

Family Guardian Survey

Final Report – April 2007
2005-2006 Data



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

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Organization of Report

Nine states and one local developmental disability authority conducted the National Core Indicators (NCI) Family Guardian Survey during the 2005-2006 project year and submitted their data. The Family Guardian Survey was administered to individuals having an adult family member with disabilities living outside of the family's home. This Final Report provides a summary of results, based on the data submitted by September 2006.

This report is organized as follows:

I. INTRODUCTION

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

II. FAMILY GUARDIAN SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

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

IV. RESULTS

This section provides aggregate and state-by-state results for demographic, service utilization, service planning, access and delivery, choice and control, community connections, satisfaction and outcome data. It also provides an overall view of the aggregate survey results and takes a look at state trends, comparing individual state results against the state averages.

I. Introduction

Overview of National Core Indicators

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

Phase I – Phase I of CIP Phase began in 1997 when the CIP Steering Committee selected a “candidate” set of 61 performance/outcome indicators (focusing on the adult service system), in order to test their utility/feasibility. Seven states conducted a field test of these indicators, including administering the project's consumer and family surveys and compiling other data. The results were compiled, analyzed and reported to participating states in September 1998.

1999 - 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) – 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. During this time, the CIP staff and participants continued to develop and refine the indicators, and recruit additional states to participate.

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

2002 – 2003 (Phase V) - Maine, South Carolina and South Dakota joined NCI.

2003 – 2004 (Phase VI) –North Dakota and the District of Columbia joined NCI.

2004 – 2005 (Phase VII) - Project participation diminished slightly this year, with 17 states, one local DD authority, and the District of Columbia involved.

2005 – 2006 (Phase VIII) – Arkansas, Georgia, New Mexico and Texas joined NCI. South Dakota rejoined NCI after a one-year hiatus.

The figure on the following page summarizes state participation in the National Core Indicators since its inception through the 2005-2006 data collection cycles. States are listed if they participate in one or more of the NCI activities (e.g., consumer survey, family surveys, expenditure/utilization data, etc.).

Table 1 State Participation in National Core Indicators							
Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003	Phase VI 2003-2004	Phase VII 2004-2005	Phase VIII 2005-2006
AZ	AZ	AZ	AL	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	AR
MO	KY	DE	CA - RCOC	CA - RCOC	CA - RCOC	CA-RCOC	AZ
NE	MA	IA	CT	CT	CT	CT	CA-RCOC
PA	MN	KY	DE	DE	DE	DE	CT
VT	NE	MA	HI	HI	DC	DC	DE
VA	NC	MN	IL	IN	HI	HI	DC
	PA	MT	IN	IA	IN	KY	GA
	RI	NE	IA	KY	KY	MA	HI
	VT	NC	KY	MA	MA	ME	KY
	VA	PA	MA	ME	ME	NC	MA
	WA	RI	NE	NE	NE	OK	ME
		UT	NC	NC	NC	PA	NM
		VT	OK	OK	ND	RI	NC
		WA	PA	PA	OK	SC	OK
			RI	RI	PA	VT	PA
			UT	SC	RI	WA	RI
			VT	SD	SC	WV	SC
			WA	VT	SD	WY	SD
			WV	WA	VT		TX
			WY	WV	WA		VT
				WY	WV		WA
					WY		WV
							WY

Denotes first year of participation in NCI.

Family Indicators

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

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

**Table 2
Family Indicators**

Table 2 Family Indicators			
DOMAIN	FAMILY INDICATORS		
	The project's family indicators concern how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.		
SUB-DOMAIN	CONCERN	INDICATOR	DATA SOURCE
Information & Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.	The proportion of families who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	All Surveys
		The proportion of families who report they have the information needed to skillfully plan for their services and supports.	All Surveys
		The proportion of families reporting that their support plan includes or reflects things that are important to them.	All Surveys
		The proportion of families who report that staff who assist with planning are knowledgeable and respectful.	All Surveys
Choice & Control	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.	The proportion of families reporting that they control their own budgets/supports (i.e. they choose what supports/goods to purchase).	Children & Adult Family Surveys
		The proportion of families who report they choose, hire and manage their service/support providers.	All Surveys
		The proportion of families who report that staff are respectful of their choices and decisions.	All Surveys
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.	The proportion of eligible families who report having access to an adequate array of services and supports.	All Surveys
		The proportion of families who report that services/supports are available when needed, even in a crisis.	All Surveys
		The proportion of families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication .	All Surveys
		The proportion of families who report that service and support staff/providers are available and capable of meeting family needs.	All Surveys
		The proportion of families who report that services/supports are flexible to meet their changing needs.	All Surveys
		The proportion of families who indicate that services/supports provided outside of the home (e.g., day/employment, residential services) are done so in a safe and healthy environment.	Both Adult Surveys
Community Connections	Families/family members use integrated community services and participate in everyday community activities.	The proportion of families/family members who participate in integrated activities in their communities.	All Surveys
		The proportion of families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	All Surveys
Family Involvement	Families maintain connections with family members not living at home.	The proportion of families/guardians of individuals not living at home who report the extent to which the system supports continuing family involvement.	Family/Guardian Survey
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	All Surveys
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Children & Adult Family Surveys

II. Family Guardian Survey

Background

This report focuses on the Family Guardian Survey.

1999-2000 – The Family Guardian Survey was developed and first utilized during Phase II, in response to various states’ interest in finding out whether family members of individuals with disabilities were involved in their family members’ lives, whether they were supported in their efforts to be involved, and their level of satisfaction with how the service system was meeting the needs of their family member with disabilities. In this effort, seven states administered the Family Guardian Survey. Over 13,600 surveys were mailed out, and the overall return rate was 39.4%.

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

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

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

2003-2004 - Ten states participated. Response rates range from 33% to 48%, and over 4,800 completed surveys were analyzed.

2004-2005 –Seven states participated, with nearly 2,800 surveys analyzed.

2005-2006 – The results from this year’s survey are explored in this report. Ten states participated, with over 5,000 surveys analyzed.

State Participation

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

Table 3 State Participation in NCI Family Guardian Survey (Adults Living Out-of-Home)							
Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003	Phase VI 2003-2004	Phase VII 2004-2005	Phase VIII 2005-2006
NA	CT	AZ	CA-RCOC	AZ	AZ	AZ	CA - RCOC
	KY	DE	HI	CA - RCOC	CA - RCOC	CA - RCOC	CT
	MN	MA	NE	HI	CT	CT	GA
	NE	MN	NC	IN	ME	HI	ME
	PA	NC	PA	MA	NC	PA	NC
	VA	PA	UT	NC	ND	SC	PA
	WA	RI	WA	PA	PA	WY	SC
				SC	SC		SD
				SD	WA		WA
				WY	WY		WY

Survey Instrument

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

The Family Guardian Survey used in 2005-2006 not only asks families to express their overall level of satisfaction with services and supports their family member receives, it also probes specific aspects of the service system's capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; satisfaction and outcomes. Combined, this information provides an overall picture of family satisfaction within and across states.

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

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

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

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

III. Methods

Sampling & Administration

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

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

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

Response Rates

During 2005-2006, nine states and one local developmental disability authority administered the Family Guardian Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis. The desired response rate (the percentage of surveys returned versus the number mailed) is 40%.

Table 4				
Family Guardian Survey - State Response Rates				
State	Surveys Mailed	Surveys Returned	Response Rate	Usable Surveys
CA - RCOG	863	271	31%	267
Connecticut	1,200	285	24%	274
Georgia	2,000	576	29%	517
Maine	988	528	53%	509
North Carolina	1,000	250	25%	218
Pennsylvania	2,760	1,248	45%	1,173
South Carolina	1,100	380	35%	349
South Dakota	1,454	923	63%	904
Washington	1,415	670	47%	636
Wyoming	635	251	40%	238
Overall	13,415	5,382	39%	5,085

Table 4 shows the response rates by state, based on the number of returned surveys entered into the database and submitted for analysis, compared to the total number mailed out. Unless noted, the “surveys mailed” figures include some number of “undeliverable” surveys (e.g. those returned due to incorrect addresses) or surveys that were returned but were excluded from the database for other reasons (e.g. did not meet the state's inclusion criteria).

Data Analysis

NCI data management and analysis is coordinated by HSRI. Data is entered by each state, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. HSRI utilizes SPSS (v. 15) software for statistical analysis and N6 software for support in analysis of open-ended comments.

IV. Results

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

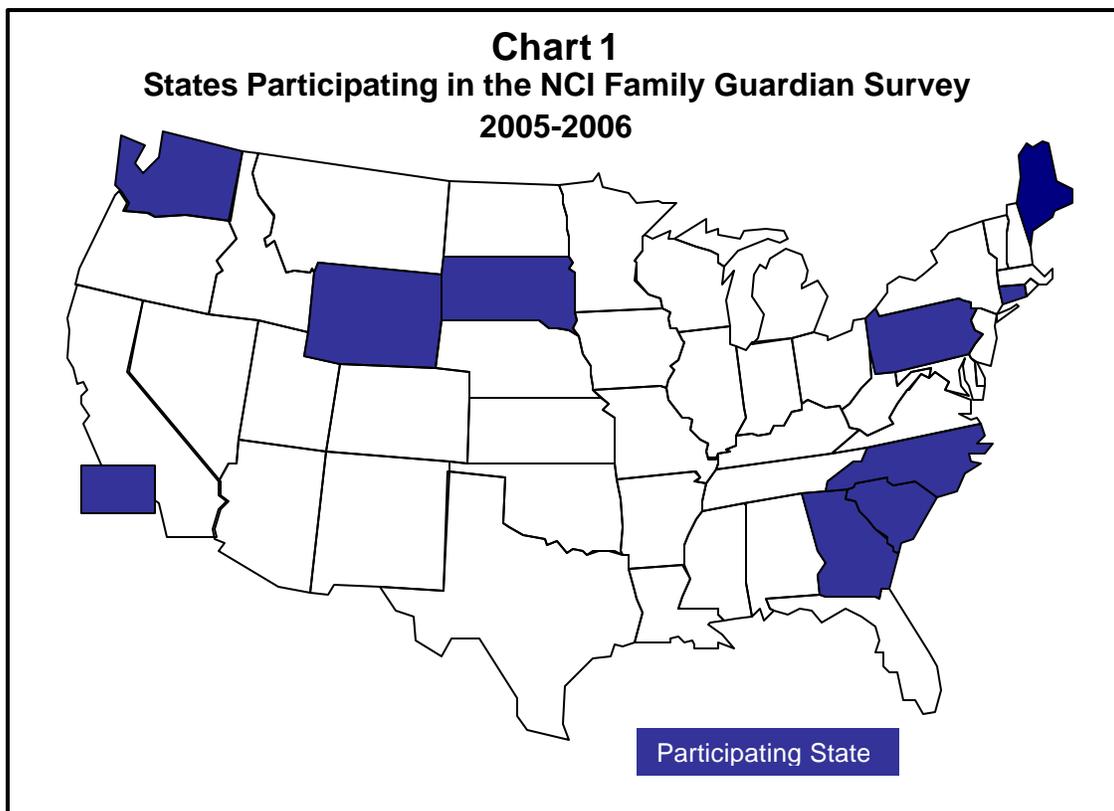
Please note that the TABLES provide individuals state results and result averages that are calculated through two separate methods:

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

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

Participating States

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



Characteristics of Family Members with Disabilities

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

- On average, across the states, over half (55%) of the family members with disabilities lived in group home settings. 16% lived in their own homes or apartments, 12% in specialized facilities, 6% lived in agency-owned apartments, 5% lived in adult foster care or host family homes, 2% in nursing homes, and 5% in a variety of other settings.
- On average, 56% of family members were male across the participating states. The remaining 44% were female.
- Across states, the average age of family members with disabilities was 44.3, with a range in age from 18 to 93.
- On average, 88% of the family members were White, 8% were Black/ African American, 2% were American Indian/Alaska Native, 2% were Hispanic, 1% were Asian, 1% were Mixed Races, less than 1% were Native Hawaiian/Pacific Islander, and less than 1% marked Other or Unknown. (In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.)
- On average, one-third (33%) of the family members with disabilities had a diagnosis of severe or profound mental retardation. Additionally, 29% were individuals with moderate mental retardation, 17% had mild mental retardation, and 4% had no mental retardation diagnosis. Additionally, 17% of respondents were unsure of their family member's diagnosis.
- In addition to mental retardation, many family members experience other disabilities as well (e.g., seizure disorder, cerebral palsy, physical disability, communication disorder). The most prevalent additional disabilities included: seizure disorders/neurological problems (30%), physical disabilities (27%), vision or hearing impairments (23%), mental illness (22%), communication disorders (21%), and cerebral palsy (17%).

Type of Residence

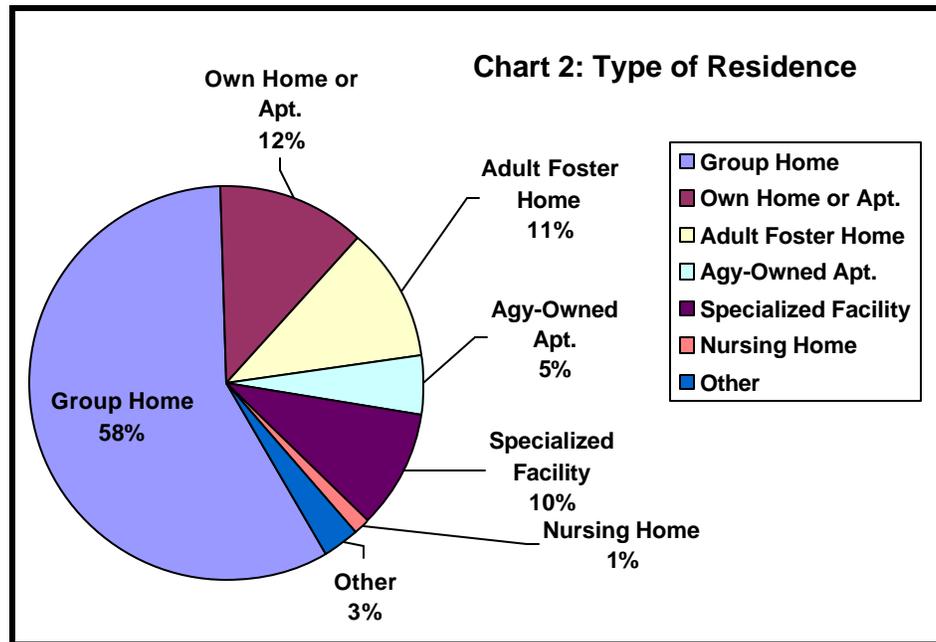
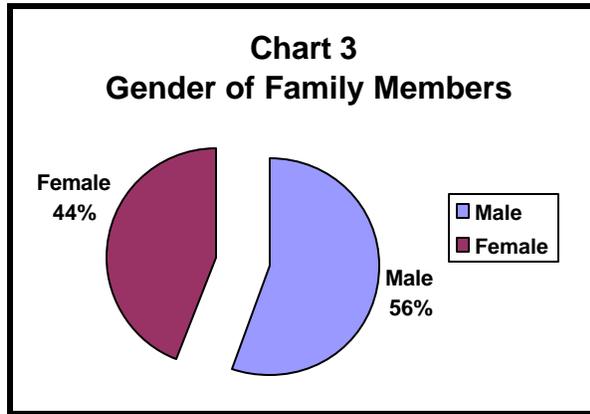


Table 5
Type of Residence in Which Family Member Lives

State	Specialized MR Facility	Group Home	Agy-Owned Apartment	Own Home/ Apartment	Adult Foster Care/ Host Family	Nursing Home	Other
CA - RCOC	5.3	68.0	0.4	15.4	3.0	3.4	4.5
CT	7.7	71.2	2.3	14.6	1.9	0.0	2.3
GA	5.2	50.8	5.6	23.2	7.7	1.0	6.5
ME	13.0	52.1	6.8	8.7	8.7	6.0	4.7
NC	10.3	62.6	2.8	10.7	4.2	4.7	4.7
PA	20.7	51.7	3.5	9.5	5.4	4.5	4.7
SC	15.4	57.5	9.6	11.1	2.4	0.3	3.6
SD	7.5	47.7	13.9	27.5	0.3	0.0	3.0
WA	18.0	31.9	6.0	25.0	7.5	1.5	10.1
WY	6.8	66.2	7.2	11.4	5.9	0.0	2.5
Total n	623	2,549	321	826	234	113	242
Total %	12.7	51.9	6.5	16.8	4.8	2.3	4.9
State Avg. %	11.6	54.6	6.4	15.7	4.9	2.0	4.7

Gender of Family Member



**Table 6
Gender**

State	% Male	% Female
CA - RCOC	62.8	37.2
CT	56.0	44.0
GA	57.9	42.1
ME	55.3	44.7
NC	58.2	41.8
PA	55.6	44.4
SC	50.8	49.2
SD	52.5	47.5
WA	54.7	45.3
WY	53.0	47.0
Total n	2,700	2,187
Total %	55.2	44.8
State Avg. %	55.7	44.3

Age of Family Member

**Table 7
Age of Family Member**

State	Average Age	Range
CA - RCOC	43.3	18-89
CT	45.0	18-93
GA	43.0	18-84
ME	45.5	18-86
NC	45.2	20-84
PA	46.6	18-91
SC	46.8	19-84
SD	43.8	18-85
WA	45.1	19-91
WY	39.1	21-76
Total n	4,891	
Total Avg.	44.8	18-93
State Avg.	44.3	

Race of Family Member

Table 8 Race/Ethnicity of Family Member (%)								
State	White	Black/ African American	Asian	Amer. Indian/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
CA - RCOC	89.9	1.9	3.0	2.2	0.4	2.2	0.7	3.0
CT	91.1	4.3	0.0	1.6	0.0	1.2	0.8	5.1
GA	73.4	25.4	0.6	1.4	0.0	0.8	0.2	1.7
ME	97.8	0.2	0.2	1.0	0.0	0.8	0.2	0.2
NC	82.5	16.0	0.0	1.4	0.0	0.5	0.5	0.5
PA	96.4	1.9	0.4	0.8	0.2	0.8	0.2	0.4
SC	73.2	25.3	0.3	1.5	0.0	0.3	0.0	0.0
SD	92.8	0.1	0.2	7.2	0.1	0.9	0.0	0.3
WA	91.8	2.8	1.6	2.2	0.2	0.8	0.3	1.6
WY	86.6	0.9	0.4	3.0	0.0	5.2	0.0	3.4
Total n	4,440	308	30	123	5	53	11	57
Total %	89.7	6.2	0.6	2.5	0.1	1.1	0.2	1.2
State Avg. %	87.6	7.9	0.7	2.2	0.1	1.4	0.3	1.6

Level of Mental Retardation of Family Member

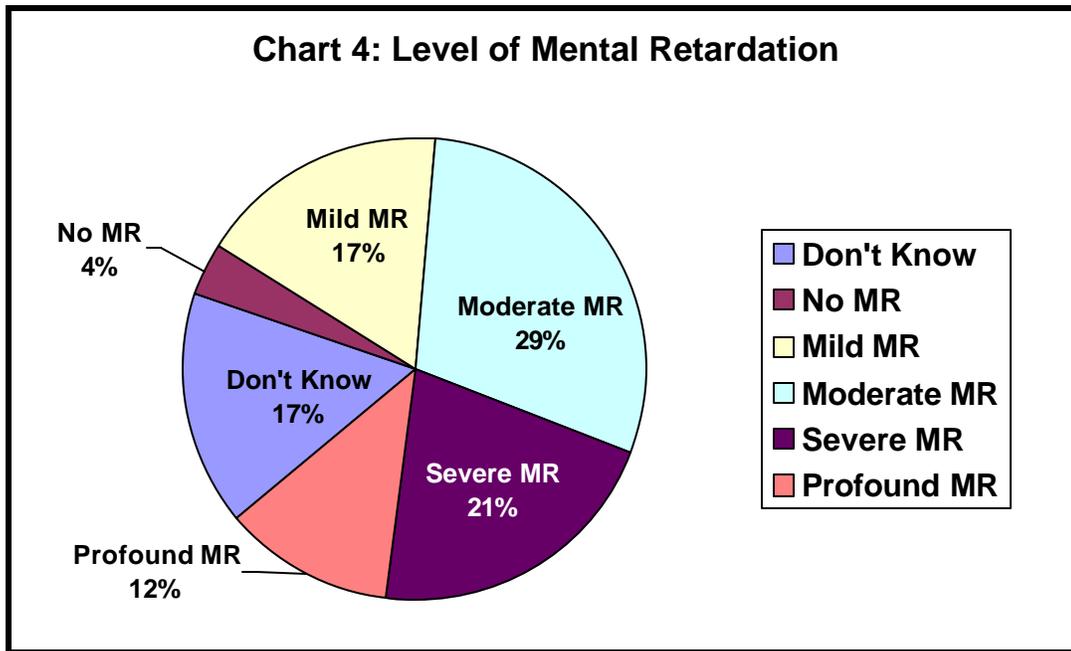


Table 9 Level of Mental Retardation of Family Member						
State	No MR Diagnosis	Mild MR	Moderate MR	Severe MR	Profound MR	Don't Know
CA - RCOC	3.4	22.6	32.1	22.3	8.7	10.9
CT	2.4	17.6	28.0	20.0	13.6	18.4
GA	3.6	17.0	28.7	21.6	11.3	17.8
ME	2.1	12.6	30.9	23.6	17.0	13.8
NC	6.9	18.6	24.5	20.1	9.8	20.1
PA	1.0	14.7	26.1	22.0	16.6	19.6
SC	5.0	20.4	29.2	20.4	9.1	15.7
SD	3.9	19.7	27.6	17.7	9.5	21.5
WA	5.2	12.0	33.1	21.5	14.2	14.0
WY	2.5	18.2	34.3	21.2	10.2	13.6
Total n	155	800	1,395	1,011	619	840
Total %	3.2	16.6	28.9	21.0	12.8	17.4
State Avg. %	3.6	17.3	29.5	21.0	12.0	16.5

Other Disabilities of Family Member

Table 10A Other Disabilities of Family Member						
State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
CA - RCOG	16.5	17.2	23.6	14.2	28.8	0.7
CT	20.1	7.7	18.8	8.5	29.1	1.3
GA	22.9	12.7	15.3	12.7	27.7	0.7
ME	22.0	13.2	17.8	9.4	31.0	0.2
NC	26.3	11.6	12.6	12.6	26.8	2.0
PA	23.6	8.3	17.7	10.3	31.5	1.3
SC	25.7	7.7	9.3	7.1	25.4	1.2
SD	19.1	8.1	15.1	9.9	29.8	0.6
WA	21.9	15.1	17.3	10.6	30.0	0.9
WY	23.5	5.7	17.8	12.6	35.7	1.3
Total n	1,043	496	784	499	1,415	45
Total %	22.0	10.5	16.6	10.5	29.9	1.0
State Avg. %	22.2	10.7	16.5	10.8	29.6	1.0

Table 10B Other Disabilities of Family Member						
State	Vision/ Hearing Impairment	Physical Disability	Communi- cation Disorder	Alzheimer's Disease	Down Syndrome	Other Disability
CA - RCOG	20.2	27.0	17.2	0.4	10.9	16.9
CT	27.8	25.6	21.4	2.6	14.5	12.8
GA	21.0	25.5	21.4	0.7	14.6	13.1
ME	22.9	33.8	26.8	1.5	12.8	15.3
NC	21.2	19.7	16.2	1.5	14.1	12.1
PA	22.1	27.9	20.4	1.3	12.4	15.9
SC	21.7	19.2	14.9	1.9	11.2	12.1
SD	22.0	25.1	19.8	0.7	15.7	16.3
WA	24.1	34.2	27.4	1.7	11.0	17.1
WY	22.2	30.9	21.3	0.4	13.5	17.8
Total n	1,060	1,305	1,005	58	621	727
Total %	22.4	27.6	21.2	1.2	13.1	15.4
State Avg. %	22.5	26.9	20.7	1.3	13.1	14.9

Characteristics of Respondents

This section provides information about survey respondents. Respondents are the individuals who completed the survey forms, not the individual with disabilities living outside of the household.

- Across states, most respondents (55%) fell between the ages of 55 and 74. One-fourth (25%) of respondents were 35 to 54, and one-fifth were 75 years old or over (18%).
- Three-fifths of respondents were parents of adult children with disabilities (60%). Twenty-four percent (24%) were siblings, less than 1% were spouses, and the remaining 15% had other relationships to the individual.
- On average, over half (60%) of respondents indicated they saw their family member more than twelve times per year (e.g., once a month or more). Others visited with their family members less frequently: 15% saw their family member 7 to 12 times per year, 12% visited their family member four to six times per year, 10% saw their family member one to three times per year, and the remaining 4% less than once per year.
- On average, 71% of respondents indicated that they were their family member’s legal guardian or conservator. In Maine and Wyoming, nearly all respondents served as their family member’s guardian, while in Georgia, Pennsylvania and South Carolina, fewer than half of respondents held this role.

Age of Respondent

Table 11 Age of Respondent				
State	Under 35	35-54	55-74	75 or Older
CA - RCOG	1.1	15.9	57.6	25.4
CT	1.5	21.0	48.5	29.0
GA	2.3	23.5	58.3	15.9
ME	1.0	24.9	57.2	16.9
NC	2.3	25.9	54.6	17.1
PA	1.1	25.1	54.3	19.4
SC	3.6	29.6	52.1	14.8
SD	3.2	26.4	53.7	16.8
WA	1.8	22.7	54.5	21.0
WY	2.6	31.6	56.8	9.0
Total n	99	1,231	2,720	915
Total %	2.0	24.8	54.8	18.4
State Avg. %	2.1	24.7	54.8	18.5

Relationship of Respondent to Individual with Disabilities

Table 12 Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
CA - RCOC	78.5	17.7	0.0	3.8
CT	68.3	18.9	0.0	12.9
GA	57.5	21.9	0.6	20.0
ME	59.9	26.2	0.0	13.9
NC	56.0	24.2	0.0	19.8
PA	56.0	36.1	0.3	7.7
SC	41.9	29.6	0.6	27.8
SD	59.9	25.5	0.0	14.6
WA	64.4	21.0	0.3	14.3
WY	60.9	19.1	0.0	20.0
Total n	2,895	1,283	10	688
Total %	59.4	26.3	0.2	14.1
State Avg. %	60.3	24.0	0.2	15.5

Frequency of Visits between Respondent and Individual with Disabilities

Table 13 Frequency of Visits with Family Member					
State	Less than once/year	1-3 times/year	4-6 times/year	7-12 times/year	More than 12x/year
CA - RCOC	2.3	8.3	9.8	12.8	66.8
CT	4.3	7.9	14.2	14.6	58.9
GA	2.4	8.1	6.5	15.4	67.5
ME	2.6	8.1	12.0	16.9	60.4
NC	2.3	8.7	11.5	17.4	60.1
PA	8.0	13.5	13.4	13.4	51.7
SC	2.7	7.8	11.0	13.1	65.4
SD	4.0	13.7	12.1	14.6	55.6
WA	5.1	13.9	11.2	14.6	55.1
WY	4.6	12.2	15.5	12.6	55.0
Total n	226	560	584	718	2,873
Total %	4.6	11.3	11.8	14.5	57.9
State Avg. %	3.8	10.2	11.7	14.5	59.7

Respondent's Role as Guardian or Conservator

Table 14		
Respondent is Legal Guardian or Conservator		
State	% Yes	% No
CA - RCOC	67.3	32.7
CT	86.8	13.2
GA	38.9	61.1
ME	98.4	1.6
NC	76.2	23.8
PA	47.7	52.3
SC	46.1	53.9
SD	76.2	23.8
WA	76.3	23.7
WY	99.6	0.4
Total n	3,266	1,568
Total %	67.6	32.4
State Avg. %	71.4	28.7

Services and Supports Received

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

Table 15 Services and Supports Received (%)				
State	Residential supports	Day/ Employment supports	Transportation	Other
CA - RCOG	96.2	86.9	85.0	55.0
CT	96.9	90.1	96.9	77.0
GA	89.2	83.0	93.8	54.1
ME	98.6	82.1	96.5	80.1
NC	94.3	77.6	91.0	72.0
PA	96.2	73.1	89.0	74.7
SC	98.8	89.1	97.3	72.6
SD	98.0	89.0	94.3	75.8
WA	94.8	66.5	89.3	69.3
WY	97.8	92.5	95.7	84.1
Total n	4,647	3,795	4,419	3,080
Total Avg. %	96.1	81.1	92.4	72.1
State Avg. %	96.1	83.0	92.9	71.5

National Core Indicators

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

For each question, a Figure and Table is provided.

- ◆ The Figure illustrates the State Average results (i.e., the average percentage across the nine states and one local DD authority that conducted this survey).
- ◆ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state results).
- ◆ In the Tables, a (↑) next to a state name indicates, that its results are **5% or more ABOVE** the state average among respondents who answered “Always or Usually” to each question.
- ◆ In the Tables, a (↑↑) next to a state name indicates, that its results are **10% or more ABOVE** the state average among respondents who answered “Always or Usually” to each question.
- ◆ A (↓) next to a state name indicates that its results are **5% or more BELOW** the state average among respondents who answered “Always or Usually” to each question.
- ◆ A (↓↓) next to a state name indicates that its results are **10% or more BELOW** the state average among respondents who answered “Always or Usually” to each question.
- ◆ In general, when a Table has many arrows (up and down), it indicates that there is considerable variance in results among states. When there are few arrows, responses across states are more uniform.

Following all of the individual question results, an overview of results by topic grouping (e.g., information and planning, choice and control) is offered, providing a crude overview of how states measured up, overall, against the state averages.

Information and Planning

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

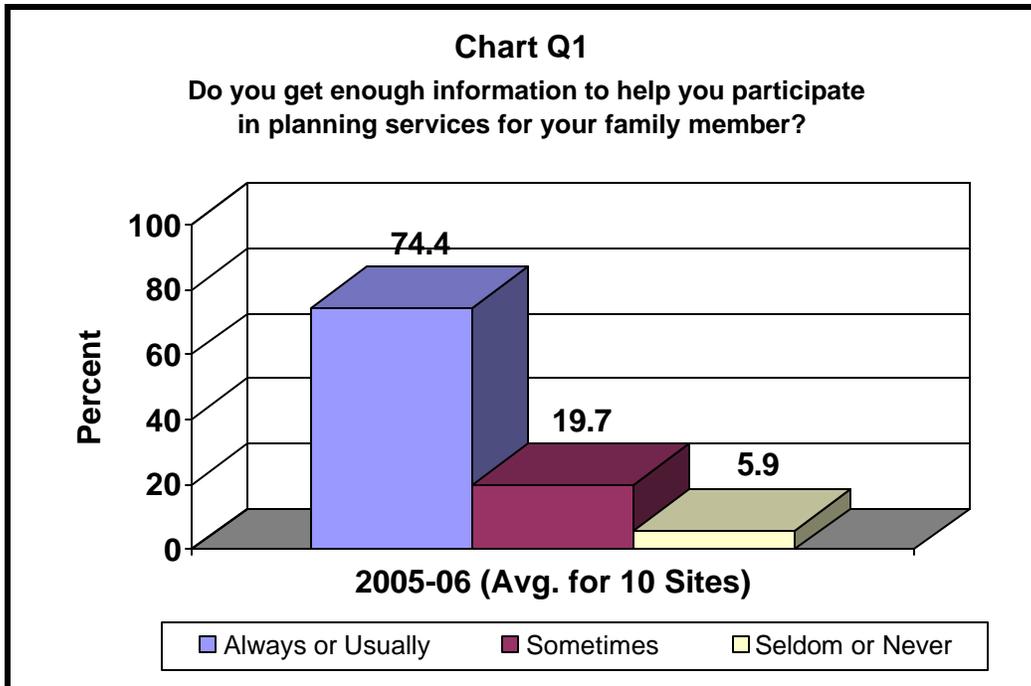


Table Q1
Do you get enough information to help you participate in planning services for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	↓	68.3	24.7	6.9	259
CT		76.1	19.4	4.5	247
GA	↓↓	58.0	28.9	13.1	474
ME	↑↑	87.4	11.6	1.0	484
NC		73.8	17.8	8.4	202
PA		71.6	21.8	6.6	1,024
SC		74.6	16.9	8.5	331
SD	↑	82.3	16.0	1.7	869
WA		71.2	22.2	6.6	573
WY	↑	80.3	18.1	1.7	238
Total %		74.6	19.8	5.7	4,701
State Average %		74.4	19.7	5.9	n = 10

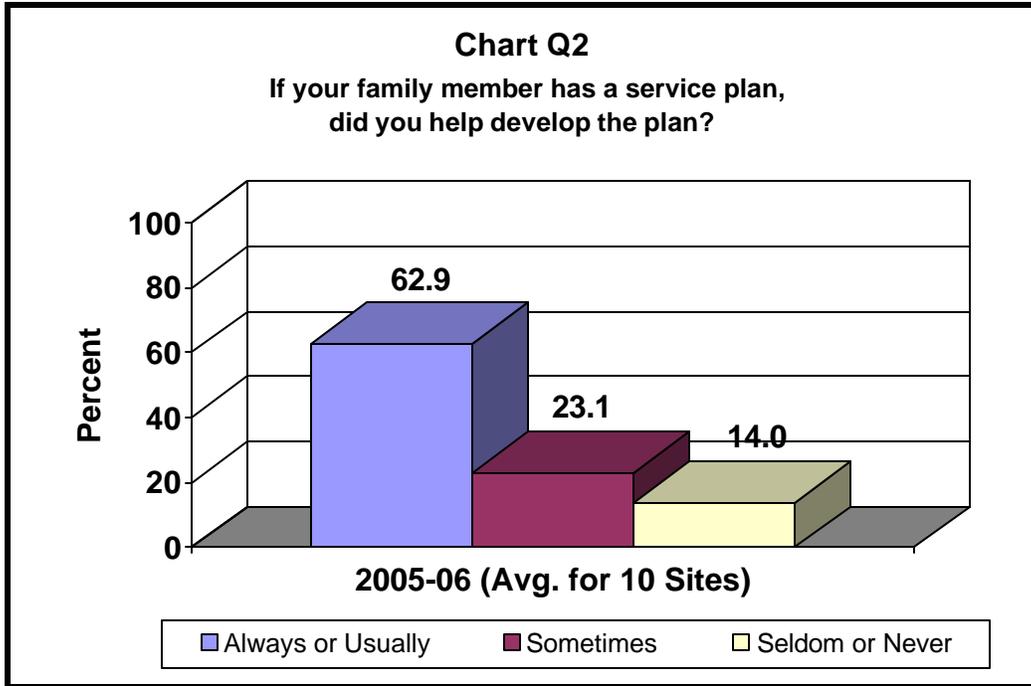


Table Q2
If your family member has a service plan, did you help develop the plan?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOG		58.5	25.6	15.8	234
CT		59.8	28.5	11.7	214
GA	↓↓	51.3	27.8	20.8	413
ME	↑↑	73.5	20.7	5.8	449
NC		65.5	20.9	13.6	177
PA	↓↓	43.2	29.9	26.9	850
SC		62.8	19.1	18.1	282
SD	↑	70.2	21.2	8.6	806
WA		63.5	21.9	14.7	498
WY	↑↑	80.7	14.9	4.4	228
Total %		61.0	23.8	15.2	4,151
State Average %		62.9	23.1	14.0	n = 10

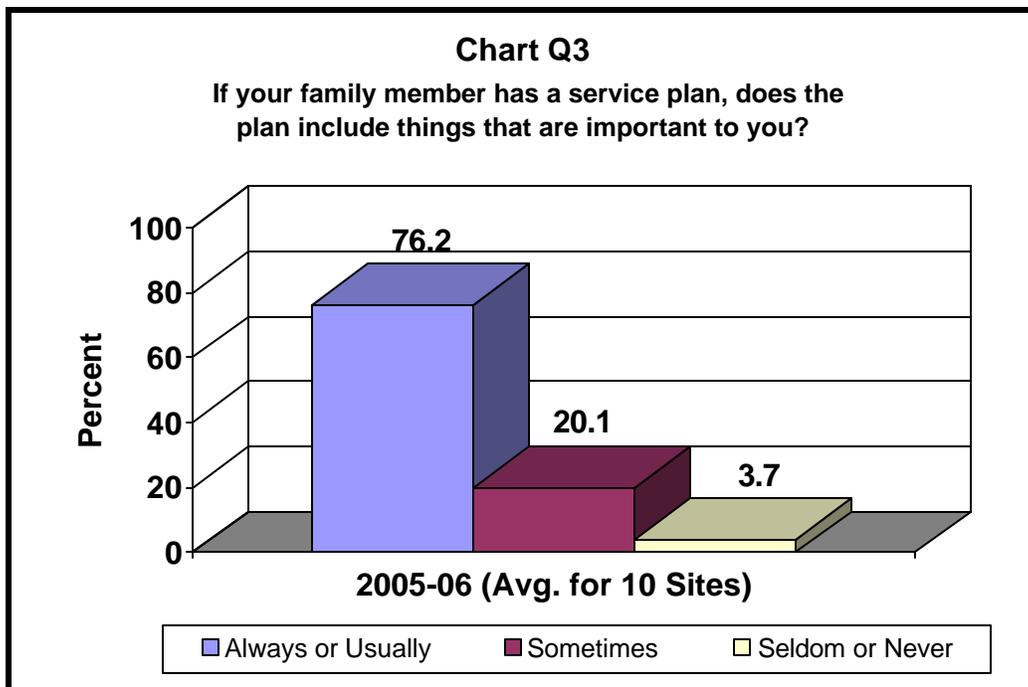


Table Q3
If your family member has a service plan, does the plan include things that are important to you?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC		73.4	23.6	3.0	237
CT		74.9	23.7	1.4	219
GA	↓↓	65.1	27.8	7.0	413
ME	↑↑	86.7	11.9	1.4	487
NC		77.0	18.4	4.6	174
PA	↓	70.8	23.6	5.5	867
SC		74.2	19.2	6.5	291
SD		80.0	18.1	1.8	822
WA		77.2	18.0	4.8	500
WY	↑	82.8	16.3	0.9	233
Total %		76.1	20.1	3.8	4,243
State Average %		76.2	20.1	3.7	n = 10

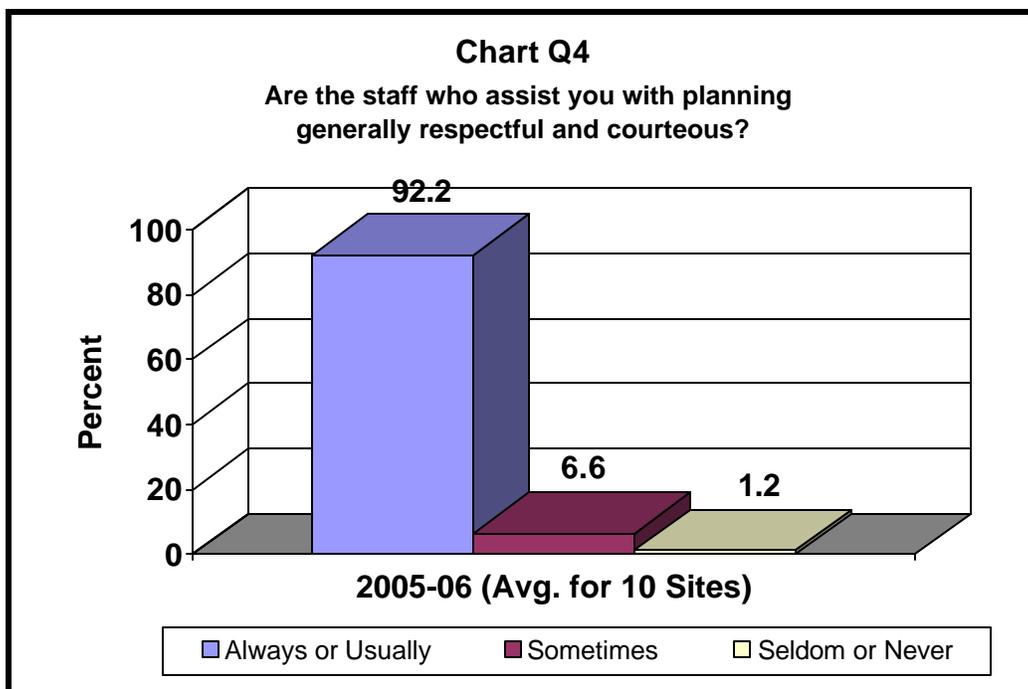


Table Q4
Are the staff who assist you with planning generally respectful and courteous?

State	Always or Usually	Sometimes	Seldom or Never	n
CA - RCOG	93.9	4.6	1.5	263
CT	93.4	6.2	0.4	243
GA	↓ 86.8	11.0	2.2	453
ME	96.1	3.7	0.2	491
NC	92.7	6.8	0.5	192
PA	91.4	6.8	1.8	956
SC	91.5	5.7	2.8	318
SD	93.2	5.9	0.9	865
WA	92.3	6.3	1.4	557
WY	90.2	9.4	0.4	235
Total %	92.1	6.5	1.3	4,573
State Average %	92.2	6.6	1.2	n = 10

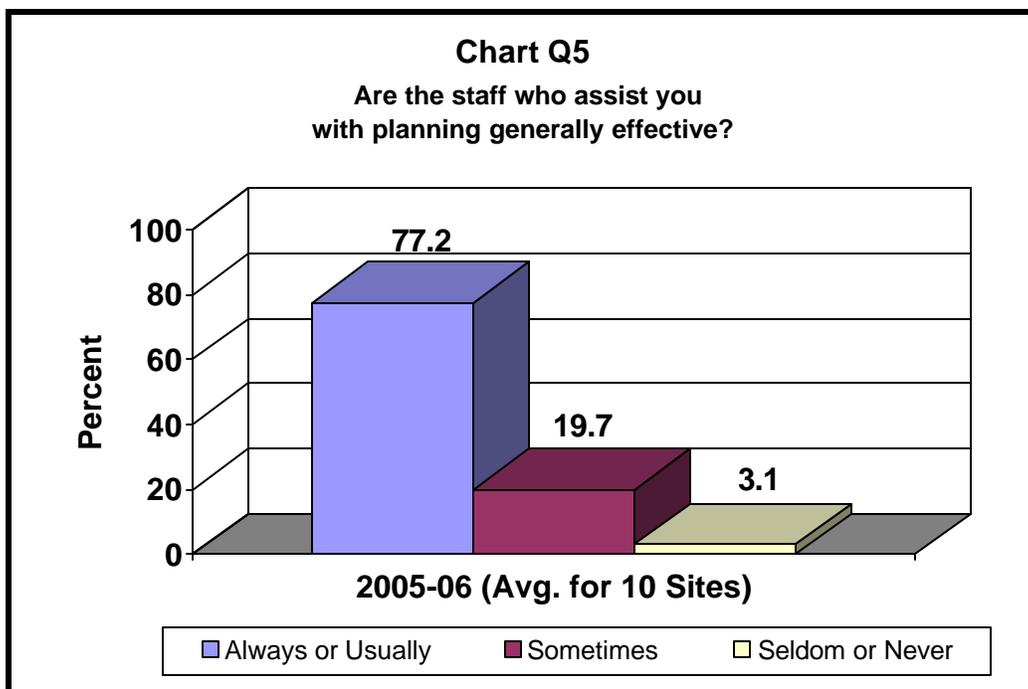


Table Q5
Are the staff who assist you with planning generally effective?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC		74.8	20.9	4.3	254
CT	↑	83.3	13.7	3.0	233
GA	↓	68.1	26.4	5.6	432
ME	↑↑	88.1	11.1	0.8	486
NC		76.6	19.7	3.7	188
PA		75.5	21.2	3.3	937
SC		79.9	16.6	3.5	314
SD		77.0	21.1	1.9	852
WA		73.1	22.9	3.9	536
WY		75.1	23.6	1.3	233
Total %		76.8	20.1	3.0	4,465
State Average %		77.2	19.7	3.1	n = 10

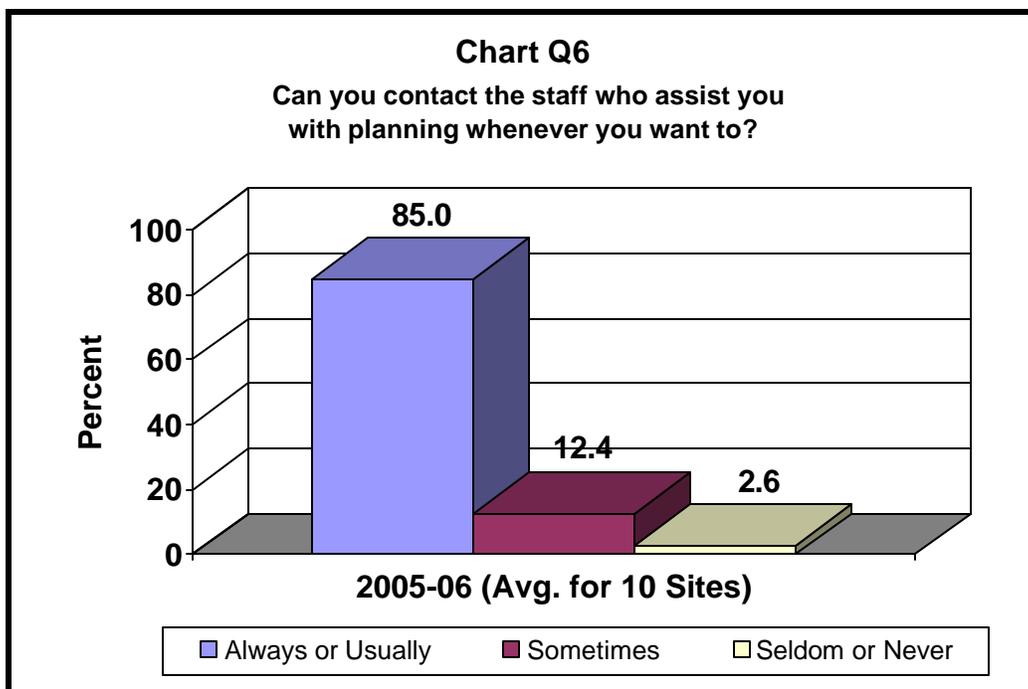


Table Q6
Can you contact the staff who assist you with planning whenever you want to?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	↓	80.0	16.4	3.6	250
CT		89.4	8.9	1.7	236
GA	↓	77.2	17.9	5.0	464
ME	↑	93.3	5.7	1.0	489
NC		82.7	14.2	3.0	197
PA		86.8	10.8	2.4	953
SC		85.4	11.1	3.5	316
SD	↑	91.1	7.9	1.0	865
WA	↓	79.5	16.4	4.1	556
WY		84.2	15.0	0.9	234
Total %		85.8	11.7	2.5	4,560
State Average %		85.0	12.4	2.6	n = 10

Access to and Delivery of Services and Supports

- On average, most respondents (81%) stated that their service coordinator helped them get needed supports when they asked. Sixteen percent said this only happened some of the time, and 3% indicated that their service coordinator was seldom or never helpful in getting their family member the assistance needed.
- Eighty-one percent (81%) of respondents, on average, indicated that their family member always or usually gets the services and supports they need.
- Among those respondents whose family member with disabilities did not speak English, or who used different ways to communicate, the majority (79%) indicated there were enough staff to communicate with their family member. Seventeen percent stated that these staff were available some of the time, and another 5% did not have staff available to communicate with their family members in their preferred means of communication/ languages.
- On average, 88% of respondents indicated that their family member had access to the special equipment or accommodations that s/he needs. Twelve percent stated that equipment was only seldom or sometimes available.
- Nearly four-fifths of respondents (79%) indicated that frequent changes in support staff were a problem for their family at least some of the time. The remaining 21% stated that this was not an issue for them.
- Among those receiving residential supports, nearly all (88%) felt their family member's residential setting was a safe and healthy environment, however 12% felt their family member's residence was only sometimes or seldom safe.
- Among those receiving day/employment supports, nearly all (89%) felt their family member's day/employment setting was a safe and healthy environment. The remaining 11% felt their family member's day setting was sometimes or seldom safe.

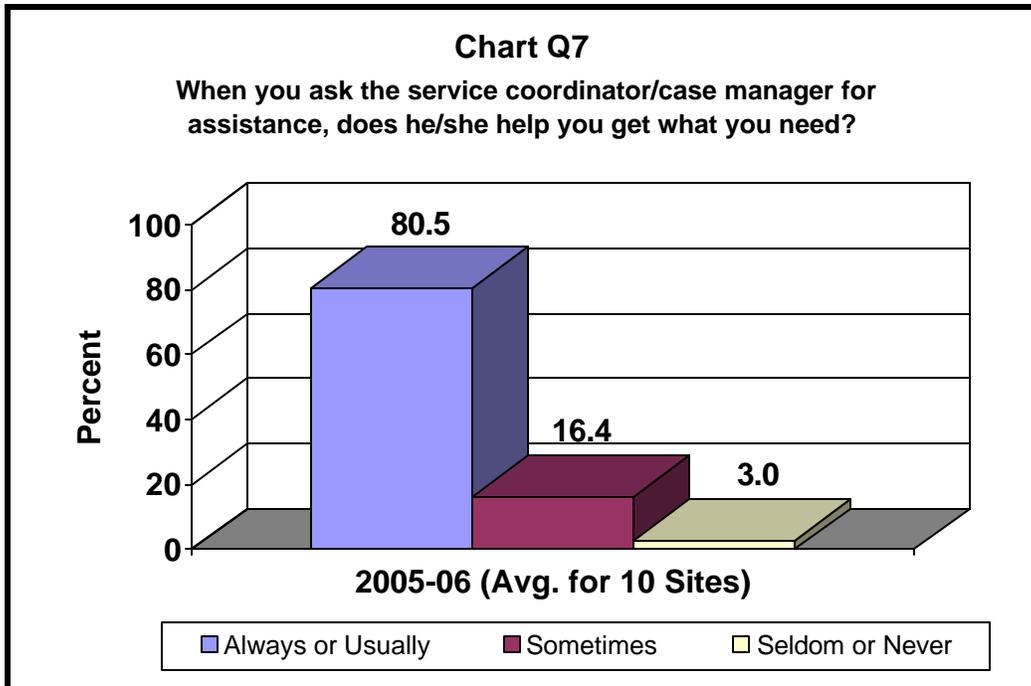


Table Q7
When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	↓	73.6	22.9	3.5	231
CT		84.5	14.6	0.9	226
GA	↓	70.6	20.5	8.9	463
ME		84.8	13.3	1.9	427
NC		77.4	17.4	5.1	195
PA		82.2	15.7	2.1	994
SC		81.6	16.0	2.4	332
SD	↑	87.9	11.2	0.9	866
WA		77.0	18.7	4.3	530
WY	↑	85.5	14.0	0.4	235
Total %		81.3	15.8	2.9	4,499
State Average %		80.5	16.4	3.0	n = 10

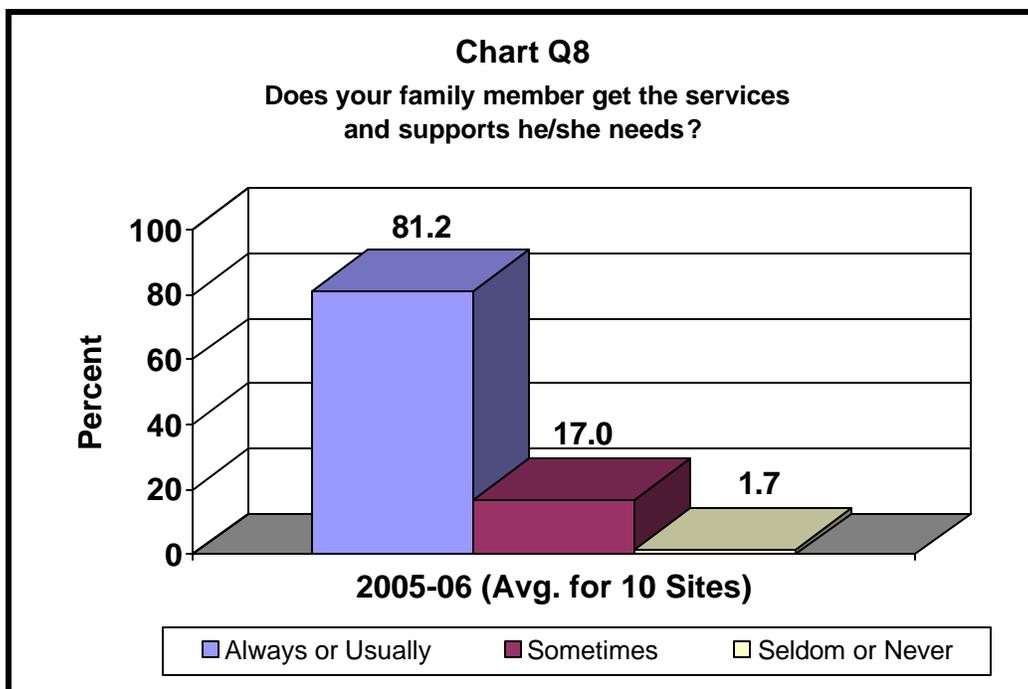


Table Q8
Does your family member get the services and supports he/she needs?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	↓	75.2	23.2	1.6	250
CT		85.6	13.2	1.2	250
GA	↓	74.1	22.8	3.1	483
ME	↑	86.6	12.4	1.0	493
NC		78.8	18.3	2.9	208
PA		83.5	15.0	1.5	1,078
SC		83.2	14.0	2.7	328
SD		84.3	15.0	0.7	869
WA		77.2	20.9	1.9	578
WY		83.9	15.3	0.8	236
Total %		81.7	16.7	1.6	4,773
State Average %		81.2	17.0	1.7	n = 10

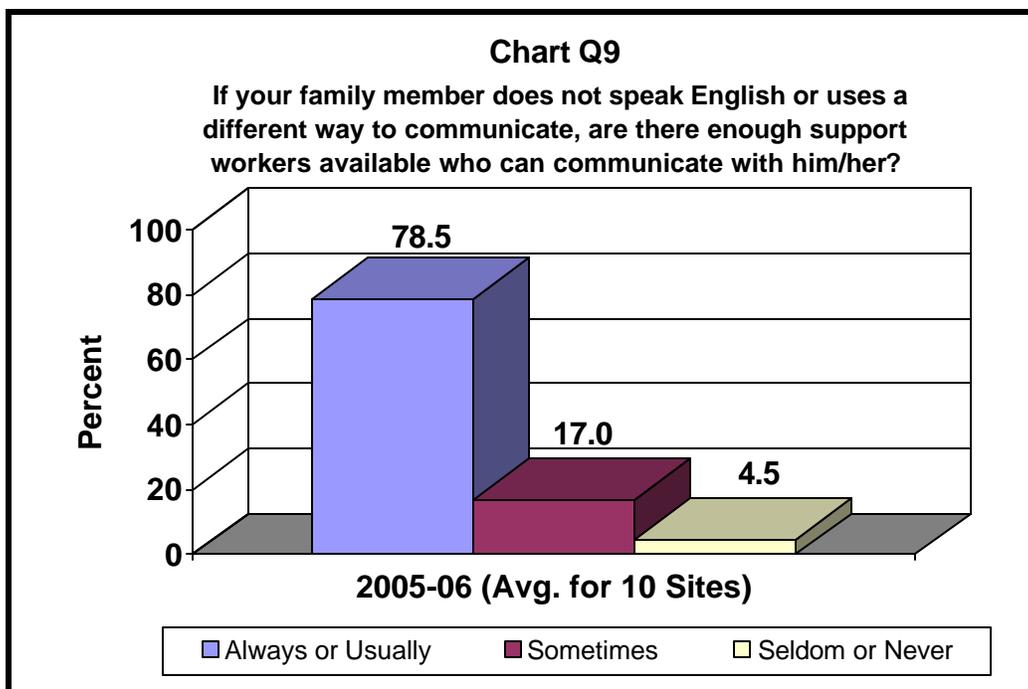


Table Q9
If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOG	↓	71.8	19.2	9.0	78
CT	↑	84.6	12.1	3.3	91
GA	↓↓	62.6	23.9	13.5	163
ME	↑	85.1	12.7	2.3	221
NC		80.6	16.1	3.2	62
PA		80.7	16.1	3.3	398
SC	↑↑	89.6	8.7	1.7	115
SD		83.4	15.5	1.1	349
WA		74.7	21.4	3.8	182
WY	↓	71.8	24.4	3.8	78
Total %		79.4	16.6	3.9	1,737
State Average %		78.5	17.0	4.5	n = 10

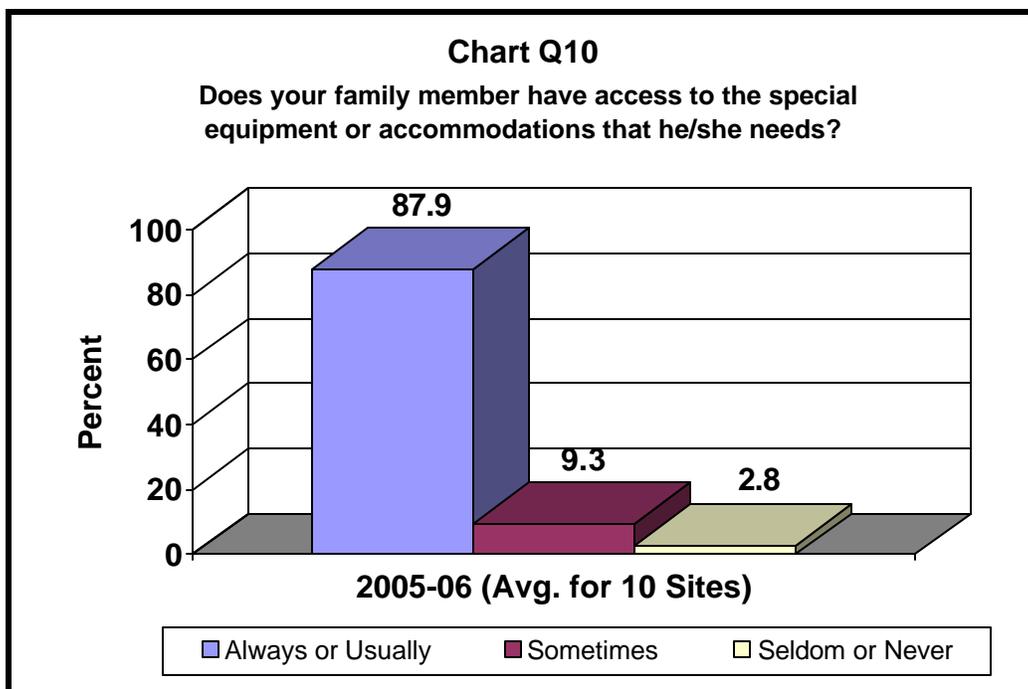


Table Q10
Does your family member have access to the special equipment or accommodations that he/she needs?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOG	↓	78.1	17.1	4.8	105
CT		92.2	7.1	0.7	141
GA		83.6	10.4	6.0	250
ME		90.6	7.5	2.0	307
NC		86.6	8.2	5.2	97
PA		90.3	7.0	2.7	641
SC		91.3	6.6	2.2	183
SD		92.0	7.1	0.9	538
WA		86.6	11.3	2.1	337
WY		88.0	10.6	1.4	142
Total %		89.1	8.5	2.4	2,741
State Average %		87.9	9.3	2.8	n = 10

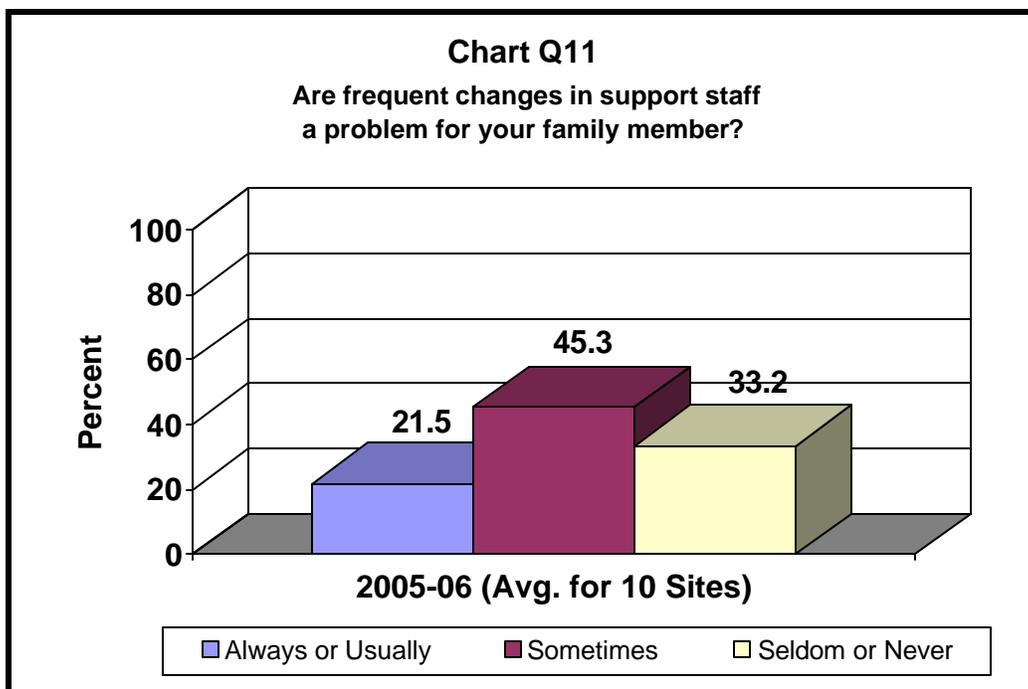


Table Q11
Are frequent changes in support staff a problem for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	↑	14.7	44.6	40.7	231
CT		21.3	47.4	31.3	211
GA		19.0	45.4	35.6	416
ME		22.6	44.9	32.5	421
NC		19.8	39.0	41.3	172
PA		25.9	41.9	32.1	906
SC		25.7	43.8	30.4	276
SD		19.4	49.5	31.1	769
WA		19.0	40.0	40.9	457
WY	↓	27.5	56.4	16.2	204
Total %		21.8	45.0	33.2	4,063
State Average %		21.5	45.3	33.2	n = 10

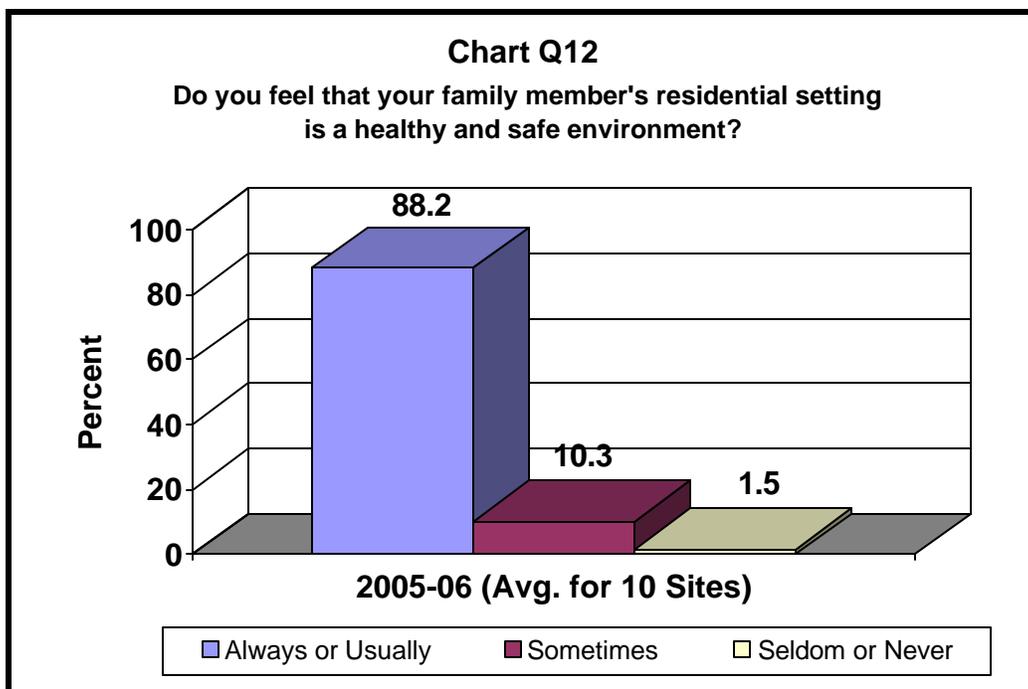


Table Q12
Do you feel that your family member's residential setting is a healthy and safe environment?

State	Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	89.4	9.9	0.8	263
CT	88.1	9.9	2.0	252
GA	85.6	12.3	2.1	486
ME	92.3	6.9	0.8	492
NC	86.1	10.5	3.3	209
PA	89.3	9.2	1.5	1,117
SC	88.4	10.1	1.5	337
SD	88.5	11.1	0.5	877
WA	89.2	8.8	2.0	604
WY	84.6	14.5	0.9	234
Total %	88.6	10.0	1.4	4,871
State Average %	88.2	10.3	1.5	n = 10

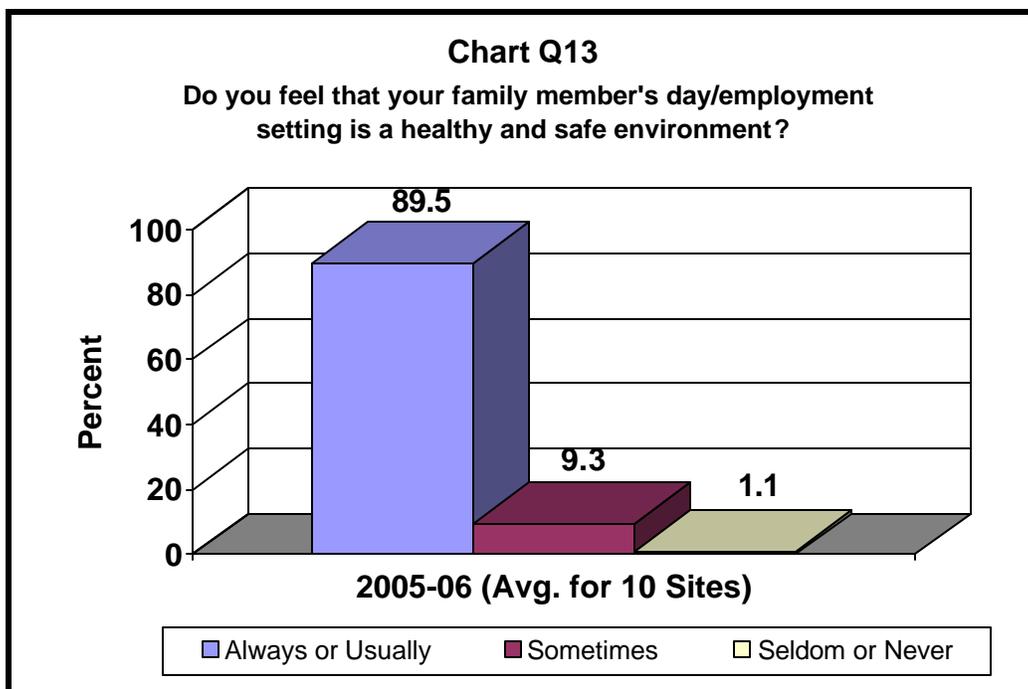


Table Q13
Do you feel that your family member's day/employment setting is a healthy and safe environment?

State	Always or Usually	Sometimes	0.4	n
CA - RCOC	88.5	11.0	0.4	227
CT	90.5	8.6	0.9	222
GA	85.2	13.6	1.2	419
ME ↑	94.6	5.4	0.0	410
NC	89.4	8.2	2.4	170
PA	90.3	9.1	0.6	846
SC	85.4	11.9	2.6	302
SD	92.3	7.4	0.2	808
WA	90.7	8.1	1.3	396
WY	88.5	9.7	1.8	226
Total %	90.1	9.0	0.9	4,026
State Average %	89.5	9.3	1.1	n = 10

Choices and Control

- Among families where the individual with disabilities received residential services, 78% of respondents stated that the agency involved them in important decisions. Another 16% stated that this happens some of the time, and 6% said the agency seldom or never involved them in important decisions.
- Among families where the individual with disabilities received day or employment services, 60% of respondents stated that the agency involves them in important decisions. Another 25% stated that this happens sometimes, and 15% said the agency seldom or never involves them in important decisions.
- On average across states, almost three-fourths of respondents (71%) seldom or never chose the support staff who work with their family members.
- Across states, only 9% of respondents said that they had control or input over the hiring and management of their support staff, with an additional 9% indicated they had this type of control sometimes. Eighty-two percent, however, had little or no input or control over the hiring or management of their family's support staff.
- While only 18% of respondents said they had any amount of control over the hiring or management of their support workers, here 62% of respondents indicate that they want some control over the hiring and management for their support staff.
- Twenty-four percent (24%) of respondents, on average, knew how much money was spent on behalf of their family member. Two-thirds (65%), however, had no idea. In Wyoming, a far greater percentage of families (70%) knew the amount of money spent.
- On average across states, less than half of the families surveyed (44%) had at least some decision-making authority over how the money allocated to their family member with disabilities by the MR/DD agency was spent. The majority (56%), however, did not.

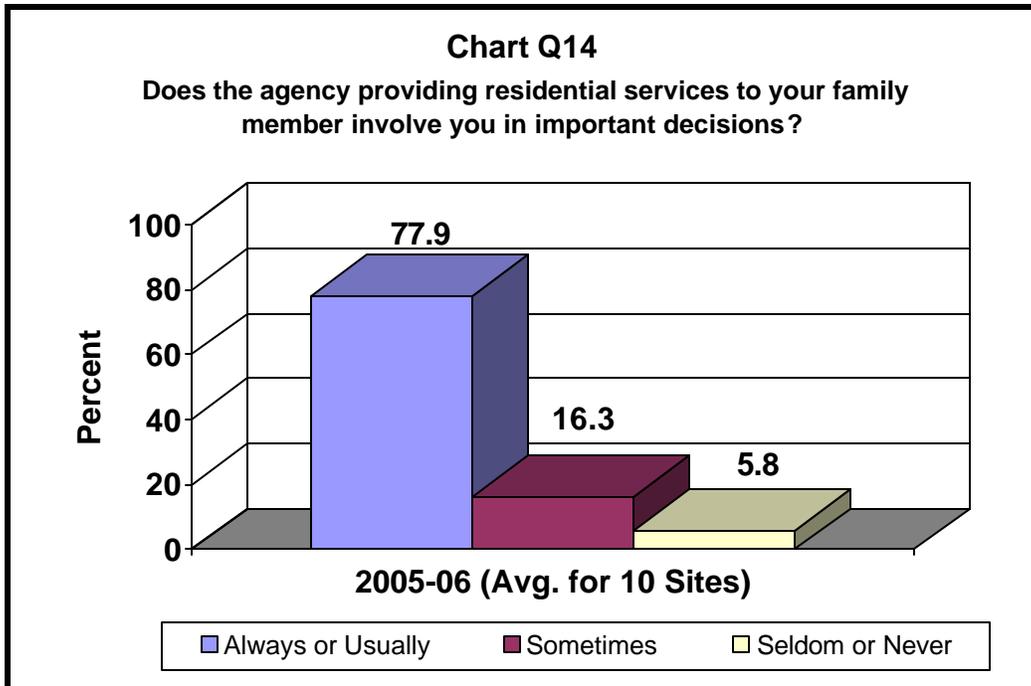


Table Q14
Does the agency providing residential services to your family member involve you in important decisions?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	↓	71.9	22.1	5.9	253
CT		79.3	16.7	4.0	251
GA	↓	68.4	18.5	13.2	471
ME	↑↑↑	93.0	5.6	1.4	486
NC		76.7	18.3	5.0	202
PA	↓	70.7	21.3	8.1	1,043
SC		76.1	16.9	6.9	331
SD		80.1	16.9	3.0	874
WA		79.1	13.1	7.8	574
WY	↑	83.2	13.8	3.0	232
Total %		77.3	16.6	6.1	4,717
State Average %		77.9	16.3	5.8	n = 10

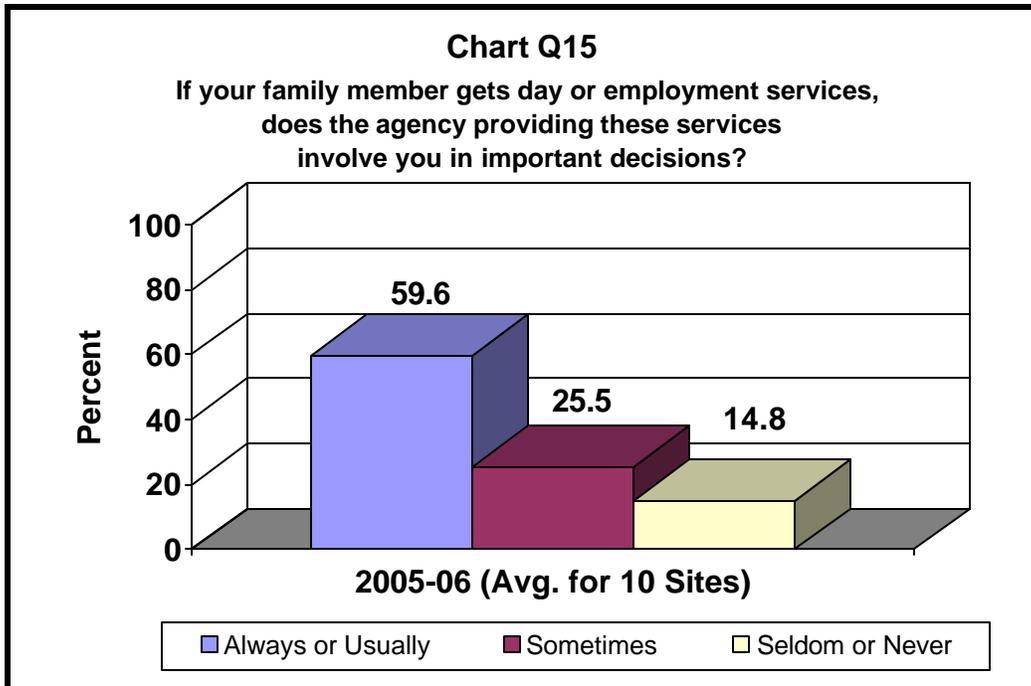


Table Q15
If your family member gets day or employment services, does the agency providing these services involve you in important decisions?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	↓	50.5	31.0	18.5	200
CT		57.3	27.1	15.6	218
GA	↓↓	49.0	29.1	21.9	398
ME	↑↑	78.6	16.0	5.4	387
NC	↓	51.9	28.5	19.6	158
PA	↓	51.1	26.7	22.2	730
SC	↑	64.7	19.6	15.7	286
SD	↑	67.7	24.6	7.7	731
WA		58.7	26.1	15.3	380
WY	↑	66.8	26.7	6.4	202
Total %		60.1	25.1	14.7	3,690
State Average %		59.6	25.5	14.8	n = 10

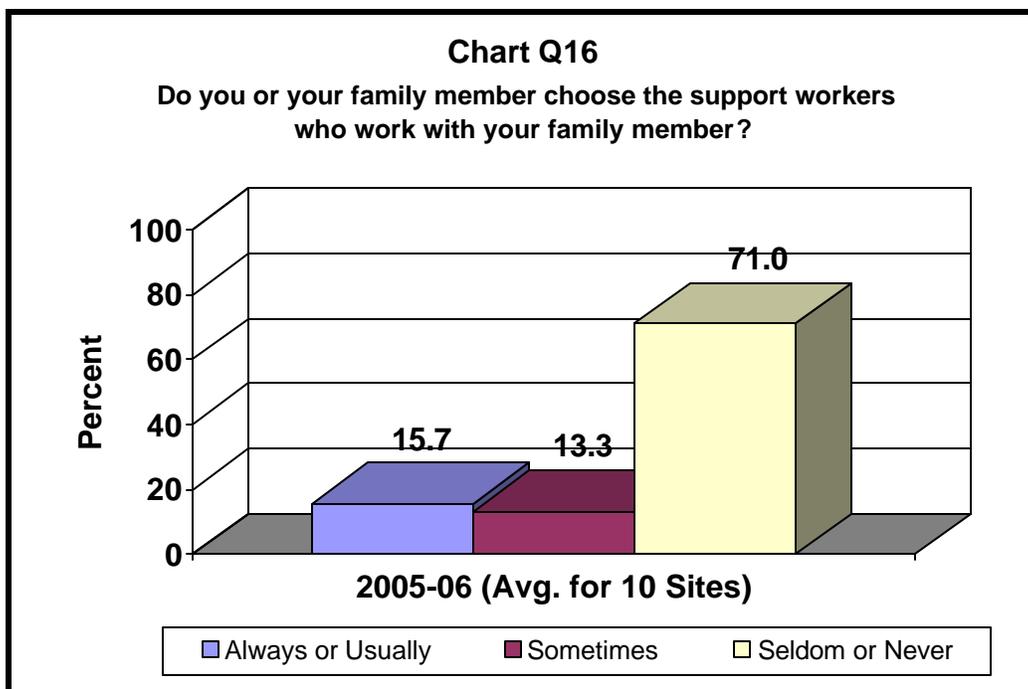


Table Q16
Do you or your family member choose the support workers who work with your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOCC		11.4	9.1	79.5	219
CT	↓	8.9	11.3	79.8	168
GA	↓	9.6	13.2	77.3	418
ME		16.9	18.5	64.6	378
NC	↑	23.4	12.0	64.7	167
PA		11.8	7.7	80.5	794
SC	↑	22.6	13.6	63.8	257
SD		11.8	11.4	76.8	710
WA		18.6	14.6	66.8	370
WY	↑	22.4	21.5	56.2	219
Total %		14.5	12.5	73.0	3,700
State Average %		15.7	13.3	71.0	n = 10

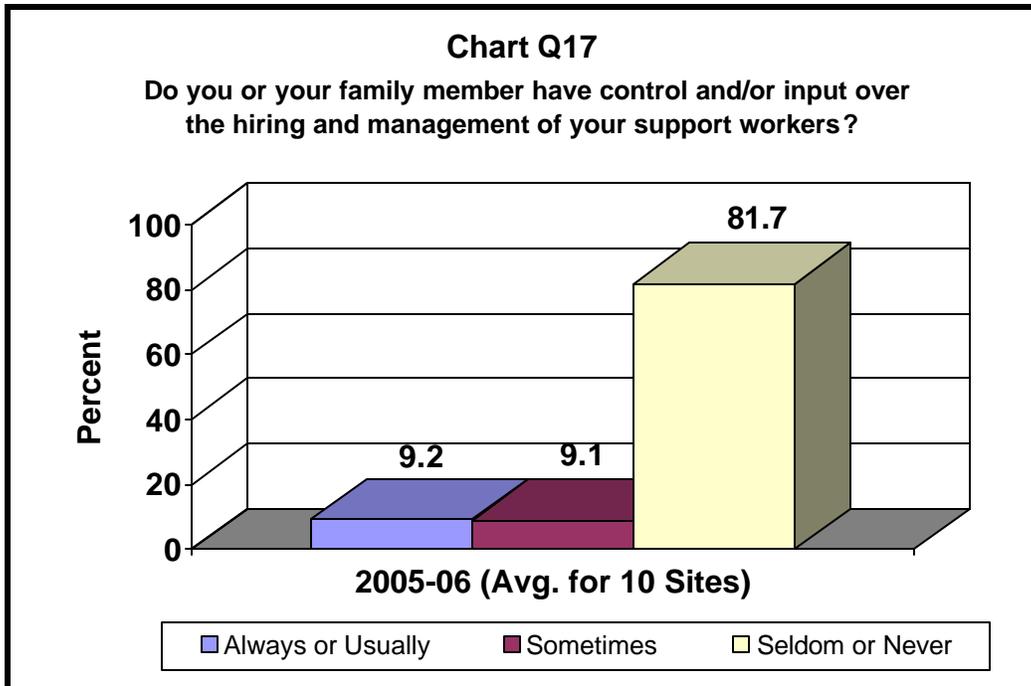


Table Q17
Do you or your family member have control and/or input over the hiring and management of your support workers?

State	Always or Usually	Sometimes	Seldom or Never	n
CA - RCOG	6.5	8.5	85.1	201
CT	6.2	7.5	86.3	161
GA	7.2	7.2	85.7	391
ME	13.0	10.1	76.9	355
NC	12.6	13.8	73.6	159
PA	6.7	5.4	87.9	763
SC	11.8	6.7	81.5	238
SD	5.5	6.9	87.6	695
WA	11.3	10.6	78.1	425
WY	11.4	14.3	74.3	210
Total %	8.5	8.2	83.3	3,598
State Average %	9.2	9.1	81.7	n = 10

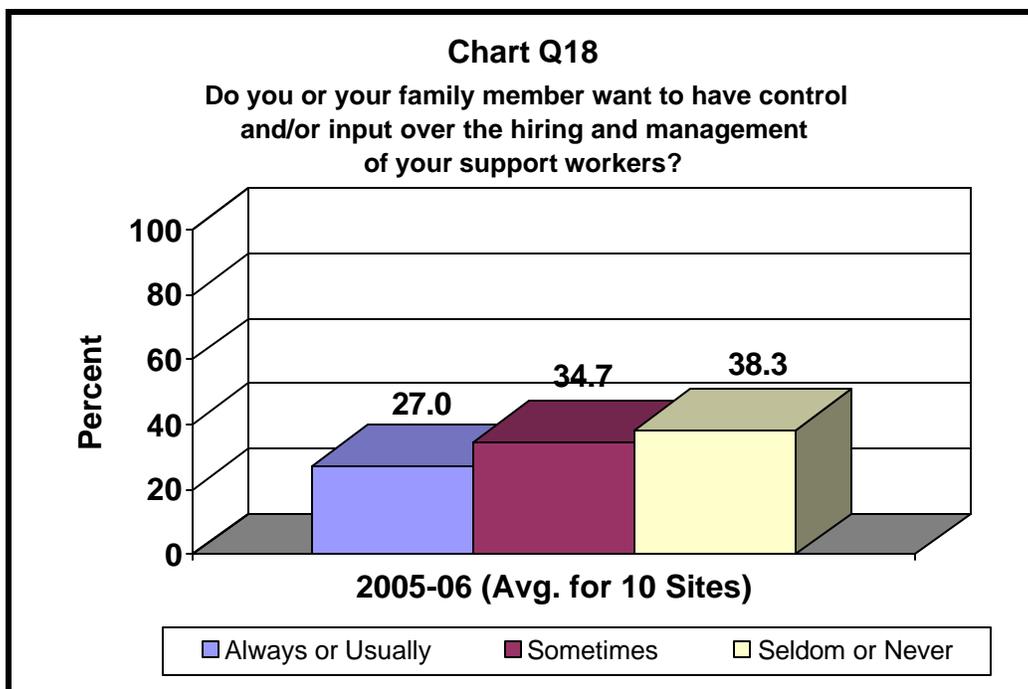


Table Q18
Do you or your family member want to have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC		24.2	35.2	40.7	182
CT	↓	20.4	40.1	39.5	162
GA		31.2	35.1	33.7	356
ME		29.0	33.1	37.9	317
NC	↑	32.4	31.8	35.8	148
PA		24.8	35.8	39.4	662
SC		29.8	34.1	36.1	208
SD	↓↓	16.4	32.5	51.1	609
WA		28.2	29.8	41.9	372
WY	↑	33.3	39.5	27.2	195
Total %		25.7	34.3	40.1	3,211
State Average %		27.0	34.7	38.3	n = 10

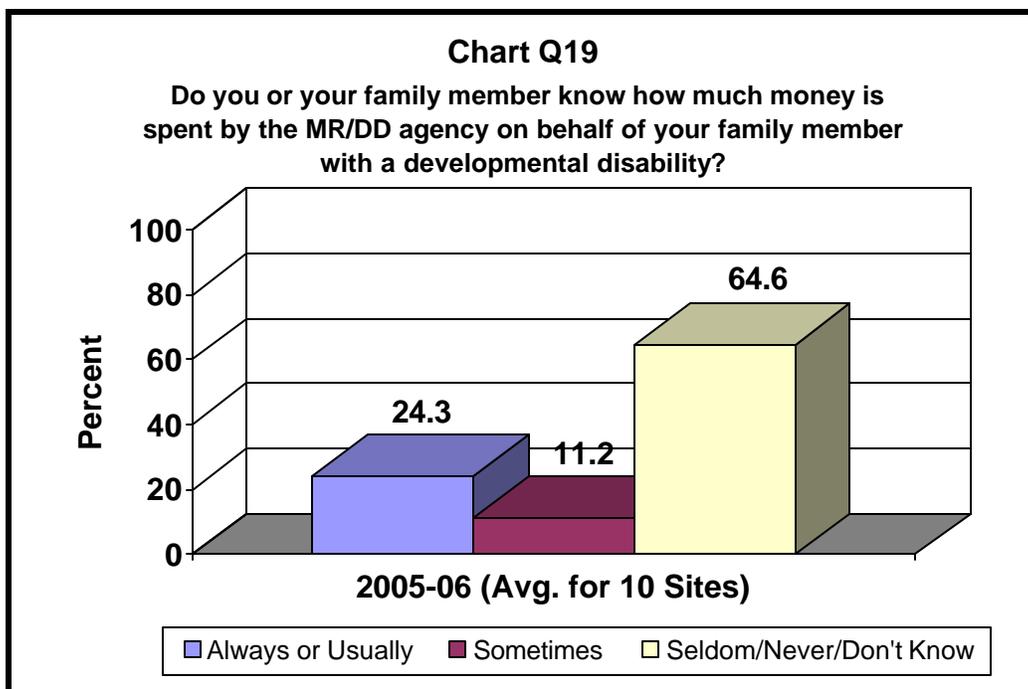


Table Q19
Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
CA - RCOG	↓↓↓	12.8	10.0	77.2	250
CT	↓	17.8	12.0	70.2	225
GA	↓↓↓	12.0	5.5	82.5	474
ME		22.3	11.8	65.9	440
NC	↓	19.0	12.3	68.7	195
PA	↓	16.9	9.9	73.2	1,011
SC		19.9	13.0	67.1	307
SD	↑	30.8	13.2	56.1	842
WA		21.3	10.2	68.5	581
WY	↑↑↑	69.7	13.9	16.5	231
Total %		22.8	10.9	66.3	4,556
State Average %		24.3	11.2	64.6	n = 10

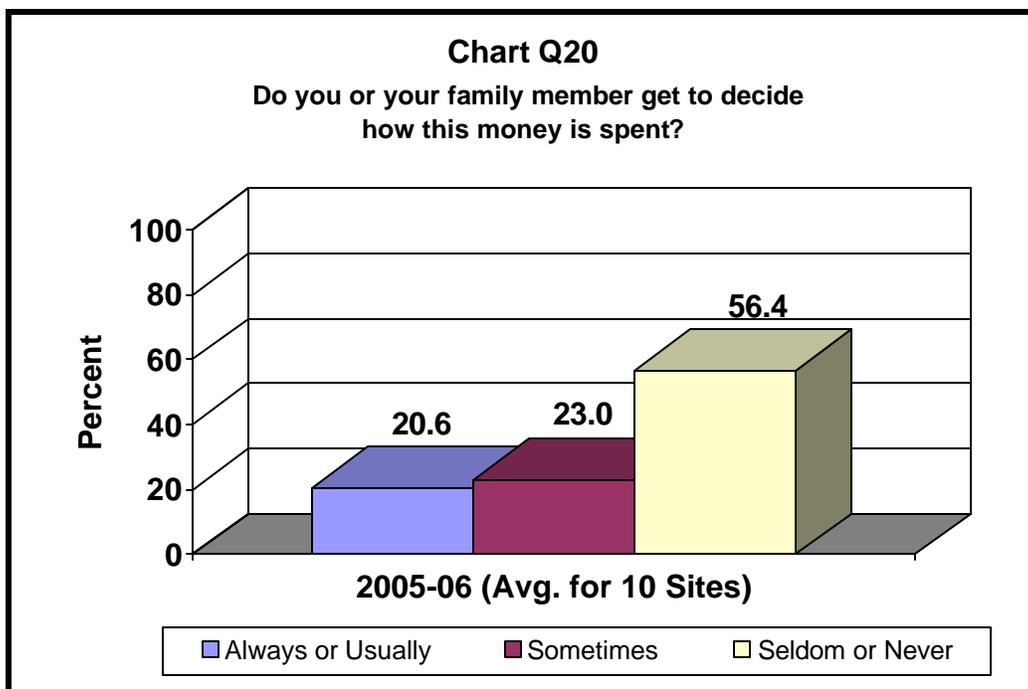


Table Q20
Do you or your family member get to decide how this money is spent?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	↓	15.5	21.9	62.6	187
CT	↓	13.3	27.1	59.7	181
GA	↓↓	9.0	13.8	77.2	378
ME		25.1	26.4	48.5	363
NC		17.5	16.2	66.2	154
PA		18.9	18.5	62.5	761
SC		22.9	20.8	56.3	240
SD		24.5	27.0	48.5	693
WA		19.5	25.4	55.1	410
WY	↑↑	40.0	32.5	27.5	200
Total %		20.6	22.7	56.7	3,567
State Average %		20.6	23.0	56.4	n = 10

Community Connections

- Sixty percent (60%) of respondents remarked that staff were usually able to help them connect with typical supports in their community (e.g., recreation programs, church activities) if they desired to do so. 27% indicated that staff could sometimes help in this way, while 13% stated that staff rarely or never provided this type of assistance.
- Of families interested in using family or friends to provide some of the supports needed, 60% stated that planning or support staff were helpful in making this happen. The remaining 40% indicated that staff were only sometimes or seldom capable of helping families utilize friends, neighbors, etc. as supports.
- About two-thirds (65%) of respondents felt that their family member typically had access to community activities.
- While 65% of families felt their family member had regular access to community activities, only 43% stated that their family member usually participated in these activities, although another 40% indicated that their family member sometimes took part in community events/activities.

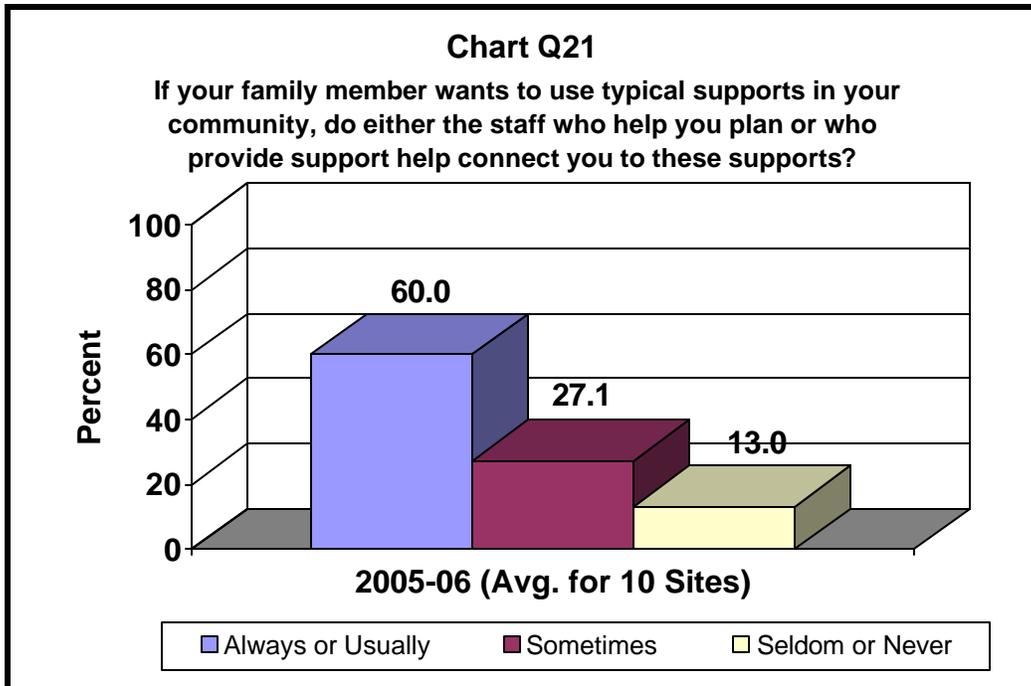


Table Q21

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOG	↓↓↓	36.1	39.1	24.8	133
CT	↑	66.5	25.9	7.6	158
GA	↓↓↓	43.9	29.0	27.2	335
ME	↑↑↑	82.4	14.6	3.0	404
NC		61.1	28.9	10.1	149
PA		62.4	27.8	9.8	686
SC		61.4	24.7	13.9	251
SD		64.9	28.2	6.9	749
WA		59.4	23.5	17.1	438
WY		61.4	29.3	9.3	215
Total %		62.1	26.2	11.7	3,518
State Average %		60.0	27.1	13.0	n = 10

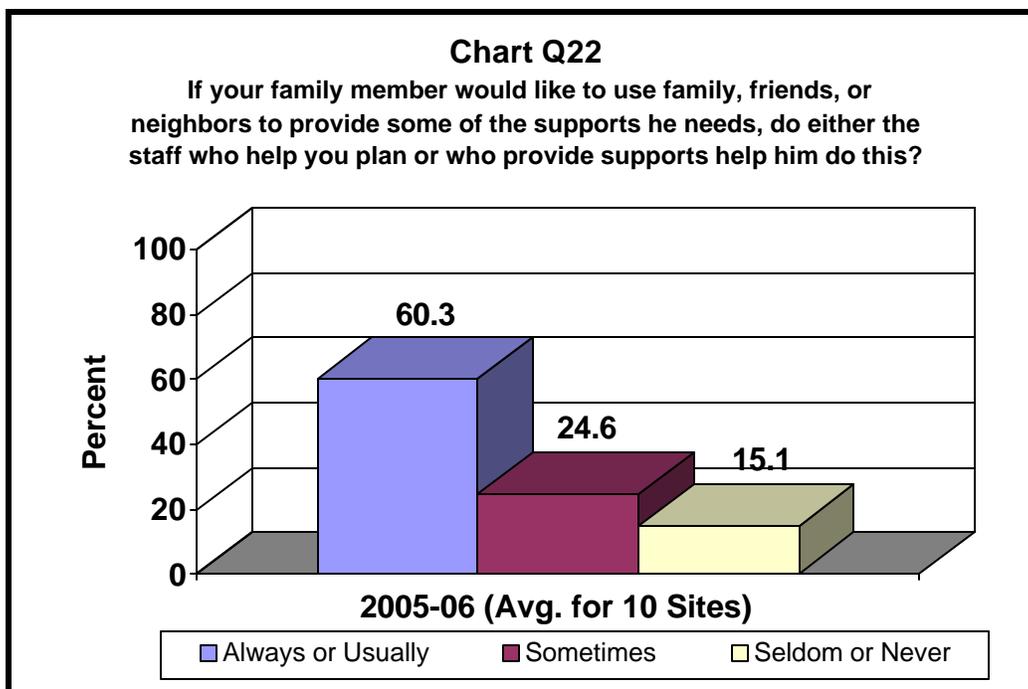


Table Q22
 If your family member would like to use family, friends, or neighbors to provide some of the supports he/she needs, do either the staff who help you plan or who provide support help him/her do this?

State	Always or Usually	Sometimes	Seldom or Never	n
CA - RCOOC ↓↓	38.5	30.3	31.2	109
CT	62.2	24.4	13.4	127
GA ↓↓	44.4	29.6	26.0	311
ME ↑↑	80.7	15.2	4.1	388
NC	60.6	22.7	16.7	132
PA	61.5	26.0	12.5	585
SC ↑	65.7	23.0	11.3	230
SD ↑	65.9	26.1	8.0	677
WA	61.2	21.7	17.1	369
WY	62.6	27.0	10.3	174
Total %	62.7	24.3	13.0	3,102
State Average %	60.3	24.6	15.1	n = 10

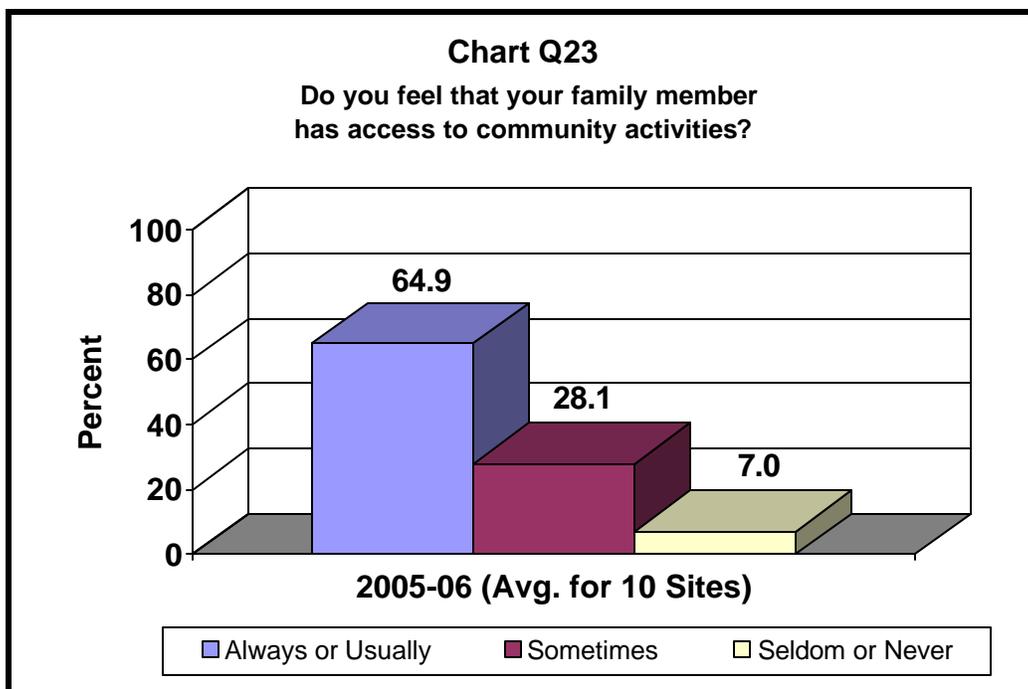


Table Q23
Do you feel that your family member has access to community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOG	↓↓↓	50.7	35.2	14.2	219
CT		68.8	27.0	4.2	215
GA	↓↓↓	53.8	33.6	12.6	452
ME	↑↑↑	80.6	17.9	1.5	469
NC		62.9	30.6	6.5	186
PA		63.8	31.1	5.1	965
SC		64.0	26.4	9.6	292
SD	↑	72.4	24.4	3.2	848
WA		63.7	26.9	9.4	540
WY		68.3	27.8	3.9	230
Total %		66.0	27.6	6.3	4,416
State Average %		64.9	28.1	7.0	n = 10

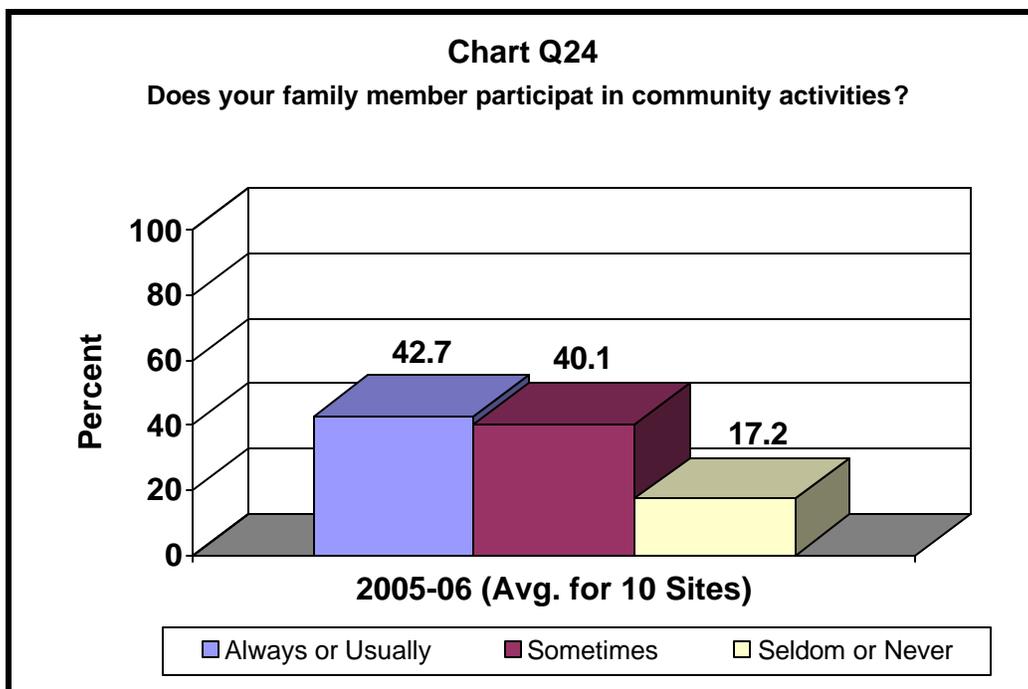


Table Q24
Does your family member participate in community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOG	⇓⇓	31.8	39.6	28.6	217
CT	↑	49.0	39.2	11.9	194
GA		39.6	41.7	18.7	422
ME	↑	51.2	38.2	10.5	408
NC		38.7	44.1	17.2	186
PA		38.5	42.5	19.1	902
SC	↑	47.9	34.5	17.6	284
SD		40.2	46.2	13.6	814
WA		39.2	36.7	24.1	515
WY	↑	51.1	38.5	10.4	221
Total %		41.7	41.0	17.3	4,163
State Average %		42.7	40.1	17.2	n = 10

Outcomes and Satisfaction with Services and Supports

- On average, most respondents (82%) were satisfied with the services and supports their family member received. 15% were only somewhat satisfied, and 2% were seldom or not satisfied.
- On average, 57% of respondents knew about their agency's grievance process, 9% knew something about it, and 35% had no knowledge of the process for lodging a complaint.
- The majority of respondents (66%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 33%, however, were either not satisfied, or satisfied only some of the time with how these matters were resolved.
- The majority of respondents (83%) felt that services and supports had a positive impact on their family's life. 16% stated that services sometime made a positive difference, and the remaining 2% indicated that supports seldom or never had a positive impact.
- Eighty-one percent of respondents felt that their family member was happy. Two percent indicated that their family member was not happy.

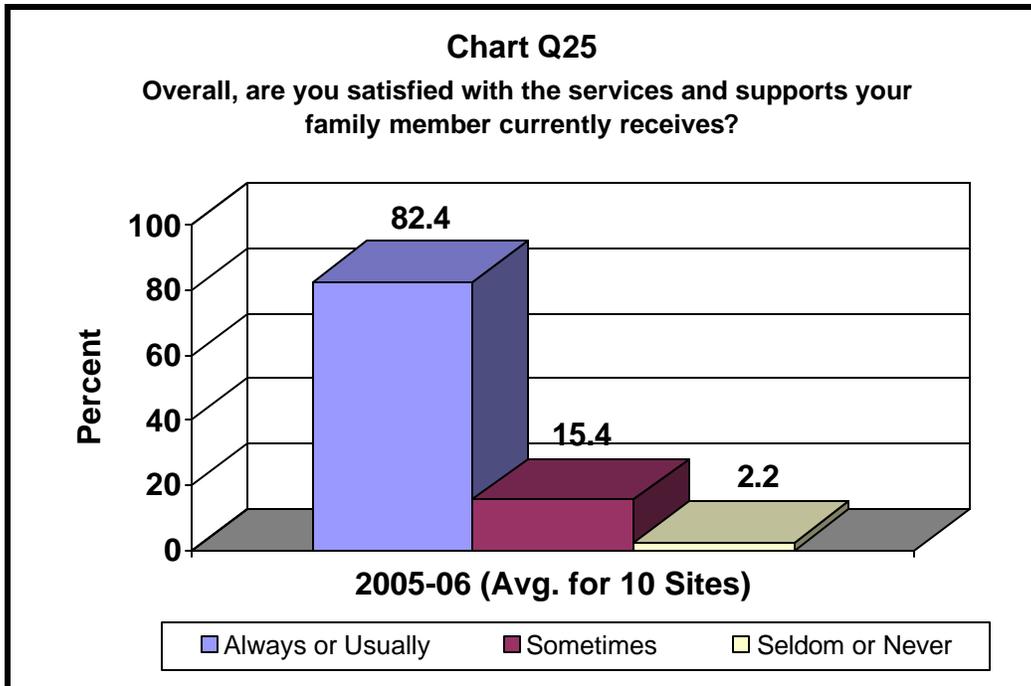


Table Q25
Overall, are you satisfied with the services and supports your family member currently receives?

State	Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	79.5	18.2	2.3	264
CT	86.9	9.7	3.4	237
GA	↓ 72.8	23.2	4.1	492
ME	↑↑ 100.0	0.0	0.0	33
NC	78.2	18.0	3.8	211
PA	81.9	16.4	1.8	1,130
SC	81.8	16.7	1.5	335
SD	84.7	14.1	1.2	887
WA	79.0	18.9	2.2	604
WY	79.5	19.2	1.3	234
Total %	81.0	16.9	2.1	4,427
State Average %	82.4	15.4	2.2	n = 10

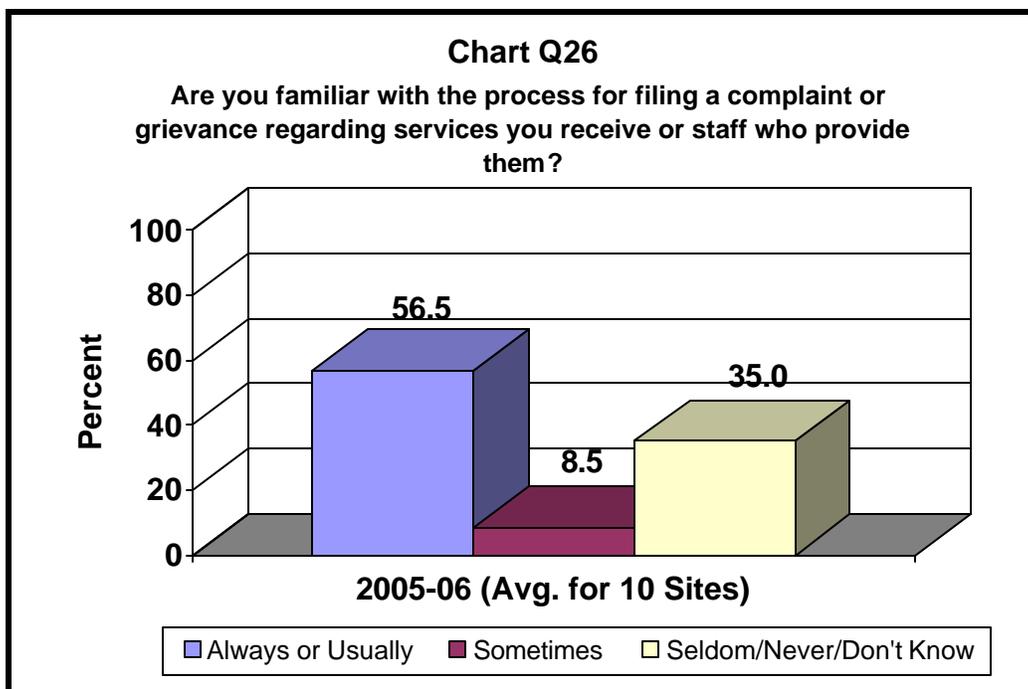


Table Q26
Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
CA - RCOG	↓	50.2	7.6	42.2	249
CT	↓	50.2	8.9	40.8	213
GA	↓↓	41.6	10.2	48.2	471
ME	↑↑	89.4	9.6	1.0	490
NC	↓	50.8	9.2	40.0	195
PA	↓	48.9	7.0	44.1	1,030
SC	↓	51.0	11.5	37.6	314
SD		59.8	7.4	32.8	811
WA	↓	50.3	5.8	43.9	565
WY	↑↑	72.7	7.9	19.4	227
Total %		56.1	8.1	35.8	4,565
State Average %		56.5	8.5	35.0	n = 10

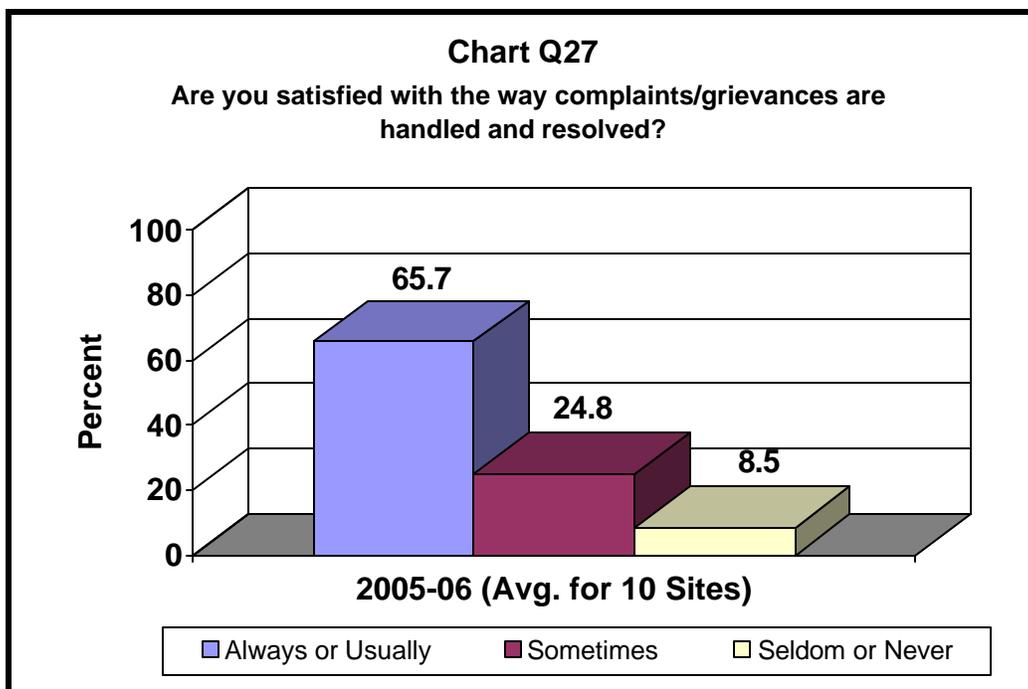


Table Q27
Are you satisfied with the way complaints/grievances are handled and resolved?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC		61.7	26.7	11.7	120
CT	⇓⇓	53.1	35.0	11.9	143
GA	⇓⇓	54.7	24.8	10.4	316
ME	⇑⇑	82.6	7.0	10.4	374
NC		64.8	26.1	9.2	142
PA		67.1	24.5	8.3	648
SC		67.1	26.4	6.5	246
SD	⇑	72.2	22.9	4.9	597
WA		69.9	22.0	8.1	296
WY		64.2	32.1	3.6	165
Total %		67.9	24.1	8.0	3,047
State Average %		65.7	24.8	8.5	n = 10

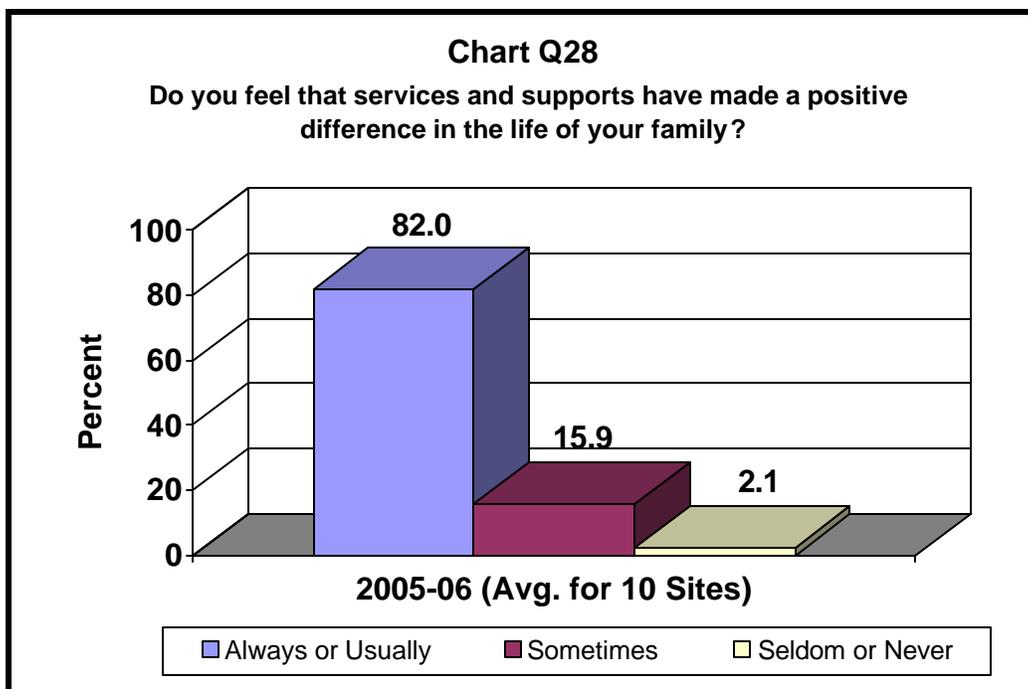


Table Q28
Do you feel that services and supports have made a positive difference in the life of your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC		78.1	19.6	2.3	260
CT	↑	88.1	10.1	1.8	227
GA	↓	76.1	22.6	1.2	486
ME		79.6	16.2	4.3	328
NC		84.1	13.0	2.9	207
PA		81.4	16.2	2.4	1,061
SC		82.0	16.5	1.5	333
SD		85.3	13.0	1.7	862
WA		81.7	16.9	1.4	585
WY		83.9	14.7	1.3	224
Total %		81.9	16.1	2.0	4,573
State Average %		82.0	15.9	2.1	n = 10

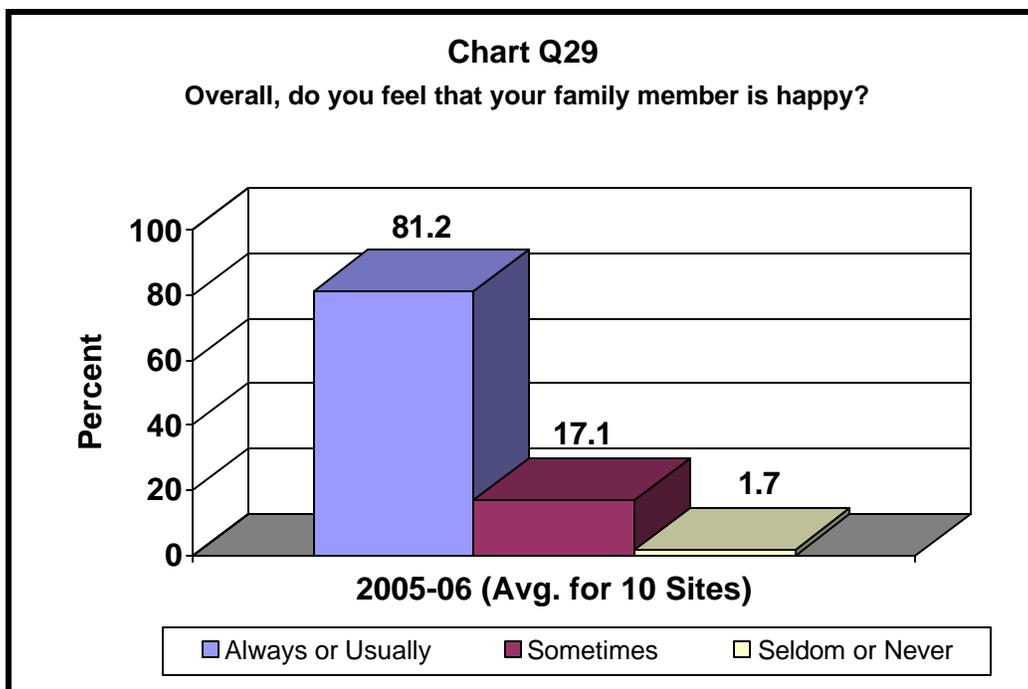


Table Q29
Overall, do you feel that your family member is happy?

State	Always or Usually	Sometimes	Seldom or Never	n
CA - RCOC	79.4	18.7	1.9	262
CT	81.3	17.0	1.7	230
GA	77.9	20.9	1.2	498
ME ^{↑↑}	91.4	7.8	0.8	474
NC	81.4	14.8	3.8	210
PA	79.5	19.5	1.0	1,110
SC	80.7	16.9	2.4	331
SD	83.6	15.6	0.8	874
WA	80.4	18.0	1.7	606
WY [↓]	76.1	22.1	1.8	226
Total %	81.4	17.2	1.4	4,821
State Average %	81.2	17.1	1.7	n = 10

Aggregate Results & State Trends

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

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

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

This compilation of results (up arrows minus down arrows) provides a crude overview of trends, across states and within topic groupings (e.g., information and planning, choice and control), illustrating how states measured up, overall, against the state averages.

As a review, the first chart illustrates state averages, and the table that follows illustrates how states compared to these state averages.

Information and Planning

- ◆ In Maine, South Dakota and Wyoming, responses to information and planning questions were generally above the overall state average. In Georgia and Pennsylvania, results were generally below the state average.

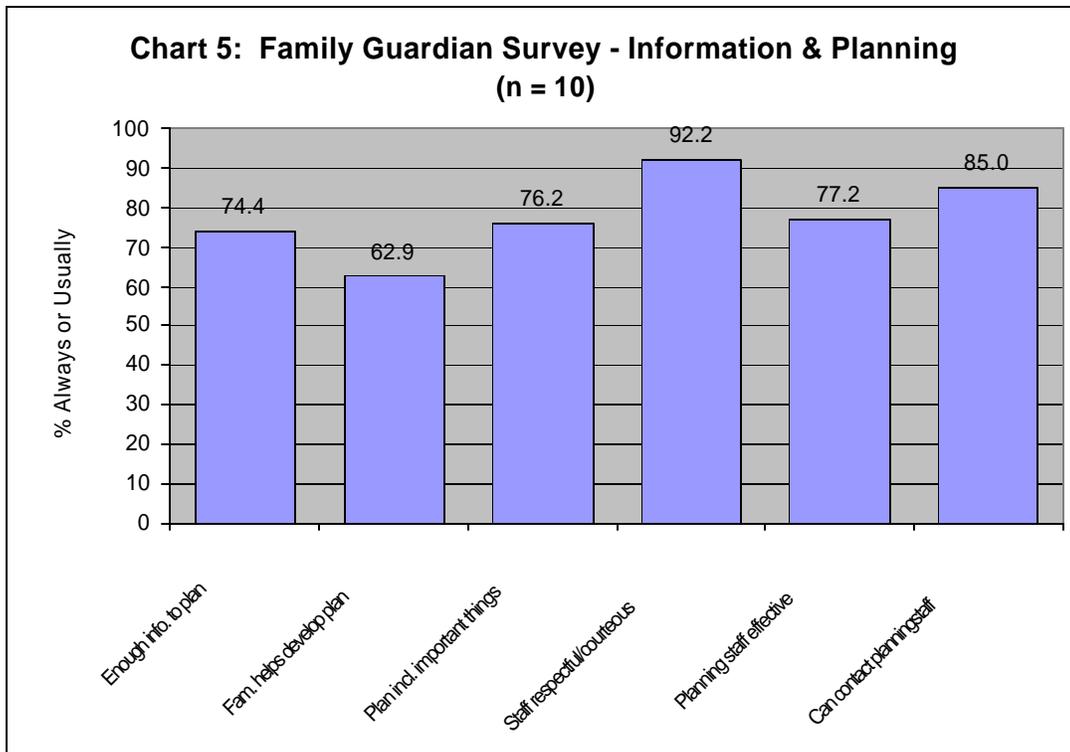


Table 16
Trends in Responses
Above & Below State Average
Information & Planning

State	Q1	Q2	Q3	Q4	Q5	Q6	Net Sum
CA - RCOC	↓					↓	-2
CT					↑		1
GA	↓↓	↓↓	↓↓	↓	↓	↓	-9
ME	↑↑	↑↑	↑↑		↑↑	↑	9
NC							0
PA		↓↓	↓				-3
SC							0
SD	↑	↑				↑	3
WA						↓	-1
WY	↑	↑↑	↑				4

Access and Delivery of Services

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

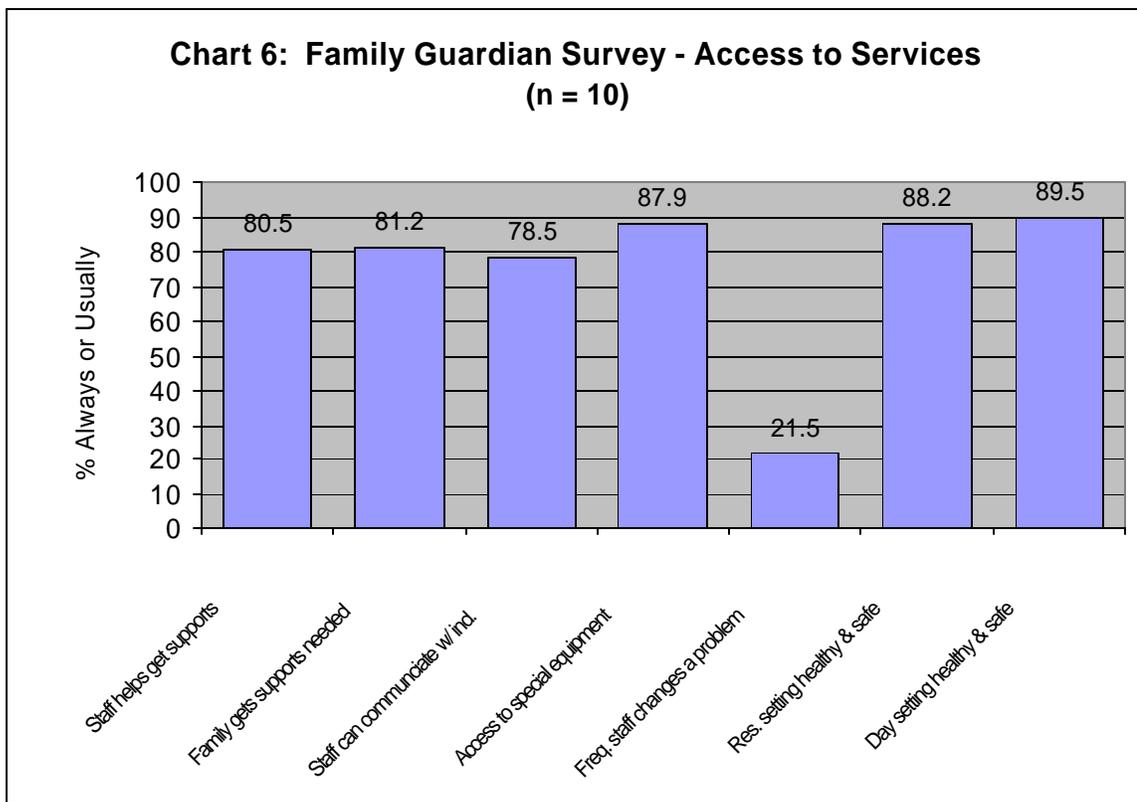


Table 17
Trends in Responses Above & Below State Average
Access to Services & Supports

State	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
CA - RCOC	↓	↓	↓	↓	↑			-3
CT			↑					1
GA	↓	↓	↓↓					-4
ME		↑	↑				↑	3
NC								0
PA								0
SC			↑↑					2
SD	↑							1
WA								0
WY	↑		↓		↓			-1

Choice and Control

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

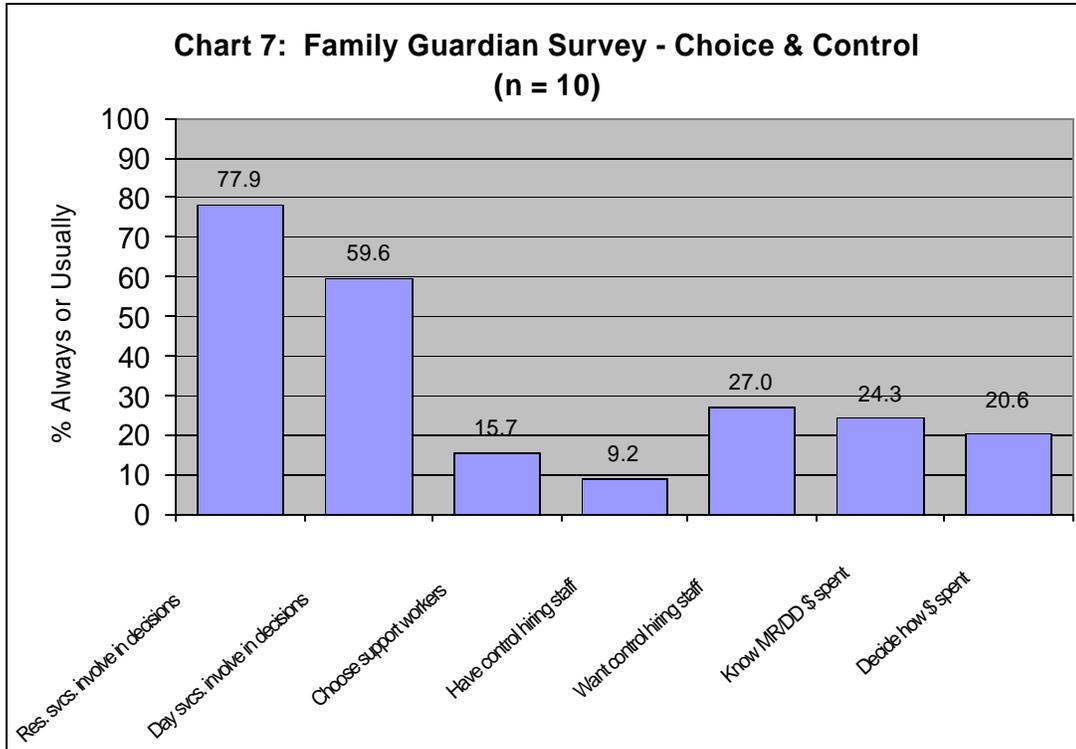


Table 18
Trends in Responses
Above & Below State Average
Choice & Control

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

Community Connections

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

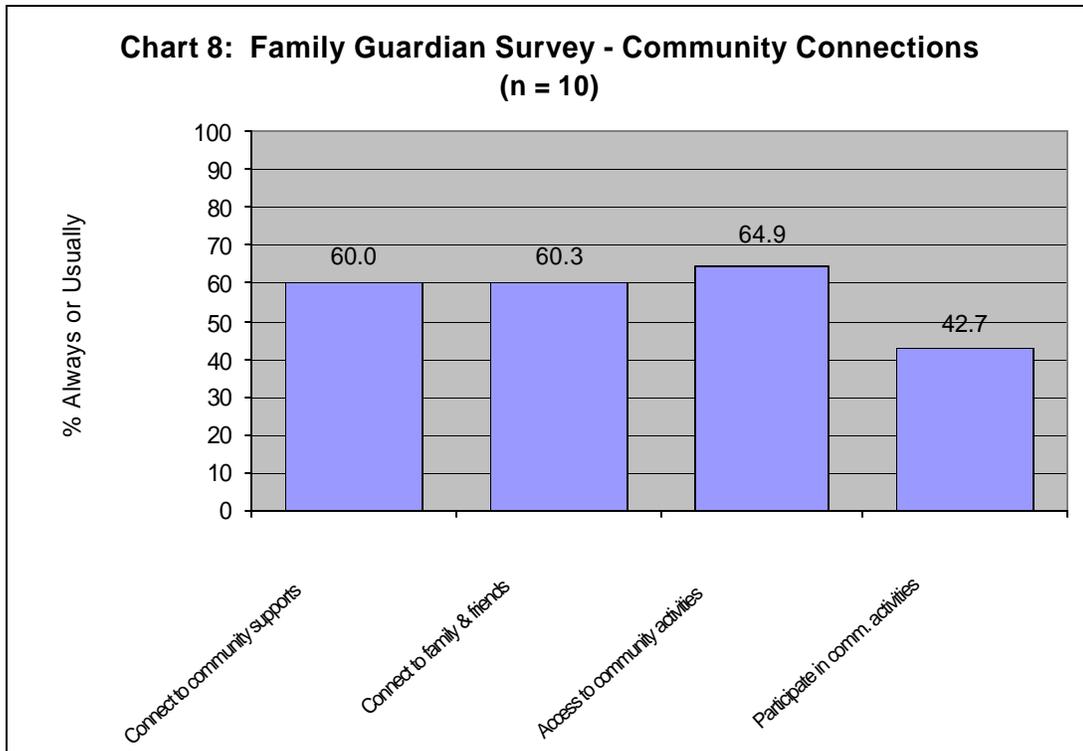
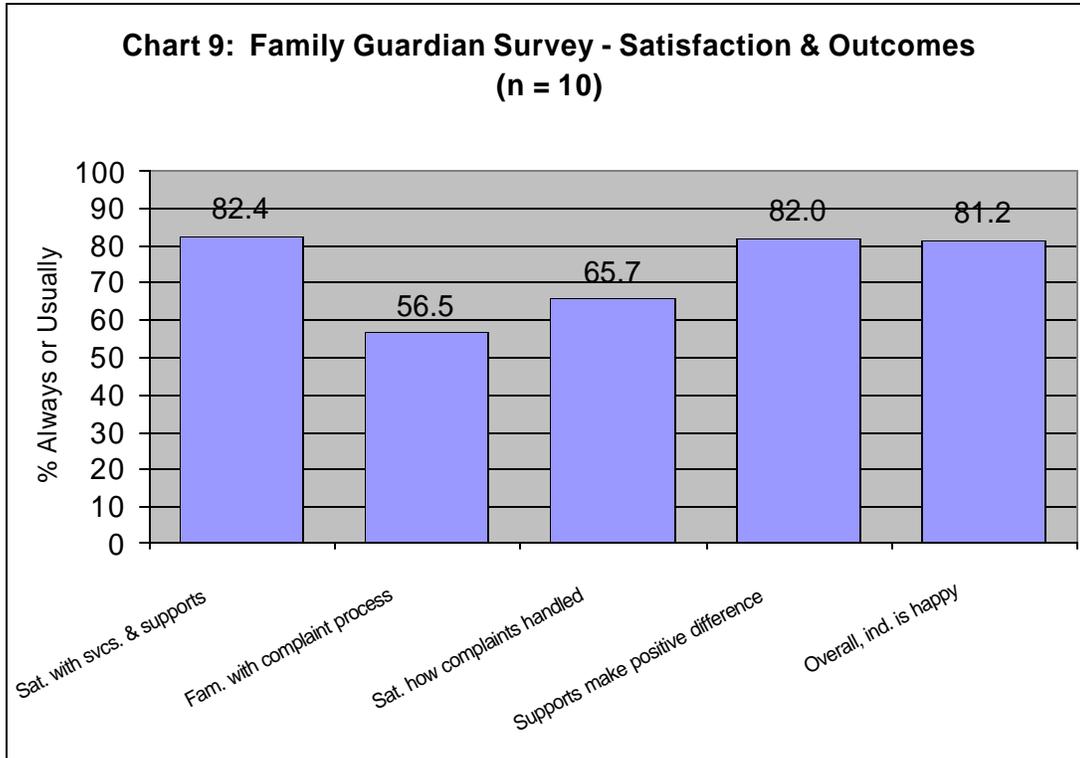


Table 19
Trends in Responses
Above & Below State Average
Community Connections

State	Q21	Q22	Q23	Q24	Net Sum
CA - RCOC	↓↓↓	↓↓↓	↓↓↓	↓↓↓	-8
CT	↑			↑	2
GA	↓↓↓	↓↓↓	↓↓↓		-6
ME	↑↑↑	↑↑↑	↑↑↑	↑	7
NC					0
PA					0
SC		↑		↑	2
SD		↑	↑		2
WA					0
WY				↑	1

Satisfactions with Services and Supports & Outcomes for Families

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



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

State	Q25	Q26	Q27	Q28	Q29	Net Sum
CA - RCOC		↓				-1
CT		↓	↓↓	↑		-2
GA	↓	↓↓	↓↓	↓		-6
ME	↑↑	↑↑	↑↑		↑↑	8
NC		↓				-1
PA		↓				-1
SC		↓				-1
SD			↑			1
WA		↓				-1
WY		↑↑			↓	1

Overall State Trends

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

Table 21 Overall Trends in Responses Above & Below State Average						
State	Information & Planning	Access & Delivery	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
CA - RCOC	-2	-3	-5	-8	-1	-19
CT	1	1	-4	2	-2	-2
GA	-9	-4	-8	-6	-6	-33
ME	9	3	4	7	8	31
NC	0	0	0	0	-1	-1
PA	-3	0	-3	0	-1	-7
SC	0	2	2	2	-1	5
SD	3	1	0	2	1	7
WA	-1	0	0	0	-1	-2
WY	4	-1	8	1	1	13

Additional Open-Ended Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. QSR N6 was used to code and to sort the qualitative comments by theme. The themes identified are detailed below, and the results of this analysis are presented by state and theme below.

NOTE: WASHINGTON'S DATA TO BE INCLUDED IN FINAL REPORT

1. Home
 - a. Satisfied with Home
 - b. Dissatisfied with Home
 - c. Accommodations with Home
 - d. Furnishings/Cleanliness of Homes
 - e. Waiting List
2. Employment and Day Programs
 - a. Satisfied with Employment
 - b. Dissatisfied with Employment
3. Health Care
 - a. Health Care Equipment
 - b. Health Care Insurance
 - c. Dental
 - d. Medical
 - e. OT/PT/ST
 - f. Vision
 - g. Psychological
4. Education and Training
 - a. Satisfied with Education/Training
 - b. Dissatisfied with Education/Training
5. Transportation
 - a. Satisfied with Transportation
 - b. Dissatisfied with Transportation
 - c. No Transportation
6. Recreation Activities
 - a. Satisfied with Recreation Activities
 - b. Dissatisfied with Recreation Activities
7. Communication
 - a. Satisfied with Communication
 - b. Dissatisfied with Communication
 - c. Information
 - d. Language Barrier
 - e. Non-communicative
 - f. Planning Meetings
 - g. Interagency
8. Aging Caregiver Issues
9. Transition Issues
10. Service Coordination
 - a. Satisfied with CM
 - b. Dissatisfied with CM
 - c. CM Turnover
 - d. Shortage of CM Workers
 - e. CM Not Qualified
 - f. Pay CM More
 - g. Service Plan
11. Staff
 - a. Satisfied with Staff
 - b. Dissatisfied with Staff
 - c. Staff Turnover
 - d. Shortage of Staff
 - e. Staff Not Qualified
 - f. Pay Staff More
 - g. Substitutes
12. Family Issues
 - a. Parents as Paid Staff or Case Manager
 - b. Family Support Group
13. General Well Being
 - a. Health
 - b. Safety
 - c. Abuse/Neglect/Mistreatment
 - d. Social
14. Respite
 - a. Satisfied with Respite
 - b. Dissatisfied with Respite
15. Crisis
16. Funding and Budget Cuts
17. Services and Supports
 - a. General Satisfaction with Services
 - b. General Dissatisfaction with Services
 - c. Access to Services/Supports
 - d. Info Regarding Services/Supports
 - e. Need More Services/Supports
 - f. General Satisfaction with Service Management
 - g. General Dissatisfaction with Service Management
 - h. Waiting List
18. Support Groups
19. General Concerns

1a. Satisfied with Home

Our group home and house manager are fabulous.

I am very satisfied with my daughter's worker. My daughter's group home is bright, clean and comfortable.

Thank you for all you do to make a difference in my sister's life. She is happy with her living arrangements, day program and all of the people she has in her life.

In the past year, my daughter was placed in a lovely family home. She is the happiest I have seen her. The caregivers are very attentive to her special needs. They are an exceptionally devoted and loving family. As a result, I am much happier. They keep her busy and she is made to feel like part of their family.

Having my son in a board and care home has been a godsend to him and to our family. He has learned many social skills. Thank you and the state for funding this program.

My family member is in a group home and has been there for 14 years. He likes it there.

2a. Satisfied with Employment/Day Programs

Thank you for all you do to make a difference in my sister's life. She is happy with her living arrangements, day program and all of the people she has in her life.

Day program {AGENCY} is very good. He is happy there.

3e. OT/PT/ST

My son would greatly benefit from speech therapy, but {AGENCY} has been unable to find it. Otherwise, I'm satisfied with his care.

6b. Dissatisfied with Recreation Activities

It would be helpful to have a section in your agency dedicated to helping consumers with recreational services such as Special Olympics. It is always a concern of mine for my brother to have access to this type of events.

9. Transition Issues

Now that my son is 20 years old, I would like to know what community/vocational services are available to him.

My son is happy at his current facility, however at 21 he must move because it's a children's facility.

10a. Satisfied with CM

Our case worker, {NAME}, is wonderful and caring.

Currently, we are very pleased with our daughter's worker. She has been the best and most effective coordinator we have had since our daughter started with {AGENCY} over 12 years ago.

{NAME} was my son's worker. She was excellent and I would highly recommend her.

10b. Dissatisfied with CM

When my son was younger, we received good services from {AGENCY}. Our service coordinator would contact us on a regular basis. For the past 10 years, we have received very little contact from {AGENCY}. Our service coordinator has not been present at my son's IPP meetings for many years.

10c. CM Turnover

I appreciate having the same {AGENCY} coordinator for a longer period of time. It wasn't always that way in the past.

My brother has had too many service coordinators. The information was not passed from coordinator to coordinator, meetings were missed, and all of {NAME}'s problems weren't dealt with in an organized manner. Now, due to major changes, I needed {NAME}'s workshop and transition to {AGENCY}, and things seem to be improving.

The quality of RCOC services is not consistent. It is only the diligence and professional concern of the individual staff person that makes the service useful. This is why it is so difficult when we finally get a really effective and professional coordinator and she/he is reassigned, and we have to go through the process of working with a new coordinator.

Frequent change in service coordinators, there's no consistency or follow-ups. The information I have received from our worker is usually out of date and incorrect.

11a. Satisfied with Staff

I love the staff. Thank you for making my brother's life easier.

My daughter is in a group home, and she is enjoying it. The staff at the home seem to enjoy and love being with them.

Being a mother of a severely challenged young adult, I find it difficult accepting the way my child is been. {NAME} and {NAME} help me get through my daily life and my child seems happy.

We are so blessed to have our son in such a wonderful group home with loving people around him. Thank you for everything.

I would like to compliment {AGENCY} for its diligence and for the staff members that care. Keep up the good work. You are needed.

The staff at {AGENCY} are outstanding. They treat my brother with great love and respect.

My son lives in a {AGENCY} home managed by {AGENCY}. The {AGENCY} staff is wonderful. They are pro-active in managing many aspects of his life. It was personnel from {AGENCY} that had the most input into his plan - simply because they have the greatest interaction with him.

The people in attendance from {AGENCY} knew what was "on paper" about my son but did not know him. I am extremely grateful for the caring staff at {NAME} at all levels - from house staff to the executive director.

11c. Staff Turnover

I value {AGENCY} and the group home. However, given the staff turnover at the home, I have expressed my serious concerns to both the case worker and the home manager. I am worried that he is getting lesser treatment because of {AGENCY}'s budget.

I have dealt with the same {AGENCY} staff, but the staff in the program and group home have a high turn over rate. This causes problems and frustration at the expense of my brother.

11d. Shortage of Staff

There is not enough staff to supervise consumers of different faiths

11e. Staff Not Qualified

I am concerned about the low wages that a caregiver receives and lack of training

11f. Pay Staff More

I am concerned about the low wages that a caregiver receives and lack of training.

13. General Well Being

I am concerned that my daughter should become sexually active, and therefore hope that she is always supervised. Thank you for your services. They are appreciated.

13a. Health

My brother is happy with {AGENCY}. We have had a problem, however. Lately, he has been having rashes on his behind because his diapers are not being changed as needed. Hopefully this issue will be resolved ASAP.

My brother is at time over medicated. It appears that once the medicine is given, there rarely is a follow-up to make sure that he is receiving the right amount of medication

13c. Abuse/Neglect/Mistreatment

{NAME} is having a real problem with her team leader. She has never had so many problems in 18 years with {AGENCY}. She is constantly being insulted and harassed by this person.

16. Funding and Budget

{AGENCY} needs to provide more financial assistance to care providers (less on administrative issues). Also, more proactive pressure for funding by legislature.

I am concerned about the closing of one hospital after another.

17a. General Satisfaction with Services/Supports

I have never needed to contact my son's worker. I am satisfied with his residential agreement and workshop attendance

17d. Information Regarding Services/Supports

When my son was younger, we received good services from {agency}. Our Service Coordinator would contact us on a regular basis. For the past 10 years, we have received very little contact from {agency}. Our SC has not been present at my son's IPP meetings for many years. Now that my son is 20 years old, I would like to know what community/vocational services are available to him.

17e. Need More Services/Supports

Years ago, my daughter learned to a certain degree, sign language. She could use more sign language lessons so that people could understand when she speaks.

Our Service Coordinator is unable to locate a support service person that knows ASL and works with a low functioning individual. I believe that {AGENCY} is unwilling to provide the money to hire a qualified person who will work with deaf clients.

17g. General Dissatisfaction with Service Management

RCOC is often an impediment to the needs of the agency who works with the client on a daily basis. Some few agencies are definitively given preferred status by RCOC.

17h. Waiting List

I contacted {agency} regarding placement, and there hasn't been a response yet.

19. General Concerns

I attend any meeting that I am informed about. We discuss changes/improvements that can be made to her quality of life, but little materializes or is followed through. Both, our daughter and us, get our hopes up about a possible change to her lifestyle, but become disappointed when nothing happens.

I am concerned about our mentally ill landing in jail. I am concerned about the health care system.

'Mom and Pop' group home need better support from {AGENCY}. I spent many years advocating for small group homes.

I do feel it is unfair to deprive him of all his workshop earnings. I don't mind providing his clothing and most entertainment, but he has no money for gifts or recreation unless the home staff contact me for extra money.

I suggest that {AGENCY} pay older day programs a daily rate comparable to newer programs so that they can provide a job developer.

I am concerned about our mentally ill landing in jail. I am concerned about the health care system.

I have never received any financial documentation on what is spent on my son. Having paid parental fees for four years, this would have been good information to know.

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1a. Satisfied with Home

{AGENCY} provides an extremely supportive environment. His bedroom is adequate. His home is just that. Staff support him throughout his life. This is in extreme contrast to {AGENCY} his previous placement.

We are fully satisfied with the care afforded by {AGENCY} and feel fortunate to have {AGENCY} to care for {NAME}.

My goal is to care for my brother in my home when he feels he wants that. We are very close and I care deeply for his quality of life. The department has provided an excellent resource to my mother by having a group home in a good neighborhood and a world of independence for him. We can not have done it without the supports of the department and care of good staff. He lives in a very nice home in a very good community. Overall, we are very happy with the mission, the quality and the supports of your department. Thank you very much!

{NAME} is very happy where she is in the condo.

{NAME} has made immeasurable progress since he has been in residential program and out of {AGENCY}. Any problems we have had have been small and handled properly by staff. {NAME} and her staff could not be more helpful. They're great!

{AGENCY} is a great organization. My son is well cared for and is happy in his home. His MR/Autism does put a limit on what he is capable of, but the staff and caregivers try to make the most of his potential. He has lived in the {AGENCY} home for nearly 10 years and never once have I considered a move. {NAME} was instrumental in getting the help that {NAME} needed and I bless him every day.

My son is at a private group home run by {AGENCY} and is well cared for, safe and involved in many community activities my husband and I would never have access to or energy enough to involve him in. Due to his being housed at a group home we are allowed a life we have not known and he seems very happy and content in his life as limited as it is. We are very grateful to be recipients of their wonderful services and remain actively involved in our son's life.

{NAME} seems to be happy in his group home and enjoys his outside activities.

I never intended to place {NAME} but I had a stroke and doctor advised that she be at least on temporary respite. Family contacted caseworker and plans were made for {NAME} to attend {AGENCY} in {TOWN}. When I returned home I was taken to the home to see {NAME}. I had to admit that the home was excellent, good staff, good program and help. {NAME} seemed quite happy. She was guaranteed a room of her own where she could be alone when she wanted to. She could have her tape machine, keyboard and radio. She had space to do puzzles but would meld with the other clients. So far, it has been satisfactory. The manager is

quire aware of her needs doctor's care and recreational experiences. Every time I've seen her, she seems well taken care of. {AGENCY} is a model for a group home.

{NAME} is very happy with his living arrangements and with his job. I am happy to know that my sister {NAME} lives in a nice home and seems to be happy.

{NAME} is very happy living in {AGENCY}. I am very impressed by the services and care he receives. Connecticut-DMR is so far superior to the care given in Mass. Thank you again for the care and dare I say love he receives from the people at {AGENCY}.

I feel that we are very fortunate to have the services for {NAME} that we now have. They are excellent. I do not believe we could do better! Since leaving the {TOWN} area and coming to the caring {AGENCY} of {TOWN}, she has consistently shown improvement in every area – living skills, speech, work skills, overall satisfaction with himself and his living conditions, etc. You just know the programs are right for {NAME}. Consistent in application, positive in approach, that's excellent! Indeed we are fortunate and have to be thankful for the efforts put into {NAME}.

Our son is in a fantastic home. He receives love and care that we are very satisfied with. He lives in an environment that helps him reach his potential. We realize how lucky we were to have found the placement our son is in. Thanks to our DMR social worker many years ago. Emotionally, physically, financially we never could have given our son the level of care he received in his group home. We realize how lucky we are. And we recognize how much {NAME} is loved and cared for every day.

My son is very happy in his group home with his three companions. He would be lost some place else.

In the ten years {NAME} has been at the {AGENCY} he has been very happy and very cared for by everyone. He also attends the {AGENCY} in {TOWN}, CT. The managers and staff at both places have always given {NAME} loving care.

I am so thankful for both the wonderful residential facility at {AGENCY} for my sister and incredible day program that she is now very active in through the {AGENCY}. We appreciate sincerely all the excellent care that is being provided and activity level she is now involved in. My sister's overall health, mental awareness and happiness has been improved immensely since entering the group home after my mom could no longer care for her.

On the whole, I am very satisfied with the care my son is receiving at {AGENCY} in {TOWN}. Special mention must be given to {NAME}, Manager of home who does a fabulous job all across the board – she is an angel!

This past has been one of the happiest and most productive for my daughter. She had spent 18 years in an ICF facility. It offered her learning experiences, but she is now in a residential setting where she has more individual responsibilities, care of self, her bedroom, shared household responsibilities. She has gained self-assurance and is very happy in her new residence both with the other clients and with the staff... I am truly appreciative that {NAME} is now in a setting suitable to her needs.

Overall I think the {AGENCY} has surpassed my expectations. The care and programs are exemplary. Anytime I have had an issue, it has been resolved to my satisfaction.

I am very pleased with the residential and support services that my daughter is receiving. Facilitating these support services enable me to keep a full time job and also allows me to be active in my church and community.

We are very appreciative of the wonderful support and care {NAME} has received at {AGENCY} in {TOWN} which is a group home supported by the {AGENCY}. The staff has made {NAME}'s house a loving home.

I am extremely happy with the services my son receives in/through {AGENCY} program and would be extremely disappointed if anything were to change because of the new waivers or any other reason. My son is very severely disabled. {AGENCY} is the only setting that gives him the kind of personal living situation. I am a single parent. If it were not for {AGENCY} I would not be able to work and would probably be on welfare.

1b. Dissatisfied with Home

Recently had OPS for my son. Home staff and PT did not have reports. The meeting was not well organized and people from the home kept getting up and going out of room on to the computer. I feel that this reflects how the home is run – in chaos. My son is happy at this home because there is some exceptional staff there. There is too much going on in the home and in the staff's personal lives which interfere with services.

Yes, I wish he were in a group home setting closer to his parents' home. The cost of driving to his group home now is more than I can afford.

{NAME} lives at a group home at {ADDRESS}. He is on medication for depression at this time. He is really not happy most of the time and gets angry with staff members.

We feel that our son is not appropriately placed. He needs a living situation with more supervision and a job where he can interact with more people than he presently interacts with. He is very social and his need to see different people and interact with them has diminished with his present job.

We feel the house our son resides in is too small. More living space is needed.

1c. Accommodations with Home

Recently, our daughter's group home provider cannot meet her needs. We are working with DMR to find another provider. Progressive mobility problems make it necessary for her to live in a one-level home (her present group home is multi-level). In the past eight months, our caseworker, {NAME}, has reported that no new openings for one-level group homes have become available.

1d. Furnishings/Cleanliness of Home

My brother, {NAME} is presently living in an apartment which is very unclean. He has a cat which may be the main cause of the problem. I understand he is moving to yet another apartment in July. We would like to make sure it is a clean and safe environment for. He liked the setting of his apartment now, so I do not know why the change. The only problem was the unclean apartment. If you would look into this, I would really appreciate it.

2a. Satisfied with Employment/Day Programs

{NAME} is very happy with his living arrangements and with his job.

I am so thankful for both the wonderful residential facility at {AGENCY} for my sister and incredible day program that she is now very active in through the {AGENCY}. We appreciate sincerely all the excellent care that is being provided and activity level she is now involved in. My sister's overall health, mental awareness and happiness has been improved immensely since entering the group home after my mom could no longer care for her. Thank you. I worked hard to find these facilities.

I am very satisfied with all of the services provided by {AGENCY} in general and with the {AGENCY}. They do an excellent job taking care of my son both at the group home and at his day program. More funding from the State would help maintain their house and could provide more activities and staff. The more "normal" they make my son's life the better.

[My daughter] is also learning a great deal in her day program. The staff truly understands {NAME}'s needs and limitations and encourages {NAME} to attempt new projects she is capable of handling. I have weekly contact with manager of group home and the supervisor of the day program.

3c. Dental

The only complaint I have about my son is his dental care.

3e. OT/PT/ST

The only issues that are unsatisfactory are the unavailability of ST/PT/OT services. This is an on-going problem and the crux of our discussions at {NAME}'s IEP. {NAME}'s GP is unwilling to assist in making these services available.

5b. Dissatisfied with Transportation

Hi my name is {NAME}. I am a {AGENCY} Provider for the past 24 plus years and along with other providers, I feel transportation and recreation for our people is of great concern... At one time, DMRs cookouts and other events had transportation and were free to attend. Now we the provider transport and the people (clients) pay or do not pay.

It would be nice if my son had help with transportation to see his family once in a while. We live in another state (VA) and it's hard to see him. We are the only ones who have provided transportation for far. We also have paid for staffing to come. Because of this we only see him about 2 times a year.

7b. Dissatisfied with Communication

When my daughter turned eighteen her guardianship was turned over from me to someone else who I do not know or had been notified of. No reports from DMR have been timely for four years and no reports from her caseworker have come to me since her eighteenth birthday. I realize this is a special situation where I live in Northern Maine, yet the lack of response by caseworker and foster mom is troublesome. I am at a loss of what to do - if I complain both the

foster mom and caseworker act out - not against my daughter, but as though I am not worthy of input.

Because our son is doing quite well at {AGENCY}, perhaps it is not necessary for us to be contacted or have services supplemented by DMR but it still would be nice to have some occasional contact with a DMR representative assigned to {NAME}'s case.

I would like to thank you for providing me this opportunity and taking interest. This is an excellent demonstration of interest by your department. Overall, the program manager at my brother's group home demonstrates concern, interest and effort. She has made many improvements to the environment since she came into her role. I am very appreciative of this. Having much responsibility, however, limits her, understandably. Thus, I feel communication is 'challenged'.

8. Aging Caregiver Issues

As my brothers-in-law (I have two brothers-in-law in a group home, ages 74 and 73) are aging, I am not sure that the facility they are in can serve them. This is a problem for the DMR as so many mentally retarded residents, who came out of institutions such as {NAME} School, as my brothers have, are aging and need different services. I worry that facilities are not adjusting quickly enough to the elderly mentally retarded needs.

10a. Satisfied with CM

I would also like to say that my sister would not be where she is today had it not been for the outstanding task of placement by her social worker {NAME} who will forever be my family's angel.

My case manager for my son from DMR has been wonderful. It is a comfort to know she has history with him and supports him.

10b. Dissatisfied with CM

House Manager and home office social worker seldom return calls and are hard to find. When they do not put much effort into something they believe they put too much effort into it.

My daughter's caseworker was/is {NAME}. Many times I called her and left a message to call me to update me on situation but she wouldn't return my call in a timely fashion. I expect a return call within one day. She would not or did not call me back for at least a week. I was/am not happy with her services. My daughter did like her, but I felt she was not helpful to me. She told me she had a very heavy caseload and that is why she wasn't able to return my calls. Whatever her excuse it's not acceptable to me.

Our DMR case manager has not been affective in helping us receive proper hours for our son. She has not made quarterly visitations/calls, has not contacted us to "check in" as to how things are going and almost never returns phone calls on a timely basis. She does not appear to be knowledgeable regarding the new IEP plan requirements.

11a. Satisfied with Staff

{NAME}'s entire family is so thankful to everyone involved in {NAME}'s care. We appreciate that we could not take care of him. Our mother was so worried about him – her big concern being, "Who will care about {NAME} when I'm gone?" I'm probably coming across as gushy regarding {AGENCY} and the team, but we are so very grateful.

The staff at the {AGENCY} is exceptional. Also, want to say {NAME} is the most professional person I have come across as well as exceptionally courteous.

All the staff is caring, concerned and loving to our daughter. I cannot say enough good things about where she lives.

I feel that the group home {NAME} is in at {AGENCY} is appropriate for him. The staff does a good job and the nurse and planning committee do a good job in caring for his medical requirements, doctor visits, dental and problems that arise.

Staff changes, so far, seem to blend in well and off hand comment would be So Far So Good! Please call if any questions or clarification needed.

I can't possibly say enough good about the support staff for my sister at {AGENCY} in {TOWN}. {NAME} and {NAME} have been a tremendous resource to me over the past six years when my parents moved out of state and I was appointed {NAME}'s guardian. Although I am unable to visit {NAME} as often as I would like, {NAME} keeps in touch and keeps me informed via e-mail and phone calls often. The staff's emotional involvement with my sister and her is truly remarkable. They are an asset to your organization and should be commended for a job well done. At times I visit {NAME} she seems happy and content. I credit the entire {AGENCY} staff providing her with the very best quality of life. I attend her care plan meetings twice a year and everyone makes me feel involved with {NAME}'s life goals. The team listens to and appreciates my input and thoughts and this means a lot to me as I cannot be as much a part of {NAME}'s life as I would like. {AGENCY} is doing a great job. It touches me so deeply to know that the entire staff and IST/Care Plan team are such enthusiastic advocates for my sister and that her happiness is their primary goal/objective.

I feel that the staff does a great job handling the needs of my son. This was especially true a year and four months ago when he lost his mother, my wife of 48 years. She was his best friend.

{NAME}, who has been working with my cousin {NAME}, is an outstanding caring person. She changed districts and is in the process of being replaced. She may come back to the old district. If she does not, I hope {NAME} gets someone like {NAME}.

The staff is doing a good job.

Our son has been involved with the {AGENCY} for twenty-seven years and they have tried to provide suitable working and living conditions for him. The staff members have always had his best interests in any work or living conditions which they have provided and have made his life as normal and happy as possible. They have included his family in most of the services which are provided for him and we have always felt the concern of the staff. Our family is blessed and so grateful to have the support services with the loving caring people who provide for our son. In short, they are our extended family.

I am pleased that my son is in a group home. Thankfully he is doing well due to the good care of staff. I commend them for all the good work that they do. There will always be room for improvement no matter how well things are going.

I really enjoyed the staff at {AGENCY}. {NAME} and {NAME} I am very sorry they both left. They treated {NAME} like a family member. I know he misses them.

The staff at {AGENCY} in {TOWN} is most considerate and helpful. This is much appreciated in the care of my retarded daughter.

Our family is extremely pleased with the care and support of our sister. The staff is considered her second family. They go above and beyond their duties.

{NAME} has done a complete turnaround for the best since she moved to {ADDRESS} (1996 roughly). The staff is very good with her and they work together (team work). I am very happy of where she is at right now. They did a wonderful job with her and her behavior has cut down a lot.

Both my brother and I are very pleased with the care our sister {NAME} is getting. Supervisors and staff do a wonderful job of caring and have always been courteous and helpful to us.

My daughter {NAME} is happy and well taken care of at {AGENCY}. She loves all the staff and they love her. She is happy with her housemates. Also they, the staff, keep me posted on all her activities and all the cute things she does. They are our extended family also wonderful caring people.

The staff at my sister's group home through {AGENCY} are outstanding. My family and I have nicknamed them our "A" Team. These staff woman go over and above not only for our sister but for the other residents. My experience has been nothing but wonderful that's to these three girls and the night staff. I know my sister is safe and happy under their care. The "house managers" have come and gone and that position is usually filled with people who are there only for the job. I am grateful though for my staff and so is my sister and it is reflected in her smile when she sees them. Please read previous page. Once again I will state how wonderful my sister's staff is. We are truly blessed with them and I would like information on how to put a positive report on their permanent work record.

My family member is very happy in his placement. He has made wonderful progress. The staff is wonderful working with him. He has progressed beyond expectations with their help. We are grateful. They do a great job despite all the budget cuts.

11b. Dissatisfied with Staff

Staff members inattentive to: home cleanliness and meal schedules. Staff members use cell phones while on duty and use client's community time for personal trips.

The home where he is a place that people resign and new people are hired. My son always has problems with new staff and his behavior go back again. The home needs to train the new staff members what my brother like and what he does not like. Maybe that is something the agency cannot control (new staff) but they should try to do as much as they can.

{NAME} was never placed with his “peers” as there never was a proper place for him originally in 1995. Although he is the only one in his group home who is ambulatory, he started to respond actively and for many years has felt secure there. The permanent help always worked with him. The temporary help always continued to a degree to keep working with him.

The staff from the group home is always changing and sometimes if I need something for my step daughter meds: like the doctor's name {NAME} they always use the wrong medical card. The house manager there promised me she would give it to me but made me wait for 3-4 mos. I went there myself and asked the staff. She wasted 10-15 mins and I got it. Why did the house manager give me a hard time? Why because I'm only step mom of my daughter. Sorry to say but that's how I feel and also they are not fair sometimes the way they treat their patient.

My person has had a couple of surgeries in the last 2 1/2 years. Both times I feel the group home staff and managers did a fine job. In my opinion the nursing staff were totally out of the situation. There was very little to no support staff, manager nor myself.

My brother has not been happy in his group home ever since {NAME} has taken over. When he had the state employees, they were like family to him. They treated him like family.

11c. Staff Turnover

The permanent help always worked with him. The temporary help always continued to a degree to keep working with him. In the past several years there is a continuous daily change of temps and recently a complete change all at once of permanents. {NAME} is non-communicative and does not know what is happening. Not being with his peers, he has no one to learn from or watch. This is causing him to lose and revert backwards to many things he previously learned. He still feels secure in this group home because he knows where he is. But he is not receiving his normal training. Temps apparently feel as long as he takes care of himself, they do not need or care to work with him, like the old permanents did. His reverting is showing up even at his day program as there is continuous help changes there also!!

Staff turnover is a problem. One year our son had 17 different staff within a twelve-month period.

Reassigning people who work with our son at times causes problems as he builds relationships only to have them destroyed for no reason he understands. His “family away from home” becomes a temporary family.

The staff from the group home is always changing and sometimes if I need something for my step daughter meds: like the doctor's name {NAME} they always use the wrong medical card.

{NAME} keeps changing help every two weeks. Naturally my brother gets upset with new faces every few weeks. It was a bad thing Governor Rowland did privatizing these few group homes.

Staff changes are an unfortunate part of group home living. This is very disruptive to home life especially for a non-verbal resident.

{AGENCY} in {TOWN} has the following issues that are continuing and are seldom addressed by the facilities manager, {NAME}. First constant turnover of staff and second four different PC in less than four years.

The home where my son lives is a place where people resign and new people are hired. My son always has problems with new staff and his behavior go back again. The home needs to train the new staff members what my brother like and what he does not like. Maybe that is something the agency cannot control (new staff) but they should try to do as much as they can.

Thank you for the opportunity to respond to this survey. I am the guardian for an elderly woman who lives in a privately operated group home run by a reputable non-profit agency. She has been in the home since it opened in the 1980s, about twenty years ago. She was “rescued” from a nursing home. {NAME} lives in a lovely home and gets very good care. Unfortunately staff turnover often due to the inadequate wages they are paid. I am concerned about the impact the recent unionization of this agency will have on her care, as I believe this will be a divisive process.

The change in staff is constant and it causes concern as you may realize. I know that this cannot be helped. I would like to be more familiar with the staff, the financial and medical aspects of my brother’s life other than quarterly reports. Almost all events are told to me through my brother who I speak with two to three times a week. I would like to improve upon this with management (we have discussed).

11d. Shortage of Staff

His private provider agency does not allocate enough hours from staff to make us feel comfortable with the level of care he receives. They spread one staff person between four persons living in three different apartments not located very close together in an apartment complex.

Under staffing (or minimal staffing) appears to be a major component of staff changes. It is ridiculous to have a 2-person minimum staffing requirement for four physically disable individuals and two ambulatory individuals.

If something happens to my son or if something gets broken in his room no one ever seems to know how the incident happened. I know it is hard for two aids to watch three active males (1 aid on night shift) all the time. However, no one ever seems to know. Overall he is happy and content.

11f. Pay Staff More

I would desire that non-profit providers have the same wages as state employees in similar jobs.

13a. Health

My son is in a good group home. He is treated well and has been there ten years or so. Being autistic he does speak but with some limitation. So at times, I feel he is not being listened to. I had to take him to the emergency room at the hospital a few times just in the last two years. I have him home almost every weekend so I know how he is doing. I have talked to the manager of the group home quite a few times about this situation. I just took him to {AGENCY} about a month ago or so with a sever case of infection of his testicles and prostate. I am asking them only to listen to him take the time to listen, please. Thanking you I am, {NAME}.

13b. Safety

Most of the times I am happy and pleased that my son is there. But he has had some problems. Last year (2005) he drank some kind of cleaner and he suffered one week at {name} Hospital. That problem caused me and his brothers a very stressful time. DMR was investigating what happened. We have not received the report.

Part II, Question 12. I answered two questions because {agency} is in the process of moving {name} to another apartment which is in a very dangerous neighborhood. There has been gang wars and shootings even one killing. I have requested that she not be moved there. The move is being held up until a meeting with the DMR caseworker is held. I am waiting for word of the meeting as of now. Until this disagreement of the apartment, I am very pleased with the care and programs that {name} has. The staff has been excellent with her. I am 82 and {name} and I are very close. She visits me every week-end and most holidays. {NAME}, Mother.

My sister {NAME} lives in an apt. with a roommate because the services are from another agency, many services are not provided together. This means (among other problems) that she spends lots of time alone including many nights. She needs more supervision, she's without defense and anybody can just get into her house because she will just open the door. Who is responsible? Sister {TELEPHONE NUMBER} or {TELEPHONE NUMBER}. P.S. Many services are not provided the way they are assigned.

13c. Abuse/Neglect/Mistreatment

{NAME} was forced to sleep on a couch in a basement. He used a sleeping bag. He wasn't taken anywhere. He was forced to sit in a "club room" for hours. They stole his money. When he moved to his new home he had approx. \$14.00- they took the rest. After two-three months, at ASI he has \$1, 200.00 approx. We asked for an investigation. Your agency is extremely negligent in handling investigations. Who is there to go to when the agency who is supposed to protect them has no regard for the person's life/well being? We are still waiting for the report. I have been in special ed for 41 years. {AGENCY} and DMR are as the worst agencies in protecting an individual's rights. {AGENCY} should be shut down!!!

13d. Social

We feel that our son is not appropriately placed. He needs a living situation with more supervision and a job where he can interact with more people than he presently interacts with. He is very social and his need to see different people and interact with them has diminished with his present job.

13e. Hygiene

My brother, {NAME}, needs to greatly improve his hand washing and his ability to wipe himself after going to the bathroom.

16. Funding and Budget

It seems that the people placed in our {AGENCY} take the brunt of all cutbacks. They are the targets of all DMR cutbacks. This is not a fair deal for our people.

I am very satisfied with all of the services provided by {AGENCY} in general and with the {AGENCY}. They do an excellent job taking care of my son both at the group home and at his day program. More funding from the State would help maintain their house and could provide more activities and staff. The more “normal” they make my son’s life the better.

17a. General Satisfaction with Services/Supports

My son is happy with his residential and day programs. This happiness is of utmost importance. This is what we want for all our children, special needs or not. I could not have designed a better program to meet his needs.

Community Integration has been a beneficial change to my son’s program and he seems to enjoy his life so much more with choices of daily activities and some recurring work.

I am very satisfied with all of the services provided by {AGENCY} in general and with the {AGENCY}. They do an excellent job taking care of my son both at the group home and at his day program. More funding from the State would help maintain their house and could provide more activities and staff. The more “normal” they make my son’s life the better.

My son is in a group home here in {TOWN}. This being a new adventure for him and his family, many of the questions on the Family Survey, are difficult to answer at this time because we are still learning. Some of the questions I do need answers for my son’s benefit. {NAME} is my son’s coordinator ... {NAME} is the House Manager of the {AGENCY}. My son is completely happy with the residential care ... his adjustment is unbelievable.

My son is happy with his residential and day programs. This happiness is of utmost importance. This is what we want for all our children, special needs or not. I could not have designed a better program to meet his needs.

I am his father/guardian, his mother passed away in 1972; I am always invited to partake in planning and evaluating his progress. One of my daughters is secondary guardian. We both take him for walks in his wheelchair once a week. We know the people who take care of him and they know us. We are very happy and confident that his future is secure even after I pass on.

{NAME}’s entire family is so thankful to everyone involved in {NAME}’s care. We appreciate that we could not take care of him. Our mother was so worried about him – her Big Concern Being, “Who will care about {NAME} when I’m gone.” I’m probably coming across as gushy regarding {AGENCY} and the Team, but we are so very grateful.

We’re very pleased!

I am very grateful for the guidance and care my sister has received. Truly a lifesaver!

I live in Massachusetts. Due to the long drive we (my husband and I) only get to visit {NAME} once a year. {NAME} is very happy living in {AGENCY}. I am very impressed by the services and care he receives. Connecticut-DMR is so far superior to the care given in Mass. Thank you again for the care and dare I say love he receives from the people at {AGENCY}.

We are very pleased with the care that our profoundly retarded daughter is getting at the group home.

I have the utmost respect and confidence in the DMR. Its staff, employees and service personnel. For them I am very thankful.

I would like to thank everyone involved with my brother's care from start to present. Everyone has been knowledgeable, thorough and straight forward about evaluating, planning, executing all services and programs regarding my brother's needs. Since in DMR care, I have seen a 95 percent improvement in my brother. I am grateful for the support, service programs and knowledgeable staff that have come from DMR and their programs. Keep up the good work. Thank you.

We the {NAME} family have always been extremely happy with {NAME}'s care and support. We would not change any of the care practices. Thanks to all.

Sorry to be late. Much of this really is N/A in {NAME}'s case. Have been very pleased with all involved in her care. {NAME}, Mom.

I live in Florida; I am also a caregiver for my husband. Thus unable to visit {NAME}. My other daughter goes occasionally. But the aides are very informative to me and call often. I appreciate it.

Feel very satisfied with all aspects of services. {NAME} is very happy with his life. Thank you.

I am overall pleased and grateful for the services provided to my family member. I fully support and stand behind DMR for the tremendous work they are doing. Thanks a million.

{NAME} was never placed with his "peers" as there never was a proper place for him originally in 1995. Although he is the only one in his group home who is ambulatory, he started to respond actively and for many years has felt secure there.

17b. General Dissatisfaction with Services/Supports

Physical therapy and speech have grossly failed due to visits too short, too much time in between visits and provider not knowing his real needs. Placating vs. challenging him. He is exceptionally well cared for but very poorly supported in the area of outside providers!

17d. Information Regarding Services/Supports

1. Thank you for the survey. 2. I would like the name of my sister {NAME}'s case worker and for her to call me. My phone # is {TELEPHONE NUMBER}. I live in {TOWN} and my name is {NAME}. 3. I am interested in information on general for elderly handicapped, such as my sister. She currently resided in {TOWN} - a long drive away. And she is aging (despite only being 54 years old). I like the group home she is currently in yet I anticipate that soon they may not be able to meet her needs. Do you have any thoughts on this? {NAME}, {ADDRESS}.

17g. General Dissatisfaction with Service Management

Facility manager is consistently untruthful in responding to client's guardians. Current investigation is ongoing. Overall the {AGENCY} has a good reputation. However, recent and continuing ongoing leadership and follow through with staff – questions safety and need for client programs continuity.

I have had difficulty getting information from the middle management tier. Staff and group home personnel are kind and friendly – but for major questions, the regional administrators are not forthcoming. I do not like a grievance system where all inquiry comes from a parent's point of view. The people more closely aware of the client's day-to-day needs should be able to suggest and complete a plan without a lengthy review initiated by the parent of guardian. Team planning has been effective for our situation – a quality of life goal should be the major focus for family.

19. General Concerns

The excessive amount of time that it takes to investigate and settle a complaint and/or recommendation is unacceptable.

My family does not visit. I am only one that has visited the group home. However I do not go anymore because once a client tried to bite me and once I was hit in the face with a metal bowl by my brother and the staff at the home just did not seem to care. Since my brother does not know me I felt for my sake it would be best to stay away. But let me say I think he gets good care and is safe. He is award of the state as far as I know if that makes a difference in the survey.

GEORGIA

1a. Satisfied with Home

However in his group home I feel he is happy and very well kept clean and orderly.

We are grateful as a family to have the supports our son needs. His provider of residential service is great and we are very comfortable with that arrangement.

I am well pleased with the group home our family member is in. It is a small group home and I feel this enables clients to get what they need without keeping staff members so distraught.

I am so blessed to have services for my child. She has great care and love. She is very happy at her group home. It is always spotless.

Recently my family member moved to a group home. His cohabitants and he are well matched. The situation is very good. It was a wonderful move. Thanks to all.

We are very fortunate to have my sister at {AGENCY}. She has received tremendous support at this facility. We are in this home on a regular basis (announced as well as unannounced) and we recognize that our family member is getting her needs met in a most gentle and kind manner. She appears to be happy and that speaks volumes. I would only hope that more funding would be available to give the quality of life that I feel kings and queens deserve.

I feel good that my daughter is in a home with a total of three ladies together. She has her own room. In seven and a half years she has been under three different companies. They have all been fairly good to good, but I wish this was more stable. In most cases she has had loving and caring workers. I feel that there is always room for improvement. She always looks nice and the home is well kept. We take her every week for lunch and ride when we take her back she is always ready to go back in her home. This was not true for the first few weeks when she first left our home. The program has been a lifesaver for me and my wife.

It has been only this year that the people at the service facility have been seeing to our concerns for my son. There must have been a changing of the guard. Previously, our requests about our son's care have fallen on deaf ears. I do not know if the apartment agency owned or not but I must say his house mother is great.

{AGENCY} is an excellent organization for support of adults with developmental disabilities. It should be a model for all of GA.

I am very happy with services that my family member is getting at the personal care home where he is living. My daughter is very happy in the place that she is in. I can tell even though she can not talk. When she comes home for more than overnight she gets very quiet and she will be ready to go back home. She will watch the door to see if her ride back is coming.

My son is a member of a private non-profit organization and we feel blessed that it is available. He has a life!

I have been very pleased with the care and kindness given my sister in the personal care home where she resides. The home is always immaculately clean, wonderful smelling food on the stove. The girls enjoy individual rooms, birthday parties, outside activities, with 24 hour caring supervision. The home provider stays in touch with me about upcoming events, her visits to doctor, eye care, and dental visits. She is diabetic and her diet is watched closely. She is happy which means a lot to know she's content, well taken care of in every way.

My daughter is happy where she is. Last time she was home I asked her if she would like to come home and live and she said she likes to visit, but she likes her group home and activities she does.

In his group home I feel he is happy and very well kept clean and orderly.

The staff has a desire to be of service to consumer. He likes going to {AGENCY}. He likes going on field trips. He enjoys going to church and other community activities. He likes his group home. He likes going to Special Olympics. We are pleased with his progress. The staff said he was acting good at group home and {AGENCY} which is a prevocational workshop. The group home is clean and neat.

I am well pleased with the care {AGENCY} gives consumer. They take him on outings to the doctor and other places. He is very happy there.

I don't know how our family would have handled my sister's disabilities at this point in our lives. Our parents are still living and they reside with me because of their ailing health. My sister loves where she lives and the family that takes care of her. They live 5 minutes from our home and they love my sister. God was watching over us. My sister receives great services that help her live her life with love and dignity.

In all the years since consumer has been in group homes I have never had a complaint on how she was treated. She is a very happy, content person. I feel satisfied when I'm gone she will be taken care of.

My daughter appears to be very happy with her new home. When I have her over she asks to go back once she has seen everyone and had a good hot meal. My main concern is I have

asked for her or sometime attempt to ask for her by leaving messages and it is not responded to, especially holiday season when consumer likes to be with the family.

The group home she is in is the best placement she could possibly have. I know that the people who run the group she is in spend money out of pocket each month as what they get for her is not enough to cover all expenses (diapers, etc).

For the past 25 years she was in several group homes with different workers. She is now in a personal care home with a lady and her helper plus one other girl that is handicapped. This is the best place she has been in. I feel she gets better care and attention now than she has ever received.

I would like to take this time to tell you about my brother's care. His provider is excellent. We thank God for the care he receives.

I personally make unannounced visits to the group home and am always pleased with conditions there. I feel that my son is more content in his group home than he is on weekend visits to my home which both disappoints me and pleases me.

I really like the agency because the residents live as independently as possible. Personal hygiene is great and residents are happy.

1b. Dissatisfied with Home

Not right kind of food prepared or served. Same meal, only turnips and rice. Money not spent right. I wished someone not connected with staff would visit. I'm from {TOWN}. I think a lot needs to be done.

My sister was in a group home for 10 years and did well. She loved her caregivers and director, and going to {AGENCY} each day. She would go on picnics, concerts, baseball games, Six Flags, etc. When she was moved because the group home dissolved, she was placed in a totally different setting with people who were not properly trained to work with the population in their care. My sister was greatly traumatized by treatment she received. She had to be removed and placed in an entirely different setting. She had to have 24 hour care, before she was semi-independent. It took almost 3 months for her to recover enough to be returned to a proper environment.

I am not too satisfied with my family being away from home from our family. She sometimes doesn't like to go back to her home provider after she has visited her home on weekends. I have thought about asking for a change to another kind of service, like a provider that could come in my home and help me with my sister. I was offered that but I didn't know how to explain about it at that time. I am not so pleased at times when she comes to visit me. I don't like the way she is clothed sometimes, but I can't explain it to the home provider. She thinks I complain too much about my sister. I wish I could bring her back home, but I would need a little help. If that could take place, please. I am so glad I am able to hear from you all. Yes I would like to talk about a change for her if it can be one.

As a parent I would like to have a facility closer to home, rather than have my daughter 225 miles away. There is nothing in {TOWN} for her.

It is so hard for us to try and find anything for him, his employment and housing I just lucked upon, because I had worked with them at one time. Even now because I can't find help for him he has lost his apartment (assisted living) and had to move 45 min away instead of 10 min, and he is not happy and I want to move him back home, and all because he doesn't make enough money between SSI and his part-time job, which he may lose because of being so far away and transportation, and they love him where he works now. It is so frustrating, because all he wants is to live a normal life, like his other 2 brothers who are normal, he doesn't want his disabilities to hold him back and my heart goes out to him, as he says "*I know something is wrong up here (head) but I'm smart.*" It's like digging for gold, and the map is hidden, forbidden thing it is not an easy thing for a proven disabled person and their families. You should try it some time, it is a big expense if you have disabilities. Thanks for your concern.

My sister was moved from {AGENCY} to other places and I'm not happy at all!

1c. Accommodations with Home

My family member has been served in the community for almost six years. We have been fortunate to have the cooperation of your office to assist us in creating an appropriate and safe community residence. Recently, it was necessary to change provider companies. Your office granted the new company a six month waiver to the waiver in order to have time to create just such a space. Last week, we were notified by email that this provider will not be creating a four person living arrangement as they agreed to in {DATE} and is no longer willing to serve our family member. We have been lied to and personally insulted. We were given 30 days to make another arrangement for our family member. In the same email, we were notified that this provider would continue to serve our family member in the present arrangement as long as they were serving others in that location. We have no idea how long that will be. This provider has not scheduled a meeting with us to discuss differences as is stated in their information packet. We immediately contact our service coordinator's company leadership at {AGENCY}.

1d. Furnishings/Cleanliness of Home

My family member is often not aware that heat, AC or other electrical appliances are not working properly. He badly needs more practical help.

In 2005 her room the floor was wet for about 6 times in 3 months. The staff did nothing to fix until I called the health department in Atlanta. I think her case worker or the person in charge of group home does not visit the group home or care about anything.

1e. Waiting List

I feel that my family member should be put into a MR home on a residential waiver. He's been on a list for 7 years. How long does it take? Other programs have been good.

2a. Satisfied with Employment/Day Programs

The reason I am late with this is because I really don't know how to word it. My daughter is 59 years old. She has C.P. She has never walked. She is in a wheelchair. She has been at {AGENCY} in a nursing home, group home, and has been in an apartment I really don't know how long. She goes a workshop 3 days a week, and is really happy. Someone comes in the morning and gets her ready for her ride to the workshop. She has breakfast and lunch at the

workshop. Someone comes in the evening, fixes her supper and helps her to bed. She is very happy. Hope this is what I was supposed to do.

We are generally pleased with both the residential program and the day service program. Particularly the day program where the same teachers and workers have been working for the nine years our son has been there. Thus, continuity, no-stress atmosphere is prevalent, contributing to everyone's benefit.

2b. Dissatisfied with Employment/Day Programs

Many times staff members are not trying to obtain work opportunities for the consumers, but would rather show movies all day. This lack of stimulation causes consumer boredom, which results in behavioral issues or problems.

44- Have been told nothing more can be done job wise. Work very spotty

The only areas I feel consumer's services are lacking are when it comes to employment and employment training. Consumer has no job and hasn't had one for years nor has she received any job training. She and her service worker fill out applications occasionally, but they don't seem diligent about it nor do they seem to follow up on the applications. Maybe they do, but I'm not around enough to see it. Since I am not consumer's guardian the caretakers aren't obligated to tell me anything, but they do and they try their very best to communicate information. My concern about consumer's employment is that she barely scrapes by and sometimes will only have bread or cereal to eat when I visit her. When I ask she just says there's not enough money. I may be wrong, but I don't remember this being the same with money and food when she was working. I think she also felt more "purposeful" when she was working.

We wish there were more work opportunities here for my son.

The workshop is a vital part of the community. Unfortunately, the contracts for work are difficult to obtain and for long periods of time the participants are without work. If there is anyway to help the workshop obtain contracts I am sure it would be appreciated by all.

The {AGENCY} where he works has very inconvenient hours when our family member has to work on weekends. They have to be at work a 7am, which means the houseparent has to get the residents up about 2 hours earlier than usual (weekdays, the work starts at 10am). This seems to me to be subjecting people who are already mentally handicapped to a 2 hour jet-lag, which certainly cannot make them any more alert. Other than these problems, we are very satisfied with his care.

3. Health Care

The health department used to keep her on meds for mental problem, but they just stayed with one level and there was no feedback when my sister asked to change it, see how medicine would be on a lesser level. So she quit taking it. Pay an MD to oversee that as well as her physical care. He is doing a great job. She is very happy.

3a. Health Care Equipment

My niece is almost totally deaf. The family is trying to get her a hearing aid. I feel she will be happy once she can hear.

There should be more active and hands on equipment for the disability people to use and learn how to use. Especially for those that don't speak. Get more computers for this.

Overall, we are very satisfied with the services provided by the state and his group home. However, adaptive technology should be utilized to further enhance client's growth and development. Learning does not cease because a student has completed his public school education. Acquire computers with touch pad keyboards and special education software available from IBM or Edmark.

Consumer needs a bath chair and a new transfer sling for his lift. He also needs repairs on his wheelchair. He needs dental care/cleaning. I do not know who to contact concerning these needs.

3b. Health Care Insurance

Family members must pay for private mental health services. Appointments are too brief to provide adequate support for clients.

3c. Dental

There should be some way the case manager could assist in obtaining preventive dental care and eyeglasses.

There is poor follow-up for medical and dental problems.

Can't find many qualified dentists that will treat disabled persons. You have to accept their limitations or get no dental services.

3e. OT/PT/ST

I have no complaints now except for lack of PT and speech therapy which I believe would benefit my daughter. With persistence and guts I got most of what was needed. I am fortunate as is my family and especially my daughter. I pray the State DHR will improve after this survey. I commend the effort.

5b. Dissatisfied with Transportation

The residential house parents tell us that the bus which takes our family member to and from work is erratic – they can't count on the time the bus will pick him up or bring him to the group home.

Also, I would like to see each site with a decent van for transportation purposes.

Our workshop is badly in need of transportation vans. The newest van has 200,000 miles on the odometer.

In general my son is doing well. He and I are reasonably pleased. The major problems affecting his life are: rural community. No public transportation. Agency does a good job with appointments and work but has no provision for transportation to social outings that are individual as opposed to group.

Consumer (...) needs improved transportation for overnight visits with me and his father.

Transportation is now handled through {AGENCY}, as the state contracted provider over the years was horrible and unsafe.

6b. Dissatisfied with Recreation Activities

Little is done through the residential program to integrate disabled person into the community. Recreation program through the residential agency is totally inadequate, practically non-existent.

Another issue, which seems to be getting more attention lately, is participation in activities, especially on weekends. There are many, many activities provided for the disabled community free of charge. Once the provider is signed on (and our provider is signed on). Therefore, we hope that our requests for more participation in these activities (such as zoo visits, concerts, circus, and horseback riding) will be pursued.

7b. Dissatisfied with Communication

The staff members seem to have trouble at change of shift to impart info to incoming staffers – forgetting some appointments, etc

The care provider is very “office hour” oriented with no sure way of contact after hours for those who live independently. Minimal or no contact in person or by phone even in event of illness. I feel his level of care would be well below the present level if I were not actively involved.

43 – Most complaints have been done verbally or letter. Not familiar with written formal grievance filing... Frequently messages are left by me when residential support workers don't show up and message is not received or handled for several days and then when new attempt to resolve the problem it happens again.

I am 78 years old with chronic health problems. The only time I hear from someone at the group where he live is when I care.

Since coming out of the {STATE HOSPITAL} and care was picked up by the {AGENCY} we have received no information except for one call telling us that his supervisor quit and another was taking over. I know nothing about medications, physical health, and mental health. This was not the case when the state was in charge.

The provider, {AGENCY}, never contacts me. I feel the host family is very possessive of my family member. I'm never made aware of an important decision or any problem that arises. I'm never involved in medication decisions. I discover changes when I dispense medication during our monthly visit. I think the families need to be kept in the loop.

Also, communications between members of all staff needs to be improved. It's very difficult to get information from staff members because no one seems to know what's going on.

Our family member has behavior problems along with his mental retardation. For the behavior, he is often put into the local psychiatric ward (hospital) to get therapy and medication adjustments. He at one point even went into the state hospital. Rarely are we told about these hospitalizations until they are well underway or even already over for quite some time. We would like to be informed as soon as they happen. Otherwise, we have no real complaints except that.

As a family member, I am rarely contacted about what services are being offered to my sibling and feel that choices are made that the client is not mentally able to comprehend and therefore are not, in my opinion, the best for his needs. Please involve willing family members to be a part of the decision making on daily services that are added or taken away. Also, no one has ever given me a list of what is available for the mentally retarded.

8. Aging Caregiver Issues

Will the care be there for her when we die?

It is even hard to find a doctor and dentist now that he is older.

As you age, group homes are a “godsend” for families. Parents age, siblings have obligations and your handicapped child likes living independently with her peers. They like her family’s routine, like being employed and like having ‘friends’.

Our only problem is the distance to visit him. As we get older we can’t visit as often as we would like but I can call at any time and am kept informed as to his health, etc.

There is nothing of value available for him when I am no longer able to care for him.

My sister is in the {AGENCY} program. I am very pleased with the program. However, she is getting older and I’m concerned about where she will live if one day she must leave the {AGENCY} program. {AGENCY} has been a life saver for our family.

9. Transition Issues

Consumer is in process of change right now. She was in a Medicaid waiver subcontracted group home but is now in Medicaid waiver group home with main provider {AGENCY}. She is being moved from there to another group home that can better meet her needs. She is also moving to a different day program since old one is too far away from new home for transportation. She is adjusting to the changes.

10a. Satisfied with CM

She has been a huge comfort and is making every effort to see that this transfer to a new provider of service takes place as soon as possible. This could take several weeks or months. She has also assured us that our family member will be served responsibly and appropriately.

10b. Dissatisfied with CM

Support coordination continues to be problematic and do not know the person. Timeliness as authorizations is 90 days late. Changing service providers is difficult because of this. Want to be able to change support coordination agencies.

Overall, we feel that our daughter's participation/resident in the group home and involvement work as via is positive and satisfying for her. However, we are disappointed with the infrequent contact with her supports coordinator.

Any problems or concerns are quickly handled by me with the providers as I don’t hear from support coordinators very often. Would like continuity in that area (consistency).

10c. CM Turnover

The biggest problem that we encounter with the agency that manages the services of my loved one is the turnover of their staff. Especially their case managers, sometimes they have two people in one year.

Too much turnover of supervisors I hardly get to know them before they leave.

Service coordinators change with great regularity. Little to no contact except for ISP meetings.

My sister's case workers are constantly changing – two in the last 3 months. No sooner to they get to know each other, they're gone.

Unfortunately, the relationship between the consumer and the service monitor has room for improvement. It's critical for the consumer to have a long-standing relationship with their service monitor. On many occasions there are lapses between when a new monitor is assigned, due to high turnover of the monitors and restructuring. The importance of a relationship between the consumer and the monitor cannot be stressed enough. The growth and well being of the consumers are dependent on the quality of this relationship.

His 'case manager' with the state agency has changed at least 4 times in the past year. I don't know who his case now belongs to- In general, there are not near enough respectable programs available for his population. The responsibility is solely on the family and I'm sure many feel as I do that we are each 'reinventing the wheel'.

11a. Satisfied with Staff

Of the original staff at this home only the lead person is still full time, providing consistency for the residents. She is a jewel and should have more support from the service provider including help with transportation. As you can tell, I have some frustrations and feel the service provider could do better and should provide more to help staff. My daughter loves her home and except for staff who are totally dedicated she would not feel the same

I appreciate everything {AGENCY} has done for my sister. However, I did not agree with the wonderful group home that was disbanded. The workers were great and having just retired after 28 years with special needs children in a school setting, I know how to recognize people that care. Thank you.

I am very happy with the staff and with the services my family member has been receiving and so is she. Our thanks to them!

We love the people who work with {NAME}. They went over the call of duty for my sister. Consumer loves each and every one. They take her to church and a lot of activities, and even their own family get-togethers. They treat her like their family. I can't tell you just how great her staff is to her. God sent these women to me and my sister.

At the present, my son is very happy with is day care and with his residence facility. His support workers really care about him and my family. It took me 6-7 years to find the right situation for my son and now I am at ease and don't worry what will happen to him now or in the future.

We are thankful for the staff and the services at the center.

My brother has been at {AGENCY} for a number of years. They are a wonderful couple and have taken care of my brother as if he is theirs. They do a great job and should be emulated by all.

My daughter lives in a group home with three other residents. The staff is very good – they are our extended family. I am so thankful for each one of them, because they do so many things for her that I am physically unable to do. I am always made welcome – they are the best. Thank you.

I feel the staff of my son's group home do an excellent job. They are loving and caring people.

Consumer is very happy and I believe she is well taken care of. But something just as important I believe these people love her like family. If she was mistreated she would let everyone know it. (...) I am so thankful for the life she has now. In my mind she began to live when she came to {AGENCY}. God has blessed her. She loves everyone and they also love her.

When I visit my daughter, I feel like the staff is doing a superb job at taking care of her and supplying her needs, according to her disability.

I am satisfied with the person staying with my family member.

We are satisfied with the people that she works with.

11b. Dissatisfied with Staff

Just sometimes, staff is short or late picking him up from work. I'd like for more balanced meals to be cooked.

She wants only to be loved. Thanks for this survey. The group home needs people who really care. Some of the staff does, but most don't. Concerned.

My brother became part of our family when he was four years old. I met him when I worked at {NAME} State Hospital and he was a patient there. He began attending a service center at that time, and has attended the center for 37 years – except for 3-4 years when he was mainstreamed into the public schools. He moved into a group home managed by the center 13 years ago. My brother has always had periodic problems with aggressive/violent behavior. However, after my father's death 9 years ago he had 5-6 months of running away and other problem behaviors. Then about 1 ½ years ago his problem behaviors began escalating again. The workshop began an incentive program which increased his work performance and decreased his problems. In {DATE} I suggested that the group home also start an incentive program. I was told they were not set up to offer incentives. His problem behaviors became more frequent and more serious. When I met with supervisors or the director of the center, I was told that they were already doing everything they could. For over 36 years my family and I never had a complaint about services my brother received. We were active in his life and in center activities – my father was on the Board for several years. Since {DATE} we have had many complaints. Three staff members and the parent of another consumer have told us that many of his problems are the result of how he is talked to and treated. Staff will not return phone calls or get back to us with information such as the number of nights he can stay out of the group home. Staff agree in meetings to implement a plan, but then several months later say that the plan didn't work and they had discontinued it. The Director has discouraged me from working with his support coordinator who has been very helpful to my brother and the family.

He has also told me that I am the problem and not my brother; he then suggested that I take him out of the center so that the Director and I could part as friends. I have talked with regional office staff and one has attended a planning meeting for my brother. {NAME} State Hospital staff presented a model support plan for him at this meeting, and everyone seemed to agree on incorporating it into his ISP. However, the next day at his ISP meeting, the Asst. Director asked what I had done to find my brother another placement. He then proceeded to insult my brother's support coordinator. I might add that {NAME} State Hospital reported to the regional office that my brother's civil rights had been violated by having his personal property taken as punishment. A few weeks later staff who conducted his annual medical review also reported another civil rights violation to the regional office. In short, staff at the center do not tolerate anyone advocating for a consumer whether it is a family or a support coordinator.

I am getting very involved with my child but would like more input on who works in the group home. We need tougher screenings on applicants, particularly the ones who work with the non-verbal clients.

33 and 34 – have no say in who's hired. Prefer ladies who are more attentive than men. Reported problem with man support worker to man and he stayed on. Re-reported to woman much later and man support worker no longer there... Residential support workers are frequently not reliable due to low pay, short hours, other jobs, and family responsibilities.

Lack of consumer supervision and commitment to providing quality services. Clients aren't always monitored as closely as necessary. Some staff is not committed to their job duties and appears to be there only to get their paycheck.

Sometimes our son's possessions we buy him are taken. We confronted the house manager about it and the person was said to have "borrowed" it. It was returned. This and similar things have happened. Most of his caretakers seem to be caring, but sometimes they don't seem to be and don't do but the bare essentials. They probably feel they don't get paid enough. Some go to great extent to make the consumers happy, others don't. I think caring is the top characteristic needed by staff- then everything else will be done well.

Supervisor over home now is inconsiderate, unorganized, doesn't consider clients needs a priority, does not communicate with parents, has advancement of career on mind more than meeting clients needs, does not give much help to staff in home if problems do occur. She creates more problems.

I am very involved in my son's care. I am not always happy because the agency seems more concerned with money than care. I think the State needs a better system to watch over the agencies regarding the care and how the money is spent. Also the caregivers are not screened always. Background checks are very important and in most cases medical training should be required.

When they have a problem and I get a call from my sister, staff calls the supervisor takes 2 hours for her to come. Medicine not given at the right time. Clothes that staff buys do not fit or not right for her. Her other sister and myself buy all of her good clothes. I have to have them dry cleaned myself or staff washes them wrong and they are ruined.

Overall we are pleased with the services that are provided for consumer. The main problem we have is with her staff. They do the best they can under most circumstances. Because her

provider must pay very low salaries they employ mostly foreigners that do not speak good English making communication difficult. There have also been problems with their dishonesty

11c. Staff Turnover

My son lives in a home with 3 other residents and live-in staff person. I really like the live-in model, but staff turnover is sometimes high and supervision has to be live-in until a care provider is hired.

Too many support worker changes.

People like my sister do not like change. Her case workers are constantly changing – two in the last 3 months. No sooner to they get to know each other, they're gone.

Staff turnover has always been a problem and I am never informed of supervision positions that are family members who to contact until a replacement is in place. (And then inform us of the new person).

Staff turnover within the group home continues as a problem, and more of the direct day to day staff speak with heavy accents which makes communication more difficult.

The biggest issue is the constant turnover of the staff. An evaluation of the turnover needs to be done and appropriate action taken.

Secondary staff at my daughter's home changes because of behaviors of other residents and only one staff person provided by service provider. Of the original staff at this home only the lead person is still full time, providing consistency for the residents.

There is a large turnover in staff. Pay scale and hours may be a problem.

His care is complicated by frequent staff changes and staff rotation.

11d. Shortage of Staff

I visit my sister weekly most of the time one Sunday. Most of the time there's only one staff on duty.

Messages are not always forwarded, staff shortages can be a problem, and supervisors are overworked, case loads are heavy

11e. Staff Not Qualified

Group home staff needs a minimum of health care training to assess/assist in times of medical needs. Most staff seem to be merely baby-sitters. They are unable to detect early signs of hypoglycemia, impending seizure activity, etc. They are qualified only to call an ambulance after the fact.

The primary concern is the lack of training for home managers on the importance of good nutrition and exercise. Many do not know the basics of a good diet.

All support workers and staff working with agencies serving the disabled should be required to have training prior to serving individuals and ongoing training while working with the disabled –

continuing education units should be required. It would be good if some type of classes and programs were developed to required certification as a support worker for the disabled, including basic CAN training and psychological and behavioral supports training. All support workers should be required to fully understand diagnosis and current care and support practices of those they serve. All support workers themselves should be required to undergo basic psychological testing and profiles for certification to determine if they have appropriate temperaments and personalities to work with the disabled. Funds should be increased for service workers training, certification, and salaries so as to provide trained, motivated and supported workers to serve this population of the most needy among us. What we provide for the least of those in our society is a reflection of our society at large.

11f. Pay Staff More

A major problem with community care are the very low wages paid to care givers and the resulting high personnel turnover. 33 - This is utopia. The question assumes support workers are available with various personalities and skills for the choosing. In fact it is difficult to find qualified support workers at the salaries that can be paid.

The salaries of both the special education teachers and caregivers needs to be upgraded and reviewed. This would reduce the high turnover and ensure a more competent and professional staff.

I wish staff were paid more money so they would stay longer.

13. General Well Being

Sometimes I go and take her out for a ride and get her something to eat and drink and have brought her home for a while. But lately I've not been well. One time this summer she had on winter clothes and I know she was hot. I got her some shorts but they will get gone. I don't see too many things for her to wear. This is true and it upsets me. They could go to Goodwill if they can't buy something for her. In the day time they don't always leave the same people to look after her.

13a. Health

My family member has gained 30 pounds since last May when he moved there. I have complained, asking for help in controlling what he eats and how he shops. Being at the apartment once when he came in from shopping I saw a lot of food wasted, and I complained but I cannot see a change. Like a full gallon of milk for 1 person, the family size can of beans. He was allowed to buy clothing like underwear and socks which he over bought (had 32 pairs of undershirts, have no idea how many pairs of socks). Thank you for all the help. PS the apt. is new, very nice and comfortable. Could not ask for better.

We worked with the {AGENCY} to improve conditions and services. Consumer, with the help of truly caring and dedicated staff, and the help of God, has survived and gone through hell and back. Right now she is happy. We do, however, have concerns about the future – such things as will she ever go to a dentist's with 21 cavities again, or have severe personal hygiene problems?

My daughter lives in a group home in {TOWN}. She is doing well and she likes living there. There is a problem, it is my daughter's doctor, her psychiatrist. My daughter was taking the

drug, Cloaziril, before she started seeing this doctor, it would make her constipated but her bowel would move. But after going to this doctor her bowels became compact. She comes to visit once a month. When she comes home I would have to give her a laxative and do everything I know to get her to have a movement. The doctor must have increased her medication. I spoke to my daughter's coordinator about this, she said that she would have the doctor call me. The doctor called, and I asked her if she would decrease the medication or wean her off of it. The doctor said that she would like to find another medication to put her on, but she didn't. I asked the coordinator to speak to her about it again, the coordinator said she did, and that the doctor said she was not going to change the medication or dosage. I then asked the manager of the group home if he would get another doctor for her, he said he would have to ask his supervisor. That was over 9 months ago, he hasn't mentioned it since. My daughter's normal weight is 132 pounds and now she weighs less than 83 pounds. I talked to the manager of the group home, and he said he made an appointment for her to see a stomach specialist. The specialist couldn't find anything wrong. The reason for that could be because the doctor also has her on Risperadol. Risperadol masks signs and symptoms of drug overdose and conditions of intestinal obstruction. My daughter has recently been put on a laxative, her bowel is moving, but she is not gaining any weight. I was given a name and number to call for problems I have. But I misplaced it. I will appreciate any help that you can give.

I am the aunt of twin ladies, one is in a group home in {TOWN}, one is in {AGENCY}, {TOWN}. They are both MR, both have Parkinson's. I worry about over medicating, especially the one in the nursing home, at times she is like a zombie. They both have multiple physical conditions. I'm really concerned about their quality of care.

I believe my provider could do more to relieve my son's aggressive behavior. I haven't been able to persuade them to give him weaker medication more often. I think they do well as they are able. He is content – my heart breaks.

The only concern I have at present is the difficulty she says she's having with pain in her legs and feet. It is hard not being able to see to those needs myself, but I am confident the staff will do all they can to find solutions to ease her discomfort. I have been concerned at my not being able to oversee her daily care, but again am thankful for those who love and care for her in my absence.

My son is addicted to crack. I know that he has to have the desire to quit strong enough to make it. But I feel that maybe if someone would help him to try harder and work with him or recommend a place maybe he would succeed. I appreciate everything you do and thank you very much.

13b. Safety

At the present time, there is a conflict with another consumer in my family member's home which I feel may potentially cause an unsafe environment. The same consumer also attends the same day-habilitation program, where there are also problems. Therefore, my family member is somewhat unhappy to be where he is.

We have had serious and dangerous issues come up with consumer over the years. From nutritional poor planning – caused seizure and hospital stay – to {AGENCY} dismissing her with no one at the group home to receive her back.

On Feb 3rd my brother was attacked by a client who has behavioral problems. He was attacked again by the same person on Feb 7th. He was taken to {name} ER. I have complained so many times about my brother can't be around anyone with a behavioral problem, my brother will not protect himself. Nothing is ever done until he gets hurt. I am very concerned for his safety. I don't understand why situations like this happen, behavioral people shouldn't be grouped together with consumers like my brother. After the client was moved from group home, he was out on an outing with my brother the next day in the day program. This does not make any sense. I worry all the time about his safety.

13c. Abuse/Neglect/Mistreatment

A little over a year ago, I became aware of my sister being brutalized (this is no overstatement) by staff members at her former group home in {TOWN}. I began documenting/photographing the abuse even while reporting it to the company and the state. The overall result was continued, even accelerated, abuse for my sister. Then she was pushed out of the home – at Christmas – where she had been for 3 years, by the group home's company. The state has continued to stay strangely quiet, evidently wanting it all to just go away. Thankfully, she is now living in a much better circumstance in another county. In my opinion, there is little hope for any disabled person who does not have an advocate. The original company is well known throughout the country and was supposed to have a fairly good reputation. It has now entered into a practice which some might consider illegal regarding (completely dependent clients) self-care, so that there can be less staff hired. I have answered questions in the questionnaire according to my sister's current situation, however: too often, in the old group home, there were staff changes, which were naturally disruptive to all the clients in the home. But a good deal of the clients' distress was due in part to new staff having grossly insufficient training. The group home was filthy (i.e. urine soaked chairs left to ferment. This was due to one of the client's diapers repeatedly being left on for many hours without being changed.) A completely paralyzed client was left unsupported on a couch to just fall over, while the only staff on duty was on the phone in another room talking to friends for over an hour, never even checking on the client. Staff were allowed to take my sister – without my permission – to their personal homes. The staff-person whom I've proved (by photos and documentation), at least to myself and others who actually care, to have beaten my sister, took my sister home quite often. I have some evidence that there may have been sexual abuse happening at those times to my sister. If this is at all disquieting to you, the reader, I will say that it has been a nightmare for my sister and for me. These are not isolated incidents. If these things can happen with one of the "better" companies, let your imagination roam to think of what is happening to human beings trapped in the truly bad ones.

My daughter has had a toenail removed. Her doctor and home are making her wear her work shoes. How can her toe get well and it hurts all the time? They won't change things when you and I know we wouldn't do that on ourselves. We need people to have mercy. Thanks.

For 7 of the 9 years my son has been in a group home I've been mostly satisfied. This past fall my son was seriously injured. He had a broken jaw which required extensive surgery and he spent two months in the hospital – 3 of which were in the ICU. He was en route from his home to his day center when this happened. The problem is that the driver reported that my son had a seizure and was bleeding from his mouth. He was taken to a hospital where he waited 8 hours to be seen. They treated him only for a seizure because that was all that was reported. Two and a half weeks later I discovered a bone jutting upward in his mouth. He had been crying often and was eating very little so I brought him home to observe him. He saw an oral surgeon 5 days later and told me a seizure would not have caused such a serious injury. It had

to come from a major impact. I am very upset that someone didn't tell the truth (an accident occurred in the van – he fell out of his wheelchair or if fell over or something else) and his injury was not addressed. That caused him a great deal of harm. The internal investigation shed no light and didn't address how he got hurt. Even meeting with high administrators gave us no satisfaction. How could all the people who care for him not know there was something wrong when he cried so much and would not eat? He lost 10 pounds and weighed 78 at the time of surgery. I worry now about his care but have no other options.

Have had evidence of man support worker not doing job and hit (punched) son at least once with fist on back/shoulder area... involved in bus accident (rolled 4xs) broken pelvis (4 cracks). Police questioned bus driver's story.

It concerns me that others, living at home and working in the same setting have been scratched/injured by fellow workers and parents have not been contacted and there has been no follow through that they know of.

13d. Social

We are also fairly pleased with his day services but would like to see more activity and involvement and less babysitting attitudes. But they are very nice and it is a safe environment.

Little is done through the residential program to integrate.

Our service provides a monthly social outing and will transport to medical appointments if I request. Otherwise visits are unorganized and inadequate, often not actually in the apartments.

I am not sure that family member is evaluated and trained for a more productive life since his graduation from high school 2 years ago, where he seemed to have more meaningful cultural and job training activities as well as social events. I am not sure there is an outlet for his social and recreational needs.

The lead staff person at my daughter's group home does all the transportation to activities, shopping and appointments. Service provider (CCS) does not provide "inclusion" in the overall community. Pizza once a month and Blockbuster for a video does not in my opinion constitute "inclusion" or recreational activities. If not for my involvement and control of her Social Security she would not have the enrichment of a normal persons life. i.e.: bowling, theatre, restaurants appropriate to learning social behavior. Too often I have been chastised for not turning over these funds carte blanche to the service provider.

I would like to see more effort put into communicating with my family member and a more structured activity schedule so I will know what he will be doing at the center or in the community. I don't think he should just go there and sit.

I would love for my family member to be involved with more community activities. I would like to meet the providers and staff that goes with his care. Starting with the DHR, provider, contractor, and members of other families. I would like to have a quarterly meeting to find out about different activities or state activities and support groups offered.

13e. Hygiene

Our son is very happy in his group home. I would like to have the staff pay more attention to brushing his teeth and shaving him every day.

My some could use a bit more reminders about hygiene and appearance. The staff is almost always very supportive and kind to my son, he needs to lose weight but I get little help in this area. Generally, I am most pleased with his care.

Support fails to be sure child is well groomed

16. Funding and Budget

Will budget cuts destroy an already bleeding system? Thanks for caring to survey.

My concern over community residential placement involves several issues. First and foremost is funding. More money is needed in so many areas. Operational funds, staff salary, and staff ongoing training are just a start. Provider companies require at least four fully funded persons to share a residence. This creates a difficult match-up obstacle and staffing situation. Now that we are transferring to a third company, the initial funds to establish a home are no longer. It would be helpful if the money for set up could follow the person. Right now we are faced with no start-up money for a new home. Any agency elected to serve our family member will have to create a living space with no additional start-up money. This is an obstacle that must be overcome, but state funds for this purpose would be helpful. The question is how to get more money to address the needs of the developmentally disabled. It remains for us to continue to be open to new ideas and ways to give our family member what she needs to live in the community safely. In closing, thank you for this survey and the chance to be heard as an advocate.

There are not enough MR programs available. The people born with MR seem to be pushed to the back of everything. They did not have a choice to be born normal. There should be more of everything to help with them and their families. People who drink and take drugs have a choice to do it or not. People born with MR have no choice so they should be at the top of all services. It seems right the opposite. Why do the MR programs keep getting cut and the alcohol and drug programs keep getting more?

There are 750 developmentally disabled people in need of residential placement but no funds set aside in the state 07 budget. This should be a priority and added to the budget.

It concerns me that when money is short the retarded people are the first ones cut. I believe that people that are dependent on someone else to exist, they should be taken care of. Most of the time, people that are in prison are cared for better and quicker than a person with mental disabilities. Thank you.

I feel that the cuts in funds for the staff of the MR patients have hurt tremendously in areas of services of the MR Patients/clients. Also, this has forced the staff to make placement decisions for the MR clients as a have to instead of a need to basis. They are forcing these clients into the communities where they are not understood or sometimes accepted. Clients with severe disabilities and behavioral problems are being placed in homes with higher functioning clients and putting them at risk for harm, placing more pressure on the staff and families of these clients.

The lack of supports for day treatment, limited employment and dental and eye care are limited or non-existent. We are very involved with our child to give “foster mother”/caretaker an occasional break. Our bottom line feeling is that too much money is spent on drug and alcohol rehab which seldom works (and these people had made their own choices) and the mentally ill/mentally challenged/physically challenged receive the short end of the financial help. These need to be separate agencies. The challenged person has a lot to offer. The alcoholic/drugged people don’t even care to help themselves.

22-25 - Dollars have been cut in state and federal budgets to a point that DD clients suffer... 36
- The provider of services to my family member must conduct fundraising drives in order to provide adequate services for people with handicaps that range from moderate to profound. The money spent by the Div of DD is not enough to adequately provide these services. I think that funding for severely and profoundly handicapped should be increased. In other words, a sliding scale based upon degree of handicap.

I’m very concerned about any budget cuts to programs that assist people with disabilities who are not capable of supporting themselves.

17a. General Satisfaction with Services/Supports

Overall, I am pleased with my son’s level of care from his home to the state level. If asked, my son will tell you that he is blessed. He couldn’t be any better.

Our son is brain damaged. He does not speak but is able to communicate his wants and needs. He is physically handicapped and is in total care. Our son is happy and healthy in his present environment. We are well pleased with his care.

The folks at {AGENCY} in {TOWN} do an excellent job overall. My family feels very fortunate and blessed to have found services for our son with this organization.

I really like the agency because the residents live as independently as possible. Personal hygiene is great and residents are happy.

{AGENCY} provides residential services for my son, who used to be in the state program. Since his move to the {AGENCY} program we have seen vast improvements in his emotional and physical well-being. {AGENCY} helped to create an individualized program to meet my son’s needs. Because he is happier now some of his negative behaviors have decreased. He has gained 40 lbs which was badly needed and he is now at a normal, healthy weight. All programs are not created equal. I thank God for {AGENCY}.

First I would like to thank those who care for my half sister. She seems happy and enjoys her work, her time spent with her church family and with her family at the group home. “Since I have had health issues and am now diabetic and because I live so far away (7 hours) it is difficult to see her often. I do call her each week and look forward to her visit during the holidays.

Overall his program rates an A+++ thank you. Services are provided by {AGENCY}.

Our son is being well cared for. Thanks.

I am really pleased with the care and support consumer is receiving.

We are grateful as a family to have the supports our son needs. His provider of residential service is great and we are very comfortable with that arrangement. We are also fairly pleased with his day services but would like to see more activity and involvement and less babysitting attitudes. But they are very nice and it is a safe environment. Transportation is now handled through {AGENCY}, as the state contracted provider over the years was horrible and unsafe. Any problems or concerns are quickly handled by me with the providers as I don't hear from support coordinators very often. Would like continuity in that area (consistency)... A few "tweaks" to the system is all that is needed to have a really great regional system and, of course, additional dollars to reduce the waiting lists and completely fund programs for people with disabilities. Thanks for being there and asking these questions. Send more surveys and take results to legislators, they need education to work responsibly at the capital.

The restructuring of the regional boards has been very beneficial. They are, the regions, more actively involved in all activities. They demonstrate follow-through that was never evident in the past. The region makes sure all policies are implemented properly before, during, and after a house is opened. I appreciate the thoroughness in making sure everything was properly done before a license was given. {AGENCY} also deserves credit in making sure policies were effectively enforced. I feel confident that the region and {AGENCY} have my son's interests in mind... Overall, I am pleased with my son's level of care from his home to the state level. If asked, my son will tell you that he is blessed. He couldn't be any better. Thank you.

Overall I agree with the help and treatment my sister gets. However I would like for the state to check with the training center she attends about her attitudes and behavior. They are with her five days a week and know her pretty well. Some people that see her a few days a month or a few times a year can't judge her thinking and habits on just a few minutes with her. I suspect that this is how the guidelines for everyone are set up. Me and my family do appreciate all that the agencies do for our sister. Bless you for seeing the need and doing it.

My family member is very happy in his surroundings. He has always been a happy person and loves people. He's been in trouble in the past but it was handled in a friendly manner and he is a much better person today because of it. He lived with me several years before we found this place. I was getting on in age and often worried about his future but I am not worried now. I know he is in a good place and is with other consumers in the same condition he is in. That is why my daughter is also co-guardian with me – so she can be there for him when I can't. We are both very pleased with the care our family member is receiving. When problems arise we all sit around a table together and discuss it and everyone gets a chance to give their opinion and work toward a solution. In the very best of plans, problems do come up, but are soon solved by everyone working together in a friendly manner.

My son is severely retarded, and does not talk. Therefore, it is hard to know what he feels or what he thinks. I try to just drop in when I go to see him, so I can get an idea of how things are going with him. Usually, he seems to be ok. Thanks for your interest.

I am so pleased with the care and help my daughter has received. She is able to hold a job and be somewhat independent with a houseparent checking on the 3 girls who share an apartment. I'm thankful for her ability to do so well and be happy also.

I feel they do a good job and provide good services.

All of the services that my family member receives is excellent and we're happy so far with it. We really appreciate the survey and the concern.

Our family is pleased with the support our brother receives. We are appreciative the support is available because we would not be able to give him the same level of care at home now that our parents have passed away.

We have been very pleased with all services. We have been well informed and are pleased with the conscientious effort on behalf of our son.

Consumer is in a home operated by UCP. Overall we have been very satisfied and thankful for their services.

I am thankful for the services provided. Nothing is perfect and there is always room for improvement. But, all in all I feel if the families worked with the group home and the Arc we can make it work well for us and our family member. So thanks from a family that is appreciative of all they do.

Thank you for making the effort to better provide appropriate care for our DD child.

{AGENCY} is a state of the art facility in {TOWN} whose mission is to provide persons with disabilities opportunities for living and working in the community. Our son is buying his own home and lives independently with some support from {AGENCY} and us, his parents. We are extremely grateful for this organization that assists us tremendously in caring for our son.

This is to answer all your questions. I am happy with the organization who are taking care of consume.”

My daughter adjusted well. No one outside gives the care of a real mother. I have peace of mind about her care. I’m very grateful for the help received.

My son is being served by {AGENCY} and by the {AGENCY}. We are extremely satisfied with both.

We are very satisfied with the service that consumer has received from all the case workers and staff. They are the best. Consumer is very happy they contact us about changes re appointments, etc. The services have been a blessing to us.

My child receives excellent care. It has made my life much better. I receive all the support I need to provide a quality of life that far surpasses what I thought we’d ever be able to do.

Financially she is well taken care of in a state regulated personal care home and is in a family setting with peers. It is a clean and safe environment and she is very happy and content (as she can be). She receives financial help from the state which we could not possibly afford even before we retired to fixed incomes.

Yes, I am very pleased with the services.

Our loved one is autistic and unable to speak. We feel that his care is good and that he is as happy as is possible for him.

17b. General Dissatisfaction with Services/Supports

I’m not happy at all of the services he receives at the {AGENCY}.

My daughter is not happy with her adult day center. Not enough staff to work with her – it's basically a glorified adult sitting service. The agency providing her care is looking to provide her day support without walls, with one person working with my daughter in the community several hours a day

Day habilitation center is a very dark, isolated building in a very crummy area. Staff does not follow up with goals that are written in ISP plan. They never contact me regardless of the situation. My son hates attending this center but I have not received any support from support coordinator (or any staff member) to obtain better building in nicer, safer area, where staff are willing to work on carrying out goals. I have been working on obtaining better day habilitation services for my son for several years. I receive promises that are never fulfilled.

The day program is handled by the county and it is not much more than glorified babysitting.

17c. Access to Services/Supports

There are not enough group homes to house patients.

17d. Information Regarding Services/Supports

I would like to be more involved with his health needs.

We do not know how or what her money is spent on. She draws over 600 from the state and from tearing paper make money.

Need more information on what I need to do to be my son's legal guardian or conservator. I'm the parent of this 30 year old black male, should I be concerned about legal guardianship or conservator? Need more information about how son's money and waiver are spent. How much was in his waiver?

Info is sent home with him and I'm not aware of it.

As a family member, I rarely am contacted about what services are being offered to my sibling and feel that choices are made that the client is not mentally able to comprehend and therefore are not, in my opinion, the best for his needs. Please involve willing family members to be a part of the decision making on daily services that are added or taken away. Also, no one has ever given me a list of what is available for the mentally retarded.

17e. Need More Services/Supports

He needs speech therapy and needs to be involved in the dynamics of conversation. He can carry on a conversation but he needs to be encouraged to do so.

I like my child's facility but would like more activities to be available to him. He's not able to work or talk. He signs a little but does enjoy getting out even if he can't work.

My son could benefit greatly if he had some academic training. He can read some (self taught) knows all the numbers, counts to hundreds.

1- Has had a single apartment, but has spent much time with us due to limited services and illnesses... 17- recreational therapy only, but not enough... 40-42- not enough community

activities and services and supports have been lacking to date... 45- some, but both job and residential services have been lacking.

I feel that there should be more support services for the mentally & physically handicapped. There are few to nil in this area.

I am very disappointed that no residential support is available in {TOWN}. My relative has been moved to {TOWN} recently. No agency can or will serve him in {TOWN} for his residential needs.

There are not enough MR programs available. The people born with MR seem to be pushed to the back of everything. They did not have a choice to be born normal. There should be more of everything to help with them and their families. People who drink and take drugs have a choice to do it or not. People born with MR have no choice so they should be at the top of all services. It seems right the opposite. Why do the MR programs keep getting cut and the alcohol and drug programs keep getting more?

It would be wonderful for my brother to receive more state assistance.

I have contacted several agencies in order to keep my brother at home and not put him in a nursing home and no one has tried to help me at all. I had to get him on Medicaid QMB myself because the lady was not helpful at all or any of the state coordinators. I had to put my brother in a nursing home {date}.

17g. General Dissatisfaction with Service Management

Issues and concerns with Service Center. Lack of professionalism in the management of the service center. The Director is not open to discussing matters with family members or other concerned parties. The Director uses intimidation and control tactics to avoid handling issues and concerns by staff, board members, and other concerned individuals. She is very close minded and lacks the degree of professionalism needed to adequately run this center. Additionally, there appears to be little scrutiny into hiring staff to supervise consumers. There have been known thefts of service center property that has been ignored and never investigated. There is little to no staff supervision by the Director. Director is not available or accessible to staff when issues arise, because of her frequent absence from the center. Some staff salaries are too high for the amount of work they produce. There is no consistency in how raises are given, which reflects favoritism. There is much turnover with the Board of Directors, because of her inability to accept constructive criticism. Although there is an Interdisciplinary Team to screen and review consumer admissions, team input is rarely used as the Director makes sole admission decisions. Because of poor judgment admission decisions by the Director, some more aggressive consumers have actually injured other consumers not able to defend themselves. This is also obvious because the weaker, less defensive consumers show fear and avoid being close to them.

My family member has been served in the community for almost six years. We have been fortunate to have the cooperation of your office to assist us in creating an appropriate and safe community residence. Recently, it was necessary to change provider companies. Your office granted the new company a six month waiver to the waiver in order to have time to create just such a space. Last week, we were notified by email that this provider will not be creating a four person living arrangement as they agreed to in {date} and is no longer willing to serve our family member. We have been lied to and personally insulted. We were given 30 days to make

another arrangement for our family member. In the same email, we were notified that this provider would continue to serve our family member in the present arrangement as long as they were serving others in that location. We have no idea how long that will be. This provider has not scheduled a meeting with us to discuss differences as is stated in their information packet. We immediately contact our service coordinator's company leadership at {AGENCY}. She has been a huge comfort and is making every effort to see that this transfer to a new provider of service takes place as soon as possible. This could take several weeks or months. She has also assured us that our family member will be served responsibly and appropriately.

17h. Waiting List

1. Consumer has been on the short list for a Medicaid waiver for 4 years. We were assured 6 years ago that he would get a waiver as we still help supplement his group home room and board – this is ridiculous. 2 – There should be some way the case manager could assist in obtaining preventive dental care and eyeglasses. 3 – It took over 2 years for consumer to get into a program after high school. He had nothing to do during that time. It was only after constant calling by me about his increased behavior problems that something was done.

My child is supposed to start a day program soon. He has been in a group home almost 10 years and has never been involved in a day program.

19. General Concerns

As is Social Security goes directly to his residential company, I would like to receive a statement yearly or quarterly stating how funds were used for his care.

No accountability for money spent is provided to family member or family by residential and job support agencies.

16, 36, 37 – I handle financial and medical and transport to medical and other activities... 29 – moving to shared apartment (when recouped from ankle surgery) with more supervision. Has been at our home this time for over a month and may be here 3-7 weeks more depending on outcome... 38 – I handle some and he walks to church. Support worker also takes him out... 46 – He's a happy person most of the time. Frustrated when no support worker or no work.

I recently called and asked about burial insurance (of which part of his \$ was put into at {TOWN}) they knew nothing. As we are unable to take care of this in the event of death, we are very concerned as I do not want my children have to assume this burden in the event of my death.

I feel that people with disabilities is not enough on the "Priority List" of people in government. Georgia (especially South GA) needs to catch up with other States in helping provide supports for people with disabilities! My family is very appreciative for our Medicaid waiver and hope that soon there will not be a "waiting list" Thank you!!

Getting my son appropriate services & placement was a full time job. Monitoring & staying 'on top of' his placement also takes a great deal of time. Fortunately, I have the time to devote to being sure he is safe & relatively happy. If a change should be needed in the future, I would start the process over.

I think sometimes more could have been done for my child. Sometimes people act like the money belongs to them, and they give it out to who they want to get it. Thanks so much for help and funds my child did receive. Thanks.

My mother has Alzheimer's and my sister lives with her. I would say that she is mildly mentally retarded. Mother is getting to the point that she needs more help than we are able to give her and we know she would be better off in a nursing home. She sits at home all day by herself so far she hasn't strayed off. She doesn't take her medicine right. She doesn't know how to work the microwave and she burns things up when she tries to cook. She can hardly walk but refuses to use a walker or cane. She is very stubborn. She will not bath or change her clothes. I take both my sis and her to the beauty shop every Saturday. I am trying to get her meals on wheels started because she is starving to death. When my sister gets home after 2pm sometimes she thinks I call her sister her mother. She even thinks we are still living at home even though we are married and have families of our own. She has 5 children but I am the only one she can count on to help her. I pay all of her bills and buy their groceries. I know she is driving my sister crazy but even with mama in a nursing home I would still have a problem with my sister. Where would she go? She could come live with me but she loves her job and I don't know if we could work out transportation. I also work and I live about 16 or 18 away.

In regard to question # 36. I feel they should provide information, upon request, about his finances/checkbook. How much he pays for housing, rent, lights, and cable. How this is paid, by whom.

We have a great deal of trouble obtaining timely reports on the family member's finances. I have repeatedly requested that financial reports be sent to me monthly, but I only get a report when I go into the office and ask for it, and not always then. Over the years, I have occasionally uncovered errors in the finances (always corrected) and in the distant past have suspected some misappropriation of funds (unprovable). Overall, I am satisfied (not pleased) with the level of service we received. It could be better.

Unfortunately, after her release from {AGENCY}, the State did a poor job of selecting providers. It took me 3 years to find a good place on my own. The person who runs the group home needs/deserves her own provider license, but the State has been lax in giving her one after she submitted. She is absolutely the best person who I have known for my daughter. The provider for whom she works is less than that, but ok. My experience with the State DHR has not been good although I have volunteered to participate. {AGENCY} has almost killed my daughter by poor supervision of Meds (6 years ago) before I found her present residence.

The choices for services seem to be very limited. I am also shocked that there seem to be limited protection for adults with special needs, at least none in writing that I have found. I am very involved in my son's life – workshop, group home, etc, I even serve on the Board of Directors of {NAME} which provides social activities for special needs adults. It is still very difficult to find good services and protect the not so good services. I'm up for any changes.

PENNSYLVANIA

1a. Satisfied with Home

We are happy {NAME} is in a safe and caring environment. Our wish is for her happiness and to live a productive life to the best of her ability.

I am quite pleased with the facility my sister is living in. She has been a resident there since the age of 8 yrs old (43 years). The staff that works with her is quite amazing and I am thankful for what they do with the residence at this facility. I have never had a problem with getting answers when I have a question about my sister. I could not imagine her being anyplace else. I am grateful the facility exists.

Overall, we feel that our daughter's participation/residence in the group home and involvement work is positive and satisfying for her.

I am grateful for MH/MR/BHC system helping my family get placement at {AGENCY}. This placement has been a positive one for my sister. She feels needed and has a sense of purpose there. She enjoys the work she does there and gets along with most of the staff there. I appreciate the patience staff have with her as I know at times it can't be easy. I am very satisfied with the care my loved one gets there.

I am very pleased with the facility our child has been placed. I feel blessed. She is happy and more communicative and has a higher self-esteem. I am grateful for the good care she receives. Thank you.

Over all, I am pleased with my daughter treatment in the group home. She seems happy and healthy when we visit her at the group home.

My family member is very happy where he is. I am very pleased with his living arrangements.

We love the family who cares for our sister. She is very happy; I only wish I could supply the same.

We have found the leadership of {NAME} group home to be sincerely caring about the clients and careful in choosing the staff. We feel very fortunate to have {NAME} in this home. He is obviously happy here. {NAME} {ADDRESS} {NAME} is doing very well in {NAME} home under her care she is very attentive to {NAME} needs and very caring. Her new meds with her new doctor have made a remarkable change in her vocalization and being able to understand her more than ever before. She appears to be happy going into another year - she recently turned 85! And seems more "positive" than before.

Since moving from a large institution to a group home (much closer to me) I have been very satisfied with his care and no reason to exert any type of control. Since my husband death I am able to see him as often as we were younger. He seems perfectly contented in the group home.

We are very pleased with the care our daughter receives. We see her happy and content as her staff can make her. They seem to care about her very much. She is very loving with them. Her home is extremely well planned and she has some input with certain expenditures-things purchased with her in mind. She loves to ride in the van. She enjoys the day center although she does little to make staff feel she has accomplished thing they work some and teach her. As a whole we are very happy that our daughter is where she is. You should see her room. They knocked the wall out to make it pretty and get her to notice it. She is extremely happy to go in there and sleep. We really care for the staff and have a favorite one to keep. Although we must admit new staff seem just as great as the old. Those who have been hiring have done a wonderful job replacing the ones that leave. Our whole experience with {AGENCY} has been favorable.

The family has no problems with the services provided by the staff at the group home and the day program. We would never be able to provide this level of support. Thank you from all the family.

I am glad that {NAME} has a safe home and that he gets good care, I feel that it would be impossible for me to care for him.

For the past 20 years my daughter has resided at the {AGENCY} located in {TOWN}, PA. She receives excellent care, love and support from staff and the whole community. I thank the county's MH/MR program for making it possible for her to live in a community setting that is so focused on the welfare, happiness and growth of its residents. I have a close working relationship with the staff. The facility provides an environment where the resident is "at home" and this is evident everywhere on campus.

{NAME} is a content happy person. He really likes {NAME} and {NAME} at the group home. Also the work at {AGENCY} is wonderful. It makes {NAME} feel he is a contributing member of society.

My son is very happy and content in the group home he does get upset if they keep changing the care givers especially {NAME} who is very good with him. As far as {NAME}'s money is concerned I turned it over to {AGENCY}. My husband was very ill for a number of years so it became to much for me to handle {NAME}'s needs. {AGENCY} lets me know if there is money to be spent and this is fine with me. He is taken to his eye doctor in {TOWN}. He has his teeth and medical check ups and I'm informed on his constitution. I have {NAME} home every Sunday unless he has somewhere to go. He calls me twice a week so all in all he is happy and gets along very well with the clients he lives with. Thank you {NAME}

The services and care of my son at {AGENCY}, by {NAME} and {NAME} and others has been excellent. He gets health care, all meds taken to the workshop, he goes shopping with the supervisor and he likes to help around the residence he shares with 2 other young men. They seem to get along together and he seems to be happy when I visit him or he calls on the phone. The supervisor dials for him. I'm happy for him as long as he is happy.

My son is so happy in his living arrangement - I just love it! {AGENCY} has been a fantastic provider of services to {NAME}, and he is incredibly happy in his living environment.

{NAME} lives in a wonderful home. Can't wait to go back when he comes to visits mom. This was not the case in the past. He has a nice bedroom. I feel he gets out into the community enough. Always looks well dressed and healthy.

Overall I would say my sister is happy living in her group home with her new housemates. She always seems happy when I talk to her and says she likes her staff, I don't know her housemates very well, I have met most of her staff and they all seem very nice. I live far from my sister so when I get to town and want to see her I don't have a problem. When I take her home with me I only have to give notice so they have enough medicine to send with her.

We are extremely satisfied with the care {NAME} receives at {AGENCY}. He had previously spent some time in {AGENCY} and we were horrified at the way he was treated. {AGENCY} has been excellent and we can't imagine {NAME} getting equivalent care in a community setting

Our family member lives at {AGENCY} we are very pleased with the care and attention he receives there, and he is very happy there.

Though nothing is perfect in this life, the facility where my daughter resides comes close! We can participate in as little or as much of her programming as we want. It has been our experience (through comparison) that {AGENCY} is a gift. My daughter's care and well being are primary concern to the entire staff-from director, staff, to volunteers. This facility is a blessing.

Our daughter, {NAME}, has lived in a single family residence run by {AGENCY} for the past 7 years. {AGENCY} was a godsend to us when {NAME}'s mother could no longer take care of {NAME} due to the progression of her mother's multiple sclerosis. {AGENCY} is a wonderful facility; our daughter is receiving excellent care. God answered our prayers when {AGENCY} agreed to admit our daughter.

My daughter resides at {AGENCY}. I am very, very pleased with this facility and would recommend this facility to anyone who might be thinking about placement of a family member. It is a wonderful, caring, loving place. My daughter has learned so much (like how to eat food through her mouth). She never liked or knew how to eat. But with caring and patient staff she was taught.

My sister is living at {AGENCY}. I believe she is getting excellent care in a very safe and healthy environment.

My family member has excellent residential support by the provider. He lives in an excellent residential setting.

My child is in a facility that takes very good care of him. I am well satisfied with the care he receives. Our son has matured in the 10 yrs that he has been in the group home. He seems happy and gets along well with other clients and staff. We feel we are fortunate to have placed our son in such a friendly and caring environment. Because of our age we know that we could not attend to his needs as he has been taken care of where he is now.

Very happy with group home and the care they give.

My brother currently resides at {AGENCY}. It is by far the best place for him. My brother and family went through 5 years of very harrowing experiences. From nursing homes, psych wards and group homes. I feel that {AGENCY} is definitely the closest to a home type atmosphere. The employees and staff are superb human beings. I truly believe that the entire MR system would benefit greatly by taking time to see how a program such as {AGENCY} operates. Mentally and physically challenged people are special and should be treated as such!

Very pleased with the care son is receiving through {AGENCY}. He is very happy there. We are most grateful the he receives such excellent attention, commitment, stimulation and affection. All are very important to him.

{NAME} is very happy living in a group home. She is able to make her own decisions and with counseling seem to be doing more on her own then she ever would if she lived at home. Also, she goes places that she would never if at home. {NAME} enjoys working and being responsible, not depending on family to do simply things she is capable of doing. She has her independence, she is moving on with her life and seems to understand her illness.

My brother seems to have finally found a place where he is content. He seems to be able to be more of his own person, with his own room and things, even though he is in a group environment. And he seems to get along better with his new housemates. The staff seem to have a good connection with my brother, his needs and more importantly to him- his rights!

The program has provided opportunity for development and care not available in our home. She has improved in sociability and living skills. We enjoy close contact with her but with the security of knowing she will be cared for as we continue to age and face the uncertainties of physical limitations ourselves.

My brother is in a group home and is well taken care of. We visit monthly. The care in the group home is superior to the care he had in the main building.

I feel {NAME} is happy where she is at. They are wonderful with her. The place is beautiful and clean and all the staff is wonderful with her. They keep us up to date on everything.

My sister is 66 years old totally blind but seems to be quite well with her staff and the two girls that live with her. And I am quite happy with the {AGENCY} and staff.

My daughter is very well taken care of at the {AGENCY}. I couldn't have chosen a better place. They take good care of {NAME} and she seems to be very happy there. They even bring her down to my mother and dad's so I can visit with her. She is always well dressed and very clean and seems to be doing very well. I am very happy and relieved to know that she stays there and I hope she can live there for the rest of her life.

I feel comfortable knowing that my child who lives at the {AGENCY} in {TOWN} is well taken care of. I understand that he will have a home there as long as he lives. I am confident that he has a good home with good people caring for him. He comes home for visits regularly and always seems happy to return there. Sometimes there's a high staff turnover in direct care workers and this does concern me. Management always lets me know about any illness or accidents.

{NAME} is very happy in his group home setting. Staff is wonderful to him and to us. It was a good thing for {AGENCY} and we couldn't be happier! Thanks to all!!

We are very happy with {NAME} placement. We see the same staff that he had when he entered {AGENCY}. He has made small improvements to us, but big ones for him since entering {AGENCY}. He is happy there and is very content.

Daughter is very happy in the place she lives.

I feel that my son is very happy in the group home where he lives now. When we bring him home, he is always ready to go back to his group home. He enjoys going fishing, shopping, church and where else he goes. He seems to like his staff members. I am pleased with the work that the staff does for him. My son is doing very well at his home. We miss him very much but the staff can handle him more then I can.

My sister couldn't have a better life anywhere else. She has been there 47 years. They have done a superb job. This is home to her. We bring her to {STATE SCHOOL} every year for a month. She enjoys coming, but always glad to get back to {STATE SCHOOL}, she gets homesick, I believe, she misses {STATE SCHOOL}.

{NAME} has been a resident at {AGENCY} for more than 40 years. The quality of his care has been excellent. He is non-verbal but staff can communicate with him very well. We have been opposed to community placement and I still am opposed. He so well-adjusted to staff and facilities that it would be cruel to disrupt his life.

My brother has always received the very best care at the {AGENCY}. We have always been very pleased with all aspects of his care. We would never want him anywhere else since he has been at the center for years with the best care. We couldn't ever foresee moving him.

She is at {AGENCY}, being very well taken care of as she is completely helpless. Always she is clean, healthy looking, and content.

{NAME} has been in {AGENCY} for a long time. It has become her home and a wonderful place for her to learn and be happy. The workers have always been good, kind and thoughtful to her and also to me. It is a blessing to me to have {AGENCY} so close to my home.

{NAME} has been at {AGENCY} since he was 16 years old. He receives great care. He has had schooling, job training, etc. {NAME} could not be in an outside residence, it has been tried and failed badly. We are very pleased he is there receiving the very best of care.

My son is at {AGENCY}. I am completely satisfied with {NAME}'s care there. He receives great care and the employees are the very best.

The {AGENCY} has provided a stable and caring environment for {NAME} for many years. He is profoundly mentally retarded. Some behavioral issues. He is essentially non-communicative. He gets care 24/7 in a safe environment. He has progressed very little in half a century. A severity of his MR, not programming issues. He continues to be a candidate for 24/7 supervision and has no family remaining in {COUNTY} at present.

Our {NAME} is very happy at {AGENCY}. He is well cared for. We visit him about once a week. We take him to {NAME} mall in his wheelchair. He doesn't speak, but he smiles and waves to people. He knows and loves us and we love him dearly.

{AGENCY} has been a superior home for our child. {NAME} is very happy there... We sincerely want her to remain at {AGENCY} and not be transferred to {AGENCY}.

1b. Dissatisfied with Home

{NAME}'s apt is cold in the winter.

{NAME} lives in a church-run home. We would be happier if there were more facilities available thru the county so we would have a choice.

I feel that not enough consideration is given to the client living in the group home. Sometimes there seems to be constant stress between residents and I do not feel that this is adequately dealt with. I feel that in this situation an evaluation should be done and perhaps one of the residents moved to a different facility.

{NAME} is in a nursing home in media. {AGENCY} gave no good care. He is still not shaved properly, bathed. No one to see him. No one cares. Case manager does not do her job or staff. I have no transportation to see {NAME}. Bag still on side for feces. {AGENCY} did not

operate to correct mistake. His care is a disgrace to Mental Health system. They did not find what he swallowed. I have no say in the matter of {NAME}. It is inhuman.

I can always go to my sister's case worker from MR - {COUNTY} and get results for whatever the problem is. I feel the MR department of {COUNTY} bends over backwards to help my sister. I do not get the same response from her housing sponsor. They either don't know the answer, skirt around the issue or hope I never find out about whatever the problem is.

I am dissatisfied with the group home in which my family member resides.

I feel we need nicer group homes and I think the people in the homes so at least have something in common. Some homes have all well behaved people and some have all that need more attention than others.

Wish there were only three in a group home, instead of four, with only one bathroom. It makes it very inconvenient.

Over two weeks ago I left message for head of group home to contact me. Clothes I purchased for my daughter came home with her for visit with her initials marked through clothes with indelible marker. I think this is wrong as if she's retarded so make her look it... I never receive information on her money and bras (specifically) and other clothing is often cheap garbage. Inappropriate for large busted women. Complaints meet no results. I have told them often in past year I would bring my daughter home if it was possible. But having a disabled husband and raising twin grandchildren 3 years old it is not possible to give her time required at this time. When I go to the planning meeting, they talk over me as if I wasn't even there or stupid. I feel it is a total waste of my time. When asked they say my daughter is happy and laughs. My family (sister, my mother, my husband family) never see this now. She is a doped up unresponsive person from the person we knew.

My biggest concern is the incorrect placement of a resident in my son's home. This has caused numerous staff changes, confusion and sometimes violence, from this resident, the inability of staff to be able to take my son and another resident to classes, week-end outings, etc, due to the behavior of this resident. My son has learned to cope with this to the best of his ability, but it distresses me that he has to cope with this situation.

While I understand that finding residential homes are often difficult for the MR community from a personal stand point, having my sister in a residential home closer to her family would make seeing her more often easier. Think she would of the family who is caring for and loving my sister and I would not change that environment and upset her routine. It would be helpful if she were closer to us. My work schedule does not afford me the opportunity of being at her meeting this I am not as involved as I would like.

There have been promises of a new building for clients for some time now, but I see no results in the future. I am always very thankful for being able to have my daughter in such a facility as {AGENCY}.

She would be happier if she lived closer to her family.

My son is not happy where he is living and wants to move. Doctor's orders are not being met. Not happy with the people he lives with. Main complaint is the train noise and the problems that are occurring because of it.

I would like my son transferred closer to me. I have expressed this over and over again to whoever is my son's counselor or caseworker over the years. No response. I live in the state of Washington; he is in the state of Pennsylvania.

My son would like to live with guys closer to his age.

1c. Accommodations with Home

We need ramps...There is only one entrance to leave the house (reference to question #12).

Issue #1: Lack of heat in her bedroom. It is reported that if she wants heat in her room she must keep her door open at all times.

1d. Furnishings/Cleanliness of Home

{NAME} family needs help cleaning the house. The condition is awful.

2a. Satisfied with Employment/Day Programs

The work support program has been very good. They consistently enforce basic policies and offer encouragement to their clients.

The family has no problems with the services provided by the staff at the group home and the day program. We would never be able to provide this level of support. Thank you from all the family.

{NAME} is a content happy person. He really likes {NAME} and {NAME} at the group home. Also the work at {AGENCY} is wonderful. It makes {NAME} feel he is a contributing member of society.

Feel family member is well treated by family he lives with and does well at day program.

Since {NAME} has been home he has been going to the {AGENCY} and is very happy there. He started the program and he looks forward to it every day.

Overall, we feel that our daughter's participation/resident in the group home and involvement work as via is positive and satisfying for her.

I am grateful for MH/MR/BHC system helping my family get placement at {AGENCY}. This placement has been a positive one for my sister. She feels needed and has a sense of purpose there. She enjoys the work she does there and gets along with most of the staff there. I appreciate the patience staff have with her as I know at times it can't be easy. I am very satisfied with the care my loved one gets there.

My son does have a job on the grounds of the facility he is in. He likes it. - I wish I did know more of what he does and could be involved in. - I like the rule that restricts who can get in contact with him. There are those who could really mess with his mind.

2b. Dissatisfied with Employment/Day Programs

{NAME} positively despises inactivity. She loves to keep busy. While she was living with us, she was always looking for things to do. If she couldn't find something to do, she would ask if we

needed anything done. And she would attempt any task we set before her. An afterwards, she would always seek approval of her work. Consistently, the problem was finding enough tasks that were within the range of her capabilities. She has deficits in strength and coordination, in addition to her cognitive deficits. She's very good at sitting at a bench and putting green thingamabobs in red boxes and purple whatchermacallits in yellow bags. But there's a limit to those kinds of chores in a small household. In fact we had her going to a sheltered workshop twice/week in Oregon, and she loved it. We'd make her a sack lunch on Tuesday and Thursday mornings, and help her outside and onto the driveway before the bus came to pick her up. She didn't interact a great deal with the other participants, but she enjoyed the happy noise they collectively made. And she especially liked having something to do. {NAME} needs to be in a sheltered workshop. I made this clear early on the social workers here in Pennsylvania, but they've been slow to make it happen. The prevailing mindset is "hey, this lady is 74 years old. She should be retired!" that's how they think, so they project this mindset onto {NAME}. The bottom line is that {NAME} is bored! But they don't get it. So, what's it going to take to get her into a sheltered workshop?

I would be pleased if more work could be found for my son. He is bored without activity.

I think {NAME} should make more money at her job.

There are some concerns: his age vs. work productivity @ CIT

I feel {NAME} needs more than one staff during working hours until he gets employment. {NAME} needs to work but there doesn't seem like there is anywhere for him to work as he becomes aggressive. Am trying to get goodwill (where he used to work) to let him bring work at home to do. I need someone to help in this matter.

Very pleased with everything they have; however they were disappointed w/ OVR when seeking assistance w/ employment

I was disappointed when the workshop my son attends became just a training center. They seemed to really enjoy being in a work situation.

I am frustrated with my family member's work environment. When living in another state, there was a more positive work environment available. It seems that A.P.S. is the only game in town and I find it to be a stressful work environment.

3. Health Care

They are good in seeing basic health needs, such as immunizations, eye exams, foot care and annual physicals are done.

3a. Health Care Equipment

Walker problem. Have someone come out and measure {NAME}. He is too tall for the walker he is using. He has to bend too low to use the walker. Get out of the chair stretch hands out for 10 minutes to strengthen the back. Wear a pillow to support the neck. He should be taught to sit straight in his chair.

3b. Health Care Insurance

Regarding health insurance - he has none, and she never got back to me about it. So to my knowledge he has no health coverage

3e. OT/PT/ST

My sister and I feel that {NAME} needs to attend speech therapy. He is very hard to understand.

4b. Dissatisfied with Education/Training

It always bothers me that these places call themselves "training centers" and sometimes it's just like they don't want to take the time to actually work with the individual so how are they training people? To be dependant? Or independent?

5b. Dissatisfied with Transportation

I've asked to have my son to be transported to my home one time a week after his work hours. It seems to be a bit of an issue. From {TOWN} to {TOWN} which would give myself and my husband more quality time with him. We are now picking him up at his home after he gets home from work, which takes us an hour (picking up and returning). Also his hair cut appointment is now longer, possibly because they (the staff) say they cannot transport him to {TOWN} with the other clients. They can get his hair cut more locally, which is not an option because I am his stylist.

I wish my brother had the transportation available on Saturdays at 5:15-6:15pm to attend mass at {NAME} church in {TOWN}.

Transportation for recreation is unavailable. Her access to the community is limited to what her support staff arrange for her, and transport her too.

6b. Dissatisfied with Recreation Activities

The leisure time of a resident is always a concern. It is important that residents do not spend their day rocking and watching television, we feel that life in a state facility should be the same as life in a community based setting

Overall support services are adequate to meet my sister's basic needs - i.e., health and safety. Community involvement and recreational activities are severely limited and limiting to her overall happiness. She is left to find her own supports in the community. She has no friends, other than her staff. She would very much enjoy arranged activities with other consumers that function on the same level as her.

I feel that if the family member is fine, than the day program should allow them to go out and do things like see a movie, bowling, and be independent from those that are very dependent on others. If someone is not severely mentally disabled they should be able to go with staff that is willing to take them some where and have some fun.

7a. Satisfied with Communication

Basically I think we have a good working relationship between us all. We communicated quarterly and if need be via telephone at any time.

Everyone in the program is very helpful, informative from the program manager, nurse, to all house workers. I live 1,300 miles away and visit once a year but know I can call anytime and everyone is helpful, friendly and takes time answering my questions, listening to my concerns, etc. They involve me in many, many decisions for which I'm thankful. It helps me feel a part of my sister's life since I live away and we no longer have parents. Thank you for providing this service.

Before I was the guardian I seldom or never got the answers I was not satisfied with the way complaints/grievances were handled/resolved. Now that I am the guardian, I am always/usually satisfied. Years ago my sister was sexually abused by staff-not getting the answers my family was looking for led to my sister and I becoming her legal guardians. Since that time, as much as I can know, I have been told about any small mishap involving the staff.

The home, in which {NAME} lives, gives a quarterly review and if I have any questions or need any information, it is easy to contact them. Also, if anything happens, health wise, my home is contacted.

7b. Dissatisfied with Communication

Our only concern is lack of communication which often causes behavioral problems. Most of her support staff has a limited knowledge of signing.

The telephone system at the facility is outdated. It is very difficult to contact the person with whom you wish to speak. It is very frustrating to us not to be able to have a question answered by staff. When a specific incident is questioned the response is usually, "I was off that day", "I am from another cottage", "it happened on another shift", etc etc.

There are some problems with timely reaction to some of my concerns - mostly in regard to personal care I would like to see a change in the physical aspects of her residence building.

I would like to have more communication. A telephone call every 4 months from his teacher.

Our requests are ignored or forgotten. For example, we would like a monthly accounting of our daughter's finances. That has to be requested each month. We are not informed about medical visits even though we have asked to be. We are concerned that there are fewer outside -the-home activities than was originally the case. (Or is this another thing that we aren't told about?).

Contact after an incident is not always prompt

There is little, if any communication with staff at group home. Very seldom, if ever am I notified as to money needs. Was notified of a medical problem which I feel may have been caused by staff neglect.

The family is concerned about some health problems the consumer is having. The family has questioned these problems and has been told he's been check out. He continues to have these

problems and is unsure what is causing them. The family has never been told when he's been in the hospital until months afterwards. The family wants to know so they can see him.

I feel that the local residential support organization is not accustomed to working with clients with families who participate in the total plan. I recognize the fact that many clients do not have family members. The situation has improved but continues to need improvement in the areas of communication and planning.

Communication - why is a person who is not on emergency contact list called before someone who is? Also, why are we informed after a doctor appointment if we get informed at all?

{NAME} can't tell us how things are so it would be nice to have the county checking on things as well as us keeping an eye on them. They do not share what {NAME} does thru the week and frequently don't know what has caused {NAME} bruises. I called and spoke with Mr. {NAME}; he has given permission to share this survey information with county, state and provider.

{NAME} has had three staff members in the last one and a half years. All of which I was not made aware of until I had to track someone down for answers. This usually took months. I am still waiting to find out why or if {NAME} was cut from the Easter Seals fund. It's now October, I asked a supervisor of MR in July. No reply as of yet. {NAME} living arrangement needs changed and I know I will need to do all that I can to help him without assistance from MR.

One of the caregivers in my uncle's home is reluctant to share medical and daily log information. Inform them that I have a right to see this information when visiting his home, and to share any changes that have or will incur in the future regarding his care.

I would like to have an update on his physical condition. I was asked if I would consent to a wheelchair because of ambulation difficulties. I was told that an MRI was pending to assess the etiology of the neuro-ambulatory difficulty. I had asked some times the result of the MRI and I asked to speak with the doctor. I have received no phone calls nor has my request for an update on his medical condition been addressed.

The agency with which my child has been placed sometimes makes decisions for her without consulting me. These matters may seem insignificant to them, but they are important to me. I want to be more informed on where she's taken for outings, what of her property is thrown in the trash, and when and to which physicians/dentist she is taken (before they take her).

I am urging a permanent change be implemented when a request is asked for a return phone call from the house manager to the parents of the client (my son). When this problem is addressed to the director, it is taken care of for a while. The problem of not returning phone calls starts all over again. Presently, I have been waiting 2 weeks for a return phone call. This communication situation needs to be rectified permanently.

There needs to be 'more communication' between the group home, Quest, MH/MR, doctors, counselors, etc and everyone involved to us the parents. We only want the 'best' for our daughter and her needs to be met at all times.

I was promised a copy of {NAME}'s monthly report of how time with {NAME} was spent, but to date, have never received one.

The family is concerned about some health problems the consumer is having. The family has questioned these problems and has been told he's been checked out. He continues to have these problems and is unsure what is causing them. The family has never been told when he's been in the hospital until months afterwards. The family wants to know so they can see him. The family feels the staff is uncaring to other people feelings.

Family member is never contacted about any thing concerning their daughter and are very frustrated.

Does not really have time to be more involved with planning but would like QLC to keep her more informed. {NAME} has had some medical issues and the only way she has found out about them are through the Medicare statements.

Also the fact that a lot of times when one shift comes and the other leaves there was not much communication between the shifts, and it left things mixed up. That has always been a concern of mine. At the present time, I think the manager of my daughter's group home is addressing the problem.

8. Aging Caregiver Issues

I have been a step-mother for 32 years and always has been a joy, to have her at our home for a visit. Her father passed away 2 years ago and now at age 86 I am no longer able to do, as I am having health problems. My daughter also is required to use a wheelchair when outdoors. Thank you, {NAME}.

I worry about her. What's going to happen to her when I'm gone?

9. Transition Issues

My sister is in a transitional period at 5 months, after living at her former home for 27 years. We feel she has done very well, better than any of us expected. I think she needs to walk more, even though one of our biggest concerns is her precarious balance, a falling with a bone break occurring. I do want her to keep her strength. Her other home had larger spaces within the home and grounds for walking. We haven't discussed our first set of goals and how they are working yet.

My son gets ok service from {AGENCY}, but there are a few problems... 3. Planning - why does everything need to be a last minute crisis? If you knew my son was turning 21 for the last 10 years, why wait until he is 20 ½ to begin renewing his health care benefits?

Our most significant concern at this time is post-21 placement. We would like that addressed in more detail at this time to be prepared for the future.

10a. Satisfied with CM

My sister's social worker is the tops from what I can tell from our communications. The director - that's another story.

The social worker however has been thorough and her input is very much appreciated. She has been an important link with the center. I am very much impressed with her professionalism.

I have always had my questions and concerns answered by service coordinator and staff/supervisor at his residential care home. I don't drive and they always provide transportation to my home when {NAME} comes to visit.

{NAME} has had {NAME} as her coordinator and she has been there every step of the way. {NAME} knows her and is very comfortable with her and we enjoy having her part of our family.

My family has been fortunate to have a case worker who has gone above and beyond to meet our daughter's needs. Our input is welcome, no matter how difficult the situation. We have always been kept informed, phone calls are always returned with professionalism. Meetings are always attended by my daughter's case workers and others who show interest and compassion. Whether it's a hospitalization or other crisis, the team feeling is strong. We could never thank you and your team enough.

My daughter's caseworker from MH/MR is actively involved with her clients and has shown a high level of care and concern for my daughter. She does a great job.

I am extremely satisfied with my family member's caseworker. She is absolutely top notch and caring.

I am very pleased with the care and support my daughter and myself receive from the county case worker.

10b. Dissatisfied with CM

However, we are disappointed with the infrequent contact with her supports coordinator.

If my sister has a case manager through the local {AGENCY} I'm unaware who he/she is. I know when we had the last treatment plan someone was present representing {AGENCY}. I'm not sure what role {AGENCY} has with my sister except monitoring her placement there.

Mother called {AGENCY} to get a case manager for her son and was not successful.

10c. CM Turnover

Caseworkers from {AGENCY} are caring but there is so much turnover, it's difficult to know who {NAME}'s caseworker is from year to year.

11a. Satisfied with Staff

I am very grateful for the tender loving care my son receives at the group home and at workshop. They are very special, loving, caring and compassionate people. He's at a beautiful place. He's very happy and content. He has a very active social life and they give his life special meaning. I love the staff and the joy they bring into my sons life. I have no complaints and I thank god for his goodness where my son is concerned. Sincerely, {NAME}

I have made both announced and unannounced visits. In the past 10 years since I have taken over. The staff have been excellent and have provided excellent care. They are generally supportive.

I have always had my questions and concerns answered by {NAME} coordinator and staff/supervisor at his residential care home. I don't drive and they always provide transportation to my home when {NAME} comes to visit.

I have great rapport with the staff at {AGENCY}. I am informed when anything is in the wind before decisions are made. This gives me time to give my input on the subject matter. For the past 10 years my brother has been in the wonderful hands thanks to the staff. We have come a long way from the bad times to the good for my brother. We will continue to monitor {NAME} progress and pray for his happiness to continue thanks to the staff at {AGENCY}.

I have a close working relationship with the staff. The facility provides an environment where the resident is "at home" and this is evident everywhere on campus.

She is fantastic! She goes above and beyond and always looks out for {NAME} best interests. Since I do not live in the area and am unable to see {NAME} on a regular basis, I am so happy {NAME} has a person like {NAME} in her life! {NAME} is very happy!! {NAME} treats {NAME} like a part of her family. {NAME} also never hesitates to call me about vacations, meetings, health concerns, or to just have {NAME} say "hello". I am thankful that {NAME} is dedicated to providing the best to {NAME}.

I think the staff at the {AGENCY} does a wonderful job taking care of my sister. She is always kept clean and neat, seems to be happy and contented, and they show her much love. I am very grateful for each and every one of them girls that care for her.

My daughter, {NAME}, has been at ICF/MR in {TOWN} since 2005. She's adjusted to the change from home very well and is happy whenever we see her. I can't say enough good things about the entire staff - they are very loving and caring.

My son lives at the {AGENCY}, in {TOWN}. They have been very cooperative in having him meet me with a staff member, bi-weekly, for many years for a supper outing. I thank god for {NAME}, and other staff members for their support and help with my son.

{NAME} is fortunate in the longevity of some of the staff who work with him. These long term staff are strong advocates for {NAME}, especially in pursuing good medical treatment, but also in other areas of {NAME}'s life. They truly are {NAME}'s family.

I believe my family member is getting very good care and want to thank all who have charge of him as he seems to be very happy. The staff that take care of him seem to have time to listen to him and understand his needs. They are very caring people. Thanks again {NAME}'s sister, {NAME}.

Very pleased with staff at {AGENCY}.

My daughter is in a wonderful facility that accommodates her special needs and services. The {NAME} county staff are wonderful and available whenever I need questions answered or issues addressed. I feel very fortunate to have such wonderful resources and individuals available to both myself and my daughter. She is living a productive and fulfilling life and as a parent this is so important. Keep up the great work.

Most of the staff goes out of his or her way to try and make {NAME} happy. They know the things he likes and doesn't like. He gets off the campus to go out and eat and go shopping or whatever. The place is not perfect but what is? But they are trying.

The personnel at the group home are excellent and are always attentive to the needs of the residents. The home is always clean, attractive and a healthy atmosphere. The house supervisor is great, {NAME}. The office personnel are accessible to answer questions or to attend to needs that I have concerning our aunt. {NAME} and {NAME} are very efficient in handling my concerns. The workshop personnel {NAME} and {NAME} are very easy to approach and caring individuals. Our aunt really enjoys her experience at the workshop.

We continue to be very satisfied with the level of support and commitment offered to {NAME} in her group home. She seems to enjoy her work, her living arrangements and she likes the staff members at the group home. It's wonderful to have such a dedicated and caring group of folks involved in the day to day welfare and care of my sister!! Thank you doesn't begin to convey the debt of gratitude that I fell personally.

Home staff is very good with my son. We are very satisfied with them and how they handle and care for him.

The present house manager has made a tremendously positive difference. She has accessed services and activities that have added much pleasure to my sister's life.

Provider does excellent job for my family member. Staff is supportive and sensitive with his needs, in large due to low turnover of staff.

Very pleased with the service brother receives. Very impressed with the attention and consideration he receives from staff.

My sister seems very pleased to have her own room. They have helped her in every way-finding a job, shopping, and social occasions.

So many of the employees have also been [at AGENCY] for years and I know this also helps my brother. All his needs are cared for by the professional caring compassionate employees at the {AGENCY}. It is my brother's home. I simply can't say enough about how wonderful they are and have always been, in the caring for all their clients/residents.

My brother {NAME} has been in {AGENCY} for 38 yrs. The family has always been involved with his life. We feel he is happy and treated well there. If a problem arises the staff is always helpful in helping me solve it so {NAME} is happy again. I, as his sister and guardian will always see that he is well cared for and happy. I gave up financial guardianship as I felt {AGENCY} was more able to do that but I keep track that his needs are met as I would do. The family, my mother, who is 89 and I love {NAME} very much.

We are very satisfied with the help we have received. We don't know what we would have done without the help and support. {NAME} loves them all. They have been her family for so long. {NAME} is very happy. The staff are wonderful to her and to us. We are so grateful for all their help. She needs 24 hrs. Awake staff and has medical problems that are always addressed immediately. We feel so confident to have her in their care. They notice anything that bothers her or is different with her and they let us know right away.

I feel that both {NAME} and my son's county rep. {NAME} as well as handcrafters have his interest and concerns at heart. I do not know all the caregivers at his house, who change from time to time but {NAME} has been quite helpful.

11b. Dissatisfied with Staff

I know they don't have a lot to choose from, because wages aren't that great, but could do better with residential staff sometimes.

I would like to see more state and county surprise visits to her group home. My daughter has been in a group home for 18 years so I have seen many care givers come and go. Some are very good and caring people. Others lie and cover up for each other's mistakes and take my daughter out along with her 3 roommates to do personal staff's tasks, shopping.... I have seen a newborn baby of a staff person at the house and my daughter and her roommates in their bedrooms during 1 of my surprise visits. Two staff in living room, music loud. One newborn baby. One adult brother of staff and four girls in bedrooms. I have taken my daughter to the hospital on more than one occasion with her seizures very severe to need to be hospitalized and her weight to almost a critical state during another surprise visit. All this has been investigated by managers. It's two staff. I would like to see staff treat a parent like a parent instead of someone to lash out at or not talk to. Yes, no answers or going in another room and stay when I'm trying to ask how my daughter is doing and what she has been doing. This is a very old unresolved issue. I have spent so many drives home from what should have been a pleasant visit with my daughter crying and many sleepless nights. My daughter is a very special young lady. I love my daughter very much and I want to be a part of her life and I will continue to be there. Sometimes it's very hard when I have so many questions and concerns and I get one-word answers with an attitude

I feel it is extremely important that the staff supporting any person with MR/MH issues be highly trained in the area of teaching good values. Living in a group home has been a very positive experience for my daughter but there are concerns about how staff presents themselves around her (ex., using foul language, exposing daughter to inappropriate movies/TV shows, watching way too much TV instead of being actively involved in her day to day activities, speaking about other staff members in a negative way, staff members talking about personal problems, etc).

Sometimes it is very hard to reach the person who is working with my sister because of the helper's schedule. Also, it would be very much appreciated if my sister could have a permanent care taker instead of a person that is going to school and only has her for awhile. She has had some care takers that have spent a lot of time with {NAME}, taking her shopping and getting {NAME} gifts at Christmas also involving {NAME} with the care taker's family, which was very nice and then there were some care takers that just took it as a job and hardly spent any time with my sister.

The staff show no interest in completing any goals that are outlined in the plan.

I would ask that you urge staff to be consistent. I mean being consistent with keeping to a planned schedule not consistent with missing planned time. Consumers know when they are being patronized no how pleasantly it's done.

My son gets ok service from {AGENCY}, but there are a few problems: 2. Culture - having people from other cultures is great, but they must be trained to respect ours. For instance no Christmas gifts, etc... 4. Priorities - the client's needs come before the staff. Tend to clients

rather than sit them in front of TV while you go smoke, do your lottery numbers, chat on phone, etc Excluding the above, {AGENCY} does pretty good.

Huge differences in residential staff quality are disturbing - some do as little as possible, do not assist client with basic needs, do not engage client, do not create a home or family environment, and give in to their client's poor choices to make their job easier.

The family feels the staff is uncaring to other people feelings.

Due to work schedules, my husband and I are seldom available to drive 9 ½ hours to meet with staff therefore we're not as involved as we would like to be in daily living/planning for our daughter. Most of the in-house staff are excellent but we're concerned about the increased desire of staff to involve our daughter with a "boyfriend" - we have no problem with a friend relationships but their "pressure" is somewhat too much from our perspective!

Community outings are also a function of staff and their willingness to expend the effort on behalf of the residents. Some staff appear to be disinterested in making the effort.

11c. Staff Turnover

Direct care workers and residents are moved and transferred without regard for what is best for the resident. Change is often disruptive. Community connections are limited by the staffing ratio. The budgetary process controls the staffing ratio.

When staff changes he does not get his needs met, i.e. eating healthy.

When one on one staff changes it is hard for him.

Staff turnover seriously affects quality of life issues for my brother.

Staff turn-over is a major concern of ours

Staff turnover - he just gets used to one person, they quit and he must adjust to another.

Need more, consistent staff.

The quality of the direct care staff has gone down considerably over the last few years. The turnover is very high.

Frequent staff turnover compromises ongoing care... There is poor staff continuity. Supervisory changes further diminish continuity and quality care.

There are some concerns: staff turnover.

In these homes there is a lot of turnover with staff and I think it makes it hard for the two other ladies and my daughter. I know with her when someone leaves she tells me she misses them. I worry about her.

I don't like to see so many turnovers of staff at the residential group home also at {AGENCY}. This is especially hard on the children that live at these group homes. They never know who's going to be working. They just get used to one and really like her and the she's gone.

We feel that there is too much turn over and different staff all the time is hard on residents to adjust to. We as parents, get used to staff that we see on a regular basis and communication is better when you get to know someone.

We never get to help choose support staff. Support staff is always changing and this really affects his emotions because he always has to readjust his way of living.

Change in staff is sometimes a problem. When you finally get to know the staff, and the staff gets to know and understand the family member—they leave.

The most negative effect on my son's life is the change in staff that work in his group home. I know that it is the nature of the industry to have staff turn over, but I feel that if these people were better paid, the turn over would not be such a big problem.

Less staff changes in the home would help. Since my uncle's way of communicating is hard to understand and takes time and attention, by not changing the staff every few months, he would receive better communications and his needs would be better served.

Most of the problems our family has encountered over the years have been from frequent staff changes. It is hard on our daughter especially.

Frequent changes in support staff are disturbing to my sibling as well as disruptive in his care, as it takes time to train new staff. The quality of his overall care is very good.

Too many staff changes is sometimes difficult for my sister.

I feel that to ensure a better quality of service to MH/MR clients, more funding needs to be made available to avoid the high turn-over status of MH/MR staff members who provide direct contact with the clients.

Staff turnover and the gaps in service during the resulting transitions are the biggest problem.

Staff turn over is a problem.

Also, the larger turnover and the many subs do not contribute to the structure and consistency she so badly needs. But, we do understand the difficulty of the position. We only want the best for {NAME}.

The staff changes so much I do not get much information. Frequent staff changes are very much a problem for my family member.

11d. Shortage of Staff

The regular staff at the house is awesome, but their hands are tied because of under staffing. This has impacted the community outings and involvement.

Staffing shortages eliminate outings and recreational possibilities and client ends up sitting alone in room more and more.

We are very happy for this service except we need more employees. Short of staff.

The only negative thing I don't like is one staff person is in the home. The other 3 people have many more needs than {NAME}. {NAME} is able to get around with her walker and she needs more interaction. Sometimes she can't go places because there aren't 2 workers. {NAME} likes to talk and do something. The other 3 aren't able to do that so there is nothing but the TV or video for her to sit and watch.

Due to necessary restrictions (legal) this individual's activities are limited. If he was in a group home with two staff members, he would be able to take part in Special Olympics and also attend church services.

11e. Staff Not Qualified

I do not feel that most of the staff is qualified to work with these people. I think they should be better trained and educated.

I feel that regular staff positions' qualifications are slim. In an all women residence, more training is required so all staff treat the residents well, and not act like this is any other job. I realize it is difficult to find qualified, caring people willing to work with the MR for the kind of salaries the pay.

Also, some staff are overstretched in their responsibilities, and other are not always adequately trained or supervised.

Need better staff more training DFS has done best with {NAME}. {NAME} is very well liked and respected by {NAME}.

11f. Pay Staff More

A major problem with community care are the very low wages paid to care givers and the resulting high personnel turnover.

We have heard that other providers pay better than our daughter's provider. That should be checked and corrected.

We are well pleased with her professional staff, not as happy with the non-professional day care staff in the home. The salaries offered to non-professionals in this field is unlikely to attract higher caliber care staff.

{NAME} gets upset when there's a change in staff; maybe more money to staff will help the problem.

The most negative effect on my son's life is the change in staff that work in his group home. I know that it is the nature of the industry to have staff turn over, but I feel that if these people were better paid, the turn over would no be such a big problem.

Better pay for the staff.

I'd like to give my personal opinion on how to get the staff turnover to perhaps lessen: up the pay scale with incentives for increases. The job they have is so very hard. The staff that truly care deserve better than those who don't pull their own weight.

A significant problem is loss of good staff, primarily because of poor pay... Status of care staff needs to be raised with higher pay and better training.

12. Family Issues

If I took my sister in my house when it is done, how much money would I get to take care of her? I would probably have to hire a part time assistant. Currently I have no job other than part time office work.

Parents need a chance to be more involved in group homes. A parent committee needs to be formed to help with funding. It is hard to leave your child with someone you do not know.

13. General Well Being

I am satisfied with {AGENCY} however he seems to get upset over weekends and breaks his forehead open. I think maybe he is getting bored and maybe they should do more or take him out. He needs to have something to look forward to. Maybe go to the store or walk or ride and not be ignored. He doesn't have these problems when with {NAME} who does a good job with him.

I found a couple questions in here I need to comment on (filing a complaint) I was never told whom I should file one to! I've never had to file one in all the years my sister has been there, but I do have two complaints I'd like to comment on, to you if I can. Twice this winter {NAME} has come to family gatherings, both times she came "not dressed for the weather", they were both very cold days, the one day it was snowing and she had no coat, hat or gloves on the wind was very sharp. I understand how hard it is to dress her and they assume the van is warm, but what if the van broke down from {TOWN} to {TOWN}, she would get cold very fast. I asked her caregiver please make sure she's dressed warmer the next time, I know she has these items, we've bought her them.

{NAME} is a happy, well adjusted woman. If I have a desire, it was for someone to help her exercise or take walks. Being blind she needs this assistance. She has gotten heavy. In summer I take her walking once a week and swimming with blind association

{NAME} has never had a cavity or yellow teeth. Just once I didn't have to clean his glasses so that he could see through them. I've seen him sit in dry and wet shirt of urine two times and informed the workers of this. {NAME} was questioned why he didn't inform them while he was like that. Someone came to pick him up for a day and a half and {NAME} was the same way when the person got there. Refused to put {NAME} in the truck until he was changed by the staff. Is this a problem or lack of communication on {NAME} part for saying what he really can't say? I don't complain anymore because I haven't seen this in awhile. {NAME} should never be reprimanded for something he can't control.

Often we are not pleased with our relative's cleanliness or neatness in dress and appearance. Sometimes shoes are on the wrong feet, clothing is sometimes in need of repair or should be thrown away. I would rather these items would not be worn and left for me to assess. Hair is usually messy and finger and toe nails are often extremely long (I have seen them up to 1/2 inch long).

My son is not happy where he is living and wants to move. Doctor's orders are not being met. Not happy with the people he lives with. Main complaint is the train noise and the problems that

are occurring because of it. When staff changes he does not get his needs met, i.e. eating healthy.

13a. Health

My son is not dressed appropriately for weather. Late October on an extremely cold day, I picked him up at his workshop - he was wearing shorts. I brought him home and had no trouble giving him long pants from the closet. He had long pants at the group home. During summer (high 90's) he had an undershirt under his shirt. I told staff to dress him as they do themselves. Another time, I went to his doctor's appointment. It was on 12-20-05 and he was wearing a short sleeve shirt. It was an extremely cold day. I was told he dressed himself. They have 5 residents. All 4 are dressed for weather - not him - he needs assistance picking out clothes. He has had 2 kidney infections within 2 months. They make him wear male Depends. Plastic was near his body when undressed him for bath. They do not use Clorox or Lysol in shower. He has problem with toe fungus infection. He doesn't need Depends!!! He needs to be reminded occasionally to use the bathroom at work and group home. At home, he usually tells me he has to go, or I take him there periodically.

Consumer's weight loss is unacceptable. Support staff must control meal portions and refuse her when asks for seconds, thirds, and desserts.

I am concerned with the alcohol consumption my brother claims he has on Mondays and Wednesday during the fall months {NAME} plays in a shuffleboard league at various bars. {NAME} claims he consumes 2-beers and 1-shot of whiskey each time then {NAME} goes every Thursday to Fat Boys for more shuffleboard and alcohol consumption every Thursday throughout the year. If this is true the family feels this is excessive. Plus with all the medication my brother takes could the alcohol have any negative reactions plus the financial cost of the alcohol is a concern.

There are some concerns... health issues... lucky to have a lot of family involved.

{NAME} had a sore on his leg when he came home. I had to take him to the ER. They cut it open and put a needle to drain the fluid out. That don't the first time it happened. They said that didn't see it. If I see it then they could have seen it. He had another one on his stomach. It was big. I don't think they took care of that one either. I had too. They're getting paid to take care of him.

My ongoing concern about the medications my son {NAME} receives daily has brought forth and does surface alarming questions.

His health has really gone from bad to worse; he has lost the sight in one eye. At least every two months I get a phone call that my son was hurt in some kind of way that is not explained well enough to me. When I ask for this incident in writing, I never get it. Every time I get a call I'm afraid they are going to tell me my son is dead.

Better medication follow-up by the doctors and hospitals.

We feel that he is on too much medication!!

My sister has received excellent care over the years. The only problem I have had with her care givers is I feel they need to have a dietician check their menus. She also has elevated cholesterol and a family history of diabetes, so diet is very important to her care.

I would like to have more follow-up with doctor visits and test results.

Our daughter {NAME} needs help. She has a mental illness that at this time in her process is called bi-polar disorder (same as me). Medication helps however, there are certain times when she is more fragile. Her use of caffeine also greatly affects her behavior. She is always looking for ways to include caffeine in her life, e.g. sneaking it whenever possible, which can cause great difficulties. I know how difficult it can be dealing with {NAME}'s behavior. I also know what a sweet, loving and compassionate woman she is. The life style she is living in her home may not be appropriate for her genteel, spiritual nature. I know how difficult it can be for her when her needs are not handled in her best interests. It happened to her in our home. Thank you for taking my thoughts into consideration. I appreciate it.

In regards to the residential home is {AGENCY}, I am a little disappointed in their health care of clients such as my son {NAME}. He was placed there {DATE} with our approval: his parents {NAME} and {NAME}. It was kind of an emergency. We were advised not allow visitation to his home for 4 months. At the end of the time we picked him up and he had a problem with bowel control and still does- loose bowels but {AGENCY} did not address problem, never consulted a doctor, which I finally did- colon clinic. I make appointments and also his medical doctor. That is my comment. He still has this problem. Terrible.

13b. Safety

My son gets ok service from {AGENCY}, but there are a few problems... 6. Security - it has been a my experience that in an effort to have good community relations, {AGENCY} will give out information over the phone to anyone that calls claiming to be a relative, for instance they gave out an address over the phone.

{NAME} residential program is not safe because of the extreme behavior of a house mate. Everybody shouldn't have to suffer there should be a placement for this individual that will meeting his needs. When situation like this exists a change should be made with the person who has the problem and not the people who are the victims of this problem

Family member should be notified immediately when the consumer is unsafe. It is harmful watching a staff get assaulted or furniture being destroyed. Harmful and violent people should be put into a different group home.

At the present time I feel he is not in a safe environment because of the other person living in his house. Until now I felt he was very safe. I feel that the turn-over you're having with staff right now is due to the person living with bill now. Not that it's his fault but he is very unpredictable and a danger to both my brother and the staff. He has hurt both bill and staff several times. My brother is blind and cannot defend himself. I myself have witnessed this behavior. I called the butler office to complain once and spoke with several people. Maria informed me that there wasn't any other place for this other person and the staff just have to keep a closer watch on bill. A behavior problem and a vision impaired person should not share the same home. Bill loves living there and it's close to me so we can visit often and do things together. He loves his staff and now he's losing some of the ones who have been with him a long time.

13c. Abuse/Neglect/Mistreatment

It took 2 months and finally contacted head of organization to get results of why my daughter had bruises all over her. No one had answers of how she received them. After contacting head of organization they stopped immediately.

Sometimes I am concerned about my brother's personal items that we (I and other family members) have purchased for him (my brother). Some items come up missing even though his name is clearly marked on the items. There is never a clear answer to me whether the items were taken by other inmates or changing staff personnel. My brother is non-verbal, so he cannot tell me anything.

I believe it is sometimes too hard to hire honest people when dealing with client's money. In the last couple of years, someone has been taking my child's money. After investigating, nothing can be proven, so nothing is done.

Also my brother seems to fall a lot and receives cuts and bruises that seem excessive. I do worry about his treatment. I have been assured that 'it was an accident'.

Regular medication reviews of client medications and medication administration sheets by a licensed pharmacist should be initiated. Several years ago I contacted the state licensing board regarding a problem which was causing physical abuse to my daughter. No one, to my knowledge, did a thing. The state never responded to me. The problem is resolved.

Over the years, my brother has shown signs of abuse many times. No one can ever explain how he gets the scratches, bruises and black eyes. Once when a staff person witnessed the abuse, she was fired before the abuser was. The reason was that she waited too long to make a report. Having my brother live in a group home is not an ideal situation, but it is the best my family is able to do. We try to visit once a week and stay involved in planning his I.H.P.

13d. Social

Having more active free time would go a long way in enhancing the lives of the handicapped. I think it is extremely important especially for high energy clients.

On the positive side {AGENCY} is very good about socializing residents. The new have been consistently reliable.

I would like to see them take the clients on more community outings other than grocery shopping, like {TOWN} car show or bike night. Pictures of our loved ones from events would be nice too. These types of events are free and would not affect budgets at all.

Overall I am pleased with the care my sister receives from {NAME}. I would like to see her participate in community activities outside of her home and work environments.

Issue #3: grandmother feels she could benefit from a more active role in her community.

Depending on the severity of the disability, various activities could be implemented to more adequately use free time for those consumers at home or living in group homes. This, of course, depends on the number of aides present at any given time due to the need for close supervision. There are some recreational activities that are fairly simple to set up such as bocce

ball, croquet, horseshoes and gymnastics (physical exercises set to music are fun.) Gardening is also enjoyable, learning activity in that it shows the need for proper soil, nutrients and water. In a real sense, it provides care and awareness of our environment. I think of the above suggestions as mental exercises for those who sorely need challenges and provide a sense of achievement and confidence. Often there is adequate space in the home to initiate the activities, or there is access to a nearby park or recreation center. If there is a regular routine for these games and activities, it is most likely that parents, guardians or friends would be willing to volunteer. Being aware of activities in the community offers enjoyment and enrichment. A wonderful source also for helping handicapped persons is "the Special Olympics" that provides a wide array of activities. I think the programs help them be aware that they are sharing friendships with other people and lessens for some depression. The television is a wonderful invention, but looking at it all day is not productive. So the above suggestions may to some extent improve the quality of life for those people so precious to us.

Overall support services are adequate to meet my sister's basic needs - i.e., health and safety. Community involvement and recreational activities are severely limited and limiting to her overall happiness. She is left to find her own supports in the community. She has no friends, other than her staff. She would very much enjoy arranged activities with other consumers that function on the same level as her.

I feel there needs to be more community activities and to connect with other peers his age. Due to {NAME} slowness that usually hinders his extra activities. The agency working with {NAME} hasn't really made any attempts to put something together with anyone else. The do go to the YMCA once in a while. He needs more community outings with others.

13e. Hygiene

Often we are not pleased with our relative's cleanliness or neatness in dress and appearance. Sometimes shoes are on the wrong feet, clothing is sometimes in need of repair or should be thrown away. I would rather these items would not be worn and left for me to assess. Hair is usually messy and finger and toe nails are often extremely long (I have seen them up to 1/2 inch long). Thank you.

His body cleanliness needs to be worked on also. Thank you, {NAME}.

16. Funding and Budget

We read that there are serious issues regarding Cal-Optima funding, and hospitals not being able to see our consumers because of costs. Is this being re-addressed? Six bed and board care homes for adults are quite crowded. Four residents would be more appropriate.

I think that {AGENCY} does the best that they can with the resources which they have but more resources (such as group homes and beds at treatment facilities) are needed

{NAME} is a happy young man who enjoys his home at the {AGENCY} we are hopeful (as his parents) that the center will remain open, but we are equally confident that in the event of the center closure, {NAME} will adapt and adjust to his new surroundings at the {AGENCY}. We are not thrilled with the governor's inconsideration of our son's home. The staff and other residents are his family and the impending closure has disrupted the emotional well being of residents, staff, and family members. We pray for a change of heart to allow the {AGENCY} to remain open.

In general the provider has excellent staff and administration. Due to funding problems however, there have been a few problems with a few of the front line staff. The provider has been notified and has addressed the situation as best as possible with the limited funding.

Question: why is it that when states and or feds work on budgets the first cuts are cuts affecting those with disabilities?

It seems to me that if the state would stop cutting back on funds for the retarded, maybe they could get staff that would stay and also get more help.

17a. General Satisfaction with Services/Supports

My daughter resides at {AGENCY}. I am satisfied with her overall care.

I think MH/MR {COUNTY} is doing a great job for my family member. They have been a great help to me in the many difficult situations.

My son resides at {AGENCY} thru Catholic Social Services and attends a specialized DCIU program at {NAME} high school. We have no serious issues with either. Any concerns have been resolved readily.

We are elderly and do not see our daughter too often. However, we have a good relationship with her caregivers and have been very happy with her living situation and her day-care program. All the people involved are very good to her and keep us informed.

For the past 20 years my daughter has resided at the {AGENCY} located in {TOWN}. She receives excellent care, love and support from staff and the whole community. I thank the county's MH/MR program for making it possible for her to live in a community setting that is so focused on the welfare, happiness and growth of its residents.

I'm very satisfied with the care my son gets at {center}. I think it is a sin to move him somewhere else or to close down the {AGENCY} or any other state center.

The most effective response by your agency was placing {NAME} in a safe and clean apartment. Also, your agency takes {NAME} to a number of different social events over the years. I am pleased with her medical support and medications. To correspond via telephone or by mail.

{NAME} seems to be adjusting well to his new home. I hear that he likes the backyard. He seems happy when he is home. He never gives us a hard time about going back to his house.

My daughter {NAME} was born profoundly retarded because of lack of oxygen to brain before birth. She is non-verbal so not able to communicate. For the last few years she has been in a wheelchair most of the time because of leg crippling and hands also handicapped. She is completely dependent on others for her very existence. We cared for her at home till we were no longer able to do it. She was admitted to {AGENCY} in {DATE}. I am so thankful for {AGENCY} and the care she gets. Before her father's death we visited her 2 times a month but since, far less often on account of transportation. I do not, and never drove a car. The {AGENCY} staff have tried numerous plans to get her to do things on her own, without success. She used to have terrible tantrums but is much better now. I would say {agency} has been made into a place much like at home and make the clients happy as possible. They have

religious services and I know they take my daughter to them. Also she has summer camp and outings to see and enjoy special seasons and "eat out". I get word of all changes in program. All in all I am very satisfied.

Our daughter is well cared for at {AGENCY}.

I thank god every day {NAME} is doing as well as she is. I feel {NAME} will be perfect in heaven, but in my heart I feel we are doing the best we can for {NAME}. Thank god -- thank you at B.H.C.; especially {NAME} who was very helpful in getting {NAME} help. Along with I'm sure many others. God will reward you and {NAME}. With gratitude, {NAME}, {NAME}'s (big sister)

I found some of the questions confusing and am not sure they are answered correctly. I am happy and satisfied with services at {NAME} center.

Family is very happy w/ his progress.

My daughter is in the Mentor Program. It has been really good for her and I am so pleased.

Very, very happy.

Everyone has been a tremendous help over the years.

My husband and I feel that our son is very happy and that {AGENCY} has given exceptional attention to all of his needs for many years.

{NAME} does enjoy going places, I appreciate what is being done for him. Thanks, {NAME}

{AGENCY} takes care of my son. Overall, I think they do a good job.

The most effective response by your agency was placing {NAME} in a safe and clean apartment. Also, your agency takes {NAME} to a number of different social events over the years. I am pleased with her medical support and medications. To correspond via telephone or by mail.

{AGENCY} is 1000 times better than {AGENCY}. I thank god for the people in {AGENCY} they are working with my son.

We are pleased with the care that our daughter receives at the {NAME} center. A group home setting would not suit or daughter's needs.

I am more than satisfied with the service my sister is receiving. All employees connected with her services have been excellent. I cannot say or give enough praise! I hope that services continue as they have been provided in the past. Thank you, {NAME}.

I am very pleased with the care that my brother is receiving. I am so thankful for those who take care of his everyday needs.

Thank you for the good care provided to my daughter.

We're happy with your program. Thank you.

In my opinion {AGENCY} is the finest facility for its residents.

{AGENCY} provides top notch care to all their clients. Parent concerns are answered in a timely fashion and addressed until all parties involved are satisfied. Funding is spent wisely and used to benefit the clients and improve working conditions for the staff. Considering the funding cuts of the last few years, {agency name} has managed to maintain the level of care needed to assist their clients.

We are thankful and appreciative of the care {NAME} receives. She seems happy and comfortable when we speak long distance. Her care seems to be of the best quality when we question her on her physician visits and on her outings, she is very happy. I and my two sisters are going to try to visit there about the 3rd week of July 2006.

{NAME} gets very good care at {AGENCY}.

{NAME} program has been wonderful. {NAME} finally has a life

Family is very happy w/ the program.

Sister is happy w/ the services that he is getting.

My family and I are very pleased with the high quality of care my daughter receives. There have been many changes in the MR system that have impacted positively on her. Although she can not express it in words, her demeanor and behavior speaks volumes about her satisfaction with her current living arrangement, day program, recreational and religious activities, and support coordinator. She is well cared for in a loving environment and it shows.

Family is very pleased w/ the staff and services.

We wish to thank {county} MH/MR for the fine work they are doing.

Family is very pleased.

Person is very content with his living and well being. This is the happiest he has been through the many years of institutional living.

My family is very appreciative of the support that has been provided to my brother in ensuring he has as independent and active life as he can have.

We feel {NAME} gets the care he needs also the understanding that is needed thank you {NAME}.

So pleased with friendship community's unique fit in meeting {NAME}'s needs.

We know that there are many opportunities for {NAME}, but he has to be agreeable to participate and so far he has resisted. Time and again we have been told of his rights so the only thing we can do is be supportive when he asks for help and pray that god has angels watching over him. Thank you for whatever help and assistance you have been able to extend including the help with acquiring a new hearing aid. We had the old one repaired so that he at least has a spare. Thank you.

It is a peaceful/awesome thing that I can now fill in a questionnaire that reflects how happy and contented the individual referred to in this questionnaire is with his choices. Thank you.

{NAME} is receiving the type of care and training he should have 6 years ago. We are pleased with his current care. {NAME} is 35 years old and his mental capabilities of an 8 to 10 year old.

We are happy and grateful for the care that our daughter receives.

I thank you for this opportunity to "thank you everyone directly and indirectly" involved with helping the disabled and mentally challenged to live in the community, work, go to recreation programs and attend church and receive medical attention. I realize there are so many persons involved in this understanding and I ask god to bless each of you for your dedication. I most of all, I realize my family member would have "never" developed to her potential had she remained at home and not been challenged as she is in her setting. Thank you again and blessings of divine and merciful love be yours always. Sincerely

The {AGENCY} and its services have been a blessing to our family. I appreciate all the hard work provided by the staff. Thank you.

I filled this out for {NAME} and his brother {NAME} who at one time was more involved with {NAME}. {NAME} is very sick and cannot participate as much as in the past, but in past meetings we were very much satisfied with the managed care that was given. We are grateful and thankful to all concerned. Thanks.

My cousin, {NAME} is an unusual case - more or less abandoned by family for most of his life. (I thought he was dead until I first located him 16 years ago.) His brother and sister found out he existed for the first time 12-15 years ago. {NAME} mother's choice not to tell them until then.) His brother and sister were given photos of {NAME} and all contact information at that time, but neither chose to make contact. (other than results of blood tests to show if {ILLEGIBLE} was genetic.) Recently his brother has expressed interest in contacting {NAME} for the first time! This program has been wonderful for {NAME}. After leaving {AGENCY} I didn't find him until he was already safely in a group home. The program is excellent - an absolute blessing. I was so relieved to find him in such an excellent program and in good care. I would be unable to provide care anywhere nearly as good. I am very, very grateful all those who worked so hard to advocate for {NAME} and others like him did all that they did. He is a good, happy, healthy man. I am very proud of him and thank all those involved with his care.

{NAME} is 61 years old and still very hard to deal with at times. I don't know what I would have done without {NAME} state school. I feel he has had as good a care as is possible considering his condition {NAME} (mother).

I am completely satisfied with the staff and the service's she receives at the center.

{NAME} has received excellent care, very satisfied and has never had a complaint.

My name is {NAME}. I am {NAME}'s brother. I don't know if {NAME} is happy or not. I cannot put into words what {AGENCY} has done for {NAME} except for this. {NAME} has a life now, and that is more than before.

I would hate to see my sister go anywhere else but where she is today. For me and my siblings, we feel there are no better home then the friends residence. She has been there for about 2 1/2 years now. We have the utmost confidence in the friends/family atmosphere. Overall we are pleased how things are handled with the services my sister is provided. Thank you.

We are very pleased with the care and attention that our daughter receives. The staff is excellent. We have never had a complaint. Thank them all for their special talents and caring ways.

Please note that the family member's name is {NAME}, not {NAME}. I presume this is a minor mistake. He receives good care and attention and I am very satisfied, as he seems reasonably happy. I talk with him at least once a week via telephone, visit him on several weekends a year and bring him to stay with me in a different state. Other family members keep in touch with him as well. Thank you.

{NAME} has done an exceptional job with {NAME} and has provided her with aids from {AGENCY} which has been so helpful. I presently am 69 years of age and have our mother who has come living with me and appreciate all the help you have given {NAME}. Thank you and {NAME} for a job well done.

{AGENCY} has been fabulous in helping my brother. I am amazed at how much care has been provided and how it has enhanced his quality of life. It is a great comfort to his family members that he will be looked after when (if) we are gone. Thank you.

We have been very satisfied with the services our daughter has received.

I am satisfied with {AGENCY}, as they have been very supportive.

My daughter has been a member of {AGENCY} for 18 years. She is now in rehabilitation, so she does not have her own place to live. I want to thank {AGENCY} for the wonderful help that has been providing. I also want to thank the Service Coordinator, {NAME} for the great work she has done for us.

I feel that {AGENCY} does provide good services to the DD population and their families.

Thank you to {AGENCY} for all the assistance given.

Thank you for all you do to provide services for my family member. It is appreciated by our family.

My husband and I cannot express our thanks and gratitude for what {AGENCY} has done for our son.

Thank you for your services.

Very satisfied with the services received.

We are very grateful for the services and support provided by {AGENCY}.

We have been part of {AGENCY} since late 1991. We've been fairly evaluated and supported. The conservator has been enormously supportive on all stages of change for my brother. We've gone from fair functioning to severe mobility and {AGENCY} has been able to back and support in ways we needed.

We are extremely grateful for the assistance received and have worked with many really wonderful people from {AGENCY}. Thank you.

Thanks for all the hard work and team effort on behalf of all the clients with disabilities.

{NAME} does an excellent job of handling problems that may occur. Most recently, there was a problem with {AGENCY} charging clients too much for the activities. Tim stepped in and got {AGENCY} back in track. All in all, {AGENCY} does a good job of helping my sister remain independent in the community.

We appreciate the services that {AGENCY}'s staff provides. Thank you.

{AGENCY} is doing just fine for my son. I truly appreciate it.

I'm satisfied that my son is getting good care.

I am very happy with my daughter's worker and all the services that she receives at {AGENCY}. {NAME} has always gone the extra mile not just for my daughter, but for me too. She returns my calls in a quick manner. I cannot imagine how it would be without {NAME} support and help. I would also like to thank the "On-Call" worker who has helped {NAME} with her problems.

I am very happy with all that is being done for my child whose life has been so enriched by the services provided.

I'm satisfied with the services provided.

I have always been impressed with the services provided by {AGENCY}. Keep up the good work

17b. General Dissatisfaction with Services/Supports

I feel day program is a sitting service. I don't think they have enough staff, and enough motivation. Workers may get lax. I don't think workers home/day program keep up with their end of things??? They (workers) always seem to appease us parents by saying "yes, we do that," we, as parents can only hope they're telling us the truth.

The client needs speech therapy, clothes (dress) that FIT- teeth which were pulled without my knowledge or permission - now 1/4 of his teeth on one side top have been pulled (he needs more cleanings.) He needs a ride to church and back and proper clothes to wear there. He needs a job where it is clean and safe. His father is in last stage lung disease and is in skilled nursing. I have to staff with him - almost 4 years now. (Name) was removed from the competitive job program without my knowledge. I want him placed back on the program. No one knows why he was removed. He did not go in and request that.

The planning process is very bureaucratic. Reports and plans completed by staff comply with guidelines they know will meet the criteria established by the department. They are careful to word items that produce desired results and statistics within the system. Follow up to assure implementation could be strengthened with appropriate interim adjustments being made. Access and delivery of services is controlled by budgetary constraints. Staffing levels are adjusted to comply with the dictates of the state without regard to the quality of service that is necessary and being delivered. Choice & control of residential services is controlled by the facility director to comply with budgetary constraints. The best setting for the resident is not a primary concern.

17d. Information Regarding Services/Supports

I need help for my daughter. I do not know where to turn to get the help she needs. I paid so much to get answers, now I do not know where to turn to get help now that I have the answers. Please help or point me in the right direction. I will follow up the best I can. Ps. What is this organization, I never heard of it.

How is my daughter's SSI income spent? She never seems to have money?

I would like to speak to someone about {name} regarding her future if illness or something else happens to her. We need to know if there is anything to do about final arrangements, cemetery lots etc.

Better information and counseling services.

{NAME} I didn't know we could have any control or input over the hiring of my sisters support workers. It thought only the agency could do that. Thank you, {NAME}

Mother as learned a lot about the service, but still has more to learn.

17e. Need More Services/Supports

It is unfortunate that we had to find the appropriate services out of our county, more availability in our area would be very helpful, and it would allow us to be more involved in our daughter's life.

I feel bad for not being on the positive side. My brother {name} is not getting the services he needs. He does have his own apartment- but without me his sister helping him 5 days a week he could not make it on his own. Somerset MHMR is not doing anything. His caseworker {NAME} is not helping. I can not do it I need help! My brother can not live independent!

Would like a day program 1 or 2 days a week

Needs more supports from M.R.

I feel as a parent/legal guardian there are not enough services for a person as like my son. He was not allowed to attend a day program, we couldn't find a summer recreation program that could take him due to his disabilities. It seems every time we ask for extra money there is none. As his parent I felt he needed to do something all summer. I went out and begged the YMCA in {city name} to give him a reduced rate so he could go swimming there. I pay for this out of my pocket. Why can't we use state money to help people like my son?

17h. Waiting List

My brother has been waiting for a new wheelchair for years I don't understand why he is not able to get one

19. General Concerns

I was never appointed by a court of law to my brother's legal guardian. My mother asked me to do it and I told her I would. I am the oldest. I wanted to verify this matter

The policy for dealing with disruptive clients needs to be reviewed.

Grandmother feels there could be a better choice of foods offered.

I would like a better accounting of the social security money that the facility receives for my brother.

“How is my daughter's SSI income spent? She never seems to have money?”

{NAME} school has been very cooperative with us and tries to make our daughter as happy and comfortable as possible. We moved across the country 6 years ago in order to gain employment after our jobs were gone in {TOWN}. Our first choice was to bring our daughter with us, but there were no facilities in our new state and we did not wish to uproot her from what she experiences at AVS. We are there often - as you can see. Last month we spent a week in Pittsburgh and saw her 4 times. We are very involved in her life and with the staff at {AGENCY}. Our other grown children are physically close by to her in case of an emergency. Since {AGENCY} closed we have not seen the case manager for our daughter at her annual staffings. We also had to go to court to make certain that your agency did not put her in a sustained facility, as they had wanted to do. My husband was in the field and only by "twisting a few arms" were we able to have her at {AGENCY}. We knew the system, others do not and your agency needs to provide advocates for the families that need help. We had to have 3 court proceedings over the years to get our child a decent facility for nursery, residential, before 21 years of age in Philadelphia and then to AVS. This was outrageous! It depleted our funds and the emotional stress of having to fight for our daughter and losing her younger brother to a metabolic disease with MR, almost put us over the edge!

Why do they have her sign papers when she can't even write or read what she is signing? At her meetings and for other things they have her sign her name. All she makes are lines.

My family member has been told by the MH/MR staff that she has her rights. So she is doing what ever she wants. There is no supervision in the house she lives in. She works 3 days a week, I don't know how much she earns or what she spends the money on.

My nephew is mildly retarded. He has a part time job and I provide all his transportation-doctors, shopping, work, etc. His apartment was obtained through the help of MH/MRD over a 2 year period. Many phone calls and visits to {NAME}, her support and encouragement made it happen. My son does not speak or communicate and cannot speak of his likes or dislikes. I am his guardian and am strongly opposed to him being placed in a community home. He has no knowledge of a stove, hot water, cars etc. His life would be in danger in a community home.

The only area that is gray is her financial support, savings and last will and testament. I really do not know what to expect if she dies. Overall, I am well pleased.

We asked the worker at {NAME} home about a year ago who is going to bury {NAME} when she dies. They are not sure about that, they said {NAME} don't have money for that so where is all {NAME} money going.

I would like to know more about my brother {NAME}.

The questions that were left unchecked I wasn't sure of how to answer. I am satisfied with {AGENCY} and MR services. I was very unhappy with {AGENCY} and how they pulled the TSS

from {NAME}. The {AGENCY} should not be allowed to put the client and the family through the unnerving situation which caused the client and staff difficult times.

If there is any way possible for him to learn to speak I would be thrilled.

I would like to know who take care of {NAME} money only for one reason. Because when it comes around for the holidays I don't like some of the gifts that be bring home. Some things he brings is unreal. I have asked for him to buy for his nephew {NAME} size 4t. And for his nieces {NAME} size 18 months. {NAME} likes CDs or size L clothes. And Steelers shirt XL. Thank you

I realize that my brother (and all the other participants) is an adult and has rights and privileges that all humans being are given. It is important that some rules and laws are more of a hindrance than help in the everyday living aspects that these adults must participate in society. For example when there is a law broken a consequence is given also when society rules (and house rules) are broken consequences should be given to the individuals. I don't know how the house supervisor counselors and staff do such a wonderful job when their hands are tied. Figuratively speaking sometimes reasoning just will not do. Sometimes if staff could have some privileges to i.e. a snack, cake, or cookies just something small to let them know how some behaviors are unacceptable. Thanks for listening his sister.

My daughter is not progressing at all. In fact just the opposite. In fairness I must say this in some what her own fault. She can be very stubborn and uncooperative.

I would like to be involved in the hiring aspect of the employees and future employees. I think the parent should have some decision of who works for my (our) children. Thank you!!

The only concern: I receive Medicare records of payments of medical treatment however I don't receive information about the medical problem. For example the bill says payment for subsequent nursing care and I don't know for what.

I would like a better accounting of the social security money that the facility receives for my brother.

Choice and Control #20 - I don't have control over any money issues, and I do not want control... Also, when he is at the home over the weekends, they will sometimes plan their days out (at the movies) without regard to his work schedule.

SOUTH CAROLINA

1a. Satisfied with Home

In general {NAME} is happy. We have just moved her into a retirement home... The place she is in has planned activities, transportation, 3 meals daily, weekly housekeeping, cable and trips. All is included in the monthly fee. Only extra is the telephone. This place has other facilities located all over the US, Canada and England. Since her brother lives in MA, if something should happen to us she could be transferred up there. I feel very fortunate to think we located such a wonderful, safe and adequate facility we can afford.

Myself, my husband, sister and brother-in-law visited with client and his twin brother last March and we were overall pleased with seeing the residences there in {TOWN} and meeting with some of the healthcare staff. I've kept in touch by phone fairly often and spoke to the head

people in charge of their care as legal guardian. I have taken over responsibility. Unfortunately, I'm not able to go out and visit often as I'd like so I do call and inquire about them from staff.

My son is in a group home here in {TOWN}... My son is completely happy with the residential care his adjustment is unbelievable.

{AGENCY} provides a wonderful home and the staff is great, so good to the men living there. All the men get along so well. We thank God each and every day and pray for all the individuals who dedicate themselves to caring for those who cannot care for themselves.

Our daughter who was born Down Syndrome has been in the {AGENCY} since she was 4 years old... We are grateful for the care she has received and God bless each one of you.

I feel that my brother is doing great since he went to {AGENCY}. I have never seen him happier and better adjusted. I think everyone is doing a terrific job.

Since moving into a residential facility of {AGENCY}, my son is more social; he responds better to other people; he is more aware of those around him. He talks more with me while on home visits. Living with 3 other adult men has helped him a great deal and also meant a great deal to his family.

The {NAME} home our daughter resides in is the best. The four ladies are all so different (as with any family), but all interests are taken into consideration. They are very active and involved in the community. There is very little turnover of staff. They have the best interest of the ladies. They are well cared for. Our daughter has matured through the training and daily skills she receives in this structured environment. We are so pleased she is part of {NAME} in South Carolina.

{NAME} is very happy where he lives and so are we.

{NAME} is taken care of by the staff at {NAME} Center very well. She is happy with her house and would not want to move.

I am very please for the home and the care that my family member is receiving.

My sister is not able to speak, but she seems quite happy where she is located.

1b. Dissatisfied with Home

We have requested that {NAME} be placed back in {NAME} closer to family but no response so far. At one time she was in the {AGENCY} program in {AGENCY} where she shared an apartment with another lady. I'm not sure that would be a possibility now that she has become so dependent on the staff at {AGENCY} in {TOWN}.

In addition, a new client (in her residence) was aggressive and our daughter did not adjust to her. We requested a change of residence which has been made.

Sister was moved to new home last year and has not been happy with change in schedule, staff, and facility. I had no input into the decision to move her. I was not even aware change was to take place. I didn't know when she was moved or new address. There have been

problems since the move. She had always been happy before. I appreciate all that is done for her and try to work within their program. I must find a way to have more oversight.

Overall services are fairly good my family member receives great care in the facility he resides my only complaint is I want him in an area closer to my home and I've asked for this some time ago and I would like to know what are the chances of that happening soon. My brother wants this also so that extended family members will be able to visit him. I feel this would help with his behaviors and depression.

{NAME} has been in a group home since the first one opened in {NAME} County. She has lost too much of her independence during the last 20 years. Before entering the group home, {NAME} rode her bicycle around her neighborhood walked to softball games and crossed the street to buy her family's groceries using a list her mother gave her. At this point, {NAME} has been in homes with ladies who were not near her mentality or communication level and seems to us to have regressed... She had a pet dog at home she desires one now, but due to rules/regulations, etc, cannot have one. A few changes in {NAME}'s routine would make her a much happier, productive person. {NAME} misses going to church as well. She has a large family but her brother, (my husband) and I are her only contacts for home visits, reunions, holidays.

The only complaint I have is she is in a facility in {TOWN} and we live in {TOWN}. It would be a gift from heaven to have her here in {TOWN}.

1d. Furnishings/Cleanliness of Home

Wish there was a cleaning service available to help in cleaning his apartment. He does not know how to do any deep cleaning.

Things that could improve: Living conditions- the apartment is in "bad shape" dirty walls, & carpet. Air filters not properly replaced, would like to be informed when big purchases are made. Ex: bedroom suite. Air conditioner is not working in apartment, was told that it would "eventually" be repaired.

2b. Dissatisfied with Employment/Day Programs

As to the Day/Employment Support my son, in all these years, has never been placed in a satisfactory place for his capabilities. Thank you for your interest and all that you do for our special family members who depend on us for their care.

We have been happy for the most part with York staff. (NAME) certainly has more opportunities socially & recreationally than we could give her considering our busy work schedule. If she could just get a job or even maybe do some volunteering at a nursing home in some capacity I think she would be more fulfilled. Thank you this chance to air 'our' concerns.

She goes to a workshop M-F and is obviously bored when she shares with me. She is very capable of holding a job with close supervision -- such as house cleaning, hostessing at fast food chains, working with animals.

I wish that {company} could take in work outside {NAME} County so that there might possibly be more work for people with severe disabilities. Very little work comes in that she can do. She gets bored because there are not enough activities to fill in for those who have no work.

He needs a job where it is clean and safe. {NAME} was removed from the competitive job program without my knowledge. I want him placed back on the program. No one knows why he was removed. He did not go in and request that.

Currently, we are pressing for her to have a program other than workshop which she hates and has hated for a long time. These past few months she has had temper tantrums and scratched other clients. A psychiatric evaluation has been done which also states she should have another program. Up to the present, it seems clients either need to be in workshop (if only 1/2 time) or be in adult day care.

Not enough work for her to do.

We have met and met to try to have my daughter work outside of the workshop setting and have made little progress. She is non-verbal but understands quite a lot. She tells everyone she is not happy at the workshop and she wants to leave. Her requests have continued to fall on deaf ears until just recently the director has agreed for her to work outside of the workshop two days a week for one hour each day! Although this is certainly not what we'd hoped for, we are taking the offer. Although she is non-verbal and does use a small sign language vocabulary; it is like pulling eye-teeth to get staff to look at the signs that have been provided both in the home and at the workshop. They contend they can understand what she wants. There is little to no work for the people to do in the workshop. It has been this way for years. Many individuals want to work and are not allowed. When we confront the administrators we are told they don't have the resources.

She lost her job November '05. Since then there has been nothing for her to do. It took till the end of January '06 to get a job coach and at this time no success.

I feel your department has done a disservice to my son emotional and educational needs. He is presently 21 years living in a group home with no marketable job skills. Yes, it true that he has been diagnosed as being paranoid schizophrenia. I still think that he should have a chance to learn a job skill. The only benefit he is receiving educational wise is adult education classes. I know there is a {STORE} in Columbia. Here in Greenville, the {STORE} has a job training program. My son needs a chance to learn a job skill and independent living skills even if he has an education certificate without a job skill. In my opinion his future is meaningless. I want DDDS to help my son in the future instead of just giving him and I lip service. I will continue to fight and advocate for my son rights even if DDDS doesn't wants to.

3a. Health Care Equipment

Equipment care and maintenance is a real problem. This persons very hard on his chair and has frequent break downs- broken footplate, head rest, etc. Part of the problems is funding, part is severity of abnormal reflux patterns. Part is in the basic design of the power chair. While he was at home, we were able to keep up with repair and maintenance, using some of our own funds. Now they are using Waivers and Medicaid, however both are somewhat restrictive. They do make an effort, but with no in-house specialist in repair it is difficult. (He once lived in a hospital school with its own brace and wheelchair shop - an ideal situation) but then we moved away from that area.

5b. Dissatisfied with Transportation

Community Connections #24 - I believe my son would enjoy sports i.e. basketball, but there has always been an issue w/ transportation and staffing. DDSN decided to move my child to a different group home. I agreed to a different group home. I agreed with the condition there would not be a problem transporting him to my home. (I was moving 20 miles further away.) They assured me transportation would not be a problem. I moved 1½ years ago and they have only been able to bring him to me 2 times.

The one complaint I have with the service is when my son and the other 3 men are transported to the work shop and the other places in the van, there are 2, him and another man in wheelchairs, to get both chairs in they are wedged in very tight, I think it would be very dangerous in case of an accident to get them out.

Transportation for clients to and from day care is a main issue.

6b. Dissatisfied with Recreation Activities

While we are thankful for the services we have, we feel there are issues that need to be addressed and improvements to be made: Access to community activities and recreational opportunities (on a regular basis.)

Also, I am concerned whether my nephew and his fellow residents are getting recreational trips. My nephew no longer has family members in South Carolina so he needs to be able to access recreational events as part of his residential living. When I ask him whether he's gone to the movies or bowling or a baseball game, etc., he says that he has not. I think it is important that he gets an opportunity to enjoy these types of outings.

I appreciate all that is done for and with my son, {NAME}. I feel that I pretty well know what goes on five days each week. But what about weekends? Does he do anything special for recreation on weekends? Does he attend church? If none of the local churches have a program for special guys, could he be transported to {NAME} Center where he has been to services years ago and really liked it?

7b. Dissatisfied with Communication

Sometimes communication needs to be improved with several issues, including Dr. appts., outings, community services & activities in which my daughter could benefit from.

Communication between the center itself and the residential staff and us as guardians leaves something to be desired also

Communication between agency departments etc needs to improve.

Communication is at an all time low! Why is this not important to this service? I have just been advised about a family advisory meeting that meets in {TOWN} county four times per year and my child has been in this service area for about ten years. What do you do with results of surveys like this beside make grafts? Communications!!! Help!!!

Also, there has been a step-mother who lives in {TOWN} and has been seeing them often since my father's death. Lately, she has health problems which make it harder for her to do so, and I

have asked for assistance from an outside agency that could send me a report concerning my brother's welfare. So far no one has given me this help. My sister is visiting this May so that will be of great relief. In the future, I hope to travel there more often.

I recognize that because my nephew is living in South Carolina and I am in {STAE}, that it is difficult for me to be as fully involved as I would like. I am in constant touch with my nephew and hope that in the near future that he will be able to get on to the internet so that we can keep in touch more frequently and less costly than by telephone. Distance and age prevents me from visiting with my nephew; however, I have asked several times for a report of my nephew's finances so I can understand how fees are applied as well as where his SSI funds and wages are utilized. I believe that my nephew has given permission for this information to be provided to me.

8. Aging Caregiver Issues

My family member is contrary too but, his parents which is a large part of his life, we passed away we wonder about his need being met. We see time when he needs food in house or help being taught skills the home washing his clothes cleaning his apartment

My sister is in the {NAME}, in {NAME} County. She has been there for a number of years. Our Mother died some 9 years ago at age 95. I, myself, retired from work in 1989, on doctors' advice. My memory is getting bad. To visit her requires a trip of about 150 miles each way making an all day trip, getting home in the Atlanta, going home tiring which is always awful

10c. CM Turnover

My son's service coordinator seems to change on an annual basis. With the case load and turnover of service coordinators, I see no way for an individual service coordinator to provide specialized support. This is not because they do not try, it is because, given the case load, it is impossible. Perhaps this is what leads to the high turnover.

Staff turn over is a huge frustration because it happens so frequently and every time it happens we need to "start over", explaining what works and what he likes and does not like and he needs to adjust to new people again. This includes new case managers - we have had 4 in the past year. Direct care staff has no idea what the history is so will try to do things that were learned in the past did not work or were not liked.

11a. Satisfied with Staff

16, 17, 18 are difficult questions to answer; I do not feel qualified as a lay person to be in on the hiring of any workers. Our staff administrators do a good job of that.

The {AGENCY} office is in terrible condition and gives a bad impression to visitors. I hope an upgrade is in the works. The staff certainly deserves it. They are hard working, conscientious, caring people and make me feel secure that my sister is receiving all she needs in the best possible setting. The Supervised Living Program is perfect for her. Thank you.

The staff is nice to meet us halfway as it is an hour and 20 minutes round trip to pick her up if she wants to go to church with us.

{NAME} has recently moved from a facility in {TOWN} to one closer to home in {TOWN} County. It has been a wonderful move for all concerned. {NAME} is happier and we see her every weekend. She is the only one in {town} County with her particular disability and the staff has worked diligently to understand my daughter and her needs. I appreciate all that has been done for her.

My son lives in a {AGENCY} home managed by {AGENCY}. The {AGENCY} staff is wonderful. They are pro-active in managing many aspects of my life. It was personnel from {AGENCY} that had the most input into his plan - simply because they have the greatest interaction with him. The people in attendance from {AGENCY} knew what was "on paper" about my son but did not know him. I am extremely grateful for the caring staff at {NAME} at all levels - from house staff to the executive director.

Our son is served by the {AGENCY}. The {AGENCY} is a well managed organization staffed by caring, competent employees.

I am very happy with the care that my sister is getting. I couldn't have asked for any thing better the staff is so good to her. My sister is spoil.

I am well pleased with the care of {NAME}. The staff is pleasant to work with.

My sister has received so much in her growth and development of her everyday skills and self sufficiency since she has been with {AGENCY}. We feel that for the most part her care givers and other staff at the work center have been very caring and considerate of her needs and have helped her achieve her goals. My heartfelt thanks and appreciation go out to them.

We feel very fortunate with the services and care that my daughter (Down Syndrome) has received for many years. The treatment that {NAME} receives from the staff is fine. And I find that it is remarkable how the plans including meals, work projects, trips, etc. are carried out beautifully. I am very grateful that my daughter receives such great care and has for many years. Hope things will always continue in this way.

{NAME} resides at {AGENCY}, he is very happy there and considers that his home. The staff are extremely well connected with him. They are certainly the key to his being a happy functioning man. When he does have problems they handle it in a very professional way and the house manager always calls me to discuss any situations that may arise. As my husband and I get older, it is very comforting that {NAME} is where he wants to be.

I am involved with the parents club and know first hand what a dedicated support staff my brother has.

Our son resides in a {AGENCY} and has been with {AGENCY} for 20 years. We are and always have been very satisfied with {AGENCY} and do not wish to receive services from any other provider. It is almost beyond belief the quality of staff that {AGENCY} has, especially considering what they are able to pay them.

God Bless the {NAME} staff that is taking care of my brother whenever I see him he is always clean. I thank God for people like you all. Keep up the good work.

I am very happy with the staff and service my son gets. He loves them and they love him.

I would like to thank the entire staff for doing a very good job. Thanks again!

One of the most important issues in his good behavior and happiness is to have consistent staff that understand him and that he can communicate with in his own special way. A small group home is a must as well as a controlled routine that he can count on

I am satisfied with the support and attention {NAME} gets from the staff in the house in which he lives at the present time. He has decided to call it home. I am pleased with the progress he has made since his illness. (...)

I feel the staff have gone out of their way to help {NAME} adjust. I'm impressed with their devotion to the clients.

11b. Dissatisfied with Staff

The staff are non-productive in the day programs. It would make sense to me to have staff take small groups outside of the workshop to work in enclaves. As a parent, I am very frustrated with the DD system. Residentially, staff appear to only be contented to sit and "watch" the individuals. I am fortunate in that my daughter is in a {agency} where they are pushed by the manager to keep the individuals active. Our Foundation raises money but it doesn't appear that much of it gets back to the individuals. Request for trips, outings, etc. are planned then they are denied funding and everything gets cancelled. Staff morale is poor. My daughter has been in the system approximately twenty-six years. I'm very concerned that we are taking giant leaps backwards in the services to the individuals. Staff attitude is complacent... many appear to be content to ride the system out to retirement. I would like to see a radical change in our DD system where the individual has a voice and people understand that they have a job and that job is to provide appropriate services to these individuals.

There are a lot of complaints that are never carried out through the staff and workers with the clients' families. I have had problems with my family member and never get a satisfied answer and usually the staff and workers say one thing and never follow-up.

Another thing that concerns me is that staff will say we need to let {NAME} make adult decisions knowing that she has the mentality of a 12-15 years old. For example, a couple of years back {NAME} had excess money saved in her checking account that needed to be spent. Staff went with her, and most likely they encouraged her to purchase about \$1,000 worth of exercise equipment that she doesn't use and now they expect us to move it because they are out of space. {NAME} is Down syndrome and is very moody and I have witnessed staff talking to her like a baby. So which is she?? When we have her for visits she seems to be full of conversation yet when I see her in her daily setting she responds with grunts very often.

Where my daughter lives, they have one caregiver who is not friendly. She can be needy and when she talks to the clients, her voice comes out hateful. It takes a special person to take care of them and sometimes I think she is not one of them.

The residential staff definitely needs improving upon in our situation! ... In our world today too many people want the money and the check, but don't really want to do the work ex. the residential staff.

11c. Staff Turnover

Because of our daughter's autism she does better in a quiet environment with stability and little confusion. This past year has been difficult for her because there were several staff changes which she did not adjust to.

His care is complicated by frequent staff changes and staff rotation.

While we are thankful for the services we have, we feel there are issues that need to be addressed and improvements to be made: Less staff turnover. Staff members are usually pleasant and courteous. However, there seems to be a frequent turnover and abrupt changes in personnel. This is definitely a problem for us.

Employees change on regular basis. I feel the program is not as good as when my sister went into the program 15 years ago.

Turn over of staff that works with my sister on a daily/24 hour basis has become a real concern. Firing employees has become too common. It takes a long time to learn all my sister's needs and every step possible to keep employees should be taken. With so many personnel changes, I worry that someone will inadvertently harm her. I would like to see mediation, training, or reassignments used to solve problems rather than firing.

I appreciate the work that the {AGENCY} has put into my brother's care. Due to frequent staff changes and due to a young and inexperienced staff, I believe that there are times when things are not always well managed. Overall, I am grateful for the help they have provided.

Because of our daughter's autism she does better in a quiet environment with stability and little confusion. This past year has been difficult for her because there were several staff changes which she did not adjust to.

Staff members are usually pleasant and courteous. However, there seems to be a frequent turnover and abrupt changes in personnel. This is definitely a problem for us.

I am very grateful for the family services provided to my sister, since she has been in the program for the last 14 years, she has made tremendous progress given her level of disability. I do have a concern about the staff turnover [considering that] sometimes, my sister has difficulty relating to or adjusting to the individual.

11d. Shortage of Staff

The staff at {NAME} facility in {TOWN} seems to always be short of staff, or at least that is what I am told every time I ask for special service for my sister.

{NAME} likes to go to church on Sundays but doesn't always get to go because of shortage of staff. She reads her Bible daily and religion plays a large part in her life.

11e. Staff Not Qualified

The folks try, but inexperience, turnover in staff, and lack of professionalism sometimes seem apparent with the staff that manages the facility. The apartment is okay, and the support

services are okay, but could be better- facility and help wise. As a family we are grateful for the services and it helps us out a lot, but we feel like it could be better.

I appreciate the work that the {AGENCY} has put into my brother's care. Due to frequent staff changes and due to a young and inexperienced staff, I believe that there are times when things are not always well managed. Overall, I am grateful for the help they have provided.

The staff selected for employment at the residence homes should be more qualified for their positions!! The homes need personnel that could help the individuals modify their behavior. The staff at the homes should take more active role in the home. Instead, some of the individuals are used to complete almost all tasks (vacuuming, dishwashing, trash, ironing and cleaning) while staff does nothing. This can prove to be dangerous to the individuals living at the home and puts the entire residential program at risk.

I also feel that regular staff positions and qualifications are slim. In an all women residence, if more training is required so all staff treat the residents well, and not act like this is any other job. I realize it is difficult to find qualified, caring people willing to work with the MR for the kind of salaries the pay.

11f. Pay Staff More

The S.C. Dept. of disabilities is inadequately funded and this limits what can be achieved. The most obvious problem is the pay scale for direct care personnel. The pay is far too low to attract and retain well-educated and well-trained people with an in-depth knowledge and career interest in working with mentally retarded people. An enriched program could be provided if funding were better - or more realistic. On the whole, I (we) believe that the staff does a good job with the resources available.

13. General Well Being

I wish that the staff for my brother would pay more attention when it comes to dressing accordingly for the weather. That is to wear proper under wear, tee-shirts etc. especially when it is freezing outside and also to make sure the resident wears a coat when it is cold outside.

Lower calorie cooking and increased exercise have contributed to improvements in his physical condition. Please do not change anything in the current programs. However, additional services are greatly needed for families with Autistic members throughout South Carolina.

13a. Health

If child has real bad seizure don't think the child should be made to go to the work shop. As the child or children get older they should stay at home.

The only complaint I have is the way my sister and her husband get their groceries. They are dropped off at {STORE} and later picked up. I really feel they need a little assistance getting the food they need to eat. Since my brother in-law, {NAME}, is a diabetic and {NAME} is overweight, and has health issues, too. They do really well otherwise and we go over weekly my sisters and visit.

My sister wears diabetic shoes, although to my knowledge, she is not a diabetic.

Our daughter has gained too much weight. Recently they have her on a diet plan. She has lost some weight and is more active. I hope they will keep the plan going. It has really helped our daughter. The staff and workers are excellent in working with our daughter.

I am concerned about her health issues. Of course, I am worried about her diabetes and the change in medication that left her in the ICU in November. I am worried about her oral hygiene.

I am satisfied with the services {NAME} receives & she seems to be happy! But I would like to see her getting more exercise & a better diet. She needs to lose weight as she is way too heavy & she can't get around too good.

While we are thankful for the services we have, we feel there are issues that need to be addressed and improvements to be made:

- More attention given to family member's hygiene and personal health (shaving, bathing, tooth brushing etc.)
- Attention to and improvement in nutrition and diet. (Too many "empty" calories and carbohydrates.)
- More physical exercise needed (in an adaptable program.)

Too much medication used for client control rather than discipline!!

I feel {NAME} is getting the help & attention she needs. They have to put up with a lot when {NAME} has behavior problems. I do feel that the meals {NAME} consumes are not exactly the best. She weighs more now than she ever has, which I feel hinders her in her walking, going up stairs. Otherwise I think it is a great place for {name} to be. Our parents both died in 1986, but as far as I feel {AGENCY} & her living arrangements are home to her.

His eating habits are very unhealthy and I don't feel the support is there for him at meal time.

I believe {name} is taking too many prescription drugs with not enough non-drug treatment for his mental illness.

My son is in a group home. Meals are supposed to be provided to meet his needs calorie controlled diet yet he spends his own money for groceries. I have not seen any adjustment made to his cost of care to offset this. Also he is overweight and in the past 4 years he has regained at least 100 lbs he had previously lost, it is imperative he does not gain weight.

My daughter has a lot of back and knee problems and I feel they should consider having her work less hours at the Federal Building or a different type of work; we will have to decide on this at her yearly meeting coming up.

I don't think that his med are working well for him, he has anger problems.

My son has severe sleep apnea and is on a by pap machine. He is known to remove the machine frequently which leads to a dangerous situation for him. We are working to place him in a living situation with night staff to check on him so the machine will be replaced. I have found him cyanotic (purple) on home visits which also may account for some of his mental decline.

13c. Abuse/Neglect/Mistreatment

Some client at "Mentor" clothes has been stole and in their rooms they have broke dresser and they won't replace the furniture and some time the staff don't treat the client right. Instead of helping if thing go wrong the house manager get mad with the patient if they complained about something staff his won't to {ILLEGIBLE} staff won't to hit client got the staff upset. They should write them up client need clothes but they don't get none. What happen with their money? What would the people on news WITX say about this? People have been treated wrong.

13d. Social

I would like for my family member to have more things to do with people with the capability that he has. No put him in a facility with severe handicap people everyday.

I'm unhappy in that staff rarely takes my daughter anywhere on weekends. They never go to church. I always take my daughter to church when I get here for weekend visits. She loves to go to church. She would love to go to the park for a picnic. They do take her during the week to doctor appointments, for MH counseling. They usually pickup food instead of eating out.

The only complaint I have is sometimes my niece doesn't get to go some places, because one of the residents won't get out of the bed. If all don't go none can go.

I would like for my son who does not have a job, to have regular activities every day, so that he does not just spend time at his house in his room.

13e. Hygiene

Personal hygiene is a problem

The only complaint is the care of my son's teeth. In all fairness they are doing better than in the past. But still, his breath is bad and when I bring him home his gum line will have a noticeable deposit (white) of food and bacteria. When I brush this clean then it is red & tends to bleed. The good part is that on 3 or 4 days of brushing 3 times a day that the gums start to look normal. After that I start to floss and by ten days they look pretty good and his breath is much better. I took care of his teeth for 20 years before he moved to {town}. I know he cooperates better with me than when they clean his teeth. But with practice I know it will continue to improve for them. My suggestion is that his teeth & gums receive a thorough brushing every night after he is through eating and at least once more during the day. I think if a couple of workers would work with {name} and gain his confidence and theirs, it would help. His gums are better than in past of which I'm extremely grateful. But with a little more thorough brushing his gums would be protected and his breath so much better. He takes a medication for his breath. It doesn't work. But when I get his teeth cleaned the bad breath stops. I am willing to help the workers to learn better skills. He does not bite; sometimes you have to remind him. I might add I am fussier than most about clean teeth.

16. Funding and Budget

It seems like cutbacks in Babcock funding hurt the overall effort, in the past. Thank you for the opportunity to offer feedback.

17a. General Satisfaction with Services/Supports

The services and support my brother currently receives are excellent.

My sister is very happy living in {TOWN}, South Carolina Special Needs Program. She has been there since 1981. She is able to read a little and handle so much everyday life ups and downs. She has held a job for fourteen years with {COMPANY}.

Services and support provided has made a big difference in my brother's life. He enjoys living with the people.

I believe my sister is receiving excellent care. Problems over the years have been few and the problems that have occurred have always been resolved quickly and with courtesy.

I have been very pleased with the services my brother has received thru the Disabilities Board. No complaints.

The {AGENCY} Day Care and Group Homes seem to be a blessing to many families of disabled adults. It takes a lot of caring and dedication to provide the variety of difficult needs that must be met. In my family's situation, the mother of the disabled adult is living apart from her child and the caregiver does her best to see they visit the mother each week, as possible. This is important and maintains the vital link between mother and child and has been of continuing importance for a few years now. The mother and deceased father of the disabled adult were early planners and supporters of the {AGENCY} over 30 years ago. It is good to know their work has now become a kind of stability both family members need at this time in their lines. (It would have been a horrible wrench if the child had been sent to Columbia.) The {AGENCY} provides great services!

Living a great distance from my daughter does not allow me to participate often in her service plan. Overall, I am satisfied with the level of care provided.

I am pleased with services to my family member. All of her needs are met and I am in contact with the staff as necessary regarding her. The {AGENCY} is doing a great job of meeting all of our {NAME} needs in York County. (SIGNED)

My family member receives excellent treatment, these services are an asset to the community. Thank you. 4/17/06

We have been pleased with the care our son has had the past 35 years he has been in the care the S.C. Dept. of Disability & Special need. First with {AGENCY}, then the resident of {AGENCY}, Then the {AGENCY}. Thanks.

This family member has Prader-Willi Syndrome. He has resided in a {AGENCY} for ten years - is happy, well-adjusted and as his parents, we feel he is safe and lives in a very caring environment which we and he expect to be his lifelong home. {AGENCY} members have kept current with knowledge of management of PWS.

Thank you for all that you do for (name), patiently working with her. She seems to be happy and well-adjusted.

I answered to the best of my knowledge. I feel that he is happy and any time a problem comes up they feel to involve me they do so. Thank you.

We feel that the agency (NAME) is a part of us and has done an excellent job of managing her affairs and with her-who can be very difficult. I am her Grandmother and am 86 years old. Her Grandfather is deceased as of {DATE}. Her Mother is in an assisted living home - so we are especially happy with (NAME)'s help and care and supervision.

I am very please for the home and the care that my family member is receiving. Mother

Everyone at the {AGENCY} Board of Disabilities has been very helpful with any problems my brother has had with any problem. Thank you

I am very grateful for the family services provided to my sister, since she has been in the program for the last 14 years; she has made tremendous progress given her level of disability.

17b. General Dissatisfaction with Services/Supports

This is the second time I have completed this type of survey and unfortunately nothing has changed. The day program services at {AGENCY}.are still unsatisfactory; even by the administration's account; "a baby-sitting service".

17d. Information Regarding Services/Supports

Would like to speak with someone; face to face, about all legal aspects pertaining to the care of the disabled individual: Life time residential housing? DDSN? State guidelines? Monies?

{NAME} is in a loving and caring, supportive environment. Since she has severe and life changing additional needs, i.e. dementia, she may need different level of care at some point in the near future. I fear for her being cared for in a larger facility. I would like to know all options available to us when the time comes. {NAME} currently lives in a CTH1. Thank you.

I would like to know how she is doing; her case worker never lets me know anything. And I would like to know what program she is under. Because I have a son who was getting SSI; and doesn't get it anymore. He also was in Special Ed in {TOWN} MN. They said he wasn't qualified to get it anymore.

I do not even understand all the programs and what my son is eligible for. There are forms I do not know how to fill out. I was stressed out today when {NAME} told me that I didn't complete an annual review form and so by {DATE} my son's Home Community Based services - will be closed. I didn't even receive an application form, I did not even know that {NAME} in {agency} was the new economic benefit specialist it was changed from {NAME} in {AGENCY} no one informed me that I had to work with another person now. Also Food Stamp office was changed to someone in {agency}, I was not informed of that either. I called my son's case manager crying, she agreed to help me with the application when it comes in the mail this time. I feel stressed much.

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17e. Need More Services/Supports

{NAME} needs more help with his autistic disability. He was diagnosed at 49 (as stated on questionnaire). He also attended a five day observation and testing session at the University (April 05) of {NAME} for autistic persons. Mental retardation and Autism require entirely different supports. Thank you.

The services and support my brother currently receives are excellent. One of the most important issues in his good behavior and happiness is to have consistent staff that understand him and that he can communicate with in his own special way. A small group home is a must as well as a controlled routine that he can count on. Lower calorie cooking and increased exercise have contributed to improvements in his physical condition. Please do not change anything in the current programs. However, additional services are greatly needed for families with Autistic members throughout South Carolina.

17g. General Dissatisfaction with Service Management

Very seldom does a problem get solved. I have been involved in P. T. A. meetings regularly for forty years. Now meetings have been dismissed. I am always interested in the welfare of my sons. I would like to have more input when problems arise. The Board members and higher staff does not take the family members problem a concern.

19. General Concerns

I feel that he does not have the capacity to handle the amount of freedom that he is given. I feel that he does not have enough one-on-one supervision. I do not feel that he was ready to move to the level he is at now. He should be moved back to the previous level.

Concerned about finances and health issues.

I would like to see a financial statement every quarter so that I could make sure my family member has monies in case I am out of town. Thanks.

I recognize that because my nephew is living in South Carolina and I am in New Jersey, that it is difficult for me to be as fully involved as I would like. I am in constant touch with my nephew and hope that in the near future that he will be able to get on to the internet so that we can keep in touch more frequently and less costly than by telephone. Distance and age prevents me from visiting with my nephew; however, I have asked several times for a report of my nephew's finances so I can understand how fees are applied as well as where his SSI funds & wages are utilized. I believe that my nephew has given permission for this information to be provided to me.

I think there should be copies of what each person has in there accounts & a copy should be sent out showing what each person's money is spent on. Thank You!

I am (NAME)'s aunt his mother is deceased, I am his guardian, I would like to see him 1 month or 2 twice month I haven't seen him since last year. It's important for me too see him in this month, so make arrangement for him too come 2 twice month and see about this matter soon.

My son's bank was changed, but an automatic draft was not transferred to the new account for the purpose of pre-paying his burial. I feel that this should have been done.

We don't know how his money is spent we have no way of seeing his bills paid or where his monthly check goes they tell me they have a person who does this.

I think my family member is very unhappy because he can't come home for a visit. He loves to come home. They tell me he could come home for a day visit if someone will bring him but they can't get anyone to bring him. I would like to ask why?

Item # 19 page 5 I don't know but she receives approximately \$1100.00 from rail road pension that is paid to {AGENCY}. Some of this is supposed to be being put aside for her final expenses. I would like to see a record of how her money is spent. In other words, where does this money go? Thank you.

SOUTH DAKOTA

1a. Satisfied with Home

{AGENCY} as ability building services has been the home for my sister since 1985 - they have been excellent in all areas of service. I visit the home and observed their programs. I'm pleased with the workers at the home my sister lives. They are wonderful.

We are happy {NAME} is at {AGENCY} he likes to come home but never complains about going back. We do go and take him out for an evening meal.

I feel my cousin {NAME} receives excellent compassionate care. He is happy and his health is monitored regularly. His social needs are met by attendance at church and social outings such as going shopping, dining and other trips to zoos etc. His caretakers go the extra mile to please him (actually they spoil him) I only have positive things to say and am thankful there is a place like {NAME} for {NAME}. I could never physically care for him at home myself. Thank you folks for all you do.

I am my brother {NAME} guardian and have always been very satisfied with the care and guidance he receives at {AGENCY} in {TOWN}. We have a friend, who is like family who lives in {TOWN} and he believes {NAME} is well taken care of. {NAME} Is happy where he is when he visits here in CA and AZ. He is always happy to come see us. But is always ready to go home. Likes to call his apartment while gone. Yes, we are all happy with {AGENCY}.

Seems happy at the place he lives and also at the {AGENCY}. It's one of the best things that have happened in his life.

Our son is very happy with his own apartment and day job. He is real happy with everyday.

We are very grateful that there is a residential house for our person to live in. This not only provides him a safe place to live one that he can call home but also provides him with friends.

{NAME} and his roommate like the apartment they are in I think it's a good match. I don't feel they are able to buy and take care of a house on their own, be responsible for all the things that can go wrong in their own home that they would own up keep etc. Would be a gigantic nightmare.

{NAME} has been living in an apartment with a roommate for 4+ years. He seems to do well in this environment. He gets along well with his roommate. We are always satisfied with the supervision he receives from {AGENCY} staff. They handle questions or concerns quickly his assistants are capable caring people.

I feel that {AGENCY} is doing a good job with their residents. I don't know where my brother would be today if it wasn't for {AGENCY}, I would not have been able to take care of him full time. They have taught him a lot.

My brother is fortunate and deserving to have the attentive love, care and support he has had. The group facility is nice and comfortable, and my brother seems content and happy. He loves to go to and is usually able to work outside his home with peers from his facility.

Our son is very well cared for and lives in a cheerful family-like environment. We are always contacted should anything arise about {NAME}. We are extremely satisfied with his home and his care.

{AGENCY} is a wonderful, caring, and totally helpful place in every way for my sister.

As her loving father I am most happy and satisfied in the way my darling daughter is loved and cared for by the {AGENCY} and training center, nothing could be better.

We are satisfied with the group home our daughter is in. They have activities and take her into the community which she enjoys them take good care of her and keep in constant with us concerning issues pertaining to her.

My son would not have quality of life he has now if he did not have support and assistance from {AGENCY}.

I am completely satisfied with the facility and everything they do.

Our family is so grateful for the loving care and support shown the clients at {AGENCY} they are genuinely concerned in giving the best care at the center and the homes.

{NAME} goes to {AGENCY}, South Dakota. He lives in a group home and gets very good care. He is very happy there. He is 34 and he's been there since he was 16. (...) {AGENCY} is a wonderful agency.

{NAME} gets excellent care where he lives and he loves it there. I wouldn't change anything on the care {NAME} gets. The staff and people that work with {NAME}: are great people who care about him. He is happy there and so are the rest of his family members.

My daughter lives in {TOWN} and is at a group home affiliated with {AGENCY}. Great place for her and is well satisfied and she has now been there for 6 years.

My daughter is with {AGENCY} in {TOWN}. I am very pleased with them. She is happy there. The place is always clean. The staffs always are happy and take good care of the clients.

My daughter is at {AGENCY} in {TOWN}... she is happy and I am happy. I have known the staff and consider them my friends. I feel that if something happens to me she will be taken care of.

{NAME} seems well taken care of. Is willing to return to the facility after a weekend at original home or trip away. Medical situations are taken care of and we are pleased with the care he gets at {AGENCY} in {TOWN} S.D.

We are very pleased with our sibling's placement and care and are so thankful such facilities are available.

As my husband and I get older we are more thankful than ever that our daughter can live in a caring, safe family - type environment. She is happy and this makes us happy.

I think the {AGENCY} is doing a great job - {NAME} has grown so much over the last 19 years that we've been with him.

The {AGENCY} is the best place our son has been in. The staff both residential and vocational is the best. The residence where he lives at is great. He is happy and well cared for.

{AGENCY} was the best thing that happened to those who were placed there from the SDDC - Custer. SDDC -Custer did well but {AGENCY} does much better. State should have done the same with those from {AGENCY}.

I love where {NAME} is now. He gets wonderful care from all the staff. It's a small town and he can go out more and go places he couldn't before.

I appreciate the wonderful care my son receives in his group setting. My life is much more enjoyable. My son requires 24 hr care; it would be next to impossible to care for him at home. Thanks again for the care and many more opportunities for my son to enjoy his life to the fullest.

We have always been very pleased with the care {NAME} has received at the center. He always seems happy and says that everything is fine. We have found the staff very pleasant and easy to work with.

They do an excellent job at {AGENCY} they truly do care for my family member. I am kept informed of what he is doing thru correspondence and phone call. He does many things which are great. When there have been health issues they keep me up to date and have even offered their home phone number. We and he is blessed to be at such a wonderful care facility.

The service my sister receives are wonderful - we are so grateful for everything {AGENCY} has done for her - she is happy and so are we.

I have enjoyed working with the {AGENCY} staff, and the Developmental Disabilities of South Dakota. Any questions I have or anything I think {NAME} should have is always looked into, taken under advisement and discussed with him. We work as a team to allow {NAME} to live his life to the fullest, as he also sees fit. It's been a wonderful 7 years!

The group home is so wonderful for these people - it's so nice they can be together in a group setting than in an individual home. When as parents our health will no longer let us do what we wish we could. They are happy to be with those that are like them, yet have their own room, a real blessing.

My daughter has been at {AGENCY} in {TOWN} for over twenty years! It is such an excellent place! It just keeps getting better! How fortunate we are to have caring workers and staff.

My sister's health has failed in the past few years. She is the oldest Down syndrome that I have known of. Her care in {TOWN} at {AGENCY} has been simply excellent! Her care has been a comfort for the others in her family. {AGENCY} continues to improve the quality of services. This has been done by hiring employees with proper training and education. We are very satisfied with the services our son receives.

My sister has been under the care of {AGENCY} since 1984. They treat her like family. They do an excellent job of meeting her needs we couldn't ask for better service.

Totally satisfied with the help received from {AGENCY} they are great and do so much for him.

{NAME} comes from a large family and we are very pleased with the care she gets. She is happy in her location and environment, and we feel {AGENCY} has been very good for her.

Our daughter is with {AGENCY} at {TOWN} and we are very satisfied with the agency and highly recommend it to anyone in need.

He seems to be happy at {AGENCY}. He stays with me every other week-end and holidays. He never objects to going back to {AGENCY} after his week-end with me now. He is happy both places.

{AGENCY} has truly gone out of their way to do whatever it takes to serve {NAME}. They have made changes on a large scale at their agency to help make {NAME} happier than he has ever been.

I am very happy that my son likes where he lives and he stays very active all the time and he has come a long way in life.

{AGENCY} has been very straight forward and open about anything to do with {NAME}. Always keep me informed and are open to anything I have to say, they put {NAME} happiness and welfare 1st and never cover up if an incident happens. Very pleased with them and he is content.

My son has improved since he was moved to {AGENCY} in {TOWN} S.D. My son is getting up in the morning and going to work at the workshop. My son has not worked any place for at least 5 to 6 yrs. This is a very good improvement. My son was way over weight a year ago. My son was wearing size 46 pants. He is now wearing 38 size pants. My son has his personality back he talks and laughs and jokes around again. My son looks great a year ago I really didn't think my son was going to be with us. He was sent up to the {AGENCY} in {TOWN} S.D. I was so disappointed in that place. He was so overly medicated and dirty that my own son did not even know me. If {AGENCY} wouldn't have had an opening for my son I think he would be dead or a vegetable by now. Thank God and the {AGENCY} staff.

{AGENCY} in {TOWN} has done a wonderful job for my daughter over the years we have many different types of settings and living arrangements, same with very negative outcomes. In {AGENCY}, she is doing better than she ever has.

I think our family member is about as happy or satisfied as he could be in this setting. Has been in this home for some time and most things are good. Has good medical care, and seems to be adjusted to his environment mostly the workers and helpers have been considerate and respected his feelings Don't know everything about his situation as we live on the other end of the state.

I am well satisfied where she is. She seems real happy.

Every one has been very polite and helpful for our granddaughter and me. She has really grown up a lot and learned a lot over the years. She seems very happy most of the time but gets lonely sometimes. She calls at least once a week and I call her every other week. She comes home for holidays and during the Sturgis Rally. She is happier than she was in {AGENCY} and treated better. Thanks for everything you do to help all these children.

Over all I am satisfied with her care. They contact me whenever something happens to her or if there needs to be a med change.

{NAME} enjoys coming home about every 3 weeks for 3 or 4 days, but she also is ready to help get ready to pack her things and return to {AGENCY} group home in {TOWN}. She likes being in a room by herself as she isn't a mixer she doesn't seem to have really close friends. She likes to go for walks and shopping - and enjoys her favorite foods: apples, pears, tomatoes, spinach, potatoes, ham, eggs, bacon and hot dogs and bologna and roasted chicken. I am satisfied with staff they been are very helpful.

I think the {AGENCY} is wonderful; wonderful facility and they have great employees.

1b. Dissatisfied with Home

I still would like to have him closer to {NAME} so I could do more.

Our family member is living under restrictions being imposed because of the other people living in the same house. These are restrictions that stop our family member from becoming more independent in daily living skills.

1d. Furnishings/Cleanliness of Home

There is one possible improvement and that is on {NAME} house keeping skills. He is a lazy housekeeper - it could be he is a lazy bachelor and maybe that can't be changed.

I am very unhappy with the living conditions; the rooms are smaller than a jail cell, no room for a chair only a single bed on each wall. They eat, sleep and work with the same people. If you go to your room and sit on the edge of your bed you can have privacy, you can listen to your CD player in quiet. Please help us to improve housing.

And improvement on apartments, houses etc need to be checked and fixed yearly.

The facility where my person lives needs some serious attention. Not always sure it is safe old building.

We would like to see better upkeep on the home as to repair and cleaning and up keep we will always be supportive of everyone that cares for our son and as always our son's health and well being is most important to us.

The group home she's living in and he's lived in isn't as clean as it used to be and a lot of times when I go there it smells. I have a concern about a table they have there that is always cluttered with stuff bags purses left open etc. It is usually so full of things I don't know if there is anything on it she could get at and hurt herself.

I have been upset sometimes with the cleanliness of his apartment, his refrigerator, and dishes in the cupboard. When addressed to the case manager it does improve. I feel that I need to keep checking on these things.

We would like to see better up keep on the home as to repair and cleaning and up keep we will always be supportive of everyone that cares for our son and as always our sons health and well being is most important to us.

The apt. should be checked for neatness, cleanliness, the clients are to do this what if they don't.

I'd like to see {NAME} cleaner clothes & body - also his apartment.

I feel my family should be included in more decisions involving our daughter's living environment. I'm expected to provide furniture for her apartment but when it comes to decorating they want to leave it up to my daughter, as a mother I want to be more involved, also I feel more money is spent on some living facilities in the community, whereas my daughter can't even get her apartment painted, I as a parent had to put up a fight for that. {AGENCY} needs to be fairer.

I firmly believe she is in a safe and caring environment that supports her medical conditions. There are some issues where staff have taken little or no effort to resolve - e.g. - broken mailbox where her independence to retrieve her own mail is no unavailable (it's been broken for more than 1 year). Thank you for the opportunity to participate in the survey.

2a. Satisfied with Employment/Day Programs

Our son is very happy with his own apartment and day job. He is real happy with everyday.

He has a job now and very happy!

We are also grateful that he has a place where he can work and experience the feeling of satisfaction of the routine that goes with having a job. All of our lives would be much different without these services.

This is a wonderful opportunity for this person to work and be educated. Fabulous staff at the facility/work site.

My brother has a job at the hospital that gives him something to be proud of and that he has accomplished something. He is involved in bowling. Exercise, outings, church, etc.

2b. Dissatisfied with Employment/Day Programs

They need more work hrs in order to meet state guidelines say 20 hrs {AGENCY} provides 5 hrs per wk change state guidelines.

Also forcing the recycling to close because they didn't pay minimum wages was wrong, I would rather my daughter earn .20 an hour and have something to work at than earn minimum wage and sit and stare at the walls with nothing to do.

My son would like a job. It would be beneficial to him. I understand the economy has a lot to do with his unemployment. I have seen aliens with green cards take his job to benefit them. That's wrong.

My son would be a happier person if he could find a job. He has cerebral palsy and uses a wheel chair. He is 24 yrs old has no problem with communicating, but has not been able to find employment.

I feel my family member needs to find employment on a regular basis so he isn't constantly sitting in the apartment. It seems like it takes forever to find employment for him.

{NAME} has worked at {NAME} for over 12 years and it seems to work well but he complains his knees bother him and the work is hard and he wants to find a different job perhaps in a grocery store, carry out, stock shelves etc. I don't know if it's possible or not. He talks about it all the time and the staff has been helping him to find a job so he says, they have not spoken to me.

I would like to see my daughter have some type of job that would make her feel useful and important.

He's not working right now and needs a job to keep busy and out of too much time on his hands. Apt to get in trouble.

The removal of the individuals from the afternoon workshops at the training center greatly upsets us. We would like to have the afternoon workshops open to all individuals, regardless of their part-time employment. Those who no longer go to the training center are left to sit in their apartments most of their days. When activities are planned to help keep them occupied there is always an associated cost for the individuals and that cost is hard to afford on small, less than part time income. There have been no classes or craft lessons offered as of yet and we were told in September that these things would be offered for those no longer allowed at the training center. We are upset about the lack of involvement in the center. These individuals had daily activities and work opportunities to better their self worth.

I would like to see son's different employment opportunities instead of being at industries all day.

We are concerned because our family member has no job skills/appropriate options. We are told our facility has no contracts appropriate for the disability. Our family member just sits around the workshop. Often it seems meaningful activities are not provided - just sitting around.

The only thing I wish was different would be the employment opportunities available to them in the community. There doesn't seem to be enough of them for people with disabilities in them.

Employment opportunities are terrible I see no future prospects.

My greatest concerns...2. Stimulating job availability

I would like to see more jobs offered to my son - even outside the day programs at the facility.

I would like to see my family member be offered more employment opportunities possibly through job shadowing, etc. Also it is my understanding that my family member works very part-time and I would like to see him work more hours as I know he enjoys the work when he is able to do it.

Employment for people with disabilities in {TOWN} is tenuous at best - in the summer it's pretty good. There are a lot of barriers thrown up constantly. {NAME} got a good job with community custodial crew which pays 5.15 an hour. It was a high endeavour to get him the job which took a lot of advocacy on my part as the job had been promised to him twice and then revoked because another person with a disability had recently been laid off from the base and the workshop wanted to place that person first then because {NAME} displayed some behaviors the supervisor wanted to get rid of him but because of more advocacy and the help of a job coach paid for by VR he is still on a two week probationary period.

15. We need work project for her and other clients

3a. Health Care Equipment

He needs more advancement in equipment like a special {ILLEGIBLE} communication board and one at home each of these to be consistent

Our main complaint is the amount of time it takes to get orthopedics, equipment, etc, repaired or replaced

3c. Dental

I know that I had a lot of difficulty getting adequate dental care for my brother who resides at {AGENCY}.

Dental services that accept Medicaid. I would like more say in his dental hygiene care and not enough dentists accept Medicaid the need an incentive from state so we parents may have a choice of provider.

3e. OT/PT/ST

We don't feel she gets as much PT and others as needed.

4a. Satisfied with Education/Training

The training centers are very wonderful places. They have made a real difference in my family. They are happy to have jobs pretty much on their own. They have all the resources and help that they need. I trust them with everything. I don't know what I would have done if these places

were not around. My hats off to these people they're wonderful. If people don't understand the need to be in my shoes (!!!) or any other person that has family with special needs.

We have been very satisfied with the help we have received from our training center. He has a very good safe apartment. They have found him several jobs. He has had the same job nearly 6 years. He really likes it and the people there are very good to him.

As her loving father I am most happy and satisfied in the way my darling daughter is loved and cared for by the {AGENCY} and training center, nothing could be better.

My son has been associated with the {AGENCY} for approximately 35 years. Under this supervision he has received training which has allowed him to become a useful member of society. He has been able to hold paying jobs and with the aid of the {AGENCY} has lived independently and has purchased a house in {TOWN}, SD.

These people have every right to get an education as anyone else. I'm sure they will surprise everyone what they can do.

4b. Dissatisfied with Education/Training

My daughter is very cooperative & easily swayed by staff. It is a continuing battle to get what she is entitled to: It has been 10 month request and she still has not gone to church as requested the training center does well with clients that have no families but shuts out families that are still part of the life of the family member who receives services, there is no respect or input wanted from parents. I have raised this child in home with little help for 20 years & was hoping for a smooth transition to adult services. When she went to the training center. I was promised a lot but things have declined. We received services from the state of Iowa for 15 years & it is a shame that this state can not provide quality programs such as Iowa. I will pursue on my daughters behalf: continued education, independent opportunities, community involvement, job for at least minimum wage, (not 7 cent piece rate) & what ever it takes to keep this whole family together! As you can see, I am very upset and need more for her.

Since age 3 our son has enjoyed learning and growing to walk and talk and family members worked hard to help him be happy. He has been a traveling ambassador for meeting SD special needs families clients and professionals he has excelled in remembering many places situations and names at age 15 we as parents were told he MUST be placed at {AGENCY} at that time we understood a plan further his excellent spelling and typing and computer training would be addressed and his out going personalities to work with and enjoy cheering on other people would be an asset to further his adult education and job training. At age 29 he is telling us how unhappy he has become and discouraged with his plan to success and to be a MAN. He says all the people who write-up and tell him they will help move away to more money and happy futures and now maybe he too should leave because {AGENCY} can't help him find a good education and job. He is tired making them all happy and he is not.

More emphasis and efforts to develop stimulating and rewarding job skills for the profound handicapped, that will build self esteem and sense of pride that they are making a difference in the community.

I would like to see my adult child have an opportunity to be with people her own age and people that are more on her level. You know it's bad when your disabled person calls the people around her kooks (interesting and unbelievable yes but true). It would be nice to get the

disabled work that is not in fast food or janitorial services; we need job coaches who are really interested in helping our disabled.

Is there a program to help our son to relearn how to write his name? Do some ready so he can use the phone? Help with money? Are these just things he has to survive without?

5b. Dissatisfied with Transportation

I feel the agency should be able to give transportation to my family member to and from his job. At the present it would cost him about \$7.00 per day for cab fare to get to and from his job. At present our family member's dad provides rides for him. I don't feel this should be occurring.

My son's job now requires his own transportation to and from each day which gets costly am wondering if that expense could be deducted from his HCBS waiver at least part of it.

I wish he had access to more transportation, He uses the city transportation, but it doesn't run nights or weekends. He ends up having to pay for a taxi or more often is walking. This worries me in the winter and at night. He has had encounters with some not so nice people. I worry that someone could hurt him. He's very trusting. He's better about not going when he doesn't have a ride, but still goes out at times.

I wish there was more transportation available on the weekend if they'd like to attend a social event, movie etc. It seems like there's not enough help or transportation to get my family member to the things she'd like to attend.

We would like to have our son have a little more freedom (unsupervised for short periods of time). Are there any funds for mileage? Every other weekend we travel to {AGENCY} to pick our sons up then have to return them on Sunday or Monday my husband is disabled so it's hard to make ends meet, when we have to make that many miles.

As parents if we can't take him out, he doesn't get to go. He loves sports events but has no way to get there. Cabs run minimum of \$8.00 each way far too much for his finances.

Transportation thank goodness for {AGENCY} in {TOWN}. {NAME} uses this service independently and certainly the bus insures a great deal of independence. The only thing that would make the service better was if it could include Sundays.

6b. Dissatisfied with Recreation Activities

There needs to be more social recreation activities. There should always be some activity going on, like once or twice a week. It could be like movies or exercise or trips or classes or cooking, money etc.

We are pleased with the care our son {NAME} receives at {AGENCY}. We would like to see him involved in more activities, i.e. swimming (water activities), sensory stimulation, and music he enjoys - in summer outdoor walk and park visits.

We would like to have him have more opportunity to do recreational activities - he only gets a chance once a week - he is overweight, so more often would be great for him - not only for physical needs but also for mental needs, he is very introverted and has a problem with depression.

7a. Satisfied with Communication

I live 3,000 miles away from my family member. Her facility is in touch with me often and I am very comfortable with her living in the facility.

We as a family feel {NAME} has good care and is included in deciding what is best for him. They also keep the family informed of changes and decisions. We feel they are doing a good job.

{NAME} is usually a very happy and loving individual - I feel {AGENCY} has helped her to grow a lot. She is usually very responsible and is not afraid to voice her wants or needs to staff members. She knows someone is always there for her if she needs them. The staff is very good at keeping me informed on her progress and notifies me if there are problems.

{NAME} seems to be real happy in the {AGENCY} center and they keep me informed of any sickness or things she needs. They give me a full report on her money as to how much she has spent and for what. I am 83 years old and don't drive much so don't get to see her as often as I would like but am real pleased with the care she is getting.

I feel confident in the people who work with my brother in every way possible, they are very knowledgeable in the work they do with people such as my brother. I have no reason to think otherwise. I have an open communication with the staff of {AGENCY} at all times. I have no reason to worry about my brother.

I am so happy and satisfied for the services my son is getting. I am always notified of any changes in his work and also know about his living arrangements and how he is doing there. If there are any major problems with {NAME} I am always notified. {AGENCY} has done a fantastic job of seeing that my son is well taken care of and has wonderful living arrangements. Every one has been so wonderful with {NAME} for a long time and {NAME} looks up to him for guidance.

Nursing and social work do a good job of keeping me informed.

7b. Dissatisfied with Communication

My involvement with person receiving your services is as guardian only; therefore I do not get as involved as a family member might. I am satisfied with the services but would like more frequent updates as to progress and service.

I would like to be more involved with medical decisions. I am not informed when she has Dr. appointments or what they are for. Our family Dr. has requested my presence.

I would like to know how she is doing; her case worker never lets me know anything. And I would like to know what program she is under. Because I have a son who was getting SSI; and doesn't get it anymore. He also was in Special Ed in {TOWN} MN. They said he wasn't qualified to get it anymore.

We have had in the past many communication problems in the past and still continue to have them. I have spoken with {NAME} and {NAME} in the past and still communication is just not of the essence in other staff. They have been very helpful though.

We would like to hear more information about our sibling if something happens to them.

The state should talk to parents/ guardians before making decisions that affect these people; closing {NAME} State Hospital was a big mistake!

As his mother we would appreciate more phone calls leaving us know how our son is doing by the staff. We try to call weekly ourselves but it would be nice if once quarterly they called us to report on him health wise and how he's been otherwise Giving things like Doctor, Dentist and other visits also things like his weight and medicine changes, also we'd like to know if he's been doing like movies, bowling, circus and such he's attended. We miss his bulletin board. In his room where he used to have photos and such to stay in touch things, wish he still could have it.

Sometimes there needs to be better communication between staff when one staff goes off duty and another comes on - the staff coming on duty is not totally aware of what is going on or taking place with their clients.

I stay in constant communication with the staff who works with my son however I still feel "out of the loop" on a lot of little things (which sometimes snowball).

During the past year internal communication between/among staff seems to have declined at this agency hopefully this will get better in 2006.

My other complaint is not returning my calls!!! When I call very rarely are my calls returned!! These are calls I've made to the training center!

There is room for improvement in all segments of communication. Communication among the employees/staff, communication between staff and parents/guardians. Communication on all levels could improve.

We have a huge communication problem with the daily support staff messages do not get passed along. For example we will tell staff when we are going to be getting our family member and when we show up the staff on duty knows nothing about it. It is very hard to get a hold of the team leader and when we do we are apt to be told to talk to the other staff person in the other house.

Communication is an area I wish could be improved. In the past, I introduced the traveling notebook as it proved to be a helpful means of communication while our son was a part of the school system. This notebook was merely one that the staff would write notes in, They would share his activities, ask their questions or discuss events of one sort or another. When our son came home he would have this notebook in his school bag. I would read it and make comments (I usually would use a different colored ink and write in the margins I generally tried to give positive feedback such as terrific great thanks much for including our son in that activity etc. This notebook was also available for questions and also a way to communicate any problems such as please take notice of our son's enzyme on his left upper leg etc. The notebook eventually lost out to the activities log which was written by the staff a copy of that was sent to us infrequently with the range of time being every 2 weeks to once in 2 to 3 months. That lack of consistency and frequency didn't offer me much of a chance to respond inform nor ask questions. Nowhere activity logs have also been discontinued. An internet check list I guess is to have replaced the activity log. Since we got our last computer here, I have not taken the time nor effort to acquaint myself with it. As a result communication is now primarily left to

requesting meetings or making long distance phone calls. I miss the original and most complete exchange that the traveling notebook provided.

Workers seem interested and friendly they say they'll find out info but you can't count on it. They don't seem to keep good records or pass on info to each other. Reports seem almost contrived at times.

It's hard to get answers record keeping and passing on information seems poor. I was told my family member was moved to a different home then later told he was at the same old address and no one could find out what really happened. I had even sent his Christmas present to the new address.

No outside input is generally allowed. Don't know an event occurred until after the fact. Example individual's dad died and no one from agency has notified me as of yet (found out other ways).

Problems addressed at meetings are not always followed.

8. Aging Caregiver Issues

I think {NAME} gets way good care. However, I do wish there was some kind of "401k" system for handicapped people to help them in their old age time of life, when they are young & healthy and make more money it would be nice if some of it could go for their old age.

10a. Satisfied with CM

I think {NAME}'s case worker does a good job for him. He is well protected and she helps him make the right decisions. She is very good to him.

Our loved one's case worker is very supportive not only in her services and quality of life, but in understanding the needs of the family as well.

Support services get increasingly responsive to her needs. Having the same people working with her over an extended time helps make this happen, as they know her better and better.

11a. Satisfied with Staff

I am completely satisfied with the progress my son has made under the guidance and dedication of the staff at {AGENCY} incorporated in {TOWN}, S.D. He is cared for real well.

My sister has great support at the {AGENCY}. I'm in contact with her daily and help with any issues that arise. She does have issues with different service coordinators, but with my support she gets through it. I have always been happy with {AGENCY}. They listen and will help us get through any situations. They are a great bunch of people and truly enjoy what they do. My sister knows she has a great support system and will do what ever to make sure she is happy and has a wonderful life.

My son is getting the help he needs with the staff at {AGENCY} and the doctor. They are great people and I can call any time if I have any questions or to check on my son. My son would not be where he is today, with out this help. I thank god for all the great people at {AGENCY} and others who help.

The {AGENCY} take good care of my daughter and calls if something seems to be a miss. Very caring workers who have her best interest in mind.

I the parent am fully informed about my daughter appointments for her health needs - I feel the staff at the {AGENCY} do a good job with the clients.

I have been very happy with the support my child has received thru this agency. I have seen growth and maturity in ways I never imagined would be accomplished. I have never had to file a complaint or ever had a grievance. I usually am able to speak to the support staff for any problems and it is taken care of. My child has become very independent with their help. Thanks to all who participated in this.

The staff is good to her and encourage her to take part in other activities. {NAME} is usually quite inactive, so it takes a lot of diplomacy and encouragement to get her to take part in many activities. The staff are good about attending to her needs. Whether medication or otherwise. I am grateful for a place like {AGENCY}.

{AGENCY} is an excellent state managed program that provides excellent services. The staff at {TOWN} is concerned and sincerely attempts to make or recommend the right decisions in the individual.

Our daughter (...) wanted to have a cat (...) [and] {AGENCY} staff gave us excellent support in achieving {NAME}'s dream and found and placed her with her best friend in another community home where she could have a cat! (...) It has been a ruff adjustment on {NAME} but we are pleased with the patience and ideas of staff to make {NAME} comfortable and happy.

My daughter has truly matured as a member of our local community through her ongoing involvement with the wonderful {AGENCY}. They are a Godsend {NAME} and the rest of the support staff have been such wonderful help to {NAME} in learning how to carry out daily business. Work at a job, set priorities, meet goals and care for daily living needs. {NAME} is sincerely happy to be living here and working with the {AGENCY} they have taken her further along the path to real independent life than I ever could have done for her. Thank God for the {AGENCY}.

All of the staff at {AGENCY} work and his apartment are great. {NAME} enjoys all the staff he tells us funny little stories. I can't tell you how much I really appreciate everyone and feel very, very blessed to have your staff in {NAME}'s life.

I have always been thankful my son has been able to participate and be a part of the {AGENCY} I thank God he has had a caring and capable staff care for him, they are very special people.

The family feels that the staff and workers do a good job with all of the disabled individuals in their care.

{NAME} gets excellent care where he lives and he loves it there. I wouldn't change anything on the care {NAME} gets. The staff and people that work with {NAME}: are great people who care about him. He is happy there and so are the rest of his family members

We are very happy with the care {NAME} gets. The staff is very good to {NAME}. Her programs are very good for her.

{NAME} is very happy @ {AGENCY} and is well cared for they are in tune to her needs and wants and even though it is hard for her to communicate - they figure out what she is trying to say. We are definitely satisfied with her care and comfortable with the compassionate and very capable staff.

My daughter is at {AGENCY} in {TOWN}. My husband was chairman of {AGENCY} for many years so, therefore we visited each facility that was in South Dakota, at that time we choose {AGENCY} and never have been sorry. {NAME} passed away in 1993 but I have kept her in {AGENCY}. She is happy and I am happy. I have known the staff and consider them my friends. I feel that if something happens to me she will be taken care of. Thank you for sending me this survey.

{NAME} has made amazing changes since he went to {AGENCY} at first I really didn't think things would ever change, and worried that this facility wasn't going to be any different, than any of the other places he'd been - but they stuck with him through the tough times and worked to find the right meds, the right counseling and he has worked hard also, so he has made a life for himself. He married and has a home and considers {AGENCY} his home. With out {AGENCY} this never would have been possible, with out {NAME} and all the staff at {AGENCY} when things were rough. {NAME} Would have slipped through the cracks as the expression goes. I would never have believed {NAME} could come this far. Of course he still has bad times and has had cancer and cancer treatments and again {AGENCY} was there and included me - I'm not his guardian, but they have been wonderful and I'm sorry if this sounds repetitive, but {NAME} would not be as healthy or as happy as he is with out the dedication of the staff at {AGENCY} of {TOWN}, S.D.

We are very satisfied with {NAME} care, his support staff and he is a very happy guy.

{AGENCY} {TOWN}, S.D. I am satisfied with the staff and support system. I am usually notified of any changes in her program etc.

The staff is very caring and compassionate. She is very happy there, even though it would be nice for her to be closer to family.

This is one of the best groups of people a person could hope to have helping them.

We are very appreciative of the adult way our daughter is treated like one of the staff. She seems content and happy there.

I am very satisfied with the dedicated staff that provides training and support for my disabled son. My son has made tremendous progress the past 2 years. My son's constant ear aches affected his behavior. But his support workers took him to a good ear specialist who cured him and found out it wasn't ear infection. Ear aches were caused from sinus infection. My son's support workers have his ears and sinus checked on regular basis to prevent severe ear pain. My son is deaf, autistic, and retarded so it's difficult to communicate with him. His support workers use sign language as best they can; they do a good job even though they weren't trained to work with the deaf.

The care givers do a wonderful job and only have the best interest of my brother in mind.

My family member and I are so grateful for the angels who provide for her care and wellbeing with unending love, patience and compassion. Thank you for this opportunity to tell you that and to let you know about the wonderful programs and staff offered at {AGENCY}.

My family member gets wonderful care, the member that take care of him are helpful and wonderful.

{NAME} has very little cognitive ability. The one thing that is most important to him is walking the residence he is in has a circular hallway and he is allowed to walk the hall when ever he pleases. He is happy where he lives and the staff is very good with his care and with the care of the other residents at the 34th Street facility. Knowing he is well cared for is a great relief to us.

I feel the {NAME} home of the {AGENCY} is a great place and the staff is competent and does a wonderful job with the residents.

{NAME} is very happy where she is at {AGENCY}. I see her several times a week and she does not like to spend the night away from her apartment. The staff at {AGENCY} are very good to {NAME} and she loves each and every one of them. She wants to come home they are always ready to give her a ride.

I feel confident in the people who work with my brother in every way possible, they are very knowledgeable in the work they do with people such as my brother. I have no reason to think otherwise. I have an open communication with the staff of {AGENCY}. at all times. I have no reason to worry about my brother.

I'm very pleased with the services provided by {AGENCY}. They have had a fairly stable staffing situation with their permanent "employees" and their temporary support staff (student trainees) have all had very acceptable recommendations; so it is hard to answer some of the survey questions regarding the choice of support personnel (questions 16-20) which are slanted at changes to {NAME} support which just doesn't happen. I suppose most of these questions should have been marked "N/A".

Staffs at the group home are great.

The entire staff at {AGENCY} does a wonderful job in the care of my sister.

This has been hard to evaluate as there is never much improvement in her due to her severe MR, but the staff is very caring and she seems happy there always. They try to find things that interest her but the choices are very limited. I am satisfied that they are doing their best to keep her healthy and happy and I appreciate all they do for her.

My brother works at {AGENCY} and they hire the people who staff the home where he lives. I can't say enough good things about the facility and the staff. They are all fantastic.

She is at {AGENCY} in {TOWN}. She loves it! The staff at home and at work is great. It's been a true lifesaver for all of us.

The staff at {AGENCY} has been great to work with.

My now 50 year old daughter was transferred to {AGENCY} from the facility at {AGENCY} where she had resided for many years. I felt she was receiving excellent care at {AGENCY},

however the social worker there thought my daughter needed a more community based facility. I was very apprehensive at the change because she did not handle any change well. The change proved to be a very positive one, with a few exceptions which the {AGENCY} staff recognized and made every effort to handle. Example she opened the door and walked out of the group home. She had a fractured leg which no one knew how it happened. She gained 30LBs in a short time. Registered my concern and was told they would watch her diet, etc. At Christmas staffing I noticed she had gained even more weight. Staff attributed this to medications from her psychiatrist, and lack of exercise due to the weather. I am very pleased and amazed at how much she has calmed down (perhaps changes in meds) and how her behavior has mellowed. She is much more acceptable in society, and responds to staff behavior modifications. The staff is exceptionally interested in her and it is apparent she has a close relationship with everyone who has contact with her. The staffing we have attended are remarkable she shows great improvement in her daily behavior. She calls home every week and we have a good visit with much repetition. Because she is so verbal she can wheedle something out of anyone with her compulsive behavior she can be a bit difficult to handle, however the staff does a remarkable job of curtailing these habits. I am truly beholden to the people who work with her for their compassionate, but firm understanding and care. Her progress is remarkable, and I cannot think of anywhere else she could get this kind of care.

I'm always impressed with the way they have helped him integrate into the community. When I visit him, we never go anywhere without someone saying hello to him. Fact is when he visited me here in the Twin cities this past Christmas season, someone in the airport said hello to him and asked him what he was doing there. I can go to the airport and never see anyone I know! The staff at {AGENCY} always works to make his summer progress report is at a time when we can be there. They are nothing but professional and very caring individuals concerned about all aspects of their clients life. I have been very impressed with the staff and their commitment to their clients. They have done so much to add to his quality of life. He is very fortunate to be in a community and an agency that works to make everyone's life regardless of their limitations or challenges a life full of all the things that mean the most to them.

We have been very satisfied with the care {NAME} has received in {AGENCY}. We are age 92 and 85 and it would be impossible for us to give him the care and opportunities that he has in {AGENCY}. The staff has been courteous helpful and we are appreciative of the fact that there is such a facility as this for him.

We think the staff and leaders are doing what is best for our daughter. She is served by {AGENCY}.

{AGENCY} does a great job with my son. The staff is friendly and enjoys it there.

When I call the group home or the office the staff is friendly and polite. The staff at the group home will hold the phone so that I can talk to my son. I call him twice a week. Sometimes I will send him mail or send him an e-mail which they will read it to him he seems to enjoy my calls and mail.

I want you to know I truly appreciate the people taking care of {NAME}. These people are a true blessing. Thank you for your concerns in these matters.

The staff at {AGENCY} provides a safe and happy environment for their residents.

11b. Dissatisfied with Staff

I believe it takes a certain type of person that can have compassion, empathy, and still be oriented to teaching and training persons with a disability to achieve their 110% and not let personal feelings, or emotions impact their ability to provide the service they are paid to do. I continue to see issues that need improvement and will continue to work through these concerns. Thank you for allowing me to tell you what I see I hope this will help improve our systems we have for helping the disabled.

My son doesn't receive the support that he needs. He receives 2 contacts a day usually (not always). Supportive staff calls him by phone to see if he took his medicine AM and PM, or if he is in town they will stop in to look at how many pills are left. He has a supportive staff person available to him if he calls them, but frequently he is told to do it by himself or that he is responsible for it and they do not want to do it.

As a parent, I feel "absolutely" intimidated by the {AGENCY} staff and case manager. I am afraid to go to any meetings they have, I usually end up in tears and do not want to attend any more. The staff gang up on me and accuse me of things that I am not guilty of.

I feel that staff people and {AGENCY} reps talk about choice until it becomes hard or takes too much work. I don't like the attitude that is taken on jobs. Our son has a work ethic - (not trained to him just part of his make up) he knows how he should look, that he should be on time and do a good job. Many times jobs or appointments are looked at as not that important. For instance thinking its okay to show up 20 minutes late for an appointment (often) and think they can use the "we're running late" angle. This puts the people with disabilities in a bad light and again marked as less than or different - no-one else can run their job or appointments that way yet staff considers this okay. Our son found his own job - and is accepted and respected by his co-workers yet we're always having to check on and guard this job. It is 1/2 day a wk and in that time our agency is always trying to send 2 more individuals to a sale barn job as a tag along. They have no regard for an employer trying to run a business, our son has found a place that is perfect for him yet we have to always play the bad parents to keep 2 more people in chairs out of this setting. The {AGENCY} wants to push willing employers over the edge. They have the attitude that our town owes the {AGENCY} clients jobs, a bye for coming late to everything and be happy doing it. Our son has more common sense and fair play than the whole damn works of them.

Left individual at grocery store for hours, staff forgot him.

My son is very happy in his home, which is a 4 bedroom, 2 baths, and 1 half in a town house and mostly staffed while clients are there. My one big complaint is on week-ends there are subs that are scheduled for times the fellows are up and are late getting there such as Saturday and Sunday scheduled to be in the house at 10:00 AM I've talked to the powers that be and it has not changed I do not like this at all. It's probably a bigger problem for some than my son as he's become accustomed to this set up the full time staff are great people.

Staff sometimes hears clients and their problems but do not really take the time or interest to really listen to what client is saying sometimes it takes a little time for clients to express their concerns and problems and staff misinterprets the problem.

Some staff does not take time to visit.

A worker that works with my son, He has requested time and time again he does not want to work with her. He requested working with a man. I have requested a change also, has never been done.

Highly recommend drug free environment. Staff needs to be random tested for drugs and alcohol. All staff functions should be alcohol and drug free. Staff needs to learn more about alcohol and what medications you can not consume alcohol with. Staff has been seen on numerous occasions in bars with clients consuming alcohol. This is not being good role models.

And I feel the staff should be men and women working not just men.

We are not informed about who is hired.

Staff services are too slow in responding to needs and any repairs needed are not responded to in a timely manner. The response buttons are not answered in a timely manner, I fear an emergency. It appears that there are too many up the chain of command to get things done as needed most of the staff personally caring for my daughter.

11c. Staff Turnover

Turnover of staff at {AGENCY} is a major concern for me as it disrupts my child's programming.

Most of the time I am comfortable with everything involving our family member. It seems that it is difficult for the staff to keep the follow along (DSP) for very long. There has been quite a turn over of these people. I don't know what the problem has been the staff won't tell me why the DSP has been fired. If it involves our family member, I should be told.

Our daughter relocated to SD from Iowa into the new community home environment with {AGENCY}. She had previously lived in a similar home in Iowa administrated by {AGENCY} of {TOWN} for seven years. Since this was a new program with {AGENCY} the personnel assigned to supervise the program lacked experience in selecting clients and staff. This has resulted in a large turnover of clients and even larger turnover of support staff. Our attempts to offer ideas have largely been ignored. Our daughter is Down Syndrome and does not deal well with changes. The largest being relocation to this home from Iowa but the constant turmoil we feel has contributed to her developing a bad coping mechanism.

Most of the time I am comfortable with everything involving our family member. It seems that it is difficult for the staff to keep the follow along (DSP) for very long. There has been quite a turn over of these people. I don't know what the problem has been the staff won't tell me why the DSP has been fired. If it involves our family member, I should be told.

We feel that there is too much turn over and different staff all the time is hard on residents to adjust too. We as parent, get use to staff that we see on a regular basis and communication is better when you get to know someone.

Too many turnovers in personnel both at group home and in supervisors.

One thing that bothers me is how often the help changes - some are careless about their personal appearance.

Change in staff is upsetting my developmentally handicapped family member. Change in staff seems to happen too often.

Overall my family member receives good care from staff. I feel if staff were paid a better salary you wouldn't have too much of a change in staff. Clients are more comfortable with same staff and will be more cooperative with staff.

Staff turn over is a huge frustration because it happens so frequently and every time it happens we need to "start over", explaining what works and what he likes and does not like and he needs to adjust to new people again. This includes new case managers - we have had 4 in the past year. Direct care staff has no idea what the history is so will try to do things that were learned in the past did not work or were not liked.

The high turnover rate among the staff that deal with {NAME} on a 7 day a week basis is housing employees. When {AGENCY} hires a good person in his residential setting they immediately promote that person to an office position. I don't know the stats on their upper management team to each resident but I would wager that it would be the highest of any business in {TOWN}. Also their turnover rate for average workers (usually non college people). Would also be an embarrassing percentage?

Please note that the turnover of supervisors on this crew has been phenomenal every week there is someone different a factor which can be highly stressful to someone with autism.

Staff turn over especially at the group home is a continuing challenge. SD - {AGENCY} needs to look at wages/ benefits/ training to help reduce this problem

I believe that the continue turn over in staff effects {NAME} as {NAME} just gets use to staff and then there is a change. I feel the "change" of hours that just went into effect at the {AGENCY} has caused a "shortage of staff". It is not fair to staff and clients for staff to work extra long hours, so they can get a 40 hour week. I feel that of the {AGENCY} would make the working environment more desirable it would encourage staff longevity and decrease turn over. We feel that "staffs turn over" has a negative impact on the clients "health and happiness".

Turnover of staff is high

Generally we're happy with our child's care [however] turnover in staff is a problem.

Staff Turnover a big problem.

I really think there has been a lot of positive things happening. I think [one] of the weak areas for the agency [is] staff turnover.

Staff turnover does not allow for familiarity of our sons habits, needs, or wishes.

Another problem I see is the larger number of different staff that is in contact with our son in his townhouse. In December I believe the number of come and go staff was thirteen. Implementing a consistent program has to be difficult. We as parents have only met about 3 or 4 of the staff who now work with our son there seems to be a large turnover of staff which also leads to inconsistency in handling our son's activities and getting to really know how to best deal with him.

My biggest concern is the constant turnover in house staff and service coordinators. It is difficult for my client, because it takes so long to get to know her and become knowledgeable with her history and care. Portions of her planning program never get completed because of this. It is difficult for me, because I never know the persons at the home. It is not the same staff so I never know what they know about her.

My concern is the constant turn-over in staff that works directly with him.

The turn over in staff is a problem.

My greatest concerns: 1. Frequently staff changes.

Overall we are well satisfied with the services provided. She does occasionally get frustrated with the change often of instructor for her apartment (not job) assistance.

The reason the sometimes column is marked so frequently for my answers, appears to me that due to such frequent changes in staff it is hard to maintain consistency in programs also excuses, we are short staffed and a lot of the times I have heard "well I'm having a bad day too.

Some of the staff do not "connect" relationships do not develop - staff changes often.

Lots of staff turnover.

I feel many times they miss out where my niece needs the most help. A lot of this is from the big change over of staff but it comes from putting too many decisions on her shoulders alone. Someone comes in who has worked little with her for a month and they want to change everything that has been done because she is capable of doing for herself. No she can't that's how she gets into trouble in the first place.

Meet new staff most of visits (2x monthly or more).

I feel that the expectations of the agency are not realistic and it is impossible for the staff to do what they are expected. Turn over of staff is very high. Hate to complain too much because the client likes his independence and does not want to go back to a group home.

I do have a concern about the staff turnover. Sometimes, my sister has difficulty relating to or adjusting to the individual.

The high turnover of workers is not in the best interest of the least of our brethren and they deserve better.

I believe that the continue turn over in staff effects {NAME} as {NAME} just gets use to staff and then there is a change.

11d. Shortage of Staff

Do not know what is going on at the apartments there are too few staff at the apartments.

He has lived at {NAME} Apartments for about 1 ½ yrs the last 6 months he did not have overnight staff. Which made my husband and I very uncomfortable as he has seizures now Feb 1 he will be moving to another apartment same building with staff at night. Really feel people

that have disabilities should not be left at night with out supervision. This is the one complaint I had but now that complaint has been corrected.

Also, some staff are overstretched in their responsibilities, and other are not always adequately trained or supervised.

We wish that there were more activities that the staff could do with {NAME}, but these are kind of limited due to weight problem (She has Prader-Willi and Diabetes) and there is a shortage of staff I guess plus trying to find large size socks for her legs is a problem.

The worker has too many people to take care of and not much time for each person. When they have time my son says it's not for long.

{NAME} is in a group home and it has always been very satisfactory since {NAME} went there in 1994. The staff is always pleasant and very good to the clients. We feel that there are too many clients for the staff at {NAME} now. I think the staff there are sometimes too busy can't make the rounds.

Just not enough staff

I feel the "change" of hours that just went into effect at the {AGENCY} has caused a "shortage of staff". It is not fair to staff and clients for staff to work extra long hours, so they can get a 40 hour week. I feel that of the {AGENCY} would make the working environment more desirable it would encourage staff longevity and decrease turn over. We feel that "staffs turn over" has a negative impact on the clients "health and happiness".

Community activities seldom happen because of too few staff.

Residential management is stretched too thin so they are unable to effectively manage "one" group home. - Direct care staff and clients need the manager around for support.

He would have more opportunity to do and participate in more community activities if staff was more available. Not enough staff.

I would like to see him attend church more. Sometimes staff needs to go with him, but usually there is not enough staff on hand.

I also am not happy about the fact that there is no one at night in their group home. Having someone coming from the house next door every 2 hrs. To make a bed check is not satisfactory especially if it's a man making these bed checks in a house of all girls.

Nursing staff (at least one) should be on duty 24hrs rotating shifts.

11e. Staff Not Qualified

Inexperience of personnel at group home leads to insecurity of clients.

Residential staff lacks knowledge of different diagnosis and therapy skills.

Hiring a mature staff person to work at the apartments is a step in the right direction. I have felt that some of the helpers haven't had the experience needed to be helpful to residents of need. They didn't grasp the needs and weren't observant enough to ward off problem situations.

There are many times staff is hired and not trained to understand as how to handle people with disability this is frustrating for {NAME} as well as for me.

Too many facilities have personal care staff that is uncaring and thoughtless. We need to find a way to eliminate that problem from all care facilities. Training may be the first step.

11f. Pay Staff More

We are generally satisfied with the services we receive for our son, but the job the staff has to do day in and day out is hard, stressful and very thank less. And we would hope they could get paid better and have better conditions to work in.

Those who work at the {AGENCY} and group homes should be paid better then there would be more consistency for the residents. Also one could expect more from them.

{AGENCY} in {TOWN} SD is such a fantastic place - the staff is great - I wished the staff could make more money - So there wouldn't be a turn over rate.

A fair and competitive wage for staff (personal care) is very important. We need to attract and keep the kind and caring people.

I feel that any staff who personally work with the clients are underpaid and do not get enough praise. We have been fortunate that those who support our son are excellent support personnel. We all need to say Thank you more.

We are generally satisfied with the services we receive for our son, but the job the staff has to do day in and day out is hard, stressful and very thank less. And we would hope they could get paid better and have better conditions to work in.

We do wish there were not so such a change in staff more wages

Probably starting wages to low. Our feeling is that the top staff, director and service coordinator etc., receive the big bucks. Direct care staff is a different story. Was told beginning hourly wage for residential is \$6.00. We see to many staff that wants hours for not doing anything and of course want a pay check. This is an on going problem at {AGENCY}.

Not paid well enough to stay & a high turn over rate is also an issue.

12. Family Issues

Support group for family members should be offered to help with dealing with special needs family members.

I wish that the parents of a challenged person would have more support from the facility that is serving their family member. I wish that parents would be made to feel that they were really part of the planning team - not just invited to the meetings so they can be chewed out for all the problems the challenged person has. Parents don't have all the answers on how to do everything perfectly by the book - but they try to do it perfectly and when it doesn't work out like they had hoped they feel so guilty then they try harder only to have people who don't really know what working with a challenged person is like, criticized the parent more & more and look

down on them in judgment. The parent feels defeated, alone, confused and doesn't know which way to turn anymore, misunderstood all the time.

13. General Well Being

Well {NAME} needs shoes that fit her and she needs warm clothes when she comes home. If she has the money use it on her needs.

I would like to see more exercise activity in their own workshop. Having an Olympic size pool to swim in. Using the YMCA is out of the question having their own pool facility makes better sense. Also with the pool, whirlpools for therapy are much needed. Most handicap persons would do better in the water for exercise. I would like to see their diets to be more on fresh vegetables and fresh fruit and get rid of the starchy foods the clients are fed.

I am forever thankful and grateful to the {AGENCY} for caring for my son. The staff at {NAME} apartments has been wonderful over the years. {NAME} is about to leave your employment and I am concerned about {NAME} well being. I have faith that someone like {NAME} will fill his shoes. It's important that {NAME} have a male role model. {NAME} Is very shy around women. I would like to see {NAME} be more encouraged to make at least one good friend. I continue to encourage {NAME} to keep in touch with his brothers and myself.

13a. Health

I would like more training for the clients on nutrition, exercise, and sex education and social skills. I think to sell clients on diet and exercise it has to do with the approach and I think staff should also be involved Americans are very heavy nowadays and too inactive.

13b. Safety

I bring her home on all holidays and every other weekend. On the weekends she is not home overnight I get her out Saturday afternoon and pick her up at 10 AM Sunday and she is home all day. I get her out 2 nights a week. She now resides in a group home with 5 other ladies. She had a female staff over night (and this worked well) about 6 months ago this changed. She now has a bed check every 2 hours by a staff that resides in another group home close by. Sometimes this staff is male I do not feel this is safe. My son co-guardian and another set of parents and me have had 4 meetings with staff over this change. They are courteous and very well to meet with us. But no changes and no real reason for the change there have been 3 times something happened (like 6 o'clock staff not showing up) no one has been hurt but feel loopholes are there and something could happen.

Additionally, with the number of clients in one home who have walkers, wheelchairs, etc, it is sometimes difficult to see safety measures are done adequately.

Often the agency looks at dollar signs versus client safety. Example: individuals w/ significant needs wandered off frost bitten and couldn't put a fence around his home. Therefore, individual wandered away again in very busy intersection.

Again male staff over night is not safe.

13d. Social

The program could use more in - house and out of house activities. It needs to be done on a daily basis. Choice is fine but many of the choices at annual time are very unrealistic ideas. The person is not able to do.

{NAME} is not kept busy enough and I feel living alone is just too lonesome for him.

I would like to see her have more of a social life with community projects & activities.

{AGENCY} has good people who try hard. Not always possible to provide exactly what she needs because many of her needs do not fit in the ordinary categories. I do wish they would do more to get her involved in the community and help her with socializing. Problem is she has few or no peers, no one to be her friend, to hang out together or go places. They are good to her and treat her with respect and kindness.

I think {NAME} could enter more into some community events but he is doing as much he cares to I guess. He bowls on a team belongs to a church. Goes out and gets together with friends.

Our son also needs more help with house keeping skills, such as cooking, laundry, getting outside activities.

My daughter calls home a lot, if she needs certain food items etc. Need more contact with people outside the apt. unit, more planned events.

We realize aphasia is difficult for people who have no training in dealing with it. We wish she could be busier with one on one crafts etc. But she also needs rest due to physical disabilities. Over all we are more than pleased having her at {AGENCY}. I often wonder just what if she is left alone too long - so far so good.

13e. Hygiene

My only concern is personal hygiene she is not capable of wiping herself and when I pick her up to take her out she smells very strong of urine - it's bad she needs to be cleaned more often during the day. And she has some facial hairs that seem to only get clipped when I arrive and lastly her hair is always a mess a quick combing would be great.

She's not kept as neat as she used to be. Her clothes are either too big or too tight for her. A lot of times her pants are way too long for her and she could trip on them.

17a. General Satisfaction with Services/Supports

I believe the program that my son is in is a very good beneficial program.

My brother is very content & happy since he is at the ability building services. We are very pleased with his care as there is not much he can do.

I think {NAME} is getting all the help she needs plus what we help her with.

We are very satisfied with advances program. They take good care of her.

{NAME} is one of six of our children, two of which live in or near {TOWN}. {NAME} mother is deceased. I am {NAME} Father a WW2 Veteran of the South Pacific area. {NAME} has five other family members all not affected by P.K.U. no other relatives that we know have it. {NAME} and I are very grateful for the care for {NAME}. May god continue to bless you all for your care and devotion? If there is anything that I could give let me know.

{NAME} is at a home in {TOWN} & he gets to the {AGENCY} I am very satisfied with their care.

On the whole {NAME} is satisfied at the {AGENCY} a person cannot always agree to what goes on but like I said on the whole we are satisfied.

I am satisfied with the care she is receiving.

We just participate in the annual ISP process and are very pleased with the service, care & attention provided.

We are very satisfied with the care being provided our family member.

We are very satisfied with the services provided to my brother. Thank you for everything.

I am very satisfied with care my brother gets.

I am well pleased with the support and care he is getting

Wonderful support for my brother.

Because our family member lives across the state we are unable to participate on a daily basis. We feel he is getting adequate care and we are kept up to date on everything.

You do far better than we could. Thank you.

I appreciate all of the services that have been made available and compliment the staffs who administer the same.

I have no complaints {NAME} is or seems to be very happy where she is.

We lost our mother in March of 2004 2 weeks before her 64th birthday. She cared for our youngest sister at home for 30 years. All the siblings have jobs or family to care for, I can not express in words the appreciation I have for the services provided to us by South Dakota starting from the lady in {AGENCY} to the staff in {TOWN} SD. My sister is the closest she will be to independent with her disability. She has matured a lot and improved in so many ways. Thank you.

{AGENCY} is a wonderful facility; we are blessed to have such a needed service available in our community.

{AGENCY} {TOWN}, S.D. I am satisfied with the staff and support system. I am usually notified of any changes in her program etc.

I am satisfied with the way everything is going.

I am very satisfied with services offered. As a parent I think I need to ask questions if the need arises. Usually my questions are answered in a timely manner.

I feel that she is receiving good services that provide for her overall well - being.

I am confident he is receiving quality services to ensure that he is healthy & happy.

We are very glad that we have the type and quality of facilities and services that we've got in western South Dakota. We are lucky also that they are located as close as they are. Overall it is a tremendous plus to our communities. The benefits to the families and the individuals involved are huge.

We think that the program here in {TOWN} is wonderful.

Our family is very happy with the care our family member gets. He has great support and excellent people who take care of him and his needs we very much appreciate all they do for him.

Of course always room for improvement but I am generally very happy with her care & community activities.

She receives excellent care / your services are truly a blessing to both her and I.

We have been satisfied with staff decisions and appreciate assistance received.

She has been a foster member of our family for forty years she started to get services with {AGENCY} when she was sixteen years old. They have been great with her & she is very independent now thanks to {AGENCY}. They have been there for her with all her problems & always kept us informed. I can't say enough well about {AGENCY} services.

I am very pleased with the care that my family member receives.

I have very little to do with sibling. They call me for important decisions he attends ball games shopping etc. allowed to spend money for clothes few things in his budget. Always ask my permission for larger purchases. I'm convinced he is getting best care available I have very little to do with care. I trust them to care for his health other things necessary. I'm convinced he gets the best care available at this time.

The general level of care is very good. My level of satisfaction is also very good. My son likes where he lives, where he works and the people who help him.

I am forever thankful and grateful to the {AGENCY} for caring for my son. The staff at {NAME} apartments has been wonderful over the years. {NAME} is about to leave your employment and I am concerned about {NAME}'s well being. I have faith that someone like {NAME} will fill his shoes. It's important that {NAME} have a male role model. {NAME} is very shy around women. I would like to see {NAME} be more encouraged to make at least one good friend. I continue to encourage {NAME} to keep in touch with his brothers and myself. He calls almost everyday, and I'm thankful to be able to keep in touch this way... {NAME} has been wonderful to {NAME} and a friend to {NAME}, me and my husband; we will miss {NAME}. Thank you again to all of you who work with those people like our son, who need you and depend on you to help them live as independent as possible. Keep on keeping on.

We, as a family are happy with the way things are handled. I as a mother am 82 yrs old, so I only get to visit my daughter about 2 or 3 times a year. I really don't know how I could manage without the program.

{NAME} is perhaps one of the most contented persons any one could hope for. {AGENCY} does a wonderful job.

We have gone to two other facilities and not one of them could hold a candle to {AGENCY} they take very good care of my son. They treat him like he was one of their own kids. Just can't say enough about the group of people.

The {AGENCY} has been a wonderful asset for {NAME} and our family is coping with {NAME}'s disabilities.

My son is his own guardian; he lives in an apartment in a group home. He's very social, has a job as a greeter in a grocery store, and goes to sports events, church, etc. In summer he goes all over {TOWN} in his electric wheel chair he arranges his own rides with the group home or city transit. I would like to know more about his plans and finance but I'm only his mother I have no rights. He's very happy. Wonderful life he doesn't need me anymore guess we reached our goal. God has blessed him.

As of Feb. 1 2006 he came home each weekend so we have much visitation with him. There were a couple of questions I really did not know how to answer them. All in all we are pleased with our son's services through {AGENCY} in {TOWN}.

17b. General Dissatisfaction with Services/Supports

Our daughter has difficulty with change and changes made without plans. {AGENCY} blames her for having this difficulty when in fact it is part of her disability. There has not been any follow through for any of her supports and services. Because of our disappointment with {AGENCY} services and their treatment of our daughter we will be discontinuing services in the next 2 weeks after other arrangements are finalized.

17e. Need More Services/Supports

I take care of a lot of {name} needs. Sometimes in the winter I can't get to town & then he needs more assistance. His case worker then helps him to get groceries etc.

I don't understand your survey. My son has had knees & hands, lost of hearing in both ears one with only no sound, bad eyes & no service because we don't have the money.

My son doesn't receive the support that he needs. He receives 2 contacts a day usually (not always). Supportive staff calls him by phone to see if he took his medicine AM & PM, or if he is in town they will stop in to look at how many pills are left. He has a supportive staff person available to him if he calls them, but frequently he is told to do it by himself or that he is responsible for it and they do not want to do it.

The sudden cease of the local day program at the center was very poorly initiated. There was no notice given to parents/guardians members were removed from the center with no plan or replacement activity load. The members went from 8 - 3 M-F with structured activities & classes, to "don't come back Monday". Now I'm sure this probably fits some independent living profile

designed to make everyone's life better, but in reality the short term results so far are limited social interaction anymore with other members, No time structure, No schedule for activities, up all night/sleep all day. But independent right. Poor results from poor communications how can service coordinators stay connected with a once a week 5 min. phone conversation? They can't and don't I'm pretty disillusioned with these new changes, Targeted Improvement sound good , but so far the reality of these actions have been terribly in effective, with very little support and information from staff.

17h. Waiting List

Our main complaint is the amount of time it takes to get orthotics, equipment, etc. repaired or replaced. We don't feel she gets as much P.T. and others as needed. The staff at her home is for the most part, wonderful with her & her needs. We feel she is well taken care of.

19. General Concerns

Monetary accounting to the families is not part of the big picture at {TOWN}. I feel that eve" Also when I have asked about my son's health I have been told that I cannot make any decisions for him because I signed some document again this is wrong.

We get sent an awful lot of paperwork, seems like once a month we ok {NAME} flu shots Doc Lists etc.

I do wish there would be a way to put some of her money aside for burial expenses.

Our son can be difficult and uncooperative, sometimes. In discussions with staff his feelings can't always be determined, sometimes refuses to take meds from certain individuals. When he was at our home he took them after eating breakfast and in training they want him to take them when they wake him (we understand they need to see him take meds and have other individuals to witness). Our son has lost many friends and feels depression evident. He also refuses a repeat of activities if not much variety. Weather determines if he'll go to work.

We are lucky to be close to where our daughter resides. Many clients do not have family close to them. These clients need strong advocates to ensure their needs are met. Sometimes these advocates are also employed by the facility the client works with. This situation leaves the advocate in a difficult position. Do they do what is the best interest of their friend or keep their job? There should be a state wide advocate system that concerned people can go to. If there is such an organization, many people are not aware of it.

Would like to know why they take \$100.00 out of mother's social security check I only get \$277.00?

As indicated earlier, my wife and I are full time RVers for the last 3 years. Mother lives in {TOWN} so she is close to {NAME}. Over sees {AGENCY} actions concerning our son at all times. She has fulfilled that spot for our family since we started our retirement program. I have a genuine appreciation for what they have done for our son since 1984. He is probably the happiest individual in this whole equation. Questions 16 thru 20 have always been a concern for me... I fully realize that each of their some 600 residents provide a large part of their annual income on their P & L statement. Monetary accounting to the families is not part of the big picture at {TOWN}. I feel that every penny that {NAME} brings to {AGENCY} should be disclosed as well expenses should be discussed with family on a regular basis.

I have voiced my concerns about one aspect of his care and have visited at length with his CLI about how to make things better so I want you to know that the workshop has heard my concern and is trying to help. This came to light because of accreditation requirements. In protecting the disabled person's rights, I believe some of my brother's needs have been overlooked. They used to shut off his lights at 10:00pm because {NAME} would stay up all night watching TV. To protect his rights, they can no longer do that and {NAME} dozes in front of his TV all night long. There is a requirement that he has to have money available to him at all times. What ever he gets, {NAME} takes to work with him and buys candy bars with all of it. He is seriously overweight and has blood clots. {NAME} operates at a 3rd to 4th grade level and it's my feeling that a parent wouldn't give a 9 year old unlimited access to make his own decisions about when, or if, to go to bed and no input on how he spends money that is available to him. He is making poor choices, as would any 9 year old. When these issues first came up, I was told at a staff meeting that it was necessary give him these rights or they would not meet accreditation standards. I don't want {NAME} taken advantage of, but I also want him protected from himself.

The group home she is in has both men & women but some guys are in wheel chairs so they can't always get out as a group

I have to send in pay stubs each month from her jobs. As her income hasn't varied very much in 10 years why couldn't this obligation be quarterly or semi annual? Social security used to request the same info often 2 or 3 years of level income they told me to no longer send in the stubs unless she had a large increase in pay.

My family member receives a Social Security check monthly. I would like to know the amount of the check and how it is spent. Could there be a semi annual or yearly report, given to a guardian.

I live 35 - 40 mins drive away from where he lives, I work long hours at a nursing home, I try to run over to {AGENCY} on days off or at nights to help him with his banking, shopping, cleaning his apartment etc. - I feel as though I am responsible for him 98.9% of the time by myself - so if something goes wrong or my son has a tantrum or gets into some trouble - I am always the one who gets all the blame. My family rarely helps me out, I feel that {AGENCY} could help him more, I feel so alone with the challenge. {AGENCY} gave me full responsibility with my sons budgeting, banking, finances - they became frustrated because they couldn't make the money stretch with the limited amount {NAME} received from SSI {NAME} had a temper tantrum when he wanted money and it was gone so his case manager refused to continue to manage the money for him anyone and made me take all the responsibility back.

More independent individuals should have more "natural" consequences, especially if individual knows and intentionally does what is wrong and knows the individual will be protected by agency. Therefore, the behaviors do not /rarely change.

She could use more money; she is a very thrifty spender. She should not have to decide between shampoo, and food. She only has money for the necessity; No one should have to do that. She's young she should be doing thing like movies, and concerts, and bowling, these are social events a person needs to do for his or her self being.

I feel people with mental disabilities should be allowed to have personal comforts equal to their age with their disability not their chronological age i.e. books, tapes, videos and stuffed animals.

In regards to questions 19 - 20 we receive quarterly reports on {NAME} personal finances but we have no idea what percentage of the facilities budget is spent on our family member's behalf.

I'm somewhat concerned that staff has reported signs of dementia in our family member. Yet over the past 12 months or so and after several visits (some up to 5 days together) none of our family member's siblings (5 of us) has seen or experienced signs of dementia. We wonder if there was need for his group home spot and with this: dementia information our family member could more easily be moved to a different setting of care which would create a housing opening.

He had a difficult time in the past six months because of moving from an independent living to a group home. The reason was stated as cost mainly, I think it was loss of independence.

My greatest concerns... I don't completely understand her finances.

I would like to know how the money is spent for my child's services

18. We would like to be informed. 19. We do not know how much money is spent on her behalf. 20. We would like more input. In general we feel the agency is working hard for our daughter. However you have asked if we could think of things that would better her life.

I would like to ensure that when a service plan is developed for my daughter that the plan and follow through steps are reviewed periodically to ensure that the plan is followed. Some things seem to get forgotten until the next plan is developed. I also want to ensure that my daughter is receiving more help with managing her money. They let her have too much freedom with her spending and she goes over her budget

I do not like the new ruling of having my sister leave her apt. to have /get a certain amount of time with group etc. That is recognized by the state. She has very fragile health & {AGENCY} has worked very hard the last 5yrs to keep her healthy & out of the hospital. She was teaching a sign language class in her apartment but now has to go else where to do this - so it will count as an activity/time with the state ruling.

I take care of her finances etc. {NAME} lives in a supervised apt. with a roommate I am not too happy about the food they eat for supper etc. It needs more variety.

I fully realize that each of their some 600 residents provide a large part of their annual income on their P and L statement ry penny that {NAME} brings to {AGENCY} should be disclosed as well expenses should be discussed with family on a regular basis.

WASHINGTON

1a. Satisfied with Home

My sister has been in {name} state school since about 1946. I am her legal guardian since my parents passed away. I am very pleased with rainier so much as I had my younger sister placed there from {name} state school. They meet the needs of both my sisters, they take very good care of them.

My sister lives at {name} state school. I had her transferred from {name} state school where she had been for about 46 years of her life. I was not happy with how they handled matters. I have

an older sister at {name} state school and have been very happy with their care of her. I am very pleased with how they handled matters. They are always in contact with me about everything. Thank you

{Name} has been dd at birth. At 53, he is around 12 years old. He has behavioral problems and suffers from depression; unable to stay on task, and needs constant - mod direction in ADL's. At {agency}, he receives excellent supervision and direction. He attends exercise classes, socializes at meal time and walk's many halls. He has had annual medial care, dental and eye care. {Name} has adapted fairly well to {agency} and enjoys his life. He's has heart disease and is on antipsychotic medication to control behavior. But he's my brother and I love him and watch out for him on weekly basis.

I am very happy with the care {name} receives at {agency}. She is healthy and happy I do wish I could see her more often.

I have been very satisfied by the care provided to my brother. He has lived at the facility for just over 2 years. The care givers and case manager have been very responsive to any questions or concerns that have arisen.

My brother has been living at {name} state school now for more than 50 years. My family and I have always been very pleased and happy with the care he has received.

I love his home and the home site staff. They work with me and my son is happy. Working with me is great, but my son's happiness and well being is my prime concern.

As {name} brother and legal guardian, I am extremely happy with the care he receives at {name} state school and fervently wish him to remain there. {Name} state school keeps me apprised of his condition, care, treatment, and finances on a regular bases and I am very happy with the procedures and staff.

{Name} group home is one the three finest residences in this state! {Agency} continues to seek support and funding from DSHS DDD in order to maintain this standard of excellence (while costs continue to escalate).

I really appreciate the care my brother is receiving at {agency}. I've communicated with the staff there much more than with his case worker, so I wasn't sure how to answer the questions about her - - but I've had no reason to complain. Thanks for your continued efforts to provide these valuable services.

Our brother has been at {name} state school since he was a boy. He is receiving excellent care with the quality of his care and the staff that provide for his needs. {Name} state school is his home and he is very happy there.

My son resides at {name} state school and has most of his life. He is happy there and it is "home" to him. Several times I have been approached about moving him to a community home and I have adamantly refused. He has had a series of surgeries and now fed through a tube implanted directly into his stomach. The people who care for him are good to him and he is content with his surroundings. He has never spoken, so it makes it somewhat difficult to know his wishes - but over the years he has found way to make his wishes known.

Our son has lived at {name} state school for almost fifteen years. He is profoundly multiply impaired with recurring medical problems. These medical problems are quickly and appropriately dealt with at {name} state school. Because of staff attention to his needs, he has generally been happy and healthy for this 15 year period. We simply would be overwhelmed without the professional and caring help our son receives at {name} state school.

Very happy with {agency} home's service.

My brother is at {name} state school. I am so fortunate to have a great facility like that for him. The care is delivered with sensitivity and love. The staff surrounding him is very stable, many have known him most of his life.

Our daughter has been a resident of {name} state school for many years and does receive excellent care there.

{Name} is very happy at {name} state school and all the caregivers are wonderful and take excellent care of her. We do not have to worry about her being teased or tormented by people who are at best unaware of her mental problems or at worst would take advantage of her. If left on her own she could not handle money and would live on peanut butter and jelly sandwiches and coke.

The care and service of {agency} for {name} has been outstanding. My mother, my sister and I are always in contact with {name} care givers. We thank god for the love and support of these people. Thank you

We have a wonderful group home with appropriate management! I trust the integrity and care giving out of their place with working with my daughter. Many thanks to the state office for their support.

{Name} has come a long way since he entered community living he is calmer and has no skin break downs. He gets a chance to be himself and enjoy going to senior nursing home he loves it. I don't worry about him as much. He has grown into a well rounded young man. I'm so proud of him. I've always told him I'd always be his mom because I'd never lie to him or abandon him. Never have, never will.

This is the happiest I've seen or heard of, is where he's at now. When he's happy, I'm happy. He and I were born right there in {city} at and near where the boat haven is now. So he's at home and happy. I'm so very happy with where he' staying, the care he's given by the people there. So thank you all so much for caring for him.

I am happy with the service I receive from the adult family home. They interact with the state on a more regular basis than I do. I do receive report annually from the case worker, but I haven't had a need to contact her. I talk to my sister's care giver often and am very happy with her.

I am very satisfied with the services {agency} provides. I do not feel closer monitoring would seem to be necessary.

{Name} is a resident at {name} state school. She has been there since she was 8 1/2 yrs old (she is now 32). {Name} state school is her home. She receives excellent care from staff. She requires nursing supervision 24/7. She of course has her favorite staff members and loves these

people dearly. I feel fortunate to have her at {name} state school and would never consider moving her.

{Name} state school I has been great for our family for years. We expect nothing less in the future.

The programs in home living does a great job, and the group home under the management of {name} could not be better.

Overall he is at a good place, we can see him as often as we like.

My stepdaughter has lived at {name} state school since 1977. They provide the care my late husband and I could not do. During his illness and after his death, they provided excellent support to {name} and to me. I can't express enough appreciation for all they do.

My sister is at {name} state school. She needs 24 hour a day care. I am her brother and legal guardian. I hope you don't plan on trying to remove her from or try to close this place. People like my sister need all the help they can get. One person cannot do it all alone. She gets very good care at {name} state school.

{Name} seems to be happy in the apt/with staff members. I bring her home every two weeks for the weekend and on all holidays, so she knows she is a member of the family. We talk on the phone every night before she goes to bed. We are very satisfied where she is living and the arrangements. They could use more recreation, but whit short staff I understand how hard it is especially during the winter months.

My brother is in a parents' cooperative home in {city}. I sit on the board as do all other parent/guardians/interested. It works well and we are very pleased.

We are very satisfied with the care and support {name} receives at {name} state school. Why not take a trip out to {name} state school and see how well things are going for their clients.

I am glad my son is in {name} state school and I hope he can stay for the rest of his life, I love take care of him but he is to sick and I am 76 years old I can't even lift him up anymore.

1b. Dissatisfied with Home

My son was taken from an institution where he received 24 hour care, because his disability required it. When I took him out I was assured he would receive services in the community that would cover his needs, i.e. 24 hour care if need, well now that need is still there but he only receives 15 hours of care. Sometime back, about 2 months ago a crisis occurred where his provider was not going to be able to provide 24 hour care for him because they were no paid. (His brother had been providing overnight care for him but he became ill and not able to care for his brother of course he was not paid for his care of his brother) my feelings are these - 1. He needs to have 24 hours care. If it cannot be provided in the community then we need to look at returning him to {name} for his safety and care. I'd prefer to work it out where I am not relying on a DD housemate, to fill out those 9 hours at night, and that he has his own hours so that we're not relying on someone else, nor are we tied to someone else's whip of where they want to live.

He isn't happy with the neighborhood he's in and never seems to be included with others. He likes to be closer to places he can walk to and shop and look around.

We have been trying to find her a place much closer to me and her siblings, so that we could spend more time with her, but are having a difficult time getting help to find such a place north {city}.

1d. Furnishings/Cleanliness of Home

{Name} case manager works directly with him. I have contact once or twice a year. I have been satisfied with their planning. My only complaint would be that I'd like to see his apartment kept cleaner either w/assistance or by having him help more.

2a. Satisfied with Employment/Day Programs

{Name} is employed at {name} industries. It is the best work environment for her. I am grateful to have her learn and be productive there. {Name} and {name} industries are a critical component in {name} well being. The staff of {name} services provide the support she needs to lead an active and independent life.

2b. Dissatisfied with Employment/Day Programs

Over all we are satisfied. We don't like the idea that {name} may have to work more than part times with the new "working age adult policy". He has many personal help needs which leave only a few hours for work or recreation.

We are currently trying to get our son employed. This has been a challenge! We know something will turn up eventually.

Employment for people with profound and severe disabilities has been diminishing in our area. Places that provided services for more than 100 clients have closed leaving disabled people with little or no choice of employment or day programs. After working in the same good environment for several years, this change is very difficult for the disable individuals and confusing. State services need to work with the businesses to ensure they keep the business running that provides job for severe and profoundly disabled people. Also bring an interest to our community to give opportunities of employment and day programs to the clients who are now displaced workers.

We are the foster family who raised her. Overall she seems to be happy but needs to find a job. She wants to work, I know she is bored she need to be busy. We know she is well looked after, but has many hours of boredom.

3. Health Care

{Name} could definitely be fitted for a new wheelchair larger and better to fit her growing body and back scoliosis problem.

Since the summer of 2004 we have unsuccessfully tried to replace {name} wheel chair. It has been denied by the state several times. They claim coverage guidelines have not been met. Since 11-02-05 he has been using a loaner chair. This chair does not meet his needs. It is not adapted or adjusted to his size. It does not propel adequately and restricts his mobility severely. He uses this chair up to 9 hours a day and is not even cushioned (we have placed our own cushions there for some comfort for him.) When assisting him, the chair is very difficult to maneuver and extremely heavy. I feel this chair is both unhealthy and unsafe for him.

3e. OT/PT/ST

Physical therapy or exercise programs on an on-going basis are a real need. My brother is a paraplegic and caregivers never have time for exercises. There are no programs that are available for continual care.

This client would benefit from physical therapy but it is not covered!! She is becoming very contracted and stiff.

5. Transportation

Our son's adult family home provider only schedules with access to transportation to day programs. All other transportation for medical and dental appointments, sporting activities, camps, movies and all other entertainment is provided by his parents. The adult family home provider never offers to provide transportation for these activities.

Transportation is a huge barrier to services for both hiring staff and for getting to work for those who live out of town (20 miles from city in Whatcom County).

We have tried several times to receive bus (transport) for my daughter, and have been denied. I feel she is trying to be independent - she has a part time job 3-4 hrs daily, need transport to and from. It is a great hardship for her to walk to work and home since she has so many medical disabilities. It doesn't see right that she is denied. One service only that we need.

7b. Dissatisfied with Communication

I think DSHS is doing the best they can with their large work load and limited staff. When DSHS changes "case managers" for their clients, I would like a letter from the new case manager. Introducing themselves and a phone number so I can reach them if need be.

I would like the results after medical exam, which I never do. As a mother (guardian) I am entitled for this information.

I am a person who has worked with and known {name} for 20 years. She has no family and the long time support staff and myself - her payee and a mental health boyfriend are all she has. I do not know whether case management has a clue about me because I have never been contacted by them. It would be nice to have some contact - yearly.

When my child was growing up, I took care of her and sought out programs for her until she was 22 year old and went to live in the {name} residential center. When I look back, that was when I felt a communication break-down accrued. I think there was more at that point, and on, between, the residential providers and the case worker, but with me only once a year. I have fought for many things on my own as a parent. I have felt that if I had even tried to involve the state it could be a negative for my child. I think that it would be a great idea to have more communication between the case workers and legal guardians after age 22 if possible.

I wish I knew more of the structure of the system and had a contact.

I would very much appreciate better communication with the program my son is in - which contracts with DDD - my son was put on SSA a couple years ago- I was not notified, some major laws and rules were changed concerning community protection programs. I was not told

nor notified. This program trained my son's father and I to be chaperones for our son almost 8 yrs ago and have never updated us on new things they do nor monitored us besides as a result our son did something inappropriate out in public - it is a police case - and reported to APS. I was at fault and mostly out of ignorance it would have been very helpful if the program had monitored, refreshed training at least one a year. This whole incident could have been avoided.

Need better communication with family members with staff. Need set time and days for there family be with them. If need put whole family through counseling.

Don't know even if she has a case manager or services. It would be helpful to know what help she is receiving. Communication is lacking. She doesn't clearly communicate who or if she has help, so it would be important for the service people to communicate for her. We could help if we knew more.

I would like to see the treatment team more open to listen to families' feedback. I know they care about my son, but so do I. I cared for him my home with no help until (age 17) the last year he was with me. I'm a single parent. I stayed with my son trying to give him a normal family life. He has 2 older sisters. He went to a regular school classroom. He was a part of our everyday life. The only reason he left my home was because his seizure took a turn for the worse during puberty. I am very thankful to have help with my son. I feel they suppress the house staff to talk to families. The treatment team act like they have something to hide and they are afraid the families will find out and more trouble for them. Secrecy breeds mistrust and the house begins to crumble. Life is ever evolving and requires regular evaluating and change to get better. Involve families in house change and get feed back about what we would like for our loved one. I think they don't realize, when they car for my son, they're caring for our whole family.

7d. Language Barrier

Residential provider utilizes staff many of whom have difficulty communicating in English very difficult for clients' with speech impairments.

When I call his home, generally have difficulty speaking with staff. English can be problem for them. When the client signs and comprehends the English language, you wonder what king of a communication problem exists in the home.

7f. Planning Meetings

I am not in contact with my daughter's case manager. Her residential care taker is, but I would like to be contacted and be present at her evaluations and goal planning's.

When care manager does interview with {name}, it would benefit everyone if care giver and a family member would be present for yearly assessment, so everyone involved could give input.

10a. Satisfied with Case Manager

Our case manager works part time so cannot always be contacted promptly - however is very courteous and responsive.

The case manager assigned to us seems genuinely interested in our son. He does a fine job.

Our son has had at least 20 case managers. Some we never met in the past. We only knew they had changed because we received a note from DDD. We have had {name} for quite awhile and fell very fortunate to have her as our sons case worker. She is a wonderful and caring person. Hope you can hire more people like her.

We are really pleased with case worker. She is quick to respond and address situations when called upon. She is delightful and does a great job. We have been very fortunate to have excellent case workers. We are so grateful to have the support of DDD. It's a wonderful organization.

Mr. {name} lives at {name} state school. I work very closely wit the staff, but mostly with the social worker. She is beyond incredible at her job. She keeps me informed on every level of {name} care. I attend the care conferences and find all the staff to be friendly and cooperative on every level. He is happy at {name} state school and I want him to continue there.

{Name} is an excellent advocate for all aspects of {name} care. She goes beyond and above what most case managers do. I was a case manager with DDD for 8 years so, I have some understanding of what the job requirements are although this was several years ago and I'm sure job duties have changed.

Case manager does an excellent job and has for many years. We would have great difficulty handling our situation. Our manager is a super human being.

Case manager is knowledgeable, informed, focused, and gets things done. She has been a delight to work with.

Case worker has been especially helpful as {name} copes with the death of his father. She has provided such understanding of the impact of this loss on {name}. She's providing extra services. We appreciate her!

New case manager is the first one to really care about him and really wants to help him where no one else really cared. He is right now with {agency}. They are not a very good out fit, {name} case manager is helping us to get him transferred.

{Name} is our new case manager, which we have only met with once. We are both satisfied with her assistance. We have had trouble with {agency} and with her job coach's.

I hope {name} has long and healthy life. Her dedication to her clients is very evident. I did not know before I met her, that case manager did anything more than an evaluation every 2-3 yrs. I didn't know they could do anything. She should be honored as case manager if the year, for the state of Washington. I will never be able to thank her enough for everything she has done for my daughter.

I would just like to comment on my son's case manger. She has been very, very supportive and helpful in securing services for my son. She is easy to talk to and makes us all feel a part of a team for our son. She is easy to reach by phone with any questions I might have. She's the best case manager we have had to date and I hope she is with us for a long time. We appreciate all the support DD and {name} have given our son. Things are going well for us.

I am very happy with my son's case manager. She is very professional, yet kind and listens to our concerns very sincerely.

I am very happy with the services provided for my sister. My or her case manager has been instrumental in helping provide the necessary and right services for her.

My case manager has been involved with my family for many years. She is able to be good resource for 4 of my disabled family members. We thank her for caring.

{Name} is my daughter's case manager. He has been instrumental in providing services that allow her to be part of her community despite the severity of her disability. He has followed up on construction that allowed for a safe showering environment for my daughter and her caregivers. He is a caring person with good insight and knows how to provide listening time and resources efficiently.

We are very grateful for the case managers we have; and know she is doing everything possible to meet the need for {name}.

We are very happy with our case manager. She is an excellent case manager.

My son's case manager is the best. He is one of the very best. {Name} has been wonderful. But my other case managers have been hard to get a hold of or not very helpful when they are reached. They complain that their case loads are too large. We want to stay with {name} since he is always there for us.

10b. Dissatisfied with Case Manager

September 2005 I called case manager, for some information on what east Washington services might be. That I might be moving there in couple of years. I want to know if they had anything like she has here. I was only asking for information at this time. The case manager at first refuse to give me any information until I said that this could go to court if need be at that time the case manager said she would call over to {city} and send me some information on a contact person. If felt that as I am {name}'s mother I should be able to get help from her case worker without all the trouble I had to.

I live in Arizona and visit once a year. Always meet with the caseworker then. I really liked her last caseworker. He really showed an interest in my daughter. Her present one is ok, but does not seem to be as involved.

When I appealed a decision I felt the case worker was against me.

My son currently has a case manger who is temporarily filling in while the actual one taking a leave. The temp is hard to communicate with.

New case manager has not called - not sure if she knows the intricacies of the family members case - don't fell comfortable with new person who just sends a form letter and no business card.

Only seem to get a call from case worker when evaluations are due. I personally have not met our case worker in several years. Our son is low maintenance when compared to other cases, so are probably put on the bottom of stack.

I do not think that the DDD case manager keeps me informed. I have never been invited any ihp/ieps. I have never received any advanced notice of any staffing or meeting that may have an effect on services to her.

I would like to see the case manager follow through with monitoring tcrs's services. Sometimes they need a little "push". There seems to be difficulty implementing some of {name} program needs (on the level of staff at his home).

The case manager currently assigned to us is very unsatisfactory. She made no attempt to invite me to the annual plan of care and care assessment, other than notifying the AFH provider the day prior to the meeting for the care assessment. She then prepared the POC document with information from the previous year which was inaccurate. She listed the vocational provider as present, included inaccurate information about that program that provider, like myself, was never invited. I requested a new POC management so both us could attend and participate. (mid-April) currently, I am still waiting for the completed POC and corrected care assessment. I requested a new case manager, but haven't had response yet.

I don't know the case manager. She never tries to call to introduce herself. Sometimes they seem to be too busy to look into matters that need attention. Or too busy to try to contact you if a matter that needs looking into. I'm very dissatisfied with them. Need more concern and caring case workers that will meet the criteria.

Case manager haven't contacted us for at least one year. We have many concerns of {name} new providers. I've answered N/A to most of the questions because there's been non contact since early last year 2005, we didn't even know we had a new case manager.

Due to the distance separating myself and my sister, we don't get to see her often. The current price of fuel also hurts us. I have been trying to get help to move my sister to (name) state school for the last three years. I have explained the situation to three different case workers and I have received no help at all. As I got older this problem will get worse.

I had difficulty contacting the former case manager. It took a couple months together to address my concerns.

There is no question that my family has benefited and appreciates the services my sister has received through the WA state office of developmental disabilities. We could not have provided her with the same level of support without your financial assistance. My main concern is that your case managers have an extremely high caseload - too high. They cannot accurately follow the needs of their clients. Over the years they have consistently had an unrealistic view of my sister's level of functioning. They have always projected her functioning at too high of a level resulting in disastrous effects - rapid weight gain, too much independence, inappropriate job placement. They need to be more familiar with cognitive delays as they relate to level of functioning. Thank you for your financial support!

10c. Case Manager Turnover

Too many case manager changes. There have been 3 to 4 changes in a year.

It was hard to answer some questions regarding "case manager." In the past few years my daughter has had 3 different case managers. One was replaced before we ever met them. This can cause problems when the person never gets to know my daughter and her specific needs before moving on.

I realize case workers are hard to keep, but now and then it seems that they change fairly often. Just get use to one and his/her ways and then there is a change. I think the once a week is great for one client.

The frequency of case manger changes seems aimed at keeping both the client and the people involved with the clients care off-balance. Continuity is an important aspect of disabled people's lives. Having case manger changes happening often disrupts that continuity and efforts to keep changes to a minimum would be helpful.

Too may times case manager change where we often don't know who our current case manager is. The new one does not respond very well to our needs.

The case manager for my son is new. I have only talk to her once in the past 3 months. His case manager before was helpful gave me a lot of assistance with his placement. The new case manager has not called to introduce herself to me or even to tell me her name. I do not understand why they change them so often. I think it is important that they know their client and family. I know the case loads they have are a lot. I have been told that this case manager is great too.

Don't change case managers so often.

I did take time to fill out his form, but I really have very little to do with her case manager. I'm not even sure who it is. They seem to change a lot. My sister is doing well in the foster home she lives in. In the past I have had good luck with her case managers.

{Name} case manager has changed a lot during the past two years. Any questions regarding this subject are fairly sketchy we've had very little contact with the DSHS case workers.

Major concerns: frequent change of case managers - no formal notification to client.

{Name} has been given to a new case manager. Neither she nor I have met her. She received a letter earlier in the year naming her new case manager. I did not receive a copy and I have not heard from her.

My son has had several case managers over the years. It would be great if his case manager would not constantly be changing.

We have had three case mangers in less than one year. The current one we met last month (April 2006) and weren't aware we had a new one until she called to set a date for the care plan meeting. The previous manager didn't tell us she was moving on. Fortunately, our son's plan is in place and we actively participate and monitor. We are able to access and support his needs.

Case managers have too many cases to fully appreciate their clients need. They do the best they can. I handle any problems on site if and when they arise.

I think the case mangers are over-loaded. We see ours once a year at the PCP meeting. He never makes contact otherwise.

11a. Satisfied with Staff

I am very pleased with all the help that {name} provides. He seems very caring towards my family member and myself. {Name} is great!

As parents we are very pleased with the overall care that my son receives. All of the workers are wonderful people and will do everything to make things work for {name}*, he loves everybody that works with him, and that's all that matters to use he is getting good care, it is a blessing the whole staff.

I am impressed with {name} he seems very conscientious and knowledgeable. He found mis-information that {name} had provided - she held conferences and filled out forms to which I had not been notified. I hope he "hangs in" with us for a long time. I've met him twice p telephoned once with co-operation. Many of your questions I cannot answer or relate to, as I can usually work out problems (issues) with her care givers.

Care givers are very good with {name}. She truly needs their help.

The staff at {name} state school have always been kind and good to my child and the others. They feel secure there. I know this, because my daughter is always happy to come home visits, and she is also nappy and acceptable to be returned to {name} state school. This was not the way, when she was at {name} where she would scream and cry and not want to return and my husband and I would be upset all the way home for having to leave her. I cannot say enough good things about {name} state school. The staff is kind and concerned and often they spend their own money supply treats for the children. I want {name} to stay at {name} state school, it has been the best place that she's been in. I thank you too for caring and checking on the children's care and how they are feeling.

I am very satisfied with all workers who are in contact with my daughter. I can not say how much better they could be.

{Name} is doing a great job with {name}. They are right on top of health issues and make sure that he has everything he needs. He seems very content and happy living there. {Name} and {name} are very caring people and I am very grateful everyday for them.

We have regular communication with providers. We have nothing but good to say about the way they care for {name}.

The services provided is excellent and my client could not possibly exist with out it or in another facility. Any problems that come up I am always contacted. The people who work with her are so helping and caring. I never have to worry or check on her constantly because I know she is getting such great care and is safe from the outside world. I am so thankful that she is surrounded by such an excellent group of people.

{Name} seems very happy in his home which he shares with other retarded. The staff is very caring and so good to him.

I was confused by some of the questions in this survey. The answers are the opinion of the persons guardian and we can only give our thoughts and what we see when we visit the facility. When I visit {name} state school, the personal have been very accommodating and pleasant, so I am very happy my son is at {name} state school.

We are very pleased with the care our daughter receives. The staff is very good about calling us whenever there is a problem. We would not consider placing her anywhere else.

I wish our son could be closer to us. We know he is happy where he is. When we go see him he is very relaxed and he recognizes his dad's voice and blinks his eyes a lot when he hears it. We are very happy with the staff that takes care of him. We don't have to worry at all about the care he gets. We could not be happier with the care he gets.

I am pleased with the staff, the care and the agency as a whole who manage {name} care. I'm confident about their decisions for her and that they are in her best interest.

{Name} is well taken care of and the people around him are trying to upgrade his skills and understanding of his environment they plan his work schedule and his home life. I am very satisfied with his care.

We have had a good experience with {agency}. The individual working with our son have demonstrated considerable ability and care.

My daughter has been a resident in {name} for 33 yrs and is completely happy there would not think of moving close to me. The staff has always seen to her best interests and care. I have always thought I was lucky to have her there. I am 89 yrs old so I don't get to {name} often anymore. We talk every day on the phone and her being happy with the staff what more could I ask.

My daughter moved in Nov 2004 from {name} state school to {name} state school. The prime motivation for this move was the fact that there was a possibility that {name} state school would close or, at least be severely downsized. I felt that the move was handled very professionally. {name} state school personnel visited {name} state school, and {name} state school personnel visited my daughter at {name} state school, to make sure that the move was appropriate. I have been very impressed by the staff at {name} state school the assessment of the move done by DDD personnel.

My brother has lived happily at the {name} center for a good portion of his life. The staff provide him with excellent support and care for him (they are his second family). Overall the center is wonderful however there has been some staff turnover in the last years.

I would like to compliment all the caregivers I have known. Generally I feel she is well cared for. The staff persons are kind, very patient, friendly and dependable. Since I no longer drive, they bring her for visits.

My family and I are very very satisfied with the care that my sister is getting at {agency}. The staff is excellent. They truly love my sister. My parent visit every week-end. The staff always assist in getting my sister in and out of their car.

My profoundly retarded brother has been in the excellent care of the caring professionals at {name} state school for over 50 years. There is no better place for him.

Assisted living where my brother lives. Is a great place for him. I am very happy with his living situation. I'm very proud to say the staff that works with him does a very outstanding job and should be very highly recommended with all their patients, understanding and care that they put into their job on one to one care. His living arrangement is outstanding. I possibly couldn't say

anymore. My hats are off to those people. His living situation very clean and spotless, warm and inviting.

My son is now 54 yrs old and has been a resident of {name} state school since the age of 9. He had polio at the age of 15 months. He has a hard time walk, cannot talk, dress himself, wears a diaper. But he is so beautifully taken care of. The staff is wonderful and I thank god every day for such a lovely place as {name} state school.

The case worker and support personnel are caring and well trained people. I am generally impressed.

My daughter is at {name} state school she needs 24 hour nursing care. She has cerebral palsy, so she has no control over her body or body functions. She has Retts syndrome and lost her ability to swallow, so she has a tube into her stomach, and gets along well with that. She doesn't walk or talk. She recognizes us - she also has family pictures in her room and we have made her cassettes tapes of our voices which they play for her. The staff at her hall never know when we will be there and we always find her very clean, her hair cut regularly, and she smells so good. We are very grateful for the care that she gets. The attention and love that she receives. We couldn't possibly care for her at home and she is comfortable and happy.

{Agency} is a wonderful support providing service. We are very happy with {agency} care provider's; and also are most impressed with {name} professionalism and assistance.

We are very pleased with our daughters current support person. The lady has had experience in raising a family and she has used her knowledge in a positive way. Our daughter has had many support people in her stay with {agency}. Some good - some very poor, but she is a survivor and her current supporter has given her a steady and trusting relationship which we hope will continue "hopefully" for a long time. She has kept us abreast of all happenings and respected our input.

11b. Dissatisfied with Staff

My brother is living in an adult family home for disabled adults. Staff members have often in the past had Tupperware parties and home decorating parties to name a few with the idea of the disabled residents making purchases (this helps the staff person's objective in selling the products, both the residents usually do not have a clue about their purchases.)

11c. Staff Turnover

{Name} lives 3 hours away from home. I can't visit as I would like, but am not comfortable with the drive anymore. I have to trust that he is receiving good care. It does seem like the house staff is constantly changing.

My son fort he most part has very good staff and case manager. His lack of involvement is mostly of his own choosing. If I were to have a complaint it would be the turn over in staff. About the time things are going well there will be a big change around of staff. I do however realize it is a high stress, high turn-over job and we try to roll with it, but sometimes it has been very disruptive.

My son lives in {agency} in {city}, WA. The staff support at that facility is constantly changing with the exception of the home managers who have been there for 2 + years. The young people

they hire for minimum wage stay 3-6 months. This does not give my son any sense of “family” new ones are constantly being introduced and have to get to know my son. Also his work program providers and staff are changing all the time. We are re-inventing the wheel every 3-6 months! A lot of “spinning” and getting no where.

I'm pretty pleased most of the time, however we had to be very “squawky” because {name} needs are so great! We have been mostly happy with place one. The biggest problem has been the large staff turnover it hard on {name}.

11d. Shortage of Staff

On weekends not enough staff - no nurse! My son is diabetic has shot everyday sometimes twice monitored 4 times daily sometimes five - pinch him a lot!

Insufficient staff to attend local facilities when special entertainment provided for residents.

11e. Staff Not Qualified

Needs improvement: 1. Lack of sufficient staff. 2. Pulling in untrained staff that do not know the residents or special needs.

Group home staff are (mostly) well-meaning, but not highly educated. They are poorly paid for the level of difficulty of their work and need nearly as much monitoring as their clients.

{Name} provider does not adequately train new staff for dealing with individual clients. It's “trial by error”.

11f. Pay Staff More

Our service from community living and our current case worker has been excellent. Turnover in staff has been a problem and will remain so until wages are more equitable. These people are all really trying hard to make life good for our disabled children and adults.

Better funding needed in order to retain good staff - they leave for better paying positions in the community. If they could make \$12-13/hr they would stay.

I am concerned about turn-over of residential staff due to low wages and minimal (if any) health benefits. This is the critical level for daily living. Residential staff need to be skilled and motivated to work well and long-term with {name} and others receiving their services. A living wage with health benefits would help.

12b. Family Support Group

I wish there were support groups for parents whose disabled child moves out of the home, to decrease feelings of isolation and to help each other while hopefully improving the system of transition our “special children”. I know I've gone through some unimaginable stuff these last 6 months & have always felt pretty close to being a lone trailblazer.

13. General Well-Being

I was taken more seriously, as {name} mother, when I had legal guardianship. However I could not afford to pay the lawyer \$160 an hour for him to return to court. My daughter was moved to

a house a few years ago in spite of my objecting to this the bedroom down a long flight of stairs, and she has uncontrolled grand mal seizures. After a voice mail message at the last minute that the move was taking place. When I returned said message, the case manager said she did not receive my message in time. I feel that I was lied to and deliberately deceived, because this particular case manager (who thank god is not the one directing my daughter's life now) was anxious to wind up the paper work. I could not believe that a case manager would be so uncaring of my daughter's medical fragileness. Her name was {name}. Sure enough, after the move my daughter had a seizure on the steps going to her room an then another house was found.

On a whole, I have felt very positive toward the care and involvement from case worker, staff etc. This last 1.5-2 years has given me a sense of uneasiness with my brother's care: the programs have become much more bureaucratic, but also inconsistent and impersonal. There is good first line communication, but almost zero follow through or follow-up as it relates to the action item 2 and place that is arrival at. The physical and mental health care as well as job performance issues have not been satisfactory. I am very concerned about dramatic changes in my sibling's mental health currently and have been for sometime.

I would like to see more fun outings and activities for the handicapped and people with mental problems, this is so very important for their well being and having something to look forward to is a must!!!! We are lacking in this area. As a caregiver I take my clients out for drives and picnics. I see how much it means to them, not all caregivers can or will do this, we so need help with this.

I am overall pleased with the services that DDD gives my son, my biggest concern is what is available out in the community and staff's ability or attitude to deliver these opportunities, daytime services in the community for those folks with more significant disabilities is not as plentiful as hoped for and is left up to the residential providers or guardians, most staff providers don't have an idea of what can be done to fill the day with meaningful activities, maybe it is a matter of training or resources to find these. It would be wonderful if some of these staff people and agency program mangers would be able to attend the residential conferences in September 06. They would need backup staff to do this.

I have asked to have {name} attend any kind of Christian group for young people. She sings too, loves music and could attend community activities with an escort. She can afford these activities, and usually needs to have a spend down a couple times a year. She loves to ride the ferries, camping. She needs to exercise on a regular basis to control her border line diabetes. Always needs a companion, preferably a person she knows well.

My son is a hard worker, honest, sincere and devoted to my wife and myself. He is king and always willing to go out of his way to help anyone. Although he is always clean, he dresses rather sloppy and does not care to look or dress neatly. He has no pride in keeping a clean house, in fact his filthy house keeping could lead to unsanitary health disorder some day. He's handling of finances is a disaster, he cannot handle his check book account at the present time his paycheck is garnished and has filed bankrupts once and it could happen again. He doe not cook or try to. I have tried very very hard to teach him to live an organized life, but is his own worse enemy because he is not self motivated. He does not tend to his bills, or make health appointments.

I think the hygiene is not as good as it could be. I will be talking to the group home and discussing my concerns. I'm quite sure they will look into this.

I would like to see his hygiene better cared for, at times I pick him up for a home visit and his bottom is crusted and not wiped clean. Also his right groin is very very red at times. I know this is because he isn't being changed enough, from wet diapers. I usually call their attention to this, but nothing ever happens.

13a. Health

I believe {name} is in a good environment. He is getting good care from the caregivers who work with him personally. I don't like it when his medications are changed because of state pressure to try new drugs. {Name} has had both legs broken due to drop seizures when his medication were changed. The new drugs are not always the best. I don't want {name} used as a guinea pig because someone thinks he would be better off. These ideas usually come from the state of Washington department of social and health services.

I wish autism was more understood - sometimes the excessive activities require more food to regulate his weight or keep it at a healthy level.

My daughter moved into {name} group home in Feb. '05. Her weight at that time was about 163. As of may 15, 2006 the group home reports that she now weight 182 pounds. It is Dr. {name} (who has been her pediatrician since birth) order that she maintain her ideal weight between 150-160 pounds. I have repeatedly requested that the group home understand that this not optional and that they take measures to see that she returns to and maintains her ideal weight. I have discussed it with the staff in charge including the nurse. They see positive and responsive to the need; however, I feel the breakdown is with the support staff that may be less closely supervised to actually observe the way she is being fed. I am referring to issues such a portion control, weighing the food, and serving less caloric meals. I am generally very happy with everything else that concerns {name} at the group home. She is loved, happy and safe! Although I am frustrated with this issue I know that it is quite easily solvable, I had her in my home for 27 years and know that this is not an impossible task. It just takes diligence to make it happen. I have often and repeatedly expressed my concerns to the group home as I have observed her continual weight gain. It is my desire to work through this in a reasonable manner, but will have to press further if it is not taken seriously.

She needs more supervision when it comes to her healthy and personal hygiene. The provider is not doing her job correctly and I believe there has been no improvement from when she was doing thing herself. They still never get done.

{Name} needs are met by third parties- the state, {name} and his group home, my distance from him limits my involvement of his day-to-day case management. I do not see this situation changing any time soon. When I am able to visit, {name} seems to be doing okay, his needs are met-food, water, shelter, social interaction, and the like. I am concerned about his weight. He needs to be placed on a diet and loose weight.

13c. Abuse/Neglect/Mistreatment

{Name} has been left off a feeding tube 2 times in the past and been abused 2 times in past years (that we know about!) Investigation was made. We wanted one person fired (and he was not!) Just moved the worker to a different area. Both times were probably 2 different people. Workers in these places who care for these kinds of people are just babysitters with babysitter wages hired off the street as best I can tell. Someone should be watching them too!!

13d. Social Well-Being

I am pleased that my brother is now in a once a week program at elder house on {name} road. Transportation is provided and he seems to enjoy it. I don't know whether his case manager arranged it or his group home. When I called his case manager over questions about a Medicare drug plan she asked if I were satisfied with services he received. I said, at that time, I wished he could get out and about more as he mostly sat all day at the group home. I am very pleased he is getting out more and having more stimulation in his daily routine.

I think more help could be given to my daughter, for social activates. She enjoys going out and meeting people. She sits all day at her job, and then most evenings sitting in front of a TV, which has few programs she enjoys. I am 80 years old and it is getting more difficult for me to provide "fun" things for her. Thank you for listening.

Overall, I am satisfied with the services the DDD offers and I am pleased with the performance of her case manager. I am very disappointed, however in the lack of funding for services like local focus. She could greatly benefit by getting out into the community more and participating in activities with other people with disabilities like hers.

16. Funding and Budget Cuts

To cut back on the funding for this type of support to families is criminal! That is my educated opinion.

The group homes I have worked with are great! Also the case manager and local DDD office have helped us beyond what they had to. However, with the new program that has gone into effect I have spent sleepless nights and worried filled days as threats of lost funding has been thrown at me. After 44 years of service with the last 16 of those at the same group home. I am angered that removal of funding is even an issue. I know cut backs are needed, but not at the expense of helpless people. That would cause them terrible pain and death.

{Name} is in a wonderful home. He is now in Special Olympics. One case manager was wonderful. She found this home when we were down at the bottom. We miss her. The state has cut {name} aid. This is a concern for us and those at home. You must realize that he is 6 ft 2 inches very large and imposing. He needs this aid for basic help (dressing, etc.) Plus behavior problems.

17a. General Satisfaction with Services

We are always thanking god that there is a program available to take care of people like our son. Thank you DDD

DDD has been a great help through the years. They know what to do about the social security arrangements that are so confusing and DSHS. I don't know what we would have done without you DDD people to help us!

{Name} receives residential support services from {agency} and associates and has since she moved out of our house at age 24 yrs. (she is now 39 yrs) approximately 2 yrs she lived in an apartment setting - we were then able to contract with the state/{agency} to use the house we purchased for her and other housemates. They moved into the house august 1994. We have been very pleased with the support from that agency and from those who have been her case

managers. Thank you for asking us for our input. I also like the new planning tool you have instituted: I know it took much long to implement - we still find one part of the questionnaire rather useless it seems to rely on a medical model, which is not very helpful.

I have read the individual habilitation plan for my son. I find the plan to be an all-inclusive, thorough plan that leaves no stone unturned in the effort to provide him with the best of well thought out care. I compliment the staff that has put this plan forward. It reflects the keen observance and dedication of each and every one of them to improve and make life pleasant and comfortable for my son.

Without the support of DDD our life would be more difficult.

My name is {name}, my brother {name} and I are co-guardians, along with our father. We are all very satisfied with care that {name} has gotten over the years at {name} state school. All staff and doctors have always been very communicative over the years, and have taken very good care of {name}. We are all appreciative of time and effort that has been given to him. We would like to see the facilities stay operational.

I am very happy with the care my son receives at {name} state school in {city}. As far as the name "case worker" goes I believe the person in charge is {name}. I hear from him often. I can't say enough good things about the care he has received and I'm sure my whole family feels the same.

We are very happy with care. He's very happy and has good quality of life for his disabilities. Close for all family members to see him whenever they want. Always feel welcome at his home.

We feel that the DDD is doing a great job in helping our daughter - thank you all very much.

I would like to say - everyone involved with care for our child has been wonderful - they keep us informed - involved as in setting goals - community events, etc. Staff is always supportive - helpful all the time.

I am so much more at ease since {name} and {name} moved from {agency}. He has not been ill near as much. They still have transportation access and just knowing there is an attendant in the house 245 hrs a day is a big relief. Thank you for all you have done for him and his wife.

I am pleased with her care and I don't have to worry about her care.

We are very pleased with the care and life {name} has at serenity. DDD has also been very helpful over the years.

We have been pleased with the services so far. {Agency} services has helped us many, many times. We have had a few problems with a couple of the staff members (they did not understand {name} disability) but it was resolved.

My sister had lived at home with "mom" for 60 yrs, wanting to be on her own for years, but mom was very against it. Mom did make sure she had workshops to go to as she would not have to set home all day. When those programs went away she was able to have hang out at {agency} in {name}, then went to {name} enterprises. When mom had to go into a nursing home I was beside myself to find somewhere for {name} to live on her own as she fell between the cracks of the system being "physically challenged". Anyway as miracles have it we hooked up (after 2 wks

of calling everyone and getting no where) with {name} social services and she got us in touch with {agency} of WA, which has made {name} so happy to be on her "own" finally.

Thanks for all the help my brother. We are grateful.

Case managers seem to switch yearly. It would not be fair to rank them for anything, but the services evaluation we do each fall. Each caseworker has been polite and respectful to {name}. They have all listened carefully to what {name} care giver and I have to say. We do not need to communicate much with them in most years, and we consider this a good thing. That means that all services etc. are going as planned.

The services received are very definitely improved, because legal involvement was necessary.

Over the past 4 years DDD has made significant improvement for the quality of life of my brother. They have initiated and provided services for housing and care + have assisted him in finding work and a sense of belonging from that work. His physical condition has prevented his continuing to work and the agency has had difficulty in finding new work that is not so physically demanding. I think DDD providers do care about my brother, at times they commit to do more than they can. Despite clear areas where there could be improvement, I am very happy with the help and services provided during the last couple of years.

My son has received excellent services throughout most of his life as he is a very high needs individual with very difficult behaviors. Because I have advocated for him, DDD has always provided the needed services. Otherwise we would not have been able to keep him home until he was 18. However, many families have-not been nearly as fortunate. I am afraid our situation is very much the exception and not the rule.

We and our family member are satisfied.

I feel my family member is getting the best possible care available. I am most pleased with their efforts to care for her needs. I sense that they sincerely care and are doing the best they can to meet her needs.

Very pleased with the support my brother is getting. He has diverse activities at {agency}, artisans ark and at the {name} group home. His health needs are fully attended to (doctor, dentist, and glasses) and he gets to attend some great activities (dances, Broadway plays, hockey and baseball games, Silverwood theme park, etc.) He is very healthy and very happy. Thank you

The case manager is new and there has been no need to communicate. Caregivers are employed by an agency. I see him every five days when I do the grocery shopping for him and his room-mate. I take him to doctor's appointments and hair cuts by choice. The agency would take him if asked. Relations with the agency are good enough. There is no need to contact the case manager. His needs are well documented. There was a struggle with DSHS to provide services, but it appears settled.

Our lives are enriched and as normal as possible due to the services provided for my daughter's developmental needs. Thanks!

I just want to say that {name} and I are very happy with the living arrangement he has here in {city}. He lived in two different group homes for 11years while we were in {state}. They were not

near as nice as this one he is in now. The home manager is exceptionally kind and caring too. We are also very happy with his case worker, he recommended this setting for him. Now we are also hoping to find him some sort of employment. He had a job in {state} in a business called "life experiences" where they employed the handicapped. They had several different departments, one of which was a bakery. {Name} washed pots and pans. He could not handle fine detail jobs because of his voluntary tremors.

This has been a great help for me and {name}. I was the sole person to take her everywhere to everything she needed before we were offered these services and it has greatly freed me up to do other things. This has given {name} a much greater sense of independence also. She is currently signing up for job training at pat's college for summer and to look for employment part time, but has not actually done anything yet.

She has the best care and supports possible.

{Name} is having a useful and happy adulthood. He works (though only 12 hours a week). He volunteers he participates in many activities, including bowling, dances and vacations. Family vacations with me, his sister and his niece. I usually have him every week, unless he is too busy or I am out of town. I live ten minutes from his residential home and am there frequently.

I'm very happy with my daughter's care. I do think she needs a little more spending money as I don't know what she gets, from what I heard about a year or 2 ago it was 55 dollars, which is darn little. Other than that the staff is doing an excellent job.

We are happy with the service {name} receives. The staff have always been supportive of his needs and wishes. We are grateful for the help that DSHS gives and has given to {name}. He is happy and enjoys his life.

DDD regional office is terrific even with budget challenges and changes to waiver the last couple of years - this particular office is excellent. Best run DD regional office I've ever seen. Caseworker is also excellent she's there when needed, and we work to stay involved in {name} life. It all goes well, given budget limitations and waiver restrictions. My sister has excellent AFH services. We are very fortunate.

{Name} yearly evaluation provides me with information that shows she is well taken care of. She is comfortable with what is familiar. At one evaluation we decided she shouldn't be wheel-chaired in the blooms day run, because there are too many people, and she get sunburned. Thank you for your professional care. I'll see you at the next evaluation.

We had misgivings about our son going into independent living. We are pleased with the personal growth he has gained in independent living. He is happy. He likes his job and his case worker. One thing that hasn't changed is his grooming. This has been a life long challenge. We feel he has finally found his niche. We thank all of the great people that helped him achieve this. Our goal was to be as independent as he could be. We are very thankful

Outstanding service! Well done.

I don't know much about the case manager from WA state but I try to be involved in his life through {agency} who provides care assistance to him. Thanks for your hard work dealing and managing my brother's life.

17b. General Dissatisfaction with Services

My son needed hospital care and the hospital staff didn't seem able to support his needs. I contacted the school {name} state school. I told them he needed support, with there help and was told they couldn't send staff to help support his needs. I was not happy with the situation. I feel he didn't receive proper care while in the hospital. I believe this policy of not supporting the clients while in the hospital needs to be reviewed.

During care plans - the plan is according to "the team" not the client and families wishes. I had planned on typing up more, but my husband thinks these are to validate that DD is doing a good job. I'm sorry but that is not our experience. We have been lied to, tricked, threatened, black mailed, ignored and generally told and experienced "we'll do-what we want and there's nothing you can do."

My concerns with my daughters care are related to her diagnosis of prader-willi syndrome. My last survey expressed my concerns but perhaps was not heard. The state of WA has prader willi services in {city} WA which help a select few (14?). For years I requested placement in this facility but was turned down repeatedly. At age 27, {name} was placed in a group home because she could not secure a place in a home specific to her needs. {Agency} does their best, but she is 4'10" and weighs about 205 lbs. If she lived in a prader willi facility with like clients, her needs could be met. 20 years ago WA was leading the nation in quality care for prader willi people. The state has let us down, her life is threatened by this disability. I wonder if she will live to see 40 with obesity, diabetes, high cholesterol, sleep apnea, etc.

I would like to see {name} involved in some services to increase his daily activities. He sets in his chair at home, he needs some stimulation. He loves water pass a supervised swim or water activities. After he graduated from school any and all services to improve his life and stimulate him were stopped.

{Name} must be under constant care. He cannot make decision about his life style on his own. He will agree with about almost anything that you bring up. He always wants to help people and will be one of the first one to contribute. He has a third grad education. He needs to be cared for 24/7.

It took over 6 years to get DD to support my ward in getting adequate mental health services, despite the fact that she was on 6 pryor active medications. This is unacceptable and has resulted in a medical condition secondary to long term use of one of the psych meds. The case manager is currently assisting in correcting the above problem, but help was not forth coming in the past.

I have seen {agency}'s care giving staff frustrated and upset because they have so little support from the supervisors and management level of the program, they are unable to do their job effectively. To my knowledge none of the supervisors or management have had any college education to draw from in a professional capacity. It also seems that there is a lot of nepotism in the {agency} staffing. I have seen many mistakes and inaccuracies covered up or blamed on someone else. I feel that there should be an investigation into what is really going on in this program and possible reorganization, to be sure of quality control and maintain it's longevity as a quality program. At this point I don't feel comfortable leaving my son in this program, unless some major changes are made in the supervisory and management level.

Any programs relating to my non verbal sons needs must be approached objectively which was finally appreciated during his last few school years. His lack of communication skills is not being addressed effectively along with his ADHD concerns, and non-ability to cope with any change results very few gains, and some set backs occur. Consistency and repetition must be appreciated, by all involved, with any program set up for my son.

17c. Access to Services

Do you have any arrangement where I can teach her to read? I am a teacher, but I have been paying \$25.00 an hour for a special teacher. {Name} does read some. I think she could do more.

We are very pleased with our daughter's program but we are concerned regarding the apparent reduction in the availability of placement choices. There has been an erosion of available choices. Group homes are no longer available--we have been told on very good authority that only adult family homes are now available. We believe it is the responsibility of the division of developmental disabilities to insure that the rights promised in the core waivers are made available. Each person has the right to live in the facility that best meets their needs, to participate in the program that provides the greatest potential, and be assured all health and safety requirements are met.

17d. Information Regarding Services and Supports

Would like contact with case manager to see what activities, therapies etc. are available for our daughter.

Would like to receive a list of services and support available through DSHS for developmentally disabled individuals. Feel very isolated on what is available and I am concerned about future. What happens when family member who disabled can't physically live at group home anymore because of needs? What do I do then? How do I choose another facility? How will cost be done? Is there a brochure that list "what to do as person ages and needs more assistance?"

We as family members would like to know about the services that are available to her. We would also like to know how her money is spent. That she has been provided all there services that are out there and she knows about them all.

The biggest frustration I have had is trying to understand the ever changing state programs. Most problems have been with our CSO, not DDD or the case worker (who has been helpful and supportive). The issues we have revolve around work issues - how to keep services while working. I'd like more counseling regarding the rules/regulations. Exactly how much can be earned etc. I'm especially concerned about maintaining health coverage. The CSO has been a headache - little cooperation or assistance regarding health issues. Many letters that have either repetitive, conflicting, or incorrect interpretations, etc. Our DDD caseworker has been great.

All DSHS staff in {city} need to know about roar (residential, recreational, opportunities and activities representatives, inc.). I talked to several people when seeking services (admittedly, new/or recently assigned - but they should be trained to know), and no one knew about this valuable resource. It was perfect for our child, yet the only way we found out about it was to speak to individuals in Olympia. Why weren't DSHS staff in our own community aware of it? Why weren't we immediately referred? Also, we need more daily community activities for the severely impaired.

17e. Need More Services and Supports

Problem: funding for job services or day programming, not on waiver so no one will assist.

My daughter's physical and mental health have deteriorated over the last 3 years. She has developed an imaginary world of people to interact with because she has limited access to friends and community through her residential program. My daughter's inappropriate supports for her needs have "institutionalized" her within her apartment. She only gets seven hours a day of support. She has no job. She has no day program. This current system of support needs to be overhauled. My daughter needs effective behavioral supports, interaction with real folks in the community, a circle of friends and a job. Residential support services need more technical support on how to help people with DD make informed choices which lead to healthy productive lifestyles.

{Name} has been without any service provided normally by {agency} for past few weeks. {Name}* should be "an exception to policy" for community access. When I tried to find answers to why his community access had stopped, I was told he was "employable age". If you know him like I do, I truly believe he should be reinstated on the community access program. He is basically unemployable. Please help get him back on weekly outings.

17f. General Dissatisfaction with Service Management

Getting the needed help is fraught with bureaucracy, making the whole process complicated for the family member who is advocating for the disabled person. There seem to be numerous categories and labels that do or do not entitle a person to various services, often with weird names like "cap waiver" which make no sense to the lay person. And the "help" often just means lists of providers or other resources. It all adds up to lots of time on the phone or in appointments which lead to other phone calls and more appointments and referrals. What would be my dream would be a "one-stop shopping" service, where an expert would find out from us what's needed and then they would fine those things and plug us inc. (that's probably what they think they're doing, but from our perspective it usually feels like I do an incredible amount of case management, resource location and evaluation, emergency triage, etc. On top of the rest of my life.) My advice: simplify!!

Problem is not direct staff for local case management. Most problems - lack of communication, culture of secrecy, little to no communication, lack of advocacy for the local region, ect. comes from our regional administration-not the local level.

17h. Waiting List for Services and Supports

{Name} has gotten zero service most of his life. He lived with his mother until she was almost 75 years old! I think he only got a decent place to live because he finally made it on the list because the state couldn't dump on her anymore. Bottom line is too few people get adequate services while most get nothing. I barely know {name} has a DDD case mgr. I am sure that oversight is important. Finally he is getting a lot he needs. Why did it take so long? We looked for a long time, and most of what has been available was grossly inadequate you need a lot more places like integrated living services.

APPENDIX A

Summary Tables of Survey Responses

Table A - Characteristics of Family Member with a Disability: 2005-06 Data

STATES	Total %		State Avg.	CA-RCOC		CT		GA		ME		NC		PA		SC		SD		WA		WY	
Number of surveys	n	%		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Gender:																							
Male	2,700	55.2	56.5	164	62.8	141	56.0	299	57.9	264	55.3	124	58.2	628	55.6	165	50.8	446	52.5	347	54.7	122	53.0
Female	2,187	44.8	43.5	97	37.2	111	44.0	217	42.1	213	44.7	89	41.8	501	44.4	160	49.2	404	47.5	287	45.3	108	47.0
Age:																							
Mean	44.8		44.3	43.3	45.0	43.0	45.5	45.2	46.6	46.8	43.8	45.1	39.1										
Range	18-93			18-89	18-93	18-84	18-86	20-84	18-91	19-84	18-85	19-91	21-76										
Type of Residence																							
Specialized MR Facility	623	12.7	11.0	14	5.3	20	7.7	26	5.2	61	13.0	22	10.3	236	20.7	51	15.4	66	7.5	111	18.0	16	6.8
Group Home	2,549	51.9	56.0	181	68.0	185	71.2	252	50.8	245	52.1	134	62.6	590	51.7	191	57.5	418	47.7	196	31.9	157	66.2
Agency-Owned Apartment	321	6.5	4.5	1	0.4	6	2.3	28	5.6	32	6.8	6	2.8	40	3.5	32	9.6	122	13.9	37	6.0	17	7.2
Own Home/Apartment	826	16.8	15.4	41	15.4	38	14.6	115	23.2	41	8.7	23	10.7	109	9.5	37	11.1	241	27.5	154	25.0	27	11.4
Adult Foster Care/ Host Family Home	234	4.8	5.7	8	3.0	5	1.9	38	7.7	41	8.7	9	4.2	62	5.4	8	2.4	3	0.3	46	7.5	14	5.9
Nursing Home	113	2.3	2.3	9	3.4	0	0.0	5	1.0	28	6.0	10	4.7	51	4.5	1	0.3	0	0.0	9	1.5	0	0.0
Other	242	4.9	5.0	12	4.5	6	2.3	32	6.5	22	4.7	10	4.7	54	4.7	12	3.6	26	3.0	62	10.1	6	2.5
	4,908			266		260		496		470		214		1142		332		876		615		237	
Race/Ethnicity* (duplicated counts):																							
White	4,440	89.7	89.6	240	89.9	234	91.1	379	73.4	484	97.8	175	82.5	1094	96.4	243	73.2	811	92.8	580	91.8	200	86.6
Black/ African-American	308	6.2	5.3	5	1.9	11	4.3	131	25.4	1	0.2	34	16.0	21	1.9	84	25.3	1	0.1	18	2.8	2	0.9
Asian	30	0.6	0.9	8	3.0	0	0.0	3	0.6	1	0.2	0	0.0	4	0.4	1	0.3	2	0.2	10	1.6	1	0.4
American Indian/ Alaska Native	123	2.5	1.7	6	2.2	4	1.6	7	1.4	5	1.0	3	1.4	9	0.8	5	1.5	63	7.2	14	2.2	7	3.0
Hawaiian/ Pacific Islander	5	0.1	0.1	1	0.4	0	0.0	0	0.0	0	0.0	0	0.0	2	0.2	0	0.0	1	0.1	1	0.2	0	0.0
Hispanic	57	1.2	2.2	8	3.0	13	5.1	9	1.7	1	0.2	1	0.5	4	0.4	0	0.0	3	0.3	10	1.6	8	3.4
Mixed Races	53	1.1	1.7	6	2.2	3	1.2	4	0.8	4	0.8	1	0.5	9	0.8	1	0.3	8	0.9	5	0.8	12	5.2
Other/Unknown	11	0.2	0.3	2	0.7	2	0.8	1	0.2	1	0.2	1	0.5	2	0.2	0	0.0	0	0.0	2	0.3	0	0.0

Table B - Characteristics of Family Member with a Disability: 2005-06 Data																							
	Total %		State Avg.	CA-RCOC		CT		GA		ME		NC		PA		SC		SD		WA		WY	
Number of surveys	n	%		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Level of MR:																							
No MR label	155	3.2	2.9	9	3.4	6	2.4	18	3.6	10	2.1	14	6.9	11	1.0	16	5.0	34	3.9	31	5.2	6	2.5
Mild	800	16.6	16.4	60	22.6	44	17.6	84	17.0	59	12.6	38	18.6	165	14.7	65	20.4	170	19.7	72	12.0	43	18.2
Moderate	1,395	28.9	30.5	85	32.1	70	28.0	142	28.7	145	30.9	50	24.5	293	26.1	93	29.2	238	27.6	198	33.1	81	34.3
Severe	1,011	21.0	21.7	59	22.3	50	20.0	107	21.6	111	23.6	41	20.1	247	22.0	65	20.4	152	17.7	129	21.5	50	21.2
Profound	619	12.8	13.1	23	8.7	34	13.6	56	11.3	80	17.0	20	9.8	186	16.6	29	9.1	82	9.5	85	14.2	24	10.2
Don't know	840	17.4	15.4	29	10.9	46	18.4	88	17.8	65	13.8	41	20.1	220	19.6	50	15.7	185	21.5	84	14.0	32	13.6
	4,820			265		250		495		470		204		1122		318		861		599		236	
Other disabilities* (duplicated counts):																							
Mental illness	1,043	22.0	21.5	44	16.5	47	20.1	105	22.9	105	22.0	52	26.3	263	23.6	83	25.7	162	19.1	128	21.9	54	23.5
Autism	496	10.5	11.4	46	17.2	18	7.7	58	12.7	63	13.2	23	11.6	93	8.3	25	7.7	69	8.1	88	15.1	13	5.7
Cerebral Palsy	784	16.6	18.3	63	23.6	44	18.8	70	15.3	85	17.8	25	12.6	197	17.7	30	9.3	128	15.1	101	17.3	41	17.8
Brain injury	499	10.5	11.2	38	14.2	20	8.5	58	12.7	45	9.4	25	12.6	115	10.3	23	7.1	84	9.9	62	10.6	29	12.6
Seizure disorder/ neurological problem	1,415	29.9	30.5	77	28.8	68	29.1	127	27.7	148	31.0	53	26.8	351	31.5	82	25.4	252	29.8	175	30.0	82	35.7
Chemical dependency	45	1.0	0.9	2	0.7	3	1.3	3	0.7	1	0.2	4	2.0	15	1.3	4	1.2	5	0.6	5	0.9	3	1.3
Vision or hearing impairments	1,060	22.4	22.9	54	20.2	65	27.8	96	21.0	109	22.9	42	21.2	246	22.1	70	21.7	186	22.0	141	24.1	51	22.2
Physical disability	1,305	27.6	29.3	72	27.0	60	25.6	117	25.5	161	33.8	39	19.7	311	27.9	62	19.2	212	25.1	200	34.2	71	30.9
Communication disorder	1,005	21.2	22.3	46	17.2	50	21.4	98	21.4	128	26.8	32	16.2	227	20.4	48	14.9	167	19.8	160	27.4	49	21.3
Alzheimer's disease	58	1.2	1.2	1	0.4	6	2.6	3	0.7	7	1.5	3	1.5	15	1.3	6	1.9	6	0.7	10	1.7	1	0.4
Down Syndrome	621	13.1	12.8	29	10.9	34	14.5	67	14.6	61	12.8	28	14.1	138	12.4	36	11.2	133	15.7	64	11.0	31	13.5
Other disability	727	15.4	15.6	45	16.9	30	12.8	60	13.1	73	15.3	24	12.1	177	15.9	39	12.1	138	16.3	100	17.1	41	17.8

Table C - Characteristics of Respondents: 2005-06 Data

STATES	Total %	State Avg.	CA-RCOC	CT	GA	ME	NC	PA	SC	SD	WA	WY											
Number of surveys																							
Age of Respondent:																							
	n	%	%	n	%	n	%	n	%	n	%	n	%										
Under 35	99	2.0	2.1	3	1.1	4	1.5	12	2.3	5	1.0	5	2.3	13	1.1	12	3.6	28	3.2	11	1.8	6	2.6
35 - 54	1,231	24.8	24.6	42	15.9	55	21.0	120	23.5	124	24.9	56	25.9	289	25.1	100	29.6	233	26.4	138	22.7	74	31.6
55 - 74	2,720	54.8	53.9	152	57.6	127	48.5	298	58.3	285	57.2	118	54.6	625	54.3	176	52.1	474	53.7	332	54.5	133	56.8
75 and Over	915	18.4	19.3	67	25.4	76	29.0	81	15.9	84	16.9	37	17.1	223	19.4	50	14.8	148	16.8	128	21.0	21	9.0
	4,965			264		262		511		498		216		1,150		338		883		609		234	
Relationship to Family Member:																							
	n	%	%	n	%	n	%	n	%	n	%	n	%										
Parent	2,895	59.4	61.4	208	78.5	170	68.3	281	57.5	297	59.9	116	56.0	647	56.0	140	41.9	497	59.9	396	64.4	143	60.9
Sibling	1,283	26.3	24.0	47	17.7	47	18.9	107	21.9	130	26.2	50	24.2	417	36.1	99	29.6	212	25.5	129	21.0	45	19.1
Spouse	10	0.2	0.2	0	0.0	0	0.0	3	0.6	0	0.0	0	0.0	3	0.3	2	0.6	0	0.0	2	0.3	0	0.0
Other	688	14.1	14.4	10	3.8	32	12.9	98	20.0	69	13.9	41	19.8	89	7.7	93	27.8	121	14.6	88	14.3	47	20.0
	4,876			265		249		489		496		207		1,156		334		830		615		235	
Respondent is guardian or conservator:																							
Yes	3,266	67.6	71.4	175	67.3	217	86.8	195	38.9	497	98.4	160	76.2	517	47.7	143	46.1	658	76.2	471	76.3	233	99.6
Frequency of Visits with Family Member:																							
Less than once/year	226	4.6	4.4	6	2.3	11	4.3	12	2.4	13	2.6	5	2.3	92	8.0	9	2.7	35	4.0	32	5.1	11	4.6
1-3 times/year	560	11.3	11.0	22	8.3	20	7.9	41	8.1	40	8.1	19	8.7	155	13.5	26	7.8	121	13.7	87	13.9	29	12.2
4-6 times/year	584	11.8	12.5	26	9.8	36	14.2	33	6.5	59	12.0	25	11.5	154	13.4	37	11.0	107	12.1	70	11.2	37	15.5
7-12 times/year	718	14.5	13.7	34	12.8	37	14.6	78	15.4	83	16.9	38	17.4	154	13.4	44	13.1	129	14.6	91	14.6	30	12.6
More than 12 times/year	2873	57.9	58.4	177	66.8	149	58.9	341	67.5	297	60.4	131	60.1	593	51.7	219	65.4	491	55.6	344	55.1	131	55.0
	4,961			265		253		505		492		218		1,148		335		883		624		238	

Table D - Services and Support Received: 2005-06 Data

STATES	Total %		State Avg.	CA-RCOC		CT		GA		ME		NC		PA		SC		SD		WA		WY	
	n	%	n = 7	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Residential Supports	4,647	96.1	97.0	251	96.2	254	96.9	422	89.2	477	98.6	199	94.3	1073	96.2	331	98.8	868	98.0	545	94.8	227	97.8
Day/Employment Supports	3,795	81.1	83.9	226	86.9	228	90.1	404	83.0	386	82.1	152	77.6	778	73.1	294	89.1	754	89.0	363	66.5	210	92.5
Transportation	4,419	92.4	92.5	221	85.0	247	96.9	469	93.8	463	96.5	192	91.0	956	89.0	326	97.3	823	94.3	500	89.3	222	95.7
Other Services/ Supports	3,080	72.1	72.6	127	55.0	177	77.0	222	54.1	343	80.1	131	72.0	721	74.7	204	72.6	594	75.8	371	69.3	190	84.1

Table E - Information and Planning: 2005-06 Data

STATES	TOTAL	STATE										
	%	AVG.	CA-RCOC	CT	GA	ME	NC	PA	SC	SD	WA	WY
Q1 - Do you get enough information to help you participate in planning services for your family member?												
Number of surveys	4,701	n = 7	259	247	474	484	202	1,024	331	869	573	238
% always or usually	74.6	74.4	68.3	76.1	58.0	87.4	73.8	71.6	74.6	82.3	71.2	80.3
% sometimes	19.8	19.7	24.7	19.4	28.9	11.6	17.8	21.8	16.9	16.0	22.2	18.1
% seldom or never	5.7	5.9	6.9	4.5	13.1	1.0	8.4	6.6	8.5	1.7	6.6	1.7
Q2 - If your family member has a service plan, did you help develop the plan?												
Number of surveys	4,151	n = 7	234	214	413	449	177	850	282	806	498	228
% always or usually	61.0	62.9	58.5	59.8	51.3	73.5	65.5	43.2	62.8	70.2	63.5	80.7
% sometimes	23.8	23.1	25.6	28.5	27.8	20.7	20.9	29.9	19.1	21.2	21.9	14.9
% seldom or never	15.2	14.0	15.8	11.7	20.8	5.8	13.6	26.9	18.1	8.6	14.7	4.4
Q3 - If your family member has a service plan, does the plan include things that are important to you?												
Number of surveys	4,243	n = 7	237	219	413	487	174	867	291	822	500	233
% always or usually	76.1	76.2	73.4	74.9	65.1	86.7	77.0	70.8	74.2	80.0	77.2	82.8
% sometimes	20.1	20.1	23.6	23.7	27.8	11.9	18.4	23.6	19.2	18.1	18.0	16.3
% seldom or never	3.8	3.7	3.0	1.4	7.0	1.4	4.6	5.5	6.5	1.8	4.8	0.9
Q4 - Are the staff who assist you with planning generally respectful and courteous?												
Number of surveys	4,573	n = 7	263	243	453	491	192	956	318	865	557	235
% always or usually	92.1	92.2	93.9	93.4	86.8	96.1	92.7	91.4	91.5	93.2	92.3	90.2
% sometimes	6.5	6.6	4.6	6.2	11.0	3.7	6.8	6.8	5.7	5.9	6.3	9.4
% seldom or never	1.3	1.2	1.5	0.4	2.2	0.2	0.5	1.8	2.8	0.9	1.4	0.4
Q5 - Are the staff who assist you with planning generally effective?												
Number of surveys	4,465	n = 7	254	233	432	486	188	937	314	852	536	233
% always or usually	76.8	77.2	74.8	83.3	68.1	88.1	76.6	75.5	79.9	77.0	73.1	75.1
% sometimes	20.1	19.7	20.9	13.7	26.4	11.1	19.7	21.2	16.6	21.1	22.9	23.6
% seldom or never	3.0	3.1	4.3	3.0	5.6	0.8	3.7	3.3	3.5	1.9	3.9	1.3
Q6 - Can you contact the staff who assist you with planning whenever you want to?												
Number of surveys	4,560	n = 7	250	236	464	489	197	953	316	865	556	234
% always or usually	85.8	85.0	80.0	89.4	77.2	93.3	82.7	86.8	85.4	91.1	79.5	84.2
% sometimes	11.7	12.4	16.4	8.9	17.9	5.7	14.2	10.8	11.1	7.9	16.4	15.0
% seldom or never	2.5	2.6	3.6	1.7	5.0	1.0	3.0	2.4	3.5	1.0	4.1	0.9

Table F - Access and Delivery of Services and Supports: 2005-06 Data

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	GA	ME	NC	PA	SC	SD	WA	WY
Q7 - When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?												
Number of surveys	4,499	n = 7	231	226	463	427	195	994	332	866	530	235
% always or usually	81.3	80.5	73.6	84.5	70.6	84.8	77.4	82.2	81.6	87.9	77.0	85.5
% sometimes	15.8	16.4	22.9	14.6	20.5	13.3	17.4	15.7	16.0	11.2	18.7	14.0
% seldom or never	2.9	3.0	3.5	0.9	8.9	1.9	5.1	2.1	2.4	0.9	4.3	0.4
Q8 - Does your family member get the services and supports he/she needs?												
Number of surveys	4,773	n = 7	250	250	483	493	208	1,078	328	869	578	236
% always or usually	81.7	81.2	75.2	85.6	74.1	86.6	78.8	83.5	83.2	84.3	77.2	83.9
% sometimes	16.7	17.0	23.2	13.2	22.8	12.4	18.3	15.0	14.0	15.0	20.9	15.3
% seldom or never	1.6	1.7	1.6	1.2	3.1	1.0	2.9	1.5	2.7	0.7	1.9	0.8
Q9 - If your family member does not speak English or uses a different way to communicate (e.g., sign language), are there enough support workers available who can communicate with him/her?												
Number of surveys	1,737	n = 7	78	91	163	221	62	398	115	349	182	78
% always or usually	79.4	78.5	71.8	84.6	62.6	85.1	80.6	80.7	89.6	83.4	74.7	71.8
% sometimes	16.6	17.0	19.2	12.1	23.9	12.7	16.1	16.1	8.7	15.5	21.4	24.4
% seldom or never	3.9	4.5	9.0	3.3	13.5	2.3	3.2	3.3	1.7	1.1	3.8	3.8
Q10 - Does your family member have access to the special equipment or accommodations that he/she needs (e.g., wheelchairs, ramps, communication boards)?												
Number of surveys	2,741	n = 7	105	141	250	307	97	641	183	538	337	142
% always or usually	89.1	87.9	78.1	92.2	83.6	90.6	86.6	90.3	91.3	92.0	86.6	88.0
% sometimes	8.5	9.3	17.1	7.1	10.4	7.5	8.2	7.0	6.6	7.1	11.3	10.6
% seldom or never	2.4	2.8	4.8	0.7	6.0	2.0	5.2	2.7	2.2	0.9	2.1	1.4
Q11 - Are frequent changes in support staff a problem for your family member?												
Number of surveys	4,063	n = 7	231	211	416	421	172	906	276	769	457	204
% always or usually	21.8	21.5	14.7	21.3	19.0	22.6	19.8	25.9	25.7	19.4	19.0	27.5
% sometimes	45.0	45.3	44.6	47.4	45.4	44.9	39.0	41.9	43.8	49.5	40.0	56.4
% seldom or never	33.2	33.2	40.7	31.3	35.6	32.5	41.3	32.1	30.4	31.1	40.9	16.2
Q12 - Do you feel that your family member's residential setting is a healthy and safe environment?												
Number of surveys	4,871	n = 7	263	252	486	492	209	1,117	337	877	604	234
% always or usually	88.6	88.2	89.4	88.1	85.6	92.3	86.1	89.3	88.4	88.5	89.2	84.6
% sometimes	10.0	10.3	9.9	9.9	12.3	6.9	10.5	9.2	10.1	11.1	8.8	14.5
% seldom or never	1.4	1.5	0.8	2.0	2.1	0.8	3.3	1.5	1.5	0.5	2.0	0.9
Q13 - Do you feel that your family member's day/employment setting is a healthy and safe environment?												
Number of surveys	4,026	n = 7	227	222	419	410	170	846	302	808	396	226
% always or usually	90.1	89.5	88.5	90.5	85.2	94.6	89.4	90.3	85.4	92.3	90.7	88.5
% sometimes	9.0	9.3	11.0	8.6	13.6	5.4	8.2	9.1	11.9	7.4	8.1	9.7
% seldom or never	0.9	1.1	0.4	0.9	1.2	0.0	2.4	0.6	2.6	0.2	1.3	1.8

Table G - Choices and Control: 2005-06 Data

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	GA	ME	NC	PA	SC	SD	WA	WY
Q14 - Does the agency providing residential services to your family member involve you in important decisions?												
Number of surveys	4,717	n = 7	253	251	471	486	202	1,043	331	874	574	232
% always or usually	77.3	77.9	71.9	79.3	68.4	93.0	76.7	70.7	76.1	80.1	79.1	83.2
% sometimes	16.6	16.3	22.1	16.7	18.5	5.6	18.3	21.3	16.9	16.9	13.1	13.8
% seldom or never	6.1	5.8	5.9	4.0	13.2	1.4	5.0	8.1	6.9	3.0	7.8	3.0
Q15 - If your family member gets day or employment services, does the agency providing these services involve you in important decisions?												
Number of surveys	3,690	n = 7	200	218	398	387	158	730	286	731	380	202
% always or usually	60.1	59.6	50.5	57.3	49.0	78.6	51.9	51.1	64.7	67.7	58.7	66.8
% sometimes	25.1	25.5	31.0	27.1	29.1	16.0	28.5	26.7	19.6	24.6	26.1	26.7
% seldom or never	14.7	14.8	18.5	15.6	21.9	5.4	19.6	22.2	15.7	7.7	15.3	6.4
Q16 - Do you or your family member choose the support workers that work with your family?												
Number of surveys	3,700	n = 7	219	168	418	378	167	794	257	710	370	219
% always or usually	14.5	15.7	11.4	8.9	9.6	16.9	23.4	11.8	22.6	11.8	18.6	22.4
% sometimes	12.5	13.3	9.1	11.3	13.2	18.5	12.0	7.7	13.6	11.4	14.6	21.5
% seldom or never	73.0	71.0	79.5	79.8	77.3	64.6	64.7	80.5	63.8	76.8	66.8	56.2
Q17 - Do you or your family member have control and/or input over the hiring and management of your family member's support workers?												
Number of surveys	3,598	n = 7	201	161	391	355	159	763	238	695	425	210
% always or usually	8.5	9.2	6.5	6.2	7.2	13.0	12.6	6.7	11.8	5.5	11.3	11.4
% sometimes	8.2	9.1	8.5	7.5	7.2	10.1	13.8	5.4	6.7	6.9	10.6	14.3
% seldom or never	83.3	81.7	85.1	86.3	85.7	76.9	73.6	87.9	81.5	87.6	78.1	74.3
Q18 - Do you or your family member want to have control and/or input over the hiring and management of your support workers?												
Number of surveys	3,211	n = 7	182	162	356	317	148	662	208	609	372	195
% always or usually	25.7	27.0	24.2	20.4	31.2	29.0	32.4	24.8	29.8	16.4	28.2	33.3
% sometimes	34.3	34.7	35.2	40.1	35.1	33.1	31.8	35.8	34.1	32.5	29.8	39.5
% seldom or never	40.1	38.3	40.7	39.5	33.7	37.9	35.8	39.4	36.1	51.1	41.9	27.2
Q19 - Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?												
Number of surveys	4,556	n = 7	250	225	474	440	195	1,011	307	842	581	231
% always or usually	22.8	24.3	12.8	17.8	12.0	22.3	19.0	16.9	19.9	30.8	21.3	69.7
% sometimes	10.9	11.2	10.0	12.0	5.5	11.8	12.3	9.9	13.0	13.2	10.2	13.9
% seldom or never	66.3	64.6	77.2	70.2	82.5	65.9	68.7	73.2	67.1	56.1	68.5	16.5
Q20 - Do you or your family member get to decide how this money is spent?												
Number of surveys	3,567	n = 7	187	181	378	363	154	761	240	693	410	200
% always or usually	20.6	20.6	15.5	13.3	9.0	25.1	17.5	18.9	22.9	24.5	19.5	40.0
% sometimes	22.7	23.0	21.9	27.1	13.8	26.4	16.2	18.5	20.8	27.0	25.4	32.5
% seldom or never	56.7	56.4	62.6	59.7	77.2	48.5	66.2	62.5	56.3	48.5	55.1	27.5

Table H - Community Connections: 2005-06 Data

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	GA	ME	NC	PA	SC	SD	WA	WY
Q21 - If your family member wants to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help plan or who provide support help connect him/her to these supports?												
Number of surveys	3,518	n = 7	133	158	335	404	149	686	251	749	438	215
% always or usually	62.1	60.0	36.1	66.5	43.9	82.4	61.1	62.4	61.4	64.9	59.4	61.4
% sometimes	26.2	27.1	39.1	25.9	29.0	14.6	28.9	27.8	24.7	28.2	23.5	29.3
% seldom or never	11.7	13.0	24.8	7.6	27.2	3.0	10.1	9.8	13.9	6.9	17.1	9.3
Q22 - If your family member would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help plan or who provide support help him/her do this?												
Number of surveys	3,102	n = 7	109	127	311	388	132	585	230	677	369	174
% always or usually	62.7	60.3	38.5	62.2	44.4	80.7	60.6	61.5	65.7	65.9	61.2	62.6
% sometimes	24.3	24.6	30.3	24.4	29.6	15.2	22.7	26.0	23.0	26.1	21.7	27.0
% seldom or never	13.0	15.1	31.2	13.4	26.0	4.1	16.7	12.5	11.3	8.0	17.1	10.3
Q23 - Do you feel that your family member has access to community activities?												
Number of surveys	4,416	n = 7	219	215	452	469	186	965	292	848	540	230
% always or usually	66.0	64.9	50.7	68.8	53.8	80.6	62.9	63.8	64.0	72.4	63.7	68.3
% sometimes	27.6	28.1	35.2	27.0	33.6	17.9	30.6	31.1	26.4	24.4	26.9	27.8
% seldom or never	6.3	7.0	14.2	4.2	12.6	1.5	6.5	5.1	9.6	3.2	9.4	3.9
Q24 - Does your family member participate in community activities?												
Number of surveys	4,163	n = 7	217	194	422	408	186	902	284	814	515	221
% always or usually	41.7	42.7	31.8	49.0	39.6	51.2	38.7	38.5	47.9	40.2	39.2	51.1
% sometimes	41.0	40.1	39.6	39.2	41.7	38.2	44.1	42.5	34.5	46.2	36.7	38.5
% seldom or never	17.3	17.2	28.6	11.9	18.7	10.5	17.2	19.1	17.6	13.6	24.1	10.4

Table I - Satisfaction with Services and Outcomes: 2005-06 Data

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	GA	ME	NC	PA	SC	SD	WA	WY
Q25 - Overall, are you satisfied with the services and supports your family member currently receives?												
Number of surveys	4,427	n = 7	264	237	492	33	211	1,130	335	887	604	234
% yes or most of the time	81.0	82.4	79.5	86.9	72.8	100.0	78.2	81.9	81.8	84.7	79.0	79.5
% some of the time	16.9	15.4	18.2	9.7	23.2	0.0	18.0	16.4	16.7	14.1	18.9	19.2
% no or not at all	2.1	2.2	2.3	3.4	4.1	0.0	3.8	1.8	1.5	1.2	2.2	1.3
Q26 - Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?												
Number of surveys	4,565	n = 7	249	213	471	490	195	1,030	314	811	565	227
% yes or most of the time	56.1	56.5	50.2	50.2	41.6	89.4	50.8	48.9	51.0	59.8	50.3	72.7
% some of the time	8.1	8.5	7.6	8.9	10.2	9.6	9.2	7.0	11.5	7.4	5.8	7.9
% no or not at all	35.8	35.0	42.2	40.8	48.2	1.0	40.0	44.1	37.6	32.8	43.9	19.4
Q27 - Are you satisfied with the way complaints/grievances are handled and resolved?												
Number of surveys	3,047	n = 7	120	143	316	374	142	648	246	597	296	165
% yes or most of the time	67.9	65.7	61.7	53.1	54.7	82.6	64.8	67.1	67.1	72.2	69.9	64.2
% some of the time	24.1	25.8	26.7	35.0	34.8	7.0	26.1	24.5	26.4	22.9	22.0	32.1
% no or not at all	8.0	8.5	11.7	11.9	10.4	10.4	9.2	8.3	6.5	4.9	8.1	3.6
Q28 - Do you feel that services and supports have made a positive difference in the life of your family?												
Number of surveys	4,573	n = 7	260	227	486	328	207	1,061	333	862	585	224
% yes or most of the time	81.9	82.0	78.1	88.1	76.1	79.6	84.1	81.4	82.0	85.3	81.7	83.9
% some of the time	16.1	15.9	19.6	10.1	22.6	16.2	13.0	16.2	16.5	13.0	16.9	14.7
% no or not at all	2.0	2.1	2.3	1.8	1.2	4.3	2.9	2.4	1.5	1.7	1.4	1.3
Q29 - Overall, do you feel that your family member is happy?												
Number of surveys	4,821	n = 7	262	230	498	474	210	1,110	331	874	606	226
% yes or most of the time	81.4	81.2	79.4	81.3	77.9	91.4	81.4	79.5	80.7	83.6	80.4	76.1
% some of the time	17.2	17.1	18.7	17.0	20.9	7.8	14.8	19.5	16.9	15.6	18.0	22.1
% no or not at all	1.4	1.7	1.9	1.7	1.2	0.8	3.8	1.0	2.4	0.8	1.7	1.8