

Adult Family Survey

Final Report – May 2009
2007-2008 Data



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

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Organization of Report

Fifteen states conducted the National Core Indicators (NCI) Adult Family Survey during the 2007-2008 project year and submitted their data. The Adult Family Survey was administered to individuals having an adult family member with disabilities living at the family's home. This Final Report provides a summary of results, based on the data submitted by June 30, 2008.

This report is organized as follows:

I. INTRODUCTION

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

II. ADULT FAMILY SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

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

IV. RESULTS

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

I. Introduction

Overview of National Core Indicators

In December 1996, the NASDDDS Board of Directors launched the Core Indicators Project (CIP). The aim of CIP was to support state developmental disabilities authorities (SDDAs) in developing and implementing performance/outcome indicators and related data collection strategies that would enable them to measure service delivery system performance. This effort, now called National Core Indicators or NCI, 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. The Association's active sponsorship of NCI facilitates states pooling their knowledge, expertise and resources in this endeavor.

NCI Phase I began in January 1997. In August 1997, the Phase I Steering Committee selected a "candidate" set of 61 performance/outcome indicators in order to test their utility/feasibility. Six states agreed to conduct a field test of these indicators, including administering the NCI consumer and family surveys and compiling other data. Field test data were transmitted to NCI staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

NCI Phase II was launched in January 1999. Phase II data collection wrapped up in June 2000 and set the stage for continuation and further expansion of the NCI. During Phase II, the Phase I indicators were revised, and data collection tools and methods were improved. The Version 2.0 indicator set consisted of 60 performance and outcome indicators. Going forward, NCI expanded its scope to include services for children with developmental disabilities and their families, continued to develop and refine the indicators, and recruited additional states to participate in the collaboration. Phase II data are considered baseline NCI data. Phase II technical reports and other selected documents are available online at www.nationalcoreindicators.org.

Twelve states (AZ, CT, KY, MA, MN, NE, NC, PA, RI, VA, VT, WA) participated in Phase II. Four additional states joined during the following year (DE, IA, MT, UT), and seven states joined in 2001 (AL, HI, IL, IN, OK, WV, WY). Virginia, Nebraska, Iowa, Minnesota, Montana, and Utah are currently on hiatus. South Dakota, South Carolina, and Maine signed on in 2002. Arkansas, Georgia, New Mexico, and Texas joined in 2005. Over the next two years, New Jersey, Louisiana and New York joined and Missouri rejoined. Since last year's report, Ohio and New Hampshire have joined and Illinois has rejoined thus bringing the total to 30 participating states plus Orange County, CA. State participation in NCI is entirely voluntary. For a complete list of NCI states, visit www.nationalcoreindicators.org.

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	Phase X 2007-2008
AZ	AZ	AZ	AL	AL	AL	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	AR	AR	AR
MO	KY	DE	CA - RCOC	CA - RCOC	CA - RCOC	CA-RCOC	AZ	AZ	AZ
NE	MA	IA	CT	CT	CT	CT	CA-RCOC	CA-RCOC	CA-RCOC
PA	MN	KY	DE	DE	DE	DE	CT	CT	CT
VT	NE	MA	HI	HI	DC	DC	DE	DE	DE
VA	NC	MN	IL	IN	HI	HI	DC	GA	GA
	PA	MT	IN	IA	IN	KY	GA	HI	HI
	RI	NE	IA	KY	KY	MA	HI	IN	IN
	VT	NC	KY	MA	MA	ME	KY	KY	KY
	VA	PA	MA	ME	ME	NC	MA	MA	LA
	WA	RI	NE	NE	NE	OK	ME	ME	MA
		UT	NC	NC	NC	PA	NM	NM	ME
		VT	OK	OK	ND	RI	NC	NC	MO
		WA	PA	PA	OK	SC	OK	OK	NC
			RI	RI	PA	VT	PA	PA	NJ
			UT	SC	RI	WA	RI	RI	NM
			VT	SD	SC	WV	SC	SC	NY
			WA	VT	SD	WY	SD	TX	OK
			WV	WA	VT		TX	VT	PA
			WY	WV	WA		VT	WA	RI
				WY	WV		WA	WV	SC
					WY		WV	WY	TX
							WY		VT
									WA
									WV
									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. Adult Family Survey

Background

This report focuses on the Adult Family Survey.

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

During Phase II, twelve states administered the revised survey. Only minor changes were made following Phase II. Some graphics were added to make the survey more visually interesting, easier to follow, and more appealing to answer; and some of the demographic questions were reworded and clarified based on feedback from participating states. In addition, a few questions were added to gauge the level of interest in self-management of supports and services.

Between 2001 and 2008, eight to fifteen states have participated each year. Response rates within states have varied greatly, between 13% - 80%, yet each year, NCI has had between 4,000 – 6,500 completed surveys available for analysis.

State Participation

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

Table 3 State Participation in NCI Adult Family Survey (Adults Living at Home with Family)									
Phase I Field Test	Phase II 1999- 2000	Phase III 2000- 2001	Phase IV 2001- 2002	Phase V 2002- 2003	Phase VI 2003- 2004	Phase VII 2004- 2005	Phase VIII 2005- 2006	Phase IX 2006- 2007	Phase X 2007- 2008
AZ	AZ	CT	AZ	CA - RCOC	AZ	CA-RCOC	AZ	CT	AZ
CT	CT	DE	CA-RCOC	CT	CA-RCOC	CT	CA-RCOC	DE	CA-RCOC
MO	KY	IA	HI	DE	CT	HI	CT	GA	CT
NE	NE	KY	IL	HI	ME	OK	GA	HI	GA
PA	NC	MA	IA	IN	NC	PA	KY	ME	LA
VT	PA	MN	NE	IA	ND	SC	ME	NM	ME
VA	VT	MT	NC	ME	OK	WV	NC	OK	MO
	WA	NE	OK	MA	PA	WY	OK	PA	NC
		NC	PA	NC	SC		PA	VT	NJ
		PA	UT	OK	WA		SC	WV	OK
		RI	VT	PA	WV		SD	WY	PA
		UT	WA	SC	WY		WA		SC
			WV	SD			WV		WA
			WY	WV			WY		WV
				WY					WY

Survey Instrument

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

The Adult Family Survey used in 2007-2008 not only asks families to express their overall level of satisfaction with services and supports, it also probes specific aspects of the service system's capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; and outcomes. Combined, this information provides an overall picture of family satisfaction within and across states.

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

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

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

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

III. Methods

Sampling & Administration

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

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

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

Response Rates

During 2007-2008, 15 states administered the Adult Family Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis.

Table 4 Adult Family Survey - State Response Rates				
State	Surveys Mailed	Surveys Returned	Response Rate (%)	Usable Surveys
Arizona	1,000	362	36%	302
CA- Orange County	3,596	882	25%	881
Connecticut	1,200	399	33%	348
Georgia	2,000	670	34%	636
Louisiana	1,596	469	29%	453
Maine	1,500	392	26%	353
Missouri	1,100	402	37%	325
North Carolina	328	173	53%	172
New Jersey	1,000	395	40%	322
Oklahoma	1,609	575	36%	532
Pennsylvania	4,032	1,254	31%	1,051
South Carolina	3,000	400	13%	322
Washington	1,250	469	38%	411
West Virginia	1,000	190	19%	181
Wyoming	300	70	23%	32
Overall	24,511	7,102	29%	6,321

The desired response rate (the percentage of surveys returned versus the number mailed) to these surveys is 40%. Table 4 shows the response rates by state, based on the number of returned surveys entered into the database and submitted for analysis, compared to the total number mailed out.

Data Analysis

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

IV. Results

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

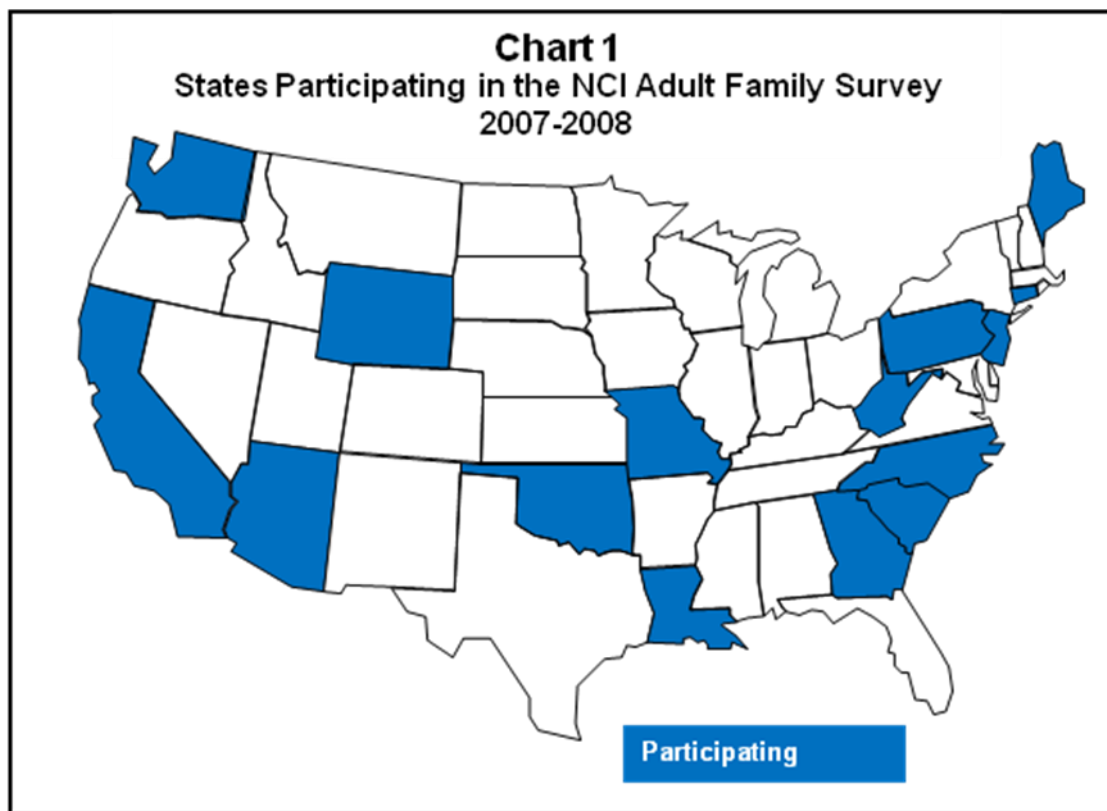
It is important to note that the TABLES provide individual state results and result averages that are calculated through two separate methods:

1. **Total Percentages** indicate the average percentage across all individual respondents.
2. **State Averages** indicate the average percentage across the fifteen states that conducted this survey.

The CHARTS and text in this section illustrate the state average results.

Participating States

- ◆ Fifteen states provided data for this Report. They include: Arizona, Connecticut, Georgia, Louisiana, Maine, Missouri, North Carolina, New Jersey, Oklahoma, Pennsylvania, South Carolina, Washington, West Virginia, Wyoming, and the Regional Center of Orange County, California.



Characteristics of Family Members with Disabilities

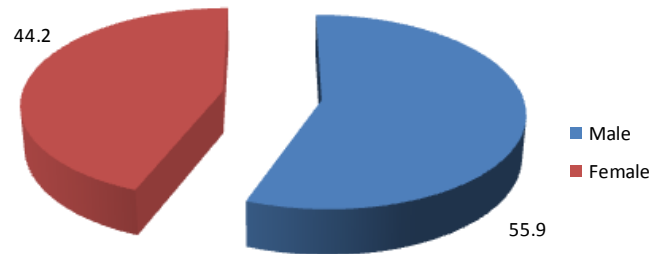
This section provides information about the individual with disabilities living in the household.

- ◆ On average, across participating sites, 56% of family members with disabilities were male, 44% were female.
- ◆ The average age of family members with disabilities was 34, with a range in age from 18 to 91.
- ◆ Seventy-four percent (74%) of the family members were White, 14% were Black/African-American, 7% were Hispanic/Latino, 3% were Asian-American, 3% were American Indian/Alaska Native, less than 1% were Native Hawaiian/Pacific Islander, and 2% were Mixed Races.
- ◆ Fourteen percent (14%) of households include more than one individual with a developmental disability.
- ◆ Almost one-third (31%) of the family members with disabilities had a diagnosis of moderate mental retardation. Additionally, 23% were individuals with severe/profound mental retardation, 21% had mild mental retardation, and 8% had no mental retardation diagnosis. Sixteen percent (16%) of respondents were unsure of their family member's diagnosis.
- ◆ Many family members experience disabilities in addition to mental retardation. The most prevalent "other" disabilities include: seizure disorders/neurological problems (29%), physical disabilities (28%), vision/hearing impairments (24%), and communication disorders (22%).

Gender of Family Member

Table 5 Gender (%)		
State	Male	Female
AZ	51.6	48.4
CA-RCOC	54.6	45.4
CT	53.2	46.8
GA	58.6	41.4
LA	55.9	44.1
ME	55.9	44.1
MO	53.9	46.1
NC	48.8	51.2
NJ	63.2	36.8
OK	58.6	41.4
PA	56.3	43.8
SC	60.5	39.5
WA	55.0	45.0
WV	52.3	47.7
WY	59.4	40.6
Total N	3,433	2,690
Total %	56.1	43.9
State Avg %	55.9	44.2

CHART 2: Gender of Family Members



Age of Family Member

Table 6		
Age of Family Member (%)		
State	Average Age	Range
AZ	32.6	18-69
CA-RCOC	32.2	18-82
CT	35.4	18-78
GA	35.5	18-83
LA	36.0	18-79
ME	32.5	18-77
MO	30.0	18-62
NC	34.1	19-81
NJ	31.5	18-91
OK	31.1	18-79
PA	35.1	18-86
SC	35.9	18-87
WA	31.7	19-76
WV	33.9	18-70
WY	42.6	21-78
Total N	6,207	
Total Avg.	33.5	
State Avg.	34.0	18-91

Race/Ethnicity of Family Member

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

Table 7 Race/Ethnicity of Family Member (%)								
State	White	Black/African American	Asian	American Indian/Alaska Native	Hawaiian/Pacific Islander	Mixed Races	Other/Unknown	Hispanic/Latino
AZ	64.8	6.6	3.4	4.5	0.3	5.2	0.3	23.4
CA-RCOC	46.2	1.6	21.9	0.9	1.0	3.0	1.4	26.3
CT	81.8	10.7	2.4	1.5	0.0	1.5	0.3	5.4
GA	63.5	33.6	1.1	0.3	0.0	1.6	0.5	2.1
LA	61.3	35.5	0.5	0.9	0.0	0.9	0.0	1.8
ME	96.2	0.9	1.2	3.5	0.3	0.3	0.9	0.6
MO	83.7	9.5	0.0	0.9	0.0	1.2	0.3	0.6
NC	61.0	33.1	1.7	2.9	0.0	1.7	2.3	1.2
NJ	69.5	17.6	6.3	1.8	0.0	1.8	0.7	12.1
OK	82.1	8.3	1.2	11.9	0.0	1.9	0.2	2.1
PA	92.1	3.7	1.4	1.5	0.2	0.5	0.2	1.7
SC	59.5	37.5	1.0	0.7	0.0	1.6	0.0	0.3
WA	77.8	5.2	6.7	3.4	1.2	5.4	1.7	7.6
WV	94.4	4.5	2.8	3.4	2.2	2.8	2.2	3.9
WY	81.3	3.1	0.0	3.1	0.0	6.3	0.0	12.5
Total N	4,498	802	299	157	22	122	41	449
Total %	73.1	13.0	4.9	2.6	0.4	2.0	0.7	7.3
State Avg %	74.3	14.1	3.4	2.7	0.3	2.4	0.7	6.8

More Than One Person with Disabilities Living in Household

Table 8		
More Than One Person in Household with a Developmental Disability (%)		
State	Yes	No
AZ	13.0	87.0
CA-RCOC	10.4	89.6
CT	11.1	88.9
GA	15.2	84.8
LA	12.1	87.9
ME	14.1	85.9
MO	20.3	79.7
NC	11.2	88.8
NJ	11.5	88.5
OK	8.3	91.7
PA	12.7	87.3
SC	13.0	87.0
WA	11.5	88.5
WV	14.6	85.4
WY	25.0	75.0
Total N	775	5,388
Total %	12.6	87.4
State Avg %	13.6	86.4

Level of Mental Retardation/Intellectual Disability of Family Member

CHART 3: Level of MR/ID of Family Member

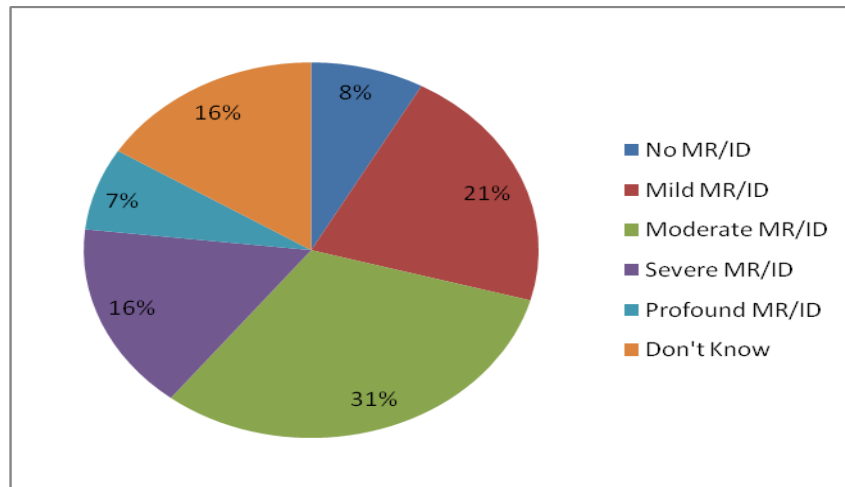


Table 9 Level of Mental Retardation of Family Member (%)						
State	No MR Diagnosis	Mild MR	Moderate MR	Severe MR	Profound MR	Don't Know
AZ	7.1	13.5	40.4	17.0	6.4	15.6
CA-RCOC	9.3	19.7	31.1	15.9	7.7	16.3
CT	3.2	29.7	34.1	11.7	2.8	18.6
GA	3.2	17.8	34.3	19.6	10.6	14.4
LA	11.5	18.1	30.0	17.1	9.9	13.4
ME	5.8	25.1	33.3	13.1	3.1	19.6
MO	13.8	22.8	23.5	18.5	5.0	16.4
NC	3.7	16.7	32.1	17.9	14.2	15.4
NJ	17.8	11.1	27.4	17.8	4.8	21.1
OK	2.9	18.1	32.9	21.0	9.8	15.4
PA	1.8	24.0	37.6	11.1	5.4	20.1
SC	16.6	10.3	26.2	18.5	9.9	18.5
WA	6.4	13.6	33.6	19.7	5.4	21.3
WV	2.8	21.6	36.9	21.0	8.5	9.1
WY	16.1	58.1	16.1	3.2	0.0	6.5
Total N	411	1,172	1,966	984	433	1,025
Total %	6.9	19.6	32.8	16.4	7.2	17.1
State Avg %	8.1	21.3	31.3	16.2	6.9	16.1

Family Member's Disabilities – Other than Mental Retardation

Table 10A						
Other Disabilities of Family Member (%)						
State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
AZ	14.5	16.6	17.0	7.6	27.3	1.7
CA-RCOC	13.5	15.1	17.7	8.7	23.6	0.9
CT	13.4	13.4	15.4	4.3	24.8	0.7
GA	18.4	15.3	19.7	10.4	32.5	0.6
LA	15.4	13.7	21.4	11.8	32.2	1.2
ME	18.7	17.8	12.1	6.9	24.0	0.6
MO	18.5	18.8	20.3	9.2	27.4	0.3
NC	12.8	15.1	23.8	5.8	32.6	0.0
NJ	14.8	18.9	17.9	8.6	30.2	0.7
OK	12.8	12.4	30.1	10.6	36.6	1.2
PA	15.5	10.2	16.9	8.0	25.8	1.2
SC	17.3	15.0	19.0	15.3	32.3	0.7
WA	17.4	18.2	21.5	10.0	30.7	0.5
WV	25.0	15.3	28.4	14.8	42.0	3.4
WY	19.4	0.0	12.9	9.7	19.4	3.2
Total N	954	880	1,177	559	1,748	58
Total %	15.9	14.6	19.6	9.3	29.0	1.0
State Avg %	16.5	14.4	19.6	9.4	29.4	1.1

Table 10B						
Other Disabilities of Family Member (%)						
State	Vision/Hearing Impairment	Physical Disability	Communication Disorder	Alzheimer's Disease	Down Syndrome	Other Disability
AZ	23.9	29.4	20.1	1.4	24.2	20.8
CA-RCOC	19.6	22.8	19.4	0.9	16.0	15.8
CT	23.2	18.3	13.4	0.7	21.3	17.0
GA	24.4	27.8	23.1	0.5	15.6	16.4
LA	26.7	34.9	23.6	0.5	14.7	19.5
ME	26.2	22.8	23.4	0.0	19.9	18.4
MO	22.8	24.4	18.8	0.0	12.9	18.2
NC	23.8	27.3	20.3	0.6	11.6	16.9
NJ	19.6	25.4	20.3	1.4	20.3	22.7
OK	28.0	34.6	29.3	1.0	16.5	20.5
PA	22.7	22.3	17.7	0.2	22.5	14.8
SC	24.8	34.7	25.5	1.7	13.6	17.7
WA	25.6	33.8	25.8	1.3	22.3	23.3
WV	34.1	38.6	35.8	2.3	12.5	26.7
WY	16.1	16.1	12.9	0.0	9.7	25.8
Total N	1,438	1,639	1,311	45	1,078	1,096
Total %	23.9	27.2	21.8	0.7	17.9	18.2
State Avg %	24.1	27.5	22.0	0.8	16.9	19.6

Characteristics of Respondents

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

- ◆ Across all states, 49% of respondents (individuals who completed the surveys) fell into the age category of 55 to 74 years old. Ten (10%) percent of respondents were over age 75, and the remaining 42% were under 55.
- ◆ The vast majority of respondents were parents of adult children with disabilities (82%). The remaining respondents included siblings (8%), spouses (1%), and others (9%).
- ◆ Ninety-four (94%) percent of all respondents considered themselves to be the primary caregiver for their family member with disabilities. This was consistent across all of the states except for Wyoming.
- ◆ Almost two-thirds (65%) of respondents indicated that they were their family member's legal guardian or conservator. Across the states, results varied from 45% in Wyoming and Orange County, CA, to 79% in Connecticut and North Carolina.
- ◆ Most respondents (71%) indicated that they were in good or excellent health, however over one-quarter of respondents (29%) categorized their health as being fair or poor.
- ◆ Half (50%) of respondents had an annual household income (including all wage earners within the household) of \$25,000 or less. Twenty-six percent (26%) had a household income between \$25,001 and \$50,000, and 25% had an income over \$50,000.

Age of Respondent

Table 11				
Age of Respondent (%)				
State	Under 35	35-54	55-74	75 or Older
AZ	5.1	47.1	40.7	7.1
CA-RCOC	4.3	34.9	47.1	13.7
CT	4.5	29.2	53.9	12.3
GA	3.0	32.5	54.5	10.0
LA	3.6	37.3	46.6	12.4
ME	2.6	42.9	47.3	7.2
MO	5.7	41.4	42.7	10.2
NC	2.3	37.8	52.3	7.6
NJ	4.7	37.5	48.3	9.5
OK	3.8	37.0	50.4	8.9
PA	3.1	35.0	47.9	14.0
SC	3.5	35.9	50.8	9.8
WA	3.7	31.4	56.6	8.3
WV	5.5	39.8	46.4	8.3
WY	15.6	34.4	43.8	6.3
Total N	241	2,250	3,046	672
Total %	3.9	36.2	49.1	10.8
State Avg %	4.7	36.9	48.6	9.7

Relationship of Respondent to Individual with Disabilities

Table 12				
Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
AZ	80.0	9.8	0.3	9.8
CA-RCOC	90.0	6.6	0.1	3.3
CT	83.5	11.4	0.3	4.8
GA	81.4	8.9	1.0	8.8
LA	80.0	11.0	0.5	8.6
ME	81.5	8.8	0.9	8.8
MO	91.6	1.9	0.6	5.8
NC	88.5	7.9	0.0	3.6
NJ	91.1	4.8	1.4	2.7
OK	88.0	4.2	0.0	7.8
PA	86.0	9.5	0.1	4.4
SC	76.0	8.0	2.2	13.8
WA	88.3	6.7	0.0	5.0
WV	81.1	9.4	1.1	8.3
WY	35.5	16.1	3.2	45.2
Total N	5,238	487	31	408
Total %	85.0	7.9	0.5	6.6
State Avg %	81.5	8.3	0.8	9.4

Respondent's Role as Primary Caregiver

Table 13		
Respondent is Primary Caregiver (%)		
State	Yes	No
AZ	94.6	5.4
CA-RCOC	95.6	4.4
CT	95.5	4.5
GA	97.8	2.2
LA	95.0	5.0
ME	97.1	2.9
MO	94.9	5.1
NC	97.0	3.0
NJ	97.9	2.1
OK	96.9	3.1
PA	97.9	2.1
SC	97.4	2.6
WA	92.3	7.7
WV	92.7	7.3
WY	66.7	33.3
Total N	5,921	242
Total %	96.1	3.9
State Avg %	94.0	6.0

Respondent's Role as Guardian or Conservator

Table 14 Respondent is Legal Guardian or Conservator (%)		
State	Yes	No
AZ	65.0	35.0
CA-RCOC	45.0	55.0
CT	79.4	20.6
GA	49.6	50.4
LA	70.6	29.4
ME	75.0	25.0
MO	67.9	32.1
NC	78.8	21.2
NJ	71.2	28.8
OK	65.0	35.0
PA	57.8	42.2
SC	63.1	36.9
WA	62.5	37.5
WV	73.6	26.4
WY	45.2	54.8
Total N	3,677	2,257
Total %	62.0	38.0
State Avg %	64.6	35.4

Health of Respondent

Table 15 Health of Respondent (%)				
State	Excellent	Good	Fair	Poor
AZ	25.0	55.8	17.5	1.7
CA-RCOC	19.2	54.5	21.1	5.3
CT	18.8	55.0	22.4	3.8
GA	15.7	54.8	23.8	5.7
LA	12.9	46.3	32.0	8.8
ME	23.6	55.6	17.4	3.4
MO	13.1	48.9	31.6	6.4
NC	20.1	51.5	22.5	5.9
NJ	15.3	53.9	28.1	2.7
OK	22.6	55.9	16.5	5.0
PA	18.1	53.9	24.4	3.6
SC	14.6	46.9	32.4	6.1
WA	20.8	55.3	19.8	4.2
WV	17.4	56.2	24.7	1.7
WY	22.6	41.9	25.8	9.7
Total N	1,136	3,300	1,454	294
Total %	18.4	53.4	23.5	4.8
State Avg %	18.7	52.4	24.0	4.9

Household Income

Table 16					
Household Income (%)					
State	Below \$15,000	\$15,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	Over \$75,000
AZ	28.0	19.5	30.5	12.2	9.8
CA-RCOC	21.4	20.1	24.3	16.8	17.5
CT	19.4	16.5	26.2	19.0	19.0
GA	29.7	20.5	24.0	14.6	11.1
LA	40.3	21.7	21.9	8.6	7.6
ME	Question not asked in Maine				
MO	32.4	23.0	23.4	10.8	10.4
NC	24.7	20.5	28.8	9.6	16.4
NJ	21.0	18.3	20.2	18.3	22.2
OK	20.6	21.5	30.7	14.6	12.6
PA	26.8	25.8	26.5	13.2	7.6
SC	35.7	17.7	26.1	12.0	8.5
WA	18.8	20.4	31.8	16.3	12.8
WV	28.6	31.2	25.3	9.1	5.8
WY	57.1	17.9	17.9	7.1	0.0
Total N	1,346	1,085	1,310	702	609
Total %	26.6	21.5	25.9	13.9	12.1
State Avg %	28.9	21.0	25.5	13.0	11.5

Services and Supports Received

- ◆ Across participating states, on average, day/employment and transportation services were the supports most often provided (65% and 59% respectively) to the family member with disabilities.
- ◆ Additionally, 39% received financial support, 39% obtained in-home supports, 29% utilized out-of-home respite care obtained in-home supports, and 27% received other needed supports.

Table 17						
Services and Supports Received (%)						
State	Financial support	In-home support	Out-of-home respite care	Day / employment supports	Transportation	Other
AZ	31.0	48.4	50.5	67.6	56.6	30.7
CA-RCOC	50.7	30.4	25.1	57.1	55.3	16.2
CT	39.1	20.2	31.2	86.7	75.2	18.1
GA	33.4	23.2	21.8	82.9	72.7	21.7
LA	30.4	67.3	29.2	44.0	47.5	15.3
ME	37.7	24.9	21.7	78.3	72.2	27.4
MO	33.6	31.2	27.8	52.9	51.4	23.5
NC	28.2	56.6	32.5	66.1	52.7	16.5
NJ	51.4	22.1	21.2	66.4	63.5	25.5
OK	36.6	71.3	15.2	48.2	45.9	34.1
PA	43.7	24.5	30.0	70.6	61.2	25.2
SC	41.7	37.7	26.4	59.4	58.0	21.0
WA	52.7	29.8	46.5	47.8	45.4	25.5
WV	40.2	56.6	43.6	66.9	61.9	44.8
WY	37.0	36.7	16.7	73.3	67.7	56.3
Total N	2,269	2,188	1,702	3,853	3,535	1,416
Total Avg. %	40.7	36.4	28.5	63.8	58.5	23.9
State Avg %	39.2	38.7	29.3	64.5	59.1	26.8

National Core Indicators

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

For each question, a Figure and Table is provided.

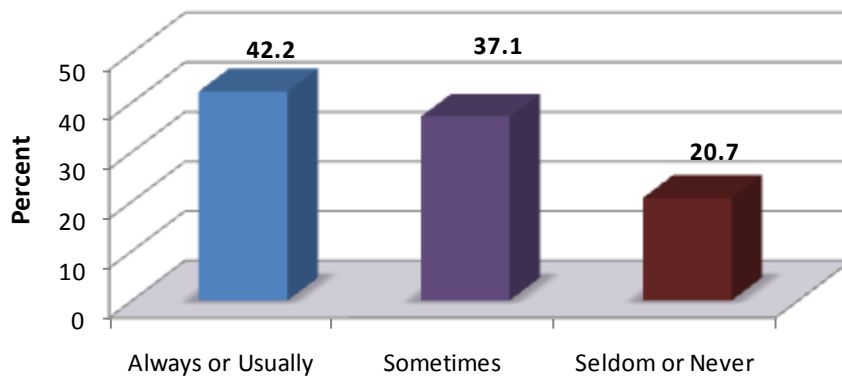
- ◆ The Figure illustrates the State Average results (i.e., the average percentage across the eleven states that conducted this survey).
- ◆ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state 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

- Across all participating states, fewer than half (42%) of respondents indicated they always or usually receive information about the services and supports available to them. Individual state results varied considerably, ranging from 23% in New Jersey to 70% in Wyoming.
- Among those who receive information, over half (53%) found the information easy to understand, while the remaining 47% found the information, at least sometimes, difficult to understand.
- Half of the respondents (50%) stated that they got enough information to help them participate in planning, while the other half indicated they only sometimes, seldom, or never had enough information.
- Three-fourths (75%) of respondents indicated that they helped in developing their family member's service plan.
- Of those families with a service plan, 71% stated that the plan included things important to the respondent. Twenty-nine percent (29%) of respondents indicated that the plan only sometimes, seldom or never included things important to them.
- Over half (61%) of respondents indicated that planning staff would help them figure out the supports they needed. However, a large percentage (39%) stated that this was only sometimes, seldom, or never the case.
- Just over three-fourths (79%) of respondents felt that staff respect their choices and opinions.
- Nine of ten (89%) respondents felt that agency staff were generally respectful and courteous.
- Sixty-six percent (66%) of all respondents felt that agency staff were generally effective.
- Seventy-six percent (76%) of respondents indicated they could typically contact staff when desired.

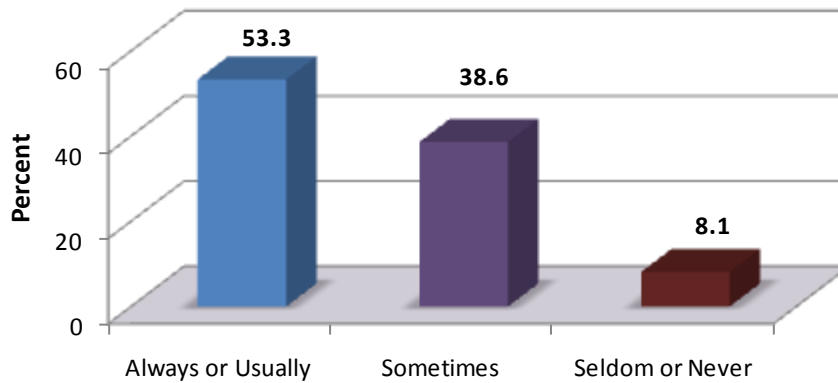
Chart Q1 Do you receive information about the services and supports that are available to your family?



2007-08 Average for 15 States

Table Q1					
Do you receive information about the services and supports that are available to your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		43.6	36.2	20.2	287
CA-RCOC	↑↑	54.8	34.9	10.3	843
CT		41.6	42.3	16.1	305
GA	↓↓	26.1	41.5	32.4	605
LA	↑	46.5	34.9	18.6	424
ME		38.8	41.4	19.8	343
MO		41.2	38.6	20.1	308
NC	↓	33.1	40.5	26.4	163
NJ	↓↓	22.8	41.8	35.4	285
OK		41.7	41.9	16.3	520
PA		46.4	36.7	16.9	984
SC		41.0	35.9	23.1	290
WA		40.2	38.9	20.9	378
WV		44.5	41.6	13.9	173
WY	↑↑	70.0	10.0	20.0	30
Total %		42.0	38.3	19.7	5,938
State Avg %		42.2	37.1	20.7	

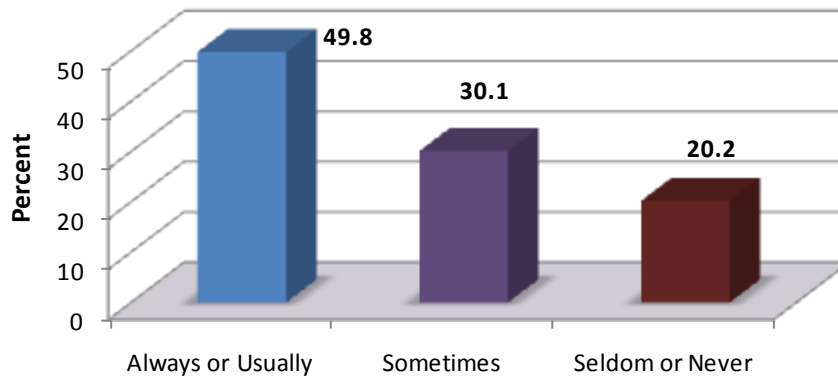
Chart Q2 If you receive information, is it easy to understand?



2007-08 Average for 15 States

Table Q2					
If you receive information, is it easy to understand? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		55.1	36.1	8.7	263
CA-RCOC	↑↑	70.5	25.7	3.8	787
CT	↓	46.8	46.8	6.4	280
GA	↓↓	41.0	47.3	11.7	529
LA		49.9	41.9	8.2	401
ME		50.5	42.0	7.5	307
MO		56.7	37.2	6.0	282
NC	↓	46.5	42.4	11.1	144
NJ	↓	46.5	41.6	11.9	226
OK		53.9	40.5	5.7	477
PA	↑	59.3	35.1	5.6	909
SC		57.8	32.8	9.3	268
WA		49.6	44.5	5.9	339
WV		48.5	47.3	4.2	165
WY	↑↑	66.7	18.5	14.8	27
Total %		54.6	38.3	7.1	5,404
State Avg %		53.3	38.6	8.1	

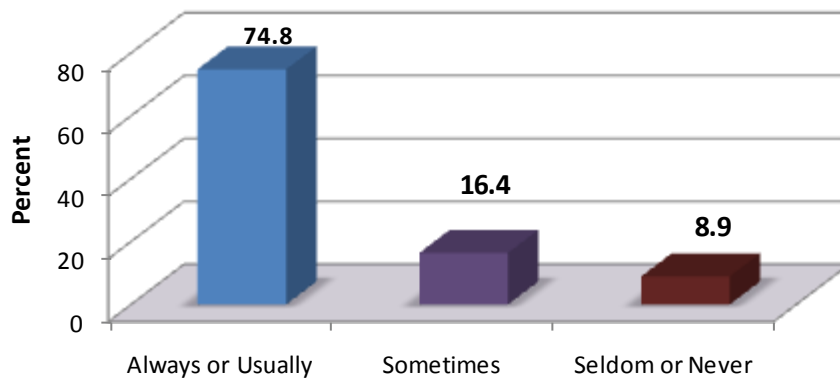
Chart Q3 Do you get enough information to help you participate in planning services for your family?



2007-08 Average for 15 States

Table Q3					
Do you get enough information to help you participate in planning services for your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		47.0	34.2	18.8	266
CA-RCOC	↑	55.7	30.1	14.2	767
CT		45.4	39.9	14.7	273
GA	↓↓	36.4	32.9	30.7	566
LA		53.7	27.6	18.7	402
ME	↑↑	61.6	24.8	13.7	315
MO		50.2	30.0	19.8	293
NC		46.8	32.5	20.8	154
NJ	↓↓	18.8	34.7	46.5	245
OK		53.4	31.0	15.7	504
PA	↑	55.7	29.0	15.3	931
SC		48.1	27.2	24.7	283
WA	↓	44.4	31.3	24.3	358
WV		54.4	31.4	14.2	169
WY	↑↑	75.0	14.3	10.7	28
Total %		49.6	30.6	19.8	5,554
State Avg %		49.8	30.1	20.2	

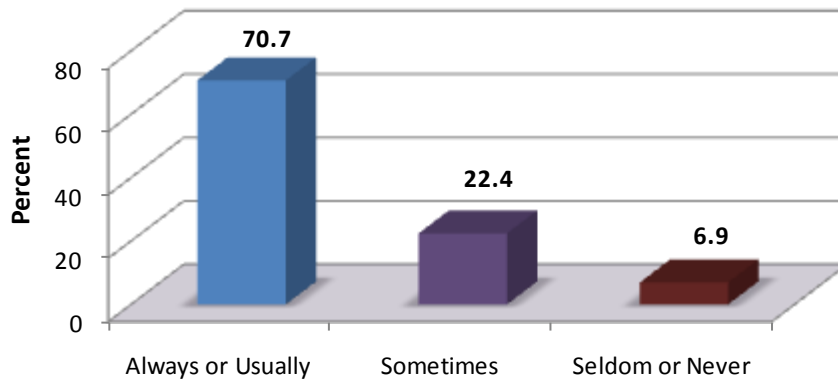
Chart Q4 If your family member has a service plan, did you help develop the plan?



2007-08 Average for 15 States

State		Always or Usually	Sometimes	Seldom or Never	N
AZ		75.6	14.9	9.5	242
CA-RCOC		71.0	17.7	11.3	637
CT		75.1	15.7	9.2	217
GA	⇓⇓	61.8	23.7	14.5	518
LA		77.8	15.0	7.2	347
ME	↑	80.1	12.7	7.1	322
MO	↑	81.0	9.9	9.2	273
NC	↑	80.7	15.2	4.1	145
NJ	⇓⇓	51.9	30.1	18.0	133
OK	↑	83.1	11.5	5.4	485
PA		76.9	14.9	8.2	785
SC	↓	69.5	17.6	12.9	256
WA		77.4	15.0	7.7	287
WV	↑	81.6	13.5	4.9	163
WY		78.6	17.9	3.6	28
Total %		74.7	16.0	9.2	4,838
State Avg %		74.8	16.4	8.9	

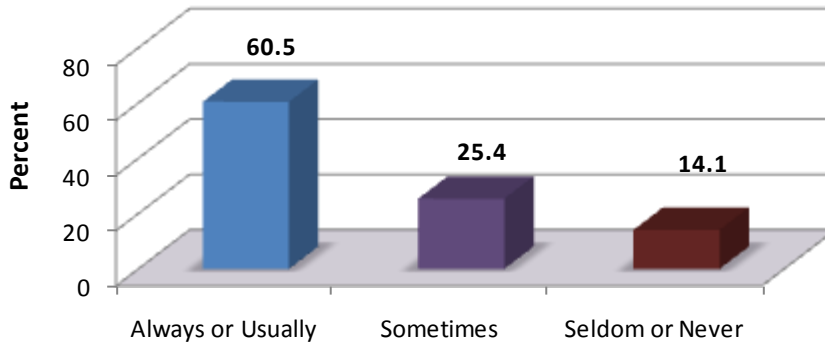
Chart Q5 If your family member has a service plan, does the plan include things that are important to you?



2007-08 Average for 15 States

Table Q5					
If your family member has a service plan, does the plan include things that are important to you? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		69.9	22.2	7.9	239
CA-RCOC		66.1	25.2	8.7	634
CT		66.4	28.4	5.2	211
GA	↓↓	54.8	35.1	10.2	502
LA		74.6	20.2	5.2	366
ME	↑	78.1	17.3	4.6	324
MO		74.9	16.4	8.7	275
NC		71.6	24.3	4.1	148
NJ	↓↓	48.6	32.6	18.8	138
OK	↑	79.4	16.9	3.7	486
PA		73.0	21.5	5.5	795
SC		67.5	23.2	9.3	246
WA		69.3	24.4	6.3	287
WV	↑	76.6	21.0	2.4	167
WY	↑↑	90.0	6.7	3.3	30
Total %		70.0	23.1	6.9	4,848
State Avg %		70.7	22.4	6.9	

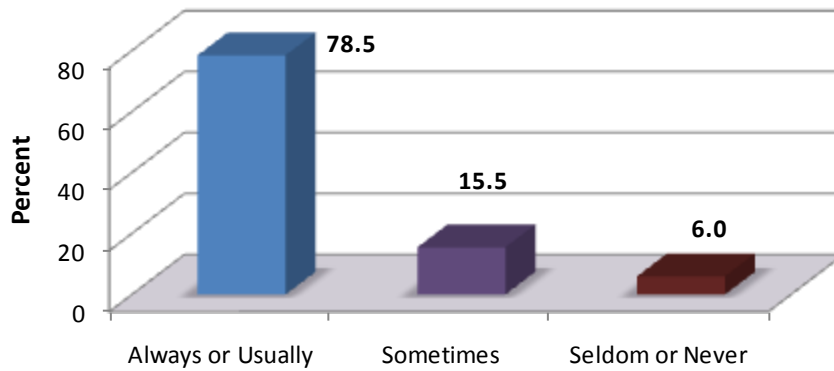
Chart Q6 Do the staff who assist you with planning help you figure out what you need as a family to support your family member?



2007-08 Average for 15 States

Table Q6					
Do the staff who assist you with planning help you figure out what you need as a family to support your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ	↓	52.3	30.5	17.2	262
CA-RCOC	↓	53.6	31.2	15.2	791
CT		65.4	25.7	8.9	237
GA	↓↓	45.8	33.7	20.5	552
LA	↑	68.0	22.3	9.7	381
ME		64.9	24.5	10.6	322
MO		59.3	27.2	13.4	290
NC		63.9	21.8	14.3	147
NJ	↓↓	39.9	26.4	33.7	163
OK	↑	66.1	24.2	9.7	505
PA		64.1	25.4	10.5	846
SC		56.7	29.1	14.2	268
WA		59.8	25.0	15.2	316
WV		61.5	30.5	8.0	174
WY	↑↑	86.2	3.4	10.3	29
Total %		59.0	27.3	13.7	5,283
State Avg %		60.5	25.4	14.1	

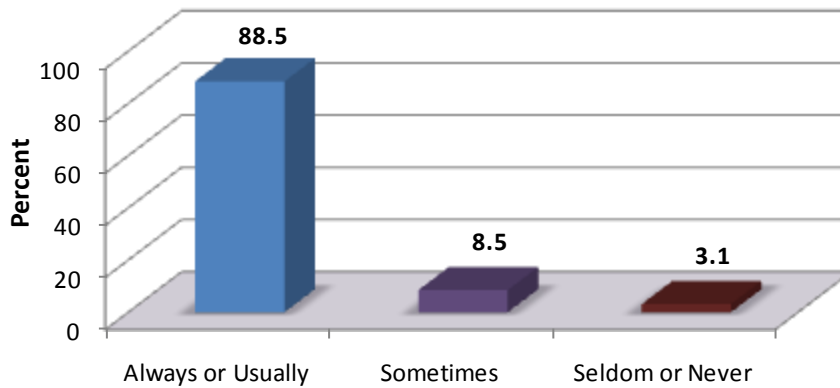
Chart Q7 Do the staff who assist you with planning respect your choices and opinions?



2007-08 Average for 15 States

Table Q7 Do the staff who assist you with planning respect your choices and opinions? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		73.9	18.9	7.2	264
CA-RCOC		82.9	13.9	3.2	789
CT		79.4	14.8	5.8	243
GA	↓	70.1	20.0	9.9	546
LA	↑	83.8	13.1	3.1	388
ME		81.5	13.9	4.5	330
MO		82.1	14.0	3.9	285
NC		80.7	13.3	6.0	150
NJ	↓↓	67.3	15.2	17.5	171
OK		79.4	16.0	4.6	501
PA		80.1	16.6	3.4	864
SC		74.4	18.8	6.8	266
WA		78.9	16.0	5.1	313
WV		76.2	21.5	2.3	172
WY	↑	86.7	6.7	6.7	30
Total %		78.7	16.0	5.3	5,312
State Avg %		78.5	15.5	6.0	

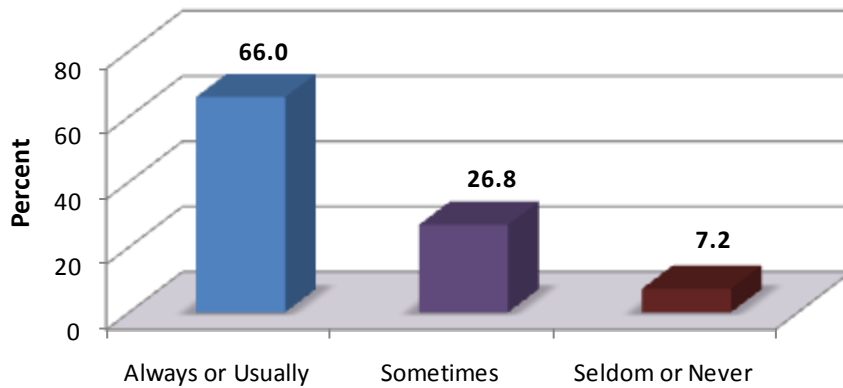
Chart Q8 Are the staff who assist you with planning generally respectful and courteous?



2007-08 Average for 15 States

Table Q8				
Are the staff who assist you with planning generally respectful and courteous? (%)				
State	Always or Usually	Sometimes	Seldom or Never	N
AZ	84.8	11.5	3.7	270
CA-RCOC	90.9	7.9	1.2	843
CT	90.9	6.6	2.5	243
GA	83.9	11.9	4.2	553
LA	90.7	7.8	1.5	399
ME	90.5	7.4	2.1	336
MO	91.5	6.1	2.4	295
NC	88.9	8.5	2.6	153
NJ	85.7	7.4	6.9	175
OK	88.1	10.1	1.8	504
PA	91.6	7.1	1.4	888
SC	84.5	13.0	2.5	277
WA	90.9	7.0	2.1	330
WV	87.5	11.4	1.1	176
WY	86.7	3.3	10.0	30
Total %	89.1	8.7	2.3	5,472
State Avg %	88.5	8.5	3.1	

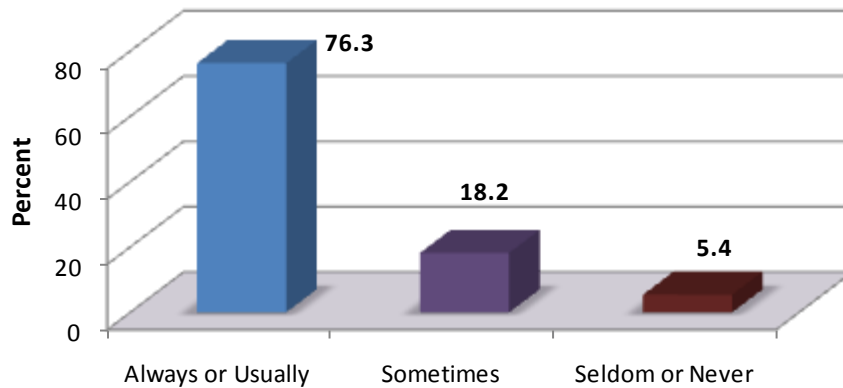
Chart Q9 Are the staff who assist you with planning generally effective?



2007-08 Average for 15 States

Table Q9					
Are the staff who assist you with planning generally effective? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ	↓	59.3	33.3	7.4	270
CA-RCOC	↑	71.8	22.7	5.5	799
CT		70.9	23.1	6.0	234
GA	↓↓	54.2	35.8	10.0	548
LA	↑	72.4	22.4	5.1	392
ME		70.2	23.2	6.6	332
MO		67.0	26.0	6.9	288
NC		69.6	25.7	4.7	148
NJ	↓↓	50.9	33.1	16.0	175
OK	↑	72.3	23.5	4.2	502
PA	↑	71.7	22.9	5.4	865
SC		61.1	28.1	10.7	270
WA		62.5	31.9	5.6	323
WV		63.6	33.0	3.4	176
WY	↑	72.4	17.2	10.3	29
Total %		66.9	26.4	6.6	5,351
State Avg %		66.0	26.8	7.2	

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



2007-08 Average for 15 States

Table Q10					
Can you contact the staff who assist you with planning whenever you want to? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ	↓	69.2	22.3	8.4	273
CA-RCOC		73.4	21.7	4.9	831
CT	↑	81.6	14.2	4.2	239
GA	↓	70.5	22.4	7.1	549
LA	↑	82.1	15.1	2.8	397
ME	↑	85.1	11.6	3.3	335
MO		79.7	15.8	4.5	291
NC	↑	82.9	13.2	3.9	152
NJ	↓↓	61.9	23.2	14.9	181
OK		76.4	20.0	3.6	504
PA		80.7	14.9	4.4	892
SC		74.4	22.1	3.6	281
WA		71.6	24.5	4.0	327
WV		79.5	18.7	1.8	171
WY		75.9	13.8	10.3	29
Total %		76.4	18.7	4.9	5,452
State Avg %		76.3	18.2	5.4	

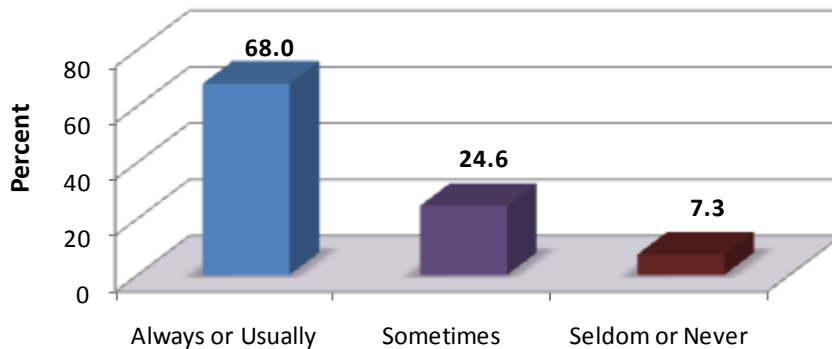
Access to and Delivery of Services and Supports

- Overall, 68% of families indicated their service coordinator helped them get needed supports when asked. Twenty-five percent (25%) said this happened sometimes, and the remaining 7% indicated their service coordinator was rarely or never helpful in getting the assistance needed.
- Over half (57%) of respondents always or usually received the services/supports needed. Thirty-two percent (32%) got them sometimes, while 10% seldom or never received needed supports.
- The majority (55%) said the supports received met their families' needs. Thirty-five percent (35%) stated that supports sometimes met their needs, while 10% felt supports seldom/never met their needs.
- For just over one-half of families (53%), supports were always or usually available when needed. However, almost as many families indicated that supports were only sometimes available (35%), seldom or not available (12%) when needed.
- Forty percent (40%) of respondents stated that families in their area asked for different types of supports than the ones that were currently being offered.
- On the occasions when families did request different types of supports, 41% indicated that the state agency or provider agency was usually or always responsive to these requests.
- Slightly more than half (52%) of families who asked for assistance in an emergency or crisis received help right away.
- Among respondents whose first language was not English, 72% indicated that staff or translators were available to speak with them in their preferred languages. Eleven percent (11%) indicated that staff/translators were sometimes available, and 17% stated that staff/translators who spoke in the families' preferred languages were seldom or not available.
- Among respondents with family members who did not speak English, or used a different means to communicate (e.g., sign language), just over half (53%) of families said there were enough support staff regularly available who could communicate with their family member.
- Just over three-fifths of respondents (61%) felt their family member had access to the special equipment or accommodations needed.
- Most respondents (88%) felt they had access to health services for their family member.
- Compared to access to health care, fewer families (74%) felt they had access to appropriate dental services for their family member. Sixteen percent (16%) had seldom or no access to dental services.¹
- Nearly all respondents (93%) felt they had access to necessary medications for their family member with a disability.

¹ The State of Arizona indicated that their legislature had provided specific state funding for Adult Dental for the first time ever in State FY2008. Because of the significant budget shortfall in State FY2009, the legislature removed the funding.

- Over half of respondents (58%) indicated that frequent changes in support staff were a problem for their family at least some of the time.
- When the family member with a disability received day/employment supports, the vast majority of respondents (84%) felt that day/employment setting was a safe and healthy environment.
- Approximately nine out of ten families (89%) felt that support staff were respectful and courteous.

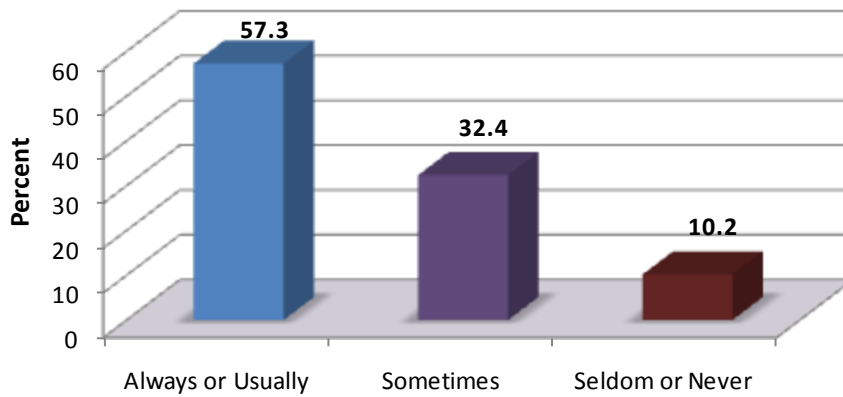
Chart Q11 When you ask the service/support coordinator for assistance, does he/she help you get what you need?



2007-08 Average for 15 States

Table Q11					
When you ask the service/support coordinator for assistance, does he/she help you get what you need? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ	↓	61.6	28.2	10.2	284
CA-RCOC		66.1	27.3	6.7	796
CT		67.1	24.3	8.6	243
GA	↓↓	55.7	29.4	14.9	558
LA		71.5	23.2	5.3	393
ME		68.2	27.4	4.4	318
MO		64.7	28.7	6.6	289
NC		69.7	23.0	7.2	152
NJ	↓↓	48.2	35.9	15.9	220
OK	↑	74.3	20.7	5.0	518
PA		72.0	23.5	4.5	898
SC		67.6	25.2	7.2	290
WA		71.6	22.5	5.8	377
WV	↑	73.4	22.6	4.0	177
WY	↑↑	88.5	7.7	3.8	26
Total %		67.2	25.5	7.3	5,539
State Avg %		68.0	24.6	7.3	

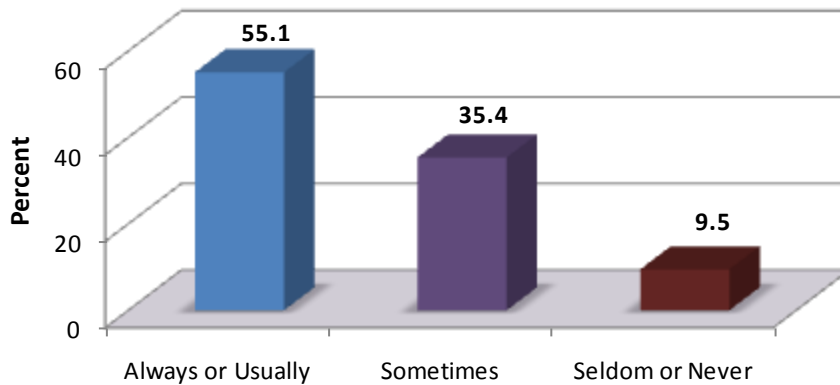
Chart Q12 Does your family get the services and supports you need?



2007-08 Average for 15 States

Table Q12					
Does your family get the services and supports you need? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		58.8	31.8	9.4	277
CA-RCOC		58.5	31.6	9.9	779
CT		55.0	38.2	6.8	251
GA	↓↓	45.2	41.2	13.6	588
LA	↑	65.1	26.8	8.2	392
ME	↑	63.2	30.8	6.0	318
MO	↓	51.5	36.6	11.9	303
NC		55.1	34.0	10.9	156
NJ	↓↓	32.3	42.2	25.6	223
OK	↑	62.4	31.1	6.5	521
PA	↑	64.8	26.9	8.3	921
SC		54.7	33.4	11.8	287
WA		53.3	39.4	7.3	368
WV		57.9	35.4	6.7	178
WY	↑↑	82.1	7.1	10.7	28
Total %		57.1	33.1	9.8	5,590
State Avg %		57.3	32.4	10.2	

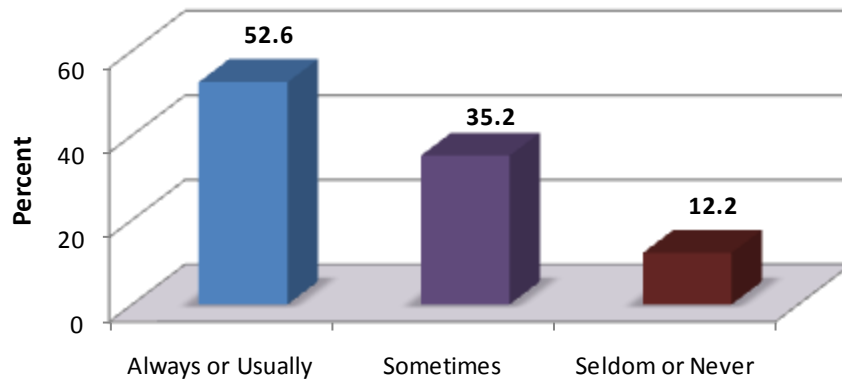
Chart Q13 Do the services and supports offered meet your family's needs?



2007-08 Average for 15 States

Table Q13					
Do the services and supports offered meet your family's needs? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		55.7	38.6	5.7	280
CA-RCOC	↑	60.1	32.3	7.7	781
CT		54.2	39.0	6.8	251
GA	↓↓	44.4	42.7	12.8	576
LA	↑	60.8	32.3	7.0	400
ME		59.9	32.4	7.7	324
MO		55.1	35.5	9.5	296
NC		53.6	37.1	9.3	151
NJ	↓↓	31.4	44.2	24.3	226
OK	↑	60.4	34.2	5.4	518
PA	↑	61.2	31.0	7.8	898
SC		52.8	35.6	11.6	284
WA		51.2	40.4	8.3	361
WV		54.0	42.0	4.0	176
WY	↑↑	71.4	14.3	14.3	28
Total %		55.5	35.7	8.8	5,550
State Avg %		55.1	35.4	9.5	

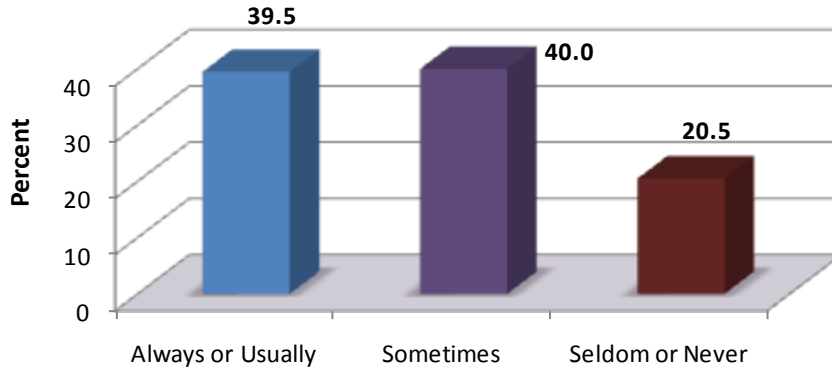
Chart Q14 Are supports available when your family needs them?



2007-08 Average for 15 States

Table Q14					
Are supports available when your family needs them? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		50.7	37.2	12.0	274
CA-RCOC	↑	58.8	33.6	7.6	726
CT		50.9	38.9	10.3	234
GA	↓	43.8	38.7	17.5	553
LA	↑	60.0	32.8	7.2	390
ME		53.4	36.6	10.0	309
MO	↓	45.9	42.0	12.0	283
NC	↑	57.9	30.9	11.2	152
NJ	↓↓	29.8	39.6	30.7	225
OK		55.2	36.6	8.1	505
PA		57.1	33.2	9.6	882
SC		50.7	34.7	14.6	268
WA		50.7	36.7	12.6	341
WV		49.7	41.7	8.6	175
WY	↑↑	74.1	14.8	11.1	27
Total %		52.6	35.9	11.5	5,344
State Avg %		52.6	35.2	12.2	

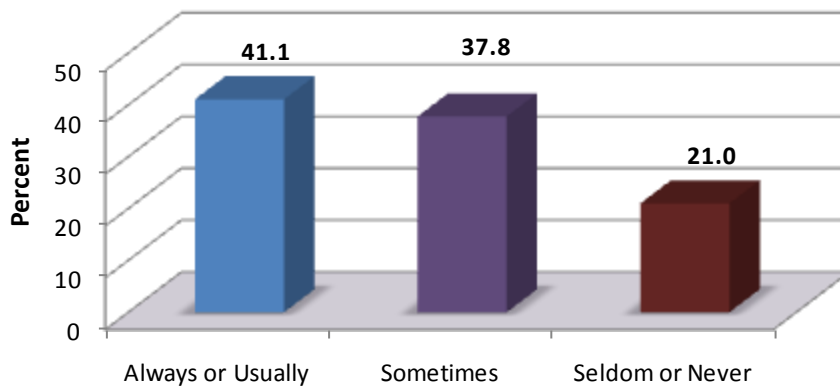
Chart Q15 Do families in your area request that different types of services and supports be made available in your area?



2007-08 Average for 15 States

Table Q15				
Do families in your area request that different types of services and supports be made available in your area? (%)				
State	Always or Usually	Sometimes	Seldom or Never	N
AZ	33.9	43.1	22.9	109
CA-RCOC	31.7	38.8	29.5	183
CT	46.2	41.0	12.8	78
GA	39.5	37.6	22.9	271
LA	45.8	36.9	17.3	179
ME	33.3	46.0	20.6	126
MO	39.7	42.1	18.3	126
NC	42.9	35.7	21.4	70
NJ	23.8	53.8	22.5	80
OK	37.8	42.7	19.5	185
PA	37.7	44.5	17.8	353
SC	43.5	40.0	16.5	115
WA	48.7	36.3	15.0	113
WV	41.4	41.4	17.2	87
WY	46.7	20.0	33.3	15
Total %	38.9	41.1	20.0	2,090
State Avg %	39.5	40.0	20.5	

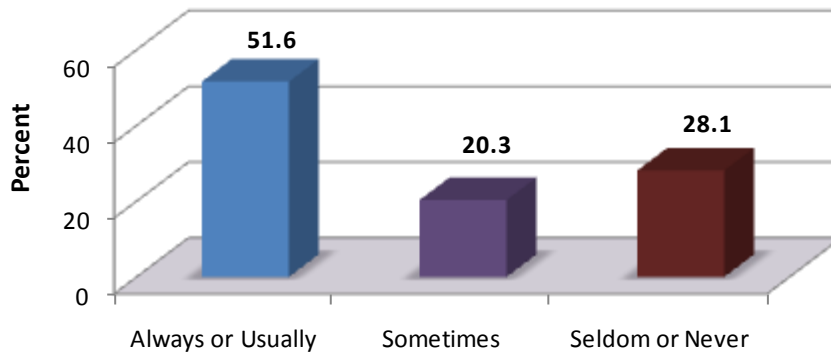
Chart Q16 If yes, does either the state agency or provider agency respond to their requests?



2007-08 Average for 15 States

Table Q16					
If yes, does either the state agency or provider agency respond to their requests? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		36.7	41.1	22.2	90
CA-RCOC	↑↑	56.7	31.7	11.6	224
CT	↑↑	54.2	37.5	8.3	96
GA	↓↓	24.2	49.4	26.4	231
LA	↑↑	56.0	29.3	14.7	150
ME	↓	35.8	49.5	14.7	95
MO		41.2	41.2	17.5	97
NC	↓	31.4	37.3	31.4	51
NJ	↓↓	27.9	27.9	44.3	61
OK		39.7	43.8	16.4	146
PA		37.7	44.3	18.0	289
SC		40.2	28.0	31.8	107
WA		38.0	42.4	19.6	92
WV	↓	32.4	46.5	21.1	71
WY	↑↑	64.7	17.6	17.6	17
Total %		40.6	39.7	19.6	1,817
State Avg %		41.1	37.8	21.0	

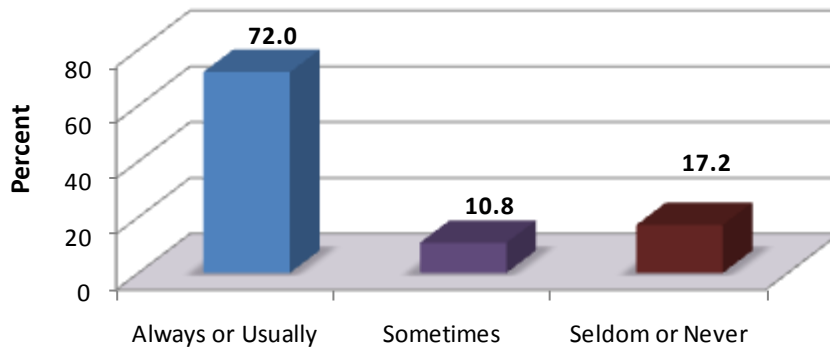
Chart Q17 If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?



2007-08 Average for 15 States

Table Q17					
If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ	↓	44.5	21.3	34.2	155
CA-RCOC		50.8	19.8	29.4	323
CT	↑	56.6	20.8	22.6	106
GA	↓	45.0	21.7	33.3	309
LA	↑	57.6	18.0	24.3	255
ME		51.4	19.6	29.1	148
MO		50.6	23.3	26.2	172
NC		56.0	22.0	22.0	91
NJ	↓↓	33.6	16.4	50.0	110
OK		55.0	19.7	25.3	249
PA		54.6	17.9	27.5	425
SC		49.1	19.6	31.3	163
WA		49.7	23.1	27.2	169
WV		50.5	23.2	26.3	95
WY	↑↑	68.8	18.8	12.5	16
Total %		51.0	20.1	28.9	2,786
State Avg %		51.6	20.3	28.1	

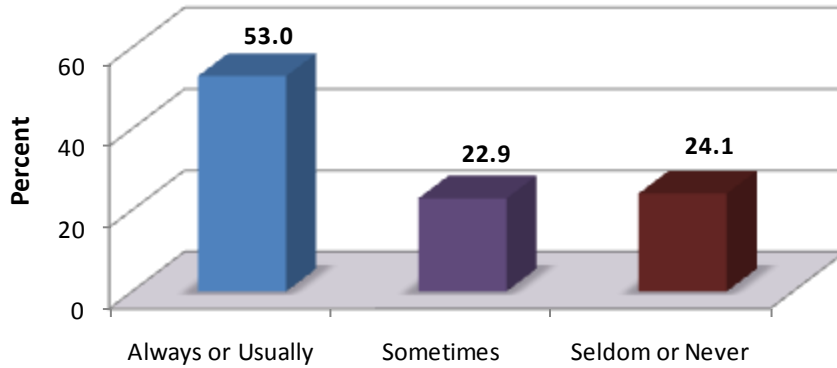
Chart Q18 If English is not your first language, are there support workers or translators available to speak with you in your preferred language?



2007-08 Average for 15 States

Table Q18					
If English is not your first language, are there support workers or translators available to speak with you in your preferred language? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		69.0	22.4	8.6	58
CA-RCOC	↑	78.6	12.0	9.4	309
CT		71.0	16.1	12.9	31
GA	↓↓	61.2	14.9	23.9	67
LA	↑	78.0	8.0	14.0	50
ME		73.7	5.3	21.1	19
MO	↑↑	82.4	5.9	11.8	17
NC	↑↑	87.5	0.0	12.5	8
NJ	↓↓	35.1	21.6	43.2	37
OK	↓	66.7	13.9	19.4	36
PA	↓	64.8	8.5	26.8	71
SC		74.1	3.7	22.2	27
WA		72.9	12.5	14.6	48
WV	↑↑	93.3	6.7	0.0	15
WY	Wyoming did not have any data for this question				
Total %		72.1	12.4	15.5	793
State Avg %		72.0	10.8	17.2	

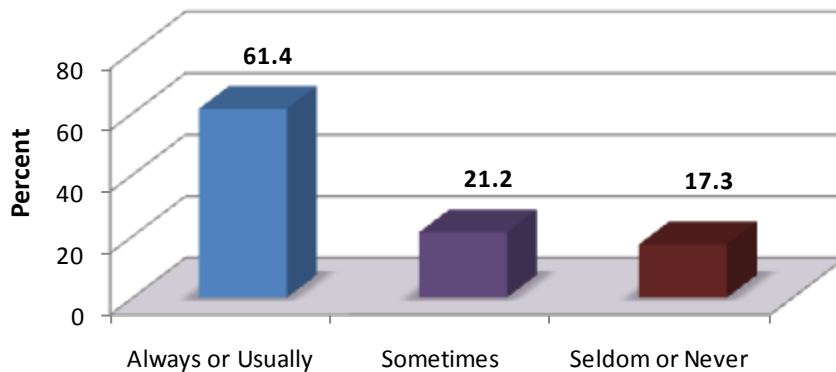
Chart Q19 If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?



2007-08 Average for 15 States

Table Q19					
If your family member does not speak English or uses a different way to communicate (for example, sign language), are there enough support workers available who can communicate with him/her? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		52.9	24.3	22.9	70
CA-RCOC	↑↑	68.8	17.2	14.1	192
CT	↑↑	72.2	19.4	8.3	36
GA	↓↓	43.0	34.0	23.0	100
LA	↑↑	65.1	17.5	17.5	63
ME	↑	59.0	23.1	17.9	39
MO		56.8	13.5	29.7	37
NC	↓↓	34.6	46.2	19.2	26
NJ	↓↓	37.8	20.0	42.2	45
OK		56.5	20.7	22.8	92
PA	↓↓	40.2	34.4	25.4	122
SC		52.5	17.5	30.0	40
WA		54.0	22.0	24.0	50
WV	↓↓	34.3	34.3	31.4	35
WY	↑↑	66.7	0.0	33.3	3
Total %		53.9	24.0	22.1	950
State Avg %		53.0	22.9	24.1	

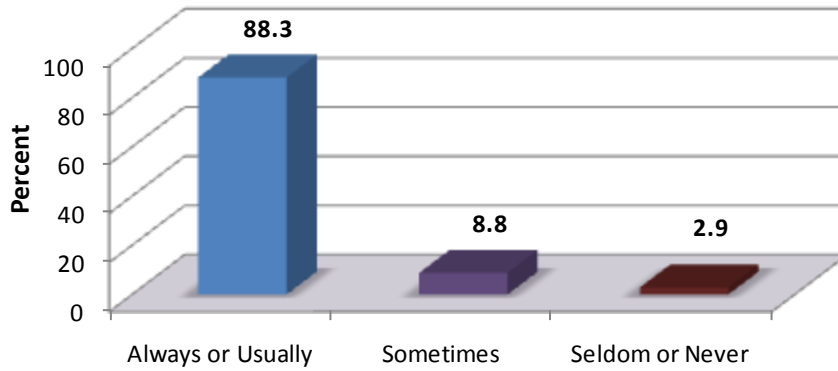
Chart Q20 Does your family member have access to the special equipment or accommodations that he/she needs?



2007-08 Average for 15 States

Table Q20					
Does your family member have access to the special equipment or accommodations that he/she needs? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		59.8	21.3	18.9	122
CA-RCOC	↓	56.1	21.6	22.3	269
CT		60.3	20.6	19.1	68
GA	↓	53.1	27.3	19.6	271
LA	↑	68.2	15.0	16.7	233
ME	↓↓	48.7	30.1	21.2	113
MO	↓	56.3	24.2	19.5	128
NC		59.0	23.1	17.9	78
NJ	↓	52.0	24.0	24.0	100
OK		63.1	26.6	10.3	271
PA	↑	66.7	17.0	16.4	330
SC		70.5	15.1	14.4	146
WA		60.2	24.0	15.8	171
WV	↓	56.4	28.7	14.9	101
WY	↑↑	90.9	0.0	9.1	11
Total %		60.4	22.1	17.5	2,412
State Avg %		61.4	21.2	17.3	

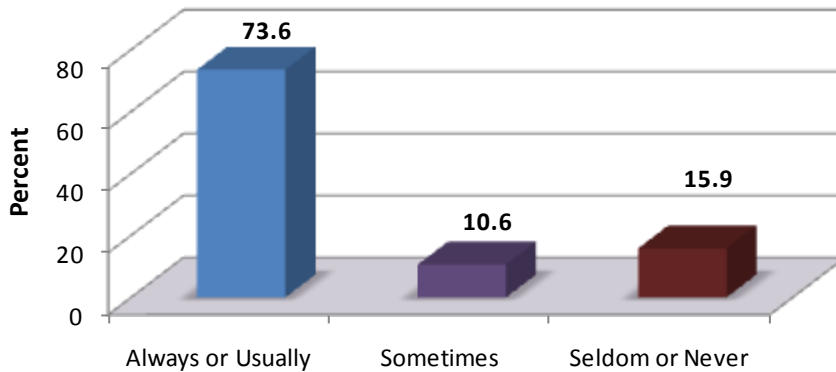
Chart Q21 Do you have access to health services for your family member?



2007-08 Average for 15 States

Table Q21					
Do you have access to health services for your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		88.9	7.3	3.8	289
CA-RCOC		90.5	7.5	2.0	797
CT		89.9	8.9	1.2	257
GA		84.4	13.2	2.4	590
LA		86.3	9.2	4.5	424
ME		92.4	5.9	1.8	340
MO	↓	83.2	11.5	5.3	304
NC		87.7	9.9	2.5	162
NJ	↓	81.1	11.3	7.6	238
OK		90.5	7.1	2.3	518
PA		92.9	5.3	1.8	955
SC		85.7	11.5	2.8	286
WA		87.7	10.5	1.8	382
WV		92.5	6.9	0.6	174
WY		90.6	6.3	3.1	32
Total %		88.7	8.6	2.7	5,748
State Avg %		88.3	8.8	2.9	

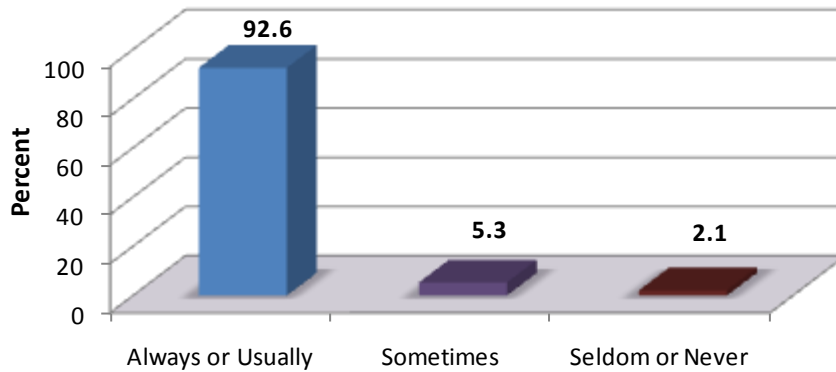
Chart Q22 Do you have access to dental services for your family member?



2007-08 Average for 15 States

Table Q22					
Do you have access to dental services for your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ	↓	64.2	15.5	20.4	265
CA-RCOC	↑	81.8	9.5	8.6	776
CT	↑	81.0	6.5	12.6	247
GA	↓	67.1	11.5	21.4	566
LA	↓↓	54.5	12.1	33.4	365
ME	↑	79.9	6.4	13.7	328
MO	↓↓	55.4	17.4	27.2	298
NC	↑	80.3	12.5	7.2	152
NJ		74.8	10.3	14.9	242
OK		69.6	11.6	18.8	473
PA	↑	79.5	8.1	12.5	930
SC		72.9	12.1	15.0	273
WA	↑	80.7	7.4	11.9	378
WV		75.5	11.0	13.5	163
WY	↑↑	86.2	6.9	6.9	29
Total %		73.5	10.4	16.1	5,485
State Avg %		73.6	10.6	15.9	

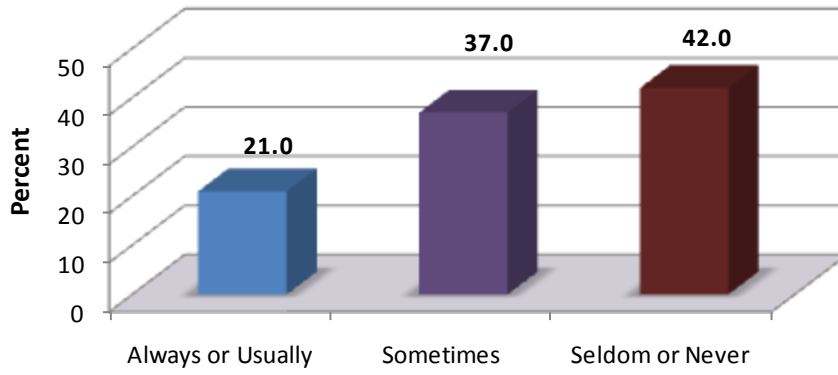
Chart Q23 Do you have access to necessary medications for your family member?



2007-08 Average for 15 States

Table Q23				
Do you have access to necessary medications for your family member? (%)				
State	Always or Usually	Sometimes	Seldom or Never	N
AZ	90.5	6.6	2.9	273
CA-RCOC	90.5	6.7	2.8	788
CT	95.2	2.8	2.0	251
GA	92.0	6.3	1.7	588
LA	89.4	6.9	3.7	405
ME	95.7	3.4	0.9	323
MO	90.2	6.2	3.6	305
NC	94.3	4.4	1.3	159
NJ	89.1	5.3	5.7	247
OK	94.9	4.5	0.6	514
PA	95.5	3.6	0.9	957
SC	90.5	6.8	2.7	296
WA	90.5	7.7	1.8	388
WV	96.5	2.3	1.2	171
WY	93.5	6.5	0.0	31
Total %	92.5	5.4	2.1	5,696
State Avg %	92.6	5.3	2.1	

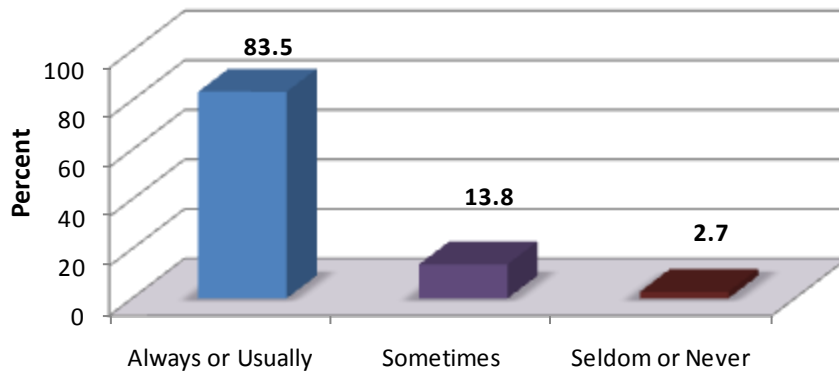
Chart Q24 Are frequent changes in support staff a problem for your family?



2007-08 Average for 15 States

Table Q24					
Are frequent changes in support staff a problem for your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		23.0	40.6	36.5	244
CA-RCOC	⇓⇓	34.1	0.0	65.9	416
CT	⇑	14.0	46.2	39.8	186
GA		25.5	34.8	39.7	514
LA		23.7	29.5	46.8	342
ME		20.4	43.8	35.8	274
MO		16.7	34.3	49.0	245
NC		16.2	44.1	39.7	136
NJ		17.2	39.9	42.9	163
OK		20.0	35.6	44.3	424
PA		18.1	39.2	42.8	781
SC		20.1	36.0	43.9	239
WA	⇑	15.1	37.7	47.3	292
WV	⇓	29.3	50.3	20.4	157
WY		21.4	42.9	35.7	28
Total %		21.5	34.6	43.9	4,441
State Avg %		21.0	37.0	42.0	

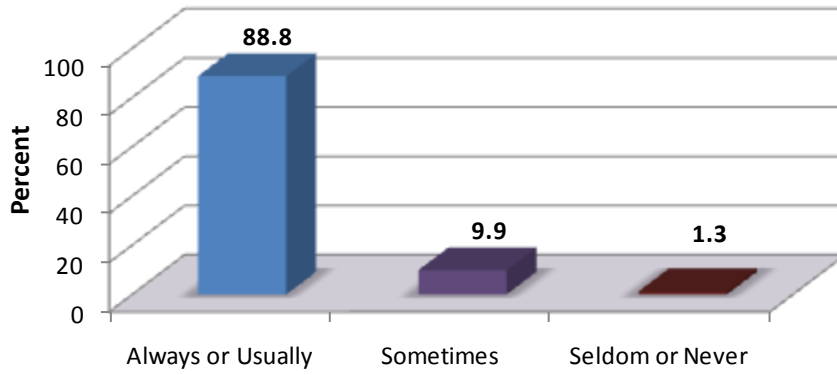
Chart Q25 Do you feel that your family member's day/employment setting is a healthy and safe environment?



2007-08 Average for 15 States

Table Q25					
Do you feel that your family member's day/employment setting is a healthy and safe environment? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		83.5	13.0	3.5	230
CA-RCOC		83.7	14.3	2.0	645
CT		87.1	11.2	1.6	249
GA		80.2	18.1	1.7	540
LA		86.5	9.2	4.3	327
ME		87.0	10.9	2.1	284
MO		81.3	13.8	4.9	225
NC		83.3	16.0	0.7	144
NJ		79.9	14.2	5.9	219
OK		81.2	16.7	2.2	372
PA		83.9	14.6	1.5	816
SC		78.6	18.6	2.8	215
WA		86.1	11.2	2.7	223
WV		80.7	18.5	0.7	135
WY	↑	88.9	7.4	3.7	27
Total %		83.2	14.3	2.4	4,651
State Avg %		83.5	13.8	2.7	

Chart Q26 Are support staff generally respectful and courteous?



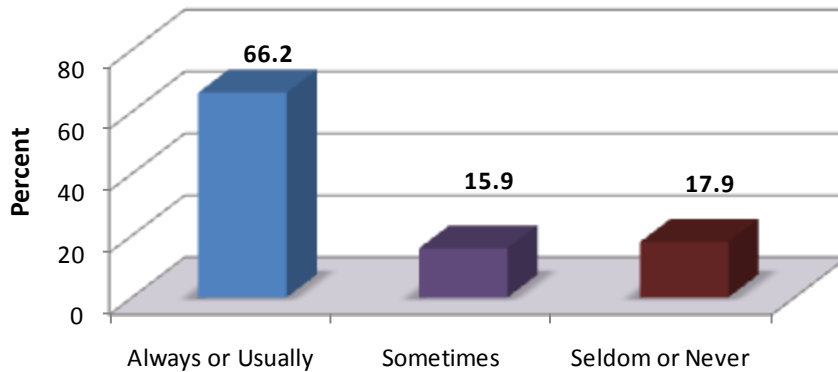
2007-08 Average for 15 States

Table Q26					
Are support staff generally respectful and courteous? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		85.9	12.7	1.4	284
CA-RCOC		92.4	6.8	0.8	753
CT		92.9	5.8	1.2	241
GA		86.6	12.6	0.8	589
LA		89.5	9.3	1.2	421
ME		89.1	9.9	0.9	322
MO		84.9	13.4	1.8	284
NC		89.4	10.0	0.6	160
NJ		85.3	12.0	2.8	217
OK		88.3	10.9	0.8	488
PA		91.1	8.4	0.5	951
SC		88.9	10.0	1.1	280
WA	↑	94.5	4.6	0.9	329
WV	↓	82.9	16.0	1.1	175
WY		90.3	6.5	3.2	31
Total %		89.4	9.6	1.0	5,525
State Avg %		88.8	9.9	1.3	

Choices and Control

- Across the states, on average, 66% of respondents chose the agencies or providers who work with their families. In Louisiana, Oklahoma and Wyoming, this percentage was considerably higher, with 83% or more of families choosing their service providers.
- While 66% of respondents typically chose their family's provider agency, only 48% typically chose the support workers who worked directly with their family.
- Across the states, 70% of families who received day/employment supports felt the provider agency regularly involved them in important decisions.
- Among all respondents, 42% had control or input over the hiring and management of their support staff, and 15% indicated they had this control sometimes. Forty-three percent (43%), however, did not have any input or control over the hiring or management of their family's support staff.
- While only 57% of respondents had at least some control over the hiring or management of their support workers, 84% wanted this type of control at least sometimes.
- Twenty-three percent (23%) of respondents or their family members knew how much money was spent by the MR/DD agency on behalf of their family member. Sixty-nine percent (69%), however, had little or no idea. (Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses.)
- Overall, 57% had at least some decision-making authority over how the money available to their family member with disabilities by the MR/DD agency was spent. Forty-three percent (43%), however, did not.

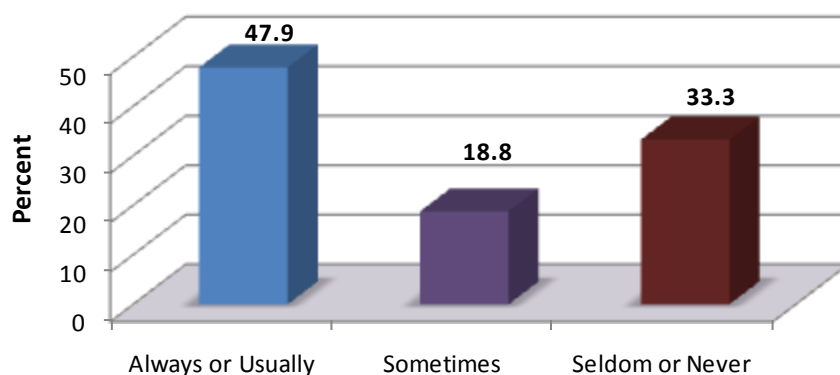
Chart Q27 Do you or your family member choose the agencies or providers that work with your family?



2007-08 Average for 15 States

Table Q27					
Do you or your family member choose the agencies or providers that work with your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		66.0	16.2	17.8	259
CA-RCOC		65.0	21.9	13.1	602
CT	↓	60.3	15.6	24.1	224
GA	↓↓	51.0	19.4	29.5	535
LA	↑↑	84.4	7.0	8.6	384
ME		66.8	16.9	16.3	313
MO	↓↓	53.0	22.8	24.2	281
NC	↑	74.8	13.5	11.6	155
NJ	↓↓	48.0	14.1	37.9	198
OK	↑↑	83.3	9.8	6.8	498
PA	↓	56.5	20.8	22.7	788
SC	↓	59.0	18.7	22.3	251
WA		65.2	15.0	19.9	287
WV	↑↑	76.2	16.1	7.7	168
WY	↑↑	83.3	10.0	6.7	30
Total %		64.6	16.9	18.6	4,973
State Avg %		66.2	15.9	17.9	

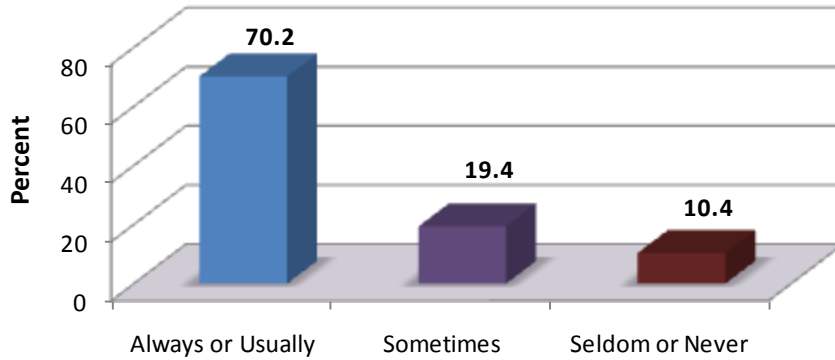
Chart Q28 Do you or your family member choose the support workers who work with your family?



2007-08 Average for 15 States

Table Q28					
Do you or your family member choose the support workers who work with your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		46.0	22.4	31.6	250
CA-RCOC	↑	56.2	21.5	22.3	587
CT	↓↓	34.3	20.3	45.4	207
GA	↓↓	23.3	20.7	56.1	537
LA	↑↑	73.6	12.1	14.3	364
ME	↓	39.1	21.2	39.7	297
MO	↓↓	36.3	19.1	44.7	262
NC	↑↑	66.9	15.3	17.8	157
NJ	↓↓	28.7	19.0	52.3	174
OK	↑↑	68.6	16.0	15.4	481
PA	↓↓	36.8	20.9	42.3	750
SC	↓↓	37.7	23.0	39.3	239
WA		47.9	20.7	31.4	242
WV		49.4	22.9	27.7	166
WY	↑↑	74.1	7.4	18.5	27
Total %		46.2	19.6	34.2	4,740
State Avg %		47.9	18.8	33.3	

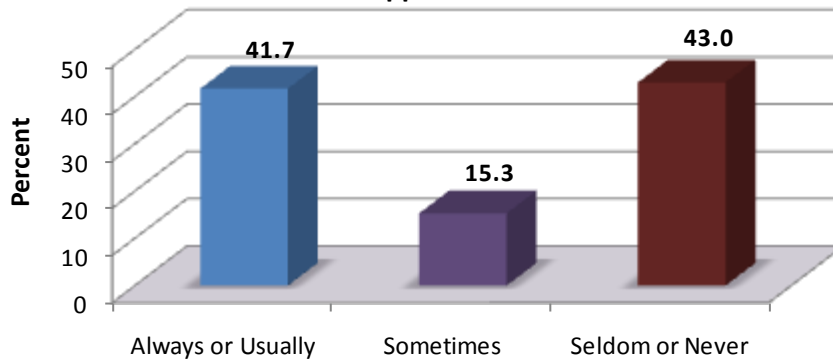
Chart Q29 If your family member gets day or employment services, does the agency providing these services involve you in important decisions?



2007-08 Average for 15 States

State		Always or Usually	Sometimes	Seldom or Never	N
AZ		69.7	21.2	9.1	198
CA-RCOC	↓	60.4	24.3	15.4	482
CT		72.8	21.5	5.7	228
GA	↓	64.3	25.7	10.0	479
LA	↑	75.5	13.2	11.3	257
ME	↑↑	80.5	13.0	6.5	261
MO	↓	64.2	22.6	13.2	190
NC		73.5	22.7	3.8	132
NJ		67.1	14.8	18.1	155
OK		73.1	18.9	8.0	301
PA		72.0	20.1	8.0	703
SC	↓	64.4	19.6	16.0	194
WA	↑	73.6	16.2	10.2	197
WV		65.6	25.0	9.4	128
WY		76.9	11.5	11.5	26
Total %		69.4	20.3	10.3	3,931
State Avg %		70.2	19.4	10.4	

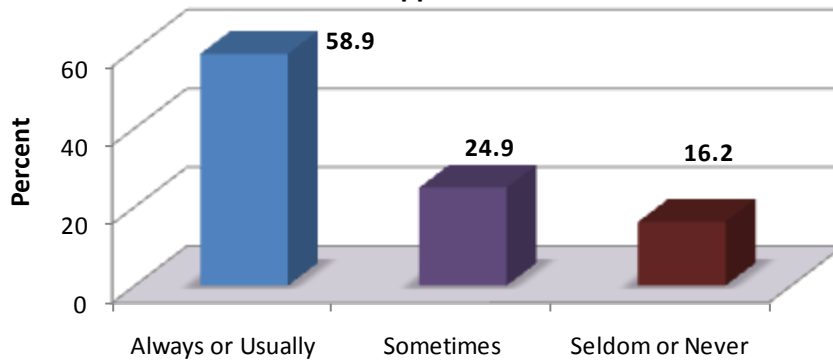
Chart Q30 Do you or your family member have control and/or input over the hiring and management of your support workers?



2007-08 Average for 15 States

Table Q30					
Do you or your family member have control and/or input over the hiring and management of your support workers? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		39.2	19.3	41.5	212
CA-RCOC		42.7	17.7	39.6	379
CT	↓↓	30.9	12.6	56.6	175
GA	↓↓	13.7	13.7	72.7	432
LA	↑↑	72.5	11.8	15.7	338
ME	↓↓	26.4	15.7	57.9	254
MO		32.5	12.6	54.9	206
NC	↑↑	56.2	21.9	21.9	137
NJ		35.1	16.0	48.9	131
OK	↑↑	68.6	14.1	17.3	427
PA	↓↓	31.0	15.1	53.9	597
SC		32.4	14.4	53.2	188
WA	↑↑	57.1	13.4	29.5	224
WV		44.0	22.7	33.3	141
WY		43.5	8.7	47.8	23
Total %		41.4	15.2	43.4	3,864
State Avg %		41.7	15.3	43.0	

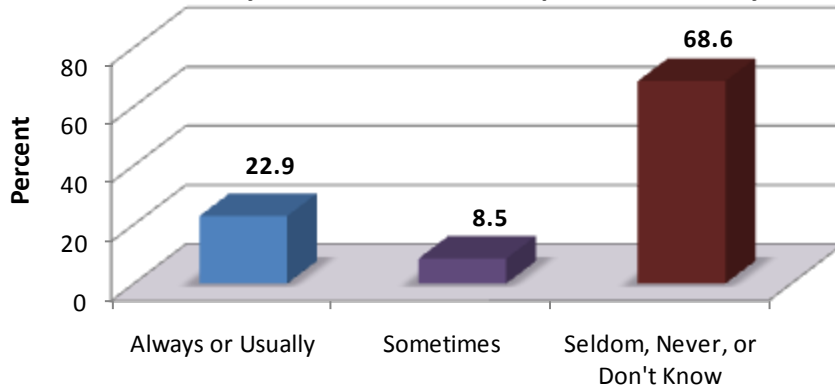
Chart Q31 Do you or your family member want to have control and/or input over the hiring and management of your support workers?



2007-08 Average for 15 States

Table Q31					
Do you or your family member want to have control and/or input over the hiring and management of your support workers? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		61.7	25.7	12.6	214
CA-RCOC		54.5	27.6	17.8	387
CT	↓	51.2	35.1	13.7	168
GA	↓↓	41.5	30.1	28.4	422
LA	↑↑	82.7	10.0	7.3	341
ME	↓↓	45.8	30.3	23.9	238
MO	↓	50.7	26.1	23.2	207
NC	↑↑	72.2	18.8	9.0	133
NJ		54.9	27.4	17.7	164
OK	↑↑	81.5	11.6	6.9	432
PA	↓	51.2	26.8	22.1	594
SC		61.9	23.2	14.9	181
WA	↑	67.7	22.4	9.9	223
WV	↑	66.4	24.1	9.5	137
WY	↓↓	39.1	34.8	26.1	23
Total %		59.7	23.8	16.5	3,864
State Avg %		58.9	24.9	16.2	

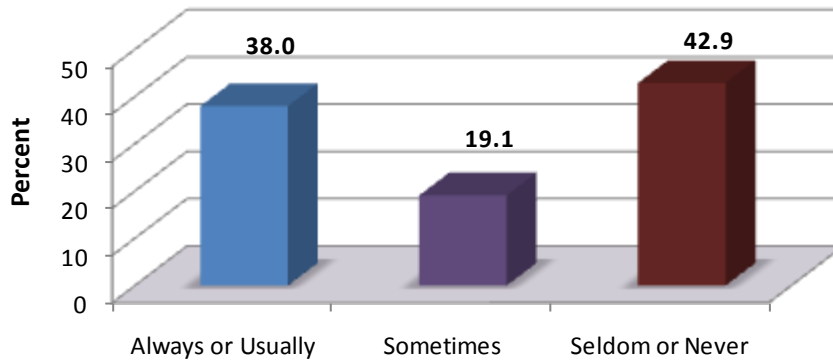
Chart Q32 Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?



2007-08 Average for 15 States

Table Q32 Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?					
State		Always or Usually	Sometimes	*Seldom, Never, or Don't Know	N
AZ	⇓⇓	12.8	7.8	79.4	281
CA-RCOC	⇓⇓	11.4	5.9	82.7	774
CT		26.7	14.5	58.9	311
GA	⇓⇓	8.7	7.3	84.0	587
LA	⇑⇑	33.3	6.4	60.4	409
ME	⇓⇓	7.1	6.1	86.7	310
MO	⇓	16.2	9.1	74.6	296
NC	⇓	16.7	9.3	74.1	162
NJ	⇓⇓	11.3	3.6	85.0	247
OK	⇑⇑	48.2	16.8	35.0	506
PA	⇑	29.3	11.9	58.8	923
SC	⇓	14.6	5.0	80.4	281
WA	⇓	15.9	9.3	74.9	378
WV	⇑⇑	39.9	11.3	48.8	168
WY	⇑⇑	51.7	3.4	44.8	29
Total %		21.5	9.1	69.4	5,662
State Avg %		22.9	8.5	68.6	

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



2007-08 Average for 15 States

Table Q33					
Do you or your family member get to decide how this money is spent? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ	↓	31.4	13.5	55.1	185
CA-RCOC		41.5	13.2	45.3	342
CT		40.8	23.8	35.4	223
GA	↓↓	15.9	12.8	71.3	421
LA	↑	46.2	11.5	42.3	260
ME	↓↓	24.5	18.9	56.6	212
MO	↓	31.1	18.1	50.8	193
NC	↓↓	27.8	15.7	56.5	108
NJ		39.9	16.3	43.8	153
OK	↑↑	57.2	22.6	20.2	421
PA	↑↑	48.0	22.1	29.9	629
SC	↓	32.8	11.3	55.9	186
WA		37.4	22.6	40.0	230
WV	↑	43.9	28.1	28.1	139
WY	↑↑	52.0	36.0	12.0	25
Total %		38.8	18.2	43.0	3,727
State Avg %		38.0	19.1	42.9	

Community Connections

- On average, just over one-third of respondents (34%) felt that planning or support staff were regularly available to help them use typical community supports (e.g., from a local health club, church or recreation activities) if desired. Another 25% said that staff were sometimes helpful, but 41% stated that planning and support staff were seldom or never helpful in connecting their family members to typical community supports or resources.
- Overall, there was a split between respondents who indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (58% say always, usually or sometimes, 42% say seldom or never).
- Only 52% of families felt their family member always or usually had access to community activities. Eighteen percent (18%) stated their family member seldom or never had access to the community.
- While 52% had regular access to community activities, only 33% of family members regularly participated in them. Twenty-nine percent (29%) of respondents said that their family member seldom or never participated in community activities or events.

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

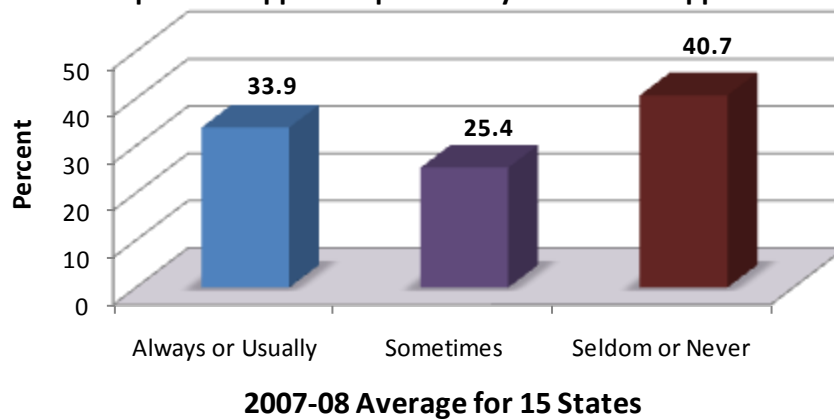
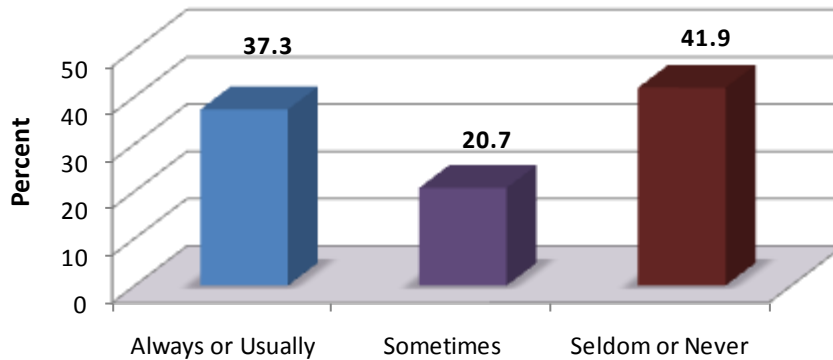


Table Q34					
If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		30.3	23.9	45.7	188
CA-RCOC		31.8	26.3	41.9	437
CT		32.2	29.6	38.2	199
GA	↓↓	18.8	21.7	59.4	414
LA	↑↑	45.7	15.5	38.9	265
ME	↑	41.8	24.6	33.6	232
MO		35.5	26.8	37.7	228
NC		34.5	25.9	39.7	116
NJ	↓↓	23.0	18.2	58.8	148
OK	↑	39.9	24.1	35.9	373
PA		31.2	30.1	38.7	542
SC		30.6	22.2	47.2	180
WA	↓	25.2	27.4	47.4	234
WV		30.8	34.2	35.0	117
WY	↑↑	56.5	30.4	13.0	23
Total %		32.3	25.1	42.6	3,696
State Avg %		33.9	25.4	40.7	

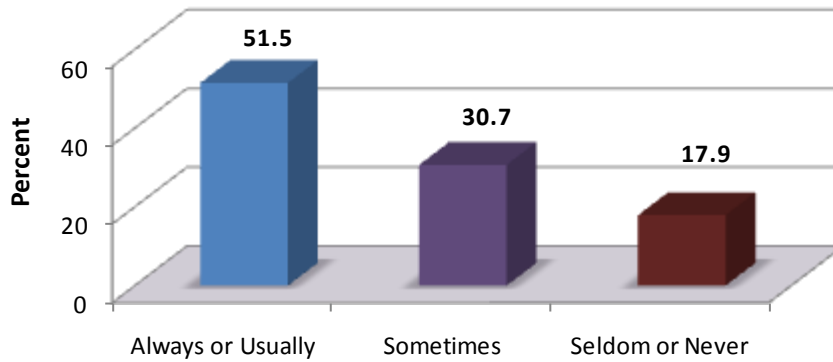
Chart Q35 If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do the staff who help you plan or provide support help you do this?



2007-08 Average for 15 States

Table Q35					
If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		40.3	23.0	36.6	191
CA-RCOC		36.6	25.5	37.9	404
CT	↓	29.1	22.3	48.6	175
GA	↓↓	16.3	19.8	64.0	400
LA	↑↑	53.5	14.8	31.6	297
ME		37.2	16.8	46.1	191
MO		35.9	20.6	43.5	209
NC		35.9	20.4	43.7	103
NJ	↓↓	22.0	15.9	62.1	132
OK	↑↑	48.4	20.6	31.0	378
PA		37.2	21.6	41.2	556
SC		35.7	20.0	44.3	185
WA	↓	27.5	21.3	51.3	240
WV	↑↑	52.2	24.6	23.1	134
WY	↑↑	52.4	23.8	23.8	21
Total %		36.4	20.7	42.9	3,616
State Avg %		37.3	20.7	41.9	

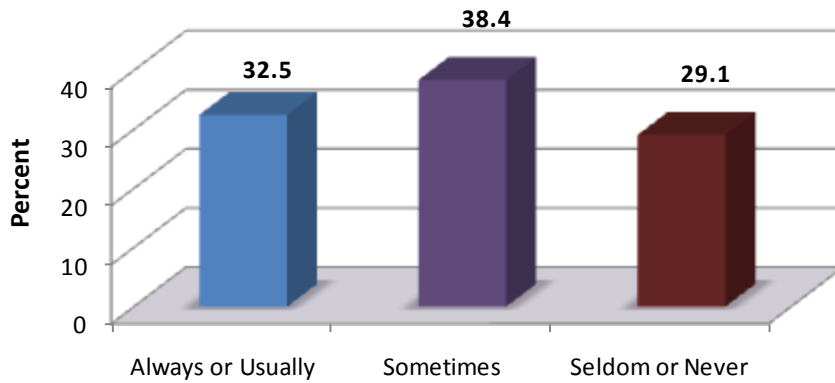
Chart Q36 Do you feel that your family member has access to community activities?



2007-08 Average for 15 States

State		Always or Usually	Sometimes	Seldom or Never	N
AZ		50.8	30.9	18.3	262
CA-RCOC	⇓⇓	39.8	39.5	20.7	704
CT	⇓	44.4	35.2	20.4	270
GA	⇓⇓	41.1	37.7	21.2	567
LA		56.1	22.5	21.4	378
ME	⇑	60.2	26.9	12.9	309
MO		53.5	26.9	19.5	297
NC		48.7	38.0	13.3	150
NJ	⇓⇓	30.0	30.9	39.2	217
OK	⇑	59.0	30.9	10.1	495
PA		52.6	32.0	15.4	881
SC	⇓⇓	41.0	33.7	25.3	249
WA		46.9	36.9	16.2	339
WV	⇑	58.2	30.9	10.9	165
WY	⇑⇑	89.7	6.9	3.4	29
Total %		48.9	32.7	18.4	5,312
State Avg %		51.5	30.7	17.9	

Chart Q37 Does your family member participate in community activities?



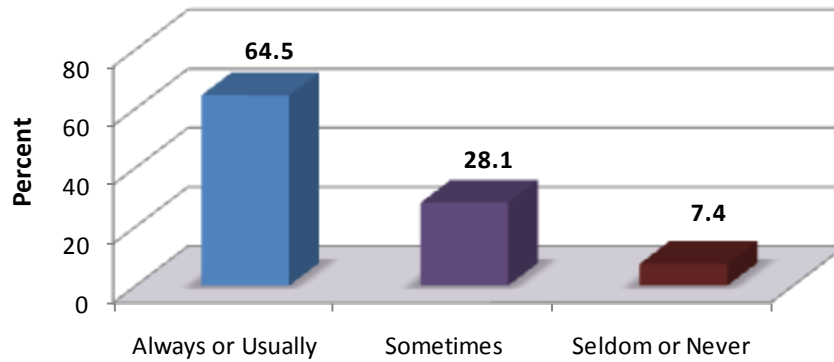
2007-08 Average for 15 States

Table Q37					
Does your family member participate in community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ	↑	38.9	35.1	26.0	262
CA-RCOC	↓↓	20.2	34.3	45.5	718
CT	↓	25.7	41.2	33.1	284
GA		28.7	42.7	28.5	578
LA		37.4	32.3	30.3	390
ME		37.0	40.9	22.1	308
MO		32.6	36.2	31.3	304
NC		34.4	46.5	19.1	157
NJ	↓↓	18.8	27.8	53.4	234
OK	↑	38.9	41.9	19.2	504
PA		31.4	37.4	31.2	926
SC	↓	23.0	35.3	41.6	269
WA	↓	26.9	39.9	33.2	361
WV	↑↑	44.6	39.9	15.5	168
WY	↑↑	48.3	44.8	6.9	29
Total %		30.6	37.8	31.6	5,492
State Avg %		32.5	38.4	29.1	

Outcomes and Satisfaction with Services and Supports

- Overall, almost two-thirds of families (65%) were always or usually satisfied with the services and supports they received. Twenty-eight percent (28%) were somewhat satisfied, and 7% were seldom or never satisfied.
- On average, only 47% of respondents knew about their agency's grievance process, while 43% had little or no familiarity with the process for lodging a complaint. (Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses.)
- The majority of respondents (57%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 43%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.
- Seventy-one percent (71%) of families felt that services and supports have made a positive difference in their lives. Only 5% stated that they seldom or never felt this way.
- Just over three-fourths (77%) of respondents indicated that services have made a difference in helping them keep their family members at home.
- Most families (82%) indicated that their family member would still be living at home, even without services. Thirteen percent (13%) of respondents, however, stated their family member would seldom or would not be at home without needed services.
- Eighty-three percent (83%) of respondents felt that their family member was usually happy.

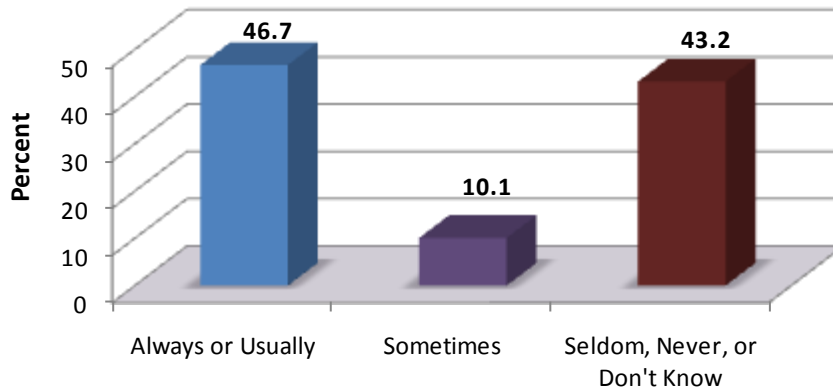
Chart Q38 Overall, are you satisfied with the services and supports your family and family member currently receive?



2007-08 Average for 15 States

Table Q38					
Overall, are you satisfied with the services and supports your family and family member currently receive? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		64.8	30.3	4.9	287
CA-RCOC	↑	74.0	20.2	5.8	830
CT		60.9	30.9	8.2	304
GA	↓	55.7	33.6	10.7	596
LA	↑	71.5	21.1	7.4	431
ME	↑	70.4	25.1	4.5	331
MO		61.6	31.6	6.8	307
NC		65.1	29.5	5.4	166
NJ	↓↓	46.3	37.3	16.4	244
OK	↑	70.6	23.5	5.9	527
PA	↑	71.1	22.3	6.6	970
SC	↓	59.5	31.1	9.5	296
WA		61.2	33.9	4.9	384
WV		61.7	33.7	4.6	175
WY	↑	73.3	16.7	10.0	30
Total %		65.9	27.0	7.2	5,878
State Avg %		64.5	28.1	7.4	

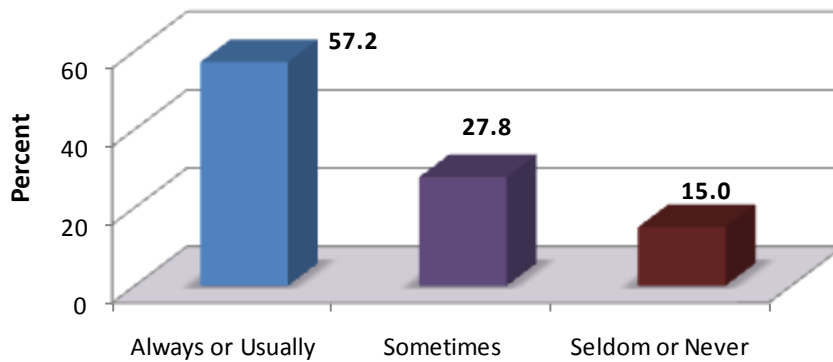
Chart Q39 Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?



2007-08 Average for 15 States

Table Q39 Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them? (%)					
State		Always or Usually	Sometimes	*Seldom, Never, or Don't Know	N
AZ	↓	38.9	12.8	48.3	265
CA-RCOC		51.2	11.2	37.6	779
CT	↓↓	33.7	10.3	55.9	261
GA	↓↓	36.1	10.1	53.8	582
LA	↑↑	59.6	8.1	32.4	408
ME		49.7	8.8	41.6	308
MO		46.8	5.6	47.6	284
NC		51.6	11.6	36.8	155
NJ	↓↓	15.0	7.1	77.9	226
OK	↑↑	68.3	8.8	22.9	498
PA		50.0	9.4	40.7	896
SC		43.4	9.0	47.6	267
WA		44.7	10.3	45.0	351
WV		51.2	14.3	34.5	168
WY	↑↑	60.7	14.3	25.0	28
Total %		47.6	9.7	42.7	5,476
State Avg %		46.7	10.1	43.2	

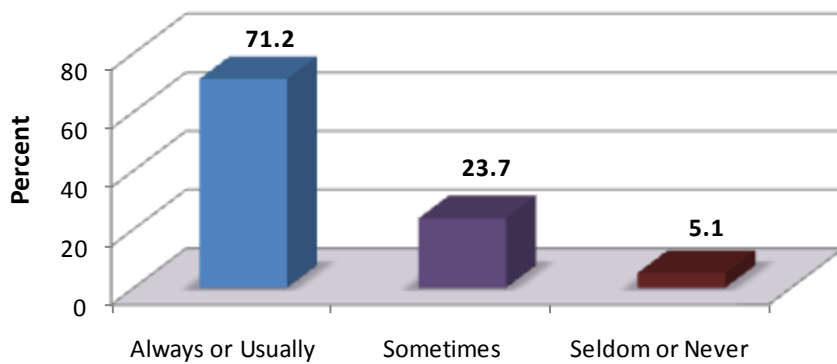
Chart Q40 Are you satisfied with the way complaints/grievances are handled and resolved?



2007-08 Average for 15 States

Table Q40					
Are you satisfied with the way complaints/grievances are handled and resolved? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		54.3	26.8	18.8	138
CA-RCOC	↑↑	67.6	25.2	7.2	361
CT	↓	49.6	34.2	16.2	117
GA	↓	49.4	31.4	19.2	318
LA	↑↑	71.8	20.4	7.8	245
ME		58.5	27.6	13.8	123
MO	↓	51.7	28.4	19.8	116
NC	↓	48.0	32.7	19.4	98
NJ	↓↓	41.6	24.7	33.8	77
OK	↑	63.4	25.6	11.0	273
PA	↑	62.9	26.5	10.6	423
SC		57.6	25.8	16.6	151
WA		54.6	29.6	15.8	152
WV		57.8	33.3	8.8	102
WY	↑↑	68.8	25.0	6.3	16
Total %		59.0	27.3	13.7	2,710
State Avg %		57.2	27.8	15.0	

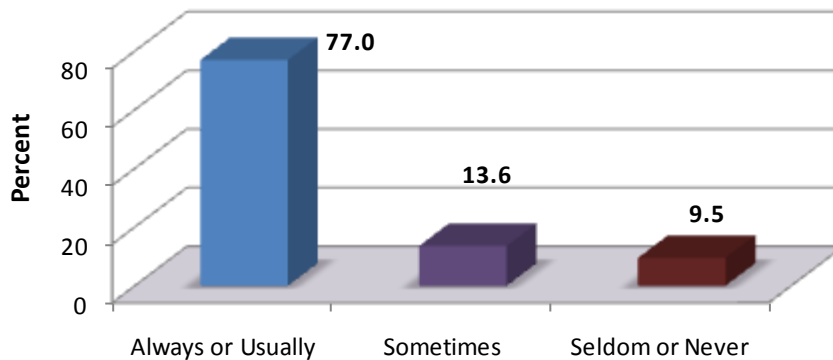
Chart Q41 Do you feel that services and supports have made a positive difference in the life of your family?



2007-08 Average for 15 States

Table Q41					
Do you feel that services and supports have made a positive difference in the life of your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		73.6	23.2	3.2	280
CA-RCOC		71.9	22.5	5.6	766
CT	↓	65.4	29.0	5.7	283
GA	↓↓	59.9	31.7	8.4	586
LA	↑	79.9	15.3	4.8	418
ME		72.3	23.1	4.7	321
MO		71.3	23.0	5.7	300
NC		74.4	23.2	2.4	164
NJ	↓↓	51.4	32.1	16.5	218
OK	↑	81.0	17.3	1.7	521
PA		74.0	20.9	5.1	924
SC	↓	63.6	30.0	6.4	283
WA		66.6	30.2	3.2	374
WV		72.8	24.3	2.9	173
WY	↑↑	89.7	10.3	0.0	29
Total %		70.8	23.9	5.3	5,640
State Avg %		71.2	23.7	5.1	

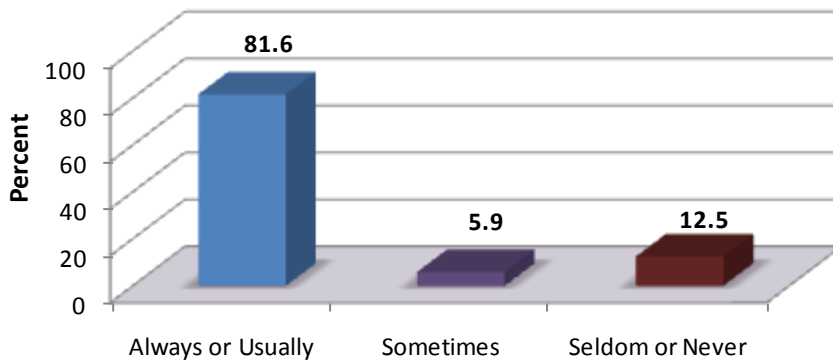
Chart Q42 Have services made a difference in helping keep your family member at home?



2007-08 Average for 15 States

Table Q42 Have services made a difference in helping keep your family member at home? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		80.6	11.6	7.8	258
CA-RCOC		76.4	13.4	10.3	673
CT	↓↓↓	65.0	24.5	10.5	257
GA	↓	70.7	17.7	11.6	519
LA	↑	86.5	7.5	6.0	400
ME		78.5	12.8	8.8	274
MO	↓	71.8	16.8	11.4	273
NC	↑↑↑	88.2	7.6	4.2	144
NJ	↓↓↓	59.6	19.2	21.2	198
OK	↑	85.7	10.7	3.6	497
PA		76.3	13.3	10.4	828
SC	↓	71.3	16.5	12.3	261
WA		77.7	14.0	8.3	363
WV		81.3	13.3	5.4	166
WY	↑	85.0	5.0	10.0	20
Total %		76.7	13.9	9.4	5,131
State Avg %		77.0	13.6	9.5	

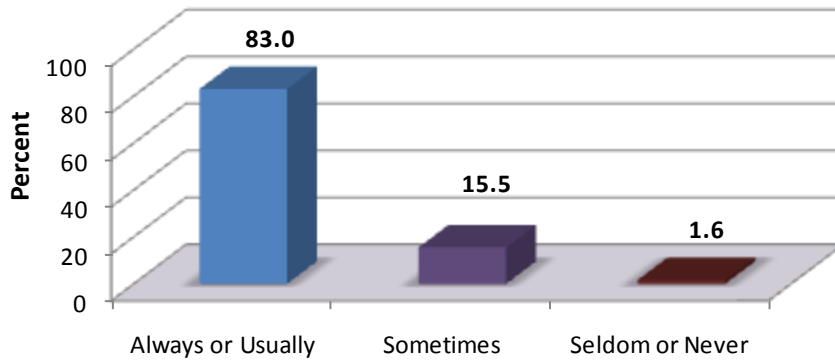
Chart Q43 Would your family member still be at home if you did not receive any supports?



2007-08 Average for 15 States

Table Q43				
Would your family member still be at home if you did not receive any supports? (%)				
State	Always or Usually	Sometimes	Seldom or Never	N
AZ	81.0	3.4	15.6	205
CA-RCOC	81.6	8.6	9.8	581
CT	82.5	5.3	12.3	228
GA	84.0	6.7	9.2	476
LA	81.2	5.5	13.3	308
ME	83.8	4.1	12.2	222
MO	82.5	6.3	11.2	223
NC	76.9	7.7	15.4	117
NJ	78.3	8.3	13.4	157
OK	86.5	6.2	7.3	371
PA	87.6	2.8	9.7	725
SC	81.6	5.3	13.2	228
WA	73.3	5.5	21.2	273
WV	81.3	4.2	14.6	144
WY	81.8	9.1	9.1	22
Total %	82.7	5.6	11.7	4,280
State Avg %	81.6	5.9	12.5	

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



2007-08 Average for 15 States

Table Q44					
Overall, do you feel that your family member is happy? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
AZ		87.0	11.6	1.4	292
CA-RCOC		81.6	17.0	1.3	817
CT		82.3	16.1	1.6	317
GA		79.3	18.8	1.9	622
LA		86.2	12.4	1.4	434
ME		85.7	13.4	0.9	336
MO		78.5	18.3	3.2	311
NC		85.7	13.7	0.6	168
NJ	↓	75.3	19.8	4.9	263
OK	↑	90.5	8.5	0.9	529
PA		85.0	14.0	1.0	1,002
SC	↓	77.5	20.1	2.3	298
WA		83.9	15.1	1.0	398
WV		85.9	13.0	1.1	177
WY		80.0	20.0	0.0	30
Total %		83.3	15.1	1.6	5,994
State Avg %		83.0	15.5	1.6	

Aggregate Results & State Comparisons

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

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

For each category, there is also a TABLE that looks at the arrows (i.e., \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 Wyoming, responses to information and planning questions were generally above the overall state average. In New Jersey and Georgia, results fell noticeably below the state average.

Chart 4: Adult Family Survey - Information & Planning

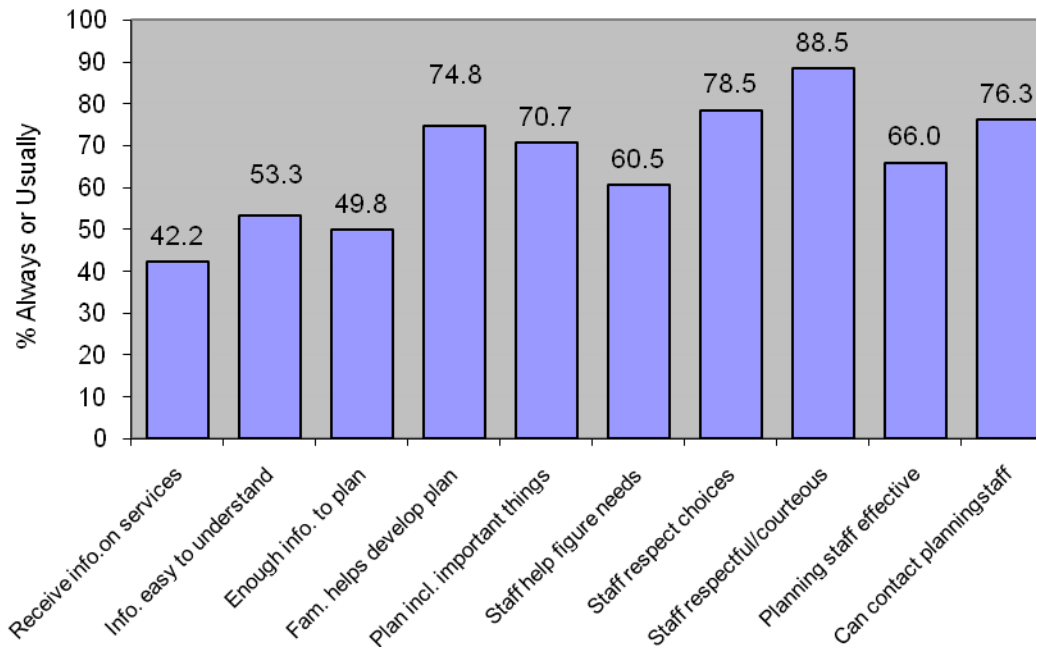


Table 18
Deviation in Responses Above & Below State Average
Information & Planning

State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Net Sum
AZ						↓			↓	↓	-3
CA											
RCOC	↑↑	↑↑	↑			↓			↑		5
CT		↓								↑	0
GA	↓↓	↓↓	↓↓	↓↓	↓↓	↓↓	↓		↓↓	↓	-16
LA	↑					↑	↑		↑	↑	5
ME			↑↑	↑	↑					↑	5
MO				↑							1
NC	↓	↓		↑						↑	0
NJ	↓↓	↓	↓↓	↓↓	↓↓	↓↓	↓↓		↓↓	↓↓	-17
OK				↑	↑	↑			↑		4
PA		↑	↑						↑		3
SC				↓							-1
WA			↓								-1
WV				↑	↑						2
WY	↑↑	↑↑	↑↑		↑↑	↑↑	↑		↑		12

Access and Delivery of Services

- ◆ In Wyoming, Louisiana and Connecticut, responses to access and delivery of services questions were generally above the overall state average. In Georgia and New Jersey, results were generally below the state average. Please note that Question 15 is considered a “neutral question”, and therefore was not used in the calculation of state deviations from the average.

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

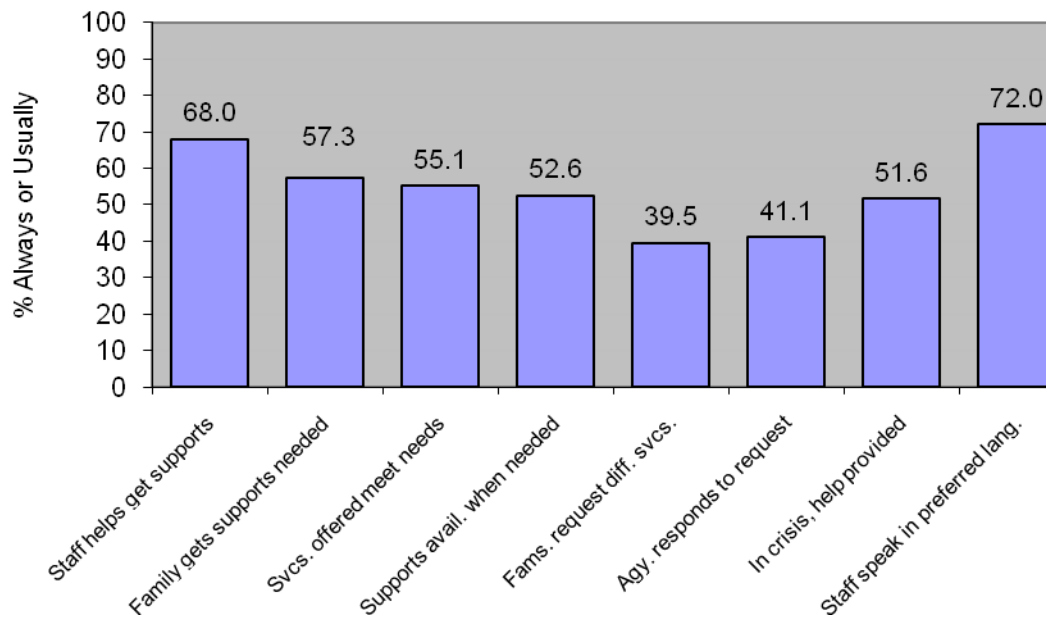


Chart 5: Adult Family Survey - Access to Services (2)

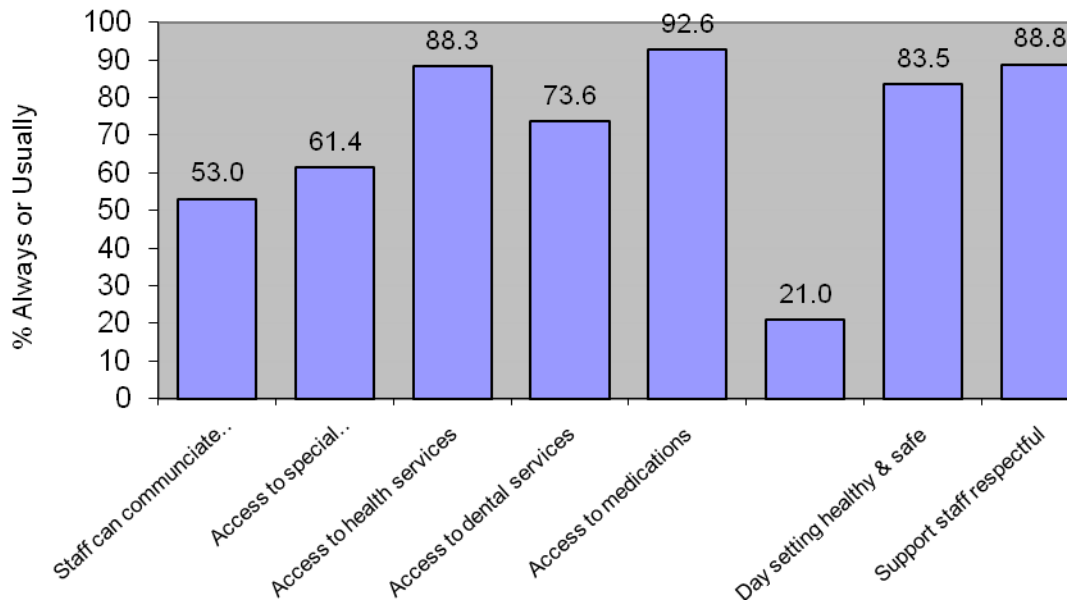


Table 19
Deviation in Responses Above & Below State Average
Access to Services & Supports

State	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Net Sum
AZ	↓						↓					↓					-3
CA-RCOC			↑	↑		↑↑		↑	↑↑	↓		↑		↓↓			5
CT						↑↑	↑		↑↑			↑		↑			7
GA	↓↓	↓↓	↓↓	↓		↓↓	↓	↓↓	↓↓	↓		↓					-16
LA		↑	↑	↑		↑↑	↑	↑	↑↑	↑		↓↓					8
ME		↑				↓			↑	↓↓		↑					0
MO		↓		↓				↑↑		↓	↓	↓↓					-4
NC				↑		↓		↑↑	↓↓			↑					1
NJ	↓↓	↓↓	↓↓	↓↓		↓↓	↓↓	↓↓	↓↓	↓	↓						-18
OK	↑	↑	↑					↓									2
PA		↑	↑					↓	↓↓	↑		↑					1
SC																	0
WA												↑		↑		↑	3
WV	↑					↓		↑↑	↓↓	↓				↓		↓	-3
WY	↑↑	↑↑	↑↑	↑↑		↑↑	↑↑		↑↑	↑↑		↑↑			↑		19

Choice and Control

- ♦ Louisiana and Oklahoma's responses to choice and control questions were generally above the overall state average. Georgia, Missouri, and Maine's results were below the state average.

Chart 6: Adult Family Survey - Choice & Control

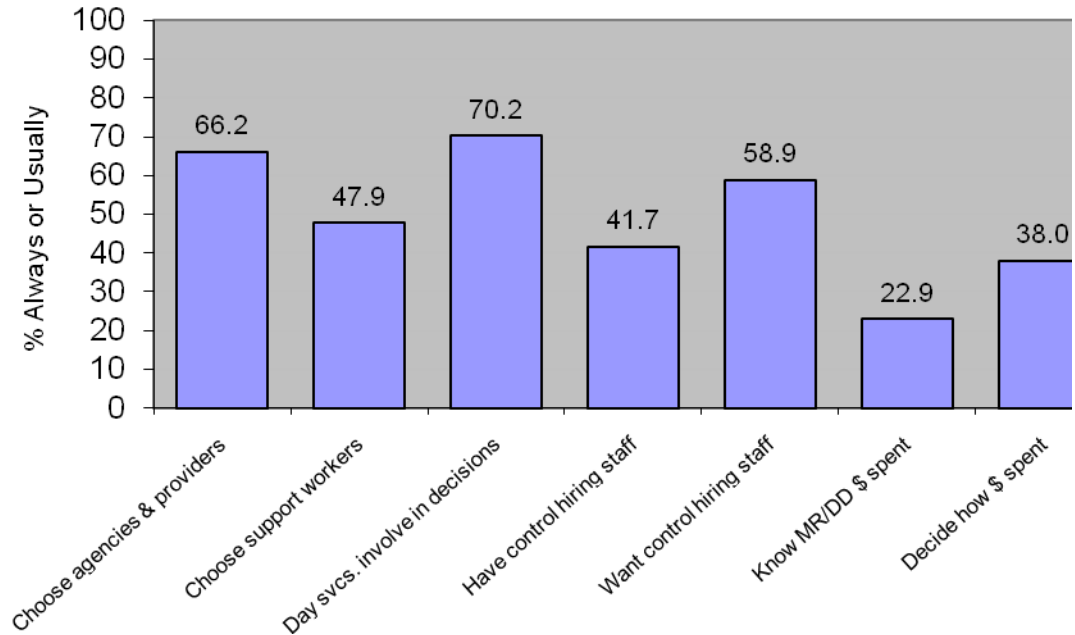


Table 20 Deviation in Responses Above & Below State Average Choice & Control								
State	Q27	Q28	Q29	Q30	Q31	Q32	Q33	Net Sum
AZ						↓↓	↓	-3
CA-RCOC		↑	↓			↓↓		-2
CT	↓	↓↓		↓↓	↓			-6
GA	↓↓	↓↓	↓	↓↓	↓↓	↓↓	↓↓	-13
LA	↑↑	↑↑	↑	↑↑	↑↑	↑↑	↑	12
ME		↓	↑↑	↓↓	↓↓	↓↓	↓↓	-7
MO	↓↓	↓↓	↓		↓	↓	↓	-8
NC	↑	↑↑		↑↑	↑↑	↓	↓↓	4
NJ	↓↓	↓↓				↓↓		-6
OK	↑↑	↑↑		↑↑	↑↑	↑↑	↑↑	12
PA	↓	↓↓		↓↓	↓	↑	↑↑	-3
SC	↓	↓↓	↓			↓	↓	-6
WA			↑	↑↑	↑	↓		3
WV	↑↑				↑	↑↑	↑	6
WY	↑↑	↑↑			↓↓	↑↑	↑↑	6

Community Connections

- ◆ In Wyoming, Oklahoma, and West Virginia, responses to community connections questions were generally above the overall state average. In New Jersey, Georgia, and Orange County, results were generally below the state average.

Chart 7: Adult Family Survey - Community Connections

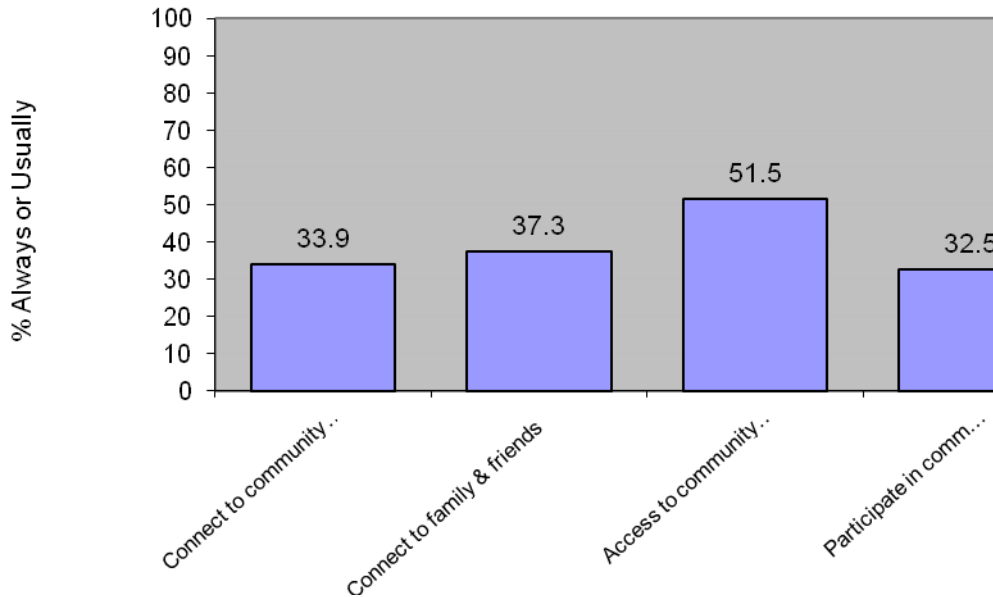


Table 21 Deviation in Responses Above & Below State Average Community Connections					
State	Q34	Q35	Q36	Q37	Net Sum
AZ				↑	1
CA-RCOC			↓↓	↓↓	-4
CT		↓	↓	↓	-3
GA	↓↓	↓↓	↓↓		-6
LA	↑↑	↑↑			4
ME	↑		↑		2
MO					0
NC					0
NJ	↓↓	↓↓	↓↓	↓↓	-8
OK	↑	↑↑	↑	↑	5
PA					0
SC			↓↓	↓	-3
WA	↓	↓		↓	-3
WV		↑↑	↑	↑↑	5
WY	↑↑	↑↑	↑↑	↑↑	8

Satisfactions with Services and Supports & Outcomes for Families

- ◆ In Wyoming, Oklahoma, and Louisiana, responses were generally above the overall state average. In Connecticut, New Jersey, and Georgia, results were generally below the state average. Note that Question 43 is considered a “neutral question”, and was not used in the calculation of deviation from the average.

Chart 8: Adult Family Survey - Satisfaction & Outcomes

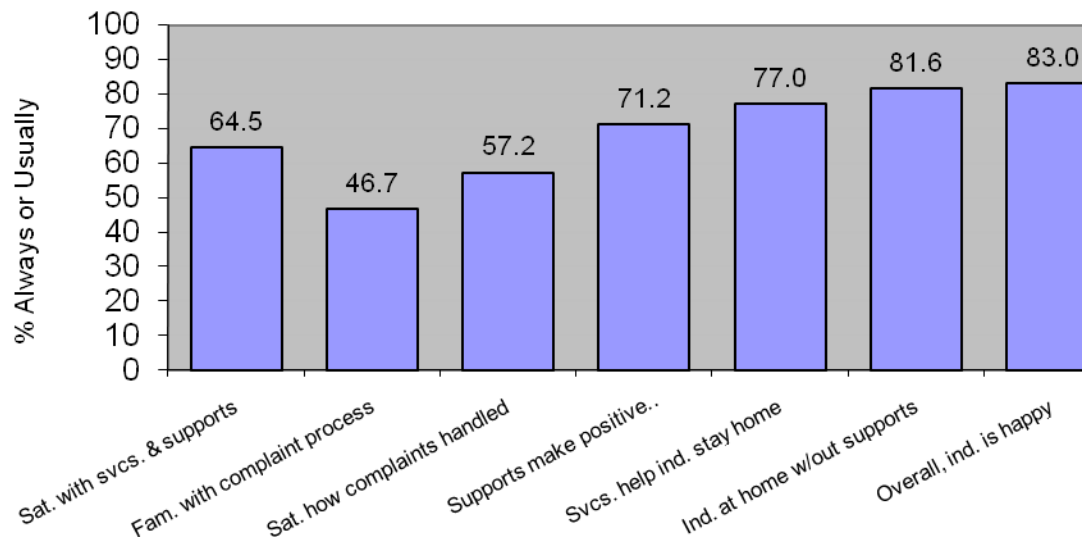


Table 22 Deviation in Responses Above & Below State Average: Satisfaction & Outcomes								
State	Q38	Q39	Q40	Q41	Q42	Q43	Q44	Net Sum
AZ		↓						-1
CA-RCOC	↑		↑↑					3
CT		↓↓	↓	↓	↓↓			-6
GA	↓	↓↓	↓	↓↓	↓			-7
LA	↑	↑↑	↑↑	↑	↑			7
ME	↑							1
MO			↓		↓			-2
NC			↓		↑↑			1
NJ	↓↓	↓↓	↓↓	↓↓	↓↓		↓	-11
OK	↑	↑↑	↑	↑	↑		↑	7
PA	↑		↑					2
SC	↓			↓	↓		↓	-4
WA								0
WV								0
WY	↑	↑↑	↑↑	↑↑	↑			8

Overall State Results

- ◆ Looking at results across all categories, Wyoming, Louisiana, and Oklahoma received results that were generally above the overall state average. In New Jersey and Georgia, results were substantially below the overall state average.

Table 23 Overall Deviation in Responses Above & Below State Average	
State	Total Sum
AZ	-9
CA- RCOC	7
CT	-8
GA	-58
LA	36
ME	1
MO	-13
NC	6
NJ	-60
OK	30
PA	3
SC	-14
WA	2
WV	10
WY	53

APPENDIX A

Analysis of Open-Ended Comments

Analysis of Open-Ended Comments

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

Overall, there were all positive and no negative comments regarding general satisfaction of state services and supports. More specifically, family members in Arizona commented most frequently on Satisfaction with Service Coordination. Representative of these comments is this one:

Our DDD case worker (Name) has been a terrific help to our family. I know she will be retiring soon and I hope her replacement will be as great an asset as (Name) has been.

Following satisfaction with service coordination, the most frequent comments were in the Dental Services domain. These comments tended to reflect areas where family members feel frustration these services. Representative is this comment:

I feel we need to get either monies or services for dental care for adults. We have need this for years and it needs attention ASAP.

Turnover in Case Managers was the third most frequently commented upon domain. Comments ranged from hope that the current case manager would not change to frustration with annual changes such as this family has experienced:

I want to keep current DDD case manager. In 20 years we have had 19 case managers. We want to keep (Name) no matter what.

CONNECTICUT

Regarding general satisfaction with services, there was a 4 to 1 ratio of positive comments compared with negative ones. In Connecticut, the Need for More Services/Supports was most frequently reported by families. Of these comments, families most often noted the need for additional social and recreational activities. Below is a typical comment:

We used to get recreation such as dancing, bowling, but they stopped transportation. (Name) used to go once a month to a deaf group but that also stopped.

Comments pertaining to Satisfaction with Service Coordination followed those noting a need for more services. With respect to service coordination, families' expressions of their case workers' contributions are full of respect and appreciation. Typical is this comment:

We've (Name and I) have had the pleasure of working with (Name) in your North Region office. She has been a godsend. She's not only knowledgeable and professional, but very caring and concerning. She's always gone over what's expected from her.

Dissatisfaction with dental services and with communication were tied as the categories with the third most comments:

It would be wonderful if the dental plan could compensate the state's dentists well enough for them to accept Medicaid. Every dentist I've spoken to over the years (at least 20) has refused to accept it. What is the use of the Medicaid card...

DMR Case Managers are Very Hard to get a hold of. DMR Case Managers do not call back promptly (ASAP). DMR Case Managers help with work services fairly good. DMR Case Managers DO NOT call just to see how you are.

GEORGIA

In Georgia, there was only one more general satisfaction comment than general dissatisfaction comment. More specifically, families most frequently provided comments about Funding and Budget Cuts. The majority of these comments express family members' interest in more transparency in funding. They want to know more about how much money the state receives for care of their family member, and how much of this is passed along to providers:

Family should receive at least a quarterly statement as to how much of waiver is spent so far. How much is left before fiscal year is up. Difficult to plan staff as well as family when you don't have that info.

Several other comments also illustrate that families in Georgia are interested in individual budgets and self directing services:

I am given some information about the amount of money received for her support, but the agency will not tell what percent they keep. I am interested in the new waiver option of self-direction as I need more money going to direct support staff.

After funding comments, families reported on their Need for More Services/Supports. Families want more help with finding homes for individuals to live in, for home modification, for respite supports, and just finding information about services available in their areas. Typical is this comment:

Residential services are a desperate need in Georgia.

Also in the top three comment areas were those regarding Dental services. These comments reveal deep frustration with accessing the most basic oral care. Some families are able to access dental services only by driving four hours (one way). Others have no access at all as this family relates:

There is no dental help for my son! He needs it very bad! I have called every dentist and no one does it!! My son is (Name) and my phone is (phone number).

MISSOURI

Regarding general satisfaction with services, there was a greater than a 3 to 1 ratio of positive comments compared with negative ones. As with many of the states conducting the NCI Family survey, Missouri families most often commented on the Need for More Services/Supports. In some cases, the Need for More Services is the need to be moved off the waiting list to receiving waiver services. This comment illustrates the experiences of these families:

Our son is 24. We have asked for services repeatedly throughout the year. Even in emergencies, we've been pushed on a "waiting list" as there were no services available. Ask for help in researching services for young adults. Nothing available, no (funding)...

Families in Missouri comment on being very satisfied with Service Coordination. Many expressed hope of retaining their current case manager just as this family member notes:

I don't want to change SC. I want to keep (Name). (Regional Office) helped get services for her daughter too, when first started school and also during Christmas hard times.

The next most frequent commented upon area for families living in Missouri is concern over inadequate Funding. Parents have been advised there is no funding available; and still the services are being cut more deeply:

My husband and I serve on two different boards in our county that serve adults and children with disabilities through their various organizations. The lack of funding for adults in our area is CATASTROPHIC.

NORTH CAROLINA

There were the same amount of comments of families expressing general satisfaction than there were comments expressing general dissatisfaction. More specifically, family responses from North Carolina were most frequently about the Need for More Services/Supports. Families even offered ideas such as this:

I would like to see more "team" volunteer work available. My son will be graduating next year and would do well with 2 or 3 other peers doing work together with 1 job coach. This would be beneficial socially and would also be a wise use of resources. I realize this would not work for everyone – but for some it would be a great fit. Please consider this approach as an option for 2 to 3 hours a day.

Closely following comments on needs for additional services were comments expressing Satisfaction with Work or Day Programs. Family members noted that individuals are proud of working and making things, and that staff take time to help people.

I pick (Name) up every day and when she is working on a Kindermusik (or whatever type contract work they have) she comes running to me and says – Look what I'm doing! – and is so proud of what she has accomplished. I want her to continue being proud of what she has accomplished. I want her to continue being proud of what she does.

Several categories of comments tied for third place in terms of numbers of comments: Funding, Substitute Staff, and Dissatisfaction with Work or Day Programs. Families suggested having 'floaters' available to cover when workers don't show, reviewing need for services frequently so that there is an appearance of fairness to the distribution of funding and services, and that the work and day support programs should only be hiring caring staff.

NEW JERSEY

In New Jersey, there was only one more general satisfaction comment than general dissatisfaction comment. Families in New Jersey provided feedback most often in the category of General Concerns and Need for More Services/ Supports. General concerns included a number of the stories for those waiting for services and confusion about how the system works and what options for support exist. The following comments illustrate those waiting for a service:

I never got any help to support my disability child. I call all the time. No one returned my calls.

We have not received any services for years. We have been trying to get guardianship for at least 12 years. A caseworker used to call once a year but that has not happened in several years. Obviously we receive nothing from DDD. I have called again for guardianship.

Next most frequent were family comments regarding the Need for More Services/Supports. The need for housing is raised in almost of these comments.

I appreciate the effort that your are making in doing this survey, but had a tough time answering the questions because they do not in any way reflect reality. ... The question about whether the child would be living at home without supports or services provided by DDD is a joke and an insult. First there are no supports or services available-everything I have for my child is paid for, provided and found by me. Second, there is no earthly chance that my child could ever get into a group home even in the case of total family emergency because the State of NJ has completely dropped the ball and there are simply too few group homes available to service the thousands and thousands of people who are so desperately in need of them.

Aging Caregiver Issues also rose to the top three issues in New Jersey. Almost all of these comments were from parents expressing concern that they are aging and are not assured that housing will be there when they are no longer able to care for their son or daughter. This comment is from a couple that has advocated within the system and are distraught that after 25 years there is not more change:

My husband and I have worked very hard in the last 25 years with the state and followed all the rules to try and get what our son needs. My chief complaint and our ultimate concern is what happens to our son when we die. The disgraceful priority list for residential services for the disabled has no way of working for all of our most vulnerable citizens. Some of the archaic rules to remove the disabled from the waiting list must change. I was one of a group of parent that met with Commissioner Valez and her assistant and staff a few months back to ask their help in trying to look at other options, for example [private program]. We were basically told because it is private, the state would not help fund a project such as this even though it could cost less than what they would have to fund for a group home or RLC allocation. The state must change. We should all be addressing human beings, not rules!!! 8,000+ and no way to get off the list except for an emergency and the place would be inadequate!!!

OKLAHOMA

There was almost a 6 to 1 ratio of positive general comments to negative general comments. Families receiving services in Oklahoma most often commented on challenges to securing adequate Dental services. All the comments expressed the hope for additional financial support and many remarked on the lack of dentists that accept Medicaid or state payment. Several of the comments noted that families were paying out of pocket for dental care, but others, such as this comment, note the frustration of not having adequate private funds:

I would like my daughter to have dental work on her teeth. I don't have that. Unless I will have to pay for it out of my pocket. Myself. I do not have the money to do that. Her teeth need to be cleaned and also need to be checked because they bleed a lot.

Following closely to comments regarding dental care were Satisfaction with Service Coordination comments. These families express extremely high satisfaction with availability, information shared, going beyond the expected, and being an asset to the agency. Below is a representative comment:

Case Manager (Name) is WONDERFUL! She goes out of her way to attend to detail and make sure we have what we need. She is an asset to DDS.

Also close in frequency to the above comments were those related to Funding services. Families want information on how much money is spent for services such as occupational therapy and are concerned that

too much money is allocated to providers for management instead of direct services. Several comments expressed a preference to control their own funds, such as this comment:

We would like to manage the funds that pay for our family member's services such as HTS and job coaching hours.

PENNSYLVANIA

Pennsylvania families had more than a 2 to 1 ratio of general satisfaction comments compared to general dissatisfaction comments. The most common comments in Pennsylvania expressed Satisfaction with Service Coordination. Several of these comments related high satisfaction from families that received new support coordinators that found new supports for the individual; thus even new case workers are perceived to be very helpful. Typical is this comment:

I've been waiting for 5 years for some kind of help for my sister. My new support worker (Name) has done more for (Name) than I ever expected. With the help of (Name), my sister has a chance to attend a school this October. I'm very thankful to (Name).

After comments of satisfaction with case workers were comments of families Satisfied with Employment and Day Programs. These included individuals who were supported for years in a workshop to those attending senior day programs. Several of the comments mentioned that as a result of participating in the work or day programs, the individuals supported were happier than they'd ever been. This comment exemplifies these:

Since (Name) has been associated with (provider's Name) Adult Day Care Program – she is the happiest I've ever seen her. She simply can't wait to get to the senior center in (city). The staff at the senior center are all to be congratulated.

There were also many comments from families indicating that they need more services and supports. The following comment is just one example:

We greatly need more services. Our emergency and waiting lists have got to be met. Families want to keep their individuals home with him as long as possible but we do need help and support.

REGIONAL CENTER OF ORANGE COUNTY, CALIFORNIA

There is a greater than 5 to 1 ratio of general comments expressing satisfaction than general comments expressing dissatisfaction. Orange County families receiving services through the Regional Center commented most often on their Satisfaction with Service Coordination services. Service coordinators are described as helpful, responsive, professional and truly caring. Several noted years of experience with the same Service Coordinator. This comment embodies the gratefulness families expressed when they feel supported by a competent Service Coordinator:

Our RCOC coordinator does the best that she can with the resources she is provided. I feel that she truly cares about my son and his well-being. Families and parents need more emotional support. Care giving takes a lot away from one's health, relationships.

The next highest amount of comments had to do with family members wanting more information about services and supports. The following comment is similar to several in this category:

I don't know what help (Name) is getting now or what does he qualify for. He was getting the bus pass and that's it. Is there's anything else he can get?

Families also often commented on their Satisfaction with Employment and Day Programs. They wrote that working or attending a day program makes a significant difference in the quality of life. This comment illustrates family appreciation:

My son's life has been enriched through his employment with (Provider). Although his job coaches may change somewhat frequently, he has been able to adapt and has never complained. His work gives him a sense of purpose.

SOUTH CAROLINA

Fewer comments were received from South Carolina than most of the other participating states. Regarding general comments, families by a 3 to 2 margin expressed general satisfaction of services and supports. Of families that did offer more specific comments, those regarding dissatisfaction with Respite Services were most frequent. These comments note that Respite services are harder to secure approval for and even harder to find certified respite caregivers. This comment illustrates the frustration:

Cannot get any respite help; no one is available! Have called when needed, but didn't have anyone! I don't get a break unless a friend will come in or I take him to her home for a few hours.

Tied for the next most frequent comments in South Carolina are those satisfied and those dissatisfied with Employment and Day Programs. One positive comment was this example:

The (Provider) center in (City) is a well organized and efficiently administered organization. The off-campus day program provided by (Provider) has given my son a tremendous sense of purpose and has expanded his physical and social skills.

One dissatisfied family noted that their family member was not being offered work or a day program:

My son gets bored during the summer, and wants something to do (employment or a learning environment), where he gets to be around other people. I don't know if camp would be good at his age. He wants to earn money and be around people. If there are people in the community who would hire special needs people and work with them would be great.

WASHINGTON

In Washington, families had more comments on their general satisfaction of services and supports than dissatisfaction at greater than a 4 to 1 ratio. Concerning specific comments, families were as likely to comment on the need for Additional Information on Services and Supports as on their Need for More Services and Supports. Comments pertaining to the need for additional information requested information on a range of supports from autism services to dental care to how to find low income housing. No two comments shared the same request for information. These two comments are representative:

I always feel there may be more information I'm not aware of, services, etc., benefiting our daughter. For example, I just learned I could use some respite hours to pay for recreational classes.

We have recently had the death of (Name's) mother. She was the primary caregiver and now we are struggling to find out all we can about the services available for (Name).

Families expressing a Need for More Services and Supports were also very specific, mentioning help with rent, food, financial planning, community activities, and help with behavior such as Prader Willi Syndrome.

I NEED ASSISTANCE moving my daughter out into the community, developing independent skills. She is TRAPPED in our home, but she is capable of functioning independently with support. I cannot afford to pay for the support and I cannot find any services...

There were many comments concerning where the family member lives. Although some of the comments indicated the desire for their family member to live in the "community", most of the comments relayed the family's wish to keep their family member at home with them.

The only comment I wish to make is that I will try to care for my son as long as God gives me the strength to, but I would not like my son to be separated from me. For this reason, I ask you to pardon me if there are some questions that I don't understand.

WEST VIRGINIA

Fewer families in West Virginia provided comments. Of those that did, a majority provided general comments pertaining to receiving services and supports. Of these comments, there were three times more indicating satisfaction with services and supports than dissatisfaction. For those comments that were more specific, most frequent were statements of Satisfaction with Work and Day Programs. Families report that their family member is happy at the day program or sheltered workshop. Time the individual supported is in a program is time available to the family member to conduct their own lives. This comment is representative:

The day program that my daughter attends is a life line for her. Without it, she would digress. Without it, I would not be able to work.

After comments expressing satisfaction with work or day programs, families offered comments most often on Case Manager Turnover. All of these comments reflect on turnover as a negative experience, such as this comment:

The agency is always changing support coordinators. We didn't have one from 7 months last year. We didn't have a home visit for 7 months. I was not happy about this. I would call the agency all the time about this.

The following categories had the next most number of comments: Funding and Budget Cuts, Dissatisfaction with Respite, and Shortage of Staff. Here is a comment representative from the families dissatisfied with respite services:

It would be nice if they provided more respite providers.

WYOMING

There were only a couple of comments received from Wyoming this year. There was only one comment stating general satisfaction with services and supports and one comment stating general dissatisfaction with services and supports. Here is one of the few other comments:

About my case worker (Name) she does help me understand things. For example: I may not know much about filing complaints but she explains and walks me through the way of doing it.

So if I have any questions at all for anything she is happy to try to help. (Satisfied with Case Management)

