Continued Commitment to Excellence:

Evaluating Pennsylvania's Family Driven Family Support Services Program

Final Evaluation Report
Winter 1998

Institute on Disabilities/
UAP

Human
Services
Research
Institute

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Table of Contents

1. Introduction and Study Purpose

Over the past two decades, the nation's response to children with developmental disabilities and their families has shifted dramatically, moving from an historical awareness of disability based in segregation and exclusion to one that favors the inclusion of people with disabilities into the mainstream of community life. In 1972 Pennsylvania became the first state to offer some measure of support to families who provide care at home to children with mental retardation. Since that time all but one state have developed initiatives to provide families with a variety of supportive goods and services.

Family support means different things to different families. While no single definition of the concept has gained sway nationally, the idea is simply to provide families with *whatever it takes* for families of people with disabilities to live as much like other families as possible. More specifically, the term "family support" can mean supports, resources, services, and other assistance provided to families of children with disabilities that are designed to (a) support families in their efforts to raise their children with disabilities in the family home, (b) strengthen the role of the family as primary care-giver, (c) prevent inappropriate and unwanted out-of-home placement and maintain family unity, and (d) reunite families with children with disabilities who have been placed out of the home.

In Pennsylvania, family support services represent a service approach that recognizes the family as the most significant provider of services to people with mental retardation. Additionally, the design of the system of delivering family support places the family at the center of the decision making process for their family member. Building on this tradition, in 1987-1988 the Pennsylvania Office on Mental Retardation began funding 11 *family driven family support services program (FDFSS program)* pilots, expanding this number by 15 in 1990 and steadily thereafter. These projects are operated through county Mental Retardation programs. The services offered could include things like respite care, sitter services, homemaker services, specialized therapies, special foods, and others, and may be delivered as direct services or by voucher or direct cash assistance. Other innovative services and supports are also offered.

OMR is committed to continuing its tradition of excellence in responding to the needs of families who provide care at home to people with disabilities. Yet OMR recognizes that from time to time it is advisable to take a hard look at the overall family support system to identify ways for improving the service response. Within this context, the Institute on Disabilities at Temple University and the Human Services Research Institute are collaborating to collect relevant information concerning the FDFSS programs in

Pennsylvania and facilitate a participatory process for improving the family support system. As this project unfolds, Pennsylvanians will:

- ✯ Evaluate their family support system based on their own set of standards and guiding principles;
- ✯ Assess their family support system based on a set of nationally validated quality indicators;
- ✯ Develop their own conclusions over how to proceed with their system of services and supports to families based on the information obtained.

To achieve these goals, a mail survey of a representative sample of families who receive family support services was conducted. In addition, follow-up interviews of a portion of these families were conducted and focus groups convened to discuss the findings. Finally, based on all project findings, recommendations for improving the family support system are offered to OMR. In this *Final Repor the* findings emerging from these activities are presented, as are the resulting recommendations.

The remainder of the report is organized into the following sections:

Chapter 2: Summary of Evaluation Methods presents an overview of the primary methods of information gathering and analysis used to conduct the survey including descriptions of the survey form, the sampling plan, survey distribution and data entry methods.

Chapter 3: Results of the Mail Survey presents the results of the mail survey and includes frequency distributions by survey question.

Chapter 4: Results of the Focus Groups presents the findings of focus groups held in eight sites across the Commonwealth.

Chapter 5: Results of the Follow Up Interviews presents the findings generated from interviews with a sample of family members who completed the original mail survey.

Chapter 6: Concluding Thoughts and Recommendations presents discussion related to the study findings and offers recommendations to the Office of Mental Retardation in order to improve the Family Driven Family Support Services program.

2. Methods

The evaluation of Pennsylvania's current FDFSS program was initiated during 1995 when HSRI and the Institute on Disabilities finalized its evaluation strategy based on discussions with the Office on Mental Retardation. OMR was interested in knowing how satisfied families were with FDFSS, and how it could be improved to be more responsive to the needs of Pennsylvania's families that included a member with mental retardation. In addition, as the state moves toward a system of self-determination in the delivery of supports and services, the experience gained from the FDFSS program will be invaluable in crafting the emerging system.

The evaluation strategy involved completion of three activities:

1. A mail survey of a sample of families receiving FDFSS services;
2. Focus groups involving family members, FDFSS staff, county and OMR regional office staff; and
3. Follow up telephone interviews with a sample of families who participated in the initial mail survey.

Each of these activities is described below.

The Mail Survey

The Sampling Plan

In order to include the breadth of experiences of families who participated in the FDFSS program, a sampling strategy had to be developed that represented the entire state, reflecting the diversity of Pennsylvania in terms of its rural population and ethnic diversity . A two stage sampling design was developed, where in the first stage, two counties were selected from each of the OMR regions; one urban and one rural. However, it was decided by project staff that because of the large numbers of families participating in the FDFSS program from Philadelphia and Allegheny Counties it was necessary to ensure their representation in the study. There was an additional exception; the Southeast region does not include a county that is defined by the census as rural. Therefore, in the Southeast region an urban county, in addition to Philadelphia was selected for inclusion in the study. All 45 county programs were designated as either urban or rural, and then entered onto the computer and divided into regions. The computer randomly selected an urban and a rural county from each region.

Once the counties were chosen, a second level of sampling occurred. Based on information provided by OMR, the number of families served by each county was identified. Using those numbers as a guide, decisions were made as to how many families to include from each county. If the county served large numbers of individuals, such as Philadelphia and Allegheny, 15% of the respondents were included in the study. In small counties, all families were included. In this two stage sampling strategy, large counties were oversampled in the first stage, and small counties were oversampled in the second stage, providing an equitable distribution of families across the Commonwealth. The number of FDFSS recipients and the number of individuals sampled in each county is presented in Table 1.

Table 1

Number of FDFSS Recipients by County

County	# of Recipients	# in Sample
Allegheny	2,647	397
Bradford/Sullivan	109	109
Chester	520	200
Huntington/Jun./Mifflin	161	161
Lancaster	446	200
Mercer	457	200
Northampton	280	100
Philadelphia	2,248	337
Fayette	124	124
TOTAL	**6,992**	**1,854**

After the number of families selected for inclusion in the study was determined for each county, a process was developed for the counties to conduct a systematic random sample of their FDFSS recipients. A letter was prepared by the Institute on Disabilities, advising counties of the number of individuals to be selected in total. In those counties where FDFSS recipients would be sampled, counties were told to take their entire FDFSS recipient list and take the Nth individual (based on the number we wanted to survey) and send a survey packet to that individual.

Because we wanted to ensure confidentiality, the survey packets were sent out by the counties, rather than by project staff. In that way, only those families interested in participating in the survey became known to project staff. Each county was sent a package that included survey forms, an introductory letter to the families from Nancy Thaler, Deputy Secretary of OMR, a stamped, addressed envelope to return the form, and a letter from the Institute on Disabilities with instructions to the counties.

Design Of The Survey Form

The survey form was designed to gather information on those families receiving services and supports for their family member with mental retardation through the county Mental Retardation program. The services could include things like respite care, sitter services, homemaker services, specialized therapies, special foods, and others. The survey did not pertain to school services (e.g., special education) community living or adult residential services or adult day services.

The survey form covered eight primary areas of inquiry, included 68 questions and was designed to take approximately 30 minutes to complete (See Appendix A). Descriptions of the six domains and the types of questions included within each follows:

✔ **Family Opinion:** This section included 46 questions designed to solicit respondents' opinions about their experiences with the family support program, including opinion on:

- How the respondent is treated by the local family support program (seven items);
- The information exchanged between the family and the program (eight items);
- How much control the family has and the service planning process (17 items)
- The supports received by families (14 items)

✔ **Family satisfaction with program impacts:** This one question is composed of 16 sub-items to gauge the level of program impact on various aspects of family life.

✔ **Your family and your family member:** This section included: (a) seven questions about characteristics of caregiving families (e.g., county of residence, household composition, care responsibilities, family income, opportunity costs), and (b) four questions about the family member with mental retardation (e.g., age, sex, and level of assistance required).

✔ **The services the family receives:** In this section five questions are asked to acquire information on the sources of support utilized by families, including those offered by the family support program, government benefits, health services, and informal help. In addition, one of the questions asked that respondents indicate in what form (voucher, cash, services) supports are received from the family support program, and another asks in what form such support would be most preferred.

- ✔ **Response to open-ended questions:** This final section includes five questions, designed to solicit "open-ended" feedback from respondents.

Distribution Of The Survey Forms and Response Rate

1854 prepared survey packets were packaged by the Institute on Disabilities and distributed to families through the county programs. The packets included a letter from the Deputy Secretary of the Office of Mental Retardation to families to introduce the survey, and a pre-stamped and addressed envelope for respondents to return completed questionnaires to the Institute offices.

To track the response pattern, each packet and survey form was given a number from 1-9, to identify the responding county. Each of the returned forms was precoded to track return patterns and to simplify the data compilation process. Returned questionnaires first were screened to assess whether the information could be used. Survey forms were to be removed from further consideration if: (a) numerous questions were left unanswered or responses could not be understood, or (b) the family did not participate in the family support program.

The number of families returning survey forms totaled 530 of 1854, a response rate of 29%. Table 2 displays the response pattern by county.

Table 2

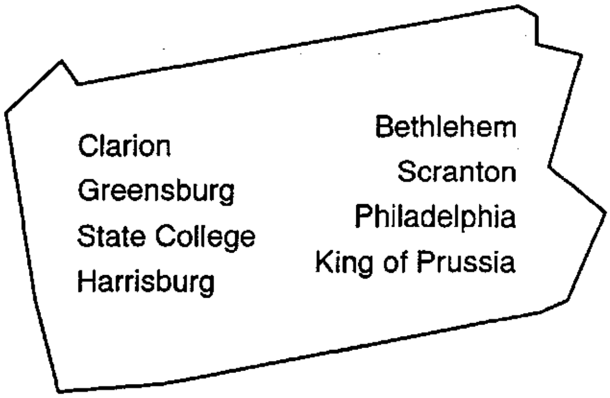
Response Rate by County

County	# Sent	# Returned	% Returned
Allegheny	397	117	29%
Bradford/Sullivan	109	29	27%
Chester	200	59	29%
Huntington/Jun/Mif	161	42	26%
Lancaster	200	96	48%
Mercer	200	50	25%
Northampton	100	34	34%
Philadelphia	337	72	21%
Fayette	124	31	25%
OVERALL	**1,854**	**530**	**29%**

Following initial review, data from returned surveys were entered into a specially designed microcomputer data base and prepared for analysis through extensive error checks. A specialized data entry program was used to ensure maximum accuracy and efficiency by trained data entry personnel. Once the data was entered, *SPSS PC+* statistics software was used in subsequent analyses.

The Focus Groups

During the week of June 9 -12, 1997 public forums related to Pennsylvania's Family Driven Family Support Service Programs were held in eight sites across the Commonwealth.[1] Meetings were held in Clarion, Greensburg, State College and Harrisburg, Bethlehem, Scranton, Philadelphia and King of Prussia. The forums were facilitated by John Agosta and Kerri Melda of HSRI, Celia Feinstein and Robin Levine of Temple University, and Fran Smith, a private consultant from California.



The sessions were pre planned in coordination with regional OMR or county offices. Meeting announcements were sent out in advance by local organizations. All the sessions were designed to last about 2-3 hours and included the following:

✔ Overview of the Family Driven Family Support Services program;

✔ Breakout into small groups to discuss FDFSS strengths and weaknesses, and what might be done to improve the program. Two groups were established: (a) family members and advocates, and (b) FDFSS professional staff and other program staff. At two sites the number of participants was too few to allow for small group breakouts.

✔ Large group discussion where the findings of each group were described, compared and reconciled. The intent was to have each group consider the FDFSS program from the other's perspective, and to facilitate discussion leading to a joint commitment to improve the program.

An agenda that was distributed at the meetings and used to guide the discussions is displayed on the following page.

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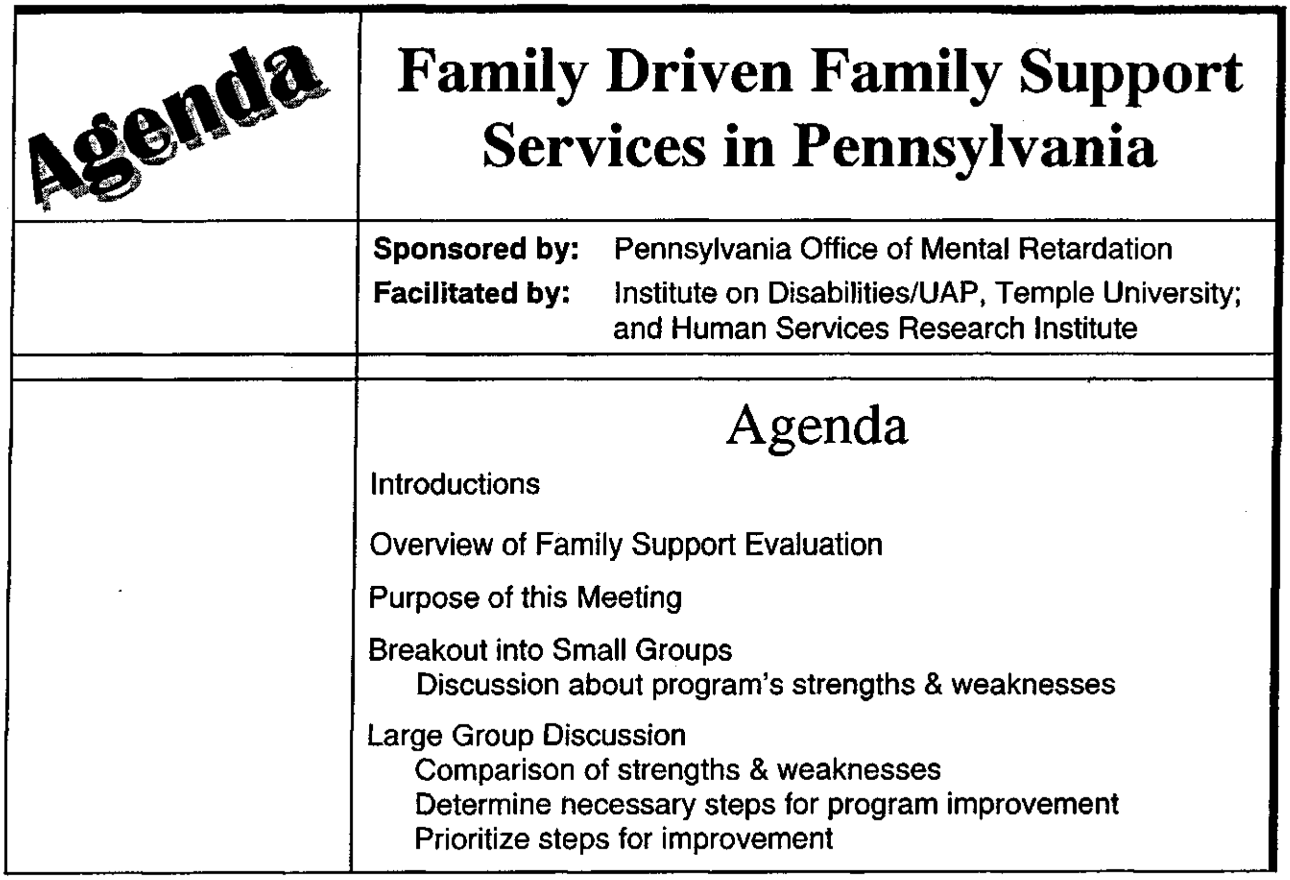
[1] These focus groups were facilitated by the authors of this report and by Fran Smith who assisted as an additional facilitator. Ms. Smith is a parent of two children with disabilities and is a long standing advocate for and student of family support services nationwide.



Agenda

Family Driven Family Support Services in Pennsylvania

Sponsored by: Pennsylvania Office of Mental Retardation
Facilitated by: Institute on Disabilities/UAP, Temple University; and Human Services Research Institute

Agenda

Introductions

Overview of Family Support Evaluation

Purpose of this Meeting

Breakout into Small Groups
  Discussion about program's strengths & weaknesses

Large Group Discussion
  Comparison of strengths & weaknesses
  Determine necessary steps for program improvement
  Prioritize steps for improvement

The Follow Up Surveys

At the end of the mail survey, respondents were asked whether they would be willing to participate in a more in-depth survey. More than half of the respondents indicated that they would be willing, and provided their names and addresses at the end of the survey form. In an effort to obtain approximately 50 in-depth interviews, the respondents who were willing to participate were sorted by county. Seventy-three individuals were selected, assuring representation from each of the counties involved in the mail survey.

Prior to selecting the sample, a group of individuals including project staff, OMR staff, families, FDFSS coordinators and county staff gathered to develop the in-depth survey. The survey protocol is included as Appendix B.

Once the families were selected to participate in the in-depth surveys, data collectors were recruited from around the state, to conduct the interviews by telephone. All of the data collectors are parents of people with mental retardation; none of the data collectors collected data in the county in which they live or receive services. The data collectors were trained in a teleconference with project staff. Project staff were available throughout the process, to respond to questions that arose in the field. The following table displays the number of individuals selected for participation in the survey, as well as the number of responses received, by county.

Table 3

Number of Respondents Selected and Responded by County

County	# Selected	# Responded
Allegheny	17	12
Bradford/Sullivan	4	2
Chester	9	7
Huntington/Jun/Mif	7	5
Lancaster	15	11
Mercer	7	4
Northampton	3	1
Philadelphia	8	5
Fayette	3	0
TOTAL	73	47

Of the individuals who did not respond, six changed their minds and were no longer willing to participate in the interview, 14 could not be reached after multiple attempts, one person moved and left no forwarding number, one person died, and four individuals had either had their phones disconnected or the phone numbers we had were incorrect.

3. Results Of The Mail Survey

Survey results are illustrated in three ways: (a) data tables listing frequency counts for all survey items; (b) figures depicting computed scale scores based on frequencies; and (c) a sampling of family responses to a series of open-ended questions. Appendix C contains a summary of these findings.

Listing of Data Tables & Figures

Data Tables/ Frequencies

A. How Families are Treated
B. The Exchange of Information
C. Having Control & Making Decisions
D. The Supports Families Receive
E. Impact on Family Life
F. Demographic information
G. Services Families Receive
H. Family Comments

Figures / Scale Scores

1. Feeling Welcome & Heard
2. Exchanging Information
3. Having Control & Deciding What you Need
4. Getting What You Need
5. Judging the Results

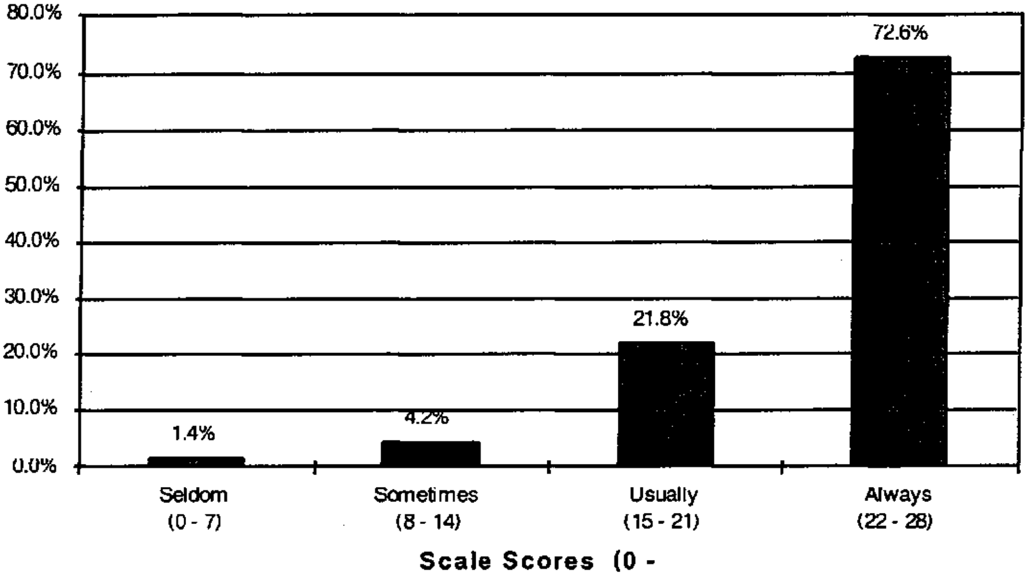
Frequency counts and open-ended responses are fairly straightforward. Scale scores, however, allow us to look at a series of related survey items, and illustrate how families responded to a group of questions as a whole. Throughout the survey, clustered items were scored in ways that form scales. These scales then provide a unit of progressive measurement to assess the relative level, importance, or rank of some issue or property (e.g., satisfaction, impact on family life). An analysis of the findings is offered after all the data are presented. The illustration below provides an overview of the sequence in which figures will be presented:

How Families Are Treated

Families want to feel welcomed by service providers, supported in their decisions, and not pre-judged. They expect their opinions to be heard, respected, and acted upon. The first survey section investigated how comfortable families feel with their family support program and its staff. They were asked if program staff listened to, respected, and cared about their family. Listed below are data depicting how families responded to each specific question (Table A), followed by Figure 1 illustrating families' overall impressions with how "welcome and heard" they feel with their program.

A. How Families Are Treated...	*Never*	*Sometimes*			*Always*	*Missing*
1. Does the FDFSS coordinator/case manager acknowledge that you are informed and knowledgeable about your *family member*?	5	20	48	149	296	20
2. Do they *listen* to you?	3	8	44	151	314	18
3. Do they respect your opinions?	4	9	38	169	303	15
4. Are they sensitive to your family's unique needs, strengths, and multi-cultural values?	5	16	55	140	299	23
5. Do they honestly care about your *family member* and your family?	10	12	50	155	289	22
6. Do you feel *better* after meeting with the FDFSS coordinator/ case manager?	13	27	75	187	209	27
7. Are you comfortable when you talk with the FDFSS coordinator/ case manager?	6	7	49	162	296	18

Figure 1
Feeling Welcome and Heard



This scale was computed based on responses to items 1-7. Each item was scored 0 (never) to 4 (always), and then summed. The scale score could vary from 0-28. For this scale on feeling welcome and heard:

Mean: 23.7
Median: 25.0
Range: 0-28
Alpha: .9350

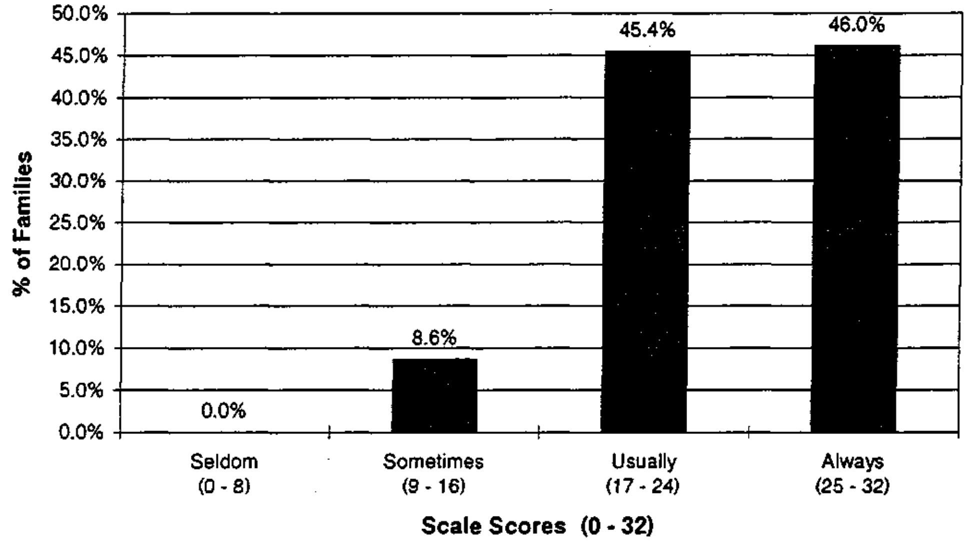
The Exchange of Information

Information flows in two directions. Families need timely and up-to-date information about their family member's specific disability, about appropriate services and supports, and about eligibility requirements in order to make informed decisions. Service providers also need information about families. Below, Data Table B and Figure 2 display how satisfied families are with how this exchange of information takes place.

B. The Exchange of Information ...	Never		Sometimes		Always	Missing
1. Does information about this program come to you, rather than you having to search for it?	16	49	90	183	188	12
2. Is the information easy to understand?	3	13	96	256	155	15
3. Does the information help you to make an informed choice, rather than confusing you?	8	20	100	264	123	23
4. Is it easy for you to contact the FDFSS coordinator/case manager -- when you want to talk to them?	9	31	71	206	210	11
5. Do they ask for information that is unnecessary?	219	202	59	21	19	18
6. Do they ask questions that make you feel uncomfortable because they are too personal?	311	154	46	5	7	15
7. Does the process of exchanging information take too long?	186	194	98	23	22	15
8. Do you have opportunities to talk and share information with other parents/families in your community?	81	105	146	114	75	17

Figure 2

Exchanging Information



This scale is based on responses to items 1-8. Items 1-4 and 8 were scored 0 (never) to 4 (always). Items 5-7 were inversely scored. All items were then summed. The scale score could vary from 0-32. For this scale on exchanging information:

Mean: 23.5
Median: 24.0
Range: 9-32
Alpha: .7650

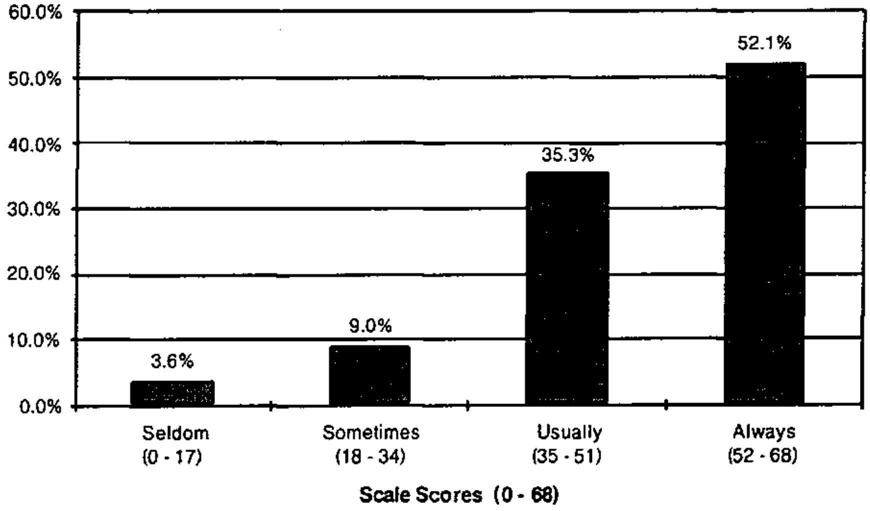
Having Control & Making Decisions

Families want to have real control when it comes to making decisions about meeting their needs. This control and decision-making power happens while planning for their families' support needs, in making decisions about when and where meetings take place, what services are obtained, and at the program policy-setting level (e.g., on advisory councils or governing boards). Below, Data Table C and Figure 3 illustrate family responses to how much control and decision-making power they feel they have.

C. Having Control & Making Decisions...	*Never*		*Sometimes*		*Always*	*Missing*
1. Do FDFSS staff meet with your family *individually* to discuss and plan for the supports you'll receive (in your preferred language)?	58	53	81	109	218	19
2. Are you given a choice regarding the time and place that you meet with the coordinator/case manager ?	28	25	37	153	274	21
3. Are you recognized as the expert regarding your family's needs?	12	11	51	178	269	17
4. Do FDFSS staff present an array of options to meet your needs?	26	53	94	203	141	21
5. Do they encourage you to say how you want your needs to be met?	23	33	67	185	209	21
6. Do FDFSS staff respect your choices and preferences?	6	20	41	191	259	21
7. Do you have primary decision-making power over the supports and services that you receive?	20	26	55	175	242	20
8. Do you choose who - or what vendor - provides you services?	36	34	64	141	234	29
9. Is an agreement developed that details *which supports* will be provided (*when and by whom*), and *who* will pay?	33	36	47	158	221	43
10. Is there a *written plan* developed that states which supports will be provided?	30	36	43	134	250	45
11. Can you change your mind about the supports you receive?	28	20	60	167	208	55
12. Do you have enough control in the planning of the supports you receive?	21	38	56	173	219	31
13. Is planning for your family's supports a comfortable process?	25	35	69	203	176	30
14. Are you included, to the extent that you desire, in the program's policy-making process?	60	40	76	170	142	50
15. Do you feel that your viewpoints are represented on your Family Advisory Council?	37	39	84	166	134	78
16. Do you have input on what supports or activities are provided in other <u>*informal*</u> ways (e.g., a suggestion box, family forums)?	68	74	105	129	97	65
17. Do you believe that you and other families have influence over the types of services available in your area?	56	89	138	140	73	42

Figure 3

Having Control & Deciding What You Need



This scale was computed based on responses to items 1-17. Each item was scored 0 (never) to 4 (always), and then summed. The scale score could vary from 0-68. For this scale on having control and making decisions:

Mean: 49.7
Median: 52.0
Range: 0-68
Alpha: .9403

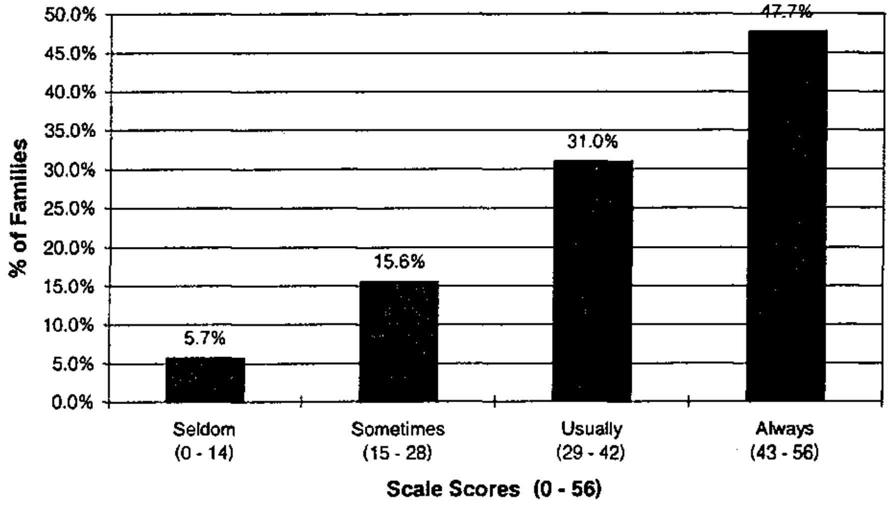
The Supports Families Receive

No two families are alike. Each family has unique needs, strengths, and preferences. Families want programs that offer a broad array of supports that can be flexible in meeting their changing needs. Data Table D and Figure 4, give family responses relating to their satisfaction with supports they receive

D. The Supports Families Receive ...	*Never*		*Sometimes*		*Always*	*Missing*
1. Do the FDFSS staff make an effort to meet your family's needs?	6	27	66	202	221	16
2. Once supports are agreed upon, do they begin promptly?	13	26	76	210	191	22
3. Are you getting less support than you need because of the severity of your *family member's* disability?	221	90	93	45	38	51
4. Are supports available when your family wants and needs them?	16	36	128	221	105	32
5. *<u>In a crisis</u>*, are supports readily available?	29	47	89	140	101	132
6. FDFSS program flexible enough to meet your changing needs?	25	47	83	214	122	47
7. Are you satisfied with the delivery of the supports you receive?	14	24	70	196	204	30
8. Are FDFSS staff "in touch" with your community and the resources it has available for families?	18	48	75	180	164	53
9. Are FDFSS staff knowledgeable about the various public benefits available to assist families (e.g., food stamps, EPSDT, SSI).	16	24	60	192	198	48
10. Do FDFSS staff give you as much help as you want or need to access community resources or public benefit programs?	21	47	82	187	163	38
11. Does the FDFSS program coordinate with other resources in your community (e.g., schools, day care centers, health services) to prevent gaps in services to your family?	38	48	89	153	128	82
12. If the services that you need are not available locally, do the FDFSS staff help you to *create* the supports needed?	51	64	82	129	76	136
13. Are you getting the level of support or services that you need?	32	43	82	194	153	34
14. Do you think that the FDFSS program does a good job providing services with the resources they have available?	11	23	69	168	238	29

Figure 4

Getting What You Need



This scale is based on responses to items 1-14. Items 1,2,4-14 were scored 0 (never) to 4 (always). Item 3 was inversely score. All items were then summed. The scale score could vary from 0-56. For this scale on the supports families receive:

Mean: 39.2
Median: 42.0
Range: 0-56
Alpha: .9541

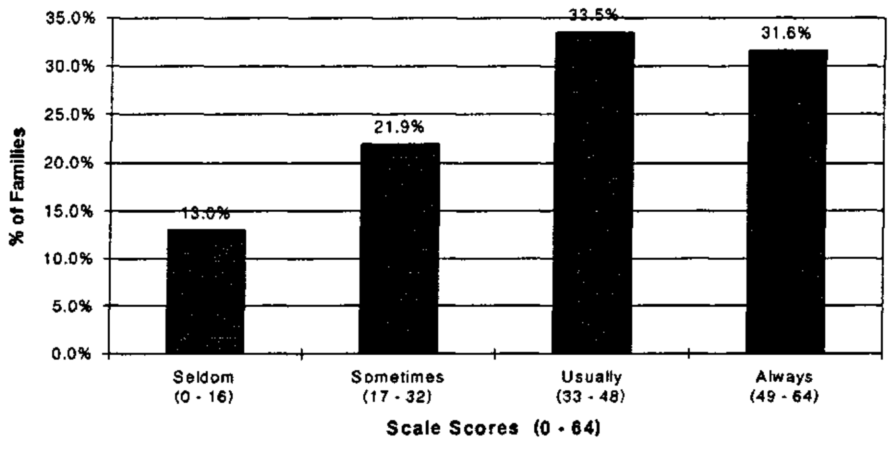
Impact on Family Life

When family support programs welcome and listen to families, connect families to information and supports, and incorporate families as decision-makers -- a program can effect families' lives in many ways. Data Table E and Figure 5 below show several potential impacts on family life and detail family responses.

E. Impact on Family Life...	*Never*		*Sometimes*		*Always*	*Missing*
1. Does this FDFSS program:						
a) Offer the necessary supports to meet your family's unique needs?	14	30	106	214	136	38
b) Help your family feel more connected to your community?	34	82	124	160	81	57
c) Help your *family member* to be more included in the community?	50	82	102	152	93	59
d) Help you and your family feel more connected to your community?	49	79	109	153	79	69
e) Help you meet other parents and have a better support network?	68	87	115	125	87	56
f) Help you feel more confident in your parenting?	52	56	95	147	122	66
g) Help you feel informed about your *family member's* development?	62	70	79	157	109	61
h) Make problem-solving concerning your family member easier?	44	56	109	171	103	55
i) Enhance your ability to meet the needs of your *family member*?	37	38	111	172	128	52
j) Help you feel more in control of your life?	50	59	107	149	114	59
k) Help you to keep your family together?	66	43	70	138	144	77
l) Help your family to make financial ends meet more consistently?	55	60	92	129	132	70
m) Help you and your family improve relationships with one another?	88	55	95	110	98	92
n) Help you and your family have fewer physical health problems?	113	72	73	99	78	103
o) Better allow you to live as much like other families as possible?	67	47	93	141	115	75
p) Make a positive difference in the life of your family?	45	33	86	158	156	60

Figure 5

Judging the Results



This scale was computed based on responses to items 1a-1p. Each item was scored 0 (never) to 4 (always), and then summed. The scale score could vary from 0-64. For this scale on judging the results:

Mean: 38.8
Median: 41.0
Range: 0-64
Alpha: .9721

Demographic Information

A selection of demographic data was also collected from families responding to the survey. The questions and family responses are detailed below.

Figure 6: Information About Families Surveyed

Which of the following describes your household?

360	Two parents in the home
133	Single parent household
24	Living with relatives
8	Sharing household with non-relatives
31	Other (specify)

Who is primarily responsible for caring for your family member? (Missing: 12)

283	Mother
19	Father
194	Mother and father equally
30	Other

What was the total taxable income last year (1995) of primary wage earners in your house? (Missing: 93)

98	Less than $10,000	72	$30,001 - $40,000	14	$60,001 - $70,000
94	$10,001 - $20,000	51	$40,001 - $50,000	6	$70,001 - $80,000
65	$20,001 - $30,000	28	$50,001 - $60,000	17	Over $80,000

Figure 7: Family's Future Plans

<u>When you applied for family support</u>, were you planning to request that your family member be placed in a living arrangement outside your home (e.g., to a foster home, community residence), or was your family member already living outside of your home? (Missing: 26)

4	Yes -- Our *family member* was living in an out-of-home placement.
17	Yes -- Our family had already applied for an out-of-home placement.
18	Yes -- Our family was planning to request an out-of-home placement.
54	Maybe -- Our family was discussing the issue, but we had not decided on what to do.
25	Don't Know -- Our family had not discussed this issue.
394	No -- Our family had no plans to seek an out-of-home placement.

Has anything about your decision to place, or not to place your family member changed since you began receiving support from this program? (Missing: 42)

404	No change.
9	Yes, our *family member* is now living in an out-of-home placement
13	Yes, we have decided to seek an out-of-home placement for our *family member.*
9	Yes, we are no longer considering placing our *family member* outside our home.
3	Yes, we were able to bring our *family member* home.
58	Maybe, we are discussing the issue, but have not decided on what to do.

Figure 8: Effects of Disability on Family Residence & Employment

Has your family member's disability influenced where your family lives?

350 No 140 Yes

IF YES, CHECK ALL THAT APPLY: (missing: 48)

31 Our family moved to be closer to services for our *family member.*

38 Our family moved because our home did not meet our *family member's* physical needs and we were unable to make the needed modifications (e.g., ramp, accessible bathroom).

7 Our family moved because our *family member's* disability disturbed the landlord or neighbors.

28 We have not moved to a better home because of the cost of care for our *family member.*

39 We have not moved because we do not want to lose our current services.

63 Other

To meet the needs of your family member, has anyone in your household:

		Missing			
Given up a paying job?	371	No	115	Yes	52
Not looked for a job?	320	No	151	Yes	67
Limited their job choice to meet care demands?	253	No	220	Yes	65
Lost a job because of care demands?	417	No	41	Yes	80
Refused a job transfer or promotion?	401	No	55	Yes	82
Changed jobs for better medical benefits?	424	No	30	Yes	84
Changed jobs for different hours?	369	No	91	Yes	78
Quit school or not gone back to school?	403	No	55	Yes	80
Lost health insurance coverage?	429	No	27	Yes	82
Taken a second job to increase their income?	392	No	68	Yes	78
Accepted a lower paying job	390	No	66	Yes	82
Not changed jobs because the change would have meant losing health benefits?	393	No	61	Yes	84

Figure 9: Information About Family Members

What sex is your family member?

280	Male
212	Female
46	Missing

How old is your family member?

Range from birth to 76 years
Mean 20 years
Median 17 years

Indicate the degree of assistance that your family member requires in completing the following activities

	None	Little	Moderate	Complete	Missing
Toileting	186	79	57	188	38
Eating	133	84	87	211	23
Bathing	106	97	137	174	24
Grooming	142	103	90	180	23
Dressing	214	104	73	119	28
Communicating needs	278	63	65	103	29
Movement within home	102	99	95	219	23
Travel out of home	89	53	101	270	25

How often does your family member BEHAVE *in ways that pose a major problem for you or others in your family (excessive tantrums, breaks things, hits others or him/herself)?*

(Missing: 25)

302	Never/less than monthly	78	Weekly
31	Monthly	102	Daily

Services Families Receive

Families were also asked a series of questions relating to the specific services and supports they receive from their family support program, and also from other formal and informal sources in their communities.

Figure 10: Services & Supports Received Through FDFSS Program

What types of services has your family received during the past 12 months from the FDFSS Program?

First, indicate *whether* you received any of the services listed (Check one - yes or no - per service). Then, for the services you received, indicate *how* you obtained it primarily. Did you receive cash, a voucher or simply the service? (Check one for each service you received)

	Received it?			If yes, how did you obtain it primarily?			
	Don't						
Service Type	No	Yes	Miss	Service	Voucher	Cash	Know
Respite Care	263	190	85	61	44	85	7
Family Aide/ Sitter Services	226	242	70	34	68	117	6
Homemaker Services	396	13	129	7	3	4	3
Recreation	218	233	87	59	68	88	5
Specialized Therapies	331	88	119	63	5	14	7
Information and Referral	308	108	122	86	2	3	10
Family Training/Education	367	51	120	31	6	9	7
Adaptive Appliances	345	71	122	20	15	24	9
Home Modifications	384	30	124	9	8	10	3
Special Diets	392	17	129	5	2	11	2

In general, how would you most prefer that the FDFSS program offer support to you?
(Missing: 49)

129	I prefer services that the FDFSS program delivers services and supports directly to me.
85	I prefer a voucher that I can use to obtain services.
275	I prefer cash that I can use to obtain supports and pay for them directly.

Figure 11: Services & Supports Received Through Other Sources

Day to day, who do you consider a significant help to you and your family in meeting the challenges you face because of your family member's disability?

217	Family members who live with us
277	Relatives outside the home
206	Friends
94	Other parents of family members with disabilities
90	Church members
85	Neighbors
167	Professional helpers
26	Co workers

What type of health care plan does your family have? (Check all that apply.)

19	NONE (our family does not have a health care plan)
129	Health Maintenance Organization (HMO)
40	Preferred Provider Organization (PPO)
136	Private Health Insurance Policy
160	Medicaid
127	Medicare
125	Other (specify)

Is your family member or family NOW receiving any of these other services or benefits -- from someplace <u>other than</u> the Family Support Services Program: (Check all that apply.

19	NONE (none of the services or benefits listed below are received)
96	Service coordination/case management
18	Early intervention services (Birth to Three)
36	EPSDT services
229	School services (special ed., related svcs.)
158	Specialized therapies (physical, speech)
70	Adult Day Svcs. (day habilitation, employment)
20	Vocational Rehabilitation Services
91	Recreation program
23	Parent/sibling support groups
8	Pennsylvania Protection & Advocacy (legal assist.)
4	Family Centers (Parents as Teachers Program)
253	Supplemental Security Income (SSI)
54	Social Security Disability Ins. (SSDI)
80	Social Security
186	Medicaid Medical
110	Medicare
3	Veterans Benefits
15	Housing subsidy
28	Energy assistance (heat, electric)
24	Women, Infants & Children (WIC)
48	Food Stamps
47	Public Aid/Welfare/AFDC
52	Other

Family Comments

Finally, families were asked the extent to which their family support program meets their overall needs. Each of these questions was followed by an opportunity to explain their responses.

Figure 12: Overall Family Comments

For how many months has your family received services from this FDFSS program?

Range from less than a month to 180 months.
Mean: 36 months.
Median: 27 months
Missing: 141

Has your family received the help you expected to receive?

109 No 367 Yes 62 Missing

Is there something more you need?

211 No 228 Yes 99 Missing

Do you have any suggestions for improving the FDFSS program?

243 No 154 Yes 141 Missing

A Sample of Family Comments

Has your family received the help you expected to receive?

- I was not able to use the remainder of funds allotted to my son because funds had to go to other emergencies. This has been hard to deal with.
- Yes and no. We receive everything they've promised but we have been turned down for other things we've requested.
- FDFSS allows for the extras - recreation such as swimming exercise programs, speech therapy, that we would have to think twice about.

- Sometimes services were really good, but now today they aren't. I actually couldn't tell you who my caseworker is for my daughter.

- Yes and no - be great if there were more recreation. Also, more respite available.

Is there something more you need?

- Raising my child with disabilities is a very trying and rewarding venture. I would like to know about extra-curricular activities for my son to keep him busy after school to help him obtain a full life and to help give me a respite.
- The FDFSS is now out of money. This has put a hardship on my family because I cannot afford to pay for services my child needs. He is very hyperactive and has a lot of behavior problems that is very hard to deal with at times. He is ADHD. It is very hard getting sitters for him. I can't afford it either.
- My son needs someone in the morning to help him bathe and dress and maybe shop for groceries. But living alone is what he really wants, desperately.
- Reimbursement throughout the year for needs, i.e., item comes up in Mar.-Apr.-May-June - told "no more funds to cover." What good is the program if your allotted amount of money is not available?!
- Someone to be able to keep my daughter for a week or so for me to have a little time away from the stress of everyday dealing with the pressure.
- Transportation would be nice.
- More information on conferences for families regarding issues pertaining to MR - conferences are held all over the state and parents are never notified.
- I sometimes have difficulty finding a qualified person to stay with my son when I need to go out primarily in the evenings (meetings, choir practice, etc.). It would be nice to have a list of qualified persons to call on.
- We feel a need merely to be kept better informed as to what services are available. We seldom if ever hear from our case manager as to programs/services that may be appropriate for our son.
- There is a huge gap. Children receive services from birth to 18 years old and then our county has very little to offer our adults. I'm frightened for the future.
- The cash instead of waiting for the voucher system to come through with the money.
- More funds to hire a personal aide so that our daughter could be included in programs, be able to go to friends home, roller skating events, etc. Inclusive summer camps. Just to be able to enjoy the things other children her age get to enjoy.

Do you have any suggestions for improving the FDFSS program?

- I would like to have our parents meetings started up again. We used to have them on a regular basis but we haven't had one since September 1995.
- A monthly newsletter or maybe a compiled book of services available. My son has been in the FDFSS programs for 8.5 years. I have throughout the years only heard about services via word of mouth from other families. Then I would call and inquire about the service.
- I think transportation could be the help that many people are looking for, which would solve a lot of problems. We should not have to depend on family members.
- They need more funds so families such as myself do not have to be faced with cuts in funding to us in need. It is very hard trying to meet his needs and my sanity when there are no funds available. My needs are just as important as others.
- Please keep up the good work.
- Need a network of "service" providers - as in a resource manual that our county is in the process of doing.
- Before deducting money from a family because they are not using it, please call and find out why. We are having difficulty finding a sitter for respite and because of this we are not using our money. I am sure that next year we will have a decrease in our money because of this. I don't feel this is right!
- This is a good program and it helps us very much. Some "rules" need to be ironed out and some universal decisions made.
- Case workers change a lot. More experienced case workers and willing to get information. My son's case worker always has to ask her supervisor and it seems to take a long time to get an answer.
- More money has to be allocated to FD/FSS. A lot of families are their own case managers but continue to see the county charge for that service even though they aren't using it. I would rather pay for case managers when I needed that service not automatically be billing the state because my child is on the books. Give the families choice in that area. I believe in natural supports and attitudes we need today for the supporters to make inclusion work and become a way of life.
- We need to be able to provide able people to provide the services that will physically and mentally help the parents. To give them the cash is not enough if there is no one available to hire for the help most needed. They should have trained personnel to assist with self-help skills if needed.

If you have anything else you want to tell us, please use the space below.

- The attitude and caring of the workers is very important. Caring individuals help, even when they can't do anything tangible.
- Funds have been very helpful in purchasing expensive educational toys for our daughter. They have also been beneficial for recreational activities and in obtaining a baby-sitter. It's a great program. It's nice to see our tax dollars going toward something so useful.
- Funds have been made available and we are thankful that we can make the decisions on how to use them. I would suggest a quarterly reporting of funds used since the funds are received quarterly.
- Our FDFSS program motivated my husband and I to have a guilt-free social life (no guilt as to how money was being spent on unnecessary baby-sitting). I feel this together time when our son was first born was one of the best things for our whole family.
- Overall the FDFSS program has been an assist to my family. But because of funds being needed for emergency needs, it has placed a real hardship on my family. My well being and sanity depends on being able to get sitters for my son. I cannot afford to do this on my own and it really helped when I had the services available to me. I know I will get them back next fiscal year but three months of not having service can do more harm mentally not only to my son but to others in the household.
- Overall we have been very pleased with the FDFSS program. It has helped tremendously, provided adaptive equipment that has helped us take care of our son. We do hope that such services would continue.
- Without FDFSS funds we would not have any quality time with our other children because our special needs child takes a lot of attention out in community settings. With him going to respite every other month we have free time. Also with a care giver coming to our home for evening we have this luxury.
- We really depend on our FD-FSS grant to "give us a life" and enhance our son's life too. I especially like the control I have in choosing services to meet his needs. I just always wish there were more funds - we budget very carefully.
- Give us more freedom to use money to buy things for our family member that he can enjoy at home. Most of the funds must be used for services outside the home. We enjoy doing things as a family and don't use outside services. We lost most of the funds at the end of year; our son would like to use it for some fun things at home.
- It is absolutely essential that MH/MR listen to families and increase funding and allowable services. Families who keep their disabled member at home are often penalized and overlooked as a priority - yet if they all decided to place their children

the system would go under - help them do what they can to prevent placement. Make families the priority!

- We think FDFSS is an outstanding program. Instead of providing services that we may never need, it allows us to determine our daughter's requirements and to satisfy them directly. It is regrettable such an excellent program has not received more support.
- If it weren't for the FDFSS program, at times we would be lost. Having my son and husband both disabled has put a strain on our finances. As a result I have had to drop out of college and return to work. The support we receive enables me to continue to work. Even during crisis periods, i.e. when my husband is hospitalized or is having an attack and cannot watch the children.

Summary Analysis

The many Family-Driven Family Support Services programs have put a number of support options for serving families in place. Through this survey, there are a few basic questions that we have set out to answer. For instance:

1. Who receives family support?
2. What services do families use?
3. How do families feel about their programs?

Who receives family support?

According to current policy, individuals with a diagnosis of mental retardation who are living either at home with their families or independently in the community are eligible for family support services. Results of the family survey provide us with the following descriptive information on families participating in the family support programs:

- ✔ Two thirds of the families responding (67%) consisted of two-parent households. Another quarter (25%) are single-parent households.
- ✔ Most families (54%) indicate that the individual's mother is primarily responsible for providing care, though 36% indicate that it is the mother and father equally.
- ✔ Most families (58%) had a total taxable income in 1995 of $30,000 or less.
- ✔ The individuals with disabilities being served range in age from a year old to 76 years old, though (34%) are 11 years old or younger.
- ✔ Over half of the individuals served require moderate to complete assistance in completing activities of daily living such as eating, bathing, grooming, movement within the home, and travel out of the home.

✔ While the great majority (59) seldom behave in ways that pose major challenges, a significant number do on a daily basis (20%).

✔ To meet the needs of the family member, most families (56%) report that someone in their household has given up a paying job, not looked for a job, or limited their job choice.

While it would be unfair to generalize this scenario to all families, our initial findings clearly suggest that as a whole, most families now being served have a family member with fairly extensive caregiving needs, and are caring for their family member on a low to moderate income.

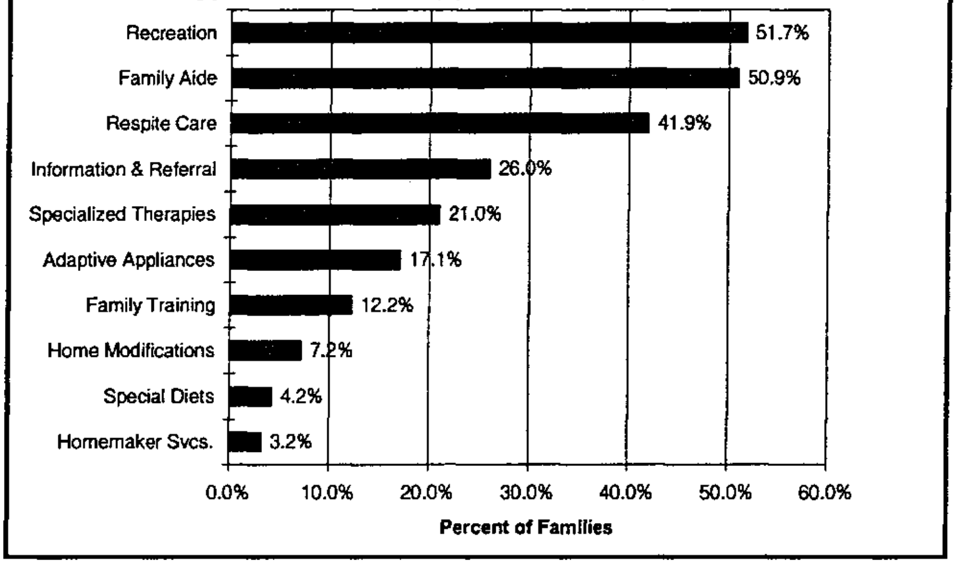
What services and supports do families use?

Families receive support through the FDFSS programs and also through informal personal and community networks. The figure below illustrates the percentage of families using various types of supports offered by the family support programs during the past year. For example, 51.7% of families used recreation services at least once during the past year, 50.9 used a family aide or sitter services, and 41.9 received respite care. As shown, while some supports were used by more families, families have taken advantage of the full spectrum of supports offered.

Our findings show that families receive each of these supports either as direct services, by voucher, or through cash assistance. Most families (56%), however, prefer to receive direct cash assistance with which they can purchase the supports they need. 17% prefer to receive vouchers, and 26% prefer receiving direct services.

Figure 13

Types of FDSS Supports Used by Families



Outside of the FDFSS programs, families indicate that the most significant sources of help are relatives (52%), live-in family members (40%), friends (38%), and professionals (31%). Nearly all families have medical insurance of some kind, and all have access to at least some of the other community support resources available (e.g., school services, SSI, specialized therapies, Medicaid Medical, service coordination).

How do families feel about their programs?

Survey respondents registered their satisfaction by responding to 46 different quality indicators. Overall, we found that families -- on average -- are greatly satisfied with the family support services they receive. Families do see room for improvement, however, and continue to seek, greater flexibility, diversity of supports, and control over the services and supports they receive.

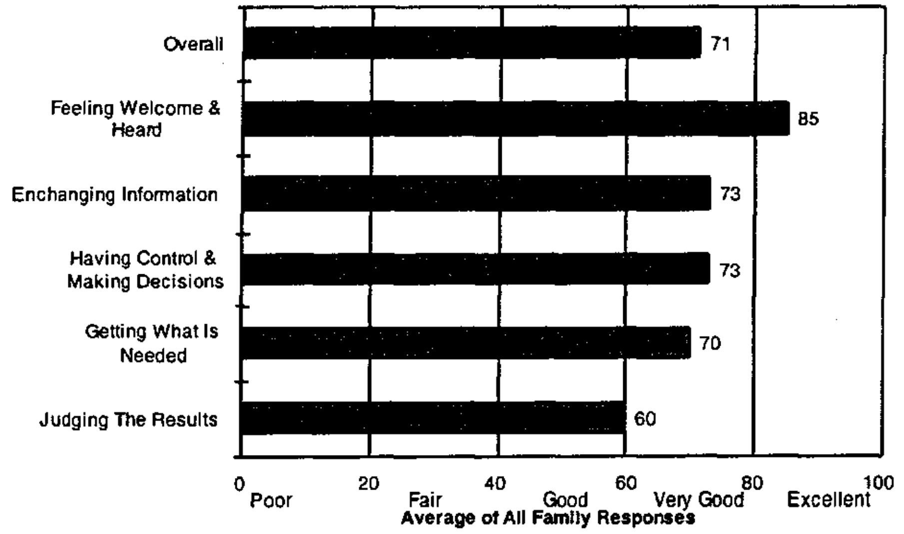
Satisfaction is greatly determined by the relation between one's expectations for a service, and one's perception of the services that are actually received. On a statewide level, survey activities show that most families are indeed very satisfied with the services and supports they personally receive. As is shown here, families on average rate their family support programs as very good or excellent. The area in which families are most satisfied is in feeling that program staff welcome and listen to families, and respect their opinions. Additionally, they are also quite happy with how their family support programs support them while exchanging information, planning and making decisions, and in getting the supports they need and prefer. In judging the results or family outcomes overall, the average score is slightly lower, but this can be expected as it takes time to make <u>substantial</u> impacts on the lives of families with significant caregiving needs.

Each of these category ratings (e.g., Feeling Welcome and Heard = 85) is derived from taking the average scale score (mean) for each category and adapting them to a 100-point scale for comparison.

Overall, this survey's results demonstrate that families are happy with the supports they

Figure 14

Satisfaction Scales



receive. The people involved with family support in Pennsylvania should feel very proud of what they have been able to accomplish. But family support, by its very nature, is constantly undergoing change. As the strengths and needs of families and communities change, family support must be ready and prepared to respond in ways that correspond with the values and principles of Pennsylvania's citizens, and demonstrated best practices throughout the country.

This survey validates, to some extent, what many involved with the Family-Driven Family Support Services programs have known for some time. Family support, when families are given considerable control over the supports they receive, can be an accessible, effective, flexible and responsive approach to meeting the needs of families caring for a loved one with mental retardation at home.

4. Results of the Focus Groups

The mail survey findings provide a wealth of information about the FDFSS system, with much of data shedding favorable light on the program. Focus groups, however, have potential for viewing the program's strengths and weaknesses from varying perspectives. Family members and program staff were encouraged to attend the focus group meetings and speak candidly about the programs and what might be done to improve them. The separate discussions held among parents and professionals yielded information about the programs that was not always favorable, and provided both groups -- when brought together - an opportunity to consider means for improving the program.

Eight public forums were held. What follows are the general impressions of the project team based on their facilitation of each meeting. Note that <u>these are generalizations, and conditions vary between programs and often within counties</u>.

On the Bright Side

✔ **There is a general feeling that the programs are helping families.** Families do not want to lose the program. They want the programs to grow, both in size and in quality.

✔ **The philosophy of FDFSS is permeating the design and intention of supports and services in Pennsylvania.** This is evidenced by the goals and objectives of the OMR Multi-Year Plan.

✔ **FDFSS program staff are generally good and caring people.** Staff are working hard to deliver needed supports to families. To a significant extent, FDFSS program staff are connecting people with needed resources.

✔ **Families are generally modest in what they ask for.** Many are satisfied with the modest allocations they are offered.

✔ **The Family Support Councils that exist take their work very seriously.** Councils are working hard to make the best decisions they can to assure, that at the local level, the FDFSS program is effective.

✔ **Creative approaches to helping families are being utilized.** Programs typically seek to utilize FDFSS resources as a "last resort." Some program staff are extraordinarily innovative at identifying available community resources to assist families. Others show creativity in altering their program routines to make them more efficient or to relieve staff and family stress.

On The "Challenging" Side

✔ **The FDFSS Coordinators role has been diluted.** Originally there were FDFSS coordinators for whom this was a primary job. This is no longer true in some counties where there has been a move from a direct service to a supervisory (troubleshooting) role. In other instances, the FDFSS Coordinator is a generic case manager utilizing FDFSS as another source for funding supports to individuals.

✔ **Programs vary from county to county, with some counties clearly undercutting the original spirit and intent of FDFSS.** Once approved to deliver FDFSS services, county programs have generally gone their own road. In a few instances, the county FDFSS program has ceased to function within the principles of the FDFSS initiative.

✔ **There is a growing emphasis on using Medicaid to pay for services, raising concern over maintaining program flexibility.** Much of FDFSS spending relies on state and county resources. Tying into Medicaid funding, however, offers a means for expanding program budgets. Yet this tactic is not so easily applied to FDFSS services and there is the risk of losing some of the program flexibility promised by FDFSS. In addition, in some instances this is happening with little information or incorrect information about implications and ramifications. This is particularly true where families are switched from FDFSS to in-home waiver supports.

✔ **FDFSS programs generally distribute help within a "needs-based" framework.** With just a few exceptions, the programs use a "needs-based" protocol for determining who gains entrance to the program and/or the amount of a family's allocation. Programs often use a questionnaire of some sort to rate or score family circumstances; the greater the score the greater the allocation or the chance of receiving help. Programs do not use the same protocol, each program having developed their own. This approach encourages competition among families for resources, and places greater power in the hands of program staff. Moreover, as program demand increases, so does the competitive intensity.

In a few cases, programs use "random selection" practices and/or a set allocation per family to distribute resources. These tactics eliminate the competition among families and reduce the power wielded by program staff. However, the approach cannot guarantee that the families most in need will be selected or that families will have access to all the support they need. The exception to this framework is in those counties that have decided that everyone should get something - this is a problem in whether the FDFSS funds can really make a difference. In general, there is a lack of consistency in how money is allocated.

✔ **Many areas report the demise of the family advisory councils.** People report that in several counties family advisory councils no longer exist or have been sufficiently weakened due to a lack of mission and purpose.

✔ **FDFSS programs have modest budgets and have not had significant budget increases in years, yet program demand continues to rise.** All the programs are faced with a common dilemma: too few resources to accommodate too much (and growing) need. The dynamic has led most programs to cut back on the average annual family allocation and to intensify the want to help only those families who "really need it." We often heard that program staff must distinguish between "needs" and "wants." Of course, in making such distinctions program staff place themselves before families as chief decision-makers.

✔ **The timing and availability of funds seems to conflict with family choice and self-determination.** If you are efficient in the use of money, you often receive less financial support. Families who want to use FDFSS as end of the year back-up sometimes find that there is no money left.

✔ **Programs are defined and limited by regulations, yet have become masterful at working around them.** Program regulations were meant to guide the actions of FDFSS programs. Over the years they have come to limit what programs can do to support families. Program staff have, however, discovered innumerable ways to get the families the help they need, regulations or not. As a result, the regulations become an arbitrary barrier, utilized or worked around depending on the will and creativity of local program staff. Exceptions have become the rule with many supports offered considered as innovative, and taking an extraordinarily long time to approve.

✔ **FDFSS programs expend extraordinary administrative energy to manage modest family allocations.** In the areas visited in the Western and Central parts of the state, the annual family allocation amounted to about $500-$700. Yet the administrative time spent to manage this money easily exceeded the amount of the allocation. Consider that generally for a new family:

- Families need to visit with a case manager and perhaps a family support worker afterwards. Workers will travel to the family residence if desired (this amounts to at least two meetings with staff with the potential of paying additionally for staff travel time and mileage).
- Families typically fill out a form that must be scored by program staff.
- Program staff meet to determine the allocation for each family in relation to the family test scores and all other families.
- Families are informed of their allocation and guided over how to use it.

✔ **There is the impression that the commitment from OMR has changed.**

In comparison to the overall OMR budget and other specific programs funded by OMR, FDFSS receives too little money for OMR to provide the needed amount of attention and direction.

Comparison to National Trends

✔ **The programs are more "child centered" than "family centered" family support.** That is, the supports offered focused much more on the needs of the child with mental retardation than on other family needs.

Family needs (such as, assistance to help a parent get to work, family counseling) are not generally approved. Likewise, requests that may benefit others in the family in addition to the child with disabilities (e.g., purchase of a television or air conditioner) are also typically met with disapproval. Although it is argued that a service like respite is meant to give relief to family caregivers, the service is centered around the child with disabilities. Technically, the respite worker cannot provide respite to the child's brothers or sisters.

✔ **The programs are not strongly family-driven, both at the individual and systems level.** At the individual level, there is the consistent claim that families get "what they need." There are four factors that undermine this position:

a) the meager annual allocation per family, averaging between $500-$700 per family in many of the areas visited; this is not enough money to make a difference in the lives of families and is significantly lower than other programs across the country (Illinois, for example, grants families $5616 per year in its family support financial assistance program),

b) program rules and regulations that channel family demand for supports or services that may be approved,

c) arbitrary local decision-making that leads to wide variance in what is approved or disapproved from county program to county program, and

d) an overwhelming sense of accountability to taxpayers and the system to provide only what is really needed and not more than the average family next door.

Overall, at the individual family level a great deal of responsibility (and control in decision-making) rests with the case manager and/or family support worker. Yet these individuals typically have high case loads and do not often visit with families. As a result, they fail to establish meaningful rapport with families, further reducing the help delivered by the program to a mechanical paper processing routine, rather than a support presence in the family's life.

At the systems level, the membership of family support councils has eroded, and the participation of the Councils in program decision-making is uneven. These circumstances have pushed greater responsibility on the program staff for making decisions about the program. Moreover, even when a Council is functional, turnover may be high so that it is difficult for the Council to maintain a strong driving role in the program. The diminished role of the Council also reduces the likelihood of a secondary gain for members to partake in an opportunity to develop leadership skills. This issue of leadership development is recognized on a national level.

✔ **FDFSS programs focus little on the potential use of informal or natural support systems.** Program staff have little or no time to develop natural support systems for families, either at the community (e.g., little league, Scouts, churches, clubs) or neighborhood (e.g., neighbors, extended family) levels. As a result, the programs focus exclusively on managing the modest family allocations, assuring that the funds are judiciously expended and accounted. Creativity has diminished due to waning support from mid-mangers resulting in a preponderance of requests for respite care rather than other supports.

✔ **FDFSS program staff receive little training related to best practices in family support.** Over time FDFSS staff have not received sufficient training to develop skills related to "positive help-giving", or the technical assistance to help programs overcome the administrative challenges each program faces. Nor is excellence regularly acknowledged and held high for all to see. These circumstances result in failure to develop a statewide "culture of excellence" related to family support. Certainly some amount of program variance is desirable, owing to geographic differences and the desire to promote local innovation. Yet the present variance seems less a product of well conceived innovation, but more the result of unguided wandering in response to limited budgets and growing service demands.

5. Results of the Follow Up Interviews

Two types of results are shown. First, data tables are displayed to list the frequency counts for any interview questions where the results could be tabulated. Second, findings resulting from open ended interview questions are provided.

Frequency Findings From The Follow-up Interviews

Frequency counts are shown for the following topic areas:

- ✔ Meeting With the FDFSS Coordinator
- ✔ Interacting With FDFSS Coordinators and Case Managers
- ✔ Exchanging Information
- ✔ Family Advisory Committees
- ✔ Having Control & Getting What You Need
- ✔ Supports You Receive
- ✔ Direct Services, Vouchers and Cash Assistance
- ✔ Judging The Results

Figure 15 provides information on the interaction between family members and the FDFSS coordinator. As shown, most respondents (65%) indicate that they feel better after a meeting and 70% indicate that something is accomplished at these meetings.

Figure 16 offers additional information concerning the relationship between the family respondents and FDFSS workers. Findings show that the respondents generally have been involved with FDFSS for several years (median = 54 months), and that case managers and FDFSS coordinators do turn over, though not terribly frequently. Most respondents (82%) also report their needs are addressed "in a helpful way". Of special note is the relationship between the case manager and FDFSS coordinator. For nearly half the respondents (21 of 44 or 48%), the FDFSS Coordinator and case manager is the same person.

Figure 15: Meeting With the FDFSS Coordinator

Do you feel better after meeting with the FDFSS Coordinator?		Did you accomplish anything at your meeting?	
30	Yes	31	Yes
12	No	10	No
2	Sometimes	3	Sometimes
2	Don't know	0	Don't know
1	Missing	3	Missing

Figure 16: Interacting With FDFSS Coordinators and Case Managers

How long have you been involved in FDFSS?	Range:	10-300 months
	Mean:	75 months
	Median:	54 months
	Respondents:	46
How long have you had this case manager?	Range:	1-60 months
	Mean:	23 months
	Median:	18 months
	Respondents:	45
How many case managers have you had in the past five years?	Range:	1-15
	Mean:	3
	Median:	3
	Respondents:	44
How long have you had this FDFSS Coordinator?	Range:	1-120 months
	Mean:	33 months
	Median:	36 months
	Respondents:	35
Are FDFSS Coordinator and Case Manager the same person?	Yes	21
	No	23
	Don't Know	2
Do the Case Manager and FDFSS Coordinator respond to you?	Yes	38
	No	3
	Sometimes	3
Is everything you asked for responded to in a helpful way? (e.g., other resources suggested, etc.)	Yes	37
	No	5
	Sometimes	3
Do you think your case manager gets the administrative support he/she needs to do their job?	Yes	26
	No	8
	Don't Know	12
How many discussions did you have with your case manager before they mentioned FDFSS??	Range:	1-21
	Mean:	1.44
	Median:	1
	Respondents:	36

Figure 17 displays information related to the exchange of information between FDFSS program and families. It is of interest to note (Figure 18), that newsletters and case managers rank as the most frequently cited sources of information about the program.

Figure 17: Exchanging Information

How long ago did you find out about FDFSS?	Range:	1-180 months
	Mean:	60
	Median:	54
	Respondents:	44
When did you start receiving FDFSS?	Range:	1-180
	Mean:	57
	Median:	48
	Respondents:	42
How does information generally come to you?	Newsletter	30
	Case Manager	28
	BSU	12
	Provider	11
	Phone Tree	2
	Other	9

Fig 18: How Information Gets To Families

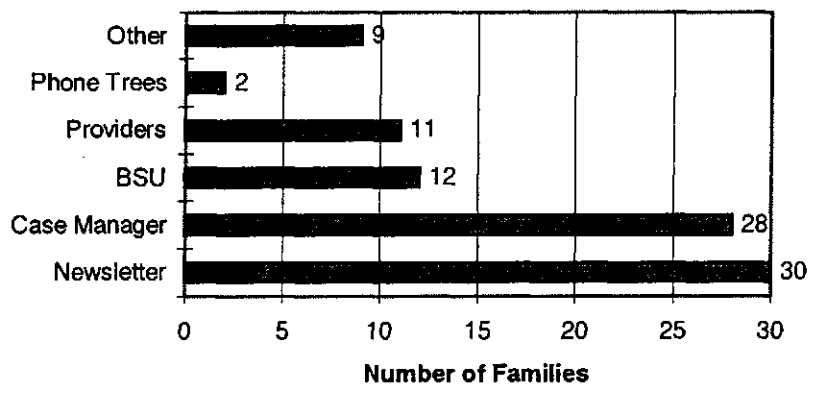
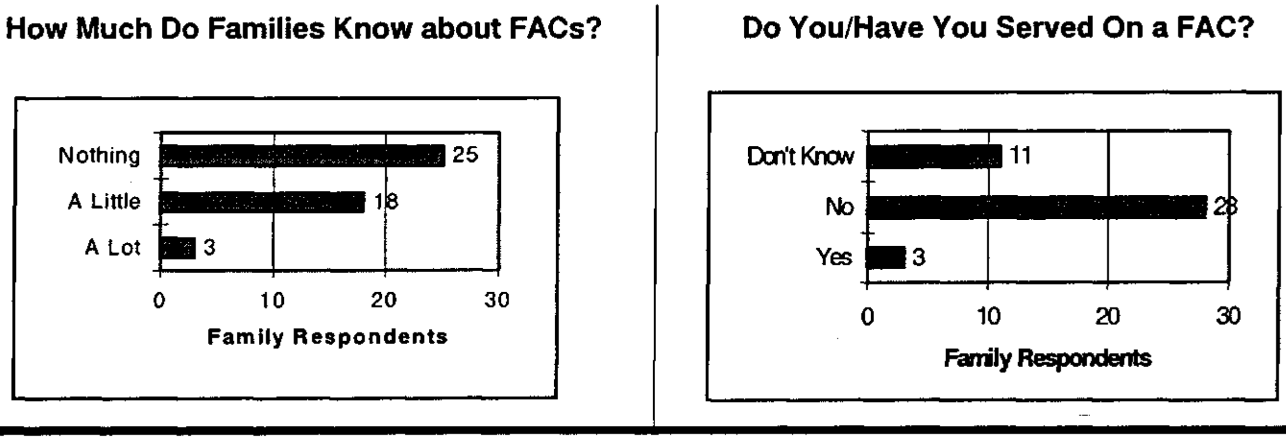


Figure 19 focuses on results related to FDFSS Family Advisory Committees. Generally, the findings illustrate that the family respondents have little awareness of or involvement with these committees (Figure 20).

Figure 19: Family Advisory Committees

How much do you know about your family advisory council (FAC)?	A Lot	3
	A Little	18
	Nothing	25
Do you go to the family advisory council meetings?	Yes	6
	No	32
	Don't know	7
Are there barriers or obstacles to the functioning of the FAC?	Yes	4
	No	10
	Don't know	29
Is there a real partnership between the FAC and the county?	Yes	5
	No	5
	Don't know	32
Is the FAC a rubber stamp for the county's activities?	Yes	1
	No	6
	Don't know	32
Do you serve or have you served on your county's FAC?	Yes	3
	No	28
	Don't know	11

Figure 20: Focus On Family Advisory Committees



How Much Do Families Know about FACs?

Do You/Have You Served On a FAC?

Figures 21 and 22 focus on the control families have over services and supports they receive from the FDFSS. Overall, the findings generally illustrate that families know how to go about asking for and receiving the services they want. Of special note in Figure 22 is a finding related to the receptivity of the community to families that include children with disabilities. As shown, 21 of 46 say that the community is "very receptive", while only 3 say that the community is "not at all" receptive.

Figure 21: Having Control And Getting What You Need

Do you know how to go about making changes in the supports you receive?	Yes	34
	No	12
	Don't know	0
Is the case manager agreeable when requests for changes are made?	Yes	25
	No	4
	Somewhat	2
	Never Asked	13
If the county chooses your support providers do you have the right to disapprove?	Yes	24
	No	2
	Don't Know	5
If yes and you disapprove, do you get another choice?	Yes	15
	No	5
	Don't Know	3
Are you given guidance/support in choosing providers? (Individual or agency providers)	Yes	19
	No	18
	Don't Know	1

Figure 22: Supports You Receive

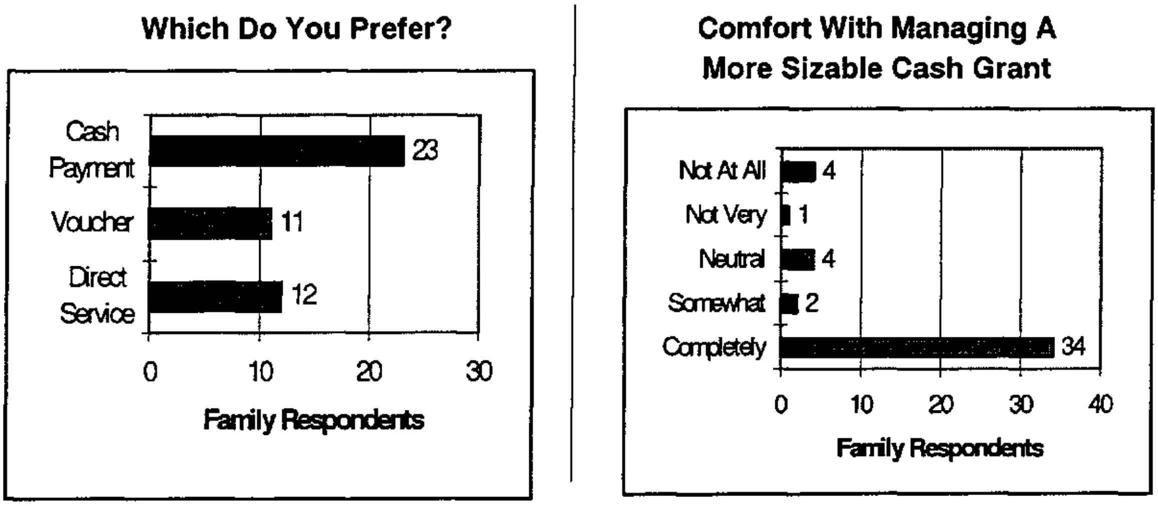
Are there any supports in the written plan that you are currently not receiving?	Yes	6
	No	39
Do your other family members have the information and resources needed to be helpful to you or your relative?	Yes	29
	No	15
How receptive is your community to families that include member(s) with disabilities?	Very Receptive	21
	Somewhat Receptive	11
	Neutral	7
	Not Very	4
	Not At All	3

Figure 23 focuses on results related to means of service delivery. Of the three options (cash, vouchers, direct services), the most frequently used option is cash (26 of 53 responses or 49%). Most (23 of 46 respondents or 50%) prefer cash payments, with the remaining respondents split between vouchers and direct services. Of note is the finding that most respondents (34 of 45 or 76%) say they would be "completely comfortable" with managing a sizable cash grant that goes beyond FDFSS (e.g. residential or vocational).

Figure 23: Direct Services, Vouchers and Cash Assistance

How is FDFSS currently delivered to you?	Direct Service	18
	Voucher	9
	Cash Payment	26
If you had your choice which one of the three methods would you most prefer?	Direct Service	12
	Voucher	11
	Cash Payment	23
How comfortable would you feel managing a sizable cash grant that goes beyond FDFSS (e.g. residential or vocational)?	Completely comfortable	34
	Somewhat	2
	Neutral	4
	Not very	1
	Not at all	4

Figure 24: A Preference For Cash Payments...



Which Do You Prefer?

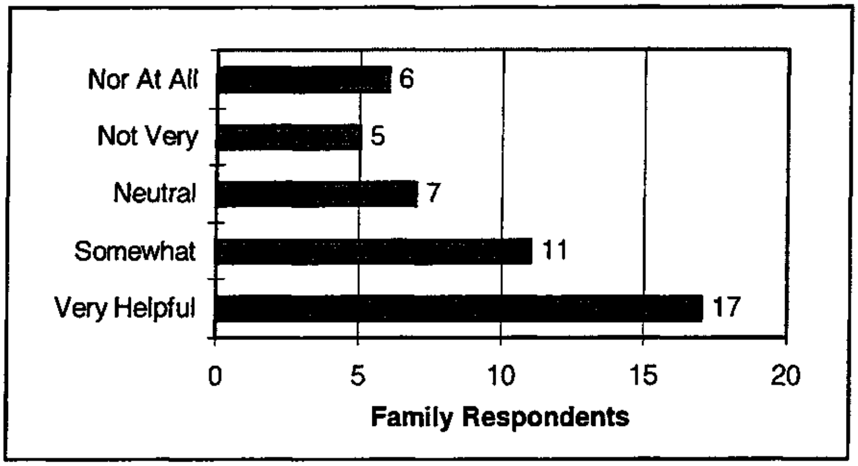
Comfort With Managing A More Sizable Cash Grant

Figure 25 is related to the results of the FDFSS program. Most (28 of 46 respondents or 61 %) say that the county OMH/MR office is "somewhat" or "very helpful" in meeting their needs, with 17 or 37% saying that the offices are "very helpful" (Figure 26). Most (29 of 37 or 78%) also believe that FDFSS program is "valued by the county office."

Figure 25: Judging The Results

How helpful is the county OMH/MR office in meeting your needs?	Very Helpful	17
	Somewhat	11
	Neutral	7
	Not very	5
	Not at all	6
Do you believe that the FDFSS program is valued by your county office?	Yes	29
	Somewhat	5
	No	3

Figure 26: How Helpful Is The County OMH/MR Office?



6. Concluding Thoughts and Recommendations

> "A service system for [people with disabilities] and others in need of support will have to be a system in constant change. It has to be continuously developed, if the 'customers' are not to be left behind and to become hostages of an outdated way of doing things."
>
> Alfred Dam (undated)
> Denmark

Since the program's inception in 1987-1988, over 10,000 families have received Family Driven Family Support Services in Pennsylvania. Indeed, this program is much appreciated by many, and aside from its statewide appeal, it has acted as a model for planners in other states. To help expand on this tradition of excellence, this evaluation effort provides a wealth of information on the program related to the demographics of those served, underlying program dynamics, and opinion on what could be done to improve the program.

The findings, however, did not yield a consensus view of the FDFSS program, an outcome that makes interpretation of the findings difficult.

- ✔ The mail survey, for instance, resulted in mostly positive findings where one might conclude that the great majority of families have high regard for the FDFSS program (See Chapter 3 and Appendix C).
- ✔ In contrast, the focus group forums held across the state with family members and professionals generated a more disapproving perspective in terms of both program policy and practice (See Chapter 4).
- ✔ Finally, the follow-up interviews yielded findings that were more consistent with the mail survey, offering a more positive view (See Chapter 5).

Based on these findings, it is clear that the FDFSS programs does a great many good things to help families throughout the state, but that in other ways the programs can do better.

Before proceeding, it must be recognized that -- fundamentally -- the family support business is based on localized decision making, with the county serving as the chief administrator of the FDFSS programs. At each FDFSS program, information is collected on families to bring some level of objectivity to the process, but the forms used and procedural protocol vary by program. Ultimately, case managers and FDFSS service coordinators, though guided by regulatory rules and procedural protocol, must act on requests made by individual families, decisions that inevitably require that judgments be made about families. In the end, nearly all aspects of the FDFSS system, from program admittance, level of need determination, funding allotments, and service delivery are driven by local decisions and judgments. These conditions, over time, promote variance in decision making both within and across counties, an outcome that brings both beneficial and undesirable results.

This challenging business is made more so by the need to keep pace with evolving ideas about what constitutes "best family support practice" and the inevitable impact of larger trends in the field (e.g., concern over funding and waiting lists, the push for system reform to emphasize self-determination). In specific, programs feel continual stress given increasing service demand in the face of relatively stagnant budgets.

All these factors -- a program dynamic that encourages increased statewide program variance, changing ideas about best practice, and larger system trends -- greatly complicate the family support process. Still, the Pennsylvania Office of Mental Retardation must stand committed to its mission and seek to improve the FDFSS program over time. To succeed, OMR must finds ways to guide policies that are decided and implemented within county-based systems.

Certainly, the Commonwealth and OMR in particular, are already engaged in actions dedicated to improving services for people with mental retardation. The Governor's 1997 "disability agenda" articulates a variety of policy goals "to eliminate barriers and mitigate obstacles so all persons with disabilities are afforded the opportunity to be as productive as possible and fully participate in society."

Likewise, OMR's 1997 "Multi Year Plan" describes a broad plan to: (a) restructure the service system to one that is consumer driven, values based, outcome oriented and cost efficient, and (b) realign existing resources to meet the needs of those on the waiting list while maintaining necessary supports and services for those currently receiving them.

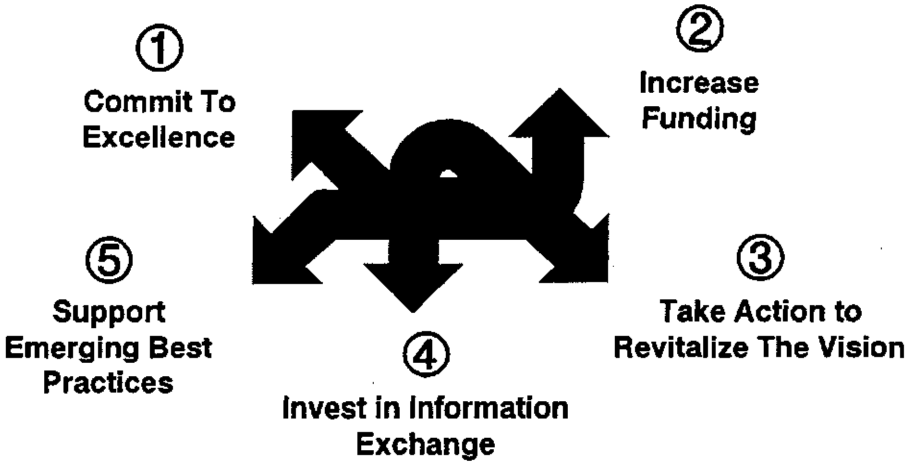
In this context, this evaluation suggests a number of additional actions that OMR could pursue to improve the FDFSS program. What follows is a series of recommendations related to the primary findings and analysis provided in Chapters 3-5. These recommendations are fully consistent with OMR's Multi Year Plan, and are tied to five core areas: (a) a **commitment to excellence,** (b) **increased funding** for FDFSS programs, (c) **action to revitalize a** vision driven FDFSS culture, (d) **investment in information exchange** among all FDFSS constituencies, and (e) **supporting emerging best practices.**

So, What Should FDFSS Programs Do?

It's not a matter of just doing a **better** job -- improving on what is already done.

The challenge also involves learning to do a **different** job.

Five Core Areas For Action



❶ OMR, County FDFSS Staff and Participating Families Must Commit to Excellence in FDFSS Policy and Practice.

This sounds like a simple recommendation to follow, one that most would argue is already embraced and put to work daily. Excellence, however, is not a condition that programs achieve and put to rest. Achieving excellence is an evolutionary process. It requires that individuals re-examine standing agency policies and practice continually, and alter these as needed to make sure that program actions stay true to the FDFSS vision and consistent with "best practices."

To succeed:

✔ <u>OMR must renew and affirm its Vision for effective family support</u>. OMR already has a strong position to underpin its family support policies. The agency has consistently articulated that:

* Its mission is to promote, improve, and sustain the quality of family life.

* The basis of this mission is that the family is the primary unit for nurturing, emotional support, economic support, socialization, and care of its members, including those with mental retardation, and

* County mental retardation programs should acknowledge and enhance the role of the family as the primary responsible unit for caring for members with mental retardation and should assist families in providing a supportive,

nurturing environment so that out-of-home placements are minimized when the family chooses to continue to provide care at home.

Further, with specific regard to FDFSS programs, OMR has indicated that the following principles must be used to guide operations:

> **There is no destination called "excellence." Striving for excellence is an evolutionary process for both the individual and the organization.**
>
> **Kristen Magis-Agosta, 1995**

- Families must be directly and meaningfully involved in planning, implementing, monitoring, and evaluating the provision of supports to them;
- Families must be consistently educated about which services exist and are available initially and throughout the project;
- Human services should be guided by a clearly stated mission and purpose;
- Local community resources and informal supports typically used or available to all members of a given community should be used to the extent feasible to avoid duplication or the creation of another layer of specialized services;
- Service delivery should promote client growth and development, and result in family/client satisfaction;
- The family's strengths should be identified and family supports should then build on these existing sources of support;

These principles are all generally accepted by family support advocates and professionals throughout the state. Still, after 10 years of operation and steady expansion across the state, the factors noted above have taken their toll. The result is significant variance in policy and practice across counties, a circumstance that will persist and grow stronger as each program seeks to cope with these factors in its own way. Certainly, some amount of program variance is desirable, since programs can be tailored to local preferences and test various innovations. Yet, the evaluation findings -- especially the focus group findings -- present evidence that local programs have "lost their way" (See Chapter 4), suggesting that the existing OMR vision no longer fully guides local policy and practice.

Within a context of systems change, time must be taken to re-examine the OMR family support vision, and to contrast this vision with standing FDFSS culture and practices. Such action is consistent with the OMR Multi Year Plan which calls for system reform that is consumer driven and values based.

This process may well result in a renewed commitment to the vision, but with some clarifications (small or large) made to illustrate the changes that must be pursued to make local FDFSS actions ever more consistent with the stated vision. Yet, change can be an unsettling concept for many, and so it is essential that OMR maintain a clear purpose of where it is headed and to what end.

✔ <u>OMR should host a statewide meeting of county FDFSS programs and participating families to re-affirm the FDFSS vision and mission</u>. At such a meeting OMR should take the opportunity to:

⇒ revise -- as warranted -- the existing FDFSS guiding principles and assure that each FDFSS program is in agreement with the finalized vision.

⇒ encourage county FDFSS program staff to reflect on these evaluation findings, taking ownership of the strengths and weaknesses uncovered, and accepting the challenge to make needed changes.

✔ <u>State OMR must play a stronger leadership role in FDFSS</u>. OMR must "set the tone" and invest energy and resources accordingly. It is recognized that the FDFSS programs are county administered and that OMR lacks commanding authority over the local programs. Yet, OMR can still greatly influence local operations. The meeting noted above is a start, but as illustrated by subsequent recommendations, numerous other actions could be taken.

✔ <u>While OMR must play a stronger leadership role, local FDFSS staff need not wait for OMR to act</u>. "Leaders" exist throughout the state, and in fact each individual associated with the FDFSS programs has a capacity to lead by example of their own actions. Aside from the actions taken by OMR, local FDFSS staff can act to change policies and practices within their own programs.

❷ OMR should commit to increase funding for the FDFSS program.

The FDFSS programs have been operating over the years with a relatively static budget, even while the number of families seeking support has increased. Stagnant budgets and growing demand is a deadly combination. The FDFSS programs are trying hard to cope with these circumstances. None want waiting lists and so they must find means to spread the existing resources further. As a result, programs often pursue policy and practice that is at odds with the stated FDFSS vision and guiding principles.

Programs, for example, have steadily reduced allowable annual funding allotments per family. During our site visits we found annual allotments across counties ranging from less than $500 to about $1,800 per year. In some instances, one can question whether the help makes much of a difference.

In addition, most programs scrutinize family needs with ever increasing care, promoting competition among families for scarce resources where those demonstrating the greatest need win out over others. While programs typically use paper and pencil questionnaires to "objectify" family needs and set funding allotments, this practice fails to build on family strengths. Instead, from the start, family assessment and planning places value on dysfunction over function.

Staff may also attach great importance to distinguishing between family "needs" and "wants." Subsequently, case managers or FDFSS coordinators routinely must render an appropriate judgment, where family "wants" typically go unfunded.

Making matters worse, the effort taken to administer these and other cost conscious routines itself takes staff time, and so costs money. It also takes time away from other important program functions. Few programs, for example, exert vigorous effort at developing informal community resources for families.

To help alleviate the pressures that contribute to such policy and practice, OMR must take action to increase the funding for FDFSS programs.

✔ The State OMR should include a significant increase for FDFSS in its upcoming budget requests made to the Governor and/or the state legislature.

✔ State and County authorities should continue their careful exploration of utilizing Medicaid financing for FDFSS. By utilizing Medicaid, existing state or county resources can be matched for federal reimbursement. As a result, the existing resource base can be stretched much further. While attractive from a fiscal view, Medicaid will come with a variety of federal and state requirements that may be inconsistent with FDFSS principles. To resolve such issues, changes in the existing state HCBS waiver may be needed, although tradeoffs in guiding principles must be weighed against the promise of additional funds.

❸ **OMR should act to revitalize the prevailing culture surrounding the FDFSS program.**

Any organization has among its staff shared experiences, assumptions, values and procedural protocol formal or not -- that lead to patterns of behavior. The FDFSS program also has an underlying culture that influences policy and day-to day behavioral patterns. This culture may well resonate with the current FDFSS vision, as well as its standing rules and regulations. But more than that, the prevailing culture reflects the attitude and beliefs that FDFSS staff bring to their work, affecting how staff interact with families and respond to family needs.

Consistent with any renewed sense of vision or action, a complementary learning culture for the desired changes must be established. Beyond setting a vision for

FDFSS or enforcing its associated rules, OMR must also act to influence this underlying culture. By doing so, OMR may guide -- not direct -- local operations.

✔ Regulations governing FDFSS should be re-examined, and potentially eliminated and replaced with performance standards. Present FDFSS regulations are meant to guide local operations. In practice, however, FDFSS staff have learned to "interpret" these regulations as needed. For instance, the regulations specify what services FDFSS funds can be used to purchase. Yet the evaluation staff discovered significant variability in how these regulations were applied across counties. On one hand, local creativity in applying the regulations may be applauded. On the other hand, such variance greatly frustrates families and inevitably shifts decision making power from the family to potentially capricious FDFSS decision makers.

At the least, OMR should re-examine the standing regulations, seeking to make them more consistent with: (a) emerging practices in family support, and (b) prevailing best practices already in place in FDFSS programs. Such action would be consistent with the OMR Multi Year Plan to pursue needed regulatory reform.

As an alternative, OMR should consider doing away with FDFSS regulations altogether, relying entirely on its guiding principles and stated performance expectations. This approach would eliminate the "creative interpretation" of regulations that programs pursue, placing strong emphasis on a general way of doing things (the guiding principles) and on outcomes. This approach is consistent with the OMR Multi Year Plan where OMR states its commitment to developing reliable standards and measures for monitoring system performance.

✔ FDFSS programs should be certified with the new standards - with a loss of certification possible. At present a county may establish a family support program and gain "FDFSS" status from OMR given that certain criteria are satisfied. Once the status is granted, however, the county program keeps it, regardless of its performance.

OMR cannot dictate local county FDFSS operations, nor can it easily reduce or eliminate funding that it has committed to a county FDFSS program. But it can judge the performance of the FDFSS program and remove its "FDFSS" designation if the program fails to perform in ways consistent with the FDFSS principles or expected outcomes.

In demonstrating its commitment to FDFSS principles and its willingness to play a strong leadership role, OMR should set a clear standard for what an FDFSS program is and what it is not. Subsequently, OMR should annually certify programs as FDFSS only if they have met the standards. This recommendation is consistent with the approach taken in the OMR Multi Year Plan where a restructuring of the state - county relationship was explored to establish where specific outcomes and performance standards would be set for counties.

✔ The Peer Review process for FDFSS programs should be re-established. A peer review process tied to FDFSS was previously employed in the state, but was terminated. The peer review process where family members and FDFSS staff work together to review FDFSS programs should be re-established and linked directly to the standards set by OMR for FDFSS programs. This action is consistent with the OMR Multi Year Plan which calls for development of independent teams at the local level to monitor the quality of services delivered by county systems.

✔ The statewide family support advisory committee should be re-established. For years a statewide FDFSS advisory committee met to guide the development and expansion of FDFSS programs across the state. The committee was disbanded recently.

OMR should consider re-instating this committee to help re-establish a vibrant learning culture that is consistent with the FDFSS vision and guiding principles. The committee could help shape state OMR family support policy, help to evaluate local programs for purposes of determining their FDFSS status, coordinate needed staff and family training, or coordinate a statewide newsletter on FDFSS. Such action would be consistent with the OMR Multi Year Plan which places a high regard on the need for service recipients to be a part of the decision making process that effects them.

✔ The very existence of local Family Advisory Committees (FACs) should be re-examined. One key principle tied to FDFSS states that "families must be directly and meaningfully involved in planning, implementing, monitoring, and evaluating the provision of supports to them." Given this tenet, the development of local family advisory committees to guide FDFSS policy and practice seems essential.

Yet, though there were exceptions, this evaluation found that FACs across the state are experiencing great difficulty by way of reduced membership, trouble with recruiting and shortened tenure. There may be any number of reasons for the problem (e.g., ambiguous or unclear mission for the FACs, insufficient compensation for FAC members). But regardless of the reasons, the impact on the FDFSS programs is undesirable.

Where FACs are weak or inoperable, policy or program decisions that would ordinarily tie back to the FAC are left to staff. In addition, family members who do serve on their FAC may do so with little instruction on what constitutes best practice in family support.

Inevitably, OMR must decide whether or not the local FACs are essential to the FDFSS system. If they are, then OMR must take steps to understand why the FACs are troubled and to re-establish a strong FAC presence throughout the state. This would involve a significant investment to: (a) establish a clear mission for the FACs, (b) recruit families to participate in FACs, (c) provide training on family support practices to the families on FACs, (d) compensate FAC members (e.g., travel, child care) for their participation.

❹ OMR must invest in information exchange involving families and FDFSS staff.

Consistent with an affirmation of vision and culture for FDFSS, OMR must also promote a vibrant exchange of ideas associated with the program. OMR should implement means to: (a) inform families and staff statewide about "best practices" in family support and promising FDFSS activities across the state, and (b) promote interactions among family members and FDFSS staff.

✔ OMR and local authorities must invest in continued staff training and technical assistance. While this evaluation did not directly explore the training received by case managers and FDFSS staff, it became clear that these staff received little direct training related to best practices in family support.

In establishing a strong culture for FDFSS, OMR should establish a training program for local staff to cover best practices in family support and its emerging trends. Such training will - over time -- increase the quality of the services offered. One key topic, for instance, where staff indicated a need for training concerned the use of informal supports for families. Training in this area would be consistent with the OMR Multi Year Plan which calls for a shifting of priorities for resource allocation from facility based programs to services that build on natural supports. In addition, aside from establishing a sound learning culture for FDFSS, consistent staff training may also help to reduce the variability in program design that is apparent across the state.

✔ OMR should act to:

- Establish a statewide FDFSS newsletter for family members and staff alike to exchange information on family support in the Commonwealth.
- Establish a website (or build on an existing OMR website) dedicated to family support in Pennsylvania.

- Establish a learning track at the well attended annual "Everyday Lives" statewide conference that is dedicated to family support.
- Conduct periodic regional family support meetings to provide information on family support and exchange ideas on how to improve the FDFSS system.

❺ **OMR should encourage FDFSS programs to explore practices that are consistent with emerging best practices in family support.**

Included in these efforts should be increased advocacy on behalf of:

✔ Direct cash assistance - 56% of the families surveyed in the mail survey indicated that they preferred that support be delivered to them in direct cash payments. In the follow-up surveys, 50% of the respondents indicated a preference for cash rather than vouchers or services. In addition, 76% of the families surveyed in the follow-up surveys said they would feel completely comfortable managing a sizable cash grant that goes beyond FDFSS (e.g. to purchase residential or vocational supports).

Given that families are satisfied with direct cash payments, and many would be willing to manage a larger cash grant, it is recommended that OMR develop a pilot project, where families would have the opportunity to manage a more substantial grant. The researchers are ware that such an effort is being undertaken through the Robert Wood Johnson self-determination project. It is recommended that some of these families be included in such efforts.

✔ Informal and community generic supports - early in the pilot projects, great emphasis was placed on the role of the resource developer/resource coordinator. It was the role of that individual to assist in developing community generic resources. As funds became more scarce and the FDFSS coordinator and in some counties, the resource developer were given additional responsibilities, the role of developing informal and generic supports dissolved. The individuals currently charged with the responsibilities of FDFSS coordination have little time and often no expertise in helping families develop their informal support networks and in teaching families strategies for accessing community generic resources.

It is recommended that OMR recommit itself to helping families develop informal supports by providing training opportunities for families and for FDFSS staff around the development of informal support systems (babysitting Co-ops, etc.) In addition, continued importance should be placed on the role of resource and support development by the FDFSS staff.

✔ Family support consultants - early on in the pilot projects, counties developed positions called FDFSS coordinators. As time has progressed, many counties have had to assign additional duties to the FDFSS coordinators, primarily as a result of budget shortfalls. As a result, the role of the FDFSS coordinator is often one of several roles held by a case manager. It is our recommendation that although the FDFSS coordinator may have additional obligations, s/he must be able to fulfill the job of family support consultant. The basic requirements of family support consultants are: small enough caseloads to have an impact on the families supported (not more than 50) and adequate knowledge about family support services, community generic services and the development of informal supports to be able to guide families through the process of plan development and implementation.

Concluding Remarks

> Only man is not content to leave things as they are but must always be changing them, and when he has done so, is seldom satisfied with the result.
>
> Elspeth Huxley
> *The Mottled Lizard,* ch. 4 (1962).

Aside from the several positive findings concerning the FDFSS programs, this evaluation -- rooted in the want to improve family support services -- emphasizes the things that OMR can do to improve the FDFSS system.

These findings and the resulting recommendations are offered as part of the groundwork being laid by OMR to improve its entire service system -- to maintain and expand its commitment to excellence.

These recommendations collectively call for OMR to alter how it does business. Among other things, we call for: (a) a reaffirmation of the guiding FDFSS vision and its associated principles, (b) increased funding, (c) revitalization of the prevailing culture surrounding the FDFSS program, and (d) investment in information exchange involving families and FDFSS staff. We call for an altered approach to FDFSS programs, one that reaffirms OMR's commitment to enable and empower service recipients. And we call for vigorous collaboration with many, including state OMR staff, county staff, FDFSS workers and family members. The direction these and other recommendations suggest will test OMR over the coming years. After all, change is not a concept organizations generally embrace with enthusiasm. The idea of change can easily be undercut by an absence of any urgency to change, active resistance from skeptical staff, or simply the numbing passage of time.

In the end, we hope that -- at the least -- this report provides a basis for OMR and others in Pennsylvania to discuss what must be done to improve the current response to family needs and to improve the FDFSS program. Indeed, this work -- as evidenced by OMR's Multi year Plan -- has in some ways already begun. At the most, we expect that this report will serve as an impetus for concrete action at OMR to improve FDFSS programs in Pennsylvania. Given OMR's continued commitment to excellence, we fully expect that it will.

Appendix A:

The Mail Survey Measure

Evaluating
Family Support in
Pennsylvania

Survey Of Program Participants

Across the nation, there is a growing network of families promoting changes in how family support is offered. This survey - based on principles developed by families across the country -- and in Pennsylvania - is for you to use in evaluating the quality of supports offered to you, and improving your family support program.

We expect it will take about 30 minutes to complete this survey. The form will help you and us to collect information on:

A. How you are treated by your family support program;
B. The information exchanged between you and the program;
C. How much control you have and the service planning process;
D. Your satisfaction with the services you receive;
E. The impact of the program on your life;
F. Your Family and your family member;
G. Other services your family receives; and
H. Various comments you may have about the program.

Before beginning, please keep these pieces of information in mind:

- ✔ The term *family driven support services program {FDSS program)* is used throughout the survey. For you, this refers to the services and supports your <u>family receives</u> through your county Mental Retardation program for your family member with mental retardation. The services could include things like respite care, sitter services, homemaker services, specialized therapies, special foods, and others. This survey <u>*does not*</u> pertain to school services (e.g., special education), community living or adult residential services or adult day services.
- ✔ Also, the term *family member* refers to the person with mental retardation living with you at home;

Remember that your answers will be kept **strictly confidential.** If you come to a question that you feel uncomfortable answering, skip it. However, for us to get complete information, it is very important that you try to answer each question as accurately as you can.

When you have completed the questionnaire, please return it to us in the enclosed pre-addressed and pre-stamped envelope.

Please Send Your Completed Survey To Us
Within The Next Two Weeks!
Thank You!

Pennsylvania Family Support Survey
Institute on Disabilities
Ritter Annex (004-00)
Temple University
Philadelphia, PA 19122
(215) 204-1356

Human Services Research Institute -- Institute on Disabilities at Temple University

Code: ______

Pennsylvania Family Support Survey

A. How You Are Treated... (Circle One Per Item)

		Never	Seldom	Sometimes	Usually	Always
1.	Does the FDSS coordinator/case manager acknowledge that you are informed and knowledgeable about your *family member*?	0	1	2	3	4
2.	Do they *listen* to you?	0	1	2	3	4
3.	Do they respect your opinions?	0	1	2	3	4
4.	Are they sensitive to your family's unique needs, strengths, and multi-cultural values?	0	1	2	3	4
5.	Do they honestly care about your *family member* and your family?	0	1	2	3	4
6.	Do you feel *better* after meeting with the FDSS coordinator/case manager?	0	1	2	3	4
7.	Are you comfortable when you talk with the FDSS coordinator/case manager?	0	1	2	3	4

B. Exchanging Information ... (Circle One Per Item)

		Never	Seldom	Sometimes	Usually	Always
8.	Does information about this program come to you, rather than you having to search for it?	0	1	2	3	4
9.	Is the information easy to understand?	0	1	2	3	4
10.	Does the information help you to make an informed choice, rather than confusing you?	0	1	2	3	4
11.	Is it easy for you to contact the FDSS coordinator/case manager -- when you want to talk to them?	0	1	2	3	4
12.	Do they ask for information that is unnecessary?	0	1	2	3	4
13.	Do they ask questions that make you feel uncomfortable because they are too personal?	0	1	2	3	4
14.	Does the process of exchanging information take too long?	0	1	2	3	4
15.	Do you have opportunities to talk and share information with other parents/families in your community?	0	1	2	3	4

C. Having Control & Deciding What You Need (Circle One)

		Never	Seldom	Sometimes	Usually	Always
16.	Do the FDSS staff meet with your family *individually* to discuss and plan for the supports you'll receive (in your preferred language)?	0	1	2	3	4
17.	Are you given a choice regarding the time and place that you meet with the coordinator/case manager ?	0	1	2	3	4
18.	Are you recognized as the expert regarding your family's needs?	0	1	2	3	4
19.	Do FDSS staff present an array of options to meet your needs?	0	1	2	3	4
20.	Do they encourage you to say how you want your needs to be met?	0	1	2	3	4
21.	Do FDSS staff respect your choices and preferences?	0	1	2	3	4
22.	Do you have primary decision-making power over the supports and services that you receive?	0	1	2	3	4

23. Do you choose who - or what vendor - provides you services?	0	1	2	3	4
24. Is an agreement developed that details *which supports* will be provided (*when and by whom*), and *who* will pay?	0	1	2	3	4
25. Is there a *written plan* developed that states which supports will be provided?	0	1	2	3	4
26. Can you change your mind about the supports you receive?	0	1	2	3	4
27. Do you have enough control in the planning of the supports you receive?	0	1	2	3	4
28. Is planning for your family's supports a comfortable process?	0	1	2	3	4
29. Are you included, to the extent that you desire, in the program's policy-making process?	0	1	2	3	4
30. Do you feel that your viewpoints are represented on your Family Advisory Council?	0	1	2	3	4
31. Do you have input on what supports or activities are provided in other informal ways (e.g., a suggestion box, family forums)?	0	1	2	3	4
32. Do you believe that you and other families have influence over the types of services available in your area?	0	1	2	3	4

D. The Supports You Receive ... (Circle One Per Item)

	Never	*Seldom*	*Sometimes*	*Usually*	*Always*
33. Do the FDSS staff make an effort to meet your family's needs?	0	1	2	3	4
34. Once supports are agreed upon, do they begin promptly?	0	1	2	3	4
35. Are you getting less support than you need because of the severity of your *family member's* disability?	0	1	2	3	4
36. Are supports available when your family wants and needs them?	0	1	2	3	4
37. *In a crisis*, are supports readily available?	0	1	2	3	4
38. Is your FDSS program flexible enough to meet your changing needs?	0	1	2	3	4
39. Are you satisfied with the delivery of the supports you receive?	0	1	2	3	4
40. Are FDSS staff "in touch" with your community and the resources it has available for families?	0	1	2	3	4
41. Are FDSS staff knowledgeable about the various public benefits available to assist families (e.g., food stamps, EPSDT, Supplemental Security Income).	0	1	2	3	4
42. Do FDSS staff give you as much help as you want or need to access community resources or public benefit programs?	0	1	2	3	4
43. Does the FDSS program coordinate with other resources in your community (e.g., schools, day care centers, health services) to prevent gaps in services to your family?	0	1	2	3	4
44. If the services that you need are not available locally, do the FDSS staff help you to *create* the supports needed?	0	1	2	3	4
45. Are you getting the level of support or services that you need?	0	1	2	3	4
46. Do you think that the FDSS program does a good job providing services with the resources they have available?	0	1	2	3	4

E. Judging The Results ... **(Circle One Per Item)**

47. Does this FDSS program:	*Never*	*Seldom*	*Sometimes*	*Usually*	*Always*
a) Offer the necessary supports to meet your family's unique needs?	0	1	2	3	4
b) Help your family feel more connected to your community?	0	1	2	3	4
c) Help your *family member* to be more included in the community?	0	1	2	3	4
d) Help you and your family feel more connected to your community?	0	1	2	3	4
e) Help you meet other parents and have a better support network?	0	1	2	3	4
f) Help you feel more confident in your parenting?	0	1	2	3	4
g) Help you feel more informed about your *family member's* development?	0	1	2	3	4
h) Make problem-solving concerning your family member easier?	0	1	2	3	4
i) Enhance your family's ability to meet the needs of your *family member*?	0	1	2	3	4
j) Help you feel more in control of your life?	0	1	2	3	4
k) Help you to keep your family together?	0	1	2	3	4
l) Help your family to make financial ends meet more consistently?	0	1	2	3	4
m) Help you and your family improve relationships with one another?	0	1	2	3	4
n) Help you and your family have fewer physical health problems?	0	1	2	3	4
o) Better allow you to live as much like other families as possible?	0	1	2	3	4
p) Make a positive difference in the life of your family?	0	1	2	3	4

F. About Your Family...

Next, a few important questions about your family member with a disability, and also about your family. Please remember that your answers will be kept strictly confidential.

48. Which of the following describes your household. **(Check all that apply)**

☐ (a) Two parents in the home
☐ (b) Single parent household
☐ (c) Living with relatives
☐ (d) Sharing household with non-relatives
☐ (e) Other (specify) ________________

49. Who is primarily responsible for caring for your *family member*? **(Check one)**

☐ (1) Mother
☐ (2) Father
☐ (3) Mother and father equally
☐ (4) Other (specify) ________________

50. What was the total **taxable** income last year (1995) of primary wage earners in your house? **(Check one)**

☐ (1) Less than $10,000
☐ (2) $10,001 - $20,000
☐ (3) $20,001 - $30,000
☐ (4) $30,001 - $40,000
☐ (5) $40,001 - $50,000
☐ (6) $50,001 - $60,000
☐ (7) $60,001 - $70,000
☐ (8) $70,001 - $80,000
☐ (9) Over $80,000

51. _At the time you applied for family support_, were you planning to request that your *family member* be placed in a living arrangement outside your home (e.g., to a foster home, community residence, state institution), or was your *family member* already living outside of your home? **(Check one)**

- ☐ (1) Yes -- Our *family member* was living in an out-of-home placement.
- ☐ (2) Yes -- Our family had already applied for an out-of-home placement.
- ☐ (3) Yes -- Our family was planning to request an out-of-home placement.
- ☐ (4) Maybe -- Our family was discussing the issue, but we had not decided on what to do.
- ☐ (5) Don't Know -- Our family had not discussed this issue.
- ☐ (6) No -- Our family had no plans to seek an out-of-home placement.

---

52. Has anything about your decision to place, or not to place your *family member* changed since you began receiving support from this program? **(Check one)**

- ☐ (1) No change.
- ☐ (2) Yes, our *family member* is now living in an out-of-home placement
- ☐ (3) Yes, we have decided to seek an out-of-home placement for our *family member.*
- ☐ (4) Yes, we are no longer considering placing our *family member* outside our home.
- ☐ (5) Yes, we were able to bring our *family member* home.
- ☐ (6) Maybe, we are discussing the issue, but have not decided on what to do.

---

53. Has your *family member's* disability influenced where your family lives?

○ (0) No ○ (1) Yes ☞ IF YES, CHECK ALL THAT APPLY:

- ☐ (a) Our family moved to be closer to services for our *family member.*
- ☐ (b) Our family moved because our home did not meet our *family member's* physical needs and we were unable to make the needed modifications (e.g., ramp, accessible bathroom).
- ☐ (c) Our family moved because our *family member's* disability disturbed the landlord or neighbors.
- ☐ (d) We have not moved to a better home because of the cost of care for our *family member.*
- ☐ (e) We have not moved because we do not want to lose our current services.
- ☐ (f) Other (specify) ______________________________

---

54. To meet the needs of your *family member*, has anyone in your household: **(Check one for each)**

(a)	Given up a paying job?	☐ (0) No	☐ (1) Yes
(b)	Not looked for a job?	☐ (0) No	☐ (1) Yes
(c)	Limited their job choice to meet care demands?	☐ (0) No	☐ (1) Yes
(d)	Lost a job because of care demands?	☐ (0) No	☐ (1) Yes
(e)	Refused a job transfer or promotion?	☐ (0) No	☐ (1) Yes
(f)	Changed jobs for better medical benefits?	☐ (0) No	☐ (1) Yes
(g)	Changed jobs for different hours?	☐ (0) No	☐ (1) Yes
(h)	Quit school or not gone back to school?	☐ (0) No	☐ (1) Yes
(i)	Lost health insurance coverage?	☐ (0) No	☐ (1) Yes
(j)	Taken a second job to increase their income?	☐ (0) No	☐ (1) Yes
(k)	Accepted a lower paying job	☐ (0) No	☐ (1) Yes
(l)	Not changed jobs because the change would have meant losing health benefits?	☐ (0) No	☐ (1) Yes

55. What sex is your *family member?* ☐ (1) Male ☐ (2) Female

56. How old is your *family member?* ______ years

57. Indicate the degree of assistance that your *family member* requires in completing the following activities **(Check One per item):**

	None	Little	Moderate	Complete
Toileting	0	1	2	3
Eating	0	1	2	3
Bathing	0	1	2	3
Grooming	0	1	2	3
Dressing	0	1	2	3
Communicating needs	0	1	2	3
Movement within home	0	1	2	3
Travel out of home	0	1	2	3

58. How often does your *family member* **BEHAVE** in ways that pose a major problem for you or others in your family (excessive tantrums, breaks things, hits others or himself, eats inappropriate things)? **(Check one)**

☐ (0) Never/less than monthly ☐ (1) Monthly ☐ (2) Weekly ☐ (3) Daily

G. About The Supports Your Family Receives...

59. What types of services has your family received during the past 12 months from the FDSS Program? First, indicate *whether* you received any of the services listed **(Check one** - yes or no - **per service).** Then, for the services you received, indicate *how* you obtained it primarily. Did you receive cash, a voucher or simply the service? **(Check one for each service you received)**

	Received it?		If yes, how did you obtain it primarily?				
Service Type	No	Yes		Service	Voucher	Cash	Don't Know
(a) Respite Care	0	1	If Yes ☞	1	2	3	4
(b) Family Aide/ Sitter Services	0	1	If Yes ☞	1	2	3	4
(c) Homemaker Services	0	1	If Yes ☞	1	2	3	4
(d) Recreation	0	1	If Yes ☞	1	2	3	4
(e) Specialized Therapies	0	1	If Yes ☞	1	2	3	4
(f) Information and Referral	0	1	If Yes ☞	1	2	3	4
(g) Family Training/Education	0	1	If Yes ☞	1	2	3	4
(h) Adaptive Appliances	0	1	If Yes ☞	1	2	3	4
(i) Home Modifications	0	1	If Yes ☞	1	2	3	4
(j) Special Diets	0	1	If Yes ☞	1	2	3	4
(k) Other ______________	0	1	If Yes ☞	1	2	3	4

60. In general, how would you *most* prefer that the FDSS program offer support to you? **(Check one)**

☐ (1) I prefer services that the FDSS program delivers services and supports directly to me.

☐ (2) I prefer a voucher that I can use to obtain services.

☐ (3) I prefer cash that I can use to obtain supports and pay for them directly.

61. Day to day, who do you consider a significant help to you and your family in meeting the challenges you face because of your *family member's* disability? (**Check all that apply**)

- ☐ (a) Family members who live with us
- ☐ (b) Relatives outside the home
- ☐ (c) Friends
- ☐ (d) Other parents of family members with disabilities
- ☐ (e) Church members
- ☐ (f) Neighbors
- ☐ (g) Professional helpers
- ☐ (h) Co workers

62. What type of health care plan does your family have? (**Check all that apply.**)

○ NONE (our family does not have a health care plan)

- ☐ (a) Health Maintenance Organization (HMO)
- ☐ (b) Preferred Provider Organization (PPO)
- ☐ (c) Private Health Insurance Policy
- ☐ (d) Medicaid
- ☐ (e) Medicare
- ☐ (f) Other (specify) _______________

63. Is your *family member* or family **NOW** receiving any of these other services or benefits -- from someplace *other than* the Family Support Services Program: (**Check all that apply.**)

○ NONE (none of the services or benefits listed below are received)

- ☐ (a) Service coordination/case management
- ☐ (b) Early intervention services (Birth to Three)
- ☐ (c) EPSDT services
- ☐ (d)) School services (e.g., special education, related services)
- ☐ (e) Specialized therapies (e.g., physical, speech)
- ☐ (f) Adult Day Services (e.g., day habilitation, employment)
- ☐ (g) Vocational Rehabilitation Services
- ☐ (h) Recreation program
- ☐ (i) Parent/sibling support groups
- ☐ (j) Pennsylvania Advocacy (legal assistance)
- ☐ (k) Family Centers (Parents as Teachers Program)
- ☐ (l) Supplemental Security Income (SSI)
- ☐ (m) Social Security Disability Insurance (SSDI)
- ☐ (n) Social Security Administration (SSA)
- ☐ (o) Medicaid Medical
- ☐ (p) Medicare
- ☐ (q) Veterans Benefits
- ☐ (r) Housing subsidy
- ☐ (s) Energy assistance (heat, electric)
- ☐ (t) Women, Infants & Children (WIC)
- ☐ (u) Food Stamps
- ☐ (v) Public Aid/Welfare/AFDC
- ☐ (w) Other (specify) _________________
- ☐ (x) Other (specify) _________________

H. Comments...

64. For how many months has your family received services from this FSDD program? ________ months.

65. Has your family received the help you expected to receive? ☐ (0) No ☐ (1) Yes

66. Is there something more you need? ☐ (0) No ☐ (1) Yes

67. Do you have any suggestions for improving the FDSS program? ☐ (0) No ☐ (1) Yes

68. If you have anything else you want to tell us, please use the space below.

We greatly appreciate the time you took to complete this survey. But in many ways there is no substitute for face-to-face conversation. To complement this survey, our staff will be interviewing about 100 families throughout Pennsylvania over the next few months. We hope that our talks with people like you will help us to understand more about our survey findings and about how services can be improved.

If you are willing to be interviewed, please provide us with your name, address and telephone number. If you are selected, one of our staff will contact you directly to set up a time and place for the interview. If you would like, our staff will visit you at your home or wherever is convenient for you. As always, the information you share with us during the interview will be strictly confidential.

✓ YES,

I am willing to be interviewed!

Name: ____________________

Address: ____________________

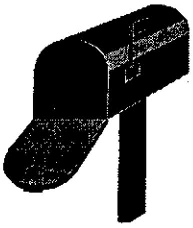
____

Phone: (___) ____________________

Thank You!

Please send your completed survey to us within the next two weeks!

Pennsylvania Family Support Survey
Institute on Disabilities
Ritter Annex (004-00)
Temple University
Philadelphia, PA 19122



Appendix B:

The Follow Up Interview Protocol

FDSS FOLLOW-UP SURVEY

HOW ARE YOU TREATED?

1. Do you feel better after meeting with the FDSS Coordinator? (Check one)

____Yes ______ No

Please explain ____

2. Did you accomplish anything at your meeting? (Check one)

____Yes ______ No

Please describe ____

3. How long have you been involved in FDSS? Record number of months. _________

4. How long have you had this case manager? Record number of months. _________

5. How many case managers have you had in the past five years? _________

6. How long have you had this FDSS Coordinator? Record number of months. _________

7. Are FDSS Coordinator and Case Manager the same person? (Check one)

____Yes ______ No

8. Do the Case Manager and FDSS Coordinator respond to you? (Check one)

____Yes ______ No

Please describe ____

9. Is everything you asked for responded to in a helpful way? (e.g., other resources suggested, etc.)

____Yes ______ No

10. Do you think your case manager gets the administrative support he/she needs to do their job?

____Yes ______ No

If not, please explain ____

11. How many discussions did you have with your case manager before they mentioned FDSS?

____

EXCHANGING INFORMATION

1. How did you find out about FDSS? ______________________________

____

2. When did you find out about FDSS? ______________________________

3. When did you start receiving FDSS? ______________________________

4. In general, when you call your case manager, how long does it take for your case manager to call you back? ____________

5. How does information regarding FDSS and other issues related to your relative with a disability generally come to you? Check all that apply.

___ Newsletter
___ Case Manager
___ BSU
___ Phone Tree
___ Provider
___ Other (specify)

6. How receptive is your community to families that include member(s) with disabilities? Use a Scale of 1 to 5.

_____ 1 = Very Receptive, 2 = Somewhat, 3 = Neutral, 4 = Not Very, 5 = Not at all

7. What supports do you get from:

Family ______________________________

Friends ______________________________

Neighbors ______________________________

Community ______________________________

8. What additional supports could you benefit from? ______________________________

____

9. What kind of opportunities do you have to talk to and share information with other parents/members of your community? ______________________________

____

HAVING CONTROL AND DECIDING WHAT YOU NEED

1. How much do you know about the Family Advisory Council (FAC) in your BSU/county? (Check one)

___ A lot ______ a little ______nothing

2. Do you go to the Family Advisory Council meetings?

____Yes ______ No Why or why not? ____

3. What is the role of the FAC in your BSU/county? ____________________________________

____

4. Are there barriers or obstacles to the functioning of the FAC?

____Yes ______ No

If yes, what are they? ____

5. Is there a real partnership between the FAC and the county?

____Yes ______ No

If yes, please give examples. ____

6. Is the FAC a rubber stamp for the county's activities?

____Yes ______ No

7. Do you serve or have you served on your county's FAC?

____Yes ______ No

8. What are the greatest strengths of your BSU's/county's FAC? ___________________________

____

9. What are the greatest weaknesses of your BSU's/county's FAC? __________________________

____

10. Do you know how to go about making changes in the supports you receive?

____Yes ______ No

11. Is the case manager agreeable when requests for changes are made?

____Yes ______ No

12. If the county chooses your support providers do you have the right to disapprove?

____Yes ______ No

13. If yes, and you disapprove of the support provider chosen by the county, do you get another choice?

____Yes ______ No

14. Are you given guidance/support in choosing providers? (Individual or agency providers)

____Yes ______ No

SUPPORTS YOU RECEIVE

1. Are there any supports in your written plan that you are currently not receiving?

____Yes ______ No

If yes, what and why? ____

2. What kind of crises have you experienced in the past two years? ____________________

____

3. What kind of supports were readily available to you during those times? ______________

____

4. Do your other family members have the information and resources needed to be helpful to you or your relative?

____Yes ______ No

If yes, what has been helpful (e.g. county MH/MR. program, ARC, UCP) ________________

____

If not, what additional information and resource would be helpful? ____________________

____

5. What services were created with the assistance of FDSS staff that were otherwise unavailable in your area? ____

JUDGING THE RESULTS

1. How helpful is the county OMH/MR office in meeting your needs? Use a scale from 1 to 5.

______ 1 = Very Helpful, 2 = Somewhat, 3 = Neutral, 4 = Not very, 5 = Not at all

2. Do you believe that the FDSS program is valued by your county office? Use a scale from 1 to 3.

______ 1 = Yes, 2 = Somewhat, 3 = No

3. How is FDSS currently delivered to you? Check all that apply.

___ Direct Service
___ Voucher
___ Cash Payment

4. If you had your choice which one of the three methods would you most prefer?

___ Direct Service
___ Voucher
___ Cash Payment

5. What is the best thing about the FDSS program in your county? ____________________

____

6. What is the worst thing about the FDSS program in your county? ____________________

____

7. Are there any questions we should have asked, but didn't? What are they? ____________________

____

8. How comfortable would you feel managing a sizable cash grant that goes beyond FDSS (e.g. residential or vocational)? Use a scale from 1 to 5.

______ 1 = Completely comfortable, 2 = somewhat, 3 = neutral, 4 = not very 5 = not at all

9. Is there anything else you want to tell us? ________________________________

____

____

Appendix C:

Research Brief Regarding The Mail Survey

Selected Survey Findings Related To OMR's Family Driven Support Services Programs

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Human Services Research Institute & the Institute on Disabilities

Continued Commitment to Excellence: Evaluating Pennsylvania's Family Support Program
Research Brief No. 1
Fall 1996

About This Project

Over the past two decades, the nation's response to children with developmental disabilities and their families has shifted dramatically, moving from an historical awareness of disability based in segregation and exclusion to one that favors the integration of people with disabilities into the mainstream of community life. In 1972 Pennsylvania became the first state to offer families who provide care at home to children with mental retardation some measure of support. Since that time all but one state have developed initiatives to provide families with a variety of supportive goods and services.

Family support means different things to different families. While no single definition of the concept has gained sway nationally, the idea is simply to provide families with whatever it takes for families of people with disabilities to live as much like other families as possible. More specifically, the term "family support" can mean supports, resources, services, and other assistance provided to families of children with disabilities that are designed to (a) support families in their efforts to raise their children with disabilities in the family home, (b) strengthen the role of the family as primary care-giver, (c) prevent inappropriate and unwanted out-of-home placement and maintain family unity, and (d) reunite families with children with disabilities who have been placed out of the home.

In Pennsylvania, family support services represent a service approach that recognizes the family as the most significant provider of services to people with mental retardation. Building on this tradition, in 1987-1988 the Pennsylvania Office on Mental Retardation began funding 11 family driven support services program (FDSS program) pilots, expanding this number by 15 in 1990 and steadily thereafter. These projects are operated through county Mental Retardation programs. The services offered could include things like respite care, sitter services, homemaker services, specialized therapies, special foods, and others, and may be delivered as direct services or by voucher or direct cash assistance.

OMR is committed to continuing its tradition of excellence in responding to the needs of families who provide care at home to people with disabilities. Yet OMR recognizes that from time to time it is advisable to take a hard look at the overall family support system to identify ways for improving the service response. Within this context, the Institute on Disabilities at Temple University and the Human Services Research Institute are collaborating to collect relevant information concerning the FDSS programs in Pennsylvania and facilitate a participatory process for improving the family support system. As this project unfolds, Pennsylvanians will:

- ✯ Evaluate their family support system based on their own set of standards and guiding principles;
- ✯ Assess their family support system based on a set of nationally validated quality indicators;
- ✯ Come to their own conclusions over how to proceed with their system of services and supports to families based on the information obtained.

To achieve these goals, the Institute on Disabilities and HSRI have conducted a survey of a representative sample of families who receive family support services. Follow-up interviews of a portion of these families will be conducted and focus groups will be convened to discuss the findings. Finally, based on all project findings, recommendations for improving the family support system will be offered to OMR. In this Research Brief selected findings emerging from the mail survey of participating families are described.

What Did We Want To Know?

In conducting this survey we wanted to collect information directly from families to: (a) gain fundamental demographic information on participating families, (b) identify the overall sources of support that families utilize, (c) assess family satisfaction based on a series of quality indicators, (d) assess associated program outcomes, and (e) hear what families think OMR should do to improve the family support system. In six pages, the survey form included 68 questions.

The Family Support Survey Form

Demographics (9 questions)
Types & sources of support (5 questions)
Quality indicators (46 questions)
Program outcomes (3 questions)
Opinion (5 questions)

About the Survey Process

During the summer of 1996, survey forms were sent to 1,834 participants of the OMR FDSS programs that are operated through county offices. The participants were selected from 12 counties -- balanced for urban and rural differences -- to provide a representative sample of all those receiving services.

We received completed forms from 538 respondents, a 29% response rate. As shown, the responses were not evenly distributed across sites, ranging from 115 responses (Allegheny county) to 29 responses (Bradford/ Sullivan counties). Taken together, the responses offer ample opportunity to examine the family support program.

Survey Responses By County	
Allegheny	115
Bradford/Sullivan	29
Chester	61
Huntington/Mifflin/Juniata	43
Lancaster	94
Mercer	50
North Hampton	36
Philadelphia	74
Fayette	32
Unknown	4
Total	**538**

What Did We Learn?

A great deal of information was collected, though not all the findings will be reported here. What follows is a series of selected findings related to: (a) demographics of the families who responded, (b) the types of services or support families receive, (c) satisfaction with the family support services, and (d) associated program outcomes.

Demographic information

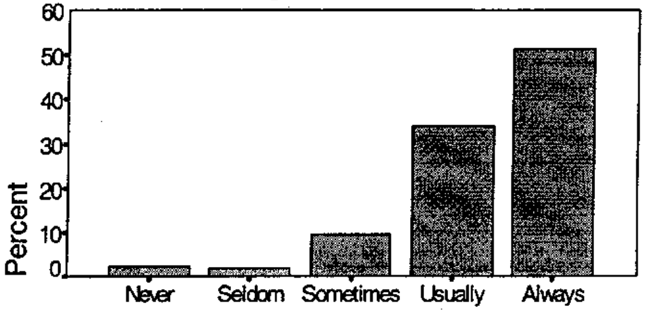
Concerning the individuals with disabilities living at home, we found that:

- ✔ **Ages range from under a year old to 76 years old, though (34%) are 11 years old or younger. The median age is 17 years old.**
- ✔ **More individuals with disabilities are male (280 or 57%) than female (212 or 43%)**
- ✔ **Regarding the need for assistance to complete daily activities, significant proportions require** *complete* **assistance with toileting (188 or 37%), eating (211 or 41 %), bathing (174 or 34%), grooming (180 or 35%), dressing (119 or 23%), communication (103 or 20%), movement within the home (219 or 42%), and travel out of the home (270 or 52%).**
- ✔ **While the great majority (302 or 59%) seldom behave in ways that pose major challenges, a significant number do on a daily basis (102 or 20%).**

Regarding the families who provide care at home for these individuals, we found that:

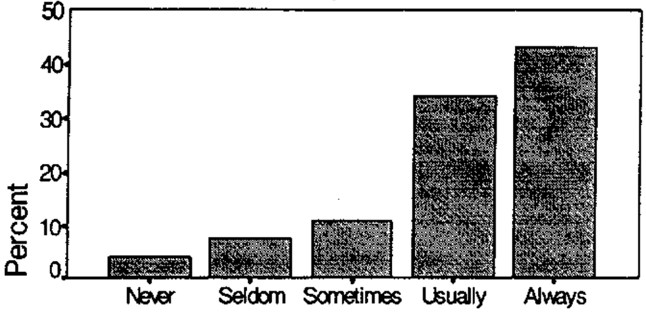
- ✔ **Two thirds of the respondents (360 or 67%) indicate that their household included two parents in the home, though another 25% (133) indicate that their's was a one parent household.**
- ✔ **Most (283 or 54%) indicate that the individual's mother was primarily responsible for providing care, though 36% (194) indicate that it was the mother and father equally.**
- ✔ **Most families (257 or 58%) had a total taxable income in 1995 of $30,000 or less.**
- ✔ **To meet the needs of the family member, most families (301 or 56%) report that someone in their household has given up a paying job, not looked for a job, or limited their job choice.**

Are Families Recognized as an Expert Concerning Their Needs? (n=521)



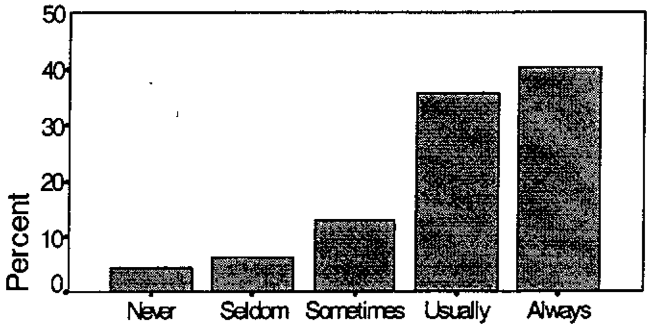
PA Family Support Survey, 1996

Do Families Have Control Over the Service Planning Process? (n=507)



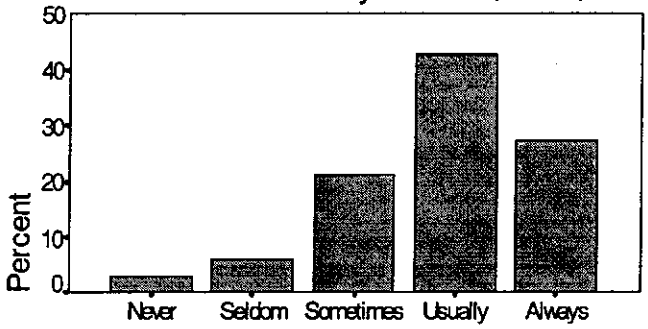
PA Family Support Survey, 1996

Are Families Encouraged To Say How Their Needs Should Be Met? (n=517)



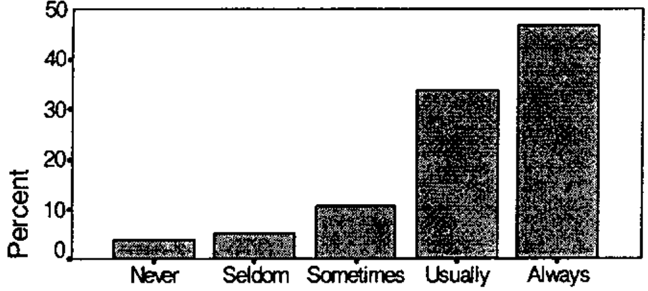
PA Family Support Survey, 1996

Does the FDSS Program Offer the Services the Family Needs? (n=500)



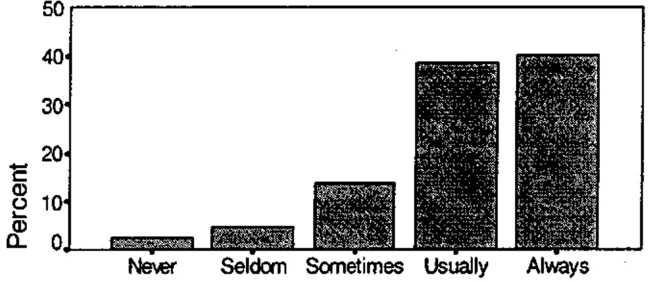
PA Family Support Survey, 1996

Are Families the Primary Decision-Makers Concerning the Help They Receive? (n=518)



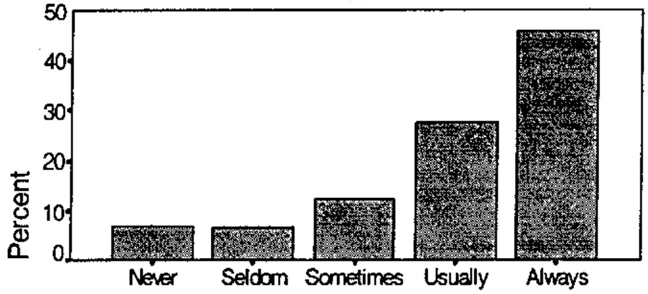
PA Family Support Survey, 1996

Are Families Satisfied with the Services and Supports They Receive? (n=508)



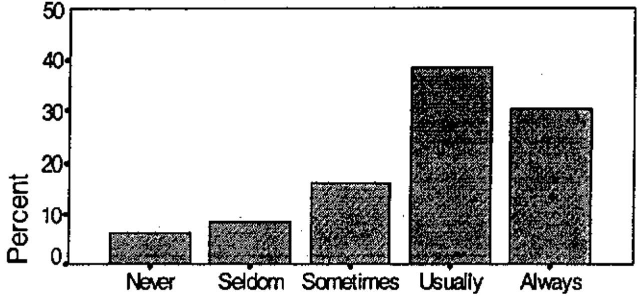
PA Family Support Survey, 1996

Do Families Choose Who Provides Services or Supports? (n=509)

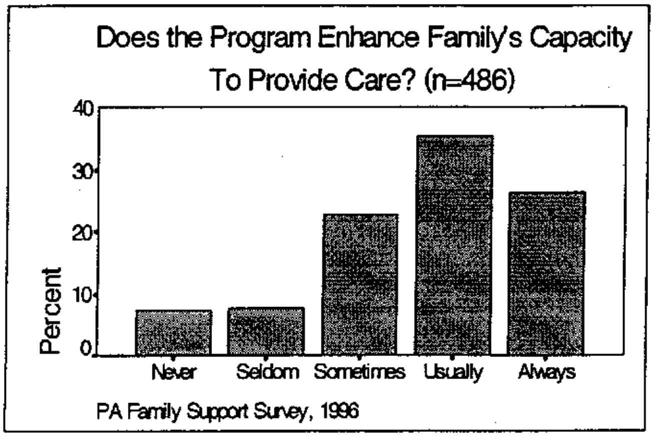


PA Family Support Survey, 1996

Are Families Getting the Amount of Services and Supports They Need? (n=504)

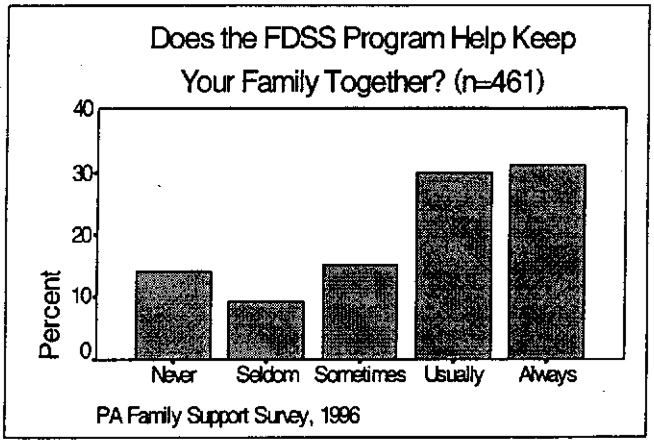


PA Family Support Survey, 1996



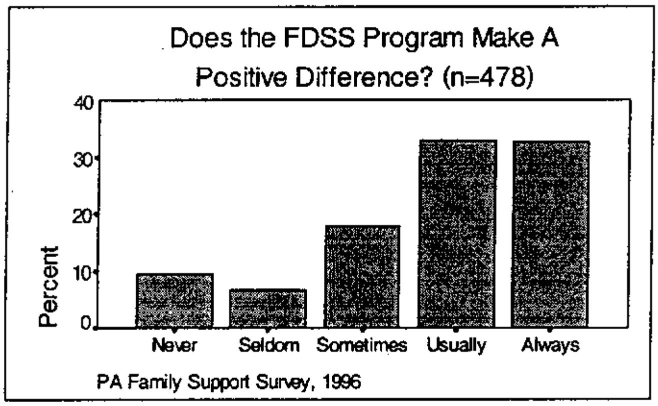
Does the Program Enhance Family's Capacity To Provide Care? (n=486)

PA Family Support Survey, 1996



Does the FDSS Program Help Keep Your Family Together? (n=461)

PA Family Support Survey, 1996



Does the FDSS Program Make A Positive Difference? (n=478)

PA Family Support Survey, 1996

The Supports Families Receive

Families receive support from a variety of resources:

- By participating in the family support program, families choose from a variety of services, though the most popular include respite care (190 families), family aide or sitter services (242 families), recreation supports (233 families, and information and referral (108 families). Our findings also show that families receive these supports either as direct services or by voucher or cash assistance.
- Most families (275 or 56%) prefer that supports be offered as cash assistance. Another 129 (26%) prefer vouchers.
- The most significant sources of help for families are live-in family members (217 or 40%), relatives (277 or 52%), friends (206 or 38%) and professionals (167 or 31%).

Satisfaction With Family Support

Survey respondents registered their satisfaction by responding to 46 quality indicators. The indicators covered four topic areas (how families are treated, the exchange of information, the control families have over deciding what services are needed, and the supports received), and required responses on a five point Likert scale.

Overall, we found that families -- on average - are greatly satisfied with the family support services they receive. Of course, the responses were not altogether uniform and the resulting response variance suggests several areas worthy of further exploration. The graphics shown on the previous page illustrate several important findings.

Most families indicate that they are either:

- Always (269 or 52%) or usually (178 or 34%) recognized as a expert regarding their families' needs.
- Always (209 or 40%) or usually (185 or 36%) encouraged to say how their needs should be met.
- Always (242 or 47%) or usually (175 or 34%) have primary decisionmaking power over the supports or services they receive.
- Always (234 or 46%) or usually (141 or 28%) choose who or what vendor provides services.
- Always (219 or 43%) or usually (173 or 34%) have enough control in planning the supports they receive.
- Always (136 or 27%) or usually (214 or 42%) offered the supports needed to meet the families' needs.
- Always (204 or 40%) or usually (153 or 37%) satisfied with the delivery of services.
- Always (153 or 30%) or usually (194 or 39%) get the level of support or services that are needed.

Associated Program Outcomes

Respondents were asked to judge the results of the program based on a series of 16 likert scaled quality indicators, and in terms of program impacts on family placement decisions. Again, there was some amount of variance in the responses, but among the several findings, we found that most families indicated that the program either:

✔ Always (128 or 23%) or usually (172 or 35%) enhanced their ability to meet the needs of their family member with a disability.

✔ Always (144 or 31%) or usually (138 or 30%) helped keep the family together. However, it must be understood that most families (394 or 79%) report that that they had no plans to seek an out of home placement for their family member when they first applied for family support. Families generally expect to stay together with or without formal support. As a result, while the program is appreciated by families, it cannot dramatically effect placement preferences.

✔ Always (156 or 33%) or usually (158 or 33%) made a positive difference in the life of the family.

Next Steps

As informative as these survey findings are, they offer an incomplete view of the circumstances in Pennsylvania surrounding family support. As noted earlier, the findings are not entirely uniform, suggesting several topics worthy of further inquiry. In addition, most would agree that these findings must be carefully examined within a changing federal and state context regarding the overall financing of developmental disabilities services.

In the coming months, a sample of survey respondents will be selected to participate in follow-up interviews. These discussions will be structured to gain further insight into the needs of families, their satisfaction with the current service response, and what might be done to improve the family support system. Next, eight focus groups will be held throughout the Commonwealth to discuss the findings. Finally, recommendations will be offered to OMR regarding what it could do to improve family supports in Pennsylvania.

This project is being sponsored by the Pennsylvania Office of Mental Retardation, although the opinions or thoughts expressed in this Research Brief are solely those of the authors. This project is a collaborative effort that combines the resources of the Institute on Disabilities at Temple University and the Human Services Research Institute . For more information, contact Celia Feinstein (at Temple) at 215-204-6561 or John Agosta (at HSRI in Oregon) at 503-362-5682.