

Adult Family Survey

Final Report– July 2010
2008-2009 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

Eleven states conducted the National Core Indicators (NCI) Adult Family Survey during the 2008-2009 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, 2009.

This report is organized as follows:

I. INTRODUCTION

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

II. ADULT FAMILY SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

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

IV. RESULTS

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

I. Introduction

Overview of National Core Indicators

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

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

During Phase II (1999-2000), the original indicators were revised and data collection tools and methods were improved. The new (Version 2.0) indicator set consisted of 60 performance and outcome indicators. Twelve states (see below) participated in Phase II, and this data is considered baseline project data. In Phase III (2000-2001), additional states joined the effort and the project expanded its scope to include services for children with developmental disabilities and their families.

In 2002, the Core Indicators Project changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. And between 2002 and 2009, the NCI effort continued to expand. The following figure summarizes state participation in the National Core Indicators since its inception through the 2008-2009 data collection cycle. States are listed if they participate in one or more of the NCI activities (e.g., consumer survey, family surveys, etc.).

TABLE 1: NCI State Participation										
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 2006-07	Phase X 2007-2008	Phase XI 2008-2009
AZ	AZ	AZ	AL	AL	AL	AL	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	AR	AR	AR	AR
MO	KY	DE	CA-RCOC	CA-RCOC	CA-RCOC	CA-RCOC	AZ	AZ	AZ	AZ
NE	MA	IA	CT	CT	CT	CT	CA-RCOC	CA-RCOC	CA-RCOC	CT
PA	MN	KY	DE	DE	DE	DE	CT	CT	CT	DE
VT	NE	MA	HI	HI	DC	DC	DE	DE	DE	GA
VA	NC	MN	IL	IN	HI	HI	DC	GA	GA	HI
	PA	MT	IN	IA	IN	KY	GA	HI	HI	IL
	RI	NE	IA	KY	KY	MA	HI	IN	IN	IN
	VT	NC	KY	MA	MA	ME	KY	KY	KY	KY
	VA	PA	MA	ME	ME	NC	MA	MA	LA	LA
	WA	RI	NE	NE	NE	OK	ME	ME	MA	MA
		UT	NC	NC	NC	PA	NC	NM	ME	ME
		VT	OK	OK	ND	RI	OK	NC	MO	MO
		WA	PA	PA	OK	SC	PA	OK	NC	NC
			RI	RI	PA	VT	RI	PA	NJ	NJ
			UT	SC	RI	WA	SC	RI	NM	NM
			VT	SD	SC	WV	SD	SC	NY	NY
			WA	VT	SD	WY	TX	TX	OK	OH
			WV	WA	VT		VT	VT	PA	OH- HC
			WY	WV	WA		WA	WA	RI	OH- MC
				WY	WV		WV	WV	SC	OH-MEORC
					WY		WY	WY	TX	OK
									VT	PA
									WA	SC
									WV	TX
									WY	WA
										WY

Denotes first year 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 2009, 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	Phase XI 2008-2009
AZ	AZ	CT	AZ	CA - RCOC	AZ	CA-RCOC	AZ	CT	AZ	GA
CT	CT	DE	CA-RCOC	CT	CA-RCOC	CT	CA-RCOC	DE	CA-RCOC	HI
MO	KY	IA	HI	DE	CT	HI	CT	GA	CT	IL
NE	NE	KY	IL	HI	ME	OK	GA	HI	GA	LA
PA	NC	MA	IA	IN	NC	PA	KY	ME	LA	ME
VT	PA	MN	NE	IA	ND	SC	ME	NM	ME	MO
VA	VT	MT	NC	ME	OK	WV	NC	OK	MO	NM
	WA	NE	OK	MA	PA	WY	OK	PA	NC	OH
		NC	PA	NC	SC		PA	VT	NJ	OK
		PA	UT	OK	WA		SC	WV	OK	PA
		RI	VT	PA	WV		SD	WY	PA	SC
		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 2008-2009 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 the services that family members and families receive 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. Final sample size of 400 would provide a 95% confidence level and a 5% margin of error when interpreting the results. 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 2008-2009, 11 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
Georgia	1,200	341	28%	270
Hawaii	1,000*	411	41%	370
Illinois	3,976	603	15%	411
Louisiana	1,600	583	36%	540
Maine	1,350	400	30%	362
Missouri	1,150	402	35%	363
New Mexico	1,364	539	40%	531
Ohio	1,000	269	27%	233
Oklahoma	1,624	571	35%	502
Pennsylvania	4,300	1,279	30%	1075
South Carolina	1,600	400	25%	329
Overall	20,164	5,798	29%	4,986

*Approximate

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.

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.

Important note about how the results are displayed:

Response rates varied by state, and some states were more successful than others in obtaining the recommended sample size of 400 returned surveys. In order to include as many states as possible but still maintain acceptable research standards, we made the decision to exclude states with final samples of less than 200 returned surveys. States that submitted a final sample that resulted in a margin of error of between 5% and 7% were included in the analysis, but are listed separately in the tables because they do not meet the accepted minimum standard. States that met the minimum standard of a 5% margin of error are grouped together at the top of the tables.

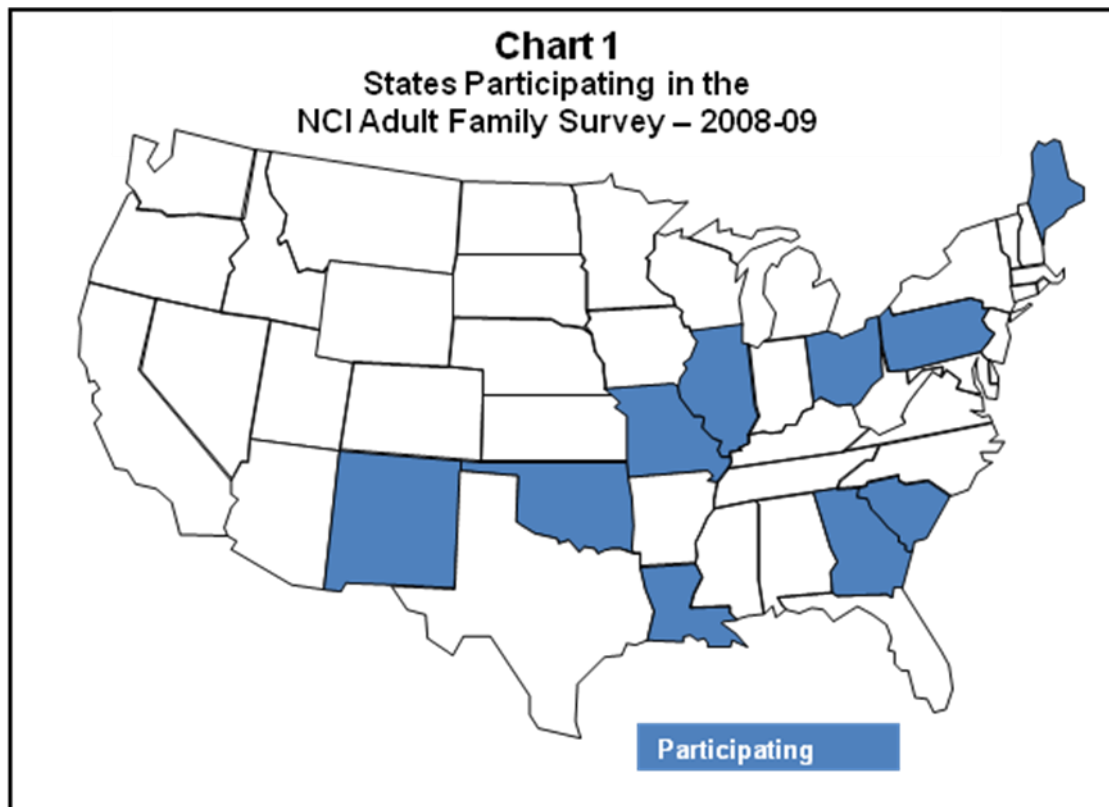
The term “margin of error” is also known as the “confidence interval.” A margin of error of 5% means that the true percentage for the population is within plus or minus 5% of the estimate from the sample. A higher margin of error indicates a less precise estimate of the population, and these results should be interpreted with greater caution. A confidence interval of 95% combined with margin of error of 5% means that we can be 95% certain that the true percentage for the population is within 5% of the estimate.

All of the states listed in the tables are included in the total percentage and state average displayed at the bottom of each table.

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

Participating States

- ♦ Eleven states provided data for this Report. They include: Georgia, Hawaii, Illinois, Louisiana, Maine, Missouri, New Mexico, Ohio, Oklahoma, Pennsylvania, and South Carolina (Map below does not include Hawaii)



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 33, with a range in age from 18 to 94.
- ♦ Seventy percent (70%) of the family members were White, 14% were Black/African-American, 6% were Hispanic/Latino, 6% were Asian-American, 3% were American Indian/Alaska Native, 3% were Native Hawaiian/Pacific Islander, and 4% were Mixed Races.
- ♦ Twelve percent (12%) of households include more than one individual with a developmental disability.
- ♦ One-third (33%) of the family members with disabilities had a diagnosis of moderate mental retardation. Additionally, 24% were individuals with severe/profound mental retardation, 19% had mild mental retardation, and 7% 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 (30%), physical disabilities (28%), vision/hearing impairments (24%), and communication disorders (22%).

Gender of Family Member

Table 5 Gender (%)		
State	Male	Female
Margin of Error \leq 5%		
HI	61.3	38.7
IL	58.5	41.5
LA	57.5	42.5
ME	55.2	44.8
MO	56.3	43.7
NM	53.1	46.9
OK	55.1	44.9
PA	55.3	44.7
Margin of Error > 5%		
GA	55.9	44.1
OH	53.6	46.4
SC	51.9	48.1
Total N	2,687	2,129
Total %	55.8	44.2
State Avg %	55.8	44.2

Age of Family Member

Table 6 Age of Family Member (%)		
State	Average Age	Range
Margin of Error \leq 5%		
HI	30.9	18-89
IL	31.0	18-82
LA	32.6	18-72
ME	34.2	19-80
MO	33.0	18-61
NM	33.8	18-94
OK	31.1	18-74
PA	34.4	18-94
Margin of Error > 5%		
GA	34.7	18-71
OH	35.7	18-66
SC	32.0	18-83
Total N	4,328	
Total	33.1	
State Avg	33.0	18-94

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
Margin of Error < 5%								
HI	22.9	1.7	49.6	1.7	29.0	18.3	2.9	4.1
IL	72.3	15.0	2.7	1.5	0.7	2.0	0.2	8.1
LA	67.9	30.0	0.0	0.2	0.4	1.0	0.0	0.6
ME	97.5	0.3	0.3	3.4	0.0	1.4	0.0	0.8
MO	91.4	3.9	0.6	2.8	0.6	1.1	0.0	0.6
NM	40.0	0.8	0.8	5.2	0.2	9.8	0.6	45.4
OK	76.4	11.2	2.9	15.9	0.0	3.3	0.2	2.1
PA	92.6	3.9	1.6	0.9	0.0	1.1	0.0	1.5
Margin of Error > 5%								
GA	57.3	39.6	0.8	0.8	0.0	1.5	0.4	0.4
OH	88.0	8.9	1.3	0.4	0.0	1.3	0.0	1.8
SC	53.4	42.3	2.5	1.9	0.0	0.9	0.3	2.5
Total N	3,472	599	233	157	108	173	17	330
Total %	71.6	12.3	4.8	3.2	2.2	3.6	0.4	6.8
State Avg %	69.1	14.3	5.7	3.2	2.8	3.8	0.4	6.2

More Than One Person with Disabilities Living in Household

Table 8 More Than One Person in Household with a Developmental Disability		
State	Yes	No
Margin of Error \leq 5%		
HI	11.7	88.3
IL	13.2	86.8
LA	10.7	89.3
ME	8.9	91.1
MO	10.4	89.6
NM	12.6	87.4
OK	9.5	90.5
PA	13.1	86.9
Margin of Error $>$ 5%		
GA	13.1	86.9
OH	7.5	92.5
SC	18.6	81.4
Total N	586	4,328
Total %	11.9	88.1
State Avg %	11.8	88.2

Level of Mental Retardation/Intellectual Disability of Family Member

CHART 3: Level of MR/ID of Family Member

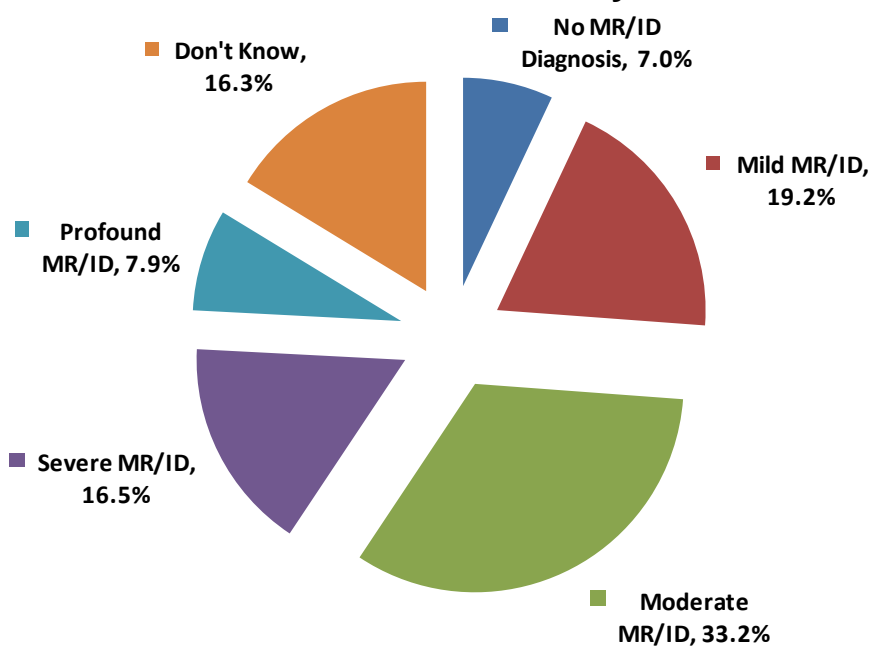


Table 9 Level of Mental Retardation / Intellectual Disability of Family Member (%)						
State	No MR/ID Diagnosis	Mild MR/ID	Moderate MR/ID	Severe MR/ID	Profound MR/ID	Don't Know
Margin of Error ≤ 5%						
HI	7.6	17.8	30.5	17.5	7.3	19.3
IL	5.6	15.9	32.2	20.9	11.6	13.8
LA	10.2	17.0	31.8	19.3	11.0	10.8
ME	6.6	23.1	39.7	10.9	3.4	16.3
MO	9.9	19.7	27.2	19.7	5.8	17.7
NM	6.6	19.2	33.7	16.2	6.2	18.2
OK	1.3	19.8	36.7	20.5	7.0	14.8
PA	2.5	23.5	37.0	12.6	5.8	18.5
Margin of Error > 5%						
GA	3.9	13.7	40.4	17.6	10.6	13.7
OH	5.5	25.7	33.5	12.4	5.0	17.9
SC	17.2	15.3	22.1	14.0	13.6	17.9
Total N	293	917	1,570	754	354	762
Total %	6.3	19.7	33.8	16.2	7.6	16.4
State Avg %	7.0	19.2	33.2	16.5	7.9	16.3

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
Margin of Error \leq 5%						
HI	11.1	18.6	21.4	9.1	32.0	0.6
IL	11.9	23.3	26.6	7.4	33.7	0.2
LA	15.1	12.3	22.2	11.1	30.3	0.8
ME	14.6	16.0	15.2	5.2	25.9	0.0
MO	10.7	17.9	23.1	10.2	27.0	0.6
NM	13.3	13.5	20.8	9.3	27.4	1.0
OK	15.5	14.9	27.5	14.9	38.0	1.1
PA	15.1	11.6	18.8	7.1	23.8	0.6
Margin of Error > 5%						
GA	16.9	13.7	18.5	9.2	33.3	0.0
OH	12.9	12.4	19.4	9.7	26.7	0.5
SC	18.8	18.4	23.0	16.4	33.9	1.3
Total N	672	714	1,014	457	1,391	30
Total %	14.2	15.1	21.5	9.7	29.5	0.6
State Avg %	14.2	15.7	21.5	10.0	30.2	0.6

Table 10B						
Other Disabilities of Family Member (%)						
State	Vision/ Hearing Impairment	Physical Disability	Communi- cation Disorder	Alzheimer's Disease	Down Syndrome	Other Disability
Margin of Error \leq 5%						
HI	20.3	26.0	19.1	1.7	16.6	19.7
IL	20.1	29.5	22.6	0.2	16.4	24.3
LA	27.8	33.0	23.6	0.2	14.4	17.6
ME	21.3	20.4	17.5	0.3	25.9	14.9
MO	24.2	27.8	18.2	0.3	16.3	20.4
NM	26.6	29.6	29.6	1.0	23.4	21.4
OK	27.7	36.8	28.4	0.6	17.6	18.9
PA	21.8	22.7	15.6	0.6	20.7	14.1
Margin of Error > 5%						
GA	26.1	25.3	19.7	0.0	15.3	16.5
OH	19.4	24.0	19.4	0.0	20.7	14.3
SC	29.9	36.5	25.7	2.0	10.5	22.7
Total N	1,137	1,327	1,014	30	869	69
Total %	24.1	28.1	21.5	0.6	18.4	18.3
State Avg %	24.1	28.3	21.8	0.6	18.0	18.6

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, 51% 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 39% were under 55.
- ♦ The vast majority of respondents were parents of adult children with disabilities (86%). The remaining respondents included siblings (7%), spouses (1%), and others (7%).
- ♦ Ninety-seven (97%) 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.
- ♦ Over two-thirds (68%) of respondents indicated that they were their family member's legal guardian or conservator. Across the states, results varied from 49% in Georgia to 86% in Connecticut and Illinois.
- ♦ Most respondents (76%) indicated that they were in good or excellent health, however over one-quarter of respondents (24%) categorized their health as being fair or poor.
- ♦ Almost half (46%) of respondents had an annual household income (including all wage earners within the household) of \$25,000 or less. Twenty-eight percent (28%) had a household income between \$25,001 and \$50,000, and 26% had an income over \$50,000.

Age of Respondent

Table 11				
Age of Respondent (%)				
State	Under 35	35-54	55-74	75 or Older
Margin of Error \leq 5%				
HI	6.5	36.5	49.9	7.1
IL	3.4	40.0	48.5	8.0
LA	6.9	35.6	46.9	10.6
ME	2.2	32.7	54.5	10.6
MO	2.8	31.6	54.7	10.9
NM	5.3	32.3	53.7	8.7
OK	4.7	35.6	50.8	8.8
PA	2.1	33.2	51.3	13.4
Margin of Error > 5%				
GA	5.2	31.7	53.7	9.3
OH	2.2	28.3	57.1	12.4
SC	8.7	45.2	39.0	7.1
Total N	212	1,706	2,493	499
Total %	4.3	34.7	50.8	10.2
State Avg %	4.5	34.8	50.9	9.7

Relationship of Respondent to Individual with Disabilities

Table 12 Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
Margin of Error \leq 5%				
HI	83.2	7.7	0.6	8.5
IL	85.7	8.6	1.5	4.2
LA	88.7	7.2	0.2	3.9
ME	85.3	8.1	0.6	6.1
MO	96.1	1.9	0.0	1.9
NM	85.1	8.3	0.4	6.2
OK	88.4	4.3	0.0	7.2
PA	87.6	8.2	0.2	4.0
Margin of Error > 5%				
GA	79.0	9.0	0.0	12.0
OH	85.2	10.5	0.4	3.9
SC	77.7	5.6	2.2	14.6
Total N	4,240	355	23	296
Total %	86.3	7.2	0.5	6.0
State Avg %	85.6	7.2	0.6	6.6

Respondent's Role as Primary Caregiver

Table 13 Respondent is Primary Caregiver (%)		
State	Yes	No
Margin of Error \leq 5%		
HI	95.2	4.8
IL	97.3	2.7
LA	95.3	4.7
ME	96.6	3.4
MO	97.5	2.5
NM	97.7	2.3
OK	98.1	1.9
PA	96.0	4.0
Margin of Error > 5%		
GA	95.9	4.1
OH	97.3	2.7
SC	95.6	4.4
Total N	4,718	168
Total %	96.6	3.4
State Avg %	96.6	3.4

Respondent's Role as Guardian or Conservator

Table 14 Respondent is Legal Guardian or Conservator (%)		
State	Yes	No
Margin of Error \leq 5%		
HI	84.3	15.7
IL	85.7	14.3
LA	70.7	29.3
ME	82.8	17.2
MO	68.4	31.6
NM	79.7	20.3
OK	63.7	36.3
PA	53.2	46.8
Margin of Error $>$ 5%		
GA	49.4	50.6
OH	53.4	46.6
SC	55.8	44.2
Total N	3,128	1,530
Total %	67.2	32.8
State Avg %	67.9	32.1

Health of Respondent

Table 15 Health of Respondent (%)				
State	Excellent	Good	Fair	Poor
Margin of Error \leq 5%				
HI	20.3	63.8	12.7	3.1
IL	18.1	55.2	23.0	3.7
LA	18.6	44.6	29.8	7.0
ME	23.3	58.2	15.5	3.0
MO	16.8	52.3	25.6	5.4
NM	29.2	55.9	13.7	1.2
OK	19.6	54.4	22.9	3.1
PA	16.0	58.1	22.7	3.2
Margin of Error $>$ 5%				
GA	14.6	61.8	21.3	2.2
OH	18.3	63.8	14.7	3.1
SC	18.6	53.1	23.9	4.3
Total N	941	2,721	1,029	175
Total %	19.3	55.9	21.1	3.6
State Avg %	19.4	56.5	20.5	3.6

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
Margin of Error \leq 5%					
HI	17.5	17.5	34.2	17.2	13.5
IL	16.7	16.1	28.7	23.2	15.3
LA	28.1	22.1	27.3	10.7	11.8
ME	not asked in Maine				
MO	24.9	27.9	26.6	13.6	7.0
NM	25.9	23.0	28.5	14.8	7.8
OK	21.6	19.5	31.6	13.9	13.5
PA	22.7	24.4	29.1	13.5	10.2
Margin of Error > 5%					
GA	31.8	21.5	24.5	11.2	11.2
OH	22.6	19.5	26.7	13.8	17.4
SC	39.4	18.0	25.3	8.7	8.7
Total N	979	858	1,141	563	449
Total %	24.5	21.5	28.6	14.1	11.3
State Avg %	25.1	21.0	28.3	14.1	11.6

Services and Supports Received

- ♦ Across participating states, on average, day/employment and transportation services were the supports most often provided (68% and 60% respectively) to the family member with disabilities.
- ♦ Additionally, 41% received financial support, 41% obtained in-home supports, 29% utilized out-of-home respite care obtained in-home supports, and 29% 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
Margin of Error \leq 5%						
HI	42.2	32.6	29.4	65.5	59.1	24.9
IL	41.3	56.8	23.4	67.3	50.4	31.3
LA	35.0	71.8	30.5	48.9	52.5	14.9
ME	47.8	21.7	18.1	84.6	74.4	25.3
MO	34.4	33.5	28.5	62.5	51.8	20.3
NM	54.4	47.2	69.1	70.0	48.0	82.1
OK	43.0	65.6	13.5	45.5	43.1	27.4
PA	41.5	26.9	28.9	71.8	61.0	23.4
Margin of Error > 5%						
GA	33.9	25.6	18.9	80.3	72.2	23.2
OH	34.6	29.1	25.6	87.8	82.7	25.0
SC	43.6	41.4	27.4	58.4	59.9	23.2
Total N	1,857	2,004	1,423	3,165	2,811	1,423
Total %	41.7	41.8	29.9	66.2	57.8	30.0
State Avg %	41.1	41.1	28.5	67.5	59.5	29.2

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.

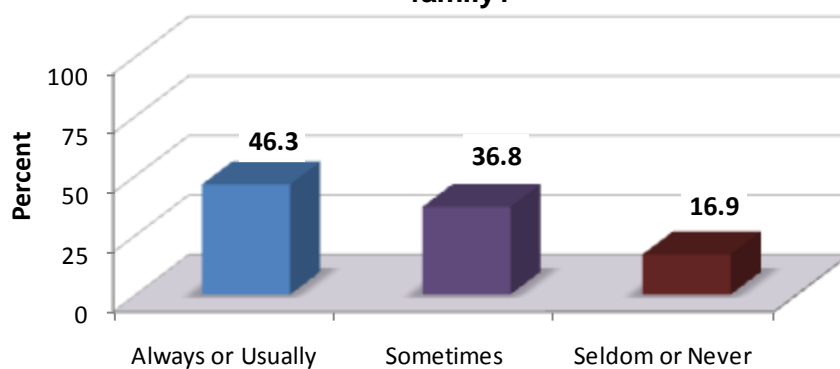
- ♦ The Figure illustrates the State Average results (i.e., the average percentage across the eleven states that conducted this survey).
- ♦ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state 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 (46%) of respondents indicated they always or usually receive information about the services and supports available to them. Individual state results varied, ranging from 34% in Georgia to 59% in New Mexico.
- Among those who receive information, over half (55%) found the information easy to understand, while the remaining 45% found the information, at least sometimes, difficult to understand.
- Just over half of the respondents (54%) stated that they got enough information to help them participate in planning, while 46% indicated they only sometimes, seldom, or never had enough information.
- Four-fifths (80%) of respondents indicated that they helped in developing their family member's service plan.
- Of those families with a service plan, 74% stated that the plan included things important to the respondent. Twenty-six percent (26%) of respondents indicated that the plan only sometimes, seldom or never included things important to them.
- Almost two-thirds (65%) of respondents indicated that planning staff would help them figure out the supports they needed. However, (36%) stated that this was only sometimes, seldom, or never the case.
- Just over four-fifths (82%) of respondents felt that staff respect their choices and opinions.
- Nine of ten (90%) respondents felt that agency staff were generally respectful and courteous.
- Seventy percent (70%) of all respondents felt that agency staff were generally effective.
- Eighty-one percent (81%) of respondents indicated they could typically contact staff when desired.

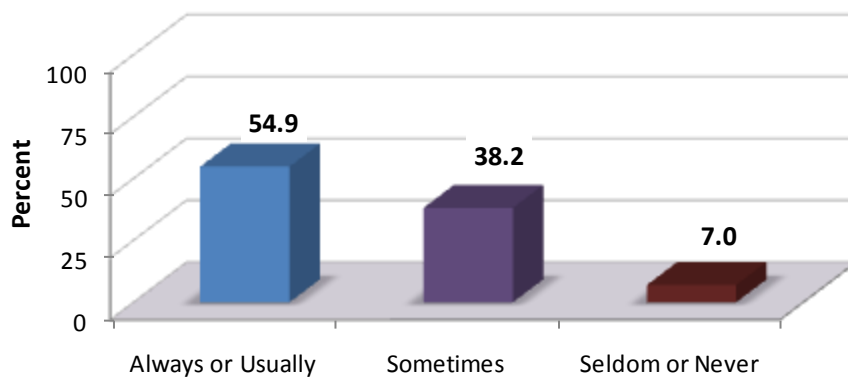
Chart Q1 Do you receive information about the services and supports that are available to your family?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↑	53.7	35.7	10.6	350
IL		41.4	45.2	13.4	396
LA	↑	52.3	35.5	12.2	516
ME		43.0	38.2	18.8	351
MO		41.8	35.8	22.3	349
NM	↑↑	59.3	31.4	9.2	519
OK	↓	41.0	40.2	18.8	480
PA		49.6	36.2	14.3	1029
Margin of Error > 5%					
GA	↓↓	34.4	34.0	31.6	256
OH		50.2	32.9	16.9	225
SC		42.4	39.5	18.1	309
Total %		47.4	36.8	15.8	4780
State Avg %		46.3	36.8	16.9	

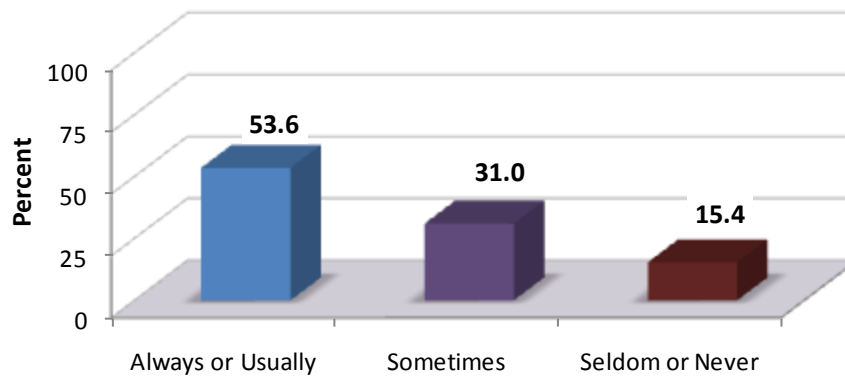
Chart Q2 If you receive information, is it easy to understand?



2008-09 Average for 11 States

Table Q2					
If you receive information, is it easy to understand? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error \leq 5%					
HI		54.4	40.0	5.6	340
IL	↓	49.2	42.3	8.5	378
LA		52.3	42.0	5.7	491
ME	↓	49.7	44.7	5.7	318
MO	↑	60.1	32.0	7.9	303
NM	↑	62.6	34.7	2.6	495
OK		50.5	41.6	8.0	440
PA	↑	60.2	34.6	5.2	964
Margin of Error > 5%					
GA	↓	46.1	38.4	15.5	219
OH		56.9	38.3	4.8	209
SC	↑	61.5	31.3	7.2	291
Total %		55.7	37.9	6.4	4448
State Avg %		54.9	38.2	7.0	

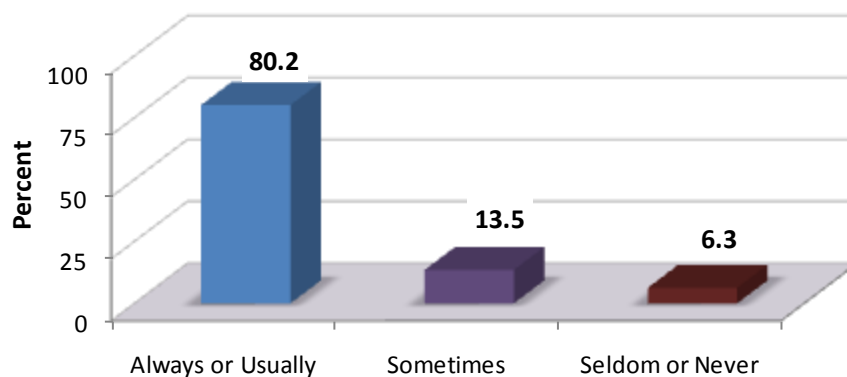
Chart Q3 Do you get enough information to help you participate in planning services for your family?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↑	60.3	29.7	9.9	343
IL	↓	47.5	35.9	16.6	379
LA		57.1	30.6	12.3	497
ME		54.4	31.8	13.8	333
MO		51.5	28.2	20.2	326
NM	↑↑	67.4	25.9	6.7	509
OK		51.0	32.8	16.3	461
PA		55.9	29.3	14.8	968
Margin of Error > 5%					
GA	↓↓	39.0	34.4	26.6	241
OH		55.3	31.1	13.7	219
SC		49.7	31.5	18.9	286
Total %		54.7	30.6	14.7	4562
State Avg %		53.6	31.0	15.4	

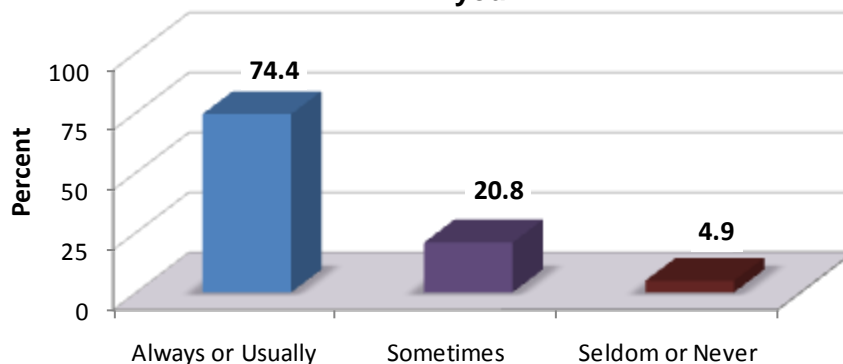
Chart Q4 If your family member has a service plan, did you help develop the plan?



2008-09 Average for 11 States

Table Q4					
If your family member has a service plan, did you help develop the plan? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		84.8	11.7	3.5	341
IL		78.5	15.4	6.1	344
LA		82.3	14.0	3.7	458
ME		85.0	10.9	4.0	321
MO		84.7	10.4	4.9	307
NM	↑↑	91.5	6.7	1.8	495
OK		80.2	14.8	5.0	440
PA		77.8	12.7	9.5	850
Margin of Error > 5%					
GA	↓↓	67.8	19.6	12.6	230
OH		79.9	14.3	5.8	189
SC	↓↓	70.0	17.9	12.2	263
Total %		80.9	13.0	6.2	4238
State Avg %		80.2	13.5	6.3	

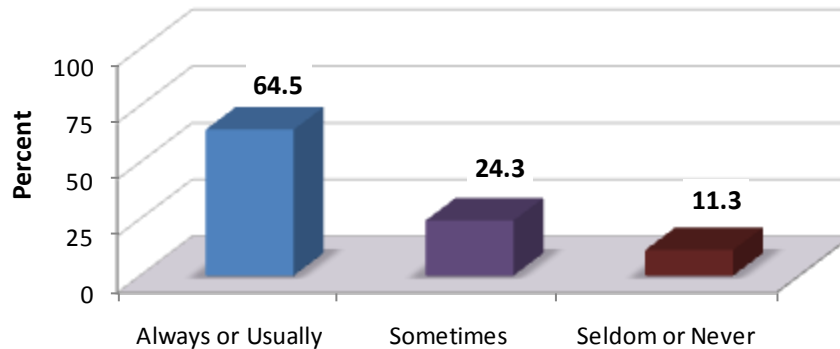
Chart Q5 If your family member has a service plan, does the plan include things that are important to you?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↑	82.5	16.3	1.2	343
IL		71.4	23.9	4.7	339
LA	↑	79.6	15.9	4.5	471
ME		78.5	17.4	4.0	321
MO		78.9	16.3	4.8	313
NM	↑	83.2	13.4	3.4	494
OK		74.9	21.0	4.1	438
PA		72.2	21.8	6.0	857
Margin of Error > 5%					
GA	↓↓	56.7	32.9	10.4	231
OH		71.3	26.1	2.7	188
SC	↓	68.8	23.6	7.6	263
Total %		75.2	20.0	4.8	4258
State Avg %		74.4	20.8	4.9	

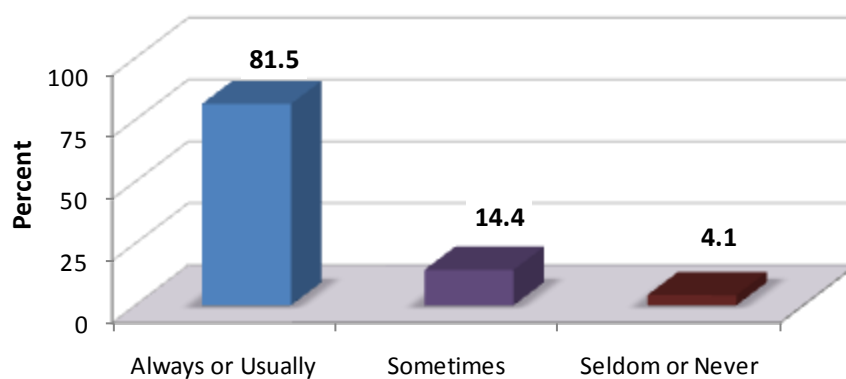
Chart Q6 Do the staff who assist you with planning help you figure out what you need as a family to support your family member?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↑	71.1	20.9	8.0	349
IL		61.3	29.4	9.3	364
LA	↑	71.5	20.2	8.4	491
ME		66.6	23.4	10.0	329
MO		62.3	27.1	10.6	310
NM	↑↑	77.4	17.7	4.9	509
OK		67.5	23.5	9.0	456
PA		63.8	24.2	12.0	905
Margin of Error > 5%					
GA	↓↓↓	47.9	30.9	21.2	236
OH	↓	56.4	27.9	15.7	204
SC		63.3	21.6	15.1	278
Total %		65.8	23.6	10.6	4431
State Avg %		64.5	24.3	11.3	

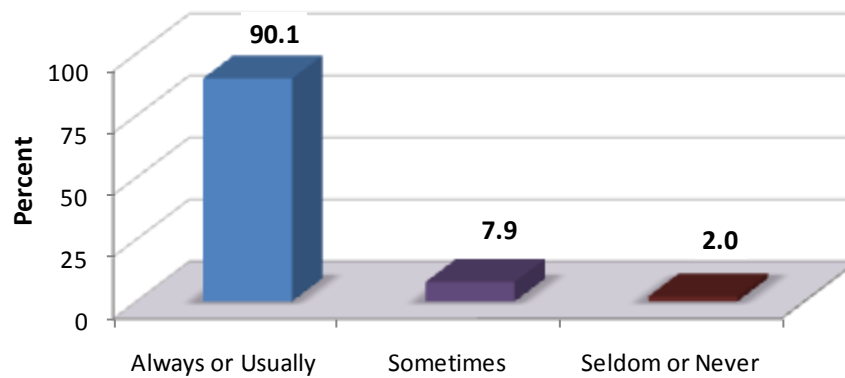
Chart Q7 Do the staff who assist you with planning respect your choices and opinions?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		85.1	13.2	1.7	356
IL		84.9	11.9	3.2	371
LA		83.6	13.6	2.8	499
ME		82.2	14.2	3.6	331
MO		83.4	12.5	4.1	319
NM	↑	87.9	10.5	1.6	513
OK		78.1	17.5	4.4	452
PA		81.8	14.0	4.2	905
Margin of Error > 5%					
GA	↓↓	70.9	19.4	9.7	237
OH		81.0	16.1	2.8	211
SC		78.1	15.1	6.8	279
Total %		82.1	14.0	3.8	4473
State Avg %		81.5	14.4	4.1	

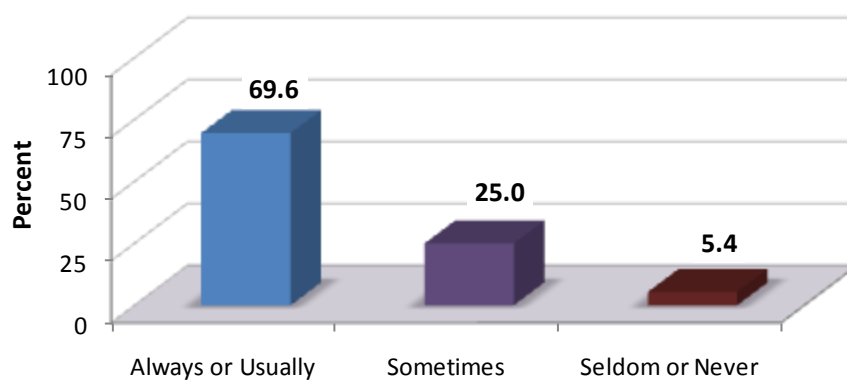
Chart Q8 Are the staff who assist you with planning generally respectful and courteous?



2008-09 Average for 11 States

Table Q8					
Are the staff who assist you with planning generally respectful and courteous? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		88.0	10.1	2.0	357
IL		93.1	5.5	1.3	379
LA		93.2	6.4	0.4	503
ME		90.8	8.0	1.2	337
MO		93.2	5.0	1.9	323
NM		94.2	5.2	0.6	516
OK		86.0	12.3	1.7	463
PA		91.4	6.4	2.3	925
Margin of Error > 5%					
GA	↓	84.2	10.0	5.8	241
OH		93.1	6.0	0.9	216
SC	↓	84.2	12.0	3.9	284
Total %		90.6	7.6	1.8	4544
State Avg %		90.1	7.9	2.0	

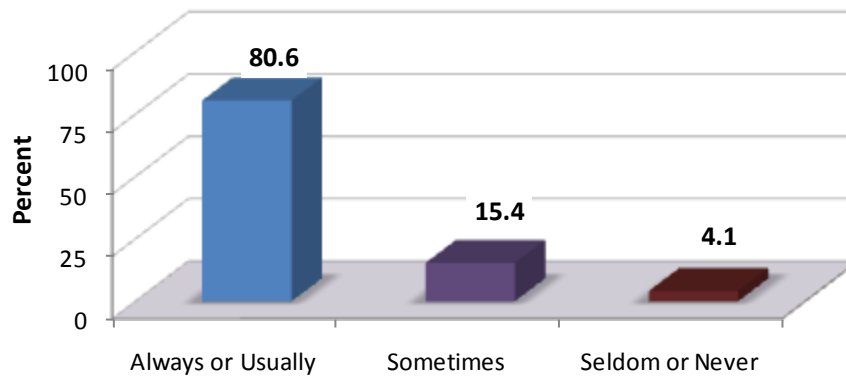
Chart Q9 Are the staff who assist you with planning generally effective?



2008-09 Average for 11 States

Table Q9					
Are the staff who assist you with planning generally effective? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		68.9	26.6	4.5	354
IL		67.9	27.5	4.6	371
LA	↑	75.1	21.3	3.6	498
ME	↑	74.9	20.9	4.2	335
MO		68.0	24.8	7.2	319
NM	↑	76.6	21.5	1.9	516
OK		69.3	25.7	5.0	459
PA		69.7	24.8	5.5	908
Margin of Error > 5%					
GA	↓↓	57.6	31.7	10.7	243
OH		72.7	22.5	4.8	209
SC	↓	64.5	28.0	7.4	282
Total %		70.3	24.7	5.1	4494
State Avg %		69.6	25.0	5.4	

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



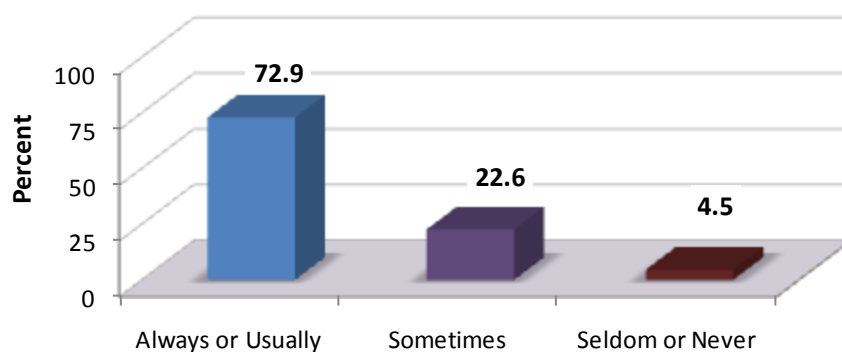
2008-09 Average for 11 States

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
Margin of Error ≤ 5%					
HI		81.1	16.1	2.8	355
IL		82.2	15.1	2.7	377
LA		83.3	14.9	1.8	504
ME		83.4	14.2	2.4	338
MO		82.4	12.0	5.6	324
NM		85.0	13.7	1.4	512
OK	↓	73.9	20.2	5.9	460
PA		80.5	15.1	4.4	922
Margin of Error > 5%					
GA	↓	70.8	19.8	9.5	243
OH	↑	86.1	11.1	2.8	216
SC		77.5	16.8	5.6	285
Total %		80.8	15.4	3.9	4536
State Avg %		80.6	15.4	4.1	

Access to and Delivery of Services and Supports

- Overall, 73% of families indicated their service coordinator helped them get needed supports when asked. Twenty-three percent (23%) said this happened sometimes, and the remaining 5% indicated their service coordinator was rarely or never helpful in getting the assistance needed.
- Sixty-four percent (64%) of respondents always or usually received the services/supports needed. Thirty percent (30%) got them sometimes, while 7% seldom or never received needed supports.
- The majority (62%) said the supports received met their families' needs. Thirty-two percent (32%) stated that supports sometimes met their needs, while 6% felt supports seldom/never met their needs.
- For over one-half of families (58%), supports were always or usually available when needed.
- Forty-two percent (42%) 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, 42% indicated that the state agency or provider agency was usually or always responsive to these requests.
- Slightly more than half (56%) of families who asked for assistance in an emergency or crisis received help right away.
- Among respondents whose first language was not English, three-quarters (75%) indicated that staff or translators were available to speak with them in their preferred languages. Thirteen percent (13%) indicated that staff/translators were sometimes available, and 12% 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 (55%) of families said there were enough support staff regularly available who could communicate with their family member.
- Sixty-five percent (65%) of respondents felt their family member had access to the special equipment or accommodations needed.
- Most respondents (90%) felt they had access to health services for their family member.
- Compared to access to health care, fewer families (76%) felt they had access to appropriate dental services for their family member. Fourteen percent (14%) had seldom or no access to dental services. Nearly all respondents (94%) felt they had access to necessary medications for their family member with a disability.
- Over half of respondents (57%) 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.
- Nine out of ten families (90%) felt that support staff were respectful and courteous.

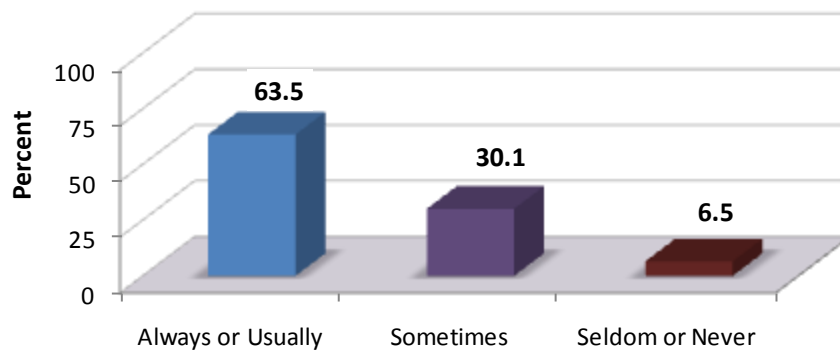
Chart Q11 When you ask the service/support coordinator for assistance, does he/she help you get what you need?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		71.0	25.6	3.4	355
IL		68.2	29.2	2.6	384
LA		71.1	25.1	3.8	498
ME	↑	81.7	16.0	2.4	338
MO		69.2	24.6	6.2	321
NM	↑	82.5	16.5	1.0	515
OK		69.9	23.9	6.2	452
PA		73.3	21.2	5.5	955
Margin of Error > 5%					
GA	↓	63.0	27.7	9.4	235
OH	↑	78.4	18.8	2.9	208
SC		73.7	20.5	5.7	297
Total %		73.2	22.4	4.4	4558
State Avg %		72.9	22.6	4.5	

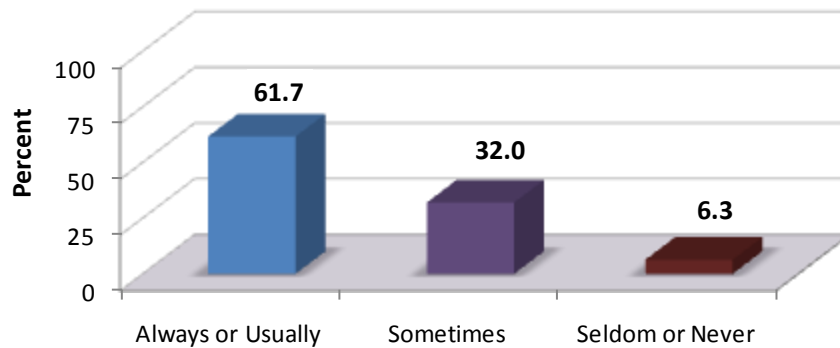
Chart Q12 Does your family get the services and supports you need?



2008-09 Average for 11 States

Table Q12					
Does your family get the services and supports you need? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		63.1	34.1	2.8	352
IL		60.8	32.9	6.3	380
LA		65.9	27.8	6.3	511
ME		63.2	30.1	6.7	345
MO		60.4	33.2	6.4	328
NM	↑↑	75.5	22.5	1.9	519
OK		63.6	28.6	7.8	472
PA		64.0	28.5	7.4	967
Margin of Error > 5%					
GA	↓↓	53.0	35.2	11.9	236
OH		66.7	27.1	6.3	207
SC		62.0	30.7	7.3	300
Total %		64.2	29.4	6.3	4617
State Avg %		63.5	30.1	6.5	

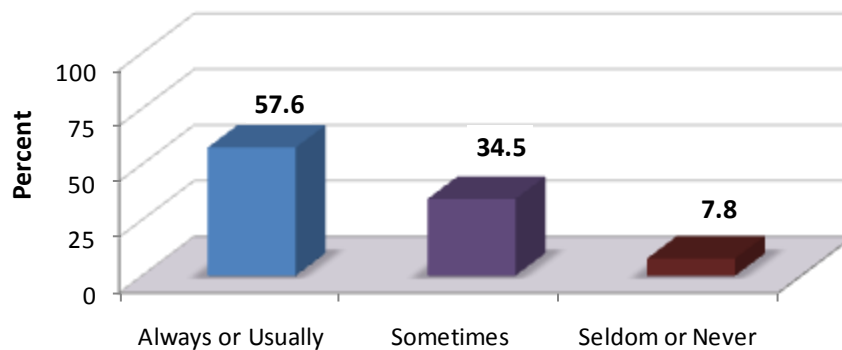
Chart Q13 Do the services and supports offered meet your family's needs?



2008-09 Average for 11 States

Table Q13					
Do the services and supports offered meet your family's needs? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		64.7	31.3	4.0	348
IL	↓	56.1	37.9	6.0	383
LA	↑	66.7	28.4	4.9	511
ME		61.8	31.8	6.4	343
MO		59.8	31.7	8.5	331
NM	↑	71.5	26.3	2.1	520
OK		61.3	31.0	7.7	468
PA		59.2	34.0	6.8	966
Margin of Error > 5%					
GA	↓	54.4	35.9	9.7	248
OH	↑	67.5	28.6	3.9	206
SC	↓	55.3	35.3	9.3	300
Total %		61.9	31.9	6.2	4624
State Avg %		61.7	32.0	6.3	

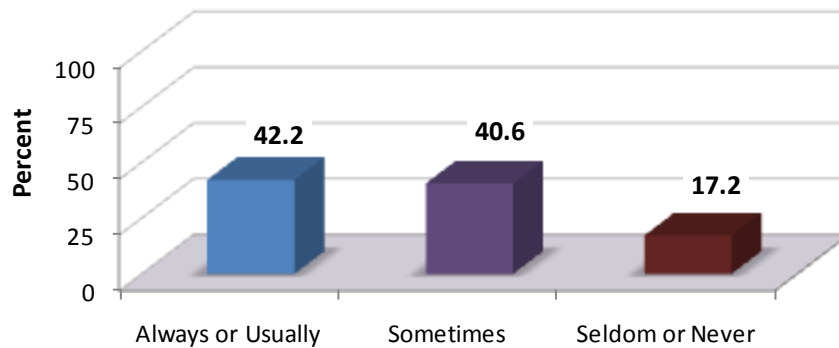
Chart Q14 Are supports available when your family needs them?



2008-09 Average for 11 States

Table Q14					
Are supports available when your family needs them? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		56.8	35.7	7.5	345
IL	↓	52.3	39.4	8.3	373
LA	↑	63.3	30.9	5.8	501
ME		58.4	35.0	6.6	334
MO		56.4	33.2	10.3	319
NM	↑	66.7	30.8	2.5	510
OK		58.8	33.9	7.3	451
PA		56.8	34.1	9.1	917
Margin of Error > 5%					
GA	↓↓	47.4	38.8	13.8	232
OH	↑	62.8	31.9	5.2	191
SC		54.2	35.9	9.9	284
Total %		58.2	34.2	7.6	4457
State Avg %		57.6	34.5	7.8	

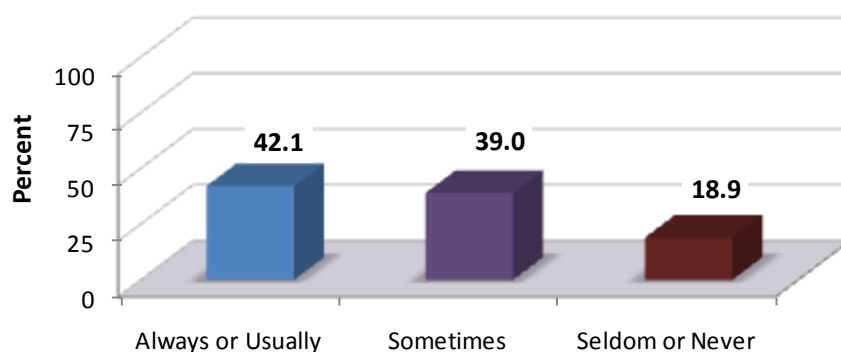
Chart Q15 Do families in your area request that different types of services and supports be made available in your area?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		44.6	42.3	13.1	130
IL		45.7	39.6	14.6	164
LA		46.8	36.9	16.2	222
ME		44.5	39.5	16.0	119
MO		40.8	40.8	18.5	130
NM		43.1	41.6	15.3	255
OK	↓	36.0	48.3	15.7	172
PA		41.9	37.3	20.8	322
Margin of Error > 5%					
GA		42.7	38.5	18.8	117
OH		38.8	42.5	18.8	80
SC		39.2	39.2	21.6	148
Total %		42.4	40.2	17.3	1859
State Avg %		42.2	40.6	17.2	

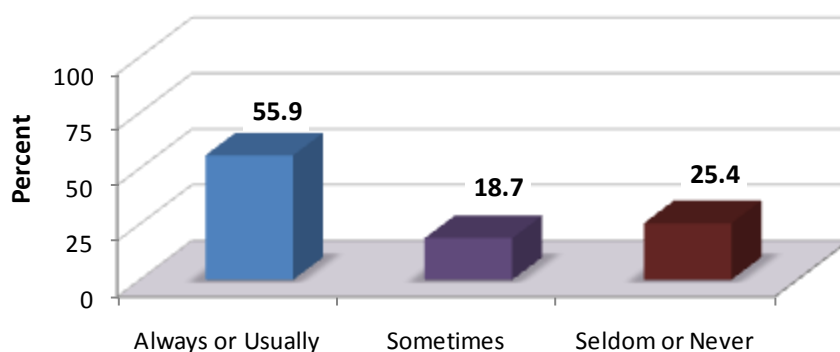
Chart Q16 If yes, does either the state agency or provider agency respond to their requests?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↑	49.6	38.0	12.4	121
IL	↓	36.9	39.7	23.4	141
LA	↑	51.0	35.9	13.0	192
ME		40.4	39.4	20.2	94
MO		38.9	40.7	20.4	113
NM	↑↑	52.3	39.0	8.7	218
OK		41.3	40.6	18.2	143
PA	↓↓	28.1	48.1	23.8	260
Margin of Error > 5%					
GA	↓↓	26.3	42.1	31.6	95
OH	↑	49.1	36.8	14.0	57
SC	↑	48.7	28.6	22.7	119
Total %		41.8	39.7	18.5	1553
State Avg %		42.1	39.0	18.9	

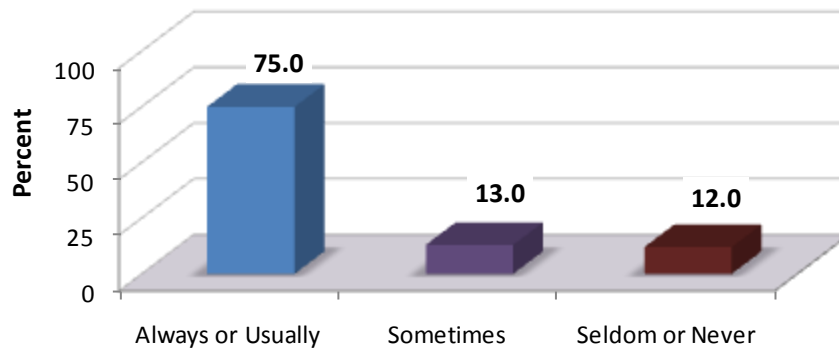
Chart Q17 If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		55.8	21.8	22.4	165
IL	↓	50.6	17.2	32.2	174
LA	↑↑	68.3	14.6	17.2	309
ME		55.7	16.1	28.2	149
MO		59.4	19.4	21.3	155
NM	↑↑	70.1	15.1	14.8	291
OK	↓	46.5	22.5	31.0	200
PA		52.5	21.8	25.7	413
Margin of Error > 5%					
GA	↓	48.0	19.7	32.3	127
OH		53.7	16.8	29.5	95
SC		54.1	20.6	25.3	170
Total %		57.1	18.7	24.2	2248
State Avg %		55.9	18.7	25.4	

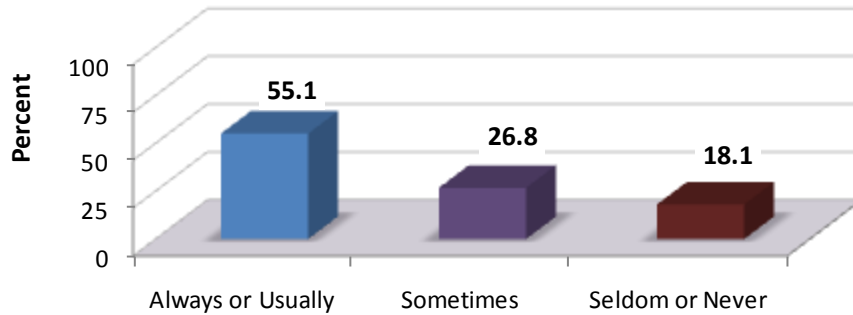
Chart Q18 If English is not your first language, are there support workers or translators available to speak with you in your preferred language?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↓↓	64.3	18.6	17.1	70
IL	↓	66.7	15.8	17.5	57
LA	↑	84.4	4.7	10.9	64
ME		78.6	10.7	10.7	28
MO	↑	81.3	12.5	6.3	16
NM		73.7	22.1	4.2	95
OK	↑	82.2	11.1	6.7	45
PA	↓↓	60.7	19.7	19.7	61
Margin of Error > 5%					
GA	↑↑	100.0	0.0	0.0	18
OH	↓	66.7	11.1	22.2	18
SC	↓	66.7	16.7	16.7	42
Total %		72.8	15.0	12.3	514
State Avg %		75.0	13.0	12.0	

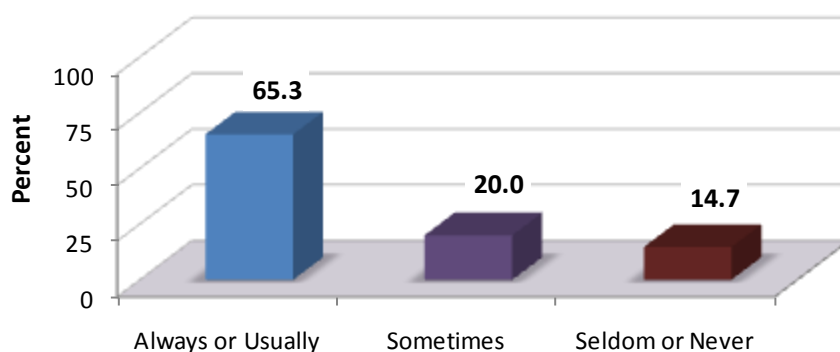
Chart Q19 If your family member does not speak English or uses a different way to communicate are there enough support workers available who can communicate with him/her?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		52.3	25.6	22.1	86
IL		52.8	33.7	13.5	89
LA	↑	64.4	20.0	15.6	90
ME		59.5	19.0	21.4	42
MO		52.2	28.3	19.6	46
NM	↑	63.2	21.5	15.3	144
OK		56.1	19.5	24.4	82
PA		51.3	26.5	22.1	113
Margin of Error > 5%					
GA	↓	47.7	38.6	13.6	44
OH	↓	48.5	39.4	12.1	33
SC		58.5	22.6	18.9	53
Total %		56.2	25.5	18.2	822
State Avg %		55.1	26.8	18.1	

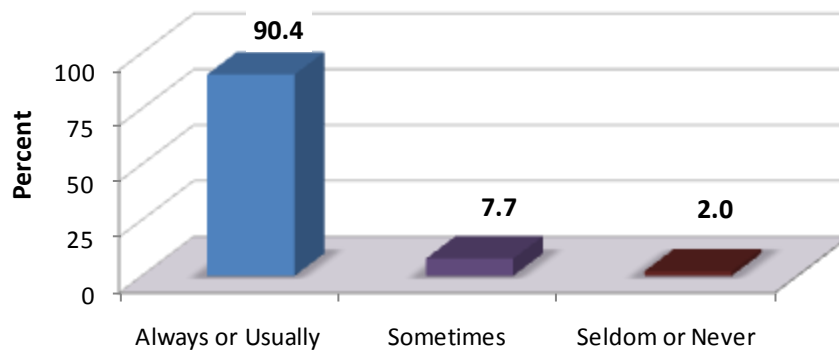
Chart Q20 Does your family member have access to the special equipment or accommodations that he/she needs?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↓↓	53.0	26.2	20.8	149
IL		61.1	23.8	15.1	185
LA		67.3	16.2	16.5	272
ME		60.6	22.0	17.4	109
MO	↑	70.6	16.3	13.1	153
NM	↑	75.0	19.0	6.0	252
OK		62.1	25.0	12.9	240
PA		67.8	18.7	13.6	332
Margin of Error > 5%					
GA		60.7	18.7	20.6	107
OH	↑	74.7	13.7	11.6	95
SC		65.7	19.9	14.5	166
Total %		65.9	20.0	14.1	2060
State Avg %		65.3	20.0	14.7	

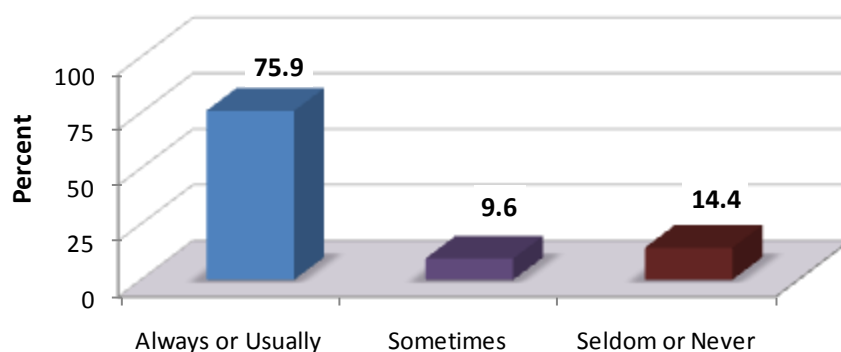
Chart Q21 Do you have access to health services for your family member?



2008-09 Average for 11 States

Table Q21 Do you have access to health services for your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error \leq 5%					
HI		87.9	9.4	2.7	339
IL		92.4	5.8	1.8	382
LA		91.5	6.8	1.7	515
ME		94.8	4.9	0.3	347
MO		87.6	10.1	2.3	347
NM	↑	97.1	2.7	0.2	520
OK		89.0	10.2	0.8	482
PA		91.6	7.0	1.5	1006
Margin of Error > 5%					
GA		86.4	10.4	3.2	250
OH		91.3	6.3	2.4	206
SC	↓	84.4	10.9	4.6	302
Total %		90.9	7.4	1.7	4696
State Avg %		90.4	7.7	2.0	

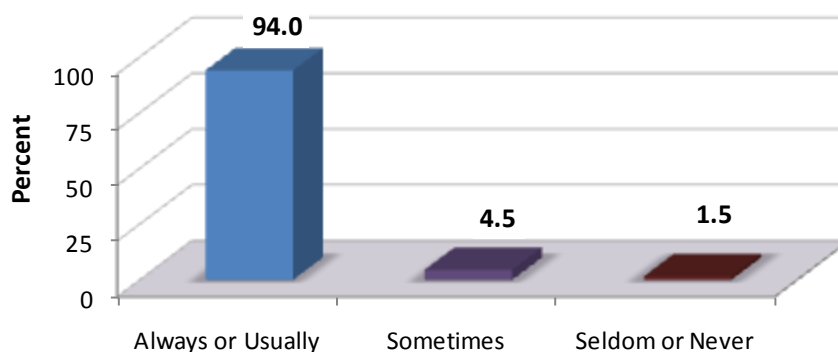
Chart Q22 Do you have access to dental services for your family member?



2008-09 Average for 11 States

Table Q22					
Do you have access to dental services for your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error \leq 5%					
HI		80.3	9.7	10.0	340
IL		73.3	12.0	14.7	375
LA	↓↓	65.6	10.4	24.0	454
ME	↑	84.5	6.8	8.6	336
MO	↓↓	60.4	17.4	22.1	321
NM	↑↑	92.4	4.5	3.1	513
OK	↓	70.0	10.6	19.4	453
PA	↑	81.1	7.6	11.4	966
Margin of Error > 5%					
GA	↓↓	65.6	12.4	22.0	241
OH	↑↑	86.3	3.9	9.8	204
SC		75.9	10.8	13.2	295
Total %		76.8	9.3	13.9	4498
State Avg %		75.9	9.6	14.4	

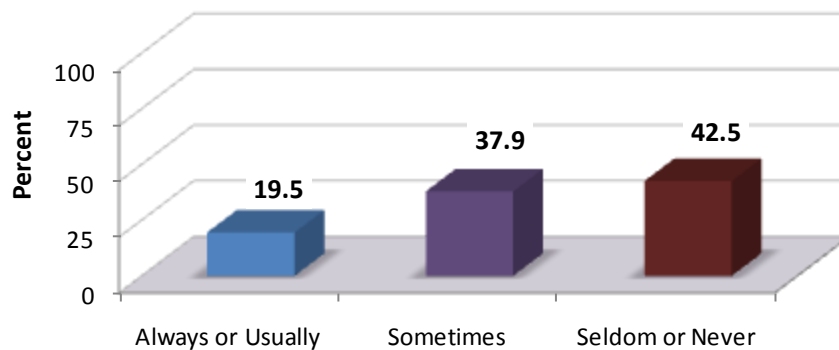
Chart Q23 Do you have access to necessary medications for your family member?



2008-09 Average for 11 States

Table Q23 Do you have access to necessary medications for your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error \leq 5%					
HI		93.1	6.0	0.9	334
IL		95.2	3.2	1.6	374
LA		95.3	3.1	1.6	510
ME		97.9	1.8	0.3	336
MO		92.8	6.3	0.9	333
NM		96.5	3.3	0.2	514
OK		92.9	6.0	1.0	481
PA		94.4	4.6	1.0	994
Margin of Error > 5%					
GA		91.8	4.7	3.5	255
OH		93.2	4.4	2.4	206
SC		90.5	6.3	3.3	304
Total %		94.2	4.5	1.3	4641
State Avg %		94.0	4.5	1.5	

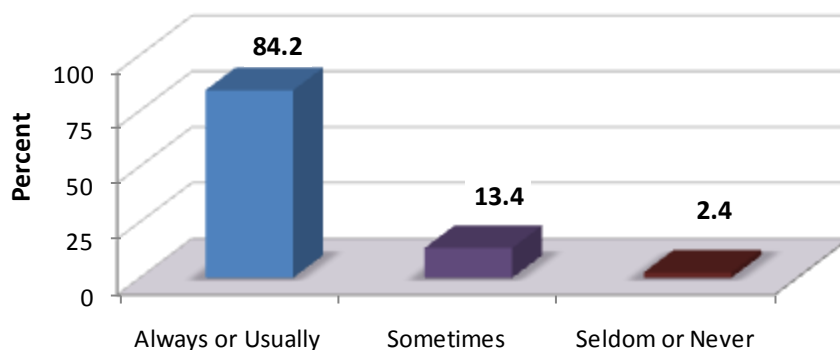
Chart Q24 Are frequent changes in support staff a problem for your family?



2008-09 Average for 11 States

Table Q24 Are frequent changes in support staff a problem for your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		23.3	45.8	30.9	288
IL		17.0	39.7	43.2	317
LA		23.2	34.3	42.5	440
ME		17.0	39.1	43.9	271
MO		18.3	35.8	45.9	279
NM		21.6	40.0	38.4	445
OK		19.2	35.5	45.3	391
PA		17.9	38.8	43.3	815
Margin of Error > 5%					
GA		21.4	39.5	39.1	220
OH	↑	12.8	33.1	54.1	172
SC		23.1	35.8	41.2	260
Total %		19.7	38.1	42.3	3898
State Avg %		19.5	37.9	42.5	

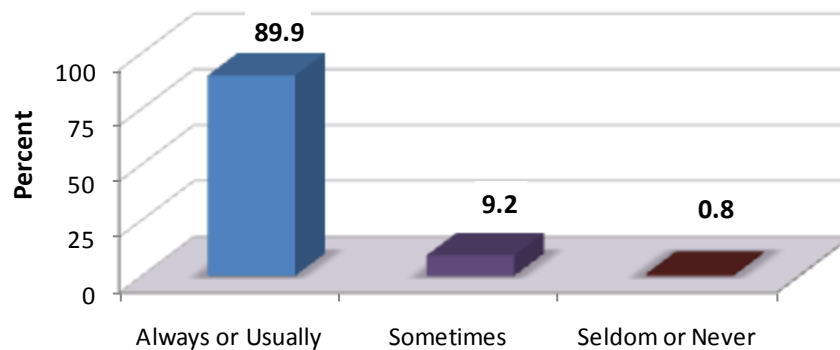
Chart Q25 Do you feel that your family member's day/employment setting is a healthy and safe environment?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		83.8	14.1	2.1	291
IL		86.4	11.0	2.6	272
LA		87.2	10.8	2.0	399
ME		88.3	10.4	1.3	307
MO		86.9	10.6	2.6	274
NM		82.9	15.5	1.7	420
OK		81.8	16.5	1.7	357
PA		87.3	11.2	1.5	860
Margin of Error > 5%					
GA		79.7	15.9	4.4	227
OH		84.4	13.7	1.9	211
SC	↓	78.0	17.2	4.8	227
Total %		84.9	13.0	2.2	3845
State Avg %		84.2	13.4	2.4	

Chart Q26 Are support staff generally respectful and courteous?



2008-09 Average for 11 States

Table Q26					
Are support staff generally respectful and courteous? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		87.9	11.5	0.6	348
IL		92.1	7.3	0.5	381
LA		89.9	9.7	0.4	506
ME		89.9	9.8	0.3	338
MO		91.9	7.5	0.6	322
NM		89.6	9.2	1.2	511
OK		88.1	11.2	0.7	455
PA		93.7	5.9	0.4	973
Margin of Error > 5%					
GA		85.4	12.6	2.0	254
OH		92.1	7.0	0.9	215
SC		88.7	9.6	1.7	293
Total %		90.5	8.8	0.7	4596
State Avg %		89.9	9.2	0.8	

Choices and Control

- Across the states, on average, 68% of respondents chose the agencies or providers who work with their families. In Louisiana and New Mexico, this percentage was considerably higher, with 88% of families choosing their service providers.
- While 68% of respondents typically chose their family's provider agency, only 50% typically chose the support workers who worked directly with their family. There was much variation between states.
- Across the states, 73% of families who received day/employment supports felt the provider agency regularly involved them in important decisions.
- Among all respondents, 46% had control or input over the hiring and management of their support staff, and 15% indicated they had this control sometimes. Thirty-nine percent (39%), however, did not have any input or control over the hiring or management of their family's support staff.
- While only 61% 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-eight percent (28%) of respondents or their family members knew how much money was spent by the MR/DD agency on behalf of their family member. Sixty-one percent (61%), 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, 61% 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. Thirty-nine percent (39%), however, did not.

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

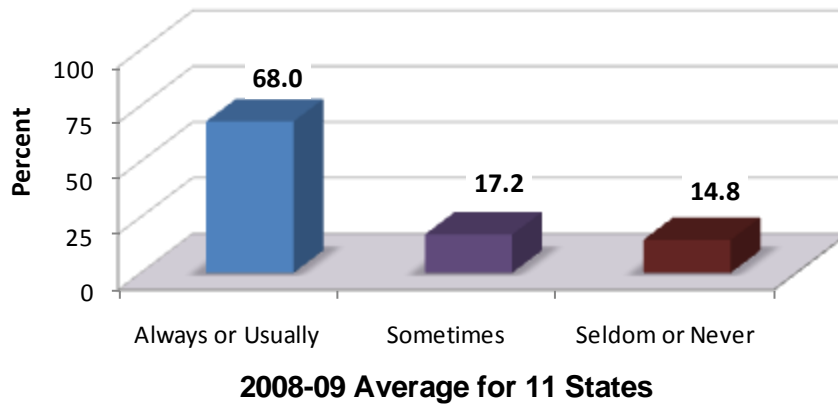
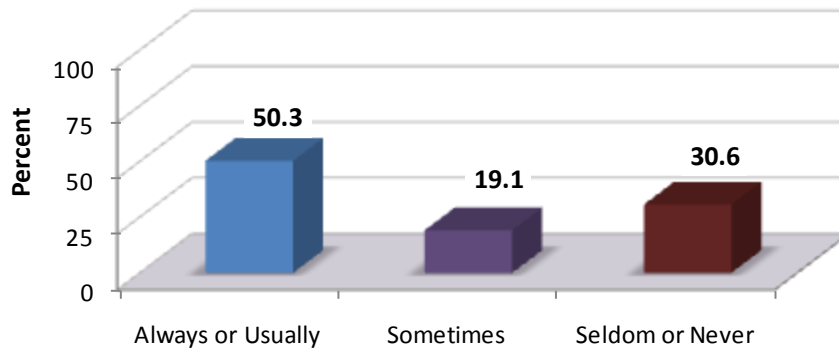


Table Q27 Do you or your family member choose the agencies or providers that work with your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		69.7	20.6	9.7	330
IL		70.1	17.3	12.6	364
LA	↑↑	88.1	8.0	3.9	488
ME		67.2	17.2	15.6	314
MO	↓	60.9	23.1	16.1	299
NM	↑↑	88.4	7.9	3.7	519
OK	↑↑	78.7	13.6	7.7	455
PA	↓↓	57.6	17.8	24.6	861
Margin of Error > 5%					
GA	↓↓	54.1	21.6	24.3	218
OH	↓↓	57.6	19.6	22.8	184
SC	↓↓	55.6	22.2	22.2	270
Total %		69.6	16.1	14.3	4302
State Avg %		68.0	17.2	14.8	

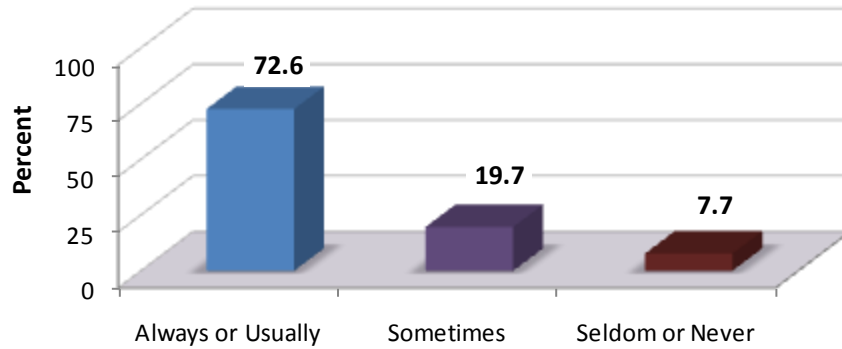
Chart Q28 Do you or your family member choose the support workers who work with your family?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		53.5	20.0	26.5	325
IL	↑↑↑	64.3	12.0	23.7	350
LA	↑↑↑	74.9	12.2	12.8	475
ME	↓↓↓	38.6	22.7	38.6	295
MO	↓↓↓	40.1	17.9	41.9	279
NM	↑↑↑	71.4	17.3	11.3	504
OK	↑↑↑	68.8	14.3	16.9	426
PA	↓↓↓	37.7	18.3	44.0	809
Margin of Error > 5%					
GA	↓↓↓	22.9	26.7	50.5	210
OH	↓↓↓	38.3	26.3	35.4	175
SC	↓	42.4	22.3	35.2	264
Total %		52.7	18.0	29.4	4112
State Avg %		50.3	19.1	30.6	

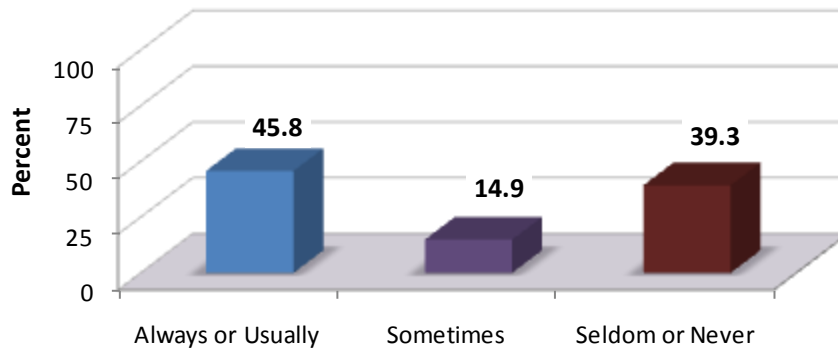
Chart Q29 If your family member gets day or employment services, does the agency providing these services involve you in important decisions?



2008-09 Average for 11 States

Table Q29					
If your family member gets day or employment services, does the agency providing these services involve you in important decisions? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI	↑	78.3	16.4	5.3	244
IL		76.1	19.6	4.3	230
LA	↑	78.7	15.4	6.0	319
ME		73.2	23.2	3.6	276
MO		68.9	23.1	8.0	225
NM		75.5	16.8	7.7	376
OK		68.0	22.7	9.4	278
PA		73.9	19.3	6.8	709
Margin of Error > 5%					
GA	↓	67.2	20.9	11.9	201
OH		75.1	19.6	5.3	189
SC	↓	64.1	19.7	16.2	198
Total %		73.2	19.4	7.4	3245
State Avg %		72.6	19.7	7.7	

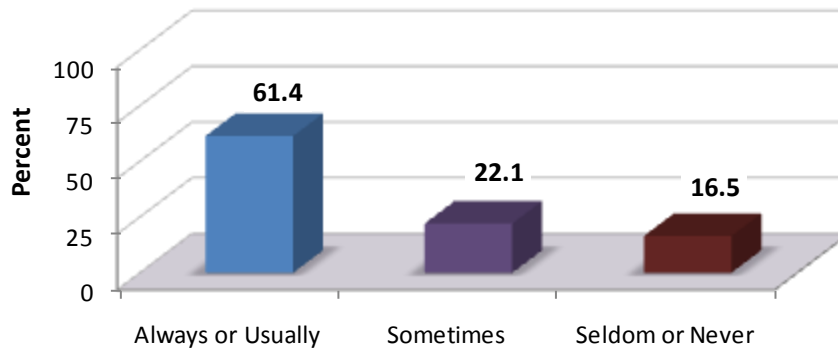
Chart Q30 Do you or your family member have control and/or input over the hiring and management of your support workers?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↑↑↑	56.9	18.7	24.4	262
IL	↑↑↑	66.8	11.1	22.2	325
LA	↑↑↑	69.5	14.9	15.6	416
ME	↓↓↓	26.6	13.9	59.4	244
MO	↓↓↓	31.7	13.9	54.3	230
NM	↑↑↑	57.9	16.7	25.5	432
OK	↑↑↑	63.3	12.9	23.8	357
PA	↓↓↓	34.5	12.3	53.2	649
Margin of Error > 5%					
GA	↓↓↓	20.3	15.9	63.7	182
OH	↓	35.9	17.9	46.2	145
SC	↓	40.3	15.8	43.9	196
Total %		48.3	14.5	37.2	3438
State Avg %		45.8	14.9	39.3	

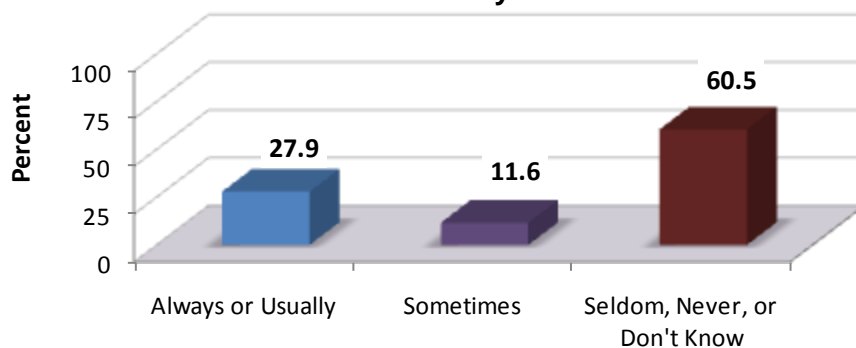
Chart Q31 Do you or your family member want to have control and/or input over the hiring and management of your support workers?



2008-09 Average for 11 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
Margin of Error \leq 5%					
HI	↑	70.7	18.5	10.8	249
IL	↑↑	76.3	14.3	9.3	300
LA	↑↑	79.7	14.5	5.8	414
ME	↓	52.9	25.0	22.1	240
MO	↓↓	47.5	26.7	25.8	217
NM	↑	70.1	22.1	7.8	408
OK	↑↑	75.5	16.5	8.0	375
PA	↓↓	50.2	24.1	25.7	651
Margin of Error > 5%					
GA	↓↓	48.3	30.1	21.6	176
OH	↓↓	51.0	25.5	23.5	149
SC	↓	53.6	25.4	21.1	209
Total %		63.0	21.3	15.8	3388
State Avg %		61.4	22.1	16.5	

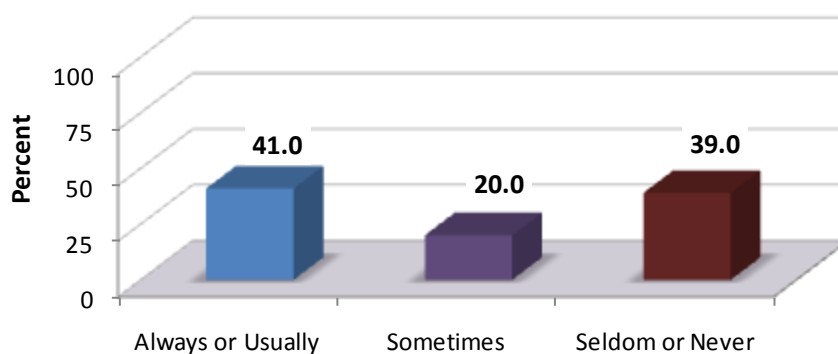
Chart Q32 Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↑	36.2	16.8	47.0	340
IL	↑↑	39.6	10.0	50.4	389
LA		28.8	7.8	63.3	486
ME	↓↓	8.7	10.6	80.6	310
MO	↓	19.5	9.9	70.7	334
NM	↑↑	40.8	16.6	42.6	505
OK	↑↑	44.0	19.0	37.1	480
PA		24.9	12.3	62.8	957
Margin of Error > 5%					
GA	↓↓	13.9	4.6	81.8	194
OH		26.0	11.2	62.8	215
SC		24.1	9.2	66.7	282
Total %		29.3	12.3	58.4	4492
State Avg %		27.9	11.6	60.5	

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



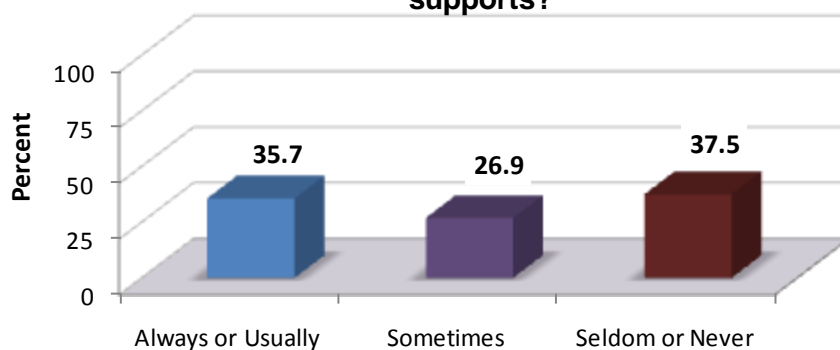
2008-09 Average for 11 States

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
Margin of Error ≤ 5%					
HI		42.8	27.6	29.6	257
IL	↑↑↑	57.0	21.5	21.5	321
LA		40.3	12.7	47.1	308
ME	↓↓↓	21.8	13.8	64.4	225
MO	↓	31.6	17.2	51.2	215
NM	↑↑↑	62.4	21.6	16.0	431
OK	↑↑↑	56.8	26.3	16.8	410
PA		41.9	19.1	39.0	680
Margin of Error > 5%					
GA	↓↓↓	23.6	20.3	56.1	148
OH	↓	34.6	21.3	44.1	136
SC		38.6	18.6	42.9	210
Total %		44.4	20.2	35.3	3341
State Avg %		41.0	20.0	39.0	

Community Connections

- On average, just over one-third of respondents (36%) felt that planning or support staff were regularly available to help them use typical community supports (e.g., from a local health club, church or recreation activities) if desired. Another 27% said that staff were sometimes helpful, but 38% 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 (62% say always, usually or sometimes, 38% say seldom or never).
- Only 55% of families felt their family member always or usually had access to community activities. Fifteen percent (15%) stated their family member seldom or never had access to the community.
- While 55% had regular access to community activities, only 37% of family members regularly participated in them. Twenty-eight percent (28%) of respondents said that their family member seldom or never participated in community activities or events.

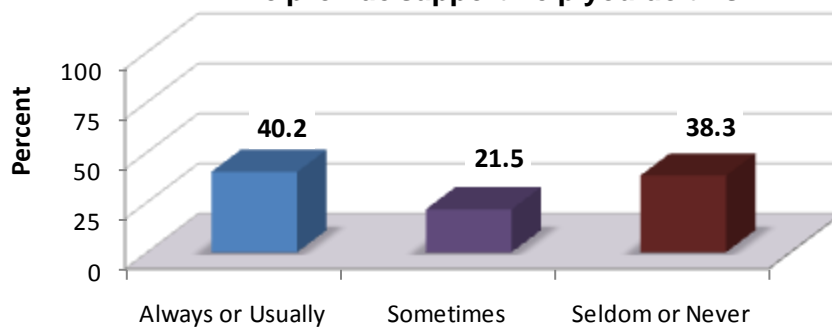
Chart Q34 If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?



2008-09 Average for 11 States

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
Margin of Error ≤ 5%					
HI		34.0	33.5	32.5	212
IL	↓	30.1	24.8	45.1	286
LA		38.6	22.9	38.6	345
ME		35.1	30.3	34.6	211
MO	↓	28.5	33.5	38.0	221
NM	↑↑	49.9	28.0	22.2	415
OK		38.4	28.1	33.5	331
PA	↓	30.6	26.6	42.8	568
Margin of Error > 5%					
GA	↓	28.9	16.1	55.0	180
OH		39.3	32.9	27.9	140
SC		38.9	18.7	42.4	203
Total %		36.1	26.7	37.2	3112
State Avg %		35.7	26.9	37.5	

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



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↑	48.5	24.7	26.9	227
IL		43.8	22.9	33.3	288
LA	↑	48.5	18.6	33.0	355
ME	↓	31.4	20.6	47.9	194
MO	↓	32.1	21.5	46.4	209
NM	↑↑	56.9	22.4	20.7	415
OK	↑↑	51.5	20.0	28.5	330
PA	↓	33.7	23.4	42.9	581
Margin of Error > 5%					
GA	↓↓	21.8	14.9	63.2	174
OH	↓	33.1	24.0	43.0	121
SC		40.5	23.8	35.7	210
Total %		41.9	21.7	36.4	3104
State Avg %		40.2	21.5	38.3	

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

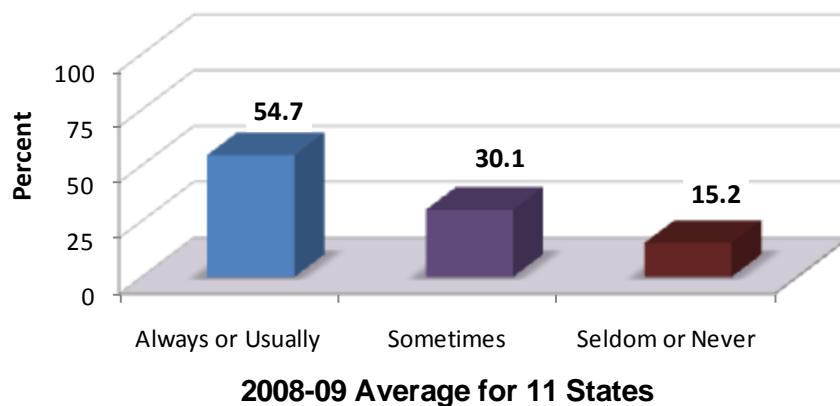


Table Q36 Do you feel that your family member has access to community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		51.8	34.0	14.2	303
IL		50.5	31.2	18.3	372
LA		53.8	29.3	16.9	474
ME	↑	61.0	27.3	11.7	326
MO		55.4	32.6	12.0	325
NM	↑↑	73.6	22.7	3.8	503
OK	↑	60.0	28.6	11.4	448
PA	↓	48.8	35.6	15.6	891
Margin of Error > 5%					
GA	↓↓	44.1	29.7	26.1	222
OH		57.8	31.4	10.8	204
SC	↓	45.1	28.8	26.1	264
Total %		55.1	30.4	14.5	4332
State Avg %		54.7	30.1	15.2	

Chart Q37 Does your family member participate in community activities?

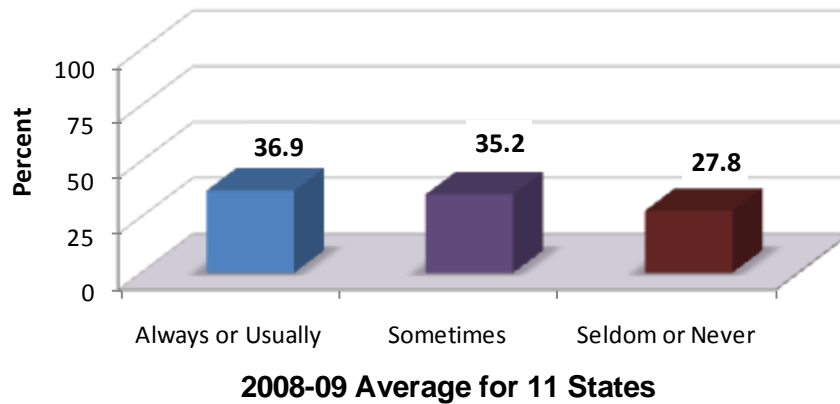
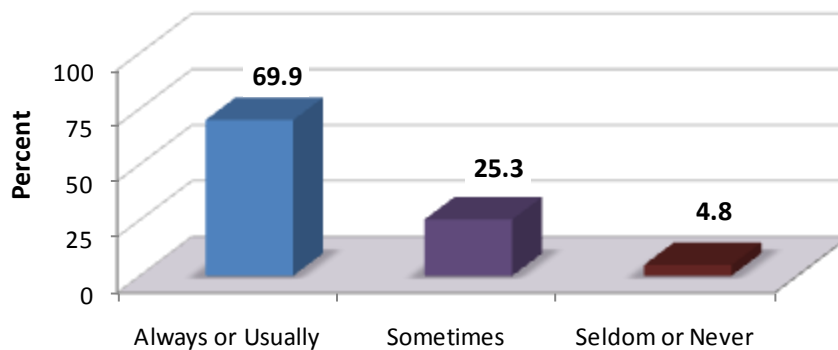


Table Q37 Does your family member participate in community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		36.6	35.3	28.1	317
IL		32.6	37.2	30.2	374
LA		35.9	34.6	29.5	485
ME		33.5	41.8	24.7	328
MO		40.7	34.7	24.6	334
NM	↑↑	62.6	26.4	11.0	516
OK		40.6	36.9	22.5	458
PA	↓	28.4	37.8	33.8	931
Margin of Error > 5%					
GA		34.6	33.3	32.0	228
OH		32.2	37.1	30.7	202
SC	↓	28.6	32.5	38.9	283
Total %		37.2	35.3	27.6	4456
State Avg %		36.9	35.2	27.8	

Outcomes and Satisfaction with Services and Supports

- Overall, sixty-five percent (65%) of families were always or usually satisfied with the services and supports they received. Twenty-five percent (25%) were somewhat satisfied, and 5% were seldom or never satisfied.
- On average, only 55% of respondents knew about their agency's grievance process, while 35% 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 (64%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 36%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.
- Seventy-six percent (76%) of families felt that services and supports have made a positive difference in their lives. Only 3% stated that they seldom or never felt this way.
- Just over four-fifths (81%) of respondents indicated that services have made a difference in helping them keep their family members at home.
- Most families (83%) indicated that their family member would still be living at home if without receiving services.
- Eighty-six percent (86%) of respondents felt that their family member was usually happy.

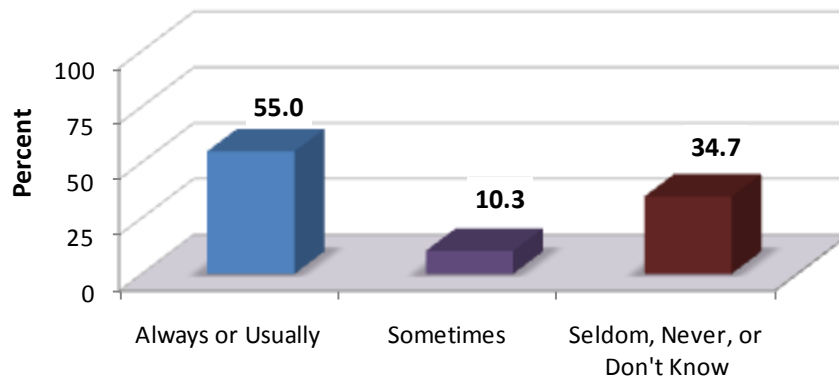
Chart Q38 Overall, are you satisfied with the services and supports your family and family member currently receive?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		67.6	28.1	4.3	349
IL		67.3	27.9	4.8	394
LA		74.3	20.9	4.8	522
ME		73.6	22.7	3.7	348
MO		69.6	24.0	6.4	342
NM	↑↑	80.3	18.6	1.1	527
OK		71.1	25.6	3.4	477
PA		69.5	24.9	5.5	994
Margin of Error > 5%					
GA	↓↓	57.1	35.1	7.8	245
OH		73.5	22.8	3.7	219
SC		65.1	27.6	7.3	301
Total %		70.6	24.7	4.7	4718
State Avg %		69.9	25.3	4.8	

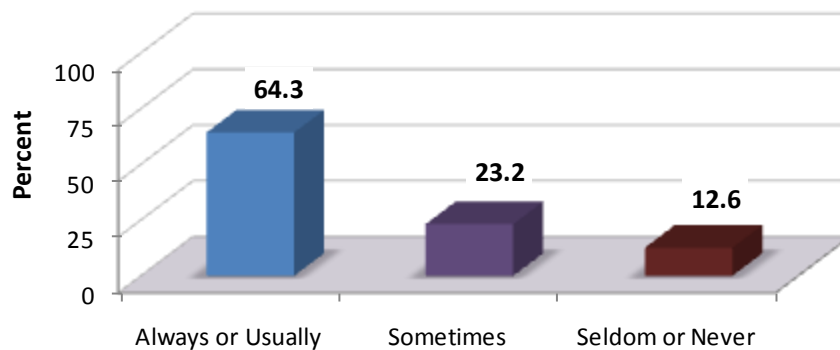
Chart Q39 Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		53.3	16.1	30.7	336
IL	↓	47.8	10.1	42.2	368
LA	↑↑	69.5	8.8	21.6	499
ME		54.0	9.6	36.4	302
MO	↓	45.4	9.8	44.8	317
NM	↑↑	79.6	7.0	13.4	515
OK	↑↑	66.2	10.8	23.0	452
PA	↓	49.6	12.8	37.7	938
Margin of Error > 5%					
GA	↓↓	39.6	7.1	53.4	240
OH		55.1	10.1	34.8	207
SC	↓	45.4	11.0	43.6	282
Total %		56.6	10.5	32.9	4456
State Avg %		55.0	10.3	34.7	

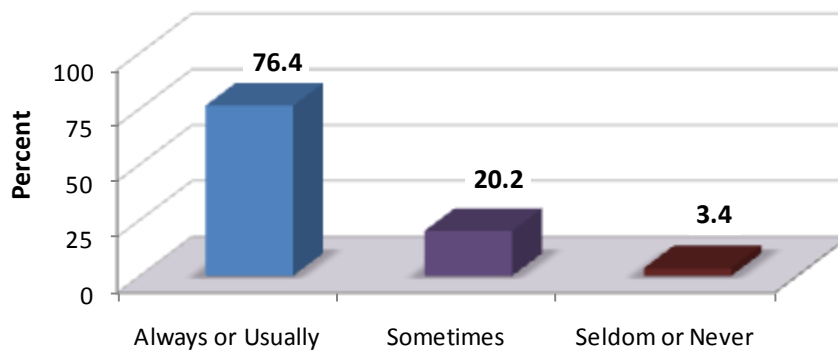
Chart Q40 Are you satisfied with the way complaints/grievances are handled and resolved?



2008-09 Average for 11 States

Table Q40 Are you satisfied with the way complaints/grievances are handled and resolved? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		61.1	23.8	15.1	185
IL		64.7	19.2	16.0	156
LA	↑↑	75.4	16.2	8.4	321
ME		64.6	22.8	12.6	127
MO	↓↓	54.1	29.3	16.5	133
NM	↑↑	75.6	17.0	7.4	336
OK		66.8	22.0	11.2	232
PA		62.7	27.8	9.5	421
Margin of Error > 5%					
GA	↓	56.4	22.2	21.4	117
OH		64.8	28.6	6.7	105
SC		60.6	25.8	13.5	155
Total %		66.0	22.5	11.5	2288
State Avg %		64.3	23.2	12.6	

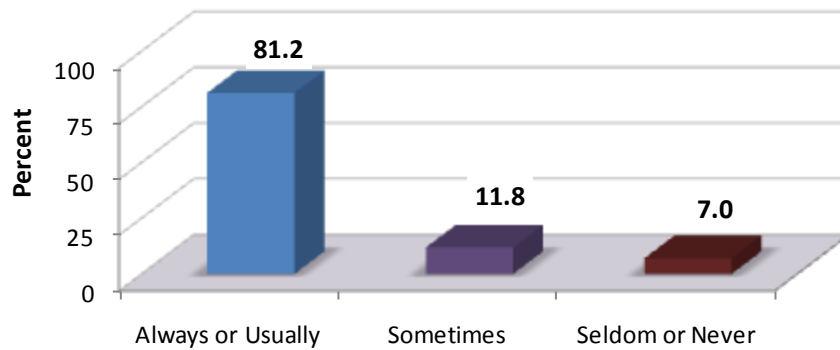
Chart Q41 Do you feel that services and supports have made a positive difference in the life of your family?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		78.4	19.8	1.7	343
IL		75.3	21.6	3.1	384
LA	↑	83.9	13.0	3.1	516
ME		77.1	19.9	2.9	341
MO		73.2	23.2	3.6	332
NM	↑↑	86.8	11.6	1.5	517
OK	↑	81.5	16.4	2.1	475
PA		72.5	22.9	4.6	977
Margin of Error > 5%					
GA	↓	68.2	27.3	4.5	245
OH		73.1	23.1	3.7	216
SC	↓	70.2	23.5	6.2	289
Total %		77.0	19.6	3.4	4635
State Avg %		76.4	20.2	3.4	

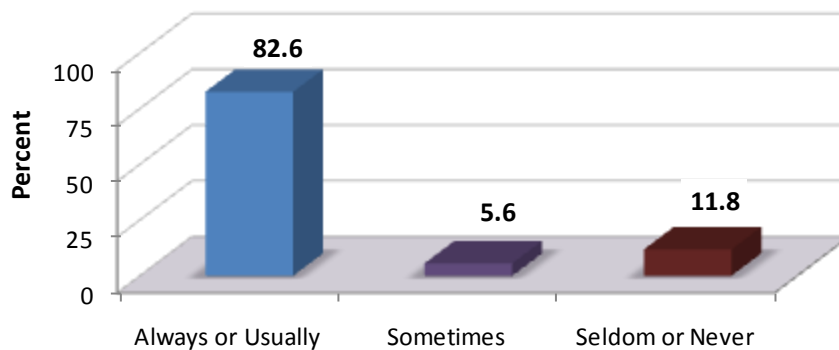
Chart Q42 Have services made a difference in helping keep your family member at home?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI		82.6	14.6	2.8	321
IL	↑	87.1	10.0	3.0	371
LA	↑	88.3	7.8	3.9	488
ME		79.4	11.8	8.8	306
MO	↓	75.3	12.2	12.5	312
NM	↑	90.6	6.4	3.0	501
OK	↑	87.9	8.8	3.3	453
PA	↓	74.5	14.6	11.0	831
Margin of Error > 5%					
GA	↓	75.9	16.0	8.0	212
OH	↓	74.3	11.8	13.9	187
SC		77.4	15.9	6.7	270
Total %		81.8	11.5	6.7	4252
State Avg %		81.2	11.8	7.0	

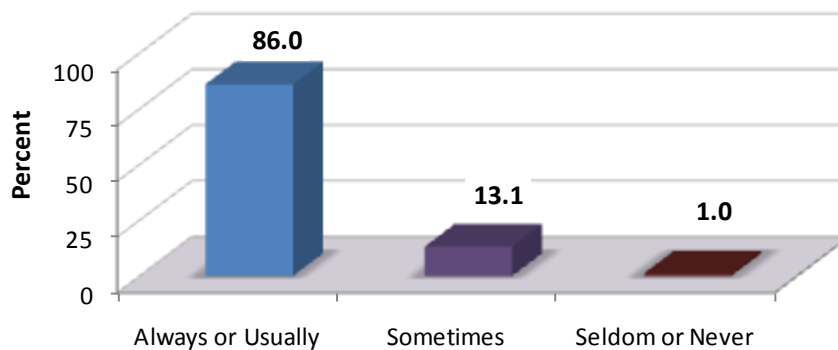
Chart Q43 Would your family member still be at home if you did not receive any supports?



2008-09 Average for 11 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
Margin of Error ≤ 5%					
HI	↓	77.4	7.9	14.7	252
IL	↓↓	72.4	6.1	21.5	214
LA		85.1	3.6	11.3	363
ME		86.4	3.5	10.1	257
MO		83.5	5.2	11.2	249
NM		83.5	5.4	11.2	411
OK		84.7	4.9	10.4	367
PA		84.7	6.0	9.4	756
Margin of Error > 5%					
GA		86.2	6.6	7.1	196
OH		86.3	6.3	7.5	160
SC		78.1	6.5	15.3	215
Total %		83.1	5.5	11.4	3440
State Avg %		82.6	5.6	11.8	

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



2008-09 Average for 11 States

Table Q44					
Overall, do you feel that your family member is happy? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
HI		87.3	11.9	0.8	353
IL		86.0	13.5	0.5	401
LA		86.8	12.0	1.1	523
ME		85.3	14.4	0.3	353
MO		89.5	10.0	0.6	351
NM	↑	93.3	6.5	0.2	524
OK		88.1	11.5	0.4	488
PA		85.0	13.4	1.6	1037
Margin of Error > 5%					
GA	↓	80.6	18.7	0.8	252
OH		84.4	14.7	0.9	224
SC	↓	79.3	17.4	3.3	305
Total %		86.4	12.6	1.0	4811
State Avg %		86.0	13.1	1.0	

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 New Mexico, responses to information and planning questions were generally above the overall state average. In Georgia, results fell noticeably below the state average.

Chart 4: Information and Planning

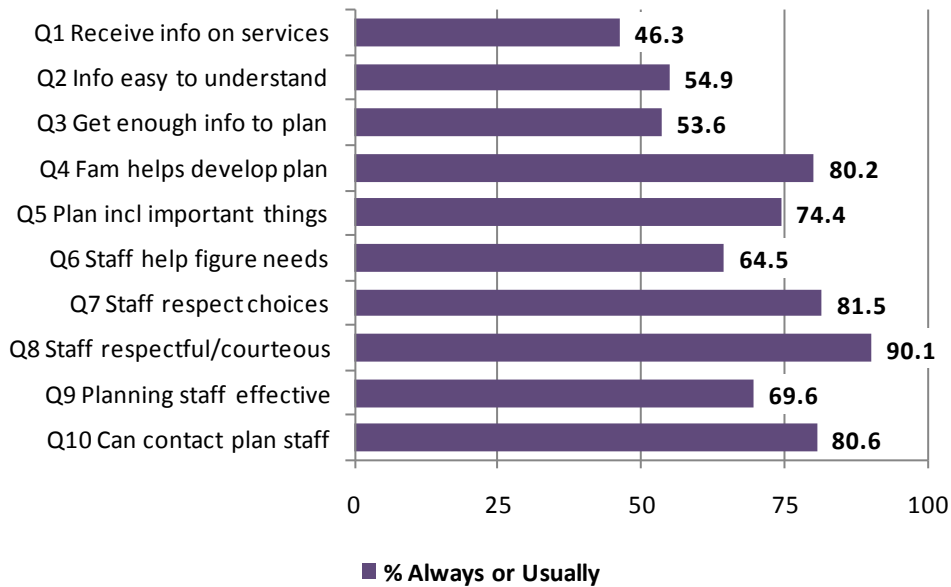


Table 18 Deviation in Responses Above & Below State Average Information & Planning											
State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Net Sum
HI	↑		↑		↑	↑					4
IL		↓	↓								-2
LA	↑				↑	↑			↑		4
ME		↓							↑		0
MO		↑									1
NM	↑↑↑	↑	↑↑↑	↑↑↑	↑	↑↑↑	↑		↑		12
OK	↓									↓	-2
PA		↑									1
GA	↓↓↓	↓	↓↓↓	↓↓↓	↓↓↓	↓↓↓	↓↓↓	↓	↓↓↓	↓	-17
OH						↓				↑	0
SC		↑		↓↓↓	↓			↓	↓		-4

Access and Delivery of Services

- ♦ In New Mexico, responses to access and delivery of services questions were generally above the overall state average. In Georgia, 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: Access to Services (1)

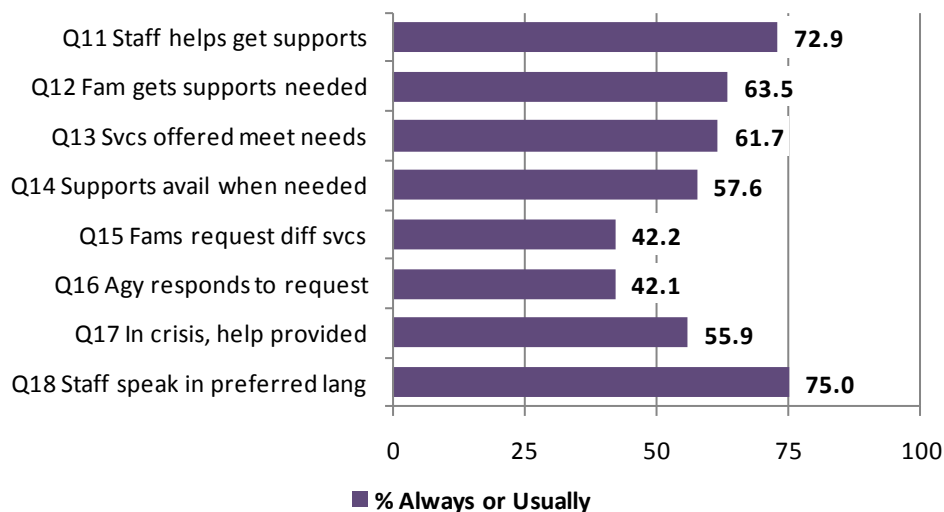


Chart 6: Access to Services (2)

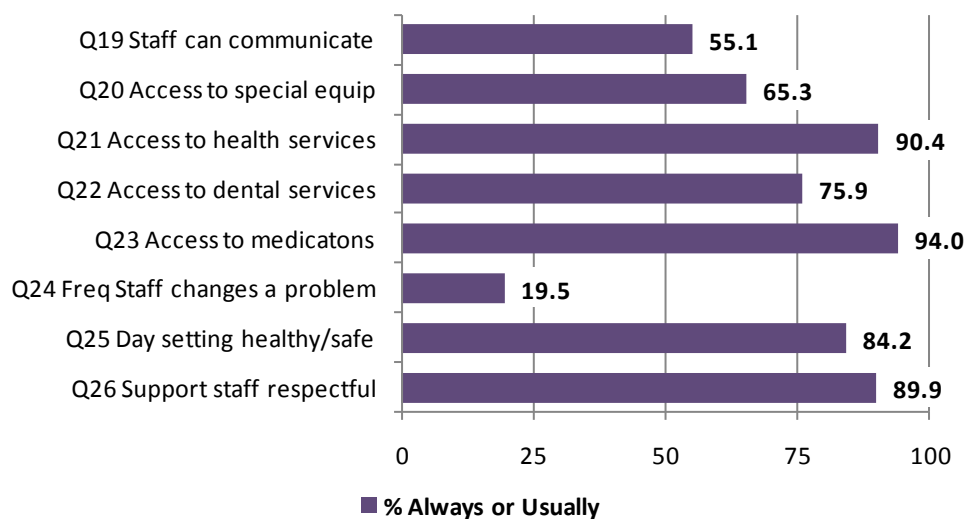


Table 19
Deviation in Responses Above & Below State Average
Access to Services & Supports

State	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Net Sum
HI						↑		↓↓↓		↓↓↓							-3
IL			↓	↓		↓	↓	↓									-5
LA			↑	↑		↑	↑↑	↑	↑			↓↓↓					-5
ME	↑											↑					2
MO								↑		↑		↓↓↓					0
NM	↑	↑↑	↑	↑		↑↑	↑↑		↑	↑	↑	↑↑					14
OK					↓		↓	↑				↓					-2
PA						↓↓↓		↓↓↓				↑					-3
GA	↓	↓↓↓	↓	↓↓↓		↓↓↓	↓	↑↑	↓			↓↓↓					-10
OH	↑		↑	↑		↑		↓	↓	↑		↑↑		↑			6
SC			↓			↑		↓			↓				↓		-3

Choice and Control

- ♦ In Louisiana, Oklahoma, New Mexico, and Illinois, responses to choice and control questions were generally above the overall state average.

Chart 7: Choice & Control

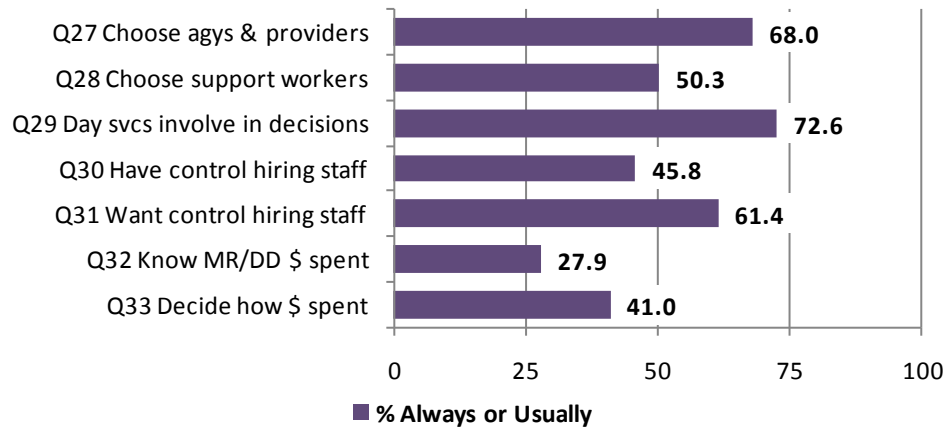


Table 20 Deviation in Responses Above & Below State Average Choice & Control								
State	Q27	Q28	Q29	Q30	Q31	Q32	Q33	Net Sum
HI			↑	↑↑	↑	↑		5
IL		↑↑		↑↑	↑↑	↑↑	↑↑	10
LA	↑↑	↑↑	↑	↑↑	↑↑			9
ME		↓↓		↓↓	↓	↓↓	↓↓	-9
MO	↓	↓↓		↓↓	↓↓	↓	↓	-9
NM	↑↑	↑↑		↑↑	↑	↑↑	↑↑	11
OK	↑↑	↑↑		↑↑	↑↑	↑↑	↑↑	12
PA	↓↓	↓↓		↓↓	↓↓			-8
GA	↓↓	↓↓	↓	↓↓	↓↓	↓↓	↓↓	-13
OH	↓↓	↓↓		↓	↓↓		↓	-8
SC	↓↓	↓	↓	↓	↓			-6

Community Connections

- ♦ In New Mexico, responses to community connections questions were generally above the overall state average.

Chart 8: Community Connections

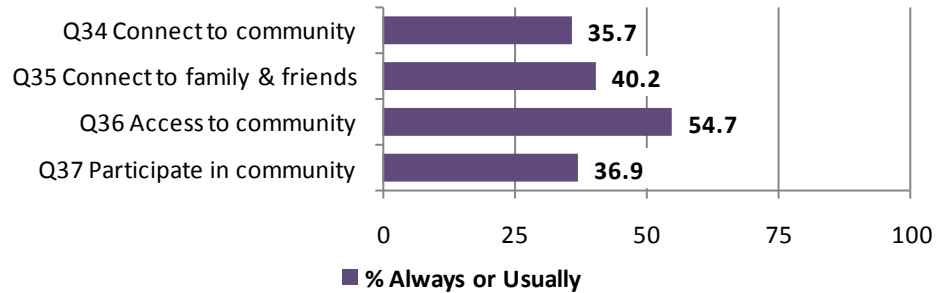


Table 21 Deviation in Responses Above & Below State Average Community Connections					
State	Q34	Q35	Q36	Q37	Net Sum
HI		↑			1
IL	↓				-1
LA		↑			1
ME		↓	↑		0
MO	↓	↓			-2
NM	↑↑	↑↑	↑↑	↑↑	8
OK		↑↑	↑		3
PA	↓	↓	↓	↓	-4
GA	↓	↓↓	↓↓		-5
OH		↓			-1
SC			↓	↓	-2

Satisfactions with Services and Supports & Outcomes for Families

- ♦ In New Mexico, Oklahoma, and Louisiana, responses were generally above the overall state average.

Chart 9: Satisfaction & Outcomes

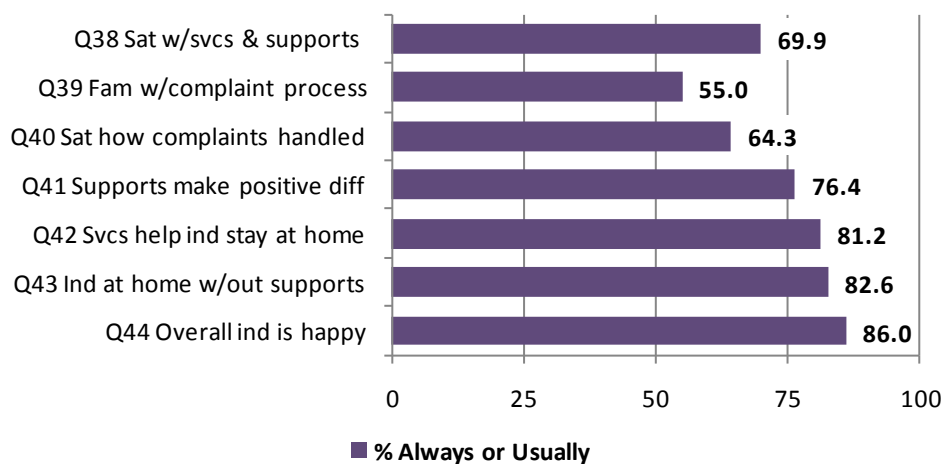


Table 22 Deviation in Responses Above & Below State Average Satisfaction & Outcomes								
State	Q38	Q39	Q40	Q41	Q42	Q43	Q44	Net Sum
HI						↓		-1
IL		↓			↑	↓↓		-2
LA		↑↑	↑↑	↑	↑			6
ME								0
MO		↓	↓↓		↓			-4
NM	↑↑	↑↑	↑↑	↑↑	↑		↑	10
OK		↑↑		↑	↑			4
PA		↓			↓			-2
GA	↓↓	↓↓	↓	↓	↓		↓	-8
OH					↓			-1
SC		↓		↓			↓	-3

Overall State Results

- ♦ Looking at results across all categories, New Mexico received results that were generally above the overall state average. In Georgia, results were substantially below the overall state average.

Table 23 Overall Deviation in Responses Above & Below State Average						
State	Information & Planning	Access	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
HI	4	-3	5	1	-1	6
IL	-2	-5	10	-1	-2	0
LA	4	-5	9	1	6	15
ME	0	2	-9	0	0	-7
MO	1	0	-9	-2	-4	-14
NM	12	14	11	8	10	55
OK	-2	-2	12	3	4	15
PA	1	-3	-8	-4	-2	-16
GA	-17	-10	-13	-5	-8	-53
OH	0	6	-8	-1	-1	-4
SC	-4	-3	-6	-2	-3	-18

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. The themes identified are detailed here, and the main results of this analysis are presented below.

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. Access to Services/Supports
 - b. Info Regarding Services/Supports
 - c. Need More Services/Supports
 - d. General Satisfaction with Service Management
 - e. General Dissatisfaction with Service Management
 - f. Waiting List
18. Not Analyzed
19. General Concern

Families across the six states who conducted the Adult Family Survey in 2008-09 wrote a wide array of comments. The following three areas were commented on the most:

Access to Services/Supports

"The provider for my family member has not in the past informed me of all available supports he was entitled to. He did not have services for more than 6 months with 9 different employees."

"One of my major complaints is the ability to access programs. When receiving maintenance medications we have experienced week delays in the approval process. My son's doctor has written, spoken and complained about the necessity of a drug and the drugs will still be denied. It took over a week to get approval, it was a breathing medication, and a week could have been detrimental. We should not have this hassle."

"I was very disappointed in how long it took to process my child's all kids insurance. It was of great need and as a result we lost all services, PT OT and speech. The local DHS office was unfriendly and overcrowded. I would be much easier for parents applying for all kids to be separate from food stamps, etc."

"There is still a lack of support and funding for day services. The waiting lists are far too long. There is a waiting list for funding. This is not right. There has been a general lack of planning and program development in this state for disabled adults. We still fall far behind most states. (This was during good times, not just these financially challenging times.)"

"The waiting list for waiver is too long. It should not take years and years to get waiver services. Services should cross state lines and you should not have to start all over when you move."

"I wish the process of qualifying a person for services was simpler and more individualized. We only wanted job coaching and transportation for our son. We wish this was not connected to receiving Medicaid or SSI."

"I cannot find a word strong enough to describe my outrage that my son has been waiting 4 years to receive funding for supported employment. I am a single mother with sole guardianship and care of my child."

"We have requested information 3 times on a Respite care program; we understand is administered by (name) county MRDD. We have never received the information. (Individual receiving services) is 50 years old. My wife and I are 66-65. We have cared for him for 38 years. We have asked about group homes and are always told the "list" is very long and we are on the bottom. We are worried about the future."

"I'm having a hard time finding or seeking medical, dental and mental help for my son here in the [town] area. I would also want him to be involved with more activities in

the community, like a counseling group, a group of people that has the same disabilities he does, so he won't feel out of place."

"We're in [city] so everything comes through [provider]. The answer you always get is 'we can't because...'"

Needs More Services/Supports

"I feel there is such a lack of services for the developmentally disabled. I have to pay for his dental services. He (my son) needs more training, job development and counseling. There should be more group homes."

"Appropriate services for those 18 and [in area] are almost nil. Services need to be appropriate and focus on the strengths of the adult--not create programs and "fit" them into these programs."

"The services are limited for children with higher functioning autism. Children with autism in the higher range have been overlooked for the need of social activities."

"I would like to see the waiver plan change how the hours are used. I would appreciate it very much if I could use more hours in the summer months. We are providing him with ABA in home therapy. We would be able to provide him more therapy if more hours were available."

"I have concerns about getting my son into a day workshop so he will be able to continue living at home. However, if this doesn't happen, we may be forced to put him in a group home so he would automatically get into a workshop. The lottery has pulled few names to get funding for this. I fear he will be sitting at home with nothing to do once he is done with school."

"Most young adults celebrate their 21st birthday as a monumental milestone into adulthood. For our family members, it is a bleak and depressing milestone when the only services they have known through the school system and appropriate social opportunities all cease. Please, please address the discouraging and desperate need for an array of adult services in [state]. I would love to see funding for community based services for adults, in lieu of currently placing a segregated program in a building within a regional area."

"Obtaining reliable weekend services has been a problem constantly...still struggling with appropriate weekend care since receiving the waiver in March 2008."

"The State of [name] is greatly in need of services for adults with autism. [State] needs to step up and provide for adults with autism. Once a person with autism reaches the age of 21, their disability does not go away. Show me [state] that you care."

"More services should be provided in the minority community. Many disabled are not provided resources available."

"The most difficult issue w/ our family member is finding staff in Day Programs or the community who are fluent in American Sign Language. We have hesitated placing her in a Day Program with individuals who have very limited skills in ASL. For this same reason it has been difficult to find a job-coach."

Satisfied with Case Manager/Service Coordinator

"We are so grateful for the services our daughter receives and for a wonderful case management team that partners with us to help her function with the home, family circle, church & community and society in general--as close to normal as she possibly can."

"The case manager makes a huge difference. My child did have a case manager that was unsatisfactory. This person did not inform us of all our options. She was basically a "non-existent" case manager. Currently, we are very pleased with our case manager."

"We are thankful and blessed to have the support of our regional OCDD office...without the assistance of our case manager we would be lost in the bureaucratic nightmare of Medicaid/health/hospitals."

"We are happy with the services provided by (area) Regional Office, and the case manager assigned to our daughter. The case manager has been very helpful to ensure that she received the goods and services she needs to help make her life easier."

"Our services are very appropriate, solely because our case manager is very knowledgeable and is very dedicated to her work. Services are often very poor without proper case management."

"Her case manager is (name), who watch my daughter and I respect and rely on. She's done an outstanding job of communicating with both of us and answering any questions we've had. We hope to keep her as our case manager!! Losing her would be a great loss."

"I have been lucky enough to have the same FCBMRDD care manager. She understands my sister and is always there to help. If something would happen to me I know she could see that my sister is well cared for. She does a terrific job and is good at it. I thank God for her every day."

"Our new case manager is great. [Name] will answer my emails almost immediately. If she doesn't know an answer, she finds out. She works hard to make sure we are taken care of. This is such a difference from the last case manager. I hope we can keep her."

"The support service coordinator was invaluable in getting my son into a day program. He helped me to make an informed choice of program. I realize the

coordinator is extremely busy. Sometimes I cannot reach him and will call the supervisor for assistance.”

“Our MH/MR supports coordinator has been very good and effective. Our country MH/MR office has provided a high level of support, which has allowed us to keep [name] at home instead of being institutionalized.”