Dakota County Account Management Project

I. Introduction

Dakota County, with support from the Governor's Planning Council on Disabilities, has developed and implemented over the past two years a project designed to place more control of service decision-making and government funds in the hands of families of children with disabilities rather than with county social workers.

Concerns of parents regarding service cost, effectiveness and quality of county-contracted respite care provided an impetus for this project.

"The seed of the account management project was families' dissatisfaction with the respite care they were receiving through county-contracted agencies. As county staff heard from many families, the countycontracted respite providers were too expensive, and were not flexible enough with their schedules. Families also complained that frequent personnel changes disrupted any continuity of care. families with more than one child found that these providers would only look after the child with disabilities, so they would have to hire a second caregiver for the rest of the family just to go out to dinner. With such a litany of complaints, families saw the project as a way to get respite care services from providers other than the county contractors." (Final Report on Dakota County Account Management Project, p. 1).

The second year of the account management project (formerly the Dakota County voucher project) included three key differences from the first year of operation:

- The project participant size expanded from 12 to 25 families.
- The project included families whose members with disabilities were over 18 years of age.
- The project included eight social workers in addition to the social worker from the first year.

II. Evaluation Overview

In addition to the evaluation activities of Dakota County staff, a survey questionnaire including a stamped, self-addressed envelope was mailed in 1992 by the external evaluator to all Year

1 and Year 2 participants (two parent families received two questionnaires). The evaluation was conducted in 1992 in order to insure that all participants had been involved in the project for an extended period of time. Of the 43 questionnaires 18 or 43 percent were returned. Since each parent received a questionnaire, it is likely that in some instances only one questionnaire was returned from a two-parent family. While the perspectives of non-respondents might be similar to those who completed the questionaire, it is uncertain how they would have responded.

The questionnaire included three structured or close-ended items, and ten open-ended items. The main areas covered included:

- Overall evaluation of project
- Overall evaluation of project's effectiveness in assisting parents in service management
- Satisfaction with service provider arrangements prior to project participation
- Main reasons for project participation
- Impact of project on service management
- Impact of project on child and family
- Impact of project on emotional, physical and financial strain
- Most important aspect of project
- Conditions for returning to previous service arrangements
- Recommendation of project to other parents
- Additional comments on project

III. Evaluation Findings

The key findings of the evaluation are presented in the following pages. For many of the questionnaire items, responses of the parents are given providing a more realistic, sensitive and authentic voice.

Participants were first asked how they would now evaluate the Dakota County Voucher project. As seen in Table 4, all responded either "excellent" or "good".

Question: Overall, How Would You Now Evaluate the Dakota County Voucher Project?

	Year 1	Year 2	Total
	· # %	# %	# %
Excellent	8 100.0	7 70.0	15 83.3
Good	0 0	3 30.0	3 16.7
Average/Fair	0 0	0 0	0 0
Poor	0 0	0 0	0 0
Very Poor	0 0	0 0	0 0
Total	10 100.0%	8 100.0%	18 100.0%

Next, participants were asked their evaluation of the voucher project in assisting them to more fully participate in the management of services for their child. Again, all of the participants responded "excellent" or "good". Table 5 presents these results.

Question: Specifically, How Would You Now Evaluate the Dakota County Voucher Project in Assisting You to Participate More Fully in the Management of Services for Your Child with a Disability?

	<u>Year 1</u>	Year 2	Total
	# %	# %	# %
Excellent	8 100.0	6 60.0	14 77.8
Good	0 0	4 40.0	4 22.2
Average/Fair	0 0	0 0	0 0
Poor	0 0	0 0	0 0
Very Poor	0 0	0 0	0 0
Total	10 100.0%	8 100.0%	18 100.0%

When asked about their satisfaction with provider arrangements prior to enrolling in the voucher project, about thirty percent (27.8%) indicated that they were either "very satisfied" or "satisfied". Approximately two-thirds (61.1%) stated they were either "dissatisfied" or "very dissatisfied". These findings are given in Table 6.

Question: Prior to Enrolling in the Voucher Project, How Would You Rate Your Overall <u>Satisfaction</u> with Your Provider Arrangements?

	Year 1		Yea	r 2		Total		
	#	ક	#	8	#	क्ष		
Very Satisfied	1	12.5	1	10.0	2	11.1		
Satisfied	1	12.5	2	20.0	3 '	16.7		
Dissatisfied	3	37.5	4	40.0	7	38.9		
Very Dissatisfied	3	37.5	2	20.0	5	27.8		
Don't Know/Uncertain	0	0	1	10.0	1	5.6		
Total	8	100.0%	8	100.0%	18	100.1%		

^{*} Does not equal 100 percent due to rounding.

Additional comments made by parents regarding their satisfaction with previous provider arrangements are given below.

"Could not find providers to take care of our children."

"Very high turnover rate, undependable, lack of privacy."

"We felt very restricted in our options. We feel that we have been allowed more freedom to choose what best fits our needs."

"I really was never unsatisfied. I just knew there must be a better more economic way."

"We did not feel comfortable with all providers as most of the time they were complete strangers to us."

"High turnover - and long waiting list for items needed."

"A cycle of who's responsible and red tape."

"I have always enjoyed working with Dakota County."

"Didn't know the options of help I could get. Didn't know what things I could get assistance for."

"Our family made very little use of programs or services before the voucher project."

"Not enough options."

"We had about five weekend respite care per year."

"There was a lack of homes available, so it was hard to use your allotted funds."

Main Reasons for Participation in Project

Next, participants were asked about the <u>main</u> reason(s) they first decided to participate in the Dakota County Voucher project. Their responses are given below.

"We <u>asked</u> to have a voucher years ago because the service system was not meeting our needs. Also, we live in a rural area on the edge of the county, and couldn't get providers."

"The idea to be more flexible with our money to make our son's life as fulfilling as possible. Also to do extra activities for his sister who sometimes feels left out."

"I was frustrated by county programs that were good intentioned, but didn't meet our family's needs."

"Problems with agencies in receiving care for my daughter. People were late, or new people sent (my daughter is not good with "new" people) or people never "showed"."

"I wanted more control over who were our caregivers and I felt that this program could save money."

"To provide staff who were really interested in working with our son and are dependable."

"Because of the elite disability of my young person, it is much easier for us as a family to find or provide the services - also we like to be able to directly contact - much more personal and <u>less</u> tense for all."

"To be more directly involved in decision making regarding purchasing supplies and finding services for my child. Also I viewed it as a money saver."

"Knowing I could get help of my choosing."

"The Voucher Program was an option to a group home placement for our child."

"I felt we had more control of the providers that our son would be with and the types of activities he would be involved with."

"To evaluate our child and family needs - and to decide what is best for us."

"We wanted the opportunity to manage the services and equipment that our child needs. Prior to that we felt that we had limited opportunities to actually research and manage those services."

"As a single parent, I lacked the funds to provide social experiences with myself and with peers for my child."

"There was absolutely no way the traditional service delivery plans would work for our child due to complicated medical considerations."

"I was never able to get the respite care when I needed it, I had to use respite care where there was an opening, and I was also very unsatisfied with the homes that were available."

"It gave us the power to use the funds as we saw best within reason."

"With its flexibility and individual options, it filled the gap that other programs didn't."

Impact of Project on Service Management

Participants were also asked to describe the impact of the project on their management of services. Several of their responses are given below.

"We feel more control of the situations - means more work for \underline{us} , but the learning of knowledge and how it works is \underline{well} worth the time."

"I'm able to pay for what the services are worth to me; not the fee schedule the system has set up. I'm able to shop around and price things for a better deal."

"We have become much better at researching the provider services - finding those that more closely blend with our family styles and expectations for our daughter."

"Flexibility is the single most important factor. We've been able to choose caregivers and pay them without never ending paperwork (like the county required)."

"I have the say in services I choose. I'm the one who knows what I need help for - no one else does. And if I'm unhappy with the service - I can change things - I'm more in control."

"Priority over items needed. My daughter has a power wheelchair. We used the voucher money to ramp our house. Next item is a van lift - then computer for our daughter."

"Money can mean freedom - I saw my child use it for her personal wants - going into a store, picking out and paying - she may not be sure of the cost and what amount she has to pay, but it was her experience of choice, want and having it fulfilled."

"We just started the program. We will be putting most of our funds into a van needed to transport our son's adaptive equipment and wheelchair. This will be great that we can now take all the extra equipment to make vacations easier."

"We have hired our own caregiver for vacations and could have someone we knew who was comfortable with our family."

"I can hire who I want, people I can trust to be there. Also, people who discipline the way I do. Because I could hire a family member this ended a lot of arguments when asking my older children to do daycare."

"We have been able to increase our respite provider network; use people we know and trust who have special interests - love for our child; and we have found a unique and very needed way to include all of our family in our child's life."

"It has assisted us in a clearer understanding of programs, their function and how we can be within the "system" and still meet the needs of our child."

Impact of Project on Child and Family

Next, participants were asked to describe how things have been different for themselves, their child and/or their family since participating in the voucher project. Several of their responses are noted below.

"For us as a family, the "best" difference is <u>less stress</u>. Not having to argue for a <u>need</u> but to weigh it yourself and be responsible. Of course, the flexibility of the funds allow this. Doing things as a family can be expensive - sometimes members are left out. Now the sibling with the disability (that mom and dad spend more time and money on) can treat for an event that includes all - a value not a handicap."

"We are happier. We can go out to dinner, as a family. We have the support people we need, when we need them. We have a little extra money to play with. We are starting to be able to look at what our daughter really needs."

"It has created an environment that does not put my needs against her needs."

"We can do things our other care hours allotment would not permit, especially in the summer when our other child has a lot of sports in the evenings."

"There has been a lot less arguing in the house because of the voucher. My daughter would watch the same movie over and over again. I think it takes her this long to understand the film. With the voucher funds, we were able to buy a TV with a VCR built in. Our daughter would also stand at the end of the driveway and watch the other kids on bicycles, now that she has a special bike that looks like an adult tricycle, she can join them. It's great to see her join the other kids. As I write this she's at the local high school weight room - getting stronger physically and emotionally by learning to be a social being."

"Don't have to worry so much about where the money is coming from and what items we can only get - our quality of family life has been better - our daughter can be included in more family functions and she has more independence."

"We really enjoyed the training meetings and the networking with other families. Prior to our participation, we had limited funds and opportunities available to us. We could not afford many leisure activities - taking our child into the community for family dinner and movies, for example. We have made some very worthwhile purchases. For example, we bought a sturdy swing for our patio so she could be outside

with us. Yet not have to stay in her wheelchair. We also purchased a video recorder, so we can capture special outings, events, and even activities that she has participated in. We also tape therapy activities - these have been very helpful for school personnel, and new PCA's working with us."

"We have more outings."

"Increased freedom for the whole family. Lower stress level - I know my son's workers will be here and my husband and I are able to have time alone weekly which is very important."

"We have felt more in control of our own destiny in our commitment to our child's care. We've had a strong desire to do this, but had become frustrated at lack of support."

"It has enabled us to meet the needs of our child without sacrificing the needs of our family."

Impact of Project on Emotional Strain

The study also attempted to learn about the project's impact on the strain experienced by the parents. First, they were asked how participation had affected the amount of emotional strain that they experience as parents of a child with a disability. The overwhelming response was that the project significantly lessened the stress. Their responses are given below.

"I know our vacations will be fun because we choose our own caregiver. This helps with stress."

"Yes. I am able to get away for a while - knowing I have the means to get away even helps. Sometimes I am unable to deal with the pressure - and knowing I have an "emergency" plan to help me cope helps enormously."

"Very much so, as we get family relief as well as individual relief knowing he is cared for away from us as best we know how to."

"Yes - it has <u>lessened!</u>"

"Having a child with severe disabilities tests emotions daily. Our opportunities to get relief from those daily stresses are rare. We try to arrange time for us as a couple by arranging for respite time for our child. We can have her and her respite person go to a movie or a play, etc., while we might spend time together or with our other child."

"Definitely, not only as a parent, but on his brothers also. We used to have to use County facility home for respite and my sons didn't like him going there and asked me not to take him, they would rather not have respite than take him there."

"Yes, it has helped a great deal. We have less stress in the house. Also, we have a lot more options in the care for our child."

"I hope it will, anything like this <u>should</u> help. We hope to go more places, even without the children, to just get away from all the daily demands."

"Emotionally, finding and picking people you know is of great comfort. Also, paying vs. favor thing is important. The family participates and can be of value (pay equity) not just relying on parents only."

"It has decreased the strain as I know the people coming to my house and feel they are an extension of the family and not strangers."

"Yes. Because the voucher is <u>there</u> to allow choices, it allowed for some now things rather than always have to be ready for the tomorrow things."

"Very much so, we were able to send my other child to camp to get away from our daughter with mental retardation. Also, to hire a companion to play games with her after school and on weekends. Also, purchasing a fire window she can open in an emergency."

"Yes - the paperwork at times has been overwhelming, but the feeling we can get what we need for our daughter makes up for that."

"Yes - it has extremely lowered our stress - we can cope better."

""Very much. I feel more part of a team with the same goals
in sight."

"Yes, when I feel overwrought - I know instead of feeling at a loss, I can search for ways to help - whether it's babysitting or respite - I have an out."

Impact of Project on Physical Strain

Next, participants were asked whether the voucher project has affected the amount of physical strain they experience. Many of their responses are presented below.

"It takes a tremendous amount of energy caring for a child with a disability, and there are many times when you have no more energies to cope, and then you can provide him and yourself with help."

"Many of our purchases have focused on our child's becoming more independent - both functionally and physically. Our child is non-mobile - she has made many gains in her ability to ambulate - so physically in the true sense has become much better."

"The physical and emotional strain is there but the increased number of outings helps."

"I feel it will, I hope to have family members help more with our son. I won't feel I am burdening them if I can pay them. I know then he's in good hands."

"Not much effect."

"Yes. Some of the funds have gone for labor to paint my house. (I am a single mother) and cutting the grass. I could just as well hire caregivers for my daughter - but would end up spending the same amount of money (while I did the work)."

"It has lessened it as we are able to purchase more hours of care and our son requires quite a bit of physical care."

"The physical strain has never been so bad, as she is mobile."

"No."

"We were able to purchase linen, more expense quality items that last longer because of her accidents. The next big need would be a sink like a hairdresser's, to be able to wash her hair without getting water in her ears, because of her ear infections."

"Yes, I've been able to arrange for more help and have purchased equipment to accommodate his growing size."

"Hopefully with the use of funds, I will be able to purchase more equipment - have adapters to lessen the physical strain."

"Yes, and in the last year he has passed me up in height and weight, I'm able to have help with the bathing."

"Yes. By constructing a ramp, reduce back strain and an accessible bath reduce stair climbing."

Impact of Project on Financial Strain

When participants were asked if the project has affected the amount of financial strain they experience, the majority of respondents indicated that it had. Their responses are noted below.

"Because the opportunity for "earned income" is so limited, it allows my child to do and have some of the opportunities "regular" teens get to experience with their job salaries."

"Very much - his disproportionate expenses had become a source of financial and emotional stress."

"Definitely - It has lessened it."

"Yes! We feel it will help a great deal. Anything helps when dealing with a child with special needs."

"Yes, I know the extra hours are there when I need them."

"Yes - Our young person is not a child - she is over 18 - we've always made payments and improvised."

"Yes. I would not have the funds for respite."

"Yes - We know how much money we are going to have to spend."

"We are very limited financially and through the voucher we have been able to purchase items for our daughter that we could never have afforded on our own. However, these things make a very positive impact on all of our lives. We also have more opportunity to take her horseback riding or send her to camp, or other community activities that we could not otherwise afford."

"Definitely, it has helped our finances immensely."

"Absolutely!"

"Yes, it's one less worry that he'll have things he really needs."

Most Important Aspect of Project

Participants were asked what one thing about the voucher project was most important to them. Major themes flowing through their responses included more control in decision-making regarding providers and services, increased flexibility in use of monies to better address the specific needs of the child and family, reduction of stress, and empowerment.

"The empowerment of the funds to do what is best for our child and family. We can make the decisions."

"Funds for respite and the fact that I can hire <u>anyone</u> I feel comfortable with. My choices are not limited to only a couple agencies who offer only a couple of people. I can hire people who know my daughter."

"I can't believe all the help there is in the Dakota County area. This program is going to make us feel we can do the best to make our son's life great even being disabled."

"Being "in control" which is not always the case in the social service system."

"Ending the arguments, over our daughter, whether it's her behavior, the money, her watching the same TV over and over,. Our house is a lot quieter now. Some days it almost feels like a regular house."

"Flexibility and/or usage of money to fill need - allows for family breaks and family unity."

"Having the flexibility and control of providers and services and entertainment when you plan each month."

"The financial opportunities - we can purchase things that are great for our daughter. We recently purchased "ablenet" switches, so she can help me in the kitchen and have some more choices for her to make."

"The ability to choose what our family needs to most enable us to follow through on our commitment to care for our child."

"Management of the funds and seeing the positive results first hand."

"We can chose our sitters, siblings of our child and our friends now get paid."

"Being in control of that part of our lives. The lack of control was very stressful."

"The freedom to pick and choose!"

"The <u>flexibility</u> to meet our needs. Also, we feel there's less waste - there weren't any checks and balances in the old way - sometimes the bills submitted to the county by the agencies were wrong."

"Allowing to make our own choices and prioritize our own families needs - to have services available immediately when we need them."

"The self-empowerment. Also, as part of the voucher, we receive mailings that include excellent information. We live outside the twin cities areas and wouldn't hear about some programs unless they were sent to us."

"The flexibility."

"The creative approach to each family as a separate unit."

Conditions for Returning to Previous Service Arrangements

Participants were also asked under what conditions they would consider returning to the previous way the county provided and paid for services for their child. The responses noted below indicate their overwhelming desire to not return to the old system.

"This is difficult because the current program has brought us so close to ideal. We would prefer not to go back."

"Having a guarantee that the providers would be here when I need them. Also, that they would discipline the way she needs to be to avoid inappropriate behavior."

"I wouldn't want to because it would cut our hours and raise the respite hassles."

"Would not - we'd be doing it alone again. County services burn a person out trying to get information through the paperwork maze."

"It is difficult (really) to say because we feel so fortunate to be able to participate. I suppose if we had more flexibility with management of funds."

"Only if I could still get caregivers of my choosing."

"Would not like to at all."

"Never."

"Only if forced to do it!"

"None that I can think of."

"Of course I would go back to the previous way and be thankful for the county help. But I would not want to."

"Force of the system. The traditional service would be impossible to utilize based on our child's medical needs."

"We are happy with present conditions."

"Because I did not involve us in the county programs before this program was offered to us, I can't compare."

"Only if forced to by lack of options. I'm not sure our family could function under the old system."

"I can think of none."

"That I be able to use my own choice of respite homes. Have respite when I need it."

"Would not like to at all."

Recommendation of Project to Other Parents

When the participants were asked if they would recommend this voucher project to another parent of a child with a disability, all responded affirmatively. Several of their responses are given below.

"Yes and I have to several parents - some were accepted."

"Yes - definitely."

"Very much."

"Yes, provided they are willing to spend the time and energy it takes to hire and organize your respite and other services."

"Yes!"

"Yes, yes, yes."

"Definitely."

"Yes, unless they need strict structure."

"Yes, with some training."

"Yes."

"Yes - but due to the necessity of money management, it would not be appropriate for everyone - could reduce services for some families."

"Yes, and I have mentioned it to other families."

Additional Comments by Participants

Finally, the participants were asked if there were any other comments they would like to share regarding the voucher project. Their comments, which were very positive, are noted below.

"We are fortunate to be in the project - it has given us better management skills."

"In our child's 12 1/2 years, this has been the first program that has encouraged and supported us in our attempt to continue caring for our child."

"It made a difference in our lives at a time when we were at a crossroads. Can we meet his needs? How will we do it? How can we afford it? The Voucher Project gave us a green light to move ahead together instead of apart. Thank you.

"Great, keep it going!"

"I appreciate the county case managers being involved and available for questions and thoughts, but letting us decide."

"It's been a real lifesaver."

"We are very happy with this project and feel fortunate to be a part of it."

"We've enjoyed the training sessions and the chance to get to know many other families involved in the project. It has been great!"

"I am certain our son would be in an out of my home placement if the voucher program had not come along."

"I would like the "categories" to include other items, as needs of "teen", "adult" persons with disabilities are different than the youth or infant children with disabilities."

"I feel Lura Jackson and Meg Grove are excellent leaders for this project."

"It's also been a positive effect for my respite parents and their children to influence and care for a special child. It's made a difference for their small children, some kids are scared of these kids but they come to him."

IV. Summary

The findings of this evaluation indicate a very positive assessment of the project by the parents who responded to the mailed survey questionnaire. Some of the highlights are noted below.

- Parents gave an overall high rating to the project.
- Parents also gave it high marks on assisting them to more fully participate in managing services for their child.
- Parents reported considerable dissatisfaction with the county provider arrangements they had prior to the project.
- Several key themes run through the evaluations of the project:
 - it increased flexibility in the use of monies and enhanced accessibility to a range of providers thereby allowing parents to more effectively address the needs of the child and the family in an individualized, timely manner.
 - it lessened the strain (especially emotional strain) experienced by parents of a child with a disability.
 - it empowered parents by providing them with more choice and control in service decisions affecting their child and the family.
- Parents reported overwhelmingly their desire to not return to the previous, traditional county arrangements.
- All parents reported that they would recommend this project to another parent of a child with a disability.

After two years of involvement assessing the Dakota County Account Management Project, this evaluator finds it to be an exciting and innovative initiative. The project takes a refreshing, bold, yet considered initial step in rethinking and redesigning service management at the county level. It speaks loudly, and with a humane voice to issues of flexibility, accessibility, choice, effectiveness, and partnerships. Also,

this project acknowledges and responds to the reality that families, not formal service providers, are the main source of care and support for children with disabilities, and that government needs to more effectively work in partnerships with families. The Dakota County Account Management Project has offered a new perspective, perhaps a new vision to the redesign of human service systems.

Situa- tion	:	child #2	child #3 	Child #4 	Child #5	child #6	Child #7 	Child#8 	[child#:9	child #10	child #11
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Client Age(\$)	11 yrs	7 yrs	13 yrs 	14 yrs	2 yrs	2 yrs	13 yrs	11 yrs 	 11 yrs	9 yrs 	6 yrs
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client	non-verbal	controlled		İ	diapered	į	į	gastro	İ
	non-mobile	seizures	İ	Ī	İ	i	į	tube	i
	ii	i	Ì	i	İ	ì	i	i	i

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Situa- tion	Adult #1	Adult #2	Adult #3	Adult #4	Adult #5	l
I	<u> </u>	<u> </u>		<u> </u>	<u> </u>	<u> </u>
 Client		l J 18	l 19	[] 20	l 20	! ! ! !
Age(s)	 	<u> </u>	 	\ !	{	}
#,ages	i		<u> </u>	İ	İ	1
other	1	ľ	Older	two-	foster	i 1
child.	1	1	brother	12, 19	care	1
at home 	 	} !]	1]	! ! ! !
'' 	Severe	Moderate	Koderate	Severe	Profound	MR
Devel.	MR, CP,	MR	HR	MR,	MR, non-	! !
Disab.	non-verbat	1		legally	ambulatory	1 1
of	1	1	1	blind	non-verbal	1 1
child	ļ	ļ	ļ	1	!	!!
 		SSI or	l I	- 	MA, SSI,	
State	L MA, SSI	•	MA, SSI	 MA	RSDI	
Asst.	i	i	!	i	i	i i
ii	İ	i	i	_i	i	ii
 Amt. of	 \$1,800	 \$2,976	 \$5,028	 \$4.620	 \$9,930]
Co.Asst	•	 1	i i	i	i	i i
(/yr)	į	İ	į	į	į	į į
 Medical		Scoliosis,	\ }	 Heart	. 	\\
Con-	•	knee and	İ	problems,	i	
ditions	•	dental	İ	chronic	i] i
of	ii	problems	İ	respir.	İ	1
client	11	1	1	problems	Ì	į
!			[!		
1		1	[1	1	1 1
I		I	1	-1	.	!

Year Two Expenditures by Category







