

EVALUATION  
OF  
A FAMILY SUPPORT  
PROGRAM  
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## ABSTRACT

The results of a grant project to provide extensive support services including a cash subsidy, in-home intervention, casemanagement, respite care, training and professional consultation to families with developmentally disabled members are presented. The primary goal of the project to prevent institutional placements from at-risk families or return already placed developmentally disabled children to their natural homes was successfully realized for participating families. Measures of adaptive behaviors of the child, quality of life of the family, and changes in target complaints of the family were measured at periodic intervals over the course of the two year project. Control group comparisons are presented. Results suggest positive impact of the project.

## EVALUATION OF A FAMILY SUPPORT PROGRAM

More and more interest is being shown in maintaining handicapped children in their own homes (Jenning, 1982). Across the country fourteen states have family support programs, reflecting a trend toward directing public resources toward the family to enable developmentally disabled members to remain at home (Bates, 1983). This trend is in part a result of judicial mandates of the right to least restrictive environments and the recognition of the deleterious effects of institutionalization with paradoxically increasing costs.

The importance of the family unit for growth and development of a retarded individual has been recorded in a summary of studies done by the President's Panel on Mental Retardation (Ehlers, 1966). While parents of handicapped children report more stress than families of non-handicapped children (Friedrick and Friedrick, 1981), there is also evidence that care of handicapped children at home has some positive effect on the family in enrichment of family life (Willer, 1981).

The need to provide services which enable continued home care is supported by the results of a recent county-wide survey in Michigan of families of severely mentally and multiply impaired children. The survey suggests that some supportive services are needed by all families raising severely impaired children and that, in fact, for some families placement can be averted by the provision of those services (Rosenau, 1982).

The State Planning Council for Developmental Disabilities in Michigan recently funded a grant to pilot projects to demonstrate the effect of family support services on three areas: (1) the prevention or termination of institutional care for developmentally disabled children, 2) the adaptive growth of the child, and (3) the quality of life of the family. The results of one of those projects is reported here.

## Description of the Project

The Family Support Program was a demonstration project operated jointly by Life Consultation Center, which is the Community Mental Health agency in Macomb county and Macomb-Oakland Regional Center, the state Department of Mental Health agency. Its intent was to fill gaps in the range of services available to families with developmentally disabled children. By providing additional components to existing resources, a comprehensive package of services would be made available or accessible to families at risk of seeking placement of their disabled child and to families with an already institutionalized son or daughter returning to the natural home.

The project is clearly a reversal of the paradox of extensive resources available to non-related persons to care for developmentally disabled children. For families no longer able to care for their child at home, placement in the catchment area served by the project has been available through specialized foster care. That placement program provides a home for the child in a foster family who receives training, support, and financial reimbursement not only for basic needs but also reimbursement for provision of an individual training program for the child. The amount paid for this program implementation varies dependent on the needs of the child ranging from \$10 to \$15 per diem (above and beyond the cost of basic food and shelter) to encourage families to provide care to a child whose disabilities are very demanding of their time, and physical and psychological energy. The Family Support grant was designed to provide this same level of financial assistance to natural families. It correspondingly serves the same purposes:

- (1) reimbursement for extra expenses incurred in caring for a disabled person.
- (2) reimbursement for a para-professional role in implementation of a special training program.

- (3) incentive to continue the care of someone whose care is demanding and who would otherwise be cared for in a more costly, residential setting.
- (4) mechanism to allow a family to enjoy the normal routine their neighbors enjoy which would otherwise be unavailable to them. (For example, the ability to afford a sitter to allow the parents to go out alone; a normal family income does not have to accommodate sitter expenses for a sixteen year old).
- (5) mechanism to meet the diversity of requests for services.
- (6) mechanism to allow the family a choice in how best to meet their needs. (For example, to choose to purchase an agency service or generic service as they wish.)

The grant provided \$16 per diem in financial assistance. In addition, families in the program had access to a number of services including case-management, respite care, in-home intervention using a staff person in the home up to 20 hours per week, training, and support services of an interdisciplinary team of professionals.

#### Subjects

The program proposed to serve ten families: five at risk of out-of-home placement and five returning from institutional settings. Admission criteria included family residence in Macomb county, client age 0-26, and client functioning in the severe or profound ranges of retardation or in the moderate range with accompanying secondary handicap.

At risk families were quickly identified. Families wishing to return their children to their home from placement settings were more difficult to identify. After one year of attempts, no families had yet been identified from any setting who agreed to take their children home. Table I is a summary of the data collected during the search:

TABLE I

<u>Description of Population in Placements</u>	
Number of clients in institutional settings	84
Number of clients in community settings	<u>145</u>
Total	229
Average age of client	20.9
Average # of years in placement	11.7
# of clients institutionalized before age 6	47%

It seemed clear that our attempts to facilitate return were much too late in the developmental stage of this group of families.

The program was initiated with five at risk families in October, 1980. In January, 1982, eight additional families were added. Of these, five were at risk and three were eventually found who returned from placement settings (one from a nursing home, one from a group home, and one from a foster home).

The project served a wide range of handicapping conditions. Table II describes the children.

TABLE II

<u>Handicapped Child Characteristics</u>					
Ages		Educational Classification		Presenting Problems	
Under 13	6	Severely Multiply Impaired	3	Physical handicap	3
13 - 17	5	Severely Mentally Impaired	8	Severe behavior	
18 or over	2	Emotionally Impaired	1	problem	6
		Trainably Mentally Impaired	1	Autistic	1
				Multiple handicaps	4

The project also served a wide range of family situations. Table III describes the families.

TABLE III

<u>Family Characteristics</u>					
Marital Status		Income		Family Size	
Single Parent	3	Social Security	2	Two	2
Two parents	8	Public assistance	1	Three	2
Parent/step parent	2	Unemployed (at onset)	3	Four	5
		Under \$15,000	1	Five	2
		\$15,000 - \$25,000	4	Six or more	2
		Over \$25,000	2		

## Method

A comparison study using pre and post measures was utilized to evaluate the effects of the program on the developmentally disabled child and his family. Ten "at risk" families were initially identified as meeting admission criteria for the grant. Through a random draw, five families were assigned to receive the subsidy by the grant. These families became the Experimental group. The remaining five families served as the Control group. They received services already existing in the community but not the additional subsidy. All families received a battery of assessments prior to the beginning of the program and at periodic intervals thereafter. The battery consisted of three tools:

- (1) The AAMD Adaptive Behavior Scale: measuring adaptive skills and maladaptive behaviors of the disabled children.
- (2) The Flannigan Quality of Life Survey: measuring satisfaction with a variety of areas which measure quality of life of the parents.
- (3) Problem Rating Scale: rating of family-identified target complaint changes over time.

After fourteen months, because of the inability to locate sufficient numbers of families to return their children from placement settings, the decision was made to offer the subsidy to families in the Control group. (Neither the Control group nor the program evaluators had expected this to occur.) This allowed not only comparison of the Experimental and Control groups; but a comparison of the Control families over a period without assistance and a period when assistance was provided. Comparisons were made between changes from baseline on the three tools over the course of the grant period.

## Results

AAMD Part 1 - Adaptive Skills: A comparison of the Experimental group and Control group shows a greater increase in adaptive skills for children of families receiving the subsidy than families who did not receive the subsidy. Children of subsidy families showed an average increase of 28.6% over baseline scores while

children of families not receiving the subsidy showed an increase of only 2.3%. After receiving the subsidy, Control family children showed an average increase of 10.4% on adaptive skills over baseline levels. When the three new families, who had children returning from placement settings, were included the average change for the entire population showed a 13.9% increase. (Table IV)

AAMD Part II - Maladaptive Behaviors: Comparing the Experimental group and Control group prior to Control receipt of the subsidy shows a significant difference between the two groups. The Experimental families (receiving the Subsidy) showed an average decrease of 17% in their child's maladaptive behaviors while the Control group (not receiving the Subsidy) showed an average increase of 1.2%. At the end of the program when the Control group also received subsidy services, there was an average decrease of 14.6% in maladaptive behaviors. The population taken as a whole at the end of the program showed an average decrease of 38.8% in maladaptive behaviors of the child. (Table IV)

Quality of Life: A comparison of the Experimental group and Control group shows families who received the subsidy increased an average of 14.6% on satisfaction with their quality of life while families not receiving the subsidy had a decrease of an average of 5.6% on satisfaction with their quality of life. At the end of the program the Control group and Experimental group, both receiving the subsidy, had similar rates of increase with an average increase of 3.0% and 3.4% respectively. New families receiving the subsidy had a decrease in satisfaction of 20%. These were families whose children returned to the home from placement settings. These families were free of the burden of care of their handicapped children at the pre test and resume that care by the post test. Even with the subsidy, the extent of the burden of care of a handicapped child may be reflected in the decreased quality of life satisfaction for these families. (Table IV)

Problem Ratings: The problem ratings were measures of changes in complaints families targeted at the beginning of the program. Each family identified individual areas of concern. Following is a list of the most frequently cited problems:

- (1) Child's disability (Lack of independence, physical care demands, and inability to communicate needs or behavior problems as a source of constant strain.)
- (2) Parents lack of, or limited social opportunities.
- (3) Inability to find and/or afford sitter.
- (4) Financial strain.
- (5) Lack of or limited quality family time, normal family activities.
- (6) Worry about the child's future.
- (7) Lack of parental time alone.

Comparing the Experimental families and Control families reveals an average decrease in problem ratings for families receiving the subsidy of 32.6% while Control families not receiving the subsidy showed problems remained the same as at the initial testing with a slight average increase of 0.8%. By the end of the program both the Experimental and Control groups, all receiving the subsidy, showed decreases. The Experimental group had an average decrease of 35.4% and the Control group an average decrease of 27.6%. Overall, with all families included, the average decrease in problem ratings was 32.3%. (Table IV)

A follow-up questionnaire was sent to all families after the end of the grant. Families were asked to comment on the program and its impact on their child and family. Without exception, families report great satisfaction with the program. The following areas were reported as reasons for their satisfaction:

- (1) Ability to do more as a family.
- (2) Reduced tension, anxiety, stress, worry.
- (3) Happier, more content, more patient.
- (4) More normal life style.

(5) Improved behavior, skills, awareness of child.

(6) Sense of worth, recognition.

Eight out of 12 families responding to the questionnaire would have definitely sought placement outside the home if the Family Support Program had not been available to them. An additional two indicated they probably would have sought placement. (Of the remaining two, one is a single 63 year old woman raising her profoundly retarded, totally dependent son alone on a social security income).

Families were asked to identify any services they needed which they were not able to get using the grant services. Seven of the 12 responding indicated there were none. Five who indicated unmet needs listed the following:

(1) More months of in-home trainer.

(2) Better trainer.

(3) Adult out-of-home respite not as available as needed.

(4) Adult group home for respite preferred over foster care but unavailable.

(5) Support group.

### Discussion

Families completed monthly reports describing what impact the program made on their family. The most important aspects of the subsidy frequently cited in these reports was the freedom of choice it gave them in controlling their own lives and the decrease in tension previously resulting from choices of whether to neglect family needs in order to accommodate the handicapped child or whether to neglect the handicapped child's needs in order to accommodate normal family needs.

Families monthly reports included an explanation of how the subsidy was used. Following are the services most frequently used by the 13 families in order of that use:

- (1) Sitters
- (2) Camp (respite)
- (3) Clothing
- (4) Household (replacement, repair, and adaptation)
- (5) Recreational activities
- (6) Vacation
- (7) Educational toys and materials
- (8) Therapeutic intervention (speech, PT, psychology)
- (9) Medical expenses (non-insured)
- (10) Transportation

It is interesting to note that most needs were accommodated within the families' network of relationships using the additional income rather than utilizing an agency service. For example, families reported purchasing 2,833 hours of sitter services. Of those hours, 2,826 were arranged by families themselves, while 7 were arranged through an agency, Life Consultation Center's special sitter program.

Reporting of how the money was used did not require families to account for all expenditures. About 40% of the subsidy money was not accounted for. In some cases, this is a result of not receiving a monthly report. In many cases, this is a reflection of the inability to account for all funds because of the myriad of uses not easily identified. One mother, for example, reported she was unable to account for how much money was spent on extra laundry detergent, hot water for additional laundry requirements, paper towels and kleenex merely to deal with her daughter's excessive drooling. Clearly this one behavior cannot account for great sums of money, but over a period of years certainly contributes to the family expenses.

### Conclusions

The pilot project serviced 13 families with mentally retarded children. The primary service provided was a financial subsidy of \$480 per month. In addition, families had access to casemanagement, and a home-trainer (a staff person in the home about 20 hours per week). Families used the subsidy to purchase additional services needed. Most needs were accommodated within the families network of relationships using the additional income rather than using an agency service.

Children of families with financial subsidies had higher rates of growth in adaptive skills and greater reduction in maladaptive behaviors than children of families not receiving the subsidy. Families receiving the subsidy reported greater satisfaction with the quality of their lives and greater reductions in problem

complaints than families not receiving the subsidy. Ten out of 12 families responding to a questionnaire would have sought placement outside of the home if the subsidy had not been available.

TABLE IV  
RESULTS OF FSP EVALUATIONS

	Percent of Change from Baseline			
	AAMD Adaptive Scale	AAMD Maladaptive Scale	Quality of Life	Problem Rating
Experimental At Risk Families				
Time 1 with subsidy	28.6%	-17.0%	14.6%	-32.6%
Time 2 with subsidy	20.6%	-56.0%	3.4%	-35.4%
Control At Risk Families				
Time 1 without subsidy	2.3%	1.2%	- 5.6%	0.8%
Time 2 without subsidy	10.4%	-14.6%	3.0%	-27.6%
New Families with DD family member returned to family from placement setting	6.0%	-42.5%	-20.0%	-36.5%
TOTAL	13.9%	-38.8%	- 0.6%	-32.3%

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# FAMILY SUPPORT SUBSIDY PROGRAM

Michigan has a program to provide financial support to families with severely handicapped children living at home. The subsidy program is intended to pay for special expenses the family incurs while caring for a severely disabled child. This financial support may prevent or delay institutionalization or other residential out-of-home placements. In other cases, the program may provide the funds necessary to allow children to return home from institutional placements.

Supporting families of children with severe disabilities in this way enables the families to stay together; allows them flexibility in purchasing special services at a local level; and saves money for the taxpayer by avoiding and/or reducing the need for more costly out-of-home placements.

The program was authorized by the Michigan Legislature after more than two years of work by a group of parents and professionals. House Bill 4448 became Public Act 249 of 1983 when Governor Blanchard signed the bill on December 15, 1983.

## WHO IS ELIGIBLE?

Families may be eligible for this program if they have a child under age 18 who has been recommended by a public school district's multidisciplinary team as:

- severely mentally impaired (SMI)
- severely multiply impaired (SXI)
- autistic impaired (AI)

Autistic impaired children must be enrolled in a classroom for severely mentally impaired or be in a program for the autistic impaired that qualifies.

In cases in which the child is not receiving special education services or in which the eligibility status of a child is not known, parents may contact the director of special education at the local or intermediate school district or call Project Find at 1-800-252-0052.

Families can be headed by natural parent(s), adoptive parent(s), or legal guardian(s). The child must be living in the home of the family and the family must reside in Michigan.

Under the law, the taxable income for the family may not exceed \$60,000. In addition, the family cannot receive a medical subsidy from the Adoption Subsidy Program administered by the Department of Social Services if they choose to apply for this program.

## HOW TO APPLY

Applications for the family support subsidy program may be obtained from and submitted to offices of Michigan's 55 community mental health boards. Your local community mental health board determines eligibility for this subsidy program.

Community mental health boards are listed in most telephone books. If you cannot obtain the number, call the family subsidy office in Lansing (517/373-3763).

Applications may be obtained and submitted any time. Coverage in the family support subsidy program will begin for the calendar month following the month of application. Actual payment for the first covered month may be delayed during the processing of the application. Yearly re-applications for continuation of the program shall be made in or just prior to the child's birth month.

Applicants will need to gather the following documents to submit with applications:

- The child's birth certificate.
- A copy of the family's Michigan Tax Return for the preceding year.
- A written verification from the school district which certifies that the child has been recommended for an eligible diagnostic category and, if categorized as autistic, a classroom which meets the requirements for the program.

- The child's social security number.

Parents whose child is presently placed out of their home may contact their local community mental health board to explore possibilities for being reunited. The subsidy program allows parents a one time advance payment equal to a two-month amount in order to prepare for their child's homecoming.

## PAYMENTS

Payments are uniform for all families and there are no provisions under the law for larger or smaller payments.

The subsidy rates are patterned after the federal Supplemental Security Income (SSI) payments. The exact amount of the payment will be determined annually when the federal government establishes its SSI payment rate

and when the Michigan Legislature sets the appropriation for the program.

Families are not eligible for payments after a child reaches age 18, because the child then becomes eligible, in almost all cases, for a payment under the federal SSI program.

#### ADMINISTRATION

The Department of Mental Health and the community mental health boards are vested with administrative authority to implement this Act because they have statutory responsibility for the well-being of all developmentally disabled children and have made a commitment to avoid institutionalization and other placements outside the home.

#### PROGRAM BENEFITS

Many severely impaired children cannot eat, walk, dress, or talk on their own. They often have both mental and physical impairments and require 24-hour care.

Families with severely disabled children have many expenses that other families do not have. Mental health staff report that many families requesting out-of-home placements would not have sought placement had more financial resources been available.

The Act recognizes that each family has differing and unique needs that often cannot be met by specific agency services. Possible uses of the subsidy payments might be the purchase of special equipment, special diets, large paper diapers, unique transportation costs, in-home specialized care, respite (baby-sitting) care, family counseling, support groups, general household expenses, family recreation and home remodeling to accommodate the needs of the impaired child.

This list is not all inclusive. A unique feature of the subsidy is that the family determines its use to suit their needs.

#### INFORMATION

Michigan's 55 community mental health boards can provide additional information on the family support subsidy program. Questions and/or requests for applications should be directed to your local community mental health board. For the phone number and contact person at your local community mental health board, call Department of Mental Health, Family Support Subsidy Program office in Lansing at 517/373-3763.

**FAMILY SUPPORT  
SUBSIDY PROGRAM**



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Michigan Department of Mental Health  
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Michigan Department of Mental Health