

Family Guardian 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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Table of Contents

List of Tables & Figures

Organization of Report

I. Introduction	3
Overview of National Core Indicators	3
Family Indicators	4
II. Family Guardian Survey	6
Background	6
State Participation	6
Survey Instrument	7
III. Methods	7
Sampling & Administration	7
Data Analysis	8
IV. Results	9
Participating States	9
Characteristics of Family Members with Disabilities	11
Characteristics of Respondents	17
Services and Supports Received	20
National Core Indicators	21
Information and Planning	22
Access to and Delivery of Services and Supports	29
Choice and Control	37
Community Connections	45
Outcomes and Satisfaction with Services and Supports	50
Aggregate Results & State Comparisons	56

Appendix A – Analysis of Open-Ended Comments

List of Tables & Figures

Tables

Table 1	State Participation in National Core Indicators	4
Table 2	Family Indicators.....	5
Table 3	State Participation in NCI Family Guardian Survey.....	6
Table 4	Family Guardian Survey – State Response Rates.....	8
Table 5	Type of Residence.....	12
Table 6	Gender of Family Member.....	13
Table 7	Age of Family Member	13
Table 8	Race/Ethnicity of Family Member.....	14
Table 9	Level of Mental Retardation of Family Member.....	15
Tables 10A-B	Other Disabilities of Family Member.....	16
Table 11	Age of Respondent.....	17
Table 12	Relationship of Respondent to Individual with Disabilities.....	18
Table 13	Frequency of Visits	18
Table 14	Respondent is Legal Guardian/Conservator	19
Table 15	Services and Supports Received	20
Tables Q1-6	Information and Planning.....	23-28
Tables Q7-13	Access and Delivery of Supports.....	30-36
Tables Q14-20	Choices and Control	38-44
Tables Q21-24	Community Connections	46-49
Tables Q25-29	Outcomes and Satisfaction.....	51-55
Tables 16-21	State Comparisons in Responses Above & Below State Average	57-62

Charts

Chart 1	States Participating in NCI Family Guardian Survey.....	10
Chart 2	Type of Residence of Family Member.....	12
Chart 3	Gender of Family Member.....	13
Chart 4	Level of Mental Retardation of Family Member.....	15
Charts Q1-Q6	Information and Planning.....	23-28
Charts Q7-Q13	Access and Delivery of Supports.....	30-36
Charts Q14-Q20	Choices and Control	38-44
Charts Q21-Q24	Community Connections	46-49
Charts Q25-Q29	Outcomes and Satisfaction.....	51-55

Organization of Report

Twelve states conducted the National Core Indicators (NCI) Family Guardian Survey during the 2008-2009 project year and submitted their data. The Family Guardian Survey was administered to individuals having an adult family member with disabilities living outside of the family's home. This Final Report provides a summary of results, based on the data submitted by June 2009.

This report is organized as follows:

I. INTRODUCTION

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

II. FAMILY GUARDIAN SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

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

IV. RESULTS

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

I. Introduction

Overview of National Core Indicators

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

Background

This report focuses on the Family Guardian Survey.

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

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

Between 2001 and 2009, seven to twelve states have participated each year. Response rates within states have varied greatly, between 12% - 81%, yet each year, NCI has had between 2,800 – 5,600 completed surveys available for analysis.

State Participation

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

Table 3 State Participation in NCI Family Guardian Survey (Adults Living Out-of-Home)										
Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003	Phase VI 2003-2004	Phase VII 2004- 2005	Phase VIII 2005- 2006	Phase IX 2006- 2007	Phase X 2007-2008	Phase XI 2008-2009
NA	CT KY MN NE PA VA WA	AZ DE MA MN NC PA RI	CA-RCOC HI NE NC PA UT WA	AZ CA-RCOC HI IN MA NC PA SC SD WY	AZ CA-RCOC CT ME NC ND PA SC WY	AZ CA-RCOC CT HI PA SC WY	CA-RCOC CT GA ME NC PA SC SD WA WY	AZ CT DE GA HI ME NM PA WY	GA LA ME MO NC NJ PA CA-RCOC SC WA WY	AZ CT GA IL LA ME MO NM OH PA SC WY

Survey Instrument

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

The Family Guardian Survey used in 2008-2009 not only asks families to express their overall level of satisfaction with services and supports their family member receives, it also probes specific aspects of the service system's capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; satisfaction and outcomes. Combined, this information provides an overall picture of the services that family members 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, relationship to individual, level of involvement with family member).

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

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

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

III. Methods

Sampling & Administration

States were asked to administer the Family Guardian Survey by selecting a random sample of 1,000 families who: a) have an adult family member with developmental disabilities living outside of the family home, and b) receive service coordination and at least one additional "direct" service or support. Adults were defined as individuals with disabilities age 18 or older. A sample size of 1,000 was selected in anticipation that states would obtain at least a 40% return rate, yielding 400 or more usable responses per state. 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 responses into a standard file format and sent the data file to HSRI for analysis. As necessary, HSRI personnel “cleaned” (i.e., excluded invalid responses) based on three criteria:

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

Response Rates

During 2008-09, 12 states administered the Family Guardian Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis. The desired response rate (the percentage of surveys returned versus the number mailed) is 40%.

Table 4 Family Guardian Survey - State Response Rates				
State	Surveys Mailed	Surveys Returned	Response Rate	Usable Surveys
Arizona	1,000	242	24%	237
Connecticut	1,200	451	38%	395
Georgia	1,200	358	30%	304
Illinois	6,237	1,278	20%	1,136
Louisiana	1,600	414	26%	404
Maine	1,266	475	38%	474
Missouri	1,200	414	35%	402
New Mexico	1,508	402	27%	402
Ohio	1,000	238	24%	225
Pennsylvania	4,300	1,318	31%	1,195
South Carolina	1,570	311	20%	241
Wyoming	418	217	52%	214
Overall	22,499	6,118	27%	5,629

Data Analysis

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

IV. Results

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

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

1. **Total Percentages** indicate the average percentage across all individual respondents.
2. **State Averages** indicate the average percentage across the twelve 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 the text statistics in this report illustrate the state average results.

Participating States

- ◆ Twelve states provided data sets to be included in the Final Report. They include Arizona, Connecticut, Georgia, Illinois, Louisiana, Maine, Missouri, New Mexico, Ohio, Pennsylvania, South Carolina and Wyoming.

Chart 1
States Participating in the
NCI Family Guardian Survey – 2008-09



Characteristics of Family Members with Disabilities

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

- On average, across the states, over half (53%) of the family members with disabilities lived in group home settings. Sixteen percent (16%) lived in their own homes or apartments, 13% lived in specialized facilities, 6% lived in agency-owned apartments, 6% lived in adult foster care or host family homes, 4% in a variety of other settings, and 3% in nursing homes.
- On average, 56% of family members were male across the participating states. The remaining 44% were female.
- Across states, the average age of family members with disabilities was 45, with a range in age from 18 to 92.
- On average, 82% of the family members were White, 9% were Black/African American, 5% were Hispanic, 3% were American Indian/Alaska Native, 2% were Mixed Races, 1% were Asian, less than 1% were Native Hawaiian/Pacific Islander, and less than 1% marked Other or Unknown. (In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.)
- On average, one-third (33%) of the family members with disabilities had a diagnosis of severe or profound mental retardation. Additionally, 31% were individuals with moderate mental retardation, 18% had mild mental retardation, and 3% had no mental retardation diagnosis. Additionally, 15% of respondents were unsure of their family member's diagnosis.
- In addition to mental retardation, many family members experience other disabilities as well (e.g., seizure disorder, cerebral palsy, physical disability, communication disorder). The most prevalent additional disabilities included: seizure disorders/neurological problems (30%), physical disabilities (26%), mental illness (26%), vision or hearing impairments (23%), communication disorders (21%), and cerebral palsy (16%).

Type of Residence

Chart 2. Type of Residence

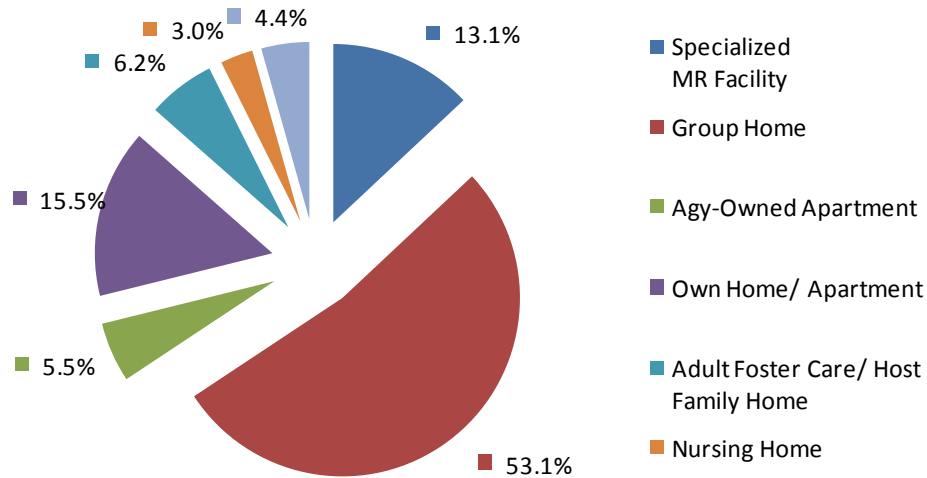


Table 5 Type of Residence in Which Family Member Lives (%)							
State	Specialized ID Facility	Group Home	Agy-Owned Apartment	Own Home/ Apartment	Adult Foster Care/ Host Family Home	Nursing Home	Other
Margin of Error ≤ 5%							
CT	6.2	73.4	4.1	9.8	2.1	0.3	4.1
IL	20.3	64.5	4.3	3.0	0.9	4.1	2.9
LA	27.1	10.3	5.4	49.7	1.5	0.0	5.9
ME	10.4	51.4	6.5	10.2	12.4	4.3	4.8
MO	7.1	43.2	10.4	25.0	1.8	6.6	6.1
NM	1.8	53.0	5.9	20.9	12.1	0.0	6.2
PA	17.8	53.9	2.5	10.7	4.7	4.9	5.4
WY	11.8	59.0	8.0	10.4	9.0	0.0	1.9
Margin of Error > 5%							
AZ	8.1	73.6	1.7	3.0	9.8	0.9	3.0
GA	4.0	58.7	3.4	13.4	13.8	0.7	6.0
OH	22.1	36.4	5.5	24.4	3.7	5.1	2.8
SC	20.7	59.9	8.2	5.2	2.2	0.4	3.4
Total N	801	2,982	271	752	286	167	248
Total %	14.5	54.1	4.9	13.7	5.2	3.0	4.5
State Avg %	13.1	53.1	5.5	15.5	6.2	3.0	4.4

Gender of Family Member

Table 6 Gender (%)		
State	Male	Female
Margin of Error ≤ 5%		
CT	56.2	43.8
IL	56.6	43.4
LA	55.8	44.2
ME	55.9	44.1
MO	53.0	47.0
NM	61.3	38.7
PA	58.0	42.0
WY	52.7	47.3
Margin of Error > 5%		
AZ	51.1	48.9
GA	59.1	40.9
OH	50.2	49.8
SC	67.2	32.8
Total N	3,070	2,335
Total %	56.8	43.2
State Avg %	56.4	43.6

Age of Family Member

Table 7 Age of Family Member (%)		
State	Average Age	Range
Margin of Error ≤ 5%		
CT	47.1	18-85
IL	46.7	18-92
LA	45.0	18-85
ME	46.7	19-89
MO	49.2	18-89
NM	43.8	18-88
PA	48.3	18-89
WY	40.5	21-71
Margin of Error > 5%		
AZ	45.3	19-86
GA	42.6	18-82
OH	47.4	21-87
SC	39.2	18-82
Total N	5,512	
Total %	46.1	18-92
State Avg %	45.1	

Race/Ethnicity of Family Member

Table 8 Race/Ethnicity of Family Member (%)								
State	White	Black/ African American	Asian	Amer. Indian/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
Margin of Error ≤ 5%								
CT	88.6	6.2	0.3	1.6	0.0	1.8	0.0	3.4
IL	88.0	7.7	1.0	1.3	0.2	1.3	0.2	2.0
LA	76.6	19.8	0.8	1.5	0.3	0.5	0.5	1.0
ME	97.2	0.0	0.2	2.2	0.0	1.7	0.2	0.2
MO	90.6	5.1	0.5	1.3	0.8	1.3	0.8	0.3
NM	49.2	2.3	0.3	10.6	0.0	8.5	0.5	28.9
PA	96.1	2.1	0.0	1.2	0.1	0.5	0.3	0.5
WY	92.4	0.5	0.0	2.4	0.5	2.9	0.5	3.3
Margin of Error > 5%								
AZ	68.0	3.1	1.8	12.3	0.4	3.1	1.3	15.8
GA	76.3	21.0	0.3	0.7	0.0	2.7	0.0	0.0
OH	90.2	8.9	0.0	0.5	0.0	0.5	0.0	0.0
SC	70.8	27.1	1.3	0.4	0.0	0.8	0.0	0.0
Total N	4,679	395	27	134	9	99	18	202
Total %	85.2	7.2	0.5	2.4	0.2	1.8	0.3	3.7
State Avg %	82.0	8.7	0.5	3.0	0.2	2.1	0.4	4.6

Level of Mental Retardation of Family Member

Chart 3. Level of MR/ID

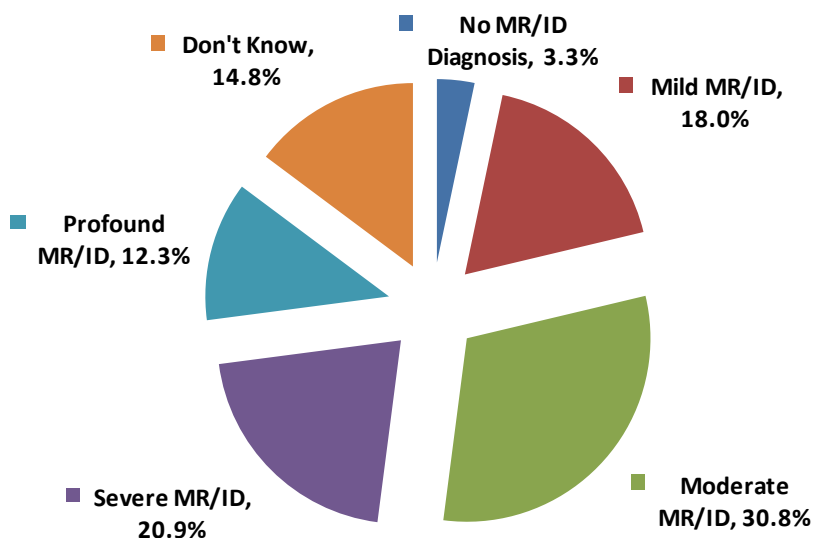


Table 9 Level of Mental Retardation of Family Member (%)						
State	No MR Diagnosis	Mild MR	Moderate MR	Severe MR	Profound MR	Don't Know
Margin of Error ≤ 5%						
CT	0.8	17.9	28.1	22.9	14.3	16.0
IL	1.5	12.4	34.6	23.3	18.2	10.0
LA	4.9	15.4	22.6	21.0	20.8	15.4
ME	1.5	12.4	33.2	24.7	13.2	15.0
MO	7.0	30.2	25.3	19.4	3.1	15.0
NM	3.7	18.9	29.7	21.5	12.1	14.2
PA	1.8	15.4	26.6	21.9	15.1	19.2
WY	2.9	20.5	39.5	17.6	8.1	11.4
Margin of Error > 5%						
AZ	4.4	14.5	28.9	25.0	13.6	13.6
GA	2.7	18.4	27.9	22.8	14.3	13.9
OH	5.1	15.4	36.0	15.9	11.7	15.9
SC	3.5	24.3	37.0	14.3	3.5	17.4
Total N	151	905	1,639	1,176	752	802
Total %	2.8	16.7	30.2	21.7	13.9	14.8
State Avg %	3.3	18.0	30.8	20.9	12.3	14.8

Other Disabilities of Family Member

Table 10A						
Other Disabilities of Family Member (%)						
State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
Margin of Error ≤ 5%						
CT	21.6	21.1	16.6	6.4	26.3	0.6
IL	22.1	15.2	18.1	9.0	29.7	0.6
LA	25.7	7.4	16.0	14.2	35.6	2.5
ME	26.1	15.1	17.1	7.6	29.2	0.6
MO	29.1	7.2	13.4	8.0	19.1	1.3
NM	26.9	12.7	18.0	14.1	31.3	1.9
PA	23.7	10.3	18.2	8.6	29.6	1.0
WY	29.3	7.3	16.1	15.1	34.1	1.0
Margin of Error > 5%						
AZ	17.1	9.7	22.1	8.8	38.7	0.5
GA	26.7	13.2	17.1	11.7	29.5	1.1
OH	30.6	12.4	13.4	8.6	31.6	1.9
SC	30.0	11.3	10.8	6.6	21.6	1.4
Total N	1,321	654	903	507	1,566	57
Total %	24.8	12.3	17.0	9.5	29.4	1.1
State Avg %	25.7	11.9	16.4	9.9	29.7	1.2

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 ≤ 5%						
CT	27.7	26.0	18.3	0.8	17.2	15.0
IL	22.1	24.4	22.3	1.6	14.0	16.3
LA	23.4	31.8	27.7	0.0	7.1	17.3
ME	24.2	30.2	27.0	1.9	14.0	16.8
MO	14.4	19.6	13.1	2.8	10.8	22.7
NM	24.1	25.8	26.3	2.2	12.2	28.0
PA	25.3	26.3	20.4	2.8	12.8	14.6
WY	21.5	27.3	18.0	2.0	13.2	18.0
Margin of Error > 5%						
AZ	21.7	27.2	21.2	1.4	10.1	22.6
GA	25.3	28.1	23.1	0.4	14.2	18.1
OH	27.8	29.7	16.7	2.4	10.5	19.6
SC	18.3	20.2	14.1	0.9	10.3	16.0
Total N	1,235	1,393	1,134	95	673	945
Total %	23.2	26.2	21.3	1.8	12.6	17.8
State Avg %	23.0	26.4	20.7	1.6	12.2	18.8

Characteristics of Respondents

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

- Across states, a majority of respondents (55%) fell between the ages of 55 and 74. One-fourth (25%) of respondents were 35 to 54, while 17% were 75 years old or over.
- Fifty-three percent (53%) of respondents were parents of adult children with disabilities. One-fourth (25%) were siblings, less than 1% were spouses, and the remaining 22% had other relationships to the individual.
- On average, almost three-fifths (58%) of respondents indicated they saw their family member more than twelve times per year (e.g., once a month or more). Others visited with their family members less frequently: 14% saw their family member 7 to 12 times per year, 14% visited their family member four to six times per year, 11% saw their family member one to three times per year, and the remaining 4% less than once per year.
- On average, 78% of respondents indicated that they were their family member's legal guardian or conservator. In Illinois, Maine and Wyoming, nearly all respondents served as their family member's guardian, while in Pennsylvania and South Carolina, fewer than half of respondents held this role.

Age of Respondent

Table 11				
Age of Respondent (%)				
State	Under 35	35-54	55-74	75 or Older
Margin of Error ≤ 5%				
CT	2.1	19.3	51.0	27.6
IL	0.9	14.9	56.9	27.3
LA	4.0	23.8	55.9	16.3
ME	1.3	19.2	61.3	18.2
MO	1.3	35.1	50.1	13.4
NM	6.2	27.8	52.1	13.9
PA	1.0	23.3	53.3	22.4
WY	2.9	22.9	61.0	13.3
Margin of Error > 5%				
AZ	1.7	31.8	53.2	13.3
GA	0.3	21.3	62.3	16.0
OH	9.6	23.4	54.1	12.8
SC	8.2	38.6	48.1	5.2
Total N	132	1,272	3,036	1,079
Total %	2.4	23.0	55.0	19.6
State Avg %	3.3	25.1	54.9	16.6

Relationship of Respondent to Individual with Disabilities

Table 12				
Relationship to Individual with Disabilities (%)				
State	Parent	Sibling	Spouse	Other
Margin of Error ≤ 5%				
CT	58.8	24.4	0.0	16.8
IL	63.9	21.5	0.2	14.4
LA	56.1	25.2	1.0	17.7
ME	60.1	28.5	0.0	11.5
MO	28.9	44.6	0.0	26.5
NM	49.9	21.6	0.3	28.3
PA	52.6	41.2	0.3	5.9
WY	64.8	15.5	0.0	19.7
Margin of Error > 5%				
AZ	46.8	20.2	0.0	33.0
GA	60.9	24.4	0.0	14.7
OH	45.2	22.4	0.0	32.4
SC	48.1	13.1	0.4	38.4
Total N	3,025	1,549	11	960
Total %	54.6	27.9	0.2	17.3
State Avg %	53.0	25.2	0.2	21.6

Frequency of Visits between Respondent and Individual with Disabilities

Table 13					
Frequency of Visits with Family Member (%)					
State	Less than once/year	1-3 times/year	4-6 times/year	7-12 times/year	More than 12x/year
Margin of Error ≤ 5%					
CT	7.3	14.9	12.0	15.1	50.7
IL	3.8	9.3	12.4	15.2	59.3
LA	5.5	12.6	10.3	9.0	62.6
ME	3.0	7.5	14.5	16.2	58.8
MO	3.8	18.4	14.1	13.4	50.3
NM	4.6	10.0	7.2	13.1	65.1
PA	5.5	15.1	13.3	14.6	51.5
WY	2.8	13.6	15.4	16.8	51.4
Margin of Error > 5%					
AZ	2.6	11.2	24.0	16.3	45.9
GA	1.7	8.1	8.4	13.1	68.8
OH	1.4	5.9	20.9	10.0	61.8
SC	2.2	7.5	9.7	11.9	68.7
Total N	229	645	716	779	3,159
Total %	4.1	11.7	13.0	14.1	57.1
State Avg %	3.7	11.2	13.5	13.7	57.9

Respondent's Role as Guardian or Conservator

Table 14		
Respondent is Legal Guardian or Conservator (%)		
State	Yes	No
Margin of Error ≤ 5%		
CT	91.3	8.7
IL	97.2	2.8
LA	68.3	31.7
ME	98.5	1.5
MO	81.3	18.7
NM	79.6	20.4
PA	48.8	51.2
WY	98.1	1.9
Margin of Error > 5%		
AZ	88.4	11.6
GA	62.9	37.1
OH	71.0	29.0
SC	44.3	55.7
Total N	4,179	1,238
Total %	77.1	22.9
State Avg %	77.5	22.5

Services and Supports Received

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

Table 15				
Services and Supports Received (%)				
State	Residential supports	Day/ Employment supports	Transportation	Other
Margin of Error ≤ 5%				
CT	98.2	93.0	96.5	78.7
IL	97.1	91.6	96.3	80.9
LA	89.4	50.4	82.9	55.4
ME	98.9	77.2	95.1	77.4
MO	94.2	56.1	76.4	44.7
NM	97.7	88.3	95.4	96.1
PA	95.5	71.2	86.5	72.5
WY	99.5	94.0	95.6	86.6
Margin of Error > 5%				
AZ	98.7	90.9	97.4	67.1
GA	97.0	86.2	92.2	54.8
OH	94.6	89.4	94.1	68.3
SC	96.2	86.7	94.1	59.9
Total N	5,261	4,221	4,897	3,528
Total %	96.3	80.2	91.4	72.6
State Avg %	96.4	81.3	91.9	70.2

National Core Indicators

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

For each question, a Figure and Table is provided.

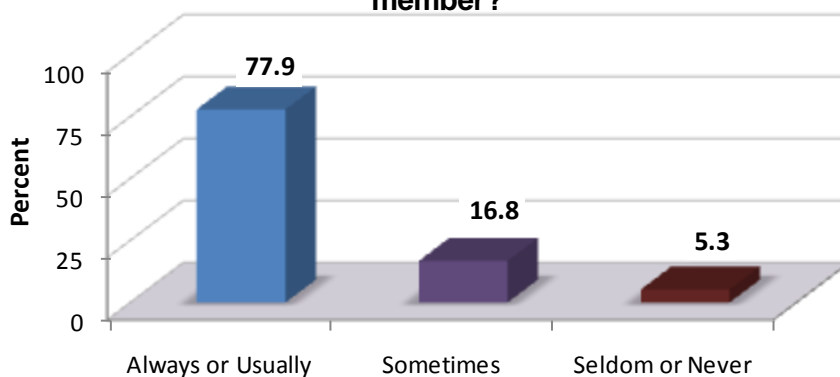
- ◆ The Figure illustrates the State Average results (i.e., the average percentage across the eleven states that conducted this survey).
- ◆ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state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

- On average, just over three-fourths of respondents (78%) stated that they got enough information to help them participate in planning.
- About two-thirds of respondents (67%), on average, indicated that they typically helped to develop their family member's service plan.
- On average across states, about four-fifths (79%) of respondents surveyed indicated that their family member's service plan included things that were important to them. Seventeen percent (17%) stated this was only true some of the time, while the remaining 4% stated the service plan seldom or never included things important to the respondent.
- Across states, nearly all respondents (92%) felt that planning staff were generally respectful and courteous.
- Across states, 79% felt that planning staff were generally effective.
- Across states, 88% felt they were able to contact planning staff when needed.

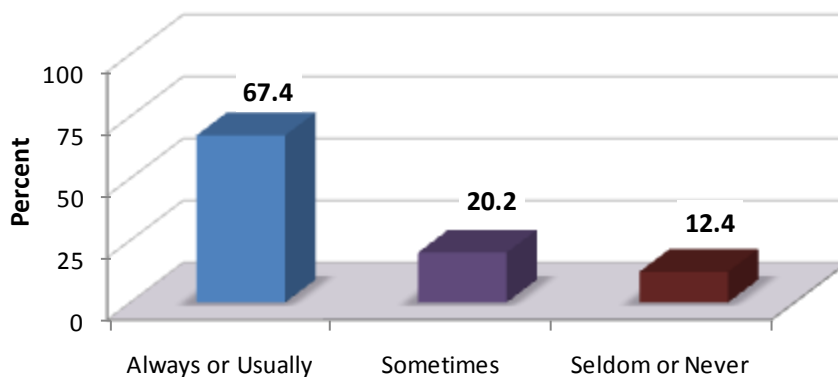
Chart Q1 Do you get enough information to help you participate in planning services for your family member?



2008-09 Average for 12 States

Table Q1					
Do you get enough information to help you participate in planning services for your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT	↑	83.8	12.7	3.5	346
IL		80.3	16.4	3.3	1070
LA	↓	71.7	21.4	6.9	378
ME	↑	85.2	12.7	2.1	466
MO		77.9	12.8	9.4	384
NM		74.1	19.7	6.2	390
PA		73.9	18.5	7.6	1079
WY	↑	87.3	12.2	0.5	213
Margin of Error > 5%					
AZ		82.5	15.3	2.2	229
GA	↓↓	65.5	26.1	8.4	287
OH		81.0	14.3	4.8	210
SC	↓	72.1	19.5	8.4	226
Total %		77.6	17.0	5.4	5,278
State Avg %		77.9	16.8	5.3	

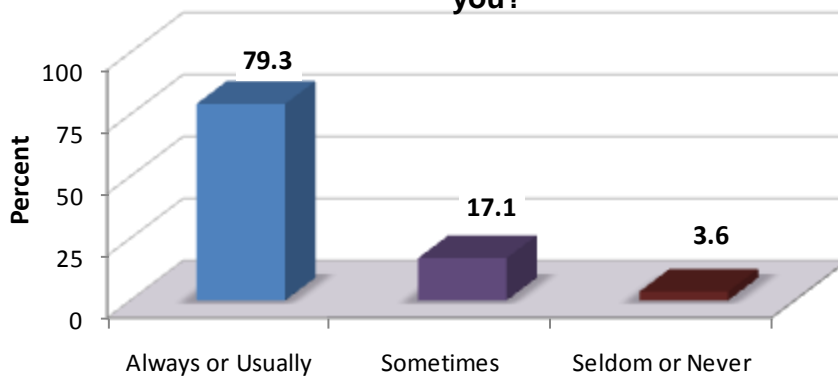
Chart Q2 If your family member has a service plan, did you help develop the plan?



2008-09 Average for 12 States

Table Q2 If your family member has a service plan, did you help develop the plan? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT	↓	61.9	25.8	12.3	333
IL		63.0	26.1	10.8	979
LA	↓	59.8	23.6	16.6	331
ME	↑	74.4	21.3	4.3	442
MO		69.1	14.9	16.0	362
NM		70.4	18.1	11.6	371
PA	↓↓	45.7	26.3	28.0	930
WY	↑↑	82.4	14.1	3.4	205
Margin of Error > 5%					
AZ	↑↑	80.8	12.7	6.6	213
GA		64.8	25.8	9.5	264
OH		71.3	15.4	13.3	195
SC		65.7	17.7	16.7	198
Total %		63.6	22.2	14.2	4,823
State Avg %		67.4	20.2	12.4	

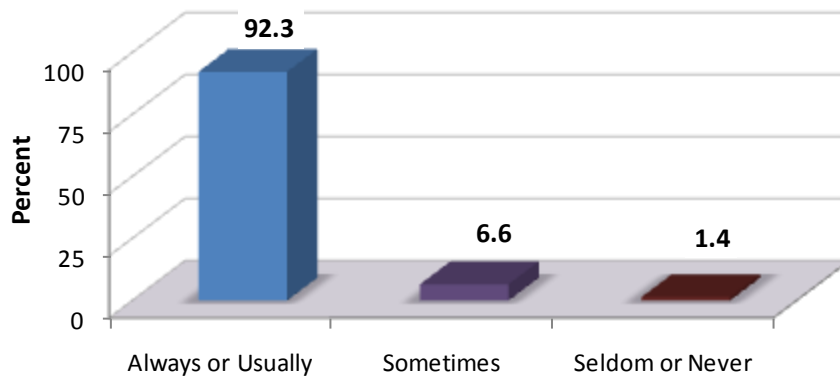
Chart Q3 If your family member has a service plan, does the plan include things that are important to you?



2008-09 Average for 12 States

Table Q3					
If your family member has a service plan, does the plan include things that are important to you? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		79.8	19.1	1.2	341
IL		78.4	17.6	3.9	992
LA	↓	73.4	22.7	3.9	335
ME	↑	86.1	13.1	0.9	452
MO		80.8	11.6	7.6	344
NM		76.8	17.6	5.7	370
PA	↓	72.7	20.8	6.5	933
WY	↑	88.5	10.0	1.4	209
Margin of Error > 5%					
AZ		83.4	14.8	1.8	223
GA	↓	71.3	25.0	3.7	268
OH	↑	85.7	13.3	1.0	196
SC		75.1	19.5	5.4	205
Total %		78.2	17.7	4.1	4,868
State Avg %		79.3	17.1	3.6	

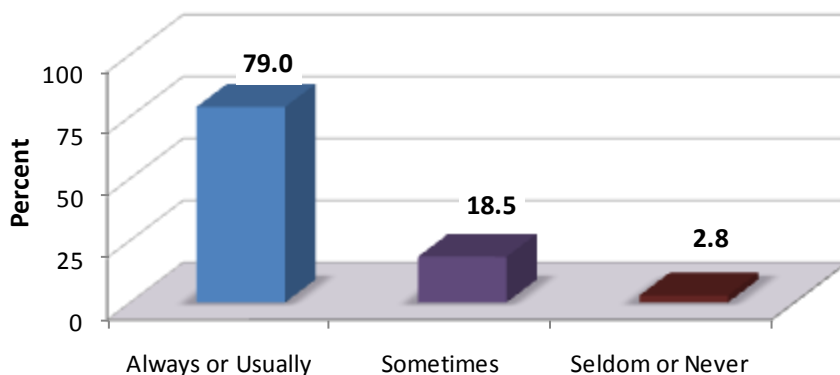
Chart Q4 Are the staff who assist you with planning generally respectful and courteous?



2008-09 Average for 12 States

Table Q4 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%					
CT		94.5	4.1	1.4	364
IL		92.6	6.3	1.0	1059
LA		91.3	8.7	0.0	356
ME		94.3	5.2	0.4	459
MO		92.7	5.1	2.2	369
NM	↓	85.5	11.6	2.9	379
PA		94.0	4.4	1.6	1004
WY		95.2	4.8	0.0	210
Margin of Error > 5%					
AZ		93.6	5.5	0.9	218
GA		88.8	10.5	0.7	277
OH		94.6	4.4	1.0	204
SC		90.5	8.2	1.4	220
Total %		92.5	6.3	1.2	5119
State Avg %		92.3	6.6	1.4	

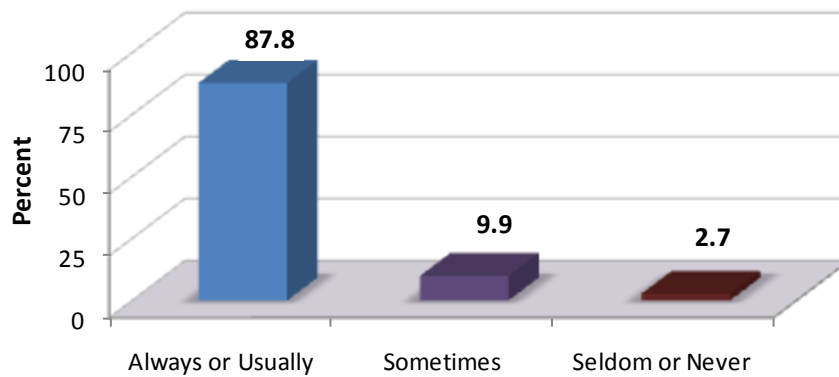
Chart Q5 Are the staff who assist you with planning generally effective?



2008-09 Average for 12 States

Table Q5 Are the staff who assist you with planning generally effective? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		82.9	14.8	2.3	351
IL		77.8	19.5	2.7	1039
LA		78.6	19.7	1.7	345
ME		81.3	16.5	2.2	449
MO		81.2	14.9	3.9	356
NM	↓	73.8	21.7	4.5	374
PA		79.6	17.7	2.7	964
WY		83.8	16.2	0.0	210
Margin of Error > 5%					
AZ		80.2	18.0	1.8	222
GA	↓↓	68.9	28.2	2.9	273
OH		83.2	14.9	2.0	202
SC		76.1	19.7	4.1	218
Total %		78.8	18.5	2.7	5003
State Avg %		79.0	18.5	2.8	

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



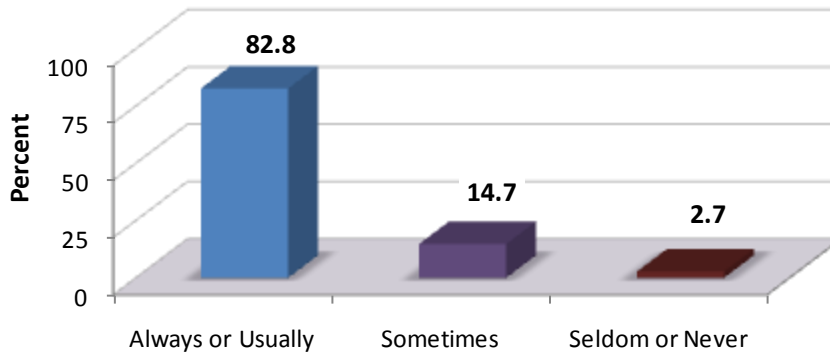
2008-09 Average for 12 States

Table Q6 Can you contact the staff who assist you with planning whenever you want to? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		92.5	6.6	0.8	362
IL		87.9	10.5	1.6	1058
LA		87.4	11.3	1.4	364
ME		92.2	6.7	1.1	461
MO		88.5	7.5	4.0	374
NM		83.2	12.3	4.5	382
PA		89.5	8.0	2.6	1015
WY	↑	92.9	7.1	0.0	210
Margin of Error > 5%					
AZ		86.1	12.5	1.4	216
GA	↓	80.4	13.0	6.5	276
OH		90.0	10.0	0.0	209
SC		83.2	13.6	3.2	220
Total %		88.2	9.6	2.3	5147
State Avg %		87.8	9.9	2.7	

Access to and Delivery of Services and Supports

- On average, most respondents (83%) stated that their service coordinator helped them get needed supports when they asked. Fifteen percent (15%) said this only happened some of the time, and 3% indicated that their service coordinator was seldom or never helpful in getting their family member the assistance needed.
- Eighty-three percent (83%) of respondents, on average, indicated that their family member always or usually gets the services and supports they need.
- Among those respondents whose family member with disabilities did not speak English, or who used different ways to communicate, a large majority (79%) indicated there were enough staff to communicate with their family member. Seventeen percent (17%) stated that these staff were available some of the time, and another 4% did not have staff available to communicate with their family members in their preferred means of communication/ languages.
- On average, 88% of respondents indicated that their family member had access to the special equipment or accommodations that s/he needs.
- Two-thirds of respondents (66%) indicated that frequent changes in support staff were a problem for their family at least some of the time. The remaining 34% stated that this was not an issue for them.
- Among those receiving residential supports, nearly all (90%) felt their family member's residential setting was a safe and healthy environment.
- Among those receiving day/employment supports, nearly all (89%) felt their family member's day/employment setting was a safe and healthy environment. The remaining 11% felt their family member's day setting was sometimes, seldom, or never safe.

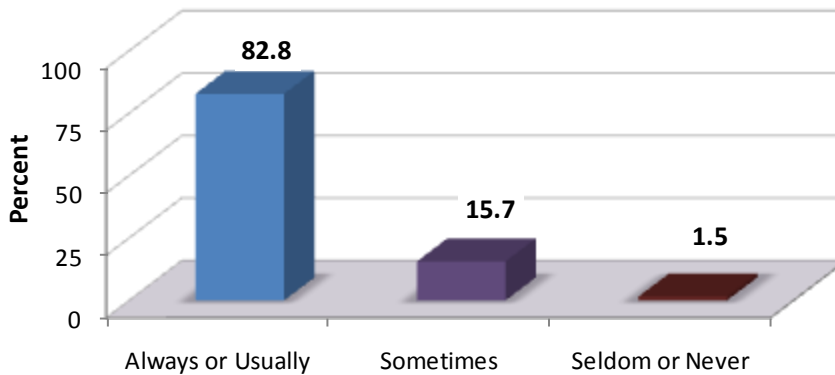
Chart Q7 When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?



2008-09 Average for 12 States

Table Q7					
When you ask the service coordinator/case manager for assistance, does he/she help you get what you need? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		83.9	14.6	1.4	355
IL		83.7	14.9	1.3	1064
LA		80.3	18.1	1.6	371
ME		84.1	13.2	2.8	433
MO		83.4	11.9	4.7	361
NM		82.5	13.1	4.5	382
PA		84.5	12.8	2.7	1019
WY	↑	91.4	8.6	0.0	210
Margin of Error > 5%					
AZ		84.1	13.7	2.2	227
GA	↓	73.2	22.5	4.3	276
OH		84.1	14.0	1.9	207
SC		77.9	19.5	2.7	226
Total %		83.1	14.5	2.5	5,131
State Avg %		82.8	14.7	2.7	

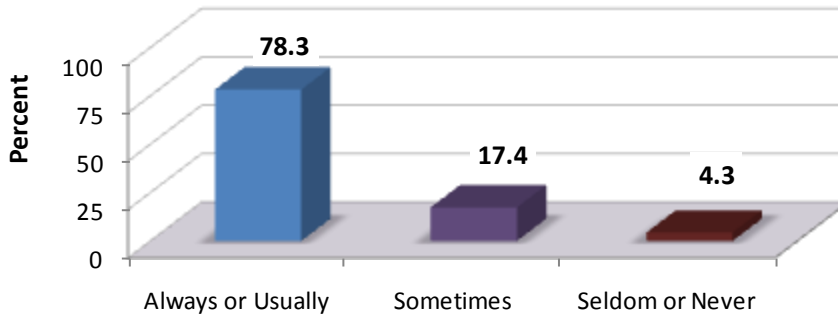
Chart Q8 Does your family member get the services and supports he/she needs?



2008-09 Average for 12 States

Table Q8					
Does your family member get the services and supports he/she needs? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		85.8	13.4	0.8	381
IL		82.2	15.7	2.1	1086
LA		82.0	15.9	2.1	384
ME		85.0	13.5	1.5	467
MO		85.0	12.7	2.3	387
NM		80.8	17.8	1.3	381
PA		86.9	11.5	1.6	1068
WY		85.2	14.3	0.5	210
Margin of Error > 5%					
AZ		81.4	18.2	0.5	220
GA	↓	73.1	24.5	2.4	290
OH		84.8	13.8	1.4	217
SC		81.6	16.7	1.8	228
Total %		83.4	14.9	1.7	5,319
State Avg %		82.8	15.7	1.5	

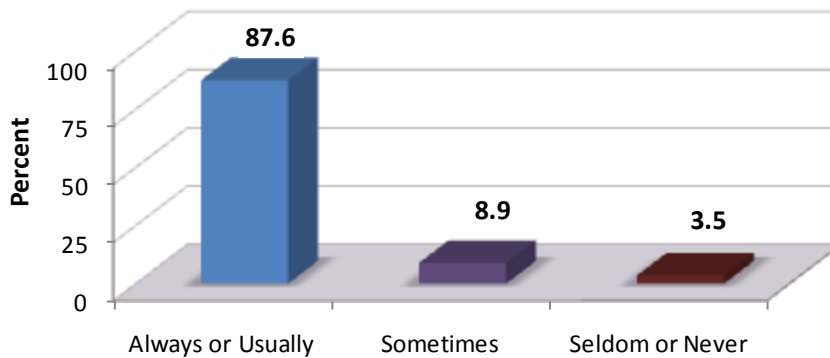
Chart Q9 If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?



2008-09 Average for 12 States

Table Q9					
If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT	↑	83.5	12.2	4.3	139
IL		77.1	17.3	5.6	410
LA		74.2	19.5	6.3	159
ME		77.1	20.0	2.9	175
MO		76.1	19.6	4.3	92
NM	↑	84.1	12.6	3.3	182
PA	↑↑	83.6	12.4	4.0	427
WY	↓↓↓	68.2	25.8	6.1	66
Margin of Error > 5%					
AZ	↑↑	87.7	9.4	2.8	106
GA	↓↓↓	66.3	27.2	6.5	92
OH		76.8	20.7	2.4	82
SC	↑	84.7	11.8	3.5	85
Total %		79.4	16.2	4.4	2,015
State Avg %		78.3	17.4	4.3	

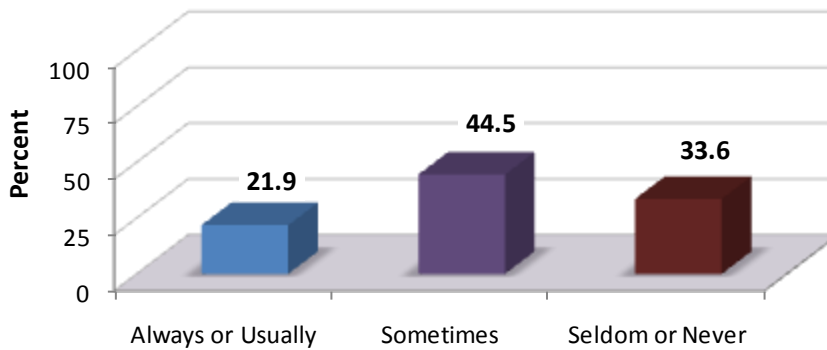
Chart Q10 Does your family member have access to the special equipment or accommodations that he/she needs?



2008-09 Average for 12 States

Table Q10					
Does your family member have access to the special equipment or accommodations that he/she needs? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		91.1	6.3	2.7	224
IL		86.7	10.3	3.0	630
LA		88.1	8.8	3.1	226
ME		85.8	12.8	1.4	288
MO		85.1	6.2	8.8	194
NM		83.1	13.3	3.5	255
PA		92.3	5.8	1.9	673
WY		89.7	9.4	0.9	117
Margin of Error > 5%					
AZ		89.5	6.0	4.5	133
GA	↓	79.4	15.3	5.3	131
OH		90.4	6.6	2.9	136
SC		89.4	6.5	4.1	123
Total %		88.0	8.8	3.1	3,130
State Avg %		87.6	8.9	3.5	

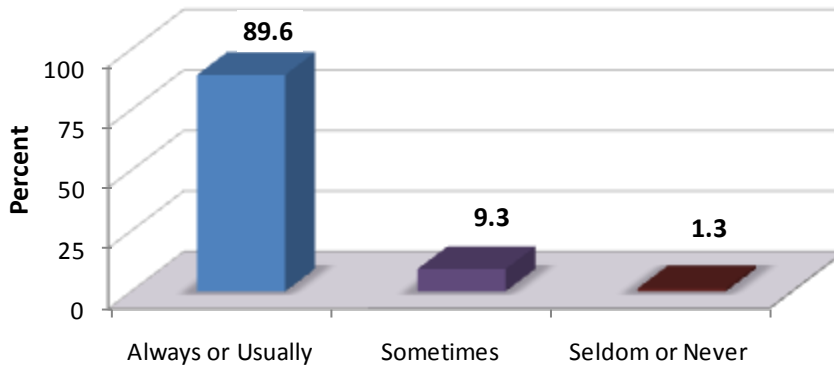
Chart Q11 Are frequent changes in support staff a problem for your family member?



2008-09 Average for 12 States

Table Q11					
Are frequent changes in support staff a problem for your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		18.0	48.3	33.6	327
IL		19.4	47.8	32.8	942
LA		21.3	36.9	41.9	320
ME		23.0	46.5	30.5	417
MO	↑	14.8	37.0	48.1	351
NM	↓	29.8	47.5	22.7	366
PA		23.2	42.5	34.3	918
WY	↓	27.1	54.8	18.1	199
Margin of Error > 5%					
AZ	↓	27.4	42.3	30.2	215
GA		22.8	44.0	33.2	250
OH	↑	15.0	42.2	42.8	187
SC		20.5	44.5	35.0	200
Total %		21.7	44.6	33.7	4,692
State Avg %		21.9	44.5	33.6	

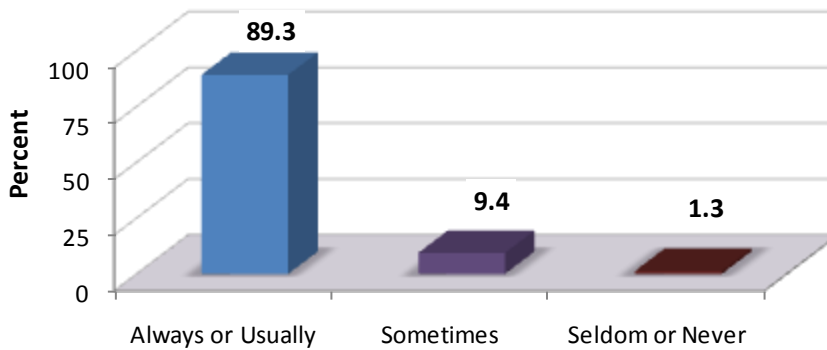
Chart Q12 Do you feel that your family member's residential setting is a healthy and safe environment?



2008-09 Average for 12 States

Table Q12 Do you feel that your family member's residential setting is a healthy and safe environment? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		89.1	10.1	0.8	385
IL		90.0	8.9	1.1	1111
LA		90.0	8.9	1.0	381
ME		91.4	7.5	1.1	466
MO		92.7	5.7	1.6	386
NM		86.0	13.2	0.8	385
PA		91.3	7.5	1.2	1149
WY		89.6	10.4		211
Margin of Error > 5%					
AZ		90.7	8.8	0.4	226
GA		86.7	11.2	2.0	294
OH		89.3	7.9	2.8	214
SC		87.8	10.9	1.3	229
Total %		90.0	8.9	1.2	5,437
State Avg %		89.6	9.3	1.3	

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



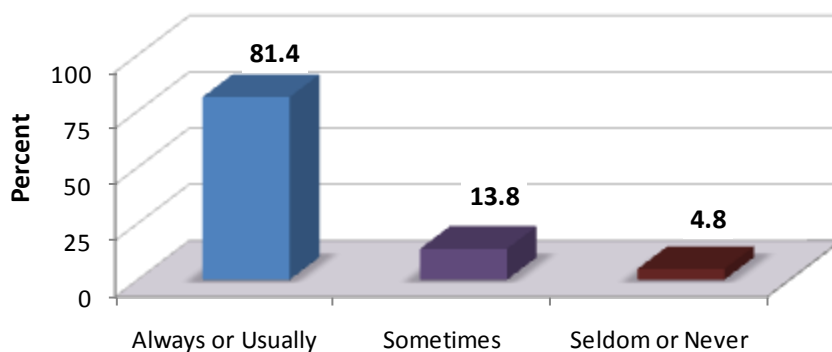
2008-09 Average for 12 States

Table Q13					
Do you feel that your family member's day/employment setting is a healthy and safe environment? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		91.4	7.5	1.1	348
IL		91.0	7.6	1.4	1015
LA		88.9	10.0	1.1	280
ME		92.0	7.5	0.6	362
MO		90.0	7.7	2.3	260
NM	↓	83.5	15.6	0.9	340
PA		92.6	6.6	0.8	861
WY		90.1	9.4	0.5	191
Margin of Error > 5%					
AZ		90.6	8.0	1.4	212
GA	↓	82.0	15.1	2.9	245
OH	↑	94.4	5.1	0.5	195
SC		84.8	12.8	2.4	211
Total %		90.0	8.8	1.2	4,520
State Avg %		89.3	9.4	1.3	

Choices and Control

- Among families where the individual with disabilities received residential services, 81% of respondents stated that the agency involved them in important decisions. Another 14% stated that this happens some of the time, and 5% said the agency seldom or never involved them in important decisions.
- Among families where the individual with disabilities received day or employment services, 66% of respondents stated that the agency involves them in important decisions. Another 22% stated that this happens sometimes, and 12% said the agency seldom or never involves them in important decisions.
- On average across states, two-thirds of respondents (66%) seldom or never chose the support staff who work with their family members.
- Across states, only 13% of respondents said that they had control or input over the hiring and management of their support staff, with an additional 11% indicated they had this type of control sometimes. Seventy-six percent (76%), however, had little or no input or control over the hiring or management of their family's support staff.
- While only 24% of respondents said they had any amount of control over the hiring or management of their support workers, here 65% of respondents indicate that they want some control over the hiring and management of their support staff.
- Forty-two percent (42%) of respondents, on average, knew how much money was spent on behalf of their family member at least some of the time. Fifty-eight percent (58%), however, had no idea.
- On average across states, almost half of the families surveyed (49%) had at least some decision-making authority over how the money allocated to their family member with disabilities by the MR/DD agency was spent. The majority (51%), however, did not.

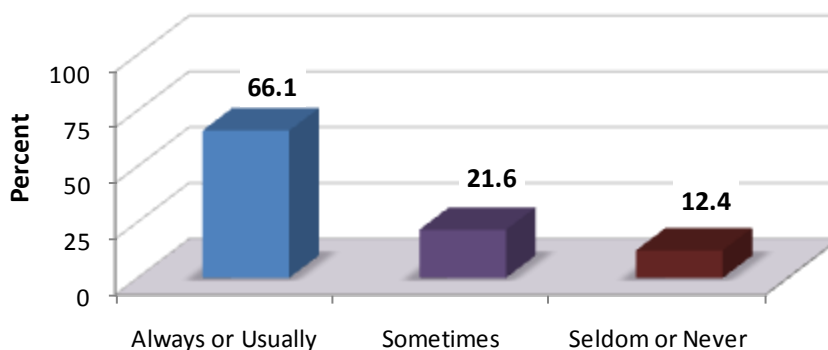
Chart Q14 Does the agency providing residential services to your family member involve you in important decisions?



2008-09 Average for 12 States

Table Q14					
Does the agency providing residential services to your family member involve you in important decisions? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		83.7	12.3	3.9	381
IL		84.4	13.2	2.5	1101
LA		82.0	13.6	4.4	361
ME	↑	87.9	10.3	1.7	464
MO		83.7	9.1	7.2	363
NM	↓	76.2	18.2	5.7	369
PA	↓	74.2	18.5	7.3	1066
WY	↑	89.6	9.9	0.5	212
Margin of Error > 5%					
AZ	↑	87.4	9.9	2.7	222
GA	↓↓	71.0	21.0	8.0	286
OH		81.1	14.1	4.9	206
SC	↓	75.3	15.7	8.9	235
Total %		80.9	14.3	4.8	5,266
State Avg %		81.4	13.8	4.8	

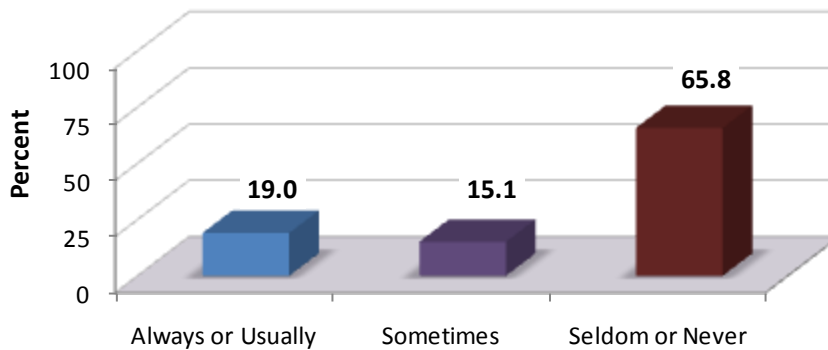
Chart Q15 If your family member gets day or employment services, does the agency providing these services involve you in important decisions?



2008-09 Average for 12 States

Table Q15					
If your family member gets day or employment services, does the agency providing these services involve you in important decisions? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		62.3	21.3	16.5	334
IL		69.1	22.9	8.0	949
LA		67.6	19.1	13.3	241
ME	↑↑	77.9	16.9	5.2	344
MO		63.7	13.2	23.1	234
NM		61.7	24.6	13.6	336
PA	↓	59.1	25.0	15.9	765
WY	↑	72.1	24.0	3.9	179
Margin of Error > 5%					
AZ	↑	74.4	19.5	6.2	195
GA	↓↓↓	54.2	28.6	17.2	238
OH		69.8	22.3	7.8	179
SC	↓	60.8	21.6	17.6	199
Total %		65.6	22.2	12.2	4,193
State Avg %		66.1	21.6	12.4	

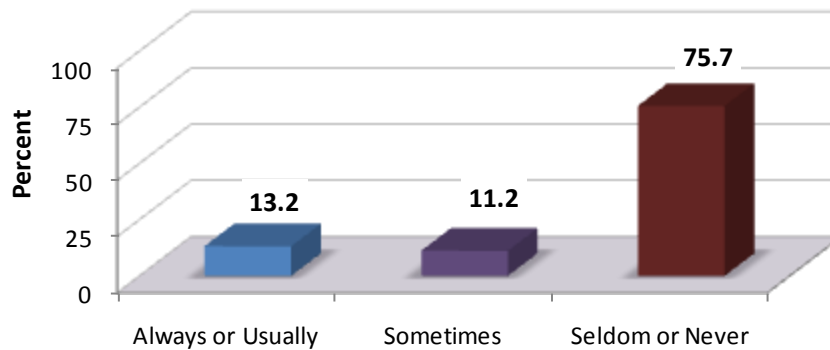
Chart Q16 Do you or your family member choose the support workers who work with your family member?



2008-09 Average for 12 States

Table Q16					
Do you or your family member choose the support workers who work with your family member? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT	↓	9.1	13.6	77.3	286
IL		15.0	10.2	74.8	893
LA	↑↑	33.6	14.8	51.6	304
ME		17.8	19.5	62.7	365
MO	↓	11.9	10.8	77.3	344
NM	↑	25.1	22.6	52.3	350
PA		14.8	8.2	77.0	844
WY	↑↑	29.2	21.0	49.7	195
Margin of Error > 5%					
AZ		16.5	17.6	66.0	188
GA	↓	13.5	17.8	68.7	230
OH		16.9	14.1	68.9	177
SC	↑	25.1	11.5	63.4	183
Total %		17.8	13.6	68.6	4,359
State Avg %		19.0	15.1	65.8	

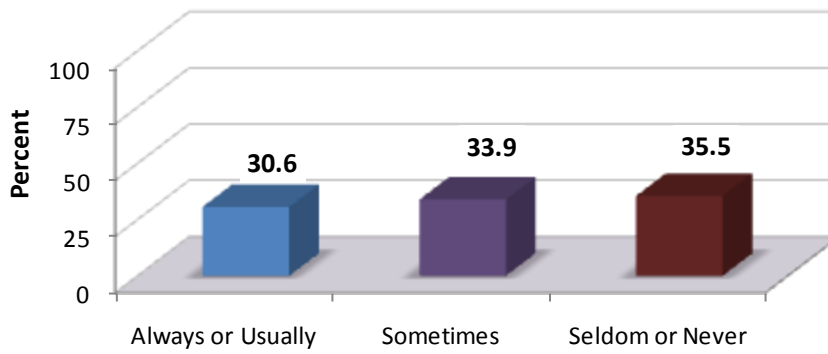
Chart Q17 Do you or your family member have control and/or input over the hiring and management of your support workers?



2008-09 Average for 12 States

Table Q17					
Do you or your family member have control and/or input over the hiring and management of your support workers? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT	↓	5.5	8.0	86.5	289
IL	↓	7.0	5.7	87.2	838
LA	↑↑	30.9	16.1	53.0	304
ME		11.1	12.3	76.6	351
MO	↓	7.2	9.9	82.9	333
NM	↑↑	21.0	17.8	61.2	343
PA	↓	7.9	7.0	85.0	782
WY		16.4	14.2	69.4	183
Margin of Error > 5%					
AZ	↓	5.9	10.6	83.5	188
GA		11.2	12.5	76.3	224
OH		16.1	10.1	73.8	168
SC		17.8	9.8	72.4	174
Total %		11.7	10.1	78.2	4,177
State Avg %		13.2	11.2	75.7	

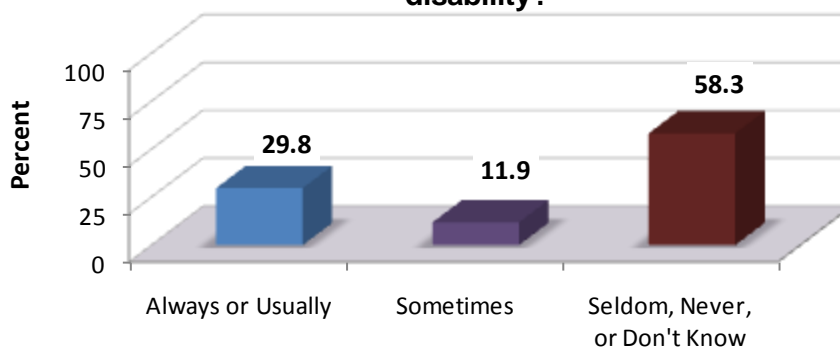
Chart Q18 Do you or your family member want to have control and/or input over the hiring and management of your support workers?



2008-09 Average for 12 States

Table Q18 Do you or your family member want to have control and/or input over the hiring and management of your support workers? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT	↓	24.8	40.3	34.9	238
IL	↓	21.8	34.8	43.4	779
LA	↑↑	52.7	27.3	20.0	275
ME		30.8	35.1	34.1	328
MO	↓↓	14.4	22.2	63.4	306
NM	↑↑	42.1	34.6	23.4	321
PA	↓	24.0	33.6	42.5	697
WY		28.6	33.3	38.1	168
Margin of Error > 5%					
AZ	↓	21.9	38.4	39.7	146
GA	↑	39.9	35.7	24.4	213
OH		30.3	36.4	33.3	165
SC	↑	36.3	35.0	28.8	160
Total %		28.8	33.6	37.6	3,796
State Avg %		30.6	33.9	35.5	

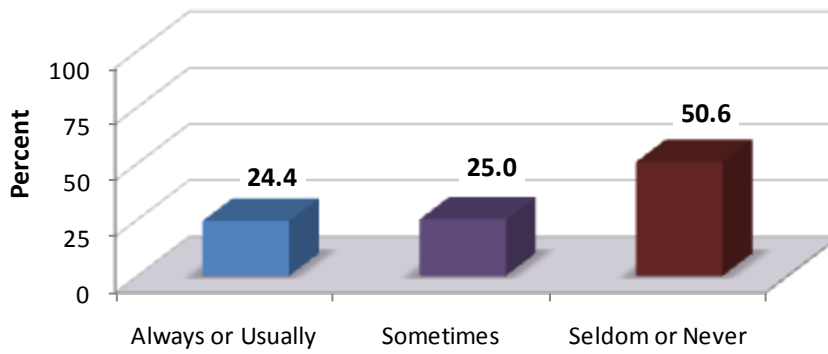
Chart Q19 Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?



2008-09 Average for 12 States

Table Q19					
Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability? (%)					
State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	N
Margin of Error ≤ 5%					
CT	↓↓	17.9	12.6	69.5	358
IL		26.4	10.7	62.9	1052
LA		25.6	8.5	65.9	363
ME	↓	23.8	12.1	64.1	437
MO	↓	23.9	8.6	67.5	372
NM	↑↑	40.4	13.6	46.0	374
PA	↓↓	15.2	9.5	75.3	1021
WY	↑↑	77.9	13.2	8.8	204
Margin of Error > 5%					
AZ		28.5	12.7	58.7	228
GA	↓↓	16.5	18.3	65.1	278
OH		31.0	12.3	56.6	203
SC		30.0	10.6	59.4	227
Total %		26.1	11.3	62.6	5,117
State Avg %		29.8	11.9	58.3	

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



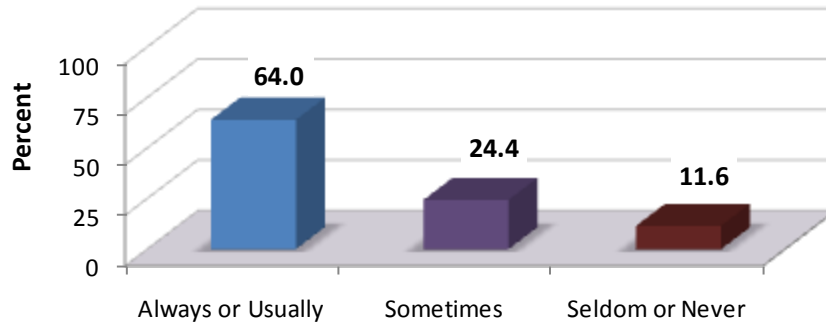
2008-09 Average for 12 States

Table Q20					
Do you or your family member get to decide how this money is spent? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT	↓↓↓	13.3	27.3	59.4	271
IL	↓	17.7	19.8	62.5	818
LA		25.2	22.9	51.9	258
ME		22.6	27.8	49.6	349
MO		26.2	18.4	55.4	294
NM	↑↑	42.4	29.1	28.5	330
PA	↓	14.6	19.4	65.9	751
WY	↑↑	39.4	33.7	26.9	193
Margin of Error > 5%					
AZ		25.1	22.9	52.0	179
GA	↓↓↓	13.5	27.9	58.5	229
OH		22.8	31.5	45.7	162
SC	↑	29.4	19.3	51.3	187
Total %		22.3	23.5	54.2	4,021
State Avg %		24.4	25.0	50.6	

Community Connections

- Sixty-four percent (64%) of respondents remarked that staff were usually able to help them connect with typical supports in their community (e.g., recreation programs, church activities) if they desired to do so. Twenty-four percent (24%) indicated that staff could sometimes help in this way, while 12% stated that staff rarely or never provided this type of assistance.
- Of families interested in using family or friends to provide some of the supports needed, 64% stated that planning or support staff were helpful in making this happen. The remaining 37% indicated that staff were only sometimes, seldom, or never capable of helping families utilize friends, neighbors, etc. as supports.
- Just over two-thirds (68%) of respondents felt that their family member typically had access to community activities.
- While 68% of families felt their family member had regular access to community activities, only 48% stated that their family member usually participated in these activities, although another 38% indicated that their family member sometimes took part in community events/activities.

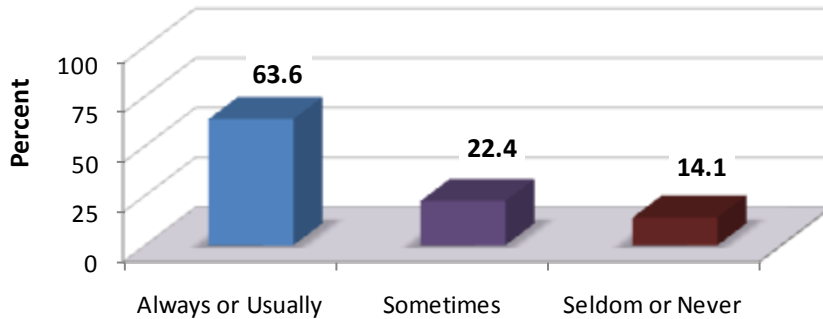
Chart Q21 If your family member wants to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?



2008-09 Average for 12 States

Table Q21					
If your family member wants to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT	↓	55.1	30.3	14.6	274
IL		64.3	24.7	11.0	819
LA		65.4	21.3	13.3	263
ME	↑↑	78.4	17.5	4.1	388
MO		67.6	19.3	13.1	321
NM		63.4	26.9	9.7	331
PA		62.3	26.4	11.3	708
WY		65.2	25.8	9.0	178
Margin of Error > 5%					
AZ		68.4	21.1	10.5	171
GA	↓↓	48.8	32.2	19.0	205
OH		62.2	27.8	10.0	180
SC		67.4	19.2	13.4	172
Total %		64.4	24.4	11.2	4,010
State Avg %		64.0	24.4	11.6	

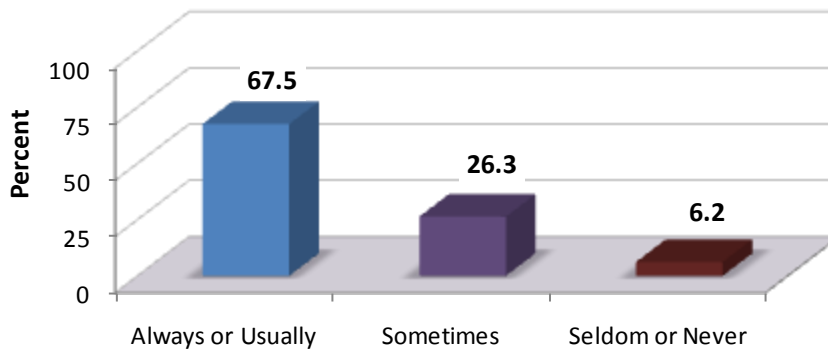
Chart Q22 If your family member would like to use family, friends, or neighbors to provide some of the supports he/she needs, do either the staff who help you plan or who provide support help him/her do this?



2008-09 Average for 12 States

Table Q22					
If your family member would like to use family, friends, or neighbors to provide some of the supports he/she needs, do either the staff who help you plan or who provide support help him/her do this? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT	↓	56.8	28.2	15.0	227
IL		62.0	23.0	15.0	726
LA		68.2	18.9	12.9	233
ME	↑↑	77.8	16.5	5.7	334
MO		62.9	19.0	18.1	232
NM	↓	57.9	27.9	14.1	290
PA		61.1	23.7	15.1	628
WY		66.9	24.2	8.9	157
Margin of Error > 5%					
AZ		67.1	17.1	15.8	152
GA	↓↓	47.0	26.5	26.5	185
OH		66.7	23.7	9.6	156
SC	↑	68.6	19.5	11.9	159
Total %		63.3	22.6	14.1	3,479
State Avg %		63.6	22.4	14.1	

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



2008-09 Average for 12 States

Table Q23					
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%					
CT		66.6	27.4	6.0	350
IL		62.8	30.5	6.7	1000
LA		65.0	26.2	8.7	343
ME	↑↑	78.4	19.3	2.2	450
MO	↑	76.9	17.1	6.0	368
NM		67.8	28.1	4.1	367
PA		67.1	27.4	5.5	999
WY	↑	73.7	22.0	4.4	205
Margin of Error > 5%					
AZ		64.9	29.4	5.7	211
GA	↓↓	54.0	36.9	9.1	252
OH		68.3	24.9	6.8	205
SC		64.9	26.4	8.7	208
Total %		67.3	26.7	6.0	4,958
State Avg %		67.5	26.3	6.2	

Chart Q24 Does your family member participate in community activities?

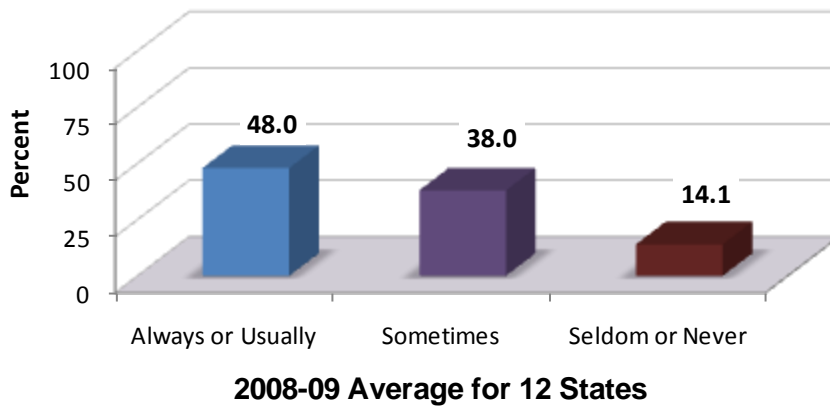
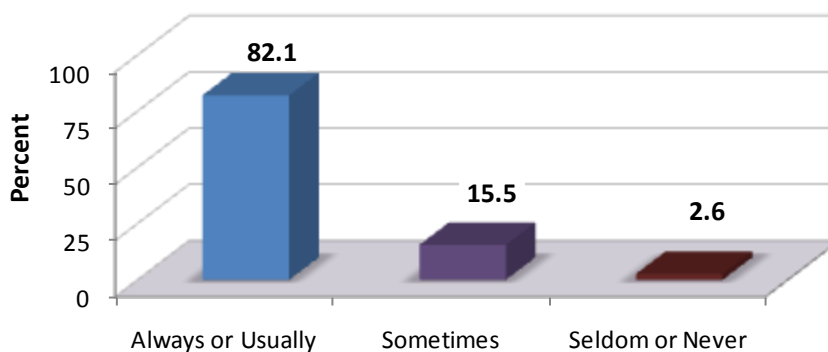


Table Q24 Does your family member participate in community activities? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		50.6	36.6	12.8	336
IL	↓	41.8	43.5	14.7	967
LA		46.0	35.0	19.0	326
ME	↑	56.3	34.0	9.8	430
MO	↑	53.7	32.6	13.7	365
NM		49.9	41.6	8.5	363
PA		43.2	40.6	16.3	929
WY	↑	53.0	37.0	10.0	200
Margin of Error > 5%					
AZ		46.8	40.9	12.3	203
GA	↓↓	35.9	44.5	19.6	245
OH		46.1	40.7	13.2	204
SC		52.2	29.1	18.7	203
Total %		46.8	39.0	14.2	4,771
State Avg %		48.0	38.0	14.1	

Outcomes and Satisfaction with Services and Supports

- On average, most respondents (82%) were satisfied with the services and supports their family member received. Sixteen percent (16%) were only somewhat satisfied, and 3% were seldom or not satisfied.
- On average, 62% of respondents knew about their agency's grievance process, 7% knew something about it, and 31% had seldom or no knowledge of the process for lodging a complaint.
- The majority of respondents (70%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 30%, however, were either not satisfied, or satisfied only some of the time with how these matters were resolved.
- The majority of respondents (85%) felt that services and supports had a positive impact on their family's life. Thirteen percent (13%) stated that services sometime made a positive difference, and the remaining 2% indicated that supports seldom or never had a positive impact.
- Eighty-two percent (82%) of respondents felt that their family member was happy. One percent (1%) indicated that their family member was seldom or never happy.

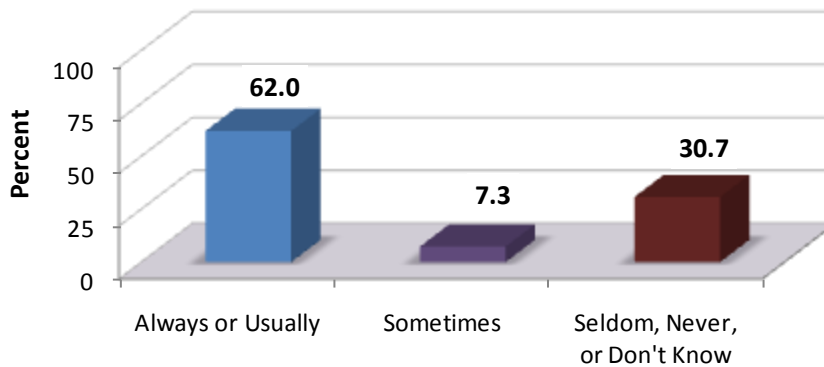
Chart Q25 Overall, are you satisfied with the services and supports your family member currently receives?



2008-09 Average for 12 States

Table Q25					
Overall, are you satisfied with the services and supports your family member currently receives? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		86.5	11.9	1.6	379
IL		82.8	14.4	2.9	1087
LA		83.5	13.9	2.6	389
ME		86.8	12.1	1.1	462
MO		85.9	10.0	4.1	390
NM	↓	74.9	22.5	2.6	387
PA		84.5	13.4	2.1	1144
WY		86.4	13.6	0.0	213
Margin of Error > 5%					
AZ		82.4	15.0	2.6	233
GA	↓↓	70.8	25.1	4.1	291
OH		82.9	15.3	1.9	216
SC		77.7	18.9	3.4	233
Total %		82.7	14.8	2.4	5,424
State Avg %		82.1	15.5	2.6	

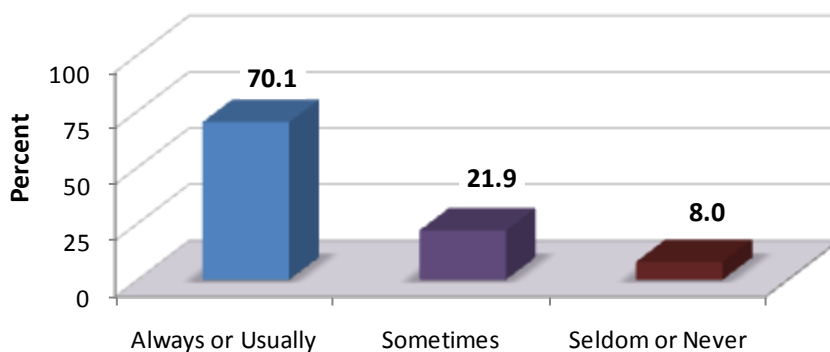
Chart Q26 Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?



2008-09 Average for 12 States

Table Q26 Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them? (%)					
State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	N
Margin of Error ≤ 5%					
CT	↓	56.4	7.7	35.9	337
IL		66.9	7.9	25.2	1026
LA		62.2	5.6	32.2	373
ME	↑	71.8	6.5	21.7	433
MO		58.6	4.8	36.6	372
NM	↑↑	76.5	6.1	17.4	375
PA	↓↓	50.1	7.5	42.3	1049
WY	↑	71.8	8.9	19.3	202
Margin of Error > 5%					
AZ		57.4	11.1	31.5	216
GA	↓↓	51.3	8.4	40.3	263
OH		66.2	5.3	28.5	207
SC	↓	54.3	8.1	37.6	221
Total %		61.3	7.3	31.4	5,074
State Avg %		62.0	7.3	30.7	

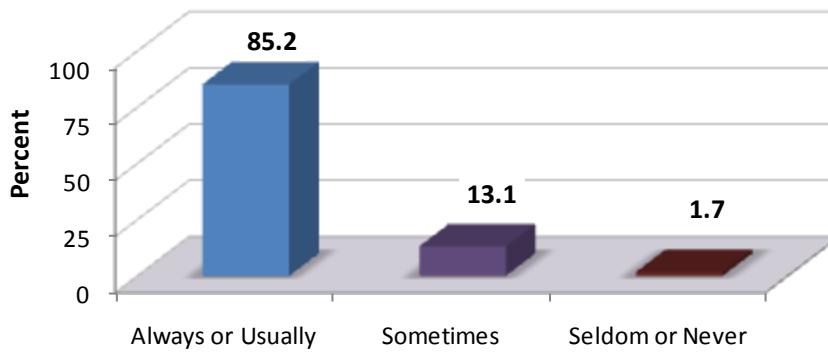
Chart Q27 Are you satisfied with the way complaints/grievances are handled and resolved?



2008-09 Average for 12 States

Table Q27					
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%					
CT		65.6	27.9	6.6	244
IL		69.3	23.6	7.2	794
LA		74.6	17.2	8.2	291
ME	↑	76.3	18.5	5.2	287
MO		73.2	16.1	10.7	205
NM		71.5	21.2	7.4	312
PA		72.3	19.9	7.8	664
WY		72.3	21.4	6.3	159
Margin of Error > 5%					
AZ		65.5	26.1	8.5	142
GA	↓↓	57.5	30.1	12.4	186
OH	↑	75.8	18.5	5.7	157
SC		67.8	22.2	9.9	171
Total %		70.6	21.7	7.8	3,612
State Avg %		70.1	21.9	8.0	

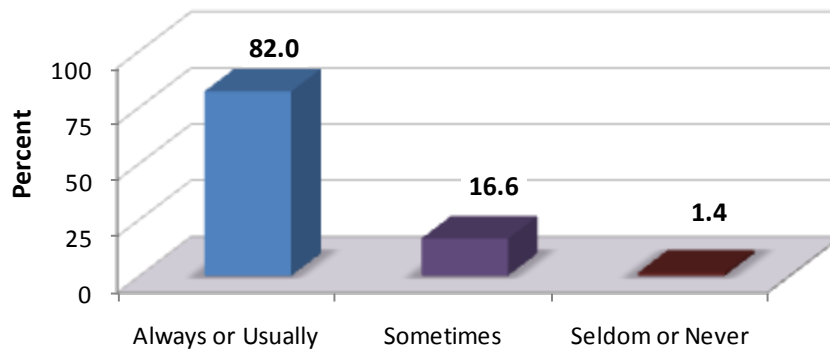
Chart Q28 Do you feel that services and supports have made a positive difference in the life of your family?



2008-09 Average for 12 States

Table Q28					
Do you feel that services and supports have made a positive difference in the life of your family? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		87.1	10.8	2.2	372
IL		84.9	13.4	1.7	1065
LA		84.9	14.3	0.8	385
ME		89.8	9.1	1.1	451
MO		87.0	10.4	2.6	384
NM		83.0	14.1	2.9	376
PA		83.9	13.7	2.4	1099
WY		85.6	13.9	0.5	209
Margin of Error > 5%					
AZ		86.9	12.6	0.5	222
GA	↓	79.2	19.4	1.4	283
OH		89.2	9.4	1.4	212
SC		80.9	16.1	3.0	230
Total %		85.1	13.1	1.8	5,288
State Avg %		85.2	13.1	1.7	

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



2008-09 Average for 12 States

Table Q29					
Overall, do you feel that your family member is happy? (%)					
State		Always or Usually	Sometimes	Seldom or Never	N
Margin of Error ≤ 5%					
CT		84.9	14.3	0.8	378
IL		83.2	15.1	1.8	1069
LA		81.7	17.5	0.8	388
ME		86.5	13.1	0.4	459
MO		84.6	12.6	2.8	389
NM		77.3	21.4	1.3	383
PA		82.2	16.0	1.8	1139
WY		84.8	14.7	0.5	211
Margin of Error > 5%					
AZ		81.0	18.6	0.4	226
GA		78.2	20.4	1.4	285
OH		81.7	16.4	1.8	219
SC		78.4	18.6	3.0	231
Total %		82.4	16.1	1.5	5,377
State Avg %		82.0	16.6	1.4	

Aggregate Results & State Comparisons

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

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

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

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

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

Information and Planning

- ◆ In Wyoming and Maine, responses to information and planning questions were generally above the overall state average.

Chart 5: Information and Planning

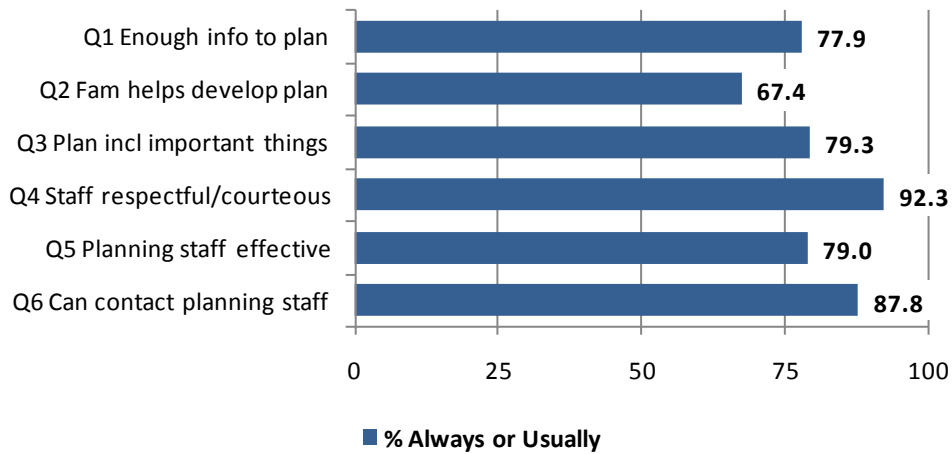


Table 16 Deviation in Responses Above & Below State Average: Information & Planning							
State	Q1	Q2	Q3	Q4	Q5	Q6	Net Sum
CT	↑	↓					0
IL							0
LA	↓	↓	↓				-3
ME	↑	↑	↑				3
MO							0
NM				↓	↓		-2
PA		↓↓	↓				-3
WY	↑	↑↑	↑			↑	5
AZ		↑↑					2
GA	↓↓		↓		↓↓	↓	-6
OH			↑				1
SC	↓						-1

Access and Delivery of Services

- ◆ In this series of questions, responses were generally consistent across states. However, Ohio tended to score somewhat higher than the state average.

Chart 6: Access to Services

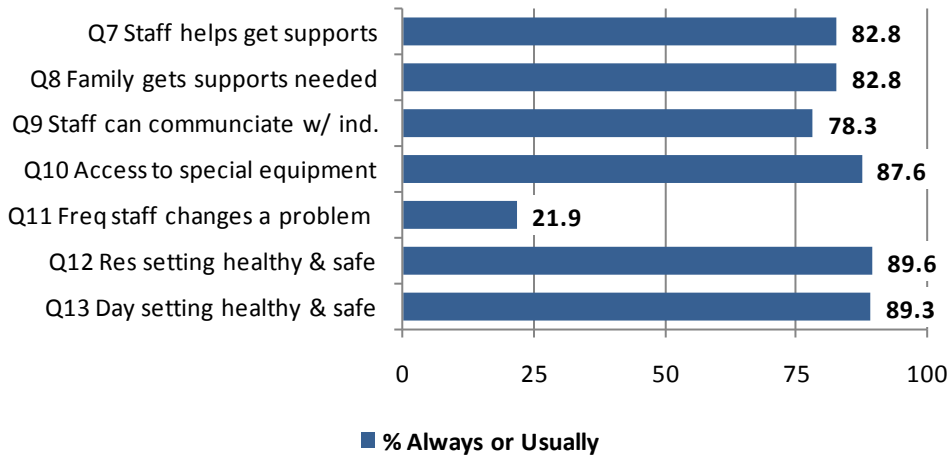


Table 17 Deviation in Responses Above & Below State Average: Access to Services & Supports								
State	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
CT			↑					1
IL								0
LA								0
ME								0
MO					↑			1
NM			↑		↓		↓	-1
PA			↑					1
WY	↑		↓↓↓		↓			-2
AZ			↑		↓			0
GA	↓	↓	↓↓↓	↓			↓	-6
OH					↑		↑	2
SC			↑					1

Choice and Control

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

Chart 7: Choice & Control



Table 18								
Deviation in Responses Above & Below State Average: Choice & Control								
State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Net Sum
CT			↓	↓	↓	↓↓	↓↓	-7
IL				↓	↓		↓	-3
LA			↑↑	↑↑	↑↑			6
ME	↑	↑↑				↓		2
MO			↓	↓	↓↓	↓		-5
NM	↓		↑	↑	↑↑	↑↑	↑↑	7
PA	↓	↓		↓	↓	↓↓	↓	-7
WY	↑	↑	↑↑			↑↑	↑↑	8
AZ	↑	↑		↓	↓			0
GA	↓↓	↓↓	↓		↑	↓↓	↓↓	-8
OH								0
SC	↓	↓	↑		↑		↑	1

Community Connections

- ◆ In Maine, responses to community connections questions were above the overall state average.

Chart 8: Community Connections

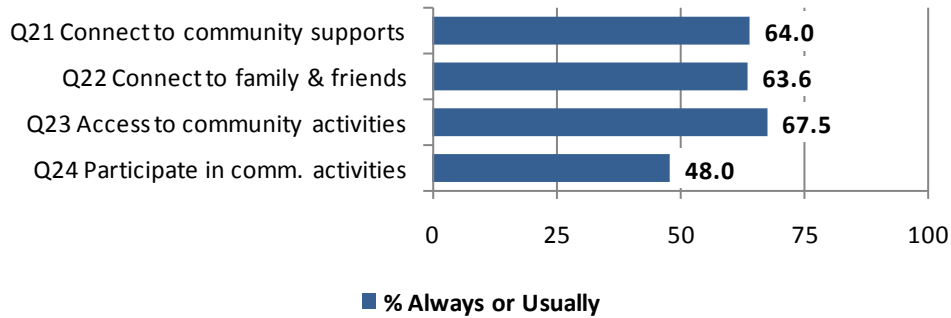


Table 19 Deviation in Responses Above & Below State Average: Community Connections					
State	Q21	Q22	Q23	Q24	Net Sum
CT	↓	↓			-2
IL				↓	-1
LA					0
ME	↑↑	↑↑	↑↑	↑	7
MO			↑	↑	2
NM		↓			-1
PA					0
WY			↑	↑	2
AZ					0
GA	↓↓	↓↓	↓↓	↓↓	-8
OH					0
SC		↑			1

Satisfactions with Services and Supports & Outcomes for Families

- ◆ In this series of questions on satisfaction and outcomes, responses were generally consistent across states. However, Maine tended to score somewhat higher than the state average.

Chart 9: Satisfaction & Outcomes

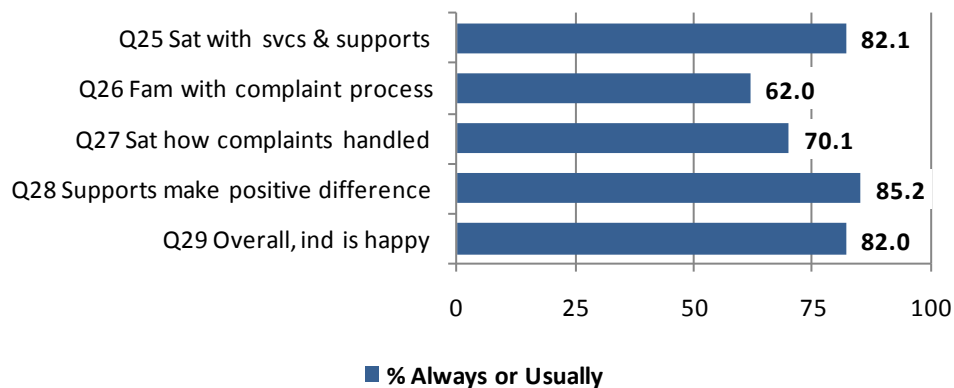


Table 20 Deviation in Responses Above & Below State Average: Satisfaction & Outcomes						
State	Q25	Q26	Q27	Q28	Q29	Net Sum
CT		↓				-1
IL						0
LA						0
ME		↑	↑			2
MO						0
NM	↓	↑↑				1
PA		↓↓				-2
WY		↑				1
AZ						0
GA	↓↓	↓↓	↓↓	↓		-7
OH			↑			1
SC		↓				-1

Overall State Results

- ◆ Looking at results across all categories, Maine and Wyoming consistently received results that were above the overall state average.

State	Information & Planning	Access	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
CT	0	-2	-7	-2	-1	-12
IL	0	-1	-3	-1	0	-5
LA	-3	0	6	0	0	3
ME	3	7	2	7	2	21
MO	0	3	-5	2	0	0
NM	-2	-1	7	-1	1	4
PA	-3	0	-7	0	-2	-12
WY	5	2	8	2	1	18
AZ	2	0	0	0	0	2
GA	-6	-8	-8	-8	-7	-37
OH	1	0	0	0	1	2
SC	-1	1	1	1	-1	1

APPENDIX A

Analysis of Open-Ended Comments

Additional Open-Ended Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. 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 Concerns

Families across the 12 states who conducted the Family Guardian Survey in 2008-09 wrote a wide array of comments. The following three areas were commented on the most:

Satisfied with Home

"My wife and I are completely satisfied with the care and support our daughter, (Individual receiving services), receives from (Residential Placement) at her group home. They are always extending themselves to involve us in decisions that affect (Individual)'s quality of life."

"We have been fortunate to have (Agency) looking after my daughter's group home. They have done an exemplary job of hiring responsible staff and caregivers under often adverse financial conditions."

"My sister had birth brain damage. We always cared for her at home until it became physically impossible for us due to aging. She is now living in a group home locally. This has saved us in so many ways. We visit with her at a minimum of twice a week."

"I certainly like the group home and workshop and the people employed there. I'm sure it must be a complex job to take care of a group. It is lot of work. All the group homes are great and have different personalities which make them more interesting."

"Family member participates in [state] host/life sharing program. This is a far better placement than a group home, providing more individual attention, better health monitoring and a family environment, with more normal social opportunities."

"Overall we are extremely happy with our daughter's care and support. She is in a group home in [provider]. The staff is great in dealing with her and us. This has given our daughter a better sense of independence and maturing. She is honestly, sometimes quite difficult, anger issues and bizarre behaviors. The staff is amazing with her and in spite of herself; they always treat her with respect and kindness."

"We the parents of a group home resident feel at peace, especially at our advancing ages, knowing our child is well care for in a safe, protective environment. We have seen many changes over the years leading up to the final stage - "group homes," a more normal way of life for the young and older adults who reside in them. It's been a positive experience and we are grateful this has come about in our daughter's lifetime and ours."

"I am very grateful for (residential placement). Every time I visit the facility my family member is always clean and the staff is very friendly and helpful. They answer any and all of my questions. I do not know what we would do without this facility."

"My brother, (individual receiving services) is a resident at the (Residential placement) in (city), (state). He is getting the utmost best of care. The staff is wonderful with him. I have observed many of the staff members with him and they are trained very well to handle him. They contact me in the decision making of any changes and have me very involved for the best of care. This facility is very clean, they serve great food. I can't praise the staff enough for taking such good care of our family member. I thank God every day for this MRDD facility."

Satisfied with Support Staff

"The staff that works with my son at the group home seems very efficient and is always nice and gracious to me. I feel my son is happy being in the group home. The home always calls to let me

know whatever and whenever my son experiences something negative. (ie. seizures, bruises or other mishaps.)”

“My daughter’s personal care provider [agency] (the caregiver who works with her daily) is incredible. She is part of our extended family. I want agencies to stay focused on retention programs.”

“I have been very pleased with the care and programming my son has received throughout the years. The staff is very caring and concerned and has enabled my son to have a happy life. I certainly appreciate all of those who contribute at whatever level to my son’s life, and I am thankful to the state of [name] for providing this care.”

“I am extremely pleased with the services provided. Everyone in the support team is qualified in what they do, plus each one seems to really care about the work they do. It gives me a great deal of peace of mind to know that my family member is being provided with excellent care.”

“The services provided to our family member meet this family’s satisfaction. It is well knowing each time we visit our family member, she is, and appears to be happy with the staff providing care for her. I personally want to thank this organization for providing care to their clients in a manner that meets the goals of all those involved in the process.”

“We are very happy with the care our son receives. The case worker who works with him is wonderful. They truly took a very disturbed and troubled individual and turned his life around. They are truly angels.”

“I am extremely well pleased with the care [consumer] is receiving. The staff in his group home goes way beyond what they are paid to do. They are always finding ways to get him involved in community activities which really improves the quality of his life.”

“My brother is mild to moderately retarded and has emotional and mental illness. I just want to thank the staff for their hard work in creating the loving home environment my brother enjoys. The staff goes out of their way to keep me informed. The counseling my brother has received along with a staff who really cares has created an environment my brother is very happy and content with.”

“I couldn’t be happier with the services my sister receives. [Provider Name] has truly been a blessing to my sister, and to me. I have a great relationship with them, and I know they truly understand (individual receiving services). They truly make me feel that I have their support as I try to provide my sister with the best quality of life that I can. I am the only sibling, and our parents are both deceased. Everyone who helps me care for (individual receiving services) is like extended family. I am blessed!”

“The services and advisors that work with my brother are excellent. The advisors are professional and very aware of his needs. All of the staff that we’ve dealt with have been a benefit to the program and are genuinely concerned about what’s best for the client. It is certainly a well managed program, in my opinion. Keep up the great work!”

Information Regarding Services/Supports

“1. Need more information on long-term planning when family can no longer provide support. 2. Many people do not realize they can get waiver money to support a child living independently. Since this money is often used by parent to pay for child’s expenses this should be discussed early on with parent, at least when child is in high school. Parents worry how to fund a child who can/wants to live independently in community, and knowing there is a funding source would relieve a lot of parental anxiety.”

“I have requested for copies or something to see what all is her money used for but was unable to get it. I would like for my own purpose like to get monthly reports or something seeing where her money goes, and what it is spent on.”

“Fortunately, we never needed to file a grievance. Where my son lives, I would go directly to the people in charge, but I would not know how to file a grievance at this day program. I would probably go to file with the Director, in any case, I would find out the procedure.”

“As parent, we would like to have control over hiring support staff, be aware of the cost of care and decide how to use the money. Information on how to handle finances would be appreciated.”

“Some discussion on the services received at mental health would be helpful. Focus group has been very helpful.”

“I would like to see a booklet of the rules and regulations that institutions must follow to get their funding. I would also like to know what rights my sister has. What she should expect, etc.”

“What kinds of services are available specifically for adults with autism? It's like after 18, they are thrown altogether and it just doesn't work. Things don't just magically change because now they are considered adults.”

“It is very important to inform the family of all options with disabled individuals who live in residential/agencies that provide/offer services.”

“I think information on how much money is being spent by the [state agency] on behalf of family members should be available to the DD individual and their families. We do not know anything about this so it would be difficult to decide how best to spend any money. I know there are a lot of DD individuals in the same program as my brother and I know they need things but don't have money, (or so they are told).”

“Could there be a central location for information? For families it is almost impossible to gather information we need. Add the codes and we are left scratching our head. I'm sad to say that [regional office name] has not given much support at all.”