

Family Guardian Survey

Final Report – April 2008
2006-2007 Data



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

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Organization of Report

Nine states conducted the National Core Indicators (NCI) Family Guardian Survey during the 2006-2007 project year and submitted their data. The Family Guardian Survey was administered to individuals having an adult family member with disabilities living outside of the family's home. This Final Report provides a summary of results, based on the data submitted by September 2007.

This report is organized as follows:

I. INTRODUCTION

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

II. FAMILY GUARDIAN SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

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

IV. RESULTS

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

I. Introduction

Overview of National Core Indicators

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

Phase I of CIP 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 back to participating states.

During Phase II (1999-2000), 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 (see below) participated in Phase II, and this data is considered baseline project data. In Phase III (2000-2001), additional states joined the effort and the project expanded its scope to include services for children with developmental disabilities and their families.

In 2002, the Core Indicators Project changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. And between 2002 and 2007, the NCI effort continued to expand. The following figure summarizes state participation in the National Core Indicators since its inception through the 2006-2007 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	Phase IX 2006-2007
AZ	AZ	AZ	AL	AL	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	AR	AR
MO	KY	DE	CA - RCOC	CA - RCOC	CA - RCOC	CA-RCOC	AZ	AZ
NE	MA	IA	CT	CT	CT	CT	CA-RCOC	CA-RCOC
PA	MN	KY	DE	DE	DE	DE	CT	CT
VT	NE	MA	HI	HI	DC	DC	DE	DE
VA	NC	MN	IL	IN	HI	HI	DC	GA
	PA	MT	IN	IA	IN	KY	GA	HI
	RI	NE	IA	KY	KY	MA	HI	IN
	VT	NC	KY	MA	MA	ME	KY	KY
	VA	PA	MA	ME	ME	NC	MA	MA
	WA	RI	NE	NE	NE	OK	ME	ME
		UT	NC	NC	NC	PA	NM	NM
		VT	OK	OK	ND	RI	NC	NC
		WA	PA	PA	OK	SC	OK	OK
			RI	RI	PA	VT	PA	PA
			UT	SC	RI	WA	RI	RI
			VT	SD	SC	WV	SC	SC
			WA	VT	SD	WY	SD	TX
			WV	WA	VT		TX	VT
			WY	WV	WA		VT	WA
				WY	WV		WA	WV
					WY		WV	WY
							WY	

Denotes first year of participation in NCI.

Family Indicators

Getting direct feedback from families is an important way for states to gauge service and support satisfaction, as well as pinpoint areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to compare changes in performance over time, as well as compare its own performance against that of 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 surveys 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.** The structure of each family survey follows this framework.

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

II. Family Guardian Survey

Background

This report focuses on the Family Guardian Survey.

The Family Guardian Survey was developed and first utilized during Phase II of the Core Indicators Project (1999-2000), in response to various states' interest in finding out whether family members of individuals with disabilities were involved in their family members' lives, whether they were supported in their efforts to be involved, and their level of satisfaction with how the service system was meeting the needs of their family member with disabilities. In this effort, seven states administered the Family Guardian Survey.

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 outside of the family household and (2) the individual 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.

Between 2001 and 2007, seven to ten states have participated each year. Response rates within states have varied greatly, between 23% - 81%, yet each year, NCI has had between 2,800 – 5,000 completed surveys available for analysis.

State Participation

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

Table 3 State Participation in NCI Family Guardian Survey (Adults Living Out-of-Home)								
Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003	Phase VI 2003-2004	Phase VII 2004-2005	Phase VIII 2005-2006	Phase IX 2006-2007
NA	CT KY MN NE PA VA WA	AZ DE MA MN NC PA RI	CA-RCOC HI NE NC PA UT WA	AZ CA-RCOC HI IN MA NC PA SC SD WY	AZ CA-RCOC CT ME NC ND PA SC WA WY	AZ CA-RCOC CT HI PA SC WY	CA-RCOC CT GA ME NC PA SC SD WA WY	AZ CT DE GA HI ME NM PA WY

Survey Instrument

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

The Family Guardian Survey used in 2006-2007 not only asks families to express their overall level of satisfaction with services and supports their family member receives, it also probes specific aspects of the service system's capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; satisfaction and outcomes. Combined, this information provides an overall picture of family satisfaction within and across states.

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

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

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

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

III. Methods

Sampling & Administration

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

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

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

Response Rates

During 2006-2007, nine states administered the Family Guardian Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis. The desired response rate (the percentage of surveys returned versus the number mailed) is 40%.

Table 4 Family Guardian Survey - State Response Rates				
State	Surveys Mailed	Surveys Returned	Response Rate	Usable Surveys
Arizona	1,000	237	24%	171
Connecticut	1,200	331	28%	319
Delaware	768	284	37%	275
Georgia	1,669	583	35%	545
Hawaii	191	154	81%	139
Maine	922	421	46%	420
New Mexico	1,013	431	43%	424
Pennsylvania	2,760	1,320	48%	1,243
Wyoming	815	325	40%	255
Overall	10,338	4,086	42%	3,791
* denotes data missing				

Table 4 shows the response rates by state, based on the number of returned surveys entered into the database and submitted for analysis, compared to the total number mailed out.

Data Analysis

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

IV. Results

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

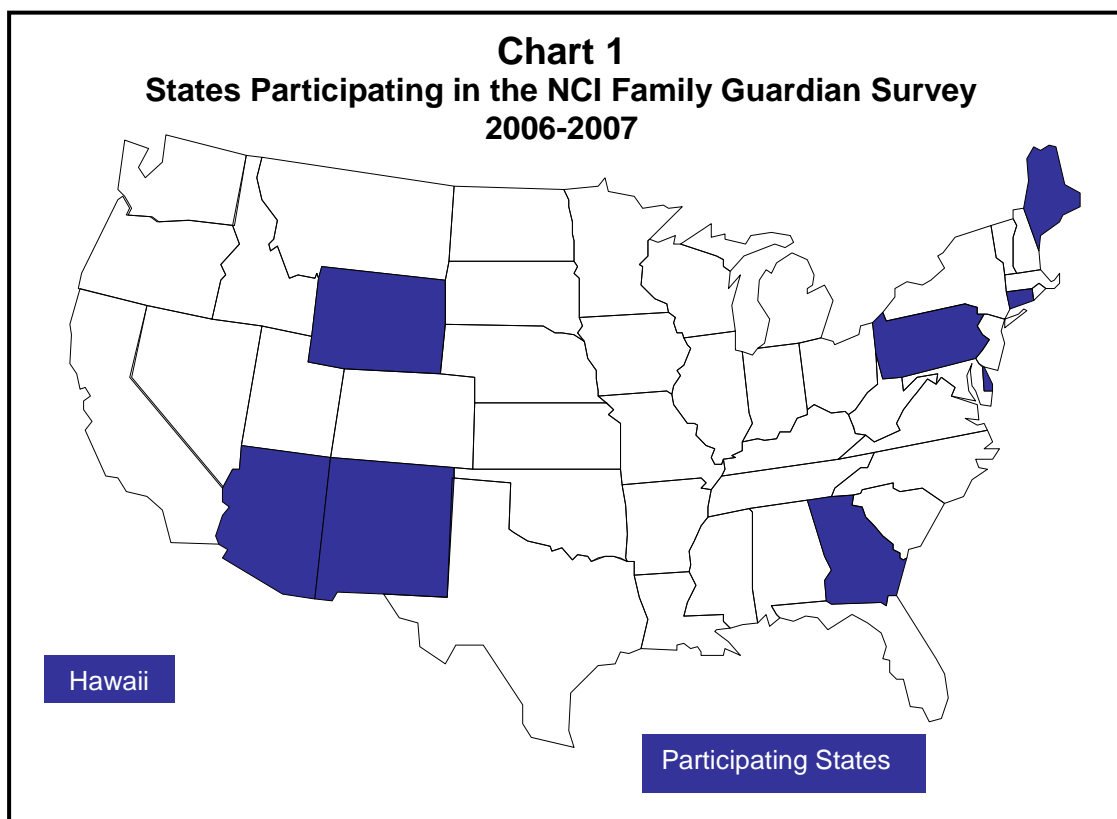
Please note that the TABLES provide individuals state results and result averages that are calculated through two separate methods:

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

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

Participating States

- ◆ Nine states provided data sets to be included in the Final Report. They include Arizona, Connecticut, Delaware, Georgia, Hawaii, Maine, New Mexico, Pennsylvania, and Wyoming.



Characteristics of Family Members with Disabilities

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

- On average, across the states, over half (55%) of the family members with disabilities lived in group home settings. 13% lived in adult foster care or host family homes, 11% lived in their own homes or apartments, 11% in specialized facilities, 5% lived in agency-owned apartments, 1% in nursing homes, and 4% in a variety of other settings.
- On average, 55% of family members were male across the participating states. The remaining 45% were female.
- Across states, the average age of family members with disabilities was 44.4, with a range in age from 18 to 94.
- On average, 77% of the family members were White, 7% were Asian, 6% were Hispanic, 5% were Black/ African American, 5% were American Indian/Alaska Native, 3% were Mixed Races, 2% were Native Hawaiian/Pacific Islander, and less than 1% marked Other or Unknown. (In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.)
- On average, over one-third (37%) of the family members with disabilities had a diagnosis of severe or profound mental retardation. Additionally, 29% were individuals with moderate mental retardation, 14% had mild mental retardation, and 3% had no mental retardation diagnosis. Additionally, 17% of respondents were unsure of their family member's diagnosis.
- In addition to mental retardation, many family members experience other disabilities as well (e.g., seizure disorder, cerebral palsy, physical disability, communication disorder). The most prevalent additional disabilities included: seizure disorders/neurological problems (30%), physical disabilities (27%), vision or hearing impairments (23%), mental illness (22%), communication disorders (21%), and cerebral palsy (17%).

Type of Residence

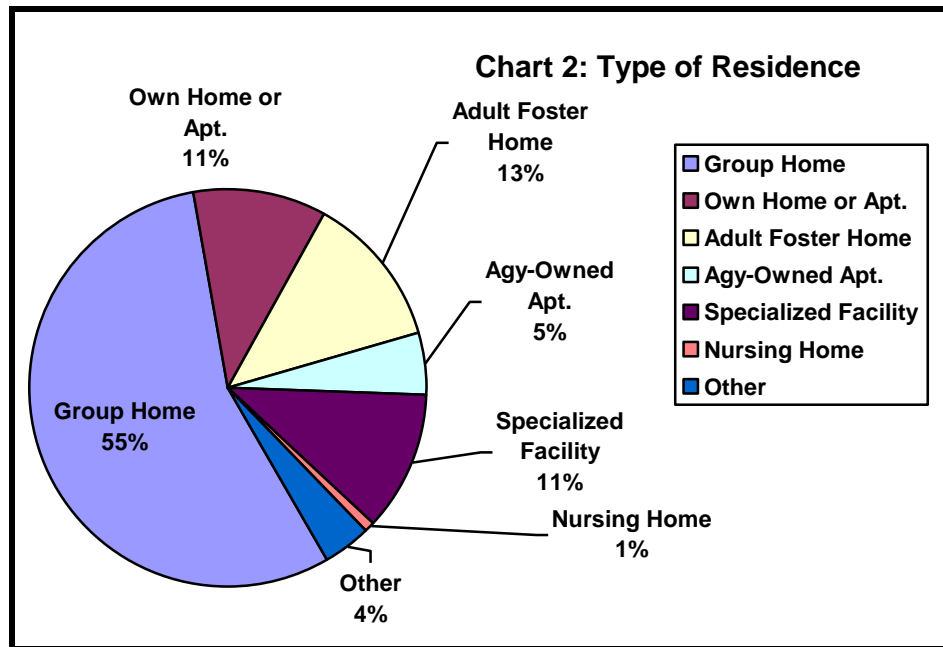


Table 5
Type of Residence in Which Family Member Lives

State	Specialized MR Facility	Group Home	Agy-Owned Apartment	Own Home/ Apartment	Adult Foster Care/ Host Family	Nursing Home	Other
AZ	13.1	66.1	2.4	7.1	6.5	1.2	3.6
CT	18.9	67.6	2.7	8.1	0.0	0.0	2.7
DE	10.5	67.8	7.1	3.4	9.4	0.0	1.9
GA	5.3	48.6	7.9	22.4	8.1	0.9	6.8
HI	6.3	27.6	2.4	7.1	53.5	1.6	1.6
ME	14.4	62.4	3.2	4.7	10.2	1.7	3.2
NM	6.7	51.3	7.0	19.7	8.6	0.2	6.5
PA	18.2	54.8	2.9	10.5	5.1	3.9	4.7
WY	9.1	64.7	6.7	10.7	6.0	0.0	2.8
Total n	424	1,908	163	408	301	65	154
Total %	12.4	55.7	4.8	11.9	8.8	1.9	4.5
State Avg. %	11.2	55.6	5.0	10.8	12.6	1.0	3.8

Gender of Family Member

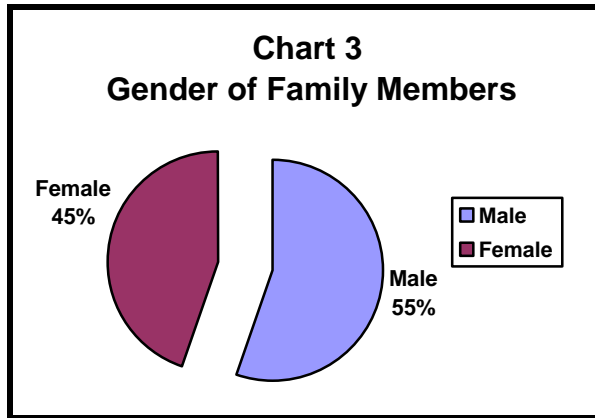


Table 6
Gender

State	% Male	% Female
AZ	54.7	45.3
CT	51.4	48.6
DE	53.9	46.1
GA	60.7	39.3
HI	53.2	46.8
ME	53.7	46.3
NM	57.8	42.3
PA	56.4	43.6
WY	56.1	43.9
Total n	1,908	1,470
Total %	56.5	43.5
State Avg. %	55.3	44.7

Age of Family Member

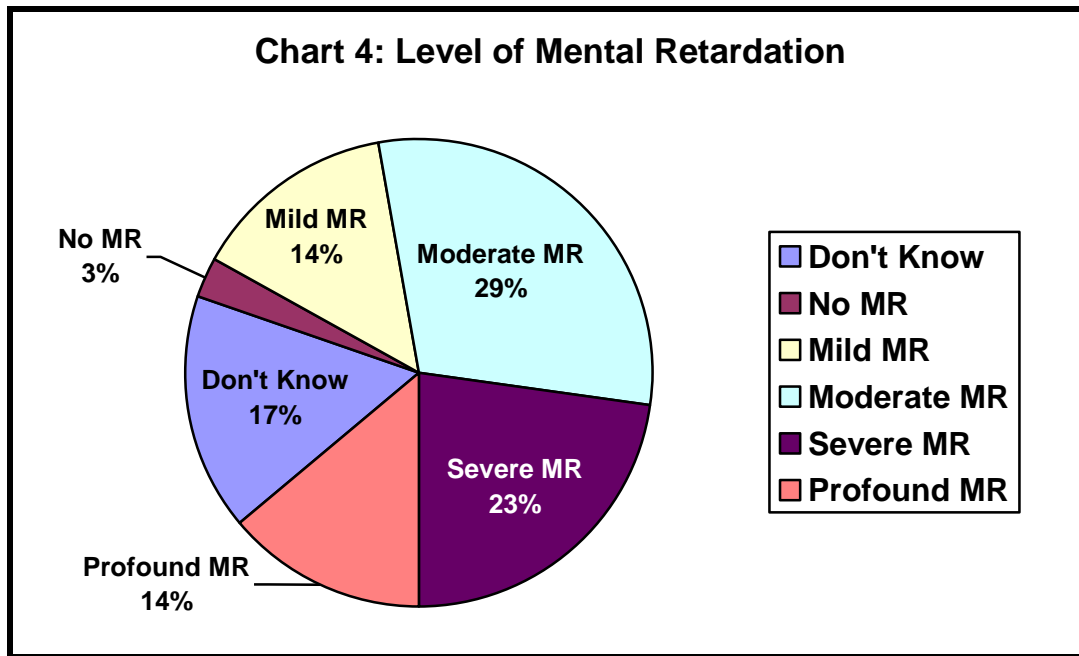
Table 7
Age of Family Member

State	Average Age	Range
AZ	44.2	18-82
CT	45.2	18-89
DE	45.1	18-92
GA	43.0	18-86
HI	43.8	18-85
ME	46.6	18-86
NM	43.6	18-94
PA	47.1	19-86
WY	40.9	21-84
Total n	3,659	
Total Avg.	45.1	18-94
State Avg.	44.4	

Race/Ethnicity of Family Member

Table 8 Race/Ethnicity of Family Member (%)								
State	White	Black/ African American	Asian	Amer. Indian/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
AZ	71.5	3.0	1.8	12.7	0.0	2.4	0.6	12.1
CT	93.1	4.6	0.3	1.3	0.0	1.0	1.0	2.6
DE	89.1	10.1	0.0	1.6	0.0	0.4	0.0	0.4
GA	75.0	23.3	0.4	0.6	0.0	1.3	0.2	0.9
HI	28.9	2.3	57.8	3.9	17.2	14.1	0.8	2.3
ME	97.3	0.2	0.0	1.4	0.0	1.0	0.0	0.2
NM	55.1	1.9	1.4	14.5	0.2	3.6	0.0	30.2
PA	96.5	1.9	0.2	0.6	0.0	0.3	0.1	0.7
WY	88.4	1.2	0.8	4.8	0.0	3.6	0.4	4.4
Total n	3,102	210	91	122	23	65	8	183
Total %	84.0	5.7	2.5	3.3	0.6	1.8	0.2	5.0
State Avg. %	77.2	5.4	7.0	4.6	1.9	3.1	0.3	6.0

Level of Mental Retardation of Family Member



**Table 9
Level of Mental Retardation of Family Member**

State	No MR Diagnosis	Mild MR	Moderate MR	Severe MR	Profound MR	Don't Know
AZ	4.2	12.7	33.3	24.2	13.3	12.1
CT	1.7	13.1	29.8	24.9	16.6	13.8
DE	3.6	10.0	31.9	21.9	10.8	21.9
GA	2.9	19.3	29.1	21.6	11.5	15.5
HI	2.4	7.3	27.4	27.4	15.3	20.2
ME	2.0	12.1	28.5	21.0	20.2	16.2
NM	4.3	16.2	25.4	20.3	16.4	17.4
PA	1.9	15.8	26.4	20.2	14.8	20.9
WY	2.4	18.6	39.9	22.5	6.3	10.3
Total n	94	545	1,043	780	518	634
Total %	2.6	15.1	28.9	21.6	14.3	17.5
State Avg. %	2.8	13.9	30.2	22.7	13.9	16.5

Other Disabilities of Family Member

Table 10A Other Disabilities of Family Member						
State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
AZ	24.5	12.3	19.0	10.4	26.4	1.2
CT	15.7	17.8	18.5	7.0	26.5	0.7
DE	16.6	17.8	14.6	7.1	29.6	0.4
GA	25.9	11.7	12.3	12.5	25.0	0.6
HI	15.4	12.0	17.1	7.7	28.2	2.6
ME	23.6	14.7	21.0	10.2	35.4	1.6
NM	28.6	10.2	20.9	14.7	34.8	0.7
PA	24.1	8.2	17.1	10.6	29.2	0.9
WY	26.2	6.0	15.3	12.5	33.1	0.8
Total n	835	401	608	384	1,059	33
Total %	23.5	11.3	17.1	10.8	29.8	0.9
State Avg. %	22.3	12.3	17.3	10.3	29.8	1.1

Table 10B Other Disabilities of Family Member						
State	Vision/ Hearing Impairment	Physical Disability	Communi- cation Disorder	Alzheimer's Disease	Down Syndrome	Other Disability
AZ	23.3	22.7	17.8	1.2	8.0	20.2
CT	22.0	23.0	18.8	1.7	18.5	14.6
DE	21.7	26.1	19.0	1.6	13.0	12.6
GA	19.8	23.9	19.4	0.2	11.2	11.7
HI	22.2	23.9	20.5	1.7	18.8	17.1
ME	24.1	34.9	26.8	2.4	12.6	14.2
NM	25.6	29.9	29.1	1.2	7.2	22.9
PA	24.4	27.7	18.5	0.9	11.6	13.9
WY	26.6	31.5	23.0	0.0	13.3	15.7
Total n	834	979	752	39	426	537
Total %	23.5	27.5	21.1	1.1	12.0	15.1
State Avg. %	23.3	27.1	21.4	1.2	12.7	15.9

Characteristics of Respondents

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

- Across states, most respondents (61%) fell between the ages of 55 and 74. One-fourth (25%) of respondents were 35 to 54, and 12% were 75 years old or over.
- Three-fifths of respondents were parents of adult children with disabilities (58%). Twenty-four percent (24%) were siblings, less than 1% were spouses, and the remaining 17% had other relationships to the individual.
- On average, half (51%) of respondents indicated they saw their family member more than twelve times per year (e.g., once a month or more). Others visited with their family members less frequently: 18% saw their family member 7 to 12 times per year, 15% visited their family member four to six times per year, 12% saw their family member one to three times per year, and the remaining 3% less than once per year.
- On average, 76% of respondents indicated that they were their family member's legal guardian or conservator. In Maine and Wyoming, nearly all respondents served as their family member's guardian, while in Georgia and Pennsylvania, fewer than half of respondents held this role.

Age of Respondent

State	Under 35	35-54	55-74	75 or Older
AZ	6.2	39.8	46.0	8.1
CT	1.3	18.4	53.2	27.1
DE	0.0	18.0	60.5	21.4
GA	1.5	22.7	60.8	15.0
HI	0.0	14.7	58.1	27.1
ME	1.2	23.0	57.6	18.2
NM	1.9	29.5	51.3	17.3
PA	1.5	21.5	54.3	22.8
WY	2.8	24.7	60.6	12.0
Total n	60	855	2,076	727
Total %	1.6	23.0	55.8	19.6
State Avg. %	1.8	23.6	55.8	18.8

Relationship of Respondent to Individual with Disabilities

Table 12 Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
AZ	42.1	20.1	0.0	37.8
CT	63.0	24.4	0.3	12.2
DE	61.6	25.0	0.4	13.1
GA	61.8	22.7	0.0	15.5
HI	69.2	19.2	0.0	11.5
ME	56.0	29.7	0.0	14.3
NM	55.8	23.0	0.0	21.1
PA	56.3	37.2	0.2	6.3
WY	57.8	18.3	0.4	23.5
Total n	2,140	1,040	5	513
Total %	57.9	28.1	0.1	13.9
State Avg. %	58.2	24.4	0.1	17.3

Frequency of Visits between Respondent and Individual with Disabilities

Table 13 Frequency of Visits with Family Member					
State	Less than once/year	1-3 times/year	4-6 times/year	7-12 times/year	More than 12x/year
AZ	1.2	10.9	20.0	11.5	56.4
CT	0.0	10.8	21.6	5.4	62.2
DE	6.7	10.7	14.1	13.7	54.8
GA	2.0	6.9	10.6	11.7	68.8
HI	3.9	19.5	14.8	61.7	0.0
ME	2.2	9.4	17.1	18.6	52.8
NM	5.0	13.8	11.7	13.1	56.4
PA	6.6	13.8	13.3	12.3	53.9
WY	4.3	16.1	11.8	14.9	52.9
Total n	158	420	468	521	1,885
Total %	4.6	12.2	13.6	15.1	54.6
State Avg. %	3.5	12.4	15.0	18.1	50.9

Respondent's Role as Guardian or Conservator

Table 14 Respondent is Legal Guardian or Conservator		
State	% Yes	% No
AZ	80.4	19.6
CT	88.2	11.8
DE	62.7	37.3
GA	40.0	60.0
HI	93.9	6.1
ME	100.0	0.0
NM	76.5	23.5
PA	46.9	53.1
WY	98.8	1.2
Total n	2,425	1,201
Total %	66.9	33.1
State Avg. %	76.4	23.6

Services and Supports Received

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

Table 15 Services and Supports Received (%)				
State	Residential supports	Day/ Employment supports	Transportation	Other
AZ	97.0	82.2	86.7	69.7
CT	98.6	92.2	97.4	75.6
DE	98.9	89.1	96.2	65.0
GA	88.2	82.4	93.4	53.6
HI	98.6	88.1	92.5	67.8
ME	97.8	79.9	97.6	83.2
NM	98.1	84.9	94.1	94.1
PA	95.3	73.7	87.4	71.1
WY	98.4	92.2	98.0	85.9
Total n	3,473	2,872	3,323	2,354
Total Avg. %	95.8	81.8	92.5	73.7
State Avg. %	96.8	85.0	93.7	74.0

National Core Indicators

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

For each question, a Figure and Table is provided.

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

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

Information and Planning

- On average, three-fourths of respondents (76%) stated that they got enough information to help them participate in planning.
- About two-thirds of respondents (66%), on average, indicated that they typically helped to develop their family member's service plan.
- On average across states, four-fifths (79%) of respondents surveyed indicated that their family member's service plan included things that were important to them. 17% stated this was only true some of the time, while the remaining 3% stated the service plan seldom included things important to the respondent.
- Across states, nearly all (92%) felt that planning staff were generally respectful and courteous.
- Across states, approximately three-fourths (76%) felt that planning staff were generally effective.
- Across states, 85% felt they were able to contact planning staff when needed.

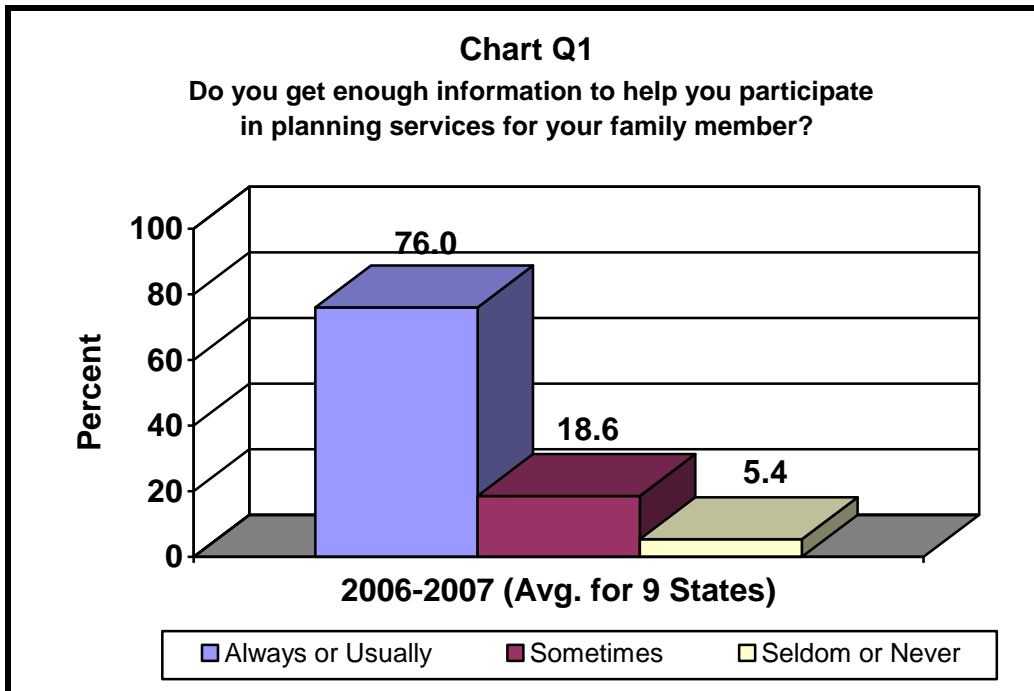


Table Q1
Do you get enough information to help you participate in planning services for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		78.4	18.5	3.1	162
CT	↑	82.7	13.7	3.5	284
DE		71.6	25.3	3.1	257
GA	↓↓	54.9	30.9	14.1	517
HI	↑	82.4	13.0	4.6	131
ME	↑↑	90.1	8.9	1.0	404
NM	↓	68.6	22.3	9.2	404
PA	↓	69.2	21.9	8.9	1,089
WY	↑	85.9	12.9	1.2	248
Total %		72.8	20.2	7.0	3,496
State Average %		76.0	18.6	5.4	9

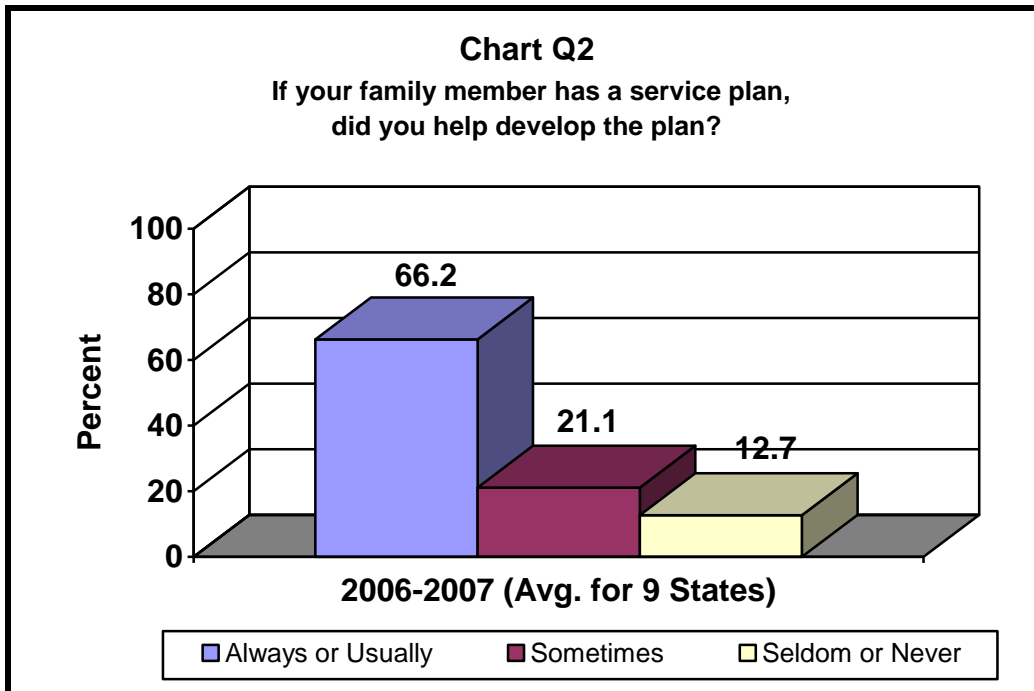


Table Q2
If your family member has a service plan, did you help develop the plan?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑↑	78.4	15.0	6.5	153
CT	↓	60.7	27.5	11.8	262
DE		65.8	21.9	12.3	219
GA	↓↓	54.5	23.7	21.8	435
HI		70.7	19.0	10.3	116
ME	↑	72.3	19.1	8.6	382
NM		65.8	20.1	14.2	374
PA	↓↓	47.3	26.1	26.6	930
WY	↑↑	80.2	17.8	2.1	242
Total %		61.0	22.6	16.5	3,113
State Average %		66.2	21.1	12.7	9

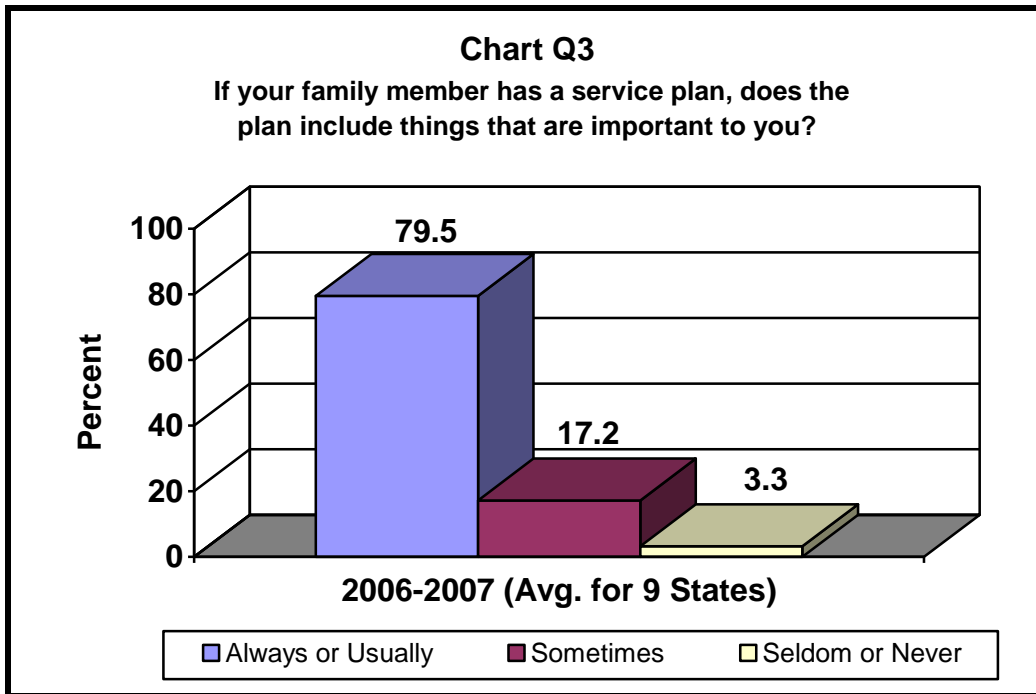


Table Q3
If your family member has a service plan, does the plan include things that are important to you?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		81.9	16.1	1.9	155
CT		79.8	17.6	2.7	262
DE		81.5	16.7	1.9	216
GA	↓↓↓	64.4	26.8	8.8	421
HI	↑	84.9	14.3	0.8	119
ME	↑	86.8	12.5	0.8	400
NM		76.7	17.2	6.2	373
PA	↓	72.9	21.5	5.5	924
WY	↑	86.9	12.2	0.8	245
Total %		77.2	18.6	4.2	3,115
State Average %		79.5	17.2	3.3	9

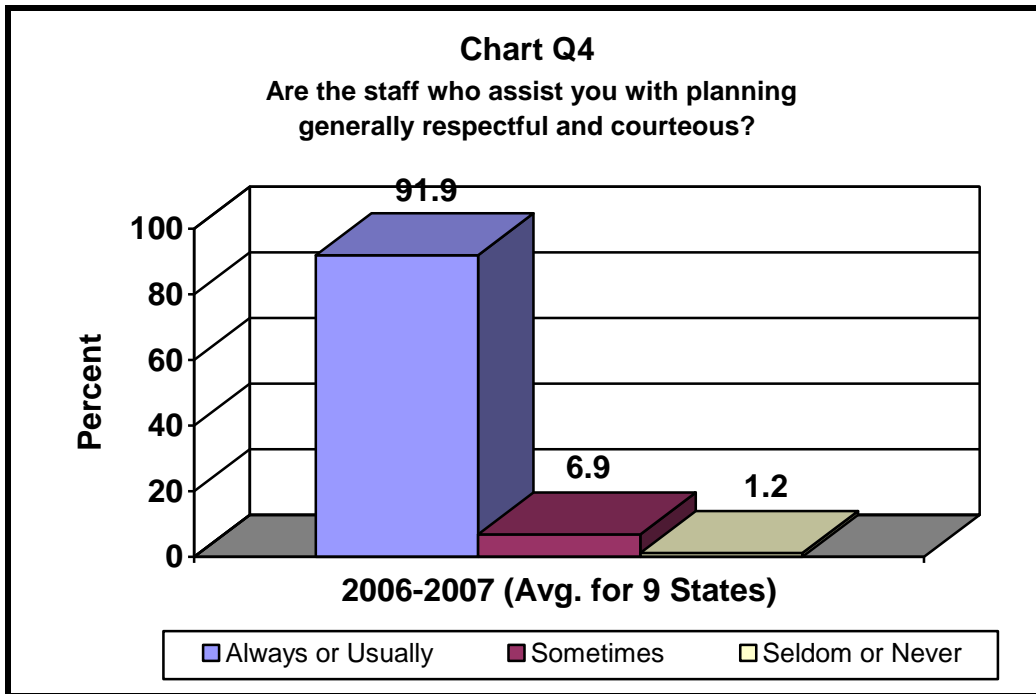


Table Q4
Are the staff who assist you with planning generally respectful and courteous?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	89.8	9.6	0.6	166
CT	95.3	4.4	0.4	274
DE	94.7	4.9	0.4	246
GA	88.4	8.5	3.1	482
HI	92.1	6.3	1.6	126
ME	96.8	2.9	0.2	408
NM	↓ 86.4	11.1	2.5	396
PA	90.4	8.1	1.6	1,016
WY	93.5	6.0	0.4	248
Total %	91.4	7.2	1.4	3,362
State Average %	91.9	6.9	1.2	9

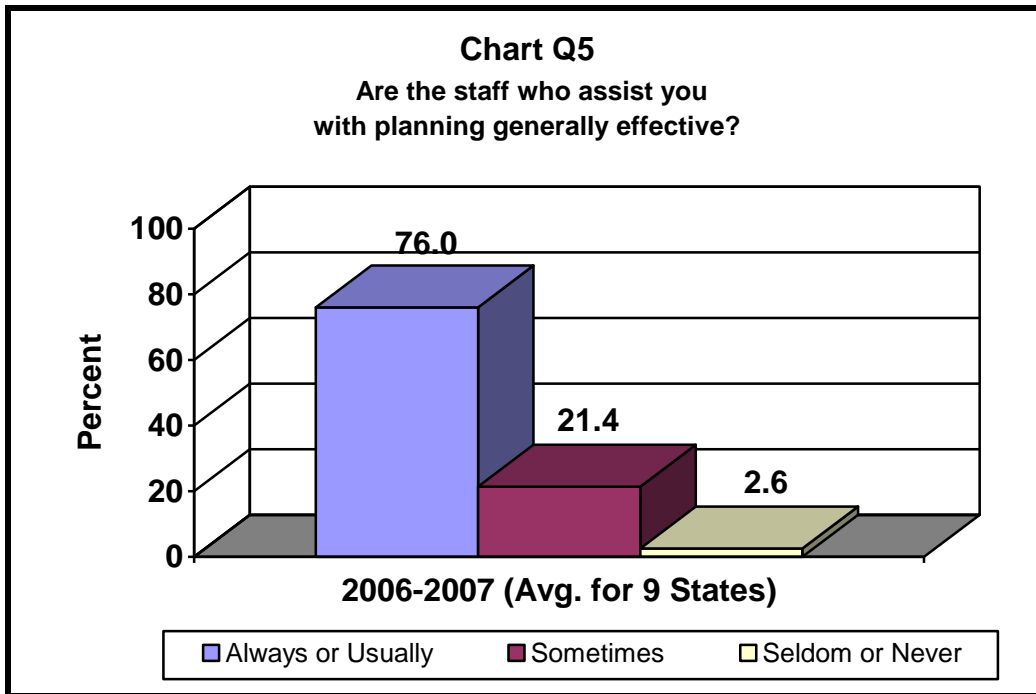


Table Q5
Are the staff who assist you with planning generally effective?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		78.5	19.0	2.5	163
CT	↑	83.3	15.2	1.5	269
DE		74.0	24.8	1.2	242
GA	↓	66.8	28.1	5.1	467
HI		76.2	20.6	3.2	126
ME	↑↑	87.4	12.1	0.5	398
NM	↓	66.8	27.8	5.5	385
PA		76.6	20.3	3.1	978
WY		74.1	25.1	0.8	251
Total %		75.6	21.5	2.9	3,279
State Average %		76.0	21.4	2.6	9

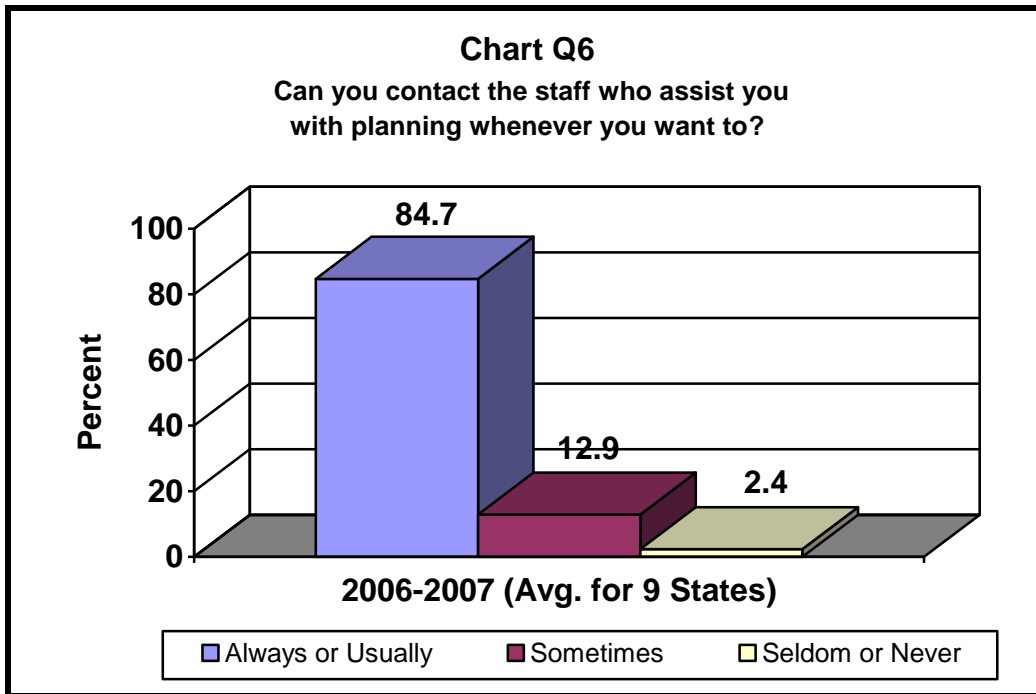


Table Q6
Can you contact the staff who assist you with planning whenever you want to?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	78.4	18.5	3.1	162
CT		86.3	12.2	1.4	278
DE		85.0	12.6	2.4	246
GA	↓	78.9	16.1	5.0	484
HI	↑	90.4	9.6	0.0	125
ME	↑	93.3	5.2	1.5	406
NM	↓↓	74.6	21.7	3.8	397
PA		84.6	12.9	2.4	1,021
WY	↑	90.8	7.6	1.6	249
Total %		84.2	13.2	2.6	3,368
State Average %		84.7	12.9	2.4	9

Access to and Delivery of Services and Supports

- On average, most respondents (81%) stated that their service coordinator helped them get needed supports when they asked. Sixteen percent said this only happened some of the time, and 3% indicated that their service coordinator was seldom or never helpful in getting their family member the assistance needed.
- Eighty-one percent (81%) of respondents, on average, indicated that their family member always or usually gets the services and supports they need.
- Among those respondents whose family member with disabilities did not speak English, or who used different ways to communicate, the majority (79%) indicated there were enough staff to communicate with their family member. Seventeen percent stated that these staff were available some of the time, and another 4% did not have staff available to communicate with their family members in their preferred means of communication/ languages.
- On average, 89% of respondents indicated that their family member had access to the special equipment or accommodations that s/he needs. Eleven percent stated that equipment was only seldom or sometimes available.
- Three-fourths of respondents (77%) indicated that frequent changes in support staff were a problem for their family at least some of the time. The remaining 23% stated that this was not an issue for them.
- Among those receiving residential supports, nearly all (88%) felt their family member's residential setting was a safe and healthy environment, however 12% felt their family member's residence was only sometimes or seldom safe.
- Among those receiving day/employment supports, nearly all (88%) felt their family member's day/employment setting was a safe and healthy environment. The remaining 12% felt their family member's day setting was sometimes or seldom safe.

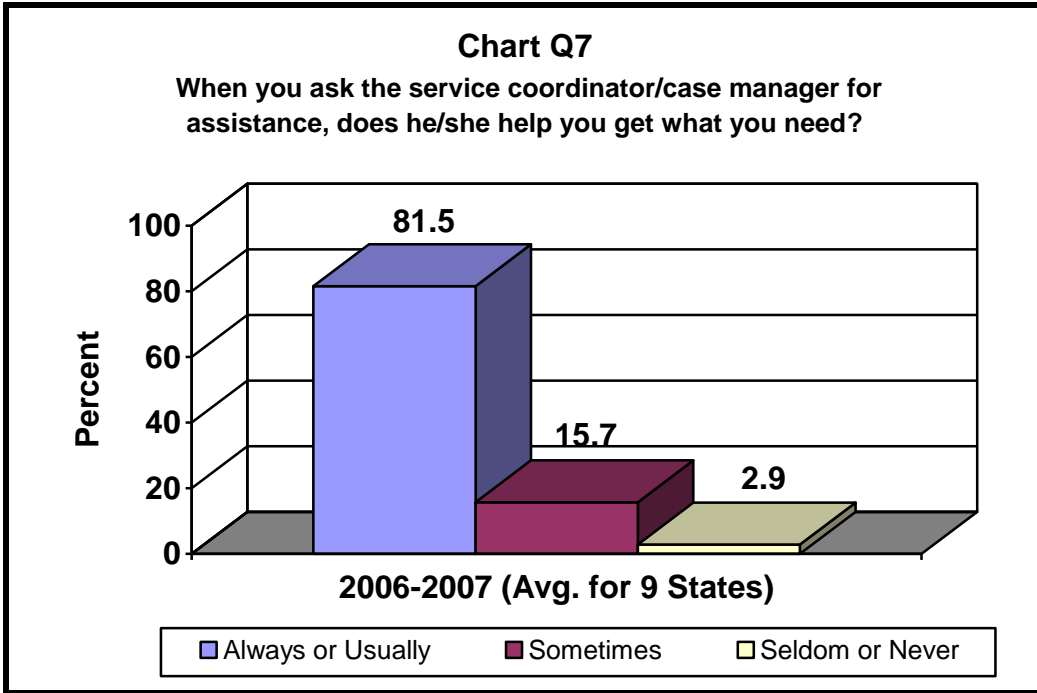


Table Q7
When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		79.8	17.8	2.5	163
CT		83.5	14.7	1.8	273
DE		79.9	16.3	3.8	239
GA	↓↓	71.2	21.7	7.1	493
HI	↑	88.5	10.7	0.8	131
ME		84.6	13.4	2.0	350
NM	↓	76.5	19.9	3.5	396
PA		81.1	15.5	3.4	1,056
WY	↑	88.1	11.1	0.8	253
Total %		80.3	16.3	3.4	3,354
State Average %		81.5	15.7	2.9	9

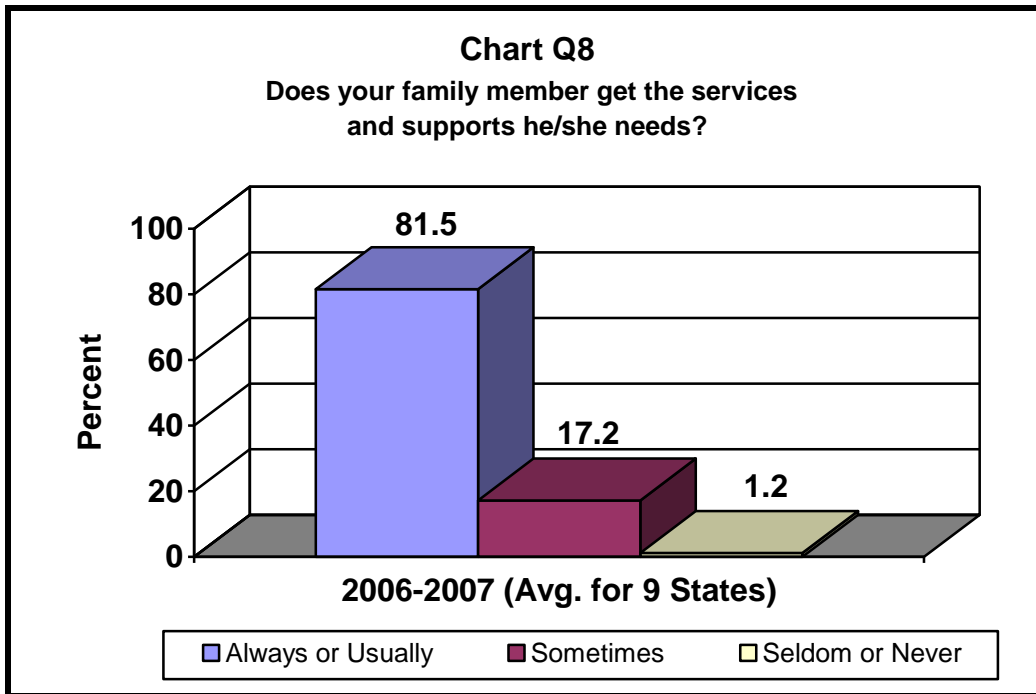


Table Q8
Does your family member get the services and supports he/she needs?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		81.6	18.4	0.0	158
CT	↑	86.7	12.6	0.7	285
DE		77.9	21.7	0.4	253
GA	↓↓	71.4	24.9	3.7	514
HI		85.8	12.6	1.6	127
ME		86.0	13.2	0.7	408
NM	↓	75.2	23.3	1.5	403
PA		84.7	13.2	2.2	1,116
WY		84.6	15.0	0.4	254
Total %		81.4	17.0	1.6	3,518
State Average %		81.5	17.2	1.2	9

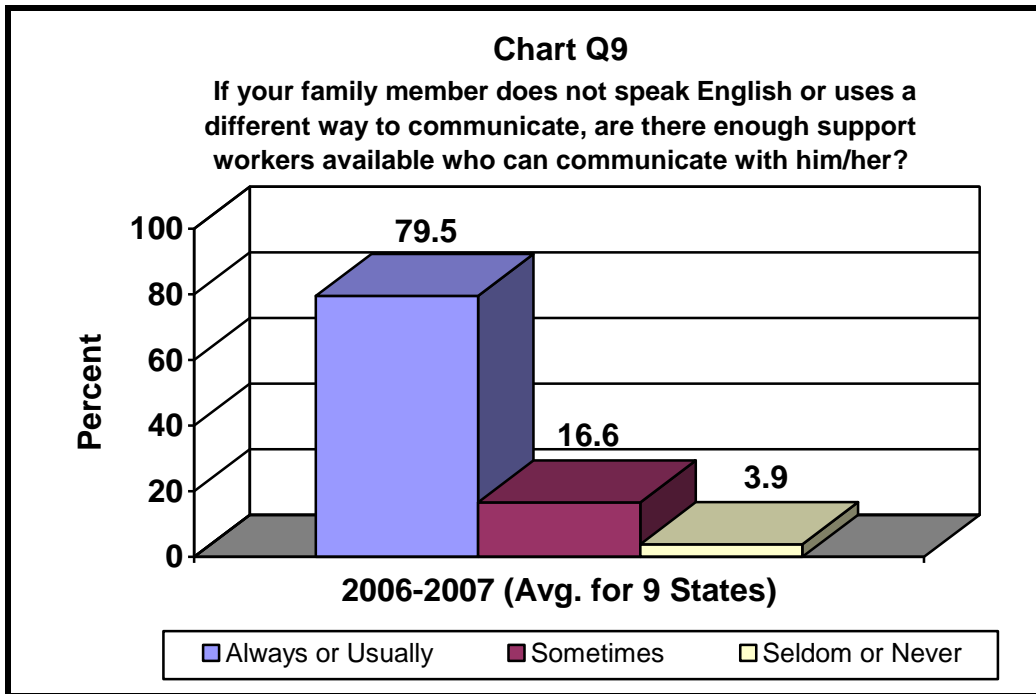


Table Q9
If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		84.4	14.3	1.3	77
CT	↑↑↑	93.1	4.9	2.0	102
DE		81.0	16.7	2.4	84
GA	↓↓↓	65.1	25.1	9.7	175
HI		80.9	13.2	5.9	68
ME		79.7	18.3	2.0	197
NM		76.6	17.3	6.1	197
PA		83.0	13.9	3.1	417
WY	↓	72.0	25.6	2.4	82
Total %		79.3	16.6	4.1	1,399
State Average %		79.5	16.6	3.9	9

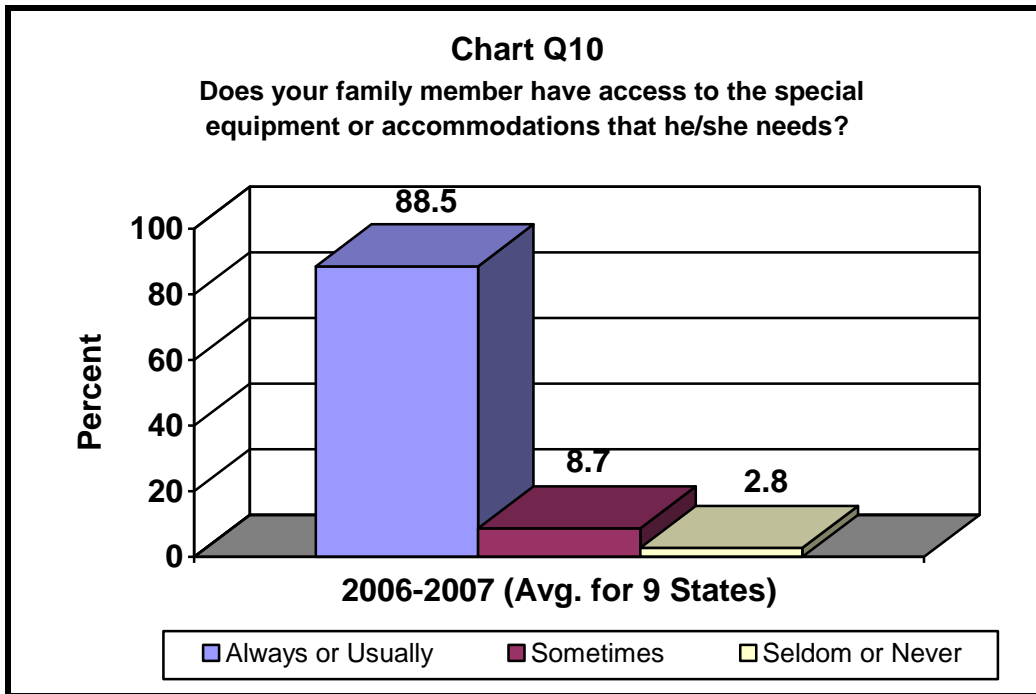


Table Q10
Does your family member have access to the special equipment or accommodations that he/she needs?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		90.0	7.0	3.0	100
CT	↑	93.5	5.8	0.6	154
DE		92.8	5.0	2.2	139
GA	↓	82.9	11.8	5.3	246
HI	↓	82.9	11.4	5.7	70
ME		91.1	7.0	1.8	271
NM	↓	80.7	16.7	2.7	264
PA		90.1	7.3	2.6	645
WY		92.2	6.4	1.4	141
Total %		88.5	8.8	2.7	2,030
State Average %		88.5	8.7	2.8	9

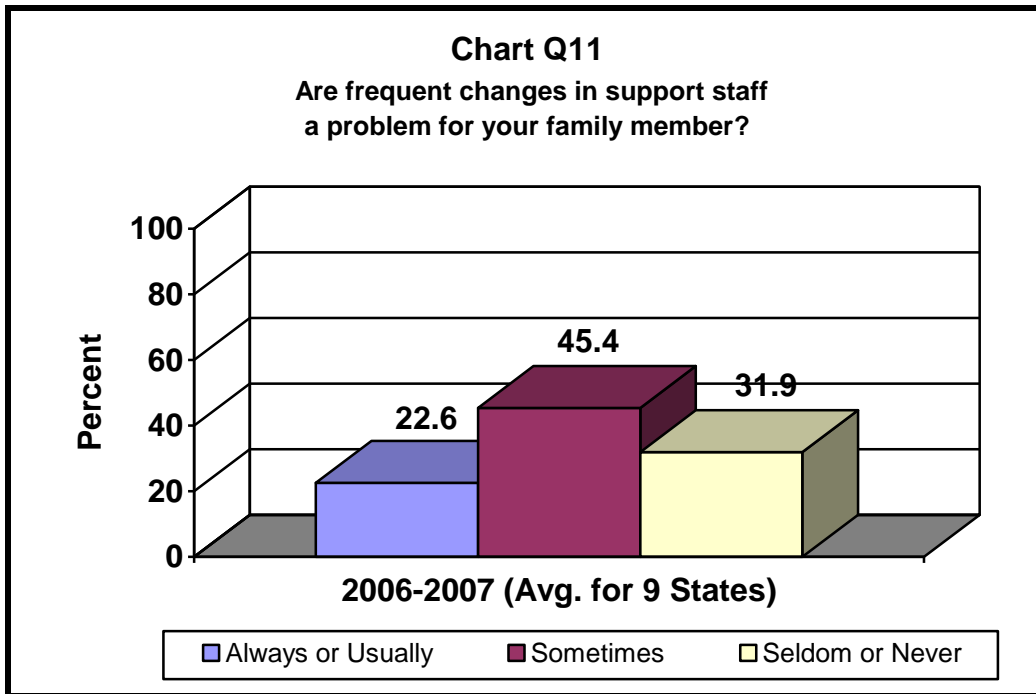


Table Q11
Are frequent changes in support staff a problem for your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		22.9	36.6	40.5	153
CT	↑	15.7	49.0	35.3	249
DE		24.4	47.9	27.6	217
GA		19.3	43.1	37.6	450
HI		24.0	36.0	40.0	100
ME		26.5	46.8	26.7	344
NM	↓↓	32.9	45.0	22.1	371
PA		19.9	42.7	37.4	956
WY		18.0	61.7	20.3	222
Total %		22.2	45.2	32.5	3,062
State Average %		22.6	45.4	31.9	9

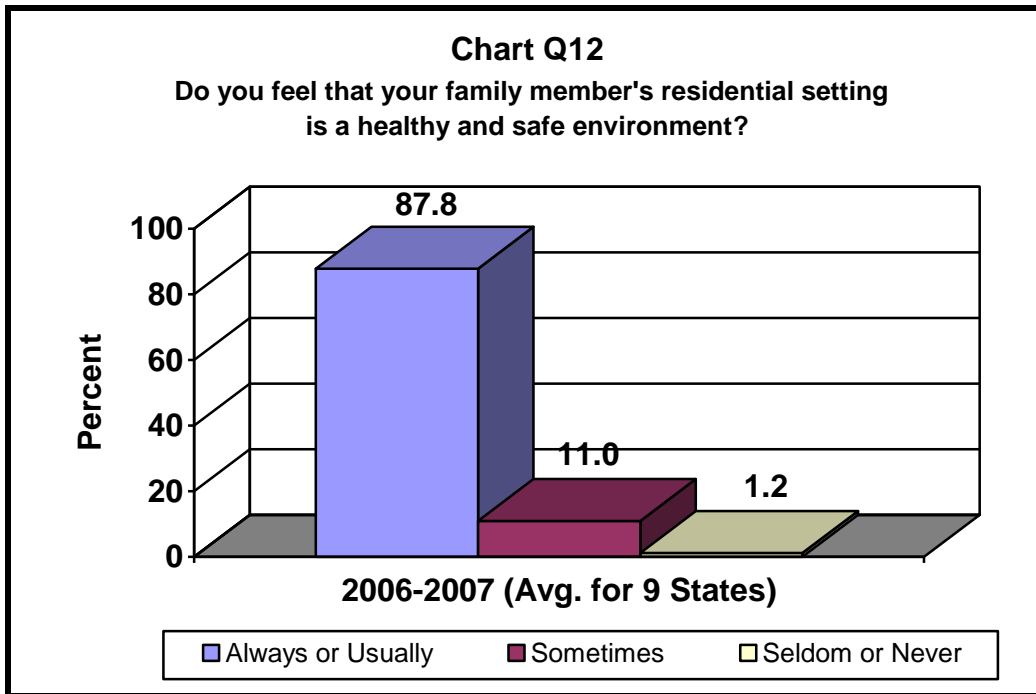


Table Q12
Do you feel that your family member's residential setting is a healthy and safe environment?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	85.0	13.8	1.2	167
CT	88.9	10.5	0.7	287
DE	89.0	9.8	1.1	264
GA	85.7	12.9	1.4	512
HI	91.0	9.0	0.0	133
ME	91.5	7.2	1.2	414
NM	82.9	14.4	2.7	410
PA	89.1	9.1	1.8	1,166
WY	87.3	12.0	0.8	251
Total %	87.9	10.6	1.5	3,604
State Average %	87.8	11.0	1.2	9

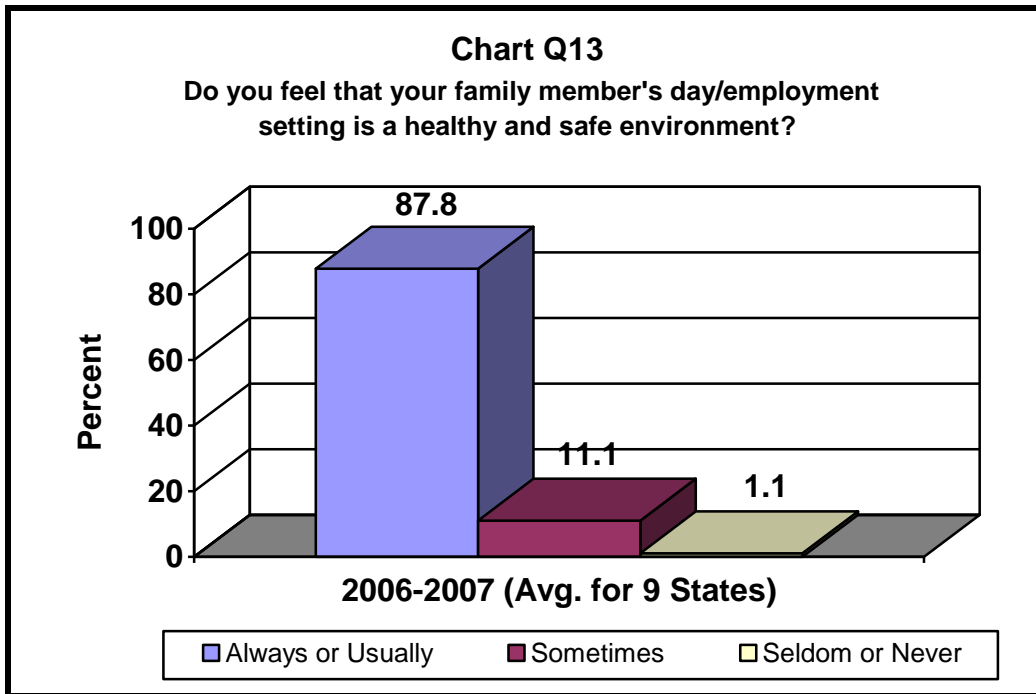


Table Q13
Do you feel that your family member's day/employment setting is a healthy and safe environment?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	86.9	11.0	2.1	145
CT	91.5	8.1	0.4	259
DE	87.0	13.0	0.0	231
GA	85.0	12.7	2.3	440
HI	87.0	13.0	0.0	108
ME	91.4	7.4	1.2	337
NM ↓	82.5	15.7	1.8	338
PA	90.4	8.5	1.1	914
WY	88.4	10.3	1.2	242
Total %	88.2	10.6	1.2	3,014
State Average %	87.8	11.1	1.1	9

Choices and Control

- Among families where the individual with disabilities received residential services, 79% of respondents stated that the agency involved them in important decisions. Another 16% stated that this happens some of the time, and 5% said the agency seldom or never involved them in important decisions.
- Among families where the individual with disabilities received day or employment services, 65% of respondents stated that the agency involves them in important decisions. Another 22% stated that this happens sometimes, and 13% said the agency seldom or never involves them in important decisions.
- On average across states, two-thirds of respondents (68%) seldom or never chose the support staff who work with their family members.
- Across states, only 11% of respondents said that they had control or input over the hiring and management of their support staff, with an additional 10% indicated they had this type of control sometimes. Seventy-eight percent, however, had little or no input or control over the hiring or management of their family's support staff.
- While only 21% of respondents said they had any amount of control over the hiring or management of their support workers, here 65% of respondents indicate that they want some control over the hiring and management for their support staff.
- Twenty-eight percent (28%) of respondents, on average, knew how much money was spent on behalf of their family member. Sixty percent, however, had no idea. In Wyoming, a far greater percentage of families (76%) knew the amount of money spent.
- On average across states, about half of the families surveyed (48%) had at least some decision-making authority over how the money allocated to their family member with disabilities by the MR/DD agency was spent. The majority (52%), however, did not.

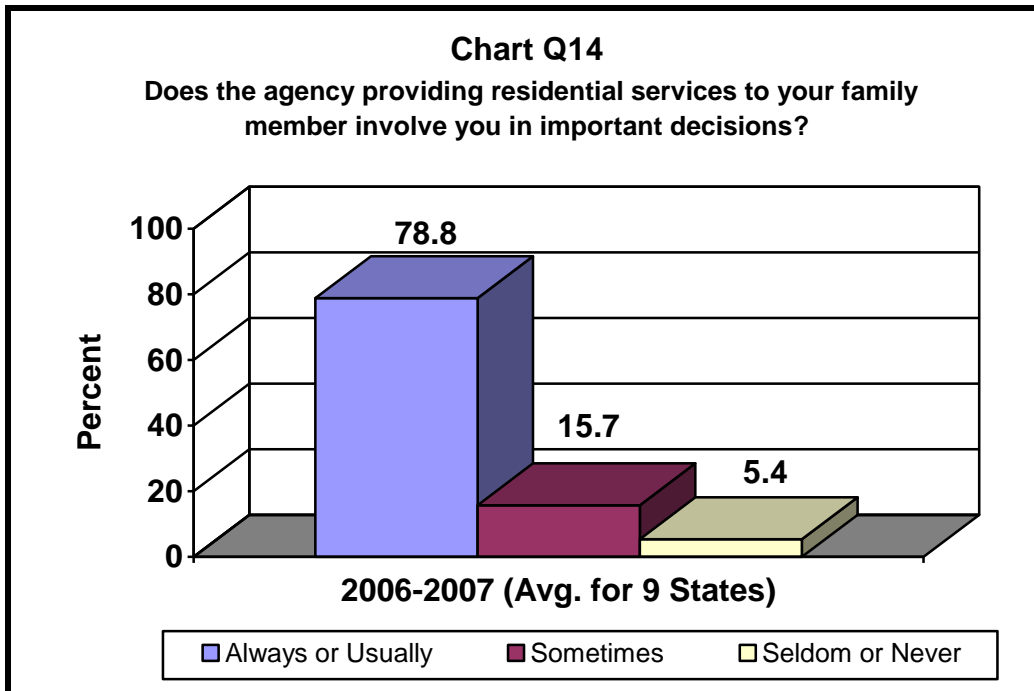


Table Q14
Does the agency providing residential services to your family member involve you in important decisions?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		79.4	18.1	2.5	160
CT	↑	86.7	9.8	3.5	286
DE		76.9	16.2	6.9	260
GA	↓↓	67.1	20.7	12.2	493
HI	↑	84.1	12.7	3.2	126
ME	↑↑	92.6	6.2	1.2	405
NM	↓	69.1	21.9	9.0	411
PA	↓	72.0	19.1	8.9	1,099
WY		81.6	16.8	1.6	250
Total %		76.4	16.7	6.9	3,490
State Average %		78.8	15.7	5.4	9

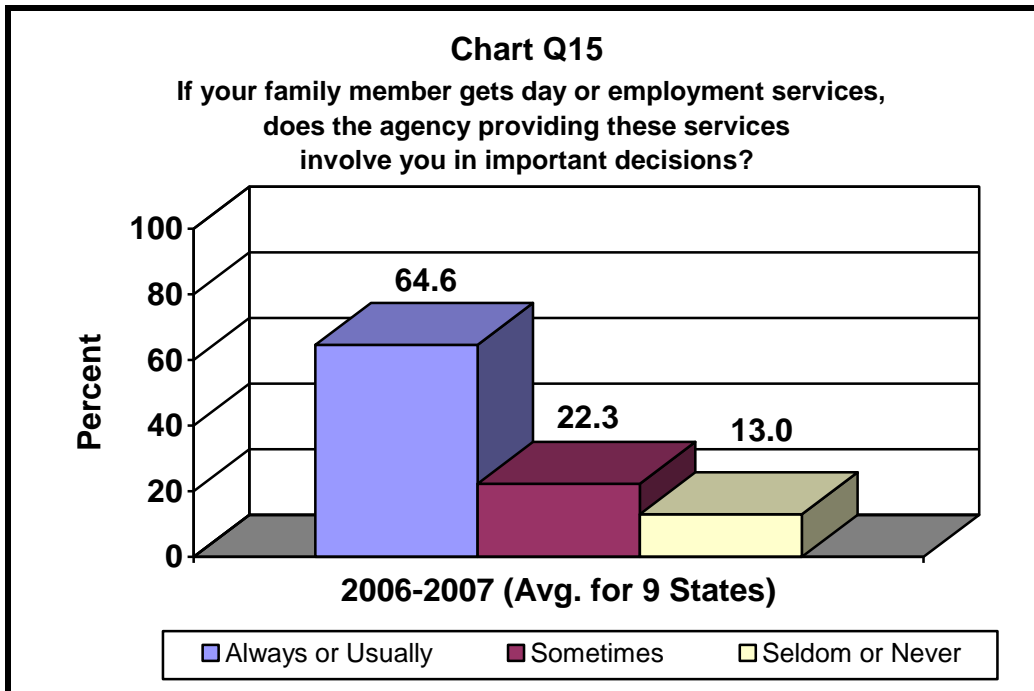


Table Q15
If your family member gets day or employment services, does the agency providing these services involve you in important decisions?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	70.4	21.5	8.1	135
CT		67.7	18.3	14.0	235
DE	↓	58.9	22.8	18.3	219
GA	↓↓	53.7	24.7	21.6	417
HI	↑	73.3	17.8	8.9	101
ME	↑↑	75.1	18.9	6.0	317
NM	↓	55.0	30.0	15.0	347
PA	↓	56.6	22.5	20.9	795
WY	↑	71.0	24.4	4.6	217
Total %		61.6	23.0	15.5	2,783
State Average %		64.6	22.3	13.0	9

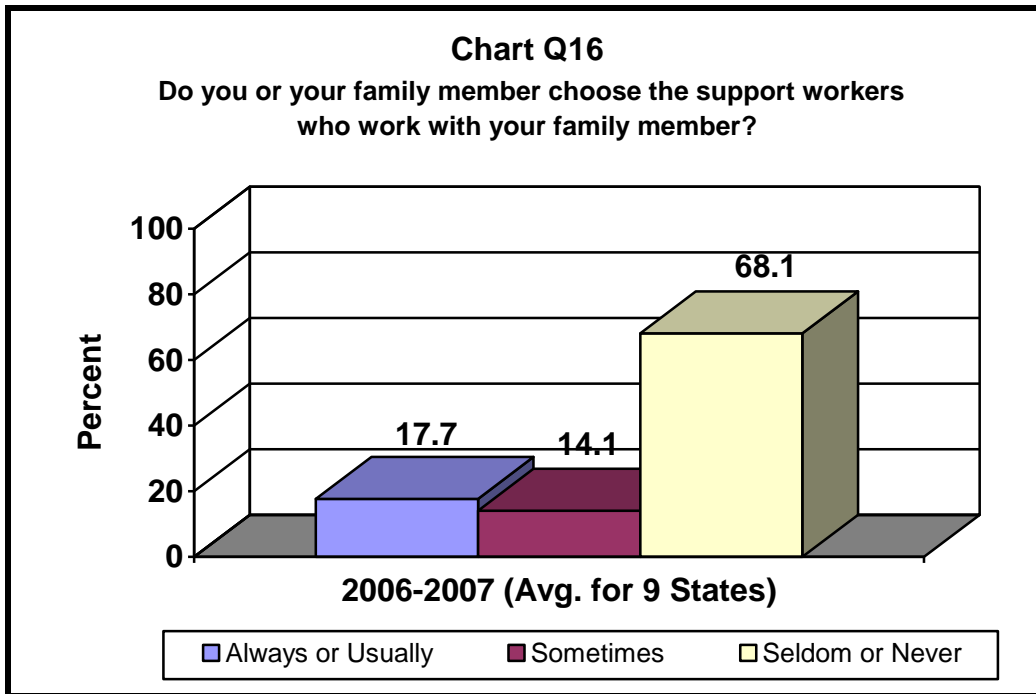


Table Q16
Do you or your family member choose the support workers who work with your family member?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		19.6	11.2	69.2	143
CT	↓	9.9	8.2	81.9	232
DE		13.3	10.0	76.8	211
GA	↓	9.7	13.8	76.5	443
HI	↑↑	32.3	16.7	51.0	96
ME		15.4	16.3	68.3	306
NM		17.8	16.3	65.9	349
PA		14.3	9.9	75.8	817
WY	↑	27.4	24.8	47.8	230
Total %		15.6	13.4	71.0	2,827
State Average %		17.7	14.1	68.1	9

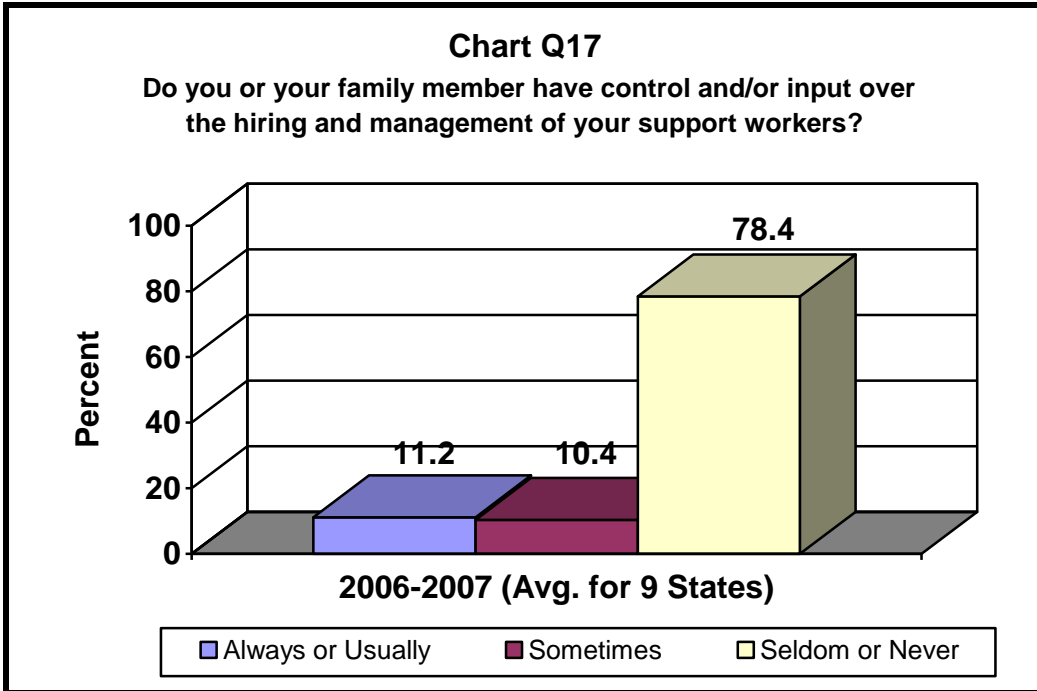


Table Q17
Do you or your family member have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		11.3	9.8	78.9	133
CT	↓	4.6	7.3	88.1	219
DE		8.3	6.3	85.4	206
GA		6.5	8.2	85.4	417
HI	↑↑	27.4	12.6	60.0	95
ME		8.4	11.0	80.6	299
NM		11.1	13.7	75.2	351
PA		7.4	6.9	85.6	792
WY		15.6	17.9	66.5	224
Total %		9.2	9.6	81.1	2,736
State Average %		11.2	10.4	78.4	9

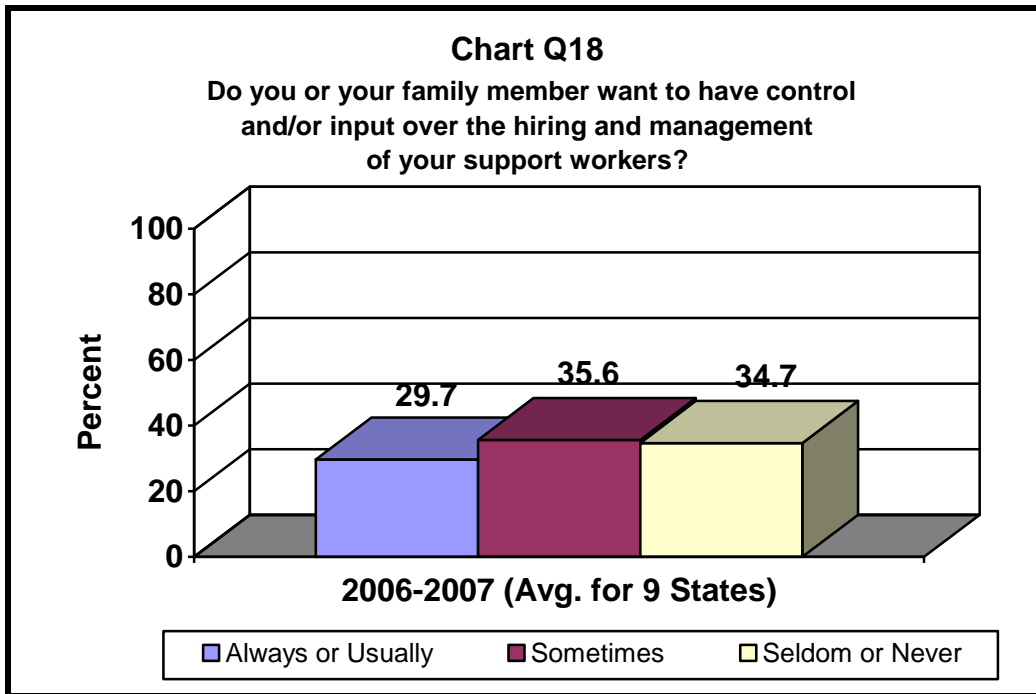


Table Q18
Do you or your family member want to have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	35.9	31.6	32.5	117
CT		27.7	32.4	39.9	188
DE		30.8	40.7	28.6	182
GA		27.2	35.8	37.1	383
HI	↑	37.6	30.6	31.8	85
ME	↓	23.0	35.5	41.5	265
NM	↑	34.7	37.9	27.3	311
PA	↓	24.5	33.6	41.9	714
WY		25.9	42.1	31.9	216
Total %		27.9	35.7	36.4	2,461
State Average %		29.7	35.6	34.7	9

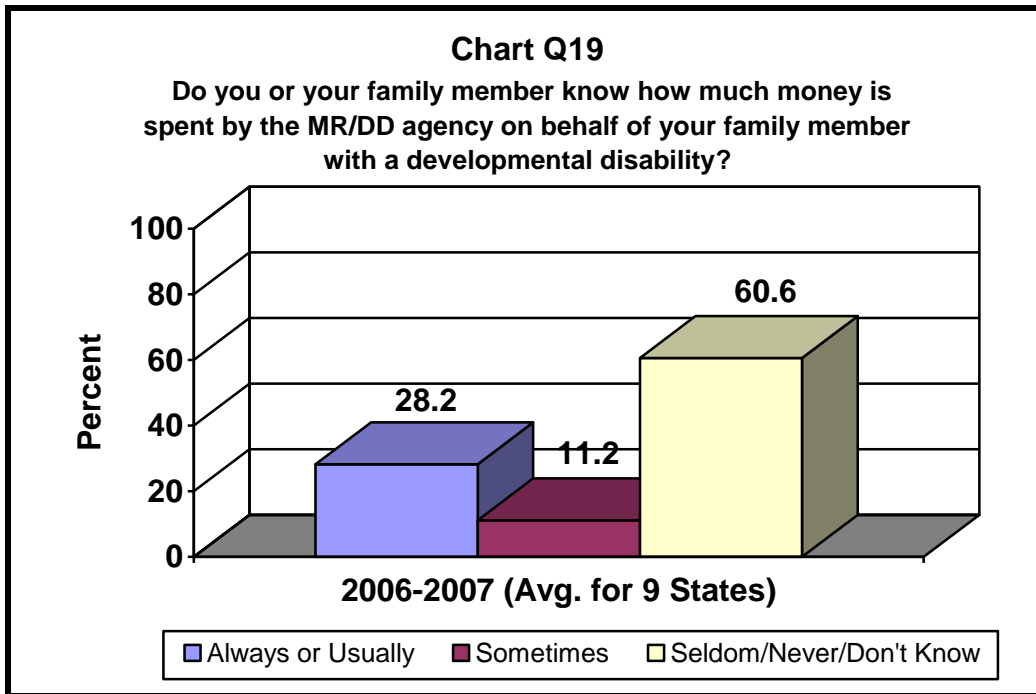


Table Q19
Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ		30.8	16.0	53.2	156
CT	↓	21.0	10.9	68.1	276
DE	↓↓↓	16.0	7.6	76.4	250
GA	↓↓↓	9.3	6.1	84.6	494
HI		32.3	17.3	50.4	127
ME	↓	20.6	10.8	68.6	369
NM		30.2	10.1	59.7	397
PA	↓↓↓	17.7	10.5	71.8	1,085
WY	↑↑↑	75.7	11.6	12.7	251
Total %		23.8	10.2	65.9	3,405
State Average %		28.2	11.2	60.6	9

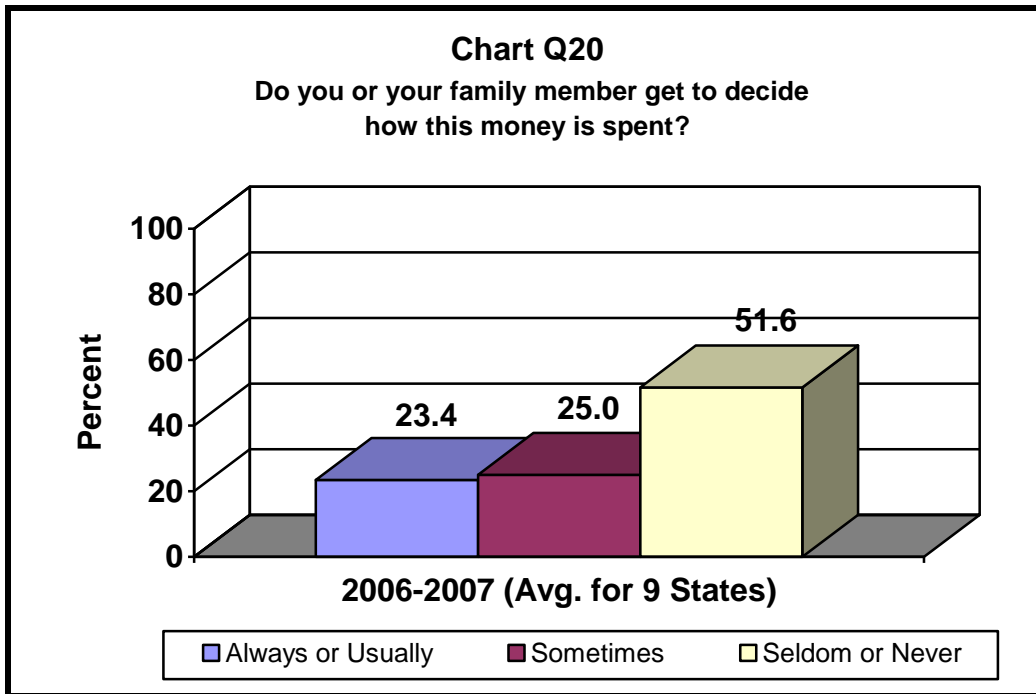


Table Q20
Do you or your family member get to decide how this money is spent?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	29.5	21.2	49.2	132
CT	↓	15.0	25.7	59.3	226
DE	↓↓↓	12.3	27.2	60.5	195
GA	↓↓↓	9.5	15.7	74.8	401
HI	↑	28.7	30.9	40.4	94
ME	↑	32.4	25.5	42.1	247
NM	↑	29.4	25.2	45.3	333
PA	↓	17.2	20.2	62.6	810
WY	↑↑↑	36.6	33.0	30.4	224
Total %		21.1	23.1	55.8	2,662
State Average %		23.4	25.0	51.6	9

Community Connections

- Sixty percent (60%) of respondents remarked that staff were usually able to help them connect with typical supports in their community (e.g., recreation programs, church activities) if they desired to do so. 28% indicated that staff could sometimes help in this way, while 13% stated that staff rarely or never provided this type of assistance.
- Of families interested in using family or friends to provide some of the supports needed, 60% stated that planning or support staff were helpful in making this happen. The remaining 40% indicated that staff were only sometimes or seldom capable of helping families utilize friends, neighbors, etc. as supports.
- Two-thirds (66%) of respondents felt that their family member typically had access to community activities.
- While 66% of families felt their family member had regular access to community activities, only 45% stated that their family member usually participated in these activities, although another 42% indicated that their family member sometimes took part in community events/activities.

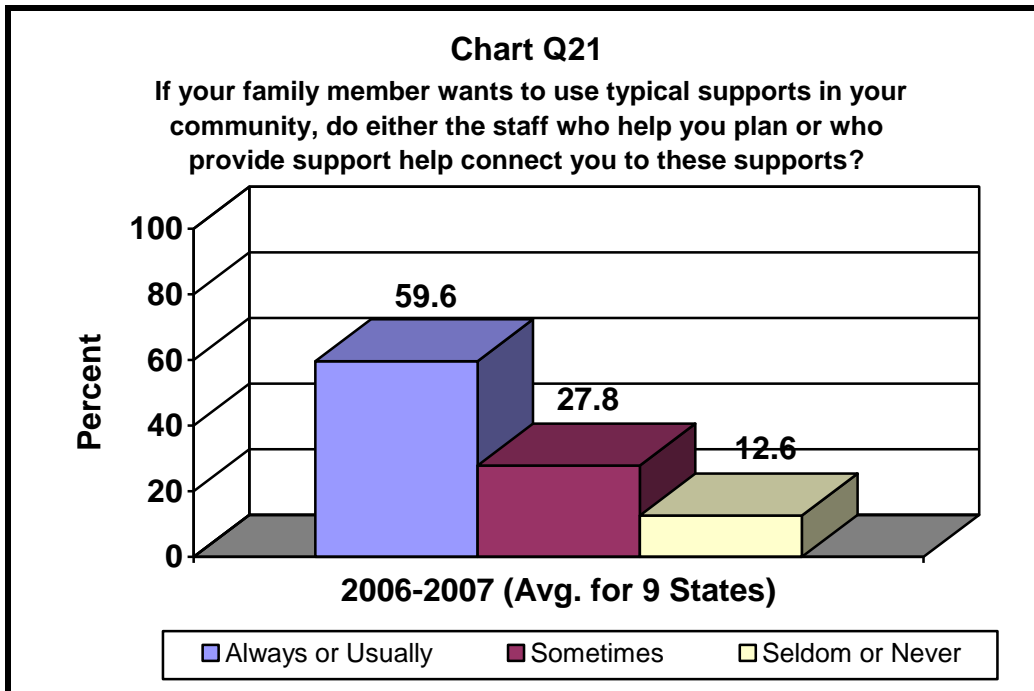


Table Q21

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

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		57.7	31.7	10.6	123
CT		58.5	25.5	16.0	200
DE		55.4	33.1	11.4	175
GA	↓↓	44.8	32.4	22.8	355
HI		59.7	23.9	16.4	67
ME	↑↑	80.9	16.3	2.8	319
NM		55.1	30.5	14.4	334
PA		61.3	27.2	11.5	736
WY		63.1	29.3	7.6	225
Total %		59.9	27.6	12.5	2,534
State Average %		59.6	27.8	12.6	9

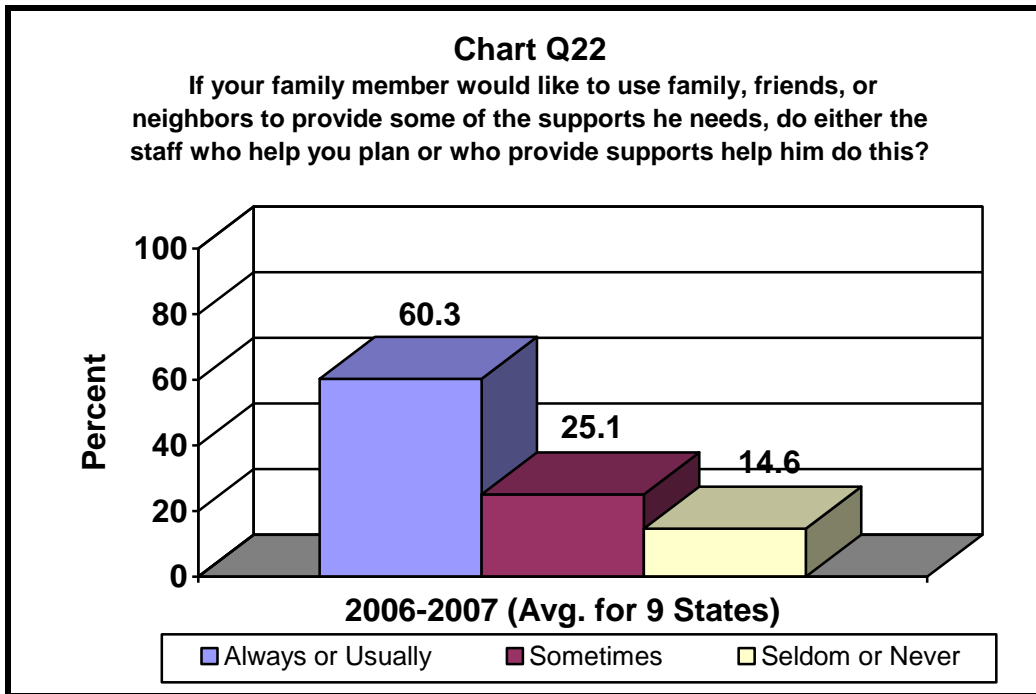


Table Q22
 If your family member would like to use family, friends, or neighbors to provide some of the supports he/she needs, do either the staff who help you plan or who provide support help him/her do this?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	66.4	23.3	10.3	116
CT		61.1	23.6	15.3	157
DE		55.8	32.1	12.1	165
GA	↓↓	44.3	32.9	22.8	334
HI	↓	54.5	19.7	25.8	66
ME	↑↑	80.3	16.8	3.0	304
NM	↓↓	47.8	31.8	20.4	274
PA		64.3	23.3	12.4	635
WY	↑	68.6	22.0	9.4	191
Total %		60.8	25.3	13.9	2,242
State Average %		60.3	25.1	14.6	9

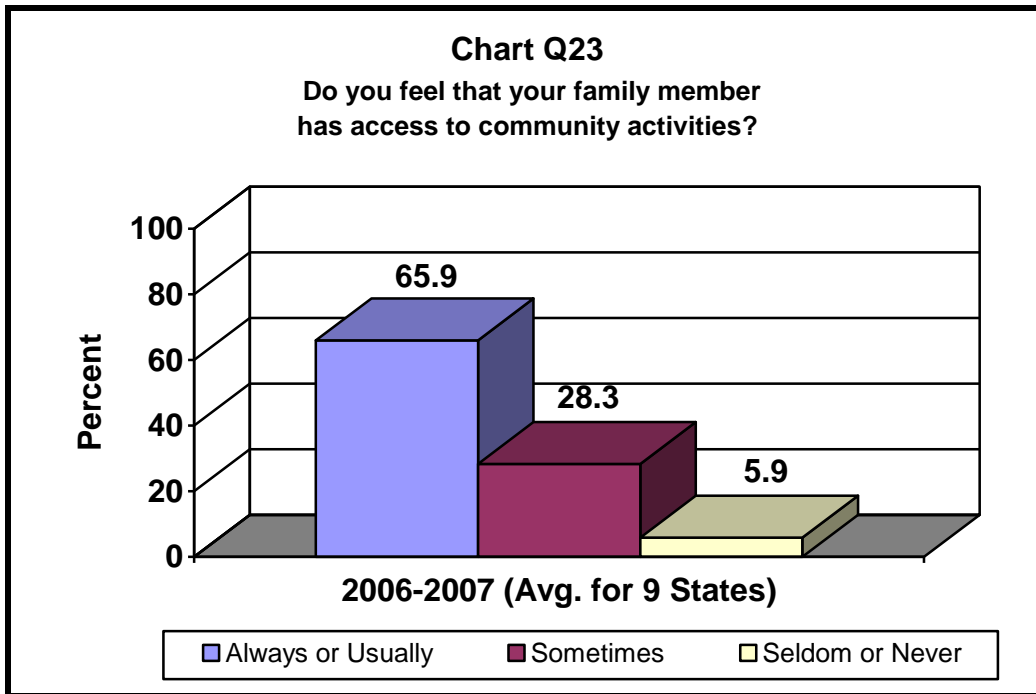


Table Q23
Do you feel that your family member has access to community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		67.8	25.5	6.7	149
CT		67.1	29.0	4.0	252
DE	↓↓↓	53.1	37.1	9.8	224
GA	↓↓↓	53.7	36.5	9.8	471
HI		64.5	29.9	5.6	107
ME	↑↑↑	86.3	11.1	2.6	380
NM	↑↑↑	63.3	31.0	5.7	384
PA	↑↑↑	62.9	31.2	5.8	1,012
WY	↑	74.2	23.0	2.9	244
Total %		65.2	28.9	6.0	3,223
State Average %		65.9	28.3	5.9	9

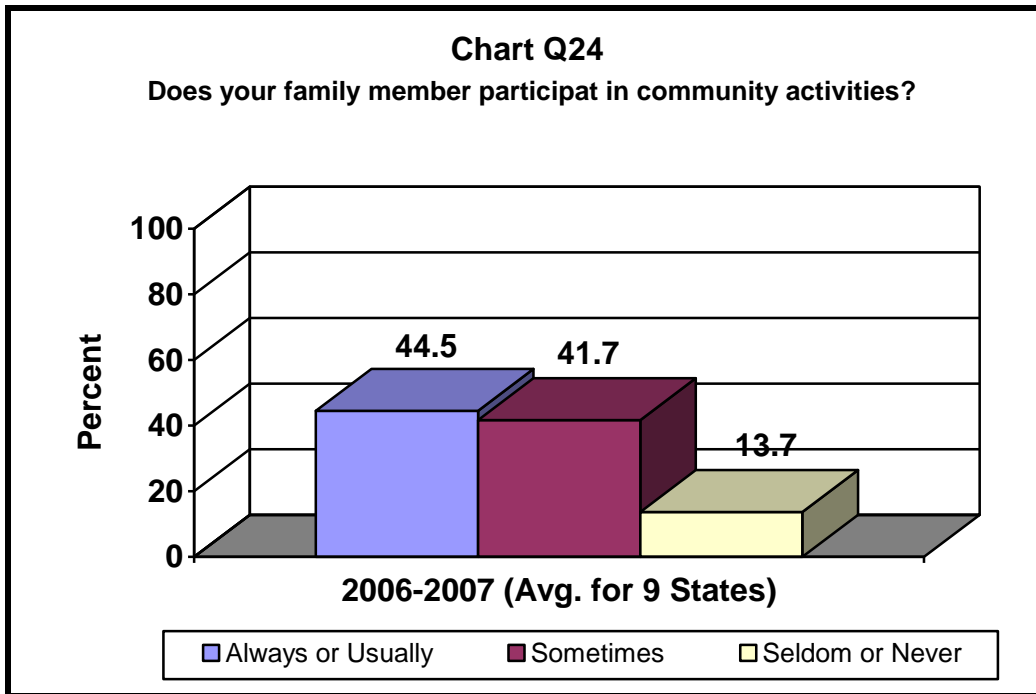


Table Q24
Does your family member participate in community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		48.3	31.7	20.0	145
CT	↑	50.4	36.0	13.6	236
DE	↓↓↓	28.6	54.9	16.5	206
GA	↓	36.7	45.9	17.4	477
HI		40.6	48.5	10.9	101
ME	↑↑	59.0	32.5	8.5	354
NM		43.9	43.1	13.0	376
PA		42.3	40.2	17.5	948
WY	↑	50.8	42.9	6.3	238
Total %		44.1	41.3	14.6	3,081
State Average %		44.5	41.7	13.7	9

Outcomes and Satisfaction with Services and Supports

- On average, most respondents (81%) were satisfied with the services and supports their family member received. 17% were only somewhat satisfied, and 2% were seldom or not satisfied.
- On average, 55% of respondents knew about their agency's grievance process, 9% knew something about it, and 36% had no knowledge of the process for lodging a complaint.
- The majority of respondents (67%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 33%, however, were either not satisfied, or satisfied only some of the time with how these matters were resolved.
- The majority of respondents (85%) felt that services and supports had a positive impact on their family's life. 14% stated that services sometime made a positive difference, and the remaining 1% indicated that supports seldom or never had a positive impact.
- Eighty-two percent of respondents felt that their family member was happy. One percent indicated that their family member was not happy.

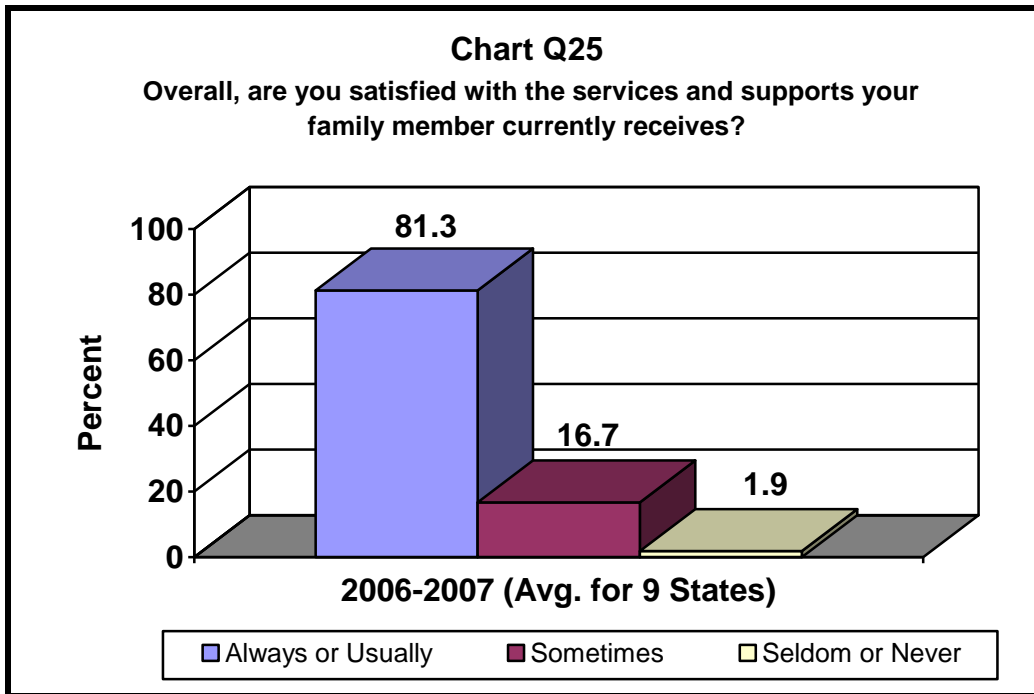


Table Q25
Overall, are you satisfied with the services and supports your family member currently receives?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		77.3	20.9	1.8	163
CT		85.3	13.6	1.1	279
DE		82.3	17.7	0.0	265
GA	↓	72.0	23.2	4.8	521
HI		82.0	17.2	0.8	128
ME	↑↑	91.9	6.9	1.2	407
NM	↓	73.3	24.0	2.6	416
PA		82.7	14.3	3.0	1,179
WY		85.2	12.8	2.0	250
Total %		81.2	16.4	2.4	3,608
State Average %		81.3	16.7	1.9	9

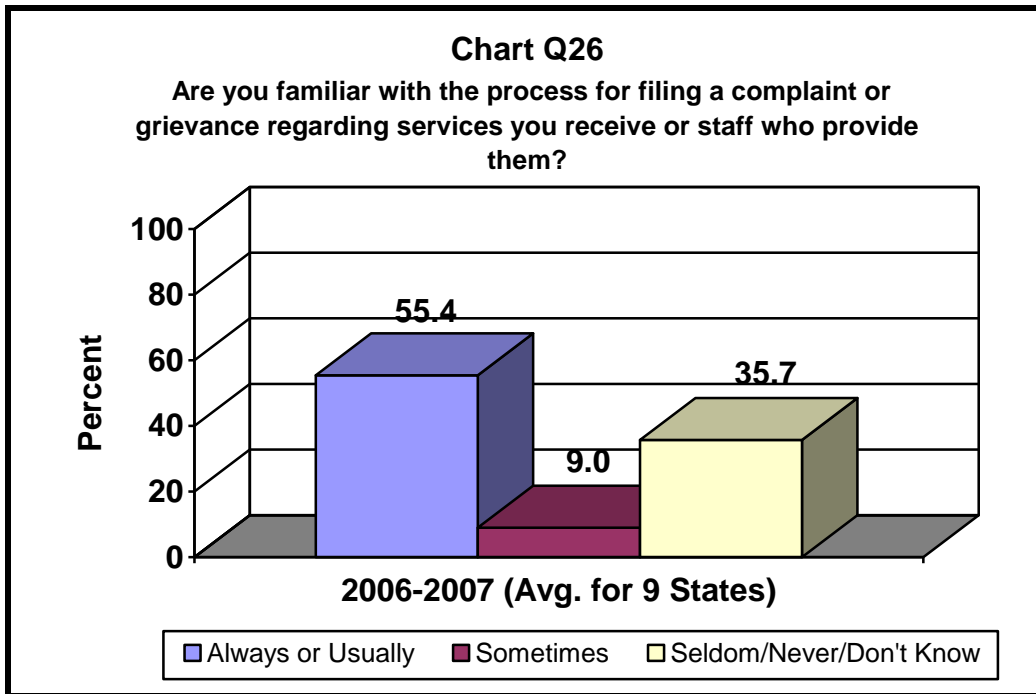


Table Q26
Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ		59.8	10.4	29.9	164
CT		52.2	10.0	37.8	249
DE	↓↓↓	43.4	8.4	48.2	249
GA	↓↓↓	42.6	8.0	49.4	498
HI		50.8	8.1	41.1	124
ME	↑↑↑	70.5	5.8	23.7	380
NM		63.9	10.9	25.3	396
PA	↓	46.8	7.5	45.7	1,078
WY	↑↑↑	68.5	11.6	19.9	241
Total %		53.3	8.5	38.2	3,379
State Average %		55.4	9.0	35.7	9

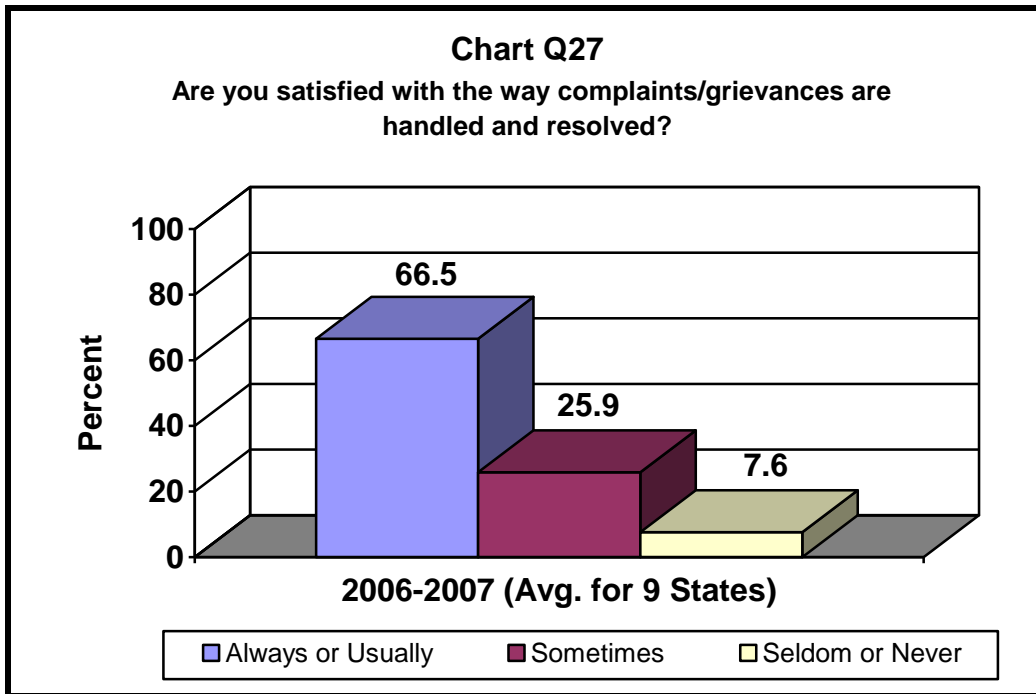


Table Q27
Are you satisfied with the way complaints/grievances are handled and resolved?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		62.9	30.2	6.9	116
CT		66.5	27.7	5.8	155
DE		62.0	28.8	9.2	163
GA	↓↓	56.0	32.7	11.3	336
HI	↑	72.3	18.5	9.2	65
ME	↑↑	77.0	19.3	3.6	274
NM	↓	59.9	30.1	10.0	299
PA		69.5	22.8	7.7	688
WY	↑	72.0	22.9	5.1	175
Total %		66.3	25.8	7.8	2,271
State Average %		66.5	25.9	7.6	9

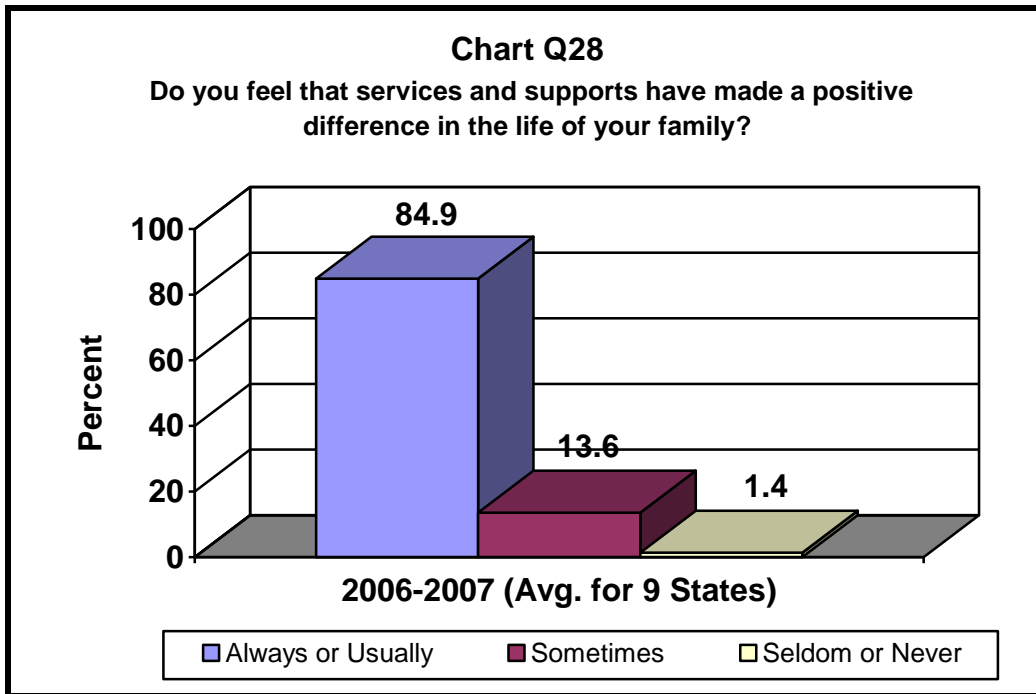


Table Q28
Do you feel that services and supports have made a positive difference in the life of your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		80.1	18.0	1.9	161
CT		89.3	9.6	1.1	271
DE		85.4	13.5	1.2	260
GA	↓	77.3	20.4	2.3	519
HI		88.3	10.8	0.8	120
ME	↑	93.3	6.5	0.3	400
NM	↓	78.9	19.4	1.7	403
PA		83.2	14.7	2.1	1,134
WY		88.7	9.7	1.6	247
Total %		84.0	14.3	1.7	3,515
State Average %		84.9	13.6	1.4	9

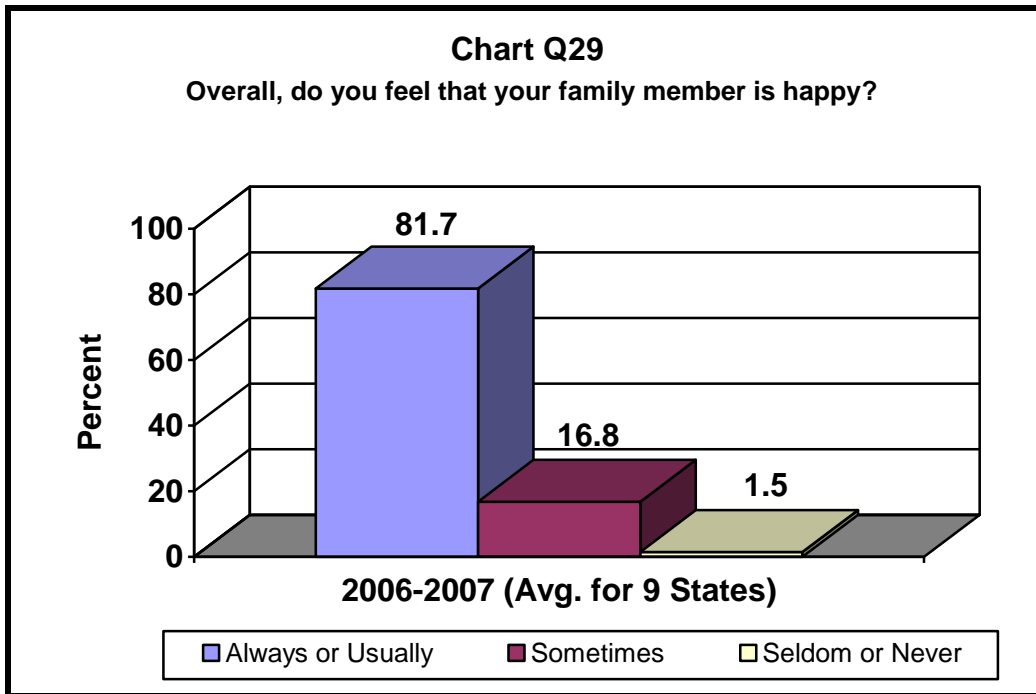


Table Q29
Overall, do you feel that your family member is happy?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		80.1	16.1	3.7	161
CT		85.6	13.4	1.1	277
DE		83.8	15.4	0.8	260
GA		77.3	20.7	2.1	532
HI		84.8	15.2	0.0	125
ME	↑	90.4	8.9	0.7	405
NM	↓↓	71.2	26.4	2.5	406
PA		81.2	17.1	1.7	1,174
WY		80.9	18.3	0.8	246
Total %		81.1	17.3	1.6	3,586
State Average %		81.7	16.8	1.5	9

Aggregate Results & State Comparisons

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

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

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

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

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

Information and Planning

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

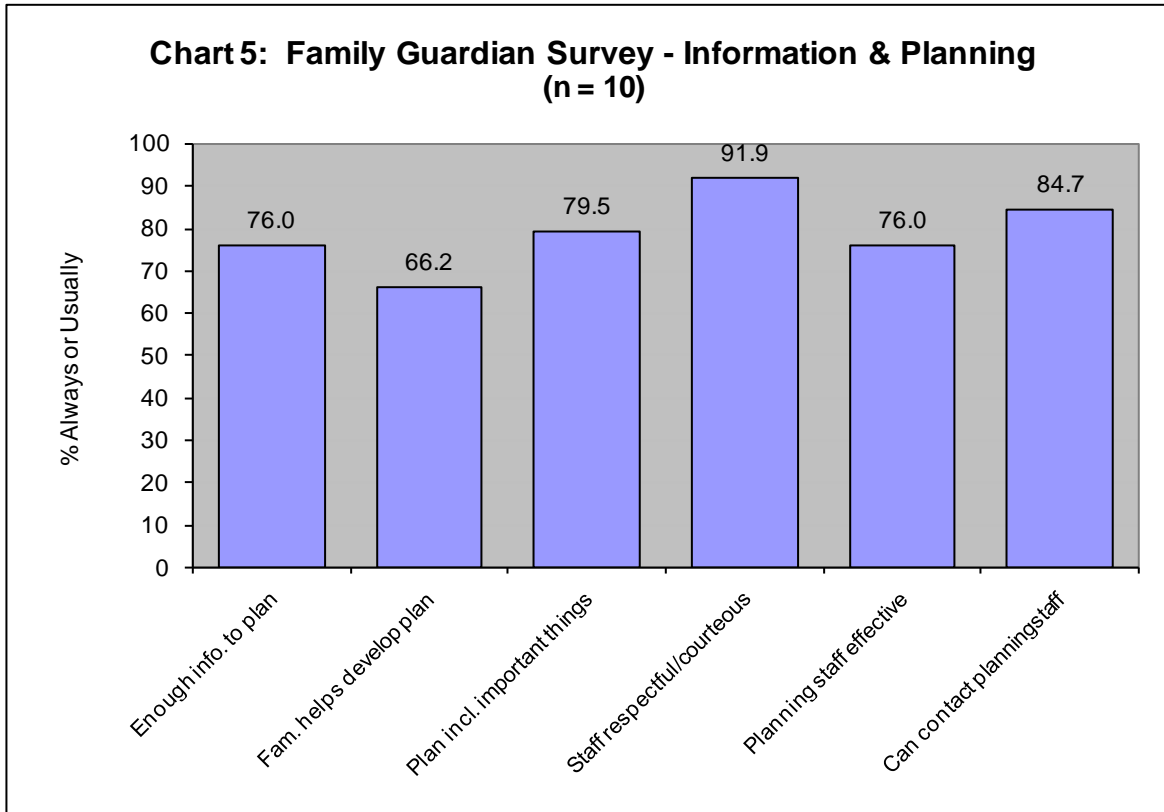


Table 16
Deviation in Responses
Above & Below State Average
Information & Planning

State	Q1	Q2	Q3	Q4	Q5	Q6	Net Sum
AZ		↑↑				↓	1
CT	↑	↓			↑		1
DE							0
GA	↓↓↓	↓↓↓	↓↓↓		↓	↓	-8
HI	↑		↑			↑	3
ME	↑↑	↑	↑		↑↑	↑	7
NM	↓			↓	↓	↓↓↓	-5
PA	↓	↓↓↓	↓				-4
WY	↑	↑↑	↑			↑	5

Access and Delivery of Services

- ◆ In this series of questions, responses were generally consistent across states. However, Connecticut did score somewhat higher than the other states, while Georgia and New Mexico scored somewhat lower than the state average.

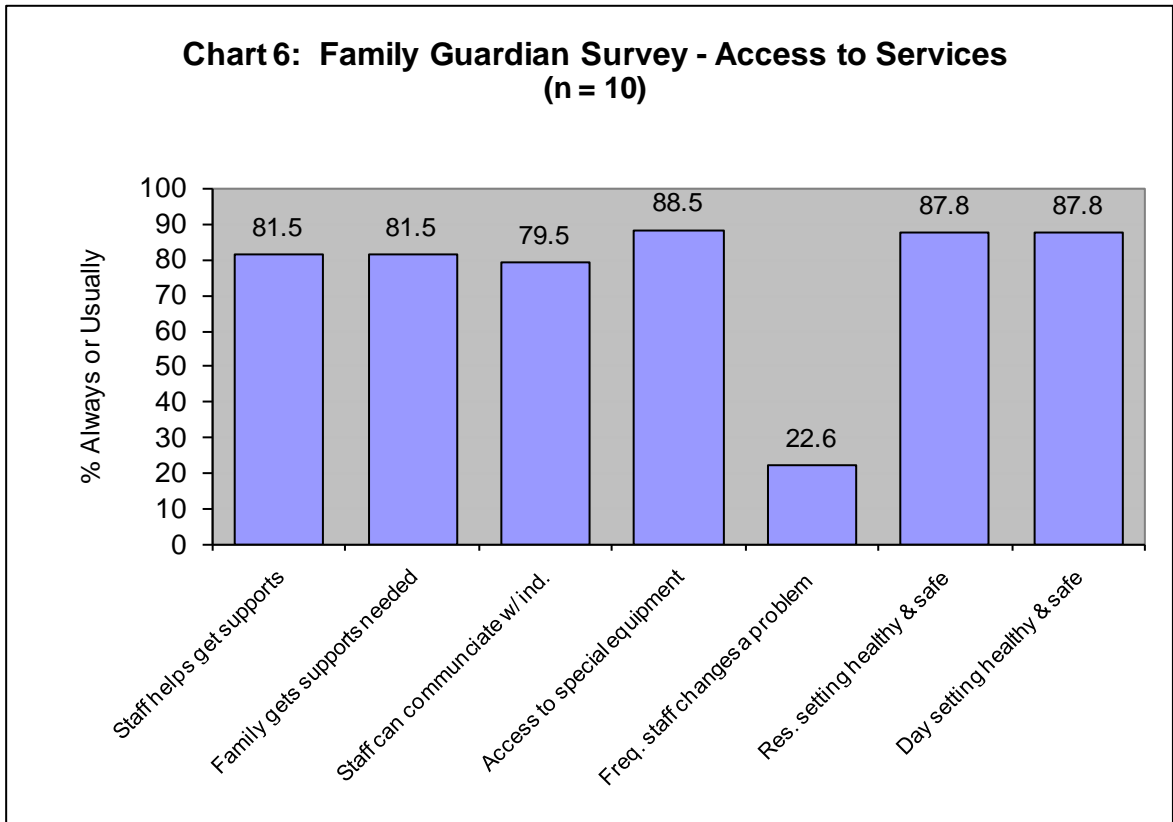


Table 17
Deviation in Responses Above & Below State Average
Access to Services & Supports

State	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
AZ								0
CT		↑	↑↑	↑	↑			5
DE								0
GA	↓↓	↓↓	↓↓	↓				-7
HI	↑			↓				0
ME								0
NM	↓	↓		↓	↓↓		↓	-6
PA								0
WY	↑		↓					0

Choice and Control

- ◆ In Hawaii and Wyoming, responses to choice and control questions were generally above the overall state average. In Delaware, Georgia and Pennsylvania, results were generally below the state average.

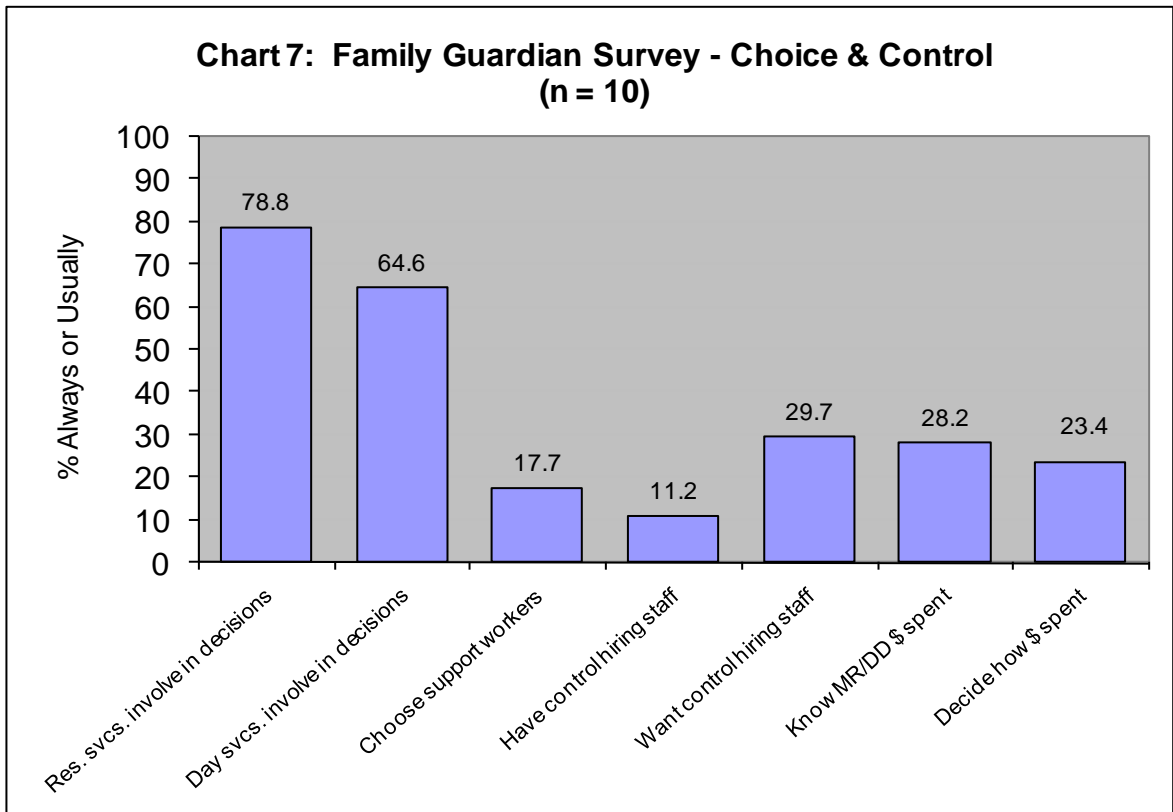


Table 18
Deviation in Responses
Above & Below State Average
Choice & Control

State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Net Sum
AZ		↑			↑		↑	3
CT	↑		↓	↓		↓	↓	-3
DE		↓				↓↓	↓↓	-5
GA	↓↓	↓↓	↓			↓↓	↓↓	-9
HI	↑	↑	↑↑	↑↑	↑		↑	8
ME	↑↑	↑↑			↓	↓	↑	3
NM	↓	↓			↑		↑	0
PA	↓	↓			↓	↓↓	↓	-6
WY		↑	↑			↑↑	↑↑	6

Community Connections

- ◆ In Maine and Wyoming, responses to community connections questions were above the overall state average. In Delaware and Georgia, results were below the state average.

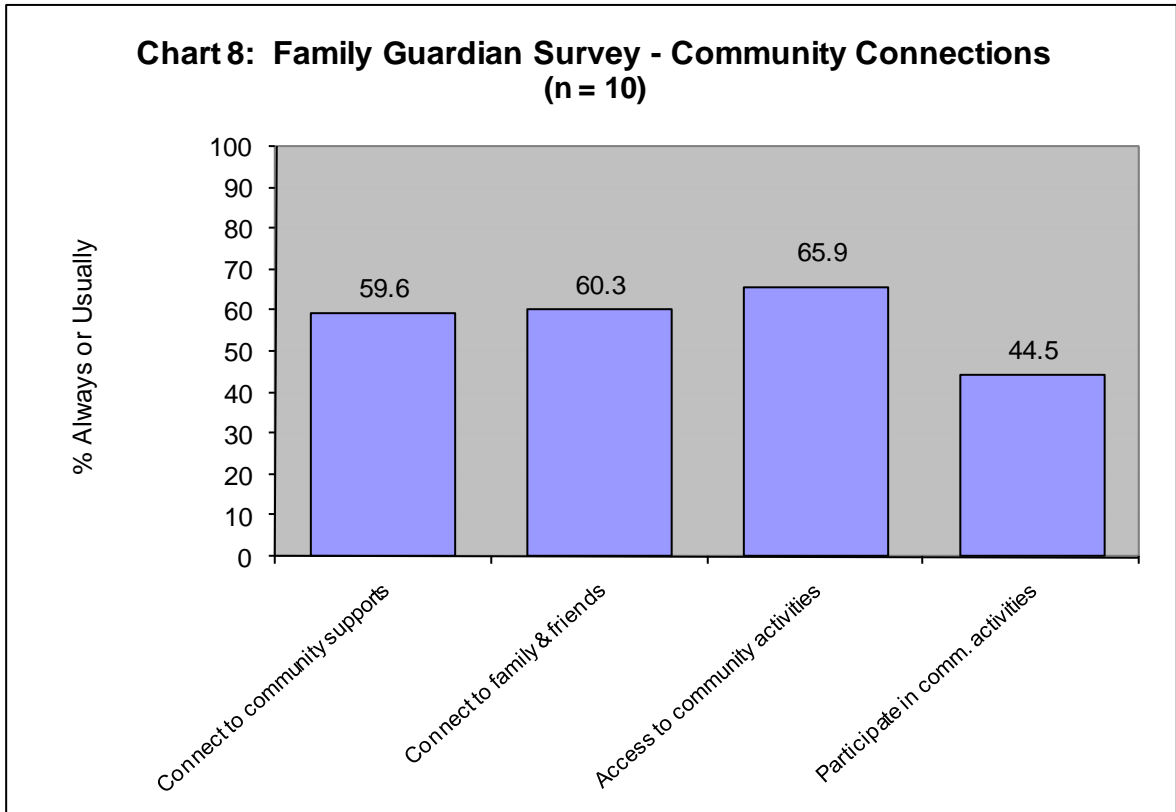
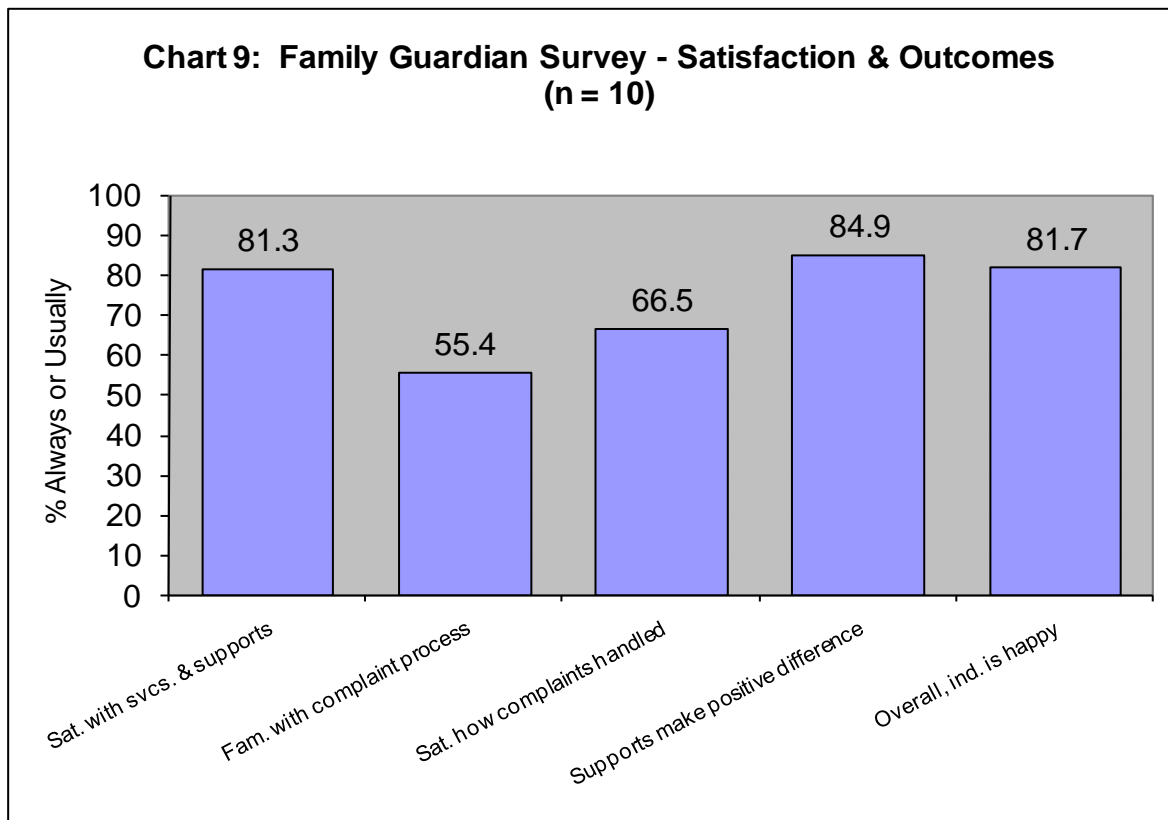


Table 19
Deviation in Responses
Above & Below State Average
Community Connections

State	Q21	Q22	Q23	Q24	Net Sum
AZ		↑			1
CT				↑	1
DE			↓↓	↓↓	-4
GA	↓↓	↓↓	↓↓	↓	-7
HI		↓			-1
ME	↑↑	↑↑	↑↑	↑↑	8
NM		↓↓	↑↑		0
PA			↑↑		2
WY		↑	↑	↑	3

Satisfactions with Services and Supports & Outcomes for Families

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



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

State	Q25	Q26	Q27	Q28	Q29	Net Sum
AZ						0
CT						0
DE		↓↓				-2
GA	↓	↓↓	↓↓	↓		-6
HI			↑			1
ME	↑↑	↑↑	↑↑	↑	↑	8
NM	↓		↓	↓	↓↓	-5
PA		↓				-1
WY		↑↑	↑			3

Overall State Results

- ◆ Looking at results across all categories, Maine and Wyoming consistently received results that were above the overall state average. In Georgia and New Mexico, results were generally below the overall state average.

Table 21 Aggregate Deviation in Responses Above & Below State Average						
State	Information & Planning	Access & Delivery	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
AZ	1	0	3	1	0	5
CT	1	5	-3	1	0	4
DE	0	0	-5	-4	-2	-11
GA	-8	-7	-9	-7	-6	-37
HI	3	0	8	-1	1	11
ME	7	0	3	8	8	26
NM	-5	-6	0	0	-5	-16
PA	-4	0	-6	2	-1	-9
WY	5	0	6	3	3	17

APPENDIX A

Summary Tables of Survey Responses

Table A - Characteristics of Family Member with a Disability: 2006-07 Data

STATES	Total %		State Avg.	AZ		CT		DE		GA		HI		ME		NM		PA		WY	
Number of surveys	3,791		n = 9	171		319		275		545		139		420		424		1243		255	
	n	%		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Gender:																					
Male	1,908	56.5	55.3	88	54.7	19	51.4	137	53.9	331	60.7	66	53.2	218	53.7	231	57.8	684	56.4	134	56.1
Female	1,470	43.5	44.7	73	45.3	18	48.6	117	46.1	214	39.3	58	46.8	188	46.3	169	42.3	528	43.6	105	43.9
Age:																					
Mean	45.1		44.4	44.2		45.2		45.1		43.0		43.8		46.6		43.6		47.1		40.9	
Range	18-94			18-82		18-89		18-92		18-86		18-85		18-86		18-94		19-86		21-84	
Type of Residence																					
Specialized MR Facility	424	12.4	11.4	22	13.1	7	18.9	28	10.5	28	5.3	8	6.3	58	14.4	28	6.7	222	18.2	23	9.1
Group Home	1,908	55.7	56.8	111	66.1	25	67.6	181	67.8	258	48.6	35	27.6	251	62.4	214	51.3	670	54.8	163	64.7
Agency-Owned Apartment	163	4.8	4.7	4	2.4	1	2.7	19	7.1	42	7.9	3	2.4	13	3.2	29	7.0	35	2.9	17	6.7
Own Home/Apartment	408	11.9	10.4	12	7.1	3	8.1	9	3.4	119	22.4	9	7.1	19	4.7	82	19.7	128	10.5	27	10.7
Adult Foster Care/ Host Family Home	301	8.8	11.9	11	6.5	0	0.0	25	9.4	43	8.1	68	53.5	41	10.2	36	8.6	62	5.1	15	6.0
Nursing Home	65	1.9	1.1	2	1.2	0	0.0	0	0.0	5	0.9	2	1.6	7	1.7	1	0.2	48	3.9	0	0.0
Other	154	4.5	3.8	6	3.6	1	2.7	5	1.9	36	6.8	2	1.6	13	3.2	27	6.5	57	4.7	7	2.8
	3,423			168		37		267		531		127		402		417		1222		252	
Race/Ethnicity* (duplicated counts):																					
White	3,102	84.0	77.2	118	71.5	284	93.1	229	89.1	409	75.0	37	28.9	404	97.3	228	55.1	1171	96.5	222	88.4
Black/ African-American	210	5.7	5.4	5	3.0	14	4.6	26	10.1	127	23.3	3	2.3	1	0.2	8	1.9	23	1.9	3	1.2
Asian	91	2.5	7.0	3	1.8	1	0.3	0	0.0	2	0.4	74	57.8	0	0.0	6	1.4	3	0.2	2	0.8
American Indian/ Alaska Native	122	3.3	4.6	21	12.7	4	1.3	4	1.6	3	0.6	5	3.9	6	1.4	60	14.5	7	0.6	12	4.8
Hawaiian/ Pacific Islander	23	0.6	1.9	0	0.0	0	0.0	0	0.0	0	0.0	22	17.2	0	0.0	1	0.2	0	0.0	0	0.0
Hispanic	183	5.0	6.0	20	12.1	8	2.6	1	0.4	5	0.9	3	2.3	1	0.2	125	30.2	9	0.7	11	4.4
Mixed Races	65	1.8	3.1	4	2.4	3	1.0	1	0.4	7	1.3	18	14.1	4	1.0	15	3.6	4	0.3	9	3.6
Other/Unknown	8	0.2	0.3	1	0.6	3	1.0	0	0.0	1	0.2	1	0.8	0	0.0	0	0.0	1	0.1	1	0.4

Table B - Characteristics of Family Member with a Disability: 2006-07 Data

	Total %		State Avg.	AZ		CT		DE		GA		HI		ME		NM		PA		WY	
Number of surveys	3,791		n = 9	171		319		275		545		139		420		424		1243		255	
	n	%		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Level of MR:																					
No MR label	94	2.6	2.8	7	4.2	5	1.7	9	3.6	15	2.9	3	2.4	8	2.0	18	4.3	23	1.9	6	2.4
Mild	545	15.1	13.9	21	12.7	38	13.1	25	10.0	101	19.3	9	7.3	48	12.1	67	16.2	189	15.8	47	18.6
Moderate	1,043	28.9	30.2	55	33.3	86	29.8	80	31.9	152	29.1	34	27.4	113	28.5	105	25.4	317	26.4	101	39.9
Severe	780	21.6	22.7	40	24.2	72	24.9	55	21.9	113	21.6	34	27.4	83	21.0	84	20.3	242	20.2	57	22.5
Profound	518	14.3	13.9	22	13.3	48	16.6	27	10.8	60	11.5	19	15.3	80	20.2	68	16.4	178	14.8	16	6.3
Don't know	634	17.5	16.5	20	12.1	40	13.8	55	21.9	81	15.5	25	20.2	64	16.2	72	17.4	251	20.9	26	10.3
	3,614			165		289		251		522		124		396		414		1200		253	
Other disabilities* (duplicated counts):																					
Mental illness	835	25.0	22.3	40	24.5	45	15.7	42	16.6	141	25.9	18	15.4	90	23.6	115	28.6	279	24.1	65	26.2
Autism	401	12.0	12.3	20	12.3	51	17.8	45	17.8	64	11.7	14	12.0	56	14.7	41	10.2	95	8.2	15	6.0
Cerebral Palsy	608	18.2	17.3	31	19.0	53	18.5	37	14.6	67	12.3	20	17.1	80	21.0	84	20.9	198	17.1	38	15.3
Brain injury	384	11.6	10.3	17	10.4	20	7.0	18	7.1	68	12.5	9	7.7	39	10.2	59	14.7	123	10.6	31	12.5
Seizure disorder/ neurological problem	1,059	31.3	29.8	43	26.4	76	26.5	75	29.6	136	25.0	33	28.2	135	35.4	140	34.8	339	29.2	82	33.1
Chemical dependency	33	1.0	1.1	2	1.2	2	0.7	1	0.4	3	0.6	3	2.6	6	1.6	3	0.7	11	0.9	2	0.8
Vision or hearing impairments	835	24.9	23.3	38	23.3	63	22.0	55	21.7	108	19.8	26	22.2	92	24.1	103	25.6	283	24.4	66	26.6
Physical disability	979	29.1	27.1	37	22.7	66	23.0	66	26.1	130	23.9	28	23.9	133	34.9	120	29.9	321	27.7	78	31.5
Communication disorder	752	22.4	21.4	29	17.8	54	18.8	48	19.0	106	19.4	24	20.5	102	26.8	117	29.1	215	18.5	57	23.0
Alzheimer's disease	39	1.2	1.2	2	1.2	5	1.7	4	1.6	1	0.2	2	1.7	9	2.4	5	1.2	11	0.9	0	0.0
Down Syndrome	427	12.8	12.7	13	8.0	53	18.5	33	13.0	61	11.2	22	18.8	48	12.6	29	7.2	134	11.6	33	13.3
Other disability	539	16.2	15.9	33	20.2	42	14.6	32	12.6	64	11.7	20	17.1	54	14.2	92	22.9	161	13.9	39	15.7

Table C - Characteristics of Respondents: 2006-07 Data

STATES	Total %	State Avg.	AZ	CT	DE	GA	HI	ME	NM	PA	WY										
Number of surveys	3,791	n = 9	171	319	275	545	139	420	424	1243	255										
Age of Respondent:																					
	n	%	%	n	%	n	%	n	%	n	%	n	%								
Under 35	60	1.6	1.8	10	6.2	4	1.3	0	0.0	8	1.5	0	0.0	5	1.2	8	1.9	18	1.5	7	2.8
35 - 54	855	23.0	23.6	64	39.8	57	18.4	48	18.0	123	22.7	19	14.7	95	23.0	123	29.5	264	21.5	62	24.7
55 - 74	2,076	55.8	55.8	74	46.0	165	53.2	161	60.5	329	60.8	75	58.1	238	57.6	214	51.3	668	54.3	152	60.6
75 and Over	727	19.6	18.8	13	8.1	84	27.1	57	21.4	81	15.0	35	27.1	75	18.2	72	17.3	280	22.8	30	12.0
	3,718			161		310		266		541		129		413		417		1,230		251	
Relationship to Family Member:																					
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Parent	2,140	57.9	58.2	69	42.1	191	63.0	165	61.6	324	61.8	90	69.2	228	56.0	235	55.8	693	56.3	145	57.8
Sibling	1,040	28.1	24.4	33	20.1	74	24.4	67	25.0	119	22.7	25	19.2	121	29.7	97	23.0	458	37.2	46	18.3
Spouse	5	0.1	0.1	0	0.0	1	0.3	1	0.4	0	0.0	0	0.0	0	0.0	0	0.0	2	0.2	1	0.4
Other	513	13.9	17.3	62	37.8	37	12.2	35	13.1	81	15.5	15	11.5	58	14.3	89	21.1	77	6.3	59	23.5
	3,698			164		303		268		524		130		407		421		1,230		251	
Respondent is guardian or conservator:																					
Yes	2,425	66.9	76.4	135	80.4	270	88.2	165	62.7	210	40.0	124	93.9	420	100.0	313	76.5	541	46.9	247	98.8
Frequency of Visits with Family Member:																					
Less than once/year	158	4.6	3.5	2	1.2	0	0.0	18	6.7	11	2.0	5	3.9	9	2.2	21	5.0	81	6.6	11	4.3
1-3 times/year	420	12.2	12.4	18	10.9	4	10.8	29	10.7	37	6.9	25	19.5	39	9.4	58	13.8	169	13.8	41	16.1
4-6 times/year	468	13.6	15.0	33	20.0	8	21.6	38	14.1	57	10.6	19	14.8	71	17.1	49	11.7	163	13.3	30	11.8
7-12 times/year	521	15.1	18.1	19	11.5	2	5.4	37	13.7	63	11.7	79	61.7	77	18.6	55	13.1	151	12.3	38	14.9
More than 12 times/year	1885	54.6	50.9	93	56.4	23	62.2	148	54.8	371	68.8	0	0.0	219	52.8	237	56.4	659	53.9	135	52.9
	3,452			165		37		270		539		128		415		420		1,223		255	

Table D - Services and Support Received: 2006-07 Data

STATES	Total %		State Avg.	AZ		CT		DE		GA		HI		ME		NM		PA		WY	
	n	%	n = 9	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Residential Supports	3,473	95.8	96.8	162	97.0	283	98.6	263	98.9	455	88.2	136	98.6	401	97.8	405	98.1	1122	95.3	246	98.4
Day/Employment Supports	2,872	81.8	85.0	134	82.2	261	92.2	229	89.1	425	82.4	118	88.1	321	79.9	325	84.9	833	73.7	226	92.2
Transportation	3,323	92.5	93.7	144	86.7	266	97.4	251	96.2	497	93.4	124	92.5	399	97.6	382	94.1	1017	87.4	243	98.0
Other Services/ Supports	2,354	73.7	74.0	108	69.7	198	75.6	145	65.0	240	53.6	78	67.8	307	83.2	370	94.1	707	71.1	201	85.9

Table E - Information and Planning: 2006-07 Data

STATES	TOTAL %	STATE AVG.	AZ	CT	DE	GA	HI	ME	NM	PA	WY
Q1 - Do you get enough information to help you participate in planning services for your family member?											
Number of surveys	3,496	n = 9	162	284	257	517	131	404	404	1,089	248
% always or usually	72.8	76.0	78.4	82.7	71.6	54.9	82.4	90.1	68.6	69.2	85.9
% sometimes	20.2	18.6	18.5	13.7	25.3	30.9	13.0	8.9	22.3	21.9	12.9
% seldom or never	7.0	5.4	3.1	3.5	3.1	14.1	4.6	1.0	9.2	8.9	1.2
Q2 - If your family member has a service plan, did you help develop the plan?											
Number of surveys	3,113	n = 9	153	262	219	435	116	382	374	930	242
% always or usually	61.0	66.2	78.4	60.7	65.8	54.5	70.7	72.3	65.8	47.3	80.2
% sometimes	22.6	21.1	15.0	27.5	21.9	23.7	19.0	19.1	20.1	26.1	17.8
% seldom or never	16.5	12.7	6.5	11.8	12.3	21.8	10.3	8.6	14.2	26.6	2.1
Q3 - If your family member has a service plan, does the plan include things that are important to you?											
Number of surveys	3,115	n = 9	155	262	216	421	119	400	373	924	245
% always or usually	77.2	79.5	81.9	79.8	81.5	64.4	84.9	86.8	76.7	72.9	86.9
% sometimes	18.6	17.2	16.1	17.6	16.7	26.8	14.3	12.5	17.2	21.5	12.2
% seldom or never	4.2	3.3	1.9	2.7	1.9	8.8	0.8	0.8	6.2	5.5	0.8
Q4 - Are the staff who assist you with planning generally respectful and courteous?											
Number of surveys	3,362	n = 9	166	274	246	482	126	408	396	1,016	248
% always or usually	91.4	91.9	89.8	95.3	94.7	88.4	92.1	96.8	86.4	90.4	93.5
% sometimes	7.2	6.9	9.6	4.4	4.9	8.5	6.3	2.9	11.1	8.1	6.0
% seldom or never	1.4	1.2	0.6	0.4	0.4	3.1	1.6	0.2	2.5	1.6	0.4
Q5 - Are the staff who assist you with planning generally effective?											
Number of surveys	3,279	n = 9	163	269	242	467	126	398	385	978	251
% always or usually	75.6	76.0	78.5	83.3	74.0	66.8	76.2	87.4	66.8	76.6	74.1
% sometimes	21.5	21.4	19.0	15.2	24.8	28.1	20.6	12.1	27.8	20.3	25.1
% seldom or never	2.9	2.6	2.5	1.5	1.2	5.1	3.2	0.5	5.5	3.1	0.8
Q6 - Can you contact the staff who assist you with planning whenever you want to?											
Number of surveys	3,368	n = 9	162	278	246	484	125	406	397	1,021	249
% always or usually	84.2	84.7	78.4	86.3	85.0	78.9	90.4	93.3	74.6	84.6	90.8
% sometimes	13.2	12.9	18.5	12.2	12.6	16.1	9.6	5.2	21.7	12.9	7.6
% seldom or never	2.6	2.4	3.1	1.4	2.4	5.0	0.0	1.5	3.8	2.4	1.6

Table F - Access and Delivery of Services and Supports: 2006-07 Data

STATES	TOTAL %	STATE AVG.	AZ	CT	DE	GA	HI	ME	NM	PA	WY
Q7 - When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?											
Number of surveys	3,354	n = 9	163	273	239	493	131	350	396	1,056	253
% always or usually	80.3	81.5	79.8	83.5	79.9	71.2	88.5	84.6	76.5	81.1	88.1
% sometimes	16.3	15.7	17.8	14.7	16.3	21.7	10.7	13.4	19.9	15.5	11.1
% seldom or never	3.4	2.9	2.5	1.8	3.8	7.1	0.8	2.0	3.5	3.4	0.8
Q8 - Does your family member get the services and supports he/she needs?											
Number of surveys	3,518	n = 9	158	285	253	514	127	408	403	1,116	254
% always or usually	81.4	81.5	81.6	86.7	77.9	71.4	85.8	86.0	75.2	84.7	84.6
% sometimes	17.0	17.2	18.4	12.6	21.7	24.9	12.6	13.2	23.3	13.2	15.0
% seldom or never	1.6	1.2	0.0	0.7	0.4	3.7	1.6	0.7	1.5	2.2	0.4
Q9 - If your family member does not speak English or uses a different way to communicate (e.g., sign language), are there enough support workers available who can communicate with him/her?											
Number of surveys	1,399	n = 9	77	102	84	175	68	197	197	417	82
% always or usually	79.3	79.5	84.4	93.1	81.0	65.1	80.9	79.7	76.6	83.0	72.0
% sometimes	16.6	16.6	14.3	4.9	16.7	25.1	13.2	18.3	17.3	13.9	25.6
% seldom or never	4.1	3.9	1.3	2.0	2.4	9.7	5.9	2.0	6.1	3.1	2.4
Q10 - Does your family member have access to the special equipment or accommodations that he/she needs (e.g., wheelchairs, ramps, communication boards)?											
Number of surveys	2,030	n = 9	100	154	139	246	70	271	264	645	141
% always or usually	88.5	88.5	90.0	93.5	92.8	82.9	82.9	91.1	80.7	90.1	92.2
% sometimes	8.8	8.7	7.0	5.8	5.0	11.8	11.4	7.0	16.7	7.3	6.4
% seldom or never	2.7	2.8	3.0	0.6	2.2	5.3	5.7	1.8	2.7	2.6	1.4
Q11 - Are frequent changes in support staff a problem for your family member?											
Number of surveys	3,062	n = 9	153	249	217	450	100	344	371	956	222
% always or usually	22.2	22.6	22.9	15.7	24.4	19.3	24.0	26.5	32.9	19.9	18.0
% sometimes	45.2	45.4	36.6	49.0	47.9	43.1	36.0	46.8	45.0	42.7	61.7
% seldom or never	32.5	31.9	40.5	35.3	27.6	37.6	40.0	26.7	22.1	37.4	20.3
Q12 - Do you feel that your family member's residential setting is a healthy and safe environment?											
Number of surveys	3,604	n = 9	167	287	264	512	133	414	410	1,166	251
% always or usually	87.9	87.8	85.0	88.9	89.0	85.7	91.0	91.5	82.9	89.1	87.3
% sometimes	10.6	11.0	13.8	10.5	9.8	12.9	9.0	7.2	14.4	9.1	12.0
% seldom or never	1.5	1.2	1.2	0.7	1.1	1.4	0.0	1.2	2.7	1.8	0.8
Q13 - Do you feel that your family member's day/employment setting is a healthy and safe environment?											
Number of surveys	3,014	n = 9	145	259	231	440	108	337	338	914	242
% always or usually	88.2	87.8	86.9	91.5	87.0	85.0	87.0	91.4	82.5	90.4	88.4
% sometimes	10.6	11.1	11.0	8.1	13.0	12.7	13.0	7.4	15.7	8.5	10.3
% seldom or never	1.2	1.1	2.1	0.4	0.0	2.3	0.0	1.2	1.8	1.1	1.2

Table G - Choices and Control: 2006-07 Data

STATES	TOTAL %	STATE AVG.	AZ	CT	DE	GA	HI	ME	NM	PA	WY
Q14 - Does the agency providing residential services to your family member involve you in important decisions?											
Number of surveys	3,490	n = 9	160	286	260	493	126	405	411	1,099	250
% always or usually	76.4	78.8	79.4	86.7	76.9	67.1	84.1	92.6	69.1	72.0	81.6
% sometimes	16.7	15.7	18.1	9.8	16.2	20.7	12.7	6.2	21.9	19.1	16.8
% seldom or never	6.9	5.4	2.5	3.5	6.9	12.2	3.2	1.2	9.0	8.9	1.6
Q15 - If your family member gets day or employment services, does the agency providing these services involve you in important decisions?											
Number of surveys	2,783	n = 9	135	235	219	417	101	317	347	795	217
% always or usually	61.6	64.6	70.4	67.7	58.9	53.7	73.3	75.1	55.0	56.6	71.0
% sometimes	23.0	22.3	21.5	18.3	22.8	24.7	17.8	18.9	30.0	22.5	24.4
% seldom or never	15.5	13.0	8.1	14.0	18.3	21.6	8.9	6.0	15.0	20.9	4.6
Q16 - Do you or your family member choose the support workers that work with your family?											
Number of surveys	2,827	n = 9	143	232	211	443	96	306	349	817	230
% always or usually	15.6	17.7	19.6	9.9	13.3	9.7	32.3	15.4	17.8	14.3	27.4
% sometimes	13.4	14.1	11.2	8.2	10.0	13.8	16.7	16.3	16.3	9.9	24.8
% seldom or never	71.0	68.1	69.2	81.9	76.8	76.5	51.0	68.3	65.9	75.8	47.8
Q17 - Do you or your family member have control and/or input over the hiring and management of your family member's support workers?											
Number of surveys	2,736	n = 9	133	219	206	417	95	299	351	792	224
% always or usually	9.2	11.2	11.3	4.6	8.3	6.5	27.4	8.4	11.1	7.4	15.6
% sometimes	9.6	10.4	9.8	7.3	6.3	8.2	12.6	11.0	13.7	6.9	17.9
% seldom or never	81.1	78.4	78.9	88.1	85.4	85.4	60.0	80.6	75.2	85.6	66.5
Q18 - Do you or your family member want to have control and/or input over the hiring and management of your support workers?											
Number of surveys	2,461	n = 9	117	188	182	383	85	265	311	714	216
% always or usually	27.9	29.7	35.9	27.7	30.8	27.2	37.6	23.0	34.7	24.5	25.9
% sometimes	35.7	35.6	31.6	32.4	40.7	35.8	30.6	35.5	37.9	33.6	42.1
% seldom or never	36.4	34.7	32.5	39.9	28.6	37.1	31.8	41.5	27.3	41.9	31.9
Q19 - Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?											
Number of surveys	3,405	n = 9	156	276	250	494	127	369	397	1,085	251
% always or usually	23.8	28.2	30.8	21.0	16.0	9.3	32.3	20.6	30.2	17.7	75.7
% sometimes	10.2	11.2	16.0	10.9	7.6	6.1	17.3	10.8	10.1	10.5	11.6
% seldom or never	65.9	60.6	53.2	68.1	76.4	84.6	50.4	68.6	59.7	71.8	12.7
Q20 - Do you or your family member get to decide how this money is spent?											
Number of surveys	2,662	n = 9	132	226	195	401	94	247	333	810	224
% always or usually	21.1	23.4	29.5	15.0	12.3	9.5	28.7	32.4	29.4	17.2	36.6
% sometimes	23.1	25.0	21.2	25.7	27.2	15.7	30.9	25.5	25.2	20.2	33.0
% seldom or never	55.8	51.6	49.2	59.3	60.5	74.8	40.4	42.1	45.3	62.6	30.4

Table H - Community Connections : 2006-07 Data

STATES	TOTAL %	STATE AVG.	AZ	CT	DE	GA	HI	ME	NM	PA	WY
Q21 - If your family member wants to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help plan or who provide support help connect him/her to these supports?											
Number of surveys	2,534	n = 9	123	200	175	355	67	319	334	736	225
% always or usually	59.9	59.6	57.7	58.5	55.4	44.8	59.7	80.9	55.1	61.3	63.1
% sometimes	27.6	27.8	31.7	25.5	33.1	32.4	23.9	16.3	30.5	27.2	29.3
% seldom or never	12.5	12.6	10.6	16.0	11.4	22.8	16.4	2.8	14.4	11.5	7.6
Q22 - If your family member would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help plan or who provide support help him/her do this?											
Number of surveys	2,242	n = 9	116	157	165	334	66	304	274	635	191
% always or usually	60.8	60.3	66.4	61.1	55.8	44.3	54.5	80.3	47.8	64.3	68.6
% sometimes	25.3	25.1	23.3	23.6	32.1	32.9	19.7	16.8	31.8	23.3	22.0
% seldom or never	13.9	14.6	10.3	15.3	12.1	22.8	25.8	3.0	20.4	12.4	9.4
Q23 - Do you feel that your family member has access to community activities?											
Number of surveys	3,223	n = 9	149	252	224	471	107	380	384	1,012	244
% always or usually	65.2	65.9	67.8	67.1	53.1	53.7	64.5	86.3	63.3	62.9	74.2
% sometimes	28.9	28.3	25.5	29.0	37.1	36.5	29.9	11.1	31.0	31.2	23.0
% seldom or never	6.0	5.9	6.7	4.0	9.8	9.8	5.6	2.6	5.7	5.8	2.9
Q24 - Does your family member participate in community activities?											
Number of surveys	3,081	n = 9	145	236	206	477	101	354	376	948	238
% always or usually	44.1	44.5	48.3	50.4	28.6	36.7	40.6	59.0	43.9	42.3	50.8
% sometimes	41.3	41.7	31.7	36.0	54.9	45.9	48.5	32.5	43.1	40.2	42.9
% seldom or never	14.6	13.7	20.0	13.6	16.5	17.4	10.9	8.5	13.0	17.5	6.3

Table I - Satisfaction with Services and Outcomes: 2006-07 Data

STATES	TOTAL %	STATE AVG.	AZ	CT	DE	GA	HI	ME	NM	PA	WY
Q25 - Overall, are you satisfied with the services and supports your family member currently receives?											
Number of surveys	3,608	n = 9	163	279	265	521	128	407	416	1,179	250
% yes or most of the time	81.2	81.3	77.3	85.3	82.3	72.0	82.0	91.9	73.3	82.7	85.2
% some of the time	16.4	16.7	20.9	13.6	17.7	23.2	17.2	6.9	24.0	14.3	12.8
% no or not at all	2.4	1.9	1.8	1.1	0.0	4.8	0.8	1.2	2.6	3.0	2.0
Q26 - Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?											
Number of surveys	3,379	n = 9	164	249	249	498	124	380	396	1,078	241
% yes or most of the time	53.3	55.4	59.8	52.2	43.4	42.6	50.8	70.5	63.9	46.8	68.5
% some of the time	8.5	9.0	10.4	10.0	8.4	8.0	8.1	5.8	10.9	7.5	11.6
% no or not at all	38.2	35.7	29.9	37.8	48.2	49.4	41.1	23.7	25.3	45.7	19.9
Q27 - Are you satisfied with the way complaints/grievances are handled and resolved?											
Number of surveys	2,271	n = 9	116	155	163	336	65	274	299	688	175
% yes or most of the time	66.3	66.5	62.9	66.5	62.0	56.0	72.3	77.0	59.9	69.5	72.0
% some of the time	25.8	25.9	30.2	27.7	28.8	32.7	18.5	19.3	30.1	22.8	22.9
% no or not at all	7.8	7.6	6.9	5.8	9.2	11.3	9.2	3.6	10.0	7.7	5.1
Q28 - Do you feel that services and supports have made a positive difference in the life of your family?											
Number of surveys	3,515	n = 9	161	271	260	519	120	400	403	1,134	247
% yes or most of the time	84.0	84.9	80.1	89.3	85.4	77.3	88.3	93.3	78.9	83.2	88.7
% some of the time	14.3	13.6	18.0	9.6	13.5	20.4	10.8	6.5	19.4	14.7	9.7
% no or not at all	1.7	1.4	1.9	1.1	1.2	2.3	0.8	0.3	1.7	2.1	1.6
Q29 - Overall, do you feel that your family member is happy?											
Number of surveys	3,586	n = 9	161	277	260	532	125	405	406	1,174	246
% yes or most of the time	81.1	81.7	80.1	85.6	83.8	77.3	84.8	90.4	71.2	81.2	80.9
% some of the time	17.3	16.8	16.1	13.4	15.4	20.7	15.2	8.9	26.4	17.1	18.3
% no or not at all	1.6	1.5	3.7	1.1	0.8	2.1	0.0	0.7	2.5	1.7	0.8

APPENDIX B

Analysis of Open-Ended Comments

Additional Open-Ended Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. QSR N6 was used to code and to sort the qualitative comments by theme. The themes identified are detailed here, and the main results of this analysis are presented by state below. Most states had a majority of family comments coded into the “General Satisfaction” and “General Dissatisfaction” themes, with all states having more positive general comments about services and supports than negative comments. However, there was great variation from state to state. Therefore, the analysis below will begin by describing how each state did on the “general” themes, and then will highlight specific themes that were commented upon with the greatest frequency and provide examples of typical comments.

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

ARIZONA

Arizona had only a few more comments indicating general satisfaction with services and supports than comments indicating general dissatisfaction.

More specifically, families stated satisfaction with residential services:

I am very grateful for the group home. My son is now (there) for the past 8 months. He has made significant improvements in his health, spirit and mental being! He is very secure, and happy. I appreciate the group home management and daily staff openness in communication on a continuous basis. They have done (doing) a great job making it "home" for my son.

There were many comments pertaining to satisfaction with staff members:

The staff owners of (Provider) Home treat our son like a member of their family while being the utmost professionals. This is very important to us since he is in Arizona and we are [out-of-state]. They do everything humanly possible to provide quality of life for our son.

The lack of communication was an issue with families, mainly concerning case managers:

Would like the case manager to make monthly calls it would be nice to hear them ask what they could do for you and then do it. Too often you have to keep calling and asking how to go about requesting something.

CONNECTICUT

There were many more comments indicating general satisfaction with services and supports by Connecticut families than comments stating dissatisfaction.

Specifically, the most comments pertained to families' satisfaction with home services...

My son lived at home for many years and we were very lucky to find a wonderful group home owned by (Provider) in (Town) 7 years ago. My son is so happy. He has grown to be a wonderful young man who is so proud of his accomplishments. He is blessed with the most wonderful group of staff members who leave their personal problems at the door and make this home the best home you could ever walk into. I myself have worked in some way with handicapped people and of course staff for many years. So I know that there are all kinds of people who work in this field. I feel my son is getting the very best care he could ever receive. Every group home should be run like XX

...and satisfaction with staff members:

I feel (Name) is well cared for & respected. The staff keep me aware of my(any?) problems that oversee (medical issues). I'm comfortable with the staff when I need to ask questions or give suggestions.

Although Connecticut families are satisfied with the staff, they are concerned about the amount of staff turnover:

I am very satisfied with my sister's care – activities etc. Except a recent change in her afternoon caregiver to whom she was devoted. The caregiver was transferred within the

apartment complex without notice to me. This was very upsetting to her. She cried and cried. Almost like a grieving person. When she visited me she had trouble sleeping, unlike previous visits. I still have not spoken to the supervisor who sent a message that it was “all over”. True, my sister is better but I believe that the supervisor needs to speak to me to give me a couple of answers.

DELAWARE

Delaware had many more families indicate general satisfaction with services and supports than families who stated general dissatisfaction.

Like Arizona and Connecticut, the themes of satisfaction with home services and satisfaction with staff resonated strongly with Delaware families:

My Sister is very happy in her current home environment. We know she is taken care of in all aspects or (of?) her care which gives her Father (elderly) peace of mind for her future. The (Provider) is very helpful and capable.

I have been very happy with the way the staff and social workers have taken my daughter under their wings and made her family. I believe my daughter loves them and the staff love her very much. I can't tell you how much that means to a parent.

Although many families are satisfied with staff members, some expressed dissatisfaction with staff, agency, and provider communication; below is an example of staff communication (or the lack of):

I didn't like they took him from his own dentist and gave him a new one, without asking me. I do want to go to Doctor's appointments when he goes and I would like if someone could (tell me).

GEORGIA

The vast majority of Georgia's “general” comments indicated that families were satisfied with services and supports.

More specifically, comments related to residential services were split between those expressing satisfaction...

I, as his mother, am very happy with the personal home care where my son is staying. You ask if he is happy, I know for when I take him back he is always ready to go back. He is also happy to come home. He has learned so much since his is in the personal care home. I can rest good knowing he has people with him who care. I am not in very good health, so you can guess how good I feel, knowing he likes it there. Also, where I live and where he goes to the workshop is not very far from me. My heart goes out to the people who have chosen that kind of work-for I know it is very hard.

...and dissatisfaction:

This home is a 2 Bedroom 1Bath with a Dining Room and Living Room. Four men live here. Three are in wheelchairs at all times. The bathroom is not large enough to accommodate wheelchairs and to get a lift inside the room to lift them into the tub. These three men cannot bath themselves, but are expected to do so without assistance.

They do not have enough staff to assist them all day-meals, etc. What staff they hire usually have a back, shoulder or something wrong that they cannot lift these men. Cleanliness of the house is not good at all-floors, furniture, kitchen, etc.

Georgian families also indicated that although they are satisfied with staff members...

My nephew is cared for by a lady and her family. She cared for him in his home before my brother passed. Now he lives with her and family. He is treated and looked at like "he's part of their family". She keeps me informed on him and when a decision is needed for medical treatment, she always asks for my input or "what do you think?" I am blessed to have such a loving and caring person to care for him. I am truly thankful. (He eats better now than he ever has-as far as I know. He acts like he's happy and content.)

...staff turnover is a problem:

Biggest problem is staff turnover. It is difficult to keep up with who is in the home and who is in charge. Info I share with staff is soon lost. ISP includes outings that E enjoys, but I don't think staff are consistent in taking her-such as getting manicure and haircut. Lapse in these activities is probably related to staff turnover.

HAWAII

Hawaii had the least amount of comments of any state in the survey. Hawaiian families tended to have much more general satisfaction towards services and supports than dissatisfaction.

The majority of specific comments were related to staff and case managers/service coordinators. For both groups, families mostly expressed satisfaction:

We are fortunate to have the care and support being provided by the caregiver, case manager and all the personnel at (Provider) especially (Name) and her staff. We see that they show their love and dedication towards all the ward members

Generally with consideration of the questions asked here, all of the people of (Provider) who are involved with my son's work, training & care serve beyond the requirement of the job.

(Name) has been (Name's) case worker for many years. She has always gone out of her way to ensure (Name) has been taken care of. We feel without (Name's) guidance with (Name's) homecare & programs, (Name) would not have made such good progress.
Mahalo

NEW MEXICO

There were far more comments indicating general satisfaction with services and supports than those comments which stated general dissatisfaction.

A major topic for New Mexican families was staff. Like Georgia, most of the comments pertaining to staff had to do with families being satisfied with the staff members themselves, but dissatisfied with the amount of turnover:

I very much appreciate and consideration given my daughter by the staff of the (Provider) in (Town). These people are very dedicated to their jobs, and I truly don't know how we would exist without them!!! Please extend my heartfelt thanks to your agency and all who are involved in the lives of the mentally challenged. God bless everyone and Merry Christmas.

Biggest drawback is the staffing and constant turnover. Salaries are highly responsible for turnover, consequently resulting in unstable behaviors and emotional problems - also causing the hiring of less than qualified staff people

Families in New Mexico were also very satisfied with the residential services provided:

Our daughter, xxxxxxx, has been with (Provider) for twenty years now and has lived in various settings under their aegis! At this stage of her life, we feel grateful for her present residential setting and for the caring environment provided there! She resides with two other women who are roughly her age has her own room in the house and they (Provider) have been instrumental in helping her to lose over 100 lbs. in the time she has resided there (almost two years!) (Provider) has recently provided a person whom xxxxx is delighted with, and who takes her out and about for a few hours 4 days a week! We could not ask for more!

However, they were not very satisfied with communication. Two examples:

The system is structured in a way that limits input and involvement from loving committed parents unless they are able to keep their child in their home. When this is not possible, we become bystanders with very little say. This negatively impacts the individual in that his main support system is diminished to having to practically beg for appropriate care with no guarantees that their requests will be honored. Even when it is agreed upon and ordered by the IDT and confirmed by Metro and higher there are little, if any enforcement measures in place to insure the changes are made. Meanwhile the agencies failing to provide care are allowed to continue to fail while the parents are labeled the problem.

It has been difficult to assess and monitor our family member's service delivery, access to community, quality services... As we don't have legal authority and our family member has chosen not to sign a release to include us in his services. As a result we have very limited information about the services he is receiving. Initially when he first received the DD Waiver services about 3 or 4 yrs ago, it seemed that the serious interest from agency staff to gather historical / diagnostic info from us yet it appeared that this info was not taken into account re: how to work w/ him. The agency does not communicate with us and we are limited to what our son tells us. Very concerning! Very frustrating.

PENNSYLVANIA

Pennsylvania families were much more likely to express comments stating their general satisfaction to services and supports provided than general dissatisfaction.

In comments regarding staff, families overwhelmingly stated their satisfaction:

I thank god everyday for the wonderful care and love my son (name) receives at the (name of) home. He has learned so much thanks to the staff. Staff informs me about what he is doing, as the things he is doing is very important to me.

Families were also satisfied with residential services...

My daughter seems to be doing very well where she is residing. She is eating more variety of food. She is happy to come home with us and she is happy when she returns. We are pleased with the setting and feel it is working for her benefit.

...but, there were some who were not so satisfied:

I am in the process of finding another provider for my brother. He was in one group home for 8 years since coming out of an institution setting. The manager stole all his money. I moved him to this current home and i am very dissatisfied at this present

Similarly to New Mexico, although families were satisfied with staff and mainly satisfied with the home services being provided, they were not as satisfied with the lack of communicating between parties:

Family members live a distance away. Meetings are never scheduled w/ their interests or travel dates. Family has been disappointed in staff changes. Family doesn't know about these changes b/c of their distance.

WYOMING

Wyoming families wrote more comments stating general satisfaction with services and supports than comments stating general dissatisfaction.

Staff turnover was a main issue for Wyoming families:

The care facility where my Daughter is a client has had many staff changes in the past year causing some confusion in all areas about care plans etc. However I have always received attention to my concerns sometimes on a slow basis. It seems there is a lack of communication

While most of the other states in this survey had many comments relating to the satisfaction of staff, Wyoming families were very satisfied with the case managers/service coordinators:

(Name) has been our Case Manager for 15 years or more. She is excellent—we cannot say enough to praise her dedication and professional attention to our child and all of us. Please do not over-load her with cases, as she already works so hard! Happy New Year and good health to all. Thank you.

Additionally, while most of the other states in this survey had many comments regarding the lack of communication, Wyoming families were mostly satisfied with communication:

I just received a Christmas card with a picture of (Name). The letter was handwritten and signed by all who work with him. (Name) is great at corresponding. The communication makes it so that I can feel completely comfortable. They all are wonderful.