Family Guardian Survey

Final Report – April 2011
2009-2010 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

Six states conducted the National Core Indicators (NCI) Family Guardian Survey during the 2009-2010 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 30, 2010.

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, satisfaction and outcome data.

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. From 2002 to the present, the NCI effort has continued to expand. The following figure summarizes state participation in the National Core Indicators since its inception through the 2009-10 data collection cycle. States are listed if they collect data from one more of the NCI survey tools (e.g., consumer survey, family surveys, etc.) during the data collection cycle.

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	Phase XII 2009-10
AZ	AZ	AZ	AL	AL	AL	AL	AL	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	AR	AR	AR	AR	AR
MO	KY	DE	CA-RCOC	CA_RCOC	CA_RCOC	CA_RCOC	AZ	AZ	AZ	AZ	AZ
NE	MA	IA	CT	CT	CT	CT	CA-RCOC	CA-RCOC	CA-RCOC	CT	CA-RCOC
PA	MN	KY	DE	DE	DE	DE	CT	CT	CT	DE	DC
VT	NE	MA	HI	HI	DC	DC	DE	DE	DE	GA	FL
VA	NC	MN	IL	IN	HI	HI	DC	GA	GA	HI	GA
	PA	MT	IN	IA	IN	KY	GA	HI	HI	IL	IL
	RI	NE	IA	KY	KY	MA	HI	IN	IN	IN	KY
	VT	NC	KY	MA	MA	ME	KY	KY	KY	KY	LA
	VA	PA	MA	ME	ME	NC	MA	MA	LA	LA	ME
	WA	RI	NE	NE	NE	OK	ME	ME	MA	MA	MO
		UT	NC	NC	NC	PA	NC	NM	ME	ME	NC
		VT	OK	OK	ND	RI	OK	NC	MO	MO	NH
		WA	PA	PA	OK	SC	PA	OK	NC	NC	NJ
			RI	RI	PA	VT	RI	PA	NJ	NJ	NY
			UT	SC	RI	WA	SC	RI	NM	NM	OH
			VT	SD	SC	WV	SD	SC	NY	NY	OH-HC
			WA	VT	SD	WY	TX	TX	OK	OH	OH-MC
			WV	WA	VT		VT	VT	PA	OH- HC	OH-MEORC
			WY	WV	WA		WA	WA	RI	OH- MC	OK
				WY	WV		WV	WV	SC	OH-MEORC	PA
					WY		WY	WY	TX	OK	TX
									VT	PA	WA
									WA	SC	WY
									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 original 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 familes/guardians of individuals not living at home who report the extent to which the system supports continuing family involvement.	Family/Guardian Survey
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	All Surveys
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Children & Adult Family Surveys

II. 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 instruction 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 2010, six 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 the first year of data collection in 2000.

Table 3
State Participation in NCI Family Guardian Survey
(Adults Living Out-of-Home)

Phase II	Phase III	Phase IV	Phase V	Phase VI	Phase VII	Phase VIII	Phase IX	Phase X	Phase XI	Phase XII
1999-2000	2000-2001	2001-2002	2002-2003	2003-2004	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010
CT	AZ	CA-RCOC	AZ	AZ	AZ	CA-RCOC	AZ	GA	AZ	GA
KY	DE	HI	CA-RCOC	CA-RCOC	CA-RCOC	CT	CT	LA	CT	LA
MN	MA	NE	HI	CT	CT	GA	DE	ME	GA	ME
NE	MN	NC	IN	ME	HI	ME	GA	MO	IL	NH
PA	NC	PA	MA	NC	PA	NC	HI	NC	LA	PA
VA	PA	UT	NC	ND	SC	PA	ME	NJ	ME	WA
WA	RI	WA	PA	PA	WY	SC	NM	PA	MO	
			SC	SC		SD	PA	CA-RCOC	NM	
			SD	WA		WA	WY	SC	OH	
			WY	WY		WY		WA	PA	
								WY	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 2009-2010 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.

In order to better align the NCI indicators with CMS waiver assurances, the 2009-10 survey included nine questions that were added or revised from the 2008-09 version.

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. A final sample size of 400 would guarantee a 5% margin of error and a 95% confidence level when interpreting the results (see the "Results" section for more information on

margin of error). In states where there were fewer than 1,000 potential respondent families, states were asked that surveys be 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 2009-10, six states administered the Family Guardian Survey and have their data included in this report. 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
Georgia	1,796	345	19%	291
Louisiana	1,500	567	38%	556
Maine	1,469	490	33%	488
New Hampshire	1,212	511	42%	436
Pennsylvania	3,600	1,198	33%	1,126
Washington	1,217	557	46%	475
Overall	**10,794**	**3,668**	**34%**	**3,372**

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. 18) software for statistical analysis.

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 six 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 a final sample where the margin of error was greater than 7%. Georgia was the only state that submitted a final sample that resulted in a margin of error of between the standard 5% and 7%. While included in the analysis, their results should be interpreted with greater caution than the other states (see below).

The term "margin of error" is also known as the "confidence interval." A margin of error of 5% means we can be confident 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 *level* 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

- Six states provided data sets to be included in the Final Report. They include Georgia, Louisiana, Maine, New Hampshire, Pennsylvania, and Washington.

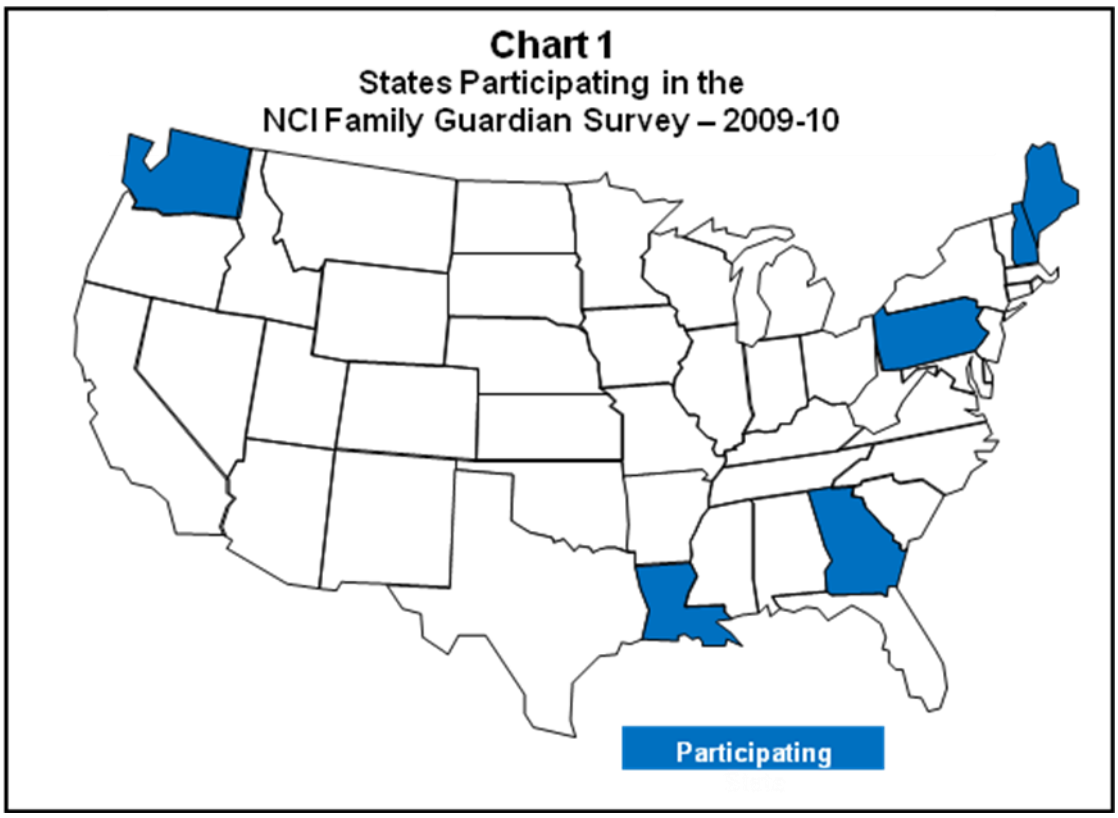


Chart 1
States Participating in the
NCI Family Guardian Survey – 2009-10
Participating

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, the majority (45%) of the family members with disabilities lived in group home settings. Nineteen percent (19%) lived in their own homes or apartments, 12% lived in specialized ID facilities, another 12% lived in adult foster care or host family homes, 5% in a variety of other settings, 4% lived in agency-owned apartments, and 2% in nursing homes.

- On average, 58% of family members were male across the participating states. The remaining 42% were female.

- Across states, the average age of family members with disabilities was 46, with a range in age from 18 to 100.

- On average, 88% of the family members were White, 9% were Black/African American, while all the other race/ethnicity categories (American Indian/Alaska Native, Asian, Native Hawaiian/Pacific Islander, Hispanic/Latino, Two or More Races, Other or Unknown) each had less than 2% (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 intellectual disability (20% and 13% respectively). Additionally, 29% were individuals with moderate intellectual disability, 16% had mild intellectual disability, and 5% had no intellectual disability diagnosis. Additionally, 18% of respondents were unsure of their family member's diagnosis.

- In addition to an intellectual disability, 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 (28%), mental illness (26%), vision or hearing impairments (23%), communication disorders (23%), and cerebral palsy (17%).

Type of Residence

Chart 2. Type of Residence

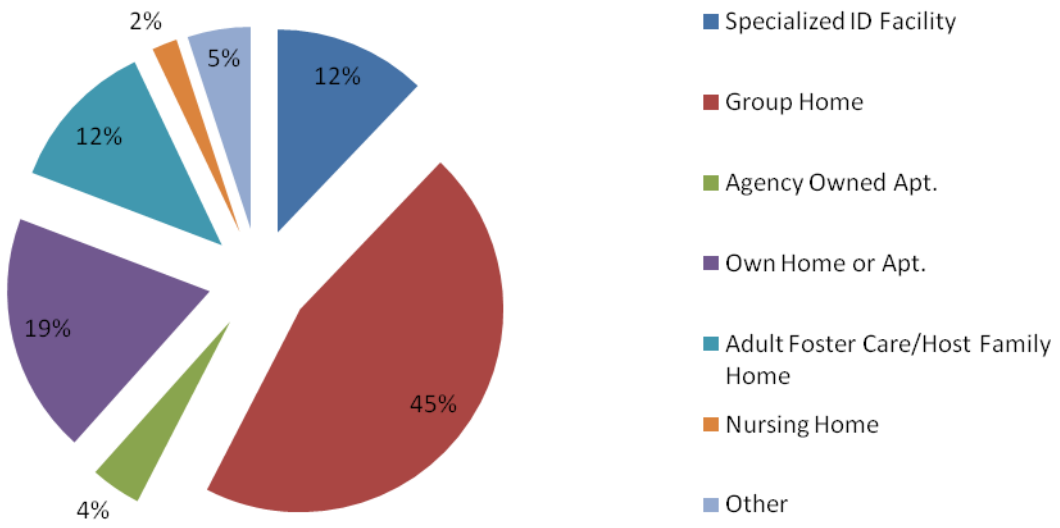


Table 5 Type of Residence in Which Family Member Lives (%)							
State	**Specialized ID Facility**	**Group Home**	**Agency Owned Apartment**	**Own Home or Apartment**	**Adult Foster Care or Host Family Home**	**Nursing Home**	**Other**
GA	6.9	47.9	4.5	20.1	15.6	0.7	4.2
LA	30.4	52.7	1.1	12.5	0.2	0.4	2.8
ME	13.9	50.9	7.6	10.1	9.3	4.8	3.4
NH	2.4	26.0	2.9	28.3	31.7	0.2	8.6
PA	15.5	53.7	3.3	12.8	4.8	5.5	4.5
WA	4.8	40.3	5.7	32.6	8.3	0.7	7.7
Total N	**453**	**1,549**	**129**	**583**	**314**	**91**	**163**
Total %	**13.8**	**47.2**	**3.9**	**17.8**	**9.6**	**2.8**	**5.0**
State Avg %	**12.3**	**45.3**	**4.2**	**19.4**	**11.7**	**2.1**	**5.2**

Gender of Family Member

Table 6 Gender (%)		
State	**Male**	**Female**
GA	56.3	43.7
LA	58.2	41.8
ME	58.6	41.4
NH	64.8	35.2
PA	57.6	42.4
WA	54.4	45.6
Total N	**1,904**	**1,367**
Total %	**58.2**	**41.8**
State Avg %	**58.3**	**41.7**

Age of Family Member

Table 7 Age of Family Member (%)		
State	**Average Age**	**Range**
GA	43.7	19-91
LA	46.7	18-87
ME	47.2	20-100
NH	45.1	19-85
PA	48.7	18-91
WA	46.2	19-91
Total N	**3,362**	
Total %	**46.9**	**18-100**
State Avg %	**46.3**	

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**	**Two or More Races**	**Other/ Unknown**	**Hispanic/ Latino**
GA	72.2	26.8	0.7	1.8	0.0	0.0	0.4	0.0
LA	77.0	21.0	0.5	1.1	0.0	0.5	0.2	0.2
ME	96.2	0.0	0.4	1.9	0.0	1.0	0.4	0.0
NH	96.7	1.2	0.9	1.7	0.2	0.7	0.0	0.2
PA	95.2	2.8	0.4	0.8	0.0	0.5	0.1	0.5
WA	89.2	2.8	2.8	2.3	0.2	2.3	3.2	1.9
Total N	**2,961**	**241**	**28**	**47**	**2**	**28**	**20**	**16**
Total %	**89.6**	**7.3**	**0.8**	**1.4**	**0.1**	**0.8**	**0.6**	**0.5**
State Avg %	**87.8**	**9.1**	**1.0**	**1.6**	**0.1**	**0.8**	**0.7**	**0.5**

Level of Intellectual Disability of Family Member

Chart 3. Level of ID

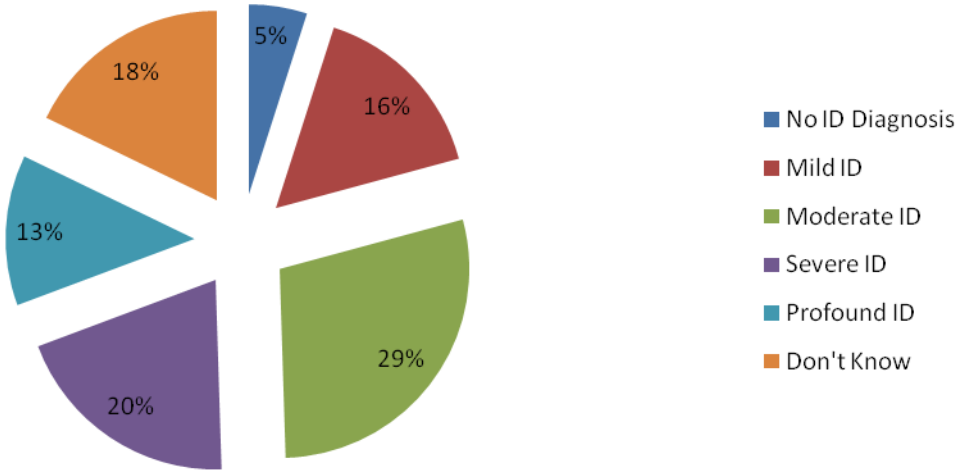


Table 9 Level of Intellectual Disability of Family Member (%)						
State	**No ID Diagnosis**	**Mild ID**	**Moderate ID**	**Severe ID**	**Profound ID**	**Don't Know**
GA	1.8	16.4	27.0	20.3	16.7	17.8
LA	3.2	12.4	21.7	26.0	19.1	17.6
ME	2.2	16.0	34.1	17.7	14.3	15.8
NH	12.5	17.5	29.6	18.5	6.5	15.4
PA	2.1	17.8	26.6	18.9	15.6	18.9
WA	6.5	13.3	35.3	18.1	7.4	19.4
Total N	**137**	**513**	**923**	**643**	**445**	**575**
Total %	**4.2**	**15.9**	**28.5**	**19.9**	**13.8**	**17.8**
State Avg %	**4.7**	**15.6**	**29.1**	**19.9**	**13.3**	**17.5**

Other Disabilities of Family Member

Table 10A Other Disabilities of Family Member (%)							
State	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency	Vision/ Hearing Impairment
GA	27.0	12.0	16.6	8.5	29.7	0.4	20.1
LA	26.9	7.4	14.4	13.1	30.5	0.9	25.8
ME	25.5	15.8	18.4	9.3	29.8	0.4	24.6
NH	24.0	12.1	16.5	17.9	30.0	0.7	25.2
PA	25.9	12.2	16.5	10.9	33.0	0.8	25.0
WA	25.6	15.3	17.4	6.7	26.7	0.5	19.5
Total N	**813**	**388**	**522**	**325**	**964**	**21**	**755**
Total %	**25.8**	**12.3**	**16.6**	**11.2**	**30.6**	**0.7**	**24.0**
State Avg %	**25.8**	**12.5**	**16.6**	**11.1**	**30.0**	**0.6**	**23.4**

Table 10B Other Disabilities of Family Member (%)							
State	Physical Disability	Communi-cation Disorder	Alzheimer's Disease	Down Syndrome	Other Disability	No Other Disability	Don't Know
GA	25.5	23.2	0.8	12.7	11.6	10.8	13.6
LA	26.5	25.8	2.1	11.7	18.8	7.2	13.6
ME	29.6	25.1	1.9	15.8	16.0	4.8	5.4
NH	31.7	23.7	2.2	12.8	19.4	4.1	5.0
PA	29.8	19.8	1.3	10.8	14.7	5.4	11.8
WA	27.4	17.4	1.2	10.9	20.0	10.9	8.5
Total N	**907**	**695**	**50**	**382**	**524**	**209**	**320**
Total %	**28.8**	**22.1**	**1.6**	**12.1**	**16.6**	**6.6**	**10.0**
State Avg %	**28.4**	**22.5**	**1.6**	**12.5**	**16.8**	**7.2**	**9.7**

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 (61%) fell between the ages of 55 and 74. Nineteen percent (19%) of respondents were 35 to 54 and an additional 19% were 75 years or older. Only 2% were under 35 years old.

- Fifty-six percent (56%) of respondents were parents of adult children with disabilities. Thirty percent (30%) were siblings, less than 1% were spouses, and the remaining 14% 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: 15% saw their family member 7 to 12 times per year, 14% visited their family member four to six times per year, 10% saw their family member one to three times per year, and the remaining 4% less than once per year.

- The majority of respondents (70%) indicated that they were their family member's legal guardian or conservator. This varied by state. In Maine, all respondents served as their family member's guardian (100%), while in Pennsylvania 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**
GA	2.8	16.7	67.6	12.8
LA	1.6	20.7	57.9	19.8
ME	0.8	18.1	62.4	18.7
NH	0.9	21.9	59.0	18.2
PA	1.5	19.7	57.2	21.6
WA	3.0	15.4	60.9	20.7
Total N	**56**	**631**	**1,980**	**648**
Total %	**1.7**	**19.0**	**59.7**	**19.5**
State Avg %	**1.8**	**18.8**	**60.8**	**18.6**

Relationship of Respondent to Individual with Disabilities

Table 12 Relationship to Individual with Disabilities (%)				
State	**Parent**	**Sibling**	**Spouse**	**Other**
GA	54.7	28.4	0.0	17.0
LA	53.9	30.5	0.2	15.4
ME	57.9	30.8	0.2	11.1
NH	61.3	27.1	0.7	10.9
PA	52.4	39.9	0.4	7.3
WA	56.3	23.5	0.0	20.3
Total N	**1,841**	**1,066**	**9**	**410**
Total %	**55.4**	**32.1**	**0.3**	**12.3**
State Avg %	**56.1**	**30.0**	**0.3**	**13.7**

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
GA	2.1	5.5	11.8	12.1	68.5
LA	6.7	16.2	19.5	20.0	37.6
ME	1.9	6.0	15.4	16.0	60.7
NH	1.4	10.0	10.9	14.2	63.5
PA	5.6	11.7	14.5	14.4	53.8
WA	4.7	8.7	11.1	13.4	62.1
Total N	**142**	**347**	**473**	**504**	**1,854**
Total %	**4.3**	**10.5**	**14.2**	**15.2**	**55.8**
State Avg %	**3.7**	**9.7**	**13.9**	**15.0**	**57.7**

Respondent's Role as Legal Guardian or Conservator

Table 14 Respondent is Legal Guardian or Conservator (%)		
State	Yes	No
GA	54.3	45.7
LA	66.2	33.8
ME	100.0	0.0
NH	86.4	13.6
PA	48.8	51.2
WA	61.9	38.1
Total N	**2,158**	**1,075**
Total %	**66.7**	**33.3**
State Avg %	**69.6**	**30.4**

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
GA	95.4	83.8	93.5	60.1
LA	95.0	66.5	87.3	75.0
ME	98.3	86.9	95.3	71.4
NH	95.2	69.9	87.6	64.7
PA	93.8	70.0	86.9	72.2
WA	91.0	63.2	83.3	55.5
Total N	**2,993**	**2,138**	**2,716**	**1,829**
Total %	**94.7**	**72.6**	**88.5**	**68.2**
State Avg %	**94.8**	**73.4**	**89.0**	**66.5**

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.
- *Denotes questions added to the 2009-10 survey, asked by only three states.

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 (76%) stated that they always or usually got enough information to help them participate in planning.

- Fifty-nine (59%) percent of respondents indicated their family member takes part in developing his or her plan, while one quarter (25%) indicated this seldom or never occurred; 17% of family members sometimes help develop their plan.

- A majority of respondents (62%), on average, indicated that they typically helped to develop their family member's service plan.

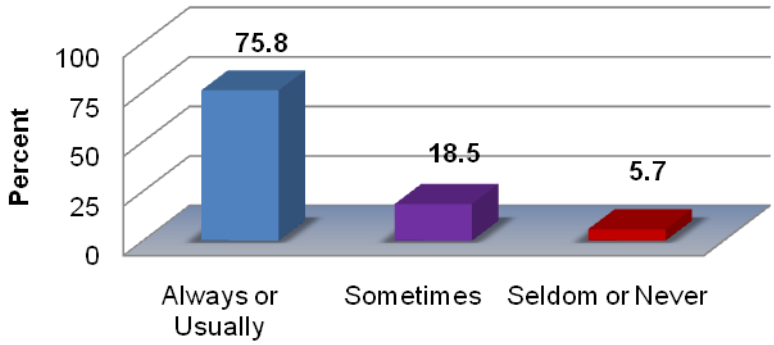
- On average across states, about four-fifths (78%) of respondents surveyed indicated that their family member's service plan included things that were important to them. Nineteen percent (19%) stated this was only true some of the time, while the remaining 3% stated the service plan seldom or never included things important to them.

- Across states, nearly all respondents (94%) felt that planning staff were generally respectful and courteous.

- Across states, 80% felt that planning staff were generally effective.

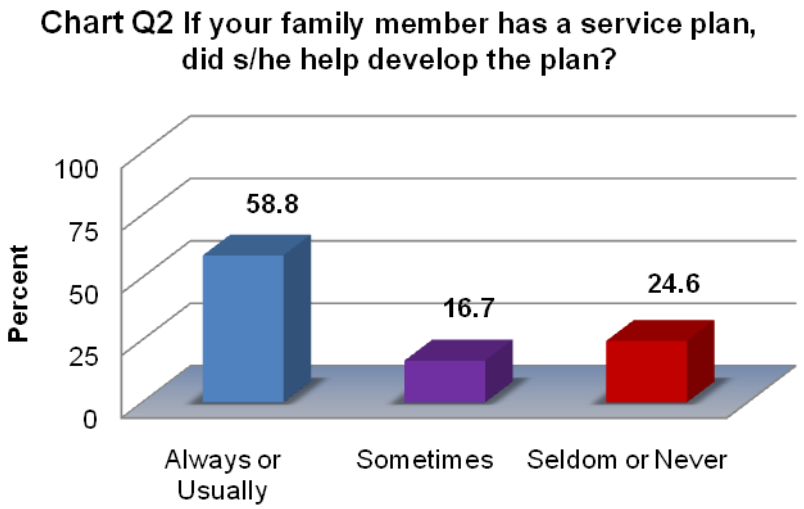
- Across states, 88% felt they were able to contact planning staff when needed.

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



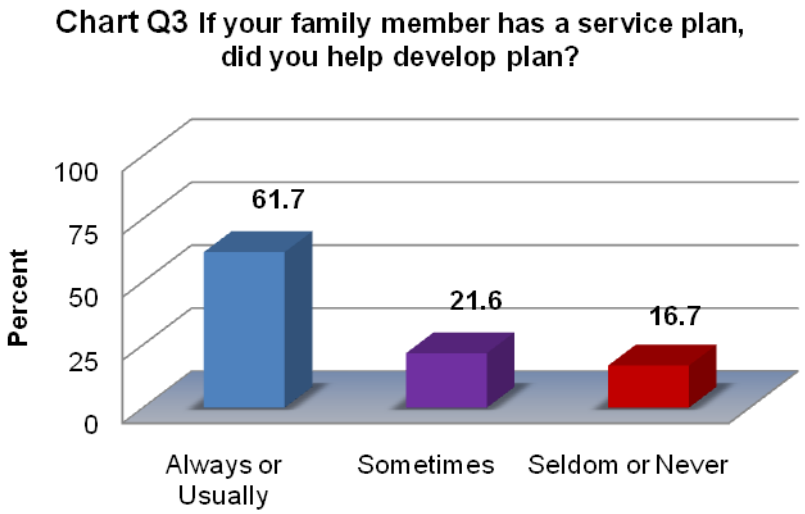
2009-10 Average for six states

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**
GA	↓↓	64.4	26.8	8.8	261
LA		76.2	17.5	6.2	513
ME	↑↑	86.4	11.9	1.7	471
NH	↑	83.8	13.8	2.4	420
PA		71.7	20.5	7.7	1,008
WA		72.1	20.5	7.4	430
Total %		**75.8**	**18.3**	**5.9**	**3,103**
State Average %		**75.8**	**18.5**	**5.7**	



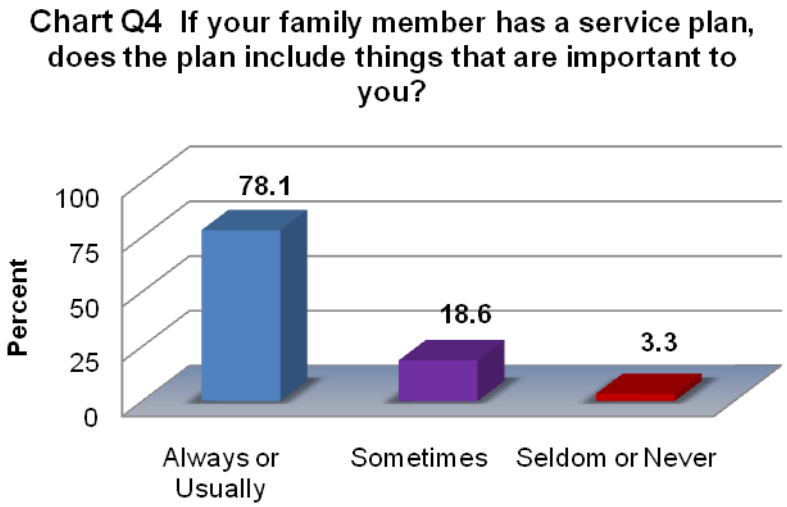
2009-10 Average for three states

Table Q2* If your family member has a service plan, did s/he help develop the plan? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	-	-	-	-	-
LA		59.7	13.7	27.1	291
ME		62.6	17.6	19.7	380
NH		54.1	18.8	27.1	351
PA	-	-	-	-	-
WA	-	-	-	-	-
Total %		**58.7**	**16.9**	**24.4**	**1,022**
State Average %		**58.8**	**16.7**	**24.6**	



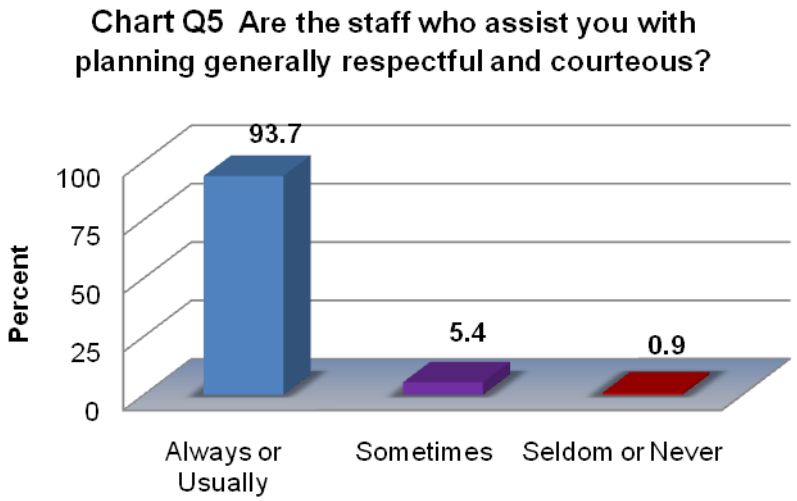
2009-10 Average for six states

Table Q3 If your family member has a service plan, did you help develop plan? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		62.2	20.3	17.4	241
LA	↓↓	50.9	26.8	22.3	399
ME	↑↑	76.1	16.7	7.2	443
NH	↑↑	74.9	18.8	6.3	399
PA	↓↓	40.9	27.2	31.9	841
WA		65.1	19.6	15.3	398
Total %		**58.5**	**22.5**	**19.0**	**2,721**
State Average %		**61.7**	**21.6**	**16.7**	



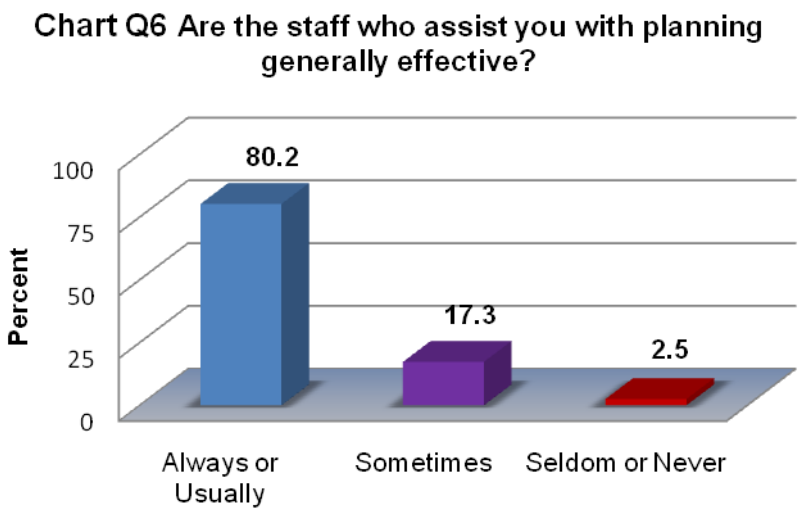
2009-10 Average for six states

Table Q4 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**
GA		73.2	23.7	3.1	228
LA		79.0	15.9	5.0	439
ME	↑	84.6	13.4	2.0	447
NH		81.3	15.6	3.2	411
PA	↓	71.3	24.8	3.9	844
WA		79.4	18.1	2.5	393
Total %		**77.5**	**19.1**	**3.4**	**2,762**
State Average %		**78.1**	**18.6**	**3.3**	



2009-10 Average for six states

Table Q5 Are the staff who assist you with planning generally respectful and courteous? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		90.3	8.9	0.8	248
LA		92.6	5.8	1.6	499
ME		98.3	1.7	0.0	474
NH		94.3	5.0	0.7	420
PA		93.0	5.7	1.2	961
WA		93.5	5.3	1.2	414
Total %		**93.8**	**5.2**	**1.0**	**3,016**
State Average %		**93.7**	**5.4**	**0.9**	



2009-10 Average for six states

Table Q6 Are the staff who assist you with planning generally effective? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	↓	70.7	26.8	2.4	246
LA		82.0	14.0	4.0	477
ME	↑	88.2	10.9	0.9	466
NH		81.7	16.1	2.2	415
PA		78.4	19.6	2.1	915
WA		79.9	16.6	3.5	403
Total %		**80.6**	**17.0**	**2.4**	**2,922**
State Average %		**80.2**	**17.3**	**2.5**	

2009-10 Average for six states

Table Q7 Can you contact the staff who assist you with planning whenever you want to? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	↓	80.2	16.3	3.6	252
LA		89.0	9.4	1.6	502
ME	↑	93.0	6.4	0.6	471
NH		89.5	9.3	1.2	421
PA		88.4	9.0	2.6	955
WA		84.7	12.4	2.9	411
Total %		**88.2**	**9.8**	**2.1**	**3,012**
State Average %		**87.5**	**10.5**	**2.1**	

Access to and Delivery of Services and Supports

- When asked whether *all* services from the family member's service plan were received, an average of 86% of respndents across states stated that this always or usually occurred, while this happened sometimes 13%. In only 1% of cases, this seldom or never transpired.

- On average, most respondents (84%) stated that their service coordinator helped them get needed supports when they asked. Fourteen percent (14%) 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 s/he needs.

- In an average of 81% of respondents, supports changed when the family member's needs changed. Sixteen percent (16%) of respondents expressed that this happened sometimes and 3% said this seldom or never happened.

- Among those respondents whose family member with disabilities did not speak English, or who used different ways to communicate, a large majority (78%) 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/ language.

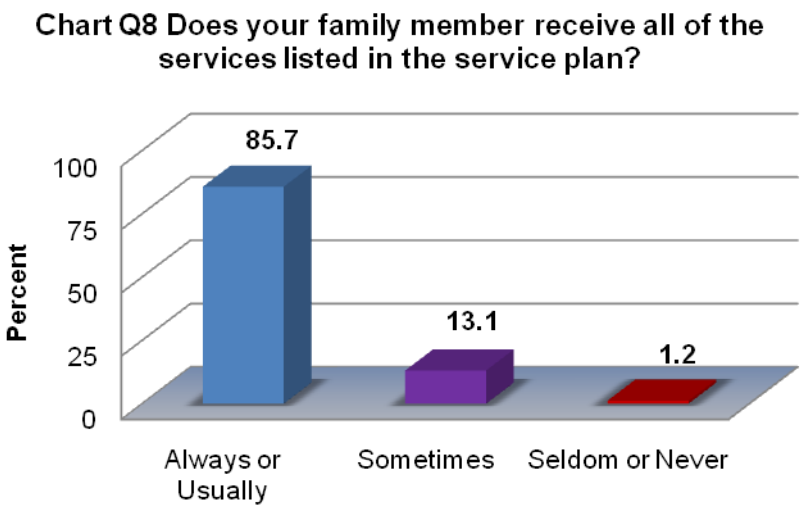
- On average, 88% of respondents indicated that their family member had access to the special equipment or accommodations that s/he needs.

- Two-thirds (60%) of respondents indicated that frequent changes in support staff were a problem for their family at least some of the time (21% expressed that this was always or usually an issue and 39% said this was sometimes a problem). The remaining 41% stated that staff changes were not an issue for them.

- More than three-quarters of respondents (78%) said staff have proper training to meet their family member's needs.

- Among those receiving residential supports, nearly all (90%) felt their family member's residential setting was a safe and healthy environment.

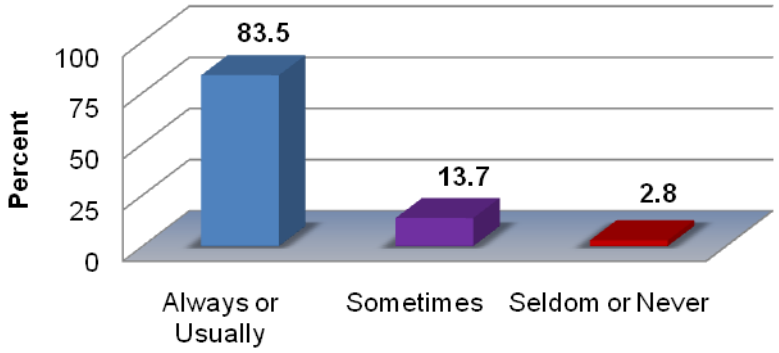
- Among those receiving day/employment supports, nearly all (90%) felt their family member's day/employment setting was a safe and healthy environment. The remaining 10% felt their family member's day setting was sometimes, seldom, or never safe.



2009-10 Average for three states

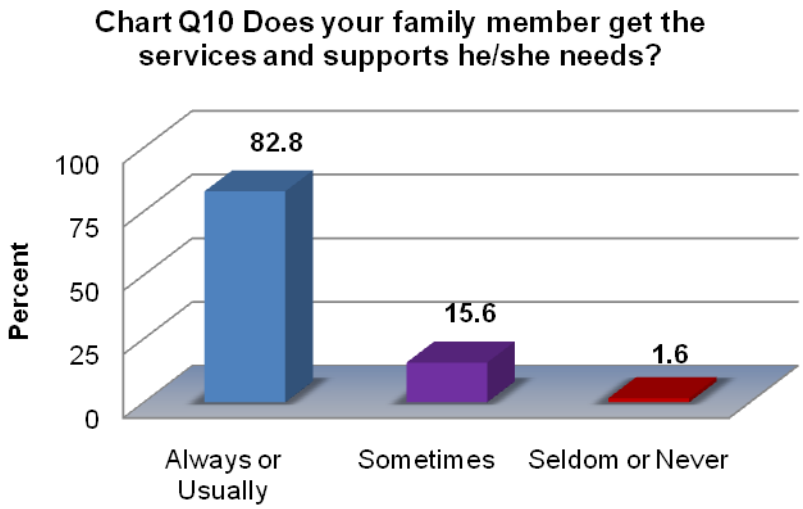
Table Q8* Does your family member receive all of the services listed in the service plan? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	-	-	-	-	-
LA		86.1	11.9	2.0	404
ME		88.0	11.5	0.5	443
NH		83.0	16.0	1.0	399
PA	-	-	-	-	-
WA	-	-	-	-	-
Total %		**85.8**	**13.1**	**1.1**	**1,246**
State Average %		**85.7**	**13.1**	**1.2**	

Chart Q9 When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?



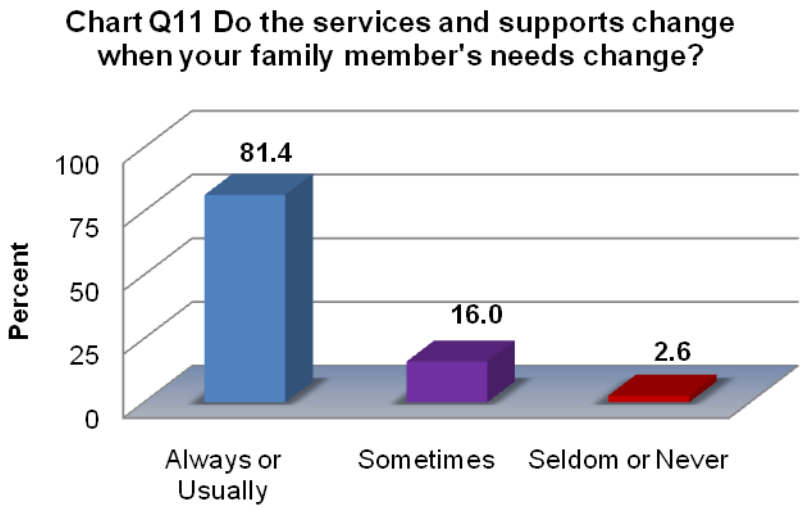
2009-10 Average for six states

Table Q9 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**
GA		79.0	16.7	4.3	257
LA		85.6	12.2	2.2	500
ME		86.3	11.7	2.0	444
NH		84.6	13.7	1.7	416
PA		83.3	14.3	2.5	938
WA		82.2	13.7	4.2	409
Total %		**83.8**	**13.6**	**2.6**	**2,964**
State Average %		**83.5**	**13.7**	**2.8**	



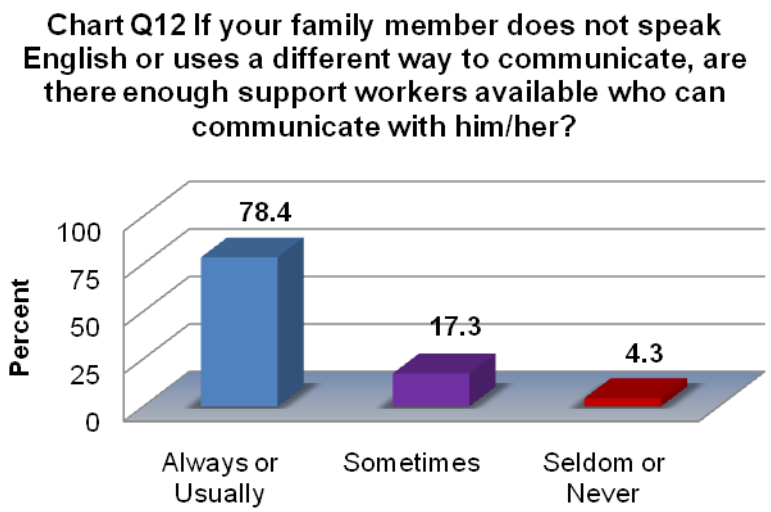
2009-10 Average for six states

Table Q10 Does your family member get the services and supports he/she needs? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		78.1	19.3	2.6	270
LA		87.5	10.3	2.2	503
ME		86.9	12.7	0.4	480
NH		80.2	18.6	1.2	424
PA		85.5	12.6	1.9	993
WA		78.6	20.3	1.2	434
Total %		**83.7**	**14.7**	**1.6**	**3,104**
State Average %		**82.8**	**15.6**	**1.6**	



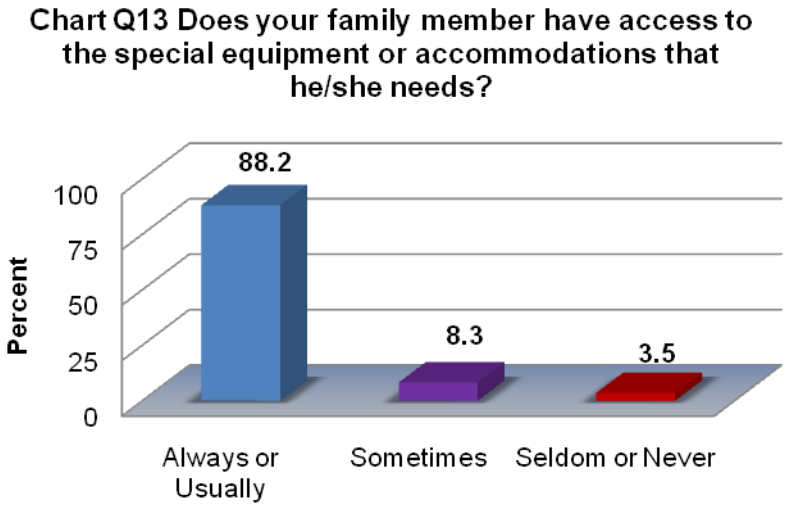
2009-10 Average for three states

Table Q11* Do the services and supports change when your family member's needs change? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	-	-	-	-	-
LA		82.7	14.3	3.0	462
ME		81.7	16.3	2.0	443
NH		79.7	17.5	2.8	399
PA	-	-	-	-	-
WA	-	-	-	-	-
Total %		**81.4**	**16.0**	**2.6**	**1,304**
State Average %		**81.4**	**16.0**	**2.6**	



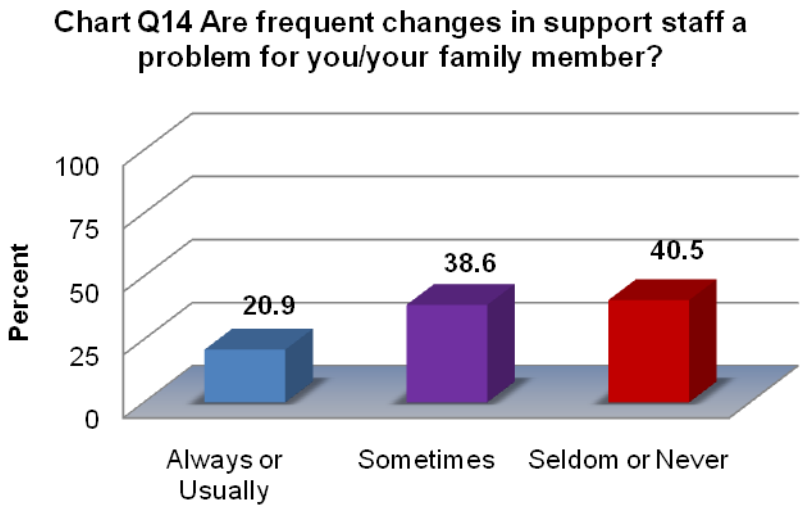
2009-10 Average for six states

Table Q12 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**
GA	↓↓	68.3	27.7	4.0	101
LA	↑	86.0	10.0	4.1	221
ME		73.0	23.0	4.0	100
NH		77.0	18.5	4.4	135
PA		82.5	11.9	5.6	377
WA	↑	83.8	12.6	3.6	111
Total %		**80.4**	**15.0**	**4.6**	**1,045**
State Average %		**78.4**	**17.3**	**4.3**	



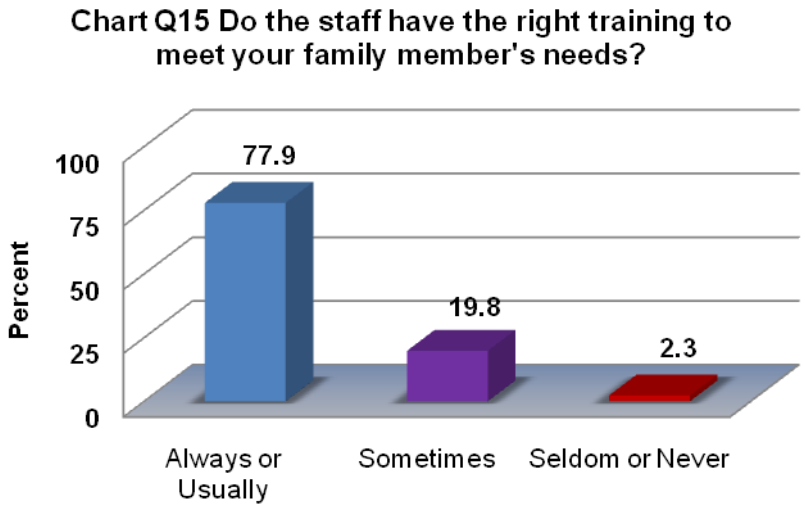
2009-10 Average for six states

Table Q13 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**
GA		89.7	9.0	1.4	145
LA		89.0	6.1	4.9	309
ME		87.3	9.3	3.5	259
NH		87.1	10.7	2.2	224
PA		90.0	6.2	3.8	633
WA		86.3	8.7	5.0	219
Total %		**88.6**	**7.7**	**3.7**	**1,789**
State Average %		**88.2**	**8.3**	**3.5**	



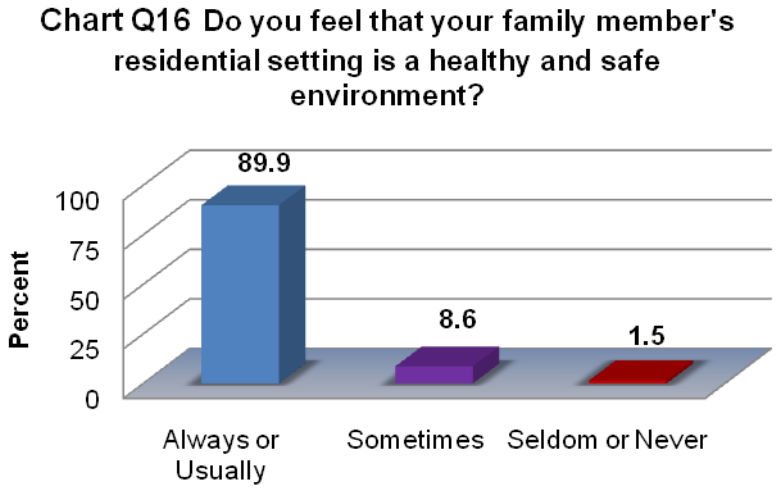
2009-10 Average for three states

Table Q14* Are frequent changes in support staff a problem for you/your family member? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	-	-	-	-	-
LA		23.1	25.7	51.2	428
ME		23.3	47.2	29.5	424
NH		16.3	42.9	40.8	387
PA	-	-	-	-	-
WA	-	-	-	-	-
Total %		**21.1**	**38.4**	**40.5**	**1,239**
State Average %		**20.9**	**38.6**	**40.5**	



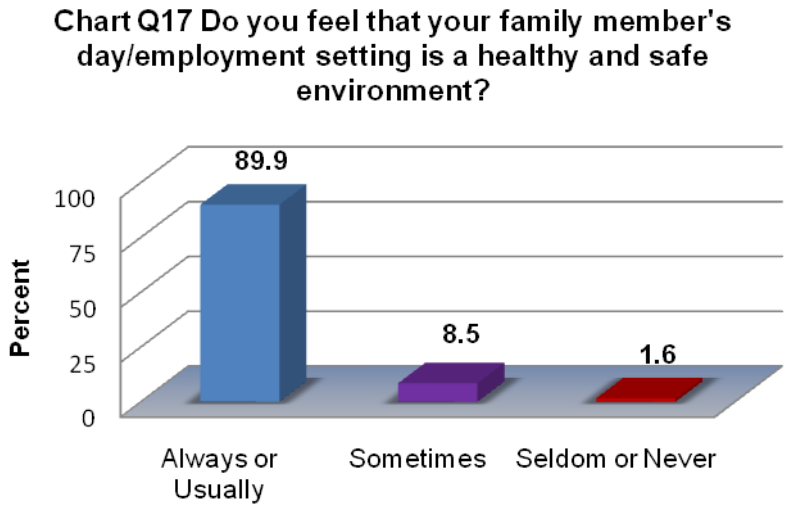
2009-10 Average for three states

Table Q15* Do the staff have the right training to meet your family member's needs? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	-	-	-	-	-
LA		77.9	18.4	3.7	456
ME		81.2	17.4	1.4	425
NH		74.6	23.6	1.8	398
PA	-	-	-	-	-
WA	-	-	-	-	-
Total %		**78.0**	**19.7**	**2.3**	**1,279**
State Average %		**77.9**	**19.8**	**2.3**	



2009-10 Average for six states

Table Q16 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**
GA		87.3	10.5	2.2	276
LA		90.3	8.2	1.5	525
ME		91.0	8.2	0.8	478
NH		91.7	6.9	1.4	420
PA		89.6	8.3	2.1	1,062
WA		89.7	9.2	1.1	448
Total %		**90.0**	**8.4**	**1.6**	**3,209**
State Average %		**89.9**	**8.6**	**1.5**	



2009-10 Average for six states

Table Q17 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**
GA		90.8	6.6	2.6	228
LA		90.0	7.8	2.2	410
ME		92.3	7.4	0.2	405
NH		86.1	11.5	2.5	323
PA		90.1	8.8	1.1	805
WA		90.3	8.8	0.9	318
Total %		**90.0**	**8.6**	**1.4**	**2,489**
State Average %		**89.9**	**8.5**	**1.6**	

Choices and Control

- Among families where the individual with disabilities received residential services, 80% of respondents stated that the agency involved them in important decisions. Another 15% stated that this happens some of the time, and 6% 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 21% stated that this happens sometimes, and 14% said the agency seldom or never involves them in important decisions.

- On average across states, three quarters of respondents (75%) stated that their family members seldom or never chose their case manager/service coordinator

- Nearly half of respondents (48%) stated that their family members seldom or never chose provider agencies. Paradoxically, 43% said family members always or usually made these choices.

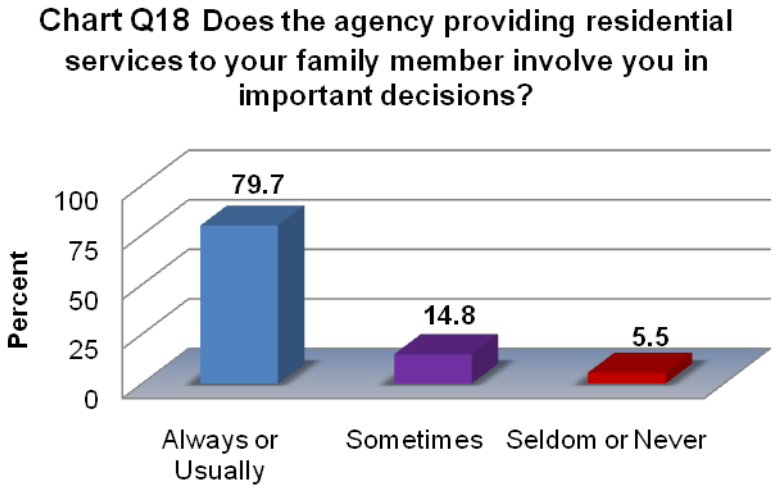
- On average across states, over two-thirds of respondents (69%) indicated that they or their family members seldom or never chose the support workers who work with their family members.

- Across states, only 15% of respondents said that they or their family members had control or input over the hiring and management of their family member's support staff, while an additional 12% indicated they had this type of control sometimes. Almost three-quarters (74%), however, indicated they or their family members had little or no input or control over the hiring or management of their support staff.

- While only 27% of respondents said they or their family members had any amount of control over the hiring or management of the support workers, 63% of respondents indicate that they or their family members want at least some control over the hiring and management of their support staff.

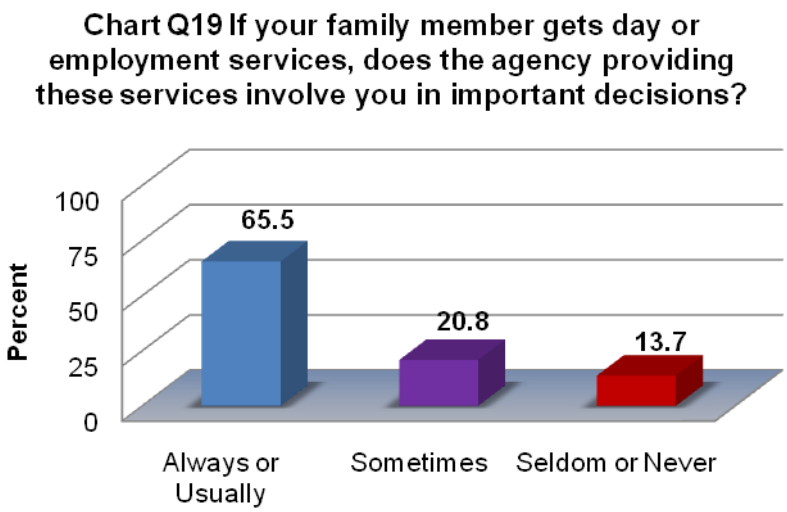
- Thirty-two percent (32%) of respondents, on average, indicated they or their family members knew how much money was spent on behalf of their family member at least some of the time – 20% knew most of the time and 11% knew sometimes. Sixty-eight percent (68%), either seldom or never had knowledge of the amount of money spent.

- On average across states, forty-five percent (45%) of families surveyed had at least some decision-making authority over how the money allocated to their family member with disabilities was spent by the ID/DD agency. The majority (55%), however, did not.



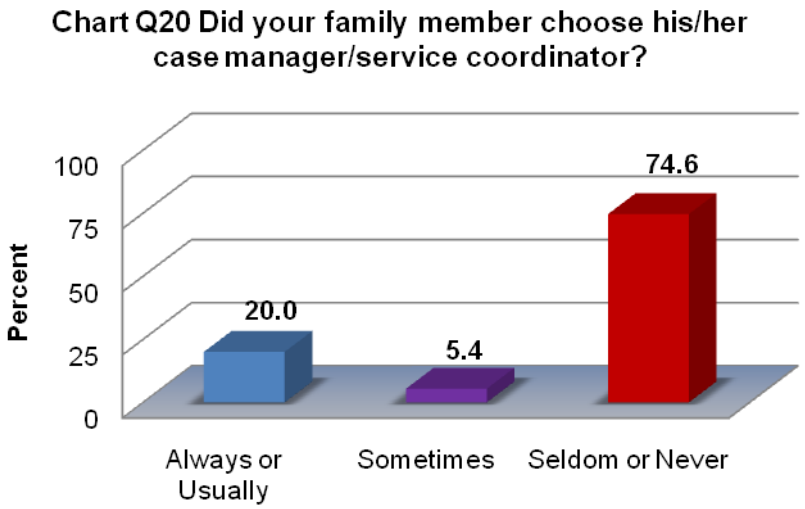
2009-10 Average for six states

Table Q18 Does the agency providing residential services to your family member involve you in important decisions? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	↓	70.8	20.1	9.1	264
LA		81.7	13.6	4.7	509
ME	↑↑	90.2	8.8	1.1	468
NH	↑	88.0	8.2	3.7	401
PA	↓	72.8	19.1	8.0	1,008
WA	↓	74.4	19.1	6.5	403
Total %		**79.0**	**15.3**	**5.7**	**3,053**
State Average %		**79.7**	**14.8**	**5.5**	



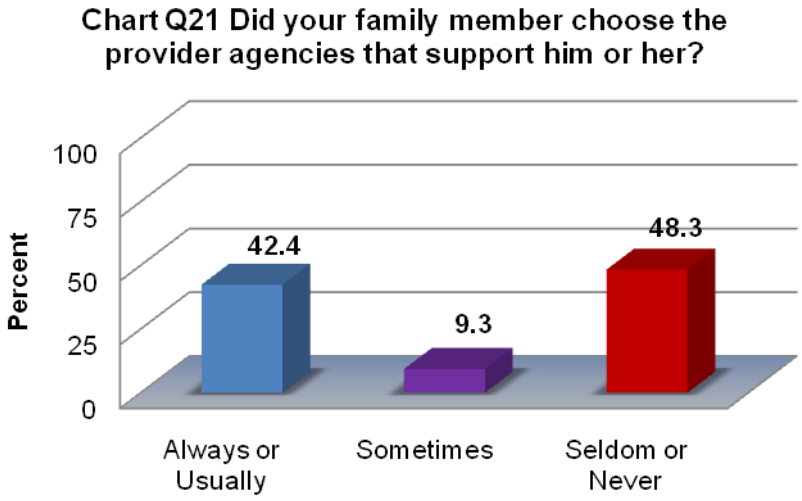
2009-10 Average for six states

Table Q19 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**
GA	↓	58.8	23.5	17.6	221
LA	↓	60.1	19.6	20.3	316
ME	↑↑	81.1	15.2	3.6	387
NH	↑	73.2	18.8	8.0	313
PA	↓	59.1	22.3	18.6	705
WA		60.8	25.1	14.1	311
Total %		**65.2**	**20.7**	**14.1**	**2,253**
State Average %		**65.5**	**20.8**	**13.7**	



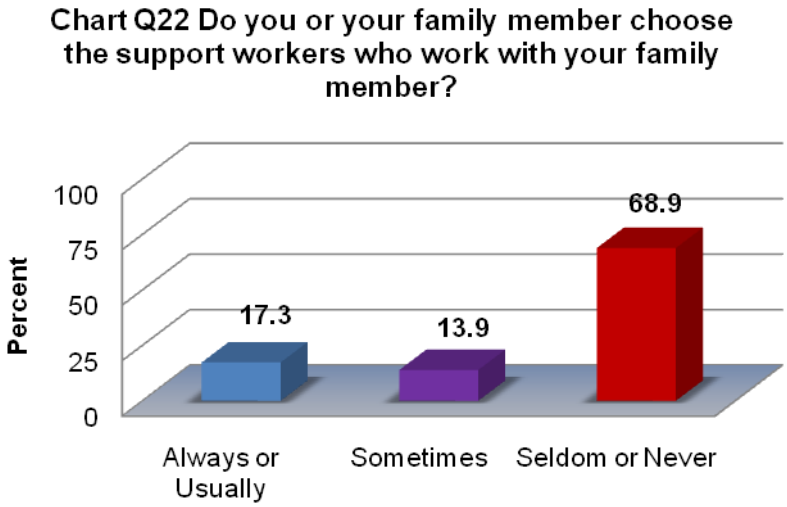
2009-10 Average for three states

Table Q20* Did your family member choose his/her case manager/service coordinator? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	-	-	-	-	-
LA	↑↑	30.1	6.2	63.6	209
ME	↓	15.0	4.7	80.4	341
NH	↓	14.8	5.3	79.8	243
PA	-	-	-	-	-
WA	-	-	-	-	-
Total %		**18.9**	**5.3**	**75.8**	**793**
State Average %		**20.0**	**5.4**	**74.6**	



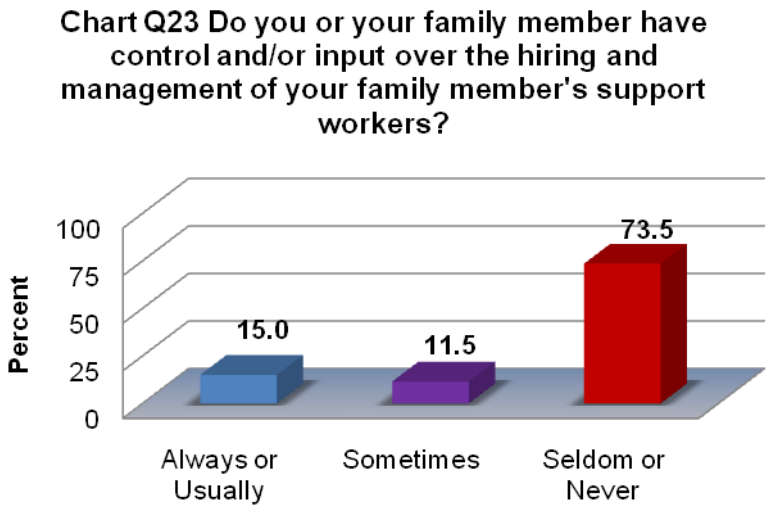
2009-10 Average for three states

Table Q21* Did your family member choose the provider agencies that support him or her? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	-	-	-	-	-
LA	↑	51.6	6.2	42.2	258
ME		45.3	12.9	41.8	364
NH	↓↓	30.3	8.8	61.0	251
PA	-	-	-	-	-
WA	-	-	-	-	-
Total %		**42.8**	**9.7**	**47.4**	**873**
State Average %		**42.4**	**9.3**	**48.3**	



2009-10 Average for six states

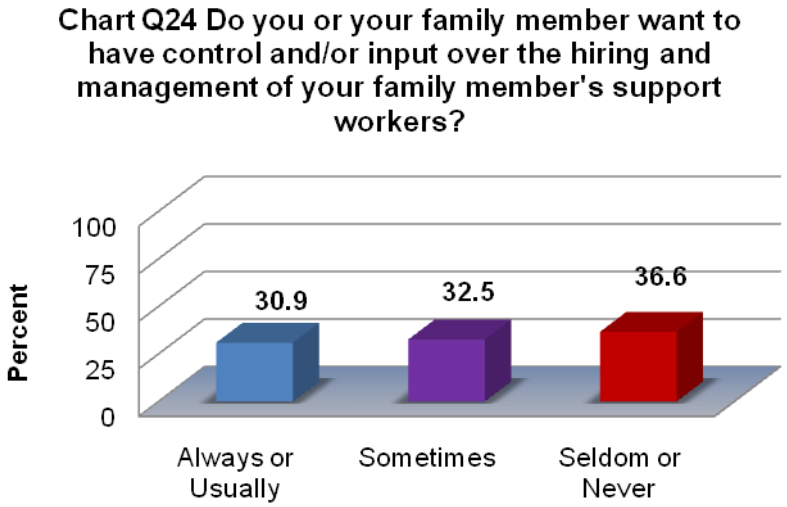
Table Q22 Do you or your family member choose the support workers who work with your family member?(%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		16.9	16.0	67.1	225
LA		16.0	13.6	70.3	337
ME		14.4	13.9	71.7	374
NH	↑↑	27.9	18.0	54.1	333
PA	↓	11.5	4.4	84.2	480
WA		16.9	17.3	65.8	272
Total %		**16.8**	**13.0**	**70.2**	**2,021**
State Average %		**17.3**	**13.9**	**68.9**	



2009-10 Average for six states

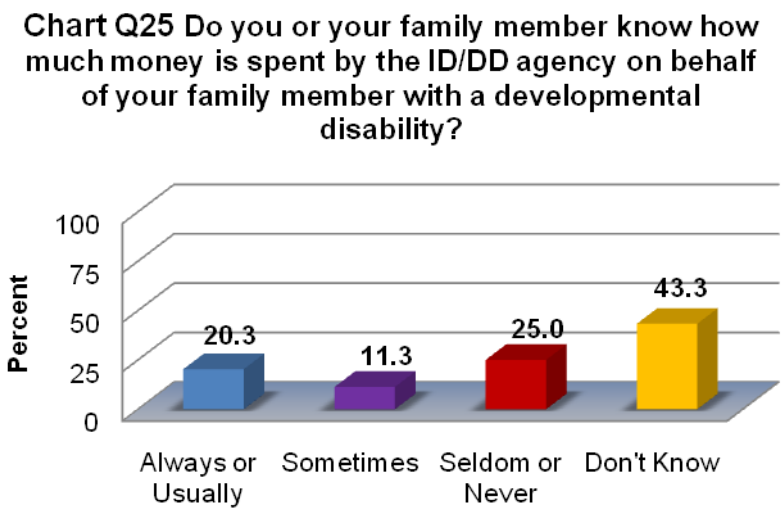
Table Q23
Do you or your family member have control and/or input over the hiring and management of your family member's support workers? (%)

State		Always or Usually	Sometimes	Seldom or Never	N
GA		12.6	14.4	73.0	215
LA		15.3	7.6	77.1	314
ME	↓	8.9	12.5	78.6	359
NH	↑↑	25.2	18.6	56.2	322
PA	↓	9.7	8.1	82.3	682
WA		18.2	8.0	73.8	325
Total %		**14.1**	**10.9**	**75.0**	**2,217**
State Average %		**15.0**	**11.5**	**73.5**	



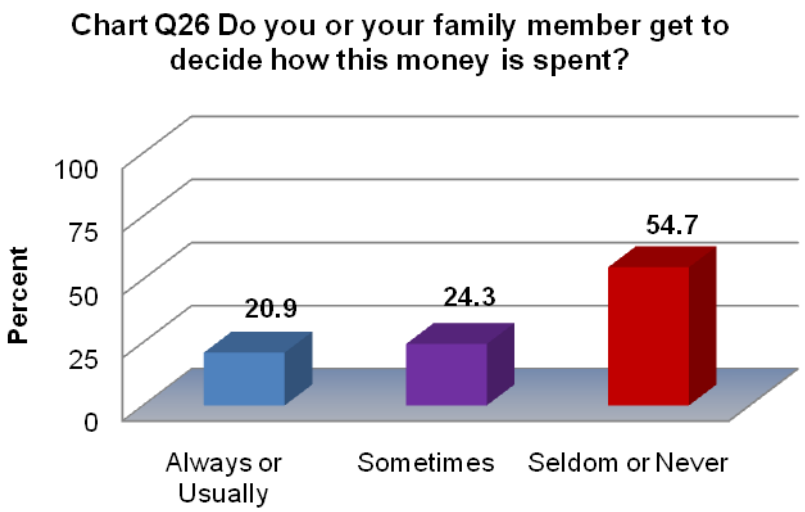
2009-10 Average for six states

Table Q24 Do you or your family member want to have control and/or input over the hiring and management of your family member's support workers? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	↑	38.1	31.2	30.7	189
LA		29.7	27.1	43.2	310
ME	↓	21.3	40.1	38.6	329
NH	↑↑	41.9	30.7	27.4	332
PA		27.1	30.4	42.5	654
WA		27.5	35.3	37.2	309
Total %		**29.9**	**32.3**	**37.8**	**2,123**
State Average %		**30.9**	**32.5**	**36.6**	



2009-10 Average for six states

Table Q25 Do you or your family member know how much money is spent by the ID/DD agency on behalf of your family member with a developmental disability? (%)						
State		**Always or Usually**	**Sometimes**	**Seldom, Never**	**Don't Know**	**N**
GA		21.8	11.9	26.8	39.5	261
LA		18.8	7.1	23.0	51.0	478
ME	↑	28.2	12.2	27.1	32.5	443
NH		15.5	15.3	31.0	38.2	406
PA	↓	15.3	11.0	24.1	49.6	960
WA		22.3	10.5	18.1	49.1	430
Total %		**19.4**	**11.1**	**24.7**	**44.8**	**2,978**
State Average %		**20.3**	**11.3**	**25.0**	**43.3**	



2009-10 Average for six states

Table Q26 Do you or your family member get to decide how this money is spent? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		17.9	25.4	56.7	201
LA		19.9	21.9	58.2	311
ME	↑	28.0	24.6	47.4	378
NH		18.4	29.8	51.8	332
PA		21.3	21.6	57.1	685
WA		20.1	22.7	57.1	308
Total %		**21.4**	**23.9**	**54.8**	**2,215**
State Average %		**20.9**	**24.3**	**54.7**	

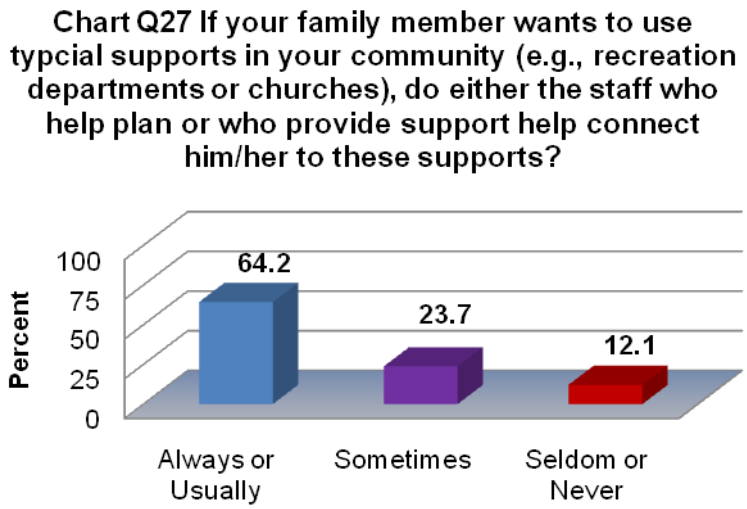
Community Connections

- Sixty-four percent (64%) of respondents remarked that staff were usually able to help their family member 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 family members interested in using family or friends to provide some of the supports needed, 63% respondents 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.

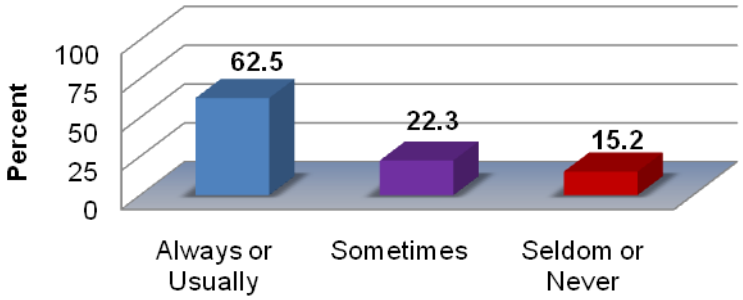
- While 68% of families felt their family member had regular access to community activities, only 47% stated that their family member usually participated in these activities, although another 38% indicated that their family member sometimes took part in community events/activities.



2009-10 Average for six states

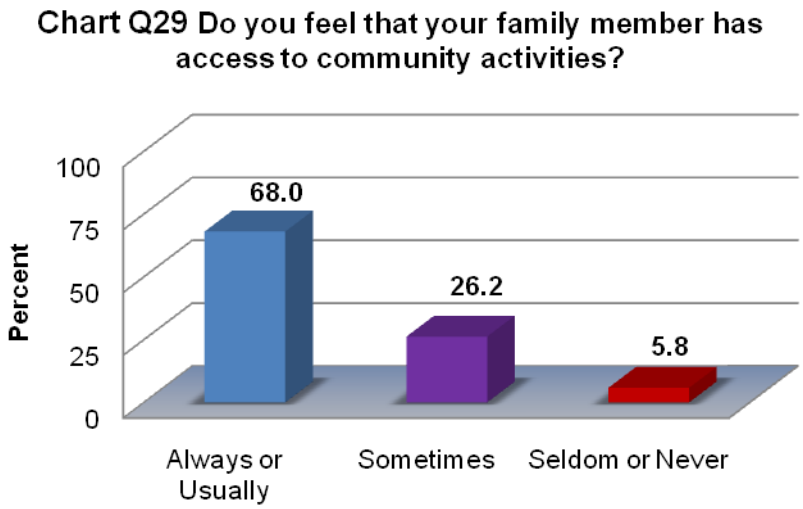
Table Q27 If your family member wants to use typical supports in your community (e.g., recreation departments or churches), do either the staff who help you plan or who provide support help connect him/her to these supports? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		66.0	24.0	10.0	200
LA		67.4	18.8	13.8	325
ME	↑	73.1	19.1	7.7	376
NH		61.8	25.8	12.4	322
PA		59.7	26.6	13.7	665
WA	↓	56.9	28.0	15.0	346
Total %		**63.5**	**24.1**	**12.4**	**2,234**
State Average %		**64.2**	**23.7**	**12.1**	

Chart Q28 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?



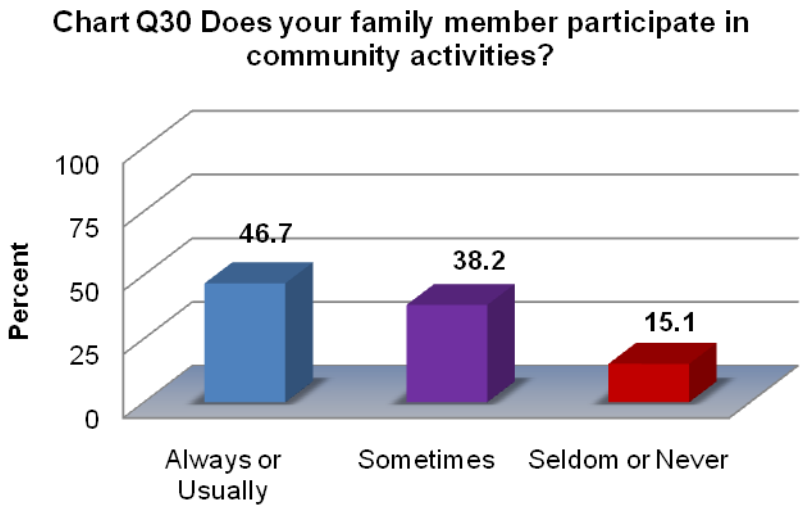
2009-10 Average for six states

Table Q28 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**
GA		62.8	24.6	12.6	183
LA		64.8	20.6	14.6	281
ME		66.6	18.3	15.2	290
NH		61.7	22.1	16.2	290
PA		61.8	22.7	15.5	581
WA	↓	57.5	25.4	17.1	299
Total %		**62.4**	**22.2**	**15.4**	**1,924**
State Average %		**62.5**	**22.3**	**15.2**	



2009-10 Average for six states

Table Q29 Do you feel that your family member has access to community activities? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		65.5	27.4	7.1	252
LA		68.5	25.2	6.3	460
ME	↑	74.7	22.0	3.3	455
NH		66.5	27.3	6.2	403
PA		67.2	26.8	6.0	919
WA		65.5	28.7	5.8	411
Total %		**68.1**	**26.2**	**5.7**	**2,900**
State Average %		**68.0**	**26.2**	**5.8**	



2009-10 Average for six states

Table Q30 Does your family member participate in community activities? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		51.0	34.0	14.9	241
LA		50.9	33.8	15.3	426
ME	↑	54.3	35.6	10.1	444
NH		43.6	41.1	15.3	399
PA	↓	40.6	41.8	17.6	874
WA	↓	39.5	42.9	17.6	408
Total %		**45.5**	**39.0**	**15.5**	**2,792**
State Average %		**46.7**	**38.2**	**15.1**	

Satisfaction with Services and Supports and Outcomes

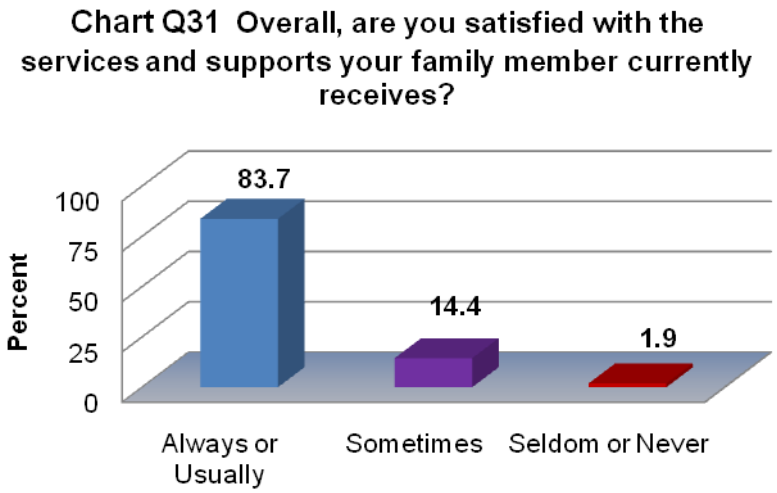
- On average, most respondents (84%) were satisfied with the services and supports their family member received. Fourteen percent (14%) were only somewhat satisfied, and 2% were seldom or never satisfied.

- On average, 68% of respondents knew about their agency's grievance process, 6% knew something about it, and about a quarter of respondents (26%) had seldom or no knowledge of the process for lodging a complaint.

- Just over three-quarters of respondents (76%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. Six percent (6%) were either seldom or never satisfied.

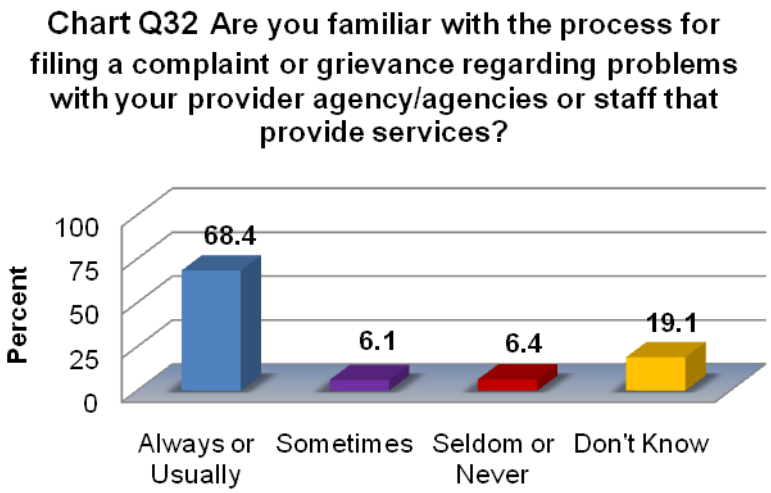
- The majority of respondents (86%) felt that services and supports had a positive impact on their family's life. Twelve percent (12%) stated that services sometime made a positive difference, and the remaining 1% indicated that supports seldom or never had a positive impact.

- Eighty-four percent (84%) of respondents felt that their family member was happy. Two percent (2%) indicated that their family member was seldom or never happy.



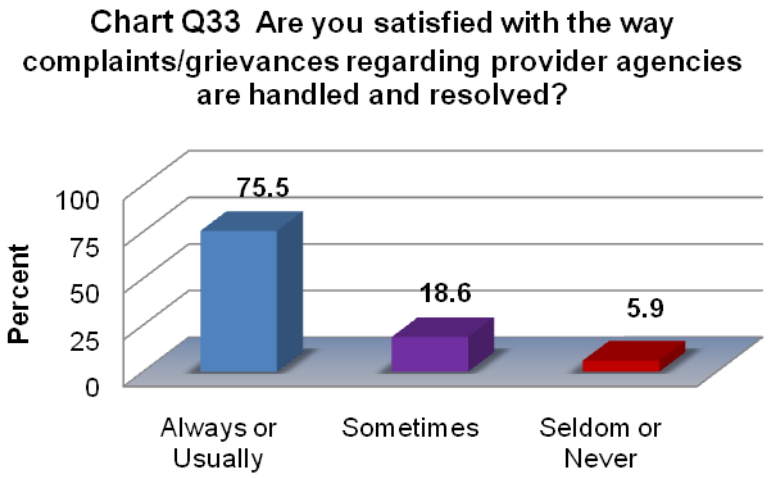
2009-10 Average for six states

Table Q31 Overall, are you satisfied with the services and supports your family member currently receives? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		80.7	16.1	3.2	280
LA		84.8	13.1	2.1	525
ME	↑	91.5	8.3	0.2	482
NH		80.5	17.8	1.6	426
PA		83.3	14.4	2.3	1,063
WA		81.1	16.7	2.2	450
Total %		**83.9**	**14.2**	**1.9**	**3,226**
State Average %		**83.7**	**14.4**	**1.9**	



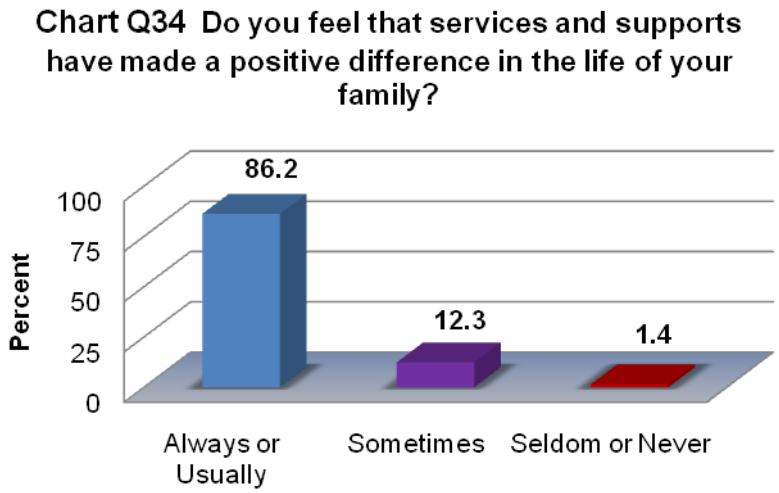
2009-10 Average for three states

Table Q32* Are you familiar with the process for filing a complaint or grievance regarding problems with your provider agency/agencies or staff that provide services? (%)						
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**Don't Know**	**N**
GA	-	-	-	-	-	-
LA		65.5	7.7	5.5	21.3	493
ME		70.3	5.4	6.5	17.9	448
NH		69.5	5.1	7.3	18.2	413
PA	-	-	-	-	-	-
WA	-	-	-	-	-	-
Total %		**68.3**	**6.1**	**6.4**	**19.2**	**1,354**
State Average %		**68.4**	**6.1**	**6.4**	**19.1**	



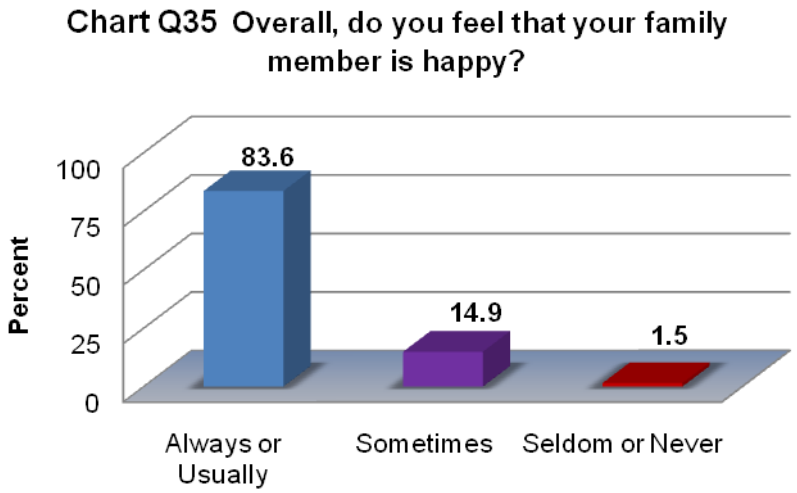
2009-10 Average for three states

Table Q33* Are you satisfied with the way complaints/grievances regarding provider agencies are handled and resolved? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA	-	-	-	-	-
LA		75.7	17.0	7.3	371
ME		77.7	18.0	4.3	305
NH		73.0	20.9	6.1	296
PA	-	-	-	-	-
WA	-	-	-	-	-
Total %		**75.5**	**18.5**	**6.0**	**972**
State Average %		**75.5**	**18.6**	**5.9**	



2009-10 Average for six states

Table Q34 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**
GA		87.9	11.4	0.7	280
LA		84.3	13.7	1.9	517
ME		90.8	8.4	0.8	477
NH		87.1	11.7	1.2	426
PA		82.3	15.2	2.4	1,025
WA		84.9	13.5	1.6	438
Total %		**85.4**	**12.9**	**1.7**	**3,163**
State Average %		**86.2**	**12.3**	**1.4**	



2009-10 Average for six states

Table Q35 Overall, do you feel that your family member is happy? (%)					
State		**Always or Usually**	**Sometimes**	**Seldom or Never**	**N**
GA		86.0	12.6	1.4	278
LA		82.5	15.2	2.3	526
ME	↑	88.6	11.0	0.4	482
NH		82.7	15.7	1.6	427
PA		81.4	16.5	2.2	1,069
WA		80.4	18.5	1.1	453
Total %		**83.1**	**15.3**	**1.6**	**3,235**
State Average %		**83.6**	**14.9**	**1.5**	

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 summarizes the arrows (i.e., ⇧ and ⇩) of the Tables displayed earlier in this report, with single arrows representing state results ± 5% from the state average, and double arrows (⇧⇧ and ⇩⇩) representing ± 10% from the state average.

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

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

Information and Planning

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

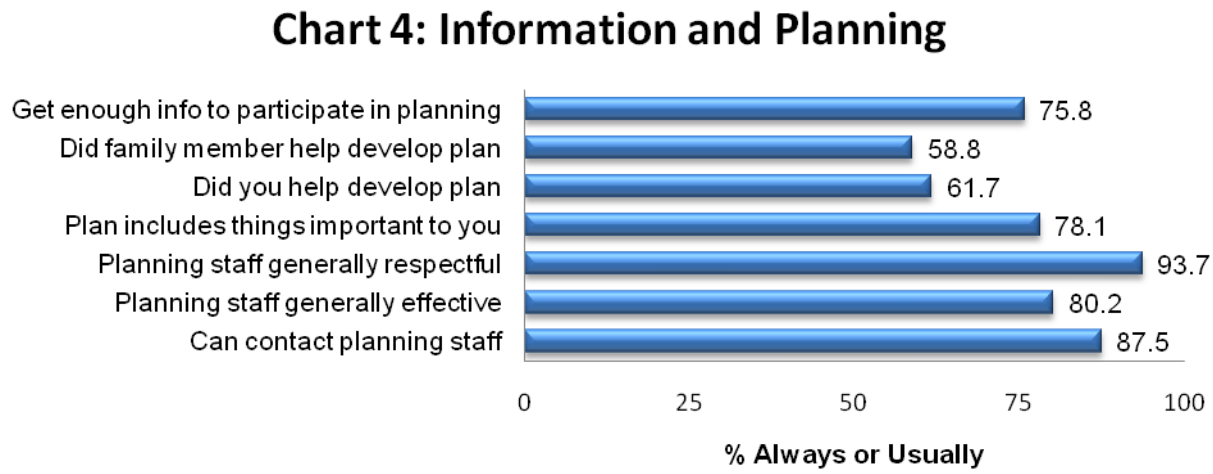


Table 16 Deviation in Responses Above & Below State Average: Information & Planning								
State	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Net Sum**
GA	↓↓	-				↓	↓	**-4**
LA			↓↓					**-2**
ME	↑↑		↑↑	↑		↑	↑	**7**
NH	↑		↑↑					**3**
PA		-	↓↓	↓				**-3**
WA		-						**0**

Access and Delivery of Supports

- In this series of questions, responses were generally consistent across states.

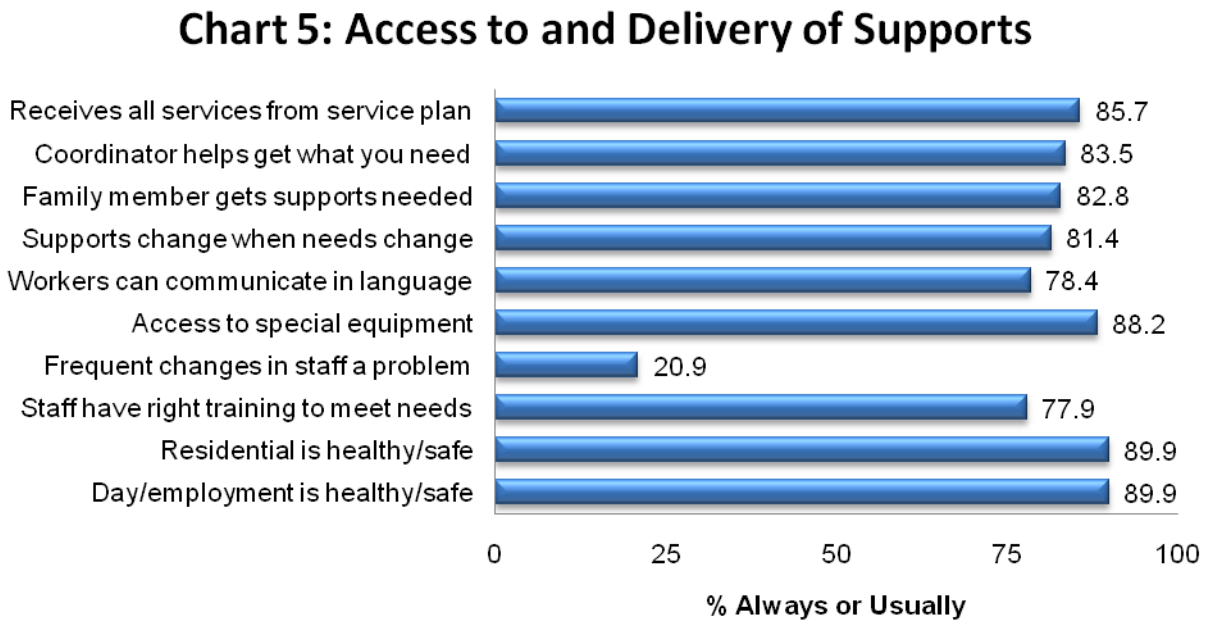


Table 17 Deviation in Responses Above & Below State Average: Access to and Delivery of Supports											
State	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Net Sum
GA	-			-	↓↓		-	-			-2
LA					↑						1
ME											0
NH											0
PA	-			-			-	-			0
WA	-			-	↑		-	-			1

Choice and Control

- In this series of questions, most states had above and below average responses. Therefore, overall the net sum of the arrows was generally consistent across states.

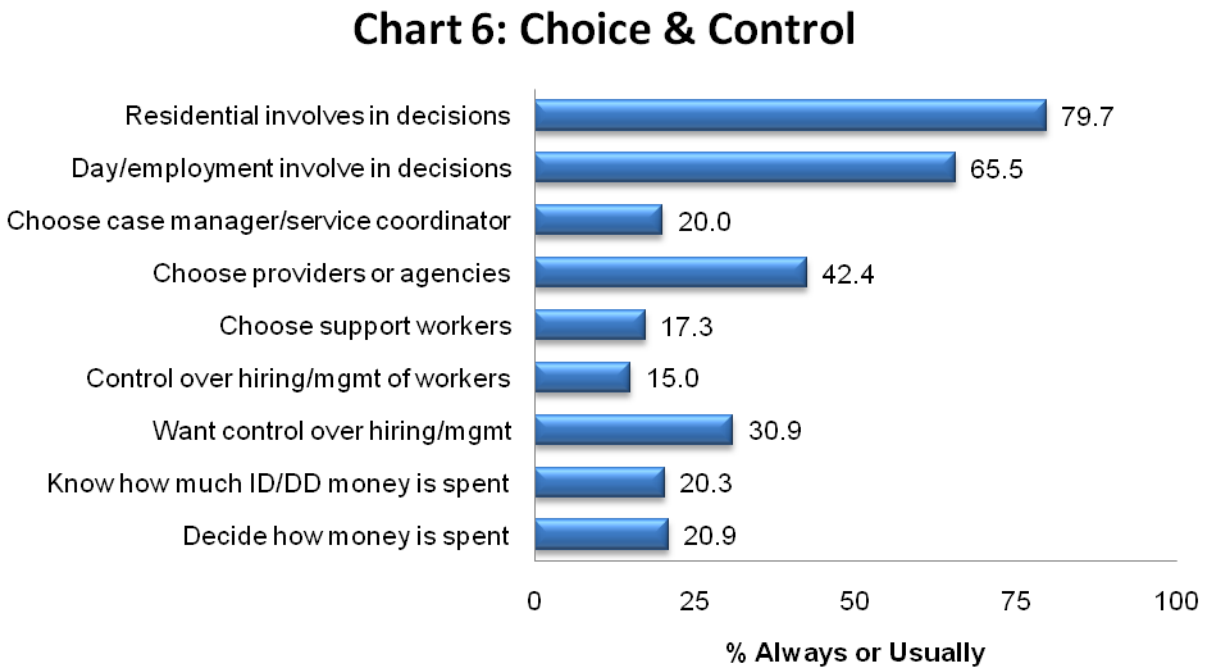


Table 18 Deviation in Responses Above & Below State Average: Choice & Control										
State	**Q18**	**Q19**	**Q20**	**Q21**	**Q22**	**Q23**	**Q24**	**Q25**	**Q26**	**Net Sum**
GA	↓	↓	-	-			↑			**-1**
LA		↓	↑↑	↑						**2**
ME	↑↑	↑↑	↓			↓	↓	↑	↑	**3**
NH	↑	↑	↓	↓↓	↑↑	↑↑	↑↑			**5**
PA	↓	↓	-	-	↓	↓		↓		**-5**
WA	↓		-	-						**-1**

Community Connections

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

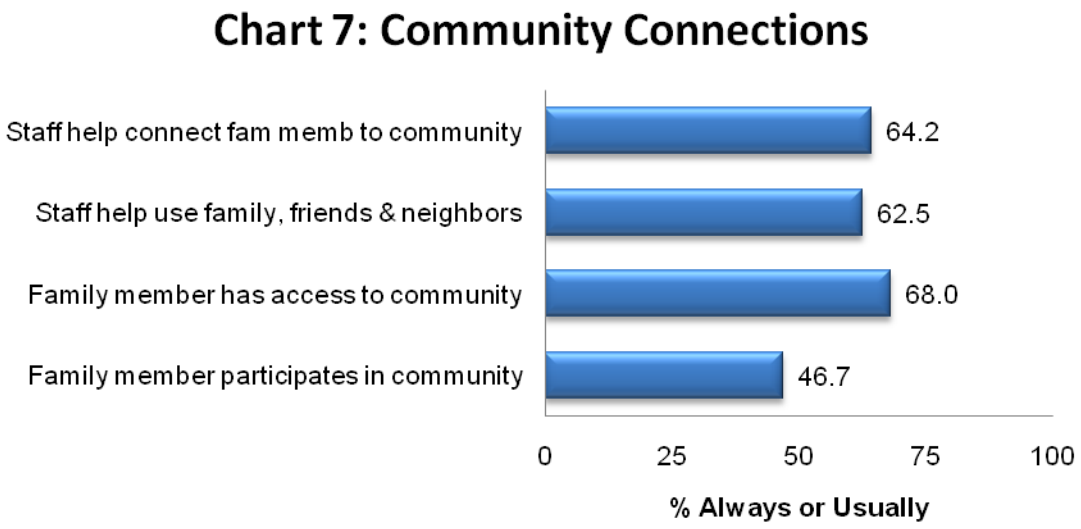


Table 19 Deviation in Responses Above & Below State Average: Community Connections					
State	**Q27**	**Q28**	**Q29**	**Q30**	**Net Sum**
GA					**0**
LA					**0**
ME	↑		↑	↑	**3**
NH					**0**
PA				↓	**-1**
WA	↓	↓		↓	**-3**

Satisfaction 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 on a couple of questions.

Table 20 Deviation in Responses Above & Below State Average: Satisfaction & Outcomes						
State	**Q31**	**Q32**	**Q33**	**Q34**	**Q35**	**Net Sum**
GA		-	-			**0**
LA						**0**
ME	↑				↑	**2**
NH						**0**
PA		-	-			**0**
WA		-	-			**0**

Overall State Results

- Looking at results across all categories, Maine and New Hampshire received results that were above the overall state average.

Table 21 Aggregate Deviation in Responses Above & Below State Average						
State	Information & Planning	Access to and Delivery of	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
GA	-4	-2	-1	0	0	-7
LA	-2	1	2	0	0	1
ME	7	0	3	3	2	15
NH	3	0	5	0	0	8
PA	-3	0	-5	-1	0	-9
WA	0	1	-1	-3	0	-3

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