Adult Family Survey

Final Report – April 2007
2005-2006 Data

A Collaboration of
National Association of State Directors of Developmental Disabilities Services and
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Organization of Report

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

This report is organized as follows:

I. INTRODUCTION

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

II. ADULT FAMILY SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

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

IV. RESULTS

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

I. Introduction

Overview of National Core Indicators

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

Phase I – Phase I of CIP Phase began in 1997 when the CIP Steering Committee selected a "candidate" set of 61 performance/outcome indicators (focusing on the adult service system), in order to test their utility/feasibility. Seven states 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

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 familes/guardians of individuals not living at home who report the extent to which the system supports continuing family involvement.	Family/Guardian Survey
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	All Surveys
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Children & Adult Family Surveys

II. Adult Family Survey

Background

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

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

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

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

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

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

2002-2003 – Fifteen states participated and mailed out over 15,000 Adult Family Surveys. Response rates ranged from 24% to 53%, and approximately 5,200 completed surveys were utilized for analysis.

2003-2004 – Twelve states participated. Response rates ranging from 27% to 50%, and approximately 4,800 completed surveys were utilized for analysis.

2004-2005 –Eight states participated, with approximately 4,000 completed surveys analyzed.

2005-2006 - The results from this year's survey are explored in this report. Fourteen states/sites participated, with approximately 5,000 completed surveys analyzed.

State Participation

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

Table 3
State Participation in NCI Adult Family Survey
(Adults Living at Home with Family)

Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003	Phase VI 2003-2004	Phase VII 2004-2005	Phase VIII 2005-2006
AZ	AZ	CT	AZ	CA - RCOC	AZ	CA-RCOC	AZ
CT	CT	DE	CA-RCOC	CT	CA-RCOC	CT	CA-RCOC
MO	KY	IA	HI	DE	CT	HI	CT
NE	NE	KY	IL	HI	ME	OK	GA
PA	NC	MA	IA	IN	NC	PA	KY
VT	PA	MN	NE	IA	ND	SC	ME
VA	VT	MT	NC	ME	OK	WV	NC
	WA	NE	OK	MA	PA	WY	OK
		NC	PA	NC	SC		PA
		PA	UT	OK	WA		SC
		RI	VT	PA	WV		SD
		UT	WA	SC	WY		WA
			WV	SD			WV
			WY	WV			WY
				WY			

Survey Instrument

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

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

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

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

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

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

III. Methods

Sampling & Administration

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

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

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

Response Rates

During 2005-2006, thirteen states and one local developmental disability authority administered the Adult Family 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.

Table 4
Adult Family Survey - State Response Rates

State	Surveys Mailed	Surveys Returned	Response Rate (%)	Usable Surveys
Arizona	1,000	387	39%	314
CA-Orange Co	3,273	802	25%	686
Connecticut	1,200	313	26%	271
Georgia	2,000	694	35%	644
Kentucky	445	112	25%	108
Maine	888	266	30%	235
North Carolina	1,000	267	27%	215
Oklahoma	1,395	486	35%	447
Pennsylvania	2,760	1,255	45%	1,066
South Carolina	1,100	320	29%	256
South Dakota	242	94	39%	92
Washington	1,494	550	37%	455
West Virginia	989	326	33%	287
Wyoming	335	73	22%	65
Overall	**17,121**	**5,945**	**31%**	**4,827**

The desired response rate (the percentage of surveys returned versus the number mailed) to these surveys is 40%. 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. 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 Human Services Research Institute (HSRI). Data is entered by each state, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. HSRI utilizes SPSS (v. 15) software for statistical analysis and N6 software for support in analysis of open-ended comments.

IV. Results

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

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

1. **Total Percentages** indicate the average percentage across all individual respondents.
2. **State Averages** indicate the average percentage across the thirteen 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).

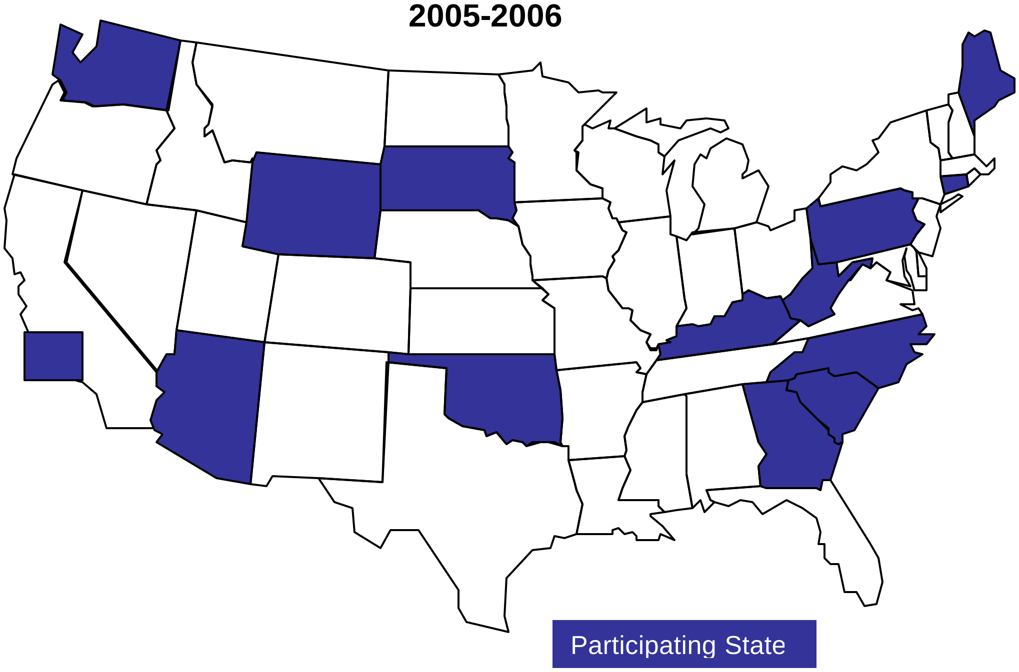
Participating States

- Thirteen states and one local DD authority provided data for this Report. They include Arizona, California's Orange County Regional Center, Connecticut, Georgia, Kentucky, Maine, North Carolina, Oklahoma, Pennsylvania, South Carolina, South Dakota, Washington, West Virginia and Wyoming.

Chart 1

States Participating in the NCI Adult Family Survey

2005-2006



Characteristics of Family Members with Disabilities

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

- On average, across participating sites, 54% of family members with disabilities were male, 46% were female.
- The average age of family members with disabilities was 33.4, with a range in age from 18 to 86.
- Seventy-eight percent (78%) of the family members were White, 12% were Black/African-American, 5% were Hispanic/Latino, 3% were Asian-American, 3% were American Indian/Alaska Native, 2% were Mixed Races, and less than 1% were Native Hawaiian/Pacific Islander.
- Twelve percent of households include more than one individual with a developmental disability.
- One-third (33%) of the family members with disabilities had a diagnosis of moderate mental retardation. Additionally, 26% were individuals with severe/profound mental retardation, 19% had mild mental retardation, and 5% had no mental retardation diagnosis. 18% of respondents were unsure of their family member's diagnosis.
- Many family members experience disabilites in addition to mental retardation. The most prevalent "other" disabilities include: seizure disorders/neurological problems (30%), physical disabilities (29%), communication disorders (25%), and vision/hearing impairments (25%).

Gender of Family Member

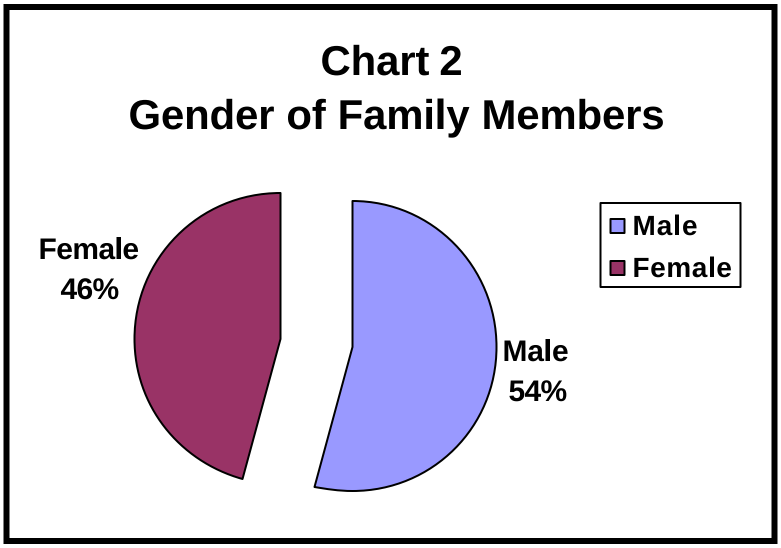


Chart 2
Gender of Family Members

Table 5
Gender

State	% Male	% Female
AZ	52.6	47.4
CA - RCOC	56.4	43.6
CT	55.9	44.1
GA	55.2	44.8
KY	47.5	52.5
ME	55.5	44.5
NC	53.4	46.6
OK	53.8	46.2
PA	53.6	46.4
SC	53.9	46.1
SD	59.0	41.0
WA	58.1	41.9
WV	55.9	44.1
WY	46.9	53.1
Total n	2,735	2,259
Total %	54.8	45.2
State Avg. %	54.1	45.9

Age of Family Member

Table 6
Age of Family Member

State	Average Age	Range
AZ	32.3	18-82
CA - RCOC	32.3	18-83
CT	33.2	18-86
GA	37.3	18-83
KY	37.4	18-68
ME	33.1	18-84
NC	36.2	19-74
OK	31.0	18-84
PA	34.5	18-84
SC	34.4	18-84
SD	33.3	18-65
WA	31.2	19-75
WV	32.8	18-76
WY	29.2	21-58
Total n	5,027	
Total Avg.	33.6	18-86
State Avg.	33.4	

Race of Family Member

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

Table 7
Race/Ethnicity of Family Member (%)

State	White	Black/ Af. American	Asian	Amer. Indian/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
AZ	68.2	6.2	1.0	3.2	0.0	4.2	0.7	19.5
CA - RCOC	48.8	2.0	21.9	1.3	1.3	3.4	0.9	22.9
CT	77.5	9.1	1.6	2.0	0.8	0.8	0.4	11.5
GA	61.2	37.1	0.2	0.5	0.2	1.1	0.2	0.9
KY	92.3	6.7	0.0	1.0	0.0	1.0	1.0	0.0
ME	94.5	0.4	0.4	2.6	0.0	0.9	0.0	0.4
NC	56.9	38.9	1.4	1.9	0.0	0.5	0.5	0.5
OK	77.6	10.1	3.7	11.3	1.8	5.3	1.8	4.1
PA	92.6	3.3	0.9	1.5	0.0	1.2	0.5	1.3
SC	54.5	43.4	1.6	2.5	1.2	2.1	0.8	1.2
SD	95.7	0.0	0.0	3.3	0.0	1.1	1.1	0.0
WA	83.3	2.9	4.9	2.9	0.7	4.7	0.9	4.5
WV	92.3	3.9	0.7	4.2	0.0	0.4	0.0	0.0
WY	93.7	1.6	3.2	0.0	0.0	0.0	1.6	4.8
Total n	3,776	594	217	136	26	112	33	311
Total %	75.0	11.8	4.3	2.7	0.5	2.2	0.7	6.2
State Avg. %	77.8	11.8	3.0	2.7	0.4	1.9	0.7	5.1

More Than One Person with Disabilities Living in Household

Table 8 More Than One Person in Household with a Developmental Disability		
State	% Yes	% No
AZ	15.6	84.4
CA - RCOC	8.7	91.3
CT	11.9	88.1
GA	10.9	89.1
KY	16.5	83.5
ME	13.2	86.8
NC	18.7	81.3
OK	11.3	88.7
PA	12.6	87.4
SC	13.5	86.5
SD	14.4	85.6
WA	12.5	87.5
WV	9.5	90.5
WY	4.7	95.3
Total n	603	4,405
Total %	12.0	88.0
State Avg. %	12.4	87.6

Level of Mental Retardation of Family Member

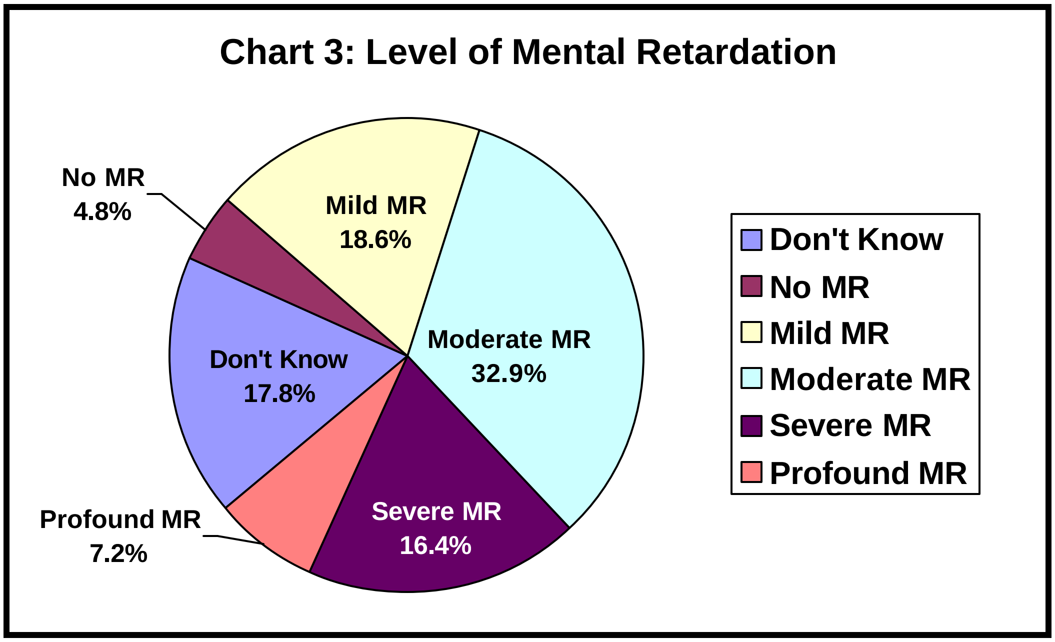


Table 9
Level of Mental Retardation of Family Member

State	No MR Diagnosis	Mild MR	Moderate MR	Severe MR	Profound MR	Don't Know
AZ	6.4	15.4	35.1	22.7	4.3	16.1
CA - RCOC	6.7	19.1	32.1	16.6	4.6	20.8
CT	1.7	15.7	42.1	14.9	6.6	19.0
GA	3.2	17.5	35.2	20.4	8.3	15.4
KY	4.8	20.0	21.9	33.3	10.5	9.5
ME	3.6	18.6	38.2	14.1	5.5	20.0
NC	8.5	17.1	21.1	26.1	10.1	17.1
OK	2.8	18.4	31.5	24.5	10.0	12.8
PA	1.5	23.0	35.4	13.2	6.8	20.2
SC	8.7	15.2	24.7	11.3	10.0	30.3
SD	5.6	24.7	29.2	13.5	3.4	23.6
WA	7.4	16.6	35.5	16.6	6.0	18.0
WV	1.9	13.4	36.3	19.8	14.9	13.7
WY	4.8	25.4	42.9	14.3	0.0	12.7
Total n	210	906	1,639	868	357	887
Total %	4.3	18.6	33.7	17.8	7.3	18.2
State Avg. %	4.8	18.6	32.9	18.7	7.2	17.8

Family Member's Disabilities – Other than Mental Retardation

Table 10A
Other Disabilities of Family Member

State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
AZ	13.1	14.4	22.6	14.1	27.2	0.7
CA - RCOC	14.6	11.5	15.5	9.9	21.0	0.1
CT	13.4	13.0	17.7	7.3	23.4	0.9
GA	20.0	9.5	16.9	8.8	31.0	0.7
KY	19.0	19.0	41.3	10.0	38.0	0.0
ME	18.1	15.3	14.4	8.4	27.0	0.0
NC	18.3	16.8	22.3	6.6	31.0	0.0
OK	14.0	11.0	30.7	14.6	40.5	0.9
PA	16.7	8.6	17.7	8.6	28.2	0.4
SC	22.3	10.5	13.1	14.7	29.8	2.1
SD	8.8	17.6	22.0	9.9	22.0	0.0
WA	13.5	14.4	24.3	10.8	32.3	0.5
WV	22.3	15.5	29.9	12.9	38.8	3.6
WY	17.7	14.5	22.6	9.7	30.6	0.0
Total n	801	583	991	503	1,434	34
Total %	16.5	12.0	20.5	10.4	29.6	0.7
State Avg. %	16.6	13.7	22.2	10.5	30.1	0.7

Table 10B
Other Disabilities of Family Member

State	Vision/ Hearing Impairment	Physical Disability	Communi-cation Disorder	Alzheimer's Disease	Down Syndrome	Other Disability
AZ	23.9	26.9	24.6	0.7	26.2	16.4
CA - RCOC	22.0	21.4	20.1	0.9	19.4	15.5
CT	22.1	26.0	21.6	1.3	23.4	16.9
GA	23.2	25.4	19.7	0.7	17.5	16.1
KY	21.0	31.0	40.0	3.0	13.0	20.0
ME	20.5	21.4	23.3	0.0	26.0	12.6
NC	32.5	33.5	28.4	1.0	9.6	12.2
OK	30.9	39.7	29.1	0.9	15.1	19.5
PA	24.3	25.3	16.0	0.7	23.0	13.8
SC	21.8	33.2	22.8	1.7	11.8	19.4
SD	26.4	18.7	14.3	0.0	20.9	19.8
WA	31.7	33.0	29.8	1.4	21.3	25.2
WV	32.0	41.4	37.1	2.2	18.0	23.7
WY	21.0	27.4	29.0	1.6	22.6	14.5
Total n	1,231	1,376	1,127	48	954	831
Total %	25.4	28.4	23.2	1.0	19.7	17.1
State Avg. %	25.2	28.9	25.4	1.2	19.1	17.5

Characteristics of Respondents

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

- Across all states, 48% of respondents (individuals who completed the surveys) fell into the age category of 55 to 74 years old. Ten percent of respondents were over age 75, and the remaining 42% were under 55.
- The vast majority of respondents were parents of adult children with disabilities (86%). The remaining respondents included siblings (8%), spouses (1%), and others(6%).
- Ninety-six percent of all respondents considered themselves to be the primary caregiver for their family member with disabilities. This was consistent across all of the states.
- Two-thirds (67%) of respondents indicated that they were their family member's legal guardian or conservator. Across the states, results varied from 46% in Orange County, California to 83% in Wyoming.
- Most respondents (70%) indicated that they were in good or excellent health, however nearly one-third of respondents (30%) categorized their health as being fair or poor.
- Half (50%) of respondents had an annual household income (including all wage earners within the household) of $25,000 or less. 27% had a household income between $25,001 and $50,000, and 22% had an income over $50,000.

Age of Respondent

Table 11
Age of Respondent

State	Under 35	35-54	55-74	75 or Older
AZ	3.9	37.5	49.8	8.7
CA - RCOC	3.8	36.4	49.3	10.5
CT	7.0	36.0	43.4	13.6
GA	1.9	31.3	56.0	10.8
KY	1.9	27.9	51.0	19.2
ME	7.3	38.5	45.7	8.5
NC	3.8	36.3	46.2	13.7
OK	5.9	42.9	44.5	6.8
PA	3.7	35.6	46.8	13.8
SC	7.3	41.9	41.5	9.3
SD	1.1	46.7	43.3	8.9
WA	4.0	38.0	50.8	7.3
WV	3.5	48.6	39.1	8.8
WY	3.1	31.3	60.9	4.7
Total n	209	1,889	2,424	537
Total %	4.1	37.3	47.9	10.6
State Avg. %	4.2	37.8	47.7	10.3

Relationship of Respondent to Individual with Disabilities

Table 12
Relationship to Individual with Disabilities (%)

State	Parent	Sibling	Spouse	Other
AZ	83.3	6.4	0.6	9.6
CA - RCOC	88.8	7.5	0.0	3.7
CT	88.2	7.7	0.0	4.1
GA	78.9	12.3	1.5	7.3
KY	85.0	8.4	0.0	6.5
ME	84.4	8.7	0.9	6.1
NC	85.8	5.4	1.5	7.4
OK	88.5	6.5	0.5	4.5
PA	85.9	9.1	0.5	4.6
SC	76.4	11.4	2.4	9.8
SD	93.4	4.4	0.0	2.2
WA	86.1	6.7	0.0	7.2
WV	84.8	8.8	0.0	6.4
WY	93.8	1.5	0.0	4.6
Total n	4,279	418	29	293
Total %	85.3	8.3	0.6	5.8
State Avg. %	86.0	7.5	0.6	6.0

Respondent's Role as Primary Caregiver

Table 13
Respondent is Primary Caregiver

State	% Yes	% No
AZ	92.9	7.1
CA - RCOC	96.2	3.8
CT	95.6	4.4
GA	98.3	1.7
KY	94.3	5.7
ME	93.5	6.5
NC	95.1	4.9
OK	97.1	2.9
PA	97.5	2.5
SC	96.7	3.3
SD	96.7	3.3
WA	92.2	7.8
WV	98.6	1.4
WY	98.4	1.6
Total n	4,818	190
Total %	96.2	3.8
State Avg. %	95.9	4.1

Respondent’s Role as Guardian or Conservator

Table 14
Respondent is Legal Guardian or Conservator

State	% Yes	% No
AZ	61.1	38.9
CA - RCOC	45.8	54.2
CT	82.3	17.7
GA	53.5	46.5
KY	62.6	37.4
ME	79.1	20.9
NC	78.8	21.2
OK	65.5	34.5
PA	53.2	46.8
SC	63.0	37.0
SD	69.6	30.4
WA	61.8	38.2
WV	79.9	20.1
WY	83.1	16.9
Total n	2,990	1,892
Total %	61.2	38.8
State Avg. %	67.1	32.9

Health of Respondent

Table 15
Health of Respondent (%)

State	Excellent	Good	Fair	Poor
AZ	19.3	51.6	25.5	3.6
CA - RCOC	23.9	50.4	21.6	4.1
CT	16.6	52.9	26.6	3.9
GA	13.1	56.1	26.6	4.2
KY	10.4	47.2	34.0	8.5
ME	24.8	49.1	23.9	2.1
NC	15.4	54.3	23.6	6.7
OK	19.0	53.5	22.3	5.2
PA	16.5	53.5	26.4	3.6
SC	13.6	40.9	39.3	6.2
SD	25.3	47.3	25.3	2.2
WA	22.9	56.0	17.8	3.3
WV	13.8	56.9	25.4	3.9
WY	18.5	63.1	16.9	1.5
Total n	914	2,663	1,259	209
Total %	18.1	52.8	25.0	4.1
State Avg. %	18.1	52.3	25.4	4.2

Household Income

Table 16
Household Income

State	Below $15,000	$15,001 - $25,000	$25,001 - $50,000	$50,001 - $75,000	Over $75,000
AZ	28.3	22.8	30.1	10.3	8.5
CA - RCOC	21.6	24.9	24.5	14.7	14.3
CT	27.9	18.6	25.7	14.6	13.3
GA	30.7	22.9	23.6	13.3	9.5
KY	36.0	23.6	18.0	15.7	6.7
ME	Question not asked in Maine				
NC	33.7	21.3	26.4	15.2	3.4
OK	27.9	21.1	28.6	21.1	1.3
PA	29.6	24.8	26.3	10.9	8.4
SC	44.1	19.5	16.4	11.8	8.2
SD	25.9	16.0	30.9	18.5	8.6
WA	17.2	20.2	35.5	16.7	10.3
WV	34.9	25.6	29.1	7.8	2.7
WY	14.8	19.7	41.0	23.0	1.6
Total n	1,192	957	1,131	587	357
Total %	28.2	22.7	26.8	13.9	8.5
State Avg. %	28.7	21.6	27.4	14.9	7.4

Services and Supports Received

- Across participating states, on average, day/employment and transportation services were the supports most often provided (71% and 61% respectively) to the family member with disabilities.
- Additionally, 39% received financial support, 36% obtained in-home supports, 34% utilized out-of-home respite care, and 32% received other needed supports.

Table 17
Services and Supports Received (%)

State	Financial support	In-home support	Out-of-home respite care	Day / employment supports	Transportation	Other
AZ	28.7	43.2	44.4	71.4	58.1	33.6
CA - RCOC	34.3	26.9	27.4	69.1	62.4	18.1
CT	43.5	20.0	24.9	76.6	65.2	16.2
GA	26.9	16.2	20.7	85.8	76.4	20.3
KY	41.7	56.7	50.5	78.1	61.0	53.9
ME	44.0	25.6	25.2	82.1	75.9	32.1
NC	38.3	47.1	38.8	65.4	51.0	23.2
OK	39.8	72.4	18.9	44.2	45.0	36.8
PA	45.3	26.5	31.1	70.4	60.9	24.8
SC	36.3	29.8	24.6	61.8	62.7	25.0
SD	33.7	20.7	21.8	87.9	67.0	42.9
WA	53.1	29.1	44.2	48.9	37.9	20.8
WV	41.8	56.6	40.6	69.3	66.8	41.8
WY	41.4	35.5	57.1	79.0	57.1	54.0
Total n	1,793	1,647	1,508	3,417	3,014	1,291
Total Avg. %	39.2	33.6	30.8	68.8	60.4	26.7
State Avg. %	39.2	36.2	33.6	70.7	60.5	31.7

National Core Indicators

In the 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 thirteen 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

- Across all participating states, fewer than half (41%) of respondents indicated they receive information about the services and supports available to them. Individual state results varied considerably, ranging from 27% in North Carolina to 63% in Orange County, CA.

- Among those who receive information, over half (53%) found the information easy to understand, while the remaining 47% found the information, at least sometimes, difficult to understand.

- Half of respondents (50%) stated that they got enough information to help them participate in planning, while the other half indicated they only sometimes or seldom had enough information.

- Three-fourths (74%) of respondents indicated that they helped in developing their family member's service plan.

- Of those families with a service plan, 68% stated that the plan included things important to the respondent. One-third of respondents (32%) indicated that the plan only sometimes, seldom or never included things important to them.

- Over half (57%) of respondents indicated that planning staff would help them figure out the supports they needed. However, a large percentage (43%) stated that this was only sometimes or even seldom the case.

- Three-fourths (75%) of respondents felt that staff respect their choices and opinions.

- Nine of ten (88%) felt that agency staff were generally respectful and courteous.

- Sixty-five percent of all respondents felt that agency staff were generally effective.

- Seventy-six percent of respondents indicated they could typically contact staff when desired.

Chart Q1

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

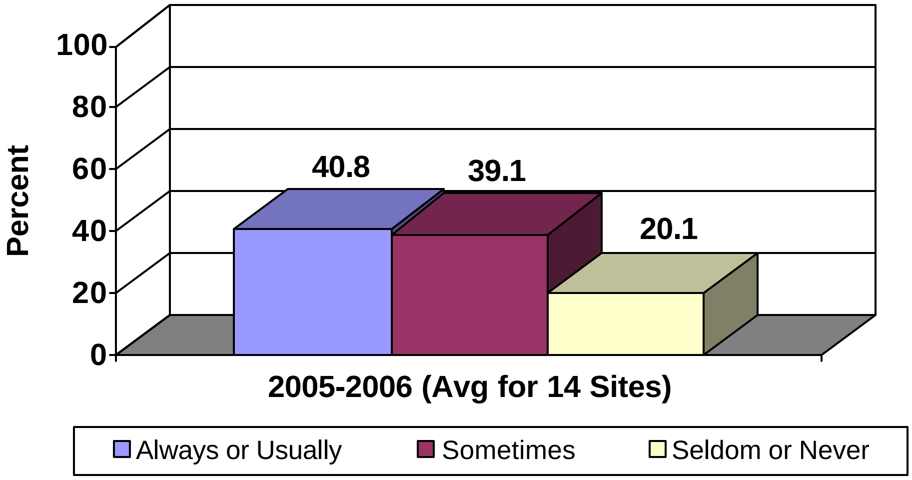


Table Q1

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		43.5	36.9	19.6	306
CA - RCOC	⇧⇧	62.7	30.5	6.7	655
CT	⇩	33.5	45.7	20.8	245
GA	⇩	31.5	35.6	32.9	604
KY		44.2	35.6	20.2	104
ME	⇩	35.7	45.2	19.0	221
NC	⇩⇩	27.1	45.2	27.6	199
OK		41.9	36.4	21.7	401
PA		44.6	38.5	16.9	997
SC		38.5	35.1	26.4	239
SD		42.2	40.0	17.8	90
WA	⇩	34.0	40.5	25.5	427
WV		44.7	38.9	16.4	275
WY	⇧	47.6	42.9	9.5	63
Total %		**42.2**	**37.8**	**20.0**	**4,826**
State Average %		**40.8**	**39.1**	**20.1**	**14**

Chart Q2

If you receive information, is it easy to understand?

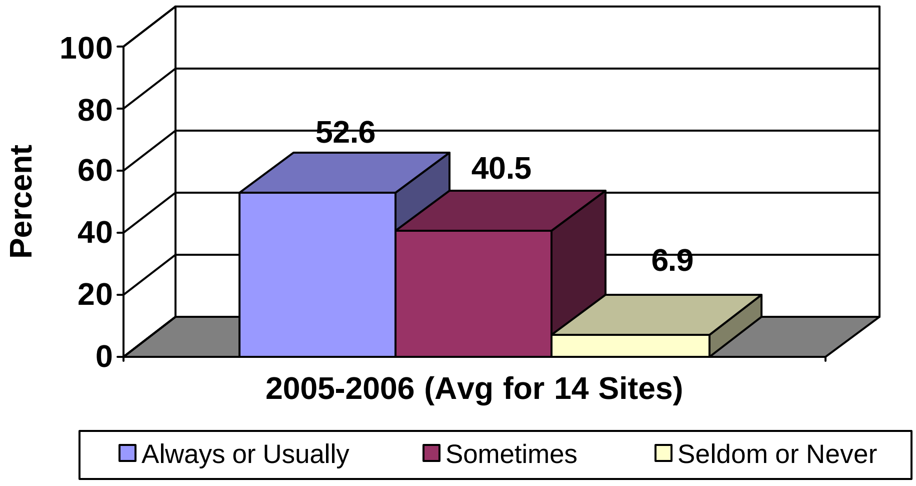


Table Q2

If you receive information, is it easy to understand?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		56.1	37.1	6.8	280
CA - RCOC	⇧⇧	73.0	24.2	2.7	627
CT	⇩	47.2	44.5	8.3	229
GA		50.0	38.4	11.6	508
KY	⇩	44.7	45.7	9.6	94
ME		55.2	40.6	4.2	192
NC	⇩⇩	40.4	50.0	9.6	178
OK		50.0	41.7	8.3	372
PA		56.5	39.5	4.0	920
SC		54.4	36.7	8.8	215
SD	⇧⇧	65.1	30.1	4.8	83
WA		50.8	41.4	7.8	384
WV		49.2	43.5	7.3	260
WY	⇩	43.3	53.3	3.3	60
Total %		**55.0**	**38.4**	**6.6**	**4,402**
State Average %		**52.6**	**40.5**	**6.9**	**14**

Chart Q3

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

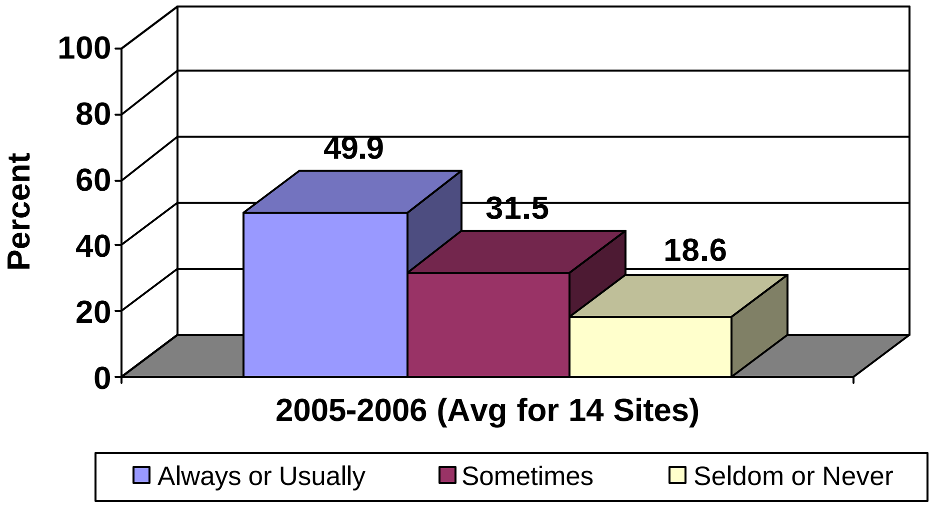


Table Q3

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		49.0	30.1	21.0	286
CA - RCOC	⇧⇧	60.2	31.0	8.9	620
CT	⇩⇩	39.0	33.1	28.0	236
GA	⇩	40.0	27.9	32.0	562
KY		50.5	32.0	17.5	97
ME	⇧⇧	63.9	26.0	10.1	208
NC		46.7	32.6	20.7	184
OK		49.6	32.2	18.2	401
PA		51.5	31.7	16.8	922
SC		49.3	29.2	21.5	219
SD		50.0	33.3	16.7	84
WA	⇩⇩	39.5	36.1	24.4	385
WV		53.7	32.5	13.8	268
WY	⇧	55.6	33.3	11.1	63
Total %		**49.7**	**31.3**	**19.1**	**4,535**
State Average %		**49.9**	**31.5**	**18.6**	**14**

Chart Q4

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

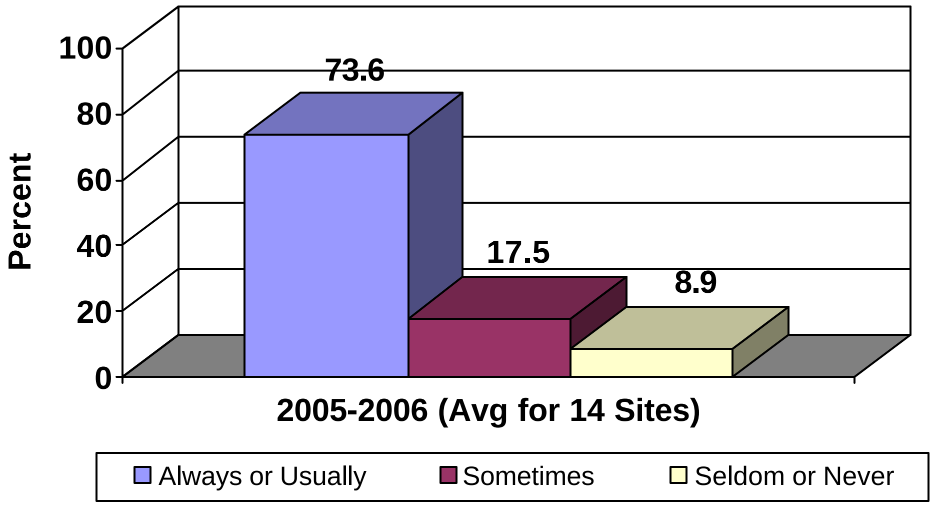


Table Q4

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		73.4	18.8	7.8	256
CA - RCOC		72.4	18.1	9.4	519
CT	⇩⇩	61.6	22.6	15.7	159
GA	⇩⇩	60.1	26.3	13.7	476
KY		72.5	18.7	8.8	91
ME		72.1	16.2	11.8	204
NC		77.3	17.5	5.2	154
OK		81.0	12.5	6.5	369
PA		73.8	15.4	10.8	780
SC	⇩	65.0	22.0	13.0	200
SD		78.5	17.7	3.8	79
WA		75.7	12.8	11.5	304
WV	⇧	79.3	15.5	5.2	251
WY	⇧⇧	87.3	11.1	1.6	63
Total %		**72.5**	**17.6**	**9.9**	**3,905**
State Average %		**73.6**	**17.5**	**8.9**	**14**

Chart Q5

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

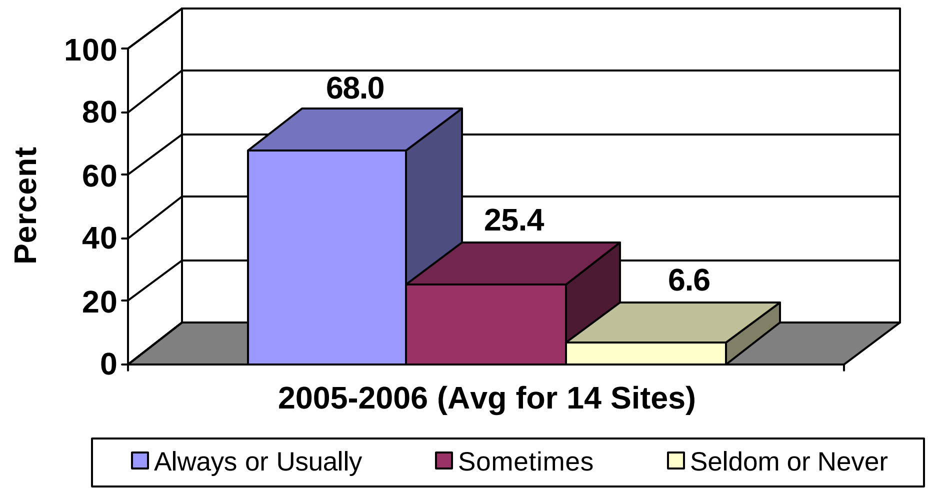


Table Q5

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		69.9	24.6	5.5	256
CA - RCOC		71.8	23.5	4.6	497
CT	⇩⇩	57.3	32.3	10.4	164
GA	⇩⇩	56.5	32.4	11.0	481
KY	⇩	63.0	32.6	4.3	92
ME	⇧	76.6	20.1	3.3	209
NC		68.1	25.8	6.1	163
OK	⇧	73.1	21.2	5.6	372
PA		70.1	23.2	6.7	788
SC	⇩	58.5	29.5	12.0	200
SD		72.2	25.3	2.5	79
WA		66.1	24.6	9.3	301
WV		71.2	24.2	4.6	260
WY	⇧⇧	78.1	15.6	6.3	64
Total %		**67.8**	**25.2**	**6.9**	**3,926**
State Average %		**68.0**	**25.4**	**6.6**	**14**

Chart Q6

Do the staff who assist you with planning help you figure out what you need as a family to support your family member?

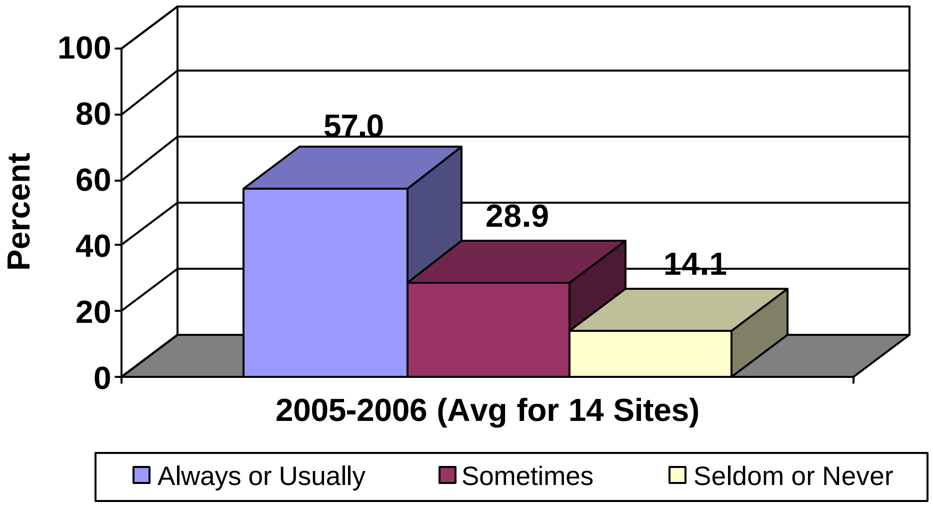


Table Q6

Do the staff who assist you with planning help you figure out what you need as a family to support your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		54.9	28.2	16.9	266
CA - RCOC		59.0	28.2	12.8	625
CT		55.3	26.9	17.8	197
GA	⇩⇩	47.0	31.5	21.6	515
KY		57.0	31.2	11.8	93
ME	⇧	65.2	21.7	13.0	207
NC		56.2	31.4	12.4	169
OK	⇧	63.1	25.9	11.1	379
PA	⇧	62.8	23.6	13.6	830
SC		55.8	32.2	12.0	208
SD	⇩	48.1	30.9	21.0	81
WA	⇩	50.6	31.5	17.9	330
WV	⇧	62.5	26.8	10.7	272
WY		60.3	34.9	4.8	63
Total %		**57.6**	**27.8**	**14.6**	**4,235**
State Average %		**57.0**	**28.9**	**14.1**	**14**

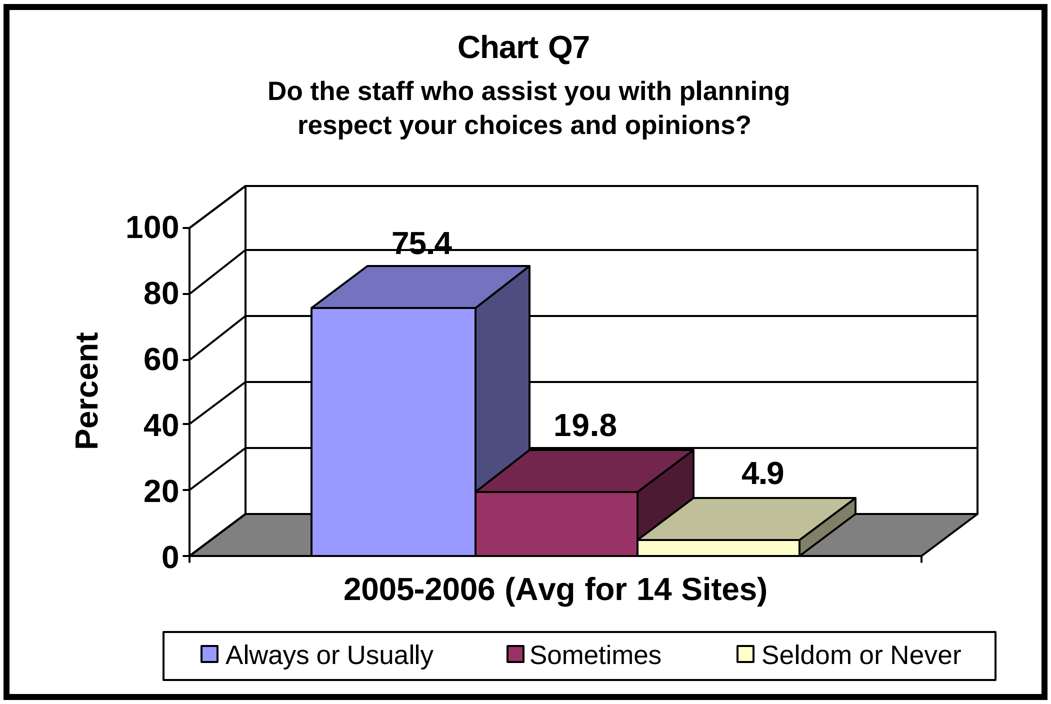


Chart Q7

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

Table Q7

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		74.4	19.9	5.8	277
CA - RCOC	⇧	84.3	14.4	1.3	619
CT	⇩	70.1	22.8	7.1	197
GA	⇩	66.6	23.0	10.4	518
KY	⇩	70.1	26.8	3.1	97
ME	⇧	82.1	13.2	4.7	212
NC		77.5	18.5	4.0	173
OK	⇧	81.2	15.4	3.4	382
PA		78.8	16.3	5.0	843
SC		74.5	18.1	7.4	216
SD		78.6	17.9	3.6	84
WA		75.2	17.5	7.3	331
WV		70.6	24.6	4.8	272
WY		71.4	28.6	0.0	63
Total %		**76.4**	**18.4**	**5.2**	**4,284**
State Average %		**75.4**	**19.8**	**4.9**	**14**

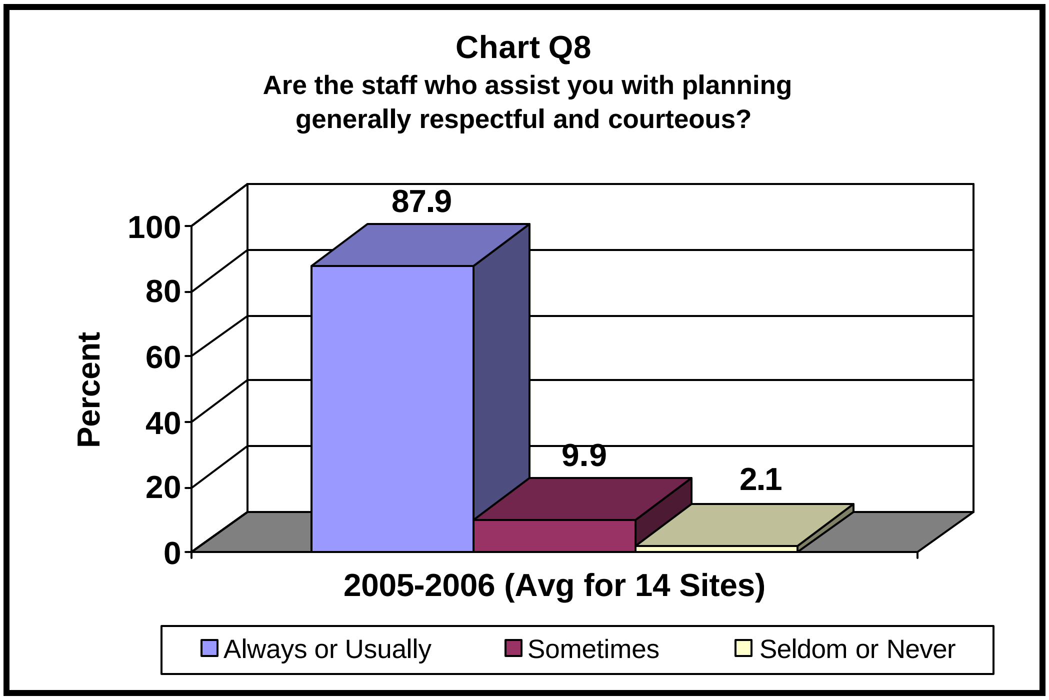


Chart Q8
Are the staff who assist you with planning generally respectful and courteous?

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		86.8	12.5	0.7	281
CA - RCOC	⇧	94.4	4.8	0.8	660
CT		84.5	10.6	4.8	207
GA	⇩	81.7	12.5	5.8	536
KY	⇩	78.2	19.8	2.0	101
ME		91.9	6.2	1.9	211
NC		91.6	6.7	1.7	178
OK		89.1	7.6	3.3	393
PA		90.8	7.3	1.8	874
SC		88.0	9.3	2.7	225
SD		87.4	11.5	1.1	87
WA		90.6	7.1	2.3	350
WV		85.5	13.4	1.1	276
WY		90.6	9.4	0.0	64
Total %		**88.8**	**8.9**	**2.3**	**4,443**
State Average %		**87.9**	**9.9**	**2.1**	**14**

Chart Q9

Are the staff who assist you with planning generally effective?

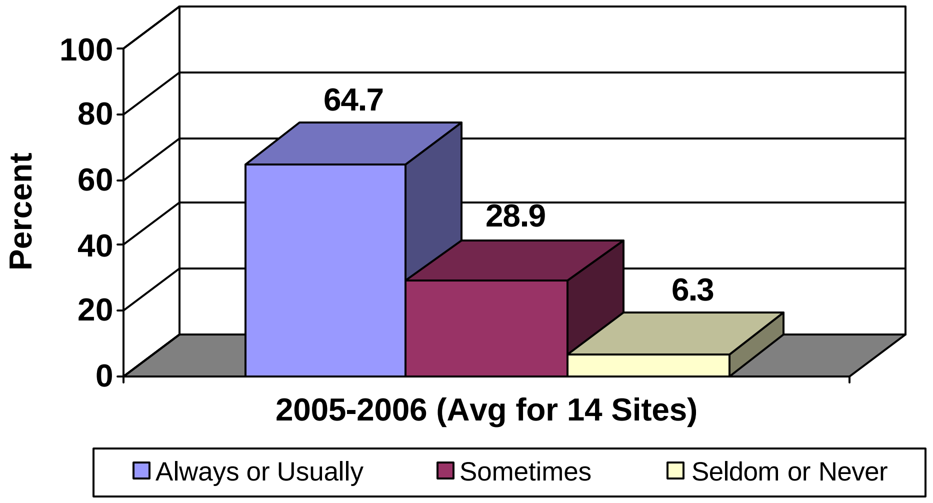


Table Q9

Are the staff who assist you with planning generally effective?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		64.2	29.9	5.8	274
CA - RCOC	⇧⇧	75.3	21.9	2.8	640
CT		61.9	28.9	9.3	194
GA	⇩⇩	53.9	33.7	12.4	523
KY		62.0	30.0	8.0	100
ME	⇧	71.7	24.1	4.2	212
NC		68.2	26.6	5.2	173
OK	⇧	69.9	25.1	5.1	395
PA		69.4	25.6	5.0	853
SC		64.1	25.9	10.0	220
SD		60.2	34.9	4.8	83
WA		63.7	28.9	7.4	336
WV		60.6	33.8	5.6	269
WY		60.9	35.9	3.1	64
Total %		**66.1**	**27.6**	**6.3**	**4,336**
State Average %		**64.7**	**28.9**	**6.3**	**14**

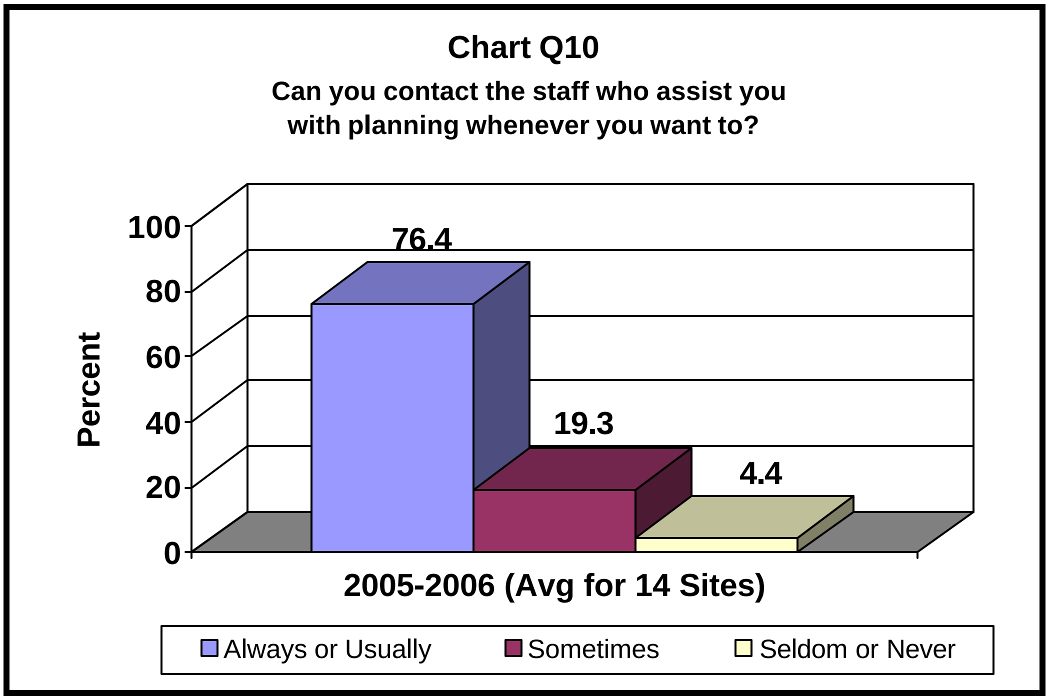


Chart Q10

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

Table Q10

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇩	69.0	25.3	5.7	281
CA - RCOC		77.0	20.1	2.9	653
CT	⇩	71.4	21.2	7.4	203
GA	⇩	71.3	21.4	7.3	537
KY		77.7	16.5	5.8	103
ME	⇧	81.7	16.0	2.3	213
NC		78.4	17.0	4.5	176
OK		78.3	17.3	4.3	392
PA		79.2	17.6	3.2	875
SC		79.4	14.8	5.8	223
SD		81.0	16.7	2.4	84
WA	⇩	67.3	25.0	7.7	352
WV		73.1	24.7	2.2	275
WY	⇧	84.1	15.9	0.0	63
Total %		**75.7**	**19.8**	**4.5**	**4,430**
State Average %		**76.4**	**19.3**	**4.4**	**14**

Access to and Delivery of Services and Supports

- Overall, 67% of families indicated their service coordinator helped them get needed supports when asked. Twenty-seven percent said this happened sometimes, and the remaining 6% indicated their service coordinator was rarely helpful in getting the assistance needed.
- Over half (56%) of respondents always or usually received the services/supports needed. Thirty-four percent got them sometimes, while 9% seldom or never received needed supports.
- The majority (54%) said the supports received met their families' needs. 37% stated that supports sometimes met their needs, while 9% felt supports seldom/never met their needs.
- For one-half of families (51%), supports were always or usually available when needed. However, almost as many families indicated that supports were only sometimes available (39%), or not available (10%) when needed.
- Forty-two percent of respondents stated that families in their area asked for different types of supports than the ones that were currently being offered.
- On the occasions when families did request different types of supports, 37% indicated that the state agency or provider agency was usually or always responsive to these requests.
- Slightly more than half (57%) of families who asked for assistance in an emergency or crisis received help right away.
- Among respondents whose first language was not English, 67% indicated that staff or translators were available to speak with them in their preferred languages. Fifteen percent indicated that staff/translators were sometimes available, and 19% stated that staff/translators who spoke in the families' preferred languages were not available.
- Among respondents with family members who did not speak English, or used a different means to communicate (e.g., sign language), about half (54%) of families said there were enough support staff regularly available who could communicate with their family member.
- About two-thirds of respondents (64%) felt their family member had access to the special equipment or accommodations needed.
- Most respondents (90%) felt they had access to health services for their family member.
- Compared to access to health care, slightly fewer families (77%) felt they had access to appropriate dental services for their family member. Fourteen percent had significant difficulty accessing dental services.
- Nearly all respondents (93%) felt they had access to necessary medications for their family member with a disability.
- Two-thirds of respondents (63%) indicated that frequent changes in support staff were a problem for their family at least some of the time.
- When the family member with a disability received day/employment supports, the vast majority of respondents (82%) felt that day/employment setting was a safe and healthy environment.
- Nine out of ten families (88%) felt that support staff were respectful and courteous.

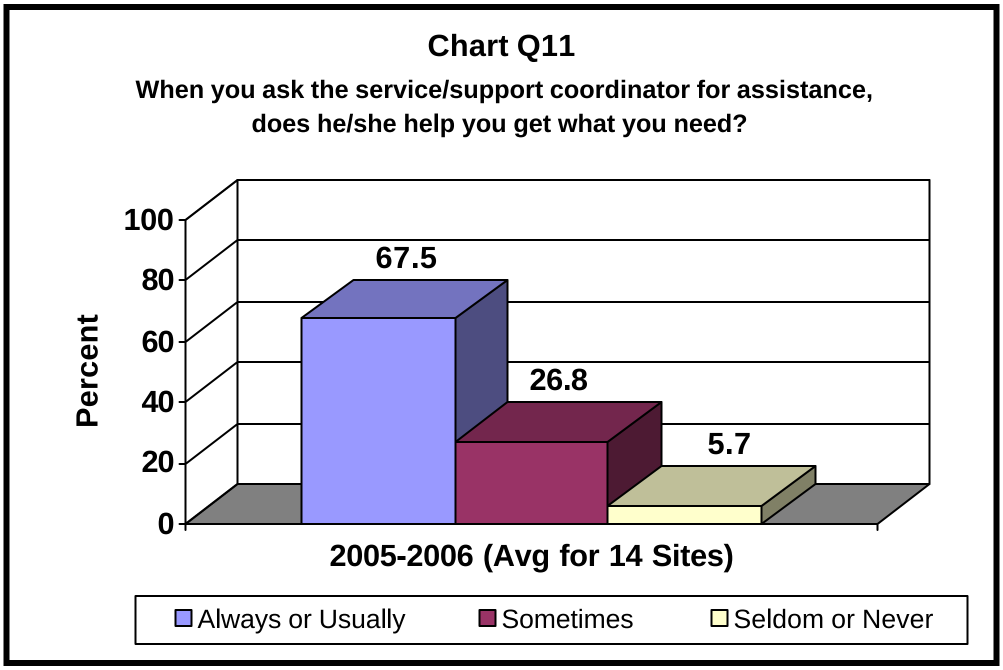


Chart Q11

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

Table Q11

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		65.8	27.4	6.8	281
CA - RCOC		72.3	23.3	4.4	631
CT	⇩	57.7	32.8	9.5	201
GA	⇩	60.5	29.0	10.5	562
KY		70.2	23.1	6.7	104
ME		71.9	24.1	3.9	203
NC		64.4	32.2	3.3	180
OK		72.0	23.4	4.6	389
PA		69.2	25.4	5.4	912
SC		66.5	24.9	8.6	233
SD	⇧	75.6	22.1	2.3	86
WA		68.0	23.6	8.4	394
WV		65.6	31.2	3.3	276
WY		65.1	33.3	1.6	63
Total %		**67.6**	**26.2**	**6.2**	**4,515**
State Average %		**67.5**	**26.8**	**5.7**	**14**

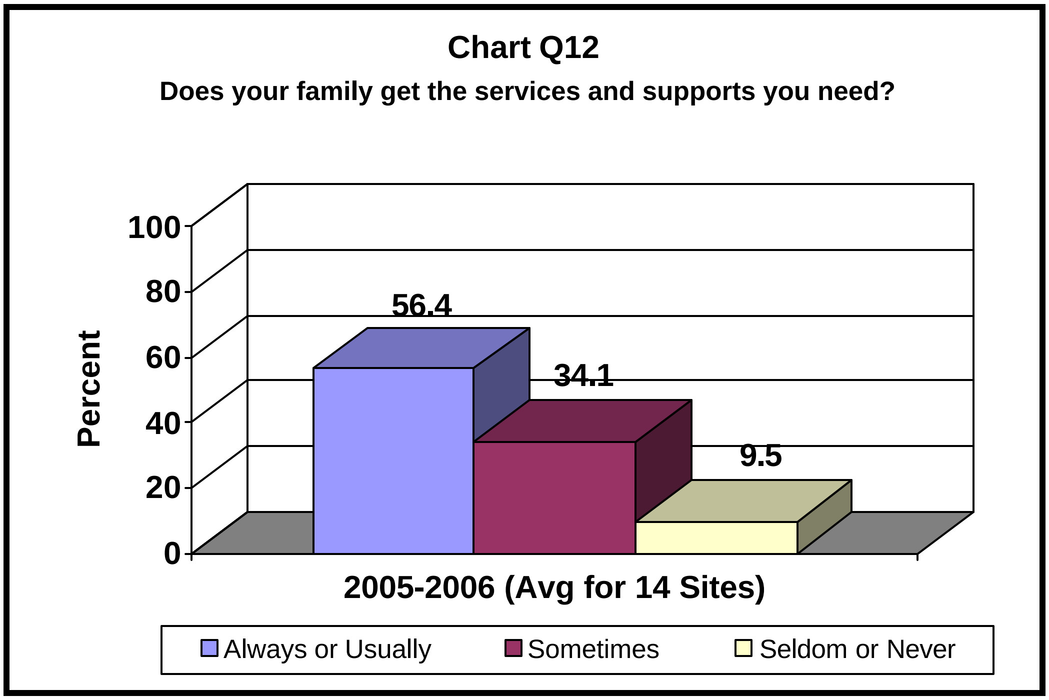


Chart Q12

Does your family get the services and supports you need?

Table Q12

Does your family get the services and supports you need?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇧	63.3	28.5	8.2	281
CA - RCOC	⇧	63.8	28.5	7.7	611
CT	⇩⇩	42.4	39.3	18.3	224
GA	⇩	49.5	36.2	14.3	580
KY		55.2	34.3	10.5	105
ME		59.7	34.1	6.2	211
NC		53.0	35.7	11.4	185
OK		59.7	33.7	6.6	392
PA		60.2	30.7	9.1	931
SC		52.6	35.8	11.6	232
SD		58.1	36.0	5.8	86
WA		53.3	36.3	10.5	400
WV		57.6	35.5	6.9	276
WY		61.3	32.3	6.5	62
Total %		**57.0**	**33.2**	**9.8**	**4,576**
State Average %		**56.4**	**34.1**	**9.5**	**14**

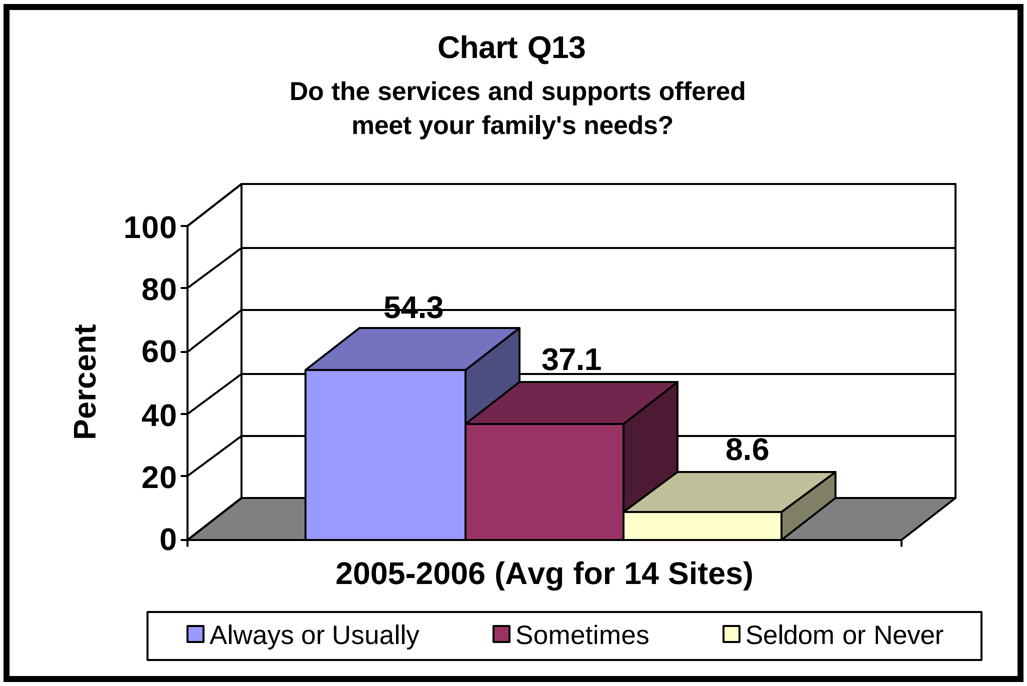


Chart Q13

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

Table Q13

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		58.1	35.5	6.5	279
CA - RCOC	⇧	63.5	31.8	4.7	611
CT	⇩⇩	39.2	41.0	19.8	212
GA	⇩	47.4	38.4	14.2	563
KY		51.0	39.4	9.6	104
ME		56.4	36.0	7.6	211
NC		53.8	38.7	7.5	186
OK		57.6	36.1	6.3	410
PA		55.6	35.6	8.8	932
SC		51.1	38.6	10.3	233
SD	⇧	60.0	36.5	3.5	85
WA	⇩	47.8	41.6	10.6	387
WV	⇧	60.1	32.5	7.4	271
WY		59.0	37.7	3.3	61
Total %		**54.6**	**36.5**	**9.0**	**4,545**
State Average %		**54.3**	**37.1**	**8.6**	**14**

Chart Q14

Are supports available when your family needs them?

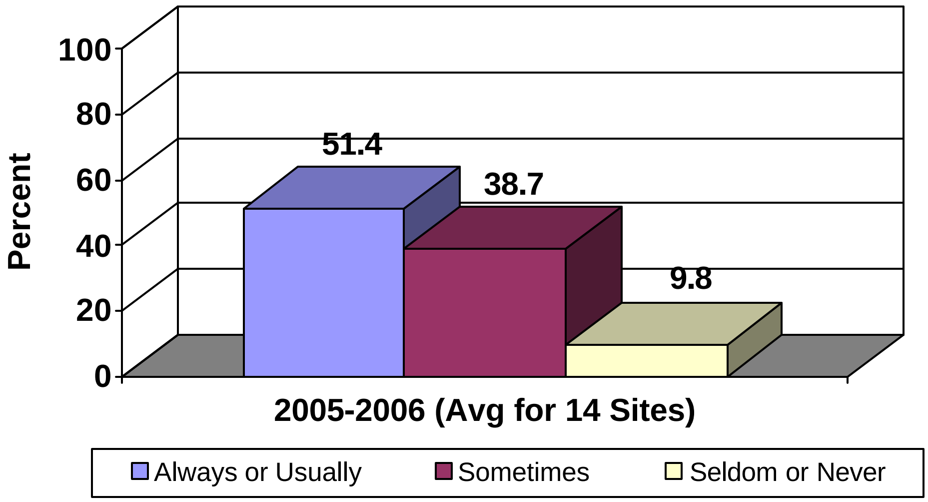


Table Q14

Are supports available when your family needs them?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		49.4	42.3	8.2	267
CA - RCOC	⇧⇧	61.5	33.0	5.4	569
CT	⇩⇩	40.9	36.9	22.2	203
GA	⇩	44.9	39.4	15.7	523
KY		50.5	41.7	7.8	103
ME		52.9	39.3	7.8	206
NC		53.8	36.6	9.7	186
OK		51.5	41.9	6.7	406
PA		53.4	35.6	11.0	891
SC		48.7	41.1	10.3	224
SD	⇧	58.0	37.0	4.9	81
WA	⇩	44.8	41.5	13.6	359
WV		53.2	37.5	9.4	267
WY	⇧	56.7	38.3	5.0	60
Total %		**51.5**	**38.1**	**10.4**	**4,345**
State Average %		**51.4**	**38.7**	**9.8**	**14**

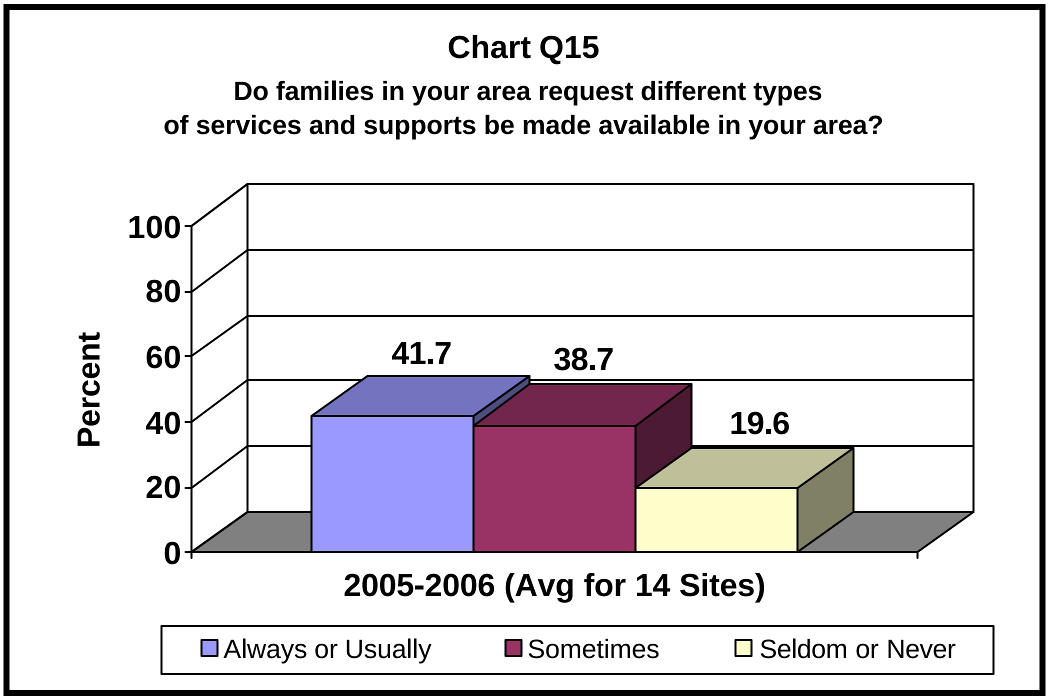


Chart Q15

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

Table Q15

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		37.0	43.5	19.6	92
CA - RCOC		29.1	36.1	34.8	158
CT		35.6	41.4	23.0	87
GA		46.3	32.9	20.8	255
KY		49.1	35.1	15.8	57
ME		38.9	43.1	18.1	72
NC		42.4	37.0	20.7	92
OK		39.5	40.8	19.7	157
PA		35.8	41.3	23.0	344
SC		44.1	29.7	26.1	111
SD		55.9	35.3	8.8	34
WA		41.8	39.7	18.4	141
WV		44.8	37.9	17.2	116
WY		44.0	48.0	8.0	25
Total %		**40.1**	**38.2**	**21.7**	**1,741**
State Average %		**41.7**	**38.7**	**19.6**	**14**

Chart Q16

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

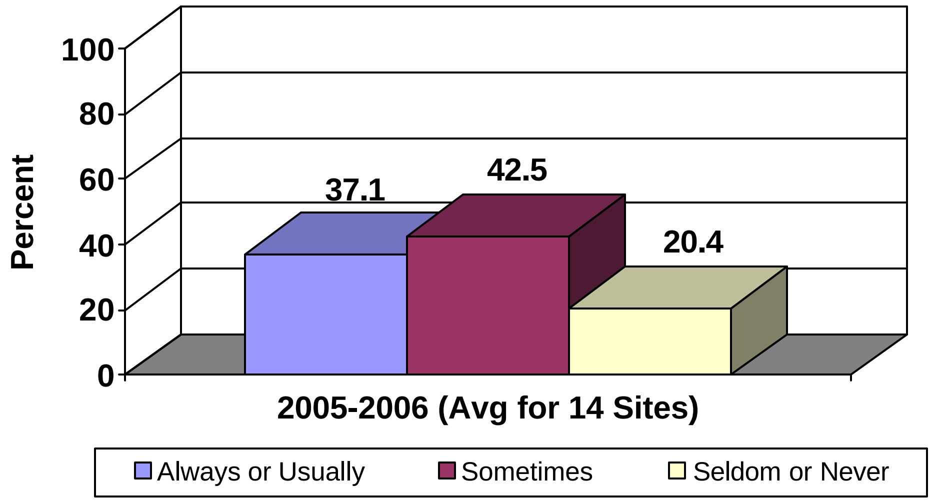


Table Q16

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇧	43.2	43.2	13.6	88
CA - RCOC	⇧⇧	66.3	27.1	6.6	166
CT		39.4	36.2	24.5	94
GA	⇩	30.8	38.9	30.3	221
KY	⇩	28.9	53.3	17.8	45
ME	⇩	30.4	57.1	12.5	56
NC		36.5	44.6	18.9	74
OK	⇩	31.8	50.0	18.2	132
PA		37.0	40.0	23.0	265
SC	⇩	29.0	38.7	32.3	93
SD	⇧	44.4	44.4	11.1	27
WA	⇩	31.1	45.6	23.3	103
WV		41.6	34.7	23.8	101
WY	⇩	29.2	41.7	29.2	24
Total %		**38.3**	**40.6**	**21.2**	**1,489**
State Average %		**37.1**	**42.5**	**20.4**	**14**

Chart Q17

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

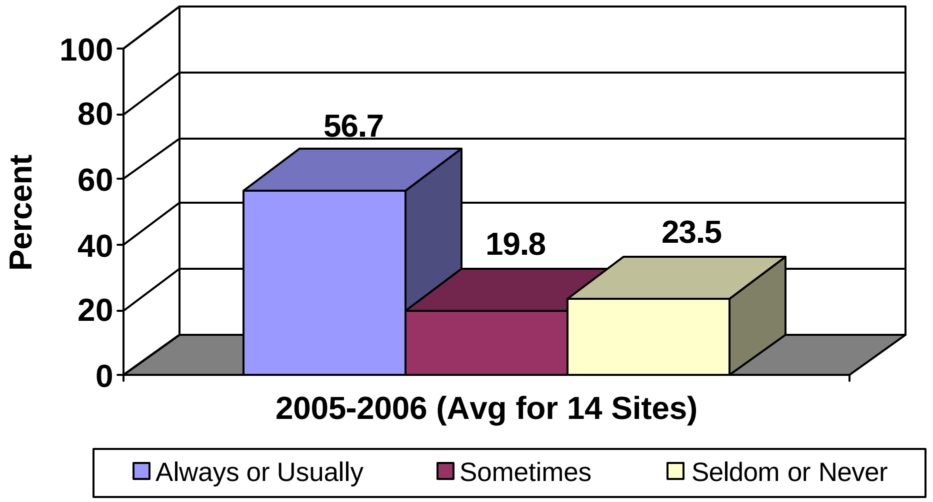


Table Q17

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇩	50.6	23.1	26.3	156
CA - RCOC		57.0	15.4	27.6	272
CT	⇩⇩	42.0	21.0	37.0	100
GA		54.0	21.4	24.6	313
KY		58.8	26.5	14.7	68
ME		59.5	16.2	24.3	111
NC		60.3	23.1	16.5	121
OK		52.0	21.1	26.9	227
PA		56.0	16.7	27.3	436
SC	⇩	51.1	21.6	27.3	139
SD	⇧⇧	75.7	13.5	10.8	37
WA	⇩	50.5	17.0	32.4	188
WV		55.4	20.3	24.3	148
WY	⇧⇧	70.8	20.8	8.3	24
Total %		**54.7**	**19.4**	**26.0**	**2,340**
State Average %		**56.7**	**19.8**	**23.5**	**14**

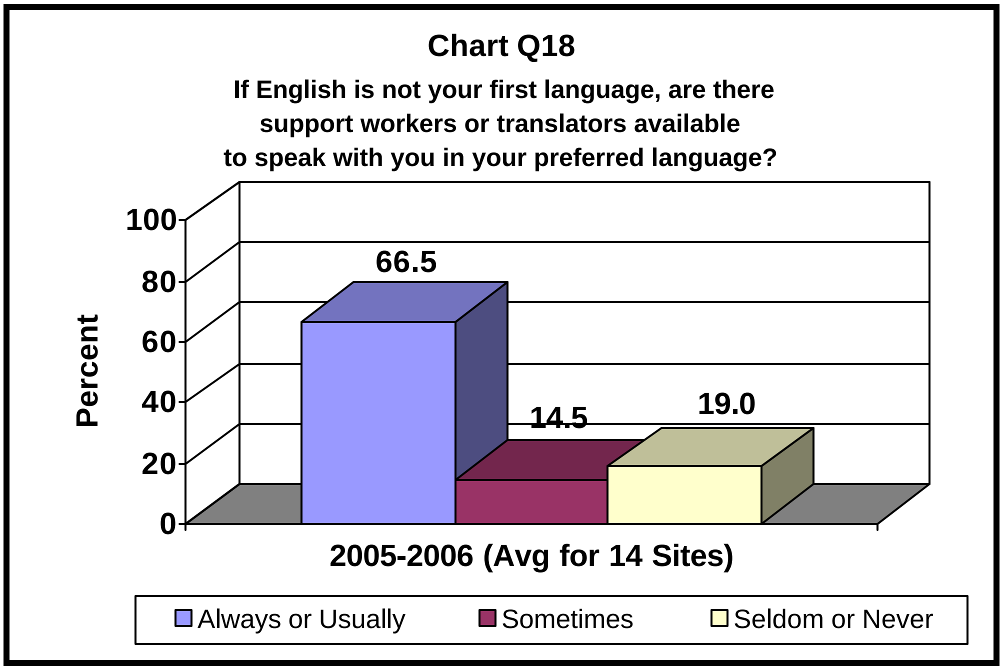


Chart Q18

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

Table Q18

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇧⇧	79.2	16.7	4.2	48
CA - RCOC	⇧⇧	88.1	7.8	4.1	219
CT		66.7	6.1	27.3	33
GA	⇧	73.3	15.0	11.7	60
KY	⇧⇧	85.7	0.0	14.3	7
ME		62.5	12.5	25.0	16
NC		63.2	26.3	10.5	19
OK		66.7	22.2	11.1	36
PA		68.1	17.4	14.5	69
SC		69.4	13.9	16.7	36
SD	⇩⇩	50.0	50.0	0.0	2
WA	⇧	73.5	14.7	11.8	34
WV	⇧⇧	85.0	0.0	15.0	20
WY	⇩⇩	0.0	0.0	100.0	1
Total %		**77.3**	**12.3**	**10.3**	**600**
State Average %		**66.5**	**14.5**	**19.0**	**14**

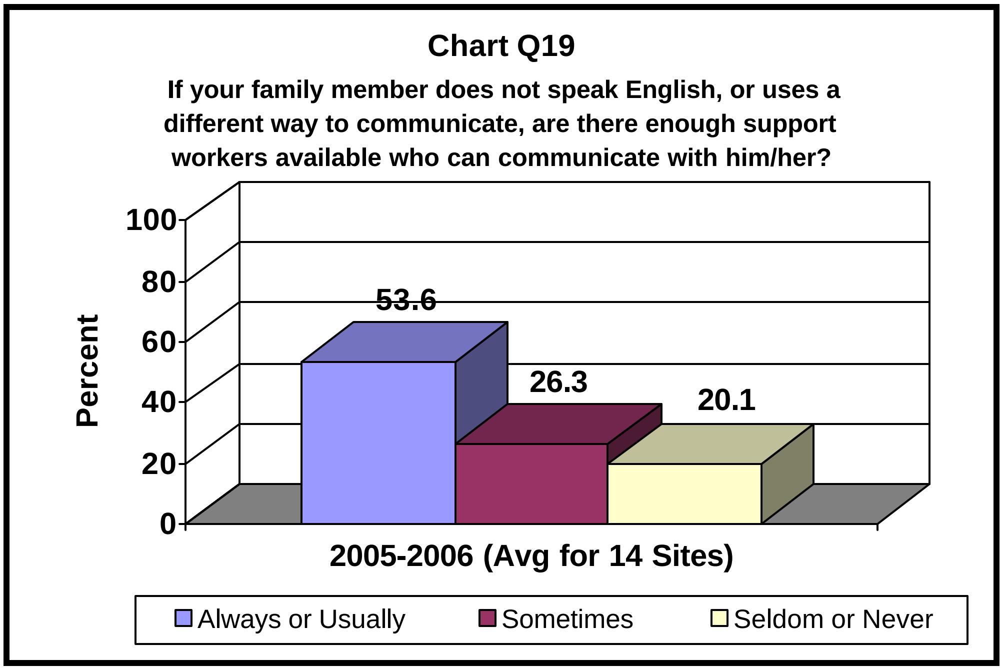


Chart Q19

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

Table Q19

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		57.8	32.8	9.4	64
CA - RCOC	⇧⇧	72.3	16.3	11.4	166
CT	⇩	44.8	31.0	24.1	29
GA		57.7	25.8	16.5	97
KY	⇩	45.0	40.0	15.0	20
ME	⇩	48.6	25.7	25.7	35
NC		54.8	25.8	19.4	31
OK		51.5	23.5	25.0	68
PA	⇩	48.0	31.5	20.5	127
SC	⇧	60.5	18.6	20.9	43
SD	⇧	62.5	25.0	12.5	8
WA		51.0	21.6	27.5	51
WV		50.9	28.3	20.8	53
WY	⇩	44.4	22.2	33.3	9
Total %		**56.6**	**25.1**	**18.4**	**801**
State Average %		**53.6**	**26.3**	**20.1**	**14**

Chart Q20

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

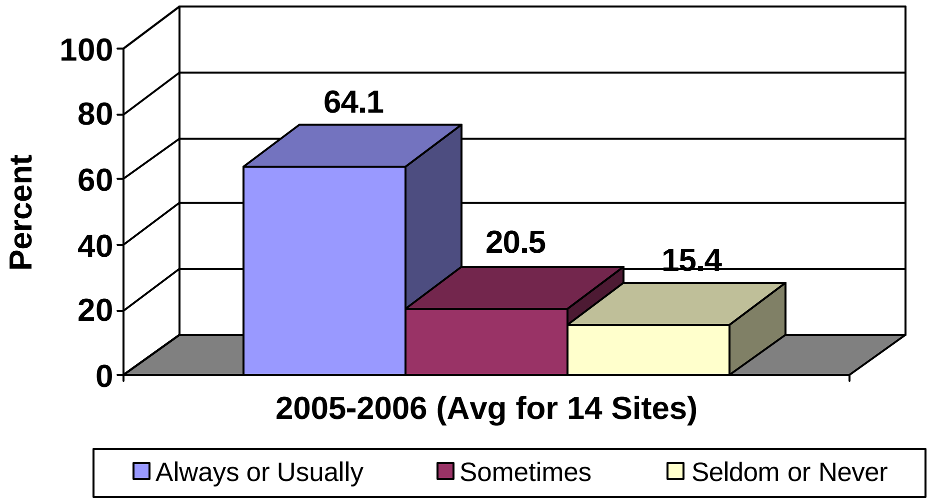


Table Q20

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		64.2	24.2	11.7	120
CA - RCOC	⇩	55.5	17.0	27.5	200
CT	⇩	58.8	22.1	19.1	68
GA		64.1	21.1	14.7	251
KY	⇩	57.4	27.8	14.8	54
ME		65.5	16.1	18.4	87
NC	⇩	55.7	30.9	13.4	97
OK		65.3	24.6	10.2	236
PA		66.1	20.1	13.8	348
SC		64.7	13.8	21.6	116
SD		63.6	21.2	15.2	33
WA		59.4	20.0	20.6	165
WV		64.6	24.2	11.2	161
WY	⇧⇧	92.0	4.0	4.0	25
Total %		**63.0**	**21.1**	**15.9**	**1,961**
State Average %		**64.1**	**20.5**	**15.4**	**14**

Chart Q21

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

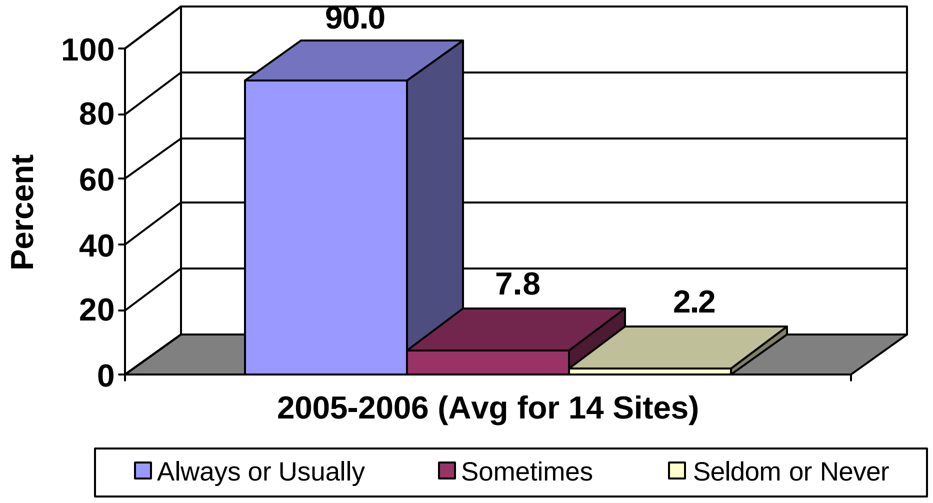


Table Q21

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		92.3	6.4	1.3	298
CA - RCOC		90.3	5.4	4.3	610
CT	⇩	84.5	10.3	5.2	232
GA		87.7	7.5	4.8	585
KY		87.0	8.0	5.0	100
ME		93.8	5.8	0.4	226
NC	⇧	96.0	3.5	0.5	201
OK		87.1	11.2	1.7	420
PA		90.2	7.6	2.2	968
SC		89.9	8.0	2.1	237
SD		93.3	6.7	0.0	89
WA		88.6	9.3	2.1	421
WV		89.6	9.6	0.7	270
WY		90.3	9.7	0.0	62
Total %		**89.7**	**7.7**	**2.6**	**4,719**
State Average %		**90.0**	**7.8**	**2.2**	**14**

Chart Q22

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

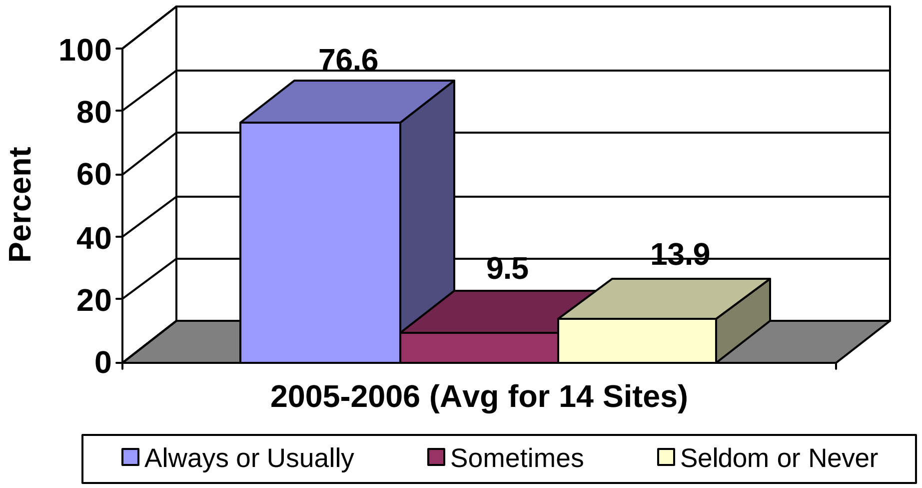


Table Q22

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇩⇩	54.3	11.2	34.6	269
CA - RCOC	⇧	82.9	9.1	8.0	615
CT	⇩	70.6	9.6	19.7	228
GA		73.4	9.2	17.4	575
KY	⇧	82.4	8.8	8.8	102
ME		77.3	9.0	13.7	211
NC	⇧	85.2	9.2	5.6	196
OK	⇩⇩	66.4	10.3	23.3	387
PA		79.8	8.6	11.7	934
SC		77.3	8.3	14.4	229
SD	⇧⇧	94.5	4.4	1.1	91
WA		77.7	14.3	8.0	413
WV		77.6	10.4	12.0	259
WY		73.3	10.0	16.7	60
Total %		**76.3**	**9.7**	**14.1**	**4,569**
State Average %		**76.6**	**9.5**	**13.9**	**14**

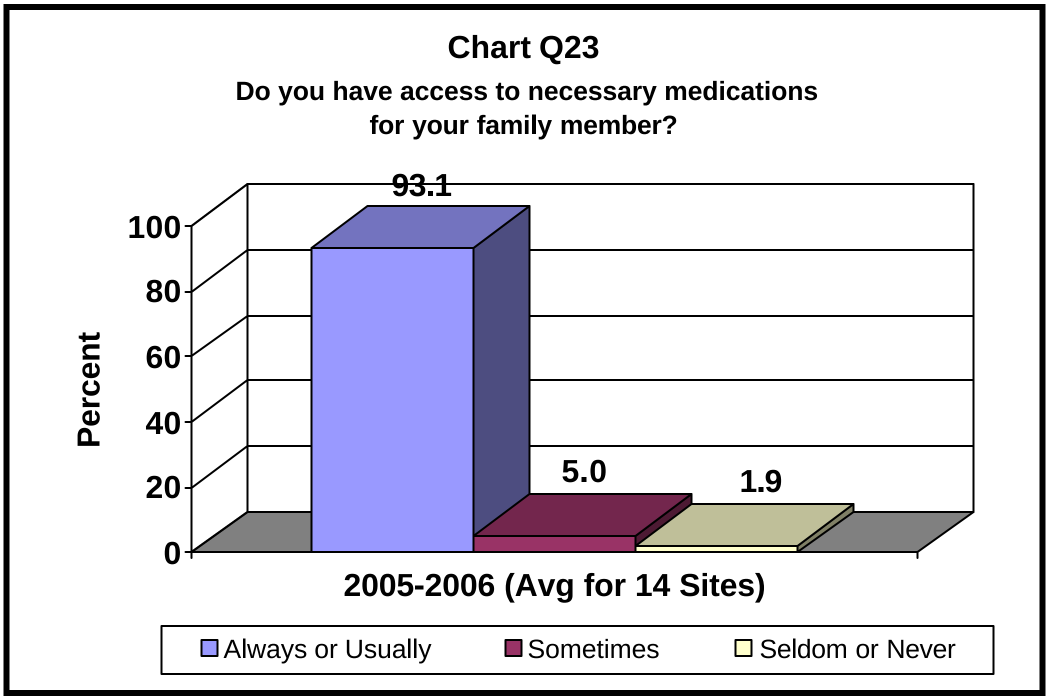


Chart Q23

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

Table Q23

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		93.2	5.1	1.7	292
CA - RCOC		89.3	7.0	3.7	615
CT		93.2	3.7	3.2	219
GA		92.1	4.7	3.2	595
KY	⇩	86.4	9.7	3.9	103
ME		96.7	2.3	0.9	214
NC		97.5	2.0	0.5	204
OK		89.8	8.8	1.4	420
PA		92.9	4.7	2.4	964
SC		92.1	6.3	1.7	239
SD		96.5	3.5	0.0	85
WA		94.0	5.7	0.2	418
WV		95.2	3.7	1.1	271
WY		93.8	3.1	3.1	64
Total %		**92.6**	**5.3**	**2.1**	**4,703**
State Average %		**93.1**	**5.0**	**1.9**	**14**

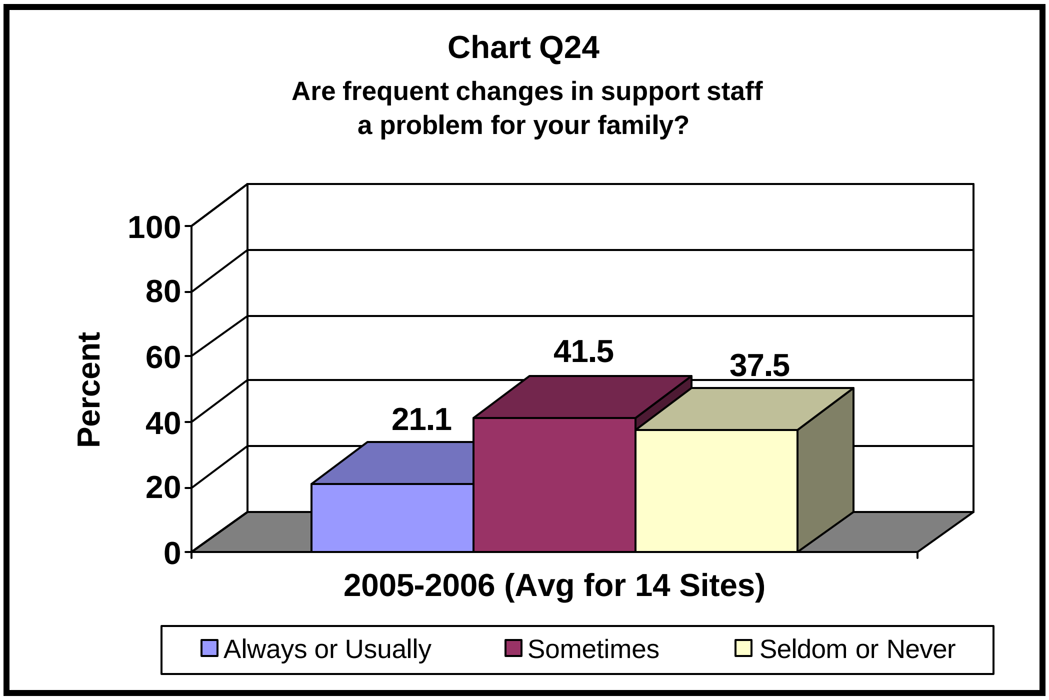


Chart Q24

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

Table Q24

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇩	28.6	39.0	32.4	259
CA - RCOC		19.6	36.8	43.6	475
CT		20.9	43.5	35.6	177
GA		22.4	33.9	43.6	495
KY		23.9	51.1	25.0	92
ME		16.8	37.1	46.1	167
NC		19.5	48.8	31.7	164
OK		20.1	38.2	41.6	353
PA		17.9	39.4	42.7	803
SC		23.4	35.4	41.1	192
SD	⇧	14.5	39.5	46.1	76
WA		18.7	40.1	41.3	327
WV	⇩⇩	32.7	41.9	25.4	248
WY	⇧	15.8	56.1	28.1	57
Total %		**21.1**	**39.3**	**39.6**	**3,885**
State Average %		**21.1**	**41.5**	**37.5**	**14**

Chart Q25

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

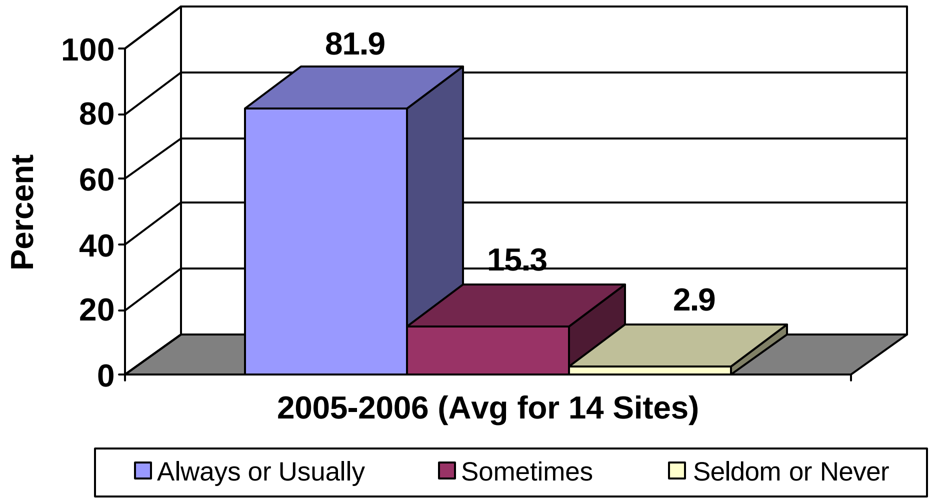


Table Q25

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		82.6	14.9	2.5	242
CA - RCOC		84.4	13.5	2.1	533
CT		82.7	14.1	3.2	220
GA		82.7	13.5	3.8	549
KY	⇩	75.0	19.0	6.0	84
ME		85.6	11.9	2.5	202
NC		83.2	14.3	2.5	161
OK		83.2	14.5	2.4	297
PA		83.6	14.3	2.1	817
SC	⇩⇩	71.6	23.7	4.7	190
SD		78.8	18.8	2.4	85
WA	⇧	89.0	10.2	0.8	264
WV		78.8	17.6	3.6	222
WY		85.0	13.3	1.7	60
Total %		**82.8**	**14.5**	**2.7**	**3,926**
State Average %		**81.9**	**15.3**	**2.9**	**14**

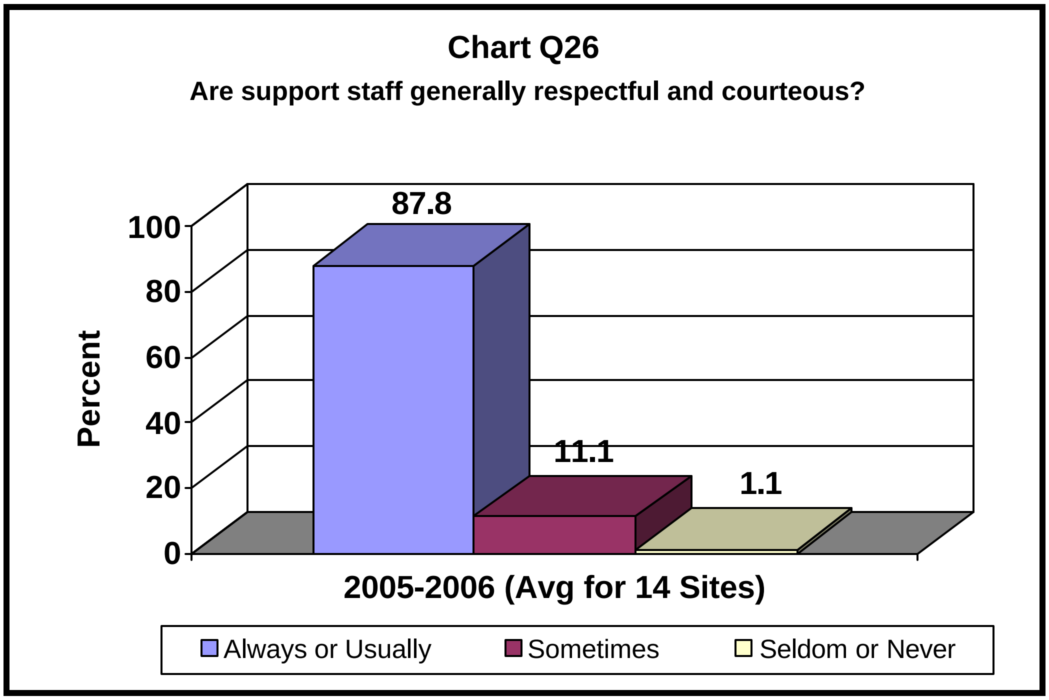


Chart Q26

Are support staff generally respectful and courteous?

Table Q26

Are support staff generally respectful and courteous?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		87.5	11.5	1.0	295
CA - RCOC	⇧	92.8	6.4	0.8	629
CT		90.1	8.0	1.9	213
GA		87.3	11.2	1.5	605
KY	⇩	80.2	17.8	2.0	101
ME		89.4	9.3	1.4	216
NC		88.7	11.3	0.0	195
OK		88.8	11.0	0.3	400
PA		90.4	8.2	1.5	955
SC		84.7	12.8	2.6	235
SD		84.4	14.4	1.1	90
WA		91.3	7.2	1.4	346
WV		86.6	13.4	0.0	276
WY		86.7	13.3	0.0	60
Total %		**89.0**	**9.8**	**1.1**	**4,616**
State Average %		**87.8**	**11.1**	**1.1**	**14**

Choices and Control

- Across the states, on average, 63% of respondents chose the agencies or providers who work with their families. In Kentucky, Wyoming and Oklahoma, this percentage was considerably higher, with 80% or more of families choosing their service providers.

- While 63% of respondents typically chose their family's provider agency, only 42% typically chose the support workers who worked directly with their family. Here again, the results were considerably higher in Oklahoma.

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

- Among all respondents, 36% had control or input over the hiring and management of their support staff, and 15% indicated they had this control sometimes. Forty-eight percent, however, did not have any input or control over the hiring or management of their family's support staff.

- While only 51% of respondents had at least some control over the hiring or management of their support workers, 82% wanted this type of control at least sometimes.

- About one-fifth (22%) of respondents or their family members knew how much money was spent by the MR/DD agency on behalf of their family member. Two-thirds (69%), however, had little or no idea. (Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses.)

- Overall, approximately half of the families surveyed (55%) had at least some decision-making authority over how the money available to their family member with disabilities by the MR/DD agency was spent. Forty-one percent (45%), however, did not.

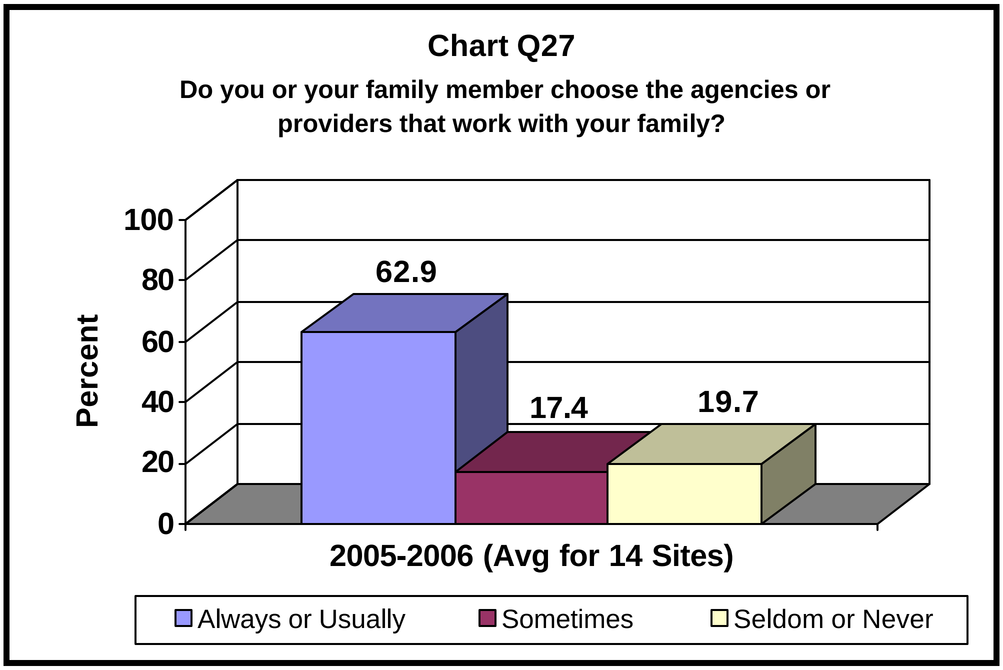


Chart Q27

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

Table Q27

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		63.1	18.8	18.1	271
CA - RCOC	⇩	56.2	18.5	25.3	514
CT	⇩⇩	50.7	19.2	30.0	203
GA	⇩⇩	49.1	19.1	31.8	491
KY	⇧⇧	83.7	7.6	8.7	92
ME		62.2	18.1	19.7	188
NC	⇧	72.6	16.6	10.9	175
OK	⇧⇧	80.6	12.3	7.1	397
PA	⇩⇩	51.0	23.3	25.7	836
SC	⇩⇩	50.5	20.1	29.4	194
SD	⇩⇩	50.0	23.7	26.3	76
WA		58.6	20.1	21.3	338
WV	⇧	69.4	15.3	15.3	255
WY	⇧⇧	82.8	10.9	6.3	64
Total %		**59.5**	**18.7**	**21.9**	**4,094**
State Average %		**62.9**	**17.4**	**19.7**	**14**

Chart Q28

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

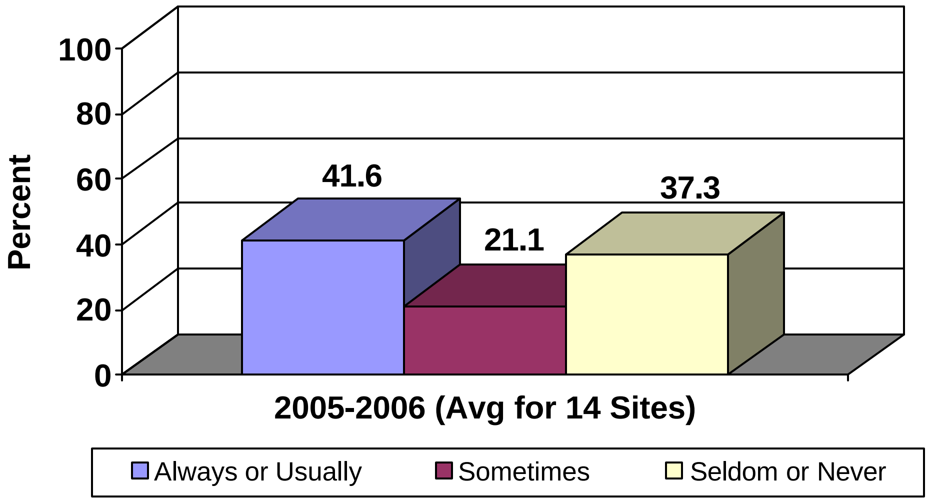


Table Q28

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		43.8	19.0	37.2	258
CA - RCOC		37.0	20.4	42.7	457
CT	⇩	32.2	20.2	47.5	183
GA	⇩⇩	27.0	16.0	57.0	493
KY		44.7	28.7	26.6	94
ME	⇩	32.2	26.8	41.0	183
NC	⇧⇧	51.8	27.4	20.8	168
OK	⇧⇧	69.5	16.1	14.5	380
PA	⇩	32.2	21.3	46.5	798
SC		40.8	18.4	40.8	179
SD	⇩⇩	25.3	18.7	56.0	75
WA		43.9	20.7	35.4	285
WV	⇧	46.7	20.7	32.5	246
WY	⇧⇧	55.6	20.6	23.8	63
Total %		**40.1**	**20.2**	**39.6**	**3,862**
State Average %		**41.6**	**21.1**	**37.3**	**14**

Chart Q29

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

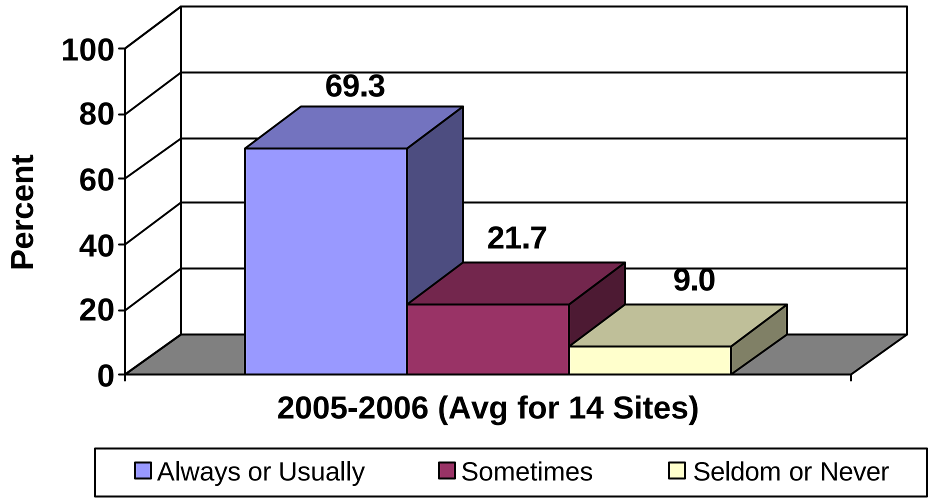


Table Q29

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		70.0	24.0	6.0	200
CA - RCOC	⇩	61.8	23.7	14.5	435
CT		68.1	20.4	11.5	191
GA		65.4	23.5	11.1	486
KY		69.7	21.2	9.1	66
ME	⇧	79.2	14.6	6.2	178
NC		68.0	22.4	9.5	147
OK		67.0	20.0	13.0	230
PA		72.9	18.5	8.6	709
SC		64.8	23.3	11.9	159
SD		70.6	23.5	5.9	85
WA		67.5	22.6	9.9	243
WV		71.1	21.4	7.5	201
WY		73.6	24.5	1.9	53
Total %		**68.7**	**21.3**	**10.0**	**3,383**
State Average %		**69.3**	**21.7**	**9.0**	**14**

Chart Q30

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

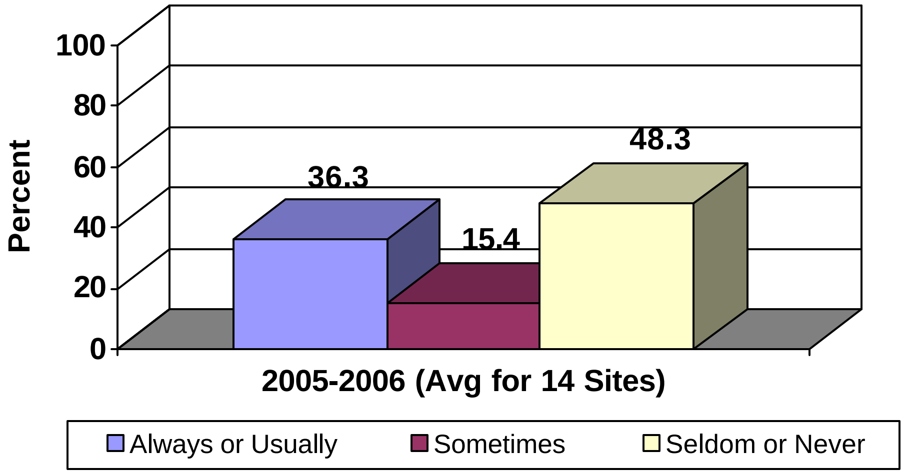


Table Q30

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		37.4	15.2	47.4	211
CA - RCOC		40.0	17.0	43.0	370
CT	⇩	26.7	8.9	64.4	146
GA	⇩⇩	15.6	10.6	73.8	405
KY	⇩	31.2	23.4	45.5	77
ME		31.6	14.2	54.2	155
NC	⇧	46.2	22.4	31.5	143
OK	⇧⇧	69.8	14.1	16.2	334
PA	⇩	30.2	14.1	55.8	633
SC		36.3	15.1	48.6	146
SD	⇩⇩	11.3	14.5	74.2	62
WA	⇧⇧	53.5	14.3	32.2	245
WV	⇧	44.0	18.2	37.8	209
WY		34.0	14.0	52.0	50
Total %		**37.4**	**14.8**	**47.8**	**3,186**
State Average %		**36.3**	**15.4**	**48.3**	**14**

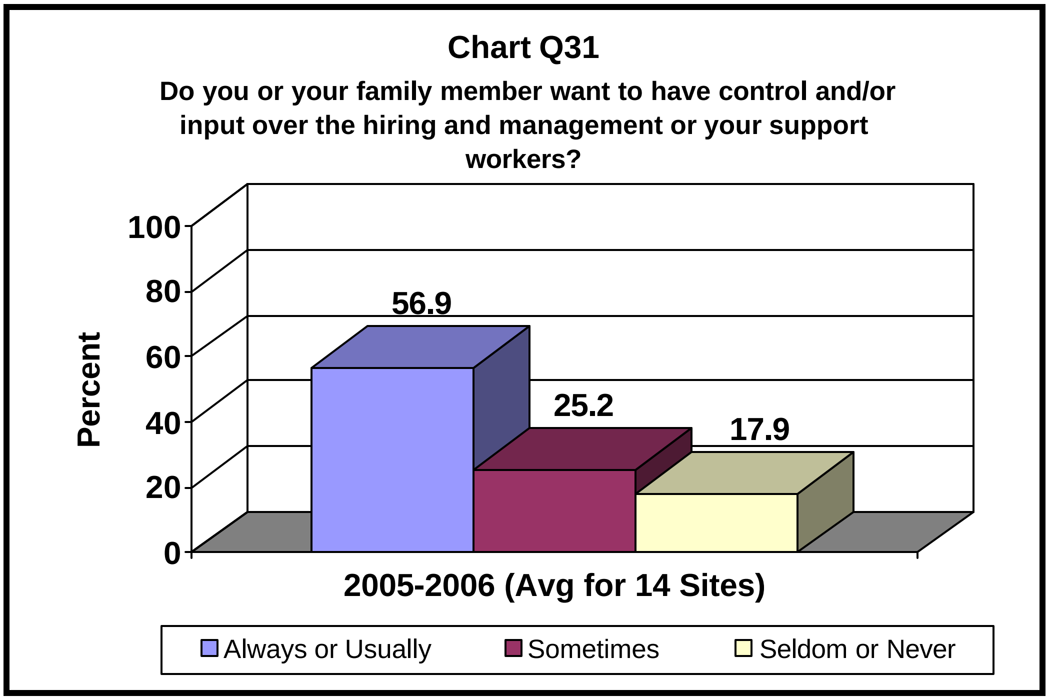


Chart Q31

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

Table Q31

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇧	62.9	24.3	12.9	202
CA - RCOC		54.4	22.5	23.1	351
CT		52.8	28.2	19.0	142
GA	⇩⇩	37.2	25.9	36.9	401
KY		58.4	26.0	15.6	77
ME		55.5	24.0	20.5	146
NC	⇧⇧	69.1	22.8	8.1	149
OK	⇧⇧	78.4	15.7	5.9	338
PA	⇩	47.6	27.0	25.4	618
SC		56.2	26.0	17.8	146
SD	⇩⇩	40.4	29.8	29.8	57
WA	⇧⇧	68.7	21.2	10.1	278
WV	⇧⇧	67.6	25.1	7.3	219
WY	⇩⇩	46.9	34.7	18.4	49
Total %		**56.6**	**24.2**	**19.2**	**3,173**
State Average %		**56.9**	**25.2**	**17.9**	**14**

Chart Q32

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

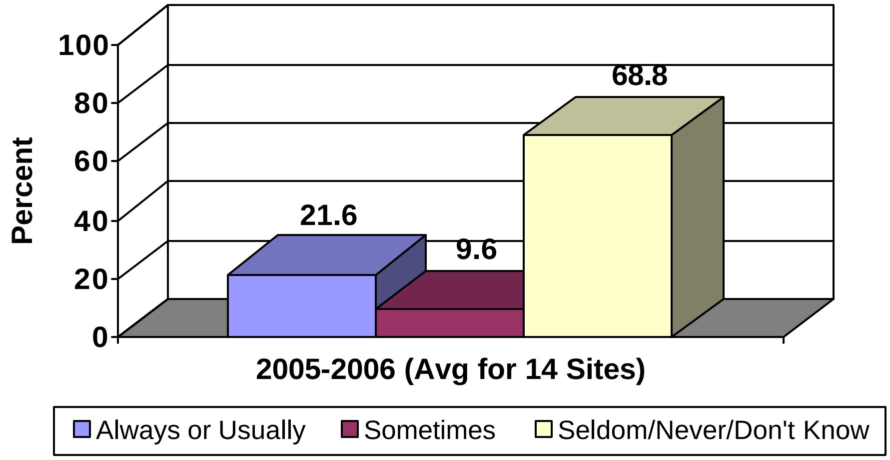


Table Q32

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

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ	⇩	14.3	12.2	73.4	286
CA - RCOC	⇩⇩	10.5	5.4	84.2	631
CT		19.9	10.4	69.7	231
GA	⇩⇩	7.5	4.5	88.0	573
KY	⇩	15.5	15.5	69.1	97
ME	⇩	13.8	9.5	76.7	210
NC		21.6	10.3	68.0	194
OK	⇧⇧	39.8	18.3	41.9	399
PA	⇧⇧	33.5	12.4	54.1	939
SC	⇩	13.4	2.8	83.9	217
SD	⇩⇩	6.0	4.8	89.2	83
WA		21.7	9.1	69.2	406
WV	⇩	16.2	10.2	73.7	266
WY	⇧⇧	68.3	9.5	22.2	63
Total %		**21.0**	**9.6**	**69.4**	**4,595**
State Average %		**21.6**	**9.6**	**68.8**	**14**

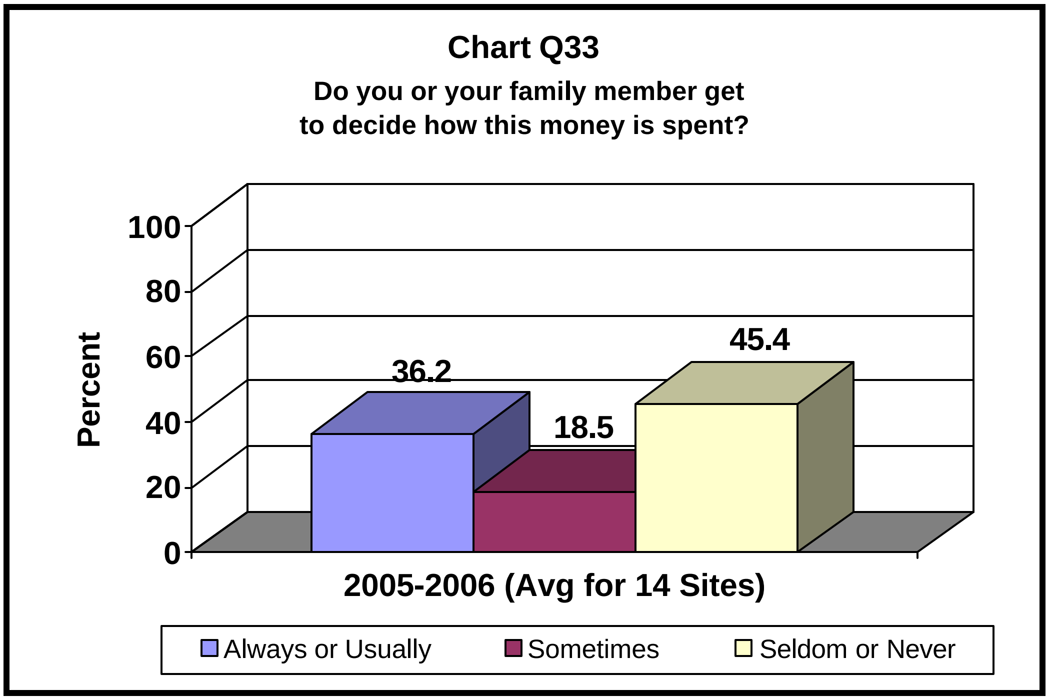


Chart Q33

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

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇩	27.7	15.2	57.1	184
CA - RCOC		33.1	17.2	49.7	314
CT		39.2	21.6	39.2	153
GA	⇩	27.1	9.2	63.8	436
KY	⇩⇩	23.6	26.4	50.0	72
ME		33.8	17.9	48.3	145
NC		38.2	24.3	37.5	144
OK	⇧⇧	57.4	22.0	20.7	305
PA	⇧⇧	46.5	23.9	29.6	707
SC		32.8	15.3	51.8	137
SD	⇩⇩	7.1	7.1	85.7	56
WA	⇧	41.3	18.9	39.8	264
WV	⇩	28.7	21.3	50.0	188
WY	⇧⇧	70.0	18.0	12.0	50
Total %		**38.2**	**18.9**	**42.9**	**3,155**
State Average %		**36.2**	**18.5**	**45.4**	**14**

Community Connections

- On average, one-third of respondents (30%) felt that planning or support staff were regularly available to help them use typical community supports (e.g., from a local health club, church or recreation activities) if desired. Another 29% said that staff were sometimes helpful, but 41% stated that planning and support staff were seldom or never helpful in connecting their family members to typical community supports or resources.

- Overall, there was a split between respondents who indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (54% say always, usually or sometimes, 46% say seldom or never).

- Only 49% of families felt their family member always or usually had access to community activities. 17% stated their family member seldom or never had access to the community.

- While 49% had regular access to community activities, only 32% of family members regularly participated in them. Twenty-eight percent of respondents said that their family member seldom or never participated in community activities or events.

Chart Q34

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

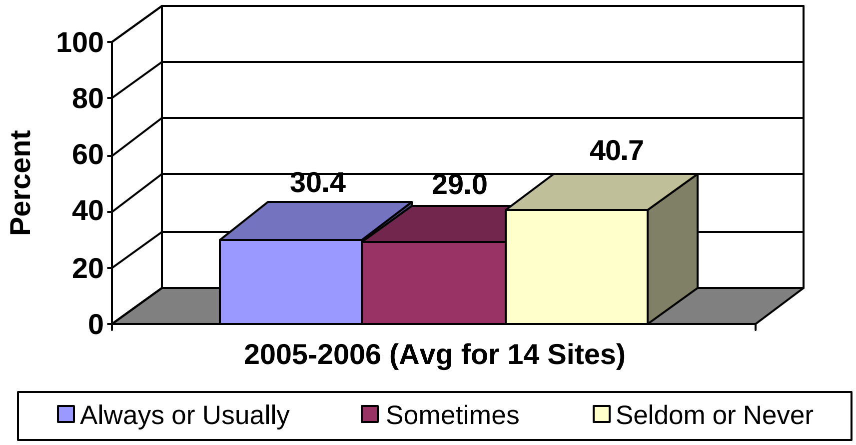


Table Q34

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	⇩	22.3	26.6	51.1	188
CA - RCOC	⇧	36.3	28.6	35.1	353
CT	⇩	25.3	22.1	52.6	154
GA	⇩	24.4	21.9	53.7	397
KY		27.8	26.4	45.8	72
ME	⇧	36.6	28.3	35.2	145
NC	⇩	25.0	38.2	36.8	136
OK	⇧	40.1	27.5	32.4	262
PA		32.6	27.4	40.0	598
SC		34.3	24.5	41.3	143
SD	⇧	38.7	33.9	27.4	62
WA	⇩	25.1	22.4	52.5	255
WV		34.4	27.6	38.0	192
WY	⇩	22.7	50.0	27.3	44
Total %		**30.9**	**26.9**	**42.2**	**3,001**
State Average %		**30.4**	**29.0**	**40.7**	**14**

Chart Q35

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

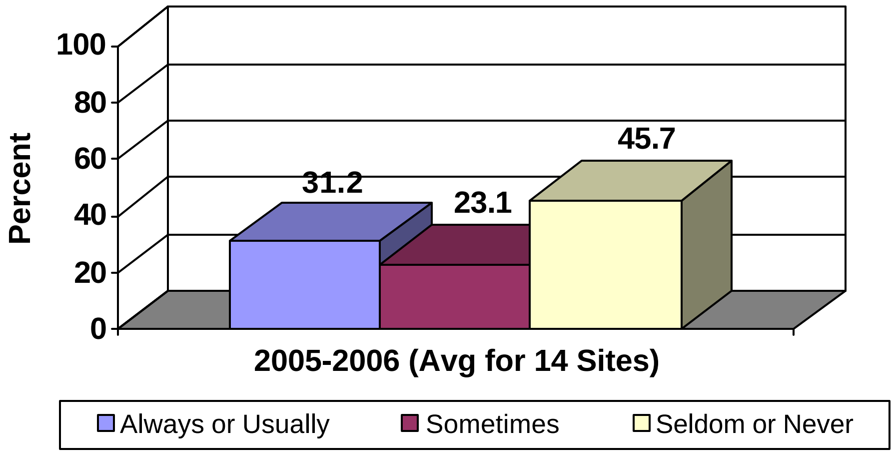


Table Q35

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		30.2	18.7	51.1	182
CA - RCOC	⇧	40.3	24.8	34.9	318
CT	⇩	21.7	15.9	62.3	138
GA	⇩⇩	17.8	16.8	65.4	381
KY		26.3	17.1	56.6	76
ME		30.4	25.2	44.4	135
NC		26.5	35.3	38.2	136
OK	⇧⇧	42.1	24.0	33.9	271
PA		34.9	21.5	43.5	604
SC		33.3	25.5	41.2	153
SD	⇩	24.5	28.3	47.2	53
WA		34.1	18.8	47.1	255
WV	⇧⇧	44.4	26.9	28.7	223
WY		30.0	25.0	45.0	40
Total %		**32.5**	**22.3**	**45.2**	**2,965**
State Average %		**31.2**	**23.1**	**45.7**	**14**

Chart Q36

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

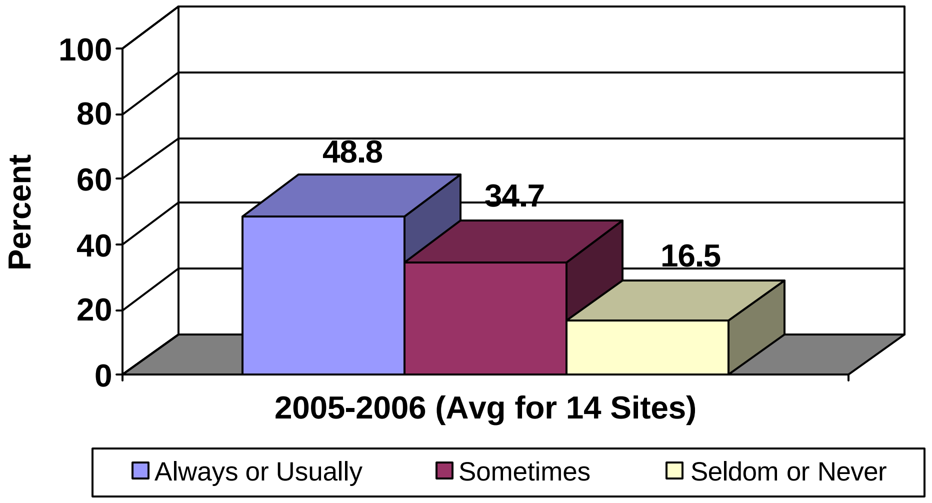


Table Q36

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		46.2	37.6	16.2	266
CA - RCOC		48.1	33.9	18.0	528
CT	⇩⇩	37.0	35.2	27.8	216
GA		45.5	36.2	18.2	538
KY		50.5	31.2	18.3	93
ME	⇧	55.8	29.8	14.4	208
NC	⇩	40.7	42.4	16.9	177
OK	⇧	54.4	33.5	12.1	379
PA		48.1	35.4	16.5	896
SC	⇩⇩	38.2	40.8	20.9	191
SD		50.0	37.5	12.5	88
WA		48.6	31.8	19.7	381
WV	⇧⇧	59.9	27.9	12.3	269
WY	⇧⇧	60.0	32.3	7.7	65
Total %		**48.3**	**34.6**	**17.0**	**4,295**
State Average %		**48.8**	**34.7**	**16.5**	**14**

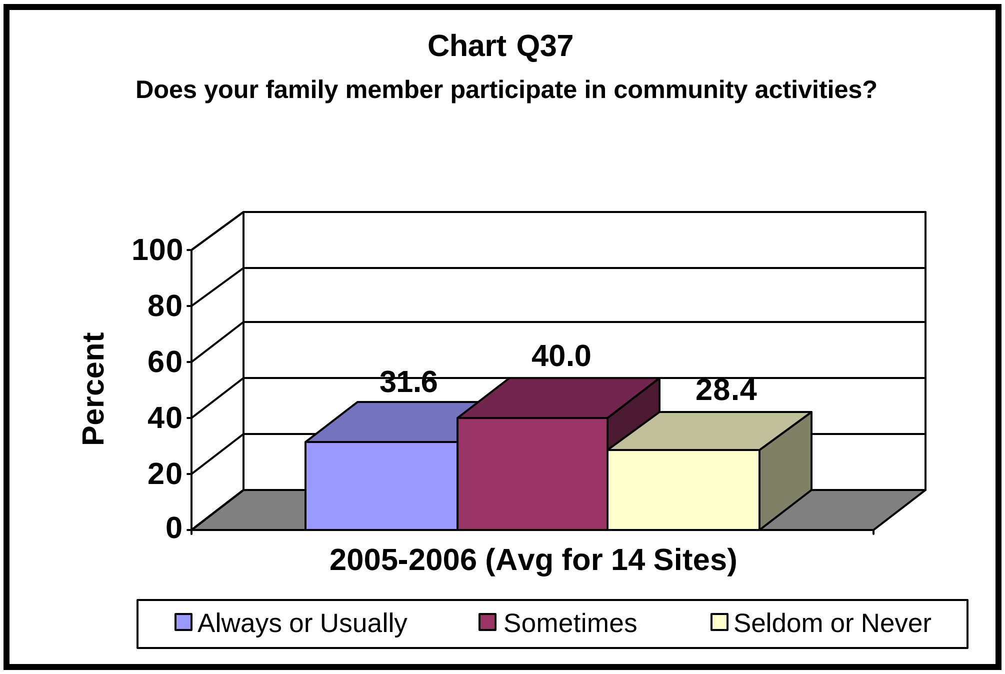


Chart Q37

Does your family member participate in community activities?

Table Q37

Does your family member participate in community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		29.6	42.5	27.9	287
CA - RCOC	⇩⇩	21.4	39.2	39.4	574
CT	⇩⇩	20.5	39.5	40.0	215
GA		31.1	42.1	26.7	572
KY	⇧	39.6	38.5	22.0	91
ME	⇧	37.3	34.4	28.3	212
NC	⇩	24.0	45.9	30.1	183
OK		35.2	37.9	26.9	383
PA		30.7	35.7	33.6	928
SC	⇩	24.6	38.6	36.7	207
SD		32.2	44.4	23.3	90
WA		28.6	34.1	37.3	402
WV	⇧⇧	42.6	39.6	17.8	270
WY	⇧⇧	45.3	46.9	7.8	64
Total %		**30.1**	**38.7**	**31.2**	**4,478**
State Average %		**31.6**	**40.0**	**28.4**	**14**

Outcomes and Satisfaction with Services and Supports

- Overall, two-thirds of families (64%) were always or usually satisfied with the services and supports they received. 29% were somewhat satisfied, and 7% were seldom or never satisfied.

- On average, only 47% of respondents knew about their agency's grievance process, while 41% had little or no familiarity with the process for lodging a complaint. (Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses.)

- The majority of respondents (55%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 45%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.

- Seventy percent (70%) of families felt that services and supports have made a positive difference in their lives. Only 5% stated that they seldom felt this way.

- Three-fourths (77%) of respondents indicated that services have made a difference in helping them keep their family members at home.

- Most families (80%) indicated that their family member would still be living at home, even without services. Thirteen percent of respondents, however, stated their family member would not be at home without needed services.

- Eighty-four percent (84%) of respondents felt that their family member was usually happy.

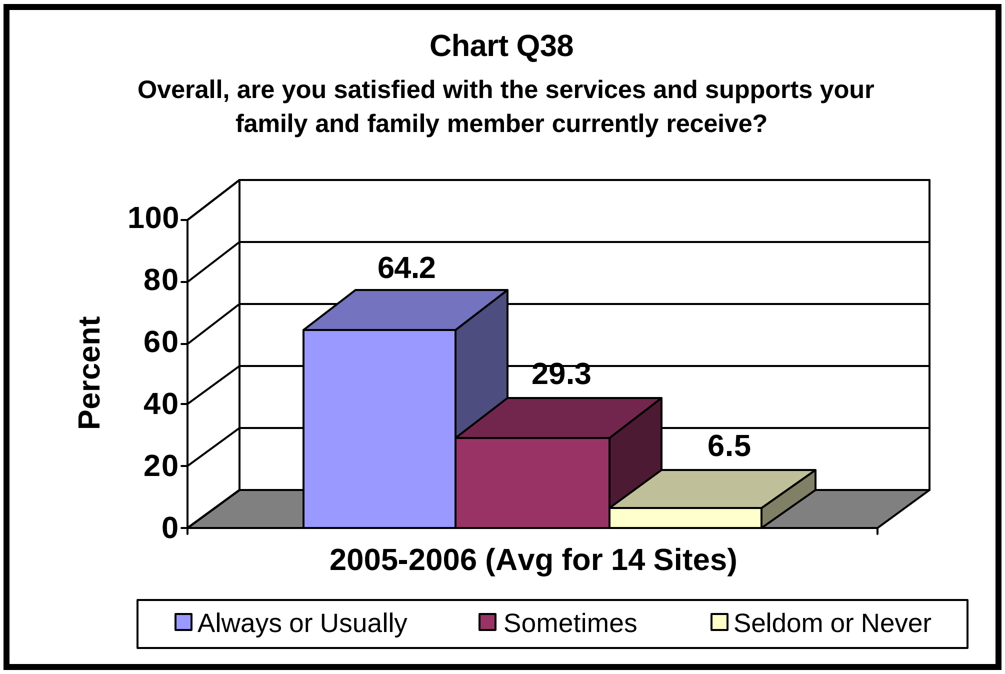


Chart Q38

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

Table Q38

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		64.7	31.0	4.3	303
CA - RCOC	⇧⇧	78.2	19.0	2.8	633
CT	⇩⇩	50.4	38.1	11.5	226
GA	⇩	55.9	34.9	9.2	610
KY		64.1	28.2	7.8	103
ME		69.1	24.7	6.3	223
NC		61.3	31.2	7.5	199
OK		68.4	26.2	5.4	427
PA		67.5	26.0	6.6	974
SC		61.1	29.3	9.6	239
SD	⇧	69.3	27.3	3.4	88
WA	⇩	57.6	35.2	7.1	420
WV		67.1	29.6	3.2	280
WY		64.6	29.2	6.2	65
Total %		**65.1**	**28.6**	**6.4**	**4,790**
State Average %		**64.2**	**29.3**	**6.5**	**14**

Chart Q39

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

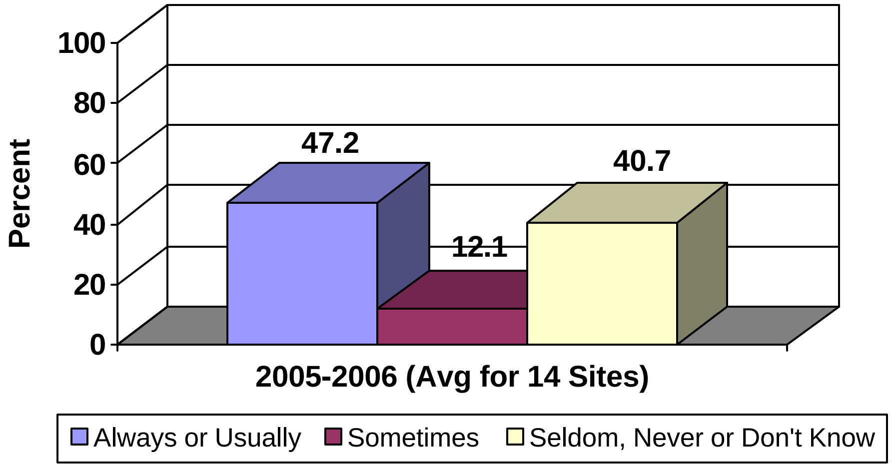


Table Q39

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

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ		43.8	12.0	44.2	276
CA - RCOC		47.1	11.2	41.7	597
CT	⇩⇩	30.6	13.6	55.8	206
GA	⇩⇩	35.6	7.9	56.5	559
KY		49.5	22.1	28.4	95
ME		50.2	10.3	39.4	203
NC		51.4	11.7	36.9	179
OK	⇧⇧	62.9	11.5	25.6	410
PA		45.6	13.0	41.4	910
SC	⇩	39.6	10.8	49.5	222
SD	⇧⇧	61.0	9.8	29.3	82
WA	⇩	40.2	13.4	46.5	396
WV		50.2	10.9	38.9	265
WY	⇧	52.5	11.5	36.1	61
Total %		**45.7**	**11.7**	**42.6**	**4,461**
State Average %		**47.2**	**12.1**	**40.7**	**14**

Chart Q40

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

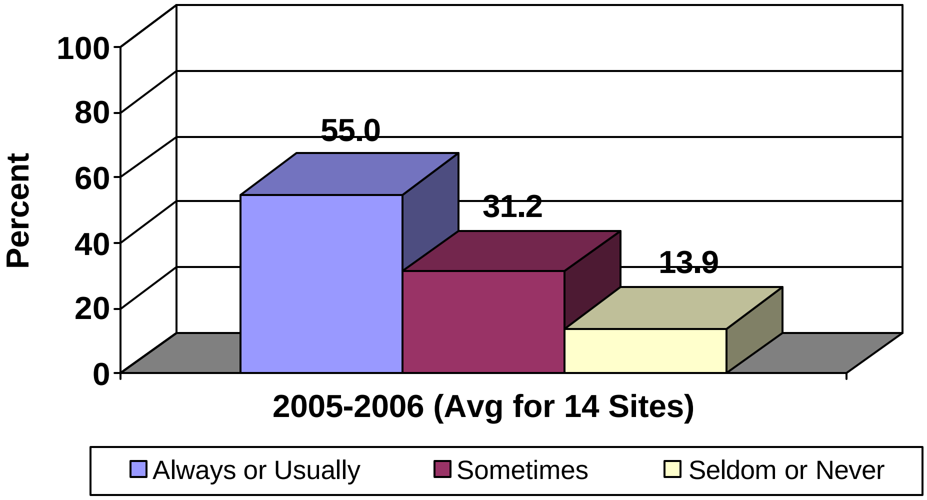


Table Q40

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		54.8	31.7	13.5	126
CA - RCOC	⇧⇧	71.2	21.2	7.7	274
CT	⇩⇩	39.8	31.8	28.4	88
GA	⇩	47.7	35.5	16.8	321
KY		57.6	32.2	10.2	59
ME	⇧	63.3	23.9	12.8	109
NC	⇩	47.4	39.5	13.2	114
OK	⇧⇧	69.0	22.3	8.7	229
PA	⇧	60.0	26.7	13.3	435
SC		55.7	31.3	13.0	131
SD		58.3	31.3	10.4	48
WA		55.7	27.8	16.5	158
WV		59.2	26.5	14.3	147
WY	⇩⇩	30.3	54.5	15.2	33
Total %		**57.8**	**28.8**	**13.4**	**2,272**
State Average %		**55.0**	**31.2**	**13.9**	**14**

Chart Q41

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

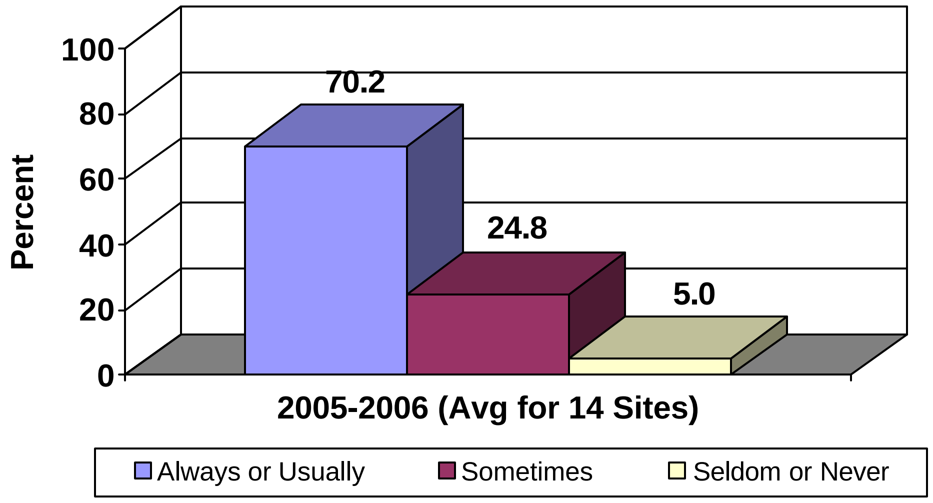


Table Q41

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		73.1	23.8	3.1	290
CA - RCOC		73.2	21.5	5.3	608
CT	⇩⇩	58.4	30.4	11.2	214
GA	⇩	64.8	28.4	6.8	588
KY		72.1	25.0	2.9	104
ME		68.2	27.0	4.7	211
NC	⇧	76.8	19.5	3.7	190
OK	⇧	78.3	19.6	2.1	419
PA		69.4	24.7	6.0	953
SC	⇩	64.7	27.6	7.8	232
SD		71.4	25.0	3.6	84
WA		67.1	27.1	5.9	410
WV	⇧	75.5	22.3	2.2	274
WY		70.3	25.0	4.7	64
Total %		**70.1**	**24.6**	**5.3**	**4,641**
State Average %		**70.2**	**24.8**	**5.0**	**14**

Chart Q42

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

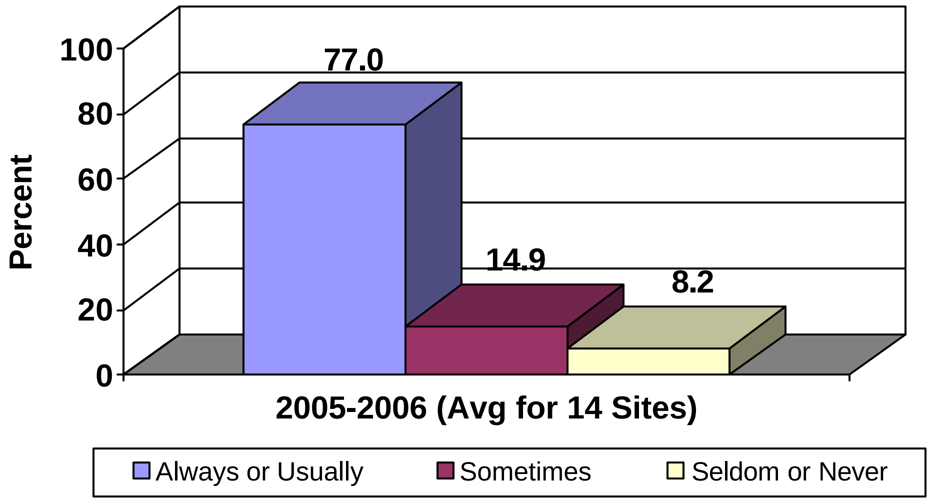


Table Q42

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		79.3	16.0	4.7	275
CA - RCOC		76.4	13.1	10.4	518
CT	⇩⇩	66.7	22.4	10.9	192
GA	⇩	71.7	15.9	12.4	498
KY		80.4	14.4	5.2	97
ME	⇩	69.1	15.7	15.2	191
NC	⇧	82.7	13.9	3.5	173
OK	⇧	83.8	12.0	4.2	401
PA		75.2	13.6	11.3	833
SC		75.2	15.0	9.8	214
SD		78.9	17.1	3.9	76
WA		75.9	15.4	8.6	382
WV	⇧	84.9	9.6	5.6	251
WY		77.6	13.8	8.6	58
Total %		**76.5**	**14.4**	**9.1**	**4,159**
State Average %		**77.0**	**14.9**	**8.2**	**14**

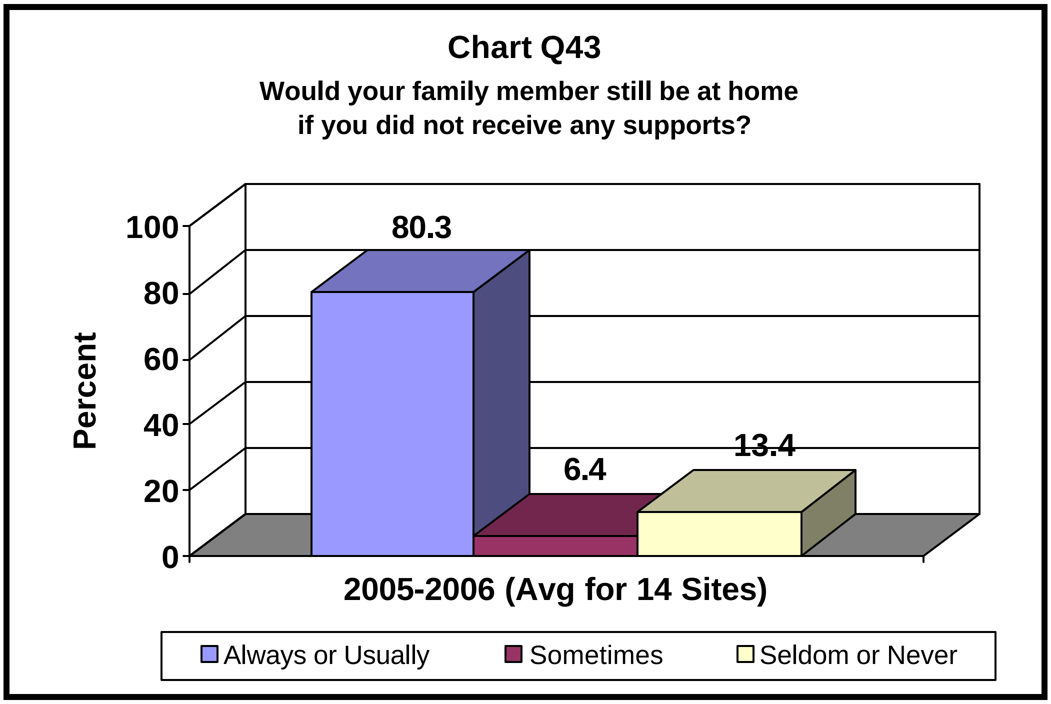


Chart Q43

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

Table Q43

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

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	80.5	5.0	14.5	220
CA - RCOC	84.6	6.3	9.1	441
CT	82.7	3.8	13.5	156
GA	88.1	3.2	8.7	469
KY	65.2	12.1	22.7	66
ME	78.8	6.1	15.2	165
NC	70.0	9.3	20.7	140
OK	80.2	7.2	12.6	318
PA	85.6	4.3	10.2	727
SC	81.7	7.0	11.3	186
SD	87.7	6.8	5.5	73
WA	76.0	4.7	19.3	296
WV	81.9	5.6	12.6	215
WY	81.1	7.5	11.3	53
Total %	**82.3**	**5.5**	**12.3**	**3,525**
State Average %	**80.3**	**6.4**	**13.4**	**14**

Chart Q44

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

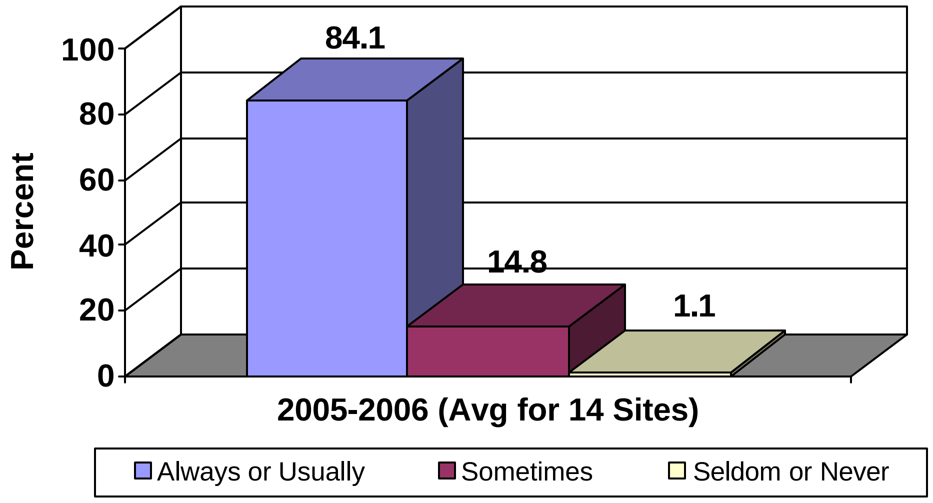


Table Q44

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		87.6	11.8	0.7	306
CA - RCOC		82.5	16.2	1.4	650
CT		79.3	17.8	2.9	242
GA		81.6	16.7	1.8	618
KY		85.6	12.5	1.9	104
ME		86.2	13.8	0.0	218
NC	⇩	77.2	21.3	1.5	202
OK		88.9	10.4	0.7	433
PA		84.2	14.3	1.5	1,013
SC	⇩	77.0	20.9	2.0	244
SD		89.0	11.0	0.0	91
WA		82.8	16.6	0.7	441
WV	⇧	89.6	10.1	0.4	278
WY		86.2	13.8	0.0	65
Total %		**83.8**	**15.0**	**1.2**	**4,905**
State Average %		**84.1**	**14.8**	**1.1**	**14**

Aggregate Results & State Trends

In the previous section, 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/sites, of respondents who answered each question with an “always or usually” response. In nearly all cases, the higher this response, the more satisfied the respondents were with their supports.

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

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

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

Information and Planning

- In Orange County, CA, Maine and Wyoming, responses to information and planning questions were generally above the overall state average. In Connecticut, Georgia and Washington, results were generally below the state average.

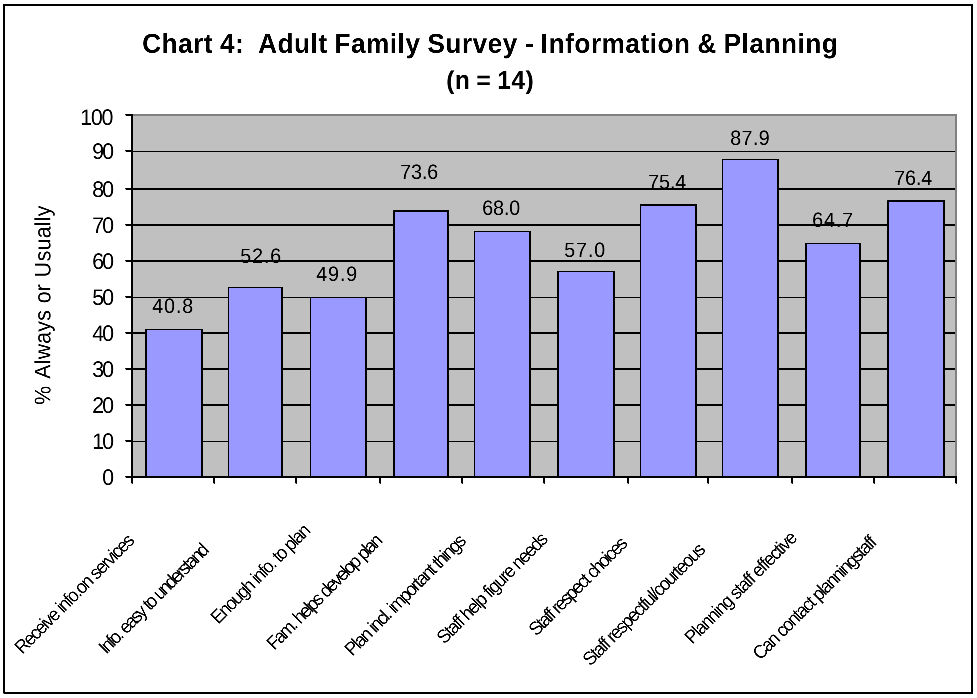


Chart 4: Adult Family Survey - Information & Planning
(n = 14)

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

State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Net Sum
AZ										⇩	-1
CA - RCOC	⇧⇧	⇧⇧	⇧⇧				⇧	⇧	⇧⇧		10
CT	⇩	⇩	⇩⇩	⇩⇩	⇩⇩		⇩			⇩	-10
GA	⇩		⇩	⇩⇩	⇩⇩	⇩⇩	⇩	⇩	⇩⇩	⇩	-13
KY		⇩			⇩		⇩	⇩			-4
ME	⇩		⇧⇧		⇧	⇧	⇧		⇧	⇧	6
NC	⇩⇩	⇩⇩									-4
OK					⇧	⇧	⇧		⇧		4
PA						⇧					1
SC				⇩	⇩						-2
SD		⇧⇧				⇩					1
WA	⇩		⇩⇩			⇩				⇩	-5
WV				⇧		⇧					2
WY	⇧	⇩	⇧	⇧⇧	⇧⇧					⇧	6

Access and Delivery of Services

- In Orange County, CA and South Dakota, responses to access and delivery of services questions were generally above the overall state average. In Connecticut, results were generally below the state average. Please note that Question 15 is considered a “neutral question”, and therefore was not used in the calculation of state trends.

Chart 5: Adult Family Survey - Access to Services (1)
(n = 14)

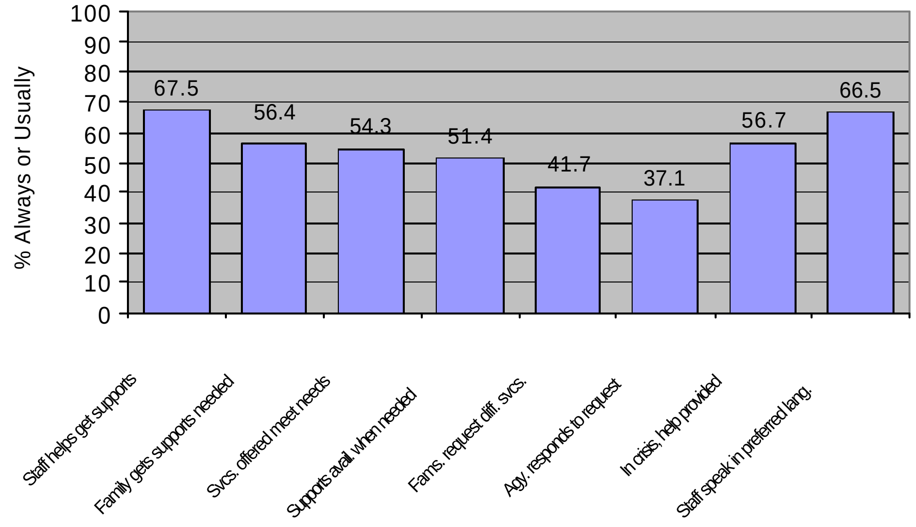


Chart 5: Adult Family Survey - Access to Services (2)
(n = 14)

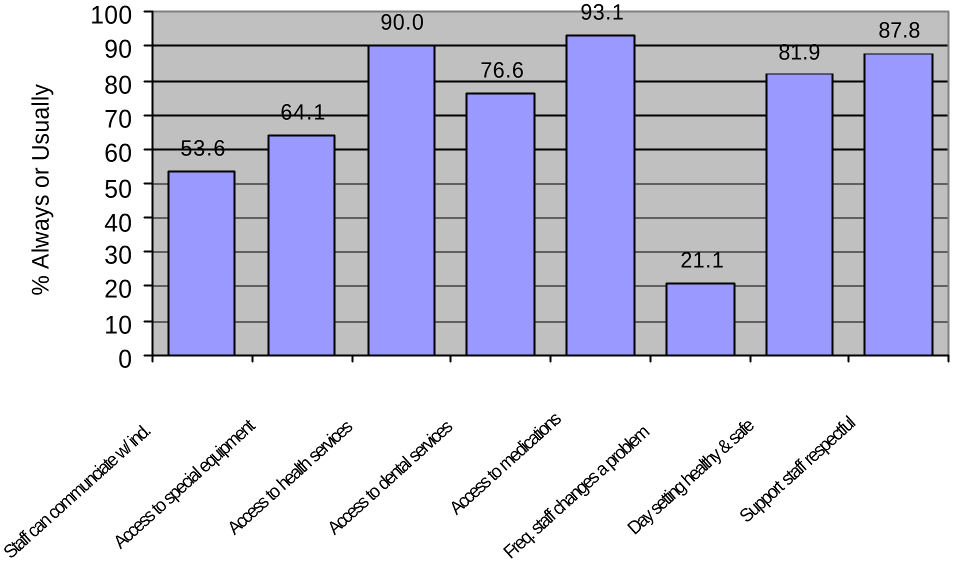


Table 19
Trends in Responses Above & Below State Average
Access to Services & Supports

State	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Net Sum
AZ		⇧				⇧	⇩	⇧⇧				⇩⇩		⇩			0
CA - RCOC		⇧	⇧	⇧⇧		⇧⇧		⇧⇧	⇧⇧	⇩		⇧				⇧	11
CT	⇩	⇩⇩	⇩⇩	⇩⇩			⇩⇩		⇩	⇩	⇩	⇩					-13
GA	⇩	⇩	⇩	⇩		⇩		⇧									-4
KY						⇩		⇧⇧	⇩	⇩		⇧	⇩		⇩	⇩	-3
ME						⇩			⇩								-2
NC										⇩	⇧	⇧					1
OK						⇩						⇩⇩					-3
PA									⇩								-1
SC						⇩	⇩		⇧						⇩⇩		-3
SD	⇧		⇧	⇧		⇧	⇧⇧	⇩⇩	⇧			⇧⇧		⇧			8
WA			⇩	⇩		⇩	⇩	⇧							⇧		-2
WV			⇧					⇧⇧						⇩⇩			1
WY				⇧		⇩	⇧⇧	⇩⇩	⇩	⇧⇧				⇧			2

Choice and Control

- North Carolina, Oklahoma, Washington and Wyoming's responses to choice and control questions were generally above the overall state average. Orange County, CA, Connecticut, Georgia and South Dakota's results were below the state average.

Chart 6: Adult Family Survey - Choice & Control
(n = 14)

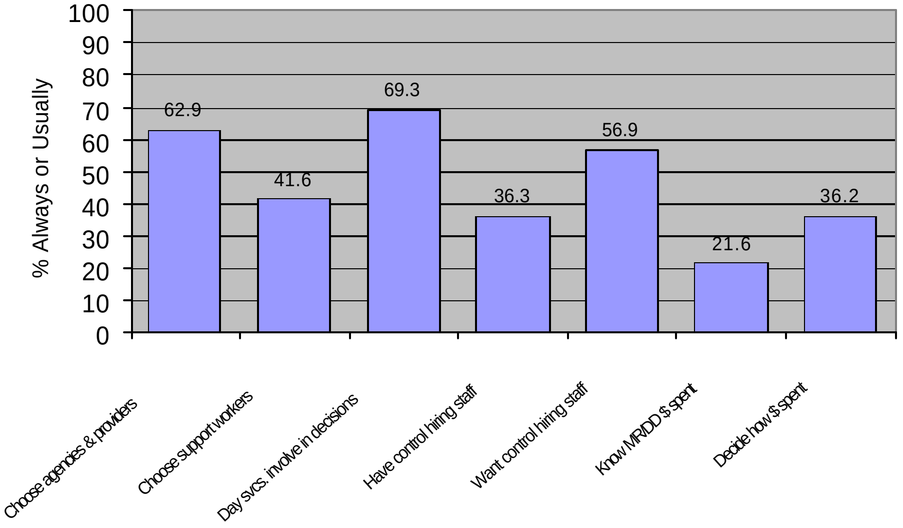


Table 20
Trends in Responses
Above & Below State Average
Choice & Control

State	Q27	Q28	Q29	Q30	Q31	Q32	Q33	Net Sum
AZ					⇧	⇩	⇩	-1
CA - RCOC	⇩		⇩			⇩⇩		-4
CT	⇩⇩	⇩		⇩				-4
GA	⇩⇩	⇩⇩		⇩⇩	⇩⇩	⇩⇩	⇩	-11
KY	⇧⇧			⇩		⇩	⇩⇩	-2
ME		⇩	⇧			⇩		-1
NC	⇧	⇧⇧		⇧	⇧⇧			6
OK	⇧⇧	⇧⇧		⇧⇧	⇧⇧	⇧⇧	⇧⇧	12
PA	⇩⇩	⇩		⇩	⇩	⇧⇧	⇧⇧	-1
SC	⇩⇩					⇩		-3
SD	⇩⇩	⇩⇩		⇩⇩	⇩⇩	⇩⇩	⇩⇩	-12
WA				⇧⇧	⇧⇧		⇧	5
WV	⇧	⇧		⇧	⇧⇧	⇩	⇩	3
WY	⇧⇧	⇧⇧			⇩⇩	⇧⇧	⇧⇧	6

Community Connections

- In Maine, Oklahoma, West Virginia and Wyoming, responses to community connections questions were generally above the overall state average. In Connecticut, Georgia, North Carolina and South Carolina, results were generally below the state average.

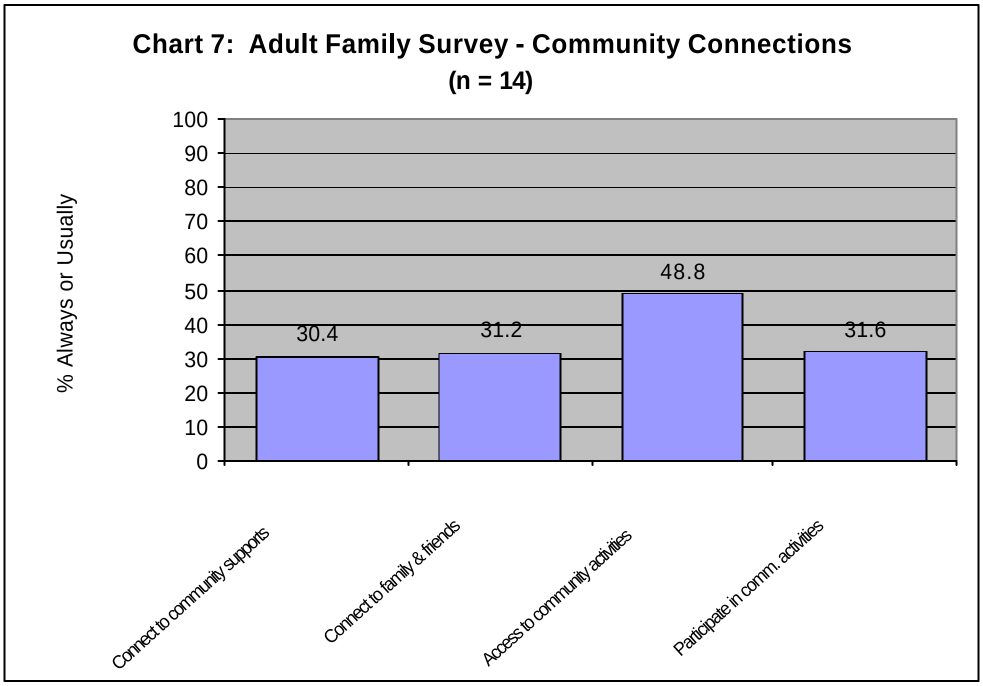


Chart 7: Adult Family Survey - Community Connections
(n = 14)

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

State	Q34	Q35	Q36	Q37	Net Sum
AZ	⇩				-1
CA - RCOC	⇧	⇧		⇩⇩	0
CT	⇩	⇩	⇩⇩	⇩⇩	-6
GA	⇩	⇩⇩			-3
KY				⇧	1
ME	⇧		⇧	⇧	3
NC	⇩		⇩	⇩	-3
OK	⇧	⇧⇧	⇧		4
PA					0
SC			⇩⇩	⇩	-3
SD	⇧	⇩			0
WA	⇩				-1
WV		⇧⇧	⇧⇧	⇧⇧	6
WY	⇩		⇧⇧	⇧⇧	3

Satisfactions with Services and Supports & Outcomes for Families

- In Orange County, CA, Oklahoma, South Dakota and West Virginia, responses were generally above the overall state average. In Connecticut, Georgia and South Carolina, results were generally below the state average. Note that Question 43 is considered a "neutral question", and was not used in the calculation of state trends.

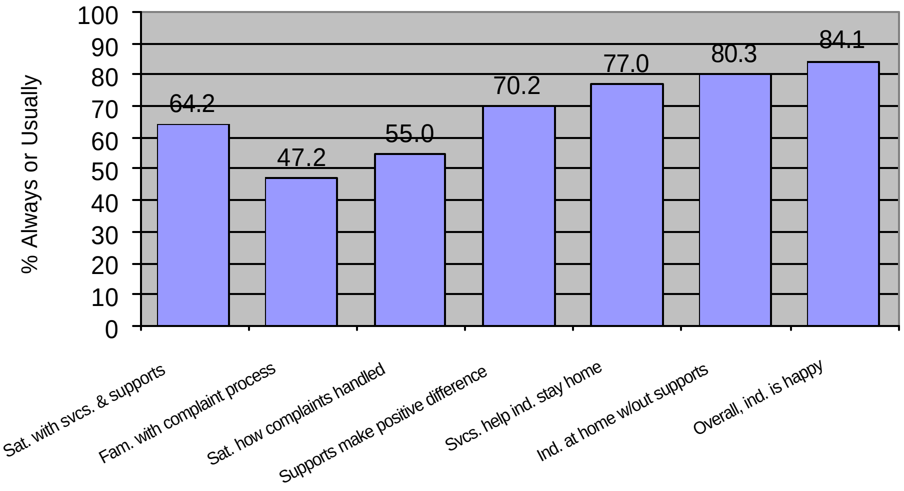


Chart 8: Adult Family Survey - Satisfaction & Outcomes
(n = 14)

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

State	Q38	Q39	Q40	Q41	Q42	Q43	Q44	Net Sum
AZ								0
CA - RCOC	⇧⇧		⇧⇧					4
CT	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩⇩			-10
GA	⇩	⇩⇩	⇩	⇩	⇩			-6
KY								0
ME			⇧		⇩			0
NC			⇩	⇧	⇧		⇩	0
OK		⇧⇧	⇧⇧	⇧	⇧			6
PA			⇧					1
SC		⇩		⇩			⇩	-3
SD	⇧	⇧⇧						3
WA	⇩	⇩						-2
WV				⇧	⇧		⇧	3
WY		⇧	⇩⇩					-1

Overall State Trends

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

Table 23
Overall Trends in Responses
Above & Below State Average

State	Information & Planning	Access & Delivery	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
AZ	-1	0	-1	-1	0	-3
CA - RCOC	10	11	-4	0	4	21
CT	-10	-13	-4	-6	-10	-43
GA	-13	-4	-11	-3	-6	-37
KY	-4	-3	-2	1	0	-8
ME	6	-2	-1	3	0	6
NC	-4	1	6	-3	0	0
OK	4	-3	12	4	6	23
PA	1	-1	-1	0	1	0
SC	-2	-3	-3	-3	-3	-14
SD	1	8	-12	0	3	0
WA	-5	-2	5	-1	-2	-5
WV	2	1	3	6	3	15
WY	6	2	6	3	-1	16

Analysis of Open-Ended Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. QSR 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: SOUTH CAROLINA, WASHINGTON AND WEST VIRGINIA'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

1b. Dissatisfied with Home

My family member does not want sexual activity unless married in his church. However, there are some individuals who have sexual relations with people they don't really know. There should be a strong protection on these people to prevent pregnancy and sexually transmitted diseases.

2. Employment and Day Programs

I would like to know if {Agency} could help me get a job or an activity for {Name}.

2a. Satisfied with Employment

From the time {Name} starting attending the day program, funded by {Agency}, his attitude and lifestyle have improved a lot. Many thanks.

She enjoys her program.

My daughter's job is wonderful, and so is school.

We are very satisfied with {agency} and its staff. The Easter Seals program is a blessing. Thank you.

{Agency} has been a blessing for my son. They referred me to {Agency}, which has been a great employer.

2b. Dissatisfied with Employment

It is sad and unrealistic that a new job search cannot be initiated until the current job is stopped.

The day programs need to develop daily living skill activities to train consumers.

Day programs mix verbal and non-verbal clients which has frightened my verbal son.

3. Health Care

Medical, dental, vision are difficult because my child is uncooperative in normal care for those needs.

3a. Health Care Equipment

Sight problems and needs glasses.

3b. Health Care Insurance

We do not receive outside assistance for any of {Name}'s needs. We pay from our own pockets for insurance and all his medications. We asked for help last year to get medical insurance and benefits. No one claimed that it was their job to help.

I would like to know more information about activities and health insurance/dental help.

However, I am worried because she does not have medical insurance, and she gets sick often, and I don't have to resources to take care of it. Could you please help me? Thank you.

My daughter received respite, and is in need of health and dental insurance.

I would like my son to get assistance in getting MediCal and social security benefits. He was denied the services and six months after we appealed, we still haven't heard anything.

3c. Dental

About six months ago, I had a problem with getting a dental service done for my daughter. I paid for it because she was in desperate need of the service.

I would like to know more information about activities and health insurance/dental help.

My son needs medical and dental assistance.

He has no dental coverage at all.

3d. Medical

My son needs medical and dental assistance.

{Name} is extremely restrictive in covering medical care for my son who needs specialized care for complex medical needs.

3e. OT/PT/ST

{Name} is severely handicapped with Cerebral Palsy and he needs more swimming lessons or water therapy to avoid severe muscle degeneration in his lower extremities.

I would like to know if {Agency} could provide speech therapy for my son.

4. Education and Training

Would like to receive information regarding education.

4a. Satisfied with Education/Training

My daughter's job is wonderful, and so is school. We are also thankful for respite and the opportunity to send my daughter to camp.

5a. Satisfied with Transportation

I would like to thank {Agency} for all the help provided regarding transportation to his work place.

I've been pleased with the promptness, regularity, pleasantness of the driver and of the phone answering personnel at {Agency}.

5b. Dissatisfied with Transportation

I need a person who can talk to {Name} regularly or socialize with her and take her places.

There are no available transportation pickup close to us. More coaches could do this after hours or on weekends.

I don't like bus transportation.

My daughter cannot have a social life due to transportation issues. She takes the bus to work or school, but can only see her friends if I drive her.

No help given to us on questions about transportation needs.

6. Recreation Activities

I would like more information about recreational activities.

6a. Satisfied with Recreation Activities

My daughter's job is wonderful, and so is school. We are also thankful for respite and the opportunity to send my daughter to camp.

9. Transition Issues

My son should have been started in a transitional programs three years ago.

10a. Satisfied with CM

{Name}was his outstanding and long term coordinator. Thank you.

{Agency} case workers put in their best effort.

We love our case worker, {Name}. She is awesome. Please keep her around.

My son has been a {Agency} client for the past 10 or so years. He has been fortunate enough to have the same case worker, {Name}, for over 4 years, and she has always been responsive to his wants/needs.

We are grateful to {Agency} for the services provided. We have had the same case worker, {Name}, for years. He continues to do an outstanding job for our son.

{Name} has been a very helpful and consistent case manager. We sincerely appreciate her help and interest in our son.

However, my relationship with his coordinator has been pleasant and friendly.

Our counselor from {Agency} is wonderful.

Thank you for our case worker, {Name}.

We have had the best {Agency} worker, {Name}. She helps me quickly with my problems.

Thank you {Agency}. We have had our case worker, {Name}, for several years. Her consistency has made our lives easier. She is knowledgeable and if she does not know an answer, she asks for help. She is compassionate, helpful and professional.

I just want to express our gratitude to {Name}. She always goes out of her way to make sure that my child gets what she needs. Her interest in her well-being and training have always been sincere and we appreciate her.

{Name} has been as much help and a blessing.

We have been very happy with our case worker. He has always given me assistance when I needed information or support.

{Name} is a good SC. Whenever we have questions, he has given me good/correct answers right away.

{Name} is very active and enthusiastic. Whenever we need him, he is always more than willing to help.

{Name} is an excellent Service Coordinator. He makes the programs come alive.

We are thankful for our service coordinator, {Name}. She always responds quickly to our needs and questions. She arranged interview with vendors for jobs. My daughter's job is wonderful, and so is school.

We have had the best Service Coordinators. {Name} has been a blessing, as she is always helpful in getting us the information that we need.

{Name} has been the most wonderful and helpful person for my daughter.

{Name} has been a great support to us. Thank you.

However, the person who replaced my worker, who was on maternity leave, returned my call and was helpful.

I also want to thank my daughter's worker.

10b. Dissatisfied with CM

Our current case worker is not a good listener. She'll ask a question, not listen to my answer, then try to say back what I just said and get it all wrong, or ask the same question later. Another frustration was that she asked me if we needed more respite hours. At the time, I said no, but a few months ago later, I called and asked her if we could get some more hours. She replied that we didn't qualify.

We have only seen our son's worker once and that was at his review.

When a new worker is assigned to my daughter, I would like them to be able to answer to my questions.

Also, that they are committed as some workers do not show to appointments and do not communicate with us.

My only complaint is that our worker only visits us once a year. For the past two years, she has called the same day she plans on coming over. When I have any questions, she does not answer my calls.

I would like it if my Service Coordinator would speak up when she is talking on the phone so that people can understand her.

I would like more information regarding computer classes available for my son. I have tried to contact my worker, but I haven't gotten a response.

My daughter's worker never calls her back.

I asked the social worker to help me find a psychologist for my son. The only suggestion she gave me was to have him take medication. I don't want my son to take medication. Instead, I'd like him to go to counseling so that he can stop certain behaviors. I don't feel that the social worker is helpful.

I would appreciate respect from other employees who work at your agency. When I tried to tell staff that my bus pass had expired, the worker was rude, and would not listen to what I had to say.

10c. CM Turnover

Why do we have a different {Agency} worker every year? It's hard for them to get to know us and for us to trust them when they keep changing.

This is his last year. We have not been happy since our case worker was transferred and we were never contacted by our new worker.

Every time we get a good Service Coordinator, we lose them and have to adjust to a new one.

10g. Service Plan

We are in need of help for our son's future now.

The last {Agency} assessment reported my son as active when he uses a wheelchair due to congenital heart disease and pulmonary hypertension. It's a tough job for

I asked for help in mental care, but I was told that I would need to get this help from a private physician. I felt that I should have gotten better advice or recommendation. I was willing to pay for such services. Sometimes a private physician cannot offer a good recommendation or brushes off the idea that someone with moderate challenges would benefit from counseling by someone who has expertise in this field. I wish you would address this problem in future newsletters.

11a. Satisfied with Staff

{Agency} has been a big help to my daughter. I truly appreciate the staff and their dedication. Thank you.

We are happy with {Agency}'s staff.

{Agency}'s staff is very helpful. Our family is happy because whenever we need help, they are ready to assist us. Thanks.

We are very satisfied with {Agency} and its staff. The Easter Seals program is a blessing. Thank you.

11c. Staff Turnover

{Agency} staff has been good but consistency would be great. We've had 4-5 workers in the past 4-5 years.

{Agency}'s staff changes too often. New worker never follow through with recommendations, and seem to lack information.

11e. Staff Not Qualified

{Agency} staff was ignorant about caring for DD adults and also crisis managed vs. communicating in a timely manner to avoid crisis.

12. Family Issues

{Name} is sick and very old, and I gave away the right to take care of him to my brother {Name}. From now on, please send any paper work to my brother's address. Thank you.

{Agency} does not offer anything to families in crisis.

12a. Family as Paid Staff or CM

I would like to stay home and take care of my child, and that the money be paid to me instead of to an agency.

12b. Family Support Group

I would like to network with the other people in my family member's group, parents or guardians to see if after work day activities. Events such as bowling, golfing, etc.

What parent groups are available, either for communication or fund raising for programs?

13. General Well Being

I need a person who can talk to {Name} regularly or socialize with her and take her places.

13a. Health

My son is depressed over his retardation. He does not fraternize with other mentally handicapped and does not like being around them. He stays at home, so it was difficult to answer to some of the questions.

We would like assistance in getting counseling for {Name}. Thank you.

I asked the social worker to help me find a psychologist for my son. The only suggestion she gave me was to have him take medication. I don't want my son to take medication. Instead, I'd like him to go to counseling so that he can stop certain behaviors.

14. Respite

The only changes I would like to see is that after respite is used, the remaining hours will appear on your next time sheet.

The only services that he receives from {Agency} is respite.

14a. Satisfied with Respite

My son has not had the opportunity to use any of {Agency}'s services other than respite hours. This service is very important to us. Thank you for your help.

Our family is appreciative of the respite hours that we receive. Our son is happy, healthy and a participant in life.

Thank you for the respite care. It's a great help to my husband and I.

We are also thankful for respite and the opportunity to send my daughter to camp.

14b. Dissatisfied with Respite

I would like a little bit more assistance when I request for respite services. I don't use it regularly, but once a year, it'd be helpful.

We quit applying for the monthly respite funds because the paperwork was a hassle. The idea of the funds is a great one, but we would never allow anyone outside of the family to baby sit our son. We would give the respite funds to either our adult married son or daughter. The paperwork involved in the arrangement was not worth the trouble.

It's be approximately three years since my daughter received respite

I have asked for some type of respite services or perhaps placement for my son, and nothing has been done about it.

I have had to hire a caregiver and pay her myself. Respite care was also not helpful. With my son's condition, we need LVN. {Agency} would only take my case if they had a minimum of 40 hours. I only need the respite worker for certain occasions and family trips.

I wish that {Agency} would give more than 24 hours of respite in a month. Our daughter is very difficult to care for. Double time would help a lot.

Respite is what is most helpful to us, but it is much too complicated to use because of the paperwork. The work involved negates the benefits, therefore we can't use it. Make it simpler and it would be more effective.

17a. General Satisfaction with Services/Supports

{Agency} has been a big help to my daughter. I truly appreciate the staff and their dedication. Thank you.

My son passed away on {date}. {Agency} has been a strong resource and support for 30 years. We wanted to keep our son in our home and we were blessed to be able to do that. He died peacefully at home in his own bed with family caring for him{Name}was his outstanding and long term coordinator. Thank you.

We are grateful to {Agency} for the services provided.

{Agency} services have been very good to us. {Name} loves going to {Agency}. Thank you for our case worker, {Name}.

Working with {Agency} has been a positive experience. Thank you for the support.

{Agency} is doing a good job helping people with developmental disabilities.

Thank you {Agency} for helping my son.

Thank you for the information provided. I am very satisfied with {Agency}.

{Agency} is good for people who need help.

Thank you for the help provided to all the families that needed it.

{Agency} is good.

I would like to thank {Agency} for all the help and services provided.

{Agency} has helped in all my needs.

Extremely grateful to {Agency} for the services provided for my son.

We are satisfied with the services we have.

All the services are great. Thank you for helping to keep my son at home and for supporting our family.

Thank you for the help provided.

The services that {Agency} provides are good and helpful.

Thank you for all the help provided.

I am very satisfied with the program and all the services that we receive.

In general, I am happy with the services provided by {Agency}. Fortunately, my daughter is very independent and healthy.

We are very thankful for all the support provided.

Thank you for the help provided.

I get all the support I need and feel like they are always there to help.

{Agency} is good and provides positive results.

I'm satisfied with all the services provided by {Agency}. Thanks.

Many thanks to {Agency} for making a difference in our lives.

The services provided by {Agency} are very helpful.

Thank you {Agency}.

We are very happy with all the services provided by {Agency}. For the

past year, the services have been very helpful to my family. Thank you.

Thank you {Agency} for everything you have done.

Since our daughter has turned 18, I feel that {Agency} has made a greater effort to provide services to help our family, and keep my daughter home.

We appreciate the support and help in pursing residential/group home placement in the near future.

My daughter has had Cerebral Palsy since birth, and is non-verbal. She goes to ADP programs. I am very happy with the services and information

{Agency} has been helpful in recommending conservatorship attorney, special needs trust info, etc. It is nice to know that they are there if we need more support in the future.

I appreciate {Agency}. Thank you.

{Agency} is much better equipped to access their clients needs, specially the economics of the PDD. My son receives over $200 less a month. Do you have any idea how many times we have been short and had to make up for the previous paid amounts? {Agency} knows their people as well as the cost in So. Cal.

{Agency} has been very valuable in the care and services that my daughter has received over the years. Thanks for all you do.

Since my son was placed with {Agency}, his life has improved 100%. Thank you for your services.

Thank you for your loving service. We are thankful for our family member's happiest face.

{Name} has been helpful. Thank you for taking good care of my child and family.

Especially appreciated the {Program}. The program has been wonderful for my son. Thank you.

{Agency} does a good job. {Name}does great with {Name}. Thank you.

We are very satisfied with {Agency} and its staff. The Easter Seals program is a blessing. Thank you.

I am pleased and thankful for the program my child is involved in. Thank you for all of the assistance provided. Our daughter's life would be far different if it weren't for {Agency} and the services provided.

We are happy with all the help and service that {Agency} has provided, especially {Name}. Thank you.

{Agency} has been a blessing for my son. They referred me to {Agency}, which has been a great employer.

{Agency} has been a great resource for us. Thank you.

17b. Dissatisfaction with Services

{Agency} has done nothing except give lip service.

I've always felt that the disabled adult isn't given the equal or same status as the young ones. My child has been given very little choices for anything since she's unable to communicate and backed by a school system that doesn't give her the communication help she has always needed.

I think diapers should be provided until the person is not longer around. I have a nursing agency that can't even provide nursing for us when we need it. The nursing agencies definitively need to improve.

When I need immediate attention, {Agency} is never there.

17c. Access to Services/Supports

There aren't any community services in {Town} that are close by. Everything's in another town or too far.

We need more day care centers for young adults in South OC. It takes more than 80 minutes each way to go to this programs.

17d. Info Regarding Services/Supports

Would be good to know what is available since he is currently living at home again. A meeting with {Agency} might be very beneficial for us.

Thank you {Agency} for helping my son. I would like to request help finding a lawyer so that my son can become a citizen.

Thank you for the information provided. I am very satisfied with {Agency}.

Provide with a list of qualifying illnesses or diagnoses that indicate a person is eligible for {Agency} services and what's available.

I will contact our worker and ask her about services that we could benefit from.

We are not clear about the responsibilities of a Service Coordinator and about {Agency} services. I want to meet with an SC to find out.

I would like more information regarding any other services from Social Services. Thank you.

We would like to see our daughter make friends and not lead such a lonely existence. She has physical injuries and is a diabetic. we are elderly and would like to know more about housing and her future living with so many problems.

I would like more information regarding computer classes available for my son. I have tried to contact my worker, but I haven't gotten a response.

Would like to have {Agency} give a training and sending more information.

I do not know alternative ways to receive these services.

Thank you for the chance to communicate. My brother-in-law came to us three years ago. I have been his caretaker since then. I have since been told that {Name} should have a paid home-cook and cleaner. I will look for a lawyer to help know better what {Name}'s rights are. Please call me with guidance and to set up for his meals and day care.

17e. Need More Services/Supports

We do not receive outside assistance for any of {Name}'s needs.

Although my daughter is not 22, I have not received many services that may be available to us but {Name} has been as much help and a blessing.

I would like to see more agencies available to help the needs of families. Also, that they are committed as some workers do not show to appointments and do not communicate with us. Day care programs for adults is also needed.

There is a need for more social activities.

I am not receiving the help that I used to get. It's been more than a year since I've received the assistance.

My son is brain damaged and affected in different areas. Your services seem to only pertain to severely retarded people and not for the people who fall in between.

There's little available for young adults with higher functioning autism available. We choose to surround him with those who have few to no disabilities. he is enrolled in {Program}at {College}and receives minimal help with his curriculum. I was unaware of the fact that the state department of rehab, will help with supplies and books, which I have privately been paying for. Thank you for your care and concern.

Discontinuing the parent service coordinator program was a big mistake. The program provided the most incredible opportunity to feel involved, valued, useful and in control. It really helped the coordinator to meet the needs of the clients.

17g. General Dissatisfaction with Service Management

When I need immediate attention, {Agency} is never there. The supervisor {Name} is very rude and doesn't listen.

ARIZONA

1b. Dissatisfied with Home

My grandson was put in an apartment with and aide to help him, but most of the time the different aides would be late or not show up at all with the consequences were he got involved with gangs that stole off him, and put him in danger. So when I found out, I immediately took him out of the apartment and brought him to my home where he is to this day.

1d. Furnishings/Cleanliness of Homes

Need more sanitary supply services.

Need more sanitary supply services.

Help is supposed to come for cleaning and the people sent aren't listening to her request. Things get broke or thrown out - vacuum, silverware, etc.

2a. Satisfied with Employment

Thank you for supporting {Agency} workshop on country club in {Town}. We tend to take it for granted. Thank you so much

They go to a local workshop & enjoy going.

I really appreciate the day program that both of my sons are in as they enjoy what they do and gives them time to be away from us as parents and do things out in public.

He loves his 7pm to midnight job cleaning city buses

3c. Dental

An individual with a severe disability, which his family has been paying taxes over the years should have free dental care when he becomes an adult. As a citizen he deserve that. A full health coverage. This country needs an universal health coverage like many other country like England, Spain, Germany, France, etc, etc

You know dental is very much needed for a lot of the children. Is their help out their? Thank you

We feel that our income taxes are being used unfairly & unjust. My daughter's dental work is running into the hundreds I have to drive her 35 miles just to get dental services

The worst chasm is the lack of prophylactic dental care. Most of these folk can't or don't take care of their teeth. It isn't covered by ahcccs and most have very little discretionary funds. This results in avoidance, including repulsion and revulsion by some of the "normal" folk and why not! They need dental care to end the common peritonites, thoroughly clean the teeth to, perhaps, prevent and certainly delay the onset of rotting/missing teeth, bad breath, etc.

Need more dental & vision services

Need more dental services.

My son is 40 & last year took him to a dentist & we thought he needed a check up & might have a cavity. He is on (access) & they refused to see him because of his age. My funds are limited & we could use the help there

Also I would like to see dental coverage for older adults. I resent having to have my son's teeth pulled when the cavities get so bad he is in pain.

Dental services are totally inadequate, preventative dental services should be covered.

Dental needs to be easier to provide. We need {Name} to be asleep during any procedure and it is always a fight & dentists don't always understand the need

3d. Medical

Our daughter has had 2 doctors through apipa. {Name} and {Name}. We have had problems with both. They have not been sensitive to our daughter's health needs. She has had a chronic sore throat. Because she has downs syndrome, she has a large thick tongue. You cannot even see her throat/tonsils unless a depressor is used. Neither doctor used a tongue depressor in most all of our scheduled visits. Both doctors dismissed her chronic sore throat discomforts

Dr. Is slow to respond to {Name} calls.

3e. OT/PT/ST

We need to have more choices for speech therapists and personal living skills providers

However, we have had very little success in securing and keeping appropriate OT and PT services (appropriate, meaning home-based as opposed to 45 minutes from home at a center). We live in the NE valley and are told that there a simple no providers in this area. {Name} has been without physical therapy for almost three years

{Name} needs ongoing physical therapy. She was so close to walking when she was receiving OT/PT. If she had been able to continue with a therapist on a regular basis, she would have been walking with a walker short distances; we would have needed her wheelchair only away from home. Being under the supervision of a therapist rather than a habilitation worker(which we have just found) would have relieved us of much physical stress. She has now regressed & lost much of her walking ability

Needs PT he is so far behind because of the lack of PT (I'm mad) Idid his PT and hurt my back...I was trying to help my son. I taught him how to walk and swim in our pool. Doctors would not give him a walker cause they said he couldn't walk. I proofed them wrong. Friend let me have one, took it to doctor then he was given a walker.

My son attends {Agency} 4 days a week, which is what we want. He has not received PT, Speech or OT therapies, yet.

Problems getting therapy, speech, PT, OT professionals. Perhaps arrangements could be made for my son to go to outside therapists. My son has down syndrome with moderate to severe retardation.

It is extremely difficult to receive services such as speech therapy. You have to be on such a long waiting list that it is impossible!

I think {Name} needs more at home therapies, speech - motor skills. Thank You

3f. Vision

Need more dental & vision services

Need more vision services

Eye glasses services are also completely and totally inadequate; eye glasses should be covered; for example, one pair of glasses every two years

4a. Satisfied with Education/Training

The special ed program is excellent. They have different activities that keep her occupied but they do not have sufficient funds to help the way the program would like

4b. Dissatisfied with Education/Training

{Name} is still in school. While we have fought hard for {Name} to give him the best possible situation, the "school" IEP process is a joke and very difficult to monitor. We are at the mercy of whoever the teacher is and there level of commitment. This changes a lot and you have few alternatives.

Also the school gave general education the biggest classroom in the building, leaving our

handicap, wheel-chair kids with no room to move around. We are still fighting (in our second year) to get the room back to the much needed wheel-chair bound children.

5a. Satisfied with Transportation

They provide safe transportation (so I don't have to worry that he missed his bus or lost his ticket as with past jobs).

5b. Dissatisfied with Transportation

My only complaint concerns handicar. There have been days especially every other Monday where {Name} rides for 2-3 hours because of short supply of drivers. For some reason {Name} was deleted from their route yesterday and today. No explanation. Schedule has been the same for 3 months

They have a new transportation co who is always late - picking them up about 40 min later than the former transportation carrier and bringing them home about an hour later.

5c. No Transportation

We have no way to transport him out of this house. We would or could really use a wheelchair accessible van so he can go to doctors appointment, go to any kind of entertainment. These are real needs.

7b. Dissatisfied with Communication

When our school district planned & constructed a new all-inclusive school for our children, the parents of special needs was not included, leaving us with a number of necessities that cannot be obtained.

Sometimes I've had to find out from another parent of a child w/ special needs of some services available

It is very difficult to communicate with people at {Agency}, {Agency} and {Agency} to obtain proper medical care information.

I think there is a great gap in voluntary information about how to find & select facilities to help with special children. Until my child turned 18, I had no idea that the process to replace existing services with age appropriate services would be such a do it yourself process.

We usually learn from other foster parents what we should be getting. Why not tell everyone what's available and reimburse us all equally?

I am happy with the services that my son receives, but I have always had minimal contact with a support coordinator. I often wonder if there are more services out there for him. I know they all have large caseloads, but we have a new support coordinator & I'm hoping there is more communication in the future

If there are activities for the handicapped, one has to hear from "the grapevine" in order to know about it. I only hear about special olympics which my daughter can't participate in but we'd like to go if we knew where it was being held. We only get a request for contribution.

7c. Information

It has been hard getting information on the mercy care plan. E.g. How does it compliment/supplement Medicare; what is the "DD general" plan and how does it differ from the standard plan; is there an alternative plan?

7d. Language Barrier

My agency is {Agency}. I have been with them 9 years. I've always had a problem with them not returning phone calls & sending staff over here that don't understand or speak English. Sometimes not speaking English at all.

8. Aging Caregiver Issues

{Name} has a learning disability and a speech problem. I am 60. I am his payee rep and he lives at home. Working to get him out on his own before something happen to{Name} and myself.

9. Transition Issues

We keep putting off the transition to a group home and probably will while our health remains good.

As kids leave high school, it would help to have access to "maintenance" programs for basics - math/reading for those not able to attend any college classes

10a. Satisfied with CM

We have the most caring caseworker anyone could possible have. Her name is {Name} . She is always willing to help us

We are very pleased with {Name}. She is great!

We are very happy with our case manager and the services we are receiving

Very happy lately with my support coordinator. I hate when you agency change our coordinator

Our DD case worker is wonderful. He has been there for us, listens and tries hard to help us find our way through the maze. We feel he truly cares about his clients and advocates for them.

{Name} is our support coordinator and she is wonderful

Present case manager is excellent in attention to her clients. First manager to contact us on a regular basis & assist with any problems

Overall we are pleased with the services provided by our support coordinator and our day program staff.

My daughters support coordinator {Name}, has been the greatest. She has helped my daughter and I solve a lot of our problems with {Name} medical attention and continues to visit and ask if we need anything else. I thank god for hope{Name}, {Name} mother. Ps. She even put {Name} down for a Christmas "wish list" thank you

My daughter's {Agency} caseworker and {Name} I staff provided great assistance in providing a program to improve my daughter's overall behavior. Initially she did not like going to the {Agency}. After formulating a behavior program with staff and DD caseworkers her behavior is greatly improved and she loves going to the {Agency} now. I greatly appreciate the assistance {Agency} and {Name} has provided my daughter.

{Name}has been absolutely wonderful as our support person. She returns my phone calls right away, always follows up on what she says she is going to do - she's just excellent!

I think that the services provided are the best & the coordinators are very honest and we can depend on them with whatever we need. Thank you for your concerns. We are very pleased.

I have found the caseworkers very helpful in {Agency} - compassionate & respectful. Quick to return phone calls. They offer choices and information and allow us freedom to act on them

The case manager that I have now for {Name}is helping me.

Also a new case manager or coordinator has provided some new insight.

We are very happy to be able to count on the assistance from DDD especially that we have our worker. We hope to always have her.

10b. Dissatisfied with CM

We need a worker who positively helps the patient and heartfully understands him. "not to come every 3 mos. Or every year, just to complete his paper work and work away."

Support coordinators do not support or coordinate any thing for client in this case. State rules request support coordinator to make home visit to clients. These are strangers that we allow into hour homes, to show our willingness to work with them, but when it comes down to the reality of it, these people don't have to help, they can't be made to help and they most often don't. They cause fights some cases and if this is why they get hired, then we don't want them

My case manager does not give us enough advance notice to easily plan a meeting. Usually we have less than a week. She also chats way too much about her own personal issues/family thus wasting time & dragging out the planning meeting

I am not happy with the support coordination. The support coordinator's come & go so often that they never really know my son or his needs. They try, but between large caseloads & the time it takes them to learn the system they are usually not very effective. I have learned over the last 20 years that I must be a very strong advocate for my son. If I wasn't, he would not be receiving the services he has.

{Name} has schizophrenia and bipolar. For some reason her agency ({Agency}) does not have enough coordination to keep a provider for {Name} {Name} does not ask for much, but to date... {Name} has been a "huge" disappointment. {Name} is not happy with {Name}

10c. CM Turnover

I hate when you agency change our coordinator

Too many new case coordinators. Calls often go unanswered and return calls are generally not made. Only exception is when their paperwork is overdue!

I am a caregiver to a 23 year old with Cerebral Palsy. He has mind of five year old. His caseworker called once and I never heard from her since and don't know how to get hold of her! It seems we just get comfortable with his caseworker and then they switch on us! I am at a lost! Thanks!

Have been assigned 3 case workers over the last 18 months.

10d. Shortage of CM Workers

Overall we are pleased with the services provided by our support coordinator and our day program staff. Access & delivery of supports could be enhanced by reduced caseloads

10e. CM Not Qualified

Your support coordinator's need more training on there job. When they don't know there job, its hard to get the services needed for family member.

10g. Service Plan

We need to have more choices for speech therapists and personal living skills providers

The day program provider in our case needs to be told that they cannot force us to use them for other services, i.e. Respite. They will not allow us others. Perhaps others experience the same dilemma

He has attended {Agency} for almost a year. We have not had a planning meeting yet.

My case manager does not give us enough advance notice to easily plan a meeting. Usually we have less than a week. She also chats way too much about her own personal issues/family thus wasting time & dragging out the planning meeting

Meetings are held but actions aren't taking. My daughter has had broken braces for her feet since our last meeting. She never sees a dentist or gets the opportunity to get glasses or rides to her dr. Appt.

Years ago I had a list of services provided & if certain things were covered. It would be nice to have such a list. If I'm not content with the day care provider it would be nice to know if there is any other in the area.

11. Staff

There have been major problems w/your staff (intake people) in the past. I think over the 21 yrs I have seen much improvement. It's too bad we didn't have good staff when he was young - missed out on a lot of therapies that were necessary. {Name} {Name}, {Name} were the best. They really know this stuff. If it wasn't for me my son would not be at the level he is. You all have got a ways to go! {Name}, is his case manager now - he's good too. Too bad you overwork, overbook w/so many clients

11a. Satisfied with Staff

My son {Name} lives in a group home, is supervised & works for {Agency}, {Town}. Thank god for {Name}, {Name}, & all the staff.

The staff is always attentive and helpful

My daughter's {Agency} caseworker and {Name} I staff provided great assistance in providing a program to improve my daughter's overall behavior. Initially she did not like going to the {Agency}. After formulating a behavior program with staff and DDD caseworkers her behavior is greatly improved and she loves going to the {Agency} now. I greatly appreciate the assistance {Agency} and {Name} has provided my daughter {Name}.

I only hope his wonderful job coach doesn't quit for a better paying job!

11b. Dissatisfied with Staff

I would like staff to pay more attention to what surrounds them or the needs families have. Should not only do their jobs because they get paid to do so.

11c. Staff Turnover

The turnover in staff is too high. An increase in wages might improve this turnover rate and improve the quality of the staff personnel

The only problem we have, is finding & keeping respite caregivers. They seem to always move on

There is a very big turn over in office staff in the past 3 months. Its changed almost all the staff. If the state can look into it, it would be very much appreciated.

11d. Shortage of Staff

Sadly the company that supplies services to my family member cannot find enough employees to supply the services the way they have in the past. Hopefully in the near future they will employ enough employees to once again function the way they have in the past - which I was very happy with

11e. Staff Not Qualified

I feel there have been times the {Agency} staff is not always on the same page so to say. I have been involved in a process where misinformation was not brought to surface until 3 years later. This information was due to lack of training, and because of this, family members, who I can trust with my handicapped daughter can no longer do respite care when I am out of town.

Better training for housekeeping and respite providers would be helpful

11f. Pay Staff More

Too many cut backs in caregiver's salaries, not enough quality of care. I don't trust most of the people you hire to do more than respite, even that is questionable. Fair wages! You get what you pay for medical front desk/receptionist make $12 - 15 per hour without any caregiver qualifications – CPR, etc. Bring back a decent wage so we can have quality care

The turnover in staff is too high. An increase in wages might improve this turnover rate and improve the quality of the staff personnel

Also I feel that the decreases in certified caregivers pay, has also decreased the ambition of the caregivers.

I feel that higher wages would attract better people. My experience is that staff working directly with my son change rapidly. The staff are looking for a job with higher wages so that they can pay their bills. I think that people who actually work with the client should make at least as much as those who do paperwork, etc. In the offices or more!

I'd like to share the latest concerns about the new way of how independent contractors-caregivers are getting (or not getting) paid. Caregivers express a great deal of dissatisfaction regarding the contracted accountants in {Town} area. There have been frequent instances of lost paperwork, unrelated staff, miscommunication between {Town} -based caregivers & accounting office in {Town}. As a result many caregivers are giving up & threaten to quit contract with {Town}.

11g. Substitutes

{Name} having difficulty finding a replacement respite provider

12. Family as Paid Staff or CM

The care I was receiving from providers to come into the home wear not doing there job,

at this time I am trying to get paid at home. Hopefully this will be a lot more helpful.

{Name} is a happy man. I, {Name}, his mother take care a him a 100%. I resign my job to take care a him. I would like to get pay. For respite.?

13a. Health

This is a thought and concern with disabled family member. After the age of 22 if there could be a gym exercise with all equipment, so that they could continue to build their muscle tone

13b. Safety

nephew works at a {Agency}! They told me he gets up and wonders and he might get hurt.

13c. Abuse/Neglect/Mistreatment

1) my 41 yr old son is non-verbal & moderately retarded. I used respite services 20-25 years ago & suspected abuse. I've been afraid to ask for respite but have needed it. I don't know what safeguards you have in place, now.

13d. Social

They like to bowl and go to parties, dances & other activities.

14a. Satisfied with Respite

I used the na because the only services I get are respite which I am very satisfied with.

14b. Dissatisfied with Respite

I have been trying to get respite for the last 20 yr. And haven't gotten any where. It seems like I get the laziest support coors' they do the lest they have to do and get paid.

15. Crisis

Also their emergency number half the time you don't get an answer. For maybe an hour or two later.

16. Funding and Budget

We feel that our income taxes are being used unfairly & unjust.

We do feel that the state has provided well for the funding of services for our daughter in a way that helps us keep her at home and out of an institutional environment.

I have been told I would get reimbursed for things I've purchased (i.e.: bedside toilet $100+, bed $1000, medicine). I feel I have to fight for everything. I know the rate should be higher. Nothing is straight across the board.

Being a sister with a husband on retirement, I would like to see more money used for respite care in home or out. At least to give us a break. Taking care of a downs does give one burnout. We came from a state that gave the handicap everything. Right down to learning about church & prayer. My sister lost a lot since we moved. No eyeglass or foot

coverage. There has got to be something for these people, especially downs - they did not ask to be born that way.

We went a year & a half without vocational reimbursement from the state vocational rehab dept. It took them that long to give us a coordinator & determine my son would not be eligible for their resources & would be reassigned to des for vocational training. I paid out of pocket so that my son's transition from high school to vocational training would not be interrupted & his progress derailed. I was never reimbursed. I was told it was not an option.

17a. General Satisfaction with Services/Supports

We have been very happy with all the support we have received throughout the years. Our family is very grateful for all your help that has been made available to our family. Thank you so much. You have given us the ability to keep our son at home with us

We find that most services are very useful to recipient

We are very pleased with {Name}. She is great! The {Agency} is doing a great job most of the time. A few minor problems after major staff changes but the best program we have ever been involved with

We are very happy with our case manager and the services we are receiving

These services are a wonderful help to our daughter - thank you!

Thank you very much for the services.

Thank you for the services we receive. Please don't stop the support to physical challenges.

Thank you - we are so grateful for the support we receive. Our family is able to stay together and stress is greatly reduced because of these services.

Overall I am happy with the services provided for my son.

Our daughter loves being @ {Agency} and enjoys {Agency}. I hope we don't lose {Agency}

My sister use to live in a group home. Has been at home with me three years now. Because of the support service she and our family receive has made this possible and she has grown in many ways. I believe that at home she has no boundaries and can be her own person. Her support coordinator has been a blessing. We thank you and her for all the support.

I'm thankful for the support my child is getting. It definitely has made a difference in his life.

{Name}has always had good care in all his activities and goes out in public when ever possible.

{Name} is doing real good with yes {Agency} & {Agency} in {Town}. Thank you.

If I did not have these services I could not keep my sister at home w/me, which would be terrible.

If {Name} did not go to {Agency}, I could not go to work.

I, {Name} appreciate the services that have been provided for {Name} and my family over the years and am satisfied with most of the outcome. Thank you.

I think that the services provided are the best & the coordinators are very honest and we can depend on them with whatever we need. Thank you for your concerns. We are very pleased.

I cannot stress how important it is to provide services for DD clients who live at home. Our son is in a day program with transportation. The parents assist in hiring the staff. We have respite services so that we can lead a more normal life. Our's and our son's quality of life is enhanced by the fact he receives these services.

I am very thankful to get help for my son. I will keep him at home with us until we to old and not able to do anymore. Thank you very much for all the support we receive for him.

I am very happy with {Name} agency that provides his services.

I am happy with the services that my son receives

I'm the mother of {Name}. I'm happy with {Agency} & {Agency}. We have had changes thru her 34 years. I always receive information & help when we need help. "{Agency} is always so very helpful." my daughter would not have an active life without these services. I'm so very, very grateful.

{Agency} - thank you for your dedicated work. God bless you all

Thank you for the services for my son. Very satisfied. Thanks

17b. General Dissatisfaction with Services/Supports

When I worked for DDD, our son had access to services - when I left in 2000, contact was sporadic or non-existent. We are fortunate in that we can afford care for him ourselves. We would like job counseling/training but voc rehab provides nothing. We are disgusted and fear for families who have to depend on the state for needed services.

DDD has no initiative to assist clients to improve their lives, find programs, vocational assistance, social or recreational programs. DDD releases private reports, evals and other records without obtaining written auth from client or family because they want to "speed up" the process. They skip this legal step

They do not care about others, it is just a job to them

17c. Access to Services/Supports

Is there any other place we could move to have a good care provider that don't travel to far cause those are my concerns and our care provider don't come around that often and I don't know if they even get paid for traveling in the own transportation.

17d. Info Regarding Services/Supports

still in high school and will stay there until 21-22. I am wondering how day programs work once {Name} leaves High School. I honestly feel he will always need someone to care for & watch over him. I forsee {Name} will be in a group home in about 4-5 years.

My other child that has state funding needs speech therapy badly - how can I get that support? I'm thankful for the support my child is getting. It definitely has made a difference in his life.

I needed home care because of my disability. I would like to know more about DDD service.

17e. Need More Services/Supports

Would like it easier to find someone to do care in there home when you need to go out of town or on trips

Need: to get services from 1) {Agency} for respite care; 2) work training - job coach; 3) budget skills - self help i.e. Cooking, cleaning. 4) recreation.

We ask for many things. Sometimes it doesn't help not like the way we want it to happen. Like we ask for money for spraying the house for roaches. And we ask for money to pay part of our electricity and also for diapers. Some of these things did not happen so I don't really know how you gone help me as parents with disability. We got two girls in the household. Thanks

I {Name} would like to have more than 60 hrs of respite. It's very hard on me taking care of emotional behaviors, mental illness 24 hrs every day supervisor care that needed for him. I have a health condition of hart problems. Condition's, especial to keep him from crimes, observation of medication side effects and medication adjustments. Thanks for what is being did to help me very much!

I feel that there are not enough day programs where I would be able to send him for a couple of hours some days this refers to my son sort of like dropping a little child at day care to color scribble and such. This is about {Agency}. Thank you

I would love to have someone come in at the dinner hour and help her learn to cook simple things

Currently I am unemployed, money is a problem, with us getting to get out more, we were not receiving any services, as in "dipes" and some other household items. I have found a few places on my own.

At this time {Name} receives minimal follow along employment supports. Receives no other DDD support services. Mother is primary caregiver @ home. In the future {Name} will require supports to maintain independence -- grocery shopping, bill paying, reading mail , medical appointments

Truly the assistance that is received in the community, one can say, really helps but I feel more is needed, not necessarily because we don't receive enough attention but {unable to identify some of the hand writing}

17h. Waiting List

It is extremely difficult to receive services such as speech therapy. You have to be on such a long waiting list that it is impossible!

CONNECTICUT

1c. Accommodations with Home

To keep our family member at home we need to get a larger hallway and bathroom—bedroom. We could redo the present bath and hallway by taking 3 feet of the living room. This would make the doors wider also for his chair. He needs a special bed and night nurse for 3 weekend nights. He has a night g-tube feeding. Other medical problems. We do not want him to leave the home.

1e. Waiting List

However, my son has been on the residential Waiting List for 8 years. This is increasing my concern as I am now 60

Waiting list placement initiative is too little. Those of us with younger disabled children(25-30 years old) as those being placed today. We will be 60+ years old still dealing with home care. Quite inadequate.

Client has been on group home list 17 years. I know others who have been on longer. Something needs to be done.

2a. Satisfied with Employment

I am satisfied with day services

{Agency}, {Agency}, {Agency} is an excellent day program. § {Company}

We are very happy {Name} is able to go to {Agency}. She has found a second home there. We have no need for lots of services right now while she’s still at home with family. However in the future things may change and we will need help for her. She is very much able to take care of daily needs by herself. She is happy to have found a niche at the Workshop at {Address}

3a. Health Care Equipment

I need a special toilet. I would like you to help me with {Agency}

3c. Dental

I need help understanding how to get dental care paid for. My insurance,

through my employer, covers part of the cost. Our dental office states that neither Medicare nor Medicaid pays for dental care.

Presently, my daughter receives dental care at {Agency}. Would prefer a dentist that would accept developmentally delayed persons closer to our home.

The only problem that I have and it really is not with {Agency} is the dental care is impossible to find. No dentist will accept title 19. {Agency}recommended {Agency}and the hospitals but they will not accept new title 19 patients. My brother's dentist stopped accepting title 19, two years ago. Since then I have paid out of pocket for his dental work.

While I can afford to do so some families cannot. I think this is an issue that needs to be addressed.

Our {Agency} client has everything that is needed except it would be nice if an up to date list could be furnished with all participating Dr.'s and Dentists that accept State. The list I have now everyone I called either doesn't accept new patients or has stopped taking state insurance.

Dental Services that will accept the State Med. Card are almost non-existent and if they do take the payment the quality and level of services is far lower than received by a "paying" patient or one with a standard insurance program.

Would hope to have better dental coverage. Impossible to get in at {Agency}. Is that the only option for dental care?

The dental situation is a mess. I have contacted many, many dentist and they will not accept the states program. We have our daughter use our dentist and we then pay accordingly. So far, it has been the normal type of procedures but it could become a nasty situation. If and when she would need specialized dental care it would cause a heavy financial burden for all involved.

3d. Medical

We have his medical Dr. (Pediatrician) who he has been with since birth, but he will be 21 soon and I can't find a Dr. to take him.

Our {Agency} client has everything that is needed except it would be nice if an up to date list could be furnished with all participating Dr.'s and Dentists that accept State. The list I have now everyone I called either doesn't accept new patients or has stopped taking state insurance.

I am {name} sister, he lives with me, I need help for his medications,

Have to pay extra in order to cover through parents jobs since the state Medicaid participating doctors are no good. Why disabled dependents cannot get Medicare??

3e. OT/PT/ST

She also needs speech therapy, physical therapy and occupational therapy.

3g. Psychological

Counseling for the family would be welcomed.

We also need counseling because my husband and my son do not get along sometime. Sometime they get along and sometimes they don't. My husband gets mad real easy. On the other hand, I just do not pay no mind to him. My husband thinks I should give him a hit or take things away from him. So I really need help or family counseling for all of us. I would really be happy to get some help here before things get worse and ugly. P.S. I do not want my son to be removed from my home. I would like some help. Thank you.

5a. Satisfied with Transportation

Bus is very good.

5b. Dissatisfied with Transportation

Connecticut Transit—“My Ride” Our son uses this mode of transportation to and from work everyday. Our problem is that we have to travel 5 miles to the town hall for him to get his van to work and then return again in the P.M. to pick him up to return home. There are times we wait up to an hour for these rides. Mind you we understand a ½ hour window time but it is very annoying and very tiring for our family member and parents in their 70’s. If he could only be picked up at home and delivered there at any cost it would be worth it. Thank You!

5c. No Transportation

{Agency} transportation is not available to residents of {Agency}, {Agency} and other towns beyond those served by the company. This forces parents/caregivers to drive their disabled children to and from work. With the ever-rising cost of gas and auto repairs this can place a hardship on many parents.

6. Recreation Activities

His recreation is through {Agency}, Special Olympics and family activities.

6b. Dissatisfied with Recreation Activities

My son also needs more recreation outlets. I miss the old {Agency} program and so does my son. The only recreation he currently receives is if I take him and we pay for it monthly (going up to $40 a month in September for {Agency})

Weekly rec activities (bowling, swimming, etc.) would be excellent for her if someone could pick her up, stay with her and then

7c. Communication

{Name} has never received info about services and supports—hence Part 2 is answered by all N/As. It would be appreciated if we could receive info about what is available.

We currently use very little from {Agency}, in part because we do not feel we need much and in part because we are not really aware of what is available.

The {Agency} parents should be allowed at least one weekend a month. Also if a crisis situation comes up such as a death in the family how do we handle such a situation? Who do we call? And is a plan in effect that parents can follow? We need written instructions that parents can follow. Please provide these instructions. Also we need to know in advance the time that the {Agency} will be open in the summer months. In January we should know in writing what period the {Agency} in {Town} and {Agency} and also {Town} if available will be open so that we can schedule our vacation time and please be more considerate when approving the vacation time. If someone has one or two days over the 7 days allowed please do not cross off the 2 extra days without notifying the parents. (7 days take it or leave it) It's very hurtful not to be able to take a vacation.

Please discuss it with parents first.

7d. Language Barrier

The Hispanics need more support from governmental departments. We do not have sufficient support or information regarding the rights and assistance offered. There are no community activities in which children or adults may participate, either

7e. Non-communicative

Assistance in Speaking

7g. Interagency

Also I don't like there isn't a very good relationship between {Agency}and {Agency}

8. Aging Caregiver Issues

Waiting List for 8 years. This is increasing my concern as I am now 60 years old and obviously cannot continue to care for him indefinitely

However, the "new" programs (waivers) are probably going to work fine for young parents. But, parents that have been providing care for thirty plus years (ex. Changing diapers), it's only a band-aid fix. Parents who are sixty and above are tired and need some confirmation on good solid group home plans for the future. The "waiver" help will be appreciated but is NOT the fix for the future for worn-out parents.

I am 83. All these years I have been more or less independent and able to have friends who help me when needed. When I am ill, I wonder who will watch over {Agency} when I am gone. This is a question I can not manage. His siblings can not help. He is apparently in Alzheimer's and seems to becoming more confused. {Name} and {Name} are in touch. I am very confused. I know I have to make arrangements but I am confused.

At this point we are able to care for {name} but he is really declining quickly. It would be nice to know what kind of help we could get when the time comes.

9. Transition Issues

Due to our son's age (20) {Agency} services are not yet in place. However, it would be helpful if Case Manager was proactive and said, "OK, when he's 21 and out of the school system, here's what to do…….Here's exactly what will happen……..Here's what you can do now to make the transition smoother" That would be helpful now.

My son will be exiting the school system in one year, and I am concerned that he will only work part time and spend too much time home. He loves school and keeping active. I would like to be assured that he will be active working and in a program for at least 9-3:00 each day and that he will not be home almost every day in front of the TV. This is what happens when he has school vacations because we can't find respite on school vacation weekdays.

10a. Satisfied with CM

I recently met with our new case worker. She seems interested in getting us what we need. We are hopeful that things improve for us.

We have a wonderful Case Manager.

I thank God and you for assigning an excellent social worker, {Name} to me. Thanks to her we have benefited from good services.

We are blessed to have a caring proactive case worker {Name} {Name}. She always attempts to inform both myself and my son of services available and is genuinely interested in his well-being. She has a wonderful sense of humor which aids my son to feel comfortable at meetings, etc. She does not speak down to my son, rather, treats him with great respect.

Our case manager {Name} is very helpful and does her best!

I am very happy with the {Agency}. We have {Name} as a Case Manager. Have had her since we were in the program. {Name} just loves her. Without {Name}, things would be a lot harder for me. {Name} has so much love and compassion for her job. She's the greatest! {Agency} has been a great assistance for us. Thanks

{Name}of {Agency} has always gone out of her way to help my child. {Name} has been our case worker for many years. My family and I are extremely satisfied with {Name}. {Name} has gone to many PPT meetings at school, court hearing for guardianship, made house calls and helped us receive financial help for summer camp. I look forward to maintaining this relationship as my child gets older and different services and information is needed.

10b. Dissatisfied with CM

Case Manager is {Name} (spelling?) out of {Agency}. He is HORRIBLE! Thank

goodness my son is still in the school system. I do not need him right now. Example: It has been 1 and ½ years since we used respite. He was suppose to put in for more and never did. He is a disgrace to the entire system and gives {Agency} a horrible reputation. Everyone from the town of {Town} who uses {Agency} has changed him as their case manager because he is so bad. I guess I will have to also.

I would like a {Agency} case manager who calls periodically to see if there are any concerns or needs. A case manager who returns phone calls. A case manager who helps the needs of both client and family members.

10c. CM Turnover

The frequent change of Case Managers is quite annoying. Sometimes we don't even meet them and they're gone.

You’re on the phone all day complaining you’re not heard! What Case Manager? You’ve changed them so many times we can’t keep track of who the person is anymore! Unless you’re in a group home you get “0” services!

10e. CM Not Qualified

Their schedules are pretty set 8:30-4:30, M-F, they are not trained for working w/individuals w/ DD/MR. They don't have backgrounds w/ behavioral issues, they can't administer meds and they can't take my son out for recreation.

10g. Service Plan

We would like the option of deciding whether or not our son remains in our home. We would like to be able to choose the best out-placement site for him. Neither of these options is available to us.

His current job coach is excellent although some of his previous ones were less help. We had no input in choosing them.

11a. Satisfied with Staff

I, {Name}, {Name} mother, would be lost in some areas, without “{Agency}”. Her job Coach, {Name}, is the BEST and {Name}, three of the years, as well. I personally would not be able in all areas without them.

13. General Well Being

{Name} has been treated very well in whatever placement he has been in. He does not require a lot of extra equipment or attention.

13b. Safety

I would like to be able to add a fire escape to the house as I have two children who are not able to react in an emergency immediately.

13d. Social

The only area in which I am tremendously disappointed is the lack of monies in my son’s plan for leisure activities. I know of other families who have received significant monies to hire age-appropriate normal developing peers to entertain and further socialize their child I would appreciate the same. My husband and I are our son’s constant “date” He needs to “date” or socialize with his peers, not his parents.

My daughter has experience being the only girl with 4-5 boys so many times that she doesn’t like to go. We try to schedule her with a friend but always get told it is filled. They offer a different date all the time than what I request. And I feel that when they choose movies for the clients they don’t really encourage G or PG movies. For example, this past weekend they took them to see The Break Up (PG 13) when there was a G movie (Over the Hedge) playing. My _____ didn’t like the movie (Breakup) and can’t follow these movies either.

My daughter being a young adult now needs more opportunities to get out into the community doing social activities with her peers. I need help finding agencies like {Name} to sign her up so she can have recreational/social activities.

I would like to see {Name}, available for longer than one week to older campers, two weeks would be nice. Perhaps a week in June and August at start and end of regular camp sessions. Even though they are adult age, mental age is still young and years of attending camp for more than one week is a drastic change for them to adjust to one week. Also to resume bowling would be great for social skills for those without siblings at home and limited social interaction Most older campers work and could contribute a certain amount to help with staff cost for the extra week of camp or bowling.

14a. Satisfied with Respite

Respite funds given out are used very carefully and do provide relief.

He goes to the respite center every few months on the weekends. He enjoys respite and it gives us an opportunity to get out on our own.

14b. Dissatisfied with Respite

Also respite times are pre-determined and don't benefit people wanting a real vacation. You are always asked if you'll be in the immediate area while your child is in respite. And, I was never informed of respite services in the home.

We need more respite. One weekend every 3 months is just not enough. At the {Agency} parents should be allowed at least one weekend a month.

Respite at the centers especially {Agency} is very hard to get what I need and with the right clients together. My daughter has experience

We do need more help on weekends-day and night. His respite center only takes him 1X per quarter.

More overnight respite services for weekends would be excellent, too.

More respite weeks at {Agency} are needed and for one week rather than

four days at a time. Four weeks per year would be good.

If I hire anyone to do these other things / or an overnight I use the $600/year I get for respite. That is all the $ for in-home support I receive from {Agency}. Respite center use is also difficult to access more than twice/year. The more involved the client the less respite you receive since the center is never going to call you up and offer a weekend spot in the event they had cancellations. If your son/daughter is higher functioning you get more respite!

15. Crisis

Also if a crisis situation comes up such as a death in the family how do we handle such a situation? Who do we call? And is a plan in effect that parents can follow? We need written instructions that parents can follow. Please provide these instructions.

{Name}, is very violent and attacks me frequently. I need some more time to myself.

16. Funding and Budget

If I concentrate on “today” we are doing fine! It is the future that upsets me. With two working parents our son will need a greater amount of funding after high school in two more years. Where will the funding come from?

Additional funding is needed if we are to keep our son at home. It costs us $20,000/year and the well is going dry.

I was receiving a check for respite care where I could hire someone to take my son out. It was not very much but it did help. It was discontinued about three years ago. I was told I was at the low end of the payments that were made and it has been discontinued. I would like to see it reinstated again. It was a budget issue that it was discontinued by the State of Connecticut.

Also I need help finding funding for repair of her FM set so she can hear sound. It is very costly getting her set fixed. She also needs speech therapy, physical therapy and occupational therapy. Counseling for the family would be welcomed. As well as funds to pay a sign teacher her main language.

{Name} is my niece (my youngest sister’s child) and we love her very much; however, the past three plus months are taking its toll on us financially and not having many breaks from having her with us. We are looking forward to her first respite on June 23, 2006 for the weekend. We have not been offered any financial help for her care (we are not aware there is any available).

17a. General Satisfaction with Services/Supports

My family appreciates all the services we receive for our two sons. Both boys get day services, transportation, and respite money. These services greatly enhance our lives and we thank you.

Thank you {Name} for you assistance with much appreciation {Agency}. (illegible)

The services from the Department are quite necessary for caring for the disabled. Thank you very much for you assistance. Keep up the good work.

To Whom It May Concern: The services we receive are wonderful

Although our son is only mildly retarded we have been most pleased by {Agency} help. Because he is still being help through our local public school system, our use of {Agency} services has been limited. But we have been made aware by our excellent case worker ({Name}) of various {Agency} and {Agency} opportunities and plan to use them in the future.

I, {Name}, {Name} mother, would be lost in some areas, without “{Agency}”.

{Name}and I are pleased with the help {Name}receives. Don't know what we would do without your services. Thank you.

17b. General Dissatisfaction with Services/Supports

I am very disappointed with {Agency}. Promises were made and not kept. My son is still living at home at 35 and will be until we die. The {Agency} are or should get a “0”. Shame on CT {Agency}. Unless you’re on the phone all day complaining you’re not heard!

Other than attending a {Agency} meeting {Agency} has not helped my son with anything. I have requested help for the last two years and received nothing. Now I am told my son no longer tests out as a {Agency} client only I find that hard to believe.

17c. Access to Services/Supports

We are constantly getting postcards for {Agency} get-togethers but nothing for our area since I cannot drive at night to these far away places. Please make time for us in {Agency} area. We live in {Town}.

We have inquired about respite services but it is generally not available. Last time we checked there was a long waiting list with very limited availability. Next year when our son leaves high school we will need daytime services but there doesn’t appear to be a program locally ({Town}) for him to attend.

17d. Info Regarding Services/Supports

It would be helpful to find out what community activities we can more frequently participate in. (eg. Programs like {Program})

Not sure how it is decided how much supports are needed or available for my child. Who decides this?

I would love a list of leisure services for my daughter (19 years old) in the area for after school/ vacation time

Would like to have more information available for day programs—pay scale-more options available for work. Who oversees a work program? Are there guidelines for staff rates.

A lot of the services I don’t know about. I think more work programs and living alone programs are needed.

I would like to take advantage of respite services at some point over a long weekend so that my husband and I would be able to go away without taking everyone with us. Presently we have custody of our tend year old grandson as well as being legal guardian for our autistic son and also have my 92 year old mother living with us. We usually take everyone with us (or at least the boys) but we really need respite care and babysitters so that we can have time for ourselves. My husband is not receptive to leaving {Name} in respite care so I would actually need someone to tell him how it would be beneficial for all of us. I would like to try either {Agency} or the new facility in {Town}.

We are looking for supportive care for {Name} in an apartment of her own.

17e. Need More Services/Supports

We need a break—we need to know that there are other options than having him at home forever. He is a very social person, and he would enjoy an appropriate group home that is as active and vital as his day program.

Granted my family situation is not usual, but help to keep them at home is not easy at times since my home is like that of a small group home. My family members do not receive any of the help like that in a group home. Being a caregiver is not for everyone, but for those of us who do it there's not much help for us.

We do need more help on weekends-day and night. His respite center only takes him 1X per quarter.

I get all that I need to have but I would like to get involved in more activities during the day!!!!

More overnight respite services for weekends would be excellent, too.

I would like to see the Family Support Program re-instituted in the Northwest corner. My son used to love this opportunity to socialize and go out into the community and participate in recreational activities. This program was cut and he has very few opportunities now.

What worries me is that my son is 17 and he still wets the bed. I don't know what to do. Even when he takes medication he continues to urinate, I'd like to know if you could please help me with this. I would appreciate it very much. I had to throw out the mattress and I can't by more mattresses because this situation is just no good. I have financial problems thank you very much.

My child is extremely behaviorally challenged. She is also lonely. Weekly rec activities (bowling, swimming, etc.) would be excellent for her if someone could pick her up, stay with her and then bring her home. More overnight respite services for weekends would be excellent, too.

{Agency} has been extremely attentive through the years. Unfortunately, the services to our "kids"/ {Name} are not as substantial as Medicare and Title 19 recipients (elderly). Additional support "at home" would be quite helpful for those trying to keep them there instead of being placed in "group homes" or State run agencies.

He has always lived at home. I am able to provide with social activities but weekends he could use one-on-one assistance. He doesn't enjoy going out with the group from his

A lot of the services I don't know about. I think more work programs and living alone programs are needed.

We need more respite. One weekend every 3 months is just not enough. At the {Agency} parents should be allowed at least one weekend a month.

Yes we need help because I am disabled and I cannot do things with my son. I am a wheelchair bound. I broke my spine in three places. I have problems trying to walk.

I would like to take advantage of respite services at some point over a long weekend so that my husband and I would be able to go away without taking everyone with us. Presently we have custody of our tend year old grandson as well as being legal guardian for our autistic son and also have my 92 year old mother living with us. We usually take

everyone with us (or at least the boys) but we really need respite care and babysitters so that we can have time for ourselves. My husband is not receptive to leaving {Name} in respite care so I would actually need someone to tell him how it would be beneficial for all of us. I would like to try either {Agency} or the new facility in {Town}.

I also had trouble accessing a summer camp (even one considers "special needs" w/1:1) my son is medically stable but if you can't walk, talk or feed yourself you are too handicapped for many services. It is very Frustrating.

17g. Waiting List

Waiting for placement through Waiting List settlement.

We have inquired about respite services but it is generally not available. Last time we checked there was a long waiting list with very limited availability.

Despite the fact that we emigrated from Russia in 1994 {Name} ,who has been registered with the {Agency} since then, has never received any significant attention from the Department. NO Case Worker has ever contacted us. NO “plans” have ever been made. NO information on recreation, jobs or respite have ever been sent. Last month we learned

about an “Open House” for services and vendors in {Town}. There we met {Name} and {Name} . These gentlemen helped to “coach” us how to get {Name} hooked into the {Agency} networking services. Also, reps from {Agency} helped to counsel us. We finally met our case worker, {Name} , two weeks ago. She has been very helpful since this initial meeting in getting {Name} into the system. We’ve toured a respite center and are awaiting funding so that {Name} I can be registered for day programs—job skills. Frankly after waiting for 12 years to be given the chance to work, play and grow, we think that {Name} waited long enough. He should be prioritized.

19. General Concerns

In the State of CT there are no bathroom facilities to accommodate the needs of disabled adults. In {address} the {store}. Store has recently opened and we have noticed that there are three types of bathroom facilities; women, men, and family. The women and men facilities have the wheelchair accessible within. The family bathroom has a table to

change the baby or toddler’s diaper. As a parent of a disabled incontinent adult who needs to have his diaper changed by the Home Health Aide or a family member I thought what a great idea to have a family bathroom where the whole family can go altogether. The family bathroom can be expanded to accommodate the disabled incontinent adult by adding a wall table that when closed it would flip up and flip down when opened.

The disabled adult can be laid down and have his diaper changed. Can you please look into this and see how it can be addressed when new stores, restaurants are being built. This is the other half of the disabled population whose needs still need to be met. My son does not go to the field trips that the {Agency} day program sponsor due to the fact that they go for 4 hours and there are no bathroom facilities to change his diaper. He feels bad that his friends get to go to the field trip but he cannot go and he has to stay at {Agency}. Please do something about it. Thank you. P.S. He went once and came home soaked wet (urine) due to the fact no bathroom facilities were available for his changing needs.

GEORGIA

1b. Dissatisfied with Home

I also have found out that in one of these group homes they were starving to death their patients, that they were using the patient's money for the benefit of the provider.

2. Employment and Day Programs

It is a real shame that the idea of a job coach with an enclave of 3 or 4 employees at a job site is falling by the wayside. It seems to have been the best fit for our child because she is a good worker but needs constant supervision.

Consumer would be much happier if he attended the service center 5 days a week instead of 3 days a week. He enjoys going to the service center for 6 hours a day. I hope they won't cut more days, for it helps him and myself also.

I believe with more funding there could be more training for jobs in the community, at his level he would feel more complete and not left out of life. With more funds maybe the community could be more involved and come to understand that this could be an untapped resource of employment that would be loyal to their company.

2a. Satisfied with Employment

We are very happy with the day program.

Very satisfied with day program and day program staff.

I am very thankful for the program my family member is in. She likes the work and enjoys the job very much.

We are very happy with the adult day/ work center program that our family member attends daily in {County}.

He enjoys going to the training center. I think they are doing a wonderful job

My family member is very happy where he is, they have a lot of activities at the center and he can't stand missing a day from them. He's progressed a lot emotionally, that's where he was lacking most. Now we can see a huge difference in him. We are a big family of nine and we are grateful

I am very pleased with the center that works with my son.

Our family member enjoys the day program he attends very much. He looks forward to participating. We, as his family, are grateful that he has the opportunity to be a part of this particular program. He is valued and respected as an individual and treated with courtesy, kindness and respect.

I feel day/employment services do a good job in keeping my family member happy and caring in job coaching program.

My son is always happy when he gets to go to work. He loves the workers

Our family member attends {Agency}. It is a wonderful day work program, M-F 9 to 3. It is a wonderful place. It makes our family member very happy. They look forward to getting up and there every morning.

Overall I am satisfied with the center and staff.

My family would not be able to function without the support and care of the people involved in the day program my son attends. Physically and mentally he can not be involved in many community activities. The day program gives him some place to go each weekday and he looks forward to going so much.

The center consumers goes to is very good for him.

The center we use is great.

The service my son receives at {Agency} is a very good program. The staff is very nice and my son really looks forward to going to work every day and being around others and working and doing his daily task working gives him a sense of independence.

My sister has received day support for attending our local workshop for 42 years. She always lived at home with her mother and father and then just her mother until 3 ½ years ago when our mother passed away. At that time she came to live with me and I obtained guardianship of her. She has, through the efforts of my parents, led a very social life. She has always attended Sunday school and church, she rides horses at a local riding academy for people with disabilities, she bowls, and she has always participated in Special Olympics. Through her workshop she is in the community shopping, dining, going bowling and to the movies. After she came to live with me I purchased a smaller, one level home in a retirement community. Many of my neighbors are widows with no close family and they have become very involved with my sister. They have put baskets at their front door and each afternoon when she gets home from her workshop she gets everyone's mail from their mailbox and delivers it to their basket at the front door. She walks with several neighbors when they walk their dogs. She is often invited by neighbors for dinner or a movie or shopping outing. As I meet more people over the age of 60 who are caring for their siblings, many who have sat home all their life, I appreciate more and more the opportunity that my sister had to attend a workshop and be active in her community. When comparing the two lifestyles you can almost touch the difference. One's quality and enjoyment of life truly is determined by their feeling of inclusion and self worth. My family is so fortunate and I am advocating constantly and involving myself in disability issues to insure that our State funds services for the over 5000 on the waiting list. Someone, including my parents, worked very hard to bring a workshop to our county and I feel that it is an obligation and a pleasure to work for those who come behind us. There are many, many adults with disabilities and their families whose needs are far greater than ours. We are very blessed. Even though GA has a very long waiting list, I appreciate the services that we do have.

2b. Dissatisfied with Employment

We feel that the day program for our daughter is just a warehouse with little activity and lack of motivation in management down to staff. There are many voids in her program and little choice for improvement by changing to the only other choice available in our area.

We feel the state provides the minimum. He gets a crowded van ride to a sheltered workshop that often has little work to be done.

My main concern is the lack of activity program at the service center my daughter attends.

My son only wanted to go on outings and not stack papers. They currently do not have a program to pick them up and go to town, only about two times a week. He can only be in the center if he goes to it 3 times a week.

We are in the process of changing day programs to one that can better manage dual diagnosis adults with MR with MH diagnosis due to MR.

Consumer's day program (Training Center) needs to be updated. She sits all day looking at magazines. There needs to be some quality day programs for this population. Please help them.

We are in a sheltered workshop and find that there are quite a few days that there isn't any work available. I don't know if this is a fault of the workshop or if there really isn't any work to be sought by the workshop.

I think that they should be able to take control of the clients at the {Agency}. They let a few get away with anything. They don't listen to some of the clients when they tell them what is going on. They way that there is no way that this person is being called names and not getting to work as much as others. Some get to work every day and some just a few days a week. They don't rotate like they are supposed to. It is hard to talk to some of them at the center. He comes home and is in a bad mood because they let people pick on him at the center and on transportation. They are some very cruel clients out there.

There is no handicapped parking available to the public at the center. The handicapped spaces are for center use only. There are no spaces for the public at all. This surprises me because of the nature of the center's work. I have voiced this at least three times. Twice to the director of the workshop in {Town}.

We would like to see a workshop (shelter) again as that gave the more severe retarded a job where now about all we can get is social community activities. If you stay in the center all day there are no windows and not a lot to do. That is not good for these people.

3b. Health Care Insurance

I wish that measures can be made to provide a person with disabilities to continue receiving Medicaid so they wouldn't have to pay for medication.

Medicaid, now Medicare, very difficult through the new system. Cannot call to get info re coverage of a certain medication – takes days.

It becomes expensive paying for dental, vision, and other things not covered by Medicaid since consumer became 21 years of age. Other means of assistance would be helpful.

And the new Medicare drug plan has cost us more for her medications.

3c. Dental

A major concern is the lack of support in obtaining dental care for special needs persons; few dentists accept state medical assistance and the ones who do have year-long waiting lists. Even dentists who do not participate in such programs still do not wish to accept special needs patients for a variety of reasons. We have dire needs for assistance in this area.

We need more dental help in the older kids. When they need teeth filled it costs a fortune and when you and your child are on disability it is a problem when you have no money.

Cost of dental and medical expenses are a burden. I would like to receive dental care and medical supplies for my son. I

Need help with dental services.

We receive no dental care support since the facility in Atlanta area closed. Son goes every 4 months to local dentist – cost of 90 do 100 per visit.

Consumer does not have money for dental care.

I appreciate the dental service received from DHR.

3d. Medical

Cost of dental and medical expenses are a burden.

I would like to receive dental care and medical supplies for my son.

3e. OT/PT/ST

I would love to have a PT and OT come into the center to provide therapies. My daughter needs both desperately. I have always carried my daughter and provided these services for her. Public school provides these services and I feel this should be provided at {Agency} also. This is a must!

The services he receives are generally good and helpful but when they went form a training center to a service center he no longer gets help with things like speech therapy and help with general knowledge of everyday things needed to know for daily living.

3g. Psychological

I had some difficulty finding a psychiatrist for my son. I called {Agency} to ask them to assist me in finding a doctor (psych) who would accept Medicaid. After several calls, I was told to look in the telephone book. I work at a busy clinic and it was difficult finding a doctor. I went to {Agency} and was informed that they could not service my son because of his autism. I finally had to pick a doctor (psych) out of the telephone book and have him bill me fore $300.

{Agency} said that they will subtract that from my son's family support funds. Why have {Agency} if I have to find my own provider? I feel cheated.

{County} desperately needs a mental health office on our county. My daughter needs counseling (one on one) on a regular basis. She is not group material and doesn't need to hear everyone's problems. Also, our governor and senators and representatives really need to look at mental health needs nationally and do not cut every program (what few we have) that is available for mental health.

4a. Satisfied with Education/Training

Since my brother has a speech defect and a couple other disabilities it is nice to know that he can go daily w/supervision and feel needed and also to get some training.

My brother loves the training center and the staff. They do an excellent job. He's very happy to go every day. There's plenty of community activities and their monthly outings. We moved here 11 years ago and I have no complaints. I commend the center here in {County}. They are doing an outstanding job.

Consumer goes to {Agency}. They are so good to her, and she loves the school so much. I thank God for the people over there. I tried to fill this out as best as I can. The consumer is my sister, whom I take care of after my parents died. She loves the school and teachers.

4b. Dissatisfied with Education/Training

I would like to see more support for DHR in the after school programs and recreation during the summer for young adults to enjoy their life, in the community or area which they live in. They need to not be left out. Please help them.

5b. Dissatisfied with Transportation

Transportation becomes an issue, especially when taxicabs charge $8 per day.

Transportation is a problem.

I am dissatisfied that the state has changed the transportation services that transport my sibling to and from day services. It was {Agency}. They are working hard to get another agency. But it has put stress on the facility to make sure they can get it.

Sometimes transportation they have a van which all the consumers plus the van driver actually have to bend down to get on. I think this should be a safety issue and that van should not be allowed to transport anymore.

I am concerned about transportation my daughter receives, there is not any type of phone on the van. If something should happen to someone on the van, the driver has no way to get in contact with anyone. It should have some type of phone on the van.

Lack of transportation service is the only drawback to the current level of services provided.

5c. No Transportation

We need transportation services. Without transport these individuals can never be independent.

6b. Dissatisfied with Recreation Activities

I would like to see more support for DHR in the after school programs and recreation during the summer for young adults to enjoy their life, in the community or area which they live in. They need to not be left out. Please help them.

But nothing has been said about the recreation. A dance class might be good exercise but we can't afford that.

The service center my daughter goes to is very small building with 40 to 50 people: mentally and physically disabled. They just make them sit in front of the computer which is not much use for them now and in their future life. By sitting all day make them gain weight. Instead of that, we wish the state would consider to make better place to move around and have some physical activities.

7b. Dissatisfied with Communication

I don't know about anyone else but me myself feel like there is just no one you can find out anything important you really need to know. You can call and ask this person they will tell you let me get back to you about it. When they do they will tell you well you need to get in touch with this person. Sometime we feel so helpless because it is like everyone is giving you the runaround. It really gets to be frustrating.

My son attends a work program or I am solely responsible for him because things that's important he's not really capable of answer them. So I have a problem when they question him on matters and I'm not there. If you like you can contact me. Thank you for your patience.

There is a lack of clear communication about services available to families of disabled adults. Also families don't know what to expect for their child upon their deaths apart from what the family will provide. Also what are the goals of DHR for individuals that are disabled? The state is creating a system based on philosophy and not the philosophy of the families involved. Families don't want all institutions for the disabled closed. Some adults can't be in the community. The state needs to be responsive to the opinions and goals of the families involved.

The only thing we can count on as far as the service and support system is that they will make their monthly visits but as far as meeting any of our needs they have no help or answers for us. There are no funds allocated for this or that or they are still waiting for answers for questions I've asked. By the time I get answers it is too late.

7c. Information

I have heard rumors that the days are going to be cut from five days to three days a week because there are not enough slots to put children in. Because budget has been cut by governor.

I have two college degrees and have a hard time following Medicaid documents I receive. I wonder how other folks can understand all of the jargon.

It has been a little unclear as to what services we are eligible for and even which services we are receiving, as well as who is providing them (e.g. county vs. state and by private contracted agency vs. employees of county or state). A web site explaining what services are available and whom to contact would be very helpful.

For the past 22 years I have fought long and hard for the services my son has received. Mostly through serendipity and countless phone calls which have eventually led me to the right person. I feel there should be one government organization which oversees services for the handicapped from birth to death. They should provide information about Medicaid waivers, home help, respite, SSI, and long term care directly to parents and

through school social workers. Each child should be assessed periodically to determine his or her needs and the needs of the family. Access to a case worker should always be available for emergencies and questions. I understand that this would be the ideal world and the problem always is lack of funding. However I do believe there could be more coordination between all of the agencies which provide services for the handicapped.

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7g. Interagency

It has been a little unclear as to what services we are eligible for and even which services we are receiving, as well as who is providing them (e.g. county vs. state and by private contracted agency vs. employees of county or state). A web site explaining what services are available and whom to contact would be very helpful.

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8. Aging Caregiver Issues

We are very happy with the day program. However, we need access to a local group home for our multi handicapped daughter. There are none in our area. We need to have something in place as we are both getting older. We don’t have any in home help and have to work opposite schedules (my husband works M-TH)(I work F-S-S). We are unable to go out as a couple or to vacation.

There is a need for a group home in the {County} and North GA area. My grandson has Prader/Willie Syndrome. {Agency} of {Town} is an excellent program. At age 70 I will not be able to care for my grandson much longer. Please don't cut our services we are now getting.

We are old people. My wife can't keep up with the day. Her driving is a few blocks to pick up our daughter at center. She forget where the car left or windshield wipers. Our children keeping us going. Consumer can't take care of herself. We make it with the help of our church. We drop consumer off at the center 830 am and pick her up at 230 pm. Somebody has job taking care of her night and day, 24 hr a day and 7 days a week. We do the best we can with what we have.

As our son gets older, we have real concerns about receiving residential assistance for him when we can't take care of him. It seems that resources are being used up by people who have not contributed to the system.

I am 65 and concerned what will happen to consumer when I can no longer keep him at home.

As we get older, 74 and 78, we need additional help and it has come forward. This way we can keep our son at home.

I am 69 years old and my health is beginning to fail so I hope to get him in long-term care in {town}, GA before long or I'm going to try.

In the near future, I feel that I am not going to be able to care for my daughter at home. I wish she could be placed in a host home when that time comes. I am horrified when I think of a nursing home.

I am a 70-year-old retired person and a widow. My daughter is 48 years old. My worry is that I will not be able to get her a group home. From what I understand, there are no more residential Medicaid waivers. I have no other family members that could manage her.

My husband and I are both healthy and our daughter is happy at home. What concerns us, of course, is what will happen to her after we are no longer able to care for her.

We need more living facilities available when the time comes that we can no longer take care of our developmentally disabled child.

Many elderly parents have no choice but to be stuck with an adult disabled person and they are aging/retired/sick/under-employed. There is no freedom/independence or assistance, and what happens when the parents die?

I take care of my son. I have been doing this since the minute he got sick at the age of 17. But I am 70 years old, I don't know how long I will be able to do so. What is going to happen after I'm gone? I am a widow, I have another son that is married and has his own family and I don't have any other relatives. I wouldn't like for my son to go to one of those independent group homes, but what else can I do?

10a. Satisfied with CM

I have worked with my coordinator from {agency} for a long time and she is great, in spite of the state folks.

10b. Dissatisfied with CM

I took to mean the service coordinators from the State. In general, these folks are not worth speaking with and a waste of taxpayers' dollars. They show up once a year and don't even know the person they are developing the ISP for.

I never know who my state coordinator is and I never hear from them.

I have never met the new caseworker for my daughter. She has called once. She said she did not know of my request. She has been the caseworker since December.

10c. CM Turnover

Support/Service coordinators have changed often and thus far we have not been impressed with this service. They do not appear to know my family member or the needs/wishes of my family member.

A second concern is the especially high rate of staff and coordinator turnover at the center this year, as well as personnel shortages which, in turn, have often led to curtailment of some client activities as defined in the individual's annual staffing review.

There is a lot of turnover at the state agency. The person assigned is new every time there's an evaluation due. The new person is not familiar with the history of my family member or how evaluations are previously done.

10d. Shortage of CM Workers

A second concern is the especially high rate of staff and coordinator turnover at the center this year, as well as personnel shortages which, in turn, have often led to curtailment of some client activities as defined in the individual's annual staffing review.

Support coordinators are overwhelmed and unable to do any more than the minimum required. They are unable to go outside their basic capacity to assist families in getting additional services. The attitude is that you are luck you get what you get because there are those who are not getting any services. Regional board gives lip service but in a true crisis you are on your own. Not supportive at all. I want my daughter to receive services in her home as if I am not there. I need a resource which is knowledgeable and motivated and can effect change.

10f. Pay CM More

Government could care less. They cannot keep people because they do not pay a decent wage.

10g. Service Plan

The new I&E process is ineffective. The person who represented the team at my family member's ISP didn't know how to complete the ISP and called me the next day and I had to correct several inaccuracies.

Please speed up the start date for consumer directed services. We would like to manage our own funds under NSE, so we can make the $ go further. I also would like to be able to choose who provides the services rather than being told I must choose from the list.

As his mother I am not satisfied with outside agencies coming in and deciding his future and never see him again. As his mother I have input but I know many consumers have no one to advocate for them but the agency providing support and has for many years.

Would like to see a shift to self-determination, allow the caregiver to use a pre-determined amount of money to select the care necessary in a particular case. If a CNA or higher classification is not necessary, why force the caregiver to use an agency to provide this.

Vermont has a system that works, is cost effective, and allows the caregiver the flexibility to provide services within their unique case.

Supports need to go with the individual – waivers belong to the consumers not the providers.

I think more needs to be done toward evaluating persons requesting services to determine at one evaluation if they need mental health and/or developmental disabilities and or addictive diseases assistance and plug them into the proper programs and or other available assistance from other agencies both public and private. Also there needs to be more outreach to family members providing support for challenged persons to help them help their challenged family members and attempt to help them cope with their day to day frustrations as they provide care.

Provide yearly review/summary of activities for consumer/caregiver to maintain on a regular basis.

The process for getting additional services is not working. I have been told that the ISP should contain information/request for more services and the regional board will decide on the validity of the request. I hear there is no $$$, yet I know of children/adults with lesser needs that are getting more. I have been told that my legislator can help – is that the right way to determine who has needs? I feel the current system is corrupt.

It would help if the family and consumer were given choices if and when available.

11. Staff

At the day program my son is involved in, everyone is friendly and respectful except for 1 person. She has an attitude like she is above me. When I call and she answers, she makes me feel like I am bothering her.

Support workers need to wear uniform or carry ID badges when out in public with the consumer.

11a. Satisfied with Staff

The staff is helpful and dedicated there seems to be no staff turnover with the instructors who work with the consumers.

We appreciate the assistance we receive, and the people we are associated with through the program are very helpful.

Staff at my son's center are hard working people and love their job and the ones they work with, they do the best they can on what the community will let them or the state will allow them with the funds they get. My son's life is a lot better because of the center and the staff.

My family member is very happy with the staff at the workshop. I wouldn't have it any other way. They do a wonderful job.

We are very pleased with the service that we are receiving for our family member. We couldn't ask for a better staff. They are an excellent group of people to work with. Our family member loves this place and the staff so much that she wants to go every day even on Saturday and Sunday.

The people who work with my child are some of the most kind people I know. I'm thankful for them every day.

Overall I am satisfied with the center and staff.

My brother loves the training center and the staff. They do an excellent job. He's very happy to go every day.

Consumer goes to {Agency}. They are so good to her, and she loves the school so much. I thank God for the people over there.

My family would not be able to function without the support and care of the people involved in the day program my son attends. Physically and mentally he can not be involved in many community activities. The day program gives him some place to go each weekday and he looks forward to going so much.

I know what staff is and they are great!

The staff that work with our son at his day program do a remarkable job. The services are not perfect but remarkable considering some of the obstacles the staff has had to face. In times when money has been tight and the center has been on a freeze on rehiring when staff leave, the dedicated ones who were left have worked beyond the call of duty to try to provide quality services. Money has also kept them from adding new clients when old ones die or move to other areas. They are very willing to provide services, but very constrained by the state.

11b. Dissatisfied with Staff

This support staff is unfamiliar to me.

Some staff is very rude to consumers even saying uncalled for things about sex.

The center where our family member attends spends more time doing paper work than with the client. The turnover there is unreal. The lady in charge over mental health is only in there for her glory and the big bucks.

My sister goes to the center {Agency} of {Town}. There are quite a few things I don't approve of. Some of the staff are just mean and hateful to the people. I have seen it on more than one occasion. I don't like the tone of voice they use. These adults are so pitiful, I don't go down there often because it breaks my heart. They do not let them finish their lunch. My sister eats very slow and comes home with most of what I send for her lunch. The program there is good, but certain staff members, not all of them, need to be anywhere but there working with poor disabled adults.

11c. Staff Turnover

A second concern is the especially high rate of staff and coordinator turnover at the center this year, as well as personnel shortages which, in turn, have often led to curtailment of some client activities as defined in the individual's annual staffing review.

When staff changes come, i.e. new or staff leaving it is upsetting for consumer. Not enough staff hinders this consumer in getting out in community and getting work.

They cannot keep decent staff for very long.

The turnover with CNAs is horrific. The result is poor care and uncertainty for the family and person who receives the care. Other options need to be considered.

However there is a constant turnover of the agency's employees and most of the time his care has to be sub-contracted out which is not using his funds wisely. It would be a much more cost-effective program if the employees came directly from the agency that we are contracted with.

11d. Shortage of Staff

A second concern is the especially high rate of staff and coordinator turnover at the center this year, as well as personnel shortages which, in turn, have often led to curtailment of some client activities as defined in the individual's annual staffing review.

When staff changes come, i.e. new or staff leaving it is upsetting for consumer. Not enough staff hinders this consumer in getting out in community and getting work. Overall {Agency} services are great.

Staff shortage.

They are some very cruel clients out there. They need a larger staff to know what is going on and keep them in line.

The staff also has so much paperwork to do that they can not spend as much time as the people need.

11e. Staff Not Qualified

The services we receive under a CHSS waiver are not adequate. We have mostly staffing for temp. agencies who are not trained in autism. The center and the CSB have a warehousing the retarded attitude and don't want to help people or improve the quality of life for the disabled.

Train support workers in specific illness/disability usually once a year.

When her job coach fails to complete paperwork, her transportation to work does not show up. They do not call saying it is the job coach's responsibility. The other concern I have is the level of concern I've seen from group home caregivers. I notice this at TRS activities my daughter participates in. For example, caregivers bringing group home

members to activities without coats when the weather is very cold.

11f. Pay Staff More

I wish you would pay staff more for their work. They should receive pay advances like teachers do.

They cannot keep people because they do not pay a decent wage.

Our caregiver is wonderful and we have a wonderful relationship, but sometimes the provider is 2 to 3 weeks late paying her.

The staff who do the day to day care aren't paid enough for the job they do. Therefore there is a large turnover and good people are lost to higher paying jobs with better benefits. The people who care for our child are excellent and continue to do the work because of their love of the consumers. Thank you for the chance to share our thoughts.

11g. Substitutes

Recommendations/Suggestions for improvement/coordination of services: 1 – develop or maintain alternative plan for consumer when caregiver becomes ill (plan at client's yearly review meeting).

12a. Family as Paid Staff or CM

I feel like my son should be able to hire someone or a family member to come in and take care of him and send in for money from respite later because there are times when there are emergencies. I asked for someone over a year and a half to come and help me in the evenings and weekends because I have a bad case of arthritis in my hands and shoulders and he is a big man that I have to lift twice a day.   I need help right away.

If we could have vouchers twice a month or once a month to pay someone we know and he like maybe a friend or family member. Look like the money some kind of way could be issued to the person to pick who he or she would like to take care of that person. My health is poor and I need someone to help me to give baths, get in and out of bed and dress him and feed him, in so many things I need to ask for but they say I can't do that with my money. I have had help that really didn't work out and really could not handle him.

I would like more help with my son but not always having to get help by an outsider. Relatives are always exempt from being pd by the services offered. These are the people you feel comfortable with to take care of your loved one when you're away but one services "respite" don't pay for family members. This is a joke.

There are restrictions on family members getting paid to do work that requires outside support. My wife and I both work after normal retirement pay lots of taxes and my disabled adults get substandard support.

13. General Well Being

The services he receives are generally good and helpful but when they went form a training center to a service center he no longer gets help with things like speech therapy and help with general knowledge of everyday things needed to know for daily living.

13b. Safety

Sometimes transportation they have a van which all the consumers plus the van driver actually have to bend down to get on. I think this should be a safety issue and that van should not be allowed to transport anymore.

The center that the consumer goes to, I think they need to put carpet on the floor. Because if they fall or something they hit concrete only.

I am concerned about transportation my daughter receives, there is not any type of phone on the van. If something should happen to someone on the van, the driver has no way to get in contact with anyone. It should have some type of phone on the van.

13d. Social

The family member also gets to go out for lunch and bowling that she enjoys very much.

However, I feel there is not much information on availability of social activities for adults with mental disabilities. I feel my child is pretty much cut off from social activities and meeting new people.

At the moment my daughter loves who she goes out with. My daughter is already involved in church

Consumer is a happy son – He attends the {agency} for 5 hours once a week. They take him to spend time shopping and mixing with "normal" people as well as his own MR group. Consumer attends church, church socials and visits with aunt and uncle and married sister and married brother for a break from family.

Agencies (need to) coordinate resources so there could be monthly night activities for clients 21 or older.

She's not able to do a lot, but they have computers, exercise, etc. She goes out into the community, the mall, WalMart, out to eat. We go to church, she has a best friend and we go out to eat and to the movies.

14b. Dissatisfied with Respite

We have to receive respite care out of the county. It would be nice to have at home in our home county.

There is one area of service I would like to see more of and that is money for respite care. Right now we have 1-2 night, 3 day weekend every 6 months. Respite providers charge anywhere from 80 to 120 per night. Respite money is desperately needed.

The one time I needed to use a family member for paid respite care, I was unable to do so.

I am receiving 6 hours each week for respite care. I need more hours for my son since he is 22 years and out of school. I have had problems with staff not showing up, being late, or quitting. This is not good for my son because of his autism – he needs to be kept on a routine. I also need emergency help.

I would like to see a better respite program. I would like to see the parents get the money and find respite to fit their needs. As a parent of an adult with seizures the respite program doesn't work. As with a lot of parents. The names the respite program gives us doesn't work.

Some of them has never seen a seizure. Some parents have great luck with the respite program. But for the ones it doesn't work for, we are out in the cold. I have to take my son out of state to a private program and pay. Does all the money go for half the population.

Referring to question 18 on the survey about respite. We wanted respite here in {County} where we live, but the providers told us they did not have any homes here for respite at the time, so our family member with a disability has to be transported to {Town}, GA. We had the time from 6 pm Friday to 6 pm Sunday. The support workers that were transporting him were doing good at first but then they were telling us the reason they stopped was because it would take them two months to get their mileage pay. If the money is there why can't they get paid when they are supposed to. Now the support coordinator picks him up. She might pick him up at 10 or 11 pm on a Friday night. We feel this is too late for him to be traveling at night, when he should be at his respite and in bed by that time.

15. Crisis

Nights and weekend emergencies are not available in this area.

16. Funding and Budget

One of the services received by our family member was not paid for a year – still has not been paid as far as we know. We paid for movies for about four months and we finally had to call regional board to get reimbursement that took nine months.

My son has worked for a company in our community for 10 years and just received a higher per hour wage rate of 6.50. He tried to qualify for other assistance, i.e. food stamps, but they disqualified him because he made too much money. If he wasn't living at home he wouldn't be able to support himself. I feel that DHR and the State of Georgia have not done enough for those individuals who are considered mildly handicapped.

These individuals maintain low paying jobs and can not qualify for assistance such as SSI. I'm saddened by the lack of concern from our officials which hold positions that could make a difference in their lives!

My sister has a {Agency} waiver. Just recently there was an increase in her allotment. The purpose of the increase (per request) was to provide the needed care (daily) such as respite and personal support at home. At this time, she requires one on one care. To our consternation, the increase designated to my sister was also an opportunity for the provider (Agency) to get a 50% increase for administration costs. Ultimately we are unable to get respite because the cost of personal support takes most if not all of the increase allotted by the agency. To us, this is unconscionable. It defeats the purpose of having an increase when the funds are appropriated at the whim of the provider. Family members should have the option of deciding how and where the money is spent. Who is monitoring the individual budget expenditures? Not all families are self-centered, and not have their loved one's care in mind. I am a proponent in a self-directed system.

She needs financial support. She gets a little but not enough to live on. She is in a financial struggle.

Our family member is bed confined and chronically ill. Community activities are not possible. Our greatest needs are respite and money for dental and equipment i.e. wheelchair lift for van. It is our belief that the waiver money has too many people that have to be paid before it trickles down to the consumer. Then we are told no money, no money, no money.

I just wish they would have more funding for young adults 20-49 years.

My son is one of the most severely physically disabled and profoundly mentally disabled, yet he receives the lowest amount of waiver money. People with less severe disabilities are receiving significantly more than him. This is not right, and it is not fair. His needs are not being met.

If money is received we have no knowledge of it or how it was spent.

Now that our disabled child is older and we are of retirement age, we need information on how our social security benefits will affect his SSI and Medicaid status. We need someone who can advise us on what is best for him when we are dead. We have been told that when we start to receive Social Security benefits that he must come off of his SSI and Medicaid and receive part of our Social Security benefits and be on Medicare, not Medicaid. We he still have a Medicaid waiver that allows him to attend the day center? The Social Security office could not tell us.

There isn't enough money for the NSE waiver to last a whole year when you have a family member requiring medical supplies and is enrolled in a day program.

Currently, it seems that some families receive government funded care for their family member while other families have their family member placed on a waiting list. We believe that a means based family financial participation combined with government funded would allow for care to be made available to many more family members.

Our provider sometimes tries to cut our benefits. I always protest.

The services we get are probably as good as programs with little funding available. Our physician has recommended peer support after day center hours but funds are not available.

Many persons need services that cannot be obtained. It's hard to understand why budget cuts continue for mental health and mental retardation when the state and federal governments have funds for every other conceivable need. We have too many people in charge of these programs who have little hands-on experience with disabled persons. It should be required that a person working at a top management position in DHR or other health programs be experienced in working with MH or MR persons.

My son is able to work as a bagger at a grocery store. It does provide him with an income but not enough to live on his own. SSI has turned him down because he can and does work. There is a big gap in the system for those with disabilities who function and want to contribute to society yet lack all the necessary funds to do so. We have been told it would be better if he did not work and stayed home and collected SSI. Mentally he would be worse off. There needs to be a system that supplements their income enough for them to be independent. This is very lacking in the system.

Recent cuts in funding have put families in dire straits. This is one of the most hostile administrations as far as the mentally and physically handicapped population is concerned that has ever been before. The money is there. We know it is. Yet, it is not appropriated where it is needed. Legislators want to give tax cuts. Problem – Politics!

We need financial help with extensive dental bills. We need funding for residential services. We need financial help with alternative medicine supports – i.e. homeopathic medications and supplements that are beneficial for consumer. We need financial help with hypnotherapy.

We as the family with the very deep problem hope that this survey helps the state of GA to make and help these families to get better services. But survey and research doesn't solve the problems. It takes more efforts and budgets. As the parents we can't afford to solve all problems and we need your help. Together we may help each other and make these people to have a better life. There are some problems that may never be solved unless spending more money. First the living with the retarded child will affect our own life. The services will directly effect our life, so please we beg you to support a multiple year funding plan to unlock Georgia's waiting lists by: -funding 1500 disability slots in the DHR budget as called for in the multiple year plan. – funding 152 independent care waivers (ICWP) slots in the DCH budget. –continuing to support additional funding for disability providers that will ensure direct services professionals are paid adequate wages for quality services. Wait list for 13 years. And additionally – residential waiver, -dental services. Thank you.

The staff that work with our son at his day program do a remarkable job. The services are not perfect but remarkable considering some of the obstacles the staff has had to face. In times when money has been tight and the center has been on a freeze on rehiring when staff leave, the dedicated ones who were left have worked beyond the call of duty to try to provide quality services. Money has also kept them from adding new clients when old ones die or move to other areas. They are very willing to provide services, but very constrained by the state.

Funds that are for the disabled is being cut each year, and enough is enough. If people with disabilities is increasing each year, why can't funding be provided accordingly?

The center we use is great. However we always hear that funds are being cut and more is being added to be done. We have no idea how much is being spent for what. We just take what we can get and enjoy

And the only other services he gets is respite if I need it and it's not often that I use it unless it is necessary but I would like to have some kind of financial help for myself with him so I can stay home and be here when he gets home everyday.

The only thing we can count on as far as the service and support system is that they will make their monthly visits but as far as meeting any of our needs they have no help or answers for us. There are no funds allocated for this or that or they are still waiting for answers for questions I've asked. By the time I get answers it is too late.

The State needs to fund more for this group of people and business needs to be more involved with jobs to help them have a chance to be more productive and self reliant.

Question 53 about how much money is being spent for our family member with developmental disability. I have tried to find out about the money. My family member's support coordinator told us to ask the provider. The provider never answered our question. Everyone acts like it is a big secret when I started asking about it. We figured maybe we weren't supposed to know. Is it possible for us to find out? I would like to thank you all for this survey. At least it gave us an opportunity to get some things off my mind even if it was on paper.

17a. General Satisfaction with Services/Supports

The local service provider {Agency} does an excellent job.

My daughter receives services from {Agency}. This is an invaluable service to me as a working parent. She does not like being at home all the time. She has been in either this day program or public school all her life and if after school there had been nothing – I don't know what I would have done. The people at {Agency} have been there years, some of them 20-30 years. There is not a better place for her. It would be terrible for us if we didn't have the consistency, stability and reliability of {Agency}. Places like {Agency} need more funding not less. My daughter is physically limited in what she can do in the community and {Agency} provides for her adequately.

Please keep up the good work because without this help we could not keep our family member with disabilities at home. And where would they go. And what care would they get. Thanks. God Bless.

I have been my daughter's legal guardian for 34 years. Through the agency and program that she participates in, we family members are very pleased and satisfied with the progress she has made.

The help we have in the mornings, evenings, and on weekends has made a tremendous difference for me. I am 85 years old and could not provide the care my daughter needs by myself. {Agency} of GA has been extremely helpful.

Overall {Agency} services are great.

The support GA's Division of Mental Health and Developmental Disabilities has helped a lot.

My family member is very satisfied with his agency services. He is provided with choices as far as community outings. He is not interested in a job in the community. He is happy with socializing with his peers in his day program. He has a sense of belonging in an environment with others he can communicate with.

We appreciate the assistance we receive, and the people we are associated with through the program are very helpful.

Staff at {Agency} do a super job. My son's supervisor is outstanding in all areas. We did have an issue with a coordinator not responding, but the provider did a super job in resolving the issue. We are very happy with the services rendered at {Agency}.

Because of all the services my consumer receives it has allowed me to provide her with proper care that she needs.

Overall we are very satisfied with our services. Positive difference on our family.

I am very satisfied with services provided to my family member. They are all polite, helpful and easy to talk to and actually listen. If it were not for their center I am sure my family member would be at home, watching TV instead of interacting with others.

I think everything is all right.

It has been so helpful to me and my child really, really likes it very much. May God bless all of you. I have a full time job with my child. I am a caring mother. Thank you very much.

Again I'm extremely grateful for the services that we do receive and would not be able to provide for my son without help. Thanks!

However, I know I couldn't make it without your help and I truly appreciate it.

My daughter attends {Agency} for handicapped adults and has for over 25 years and she still enjoys every day she goes there! If it was not for these great people I don't know where we would be today.

17b. General Dissatisfaction with Services/Supports

My son was receiving services from {Agency}. One of the ladies that was supposed to take my son out on an outing she was not taking him but she was getting the money for herself. They didn't do anything about it.

I feel that {Agency} has fallen short on their overall services to their clients.

We have very poor services in {County} GA {Agency} is our provider and it is a poor, poor provider.

Services are at a lower level than they were 30 years ago. The government could care less.

We have been promised services for the last several years, but nothing has been accomplished. Empty promises.

The services we receive under a CHSS waiver are not adequate.

I don't feel that my son gets the appropriate services he needs, if this is what they have to offer it is a waste of time for a handicap child. The provider comes whenever/sometimes not at all because she had something to do with her family members. I told his support coordinator and nothing was done. And when I needed to go back home last month for a funeral I asked for some help nothing was done. I had to try on my own at the last minute. The day provider doesn't have many activities, she just takes him with her on her daily business routines, they don't help him at all it is not fair to my son. The weekend before neither of the providers came, on the weekend I have to try and work and had to stay home. He got really upset and I couldn't explain to him why. I really disapprove of this and don't like it at all. If he can't get what he needs I really don't need this. She's already said she's not going to get him Saturday and I'm fed up with the bull crap. I need other help for my child.

The care for our disabled has gone down in the last 2 years.

Consumer has PWS, is blind, on a sleep machine, and can only walk short distances. {Agency} (where she worked for 11 years after graduating high school in 1988) comes in groups to visit. Tells us they will help take her on trip – but after 2 years nothing. Consumer has Medicare A, B and D. We are trying to get a wheelchair and keep Dr. bills paid and still eat.

As far as I am concerned, {Agency} is a joke and should be shut down.

Hi. I am not satisfied with {Agency} because my daughter is on Seroquel 600mg in morning and 600mg at night and they won't approve but 800mg a day and they won't work. If you cut in just 1 day she is out of control and they won't let her go to the center.

17c. Access to Services/Supports

We are very happy with the day program. However, we need access to a local group home for our multi handicapped daughter. There are none in our area. We need to have something in place as we are both getting older. We don't have any in home help and have to work opposite schedules (my husband works M-TH)(I work F-S-S). We are unable to go out as a couple or to vacation.

One factor is that a lot of respite facilities are far out and there aren't a lot closer to where I live. Hopefully there will be more, closer.

It would really be nice to have a group home available in my county for future planning.

To my knowledge there is only one agency in the area.

We used to live in {Town}, {County}. There was a {Agency} facility in {Town}, a day treatment program, a dept of community housing that placed the mentally disabled in group home under their supervision. Here in {Town} there isn't a simple facility for the mentally ill. I have to take my son to the mental health office at the city of {Town}. The only Day Treatment program they have in this county is located in the city of {Town}. There isn't a community housing dept in this county. I have found out that there are several group homes. These are independent group homes and the mental health dept in this county doesn't supervise them.

17d. Info Regarding Services/Supports

What do you mean by financial support? I need more additional material on transportation for medical appointments. Could get more assistance and financial.

My family member only receives day/employment. I've never been given information on respite care. Usually our family member goes everywhere we go. The only respite care I would be interested in would be day trips for our family member. It would give us a chance to do things the family member is unable to do because of his physical disability.

I don't know the services that are being offered in {County} for someone with mental retardation.

I would like information on aid or help for my family member.

More info needs to be provided for services and how and where they can be obtained. Not enough programs are available for family members. Need more activity-based programs.

I just need to know what services are available for my mentally handicapped daughter. I know about respite, but are there other services offered?

I live in {Town} Ga. I have 2 children with special needs. I try to research and find out as much information as possible for my children. I still know there are services out there that I don't know of.

I would also like to be informed of advocate support for autism and respite service.

Would like to know why we cannot get Medicaid Waiver because it is badly needed.

17e. Need More Services/Supports

The only drawback is the hours the program runs. It is state run and closes at 2:00. My family moved here a year ago from Florida. In FL you are assigned a support coordinator when disabled well before you are out of high school. You choose your support coordinator and receive monthly statements on what they the state is paying the coordinator as well as money spent on other services. Yes FL has other services available to the disabled. GA is so far behind FL in what is available to the disabled. When I inquire about services and supports I am told there is a waiting list even when the disabled are under the waiver. The waiver basically secures the day/work program within the state which is very important so that the placement is not under grant and aid which would differ county to county (i.e. some counties can't offer day/work program placement for you if you are not under a waiver). In FL if you care for your adult disabled child in your home, supports are offered to help care for them in your home or you may choose a work/day program that is full time so that you may work outside your home as there are not many options for you after 2. Most don't leave work until 5-6. GA should offer much more to the disabled as GA has so much to offer other citizens in this state. I would like DD services to look into the fact that GA residents under Medicaid (SSI) with a permanent lifelong disability have to pay co-pays for their prescription medications where as the poor (under a certain income) would have no co-pays but have the ability to further their education and earn more over their lifetime ore carry private insurance. In most states Medicaid is divided into categories some have co-pays some don't for medications. I would not think that with a permanent lifelong disability you would fall into a co-pay category but in the state of GA you do.

We had never had co-pays before, the waiver in FL even covers all expenses Medicaid will not cover when you have a waiver you also have med-waiver.

I would like to see some sitting services. It would be nice to go out sometime.

We need day hab facilities with transportation in {Town}. My daughter rides in a van over an hour one way to a facility in {Town}. We also need afternoon care. My daughter gets home at 3:30 and I can't get home until 4:30. We spend most of her SS check to pay for afternoon care and I had to find someone myself.

I feel we the parents or guardians of these special needs persons need to have more respect and support. Those of us that take 24/7 care of our member with no help from anyone else gets burned out too soon. Need a facility once again to give us a break. All I receive is help with my member's diapers and that is all. Surely ya'll can figure out a service to help us that do 24/7 care for our members. A way to give us a break.

Alternative living arrangements. Transportation to day program. Respite care. Services needed.

I need some help to obtain legal guardian from the courts.

Our family member is bed confined and chronically ill. Community activities are not possible. Our greatest needs are respite and money for dental and equipment i.e. wheelchair lift for van. It is our belief that the waiver money has too many people that have to be paid before it trickles down to the consumer. Then we are told no money, no money, no money.

There are not enough programs for that age group. They are always something for the elderly but not for the young people. How come?

Unfortunately, our county offers nothing for adults with disabilities.

The community we live in does not participate in the community service center with jobs. If it was not for {Employer} support to the center my son attends the job he does would not be there. Everyone wants to put this part of the community to the side where they don't have to see them or work with them.

Daily full program should be provided for each child. This is positive in parents keeping the children at home and it not being the states responsibility.

Because of health, she is only out of home 1 day per week and 1 day per month. We do not have anyone else to depend on, so in-home respite providers would be greatly appreciated, however we do not have and haven't been able to get. I'm a single mom and can't work because I need to be here with him 24/7. Help would be nice. In home respite would mean less stress.

We need to have programs that train those that are capable in things they can do to help them obtain some kind of work. In our area we need more places for respite care.

More info needs to be provided for services and how and where they can be obtained. Not enough programs are available for family members. Need more activity-based programs.

Our family resides in {County}. Our county does not support the needs of our county's disabled people. Our school systems or political leaders are not supportive. We need more day care type services. It is very difficult to find caregivers for our special needs.

We do not have none of this stuff.

Consumer has no one to help with her care at home. We would like to have some in home respite help. She is a diabetic and no one is able to give her shots.

Due to my family member's illness he needs me at home with him due to seizure activity every day. He needs PRNs daily and the staff is not licensed to give meds. He can have up to six or eight seizures a day. I have to work 40 hours a week to pay bills and keep some place for us to live. My child has to go to Atlanta several times a month to Neuro clinic. Sometimes I'm unable to go due to time at work. It has been times we didn't have money to pay bills due to absentees at work.

There needs to be more respite programs for the parents who keep their child with disabilities at home. There isn't enough money for the NSE

We are moving to another state when my son turns 21 because GA does not have adult programs for people with severe self-injurious behaviors and autism. With the rise in the autistic population, GA needs to have better placement options for those with behavioral issues.

There is a need for a group home in the {County} and North GA area. My grandson has Prader/Willie Syndrome. {Agency} of {Town} is an excellent program. At age 70 I will not be able to care for my grandson much longer. Please don't cut our services we are now getting.

I would like to see a group home for persons who are medically fragile. My son is medically fragile and it would give me and other parents a peace of mind to know there would be a place that is equipped to handle our loved ones in the event we should become unable to care for them at home.

My daughter needs more services than she receives.

Wish they had respite care for weekends or any other time that I need. Also more work available. Thank you.

We have a 30 year old that could use a community/sheltered/supported living situation (i.e. supervised female group home). There are none, and her SSI and meager income could not pay for an apartment with a full-time sitter.

We used to live in {Town}, {County}. There was a {Agency} facility in {Town}, a day treatment program, a dept of community housing that placed the mentally disabled in group home under their supervision. Here in {Town} there isn't a simple facility for the mentally ill. I have to take my son to the mental health office at the city of {City}

The only Day Treatment program they have in this county is located in the city of {Town}. There isn't a community housing dept in this county. I have found out that there are several group homes. These are independent group homes and the mental health dept in this county doesn't supervise them. I also have found out that in one of these group homes they were

{County} isn't a small county and I don't understand why there isn't any more help here for the mentally ill. There isn't a single hospital for the mentally ill in this county. In

{Town} there was the {Hospital} and there were other hospitals in the county, but over here there is nothing. I think it is time that the government should do something to correct the problem.

62 – no other option to being at home is available. 64 – do no want family member at home. No help is available. Need residential and respite!

We do need some help in the evening transferring him from the wheelchair to the toilet to the tub to bed.

17g. General Dissatisfaction with Service Management

Support coordinators are overwhelmed and unable to do any more than the minimum required. They are unable to go outside their basic capacity to assist families in getting additional services. The attitude is that you are luck you get what you get because there are those who are not getting any services. Regional board gives lip service but in a true crisis you are on your own. Not supportive at all. I want my daughter to receive services in her home as if I am not there. I need a resource which is knowledgeable and motivated and can effect change.

The metro region is not well managed. Critical decisions linked to funding and ISP decisions are made by administrative folks having no clinical/medical training with which to make those decisions. Subjectivity is the name of the game rather than objectivity/facts.

We have too many people in charge of these programs who have little hands-on experience with disabled persons. It should be required that a person working at a top management position in DHR or other health programs be experienced in working with MH or MR persons.

Comment – there are too many people on waiting lists and not enough quality service providers mainly due to lack of funding, government bureaucracy, silly rules and politics. Too many people in ivory towers making decisions that are out of touch with reality.

It is indeed unfortunate that the bureaucrats of the DHR have so little actual interest in the welfare of the handicapped persons they purport to serve.

The people who do the work are fine but there seems to be new layers of people who only are there to check up on the workers. This seems a waste of money.

17h. Waiting List

We requested personal support about two years ago for our profoundly retarded daughter with profound speech impairment to be given by her older sister that fully understands our daughters' speech and emotional needs. This request has not yet been approved. As parents we need an occasional evening out or some days free of her care. We supply many of our daughter's needs every day with no relief year round. Please help.

Our family member is still at home after waiting 15 years of placement out of home so he is not as isolated from others he would benefit from being with. He is at home alone without companionship except for parents.

I am trying and have applied for transportation for my family member. I don't drive and have been told that I will be placed on a waiting list.

I would like to see placement for my daughter. I call to find out where she is on the list. They always say there is no money for a waiver for her. I work all different kinds of hours. She comes home to an empty house many days. Other states do more for their disabled people. Michigan, NY, CA, are much more ahead of GA. What do people have to do to get a waiver? We have my mother to care for at my home, she is 84

She was on the list for 2 years and coordination wasn't good. They almost took her off the waiting list. She also got into services after another child in her class got on. She was on the list before he was.

I have a comment. My husband and I have been trying to get our son into a group home for 3 years now. People jerk us around with all kinds of reasons why is it taking so long. I have written the governor and to you no response.

He wants a residential waiver! He does not understand why he has to be on a waitlist. He has 2 other brothers who went to college and moved out and he is frustrated he does not have that option.

19. General Concerns

The local service provider {Agency} does an excellent job. But the state mandated oversight agencies have been irrelevant bureaucracies – a total waste of money. The state should give that money back to the providers which actually provide services.

Our son has a Medicaid waiver that allows him to live at home with supports. He was institutionalized for 7 years which was the worst experience our family ever had. He has been back in the community for almost 8 years now and continues to thrive. Once identified as the worst behavior problem in the institution, now he is not viewed as having behavior problems at home or in his day program. With the support of family and paid assistants, he has taken charge of his own life and is loving it!

Currently we are paying for our son's medical services and providing his transportation. He has money in his name which limits his eligibility but does not qualify for insurance at his part-time workplace. Self-insuring does not provide any security or protection if he becomes seriously ill and the government offers no secure alternative. His job coach who is paid for by a grant makes it possible for him to work. Without his medications he would not be able to. They currently cost us about what he makes.

Having the mentally handicapped and retarded grouped with the addictive disease people are not right. Having to share money is not fair. These are 2 totally different situations. Mentally handicapped and retarded is not by the peoples' doings – the addictive disease group is of their own advocation.

My sister has received day support for attending our local workshop for 42 years. She always lived at home with her mother and father and then just her mother until 3 ½ years ago when our mother passed away. At that time she came to live with me and I obtained guardianship of her. She has, through the efforts of my parents, led a very social life. She has always attended Sunday school and church, she rides horses at a local riding academy for people with disabilities, she bowls, and she has always participated in Special Olympics. Through her workshop she is in the community shopping, dining, going bowling and to the movies. After she came to live with me I purchased a smaller, one level home in a retirement community. Many of my neighbors are widows with no close family and they have become very involved with my sister. They have put baskets at their front door and each afternoon when she gets home from her workshop she gets everyone's mail from their mailbox and delivers it to their basket at the front door. She walks with several neighbors when they walk their dogs. She is often invited by neighbors for dinner or a movie or shopping outing. As I meet more people over the age of 60 who are caring for their siblings, many who have sat home all their life, I appreciate more and more the opportunity that my sister had to attend a workshop and be active in her community. When comparing the two lifestyles you can almost touch the difference. One's quality and enjoyment of life truly is determined by their feeling of inclusion and self worth. My family is so fortunate and I am advocating constantly and involving myself in disability issues to insure that our State funds services for the over 5000 on the waiting list. Someone, including my parents, worked very hard to bring a workshop to our county and I feel that it is an obligation and a pleasure to work for those who come behind us. There are many, many adults with disabilities and their families whose needs are far greater than ours. We are very blessed. Even though GA has a very long waiting list, I appreciate the services that we do have.

In 1983, consumer became a student of the {County} public school system. Teachers, administrators and other specialists worked tirelessly with him. Their collective goal was to prepare {Name} to be a competent, contributing member of our society. They taught him to dream big dreams, and that with hard work, compliance and perseverance he would one day have the opportunity to do all the things other men and women do. Those dreams are to be gainfully employed and experience as much independence as possible. Since his graduation from high school, he has had the opportunity to work and experience a type of self-esteem that all "normal" people experience. He has prepared himself to be as independent as he can through developing good social habits and taking responsibility for many things regarding his daily personal care. However, at this time, those with the greatest need receive the greatest help. Perhaps that is the way it should be. The adult, who lives independently of parental supervision, is one whose parents can financially afford it, or those who are in crisis. The young men and women who work hard, prepare themselves as well as they can, and dream big dreams are told to be satisfied to be "happy" at home with mom and dad. Isn't it a shame that at 22 years of age, developmentally disabled adults experience a disconnect between the groundwork for real life opportunities through our public school education, and actual real life opportunities through our community support services? It is also a shame that three professional organizations are assigned to consumer and financially compensated, just to tell him that he is too successful and independent to receive housing assistance.

KENTUCKY

2b. Dissatisfied with Employment

More work and better pay for them.

3b. Health Care Insurance

I take care of my daughter and need help to do so and people to help is hard to find I would not be able to survive if I did not get Medicare and Medicaid.

5b. Dissatisfied with Transportation

I drive my her to {Agency} daily 28 miles round trip, if I' am ill she stays at home transportation can not be provided unless it comes from a Dr. stating that I'm unable to transport her.

Transportation is a problem, bad driving skills, not reliable

Transportation is a problem.

5c. No Transportation

Need more transportation.

7c. Communication

Information seems very difficult to obtain- acronyms for services are confusing

We would like to be aware of the activities that he does during the day.

8. Aging Caregiver Issues

I'm 90 and I need help in taking care of my son. No services out there for him.

10g. Service Plan

With forward thinking, planning and accessing services according to the latest "Best Practice" A strong circle of support for my family member, the system becomes the road block or prohibits access to these services. We need flexible funds and services.

Want to be more involved in decision making for my son.

11c. Staff Turnover

He is an {Agency} consumer and overall I am pleased with the services my only complaint is the turnover in respite support staff.

Services for my daughter are not carried out adequate time or never there is always an excuse she receives {Agency} the staff which she attends {Agency}is constantly changing. The {Agency} person is always changing once my daughter gets comfortable with it is someone else for her to connect with.

11d. Shortage of Staff

We need more providers long term and short term, and more respite care providers so we can do what we need to do.

There is a severe shortage of appropriate services providers for specific needs, behavioral and personal care training to make our population more sufficient in living skills, learning goes a long way. To obtain this goal we need to have better salaries.

Regular hours to reduce burn out.

We have a problem finding people for respite.

11e. Staff Not Qualified

Stricter background checks random drug testing.

11f. Pay Staff More

Better benefits for workers.

16. Funding and Budget

We are assessed over $300.00 per month to participate in the {Agency}program through {Agency} the high cost began about 3 years ago and continues to rise only leaving $600.00 for living expenses and creates a hardship.

Need money for gas and more respite care.

17a. General Satisfaction with Services/Supports

My daughter likes {Agency} my husband aid also disabled from a work

At this time I'm please with {Name} and the supports and services he is able to remain at home walks to the {Agency} participates in activities. He is a Happy Camper.

He is an {Agency} consumer and overall I am pleased with the services my only complaint is the turnover in respite support staff.

I might have missed some of the questions but I'm very pleased with the help I receive.

We are totally please with our services.

I receive many supports for my daughter and with out this help I would not be able to keep her at home. Thank you.

With out he waiver and support living program I would not be able to keep my brother here he is total care.

{Name} says these programs changed his life for the better. He used to stay home and was afraid. I would not be able to stay in my home. Now I go out into the community. I go to {Agency} one day a week. I participate in Special Olympics and go to camp several times a year. I go to church and have made lots of friends. On Wednesdays I work in my garden.

17c. Access to Services/Supports

My husband does what he can to help we have no other family that can help we only have one respite care provider in our area.

17d. Info Regarding Services/Supports

We would appreciate help regarding guardianship/power of attorney which is better, what it means?

17e. Need More Services/Supports

We need more providers long term and short term, and more respite care providers so we can do what we need to do.

We need help with transportation and Respite care very much.

We have very little family support. I think the service providers are concerned more about getting funds for their agency than they are about providing services to people. KY needs more services for Autism needs.

Need a place that provides respite acre and personnel care.

We need more respite care out side of our home we want to keep our children in our home but now they want to give us less.

19. General Concerns

Patient liability is a problem

OKLAHOMA

2a. Satisfied with Employment

{Name} is very happy working at {Agency}.

We think the DDSD program is very beneficial. Our son gets to a DDSD supported workshop and has a dignified place to work (which is important).

This program has been a blessing for my son. He gets to be out and makes him feel good about himself and that he is making some money to try himself something and is proud of himself. He loves to go to work. Thanks.

{Town}Oklahoma has a wonderful workshop type store for hiring those with disabilities provided by {agency} in {town} HTS/mother of an adult child,

2b. Dissatisfied with Employment

I feel as though the clients at the workshop are being cheated on payment. Is there not one way that the jobs that they do could be increased on their paycheck? I know some of them only work 3 days a week at 1/2 days but still they do work hard and deserve a raise in pay just like everyday else.

I would like to get more information about the job coaching. So far it's not what we were hoping for. My son is not happy with what he expected or hoped for and what the reality is. I'm curious as to whether or not another agency might work out better to keep him so busy as he would like to be. I'm curious about what goodwill is like? DHS worker have always been kind and helpful. I really appreciate their work efforts!!

We are having a lot of problems the {High School}. I don't feel he is ready to graduate nor does his therapist or psychologist. He has not accomplished his goals and he is not mature enough to be in the community or work force. He loves school & enjoys learning & social skills are being developed. He also enjoys his peers. It would be horrible if he wasn't allowed to continue in school. I don't understand what the schools motive in hurting {Name} is. To me this cruel. And it is our right to keep him in school until he is 21 years old.

3a. Health Care Equipment

He just recently started receiving waiver services. So far the only thing it has helped with is purchase of diapers and wipes. We need some home modifications(bathroom, bedroom, possible 2nd ramp)

He needs a new bed, needs a bigger bed safe bed for individual who have risk of falling out.

{Name} has a hearing impairment and desperately needs hearing aid services. He wears hearing aids but when we have to have them serviced they have to be sent off to another location and this is usually a flat fee of $150.00 no matter what is needed to repair them. Thank you,

Need ramps, need help with board for tub.

It's stupid for the state to pay for wheelchairs-but not a lift or ramp to get them in your vehicle-most people receiving these services-cannot afford to get them. I am one of those people-I'm over 50 years old & I sure can't lift my daughters wheelchair into a vehicle-it weights over 200 lbs-so besides going up & down the sidewalk (which we don't have the wheelchair my daughter needs to get around is pretty well useless! I had to purchase a regular wheelchair at a second hand store-so we would actually have one we could transport-without killing ourselves-trying to get it in & out of a vehicle- I also tried to get a brace for my daughter's leg-the people who made it were a bunch of idiots-it wasn’t made correctly to begin with- it fell apart and never fit right I spent 2 years trying to get these people to fix it or get a new one-every time I took it in to fix it they would keep it for an obscene amount of time(the last time over 6 months) then they would send it back exactly the same- A HUGE WASTE OF TIME & MONEY!!! And my daughter is doing without her brace-its in the closet-still broken. Thanks.

He has not needed any other services yet. I have had little success in finding help to purchase hearing aids for him thought.

Our van which we purchased ourselves is old and needs replacing. We can't afford to purchase another one. It must have a raised roof and like the one we have now must have a wheelchair lift. We have tried to get help with this but to no avail. {Name}, our son has to travel about 30 miles one way to get medical help and we feel the van is equipment he needs similar to his wheelchair and other medical devices he must have. {Name} is with us everywhere we go. He is with us all the time. Grocery shopping, church and everywhere else we go. We need our own transportation so we can continue to keep our son with us. Our desire is to meet his needs.

3b. Health Care Insurance

We have to supply dental insurance. Have no medicine card

Medicaid no longer will pay for {Name} formula that he has to have to service if he is tube fed. Our insurance only pays 80%-we had to declare hardship because of this! Provided through my own health hours.

Dear sir or madam, {Name} only gets 25 hour a week. She was taken off her Medicaid and can not get a doctor to except Medicaid so she do not get Medicaid so it is hard for a doctor to see her so I pay cash for her doctor she get a check for $48.00 dollars so if she wants to pay on energy bill she can so we are having it ruff, and also she has a walker that ({Hospital} helped me get her, now she don't see {Hospital} no more so now she not seeing a therapist no more either, because she can't find a doctor that will accept this but they won't so it is very hard for my daughter so yes I do need help for my daughter will it take a parent dying for my daughter to get the right help for her.

Medicaid does not provide enough prescription medicines for a disabled person with medical problems. They don't pay for all medicines my son needs since he turned 21 and they capped the number of prescriptions he can receive. This is a terrible situation.

3c. Dental

Our main complaint is the lack of dental services available for our son. The dental care that he is required to have is paid by us and partly by private insurance. We have always taken responsibility for raising our son and we are tired of hearing, "If he was a member of the class action lawsuit he would be entitled to more". That is simply not right. (not fair)

We want to see a dentist who treats patients with the degree of disability that {Name} has.

Can't get dental help or extra money to help.

My son really needs help with vision and dental services.

Non class members need help with dental costs.

Only problem I have is no dental assistance.

My son {Name} was approved Sept 2005. To date no help has come to him. I just spent over $600 on his upper teeth being pulled. Next month I will get a upper plate. In May {Name} and I will move to Texas. So the funds that were approved for {Name} will hopefully be use on someone else. April, 2006. PS. It sounded to good to be true.

I have no complaints only that {name} has no dental services and they are really expensive.

I think that he would benefit with additional dental to cover fillings as well as his checkups.

I feel its wrong that our developmental family members do not have dental care after the age of 21. {Name} needs this desperately. I'd like to know what I can do to start petition or protest in someway. I'm a single mother with low income.

Although dental check ups and cleaning is written in service plan-the charges are denied for payment-consumer is an adult, they paid when he was younger but not now. Because of his MR he has to be asleep before work can be done on his teeth-all he needs is cleaning but payment is still denied.

Would like input on getting dental services for DD adult-don't know if there one any in {Town} area. Profoundly retarded and non-cooperative.

3d. Medical

Same way with his acne problems: I pay out of pocket for medications to be used as a preventative for his acne. If I did not pay for those items, we could have coverage because he would have to have cysts in his skin surgically removed. Again, what sense is that? To say that a disabled person only needs prescriptions for acne up until a certain age and then after that it is "cosmetic" - it may work into a "plan" but certainly is not in the best interest of the person with the disability.

3e. OT/PT/ST

EPSDT does not pay providers, PT, OT and speech are not allowed on plan of care through DDSD because EPSDT covers-but it doesn’t. Cannot find therapists willing to take new clients because of payment problems.

3f. Vision

My son really needs help with vision and dental services.

When our son reached a certain age he no longer qualified for certain medical things that continue to be ongoing needs. For example, glasses, eye appointments are no longer covered. What kind of sense is this? Our son with extremely low vision reaches a certain age and he no longer has a vision problem? Oh is only that could be true. While it may look nice and tidy on paper, it is NOT a reality.

5b. Dissatisfied with Transportation

Well, sometimes I get disappointed with {Agency} because they are always having trouble with their transportation. It's like every other week or so and they don't keep {Name} and his brother all day like they're supposed to.

5c. No Transportation

Needs a van for transport safety.

7b. Dissatisfied with Communication

Can not contact the case manager. She does not return my calls when I need help.

7d. Language Barrier

Should not provide services to non English.

8. Aging Caregiver Issues

He is a live wire and I just can't keep it up anymore. I have to have surgery on my legs sometime in June 2006. I and my daughter have a list of places to go and look at. Would like 3 men homes, no more than 6. I’m 62 and he needs a permanent home.

We would like to receive a full waiver for {Name} so he could be situated and settled in a life style in case something happens to me. I am 63 years old and don't know what will happen to him when I die.

I worry that when I die will she have someone to get her out into the community.

We adopted our son when he was a 1st grade student at my school. In helping him we did not realize he may live with us until we die. We hope with the waiver that someday we may explore other living options so that he may grow more independent and we can enjoy a few years of our lives with out kids. We thank you for the funding you have provided and we feel blessed to receive it.

I do worry about dying and leaving her. Without our insurance and financial support she would be poor and not have access to good medical care.

9. Transition Issues

{Name} is very happy working at {Agency}. He does not and we as parents don't want him to leave this facility and go out to work in the regular population. As he has a very hard time understanding things. Please feel free to call and discuss {Name} situation. Thanks, I would like to know who {Name} worker is at DDSD and how to contact them.

10a. Satisfied with CM

We are very pleased with {Name} current case worker. He has been with us for a period of time. Overall we are happy with the services provided.

Thank you so much for these services. Without them life for {Name} would be so much more difficult. We are so grateful to have {Name} back as our case worker this year. She is such a caring person and I feel she knows her job or is not afraid to ask for help if she has questions.

I just hope {Name} stays as [Name} case manager.

So I am taking care of him, but the agent does help a lot.

We are very happy with our DHS person assigned to {Name}- .{Name}. She has been very helpful whenever we needed something.

My daughter's case worker is the best.

Special thanks to services/support coordinator.

We are very appreciative of the support our daughter receives and are pleased with our case manager, our provider and their staff.

So far the people, the people that I have worked with have been very helpful and answered any questions that I have had for them.

We feel our case manager and HTS worker are SUPERIOR! {Name} (Case Manager) and {Name} (HTS Worker) are angels sent down from heaven! Our daughter {Name} loves {Name} with all her heart and so do we! Thanks

I'm so grateful to {Name} who made it possible for my child to attend the daycare.

We also greatly appreciate our caseworker, {Name}. She does a great job!

{Name} is a blessing to our family.

10b. Dissatisfied with CM

{Name} case manager wasn't staying in contact with {Agency}. She would not wait until I could get all my doctors reports in so she would send in reports with out all the facts! They would turn down her request and I would have to start all over again. {Name} has to have one on one care 24-7.

Can not contact the case manager. She does not return my calls when I need help.

10c. CM Turnover

Frequent changes in case managers has caused disruption in some medical services (P.T.) due to loss of paper work sent to DDSD by therapists when changing from one to the next C.M. the

Seldom see or hear from case manager. It seems we get a new or different one every few months. Never get acquainted with them or do they really get to know their client.

I would like to keep the person (Case Manager) we are use to having and not change because we are use to that person. I do not want to have to get use to another person because we all have learn each other.

10e. CM Not Qualified

At times, our DDSD case manager has not known how best to access or facilitate services, but has made every effort to find answers/solutions. I do feel that more training might be appropriate for case managers.

My child is currently 19 years old. She was on the waiver list for 5 years. When I was told she was on in home-support waivers last May, 2005. May. 2006 she hasn't received the first thing yet. The caseworker is 100 miles away and steered me wrong on who to contact locally from Dec. 2005 until March, 2006. Then it took her 9 days to fax paperwork to the other place. May, 2006 I'm waiting for the other place. A whole year, 19 years for my child, absolutely nothing in 19 years, and the state of Oklahoma "cares"??? Apparently untrue if you live outside of {Town} or {Town}. And the majority live in neither one.

10g. Service Plan

Why is it necessary that the provider agency send a representative to attend the plan of care meeting. I believe that the parents and the case manager is all that is necessary. This worked in the past. I don't still see why it is necessary for parents to threw a provider agency. That is money that could be better spent on direct services to the consumer. In home support programs are very limited to the hours and money spent on their programs.

There needs to be a list of recommended activities for all family members to go to our choice.

My son {Name} was approved Sept 2005. To date no help has come to him. I just spent over $600 on his upper teeth being pulled. Next month I will get a upper plate. In May {Name} and I will move to Texas. So the funds that were approved for {Name} will hopefully be use on someone else. April, 2006. PS. It sounded to good to be true.

We need to have more input on the person taking care of our daughter in our home. The agency tells us whom is coming and when. I would like to meet and talk with a new person at the agency with our input. The agency calls to say this person will be at our home to work. We have a stranger in our house and our daughter is with someone we have not met or know. There needs to be more training in our home on what to do and not to do. Let us do the training and make them go by the nates we leave not what the agency thinks best. This is for our daughter's safety. We have no smoking signs. The smoking rule of the state should apply to the workers. The agency knows they go outside or sit in their car. How safe is for our daughter in the house by herself? We both are working parents. 1 works day 1 works night.

Also incorrect information in the yearly plan of care is never converted over after being brought to C.M. attention every year. (I.e. incorrect birth date and other vital statistics).

It takes a long time to get services-almost always 6 months or more. When I ask about this. There are always excuses (codes changed and the responsible party didn't give us correct code 2 months ago- I'll contact her now and nothing is handled unless several phone calls are made for several months. We know that there is no such thing as a perfect program, but this one comes pretty close!! We appreciate the program and the efforts made by so many people to keep our son at home. Waivered services has helped us help him have a better quality life.

I have a friend in {Town} that has a disabled child. She receives SSI but cannot get info from DHS on DDSD or other programs to help with everyday care of her child. Her social worker has been unconcerned and not helpful at all. I did not know about DDSD until my son was 21 years old. I could have taken advantage of these services for several years before my son turned 21. DHS workers don't seem to want the burden of extra paperwork so they do not inform clients of services available to them. My friend's name is {name} & her son is less than 2 years old. She shouldn't have to wait until he's 21 to get help. Thank you.

Under information & planning, I'm not sure what a service plan is. Therefore I could not answer the questions to the best of my ability.

I would like to receive timely materials, such as meeting or conferences, before they are over or only a day or two before.

I would like for the IEP meeting to be in our home with only the case manager so our daughter can be more comfortable.

DHS seems to put us through a process every year to prove that our son is worthy of what the team decides is in his best interest. We do NOT take advantage of the situation, but rather ask for what would be in our sons best interest. One year the battle went on from March to July. We had to prove every little thing. That was the worst year. All the other years we have still had to prove why he is worthy of receiving what he needs to have in place. My concern is if I become incapacitated, what will happen to my son then? 2)

11a. Satisfied with Staff

New H.T.S. worker {Name} has made a whole new person. She is always happy and they stay very busy. We have a had a hard road to travel, but God has rescued us. And now {Name} is the sweet loving daughter she has always been. {Name}, {Agency} H.T.S and E.T.L has made a big change in our lives and we are so grateful for this.

{Name} is very happy and we are very thankful for the people that work with him. They are a real help and blessing to us. Thank you

We are very appreciative of the support our daughter receives and are pleased with our case manager, our provider and their staff.

{Name} service providers have been very good to learn the "do's and don’ts" in working with {Name}. They work along with me. Also in helping him reach his full potential. He's a "data master" and seems to do well. He needs to resume speech and language from {Name}. She was excellent with him. {Name}.

Our staff have been a great asset to our family. {Name} is professional while being empathetic to my son's needs. She is an asset to DDSD. Our HST has help tremendously with my sons socialization skills. He would be a recluse if it was not for the assistance of {Name}.

We have been extremely pleased with waivered services. My son has an HTS that has made a huge difference in his felling of independence and self esteem. He has not needed any other services yet.

We were on the waiver list for 6 years but it was worth the wait. I teach school and need some help. The OU student that is paid by waivered is wonderful. I feel that for the 1st time in 26 years I have a few breaks during the week. I am grateful for these services. We wish things were different for our daughter but any little bit of help is wonderful.

We have very good H.T.S. that work for us. I feel they really care for my child and for her well being. The only problem we ever have are few times they cannot work because of sickness, time off etc. We do have a hard time getting the agency to get someone else in. Other than that our H.T.S. are excellent.

The people who work with us are wonderful.

11b. Dissatisfied with Staff

Autism is not addressed in this state. We need a day program safe respite program and vocational services to address this needed adult population with autism. These agencies are terrible. Staff goes from one agency to another. Agencies are not making staff (H.T.S.) accountable for problems just put them in another house. I had to use a private agency for a few hours it was like night and day. My daughter liked them and they knew how to work with her. Most H.T.S. staff cannot work with autism. They are neglected by H.T.S. Adult autism is neglected in this state. They are not individualized as the IP states. Put programs that are available now, even though they are not appropriate. Staff (HTS are not trained enough to work with adult autism. My daughter has a broken front tooth, sprained ankle. This week a black-eye numerous bruises on arms, legs large bruise on breast. Staff HTS is double staffed have no idea when these happened. My daughter is severely autistic cannot speak, its hard for a mother to see your child hurt like this!

Our daughter, {Name} was terribly abused by her former H.T.S. Worker {Name}. She had us to believe {Name} was harmful to {Name} as well as being a threat to herself. {Name} had gotten to the point that she didn’t want to live here, she would rather be in an institution we knew {Name} really didn't want to leave home, but she wouldn’t tell us why. When it was finally physically abusive to {Name}.

11d. Shortage of Staff

Not enough staff provided, Staffing needed

Seems to be a problem finding support staff willing to work flexible times. We don't need help everyday at the same hour and vacations out of question.

Have trouble finding caretakers.

Case workers are grossly over worked

11e. Staff Not Qualified

Additionally it has been a challenge finding qualified people to work as HTS-I do feel this is partly due to the fact that the job possibilities are not well publicized and the job requirements are not always well defined, but primarily due to low pay combined with a great deal of paper work requirements. I would like to see more efforts made to enlist college students and especially those interested in careers in special or regular education, any medical field, social work, etc. To work as part time HTS during their college years.

11f. Pay Staff More

I am concerned with the funds the agency receives compared to the amount paid out to caregivers. This is why it is difficult to find and keep quality caregivers.

Provider agencies have problems finding staff because HTS pay is so low.

There are services I can't receive because {Town} would not approve them. Even with letters from my doctor's and my daughters, doctors. Like extra HTS hours, Taxi service to and from day center. Doing my own HTS service because the agency doesn't pay the workers enough they only get $8.00 of the $14.00 that OKC pays the agency. I could give the work the full 14.00 hr if OKC would give me the funds to pay HTS. The agency is making money off my disabled daughter that's not right. Wasted funding why doesn't OKC pay the HTS instead of payment thru a 3rd party who's making more than the workers. Low pay is why you have bad HTS care.

Legislature needs to put money into the hands of those who are on the front lines namely the HTS workers and the job coaches. Gas prices have climbed, cost of living continues and still these people are in as bad as shape as the teachers in our state, because neither is a priority. The most vulnerable and in need of protection are pushed aside. Agencies are only as good as the person you have as a program coordinator and the HTS people and job coaches. While {Agency} is a strong help for us I can say it is due to the Program Coordinator. {Name}. Still the pay for HTS is way below what is acceptable. If you could peek into the lives of these people and see how many hours they work just to try make ends meet, you would know that the hard workers are never compensated. There are several in the field who are not worthy of their salaries, but others work and give 110 percent and they are still barely making it financially speaking. The job coach situation that we use is {Agency}. It seems that there are more excuses than pro-active solutions to the hiring and keeping of decent job coaches. Again, pay is a big issue. Due to the extremely LOW pay of these people, the pool is very shallow. We have had to go out in the community ourselves and make this program happen. Had is not been for a program that our son was involved in while in high school, we would not have had places to take him and ask if there was a place he could fulfill. When we did use those resources, then we received a call from our son's former teacher asking us not to take away jobs from her high school students. It seems that it is a battle of sorts all the way around, battles have to be chosen and fought in what is the best interest of our son. So why was a 1-800 number not included in the grayed-out section. {Name} of {Town}, OK. Please feel free to forward this on to anyone who you feel could make a difference for those who are most vulnerable. Our children-our disabled-no matter what their age.

11g. Substitutes

My problem has been finding caretakers locally to help care for {Name}. Gas prices are too high for them to drive from out of town. The agency tries but has a hard time. The one I have now works 6 days a week. Need someone for when she is sick or for two days sick leave. She recently has qualified for DDSD and some more help will be available. Thank you

I would like to see that the agency's have a list of HTS personnel listed and sent to the family in case the HTS worker is sick, and that family could have a choice to call in another HTS with that agency instead of going thru the agency. When I have had to ask would they send out another HTS for several days, I was told that they could not find anyone and that it was left up to me, but the person had to have CPR/first aid. So I had to miss work for several day, which I think was unfair. I would like to see some plan put into work concerning this matter and that all the agency must follow a procedure. Thank you.

We have very good H.T.S. that work for us. I feel they really care for my child and for her well being. The only problem we ever have are few times they cannot work because of sickness, time off etc. We do have a hard time getting the agency to get someone else in. Other than that our H.T.S. are excellent.

12. Family Issues

I'm a single parent who has always cared for my child at home. The primary issue for many women in my situation is the inability to both care for their child and work-next to impossible. Caregivers often have no health insurance as a result, so their health is neglected. This has an impact over the long term in being able to continue to care for their child, especially as they get older.

12a. Family as Paid Staff or CM

I am my daughter's HTS 24/7. I get paid 8 hours a day. We would like to have additional hours so she could have another HTS so I can have some time off too. 4-8 hours a day or more?

My daughter {Name} is very happy with the care given she has now. She has a loving, caring aunt {Name} and she is the best we have ever had in our home. I am so glad that relatives are allowed to be care givers.

13a. Health

{Name} has tried working but it seems to be to stressful for her. Groups are also to stressful. She worries about everyone’s problems. She likes to be one on one. Her medicine for their month is $593.90. Stress makes her real sick.

13d. Social

Sometimes worry about depression. He seems to get more depressed lately. He has so little contact with outside people his own age? He has no way of meeting others his age. I try to take him out to eat and do thing with him but he still gets depressed. I started taking him to church but he doesn't want to go anywhere, or do anything to get out of the house. I'm worried about him. What can I do?

{Name} needs social opportunities as well as intellectual stimulation-more than we can provide. Classes and activity groups, maybe.

I would like to see more developmental or (mentally/physically challenged) dances available in the {Town} Area. Right now there is only one that I know of that has a dance on an every-other month basis and that is IOI.

14. Respite

There has been no place for respite care for the past 2-3 years since the house on 46th place was closed down. We would use this service if it was available at a reasonable location in {Town}.

Respite care is a need that I have the most difficult in providing for my son.

16. Funding and Budget

There were problems with getting equipment which caused us to lose $4,000.00 on our last plan of care because she waited too long to follow up and help keep the ball rolling so that money was taken out of this years plan of care. [Name} tried very hard to help but it was too late.

I am my sons HTS. [Name} was never in an institution . I receive $18,540 a year, however every hr I file at $9.00 an hr. the agency gets $5.00 out of the $18,540 + $14.00 is billed out of this money. {Name} also attends a job 2 days a week at {employer}. They take $12.00 an hour out of the money which comes to 432.00 a month x 12.00 mo. + 5,184.00. The agency gets approx $6000.00 a mo that’s $11,184.00 out of the 18,540, that leaves me an aging parent to care for and provide for my son very little. Why do we have to pay out of that money to have our children working and trying to be productive? If indeed this money was for their care. Which by the way would cost the state of Oklahoma 10 times that amount a mo to care for him. Why can't we parents who chose to keep our disabled child at home and not burden the state with their care like "hissom parents" who I feel are dead beat parents, however now they worry about nothing why are we being treated this way. I guess my question is why can't we be in control of all the $18,540 that indeed would make it easier to keep our children at home as we are.

And I have an issue or don't understand why some people have unlimited waivers and others are limited.

I feel all people with disabilities should all get the same amount of money to help them be ready to live on their own. There is not enough money for their needs.

They are limited because of state cuts

Also not made aware of money (amount) spent on items or balance. Most of time asked where we might be able to cut some of the expenses.

Need more food stamps. 10.00 will only buy his lunch stuff. Thank you,

My child is on the In Home Waiver. By the time {Agency} takes out 12.50 an hour for him to work there and the other agency gets there money, its not like my child gets the 18,450.00. It does help but it's a shame he has to pay so much to get to work with his friends.

{Name} dentist states she needs a root canal possibly at {Town}. I am not financially able to pay for this service. {Name} does see the dentist twice a year teeth are cleaned twice a year. I am a widow age 74 it would be very difficult financially for me if I did not have help with medications and transportation support from workshop services. Support from DHS worker.

If we could receive a quarterly statement as to DDSD balances, it would help us plan. If some of the red tape could be cut out when trying to get equipment, it would help. More money needs to be paid to HTS so they will stay with the job. HTS companies need to have a tighter reign or meeting objectives and have client input in approving activities or pay slips. DDSD $ should be carried from year to year so we can afford to meet needs.

There are services I can't receive because {Town} would not approve them. Even with letters from my doctor's and my daughters, doctors. Like extra HTS hours, Taxi service to and from day center. Doing my own HTS service because the agency doesn't pay the workers enough they only get $8.00 of the $14.00 that OKC pays the agency. I could give the work the full 14.00 hr if OKC would give me the funds to pay HTS. The agency is making money off my disabled daughter that's not right. Wasted funding why doesn't OKC pay the HTS instead of payment thru a 3rd party who's making more than the workers. Low pay is why you have bad HTS care.

I want to know how the money is spent that the state provides for my son.

After yearly plan, we feel like we shouldn't have to worry about the cuts that might be made for our daughter's services. After this years plan her therapies were cut 40-63%. She has benefited from excellent therapies over the years and has maintained her physical well being. Cuts should not be made the same for all therapies but looked at on individual basis.

We do appreciate the financial support she receives to make it possible for her to attend the day center where she participates in arts and crafts, field trips, board games, etc to keep her active in mind and physical activities.

The people who work with us are wonderful. The problems arise with the lack of funds for services and the lack of day facilities to care for an adult handicapped daughter so that I can work full time.

17a. General Satisfaction with Services/Supports

We appreciate the support provided by the DDSD. Which really make our life easier. Thank you!!

Without the support if in-home services, I would not be able to work outside of my home. Because of these services, my son can stay in the only home he has ever known with a family that loves and cares for him. If we did not have services, our quality of life would suffer greatly. Thank you for the respite and daytime care for our special needs family member.

Thank you so much for these services. Without them life for {Name} would be so much more difficult.

Everything fine and satisfactory.

I am very thankful to have the services for my daughter. It has been a great help for her and all of us. Thanks

The support I receive enables me to work. I am thankful that I have this support so I can continue to work. Otherwise I would have to quite and take of her. I would like help during the times I am home though. I am

This is a very important program to our family. Thank you.

Generally speaking, I have bee pleased with the support we have received as part of the home and community based waivered services program.

I would like to thank DDSD for all support received for my family member.

So far I have not had any complaints about how things have been done.

The state agency is doing okay with the programs for our children.

We really appreciate the services our child receives. It enables my husband and I to go to work.

These services have really made our life much easier. Thank you.

We are very appreciative of the support our daughter receives and are pleased with our case manager, our provider and their staff.

I am very satisfied with the services we get. My family member has come a long way with the guides he has had through agency he has been under. {Name}, Thank you.

My son {Name} goes to {Agency} in {Town}. He loves it. He has a bus driver {Name} that is wonderful! I'm not sure about all the services {Name} gets. I know by him getting to go to the workshop that I can continue working and care for him. I'm thankful for the help we do receive. I wish he got more but we are satisfied. I hope that when I return I will be able to keep {Name} home. Some days are hared to care for him but then he smiles and says "mama" and it is all worth it. I fill blessed to have him and I am thankful for all the state has done. Thank you

It takes a long time to get services-almost always 6 months or more. When I ask about this. There are always excuses (codes changed and the responsible party didn’t give us correct code 2 months ago- I'll contact her now and nothing is handled unless several phone calls are made for several months. We know that there is no such thing as a perfect program, but this one comes pretty close!! We appreciate the program and the efforts made by so many people to keep our son at home. Waivered services has helped us help him have a better quality life.

My daughter is very happy, energetic young lady and loves to be a social butterfly and engages in most athletic sports. Without the support we receive thru the {Agency} I would not be able to work and {Name} would not be at her position at south crest. I am extremely grateful for all the help I receive for {Name} and in turn {Name} is a very well rounded young lady. Thank you all so very much!

We are pleased with the assistance we got from the state-We are able to plan special outings-with (wheelchair) the help we get. Dusty receives diapers which are a major need. We've recently charged the pharmacy where we get them-They had diapers. We didn’t know about-they were much better- He had a rash from the other diapers we used. Since we've charged to a different brand the rash has gone away completely. (Tena ultra) brand FYI.

We appreciate the opportunity to participate in the in-home services waiver. It has made a big difference in our son's needs being met. Thank you for all your assistance. We also greatly appreciate our caseworker, {Name}. She does a great job!

We have been extremely pleased with waivered services. My son has an HTS that has made a huge difference in his felling of independence and self esteem. He has not needed any other services yet.

We appreciate the assistance we get for our daughter. It has been a tremendous help to our daughter and to our family. Thanks.

I am very satisfied with the services we have received through the school, and through the DDSD.

My family member has just recently received services. But at this point we are pleased.

This is a new service to us and is very much appreciated. After the death of clients father, help was needed.

These services have made a tremendous difference in my son's quality of life and in our whole family’s quality of life. Having the support in place to allow my son to work makes him a happier fulfilled adult.

{Name} wants to stay at home with us. DDSD services make it possible. Everyone has worked very hard to help us. We are grateful.

17b. General Dissatisfaction with Services/Supports

It is the agencies I'm not happy with, the turnovers, sending anyone to your home. Very evident that some workers slip through background check. Bottom line, agency don't care enough about their workers or clients. Thank you.

We are drowning in trying to care for this child and DDSD wants to cut HTS hours, won't pay a parent mileage, won't assign a {Agency} nurse as long as she is in the house. We have been told that we will both have to be incapacitated before she can go into community living. Why do we have to die first before she can go into the community?

However we have found the HTS program to be unsatisfactory and we have tried several. Essentially the HTS worker is not satisfactory. The providers are not helpful either. We have no control of the employees nor their selection with the workshops. Which is sometimes a concern.

17c. Access to Services/Supports

Overall I'm satisfied with the program DDSD with the only except of certain services as day programs and other services such as physical therapy, occupational therapy, or speech are not offered in our remote southeastern tip of Oklahoma. If such programs were available I believe this would enrich my daughter’s life even more.

The only concern is the variety of services available in our community.

Smaller communities such as ours have no option for jobs or work/there are no work shelters or group homes. Or adult daycare.

17d. Info Regarding Services/Supports

We have no help or information about how to obtain residential services for her and we won't be able to maintain her care in our home once she finishes school. We feel that we are headed for a crisis and no one is paying attention. Her social worker has been no help with this problem.

How do you justify getting agency campion program? We keep getting denied as {Name} health has changed this year. It is frustrating to be denied and not know what we can do qualify.

Which was not an option here. I would like to have info on guardianship voucher (grants?) and community based waivers.

I would like to get more information about the job coaching. So far it's not what we were hoping for. My son is not happy with what he expected or hoped for and what the reality is. I'm curious as to whether or not another agency might work out better to keep him so busy as he would like to be. I'm curious about what goodwill is like? DHS worker have always been kind and helpful. I really appreciate their work efforts!!

17e. Need More Services/Supports

There should be more programs in the communities for people with developmental disabilities.

After my son graduated from high school we don't have anyone working for us.

I would like help during the times I am home though. I am with her 24/7 365 days. Time off like a few hours on the weekend once a month would be nice. My daughter is 22 and I have been her primary care giver for all of these years.

We wish there was a positive day time center for our adult son, such as special care where our son can socialize with others his age. The center would have educational classes at the appropriate levels, arts, and crafts, music times and special interests. The center would have community interaction. The center would be a place where everyone would enjoy visiting with a positive and happy environment.

We are interested in some respite or possible home health care when he is out of school the local day break program was visited but was disapproved to find he could not attend this program due to his degree of care needed.

Cannot find adult daycare that is appropriate for a 20 something adult with severe to profound disabilities.

Also would like job coaching for job she may have working possibly at {Employer} a few hours a day 2-3 days a week. Needs computer so she can learn computer skills, needs PT and OT already approved for needs more mileage as we live 30 + miles from city. Thank you.

There has been no place for respite care for the past 2-3 years since the house on 46th place was closed down. We would use this service if it was available at a reasonable location in {Town}.

My son has a very complex behavior and sometimes he gets out of hand. But for the most part the DDSD services do help a lot. But I do wish it was a little bit more flexible because sometimes our children get out of hand and you need a little more help with them. From what I understand you can't use all services at once. It' either one or the other. Thank you.

Respite care is a need that I have the most difficult in providing for my son.

I am in need of a tutor for reading for {Name}. He so wants to learn but there is no one I know of to help. Thank you.

Respite care would be nice

The only thing we really need is a good person to keep {Name} for us when we want to out to eat or maybe get away for a weekend or a vacation. But I know by now that is not going to happen.

Something should be done about getting adequate "Respite" through DDSD. Foster parents of disabled clients have some. "Respite" from their duties.

My husband is 72. He has had 5 major surgeries in the last 2 years. We need respite desperately.

My family never have a vacation together. We need respite help for 1 week at least twice a year. There is a great need for handicap recreational facilities-just for handicap kid (autistic kids)

DHS is trying to cut my daughter's HTS services 2 hours per day. This would be very detrimental to her and me since I am unable to employ quality HTS's. It's for this reason that I cannot seek another job. I am 70 1/2 years of age so jobs are not readily available to me. If her services are cut, then her present HTS might quit working for her. {Name} natural support is a term applied to me, as her mother. If the 2 hours per day are taken away, there will be little "natural support". On dental care she needs 3 cleanings per year at least! Thank you for reading this. {Name}. P.S. I retired from teaching because no quality HTS could be found.

17g. General Dissatisfaction of Service Management

Care givers and DDSD are at odds with each other. Caregiver wants to obtain services while DDSD’s goal appears to be a reduce and minimize services, especially HTS hours!

HTS providers should have stricter guidelines hiring policies-audits more-too many get away with to much-there is to much of training and dirty people that do not bathe that these agencies want to send to your home. Contracts should be reviewed for shorter time periods and looked at in all areas. For example {Agency} {Town} office has a good record. {Town} surely does not. Training and management especially the director is the worst of any agency there is beside BIOS.

Final decision on requested services and/or equipment are severely delayed at the post case worker level. #-Post case worker supervisory personnel are slow in responding & some final decisions for denial of procurement of goods/services are based on ambiguous and faulty logic.

17h. Waiting List

But have yet to start this service, still waiting on them to hire someone.

My child is currently 19 years old. She was on the waiver list for 5 years. When I was told she was on in home-support waivers last May, 2005. May. 2006 she hasn't received the first thing yet. The caseworker is 100 miles away and steered me wrong on who to contact locally from Dec. 2005 until March, 2006. Then it took her 9 days to fax paperwork to the other place. May, 2006 I'm waiting for the other place. A whole year, 19 years for my child, absolutely nothing in 19 years, and the state of Oklahoma "cares"??? Apparently untrue if you live outside of {Town} or {Town}. And the majority live in neither one.

19. General Concerns

I think each person has different needs. But they are judged the same as for fair hearing they are not fair hearing, they are policies hearing. Which is wrong. They shouldn't be told that if you go for a fair hearing you can change any decision that they have made it puts family and the family member needing the change. It just makes it hard to explain to them that there is nothing you can do about it because they have been told it will be alright after the hearing. Sometimes DDSD makes it hard for the family by not being truthful with them.

My son's waivered services plan with DDSD specifies he has 25 hours per week. I feel I should have the right to use less than the 25 hours a week and more than the 25 hours per week as changing circumstances warrant. There are a certain amount of hours allotted for the year and it should be our choice as to when and how they are used as benefits my son the most.

My family member is cared for by a family member under a independent contract. I would not trust anyone else due to previous rapes of others with disabilities in workshop and group homes. I do not wish to subject my family member with a disability to this.

The system has been so abused by those who have mental a/o physical abilities to provide for themselves, that not enough money is left for those who truly need assistance. I would like to see federal/state government weed these out so that individuals without mental or physical abilities to provide their needs could get the assistance they need. Such as unlimited prescription, pt, and dental service. Thank you

PENNSYLVANIA

1. Home

No meeting has been held to decide what would be necessary to make {Name}safe and happy in a group home. No meeting have been held where group homes "bed" for {Name}.

I don't want to wait we die to then move {Name} to a group home. He's a tender soul, and losing his home and his parents at the same time would be more than he could handle. We need to be there for him for the transition.

{She’s been} with me for 12 years or a little more. She has 6 other sisters but they don't take her hardly at all. One sister takes her maybe one weekend out of a month sometimes . I will never see {Name} in a home as long as i am living and can take care of her. Thank you for the adult day care.

1b. Dissatisfied with Home

Housing: the state owned ones are awful and the individual (private) ones are too expensive. Are ther no inbetween ones? How can we improve the state ones, or provide more affordable housing for our young adults. My child has been on a housing list for 5 years and we have heard nothing.

1e. Waiting List

Waiting lists are very long for residential placements.

Also, group homes have a waiting list (which my son has been on), besides supervised housing, many day programs have a waiting list too.

Have been on a waiting list for a group home for 2 years. Always told there is no room. Even though I have told them of the problems it is causing my children with fighting, arguing. Have asked for help many times. Someone will eventually get the hint. Have talked to {Agency} case manager. They don’t care!

2. Employment and Day Programs

He has a very hard time getting and keeping a job. Thank you for caring

He is a good worker and has been employed by the {Agency} for 37 years. He is only slightly retarded and can follow instructions very well.

2a. Satisfied with Employment

My brother works for {Agency} and is quite happy. He is involved in Special Olympics and is very happy. He loves his job and his Special Olympics activities.

Her services for her 5 day a week program are good.

My son worked at {Agency} for 10 years. He loves it very much.

{Name} is quite happy going to the workshop.

Our son enjoys working at the workshop and the adult recreation program. He cries when sick and can't go to work. We're all happy with his program.

He enjoys working and looks forward to his work days.

{Name}is very happy living with me her sister {Name}. She enjoys adult day care very much and the staff is very good with {Name}.

Thank you for the adult day care, because this does give me time to do things I have to do outside of my home.

We are very pleased that the {Agency} program started in {Name}. It is much better fit for my son than a sheltered workshop. It is more flexible to his needs plus we like having more input and control.

{Name} works at the {Agency}. For the blind and handicapped. It is a god send otherwise she would be home all day- this way she has friends at the workshop- and gets a paycheck every week- which she looks forward to.

My daughter would become so depressed if she didn't have her workshop to go to. She loves her workshop, the staff and seeing her friends there. This is what makes her life happy and why she can still live at home.

Started a day program about two weeks ago after a long hard battle. things appear to be going very well.

I would also like to acknowledge the day program and partial care program for their outstanding attention and competent care. It is one thing of offer a program, it is quite another to have both programs work so well.

The difference has come thru this family member's place of employment.

{Name} goes to {Agency} adult day care services - Mon, Tues, Wed, and Fri. We are pleased with this program as parents and {Name} is too!

Support services have been wonderful providing full-time workshop employment and transportation.

{Name} works at {Agency} in {Town} and really enjoys it. He has worked there for four years.

{Name} has been in the day program for almost 5 yrs and to date she has been treated very well and loves the program. In the almost 5yrs she has been in the day program our family has had no concerns regarding her care and services. It would be very difficult on a daily basis if {Name} was not in the program. Since the death of {Name} mother 5 yrs ago the in home service that provides bathing care has been a very helpful service due to female family members not always being available to help her needs. Without his service it would become more difficult to keep her in a male only house. The day program has been helpful with teaching {Name} social skills and helping with her speech. The day program has allowed her father/caregiver to have the freedom to attend appointments and take care of personal business outside the home. Caring for {Name} is like always caring for a three yr old 24-7. Her father is 77 yrs old and has been able to continue to care for his own needs/health so that with this program and his good health {Name} will be able to remain at home where she belongs for many years to come. {Name} would not be in this program if her family had any concerns about her care or safety due to the very bad experience with a mental health facility in the 70's. Her father was very much against this program in the beginning and after giving it a working chance he very much believes in the program and system in {Name} county that cares for his daughter.

Thank you! I could not take care of {Name} and my home-bound older sister unless {Name} had access to {Agency} day services, which makes her so happy three days a week. You are a gift!

She has a little job and I sincerely thank {Agency} for it.

2b. Dissatisfied with Employment

It seems, as I have talked to other mothers, that if the system knows there is at least one parent at home to stay with the child, there is no effort to find a workshop for the person. I am a "stay at home mother".

Consumer is unhappy b/c she has no job, a few friends but can't see them b/c no transportation.

I always waited patiently for an opening in a workshop for my son. But because he was home for 7 years and regressing in his behavior staying at home, i went over to {agency} and insisted immediately that I wouldn't leave until there was an opening for him. It took another 1 1/2 years to get him in a workshop. Because of his physical abuse at the school he

I would like to see more help provided for transportation to and from work, and for vocational training. Public transportation (buses) is not always adequate.

I don't know who sets workshop wages, but they are beyond pitiful and insulting. Our children are the hardest working, most loyal employees and they get paid nothing.

We are not happy with the day program at {Agency}. We have met with the director, {Name}, on two different occasions in the past year to complain and encourage improvements. She has just recently hired a new managing director and we are hoping this will improve leadership of the program.

We contracted with {Agency} to find employment and they have done a poor job. We had our 1st meeting with {Agency} in March of 2004 and {Agency} couldn't find a job for her until June 2005. Now that she is working the job coach claims there is not enough money for her to be there often. She stopped being here after 9 shifts. One of these shifts she didn't show up at all and she was late on a few of them. Now she is only spending 6 hr. A week with her and I am told when she is there, the job coach is out smoking or just not paying attention at all to her. My daughter's employer tells me they are not happy with {Name}. If my daughter loses the job because of {Agency} she will be back to being home alone every day.

My son needs a long term, one on one job coach and {County} ovr doesn't have the money. Also, group homes have a waiting list (which my son has been on), besides supervised housing, many day programs have a waiting list too.

Need to check on his work place he is not happy there get harassed at work they keep him under an air conditioner. He is not in drend of air conditioner he got sick in the past from the air conditioner. Thank you

Family member stated they are making excuses why there isn't any money to get her grants for sheltered workshops. They have lived here for 5 yrs and she's only gone to 1 in 6 months. The family moved here from the south and they treat MR people like everyone else. The family stated the MR support is so far behind.

I only have one complaint and it is about {Agency}. Where {Name} spends her day. I understand that there are different levels of maturity, in their clients. There has to be more rotation with jobs, sections, supervisors. My daughter has been with the same supervisor for many years. They are both stagnant. {Name} needs stimulation by doing different jobs, being with any different tasks different people. If you would do the same job with any different tasks different people, would your mind grow? I don't think so. I worked in the job market for 38 yrs. The basics were the same but my day was different daily. Just moving clients supervisors to new surroundings jobs people will make their day more stimulating and hopefully they will grow with the experience. No one likes change. But change is good.

The day program is over crowded and not enough staff. They need to be in a larger facility. Staff as well as clients are very stressed by the end of the day.

3a. Health Care Equipment

I tried to find out where I could get a catalog that i could order something for {Name}, but never have any luck.

{Name} is total left and I need lift to help at home with him. Over the last year he is growing weaker and not able to crawl around as much as he used to do.

This disabled person has no active life in the community, mainly because he cannot transfer from wheelchair to or from my car. His spirits would improve if he could get out of the house and participate in some activities. We are looking for a used lift van, reasonably priced (actually, low priced!)

Our family member uses a communication device. I wish there would be more facilitators who would be trained to help out when the disabled person is not always ready to facilitate with just anybody like our member will facilitate with dad, but not mom. He has facilitated since 1999. We do need a facilitator. Before he facilitated in {date}, we did not know our young man. We have really come to know him through articles and songs, etc. That he writes with his facilitator. Praise god, he can express his needs since 1999. It is amazing. He is very happy and so are we as parents.

We definitely could use more help on a daily basis & with more equipment - we need some type of device to lower {Name} into the tub & back out. (shower chairs do not work) hopefully some of the comments will be used in providing better services for those who have severe special needs thank you.

3b. Health Care Insurance

{Name} is in two hearing aids his insurance does not pay for. Insurance does not pay for his dental or hearing doctor either since he is on med-plus. The insurance they put them on is not good. I would like to go back to access card.

They are disgusted w/ their health and dental benefits

In regard to questions 21,22,23: my son has access to health and dental services through Medicaid, but the system is so poor that I have purchased private insurance and use that for my son's health and dental care. The plans available through Medicaid in {County} do not really address problems of the special needs person. As far as necessary medications, {Name}'s

Medicaid plan {Health Plan} pays for prescriptions ordered by doctor. Generic or comparable medications are substituted even though my son may have a positive track record for specific medications purchased.

Our government just took a $35,000.00 a year raise while my 25 year old daughter has little friends and now has to pay for her medication because of Medicare guidelines. No one would be able to live on $608.00 a month. If you know a way, I'd like to see it in black and white.

Other families I know and talk to also supply their own medical through insurance, they also find these supports impractical.

This is a great help to us. My daughter has medical insurance and Medicare. I arrange for all medical needs, including her psychiatrist and her new dentist and I pay for the dentist since there is no insurance for dental work. I have power of attorney for my daughter's finances and durable power of medical attorney in case of illness. My daughter has a living will and a very small life insurance for help with her funeral if necessary. She was educated at a school for the blind.

3c. Dental

Dental needs are difficult to address and access.

However dental services are nonexistent for him. He is totally noncompliant for dental treatment

He has yearly check up with dentist, doctor, and eye doctor and i pay the bills.

The dental part is limited to only certain dentists. {Name} uses a dentist that's not on the list. You cannot imagine all the problems we have had with his teeth.

{Name} has not been to a dentist in years. We were going to {Name} to a dentist who specializes in specila needs, but arthritis in his hands prevent him from working with patients like {Name}. Also, most dentists don't take access.

And I wish there were more dentist in area who handles mentally challenged people.

Limited dental services in this area. My daughter requires "oral surgeries" no providers in this county accept the access card. This is a really serious issue.

If she could have a dental plan, it would help considerably, her medication is aid greatly by the pace program.

3d. Medical

As for medical I take him provided he needs medical attention. He goes to {Name} clinic and enjoys everyone there.

Overall I have been less than satisfied with our treatment.

He enjoys working and looks forward to his work days. Because he is dually diagnosed- mental retardation and mental health problems we had a very difficult 2003 and 2004. We had difficult time getting him in to the behavioral health unit of the local hospital and when finally admitted after a stay of several days he's be discharged but the problems just seemed to escalate. It has been an ordeal when we've had to call crisis, 911 and wait for hours in the emergency room waiting and hoping for an admittance to the {hospital}. After over a year of problems we had to get him admitted to a hospital outside of our county for a longer hospital stay and he came back with his MH problems under control on his current medication.

{Agency} has helped me a lot the last three years with {Name} doctor appointments for her medications for her bi-polar. A case worker comes twice a week to get

We are fortunate in our family to have a doctor and nurse practitioner who administer to {Name} health needs with in his home (he will go to the doctor office for his yearly physical and some illnesses) and fortunately, he has been healthy.

He has yearly check up with dentist, doctor, and eye doctor and I pay the bills.

They also could have better medical coverage so they don't need so many referrals.

{Name} was in school until 2002. That is when he graduated. I think if his dyslexia was addressed more he would have better reading abilities and be a much happier person.

3e. OT/PT/ST

Not every person needs the same thing, my daughter needs a lot of physical therapy done to keep her bones and muscles strong as she gets older.

She should be receiving daily therapy in the evenings - she has a kinesiologist 1 - 2 x's per week.

For the past 6 months, I have been requesting speech therapy for my son! His medical doctor has requested this on his annual physical form! When the interviewers for the previous survey came to my home - we discussed it then and they made note of it on their paperwork. His caseworker was going to check on availability and...nothing.

4. Education and Training

My son goes to a training center daily, is picked up by a bus.

4a. Satisfied with Education/Training

{Name} is attending {Name} feels this is a good program for {Name}. Hopeful that he would be employed when he graduates this month Dec.21.

I am deeply grateful for the services that my brother receives. His life has variety with the skills workshop and with {Agency} in {Town}. Although his first choice at {Agency} is watching tv (his #1 favorite activity at home, as well!) I have seen him kidding with certain individuals, and wanting to sit with them at meals.

Providers need to communicate more with families. I have had to raise some issues at the adult training facility (skills) where {Name} attends day programs, but my concerns have been discussed with me and resolved. {Name} is content in that setting.

I was happy to help your survey. Thanks to {Agency}, {Name} is very happy at the school for the daily program. It also helps me as her caretaker.

5. Transportation

Transportation question: no one could find transportation for my child in my area. So I transport her to and from work. I am reimbursed for my gas thru the program.

We made our own connection and we transport. {Name}goes to a recreation program at the {Name}church on Mondays. We transport and now we also pay for the privilege of letting him attend.

5a. Satisfied with Transportation

Transportation that is provided for {Name} makes it possible for him to work 32 hours a week. This service is greatly appreciated.

{Name} is able to work 32 hours a week and the transportation provided for him to and from work is very beneficial to him and his parents.

Support services have been wonderful providing full-time workshop employment and transportation.

Her daily transportation to and from school is a blessing.

I am most familiar with the support he receives from {Agency} he gets very good transportation to and from {Agency}.

5b. Dissatisfied with Transportation

Consumer is unhappy b/c she has no job, a few friends but can't see them b/c no transportation.

I would like to see more help provided for transportation to and from work, and for vocational training. Public transportation (buses) is not always adequate.

Probably the biggest problem is transportation to the workshop. We are unable to take him every day.

The only available transportation is a 2 hr. Bus ride to get to a day program 20 miles away, at 6 a.m. two miles from our house. (plus, no ride home), completely unacceptable.

Community activities for these individuals is also very limited or restricted because of transportation and like problems.

Transportation has been a problem for years. Our son lost his ride on the county vans and so his dad transports him twice a week with two round trips a day it adds up to 140 + miles per day. A request for a third work day has put him on the waiting list for approval though at one time he worked 5 days a week and rode the van. Unfortunately that made almost a two hour ride each way to and from work.

Our only complain is that the bus to {Agency} only runs three days a week and costs $10.80 per day to use. (we do get a reduced rate from {Agency}.) Of course, if there was a similar worksite in town, {Name} could work five days per week and the transportation costs would be greatly reduced.

The transportation issue is quite a problematic one for disabled adults in {Town}. Once a client finds a job, the parents need to provide transportation, live near an unreliable septa or dart route, or pay $17. One way for a cab or bucks county transport. Writing to our state representatives has done nothing. We pay $34. For transport/day to have our child employed in a job in the community. When salary nets around $21./day, it does not profit to work outside a workshop. And, yet, is this not what we are looking at for adults with MR? Self-determination is penalized.

The para-transit department of {Agency} is lacking in the area of support for the clients. The regular driver we have is good but there are times that some assistance should be offered and it is not. My sister has been dropped off at home and some drivers don't even wait to make sure she gets in the door.

My second problem has always been the means of transportation. The transportation system just doesn't work in our situation. He was spending 4 hours a day on a bus. This is unacceptable for a person with a short attention span. I am not sure I could tolerate that much time on a bus 5 days a week.

Living in a rural area, transportation is our main problem. {Agency} county transportation won't pick {Name} up at our home. We have a pick-up point, which is not the safest or most convenient. I asked them to put a flag, which I would provide, on a shepherd's hook at the pick up point if they came in the morning and {Name} wasn't there. My husband drops him off and sometimes he doesn't know if they have missed each other. We don't want {Name} waiting out in the cold. They won't do this simple thing. In any case, this is complicated and I would be happy to discuss this and anything else, if you would like to call.

Transportation: my daughter had a liver transplant in may 2004. Before the transplant, she was able to attend her {Agency} program in {Town} 4 days/week. The reason was because the van would pick her up at 9:00 am. After the transplant, I wanted to get her back into her day program, but found out the van now picks up at 7:30 am. There is no way my daughter would be able to be ready by that time because of her medications needed in the a.m., and also because she is type 2 diabetic and needs to have her shot and breakfast. I cannot have her ready to go by 7:30 am. Also, she is dealing with an impulsive aggression disorder and tiredness makes it worse, so she would be very tired by the time she arrived home because of it being such a long day. So she now attends her workshop 1 day a week because I provide the transportation down and she comes home in the van.

I also told transportation about my daughter being diabetic, and they said they are not responsible if anything would occur due to her diabetes.

We live at the southern end of {Town}. Would love to see something in {Town} area for disabled people even if only once a month. Also, it would be great if the {Agency} bus came into our area more than the 2 days they come, then my son could go to workshop more than 2 days per week. {Agency} is coming into {Town} area on at least Thursday to pick up senior citizens from a personal care home 1 mile from our home to take to {Agency} senior center; but yet will not commit to stopping here. As I understand it, the bus does go back to {Town} after dropping off seniors.

5c. No Transportation

Living in a very rural area, transportation is a problem, there is no public transportation to get my son to and from appointments.

One thing that would help at times is transportation. We are a large family and we love to do things together. Usually, we'll then take 2 cars as there are 9 of us. Sometimes only half of us go. As far as the member of our house who has downs syndrome, {Name}, he would really benefit from alternate transportation opportunities in case he needs to go somewhere and I am not able to take him. As for the whole, we would benefit too. I guess it's time for a minivan, but until then, some alternate transportation may be helpful.

We need transportation!!!

We are in need of transportation services. There is no public transportation in our neighborhood. Our son was denied access service. He works 5 days a week, approximately 9 miles from our home and transportation (lack of) is a real issue. He contributes to his income, quality of life, etc., but can't get the one service that is truly needed.

Transportation does not come near our house and we were not told how to

I would like to for {Name} to go to {Agency} if transportation was available.

Transportation my son needs transportation to his job at a grocery store.

Lacking in wheelchair access. Lacking in wheelchair transportation.

6. Recreation Activities

I just want my son to be able to have some outside socialization and/or recreational activity other than {Agency} when he comes home from school.

I wish I could get my son into after services such as maybe bowling or other recreation services so he will not get bored on the weekends

6a. Satisfied with Recreation Activities

My brother works for {Agency} and is quite happy. He is involved in Special Olympics and is very happy. He loves his job and his Special Olympics activities.

He likes baseball, basketball and football games and his money pays someone to take him to the games. {Agency} is the best thing that could happen.

Our son enjoys working at the workshop and the adult recreation program.

The only thing she does is does some recreational things with the {Agency} of {County}. Dances, bowling, etc. And she is very satisfied with that.

Involvement in Special Olympics and {Program} is also a real plus in my sons life.

6b. Dissatisfied with Recreation Activities

We are being charged for programs for recreation that used to be provided free before the boy began to receive title 19 funding.

{Agency} recreation only occurs approx. 2-5 times a year.

The only recreation my daughter gets is 5 dances and I pay for each and drive her to and from the event; other than that she gets nothing.

7. Communication

I also feel things run smoother when there is good communication and give and take when dealing with a situation to come to the best solutions where your child is concerned. Thank you.

Our family member uses a communication device. I wish there would be more facilitators who would be trained to help out when the disabled person is not always ready to facilitate with just anybody like our member will facilitate with dad, but not mom. He has facilitated since 1999. We do need a facilitator. Before he facilitated in {date}, we did not know our young man. We have really come to know him through articles and songs, etc. That he writes with his facilitator. Praise god, he can express his needs since 1999. It is amazing. He is very happy and so are we as parents.

7b. Dissatisfied with Communication

My son is happy because of his family, not because of services he receives. We work with the provider when I contact them for help. If I did not contact them, I would never hear from them, about anything, services or otherwise. I would very much like to change but do not know anything about other agencies. We have only lived in {Town} for 1 1/2 years and am not at all happy with the lack of communication with them. It was good for a little while at first, my son does not even know who his case worker is. I think she may go to his work now and again to see him for a bit, but I know nothing about it.

7c. Information

Also, I went to a couple of meetings and they talk of different programs I didn't understand.

I have no idea what {Name} does at the training center other than her work.

Who is the services/support coordinator. Is this the caseworker? I am clueless who this person is or their function

My case worker keeps me informed at my child's day program for work. Everything else I would get bits of information through other parents. Most families with their family member at home have same complaint. We do not know what is available for our children. I'm sure there are a lot of programs we are not aware of. Thank you.

I only hear from MH/MR about one a year or so. I don't know who {Name} case worker is or what they will provide for her at her age.

I feel there is very little available in this community and I am not always informed as to what I can do to change the situation.

7d. Language Barrier

It is hard for her to participate in other community affairs because she is deaf, blind, MH/MR. She communicates with me by sign language and staff is eager to learn. I recently demonstrated some signs during an in-service.

8. Aging Caregiver Issues

I do fear once I am unable to care for my daughter, that is when there will be problems. I fear for her security and safety without me to watch out for her best interests.

My concern has always been about after family members are gone what will happen to people like her, even though you try to set up friends, etc. That can help oversee her and keep her secure so she can continue to do what she has learned to do.

We would like to see {Name} safely placed in a group home while we are still alive and can monitor his transition and comfort.

Due to the fact that I am aging (77) and {name} is 61 I am trying to find a placement for her with the help of her case workers. I have had her home for 22 years since my mother and father passed.

Due to my husband's and my failing health, we must get {Name} a group home when he is 21 years. {Name} weighs 178 lbs and will be 21 in 2007. It is physically impossible to take care of {Name} at home. He is totally dependent.

My major concern at this point of my life is what is available for my son after I'm gone.

I only have two problems with the way the present system works - my son has some very specific needs and he is very hard to manage at home. The process for getting him placed in a residential setting has been taxing on me. My health is now an issue. He needs to be placed asap.

The situation for my son is satisfactory now. However, because of my age and poor health, I worry about the time when I can no longer be his caregiver. I have asked to have his name added to the waiting list for residential services, but I have no assurance that this has been done.

We are hoping that when the time comes we can no longer care for our son-that a living arrangements is available that fits his needs just as well.

My one concern is as I age I will no longer be able to take care of her. She needs a lot of physical attention. So I am hoping a good residential placement will be available for her at that point.

She lives at home with our elderly parents (75 & 76 yrs. old) who are her primary caregivers. My sister is in need of residential placement to relieve our parents' responsibility for her care.

Someday {Name} will need to live elsewhere. I will need help at that time.

9. Transition Issues

I don't want to wait we die to then move {Name} to a group home. He's a tender soul, and losing his home and his parents at the same time would be more than he could handle. We need to be there for him for the transition.

I also feel {Agency} is lacking severely with options for our special needs kids once they are out of the school setting. It is a disgrace.

My son is 19 and has 2 years of school left. Any significant down-time (1-2 wks) without daily programming leads to significant regression/withdrawal. I am very concerned that there be no significant lapse between when he leaves school and starts an adult day program.

The parent stated that they should consider placing consumer in a group home, when the family can help w/ the transaction and not wait until he loses the loved ones who taking care of him.

I would like to see transitional workshops open for people with disabilities so they can learn a skill or trade, supervised, and transition out to a job or open a business selling their "wares"! I have a "vision" and if you'd like me to share my "vision" with you feel free to contact me.

My daughter's situation is not fitting in to your questionnaire because school. She has sufficient hours of staff support and it has been a good experience currently. However I have great concerns as to what the situation will be upon graduation. She has 2 years of school left and adult facilities serious lack of funding. People are being refused and staying at home

We are looking at possibility of group home placement in the future as a further step toward independence with a lot of support from extended family residing in the community.

We are very appreciative for the funding allocated to our son to attend atw and respite. It indeed has an effect on our family and we're so proud of the transitioning that occurred from school to his adult works at {Agency}. It literally took a community to get him where his is today....thanks.

10. Service Coordination

I still have not met my child’s case worker.

Our case worker, {Name}, was the very best. We have had some not so good in the past. Rarely heard from them, not sure they even knew our daughter. New case worker called to say she was replacing {Name}. We will meet her in December. What happens if we have a problem in Oct. Or Nov.? Stop over loading staff with paper work. Better yet, hire more staff so the have time to get to know clients and families.

10a. Satisfied with CM

We have been very fortunate with our caseworker and job coach in that they have remained stable. Many acquaintances have not had this

I have no complaint. {Name} case worker, {Name}, has always been there for us and advised us on everything available to {Name} well-being now and in the future. I hope sincerely that she will always be his case worker - she's the best!

Very happy with services. Feels that sc is very helpful & courteous.

Very satisfied with our case worker/s.

I thank the lord i have {Name} as my "go for". He saves me a lot of steps. Thank all of you who help us.

Just enrolled-since {Name} has only been in the program such a short time. I cannot answer most of the questions. We had gone through the receiving of a support coord. Whom we liked very much. She had to take an emergency leave after returning she left her position. We have been assigned a new person who we have not gotten to know

We have a terrific supports person now. She has done more in her 1.5 years with us than all of the others he's had in his 28 years! She is {Name} with family links, and I hope we can keep her!

{Name} is very good to keep in touch with {Name}. We appreciate this.

The new MH/MR caseworker is the best we have had.

Our son's support coordinator helps us think in a person centered way and is available when needed despite his very busy schedule and caseload.

{Name} was a great case worker, she helped me to find the best programs for {Name}. She was always available for me when I had any questions. She will be greatly missed. Between {Name}and the case workers at {Agency}, {Name} is very busy in the community and at his job. Thank you

Our new coordinator, we feel has done much more for us and given us much more information than our previous one. She has been extremely helpful and we are pleased to have her and feel confident that she is working for us and our son.

{Name} and {Name}are really dedicated to their job. You are fortunate to have them.

Our family member is a lot happier now than he has been in a long time. We are very happy with our case worker who is very understanding and easy to work with. We hope he stay with us and doesn't move around in the system or leave because of the state budget cuts.

We received the results through the good work and help from our caseworker who has been a godsend to us.

{Name} and {Name} {Agency} were extremely supportive during a time when I was very ill and unable to care for my son for several months in 2005. Without asking for help. {Name} mad {Agency} staff aware of this situation. Their assistance was greatly appreciated. They should be commended for their performance.

I have been very pleased with {Name} kind and courteous manner. There are times when I am upset. He is always considerate and interested in my feelings and {Name} as welfare. We have been fortunate to have such a fine worker.

In summary, the case workers have taken the time to organize s support system for our family that has been working like a well oiled machine. Upon any fluctuation in our child's condition everyone is on top of the game. I make a series of calls that are returned and a solution is collectively formed. To me that means a business ran well. It tool sometime and growing pains to get here but the end result was worth it.

My husband and I {Name}are very pleased with the way our sons caseworker takes the time to visit us all and informs us of what is available if we need anything. If I have a problem or a question for {Name} I can call her any time.

My daughter, {Name}, gets lots of help from MH/MR program. I am very satisfied with her case workers and all they do to help her. Thank you for making these programs available for her.

My daughter and I live alone. Our provider is a life saver to us. My daughter was inconsolable when her father died and without her program I don't know what would have happened to her. Staff worked with her and with me to ease her pain.

To whom it may concern: we are very happy with the services {Name} receives. All of the people who work with {Name} are wonderful and our case worker goes above and beyond for us. We are all happy (including {Name}) with what we are getting and thank everyone. {Name} will be with me as long as I can care for him, but all you folks make life so much easier.

I have always had very kind and helpful case managers. Questions have always been answered promptly. The people at {Agency}. (where {Name} works) are patient, kind and caring. {Name} D.D.S. job trainer {Name} is wonderful. {Name} enjoys {Agency} activities very much. I feel very fortunate to live in an area that has so much to offer {Name} and our family. Thank you all for your hard work!

{Name}does an excellent support job as well as {Name}at skills in seeing that my son is both safe and happy.

Also, I went to a couple of meetings and they talk of different programs I didn't understand. The people at {Agency} are nice and helpful as is my caseworker.

Mother passed away nine months ago. {Name} has been very helpful.

I would just like to say that the case workers do a tremendous job considering the case loads they take on. I think they deserve a lot of recognition for their efforts. If you do let anyone see my comments, I would just like to extend my gratitude and thanks for going above and beyond for my family and all the families in Pennsylvania. Just know you are appreciated for the important work you do, and the hours and hours of time you take out of your lives to make other lives a lot better. Thank you!!

Otherwise, I am happy with his supports coordinator.

Our caseworker, {Name}, visited our home on {date}. We were very pleased with {Name}. He explained everything to us.

{Name} is an excellent caseworker. She keeps me informed and always returns my call and answers my questions.

Although my sister is not very involved in many things other than a care worker checking in periodically. She is very nice and does as much as my sister makes allowable. I hope that this survey helps. Thank you.

{Name} has been wonderful to deal with. She has been helpful and kind to {Name} and myself. If I have a question or a problem she gets back to me right away.

His support/coordinator at MH/MR is always quick to respond to any questions or other needs.

{Name} has always been helpful to us.

I am noting that I am very, very, very pleased with {Name} who is my support coordinator.

10b. Dissatisfied with CM

Consumer feels case manager is not concerned on his behalf b/c she does not follow through on things. Consumer feels there is a breach off confidentiality w/ case manager lives in same apartment and wrote a letter to their landlord

But her caseworker did not but these things in her paperwork when we started and now are told it cannot be done. {Name}mother (primary caregiver for 45 years) died in December and it is a big change for her. Her caseworker is slow getting things together and when we try to help and find out things she said it is her job and just let her do it. Would {name}call me and we can talk

My son has recently been assigned a supports coordinator in the adult unit (within the past month). He will soon turn 23, we have asked several times when this would be done and got no real answer. Some of the questions answered were from past experiences with supports coordinators.

Not enough or regular contact with state caseworker or county caseworker.

When my daughter was a teenager, her case manager came to our home for a visit. She proceeded to tell how to parent not only my child with disabilities, but other children as well. Her advice was not requested nor wanted. I was extremely offended.

At present time we don't even know who the caseworker is.

Some community services are available but caseworker does not follow through when requested. My daughter was promised a tour of the training center in {Town} and also promised to be taken to o.e.o to sign up for public transportation neither done. {Agency} never reaches us.

{Name} seldom hears from or sees her caseworker.

I have called/written {Name} different times, no reply, no response of any time. I get notices here of job personal change but that's it. A lot getting paid for services but there not done.

I have had bad service workers that ideas of getting involved with community is shopping.

10c. CM Turnover

Many acquaintances have not had this and I can see their frustration over getting new people for their child. It seems this is a big problem and one I hope we won't have to deal with.

Feels like they have a new sc every year don't really like that.

Just enrolled-since {name} has only been in the program such a short time. I cannot answer most of the questions. We had gone through the receiving of a support coord. Whom we liked very much. She had to take an emergency leave after returning she left her position. We have been assigned a new person who we have not gotten to know on a one-to-one

We went from {Agency} to {Agency} and the person assigned to us resigned before we met her. We still do not have a person assigned to us. I am sure things will chance once we have a new supports person.

Frequent changes in support staff: I don't like when they keep changing the caseworkers. I believe we should have the caseworker who stays because it is hard getting used to different ones. {Name} has had 3 caseworkers in MH/MR. Now we got a different one; it makes it hard for me and {Name}.

I'm tired of all the different case workers. They don't stay at their jobs very long

10d. Shortage of CM Workers

We went from {Agency} to {Agency} and the person assigned to us resigned before we met her. We still do not have a person assigned to us. I am sure things will chance once we have a new supports person.

10f. Pay CM More

Wages needed increased for all support workers to maintain quality services.

I appreciate all {Agency} does for myself and my young adult son, but often there is not following through and discussions seem to never bring results. I just keep talking, requesting at each meeting and nothing (again) ever comes of my questions or requests. I know that case workers are paid peanuts, and work too hard so maybe this should be your first priority in improvement. (no I am not a case worker/manager).

10g. Service Plan

{Agency}liaison followed up with sc {Name}. {Name} has discussed programming & provider issues extensively with this parent and was somewhat puzzled by these comments. She has assisted the family with referral to whole life services and has arranged for the individual to be placed on a waiting list for habilitative aide services. Individual is currently in last year of school and is transitioning at this time. Sc

facilitated tours of providers (potential). Individual is currently employed by {Agency}. He is also on the waiting list for waiver services. As for the other parent that this mother is concerned about, the sc knows that this individual/family is already linked with {Agency}. But she can not share this information with this survey respondent.

Every time we have and appointment at {Agency} I have to call to get one and we never know who the case worker is.

We have little choice when it comes to service providers.

Residential or group home will be needed. Would like program and process to help facilitate this placement before it becomes an emergency.

The only problem we have had was the delay (paperwork, etc) in getting the needed services for our daughter. Consequently we lost 6 months of the allotted $$ promised.

I would appreciate my child not being taken to places, {Agency}, {Agency}, where we do not want him to be and does not have our permission to be. As a parent, I do think that we know what is best for our child. Someone needs to listen.

It seems that once the annual ISP has been established and a financial value placed on the services for a fiscal year., there is no room for change or any requested accepted until the next ISP is due. There is no flexibility to handle anything but an extreme emergency. The choice of providers for {Town} is still limited and caregivers still can not be providers or hire the providers that they desire.

For the past 6 months, I have been requesting speech therapy for my son! His medical doctor has requested this on his annual physical form! When the interviewers for the previous survey came to my home - we discussed it then and they made note of it on their paperwork. His caseworker was going to check on availability and...nothing.

I feel when changes are made in programs or paperwork involved in the change that before the families are required to make the changes that MR staff should be completely trained in the changes, so that when they teach the families, they all teach it the same and know what they are doing themselves. Currently when {Agency} staff are asked questions their reply is usually "I don't know." the support coordinators show how to do

{Agency} paperwork all differently. But we are expected to have our paperwork complete and on time yet the supports coordinators do not agree on methods.

{Name} had case workers in the past that would meet at least once a year for an assessment but that has not happened in at least 4 years. At the present time I do not know who her case worker is. She had her 1st heart attack 9-23-00 at age 60. Because of her age the area of aging provide services. {Name} provides respite care through family support services.

There should be greater choices & opportunities for alternate living arrangement for the {Name} especially for the younger and milder.

Much "paper work" by provider allows less time for individual family member. Contact is limited due to this

To whom it may concern: {Name} has been on program with {Agency} for about 3 years now. The first 6 months she had a job coach and staff coordinator {Name}. It has been 2 years no one has contacted us, I called there, waiting patiently at {Agency} site. And they told me {Name} was her coordinator now. He has never called me or tried to even meet {Name}. I am so lost, I do not know what to do. What she is entitled to or anything. Since {Name}, no one has been in touch about 2 years. I think this is a disgrace!!! I guess I will continue on my own to take care of {Name}, with no support or help. Thanks, {Agency} of {county} (for nothing).

Old child stays home and watches TV all day. Any time I needed assistance fast everything took too long to get approved then it was too late.

I have been concerned about the support service system since the beginning of the program. Because we had to pick one agency, the one I first chose did not know my brother, they never came to the house and monitored him by phone. However, I did meet with a coordinator at his workshop. I changed agencies because I contacted our former case manager. My brother was changed, but his records were never sent back to the new agency until much later. He will lose money under the waiver because he only uses his funds for workshop and transportation. He does not need any kind of therapy or any other service covered. He could use it for vacation or recreation but I was told this is not a needed service. Everyone talks about choices but I feel we have lost our right to choose.

11a. Satisfied with Staff

For the most part staff at {Agency} is courteous and helpful.

We have been very fortunate with our caseworker and job coach in that they have remained stable. Many acquaintances have not had this

The folks we work with are great and very busy that makes it hard to get the help.

The staff at {County} Mr works industriously to enhance the lives of those with disabilities. We are grateful!

She enjoys adult day care very much and the staff is very good with {Name}.

He is doing terrific from the first day at his workshop because he has had two great aides and the people there seem to be patient. The key to his good behavior is the teacher

{Name}was instrumental in enabling {Name} to be in the house alone at night without fear (I work nights). She also got {Name} the volunteer job at {Agency} in {Town}. It has made her so much better in her social development. Thank you!

I would like to take this opportunity to applaud the program and the staff. I do not know if we would be able to keep our daughter at home if we did not have any of the services available to us. The personal and professional sacrifices are commonplace to care for a disabled child but when constant supervision is required the choices are few. We intend to do everything we can to keep our child with us in her home where she is safe and loved. The benefits and choices of the {Agency} program allow us to have that option.

I am very grateful for the services and support my family receives. The staff that assist me with planning are the best I have never filed a complaint and I'm sure I never will need to

My daughter and I live alone. Our provider is a life saver to us. My daughter was inconsolable when her father died and without her program I don't know what would have happened to her. Staff worked with her and with me to ease her pain.

The support personnel at {Agency} are wonderful and do a great job with the clients.

My daughter is taken out twice a week and I am satisfied with the kindness and compassion that she is treated. They have a lot of patience with her and I am very grateful for that. May god bless them abundantly for this work.

I have always had very kind and helpful case managers. Questions have always been answered promptly. The people at {Agency}. (where {Name} works) are patient, kind and caring. {Name} {Agency} job trainer {Name} is wonderful. {Name} enjoys {Agency} activities very much. I feel very fortunate to live in an area that has so much to offer {Name} and our family. Thank you all for your hard work!

We are thankful for the services {Name} has received and the staff that we have dealt with is all great. They have a great compassion for these children. It's wonderful the opportunities they provide for these children. It is disappointing that the area we live in, prefer not to hire children with disabilities. Thank you for people that care!

Our local {Agency} staff are hard working, dedicated & most importantly - very caring in matters concerning our son.

{Name} has a terrific respite worker. She's always on time and they do fun things together. {Name} really enjoys her.

We have truly been blessed with the 2 caretakers we have to watch our daughter at after school and summer hours

Many activities and support staff available.

11b. Dissatisfied with Staff

Also this agency has provided me with {Town} students who are not special ed students. These girls have only lasted one day. Too much paper work. Takes away time for our retarded individual.

I would really like the caretaker to become more familiar with my son and know what is expected of them before starting on a permanent basis with him.

I have 2 disabled sons, {Name} in a group home with 2 other men. {Name} who lives with me his mother {Name} was in a group home with 3 other men. {Name}was abused so I brought him home. Nothing was done about the abuse which they know about. Staff was a fault with the abuse. {Name} has to stay at group home. I cannot take of 2 disabled. {Name} gets abused also by staff and nothing done about the abuse. I'm just a poor low-income mother and senior (69). Thanking you

11c. Staff Turnover

For the most part staff at {Agency} is courteous and helpful. The problem is the intense turnover of case workers. Three or four in one year is a problem - a big problem.

Many acquaintances have not had this and I can see their frustration over getting new people for their child. It seems this is a big problem and one I hope we won't have to deal with.

We are registered with {Agency}. Because of the constant changeover in staff, there is never continuity of care. We rarely use {Agency} - will only use for extreme emergencies.

I guess the biggest problem has been the staff turnovers in our home health aides over the years.

11d. Shortage of Staff

We have often asked for specific services for our son and it is always the same, they don't have staff available at those times

"yes, but never can find staff for our program so I am paid." ; "they can't get staff for our program."

We get so many hours a week that are not used because the agencies do not have staff.

The day program is over crowded and not enough staff. They need to be in a larger facility. Staff as well as clients are very stressed by the end of the day.

I don't feel there is enough staff with flexibility. When services are requested, the time it takes to put that service/staff member in place is way too long.

The {Agency} has provided a job coach who is excellent but she is extremely overworked too many cases for one person.

11e. Staff Not Qualified

{Agency} staff are not up on SSI to help.

Rarely, are the people sent by our agency fully qualified for her care. I have repeatedly asked for information regarding in home nursing services (which other people we know receive) with a child much less handicapped than our daughter. I have watched people receive wheel chairs (several) for ambulatory children and then sell them. It upsets us to see people receive so much help & we have our minimal care needs met. Our staff was not even grinding our daughter's food (she cannot chew) although in her service plan - it specifies pureed food. I thought for 3 1/2 yrs. That her lunches were blended - I would send pre-packed lunches for convenience & for neatness (sometimes caps fall off of containers sent from home & the contents spill. I found out that due to "lack of time" they had been chopping her food with a plastic knife. I know my daughter well enough - she would have either choked or refused to eat. When asked if they would puree her food if i sent in a blender - they refused.

11f. Pay Staff More

Wages needed increased for all support workers to maintain quality services.

We have had some really good people who were genuinely concerned about {Name}, but had to move on because they couldn't make a decent living in the system. We had more good workers than bad, but I have recently made more of an effort to be included in who is hired to work in our home with {Name}.

11g. Substitutes

We have truly been blessed with the 2 caretakers we have to watch our daughter at after school and summer hours but they were ill or off arc couldn't provide us with replacements and we would lose work hours.

12. Family Issues

He lives at home with me & his nephew most of the time unless on vacation or visiting his uncle in {Name}. He does chores around the house and helps me. He goes to {Agency} for training. I cook his meals, do his wash, take him for any appointments, like haircuts, dental & eye care. Basically I do everything for him a mother would do far a 13/14 year old.

My family member {Name} received excellent services- but only because I advocated for everything she go! I was fought on almost everything I asked for. But I got everything she needs to this point.

I have taken an active role, working diligently for the safety and welfare of not only our own MR boy, but for others as well. {Name}on Saturdays with other MR people. We made our own connection and we transport.

Meet my son and offer to let him live a month with them just so they can have some understanding of a behavioral issue adult, obsessive compulsive adult, explosive disorder adult he is. (six medications which don't work.) Believe me s. Sure can be a handful. Age 21 but still a child inside.

12a. Family as Paid Staff or CM

I am a sister of a person with a developmental disability, mental health illness and systematic sclerosis (scleraderma) quit my job to take care of my sister. I could not handle her and my job too. I am living off of my savings until I am able to collect my social security check. I was told by other families with persons with disabilities that if you prefer to use a family member or friend to provide supports to the disability person that you - the family member - can be paid for these services instead of paid outside help. My sister lives with me in my home. Is it possible for me - her sister - to receive some money for the services I provide for her?

We would like to know why strangers are paid to house developmentally disabled adults and if a relative were to do this. There is no payment other than the individual's SSI. Something is wrong with this system. If I pass away tomorrow, who will take care of my daughter, a stranger who will be paid or her sister/brother who will not be paid?

13. General Well Being

I just want my son to be able to have some outside socialization and/or recreational activity other than {Agency} when he comes home from school.

Community activities for these individuals is also very limited or restricted because of transportation and like problems. In other words, much of the time without family, these individuals are isolated.

They also have parties for them take them shopping- ball games, etc.

She also got {Name} the volunteer job at {Agency} in {Town}. It has made her so much better in her social development. Thank you!

Is very supportive and he and I enjoy visiting all of our relatives. His weekends are full with shopping, eating out and visiting. {Name}, his caseworker, can fill in more information. We consider ourselves luckier than most and unless one of us gets really ill, we are living a full life.

13a. Health

Is there a weight reduction camp or retreat available?

13d. Social

Dear sirs: my son has difficulty making friends and keeping them. Also, has difficulty socializing in groups such as church. Also had difficulty when he was in grade and high school. He is very bright and was on the national honor society in high school.

{Name} gets out to social gatherings and church attendance. He's having a good life but it is going to fall apart very soon.

There are several issues we need to take time to investigate. Most of them involve a social and community life for my son. Unfortunately, he is the holdup. He's not interested in new groups or doing things beyond those he's doing now. It's going to take work, but I need for him to get out among people like himself.

There should be more social things for him.

My concerns and my child’s needs consist of the following: social activities with age appropriate young adults 18-30 years old. The people are either too young, too old, or severely handicapped, wheel chair bound, cp with no communication skills etc. There seem to be no in-between social activities or separate grouping for the less severe young adults.

14. Respite

{Name}lives with her elderly father whom he needs a lot of help that {Name} helps him with. We have asked several times to get help into the home for {Name}and someone to stay with her at times in the evenings when her father has places to go and cannot take her.

14a. Satisfied with Respite

Has respite sitter through the {Agency}was very good & works well with him.

I truly appreciate with the respite money you give us for a babysitter. It truly helps us out greatly. Thank you.

Current girl who works with her in our home for 3 hours on Sunday while I go to church and do lunch is also doing a good job.

They take great care of my daughter and she is happy there. I so not have a supportive family so respite is my only break to all me to have some time to myself.

{Name} has a terrific respite worker. She's always on time and they do fun things together. {Name} really enjoys her.

We are happy with the caregivers (respite) for {Name}. We have great confidence that they can handle him.

14. Dissatisfied with Respite

We have tried to use respite care at times but they always have failed us. We have horror stories about those times.

I think we need to have more respite for our family members.

We need to be able to hire our own respite care givers and have it covered by assist. I will not leave my child with someone I don't know or haven't chosen. There was no money to cover the person of my choice when I needed surgery. It was very expensive to pay for this care for my child as I had to have surgery 5 hours away from home and I needed it for over 2 weeks. This happened 3 times.

I have only requested respite service once in 18 years and it was provided for 2 days. I now want it again and am told there are no funds to have someone come to our home for two weeks a few hours a day. I am disappointed since I haven't asked for much to this point.

We have fought for years to get local respite. It is always too far away for our family. We have fought for a long time to get a permanent companion/daytime caregiver. We only ever get temporary college students.

I get not respite funds at all. There needs to be more money for services for these adults.

We really need to have respite. At one time we used community services in {Town}, pa., but they no longer do over night which is that we need. Our family members do ''respite' for us, so as my husband and I have a little life of normalcy. We do not think that is asking for much as we hardly ever ask for help. We are not young ourselves. We are 66 & 67 years. My husband has a heart condition, cancer. I have had a shoulder replacement, kidney stones, and asthma. Who knows how long we can take care of my sisters. We only ask for respite so as we can have some time for ourselves.

Overall I am very pleased with the care and plan my daughter receives. My only concern is that the respite home she goes to is on a very steep hill that is not accessible all year round. The home is in the middle of the hill so on a snowy day, it is hard to get stopped. It would be awesome if a new facility could be built or bought that was on flat ground. Also, the respite home is in the basement of this house which is cool and damp. My daughter is crippled with arthritis so the dampness is not good for her. The home doesn't have a wheel-in shower so it's difficult for the staff to shower her. She is confined to a wheelchair and cannot transfer by herself. I am a single mom and having the respite care is very important

For 2 years I was to receive 10 days of out of home care for my brother but there was never any rooms available I had even asked for day that were available and I would plan around them but never received any. No room was available even with 60 days or 6 months notice. This was allotted to him but never available. If these are promised I think they should be available the money is not used for him then.

I feel that money should be available for overnight respite in our own home for a caregiver we select. Example: if there is an emergency and me and my husband are unavailable and our service provider has only staff member unavailable (maybe she is on vacation). We do have someone who could come in, but the problem is she would have to be paid by us - out of pocket. This may be ok for a day or 2, but as we all know, there are times when we or our loved ones could be incapacitated for weeks, even months and we could not keep our child at home under those circumstances as 24/7 care is required.

15. Crisis

In a crisis her caseworker did place her in {Town} manor- she had a baby and had to move back home. She and her boyfriend are both mentally disabled

16. Funding and Budget

Additional funding for respite and services would be helpful. Like supports coordinator.

When people need help with money to pay bills. I'm behind in my rent. My rent is $600.00 a month and I pay my landlord $400.00 a month. So I am behind 1,600.00 from April, May, June, July, August, September, and Oct. 200., 200., 200., 200.,200., 300., 300., that adds up to $1,600.00. She needs the money to pay her taxes on her land.

I have not used community services because i am able to provide all that my son needs. But I wish to receive for him any monies that he is entitled to since he just has a volunteer fob and has no income. It would make him feel good if he had some income. Again, there are resources available in {Town}, but I have never used them.

Services or activities closer to {Town} area, additional funds is always recommended and appreciated.

Nothing has been offered by the county. We were told no funds are available.

We have to use them for transportation because we live in a rural area. We spend most of her waiver on transportation and job coaching (through {Agency}). There is no funding left for habilitation. There are no activities in our area; we have to transport her everywhere ourselves.

I have been a single parent since 1989. S. Has been my full-time job for 21 years and will be until I die. Our "pa" government have no idea what it takes to raise a mentally retarded child because if they did they sure would not keep taking services, medical changes away, but... "add" more help for us burned out parents. More "financial support" is needed, not keep "taking" away.

No funding program for her son. She finds annual meeting a waste of time is there is no funding.

The lack of transportation and there's only enough funding for a half day program.

I still need more services for my family member with disability, but I keep getting "there is no funding".

Also, these sids and adults need services yet our government keeps taking from them. I wonder if any government official had a mentally retarded child and made a lot lost money, how would they handle it! These children and adults need more services, not less. Give back the money and give more where it is

I feel there should be more money available so my family member could be out of the house more and then I could be employed.

The {Agency} funds we receive are great to help with activities. However, it does not cover all the respite services I need or it can't be used for day services such as {Agency} or another type of day activities.

Our money is from {Agency}. My son does not attend a day program at this time nor does he have a job or workshop. We understand and have been told that {Agency} money may not be used for licensed programs, but do not accept this. We were told the money is for their needs and he needs program...does not make sense. But I guess limits must be set. Also, we have heard that any "new money" for consolidate waiver recipients will be given to them so their needs are met.

Another problem we have our son's functioning level & health would not allow him to work unsupervised in the community, so that's not one of our options. Here again it all boils down to money. I am more that willing to do my part to see a new program start. I have experience in that area, but need more support. Thank you.

How is it that you must charge for recreational in county? Is there no funding for this? My son really enjoys this but I think it is very costly at times.

I don't understand why {Name} {Agency} check was cut from $720.00 a year to $200.00 a year. {Name}does a lot in summer and with only $200.00 a year it doesn't help much at all. I do not like change from center independent living who handle {Name} money to {Agency}. Those people are trouble to have. My girl who helps me with {Name} it took 6 weeks to get paid. {Agency} gives you the run around about everything.

There is not enough money allocated to meet {Name} need so planning is limited, choices of programs do not exist.

The lack of waiver money has limited the scope of my son {Name} community and social welfare. He has began stuttering and as a result of limited interaction with friends and associates. Please move the budgets lack of waiver up to full attention. {Name} {Address} {Town} county has very limited funding and can't provide many of the services larger counties can provide, such as {County}.

His caseworker, {Name}, is a wonderful, helpful woman, and she is really trying to help us, but her hands are "tied" with programs "cut" and funding short, there's little she can do to help us.

Services have gotten worse due to state budget cuts in the {Agency} service system.

Because of that and because of working at {Agency}, I did not need to find a full time job which would have left {Name} without me. As I wrote to you, {Name}, and to {Name}, I want to keep terry in my home with me. This funding has made it possible. Thank you!

Have a little more money for the one service my son does enjoy.

I also feel her must important needs are not being met by {Agency} or the state. Mainly housing with issues. I will be looking into (if possible) in budgeting her state funding myself and hopefully put in place a plan for her that will help with the more important needs (and unanswered) {Name} has at this stage in her life.

Some services that are needed are not provided for. It's so difficult to add anything to what's already offered. The answer is always - it's not in your budget; if you want to take it from your transportation or respite that's the only way to get it.

My daughter is fortunate. When she graduated there were waivers available and she was able to get services. However, for graduates today, funding is not always available. It is so important funding be made available to them so that they do not sit at home and become depressed.

A few years later when I requested funds so perhaps she could go to a workshop, we were turned down. Truthfully, I could not understand the process. I am very grateful she has now been approved for funds to work in a workshop.

Information is not freely given on what is available. The base services unit manipulates funds and routinely tells families "there is not money"

Financial support: to me this means $40.60 per day that is given to me to provide everything that I need to keep my child at home. Out of this money I pay people $10.00 a hour to come in and take care her when it is needed. This funding is to pay for in home support, respite care and other services that she needs/ {Agency} has been very considerate in the past in several emergency situations of mine and has increase this funding on a temporary per incident basis. However I know this is good sum of money. I know this amount of moneyos mpt going to continue to be enough to keep her in the home because currently we are having problems in both her health and mine. This 40.60 is not enough for me to pay someone to come in on a steady basis and still maintain the time I already need someone like when I make trips to {Town} and etc. However I have addressed this with {Agency} and I am confident they will provide the increase services when finances are available to them. Access and delivery of services: what supports are suppose to be given to my family. I submit for and receive monthly amount out of that money, I am to provide all the services that she needs. If they are none available when I need them , it is because I did not make the arrangements , or did not have the money to get the service. Are they enough? Do they meet my family's needs. My daughter needs are being met. She receives all medical, physical, and mental care she needs. However the needs of her family are far from being met.

Waiver funding also paid for a hearing aid, which has been quite successful.

I would also like to know where my son's money goes. I think some people bill for things that may not have happened or that he did not attend. I am going to start keeping track of all of this and would like to see who has bills in the future for him. Thanks for listening.

The only problem I have had in the past with the program my son is involved in was our budget being reduced. We have in home care for my son. Last spring, my son was in the hospital for 2 months which had our budget come in under our spending limit. The was the second year straight we came in under budget. Our reward for staying under budget was a reduction in the hours we receive for in home care. Personally, I didn't feel this was fair. I can't control when my son will get ill.

Has many concerns would like to be contacted for more info. On wavier money.

Funding through family driven is rarely sufficient even if it was what can be purchased is restricted. No funds available for transportation that is surely needed.

The whole issue for supports/living situations, comes down to poor funding for our state. There are many on waiting lists and no money for new residences or support. The {Agency} staff are overworked and very much underpaid. This is the population that must be taken care of - especially when parents are older or dead! Please care and get more funding. Thank you.

Much of the lack of services in not the fault of the county regulations but rather a lack of funding from the commonwealth.

We are extremely concerned about {name} ability to go to skills program (what happens after graduation this spring) told {agency}has no money to support these programs more and more taken away for the care of these children and persons in the area.

We really miss the financial help we got in the past. I feel with that help paying for sitters it was a real help in keeping our person at home longer.

The problem is that there are 'stops' that keep us from getting what we need - either at state level or county.

I am very concerned with the funding situation. {Name} will definitely get depressed if he doesn't have a program to attend. I am willing to do anything that I can to ensure that he doesn't sit home. Let me know.

It some how doesn't seen fair that because we want {Name} to be home with us that he can only get a small amount through SSI and the small amount of waiver that hardly pays anything to our daughter who is our support person during the day for {Name}. After only a few months our waiver money is totally gone and there are still many months left in the year. If {Name}was in a home where I don't know what is happening to him, he could get money for room and board, job coach and other things he would need. Some how this isn't right that we get only $400.00/ month from SSI. I know it's not your fault, these are just how we feel right now about the situation.

I still would like {Agency} funds for {Name} for the days he is not working. He needs constant supervision.

That is not enough - why can't we have more money for more program time. All these questionnaires and other things money is spent on - why can't that be used for more program time for the clients? All they can tell us is you have to wait until money becomes available. So my daughter sits at home 5 days a week and gets bored.

We are very appreciative for the funding allocated to our son to attend {Agency} and respite. It indeed has an effect on our family and we're so proud of the transitioning that occurred from school to his adult works at {Agency}. It literally took a community to get him where his is today....thanks.

17a. General Satisfaction with Services/Supports

My son receives help, support and work through an association for retarded citizens. Though his affliction is deafness - he is not retarded- however the program provides excellent support suitable to his needs. He has attended this program for at least thirty five years and has benefited emotionally and spiritually - it is his foundation. The question marks mean no, or I'm not sure that is being asked.

{Name} receives {Agency}. That has been a heaven sent. That program has helped us as a family keep him at home. Otherwise I wouldn't be able to work. And financially we would have a hard time

{Name} is very happy at {Agency} and a lot of that is because of the help and support she gets from {Agency}

Very happy with services. Feels that sc is very helpful & courteous.

Very satisfied with our case worker/s. Needed "emergency" help identifying after school care for our disabled child - worked identified a wonderful service that has fully met our needs and kept me working full-time in support of our family. SSI monies help support our family member in our home. Almost feel like support services are better for the "adult" and disability than child. Maybe I'm better informed now? We are very hopeful our experience will continue when our disabled household member is no longer covered by {Agency} day activities. Thanks!

We are new in the area and new to the programs she is now enjoying. I did not have sufficient knowledge to answer all of the question-but over all the programs have been very helpful to all of us.

He likes baseball, basketball and football games and his money pays someone to take him to the games. {Agency} is the best thing that could happen.

I have received very good services and help in making life for my daughter more pleasant and keeping up her self esteem and training in different ways to do part-time work.

The {Agency} has been great. This is the only social contact my son has.

The services and supports provided through {county Agency} are appreciated.

My son attends the {Agency}. He loves going there, and is very happy to be a part of the program. The staff is the best. They really care a lot about the clients. They work very hard, and the program grows the most beautiful plants in our area, at a nice price too! Plus their seasonal activities are always excellent. My son and I are proud to be a part of the {Agency}! {Name} and {Name}are really dedicated to their job. You are fortunate to have them.

Thank you for everything you do provide for my son because he is very happy.

Happy with services, only wish that he could attend {Agency} 5 days a week.

I am deeply grateful for the services that my brother receives. His life has variety with the skills workshop and with {Agency} in {Town}. Although his first choice at {Agency} is watching TV (his

#1 favorite activity at home, as well!) I have seen him kidding with certain individuals, and wanting to sit with them at meals.

Because of that and because of working at {Agency}, I did not need to find a full time job which would have left {Name} without me. As I wrote to you, {Name}, and to {Name}, I want to keep terry in my home with me. This funding has made it possible. Thank you!

We're satisfied.

Services received are very helpful and provided by competent caring people.

At this time everything is pretty good. We are happy that our fellow has someplace to go. The services are very good.

We are quite happy with the services we currently receive.

She really enjoys the {Agency} program, but our family activities are such that it would not be a problem to us (but I know it would be to others) if it were reduced.

{Name}is doing well, and still interested in many things. The computer has been a great learning toll for him as well as the things at our church. He is always busy and is very helpful. His sister {Name} takes him bowling every Friday night and looks forward to that. Thanks for the help that you have given us.

Overall I am very pleased with the care and plan my daughter receives.

Through the efforts of his siblings, some close relatives, and the services mark is provided through {agency} program (home health aides) and skills of {Town}, we continue to keep his home "up and running." there have been good and bad times.

Your services provide each of us with time with others and time of independent living which is necessary to physical and mental health to both. Thank you

I would like to take this opportunity to applaud the program and the staff. I do not know if we would be able to keep our daughter at home if we did not have any of the services available to us. The personal and professional sacrifices are commonplace to care for a disabled child but when constant supervision is required the choices are few. We intend to do everything we can to keep our child with us in her home where she is safe and loved. The benefits and choices of the {Agency} program allow us to have that option.

I am very grateful for the services and support my family receives.

He has been going to dec in {agency} for 27 years. He enjoys his time there.

My daughter, {name}, gets lots of help from {Agency} program. I am very satisfied with her case workers and all they do to help her. Thank you for making these programs available for her.

I am satisfied with services at this time.

Our provider has continued their good work and I am extremely grateful.

To whom it may concern: we are very happy with the services {Name} receives. All of the people who work with {Name} are wonderful and our case worker goes above and beyond for us. We are all happy (including {Name}) with what we are getting and thank everyone. {Name} will be with me as long as I can care for him, but all you folks make life so much easier.

Thank you for all your help and all you do for {name}.

We have been very satisfied with the services we receive and have not had any problems.

I have always had very kind and helpful case managers. Questions have always been answered promptly. The people at {Agency}. (where {Name} works) are patient, kind and caring. {Name}'s {Agency} job trainer {Name} is wonderful. {Name} enjoys {Agency} activities very much. I feel very fortunate to live in an area that has so much to offer {Name} and our family. Thank you all for your hard work!

We are very pleased with {Agency}. Our child is treated as an individual with special needs. She is guided with love, compassion, firmness and pride. Her victories are cheered & her failures are understood & sometimes rerouted. This is not just a day care or baby sitting service.

We are extremely grateful and happy with the services provided through our MR offices. The people are always on our side and do everything to make our lives better.

Many activities and support staff available.

As far as I am concerned my daughter has been doing quite well and I feel it's from all the services I have to use. Starting with {Agency}, to {Agency} then to {Name} school where she graduated this year and {Agency} the training she got there to get a job at a local restaurant where she works 3 days a week. She's very happy and I have her involved in the community as well as take her everywhere I go. Examples: church, the fair, the movies and on 2 bowling teams. Thanks! And keep up the good work!

I am deeply grateful for your services and supports, {Name} loves {Agency}. I doubt that {Name} would be still at home if she did not receive all your services. Thank you god bless you all.

All positive remarks are reflective of {Agency}. Always in touch and always available. Couldn't be happier. All average or below average remarks are reflective of {Agency}. P.s. thanks for the email address.

All services have been geared towards {Name}; I am very happy with all services provided.

We are happy with the supports we receive. Between our daughter and us, our son receives the best of care. He is totally dependent. He has been in diapers all of his life. He is non-verbal but we know what he wants and needs. He is happy and healthy in spite of many abnormalities. He has very limited walking. We do have a wheelchair for him. He can eat only soft food and requires an enema every other day which our daughter takes care of. Our daughter/caregiver lives across the street from us.

17b. General Dissatisfaction with Services

I have no idea who is in charge of my daughters case at the {Agency}. I also have told you guys to take my ex-husbands name off my daughters records. Things keep getting mailed to me as {Name} ---" when it should be mailed to me {Name}.

We can't change programs because there is a waiting list for all the other day programs. I've been waiting over a month for an answer from {Agency} on the use of concurrent services; e.g., when my daughter uses respite, can we also use habilitation along with the respite since it is a different service code and is in her ISP. 24 hour respite needs a better definition. We already have concurrent services going on - respite and day program run concurrently. Why not respite and habilitation? There is also a staff retention issue. I don't understand why a decision can't be made!

Your whole system stinks. Ex. We needed a wheelchair. It was not given to us but leased at $65.00 a month for 15 months. Total cost if it was purchased outright is $750.00, you do the math and tell me why there is no money.

Overall I have been less than satisfied with our treatment.

In the past 3 years there have been times that she hasn't been getting the quality of services promised through some providers.

I find it sad that with all the taxes we have paid over the years and not one agency could help us when we as a family needed it the most.

We feel the system has completely let us down.

I also feel her must important needs are no being met by {Agency} or the state. Mainly housing with issues. I will be looking into (if possible) in budgeting her state funding myself and hopefully put in place a plan for her that will help with the more important needs (and unanswered) {Name} has at this stage in her life.

As parents and guardians, we were totally disappointed in the {Agency}.

At several times in my life I have been extremely disappointed with {Agency}.

{Agency} services and programs have not made a significant difference in this family's life or family member's life.

Even though the service plan includes the family member's input and suggestions, there is still very little that {Agency} offers that is of any benefit to this family member.

Does not want name used, does not like sc-may request a new one. Would like family living for son, but doesn't like the agency's way of handling things. Disgusted with respite system. Does not feel sc cares about her son or family. Feels like state doesn't care with all their regulations-they beat up on the family.

Although our daughter is profoundly retarded, requiring full assistance in every aspect of life, we are still receiving only a (?-illegible) waiver. We are in need of equipment & more help in her care. Rarely, are the people sent by our agency fully qualified for her care. I have repeatedly asked for information regarding in home nursing services (which other people we know receive) with a child much less handicapped than our daughter. I have watched people receive wheel chairs (several) for ambulatory children and then sell them. It upsets us to see people receive so much help & we have our minimal care needs met. Our staff was not even grinding our daughter's food (she cannot chew) although in her service plan - it specifies pureed food. I thought for 3 1/2 yrs. That her lunches were blended - I would send pre-packed lunches for convenience & for neatness (sometimes caps fall off of containers sent from home & the contents spill. I found out that due to "lack of time" they had been chopping her food with a plastic knife. I know my daughter well enough - she would have either choked or refused to eat. When asked if they would puree her food if I sent in a blender - they refused.

The state {Agency}, however, is a tangled mass of bureaucratic nonsense whose mandates often seem to indicate that they have never seen a special needs individual - much less have those individuals best interests at heart. Each of our individuals is just that - an individual - whose needs, most assuredly, cannot be met by the "one size fits all" mentality of the {Agency}. The very nature of our children's problems demand flexibility in our problem sorting attempts. An individual who gouges & scratches his/her face & body cannot have gloves on to prevent these injuries because it "restrictive programming". An individual who is traumatized by group settings cannot be put in a quiet area because it is "restrictive programming". Those of us who deal daily with these special needs people know that what works today may not work tomorrow. The essence of helping our children is creativity & flexibility; two words that apparently have no meaning at {Agency}. Our children need pathways - not roadblocks. An excellent first step would be the elimination of needless paperwork, put in place for the sole purpose of justifying someone's job.

We have not been happy with any services as we have had. {Name} is currently employed at serve in {Agency} on a temporary basis but not from help from the county we called and spoke to them about taking {Name} to try to get a better recommendation for her. We feel that just because the {Agency} stated {Name} was a lost cause that her caseworker did not see fit to check out opportunities like this one.

{Name} seldom hears from or sees her caseworker. She wants to live on her own with her fiance and agency has been no help in making that happen.

When we ask for help with our disabled person we are always told there is no money. Nobody does anything to help us. It just goes in one ear and out the other. I don't even now why we have a mental health in this town! A lot depends on who you are. My son was molested by a janitor at the high school and nothing was done.

Currently, {Agency} base service unit does little if anything for my daughter.

Ever since he moved here, he has done just that. Supposedly, the {Agency} of {County}. Is waiting for some sort of voucher for him to come from the state and then he may be placed in some sort of day center or supportive employment. However, this "voucher" may never come through. We have had no help in finding him anything, not even volunteer work. As a result of this, he is regressing, he is not as independent as he once was and he misses all of his friends and the life he used to have. I feel as though he has been thrown away, a cog in an useless system. We have no idea who his case manager is because we have virtually no contact with anyone. It's sad, he was once an active member of the community, now he just takes up space and has nothing in his life to look forward to. How would you feel? * you may show this to Gov. Rendell.

17c. Access to Service/Supports

I know it's hard but we have a friend who is having a very rough time trying to get help, we need more public notices out there for folks to know who to call.

Services or activities closer to {Town} area, additional funds is always recommended and appreciated.

We applied for support services last may. We have been told that our daughter qualifies but there is nothing in this area for her.

Recognizing population growth in {Town} township, believe there is a need for a local workshop/support center.

I would gladly invite a state representative to my house and see how far away services are for us.

We live in the country on the edge of the county. We would probably like a little more socialization opportunity for our sons.

We have asked for him to attend specific activities at the local YMCA, they are never available or don't fit provider schedule. Services that are offered are often generic and my son is supposed to "fit into the mold". Tailored services for a specific "individual" are hard to come by. You can tell people what your child likes or would enjoy doing and they try to fit them into the services for the masses - too much hard mentality.

We live at the southern end of {Town}. Would love to see something in {Town} area for disabled people even if only once a month. Also, it would be great if the {Agency} bus came into our area more than the 2 days they come, then my son could go to workshop more than 2 days per week. {Agency} is coming into {Town} area on at least Thursday to pick up senior citizens from a personal care home 1 mile from our home to take to {Agency} senior center; but yet will not commit to stopping here. As I understand it, the bus does go back to {Town} after dropping off seniors.

I feel there is very little available in this community and I am not always informed as to what I can do to change the situation.

17d. Info Regarding Services/Supports

Need information in Spanish

They still have not received any contact about day outings.

I know it's hard but we have a friend who is having a very rough time trying to get help, we need more public notices out there for folks to know who to call.

We have just started to take care of her. There's a lot of things we don't know about I'm sure. We would like to see information more accessible.

This county lacks a control bank of information for families. 1) what are our options 2) what kinds of help are out there 3) how do I know which one is best for my child 4) what agencies are available 5) I had lunch yesterday with a woman whose daughter is 25 year-old, developmentally slow, not working & not currently getting any training. The mom doesn't know where to turn! This is a travesty. We need to help. ********************

I have not received any kind of information about other services available to her.

I have 2 sons who are learning disabled I have not received services and any information since they left school. There were in ls classes after that they just struggled and have been on their own. No help no meds.

Unless someone already exists, I need an SSI expert to access for questions, support.

Really don't know if all available to my son is being sent/shared with us. How can we know that? We get what is sent, that's as much as we know.

The services are very new for me. So I don't know too much about all the services that are out their for her or our family. Would like too receive any or all info that might be out their for my child. Thank you

Would like to see what is available for this kind of adult

Not enough information is given regarding available help for {name}.

If you would like to send us some information on other services please feel free. Thank you

I would like to receive more information regarding these services-not sure exactly what all is involved.

I would like to know what else is available besides day programs. He doesn't seem to enjoy it or doesn't really participate. He seems to enjoy being in his own home environment, but I sometimes could use a break.

I don’t know what services are out there for him nor do I know where to find any services or programs that my son can get. What is needed is a child advocate that knows all of the programs and can tell me what would be best.

Not completely informed of what services are available to them.

I am not aware of any services that my child can receive other than job coaching. It would be helpful to me if we received information on what services are available. There are issues such as health insurance and housing that I am not sure where to go for guidance to make decisions that are in my child's best interest. Because I don't know what agency to contact for help, I may not be getting the best services for my child.

I don't think we use the programs that often; cause some things are very confusing. To many initials for all the different organizations.

17e. Need More Services/Supports

I have been trying to get my sister into a group home in {Town} county since January and have been told there is no money. I've basically been told the only way I can get her into a group home is if I throw her out of my home. I have recently returned to work full time due to financial reasons, therefore, my sister, who has seizures, is frequently left alone for long periods of time. Help!

Currently receives only {Agency} monies, is on waiting list! In the emergency category for waiver funding which is needed to ensure his health and safety.

I would like to see more help provided for transportation to and from work, and for vocational training. Public transportation (buses) is not always adequate.

More social services should be available.

I just want my son to be able to have some outside socialization and/or recreational activity other than {Agency} when he comes home from school. Also, it would give me a little rest if one night a week this would occur. I've been doing this 7 days a week for 20 years and could use a recommendation or some help.

{Date}at this time {Name} is on a waiting list for services. No help at all right now, other than family.

I cant answer these questions I have 2 sons who are learning disabled I have not received services and any information since they left school. There were in ls classes after that they just struggled and have been on their own. No help no meds.

Recognizing population growth in {Town} township, believe there is a need for a local workshop/support center.

My daughter needs services for one on one or one on two as she functions at a 2.5 year level.

As I begin to explore services for my adult family member, I am learning about the inadequacy of choices, especially social and educational, for a person over 21 with a developmental disability. We seem to focus so much on work and neglect the other aspects important to leading a full and satisfying life.

More residential & vocational opportunities are needed in {County}.

{Agency} provides a very sparse amount of activities for handicapped people.

I wish they had more activities for the out laying areas of {Agency}. My child likes to be astine more often and going out with parents just isn't the same.

I still need more services for my family member with disability, but I keep getting "there is no funding".

County {Agency} support has been good. They try their best to make things work but we do need more providers and need to think about what the state and county will do when his parents can't do it. Call me if you have more questions some of these were not very clear.

There needs to more support for community outings for the younger adult. Up to graduation the school helps. After 40-50 years of age you have adult day care. What about the 21-40+ age where they don't really fit into adult daycare and the school is no longer involved.

I think the first priority should be those who have a low function level. Secondly, I firmly believe that those at a functional level should have more assistance in making them part of their community. (exs. - job coaches, practice places of work).

Would like a place for my son to go during summer day hours so I can continue to work. During school session it's fine 7:30-2:30 pm., but summer hurts cause most camps closed and day program isn't taking any new clients, that leaves us with him at home and me taking off June, July, and August. Most employers need special times during the school year which limits me to a better job. He is graduating this coming school year and I have no clue what I'm going do with him so I can continue to work part time as I do now, to work around his life and activities.

Also, my son may not get into any program because of waiting lists there. Seems that it would serve a lot of folks if someone would look into opening new programs so those out of school with no services can get them. Another problem we have our son's functioning level & health would not allow him to work unsupervised in the community, so that's not one of our options. Here again it all boils down to money. I am more that willing to do my part to see a new program start. I have experience in that area, but need more support. Thank you.

Services are harder to get because too many people are on the critical and emergency needs lists. Both state and federal budgets and their treatment of this population have been blatantly unfair. The waiting lists are too long.

Looking for a program that teaches everyday chores & duties to those out of school.

Some services that are needed are not provided for. It's so difficult to add anything to what's already offered. The answer is always - it's not in your budget; if you want to take it from your transportation or respite that's the only way to get it.

When my husband was killed, I contacted {Agency} because I recognized that I might need additional support with my daughter since I was now a single parent. I was rather disappointed with the limited assistance available.

I have been waiting for services for my son for almost three years now. I had applied for respite care and life skills program and we are still waiting for these services. I realize there is a waiting list, but this is really frustrating.

Waver help needed

Wish there were more options for day programs.

My daughter's life could be much improved with services she could be much happier. Stress at home reduced. Though she doesn't want to go to a group home it seems impossible for her to continue at home. She would be eligible for many more services if living elsewhere.

We very seldom see anyone. I take care of my son, with help from his sister. I work and his sister does different things with him. We don't get help and there is no help getting them a place on their own. I have tried but it is hard to find a place that will rent to them. I have no resources to turn to.

Need for more community day programs and outings. Need for 24 hour respite to family in a safe environment, just as adults with Alzheimer’s can have respite in a nursing facility

I am very concerned with the funding situation. {Name} will definitely get depressed if he doesn't have a program to attend. I am willing to do anything that I can to ensure that he doesn't sit home. Let me know.

I have never been offered any kind of support other then the $550.00 I get from{Agency} that only covers camp & 1 week of a sitter.

My son is on a waiting list for employment during the day thru {Agency}. More services and programs are needed to keep these individuals active. My son has been out of school for 2 years now and is bored. More funding is needed to get these individuals, like my son off the waiting list. They want to be active and doing something constructive. In the end they are the ones to suffer. We need more allocations for programs to benefit my son.

It is difficult to keep my daughter from becoming bored to depressed. She did not qualify for workshop program and has been unable to retain or find employment. The day support program is the highlight of her week. But 2-3 hours is not enough. Some type of program or a more frequent basis would be wonderful.

17f. General Satisfaction with Service Management

He has also developed a great fondness for the director of {Agency}, {Name}.

17h. Waiting List

Just a small note to let you know that it also took me 6 years to get my daughter into the {Agency} program upon graduation from high school.

Presently, there is no funding available. Have been waiting the past 2 years for this service. I drive my son to work and back every day, if I am ill he can't get to work. I am 67 yrs. Old and have some health concerns and my wife does not drive so I am the only transportation to his job my son has. Otherwise, I am happy with his supports coordinator.

My son is on a waiting list for employment during the day thru {Agency}. More services and programs are needed to keep these individuals active. My son has been out of school for 2 years now and is bored. More funding is needed to get these individuals, like my son off the waiting list. They want to be active and doing something constructive. In the end they are the ones to suffer. We need more allocations for programs to benefit my son.

Most of the time I have been happy with the services I've been assisted with, like camps, dances at certain locations for my son, but I do feel that the waiting lists are long for a lot of programs. I feel there needs to be a way designed to speed up the process. My son has been sitting home ever since he graduated in {date}, other than, as I've said, camps, he has benefited through the years, as a small child he really benefited because there were more weeks to attend camps. It used to be 2-3 weeks encampment, now its 1-2 weeks they can attend, and some camps want $300 for one week.

19. General Concerns

I feel as a nation we waste a lot of money on things that are not needed, eating out, going to a meeting with a costly meal, we need to focus on saving as a whole nation.

I wish {Name} in {Agency} would be able to provide extended hours for care of my family member - perhaps - from 7 am to 5 pm if others in the area are interested. I realize it could not for one family only. But something to think about. It is sometimes difficult for working families.

{Agency} let {Name} go because she took a leave of absent to care for a sick man, we heard she lost her job because of this ,we feel this was not right and {Name} missed her daily!

Have been looking for employment for family member with no success.

SOUTH CAROLINA

1e. Waiting List for Residential Supports

And group homes are never available. My child has been on a waiting list for 12 years.

2a. Satisfied with Employment

Voc Rehab was very helpful with job training and finding my son a job. He also had 2 great job coaches. The staff at Voc Rehab is wonderful.

My family member is my daughter. She is living at home with her father and I. She attends a workshop in a nearby city. She is bused from home and works 4 hrs. daily. She loves the job and we are happy to have her busy daily.

2b. Dissatisfied with Employment

I would like to see before work care and after work care for my son in the near future.

My grandson has slight brain injury due to car accident. His mother, my daughter, died last year of cancer so (Name) is living with my husband and I. My biggest complaint is that no one can seem to help (Name) get employment. Voc Rehab is so back logged and whether they can help at all is questionable. (Name) wants to work but has been in and out of trouble -- has 2 felonies on his record. We're trying to get him back on the right track but without a job and (Name)'s inability to drive, it's almost impossible to do anything.

Not enough job training at High School level. No job training available. No knowledge of possible job openings within {Agency}.

My son's case was transferred from {Agency}to {Agency}in August 05' we have been trying to set employment services for son since that time and have had no results. Job coaching appears to be ineffective for him. Any job or vocational training assistance will be very helpful and could lead to a much better quality of life.

My family member attends the day program at {Agency}is {Agency}. It is not much more than a day warehouse! No matter what time of day I "pop" in, my daughter is sitting doing nothing. It breaks my heart to have to send her there, but I have to work and have no one to care for her while I'm at work.

My son needs some work support. His coordinator need to find my son something to do. He needs to be at the center.

3a. Health Care Equipment

I believe that we need help with getting the wheelchair for (Name)- He is using a chair that we bought. Also in getting equipment faster such as shower chair & ramp.

3b. Health Care Insurance

However, I do have complaints re: Medicaid and Disability coverage.

Medicaid do not pay for certain things for her age and I do really need assistance when it comes to that point. Dentist, eye wear, cause she has become a diabetic now. She is on the pill and I try to help her maintain the weight so by the help of the Lord she would not need the needle. Thank you for letting me express how than is are going for her and the people who are trying their best.

I do not get enough diapers. Medicare will pay only for a small amount. But I can get extra from family support if there is enough money and it always is. But I wish Medicare or Medicaid would pay more because I hate to ask for extra help.

Praise God for allowing Medicaid coverage while my daughter was in {Agency} and the hospital for those 6 months. She is alive and the spiritual God lives in her. She cannot read now but is happy to be alive.

3c. Dental

Dental services are not available to adults with disabilities.

3g. Psychological

Besides this state has closed up some mental health areas so where can someone get help but another state. No therapy of any kind for him or the family. This state should have more than mental hospitals and jails for people like my son.

5a. Satisfied with Transportation

Transportation service is prompt and regular. We are very grateful for this much needed support.

5b. Dissatisfied with Transportation

We could use help with transportation--Thanks.

7b. Dissatisfied with Communication

I'd really like to have a center or day care program that would keep relatives In at least 30to 45 minutes longer and better communications with transportation services as in pick up time and drop off time better communication with {Agency}services and PCA personal care aides.

This lady has things she is supposed to work on yet we see no indication it usually happens. Also when she is called in for a meeting at the center, she is unable to communicate what it is about and we are never informed, including her recent "time tests" that decide her pay. We were never informed of the outcome and she does not know if it changed. We feel the center should focus on more communication with the families.

Family member has been at home all of his life until 2 months ago when he became ill and hospitalized. When released, he will live in a nursing home. There were times in the last year when receiving medical assistance was very difficult and support agencies were not as helpful as they should have been. Many times calls to the agency simply went into case worker's voicemail & phone calls were never returned. When my son was hospitalized a case worker showed up at the hospital and left a balloon. I've yet to met this person and he has been hospitalized to approximately six weeks. When office visits to the Agency was made, workers were standing around, but no one answered the phone when calls were made. When a local physician that the hospital recommended was contacted, I was told that the physician was not taking Medicaid patients. It was when my son was hospitalized did he receive medical attention. EMS had to be called to get medical care.

Communication with the Day Program could be better.

8. Aging Caregiver Issues

It would be nice (convenient) to have an adult day care in our immediate area. My wife and I are getting older and one day the reality is we may not be able to take care of our special child. It would be somewhat piece of mind to have a home in our area for our son and other children (adults) that cannot function on their own.

Our son 's happy, however we are 60 and husband is disabled and can not lift him. My back and hips are impaired yet there is not an adequate place for our son to be taken care of. Group homes, nursing home and etc. just are not available in the {City} area. We need help other than home care.

9. Transition Issues

I am not trying to be negative about the services or maybe I don't understand everything. The services I have asked for are good I have no problem, but the (Name) is about to turn 19 & I will not be able to keep him on my health insurance. What do I do?

10a. Satisfied with CM

The service coordinator, {Name}, does a great job.

Service coordinator support has been very helpful.

My daughter’s coordinator (Name) from the disabilities in {City}, S.C. is one of the best. She always keeps me informed of things covering my daughter at {Agency}-{address}. (Name) is {Name} coordinator at {Agency} workshop.

I think the case worker does a good job and I commend him for his job and being able to have a caring heart to relate to the disable. Thank you and your services are greatly appreciated. Keep up the good work so that more people can use the opportunity in the future for themselves or their loved ones.

(Name) has been quite ill this past year. Starting on May 25, 2005. I needed help because of my health. {Name}is our helper. No matter what it takes she gets it done. A lot of (Name) medical was more than I could ever think about paying. She helped with SS part D with Medicaid and Medicare. Plus just being on the other end of the phone. I only hope that the other helpers have people who are as pleased as we are with (Name) and {Agency}.

10c. CM Turnover

My biggest problem with the service my daughter receives is without notice we will be changed to a different service coordinator. Just recently, I received a letter from service office telling me my daughter's service coordinator had been changed. I contacted the office and they said after my request, her coordinator would not be changed. I was really happy! A few days later, I received a letter from a woman who now says she is my daughters new service coordinator. My daughter had never been taken care of in the past better than her previous coordinator. There have been times when over a period of 6 months to a year when a coordinator did not contact me about anything. In many cases, I was only contacted when there was paperwork that was mandatory to have filled out or else the service coordinator would be in trouble with {Agency}.

11a. Satisfied with Staff

Well I feel that my child is getting the right training and the staff I believe is doing their best to make that possible and I thank each and everyone for their help with my child.

{Agency} provides Aides to help with (Name) - one aid {Name}is remarkable & has been with us for over 8 yrs & we don't know what we would do without her.

Everyone are wonderful to us and I appreciate that.

11b. Dissatisfied with Staff

The agency and their aide were rude, yelling, and not sending people. Stress was put on me, my ill member, job, and etc. They said outrageous things to us and talked about our family, home, ill member behind our backs as well as to our faces.

I appreciate all the help we get & I don't want to sound ugly about the questions. We have had several serious emergencies & could not get the staff to respond, until we got almost ugly. We don't bother them unless it's necessary & that's not that often. That's the only time we even heard of any other help. It's a 24/7 job of taking care of a loved one.

Sometimes, his schedule is rearranged to accommodate the worker, and he and I are not consulted. It is done to the worker's convenience, not necessarily ours.

Not all support staff has been helpful.

In some of these agencies at times the staff is not professional or friendly. If you have a complaint. The staff sometimes some of the staff takes it personally and sometimes overall those who are over the staff does not do the best job possible.

She sometimes comes home feeling encouraged by staff to stay home the next day, while our goal is 100% attendance. She also gets mixed messages by the frequent missed days of the staff that works with her. "If they get to miss work, why do I have to go everyday?"

11f. Pay Staff More

Staff are paid very little for the highly complex and responsible jobs they have. This contributes to high turnover.

11g. Substitutes

But they don't sent anyone on times {Name} is not available & we really need help at those times too!

13b. Safety

Daughter got hit by a car due to poor supervision on job site.

13c. Abuse/Neglect/Mistreatment

I'm at work. I'm really uncomfortable with the fraud that goes on in order to receive services. I know survellience is expensive, but our most helpless citizens need protection from certain people who should not be working with handicapped people. I witnessed an incident of abuse (not my child) that came down to 'my word against hers'. Survellience would have insured that this person would not be able to continue abusing helpless people. It's a shame that society can't manage better care for our helpless citizens. They didn't ask to be born the way they were.

How we treat them and care for them is reprehensible.

13d. Social

(Name) need some support group but none is available. She sits and play spider on the computer, all day long. She doesn't want to do any thing. Tried to get her involved in the YMCA playing pool but it's a real test.

14b. Dissatisfied with Respite

We are in great need of certified respite caregivers. We have not felt very good about leaving our child (who cannot communicate) with many of the providers.

We could use help with respite care --Thanks.

The staff is outstanding, however the training for Respite providers could be complete in a shorter amount of time or compensated. It's very difficult finding quality people to care for our loved ones and those we find make little more than minimum wages when you figure out it's 15% taxes they have to pay due to being considered self employed. Thank you for your concern.

My child has no self help skills. These services offer respite care a few hours a month. But what is really needed, is somewhere that will care for her for a weekend. We never get to go away together because there no one, are nowhere that can handle children like mine. They give you a list that suppose to do this. But none of them never apply for a severely handicapped person. And group homes are never available. My child has been on a waiting list for 12 years. At the age of 52 sometimes you need a break - not just 4 or 8 hours.

Respite providers are difficult to obtain because of shortages.

Only wish there were services to help families who want to keep their member at home, such as more help during the day or night. To have some one come in 2 or 3 hrs. over a 24 hr. period is such a little time thankful for that but the family don't really have a life. My brother has never been separate from family in 58 years. We try to keep him home. Don't know how it would affect his life, there are many families in the same position, so little more help would help a person like me to keep a family member home. Thanks.

Not well enough for some outside services. However, respite has not been forthcoming promises are not followed through. Just dropped from thought. Appointments not kept and given no reason. We were told as of last week that a sitter had been hired but we will see Service Coordinator is respectful and timely with respite?

We very seldom get respite services. Need this very bad. We have no family support we really need a break.

There have been many times that I have called & asked Respite and have not gotten it. I am a single parent with 2 teenage girls. One girl is 18 & the other is 16. the 18 is the special child and there have been many times that I have needed help & there is no one to call but 911. There needs to be a number you can call to get the child out of the home if it is for a couple of days so you can regroup and start fresh. There has got to be more services out there somewhere. Help.

My brother is highly demanding and takes a lot of time to care for I feel the evaluation levels are not in sink with what people really need to take care of a family member at home, for instance I get 29 hours a week. But he's a full time job but we have to learn to live with it, wo we do and they're always trying to cut back on services. I'm at the point where the state could put him in a facility, let them pay for that. See how much more it would cost them.

16. Funding and Budget Cuts

We are totally satisfied with {Agency}. We are concern, however, that when cut-backs happen "special needs" seem to be the first hit.

We are a resourceful family and find what our son needs. My biggest dislike is the big turnover of Case Coordinators and no pay raises for Day Support programs. We need to look at spending bands and make sure they are in line with the cost of services! As we get older as parents, we would like to see more choices/funds available for residential services.

My Daughter used to get a SSI check but it was cut off just like that. She still goes to heart doctor and {agency} doctor and she still has problems. And also my wife is having to pay back on her SSI check for something that the government made. They said that they paid her too much. But it wasn't my fault they sent it to her. So I think they should not make her pay it back when it wasn't our fault.

No money is spent by {Agency}.

I'm concerned about what the State is doing to our current Medicaid. I had to wait till she was 18 yr. to get help. Now I'm afraid they are going to either take away her services are lessen them, if they redo the system.

I think the Special Needs and Disabilities Board hasn't done anything really to help us at all. Every time you ask them for something they don't have funds or some other excuse or they have budget cuts.

Hello, thank you so very much for the survey. Our daughter graduated last May from high school. She has autism, MR 7 overall developmentally delays. Unfortunately, due to budget cuts, she spends her entire day here at home. There are no day services available in our community. Due to her anxiety, boredom and possible depression, we now have her on medication. My husband (in his 60's) and myself (recovering from back surgery) decided to do what we could to keep her at home. When the time arose, we would put her in a group home. WELL, there are not group homes available either. Please do whatever you can to help our daughter have a happy, healthy lifestyle.

The staff a {Agency} does good job considering the funds they do not have. Where is the money?

17a. General Satisfaction Overall

I thank you for all the help that you offer. All I ask is that you don't give up on him because one all your help will make a difference again.

Your help is needed and appreciated.

We are totally satisfied with {Agency}.

I have recently made an application to our local county Special Needs & Disabilities Board and have been most pleased with the services rendered there.

For the most part, I am pleased with services, I just have not had to use the ones that I know about yet.

I am just thankful that there is such a program for people who need it. I know it is a great help to my family.

(Name) has been diagnosed with mild retardation. He is paralyzed from his diaphragm down. He attends {School}College at this time. Our local {Agency} has been a godsend to us.

Please keep up the Good Work. The {Agency} has been a God sent to me. Without it, I don't know what I would have done.

I am satisfied with his services, however, on a day-to-day basis.

Without this service it would be a heartship on our entire family to keep our beloved one home thank you. If there are other services available to us please contact us. Thanks again and God Bless!!

We get what we need always.

Overall we appreciate all the staff they all do a great job! {Agency} is a greatplace. Thank you All!

{Agency} has been of great assistance to me. {Name}is always there to help me and to see that (Name) gets what she needs when she needs it. (Name)'s life and mine are made better because of {Name}and the help {Agency} gives to us. Thanks.

My son is on a waiver that helps buy or pay for thing's he needs. He can not speak, due to brain damage.

Some of the questions could not be answered because (Name) is high functioning and still and will need help along the way. I her legal guardian supplies transportation to and from work. She reimburse me for gas (transportation) Her service coordinator is on call whenever we would need her. We're satisfied with the services received so far. As time goes on, things will change and for a certainty, she will need more assistance.

My 19 year old is a very special person in my life, he is my pride and joy. He has has a long journey, but over all he is very happy teenager. He has gotten a lot of help from {Agency}and {Agency}.

17b. General Dissatisfaction Overall

"The care my son receives & his well-being are due to my efforts - none from {Agency}. They simply fill out forms with intrusive questions, yet offer absolutely no assistance or services. The family members of people with special needs specify/refer to {Agency}

From what I have seen & experienced in 23 years, {Agency} is a complete waste of taxpayer money.

We have had problems receiving services thru the Contract Medical Service Providers. Also, have had changes in DDSN workers that have affected our service. However, that has improved over the last few years, more coordination within that agency. There is also a lack of community services and programs to provide disabled persons with recreational and social activities. There is a lack of people to staff service, i.e. respite care.

The small, inadequate facility needs to be replaced with adequate space, ventilation and more comfortable environment.

(Name) has Brain Damage, can not speak. {Agency} has not helped to try to get him work. {Agency} has not done anything to help us. They only check with us once a year to complete a report, to make it look as if they are doing something.

I have learned since my son became disable if your not missing a limb or in a wheel chair your not disable. We have had {Agency} close my son case. I have had the ER (City) refuse to place my son after he took an over dose in the morning. He was home that night. Never mind the at least 12 visits to the ER due to behavior, etc. My son no longer attends school. He has been to jail. I'm not sure how many times but the school called at least 3x. Most of this is before age 18. Now he's almost 19 and I'm told he can do as he feels knowing mentally he's on a 2-10-15 or 18 year old level. He doesn't think anything wrong wit him but I've been told well he's old enough to be on his own. People won't talk to me because he's 18 and "you need guardianship" paper if you need us to find him when he walks off or concerning his health. But when he can't give them the answers they need then I'll get a call. I want to take my son to another state so he can get the help he needs because he's not getting it here.

Not receiving any services for my disabled son, and is very unsatisfied with his caseworker, I have apply for a waiver for my son and has not received a response.

Need to ask more pointed questions these are vague. Job coach services should be available to all, not just some! I feel sorry for those special needs individuals whose parents are not able to help them! Life is probably bad for them. You could do better.

Some service coordinators do not always know how to locate information for the consumer. Overall, I think the majority of the agencies could do better in obtaining services for those consumers. One for particular those that have "mild". They are all generally put in the same category, not enough help or possibilities for those with disabilities.

No Quality Day or Residential Services for adults. Agencies listed who provide PCA services in the home - wrong phone #'s listed, can't provide service for hours requested. I have called every agency for 2 years now and no agency listed can provide early, early morning or evening hours. One agency sent 4 people out last summer. One quit after one day, 1 quit after 1 week, one never showed up, one unacceptable. No transition services or facilities for those "graduating" from school at age 21. No intermediate facilities for those who can function some. Case workers don't know themselves about services - one sent me a list of providers dated 2003 just this year. Case workers unavailable - don't know client's needs.

17d. Info Regarding Services/Supports

We also are unaware of activities in our community that are suitable for our child to participate in other than the Miracle League Baseball program.

Need to stay in the loop. Stay informed. Keep up with changes.Need feed back.

I really want to know how the systems works I know it takes time to get enrolled in the programs. My son is not receiving any kind of help I signed him up for Social Security but they didn't give me any help they said he had to be blind or permanently disabled. And pretty soon he has to come off of our insurance and we have turned to other agencies for help but the systems do not supply any kind of help. We take care of our son the best that we can. So you tell me where does help come from.

In the past, I have asked for certain services that we were not able to obtain. I have had great difficulty in obtaining information available to me.

Sometimes/never answers generally indicate that we are not aware of the services that are available to the receiver. We have asked for help with {Agency} and it was not followed through (ie: shower chair & folding wheel chair w/tilt back) have no idea if request has been considered.

We are still seeking help and I don't know how to get it for her. I too was afflicted in 1991, so we got a double "whammy".

17e. Need More Services/Supports

I love our workers but we need more counselors & companion services & more activities for our children.

There needs to be a larger number of providers to choose from and these providers need to be committed and dependable.

The service coordinator, {Name}, does a great job. The problem is that there is no services available, no money available and housing has been cut.

For my Sister I would like more hrs per month for respite also more financial for her and food stamps.

We receive no support benefits outside of my health insurance and my husband's disability benefits forms {Agency}. We pay out of pocket for a sitter while I work. We could use help with that expense.

After these special needs kids reach a certain age there isn't anything for them if their not in an employment program. They need recreation for breaks in the school system and for the summer. These kids have been forgotten in everybody's budget or programs. When someone wants to start a program then you can't get any funding, or help with a location or insurance. For more on this contact (Name) and ask her about all the deadends roadblocks she has gone through {agency}- Non-profit Camp for Special Needs Individuals).

I just want my child receives more support like transportation or activities that she can do. Sometimes I feel that one need to get way or do some activities that she can enjoy.

I have been told that I do not qualify for assistance because of my income. I am a single parent. I have to depend upon my aging parents to help me while I'm at work. I've never used respite care. When you work full time, it is very difficult to arrange physical exams and TB skin test for your loved one. All of these criteria that hve to be met to get assistance are very time consuming. Again I thank you for your concern.

My husband and I have kept his brother in our home for 10 yrs. He also has a sister who is in {Agency} that we oversee her care as well. The brother has attended the {Agency} day program for many years. Other than that we basically have had no support. I was only made aware in the last few months that I could receive respite funds, but I can never get more than 2 days a month. I am working part time now so that we can keep him at home with us. I am trying to work at {Agency} services but it continues to be a long and drawn-out process. I would appreciate any help or info I can get. We know we can take care of (Name) better than anyone else and we want to continue, but we have had little or no help.

My son is a paraplegic. He received his injury in March 2004. He spent months in rehab hospital. Most of the support are received after son came home from the hospital was family support. We did not know what else to do- I quit my job and my husband worked all the hours he could for us to survive. The "critical hour" we needed support was when we brought (Name) home. If there is any such plan - I was unaware of it. The transition from hospital (rehab) to home was actually cruel - we needed help. Two years later, we have {Agency}. (Name) has an outing each month. We make sure he has a therapist/psychologist (private) and someone that helps us care for him. Thank you.

Case Managers are great people and a great source for your needs, but it is impossible for them to get you all the services you need when services don't have anyone available for your use.

17h. Waiting List for Services and Supports

My son has been on the waiting list for Rehab Support for 9 years -- what a joke.

My brother is on a list of jobs & also an apartment but they haven't done anything about it. I think they could get a job cutting grass or yard work by now. We haven't heard from them in a while.

My child needs employment assistance. It has taken from Nov - Mar just to get requalified for services. And we continue to wait. She is an employable, dependable, hard worker with her own transportation. It is frustrating to my child and me that the system takes so long.

Currently family members are on a waiting list to receive services from {Agency}. A plan has been developed and is awaiting implementation once the client is moved off the waiting list which should significantly shorten the time spent waiting for services.

We recently relocated to South Carolina from Buffalo, NY. We have lived here for about 61/2 months and are now just beginning to be eligible for services for our daughter. I began phoning the {Agency}, S.C. in mid-Sept. when we arrived and my daughter is now (as of last week) on the waiting list for the day program. I feel that the length of time it has taken to be determined eligible is totally inefficient and unacceptable. I have written letters of complaint to the state senator, governor and congressmen.

To Whom this concerns ,I have lived in S.C. for years, but in July of 2005, I had to move my brother here, because my Mother fell & broke her hip, she is 90 yrs. old, In nursing center in GA. (Name) had a training center {Agency} In {City} GA & worked 10 to 12 hrs a week with them. I have been to {Agency}. He was tested to make sure he qualified and he did but is 13th on waiting list. (Name) says it could be years. We don't need a baby sitter. (Name) needs to be with other people that he can communicate with or do things with others with disabilities like himself. He missed that terribly. Thanks you for everything.

19. General Concerns

The reality of choice in service delivery hasn't made it to {Agency}yet. It would be better to forget about choices and use much needed funds to help all clients across the board rather than special interest groups.

It may help families answer your survey better if each "support" section was broken down into: Day Program Support, Respite Support, Rehab Support, etc. Then you would get a clearer picture of "support" and where problems really are.

Parents with special needs adults who live at home are always kept up-to-date on the operations of the {Agency} facility, parent meetings are held each month. The main problem is parents don’t come to the meetings. There has been a concerted effort on the {Agency} part to get families involved but to no avail. I have seen this occur in all phases of public involvement (schools, churches, and community). I don't know the answers! I do know that it hasn't stopped the {Agency} from giving the best possible services to our special needs adults.

Thank you for sending out this survey it is the only one of it's kind that I have seen in 20 years my son has autism non-verbal with plenty of behavior issues.

1b. Dissatisfied with Home

"People in group homes & centers should be cared for on an individual need basis not by any pre selected program out of a book. They are all individual people not pegs to be pushed into slots. Help them on a case by case basis; don't group them together in a ""one size fits all"" program."

2. Employment and Day Programs

enjoys very much. {Name}enjoys working or being busy with things he can do on the farm. I am not able to always keep him busy, so I feel a day at the training center is beneficial for him.

2a. Satisfied with Employment

{Agency} has a good and strong day program - teaching job skills

We think that the training center does a really good job. And we are very thankful to have a place for him to go in the day program.

2b. Dissatisfied with Employment

One day a week we take him to the {name} adjustment training center where he may do some work part of the day if they have contracts to full fill.(seldom in the last 4 months)

3b. Health Care Insurance

With the changes to add Medicare part D my daughter's diabetes supplies are not covered. She needs Medicare part B which she did not have. We are filling out the paper work but may be penalized & have to pay premiums and will not receive assistance for supplies until after July. She is on state Medicaid. 27. With the agencies available in our area we have a choice but unable to contract with an outside person of our choice if wanted, 30 Again no choice outside of agency staff. 33. Money spent limited to Medicaid guide lines.

4a. Satisfied with Education and Training

My daughter goes to the training center daily she loves being there with her friends and staff & her good care as for her home life she is happy

We think that the training center does a really good job. And we are very thankful to have a place for him to go in the day program.

4b. Dissatisfied with Education/Training

Adjustment training center in {Name} needs to show more active awareness support to help family get & keep individual with special needs in physical health helping develop exercise plan & program cardio, Walking, etc.

5b. Dissatisfied with Transportation

Other disabilities, has congenital heart problems I take him to all appointments including annual {Town} trips because he is at home he doesn't qualify for any supportive living help, like transportation to recreation.(aqua size twice a week).

{Agency}is useless as far as helping with transportation so {Name}can work. I spend about an extra 20 or 30 dollars per week taking him back and forth to work.

There is a need for transportation services for those in rural areas or small towns to access day programs / services in larger towns.

7b. Dissatisfied with Communication

Help integrating them into community programs communication between clients who live with families and the agency is poor. (Concerning transportation especially).

10. Service Coordination

Service and support have made a difference mostly because of efforts of family members at times a little provider. Key seems to be providing family with ideas and soon just having family do whatever it takes.

10a. Satisfied with CM

The immediate people who work with my child are open & supportive & helpful.

Overall again the day & day workers are fabulous

At the day program {Name} has a service manager who solves our problems he is a saint.

10b. Dissatisfied with CM

Very little communication with provider unless you really push for some, many are overloaded fact don't get to spend time or effort to accomplish much. Some at times just simply don't have the commitment required.

10c. CM Turnover

Too much turnover of providers makes a plan start to follow then you have to start all over with different provider. Very hard to accomplish anything new providers take a long time to get familiar with what plan is

10g. Service Plan

I don't know what is available to him or us. His case manager did not know if he would qualify for Medicaid if he no longer works.

Communication between service providers/ coordinators and family members is not always adequate although it has improved during the past year.

I think as for home information & planning I feel I do all on my own. No service plan or staff the same is true for access & delivery of support. Choice and control are pretty much in my hands &

responsibility as far as home life is concerned again on community connections I'm mostly the one who sees she gets out & takes her.

It would be nice to be able to pick & choose services we want for her & control her HCBS funding to pay for services. Surrounding states have this option.

11a. Satisfied with Staff

My daughter goes to the training center daily she loves being there with her friends and staff & her good care as for her home life she is happy &

The immediate people who work with my child are open & supportive & helpful.

Overall again the day & day workers are fabulous.

Over all staff at her agency is wonderful just unable to work with someone (external care management) outside of an agency.

11c. Staff Turnover

I would prefer to not have as many changes in direct care providers, but I understand they are entry level positions.

Because of turnover of staff, training is not consistent and progress is slow and limited. It's like three steps forward and two steps back we get a good trainer and we start seeing progress, the trainer quits and we start over again. I greatly doubt that our family member will ever get close to the top of her or his potential.

13. General Well Being

On # 44 we don't think anyone can say they're always happy but most of the time {Name} is.

14. Respite

What would really be nice is to have the group home be able to take our son in a few days now and then. This would give us a break & would benefit our son to be around some of the other clients a little more.

Out of home respite care is not usually needed have other family members or neighbors who help occasionally.

Would like to see a service provided that would allow us to leave our disabled person with someone to care for him her if we would like or need to be gone for an evening or weekend.

14b. Dissatisfied with Respite

Would need total care plus bowel movement care, The same is true for if I were gone for more than 2 days for personal time. In the past children's care Hospital & school provided that respite but haven't been able to continue to do that. Is that a possibility again or any other options?

Little respite care I'll be 75 on my next B day & certainly could use some!

As my husband and I get older we would like to take a few days off every now and then. We've used respite care but to have someone come to our home is very expensive & the allotment per year for respite gets eaten up quickly

16. Funding and Budget

If the federal Govt. continues to chop funding for the handicapped & the elderly we'll soon be in desperate straits.

We would like waiver funding

It would be nice to be able to pick & choose services we want for her & control her HCBS funding to pay for services. Surrounding states have this option.

17a. General Satisfaction with Services/Supports

I am most appreciative of the services my daughter receives. It has allowed her to remain in her home. Thank you.

Overall provided services are adequate and satisfactory.

My Brother who has only a minor mental disorder depends on services mainly to get him out in the community driving skills & some household skills. Services are only for an hour a week which is adequate.

Overall {Agency} has been more than helpful & cooperative in helping us keep our brother in our home situation the way he has always known.

We are still under the school district {School} and are very happy with services.

I feel that {Agency}. Does a very nice job for my daughter {Name}. She gets along very well and has no problem talking to her people that help her out. She calls them herself and they reply as soon as they can and help all the time. Right now my daughter was laid off from her job of 6 years and right away they were helping her with new applications and etc. They are very special people.

We are new to adult services. We have switched from {Agency}to {Agency}. I think {Agency} will be more accepting & open to what we want for our daughter.

17b. General Dissatisfaction with Services/Supports

My observation is that management does not have a sincere concern for the individual served rather individuals expected to serve management. The center lacks educational services absolutely no knowledge on autism other than a couple of in-services that were just provided last year and then only certain staff members were allowed to attend. I have bumped into several parents while out shopping & most are not happy with the center but are afraid to say anything just as I am. We all wish there were another alternative other than ATC. How the center ever achieved Natl. Certification is beyond me I think they need some new blood top 3 need to

17c. Access to Services/Supports

At this time we don't receive any family support & haven't for over a yr. we need some one in this area.

There is a need for transportation services for those in rural areas or small towns to access day programs / services in larger towns.

Over all staff at her agency is wonderful just unable to work with someone (external care management) outside of an agency.

17d. Info Regarding Services/Supports

We don't really have anyone who helps us with anything nor that provides any information on anything that is available the {Agency}helps with answering questions if they have answers the only service we get is help once a week for cleaning as I am physically disabled & unable to do it all myself.

{Name} no longer works or attends {Agency}; He is staying home at all times so I don't know what is available to him or us.

17e. Need More Services/Supports

One area of concern is if in an emergency and I couldn't provide the around the clock care she would need total care plus bowel movement care

{Agency} has a good and strong day program - teaching job skills they should try to place their clients out in the community - for job related skills there are many clients who live in the community(in {Agency} programs) who do not receive enough support thru their system. Clients who choose to live with family members receive no support services or help integrating them into community programs communication between

We don't really have anyone who helps us with anything nor that provides any information on anything that is available the {Agency}helps with answering questions if they have answers the only service we get is help once a week for cleaning as I am physically disabled & unable to do it all myself.

17g. General Dissatisfaction with Service Management

I find repeatedly that the "higher ups"" are not, they are defensive & strongly stand on the “"institution"" side they are top heavy & not enough filters down to the clients. Parents see that. Also community members at large see that. Days & days are spent coloring -

using time aimlessly - for one example. Overall again the day & day workers are fabulous. But try to bring a suggestion question problem concern complaint to atone in management & what a neg. defensive stance you get. Thank you"

WASHINGTON

1. Employment and Day Programs

Sheltered work shops must always be available for that segment of clients unable to function in any job that requires individual stand-alone employment. People these days are working full time to make the designation "sheltered workshop" a dirty word. I think this campaign is immoral. Workshops for our special dd people are needed to provide them with stability security and a loving "shelter" and a place to get out to form their homes or group homes for socialization and self worth and personal pride. If the term "sheltered workshop" is so offensive to some dd patients, rename them to "opportunity workshops" after all, you're trying to give the higher functioning dd people the "opportunity" to move out into "group employment" or "individual employment" or in rarer cases, "individual business ownership" that's great. The higher functioning dd people may be able to advance into those jobs and businesses and be successful. However, the very low functioning dd need to have their nitch secured and protected. It beats being pigeonholed in the old state institutions. Reality must prevail over emotions.

2a. Satisfied with Employment and Day Programs

My grandson has been a client of {Provider} for over 16 years. He has down syndrome and functions at a high level. Through the years {Provider}, personnel have secured three good jobs for him, each on better and closer to home. Their expertise and caring are outstanding and we feel very secure in their hands. Many of their clients have severe disabilities, however they receive the same care and interest as the ones who require less hands-on attention. {Provider} personnel among others include many people. Please be aware of the fine services they provide, their positive attitudes, patience and care are remarkable.

I hope I answered these questions appropriately. We use career path services as our vendor for our sons employment supervision and are extremely pleased with them! We have the name of our case worker but we don't make contact with her, career path does? Our son's needs are individual and we know if they intensified we would call DDD for further additional assistance.

He graduated from {School} in 1984 and soon after that was able to get a job through DDD/DVR. A job was a great opportunity for him and he was worked continually since 1986.

Am sorry to take so long finishing this. I have been feeling unwell & it takes time to get things done. **** has a sister who does what she can to help. She lives 40 miles away and works full time. If anything happens to me, arrangements have been made for her to take over. The only problem here is I feel quite inadequate in keeping her entertained. She works at {Employer} and I feel this is the best thing she has going for her. She has friends there and she has a feeling of accomplishment & something to look forward to. She is so proud of her paychecks when she brings it home. Ip ut it in her savings & she gets to go to disneyland once a year. I'm 71 yrs old & not the best company for her, though I try very hard to make her happy. Sincerely mother & guardian

2b. Dissatisfied with Employment and Day Programs

We really would like for our son to have a job where he can earn some money and develop more skills. We have been working with job coach for 4 years now and they haven't yet found him anything. He currently volunteers at a local non-profit organization, but i was the person who arranged that. I guess we don't feel like anything is being done to help our son make progress in this area of becoming more independent.

I was very disappointed by my daughter's employment coach/company. After 5 years, she was let go from her job. Her job coach/co asked me about finding her a place to volunteer. If they made any effort on her behalf to find gainful employment, it was not diligent or obvious. After six months, and hearing from the job coach twice (asking if I had found my daughter a job) I received a letter from the job coach/co stating they were dropping my daughter from the case list & wished us luck. This was DDD sponsored employment co. My daughter has been unemployed for 1 1/2 years, and misses being "responsible" & "adult". I would suggest finding ways to improve contact with community members to increase employment opportunities for DDD managed young adults.

He has sat at home for over a year. We were told that because he is on ssdi ($752), not ssi ($570), he is not eligible for a Medicaid card or any day program and never will be. We tried "supported employment" through dvr but he is totally unsuited for it. He needs a day service program which fits his needs, not trying to squeeze him into a job that he is not capable of doing or understanding. He is currently on vacation in England, where we came from. When he and his mother return to Vancouver, we are selling our house and moving back to England where he will be in a day service program 5 days a week, with transportation. Also 6 weeks a year respite care. This past year has been a nightmare for us. It is costing us a small fortune to move back but we can't live a normal life in this third world state. As I see it, Washington is on the same level as Mississippi or Alabama as regards to needs of develop. Disabled.

3a. Health Care Equipment

She needs her wheelchair updated. She was measured over 6 months ago and still has not had it fixed. She can not sit up right and keeps scooting down & sits on her tail bone which looks as if the skin will break open and cause a sore. Her feet are always off the foot rest and near the floor as it does not fit. A wheelchair "fix" is very necessary.

3c. Dental

Been able to find a dentist or dr. For him in Vancouver. He continues to go to {Dentist} for dental care and his pediatric cardiologist in aloha. However, he does have the services of an in-home dental hygienist who is wonderful with him, and a great help. His diapers and medications are provided. This is a good example of the problems in {County}-the medical coverage is excellent, but there are no doctors or dentists that will care for him

A major problem is a lack of dental facilities that will accept my daughters medical coupon. Most doctors refuse service when this insurance is used. Currently our only resource is {Hospital} in {City} and this is very difficult to schedule.

3d. Medical

{Physician} longer accepts dshs coupons for med care

Been able to find a dentist or dr. For him in Vancouver. He continues to go to {Dentist} for dental care and his pediatric cardiologist in aloha. However, he does have the services of an in-home dental hygienist who is wonderful with him, and a great help. His diapers and medications are provided. This is a good example of the problems in {County}-the medical coverage is excellent, but there are no doctors or dentists that will care for him

A major problem is a lack of dental facilities that will accept my daughters medical coupon. Most doctors refuse service when this insurance is used. Currently our only resource is {Hospital} in {City} and this is very difficult to schedule.

5b. Dissatisfied with Transportation

She is bipolar with autism & epilepsy. She works full time and now is medically more balanced. My biggest problem is transportation. She is qualified for access but it does not run on our street. I do see it go by on a regular basis but was told the boundaries have changed & we live outside the boundaries. I don not ever remember having access to a case manager for her. She has a sub coach who has helped her keep her job and psychiatric and psychological counseling on a regular basis. Yet transportation is difficult.

I'm sure it was noticed in my answers on the survey that I kept referring to an injury my daughter had received on May 31, 2006 on her way to her volunteer job at the food bank. I'm very concerned now how she will do when she again rides the shuttle? If ever! I trusted the shuttle to transport her safely. 1 day a week. This did not happen on 5/31.

Transportation is the issue. My husband and I are both adjacent to a college facility so that someone can take her where she needs to go. Dart is too unusual and unreliable and she cannot use it, although we are on a bus route. So for each new activity we have to figure first whether or not we can get her there. This seriously limits her community involvement.

7b. Dissatisfied with Communication

The plans and paper work look good. There is very little follow-through however. The delivery systems/agencies are so convoluted, you are told it is some other department or agency, people are very difficult to contact, and eventually you just give up.

We are in the process of placing our son after the 90 day developmental hearing. This is a process that needs to be more clear. Even the institution we want to place him in doesn't get a lot of feed back on the process. This is a cycle that stresses a person already stressed. Any family at the point to let there child/young adult go needs to help during this time and a lot of info and the time process. Sure we got a paper saying 90 days we will let you no. But, during the wait a call now and then to placing center and parent would help. Also to know who to call and talk to during this time for feed back.

My son was diagnosed with polycystic kidney disease 3 1/2 years ago. On Dec 2, 2004 he had surgery because he was starving to death. Because of the huge size of his kidneys. Both kidneys were taken out instead of pkd he had cancer. His 14" kidneys were taken out. But the cancer was also in his lymph nodes. It cam back in Sept 2005. It was then in his lungs & lymph nodes. He goes to dialysis 3 times a week. In {City} one hour away. My case worker then approved a cell phone. It has been used entirely for his care. I signed a 2 year contract for the cell phone since I had approval for help. My case worker transferred to {City} j**** a*** was my new case worker. After 3 payments, he informed me it was approved for winter only. (the 1st I was to hear that). If I applied again I would probably get approved again. I reapplied thru my new case manager in {City}. He said he had too big of a work load for us. We got our first case manager back. I never heard from them until I asked d**** t**** to contact them. M**** is now in another job & is no longer my case manager. I never received a return phone call to say if it was not approved. It felt like we got lost in the shuffle. G***** f***** is now our case manager. I've called 3 times to see if I could be eligible for emergency car repairs (brakes). His response is I have not seen the whites of s***** c**** eyes to get her approval, but I don't see why you wont be. Dshs has been very frustrating to deal with. But they are all kind compassionate people. Just not good at the follow up. My son now has terminal cancer. Home care has been wonderful getting in home oxygen. Thanks.

I filed a complaint/grievance because I was denied being a care giver to her last January. I never heard anything back. They denied me because her brother lived here and he moved out the 1st of January. The things that her brother did happened when he was 9 years old and he is 29 years old now living with his girlfriend and they are expecting a baby. If you can help me check on this complaint and why I never heard back I would appreciate it. Thank you.

I asked for help to locate good housing for my daughter. I was mailed a list of available housing. That was all. No follow-up or suggestions. How can I find a good placement? Case managers seem to do only the yearly evaluation for care giver hours-only the minimum.

He was evaluated in 1982-age 16- he was evaluated to be 4 to 4 1/2 years old. I don't agree he does things a four year old can't do. I don't hear from people unless I call myself, as far as family planning there isn't much. The only time I talk to his case worker is when I call her. He has had several ???? Some I have not even talked with. I did not get an envelope to send this back.

Case managers need to learn their role(s), duty(ies) as such. I know we have a case manager but we only hear from them once a year, (evaluation time). I have never been informed of all other support/services to help me out. I live with three people with disabilities (my brother, my mom 71, and my dad 74) who need care. I feel I don't get the help I should. I am very stressed out and I'm thinking about putting all three in care of someone else. I do not get a lot of time for myself and that is not healthy. Nobody pays me to take care of mom and/or dad. Can you send me some information? As for my brother, they are trying to cut my hours to 71 hours/month. It is a joke, please help me!

My concerns are these: I was a little disgusted when I found out that she has had the same case manager for years that I have never heard from. Then recently I found out that I could be her caregiver. I assumed because I was her parent and that she lived in our home that I could not be her caregiver. So I called her case manager and got the process started to become a caregiver. I would like to think that the case managers that work for the people with disabilities would want to make sure that they are getting the proper care they need. In the past it was a struggle for me to work outside of the home because of her care and caring for three other children. It sure would have helped if her case manager would have let me know that I could train to be her caregiver and receive some income for this service. Every time I call the case manager about a question or concern about her case i always have to call her to find out the awaited information. She never returns a call to me with the information. Since January 2006 I have asked for financial support to help for the cost of transporting her to and from there work site. I still have not been given a reply to this request. I hope that in general that most case managers are not like this and that they are actively out there working for people with disabilities. Sincerely…

7c. Information

Suggestions for support services/programs should come from case managers, since caretakers/clients usually don't know about them.

7d. Language Barrier

People with disabilities do not know English and this makes them self-conscious and they cannot communicate in places where people do not understand them. My son cannot communicate with other people. And a Russian speaking interpreter must always be provided in order for him to get help where as he does not want Russians to work in this area.

8. Aging Caregiver Issues

Would like info on living situation. Since our son is getting older & we are getting older we want a plan in place now so that he can get use to it while we are still around & can help out.

We are in our 60's and have been consistently asking the county {County} and state to provide planning assistance regarding long term residential care. We would like some kind of transition plan similar to what is required between school and work. If and when we are incapacitated by illness, our son will be harshly transitional from a loving home to whatever adult home/institution has space. This is an easily anticipated cause that should be heard of through an enlighten transition from home to adult family home. This should occur prior to our demise, not as a result of a crisis. All we ever hear is that there is not enough money in the system to provide this kind of planning help and this strikes us as irrational and short sighted.

Planning for the future care of our son would include placement in an adult home. We really like {Provider} where our son receives respite care. If it were possible we would consider placement there as a plan. We would also like to deal with placement prior to my husband or myself being ill or disabled!

My son is medically fragile. He requires around the clock care 24/7. As I get older and have my own health issues it is getting harder to take care of our son. I worry about how much longer we will be able to provide the care he needs as his health is getting worse too.

My older daughter who is a single parent and a nurse has voiced her agreement to be my disabled daughter's legal guardian and full time caregiver if and when I am no longer able to do this myself. I am 81 years old and in moderately good health and hope to continue this way for several more years with the great help I am receiving from DDD. Thank you.

I would at some point like *** to have his own place, but will never be able to afford it without outside help? I have been watching section 8 for years hoping to get him on the list and to get on the list is always full. Is he expected to be able to support himself on $600.00-$700.00 a month? As far as what will happen to him when I am gone? I don't have a clue, and I worry about that all the time. **** is not bad and can pretty much take care of himself if he had too, but he can't handle finances and will always need someone to help him budget and pay his bills and give him spending money. No one has ever offered me a plan on how to go about that. Services? I've been taking care of **** since he was 4 and no one has been there to help. He's only been on ssi for a few years and he is 23, and I had to fight to get that. For years and years we struggled and now you're asking me I'm happy with your service. I don't know what service you offer.

Now, as we age, our greatest concern as parents is to find a residential setting, where our son would find comfortable living and still work if he wished. Our recent case workers have been helpful with information, but also tell us that many group homes and places like the {Group Home} are full and have a long waiting list. My husband and I are his Medicaid personal caregivers. We have started a special needs trust and hop there will be enough funding for his care when we are gone. At this stage we need information on group homes, and other means of providing care including costs, waiting periods, requirements for admission and sources of financial aid from federal, state, or foundations.

DDD services have worked well for our family. I believe this is due, at least in part, to the fact that we as parents have been proactive advocates throughout our child's lifetime. The area that I believe we and other families with adult children with disabilities could use additional support is in the area of future planning. A resource that could assist with discussion and planning regarding various options when the parent care givers are no longer able to provide would be invaluable.

9. Transition Issues

We wish that there was a transition plan from school to adult care home. It is all so confusing-it would be good to have a plan with specific steps as to where we should go next for our options are so limited and both my husband & I work & cannot stay home with him…it would greatly help to have someone guide us to what to do next. Where to go & be aware of what our son's needs are. The case manager has so many clients. I'm sure she is overwhelmed. We want our son to have activities during the day-but to go about & find these are impossible when working. This is stressful situation…

We are no long living in Washington state as of Oct 22, 2005. However, we attempted to answer the questions for him based on the services prior to our move. The transition from WA to SD was relatively smooth and we appreciate the cooperation from DDD-wa.

She is still in high school (special education) and has one more year till she's 21. We are looking into what's available for her after that {Provider, etc.}

My greatest concern is the transition of our daughter living with me and then living in her own apartment. I want her to live with me as long as humanly possible. My concern is if I were to die suddenly that there would be immediate availability of the necessary resources at such a time. If it becomes apparent that I can no longer care for her I will transition her into her own apartment. But sudden death is a concern of mine.

I think it's a great disservice to the individual and a huge waste of taxpayers dollars to train these young adults with a job skill and then when they turn 21 and leave the school systems they enter a huge black whole. There is nothing for them to do! I found out I could use an agency to receive a support person from a co-worker when I worked. Not my case worker. In fact when I asked her about it she was very negative about it. The list of names of persons who work through the state was I believe 3 pages long. Only 1 person still was working and she never showed up to talk to me. The state needs to make this a viable means of employment so qualified people will work. I have a very sweet support person who is good with my daughter, but I don't feel safe leaving her alone with her.

As a parent the most frightening thing for me is to wonder what my son will do when he turns 21 (he is 19) and out of school, will he have enough money and resources to live a comfortable life? Having someone reassure me of this would be wonderful!

I find all of this very overwhelming. I can't seem to understand everything. We are also entering into a new phase because she will be out of school (age 21) in about 3 weeks.

The biggest concern we have is life after school. Our daughter has one more year in school and then-???!!! If we can't find an appropriate living situation for her, our lives will deteriorate very quickly. We will be in crisis every day.

10. Service Coordination

Any "trouble" answers are due to second handicapped person in household. She has few problems and requires little assistance. I rarely have any contact with case manager due to I*** but constant contact due to second person. Also, at my age and very poor health my patience grows less and less.

10a. Satisfied with CM

We are very lucky and blessed to have the extra help. Our case worker is wonderful. Thank you so much.

We are now satisfied with the services our son receives and with his caseworker. However, when he first began to access adult services, his caseworker at the time created many barriers to his care. She would not allow us to use his mac hours as we wished and would not let our son attend the day program we wanted. We felt we were in a constant battle over his plan of care. We requested and received a new caseworker and life changed. She truly worked with us rather than against us. She discovered our son was eligible for a program we hadn't known about, and that has positively impacted us and him. We have been surprised about how much time we devote to advocating for our child. His new caseworker has definitely helped in this process.

Our case manager has been wonderful for our daughter. She is knowledgeable and thorough. Always calls back whenever we nave a question & helps us whenever she can (within the guidelines of dshs). Thank you for having her in your starr & for being her case manager.

None of these responses relate to our current DDD case worker. Our current case manager has been very helpful.

My disabled son's case worker has too many cases to continue with, she is overloaded and overworked! She is wonderful, caring and hardworking

My case manager is very helpful and responsive, yet I know they have a huge caseload.

Love our caseworker. She is wonderful, very caring, compassionate, friendly, warm and a nice person. A real asset to DDD!

However DDD with my case mgr. Helped me w/support & aid within the 1st week after arriving home from the hospital! She was wonderful and caring to both my daughter and myself!

We feel very well served by caseworker!

I respect our DDD case manager. She cares and does the best she can within state provision to her!

I have been a caregiver for 4 1/2 years, and have been very happy with my brother's caseworker. They (we've had 3 different ones) have been very helpful and eager to help especially his current one. I would hope that I would be able to keep my brother until he passes away. He is very happy here with my husband and me. I know that there are services available however we prefer to deal with things ourselves, as long as we can.

I have an excellent case worker.

I am currently pleased with the quality of DDD staff case management.

He has stage 4 leukemia. His case manager has been very helpful in helping me become a paid provider for him and helping by phone and visits to be much support. As one of Jehovah' witness we have our own entertainment and recreational services. He has a large circle of friends to help support not only himself but me also.

10b. Dissatisfied with CM

After his father died, I was extremely tired and upset, having cared for him at home, plus {Name}, and I knew {Name} would feel my tension. I asked the case manager if I could get some help in finding a person to care for him for a couple of days so I could get away and get regrouped. I knew it would be a while before it sunk in that his daddy wasn't coming home, so it wouldn't be difficult for a care provider. Her only answer was there was no money for respite. I explained I would be glad to pay, I just needed help finding someone who could care for him. Her only answer was there was no money for respite and she couldn't give me any names. Every time you call and get sent to voice mail, they always admonish you that if you're having a crisis, to call a 'hotline' number. I've wondered just what would constitute a crisis severe enough to actually get some help--obviously the death of a husband of 40 years and/or a father of 37 doesn't qualify.

We do not know who our case manager is!

I would be happier if the case manager did more research on their client (my son). I do not appreciate repeated statements as : death in family, medical history, group homes, etc. My son has always lived with me very comfortably and will continue to do so.

DDD support has been non-existent for the past year. I don't even know who the case manager is. I never even saw final evaluation when someone else was her case worker manager.

DDD caseworkers have little to no knowledge of mental health issues. They need to let mental health staff deal with clients' problems. The "requirement" for DDD case managers to call adult protective services if a client does not "want"/unable to bathe should definitely be re-thought. This policy needs to be fine-tuned and aps should only be involved after a period of time with mental health involvement first, (or any other type of intervention which is successful.) DDD case managers and supervisors need to be honest; ie, do not lie to aps social workers about what the true facts about the situation are! Supervisors of case managers need to be honest regarding information about the case managers! Appropriate therapeutic facilities need to be available for mental health treatment! My son has obsessive compulsive disorder/autism and has difficulty w/hygiene because he thinks the water is bad since our pipes are old. Outside intervention by someone coming into our home and coaching him, works. I need to be able to trust DDD staff. They need to take into consideration our wishes.

10c. CM Turnover

We seldom have contact with the case worker and they seem to change so often. I don't even know who her case worker is now.

Our case worker, whom we have had the past 2 years was just wonderful. Now we have a new one, we have not met yet. Case workers come and go too fast.

My son's case manager has changed frequently. Until very recently (last 2 years; lost two case workers) there was no contact made except letters that said the case worker had been changed.

My sister helps my with {Name}. If I have any problems with {Name}, my sister helps me we work along with each other. {Name} and I do a lot of things together. {Name} has had a lot of case workers in the last two years.

I have very little contact with my case worker at DDD. I am not sure who my current case worker is. There has been high turn-over. Only when I call do I hear from my case worker. I'm sure their case loads prevent them from being pro-active.

I have not met the new case manager yet until our appt. We had e*** but now we have c***.

I had an excellent relationship with my son's case manager whom he only had for one year then we got a letter that said we had a new case manager, we have yet to meet with her. I feel that once you develop a rapport with someone it would be nice to stay with that person for at least 3-4 years

I don't even know who our caseworker is-changes are made too often.

I do not understand why case managers change so frequently. When you hear from them so infrequently & then you find out you have a new person-it is very hard for my daughter to build a trusting relationship. I have no idea what a service plan is. I didn't find out we had respite care until I changed caregiver agencies. The news agency seems to be able to follow through with schedule but I have to give 2 weeks notice if I need to have additional times. If someone asks me to do something socially after work, I have to say no because I have to give advance notice to agency. Maybe if case managers could stay at their jobs longer it would give them time to learn it well and pass on their experience to those of us that need it.

I am sorry this is so late, but I don't leave time to do surveys. I would very much like to not have to rely on services from the state but have no choice. I suppose, except for the case manager 'turn-over' I am satisfied for my situation at the present time.

Case managers should be stable ie: frequent changes in case managers is inconvenient for all.

***** is my former case manager and is still my sister's case manager. When I have questions, she is very helpful to answer them because she knows me. I have not been contacted by my new case manager ever. I would like my former case manager to be my case manager again, if I get to choose. Thank you.

10g. Service Plan

The main problem the past two-three years is the evaluation form adopted by dshs. It does not take into consideration the total needs of our son; therefore we get paid less & have less income to provide services for him. Like social activities and items for his use.

It has been 2-3 years since I have participated in a plan for my daughter.

I feel that dshs should take more things into consideration for each individual when evaluating them as in what the health care provider (which are usually the parents or relatives) does time wise & like extra laundry, expense wise such as extra electricity, water, gas, miscellaneous things like these are not taken into account and should be.

I have no idea what a service plan is.

There was previously several years between assessments. It is in my sisters best interest that assessments be performed on a regular schedule since her needs as well as mine will be changing more frequently as we both age. My own personal need is only that she has adequate services to continue her quality of life. There has been a very definite change for the better in the past 2-3 years. Advocacy is working!

11a. Satisfied with Staff

Thank you so much for your help. We love our care giver and really appreciate all you do for me and my daughter. Thank you.

I am very thankful DDD has found a great young lady to care for my nephew he adores her and looks for her next visit of care.

Each DDD person we have dealt with has been sympathetic, energetic, and affirming. We greatly appreciate each one.

11d. Shortage of Staff

This community needs access to more respite care givers or make it easier to become one.

11f. Pay Staff More

My daughter has had a caregiver since she started to program which she immediately had rapport. Her caregiver has helped her build confidence and do things she doesn't do for me. She now has her own friend and confidant. In November, they suspended payment to the caregiver. I was not notified except by the caregiver who thought things would be worked out. I called the person who suspended payment. She never called back. The caregiver calls and never receives a call back. It is difficult to find people who bond and to feel comfortable with. I do not want a different caregiver. I would like to get this resolved. It has been very upsetting to my daughter.

{Provider} wages are too low to keep a caregiver for long term employment. It is easier to flip a burger.

11g. Substitutes

Respite worker is sick-don't know if we will get her back my husband talked to caseworker-we were to get a substitute and haven't. That's why I did not answer respite worker questions.

12a. Parents as Paid Staff or CM

Stop taking out union dues and I&i from wives (care giver) paycheck. She didn't want to join the union and never gave permission to take anything out!

Receiving money as a caregiver is vital to being able to keep our son at home. (obviously the best/least expensive option for the state). Yet, we feel that one misstep could yank that money away. It scares us, especially as I approach retirement, the dshs help line is no help.

In answer this I would like to get more pay for what I do, because I do not see how your office figures out the hours that we get. I would like more money.

I provide care to my daughter 24/7, but am only allowed 109 hours per month. That doesn't even equal to 8 hrs per day. Need changes in system to allow at least 8 hours per day. 8 x 30=240 hours per month 240-109=131. At 109 hours I am only getting paid for 3.6 hours per day. Would you work 8 hours per day for 3.6 hour of pay?

I feel I should be paid for more hours. Because I am taking care of him more do to his diarrhea (chronic) and his disabilities.

I complete training in "fundamental of care giving" in March 2006 and was told I would be paid. My caseworker said as long as we signed in daily we would be paid. So far 0 in 30 months other people in the class were required to show their certificate and were paid right away. They work for an agency, and I'm an independent s.p.

I am very happy that my son is able to live with me and I can take care of him and he paid for this. It's important for him to live in the family so that not to feel lonely. I just need a break sometimes but because of language barrier it's hard to find respite care. In general we are satisfied with services from DDD. We would never be able to get it in our country. Thanks

Having an adult who doesn't like people touching or looking at him takes a lot out of a person. Right now it’s trying to get him to wash daily & shave and let me wash his bedding weekly. We also never know when he is going to be angry with people or hit them. His moods fly off the handle that is why i have been doing his respite because I'm afraid of him hurting someone he doesn't mean too. I take him to the movies once a week and to McDonalds his favorite place and things like that. Bowling too. But that has to be early morning Sunday when theirs not many people around. If he thinks someone talking about him he becomes very angry. At times if he has been good let him stay over night at his grandmothers house. But I have to buy all his food and leave her $40 for his care.

For all the years I worked, I paid a care provider privately for part of the day. I was never offered ???? For being a care provider at home until this year when I could no longer feel comfortable with his "volunteering" an of private care, so I quit my job. I was then offered money.

12b. Family Support Group

We have had no current support group of parents since he left school, except for his bowling buddies.

13c. Abuse/Neglect/Mistreatment

We have taken care of her for 48 1/2 years now. She had 3 strokes when we lived in Arizona that have left her as a 2 year old. We have pads on all of our chairs and she "bed wets" and can no longer speak as she once could. We allowed her into a sheltered works hop until I went to see how she was doing. The man in charge was jerking her by her hair hard! Because she wasn't counting to suit him. I got her coat & we left him sputtering-never to return. I will not have her abused! This girl wanted a home & family. I let her be in special olympics. 4 months later I found out they had housed her in a single mans apartment in {City}, AZ. I no longer trust the system. No one cares for your child like you do. No one has your standards like you do. She is unable to do those things she used to do. We are doing fine so far. She is slowed down by foot surgery that has left her limping, but she walks slowly around a 7 1/2 acre yard and has chickens, dogs, cats, and family-so she is happy. I don't belong to any organizations that cry on each others shoulders. Heavenly father gave her & us a challenge. We can deal with it.

13d. Social Well-Being

My son is a joy; personal, safety & dexterity are areas I cover as his caregiver & guardian. My husband has backed me in being there always with the 2 of us to keep him watched over. I am 53 and in good health. His dad & my husband of 31 yrs is 72. I hope we can keep our happy family together. Our other 2 sons are working & need to be free for their careers at this point. Major concerns are him being 20. To keep his social life active his friends are mostly are friends. We need more for his age group. Also it is wearing for my husband to keep availability constant with him not wanting to go anywhere without a days notice. Errands come up, some very important. Other family has moved away or passed away. Thank you for your support & help. My work has made me late with this reply. My apologies.

My main concern is knowing what services is available for my child. I have no knowledge of what is available for him. I would like for my child to be more involved with activities and be able to get to know other people to be able to socialize during the summer and keep in touch with others that may have disabilities like him.

We need more activities in this community for moderately retarded people; more peer access.

Am sorry to take so long finishing this. I have been feeling unwell & it takes time to get things done. **** has a sister who does what she can to help. She lives 40 miles away and works full time. If anything happens to me, arrangements have been made for her to take over. The only problem here is I feel quite inadequate in keeping her entertained. She works at {Employer} and I feel this is the best thing she has going for her. She has friends there and she has a feeling of accomplishment & something to look forward to. She is so proud of her paychecks when she brings it home. Ip ut it in her savings & she gets to go to disneyland once a year. I'm 71 yrs old & not the best company for her, though I try very hard to make her happy. Sincerely mother & guardian

14b. Dissatisfied with Respite

I have no respite services available as far as I know, other than family support monies that I use to pay for my childs summer camp- I fund day camps per summer. As a single parent with physical problems of my own I need respite help more than 8 days a year. Because of this I am not sure I will last the 6 months to 2 years I marked for keeping my daughter with me. Funding some respite monies would be cheaper than having to pay for an institution I think.

Over the years, respite care has been the "weakest link" in services available to us. For some reason, we were not "eligible" for care and so we hired caregivers ourselves over the years. It is still difficult to find someone to stay with him when we are away except for our adult children. Now, as we age,

All care providers for their families need more respite care to keep them from becoming disabled and dependent on the state.

15. Crisis

This year for the first time we had an emergency (life threatening) situation where I was hospitalized for one week. My respite provider was there for me and my dd son & cared for him until I could come home, but what was wrong is we contacted our case manager, told them the situation and they couldn't find any other care for my dd son, but yet said they could not and would not pay my respite provider for the week she cared for him. Because of their "rules" my respite provider already cared for a dd person in her home. So, my respite provider cared for my son one week and received no pay. But yet DDD could not find any other provider to care for him. What was I to do? This was an unexpected life threatening emergency. Because I already have this respite provider I naturally turned to her for help in my crisis. I think this is very wrong that she was not paid for her services and DDD needs to set aside emergency plans & money for these kinds of emergency crisis's. My respite provider gave us quality care in a crisis and is there for us when we need her but DDD failed us when we needed emergency help.

16. Funding and Budget Cuts

Not only do we not know how much money is spent by the division of developmental disabilities on behalf of him, I have had no luck finding anyone that does.

We sometimes must get a motel so much of his money I s spent going to {City} hospital for gas. Also his insure is $8.50 a box of 6 and he uses about 2-3 cans per day for his bowel management.

We do not have the family support for her that would help pay for some programs that we can't afford to provide for her at this time and some respite care.

To whom it may concern! My son has lived with me most of his life, and I'm not tired of taking care of him, but tired of not having enough money to take care of life's necessities. Such as beds, linens, mattress when they wear out. Towels, blankets, all the things it takes to keep house. When all these things wear out, it takes from my income to replace them. There's never any extra money. It would sure help to have a little extra sometimes.

To keep my family member home with me i need to have full time income paid to me. Having family member at home is so much more beneficial that an institution for persons with dd or a nursing home and the family care providers should be compensated at the same rate as an institution or nursing home. The reason for this is to have enough money to provide a quality care program to include trips that other members of society can go on like to disneyland or graceland for a DDD client that likes elvis. This is money that would be well spent and increase happiness for DDD clients.

She will always need help. I have to be there when she gets home from school which is 3 hours from the time she leaves from home. I work 24/7 for her. The case manager cuts my hours. From 107 hours to 70 hours a month. That’s 3.4 hours a day to little over 2 hours a day. I don't believe that's right do you.

My son can get dressed on his own but as for turning on a light when dark, drinking water or eating he has no sense to do that yet your test don't show that. And if there was a fire, if he had a seizure or anything he has no sense on what to do . They took 3 hours away from my son. I felt like he should have more hours awarded with caregivers. Thank you.

Like a mentioned before payment for my providers has been a huge problem not just once but many, many times. I have 2 children both have different providers-one is now in a companion home, lucky for her. The provider has not sent her away, the provider has not had a check from DDD in 4-5 months even though she has been providing care for my child. I am very lucky I haven't lost her & been told to find another place-there is none!! So I have dug into my pocket & helped pay to keep her there-all the while the provider is being told "you have been approved it just needs to be signed" do you not know lives depend on the paperwork that is not being done? Case manager did her job. Provider did her job, I have done my job. So who needs to do theirs? Please fix the payment system as all of our children could be at risk of no providers to care for them.

It would make it easier for family members to continue living at home if the government would loosen up on the restriction of monies for supportive help.

I was my daughters paid personal care provider until she lost her Medicaid. She doesn't receive any services except her job coach. I still do everything I did before. But now I don't get any compensation.

I take care of two disabled people because they live in my home, which I had built to accommodate wheel chairs, special bathrooms and so forth, the state cut my hours. T*** was to have 140 hours & p*** 250. I get 101 for t*** and 199 for p***. I am sure no one that made up the rules for cutting hours would provide the care I give to these two. I am sure they would be put into another facility. I am an r.n. And could get a much better salary with vacation & holiday time, with benefits if I were to put them back into the system, i.e. a nursing home, afh. This would also cost the state much more that what I get and give up.

17a. General Satisfaction

We are most appreciative of the program and services provided by Washington state, dept of social & health services, and DDD. We think it is the most beneficial program for the parent/provider and client that is being provided. Thank you.

We are happy with our service. Our church will always make sure we have support. But we thank you for all the services we are getting. Thank you

We are giving our adult daughter the opportunities & experiences possible to have a full life as is possible. When we travel, she goes with us. We go to dinner together. We got to the movies together. We vacation together. She uses a wheelchair & a walker, a communication device and we have them available to fulfill her choices. She is very happy in her life, and we are grateful for all DDD has done to make this possible.

Very satisfied with k**** r**** support to k**** and the rest of the family

The service is wonderful. I thank you so much.

The job our daughter has had for 10 years is what makes our lives so good and Medicaid personal care is a life saver also. That's all the services we need.

Thank you for your helping.

Sorry- we were out of the country until June 1st and did not receive this survey in time. {Name’s} services meet his needs at this time. Thank you,

Overall, I feel I/we receive good services from DDD, and our case manager is outstanding. Current concerns center on long-term issues surrounding our son's behavior and medical conditions.

Long term care for a son with cerebral palsy has been a difficult task. DDD's help is very much appreciated. Thanks!

Keep up the good work!

I'm sorry. I'm not familiar with all the language. I have asked lots of questions. Just gets confusing at times. But thanks for all you have done so far. I am grateful.

I'm happy to do this, but as i got further into it I'm not sure it was for me to fill out, as he is already in an adult family home. That we're pleased about. His provider is very good for him. I've always had help from c**** b**** too. Sincerely.

I have two autistic sons (18 & 21). I have been a single parent for 8 years. My 21 yr old is in the process of going into supported living. Without all the help from DDD I could never have kept him at home this long. It has been a very long haul for me and now it is time for him to have his own life. My other son is not on the core waiver and I don't receive enough help with him. He is not as difficult but I cannot leave him unattended for any length of time. My only job option was to work for the school where I could have the same days off, etc. I am very thankful for all the help that I've had for my 21 year old. Without it I would have gone out of my mind!

I have circled boxes that I have checked wrong. I would like to say that all his brother's and sister's are extremely happy with the means provided by the state, and state workers. We feel with out this help many of disabled people would be lost in this world.

I appreciate everything DDD has helped me to do in the past. I look forward to next 20 years.

He is my older brother and I'm very blesses to be able to help him and take care of him. Knowing he's safe and happy and in good health makes all this worth it. Thanks to all these services I'm able to care for him.

Future medical/physical diagnosis for client is polycystic kidneys, hearing is deteriorating and is requiring more "coaching" on daily activities. More care and time will be needed for client as time passes. We are truly thankful for the assistance we receive and for the many dedicated people that choose to do human services for the disabled and aging.

DDD is doing a fantastic job in supporting my son g***. Please continue the great work you are doing!

17b. General Dissatisfaction

We do not have help! No respite provider! No one to take our daughter our in the community! She has no socializing, and is a very social person. Also dshs is always trying to take hours away and I work more then they give!

The time it took to initiate services was excessive. Our disabled son was in services in CA. It appeared that WA state DDD would not use records from CA and had to be processed from step 1.

Please give attention to this! Thank you my family with the special needs man has lived in the same place more then 10 years. We expect our caseworkers to change however, we do not expect our family to transferred to an office that's not in our community when there is an office which is convenient to our family. We are not part time special needs family. The special need is always and we need service with the 24 hour period after we make a call, a message machine handled by a part time worker is unacceptable when we could always walk into the office and leave a note for our family case worker. Otherwise all is well.

For parents who are the largest group of care givers-there needs to be money put into place to help us assure of children with dd the opportunity to be independent! This state of WA does very little to help us, instead spends 15 million to support union based, large dollar institutions. Catch up with the mid-west (Ohio), embrace families who are taking care of their children with dd. Make this "dd system" user friendly by placing all pieces of the agencies under one roof, providing info to parents in a timely manner. Parents want to do the correct things for their kids however, having dd under aging is wrong! When my 94 year old mother gets the same assessment as my 20 year old daughter, there seems to be a problem. I feel wa state's system has been set up to turn parents away and discourage them at every turn. Get real Washington, join the modern age like in the mid west, make it user friendly and accommodating. We aren't asking you to raise our kids, but we do need help! I personally can't work full time and because of health & safety, she can not be alone. Wow 48 hours mpc just doesn't cut it! But if it was out of home care, show them the money!

17c. Access

Why is it so hard to get services? I feel that we are treated like second class citizens.

I like the services provided to our family, however, the financial assistance should be easier to access & more available to all dd adults/children.

Dear sir, I don't feel we have had the services that others have had. Some get much more than others. Sorry

Services are limited in the community {City}. Respite care-had only one place available in an adult foster care home with elderly ladies, (my son is 27). Formerly residential resources did respite care for him, (with other in a group home setting). This was not legal I was told! I asked my daughter who tries to fit him in th her busy schedule.

Community access is available for some people, not my son because of his "plan". I am not happy with that! Others may go to swimming, bowling etc, but he is not is that "plan" or is it no longer available I am told I provide al his community access. Services should be provided equally for those in group homes and those who are cared for privately! It is difficult to get a person into a group home and probably costs a lot more than one staying at home. If I didn't now have the care

growing dollars I am not sure how I would manage not working & caring for him. I am still basically tied to his schedule, and with rising gas prices transporting him 30 miles 3 days a week adds up. I would love for him to have more access to community services/activities, but not sure how that can happen. I would also like to be able to leave him somewhere without a huge hassle of planning, for a weekend. I am thankful, however for what services he does have!

17d. Info Regarding Services/Supports

We need access to an affordable attorney to re-do our wills & set up a special needs trust or ddlot. Also advice about what would be best for our child to ensure she is always cared for, lives where she wants to live re; small residential facility and not worry about being "sol" if Medicaid or dshs or other support sources are drying up!

We love & enjoy our son and will probably have him here living with us as long as our health allows. We'd like to see him living on his own, but he will need assisted living arrangements & that is pricey. So I'm sure we will continue to provide the "assisted living" situation that we have been doing here at home, as it works well for now. I'm currently searching for a camp that takes disabled adults for a week or two in the summer. This would give my husband and I a wonderful break & some quiet time together, & it would be a break for our son as well. I need to spend more time online looking, but have been up to my neck in homework. I take college classes at night & on weekends & work during the day. I am 2 quarters away from my degree! Then my schedule won’t be so crazy. Sorry this is late!

We are in the process of looking for an adult family home or full time care provider for 24 hours a day care.

{Name} has been too ill the past several years to participate in anything beyond medical necessities. Now, as she occasionally has a "good day" I would like to see her more involved in community activities, even if she can't commit to regular attendance. I know there are many resources, but I don't know what or whom to ask for.

This was the only time I've ever seen anything about planning for the future. Would like more info!

Our hearts sink every time we see an envelope from dshs. Understanding the regulations for eligibility, caregivers issues, etc., is next to impossible. ***** is the only person we have ever found who could wade through the bureaucratic jungle. How do people without college degrees ever cope?

More information on financial planning and employment opportunities would be helpful.

List of care provider agencies & respite care possibilities needed.

It would be most useful if more information or training was easily available. This would help parent providers keep track & organize records needed to track progress & daily living information to help respite provider or other care providers that may need to care for clients in an emergency, or after the death of a parent provider. Such as doctor visits & forms filled out by physicians & other health care providers. Although these forms are not required by parents if they were made available they would be useful to keep information in order.

I'm grateful for the support I have received for him, but I really need help to plan for his future. Thank you.

I would like to know what services i could get for my son. Just someplace fun to take him. He would really enjoy being with other people. I could use some in-home help. I'm very concerned of the capability of the people who would come in. My son has many medical problems and uncontrolled ???. I would like a ???, maybe a vacation. I could really use a vacation, but want to be sure my son is safe and kept as well as I would keep him. Where do I get this help? How much will it cost me? I'm sure it’s too expensive. My son needs a way to communicate. I know there is so much going on in his head he can't get out.

I would like to find more information on becoming my son’s legal guardian. Thank you.

I would like my son to be involved in community programs (social) or part time employment. But he needs help to start. I don't know who to get help from. I've tried to ask but get little information.

I feel like I do not understand the complex state and community agency funding. I have been assured that my daughter will receive assistance for the rest of her life, but I don't know that, (if is written somewhere I'm not aware of it). I also would like our will-which contains a special needs trust to be looked over by someone knowledgeable. For us

At last appt benefits were cut by?? He still needs the same amount of time and money for care. No body explain me or my family why? Can you check on that because we feel it happened because **** is Russian, but he is citizen of USA already. Please help us, we don't know where to go, whom to write about it. Our case manager told us that this is state decision and that is. Please help! **** parents are on ssi for disability and I can't work because I am taking care of him 24-7. The lady who made an interview with him told that mom can make food for whole family, but mom can not make food or prepare meals even for herself. She has severe arthritis. I do that please help us!!!! Thanks.

Although we haven't been provided with services that are available out there my client (uncle) has been very happy with us. We take him practically everywhere with us, even to a karaoke club. He loves music and being with friends and family. He loves to go riding. We take vacations during the summer to CA and Las Vegas, NV and we enjoy it. I feel that it may be too later for any services because he has gotten a little too unsteady and requires more assistance.

Don't really know what services are available am not sure.

17e. Need More Services/Supports

The money we get is adequate for the services that are available. It's the services I/we need, not the money. There are no respite services available to us at this time other that what I am able to find and pay for myself. Iv there are no workshops in {County}. He attends the only day program available in {County}. V. He receives what is available through the day program only. Nothing else is available to him.

More Medicaid hours are always needed.

We would really like to get respite care. It's been over 2 years without a break. I love her & wish her to stay with us, but it would be nice to get a break every once in awhile.

We have used {Provider} to leave our family member to take a vacation however we have been told that this facility is no longer available and the closest place is in {City}. Our family member very much enjoyed the staff at {Provider}. We would like to use it again if it can become available. The staff at {Provider} are very wonderful. Thank you.

To whom it may concern: 5/19/06 I have been taking care of my son for 18 years since his accident. He was only 6 years old-resulting the car accident. (he was run over by pick-up truck). He has been totally disabled-totally-he can't do nothing on his own. I get two days off. He goes to his grandparents home for 2 days. They also have been taking care of him for 18 years. I am retired from regular work. To spend more time and care for my son. 5 days a week as caregiver (primary). I wish there are programs for my son or another adult disability person to attend some sort of program but the case worker says, there are nothing out there for them. This is a small town {City}, but I do know there are few adult disabled person like my son. I am just hoping that there should be some program that my son can enjoy and attend. Thanks

Needs: 1. Transportation to work 2. Social acitivities-small groups a.) Movies b.) Concerts c.) Wrestling 3. A plan for independent living.

Need more respite hours. Need special bathrrom for him

Right now, my issues with my daughter revolve around finding a job and living situations. We are working with dvr and she is volunteering a lot in the community.

I would like to see day care type programs for adults with severe disabilities.

I would like to meet with someone regarding in house respite for the purpose to be able to go out once or twice a year for vacations.

I would like to locate service providers for respite care. If my husband and I which to leave, we need to bring him with us which negatively affects his job situation. respite care so we have "time off" w/o removing him from his employment. Lack of support affects "his" employment. I need in home support.

I would like to have someone help me to help my family member how to help herself in case blindness is a problem in the future. I have no training or patience in teaching someone with very limited attention span. She gets angry real easy when pushed beyond her limits. That would be a great help for me.

I need an occasional break so my spouse and i can have sometime together for a date occasionally or a weekend sometimes. Not having any time alone does make it hard sometimes.

I need a good home for him. Together with some king of day care program. I have tried to look at {Provider}, but they do not want him as he has nowhere to go during day hours. I need help.

I have not even spoke to anyone in the DDD for a long time. I do need to have help with some legal issues. I have been putting off due to money issues-i.e.: guardianship and long term care if I become unable to care for her. Our address has changed.

I have been in the process of working with dshs/maa for over a year! While my case worker was extremely helpful in getting me information and to the correct individuals to fill my request. I have yet to get a response for a simple wheelchair ramp. I am extremely frustrated at the lack of response from this department.

I feel that the caregiver "hours" should be more on each case-instead of a simple question. My son can't be left alone for any length of time, as he wanders off etc. He goes to school and they call me several times a week not knowing where he is. They are his job coaches, but they call me all the time with one thing or another. I almost have to be by the phone in case someone calls. I had to quit work to be home and take him around. We take him to school, pick him up, take him to work, pick him up, take him to speech etc. Maybe it's Special Olympics etc. He does bathe himself and dress etc. But i always have to check everything. It seems people I know that have several medicines daily get so many hours. When I am on the run all the time with few hours. But all in all we are thankful for the help we get, I hope someday their will be an adult home close to our area.

I am a single parent in my 60's-a realtor who works as much as I can. All I need is people to help so I can continue to work. My son has no speech, can't answer the phone, needs support to even work in a supported environment. His medical help and his ss help keep him in his own home. We live in the country 5 minutes from town. Transportation is always a problem but we figure it out. I believe it is easier in a small town to cope. He goes to church with me and shopping etc. With only 1 bowling alley and no indoor pool here we do lack some activities that would be an asset.

Hey listen up all you need to know about me or family is my name is c***** a****. I need assistance yes, and we believe in jesus christ as our personal savior. If you don't know jesus then, say this prayer alright. Dear jesus please forgive me of all my sins come into my life, and help me be more like you. Amen

Behavior management support is a great need for us. Although we have resources through the waiver, it isn't enough. We are only half-way through the year and almost out of funds.

A take care of my son who had grand-mal seizures. The only concern that I have is that the state does not give us adequate hours per month. I am glad I am able to care for him. There would not be enough hours to meet his needs if another person were to come into our home to care for him. Now he has been removed from the program at DDD. Due to a change on his medical coupon. It makes no sense. Thank you

A lot of this I either don't know or doesn't apply to us. He needs help with finances and medical providers

17g. General Dissatisfaction with Service Management

Supervisory personnel and department heads do not like to pressed for services or answers to specific questions about available services, such as where you are on a wait-list for respite care, or how money per individual services, such as where you are on a wait-list for respite care, or how money per individual is allotted, how many are being served, how many handicapped in the country. Calls are not returned, or those answers 'aren't available.' 27. Changes/assignments are made at the case manager or supervisory level and you are informed of them-if you ask.

DDD case managers and supervisors need to be honest; ie, do not lie to aps social workers about what the true facts about the situation are! Supervisors of case managers need to be honest regarding information about the case managers! Appropriate therapeutic facilities need to be available for mental health treatment! My son has obsessive compulsive disorder/autism and has difficulty w/hygiene because he thinks the water is bad since our pipes are old. Outside intervention by someone coming into our home and coaching him, works. I need to be able totrust DDD staff. They need to take into consideration our wishes.

17h. Waiting List for Services and Supports

We have been waiting for some help with respite care for many years and been on a waiting list with DDD for several years as well. Even a few hours can be a godsend and it is difficult to always feel you've burdened family and friends. We realize this is a funding issue but would still appreciate any help in this area.

He has been on a waiting list for a path plan for years.

19. General Concerns

The has been explained to me on several occasions by all the agencies involved. 3840. This is the first I've ever heard of there being a grievance procedure-or option. Might be kind of fun to go back and ask about where I'd file? 41-44. {Name} lives at home because this is where he belongs. Services make it easier, and would undoubtedly enrich his life. Since they are not available to us, we do without anything I can't provide. I would like to take this opportunity to thank for this questionnaire. It is the first time I've had any input, and have also gotten a lot of information I have never been able to dig out before. I'm very sorry it's been so long getting to you. About the only bright spot in the whole emergency has been the chance to see how our 'system' worked, and to be able to fine-tune it. It worked like a champ, I might add, and {Name} was well cared for at home, happy and his routine about 95% intact! Thank you very much.

We believe our daughter would be capable of independent living if she is adequately trained, supported, and has contacts that can assist her when needed. Our older daughter would be the person for general supervision, but she would not be living with her since she lives in snohomish! We are one of the founders of {Provider} group homes and possibly our daughter could fit into their independent living program. However, it would be desirable for there to have a broad "circle support" if possible. What is the difference between a guardian and a conservator? So for as we know the only services we have been receiving are the assessment from the work training dept at the University of WA, which has assisted our daughter in finding and holding jobs. They have done a fine job of it.

This survey is lengthy. It could be divided into 2 parts. Thank you.

These questions do not seem to be ones that meet our sons needs. He is employed by the state and has a job coach. I believe DDD is involved with this and {Provider} is responsible for the job coach. I have met one case manager (DDD) and have had letters to tell us of the changes and the names along the way. Other than that I never hear or see the DDD case manager. He can take care of himself in every way. Handles his own money, has a credit card, active in Special Olympics bowling (a very good bowler!) Has a good network of people around him, work, friends, friends of the family. Shops for his own clothing and things he wants. Capable of buying food and cooking excellent meals for the family. Helps with the lawn work. He is no burden in the home and does his share to help in everyway. This young man is not a burden in any way. Wonderful, happy personality and very capable. Because of his seizure problem it takes him longer (because of slowed brain waves) to respond. But on average he appears to be smarter than we give him credit for. We are satisfied with his progress and are providing for his future without assistance from outside our family.

Thank you for taking your time and providing this survey to us home care givers.

Thank you for caring on page #7 planning for the future.

Sometimes my mom does not understand any of these surveys, so I have to help her answer the questions. I am her daughter. I helped her with this survey the best that I could. Some of the questions even I did not understand how to answer.

Some of the questions are either a yes or no type. I would have like a "sometimes." (see care giving challenge).

Since I'm old enough to fill this survey out on my own. I did the survey with out adult supervision. I can take care of myself whether you like that or not. Who cares if I live at home? All I'm waiting for is a full time job w/cts oun benefits (the mail inside) on the envelope has my name on it. Not my mother's. You guys keep sending flyers with retarded people on it! That hurts me! And you think that I'm like that? Hell no!! I'm not okay? I am working with my "workforce" person (that's kind/friendly) in order to give me a job. Thank you for reading this entirely. Ps I was writing too fast and this is why its sloppy.

P5 "service plan" was not defined.

Nursing should have made a visit they did not this year. Mother & sister provide all transportation needs to work from work to dr to dentist. I would like information about activities for dd clients. Hired ?? {Provider} for job placement nothing after 6 months so let them go. Mother got daughter her job has been there 4 years now.

The paperwork involved with medical benefits, etc. (whether he has them, how to use them, where to use the etc.) Is daunting. When you put all the paperwork involved with the agencies that he has/could be connected to he could keep a private secretary busy.

Less paperwork

It was difficult to provide complete answers to some of your questions from a personal care provider/family member point of view.

I'm not certain I responded 100% correctly. Tried to, but we really aren't too involved in all the support system, so I'm unfamiliar with some of the terms used. Basically we just go along pretty much finding our own way providing for our sons interests & growth, on our own.

I really hate doing surveys. I'm not giving you my answers, but choosing between answers you supply. My way, of course, you can't feed into a computer, but 1 question whether this predigested date fed into a computer will yield you anything of much accuracy.

I plan to take care of my son as long as I can, and I am regularly in touch with family members who would try to help. I thank you people for your concerns. It is highly appreciated. Thanks.

I don't understand answering the questions, but I did the best I could. I take care of k*** all the time day and night. She is my daughter and I love her dearly. I couldn't do it without your financial help.

Developmental disability means limping behind normal folks. Like children, some things can be taught/learned, if slowly, with fluctuating receptivity. Like for children, responsible adult supervision must remain a constant source of scholastic, psychological, practical hands-on, spiritual and artistic example to keep nurturing the autistic to hopefully even unfolding competencies, without which (with mere physical care giving) that budding spirit would wilt, deteriorating the -these- neglected to unforeseen devastation. I'm other words: trained teachers, nurses, would be probable examples to replace aging or diseased care giving parents, to live-in with their clients.

Confusing questionnaire. Our daughter receives ssi Medicaid. Mpc money, dvr. I am assuming none of these fall under DDD. So I answer thinking that the only services we receive are having a caseworker, am I right? Perhaps these things should be spelled out up front.

Comments spattered throughout! Thank you for taking the time to assess the needs of this special population.

WEST VIRGINIA

1c. Accommodations with Home

I have tried to get the service to put up a bath tub rail for 3 years and still do not have it. Every time I ask about it, they give me an excuse as to why it hasn't been done yet and tell me they will see that it gets done.

2a. Satisfied with Employment

My son is a much happier person since going to the day center. He has friends now and likes most of them very much. He is more independent and assumes more responsibility for his daily living activities. His speech has improved. He reads very well and is very good with little children.

The workshop and respite services are a lifesaver. He would probably not be here if not for those two services.

2b. Dissatisfied with Employment

I feel there needs to be more concern shown towards the family and more interest in working towards community employment services that the individual can work with if at all possible, not just sheltered workshops but involving working with individual businesses to create services or needs that both the business could be happy with as week as the physically and mentally challenged individual could provide. This can build confidence, self-esteem and a productive life for these individuals who cannot handle the sheltered workshop environment.

I think the agency ought to find things for clients to do other than outings at Wal-Mart and out in the community. We need more jobs for our kids to work at and if the staff and client were cleaner and did a better job in communities with clients maybe the business people would let them work.

My son is not benefiting from day program because he is with severely impaired clients who are distracting. He is moderately impaired and does not like day treatment. He is very verbal in explaining how he feels.

Day treatment leaves a lot to be desired.

I would like to see workshops and jobs out there for people with disabilities.

There is no opportunity for our family member to get job coaching because she could never go to work on her own. She only gets to attend day treatment one day a week. The rest of her work is idle time.

Having a day treatment in {County} would be a big improvement.

I am disappointed that waiver has financially stopped supporting the music and art program and medication giving at my sister's day program. They need music and art. Other than that, everything is great!

Day Program services have not been implemented due to lack of staff. The mental health center says they are working on this. She has only been able to attend a Day Program for approximately 3 months out of the last 17 months.

3c. Dental

Dental care for retarded adults is almost non existent. We had to travel 300 miles for dental care for my son this is a disgrace!

3d. Medical

I would like to have a Medicaid Manual on services/supplies that are approved/authorized for Waiver clients, specifically incontinence supplies. I feel our supplier works to get my daughter the most maximum quantity allowed rather than getting a quality product. I believe my daughter could be served more dignified with a better quality product rather than doubling up on pull-up and liners or pull-up and tabbed diapers to lessen accidents. I would like to be able to get - for a month's supply 50 - tranquility brand night time pull-ups. 60 tranquility brand day time pull-ups. At this time we get a 200 supply of samecare pull-ups wear day and night dignity liner, wear day with pull-ups Tranquility tabbed diapers wear night with pull-ups.

3g. Psychological

The center needs better psychiatrists to help the clients. Most of the doctors just want to prescribe a lot of medication and spend way little time talking with the patient.

5b. Dissatisfied with Transportation

Need more handicapped transportation.

The only real complaint I have is the transportation problem. I take my sister 32 miles round trip to the day program and most of the time pick her up either at the day program or at a half way place when they used to bring and pick her up at home. This sometimes is a problem for me and it also seems the day programs are always changing drivers. (Hard to keep them)

Transportation has been an issue.

Some of the services I have requested were promised and no action. I have to furnish 3/4 of the transportation to day treatment and at being 68 years old, this is a real challenge. I also requested to be furnished a copy of what was paid to me for mileage and the program and did not receive this information in an appropriate manner when I needed it.

Need more mileage per month and higher than 30 cents per mile!

5c. No Transportation

We used to get transportation to {Provider}, but no longer do.

6b. Dissatisfied with Recreation Activities

Would like to see our family member with disability go out more for recreation when in day hab like bowling, picnics and maybe movies for the ones that can go.

Would like to see more activities, games for the children at the day program.

8. Aging Caregiver Issues

I am always concerned for our daughter when we are no longer alive.

10a. Satisfied with CM

Everything I've asked for my daughter, my caseworker has helped me get it or told me how to get it. She has been of great help. Everyone {Provider} are a lot of help.

Our son's coordinator from {Provider} (Name) does an extraordinary job. Through this agency we have been able to choose approximate and qualified supports for our son. This success resulted in him being chosen as "Employee of the Month" in December 05. It would benefit all individuals if they and their families have that same quality person centered service coordination and choice for hiring staff. This would serve the individual more effectively and be cost neutral. Our son has been given the tools to be as successful as possible through this program!

The case worker who comes into our home to check on our daughter is excellent! She is very caring and wants to help us in anyway she can.

10b. Dissatisfied with CM

Service coordinator worthless, no help with services, does not tell truth, will not train to do paper work, says she has never been trained to do hers, no appropriate day hab available, no respite workers, simply doesn't care, plays favorite with families, marks off hours and miles from some families, yet pays divorced fathers as respite workers when they have visitation with child

10c. CM Turnover

My grandson is very unhappy when they change his support worker. He cries most of the time and refused to go, so he stays at home with me.

The turn-over rate per case manager is very difficult per team meetings. Each case manager tries to implement his or her interpretation of the Waiver rules. The new ones are over confident in their understanding of the Waiver rules. They are under trained and need guidance longer than WHS supplies. Same applies to Q's.

We went through approximately 7 caseworkers in 5 years for my son.

10d. Shortage of CM workers

I have been fortunate over the years with having case managers who were basically decent people trying to do a job. It does appear that in my area, they seemed to be spread too thin, have too many clients and really just relay information when asked.

11a. Satisfied with Staff

{Name} is under the waiver program through {Provider} and both myself and my husband are very satisfied with them. They have always done things to make taking care of {Name} easier. {Name} does respite care in our home and we are very satisfied with her. The workers at {Provider}, especially {Name}, are very kind and considerate of {Name} and our whole family.

Her day care worker is also very good with {Name}. We could never ask for better treatment outside of our home for our daughter.

My son would be in a mental institution if not for support staff. He is able to maintain a good quality of life and is contributing to the community because of support staff. Thank you! Was almost forced by court, but things are better thanks to support staff.

I want to thank all the staff at the mental health center for all the help that they give {Name} and me. They take a lot of stress off of {Name} and me. They are also very helpful with all of {Name's} needs. They are the best in the world. {Name} and {Name} are always there for {Name}. They are the nicest people I have ever met. I love them all! Thank you.

Here in {County}, we have wonderful people in our {Provider} program to work with, always helpful and respectful.

11b. Dissatisfied with Staff

Service providers need more accountability in terms of organization, instead of requiring clients and families to attend meetings on short notices because they forgot to complete a form or do testing when it should have been done. Little consistency in agency personnel providing information or misinformation, timeliness when doing home visits or scheduling meetings. Agency staff need more supervision. Limited service providers in our area limits services. Required drug testing at service provider employees- one of our provider employees was arrested for cocaine use and distribution during the same time she was working with and transporting our son. Need consistent, quality training for service provider employees that work directly with clients. More funding needs to go for client services and less to support to the service provider agencies.

I wish your staff would stay and act like it's a job and its not just a place to get a check. Also I think people doing these jobs need to make more money. My staff who work with {Name} and other staff that work with other clients don't clean clients or have them look like "normal people". They need to work and have tem look even better than regular people due to their disabilities.

I think that the services and supporters should spend more time with my son. He doesn't get much treatment for his problems with the limited time they spend with him.

More activities for ones with disabilities and more concerned workers and staff to work with the ones with disabilities and people having respect instead of workers and people taking care of the ones and acting like they don't know them when they are at stores. Workers and staff is ashamed of working or knowing the disabled or mental retarded. I have seen this in some workers and staff. They take the people with disabilities to stores and then go to the next isle or stay far from them or pretend they don't know the person they are working with. I really think this is awful. If they don't like the job, they don't need to be working with people with disabilities. People like that just want the money and don't have any worries or concerns about the others.

Would like to have one worker at the day program for my son instead of being passed from one to another and I never know who he is going to be with for the time I leave him there.

Our family support at the agency my son is through is poor. The attitude of the lady we have to deal with is negative and she has said very many mean things to me about me asking for help.

11c. Staff Turnover

The only problem I've had is the change of workers. I feel this is because of low wages for their job.

The only area of concern is the turnover of staff for the "social worker." The drawback of this is the rapport between client and worker does not form. There are too many "strangers" in our home for the monthly visits. I feel the visit is spent on history about Dawn and then "looking to the future."

11d. Shortage of Staff

Our day program operates smoothly with never a problem. We have no emergency staff. We have very sub-standard staff on the week-ends, when we can get it.

Also I think if family members need a break or need help due to an emergency they ought to get overtime for staff to stay with the client. A little overtime is not going to bankrupt the agency and if it does then shut the doors.

Agency to offer CPR and first aid for Waiver families while in previous area. This was a problem finding someone to do it each year, not always able to get the same person.

Agency wont' support the staff for services requested by other professionals that takes care of client. We need overtime during week or weekend staff and can't get the agency to provide these services. We have only one staff person and we have no substitute for her when she has a family situation or illness. Staff can't provide any extra service for us when we have a family or medical emergency.

Have been denied access to other agency for Day Program due to lack of staff and case worker load (overload) Would like our current agency to be more creative and innovative in service delivery.

Staff is to be 5 days. I have 2 different workers for the 2 days they work. They could hire more people but they have to be CPR certified, etc. and {Provider} does not offer enough classes so someone can be hired for my daughter!

11f. Pay Staff More

It is very difficult to find, hire and keep good staff due to wages and lifting requirements.

Support staff needs better pay.

The actual workers are not paid enough resulting in a large turnaround and inconsistencies in the services.

Direct care workers need mandated pay increases and a higher starting rate.

One of the problems I see is income for the staff is so low, it is not keeping them with the jobs.

Direct care staff need an increase in wages. People with disabilities have not had the opportunity to progress in their lives because the system doesn't allow it to happen. Even when laws are passed, such as ADA, they are ineffective because there is no money attached.

The staff has frequent turnovers because of the low wages they are paid and they have to buy their own health insurance. The low wages paid makes it very difficult to hire replacement workers. In the eastern panhandle, where we are located, the cost of living is higher than the rest of West Virginia in general. The staff can make as much money, sometimes more, by working at fast food restaurants. With the responsibilities placed upon them, this is pathetic! A pay differential should be set up for this area.

12a. Parents as Paid Staff or CM

Siblings and other family members "living at home" should be able to provide respite without CPR and First Aid - if we feel comfortable - let us choose.

For me to work outside the home, it cost me $10 per hour for a sitter. I only make $8 an hour. I can't seem to get ahead or even break even.

I think support workers or persons familiar to the client (family members, friends, etc.) should be able to receive payment for out-of-home respite services if the family needs to go away for a week-end or emergencies. I am not comfortable with strangers coming into my home to stay with my daughter. She is more comfortable with someone she knows and trusts and likes to stay over at their homes.

{Name} wants to move back home with her family. {Provider} is saying no because they are saying there is no one to take care of her but there are three adults at home to take care of her. She isn't happy where she is. Please let her come home and be with her family. Thank you.

I also feel parents should get paid as much as respite care people do. We as parents spend more time with our children than they do.

13a. Health

She needs more physical therapy and exercise programs. I think her inactivity breeds to her depression.

13d. Social Well-Being

Would like to see more activities with peers that they can attend and get together to participate in.

14a. Satisfied with Respite

Respite is a "Godsend" We could not keep our son at home without it.

The workshop and respite services are a lifesaver. He would probably not be here if not for those two services.

Thanks to our service agency's respite program. My husband and I are able to work and also get a break from difficult times. However, the disabled family member is my son and whether there were any services or money coming in or not. I would never give him up. I raised him as a single working parent for many years without any help from any agencies, as I was not aware of them.

14b. Dissatisfied with Respite

I feel that this area needs a better respite are program.

What we have needed the most for years is almost non-existent – RESPITE

I have a person for respite 2 evenings a week but can never get anyone to come on week-ends, I am a single mother and have no social life and it makes it very depressing and lonely because all my friends and family do not call or come around on week-ends. I love my child and she is my life but I would like to get out for a few hours once in a while on the week-ends. Thank you.

16. Funding and Budget Cuts

Day Hab should be billable when client is hospitalized or out of town or state - most of these are required anyway and not billing causes hardship (loss of needed income) on family. Travel to our of state medical appointments should be billable. Centers should provide CPR and First Aid free of charge as they do other staff. Centers should offer provider's insurance and other benefits given to rest of staff, at same rates. Checks should come same day each month.

The services are a great thing to help families but the money has a cap. Ours is $1000 per family per year. My daughter's bathroom needs to be larger and because I do not have the money to do this it's a project that will be a lot more than $1000. I can't afford to do this. I just do not have the money that it will cost over the $1000 that I can get so this does not help me at all.

Don't understand why my daughter and I can't get a check from the waiver program when my daughter is on the program through the school she goes to.

Also, I have asked numerous times over the years, and to various people how waiver money was spent. I have NEVER been given an answer. I would like to know and have more input on what services and how much.

Regarding question 32, would it be possible to discuss how much money Is being spent on our son through the agency and day program? Thank you.

Q. 17 asked of assistance paying for medication not covered by insurance. Was denied by {Name} when we would not account for how our income was spent. Social Security does not ask that question. Did not feel state had that right. This caused a financial hardship for our family for several months.

It would be nice to know how much money {Agency} gets for my child. They act like anything my child needs comes from their pocket. Thanks!

Taking away parts of the money we get for trying to take care of our children causes fear of us losing them in the future due to lack of funds and Medicaid took away a lot.

It is a full time job taking care of a person with disabilities, but yet the state is cutting hours on Waiver. I think that is wrong.

17a. General Satisfaction with Services and Supports

I am very happy that this program exist. My daughter {Name} is very happy also and that makes me happy. Because of these programs she has a sense of belonging and she doesn't have to feel alone because she is special. I just wish I had known about these programs sooner because just being home is not enough. This program allows her to grow.

The services have helped my boys in many ways. They get to go out a lot more and they are happier. I can get help through family support for things the boys need but through environmental accessibility I have a real hard time getting anything.

I am a single parent who has to work and I am trying to complete my degree in education at the local university. If we did not receive the support services that we do now, I would not be able to work or go to school to complete my degree. I would never want to put my daughter in a group home, so if we did not have these supports, I would have to stay home and take care of her full-time by myself. We only have each other and there is no other family to help out. These services are extremely important to our lives!

I am very satisfied with this program. My daughter loves it and all the workers.

He seems to be contented and satisfied with the activities he is involved in.

The waiver program allows me to work and continue to earn expenses for daily living. If the waiver program ceased, we would live in poverty to the point my child staying in her home where she belongs would be seriously jeopardized.

My wife and I are very pleased with the Program. We are most grateful for the help we receive with our son {Name}. If the {Provider} would go back to five days per week instead of four the Program would be complete.

I feel that MR/DD Agency is great. It really helps us to take trips to different places and the clients really enjoy getting out and doing different things. I'm very grateful to have these services and I hope that we can keep our 1300 in mileage and sometimes, I wish we got more for the hour. Even if I didn't get anything my son would be home with me.

Over all I'm very pleased and thankful that I do have MR/DD agency. My workers are very nice and they are available when I need them. Once again, thanks for the services.

Choice was our service provider and they have been excellent in every way. I filled out questionnaire averaging all the providers we have had over the past years. We appreciate whatever help we can get to enable us to keep our son at home for as long as possible.

Without the program his quality of life, safety, his ability (and opportunity) to engage in some level of economic self sufficiency would be terminated. The absence of strict structure would cause him to lose any current or potential employment opportunity, be easily manipulated by others who might take advantage of him financially, physically or emotionally and cause him such extreme stress and anxiety that he would become reclusive and withdrawn from society. He is dependent on these services for his basic quality of life.

We are pleased with the program. {Name} is an outgoing person, she needs to work and socialize with other people. She takes pride in what she does and what she learns daily. She can not cope without the program. She needs and wants to be like a regular person and we want that for her too, not just to sit around all day and do nothing with her life. She has really matured since she has been going. Everyone needs a purpose, a reason to get up, a goal to achieve. We feel she can be all that she wants to be with the right help and guidance that she receives.

I would do everything I could to keep my family member at home but it would be difficult without the services she receives. She needs full time care and supervision and I have to work and there is no one else to provide her care if we didn't receive these other supports, ie. Respite, res hab and day hab services. It also adds to her quality of life because she has more access to what our community provides.

God bless Title 19 services!

Because of these services, my daughter has survived longer than past doctors thought she would. Because of the help she gets, her health has stabilized and she is happy and does fight. She pushes to do things. Goals are set for her. Without these services, I don't believe she would be where she is currently.

The Title 19 Waiver has been a lifesaver for myself and my loved one. I would not have been able to live in my own home and raise him without it.

{Provider} and its staff has always been helpful whenever there is a questions or problem.

My daughter has her good days and I also believe she looks forward going to school. She likes doing things together. She likes going shopping. She also likes going to church.

We are very happy with the services that we have had and the support from staff has always been helpful.

Very happy and satisfied with services that my sister receives. Thank you.

Without your services and the center's services, my son would not be able to live a close to normal life at home or in the community and wouldn't be able to afford his medications and mental health services be receives greatly to survive.

Since my son has bee in the program, it has helped our whole family to work together with staff and the service he receives.

The services my daughter receives has been a huge help for her needs. The agency has been a huge help in providing the proper services. I would hope that these services continue to help my family.

This program has helped me with the care of my brother since the death of my mother. It's helped him to learn, become more independent and feel he's special too. The center has always been there for me and offered every service available that meets our needs.

I have a son and a nephew at home with me. I get lots of help and support from {Provider}. They are just like family. I can talk to them about anything and they help all they can. I enjoy my boys and wouldn't want to be without them.

{Provider} has done a fantastic job in helping me to be able to keep my son happy and well cared for in my home. They are an excellent organization helping so many of us with disabled children

As a single parent I do not know what I would do without support services.

I think these services provided for my daughter through the {Provider} benefit her greatly. She is excited and looks forward going to the {Provider} and being with her "friends."

If my child didn't receive Title XIX waiver, he would more than likely have to be placed in a nursing home or foster care because he needs supervision 24 hours a day. He is total care. I have another child that is very young and I am a single parent. If my child had to be placed in the nursing home or foster care, it would destroy our family. I'm not sure he could handle it. He's been with me 20 years and has not been away from me much. He, my daughter, and I would not deal with it well at all.

I do not receive in-home assistance. She goes to day treatment and likes it most of the time and likes the staff. She is transported by ban and does not have a problem with transportation. I don't have a value how much is spent through waiver or Medicaid but I do appreciate it very much.

We have been pleased most of the time with support we receive. It has been difficult to get the $1000 that is provided through Environmental accessibility each year. My boys (I have 2) have been helped so much through the goals and workers that are provided.

I am glad my daughter has these services available.

We have {Provider}. I grade them a 110%.

The waiver program has been such a blessing. She is so much happier because she gets out into the community so much. I'm happy because I'm not stressed out from the day by day care. Other people help me because of the program. The service coordinator, Q's. etc., really work well with our family. I couldn’t handle it without all the supports. THANK YOU.

Just started the program and it's working well. Looks good so far and hope that continues in the future. The last 2 months he walks better and talks better in the mornings.

My daughter and myself appreciates and enjoys the services and support that we receive. Many thanks to whom it may concern.

We have a good program for our daughter. We have a good support team and excellent workers. We are very blessed!

My daughter, {Name}, is very precious to us. Her will being and happiness I very important to us. She is 27 years old, has cerebral palsy, mentally impairment and seizure disorder. All her needs are met by us. I thank God every day for the services we receive from the mental health center. Our waiver manager and staff are like our extended family and share our love for {Name}. It's a good feeling to leave for work every day and know that she is happy, safe and OK. This would not be possible without the services we receive and we are very grateful. They truly are our link to life!

I am very pleased and happy to be part of the program. My service is very nice and good and helps me to buy nice things and clothing for the children. Everybody at the school is so nice and kind and lovely. We just love them all. May God bless every one of you and have a blessed day.

I am very pleased and happy to be part of this program. My service is very nice and good. It helps me buy nice things for the children (2 kids). I take them out to dinner and sometimes we go riding. We get to go more and eat better food. I am so happy for the kids and myself.

Families needing support can generally obtain what they need by a simple search of all services available in their area. Many areas give great support by having workshops and opportunity centers that have established programs to benefit all clients and well trained staff member who help to form a strong support group for each client.

17b. General Dissatisfaction with Services and Supports

I feel that agencies want total control and they would like families to disappear. They prefer also that we have as little to do with their plans/programs as possible.

My son needs physical and occupational therapy and snoozblen which he does not receive. He has to pay all dental. We need to relocate to {City}, but cannot because there isn't any accessible housing under $200,000. 00 that will for us. and "Home of your own" will not work for us. There is no transportation to a camp in {City} for a weekend or summer camp. I have had trouble finding respite care providers. There are not matching services for respite. He is still not receiving catheters for intermittent cauterization. It is taking months, just like it took for diapers, which is wrong for people who desperately need supplies and are not going to be potty trained at 30 years old, who has been incontinent from birth! Hello!

Services could be better. I have no phone to call when I need service or staff that could be better and the coordinator needs a little improvement on planning things away from home as well as getting supplies that are needed on time. Staff does the best of their knowledge but never gets the things that were supposed to be provided to help.

There are 4 mental health organizations in {City} that I'm aware of. All of them have a different pay scale and idea on how to deliver waiver services. It is all to line their pockets with money and little about families needs. The other problem is natural family homes are not as validated as group homes. It is very difficult to deal with constant change in workers.

There is a lot that I don't know about out there for my son. He is my special gift from God and I only want the best for him. There is a lot that needs to be changed in your laws and policies, because "one don't fit all". Please feel free to contact me because I think my son is one person you could use as an example of what others may require. He has to have care 24/7 and right now I don't have that because my night person has been taken away. Now I get very little sleep. Gee, thanks to policies!

For 6 years my daughter was on waiver. I have been lied to, promises made and not kept and just treated terribly. I did not know that I had a choice in agencies. The {Provider} messed our whole family up. A nurse supervisor stole my daughters medicine. The case manager told me off and the whole company acted like we were nothing. I never received any good services until I got the WVA involved. I have now been with {Provider} for a month and they are so nice and helping me with things my daughter needs. The {Provider} never told me things that were available for my daughter like {Provider} has done. I wrote a letter when the medicines were stolen and never received any thing back and the nurse is still there.

17c. Access

The family support assistance should be more readily available to persons with disabilities. When we applied for an air conditioner for my son, it took almost a year to receive the money to buy it.

I would like to see services stay as is in the title 10 Waiver Program. Transportation is a big cost to us even though we get reimbursement, we live about 62 miles round trip to the nearest city with shopping places and a move theatre. Our small town has nothing in it except 2 banks, 2 grocery stores and 3 places to eat, which isn't very good and a {store}. Thanks.

My big complaint now is getting diapers etc. for bed time for my daughter. One time it took 4 months for approval. I would hope this could be rectified soon.

I don't understand why we have to travel 25 miles for treatment meetings instead of having them in our own town.

We live in {County} a rural area now. They are taking mileage away so now we get to go hardly anywhere. Can not find any place that will let {Name} workout here. Can not buy proper clothing. Library lets him volunteer his time. We do have {Provider} for family services.

We live in a rural area - not much to do around us - have to drive 45 to 55 minutes for most things. Support help is hard to get because no one wants to come out this far.

My child {Name} has Down Syndrome and is 40 years old. We have NO workshops in this area and the closest one is 50 miles away. My respite family is going through a medical crisis in their own home and cannot do respite for {Name} so I am left without anyone to give me a break. I am 74 years old and only have {Name} at home with me. My question is WHY can't we have a workshop on this side of the mountain? It seems like everything available goes to {City, City, or City}. Now they are hinting that with {Name} not attending a workshop she may not qualify for the Title 19 waiver. It is not my fault we have NO workshop in this area as there is definitely a need. Thank you.

17d. Info Regarding Services/Supports

I don't receive a paper on who else can provide services to our family.

There is a lot that I don't know about out there for my son.

It is difficult to get information regarding planning for the future care of the handicap person when current care givers can no longer do it. It appears such planning is impossible to do.

17e. Need More Services/Supports

I at times need help to get her to day care like when I have to be in the hospital. I am waiting to have my right knee replaced and don’t have anyone to come in the morning to dress her and take her to day care for two or three weeks. We just cannot find anyone to come for an hour in the morning. Need to pay more money on travel to day care and back with the price of gas. It's

24 miles up and back two times a day. If you know anyone that could come for an hour in the morning, let me know. Thanks.

For the services we received, we are thankful. I do with there was more support for brain injuries in WV. This state needs to take a look at other disabilities than MR. Brain injuries is a growing problem and there is really no help for them in getting back to being independent and self reliant.

I think there is a need for assistance in locating qualified respite care providers and also houses for clients in assisted living.

Starting July 1, 2006 Title 19 Waiver clients are going to have rehabilitation hours cut by two hours a day and also travel hours. There my also be other respite services cut. It is terrible that the state will let his happen to families who are just trying to care for their special children and cope with this very demanding life. There are other ways to make cuts in the system. Take a look at the salaries the CEO's of the Healthcare System are receiving.

It is difficult to answer some of these questions as asked. I would like some services not covered in this survey, such as emergency care or service when other family members are ill and as primary care giver I must divide myself to try to take care of my daughter and others.

We need a wellness center in {County} with a handicapped accessible pool and one on one day hab workers for the severely handicapped people. The only mental health provider should not be the one offering day hab services. Day hab should be provided by outside contractors. The workers need paid more money to attract good people instead of having high turnover.

There is nothing in {County} for kids with disabilities to do. They are left out. There is no group for support for TBI. There needs to be more done for kids with TBI or other disabilities.

I appreciate all the help I get. I've put in for some carpet for {Name}, but I didn't get any help. Also, I put in for a turning seat comport to get {Name} in and out of the van, but I didn't receive any help.

17g. General Dissatisfaction with Service Management

There is a new DHP Director at the {Agency}. She seems to be incompetent or inadequate to do the job compared to other directors. For instance, she was at the most recent annual meeting and never verbally spoke. She punched in a question on her palm pilot and had another person ask it, After I discussed a problem with his (my son) bath rooming which has been going on, she asked the worker if she noticed him being wet. The worker said, "no?" I observed that with rubber gloves she probably couldn't tell when he was wet. Nothing else was said by the director, {Name}. It was as though what I said was untrue, and I was dismissed. Also, there is no lift at the building even though one has been approved twice. They won't follow through.

Behavioral management for a severely mentally impaired person is a waste of money. In my son's case, I think a lot of waiver money is wasted on people doing paperwork. There are too many chiefs and not enough Indians. I hate having annual meetings with people who do the paper work, think they know what is best and do not even work with the individual or probably wouldn't know him if they passed him on the street.

The only problem is the environment - the floors and walls are dirty. The inside hasn't been painted for years, there are not protective rails for w/c. The kitchen is so old, there needs to be calm rooms, stimulus rooms, more educational posters, computers. The furniture is mismatched. {Provider's} main offices are great, but the clients are disrespectful of them as people. They know nice things from not nice. It is a shame a CEO can make such big bucks and charge expensive rates but can not give anything back to the people with disabilities.

17h. Waiting List

My child just received a slot on waiver in Sept so we are still learning what is available and how to get that. So far we have not had changes in staff and support but I hear that is very common and hard to deal with at times. This has been a great help to me and our family.

I am thankful for the respite care now given to our daughter but to wait years for it was very hard. Now we are waiting again to try to get our daughter in an apartment with staff. We have been trying for about 2 1/2 years but will be again thankful if it happens.

19. General Concerns

One thing I don't like is all the paper work. Why can't it be one form with 4 or 5 pages with mileage and hours and write s short summary of the entire month? It takes me a good 5 hours if not more to fill out the paper work. When you get used to one they change paper work again.

Also a lot of paperwork and enormous amount of meeting, too much stress on the family, time very valuable in taking care of medical, emotional needs of family member and all the other so called normal activities that families have to do.

I don't understand some of the questions. I hope I answered the questions right. If you need to talk to me and ask any questions.

I don't feel this survey benefits my special needs daughter in any way. It's a waste of time and paper.

All I can {Name} is a very sick girl

I have looked at this for a while before completing. One has to wonder the difference it will make. No one seems to listen. No one seems to care. Decisions are made, input asked for but you tend to proceed as you desire.

Each month 25-27 forms (papers) Why? This only takes time away from my son. Com. Res Hab. Daily Doc. 8 page both sides. Day Hab log 6 pages one side. Transportation log 3 pages one side evaluating narrative 1 page one side DD-12 1 page one side DD-8 1 page one side. 28 this month? Why so much?

In the month of April, 2006 42 pages of documentation was turned into Autism Services. It takes approximately 30 hours a month to do forms. This takes valuable time away from family. Any move to reduce paperwork would be appreciated!.

APPENDIX A

Summary Tables of Survey Responses

Table A - Characteristics of Family Member with a Disability: 2005-06 Data

STATES	Total %		State Avg.	AZ		CA		CT		GA		KY		ME		NC		OK		PA		SC		SD		WA		WV		WY	
Number of surveys																																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Gender:																																	
Male	2,735	**54.8**	**54.1**	162	52.6	386	56.4	137	55.9	351	55.2	47	47.5	126	55.5	111	53.4	236	53.8	551	53.6	131	53.9	46	59.0	264	58.1	157	55.9	30	46.9
Female	2,259	**45.2**	**45.9**	146	47.4	298	43.6	108	44.1	285	44.8	52	52.5	101	44.5	97	46.6	203	46.2	477	46.4	112	46.1	32	41.0	190	41.9	124	44.1	34	53.1
Age:																																	
Mean	33.6		**31.2**	32.3		32.3		33.2		37.3		37.4		33.1		36.2		31		34.5		34.4		33.3		31.2		32.8		29.2	
Range	18-86			18-82		18-83		18-86		18-83		18-68		18-84		19-74		18-84		18-84		18-84		18-65		19-75		18-76		21-58	
Race/Ethnicity* (duplicated counts):																																	
White	3,776	**75.0**	**77.8**	210	68.2	335	48.8	196	77.5	394	61.2	96	92.3	222	94.5	120	56.9	337	77.6	949	92.6	133	54.5	88	95.7	374	83.3	263	92.3	59	93.7
Black	594	**11.8**	**11.8**	19	6.2	14	2.0	23	9.1	239	37.1	7	6.7	1	0.4	82	38.9	44	10.1	34	3.3	106	43.4	0	0.0	13	2.9	11	3.9	1	1.6
Asian	217	**4.3**	**3.0**	3	1	150	21.9	4	1.6	1	0.2	0	0.0	1	0.4	3	1.4	16	3.7	9	0.9	4	1.6	0	0.0	22	4.9	2	0.7	2	3.2
American Indian/ Eskimo/Aleut	136	**2.7**	**2.7**	10	3.2	9	1.3	5	2.0	3	0.5	1	1.0	6	2.6	4	1.9	49	11.3	15	1.5	6	2.5	3	3.3	13	2.9	12	4.2	0	0.0
Hawaiian/Pacific Islander	26	**0.5**	**0.4**	0	0	9	1.3	2	0.8	1	0.2	0	0.0	0	0.0	0	0.0	8	1.8	0	0.0	3	1.2	0	0.0	3	0.7	0	0.0	0	0.0
Hispanic	311	**6.2**	**5.1**	60	19.5	157	22.9	29	11.5	6	0.9	0	0.0	1	0.4	1	0.5	18	4.1	13	1.3	3	1.2	0	0.0	20	4.5	0	0.0	3	4.8
Mixed Races	112	**2.2**	**1.9**	13	4.2	23	3.4	2	0.8	7	1.1	1	1.0	2	0.9	1	0.5	23	5.3	12	1.2	5	2.1	1	1.1	21	4.7	1	0.4	0	0.0
Other/Unknown	33	**0.7**	**0.7**	2	0.7	6	0.9	1	0.4	1	0.2	1	1.0	0	0.0	1	0.5	8	1.8	5	0.5	2	0.8	1	1.1	4	0.9	0	0.0	1	1.6
More than 1 person with DD in household:																																	
Yes	603	**12.0**	**12.4**	48	15.6	57	8.7	30	11.9	69	10.9	16	16.5	31	13.2	39	18.7	50	11.3	131	12.6	33	13.5	13	14.4	56	12.5	27	9.5	3	4.7
No	4,405	**88.0**	**87.6**	260	84.4	601	91.3	223	88.1	565	89.1	81	83.5	203	86.8	170	81.3	394	88.7	910	87.4	211	86.5	77	85.6	393	87.5	256	90.5	61	95.3
	5,008			308		658		253		634		97		234		209		444		1,041		244		90		449		283		64	

Table B - Characteristics of Family Member with a Disability: 2005-06 Data

	Total %		State Avg.	AZ		CA		CT		GA		KY		ME		NC		OK		PA		SC		SD		WA		WV		WY	
Number of surveys																															
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Level of MR:																															
No MR label	210	**4.3**	**4.8**	19	6.4	45	6.7	4	1.7	20	3.2	5	4.8	8	3.6	17	8.5	12	2.8	15	1.5	20	8.7	5	5.6	32	7.4	5	1.9	3	4.8
Mild	906	**18.6**	**18.6**	46	15.4	128	19.1	38	15.7	109	17.5	21	20.0	41	18.6	34	17.1	79	18.4	230	23.0	35	15.2	22	24.7	72	16.6	35	13.4	16	25.4
Moderate	1,639	**33.7**	**32.9**	105	35.1	215	32.1	102	42.1	219	35.2	23	21.9	84	38.2	42	21.1	135	31.5	355	35.4	57	24.7	26	29.2	154	35.5	95	36.3	27	42.9
Severe	868	**17.8**	**18.7**	68	22.7	111	16.6	36	14.9	127	20.4	35	33.3	31	14.1	52	26.1	105	24.5	132	13.2	26	11.3	12	13.5	72	16.6	52	19.8	9	14.3
Profound	357	**7.3**	**7.2**	13	4.3	31	4.6	16	6.6	52	8.3	11	10.5	12	5.5	20	10.1	43	10.0	68	6.8	23	10.0	3	3.4	26	6.0	39	14.9	0	0.0
Don't know	887	**18.2**	**17.8**	48	16.1	139	20.8	46	19.0	96	15.4	10	9.5	44	20.0	34	17.1	55	12.8	202	20.2	70	30.3	21	23.6	78	18.0	36	13.7	8	12.7
	4,867			299		669		242		623		105		220		199		429		1002		231		89		434		262		63	
Other disabilities* (duplicated counts):																															
Mental illness	801	**16.5**	**16.6**	40	13.1	100	14.6	31	13.4	118	20.0	19	19.0	39	18.1	36	18.3	61	14.0	164	16.7	53	22.3	8	8.8	59	13.5	62	22.3	11	17.7
Autism	583	**12.0**	**13.7**	44	14.4	79	11.5	30	13.0	56	9.5	19	19.0	33	15.3	33	16.8	48	11.0	85	8.6	25	10.5	16	17.6	63	14.4	43	15.5	9	14.5
Cerebral Palsy	991	**20.5**	**22.2**	69	22.6	106	15.5	41	17.7	100	16.9	38	41.3	31	14.4	44	22.3	134	30.7	174	17.7	31	13.1	20	22.0	106	24.3	83	29.9	14	22.6
Brain injury	503	**10.4**	**10.5**	43	14.1	68	9.9	17	7.3	52	8.8	10	10.0	18	8.4	13	6.6	64	14.6	85	8.6	35	14.7	9	9.9	47	10.8	36	12.9	6	9.7
Seizure Disorder/ Neurological Disorder	1,434	**29.6**	**30.1**	83	27.2	144	21.0	54	23.4	183	31.0	38	38.0	58	27.0	61	31.0	177	40.5	277	28.2	71	29.8	20	22.0	141	32.3	108	38.8	19	30.6
Chemical dependency	34	**0.7**	**0.7**	2	0.7	1	0.1	2	0.9	4	0.7	0	0.0	0	0.0	0	0.0	4	0.9	4	0.4	5	2.1	0	0.0	2	0.5	10	3.6	0	0.0
Vision or hearing impairments	1231	**25.4**	**25.2**	73	23.9	151	22.0	51	22.1	137	23.2	21	21.0	44	20.5	64	32.5	135	30.9	239	24.3	52	21.8	24	26.4	138	31.7	89	32.0	13	21.0
Physical disability	1376	**28.4**	**28.9**	82	26.9	147	21.4	60	26.0	150	25.4	31	31.0	46	21.4	66	33.5	173	39.7	249	25.3	79	33.2	17	18.7	144	33.0	115	41.4	17	27.4
Communication disorder	1127	**23.2**	**25.4**	75	24.6	138	20.1	50	21.6	116	19.7	40	40.0	50	23.3	56	28.4	127	29.1	157	16.0	54	22.8	13	14.3	130	29.8	103	37.1	18	29.0
Alzeimer's disease	48	**1.0**	**1.2**	2	0.7	6	0.9	3	1.3	4	0.7	3	3.0	0	0.0	2	1.0	4	0.9	7	0.7	4	1.7	0	0.0	6	1.4	6	2.2	1	1.6
Down Syndrome	954	**19.7**	**19.1**	80	26.2	133	19.4	54	23.4	103	17.5	13	13.0	56	26.0	19	9.6	66	15.1	226	23.0	28	11.8	19	20.9	93	21.3	50	18.0	14	22.6
Other disability	831	**17.1**	**17.5**	50	16.4	106	15.5	39	16.9	95	16.1	20	20.0	27	12.6	24	12.2	85	19.5	136	13.8	46	19.4	18	19.8	110	25.2	66	23.7	9	14.5

Table C - Characteristics of Respondents: 2005-06 Data

STATES	Total %		State Avg.	AZ		CA		CT		GA		KY		ME		NC		OK		PA		SC		SD		WA		WV		WY	
Number of surveys	**4,031**																														
Age:																															
	n	**%**	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	**%**	n	%	n	%	n	%	n	**%**
Under 35	209	**4.1**	**4.2**	12	3.9	26	3.8	18	7.0	12	1.9	2	1.9	17	7.3	8	3.8	26	5.9	39	3.7	18	7.3	1	1.1	18	4.0	10	3.5	2	3.1
35 to 54	1,889	**37.3**	**37.8**	116	37.5	247	36.4	93	36.0	200	31.3	29	27.9	90	38.5	77	36.3	190	42.9	371	35.6	104	41.9	42	46.7	172	38.0	138	48.6	20	31.3
55 to 74	2,424	**47.9**	**47.7**	154	49.8	335	49.3	112	43.4	358	56.0	53	51.0	107	45.7	98	46.2	197	44.5	488	46.8	103	41.5	39	43.3	230	50.8	111	39.1	39	60.9
75 and Over	537	**10.6**	**10.3**	27	8.7	71	10.5	35	13.6	69	10.8	20	19.2	20	8.5	29	13.7	30	6.8	144	13.8	23	9.3	8	8.9	33	7.3	25	8.8	3	4.7
	5,059			309		679		258		639		104		234		212		443		1,042		248		90		453		284		64	
Relationship to consumer:																															
Parent	4,279	**85.3**	**86.0**	260	83.3	602	88.8	217	88.2	486	78.9	91	85.0	195	84.4	175	85.8	393	88.5	901	85.9	188	76.4	85	93.4	385	86.1	240	84.8	61	93.8
Sibling	418	**8.3**	**7.5**	20	6.4	51	7.5	19	7.7	76	12.3	9	8.4	20	8.7	11	5.4	29	6.5	95	9.1	28	11.4	4	4.4	30	6.7	25	8.8	1	1.5
Spouse	29	**0.6**	**0.6**	2	0.6	0	0.0	0	0.0	9	1.5	0	0.0	2	0.9	3	1.5	2	0.5	5	0.5	6	2.4	0	0.0	0	0.0	0	0.0	0	0.0
Other	293	**5.8**	**6.0**	30	9.6	25	3.7	10	4.1	45	7.3	7	6.5	14	6.1	15	7.4	20	4.5	48	4.6	24	9.8	2	2.2	32	7.2	18	6.4	3	4.6
	5,019			312		678		246		616		107		231		204		444		1,049		246		91		447		283		65	
Respondent is primary caregiver:																															
Yes	4,818	**96.2**	**95.9**	289	92.9	633	96.2	241	95.6	625	98.3	99	94.3	217	93.5	194	95.1	428	97.1	1011	97.5	238	96.7	88	96.7	415	92.2	277	98.6	63	98.4
Respondent is guardian or conservator:																															
Yes	2,990	**61.2**	**67.1**	187	61.1	303	45.8	204	82.3	331	53.5	67	62.6	182	79.1	156	78.8	285	65.5	514	53.2	143	63.0	64	69.6	278	61.8	222	79.9	54	83.1
Health of respondent:																															
Excellent	914	**18.1**	**18.1**	59	19.3	162	23.9	43	16.6	83	13.1	11	10.4	58	24.8	32	15.4	84	19.0	172	16.5	33	13.6	23	25.3	103	22.9	39	13.8	12	18.5
Good	2,663	**52.8**	**52.3**	158	51.6	342	50.4	137	52.9	357	56.1	50	47.2	115	49.1	113	54.3	237	53.5	558	53.5	99	40.9	43	47.3	252	56.0	161	56.9	41	63.1
Fair	1,259	**25.0**	**25.4**	78	25.5	147	21.6	69	26.6	169	26.6	36	34.0	56	23.9	49	23.6	99	22.3	275	26.4	95	39.3	23	25.3	80	17.8	72	25.4	11	16.9
Poor	209	**4.1**	**4.2**	11	3.6	28	4.1	10	3.9	27	4.2	9	8.5	5	2.1	14	6.7	23	5.2	38	3.6	15	6.2	2	2.2	15	3.3	11	3.9	1	1.5
	5,045			306		679		259		636		106		234		208		443		1,043		242		91		450		283		65	
Household Income																															
Below $15,000	1,192	**28.2**	**28.7**	77	28.3	127	21.6	63	27.9	178	30.7	32	36.0			60	33.7	111	27.9	257	29.6	97	44.1	21	25.9	70	17.2	90	34.9	9	14.8
$15,001-$25,000	957	**22.7**	**21.6**	62	22.8	146	24.9	42	18.6	133	22.9	21	23.6			38	21.3	84	21.1	215	24.8	43	19.5	13	16.0	82	20.2	66	25.6	12	19.7
$25,001-$50,000	1,131	**26.8**	**27.4**	82	30.1	144	24.5	58	25.7	137	23.6	16	18			47	26.4	114	28.6	228	26.3	36	16.4	25	30.9	144	35.5	75	29.1	25	41.0
$50,001-$75,000	587	**13.9**	**14.9**	28	10.3	86	14.7	33	14.6	77	13.3	14	15.7			27	15.2	84	21.1	95	10.9	26	11.8	15	18.5	68	16.7	20	7.8	14	23.0
Over $75,000	357	**8.5**	**7.4**	23	8.5	84	14.3	30	13.3	55	9.5	6	6.7			6	3.4	5	1.3	73	8.4	18	8.2	7	8.6	42	10.3	7	2.7	1	1.6
	4,224			272		587		226		580		89		0		178		398		868		220		81		406		258		61	

Table D - Services and Support Received: 2005-06 Data

STATES	Total %		State Avg.	AZ		CA		CT		GA		KY		ME		NC		OK		PA		SC		SD		WA		WV		WY	
	n	%	n = 14	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Financial support	1,793	**39.2**	**38.7**	82	28.7	212	34.3	101	43.5	157	26.9	40	41.7	92	44.0	69	38.3	159	39.8	434	45.3	82	36.3	28	33.7	206	53.1	107	41.8	24	41.4
In-home support	1,647	**33.6**	**35.5**	130	43.2	176	26.9	51	20.0	99	16.2	59	56.7	58	25.6	97	47.1	315	72.4	269	26.5	73	29.8	18	20.7	125	29.1	155	56.6	22	35.5
Out-of-home respite care	1,508	**30.8**	**30.7**	135	44.4	181	27.4	62	24.9	126	20.7	51	50.5	57	25.2	81	38.8	80	18.9	314	31.1	60	24.6	19	21.8	194	44.2	112	40.6	36	57.1
Day/employment supports	3,417	**68.8**	**69.5**	220	71.4	457	69.1	193	76.6	543	85.8	82	78.1	183	82.1	136	65.4	191	44.2	722	70.4	152	61.8	80	87.9	213	48.9	196	69.3	49	79.0
Transportation	3,014	**60.4**	**62.1**	179	58.1	419	62.4	163	65.2	485	76.4	64	61.0	167	75.9	107	51.0	195	45.0	628	60.9	156	62.7	61	67.0	165	37.9	189	66.8	36	57.1
Other	1,291	**26.7**	**29.6**	100	33.6	119	18.1	40	16.2	124	20.3	55	53.9	70	32.1	45	23.2	158	36.8	246	24.8	60	25.0	36	42.9	90	20.8	114	41.8	34	54.0

Table E1 - Information and Planning: 2005-06 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	GA	KY	ME	NC	OK	PA	SC	SD	WA	WV	WY
Q1 - Do you receive information about the services and supports that are available to your family?																
Number of surveys	4,826	n = 14	306	655	245	604	104	221	199	401	997	239	90	427	275	63
% always or usually	**42.2**	**40.8**	43.5	62.7	33.5	31.5	44.2	35.7	27.1	41.9	44.6	38.5	42.2	34.0	44.7	47.6
% sometimes	**37.8**	**39.1**	36.9	30.5	45.7	35.6	35.6	45.2	45.2	36.4	38.5	35.1	40.0	40.5	38.9	42.9
% seldom or never	**20.0**	**20.1**	19.6	6.7	20.8	32.9	20.2	19.0	27.6	21.7	16.9	26.4	17.8	25.5	16.4	9.5
Q2 - If you receive information, is it easy to understand?																
Number of surveys	4,402	n = 14	280	627	229	508	94	192	178	372	920	215	83	384	260	60
% always or usually	**55.0**	**52.6**	56.1	73.0	47.2	50.0	44.7	55.2	40.4	50.0	56.5	54.4	65.1	50.8	49.2	43.3
% sometimes	**38.4**	**40.5**	37.1	24.2	44.5	38.4	45.7	40.6	50.0	41.7	39.5	36.7	30.1	41.4	43.5	53.3
% seldom or never	**6.6**	**6.9**	6.8	2.7	8.3	11.6	9.6	4.2	9.6	8.3	4.0	8.8	4.8	7.8	7.3	3.3
Q3 - Do you get enough information to help you participate in planning services for your family?																
Number of surveys	4,535	n = 14	286	620	236	562	97	208	184	401	922	219	84	385	268	63
% always or usually	**49.7**	**49.9**	49.0	60.2	39.0	40.0	50.5	63.9	46.7	49.6	51.5	49.3	50.0	39.5	53.7	55.6
% sometimes	**31.3**	**31.5**	30.1	31.0	33.1	27.9	32.0	26.0	32.6	32.2	31.7	29.2	33.3	36.1	32.5	33.3
% seldom or never	**19.1**	**18.6**	21.0	8.9	28.0	32.0	17.5	10.1	20.7	18.2	16.8	21.5	16.7	24.4	13.8	11.1
Q4 - If your family member has a service plan, did you help develop the plan?																
Number of surveys	3,905	n = 14	256	519	159	476	91	204	154	369	780	200	79	304	251	63
% always or usually	**72.5**	**73.6**	73.4	72.4	61.6	60.1	72.5	72.1	77.3	81.0	73.8	65.0	78.5	75.7	79.3	87.3
% sometimes	**17.6**	**17.5**	18.8	18.1	22.6	26.3	18.7	16.2	17.5	12.5	15.4	22.0	17.7	12.8	15.5	11.1
% seldom or never	**9.9**	**8.9**	7.8	9.4	15.7	13.7	8.8	11.8	5.2	6.5	10.8	13.0	3.8	11.5	5.2	1.6
Q5 - If your family member has a service plan, does the plan include things that are important to you?																
Number of surveys	3,926	n = 14	256	497	164	481	92	209	163	372	788	200	79	301	260	64
% always or usually	**67.8**	**68.0**	69.9	71.8	57.3	56.5	63.0	76.6	68.1	73.1	70.1	58.5	72.2	66.1	71.2	78.1
% sometimes	**25.2**	**25.4**	24.6	23.5	32.3	32.4	32.6	20.1	25.8	21.2	23.2	29.5	25.3	24.6	24.2	15.6
% seldom or never	**6.9**	**6.6**	5.5	4.6	10.4	11.0	4.3	3.3	6.1	5.6	6.7	12.0	2.5	9.3	4.6	6.3

Table E2 - Information and Planning: 2005-06 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	GA	KY	ME	NC	OK	PA	SC	SD	WA	WV	WY
Q6 - Do the staff who assist you with planning help you figure out what you need as a family to support your family member?																
Number of surveys	4,235	n = 14	266	625	197	515	93	207	169	379	830	208	81	330	272	63
% always or usually	**57.6**	**57.0**	54.9	59.0	55.3	47.0	57.0	65.2	56.2	63.1	62.8	55.8	48.1	50.6	62.5	60.3
% sometimes	**27.8**	**28.9**	28.2	28.2	26.9	31.5	31.2	21.7	31.4	25.9	23.6	32.2	30.9	31.5	26.8	34.9
% seldom or never	**14.6**	**14.1**	16.9	12.8	17.8	21.6	11.8	13.0	12.4	11.1	13.6	12.0	21.0	17.9	10.7	4.8
Q7 - Do the staff who assist you with planning respect your choices and opinions?																
Number of surveys	4,284	n = 14	277	619	197	518	97	212	173	382	843	216	84	331	272	63
% always or usually	**76.4**	**75.4**	74.4	84.3	70.1	66.6	70.1	82.1	77.5	81.2	78.8	74.5	78.6	75.2	70.6	71.4
% sometimes	**18.4**	**19.8**	19.9	14.4	22.8	23.0	26.8	13.2	18.5	15.4	16.3	18.1	17.9	17.5	24.6	28.6
% seldom or never	**5.2**	**4.9**	5.8	1.3	7.1	10.4	3.1	4.7	4.0	3.4	5.0	7.4	3.6	7.3	4.8	0.0
Q8 - Are the staff who help you with planning generally respectful and courteous?																
Number of surveys	4,443	n = 14	281	660	207	536	101	211	178	393	874	225	87	350	276	64
% always or usually	**88.8**	**87.9**	86.8	94.4	84.5	81.7	78.2	91.9	91.6	89.1	90.8	88.0	87.4	90.6	85.5	90.6
% sometimes	**8.9**	**9.9**	12.5	4.8	10.6	12.5	19.8	6.2	6.7	7.6	7.3	9.3	11.5	7.1	13.4	9.4
% seldom or never	**2.3**	**2.1**	0.7	0.8	4.8	5.8	2.0	1.9	1.7	3.3	1.8	2.7	1.1	2.3	1.1	0.0
Q9 - Are the staff who assist you with planning generally effective?																
Number of surveys	4,336	n = 14	274	640	194	523	100	212	173	395	853	220	83	336	269	64
% always or usually	**66.1**	**64.7**	64.2	75.3	61.9	53.9	62.0	71.7	68.2	69.9	69.4	64.1	60.2	63.7	60.6	60.9
% sometimes	**27.6**	**28.9**	29.9	21.9	28.9	33.7	30.0	24.1	26.6	25.1	25.6	25.9	34.9	28.9	33.8	35.9
% seldom or never	**6.3**	**6.3**	5.8	2.8	9.3	12.4	8.0	4.2	5.2	5.1	5.0	10.0	4.8	7.4	5.6	3.1
Q10 - Can you contact the staff who assist you with planning whenever you want to?																
Number of surveys	4,430	n = 14	281	653	203	537	103	213	176	392	875	223	84	352	275	63
% always or usually	**75.7**	**76.4**	69.0	77.0	71.4	71.3	77.7	81.7	78.4	78.3	79.2	79.4	81.0	67.3	73.1	84.1
% sometimes	**19.8**	**19.3**	25.3	20.1	21.2	21.4	16.5	16.0	17.0	17.3	17.6	14.8	16.7	25.0	24.7	15.9
% seldom or never	**4.5**	**4.4**	5.7	2.9	7.4	7.3	5.8	2.3	4.5	4.3	3.2	5.8	2.4	7.7	2.2	0.0

Table F1 - Access and Delivery of Services and Supports: 2005-06 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	GA	KY	ME	NC	OK	PA	SC	SD	WA	WV	WY
Q11 - When you ask the service/support coordinator for assistance, does he/she help you get what you need?																
Number of surveys	4,515	n = 14	281	631	201	562	104	203	180	389	912	233	86	394	276	63
% always or usually	**67.6**	**67.5**	65.8	72.3	57.7	60.5	70.2	71.9	64.4	72.0	69.2	66.5	75.6	68.0	65.6	65.1
% sometimes	**26.2**	**26.8**	27.4	23.3	32.8	29.0	23.1	24.1	32.2	23.4	25.4	24.9	22.1	23.6	31.2	33.3
% seldom or never	**6.2**	**5.7**	6.8	4.4	9.5	10.5	6.7	3.9	3.3	4.6	5.4	8.6	2.3	8.4	3.3	1.6
Q12 - Does your family get the services and supports you need?																
Number of surveys	4,576	n = 14	281	611	224	580	105	211	185	392	931	232	86	400	276	62
% always or usually	**57.0**	**56.4**	63.3	63.8	42.4	49.5	55.2	59.7	53.0	59.7	60.2	52.6	58.1	53.3	57.6	61.3
% sometimes	**33.2**	**34.1**	28.5	28.5	39.3	36.2	34.3	34.1	35.7	33.7	30.7	35.8	36.0	36.3	35.5	32.3
% seldom or never	**9.8**	**9.5**	8.2	7.7	18.3	14.3	10.5	6.2	11.4	6.6	9.1	11.6	5.8	10.5	6.9	6.5
Q13 - Do the services and supports offered meet your family's needs?																
Number of surveys	4,545	n = 14	279	611	212	563	104	211	186	410	932	233	85	387	271	61
% always or usually	**54.6**	**54.3**	58.1	63.5	39.2	47.4	51.0	56.4	53.8	57.6	55.6	51.1	60.0	47.8	60.1	59.0
% sometimes	**36.5**	**37.1**	35.5	31.8	41.0	38.4	39.4	36.0	38.7	36.1	35.6	38.6	36.5	41.6	32.5	37.7
% seldom or never	**9.0**	**8.6**	6.5	4.7	19.8	14.2	9.6	7.6	7.5	6.3	8.8	10.3	3.5	10.6	7.4	3.3
Q14 - Are supports available when your family needs them?																
Number of surveys	4,345	n = 14	267	569	203	523	103	206	186	406	891	224	81	359	267	60
% always or usually	**51.5**	**51.4**	49.4	61.5	40.9	44.9	50.5	52.9	53.8	51.5	53.4	48.7	58.0	44.8	53.2	56.7
% sometimes	**38.1**	**38.7**	42.3	33.0	36.9	39.4	41.7	39.3	36.6	41.9	35.6	41.1	37.0	41.5	37.5	38.3
% seldom or never	**10.4**	**9.8**	8.2	5.4	22.2	15.7	7.8	7.8	9.7	6.7	11.0	10.3	4.9	13.6	9.4	5.0
Q15 - Do families in your area request that different types of services and supports be made available in your area?																
Number of surveys	1,741	n = 14	92	158	87	255	57	72	92	157	344	111	34	141	116	25
% always or usually	**40.1**	**41.7**	37.0	29.1	35.6	46.3	49.1	38.9	42.4	39.5	35.8	44.1	55.9	41.8	44.8	44.0
% sometimes	**38.2**	**38.7**	43.5	36.1	41.4	32.9	35.1	43.1	37.0	40.8	41.3	29.7	35.3	39.7	37.9	48.0
% seldom or never	**21.7**	**19.6**	19.6	34.8	23.0	20.8	15.8	18.1	20.7	19.7	23.0	26.1	8.8	18.4	17.2	8.0
Q16 - If yes, does either the state agency or provider agency respond to their requests?																
Number of surveys	1,489	n = 14	88	166	94	221	45	56	74	132	265	93	27	103	101	24
% always or usually	**38.3**	**37.1**	43.2	66.3	39.4	30.8	28.9	30.4	36.5	31.8	37.0	29.0	44.4	31.1	41.6	29.2
% sometimes	**40.6**	**42.5**	43.2	27.1	36.2	38.9	53.3	57.1	44.6	50.0	40.0	38.7	44.4	45.6	34.7	41.7
% seldom or never	**21.2**	**20.4**	13.6	6.6	24.5	30.3	17.8	12.5	18.9	18.2	23.0	32.3	11.1	23.3	23.8	29.2
Q17 - If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?																
Number of surveys	2,340	n = 14	156	272	100	313	68	111	121	227	436	139	37	188	148	24
% always or usually	**54.7**	**56.7**	50.6	57.0	42.0	54.0	58.8	59.5	60.3	52.0	56.0	51.1	75.7	50.5	55.4	70.8
% sometimes	**19.4**	**19.8**	23.1	15.4	21.0	21.4	26.5	16.2	23.1	21.1	16.7	21.6	13.5	17.0	20.3	20.8
% seldom or never	**26.0**	**23.5**	26.3	27.6	37.0	24.6	14.7	24.3	16.5	26.9	27.3	27.3	10.8	32.4	24.3	8.3
Q18 - If English is not your first language, are there support workers or translators available to speak with you in your preferred language?																
Number of surveys	600	n = 14	48	219	33	60	7	16	19	36	69	36	2	34	20	1
% always or usually	**77.3**	**66.5**	79.2	88.1	66.7	73.3	85.7	62.5	63.2	66.7	68.1	69.4	50.0	73.5	85.0	0.0
% sometimes	**12.3**	**14.5**	16.7	7.8	6.1	15.0	0.0	12.5	26.3	22.2	17.4	13.9	50.0	14.7	0.0	0.0
% seldom or never	**10.3**	**19.0**	4.2	4.1	27.3	11.7	14.3	25.0	10.5	11.1	14.5	16.7	0.0	11.8	15.0	100.0

Table F2 - Access and Delivery of Services and Supports: 2005-06 Data (Cont'd)

STATES	TOTAL AVG.	STATE AVG.	AZ	CA	CT	GA	KY	ME	NC	OK	PA	SC	SD	WA	WV	WY
Q19 - If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?																
Number of surveys	801	n = 14	64	166	29	97	20	35	31	68	127	43	8	51	53	9
% always or usually	**56.6**	**53.6**	57.8	72.3	44.8	57.7	45.0	48.6	54.8	51.5	48.0	60.5	62.5	51.0	50.9	44.4
% sometimes	**25.1**	**26.3**	32.8	16.3	31.0	25.8	40.0	25.7	25.8	23.5	31.5	18.6	25.0	21.6	28.3	22.2
% seldom or never	**18.4**	**20.1**	9.4	11.4	24.1	16.5	15.0	25.7	19.4	25.0	20.5	20.9	12.5	27.5	20.8	33.3
Q20 - Does your family member have access to the special equipment or accommodations that he/she needs?																
Number of surveys	1,961	n = 14	120	200	68	251	54	87	97	236	348	116	33	165	161	25
% always or usually	**63.0**	**64.1**	64.2	55.5	58.8	64.1	57.4	65.5	55.7	65.3	66.1	64.7	63.6	59.4	64.6	92.0
% sometimes	**21.1**	**20.5**	24.2	17.0	22.1	21.1	27.8	16.1	30.9	24.6	20.1	13.8	21.2	20.0	24.2	4.0
% seldom or never	**15.9**	**15.4**	11.7	27.5	19.1	14.7	14.8	18.4	13.4	10.2	13.8	21.6	15.2	20.6	11.2	4.0
Q21 - Do you have access to health services for your family member?																
Number of surveys	4,719	n = 14	298	610	232	585	100	226	201	420	968	237	89	421	270	62
% always or usually	**89.7**	**90.0**	92.3	90.3	84.5	87.7	87.0	93.8	96.0	87.1	90.2	89.9	93.3	88.6	89.6	90.3
% sometimes	**7.7**	**7.8**	6.4	5.4	10.3	7.5	8.0	5.8	3.5	11.2	7.6	8.0	6.7	9.3	9.6	9.7
% seldom or never	**2.6**	**2.2**	1.3	4.3	5.2	4.8	5.0	0.4	0.5	1.7	2.2	2.1	0.0	2.1	0.7	0.0
Q22 - Do you have access to dental services for your family member?																
Number of surveys	4,569	n = 14	269	615	228	575	102	211	196	387	934	229	91	413	259	60
% always or usually	**76.3**	**76.6**	54.3	82.9	70.6	73.4	82.4	77.3	85.2	66.4	79.8	77.3	94.5	77.7	77.6	73.3
% sometimes	**9.7**	**9.5**	11.2	9.1	9.6	9.2	8.8	9.0	9.2	10.3	8.6	8.3	4.4	14.3	10.4	10.0
% seldom or never	**14.1**	**13.9**	34.6	8.0	19.7	17.4	8.8	13.7	5.6	23.3	11.7	14.4	1.1	8.0	12.0	16.7
Q23 - Do you have access to necessary medications for your family member?																
Number of surveys	4,703	n = 14	292	615	219	595	103	214	204	420	964	239	85	418	271	64
% always or usually	**92.6**	**93.1**	93.2	89.3	93.2	92.1	86.4	96.7	97.5	89.8	92.9	92.1	96.5	94.0	95.2	93.8
% sometimes	**5.3**	**5.0**	5.1	7.0	3.7	4.7	9.7	2.3	2.0	8.8	4.7	6.3	3.5	5.7	3.7	3.1
% seldom or never	**2.1**	**1.9**	1.7	3.7	3.2	3.2	3.9	0.9	0.5	1.4	2.4	1.7	0.0	0.2	1.1	3.1
Q24 - Are frequent changes in support staff a problem for your family?																
Number of surveys	3,885	n = 14	259	475	177	495	92	167	164	353	803	192	76	327	248	57
% always or usually	**21.1**	**21.1**	28.6	19.6	20.9	22.4	23.9	16.8	19.5	20.1	17.9	23.4	14.5	18.7	32.7	15.8
% sometimes	**39.3**	**41.5**	39.0	36.8	43.5	33.9	51.1	37.1	48.8	38.2	39.4	35.4	39.5	40.1	41.9	56.1
% seldom or never	**39.6**	**37.5**	32.4	43.6	35.6	43.6	25.0	46.1	31.7	41.6	42.7	41.1	46.1	41.3	25.4	28.1
Q25 - Do you feel that your family member's day/employment setting is a healthy and safe environment?																
Number of surveys	3,926	n = 14	242	533	220	549	84	202	161	297	817	190	85	264	222	60
% always or usually	**82.8**	**81.9**	82.6	84.4	82.7	82.7	75.0	85.6	83.2	83.2	83.6	71.6	78.8	89.0	78.8	85.0
% sometimes	**14.5**	**15.3**	14.9	13.5	14.1	13.5	19.0	11.9	14.3	14.5	14.3	23.7	18.8	10.2	17.6	13.3
% seldom or never	**2.7**	**2.9**	2.5	2.1	3.2	3.8	6.0	2.5	2.5	2.4	2.1	4.7	2.4	0.8	3.6	1.7
Q26 - Are support staff generally respectful and courteous?																
Number of surveys	4,616	n = 14	295	629	213	605	101	216	195	400	955	235	90	346	276	60
% always or usually	**89.0**	**87.8**	87.5	92.8	90.1	87.3	80.2	89.4	88.7	88.8	90.4	84.7	84.4	91.3	86.6	86.7
% sometimes	**9.8**	**11.1**	11.5	6.4	8.0	11.2	17.8	9.3	11.3	11.0	8.2	12.8	14.4	7.2	13.4	13.3
% seldom or never	**1.1**	**1.1**	1.0	0.8	1.9	1.5	2.0	1.4	0.0	0.3	1.5	2.6	1.1	1.4	0.0	0.0

Table G - Choices and Control: 2005-06 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	GA	KY	ME	NC	OK	PA	SC	SD	WA	WV	WY
Q27 - Do you or your family member choose the agencies or providers that work with your family?																
Number of surveys	4,094	n = 14	271	514	203	491	92	188	175	397	836	194	76	338	255	64
% always or usually	**59.5**	**62.9**	63.1	56.2	50.7	49.1	83.7	62.2	72.6	80.6	51.0	50.5	50.0	58.6	69.4	82.8
% sometimes	**18.7**	**17.4**	18.8	18.5	19.2	19.1	7.6	18.1	16.6	12.3	23.3	20.1	23.7	20.1	15.3	10.9
% seldom or never	**21.9**	**19.7**	18.1	25.3	30.0	31.8	8.7	19.7	10.9	7.1	25.7	29.4	26.3	21.3	15.3	6.3
Q28 - Do you or your family member choose the support workers that work with your family?																
Number of surveys	3,862	n = 14	258	457	183	493	94	183	168	380	798	179	75	285	246	63
% always or usually	**40.1**	**41.6**	43.8	37.0	32.2	27.0	44.7	32.2	51.8	69.5	32.2	40.8	25.3	43.9	46.7	55.6
% sometimes	**20.2**	**21.1**	19.0	20.4	20.2	16.0	28.7	26.8	27.4	16.1	21.3	18.4	18.7	20.7	20.7	20.6
% seldom or never	**39.6**	**37.3**	37.2	42.7	47.5	57.0	26.6	41.0	20.8	14.5	46.5	40.8	56.0	35.4	32.5	23.8
Q29 - If your family member gets day or employment services, does the agency providing these services involve you in important decisions?																
Number of surveys	3,383	n = 14	200	435	191	486	66	178	147	230	709	159	85	243	201	53
% always or usually	**68.7**	**69.3**	70.0	61.8	68.1	65.4	69.7	79.2	68.0	67.0	72.9	64.8	70.6	67.5	71.1	73.6
% sometimes	**21.3**	**21.7**	24.0	23.7	20.4	23.5	21.2	14.6	22.4	20.0	18.5	23.3	23.5	22.6	21.4	24.5
% seldom or never	**10.0**	**9.0**	6.0	14.5	11.5	11.1	9.1	6.2	9.5	13.0	8.6	11.9	5.9	9.9	7.5	1.9
Q30 - Do you or your family member have control and/or input over the hiring and management of your support workers?																
Number of surveys	3,186	n = 14	211	370	146	405	77	155	143	334	633	146	62	245	209	50
% always or usually	**37.4**	**36.3**	37.4	40.0	26.7	15.6	31.2	31.6	46.2	69.8	30.2	36.3	11.3	53.5	44.0	34.0
% sometimes	**14.8**	**15.4**	15.2	17.0	8.9	10.6	23.4	14.2	22.4	14.1	14.1	15.1	14.5	14.3	18.2	14.0
% seldom or never	**47.8**	**48.3**	47.4	43.0	64.4	73.8	45.5	54.2	31.5	16.2	55.8	48.6	74.2	32.2	37.8	52.0
Q31 - Do you or your family member want to have control and/or input over the hiring and management of your support workers?																
Number of surveys	3,173	n = 14	202	351	142	401	77	146	149	338	618	146	57	278	219	49
% always or usually	**56.6**	**56.9**	62.9	54.4	52.8	37.2	58.4	55.5	69.1	78.4	47.6	56.2	40.4	68.7	67.6	46.9
% sometimes	**24.2**	**25.2**	24.3	22.5	28.2	25.9	26.0	24.0	22.8	15.7	27.0	26.0	29.8	21.2	25.1	34.7
% seldom or never	**19.2**	**17.9**	12.9	23.1	19.0	36.9	15.6	20.5	8.1	5.9	25.4	17.8	29.8	10.1	7.3	18.4
Q32 - Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?																
Number of surveys	4,595	n = 14	286	631	231	573	97	210	194	399	939	217	83	406	266	63
% always or usually	**21.0**	**21.6**	14.3	10.5	19.9	7.5	15.5	13.8	21.6	39.8	33.5	13.4	6.0	21.7	16.2	68.3
% sometimes	**9.6**	**9.6**	12.2	5.4	10.4	4.5	15.5	9.5	10.3	18.3	12.4	2.8	4.8	9.1	10.2	9.5
% seldom/never/don't know	**69.4**	**68.8**	73.4	84.2	69.7	88.0	69.1	76.7	68.0	41.9	54.1	83.9	89.2	69.2	73.7	22.2
Q33 - Do you or your family member get to decide how this money is spent?																
Number of surveys	3,155	n = 14	184	314	153	436	72	145	144	305	707	137	56	264	188	50
% always or usually	**38.2**	**36.2**	27.7	33.1	39.2	27.1	23.6	33.8	38.2	57.4	46.5	32.8	7.1	41.3	28.7	70.0
% sometimes	**18.9**	**18.5**	15.2	17.2	21.6	9.2	26.4	17.9	24.3	22.0	23.9	15.3	7.1	18.9	21.3	18.0
% seldom or never	**42.9**	**45.4**	57.1	49.7	39.2	63.8	50.0	48.3	37.5	20.7	29.6	51.8	85.7	39.8	50.0	12.0

Table H - Community Connections: 2005-06 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	GA	KY	ME	NC	OK	PA	SC	SD	WA	WV	WY
Q34 - If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?																
Number of surveys	3,001	n = 14	188	353	154	397	72	145	136	262	598	143	62	255	192	44
% always or usually	**30.9**	**30.4**	22.3	36.3	25.3	24.4	27.8	36.6	25.0	40.1	32.6	34.3	38.7	25.1	34.4	22.7
% sometimes	**26.9**	**29.0**	26.6	28.6	22.1	21.9	26.4	28.3	38.2	27.5	27.4	24.5	33.9	22.4	27.6	50.0
% seldom or never	**42.2**	**40.7**	51.1	35.1	52.6	53.7	45.8	35.2	36.8	32.4	40.0	41.3	27.4	52.5	38.0	27.3
Q35 - If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?																
Number of surveys	2,965	n = 14	182	318	138	381	76	135	136	271	604	153	53	255	223	40
% always or usually	**32.5**	**31.2**	30.2	40.3	21.7	17.8	26.3	30.4	26.5	42.1	34.9	33.3	24.5	34.1	44.4	30.0
% sometimes	**22.3**	**23.1**	18.7	24.8	15.9	16.8	17.1	25.2	35.3	24.0	21.5	25.5	28.3	18.8	26.9	25.0
% seldom or never	**45.2**	**45.7**	51.1	34.9	62.3	65.4	56.6	44.4	38.2	33.9	43.5	41.2	47.2	47.1	28.7	45.0
Q36 - Do you feel that your family member has access to community activities?																
Number of surveys	4,295	n = 14	266	528	216	538	93	208	177	379	896	191	88	381	269	65
% always or usually	**48.3**	**48.8**	46.2	48.1	37.0	45.5	50.5	55.8	40.7	54.4	48.1	38.2	50.0	48.6	59.9	60.0
% sometimes	**34.6**	**34.7**	37.6	33.9	35.2	36.2	31.2	29.8	42.4	33.5	35.4	40.8	37.5	31.8	27.9	32.3
% seldom or never	**17.0**	**16.5**	16.2	18.0	27.8	18.2	18.3	14.4	16.9	12.1	16.5	20.9	12.5	19.7	12.3	7.7
Q37 - Does your family member participate in community activities?																
Number of surveys	4,478	n = 14	287	574	215	572	91	212	183	383	928	207	90	402	270	64
% always or usually	**30.1**	**31.6**	29.6	21.4	20.5	31.1	39.6	37.3	24.0	35.2	30.7	24.6	32.2	28.6	42.6	45.3
% sometimes	**38.7**	**40.0**	42.5	39.2	39.5	42.1	38.5	34.4	45.9	37.9	35.7	38.6	44.4	34.1	39.6	46.9
% seldom or never	**31.2**	**28.4**	27.9	39.4	40.0	26.7	22.0	28.3	30.1	26.9	33.6	36.7	23.3	37.3	17.8	7.8

Table I - Satisfaction with Services and Outcomes: 2005-06 Data

STATES	TOTAL %	STATE AVG.	AZ	CA	CT	GA	KY	ME	NC	OK	PA	SC	SD	WA	WV	WY
Q38 - Overall, are you satisfied with the services and supports your family member currently receives?																
Number of surveys	4,790	n = 14	303	633	226	610	103	223	199	427	974	239	88	420	280	65
% always or usually	**65.1**	**64.2**	64.7	78.2	50.4	55.9	64.1	69.1	61.3	68.4	67.5	61.1	69.3	57.6	67.1	64.6
% sometimes	**28.6**	**29.3**	31.0	19.0	38.1	34.9	28.2	24.7	31.2	26.2	26.0	29.3	27.3	35.2	29.6	29.2
% seldom or never	**6.4**	**6.5**	4.3	2.8	11.5	9.2	7.8	6.3	7.5	5.4	6.6	9.6	3.4	7.1	3.2	6.2
Q39 - Are your familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?																
Number of surveys	4,461	n = 14	276	597	206	559	95	203	179	410	910	222	82	396	265	61
% always or usually	**45.7**	**47.2**	43.8	47.1	30.6	35.6	49.5	50.2	51.4	62.9	45.6	39.6	61.0	40.2	50.2	52.5
% sometimes	**11.7**	**12.1**	12.0	11.2	13.6	7.9	22.1	10.3	11.7	11.5	13.0	10.8	9.8	13.4	10.9	11.5
% seldom/never/don't know	**42.6**	**40.7**	44.2	41.7	55.8	56.5	28.4	39.4	36.9	25.6	41.4	49.5	29.3	46.5	38.9	36.1
Q40 - Are you satisfied with the way complaints/grievances are handled and resolved?																
Number of surveys	2,272	n = 14	126	274	88	321	59	109	114	229	435	131	48	158	147	33
% always or usually	**57.8**	**55.0**	54.8	71.2	39.8	47.7	57.6	63.3	47.4	69.0	60.0	55.7	58.3	55.7	59.2	30.3
% sometimes	**28.8**	**31.2**	31.7	21.2	31.8	35.5	32.2	23.9	39.5	22.3	26.7	31.3	31.3	27.8	26.5	54.5
% seldom or never	**13.4**	**13.9**	13.5	7.7	28.4	16.8	10.2	12.8	13.2	8.7	13.3	13.0	10.4	16.5	14.3	15.2
Q41 - Do you feel that services and supports have made a positive difference in the life of your family?																
Number of surveys	4,641	n = 14	290	608	214	588	104	211	190	419	953	232	84	410	274	64
% always or usually	**70.1**	**70.2**	73.1	73.2	58.4	64.8	72.1	68.2	76.8	78.3	69.4	64.7	71.4	67.1	75.5	70.3
% sometimes	**24.6**	**24.8**	23.8	21.5	30.4	28.4	25.0	27.0	19.5	19.6	24.7	27.6	25.0	27.1	22.3	25.0
% seldom or never	**5.3**	**5.0**	3.1	5.3	11.2	6.8	2.9	4.7	3.7	2.1	6.0	7.8	3.6	5.9	2.2	4.7
Q42 - Have services made a difference in helping keep your family member at home?																
Number of surveys	4,159	n = 14	275	518	192	498	97	191	173	401	833	214	76	382	251	58
% always or usually	**76.5**	**77.0**	79.3	76.4	66.7	71.7	80.4	69.1	82.7	83.8	75.2	75.2	78.9	75.9	84.9	77.6
% sometimes	**14.4**	**14.9**	16.0	13.1	22.4	15.9	14.4	15.7	13.9	12.0	13.6	15.0	17.1	15.4	9.6	13.8
% seldom or never	**9.1**	**8.2**	4.7	10.4	10.9	12.4	5.2	15.2	3.5	4.2	11.3	9.8	3.9	8.6	5.6	8.6
Q43 - Would your family member still be at home if you did not receive any services?																
Number of surveys	3,525	n = 14	220	441	156	469	66	165	140	318	727	186	73	296	215	53
% always or usually	**82.3**	**80.3**	80.5	84.6	82.7	88.1	65.2	78.8	70.0	80.2	85.6	81.7	87.7	76.0	81.9	81.1
% sometimes	**5.5**	**6.4**	5.0	6.3	3.8	3.2	12.1	6.1	9.3	7.2	4.3	7.0	6.8	4.7	5.6	7.5
% seldom or never	**12.3**	**13.4**	14.5	9.1	13.5	8.7	22.7	15.2	20.7	12.6	10.2	11.3	5.5	19.3	12.6	11.3
Q44 - Overall, do you feel that your family member is happy?																
Number of surveys	4,905	n = 14	306	650	242	618	104	218	202	433	1,013	244	91	441	278	65
% always or usually	**83.8**	**84.1**	87.6	82.5	79.3	81.6	85.6	86.2	77.2	88.9	84.2	77.0	89.0	82.8	89.6	86.2
% sometimes	**15.0**	**14.8**	11.8	16.2	17.8	16.7	12.5	13.8	21.3	10.4	14.3	20.9	11.0	16.6	10.1	13.8
% seldom or never	**1.2**	**1.1**	0.7	1.4	2.9	1.8	1.9	0.0	1.5	0.7	1.5	2.0	0.0	0.7	0.4	0.0