

AN EVALUATION OF GRANTS AWARDED
FOR OCTOBER 1989 - SEPTEMBER 1990

Prepared for:

Minnesota Governor's Planning Council
on Developmental Disabilities

St. Paul

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The purpose of the project was to implement a "voucher" program in which ten families of children with developmental disabilities were given the control of county funds already budgeted for them to purchase services and goods to enable their children and themselves to manage and enrich their lives.

One driving force behind the project was a county survey finding that many families had not been satisfied with the service providers they had to use as clients of Dakota County. Some families indicated that they thought they would be able to get better services at a lower cost than what the county was getting from its contractors under purchase of service arrangements.

Twelve families participated in the project. Information on the families' situation is provided in Table 10. The Dakota County Voucher project set forth four objectives. Each of these is briefly discussed below. The first objective stated that participating families would use a larger number of alternative or informal providers (family child care, informal respite care)

during and after the project than before it. The voucher program reported that anecdotal evidence from journals and interviews with half of the participants suggested that families did use more informal providers. Participants liked being able to hire people they knew and trusted, and that they could fire those who did not work out. Some examples from the project's year end report are given below.

- One family hired a neighborhood student who knows the family well to care for the child with disabilities. "She is being wonderful - washing, ironing, doing dishes, baking cookies. I am beat when I get home, but the house is spotless and the kids fed!"
- Another family is working with a neighbor who has a college degree in special education to work with their son.
- A family which had rarely used County funds prior to the project used some of the funds to hire daughter's friends, as well as her own, to care for her son.
- One family is finally able to find respite care providers who will care for their child without disabilities, too.
- One family pointed out that the people they have hired are more "trainable" and willing to comply with family requirements than County contracted providers they have used in the past.

A second objective stated that families would have different patterns of respite care. Project staff indicated they were unable to measure this objective accurately. Currently, this evaluator is working with the project to determine if data can be collected during the project's second year to address this

question.

A third objective stated that families would express higher levels of satisfaction with their provider arrangements than before the project. As the project noted, the fact that all of the families chose to remain in the program is suggestive that the families were generally satisfied with the service arrangements they had established.

The fourth objective stated that families would use monies for services and goods traditionally not funded by the county, but would from a family's perspective maintain/reinforce family coping skills. Table 11 provides a breakdown of these expenditures. Nearly all of the monies were used for items or services which would not otherwise be covered by the county. Many of the expenditures would also not have been covered under the State Family Subsidy program. The project's year end report summarizes some of the key points regarding the expenditures.

- 31% of funds were spent on child care/respice care. This expenditure category was used by eleven of the twelve families, making it the most popular expenditure types. The most important thing to recognize is that most of these funds purchased services of informal providers. Family members, friends, neighbors, and other - few, if any, licensed - were compensated for care at rates much lower than those for which the County contracts. Families won in two ways: they got more services for the same amount of dollars, and they increased the likelihood that their informal network will remain strong.

Table 10
FAMILIES' SITUATIONS

Situation	Child #1	Child #2	Child #3	Child #4	Child #5	Child #6	Child #7	Child #8	Child #9	Child #10 Child #11	Child #12	Child #13
Client Age(s)	10 yrs.	6yrs	12 yrs	13 yrs	2yrs	2yrs	8 yrs	12 yrs	10 yrs	7 yrs 10 yrs	8 yrs	6 yrs
#, ages other child. at home	two - 12, 15 yrs	two - 3, 4 yrs	two - 14, 16 yrs	two - 9, 14 yrs	one - 8 yrs	two - 1, 10 yrs	two - 10, 16 yrs	three - 11, 15, 18 yrs	one - 9 yrs	one - 13 yrs	one - 2 yrs	eleven 2-18 yrs all adopted
Devel. Disab. of child	Profound MR, CP, non-mobile and non-verbal	Severe MR, CP, non-mobile and non-verbal	Niemann-Pick Disease	Severe MR, epilepsy	Spina bifida	Cornelia DeLange Synd., severe MR	Landau-Kleffner Syndrome	Down Syndrome	Moderate MR	Child #1 - mil MR; Child #2 - learn. disability	Autism, tuberosclerosis	CP, MR
State Asst.	TEFRA, Fam.Sub.	TEFRA, Fam. Sub.	TEFRA, Fam. Sub.	TEFRA, Fam.Sub.	TEFRA	TEFRA, Fam. Sub.		TEFRA, Fam.Sub.	TEFRA	TEFRA, Fam.SUB.	Fam. Sub.	Fam. Sub., Adopt Sub.
Amt. of Co.Asst (/yr)	\$12,048	\$2,236	\$6,310	\$7,335	\$5,741	\$4,403	\$4,847	\$4,451	\$1,698	\$4,680	\$14,409	\$6,669
Medical Con- ditions of client	Bowel/ bladder respir. infect.	Respir. infect., vision impair, bowel/ bladder, hydroceph	Muscle de- gener., gas. tube, terminal	Severe hearing loss, minor uncont. seizures, not toilet trained.	Phys.dis. L2 level hydroceph. neurgenic bladder	Hearing impair, trach., gas tube, vent dependent		Hearing/ vision im- pair, orth problems, heart defect	Hearing impair.	Uncon- trolled Seizures, bladder, migraines	Seizures, asthma/ allergies	Non-mobile non-verbal respir. infect.

Dakota County Voucher - Year 1 Expenditures

Table 11

Type of Expend.	Family #1	Family #2	Family #3	Family #4	Family #5	Family #6	Family #7	Family #8	Family #9	Family #10	Family #11	Family #12	Total \$ per type	Percent of total
Adapt. clothes, clothing	\$220 2.6%	\$80 3%	\$1010 18%	\$11 .3%							\$397 3%	\$60 2%	\$1,778	4%
Adapt. Equip.		\$50 2%			\$160 18%	\$135 6%			\$15 1%		\$121 1%		\$482	1%
Child Care Respite	\$1401 16%	\$738 32%	\$746 13%	\$1617 45%	\$51 6%	\$1078 49%		\$456 38%	\$616 36%	\$1665 43%	\$5028 39%	\$2274 66%	\$15,670	31%
Computer/TV/VCR	\$1058 12%			\$302 8%				\$150 12%			\$32 .2%	\$120 4%	\$1,682	3%
Estate Plan/Insur.											\$1560 12%		\$1,560	3%
Family rec., outings	\$646 8%	\$40 2%	\$375 7%	\$447 12%	\$448 49%			\$552 46%	\$294 17%	\$162 4%	\$795 6%	\$21 .6%	\$3,780	8%

- 20% of funds were used on home modifications and maintenance. This category was used by eight families. One family used funds to remodel a section of their home as an "apartment" for their child, something which they see as a more and pressing need as all three of their children grow up. Another family built a wheelchair ramp. A third family purchased housecleaning services every other week.
- 8% of funds were used for family outings and recreation. With nine families, this was the second most popular expenditure category. Several families paid for family "get-aways" with the funds. Two families paid for health club memberships.
- 9% of funds were used by one family to pay the loan on its van.

In addition to the evaluation data collected by the project in February 1991, a questionnaire was mailed to all participants (couples received two questionnaires). Six (31.6 percent) of the nineteen questionnaires were returned. The low response rate may in part be due to the length of the questionnaire, as well as the fact that participation in the project requires considerable ongoing paperwork. While the response rate was low, the comments by those who returned the questionnaire provide some hints to various aspects of the project. The findings on selected questions are discussed below.

First, the participants were asked what was the main reason(s) they first decided to participate in the Dakota County Voucher project. Their responses are given below.

"It allowed us flexibility of money to enhance our son's needs."

"To control my own destiny and that of my child."

"Because we live in an isolated, rural area of the county, we have trouble getting traditional services. Also, because of her autism, her needs are different from a child with some other disability - services are not really geared towards her needs."

"Our special needs child was 9 1/2 yrs. old, his developmental level was in the infant range. Our family was very stressed because there were no services meeting our needs."

"Be able to control funds within reason."

"Seemed like a better way for the county to provide services I needed."

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. Their responses are given below.

"We never want to return to that way."

"Never."

"None."

"Only if there was nothing else."

"The only condition I can imagine would be one of no-other-choice. For 9 1/2 years, we went without services because nothing worked like it was created to."

"If need be, I would return with no problem, but I would present a case in where I feel that the Voucher Project is better."

Participants were asked if participation in the Dakota County Voucher project affected the amount of emotional strain they experience as a parent of a child with a disability. All six respondents said yes to this question. They were also asked how the project affected the amount of emotional strain. Some of their responses are noted below.

"Yes, emotional strain has greatly decreased because my husband and I have been active participants in choosing people and resources that provide genuine support for us."

"We have used the money to go out to dinner as a family – we are thrilled to see the progress our daughter has made in her behavior in public – we are happy to be able to do things as a family. It has made a tremendous difference in our emotional well-being."

"Empowered me by allowing me to decide the services my child needed."

"It has reduced it, by us controlling the money - our hands and hearts are not tied!"

"It has lessened the strain, enabling us to do and try different things for our son which helps the family."

All participants also indicated that the project had reduced the amount of financial strain. Several of their responses to how the project has affected them in this area are given below.

"We were able to use some of the money to pay off part of a van we had to purchase for our child, which helped financially. Also, we are able to do things we wouldn't be able to do otherwise - like eating out."

"Yes, because of the flexibility we can view our responsibilities to our child without the extra monetary

burden weighing us down. The general picture looks brighter."

"Money-wise, we try and do things that are fun, useful, and exciting for the whole family."

"I could pay bills I couldn't have paid otherwise because they didn't fit the criteria of other programs."

"With the voucher, we have been able to purchase respite care on our own for less dollars than the county could before (1/2 as much)."

Participants were also asked in what ways have things been different for their child since participating in the project. Several of their responses are given below.

"Our daughter is more a part of the family - when we go out to dinner we thank her because it is, in essence, "her" money. She's not just taking but giving to the family, and she acts different. She seems to have grown up since we have been doing this."

"He had a better variety of stimulating toys and videos. He's had a lot of good care that exposed him to a variety of community settings. Example: last week his school aide took him to a concert."

"He is happier, independent and socially more visible. This is what he wants."

"Our child has been happier since getting out and socializing."

Participants were asked what one thing about the voucher project is most important to them. Some of their comments are noted below.

"Being able to use the money for things not covered by other programs such as family subsidy, outings, some toys, etc