Child Family Survey

Final Report – April 2007
2005-2006 Data

NCI
NATIONAL CORE INDICATORS

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

HUMAN SERVICES RESEARCH INSTITUTE

2336 Massachusetts Avenue
Cambridge, MA 02140

7420 SW Bridgeport Road, Suite 210
Portland, OR 97224

NATIONAL ASSOCIATION OF STATE DIRECTORS
OF DEVELOPMENTAL DISABILITIES SERVICES

113 Oronoco Street
Alexandria, VA 22314

April 2007

Table of Contents

List of Tables & Charts

Organization of Report

Appendix A – Summary Tables of Survey Responses

List of Tables & Charts

Tables

Charts

Organization of Report

Six states and one local developmental disability authority conducted the National Core Indicators (NCI) Child Family Survey during the 2005-2006 project year and submitted data. The Child Family Survey was administered to families having a child with disabilities living in the family's home. This Final Report provides a summary of results, based on the data submitted by September 2006.

This report is organized as follows:

I. INTRODUCTION

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

II. CHILD FAMILY SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

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

IV. RESULTS

This section provides aggregate and state-by-state results for demographic, service utilization, service access and delivery, satisfaction and outcome data.

V. DISCUSSION OF 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.

I. Introduction

Overview of National Core Indicators

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

Phase I – Phase I of CIP Phase 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 to participating states in September 1998.

1999 - 2000 – During Phase II, 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 (Arizona, Connecticut, Kentucky, Massachusetts, Minnesota, Nebraska, North Carolina, Pennsylvania, Rhode Island, Virginia, Vermont, Washington) participated in Phase II, and this data is considered baseline project data. .

2000 - 2001 (Phase III) – Moving forward, four additional states joined the project (Delaware, Iowa, Montana, Utah) and the project expanded its scope to include services for children with developmental disabilities and their families. During this time, the CIP staff and participants continued to develop and refine the indicators, and recruit additional states to participate.

2001 - 2002 (Phase IV) – The Core Indicators Project (CIP) officially changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. Participation in the National Core Indicators is entirely voluntary. For this year's round of data collection, seven new states and one local DD authority joined NCI (Alabama, Orange County in California, Hawaii, Illinois, Indiana, Oklahoma, West Virginia, Wyoming). During 2001-2002, 20 states and one local authority were active in NCI.

2002 – 2003 (Phase V) - Maine, South Carolina and South Dakota joined NCI.

2003 – 2004 (Phase VI) –North Dakota and the District of Columbia joined NCI.

2004 – 2005 (Phase VII) - Project participation diminished slightly this year, with 17 states, one local DD authority, and the District of Columbia involved.

2005 – 2006 (Phase VIII) – Arkansas, Georgia, New Mexico and Texas joined NCI. South Dakota rejoined NCI after a one-year hiatus.

The figure on the following page summarizes state participation in the National Core Indicators since its inception through the 2005-2006 data collection cycles. States are listed if they participate in one or more of the NCI activities (e.g., consumer survey, family surveys, expenditure/utilization data, etc.).

Table 1
State Participation in National Core Indicators

Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003	Phase VI 2003-2004	Phase VII 2004-2005	Phase VIII 2005-2006
AZ	AZ	AZ	**AL**	AL	AL	AL	AL
CT	CT	CT	AZ	AZ	AZ	AZ	**AR**
MO	**KY**	**DE**	**CA - RCOC**	CA - RCOC	CA - RCOC	CA-RCOC	AZ
NE	**MA**	**IA**	CT	CT	CT	CT	CA-RCOC
PA	**MN**	KY	DE	DE	DE	DE	CT
VT	NE	MA	**HI**	HI	**DC**	DC	DE
VA	**NC**	MN	**IL**	IN	HI	HI	DC
	PA	**MT**	**IN**	IA	IN	KY	**GA**
	RI	NE	IA	KY	KY	MA	HI
	VT	NC	KY	MA	MA	ME	KY
	VA	PA	MA	**ME**	ME	NC	MA
	WA	RI	NE	NE	NE	OK	ME
		UT	NC	NC	NC	PA	**NM**
		VT	**OK**	OK	**ND**	RI	NC
		WA	PA	PA	OK	SC	OK
			RI	RI	PA	VT	PA
			UT	**SC**	RI	WA	RI
			VT	**SD**	SC	WV	SC
			WA	VT	SD	WY	SD
			WV	WA	VT		**TX**
			WY	WV	WA		VT
				WY	WV		WA
					WY		WV
							WY

Denotes first year of participation in NCI.

Family Indicators

Obtaining direct feedback from families is an important means for states to gauge satisfaction with services and supports as well as to pinpoint potential areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to gauge changes in performance over time. In addition, these results permit a state to compare its own performance against 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 survey instruments 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**. Each of the three family surveys, in structure, follow this new 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. Child Family Survey

Background

This report focuses on the Child Family Survey.

2000 - 2001 – In the year 2000, five states participated and mailed out over 5,000 Child Family Surveys. Response rates among states ranged from 30% to 57%, with approximately 2,000 completed surveys returned.

2001 - 2002 – In the year 2001, four states and one local developmental disability authority participated and mailed out over 6,500 Child Family Surveys. Response rates among states ranged from 26% to 49%, with approximately 1,800 completed surveys returned.

2002-2003 – In this time frame, six states and one local DD authority participated, mailing out approximately 10,000 surveys. Response rates ranged from 21% to 51%, with over 2,200 surveys used in analysis.

2003 - 2004 – Five states and one local DD authority participated. Response rates ranged from 21% to 42%, with over 2,200 surveys analyzed.

2004-2005 – Four states and one local DD authority participated. Response rates ranged from 21% to 36%, with over 2,100 surveys analyzed.

2005 – 2006 - The results from this survey are explored, in detail, in this report.

State Participation

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

Table 3
State Participation in NCI Children Family Survey
(Children Living at Home)

Phase I Field Test	Phase II 1999 Data	Phase III 2000 Data	Phase IV 2001 Data	Phase V 2002 Data	Phase VI 2003 Data	Phase VII 2004 Data	Phase VIII 2005 Data
NA	NA	AZ MN NC UT WA	CA - RCOC NE NC UT VT	AZ CA-RCOC MA SC SD WA WY	CA-RCOC CT HI ND SC WY	AZ CA-RCOC CT WA WY	CA-RCOC CT HI SC SD TX WY

Survey Instrument

States that administer the Child Family Survey agree to employ the 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 Child Family Survey developed. Further on in the report, we discuss how the surveys were administered and how the results were analyzed.

The Child Family Survey used in 2005-2006 not only asks families to express their overall level of satisfaction with services and supports, it also probes specific aspects of the service system's capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; and outcomes. Combined, this information provides an overall picture of family satisfaction within and across states.

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

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

Service Planning, Delivery & Outcomes – The survey then contains several categories of questions that probe to specific areas of quality service provision (e.g., information and planning, access and delivery of services, community connections). 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 for their family/family member.

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

III. Methods

Sampling & Administration

States administered the Child Family Survey by selecting a random sample of 1,000 families who: a) have a child with developmental disabilities living at home, and b) receive service coordination <u>and</u> at least one additional service or support. Children were defined as individuals with disabilities under age 22. A sample size of 1,000 was selected in anticipation that states would obtain at least a 40% return rate, yielding 400 or more usable responses per state. With 400 usable responses per state, the results may be compared across states within a confidence level of ±10%. In states where there were fewer than 1,000 potential respondent families, surveys were sent to all eligible families.

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

- The question "Does your child 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 child with disabilities lived outside of the family home, yet received the Child Family Survey, their responses were dropped.
- If the respondent indicated that their family member was over the age of 21, their responses were dropped.
- If demographic information was entered into the file, but no survey questions were answered, these responses were also dropped.

Response Rates

During the 2005-2006 data year, four states and one local developmental disability authority administered the Child Family Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis.

Table 4
Child Family Survey - State Response Rates

State	Surveys Mailed	Surveys Returned	Response Rate	Usable Surveys
CA - RCOC	4,409	818	19%	688
Connecticut	1,200	259	22%	225
Hawaii	600	193	32%	180
So. Carolina	800	176	22%	169
So. Dakota	381	190	50%	186
Texas	2,034	800	39%	780
Wyoming	726	191	26%	180
Overall	**10,150**	**2,627**	**30%**	**2,408**

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

Data Analysis

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

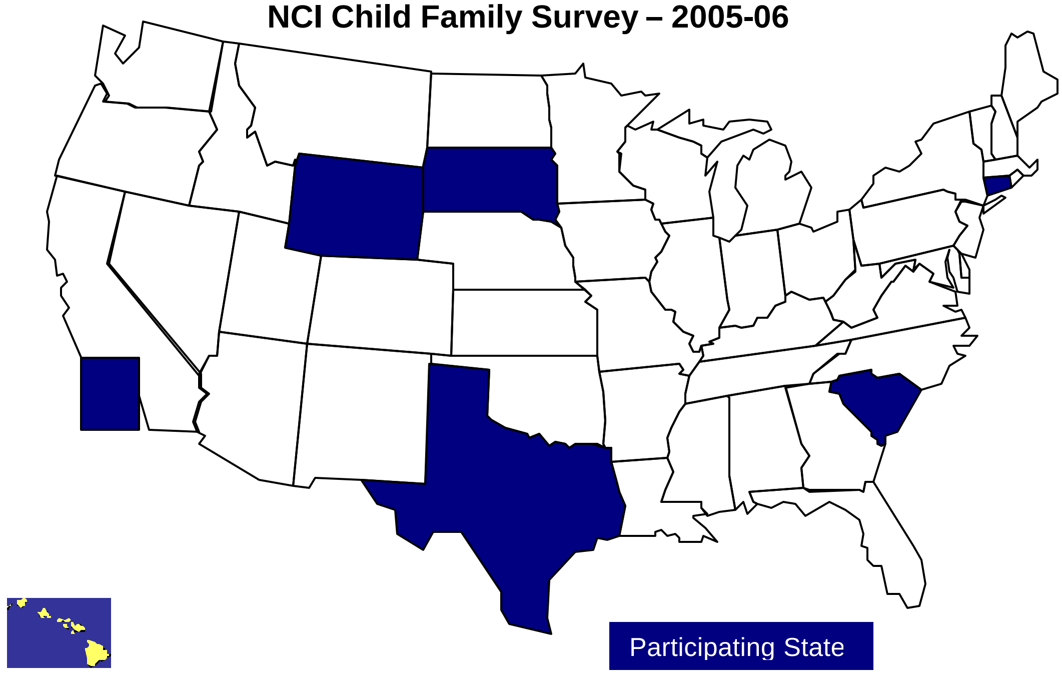
IV. Results

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

Participating States

- Six states (Connecticut, Hawaii, South Carolina, South Dakota, Texas and Wyoming) and one local developmental disabilities authority (Orange County Regional Center in California) provided data for this Report.

Chart 1
States Participating in the NCI Child Family Survey – 2005-06



Characteristics of Children with Disabilities

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

- On average, across the states, 63% of children with disabilities were male, 37% were female.
- Across all participating states, the average age of children with disabilities was 10.6, with a range in age from 1 to 21.
- Across all states, 64% of the children with disabilities were White, 10% were Black/African-American, 10% were Asian-American, 5% were Native Hawaiian/Pacific Islander, 3% were American Indian/Alaska Native, 7% were Mixed Races, and 13% were Hispanic/Latino. In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.)
- On average, 16% of households include more than one individual with a developmental disability.
- On average, 77% of children with disabilities required moderate to complete levels of assistance with activities of daily living. Twenty-three percent of children required little or no assistance with these activities.
- Many families indicated that their children have mental retardation (44%) and/or other developmental disabilities (34%). Additionally, many children experience other disabilites, such as physical disabilities (32%), autism (29%), seizure disorders (27%), communication disorders (27%), vision or hearing impairments (25%), and/or cerebral palsy (23%).

Gender of Family Member

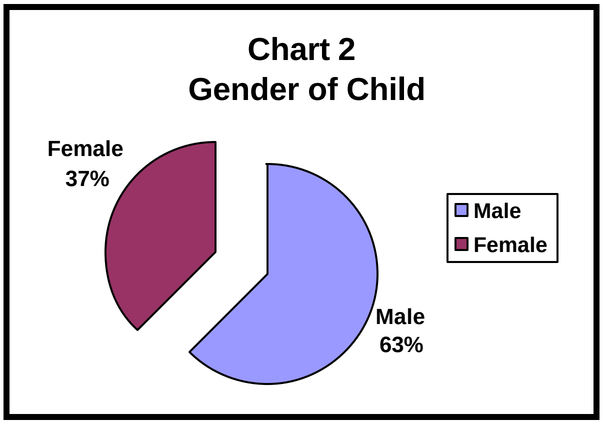


Chart 2
Gender of Child

Table 5
Gender

State	% Male	% Female
CA-RCOC	67.4	32.6
CT	62.5	37.5
HI	68.9	31.1
SC	63.9	36.1
SD	51.6	48.4
TX	58.2	41.8
WY	65.4	34.6
Total n	1,455	875
Total %	62.4	37.6
State Avg. %	62.6	37.4

Age of Family Member

Table 6
Age of Child

State	Average Age	Range
CA-RCOC	9.8	3-18
CT	11.3	1-18
HI	11.2	1-17
SC	5.4	1-18
SD	11.5	1-19
TX	13.4	1-21
WY	11.9	1-21
Total n	2,322	
Total Avg.	11.2	1-21
State Avg.	10.6	

Race of Family Member

Table 7
Race/Ethnicity of Child (%)

State	White	Black/ African	Asian	Am. Indian/ Alaska Native	Hawaiian/ Pac. Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
CA-RCOC	41.4	2.6	18.0	2.2	1.2	7.8	1.0	34.9
CT	72.1	11.5	0.5	1.0	0.5	5.3	0.0	13.9
HI	32.5	6.1	43.6	4.3	35.0	25.2	2.5	8.0
SC	61.9	32.5	2.5	1.3	0.0	0.6	0.0	4.4
SD	89.3	2.8	2.2	5.6	0.6	0.6	0.0	0.6
TX	59.4	10.5	2.1	1.6	0.3	3.3	0.3	26.6
WY	88.9	1.1	1.1	2.8	1.1	3.9	1.7	6.1
Total n	1,352	190	222	53	71	140	16	501
Total %	58.1	8.2	9.5	2.3	3.0	6.0	0.7	21.5
State Avg. %	63.6	9.6	10.0	2.7	5.5	6.7	0.8	13.5

More Than One Person with Disabilities Living in Household

Table 8
More Than One Person in Household with a Dev. Disability

State	% Yes	% No
CA-RCOC	15.2	84.8
CT	18.8	81.2
HI	13.8	86.2
SC	18.8	81.2
SD	14.6	85.4
TX	12.5	87.5
WY	15.7	84.3
Total n	345	1,989
Total %	14.8	85.2
State Avg. %	15.6	84.4

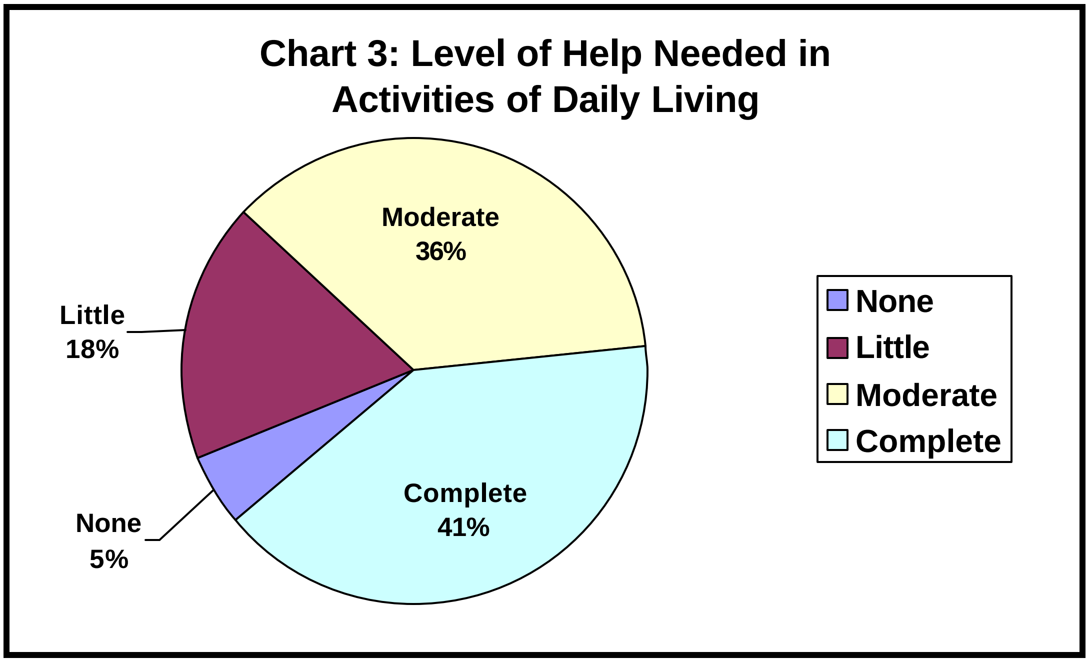


Table 9 Level of Help with Daily Activities				
State	None	Little	Moderate	Complete
CA-RCOC	4.1	18.1	38.6	39.2
CT	5.6	23.3	34.0	37.2
HI	6.7	23.3	31.3	38.7
SC	5.0	17.6	37.7	39.6
SD	2.7	16.2	48.6	32.4
TX	2.4	6.1	25.8	65.8
WY	8.3	21.7	38.9	31.1
Total n	97	355	804	1,090
Total %	4.1	15.1	34.3	46.5
State Avg. %	5.0	18.0	36.4	40.6

Family Member’s Disabilities

Table 10A
Disabilities of Child

State	Mental Retardation	Other Dev. Disability	Mental Illness	Autism	Cerebral Palsy	Brain Injury
CA-RCOC	38.2	15.0	3.8	42.3	17.4	3.5
CT	57.0	34.6	8.4	40.2	16.4	6.1
HI	39.4	34.4	2.5	37.5	18.8	5.6
SC	13.1	37.3	6.5	24.8	13.7	8.5
SD	47.5	37.6	4.4	18.2	23.8	8.3
TX	55.4	42.9	6.0	17.3	47.7	18.8
WY	56.1	33.3	8.3	25.0	22.9	11.1
Total n	1071	739	126	683	648	235
Total %	46.0	31.8	5.4	29.3	27.9	10.1
State Avg. %	43.8	33.6	5.7	29.3	23.0	8.8

Table 10B
Disabilities of Child

State	Seizure Disorder/	Chemical Dependency	Vision/Hearing Impairments	Physical Disability	Commun. Disorder	Down Syndrome	Other Disability
CA-RCOC	17.4	0.7	15.1	14.1	19.2	14.2	14.7
CT	25.2	1.4	20.1	23.8	34.6	13.6	23.5
HI	28.1	0.6	17.5	34.4	19.4	9.4	22.5
SC	15.8	2.0	17.1	22.2	19.0	5.9	32.9
SD	28.7	0.6	37.6	38.1	27.1	21.5	24.3
TX	51.9	1.6	46.0	58.5	45.2	4.9	39.8
WY	23.9	1.7	21.7	31.1	21.7	12.8	26.7
Total n	728	28	636	802	694	250	628
Total %	31.3	1.2	27.3	34.5	29.8	10.7	27.0
State Avg. %	27.3	1.2	25.0	31.7	26.6	11.8	26.3

Characteristics of Respondents

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

- Across all states, nearly all (92%) of respondents were under 55 years old, with most respondents (72%) falling in the 35 to 54 year old age category.
- The vast majority of respondents were parents of children with disabilities (96%). The remaining respondents were grandparents (3%), or others(1%).
- In total, 98% of all respondents were the primary caregiver for their child with disabilities. This was consistent across all of the states.
- Most respondents indicated that they were in good (54%) or excellent (27%) health. Nineteen percent, however, categorized their health as being fair or poor.
- Thirty-six percent of respondents (36%) had an annual household income (including all wage earners within the household) of $25,000 or less. 27% had a household income between $25,001 and $50,00, and 37% had an income over $50,000.

Age of Respondent

Table 11
Age of Respondent (%)

State	Under 35	35-54	55-74	75 or Older
CA-RCOC	19.6	71.3	8.8	0.3
CT	12.7	81.2	5.6	0.5
HI	17.3	73.2	9.5	0.0
SC	41.2	51.5	7.3	0.0
SD	16.2	77.8	5.9	0.0
TX	13.1	77.4	9.4	0.1
WY	23.3	68.9	7.8	0.0
Total n	431	1,730	197	4
Total %	18.2	73.2	8.3	0.2
State Avg. %	20.5	71.6	7.8	0.1

Relationship of Respondent to Individual with Disabilities

Table 12
Relationship to Child with Disabilities (%)

State	Parent	Sibling	Grand-parent	Other
CA-RCOC	97.8	0.0	1.3	0.9
CT	95.7	0.0	3.8	0.5
HI	92.9	0.6	4.7	1.8
SC	95.2	0.0	4.2	0.6
SD	96.8	0.5	2.7	0.0
TX	93.9	0.1	4.3	1.7
WY	96.7	0.0	1.7	1.7
Total n	2,256	3	73	27
Total %	95.6	0.1	3.1	1.1
State Avg. %	95.6	0.2	3.2	1.0

Respondent’s Role as Primary Caregiver

Table 13
Respondent is Primary Caregiver

State	% Yes	% No
CA-RCOC	98.2	1.8
CT	99.0	1.0
HI	95.8	4.2
SC	99.4	0.6
SD	98.9	1.1
TX	98.4	1.6
WY	99.4	0.6
Total n	2,295	37
Total %	98.4	1.6
State Avg. %	98.4	1.6

Health of Respondent

Table 14 Health of Respondent (%)				
State	Excellent	Good	Fair	Poor
CA-RCOC	26.7	53.9	17.7	1.8
CT	27.0	50.2	19.4	3.3
HI	26.2	56.0	14.9	3.0
SC	24.8	56.4	14.5	4.2
SD	28.8	57.6	13.6	0.0
TX	22.1	52.1	21.9	3.9
WY	35.6	51.7	11.7	1.1
Total n	612	1,261	425	63
Total %	25.9	53.4	18.0	2.7
State Avg. %	27.3	54.0	16.2	2.5

Household Income

Table 15 Household Income					
State	Below $15,000	$15,001 - $25,000	$25,001 - $50,000	$50,001 - $75,000	Over $75,000
CA-RCOC	22.8	19.8	19.8	13.4	24.2
CT	17.6	15.1	23.9	20.0	23.4
HI	20.2	15.3	29.4	16.6	18.4
SC	36.6	10.5	20.9	16.3	15.7
SD	15.0	14.4	35.0	24.4	11.1
TX	Texas did not ask this question.				
WY	17.5	11.1	35.1	21.1	15.2
Total n	328	244	379	259	303
Total %	21.7	16.1	25.0	17.1	20.0
State Avg. %	21.6	14.4	27.4	18.6	18.0

Services and Supports Received

- Across participating states, on average, specialized services and supports were most often utilized (75%) by families having a child with disabilities.

- Additionally, 41% obtained in-home supports, 40% used out-of-home respite, 36% received SSI financial support, and 32% received other types of financial support.

Table 16
Services and Supports Received (%)

State	SSI financial support	Other financial support	In-home support	Out-of-home respite care	Early intervention	Transportation	Specialized services/ supports
CA-RCOC	39.2	10.3	31.7	37.4	0	8.4	65.5
CT	28	42.4	26.1	29.4	12.9	5.8	67
HI	26.8	30.8	34.5	40.3	13.8	20.5	69.6
SC	37	16.3	40.9	15.2	53.2	4.8	85
SD	33.3	63.1	21.7	53.8	15.1	7.7	87.4
TX	43.7	22.6	89.1	37.3	4.7	16.7	73.5
WY	42.9	41.2	46.7	69.5	19.0	10.3	80.6
Total n	900	579	1,180	897	216	268	1,686
Total Avg. %	38.4	25.5	50.9	39.0	14.3	11.5	72.8
State Avg. %	35.8	32.4	41.5	40.4	17.0	10.6	75.5

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 six states and one local DD authority that conducted this survey).
- The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state results).
- In the Tables, a **(⇧)** next to a state name indicates, that its results are **5% or more ABOVE** the state average among respondents who answered "Always or Usually" to each question.
- In the Tables, a **(⇧⇧)** next to a state name indicates, that its results are **10% or more ABOVE** the state average among respondents who answered "Always or Usually" to each question.
- A **(⇩)** next to a state name indicates that its results are **5% or more BELOW** the state average among respondents who answered "Always or Usually" to each question.
- A **(⇩⇩)** next to a state name indicates that its results are **10% or more BELOW** the state average among respondents who answered "Always or Usually" to each question.
- In general, when a Table has many arrows (up and down), it indicates that there is considerable variance in results among states. When there are few arrows, responses across states are more uniform.

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

Information and Planning

- Across states, 41% of respondents indicated they regularly receive information about the services and supports available to them. Individual state results varied considerably, ranging from 21% in Connecticut to 56% in South Dakota.

- Among those who receive information, about half (55%) found the information easy to understand, while the remaining 45% found the information, at least sometimes, difficult to understand.

- Across states, less than half (47%) of respondents indicated they regularly receive information about their child's disability or development. Once again, individual state results varied quite a bit, ranging from 32% in Connecticut to 64% in South Carolina.

- Among those who receive this information, 62% found it easy to understand, and the remaining 38% found the information, at least sometimes, difficult to understand.

- Only 46% of respondents stated they got enough information to help them participate in planning. A larger percentage (54%) indicated they only sometimes or seldom had enough information.

- Three-quarters (77%) of respondents, on average across states, indicated that they typically help in developing their family member's service plan. These results varied from 63% in Connecticut to 93% in Wyoming.

- Of those families with a service plan, 73% stated that the plan included things important to the respondent. One quarter of respondents (27%) indicated that the plan only sometimes, seldom or never included things important to them.

- Across states, about half (56%) indicated that planning staff would help them figure out the supports they needed. However, a large percentage (44%) stated that this was only sometimes or even seldom the case.

- Across states, three-quarters (78%) of respondents felt that their choices and opinions were respected by staff.

- Only 37% of respondents indicated that planning staff discussed with them the public benefits that may or may not be available to them. Another quarter sometimes received this information, while 38% indicated that planning staff did not relay this information to them. Results were fairly consistent across states, with the exception of South Dakota (where almost half of families had these discussions).

- Among all respondents, 87% felt that agency staff were generally respectful and courteous. Across all states, these results were fairly consistent.

- Among all respondents, 65% felt that agency staff were generally effective.

- Across all states, 71% of respondents indicated they could typically contact staff when desired.

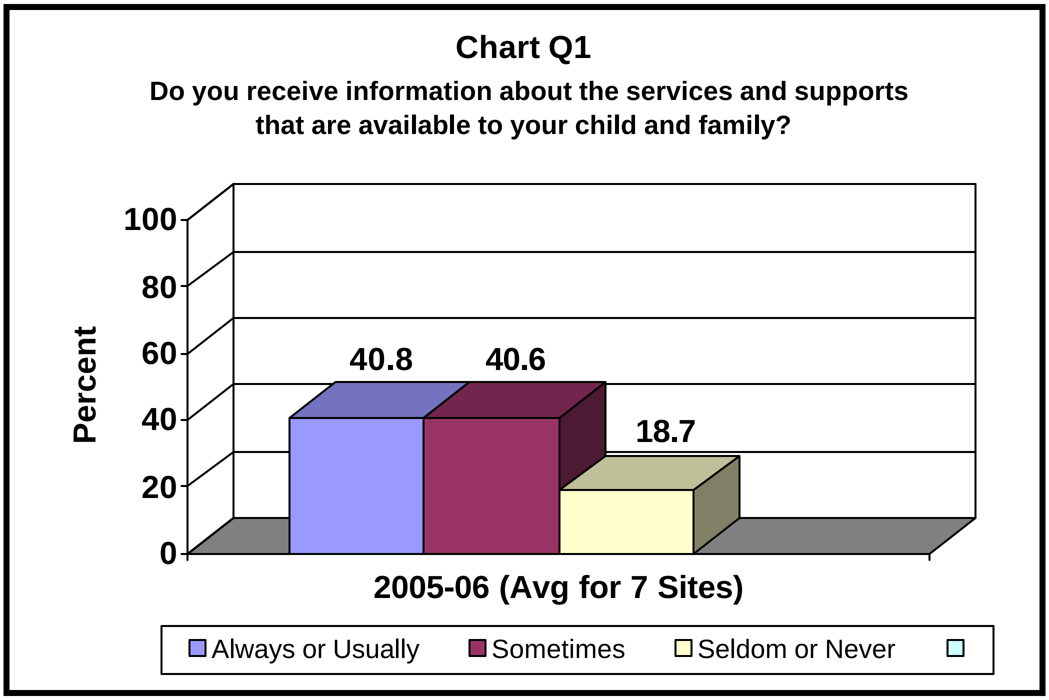


Chart Q1

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

Table Q1

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇧	48.1	38.3	13.6	668
CT	⇩⇩	21.0	45.7	33.3	210
HI		41.3	43.6	15.1	172
SC		39.8	39.1	21.1	161
SD	⇧⇧	56.0	35.3	8.7	184
TX	⇩	33.1	40.6	26.3	731
WY	⇧	46.0	41.5	12.5	176
Total %		**40.2**	**40.2**	**19.6**	**2,302**
State Average		**40.8**	**40.6**	**18.7**	**7**

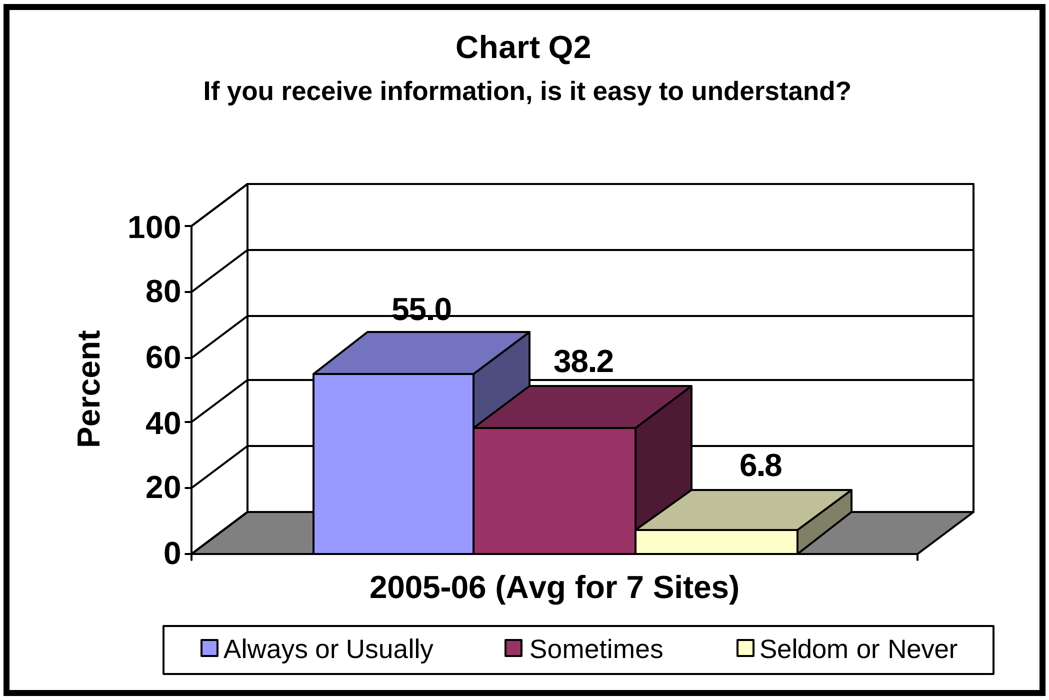


Chart Q2

If you receive information, is it easy to understand?

Table Q2

If you receive information, is it easy to understand?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇧	60.5	34.0	5.5	621
CT	⇩⇩	44.5	45.1	10.4	173
HI	⇩	49.4	45.7	4.9	164
SC	⇧	63.4	26.9	9.7	145
SD	⇧⇧	66.7	31.1	2.2	180
TX	⇩	48.0	43.6	8.4	665
WY		52.4	41.2	6.5	170
Total %		**54.5**	**38.7**	**6.8**	**2,118**
State Average		**55.0**	**38.2**	**6.8**	**7**

Chart Q3

Do you receive information about the status of your child's development?

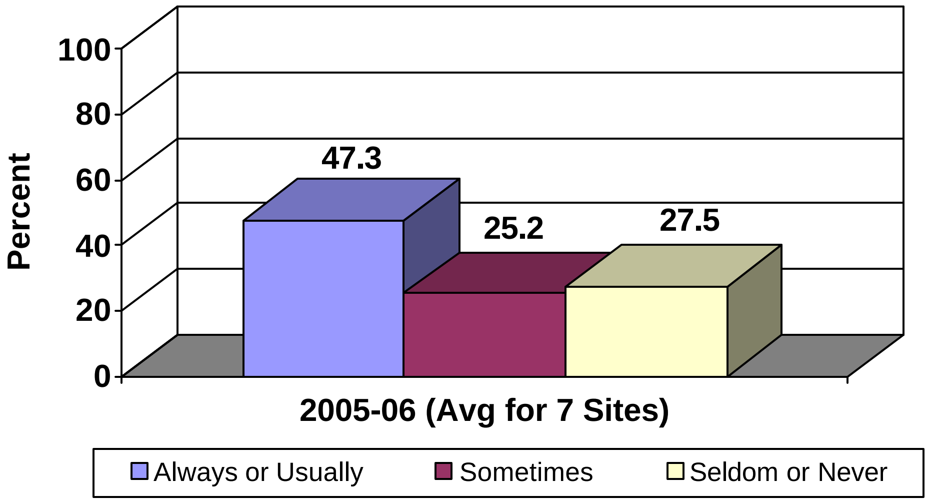


Table Q3

Do you receive information about the status of your child's development?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	40.8	30.1	29.1	625
CT	⇩⇩	32.3	21.2	46.6	189
HI		48.4	25.5	26.1	161
SC	⇧⇧	63.9	17.4	18.7	155
SD	⇧	53.4	28.7	17.8	174
TX	⇩	42.0	23.4	34.6	683
WY		50.0	30.2	19.8	172
Total %		**44.4**	**25.8**	**29.7**	**2,159**
State Average		**47.3**	**25.2**	**27.5**	**7**

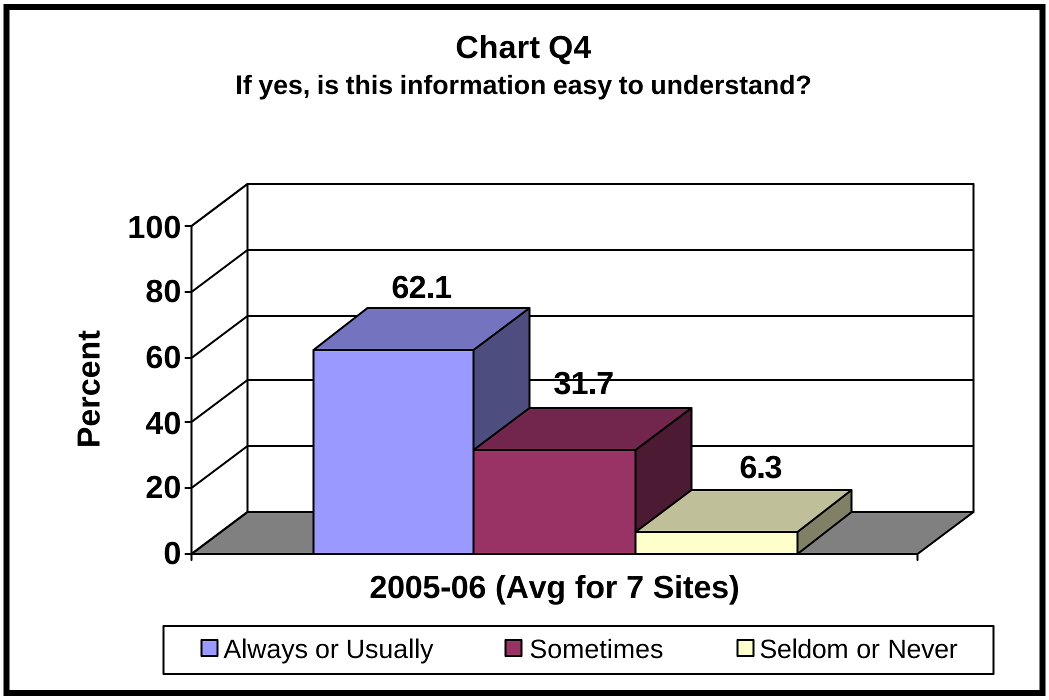


Chart Q4

If yes, is this information easy to understand?

Table Q4

If yes, is this information easy to understand?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		60.3	32.9	6.8	501
CT	⇩⇩	44.4	40.8	14.8	142
HI		62.5	35.9	1.6	128
SC	⇧⇧	75.6	21.5	3.0	135
SD	⇧	69.7	27.0	3.3	152
TX		58.4	33.4	8.2	500
WY		63.7	30.1	6.2	146
Total %		**60.9**	**32.3**	**6.8**	**1,704**
State Average		**62.1**	**31.7**	**6.3**	**7**

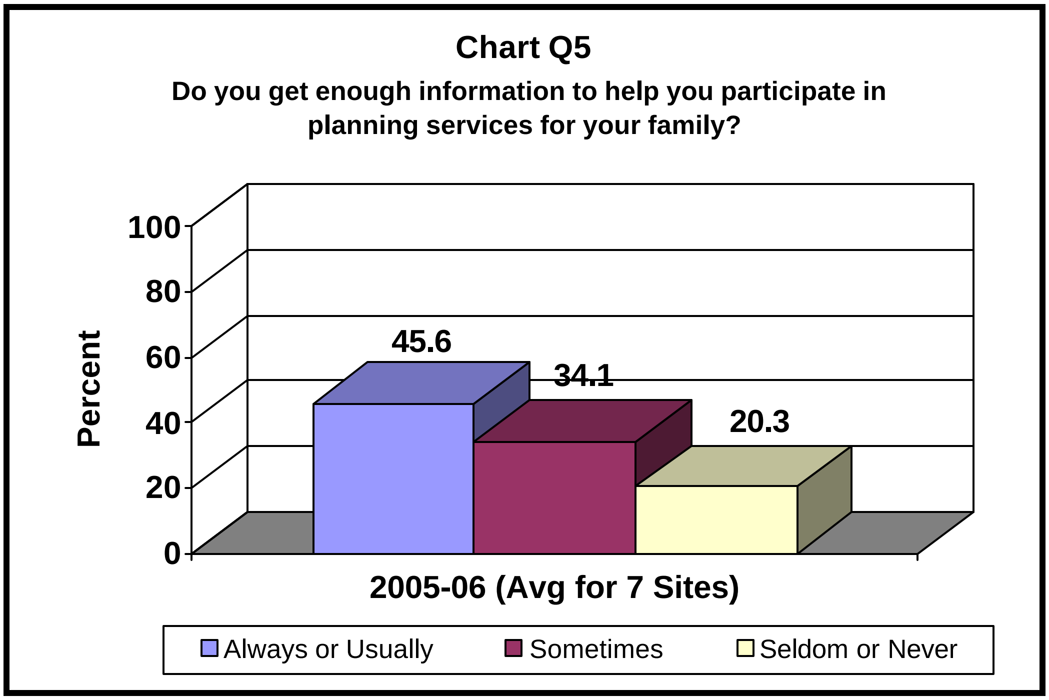


Chart Q5

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

Table Q5

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	40.5	37.6	21.9	620
CT	⇩⇩	23.7	36.6	39.7	194
HI		41.2	38.8	20.0	165
SC	⇧⇧	57.6	28.5	13.9	151
SD	⇧⇧	57.3	31.5	11.2	178
TX	⇩	40.1	35.2	24.7	688
WY	⇧⇧	58.6	30.8	10.7	169
Total %		**42.9**	**35.2**	**21.9**	**2,165**
State Average		**45.6**	**34.1**	**20.3**	**7**

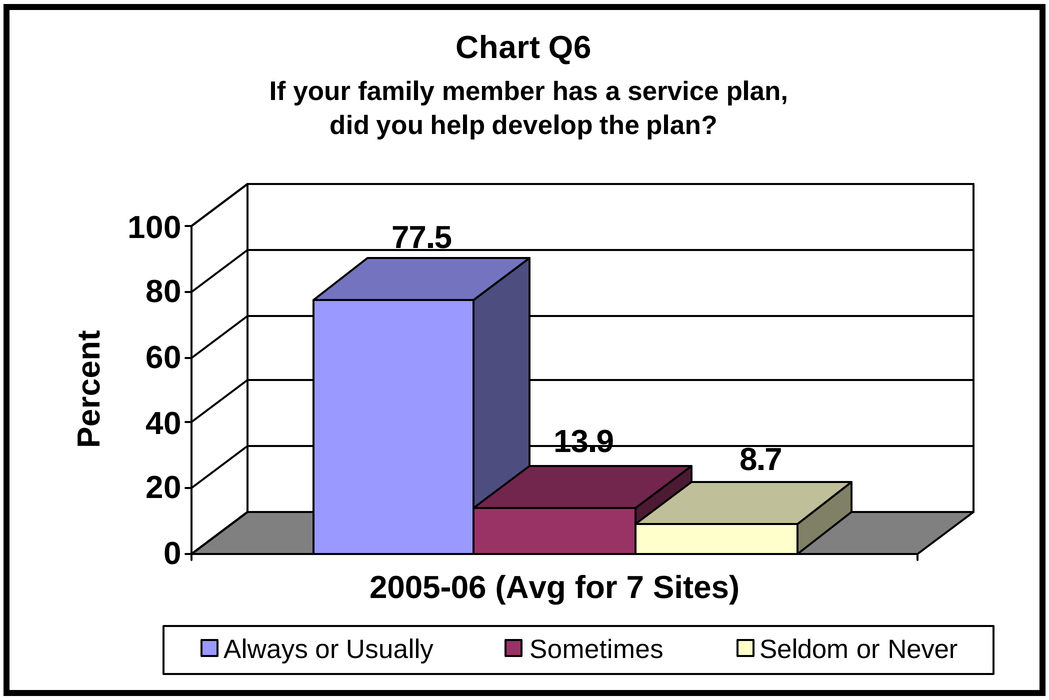


Chart Q6

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

Table Q6

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	69.8	17.6	12.6	524
CT	⇩⇩	63.5	17.4	19.1	115
HI		76.6	19.5	3.9	154
SC		76.9	14.6	8.5	130
SD	⇧⇧	88.4	9.1	2.4	164
TX		73.9	15.1	11.0	575
WY	⇧⇧	93.2	3.7	3.1	161
Total %		**75.5**	**14.8**	**9.7**	**1,823**
State Average		**77.5**	**13.9**	**8.7**	**7**

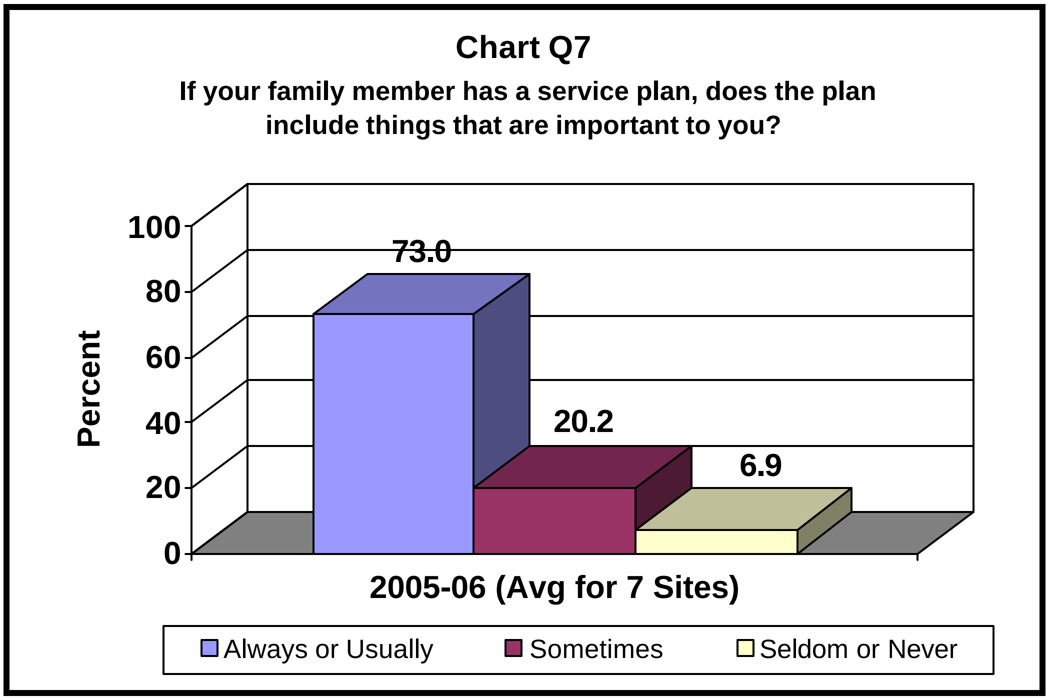


Table Q7

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
CA-RCOC	⇩⇩	60.4	28.3	11.3	512
CT	⇩⇩	54.7	27.4	17.9	117
HI	⇧	80.6	16.1	3.2	155
SC	⇧	79.5	18.9	1.6	127
SD	⇧⇧	83.2	13.7	3.1	161
TX		72.2	19.4	8.4	582
WY	⇧	80.1	17.4	2.5	161
Total %		**70.6**	**21.4**	**7.9**	**1,815**
State Average		**73.0**	**20.2**	**6.9**	**7**

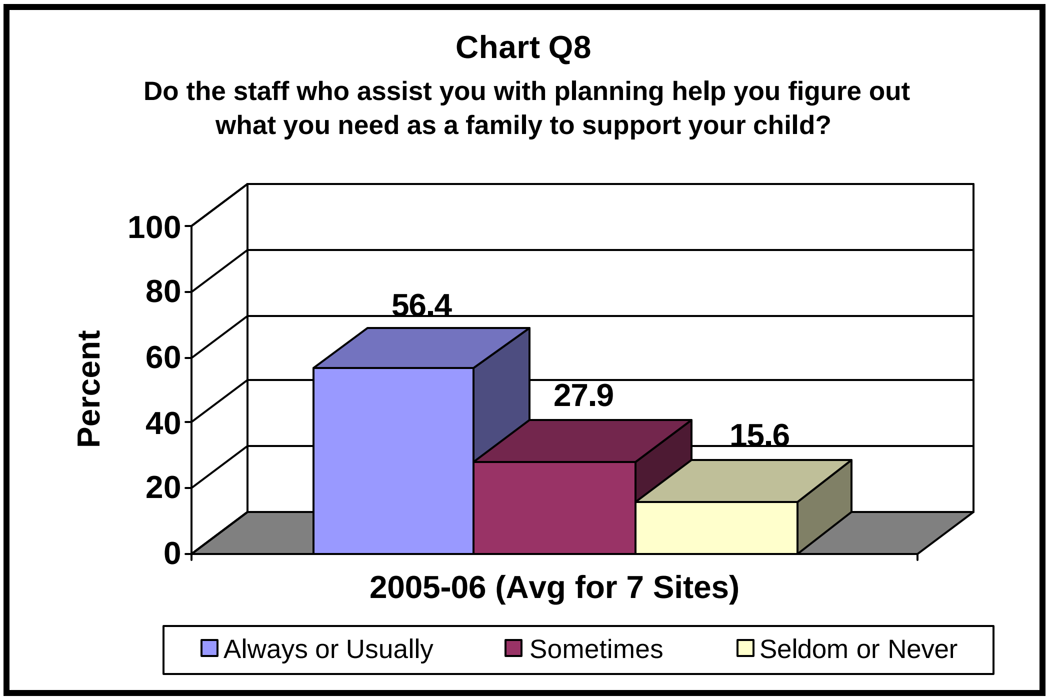


Table Q8

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩⇩	41.5	35.4	23.1	644
CT	⇩⇩	39.0	30.1	30.8	146
HI		58.2	30.9	10.9	165
SC	⇧	63.5	25.5	10.9	137
SD	⇧⇧	73.8	18.0	8.1	172
TX	⇩	50.4	30.9	18.7	637
WY	⇧⇧	68.4	24.6	7.0	171
Total %		**51.7**	**30.3**	**18.0**	**2,072**
State Average		**56.4**	**27.9**	**15.6**	**7**

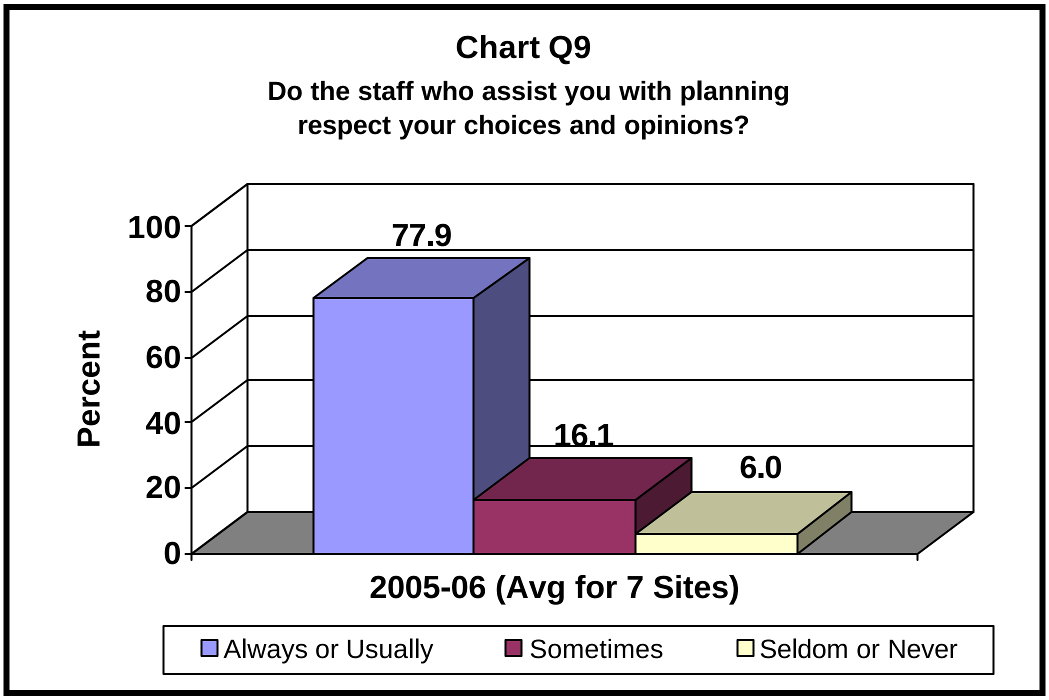


Chart Q9

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

Table Q9

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		74.3	20.7	5.0	614
CT	⇩⇩	67.8	16.8	15.4	143
HI		75.3	19.8	4.9	162
SC	⇧	84.9	11.5	3.6	139
SD	⇧	85.8	10.2	4.0	176
TX	⇩	72.0	20.3	7.7	636
WY	⇧	85.4	13.5	1.2	171
Total %		**75.8**	**18.1**	**6.1**	**2,041**
State Average		**77.9**	**16.1**	**6.0**	**7**

Chart Q10

Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)?

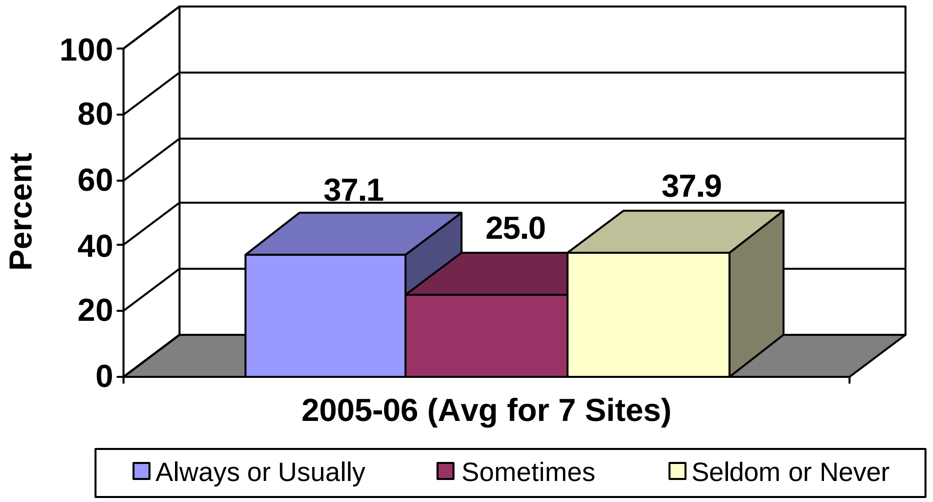


Table Q10

Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		35.2	28.6	36.2	597
CT	⇩⇩	24.7	17.3	58.0	162
HI		34.6	26.5	38.9	162
SC	⇧	42.4	21.2	36.4	132
SD	⇧⇧	49.7	28.1	22.2	167
TX		33.1	26.0	40.9	680
WY		39.9	27.5	32.7	153
Total %		**35.6**	**26.1**	**38.3**	**2,053**
State Average		**37.1**	**25.0**	**37.9**	**7**

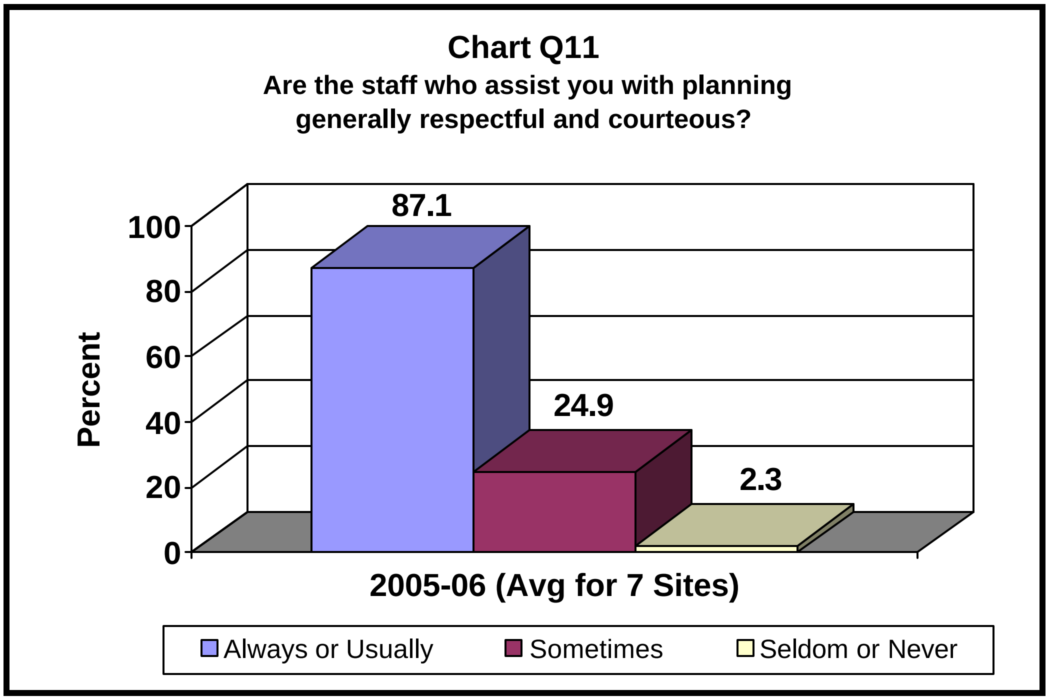


Chart Q11
Are the staff who assist you with planning generally respectful and courteous?

Table Q11

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		86.0	12.2	1.8	666
CT	⇩	81.9	11.9	6.3	160
HI		84.0	14.8	1.2	169
SC		88.7	10.0	1.3	150
SD	⇧	93.3	6.1	0.6	180
TX		82.5	113.5	4.0	669
WY	⇧	93.6	5.8	0.6	171
Total %		**85.9**	**11.6**	**2.5**	**2,165**
State Average		**87.1**	**24.9**	**2.3**	**7**

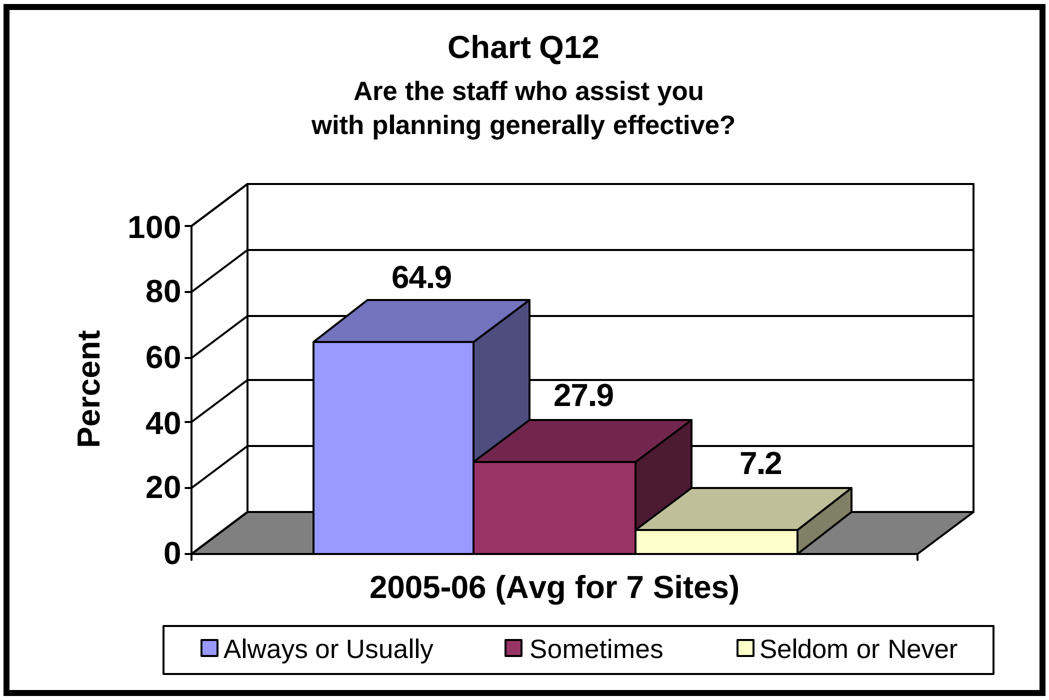


Chart Q12

Are the staff who assist you with planning generally effective?

Table Q12

Are the staff who assist you with planning generally effective?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	56.9	35.1	7.9	655
CT	⇩⇩	52.3	32.0	15.7	153
HI	⇩	59.3	33.3	7.4	162
SC		66.0	25.9	8.2	147
SD	⇧⇧	81.3	16.5	2.3	176
TX		62.7	30.3	7.1	651
WY	⇧⇧	75.7	22.5	1.7	173
Total %		**62.7**	**30.0**	**7.2**	**2,117**
State Average		**64.9**	**27.9**	**7.2**	**7**

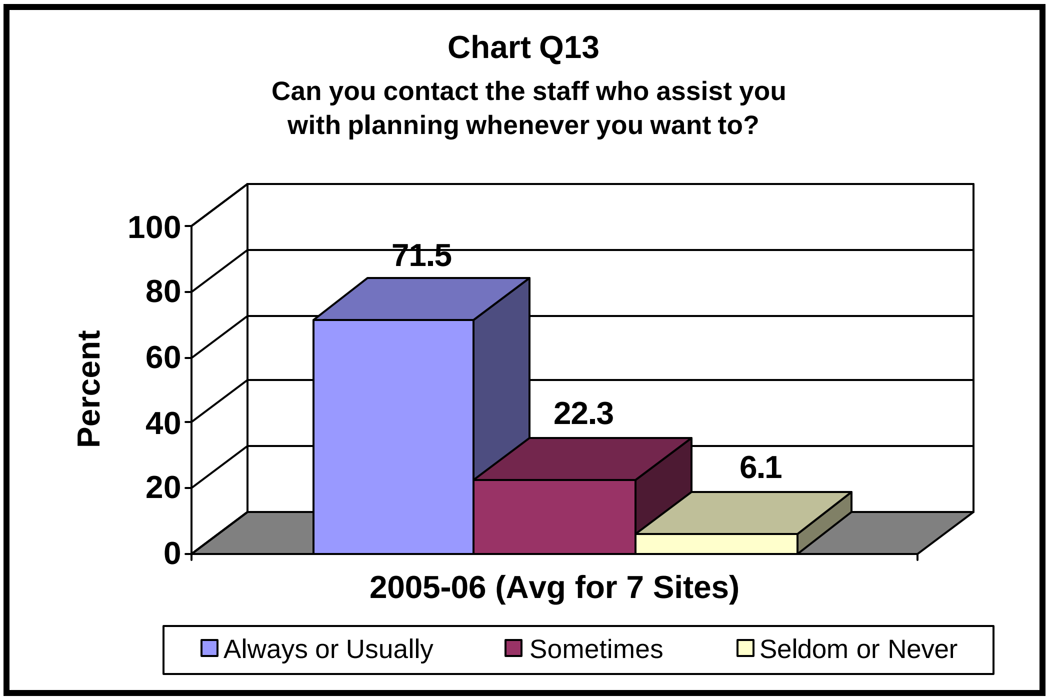


Chart Q13

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

Table Q13

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		71.8	22.9	5.3	663
CT	⇩⇩	58.5	27.7	13.8	159
HI	⇩	62.7	31.4	5.9	169
SC		71.5	21.2	7.3	151
SD	⇧⇧	86.4	12.4	1.1	177
TX		69.0	22.9	8.1	654
WY	⇧	80.9	17.9	1.2	173
Total %		**71.2**	**22.6**	**6.3**	**2,146**
State Average		**71.5**	**22.3**	**6.1**	**7**

Access to and Delivery of Services and Supports

- Overall, 67% of families stated their service coordinator helped them get needed supports when asked. Twenty-six percent said this happened sometimes, and 7% indicated that their service coordinator was rarely helpful in getting the assistance needed.

- About half of families (52%) said they always or usually get the services and supports needed. Thirty-seven percent got needed supports some of the time, and the remaining 11% seldom or never received needed supports.

- Half (49%) of respondents said that the supports received met their families' needs, although this varied from state to state. Another 39% said that the supports sometimes met their needs, while the remaining 11% seldom or never felt the supports offered met their family's needs.

- For about half of families (45%), supports were always or usually available when needed. However, even more families indicated that supports were only sometimes available (39%), or seldom/never available (16%) when needed.

- Seventy-eight percent of respondents stated that families in their area at least sometimes asked for different types of supports than the ones that were currently being offered.

- On the occasions when families did request different types of supports, only 32% indicated that the state agency or provider agency was usually or always responsive to these requests.

- Over half (54%) of families who asked for assistance in an emergency or crisis did not consistently receive help right away.

- Among respondents whose first language was not English, a majority (70%) indicated that staff or translators were available to speak with them in their preferred languages. Fifteen percent indicated that staff/translators were sometimes available, and the remaining 15% stated that staff/translators who spoke in the families' preferred languages were not available.

- Among respondents who had children who did not speak English, or who used a different means to communicate (e.g., sign language, communication board), 43% of families said there were enough support staff regularly available who could communicate with their child. The remaining 57%, however, said capable staff were only sometimes, seldom or never available.

- A little more than half of respondents (56%) felt their child had access to the special equipment or accommodations needed.

- The vast majority of respondents (91%) felt that they had access to health services for their child.

- Slightly fewer families (86%) felt they had access to appropriate dental services for their child.

- Nearly all respondents (93%) felt they had access to necessary medications for their child.

- A majority of respondents (57%) indicated that frequent changes in support staff were a problem for their family at least some of the time.

- A large majority of families (85%) felt that support staff were respectful and courteous.

Chart Q14

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

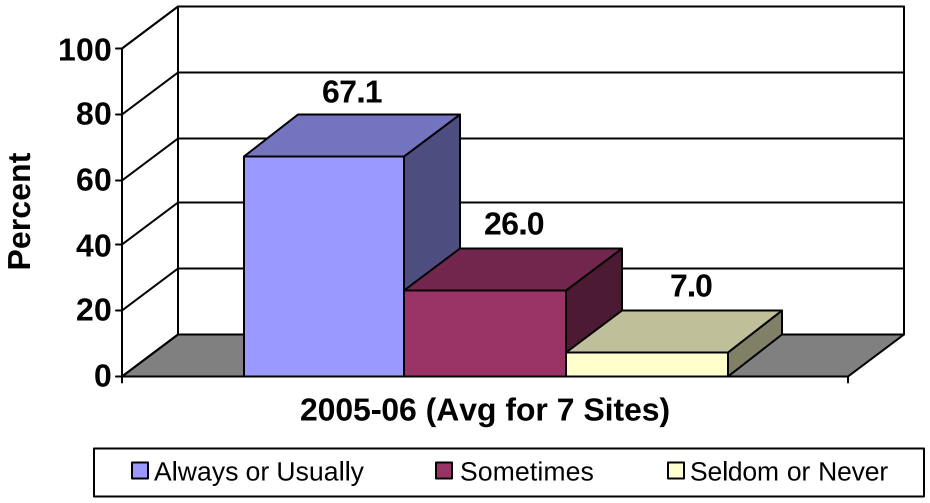


Table Q14

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	61.3	29.8	8.9	652
CT	⇩⇩	46.8	36.4	16.8	173
HI		66.3	27.8	5.9	169
SC		62.6	29.9	7.5	147
SD	⇧⇧	86.1	12.8	1.1	180
TX		68.8	24.9	6.2	722
WY	⇧⇧	77.6	20.1	2.3	174
Total %		**66.4**	**26.4**	**7.2**	**2,217**
State Average		**67.1**	**26.0**	**7.0**	**7**

Chart Q15

Does your family get the services and supports you need?

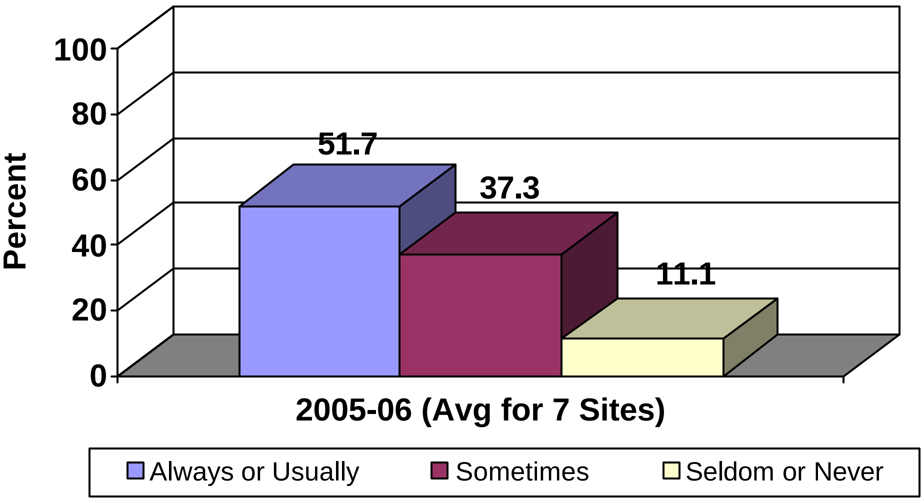


Table Q15

Does your family get the services and supports you need?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	44.7	42.3	13.1	636
CT	⇩⇩	29.0	47.8	23.1	186
HI		48.8	39.9	11.3	168
SC		50.6	35.1	14.3	154
SD	⇧⇧	73.8	24.6	1.6	183
TX		52.6	39.1	8.3	734
WY	⇧⇧	62.3	32.0	5.7	175
Total %		**50.4**	**38.8**	**10.8**	**2,236**
State Average		**51.7**	**37.3**	**11.1**	**7**

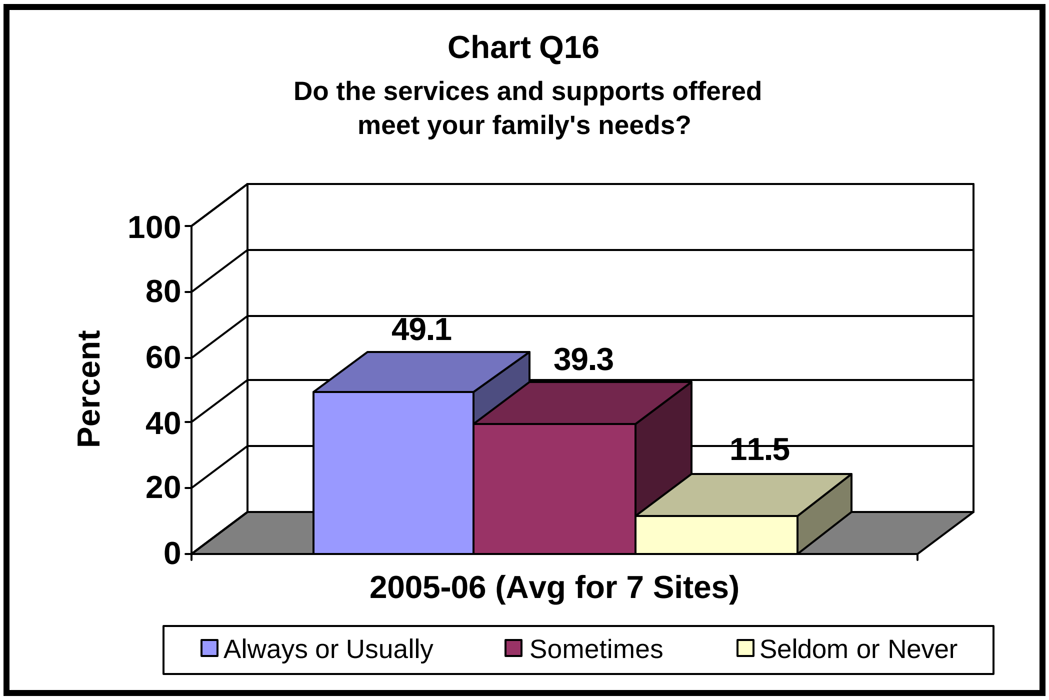


Chart Q16
Do the services and supports offered
meet your family's needs?

Table Q16
Do the services and supports offered meet your family's needs?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	41.1	45.4	13.4	632
CT	⇩⇩	25.0	44.3	30.7	176
HI		50.9	42.3	6.7	163
SC		51.3	36.7	12.0	150
SD	⇧⇧	70.3	27.0	2.7	185
TX		51.1	40.1	8.8	738
WY	⇧	54.3	39.4	6.3	175
Total %		**48.0**	**40.7**	**11.2**	**2,219**
State Average		**49.1**	**39.3**	**11.5**	**7**

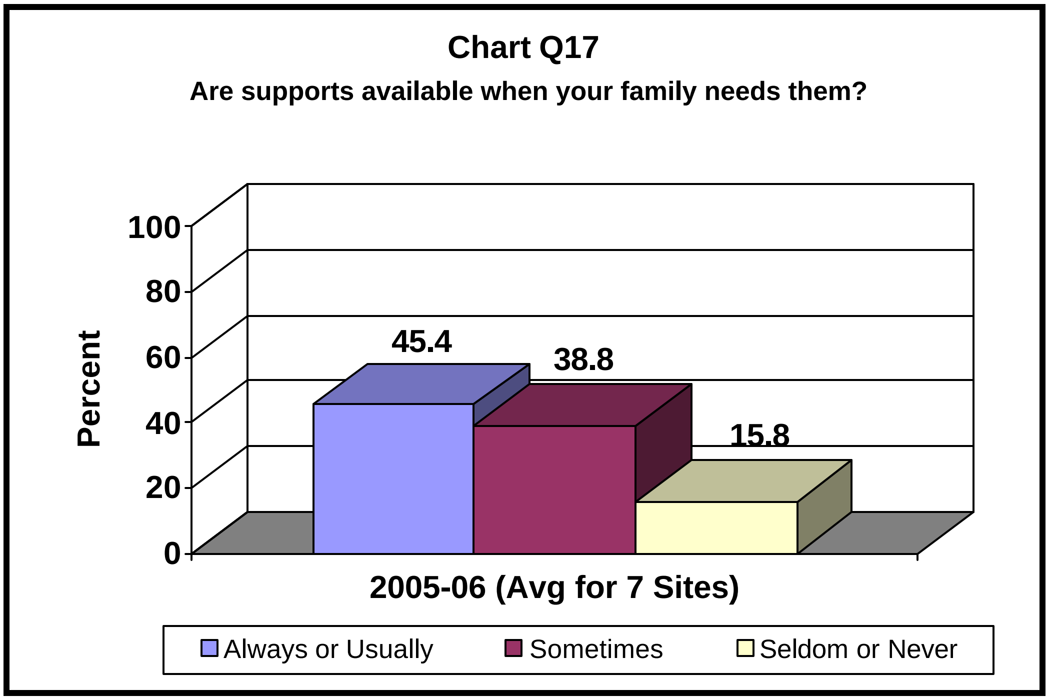


Chart Q17

Are supports available when your family needs them?

Table Q17

Are supports available when your family needs them?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	40.1	42.2	17.7	593
CT	⇩⇩	24.4	39.9	35.7	168
HI		42.1	39.6	18.3	164
SC		47.0	36.9	16.1	149
SD	⇧⇧	66.9	30.4	2.8	181
TX		45.4	43.0	11.6	723
WY	⇧	52.0	39.9	8.1	173
Total %		**44.5**	**40.5**	**15.0**	**2,151**
State Average		**45.4**	**38.8**	**15.8**	**7**

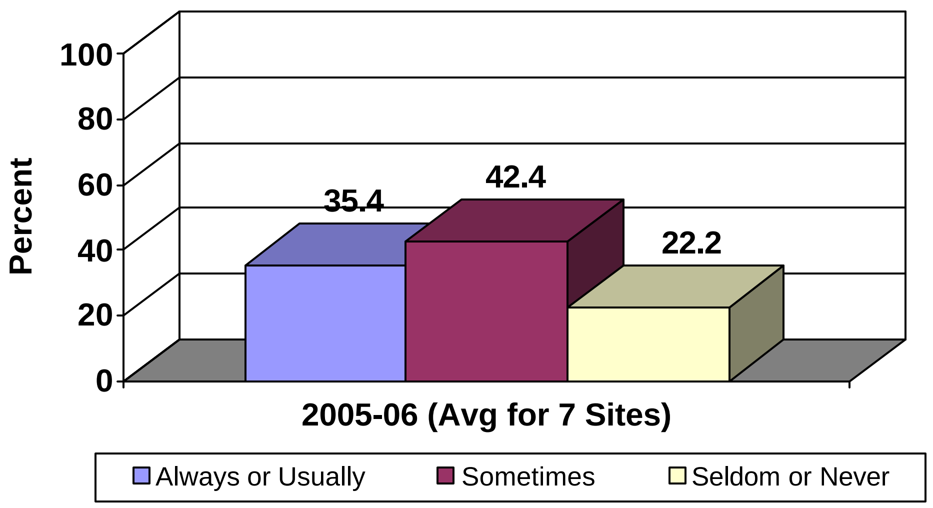


Chart Q18

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

Table Q18

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

State	Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	30.8	42.3	26.9	227
CT	30.1	42.2	27.7	83
HI	42.9	35.7	21.4	70
SC	38.6	31.4	30.0	70
SD	29.9	54.5	15.6	77
TX	36.4	42.1	21.5	316
WY	38.9	48.9	12.2	90
Total %	**34.8**	**42.6**	**22.6**	**933**
State Average	**35.4**	**42.4**	**22.2**	**7**

Chart Q19

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

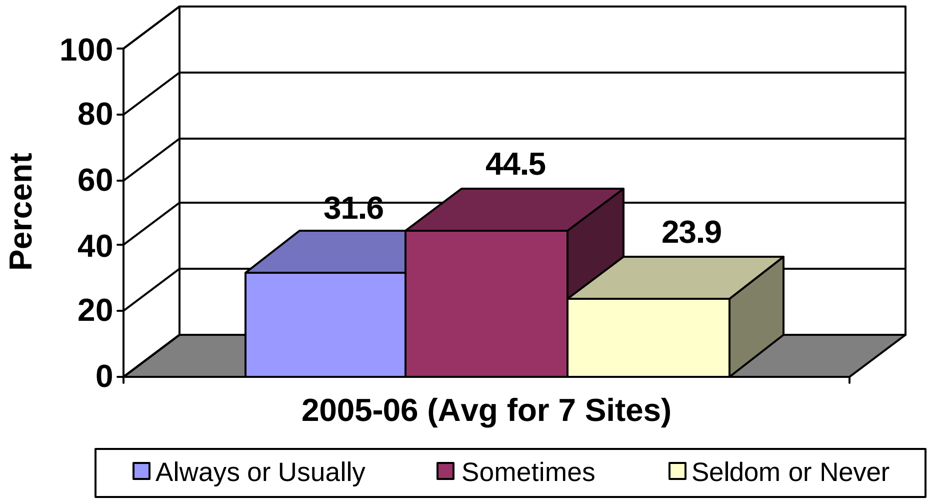


Table Q19

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇧⇧	43.0	37.9	19.1	235
CT	⇩⇩	15.3	37.3	47.5	59
HI	⇧	39.3	41.1	19.6	56
SC	⇩	25.5	46.8	27.7	47
SD		33.3	55.0	11.7	60
TX		33.9	44.5	21.7	254
WY		31.1	48.6	20.3	74
Total %		**34.8**	**43.1**	**22.2**	**785**
State Average		**31.6**	**44.5**	**23.9**	**7**

Chart Q20

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

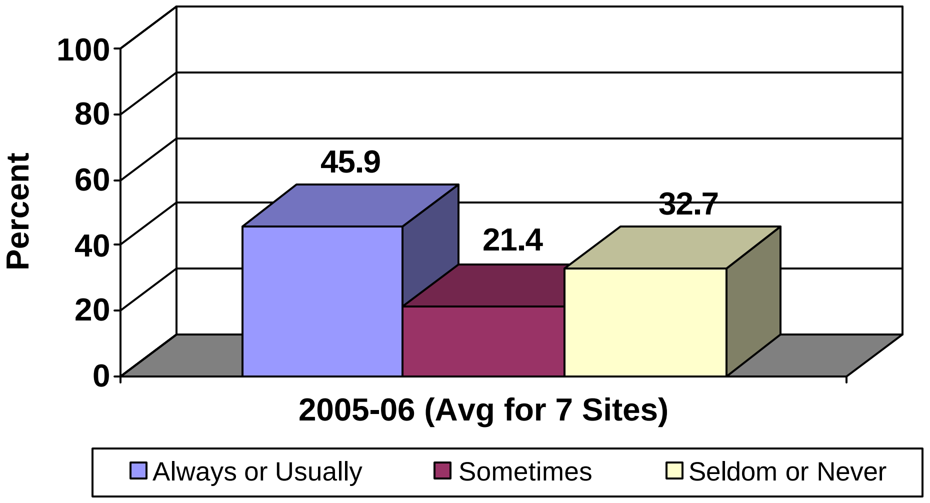


Table Q20

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	38.5	24.0	37.5	288
CT	⇩⇩	30.2	17.4	52.3	86
HI	⇩⇩	31.8	28.2	40.0	85
SC		45.7	24.3	30.0	70
SD	⇧⇧	74.5	14.9	10.6	94
TX		46.7	21.1	32.2	422
WY	⇧	53.8	19.8	26.4	91
Total %		**45.1**	**21.7**	**33.3**	**1,136**
State Average		**45.9**	**21.4**	**32.7**	**7**

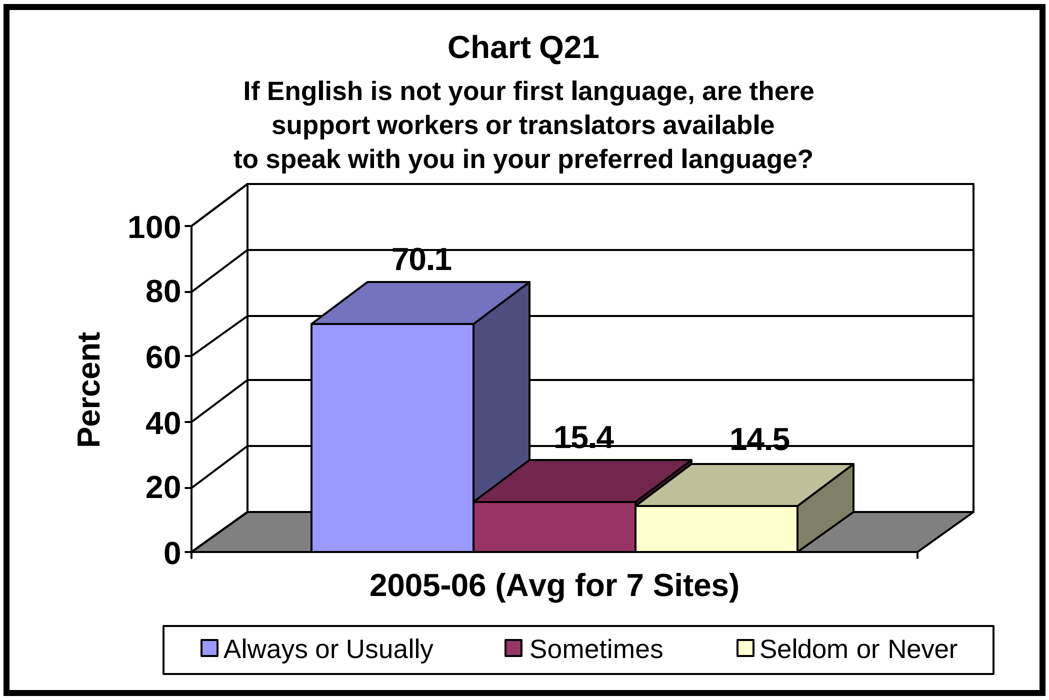


Chart Q21

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

Table Q21

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇧	77.1	14.9	8.0	275
CT		66.7	16.7	16.7	24
HI	⇩⇩	59.3	25.9	14.8	27
SC		71.4	14.3	14.3	14
SD		75.0	0.0	25.0	4
TX		71.4	15.8	12.8	133
WY		70.0	20.0	10.0	10
Total %		**73.7**	**15.8**	**10.5**	**487**
State Average		**70.1**	**15.4**	**14.5**	**7**

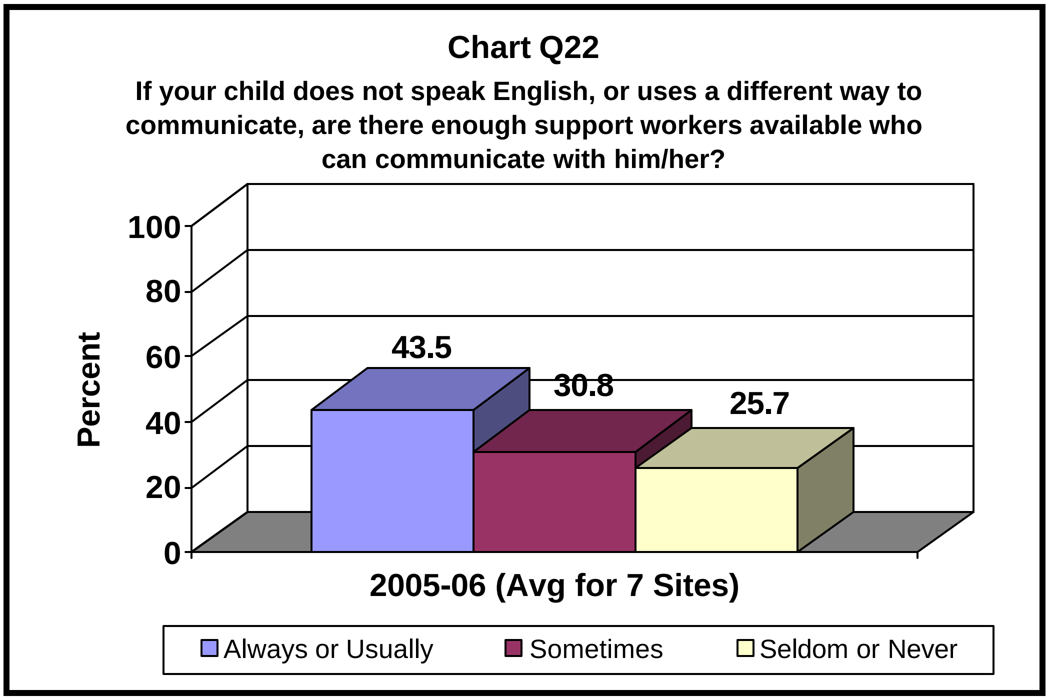


Chart Q22

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

Table Q22
If your child 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
CA-RCOC	⇧⇧	57.9	24.0	18.0	183
CT		40.8	24.5	34.7	49
HI		42.0	28.0	30.0	50
SC	⇧	53.3	30.0	16.7	30
SD	⇩⇩	26.7	43.3	30.0	30
TX		40.2	25.8	34.0	209
WY		43.3	40.0	16.7	30
Total %		**46.1**	**27.2**	**26.7**	**581**
State Average		**43.5**	**30.8**	**25.7**	**7**

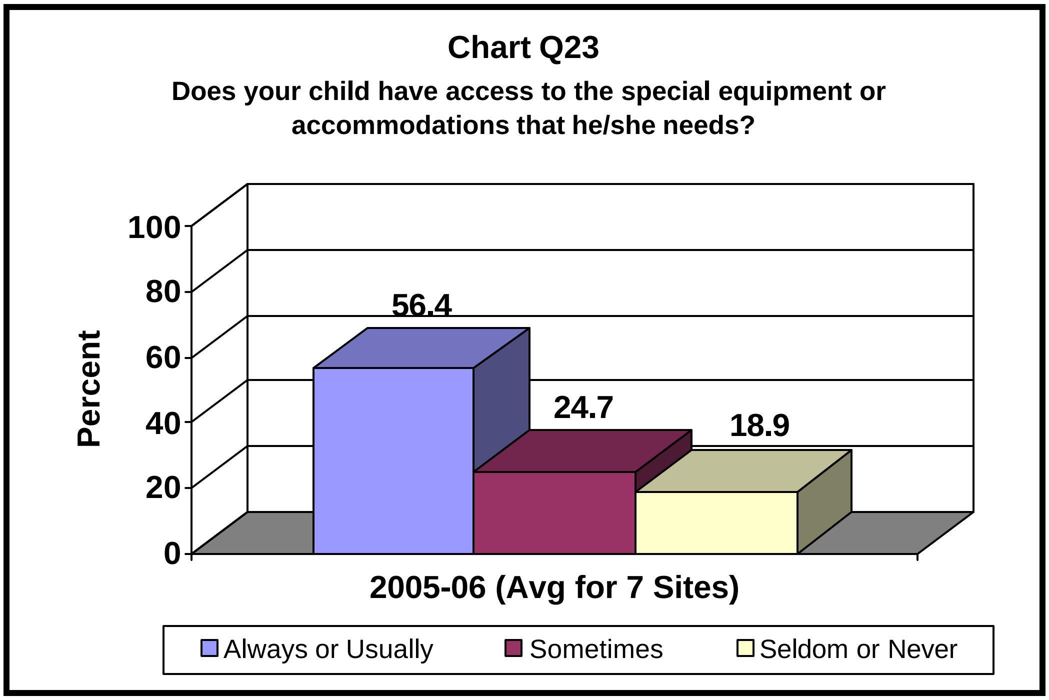


Chart Q23

Does your child have access to the special equipment or accommodations that he/she needs?

Table Q23

Does your child have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	49.4	20.3	30.3	261
CT	⇩⇩	45.1	30.4	24.5	102
HI	⇩	49.5	28.9	21.6	97
SC	⇩	50.9	17.0	32.1	53
SD	⇧⇧	74.2	20.8	5.0	120
TX	⇧	63.2	25.0	11.8	636
WY	⇧	62.5	30.8	6.7	120
Total %		**58.7**	**24.6**	**16.6**	**1,389**
State Average		**56.4**	**24.7**	**18.9**	**7**

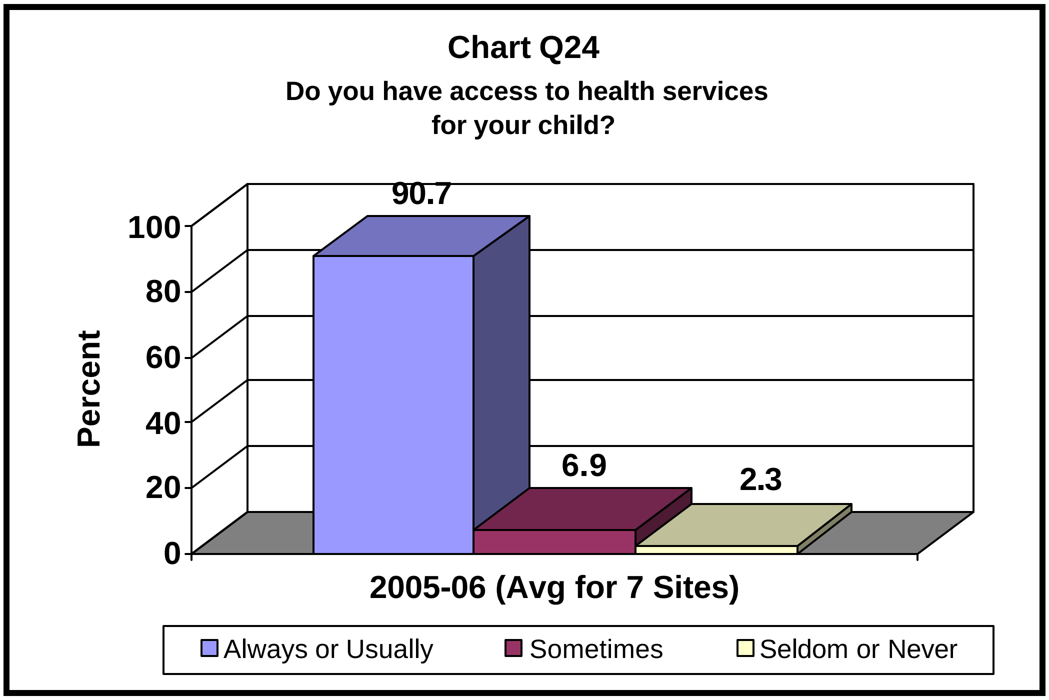


Chart Q24

Do you have access to health services for your child?

Table Q24

Do you have access to health services for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		89.5	7.7	2.8	640
CT		86.9	8.9	4.2	191
HI		89.7	7.9	2.4	165
SC		86.8	11.3	1.9	159
SD	⇧	98.4	1.1	0.5	185
TX		91.9	7.0	1.2	761
WY		92.0	4.5	3.4	176
Total %		**90.8**	**7.0**	**2.2**	**2,277**
State Average		**90.7**	**6.9**	**2.3**	**7**

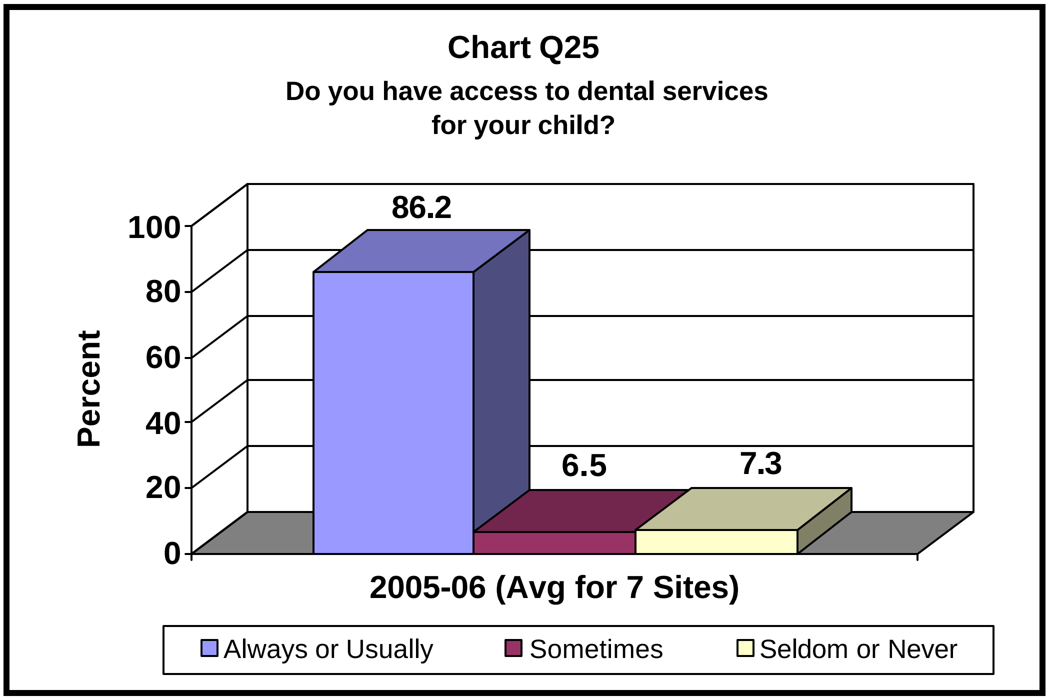


Table Q25
Do you have access to dental services for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		83.2	8.9	7.8	638
CT	⇩	79.1	8.0	12.8	187
HI		87.0	5.9	7.1	169
SC		86.3	5.2	8.5	153
SD	⇧	94.5	2.2	3.3	181
TX		88.0	7.7	4.3	750
WY		85.0	7.5	7.5	173
Total %		**86.0**	**7.3**	**6.7**	**2,251**
State Average		**86.2**	**6.5**	**7.3**	**7**

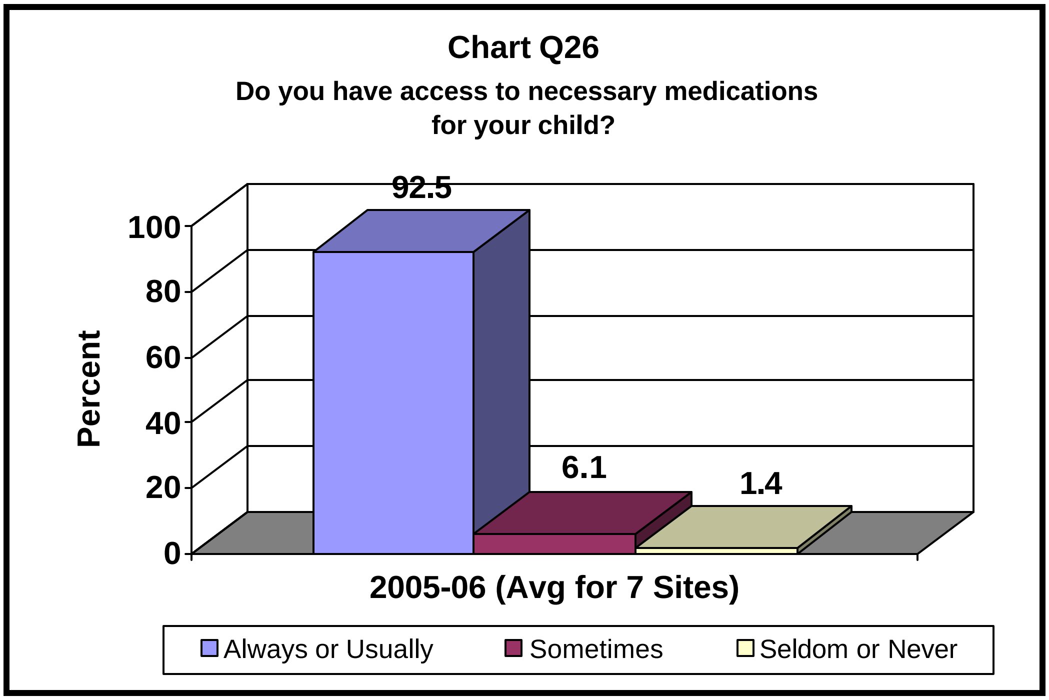


Chart Q26

Do you have access to necessary medications for your child?

Table Q26

Do you have access to necessary medications for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		90.0	7.4	2.6	619
CT		87.6	9.0	3.4	177
HI		90.1	9.3	0.6	162
SC		90.8	7.2	2.0	152
SD	⇧	99.4	0.6	0.0	180
TX		95.1	4.4	0.5	758
WY		94.6	4.8	0.6	168
Total %		**92.7**	**5.9**	**1.4**	**2,216**
State Average		**92.5**	**6.1**	**1.4**	**7**

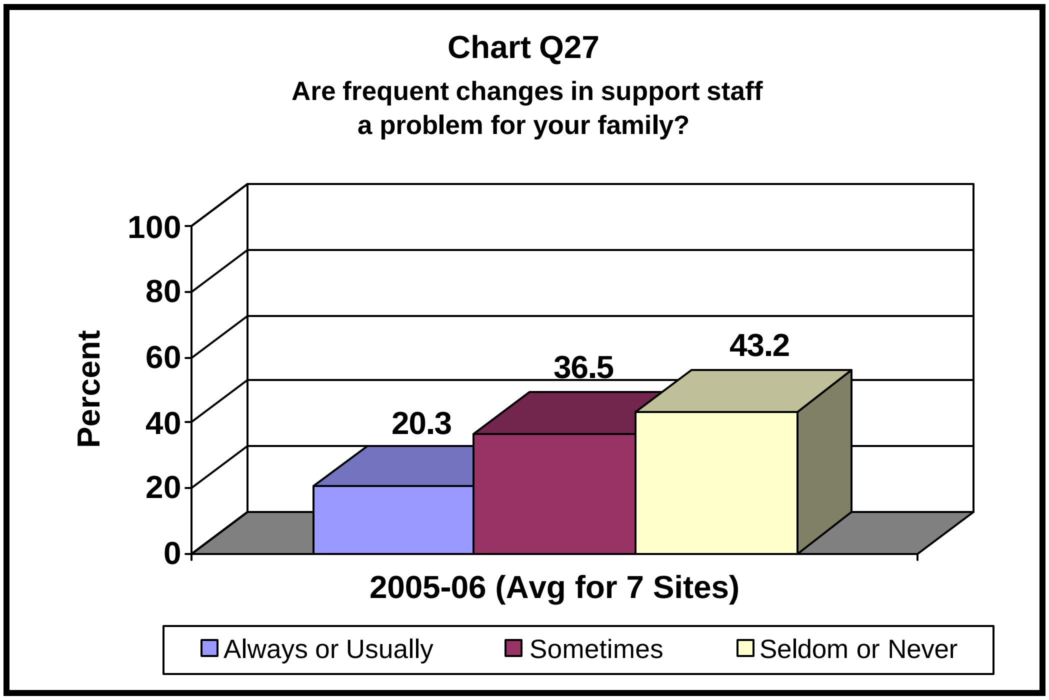


Table Q27

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		19.3	36.6	44.1	508
CT	⇩	25.9	40.6	33.6	143
HI	⇩⇩	30.3	49.3	20.4	142
SC		22.7	25.8	51.6	128
SD	⇧⇧	9.9	22.4	67.8	152
TX		22.4	41.6	36.0	673
WY	⇧	11.5	39.5	49.0	157
Total %		**20.5**	**38.0**	**41.5**	**1,903**
State Average		**20.3**	**36.5**	**43.2**	**7**

Chart Q28

Are support staff generally respectful and courteous?

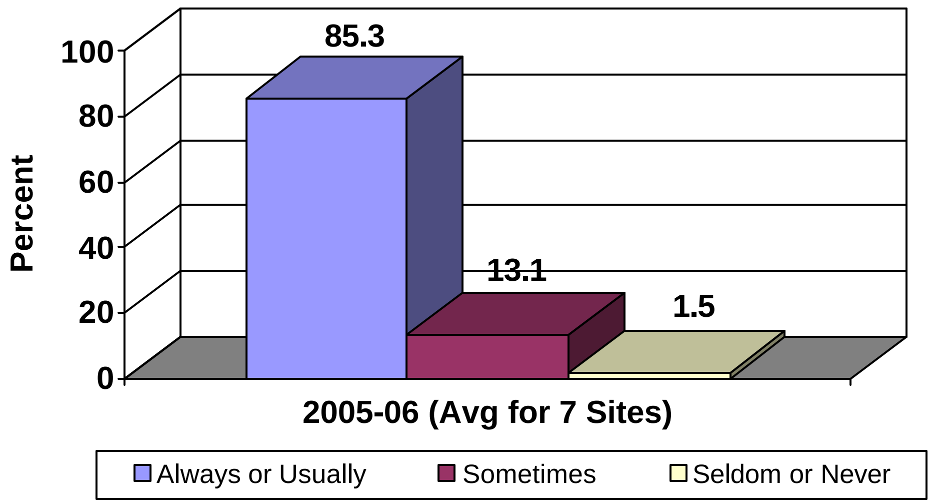


Table Q28

Are support staff generally respectful and courteous?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		84.2	13.8	2.0	608
CT	⇩	77.8	19.0	3.2	158
HI		82.4	17.6	0.0	170
SC		84.9	11.6	3.4	146
SD	⇧	94.8	4.6	0.6	174
TX		81.8	17.4	0.8	729
WY	⇧	91.5	8.0	0.6	176
Total %		**84.3**	**14.3**	**1.4**	**2,161**
State Average		**85.3**	**13.1**	**1.5**	**7**

Choice and Control

- Across the states, on average, 55% of respondents chose the agencies or providers who work with their families. In Texas and Wyoming, this percentage was considerably higher, with 78% of families choosing their service providers. In Connecticut, considerably fewer families chose their providers/agencies.

- While 55% of respondents typically chose their family's provider agency, only 41% (on average) typically chose the support workers who worked directly with their family. Once again, the results were considerably higher in Texas and Wyoming.

- Among all respondents, slightly more than one-third (35%) had control or input over the hiring and management of their support staff, and an additional 18% indicated they had this control sometimes. Forty-seven percent, however, had little or no input/control over the hiring or management of their family's support staff.

- While only 53% of respondents had at least some control over the hiring or management of their support workers, 85% wanted this type of control at least some of the time.

- Only 24% of respondents knew how much money was spent by the MR/DD agency on behalf of their family member. Two-thirds (65%), however, had little or no idea. These results vary significantly from state to state.

- Overall, more than half of the families surveyed (57%), had at least some decision-making authority over how the money available to their family member with disabilities by the MR/DD agency was spent. Forty-three percent, however, did not. Once again, results varied considerably from state to state.

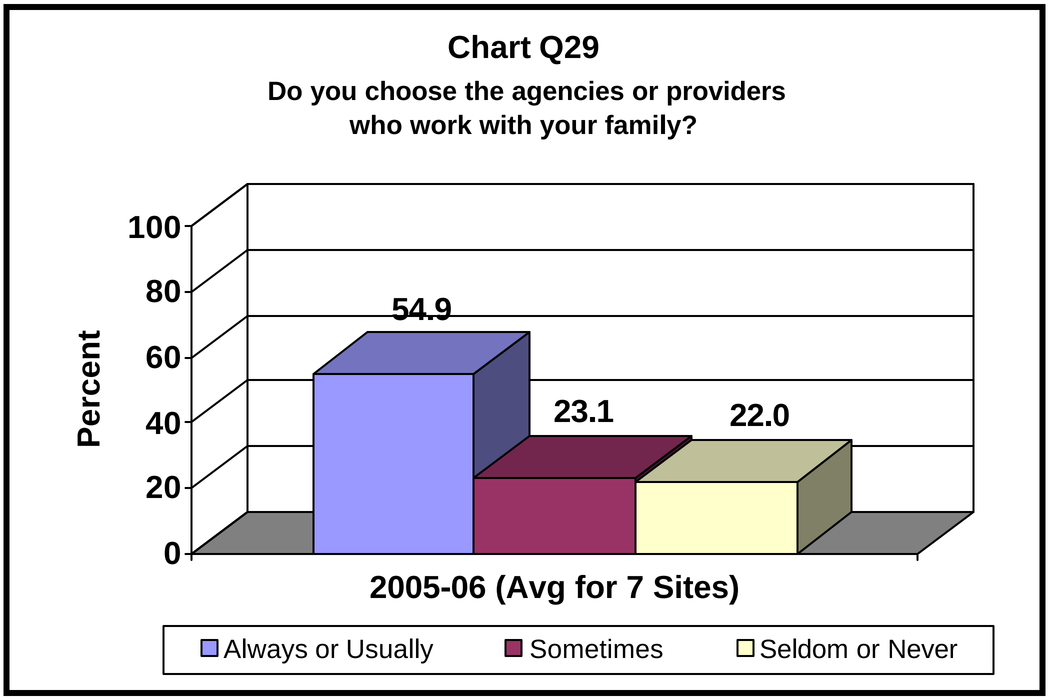


Chart Q29

Do you choose the agencies or providers who work with your family?

Table Q29

Do you choose the agencies or providers who work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩⇩	42.9	24.1	33.0	555
CT	⇩⇩	34.6	25.8	39.6	159
HI		53.5	25.2	21.3	155
SC		53.0	22.8	24.2	149
SD	⇩	45.3	29.4	25.3	170
TX	⇧⇧	77.6	16.6	5.8	746
WY	⇧⇧	77.5	18.0	4.5	178
Total %		**59.1**	**21.5**	**19.4**	**2,112**
State Average		**54.9**	**23.1**	**22.0**	**7**

Chart Q30

Do you choose the support workers who work with your family?

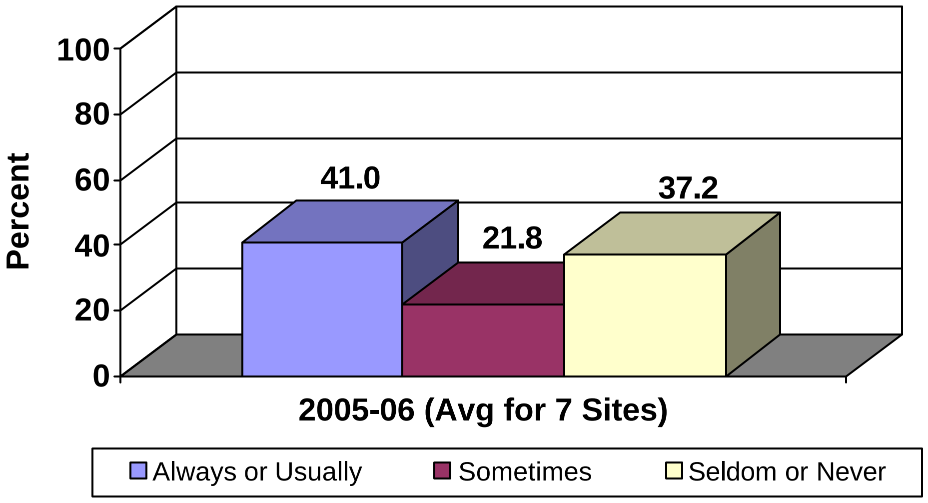


Table Q30

Do you choose the support workers who work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	31.6	18.7	49.7	529
CT	⇩⇩	23.7	16.4	59.9	152
HI	⇩	35.2	25.5	39.3	145
SC	⇩⇩	30.9	25.9	43.2	139
SD	⇩⇩	29.3	23.6	47.1	157
TX	⇧⇧	63.0	22.8	14.1	714
WY	⇧⇧	73.3	19.9	6.8	176
Total %		**45.8**	**21.5**	**32.7**	**2,012**
State Average		**41.0**	**21.8**	**37.2**	**7**

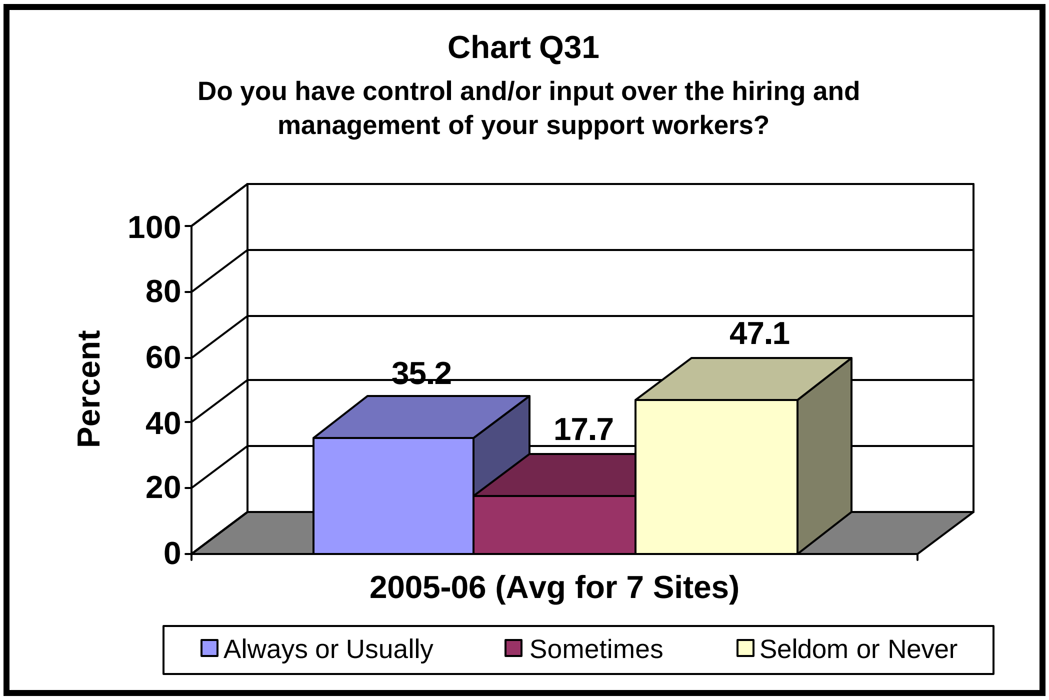


Chart Q31

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

Table Q31
Do you have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	29.5	18.0	52.5	434
CT	⇩⇩	18.2	19.8	62.0	121
HI		35.9	23.4	40.6	128
SC	⇩⇩	19.1	15.5	65.5	110
SD	⇩⇩	22.0	11.0	66.9	127
TX	⇧⇧	61.0	19.0	20.0	674
WY	⇧⇧	60.5	17.2	22.3	157
Total %		**42.9**	**18.2**	**38.9**	**1,751**
State Average		**35.2**	**17.7**	**47.1**	**7**

Chart Q32

Do you want to have control and/or input over the hiring and management or your support workers?

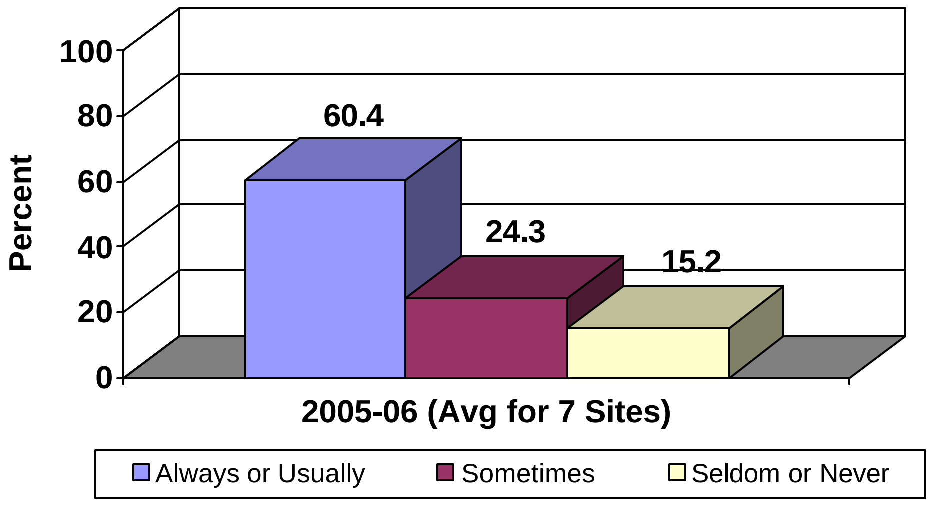


Table Q32

Do you 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
CA-RCOC	⇩	52.5	27.2	20.3	419
CT		60.3	25.6	14.0	121
HI		61.9	21.6	16.4	134
SC	⇩	52.3	29.7	18.0	111
SD	⇩⇩	44.6	26.4	28.9	121
TX	⇧⇧	77.5	18.0	4.5	627
WY	⇧⇧	73.7	21.7	4.6	152
Total %		**64.5**	**22.8**	**12.7**	**1,685**
State Average		**60.4**	**24.3**	**15.2**	**7**

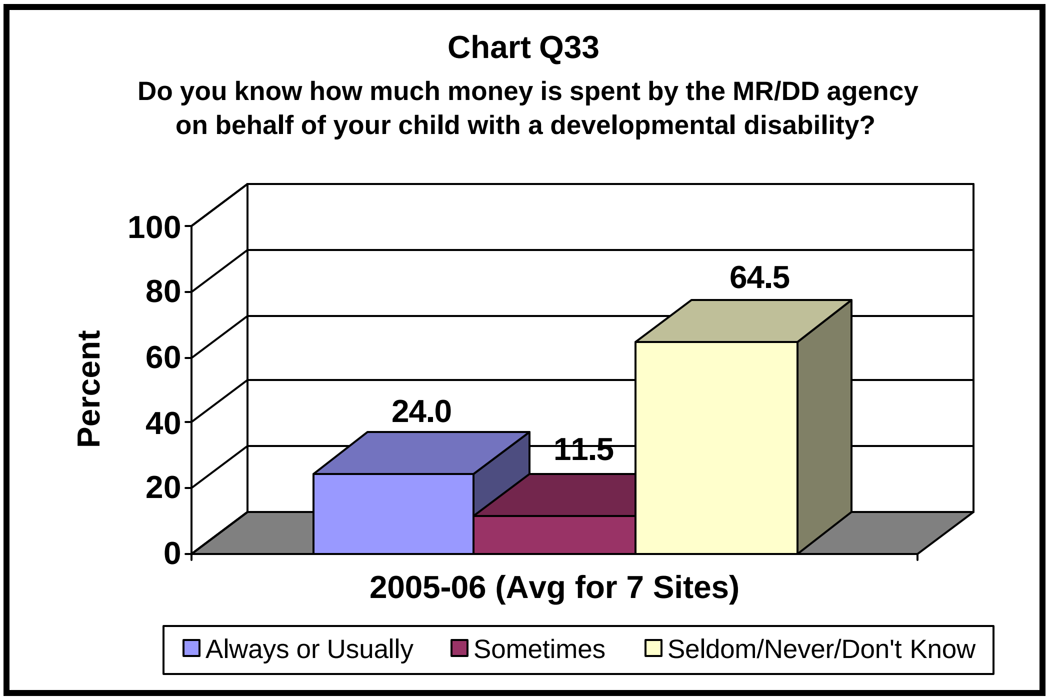


Chart Q33

Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?

Table Q33

Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
CA-RCOC	⇩⇩	11.2	6.8	82.0	649
CT	⇩⇩	10.2	6.3	83.5	176
HI	⇩⇩	13.6	11.2	75.1	169
SC	⇩⇩	9.2	3.3	87.6	153
SD	⇧	29.0	20.8	50.3	183
TX	⇧⇧	36.4	13.3	50.3	736
WY	⇧⇧	58.4	18.5	23.0	178
Total %		**24.6**	**11.1**	**64.3**	**2,244**
State Average		**24.0**	**11.5**	**64.5**	**7**

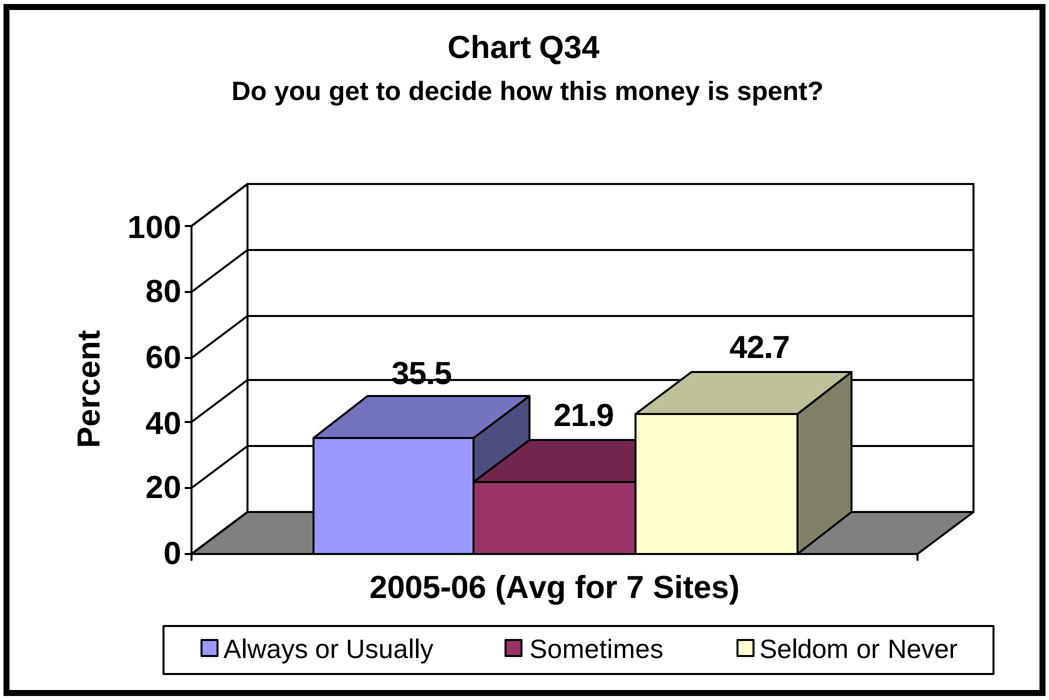


Chart Q34

Do you get to decide how this money is spent?

Table Q34

Do you get to decide how this money is spent?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩⇩	21.6	15.2	63.3	343
CT		33.1	20.2	46.8	124
HI	⇩	25.9	16.7	57.4	108
SC	⇩⇩	11.6	9.3	79.1	86
SD	⇧⇧	49.7	33.8	16.6	145
TX	⇧⇧	45.7	27.2	27.2	567
WY	⇧⇧	60.9	30.8	8.3	169
Total %		**38.1**	**23.2**	**38.7**	**1,542**
State Average		**35.5**	**21.9**	**42.7**	**7**

Community Connections

- On average, only 26% of respondents felt that planning or support staff were regularly available to help them use typical community supports (e.g., from a local health club, church or recreation activities) if desired. Another 27% said that staff were sometimes helpful, but 47% stated that planning and support staff were seldom or never helpful in connecting their family members to typical community supports or resources.

- Overall, one-third of respondents (33%) indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (41% said they received little or no help in this area, and the remaining 26% said it occasionally happens).

- Only 35% of families felt their family member always or usually had access to community activities. Twenty-nine percent stated their family member seldom or never had access to the community.

- While 35% had regular access to community activities, only 20% of children regularly participated in them. Forty-five percent of respondents said that their child seldom or never participated in community activities or events ~ and these results were fairly consistent across the states.

- About half (51%) of respondents' children regularly spend time with children who do not have disabilities ~ which leaves the other half (49%) who only spend some or little time with children without disabilities.

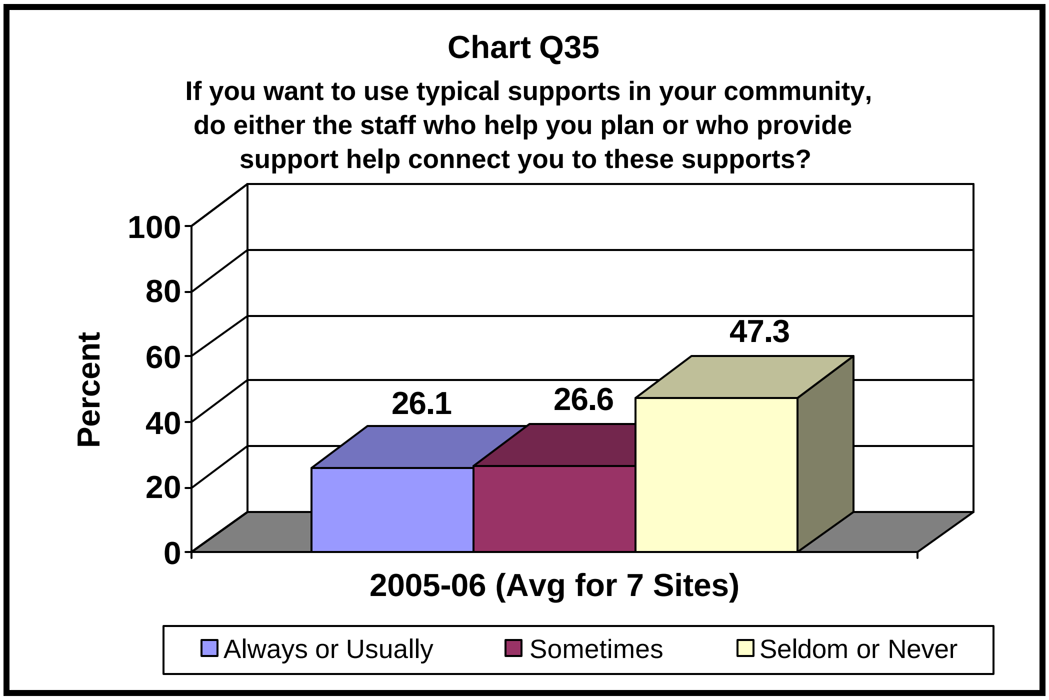


Chart Q35

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

Table Q35

If you want 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
CA-RCOC		24.2	22.1	53.7	430
CT	⇩⇩	15.9	17.4	66.7	138
HI		26.3	30.7	43.0	114
SC		25.3	28.6	46.2	91
SD	⇧	34.9	32.6	32.6	129
TX	⇩	19.5	25.8	54.7	492
WY	⇧⇧	36.7	28.8	34.5	139
Total %		**24.2**	**25.4**	**50.4**	**1,533**
State Average		**26.1**	**26.6**	**47.3**	**7**

Chart Q36

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

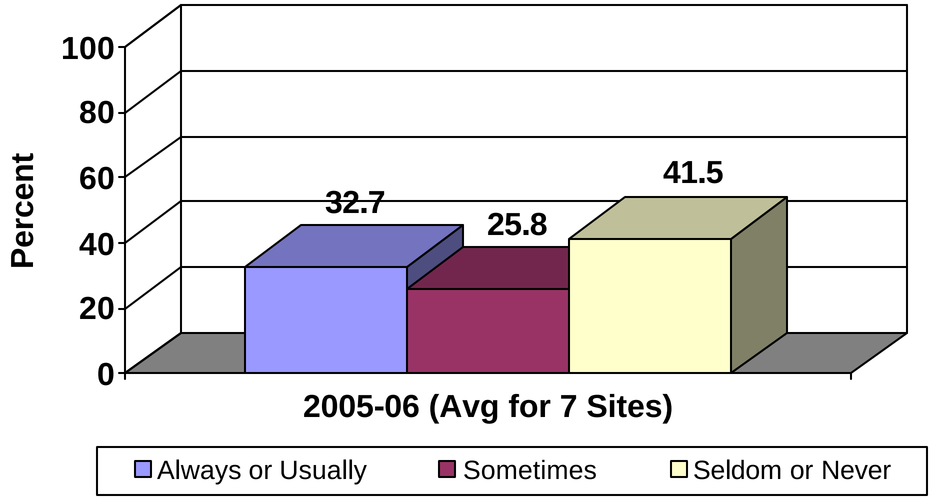


Table Q36

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		31.1	26.7	42.2	412
CT	⇩⇩	17.1	11.4	71.4	140
HI		32.3	33.9	33.9	127
SC	⇩⇩	20.3	30.4	49.4	79
SD	⇧⇧	49.3	24.0	26.7	146
TX		35.5	26.5	37.9	543
WY	⇧⇧	43.5	27.4	29.0	124
Total %		**33.6**	**25.8**	**40.5**	**1,571**
State Average		**32.7**	**25.8**	**41.5**	**7**

Chart Q37

Do you feel that your child
has access to community activities?

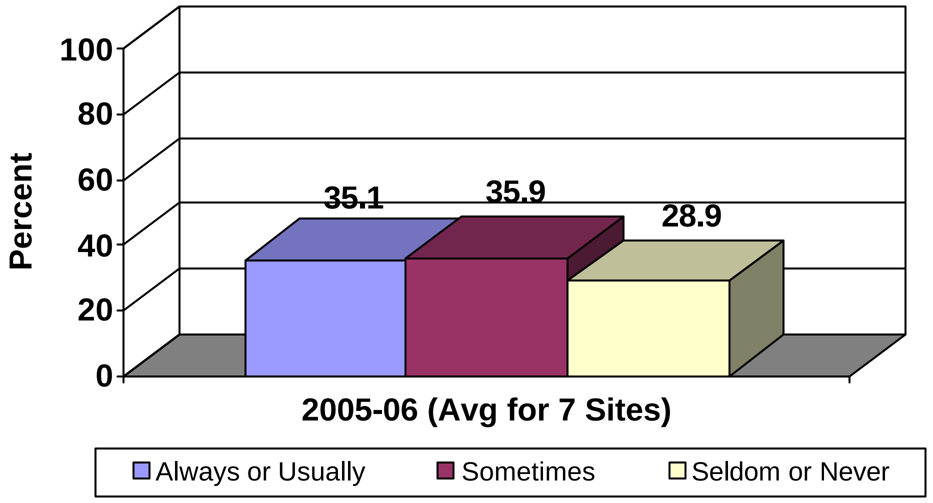


Table Q37

Do you feel that your child has access to community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	28.8	36.9	34.3	548
CT	⇩⇩	17.6	43.2	39.2	176
HI		36.9	39.4	23.8	160
SC		38.5	27.7	33.8	130
SD	⇧	44.7	36.3	19.0	179
TX		32.9	35.1	31.9	680
WY	⇧⇧	46.6	33.0	20.5	176
Total %		**33.4**	**36.1**	**30.6**	**2,049**
State Average		**35.1**	**35.9**	**28.9**	**7**

Chart Q38

Does your child participate in community activities?

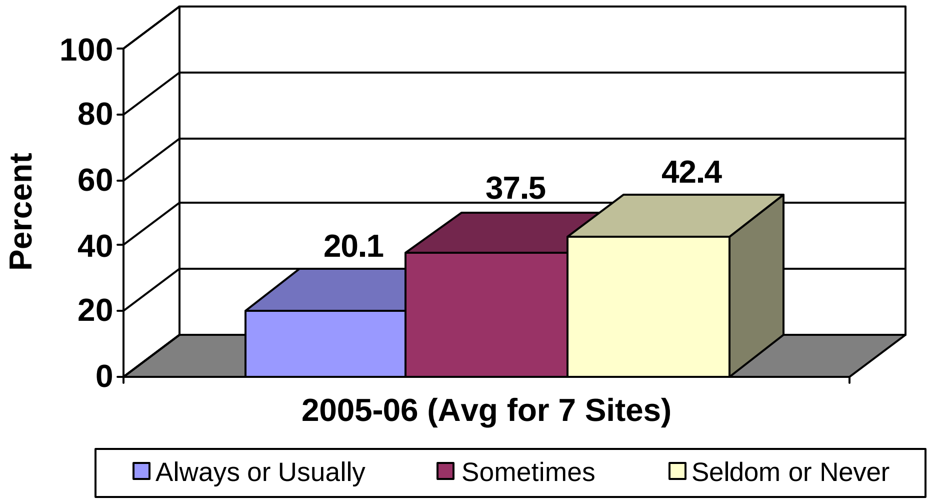


Table Q38

Does your child participate in community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		16.7	35.5	47.8	603
CT	⇩	13.8	37.6	48.7	189
HI		23.6	42.4	33.9	165
SC		16.3	31.1	52.6	135
SD		22.8	42.8	34.4	180
TX		18.2	35.0	46.8	694
WY	⇧	29.5	38.1	32.4	176
Total %		**19.0**	**36.6**	**44.4**	**2,142**
State Average		**20.1**	**37.5**	**42.4**	**7**

Chart Q39

Does your child spend time with children who do not have developmental disabilities?

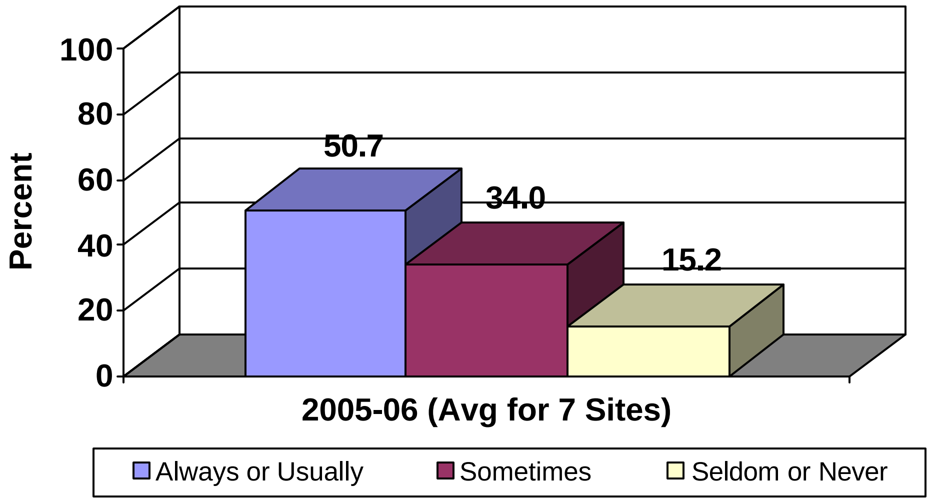


Table Q39

Does your child spend time with children who do not have developmental disabilities?

State	Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	47.7	38.0	14.3	665
CT	50.0	30.0	20.0	200
HI	48.8	36.5	14.7	170
SC	53.8	33.1	13.1	160
SD	53.5	32.4	14.1	185
TX	45.9	35.0	19.1	738
WY	55.4	33.3	11.3	177
Total %	**48.9**	**35.1**	**16.0**	**2,295**
State Average	**50.7**	**34.0**	**15.2**	**7**

Outcomes and Satisfaction with Services and Supports

- Overall, 57% were always or usually satisfied with the services and supports they received. 33% were somewhat satisfied, and 10% were seldom or never satisfied.

- On average, only 38% of respondents knew about their agency's grievance process, while 49% had little or no familiarity with the process for lodging a complaint.

- About half of respondents (52%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 48%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.

- Sixty-seven percent of families felt that services and supports have made a positive difference in their lives. Seven percent stated that they seldom felt this way.

- Nearly all families (90%) felt that family supports improved, sometimes or more often, their ability to care for their child.

- Two-thirds (70%) of respondents indicated that services have made a difference in helping them keep their child at home.

- Eighty-two percent of respondents felt that their family member was usually happy.

Chart Q40

Overall, are you satisfied with the services and supports your child and family currently receives?

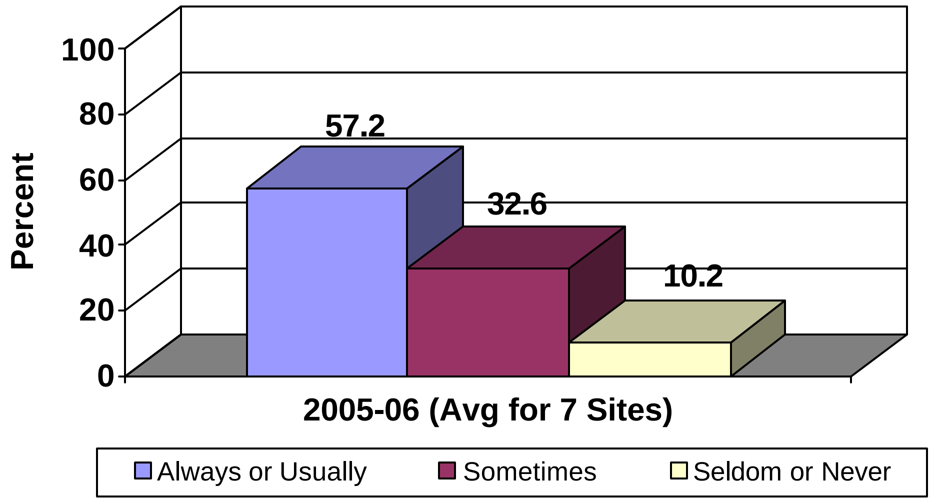


Table Q40

Overall, are you satisfied with the services and supports your child and family currently receives?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		58.2	33.1	8.7	655
CT	⇩⇩	30.4	42.9	26.6	184
HI	⇩	49.7	41.0	9.2	173
SC		58.4	28.0	13.7	161
SD	⇧⇧	76.1	21.2	2.7	184
TX	⇧	62.3	31.5	6.2	753
WY	⇧	65.1	30.3	4.6	175
Total %		**58.6**	**32.4**	**8.9**	**2,285**
State Average		**57.2**	**32.6**	**10.2**	**7**

Chart Q41

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

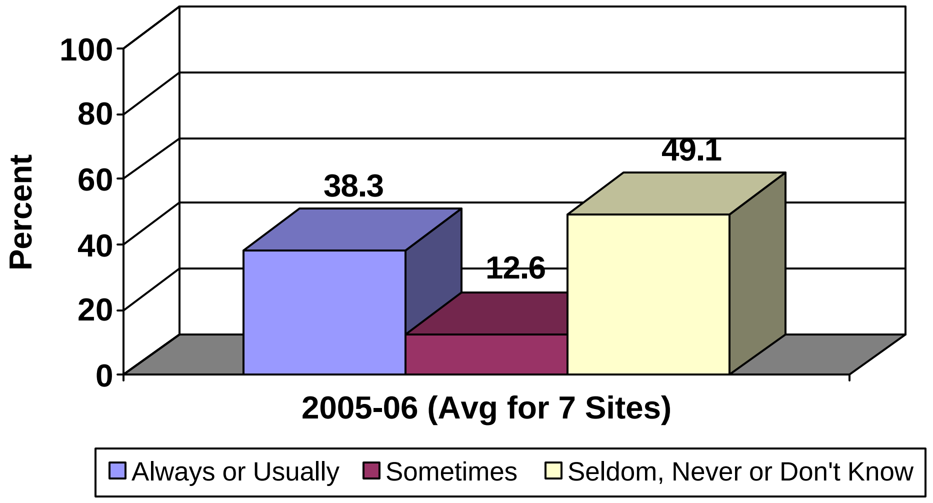


Table Q41

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
CA-RCOC		39.3	17.1	43.6	621
CT	⇩⇩	18.5	6.2	75.3	178
HI		34.6	14.8	50.6	162
SC		34.7	8.8	56.5	147
SD	⇧	46.2	12.4	41.4	169
TX	⇧⇧	49.9	14.2	35.9	741
WY	⇧	45.2	14.5	40.4	166
Total %		**41.5**	**13.9**	**44.6**	**2,184**
State Average		**38.3**	**12.6**	**49.1**	**7**

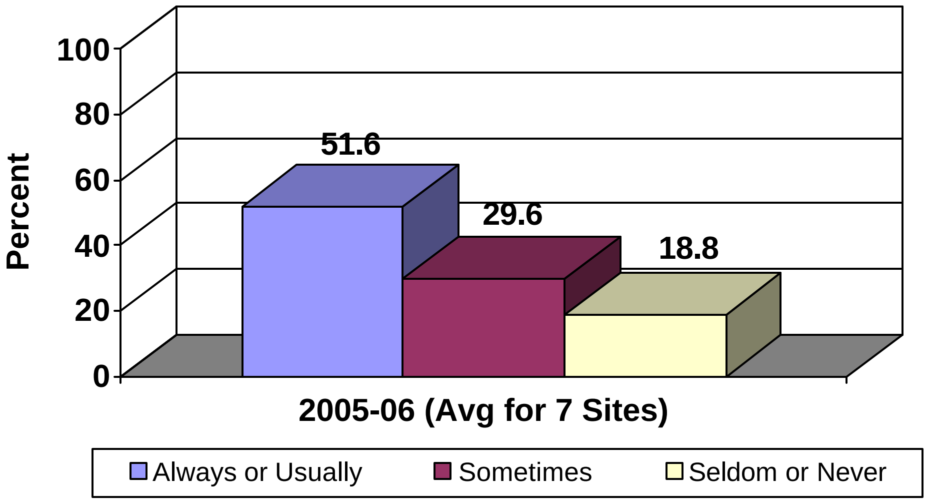


Chart Q42

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

Table Q42

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC		56.5	28.5	15.0	246
CT	⇩⇩	32.6	34.8	32.6	46
HI		48.1	35.2	16.7	54
SC		48.8	22.0	29.3	41
SD	⇧⇧	70.0	26.0	4.0	50
TX		53.1	30.0	16.9	373
WY		52.2	30.4	17.4	69
Total %		**53.4**	**29.6**	**17.1**	**879**
State Average		**51.6**	**29.6**	**18.8**	**7**

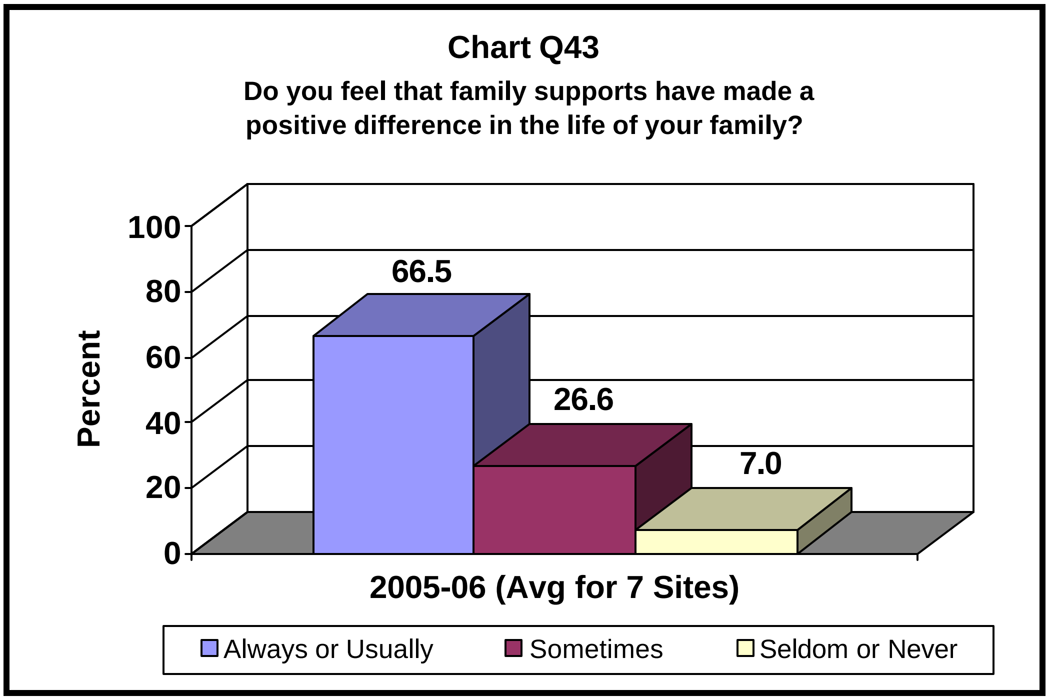


Chart Q43

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

Table Q43

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

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	58.9	33.1	8.0	598
CT	⇩⇩	43.2	41.8	15.1	146
HI		66.5	26.1	7.5	161
SC		62.9	28.0	9.1	143
SD	⇧⇧	86.4	11.4	2.2	184
TX	⇧	73.3	22.8	3.9	719
WY	⇧	74.0	23.1	2.9	173
Total %		**67.1**	**26.6**	**6.2**	**2,124**
State Average		**66.5**	**26.6**	**7.0**	**7**

Chart Q44

Do you feel that family supports have improved your ability to care for your child?

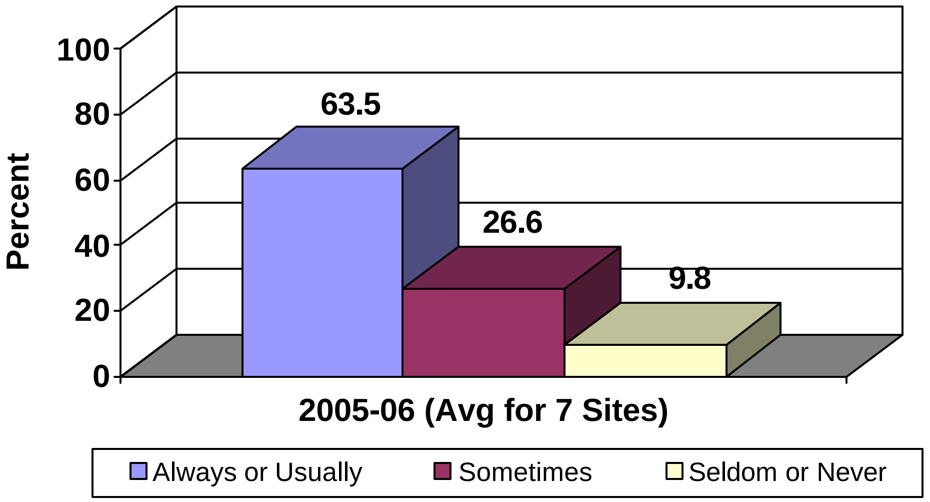


Table Q44

Do you feel that family supports have improved your ability to care for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	57.4	31.4	11.1	601
CT	⇩⇩	40.7	37.9	21.4	145
HI		65.2	25.8	9.0	155
SC	⇩	54.8	34.2	11.0	146
SD	⇧⇧	82.0	14.2	3.8	183
TX	⇧⇧	74.0	20.8	5.2	726
WY	⇧	70.5	22.2	7.4	176
Total %		**65.5**	**25.8**	**8.7**	**2,132**
State Average		**63.5**	**26.6**	**9.8**	**7**

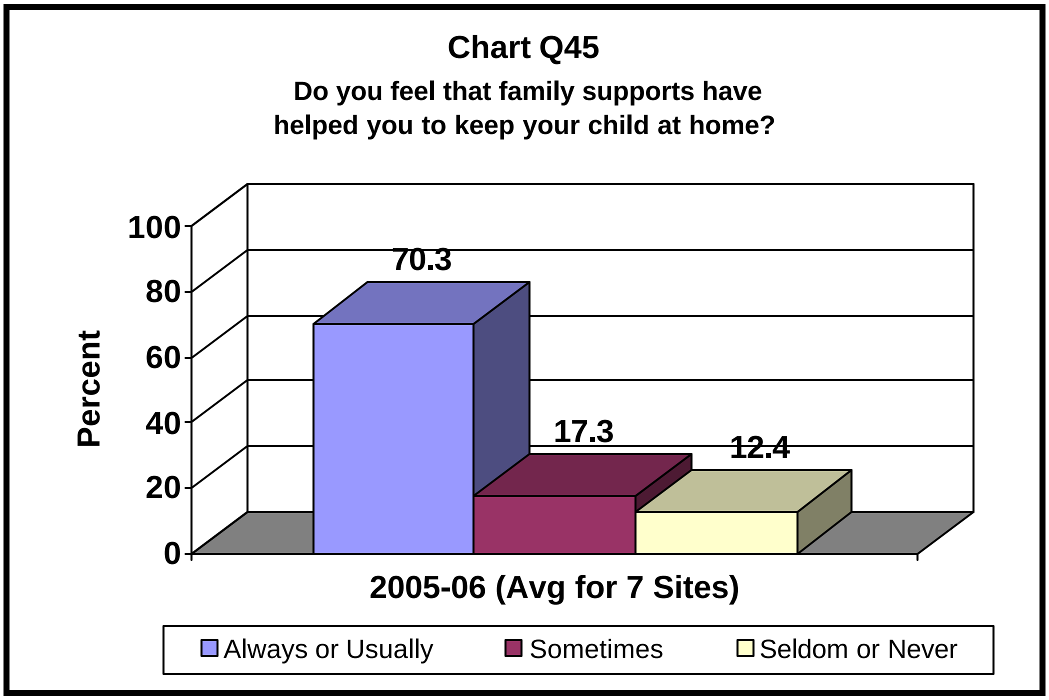


Chart Q45

Do you feel that family supports have helped you to keep your child at home?

Table Q45

Do you feel that family supports have helped you to keep your child at home?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	65.0	23.0	12.0	540
CT	⇩⇩	51.2	20.9	27.9	129
HI		70.1	20.8	9.0	144
SC	⇩	59.8	24.1	16.1	112
SD	⇧⇧	85.0	9.8	5.2	173
TX	⇧⇧	80.8	13.1	6.1	708
WY	⇧	80.1	9.3	10.6	151
Total %		**72.8**	**17.0**	**10.2**	**1,957**
State Average		**70.3**	**17.3**	**12.4**	**7**

Chart Q46

Overall, do you feel that your child is happy?

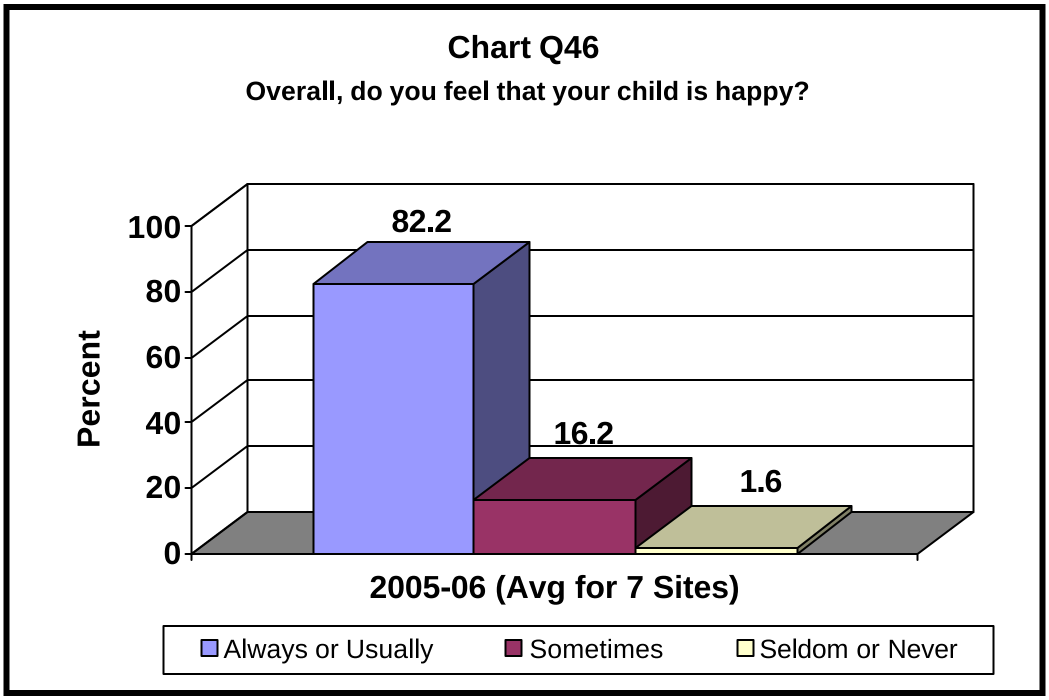


Table Q46

Overall, do you feel that your child is happy?

State		Always or Usually	Sometimes	Seldom or Never	n
CA-RCOC	⇩	77.2	21.1	1.7	650
CT	⇩	77.0	17.3	5.6	196
HI		79.4	20.0	0.6	170
SC		83.7	14.5	1.8	166
SD	⇧	88.0	12.0	0.0	184
TX	⇧	87.5	12.2	0.3	754
WY		82.4	16.5	1.1	176
Total %		**82.5**	**16.2**	**1.3**	**2,296**
State Average		**82.2**	**16.2**	**1.6**	**7**

Aggregate Results & State Trends

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 were with their supports.

For each category, there is also a TABLE that looks at the arrows (i.e., ⇧ and ⇩) of the previous Tables, 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 trends, 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 South Carolina, South Dakota and Wyoming, responses to information and planning questions were generally above the overall state average. In Connecticut, results were generally below the state average.

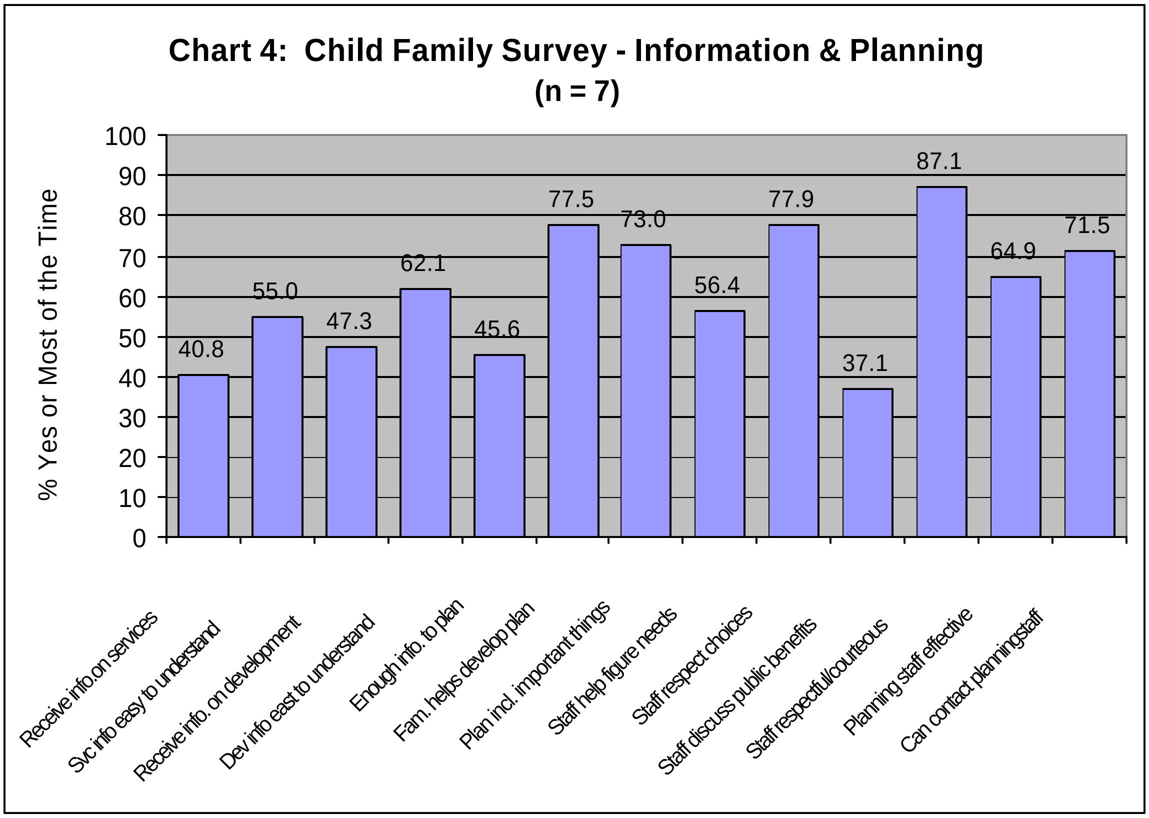


Chart 4: Child Family Survey - Information & Planning
(n = 7)

Table 17
Trends in Responses Above & Below State Average
Information & Planning

State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
CA-RCOC	⇧	⇧	⇩		⇩	⇩	⇩⇩	⇩⇩				⇩		-6
CT	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩	⇩⇩	⇩⇩	-25
HI		⇩					⇧					⇩	⇩	-2
SC		⇧	⇧⇧	⇧⇧	⇧⇧		⇧	⇧	⇧	⇧				11
SD	⇧⇧	⇧⇧	⇧	⇧	⇧⇧	⇧⇧	⇧⇧	⇧⇧	⇧	⇧⇧	⇧	⇧⇧	⇧⇧	22
TX	⇩	⇩	⇩		⇩			⇩	⇩					-6
WY	⇧				⇧⇧	⇧⇧	⇧	⇧⇧	⇧		⇧	⇧⇧	⇧	13

Access and Delivery of Services

- In South Dakota and Wyoming, responses to access and delivery of services questions were generally above the state average. In Connecticut, results were generally below the state average. Note that Question 18 is considered a “neutral question”. Therefore, up and down arrows were not used in the calculation of state trends.

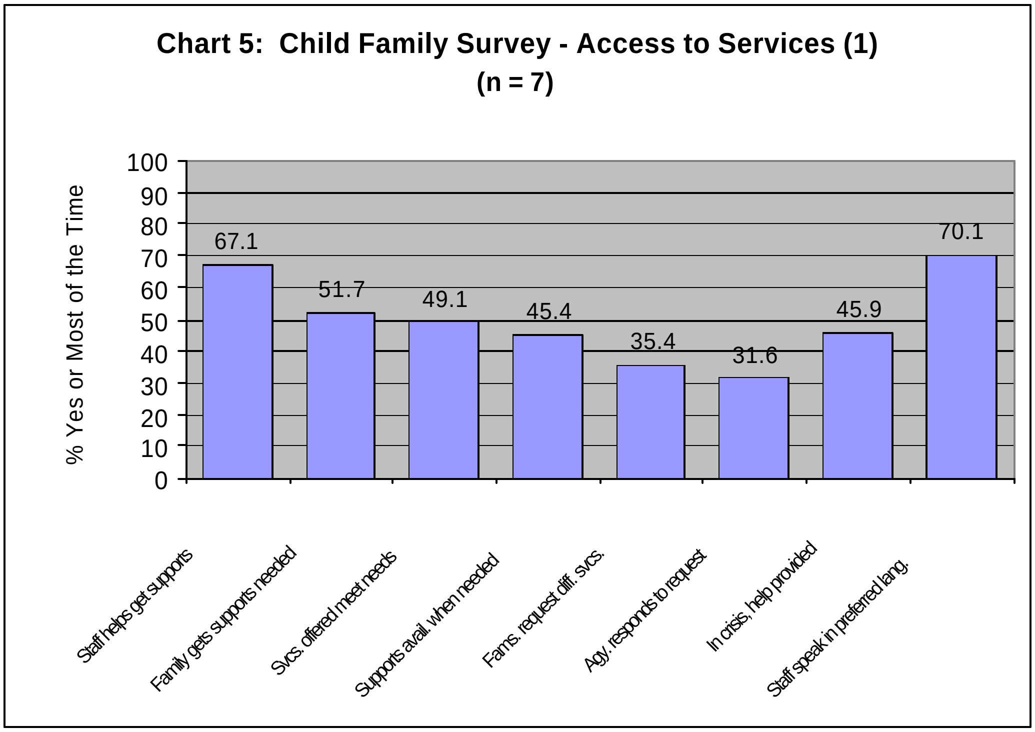


Chart 5: Child Family Survey - Access to Services (1)
(n = 7)

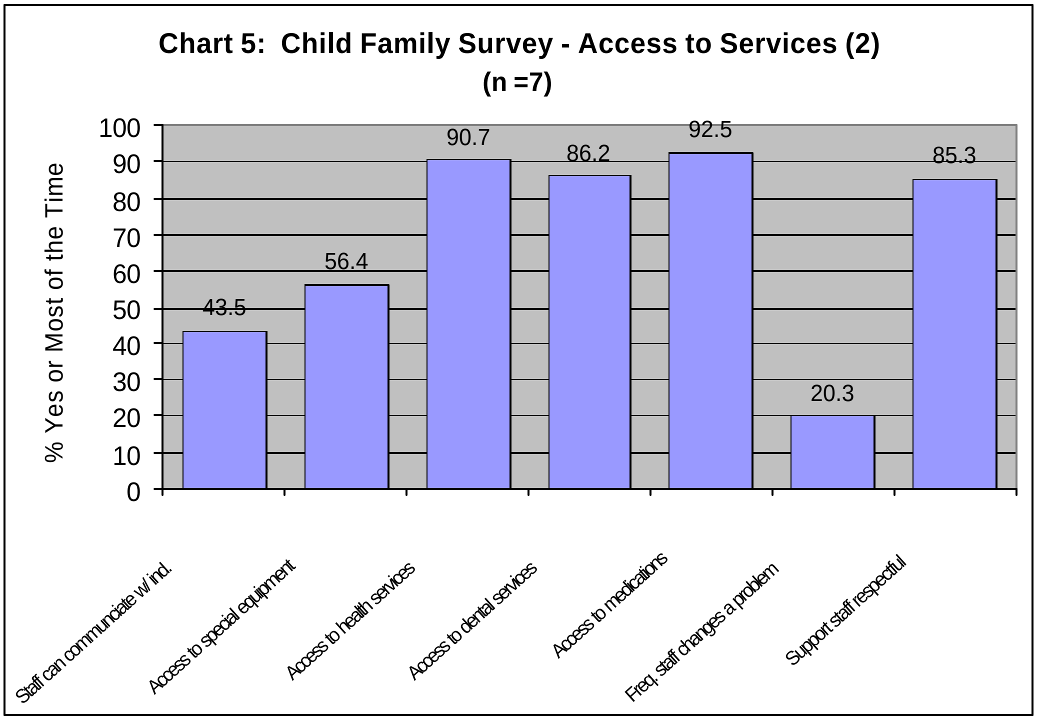


Chart 5: Child Family Survey - Access to Services (2)
(n =7)

Table 18
Trends in Responses Above & Below State Average
Access to Services & Supports

State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Q27	Q28	Net Sum
CA-RCOC	⇩	⇩	⇩	⇩		⇧⇧	⇩	⇧	⇧⇧	⇩						-1
CT	⇩⇩	⇩⇩	⇩⇩	⇩⇩		⇩⇩	⇩⇩			⇩⇩		⇩		⇩	⇩	-17
HI						⇧	⇩⇩	⇩⇩		⇩				⇩⇩		-6
SC						⇩			⇧	⇩						-1
SD	⇧⇧	⇧⇧	⇧⇧	⇧⇧			⇧⇧		⇩⇩	⇧⇧	⇧	⇧	⇧	⇧⇧	⇧	16
TX										⇧						1
WY	⇧⇧	⇧⇧	⇧	⇧			⇧			⇧				⇧	⇧	10

Choice and Control

- In this category, all states scored considerably above or below the state average, indicating that there was very little middle ground when it came to choice and control. In Texas and Wyoming, responses to choice and control questions were well above the overall state average. In all other states, results were generally below the state average.

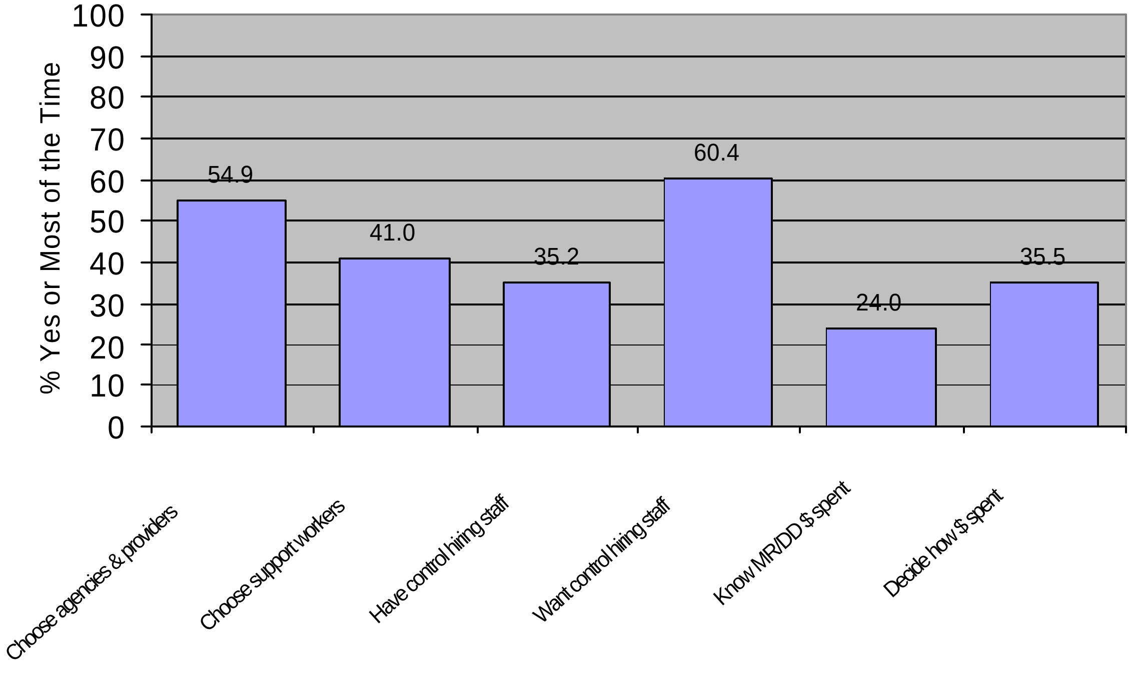


Chart 6: Child Family Survey - Choice & Control (n = 7)

Table 19
Trends in Responses
Above & Below State Average
Choice & Control

State	Q29	Q30	Q31	Q32	Q33	Q34	Net Sum
CA-RCOC	⇩⇩	⇩	⇩	⇩	⇩⇩	⇩⇩	-9
CT	⇩⇩	⇩⇩	⇩⇩		⇩⇩		-8
HI		⇩			⇩⇩	⇩	-4
SC		⇩⇩	⇩⇩	⇩	⇩⇩	⇩⇩	-9
SD	⇩	⇩⇩	⇩⇩	⇩⇩	⇧	⇧⇧	-4
TX	⇧⇧	⇧⇧	⇧⇧	⇧⇧	⇧⇧	⇧⇧	12
WY	⇧⇧	⇧⇧	⇧⇧	⇧⇧	⇧⇧	⇧⇧	12

Community Connections

- In South Dakota and Wyoming, responses to community connections questions were generally above the overall state average. In Connecticut, results were generally below the state average.

Chart 7: Child Family Survey - Community Connections
(n = 7)

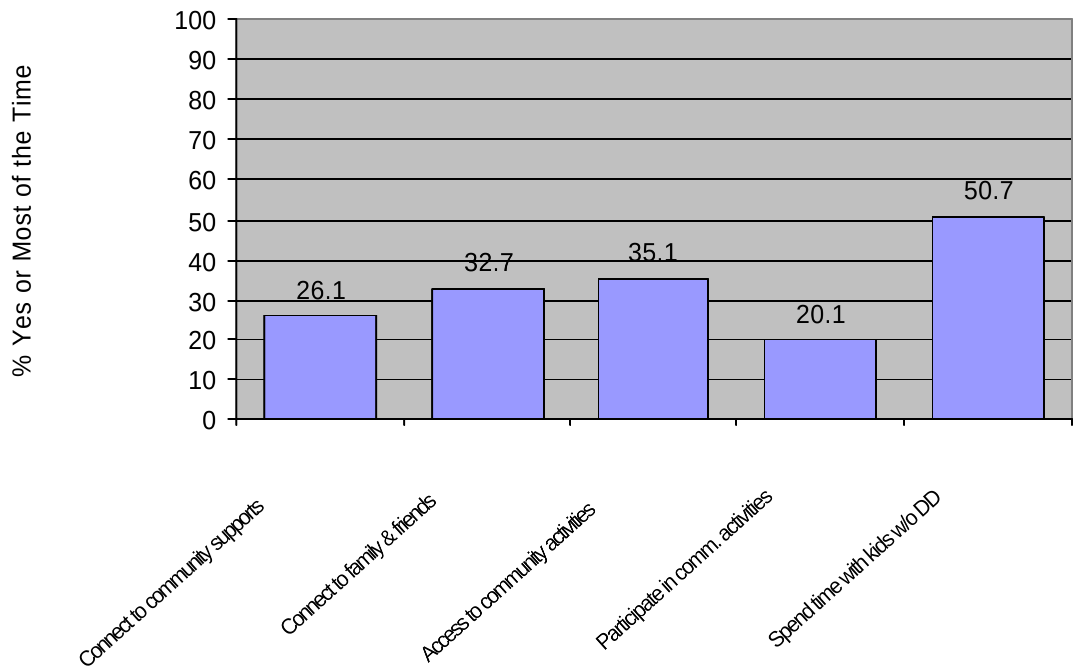


Table 20
Trends in Responses
Above & Below State Average
Community Connections

State	Q35	Q36	Q37	Q38	Q39	Net Sum
CA-RCOC			⇩			-1
CT	⇩⇩	⇩⇩	⇩⇩	⇩		-7
HI						0
SC		⇩⇩				-2
SD	⇧	⇧⇧	⇧			4
TX	⇩					-1
WY	⇧⇧	⇧⇧	⇧⇧	⇧		7

Satisfactions with Services and Supports & Outcomes for Families

- In South Dakota, Texas and Wyoming, responses to satisfaction with services and outcomes for families questions were generally above the overall state average. In Orange County, CA and Connecticut, results were generally below the state average.

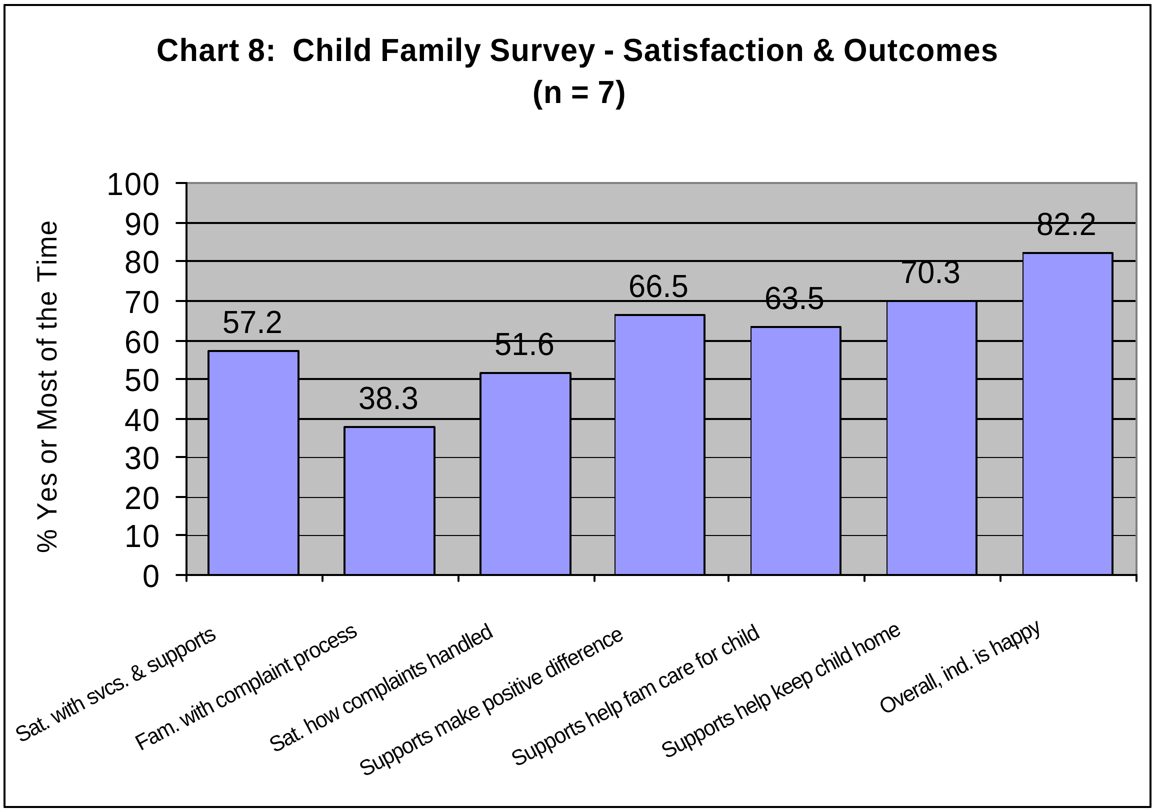


Table 21
Trends in Responses
Above & Below State Average
Satisfaction & Outcomes

State	Q40	Q41	Q42	Q43	Q44	Q45	Q46	Net Sum
CA-RCOC				⇩	⇩	⇩	⇩	-4
CT	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩⇩	⇩	-13
HI	⇩							-1
SC					⇩	⇩		-2
SD	⇧⇧	⇧	⇧⇧	⇧⇧	⇧⇧	⇧⇧	⇧	12
TX	⇧	⇧⇧		⇧	⇧⇧	⇧⇧	⇧	9
WY	⇧	⇧		⇧	⇧	⇧		5

Overall State Trends

- Looking at results across all categories, South Dakota and Wyoming had results that were well above the overall state average. In Connecticut, results were generally below the overall state average.

Table 22
Overall Trends in Responses
Above & Below State Average

State	Information & Planning	Access & Delivery	Choice & Control	Community Connections	Satisfaction & Outcomes	Total Sum
CA-RCOC	-6	-1	-9	-1	-4	-21
CT	-25	-17	-8	-7	-13	-70
HI	-2	-6	-4	0	-1	-13
SC	11	-1	-9	-2	-2	-3
SD	22	16	-4	4	12	50
TX	-6	1	12	-1	9	15
WY	13	10	12	7	5	47

Analysis of Open-Ended Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. QSR N6 was used to code and to sort the qualitative comments by theme. The themes identified are detailed below, and the results of this analysis are presented by state and theme below.
NOTE: TEXAS DATA TO BE INCLUDED IN FINAL REPORT

1. Home
   a. Satisfied with Home
   b. Dissatisfied with Home
   c. Accommodations with Home
   d. Furnishings/Cleanliness of Homes
   e. Waiting List
2. Employment and Day Programs
   a. Satisfied with Employment
   b. Dissatisfied with Employment
3. Health Care
   a. Health Care Equipment
   b. Health Care Insurance
   c. Dental
   d. Medical
   e. OT/PT/ST
   f. Vision
   g. Psychological
4. Education and Training
   a. Satisfied with Education/Training
   b. Dissatisfied with Education/Training
5. Transportation
   a. Satisfied with Transportation
   b. Dissatisfied with Transportation
   c. No Transportation
6. Recreation Activities
   a. Satisfied with Recreation Activities
   b. Dissatisfied with Recreation Activities
7. Communication
   a. Satisfied with Communication
   b. Dissatisfied with Communication
   c. Information
   d. Language Barrier
   e. Non-communicative
   f. Planning Meetings
   g. Interagency
8. Aging Caregiver Issues
9. Transition Issues
10. Service Coordination
   a. Satisfied with CM
   b. Dissatisfied with CM
   c. CM Turnover
   d. Shortage of CM Workers
   e. CM Not Qualified
   f. Pay CM More
   g. Service Plan
11. Staff
   a. Satisfied with Staff
   b. Dissatisfied with Staff
   c. Staff Turnover
   d. Shortage of Staff
   e. Staff Not Qualified
   f. Pay Staff More
   g. Substitutes
12. Family Issues
   a. Parents as Paid Staff or Case Manager
   b. Family Support Group
13. General Well Being
   a. Health
   b. Safety
   c. Abuse/Neglect/Mistreatment
   d. Social
14. Respite
   a. Satisfied with Respite
   b. Dissatisfied with Respite
15. Crisis
16. Funding and Budget Cuts
17. Services and Supports
   a. General Satisfaction with Services
   b. General Dissatisfaction with Services
   c. Access to Services/Supports
   d. Info Regarding Services/Supports
   e. Need More Services/Supports
   f. General Satisfaction with Service Management
   g. General Dissatisfaction with Service Management
   h. Waiting List
18. Support Groups
19. General Concerns

3c. Dental

I would like more information on dental assistance. I have a lot of problems with finding a dentist to see him regularly, as he doesn't let anyone check his teeth without sedating him first.

List of south county dentists (autistic specific)

I need help on taking my child to a dentist. He needs to be put to sleep in order for the dentist to work on him. He is bigger than me, so I need a male assistant for that. I tried to take him, but was not successful. Please help!

3e. OT/PT/ST

I have two children with a diagnosis of autism. My main concern is that they learn to speak and to stand on their own. {Name} needs speech therapy, and at school he only receives 30 minutes a week, which to me, is not enough.

3g. Psychological

In one occasion, we had scheduled an appointment with a psychologist at 1100, however, she called to let us know that she wasn't going to be able to make it until 1400, and then 1700. When she finally showed up, she told that she had to do the evaluation on the streets, otherwise she would not do it. She wrote in the evaluation that she had done in the house. How is it possible that a professional lies that way?

The psychologist that came to our home effectively blundered and misrepresented both our child and us. He wanted to talk about sailing. We never saw his report, and the services just stopped.

4a. Satisfied with Education/Training

All services provided to my son are given by the school district. We are very impressed by {Name}Pre-school. {Name} was transformed into a more self-sufficient person. He is happy and loves to go to school.

4b. Dissatisfied with Education/Training

I feel {Name} could learn a lot more at school, but I feel she does not get the support she needs there. If you could please help in that area, it would be appreciated.

{Agency} did nothing for my child, and stated that the school district was responsible for him after he turned three. My son is autistic and is still non-verbal at the age of four. The school's budget is limited and only provides 40 minutes of speech therapy. The neurologist recommends at least three hours of speech therapy a week.

I've always needed the support for my son regarding speech and OT. {Agency} and the school district have not been able to help me.

6b. Dissatisfied with Recreation Activities

More activity coordination is needed for grade school kids. Possibly an outing of miniature golf or Adventure City.

We need more recreational activities for our children.

I wish to have a "social activity program" for my 11 year old child. It's much better to spend some time with regular class friends as much as he can.

7b. Dissatisfied with Communication

I feel bad not having kept in touch with my child's worker. I would like that in the future, there is more communication.

I feel that the family cost participation was handled very poorly. I never received any information. I was sent a correspondence stating that I had to pay a great percentage of my cost.

I find it ironic that you put a time limit on getting this survey done. My son had his AR back in {date} and I still have not received a copy of the PCP as of {date}. This is not an isolated issue. It has happened the past several years. In the past, I have had called and asked for the report, but this year I am waiting to see how long it takes for me to receive it.

Now that my child is over three, it seems like {Agency} is minimally involved in his life. Other than the yearly IPP visit, there is virtually no communication with our service provider. His needs remain constant, and the school system handles his educationally-relevant needs, however, there is a "disconnect" when it comes to the additional needs that he has.

{Agency} is pretty silent. We just do our annual review, otherwise we don’t' hear from them, unless there's a problem.

I have not heard from {Agency} for almost a year. I have no idea who my case worker is, as it has changed so much. My child's needs are being met, though I have no idea what type of services she could be receiving through {Agency}. I never receive a newsletter either, so I have no idea what is going on with {Agency}.

I don't know what {Agency} is supposed to be helping me with or offering me!

I appreciate this survey. I have been with {Agency} for 4 years and I've had five different workers. It is very hard because I only get an annual interview. I was never given any other resources for my four kids that are part of {Agency}. My worker right now, for the last 18 months, has contacted only one time every six months. This is only because I've had questions regarding respite.

When I asked for assistance, I never get any response and when I do, it takes six months or longer to get an answer. {Agency} is terrible for assistance but good for cutting the cost of day care or respite care. I have a 12 year old that is hard to handle and they have never given me any assistance.

Our son was diagnosed with autism at age 33 months. {Agency} has been difficult to work with from the beginning. A counselor came to our house after our son's evaluation saying that he qualified for services. We asked if our son was autistic, and we were told that {Agency} did not provide that information. Instead, we needed to obtain that information on our own. It took two months for a Service Coordinator to contact us and get started. She was not compassionate, rude and less than helpful.

I strongly feel that when my child turned three years old, I did not feel supported by {Agency}. My autistic child is seven years old now, and he has just as many needs than when he was three years old. The only communication from {Agency} is once a year. I always express my child's needs to him, but nothing ever becomes of it. Children 3 year old and over, with special needs, are neglected by {Agency}.

When I ask for something from {Agency}, they tell me they will work on it and get back to me. However, I never hear from them again.

I have requested assistance but I have been denied. I have not received any response since {date}.

I would like {Agency} to respond when we call them.

7d. Communication- Language Barrier

We are pleased with the services provided by {Agency}, but when an interview or exam takes place for services, we face many difficulties due to work schedule conflict. We understand, but don't speak English. We have no translator, which makes it difficult.

9. Transition Issues

Would like to know about other services offered to my child. How can we get this information? What happens when my child turns 18?

I need help transitioning my child from middle school to high school.

My child is high functioning and doesn't require much in the way of services. It would be beneficial to have more information on transition to college and perhaps some links to the disabled student services available at local colleges.

10a. Satisfied with CM

We would like to say thank you to {Name}. We are proud that we had such a good coordinator. Thank you.

{Name} is our Service Coordinator. He has been exceptional in his abilities to help our family and get the services needed to provide help.

Since {Name} became our Service Coordinator, she has provided us with information and routes to access the services that we need. She was our previous SC, when our daughter was in the early childhood intervention. We like the continuity of the same SC, since she knows our needs and desires. We don't feel there was a smooth transition except for our current SC, and that's because of our previous relationship.

{Name} is a great Service Coordinator, who is always helpful and proactive.

I have so much respect, admiration and love for my {Agency} Service Coordinator. She is genuine in caring about my son and I.

Overall, I think the Service Coordinators do a great job.

{Name} is our Service Coordinator. She is the best. She is always there when we need her, making sure that my son has optimal care. Without her help and great knowledge, I am not sure how we would be doing.

I am very much thankful to my {Agency} coordinator for the information he gave us on some services that my child and family had. It really benefits everybody. The respite is really of great help because my son was able to play with other kids. I hope {Agency} will help with equipment, like a wheelchair. {Name} is a nice guy to work with. He is very accommodating.

I just wanted to take the time to let you know how grateful we are for the help that {Agency} provides us. Having a child with epilepsy is very hard. Our Service Coordinator, {Name}, is a hard worker and is committed to my son. He's eager, and always attends the IEPs. He has been a huge support to us.

Last year, {Name}, was our coordinator and did an awesome job. This year,

we have {Name}, and she is an excellent coordinator. She always listens to our concerns and returns our calls. {Agency} is a great place for us parents, and the people that are there to help, are wonderful.

{Name} is our Service Coordinator and she is wonderful. I always feel so supported and I know she cares for our child and tries her best to help us and make suggestions.

Last year, we had a coordinator help us find a grant, although she was not assigned to our family, and we are very grateful for her help. As a result of this assistance, my daughter was able to take part in a program that has helped her a great deal in her ability to start walking on her own.

My Service Coordinator, {Name}, has been wonderful from day one. She is kind, considerate, helpful, accessible, and much more. She was there to give me a hug when I was crying. She always listened to my concerns and took all my calls. I truly believe that it is {Name} who has made my {Agency} experience so nice.

Our coordinator, {Name}, has been very supportive and wonderful and we greatly appreciate her!

We have a great Service Coordinator, {Name}.

{Name} has recently been assigned to be my case worker and she has been an excellent source of information and moral support. She has given me the support in obtaining options for daily care on my son's case and development.

The {Agency} has been an absolute life saver. It is because of my case worker, that I have been guided through the system and made aware of what's available to help me help my daughter.

We just started our relationship with {Agency}, and the first Service Coordinator was rude and insulting stating that there "were only funds to support children of undocumented aliens." Her written report was incomplete and inaccurate. It almost appeared to be written by an illiterate person. Several months later, another Service Coordinator was assigned to us. There was a complete change in our dealings with {Agency}. The coordinator was kind, understanding and clearly willing to go an extra mile to help us.

{Name} has been very helpful and I am very happy to be working with her.

Over the years, we have had good/great service coordinators. At this time, we are assigned with someone who is OK. It's hard to have someone that cares about your child and the services needed to help the child be the best that she can be. It's difficult when you have a child that needs 24 hour care and is chronically ill.

{Name} is very kind and a good worker.

We are very satisfied with our Service Coordinator, {Name}. She is prompt, courteous, knowledgeable and effective. We would like to continue with her.

Our {Agency} coordinator has been {Name}, until recently. We have received excellent support from her. We have not met her replacement yet.

{Name} and {Name} have been wonderful.

We adore {Name}. She's caring and helpful. When my son was being beaten at school by older kids, {Name} guided me to getting my son back to his neighborhood school and in full inclusion. She believed in him. It was a struggle to convince the school district and school principal, but they gave it a chance. My son has grown and developed beyond anyone's expectation.

10b. Dissatisfied with CM

Annual visit from current coordinator is more hassle than benefit. It is a waste of time to give this person the information for an IPP. We don't see a copy of the IPP until the next annual visit.

My Service Coordinator usually can't answer my questions and says he'll get back to me and then never does

I would appreciate faster feedback from current coordinator. We understand time constraints sometimes are obstacles, but email or voicemail can satisfy these. There are pending issues that we asked about, but we have not received any answers.

My only complaint is that my case worker never comes to the IEPs. I would appreciate it if someone could make it to my daughter's annual IEP in June 2006.

My current worker does not help me with any services for my children. I don't know how to change my worker.

The young care workers are often not very knowledgeable when it comes to child development. In terms of social and educational opportunities, they are not knowledgeable either. They don't try to bring families together, who may benefit from interactions, exchanges, etc. Their interpersonal skills are also poor.

I needed in-home childcare last year, and my service provider was no help to me. My son wasn't able to go to a day care due to health issues and they were no help to me in what we considered a crisis situation. He now attends preschool fulltime and therefore isn't in need of much support from {Agency}.

Our worker comes out only once a year, and never updates her information year to year.

Our Service Coordinator has not been very helpful at all. I am very disappointed. I feel that every time I have had to request for something, it is always a hassle. I feel as though I have to fight for everything for my daughter! Raising a handicapped child is difficult and I believe your Service Coordinator should be extremely helpful and want to help. I didn't get that feeling at all.

I would like my child's worker to visit her more than once a year.

I would like to request therapy for my son, and that my worker be changed. I feel like she doesn't help me.

I would like to request that my Service Coordinator, {Name}, be changed. Whenever I have called and left him a message, he doesn't return the call until 2-3 days later claiming that he did not find any messages in his voicemail.

My coordinator only talks to me once a year. When I ask for information, he does not communicate with me. I have been waiting for a response for six months. I'm very disappointed with my coordinator because he is not responsible with his work.

10c. CM Turnover

It is very hard to receive needed services as there is a constant change of service coordinator.

{Agency} changes case managers too often. Shame on {Agency}!

I have not heard from {Agency} for almost a year. I have no idea who my case worker is, as it has changed so much. My child's needs are being met, though I have no idea what type of services she could be receiving through {Agency}.

I appreciate this survey. I have been with {Agency} for 4 years and I've had five different workers. It is very hard because I only get an annual interview. I was never given any other resources for my four kids that are part of {Agency}. My worker right now, for the last 18 months, has contacted only one time every six months. This is only because I've had questions regarding respite.

Our Service Coordinator always changes.

Stop changing Service Coordinators. Everything else is O.K.

After my son turned three, I became frustrated with the number of service coordinator who came and went. Because of this problem, we did not get the assistance necessary to apply for additional services.

Our coordinator has changed 3-4 times in the last two years, and we have not met the new worker or spoken on the phone.

I personally have no idea who my daughter's social worker is. It changes frequently and we are usually not notified by the new on-coming worker. We have met with three persons in the last 5 years that come out to perform evaluations, and we never hear from them again. They interview us and take information, but do nothing to help us with our needs.

Overall, I have found {Agency} useless in finding and getting support services for me and my son. My worker has changed four times in the past two years. I was told by the first one that the services I was looking for were not available. The current worker told me that the services are available. It has been almost six months since the meeting, and I am still waiting to receive any kind of services.

The one thing that I don't like is that every year, my worker changes. Just when we're starting to get to know them, they leave.

There is a constant turnover of service coordinators.

11a. Satisfied with Staff

I'm very thankful for our {Agency} social worker. She always helps me anytime I need her. She's a great social worker and her name is {Name}. Thank you and I appreciate everything you have done for my son and family.

Blessings to all the {Agency} workers. I am very thankful for the support that I have received. I have been able to survive due to the 24 hours of respite that were given to me since my son was little.

My son's counselor, {Name}, is always kind and always ready to help with everything we need. It's nice to have a person such as him on our side. He is a great resource of information for every questions.

So far {Agency} has been very helpful to my Down Syndrome son. They are always quick to help me whenever I call for help. Our Social worker is friendly and thorough. I could say that {Agency} is really doing its job well and has helped my son in many ways.

Thank you for the support given by {Agency} and {Name}.

{Name}, our Social Worker, is fabulous.

11b. Dissatisfied with Staff

I would like that the social workers were more focused on the needs of the children with disabilities, and that when there's an IPP, that the worker be present.

11c. Staff Turnover

{Agency} staff turnover rate way too high!

11d. Shortage of Staff

My child has many medical issues that require licensed care. My only options are agencies that can't staff.

Agencies also need to take the time to screen more qualified applicants and begin positive recruiting methods so that individuals know there is a need for social workers, counselors, case managers, PTs/OTs in this particular field.

12a. Parents as Paid Staff or Case Manager

I need to utilize the centre for the caring of my son and the benefits. Can I get paid for staying home with him?

14a. Satisfied with Respite

We do use the respite connection and we get 8 hours a month. That is a good service as long as we can plan ahead for it.

I have always had excellent experiences with {Agency}. Respite services were a complete answer to my prayers. To me, that is a priority for well being and overall health.

The respite is really of great help because my son was able to play with other kids.

I am very happy about the money received for respite care.

Respite care is great. On person stay at home and the other works. It would be nice to get respite hours so we, as a couple, could enjoy more time together. We only feel comfortable leaving our child with an LVN.

Respite is the most useful resource we have received from {Agency}. Without respite, I'm not sure we would still have our son in our home.

We would like to thank {agency} for the respite support that is provided monthly for our hyper-down syndrome child.

14b. Dissatisfied with Respite

There is a lack of respite care workers

This past year, our concern was that information about share-of-cost for respite was not given out. The form for us to fill out was not provided in a timely manner. When we received a letter telling that our cost was 80%, we then had to make an appeal. The appeal was accepted, but we feel that we were let down by {Agency}.

It is frustrating trying to find a facility that will accept my child for respite care. I feel that the EPSDT assessment should be based on the difficulty of care, not just on medical diagnosis and condition. It appears that more and more facilities are "dropping out" of general respite contracts, and appear to be related to {agency} payment or paperwork issues. In my opinion, respite care is probably the single most important service that is offered through {agency}. It gives families the time needed to get a break.

The only thing I can say, besides the excellent treatment we have received from {Agency}, is this: I desperately need more respite hours. I only get six hours a month, and it's just not enough. No other complaints!

It's unfortunate that respite hours have become such a problem to use due to child care providers having to give their SSNs.

We get respite, but have had difficulty utilizing it.

I need help with more respite hours.

Somehow respite agencies need to allow the families determine if staff is compatible with them. I have only met one of the care givers that have served us.

I just received respite at four hours a month. In Kansas, I received 21 hours a month, without a required payment on my behalf. {Agency} wants me to pay 80%.

More respite would be helpful as I have a 24 month old child. I have to go to the doctor every three months.

16. Funding and Budget Cuts

If parents of children with disabilities make a lot of money, we never get any financial support.

More funding for children who can't leave the home for activities. More funding and services for emergency crisis such as rent, food, clothing, shoes, etc. Funding and services for 18 y/o adults who need conservatorship.

I would like {Agency} to continue with more services and to not cut or take them away. If you promise something, fulfill it.

Need help with paying the meds and social skills work.

We just receive funding for respite care. We often have to pay higher prices for our son to participate in community activities. It would be better if we could use our respite dollars in a more flexible way.

17a. General Satisfaction with Services

I am very thankful for all the support that I have received.

{Agency} does a good job. If I want to call to talk to someone, {Agency} is there to help. It is a pleasure having you on the side of my daughter and our family.

{Agency} has been helpful to our son in the past.

Since finding {Agency}, I can honestly say that you have saved my family, marriage, my son's future and my sanity. I do not know if we could have gotten through the diagnosis of autism without {Agency} or the {Agency}.

I just want to thank {Agency} for the help provided.

I'm very satisfied with your help. Thank you for caring for our children.

I just want to say thank you for the help that we have received from {Agency} to pay for child care. It has meant a lot.

I just wanted to take the time to let you know how grateful we are for the help that {Agency} provides us. Having a child with epilepsy is very hard.

We are very thankful for {Agency}.

{Agency} has helped my child a lot. Keep up the good work.

We are pleased with how {Agency} works. We appreciate the help that is provided to children with developmental disabilities. Thank you.

Help from {Agency} is important, needed and appreciated to families with developmentally disabled people. Your help gives us comfort and eases away our troubles.

Our family thanks {Agency} for providing services to us. We appreciate the home services provided to our children.

I would like to thank you for all your help, especially {Name}.

Thanks for everything.

I appreciate the services I get from {Agency}. Thank you!

This survey isn't very positive, as I have little {Agency} involvement. My daughter is four years old and is being served through {Agency}. Prior to that, we did get ABA through {Agency} and that was a very meaningful connection. Additionally, {Agency} assisted during our child's first IEP. I feel like {Agency} has been good to us. If it is still possible to get services (such as behavior therapist), I would be interested in taking advantage of this.

We are very happy for the services that you provide. It helps my child come a long way. She is also doing things like dressing herself, brushes her teeth with little help. I am very amazed how my child turned out to be.

{Agency} has been a "god send" for my family. The services provided for my family have been wonderful thus far. When I talk to other parents that have children with special needs, I tell them that my only regret was not knowing {Agency} six months sooner.

Keep up the great work. I talk to people who have older children with disabilities and I am thankful for the services offered to us now. They didn't have those opportunities. Thank you again.

So far {Agency} has been very helpful to my Down Syndrome son. They are

always quick to help me whenever I call for help. I could say that {Agency} is really doing its job well and has helped my son in many ways.

Thank you! Our son's quality of life is higher. We are all so excited with his progress thanks to {Agency} and you. God bless you.

I thank you for acknowledging my son.

Thank you very much for existing. You bring support to those who need it.

{Agency} helps with my child's needs, but it doesn't change the reality that we're living, it just makes it more comfortable.

I would like to thank {Agency} for the services provided.

Thank you for the support that you have given us. Without it, we wouldn't have gotten where we are now.

{Agency} helps us with our needs.

Thank you for all that you do. The services you provide are awesome.

Thank you for the services provided.

Thank you for helping us with our son and his needs.

Thank you to {Agency} for all the support given.

I'm very happy with the assistance provided.

Thank you for all the assistance provided.

I'm very happy for all the help that {agency} has given us.

We sincerely thank {Agency}.

Thank you so much for giving me the ability to help care for my child. He will soon be utilizing an after school care and I am really looking forward to it. Thanks.

Thank you {Agency} for all of the help [that] we are receiving. My son is enjoying pre-school and I see many improvements. Keep up the good work. Thank you so much

The service of {agency} to my child is more than enough. I hope you have more information about day care service catering to people/children with special needs. Thank you.

{Agency} and {Name} have been the sole source of caregivers that enable my family to stay together.

{Agency} has been very helpful in supporting the family's needs and addressing our concerns. {Agency} makes it possible for my daughter to be happy and healthy in her home environment rather than [at] a facility. Thank you {Agency} and our Service Coordinator for supporting us.

{Name} and {Name} have been wonderful. We receive respite hours and Medicare, and {Name} attends my child's IEP meetings with me. Our experience with {Agency} has been great, and we are grateful

Thanks for being there!

We've been very pleased with the help and support provided by {Agency}. Everyone has been courteous, professional and very helpful. the programs available through {Agency} are wonderful. Our child has made incredible progress and some of that credit goes to {Agency}.

Thank you for supporting us. Thanks to you, our children are able to reach their goals.

Thank you for all the help.

Our family is pleased with the care, concern and services provided.

Thank you to {Agency} for the help provided to our child and their support.

The Dialogue is very interesting and important to us. I want to thank you for all the help that you have given us. I hope that you continue to help us and that there is an improvement in the disabled community. Thank you.

17b. General Dissatisfaction with Services

I find the {Agency} resources to be bad. The outside experts recommendations were terrible. I have never gotten any assistance that helped.

Why is OC such a bad place for children? Why can't you help those in need? Why do parents need an attorney to try to get help for their children in the schools and from the state?

We have been attempting to get the appropriate services for our son for 1 1/2 years. {Agency} has been slow and inefficient in providing the appropriate help. The service providers/vendors that {Agency} contracts with have never been completely unmonitored by {Agency} and seem to have no one to answer to. When we pointed out that the service provider was not fulfilling our son's needs, we were told to "keep at it." My son's behaviors have increased. Also, vendors lack professionalism.

I no longer use the voucher program to purchase the pull-up our daughter requires because it is time consuming and difficult to submit.

When I asked for assistance, I never get any response and when I do, it takes six months or longer to get an answer. {Agency} is terrible for assistance but good for cutting the cost of day care or respite care. I have a 12 year old that is hard to handle and they have never given me any assistance.

Overall, I don't feel that {Agency} has taken an active roll in doing anything for my child. At one time, {Agency} was paying for diapers, but then stopped. I believe that she gets a small number of respite hours quarterly, but I'm not sure we're using them, since my child gets LVN care through MediCal EPSDT program. I don't really hear from {Agency} but once a year, for my child's annual review.

My child cannot receive many of your services because he is not extremely disabled. he is trainable and I have hope for him in the future. Not much has been offered from {Agency}. I feel alone in trying to find the best resources for him.

We, and many other families, have asked {Agency} for help with providing my son access to the community and are constantly turned down. {Agency} is all about keeping the money for themselves. I have never heard such a consensus in my life about how bad they are. Again, this survey will show that parents of children with autism are not satisfied with {Agency} and again this will just be filed away.

I'm very dissatisfied with {Agency}. They contracted an agency that I feel is not helping my son. I feel that they don't care about us. Everything that I have learned, is because my other son is part of the {Name} program. I think that {Agency} should give the families the option of choosing the agencies on their own.

He never qualifies for anything because {Agency} wants to wait until he's suicidal or hits rock bottom. I want him get these services to prevent the suicidal behavior. I have been very disappointed with {Agency}'s constant hesitation to step in and help my son. Thank God for the very little that I get from the school or he'd have nothing.

{Agency} should find the way for helping the people who are really needy. I think {Agency} is not doing anything for the people in need. It has been a long time since I expected something good from {Agency}. Who cares!

It takes too long to get requested services. When I need help, I need it at the time I ask, not in six months or a year.

Your processes for day care are too cumbersome and too many hoops and paperwork. Families with special needs children, spend much time trying to apply for services and maintain them. Between school, medical, IHSS, SSI, {Agency}, and specialty groups, it is overwhelming.

I was desperate for help with school issues, and {Agency} was no help.

My son is happy because I make sure that he has all that he needs within my ability to provide it. The services that we have received from {Agency} over the years have been minimal.

The experience with {agency} has not been fulfilling to our child's needs. We had to find out about services from other parents.

{Name} is a man that shows little concern for the individual child. It appears, he only cares about "running a business." {Agency} does not make parents aware of all the services and/or financial supports that are available.

I do not receive support or assistance from {Agency}. I had inquired about respite, however, it was never followed up. I also wanted assistance during my son's IEP. I'm at a point where I'd like to hire an attorney to begin the fight for my child to receive services in the least restrictive environment.

We need Linda Mood Bell Language Processing desperately, and no one is helping.

It seems like no one from {Agency} is really involved in my son's life. They are only a referral service for respite care. We have asked for help with additional things, but I have been told that they are not available. {Agency}'s response to a request for dental services was also disappointing.

I'm a parent of a 15 year old daughter with mild retardation. I also work in this field. Parents would like to be able to use respite funds for other things, such as therapy, swimming, etc. There is a constant turnover of service coordinators. School districts have to offer inclusion. {Agency} is very restrictive and only knows about restrictive opportunities.

My child has shown some good progress, but does not speak a word. We are disappointed, as we hope for {agency} to provide other ways to improve the condition.

17c. Access to Services/Supports

I have had a difficult time getting services for my child. Too much paper work and not enough help!

17d. Info Regarding Services/Supports

Need more attention, please provide list of services available to us.

It is very difficult to find summer camp activities or after school activities for my daughter. She is seven years old but developmentally about 11 months old. Please send information available.

We would like to have access or information on having our child socialize. We need assistance for a social skills program.

I still don't really understand the respite requirements/rules, and I can't find a babysitter 18+ years of age. We just don't go out as a couple due to this problem.

We have asked for in-home support respite care for two years, but there is still no answer. Right now, my son needs a liver transplant again. Also, he can't go to school, because he is on a waiting list. I'd like to know what services my son qualifies for.

Would like to know about other services offered to my child. How can we get this information? what happens when my child turns 18?

There is a lack of respite care workers and information about community activities that our daughter can participate in.

I would like to find out about getting in-home support services and about finding childcare.

I wish I could provide you with more information. My son was just eligible and we just had a second meeting with {Agency}. I would like to enroll my oldest son with a program with physical activities or with "art/music" programs. I have asked about a list of schools, centers, communities. Please guide us.

We don't know about some of the services that {Agency} provides. We need to learn how to support our child with sign language.

I would like to know if there is a speech therapy school for my son.

Thank for everything. I would like to know more information about any other type of help available for my child.

More detailed information regarding the {Agency}, is needed. It is not clearly explained how a new family can get services.

I do wish that a stream-lined catalog of services existed.

I need information about housing assistance.

I would like to receive more information regarding the functions of {Agency} and services.

I just want to know how to apply for low income housing.

I would like some information on how to obtain respite.

I would like more information about the extra services that {Agency} provides and help for children with disabilities.

I think {Agency} can be more aggressive on obtaining services for their families. I have gotten most of my services because I asked for them. I found out about the services from other families. I feel this information should come from our {Agency} case managers.

I would like for my worker to help me find some activities for my son and myself. I would like more information about how to help my son find therapy for his speech and OT.

I would like more information regarding my case.

I hope you have more information about day care service catering to people/children with special needs. Thank you.

Would like to see a workshop offered on "who pays for what?" to provide information on how parents can get services covered for their children, whether it be through the {Agency}, SSI, insurance, etc.

I would like to receive additional information regarding in-home support services, child care and community activities for children with special needs.

I would like our daughter to be a part of a swimming program in my area, and I can't seem to find out the answer. Also, I would like to know about free transportation for her to go places on her own.

We would like more information on services and recreational activities for our son.

I would like to know more about community activities available for my child.

I just need to be educated in the area of what services are available at the school district level.

I would like to obtain more information regarding classes in Spanish regarding how to train children with disabilities on how to use the bathroom. Also, a class in Spanish training parents on how to educate a child with disabilities.

I don't know how to get my son in more community activities or transportation to get him there, and to get him around other children.

17e. Need More Services/Supports

I need in-home services for my 16 year old autistic child. The only way for us to have him continue to live at home with us, is to have a nurse come in every night to help with his daily needs. Providing someone to come in everyday would be less costly than having to put our son in a group home. We need help getting Medical, IHSS, SSI and other state and federal services.

I wish that there were more services for pre-teens. I think it is too hard to get approval for psychiatric behavior help, especially since we use few {Agency} services.

I wish that {Agency} provided speech and language therapy for children with Autism. Also needed are social skills programs and physical fitness activities.

I really need after school day care for my child, as I work full time. Her brother currently baby-sits her, but he will graduate from high school in a year and a half. There is no special needs day care in {Town}. Also, we get respite available to us, but I can't use it since my son is the sitter for my daughter even though I pay him.

I would really like to have someone qualified to come and help me with my grandson's physical activities. He is a bright child and requires a lot of mental stimulation and physical therapy.

I wish for my child to spend time with children without disabilities, to learn how to be a 12 year old. Sometimes, however, he is like a sponge and children are not always good. My son is bipolar, and uses a wheelchair.

In general, we need specific therapy support, which we are not getting. We get respite, but have had difficulty utilizing it.

I'd like for my son to have more support. He needs a minor surgery in his mouth.

{Agency} needs to give more hours to parents for respite services. Also, {Agency} needs to be aware of how hard it is to have a child with special needs and how tired parents get when they don't get the help needed. They need to have more sign language.

We desperately need better after school care for older children. The respite care restrictions are too invasive. We also need more local community support information, as well as more workshop/services directly for autistic children.

17h. Waiting List

Also, he can't go to school, because he is on a waiting list.

My son needed behavioral intervention, and I was placed on the waiting list. I called plenty of times requesting the help, as my son was in danger of hurting himself. I could not wait for the help, and I hired someone to assist us. Ten months later, my son was approved for the help he no longer needed. The help needs to be much faster.

Services after three years old take too long to get approved. I applied for behavioral services in October. He was assessed in January. It is now February, and I still haven't heard about my son receiving services.

1e. Home - Waiting List

Have been trying to find out where I stand on the list for group home placement. It is impossible to find out.

3a. Health Care Equipment

I need more assistance for my grandson, such as a Hoyer Lift, an orthopedic bed a care seat and assistance during the weekends.

I really need a lift for our van. Currently we have no leisure/recreation activities because the wheelchair is very heavy and awkward to lift.

4a. Satisfied with Education/Training

The school system has been wonderful.

Luckily we are in a school system that is family friendly and provides resource information.

4b. Dissatisfied with Education/Training

My son’s school program is terrible and I could use help with advocacy. I usually go to New York for recreation. They have so much more to offer. Connecticut is not a good place for a child with a disability.

5b. Dissatisfied with Transportation

The one thing that I need is help with is finding someone to put {name}on the bus for me in the morning and get him off the bus in the afternoon. So far no help has turned up.

6b. Dissatisfied with Recreation Activities

In the summer time it is very hard to find a summer camp because summer camps for special needs children are very costly. I would like for my child to be involved in the community, leisure is not available for him.

Also perhaps activities on weekends where we don’t have to assist.

7b. Dissatisfied with Communication

No one has answered my letters nor returned phone calls. When I am home so phone tag is the mode. I stopped. DMR worker, {Name} came by in March to do some paperwork for it to be restarted but nothing has occurred to date. Probably never will. So why am I interrupting my sleep/work schedule for someone to say HELLO? I get so little time I have to pay for out of pocket as it is, which will cease to exist this summer anyway. People are too busy to really care anyway.

DMR has not been in touch with us since {Date} either by phone, letter or in person. There has been newsletter sent to us. We do not have a current DMR worker. The last one was named

{Name}. We so not know which district we belong to as we do not have any kind of services/support from DMR since {Date}. We would appreciate any help.

My son was considered eligible for services for DMR over a year ago. I have never heard from DMR or been assigned a case worker. Currently all of my information about his educational needs comes from our Pupil Services Director in the school system. There has never been any offer for services beyond that from DMR and while we are in an income bracket that does not require assistance from the state, my child is fast approaching adulthood and 21, where he will become part of the State/Federal system and yet I have never been contacted about what services are available for him, recreationally, vocationally or otherwise. Outside of our small community (there is absolutely nothing here for him. It would be nice to have contact with other parents in the

region. At this point I am not even sure which region he is in since no one has ever contacted us. The only material I have received from DMR was a newsletter – nothelpful. Certainly there must be some kind of protocol to address his needs. Regardless of income level, he is a member of this state and we are taxpayers who deserve more than just a survey. We feel that our son may not get services that he needs due to our income level which is never guaranteed. If something was to happen to us he would become part of the system immediately. It would be nice to know hi it works. Thank you for your time. P.S. Sorry, I guess I will have to make the effort just saw the note on the front.

Since belonging to DMR I have only spoken to my case worker three times.

We have not had very much help from DMR they have stayed for the most part on the sideline. There is little communication between us. I do not know in what other way they can provide help with.

Have been trying to find out where I stand on the list for group home placement. It is impossible to find out.

Families in the same region are offered (told about) different services and grants. There seems to be a large discrepancy among case managers. They do not all seem to have the same information.

8. Aging Caregiver Issues

I need more assistance for my grandson, such as a Hoyer Lift, an orthopedic bed a care seat and assistance during the weekends. At the present time I have arthritis and I need someone to help me physically. Any other type of assistance would be appreciated as well

9. Transition Issues

As my daughter reaches 18, I would like info as what is available to her.

1. We have concerns about long-term situation following school (group home, etc.)

At this time, we are able to provide for our thirteen year old son. The school system has been wonderful. I do not have any information about services and assistance once he is out of the school system. This would be helpful to me. Thank you.

My daughter is almost eighteen years old and I will need help with guardianship. I have only met a DMR worker once. I do not remember her name. It may have been {Name}. Then we were assigned another worker who I do not know and have never met. I do not know what services I could use for my daughter. She gets most of her needs met through school and home. I would like to meet our caseworker and find out what social outings are available for my daughter. Thank you.

10a. Satisfied with CM

My son's case manager is Excellent. He goes out of his way for us.

My case worker is great. He gave me a new beginning to couple of things

Our case worker {Name}is wonderful. Very helpful with both my children.

Our case worker is very courteous and always get back to me in a timely manner. She always finds an answer or points me in the right direction.

We would like to let whoever it may concern that we are thrilled with our son's case worker, {Name}. Although my son is only four and not eligible for much at this time, we felt {Name} was truly concerned with his overall well being. He has made himself available for questions often returning my calls within that day. Something I was not expecting because of stories I had heard from other parents in dealing with DMR. Having a child with intellectual disabilities is difficult enough, especially have to constantly advocate for him in schools, churches, sometimes even playgrounds. So it was a relief to be assigned a case worker like {Name} that truly cares about my child and the rest of my family. {Name} even offered to be my advocate at my son's school if needed. Our biggest concern would be that all of you are severely underpaid (and I am sure underappreciated) with much bigger case loads that should be allotted, not allowing you to really know your clients. Our promise to you is that as long as you fight for my son, we will fight for you as well. Sincerely, {Name}. P.S. We appreciate you!

Our worker has been very helpful. Now that our daughter is getting older she now can unlock doors and she has learned to pen windows and there locks. She runs outside and has run out of the yard. So this is a issue for us. Our worker has or does her best to help us with all our needs and she is always there when we need her.

We very much like our case worker. Our lives are hectic so it is difficult to meet and really concentrate on available services. We also do not know what services are available at is our primary concern. Thanks.

My DMR case worker is a very nice gentleman who helps me get my child into{Agency} every year. He also made me aware of the Respite Stipend.

We have a new case manager, {Name} who is wonderful. She came to the PPT with me, has been helpful providing info and right away I may add. Very pleased.

DMR case management has been excellent.

Our case manager, {Name}has been very helpful.

10b. Dissatisfied with CM

We were disappointed with the change of DMR case manager. Things have not been addressed as quickly as they were with our child's previous worker.

I never see or hear from my case manager. He has never done a home visit. He never calls to see if I need any assistance. I guess I am not needy enough.

My son has been a client of DMR for approximately one year. After receiving our original letter that he had become accepted we were never contacted by our case manager. We would like to know more about what our case manager should be doing for us. Not always guessing what is available or when they should be contacting us.

The DMR worker that came to my home gave a brief overview about the "lack of services" that DMR has to offer. (DMR caseworker is {Name}) She indicated that we are entitled to two stipends per year, however did not know when this would be available to us. Our monthly medication expenses usually run us about $900 - $1100 dollars – insurance dues not cover these expenses. We have a $2,000 dollar cap per year which ran out in {Date}. So the stipend would help with this as well as adaptive equipment

– bikes, etc as {Name} cannot ride a typical bike. What the worker did say was that respite might be available -- overnights in a group home and I would not place any four year old child in someone else's home, let alone a group home. The last thing {Name} spoke about was residential placement when he turns 18 – to speak about this at his current age of four I found to be extremely inappropriate. She knew nothing about my son's skill level or potential and she spoke about residential placement; what a joke! DMR has done nothing to help my son with his disability this is a travesty to our family.

I am very unsatisfied with my case manager when I need help, sometimes I went to the {Agency} office and he never was there. I leave a message never he answers, for this reason I do not have too much information about the services that DMR offers that be good for my son, {Name}.

I have a DMR worker I do not remember her name. I choose not to deal with her so my son has not been getting services. My problem with her is that I would leave messages with her and she would not return them. So finally I called her supervisor and that's when she finally called me. When she called me the conversation was about how she says I did not leave her messages. She was not professional. She was very rude. She did not even make an effort to come to my son's PPT meeting.

However, over a year ago my son was assigned a new case worker, whom I have never met or heard from. I do not even know who it is anymore, so we have not really had any help or input from DMR for over a year. I will be calling up our regional director to find out who my son's case worker is now that I am thinking about it again.

10c. CM Turnover

I had one great caseworker, after her, we have had two more and the one now has way to many cases on his hands to give everyone the attention that they need. I just want to know what is going to happen in the future? Thanks

Since I have been a part of DMR (three years) for both my boys, this year was the first time any worker has shown up for a PPT. Since the very first meeting and initial evaluation DMR has continually changed workers. So much in fact that I was not sure who our worker was anymore. {Name}, my middle son, had be placed in Massachusetts because we were unable to find help here. My past workers never even showed for Probate yearly which are very important. If it were not for voluntary DCF services, I would have been in big trouble because DCF was n help when {Name} was in crisis at Yale for a year!!

Our case manager has changed so many times and so often we don't have any consistency or anyone really being involved in my son's life. We would love to know what is available for him through DMR and how we go about getting these services.

My case worker changes more times than I can count. Autism is based on routine. I get tired of explaining this over and over to so many people the same way with the public school systems. I have twin boys both with autism. I need more help than ever every year that they get older. I received SSI for both, now I and my wife make too much and we lost it. Now we owe them. If we make that much why are we still having thing turn off living on a week to week with so very little.

Our case manager constantly changes and never calls.

10d. Shortage of CM Workers

I have not had a case worker since {Date} and I am still waiting.

I put comments throughout survey. I feel there are not enough case workers to give the help needed to families. I cannot even tell you my son’s workers name. If anyone would like to call to discuss my numbers: Evening {telephone number} Work {telephone number} or Cell {telephone number}. Very disappointed with Services.

Our biggest concern would be that all of you are severely underpaid (and I am sure underappreciated) with much bigger case loads that should be allotted, not allowing you to really know your clients. Our promise to you is that as long as you fight for my son, we will fight for you as well. Sincerely, {Name}. P.S. We appreciate you!

My DMR caseworkers have been nice, but we are not very involved. I have not spoken with our new lady yet (one year into it). I do not want to bother or burden her. I am sure se has ten gazillion serious cases for a measly salary.

10f. Pay CM More

Our biggest concern would be that all of you are severely underpaid (and I am sure underappreciated) with much bigger case loads that should be allotted, not allowing you to really know your clients. Our promise to you is that as long as you fight for my son, we will fight for you as well. Sincerely, {Name}. P.S. We appreciate you!

My DMR caseworkers have been nice, but we are not very involved. I have not spoken with our new lady yet (one year into it). I do not want to bother or burden her. I am sure se has ten gazillion serious cases for a measly salary.

11a. Satisfied with Staff

I have been extremely happy with the support that {Name} has given to my

We would also like to thank the staff at the {Agency}. Recently our family was in a crisis situation with severe behavioral issues with one of our autistic sons. We feared we would not be able to keep our family together – the situation was so out of control. {Name} and staff at {Agency} took one son one day and our other son the next day after he came home from the hospital. This was all on short notice. This time allowed us to contact doctors and regroup. We have had very positive experiences with the staff at {Agency}. Lucky for us we have private insurance that covers our boys medical needs. We do receive support grants that have made our home safer (fences, locks, etc.). These monies also pay for in home respite. We would not be able to afford these expenses otherwise. Thank you.

14a. Satisfied with Respite

In our situation the most helpful thing to us now is respite care. The assistance we receive generally provides adequate supports for the day-to-day are of our child. However, it is so important to have a place in which we have confidence that she will be well cared for so that we can have a real and true respite from the stress and fatigue of her daily care. We utilize the respite center in the {Agency} and love it when we are accepted for a visit. However, it has become increasingly difficult to get in for a weekend and nearly impossible to get a particular date when needed. (for graduations, weddings, etc.) There need to be more respite beds made available and a better system of accommodating for

special requests.

We are very happy with the respite care provider assisting our child.

We use weekend long (4 day) DMR respite. Mostly in {Agency} 4 times per year. The staff is wonderful. The respite allows us a needed break and to spend quality time with each other and our normally developing son. Due to the intense one-on-one supervision needs of our ten year old daughter, monthly or every six weeks respite would be even better. Thank you. Question #49—We also take advantage of Saturday morning 9-1 respite in {Agency} 2-3 times a month.

Respite is by far my most beloved service.

Quarterly overnight visits to DMR respite centers have been a big help.

14b. Dissatisfied with Respite

Started receiving respite funding but services were stopped over a year ago. No one has answered my letters nor returned phone calls.

However, it has become increasingly difficult to get in for a weekend and nearly impossible to get a particular date when needed. (for graduations, weddings, etc.) There need to be more respite beds made available and a better system of accommodating for special requests.

We live in {Town} and would very much like to take advantage of respite services at the {Agency} which is ten minutes away from our home. We have been denied on several occasions and told we must use the {Town} or {Town} Centers which are a much greater distance and its too inconvenient. We do not want overnight care, just a break for a few hours to see a movie, paint the kitchen or go out for a bite to eat once in a while. When my children complete summer school which last for 21 weekdays, I'm trapped at home with them until school resumes. Because they both have autism, I can't go anywhere alone with them. The month of August is very difficult for me.

I have a fourteen year old daughter and am a single mom who has been asking for respite and relief. All I hear is the law has changed and we can't do anything for you/daughter until she is twenty-one years old. Go back to your school system for help. I have been getting the run around for last year since my daughter was accepted. I know many families on respite and yet I can't get services. I found this organization does not meet any of my many needs. I actually don't know what use or good this agency serves. As you can tell I am extremely disappointed with the help (or none) that the agency provides. As far as I am concerned I do not benefit from your agency at all. I have an extremely complicated daughter who needs a lot of intervention and instruction – I wish I could help. I would like to speak to someone who can actually help to make a difference in my daughter and my life. You can contact me at: {Name}, {Address}. I have exhausted conversation with my case manager. So please have someone else contact me. P.S. this is not a reflection of my case manager as she claims there isn't anything she can do.

The respite money from DMR is great, but honestly, it doesn't go very far. It breaks down to about five hours a month of respite which would not be bad if we could get a CNA in her to help for the twenty hours each week. I really wish something could be done about letting us find someone ourselves for those twenty hours a week.

As most families August is a tough month to find caretakers for a disabled child. I'd applied last year for a week respite at the {Agency} but they lost my paperwork and thus never granted us respite there. This year we were granted a week in July an when he is in school all day long and thus not a dime that we needed or requested. I made a request to {Name} at {telephone number} to change to August but my request wasn't responded to in any manner. I have not found DMR to be responsive. My son's caretakers are paid by the {Name} program so is my son's formula. So my answers to respite care is purely and totally from that program and not from DMR.

I wish there was a DMR respite center closer to my home that I could use more often than twice a year (I'm located in {Town}, CT). I currently use {Agency} (my child has feeding tube).

All I ever hear is "there is not enough money", "we don't do that for kids", its the parents responsibility", or "sorry, its not an emergency. Even though my child is waivered we never get respite when we request it. Financial support is never available when requested. DMR does not support families it only helps those who complain. I fear my child's future under the support or lack there of, of this agency.

We need more flexibility and longer respite – flexible respite times.

16. Funding and Budget Cuts

I really feel its time to take a look at the {Name} health programs to help families that are like ourselves. Here is our dilemma: We have four children. All are special needs, things such as cancer, autism, MR and lemophillia, etc., many compounding illnesses. We just lost {Name}. The family income slightly went over their guidelines. They transferred us to {Name}. We can't get {Name} because the kids already have a primary insurance. {Name} helped tremendously by paying for Co pays and things there primary insurance refused to pay for. We had four healthy children at the time of their births (or so it seemed). We did not decide to have a family like this with all these severe illnesses/disorders, but it is what life has dealt us. We do the best we can. The amount of bills we will be facing just in co-pays or unpaid medical bills and medicines that our primary insurance will not cover will break us. I do not doubt we will lose our home and everything. I firmly believe that {Name} income guidelines should be altered and raised depending on if you have legally recognized disable children. Your percent above poverty level for things like fuel assistance can increase if your house has anyone disabled in it. But not {Name}!!. What Gives??

Need more respite funding have more than one special needs kid.

When I ask for funding for camp, I do not usually get the full amount.

Yes, I have been waiting for daycare funds for nine years now. It is getting very hard to pay someone three hundred dollars a week to care for him. I would like to at least get some kind of funding for this if possible. Also, help with getting him a bike to ride. The school told me that the bikes cost $1,000 (one thousand dollars).

Due to lack of DMR funding my family will pay a large portion of funding needed for an after school program. My child attends the lighthouse three times a week but would benefit from five times a week. Funding is an issue due to the cost of the program.

I need and have requested more help. I remember when I was a child 50+ years ago, neighbors who had special needs children institutionalized them. Over the decades the government has tried to keep children at home to cut cost to the state. I want my son at home with us, but the state has reduced financial support and services to virtually nothing. Shame on your system! You are balancing the state budget at the expense of the defenseless and their overwhelmed families. We need affordable qualified in home care on occasion to help us meet needs of {Name} so we can make life better for our daughter. We need a buddy bike so we can take {Name} on family bike rides. We need help to pay for extra dental care which is not covered by our family dental insurance policy. We need a van to replace our 15 year old car to help transport him.

The state simply does not allocate enough money to provide adequate services. I currently have no respite funds and I am very worried about my son's future. We have an average income (actually well below average for our/this area).

It has seemed like DMR used the scale back in funding to be the excuse to ignore us as if somehow our child's needs stopped happening. I also know I cannot ever rely on you for future help. When I finally do get something it always get taken away at some point.

All I ever hear is "there is not enough money", "we don't do that for kids", its the parents responsibility", or "sorry, its not an emergency. Even though my child is waivered we never get respite when we request it. Financial support is never available when requested. DMR does not support families it only helps those who complain. I fear my child's future under the support or lack there of, of this agency.

17a. General Satisfaction with Services

Thank you for everything you wonderful people do.

We are grateful for the current support he does receive.

The new waiver is better for our family in that we can now self-direct our son's care.

I appreciate what DMR has done for us.

Thank you for your services

What support or services I get from DMR is so much appreciated. Thank you.

17b. General Dissatisfaction with Services

I found this organization does not meet any of my many needs. I actually don't know what use or good this agency serves. As you can tell I am extremely disappointed with the help (or none) that the agency provides. As far as I am concerned I do not benefit from your agency at all. I have an extremely complicated daughter who needs a lot of intervention and instruction – I wish I could help. I would like to speak to someone who can actually help to make a difference in my daughter and my life. You can contact me at: {Name}, {Address}. I have exhausted conversation with my case manager. So please have someone else contact me. P.S. this is not a reflection of my case manager as she claims there isn't anything she can do.

We just began the application process for Voluntary Services and have found it to be time-consuming and disorganized. Nobody seems to know who is responsible for what when the child already receives DMR services. It is frustrating and simply adds to the stress we already have.

The DMR worker that came to my home gave a brief overview about the "lack of services" that DMR has to offer. (DMR caseworker is {Name}) She indicated that we are entitled to two stipends per year, however did not know when this would be available to us. Our monthly medication expenses usually run us about $900 - $1100 dollars – insurance dues not cover these expenses. We have a $2,000 dollar cap per year which ran out in {Date}. So the stipend would help with this as well as adaptive equipment – bikes, etc as {Name} cannot ride a typical bike. What the worker did say was that respite might be available -- overnights in a group home and I would not place any four year old child in someone else's home, let alone a group home. The last thing {Name} spoke about was residential placement when he turns 18 – to speak about this at his current age of four I found to be extremely inappropriate. She knew nothing about my son's skill level or potential and she spoke about residential placement; what a joke! DMR has done nothing to help my son with his disability this is a travesty to our family.

We have not had very much help from DMR they have stayed for the most part on the sideline. There is little communication between us. I do not know in what other way they can provide help with.

I would love to have the services my son needs which would be an extension from school and overlap in home so all of us can be on the same page. Parents can understand and help their own children. Therapy is the best – the younger the better. My son is 6 ½ and still waiting for the right services or money to hire my own people. All I get is talk. Thank you.

The questions in this survey seem to assume that DMR is providing more for my son than DMR actually provides. My wife takes him to Mystic for swimming on Wednesdays and except for summer I would take him swimming in {Town} every other weekend (Sunday). That is all that DMR provides for my son.

My complaint is when I originally filed for Medicare waiver last summer 2005, I included my annual income. So they (CT) knew what my income was. {Name} (her supervisor is {Name} indicated to my case worker {Name} that our application would be accepted if we get medical application from {Name}doctor. I did this and according to my case worker all we had to do is interview Medicaid waiver providers in Hawaii. So

after all the time effort, time off from work to make these arrangements, we settled on {Agency} to have a person go to our home 5 times a week to have daily activities training for our daughter. Well after all we went through at the last moment {Name} rejects our claim. I was very upset that knowing what my income was at the beginning of this whole process they allowed us to go jump through all those "hoops", waste time, effort and money. Not only with our family but at the time of our case worker, the time of workers at {Agency} who came to our house for interview twice when they {Name}could have rejected our application at the very beginning. This person {Name}was also very difficult to contact. Telephone message box was too full for messages on a three day stretch once. She returned my call once and we were cut off and she never tried to call again. The last time I talked to her supervisor {Name} was to pass a message to {Name} to call me and she never did. My case worker {Name} often told me how hard it was for her to communicate with {Name} and her department. I {Name} am fully unsatisfied with the services I received from the Developmental Services Branch concerning my daughter {Name}needs.

17c. Access to Services/Supports

I usually go to New York for recreation. They have so much more to offer. Connecticut is not a good place for a child with a disability.

The family swim in {town} on Sundays is nice but with only one time available that for us usually is not convenient it would be helpful to have more times or other days (evenings) to go.

17d. Info Regarding Services/Supports

I am not looking for money, just support services and information on how he can best be treated to ensure the most success, even if, because of my income, I need to share the costs. I am not opposed to that. My only interest is getting the most services/information (which there is an extreme lack of) to best service my child.

DMR has not been in touch with us since {Date} either by phone, letter or in person. There has been newsletter sent to us. We do not have a current DMR worker. The last one was named {Name}. We so not know which district we belong to as we do not have any kind of services/support from DMR since {Date}. We would appreciate any help.

My son was considered eligible for services for DMR over a year ago. I have never heard from DMR or been assigned a case worker. Currently all of my information about his educational needs comes from our Pupil Services Director in the school system. There has never been any offer for services beyond that from DMR and while we are in an income bracket that does not require assistance from the state, my child is fast approaching adulthood and 21, where he will become part of the State/Federal system and yet I have never been contacted about what services are available for him, recreationally, vocationally or otherwise. Outside of our small community (there is absolutely nothing here for him. It would be nice to have contact with other parents in the region. At this point I am not even sure which region he is in since no one has ever contacted us. The only material I have received from DMR was a newsletter – not helpful. Certainly there must be some kind of protocol to address his needs. Regardless of income level, he is a member of this state and we are taxpayers who deserve more than just a survey. We feel that our son may not get services that he needs due to our income level which is never guaranteed. If something was to happen to us he would become part of the system immediately. It would be nice to know hi it works. Thank you for your time. P.S. Sorry, I guess I will have to make the effort just saw the note on the front.

We also do not know what services are available at is our primary concern. Thanks.

I do not know if my child is eligible for SSI benefits, medical or dental services, OT, PT or speech therapy thru DMR. We struggle in with our insurance provider through my husband's employer. I do not have assistance with school PPT and was unaware there may be help thru DMR.

Luckily we are in a school system that is family friendly and provides resource information.

I do not know what services I could use for my daughter. She gets most of her needs met through school and home. I would like to meet our caseworker and find out what social outings are available for my daughter. Thank you.

What am I suppose to be doing? How do I get support? My name is {Name}. My son is {Name}. My phone number is {telephone number}. Help!

As a single mother of three children – the oldest being handicapped, it is difficult to make ends meet. The children's father abandoned his children and moved to Florida. Child support is minimal and inconsistent. I am returning back to school to earn a Masters in Education and earning a salary will be difficult. The program is a 14 month working internship, therefore there is no pay during this time. I will look and need some programs to put the children in, especially for my handicapped child. It would be helpful to know what is available in the {Town} area. Informing DMR clients via mail or through school would be helpful.

{Name} is a fourteen year old teen with excellent skills with video games and computers. But, I want him to learn to play baseball, football, etc. His father is an excellent parent and former football (College) player but works two jobs and does not have time to do these things with him. So {Name} exercise is limited. Can you help?

17e. Need More Services/Supports

My son could use more visits at the overnight respite center than three per year allowed {Agency}. He could also use time with a young adult male to spend time with outside the home as well as to do recreational activities with him.

My child have Cerebral Palsy, seizures, low muscle tone, asthma now he is going through these episodes where he scream on top of his lungs and hit. I mention it to doctors and they are feeling its Autism, but then again I receive complaints about him yelling instead of help. The Town of {Town} gives him physical, speech, occupation therapy three times a week for two hours and they go with the school schedule which I feel its not even close to enough for my child. He needs way more therapy than what he is receiving. I just feel he is not receiving care like he should. I need help with more therapy sessions. The last time I spoke with my case worker that is what he was working with. So I am waiting to hear something about that. I just need more help period; with him, more therapy, more ways to know how to cope with situations like this. Its hard. I also wanted to look into other places where he could go for rec. with people who know how to deal with children like my son.

To Whom It May Concern: I am a single mother with a severely disabled three year old daughter. I need help and support, as well as some relief time to make my life less stressful. My daughter needs respite help and we are in dire need of financial assistance as well. We are struggling to survive. We need a case manager and someone who can contact us and begin helping AS SOON AS POSSIBLE! We have been trying for quite some time to receive services from DMR and it is at the point where we really need help in any way that you can provide it. As a mother, I have almost no time to ever do anything or get any kind of a break and I think that I am emotionally worn down by the demands of raising my precious daughter alone. I would greatly appreciate your help and your immediate consideration of the magnitude of stress that I live with each day. I would be grateful for help and support, both with her care and also any financial help that could help provide the best quality of life for my little angel. Thank you.

We need a case manager.

Need more respite funding have more than one special needs kid. Modification for home needs as the kids grow need different modification for home. Need Services other that school provides, such as, physical, speech, OT, etc.

We do not get enough support for our child who requires so much support. We wish we could have more in-home support for him. Also, you do not ask about size of family. The existence of siblings means parents need to stretch themselves and resources across a bigger group. This also speaks to greater levels of need.

Need Help, much more than given.

We strongly request group home placement. We feel this is where her needs would be best served. We are very tired. Her needs are extensive. We are both working parents and paying for daycare for her after school/school breaks/summer and it is difficult ($$) and providers limited. This option is losing its feasibility as she is getting older. More group homes needed!!

More services/after school programs for kids/teens.

Our son {Name} is four years old. He is autistic. We registered him with DMR a year and half ago. With his registration we were told that respite would be available. After a visit from a DMR representative, we were told we could not get respite based on availability and our income level. {Name} has a two year old sister named {Name} and six year old sister, {Name}, who is learning disabled. Recently, {Name} has snuck out of the house under the care of a babysitter and also has snuck away from my wife while in the driveway. Both times he has ended up in the middle of the busy street we live on that has a 45 MPH speed limit. This is deeply concerning to us as you may understand. Other than a few answered questions and the request for respite there is nothing else we have asked of DMR. This is a formal request to please help with the installation cost of fencing for our yard. This will keep our son safe from the perils of the busy street. Thank you for your time and your consideration.

17g. General Dissatisfaction with Service Management

My son’s case manager is Excellent. He goes out of his way for us. It is the upper management which is extremely slow in processing application and returning phone calls. Basically phone calls just are not returned unless threatened with a PAR and they are returned. It’s been over a year funding was promised for {date} then {date} and then {date}. Finally funding is on the books as of {date}, but as of {date} it is still not in the account of the fiduciary.

HAWAII

6b. Dissatisfied with Recreation Activities

Also, Summer Fun activities are met with resistance from the director even when our one child in the program was accompanied by a skilled trainer. Our children would greatly benefit from these programs but it is quite difficult to get them in even though they are not allowed to discriminate.

7a. Satisfied with Communication

I think the support I get from {agency} is good. The social worker is usually able to answer my questions or if not find the information and let me know my answer.

7b. Dissatisfied with Communication

It's hard to get a hold of the workers and I get no help at all. Still waiting for paperwork on getting my son's bath chair.

Hello. Thank you for this survey. I am receiving respite for my youngest son. I had to mail the paperwork to get money by {date}. One lady from DOH called me {date}. She said I didn't sign one place so she mailed me back and I needed to mail her back soon. And then I did it. But she called and left her message if she doesn't get the letter (paper) today she can't give money to me. I listened to the message evening so I called her back next morning. I said I already mail and mail is on the way. Also the paper (mail) suppose to be there now. Above her (boss) called me back and they can't do anything. I understand but why they didn't tell me when I talked to them first time. It was not good service addition my respite was ? and {date}. The last day I spent was {date} then I mail the paperwork the next day. Why respite money can't straight go to the child provider.

10a. Satisfied with CM

I'd like to thank all of you for your hard work and efforts. {Name} has made tremendous efforts to do all he could for our little foster girl. She likes and connected with him well. Thanks again for all the hard work.

I have gone through only 2 case managers who are very helpful in fulfilling the needs of my son. They are very professional who are at least trying to accommodate the services within the budgetary constraints.

We have been so lucky to have {Name} as our case manager. I have been so grateful for all that she has done for our family. She is always available and has been a great help to our family. Recently we have changed over to the CDPA--Consumer Directed Personal Assistance.

It has been wonderful and {Name} has been wonderful to work with. We are truly grateful for everything and all of the people that have supported our family throughout the years for without them our son would not grow! Thank you very much. P.S. I must say this again--{Name}has been awesome and has gone above and beyond. She even helped when my son needed to get shots. She is the BEST!!!!

Our case manager always helps and supports our son and also family. We are very happy about it.

We really do appreciate that we could get respite program and the case manager helped me understand what kind of services DOH can provide for my family. Thank you very much!

I am able to work out any problems with the supervisor if I have any questions. They have been very cooperative and are willing to work with me.

Your case workers are very responsive (DD department)

Our case manager does a great job and is always very helpful.

The positive comments are mostly the result of changing the case manager. Current case manager {Name} seems to honestly and whole heartedly try to help us as much as possible. Likewise, the previous case manager {Name} seemed to have done the opposite. We are looking forward to a long supportive relationship with our new C.M.

My child's case manager has been very helpful. It took them or the Dept. to actually start services with my child but I've been patient knowing my case manager only can do so much.

10b. Dissatisfied with CM

Lack of actual caregivers and large change of staff. Is difficult for both my sons and family. It has been easier to have NO service than the constant transitional changes. The system doesn't change with needs. Service coordinator only comes around to file quarterly reports. No follow up to see actual needs and service being performed. None of the current approved service are being supplied.

We used to have a case worker that would check with us at least once a year. Haven't heard from her in a while.

My DD Case manager would come to the IFSP meetings but then I got a new one and he

hasn't contacted me. I don't know where my son starts in the DD agency.

10c. CM Turnover

It would be good to have DOH case managers be more consistent. Families rely on the relationship that is built with them. There is too much turnover with staff.

11a. Satisfied with Staff

Kauai got the best people that helped my daughter. They (the kids) were on Maui/Oahu but Kauai's the "bomb."

11c. Staff Turnover

Constantly changing social workers are a problem because we have to take the time to get to know another social worker and let them familiarize them with my child. It also does not help with follow through as we have to go over what our goals are with the child. It seems to waste a lot of time for both the new social worker and myself especially when I know that the social worker has so much other cases. These past 5 years have given me an insight as to how things work and are constantly changing. I think if people (families) were taught in the beginning how the process works we can better understand what is available to us and what we can do to help our social worker help our child. I do like the fact that they come out and monitor what is going on in the household. It helps them understand our family's needs. I have been very satisfied with my services. I know that when I call it is always answered if not by my social worker her boss can speak to me or the nurses is always helpful. I like knowing the procedures I need to go through to help my case worker thereby helping my son. We have good communication.

14a. Satisfied with Respite

We really do appreciate that we could get respite program and the case manager helped me understand what kind of services DOH can provide for my family. Thank you very much!

16. Funding and Budget Cuts

Not sure if we are both talking apples, i.e. support workers is that PA's or case workers, etc. Re: monies from some things we have a limit. I know how much for other things. I don't know, i.e, PA services via Easter Seals as he is approved for hours. Because we have family support we do not access all that is out there. Only as needed. Tried respite monies but their procedures are too confusing. Not worth the effort.

However, several fiscal problems in HR department has had problems keeping track of updated and current records to ensure providers payment is accurate and on time.

17a. General Satisfaction with Services

I would like to express my appreciation to all the agencies and departments for the variety of assistance that has been offered to my son. I strongly believe that without the interventions that are being offered, he would not be where he is now and that there is a light at the end of the tunnel. {Name} is turning into a very well adjusted child who seems to be actively progressing in his own interaction with peers and in the community.

My daughter has benefited from DD/MR services in a positive way.

Through {Agency}, I've been able to receive help by purchasing educational toys, apply my two autistic girls for activities in the community and more. These services also helped us out financially. My husband works full time and I am on call for DOE. I appreciate all these services and help that {Agency} has given not just for my daughters but also to me and my husband.

We have been pleased with the services provided. Thank you!

Good job. A lot better than DOE.

I am very happy with the outside services that my son is receiving. I am able to work out any problems with the supervisor if I have any questions. They have been very cooperative and are willing to work with me.

I would like to take this time to thank the DD agency for all the guidance and support we have gotten for my two girls ages 6 & 8 years who were diagnosed with Autism at ages 1 & 3. At a scale of 1-10, they were about a 3 but now they're more like 8 & 9 on the scale. With all these support we've received, they both are able to feed themselves, change clothes, wash hands by themselves and more. They are very independent. When they need help, they'll ask. Again thanks a whole bunch.

I have just signed up my daughter for this type of assistance, so I'm actually going through the process of paperwork as of now. I was not able to answer appropriately. As time goes on, I will be able to know more about the program and my experience so far has been good. Takes a while for the process but it's coming through slowly but surely. It's great and wonderful support for us. Mahalo.

I have limited English so I can't explain well but I really appreciate your service. My life was so hard to stay with my autistic child. Almost I had no life but now I received private assistant for my son and I could go out without stress. Thank you so much again.

17b. General Dissatisfaction with Services

The biggest stressor is the lack of consistent, reliable skilled nursing services. It's a day-to-day problem and it burns parents out. Different options need to be looked at to give families a break.

Upon this survey, I am somewhat very happy to have received this because I am not satisfied with the help I've been getting for my son. You or whoever diagnosed my son with mental retardation but no explanation at all as to why he's the way he is. This year I want to take my son to Utah for more test but I need your help financially. This subject has come up with the last case manager we had which was {Name}. We have been waiting due to the fact that results may arise unfortunately no luck. So I am requesting that I want my son to learn sign language and I want to go to Utah for more test until I find out what is causing him not to speak. The next school break will be spring break in March. My son is now 16 and we've sat on it too long. So if you want to help my son, we need a trip to Utah. I'm only asking for help on his behalf. I moved about six months and I cannot afford a computer which we would love to have and we cannot afford a phone so your only way to contact me is by mail. I'm sorry for making things tough for you but that's my true story. Should I expect to hear from you? I sure hope so. I've waited for 16 years. I can't no longer do that.

I was very disappointed that my daughter weren't able to receive her PICL.

Why do you have to go through so many hoops to get Medicaid Waiver.

17c. Access to Services/Supports

Living in a rural area makes it almost impossible to get services for support because of distance. As we work with our community, we learn to "help ourselves" using our own resources. It would be nice to not have to "bug" agencies when you have been promised the help. We always have to climb the "ladder" of authority to get some response and then the waiting game begins with everything taking forever. If we don't do it ourselves, our kids will be old and out of school before anything is done. Money and "location, location, location" does talk. If funds were given to communities to be used for the good of our children--being responsible for these funds--we could do a lot more for our kids and more effectively. I hope someone really reads these surveys and doesn't get caught up in red tape again.

17d. Info Regarding Services/Supports

Social security is another issue. I applied for my son several years ago and was denied. I heard later from parents that it was routine for them to reject 1st applications. My case manager recently suggested we apply again. This will take hours of work. I also think Dept. of Health should advertise or be more known as a resource for citizens with disabilities. There are many DD adults in Hawaii with no services at all. It shouldn't be an egg hunt for families to find out about services.

Hello. Thank you for this survey. I am receiving respite for my youngest son. I had to mail the paperwork to get money by {date}. One lady from DOH called me {date}. She said I didn't sign one place so she mailed me back and I needed to mail her back soon. And then I did it. But she called and left her message if she doesn't get the letter (paper) today she can't give money to me. I listened to the message evening so I called her back next morning. I said I already mail and mail is on the way. Also the paper (mail) suppose to be there now. Above her (boss) called me back and they can't do anything. I understand but why they didn't tell me when I talked to them first time. It was not good service addition my respite was ? and {date}. The last day I spent was {date} then I mail the paperwork the next day. Why respite money can't straight go to the child provider. Before early intervention time was ok. But the lady said they only can pay me. I have 3 boys, 7, 6, 3. All three boys have disability but my first case manager said let's do the youngest one first. Because he was receiving services from Early Intervention at the same time second child was in IEP from DOE and now oldest child is IEP (central auditory processing problem & others). Can I apply for something to DOH? Please call me.

17e. Need More Services/Supports

Would like more speech therapy (sign language, etc.) support plus support after child is over 18 years of age.

17h. Waiting List

I'm waiting for PICL services. It's been more than 2 months. Is there any way to make it short for processing? I heard it takes about 4-6 months to get that services and I think it's too long for the family who need the services. Thank you.

SOUTH CAROLINA

3a. Health Care Equipment

Finally, why does it take so long to get equipment through DDSN? It is sad how long it takes. I requested a medical bed for my disable son because his bed broke. I have not received a new bed.

Equipment is hard to come by and if someone gets our child inappropriate equipment there is no recourse to resolve the situation. Thank you for sending this and giving us a chance to be heard.

3e. ST/PT/OT

Speech therapy not friendly at all did not like her service. Did not had

speech since December 2005.

The reason I say my child is not happy is because she have a problem with speech and when she can't get the words she will get upset and blow, she doesn't play well with her sister, she is always fighting, and with the other children as well. My child need special help in communicating skills, speech, and etc. They turn her down for disability, and I really want to appeal.

4b. Dissatisfied with Education/Training

My child has a great deal of behavioral problems and we have trouble at school more than anywhere else even though he is in the special education program. If I had to say anything that would need to improve for handicapped children, it would be within the special education systems at the schools.

5b. Dissatisfied with Transportation

No ABA services available. School bus system is terrible in Columbia.

I've try to use the transportation system. The only problem is that can get us to our first destination which is Nextstep but they said that they weren't sure about getting back home or get to school on time.

7b. Dissatisfied with Communication

Poor communication is a major setback.

Sometimes, my service provider does not tell me about programs available to me. I usually learn about the programs from other parents. I do not think the provider intentionally leaves out information, she just has a lot to do. However, it makes me wonder.

You need to check on some of the employees you have they do not communicate w/ foster parents just w/ the Case Workers that only see them once a month and don't know much about the child. The one they need to be talking to is the foster parents as well.

Our twin sons have just been approved for TEFRA coverage. During the initial application phase, I had several questions and called the TEFRA contact at the phone # provided. My calls/ messages I left were never returned. This was very discouraging. Once, I submitted an application, I was able to speak with a person once they had initiated contact with our family. I believe that families applying for TEFRA need all of the assistance available to them. The office in charge of TEFRA should make every effort to help families with questions during the entire process. With all that families of children with disabilities face on a daily basis, something like this is major to a parent who has very real and specific questions that need answering.

7d. Communication- Language Barrier

I would like to say that you all work great as a team. Also I would like for you to have more people that can speak Spanish to help the people who need you help. Thank you!

10a. Satisfied with CM

{Name}works with my son. I love her, she is always there when ever I need her she is like a part of the family. Without her I might not have come so far with my son. I'm not good with words on paper but I can say there are truly no words good enough to tell you how much she has impacted my son's and I life. Thank you for hiring her on.

Recently, We have been assigned to a new case worker named {Name}and she has worked really hard to try to get us the services we need.

Overall we are satisfied with the support we get from {Agency} and our support coordinator is wonderful and very supportive to our needs.

10b. Dissatisfied with CM

We are still waiting for a family coordinator and to hear back from long term Community Care. We really need to get help soon.

10c. CM Turnover

Because of the personnel changes and no continuity for our child, we now use {Agency} in our area for EI and coordination services. There was such an extreme change in people who were to coordinate services, well fell through the cracks in the system too many times waiting lists for special services can be up to 1 year wait and if someone fails to coordinate to put you on a list it could mean your child waiting another year. Time is so precious we have been disappointed in {Agency} in our area.

11a. Satisfied with Staff

We are receiving Speech Therapy and are very pleased with the therapist. We have a Special Instructor (EI) come to our house once a week, and she has not been very helpful - although she means very well. We are already working with our son in all the ways that she does.

Our EI is good, we like her, she is sweet, she helps as best possible. We have a lot of medical needs, have limited income and need a lot of financial support. It gets hard sometimes. A lot of agencies can't support routine needs, gas, household expenses and that is what we need.

12b. Family Support Group

In some small towns there doesn't seem to be enough networking among parents of children with disabilities, such as playgroups and support groups.

14b. Dissatisfied with Respite

One thing that needs to improve greatly is Respite. Families that care for disable children need a break and even a vacation because the families need a lot of extra, extra energy to care for disable children.

Although it would be helpful if our respite care funds were increased.

Aside from {Agency}-parents of autistic children need much more help with at home ABA programs. So many kids aren't even diagnosed until they're three yrs. Old - how are they supposed to pay for ABA! We started 2 yrs.- but continued until (Name) was 5. We spent $100,000 and are in debt up to our ear lobes. But it helped our son enormously. Too bad we had to compromise all our financial futures to do it!! Also, most services are slanted toward physical disabilities. Most of the autistic kids I know are physically normal. A program should be developed with {Agency} to recruit fit, energetic, young people to come play with our kids. We need more RESPITE! Thanks for listening.

16. Funding and Budget Cuts

Also, {Agency} needs to raise the amounts giving out in South Carolina. SSI is suppose to replace income lost for having a disable child. But in South Carolina, a parent sometimes cannot work at all due to having a disable Child.

My child had meningitis @ 6 days old. He was having seizures but they stopped. Now he is left w/ hearing loss in left ear, hydrocephalus (no shunt) & CP in his Rt leg. He has an EI through {Agency}, & goes to {Agency}. As far as Medicaid, SSI we were turned down everywhere we turned. He is on WIC now but that's only because I'm pregnant. He also gets PT, OT & Speech through {Agency}. It just upset me that we were knee deep in Medicaid bills & could not get any help financially.

We feel strongly that the services in {Agency}. are underfunded & therefore affect the development of these children.

My only complaint is trying to get Supplemental Security Income for my child. We have many expenses (new ones) because of his disability and his more recent diagnosis of an allergy to wheat - which is very costly - because almost everything has some form of wheat/gluten, so we have to buy special food and special ingredients to make the foods we can.

We need more family support funds! to be used throughout the summer. These funds should be available to all families with special needs children regardless on how much income the parent(s) make. Because families with high income doesn't mean they have extra funds left after paying their bills. The Summer funds would help provide summer activities such as a trip to the zoo or waterpark for entire family or even a day at the beach, or a movie day, out to eat where normally some families can't afford to take them. These children deserves to have fun during the summer break as anyone else. But families need support funds in order to do it. My child has been sick a lot and I know how hard it is to do things during summer because I can't afford it or the gas. I have to travel to the doctor at least once, sometimes twice a month. There is hardly any funds left after bills, gas to doctors and groceries. Especially for a family of 5.

17a. Satisfaction with Services

{Agency}is a wonderful program. Our {Agency} doctor recommended {Agency} for my son to receive speech therapy. We are very grateful for the free services which were very beneficial for my son.

I currently use a private agency for service coordination. "{agency}" offers great services.

Services are great!!!

I am very satisfied with the resources that are available.

From our experience, {Agency}and other services have had a tremendous positive impact on our son's development.

I appreciate the Medicaid, it helps us in many ways. Thank you for helping us. I enjoy my child so much. He's a joy to may heart. He is so special to me. Has so many questions to answer. I hope I answer the best of my knowledge. It's up the Case Manager chose the agency or providers who work with family? And the support workers who works with the family.

My son, (Name), was born with a heart defect called Tetrology of Fallot with Pulmonary Astresia. (Name) has also been told he has Cerebral Palsy. My husband and I weren't aware of (Name's) condition prior to his birth. He was born at 32 weeks. He is very happy, but has a hard time functioning in his day to day environment such as climbing stairs, getting dressed, and bathing. He wears DAFO braces on both feet b/c of Cerebral Palsy. We receive SSI and CRS. We have also applied for TEFRA Medicaid, but my husband is going to go over the income amount for SSI and (Name)honestly has 8 different doctors. We also have another "self plan" for (Name) through Blue Cross b/c we feared if we didn't keep it from my husband previous job he would never be picked up b/c of his heart defect. Thank you for all you do.

I am very pleased with the services I have received so far. Everyone is great and helpful!

Overall, I have been pleased with the care my son has received in the

last 3 years. There have been a lot of staff changes (EI) with {agency} in the last two

years, but timing has adjusted well with them. I feel that any extra help that can be provided for my son is a plus and my goal is for him to only be 1 year behind his typical chronological age and to get him out of the rest of his "autistic" tenancies, which we (along with the Special Ed. Dept. with (agency) Public Schools) have done. I thank everyone who has helped my son to be as close to a "normal" little boy as possible!

My child is Autistic and I had no idea what was available for him. I am very thankful for {Agency}, {Agency} and everyone else from the Board of Disabilities - I was lost until they came into our lives.

The different programs and services provided by the state/federal government have been unbelievably awesome. We would not have had any idea what to do or which direction to go in to help our son. With all we have had available to us so far - we have seen monumental improvements with our son and even better is the counsel, direction and guidance so we can implement these same techniques at home. How we are very intricately involved in all of our son's programs & therapies has enabled us to be very involved in both planning and execution of his goals. We are ever grateful for all the help provided, as without the help, both physically and financially - we never could have seen our son doing as well as he is - or have given him the great start in his new life as a function autistic. It is with deep appreciation.

My child qualified for Early Intervention because she was born 3 months early only weighing 2 pounds & 3 ounces. Our early interventionist {Name} has been working with my child every since she came home from the hospital. There is no doubt in my mind they had everything to do with my daughter is doing today. She doesn't have a disability as far as I'm concerned, but I wouldn't give up the help she has gotten and continues to get for anything in the world. Thank you all so very much.

We are new to this process and what is offered. We are very thankful that these services are available, the only issue is we plan on someone coming from special needs board, arrange schedules, nap times etc and 9 times out of 10 they cancel. Thank you again for the services we do receive.

I never filed a complaint or grievance regarding services receive always was over whelm and please all these people I had at the top of the page needed to be applauded for their accomplishment and goals of success and still meets outstandied achievements.

Since my child is only one year old we have not needed community or some services listed on the questionnaire. We are happy with his care so far.

We had twin girls that were born at 32 weeks. Both were premature one weighed 21/2 pounds and 0 the other 3/12 pounds. Very satisfied with the services we have received . Thank You!

Our TEFRA benefits enable us to provide excellent care for our daughter with special needs. Please do all that is possible to support promises for families w/children who have special needs through the South Carolina TEFRA system!

I have seen improvement with my son. {Name}, from {Agency}, was great. I just wish someone could tell me what is wrong with my son.

17b. General Dissatisfaction with Services

The State of South Carolina lacks very much on the ability to help a disable child. There are very little agencies available to help a disable child and the family that cares for the disable child.

My child have never got anything but respite one time that was in April, 2006 $40.00 so myself the foster mother could go out of town. They say they don't ever have anything.

I generally have to 'go search" on my own for services when I need them.

Everytime we need something or try to find out who we can go to get something {agency} always throws it up that they don't supply everything. I told them flat out that they didn't by no means! They bought diapers for the 1st 4 yrs. Past years was the1st time they help with anything. I still get upset know my daughter needed a nurse and aide every since she was 21 month old. {agency} did not offer this! A family had to ask me why I didn't have a nurse! And had to tell me to ask for a Medicaid waiver to me. I had to struggle to take care of her by myself and cried everyday!!!

We just moved here from NJ where we received more services.

17c. Access to Services/Supports

My child does not qualify for reassessment concerning previous diagnosis because of insurance and PDD components.

I do wish that a{Name}, SC had a developmental (peds.) clinic here, instead of us having to drive all the way to Columbia.

My son is autistic, I would like to see more help for autistic children available in {Town}. There seem to be little understanding of the disorder, and no equipment available. The school is not providing specialize classes designed to help autistic children. They are just thrown in with everyone else and is lost.

17d. Info Regarding Services/Supports

As parents we are not aware of a lot of services that are out there for our kids. Most of us are single parents without jobs, due to our kids' health. We miss out on things in life because we are normally at home caring for our kids. We find it hard.

There are so many different services. We don't know what we have or could have or who does what. My child has some rare issues therefore we don't qualify for certain things or so I'm told.

We are not well informed on all of the options to help us care for our child (ie: services like respite, waiver, etc.) We feel strongly that the services in {agency}. are underfunded & therefore affect the development of these children.

(Name) had a wonderful {Name}He is no longer that age group. {Name} is no longer with {Agency}. I have not been contacted by the {Agency} Board as to my options. (Name) gets speech therapy in school and outside private speech therapy. He has special diet needs that I don't have options for help with. His diet has made a huge difference in his quality of life. He is diet and supplement needs are expensive and effect his attitude and ability to learn as well as his physical health. I don't know all of the help that is available for him. I really don't know what is available. How do I find out? Is the {Agency} Board my only connection to find out? Thanks.

I just wish someone could tell me what is wrong with my son.

17e. Need More Services/Supports

I'm new to the area, and I know no one. Therefore I need a babysitter. Bad.(not child care, I think there's a difference. To me, babysitter implies a more "fewer & farther between" type arrangement, and even then, just for a few hours. Most day cares won't let you do that.) There are times when I so need a breather and my husband is only some what helpful. Please help me!!

Aside from {Agency}-parents of autistic children need much more help with at home ABA programs. So many kids aren't even diagnosed until they're three yrs. Old - how are they supposed to pay for ABA! We started 2 yrs.- but continued until (Name) was 5. We spent $100,000 and are in debt up to our ear lobes. But it helped our son enormously. Too bad we had to compromise all our financial futures to do it!! Also, most services are slanted toward physical disabilities. Most of the autistic kids I know are physically normal. A program should be developed with {Agency} to recruit fit, energetic, young people to come play with our kids. We need more RESPITE! Thanks for listening.

(Name) requires one-on-one all day long. During the summers & holidays are difficult when we have little outside help. Our daughter will be graduating from high school in a year & leaving for college. She is a hugh support person for us & (Name). We are on the Waiver waiting list, #900 and something. When we were in Sumter from 1999-2002, we were able to get 180 hours of additional help during the summer - but that seems to be no longer available. Because (Name) is not fully toilet trained, it limits his ability to participate in many activities.

(Name) is a very special child, very intelligent but demanding child. Needs full attention at all times. I feel we could use some help in training of his disabilities. Sometimes he very pleasant, than something turns him just the opposite. He needs outside support by going places and enjoying life, like a child his age needs and deserves. My bad knee keeps me from taking him and his brother to enjoy outside life. I love this child and had him with me since birth, so I'm very attached.

17h. Waiting List

We have been waiting for diagnosis assessment since Oct. 2005.

SOUTH DAKOTA

4b. Dissatisfied with Education/Training

I was unclear when you were asking about support programs staff whether you meant {Agency} or the assistance from the school system. I am very pleased with our {Agency} coordinator I am not so pleased with our school system my child is not involved in community activities. I would like for him to be but the choices are limited. Also I don't know how to facilitate this.

6b. Dissatisfied with Recreation Activities

The {Agency} person is wonderful. I wish my daughter could participate in more recreational activities -i.e. T-ball, soccer. This is impossible unless she can have someone with her i.e. an aid.

10a. Satisfied with CM

We feel truly blessed for this program, which makes it so much easier to care for our child. Our family support Coordinator Does an excellent job.

There are a lot of things she has needed and I can't afford, that {Name} has made sure we got. {Name} is great! She does a good job. Any questions or problems I have she helps out.

{Name} is our coordinator & she does a great job. Don't know what we'd do without her!

{Name} has been a wonderful support leader. She is truly our angel.

We really appreciate the {Agency} and our coordinator is fabulous.

I appreciate {Name} for her fast response to all my questions & her ability to relate & be very personable w/me. She's great. She's flexible & always willing to help where ever she can.

{Name} has been great. We can call her anytime & she helps us. We just moved to SD a year ago from Nebraska.

{Name}'s Medicaid is through {Agency} the support and assistance we receive from our family support person has always been good she has helped us find and purchase adaptive equipment that has been very helpful she has kept us informed of educational and training opportunities and respite care availability.

{Name} is a super person and has become a friend. I hope {Agency} will always be there to help other children.

{Name} from {Agency} is the best! She is always there to go to school meetings provide home care supplies & answer questions. She has helped us with our son since he was 3 yrs old (he is now 17) & he still lives at home with us, which I do not think would have been possible if not for her. Thanks

I'm very thankful for {Agency} it's helped our family out so much I do feel though that the coordinators are expected to do a lot. I know our coordinator has put in many hours at night & weekends not leaving her any family time. Feel guilty asking for things knowing she will do this but my family is taking away from hers w/ all they have to do.

{Agency} is a big part of our life, {Name} is so great! She is always there when we need her & is great at listening & always has great ideas.

{Agency} has been very helpful so far in helping us to provide the things we need for our son. We have been very pleased with the services we receive and have learned of services we were not aware of from our {Agency} service coordinator, {Name}. She has been very helpful in many ways to help me feel like we have support in the raising of our son. We got help to purchase materials for teaching children with Down syndrome about literacy & numeric. I learned about that at the NDSC convention in Anaheim last summer. I received assistance to attend that from {Name} office. This is an example of how the services in the state are complementary of each other.

{Name} does a super job for us. She checks in with us often and makes sure everything is going ok.

{Name} has been wonderful from an emotional side as well as assisting my family needs. I am so thankful for {Agency}. Especially when I needed {Name} to attend a meeting about my son behavior at public school I have no complaints at all.

I appreciate all of {Name}'s assistance. Now that she's in {Town} it is a lot easier to be in touch w/her.

Thank you {Name} for all you do for my son & me. You are surely a blessing & very kind & polite & helpful. We definitely would not for {Agency} & your great help.

10b. Dissatisfied with CM

When I requested assistance from my family support provider she told me to put more pillows in his bed and prop him up. I said when he is sick I usually have to rock him all night long. The family support person told me that unless I wanted to rock him at 18 years old I should stop doing this. This comment hurt my feelings and was not expecting it from a person in this position unless she would like to come over to my house when my son is sick and not rock him. I would prefer she keep her opinion to herself. I purchased the chair myself and got through the rough sick nights and called my family support person and said could I have any help with the chair was answered in a VERY short answer that this was unapproved and she was unhappy to speak with me, I did recoup 1/2 the amount of the chair and it has helped comfort my son when he is up at night with his sinuses.

My {Agency} coordinator doesn't seem to act one way or another on request until I make a follow up call or visit. This is my impression. It may not be accurate.

10d. Shortage of CM Workers

I like my {Agency} person she is helpful when called, she a busy lady and she is good at her job. But I think she could use some help.

I'm very thankful for {Agency} it's helped our family out so much I do feel though that the coordinators are expected to do a lot. I know our coordinator has put in many hours at night & weekends not leaving her any family time. Feel guilty asking for things knowing she will do this but my family is taking away from hers w/ all they have to do.

11a. Satisfied with Staff

The support we get from the therapists & {name} or {name} has been outstanding.

{Agency} has been a god send. My oldest son is only on respite care program, but my youngest son has autism. He is on {Agency}. I call my worker even when I am just out of ideas and she really helps me. She comes to all my meetings, that is a huge help because as a parent you always feel that they (teachers) are trying to push all the work, behavior or blame on to you. {Agency} simply can sit outside and see what is best for the child without egos getting in the way. I am grateful for the program and the workers I have had and have.

{Name} and {Name} are an asset to any ones lives that they touch. Their caring personalities were/are visible every time I spoke to one of them. I can't begin to express the gratitude I have for the family support program. Being a single mom the program has helped to keep a stable life for my daughter. {Name} is always there when I need her or when {Name}'s needs are too much for me, Thank you for helping families like ours.

13a. Health

My daughter w/Down syndrome has gained a lot of weight since we moved to SF SD 2 yrs ago. She has had increased medical problems because of this. We cannot afford a gym membership (w/a pool) - her joints ankles & knees hurt her. Swimming is the best exercise for her & the only option we have been given is 1 hr per week of swimming laps that is supervised. I am very worried; she has become non-active & continues to gain wt on a monthly rate. Any suggestions call me.

14a. Satisfied with Respite

We really appreciate the {Agency} & respite care programs. They provide us valuable resources and support in a challenging time in our family. Any additional funding to the programs to expand their programs would be wonderful. Thank you.

14b. Dissatisfied with Respite

Have always had trouble with respite care.

One area that is really lacking is the ability to find adequate respite care for a child (Teenager) that functions at a low level and has some behavior issues. We live in a city with a facility for special needs children but they will not do overnight or any type of respite we have been unable to find respite care providers. If we hear of someone occasionally.

We have a hard time finding someone to give Grandpa and I a break. We have tried to find someone to give us respite care but because of all of our grandson's medical issues most people won't do it. I have had a sign posted at the local bank & post office for respite care giver for over 6 mos. And no one has responded. Pretty much where grandpa and I go our grandson has to go. Every vacation we take we have to take him along. In the seven years we have had him we have only two nights without him. We are a one income family since we took our grandson in and my husband work 60 + hours a week to support us. Even though our grandson gets SSI & we get help with {agency} it still does not cover all his expenses. Then I will daycare expenses I guess I don't understand the system as if he was foster care or children care & school the state would pay for those expenses but no one will help us I have already worked three jobs and have had to give each one of them up because our grandson's illness.

I would like to get respite care & she has provided all the forms but we are unable to locate some one willing to care for the children who is sober in the community or family my only suggestion is to develop a program that could encourage people like single students (or something like that) who could be respite care providers.

I wanted to comment on the {Agency}. We are very appreciative of the supports we receive from this program; however, in no way do we receive enough support from this program alone to help us keep our child in our home. Being a middle class family, we are not eligible for SSI and had to search long and hard for a way to get Medicaid as secondary insurance for our child. We are very thankful that the program provides a Medicaid waiver! Unless you are a parent of a child with a disability, you cannot begin to understand the supports that we need or the time and energy that is required to care for a child with multiple disabilities. They go beyond financial needs! The respite money that is allotted to us is great; however, it does not go very far. We can't be expected to pay a respite provider only 5.00 am hour when they have to drive to our home and be responsible for a child that requires so much extra care. Also, it takes a great effort to find qualified people to be respite providers. After becoming a part of the local {agency}, we have a service provider that we can contact to help with our questions and needs. Until this happened, we as a family had to take the initiative to find out about this program and any other services available to us in our state on our own.

16. Funding and Budget Cuts

The most beneficial help has been the financial benefit of her Medicaid even with a primary insurance coverage we would not be able to care for our daughter in the same manner with out this Medicaid assistance this has allowed {Name} to stay at home with us.

{Name} has been wonderful to work with there is just no funding available to help us. We waited for over a year to get on the waiver service. During which time our daughter had no insurance due to pre-existing conditions. The only service we have now is 550.00 in respite care which it is difficult to find anyone to do. We are very grateful to have gotten on the program for the title XIX benefit

17a. General Satisfaction with Services

We feel truly blessed for this program, which makes it so much easier to care for our child. Our family support Coordinator Does an excellent job.

I would like to thank {Agency} as without their help our grandson would be in foster care or children care as we would not be able to cover all his expenses or needs.

I am thankful and happy that the state of South Dakota has a program like {Agency}. It has helped me take better care of my son however I asked for assistance with purchasing a bigger recliner chair because my son has many sinus infections and the only way he will sleep when he has an infection is sitting up in a recliner.

This program has made a remarkable impact on {Name}'s life. {Name} and previous to her {Name} are exceptional at their jobs. I am grateful for the support in all ways. In patience, {Name} is able to answer many questions concerning transition & growth development.

We really appreciate the {Agency} & respite care programs. They provide us valuable resources and support in a challenging time in our family. Any additional funding to the programs to expand their programs would be wonderful. Thank you.

We appreciate all of the services we receive for our daughter, but the one that has benefited our family most is Medicaid. This has allowed us to get all of the medical care she needs without having to worry about our insurance co-pay, etc. Thank you.

We really appreciate the {Agency} and our coordinator is fabulous.

Most important {Agency} is a must for families with a disabled child.

Our son is autistic. The reimbursement we receive or the payment made by the state for his nutritional supplements has been a Great Help.

{Agency} has been a god send. I am grateful for the program and the workers I have had and have.

I don't know what our family would do without {Agency}. The recreation leisure skills, community activities & especially the Medicaid waiver are the BEST. Thank you.

I would like to say a big thank you to {Agency} for everything they have done for us. It helps take the financial burden off when you get help with pads and things.

Our family has greatly appreciated the support that the {Agency}has provided to our son. With their help we have been able to keep him @ home and still get his needs covered. We have been receiving assistance for our son for many years now. And they have been a tremendous help.

I would like to thank {Agency} as without their help our grandson would be in foster care or children care as we would not be able to cover all his expenses or needs.

I'm very thankful for {Agency} it's helped our family out so much I do feel though that the coordinators are expected to do a lot.

We are very grateful for {Agency}. I don't honestly know what we would do without it. I hope someday, to give back to those who we are so grateful too. Thank you.

I can't begin to express the gratitude I have for the family support program. Being a single mom the program has helped to keep a stable life for my daughter. {Name} is always there when I need her or when {Name}'s needs are too much for me, Thank you for helping families like ours.

I'm a mother of 2 special needs children and I thank {Agency} for being their in hard times w/ my children.

Thanks so much! {Agency} has helped us so much as a family with a special

needs child we couldn't do it with out you.

{Agency} has been a life saver. Without {Provider} I'm not sure we would have been able to keep {Name} at home with his two brothers were he belongs.

Without the Family support program I fear a lot of children would not be able to live with their parents or siblings keep up the good work.

I think our {Agency} coordinator {Name} is very nice and helps us to get what we need. We are very thankful for our son gets his Medicaid it helps us to get the help and equipment that he needs for his disability. Also for the assistance with our diapers it's a big help! We're very appreciative for this program thank you.

We couldn't afford to buy all the supplies our child uses monthly. We are very pleased w/{Agency}.

{Agency} was a God send to us at the onset of my son’s disability. It gave me resources I needed to make informed decisions. {Agency} was there for me when I felt I was alone with the burden of having a child with a disability. {Agency} has eased the burden financially by helping to pay for installation of our van lift, and various other things that insurance does not pay. There are so many other things that {Agency} has done for me and our son thru the years to help us keep healthy & happy in our home.

We are very grateful for this program.

Thank you for your support. Our family could not make it without your help. Your program is a wonderful program.

Thank you {Name} for all you do for my son & me. You are surely a blessing & very kind & polite & helpful. We definitely would not for {Agency} & your great help.

I am thankful and happy that the state of South Dakota has a program like {Agency}. It has helped me take better care of my son however I asked for assistance with purchasing a bigger recliner chair because my son has many sinus infections and the only way he will sleep when he has an infection is sitting up in a recliner

17b. General Dissatisfaction with Services

South Dakota is very poor at providing Family Support. We moved here in 1993 from California, we have 2 disabled children. Partially due to the lack of family support our youngest child has been in residential placement since 1999, there are no respite providers in our area and no work respite for severely disabled children.

When we have requested services, her needs have been helped by {Name} at {Agency}. We have never received anything but grief and heartache when dealing with SSI, Medicaid or state agencies. She is probably missing out on a lot, but they leave us no alternative but to fend for ourselves.

Anytime we have had questions or need help through the state (with the exception of {Name}) we have been treated rudely, slowly and we no concept of long process involved in getting anything accomplished.

17c. Access to Services/Supports

We have been looking into home health care. The businesses that do this in our area seem either unwilling to drive to our rural community or work the hours that work for our family. What ever the case we haven't gotten this service. Our {Agency} coordinator is willing to advertise and pay for this but then we have a dollar limit as it will not go through insurance then. Our family support coordinator has contacted several businesses about this. It is hard to ask for this service much less deal with the frustration of helping with this problem. We have now looked into this twice without success and we give up rather than continuing through this hassle.

Our son is autistic. The reimbursement we receive or the payment made by the state for his nutritional supplements has been a Great Help. Small communities do not have much to offer for working moms & dads to be able to get disabled students involved in the community affairs. We spend a lot of money on special Foods due to severe allergies & don't do much outside the home. It would be nice to see our son involved with other kids in a summer program, but difficult as we live in the country & cannot be there. Communities are very ignorant to the needs of others maybe since we all have our own lives & business to tend to. These kids ought to qualify for disability.

I wanted to comment on the {Agency}. We are very appreciative of the supports we receive from this program; however, in no way do we receive enough support from this program alone to help us keep our child in our home. Being a middle class family, we are not eligible for SSI and had to search long and hard for a way to get Medicaid as secondary insurance for our child. We are very thankful that the program provides a Medicaid waiver! Unless you are a parent of a child with a disability, you cannot begin to understand the supports that we need or the time and energy that is required to care for a child with multiple disabilities. They go beyond financial needs! The respite money that is allotted to us is great; however, it does not go very far. We can't be expected to pay a respite provider only 5.00 am hour when they have to drive to our home and be responsible for a child that requires so much extra care. Also, it takes a great effort to find qualified people to be respite providers. After becoming a part of the local {Agency}, we have a service provider that we can contact to help with our questions and needs. Until this happened, we as a family had to take the initiative to find out about this program and any other services available to us in our state on our own.

I would like to get respite care & she has provided all the forms but we are unable to locate some one willing to care for the children who is sober in the community or family my only suggestion is to develop a program that could encourage people like single students (or something like that) who could be respite care providers.

But main thing, I wish there was talking supporters or advocates here on the reservations.

17d. Info Regarding Services/Supports

I am unsure what other programs if any are available to our family/child. Perhaps a newsletter would help to better inform us all. I feel that if I'm in need of the resources. I have to locate them on my own. Until recently our support from Social Service for medical mileage reimbursement was horrible. Very Unfriendly staff. Now that staffing has changed, we hope the process will be simplified and staff will be more pleasant. I'd like to have a list of names contacts and phone numbers for services also updates perhaps on special events, which may be helpful.

I was wondering if there is any place that we could get a VCR tape of signing {Name} is learning a lot for speech therapy in school and I have to go over and learn as he learns, so I know what he needs or wants! I have found some print out pages on internet but I would rather see it demonstrated to me. Secondly I was wondering if you ever pay for health gyms, I am 58, diabetic, 2x cancer surg. Chem., etc.(the past 3 yrs) it has left me weak, I just had (Sept. Ovarian cancer,2nd one, gall bladder out, and Dec I had surg. To right knee! I'm in pt but he wants me to join the gym to work out to build body back up so I can again have fun playing outside with our little boy "making memories". I want to thank you for everything your wonderful program has done to help {Name} all these yrs - May god bless keep up the great work your doing.

I'm not really aware of what all is available. SSI for instance was put in my ex.'s name & they won't provide any information, Zero, Zip, nada, to me.

Outside of the school system, we don't receive any specialized service. Our Autistic son gets Medicaid coverage we don't really know what else we are allowed to receive for our son's disability.

17e. Need More Services/Supports

I just wish there were agencies that could help me with a new washer because of the amount of laundry we have I have went through 2 clothes washers and I can't afford a new one I have been forced to buy used and they don't last but it is what I can afford. I am on SS my self and there is never extra. Being a single mother of a downs Child is very hard and I still have 2 other children one who has ADHD, ADD, and ODD so my life is very, very hard.

We need drop in Daycare for children that over 12 and not toilet trained for evening activities.

As my daughter gets older it's more and more difficult to find a daycare provider that takes special needs children. I would like to see a daycare specially designed for these kids. I would like to see staff be trained to work with them and help lessen the burden of care for my child while I work I feel this is very important issue that the state of SD should look at.

17h. Waiting List

{Name} has been wonderful to work with there is just no funding available to help us. We waited for over a year to get on the waiver service. During which time our daughter had no insurance due to pre-existing conditions. The only service we have now is 550.00 in respite care which it is difficult to find anyone to do. We are very grateful to have gotten on the program for the title XIX benefits.

The 18 month wait to get on {Agency} was much too long much of the help needed was really in our first year. We spent over $10,000.00 on medical care, diapers hearing aids, glasses, surgeries etc. with no help and we should not have had to. It was frustrating knowing we had a child that qualified for services but couldn't get him on because of a waiting list. I understand the logistics of budgets, but it still is frustrating. On a positive note, this program has been wonderful, I hope it can continue! Our support staff person is great!

TEXAS

1c. Accommodations with Home

It’s a good program but sometime we feel that was the money you guys approved has very limited usuage. For example home modification you guys only allowed only bathroom modification & widening of doorway. I have a two story house.

My son needs a wheelchair ramp at home.

For the last 3 yrs I have requested an addition or home modification to my home due to that my son is getting older and requesting more equipment to make his daily living more comfortable.

1e. Waiting List for Residential Supports

There are no group homes in the area. We have been on a waiting list for over a year.

3a. Health Care Equipment

Care giver need to have more options and resource for getting equip. for their child.

My child had surgery July 2004. After the surgery his wheelchair was no longer appropriate. The chair was already 5 years old. It took 10 months to receive approval through Medicaid to get the new chair.

It takes lots of time to get anything done. Lots of paper work. There are many "things" equipment that Medicare doesn't pay for that {Provider} could pick up. But doesn't. As your child gets older and bigger. The equipment needs to change or be added on to.

We need a ramp because my child is getting heavier to carry and it's bad on our backs.

3b. Health Care Insurance

{Agency}’s social worker, {Name} has been great, but we have had many problems getting ccp since we lost our nursing through {Company}. We have gone through our savings because we have paid for nursing out of our own pocket. Can you help with ccp?

Caring for our sons not a burden with the help we receive. The different cuts and changes Medicaid goes through or is rumored to go through is very stressful on our family. Our son's diagnosis is fatal and therefore no insurance company will cover him.

3c. Dental

I think the program could do a better job for clients who need medical or dental care in our area. It seems most doctors and dentist don't have the patience to deal with our kids.

It is also difficult to find physicians and dentists who accept patients on Medicaid!

Dental and medical have been ok

3d. Medical

I think the program could do a better job for clients who need medical or dental care in our area. It seems most doctors and dentist don't have the patience to deal with our kids.

I have a comment about medical care. It's hard for me to take my son to the doctor. I always get a different doctor and I have to tell the new doctor the whole medical story about my son.

It is also difficult to find physicians and dentists who accept patients on Medicaid!

{City} has a limited number of medical specialists. My daughter has chronic back pain (scoliosis). There is no pediatric specialist in {City} to deal with this medical condition.

Dental and medical have been ok

3e. OT/PT/ST

It would be nice to have therapist to come in and show us different activities or exercises to teach or help with specific tasks to teach her different things. We are concerned about doing certain exercise because we don't want to over do it

My child cannot receive on going physical therapy because she cannot go to school (medical) Medicaid says it's the school district's responsibility and the school says no because she does not attend.

The main thing we have had a problem with to this point is getting enough physical therapy to keep her contractures from progressing. We use to receive 2 hr a week through a program called the ppp program. When this program ended we only receive 30 min

It is very difficult to find physical, occupational & speech therapists who accept patients on Medicaid!

On question vii specialized services/supports my granddaughter receive a little physical therapy a little occupational & recreational therapy at her school and I think it is not enough because this is like once a month.

The biggest frustration is receiving therapy services through Medicaid & CLASS because the schools {School District} are supposed to be providing those services. The school my son is in does not provide therapy services to increase his abilities in the areas of ot

There seems to be a going shortage of physical therapists in the {City} area that accept Medicaid. I have been working to find one since June 05!

4b. Dissatisfied with Education/Training

My son has severe mental retardation and I'm very upset with the school programs and the services they provide. Children like my son should be in classes with children their own age.

5b. Dissatisfied with Transportation

We always borrow someone elses vehicle for transportation.

6b. Dissatisfied with Recreation Activities

We need recreation center in neighborhood and some activities for people with disability.

During the summer there are not a lot of day camps that accept disabled children

Would like my service provider to be more "active" in searching for recreational opportunities for my son.

7a. Satisfied with Communication

{Provider} in home services has generally done an excellent job in communicating with us and helping us with the caregivers

7b. Dissatisfied with Communication

Initial application for assistance in 2003 was mailed to the wrong address even though we have lived in our home for 12 years. I hand delivered my sons's 2005 application to the {Street Location} Office in {City}, and it was misplaced.

We receive $ for respite {Provider}-we weren't told up front about $ and how is was to be spent for the coming yr. Inadequate info given to us-poor communication w/staff

There is too much confusion when one is trying to pick the right program. When you've been on waiting lists for years then all of a sudden you’re at the top of the list and everyone tells you something different.

7c. Information

My name is {Name} whom has struggled with my finance due to SSI & Medicaid removing my child in 2002 without resources provided to us if I had know of there's program's long ago, my child would not had suffered not having a wheelchair

I did not realize we were receiving services and support from {Agency}. We had signed up with {Name} with a new beginning, but I have not heard anything from them since august.

I've never heard of this program before. What assistance does it provide? My daughter's nursing agency is who provides assistance. {Agency}I received assistance from in home family support for a van lift. To my knowledge, I've never been contacted

I would like to have more information about communication. My son has many needs. He is 12 years old and up to now I have not had much help.

7g. Interagency Communication

Also, it does not seem that the different programs (Medicaid, SSI, CLASS, therapist, etc. communicate together.

9. Transition Issues

Thank you for this survey. I am pleased all in all with the services we get. However, it would be nice to know what it is that us as parents need to be doing to prepare for when she turns 18. The information is so vague!

I am basically satisfied with the services {Name} currently receives. My major concern is what the future will bring. {Name} currently has approximately 70 hours of nursing a week. This will be drastically reduced when he turns 21 yr old.

Support for middle income people to stay home more before child turns 18 would be great. Waiting until they 18 can waste a great deal of valuable time in helping people learn and grow more

Yes! Please send information on schools, homes, places to live (institutions) when {Name} turns 22 and is no longer able to attend public schools. These homes can be private or state run. Thank you.

When my daughter graduates from high school this may '06 our community provides no daily recreational, occupational, social or educational services for the mentally retarded. We do not want to put our daughter in a group home. We want her to live w/us

{Name} has 14 months left on {Provider}. What agency will take over so I may continue to have help in the home with him? Po also what programs are available to {Name} after he finishes public schooling? I need to continue to work outside the home.

Why is there a difference in the support received once the transition is made from child to adult? Nothing conditionally physically or mentally changes. Will my child, who will always remain my child, be able to remain at home after age 21

My concern is that when my child ages out of {Provider} that there is no other medical help.

My concern is what will be offered to my daughter over 21? This is a big concern.

When I began answering the questions, I was thinking ahead to services we will be looking to receive after 21. We have a son with profound problems. He is complete care and many of procedures are performed daily that require medical skill.

Would like more information on our child after school years are over-where can she go while we are working? Thank you

I am very pleased with {Name's} services. I do have concerns not with just my child but all children like {Name}, that concern is that at age 21 all the benefits change however the disabilities do not.

10. Service Coordination

I am happy with the CLASS and {Provider}. This is the only people we speak with. We have had 2 case workers in the CLASS program. They are both great and keep in contact with us. The {Provider} staff has changed several times. We have not met our new case worker

10a. Satisfied with Service Coordination

{Name} is our case manager and we feel blessed.

For our deaf-blind child: we have had great support from our caseworker from what used to be the {Agency}. She was/is extremely helpful {Name} - minimal/no support from the deaf services.

The case workers I have had have always been ready to help me. They always return my calls and help me find the info I need if they don't have it. Just one suggestion!-keep up the good work-it takes a person with a caring heart to help our families and I

Our case manager at {Provider}, {Name}, has been & is an excellent source of information & assistance.

Our case manager {Name} has been wonderful. She always has the answers or if not directs me to the appropriate place or gets them for me. She goes above and beyond her job. She has made mine and my daughter's life much more enjoyable.

The case management {Name} is a godsend. She is always available and helpful. She takes the time to explain everything

My sons have been in this program since 1999 and {Provider} has been great! And {Name} is in need of a reward for all the hard work she has done. She is very understaffed and very stressed out, and it will be a great loss if we loss her!

This is all new to myself & daughter. Until moving to the {City} area there was no information available to me. I am really thankful that I have a great caseworker who is willing to listen and share all her information.

Our daughter's case manager, {Name} has been very professional, efficient and extremely helpful in working with us. We have been very pleased with {Provider}.

We have been very satisfied with case mgt services. We have seen a large turnover rate @ the direct service level and the ball gets dropped. We are very grateful that this service is available, without it group homes would be the only alternative left.

If this questionnaire replaces the one I have completed in past years, thank you very much! Our service coordinator, {Name}, is awesome. Always available; familiar with our needs and concerns; follows up and/or addresses any issues promptly.

Our family has been served by {Name} the fall she and her support staff has been excellent. They have helped us feel a part of the community of handicapped families and made us aware of resources available in the community.

I have been happy with my daughter's case worker through {Provider}.

My daughter's case mgr is {Name}, {City}. He's very knowledgeable and helpful. I recently lost my mother, and {Name} was very supportive and quick to assist me in setting up emergency respite for my daughter, {Name}. Thank you.

10b. Dissatisfied with Service Coordination

We are on the class program-it is not clear, what if anything our case manager {Provider} does to earn their monthly fee. Case managers turnover so quickly that I have to educate them vs. the opposite.

The caseworkers are also not always helpful or courteous.

My name is {Name}, my son's name is {Name}. And I have been trying to get in touch with the case worker that took {Name's} place but I have not had my phone calls returned.

Our biggest difficulty has been with our {Case Manager} for the CLASS program. Delays, insufficient information, misinformation and road blocks have caused us a lot of heartache. We have never spent half of our budget

10c. Service Coordination Turnover

For years we had a caseworker who was excellent {Name}. She knew everything and we all felt good about the things we needed now it is harder to find answers for our needs. The change has had a big downer for our family.

When my daughter first got in {Provider}, her caseworker sent me many forms, explaining benefits, and we allocated our budget together. After her caseworker was changed, I never received yearly paperwork of her services she could receive

Making sure a family deals w/ the same case manager takes a lot of stress off everyone involved.

The {Provider} program has been wonderful. My only frustration is with the change in case management social workers. I rarely know who to call with any questions or concerns, though we're pretty self-sufficient in managing the nurses.

Currently I don't know if my daughter has a planner or caseworker. The last caseworker left and the office was going through changes. I have not heard from anyone in a year.

My only disappointment is that the case workers are always changing and those who are new usually know nothing and are not very helpful.

We just lost another case manager at our local level

11a. Satisfied with Staff

First of all, I want to thank God for all the people who run these programs and agencies that help my daughter {Name}. Thank you for your support and help. Thank you and God bless you.

The nurses who help take care of my son we hand-picked by me and are wonderful.

My case worker {Name} and my RN are awesome. They are very informational. They are a great support system. I thank you for the help. You are allowing a single parent to attend school and become self sufficient and helping me become a better parent

The only service we consistently receive is supported home living. My daughter's habilitator has become part of our family. I trust her completely with my daughter. This relationship did not develop overnight. I feel consistency is of the utmost of importance

{Name} has been very helpful. She is the only staff person that I know.

I would like to thank all the {Provider} staff for always listening to me. It really helps sometimes just to know someone is there for us. Thank you

I glad to say I love the group of support that I have. They have been with me and my daughter since Nov.1999. Each year get better and better.

We are pleased with our services & attention. All the staff involved with our son {Name} (13 yrs old autistic) have been professional, caring, & co-operative individuals. He is also very comfortable with the nurse & other implementers thus far.

I sincerely believe that my experience with {Agency} is so positive because the staff I have interacted with show a genuine care and passion for the families they serve. {Name} has made the difference in our lives.

I am very happy with the caregiver that comes to my home. The caregiver that we have has been with us for four years and is wonderful.

Since {Name} been on the program I have more time for rest. Management has been very helpful with {Name's} needs. The staff that been place with our family that very good care of {Name}. We couldn't ask for nicer staff we been bless with them. Thank you

The {Provider} is a great help to us. The staff has always looked for ways to help us.

11b. Dissatisfied with Staff

I could locate the memos from an incident with and {Provider} nurse {Name} 2 years ago. I did contact the state during that time & they allowed me prevent the nurse from coming to my home & I chanced back {Provider} without trouble.

We are pleased but I wish all workers would try to understand that our children are different & needs to be understood they can't help the way they are. They picked this profession our children didn't pick them

11c. Staff Turnover

Personnel at agencies change frequently so there is little if any follow-up. Maybe better pay might make % of overturn decrease!

Sometimes I've had problems because the attendants don't last very long. They should be paid more.

Constant personnel changes at some of the support organizations such as {Provider} & {Provider} make things difficult such as getting questions answered, handling a problem etc. Also I feel I still do not have a complete grasp on what services are available to my daughter

The turnover of staff at our service provider is a concern. I can't trust my son going with a new person, I'm not comfortable with.

Consistency in staff is wonderful-but we realize that is not always possible. However, all staff has always been supportive, helpful, informative, flexible and king.

The service provider we have dealt with has had a difficult providing support to us due to turnover and/or lack of interest on their part. Because our needs are minimal, we have not pressured them to provide the service.

We have seen a large turnover rate @ the direct service level and the ball gets dropped.

I prefer to use a private nurse in my home to care for my child. I have had the same person for 6 1/2 yrs. I think the hardest part of respite care is the agencies have a big turnaround. This is why I chose not to go thru an agency for respite

11d. Shortage of Staff

We are having difficulty finding consistent nursing for our child.

The support help is available in our care plan. The problem is there is no staff in the area to provide the support we need.

We have been blessed w/ our services but there are not enough nurses in the program to cover the hours given-aides are impossible to find! With gas prices so high no one wants to drive for minimum wage to work a few hours after school & back.

My only real concern is that it is very hard to find nurses available to come in and fulfill hours allocated. Our family really needs those break times.

We have been waiting for about 4 to 5 months for our agency {Provider} to find us the nurse that my daughter need in daily basis and we are still waiting, and waiting. Do you have a clear answer for that?

But, there are times we needed outside help for our family and sometimes there are no assistance

11e. Staff Not Qualified

There is a great difficulty in finding and retain individuals to assist with the care of my child even when funds are available.

We receive more information from other parents with disability children. We have found the staff of {Agency} lack knowledge on what programs the state has to offer.

The most difficulty is finding attendant care that are caring as well as qualified I have a difficult time getting attendant care in my area so I must keep the lazy and I am able to get.

Those who work with us generally worked quite diligently, but were not always able to do the things we needed.

I cannot get quality, trained, reliable caretakers to help care for my child. These agencies that are approved with mdcd, CLASS etc., are in the business for gov't and state funds padding their pockets. They send people to your home with no experience.

Seamless access to services has always required my involvement and advocacy on behalf of my child. Often I know more about resources my child qualifies for the many state employees do. What happens to children who don't have strong parents to advocate for?

The problems I have with my service provider is their inability to hire qualified staff. We are currently receiving no respite despite having 300 hours in our annual plan, because they have not been able to hire someone who will work weekend hours.

Overall, our nursing agency is very offective. Because of {Name's} high-tech nature (she is on a vent), we have trouble finding competent nurses willing to look her case, especially at night.

Access and delivery of supports q @27 are frequent staff changes a problem for my family? Not at this current time, but it has been a major problem in the past because of non-reliability of staff providing care, forcing me to make last-minute arrangements

11f. Pay Staff More

The workers need to be paid more money. The amount that is paid is awful and you don't get really good workers for that mount of money or they have to take 2nd &/or 3rd jobs to live.

When changing from one agency to another I feel that, the nurse and/or provider who I am already with should be able to keep the pay that they were already receiving vs taking a lower pay-since the money was already allocated for the year

The {Provider} has a difficult, almost impossible job of finding attendants to staff shifts due to low salaries offered. This negatively impacts participants & their families.

11g. Substitutes

The thing most difficult is when you have nursing services and they cancel, there is never a back up person to help out.

Through our nursing agency, when our primary nurse is absent, we seldom get a replacement nurse for that shift and usually get a phone call within 10-15 minutes prior to the arrival time the nurse is suppose to arrive to tell us the nurse called in sick

12. Family Issues

My job as a mother is 24/7. I feel that I always have to be around my child. I as a mother feel I do a lot better job than nurses or providers, because I know of his needs. I don't work to be with my children especially for my son.

12a. Parents as Paid Staff or CM

I feel that a single parent should be able to take of their disable part-time and get paid because SSI only let you make a small amount of income before they cut the disable children SSI income. And it is hard to find people to care for disable child

The people on the hcs are get it the parent should get for the job the staff parent doing all the work not under the age 18 or 21

I think that you should pay the parents of the sick children instead of strangers. Parents work more without any rest.

I don't understand why the mother doesn't get paid for providing for the child at least for under 10 hours. It's the mother that continues with the care after the provider leaves.

I'm not satisfy with the case manager when (my son) need things, I always have to appeal for them, and the turn around is more than a month. It would be more of a benefit if I could be my son's provider.

13d. Social Well Being

It is difficult for my son to have opportunities to make friend with non-disabled children.

Our daughter is diagnosed with mr/pdd. She attends a regular public school and goes to regular/resource classes. Our biggest need is for her to go on social outings-mainly weekends.

I feel that the boys or girls need more time or space to be together for the once that are mainly the same to help each other to get to know each and to feel they can talk and for after that and same as them. Thank you all for your help. May god bless

As you can see, the "area in need of improvement" is community connections. Because my child has autism, adhd, and is speech impaired, the most difficult challenge in her life is developing and maintaining peer relationships, presently, she has no friends

We were told that providers were not to take child to library, community affairs or shopping. I feel that if she could get out more in the community she would be a happier child. She gets very frustrated that she cannot go places and do things.

14a. Satisfied with Respite

Having respite care for our child is a necessity for our family. If this program was ever taken away, I could see a lot of parents placing their children in state homes instead of taking care of them themselves.

I don't know how i would survive without the respite and attendant care my child receives. My child needs a break from me and I from him. It enables us to do things and have a life outside of autism. He loves his caretakers and I know they love him.

14b. Dissatisfied with Respite

Emergency respite is not available. We get one week per year when we know that our children will be at camp. Caregivers are not trained and most do not even know the disability of my children when they get to our home.

I have been using respite care through the {Provider} program. At 7.00/hr it is very hard to find a quality home health care provider. I think the hourly wage needs to be reviewed.

There are very few respite care providers in our area. We need more workers/nurses to be providers here. Our respite nurse is currently driving over an hour (one way) to help. We'd like to have access to a nearby respite nurse

16. Funding and Budget Cuts

Breakdown of money used & if there will be left over money @ the end of the year for equipment purchases.

The money needs to be spent on all supplies and whatever the child needs instead of limiting to respite and modifications. It should be available for anything necessary for the care of the person.

I know that the agency is trying to cut on cost. But, when a client has a medical need that requires brand name diapers, I don't understand why the agency can't pay for them.

My son {Name} has recently been turned down by the home and family support services because they said he was "double dipping" meaning because he has {Provider} he could have home and fam. Support. I have been utilizing both for years.

I'm not confident that the money spent is spent for services my child actually receives. I believe it is imperative that I receive monthly statements indicating exactly where the money is being spent.

Grants should be available to single parent with disability children xxx amount of dollars. Funding should be available in rent, utilities, a special phone service.

I feel like there is not enough money directed toward nursing care in the CLASS & hcs programs. Attendant care is not an option for my child, which make these programs useless for her.

My only disappointment in the way the texas med-waiver program works, other than the long waiting list is the way the money is allocated and not letting parents have more of a say so in how the dollars can and should be spent, like other states.

We have been told that my son, {Name} is at the max. Amount of $ in the {Provider} program-yet everything we have asked for has been denied. Ot-no pt-no speech-no adaptive equip-no

I think that the income levels your agency uses is not fair, one because I am a single mother w/ one income and we do not qualify for any monetary help or food stamps, especially w/ a disable child.

I fell it makes it hard for my case manager to help our family when the budget keeps getting cut. This makes things harder.

17a. General Satisfaction with Services and Supports

Our child has a lot of disabilities. She's ventilator dependent, gets sick easily, and is very time consuming to take care of/ we are very blessed in that we have been able to care for her at home - with the help of nurses.

We are very pleased with the services, without the assistance we have received, {Name} would not be as healthy and successful as she has become. The assistance received is critical to the healthcare of our daughter

These supports have made it possible for our son to live at home & remain an active, valued member of our immediate & extended family. His life will be fuller and more active, as he grows older, because of the relationships he has with his siblings & I’m very sorry it took so long to get this completed. I did receive a 2nd letter stating the importance of completing this. So again I’m sorry if there's anything else we can do to help better any programs or services for disabilities let us know thank you

Overall, the {Provider} program has been absolutely invaluable to my family. It has allowed me to work with provides health insurance for my family.

The "class" program has absolutely improved our live 100%. I am so grateful for the assistance and support. Thank you

I am very grateful and blessed to have this service. It has been a great access for my family.

{Provider} from {City} have been wonderful in helping us.

I wanted to let you know that i am so lucky and blessed to have this company in our families lives. They have always been there when I need something

I believe it's very important to have this help for the disabled children and their families

Over all everything that we are receiving are good and handled well. I'm pleased with the services we are getting. Thank you

We feel that keeping our daughter at home and in the community is essential to her health and happiness. Our neighbors tell us how much she's improved over the years, and I think its important for them to experience her development and progress.

I appreciate and am grateful for all the help my son and I receive. Without it I would not be able to keep him at home, attend college to make a better life for us and also mentally deal with all these issues.

We use a home health agency for our child and are very satisfied

The {Provider} program has been a blessing to me because it has allowed me to be able to keep my child at home and get the services I need to maintain his health and quality of life.

The program has made a big difference in our lives. I can get our more, to garage sales, bingo etc. I never left the house before, in years, because of my child's health, and not being able to afford to pay for someone to care for my child.

We are very happy in the "class" program. The people are wonderful!

The {Provider} program has been a life saver for our family. We are extremely grateful and appreciative of this wonderful program.

I'm very grateful with the program and all the help I have received for my son.

I just want thank you for your support in everything that you did for my family and others.

As a parent of a child with disabilities, it has been very beneficial to our family to have had {Provider} & {Provider} to assist with our childs care.

I believe that programs like class & cba make a huge difference in the quality of so many people's lives and assists pts & their families to be able to provide care for special needs children adults & keep them from having to be in a nursing home.

Outcomes most important to me-it has made a huge difference in our daughter life & family.

As a single mom these programs are vital to our existence. I would not be able to keep a job if I did not have the help I receive. I would not be able to afford to pay someone to take care of her while I work.

Without the help from these services there would be a lot of times I wouldn't be able to work or a lot of other important task I have to perform in my life! Thank-you!

I feel that family supports are the best form of Texas disability services I have.

With out {Provider} my child would be dead! It is the only program we qualified for out of about 55 programs. Without Medicaid as part of the benefit I could never afforded the massive medical bills

I just want to say how much we really do appreciate the help we get. We (my son) have been on the class program for 2 years now. And has benefited greatly from it. Thank you so much.

The support and help of the agencies is greatly appreciated-just that every time we get use to a case worker for a year or two they change-but everything is great. Thank for the help because I don't know where we be without everyones help. Thanks again

I don't know how we would make it without the services that we receive. My son is an extremely happy child and adapts well to all environments. I believe this is due to the fact that we treat him as a "normal" child.

These programs enable families like mine to enjoy like with our children @ home and have somewhat normalcy without increased hospitalizations or nursing home placement.

Our son has benefited from the services through CLASS-we have not needed much help accessing services & self-manage our program. We have been pleased with the services he has received.

We are very grateful for the class program. It would be very difficult for our family if we did not have the services and Medicaid waiver. Thank you!

The services are receive are {Provider} and Medicaid which allows us to have nursing care camp and occasionally equipment. We are extremely grateful for the Medicaid supplement to cover medical service, medication and nursing.

Your program has helped me & my family feel that we are doing our best for our disabled child (family member) of our home. Thank you.

The class program has been a huge help and blessing to our disabled daughter and our family! We are blessed to be receiving these services and feel that she will be able to live in our home for many, many years because of it.

I don't have any comments. I am satisfied the way things are being handled for the help for my child.

I feel like this class program has been a blessing to my family. It has help provide a better quality of life for my son.

Thanks for all the help we receive. I know that is why, I, as a parent, am able to function on a daily basis.

As of this time everything is being done to help us. My child is fine & content. Thank you

I am very pleased with the support I receive. Otherwise I really don't know what we would do.

I'm so thankful for the {Provider} program. My son will turn 13 yrs. Old in Dec. He has been dx w/autism, mr & spi. He is not toilet trained & non-verbal. I'm a single mom with a full-time job. He attends a great school {School}.

To whom it may concern, thank you thank you thank you for giving us an opportunity to live a more regular life! We will be thankful for everyday we have you! We remember what it was like when we hade no help!

I appreciate the help we have received. Especially, providers through mdcp has been extremely beneficial. I'm a teacher and am extremely involved in many aspects. Not worrying about hopes area, laundry, etc. Has been a true blessing.

I wouldn't be able to keep my daughter @ home without these services. Thank you.

I am very please with the services my son has received to this point. He is still young, living at home and doing well in school. He will be in high school next year and we want to prepare him to be an independent person and a contributing member to society

My son currently participates in the class program through {Provider}. I am very happy with the services my son gets. This program has been a blessing for us.

My son has been on the mdcp program for 7 yrs. Our family greatly appreciates the benefits the government has provided him. Every medical need has been met through the years. Thank you for your help with our difficult circumstances.

Most community activities are not appropriate for my child. As a result, we really appreciate the {Agency} services. It has made a difference for our family!

I just want to thank you for letting my daughter be in this program. It has really become beneficial in this time of need. Thank you.

We feel our child's community support program continues to benefit her by enabling her to be active in community activities and providing a safe means for her to experience self-management skills.

Thanks to programs out in our area, we are able to keep {Name} at home. We have been helped with many things (lifts, handicap shower, potty etc.) He is very happy and has made much progress thanks to many different programs we have. Thanks so much

Thank you all for this opportunity. My son {Name} has grown and matured with your help. Thank you all for providing help for all people with disabilities. It does make a difference!

Thank you for all those people whom have helped so much.

The services my daughter receives has made it easier for her dad and I to provide as near a normal life as possible. In our family, her disabilities are a part of her personality. And with her services, some of the worries are gone for us.

The services that are provided for my son have been very helpful. The people I have encountered in these programs are excellent. I am truly appreciative for everything they do to help make our lives easier. Thanks for providing these services

Overall, I'm very happy with the services my son has. He is very well integrated in the family.

Have had an excellent group. Always been there for me as well as my children. Thank you god bless

Overall, we have been very happy with the services our son has received. We never expected to receive the monetary and medical help we have received over the years, but we are more than grateful for the assistance, support and help.

As a single disabled mother I appreciate all the help I get in caring for "my" {Name} and she will grow happy and healthy because of your services. So thank you and god bless

Overall we are happy with the hcs program. Have had good and bad case managers during the period.

The program for our disabled daughter, {Name}, has allowed us to spend more time with her younger brother. It also provides more one-to-one service (communication) with {Name}. She enjoys people talking to her & playing with her.

I would like to thank you for allowing us to be able to have our daughter on this program. It is very much needed. It has provided us with very much needed assistance. I think without these services, we would probably have a very stressful life.

My daughter {Name} is 12 yrs old the class program saved my family emotionally, financially & physically we are so very grateful. My husband was the sole supporter of our family for many years. The stress and responsibility on him was overwhelming.

My family and I are very appreciative of the services and support we receive from the provider community choice. The support enables me to give my other son the necessary attention that he needs and deserves.

In my opinion, we receive good service. We have a son with physical and mental disabilities, it takes a long time to be served.

Class is the best thing that has happened to our family. Without it, I don't know how we would survive. There is no school or church that will take my child for respite or after school care.

Thank you for sending me this survey, and for all the services you provide for the children and adults who are disabled. You help us have a better way of life for our loved ones.

I would like to thank the Texas department of aging and disability services, for which we have received much support & assistance for our daughter. I would also like to express the wonderful work the staff @ {Provider} & the {Provider} agency staff do.

Thank you for whatever assistance my family has received since starting in the class program. I am sure there could be more said about how the program has helped but my family is still grieving the loss of my husband so thanks.

We have been happy with the overall plan for {Name}. She is developing to her fullest ability.

Definitely the services have made a difference in helping keep my child at home! Sometimes having so many in can be a bit overwhelming.

To whom it may concern, I am very thankful for the help we receive from the dads program. If we didn't receive this I don't know where or how we would be making a living for my daughter.

Everything is fine. Thank you for your concern.

My child and her family are very happy to have all the help we get from the agencies. It keeps close together and {Name} benefits from all the support and help we get. Thanks

My son is in the class program under the vfi option. This has been a wonderful program for him and our family. The vfi option has allowed us to find quality people to hire for attendant care.

Thank you! I am pleased with the help I get for my son. I would have it very hard if I didn't have help with him. I love my son very much and he is a happy child. So thank you for the help we get. I wish I had the medical help I need to get better.

Thanks for the HCF program that my son receives. Because of this program I'm able to go to work and provide for my family instead of getting outside financial help to pay for the bills.

Overall I feel it is a great program. Mdcp has helped a lot over the years. One thing that these programs need to take under consideration is the familes know what is best for the children because we are with them on a daily basis

Mdcp has been an extraordinary blessing in our lives. It has played a tremendous role in helping us to continue to keep our 17-year-old son at home and out of institutional care.

We thank god that {Name} is on the class program. {Name} needs one-on-one all day. With the support we get, we are able to function as a happy family. We have 2 girls ages 15 & 16.

We very much appreciate the respite and in-home caregivers, and the therapies the service does cover. Thank you.

I have really been blessed with the mdcp! It is a god send to our family. Thank you for all you do!

17b. General Dissatisfaction with Services and Supports

Nurses that can work the hours you need them to work are difficult to find. One department to the next doesn't seem to know the services that each provide. There are no checks & balances to verify hours that nurses actually submit for payment

My child is 9 years old so I have been at this awhile & have mostly what we need. However, the first 3 years were very difficult because had no help at all. No one knew what services were available, least of all the doctors.

The service provider I have now, is terrible, fixing to make changes!

It seems there are so many restrictions on services. Right now, I only have my son's grandmother (ex mother-in-law) as a caregiver. He goes to school 1/2 day due to health constraints & then spends the rest of the day at her house watching tv or sleeping

I one agency is able to provide certain basic services, then others should also. Why do the agencies try to have us expend all of our personal resources before they will lift a temporary "hand" to aid the family?

It would be great to have programs progress along with the child's age. From trying to obtain day care when my child was very young to choosing appropriate classes while my child is a teenager have been an uphill battle.

One can not get adaptive aides. It takes too long to run it through the system, the rules constantly change, and the always say whatever it is, it's to be provided by the school. The school won't provide it and you can't get denial letters

We were disappointed in the amount of time class takes to uphold a hearing officers verdict.

{Name’s} assistance with mdcp has been professional, thorough, and greatly appreciated. The hipp program, while appreciated, is extremely frustrating. It took us 4 months to prove cost-effectiveness after our rates increased.

Where do I start, I'm a parent of two boys w/autism. I didn't even bother putting my younger son on waiting lists. We're tired & broke & no one in any state funded agency has ever provided any viable solutions as far as treatment options go.

When you have a disable child you get SSI, and no help where to go service agency and disability service ready to send you around pass you around. I've ask for help but they don't look at just old people. But the young that are disable too.

At least for my child, I think the home health agency is a waste. I'd rather get more services for my son from caregiver and pay her directly from the state. The home health agency is an unneeded middle man. They are get paid a lot for nothing.

The Special Olympics in {County} was just taken away or at least the support for is gone. Parents are too over whelmed to plan activities outside the home. They are fun to the brim with responsibilities in the home. No child left behind - not -not

On the other hand, I am not always happy with the agencies. The first agency we were with bounced the caregiver's checks

I would very much like to have some say in what my child needs most. There have been times when we have had to pay for things that he needed and deserved because it wasn't worded correctly.

17c. Access

It would be nice for families like mine to have more access to community services in the rgv. Services are minimal for young children.

Rachel 18 day care & respite care for special needs children is really lacking in {City}. We are blessed of god to have the helps we have. The class program really helps with {Name's} needs.

Services need to be accessible. Caseworkers need to be more available to help with getting services.

17d. Information Regarding Services/Supports

I would like to talk to someone about my living situation

I would like to know if there's a program that will help a single parent who need a van with a lift. Please share this information to someone who can help me. I plan on keeping {Name} in the home.

You know I know there al ot of help out there. It would be nice to know if they were offered. Other options that I have would be.

More information on current providers available to help fill in hours needed that cannot be filled by regular staff.

It would be helpful to have a listing of what services are available with a list of pediatric ot, pt, speech providers in the are.

We have had great difficulty finding out what programs are available to us. Both my husband and I are college educated and phone around & network when we can but one agency never knows what else is out there.

I have completed this survey in regards to all services my child receives. I do not know what services are DADS. I think that dads should be responsible for long-term & disability Medicaid eligibility.

I didn't know we were even a part of this agency, would you please send me some information regarding your services. Thank you.

The only service I receive is to have a provider take care of my son thru mdcp as respite. We have Medicaid thru mdcp. It would be good to hear of other services available, especially as the twins age.

This survey is from DADS-1. Is this the tax department of human services? 2. How does dads relate of mdcp? 3. How does dads relate to ccp? 4. How does DADS relate to Medicaid? 5. Most of the questions are very confusing

What do other communities in Texas do or provide for young adults who are not able to work? It is very important to us that our children stay and remain active or have somewhere to go and socialize.

Would like to know where to turn for help when having difficulties w/3rd party vendors, ie, wheelchairs providiers. What agencies would we go to in order to file a complaint? Thank you

We don't know how or what kind of services are available out there. It would be nice if we didn't have to practically pull it out of our social worker.

For families who cannot continue to care for the child at home, there should be information more easily available as to what other options might exist, because there are families who feel it would serve the child and the rest of the family members best

I would like to get more information out in the community for my son {Name}.

Next time please include a list of what "dads" involved. I wasn't sure if certain services my child gets were under “dads”, so I called a local office she had no clue even what “class” was.

It would be helpful if we were informed when new or different programs come available. It is very hard to determine what services are available.

Agency: I took this essay responding toward the agency not, toward my help at home. I have no clue how to get in touch with anyone who can help my family needs at home. I have no clue how to get in touch with someone about financial needs or transportation

I would like to have more information about a program that can help my daughter for vision and physical therapy.

I'm not sure what DADS is. I've never heard of it. My baby do get respite. I don't know if I answered this questionnaire right. I receive respite with someone but not with dads I think. Thanks

Would like to receive up to date info about new laws, new guidelines, declaring guardianship.

I want to thank you for the help for my son. He has no speech. He is m.r. And also I want to know like when I have been in a company of home health. Can I change anytime, from that company. Say I don't want to be there anymore. Can I change?

I do not have a social worker to liaison with when i have a problem. Whom shall I call?

I would like to know if there are some agencies to help us build an extra room.

It would be nice to know what is going on with legislative issues concerning people with disabilities. Where do we stand in terms of money for education, Medicaid/Medicare, financial resources for a person with special needs, etc.?

I think it would be helpful to have easy access to programs in other states in case a job offer in another state became available. I have tried to compare Texas programs with programs in other states.

Need more advice sooner about out-of home placements such as icr mr group homes. Didn't know consumers under 18 are eligible.

I am confused. I don't receive any services from this department. I do receive class benefits. Are they somehow connected?? Therefore I cannot fill out the questionnaire-unless I am mistaken and should be filly it at as it relates to CLASS.

The process to get the help & support should be faster. People should be better made aware of all that is available.

Need someone to contact me on support and about service to me. Thank you

Right now, I am interested in any information that could be provided related to the possibility of help to get my daughter independent through driving.

I am not familiar with DADS. Our social worker has not contacted us. I thought once your child starts receiving Medicaid, it is automatic that the social worker should contact your family. They are supposed to be the ones who know about special services

Overall I'm still learning little by little on all the benefits be can have and will have.

I have found it difficult to find someone who knows the different waiver programs well enough to help me make a decision between class & mdcp. I have a minor child & from what I can tell class is not necessarily my best choice.

So far I'm not aware of any facility for respite out of the home here in the valley. I would like to know more about it. I was somewhat disappointed with the transfer of mdcp to cba program cause i've been waiting over 2 months for continual therapy services

I encountered many problems in trying to seek information from MHMR-to include being shuffled from one department to another when I needed information regarding memorandums mailed to my home.

I have been happy with my daughter's case worker through mdcp. My concern is, that there are programs for my daughter for after school that would help with her social skills and/or therapies she could do to help.

17e. Need More Services/Supports

Request community services and organizations (sports, cultural, etc... Private & public) to open their doors to children and people with disabilities. More inclusion in schools. Disability awareness programs to the general population.

The {Name} family would like to thank you for your support, but sometimes our child does not get what she needs. Our child got surgery on the 4th of October and she did not get any help of any kind. Thank you.

I need more services available for my son in the community church etc. I need help in that area. Please! Only that area pleased in all areas.

I think the class program is great but I should be able to other services (ex. St, ot, pt etc.) If my insurance is primary and even if he is getting theraphy at school. A lot of the therapies at school are not very good and are provided in a group settings

Community programs for adults w/autism & behavioral problems are really needed in this area. People tend to be much more accepting of people in wheelchairs as opposed to persons w/behavioral issues.

We are receiving respite funding from hcs currently. We were also told there were funds for equipment and therapies. There is one piece that would be so helpful to us (a feeder seat), and we are having such a hard time having it "okayed."

My child is totally disabled. We need ssi or money to build ramps bathroom access care transportation. It seems that the government encourages you to be a dead beat to get any support or help.

For a family unable to afford a van for a child in a wheelchair it would be a help if anyone knew where to get an affordable van or if anyone knows of a car dealership that would sponsor a van for children (or adult) who is immobile.

Thanks to all these programs and all the support we have received and continue to receive. We do need more schools that have transportation and that don't cost so much.

One of our big needs has been to keep our old van, with a w/c lift running. There isn't any help with this. Our two w/c kids are foster children, and their isn't help for the van as a foster child either. Also Medicaid isn't paying for a lot of meds

Having funding for services that are needed by your child is useless if those services are not available to you. For instance, having 60 hours per week of funding for nursing care in no way benefits the child or family if providers can't or won't staff

I'm a single white male, with 2 children {Name’s} is 8 with special needs. {Name} is 13 big a healthy. I need help with house keeping! I manage all. The rest fine. Can't seam to get time to dust, mop, clean out cabinets etc. Divorced in july of 05

My son is 13 years old. He is mentally retarded. His level is around 18 months old. I wish and hope (pray) that in the future there will be more agencies and the government will help out more with people that have mental retardation

Because our child has a very rare disorder, it is often difficult to get non pharmaceuticals or supplements approved for reimbursement. Certain vitamins and electrolyte solutions allow her to stay off of prescription medications; however these are not covered

We only receive 9 hrs of care attendant services a week through this program. This is of course better than nothing. Yet, if this was all that my family had it would not be enough.

As a parent we would like for there to be a daycare center for special children like once a week like an activity there is no place for our special needed children, that will help them also in involving with other people something similiar like normal children

We live in {County} county. For some reason it is very, very hard to get in home care here. We often have to go without due to the lack of available staff. We are in the process of looking for a new service to use.

I am pleased with the support my son receives. However, several requests have been denied or delayed. Software that was ordered May '06 has not been received. {Name's} at wrote a letter recommending hydrotherapy.

17f. General Satisfaction with Service Management

17h. Waiting List for Services and Supports

My child was denied health insurance at birth due to his disability. He now has services through hcs but he is the exception. All of his peers are still on the waiting list. It is absurd that families wait 10 yrs & for services. Not enough slots legislated

Right now, I believe our daughter {Name} is only on a waiting list. We do not receive services yet.

My son is on the class program. He is one of the fortunate children who did not have to wait on a waiting list for more than one year.-I understand the wait is now 5-8 yrs. This is unacceptable!

In my opinion, we receive good service. We have a son with physical and mental disabilities, it takes a long time to be served.

My family is very lucky that our eleven year old daughter is receiving hcs services. When my daughter was an infant we put her on the waiting list for hcs. It took 7 years, but she finally came up on the list.

Your waiting list is way to long and to many people are waiting for the end of the list to come!

My family appreciates the support-I just wish the waiting list for other families wasn't so long. For us it was seven years on the CLASS list.

19.General Concerns

Not sure who you are talking about when you say "family supports".

I am very concerned about the bidding process. We recently had an outside ramp remodification. The bidding was handled through the class program. I was shocked at what the bid was let for the project.

I felt some of the question where to general and broad to answer. I tried to answer them the best I could.

As a parent I would like to see that DADS let parent take control of hiring & choose their own provider for their loving one services & let them feel comfortable whenever a staff member step in their house.

Note: we have had in home services for 5 years the first 3 were awful. Personnel changed daily and did nothing for my son. 2 years ago we took over and have hired our own personnel and it has greatly improved. Our son now gets the care he needs

Survey should have included a "not applicable" option (n/a)-this is not the same as "don't know. We do know but the situation does not apply to us. Section for choice & control-question 32 did not understand why this question was asked

Am not really sure what this survey was about. What department or agency were we supposed to be responding on. His caseworker I think might be from the commission for the blind. Other then that person he has 1 from mdcp agency.

I am frustrated with the fact that everything that is sent to me from the Texas DADS or any agency is sent in Spanish and English. I wonder how much money is wasted in this procedure.

I didn't understand some of the questions. I hope this helps.

Parts of the survey were difficult to understand. Fact-we have a case manager through mdcp & have a care plan in place for {Name}. Fact-all of her approved funds from mdcp are used for nursing care lvn x 10 hours per week.

Correct information about program is not always known by worker causing delays/errors. Parents would do a more effective job hiring & paying workers. Agencies mostly facilitate payroll. Funds could be better used on services.

I felt that some of the choices were inadequate to respond. I am not always sure who was being referred to in each instance.

Due to the many agencies, various programs etc. That we work with, it was hard to understand precisely who we were speaking about (evaluating) for each question. It would be a great help to have a glossary of terms to refer to (staff-with which program;

I have no idea what any of this is? I could use a phone call.

I wasn't sure how to answer the questions about the dads staff b/c I don't know if I've ever talked to anyone? Is mdcp a part of this?

I don't understand many of the questions in the survey. I'm not sure whether they pertain to my daughter or to me.

The paperwork is excessive. The paperwork for caseworkers, service providers is excessive. Providers are going down is quality because of the excessive red tape involved. It is time to be focused on the participant versus "regulations."

I found questions 5-9 confusing because we don't have a specific plan.

I do my best with what ability I have to take care of my son. I was trying to get an education to help our situation. But if I go to school they count it against me, and my son - I don't get any other income because I can't come out ahead.

I have some questions & suggestion but do not know how to say out or express them.

The home health agencies like: {Name's} home health care & others should have periodic cks for: 1. Fraud (some other than client signing time sheets etc) 2. Wrong time on time sheets. 3. Proper monies being asked for only provide help 8-5 only -

Many questions are vague. I am not sure if my answers are all correct. I answered with what I thought you may be asking.

I really don't understand who the people are, or the services that are offered in which you are inquiring about. Some of the answers given may not apply to these questions. I answered them the best I understood them to mean.

I feel this was a waste of our time. I feel that the government don't really care about our disability children. This will probably get lost somewhere.

The state of Texas city of {City} is cruel. The sidewalks where we live are un-walkable. They keep us prisoners in our own home. People don't care anymore. Disable and low income are what the government are trying to get rid of.

I answered these questions based on who " I think" your(r) agency is. I answered them based on {County} co mhmr administration of {Names'} hcs program benefits.

At this moment. I think the answers to all these questions. Tell it as it is for now. I thank you for giving me a chance to be able to express my opinions on the questionnaire again thank you

APPENDIX A

Summary Tables of Survey Responses

Table A - Characteristics of Child with a Disability: 2005-06 Data

STATES	Total %		State Avg.	CA-RCOC		CT		HI		SC		SD		TX		WY	
Number of surveys																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Gender:																	
Male	1,455	**62.4**	**62.6**	460	67.4	130	62.5	111	68.9	101.0	63.9	95.0	51.6	441	58.2	117	65.4
Female	875	**37.6**	**37.4**	222	32.6	78	37.5	50	31.1	57.0	36.1	89.0	48.4	317	41.8	62	34.6
Age:																	
Mean	11.2		**11.7**	9.8		11.3		11.2		5.4		11.5		13.4		11.9	
Range	1-21			3-18		1-18		1-17		1-18		1-19		1-21		1-21	
Race/Ethnicity* (duplicated counts):																	
White	1,352	**58.1**	**63.6**	285	41.4	150	72.1	53	32.5	99.0	61.9	159.0	89.3	446	59.4	160	88.9
Black	190	**8.2**	**9.6**	18	2.6	24	11.5	10	6.1	52.0	32.5	5.0	2.8	79	10.5	2	1.1
Asian	222	**9.5**	**10.0**	124	18.0	1	0.5	71	43.6	4.0	2.5	4.0	2.2	16	2.1	2	1.1
Amer. Indian/Alaska Native	53	**2.3**	**2.7**	15	2.2	2	1.0	7	4.3	2.0	1.3	10.0	5.6	12	1.6	5	2.8
Hawaiian/ Pacific Islander	71	**3.0**	**5.5**	8	1.2	1	0.5	57	35.0	0.0	0.0	1.0	0.6	2	0.3	2	1.1
Hispanic	2,327	**21.5**	**13.5**	240	34.9	29	13.9	13	8.0	7.0	4.4	1.0	0.6	200	26.6	11	6.1
Two or More Races	140	**6.0**	**6.7**	54	7.8	11	5.3	41	25.2	1.0	0.6	1.0	0.6	25	3.3	7	3.9
Other/Unknown	16	**0.7**	**0.8**	7	1.0	0	0.0	4	2.5	0.0	0.0	0.0	0.0	2	0.3	3	1.7
More than 1 person with DD in household:																	
Yes	345	**14.8**	**15.6**	102	15.2	38	18.8	23	13.8	31.0	18.8	27.0	14.6	96	12.5	28	15.7
No	1,989	**85.2**	**84.4**	570	84.8	164	81.2	144	86.2	134.0	81.2	158.0	85.4	669	87.5	150	84.3
	2,334			672		202		167		165		185		765		178	
Level of Help with Daily Activities																	
None	97	**4.1**	**5.0**	28	4.1	12	5.6	11	6.7	8.0	5.0	5.0	2.7	18	2.4	15	8.3
Little	355	**15.1**	**18.0**	124	18.1	50	23.3	38	23.3	28.0	17.6	30.0	16.2	46	6.1	39	21.7
Moderate	804	**34.3**	**36.4**	264	38.6	73	34.0	51	31.3	60.0	37.7	90.0	48.6	196	25.8	70	38.9
Complete	1,090	**46.5**	**40.6**	268	39.2	80	37.2	63	38.7	63.0	39.6	60.0	32.4	500	65.8	56	31.1
	2,346			684		215		163		159		185		760		180	
Other disabilities* (duplicated counts):																	
Mental retardation	1,071	**46.0**	**43.8**	263	38.2	122	57.0	63	39.4	20.0	13.1	86.0	47.5	416	55.4	101	56.1
Other developmental disability	739	**31.8**	**33.6**	103	15.0	74	34.6	55	34.4	57.0	37.3	68.0	37.6	322	42.9	60	33.3
Mental illness	126	**5.4**	**5.7**	26	3.8	18	8.4	4	2.5	10.0	6.5	8.0	4.4	45	6.0	15	8.3
Autism	683	**29.3**	**29.3**	291	42.3	86	40.2	60	37.5	38.0	24.8	33.0	18.2	130	17.3	45	25.0
Cerebral Palsy	648	**27.9**	**23.0**	120	17.4	35	16.4	30	18.8	21.0	13.7	43.0	23.8	358	47.7	41	22.9
Brain injury	235	**10.1**	**8.8**	24	3.5	13	6.1	9	5.6	13.0	8.5	15.0	8.3	141	18.8	20	11.1
Seizure/neurological problem	728	**31.3**	**27.3**	120	17.4	54	25.2	45	28.1	24.0	15.8	52.0	28.7	390	51.9	43	23.9
Chemical dependency	28	**1.2**	**1.2**	5	0.7	3	1.4	1	0.6	3.0	2.0	1.0	0.6	12	1.6	3	1.7
Vision or hearing impairments	636	**27.3**	**23.6**	104	15.1	43	20.1	28	17.5	26.0	17.1	50.0	27.6	346	46.0	39	21.7
Physical disability	802	**34.5**	**31.7**	97	14.1	51	23.8	55	34.4	34.0	22.2	69.0	38.1	440	58.5	56	31.1
Communication disorder	694	**29.8**	**26.6**	132	19.2	74	34.6	31	19.4	29.0	19.0	49.0	27.1	340	45.2	39	21.7
Down Syndrome	250	**10.7**	**11.8**	98	14.2	29	13.6	15	9.4	9.0	5.9	39.0	21.5	37	4.9	23	12.8
Other disability	628	**27.0**	**26.3**	101	14.7	50	23.5	36	22.5	50.0	32.9	44.0	24.3	299	39.8	48	26.7

Table B - Characteristics of Respondents: 2005-06 Data

STATES	Total %		State Avg.	CA-RCOC		CT		HI		SC		SD		TX		WY	
Number of surveys																	
Age:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Under 35	431	**18.2**	**17.0**	134	19.6	27	12.7	29	17.3	68	41.2	30	16.2	101	13.1	42	23.3
35 to 54	1,730	**73.2**	**75.3**	486	71.3	173	81.2	123	73.2	85	51.5	144	77.8	595	77.4	124	68.9
55 to 74	197	**8.3**	**7.5**	60	8.8	12	5.6	16	9.5	12	7.3	11	5.9	72	9.4	14	7.8
75 or Over	4	**0.2**	**0.2**	2	0.3	1	0.5	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0
	2,362			682		213		168		165		185		769		180	
Relationship to consumer:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Parent	2,256	**95.6**	**96.2**	666	97.8	199	95.7	157	92.9	158	95.2	179	96.8	723	93.9	174	96.7
Sibling	3	**0.1**	**0.1**	0	0.0	0	0.0	1	0.6	0	0.0	1	0.5	1	0.1	0	0.0
Grandparent	73	**3.1**	**2.8**	9	1.3	8	3.8	8	4.7	7	4.2	5	2.7	33	4.3	3	1.7
Other	27	**1.1**	**1.0**	6	0.9	1	0.5	3	1.8	1	0.6	0	0.0	13	1.7	3	1.7
	2,359			681		208		169		166		185		770		180	
Respondent is primary caregiver:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	2,295	**98.4**	**98.8**	661	98.2	197	99.0	159	95.8	165	99.4	182	98.9	752	98.4	179	99.4
Household Income:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Below $15,000	328	**21.7**	**18.2**	146	22.8	36	17.6	33	20.2	56	36.6	27	15.0			30	17.5
$15,001-$25,000	244	**16.1**	**15.1**	127	19.8	31	15.1	25	15.3	16	10.5	26	14.4			19	11.1
$25,001-$50,000	379	**25.0**	**28.5**	127	19.8	49	23.9	48	29.4	32	20.9	63	35.0			60	35.1
$50,001-$75,000	259	**17.1**	**19.7**	86	13.4	41	20.0	27	16.6	25	16.3	44	24.4			36	21.1
Over $75,000	303	**20.0**	**18.5**	155	24.2	48	23.4	30	18.4	24	15.7	20	11.1			26	15.2
	1,513			641		205		163		153		180		0		171	
Health of respondent:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Excellent	612	**25.9**	**28.0**	183	26.7	57	27.0	44	26.2	41	24.8	53	28.8	170	22.1	64	35.6
Good	1,261	**53.4**	**53.1**	369	53.9	106	50.2	94	56.0	93	56.4	106	57.6	400	52.1	93	51.7
Fair	425	**18.0**	**16.9**	121	17.7	41	19.4	25	14.9	24	14.5	25	13.6	168	21.9	21	11.7
Poor	63	**2.7**	**2.0**	12	1.8	7	3.3	5	3.0	7	4.2	0	0.0	30	3.9	2	1.1
	2,361			685		211		168		165		184		768		180	

Table C - Services and Support Received: 2005-06 Data

STATES	Total %		State Avg.	CA-RCOC		CT		HI		SC		SD		TX		WY	
	n	%	n = 7	n	%	n	%	n	%	n	%	n	%	n	%	n	%
SSI financial support	900	**38.4**	**39.2**	265	39.2	59.0	28.0	48.0	26.8	61	37.0	61	33.3	330	43.7	76	42.9
Other financial support	579	**25.5**	**30.7**	69	10.3	89.0	42.4	53.0	30.8	26	16.3	111	63.1	161	22.6	70	41.2
In-home support	1,180	**50.9**	**46.0**	214	31.7	55.0	26.1	60.0	34.5	65	40.9	39	21.7	669	89.1	78	46.7
Out-of-home respite care	897	**39.0**	**42.6**	250	37.4	62.0	29.4	71.0	40.3	25	15.2	98	53.8	268	37.3	123	69.5
Early intervention	216	**14.3**	**18.4**	0	0	25	12.9	22	13.8	82	53.2	25	15.1	32	4.7	30	19.0
Transportation	268	**11.5**	**9.6**	57	8.4	12.0	5.8	36.0	20.5	8	4.8	14	7.7	123	16.7	18	10.3
Specialized services/supports	1,686	**72.8**	**78.4**	431	65.5	140.0	67.0	119.0	69.6	142	85.0	160	87.4	549	73.5	145	80.6

Table D - Information and Planning: 2005-06 Data

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	HI	SC	SD	TX	WY
Q1 - Do you receive information about the services and supports that are available to your child and family?									
Number of surveys	2,302	n = 7	668	210	172	161	184	731	176
% always or usually	**40.2**	**40.8**	48.1	21.0	41.3	39.8	56.0	33.1	46.0
% sometimes	**40.2**	**40.6**	38.3	45.7	43.6	39.1	35.3	40.6	41.5
% seldom or never	**19.6**	**18.7**	13.6	33.3	15.1	21.1	8.7	26.3	12.5
Q2 - If you receive information, is it easy to understand?									
Number of surveys	2,118	n = 7	621	173	164	145	180	665	170
% always or usually	**54.5**	**55.0**	60.5	44.5	49.4	63.4	66.7	48.0	52.4
% sometimes	**38.7**	**38.2**	34.0	45.1	45.7	26.9	31.1	43.6	41.2
% seldom or never	**6.8**	**6.8**	5.5	10.4	4.9	9.7	2.2	8.4	6.5
Q3 - Do you receive information about the status of your child's development?									
Number of surveys	2,159	n = 7	625	189	161	155	174	683	172
% always or usually	**44.4**	**47.3**	40.8	32.3	48.4	63.9	53.4	42.0	50.0
% sometimes	**25.8**	**25.2**	30.1	21.2	25.5	17.4	28.7	23.4	30.2
% seldom or never	**29.7**	**27.5**	29.1	46.6	26.1	18.7	17.8	34.6	19.8
Q4 - If yes, is this information easy to understand?									
Number of surveys	1,704	n = 7	501	142	128	135	152	500	146
% always or usually	**60.9**	**62.1**	60.3	44.4	62.5	75.6	69.7	58.4	63.7
% sometimes	**32.3**	**31.7**	32.9	40.8	35.9	21.5	27.0	33.4	30.1
% seldom or never	**6.8**	**6.3**	6.8	14.8	1.6	3.0	3.3	8.2	6.2
Q5 - Do you get enough information to help you participate in planning services for your family?									
Number of surveys	2,165	n = 7	620	194	165	151	178	688	169
% always or usually	**42.9**	**45.6**	40.5	23.7	41.2	57.6	57.3	40.1	58.6
% sometimes	**35.2**	**34.1**	37.6	36.6	38.8	28.5	31.5	35.2	30.8
% seldom or never	**21.9**	**20.3**	21.9	39.7	20.0	13.9	11.2	24.7	10.7
Q6 - If your family has a service plan, did you help develop the plan?									
Number of surveys	1,823	n = 7	524	115	154	130	164	575	161
% always or usually	**75.5**	**77.5**	69.8	63.5	76.6	76.9	88.4	73.9	93.2
% sometimes	**14.8**	**13.9**	17.6	17.4	19.5	14.6	9.1	15.1	3.7
% seldom or never	**9.7**	**8.7**	12.6	19.1	3.9	8.5	2.4	11.0	3.1
Q7 - If your family has a service plan, does the plan include things that are important to you?									
Number of surveys	1,815	n = 7	512	117	155	127	161	582	161
% always or usually	**70.6**	**73.0**	60.4	54.7	80.6	79.5	83.2	72.2	80.1
% sometimes	**21.4**	**20.2**	28.3	27.4	16.1	18.9	13.7	19.4	17.4
% seldom or never	**7.9**	**6.9**	11.3	17.9	3.2	1.6	3.1	8.4	2.5

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	HI	SC	SD	TX	WY
Q8 - Do the staff who assist you with planning help you figure out what you need as a family to support your child?									
Number of surveys	2,072	n = 7	644	146	165	137	172	637	171
% always or usually	**51.7**	**56.4**	41.5	39.0	58.2	63.5	73.8	50.4	68.4
% sometimes	**30.3**	**27.9**	35.4	30.1	30.9	25.5	18.0	30.9	24.6
% seldom or never	**18.0**	**15.6**	23.1	30.8	10.9	10.9	8.1	18.7	7.0
Q9 - Do the staff who assist you with planning respect your choices and opinions?									
Number of surveys	2,041	n = 7	614	143	162	139	176	636	171
% always or usually	**75.8**	**77.9**	74.3	67.8	75.3	84.9	85.8	72.0	85.4
% sometimes	**18.1**	**16.1**	20.7	16.8	19.8	11.5	10.2	20.3	13.5
% seldom or never	**6.1**	**6.0**	5.0	15.4	4.9	3.6	4.0	7.7	1.2
Q10 - Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI)?									
Number of surveys	2,053	n = 7	597	162	162	132	167	680	153
% always or usually	**35.6**	**37.1**	35.2	24.7	34.6	42.4	49.7	33.1	39.9
% sometimes	**26.1**	**25.0**	28.6	17.3	26.5	21.2	28.1	26.0	27.5
% seldom or never	**38.3**	**37.9**	36.2	58.0	38.9	36.4	22.2	40.9	32.7
Q11 - Are the staff who help you with planning generally respectful and courteous?									
Number of surveys	2,165	n = 7	666	160	169	150	180	669	171
% always or usually	**85.9**	**87.1**	86.0	81.9	84.0	88.7	93.3	82.5	93.6
% sometimes	**11.6**	**10.6**	12.2	11.9	14.8	10.0	6.1	13.5	5.8
% seldom or never	**2.5**	**2.3**	1.8	6.3	1.2	1.3	0.6	4.0	0.6
Q12 - Are the staff who assist you with planning generally effective?									
Number of surveys	2,117	n = 7	655	153	162	147	176	651	173
% always or usually	**62.7**	**64.9**	56.9	52.3	59.3	66.0	81.3	62.7	75.7
% sometimes	**30.0**	**27.9**	35.1	32.0	33.3	25.9	16.5	30.3	22.5
% seldom or never	**7.2**	**7.2**	7.9	15.7	7.4	8.2	2.3	7.1	1.7
Q13 - Can you contact the staff who assist you with planning whenever you want to?									
Number of surveys	2,146	n = 7	663	159	169	151	177	654	173
% always or usually	**71.2**	**71.5**	71.8	58.5	62.7	71.5	86.4	69.0	80.9
% sometimes	**22.6**	**22.3**	22.9	27.7	31.4	21.2	12.4	22.9	17.9
% seldom or never	**6.3**	**6.1**	5.3	13.8	5.9	7.3	1.1	8.1	1.2

Table E - Information and Planning: 2005-06 Data (cont'd)

Table F - Access & Delivery of Services & Supports: 2005-06 Data

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	HI	SC	SD	TX	WY
Q14 - When you ask your service/support coordinator for assistance, does he/she help you get what you need?									
Number of surveys	2,217	n = 7	652	173	169	147	180	722	174
% always or usually	**66.4**	**67.1**	61.3	46.8	66.3	62.6	86.1	68.8	77.6
% sometimes	**26.4**	**26.0**	29.8	36.4	27.8	29.9	12.8	24.9	20.1
% seldom or never	**7.2**	**7.0**	8.9	16.8	5.9	7.5	1.1	6.2	2.3
Q15 - Does your family get the services and supports you need?									
Number of surveys	2,236	n = 7	636	186	168	154	183	734	175
% always or usually	**50.4**	**51.7**	44.7	29.0	48.8	50.6	73.8	52.6	62.3
% sometimes	**38.8**	**37.3**	42.3	47.8	39.9	35.1	24.6	39.1	32.0
% seldom or never	**10.8**	**11.1**	13.1	23.1	11.3	14.3	1.6	8.3	5.7
Q16 - Do the services and supports offered meet your family's needs?									
Number of surveys	2,219	n = 7	632	176	163	150	185	738	175
% always or usually	**48.0**	**49.1**	41.1	25.0	50.9	51.3	70.3	51.1	54.3
% sometimes	**40.7**	**39.3**	45.4	44.3	42.3	36.7	27.0	40.1	39.4
% seldom or never	**11.2**	**11.5**	13.4	30.7	6.7	12.0	2.7	8.8	6.3
Q17 - Are supports available when your family needs them?									
Number of surveys	2,151	n = 7	593	168	164	149	181	723	173
% always or usually	**44.5**	**45.4**	40.1	24.4	42.1	47.0	66.9	45.4	52.0
% sometimes	**40.5**	**38.8**	42.2	39.9	39.6	36.9	30.4	43.0	39.9
% seldom or never	**15.0**	**15.8**	17.7	35.7	18.3	16.1	2.8	11.6	8.1
Q18 - Do families in your area request that different types of services and supports be made available in your area?									
Number of surveys	933	n = 7	227	83	70	70	77	316	90
% always or usually	**34.8**	**35.4**	30.8	30.1	42.9	38.6	29.9	36.4	38.9
% sometimes	**42.6**	**42.4**	42.3	42.2	35.7	31.4	54.5	42.1	48.9
% seldom or never	**22.6**	**22.2**	26.9	27.7	21.4	30.0	15.6	21.5	12.2
Q19 - If yes, does either the state agency or provider agency respond to their requests?									
Number of surveys	785	n = 7	235	59	56	47	60	254	74
% always or usually	**34.8**	**31.6**	43.0	15.3	39.3	25.5	33.3	33.9	31.1
% sometimes	**43.1**	**44.5**	37.9	37.3	41.1	46.8	55.0	44.5	48.6
% seldom or never	**22.2**	**23.9**	19.1	47.5	19.6	27.7	11.7	21.7	20.3
Q20 - If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?									
Number of surveys	1,136	n = 7	288	86	85	70	94	422	91
% always or usually	**45.1**	**45.9**	38.5	30.2	31.8	45.7	74.5	46.7	53.8
% sometimes	**21.7**	**21.4**	24.0	17.4	28.2	24.3	14.9	21.1	19.8
% seldom or never	**33.3**	**32.7**	37.5	52.3	40.0	30.0	10.6	32.2	26.4
Q21 - If English is not your first language, are there support workers or translators available to speak with you in your preferred language?									
Number of surveys	487	n = 7	275	24	27	14	4	133	10
% always or usually	**73.7**	**70.1**	77.1	66.7	59.3	71.4	75.0	71.4	70.0
% sometimes	**15.8**	**15.4**	14.9	16.7	25.9	14.3	0.0	15.8	20.0
% seldom or never	**10.5**	**14.5**	8.0	16.7	14.8	14.3	25.0	12.8	10.0

Table G - Access & Delivery of Services & Supports: 2005-06 Data (cont'd)

STATES	TOTAL AVG.	STATE AVG.	CA-RCOC	CT	HI	SC	SD	TX	WY
Q22 - If your child does not speak English or uses a different way to communicate (e.g., sign language), are there enough support workers available who can communicate with him/her?									
Number of surveys	581	n = 7	183	49	50	30	30	209	30
% always or usually	**46.1**	**43.5**	57.9	40.8	42.0	53.3	26.7	40.2	43.3
% sometimes	**27.2**	**30.8**	24.0	24.5	28.0	30.0	43.3	25.8	40.0
% seldom or never	**26.7**	**25.7**	18.0	34.7	30.0	16.7	30.0	34.0	16.7
Q23 - Does your child have access to the special equipment or accommodations that he/she needs (e.g., wheelchair, ramp, communication board)?									
Number of surveys	1,389	n = 7	261	102	97	53	120	636	120
% always or usually	**58.7**	**56.4**	49.4	45.1	49.5	50.9	74.2	63.2	62.5
% sometimes	**24.6**	**24.7**	20.3	30.4	28.9	17.0	20.8	25.0	30.8
% seldom or never	**16.6**	**18.9**	30.3	24.5	21.6	32.1	5.0	11.8	6.7
Q24 - Do you have access to health services for your child?									
Number of surveys	2,277	n = 7	640	191	165	159	185	761	176
% always or usually	**90.8**	**90.7**	89.5	86.9	89.7	86.8	98.4	91.9	92.0
% sometimes	**7.0**	**6.9**	7.7	8.9	7.9	11.3	1.1	7.0	4.5
% seldom or never	**2.2**	**2.3**	2.8	4.2	2.4	1.9	0.5	1.2	3.4
Q25 - Do you have access to dental services for your child?									
Number of surveys	2,251	n = 7	638	187	169	153	181	750	173
% always or usually	**86.0**	**86.2**	83.2	79.1	87.0	86.3	94.5	88.0	85.0
% sometimes	**7.3**	**6.5**	8.9	8.0	5.9	5.2	2.2	7.7	7.5
% seldom or never	**6.7**	**7.3**	7.8	12.8	7.1	8.5	3.3	4.3	7.5
Q26 - Do you have access to necessary medications for your child?									
Number of surveys	2,216	n = 7	619	177	162	152	180	758	168
% always or usually	**92.7**	**92.5**	90.0	87.6	90.1	90.8	99.4	95.1	94.6
% sometimes	**5.9**	**6.1**	7.4	9.0	9.3	7.2	0.6	4.4	4.8
% seldom or never	**1.4**	**1.4**	2.6	3.4	0.6	2.0	0.0	0.5	0.6
Q27 - Are frequent changes in support staff a problem for your family?									
Number of surveys	1,903	n = 7	508	143	142	128	152	673	157
% always or usually	**20.5**	**20.3**	19.3	25.9	30.3	22.7	9.9	22.4	11.5
% sometimes	**38.0**	**36.5**	36.6	40.6	49.3	25.8	22.4	41.6	39.5
% seldom or never	**41.5**	**43.2**	44.1	33.6	20.4	51.6	67.8	36.0	49.0
Q28 - Are support staff generally respectful and courteous?									
Number of surveys	2,161	n = 7	608	158	170	146	174	729	176
% always or usually	**84.3**	**85.3**	84.2	77.8	82.4	84.9	94.8	81.8	91.5
% sometimes	**14.3**	**13.1**	13.8	19.0	17.6	11.6	4.6	17.4	8.0
% seldom or never	**1.4**	**1.5**	2.0	3.2	0.0	3.4	0.6	0.8	0.6

Table H - Choices and Control: 2005-06 Data

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	HI	SC	SD	TX	WY
Q29 - Do you choose the agencies or providers that work with your family?									
Number of surveys	2,112	n = 7	555	159	155	149	170	746	178
% always or usually	**59.1**	**54.9**	42.9	34.6	53.5	53.0	45.3	77.6	77.5
% sometimes	**21.5**	**23.1**	24.1	25.8	25.2	22.8	29.4	16.6	18.0
% seldom or never	**19.4**	**22.0**	33.0	39.6	21.3	24.2	25.3	5.8	4.5
Q30 - Do you choose the support workers who work with your family?									
Number of surveys	2,012	n = 7	529	152	145	139	157	714	176
% always or usually	**45.8**	**41.0**	31.6	23.7	35.2	30.9	29.3	63.0	73.3
% sometimes	**21.5**	**21.8**	18.7	16.4	25.5	25.9	23.6	22.8	19.9
% seldom or never	**32.7**	**37.2**	49.7	59.9	39.3	43.2	47.1	14.1	6.8
Q31 - Do you have control and/or input over the hiring and management of your support workers?									
Number of surveys	1,751	n = 7	434	121	128	110	127	674	157
% always or usually	**42.9**	**35.2**	29.5	18.2	35.9	19.1	22.0	61.0	60.5
% sometimes	**18.2**	**17.7**	18.0	19.8	23.4	15.5	11.0	19.0	17.2
% seldom or never	**38.9**	**47.1**	52.5	62.0	40.6	65.5	66.9	20.0	22.3
Q32 - Do you want to have control and/or input over the hiring and management of your support workers?									
Number of surveys	1,685	n = 7	419	121	134	111	121	627	152
% always or usually	**64.5**	**60.4**	52.5	60.3	61.9	52.3	44.6	77.5	73.7
% sometimes	**22.8**	**24.3**	27.2	25.6	21.6	29.7	26.4	18.0	21.7
% seldom or never	**12.7**	**15.2**	20.3	14.0	16.4	18.0	28.9	4.5	4.6
Q33 - Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?									
Number of surveys	2,244	n = 7	649	176	169	153	183	736	178
% always or usually	**24.6**	**24.0**	11.2	10.2	13.6	9.2	29.0	36.4	58.4
% sometimes	**11.1**	**11.5**	6.8	6.3	11.2	3.3	20.8	13.3	18.5
% seldom/never/don't know	**64.3**	**64.5**	82.0	83.5	75.1	87.6	50.3	50.3	23.0
Q34 - Do you get to decide how this money is spent?									
Number of surveys	1,542	n = 7	343	124	108	86	145	567	169
% always or usually	**38.1**	**35.5**	21.6	33.1	25.9	11.6	49.7	45.7	60.9
% sometimes	**23.2**	**21.9**	15.2	20.2	16.7	9.3	33.8	27.2	30.8
% seldom or never	**38.7**	**42.7**	63.3	46.8	57.4	79.1	16.6	27.2	8.3

Table I - Community Connections: 2005-06 Data

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	HI	SC	SD	TX	WY
Q35 - If you want 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?									
Number of surveys	1,533	n = 7	430	138	114	91	129	492	139
% always or usually	**24.2**	**26.1**	24.2	15.9	26.3	25.3	34.9	19.5	36.7
% sometimes	**25.4**	**26.6**	22.1	17.4	30.7	28.6	32.6	25.8	28.8
% seldom or never	**50.4**	**47.3**	53.7	66.7	43.0	46.2	32.6	54.7	34.5
Q36 - If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?									
Number of surveys	1,571	n = 7	412	140	127	79	146	543	124
% always or usually	**33.6**	**32.7**	31.1	17.1	32.3	20.3	49.3	35.5	43.5
% sometimes	**25.8**	**25.8**	26.7	11.4	33.9	30.4	24.0	26.5	27.4
% seldom or never	**40.5**	**41.5**	42.2	71.4	33.9	49.4	26.7	37.9	29.0
Q37 - Do you feel that your child has access to community activities?									
Number of surveys	2,049	n = 7	548	176	160	130	179	680	176
% always or usually	**33.4**	**35.1**	28.8	17.6	36.9	38.5	44.7	32.9	46.6
% sometimes	**36.1**	**35.9**	36.9	43.2	39.4	27.7	36.3	35.1	33.0
% seldom or never	**30.6**	**28.9**	34.3	39.2	23.8	33.8	19.0	31.9	20.5
Q38 - Does your child participate in community activities?									
Number of surveys	2,142	n = 7	603	189	165	135	180	694	176
% always or usually	**19.0**	**20.1**	16.7	13.8	23.6	16.3	22.8	18.2	29.5
% sometimes	**36.6**	**37.5**	35.5	37.6	42.4	31.1	42.8	35.0	38.1
% seldom or never	**44.4**	**42.4**	47.8	48.7	33.9	52.6	34.4	46.8	32.4
Q39 - Does your child spend time with children who do not have developmental disabilities?									
Number of surveys	2,295	n = 7	665	200	170	160	185	738	177
% always or usually	**48.9**	**50.7**	47.7	50.0	48.8	53.8	53.5	45.9	55.4
% sometimes	**35.1**	**34.0**	38.0	30.0	36.5	33.1	32.4	35.0	33.3
% seldom or never	**16.0**	**15.2**	14.3	20.0	14.7	13.1	14.1	19.1	11.3

Table J - Satisfaction with Services and Outcomes: 2005-06 Data

STATES	TOTAL %	STATE AVG.	CA-RCOC	CT	HI	SC	SD	TX	WY
Q40 - Overall, are you satisfied with the services and supports your child and family currently receive?									
Number of surveys	2,285	n = 7	655	184	173	161	184	753	175
% always or usually	**58.6**	**57.2**	58.2	30.4	49.7	58.4	76.1	62.3	65.1
% sometimes	**32.4**	**32.6**	33.1	42.9	41.0	28.0	21.2	31.5	30.3
% seldom or never	**8.9**	**10.2**	8.7	26.6	9.2	13.7	2.7	6.2	4.6
Q41 - Are your familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?									
Number of surveys	2,184	n = 7	621	178	162	147	169	741	166
% always or usually	**41.5**	**38.3**	39.3	18.5	34.6	34.7	46.2	49.9	45.2
% sometimes	**13.9**	**12.6**	17.1	6.2	14.8	8.8	12.4	14.2	14.5
% seldom/never/don't know	**44.6**	**49.1**	43.6	75.3	50.6	56.5	41.4	35.9	40.4
Q42 - Are you satisfied with the way complaints/grievances are handled and resolved?									
Number of surveys	879	n = 7	246	46	54	41	50	373	69
% always or usually	**53.4**	**51.6**	56.5	32.6	48.1	48.8	70.0	53.1	52.2
% sometimes	**29.6**	**29.6**	28.5	34.8	35.2	22.0	26.0	30.0	30.4
% seldom or never	**17.1**	**18.8**	15.0	32.6	16.7	29.3	4.0	16.9	17.4
Q43 - Do you feel that family supports have made a positive difference in the life of your family?									
Number of surveys	2,124	n = 7	598	146	161	143	184	719	173
% always or usually	**67.1**	**66.5**	58.9	43.2	66.5	62.9	86.4	73.3	74.0
% sometimes	**26.6**	**26.6**	33.1	41.8	26.1	28.0	11.4	22.8	23.1
% seldom or never	**6.2**	**7.0**	8.0	15.1	7.5	9.1	2.2	3.9	2.9
Q44 - Do you feel that family supports have improved your ability to care for your child?									
Number of surveys	2,132	n = 7	601	145	155	146	183	726	176
% always or usually	66	**63.5**	57.4	40.7	65.2	54.8	82.0	74.0	70.5
% sometimes	**25.8**	**26.6**	31.4	37.9	25.8	34.2	14.2	20.8	22.2
% seldom or never	**8.7**	**9.8**	11.1	21.4	9.0	11.0	3.8	5.2	7.4
Q45 - Do you feel that family supports have helped you to keep your child at home?									
Number of surveys	1,957	n = 7	540	129	144	112	173	708	151
% always or usually	**72.8**	**70.3**	65.0	51.2	70.1	59.8	85.0	80.8	80.1
% sometimes	**17.0**	**17.3**	23.0	20.9	20.8	24.1	9.8	13.1	9.3
% seldom or never	**10.2**	**12.4**	12.0	27.9	9.0	16.1	5.2	6.1	10.6
Q46 - Overall, do you feel that your child is happy?									
Number of surveys	2,296	n = 7	650	196	170	166	184	754	176
% always or usually	**82.5**	**82.2**	77.2	77.0	79.4	83.7	88.0	87.5	82.4
% sometimes	**16.2**	**16.2**	21.1	17.3	20.0	14.5	12.0	12.2	16.5
% seldom or never	**1.3**	**1.6**	1.7	5.6	0.6	1.8	0.0	0.3	1.1