

Report to the 1979 Legislature

MENTAL RETARDATION
FAMILY SUBSIDY PROGRAM

Under Provisions of
M.S. 252.27, Subdivision A

Minnesota Department of Public Welfare
Mental Health Bureau
Mental Retardation Division

November, 1978

SUMMARY OF RECOMMENDATIONS
FOR THE
MR-FAMILY SUBSIDY PROGRAM

1. IT IS RECOMMENDED THAT THE MR-FAMILY SUBSIDY PROGRAM BE ESTABLISHED AS A PERMANENT DEPARTMENT PROGRAM FOR SELECTED FAMILIES WHO ARE PROVIDING OR WHO WOULD PROVIDE FOR THEIR MENTALLY RETARDED AND/OR DEVELOPMENTALLY DISABLED CHILD(REN) WITHIN THE NATURAL OR ADOPTIVE HOME.

The critical nature of the need for support to the family unit to provide for their retarded child has already been established through the experience of the MR-Family Subsidy Program. In addition to the waiting list of 25 families, another 90 eligible applications have been received. Additionally, telephone and written inquiries to the Division for purposes of application have averaged two inquiries per week during this past year.

Further, the Department of Public Welfare Family Task Force demonstrated the need for a comprehensive approach to meeting the needs and service delivery gaps which focuses on the natural family unit. The Family Task Force proposed "the establishment of a program which provides financial services to handicapped children in the natural or adoptive home for all expenses related to the child's disability needs, with eligibility criteria based upon the disability needs of the child". As evidenced by the Family Task Force's findings and recommendations, it appears that a program like the MR-Family Subsidy Program is needed for families who choose to provide for their retarded child within the natural or adoptive home to enable those children the opportunity to the least restrictive living environment.

2. IT IS RECOMMENDED THAT THERE BE NO LIMITING LANGUAGE ON THE NUMBER OF CHILDREN IN THE PROGRAM,

The 50-family operation limit has resulted in the return of money every year, at the expense of serving additional families within the legislative allocation. In FY '78, the 50-family ceiling prevented, at the minimum, an additional 14 families from being served. \$43,817 (25.6%) was returned in FY '78; \$20,142 (13.4%) was returned in FY '77.

3. IT IS RECOMMENDED THAT A MONTHLY SUBSIDY, NOT TO EXCEED 9250 PER CHILD, BE ALLOCATED. HOWEVER, THIS LIMIT MAY BE WAIVED IN CASES OF EXTRAORDINARY NEED, BUT MUST NOT EXCEED 50% OF THE POTENTIAL AVERAGE INSTITUTIONAL COSTS FOR THE CHILD. THE COMMISSIONER OF PUBLIC WELFARE SHALL ESTABLISH UNIFORM RULES AND REGULATIONS GOVERNING GRANT DETERMINATIONS.

The individual needs of families vary, due to the uniqueness of each situation. Seventeen (34%) of the participating families had documented needs above the \$250 per month maximum. In addition, 22 (44%) families are currently receiving less than the maximum monthly subsidy. However, according to the legislation, the unused funds a) cannot be directed to those families requiring additional assistance in excess of the \$250 limit, or b) cannot be used to place additional families on the program.

4. IT IS RECOMMENDED THAT THE SUBSIDY BE GRANTED ON A PER CHILD BASIS RATHER THAN ON A PER FAMILY BASIS.

Two families in the program each had two retarded children, but were limited to \$250 for both children. Both families had expenses in excess of the \$250 limit in order to provide for their two children.

5. IT IS RECOMMENDED THAT A LEGISLATIVE ALLOCATION OF \$1,200,000 FOR THE BIENNIUM BE GRANTED FOR SUBSIDIES TO FAMILIES.

This request is based on documentation of the need for a minimum of 200 children at \$250 per month per child. There should be no limiting language on the number of children in the program. The Department should have the latitude to go beyond 200 families, within budget constraints.

6. TO ENSURE PROGRAM COORDINATION, IT IS RECOMMENDED THAT THE BIENNIUM PROGRAM BUDGET INCLUDE A \$56,642 LINE ITEM FOR ADMINISTRATION OF THE PROGRAM.

The original MR-Family Subsidy Program Legislation carried no staff or administrative appropriations. If the program is established on a permanent basis, it is essential that there be definitive state direction and management of the program. It is recommended that the program be administered by a part-time Senior Welfare Specialist. For the first year of the biennium, the optimal administrative level would be a full-time administrator for the first six months; half-time for the remaining six months. The minimum level is a full-time administrator for the first three months; half-time for the remaining nine months. The administrator would be on a half-time basis for the second year of the biennium. Following is a breakdown of administrative costs.

The optimal level for the biennium is:

<u>per biennium</u>	\$26,642.00 - Sr. Welfare Specialist (including benefits) at six months FT; six months PT for FY 1980-81; 12 months PT for FY 1981-82
	15,000.00 - one half-time secretary (including benefits)
	5,000.00 - supplies, equipment, phone, travel, mailings
	<u>10,000.00</u> - reports, computer time, program evaluation, printing
<u>per biennium</u>	\$56,642.00 TOTAL

The minimum level for the biennium is:

<u>per biennium</u>	\$24,321.00 - Sr. Welfare Specialist (including benefits) at three months FT; nine months PT for FY 1980-81; 12 months PT for FY 1981-82
	15,000.00 - one half-time secretary (including benefits)
	5,000.00 - supplies, etc.
	<u>10,000.00</u> - computer time, etc.
<u>per biennium</u>	\$54,321.00 TOTAL

7. IT IS RECOMMENDED THAT GRANT MONEY NOT BE PERMITTED FOR PAYMENT OF EDUCATIONAL SERVICES THAT ARE THE RESPONSIBILITY OF LOCAL PUBLIC SCHOOLS UNDER P.L. 94-142.

8. IT IS RECOMMENDED THAT FUTURE ANNOUNCEMENTS REGARDING THE MR-FAMILY SUBSIDY PROGRAM BE COMMUNICATED TO COUNTY WELFARE DEPARTMENTS, DAC'S, PUBLIC SCHOOLS, MENTAL HEALTH CENTERS, AND VARIOUS CONSUMER AGENCIES.

Distribution of previous announcements was limited to county welfare departments and the Minnesota Association of Retarded Citizens. As a result, many families were unaware of the program and application until too late.

SUMMARY OF MAJOR FINDINGS

1. 86.5% of the children who participated in the MR-Family Subsidy Program had never been placed outside of the natural home.
2. Fifty-two mentally retarded children were served by the program in 1977-78. Children ranged from borderline to severe mental retardation. Twenty-five of the children were multiply handicapped and eight children were diagnosed as autistic.
3. Significant developmental growth was evidenced by the children in 11 of the total 18 skill domains: gross motor, toileting, social interaction, reading and readiness, money, eating, dressing, grooming, receptive language, writing, and time skills.
4. Based on parent ratings of the assistance provided by the MR-MSP, the program assisted families most in meeting special equipment, babysitting, medical, medications, supplementary educational programs, respite care, and special clothing.
5. According to parental response to the questionnaire, the following services would not have been provided to the family and the retarded child without MR-FSP assistance: special equipment (35%), babysitting (33%), medical (26%), specialized therapies for child (22%), respite care (20%), counseling (12%), special educational program (12%), special clothing (10%), camp (8%), adaptive housing improvements (4%), and home health care for child (2%). The program directly enabled educational/therapeutic services and items to over 50% of the families to increase the child's developmental skills that would not have been provided without the program.

6. The majority of the families was at the middle income level and, consequently, were ineligible for public financial and social assistance. As a result, many of these families faced serious problems in continuing to provide for their retarded child in the natural home. Based on parental priority ratings of service needs, the following categories are most needed in order to continue providing for the child within the family unit: educational program, medical, medication, baby sitting, respite care, and special equipment.

7. A comparison of the necessary service needs required by families and those services provided through MR-FSP concluded that the program addressed those needs.

8. The \$250 maximum monthly subsidy met the needs of 66% of the families. Thirty-four percent indicated the need for additional assistance ranging from \$20 - \$270 per month beyond the grant limitation.

9. In addition to the financial assistance, recipient parents identified the following as benefits provided by the program, which impacted upon the family unit as a whole:

- a. Family tension and strain eased; increased flexibility and freedom for the parents and family.
- b. Financial burden eased.
- c. Enabled higher quality of care for retarded child.
- d. Psychological support to family that "society cares" and is responsive to their needs.
- e. Assistance in future planning for their retarded child and family.
- f. Family unity maintained.
- g. Increased effectiveness of parents.

INTRODUCTION

This report is the result of a request by the Minnesota Legislature for annual evaluation of the Mental Retardation-Family Subsidy Program. The report evaluates the 1977-1978 operation of the program, with findings and recommendations to assist the Legislature in determining future direction of the program. The complete evaluation report is available through the Minnesota Department of Public Welfare, Mental Retardation Division.

In 1975, the Minnesota Legislature created the Mental Retardation-Family Subsidy Program (MR-FSP), a three-year experimental program which granted a public subsidy to 50 families to care for their mentally retarded child(ren) in the natural or adoptive home. Minnesota was the first state to provide direct cash assistance to families for this purpose. Eligibility requirements included children under the age of 18 years who would have been eligible for placement in a state institution or licensed community residential facility. There was no Income eligibility requirement for families. Currently, the program is operating at the full 50 families, with a waiting list of 25 families. Another 90 applications have been received. Additionally, telephone and written inquiries for purposes of application have averaged two inquiries per week during this past year.

The maximum grant was \$250 per month per family. Grants to families included the costs for (1) diagnostic assessments, medical expenses, medications; (2) special diets and special clothing; (3) special equipment; (4) parental relief and child care costs; (5) educational and training programs supplementing school programs, including visiting nurses, therapists and behavior management specialists; (6) adaptive housing; and (7) related transportation costs.

Fifty-two mentally retarded children under the age of 18 years were served in 1977-1978. Children ranged from borderline to severe mental retardation. Twenty-five of the children were multiply handicapped and eight children were diagnosed as autistic. 86.5% of the children had never been placed outside of their own home. The families were from 24 counties in Minnesota, with about 50% residing in the metropolitan area. The majority of families were in the middle income level.

PURPOSE OF THE PROGRAM

Evaluation of the program focused upon three purposes. First, the stated purpose in the legislation was to:

Determine the effectiveness of the family unit in providing alternative living arrangements and providing or arranging for the training and developmental opportunities provided in a state hospital or licensed community residential facility... (M.S. 252.27, Subd. 4).

Second, the experimental nature of the program allowed for the collection of data on needs of families providing for their mentally retarded child within the natural home. Data collected through the program provided an opportunity for the Department of Public Welfare to systematically study and describe a sample population of retarded children living in the natural home and the service needs of those children and their families.

Finally, reports from recipient families led to the conclusion that another significant purpose, not initially conceived by the legislation, was served through the program — assistance in maintaining the Integrity of the family unit. Recent interest in preservation of the family and home-based services has been evidenced by the Governor's Conference on the Family, the President's National Conference on the Family, the Minnesota Department of Public Welfare Family Task Force, and the Inter-agency Task Force on Home-Based Services.

One representative recipient family stated:

The MR-FSP has enabled our family to remain a happy, well-united group without the undue financial and emotional stress of the responsibilities of providing the costly needs of a child who is handicapped. We have been very thankful for the MR-FSP. It has enabled us to provide the full circle of programs that our son, who is multi-handicapped, has needed. Our son has remained a very happy child who is able to remain in his home and experience family living, as is his right.

Specific findings under each program purpose follow.

FINDINGS

Developmental Growth of Retarded Children, in the MR-Family Subsidy Program

An initial behavioral assessment was developed at time of admission to the MR-FSP for each child, utilizing the Minnesota Developmental Programming System (MDPS). Annual assessments were conducted thereafter to measure the child's growth. There were a total of 37 children with two MDPS administrations. The developmental growth was figured by comparing the initial assessment score to that of the subsequent annual assessment. Analysis of comparison assessments evidenced significant gains of these children in 11 of a total of 18 skill areas: gross motor, toileting, social interaction, eating, dressing, grooming, receptive language, money, reading and readiness, writing, and time skills. The analysis of mean scores of the children showed no cases of regression.

Needs Assessment of Families

Although the natural family is considered the most normalizing atmosphere, examination of federal, state and local programs found that there is little financial and social support available to the family to maintain their mentally retarded child in the home. Generally, financial and social resources became available to families only after their retarded child was placed out of the natural home.

The MR-Family Subsidy Program sought to extend the options of retarded children by providing a subsidy to their families for a planned program of home care and training. Utilizing the experience of participating families in MR-FSP, information was used to assess the scope of the problems and service needs of those children and their families. By providing a descriptive study of that type of service, this study attempted to contribute to the body of knowledge available on which the Department of Public Welfare could base responsible planning and policy development to meet the needs of that service level.

Questionnaires were mailed to the 50 participating families. Responses from 49 of the 50 families were received. Families were asked to select and rank the top four need priorities of their family, regardless of any MR-FSP assistance, from the following list of categories: medical, medications, educational program, babysitting, respite care, special clothing, special diet, special equipment, adaptive housing, transportation, camp, and counseling. The results of this analysis showed (in order of ranking) that educational program (highest); medical (second); babysitting (third); medication (fourth); respite care (fifth); and special equipment (tied fifth) were ranked as the five highest priorities for families.

To determine the extent MR-FSP addressed these priority needs, families were then asked to identify and rank the top four service categories in which the MR-FSP most helped them. In order of parental ranking, the five categories identified were special equipment, babysitting, medical, medication and educational program. It appears from the comparison of the necessary service needs required by families and those services provided through MR-FSP, that the program is currently addressing those needs.

The policy of the MR-Family Subsidy Program was to reimburse those expenses directly related to the disability needs of the child which were over and above the costs of caring for a "normal" child. Although the program provided assistance to families in several areas, evaluation sought to determine those services that would not have been provided without the MR-FSP. This question is of particular significance in terms of evaluating the need for continued assistance to children living in the natural or adoptive home to ensure that their needs are met. Table 1 identifies the areas in which families obtained assistance that they could not have obtained without MR-FSP. As shown in Table 1, 35% of the families were able to purchase special equipment as a direct result of the program; 33% were able to obtain more babysitting than would have been possible without the MR-FSP; 22% obtained specialized therapy services for their child that would not have been provided to the child without MR-FSP. It is interesting to note that the program directly enabled educational/therapeutic services and items to over half the families to increase the child's developmental skills that would not have been provided to the child without the program.

TABLE 1

Services Provided to Families Only through MR-FSP

SERVICE	NUMBER OF FAMILIES	PERCENTAGE*
Special Equipment	17	35%
Babysitting	16	33%
Specialized Therapy for Child, e.g., Speech, Occupational, Physical Therapy	11	22%
Respite Care	10	20%
Medical		
- Medical bills	7	14%
- Better medical and dental care	2	4%
- Medical specialists	1	2%
- Surgery	1	2%
- Dental care	1	2%
- Medical evaluation for child	1	2%
Counseling, Includes Counseling for Family; Behavior Management for Child	6	12%
Special Clothing	5	10%
Camp for Child	4	8%
Educational Program		
- Tutor	2	4%
- Home educational program	3	6%
- Specialized school	1	2%
“Companion” for Child	2	4%
Adaptive Housing Improvements	2	4%
Home Health Care for Child	1	2%
Advice from Social Worker at Local Social Service Agency	1	2%

*Percentages rounded off.

The average monthly subsidy as of September, 1978 was \$220.74. A total of 17 subsidies decreased since the initial subsidy, four increased, and 25 remained the same. The subsidy breakdown by category shows that the most dollars were spent for educational programs, special equipment, and babysitting.

Under law, the maximum monthly subsidy was \$250 per family. To determine whether the ceiling limit was adequate to meet the needs of the child, families were asked to indicate whether or not the maximum \$250 was sufficient and, if not, how much additional money was needed by category. Of the 49 responses, 32 families (66%) indicated that the maximum \$250 limit was currently meeting their needs. Seventeen families (34%) responded that additional financial assistance was needed to meet their child's needs, ranging from \$20 - \$270 per month above the \$250 limit. The need for additional assistance was not concentrated in any one category. The following categories were identified: medical (five families); babysitting (four families); special equipment (three families); medications (two families); special clothing (two families); adaptive housing (two families); and transportation (one family).

MR-FSP Impact on Family Unit

The MR-Family Subsidy Program was initially conceived as a de-institutionalization measure to encourage the return of institutionalized mentally retarded children to their families. However, 86.5% of the children in the program had never been placed out of their home. Frankly, it would be difficult to determine how many children were prevented from out-of-home placement as a result of the MR-FSP.

It was found, however, that the program did support the integrity and stability of — the family unit. With the recent federal and state interest in preserving families, this program outcome should be viewed as highly significant and positive.

Following are two quotes from recipient families which typify the responses expressed by participating families:

It's so much easier with MR-FSP because you really need to know someone is out there who cares. You don't feel so lonesome when you know you have someone to come in and help. The outside world seems more interested in you and your child. It doesn't seem so desolate - not such a big burden.

Another family commented:

You feel such helplessness and hopelessness. At these times, you just need to feel that some part of society is out there to help. This legislation has made us feel that society may be basically human—it gives you a different outlook. That part of the MR-FSP has meant as much to us as the actual money....

It makes society at large more humane. Every time someone sees a child like our son and accepts him, they become agents of social change and education—like the bus driver, the taxi driver, and the lady at the bakery. It's a form of social justification - not just dollars and cents.

The MR-FSP is one of the most humane pieces of legislation I've seen. It supports a humane choice. You face a penalty if you choose not to institutionalize. The Family Subsidy Program supports this choice in a real way.

In addition to evaluating the financial assistance provided to families, this report sought to determine the effect of the MR-FSP on the family unit as a whole. In what ways did the program help support the integrity and ability of the family to provide for their mentally retarded child? The mailed questionnaire attempted to draw out this type of data by requesting families to comment on "how the MR-FSP may have affected your family and your retarded child". Although there were a number of overlapping themes expressed, responses to this question generally came under the following seven broad topic areas in order of frequency of response:

1. Family tension and strain eased; increased flexibility and freedom for parents and family.
2. Financial burden eased.
3. Enabled higher quality of care for retarded child.
4. Psychological support to family that "society" cares and is responsive to their needs.
5. Assistance in future planning for their retarded child and family.
6. Family unity maintained.
7. Increased effectiveness of parents.

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