

VERMONT DIVISION OF DEVELOPMENTAL SERVICES

FAMILY SATISFACTION SURVEY



STATEWIDE RESULTS

FALL 2001

Vermont Division of Developmental Services
Department of Developmental and Mental Health Services
Agency of Human Services

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PREFACE

*“These services...help me to be a better
and much more responsible, loving, caring parent...”*

This report highlights the most notable and significant findings from 539 completed family satisfaction surveys. In addition to this report on statewide results, individual reports are sent to each agency. The individual agency reports summarize the key findings and provide the raw data from the surveys completed by families receiving services from the agency. These reports enable providers, families and people who receive services to contrast the satisfaction of families at their local agency with the statewide results.

When reviewing this and all satisfaction survey results, it is important to keep in mind that measurements of satisfaction are only truly useful when viewed in the aggregate. Measurements of satisfaction of developmental services are indications of how people perceive and feel about their services and are only one snapshot of a complex, multifaceted system of support. Information from these reports can best inform providers and their stakeholders when viewed in combination with other information about services and supports.

In an ongoing effort to improve the quality of information provided to the public by the Division of Developmental Services, we invite your feedback and suggestions on this and other reports provided by DDS. Please call or send your comments to the address inside the front cover.

INTRODUCTION

“All in all, services have been wonderful...”

BACKGROUND

In November 2001, the Division of Developmental Services (DDS) sent out a family satisfaction survey to all people who had a family member with developmental disabilities living with them who received services. Fifteen (15) developmental service agencies provided updated contact information and updated addresses to DDS. The surveys were anonymous and individual results confidential. Analysis of survey results make it possible to work to improve services and supports for people with developmental disabilities and their families in Vermont.

This was the third time DDS sent out a family satisfaction survey; the previous surveys were conducted in 1998 and 1999. Consultants from the Human Service Research Institute (HSRI) in Boston, MA designed the surveys based on considerable input from families in Vermont and around the country. Vermont is taking part in the National Core Indicators (NCI) in an effort to develop nationally recognized outcome indicators that will enable states to compare their performance in relation to other states. Preliminary results from NCI are included in this report.

PROCESS

The survey asked for basic information about the respondent, his or her family member, and services received. There were also 39 questions about supports and services using a 5-point rating scale and a section for written comments. Families were given the option to indicate if they wished to have a DDS or agency staff person contact them.

The survey was mailed on November 19, 2001 to 1208 families. A pre-addressed, stamped return envelope was enclosed for ease of mailing. A second mailing of the survey was sent out three weeks later to people who had not yet responded¹. A total of 539 surveys were completed and returned to DDS, resulting in a very high response rate of 49%².

¹ The surveys were numbered for tracking purposes only. This allowed follow-up surveys to be sent and an accurate response rate calculated. The results of the surveys remain completely confidential and anonymous.

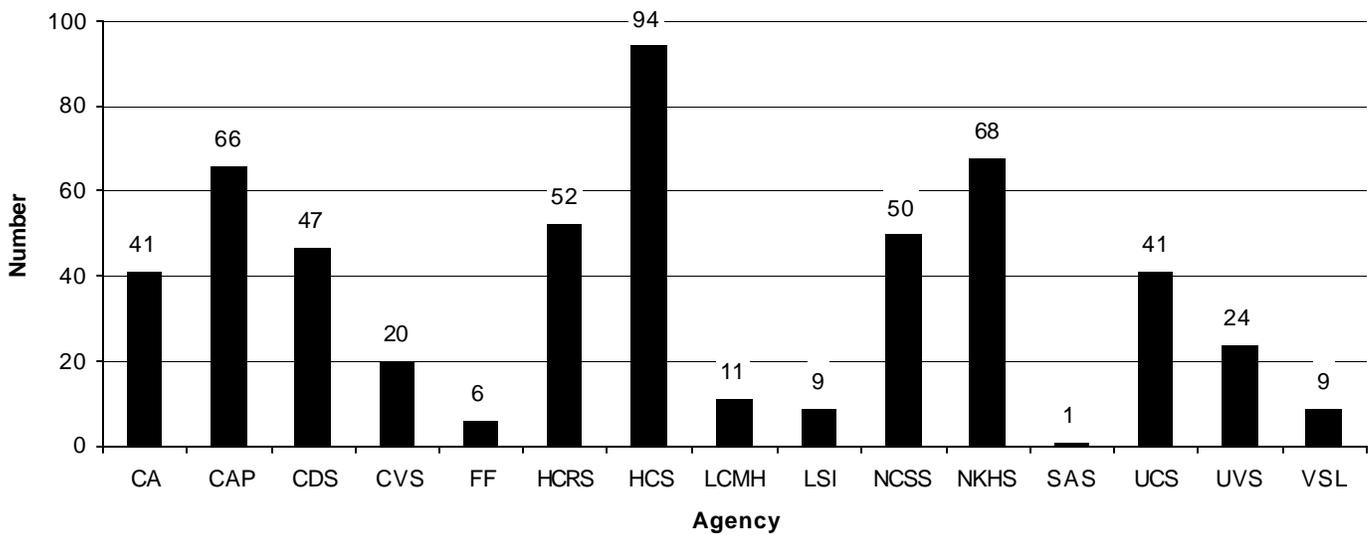
² The response rate was based on “total possible returns” of 1095 after subtracting the 113 surveys that were undeliverable or did not qualify (e.g., moved out of state, no longer in services, no longer living with their family).

BRIEF SUMMARY OF RESULTS

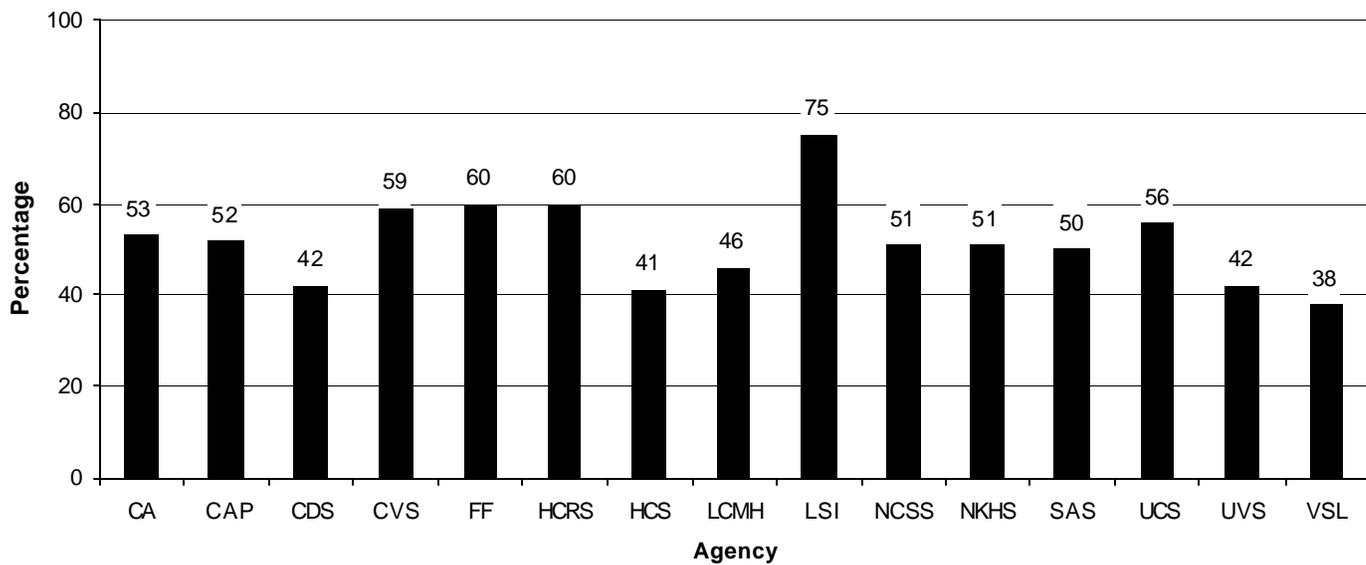
“Staff not only do their job well, they are very genuine, caring people who have helped to enrich our lives.”

RESPONDENTS BY AGENCY

Number of Survey Respondents



Survey Response Rate

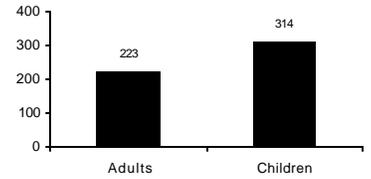


STATEWIDE OVERVIEW

	Number	Percentage
<u>Survey Response</u> (completed surveys)	539	49% (response rate)

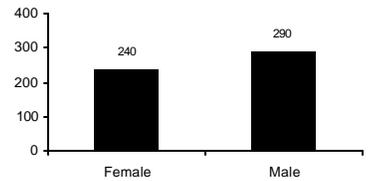
Age³ (family member with disability)

Adults (22 and older)	223	42%
Children (under 22)	314	58%



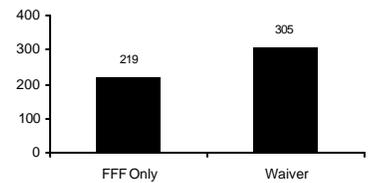
Gender

Female	240	45%
Male	290	55%



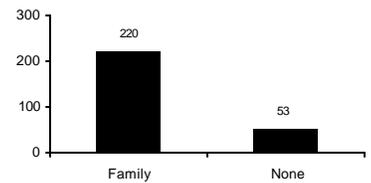
Funding Source⁴

Flexible Family Funding only	219	42%
Waiver Funding ⁵	305	58%



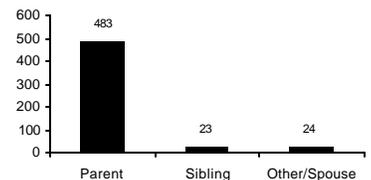
Guardian (over age 18 only)

Family or other as guardian	220	81%
No guardian	53	19%



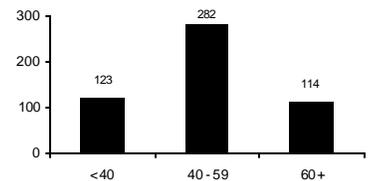
Relationship of Respondent

Parent	483	91%
Sibling	23	4%
Other Relative/Spouse	24	5%



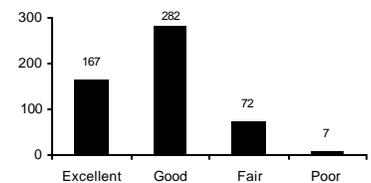
Caregiver Age

< 40	123	24%
40 – 59	282	54%
60 +	114	22%



Caregiver Health

Excellent	167	32%
Good	282	53%
Fair	72	14%
Poor	7	1%



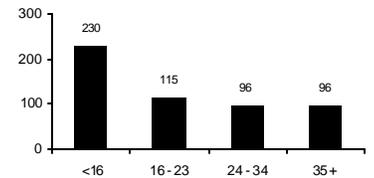
³ Adults = date of birth prior to 7/1/79. Children = date of birth 7/1/79 or after.

⁴ Sixteen (16) survey respondents received fee-for-service funding only and are left out of this count.

⁵ Waiver Funding = Home and Community-Based Waiver only and Home and Community-Based Waiver plus Flexible Family Funding or Fee-For-Service (i.e., Targeted Case Management, Personal Care Services).

(STATEWIDE OVERVIEW CONT.)

<u>Age</u> ⁶ (family member with disability)	Number	Percentage
< 16	230	43%
16 – 23	115	21%
24 – 34	96	18%
35 +	96	18%

In general, families reported satisfaction in the following areas:

- + Families know who to contact
- + Choice of support/respite workers
- + Control over hiring support/respite workers
- + Staff respect choices and opinions of families
- + Staff are generally respectful and courteous
- + Work/day supports are worthwhile

Families reported being least satisfied in the following areas:

- In a crisis, help is not always provided right away when requested
- Frequent changes in support/respite staff are sometimes a problem
- Not knowing how much money is spent on behalf of your family member

COMPARISON BETWEEN 1999 & 2001 SURVEY RESULTS⁷

Responses to individual questions and groupings of questions were compared between the 1999 Family Satisfaction Survey and the 2001 Family Satisfaction Survey. The data show families who responded to the 2001 survey were more satisfied than families who responded in 1999 in the following areas:

- + Choice (choice of workers and control over hiring and management of workers)⁸
- + Special Needs (staff who can communicate with person, access to special equipment)
- + Receiving information
- + Service planning is important to family members

⁶ This is an alternate age grouping used for the analysis starting on page 19.

⁷ Questions were chosen based on a statistical analysis of survey results from the 1999 and 2001 Family Satisfaction Surveys. Independent sample T-tests were performed to ascertain statistical significance.

⁸ Change in wording of the question from “Do you choose the *staff* that work with you?” (1999 survey) to “Do you choose the *support/respite workers* that work with you?” (2001 survey) may account for some of the increase in positive responses.

- + Staff respect choices and opinions of families
- + Choice of agency
- + Supports meet family needs
- + Supports available when family needs them
- + In a crisis, help is provided right away when requested
- + Services make a difference in keeping family member home
- + Informed of complaint and appeals process
- + Satisfied with how complaints and appeals are handled
- + Service coordinator helps get what is needed

Families were less satisfied in 2001 than in 1999 in the following area:

- Frequent changes in support staff is a problem

ANALYSIS OF DATA

The following pages depict data from the surveys in a number of different ways. Part I shows detailed results from specific survey questions in both a numeric and graphic format. Relevant quotes from the comment section of surveys that pertain to the questions are included. Quotes were chosen that appeared to be reflective of the data, however, they do not necessarily represent all comments provided on any given topic. Many of the comments provide insight as to what the family member felt was important to his or her satisfaction or lack of satisfaction.

Part II looks at how representative the survey sample was by comparing those who responded to the survey with all people who had been sent a survey. It also shows analyses of the data of survey respondents across age groups, gender and funding source. Only results that were found to be statistically significant are included⁹.

Part III provides additional comments from the surveys that seem important to include but which do not fit into any of the headings highlighted in Part I. An attachment of the survey tool annotated with the raw data completes the report.

⁹ Independent sample T-tests were performed to ascertain statistical significance.

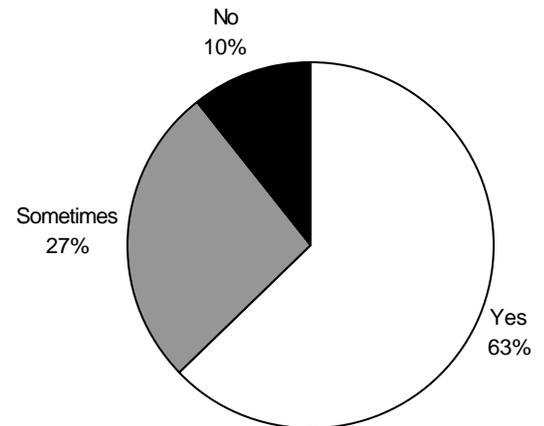
PART I – DATA SUMMARY

“Thank goodness for all their help and caring.”

OVERALL SATISFACTION

Overall Satisfaction: Overall, are you satisfied with the developmental services and supports that your family member currently receives?

	#	%
YES	312	63
SOMETIMES	132	27
NO	52	10



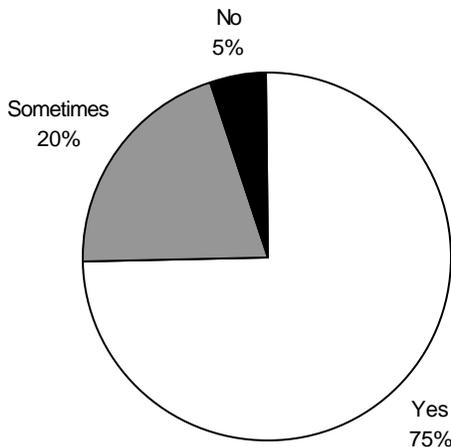
COMMENTS:

- “I think [the agency] is doing a great job!”*
- “[The agency] is wonderful, caring and helpful.”*
- “I have become very angry with [the agency] and their total lack of support.”*
- “Everyone we have been working with is great!!”*
- “Without [the agency], there is no way I could have made it.”*
- “The [agency] is an OUTSTANDING organization.”*

PLANNING

Staff Respect Choices: Do staff respect your choices and opinions?

	#	%
YES	349	75
SOMETIMES	96	20
NO	24	5

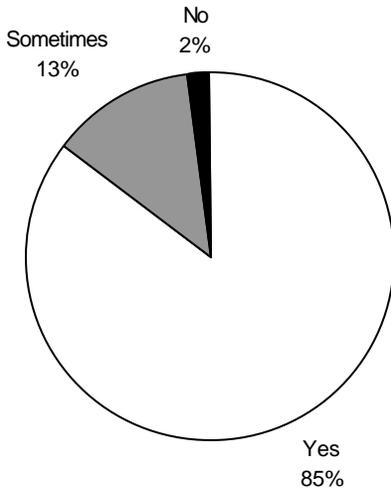


COMMENTS:

- “...while the state seems to promote choice & flexibility, that does not seem to filter down to staff at local agencies.”*
- “[The service coordinator] came to the home and listened to us and helped us to understand things.”*
- “Let parents give input on what THEY need for their children.”*

(PLANNING, CONT.)

Staff are Courteous: Are staff generally respectful and courteous?



	#	%
YES	419	85
SOMETIMES	63	13
NO	10	2

COMMENTS:

"The people at [the agency] are a great bunch – dedicated, respectful and interested..."

"Our [agency] caseworker is very sympathetic and extremely available..."

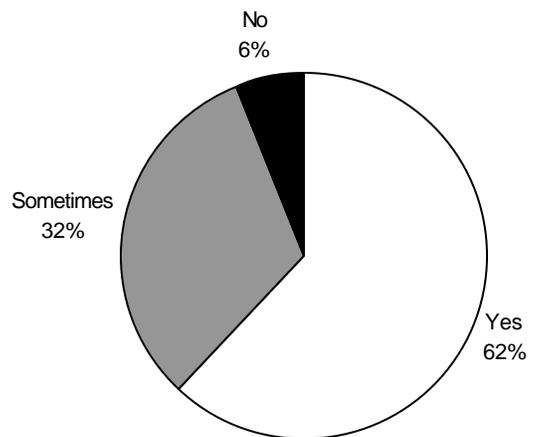
"...our respite provider...is prompt, courteous and efficient."

"Staff both of the Division and its sub-agencies need to be respectful of families using services."

"...we are very happy, and grateful for the compassionate professionalism typical of your staff."

Staff are Knowledgeable: Are staff generally knowledgeable and effective?

	#	%
YES	299	62
SOMETIMES	153	32
NO	30	6



COMMENTS:

"Case manager seldom knows answers to our questions..."

"[The agency] needs to do a better job of educating their staff on...basic finance."

"I have called [the agency] but no one there has provided any information about what is available..."

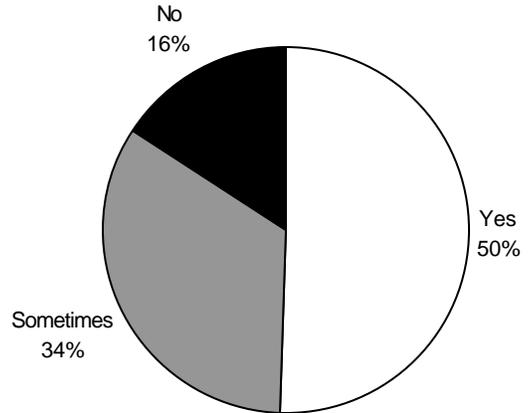
"Overall, I see a good program here... with dedicated people with experience."

"[Agency staff] generally do not know the big picture of what's available out there..."

INFORMATION

Information about Services Available: Do you receive information about services and supports that are available to your family?

	#	%
YES	257	50
SOMETIMES	172	34
NO	80	16



COMMENTS:

"I have just had a difficult time finding out, and understanding, what services and supports are 'out there' for my family."

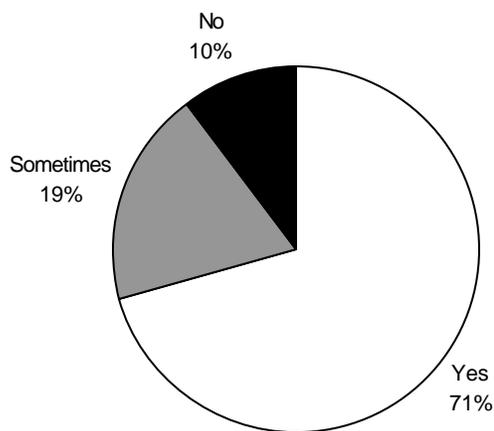
"I only know about [services] because other parents told me about them."

"Usually told what is NOT available... what [the agency] can't do..."

" [The agency] has been an excellent resource."

"...I wish I had known about this [respite] service when [my son] was younger."

Know Who to Contact for Information: Do you know who to contact for information or to make a change in developmental services?



	#	%
YES	361	71
SOMETIMES	97	19
NO	53	10

COMMENTS:

"We always feel as though there are numerous services available...but don't know what they are or how to get them."

"My agency has been helpful in identifying services..."

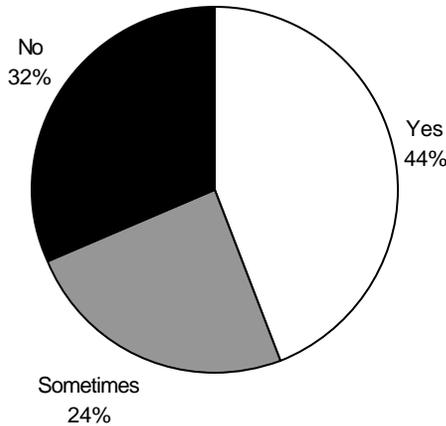
"Basically, we get no answers, no encouragement, no support and no information about possible future support."

"Receiving support remains a mysterious process to me."

(INFORMATION, CONT.)

Information about Public Benefits Available: Does someone talk to you about the public benefits that are available to you (e.g., SSI, Medicaid, food stamps, EPSDT)?

	#	%
YES	215	44
SOMETIMES	119	24
NO	154	32



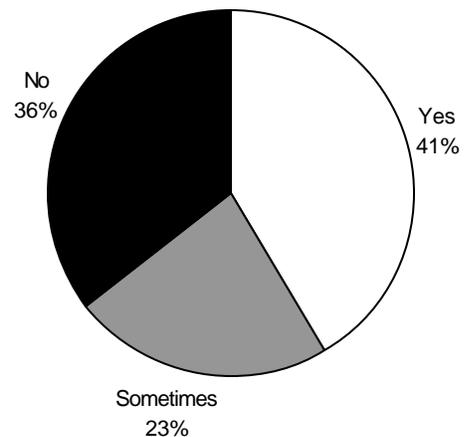
COMMENTS:

"...it would have been most useful to have known that we were actually getting Medicaid during all those years."

"No one [at the agency] could explain [questions about benefits] to me and sent me to Medicaid who sent me back to this Social Worker..."

Information about how Much Money is Spent: Do you know how much money is spent by the developmental service agency on behalf of your family member?

	#	%
YES	182	41
SOMETIMES	101	23
NO	156	36



COMMENTS:

"We have asked for a copy of the Medicaid waiver, several times...to date – nothing."

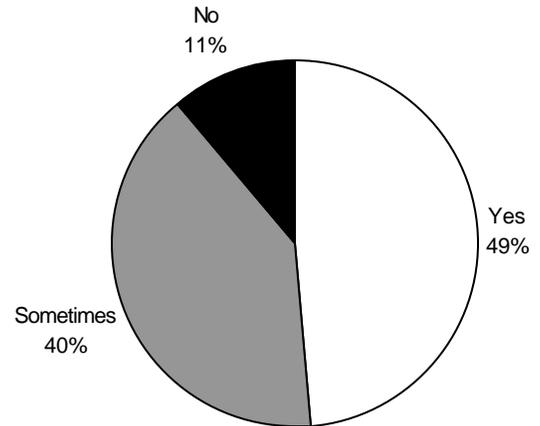
"...I would like someone to sit down and slowly explain what the waiver covers, how much funding my son should get and what he does get!"

"The assigned funding limit is left blank [on his ISA]."

ACCESS

Supports Available when Needed: Are supports available when your family needs them?

	#	%
YES	229	49
SOMETIMES	191	40
NO	52	11



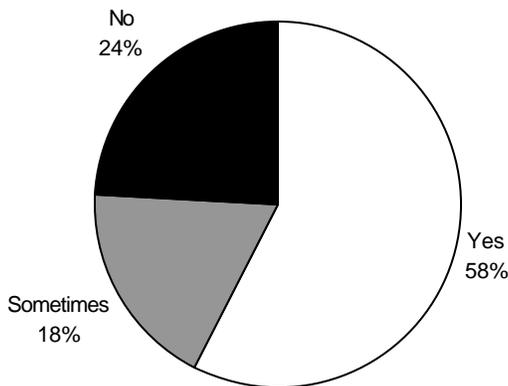
COMMENTS:

"The agency has not helped in finding services and programs at all."

"The agency has been very supportive in ensuring my requests are met."

"I find it very disappointing ...that an agency...has made it so difficult for many to receive the help they need."

Help Provided Right Away when in Crisis: If you have ever asked for the agency's assistance in an emergency or crisis, was help provided to you right away?



	#	%
YES	147	58
SOMETIMES	47	18
NO	62	24

COMMENTS:

"[The agency] was great to find respite when I had unexpected surgery and needed help."

"My case manager was very helpful and continues to be in even the most bleakest moments."

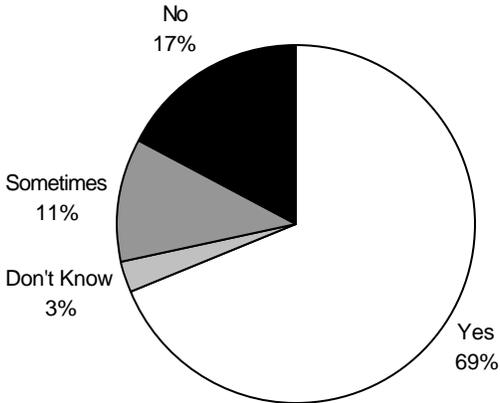
"There is no place for my daughter to go temporarily if I have a health emergency...this scares me."

"I dislike talking to an answering machine... if something has to be attended to right away."

"I wish they wouldn't wait until a crisis happens before they help families."

(ACCESS, CONT.)

Services Kept Your Family Member Home: Have services made a difference in helping keep your family member at home?



	#	%
YES	307	69
SOMETIMES	51	11
NO	77	17
DON'T KNOW	12	3

COMMENTS:

"If it wasn't for [his case manager's] help... my son would no longer be living at home."

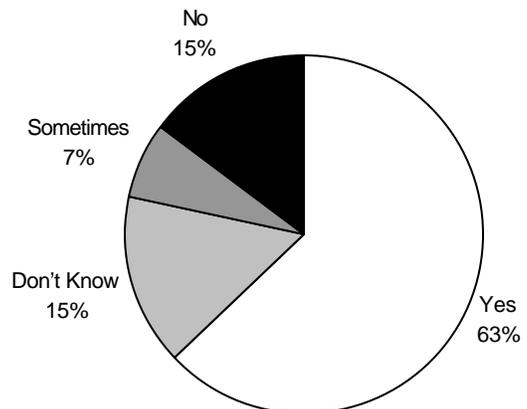
"Without their help, I don't know if our family would have stayed together."

"Because we have kept our son at home... we get extremely little support."

"I want to keep [my son] at home, but it gets harder and I'm getting older and in not as good health."

Still be at Home without Services: Would your family member still be at home if you did not receive any services?

	#	%
YES	301	63
SOMETIMES	34	7
NO	70	15
DON'T KNOW	74	15



COMMENTS:

"...with no services...we would have to give [our son]up."

"I cannot imagine not having my child at home, but I also can't imagine [trying] to do all her care without a break."

"Were it not for [the] program, our 5-year-old would have to be institutionalized."

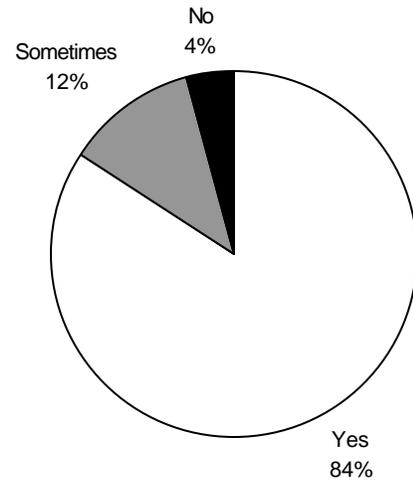
"I'll always take care of my brother."

"I do not know if [our daughter] would still be at home if we had no support."

(ACCESS, CONT.)

Work Supports Worthwhile: If your family member gets work support from the agency, is it worthwhile to your family member?

	#	%
YES	164	84
SOMETIMES	23	12
NO	8	4



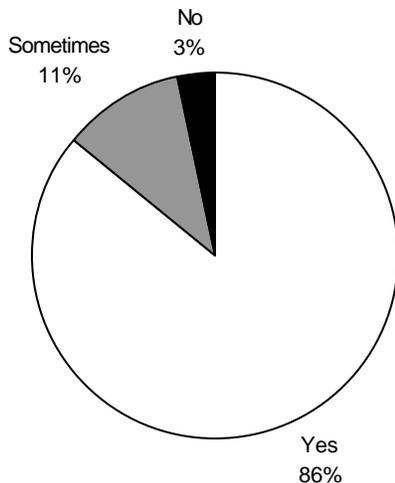
COMMENTS:

"My daughter is supported at a job and that makes all the difference in the world to our family."

"[Our daughter] enjoys the job and the companionship of coworkers."

"[The supported employment specialist] has been outstanding..."

Day Supports Worthwhile: If your family member gets day support (other than work) from the agency, is it worthwhile to your family member?



	#	%
YES	204	86
SOMETIMES	26	11
NO	8	3

COMMENTS:

"There needs to be more...socialization opportunities available."

"About the only thing I would like to see change is for my son to have some kind of social life."

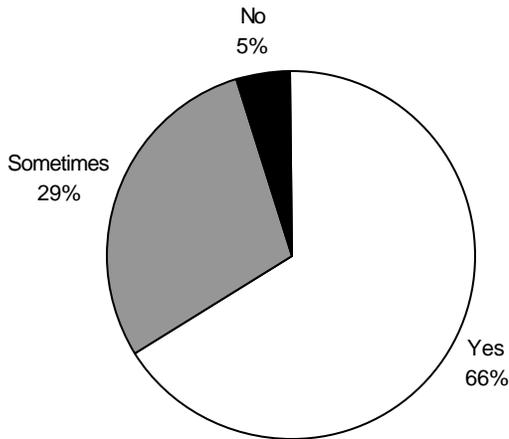
"There just isn't enough money to meet the needs of...social/respite activities."

"I think the need for recreational, out-in-the-community services is a real need..."

"[Services] has given him the means to get...more social interaction."

FAMILY INVOLVEMENT

Service Coordinator Helps: When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?



	#	%
YES	308	66
SOMETIMES	138	29
NO	22	5

COMMENTS:

"[Service coordinator]...has been our lifeline."

"Working with...the [service coordinator] and other staff there has been a positive experience for our family..."

"[My daughter's] case manager...sees a problem, finds a solution and acts on it ASAP!"

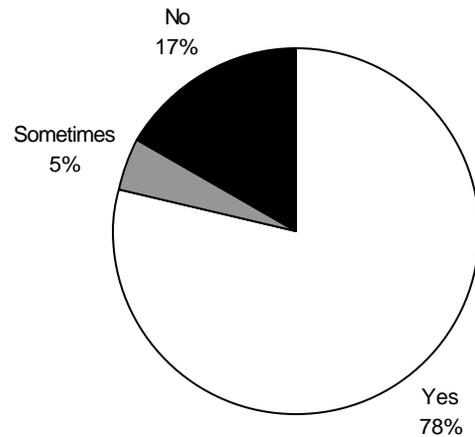
"[Our service coordinator] is very slow – unresponsive."

"[The service coordinator] always takes time to answer my questions."

"Case management...is superb!"

Staff Speak in Preferred Language: If English is not your first language, are there staff or translators available to speak with you in your preferred language?

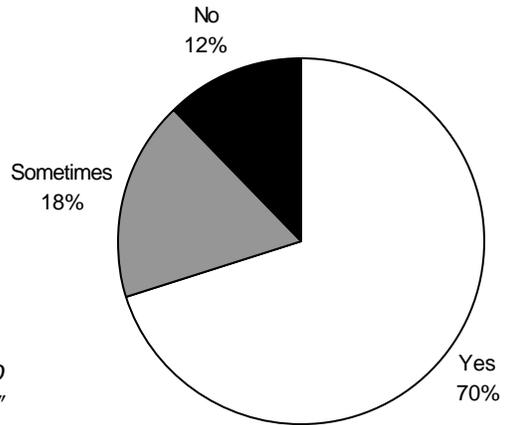
	#	%
YES	33	78
SOMETIMES	2	5
NO	7	17



CHOICES

Choice of Staff: Do you choose the support/respite workers that work with your family?

	#	%
YES	323	70
SOMETIMES	82	18
NO	56	12



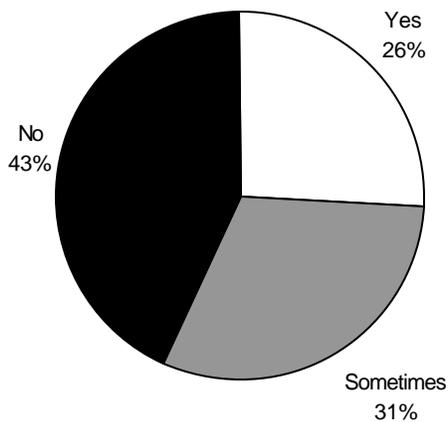
COMMENTS:

"Since I select the person to remain with...my child when away, I feel secure."

"...we find people [for respite]who would be good with [our daughter]."

Frequent Changes in Staff: Are frequent changes in support staff a problem for your family?

	#	%
YES	110	26
SOMETIMES	129	31
NO	182	43



COMMENTS:

"His case managers have changed so frequently... no one ever gets to truly understand him and his needs..."

"The turnover for workers in this field is high because pay is low and stress is high."

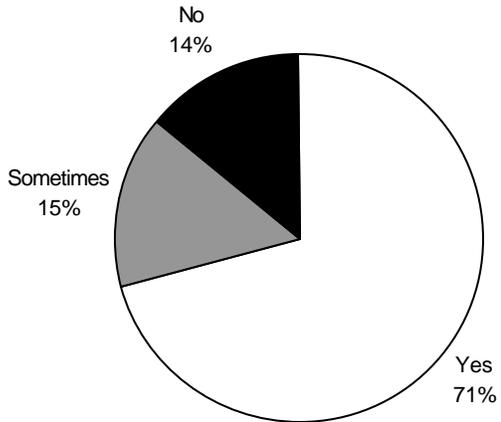
"The BIGGEST problem is people that are hired don't stick around for long."

"My son had to get use to a new person just about every month this year..."

"High turnover of support people is bad for families."

(CHOICES, CONT.)

Have Control over Workers: Do you have control and/or input over the hiring and management of your support/respite workers?



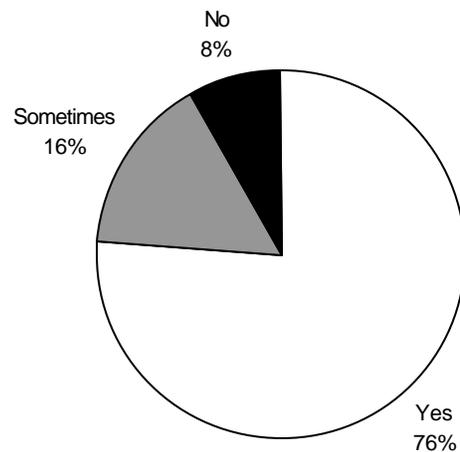
	#	%
YES	314	71
SOMETIMES	68	15
NO	63	14

COMMENTS:

- "We opted for self-management...we find it very beneficial."*
- "...I have a large influence on what my child's program and services look like."*
- "We have no say in management or pay...[Staff] deserve MUCH better pay...and we have no input in this?"*
- "We are going to self-manage starting next month, so that care can be more flexible."*
- "Accounting agencies...are unworkable, slow and create an impossible level of red tape."*

Want Control over Workers: Do you want to have control and/or input over the hiring and management of your support workers?

	#	%
YES	330	76
SOMETIMES	68	16
NO	35	8



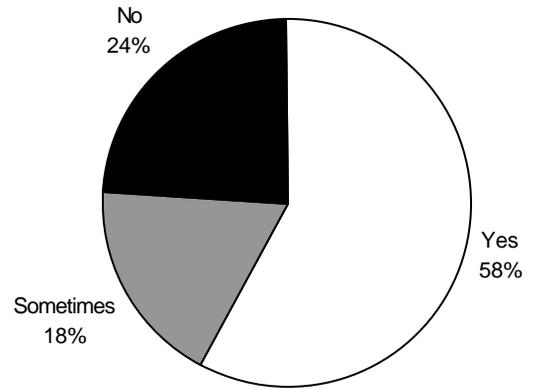
COMMENTS:

- "I'd like us to be [my son's] case manager and have more control over his funds and staff."*
- "...we feel it is up to our family to control our son's services."*

(CHOICES, CONT.)

Choice of Agency: Do you choose the developmental service agencies that work with your family?

	#	%
YES	256	58
SOMETIMES	82	18
NO	108	24



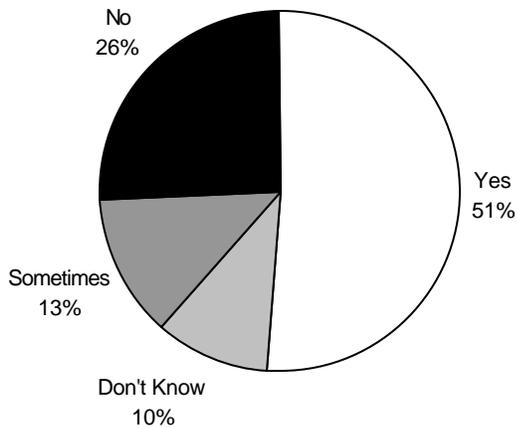
COMMENTS:

"We chose [the agency] and so far the transition was good..."

FAMILY SATISFACTION

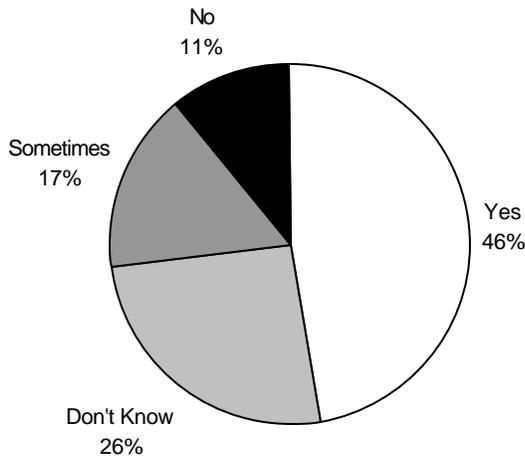
Informed of Complaint Process: Have you been informed of your agency's complaint and appeal process?

	#	%
YES	244	51
SOMETIMES	61	13
NO	126	26
DON'T KNOW	50	10



(FAMILY SATISFACTION, CONT.)

Satisfied with how Complaints are Handled: Are you satisfied with the way complaints and appeals are handled by your agency?



	#	%
YES	154	46
SOMETIMES	54	17
NO	35	11
DON'T KNOW	84	26

COMMENTS:

"I have called [the agency] on 4 different occasions to make complaints with NO success..."

"If I have a complaint, I shouldn't be told that I can't speak to Developmental Services or another agency. It should be within my rights to talk to anyone."

Staff Available who can Communicate with Family Member: If your family member does not speak, or uses a different way to communicate (for example, sign language), are there enough staff available who can communicate with him/her?

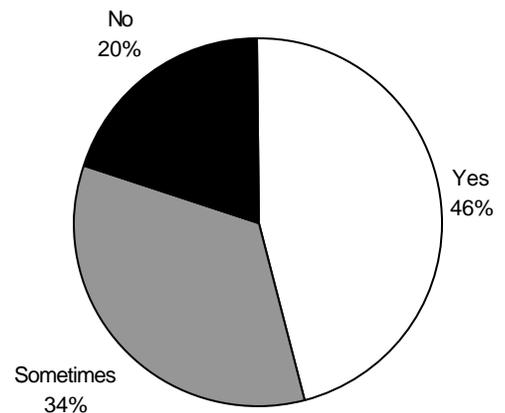
	#	%
YES	89	46
SOMETIMES	66	34
NO	39	20

COMMENTS:

"Without respite services...it would be impossible as [my son] needs constant supervision and medical attention and someone who knows how to communicate with him."

"Our son is totally deaf and blind but works with a support person who is trained and knows signing."

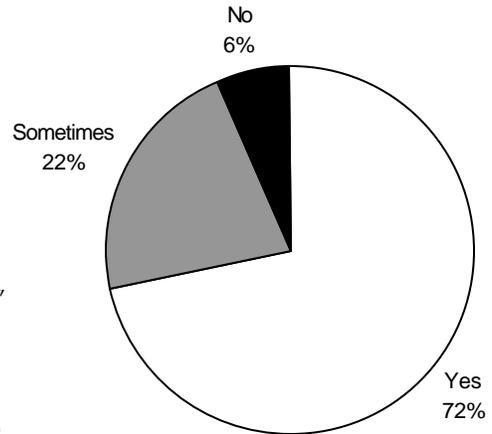
"My son needs a better way to communicate."



(FAMILY SATISFACTION, CONT.)

Family Supports Make a Positive Difference: Do you feel that family supports have made a positive difference in the life of your family member?

	#	%
YES	338	72
SOMETIMES	105	22
NO	30	6



COMMENTS:

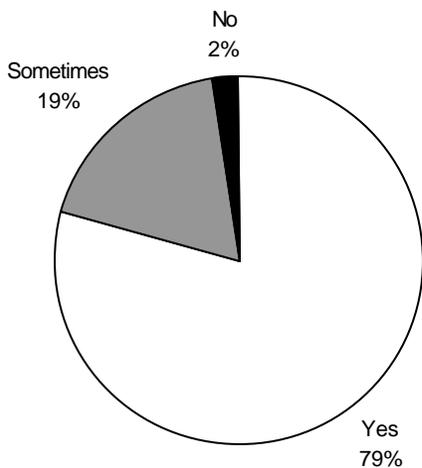
"Everything is great for my daughter and myself with this program that she is in."

"Progress has been slow but steady."

"...we've been receiving services for 2 years, which has changed all of our lives for the better."

"Services for my son has made an important difference in his life as well as our families well being."

Overall, Family Member is Happy: Overall, do you feel your family member is happy?



	#	%
YES	406	79
SOMETIMES	96	19
NO	11	2

COMMENTS:

"With these services in place... it helps my daughter to be happy! That's important."

"Generally, I think my son is very happy with [the agency]"

PART II – DATA ANALYSIS ACROSS GROUPS

“I don’t know how I could have made it over the last 5 years without [the agency’s] guidance and support.”

SURVEY SAMPLE REPRESENTATION

An analysis was conducted to see how the survey sample (those who responded to the survey) compare in relation to all the people who were sent a survey. The analysis looked at the age of the family member and the funding source.

- Of the families who answered the survey¹⁰,
 - the same proportion of families received waiver funding,
 - a greater proportion of families received Flexible Family Funding, and
 - a greater proportion of families were families of adults than for all families who were sent the survey.

Survey Responses by Age of Caregiver and Age of Family Member¹¹

Age of Caregiver	Age of Family Member				TOTAL
	< 16	16 - 23	24 - 34	35+	
< 40	103	11	7	2	123
40 – 59	118	93	47	24	282
60 +	2	8	37	66	113
TOTAL	223	112	91	92	518

- Of the families who answered the survey:
 - 41% of young adults (24 – 34 years old) who live at home have primary caregivers who are 60+ years old, and
 - 72% of older adults (35 + years old) who live at home have primary caregivers who are 60+ years old.

¹⁰ There are 31 surveys for which there are no funding source data.

¹¹ The overall total number in this chart is less than the 539 respondents because not all respondents listed the age of the primary caregiver. There is one caregiver for whom the age of the family member was not known and so is not included in this cross-tabulation chart.

Data from the surveys were analyzed across a number of variables: age group (adults versus children¹² and by age categories¹³), funding source (Flexible Family Funding only versus Waiver Funding¹⁴), and caregiver age. Areas where these variables seemed to make a difference in satisfaction are noted below¹⁵.

AGE GROUP – ADULTS VS. CHILDREN

- ◆ Families of **adults** expressed **greater satisfaction** than families of **children** in the following areas:
 - Receiving information about services*
 - Access to services*
 - Services meet family needs*
 - Informed of complaint and appeals process
 - Frequent changes in support staff
 - Staff help get what family needs*
 - Overall satisfaction

- ◆ Families of **children** expressed **greater satisfaction** than families of **adults** in the following area:
 - Control and/or input over hiring and managing workers*
 - How complaints and appeals are handled

- ◆ It was noteworthy that there was **no significant difference** in satisfaction based on the person's **age** in the following areas:
 - Respectfulness, courteousness and knowledge of staff*
 - Help provided right away in an emergency or crisis
 - Services make a difference in keeping family member at home

* Areas indicated with an asterisk incorporate two or more questions.

¹² Adults = date of birth prior to 7/1/76. Children = date of birth 7/1/76 or sooner.

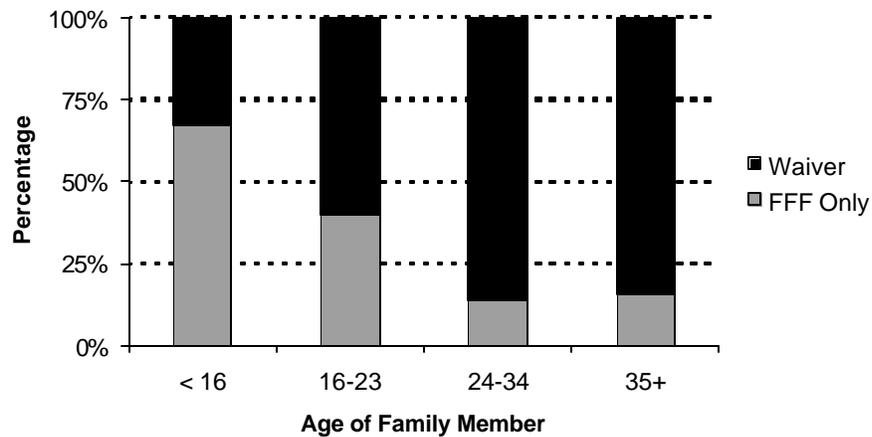
¹³ Age categories: <16 = Young Children, 16-23 = Transition Age Youth, 24-34 = Adults, 35+ = Older Adults.

¹⁴ Waiver Funding = Home and Community-Based Waiver only and Home and Community-Based Waiver plus Flexible Family Funding or Fee-For-Service (i.e., Targeted Case Management, Personal Care Services).

¹⁵ Independent sample T-tests were performed to ascertain statistical significance.

AGE GROUP – BY CATEGORIES

Survey Responses by Age of Family Member and Funding Source¹⁶



- **67%** of families of **young children** (<16 years old) receive **Flexible Family Funding only** (about the same percentage as in 1999)
- **40%** of families of **transition age youth** (16-23 years old) receive **Flexible Family Funding only** (versus 63% in 1999)
- **30%** of families of **adults** (24+ years old) receive **Flexible Family Funding only** (versus 77% in 1999)
- ◆ Families of **young children** (<16 years old) report **more satisfaction** with
 - choice of support workers, and
 - wanting control over the hiring & management of support workers
 than families of **transition age youth and adults** (16+ years old)
- ◆ Families of **young children and transition age youth** (<24 years old) report **more satisfaction** with
 - having control over the hiring & management of support workers
 than families of **adults** (24+ years old)

¹⁶ The overall total number in this chart is less than the 539 respondents because not all respondents listed the age of the primary caregiver.

- ◆ Families of **young adults** (24 - 34 years old) report **more satisfaction** with
 - receiving information about services, which is easy to understand,
 - staff helping you figure out what you need as a family, and
 - receiving help right away in an emergency
 than families of **children and older adults** (<24 and 35+ years old)

- ◆ Families of **adults** (24+ years old) report more satisfaction with
 - services and supports family member currently receives,
 - receiving information to help participate in planning services,
 - knowing who to contact for information or to make a change,
 - getting the services and supports that are needed, when they are needed*,
 - having access to special equipment or accommodations that are needed,
 - the service coordinator helping you get what you need, and
 - feeling family member is happy
 than families of **young children and transition age youth** (<24 years old)

FUNDING SOURCE

- ◆ Families who receive **Waiver Funding** expressed **greater satisfaction** than families who receive **Flexible Family Funding Only** in the following areas:
 - Receiving information*
 - Planning services*
 - Being told about available public benefits
 - Access to services*
 - Staff available to speak in preferred language, if not English
 - Services make a difference in keeping family members at home
 - Informed and satisfied with complaint/appeal process*
 - Family satisfaction*

- ◆ It was noteworthy that there was **no significant difference in satisfaction** based on **funding source** in the following areas:
 - Knowledge and effectiveness of staff
 - Access to needed special equipment or accommodations
 - Service coordinator
 - Feel that family member is happy

* Areas indicated with an asterisk incorporate two or more questions.

CAREGIVER AGE

- ◆ Families where the caregiver was **age 65+** expressed **greater satisfaction** than families where the caregiver was **younger than 65** in the following areas:
 - Receiving information*
 - Services meet family needs*
 - Frequent changes in support staff
 - Access to and help from support coordinator*
 - Feel family member is happy
 - Overall satisfaction

- ◆ Families where the caregiver was **age <35** expressed **greater satisfaction** than families where the caregiver was **older than 35** in the following areas:
 - Feel work supports are worthwhile to family member
 - Feel day supports (other than work) are worthwhile to family member

* Areas indicated with an asterisk incorporate two or more questions.

PART III – ADDITIONAL COMMENTS

“The help the family gets for my son...helps me to be able to work for an all round healthy environment in our home.”

The following quotes were taken from the survey comment section. They are grouped into categories representing common issues, often systemic in nature, and not already reflected in Part I of this report. It is not unusual to find anonymous comments from surveys having a negative slant. The confidential format of this survey provides an opportunity for people to share their frustrations and concerns in a safe manner. These quotations tend to represent the general sentiments expressed in the surveys and often contain ideas for change.

RESPITE

“We...depend on [our daughter’s] respite worker for relief and for her well-being.”

“I need more respite care. I cannot comfortably leave my son alone at home.”

“The primary problem always seems to be the ability to find respite workers...”

“The most frustrating piece...is the lack of qualified people we have had.”

“Having respite services gives me just enough break to be able to persevere.”

“I...would like a list of possible respite workers so an evening out would be possible.”

“Respite is nice, if I had a reliable person to do it.”

“Respite was a God-sent over the summer.”

“Without [flexible funding], our family would be in DEPRESSION and feeling ISOLATED!”

“I love flexible funding. I can hire who I want or use the money for something special for my child.”

WORKER WAGES

“These workers should get benefits and pay that make them want to do this long term.”

“It’s time to increase...pay and reduce the ‘administration costs’...”

“I believe that low pay is a major contributing factor to not attracting quality workers.”

“Turnover is a huge problem – need more money for agency staff!”

“Support staff...need to be paid a lot more to help decrease turnover and to focus more on consistent professional behavior.”

“[The agency] can not compensate for...the poor pay, inadequate (non-existent) benefits and lack of flexibility in hiring respite workers.”

TRAINING WORKERS

“I’d like the support people to be better trained....”

“Frustrated with not getting staff who are trained.”

“I think that staff people need to be highly trained, qualified to work with my daughter.”

“Trained and knowledgeable service providers are needed....”

“...develop a model for training that gives consumers a pool of trained people to pick from.”

“There is not enough money to attract decently trained people to...work with my son.”

COMMUNICATION

“Although we are part of [the agency], we don’t communicate much.”

“There should be more communications between case managers...and home providers.”

“Staff need to...advise families of changes which have major impacts on their lives.”

“Wish [the agency] had an 800 telephone number.”

PLANNING FOR THE FUTURE

“I have NO confidence there will be services for my child in the future.”

“I worry what will happen when [my son] becomes an adult.”

“I am extremely anxious about my child’s future given the apparent unreliability of the...system.”

“What will happen when I am no longer able to care for [my son]?”

“I am worried about what kind of supports my daughter will have. She will be out of school in 2 more years. She cannot be left alone.”

“Who will care for [my son] when I am gone...?”

HIRING & FIRING WORKERS

“The most difficult part is to always be able to find a good respite worker, or one at all.”

“I always have to find my own respite.”

“It’s impossible to get a substitute for vacation or sickness.”

“It is too bad that my son misses work because of a backup worker not available when they need one.”

RESPONSIVENESS

“I called the agency for help...and was stunned by the non-response...”

“If our family has been left in such a precarious, dangerous situation, I shudder to think what less-educated/self-advocating families are going through.”

“[Our son’s] current case manager is very responsive....”

“The service providers never contact my family to see how things are going.”

“...the processes take MONTHS before services are in place.”

“I feel I can count on [my caseworker] to give us support and guidance whenever possible.”

“...if I ever have a problem or needed anything, [my service coordinator]... is extremely helpful....”

BUDGET CONCERNS

“This [budget] cut will make the services that we get inadequate.”

“Impending budget cuts are only going to make situations worse and will ultimately lead to family tragedies.”

“I am worried and concerned that the State budget cuts will have a negative impact on the quality of life and care of my daughter as well as that of my family.”

“I fear for my son, his program and ourselves, as we try to care for him.”

AGENCY STRUCTURE/BUREAUCRACY

“[The agency] has helped our family a great deal but there is too many people to deal with.”

“...we burden [staff] with paperwork and some very mindless issues.”

“I think too much time and funds are being spent on administration.”

“Too many layers at the agency.”

FRIENDS/COMMUNITY/QUALITY OF LIFE

“My son has a full time job, but few friends....”

“...friends and family are a big part of [our daughter’s] life. Church also.”

“Parents and siblings are often isolated from the community.”

“...social life is only with our family members.”

“I would like to get [my daughter] involved with her peers more....”

“My son has little opportunity to meet socially with [others]....”

“It would be nice to have a support group with other parents.”

ATTACHMENT: Family Satisfaction Survey Responses

INFORMATION & PLANNING		YES, OR MOST OF THE TIME	SOME, OR SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
1.	Do you receive information about developmental services and supports that are available to your family? N=525	<input type="checkbox"/> 1 257	<input type="checkbox"/> 2 172	<input type="checkbox"/> 3 80	<input type="checkbox"/> 4 10	<input type="checkbox"/> 5 6
2.	If you receive information, is it easy to understand? N=509	<input type="checkbox"/> 1 283	<input type="checkbox"/> 2 149	<input type="checkbox"/> 3 18	<input type="checkbox"/> 4 13	<input type="checkbox"/> 5 46
3.	Do you get enough information to help you participate in planning services for your family member? N=522	<input type="checkbox"/> 1 245	<input type="checkbox"/> 2 155	<input type="checkbox"/> 3 92	<input type="checkbox"/> 4 15	<input type="checkbox"/> 5 15
4.	Do you know who to contact for information or to make a change in developmental services? N=527	<input type="checkbox"/> 1 361	<input type="checkbox"/> 2 97	<input type="checkbox"/> 3 53	<input type="checkbox"/> 4 13	<input type="checkbox"/> 5 3
5.	If your family member has a service plan, did you help develop the plan? N=516	<input type="checkbox"/> 1 311	<input type="checkbox"/> 2 64	<input type="checkbox"/> 3 43	<input type="checkbox"/> 4 33	<input type="checkbox"/> 5 65
6.	If your family member has a service plan, does the plan include things that are important to your family member? N=507	<input type="checkbox"/> 1 312	<input type="checkbox"/> 2 74	<input type="checkbox"/> 3 19	<input type="checkbox"/> 4 29	<input type="checkbox"/> 5 73
7.	Does someone talk to you about the public benefits that are available to you (e.g., SSI, Medicaid, food stamps, EPSDT)? N=527	<input type="checkbox"/> 1 215	<input type="checkbox"/> 2 119	<input type="checkbox"/> 3 154	<input type="checkbox"/> 4 5	<input type="checkbox"/> 5 34
8.	Do developmental services agency staff help you figure out what you need as a family to support your family member? N=524	<input type="checkbox"/> 1 216	<input type="checkbox"/> 2 151	<input type="checkbox"/> 3 113	<input type="checkbox"/> 4 14	<input type="checkbox"/> 5 30
9.	Do developmental service agency staff respect your choices and opinions? N=523	<input type="checkbox"/> 1 349	<input type="checkbox"/> 2 96	<input type="checkbox"/> 3 24	<input type="checkbox"/> 4 19	<input type="checkbox"/> 5 35
10.	Are developmental service agency staff generally respectful and courteous? N=525	<input type="checkbox"/> 1 419	<input type="checkbox"/> 2 63	<input type="checkbox"/> 3 10	<input type="checkbox"/> 4 9	<input type="checkbox"/> 5 24
11.	Are developmental service agency staff generally knowledgeable and effective? N=524	<input type="checkbox"/> 1 299	<input type="checkbox"/> 2 153	<input type="checkbox"/> 3 30	<input type="checkbox"/> 4 16	<input type="checkbox"/> 5 26
CHOICES & CONTROL		YES, OR MOST OF THE TIME	SOME, OR SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
12.	Do you choose the developmental service agencies that work with your family? N=506	<input type="checkbox"/> 1 256	<input type="checkbox"/> 2 82	<input type="checkbox"/> 3 108	<input type="checkbox"/> 4 29	<input type="checkbox"/> 5 31
13.	Do you choose the support/respice workers that work with your family? N=520	<input type="checkbox"/> 1 323	<input type="checkbox"/> 2 82	<input type="checkbox"/> 3 56	<input type="checkbox"/> 4 9	<input type="checkbox"/> 5 50
14.	Do you have control and/or input over the hiring and management of your support/respice workers? N=517	<input type="checkbox"/> 1 314	<input type="checkbox"/> 2 68	<input type="checkbox"/> 3 63	<input type="checkbox"/> 4 14	<input type="checkbox"/> 5 58

(CHOICES & CONTROL CON'T.)		YES, OR MOST OF THE TIME	SOME, OR SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
15.	Do you <u>want</u> to have control over the hiring and management of your support/respite workers? N=512	<input type="checkbox"/> 1 330	<input type="checkbox"/> 2 68	<input type="checkbox"/> 3 35	<input type="checkbox"/> 4 13	<input type="checkbox"/> 5 66
16.	Do you know how much money is spent by the developmental service agency on behalf of your family member with a developmental disability? N=521	<input type="checkbox"/> 1 182	<input type="checkbox"/> 2 101	<input type="checkbox"/> 3 156	<input type="checkbox"/> 4 53	<input type="checkbox"/> 5 29
17.	Do you get to decide how this money is spent? N=515	<input type="checkbox"/> 1 186	<input type="checkbox"/> 2 128	<input type="checkbox"/> 3 131	<input type="checkbox"/> 4 30	<input type="checkbox"/> 5 40
18.	Do you (or your family member) manage developmental service funding through Alpha One, ARIS, or other accounting service? N=513	<input type="checkbox"/> 1 159	<input type="checkbox"/> 2 18	<input type="checkbox"/> 3 171	<input type="checkbox"/> 4 82	<input type="checkbox"/> 5 83
ACCESS TO DEVELOPMENTAL SERVICES & SUPPORTS		YES, OR MOST OF THE TIME	SOME, OR SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
19.	Does your family get the services and supports you need? N=520	<input type="checkbox"/> 1 238	<input type="checkbox"/> 2 209	<input type="checkbox"/> 3 50	<input type="checkbox"/> 4 14	<input type="checkbox"/> 5 9
20.	Do the supports offered by the developmental service agency meet your family's needs? N=517	<input type="checkbox"/> 1 225	<input type="checkbox"/> 2 203	<input type="checkbox"/> 3 57	<input type="checkbox"/> 4 15	<input type="checkbox"/> 5 17
21.	Are supports available when your family needs them? N=517	<input type="checkbox"/> 1 229	<input type="checkbox"/> 2 191	<input type="checkbox"/> 3 52	<input type="checkbox"/> 4 25	<input type="checkbox"/> 5 20
22.	If you have ever asked the developmental service agency for assistance in an emergency or crisis, was help provided to you right away? N=519	<input type="checkbox"/> 1 147	<input type="checkbox"/> 2 47	<input type="checkbox"/> 3 62	<input type="checkbox"/> 4 25	<input type="checkbox"/> 5 238
23.	If English is <u>not</u> your first language, are there staff or translators available to speak with you in your preferred language? N=509	<input type="checkbox"/> 1 33	<input type="checkbox"/> 2 2	<input type="checkbox"/> 3 7	<input type="checkbox"/> 4 16	<input type="checkbox"/> 5 451
24.	Have services made a difference in helping keep your family member at home? N=521	<input type="checkbox"/> 1 307	<input type="checkbox"/> 2 51	<input type="checkbox"/> 3 77	<input type="checkbox"/> 4 12	<input type="checkbox"/> 5 74
25.	Would your family member still be at home if you did not receive any services? N=520	<input type="checkbox"/> 1 301	<input type="checkbox"/> 2 34	<input type="checkbox"/> 3 70	<input type="checkbox"/> 4 74	<input type="checkbox"/> 5 41
26.	If your family member does not speak, or uses a different way to communicate (for example, sign language), are there enough staff available who can communicate with him/her? N=517	<input type="checkbox"/> 1 89	<input type="checkbox"/> 2 66	<input type="checkbox"/> 3 39	<input type="checkbox"/> 4 23	<input type="checkbox"/> 5 300
27.	Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)? N=518	<input type="checkbox"/> 1 134	<input type="checkbox"/> 2 77	<input type="checkbox"/> 3 28	<input type="checkbox"/> 4 13	<input type="checkbox"/> 5 266
28.	Have you been informed of your developmental service agency's complaint and appeals process? N=518	<input type="checkbox"/> 1 244	<input type="checkbox"/> 2 61	<input type="checkbox"/> 3 126	<input type="checkbox"/> 4 50	<input type="checkbox"/> 5 37

ACCESS TO DEVELOPMENTAL SERVICES & SUPPORTS (CON'T.)		YES, OR MOST OF THE TIME	SOME, OR SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
29.	Are you satisfied with the way complaints and appeals are handled and resolved by your local developmental service agency? N=517	<input type="checkbox"/> 1 154	<input type="checkbox"/> 2 54	<input type="checkbox"/> 3 35	<input type="checkbox"/> 4 84	<input type="checkbox"/> 5 190
30.	Are frequent changes in support/respice staff a problem for your family? N=522	<input type="checkbox"/> 1 110	<input type="checkbox"/> 2 129	<input type="checkbox"/> 3 182	<input type="checkbox"/> 4 12	<input type="checkbox"/> 5 89
31.	If you want help getting family supports in your community (such as services offered through recreation departments or churches), do staff help connect you to these services? N=521	<input type="checkbox"/> 1 124	<input type="checkbox"/> 2 112	<input type="checkbox"/> 3 110	<input type="checkbox"/> 4 49	<input type="checkbox"/> 5 126
32.	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? N=515	<input type="checkbox"/> 1 115	<input type="checkbox"/> 2 87	<input type="checkbox"/> 3 126	<input type="checkbox"/> 4 43	<input type="checkbox"/> 5 144
33.	Can you contact your family member's service coordinator/case manager whenever you want to? N=523	<input type="checkbox"/> 1 348	<input type="checkbox"/> 2 91	<input type="checkbox"/> 3 21	<input type="checkbox"/> 4 30	<input type="checkbox"/> 5 33
34.	When you ask the service coordinator/case manager for assistance, does he/she help you get what you need? N=524	<input type="checkbox"/> 1 308	<input type="checkbox"/> 2 138	<input type="checkbox"/> 3 22	<input type="checkbox"/> 4 21	<input type="checkbox"/> 5 35
35.	If your family member gets work support from the developmental service agency, is it worthwhile to your family member? N=512	<input type="checkbox"/> 1 164	<input type="checkbox"/> 2 23	<input type="checkbox"/> 3 8	<input type="checkbox"/> 4 16	<input type="checkbox"/> 5 301
36.	If your family member gets day support (other than work) from the developmental service agency, is it worthwhile to your family member? N=513	<input type="checkbox"/> 1 204	<input type="checkbox"/> 2 26	<input type="checkbox"/> 3 8	<input type="checkbox"/> 4 15	<input type="checkbox"/> 5 260
FAMILY SATISFACTION		YES, OR MOST OF THE TIME	SOME, OR SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
37.	Do you feel that family supports have made a positive difference in the life of your family? N=515	<input type="checkbox"/> 1 338	<input type="checkbox"/> 2 105	<input type="checkbox"/> 3 30	<input type="checkbox"/> 4 14	<input type="checkbox"/> 5 28
38.	Overall, do you feel that your family member is happy? N=520	<input type="checkbox"/> 1 406	<input type="checkbox"/> 2 96	<input type="checkbox"/> 3 11	<input type="checkbox"/> 4 2	<input type="checkbox"/> 5 5
39.	Overall, are you satisfied with the developmental services and supports that your family member currently receives? N=516	<input type="checkbox"/> 1 312	<input type="checkbox"/> 2 132	<input type="checkbox"/> 3 52	<input type="checkbox"/> 4 3	<input type="checkbox"/> 5 17