

**The Self-directed Family Support Program
of
New Mexico**

Families' Satisfaction Survey

September, 2005

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■ INTRODUCTION

The Self-Directed Family Support Program provides flexible support funds to a group of New Mexico families who have a child or family member with developmental disabilities. Project participants direct their own spending of the allocated budget of \$2600. Guidance for this is provided by one of the Program's five Family Resource Support Specialists allocated to each family. Ninety-eight families started with the Project in 2001 and a further 48 families joined it in 2002. Thirty more families joined the program during 2003 and 2004 from across New Mexico.

Participants purchased a broad range of services and items, such as: assistive devices, tuition fees, social supports, housing supports, transportation/travel, health care, respite/personal care and tangible personal property. For a fuller account of the administrative and financial arrangements, as well as the actual purchasing choices, see the program's Annual Report for 2004.

Following a survey and report in 2003, which provided a snapshot picture of families' satisfaction with the Program's effect on family life, and with staff support, a more extensive and detailed survey was developed for use in 2005.

■ PROCEDURE

- In June 2005, all 162 families who took part in the program were mailed a 3-page questionnaire (see Attachment 1). Two were returned as undeliverable.
- The first set of questions assessed the effects on the family's situation; questions two and three evaluated the support they received from the family resource specialist; questions four to eight examined administrative issues, and finally the last two

questions elicited an overall satisfaction score, with opportunity to suggest improvements to the program.

- The primary care-provider, normally a parent, was asked to complete the questionnaire, and 80 (50%) were returned for review.
- Participants were mailed a different color survey depending in which of the five New Mexico regions they resided. By this means differences in satisfaction with services between regions could be examined. Between 40% and 60% of the questionnaires were returned from each of the regions – Metro area (43%, 32 from 74 mailed), Northeast (48%, 11/23), Northwest (58%, seven / 12), Southeast (65%, 13 / 20), and Southwest (53%, 17 / 32).
- Surveys were anonymous in order to encourage candid responses.

■ FINDINGS

a) Effects on Family Life

Table 1 shows that 90% or more of respondents are either satisfied or very satisfied with the program's impact on the four aspects of family life addressed in the questionnaire, with an average score of 4.4 or 4.5 for each aspect (where 4 represents 'satisfied' and 5 'very satisfied'). In fact over half of all respondents were very satisfied with the impact on the four aspects: Having a better day-to-day life (59%); Doing more things the family enjoys (51%); Easing some of the family's financial worries (62%); Reducing the family's stress level (52%).

One respondent expressed dissatisfaction with all four aspects of impact. He/she clarified with the comment: *"It's day to day help we need, not a one time amount of money to help."* Another respondent also checked 'dissatisfaction' with easing of family financial worry, even though the accompanying comment included: *".... It came in when needed."*

Table1
Respondents' Level of Satisfaction with Program's Impact on
Aspects of Family Life

Aspects of Family Life	Level of Satisfaction (number of respondents and percent of total responses)					Average Score ¹
	Very Satisfied	Satisfied	No Opinion	Dissatisfied	Very Dissatisfied	
You and your family have a better day-to-day life.	46 (59%)	28 (36%)	3 (4%)	1 (1%)	0 (0%)	4.5
You and your family do more of the things you enjoy.	40 (51%)	31 (40%)	6 (8%)	1 (1%)	0 (0%)	4.4
Ease some of your family's financial worries.	49 (62%)	22 (28%)	6 (8%)	2 (2%)	0 (0%)	4.5
Reduce your family's stress level.	41 (52%)	30 (38%)	6 (8%)	1 (1%)	0 (0%) ²	4.4

NOTE: ¹ Score derived by averaging all respondents' scores recorded for each aspect, ranging from 5 (very satisfied) through to 1 (very dissatisfied).

² Where percentage totals do not add up to 100%, it is due to rounding.

Over half the respondents (42) took the opportunity to comment on the program's impact on their family, and were overwhelmingly very positive in tone. Four examples are listed below:

"It was like a boost to be able to fix our security system, new fence to let him play in the back and wonderful respite time from the daily grind."

"It has been a Godsend! It has allowed my daughter to participate in activities that mean an enormous amount to her, such as skiing and swimming, that would not otherwise be possible. These activities bring her more into the realm of normal involvement in the community."

"This program helped us to realize how much our son needs to go out to do different things instead of just staying at home. He really enjoyed time alone with his father, and time alone with me, bowling and fishing."

"The self-directed program allowed us to have a computer that we have never been able to have. We have had a computer that always would shut down if you entered into a program that wouldn't have enough memory. Now (our daughter) dances with music, and plays programs that she is skilled at."

b) Support from the Family Resource Specialist

Table 2 shows that ALL respondents are either satisfied or very satisfied with the way the Family Specialist shows them respect, listens to their needs, and supports their decisions (apart from one respondent who had no opinion on this aspect). Although three-quarters of respondents were very satisfied with how clearly family specialists explained what the project could or could not do for them, one was dissatisfied, and three had no opinion. Four respondents had no opinion on how the family specialist worked with them as partners, and 13 had no opinion on provision of information about other community resources. In this latter case, just over half the respondents (59%) were very satisfied.

Table 2
Respondents' Level of Satisfaction with Aspects of Support from Family Specialists

Aspects of Support from the Family Resource Specialist	Level of Satisfaction (Number of respondents and percent of total responses)					Average Score ¹
	Very Satisfied	Satisfied	No Opinion	Dissatisfied	Very Dissatisfied	
Shown respect for you and your family	59 (75%)	20 (25%)	0 (0%)	0 (0%)	0 (0%)	4.7
Listened carefully to your needs.	58 (73%)	21 (27%)	0 (0%)	0 (0%)	0 (0%)	4.7
Supported you in decisions.	59 (75%)	19 (24%)	1 (1%)	0 (0%)	0 (0%)	4.7
Clearly explained what the project could and could not do for you	59 (75%)	17 (21%)	3 (3%)	1 (1%)	0 (0%)	4.6
Worked with your family as partners	55 (70%)	20 (25%)	4 (5%)	0 (0%)	0 (0%)	4.6
Provided you with information about other community resources	44 (56%)	22 (28%)	13 (16%)	0 (0%)	0 (0%)	4.4

NOTE: ¹ Score derived by averaging all respondents' scores recorded for each aspect, ranging from 5 (very satisfied) through to 1 (very dissatisfied).

Comments about the family specialists included:

"Talked in detail about family needs and then made suggestions based on the greatest need."

"She offered suggestions and discussed different areas of concern. By just talking she helped us to pursue new avenues of help."

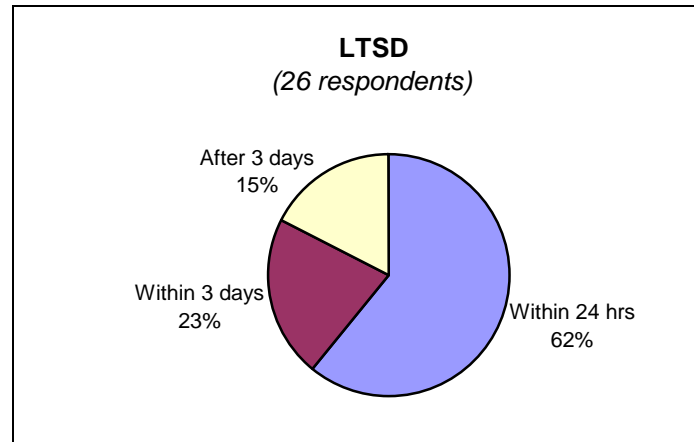
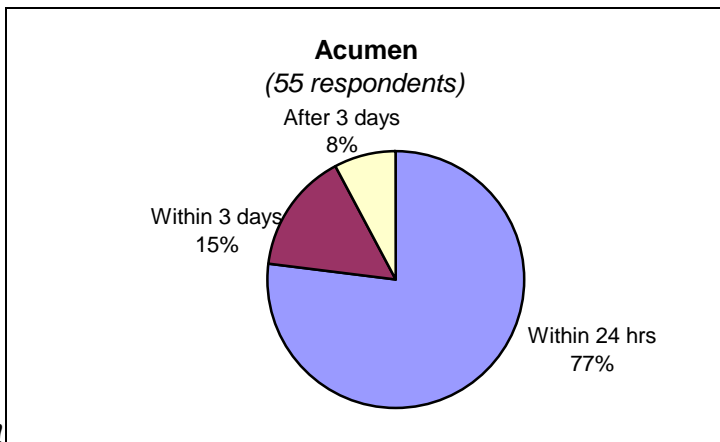
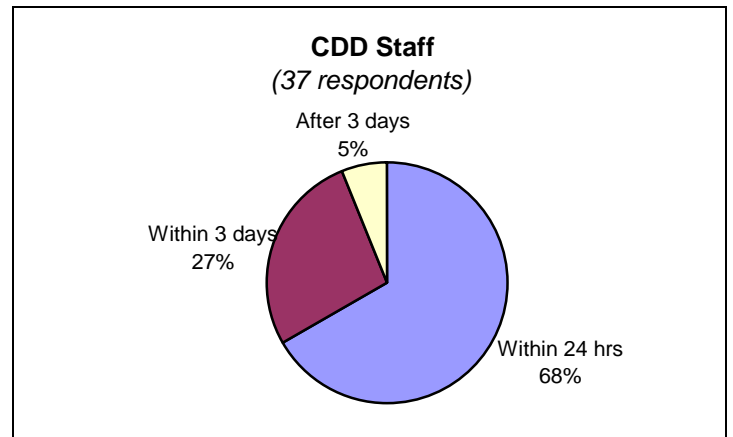
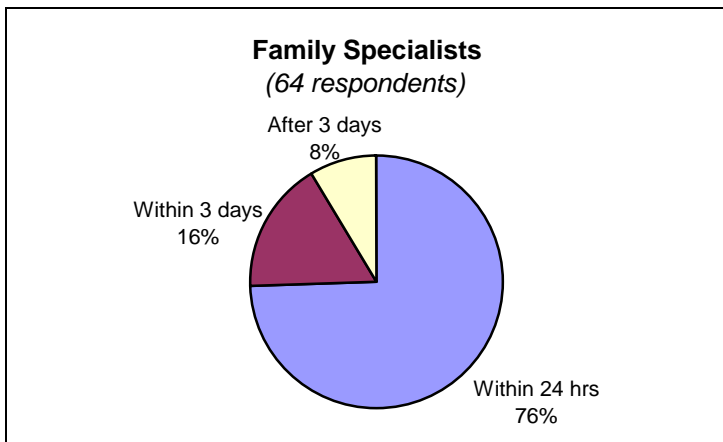
“She gave us many examples of how other families used their money. She asked us what we felt our son needed and what his interests were. She asked our son for his input.”

c) Administrative Support

1. Telephone Calls

Respondents received administrative support from four sources: Family Specialists, Center for Development & Disability staff (CDD), Acumen (the fiscal Intermediary) and Long Term Services Division Regional Office (LTSD). Respondents were asked about the speed with which their calls were returned, and whether they were satisfied with the help and information provided.

Figure 1
Speed of Return Calls from each Level of Administration.



Error!

Only individuals who made a call to any of the four organizations responded to these questions. Figure 1 shows that over 90% of calls were returned within three days, apart from those made to LTSD, where 85% of calls were returned within three days.

Figure 2 below illustrates respondents' level of satisfaction with the help and information provided by telephone.

Figure 2
Respondents' Satisfaction with Help and Information Provided by Calling Each Level of Administrative Support

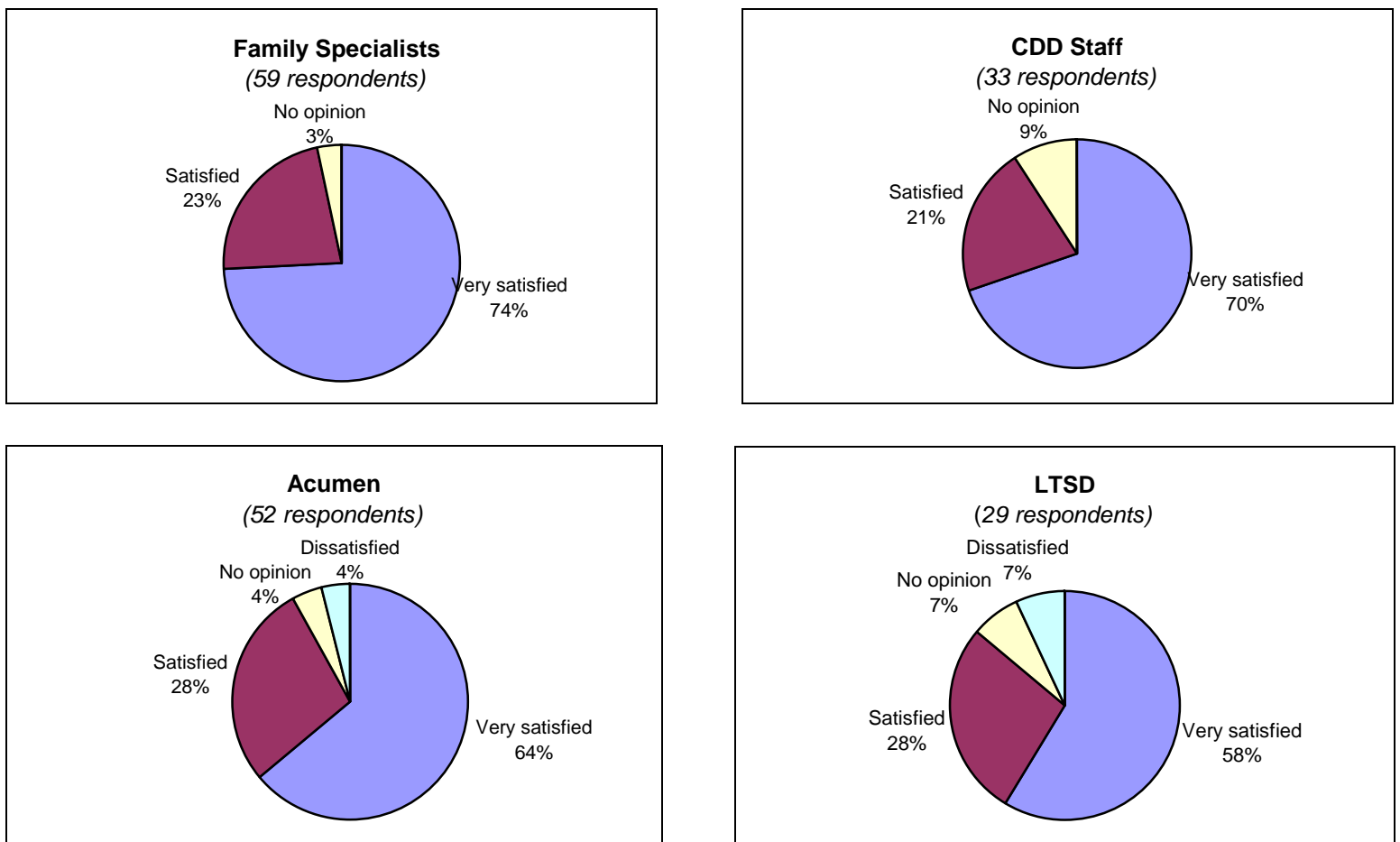


Figure 2 shows that again over 90% of callers were either satisfied or very satisfied with the help and information provided. Least satisfaction was expressed about the service from Acumen, with two respondents giving their service a 'dissatisfied' rating, and five respondents commenting as follows:

"I had to have two separate calls to Acumen to get the answer I was needing."

"I had to call Acumen a few times about one subject because the person did not take care of the situation the first time."

"Acumen was not clear on what paper they needed for repeat forms. In fact I had to send them the paper 4 times to them by fax."

"The person I talked to at Acumen was very unfriendly (phone conversation)."

"Through the 3 years Acumen has alternated between good smooth management vs. complete disorganization. Right now it is operating fairly smoothly, although I'd like to see all the staff there more trained in listening and being more empathetic rather than oblivious (at times)."

All other comments (20) about the general level of service from the other three organizations received by phone were very positive, apart from one explanation of some misunderstandings:

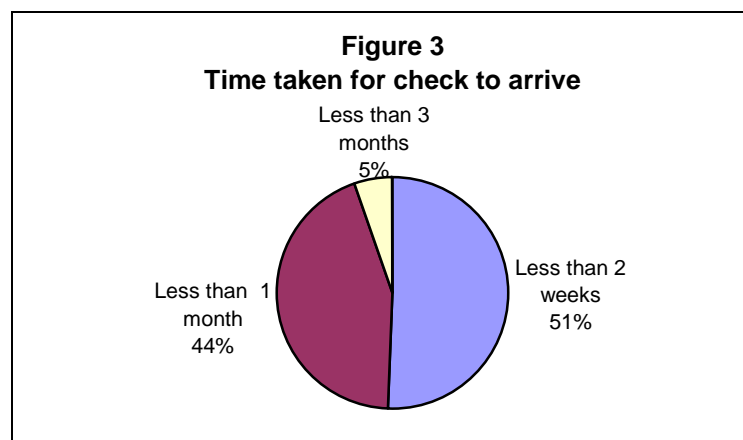
"There was a misunderstanding on how to document something which caused delays and other people were affected by this."

and another complaining about the attitude of a named individual at LTSD:

"I was very unhappy with She was very curt and abrupt with me."

2. Check's Arrival

Respondents were asked how long after submission of paperwork the check arrived. Figure 3 shows that 94% of checks arrived within one month (around half arriving in two weeks), and that no-one's check arrived after three months.



3. Items Denied

Only six respondents stated they had their initial request for items denied them. Two respondents did not specify what they had requested, but of the other four, only one person, who had requested that their check amount be placed in a special needs trust stated that the family did not know why this request had been denied. One family made several requests – gasoline, a range/oven, a storage shed, and a water heater – all of which were denied on the grounds that they were not related to the welfare of their son. One family requested a bathing chair, which they were told could be paid for by their insurance company, and another asked for money for trips and, in this case, was told that they should request a more tangible item.

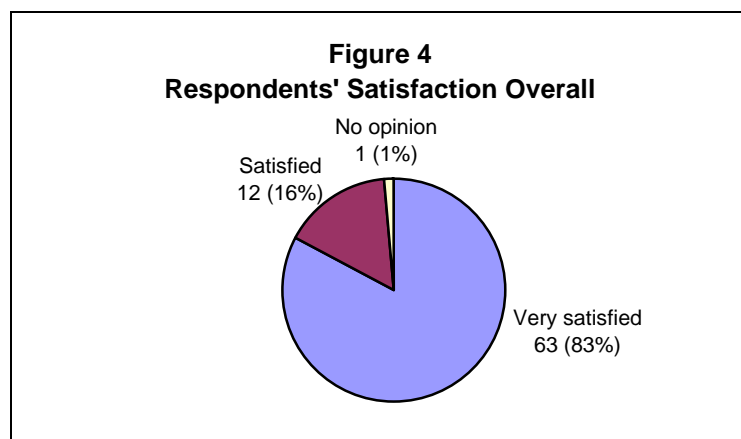
d) Overall Assessment of the Program

1. Overall Satisfaction

Respondents were asked to express their overall satisfaction with how the program had worked for their family, on a five-point scale from Very Satisfied through to Very Dissatisfied.

Four respondents missed checking this question's options, but Figure 4 shows that of the remaining 76 respondents, 63 (83%) were 'very satisfied' with the program and 12 (16%) were 'satisfied'. No one expressed dissatisfaction, but one respondent expressed 'no opinion'. This respondent's accompanying comments indicate that:

"We are new to the system We are still learning and trying to figure out what's available that our disabled daughter is interested in."



2. Suggestions for improvement

Finally, respondents were given the opportunity to suggest improvements to the program. Fifty-two respondents took the opportunity. As would be expected with a program where the satisfaction rate is so high, the comments were very positive in tone, and 31 respondents used the space provided merely to express their appreciation with no suggestions for improvement. For example:

"I have no suggestions as to better your program but I would like to say thanks again, everyone was wonderful!"

"This program came as a surprise. We were so glad to have extra money to help out with my son's diet, van repairs, and travel expenses. I can't really think of any improvements needed. Thank you so very much!"

"This has been a wonderful gift for (our son), as well as his family. There is no way I could have done for him what you guys did. Thanks!"

"Very thankful and very satisfied. Thank you very much and may God bless you like he has blessed us with this program."

Other respondents came up with some comments/suggestions about the service. These mostly centered on i) time available for the process and ii) budgeting. A third group reported actual or potential weaknesses in the service.

(i) *Time available*: Five respondents reported feeling rushed to make decisions, without having time to fully understand the process:

*"When the meeting took place the service coordinator seemed to be rushed. So **the people still had some questions and felt rushed to make some choices.**"*

"A little bit slower when explain all paper work."

*"I didn't find out about the program until November. At first I thought I had 10 months to send my allotment, but it ended up being about 3 months. I think if there was **more time** or better ways of communications with my resource specialist, it would be less stressful."*

*"Written information outlining the different organization and what they have available would be helpful. The seminars in Albuquerque would be more helpful if **more time** was given for participants to just talk about what's working for them locally. It doesn't really help me personally to find out what someone in Michigan is doing. The institute needs to be geared more for parents & families and not just agencies. Overall the institute is beneficial."*

*"**Time frame** - my family had two months to decide."*

(ii) Budgeting and money concerns

These included:

“More clarity (is needed) on when money needs to be spent. We were suddenly put onto the DD waiver while just starting the program and there was confusion/conflict between getting all the paperwork in and still thinking we had 6 months to spend on the Self-Directed Program. If you are on the (waiting list for the DD Waiver) registry & your name comes up, (your program should) inform people that money needs to be spent immediately & that the proper paperwork for DD waiver should wait until receipts have been turned in. We almost lost the money but managed to work things out so we benefited. This program is great because of the flexibility in spending on things that are important to our personal requirements. Thank You!”

“I would like to know how I can **account for this money come income tax time**, is there a special form? (My daughter) doesn't get any other income.”

“If the program could start a little earlier, then **money could be spread out more months.** Thank you very much!”

“Perhaps a **total payment could be made** based on approved budget items. **Instead of having to submit periodic request for payments** based on budget items - this could be deemed a selective, trust basis.”

“Having to get **voided receipts is a bit difficult**, also that doesn't guarantee that the items will be available. Also **some families do not always have the money to set up layaways** to be sure the items are still available. Also it's a little hard when a **family has to spend money to fax the papers**, and mail takes too long. But overall it is a wonderful program to help families.”

“I had a hard time convincing **merchants to write "invoices" without payment** and it was equally **difficult to get them to accept the Acumen check** without a waiting period.”

“It would be very helpful to **have a seamless transition from one budget year to the next.** Right now there seems to be a gap of no services between July 1st and late September. This is very hard if one of the budgeted items is respite or job coach/attendant staff. Staff hours never end so it is tough to have a gap. If need be, **develop a new budget in May so it could be approved by July 1st.**”

(iii) Miscellaneous comments/suggestions

“Walmart Store on Coors NW were very rude - they did not want to accept the check. Please inform them about your program because they did not believe it's real.”

“I believe some families may need assistance getting services or items they need. Examples - going to a store to purchase a computer, calling contractors for remodeling. We did not need this kind of assistance but I know families that would need it.”

“Make sure the specialist has all the paperwork at time of visit rather than through correspondence.”

“Written information outlining the different organizations and what they have available would be helpful.”

“My disabled daughter has attended (meetings) with me, but she is very bored and doesn't enjoy the ‘mapping’ and ‘path-finding’ “.

■ ISSUES FOR CONSIDERATION

Issues that program managers may want to consider include:

- Several respondents referred to the ‘paperwork’ and how rushed they felt to make decisions. Program managers and family specialists may consider ways in which they can make the initial procedures even more user-friendly for new participants.
- One respondent, new to the system, suggested *“Written information outlining the different organizations and what they have available would be helpful”*. Program managers may want to work on this option.
- Several respondents also referred to financial concerns such as: the gap between July & September when no checks are issued; tax accounting; flexibility in dispensing the money, namely as a total payment or spread over many months; difficulty with voided checks; etc. Some of these issues may have been considered already, but the respondents’ comments on budgeting and finances (pp. 11-12) should be reviewed to ascertain whether any could, or should, be incorporated into revised procedures.
- One respondent referred to the ‘mapping’ and ‘path-finding’ activities, saying their “disabled daughter” did not enjoy them. Program managers may want to ask questions about this part of the process in future surveys.
- There is a slight impression that occasionally participants feel demeaned when they try to get their checks accepted, such as in the respondent’s experience an Albuquerque Walmart, and having to get voided receipts, or ask for layaways. This may be an issue that improves with time as various stores and organizations become used to the program.

Overall, it is clear that the Program is running very well. There is widespread satisfaction among its participants, so much so that one of the goals of this evaluation – to determine differences in program quality between regions – is virtually impossible to

discern, since there is such uniform satisfaction both with the service provided by the family specialists, and the program in general.

SELF-DIRECTED FAMILY SUPPORT PROGRAM OF
NEW MEXICO

Please answer the following questions about how the program worked for you and your family in the following areas:

(Please check the box, which is closest to your opinion)

Impact on your family

1. Are you satisfied that the items and/or services received from the project have helped:

	Very Satisfied	Satisfied	No Opinion	Dissatisfied	Very Dissatisfied
a) You and your family have a better day-to-day life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) You and your family do more of the things you enjoy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Ease some of your family's financial worries.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Reduce your family's stress level.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

e) Please write below if you have something else to say about the program's impact on your family:

Support from your family resource specialist

2. Are you satisfied with how your family resource specialist has:

	Very Satisfied	Satisfied	No Opinion	Dissatisfied	Very Dissatisfied
a) Shown respect for you and your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Listened carefully to your needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Supported you in decisions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Clearly explained what the project could and could not do for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Worked with your family as partners?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Provided you with information about <u>other</u> community resources?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continued on next page

3. Please describe in the space below what ways your family resource specialist helped you decide how to spend the money?

Administrative Support

4. On average how quickly did the following people or organizations return your calls when you had a question? If you did not call, check the first column.

	Did not need to call	Made contact within 24 hours	Made contact within 3 days	Made contact after 3 days
a) Family Resource Specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Center for Development and Disability staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Acumen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Long Term services Division Regional Office	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

e) Please write below if you have something else to say about administrative support:

5. When you called the following people or organizations how satisfied were you with the help and information you were given? If you did not call check the first column.

	Did not need to call	Very satisfied	Satisfied	No opinion	Dissatisfied	Very dissatisfied
a) Family Resource Specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Center for Development and Disability Staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Acumen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Long Term Services Division Regional Office	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

e) Please write below if you have something else to say about the help and information given you:

Continued on next page

6. How long did it take your check to arrive after you submitted the paperwork?

Less than
two weeks

Less than
one month

Longer than
one month

Longer than
three months

7. Did you ask for items or services that you could not get? YES NO

If you answered NO, please go to question 9. If you answered YES, please continue with question 8 below:

8. *In the space below please list all the items or services you asked for, but could not get, and state the reason you were given (if you know it):*

Item or service	Reason given for denial	Do not know the reason (please check box)
_____	_____	<input type="checkbox"/>
_____	_____	<input type="checkbox"/>
_____	_____	<input type="checkbox"/>
_____	_____	<input type="checkbox"/>

Overall

9. Overall, how satisfied are you with how the program has worked for your family?

Very satisfied

Satisfied

No opinion

Dissatisfied

Very dissatisfied

10. Please help the program managers improve their service by making some suggestions in the space below.

THANK YOU VERY MUCH FOR YOUR TIME