

"We are very pleased with the services we receive and are very thankful we live in a state and community where every person has value and deserves and are given the opportunity to be all they can be."

Aging Caregiver Issues

A few respondents mentioned the difficulties they face as aging caregivers.

"I'm diabetic, hemolytic anemia, can't lift, limited use of hands and feet. Can't cook. I cath, my son, every six hours. Sometimes I have to argue with DHS and DDS to get help. They say we're not eligible for certain help. I have trouble driving cause I can't turn my head and have a lot of spasms and pain. S. was receiving unlimited medical but is cut. He was grand fathered in to stay at home when I die. Now he's not. He was in group home and another client caused a T-12 burst. S. was mostly independent until then. I care for S. after he goes to bed at night cathing him and changing bed pads from 8:00 pm to 8:00 am in an emergency, I call HTS."

"We very much appreciate the services provided our ward. We are becoming so aged and his father is in extremely poor health. We're counting on his care being continued after our demise."

"We need more help as our bodies age and can't handle the physical care as well anymore, but no help from DHS on helping us, even though we saved the State thousands over the years by not institutionalizing our daughter and keeping her with us."

"Because of my failing health, I would not be able to take care of C. at home without a lot of help. Because of my failing health with a connective tissue disease and lupus. Things are really getting hard for me to manage taking care of C. The In-Home Waiver only allots 23 hours a week and no physical and speech therapy which makes things really hard. We have no support system with her. There is only her step-dad and my parents are very elderly and sick. So there is some days I am unable to get out of bed to care for her. Sometimes I get so stressed out that I end up in the hospital. I really wish that you could help me find a answer. Believe me, I wouldn't ask for help unless I needed it."

Parents or Family as Paid Staff or Case Managers

Several respondents mentioned issues related to parents or family as paid staff or case managers.

"I have chosen to be the habilitation specialist for him and I'm very grateful for the extra income it provides. I have noticed an area that is of some concern to me as a taxpayer, though. I am very satisfied with the amount of \$7.00 per hour that I receive as the habilitation worker, however, I think the amount paid of \$5 per hour plus to a provider agency for basically just

processing payroll is far too much. There are professional payroll services that would process the checks for a lot less money if requirements could be changed to allow that to happen. Also, if the money could be considered non-taxable, the amounts of the in-home waivers for those who are taking care of their own family members could be reduced and still net the same amount of money. If at sometime it were necessary to use the money for other services, the larger amount could be reinstated.”

“We didn't have much money until I started being his H.T.S. I don't have to worry as much.”

“Family members are B.'s HTS, due to shortage of workers and limited number of hours available for B. We work for an agency which keeps over 40% of the money paid for this service. Seems like there should be a better method than that. It's hard to find someone experienced to work for just \$7.00 an hour.”

“My child services are OK as long as I do her HTS. I as a mother can see a lot of things that can be improved on. It would be very difficult without the help financially.”

Respite

A few respondents wrote comments about respite. On average, more respondents were dissatisfied with respite services. In particular, a lack of providers or lack of respite hours were mentioned. A couple of respondents indicated that they were satisfied with respite services.

“The respite care has been wonderful for us and our daughter.”

“The two nights each month give me some relaxation when she is away over night. She enjoys being away and having fun and I certainly enjoy the peace and quiet. T. enjoys her activities and leads a full life and the services she receives helps make this possible. We both feel lucky. Thank you for making our lives happier and easier!”

More respondents mentioned that they were dissatisfied with respite services.

“The lack of availability of respite care in communities statewide sometimes precludes availability for our son (and other consumers) of a room in a respite center. Individuals from other communities must access respite as there are no services available in their own areas. Increased respite rooms should be a priority in future planning of the department. [Provider] was denied another respite room to be opened in a different group home in the community and, therefore, still receives requests for help from other cities which cannot always be addressed. This vital service should be expanded and information disseminated to all consumers. I sometimes wonder if respite care was available throughout the state, how many developmentally disabled would be living at home instead of requiring placement in more expensive systems.”

“In home respite care has been the shortfall. It has been difficult to implement this service for our family.”

Respite care for the primary caregivers is needed. There is only one agency to work through. So there isn't any other choice.”

Employment

A couple of respondents wrote comments about employment issues. In particular, a couple of respondents indicated that they would not be able to work full time without the services that are provided.

“Also, I would not be able to work without the aide coming to our house to help her get ready for work. Her work at [provider] means so much to her. She loves going to work and the people there are wonderful to her.”

“I haven't felt for a long time that the workshop is handling the funds from DDSD (that pays S.'s wages) properly. Also, the supervisor won't let S. sit down while doing her job. S. comes home in tears because her feet hurt. Employees at the workshop know S. needs a chair because her feet.”

“As a widow with two adult developmentally delayed children living at home and full-time employment necessary, the current services I receive are absolutely necessary. I am appreciative of staff and case management, they are excellent.”

“I would like to say that DDSD was a lifesaver for us. My mom passed away in 2000. She had been my sister's caretaker for 39 years. My son and I did not want to see my sister go in a home. But I had to work. If it had not been for DDSD, I would not have been able to keep my job.”

Communication

Most respondents who wrote comments about communication were dissatisfied.

Commonly cited issues were poor communication between caseworkers or staff or lack of information about available services.

“Our biggest issue has been with my daughter's case manager. She gave us wrong information on almost everything we asked her for two years. Finally I asked for a new case manager. I've had a new one for almost a year and she's never ever met my daughter. Basically non-existent. Anything I get for my daughter is like pulling teeth. Need more case managers or something! The authorization decision forms that come after a decision are very confusing. They never list the exact item or service provided. It is difficult to keep track of monies spent from the fund. I would request better communication in this area. I have enclosed such an example. In the least we the lay person should have a code breaker!”

“I have not received any correspondence from anyone from these services. I have called and left messages never have returned calls. So I don't know if J. is on their program yet. I've had no home visits from the advisor or the person who heads the home supports program.”

“The only area of concern I have is being informed of changes, additions or deletions of services available for my family member. The DDSD services that we currently receive were never explained or offered until 18 months ago and my son is 23 years old. He could have used these services over 10-15 years ago but no one associated with his case made this known to us. I was informed of available services by my son's teachers in high school. I feel improvement is needed in keeping parents informed on available services/funds.”

“DHS keeps services secret. You have to know what to ask for.”

“Information regarding all services available would be helpful. We may be eligible for other services which would help our family but we don't know about them.”

Recreational and Social Activities

A few respondents indicated that they are dissatisfied with the availability of recreational and social activities.

“There are no community places to change diapers of DD adults - wheelchair access is still poor in Oklahoma, parking in parks and special community events is poor.”

“Some locations for community activities are not wheelchair accessible.... There are not many daytime activities and no public transportation on holidays or weekends.”

Using HTS's, the people like my daughter are receiving no interaction with any other people like her, no activities, no stimulation when they are at home all day. If all the people like my daughter were able to pool their money that is currently being spent on HTS's and spend it instead on an adult day facility instead, there would be enough money for a full day of staffing, food, social interaction, activities, etc.”

Transition Issues

A couple respondents noted transition issues.

“We are on the in-home support waiver and it has met our needs so far because we are under the age of 21. So what we can't do out of the waiver, EPDST picks up-but it will be another story after she reaches 21 which is 3 years away. That's when I'll get concerned.”

“In the town where I live, there are no programs for my son. No vocational programming-no programs, no PT, Speech, etc. His life has kind of just stopped. There needs to be a program in between doing nothing and the sheltered workshop-which won't take him.”

Approximately 40% of survey respondents from Pennsylvania wrote qualitative comments. These comments are summarized by theme below. Employment was the most frequently mentioned issue, followed by caseworkers, recreational activities, and transportation.

Home

Respondents noted several issues related to the home environment. Several people mentioned their family member was satisfied with their home setting. A few people stated they would like to continue to care for their family member at home. Other individuals indicated that they were seeking residential or community placement outside of the home, however this was not always possible.

“N. is very happy and content at day program and at home.”

“Both consumers are self-supporting and live in community and are active in community activities.”

“C. would be home even if I didn’t get any help.”

“My daughter lives at home and will always live at home as long as I can take care of her.”

“At age 25, J. should have had the opportunities to explore supported living outside our home.”

“We have been on a waiting list for 2 years for family living or group home. It is hard to understand why these services are not available to us.”

Employment and Day Programs

Employment was a frequently mentioned issue. Many people were satisfied with employment and day programs. Specifically, individuals mentioned that their family member enjoyed the programs.

“We are pleased with the workshop at [provider]. Our son has developed many skills and has increased in his communication.”

“We are very pleased with the current day placement at the vocational center. My daughter is much healthier and happier.”

“I am very happy with the adult day care E. attends. The staff is so nice and works with E. She enjoys going.”

“I’m thankful for the workshop, he has a place to go even if they have downtime.”

“L.’s life is so much happier going to work everyday.”

Although many people were satisfied, some respondents were dissatisfied. The main reasons for dissatisfaction included that there were not enough day programs or community work opportunities. Others noted difficulty finding a day program or employment for their family member with health or behavioral issues.

“I would like to see some type of day program in place so that my son would have something to do on a regular basis.”

"Would like to have more options for day programming and employment. We need both."

"He misses going to work. He would like to be employed."

"She would like more help in getting work out in the community."

"Not enough choice for employment in the community."

"J. has artistic, creative talents which I feel could be emphasized in the work setting."

"I feel that my loved one is not safe while attending the current day program at this time."

"C. was expelled from the workshop in June because of incontinence. I feel he should be provided with services in the workshop. I think it's unfair."

"My sister is an eloper and needs constant watching in the day program. So I am having a hard time getting her in a day program."

Education and Training

A few people mentioned issues related to education and training. Mentoring, speech therapy, reading lessons, and life-skills training were mentioned.

"He has a mentor 8 hours/week."

"Currently, at [sheltered workshop] in [city] he attends a reading class every Thursday."

"In my son's case, he would benefit by having speech therapy and reading lessons. These two things I have asked for many years to no satisfaction."

"She needs more 1 on 1 training such as daily chores and shopping skills."

Health Services and Equipment

Several respondents indicated the need for improved dental care. With regards to medical care, several people noted the need for quality mental health care. One person was satisfied with access to medical equipment, while others were dissatisfied.

"Dental we pay for most dentists will not accept the Gateway Card."

"We pay for all dental care."

"Dental care for my child is difficult to find in the area."

"M. went to the mental health clinic and they didn't want to work with him. We have tried to set up one on one for M. but this wasn't followed through."

"It is very hard to get 'specialized' psychiatric care through normal medical plan channels."

"I have complained about problems with all psychiatrists hired for human services. They only see N. for 15 minutes which is not enough time."

"I want to thank who is responsible to give us help and support to give my brother a chance to walk and ride with walker and wheelchair."

“Program needs to be expanded to cover other items that are needed to applicant.”

“I only have on problem with my daughter’s wheelchair. She needs a new one because she curved a lot more. I can’t get one for her.”

Transportation

Transportation was a frequently mentioned issue. Some people were satisfied with transportation services. Most individuals reported dissatisfaction because transportation was not readily available, reliable, or affordable. Transportation was especially difficult for individuals in rural areas.

“Without the funding he would not be able to use [transportation] which means he would not be able to get to work.”

“I appreciate the [provider] for the transportation my sister has received from [provide] to home – it has helped.”

“The bus driver is very nice and helpful.”

“The transportation is always on time.”

“Lack of timely public transportation has created a problem. Especially from the hours of 3:00 to 4:00 pm.”

“I would like to see more transportation services to and from recreational activities as well as better scheduling for current pick-ups and drop-offs.”

“Changes to van arrangement seldom advised in advance.”

“The services we desperately need is transportation to and from work at [provider].”

“I drive him to work, doctor, etc. and pick him up because [transportation] is too expensive.”

“Needs transportation assistance for rural areas for special needs adults.”

Recreational Activities

Several people were satisfied with recreational activities. Numerous people mentioned the need for recreational and social activities. However, due to limitations of funding or programs, their needs were not always met.

“Appreciate the connection and support for our son’s participation in [community program] and Special Olympics.”

“My family member currently uses family driven services funds to cover recreation activities through [provider] programming and in the community.”

“I would like to go to the movies and go bowling.”

“I would like some extra help in my brother’s personal life. Have no idea who to talk to.”

“Most of our frustrations are related to a lack of ‘social connections’ for our daughter.”

"I would like to see more involvement with the community (ex. volunteering, eating out, shopping, and sightseeing)."

"Please try to help F. get out of the house more to meet people and make friends because he don't. He stays home all the time and don't have any friends."

"My son is 18 years old and I feel he is very dependent on his family for all social activities. This is very time consuming for parents."

Communication

Communication issues were frequently mentioned. Only a few people reported satisfaction with communication, while many people were dissatisfied.

"Very happy with yearly visits to keep everything up to date."

"The [provider] takes good care of him. I write in a binder everyday what he does at home and they let me know what he does there."

"I am never contacted by my case worker. I feel I should be contacted at least once a month to keep me abreast of what's out there and available."

"When we speak on the phone with a counselor he gives me the run around."

"Would like to see better communication from the supports coordinator as well as a more sound understanding of client/family needs."

One source of dissatisfaction related to communication was a lack of information about services and supports.

"MH/MR generally does a good job. Although I have found that services are not 'advertised' to the consumer families. We generally have to ask."

"Instead of information being given to me about services, I have to ask the right questions. No one has ever said 'Gee it looks like your son might need...'"

"I don't feel we know about all of the benefits and choices available to our family."

"I am not sure exactly how all services that are provided are chosen or of all the options are available."

"If K. has a service plan, I am unaware of it. I really haven't talked to a coordinator in a couple of years."

Case Workers

Case workers were a frequently mentioned topic. Many people were satisfied with their case workers. Specifically, people mentioned that their case workers were helpful, informative, responsive, and knowledgeable.

"I'm very happy with our caseworker. She has been a big help to us and still is."

"Over the years L.'s case workers have been most cooperative and each year update her information concerning her. We appreciate this continued attention."

“Our support coordinator is a very informative worker. Our support coordinator keeps me abreast of everything.”

“In our case, our caseworker really listened and was able to help a great deal. I feel very fortunate. I know on my own, this outcome would not have happened.”

“I am very happy with my loved one’s current support coordinator. The support coordinator works very hard to get my loved one what is wanted and needed.”

“[Name] is my daughter’s case manager and by far my favorite of her last three. She has already done more than the other two put together.”

“The case managers have always been very kind, courteous, and knowledgeable.”

The primary sources of dissatisfaction with support coordinators related to communication issues and turnover.

“We usually never hear from a caseworker asking about this member of our family.”

“I get little if any information or contact from my son’s MR supports coordinator.”

“I feel case management does not have the tools to provide families with the things they need.”

“My only complaint is by the time I get to know my daughter’s caseworker I get a new caseworker. I don’t get time to bond with my daughter’s case worker.”

“There have been too many changes in case managers for my brother. Would like to have set and stable case manager.”

Staff

Several people reported satisfaction with staff. Specifically, staff were cited as helpful and caring.

“The staff and coordinators of both the adult day center and [provider] are always cooperative and helpful to us.”

“I feel [name] is a wonderful worker and has done not only for my son but has gone out of her way to help us all.”

“She has a special caregiver who has done her a world of good.”

“The staff does a very good job in caring for him in the day center.”

“I have always been pleased with the staff at [provider].”

Although many people were satisfied, some people reported dissatisfaction with staff. Reasons for dissatisfaction included turnover, lack of qualifications, and a shortage of staff.

“Staff changes frequently – you become comfortable, then you call and someone else is assigned to the client.”

“County MH/MR program people need more education work with the blind.”

"I have had in-home services for 5 years. The same on-going problem, no staff. Please increase the salary of the staff member coming the home."

Respite

While some respondents were satisfied with respite, most were not. Many people do not receive the service due to lack of funding or availability. In addition, a few people noted that respite was not available on short notice.

"We are very grateful for respite services it gives both A. and us a break."

"I feel great about having the baby sitting services."

"The only support my child receives is respite care, which I am very thankful for."

"My only desire would be a safe, secure, healthy, happy respite care environment for my brother in the event that our family could get away for a day."

"We don't receive any help at our home for the evenings if we need to go somewhere or need a break – this would be a big help."

"I applied for respite this year, but was told there wasn't enough funds to give for R. for respite."

"It is difficult to get services like respite care on a short notice. For out of home respite care we have to plan many months ahead."

"Reliable and available respite care is nearly impossible to find in our area. Also, I believe it is badly needed."

Funding and Budget Cuts

Funding and budget cuts were a concern for many families. People mentioned the need for increased funds to pay for services.

"I would like some Waiver funding or some financial support for my brother's music therapy sessions. This would be helpful."

"J. does receive FFS funds. This amount is much less than he used to receive from [county] MH/MR. This difference has made an impact."

"I could always use more money from the budget if that is possible. Being a single mother raising D. alone, it would be much appreciated."

"We have been waiting for funding. Now funding is available and we're still waiting. Nothing ever makes sense to me or other people I talk to."

"Too much money is spent on administration. Care is driven by money and how they can access points so that services are kept to a minimum."

Overall Satisfaction with Services

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

“We are extremely thankful for all that has been provided to us.”

“My son goes to [program]. He absolutely loves this program! He is very active with the program. We are very pleased with this program.”

“The family support services (DD unit) has benefited T. in a very positive way. She has a special caregiver who has done her a world of good.”

“We are very grateful for the help and support that we receive. It helps us remain somewhat ‘sane.’”

“E. is very happy and I am very thankful for the staff of MH/MR. And of course, I am very grateful for MH/MR and how it has helped us throughout the past 19 years.”

“Overall the services and supports our family receives are adequate for our needs.”

“I am pleased and grateful for the wonderful assistance I have received through the [county] Dept. of Mental Health and Retardation.”

“We are very pleased with the Waiver program and the services it provides.”

“M. has become more talkative and more understanding of what is going on with her surroundings – [program] has been absolutely a lifesaver.”

“I think that all of the services are great. They help me out. Everyone is so nice.”

“The help we receive means everything to our family. I don’t know how we would handle things without it. It is very much appreciated.”

“We are 100% satisfied.”

Even though many people reported overall satisfaction with services, not everyone’s needs were met. Specifically, numerous people mentioned there are not many options for services. Other people reported qualifying for services, but not receiving them. Access in rural areas was also noted.

“There seems to be a lack of services for his age or any services all along that I have not been aware of.”

“I feel very disappointed with the services that I got through MH/MR.”

“There are not enough options available in [county] for adults with developmental disabilities. There are a limited number of programs to choose from.”

“I am not happy with the services provided by [provider] at this present time. I do not feel that they take any notice of any input.”

“We have supports and it is not enough. However, there are not many options.”

“We feel that servicing agencies and providers need to take a more proactive approach in identifying those services that provide for the specific needs.”

“I contact MH/MR services, filled out forms and met with support coordinator. I was told I wouldn’t receive any services until available.”

"We have been waiting for waivers. This area needs attention and funding to be able to assist more persons. This is very frustrating for my sister."

"I have been put on hold for 3 years now about my son getting on the Waiver and forms filled out 3 years ago and still not processed and my son is 17 ½ years."

"Under the present point system, if our child makes any improvement in any one of the areas on the chart, her total points are lowered resulting in less services."

"Our family member has been allotted enough funds to cover most of his/our needs, however we have not received some of the services for almost 2 years."

"Has not been received total hours allotted for care from provider."

"Many of these questions don't apply to P.'s situation. We live too far for her to attend many of the activities of [provider]."

"Community services are really not available where we live – extreme southern [county] – so that using them are more trouble than it is worth."

Aging Caregiver Issues

Some people mentioned issues regarding aging caregivers.

"I need help with planning R.'s future in the event of my death. I do not want him institutionalized."

"It would help the older parents who have their son/daughter to get more living skills and support services at their home. We are both 75 years old."

Transition Issues

Another issue was the transition between children and adult systems.

"C. is still in school and will be until age 21. After that his father and I feel that the services provided are not what C. needs."

"He lives at home but have concerns when done with school if can not get him in [provider] or employment what he will do all day. I am single and work full time."

"Goal at 21 is placement in a group home. Would like to transition, i.e. place one weekend."

"Just want to say thanks for the help and support given to us as our daughter makes the transition from school to work."

Crisis Services

Only a few people mentioned crisis services – such as emergency care and placements.

"I called upon MH/MR services for placement when the family was in crisis."

"I would like to know who to contact when and if I need emergency care (such as a group home, etc.) near our community."

“It is of primary importance for the county to have a plan in place for emergency situations for instance when a client needs immediate placement.”

Support Groups

A few people mentioned the need for support groups for individuals and families.

“I feel it will be better for my son and family to know or meet with other consumers and their family in doing activities together.”

“I have requested many time for families of Waiver/Home Based programs to be able to form a support group for the parents/direct care staff and our children.”

SOUTH CAROLINA

Approximately 14% of survey respondents from South Carolina wrote qualitative comments. These comments are summarized by theme below. Employment was the most commonly mentioned issue, followed by overall satisfaction with services, and case management.

Employment and Training

Employment and training was a frequently cited issue. More than half of all respondents who mentioned this issue were satisfied with services.

“The rehab services he receives is helping him to be more comfortable around people. They are trying to help him in going to work someday. He enjoys the time he spends at rehab.”

“The support we receive from staff and facility is wonderful. B. enjoys getting up in the morning and going to the workshop, which in turn allows my wife to work and live a normal life, which as you know is tough.”

While most respondents were satisfied with employment services, some respondents were dissatisfied.

“My son works with the enclave. He goes to a plant. He sweeps and mops floors, empties trash and cleans the restrooms. He is paid \$1.00hr. I feel this is a small hourly wage for the amount of work that he provides.”

“The main concern we have as parents is the availability of services at the day center...”

Overall Satisfaction with Services or Providers

Several respondents indicated that they were satisfied overall with services or providers.

“I am very much satisfied with its services my niece receives.”

“I am very satisfied with the treatment and help of our [provider]. My son has been treated very well.

“We are very thankful for the services we receive for our daughter. She is getting older and so are we. It would be difficult to provide everything she needs without [provider]. SS worker, case worker and care giver always very supportive.”

Case Management – Satisfied

Case management was a frequently mentioned issue. About half of respondents who wrote about this issue were satisfied with services.

“We are very thankful for the services we receive for our daughter. She is getting older and so are we. It would be difficult to provide everything she needs without DDSN. SS worker, case worker and care giver always very supportive.”

“My husband and I are very pleased with the services our granddaughter receives. Her service coordinator has many years of service and knows our community well. She is very dependable and I know if she tells me something I can depend on it.”

In contrast, a little over half of respondents reported that they were dissatisfied with case management.

“Sometimes the case worker causes more problems. When a person can't comprehend things they are better left alone. When things are started they should be followed through.”

“I don't feel I am always made aware of what services are available. I don't feel the service coordinator always follows through in an efficient manner. Overall it could be worse (it has been worse!) It takes a lot of follow up on my part.”

Recreational Activities

A couple respondents reported that they were dissatisfied with the amount of recreational activities available for their children.

“As J.'s mother I would love to see overnight activities or camps for her. She would love to get away and have a change of pace sometimes. I have searched and searched but can only find one camp for 2 days and nights.”

Respite

A couple of respondents indicated that they were dissatisfied with respite services.

“There is space for great improvements, hope it will happen soon. Respite Care Home one you can trust is your family member and one you can always trust. They no longer want to use them unless they are licensed.”

“I would like to have more help as far as my daughter. To help me to be able to sit with my daughter during the week. Her caseworker told me if they give me diapers they can't support me no more than 10hrs a month because I'm not working.”

Health Care

One respondent reported that she has difficulty getting prescription medication for her son due to Medicaid restrictions on the number of prescriptions available in one month.

“The state needs to desperately improve their Medicaid system my son can get all the medication he needs right now and dental and eye care without it costing but when he becomes 21 the only thing Medicaid will cover is 3 prescriptions per month with co-payment.”

SOUTH DAKOTA

Approximately 23% of survey respondents wrote qualitative comments. These comments are summarized by theme below. Employment, home, communication, and staff were the most frequently cited issues.

Employment and Day Programs

Employment and day programs were a frequently noted issue. A couple of respondents indicated that they were satisfied with employment services.

“The day program my daughter is in is wonderful. The staff works with me. I’m a single parent with 4 kids and the oldest is handicapped, but they work with me on a week to week basis to arrange care for my daughter while accommodating my changing work schedule. I couldn’t do it without them.”

“I wish thanks could be given for help with jobs in the community. More action is needed in this area. My son has been looking for a job for over a year now. He is a client of [provider] and does not receive any communication for jobs.”

A couple of respondents indicated that they were dissatisfied with employment opportunities.

“We are grateful for the services provided by [provider]. However, we have also felt that for a certain population, there is a tendency to let them back slide. All the skills and goals we worked so hard on during the school years, seem to be let go of. It seems we are content to settle for much less than the client is capable of. Many times I have been told ‘Well, we’re cheaper than a babysitter.’ That is a poor analogy. My son makes a pittance, and at times I wonder if [provider] is too top heavy so as the profit from some of these jobs does not filter down to the client. Numerous people have been aghast at his pay stub.”

Home

The home environment was a frequently mentioned issue, particularly the availability of group homes.

“We are satisfied with my daughter in the home. She is much happier here and so are we as she was not happy at [agency] or [agency] in [city]. She was overmedicated and did little or nothing of value at either place. We have her in control and she does lots of things around here, is happy, and wants to help with many things”

“The availability of a group home (our daughter is on a waiting list—we are now told it could be years before there is an opening).”

“She is extremely happy to be home with mom and all her needs being met. I am not extremely happy because I am in my 70’s and not sure how long I can do this. Because of circumstances in her character, she isn’t able to live alone without a great deal of help because of her inability to know friend from foe. Especially by friend situations. I feel this needs much consideration from those of you who think they need to be treated at their age level. I would love to have my daughter in a supervised apartment—but much watching.”

Communication

Several respondents wrote comments asking for more information on services or providers.

"If an occasion arises where we need to take a trip without him, do we need to depend on family for help? Since I pick him up and take him to his appointments and programs, is there any available help for the transportation costs? Is there any money available for him for the prescribed exercise costs?"

"We would very much like to have information on Home Support and Respite Care."

Staff

A few respondents commented on staff issues.

"We are very much an involved family and any problem has been handled well. She has had great teachers and job coaches and responds well to all of them."

"I feel that not enough staff to fully make a team to coordinate all activities and the pay isn't enough to keep qualified workers. When there is free time to do fun things, case managers don't have the time."

"We are also concerned about staff turnover at [provider]. In a 12 month time period, we have had three different service coordinators."

Education and Training

A couple of respondents indicated that they were dissatisfied with education and training programs.

"[Provider] seems to have a very good work training program. They work well with businesses in the community to integrate work experiences with their clients."

"A major impediment to the success of our handicapped child and family has been the inflexibility, lack of empathy, and callous treatment by our school district's special education administrator. As a major resource for services for our child, his/her ability to assist has been extremely poor."

Recreational Activities

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

"The lack of social/recreational opportunities in our community. As parents, we take our daughter to movies, concerts, and out to dinner. However, she is never with a peer group in these occasions, which would be more 'normal' for a 22 year old!"

Case Management

A couple of respondents reported that they were satisfied with case management services.

"Our case manager has gone above and beyond to plan for our daughter. She has arranged respite care and transportation through several family emergencies due to illnesses and deaths. The transportation and caregiver reimbursement allow my husband and me to work full time, knowing our daughter will get to work safely on the workshop bus and it will be met on her return by a trustworthy caregiver. Our daughter enjoys the activities and sports arranged by her case manager during leisure time. We have all been involved with long range planning as well this year. The case manager is a gem. "

Well Being

A couple respondents had concerns about the well being of their family member.

“Employer only has air conditioning in the classrooms. Where my son is turning puppets, not only the clients but staff also would benefit if they had A/C in the whole building! I feel sitting in a hot room is unhealthy and unsafe!”

“Also was able to get him into a nutrition program that they did not have available to him although his weight was greatly increased over the time he was in one of their monitored apartments. I have the overseeing document for the increase of weight and presently need to document blood pressure, pulse.”

Respite

A couple respondents indicated that they lacked respite services.

“Lack of respite care has been very challenging for our family.”

Health Care

One respondent stated needs for health care equipment.

“I need a ramp for my van, but I can’t find funding for it (I can’t afford it myself). She is in an electric wheelchair, and everywhere I take her, I have to take the chair apart. One provider turned down my request and I don’t know where to try.”

Approximately 45% of survey respondents from West Virginia wrote qualitative comments. These comments are summarized by theme below. Employment was the most frequently mentioned issue followed by overall satisfaction with services, staff, and issues related to the home environment.

Employment and Day Programs

Employment and day programs were the most frequently mentioned issue. Most respondents who wrote comments about this issue were satisfied. In addition, the majority of comments were regarding satisfaction with day programs as opposed to employment.

“I’m glad there is a day program available to her to help with her everyday living. If this wasn’t available she wouldn’t have a lot to do through out the day. I wish W. attends day treatment and she really enjoys attending. I have seen her change for the better service since she started day treatment. She seems to be doing well. The day treatment workers are always willing to help and always kind and courteous.”

“D. enjoys going to day care program and having friends she can relate to.”

“P. attends an activity workshop in [city] West Virginia. P. has attended this day program for a number of years. This program means so much to P. and myself. If it wasn’t for this workshop I don’t know what we would do.”

“R. only goes to day program at [provider]. She loves it. The staff is reliable and helpful.”

Although most respondents indicated that they were satisfied with employment and day programs, some were dissatisfied.

“I would like more aggressive supported employment services which I have been requesting for 6-8 years. Presently she has had 2 trials (both cleaning) and I am afraid they have given up on her because she didn’t do well.”

“Day hab services need more workers and there is a need for someone to search in communities for volunteer work and jobs.”

“He has been phased out of day treatment (state funding) this has caused his severe mental problems. He works 2 hours a week at a hardware store.”

A couple respondents wrote about caregiver employment issues, stating that day programs or other services provide care for their family member while they work.

“... I would probably be on welfare, as day program is the only means I have of getting my son out of the house into the community while I work – otherwise I wouldn’t be able to work, because I would have no one to watch my son.”

Overall Satisfaction with Services or Agencies

Several respondents reported that they were overall satisfied with services or agencies.

“I am glad to have people help when I need it. So far I’m satisfied with everything. The service is a wonderful service to our mentally challenged people. It gives them a life. I wish more

people were aware of the program and could take advantage of it. I feel it saved my son's lifestyle."

"These services make a huge difference in his happiness, learning and speaking ability."

"The service R. receives is really helping him. It gets him out with other people and he loves to be with other people. The workers are wonderful at the school. It's great to work with them. They really like their jobs."

"Happy with service."

"We appreciate the Medicare and Medicaid our family member gets. It pays for his doctor visits and medicine. We also appreciated the med vans that takes him to daycare 2 days a week and to his medical appointments. Without this help I don't know what we'd do. Prior to receiving these services my life was totally dedicated to the life of my daughter. Now, I have the privilege of having a piece of my life for me. I am now able to work part-time, go to the grocery store..."

Home

A few respondents mentioned the home environment. Most were satisfied with this issue, noting that their family member is happy living at home, that services make it possible to keep their family member at home, or that they are looking into a group home or independent living for their family member.

"J. is very happy living at home with her family."

"We get help from [provider]. They pay people to help with our son E. Without their help we could not keep our son at home. With the money we receive we have been able to buy equipment and have the things you need for his care."

"Would like to work family member into community/small group home. Work toward independent living."

Lack of Services/Need Services

A few respondents noted that they are in need of services or lack services.

"I feel there should be more access to services and supports in our area. There's only one in own area."

"Need more one on one help."

"She needs back in day treatment."

"We receive few services at this time. Programs to meet B.'s needs doesn't seem to be available. We care for her at home."

"I wish there was more community activities for them to participate in or go to."

Health Care

A few respondents mentioned health care issues such as dental and eye care insurance, and medical care for mental health problems.

“Wish we had eye doctor to be paid half for dental services also wish we could get a communication board. D. can’t talk.”

“Thank you for your caring regarding our son. The thing that comes to mind that would also help would be more family support (grant) money and a dental program for basic cleaning, etc.”

“More dental care. Not just the cleanings.”

“I am not receiving any services or support from anyone in the care of L. Her health is deteriorating because of diabetes and depression. I just became aware of the fact that she was eligible for some services because of her disability.”

Transportation and Rural Issues

A couple respondents mentioned that that had inadequate transportation or that they lived in rural area with few services.

“Our complaining with the program is we live in a very rural most of the activities there are to do must be traveled to. There is never enough mileage to go around his doctor and the dentist is 45 minutes away. The allotted mileage for a month needs to be raised.”

“The only thing I’m having trouble with is getting T. to day care. Sometimes I have to take him there.”

Communication

A few respondents wrote comments about communication issues.

“[Agency] does a very good job of letting me know of different support and grant money agencies that are helpful to my son and family.”

“Agency contact person needs to address issues directly with client and family.”

“I have not received any information from any son’s case worker other than ending one a letter and telling us we may get a discount on certain utilities for the winter.”

“I need more info on how to become my son’s legal guardian as he will never be able to be on his own and anyone could get him to sign anything as he can’t read and doesn’t always understand things unless its broken down for him. I fear someone may take ad...Therapies are listed on service plan, but they haven’t started yet. I get the information myself because the provider doesn’t. This whole information and planning section is misleading. If I didn’t do the majority of the planning, it wouldn’t get done.”

Aging Caregiver Issues/Health Problems

A couple respondents wrote comments about aging caregiver issues.

“My wife and I are both in our 70’s and are in poor health. We do not have or receive any physical help with our daughter. It is all we can do to take care of her. When she was in school it took a lot of work off of us. It gave us a little breather.”

Case Management

A few respondents commented on case management services. Respondents used the following words to describe case managers: well informed, very good, lack of communication, and high turnover rates”.

“I am very satisfied with the services from autism services. R.’s case manager, is very well informed and always a big help with services for my son. “

“The caseworker we have is very good – the best we’ve ever had. When she tries to get us help, you people in Charleston shut it down, so I really don’t understand why you even asked for the survey. Who knows the patient better than the caseworker?”

“Too often changes made in case managers without us being notified. Current case manager called for home visit, then cancelled out (not once but twice) still waiting for home visit. (This was several months ago).”

“Turnover of case managers is very high. It always makes things more difficult with such a big turnover.”

Staff

Several respondents were satisfied with staff. Some words used to describe good staff included good communication skills and cooperative.

“Waiting for a slot to begin. I am here real pleased with the staff and workers that come into my home. They have been real nice to me.”

“We have not been in the program very long. It appears that the employees are very good and very cooperative.”

Some respondents reported that they were dissatisfied with staff.

“Local staff is more empathetic to our individual situation than agency supervisory staff. Day program staff is generally competent but there seems to be a philosophy of operation at the best interest of staff instead of clients.”

“The biggest concern is the large percentage of staff turn over although as our daughter gets older along with us we feel less upset about new people.”

Advocacy and Choice

A couple of respondents noted that they or other family members should be able to provide respite care or care arrangements, such as finding appropriate staff to do HTC.

“It is unfair siblings living at home cannot be paid by waiver for respite care. They are often the only or the best trained to do the job and make the parent and child safe. Grocery shopping is a real problem. The stores are not prepared for us.”

“I feel that I should have more impact in picking staff for C. and I also feel that is why we can't find someone for staff that restrictions such as education or being in the one should be lifted so that if we can't find staff, a member of the family could.”

Respite

A couple of respondents mentioned that they were dissatisfied with respite care.

“My respite worker is doing a good job, she lives miles from me. It would be helpful if I could have a back-up who lived closer to me.”

“Would like to have occasional respite care?”

Funding and Budget Cuts

A couple of respondents mentioned funding and budget cuts.

“My daughter was in a day program and was dropped from the program because of cut backs. This program was a life line. She shows signs of regression. She attends a community program. Male staff member in a basement with no windows.”

“Due to state cut backs and an attitude toward day programs and patients that is negative and designed to eliminate day program, my family member will soon be terminated from [provider]. This means endless days at home alone, which will cause mental deterioration.”

Overall Dissatisfaction with Services or Agencies

A few respondents noted that overall they were dissatisfied with services or agencies.

“The only service we ever had for K. was a day program years ago. He would be worse when he came home. He was always tired and sleepy. He didn't want to go. [Provider] tried one time and told us to put K. in a group home.”...

“Our daughter has been turned down twice for the waiver program so she is no program to get any of the help this survey is asking about. Services are incomplete at best. There is room for much improvement. I would welcome an opportunity to participate in planning.”

“I am pleased with most of the services my son receives. The behavior health agency is very accommodating. Whenever we have asked for help they were glad to assist us if they could. Frequent changes in service coordinators often frustrating. “

“You changed the way when M. needed clothing vouchers and it is too complicated to file myself. The caseworker use to handle it. Now you say I have to do this for M. so I don't because it should have stayed where the case worker did it.”

“I feel there is too much paperwork and red tape for everyone to fill out. It cuts down on the quality of time a person has to spend with my child because they have to document and fill out paperwork. Case managers have rooms of paperwork.”

Approximately 44% of survey respondents from Wyoming wrote qualitative comments. These comments are summarized by theme below. Respondents most frequently mentioned issues regarding staff, followed by case management, and employment.

Staff

Respondents noted both positive and negative issues regarding staff and services, however, most comments were negative.

“They usually always help me with problems we have and find out if they can't do anything personally.”

“They were hiring people off the street to work with these people who were totally unqualified and no background checks were done. People only want the money involved and the disabled people are called consumers.”

“When problems occur resolution generally fall on us. Management does not accept responsibility for their errors and uses family and service providers as scapegoats, which goes all the way up to the DDD employees. Corrective measures fall on the family with little to no support from local management.”

“The most challenging aspect is to find support willing to work around our schedule and not us working around theirs.”

“The only thing I am unhappy about is that my daughter's hours were cut in half. It made a big difference in her. She was used to her coming 3 times a week and going places with her for training. The respite care was cut completely. Now it's a fight to get her just to drive through McDonalds with her. That's just one of the things she's regressed in.”

Case Management

Several respondents mentioned that they were satisfied with case management services.

“Our services provider is [name of provider] for many, many years and everyone has been helpful friendly and our case manager and we feel very fortunate to work with him. He's a gem. Our young adult would not be independent and living on his own, if it were not for the services provided by the Adult Waiver. He would still be living at home. Our case manager and providers are just excellent this last couple of years. Before that time frame, I would have had to answer most questions with a 'seldom or never' for services received.”

“The case manager has been very efficient, on top of the situation, caring, and very professional.”

A few respondents reported being dissatisfied with their family member's case manager.

“I believe that they have not helped me much, my case manager does not seem to want to help me out she helps the more severe people.”

“Current case manager seems only to be interested in monthly home visit so she can fulfill her financial needs/or requirements. Current case manager seems to have a lack of interest in the needs of the disabled client. Currently looking for new case manager but are few available.”

Employment

Several respondents noted that they were dissatisfied with employment services and programs. Specifically, they reported that their family member did not have many options for work or did menial work.

“The way [program] is run is pathetic. It would seem that people with disabilities could enjoy life with all the money appropriated. Instead they are forced to work at menial work. [Program] takes all their disability SSI income often they do not even have adequate clothing.”

“Employment opportunities and community support for the handicapped are poor in the area. Prospective employers and business should be educated and encourage to hire the disabled and handicapped in this community.”

Aging Caregiver Issues

A few respondents mentioned that they had difficulty caring for their family member or feared how they would continue to care for them as they age.

“I pray he will go first because I hate to leave him, afraid he might be abused...”

“I’m on a widow’s income and my daughter is on social security as her father is deceased. She goes to therapy on the bus, of which I buy her tickets. I have a van with a lift for any other transportation. I have trouble finding care givers as she is a small adult and female caregivers have trouble lifting her. ... I am 64 years old so my back is not what it used to be. I still lift her on occasions but couldn't so it all day long everyday. I am very lucky to have my health and this program.”

Overall Satisfaction with Services or Agencies

Most respondents reported that overall, they were unhappy with the array and availability of services. In addition, a lack of facilities or qualified providers for persons with autism was noted by a couple of respondents.

“Most of the people seem to have to make sure they are doing what State workers want first and R.'s needs second. Sometimes is upsetting to her and myself.”

“There are no facilities for autistic persons. When I wanted auditory integration therapy I was turned down flat. When I tried to make some money, food stamps were stopped or cut back to almost nothing. Basically the only thing helped are people receiving salaries for doing nothing. When I sent my daughter to [provider] all she did was get sick because everybody was sick there. The way [provider] is run is pathetic.”

“This place does not have services available for people with disabilities. For example, no day programs, recreation programs, schooling, training etc. All programs end when the person reaches 21 years. Therapies are provided through the hospital-but the caregiver must take the client and pay for all of it. There is no overnight respite care available. Transportation is very limited. We make sure our son goes to functions in the community, but he is severely disabled so sometimes it is difficult, if not impossible to attend. Even some banks in town are hard to access with a wheelchair.”

“It also is very frustrating to know the state is willing to pay money to caregivers outside of the families and not willing to help families that choose not to take advantage of the system. I was told that families can not receive any money reimbursals because some family members have

taken advantage. Well it's asinine, in my opinion, to think people outside of the client's family don't take advantage of the system. I also take care of my son 24/7 - no respite worker at present - we had several - but none have stuck to it - no speech therapist she moved away. So I work with him on speech. Had an in home support person to work with reading skills. She never followed through. So I help with reading. Psychological counseling is the only thing at present that is being used. I also do all the help for my son's vending machine business. After all this - we found that my son's SSI was being cut in half starting December because he turned 22 and the child support was being counted against him. Also if his vending business shows any profit at the end of the year he will have 1/2 of that profit counted against him and possibly owe social security! I'd love to talk to the head people that think this is such a great thing going. Tell me how taking responsibility for my family and teaching my son to be a productive individual in society is doing any good!"

Health Care

Although only one person mentioned access to dental care, this theme was visited in the adult guardian and child family survey.

"The service which is non-existent is dental service. Medicare and Medicaid covers all medication and medical expenses. There is no coverage for dental which can be serious and expensive."

Transportation

While only one respondent mentioned transportation was a problem, accessible and adequate transportation are key to ensuring individuals can participate in the community.

"Transportation is very limited. We make sure our son goes to functions in the community, but he is severely disabled so sometimes it is difficult, if not impossible to attend. Even some banks in town are hard to access with a wheelchair."

APPENDIX A

Summary Tables of Survey Responses

Table A1 - Characteristics of Family Member with a Disability: 2002 Data

STATES	Total %		State Avg.		CA		CT		DE		HI		IA		IN		MA		ME	
Number of surveys	5,190		n = 15		724		315		261		220		317		26		448		353	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Gender:																				
Male	2,780	55.4		55.8	382	53.7	152	51.7	146	57.0	118	56.7	165	52.7	18	69.2	243	56.8	184	54.0
Female	2,241	44.6		44.2	329	46.3	142	48.3	110	43.0	90	43.3	148	47.3	8	30.8	185	43.2	157	46.0
Age:																				
Mean	33.6		33.7		32.6		32.9		34.3		29.3		32.7		38.1		37.1		33.6	
Range	18-97				18-96		18-84		18-75		18-78		18-73		18-67		18-89		18-79	
Race/Ethnicity* (duplicated counts):																				
White	3,871	76.9		76.6	374	51.7	237	80.1	183	73.8	47	23.9	265	84.1	23	92.0	395	92.3	329	97.3
Black	423	8.4		10.2	10	1.4	23	7.8	49	19.8	1	0.5	8	2.5	3	11.5	15	3.5	2	0.6
Asian	269	5.3		5.2	144	19.9	5	1.7	3	1.2	97	49.2	2	0.6	0	0.0	3	0.7	1	0.3
American Indian/ Eskimo/Aleut	145	2.9		3.1	10	1.4	6	2.0	2	0.8	3	1.5	6	1.9	1	3.8	13	3.0	6	1.8
Hawaiian/Pacific Islander	62	1.2		1.8	8	1.1	1	0.3	0	0.0	48	24.4	0	0.0	0	0.0	1	0.2	0	0.0
Hispanic	244	4.8		3.3	169	23.3	23	7.8	6	2.4	5	2.5	0	0.0	0	0.0	10	2.3	0	0.0
Mixed Races	115	2.3		2.5	26	3.6	5	1.7	4	1.6	35	17.8	0	0.0	0	0.0	3	0.7	5	1.5
Other/Unknown	48	1.0		0.9	8	1.1	1	0.3	0	0.0	8	4.1	18	5.7	0	0.0	2	0.5	0	0.0
More than 1 person with DD in household:																				
Yes	593	11.8		12.4	71	10.2	42	14.1	36	14.1	19	9.0	66	21.1	7	29.2	48	11.0	38	11.0
No	4,433	88.2		87.6	624	89.8	255	85.9	219	85.9	192	91.0	247	78.9	17	70.8	388	89.0	308	89.0
	5,026				695		297		255		211		313		24		436		346	

Table A2 - Characteristics of Family Member with a Disability: 2002 Data

STATES	Total %		State Avg.		NC		OK		PA		SC		SD		WV		WY	
Number of surveys	5,190		n = 15		390		483		1,076		193		53		253		78	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Gender:																		
Male	2,780	55.4		55.8	226	59.0	250	54.7	602	57.1	107	57.5	25	53.2	121	50.2	41	53.9
Female	2,241	44.6		44.2	157	41.0	207	45.3	452	42.9	79	42.5	22	46.8	120	49.8	35	46.1
Age:																		
Mean	33.6		33.7		35.3		30		34.7		34.1		32.5		33.9		34.5	
Range	18-97				18-97		18-83		18-77		18-74		19-63		18-87		21-55	
Race/Ethnicity* (duplicated counts):																		
White	3,871	76.9		76.6	245	62.8	365	78.7	984	93.8	76	41.3	48	90.6	229	93.9	71	92.2
Black	423	8.4		8.4	129	33.1	32	6.9	37	3.5	103	56.0	0	0.0	10	4.1	1	1.3
Asian	269	5.3		5.2	0	0.0	7	1.5	4	0.4	1	0.5	0	0.0	1	0.4	1	1.3
American Indian/ Eskimo/Aleut	145	2.9		3.1	7	1.8	56	12.1	16	1.5	2	1.1	3	5.7	12	4.9	2	2.6
Hawaiian/Pacific Islander	62	1.2		1.8	0	0.0	1	0.2	0	0.0	1	0.5	0	0.0	2	0.8	0	0.0
Hispanic	244	4.8		3.3	3	0.8	14	3.0	8	0.8	1	0.5	1	1.9	1	0.4	3	3.9
Mixed Races	115	2.3		2.5	3	0.8	21	4.5	5	0.5	3	1.6	0	0.0	3	1.2	2	2.6
Other/Unknown	48	1.0		0.9	0	0.0	4	0.9	5	0.5	1	0.5	0	0.0	1	0.4	0	0.0
More than 1 person with DD in household:																		
Yes	593	11.8		12.4	63	16.8	47	10.2	109	10.4	14	7.4	1	1.9	25	10.4	7	9.1
No	4,433	88.2		87.6	313	83.2	414	89.8	943	89.6	176	92.6	51	98.1	216	89.6	70	90.9
	5,026				376		461		1,052		190		52		241		77	

Table B1 - Characteristics of Family Member with a Disability: 2002 Data

	Total %		State Avg.		CA		CT		DE		HI		IA		IN		MA		ME	
Number of surveys	5,190		n = 15		724		315		261		220		317		26		448		353	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Level of MR:																				
No MR label	231	4.7	4.5	57	8.2	5	1.7	12	4.9	11	5.4	47	14.9	0	0.0	9	2.2	10	3.1	
Mild	918	18.8	19.1	131	18.8	56	19.4	48	19.8	34	16.7	60	19.0	3	12.5	65	15.7	89	27.5	
Moderate	1,619	33.1	34.6	217	31.1	106	36.7	82	33.7	77	37.9	104	33.0	12	50.0	187	45.1	114	35.2	
Severe	831	17.0	16.4	141	20.2	48	16.6	29	11.9	40	19.7	40	12.7	3	12.5	59	14.2	46	14.2	
Profound	316	6.5	6.6	37	5.3	12	4.2	8	3.3	10	4.9	16	5.1	3	12.5	20	4.8	8	2.5	
Don't know	971	19.9	18.8	114	16.4	62	21.5	64	26.3	31	15.3	48	15.2	3	12.5	75	18.1	57	17.6	
	4,886			697		289		243		203		315		24		415		324		
Other disabilities* (duplicated counts):																				
Mental illness	728	14.8	14.2	101	14.0	29	10.2	32	13.5	27	14.1	18	5.8	4	16.0	68	16.5	44	13.8	
Autism	432	8.8	9.9	84	11.6	33	11.6	24	10.1	23	12.0	18	5.7	6	24.0	29	7.0	26	8.2	
Cerebral Palsy	905	18.4	19.6	98	13.6	44	15.4	30	12.7	37	19.4	44	14.0	6	24.0	64	15.6	42	13.2	
Brain injury	527	10.7	11.6	78	10.8	21	7.4	17	7.2	26	13.6	40	12.7	5	20.0	20	4.9	26	8.2	
Seizure disorder/ neurological problem	1,346	27.4	27.9	175	24.2	66	23.2	62	26.2	66	34.6	80	25.4	7	28.0	92	22.4	67	21.0	
Chemical dependency	55	1.1	1.6	8	1.1	1	0.4	3	1.3	6	3.1	0	0.0	2	8.0	4	1.0	2	0.6	
Vision or hearing impairments	1136	23.1	25.2	123	17.0	60	21.1	49	20.7	52	27.2	51	16.2	7	28.0	105	25.5	67	21.0	
Physical disability	1234	25.1	25.3	146	20.2	60	21.1	45	19.0	61	31.9	61	19.4	5	20.0	88	21.4	73	22.9	
Communication disorder	996	20.3	22.3	117	16.2	63	22.1	31	13.1	35	18.3	44	14.0	8	32.0	64	15.6	58	18.2	
Alzheimer's disease	31	0.6	0.8	6	0.8	0	0.0	1	0.4	1	0.5	0	0.0	1	4.0	3	0.7	4	1.3	
Down Syndrome	938	19.3	18.6	130	18.0	68	23.9	48	20.3	43	22.5	36	11.4	3	12.0	116	28.2	80	25.1	
Other disability	702	14.3	14.8	91	12.6	39	13.7	29	12.2	37	19.4	47	14.9	5	20.0	62	15.1	46	14.4	
No other disability	417	8.5	8.0	51	7.1	29	10.2	27	11.4	12	6.3	38	12.1	1	4.0	51	12.4	31	9.7	
Don't know	328	6.7	6.8	39	5.4	14	4.9	19	8.0	5	2.6	46	14.6	3	12.0	12	2.9	17	5.3	

Table B2 - Characteristics of Family Member with a Disability: 2002 Data

	Total %		State Avg.		NC		OK		PA		SC		SD		WV		WY	
Number of surveys	5,190		n = 15		390		483		1,076		193		53		253		78	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Level of MR																		
No MR label	231	4.7	4.5	24	6.5	12	2.7	16	1.5	18	10.4	1	2.0	9	4.0	0	0.0	
Mild	918	18.8	19.1	52	14.1	67	14.9	210	20.3	28	16.2	15	30.6	44	19.4	16	21.9	
Moderate	1,619	33.1	34.6	92	25.0	140	31.1	347	33.5	33	19.1	18	36.7	57	25.1	33	45.2	
Severe	831	17.0	16.4	86	23.4	102	22.7	150	14.5	20	11.6	7	14.3	48	21.1	12	16.4	
Profound	316	6.5	6.6	53	14.4	50	11.1	62	6.0	12	6.9	3	6.1	20	8.8	2	2.7	
Don't know	971	19.9	18.8	61	16.6	79	17.6	251	24.2	62	35.8	5	10.2	49	21.6	10	13.7	
	4,886			368		450		1036		173		49		227		73		
Other disabilities* (duplicated counts):																		
Mental illness	728	14.8	14.2	77	19.7	57	12.3	158	15.7	29	16.3	3	5.7	75	32.2	6	7.8	
Autism	432	8.8	9.9	40	10.3	38	8.2	63	6.3	13	7.3	5	9.4	25	10.7	5	6.5	
Cerebral Palsy	905	18.4	19.6	79	20.3	147	31.7	180	17.9	35	19.7	13	24.5	69	29.5	17	22.1	
Brain injury	527	10.7	11.6	47	12.1	68	14.7	106	10.5	20	11.2	8	15.1	37	15.8	8	10.4	
Seizure disorder/ neurological problem	1,346	27.4	27.9	110	28.2	180	38.8	264	26.2	48	27.0	14	26.4	95	40.6	20	26.0	
Chemical dependency	55	1.1	1.6	4	1.0	7	1.5	10	1.0	3	1.7	0	0.0	4	1.7	1	1.3	
Vision or hearing impairments	1136	23.1	25.2	99	25.4	149	32.1	213	21.2	48	27.1	17	32.1	70	29.9	26	33.8	
Physical disability	1234	25.1	25.3	109	27.9	188	40.5	217	21.5	57	32.2	11	20.8	98	41.7	15	19.5	
Communication disorder	996	20.3	22.3	95	24.4	144	31.0	167	16.6	53	29.9	10	18.9	86	36.8	21	27.3	
Alzheimer's disease	31	0.6	0.8	2	0.5	2	0.4	3	0.3	1	0.6	0	0.0	7	3.0	0	0.0	
Down Syndrome	938	19.3	18.6	46	11.8	71	15.3	231	22.9	21	11.9	*	*	24	10.3	21	27.3	
Other disability	702	14.3	14.8	51	13.1	87	18.8	136	13.5	21	11.9	9	17.0	34	14.6	8	10.5	
No other disability	417	8.5	8.0	23	5.9	25	5.4	91	9.0	16	9.0	3	5.7	14	5.9	5	6.5	
Don't know	328	6.7	6.8	32	8.2	28	6.0	75	7.4	23	13.0	2	3.8	10	4.3	3	3.9	

Table C1 - Characteristics of Respondents: 2002 Data

STATES	Total %	State Avg.	CA	CT	DE	HI	IA	IN	MA	ME									
Number of surveys	5,190	n = 15	724	315	261	220	317	26	448	353									
Age:																			
	n	%	%	n	%	n	%	n	%	n	%								
Under 35	235	4.6	4.4	37	5.4	13	4.2	2	0.8	14	6.6	26	8.4	0	0.0	20	4.5	25	7.1
35 to 54	1,851	36.6	36.3	206	29.9	115	37.3	92	35.9	88	41.7	141	45.3	10	40.0	114	25.9	137	39.1
55 to 74	2,313	45.8	48.0	314	45.6	135	43.8	132	51.6	92	43.6	116	37.3	14	56.0	229	52.0	154	44.0
75 and Over	656	13.0	11.3	131	19.0	45	14.6	30	11.7	17	8.1	28	9.0	1	4.0	77	17.5	34	9.7
	5,055			688		308		256		211		311		25		440		350	
Relationship to consumer:																			
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Parent	4,298	85.3	84.5	610	89.1	274	90.4	213	81.9	178	84.8	261	83.9	21	80.8	347	79.8	292	84.6
Sibling	413	8.2	8.6	54	7.9	18	5.9	17	6.5	24	11.4	16	5.1	2	7.7	53	12.2	33	9.6
Spouse	50	1.0	0.8	1	0.1	0	0.0	1	0.4	0	0.0	16	5.1	0	0.0	13	3.0	3	0.9
Other	280	5.6	6.1	20	2.9	11	3.6	29	11.2	8	3.8	18	5.8	3	11.5	22	5.1	17	4.9
	5,041			685		303		260		210		311		26		435		345	
Respondent is primary caregiver:																			
Yes	4,770	95.6	95.7	642	95.3	288	96.0	239	94.1	204	97.6	289	95.4	25	96.2	394	91.2	329	94.5
Respondent is guardian or conservator:																			
Yes	2,930	60.6	63.1	303	45.7	242	82.6	124	51.7	165	79.7	190	61.5	12	46.2	257	60.5	239	70.3
Health of respondent:																			
Excellent	1,045	20.6	22.1	164	23.6	58	19.1	40	15.4	47	22.6	88	27.9	10	38.5	98	22.4	90	25.6
Good	2,636	52.1	52.3	380	54.8	180	59.2	152	58.7	114	54.8	164	52.1	14	53.8	230	52.5	169	48.1
Fair	1,173	23.2	21.5	130	18.7	58	19.1	56	21.6	41	19.7	59	18.7	1	3.8	94	21.5	79	22.5
Poor	207	4.1	4.2	20	2.9	8	2.6	11	4.2	6	2.9	4	1.3	1	3.8	16	3.7	13	3.7
	5,061			694		304		259		208		315		26		438		351	
Household Income																			
Below \$15,000	1,158	29.9	28.7	129	26.4	68	27.9	50	23.8	39	19.8	90	33.0	4	20.0	75	20.5	*	*
\$15,001-\$25,000	954	24.6	23.3	105	21.5	48	19.7	56	26.7	40	20.3	54	19.8	2	10.0	93	25.4	*	*
\$25,001-\$50,000	1,039	26.8	28.7	116	23.8	60	24.6	57	27.1	66	33.5	61	22.3	10	50.0	106	29.0	*	*
\$50,001-\$75,000	453	11.7	13.1	75	15.4	38	15.6	30	14.3	32	16.2	42	15.4	4	20.0	55	15.0	*	*
Over \$75,000	273	7.0	6.8	63	12.9	30	12.3	17	8.1	20	10.2	26	9.5			37	10.1	*	*
	3,877			488		244		210		197		273		20		366		0	

Table C2 - Characteristics of Respondents: 2002 Data

STATES	Total %	State Avg.	NC	OK	PA	SC	SD	WV	WY								
Number of surveys	5,190	n = 15	390	483	1,076	193	53	253	78								
Age:																	
	n	%	%	n	%	n	%	n	%	n	%						
Under 35	235	4.6	4.4	15	3.9	9	2.0	39	3.7	19	9.8	0	0.0	13	5.4	3	3.9
35 to 54	1,851	36.6	36.3	181	46.8	225	48.8	353	33.4	54	28.0	10	19.6	102	42.7	23	29.9
55 to 74	2,313	45.8	48.0	158	40.8	190	41.2	516	48.8	69	35.8	39	76.5	112	46.9	43	55.8
75 and Over	656	13.0	11.3	33	8.5	37	8.0	150	14.2	51	26.4	2	3.9	12	5.0	8	10.4
	5,055			387		461		1,058		193		51		239			77
Relationship to consumer:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Parent	4,298	85.3	84.5	317	82.1	418	89.9	911	85.2	141	75.4	45	86.5	205	89.1	65	84.4
Sibling	413	8.2	8.6	28	7.3	15	3.2	103	9.6	20	10.7	7	13.5	14	6.1	9	11.7
Spouse	50	1.0	0.8	6	1.6	0	0.0	9	0.8	0	0.0	0	0.0	1	0.4	0	0.0
Other	280	5.6	6.1	35	9.1	32	6.9	46	4.3	26	13.9	0	0.0	10	4.3	3	3.9
	5,041			386		465		1,069		187		52		230			77
Respondent is primary caregiver:																	
Yes	4,770	95.6	95.7	364	97.1	448	97.6	1021	96.6	169	92.9	50	96.2	236	97.1	72	97.3
Respondent is guardian or conservator:																	
Yes	2,930	60.6	63.1	251	66.9	257	58.1	549	56.0	103	60.6	37	72.5	145	61.2	56	72.7
Health of respondent:																	
Excellent	1,045	20.6	22.1	61	15.8	101	21.8	191	18.1	33	17.6	14	27.5	33	13.4	17	22.7
Good	2,636	52.1	52.3	189	49.1	214	46.2	558	52.7	78	41.5	28	54.9	125	50.8	41	54.7
Fair	1,173	23.2	21.5	109	28.3	119	25.7	266	25.1	67	35.6	6	11.8	73	29.7	15	20.0
Poor	207	4.1	4.2	26	6.8	29	6.3	43	4.1	10	5.3	3	5.9	15	6.1	2	2.7
	5,061			385		463		1,058		188		51		246			75
Household Income:																	
Below \$15,000	1,158	29.9	28.7	129	39.0	109	28.2	282	31.8	93	56.7	10	23.3	69	34.0	11	16.9
\$15,001-\$25,000	954	24.6	23.3	85	25.7	91	23.6	253	28.5	35	21.3	10	23.3	63	31.0	19	29.2
\$25,001-\$50,000	1,039	26.8	28.7	76	23.0	123	31.9	244	27.5	31	18.9	12	27.9	54	26.6	23	35.4
\$50,001-\$75,000	453	11.7	13.1	33	10.0	41	10.6	70	7.9	4	2.4	9	20.9	11	5.4	9	13.8
Over \$75,000	273	7.0	6.8	8	2.4	22	5.7	38	4.3	1	0.6	2	4.7	6	3.0	3	4.6
	3,877			331		386		887		164		43		203			65

Table D1 - Services and Support Received: 2002 Data																			
STATES	Total %		State Avg.	CA		CT		DE		HI		IA		IN		MA		ME	
	n	%	n = 15	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Financial support	1,772	38.4	37.3	208	32.7	101	37.3	74	31.4	83	40.5	101	35.7	7	35.0	168	42.2	153	50.0
In-home support	1,493	30.4	30.7	150	22.4	45	16.2	20	8.0	58	26.9	168	56.6	10	41.7	85	19.6	83	24.7
Out-of-home respite care	1,366	27.9	30.2	172	26.1	79	27.8	57	23.4	74	34.4	118	39.5	14	56.0	138	31.9	77	23.0
Day/employment supports	3,292	66.0	67.7	417	62.7	230	78.8	191	75.8	139	64.4	206	67.1	17	65.4	351	79.2	241	70.5
Transportation	2,950	59.2	60.4	386	57.4	188	66.0	186	73.5	123	56.7	180	59.0	15	57.7	316	71.7	217	63.5
Other	1,239	25.5	27.8	90	13.6	49	17.1	36	14.9	51	24.1	88	29.5	7	26.9	119	28.5	80	23.7

Table D2 - Services and Support Received: 2002 Data																	
STATES	Total %		State Avg.	NC		OK		PA		SC		SD		WV		WY	
	n	%	n = 15	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Financial support	1,772	38.4	37.3	115	32.6	189	43.2	409	42.5	34	20.2	21	40.4	83	39.9	26	35.6
In-home support	1,493	30.4	30.7	167	44.2	308	66.2	233	22.6	52	28.3	5	9.6	79	34.6	30	38.5
Out-of-home respite care	1,366	27.9	30.2	135	36.5	85	18.8	278	27.0	36	19.1	9	17.0	58	25.6	36	46.8
Day/employment supports	3,292	66.0	67.7	240	62.7	197	42.5	705	67.5	103	54.5	47	88.7	153	64.3	55	71.4
Transportation	2,950	59.2	60.4	208	53.7	227	49.5	572	55.0	110	58.5	34	64.2	143	60.9	45	58.4
Other	1,239	25.5	27.8	113	29.9	215	46.2	198	19.4	57	32.6	15	29.4	90	40.5	31	40.3

Table E1 - Information and Planning: 2002 Data

STATES	TOTAL STATE		CA	CT	DE	HI	IA	IN	MA	ME	NC	OK	PA	SC	SD	WV	WY
	%	AVG.															
Q1 - Do you receive information about the services and supports that are available to your family?																	
Number of surveys	4,843		678	294	221	212	302	26	421	323	368	468	1,003	179	51	222	75
% always or usually	43.8	41.8	71.1	34.4	28.5	51.9	47.7	42.3	37.5	28.2	28.8	36.1	46.0	45.3	39.2	37.4	52.0
% sometimes	37.2	37.9	22.3	47.6	44.8	38.7	39.1	46.2	38.2	38.1	39.4	44.2	38.5	33.0	31.4	36.9	30.7
% seldom or never	19.0	20.3	6.6	18.0	26.7	9.4	13.2	11.5	24.2	33.7	31.8	19.7	15.6	21.8	29.4	25.7	17.3
Q2 - If you receive information, is it easy to understand?																	
Number of surveys	4,397		658	255	195	202	286	24	373	266	312	424	928	166	40	197	71
% always or usually	58.0	55.7	72.3	55.7	54.4	63.9	54.5	50.0	57.9	49.2	47.8	48.8	63.6	52.4	67.5	41.6	56.3
% sometimes	36.0	37.8	24.3	38.8	36.9	31.7	41.3	45.8	36.5	43.2	39.4	44.8	31.7	36.1	30.0	51.8	35.2
% seldom or never	6.0	6.4	3.3	5.5	8.7	4.5	4.2	4.2	5.6	7.5	12.8	6.4	4.7	11.4	2.5	6.6	8.5
Q3 - Do you get enough information to help you participate in planning services for your family?																	
Number of surveys	4,510		636	249	211	207	286	25	396	284	341	446	922	170	51	215	71
% always or usually	51.1	49.9	65.7	39.0	37.9	57.0	58.0	52.0	45.7	38.7	49.9	47.3	52.5	55.9	52.9	45.1	50.7
% sometimes	30.0	30.7	23.7	34.1	34.1	30.9	30.8	32.0	32.3	31.3	27.6	32.3	30.2	24.7	29.4	31.6	35.2
% seldom or never	19.0	19.4	10.5	26.9	28.0	12.1	11.2	16.0	22.0	29.9	22.6	20.4	17.4	19.4	17.6	23.3	14.1
Q4 - If your family member has a service plan, did you help develop the plan?																	
Number of surveys	3,696		511	163	148	191	254	23	336	199	307	406	700	159	48	184	67
% always or usually	72.1	73.2	69.1	69.3	62.8	83.2	76.4	87.0	71.1	65.8	71.0	81.5	69.7	69.8	70.8	69.0	82.1
% sometimes	17.0	17.1	18.0	18.4	18.2	10.5	18.9	13.0	17.0	16.6	16.6	12.6	18.3	20.8	25.0	18.5	13.4
% seldom or never	10.9	10.4	12.9	12.3	18.9	6.3	4.7	11.9	17.6	12.4	5.9	12.0	9.4	4.2	12.5	4.5	4.5
Q5 - If your family member has a service plan, does the plan include things that are important to you?																	
Number of surveys	3,679		496	167	145	188	258	24	338	204	304	403	706	156	47	175	68
% always or usually	69.6	71.2	69.0	58.1	65.5	76.1	72.9	87.5	68.6	65.2	70.7	73.0	68.3	72.4	76.6	66.9	77.9
% sometimes	22.8	21.6	23.4	31.7	18.6	19.7	22.5	12.5	23.7	22.1	20.7	21.1	24.2	21.2	21.3	27.4	13.2
% seldom or never	7.6	7.7	7.7	10.2	15.9	4.3	4.7	7.7	7.7	12.7	8.6	6.0	7.5	6.4	2.1	5.7	8.8

Table E2 - Information and Planning: 2002 Data

STATES	TOTAL STATE		CA	CT	DE	HI	IA	IN	MA	ME	NC	OK	PA	SC	SD	WV	WY
	%	AVG.															
Q6 - Do the staff who assist you with planning help you figure out what you need as a family to support your family member?																	
Number of surveys	4,076		619	196	163	196	284	25	356	245	326	428	765	169	47	190	67
% always or usually	57.6	58.2	59.0	54.6	50.3	63.3	64.8	72.0	53.4	50.6	59.5	59.3	57.1	55.6	57.4	55.3	61.2
% sometimes	27.4	27.0	27.0	28.6	30.1	25.5	25.4	16.0	29.8	29.0	24.5	27.3	27.6	30.8	34.0	26.3	22.4
% seldom or never	15.1	14.8	14.1	16.8	19.6	11.2	9.9	12.0	16.9	20.4	16.0	13.3	15.3	13.6	8.5	18.4	16.4
Q7 - Do the staff who assist you with planning respect your choices and opinions?																	
Number of surveys	4,155		644	206	160	204	292	26	355	257	323	436	778	163	48	191	72
% always or usually	77.7	76.5	83.9	74.3	78.1	82.4	79.5	76.9	76.1	70.8	77.7	76.8	78.0	79.1	72.9	68.1	73.6
% sometimes	16.5	17.5	12.9	19.4	14.4	14.7	14.4	19.2	18.9	19.1	13.9	17.4	16.2	18.4	22.9	25.7	15.3
% seldom or never	5.7	5.9	3.3	6.3	7.5	2.9	6.2	3.8	5.1	10.1	8.4	5.7	5.8	2.5	4.2	6.3	11.1
Q8 - Are the staff who help you with planning generally respectful and courteous?																	
Number of surveys	4,297		675	205	166	204	304	26	368	261	328	443	824	173	48	197	75
% always or usually	88.9	89.0	93.2	86.3	89.8	89.7	88.2	96.2	87.5	86.6	86.3	86.2	89.8	90.8	91.7	86.3	86.7
% sometimes	8.8	8.7	5.8	11.7	5.4	9.8	10.5	3.8	10.1	10.3	9.8	11.1	8.3	6.9	8.3	10.2	8.0
% seldom or never	2.3	2.3	1.0	2.0	4.8	0.5	1.3	0.0	2.4	3.1	4.0	2.7	1.9	2.3	0.0	3.6	5.3
Q9 - Are the staff who assist you with planning generally effective?																	
Number of surveys	4,200		657	210	165	200	294	26	355	257	321	440	796	169	48	189	73
% always or usually	66.9	67.3	74.0	60.5	60.6	69.0	78.9	80.8	63.1	60.3	66.0	60.7	67.3	63.3	79.2	63.5	61.6
% sometimes	26.5	26.4	21.6	33.8	28.5	25.5	16.3	15.4	29.3	30.7	26.8	32.0	26.0	30.2	20.8	25.9	32.9
% seldom or never	6.6	6.4	4.4	5.7	10.9	5.5	4.8	3.8	7.6	8.9	7.2	7.3	6.7	6.5	0.0	10.6	5.5
Q10 - Can you contact the staff who assist you with planning whenever you want to?																	
Number of surveys	4,269		652	214	170	201	302	25	369	264	325	442	827	170	47	187	74
% always or usually	77.4	77.6	77.0	72.4	71.8	77.6	82.1	72.0	75.9	78.4	76.0	73.8	80.4	81.2	93.6	73.8	78.4
% sometimes	17.7	18.0	18.3	22.4	22.4	18.9	15.2	28.0	19.2	14.8	16.6	21.5	14.5	15.9	4.3	21.9	16.2
% seldom or never	4.9	4.4	4.8	5.1	5.9	3.5	2.6	0.0	4.9	6.8	7.4	4.8	5.1	2.9	2.1	4.3	5.4

Table F1 - Access and Delivery of Services and Supports: 2002 Data

STATES	TOTAL	STATE															
	%	AVG.	CA	CT	DE	HI	IA	IN	MA	ME	NC	OK	PA	SC	SD	WV	WY
Q11 - When you ask the service/support coordinator for assistance, does he/she help you get what you need?																	
Number of surveys	4,351		618	234	179	198	288	25	375	291	330	474	844	172	50	204	69
% always or usually	70.1	69.9	74.4	61.1	63.1	62.6	81.3	72.0	66.7	68.7	70.3	70.0	70.9	72.7	78.0	66.7	69.6
% sometimes	23.8	23.9	21.8	32.9	24.6	31.8	16.0	28.0	27.2	25.4	21.8	24.3	23.0	20.3	18.0	24.0	18.8
% seldom or never	6.1	6.7	3.7	6.0	12.3	5.6	2.8		6.1	5.8	7.9	5.7	6.2	7.0	4.0	9.3	11.6
Q12 - Does your family get the services and supports you need?																	
Number of surveys	4,453		619	243	191	200	294	25	385	293	350	471	895	171	50	196	70
% always or usually	58.1	57.6	65.6	41.2	50.8	58.5	72.8	60.0	53.5	57.7	54.0	53.9	60.9	63.7	66.0	45.4	60.0
% sometimes	32.0	32.2	27.9	43.6	31.4	34.5	22.4	32.0	35.8	31.4	33.7	36.5	29.7	24.6	30.0	41.3	28.6
% seldom or never	9.9	10.2	6.5	15.2	17.8	7.0	4.8	8.0	10.6	10.9	12.3	9.6	9.4	11.7	4.0	13.3	11.4
Q13 - Do the services and supports offered meet your family's needs?																	
Number of surveys	4,395		615	241	181	207	296	22	380	277	342	462	877	175	47	202	71
% always or usually	55.0	55.4	64.9	36.5	49.2	54.6	60.8	63.6	49.7	53.4	57.0	50.9	55.2	59.4	66.0	54.0	56.3
% sometimes	36.2	35.7	29.6	48.1	35.4	38.2	36.5	31.8	41.1	36.1	30.7	38.7	37.2	33.1	29.8	36.1	32.4
% seldom or never	8.8	8.9	5.5	15.4	15.5	7.2	2.7	4.5	9.2	10.5	12.3	10.4	7.6	7.4	4.3	9.9	11.3
Q14 - Are supports available when your family needs them?																	
Number of surveys	4,176		566	226	175	197	280	23	358	273	340	445	821	166	46	190	70
% always or usually	52.5	51.9	63.1	35.8	48.0	51.3	65.0	56.5	45.5	46.9	50.6	46.1	55.2	62.0	52.2	47.9	52.9
% sometimes	36.9	37.4	30.7	47.3	34.3	38.6	31.4	39.1	42.7	40.3	35.3	41.8	36.1	30.1	41.3	36.8	35.7
% seldom or never	10.5	10.6	6.2	16.8	17.7	10.2	3.6	4.3	11.7	12.8	14.1	12.1	8.8	7.8	6.5	15.3	11.4
Q15 - Do families in your area request that different types of services and supports be made available in your area?																	
Number of surveys	1,650		192	94	66	82	122	13	131	111	169	161	288	82	14	94	31
% always or usually	35.7	33.9	35.4	36.2	40.9	36.6	27.9	15.4	35.9	27.9	41.4	36.6	38.9	31.7	35.7	36.2	32.3
% sometimes	40.3	42.4	36.5	43.6	33.3	39.0	52.5	61.5	37.4	50.5	33.1	38.5	42.0	32.9	50.0	37.2	48.4
% seldom or never	24.0	23.6	28.1	20.2	25.8	24.4	19.7	23.1	26.7	21.6	25.4	24.8	19.1	35.4	14.3	26.6	19.4
Q16 - If yes, does either the state agency or provider agency respond to their requests?																	
Number of surveys	1,454		189	115	60	65	100	13	11	89	151	134	237	71	14	83	22
% always or usually	37.9	36.6	60.8	40.9	33.3	49.2	36.0	38.5	34.2	29.2	39.1	23.9	31.6	39.4	28.6	32.5	31.8
% sometimes	41.4	42.0	25.9	40.9	41.7	35.4	54.0	38.5	43.2	48.3	34.4	45.5	48.5	39.4	50.0	43.4	40.9
% seldom or never	20.7	21.4	13.2	18.3	25.0	15.4	10.0	23.1	22.5	22.5	26.5	30.6	19.8	21.1	21.4	24.1	27.3
Q17 - If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?																	
Number of surveys	2,277		283	112	95	94	152	15	192	155	247	223	413	111	32	116	37
% always or usually	55.1	55.6	54.8	52.7	44.2	46.8	59.2	73.3	58.3	53.5	56.3	52.0	56.7	66.7	53.1	50.0	56.8
% sometimes	19.6	18.0	18.0	15.2	22.1	20.2	19.7	6.7	15.1	21.3	24.7	23.8	20.3	11.7	9.4	20.7	21.6
% seldom or never	25.3	26.3	27.2	32.1	33.7	33.0	21.1	20.0	26.6	25.2	19.0	24.2	23.0	21.6	37.5	29.3	21.6
Q18 - If English is not your first language, are there support workers or translators available to speak with you in your preferred language?																	
Number of surveys	583		235	36	22	31	18	1	41	30	45	31	50	21	1	17	4
% always or usually	72.9	63.6	85.1	63.9	59.1	48.4	77.8	100.0	61.0	56.7	75.6	74.2	62.0	76.2	0.0	64.7	50.0
% sometimes	13.9	14.2	10.2	16.7	9.1	22.6	11.1		24.4	20.0	15.6	12.9	20.0	4.8	0.0	5.9	25.0
% seldom or never	13.2	24.8	4.7	19.4	31.8	29.0	11.1		14.6	23.3	8.9	12.9	18.0	19.0	100.0	29.4	25.0

Table F2 - Access and Delivery of Services and Supports: 2002 Data (Cont'd)

STATES	TOTAL STATE		CA	CT	DE	HI	IA	IN	MA	ME	NC	OK	PA	SC	SD	WV	WY
	AVG.	AVG.															
Q19 - If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?																	
Number of surveys	806		173	42	26	45	42	2	68	49	76	91	105	31	2	41	13
% always or usually	54.1	51.2	72.8	54.8	57.7	31.1	61.9	50.0	50.0	44.9	47.4	53.8	44.8	58.1	50.0	43.9	46.2
% sometimes	27.3	30.7	15.0	26.2	15.4	37.8	38.1	50.0	35.3	32.7	36.8	26.4	28.6	19.4	50.0	34.1	15.4
% seldom or never	18.6	18.1	12.1	19.0	26.9	31.1	0.0	0.0	14.7	22.4	15.8	19.8	26.7	22.6	0.0	22.0	38.5
Q20 - Does your family member have access to the special equipment or accommodations that he/she needs?																	
Number of surveys	1,776		207	62	61	72	114	12	134	108	180	263	314	85	22	113	29
% always or usually	62.3	63.6	55.1	61.3	65.6	55.6	63.2	75.0	64.9	60.2	62.2	64.3	65.3	65.9	77.3	56.6	62.1
% sometimes	20.8	18.8	19.3	12.9	21.3	26.4	26.3	8.3	20.1	18.5	20.6	21.7	21.3	23.5	4.5	23.0	13.8
% seldom or never	16.9	17.6	25.6	25.8	13.1	18.1	10.5	16.7	14.9	21.3	17.2	14.1	13.4	10.6	18.2	20.4	24.1
Q21 - Do you have access to health services for your family member?																	
Number of surveys	4,570		606	254	212	197	296	25	397	311	368	459	930	174	51	216	74
% always or usually	87.9	88.7	86.1	83.1	85.8	84.3	95.3	92.0	87.9	91.0	85.3	84.1	91.0	83.9	100.0	87.5	93.2
% sometimes	8.6	8.0	8.4	11.8	8.0	12.7	4.7	8.0	8.3	5.8	11.4	13.9	6.8	9.2	0.0	6.0	5.4
% seldom or never	3.5	3.3	5.4	5.1	6.1	3.0	0.0	0.0	3.8	3.2	3.3	2.0	2.3	6.9	0.0	6.5	1.4
Q22 - Do you have access to dental services for your family member?																	
Number of surveys	4,341		579	235	183	192	292	24	379	300	357	426	892	169	52	197	64
% always or usually	75.9	77.0	80.1	72.8	63.9	68.2	93.8	91.7	75.5	77.0	75.1	60.8	79.4	79.9	98.1	68.0	70.3
% sometimes	9.7	9.3	9.0	12.8	11.5	15.1	3.4	8.3	7.9	8.0	14.3	12.0	8.7	7.7	0.0	11.2	9.4
% seldom or never	14.4	13.7	10.9	14.5	24.6	16.7	2.7	0.0	16.6	15.0	10.6	27.2	11.9	12.4	1.9	20.8	20.3
Q23 - Do you have access to necessary medications for your family member?																	
Number of surveys	4,487		593	241	215	201	290	20	396	311	359	455	911	163	49	216	67
% always or usually	91.1	91.9	84.7	92.9	86.5	92.0	96.6	95.0	90.2	95.2	90.0	87.3	94.7	88.3	100.0	93.1	92.5
% sometimes	5.3	4.9	7.8	3.7	6.5	5.5	2.8	5.0	6.1	2.3	7.2	9.2	3.5	3.7	0.0	3.7	6.0
% seldom or never	3.6	3.2	7.6	3.3	7.0	2.5	0.7	0.0	3.8	2.6	2.8	3.5	1.8	8.0	0.0	3.2	1.5
Q24 - Are frequent changes in support staff a problem for your family?																	
Number of surveys	3,604		495	189	145	176	234	25	300	234	272	375	749	134	47	168	61
% always or usually	20.4	21.8	23.4	13.8	25.5	20.5	8.5	40.0	18.3	18.8	20.6	25.1	18.6	26.9	14.9	26.8	24.6
% sometimes	38.7	39.2	32.7	42.9	37.2	42.6	35.9	24.0	41.7	44.4	41.9	33.9	39.4	29.1	46.8	44.6	50.8
% seldom or never	40.9	39.1	43.8	43.4	37.2	36.9	55.6	36.0	40.0	36.8	37.5	41.1	42.1	44.0	38.3	28.6	24.6
Q25 - Do you feel that your family member's day/employment setting is a healthy and safe environment?																	
Number of surveys	3,912		541	235	210	176	264	20	378	280	302	312	782	136	52	161	63
% always or usually	82.6	82.1	84.1	80.4	82.9	82.4	84.1	90.0	83.3	85.4	80.5	82.1	84.3	72.8	76.9	77.6	84.1
% sometimes	14.5	15.0	13.3	17.0	13.3	14.8	14.4	10.0	13.2	12.9	17.2	15.4	12.8	22.8	21.2	18.6	7.9
% seldom or never	2.8	2.9	2.6	2.6	3.8	2.8	1.5	0.0	3.4	1.8	2.3	2.6	2.9	4.4	1.9	3.7	7.9
Q26 - Are support staff generally respectful and courteous?																	
Number of surveys	4,496		632	243	205	206	306	24	390	298	343	442	919	168	52	198	70
% always or usually	89.8	89.8	93.8	90.5	90.7	86.4	92.2	95.8	87.9	87.9	86.9	85.5	91.4	91.7	90.4	84.8	91.4
% sometimes	8.5	8.2	5.2	8.2	8.3	10.7	5.9	0.0	9.0	10.7	11.1	12.4	7.6	6.0	9.6	12.1	5.7
% seldom or never	1.7	2.0	0.9	1.2	1.0	2.9	2.0	4.2	3.1	1.3	2.0	2.0	1.0	2.4	0.0	3.0	2.9

Table G - Choices and Control: 2002 Data

STATES	TOTAL STATE		CA	CT	DE	HI	IA	IN	MA	ME	NC	OK	PA	SC	SD	WV	WY
	%	AVG.															
Q27 - Do you or your family member choose the agencies or providers that work with your family?																	
Number of surveys	3,900		493	207	171	184	274	24	327	265	330	440	734	150	47	181	73
% always or usually	56.5	57.3	56.2	51.7	48.5	60.3	62.0	79.2	41.6	54.7	66.4	73.6	51.1	40.7	44.7	56.9	72.6
% sometimes	21.1	21.4	21.1	21.7	22.8	22.3	20.4	12.5	22.0	21.9	17.3	16.1	21.4	31.3	25.5	25.4	19.2
% seldom or never	22.4	21.3	22.7	26.6	28.7	17.4	17.5	8.3	36.4	23.4	16.4	10.2	27.5	28.0	29.8	17.7	8.2
Q28 - Do you or your family member choose the support workers that work with your family?																	
Number of surveys	3,728		460	192	159	172	274	24	313	249	315	420	716	146	47	169	72
% always or usually	40.1	39.1	37.4	30.7	25.8	39.5	40.1	45.8	29.4	29.7	55.2	68.1	33.4	35.6	17.0	39.1	59.7
% sometimes	20.3	22.3	18.9	18.2	18.2	25.6	25.5	41.7	22.0	20.9	19.7	17.9	18.3	19.2	27.7	23.7	16.7
% seldom or never	39.6	38.6	43.7	51.0	56.0	34.9	34.3	12.5	48.6	49.4	25.1	14.0	48.3	45.2	55.3	37.3	23.6
Q29 - If your family member gets day or employment services, does the agency providing these services involve you in important decisions?																	
Number of surveys	3,224		418	204	166	140	218	19	321	234	253	267	616	113	50	153	52
% always or usually	67.7	69.4	60.3	62.7	74.1	76.4	72.5	84.2	66.4	66.7	71.1	68.5	69.3	60.2	68.0	65.4	75.0
% sometimes	21.7	20.6	24.4	27.5	18.1	16.4	17.4	10.5	25.9	25.6	18.6	19.1	20.5	22.1	26.0	23.5	13.5
% seldom or never	10.6	10.0	15.3	9.8	7.8	7.1	10.1	5.3	7.8	7.7	10.3	12.4	10.2	17.7	6.0	11.1	11.5
Q30 - Do you or your family member have control and/or input over the hiring and management of your support workers?																	
Number of surveys	2,994		324	169	121	140	208	22	263	212	253	384	578	95	42	132	51
% always or usually	37.7	36.1	36.1	26.0	19.8	39.3	31.7	50.0	28.9	22.2	53.8	65.4	31.7	35.8	16.7	42.4	41.2
% sometimes	15.3	14.8	15.4	9.5	11.6	17.9	26.0	13.6	14.8	17.9	17.0	15.6	14.0	5.3	16.7	12.9	13.7
% seldom or never	47.0	49.2	48.5	64.5	68.6	42.9	42.3	36.4	56.3	59.9	29.2	19.0	54.3	58.9	66.7	44.7	45.1
Q31 - 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	2,990		321	158	114	134	234	22	268	205	267	382	553	101	37	141	53
% always or usually	56.3	53.1	58.6	50.6	46.5	54.5	47.0	63.6	45.9	50.2	67.0	83.8	49.2	44.6	27.0	64.5	43.4
% sometimes	25.2	27.7	19.9	29.7	24.6	22.4	32.5	36.4	32.1	26.8	22.1	12.8	28.2	26.7	45.9	23.4	32.1
% seldom or never	18.5	19.2	21.5	19.6	28.9	23.1	20.5	0.0	22.0	22.9	10.9	3.4	22.6	28.7	27.0	12.1	24.5
Q32 - Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?																	
Number of surveys	4,549		628	275	206	202	300	24	392	295	356	466	930	161	49	192	73
% always or usually	21.0	20.3	12.6	15.3	7.3	32.2	22.7	16.7	11.2	12.9	21.1	45.1	24.4	18.6	10.2	10.9	43.8
% sometimes	9.3	9.0	6.2	9.1	5.8	13.4	15.3	8.3	7.9	9.2	9.0	14.8	8.7	7.5	4.1	5.7	9.6
% seldom/never/don't know	69.7	70.7	81.2	75.6	86.9	54.5	62.0	75.0	80.9	78.0	69.9	40.1	66.9	73.9	85.7	83.3	46.6
Q33 - Do you or your family member get to decide how this money is spent?																	
Number of surveys	3,065		336	187	114	134	218	18	258	221	232	397	641	101	35	112	61
% always or usually	38.3	34.4	39.3	27.3	21.9	41.0	34.9	38.9	28.3	32.1	34.9	58.2	43.2	28.7	11.4	31.3	44.3
% sometimes	18.9	18.0	14.3	17.6	10.5	16.4	20.2	22.2	20.9	17.6	18.5	21.2	23.1	11.9	20.0	12.5	23.0
% seldom or never	42.8	47.6	46.4	55.1	67.5	42.5	45.0	38.9	50.8	50.2	46.6	20.7	33.7	59.4	68.6	56.3	32.8

Table H - Community Connections: 2002 Data

STATES	TOTAL STATE		CA	CT	DE	HI	IA	IN	MA	ME	NC	OK	PA	SC	SD	WV	WY
	%	AVG.															
Q34 - If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?																	
Number of surveys	2,813		355	167	101	121	202	21	251	197	245	318	533	93	39	116	54
% always or usually	31.7	32.0	37.2	27.5	19.8	29.8	38.6	52.4	24.3	27.9	33.5	34.0	31.7	33.3	23.1	28.4	38.9
% sometimes	27.5	27.3	24.2	26.3	25.7	28.1	32.7	33.3	32.3	28.4	30.6	29.9	26.1	17.2	33.3	22.4	18.5
% seldom or never	40.8	40.7	38.6	46.1	54.5	42.1	28.7	14.3	43.4	43.7	35.9	36.2	42.2	49.5	43.6	49.1	42.6
Q35 - If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?																	
Number of surveys	2,770		328	150	111	125	190	23	242	186	219	324	546	114	35	133	44
% always or usually	35.2	32.9	42.7	23.3	24.3	34.4	32.6	30.4	26.9	23.1	33.3	46.3	37.2	40.4	22.9	44.4	31.8
% sometimes	22.6	23.2	20.7	18.7	27.0	21.6	26.3	26.1	25.6	26.3	23.3	19.4	22.3	22.8	25.7	19.5	22.7
% seldom or never	42.2	43.9	36.6	58.0	48.6	44.0	41.1	43.5	47.5	50.5	43.4	34.3	40.5	36.8	51.4	36.1	45.5
Q36 - Do you feel that your family member has access to community activities?																	
Number of surveys	4,162		534	238	190	171	284	24	356	299	329	433	833	154	52	194	71
% always or usually	46.4	47.8	45.7	42.4	36.3	48.5	57.7	70.8	43.8	37.8	41.9	50.8	47.9	40.9	44.2	52.1	56.3
% sometimes	33.9	33.6	33.9	34.5	32.6	35.7	30.3	20.8	35.1	41.1	34.7	33.0	32.8	31.8	44.2	32.5	31.0
% seldom or never	19.7	18.6	20.4	23.1	31.1	15.8	12.0	8.3	21.1	21.1	23.4	16.2	19.3	27.3	11.5	15.5	12.7
Q37 - Does your family member participate in community activities?																	
Number of surveys	4,391		586	261	209	187	288	25	386	309	335	448	883	157	50	194	73
% always or usually	27.4	30.5	22.7	29.1	21.1	29.4	37.5	60.0	25.9	28.5	24.8	32.1	24.3	21.7	24.0	32.5	43.8
% sometimes	37.2	38.1	33.6	37.5	34.4	42.2	38.2	20.0	35.8	37.9	42.1	34.8	36.2	38.9	56.0	40.7	42.5
% seldom or never	35.5	31.4	43.7	33.3	44.5	28.3	24.3	20.0	38.3	33.7	33.1	33.0	39.4	39.5	20.0	26.8	13.7

Table I - Satisfaction with Services and Outcomes: 2002 Data

STATES	TOTAL %	STATE AVG.	CA	CT	DE	HI	IA	IN	MA	ME	NC	OK	PA	SC	SD	WV	WY
Q38 - Overall, are you satisfied with the services and supports your family member currently receives?																	
Number of surveys	4,688		653	267	213	207	310	22	401	317	364	464	961	176	52	208	73
% always or usually	65.2	64.8	76.6	47.6	51.6	69.1	77.4	77.3	60.3	59.9	61.5	62.7	66.4	69.3	69.2	63.0	60.3
% sometimes	28.2	28.4	19.0	41.9	39.0	23.7	20.6	22.7	30.9	33.1	28.6	29.7	28.1	26.1	25.0	30.3	27.4
% seldom or never	6.7	6.7	4.4	10.5	9.4	7.2	1.9	0.0	8.7	6.9	9.9	7.5	5.5	4.5	5.8	6.7	12.3
Q39 - Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?																	
Number of surveys	4,397		589	242	207	197	288	25	386	296	352	441	895	154	51	203	71
% always or usually	42.1	42.5	44.0	29.8	30.9	34.5	45.8	44.0	39.1	31.1	44.9	59.2	41.3	45.5	64.7	38.9	43.7
% sometimes	10.6	10.5	9.0	10.3	9.7	10.2	15.3	8.0	9.8	12.2	9.9	10.9	10.4	11.7	9.8	9.4	11.3
% seldom/never/don't know	47.4	47.0	47.0	59.9	59.4	55.3	38.9	48.0	51.0	56.8	45.2	29.9	48.3	42.9	25.5	51.7	45.1
Q40 - Are you satisfied with the way complaints/grievances are handled and resolved?																	
Number of surveys	2,139		270	98	101	77	138	10	212	145	222	195	396	93	36	105	41
% always or usually	59.3	58.3	71.1	49.0	46.5	55.8	62.3	70.0	56.1	51.7	55.0	66.7	61.4	62.4	61.1	52.4	53.7
% sometimes	27.6	28.4	17.8	34.7	33.7	33.8	27.5	20.0	32.1	33.8	27.5	23.6	27.3	26.9	27.8	27.6	31.7
% seldom or never	13.0	13.3	11.1	16.3	19.8	10.4	10.1	10.0	11.8	14.5	17.6	9.7	11.4	10.8	11.1	20.0	14.6
Q41 - Do you feel that services and supports have made a positive difference in the life of your family?																	
Number of surveys	4,463		606	236	188	205	310	24	386	305	352	459	895	175	51	197	74
% always or usually	69.6	68.1	75.4	56.8	54.8	72.7	80.0	54.2	65.8	67.2	73.3	72.8	67.2	72.6	72.5	68.0	68.9
% sometimes	24.3	25.8	17.8	32.2	35.1	21.0	17.4	41.7	26.9	26.2	21.0	23.1	26.9	24.0	23.5	26.9	23.0
% seldom or never	6.1	6.1	6.8	11.0	10.1	6.3	2.6	4.2	7.3	6.6	5.7	4.1	5.9	3.4	3.9	5.1	8.1
Q42 - Have services made a difference in helping keep your family member at home?																	
Number of surveys	3,946		495	208	160	184	282	18	334	267	324	436	790	148	47	184	69
% always or usually	74.5	73.8	76.4	62.0	66.9	73.4	81.6	61.1	74.9	71.5	79.3	77.3	72.0	79.7	74.5	74.5	81.2
% sometimes	15.2	16.6	14.1	24.0	20.6	20.1	12.8	33.3	14.4	15.7	13.9	14.4	14.3	11.5	17.0	14.7	8.7
% seldom or never	10.3	9.6	9.5	13.9	12.5	6.5	5.7	5.6	10.8	12.7	6.8	8.3	13.7	8.8	8.5	10.9	10.1
Q43 - Would your family member still be at home if you did not receive any services?																	
Number of surveys	3,447		443	183	156	155	192	13	294	247	254	340	770	128	36	169	67
% always or usually	85.2	85.8	83.7	79.8	90.4	85.2	79.2	100.0	81.3	86.2	79.5	83.5	90.5	84.4	88.9	87.0	88.1
% sometimes	4.9	4.7	5.0	5.5	3.2	3.9	7.3	0.0	4.1	5.3	7.9	5.3	3.5	6.3	5.6	5.9	1.5
% seldom or never	10.0	9.5	11.3	14.8	6.4	11.0	13.5	0.0	14.6	8.5	12.6	11.2	6.0	9.4	5.6	7.1	10.4
Q44 - Overall, do you feel that your family member is happy?																	
Number of surveys	4,839		640	274	239	209	312	25	419	332	374	473	1,005	176	52	232	77
% always or usually	84.1	84.2	83.6	80.3	82.0	87.1	86.5	88.0	82.6	84.3	81.6	87.9	84.6	83.0	78.8	81.0	92.2
% sometimes	14.5	14.6	14.1	19.0	15.5	12.0	12.2	12.0	15.8	15.1	16.0	11.8	14.1	15.3	21.2	16.4	7.8
% seldom or never	1.4	1.2	2.3	0.7	2.5	1.0	1.3	0.0	1.7	0.6	2.4	0.2	1.3	1.7	0.0	2.6	0.0

Table 18 Trends in Responses Above & Below State Average Information & Planning											
State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Net Sum
CA-RCOC	↑↑	↑↑	↑↑				↑		↑		8
CT	↓		↓↓		↓↓				↓	↓	-7
DE	↓↓		↓↓	↓↓	↓	↓			↓	↓	-10
HI	↑↑		↑	↑↑		↑	↑				7
IA	↑		↑			↑			↑		4
IN		↓		↑↑	↑↑	↑↑		↑	↑↑	↓	7
MA											0
ME	↓↓	↓	↓↓	↓	↓	↓			↓		-10
NC	↓↓	↓									-3
OK	↓	↓		↑					↓		-2
PA		↑									1
SC			↑								1
SD		↑↑			↑				↑↑	↑↑	7
WV		↓↓					↓				-3
WY	↑↑			↑	↑				↓		3

Table 19 Trends in Responses Above & Below State Average Access to Services & Supports																	
State	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Net Sum
CA-RCOC		↑	↑	↑↑		↑↑		↑↑	↑↑	↓			↓				8
CT	↓	↓↓	↓↓	↓↓							↓			↑			-9
DE	↓	↓	↓				↓↓		↑			↓↓	↓				-7
HI	↓					↑↑	↓	↓↓	↓↓	↓		↓↓					-7
IA	↑↑	↑↑	↑	↑↑				↑↑	↑↑		↑	↑↑		↑↑			16
IN			↑				↑↑	↑↑		↑↑		↑↑			↑	↑	11
MA			↓	↓													-2
ME			↓			↓		↓	↓								-4
NC									↑↑								2
OK				↓			↓↓		↑↑			↓↓					-3
PA								↓									-2
SC		↑		↑↑			↑↑	↑↑	↑					↓	↓		6
SD	↑	↑	↑↑			↓		↓↓		↑↑	↑↑	↑↑	↑	↑	↓		8
WV		↓↓					↓		↓	↓		↓↓		↓	↓	↓	-10
WY								↓↓	↓			↓↓					-5

Table 20 Trends in Responses Above & Below State Average Choice & Control								
State	Q27	Q28	Q29	Q30	Q31	Q32	Q33	Net Sum
CA-RCOC			↓		↑	↓		-1
CT	↓	↓	↓	↓↓		↓	↓	-7
DE	↓	↓		↓↓	↓	↓↓	↓↓	-9
HI			↑			↑↑		3
IA						↓		-1
IN	↑↑	↑	↑↑	↑↑	↑↑			9
MA	↓↓	↓		↓	↓	↓	↓	-7
ME		↓		↓		↓		-3
NC	↑	↑↑		↑↑	↑↑			7
OK	↑↑	↑↑		↑↑	↑↑	↑↑	↑↑	12
PA	↓	↓					↑	-1
SC	↓↓		↓		↓		↓	-5
SD	↓↓	↓↓		↓↓	↓↓	↓↓	↓↓	-12
WV				↑	↑↑	↓		2
WY	↑↑	↑↑		↑	↓	↑↑	↑	7

Table 21 Trends in Responses Above & Below State Average Community Connections					
State	Q34	Q35	Q36	Q37	Net Sum
CA-RCOC	↑	↑		↓	2
CT		↓	↓		-2
DE	↓↓	↓	↓↓	↓	-6
HI					0
IA	↑		↑	↑	3
IN	↑↑		↑↑	↑↑	6
MA	↓	↓			-2
ME		↓	↓↓		-3
NC			↓	↓	-2
OK		↑↑			2
PA				↓	-1
SC		↑	↓	↓	-1
SD	↓	↓↓		↓	-4
WV		↑↑			2
WY	↑		↑	↑↑	4

Table 22 Trends in Responses Above & Below State Average Satisfaction & Outcomes								
State	Q38	Q39	Q40	Q41	Q42	Q43	Q44	Net Sum
CA-RCOC	↑↑		↑↑	↑				5
CT	↓↓	↓↓	↓	↓↓	↓↓			-9
DE	↓↓	↓↓	↓↓	↓↓	↓			-9
HI		↓						-1
IA	↑↑			↑↑	↑			5
IN	↑↑		↑↑	↓↓	↓↓			0
MA								0
ME		↓↓	↓					-3
NC				↑	↑			2
OK		↑↑	↑					3
PA								0
SC					↑			1
SD		↑↑					↓	1
WV			↓					-1
WY					↑		↑	2

Table 23 Overall Trends in Responses Above & Below State Average	
State	Total Sum
CA-RCOC	22
CT	-34
DE	-41
HI	2
IA	27
IN	33
MA	-11
ME	-23
NC	6
OK	12
PA	-3
SC	2
SD	0
WV	-10
WY	11