

# Child Family Survey

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Final Report – January 2003  
2001-2002 Data



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

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# Organization of Report

Five states conducted the National Core Indicators (NCI) Child Family Survey during the 2001-2002 project year and submitted their data. The Child Family Survey was administered to individuals 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 June 2002.

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 an overall view of the aggregate survey results, and also provides select correlations between family member and respondent characteristics and specific survey questions pertaining to service utilization, delivery, satisfaction and/or outcomes.

## I. Introduction

### Overview of the 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 agreed to conduct a field test of these indicators, including administering the project's consumer and family surveys and compiling other data. Field test data were transmitted to project staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

**1999 - 2000** – Phase II of CIP was launched in 1999, with a deadline for collection of 1999 data set in June 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)** – In the spring and summer of 2001, data from the year 2000 was collected. At this time, it was decided to switch from describing the data sets as “phases” of the project to describing them by year in which the data was collected. Therefore, Phase III was now 2000 Data. 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. Also during this time, the CIP staff and participants continued to develop and refine the indicators, and recruit additional states to participate in the project. Technical reports for Phase II (1999 Data) and 2000 Data, along with other selected documents are available online at [www.hsri.org/cip/core.html](http://www.hsri.org/cip/core.html)

**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.

The figure on the following page summarizes state participation in the National Core Indicators since its inception through the 2001-2002 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.). Project participation has grown each year. In 2002 - 2003, Maine, South Carolina and South Dakota have joined the effort.

Table 1 State Participation in National Core Indicators			
Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002
AZ	AZ	AZ	AL
CT	CT	CT	AZ
MO	KY	DE	CT
NE	MA	IA	DE
PA	MN	KY	HI
VT	NE	MA	IL
VA	NC	MN	IN
	PA	MT	IA
	RI	NE	KY
	VT	NC	MA
	VA	PA	NE
	WA	RI	NC
		UT	OK
		VT	PA
		WA	RI
			UT
			VT
			WA
			WV
			WY
			CA - Orange Co.

Denotes first year of participation in CIP project.

## 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.

Currently, there are two family-related indicators under the **Consumer Outcomes** domain of the Phase II Core Indicators. The two sub-domains are **Supporting Families** and **Family Involvement**. From these sub-domains, three family surveys have been designed: the Adult Family Survey; the Child Family Survey; and the Family/Guardian Survey. Below, greater detail is provided about the development of the Indicators and survey instruments.

## Supporting Families

In Phase I of the project, the CIP Steering Committee established the Supporting Families sub-domain/indicator to provide information about the effectiveness of service systems in supporting families who have an adult family member with a developmental disability living at home with them.

The concern statement for SUPPORTING FAMILIES reads:

*Families who have a family member living at home receive adequate and satisfactory supports.*

The indicator itself reads:

*The proportion of families with an adult family member living in the home who report satisfaction with the following: supports received by the family and the family member, availability and utility of information, choices, planning, linkages to supports, service coordination, and crisis response.*

With respect to this indicator, two stand-alone survey instruments were developed: the Adult Family Survey (developed during Phase I); and the Children Family Survey (later developed for Phase III). Both surveys are designed to be administered by mail, and survey questions were drawn primarily from similar instruments developed and tested previously by HSRI.

## Family Involvement

During Phase II, a new sub-domain – Family Involvement – was added to the core indicators set. Participating states expressed interest in obtaining feedback from family members of individuals who no longer live with the family concerning how well the individual with disabilities is supported, as well as the extent to which their ongoing involvement with the person was supported.

The concern statement for FAMILY INVOLVEMENT reads:

*Families/guardians maintain connections with family members who do not live at home.*

The indicator itself reads:

*The proportion of families/guardians of individuals not living at home who report (a) satisfaction with the services and supports their family member receives; and (b) the extent to which the system supports continuing family involvement.*

With respect to this indicator, a stand-alone Family/Guardian Survey was developed during Phase II. This survey is also designed to be administered by mail, and the questions were drawn from the Adult Family Survey, other similar instruments, and input from the CIP Steering Committee.

## 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** – The results from this survey are explored, in detail, in this report.

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### State Participation

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

<b>Table 2 State Participation in NCI Children Family Survey (Children Living at Home)</b>			
<b>Phase I Field Test</b>	<b>Phase II 1999 Data</b>	<b>Phase III 2000 Data</b>	<b>Phase IV 2001 Data</b>
NA	NA	AZ MN NC UT WA	NE NC UT VT CA - Orange Co.

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### 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 2001-2002 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 ("yes or most of the time", "some of the time", and "no or not at all"). 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 and at least one additional service or support. Children were defined as individuals with disabilities under age 18. A sample size of 1,000 was selected in anticipation that states would obtain at least a 40% return rate, yielding 400 or more usable responses per state. With 400 usable responses per state, the results may be compared across states within a confidence level of  $\pm 10\%$ . In states where there were fewer than 1,000 potential respondent families, surveys were sent to all eligible families.

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

- ◆ The question "Does your 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 18, their responses were dropped.
- ◆ If demographic information was entered into the file, but no survey questions were answered, these responses were also dropped.

## Response Rates

During 2001-2002, 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.

<b>Table 3</b>			
<b>Child Family Survey - State Response Rates</b>			
<b>State</b>	<b>Surveys Mailed</b>	<b>Surveys Returned (%)</b>	<b>Usable Surveys</b>
CA-Orange Co.	4,344	1138 (26%)	976
North Carolina	981	318 (32%)	295
Nebraska	*	*	44
Utah	578	253 (44%)	242
Vermont	575	255 (49%)	253
<b>Overall</b>	<b>6,478</b>	<b>30%</b>	<b>1,810</b>

\* denotes data missing

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. Unless noted, these figures include some number of "undeliverable" surveys (e.g. those returned due to incorrect addresses) or surveys that were returned but were excluded from the database for other reasons (e.g. did not meet the state's inclusion criteria). Response rates ranged from 26% to 49%.

## Data Analysis

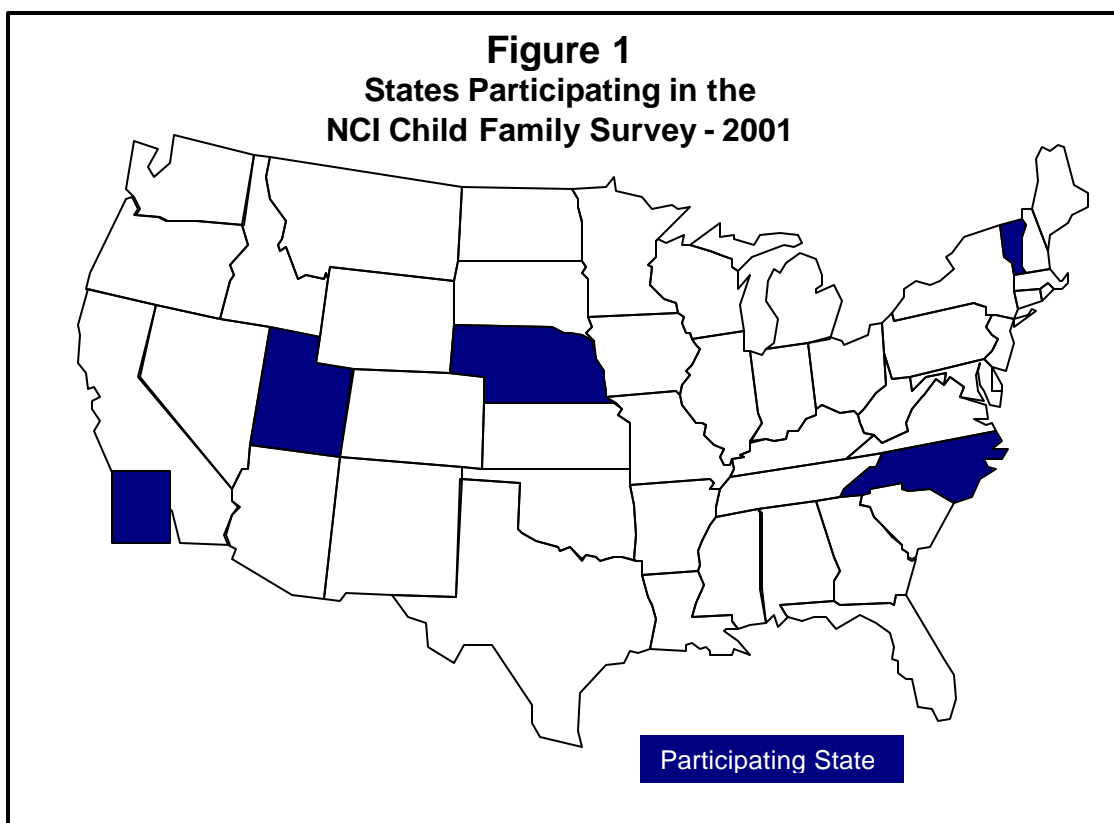
NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. HSRI utilizes SPSS (v. 10) software for statistical analysis and QSR NUD\*IST (v. 6) 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

- ◆ Four states (Nebraska, North Carolina, Utah, Vermont) and one local developmental disabilities authority (Orange County Regional Center in California) provided data for this Report.



## Characteristics of Children with Disabilities

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

### Gender of Family Member

- Overall, 64.4% of family members were male. The remaining 35.6% were female.

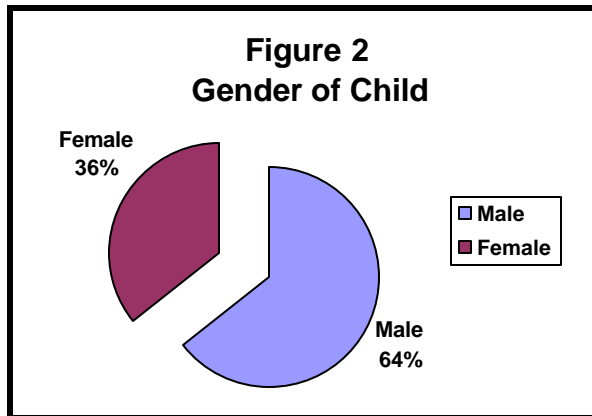


Table 4 Gender		
State	% Male	% Female
CA-Orange Co.	68.2	31.8
NC	67.9	32.1
NE	65.9	34.1
UT	62.7	37.3
VT	57.4	42.6
<b>Total n</b>	<b>1,150</b>	<b>598</b>
<b>Total Avg. %</b>	<b>65.8</b>	<b>34.2</b>
<b>State Avg. %</b>	<b>64.4</b>	<b>35.6</b>

### Age of Family Member

- Overall, the mean (average) age of children with disabilities was 10.3, with a range in age from 0 to 18.

Table 5 Age of Family Member		
State	Average Age	Range
CA-Orange Co.	9.1	0-18
NC	9.3	1-18
NE	11.9	4-18
UT	10.6	2-18
VT	10.6	1-17
<b>Total n</b>	<b>1,717</b>	
<b>Total Avg. %</b>	<b>9.6</b>	<b>0-18</b>
<b>State Avg. %</b>	<b>10.3</b>	

## Race of Family Member

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

- ◆ Overall, 74% of the family members were White, 11% were Hispanic, 7% were Black/African American, 5% were Asian/Pacific Islander, 3% were Mixed Races, 3% were American Indian/Eskimo/Aleut, and 1% marked Other or Unknown.
- ◆ The majority of family members were White/Caucasian in all states, yet Orange County, California had a notably higher percentage of Hispanic (32%) and Asian/Pacific Islander (17%) respondents, and North Carolina had a higher percentage of Black/African American (24%) respondents.

Table 6 Race/Ethnicity of Family Member (%)							
State	White	Black/ African American	Asian/ Pacific Islander	American Indian/ Eskimo/ Aleut	Mixed Races	Other/ Unknown	Hispanic
CA-Orange Co.	51.3	2.7	16.9	2.7	5.5	1.1	32.2
NC	63.7	23.7	1.3	3.0	2.3	0.0	5.2
NE	* Question not asked in Nebraska						
UT	90.6	1.3	2.1	3.8	2.1	0.4	5.9
VT	90.9	2.0	0.0	2.8	1.2	0.8	1.2
<b>Total n</b>	<b>1,104</b>	<b>104</b>	<b>164</b>	<b>50</b>	<b>66</b>	<b>13</b>	<b>330</b>
<b>Total Avg. %</b>	<b>64.7</b>	<b>6.1</b>	<b>9.6</b>	<b>2.9</b>	<b>3.9</b>	<b>0.8</b>	<b>19.3</b>
<b>State Avg. %</b>	<b>74.1</b>	<b>7.4</b>	<b>5.1</b>	<b>3.1</b>	<b>2.8</b>	<b>0.6</b>	<b>11.1</b>

## More Than One Person with Disabilities Living in Household

- ◆ On average, 19% of households include more than one individual with a developmental disability. However, the range varied dramatically from 10% in Orange County, California to 39% in Nebraska.

Table 7 More Than One Person in Household with a Developmental Disability		
State	% Yes	% No
CA-Orange Co.	10.2	89.8
NC	13.2	86.8
NE	38.6	61.4
UT	19.8	80.2
VT	14.7	85.3
<b>Total n</b>	<b>239</b>	<b>1,557</b>
<b>Total Avg. %</b>	<b>13.3</b>	<b>86.7</b>
<b>State Avg. %</b>	<b>19.3</b>	<b>80.7</b>

## Level of Mental Retardation of Family Member

- Overall, nearly three-fourths (74%) of family members required a moderate or complete level of assistance with their activities of daily living (e.g., bathing, dressing, eating). Twenty percent required a small amount of assistance, and 7% require no help in completing these activities.

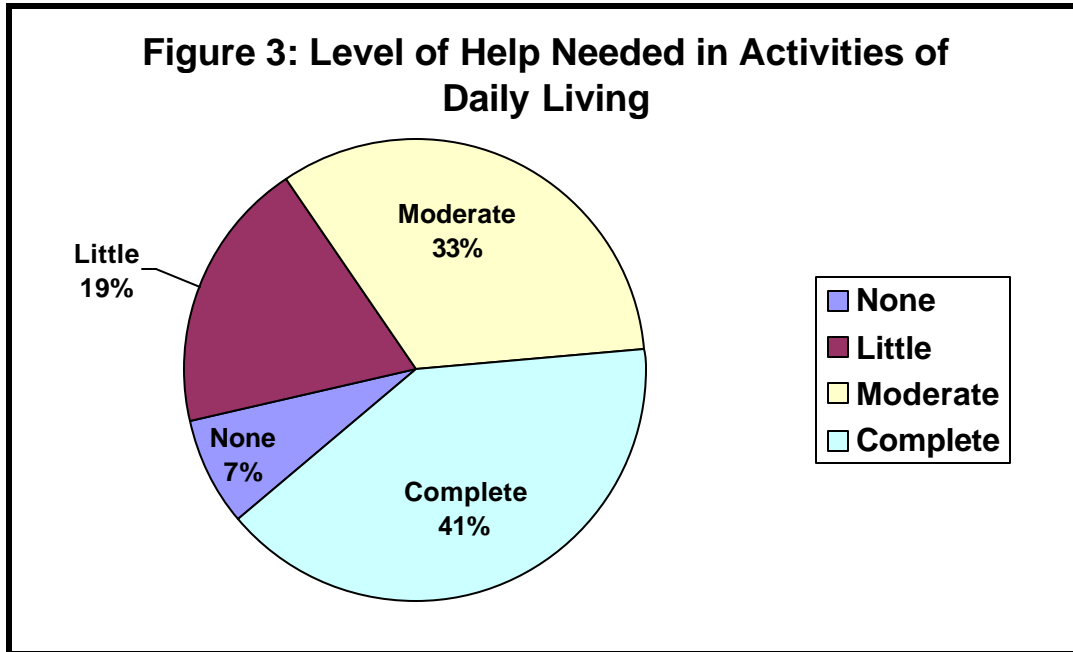


Table 8 Level of Help Needed in Activities of Daily Living				
State	None	Little	Moderate	Complete
CA-Orange Co.	5.4	23.4	35.2	36.1
NC	8.7	14.0	38.8	38.5
NE	9.1	25.0	29.5	36.4
UT	6.2	14.5	29.8	49.6
VT	* Question not asked in Vermont			
<b>Total n</b>	94	304	524	583
<b>Total Avg. %</b>	6.2	20.2	34.8	38.7
<b>State Avg. %</b>	7.4	19.2	33.3	40.2

## Family Member's Disabilities

- ◆ Many family members experience more than one disability, for instance mental retardation and cerebral palsy.
- ◆ The most prevalent disabilities include: mental retardation/developmental disabilities (62%), autism (31%), seizure disorders/neurological problems (29%), communication disorders (24%), physical disabilities (23%), and cerebral palsy (22%).

State	Mental Retardation/ Dev. Disability	Mental Illness	Autism	Cerebral Palsy	Brain Injury	Seizure Disorder
CA-Orange Co.	52.7	3.4	37.3	17.2	6.4	19.6
NC	64.7	3.7	28.3	24.3	9.3	33.7
NE	* Question not asked in Nebraska					
UT	68.2	6.6	26.0	27.3	12.0	36.4
VT	* Not asked	7.5	30.4	19.4	11.1	26.5
<b>Total n</b>	<b>852</b>	<b>78</b>	<b>574</b>	<b>349</b>	<b>145</b>	<b>439</b>
<b>Total Avg. %</b>	<b>57.6</b>	<b>4.5</b>	<b>33.2</b>	<b>20.2</b>	<b>8.4</b>	<b>25.4</b>
<b>State Avg. %</b>	<b>61.9</b>	<b>5.3</b>	<b>30.5</b>	<b>22.1</b>	<b>9.7</b>	<b>29.1</b>

State	Chemical Dependency	Vision/ Hearing Impairment	Physical Disability	Communi- cation Disorder	Other Disability
CA-Orange Co.	0.6	16.8	17.3	24.1	13.8
NC	0.7	21.7	31.7	29.7	26.0
NE	* Question not asked in Nebraska				
UT	0.4	34.3	38.0	37.6	25.3
VT	1.6	23.7	28.1	27.7	41.5
<b>Total n</b>	<b>13</b>	<b>365</b>	<b>420</b>	<b>476</b>	<b>373</b>
<b>Total Avg. %</b>	<b>0.8</b>	<b>21.1</b>	<b>24.3</b>	<b>27.5</b>	<b>21.6</b>
<b>State Avg. %</b>	<b>0.7</b>	<b>19.3</b>	<b>23.0</b>	<b>23.8</b>	<b>21.3</b>

## 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.

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### Age of Respondent

- ◆ Overall, the mean (average) age of respondents was 41.1, with a range in age from 20 to 76.

State	Average Age	Range
CA-Orange Co.	40.3	22-72
NC	39.3	20-70
NE	44.7	24-76
UT	40.4	25-64
VT	41.0	20-61
<b>Total n</b>	1,761	
<b>Total Avg. %</b>	40.3	20-76
<b>State Avg. %</b>	41.1	

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### Relationship of Respondent to Individual with Disabilities

- ◆ The vast majority of respondents were parents of children with disabilities (95%). In Nebraska, a much higher percentage of respondents (9%) were “other relatives”.

State	Parent	Sibling	Grand-parent	Other Relative
CA-Orange Co.	97.8	0.1	1.5	0.5
NC	91.8	0.0	6.5	1.7
NE	86.4	0.0	4.5	9.1
UT	99.2	0.0	0.8	0.0
VT	99.2	0.0	0.8	0.0
<b>Total n</b>	1,743	1	40	14
<b>Total Avg. %</b>	96.9	0.1	2.2	0.8
<b>State Avg. %</b>	94.9	0.0	2.8	2.3

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## Respondent's Role as Primary Caregiver

- ◆ In total, 99% of all respondents considered themselves to be the primary caregiver for their child with disabilities.

<b>Table 12 Respondent is Primary Caregiver</b>		
<b>State</b>	<b>% Yes</b>	<b>% No</b>
CA-Orange Co.	98.1	1.9
NC	98.6	1.4
NE	100.0	0.0
UT	99.2	0.8
VT	99.2	0.8
<b>Total n</b>	<b>1,769</b>	<b>26</b>
<b>Total Avg. %</b>	<b>98.6</b>	<b>1.4</b>
<b>State Avg. %</b>	<b>99.0</b>	<b>1.0</b>

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## Health of Respondent

- ◆ Most respondents (individuals who completed the surveys) indicated that they were in good (51%) or excellent (27%) health, however 22% of respondents categorized their health as being in fair or poor condition.

<b>Table 13 Health of Respondent (%)</b>				
<b>State</b>	<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>
CA-Orange Co.	27.4	55.9	13.3	3.4
NC	27.5	51.9	17.9	2.7
NE	13.6	43.2	43.2	0.0
UT	27.1	54.2	15.8	2.9
VT	39.8	50.6	8.4	1.2
<b>Total n</b>	<b>515</b>	<b>967</b>	<b>259</b>	<b>51</b>
<b>Total Avg. %</b>	<b>28.7</b>	<b>54.0</b>	<b>14.5</b>	<b>2.8</b>
<b>State Avg. %</b>	<b>27.1</b>	<b>51.2</b>	<b>19.7</b>	<b>2.0</b>

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## Household Income

- ◆ On average across states, nearly half (46%) of respondents have a household income of less than \$25,000. This varied quite a bit from state to state. For example, in Utah, 25% of respondents had a household income under \$25,000, but in Nebraska, 76% had a household income at this level.

<b>Table 14 Household Income</b>					
<b>State</b>	<b>Under 15K</b>	<b>16K-25K</b>	<b>26K-40K</b>	<b>41K-75K</b>	<b>Over 75K</b>
CA-Orange Co.	20.7	16.5	16.7	24.1	22.0
NC	31.7	15.8	21.9	16.5	14.0
NE	34.1	41.5	9.8	14.6	0.0
UT	11.6	13.7	29.6	36.5	8.6
VT	* Question not asked in Vermont				
<b>Total n</b>	318	244	287	357	260
<b>Total Avg. %</b>	21.7	16.6	19.6	24.4	17.7
<b>State Avg. %</b>	24.5	21.9	19.5	22.9	11.2

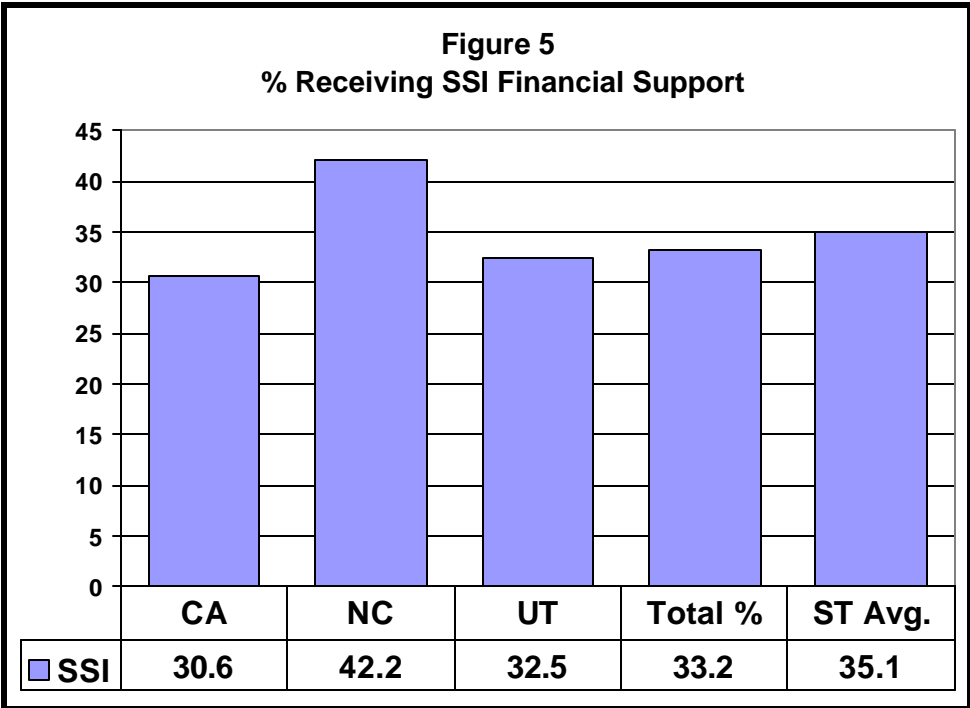
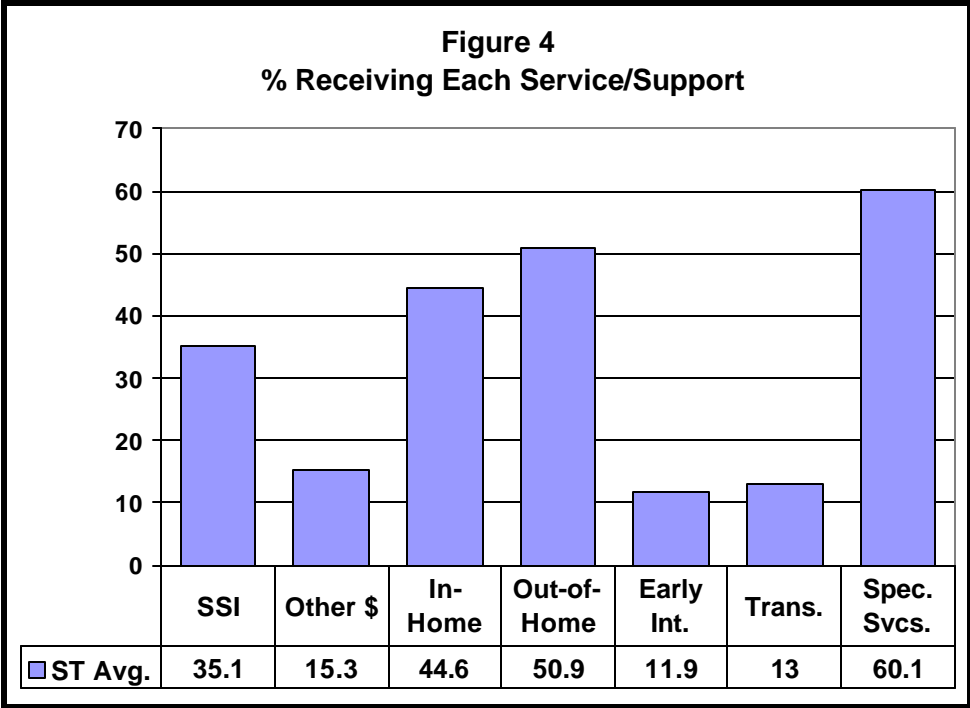
## Services and Supports Received

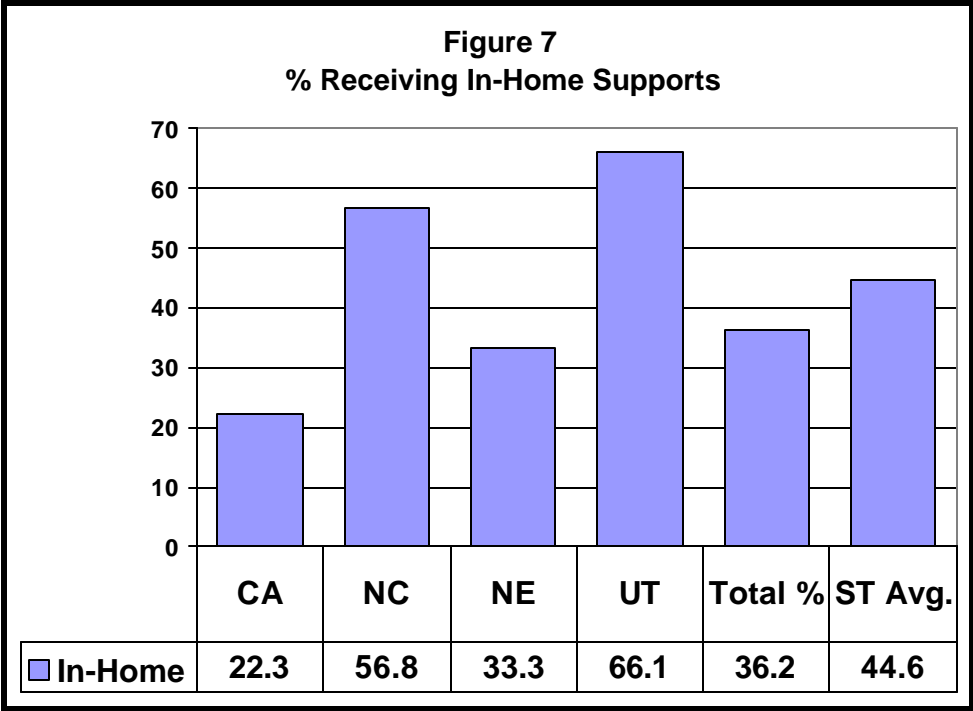
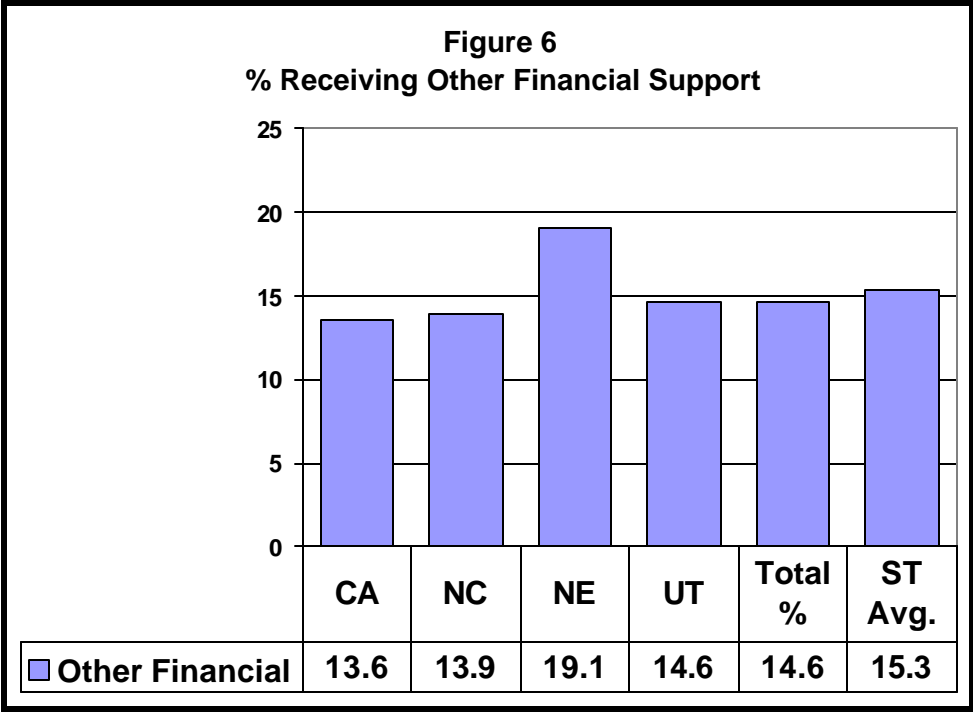
- ◆ Across states, approximately one-third (35%) of families utilized SSI financial supports, 15% received other types of financial support, and 13% used transportation services.
- ◆ In other service areas, however, there was greater variation in results among states. For instance, the percentage of families using in-home supports ranged from 22% in Orange County, California to 66% in Utah.
- ◆ The percentage of families using out-of-home respite ranged from 37% in Orange County and North Carolina to 73% in Nebraska, and the percentage of families receiving specialized services and supports varied from 33% in Orange County to 82% in North Carolina.

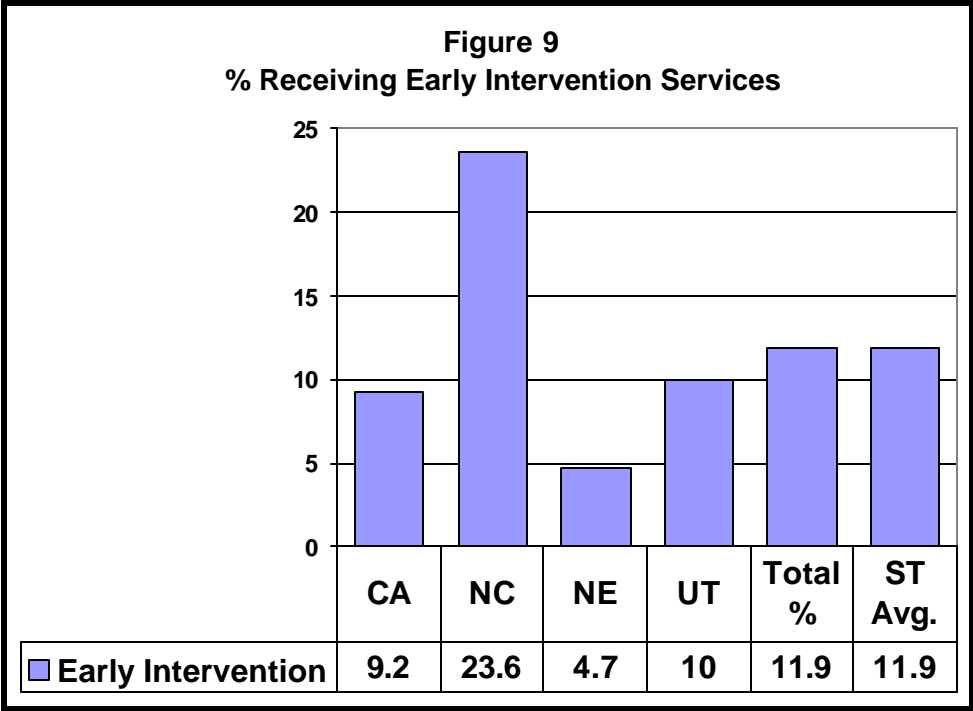
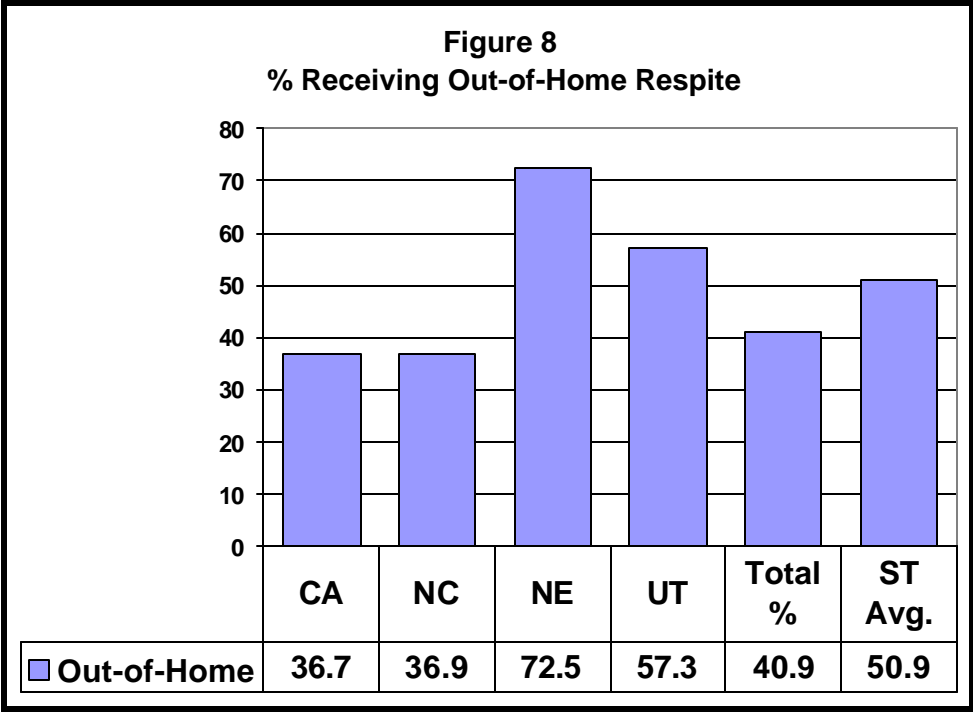
**Table 15**  
**Services and Supports Received (%)**

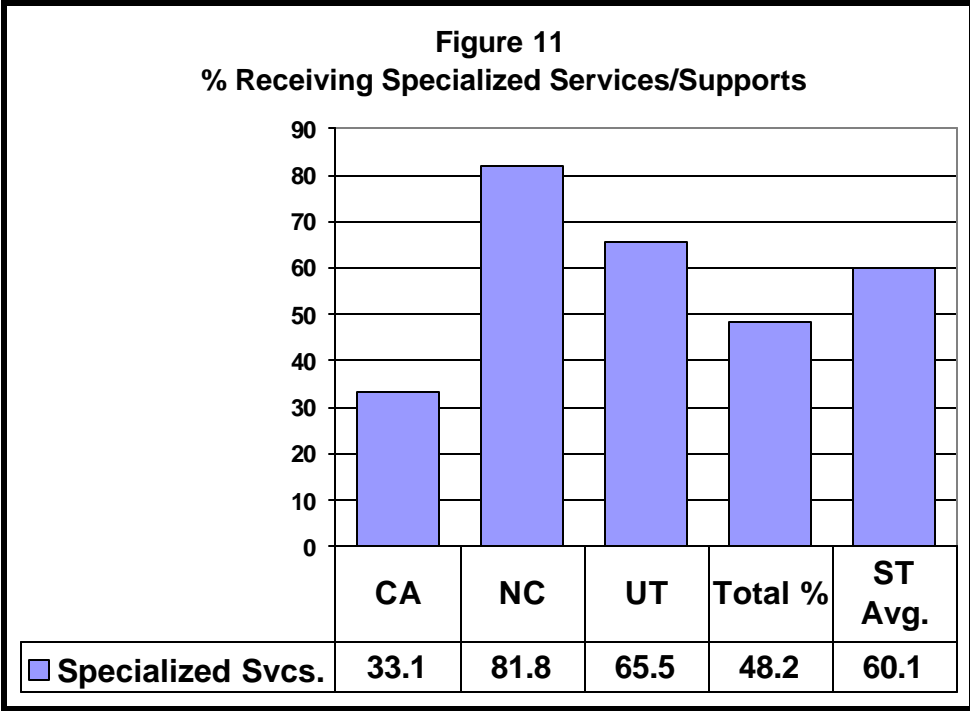
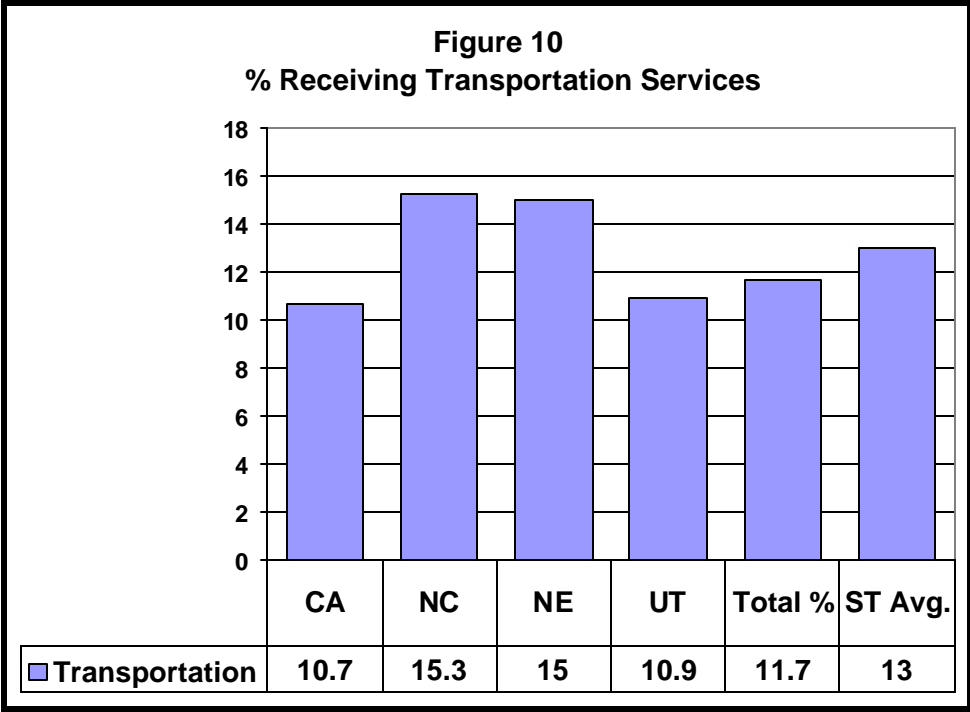
State	SSI Financial Support	Other Financial Support	In-Home Support	Out-of-Home Respite	Early Intervention	Transportation	Specialized Services & Supports
CA-Orange Co.	30.6	13.6	22.3	36.7	9.2	10.7	33.1
NC	42.2	13.9	56.8	36.9	23.6	15.3	81.8
NE	No data	19.1	33.3	72.5	4.7	15.0	No data
UT	32.5	14.6	66.1	57.3	10.0	10.9	65.5
VT	* Questions not asked in Vermont						
<b>Total n</b>	489	207	538	609	168	174	691
<b>Total %</b>	33.2	14.6	36.2	40.9	11.9	11.7	48.2
<b>State Avg. %</b>	* 35.1	15.3	44.6	50.9	11.9	13.0	* 60.1

\* indicates average is calculated across 3 states only



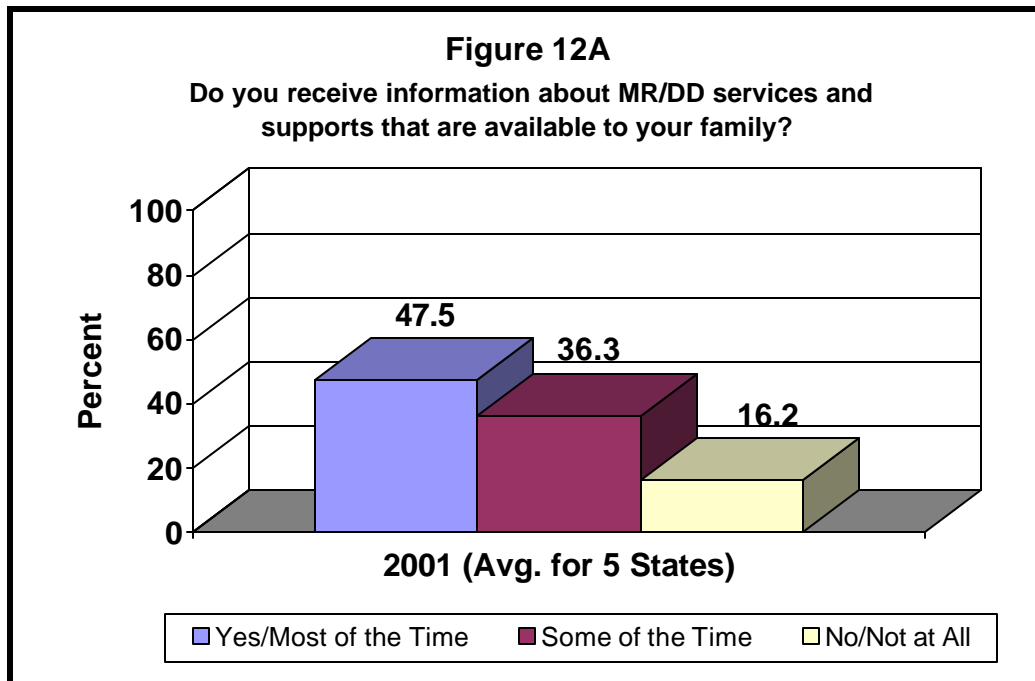






## Information and Planning

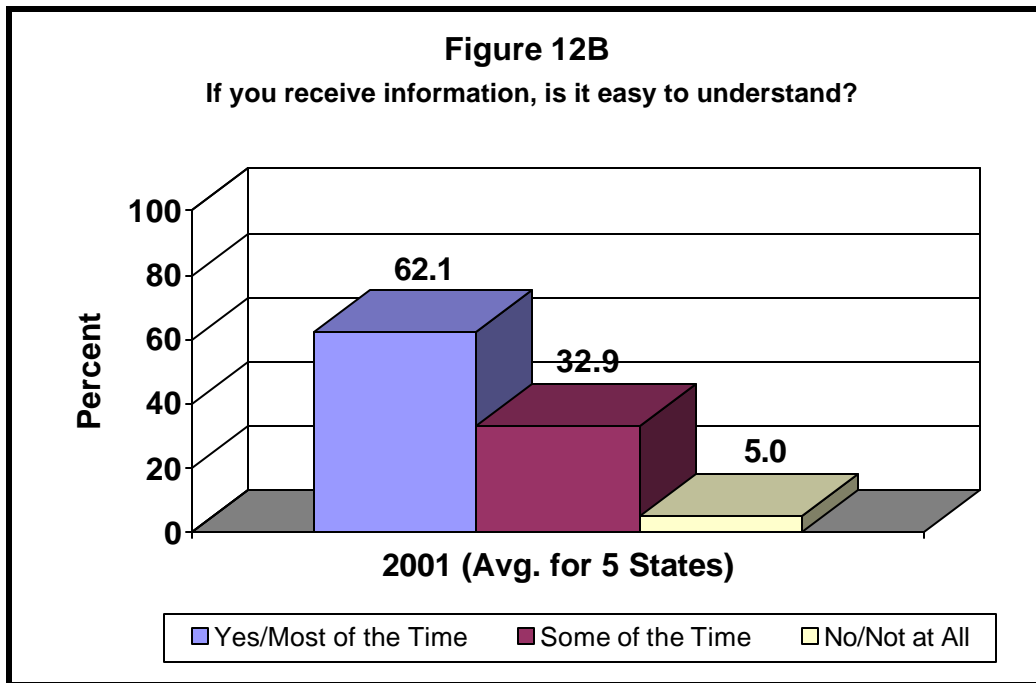
- ♦ On average, across states, fewer than half (47%) of respondents indicated that they receive information about the services and supports available to them. Individual state results varied considerably from 35% in North Carolina and Nebraska to 67% in Orange County, California.



**Table 16A**  
Do you receive information about MR/DD services and supports that are available to your family?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	67.3	26.3	6.4	943
NC	35.1	41.0	24.0	288
NE	35.7	38.1	26.2	42
UT	58.6	36.1	5.3	244
VT	40.7	39.9	19.3	243
<b>Total %</b>	<b>56.4</b>	<b>32.2</b>	<b>11.4</b>	<b>Total n = 1,760</b>
<b>State Avg. %</b>	<b>47.5</b>	<b>36.3</b>	<b>16.2</b>	<b>Total n = 5</b>

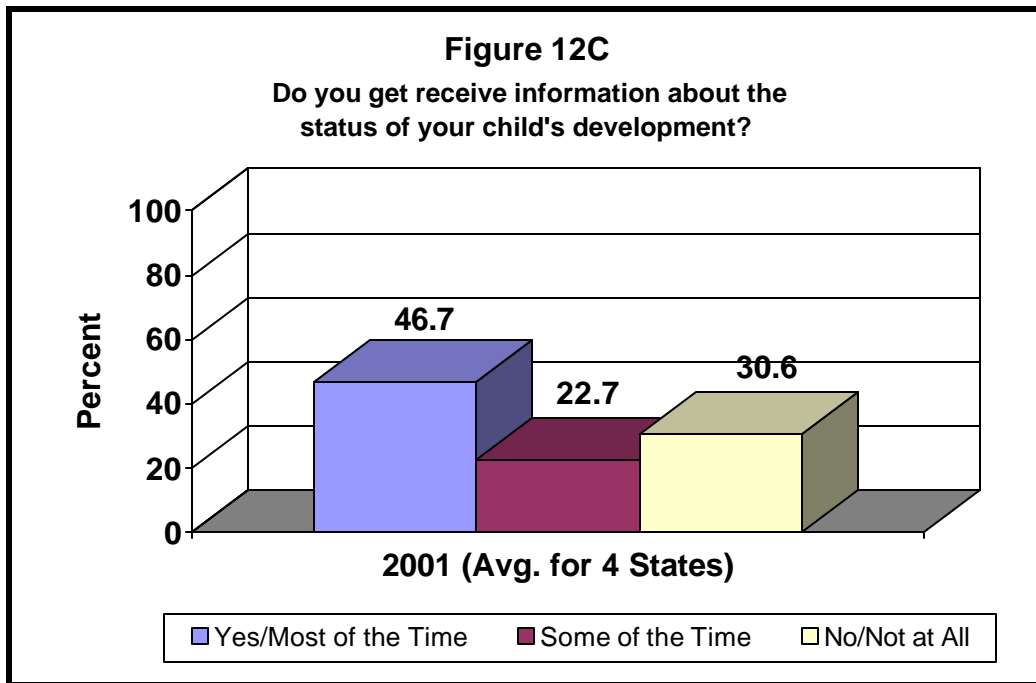
- ◆ Among those who receive information, less than two-thirds (62%) regularly found the information easy to understand.



**Table 16B**  
If you receive information, is it easy to understand?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	72.5	23.1	4.4	906
NC	52.1	40.7	7.2	236
NE	59.4	34.4	6.3	32
UT	69.7	28.2	2.1	234
VT	56.9	37.9	5.2	211
<b>Total %</b>	<b>66.8</b>	<b>28.5</b>	<b>4.6</b>	<b>Total n = 1,619</b>
<b>State Avg. %</b>	<b>62.1</b>	<b>32.9</b>	<b>5.0</b>	<b>Total n = 5</b>

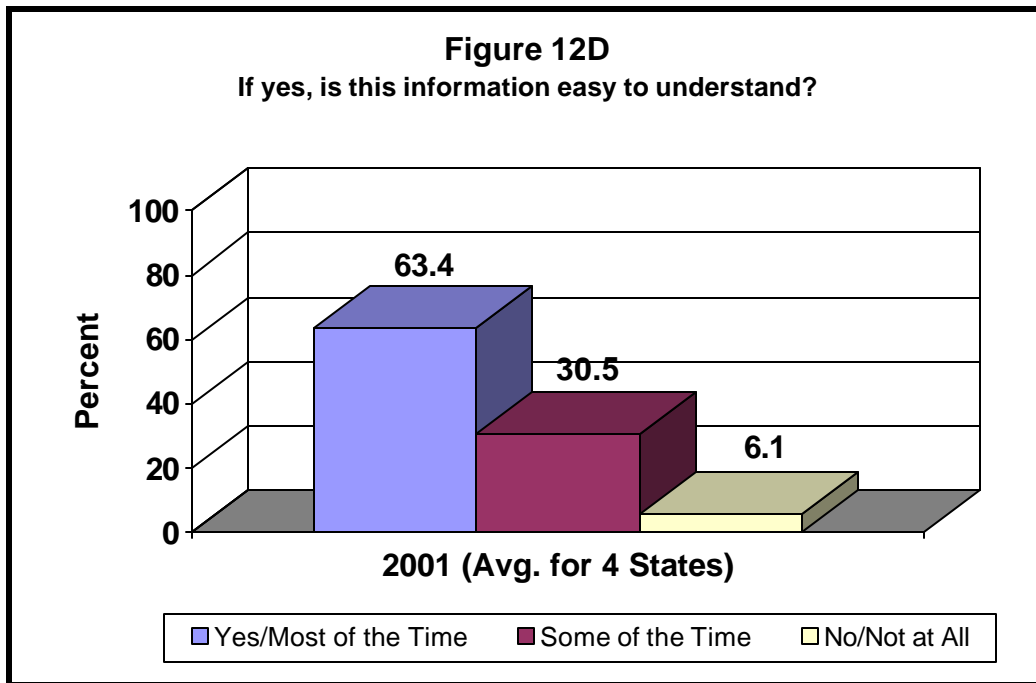
- ◆ Fewer than half (47%) of respondents stated that they receive information about the status of their child's development. Results here varied greatly, from a low of 20% in Utah to 67% in Nebraska.



**Table 16C**  
Do you receive information about the status of your child's development?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	40.4	25.4	34.2	862
NC	58.9	23.2	17.9	285
NE	67.5	20.0	12.5	40
UT	20.0	22.2	57.8	225
VT	* Vermont did not ask this question			
<b>Total %</b>	<b>41.6</b>	<b>24.3</b>	<b>34.1</b>	<b>Total n = 1,412</b>
<b>State Avg. %</b>	<b>46.7</b>	<b>22.7</b>	<b>30.6</b>	<b>Total n = 4</b>

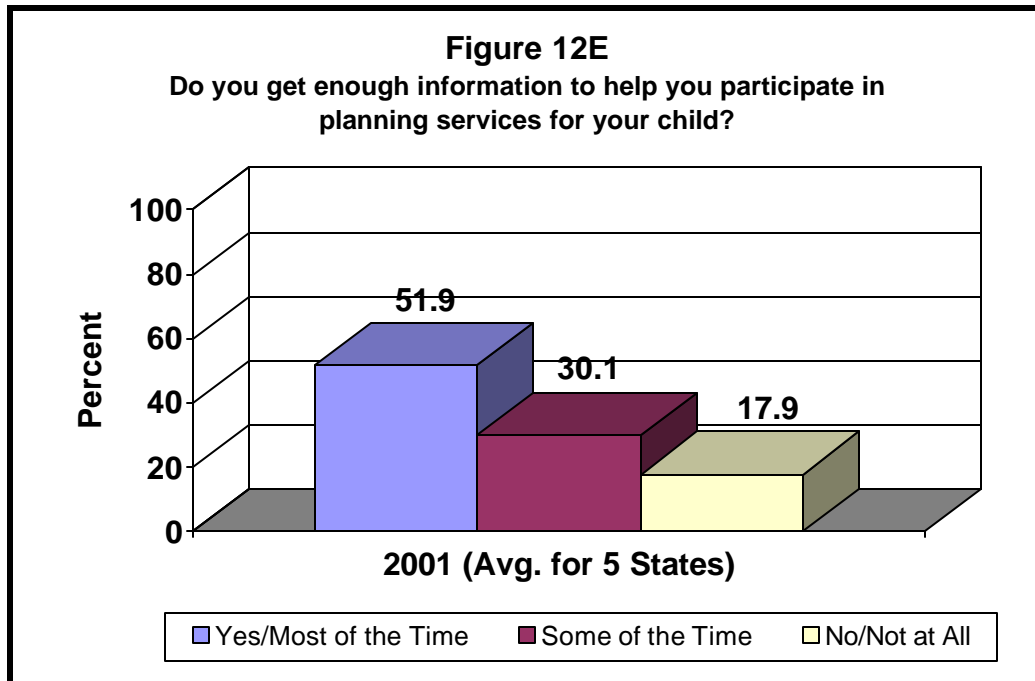
- ◆ On average, 63% of those who received information about their child's development found the information easy to understand.



**Table 16D**  
If yes, is this information easy to understand?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	70.3	22.2	7.5	589
NC	70.1	25.7	4.1	241
NE	61.8	35.3	2.9	34
UT	51.5	38.8	9.7	967
VT	* Vermont did not ask this question			
<b>Total %</b>	<b>67.9</b>	<b>25.3</b>	<b>6.7</b>	<b>Total n = 967</b>
<b>State Avg. %</b>	<b>63.4</b>	<b>30.5</b>	<b>6.1</b>	<b>Total n = 4</b>

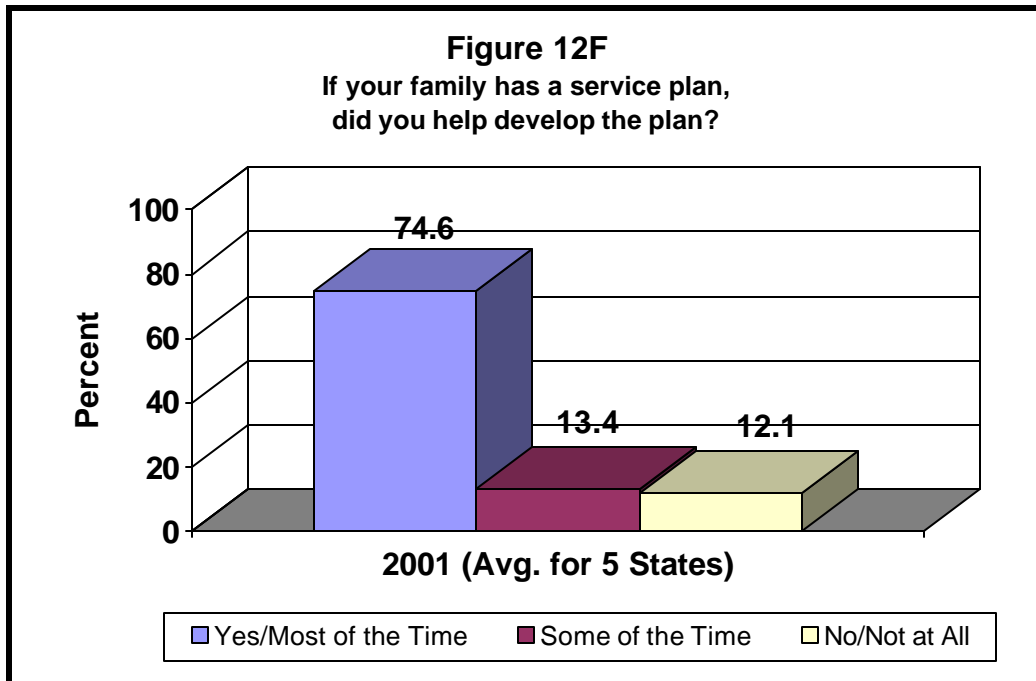
- ◆ Overall, only about half (52%) of respondents felt that got enough information to help them plan services for their child. These result varied from 41% in Vermont to 65% in Nebraska (however, please note that Nebraska had a very low number of respondents).



**Table 16E**  
Do you get enough information to help you participate in planning services for your child?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	43.9	31.1	25.0	900
NC	56.9	28.6	14.5	283
NE	65.5	13.8	20.7	29
UT	52.4	39.4	8.2	231
VT	41.0	37.7	21.3	239
<b>Total %</b>	<b>47.2</b>	<b>32.5</b>	<b>20.3</b>	<b>Total n = 1,682</b>
<b>State Avg. %</b>	<b>51.9</b>	<b>30.1</b>	<b>17.9</b>	<b>Total n = 5</b>

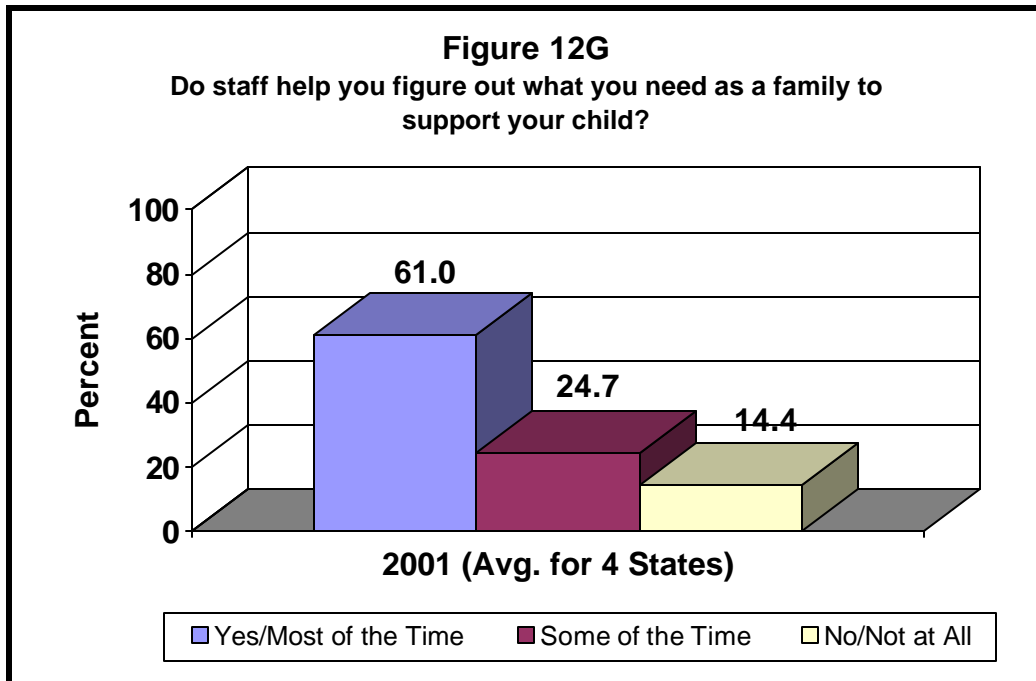
- ◆ Three-fourths (75%) of respondents, across states participated in the development of their family’s service and support plan. On the other hand, overall, 12% said they had no participation in the development of their family’s plan.



**Table 16F**  
If your family has a service plan, did you help develop the plan?

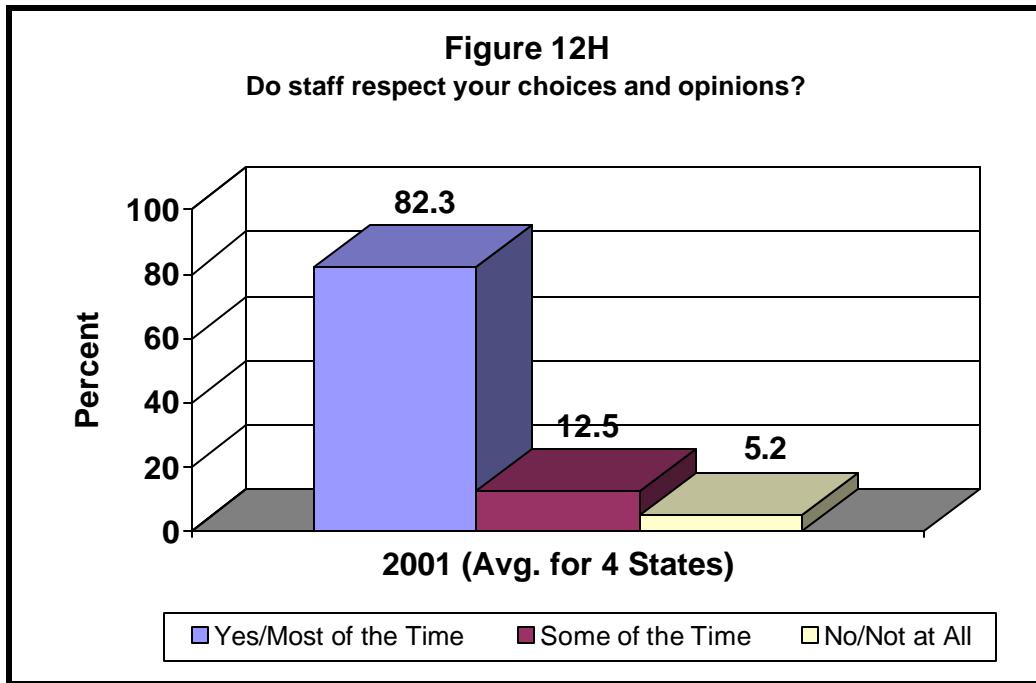
State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	65.3	16.9	17.8	763
NC	78.3	12.5	9.1	263
NE	70.4	7.4	22.2	27
UT	83.8	14.4	1.8	222
VT	75.0	15.6	9.4	180
<b>Total %</b>	<b>71.8</b>	<b>15.4</b>	<b>12.9</b>	<b>Total n = 1,455</b>
<b>State Avg. %</b>	<b>74.6</b>	<b>13.4</b>	<b>12.1</b>	<b>Total n = 5</b>

- ◆ Once again, results varied greatly by state, but overall, only 61% of respondents felt that staff regularly helped them figure out what supports were needed as a family to better support their child.



<b>Table16G</b>				
Do staff help you figure out what you need as a family to support your child?				
State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	42.8	30.6	26.6	914
NC	61.8	27.0	11.2	267
NE	73.7	15.8	10.5	38
UT	65.6	25.3	9.1	241
VT	* Vermont did not ask this question			
<b>Total %</b>	<b>55.2</b>	<b>28.7</b>	<b>20.5</b>	<b>Total n =1,460</b>
<b>State Avg. %</b>	<b>61.0</b>	<b>24.7</b>	<b>14.4</b>	<b>Total n = 4</b>

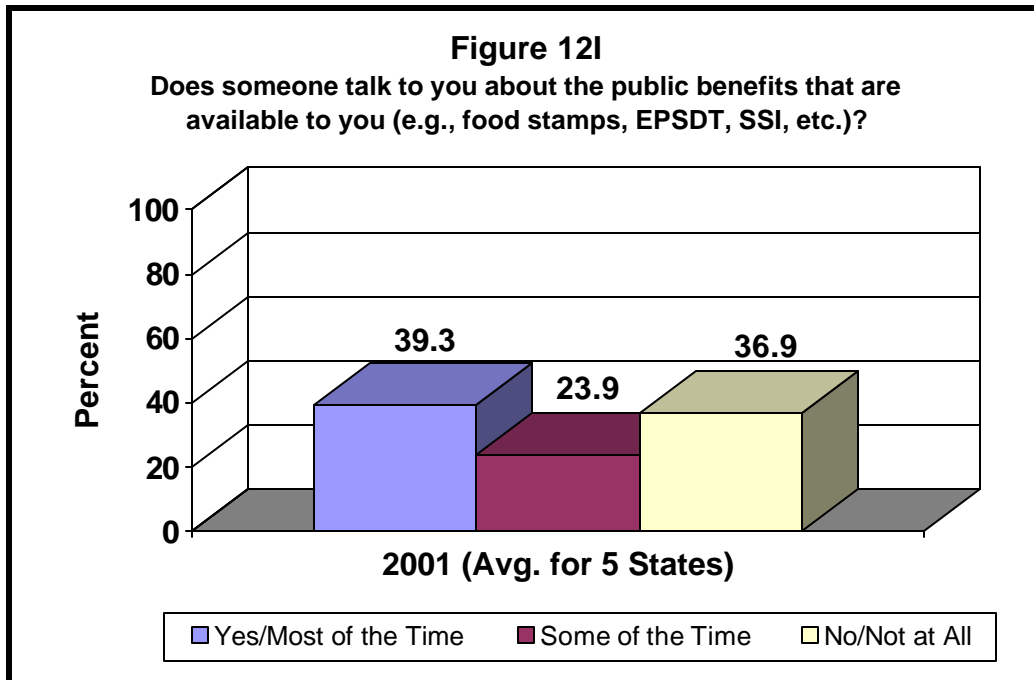
- ◆ On average, most respondents (82%) felt that staff respected their opinions and choices. This was consistent across the states.



**Table 16H**  
Do staff respect your choices and opinions?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	73.6	20.7	5.7	876
NC	83.2	10.7	6.1	262
NE	87.8	4.9	7.3	41
UT	84.7	13.6	1.7	235
VT	* Vermont did not ask this question			243
<b>Total %</b>	<b>77.7</b>	<b>17.2</b>	<b>5.2</b>	<b>Total n = 1,414</b>
<b>State Avg. %</b>	<b>82.3</b>	<b>12.5</b>	<b>5.2</b>	<b>Total n = 4</b>

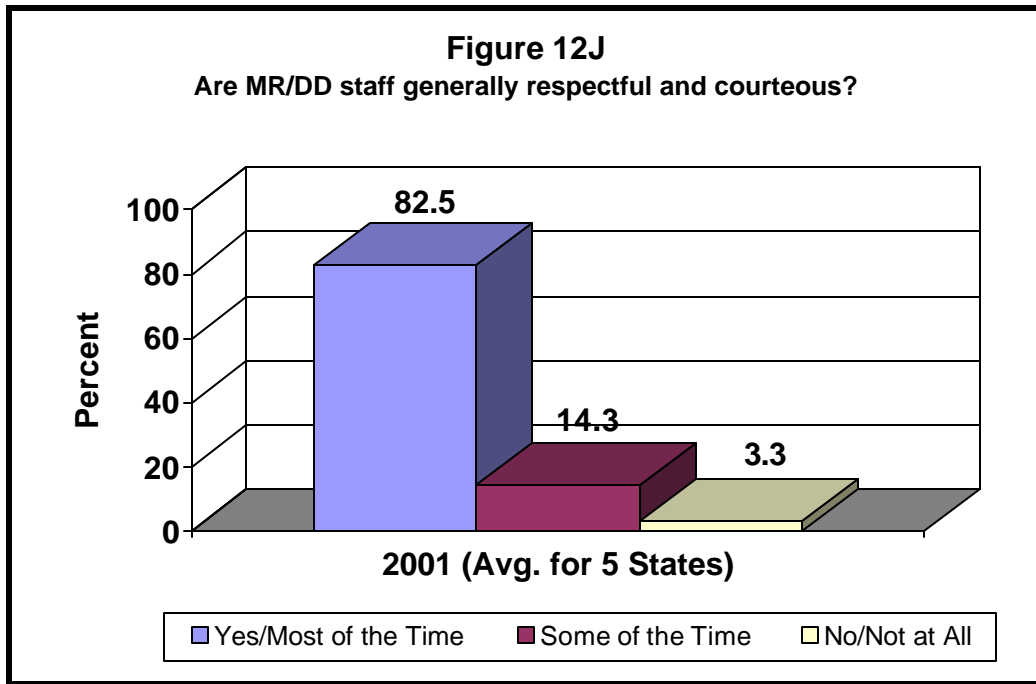
- ◆ There is a fairly even split between respondents who felt they received information about the public benefits available to them (39%) and those who did not (37%). The remaining 24% felt they received information about public benefits “some of the time”. These results were consistent across the states.



**Table 16I**  
Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	35.2	21.6	43.2	880
NC	36.5	18.6	44.9	263
NE	50.0	20.0	30.0	40
UT	36.2	31.5	32.3	232
VT	38.4	27.6	34.1	232
<b>Total %</b>	<b>36.4</b>	<b>23.3</b>	<b>40.3</b>	<b>Total n = 1,647</b>
<b>State Avg. %</b>	<b>39.3</b>	<b>23.9</b>	<b>36.9</b>	<b>Total n = 5</b>

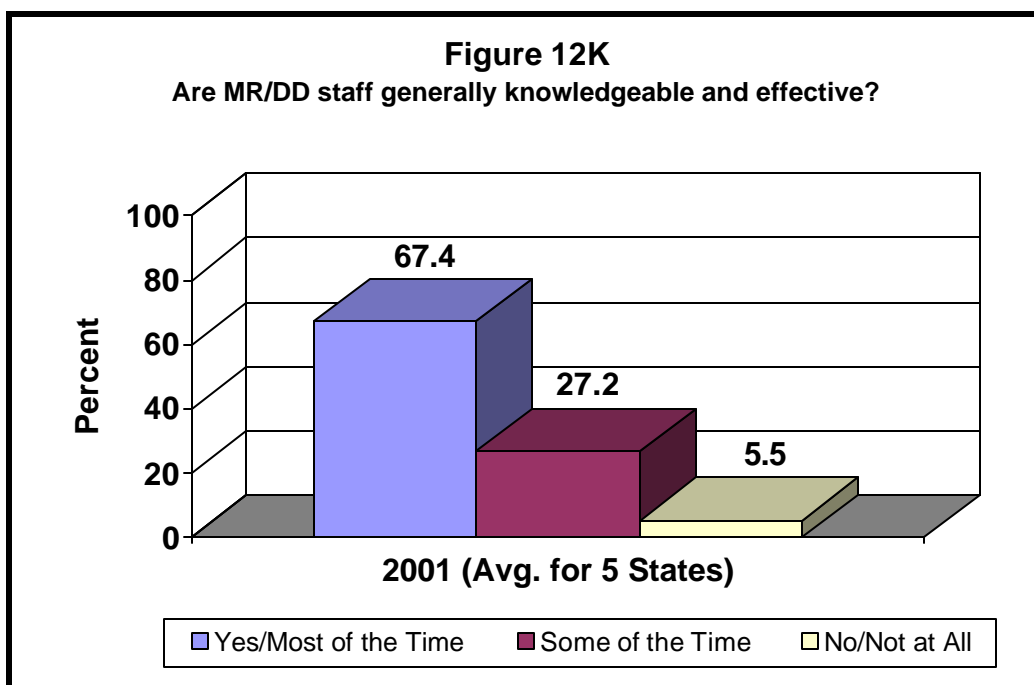
- ◆ Overall, nearly all respondents felt that agency staff were generally respectful and courteous.



**Table 16J**  
Are MR/DD staff generally respectful and courteous?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	85.4	12.4	2.2	947
NC	84.2	13.2	2.6	272
NE	65.8	26.3	7.9	38
UT	93.1	4.5	2.4	245
VT	83.8	14.9	1.3	228
<b>Total %</b>	<b>85.7</b>	<b>12.0</b>	<b>2.3</b>	<b>Total n = 1,730</b>
<b>State Avg. %</b>	<b>82.5</b>	<b>14.3</b>	<b>3.3</b>	<b>Total n = 5</b>

Overall, while 83% of respondents felt that agency staff were courteous and respectful, a smaller percentage(67%) felt that agency staff were generally knowledgeable and effective.

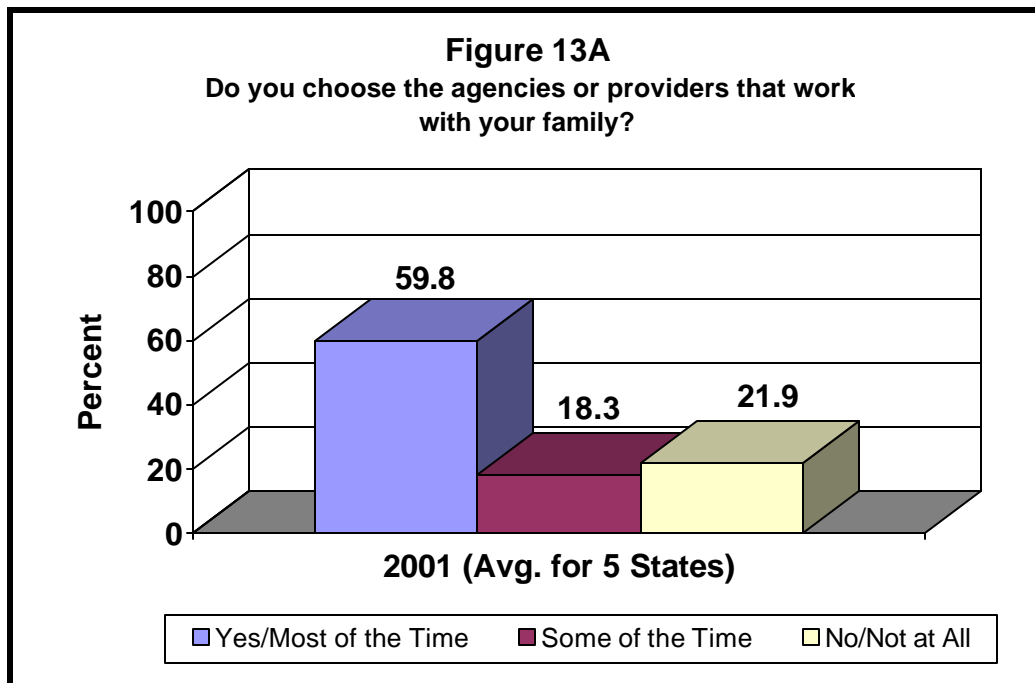


**Table 16K**  
Are MR/DD staff generally knowledgeable and effective?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	60.5	32.0	7.5	932
NC	63.6	29.4	7.1	269
NE	81.0	14.3	4.8	42
UT	74.8	23.1	2.1	242
VT	57.0	37.2	5.8	223
<b>Total %</b>	<b>63.1</b>	<b>30.6</b>	<b>6.4</b>	<b>Total n = 1,708</b>
<b>State Avg. %</b>	<b>67.4</b>	<b>27.2</b>	<b>5.5</b>	<b>Total n = 5</b>

## Choice and Control

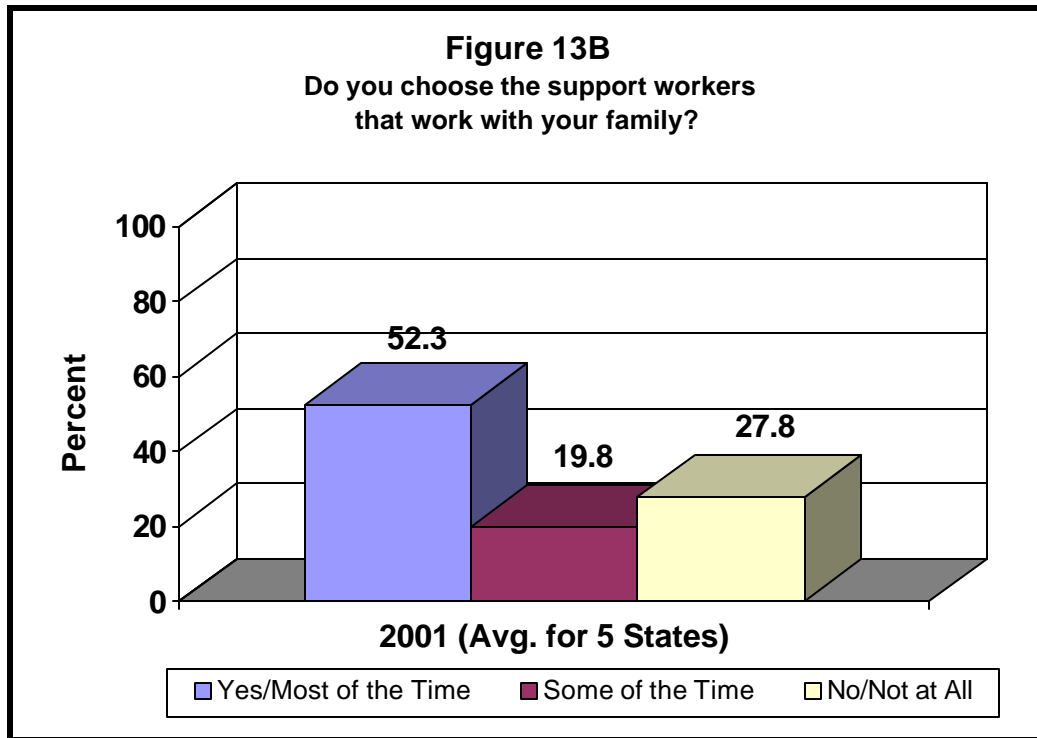
- Overall, three out of five respondents (60%) regularly chose the agencies or providers who work with their families. In North Carolina and Utah, higher percentages of families (72% and 84% respectively) made these choices.



**Table 17A**  
Do you choose the agencies or providers that work with your family?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	41.6	23.6	34.8	779
NC	71.9	14.6	13.5	274
NE	48.7	17.9	33.3	39
UT	83.7	12.6	3.8	239
VT	53.2	22.9	23.9	218
<b>Total %</b>	<b>55.3</b>	<b>20.1</b>	<b>24.7</b>	<b>Total n = 1,549</b>
<b>State Avg. %</b>	<b>59.8</b>	<b>18.3</b>	<b>21.9</b>	<b>Total n = 5</b>

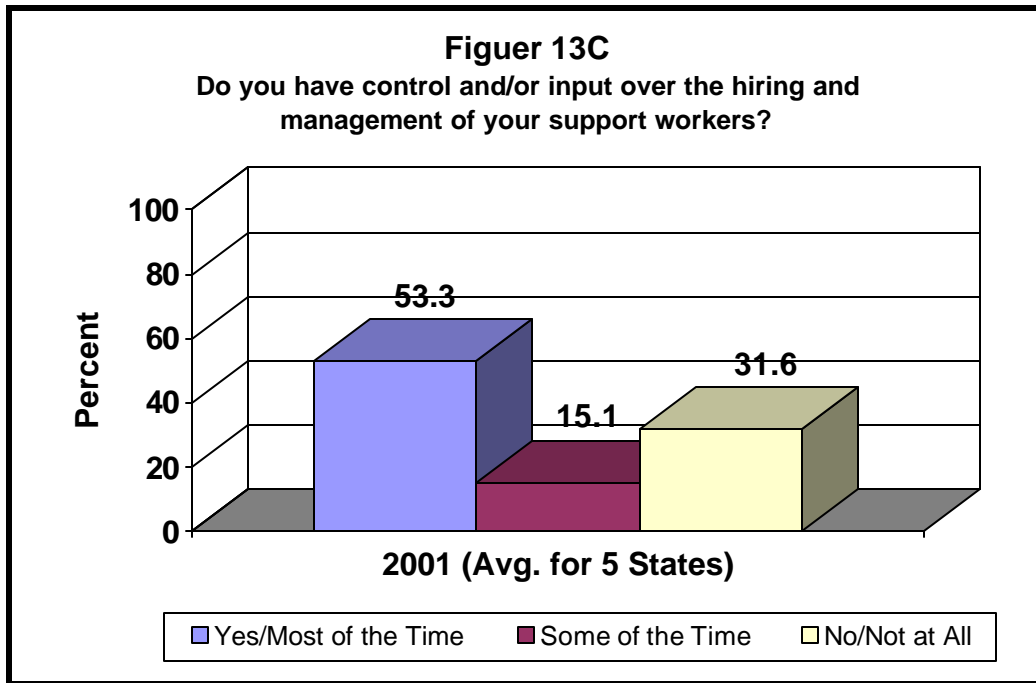
- ◆ Overall, slightly over half (52%) of respondents chose the support staff who work with their family, and another 20% chose support staff at least some of the time. The remaining 28% of respondents, however, did not choose their support workers. Results varied quite a bit from state to state, with only 16% choosing support workers in Nebraska, and over 70% making these choices in Utah and Vermont.



**Table 17B**  
Do you choose the support workers that work with your family?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	31.4	21.3	47.3	736
NC	66.9	13.7	19.4	263
NE	15.8	31.6	52.6	38
UT	73.5	15.5	11.1	226
VT	73.9	17.1	8.6	222
<b>Total %</b>	<b>50.0</b>	<b>18.7</b>	<b>31.2</b>	<b>Total n = 1,485</b>
<b>State Avg. %</b>	<b>52.3</b>	<b>19.8</b>	<b>27.8</b>	<b>Total n = 5</b>

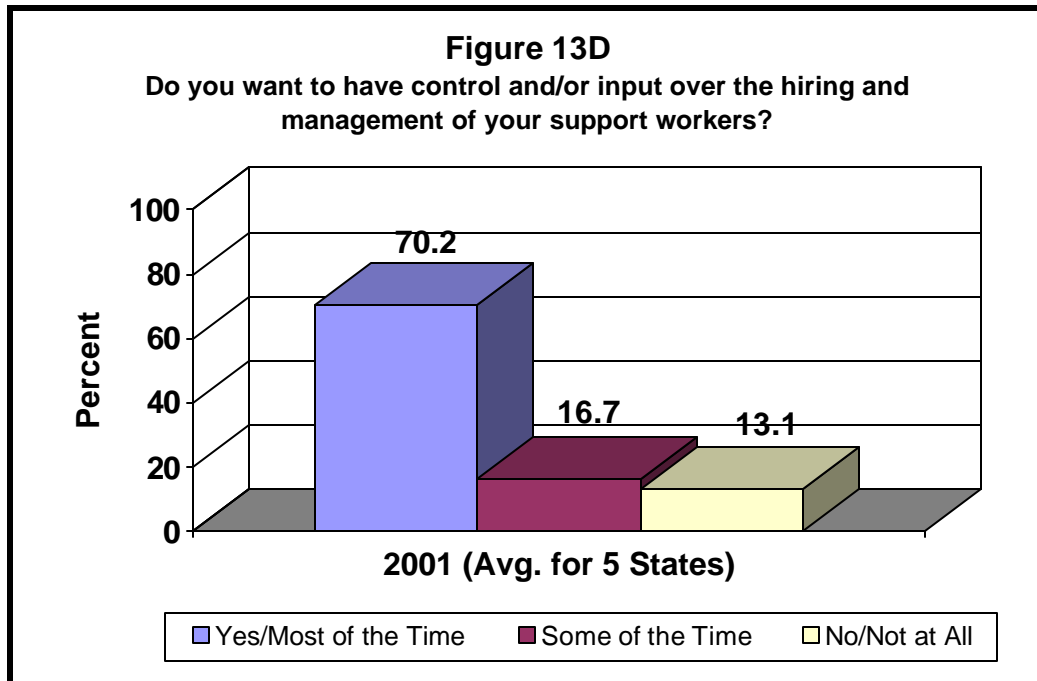
- ◆ Similar to the responses regarding choice of support workers, slightly over half (53%) of respondents had had control or input over the hiring and management of their support staff. Also, similar to the question above, results varied dramatically across states, with far higher percentages of families in North Carolina, Utah and Vermont feeling they had more control and input regarding decisions about their families' support staff.



**Table 17C**  
Do you have control and/or input over the hiring and management of your support workers?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	32.8	15.9	51.3	616
NC	58.2	10.4	31.3	249
NE	25.0	18.8	56.3	32
UT	75.5	11.8	12.7	220
VT	75.0	18.4	6.6	212
<b>Total %</b>	<b>51.2</b>	<b>14.7</b>	<b>34.2</b>	<b>Total n = 1,329</b>
<b>State Avg. %</b>	<b>53.3</b>	<b>15.1</b>	<b>31.6</b>	<b>Total n = 5</b>

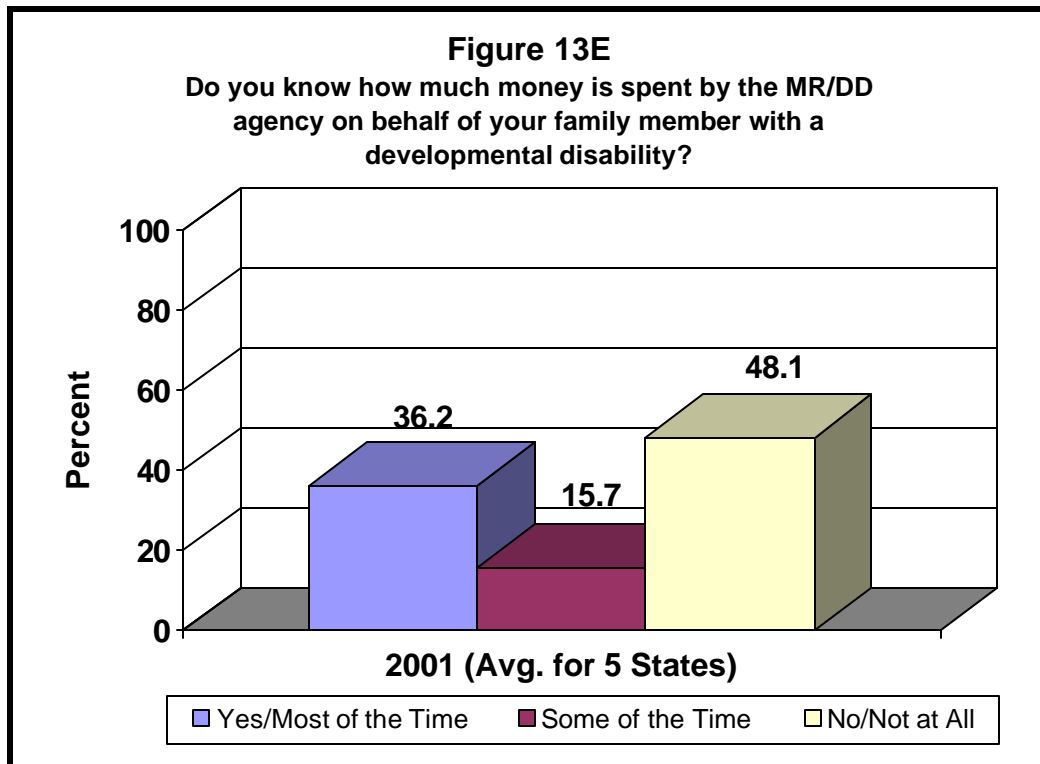
- ◆ While only 68% had any amount of control over the hiring or management of their support workers, over 87% wanted this type of control.



**Table 17D**  
Do you want to have control and/or input over the hiring and management of your support workers?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	65.5	17.4	17.1	632
NC	74.5	10.0	15.5	239
NE	46.9	31.3	21.9	32
UT	81.8	11.8	6.4	203
VT	82.1	13.0	4.8	207
<b>Total %</b>	<b>71.8</b>	<b>14.9</b>	<b>13.3</b>	<b>Total n = 1,313</b>
<b>State Avg. %</b>	<b>70.2</b>	<b>16.7</b>	<b>13.1</b>	<b>Total n = 5</b>

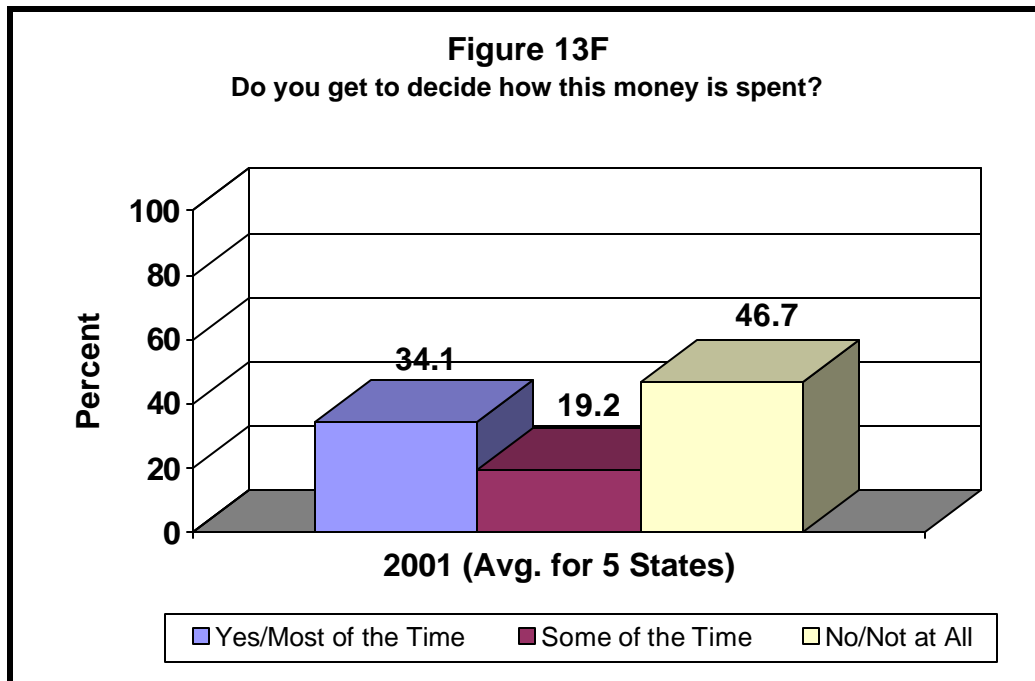
- ♦ Slightly more than one-third of respondents (36%) knew how much money was spent on behalf of their family member. Almost half (48%), however, had no idea. In Utah, a greater percentage of families were familiar with the amount of money spent.



**Table 17E**  
Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	19.4	6.0	74.6	587
NC	31.0	19.7	49.4	239
NE	22.6	9.7	67.7	31
UT	68.2	17.0	14.8	223
VT	39.7	26.3	34.0	209
<b>Total %</b>	<b>33.4</b>	<b>13.8</b>	<b>52.8</b>	<b>Total n = 1,289</b>
<b>State Avg. %</b>	<b>36.2</b>	<b>15.7</b>	<b>48.1</b>	<b>Total n = 5</b>

- ◆ About the same percentages of respondents who knew how much money was spent on their family member's behalf, indicated that they decided how this money was spent.

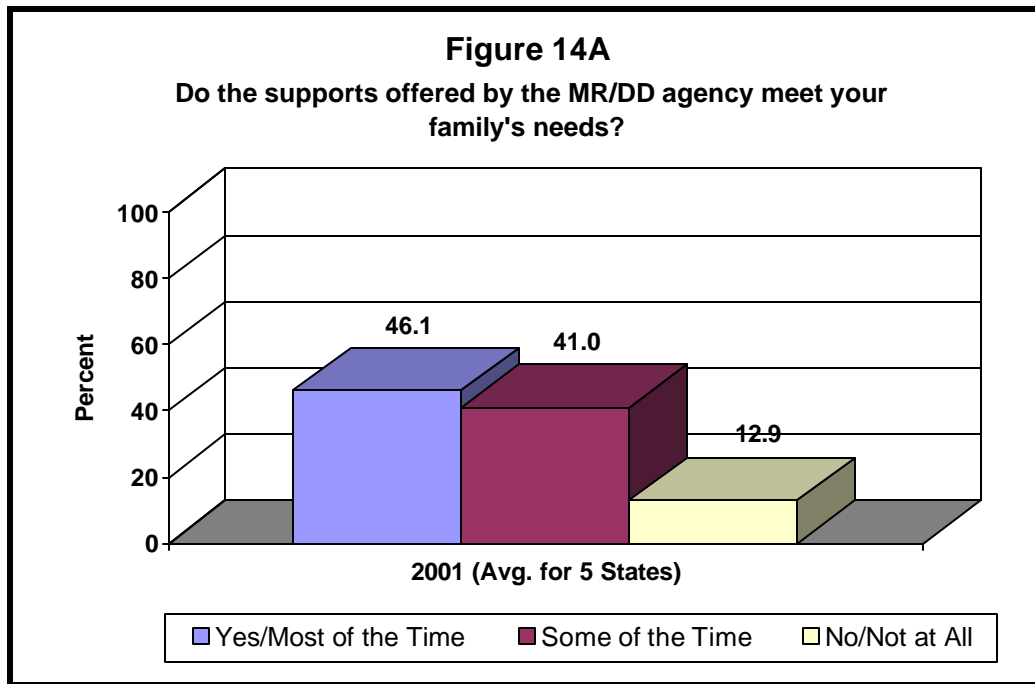


**Table 17F**  
**Do you get to decide how this money is spent?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	22.8	8.6	68.5	613
NC	27.8	23.8	48.4	248
NE	12.1	6.1	81.8	33
UT	64.7	25.9	9.5	232
VT	43.1	31.8	25.1	211
<b>Total %</b>	<b>34.0</b>	<b>18.0</b>	<b>48.0</b>	<b>Total n = 1,337</b>
<b>State Avg. %</b>	<b>34.1</b>	<b>19.2</b>	<b>46.7</b>	<b>Total n = 5</b>

## Access to and Delivery of Services and Supports

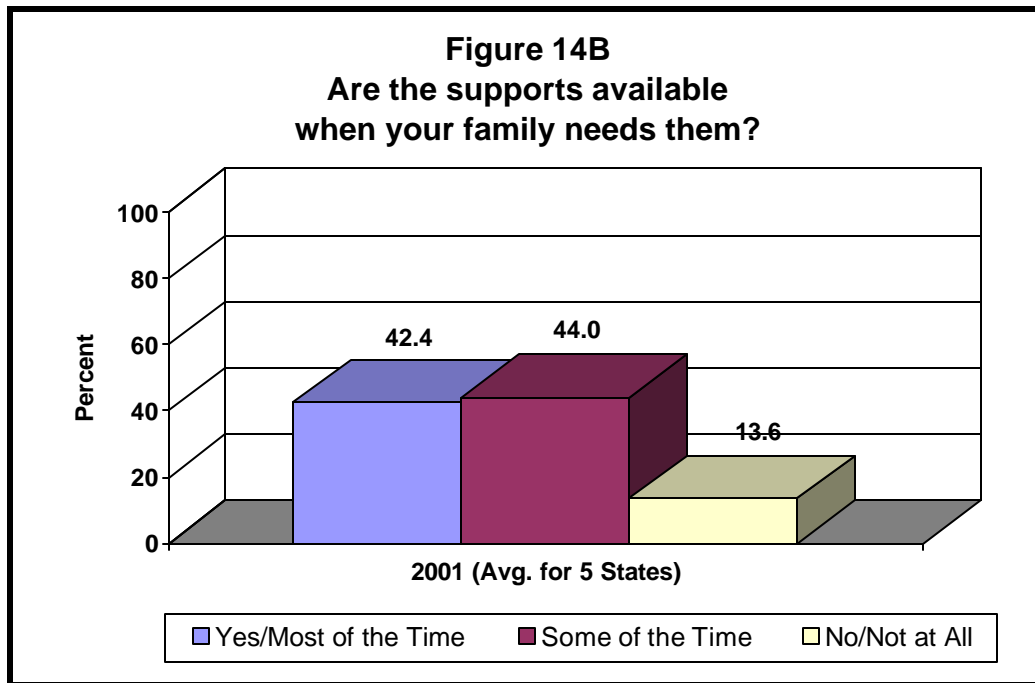
- ◆ Fewer than half of respondents (46%) indicated that the supports offered by the MR/DD agency met their needs. Forty-one percent indicated that the supports offered sometimes met their family's needs, and 12% stated that the supports offered did not meet their needs.



**Table 18A**  
Do the supports offered by the MR/DD agency meet your family's needs?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	40.7	39.8	19.4	896
NC	50.0	38.9	11.1	280
NE	41.7	41.7	16.7	36
UT	56.6	39.3	4.1	242
VT	41.4	45.2	13.4	239
<b>Total %</b>	<b>44.7</b>	<b>40.4</b>	<b>14.9</b>	<b>Total n = 1,693</b>
<b>State Avg. %</b>	<b>46.1</b>	<b>41.0</b>	<b>12.9</b>	<b>Total n = 5</b>

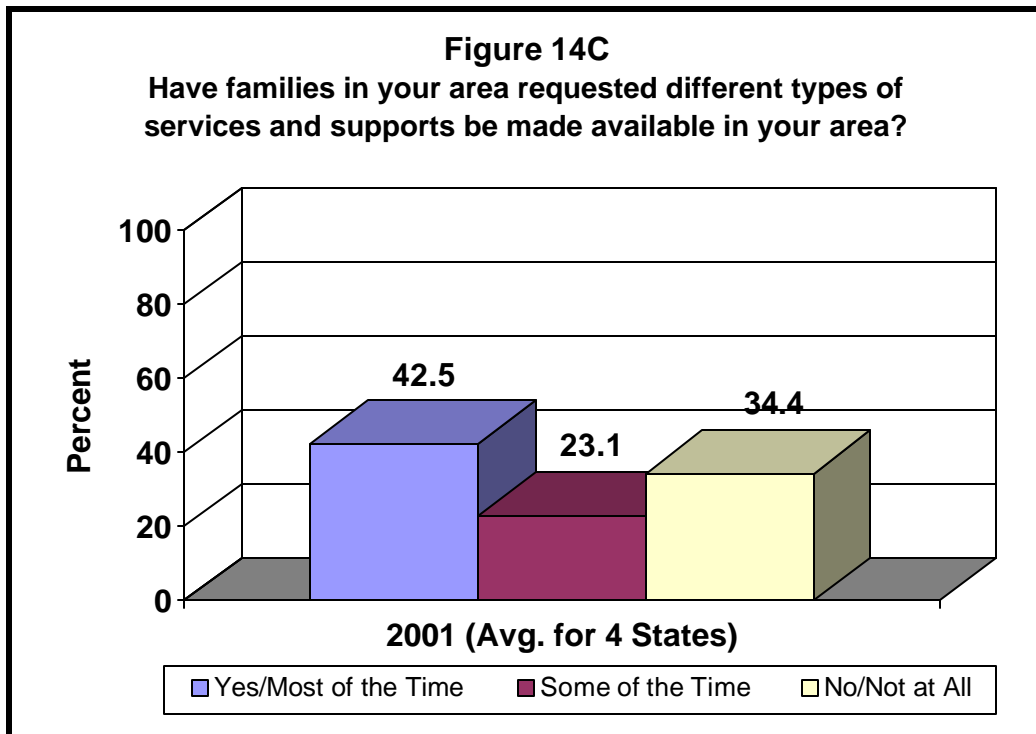
- ◆ Fewer than half of respondents (42%) indicated that supports were regularly available when needed. Forty-four percent indicated that supports available sometimes, and 14% stated that needed supports were not available.



**Table 18B**  
**Are the supports available when your family needs them?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	40.9	40.1	19.0	846
NC	45.7	40.0	14.3	280
NE	30.6	52.8	16.7	36
UT	54.2	42.0	3.8	238
VT	40.8	45.1	14.2	233
<b>Total %</b>	<b>43.4</b>	<b>41.3</b>	<b>15.2</b>	<b>Total n = 1,633</b>
<b>State Avg. %</b>	<b>42.4</b>	<b>44.0</b>	<b>13.6</b>	<b>Total n = 5</b>

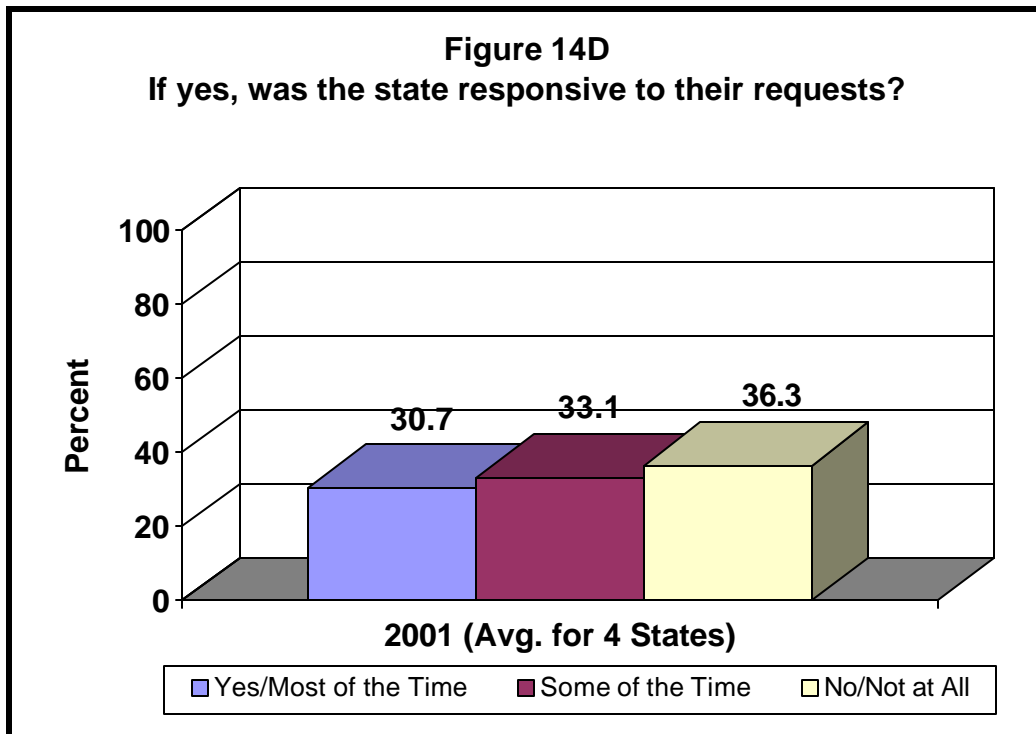
- ◆ Fewer than half (43%) of respondents knew of families in their area who had requested that different types of services and supports be made available in their area.



**Table 18C**  
**Have families in your area requested different types of services and supports be made available in your area?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	34.2	31.2	34.6	298
NC	48.1	25.0	26.9	108
NE	33.3	11.1	55.6	9
UT	54.5	25.0	20.5	88
VT	* Question not asked in Vermont			
<b>Total %</b>	<b>40.8</b>	<b>28.4</b>	<b>30.8</b>	<b>Total n = 503</b>
<b>State Avg. %</b>	<b>42.5</b>	<b>23.1</b>	<b>34.4</b>	<b>Total n = 4</b>

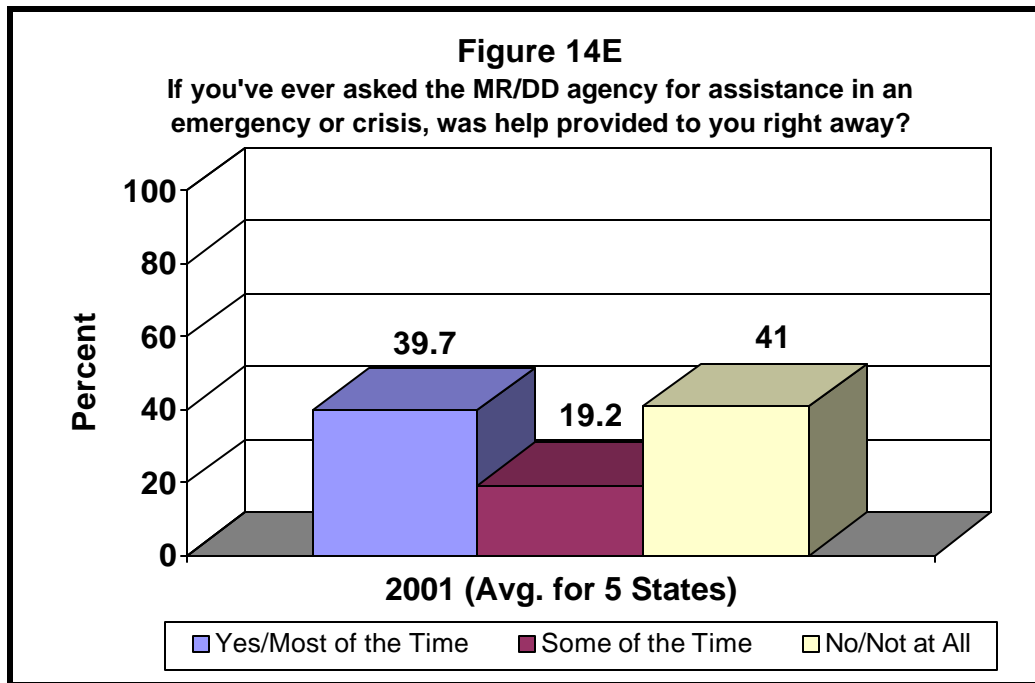
- ♦ Of those who knew of families requesting different types of services in their area, fewer than one-third (31%) felt the state was responsive to these requests.



**Table 18D**  
**If yes, was the state responsive to their requests?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	49.8	33.3	16.8	273
NC	26.8	29.6	43.7	71
NE	14.3	14.3	71.4	7
UT	31.7	55.0	13.3	60
VT	* Question not asked in Vermont			
<b>Total %</b>	<b>42.6</b>	<b>35.5</b>	<b>21.9</b>	<b>Total n = 411</b>
<b>State Avg. %</b>	<b>30.7</b>	<b>33.1</b>	<b>36.3</b>	<b>Total n = 4</b>

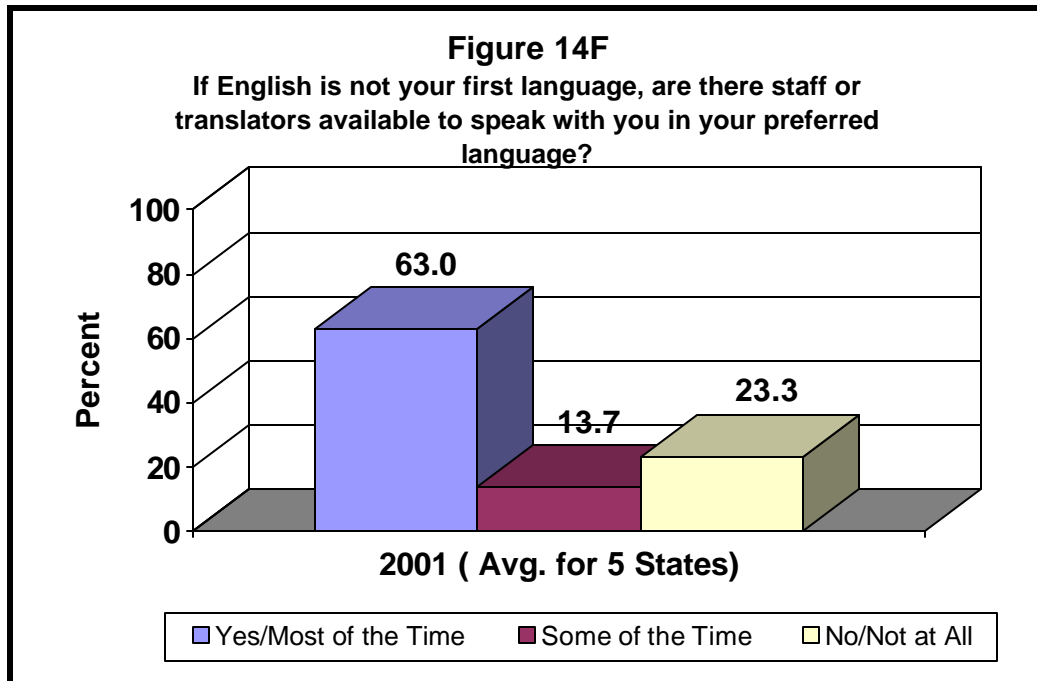
- ◆ On average, 40% of families who asked for assistance in an emergency or crisis received help right away. An equal percentage, approximately, did not receive immediate help in a crisis.



**Table 18E**  
If you have ever asked the MR/DD agency for assistance in an emergency or crisis, was help provided to you right away?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	35.8	21.9	42.3	430
NC	34.1	16.3	49.6	129
NE	30.0	16.7	53.3	30
UT	43.8	23.2	33.0	112
VT	54.9	18.0	27.0	122
<b>Total %</b>	<b>39.2</b>	<b>20.4</b>	<b>40.3</b>	<b>Total n = 823</b>
<b>State Avg. %</b>	<b>39.7</b>	<b>19.2</b>	<b>41.0</b>	<b>Total n = 5</b>

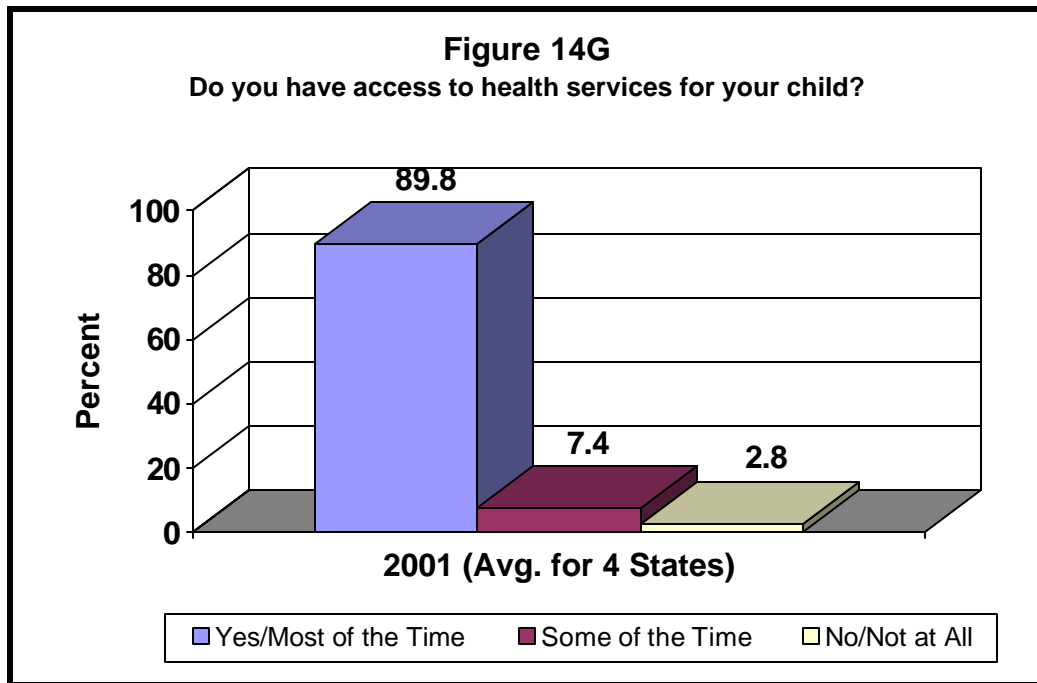
- ◆ Among respondents whose first language was not English, about two-thirds (63%) indicated that staff or translators were available to speak with them in their preferred languages. Fourteen percent indicated that staff/translators were available some of the time, and about one-fourth (23%) stated that staff/translators who spoke in the families' preferred languages were not available. Results were fairly consistent across states, with the exception of Nebraska, where results were dramatically lower (but there were very few respondents for whom this question was applicable in Nebraska).



**Table 18F**  
If English is not your first language, are there staff or translators available to speak with you in your preferred language?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	78.9	11.4	9.7	299
NC	72.4	17.2	10.3	29
NE	20.0	20.0	60.0	5
UT	71.4	14.3	14.3	14
VT	72.2	5.6	22.2	18
<b>Total %</b>	<b>77.0</b>	<b>11.8</b>	<b>11.2</b>	<b>Total n = 365</b>
<b>State Avg. %</b>	<b>63.0</b>	<b>13.7</b>	<b>23.3</b>	<b>Total n = 5</b>

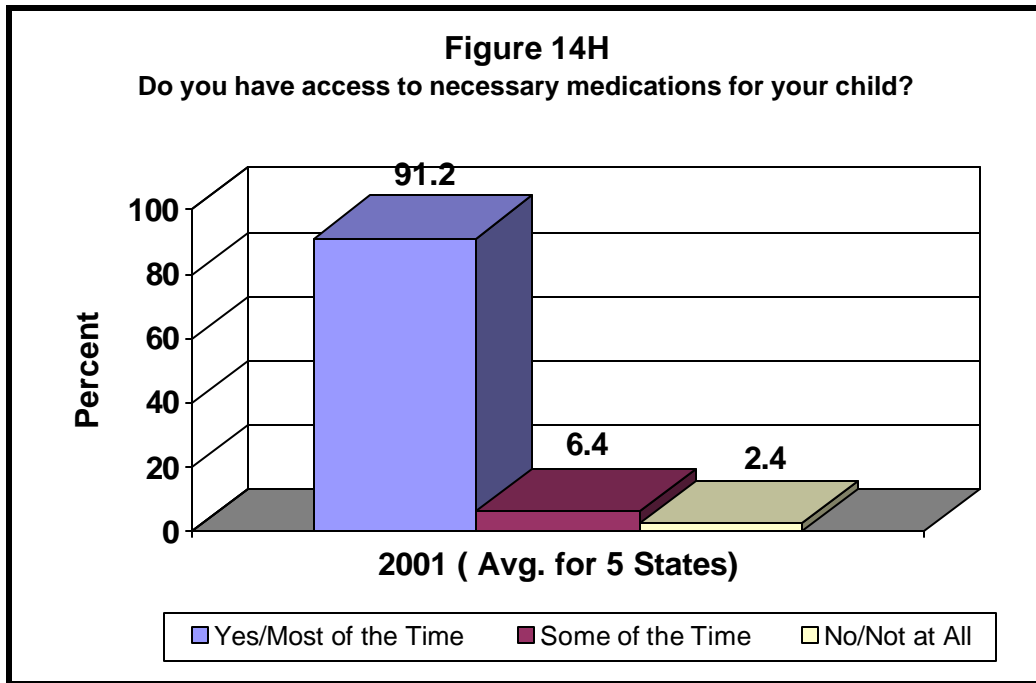
- ◆ Nearly all respondents (90%) indicated that they had access to health services for their child. These results were consistent across states.



**Table 18G**  
**Do you have access to health services for your child?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	86.3	9.3	4.4	907
NC	92.4	5.2	2.4	289
NE	88.4	9.3	2.3	43
UT	92.2	5.7	2.0	245
VT	* Question not asked in Vermont			
<b>Total %</b>	<b>88.5</b>	<b>7.9</b>	<b>3.6</b>	<b>Total n = 1,484</b>
<b>State Avg. %</b>	<b>89.8</b>	<b>7.4</b>	<b>2.8</b>	<b>Total n = 4</b>

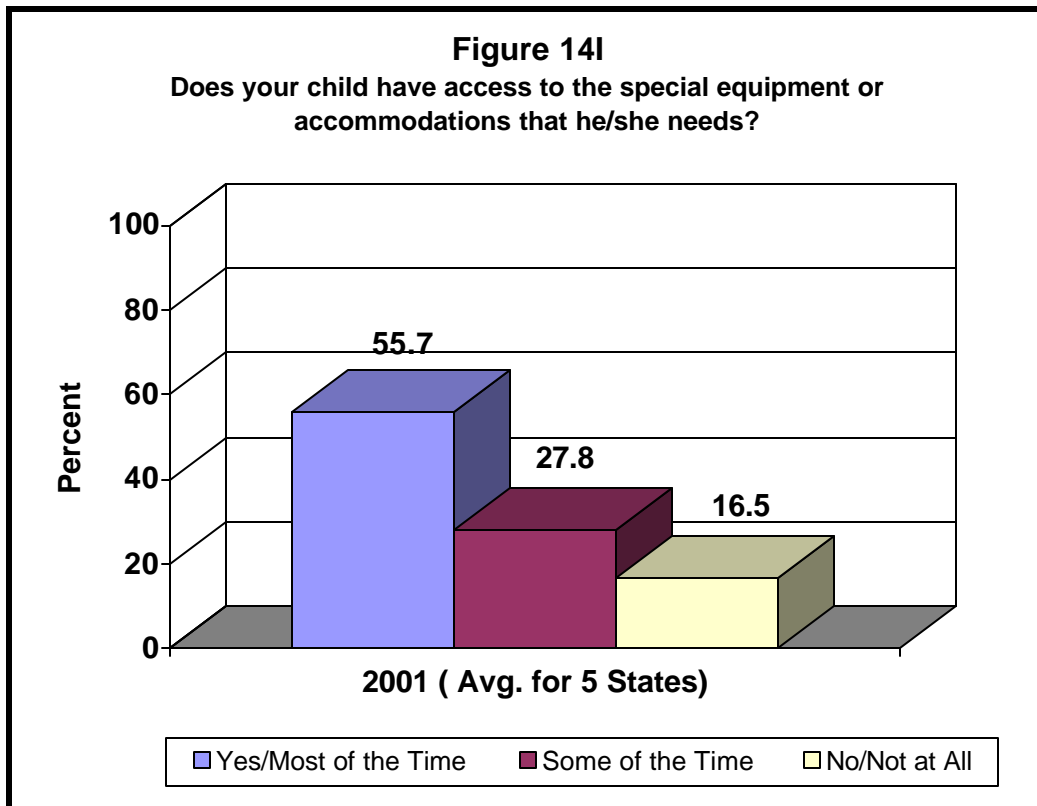
- ◆ The vast majority of respondents (91%) had access to necessary medications for their child. This, too, was consistent across states.



**Table 18H**  
Do you have access to necessary medications for your child?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	85.8	9.0	5.3	836
NC	94.8	4.1	1.1	269
NE	90.5	7.1	2.4	42
UT	93.7	5.5	0.8	238
VT	* Question not asked in Vermont			
<b>Total %</b>	<b>89.0</b>	<b>7.4</b>	<b>3.6</b>	<b>Total n = 1,385</b>
<b>State Avg. %</b>	<b>91.2</b>	<b>6.4</b>	<b>2.4</b>	<b>Total n = 4</b>

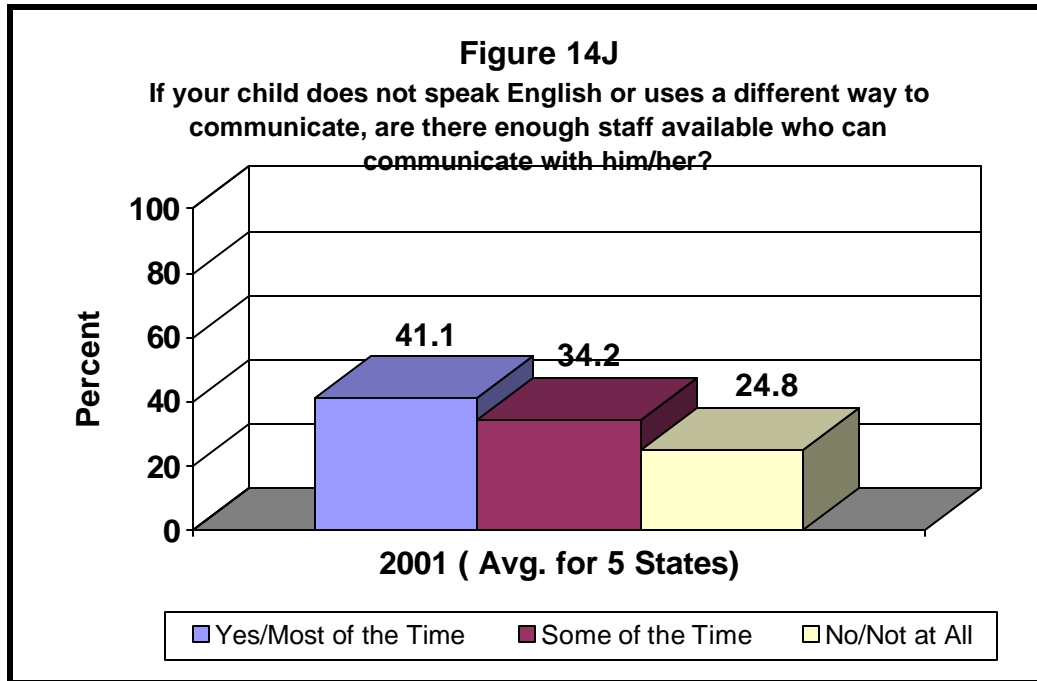
- ♦ Just over half (56%) of respondents, however, indicated that their family member regularly has access to the special equipment or accommodations that s/he needs.



**Table 18I**  
Does your child have access to the special equipment or accommodations that he/she needs?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	49.0	20.9	30.2	484
NC	60.4	25.3	14.3	182
NE	60.0	20.0	20.0	30
UT	62.4	30.6	6.9	173
VT	46.7	42.2	11.1	135
<b>Total %</b>	<b>53.4</b>	<b>26.2</b>	<b>20.4</b>	<b>Total n = 1,004</b>
<b>State Avg. %</b>	<b>55.7</b>	<b>27.8</b>	<b>16.5</b>	<b>Total n = 5</b>

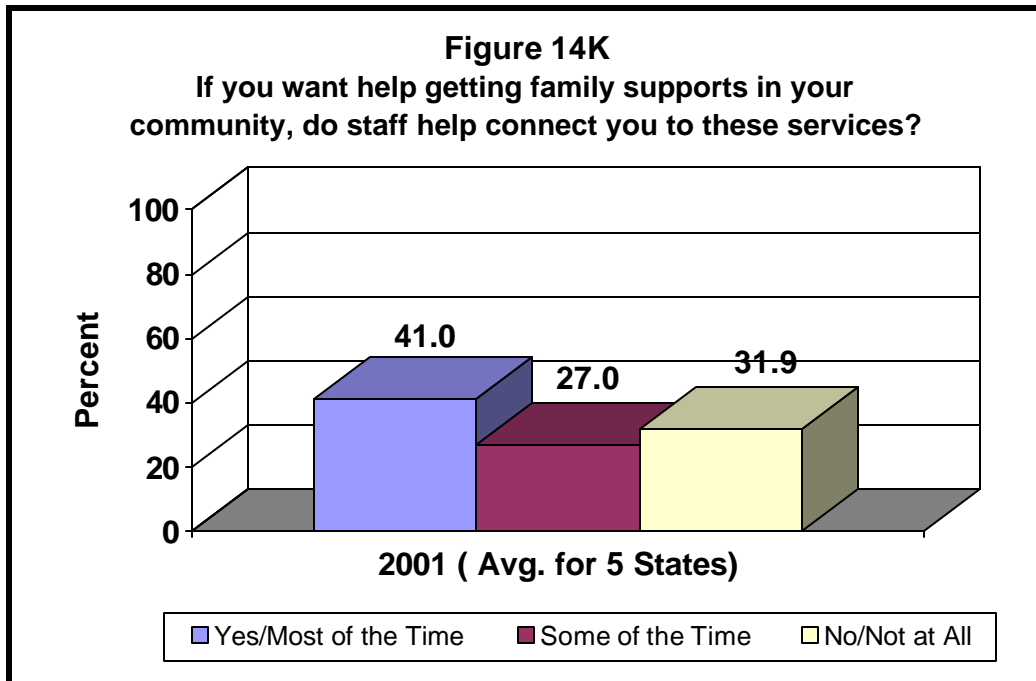
- ◆ Among those respondents whose family member with disabilities did not speak English, or who used different ways to communicate, only 41% indicated there were enough staff to communicate with their family member. About one-third (34%) stated that these staff were only available some of the time, and another 25% did not have staff available to communicate with their family members in their preferred means of communication/ languages.



**Table 18J**  
**If your child does not speak English or uses a different way to communicate, are there enough staff available who can communicate with him/her?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	40.3	24.5	35.3	278
NC	49.5	33.0	17.6	91
NE	40.0	33.3	26.7	15
UT	32.3	45.2	22.6	62
VT	43.4	34.9	21.7	106
<b>Total %</b>	<b>41.5</b>	<b>30.4</b>	<b>28.1</b>	<b>Total n = 552</b>
<b>State Avg. %</b>	<b>41.1</b>	<b>34.2</b>	<b>24.8</b>	<b>Total n = 5</b>

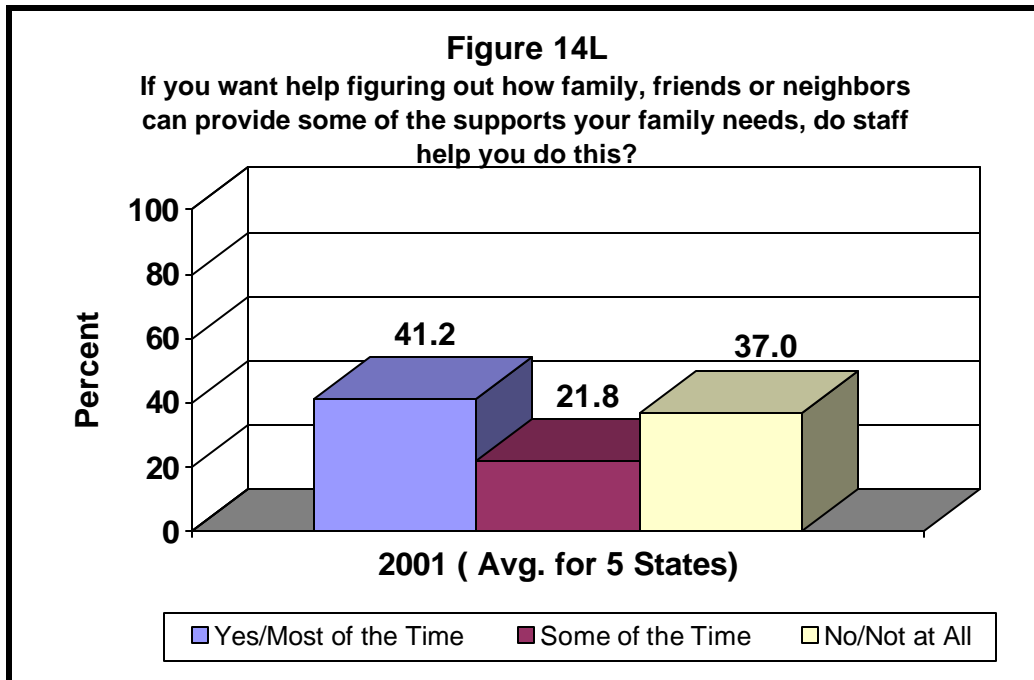
- ◆ Fewer than half (41%) of families said that staff helped them get connected to supports in their community. Another 27% stated this happened some of the time, while the remaining 32% indicated their staff did not help them connect with community supports.



**Table 18K**  
**If you want help getting family supports in your community, do staff help connect you to these services?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	37.1	22.8	40.1	696
NC	31.8	29.7	38.6	236
NE	64.3	19.0	16.7	42
UT	40.4	29.8	29.8	188
VT	31.5	33.9	34.5	168
<b>Total %</b>	<b>36.8</b>	<b>26.3</b>	<b>36.9</b>	<b>Total n = 1,330</b>
<b>State Avg. %</b>	<b>41.0</b>	<b>27.0</b>	<b>31.9</b>	<b>Total n = 5</b>

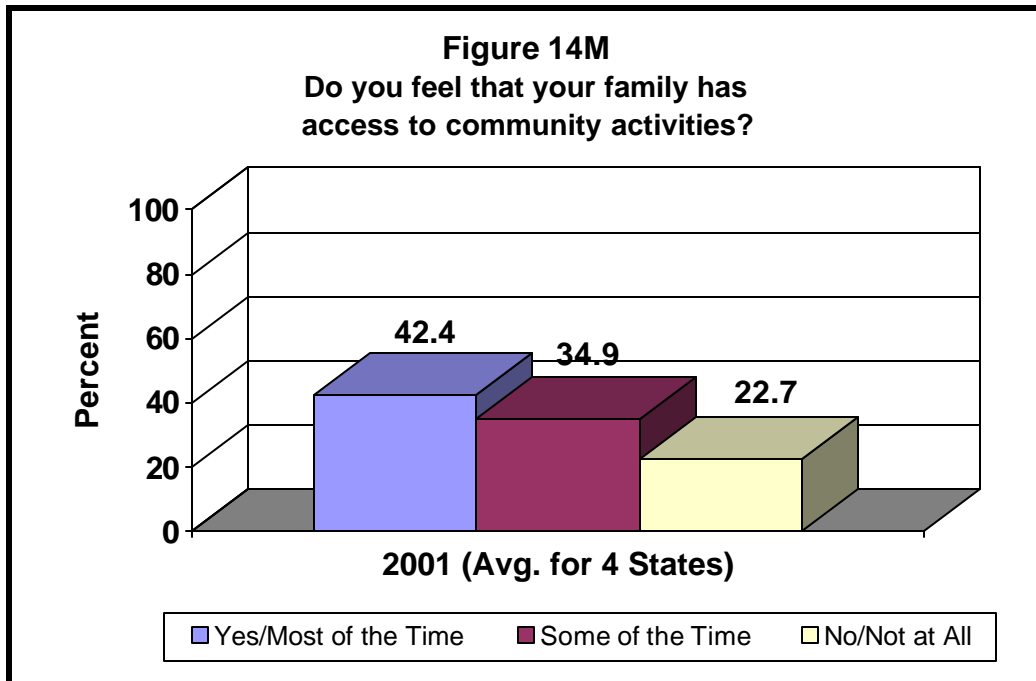
- Overall, there was a fairly even split between respondents who indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (41% say yes, 37% say no). The remaining respondents (22%) indicated that staff sometimes helped them make these needed connections.



**Table 18L**  
If you want help figuring out how family, friends or neighbors can provide some of the supports your family needs, do staff help you do this?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	34.2	20.0	45.8	666
NC	31.3	23.2	45.5	224
NE	56.7	16.7	26.7	30
UT	48.5	26.0	25.5	196
VT	35.2	23.3	41.5	159
<b>Total %</b>	<b>36.5</b>	<b>21.8</b>	<b>41.6</b>	<b>Total n = 1,275</b>
<b>State Avg. %</b>	<b>41.2</b>	<b>21.8</b>	<b>37.0</b>	<b>Total n = 5</b>

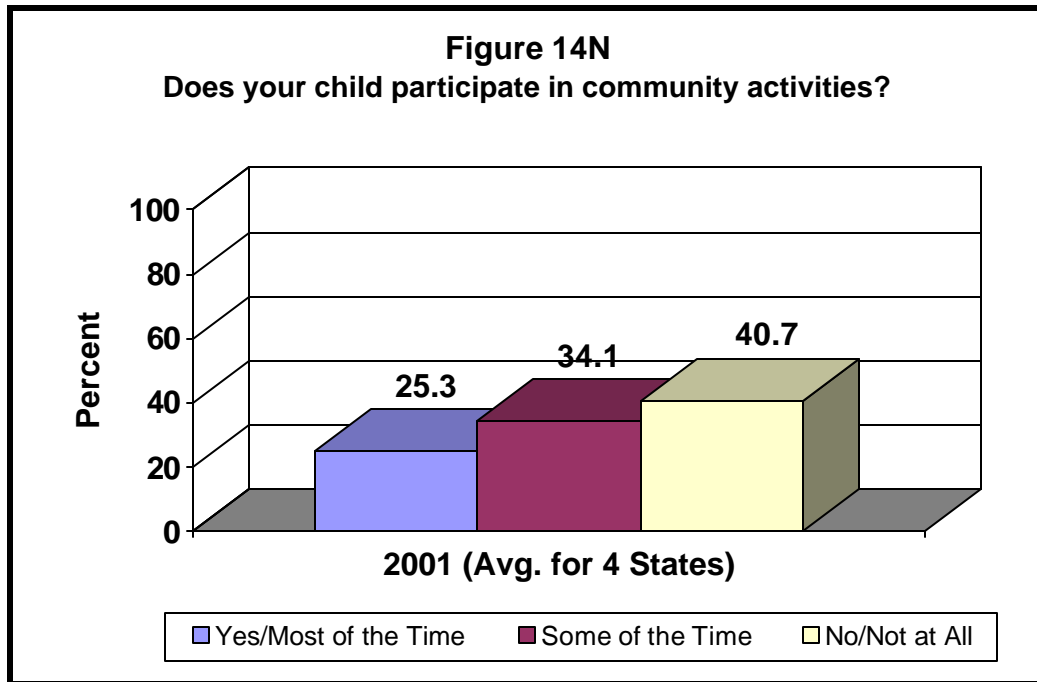
- ◆ Only 42% of respondents, on average, felt that their family had access to community activities. The majority, 58%, felt they did not have access to community activities or only had access some of the time. These results were consistent across states.



**Table 18M**  
**Do you feel that your family has access to community activities?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	39.7	31.2	29.1	827
NC	43.4	34.6	22.1	272
NE	36.6	39.0	24.4	41
UT	50.0	34.7	15.3	236
VT	* Question not asked in Vermont			
<b>Total %</b>	<b>42.1</b>	<b>32.7</b>	<b>25.2</b>	<b>Total n = 1,376</b>
<b>State Avg. %</b>	<b>42.4</b>	<b>34.9</b>	<b>22.7</b>	<b>Total n = 4</b>

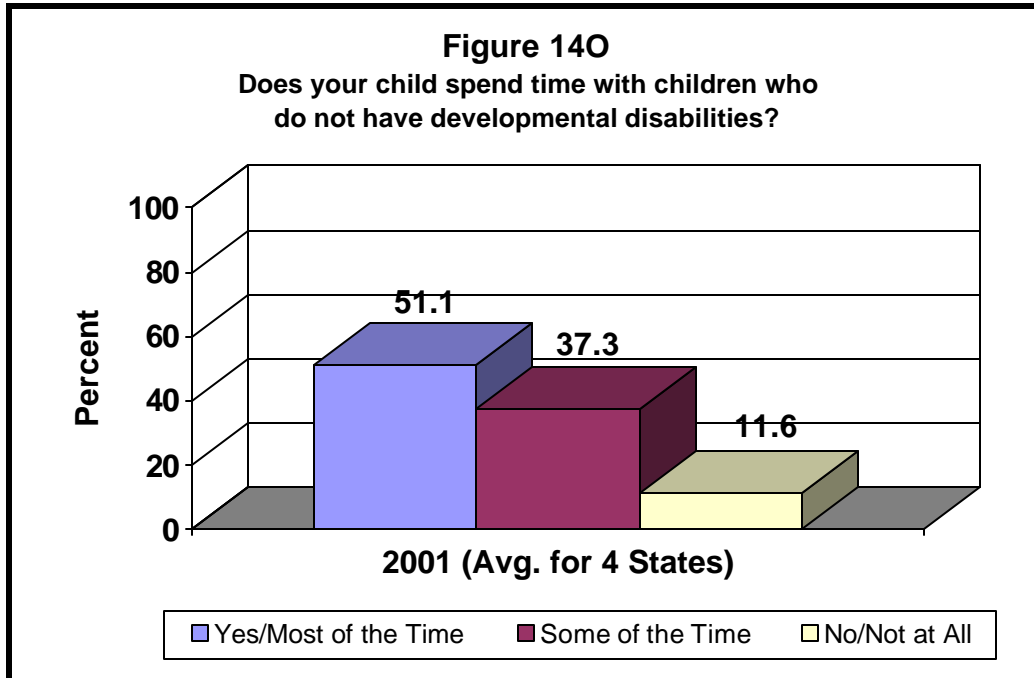
- ◆ Only one-quarter of respondents, on average, indicated that their child regularly participates in community activities.
- ◆ Forty-one percent of respondents marked that their child does not participate in community activities at all.



**Table 18N**  
**Does your child participate in community activities?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	18.2	27.9	53.9	914
NC	28.0	36.7	35.3	286
NE	31.0	28.6	40.5	42
UT	24.0	43.0	33.1	242
VT	* Question not asked in Vermont			
<b>Total %</b>	<b>21.4</b>	<b>32.1</b>	<b>46.6</b>	<b>Total n = 1,484</b>
<b>State Avg. %</b>	<b>25.3</b>	<b>34.1</b>	<b>40.7</b>	<b>Total n = 4</b>

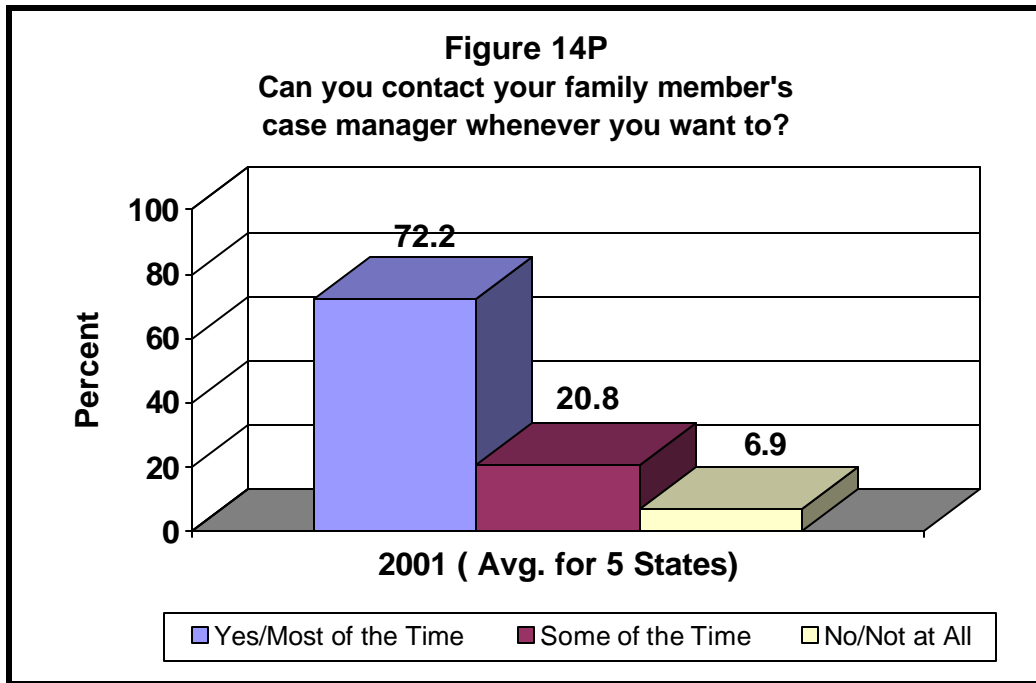
- ◆ Only about half (51%) of families indicated that their child with a disability spends most of their time with children who do not have disabilities. Twelve percent of respondents said their child spends no time with children who do not have disabilities. These results were consistent across states.



**Table 180**  
Does your child spend time with children who do not have developmental disabilities?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	55.1	33.9	11.0	955
NC	55.1	32.9	12.0	292
NE	43.2	45.5	11.4	44
UT	51.0	36.8	12.1	247
VT	* Question not asked in Vermont			
<b>Total %</b>	<b>54.1</b>	<b>34.5</b>	<b>11.4</b>	<b>Total n = 1,538</b>
<b>State Avg. %</b>	<b>51.1</b>	<b>37.3</b>	<b>11.6</b>	<b>Total n = 4</b>

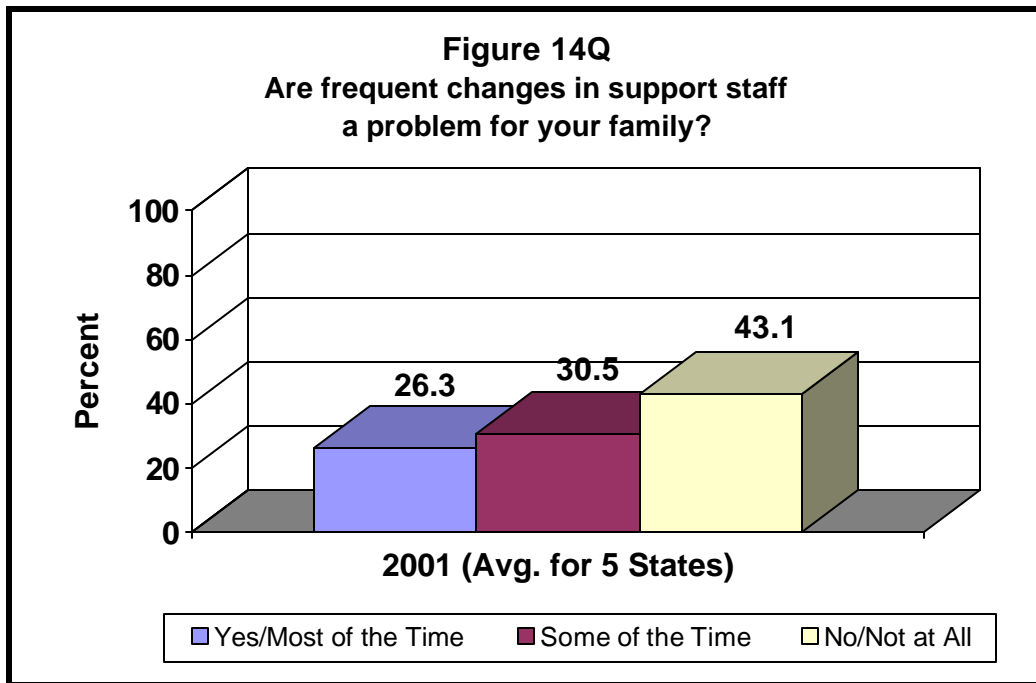
- ◆ Approximately three-fourths (72%) of respondents felt that they could regularly contact their family member's service coordinator/case manager when needed.



**Table 18P**  
**Can you contact your family member's case manager whenever you want to?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	70.3	20.3	9.4	929
NC	74.5	19.3	6.2	274
NE	69.8	18.6	11.6	43
UT	75.7	21.0	3.3	243
VT	70.8	25.0	4.2	216
<b>Total %</b>	<b>71.8</b>	<b>20.8</b>	<b>7.4</b>	<b>Total n = 1,705</b>
<b>State Avg. %</b>	<b>72.2</b>	<b>20.8</b>	<b>6.9</b>	<b>Total n = 5</b>

- ◆ Over half (57%) indicated that frequent changes in support staff were a problem for their family at least some of the time. The remaining 43% stated that this was not an issue for their family.

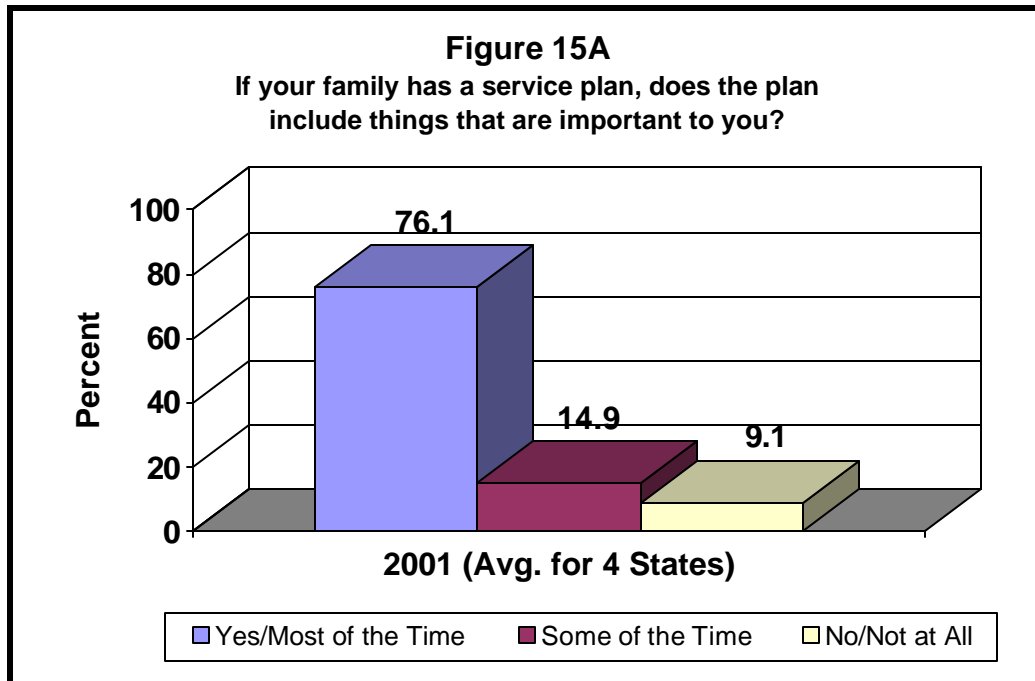


**Table 18Q**  
**Are frequent changes in support staff a problem for your family?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	32.4	27.4	40.1	715
NC	27.8	30.8	41.4	237
NE	27.6	31.0	41.4	29
UT	14.7	32.1	53.2	218
VT	29.2	31.4	39.5	185
<b>Total %</b>	<b>28.3</b>	<b>29.3</b>	<b>42.3</b>	<b>Total n = 1,384</b>
<b>State Avg. %</b>	<b>26.3</b>	<b>30.5</b>	<b>43.1</b>	<b>Total n = 5</b>

## Outcomes and Satisfaction with Services and Supports

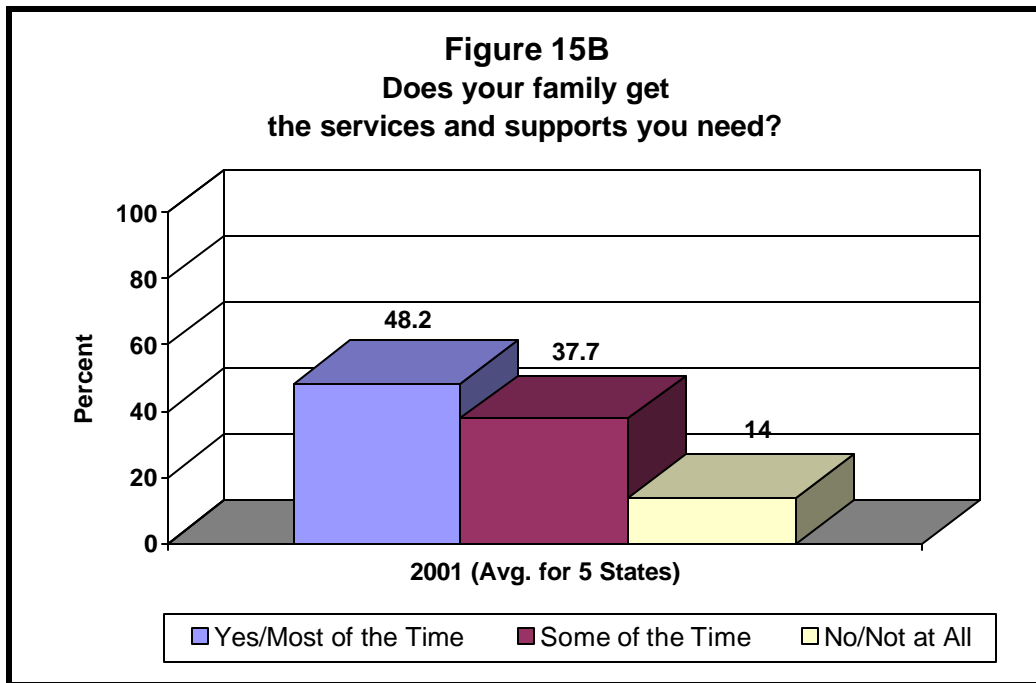
- Overall, three-fourths (76%) of the families surveyed indicated that their family member's service plan included things that were important to them. 15% stated this was only true some of the time, while the remaining 9% stated the service plan did not include things important to the respondent.



**Table 19A**  
If your family has a service plan, does the plan include things that are important to you?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	61.0	24.2	14.9	720
NC	79.4	15.4	5.1	253
NE	81.5	3.7	14.8	27
UT	82.6	16.1	1.4	218
VT	* Vermont did not ask this question			
<b>Total %</b>	<b>69.1</b>	<b>20.4</b>	<b>10.4</b>	<b>Total n = 1,218</b>
<b>State Avg. %</b>	<b>76.1</b>	<b>14.9</b>	<b>9.1</b>	<b>Total n = 4</b>

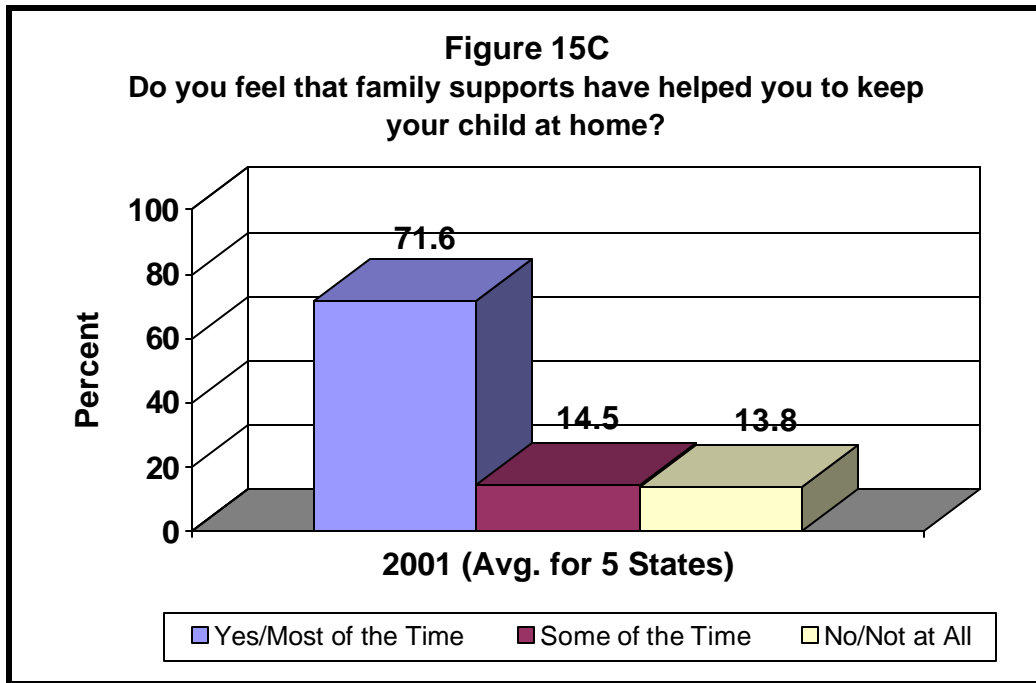
- ◆ Among all respondents, about half (48%) said that the supports received met their families' needs. Another 38% said that the supports met their needs some of the time. The remaining 14% did not feel the supports offered met family needs.



**Table 19B**  
**Does your family get the services and supports you need?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	41.6	39.7	18.7	897
NC	51.4	35.6	13.0	284
NE	47.4	28.9	23.7	38
UT	59.3	36.9	3.7	241
VT	41.4	47.5	11.1	244
<b>Total %</b>	<b>45.8</b>	<b>39.5</b>	<b>14.7</b>	<b>Total n = 1,704</b>
<b>State Avg. %</b>	<b>48.2</b>	<b>37.7</b>	<b>14.0</b>	<b>Total n = 5</b>

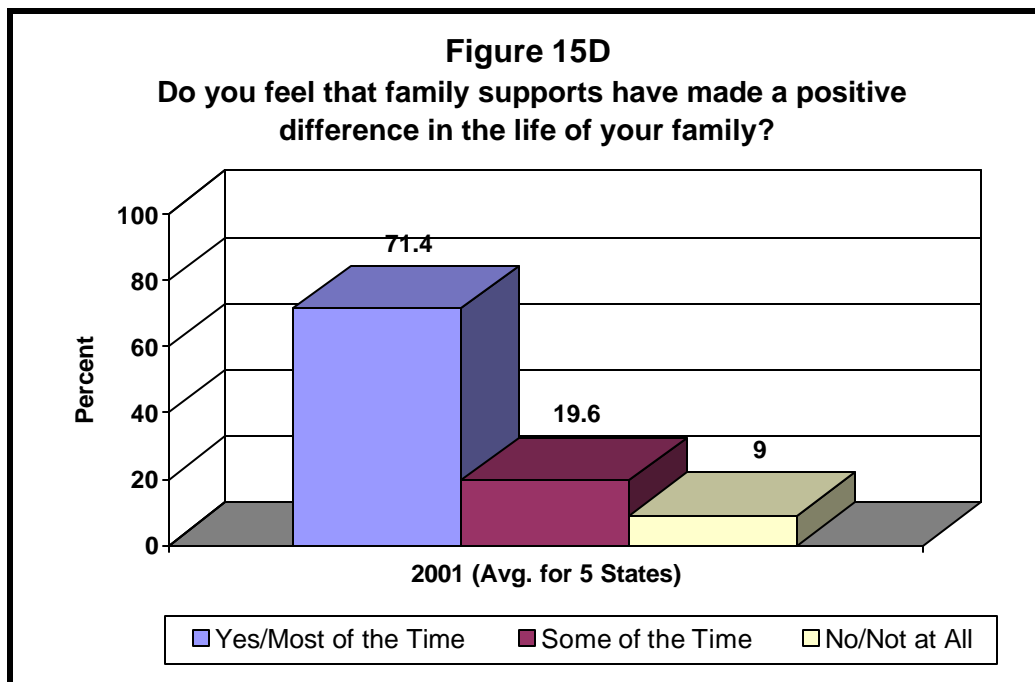
- ◆ Approximately three-fourths (72%) of respondents indicated that services have helped them keep their child at home. Additionally, 15% said that supports sometimes help in this regard.



**Table 19C**  
Do you feel that family supports have helped you to keep your child at home?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	57.3	18.3	24.3	654
NC	74.7	12.6	12.6	253
NE	68.3	19.5	12.2	41
UT	88.4	9.0	2.6	233
VT	69.3	13.2	17.5	189
<b>Total %</b>	<b>67.8</b>	<b>15.0</b>	<b>17.2</b>	<b>Total n = 1,370</b>
<b>State Avg. %</b>	<b>71.6</b>	<b>14.5</b>	<b>13.8</b>	<b>Total n = 5</b>

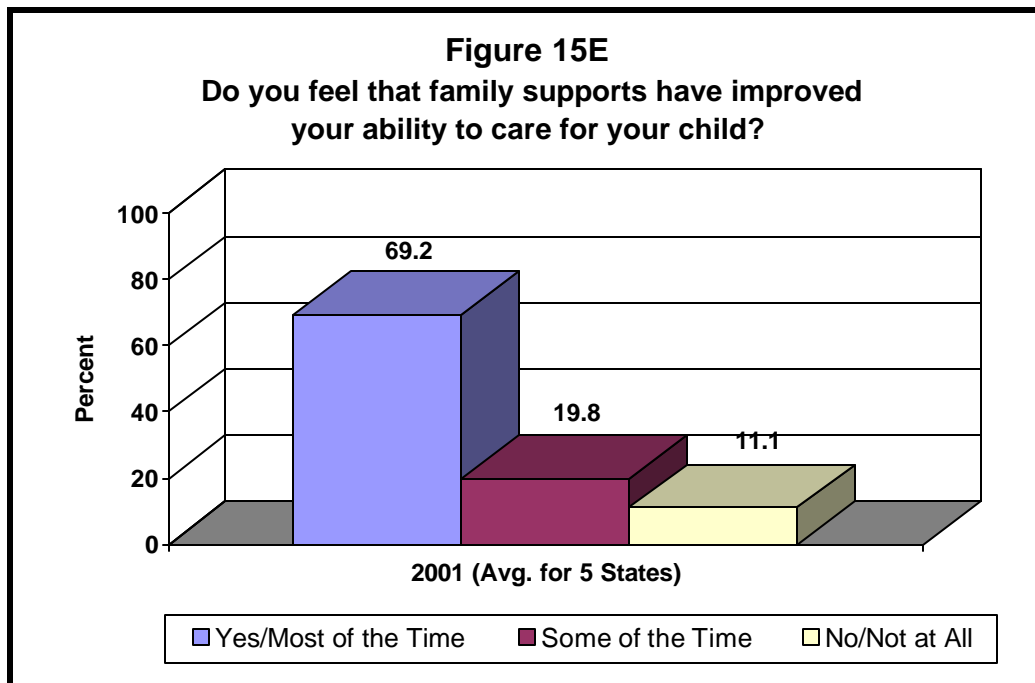
- ◆ Ninety-one percent of respondents, on average, stated that family supports to some degree have made a positive difference in their family's life. Across states, these results were fairly consistent.



**Table 19D**  
**Do you feel that family supports have made a positive difference in the life of your family?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	55.6	27.5	16.9	728
NC	72.5	19.2	8.3	265
NE	73.8	14.3	11.9	42
UT	87.5	10.4	2.1	240
VT	67.4	26.7	5.9	221
<b>Total %</b>	<b>66.0</b>	<b>22.8</b>	<b>11.2</b>	<b>Total n = 1,496</b>
<b>State Avg. %</b>	<b>71.4</b>	<b>19.6</b>	<b>9.0</b>	<b>Total n = 5</b>

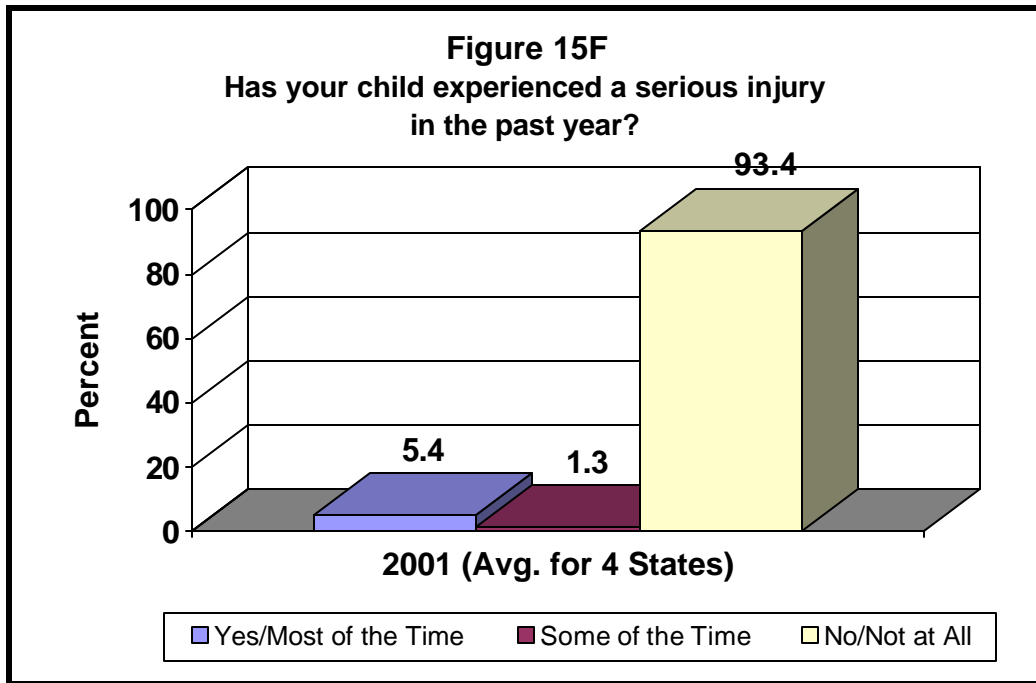
- ◆ Nearly all respondents said that family supports, to some extent, have improved their ability to care for their child.



**Table 19E**  
**Do you feel that family supports have improved your ability to care for your child?**

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	54.1	25.8	20.1	745
NC	70.4	19.5	10.1	267
NE	70.0	20.0	10.0	40
UT	82.2	13.7	4.1	241
VT	* Question not asked in Vermont			
<b>Total %</b>	<b>63.2</b>	<b>22.0</b>	<b>14.8</b>	<b>Total n = 1,293</b>
<b>State Avg. %</b>	<b>69.2</b>	<b>19.8</b>	<b>11.1</b>	<b>Total n = 4</b>

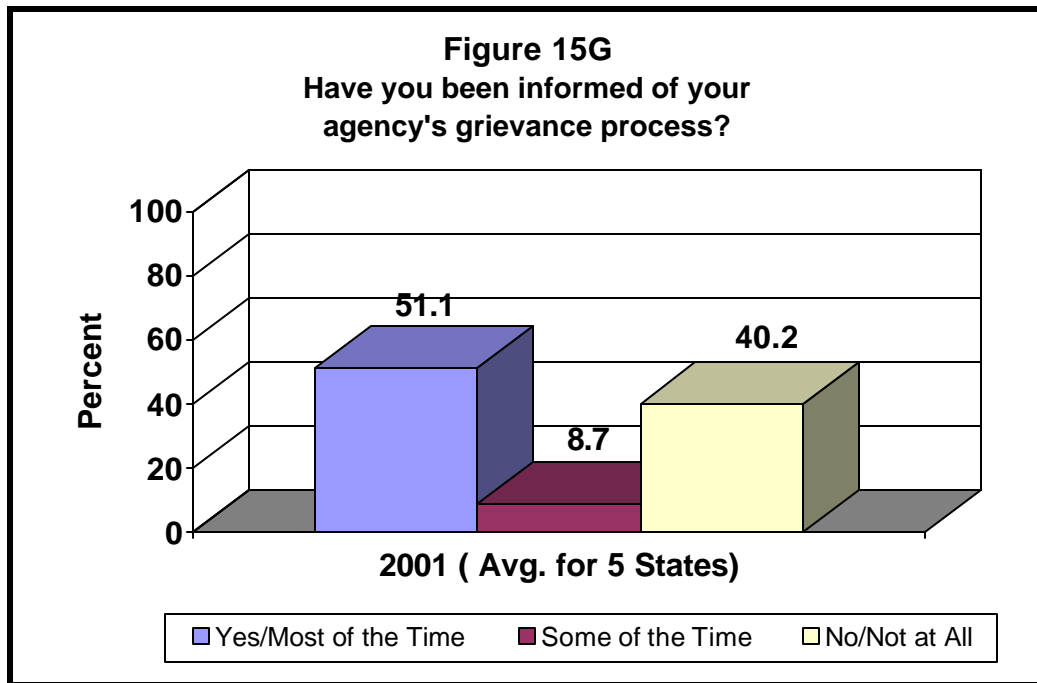
- ◆ Only 5% of respondents, on average, indicated that their child had experienced a serious injury during the past year.



**Table 19F**  
Has your child experienced a serious injury in the past year?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	5.3	2.2	92.6	875
NC	5.4	0.8	93.8	259
NE	2.5	0.0	97.5	40
UT	8.2	2.2	89.7	232
VT	* Question not asked in Vermont			
<b>Total %</b>	<b>5.7</b>	<b>1.8</b>	<b>92.5</b>	<b>Total n = 1,406</b>
<b>State Avg. %</b>	<b>5.4</b>	<b>1.3</b>	<b>93.4</b>	<b>Total n = 4</b>

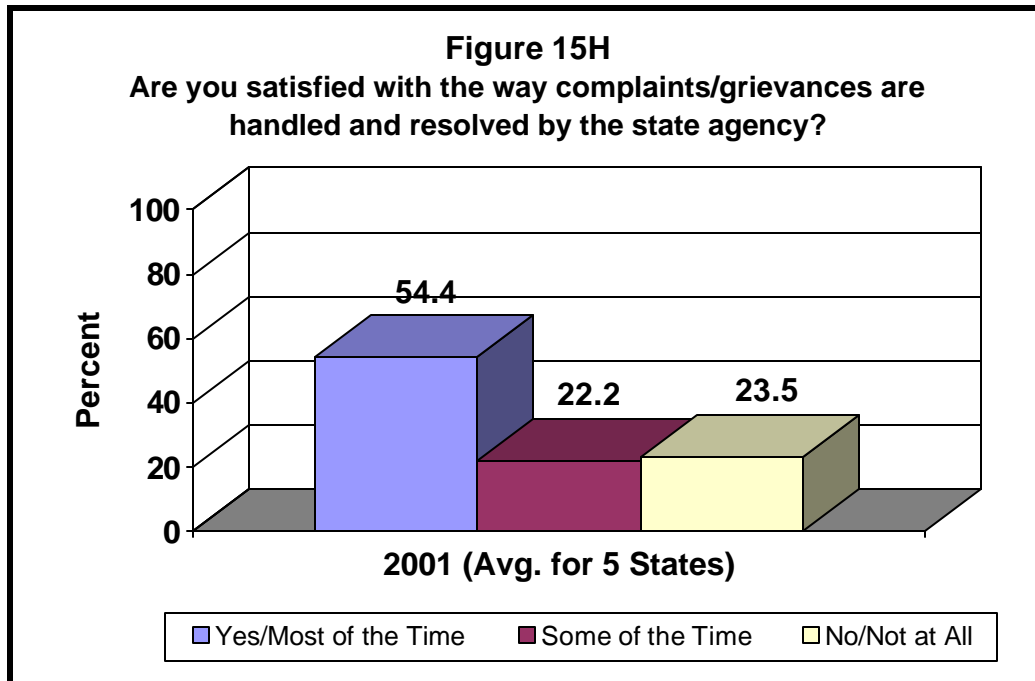
- ◆ Overall, about half (51)% of respondents knew about their agency's grievance process, while 49% were either only somewhat familiar or not at all familiar with the process for lodging a complaint.



**Table 19G**  
**Have you been informed of your agency's grievance process?**

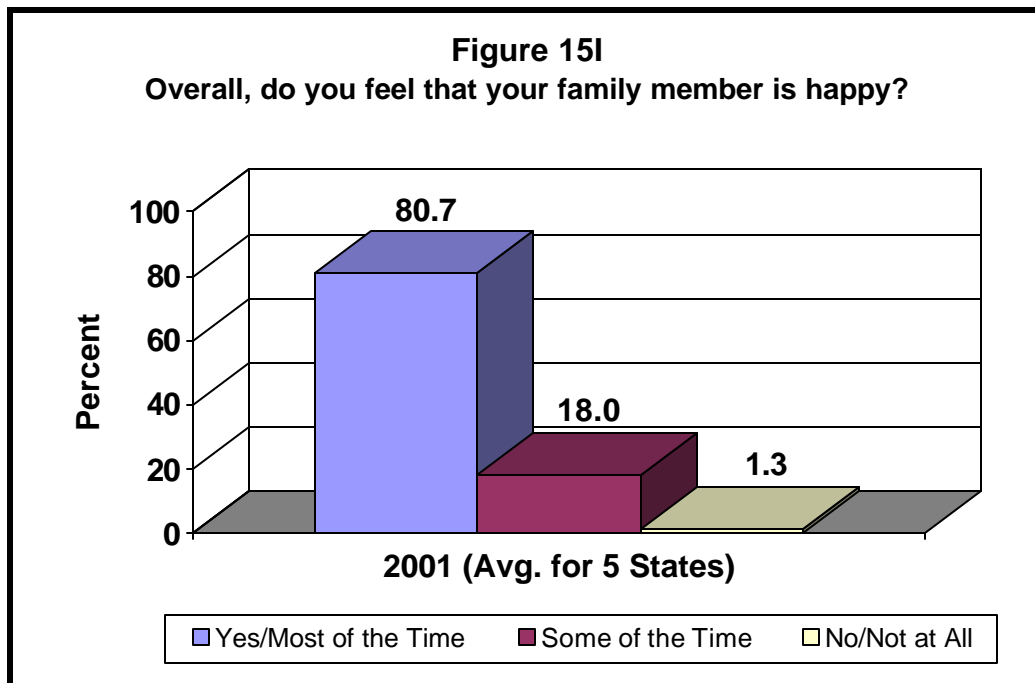
State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	65.1	9.8	25.1	768
NC	37.7	7.0	55.3	244
NE	57.1	0.0	42.9	28
UT	45.3	11.6	43.2	190
VT	50.5	15.0	34.5	206
<b>Total %</b>	<b>55.6</b>	<b>10.1</b>	<b>34.3</b>	<b>Total n = 1,436</b>
<b>State Avg. %</b>	<b>51.1</b>	<b>8.7</b>	<b>40.2</b>	<b>Total n = 5</b>

- ◆ A slight majority of respondents (54%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 46%, however, were either not satisfied, or satisfied only some of the time with how these matters were resolved.



<b>Table 19H</b>				
<b>Are you satisfied with the way complaints/grievances are handled and resolved by the state agency?</b>				
State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	60.4	20.3	19.3	389
NC	45.6	29.4	25.0	136
NE	38.5	15.4	46.2	13
UT	67.1	23.2	9.8	82
VT	60.2	22.7	17.0	88
<b>Total %</b>	<b>57.9</b>	<b>22.6</b>	<b>19.5</b>	<b>708</b>
<b>State Avg. %</b>	<b>54.4</b>	<b>22.2</b>	<b>23.5</b>	<b>Total n = 5</b>

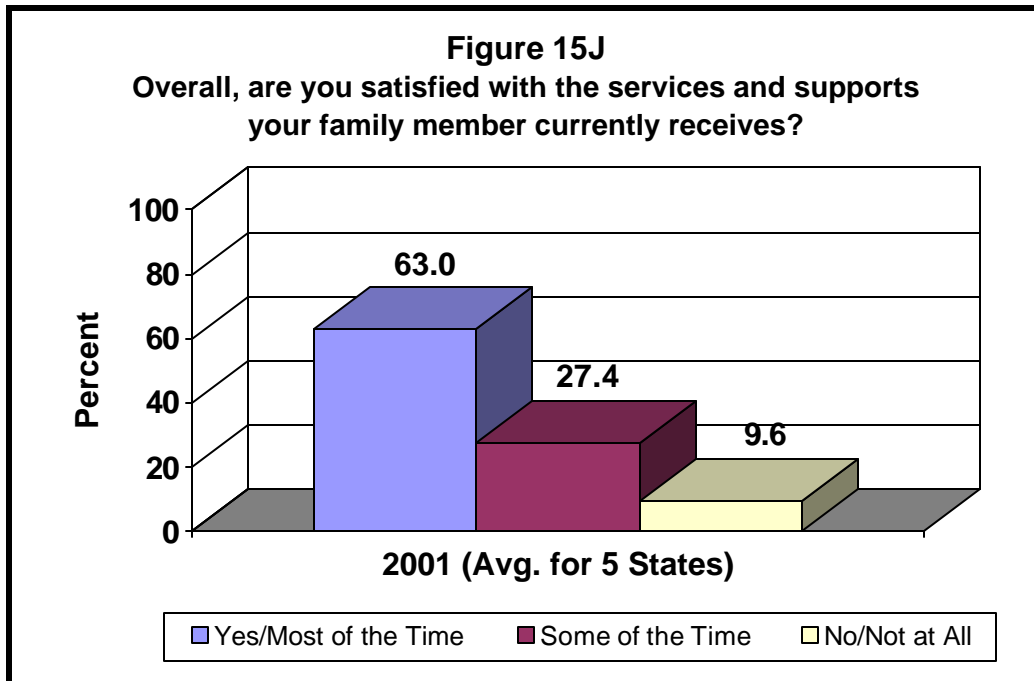
- ◆ Eighty-one percent of respondents felt that their family member was happy all or most of the time. Only 1% indicated that their family member was not happy.



**Table 19I**  
Overall, do you feel that your family member is happy?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	79.3	18.4	2.3	947
NC	81.8	17.9	0.3	296
NE	81.4	16.3	2.3	43
UT	82.0	17.6	0.4	244
VT	78.8	19.9	1.2	241
<b>Total %</b>	<b>80.1</b>	<b>18.4</b>	<b>1.6</b>	<b>Total n = 1,771</b>
<b>State Avg. %</b>	<b>80.7</b>	<b>18.0</b>	<b>1.3</b>	<b>Total n = 5</b>

- Overall, slightly less than two-thirds of respondents (63%) were satisfied with the services and supports they receive. 27% were somewhat satisfied, and 10% were not at all satisfied. Results varied quite a bit from state to state, as only 50% of respondents in Orange County, California stated they were satisfied while 78% of respondents in Utah expressed overall satisfaction with their services received.



**Table 19J**  
Overall, are you satisfied with the services and supports your family member currently receives?

State	Yes or Most of the Time	Some of the Time	No or Not at All	n
CA-Orange Co.	50.4	31.4	18.2	929
NC	64.1	26.9	9.0	290
NE	61.9	31.0	7.1	42
UT	78.4	19.6	2.0	245
VT	60.3	28.2	11.5	234
<b>Total %</b>	<b>58.2</b>	<b>28.6</b>	<b>13.2</b>	<b>Total n = 1,740</b>
<b>State Avg. %</b>	<b>63.0</b>	<b>27.4</b>	<b>9.6</b>	<b>Total n = 5</b>

## Aggregate Results

This section provides an overall view of the aggregate survey results.

- ◆ This Table illustrates the percentage of respondents who marked “Yes or Most of the Time” as their response to each survey question.
- ◆ Information and Planning – Overall, fewer than half of families felt they received the information (about services, benefits, their child’s status, or for planning) that was needed. The information they did receive, however, was easy to understand, and staff generally respected family opinions and choices.
- ◆ Choice and Control – Overall, one-third of families knew how much money was available for their services, about half of families felt they exercised choice and control over their services, while nearly two-thirds wanted control over their supports.

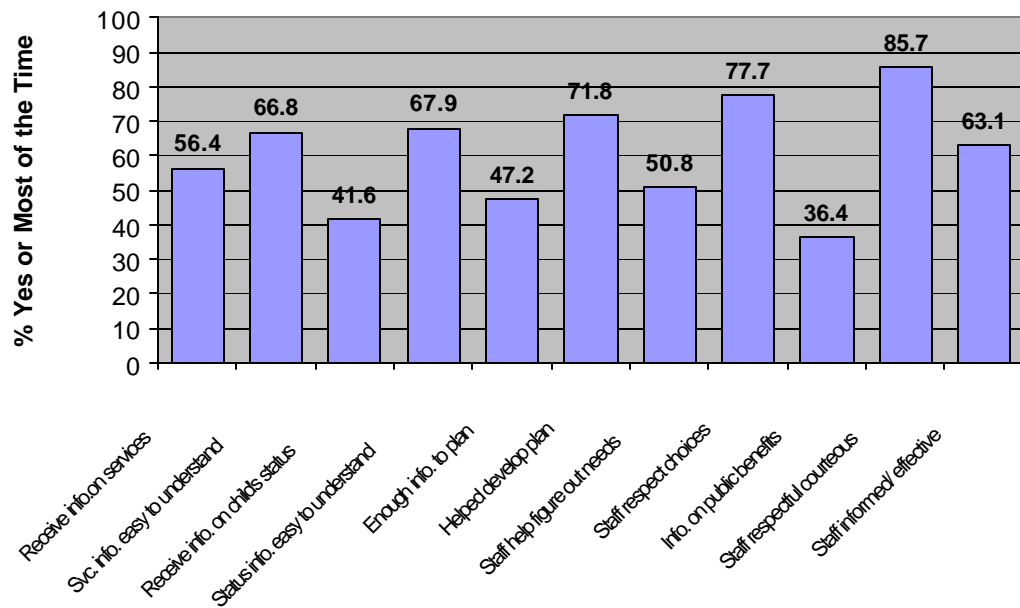
<b>Table 20A - Child Family Survey - 2001 Data</b>	
All Respondents	
% responding "Yes or Most of the Time"	
<b>Information &amp; Planning Questions</b>	<b>Total %</b>
Do you receive information about MR/DD services and supports that are available to your family?	56.4
If you receive information, is it easy to understand?	66.8
Do you receive information about the status of your child's development?	41.6
If yes, is this information easy to understand?	67.9
Do you get enough information to help you participate in planning services for your child?	47.2
If your family has a service plan, did you help develop the plan?	71.8
Do staff help you figure out what you need as a family to support your child?	50.8
Do staff respect your choices and opinions?	77.7
Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI)?	36.4
Are MR/DD staff generally respectful and courteous?	85.7
Are MR/DD staff generally knowledgeable and effective?	63.1
<b>Choice &amp; Control Questions</b>	<b>Total %</b>
Do you choose the agencies or providers that work with your family?	55.3
Do you choose the support workers that work with your family?	50.0
Do you have control and/or input over the hiring and management of your support workers?	51.2
Do you want to have control and/or input over the hiring and management of your support workers?	71.8
Do you know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?	33.4
Do you get to decide how this money is spent?	34.0

- ◆ Access to Services and Supports – Overall, fewer than half of families felt that the delivery of services and supports met their needs. A higher percentage of families had the access needed to special equipment, health services and medicines.

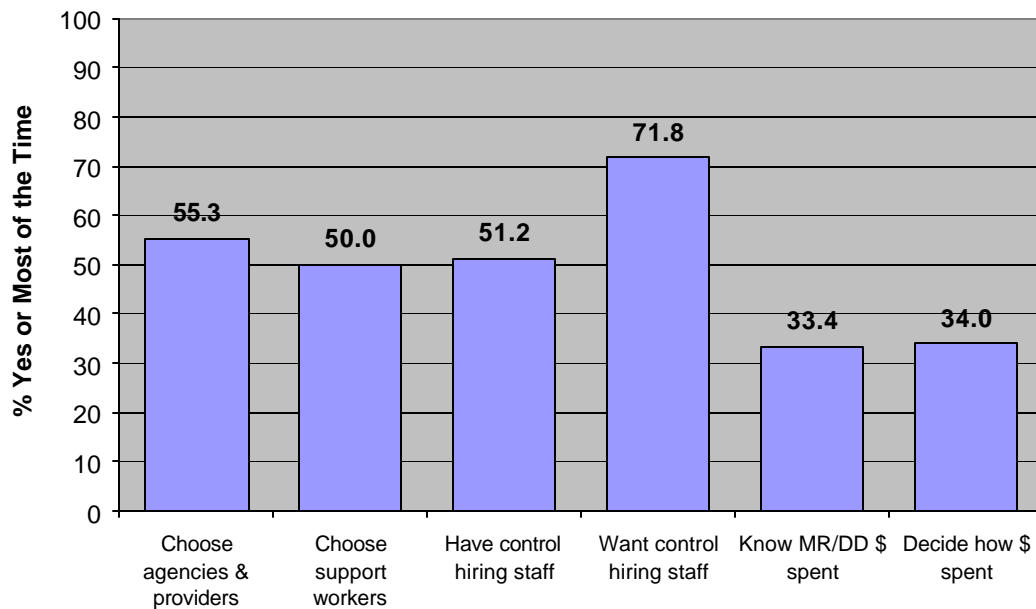
- ◆ Satisfaction and Outcomes – Overall, approximately two-thirds of families felt that services made a positive difference and helped them better care for their child at home.

<b>Table 20B - Adult Family Survey - 2001 Data</b>	
All Respondents	
% responding "Yes or Most of the Time"	
<b>Access to Services Questions</b>	<b>Total %</b>
Do the supports offered by the MR/DD agency meet your family's needs?	44.7
Are supports available when your family needs them?	43.4
Have families in your area requested different types of services and supports be made available in your area?	40.8
If yes, was the State responsive to their requests?	42.6
If you have ever asked the MR/DD agency for assistance in an emergency or crisis, was help provided to you right away?	39.2
If English is <u>not</u> your first language, are there staff or translators available to speak with you in your preferred language?	77.0
Do you have access to health services for your child?	88.5
Do you have access to necessary medications for your child?	89.0
Does your child have access to the special equipment or accommodations that he/she needs?	53.4
If your child does not speak English or uses a different way to communicate, are there enough staff available who can communicate with him/her?	41.5
If you want help getting family supports in your community, do staff help connect you to these services?	36.8
If you want help figuring out how family, friends, or neighbors can provide some of the supports your family needs, do staff help you do this?	36.5
Do you feel that your family has access to community activities?	42.1
Does your child participate in community activities?	21.4
Does your child spend time with children who do not have developmental disabilities?	54.1
Can you contact your family member's case manager whenever you want to?	71.8
Have you been informed of your agency's grievance process?	55.6
Are frequent changes in support staff a problem for your family?	28.3
<b>Satisfaction &amp; Outcomes Questions</b>	<b>Total %</b>
If your family has a service plan, does the plan include things that are important to you?	69.1
Does your family get the services and supports you need?	45.8
Do you feel that family supports have helped you to keep your child at home?	67.8
Do you feel that family supports have made a positive difference in the life of your family?	66.0
Do you feel that family supports have improved your ability to care for your child?	63.2
Has your child experienced a serious injury in the past year?	5.7
Are you satisfied with the way complaints or grievances are handled and resolved by the state agency?	57.9
Overall, do you feel that your family member is happy?	80.1
Overall, are you satisfied with the services and supports your family member currently receives?	58.2

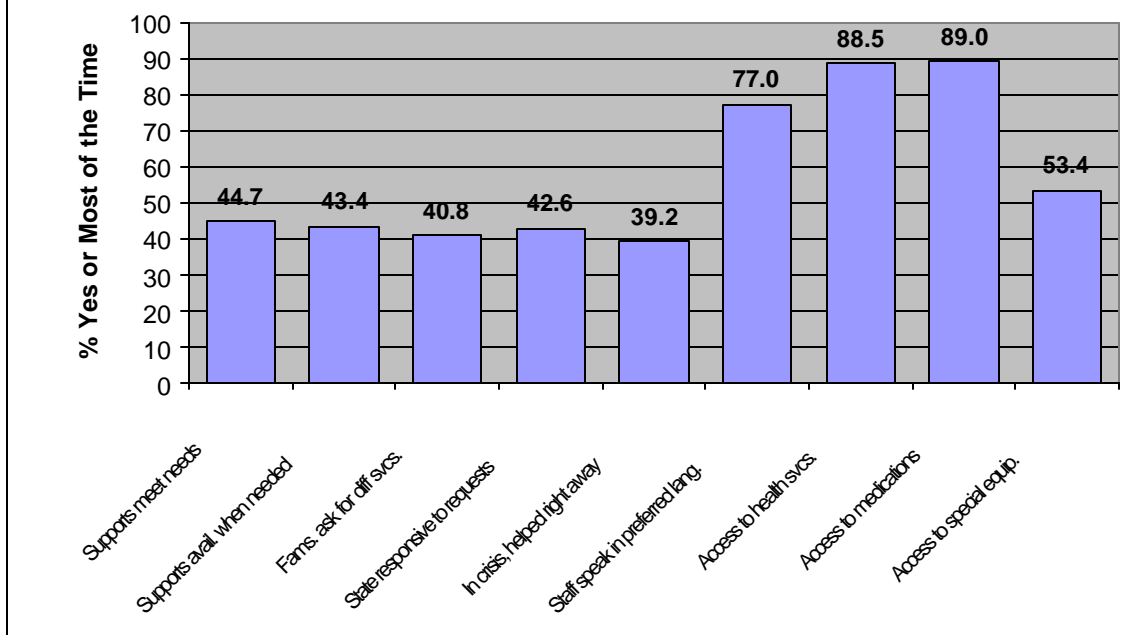
**Figure 16A: Information & Planning**



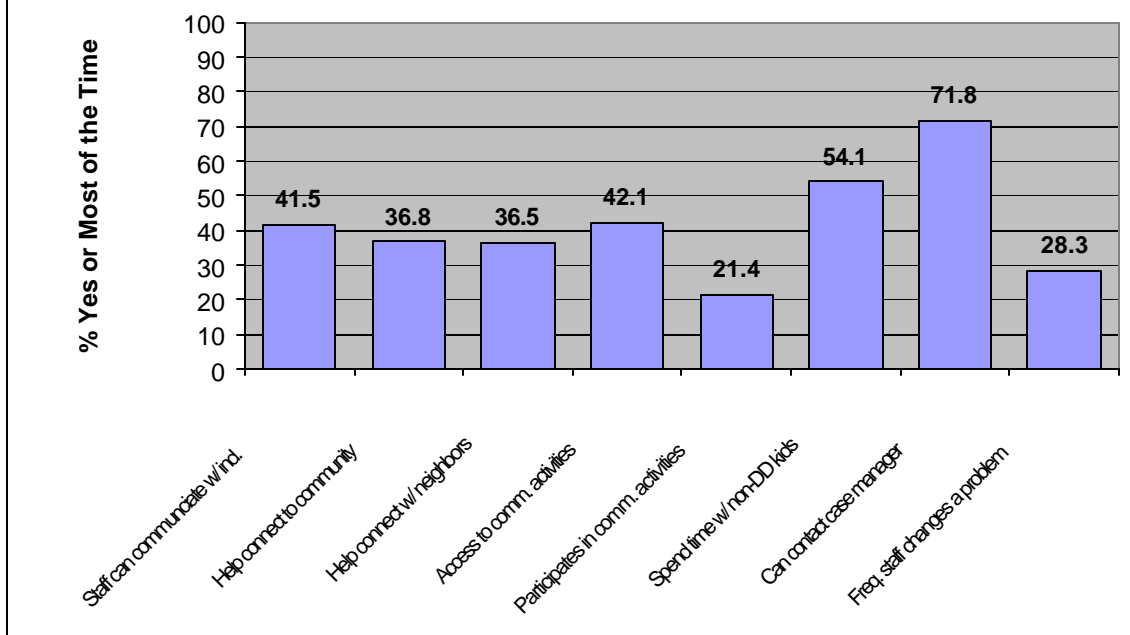
**Figure 16B: Choice & Control**



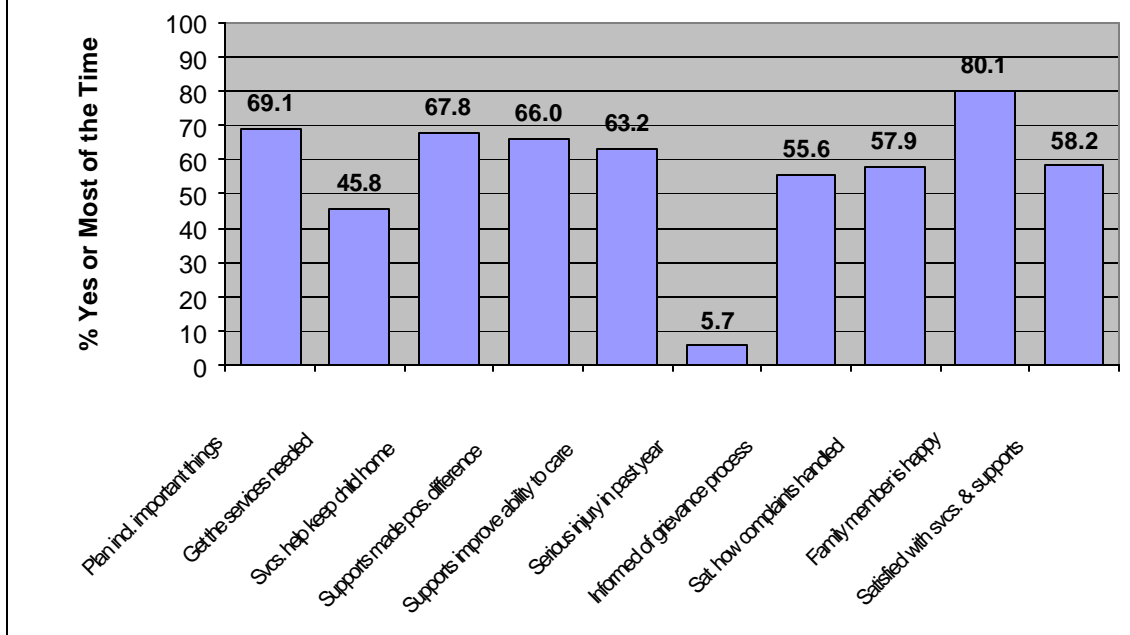
**Figure 16C: Access to Services (1)**



**Figure 16C: Access to Services (2)**



**Figure 16D: Satisfaction & Outcomes**



## Additional Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. QSR NUD\*IST (v6) was utilized to code and sort the qualitative comments by theme. Themes included home, employment and day programs, education and training, health services and equipment, transportation, recreational activities, communication, transition issues and future planning, service coordination, staff, respite, funding and budget cuts, and overall satisfaction with services. The results of this analysis are presented by state below. Note the qualitative comments from Utah were incomplete – specifically, comments were cut off due to the nature of their database. In addition, 78 comments from the California surveys were not translated and therefore were not included in this analysis. In the future, instructions will request that all responses are translated.

The analysis of qualitative comments varied substantially by the number of responses from each state. In states where the sample size was large, such as California, a clearer understanding of the data begins to emerge. Regardless of the number of responses, these comments provide insight and supplement the quantitative results presented earlier.

### CALIFORNIA

Approximately 33% of survey respondents from California wrote qualitative comments. RCOC is the Regional Center of Orange County, which services as the coordinating agency for developmental disability services in that area. These comments were only from families in Orange County.

#### Home

A few respondents noted issues related to the home environment. These people reported they were not receiving enough support to keep their child at home.

“Our system is backwards. It is extremely difficult to keep a disabled or medically fragile child home without a great deal of support and money.”

“Basic needs are not provided to these children when they remain at home...Why? The incentive should be to keep the home, not throw them out!”

“We want to keep this child in the home but RCOC has not helped us to do so!”

#### Employment and Day Programs

Most people reported dissatisfaction with issues related to employment, day programs, and day care.

“Me and my family appreciate the services provided by RCOC. I feel D. has made significant social improvement due to the help provided by RCOC in getting him a job.”

“I would like to see some sort of program started for child care for special needs children. There are none available for my child with autism, I have only found places for physically challenged children not mentally challenged. This has been a problem for our family as my husband and I are both working parents!”

“We would like RCOC to provided, or facilitate, the availability of supervised day care/activity programs for teenagers on weekdays when school is not in session, and after school ‘extended day’ programs. As a working parent, it is extremely difficult to find day care for developmentally disabled teenagers. This is a big problem and source of stress and anxiety for our family. Our attempts to find suitable programs have been unsuccessful.”

“My biggest problem is after-school care – We have no relatives in CA, making it very difficult to find someone who you could trust or even find anyone, period. I don’t want to put her in a program with 40-50 kids, there is too much chaos. We would like to find someone who wants experience working with special kids. We have great ideas on who to utilize (like college students in the field of child development and special education). But do not have the time in my life to pursue this endeavor (i.e. going to the colleges, putting out ads, etc.) If RCOC could put together a list of those college students who need CREDIT working with disabled people. We could have a resource list already and feel somewhat more comfortable finding someone who could help and tutor and care for my child without having to pay \$40 per hour for tutoring services. Help!!”

“I pay a lot for day care for my handicapped daughter. Probably more then I should because I want her well taken care of. She is ten, in diapers, and is very limited in her talking skills. I need help with this issue, I’m a single mom with three kids and my day care was cut completely!”

“I cannot find affordable child care for me to go back to work.”

“Also, I want to return to work but can’t find after school care. Can you help me with that?”

## **Education and Training**

Some people reported satisfaction with education and training. Additionally, several parents mentioned attending trainings and workshops.

“At this time, our son is going to pre-school where he continues to show improvement.”

“When we started with RCOC my daughter was 2 1/2 and they were very helpful getting her speech therapy. They were also key with getting me introduced to the special-ed preschool where she attended for two years.”

“I have also attended many of the lectures and training sessions, which are REALLY helpful.”

“We have attended several workshops.”

For the most part, people were dissatisfied with education and training opportunities. In addition, several parents mentioned they wanted to attend trainings.

“Since our son turned 3, our OT, PT, etc services have been denied even when the school district denied them as well. We now have to obtain an attorney at our cost to fight for an appropriate education and services for our son.”

“Since our child is 5 and in the public school system, we are not offered any services via the regional center that our son needs the most, e.g. speech therapy and occupational therapy. And the school district is in a financial crisis, so services are minimal.”

“I constantly battle the school system to keep my child in school and to provide him with an education that meets his needs. His education is used as a form of punishment for what they call behavioral modification. It is difficult to maintain a full time job with having to rescue my son from school due to their lack of supervision so he is suspended because he lacks the emotional capacity to ‘remember’ rules. He can’t keep his hands to himself, still wanders off, makes funny noises and is punished for this, his disability!”

“School districts are required to offer full inclusion to our children. A regular classroom SHOULD BE (by law) the first option considered. RCOC does not seem to take this same philosophy. Children with special needs should be included in all activities at school as well as social activities.”

“I really wanted to attend a conference (autism) but the case worker said they do not have a contract with this conference. But I haven’t been to a conference last 2 years. This is the one I really need to go to. We can’t afford to pay for this because we are paying extra for my son’s other therapy every month. Can you make an exception sometimes?”

“I would like to see RCOC fund more educational conferences for parents AND support staff such as teachers, principals, tutors and school psychologists. I believe most programs work best when all team members are hearing and learning the same things at the same time.”

## **Health Services and Equipment**

Insurance, dental services, and medical care were mentioned by numerous individuals.

“P. has [medical insurance] and they don’t provide much for autism.”

“We are trying to get the letters needed so we can get support from Cal Optima. We are spending over \$500 a month on our son now waiting for all of our letters and then we will have to wait for approval.”

“I feel that we are on our own with no help. We have to pay her medical insurance and it was really hard to get insurance who would take her because insurance would always deny services to my child saying she had an ongoing condition and they couldn’t take over.”

“I have been waiting years for a dentist for my son (at least 3 years) and just found one in the last couple of months that there is a program he is able to utilize for dental work. Of course now, we have to get through the weeks and weeks and weeks of paperwork before he’ll actually get to see a dentist!”

“Another area that could be improved is finding a dentist who provides services for the developmentally disabled. I called all of the dentists on the list provided and none were satisfactory.”

“Our doctor needs updated information on higher functioning autism. He is outdated and incorrect as to recent research, information, and treatment needs.”

"I was unimpressed with the doctor who did my son's medical evaluation. He seemed to know little about Asperger's Syndrome and its behaviors."

"So sad that the doctors don't watch for or identify autistic behaviors early on. We could have saved much time, and began an intervention earlier."

"I can't get adequate medical care and there is no time for anything."

The need for medical equipment and supplies was frequently mentioned.

"My child also receives one case of diapers per month. These are valuable to our family."

"Also, losing the diaper deliveries has really hurt financially."

"If the child is still in diapers, Regional Center should provide them if the child doesn't have SSI (Children Services refused to provide diapers for kids who do not have SSI)."

"He needs a light portable wheelchair. He can walk etc but I can't shop with him unless he is in wheelchair and he has out grown the children's one I had. It is for control – I shop fine if he is in wheelchair – he just sits there – no problem. Otherwise I'm chasing after him – getting him off floor and if he gets upset he hits me."

"Durable equipment – wheelchair – is not covered by my insurance."

## **Transportation**

A few people mentioned transportation issues.

"I just borrowed money to purchase a 1993 van to transfer my 16 year old son around. I have lifted him into my car all these years. I need to modify the van and could use financial help."

"My child does not receive transportation to day care from school to day care at all. The school does not provide it and I am in a due process hearing at this moment."

## **Recreational Activities**

While some respondents were satisfied with recreational and social activities, other people were dissatisfied.

"I would like more RCOC clients to be able to take advantage of the recreational therapy provided by the [horse riding club]. Perhaps more publicity is necessary to encourage participation in this outstanding community program."

"The high school has begun a special Buddies program and has paired our child with another student. It seems to be an excellent program, and we are pleased that it seems to be working out well this first year."

"We have him engaged in community activities, primarily gymnastics and roller skating for which we pay 100% of the cost. This is needed for his fine and motor skills development. We have been told in the past that your organization does not help with the financial aspect of this therapy. It's unfortunate as he has greatly improved with these activities."

"I have single handedly created ALL of my child's recreation experiences. Through hard work, and lots of money for gifts, private lessons, etc. His recreation is not a 'break' for me. I must be ever present to trouble shoot. I resent RCOC equating respite and recreation."

"Regional Center needs to take a STRONG STAND on how to get children included in all social activities including camps and after school activities plus day care options."

"Why is it that no monies/programs are available to help consumers get involved in the community? Swimming lessons, money for basketball, YMCA, league participation with an aid to more fully participate with typical peers in the community."

"I wish there were more recreational activities for children such as music, group activities, etc."

## **Communication**

Some people reported satisfaction with communication.

"[Service coordinator] stayed with us for over a year, was always made available to us, and kept us informed on discussions."

"Most of my communication has been positive with RCOC."

"I am so grateful when I got my sons social worker in our lives I think she is the best, and has always gotten back to me ASAP."

"We are included at the meetings to discuss what they recommend."

"We can contact her anytime and she gives us the information we need in a short period of time and doesn't tire or show exasperation if we ask the same question over and over. She would answer them in a cheerful and respectful manner."

Numerous people were dissatisfied with communication.

"We never get a prompt return call when we do have question for our service coordinator. We never get follow up phone calls to see how my child is doing. If we dropped off the face of the earth, our service coordinator wouldn't even know!"

"I've left a message to our current case worker about 4 days ago and have not received a reply. This aspect of your service is very stressful for us. While we realize the large amount of families a caseworker has, when someone doesn't call back (not new to us), you feel as if you (and your child!) are just numbers; and perhaps we are, but we'd refer not to feel it if it can be helped. When we have gotten replies, we've been happy with the services."

"Also, it takes constant phone calls to get things done. I can't count the number of times I called our service coordinator to get my son speech therapy."

"They see us once a year and never offer services that could help our child."

"At M.'s IEP meeting I met her new case worker, she said she was new and didn't have a card yet or knew her phone number. I haven't heard from her since. That was 5 months

ago, and I've need help in dealing with the school district and getting M. the services she deserves. I'll be calling an IEP meeting soon, maybe she'll show up."

"The only time I hear about my RCOC worker is for IEP. During IEP I ask questions and I get the response 'Maybe we should get together and resolve all your issues,' and that day never comes."

"But there have been two people who are CONSTANTLY NEGATIVE and just want to argue or turn down a request as soon as I mention it."

"Some of you staff could have a nicer way of talking to people on the PHONE like saying hello in a nicer way and calling on time not 3 to 4 days later."

"Your staff should give me a FULL LIST of services that I can request. Instead, they keep it to themselves unless I find out about a service from another parent. And they always say, 'I'm here for you' but they're never at the office when I call and when I have a question they ALWAYS have to ask someone else for the answer and get back to me. I don't feel any emotional support from your office even though they mean well."

"An orientation meeting would be helpful."

"Not really sure who to contact in an emergency."

"My son uses sign language to communicate; however he has never had a service coordinator who could communicate with him. Our service coordinator asks ME for information."

"I would be pleased if some of the RCOC coordinators can speak in Chinese and notices in Chinese writing would be good for us who are not good in English."

"Also there should be better communication between staff members."

A significant number of people noted they had many questions and were not receiving enough information.

"The RCOC newsletter is helpful."

"RCOC prints a great recreational resource guide. But too bad so few families know about it, you should send a copy to every family because how are families going to request one if they don't know it exists."

"I am satisfied with the help that we have received so far. I don't know what else we are entitled to that would help our situation. Sometimes we get so much information that it is overwhelming but most of the time we just don't know what to ask for. I don't feel like anyone has taken very much time to explain it."

"Because we are unaware of the full range of services available, we do not know if RCOC is making them available to us".

“The most frustrating thing is that there is no consistency about how RCOC dispenses information, families talk and they find out they are not getting something they are entitled to. This can cause deep frustration.”

“Unless you, as a parent specifically asks, RCOC doesn't ‘tell’ you what all is available for your child.”

“If it weren't for my foundation and network of friends I've been fortunate to make in the last almost nine years, I'd be lost. RCOC hasn't been of much help.”

“The services that I do know about I have found from other parents. I don't feel that enough information is given freely. There is not much free time in my life so time is of essence and I don't actively pursue these avenues on my own. When not working I'm caring for my child. If booklets were given out as to various services I would find it useful.”

“We feel that information is ONLY given out if a family ASKS for something. THERE SHOULD BE A LIST OF SERVICES, who is applicable, WHY and HOW to sign up – given TO ALL CLIENTS. How do we know what to ask for if we don't know what is available.”

“What is available to my autistic child? It's a mystery.”

“Hard to find out what services are available, some of the service coordinators are not well trained to provide information needed. Try to put information on your web site so everything is transparent to the user.”

“Almost without fail, I have heard of services offered by RCOC through friends and other ‘network contacts’(other people with children with disabilities), rather than through the RCOC directly. It seems like most services are only offered when SPECIFICALLY asked for. I have never been able to tell if this is so because of reluctance on the part of the RCOC because of budget constraints, or just because of disorganization. Would it be too difficult to offer a list of services and/or vendors, particularly those appropriate to a specific disability? Even if the RCOC could ask for and keep information from families that HAVE found specific services; it would be great to have somewhere to go just to find resources, even if they aren't services offered by RCOC. Just kind of a ‘bulletin board.’ Maybe a website?”

“Please put out a hand book or website on all services available in the county.”

“To this day, I still don't know ALL that you can do - or ALL that my son can be apart of or get from your agency. I know most of what I learned about how to best help my son did not come from Regional. My own efforts in finding the answers was my best methodology.”

## **Transition Issues and Future Planning**

Another issue was the transition between the children and adult systems.

“I will need assistance in being informed as to what agency can assist in his future planning as he leaves public schools.”

“In ten years when our son transitions into adult services we will really need Regional Center support and guidance.”

"I would like to know about my daughter's funds when she turns 18 or what happens when she turns 18? Does she receive SSI or what? Do we receive funds for housing her? How long do we need to notify SSI before she turns 18?"

"Your program does nothing until he is over 18. Most of the literature you send out is not useful to us. It is a waste of money. Newsletters are for young adults not for children. Our worker is nice but honestly cannot say she is any help at this point. Support will be needed when he is grown and needs to live and work on his own."

## **Service Coordination**

Service coordination was a frequently mentioned issue. Numerous people reported satisfaction with their service coordinators.

"I have been extremely fortunate to have had two service coordinators in the entire 17 years that my daughter has received services by RCOC."

"We have had the SAME service coordinator for several YEARS. We just had our third annual review. This continuity is HUGE. She's done a fabulous job."

"For the past few years we have had the same service coordinator. Because of this he was able to really get to know my child. This was an asset in helping to make appropriate choices for her."

"My service coordinator is wonderful but I feel she may be overloaded with consumers. She is always courteous, helpful and sufficient in helping us, but she is hard to get a hold of."

"I would like to say that my social worker has been the best. She is always available to us and keeps us informed with any and all new programs".

"Our service coordinator is wonderful. She is knowledgeable, considerate, understanding, and truly cares about the well being of our son. She has supported us with any concerns we have. We couldn't ask for a better friend to help us with the many challenges we face. She deserves a commendation."

"Our daughter K.'s case manager has treated her as if she were her own child. She has bent over backwards, as has the rest of your staff to make sure K. gets all that she needs to give her the best possible chance to succeed in life."

"Our coordinator is the best. Being Persian is a great asset. My husband still is in denial and she has tried to help him understand that it is no ones fault. Persian men seem to have a great difficulty in accepting that their children are not 'perfect'. We recently moved to Irvine and [service coordinator] told us she was going to have to transfer us to someone in this area. I would really love to keep her instead. She has a great rapport with my son, she helps my husband understand and she helps me cope with the situation and with the feeling of being alone. I hope all of your clients have helpers as special as [service coordinator]."

"My current coordinator is the best we've ever had. No other ever stayed more than 6 months and so never knew my son, me, our needs or what was available to help us. If you can't keep these people they can't learn and be helpful. The other problem, before her, was that it seemed the coordinators job was actually to NOT tell us all the services or cash

supports available, or explain state or federal benefits. It may have been ignorance since they had never worked there very long, but it seemed deliberate to keep us from getting services and money. [Current service coordinator] knows everything and is always forthcoming with information and ideas. She is always available, does what she says she will and is the best you've got."

Numerous people reported dissatisfaction related to service coordinators. Poor follow up, turnover, lack of qualifications, and shortage of staff were concerns.

"We have had so many different service coordinators in the last 3 years, I never know who to call. The new ones seem inexperienced and sometimes don't know answers to my questions, or have, a few times, given the wrong answer."

"Service coordinators have very little knowledge about the needs of children. They take so long to respond to any request, which in turn, leaves you little time for fair hearing."

"The service coordinators are never at their desks, never return phone calls. They act like they don't care. I had to complain about my previous coordinator she was brainless with no knowledge, I called a supervisor and then was given another coordinator. Now I get a letter in the mail saying they are changing my coordinator again."

"Also, when I have wanted specific things for my daughter I have been told that it is not in the best interest of her (by my worker). How the hell does someone who sees my daughter for 15 min once a year know what's best for her and blatantly tell me NO when I want to find out about options or programs that may be available for her."

"Our representative quit RCOC and we have not been assigned to anyone. A temp showed up for the IEP at school but nothing has occurred since then. We were to receive some information in the mail but nothing has come. We've called but we were told no one has been assigned. This makes us feel unimportant and dissatisfied with your services."

"Although the service coordinators are kind and courteous, they don't remain on my child's case long enough to understand his needs. In general, I have experienced that the coordinators don't offer assistance or services that will benefit the child. You have to know yourself, what services to inquire about."

"I just wish that there were more service coordinators. We experienced delays in services because our son's service coordinator was swamped with work. In fact, we missed out on five months of respite care since the time we got the approval."

"When service coordinators are changed, we get word from outgoing one, but a new coordinator does not contact us right away. We are still waiting to hear who our new coordinator is and it has been over 6 weeks! I don't feel coordinators are given proper training prior to dealing with clients (especially new ones to RCOC). On occasion I've had to tell a coordinator what is available and how to go about getting it handled for my child! I also think my past coordinator's case load was way too high at times to comfortably be able to handle all concerns, or look into and inform us of other things available for our specific needs. She had 80-90 clients at a time, and I know her other clients were probably more time consuming than my own child, but that cuts down on the amount of time she could spend for our child."

“Staff turnover is a MAJOR problem at RCOC. Families cannot possibly get the services for their children with uninformed service coordinators. I became a parent service coordinator to avoid this issue.”

“Perhaps something can be done to address the turnover rate – better salaries, perks, etc. to form better, longer relationships between caseworkers and consumers.”

“In the 4 years we have belonged to RCOC we have had five coordinators. That is awful.”

“One big problem is getting hold of our assigned person and then receiving new assigned person almost as much as every six months.”

“It would be helpful if our case worker knew more about community services attended IEP's, and knew about opportunities for job training. Sometimes I feel as though I'm educating my worker – instead of the other way around.”

“Please train your service coordinators more. Please let them know how they can help families.”

“We are dissatisfied with the quality of service coordinators. Their lack of knowledge is inexcusable!”

## **Staff**

Many people stated they were satisfied with staff.

“High praise for our Early Intervention Specialist who made a dramatic impact in our son's early development.”

“The knowledge and assertiveness demonstrated by [staff] have been crucial in our being able to move our son into an area that can meet his needs.”

“Your staff is always VERY courteous and sympathetic.”

“We have been extremely happy and satisfied with [staff]. They were decisive team members in our son's educational plan.”

While some people were satisfied with staff, many were not.

“I have sat in several meetings where RCOC staff have ‘rolled their eyes’ at each other to discredit the person who runs this group home who happens to be my child's teachers aid for three years.”

“We have met three of the support staff over the last 5 years. It is apparent that staff at RCOC change almost yearly. If my son had a serious problem with epilepsy, I honestly don't know how effective the support staff would be (to me) based on the revolving door rotation I've seen so far.”

“There are no respite nurses available in South Orange County.”

“All continuation workers should be given sensitivity training before they are assigned cases and have contact with families - comparisons of issues with people they know or relatives is

in-appropriate, one issue that seems funny or trivial to the worker may not be to the family when that issue is compounded with others.”

## **Respite**

Respite was a frequently mentioned issue. Many respondents were satisfied with respite, however, it was the only service that some people received.

“We usually use our respite care so that we can have a break as a family as a whole so that our other children (non-disabled) can lead a normal family life.”

“I appreciate my hours for respite RCOC gives since I have no family or friends or any other supports other than myself.”

“I am happy with my respite hours, more is always better, but it’s nice to get a break every once in a while.”

“I appreciate the respite funding we receive. It allows us time away from our son without feeling guilty for paying for child care.”

“All I get is respite money. Nothing else.”

“The only services we receive are RESPITE.”

Numerous people were dissatisfied with respite.

“My family needs respite more than anything else. My son is 9 and never in this amount of years has this support worked. In fact it adds stress rather than helps us with relief!”

“Also, friends in other states get a LOT more respite hours than I do. (They are shocked by how few I get). I need more respite!!”

“The only support/services we have received are respite reimbursement. It is impossible to find someone who is willing to care for an autistic child for \$6.75/hour (approx) which is what you reimburse for. There is no incentive. They would rather take a job babysitting a child who at 10 can speak and wipe their behinds by themselves.”

“We would like to have more respite care. The 24 hours/month is just not enough time. If could have more hours we would spend more time for family affairs than taking care of our disabled child if she was to send to an institution. We can see how much this would cost per year but we do keep her at home and provide best care but cannot get a few more hours to enjoy with our other daughter. We need more respite care for sure.”

“RCOC should have explained about respite care (and how to get it) during initial meetings.”

“No one has ever called us and told us if we could use respite care. They told us about it, but never offered it to us as something we could use. What we would be interested in is someone who could come and tube feed our son so that we could go away for ONE weekend. We have not gone away from him for nearly two years because no one will do the feedings.”

“RCOC could better support with providing respite care for this population. Parents need a break and vacations. You cannot relax if you are not comfortable with who is caring for your child.”

“I have no family members or neighbors for respite for my child, I need an agency to provide services.”

“I do appreciate the respite money although I think the rules for its use are too restrictive causing me not to be able to always use it.”

### **Funding and Budget Cuts**

Funding and budget cuts were frequently mentioned concerns. Specifically, several people stated problems qualifying for government benefits.

“RCOC has seen their funding cut due to their non-use of funds. It seems whenever you ask for assistance there is always a delay to funding issue.”

“Taxpayer’s dollars are not being used effectively to actually help those with special needs. Most all the funds are spent on administration and deluxe offices for the administrators. Real and actual help for consumers is next to nonexistent.”

“Many times it seems that the Regional Center is MORE concerned about the BUDGET than the well-being of the people they serve (generally supervisors rather than coordinators).”

“It’s not easy getting SSI for a child who’s family is making more money and the child can’t receive SSI.”

“Children with disabilities should automatically qualify for SSI, food stamps, and cash assistance, especially if they are being raised by a single parent.”

### **General Satisfaction**

In general, many people were satisfied with the services and supports their family member received.

“There is a long road ahead for our son and our family as a whole, but I have confidence in RCOC that they will be with us every step of the way and will be a big part of our success.”

“I am very grateful for the services and financial support (respite) that we receive and want you all to know how much you are appreciated and how important you are in making a positive difference in the children and their families’ lives.”

“I am very thankful that I found out about Regional Center and C. is too. I don’t really know what me and C. would have done or if I could have handled all of this responsibility by myself without Regional’s help.”

“RCOC does a very good job of offering educational opportunities for parents of autistic children.”

“We would like to thank you for providing such wonderful services for our daughter. You have made a HUGE difference in all our lives.”

"We are grateful for your dedication to serving those with disabilities. You have allowed us and her dignity and respect."

"The parents of your clients are by far THE BEST ASSET RCOC has going for it. Grass roots organizations are far more helpful with information."

"RCOC has been good to us. They have tried to help where possible, and seem to understand the problems that come with dealing with a child with autism. It is a shame that it took us so long to find out about RCOC."

"We have found RCOC to be very helpful and supportive over the past few years. There seemed to be a wonderful change in support the last 3-4 years. The only reason we are able to keep our child at home is RCOC support both with financial and verbal support from RCOC staff and management. We could not do it without you – our quality of life is much better and our son is at home!"

### **General Dissatisfaction**

Even though many people reported overall satisfaction with services, a significant number of families were dissatisfied.

"My child is eligible for services through RCOC even at age four because he has been diagnosed with autism. RCOC doesn't seem to have anything to offer! Regional Center has provided us with as limited services as a school district which is sad. These children have a right to be educated and have service to help them become as independent as another person on earth. It is sad to see a person treated with so little care and disregard of what she can do and may be able to do for society. I am very disappointed in Regional Center's services and staff. It has been a fight to get support."

"These children need assistance and so do their families when they require help it should not take 3-6 months to get it. Time is crucial for the child and family. RCOC should focus on helping not looking at ways to disqualify a child."

"RCOC is not supporting us in ANYTHING, financially or even helping us connecting to community activities, or even respite service. Please be more supportive to the parents with disabled children, rather than saying, 'Oh, its all school district's responsibilities, or you are not qualified.' We are very tired of hearing these excuses, that you do NOT want to help!"

"I am also frustrated on trying to get help with related services. The Regional Center spends all of its time in bureaucratic paperwork and unnecessary evaluations. I do not believe you are helping parents with planning services or coordinating help."

"I think that the purpose of RCOC is to support its own bureaucracy and put enough roadblocks in the way of the parent until he/she gives up. Since I have never met anyone who believes that Orange County Regional Center is helpful or supportive, I think that this practice is widespread. I think it is nothing short of criminal to force already stressed and overworked parents to fight another agency to obtain necessary services."

"I'm frustrated and disappointed in the RCOC and have given up on any help from them. It is pointless to try. I am so busy trying to care for my child with a disability, my family, and working, I don't have time to fight for services that should be given to my family!"

"We only stay connected to Regional Center in case of an emergency. Otherwise I find Regional Center absolutely useless in our situation, but we jump through the hoops anyway. It seems to me Regional Center finds excuses not to help rather than be helpful."

"RCOC is one of the most poorly run agencies and they had better get their act together soon, or they are going to be completely overwhelmed. Autism alone is skyrocketing, and the Regional Center has failed to provide any semblance of reasonable service to the newly diagnosed. Children that could have been helped immensely with intensive intervention have been instead allotted 7-8 hours of actual therapy, turning them into lifetime RCOC consumers, when if they would have had access to a 30 hour program early on, had a chance at a normal life."

RCOC has always passed off any services my daughter needs as being the 'School Districts' responsibility not theirs. I'm very unsatisfied with RCOC. They have provided us with no help or services whatsoever since my Autistic child turned three years old."

"I hate to say it, but on balance I feel Regional's influence in our daughter's life has been more negative than positive, that is, they have actually done damage through incompetence and mismanagement, although there are some sincere employees trying genuinely to help-most don't!"

"We don't feel that there is much out there as far as services or support for us as a family trying to cope with our child's disability. It seems to be true mostly because so many services are based upon the family's income, which needs to be shockingly low to receive any support (like IHSS or SSI). Our income is NOT high, but it is too high to receive much support."

"After 3 years of age it seems to me that my child was put on almost a 'permanent-ignore' status by the after 3 counselor assigned to us. She rushed through her meeting with us and basically we have had little or no contact with her. Versus, the before 3 programs sponsored and endorsed by RCOC. Our before 3 counselor was very hands on, attentive, involved, had many suggestions and was engaged in the process. To the parent (myself) it's almost like RCOC acts as though my child's disability magically disappeared once he turned three, which simply is not the case."

"We feel that RCOC has been very difficult to deal with. Their first response, when we request help is, 'NO!' Everyone is diplomatic but very little help has been provided to us without a constant battle. Other Regional Centers are easier to deal with. We have friends in other areas of California with children that have similar disabilities. Other Regional Centers are more willing to provide services that are appropriate without parents having to fight for everything. Many parents that I talk to in this area are EXTREMELY dissatisfied with RCOC but do not have the financial resources or energy to fight the system."

"All our workers have been the BEST we always loved them, but it's the services that we don't receive that I have asked about for the past three years."

"I am continually having to fight RCOC for everything. The services in Orange County are not anything like surrounding areas. For a county rich in taxes I have a hard time understanding why services are so minimal."

## NEBRASKA

Approximately 23% of survey respondents from Nebraska wrote qualitative comments. These comments are summarized by theme below.

### **Service Coordination**

A few people reported dissatisfaction with their service coordinator.

“I feel that if a service is asked for the service coordinator should set up or call and make the initial contact. I feel that’s what they’re being paid to do.”

“State of Nebraska caseworker does not help at all!”

“Me and my daughter do not have a disabilities worker and I would like to have one.”

### **Respite**

Respite was mentioned by a few respondents.

“The only service we get right now is respite care. Without it I would go crazy.”

“Because of the challenges of my child, it is difficult to get someone to stay to do respite care for him. It’s hard to find a caregiver for our son has high demands and people don’t apply to help him. This summer, as I work, it will be difficult for us for we don’t have anyone applying to work with him to keep his hours allowed – an on-going problem. He may be without a respite worker.”

“The one problem is I have to schedule months in advance to secure a spot which is not conducive to last minute or even one month advanced planning.”

### **Funding and Budget Cuts**

Some families noted the need for monetary assistance.

“I would like to receive food stamps for my child and me regardless of income. Because he is disabled and likes to eat different things. It is stupid not to receive stamps at all because of income. I think people with disabilities should automatically receive SSI and food stamps.”

“As M. grows older, it is getting progressively harder on me to handle her. Not only that but financially. I am being drained each and every month.”

“[I need] help with the utility bills.”

### **Overall Satisfaction with Services**

Overall, several people reported dissatisfaction because they were not receiving enough services or assistance.

“I can’t believe there aren’t services available until children reach 21. It should be a concerted effort between school and DDS.”

"I have been waiting for children's waiver for the last two years, the only service I do receive is respite and my service coordinator. I have been denied for in-home support and residential services."

"Day care for behaviorally disordered children is needed."

"If I could get help getting a van for transportation, that would be great."

## **NORTH CAROLINA**

Approximately 46% of survey respondents from North Carolina wrote qualitative comments. These comments are summarized by theme below. Community Alternatives Program (CAP) for Individuals with Mental Retardation and Developmental Disabilities refers to the North Carolina waiver.

### **Home**

Respondents noted issues related to the home environment including the need for accommodations and placement.

"Overall everything is great, other than I'm in the process of finding a flat level house so it can be easier for me and caring for my child, because she's 9 and weighs a lot and I'm having to carry her up and down stairs."

"I would like to find out how I could get a ramp made on to our house and how to get our house adapt to get his wheelchair in and out of our house."

"I have my child at home again and am trying to find enough services/supports so that I can. He is happier when at home and there is no group home facility in this county for him or any children, which is a shame."

"T. will be with me as long as I can keep him. Some people want him in a nursing home. No way if I can keep him."

"She needs a lot of help. I wish I knew more to help her. I think if I could get her in a group home for Autism she could learn a lot. I love her so much and I want the best for her."

"I am very happy with the support that my child and I are receiving. I really feel that without those intensive supports and without the adoption into my home my son would have ended up in an institutionalized setting."

"I love keeping my son at home with me."

### **Employment and Day Programs**

Only a few respondents reported issues related to employment and day programs. In addition, several people mentioned it was difficult to work and care for their family member.

"During the summer J. was suppose to work at [a workshop]. They had no work, J. sat at a table for 8 hours daily causing his compulsive behavior to kick in."

"I know for a fact that they are not in compliance with state day care laws. [Agency] management of [a day care program] needs to be seriously investigated."

"We want to keep them home but we have to work."

"Without these services I would not be able to work outside of the home."

## **Education and Training**

Several people mentioned issues related to education and training.

"My child is six years old and attends public school. He is in a regular class with a resource."

"I am really pleased with my daughter's preschool."

"The [learning center] where my child attends is the only service that is offered at this time. My child receives physical and occupational therapy at the center and for this I am truly grateful. This school semester in August my child will be attending public school and at this time I am concerned about his therapy, but the school notified me that they offer this service. At the current time, I am unaware as to what extent. I feel the [learning center] staff has helped my child tremendously."

"I would like to know why this county doesn't have speech therapy for my child during the summer time. She is getting it at school for just an hour a week but not in the summer time. She really needs this."

"School systems say they have no funds. They never do what they say they are going to do. Not enough teachers for each child's needs. Schools need help."

"Some provision needs to be made for children whose birthdays fall in the summer. [Early intervention] services end at age 3. The preschool programs start in August when regular school goes back. Some children may have 3 months without any [early intervention] services. There should be provision to provide services to these children until they can enter a preschool program."

## **Health Services and Equipment**

Insurance, dental services, and medical care were mentioned by numerous individuals.

"We have medical insurance through our jobs and it saved us. Our son has a rare metabolic disorder and his meds are over \$4,800 a month. We have no idea what we will do when he ages out of our insurance. SSI will not pay for them and it would not be enough anyway. Phone calls have been made to the state with no avail. Without these meds he will be in a coma in 24-48 hours and thus death will ensue."

"I did have problems getting him dental care at first but it all worked out."

"Just wish I could continue with therapy services so my child doesn't regress in her physical state. The state doesn't realize preventive therapy is what some clients require to maintain oneself to remaining healthy. Preventive therapies would be much cheaper than medical

procedures. This is what will happen without such services. Especially in my child's current state.”

“He is not able to get out, can't sit up and have to get an ambulance every time he goes to the doctor. He has big kidney stones, lots of them.”

“My son gets very little OT and PT and only if it is school related which they are now just being used as consultants. Before it was only 15 minutes every 2 weeks.”

While some people stated they received the equipment and supplies they needed, other people said they had difficulty obtaining such items.

“I have had very good help to make my son J.'s life easier. We have a hospital bed, a lift, pillows, wedges, diapers, and something he loves – a good supply of chocolate [energy drink].”

“We are very grateful for CAP services. Our daughter's disabilities require expensive therapy and adaptive equipment that our insurance company does not cover.”

“The only problems we have had are those connected with the amount of time it takes us to receive special equipment and in some cases the denial of special equipment that we believe our child needs.”

“A major problem I have is getting the equipment and supplies to take care of my child. Since I have been apart of this program I have lost supplies and not received any equipment my child needs due to the process of paperwork, the state, insurance, etc.”

“It would be helpful if families with members with disabilities could have access to small funds to order supplies, equipment, etc. without having to go through the very lengthy process of committee after committee approval. These purchases would include items immediately needed by the individual with DD.”

## **Transportation**

Numerous respondents noted dissatisfied with transportation.

“Transportation is our biggest problem. My husband and I have disabilities and our child has asthma also. We have no car, no transportation. [The agency] charges \$5.00 a trip now. Sometimes we can't get me, my husband and son are on Medicaid. Our son has transportation to pre-K but that's all. We would like to know if there is a way to get our son transportation.”

“The transportation changes have been very inconvenient for our family. [The agency] no longer provides this to us. The public school system now provides this. But our child is not able to use this because of her disabilities. The school is reimbursing us for transportation but we are having to drive one hour round trip to school. This has affected our work schedules.”

“Also I have a hard time getting me Medicaid transportation. [The agency] will not send a van for J. to go to the doctor. She can't ride the city bus. The doctor has written a letter and they still will not help with transportation. I wish the state will help me. Please.”

## **Recreational Activities**

Several people stated that there were not ample opportunities for recreational and social activities.

“Both of my boys have DD. Life for them can be somewhat challenging. There needs to be more group meetings for kids to interact with others, with flexible hours. Between school, therapies and doctor appointments, time is hard to find, but when you find time there is no special place to take kids to have fun or play.”

“We do struggle to find ways to provide normal activities as a family unit and especially for our non-disabled daughter. We have to do a lot of things separately rather than as a family.”

“They need to have some areas that have handicap equipment swings (high backs with straps and wheelchair) in the local area instead of what they call accessible (walkways) so some of these children can participate instead of just watch other children play. Personally I feel things should be important to or for the child. My child goes wherever we go. Most of the community activities are not appropriate for her because of the extent of speech problems (for others to understand), her fine motor skills, and gross motor skills.”

## **Communication**

For the most part, people were dissatisfied with communication. Many people noted they had many questions and were not receiving enough information.

“It takes an act of God to get a hold of the case managers. You learn to leave vague messages in an attempt to get a reply.”

“The only problem I have at this time is that when teaching staff changes are made the parents are ill informed, most of the information I received came from my child about staff changes.”

“In the school system the teachers need to have a cell phone or pager so I (we as parents) should have a way to contact them. I have to call the school back and forth I don't think that's right. In case of emergency the case manager and counsel should have something too.”

“I have had a hard time learning what is available for our son. I feel like I have had to do it all myself as far as finding out what is available to help us. We are not connected with Mental Health Services at this time. Through a series of phone calls I have finally spoken with the right people (I think anyway) and have an appointment to talk about services next week.”

“Most access to information has been initiated by me (parent) versus volunteered by case worker and/or other professions. I expected information to be more forthcoming versus only upon request.”

“There should be more information for families that have just found out their child has a disability.”

## Transition Issues and Future Planning

Another issue was the transition between the children and adult systems.

“My daughters are 13 and 10. I hope that they will have choices as to where to live as adults especially as my husband and I get older.”

“Our main worry is what will happen when our boys age out of the school system. There is no program for adult day service for someone with their needs. We want to keep them home but we have to work.”

“Overall we did not find out about CAP until he was 16 and then we went to the committee without any help from caseworkers. I feel there is was and continues to be a lack of continuity and services for disabilities especially for the average working family.”

## Case Management

Many people were satisfied with their case managers.

“If I call [my case manager] she does the best she can to see J. gets what he needs. If all case mangers were as concerned for the children as she is the system would run a lot smoother.”

“I don't think I could have gotten this far without my case manager. She has really been a big help.”

“Our previous case manager was the best ever. We had her for nine months and she really worked hard to help set up the program that my child is now using. That is what I attribute my son's successes to.”

“[Case manager] is the most knowledgeable person and very caring, concerned for my child's progress. Case worker of the year.”

“My child's case manager is absolutely wonderful. I couldn't ask for a better more knowledgeable or caring person. She really seems to take an interest in my situation and helps as much as she can. She's truly a blessing.”

Numerous people reported dissatisfaction related to case managers. Turnover was a primary concern.

“We feel like our child's needs are ignored by your case worker. We went to summer camp last year and met other parents with disabled children from other NC counties and all were very happy with their case workers and services.”

“Over \$500 a month for case management. What a crock. The case managers say they are bogged down and underpaid but I know many who are just slackers.”

“Case managers are not educated for their job and the last two have been trainees.”

“Our CAP/MR caseworker does not follow through on things requested of her. She also schedules appointments and either just does not show up at all or is 3 to 4 hours late.”

"My daughter has had three case managers in the past year. I, her mother have let them go because of non-communication, uninterested, unwillingness to help or answer questions. We are now on our third case manager and hopefully she will work out. Case managers need to help guide caregivers in the process of all plan of care services, goals, etc."

"J. does not have any case managers. She needs one cause of her ADHD and her mental retardation and she is developmental delayed. Please call."

"We know that our CAP slot is a blessing in a million ways. But we feel that we can't complain about our case manager. We feel that we may lose our support if we let you know that we don't think our case manager is meeting our expectations."

"We have lived in this state and area for five years and in the first three years we went throughout 6 different case managers and I learned how to work for my child."

"We have had at least 5 case managers in three years and at least 30 CAP workers in the same period of time. It's stressful and exhausting to hire or change workers (case managers). It adds more work for the families. My son can't remember the workers' names because they are never here long enough."

## **Staff**

Many people stated they were satisfied with staff.

"My son has really benefited from the services he receives. His worker really seems to genuinely care for his well being and progress."

"We have been very fortunate in our situation. Our daughter receives excellent care from her case instructor."

"We have been extremely blessed to have an excellent in home support staff."

"The mentors have been wonderful as well."

While some people were satisfied with staff, most were not. Reasons for dissatisfaction included turnover and a lack of qualified staff.

"I have noticed that in order to find a good support worker it is necessary for me to recruit people. There seems to be a tremendous shortage of people willing to work with disabled children. I think the main reason is the hourly rate offered by the agencies in the area."

"Personnel was not trained properly but was sent out [to our home]. They had no autistic training. This in turn caused even more aggressive behavior. They said this is who they had hired to work with J. and if we didn't like it to find another care provider. They would constantly send different people out due to staffing and with autism this caused escalated behavior."

"We've probably had more than a dozen workers in the past five years. We have had difficulty with workers coming in the home and not knowing very much about our son's disability. Also we have been the primary trainers for the workers in our home."

“Staff is constantly changing.”

“We have not been happy that our child's one-on-one worker now has many additional responsibilities given to her since [the agency] has taken over the school facility. They are extremely short handed. There are times I need to keep my child home because of lack of staff.”

“However, local agencies providing support staff have not been able to meet our needs for staff on weekdays and especially weekends. We go for several months without staff even though we solicit multiple agencies for staff. We rarely find anyone to do an overnight so we haven't had a vacation in six years.”

A few people mentioned they would like to be paid to provide care and case management for their family member.

“I think the parent should be hired to work. They care if the child learns. They have a difficult time holding down a job because of late workers, they quit or don't show up. It has made it a nightmare for me to work. I care if my child learns and I'm here everyday. I'd be the best teacher for my child. I want him to reach his full potential.”

“My time as the primary caregiver is never compensated. It would help to have some financial assistance so I would not have to work outside the home 30 hours a week along with managing most of the needs (doctor appointments, equipment, research, conferences, etc.).”

## **Respite**

Respite was a frequently mentioned issue. For the most part, people were dissatisfied with respite.

“Respite is also very hard to come by especially if your child may be a little work.”

“We need an overnight respite home in this county. It would be wonderful to wake up one morning FREE!”

“The respite hours need to be increased. With school out 2 months during the summer, 2 weeks at Christmas, week at Easter, and teacher work days there is not enough respite to have a break. I work and after using respite which is barely or not enough to cover when school's out there is none left for a weekend break.”

“The current situation with restrictions on respite hours makes it difficult to have some of our needs met. I need extra hours during school vacations but the rules don't allow us to use respite for that. Since I have several hundred hours of respite I can't use. It's all well and good to say that respite is for unplanned activities but if the respite provider is not scheduled for in advance there's no caregiver available. So in essence the state gives us unusable respite hours. I tried to use them recently for a trip out of state with my husband but the agency wouldn't allow my son's regular caregiver to be used and since we refused to send our son to a stranger when we were leaving town, we had to cancel the trip. Once again respite hours I need to use but can't.”

“Also respite is non-existent and I feel this could improve but agencies don't care if they pocket the money either way and parents as usual lose out in the end.”

“The inability to schedule at least some of the respite regularly is also a problem.”

### **Funding and Budget Cuts**

Funding and budget cuts were frequently mentioned concerns. Specifically, several people mentioned difficulty obtaining government benefits.

“Early intervention is the key and wait list funds are not enough. Don't cut my kids funding but spread out the CAP money that's out there.”

“I wish that each child's case would be looked at individually instead of budgeting a set amount per child.”

“There appears to be a large sum of money though I don't know the exact amount allocated to my child yearly. It would be wonderful if I could directly help in the actual allocating of the monies. Perhaps using some type of voucher system.”

“State funding freezes may ‘stop time’ in state spending but at what price? Unfortunately, the window of time available for the crucial development of a child does not stand still while state bureaucrats attempt to fix the budget.”

“With the state budget the way it is and many cuts across the board, I am very concerned as a parent what will happen in the future.”

“My child can't receive SSI because my husband and I make too much money. I don't think that it's fair because the only way my child can receive any money is for one of us to quit work and we can't do that.”

“She can't get SSI because my husband makes too much. Same for food stamps, because he has an IRA we can't get help.”

### **Overall Satisfaction with Services**

In general, many people were satisfied with the services and supports their family member received.

“I am very, very, very happy with the services that I am getting from them. It is working for my family.”

“My son has really benefited from the services he receives.”

“An excellent agency and an outstanding case manager. We know many families that have not had our success with the system. We have done our homework, conducted some very tough interviews and got very lucky.”

“Thanks for supporting the families. I hope things come better for my child because he deserves all we can give to him.”

"In all honesty, most of these positive responses are because I am very active as an advocate for my child. I do not accept 'I don't know' or 'it hasn't been done before.'"

"Thank you all for the help and support you give to me and my family in raising S. She takes a lot of work but is worth every minute when she smiles big or gives me a kiss. I am a single mom with 3 kids working and trying to succeed. Your support helps me to do just that ...Succeed."

"Since he was two weeks old he has been involved with early intervention and family services. I feel very lucky to have them in our lives and I feel that without them my son wouldn't be in the great shape he is now. I would love to move elsewhere (another county) but I am afraid that the services for my son wouldn't be as good and he also wouldn't be with people who have known him since birth. As a low income parent, this county has been an amazing county with amazing services for my son."

"We want her in our home. The system is not perfect but the system has made it possible for us to survive as a family and continue to work to provide for our family."

"Having CAP services for my son allows us to lead a somewhat normal life."

"My son and I moved to another state a few years ago after living in NC. We moved back to NC after only 6 months in the other state. The support and services we receive in NC is incomparable to the other state. NC is amazing in its commitment to all of the children here. Please keep up the great work if it were not for the services we receive my son wouldn't have made it as far as he has."

Even though many people reported overall satisfaction with services, numerous families' needs were not met. The comments below reflect this dissatisfaction.

"This county really needs to have their whole system of services look at and organized to where parents are not always having to beg and plead for their child's needs to be met. Too many parents won't fight for/advocate for their children and that is what [the agency] hopes for."

"Our area Mental Health program is very unsupportive. They do everything anti-person-centered. They don't seem to value the families or consumer opinions of the services of what they want and need."

"Due to state Medicaid policies requiring measurable progress toward individual goals, our child is no longer receiving private occupational, physical or speech therapy. In some cases, like that of our child, progress is made by just maintaining the present level of functionality. After six months of limited therapy, we are seeing signs of regression in our child. Individual education plans (IEPs) now require goals for literacy, numerical, and vocational skills. For children like our child who have no verbal skills and limited use of their hands, this is a ridiculous requirement. An IEP should reflect the individual's needs and potential. Many of our children will never fit a 'one size fits all' approach to DD."

"NC as compared to Wisconsin and Ohio is like living in the Stone Age. A huge bureaucratic structure and no services. It takes an organized staff to develop a community programs for MR/DD and NC just doesn't have it."

“Funds need to be available for more families with DD children. The waiting list is a joke. Newly diagnosed families need more supports.”

“Although my daughter has a severe disability I know many families that get no services at all. I also know other families that use the services to the max. I think everyone should get moderate services so that more children can be served. Family resources should be considered to see if families can supplement services. High income families that can afford to pay for some things are treated the same way as those with less or no resources.”

“Average person does not understand a child with these disabilities. There needs to be more brochures for people to understand. People say to me, well they look normal. Looks have nothing to do with it. There is little awareness and there needs to be more put out at schools and people's workplaces.”

“Families need better control over what the child needs and how the money is spent. Also more control over who works with the child and their level of training.”

“It takes a lot of work for the parents to get adequate services that are available. First we have to dig out what's available from case workers. Then parents have to fill out an unnecessary amount of forms and paperwork to get some help. Depending on the degrees of the child's disabilities. Some parents just don't have the energy and time to get some of the paperwork done to get some help. Personally I think case workers need to be trained to evaluate the child's condition and minimize the work that's required from the parents before she/he throws the standardized paperwork to the family. The objective here is to help the family in needs not to document everything to avoid liabilities.”

“We are a family of four. I have not worked since before my pregnancy with my daughter. I am sure that the law would say well why aren't you out there working? Well I have the right to stay at home and take care of my children just like another mother does. I could work but I have a fiancée at home that is disabled and a deaf daughter. We need laws in our government to help mothers like me who try to do the best who make sure their child gets to all of her appointments who is trying to make sure that she can communicate with the rest of the world despite her hearing loss. With an income of about \$1200 a month, two kids, two disabled people in the home, medications, and other needs, what is a mother like me to do?”

“I am a working single mother with a daughter who has special needs. I work very hard at my job. My daughter's health, happiness and well being is what I devote my life to. I have to say that I am very disappointed with fighting for everything she needs and maybe sometimes getting her the help she needs.”

“When I die of a stroke or end up in a mental hospital from the stress of caring for my child then will she get services?”

Approximately 41% of survey respondents from Utah wrote qualitative comments. These comments are summarized by theme below.

### **Home**

Respondents noted issues related to the home environment including the need for accommodations and placement.

“The money we have received from DSPD has paid for the ramp that A. uses to enter and exit our house and has helped us keep our home so A. has a place to live.”

“We would not be able to care for our child at home without family support assistance.”

“Our child is truly loved and we are soooo grateful for help in being able to keep her home with us.”

“The services we receive have made a vast difference in our lives. When we did not have services we were afraid we may not be able to keep our child at home and care for her due to many other circumstances in our lives.”

“I am beginning to see a future need for supported residential living accommodations locally for my child. I don't hear of any progress.”

### **Education and Training**

Only a few people mentioned issues related to education and training.

“I feel that Vernal has a need for a special therapy service here. In Hobbs, New Mexico- where R. was born, there was a school for handicapped infants (3 months to 3 years) where parents and infants went for help and advice.”

“I feel frustration because I don't feel it is beneficial for our daughter to be mainstreamed in school.”

“I am frustrated at getting therapy services. The preschool is unable to provide individual attention - insurance won't pay - many providers will not accept Medicaid.”

### **Health Services**

Insurance, dental services, and medical care were mentioned by a numerous individuals.

“What I need most at this time in my boy's life is medical help. All the guidelines say I make too much. So I get no help for medicine or doctors for him. And no insurance will take him.”

“Having Medicaid for our two sons has saved us a lot of money on insurance co-pays.”

“We first went to DSPD to see if we could get eyes and dental that our insurance didn't cover. We were told that we didn't qualify for anything else but we could get some respite care.”

"I really appreciate help with my child's medical bills and with respite care. He has many medical needs and it is very expensive."

## **Transportation**

A few people noted dissatisfied with transportation.

"I am disappointed in my access to transportation, but feel that it is a small price to pay for the many other needed services we receive."

"We have been very satisfied with support but we still struggle with the transportation issue. I am an older parent with arthritic tendencies and back problems and I still have to lift a 40-50 lb child from a wheelchair into the car if I am to go anywhere."

## **Communication**

Only a few people reported satisfaction with communication. For the most part, people were dissatisfied. Many people noted they had many questions and were not receiving enough information.

"We have asked several times to have family council meetings in the evening so we can attend, but they refuse to adapt their meeting schedule for people who work."

"It would be nice to know what other services we could receive."

"I am still obtaining information by keeping an open ear. Most of the time, I just don't know what questions to ask. However, because of my coordinator, she has brought about some help which has definitely benefited my son and family."

"In general, though, my experience is that the coordinator is less than forthcoming about what services are available."

"Maybe the Family Council could supply a list of respite caregivers that meet my needs. I appreciate what DSPD has done for our family. I do wish I'd get more information about the services available."

## **Transition Issues and Future Planning**

Another issue was the transition between the children and adult systems.

"I don't think our school is doing a great job with transitioning our son. We are very worried about what comes next after he is 22."

"I am not particularly satisfied with MY ability to access the services and information that could help me with my 16 year old with quadriplegia as a single mom, as he's getting more towards adulthood."

"DSPD is great. I would like to become more involved as my children get older."

## Support Coordination

For the most part, respondents were satisfied with their service coordinators. The only complaints related to turnover.

“Our support coordinator has gone out of her way to befriend our daughter with special needs. She brings holiday treats, gifts, etc, and helps her with any new transition, i.e. starting a new school year, pending surgery, etc.”

“Our support coordinator is wonderful. She visits the school often, attends T.'s IEP meetings, and calls me frequently to see if we need anything or how things are going. She is very supportive when there is a problem.”

“I am incredibly thankful - more than I can say - for the support we have received from our support coordinator and from the Home and Community Based Medicaid waiver. It has been the key ingredient in helping us get our son to where he is now.”

“[Support coordinator] has always been very helpful, knowledgeable and professional. We have worked with her for several years and it is great to work with someone who knows you, has a history with you.”

“I talk to my support coordinator frequently. She spends time not just with me but with my children with disabilities, so she knows what their needs are. I feel she does well given the budget restrictions.”

“We would like to keep the same coordinator for longer periods of time.”

## Staff

While some people were satisfied with staff, most were not. Reasons for dissatisfaction included turnover and a lack of qualified staff.

“I have found nearly all the support staff to be helpful and concerned and anxious to help us assist our child in having a fuller, more productive life.”

“I have access to two family support programs. It works well for me because I can hire my own children to care for my child or any person I feel comfortable hiring.”

“We are highly satisfied (90 %+ ) with the care-providers and the break it gives us.”

“Right now we are very happy, but in the past some staff workers smoke and swear and take these kids places our family would never go.”

“I've gone through 5 respite providers in the last year. They won't commit.”

“We have had a high turnover of employees. It seems like we are always looking for someone to work for us.”

“We are very appreciative of the services we receive. Living in rural southern Utah, we face several challenges, including a lack of adequately trained personnel.”

“I wish that the quality of the staff workers that come to our home were better.”

## **Respite**

Responses were evenly split between people who were satisfied with respite and those who were dissatisfied.

“We basically receive money for respite and a Medicaid card. These two services have helped us immensely.”

“The respite support is much needed for parents who need time away from 24 hour care for a disabled child. It is the only way to be the 'best parent' you can to your disabled child.”

“Respite services have been wonderful for our family.”

“We REALLY needed and made use of all respite money. It kept our marriage intact through a rough time.”

“Recently, two months, my child has become more of a challenge for me, a single mother, and my support coordinator has tried to help by requesting respite help. But since I need that help on weekends, it is not very available.”

“Respite services have been wonderful for our family. My child's poor health meant that funding ran out before the end of the year. I requested an increase in services for this year to cover that need.”

“My child never sits longer than 10 minutes on the same place so I want more hours respite care to give me more breaks, because I'm working mother.”

“My biggest problem is finding respite care that is clean, competent, and caring, and who is available at MY need. Maybe the Family Council could supply a list of respite caregivers that meet my needs.”

## **Funding and Budget Cuts**

Funding and budget cuts were a concern for many respondents.

“My only problem is that the money always runs out. I wish more was available. However, there are lots of families with huge needs.”

“The only thing I would change is: to have more money available. When I get thinking of what my son needs (or what I think he needs) the money runs out fast!”

“Would like to have more control of paying providers and not have to use a fiscal agent who takes part of my child's budget.”

“We have been trying to get social security for our child but have been turned down twice. Is there more information on this?”

## **Overall Satisfaction with Services**

In general, many people were satisfied with the services and supports their family member received.

"The help that our family has received has made a huge difference. It has made our life livable. Our son is a LARGE stress. It has given my husband and I breathing room. It has also given us time to spend with our other children."

"I cannot emphasize enough how these programs have bettered the life of my son and my family. My life is less stressful and my son's life - his quality of life - has increased with these programs."

"Without this DSPD aid and Medicaid our family simply would not have been able to go on for this long. I never would have believed how much time, effort, and money it takes to raise a special needs child."

"I am very happy with this service. I don't know what I would do without it! I don't think I would be able to have my child at home. I definitely know I would not be as stable and able to care for him if I was not able to have the help I do!"

"We've really enjoyed the services we've received for our son. My family and I were at a breaking point and now we are all feeling better about things. Thanks for getting to us before our family totally eroded! It helps!"

"DSPD has been a life saver for our family. They have helped our son so very much - with community activities and doing home responsibilities and learning new skills. Thanks so much for all you do."

"It can be overwhelming to begin services when first funded, however once services started they became vital to my family. It is unfortunate that we had to reach below rock bottom to be funded. We didn't ask for help until it was needed."

Even though many people reported overall satisfaction with services, numerous families' needs were not met. The comments below reflect this dissatisfaction.

"I think I understand the reasons for the waiting list for DSPD. But, I needed the MOST help when my child was born to up to two years and that is when I was on the waiting list (2 years). I almost had a nervous breakdown."

"I feel the state is doing an OK job at offering services. I would like to see more offered in the southeastern part of the state. More programs offered to involve children in mainstream community activities."

"Would like to have more than one/two providers in rural areas."

"Even with such great support it is sometimes hard to find help WHEN you need it."

"I want to bring up two points: 1) I have two children and I feel that I am forced to pick services for one over the other when requesting one-time funding. 2) As my son gets older I find I need more services."

"I have a son that continues to be denied services they say he does not qualify however some of his disabilities are the same as his younger sister with services. They both are developmentally delayed. They both have a seizure disorder."

“We have two children with disabilities. One receives services. The other does not. The one that receives services is doing well and making progress. Due to ridiculous technicalities in the classifying process our other child does not get services.”

## VERMONT

Approximately 45% of survey respondents from Vermont wrote qualitative comments. These comments are summarized by theme below.

### Home

Only a few respondents mentioned placement issues.

“[The agency] has been great. Without them there is no way I could have made it. With out [the agency]/State of Vermont, I don't think [my son] could stay at home. Thank you [agency] and the State of Vermont. [The agency] has been helpful in identifying services, however there are too few available (lack of respite workers and virtually no long-term placement options). What my son needs is long-term placement in a setting that is highly structured and consistent. Since there are no institutions in Vermont, you have institutionalized our entire family. What will happen when I am no longer capable of caring for him? What will he do and who will be responsible for him when he can no longer attend school? Will I be expected to quick my job and stay at home with him?”

“We realize that institutionalized care was never the ideal environment for persons with disabilities. However, now that the transition from institution to the home has been successfully made over the past 25 (or so) years, we (parents of disabled children) are increasingly alarmed by budget cuts and waning support in terms of provision of support personnel...We need to make sure that the direction we are headed – disabled children and adults in the HOME with MINIMAL support, is not an equally damaging or limiting environment for persons with disabilities (compared to institutionalized care).”

### Employment and Day Programs

Some people reported dissatisfaction about employment and day programs.

“Supported employment is the #1 biggest thing I want in the future for my child.”

“We are looking at supported employment beginning this summer which is not likely to happen unless we can get a PCA or a worker from [the agency] to help. This is limiting his employment options and is putting more of a burden on me as a single parent because I will have to do this part myself.”

“There should be a school age day program for families that can't find caregivers for these times.”

### Education and Training

Responses were evenly split between people who were satisfied with education and training issues and those who were dissatisfied.

“Our program truly improved when we entered the elementary school in Hardwick. Luckily, we encountered a special-ed teacher who was actually excited to work with an autistic child.”

“Our school has been the #1 biggest asset to H. They hired the best – suited 1:1 aide for her, they have continued to educate their staff on an on-going basis.”

“The school should be commended on the help they are giving.”

“I'd like to see agencies have a greater involvement in the early education of the disabled, provide greater support to parents and children at earlier years.”

“My child is in the preschool Autism Program though [an agency]. It has been a tremendous struggle for our family just to get our child going with an intensive early intervention program. While the program has come a long way since its inception a little over a year ago, it still does not seem to be a complete program. Why is Vermont so far behind the rest of the country in providing meaningful intensive early intervention services for young children with autism/PDD? We, as a family, have suffered and continue to suffer because of this gap in services.”

“I feel that the money the school district gets through Medicaid should be used on the students it is billed to. School takes the money that has been charged to my child and uses it as they wish, not in the best interest of my child.”

## **Health Services**

Insurance and medical care were mentioned by a numerous individuals.

“We recently found out that our son had had Medicaid since 1998. It may have been our own misunderstanding somehow because we thought Medicaid was linked to SSI but it would have been most useful to have known that we were actually getting Medicaid during all those years.”

“My only frustration has been with our primary health insurance which will change as of January 2002.”

“My son has some services from mental health but they are not consistent. They cancel appointment and reschedule without concern for the time factor. They don't seem to realize that life goes on and we still have our daily problems while waiting for them to reschedule appointments.”

“My daughter's health care falls more and more upon her parent's shoulders.”

## **Transportation**

Only two people mentioned problems with transportation.

“We seem to have trouble with mileage. There are not many activities our son likes to participate in close by. The staff needs to transport him to surrounding communities. It seems to be a problem when we go over in mileage.”

“One time [the case worker] didn’t show up in time to get M. off the bus and he got stuck riding the bus for over an hour. The case worker lost her driver’s license a bit ago and called M.’s aide for transportation on two different occasions. So M. had to ride in a car for long periods of time. My stories go on and on.”

## **Recreational Activities**

Some people stated that there were not ample opportunities for recreational and social activities.

“I would like to get him involved with her peers more but overall his quality of life is great.”

“J. does not know how to carry a teenage conversation so that leaves her quite alone, I always felt someone like a Big Sister Program would be good for her. I’m told that there is no program.”

“M. needs social opportunities and we both have to work and don’t have time to do it.”

“There are no vacation or summer services available for school age children.”

## **Communication**

Only a few people reported satisfaction with communication. For the most part, people were dissatisfied. Many people noted they had many questions and were not receiving enough information.

“We have seen a very positive change in communications with our respite provider who is new on the job this year.”

“Because of our geographical location, lots of my support with the case manager is done by phone. She always takes the time to answer my questions and look into any possible help my son can receive.”

“Case manager seldom knows the answers to our questions, entailing a wait for answers. Office doesn’t know her schedule to advise us of when she will be in the office to get our message. Often don’t get a return call from pager message.”

“The only time I hear from anyone concerning J. is when reviews come up.”

“The service providers never contact my family to see how things are going. We do get newsletters and surveys.”

“My husband and I are continually frustrated by the lack of coordination between support agency services for our child. This state URGENTLY needs a coordinated effort between services so that parents have ONE person—a ‘case manager’ who disseminates information/manages/advocates for the family relative to services for the individual in need. Right now the ‘case manager’ is more often than not, the parent, and involves calling numerous agencies and personnel each time a question regarding certain services arises.”

“I know there should be more help we can get but the agencies are not forth coming with information. Everything we have we have sought out and found on our own since moving here.”

“Please be assured I do not mean to sound all negative. I have just had a difficult time finding out, and understanding, what services and supports are ‘out there’ for my family. I am a single mom and admittedly have NOT had a lot of time to research this, but HAVE asked my case manager and really feel I haven’t gotten a lot of help.”

“While we are loosely satisfied with the services we receive, our case workers at [the agency] have a history of providing incorrect information regarding such things as: respite fund availability, fiscal year closing date, and other programs. We need accurate answers to our questions. If they are unsure of the answer, they need to say so and then seek out the correct answer.”

“I feel like we have figured out everything we know on our own or with the help of other parents.”

### **Transition Issues and Future Planning**

Several people mentioned concern about the transition between children and adult systems.

“At this time, my daughter (15 years old) receives Flexible Family Funding. We are pleased with this – however are more concerned with the limited supports available for the FUTURE – when she’s out of school.”

“My son is 10 years old and has autism. He is a nice kid, mostly has social problems. I worry what will happen when he becomes an adult. I believe there are good people in the system who are trying to make it better for the disabled and their families. But the system can’t make the community accept or like my son. I worry he will be alone. I’d like him to be independent. I’d like him to live with us if he chooses and if practical. I’d like us to be his case manager.”

“I have called [the agency], but no one there has provided any information about what is available for my son, what services will be there when he gets older, what adult services may look like, etc. They’ve been pretty useless.”

“We would, however, say that the ADULT services situation has us worried. Why do services diminish when a child turns an adult? That’s when older parents – especially those caring for elders and who are disabled themselves – need the most reliable help.”

### **Case Management**

Some people were satisfied with their case managers.

“They/my case manager has helped emotionally, financially and with setting up a community support group.”

“Her case manager sees a problem, finds a solution, and acts on it ASAP!”

“My son’s mental health case worker is so supportive of my son’s needs and also the family’s needs. I feel I can count on her to give us support and guidance whenever possible.”

“Our case worker is very sympathetic and extremely available however, so we do feel that ‘someone’ out there cares about our family and our situation.”

Other respondents reported dissatisfaction with case managers.

“Case manager appears to be insufficiently trained.”

“Case managers need to not judge a parent’s needs. If care can’t be provided, don’t assume the parents need to ‘spend more time with their child anyway.’”

“[Case manager] does not provide any support to any of the aides that M. has had. No phone calls or supervised visits at all.”

“My child does not have case management services!”

## **Staff**

Many people noted satisfaction with staff.

“We have excellent staff working with both of our children.”

“We have an excellent personal care attendant and a worker who comes into our home to provide support to our other children and to us, the parents.”

“His personal care aide has been wonderful and is a huge part of his life and his program.”

“People in our county that need time away from a disable person – since I can select the person to remain with/care for my child when away, I feel secure. If someone else selected, I would not be able to leave him.”

“He – and we – are very happy, and grateful for the compassionate professionalism typical of your staff.”

While some people were satisfied with staff, many were not. Reasons for dissatisfaction include turnover and a lack of qualified staff.

“My impression is that there is no one available to provide personal care services for my child, so therefore there is no help available for us.”

“One PCA was repeatedly dishonest about his hours, yet was not disciplined or fired when we reported him to [the agency].”

“I think that staff people need to be highly trained and qualified to work with my daughter. High turnover of support people is bad for the families. These workers should get benefits and pay that make want to do this long term.”

“My only complaint is that the aid’s usually quit after one year and it is hard to find another one to replace her in a timely manner.”

“And too much of a turnover in people. My son has had to get use to a new person just about every month this year. And when he has autism that makes it very hard on the family.”

“In our case, we are allotted a generous allowance of caregiver hours, but the personnel available for our rural area are few and far between – no one wants to commute 45 minutes to work a 2 hour shift.”

“The most frustrating piece to the respite care my daughter receives is the lack of qualified people we have had. The amount of energy my family puts into finding after school/weekend care was exhausting.”

“The State of Vermont needs to train and develop a model for training that gives consumers a pool of trained people to pick from. This doesn’t happen because we don’t pay them enough money.”

“The pay is poor and the people applying for positions usually do not meet my basic needs; there is not enough money to attract decently trained people to come into our home and work with my son.”

“Substitute care providers are a HUGE problem.”

## **Respite**

Respite was a frequently mentioned issue. Many people reported satisfaction with respite.

“D. receives respite once a year. This has been very helpful. We use it for family vacation time that we wouldn’t take without it.”

“Respite was a God-sent over the summer, but his respite worker has been ill recently, so our services have greatly decreased due to a lack of a provider.”

“We use it for respite time away from the family member – it gives a break. This care is very needed for people in our county that need time away from a disabled person.”

“Respite worker is very good – helps a lot – we wouldn’t know what to do without her.”

“I also have very good respite people who works with my son which makes all the difference.”

“Things like respite are making a difference. In the long run, I truly believe children with disabilities without respite will end up in more expensive out of home placements.”

Many people do not receive enough hours or have difficulty finding respite workers.

“On paper, service look good – we are eligible for 20 hours/week. However [the agency] can’t find respite workers. We’re only being able to fill 12 hours total since the beginning of August.”

“We get limited Flexible Family Funding and a personal care attendant is authorized for 15 hours per week which we have yet to find someone on a long term basis. We have gotten

college kids for the summer, but they are only short term. My child needs consistency which has yet to happen.”

“Problem is that there is nobody to hire for respite. The pay is poor and the people applying for the positions usually do not meet my basic needs.”

“I feel the ‘most-missing-piece’ in our family and developmental services is the lack of a local family respite home, as we had for almost three years between 4/92 and 5/95. The occasional (like every other weekend – that would be great) breaks from the everyday routine challenges that are everyday happenings in our life would be beneficial for us.”

## **Funding and Budget Cuts**

Concerns about funding and budget cuts were frequently mentioned.

“Many families are weary and feeling like a few get much – the rest of us get next to nothing. We are told that children who live with their families are clearly not a funding priority. I have just been informed of a mandatory budget cut on our services. This cut will make the services that we get inadequate. My son is self-abusive and we cannot afford to lose any of our supports.”

“Please do not discontinue or lessen financial ability for my daughter. With these services in place, it helps me to be a better and much more responsible, loving, caring parent and it helps my daughter to be happy!”

“State budget cuts for human services are a SERIOUS problem – it makes me very apprehensive that my child and other children throughout the state will lose critical services or supports.”

“It’s time to increase personal care attendant pay and reduce the ‘administration costs’ that the agencies skim. It’s time to involve families much more in this area!”

“It also seems that an extraordinary amount of money goes into providing this patched together care for our son. The Governor’s decision to recommend cutting respite is outrageous!! When they closed all full care facilities it cost \$80,000/patient. After waiving the income cap, we received \$1,122. That’s quite a savings but the State has forgotten why they asked parents to care for their disabled children. Money\$\$ SAVINGS! Now they want it for nothing. If the Governor is successful with his budget cuts for people with disabilities and education this state will be in more trouble than it already is. The Governor should live with people with disabilities and take care of them and see if his cuts are really worth what it will cost this state in the long run and also the families.”

## **Overall Satisfaction with Services**

In general, many people were satisfied with the services and supports their family member received.

“Flexible spending has helped our family so much. Without this, our large family WOULDN’T be able to do anything as a family. It gives us a lot of self-esteem and rewarding experiences. It’s also less stressful for us being a single mom of 6. Without this, our family would be in DEPRESSION and feeling ISOLATED!”

“I get services for my daughter through CSHN. They are fantastic in helping. I also get help through [the agency]. They have been fantastic also.”

“It would be extremely ‘hard going’ if no services were provided to N. The quality of N.’s family life benefits greatly by the supports of [the agency].”

“With these services in place, it helps me to be a better and much more responsible, loving, caring parent and it helps my daughter to be happy! That’s important.”

“Very happy with this program and my family very much so needs this. Overall, I’m satisfied with our services from [the agency]. You have a tough job and I think you manage quite well. Thanks for your time and for listening to our concerns and desires for our child.”

“The services have helped us get back on our feet as a family.”

“[The agency] has been very responsive to our and our son’s needs. We have been able to add a great deal to his programming through Flex Funding.”

“We could not be more pleased with the services [the agency] provides our autistic son. Were it not for [the agency’s] program, our 5-year old would have to be institutionalized.”

Even though many people reported overall satisfaction with services, numerous families’ needs were not met. The comments below reflect this dissatisfaction.

“I’d like to see agencies have a greater involvement in the early education of the disabled, provide greater support to parents and children at earlier years. Supports should be seamless birth to earth long term. Supports should not just be financial. Parents and siblings are often isolated from the community. Agencies need to work on that also.”

“I don’t feel that our local agency has the capacity to handle problems and therefore we get a Band-Aid instead of a solution to the problem.”

“I guess I’m feeling pretty disappointed in services (particularly the system of care changes...they scare me and that in turn only increases my resolve to advocate for others out there (some who aren’t even currently receiving services) people are being told don’t even ask for anything right now), it seems like at every turn a new horror, a new complication, a new inconsistency. On the other hand, I know that we are the leaders in the country and that regardless all the bad stuff there is good stuff too! And in the scheme of things, I have great respect for the people at the division, but my designated agency is despicable in its handling of families needs.”

“We are stretched to the limit of what we can do managing care for my son at home and managing a complex and fractured system of community supports that is inconsistent. I am frustrated at Vermont’s rigid approach to community care for our developmentally disabled members because I can barely manage the circumstances we are in and don’t know how long I will last. The one choice we have is community supports/developmental home, but these are inconsistent or unavailable because not that many people want to do this work.”

“Support is replaced by the effort to get it.”

"I think that opportunities and services are miserably deficient in our area. The people at [the agency] are a great bunch – dedicated, respectful, and interested providers of services who are forced to frustration within the confines of a budget that is a joke. You are asking the wrong questions. They do a good job given what they have to work with. But stone soup is after all still stone soup."

"My sense is that unless my child is diagnosed with PDD or autism there is very little available, while children diagnosed with those disabilities get tons of services, attention, support, and money."

"Receiving support remains a mysterious process to me; I have often been told that my son's case is being reviewed and the budget being changed before anything can happen – when it does happen, the processes take MONTHS before services are in place. My son is missing part of a chromosome. His syndrome is a known, documented fact. Because his syndrome does not fit neatly with either [agency], it seems as though too much energy is expended between asking which agency could provide services. Also because my son's disability is rare (he is the only case in Vermont) I feel that obtaining services has been difficult because nobody knows about his syndrome as opposed to a 'known' disability such as Down's syndrome, etc. I can only assume that undiagnosed individuals must encounter similar situations. That said, I want you to know that my family and I really DO appreciate what service we have got – so thank you."

"He is in a specialized program but I still believe it's not made for his needs. It's all that is available unless you want to continue to fight the rest of your life with a school system. It is very difficult when both parents have to work – sometimes it feels like you just have to do the best you can to stay together. He verbalizes sometimes that he would like to have his own life. He is tired of having folks tell him what HE needs. He has been telling all of us what the needs – but the support to make those things happen isn't there."

"I have always been very involved in my son's life/education until recently when I just couldn't fight the system anymore. It was causing our family to fall apart and for me personally it was almost a nervous breakdown. Our children do not always get what they need from school and community – and sometimes – most of the time – no one really cares! As long as it's not their family! So, we have learned to do the best we can and sometimes it's not enough but it's all we have!"

"Development Services should be in the business of family preservation not creating a system of institutional care – (which I believe will result with these large cuts in programming). Let's not go after the most vulnerable of our society."

# APPENDIX A

Summary Tables of Survey Responses

**Table A - Child/Family Survey - Characteristics of Child with a Disability: 2001 Data**

STATES	Total %		State Avg.		CA		NC		NE		UT		VT	
Number of surveys	1,810		5		976		295		44		242		253	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
<b>Gender:</b>														
Male	1,150	65.8	64.4	636	68.2	190	67.9	29	65.9	151	62.7	144	57.4	
Female	598	34.2	35.6	296	31.8	90	32.1	15	34.1	90	37.3	107	42.6	
<b>Age:</b>														
Mean	9.6		10.3		9.1		9.3		11.9		10.6		10.6	
Range	0-18				0-18		1-18		4-18		2-18		1-17	
<b>Race/Ethnicity* (duplicated counts):</b>														
White	1,104	64.7	74.1	471	51.3	191	63.7	*		212	90.6	230	90.9	
Black	104	6.1	7.4	25	2.7	71	23.7			3	1.3	5	2.0	
Asian/Pacific Islander	164	9.6	5.1	155	16.9	4	1.3			5	2.1	0	0.0	
American Indian/ Eskimo/Aleut	50	2.9	3.1	25	2.9	9	3.0			9	3.8	7	2.8	
Hispanic	330	19.3	11.1	296	32.2	16	5.3			14	5.9	3	1.2	
Mixed Races	66	3.9	2.8	51	5.5	7	2.3			5	2.1	3	1.2	
Other/Unknown	13	0.8	0.6	10	1.1	0	0.0			1	0.4	2	0.8	
<b>More than 1 person with DD in household:</b>														
Yes	239	13.3	19.3	99	10.2	38	13.2	17	38.6	48	19.8	37	14.7	
No	1,557	86.7	80.7	873	89.8	249	86.8	27	61.4	194	80.2	214	85.3	
	1,796			972		287		44		242		251		
<b>Amount of help required with daily activities:</b>														
None	94	6.2	7.4	50	5.4	25	8.7	4	9.1	15	6.2	*		
Little	304	20.2	19.2	218	23.4	40	14.0	11	25.0	35	14.5			
Moderate	524	34.8	33.3	328	35.2	111	38.8	13	29.5	72	29.8			
Complete	583	38.7	40.2	337	36.1	110	38.5	16	36.4	120	49.6			
	1,505			933		286		44		242				
<b>Other disabilities* (duplicated counts):</b>														
Mental retardation or other developmental	852	57.6	61.9	493	52.7	194	64.7	*		165	68.2	*		
Mental illness	78	4.5	5.3	32	3.4	11	3.7			16	6.6	19	7.5	
Autism	574	33.2	30.5	349	37.3	85	28.3			63	26.0	77	30.4	
Cerebral Palsy	349	20.2	22.1	161	17.2	73	24.3			66	27.3	49	19.4	
Brain injury	145	8.4	9.7	60	6.4	28	9.3			29	12.0	28	11.1	
Seizure disorder/ neurological problem	439	25.4	29.1	183	19.6	101	33.7			88	36.4	67	26.5	
Chemical dependency	13	0.8	0.7	6	0.6	2	0.7			1	0.4	4	1.6	
Vision or hearing impairments	365	21.1	19.3	157	16.8	65	21.7			83	34.3	60	23.7	
Physical disability	420	24.3	23.0	162	17.3	95	31.7			92	38	71	28.1	
Communication disorder	476	27.5	23.8	226	24.1	89	29.7			91	37.6	70	27.7	
Other disability	373	21.6	21.3	129	13.8	78	26			61	25.3	105	41.5	
* Data unavailable (question was not asked).														

**Table B - Child/Family Survey - Characteristics of Respondents: 2001 Data**

<b>STATES</b>	<b>Total %</b>	<b>State Avg.</b>	<b>CA</b>	<b>NC</b>	<b>NE</b>	<b>UT</b>	<b>VT</b>
Number of surveys	<b>1,810</b>	<b>5</b>	<b>976</b>	<b>295</b>	<b>44</b>	<b>242</b>	<b>253</b>
<b>Age:</b>							
Mean	40.3	41.1	40.3	39.3	44.7	40.4	41.0
Range	20-76		22-72	20-70	24-76	25-64	20-61
<b>Relationship to consumer:</b>							
	n %	%	n %	n %	n %	n %	n %
Parent	1,743 <b>96.9</b>	<b>94.9</b>	948 <b>97.8</b>	270 <b>91.8</b>	38 <b>86.4</b>	239 <b>99.2</b>	248 <b>99.2</b>
Sibling	1 <b>0.1</b>	<b>0.0</b>	1 <b>0.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>
Grandparent	40 <b>2.2</b>	<b>2.8</b>	15 <b>1.5</b>	19 <b>6.5</b>	2 <b>4.5</b>	2 <b>0.8</b>	2 <b>0.8</b>
Other relative	14 <b>0.8</b>	<b>2.3</b>	5 <b>0.5</b>	5 <b>1.7</b>	4 <b>9.1</b>	0 <b>0.0</b>	0 <b>0.0</b>
	1,798		969	294	44	241	250
<b>Respondent is primary caregiver:</b>							
Yes	1,769 <b>98.6</b>	<b>99.0</b>	948 <b>98.1</b>	289 <b>98.6</b>	44 <b>100.0</b>	238 <b>99.2</b>	250 <b>99.2</b>
<b>Household income:</b>							
	n %	%	n %	n %	n %	n %	n %
Below \$15,000	318 <b>21.7</b>	<b>24.5</b>	189 <b>20.7</b>	88 <b>31.7</b>	14 <b>34.1</b>	27 <b>11.6</b> *	
\$16,000-\$25,000	244 <b>16.6</b>	<b>21.9</b>	151 <b>16.5</b>	44 <b>15.8</b>	17 <b>41.5</b>	32 <b>13.7</b>	
\$26,000-\$40,000	287 <b>19.6</b>	<b>19.5</b>	153 <b>16.7</b>	61 <b>21.9</b>	4 <b>9.8</b>	69 <b>29.6</b>	
\$41,000-\$75,000	357 <b>24.4</b>	<b>22.9</b>	220 <b>24.1</b>	46 <b>16.5</b>	6 <b>14.6</b>	85 <b>36.5</b>	
Over \$75,000	260 <b>17.7</b>	<b>11.2</b>	201 <b>22.0</b>	39 <b>14.0</b>	0 <b>0.0</b>	20 <b>8.6</b>	
	1,466		914	278	41	233	
<b>Health of respondent:</b>							
Excellent	515 <b>28.7</b>	<b>27.1</b>	265 <b>27.4</b>	80 <b>27.5</b>	6 <b>13.6</b>	65 <b>27.1</b>	99 <b>39.8</b>
Good	967 <b>54.0</b>	<b>51.2</b>	541 <b>55.9</b>	151 <b>51.9</b>	19 <b>43.2</b>	130 <b>54.2</b>	126 <b>50.6</b>
Fair	259 <b>14.5</b>	<b>19.7</b>	129 <b>13.3</b>	52 <b>17.9</b>	19 <b>43.2</b>	38 <b>15.8</b>	21 <b>8.4</b>
Poor	51 <b>2.8</b>	<b>2.0</b>	33 <b>3.4</b>	8 <b>2.7</b>	0 <b>0.0</b>	7 <b>2.9</b>	3 <b>1.2</b>
	1,792		968	291	44	240	249

**Table C - Child/Family Survey - Services and Support Received: 2001 Data**

STATES	Total %		State Avg.	CA		NC		NE		UT		VT	
	n	%	n = 4 *n = 3	n	%	n	%	n	%	n	%	n	%
<b>SSI financial support</b>	489	<b>33.2</b>	<b>35.1*</b>	290	<b>30.6</b>	122	<b>42.2</b>	No data		77	<b>32.5</b>	No data	
<b>Other financial support</b>	207	<b>14.6</b>	<b>15.3*</b>	125	<b>13.6</b>	38	<b>13.9</b>	No data		44	<b>19.1</b>		
<b>In-home support</b>	538	<b>36.2</b>	<b>44.6</b>	206	<b>22.3</b>	162	<b>56.8</b>	14	<b>33.3</b>	156	<b>66.1</b>		
<b>Out-of-home respite care</b>	609	<b>40.9</b>	<b>50.9</b>	342	<b>36.7</b>	104	<b>36.9</b>	29	<b>72.5</b>	134	<b>57.3</b>		
<b>Early intervention</b>	168	<b>11.9</b>	<b>11.9</b>	82	<b>9.2</b>	62	<b>23.6</b>	2	<b>4.7</b>	22	<b>10.0</b>		
<b>Transportation</b>	174	<b>11.7</b>	<b>13.0</b>	99	<b>10.7</b>	43	<b>15.3</b>	6	<b>15.0</b>	26	<b>10.9</b>		
<b>Specialized services/supports</b>	691	<b>48.2</b>	<b>60.1*</b>	302	<b>33.1</b>	233	<b>81.8</b>	No data		156	<b>65.5</b>		

**Table D - Child/Family Survey - Information and Planning: 2001 Data**

STATES	TOTAL %	STATE AVG.	CA	NC	NE	UT	VT
<b>Do you receive information about MR/DD services and supports that are available to your family?</b>							
Number of surveys	1,760		943	288	42	244	243
% yes or most of the time	56.4	47.5	67.3	35.1	35.7	58.6	40.7
% some of the time	32.2	36.3	26.3	41.0	38.1	36.1	39.9
% no or not at all	11.4	16.2	6.4	24.0	26.2	5.3	19.3
<b>If you receive information, is it easy to understand?</b>							
Number of surveys	1,619		906	236	32	234	211
% yes or most of the time	66.8	62.1	72.5	52.1	59.4	69.7	56.9
% some of the time	28.5	32.9	23.1	40.7	34.4	28.2	37.9
% no or not at all	4.6	5.0	4.4	7.2	6.3	2.1	5.2
<b>Do you receive information about the status of your child's development?</b>							
Number of surveys	1,412		862	285	40	225	
% yes or most of the time	41.6	46.7	40.4	58.9	67.5	20.0	*
% some of the time	24.3	22.7	25.4	23.2	20.0	22.2	Not Asked
% no or not at all	34.1	30.6	34.2	17.9	12.5	57.8	
<b>If yes, is this information easy to understand?</b>							
Number of surveys	967		589	241	34	103	
% yes or most of the time	67.9	63.4	70.3	70.1	61.8	51.5	*
% some of the time	25.3	30.5	22.2	25.7	35.3	38.8	Not Asked
% no or not at all	6.7	6.1	7.5	4.1	2.9	9.7	
<b>Do you get enough information to help you participate in planning services for your child?</b>							
Number of surveys	1,682		900	283	29	231	239
% yes or most of the time	47.2	51.9	43.9	56.9	65.5	52.4	41.0
% some of the time	32.5	30.1	31.1	28.6	13.8	39.4	37.7
% no or not at all	20.3	17.9	25.0	14.5	20.7	8.2	21.3
<b>If your family has a service plan, did you help develop the plan?</b>							
Number of surveys	1,455		763	263	27	222	180
% yes or most of the time	71.8	74.6	65.3	78.3	70.4	83.8	75.0
% some of the time	15.4	13.4	16.9	12.5	7.4	14.4	15.6
% no or not at all	12.9	12.1	17.8	9.1	22.2	1.8	9.4
<b>Do staff help you figure out what you need as a family to support your child?</b>							
Number of surveys	1,460		914	267	38	241	
% yes or most of the time	50.8	61.0	42.8	61.8	73.7	65.6	*
% some of the time	28.7	24.7	30.6	27.0	15.8	25.3	Not Asked
% no or not at all	20.5	14.4	26.6	11.2	10.5	9.1	
<b>Do staff respect your choices and opinions?</b>							
Number of surveys	1,414		876	262	41	235	
% yes or most of the time	77.7	82.3	73.6	83.2	87.8	84.7	*
% some of the time	17.2	12.5	20.7	10.7	4.9	13.6	Not Asked
% no or not at all	5.2	5.2	5.7	6.1	7.3	1.7	
<b>Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI)?</b>							
Number of surveys	1,647		880	263	40	232	232
% yes or most of the time	36.4	39.3	35.2	36.5	50.0	36.2	38.4
% some of the time	23.3	23.9	21.6	18.6	20.0	31.5	27.6
% no or not at all	40.3	36.9	43.2	44.9	30.0	32.3	34.1
<b>Are MR/DD staff generally respectful and courteous?</b>							
Number of surveys	1,730		947	272	38	245	228
% yes or most of the time	85.7	82.5	85.4	84.2	65.8	93.1	83.8
% some of the time	12.0	14.3	12.4	13.2	26.3	4.5	14.9
% no or not at all	2.3	3.3	2.2	2.6	7.9	2.4	1.3
<b>Are MR/DD staff generally knowledgeable and effective?</b>							
Number of surveys	1,708		932	269	42	242	223
% yes or most of the time	63.1	67.4	60.5	63.6	81.0	74.8	57.0
% some of the time	30.6	27.2	32.0	29.4	14.3	23.1	37.2
% no or not at all	6.4	5.5	7.5	7.1	4.8	2.1	5.8

**Table E - Child/Family Survey - Choice and Control: 2001 Data**

<b>STATES</b>	<b>TOTAL %</b>	<b>STATE AVG.</b>	<b>CA</b>	<b>NC</b>	<b>NE</b>	<b>UT</b>	<b>VT</b>
<b>Do you choose the agencies or providers that work with your family?</b>							
Number of surveys	1,549		779	274	39	239	218
% yes or most of the time	<b>55.3</b>	<b>59.8</b>	41.6	71.9	48.7	83.7	53.2
% some of the time	<b>20.1</b>	<b>18.3</b>	23.6	14.6	17.9	12.6	22.9
% no or not at all	<b>24.7</b>	<b>19.9</b>	24.8	13.5	33.3	3.8	23.9
<b>Do you choose the support workers that work with your family?</b>							
Number of surveys	1,485		736	263	38	226	222
% yes or most of the time	<b>50.0</b>	<b>52.3</b>	31.4	66.9	15.8	73.5	73.9
% some of the time	<b>18.7</b>	<b>19.8</b>	21.3	13.7	31.6	15.5	17.1
% no or not at all	<b>31.2</b>	<b>27.8</b>	47.3	19.4	52.6	11.1	8.6
<b>Do you have control and/or input over the hiring and management of your support workers?</b>							
Number of surveys	1,329		616	249	32	220	212
% yes or most of the time	<b>51.2</b>	<b>53.3</b>	32.8	58.2	25.0	75.5	75.0
% some of the time	<b>14.7</b>	<b>15.1</b>	15.9	10.4	18.8	11.8	18.4
% no or not at all	<b>34.2</b>	<b>31.6</b>	51.3	31.3	56.3	12.7	6.6
<b>Do you <u>want</u> to have control and/or input over the hiring and management of your support workers?</b>							
Number of surveys	1,313		632	239	32	203	207
% yes or most of the time	<b>71.8</b>	<b>70.2</b>	65.5	74.5	46.9	81.8	82.1
% some of the time	<b>14.9</b>	<b>16.7</b>	17.4	10.0	31.3	11.8	13.0
% no or not at all	<b>13.3</b>	<b>13.1</b>	17.1	15.5	21.9	6.4	4.8
<b>Do you know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?</b>							
Number of surveys	1,289		587	239	31	223	209
% yes or most of the time	<b>33.4</b>	<b>36.2</b>	19.4	31.0	22.6	68.2	39.7
% some of the time	<b>13.8</b>	<b>15.7</b>	6.0	19.7	9.7	17.0	26.3
% no or not at all	<b>52.8</b>	<b>48.1</b>	74.6	49.4	67.7	14.8	34.0
<b>Do you <u>get</u> to decide how this money is spent?</b>							
Number of surveys	1,337		613	248	33	232	211
% yes or most of the time	<b>34.0</b>	<b>34.1</b>	22.8	27.8	12.1	64.7	43.1
% some of the time	<b>18.0</b>	<b>19.2</b>	8.6	23.8	6.1	25.9	31.8
% no or not at all	<b>48.0</b>	<b>46.7</b>	68.5	48.4	81.8	9.5	25.1

**Table F - Child/Family Survey - Access and Delivery of Services and Supports: 2001 Data**

STATES	TOTAL %	STATE AVG.	CA	NC	NE	UT	VT
<b>Do the supports offered by the MR/DD agency meet your family's needs?</b>							
Number of surveys	1,693		896	280	36	242	239
% yes or most of the time	44.7	46.1	40.7	50.0	41.7	56.6	41.4
% some of the time	40.4	41.0	39.8	38.9	41.7	39.3	45.2
% no or not at all	14.9	12.9	19.4	11.1	16.7	4.1	13.4
<b>Are supports available when your family needs them?</b>							
Number of surveys	1,633		846	280	36	238	233
% yes or most of the time	43.4	42.4	40.9	45.7	30.6	54.2	40.8
% some of the time	41.3	44.0	40.1	40.0	52.8	42.0	45.1
% no or not at all	15.2	13.6	19.0	14.3	16.7	3.8	14.2
<b>Have families in your area requested different types of services and supports be made available in your area?</b>							
Number of surveys	503		298	108	9	88	
% yes or most of the time	40.8	42.5	34.2	48.1	33.3	54.5	
% some of the time	28.4	23.1	31.2	25.0	11.1	25.0	
% no or not at all	30.8	34.4	34.6	26.9	55.6	20.5	
<b>If yes, was the State responsive to their requests?</b>							
Number of surveys	411		273	71	7	60	
% yes or most of the time	42.6	30.7	49.8	26.8	14.3	31.7	
% some of the time	35.5	33.1	33.3	29.6	14.3	55.0	
% no or not at all	21.9	36.3	16.8	43.7	71.4	13.3	
<b>If you have ever asked the MR/DD agency for assistance in an emergency or crisis, was help provided to you right away?</b>							
Number of surveys	823		430	129	30	112	122
% yes or most of the time	39.2	39.7	35.8	34.1	30.0	43.8	54.9
% some of the time	20.4	19.2	21.9	16.3	16.7	23.2	18.0
% no or not at all	40.3	41.0	42.3	49.6	53.3	33.0	27.0
<b>If English is <u>not</u> your first language, are there staff or translators available to speak with you in your preferred language?</b>							
Number of surveys	365		299	29	5	14	18
% yes or most of the time	77.0	63.0	78.9	72.4	20.0	71.4	72.2
% some of the time	11.8	13.7	11.4	17.2	20.0	14.3	5.6
% no or not at all	11.2	23.3	9.7	10.3	60.0	14.3	22.2
<b>Do you have access to health services for your child?</b>							
Number of surveys	1,484		907	289	43	245	
% yes or most of the time	88.5	89.8	86.3	92.4	88.4	92.2	
% some of the time	7.9	7.4	9.3	5.2	9.3	5.7	
% no or not at all	3.6	2.8	4.4	2.4	2.3	2.0	
<b>Do you have access to necessary medications for your child?</b>							
Number of surveys	1,385		836	269	42	238	
% yes or most of the time	89.0	91.2	85.8	94.8	90.5	93.7	
% some of the time	7.4	6.4	9.0	4.1	7.1	5.5	
% no or not at all	3.6	2.4	5.3	1.1	2.4	0.8	
<b>Does your child have access to the special equipment or accommodations that he/she needs?</b>							
Number of surveys	1,004		484	182	30	173	135
% yes or most of the time	53.4	55.7	49.0	60.4	60.0	62.4	46.7
% some of the time	26.2	27.8	20.9	25.3	20.0	30.6	42.2
% no or not at all	20.4	16.5	30.2	14.3	20.0	6.9	11.1
<b>If your child does not speak English or uses a different way to communicate, are there enough staff available who can comm</b>							
Number of surveys	552		278	91	15	62	106
% yes or most of the time	41.5	41.1	40.3	49.5	40.0	32.3	43.4
% some of the time	30.4	34.2	24.5	33.0	33.3	45.2	34.9
% no or not at all	28.1	24.8	35.3	17.6	26.7	22.6	21.7

**Table G - Child/Family Survey - Access & Delivery of Services and Supports: 2001 Data (Cont'd)**

STATES	TOTAL %	STATE AVG.	CA	NC	NE	UT	VT
<b>If you want help getting family supports in your community, do staff help connect you to these services?</b>							
Number of surveys	1,330		696	236	42	188	168
% yes or most of the time	<b>36.8</b>	<b>41.0</b>	37.1	31.8	64.3	40.4	31.5
% some of the time	<b>26.3</b>	<b>27.0</b>	22.8	29.7	19.0	29.8	33.9
% no or not at all	<b>36.9</b>	<b>31.9</b>	40.1	38.6	16.7	29.8	34.5
<b>If you want help figuring out how family, friends, or neighbors can provide some of the supports your family needs, do staff help you do this?</b>							
Number of surveys	1,275		666	224	30	196	159
% yes or most of the time	<b>36.5</b>	<b>41.2</b>	34.2	31.3	56.7	48.5	35.2
% some of the time	<b>21.8</b>	<b>21.8</b>	20.0	23.2	16.7	26.0	23.3
% no or not at all	<b>41.6</b>	<b>37.0</b>	45.8	45.5	26.7	25.5	41.5
<b>Do you feel that your family has access to community activities?</b>							
Number of surveys	1,376		827	272	41	236	
% yes or most of the time	<b>42.1</b>	<b>42.4</b>	39.7	43.4	36.6	50.0	*
% some of the time	<b>32.7</b>	<b>34.9</b>	31.2	34.6	39.0	34.7	Not Asked
% no or not at all	<b>25.2</b>	<b>22.7</b>	29.1	22.1	24.4	15.3	
<b>Does your child participate in community activities?</b>							
Number of surveys	1,484		914	286	42	242	
% yes or most of the time	<b>21.4</b>	<b>25.3</b>	18.2	28.0	31.0	24.0	*
% some of the time	<b>32.1</b>	<b>34.1</b>	27.9	36.7	28.6	43.0	Not Asked
% no or not at all	<b>46.6</b>	<b>40.7</b>	53.9	35.3	40.5	33.1	
<b>Does your child spend time with children who do not have developmental disabilities?</b>							
Number of surveys	1,538		955	292	44	247	
% yes or most of the time	<b>54.1</b>	<b>51.1</b>	55.1	55.1	43.2	51.0	*
% some of the time	<b>34.5</b>	<b>37.3</b>	33.9	32.9	45.5	36.8	Not Asked
% no or not at all	<b>11.4</b>	<b>11.6</b>	11.0	12.0	11.4	12.1	
<b>Can you contact your family member's case manager whenever you want to?</b>							
Number of surveys	1,705		929	274	43	243	216
% yes or most of the time	<b>71.8</b>	<b>72.2</b>	70.3	74.5	69.8	75.7	70.8
% some of the time	<b>20.8</b>	<b>20.8</b>	20.3	19.3	18.6	21.0	25.0
% no or not at all	<b>7.4</b>	<b>6.9</b>	9.4	6.2	11.6	3.3	4.2
<b>Are frequent changes in support staff a problem for your family?</b>							
Number of surveys	1,384		715	237	29	218	185
% yes or most of the time	<b>28.3</b>	<b>26.3</b>	32.4	27.8	27.6	14.7	29.2
% some of the time	<b>29.3</b>	<b>30.5</b>	27.4	30.8	31.0	32.1	31.4
% no or not at all	<b>42.3</b>	<b>43.1</b>	40.1	41.4	41.4	53.2	39.5

**Table H - Child/Family Survey - Outcomes and Satisfaction with Services: 2001 Data**

STATES	TOTAL %	STATE AVG.	CA	NC	NE	UT	VT
<b>If your family has a service plan, does the plan include things that are important to you?</b>							
Number of surveys	1,218		720	253	27	218	
% yes or most of the time	69.1	76.1	61.0	79.4	81.5	82.6	*
% some of the time	20.4	14.9	24.2	15.4	3.7	16.1	Not Asked
% no or not at all	10.4	9.1	14.9	5.1	14.8	1.4	
<b>Does your family get the services and supports you need?</b>							
Number of surveys	1,704		897	284	38	241	244
% yes or most of the time	45.8	48.2	41.6	51.4	47.4	59.3	41.4
% some of the time	39.5	37.7	39.7	35.6	28.9	36.9	47.5
% no or not at all	14.7	14.0	18.7	13.0	23.7	3.7	11.1
<b>Do you feel that family supports have helped you to keep your child at home?</b>							
Number of surveys	1,370		654	253	41	233	189
% yes or most of the time	67.8	71.6	57.3	74.7	68.3	88.4	69.3
% some of the time	15.0	14.5	18.3	12.6	19.5	9.0	13.2
% no or not at all	17.2	13.8	24.3	12.6	12.2	2.6	17.5
<b>Do you feel that family supports have made a positive difference in the life of your family?</b>							
Number of surveys	1,496		728	265	42	240	221
% yes or most of the time	66.0	71.4	55.6	72.5	73.8	87.5	67.4
% some of the time	22.8	19.6	27.5	19.2	14.3	10.4	26.7
% no or not at all	11.2	9.0	16.9	8.3	11.9	2.1	5.9
<b>Do you feel that family supports have improved your ability to care for your child?</b>							
Number of surveys	1,293		745	267	40	241	
% yes or most of the time	63.2	69.2	54.1	70.4	70.0	82.2	*
% some of the time	22.0	19.8	25.8	19.5	20.0	13.7	Not Asked
% no or not at all	14.8	11.1	20.1	10.1	10.0	4.1	
<b>Has your child experienced a serious injury in the past year?</b>							
Number of surveys	1,406		875	259	40	232	
% yes or most of the time	5.7	5.4	5.3	5.4	2.5	8.2	*
% some of the time	1.8	1.3	2.2	0.8	0.0	2.2	Not Asked
% no or not at all	92.5	93.4	92.6	93.8	97.5	89.7	
<b>Have you been informed of your agency's grievance process?</b>							
Number of surveys	1,436		768	244	28	190	206
% yes or most of the time	55.6	51.1	65.1	37.7	57.1	45.3	50.5
% some of the time	10.1	8.7	9.8	7.0	0.0	11.6	15.0
% no or not at all	34.3	40.2	25.1	55.3	42.9	43.2	34.5
<b>Are you satisfied with the way complaints or grievances are handled and resolved by the state agency?</b>							
Number of surveys	708		389	136	13	82	88
% yes or most of the time	57.9	54.4	60.4	45.6	38.5	67.1	60.2
% some of the time	22.6	22.2	20.3	29.4	15.4	23.2	22.7
% no or not at all	19.5	23.5	19.3	25.0	46.2	9.8	17.0
<b>Overall, do you feel that your family member is happy?</b>							
Number of surveys	1,771		947	296	43	244	241
% yes or most of the time	80.1	80.7	79.3	81.8	81.4	82.0	78.8
% some of the time	18.4	18.0	18.4	17.9	16.3	17.6	19.9
% no or not at all	1.6	1.3	2.3	0.3	2.3	0.4	1.2
<b>Overall, are you satisfied with the services and supports your family member currently receives?</b>							
Number of surveys	1,740		929	290	42	245	234
% yes or most of the time	58.2	63.0	50.4	64.1	61.9	78.4	60.3
% some of the time	28.6	27.4	31.4	26.9	31.0	19.6	28.2
% no or not at all	13.2	9.6	18.2	9.0	7.1	2.0	11.5