Report to the 1977 Legislature

MENTAL RETARDATION
FAMILY SUBSIDY PROGRAM

Under Provisions of M.S.
252.27, Subdivision 4

Minnesota Department of Public Welfare

January, 1977

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Authority

Minnesota Statutes, Section 252.27, Subdivision 4, provides that:

In order to determine the effectiveness of the family unit in providing alternate living arrangements and providing or arranging for the training and developmental opportunities provided in a state hospital or a licensed community residential facility, the commissioner of public welfare may establish an experimental program to subsidize selected families who agree to carry out a planned program of home care and training for their minor dependents who are mentally retarded.

This program shall be limited to children who otherwise would require and be eligible for placement in state hospitals or licensed community residential facilities.

Grants to families shall be determined by the commissioner of public welfare. In determining the grants, the commissioner shall consider the cost of diagnostic assessments, homemaker services, training expenses including specialized equipment, visiting nurses' or other pertinent therapists' costs, preschool program costs, related transportation expenses, and parental relief or child care costs not to exceed $250 per month per family.

An individual care andtraining plan for the child shall be established and agreed upon by theparents receiving the subsidy and the appropriate local welfare agency. Periods of parental relief, including vacations, may be included in theplan and do not require the approval of the local welfare agency. The plan shall be periodically evaluated to determine the progress of the child.

DPW Policy Bulletin 0120 and Proposed Minnesota Rule DPW 19 (refer to Appendix) were used to develop applications and begin the program.

Purpose

The experimental MR-Family Subsidy Program (MR-FSP) seeks to extend the options for retarded children by providing a public subsidy to families for a planned program of home care and training. The family home is considered the least restrictive setting, providing that the child retains the opportunity for treatment, training, and development.

Historically, public supported services have been provided after parents decide to place their mentally retarded child in an institution. The MR-FSP, on the other hand, encourages parents to care for and provide appropriate services to their retarded child in the home. Joint planning involving the parents and the county welfare department or human service agency insures an appropriate in-home program of care and training as an alternative to out-of-home placement. The purpose is to determine whether selected families can successfully provide home care which is beneficial to their MR child and cost effective when compared to institutional placement costs.

This report presents the six-month history of the program so that the Legislature may decide to extend or deny the support on the basis of past experience.

Program Implementation

The 1975 Legislature appropriated funds for the MR-FSP, and the Minnesota Association for Retarded Citizens (MARC) publicized the program to the general public. In December, 1975, DPW Policy Bulletin #120, received by all the county welfare directors, outlined the program's eligibility requirements and application procedures. Applications were to be sent from the county welfare departments upon receipt of the bulletin.

Applicants were solicited (1) from all the state hospitals through the MR-FSP and (2) from the general public through an extensive publicity campaign by MARC. By the end of March, approximately 150 applications for the program were received. Applicants were reviewed on a first-come basis. There were no applications from parents having children residing in the state hospitals. A total of nine children had been referred from the state hospitals, including two referrals from Brainerd, four from Faribault, and three from Rochester. In one case, the referral was a child who had already been released from the hospital and was living at home; she was subsequently accepted. Applications were not made by the remaining eight families for various reasons. First, several families found the decision to bring their child home from the institution very difficult. This may have been due, in part, to the emotional trauma of bringing the child home again for an experimental program of uncertain duration. Also, it was not possible to assure the family that the child could return to the same institution should the MR-FSP prove ineffective. Secondly, the social worker(s) involved could not always recommend the child be returned to the families because of difficulties in the home environment.

The screening committee, in reviewing the applicants, attempted to accept families who represented a cross section of the population. Primary variables considered in the screening process included:

1. Diagnosis and Prognosis: The major factors were the degree of retardation, the compounding effect of multiple handicaps, and the potential for developmental improvement.

2. Socioeconomic Status: A unique aspect of the MR—FSP is the exclusion of eligibility based on level of income. Subsequently, the program was able to assist marginal families who did not qualify for medical assistance programs. A cross section of families was chosen which included families ranging from single-parent welfare recipients to upper-middle income families.

3. Community Resources: The availability of therapists, consultants, babysitters, and respite care facilities were also factors.

A total of 56 families have received MR-FSP grants. As of January 1, 1977, five families had withdrawn. An additional family with two MR children was accepted in September and funded in January, 1977.

In facilitating program implementation at the community level, the team approach was used. The team typically consists of the parents, county social worker, and the teacher or therapist. The members are responsible for the assessment, planning, and evaluation of individual family program plans. The Minnesota Developmental Programming System (MDPS) provides pre-post assessment data on the child's functioning.

The MR-FSP is flexible in its guidelines; subsequently, the individual program plans reflect extensive creativity by the team in exhausting all available community resources. The subsidy maximum per month, per family, is $250. This amount includes financial assistance for: (1) medical care, (2) special diets and clothing. (3) special equipment ranging from medical devices to backyard fences and recreational equipment, (4) babysitting,

(5) respite care, (6) educational and therapeutic programs supplementing current school programs, and (7) programs for the very young child for whom no public school funds exist.

The following data report: (1) descriptions of participating children's families, (2) descriptions of the MR children, and (3) indicators of program efficacy.

Descriptors: The Families

As of January 1, 1977, five families had withdrawn from the MR-FSP. Reasons for the program terminations varied. In three situations, family circumstances altered drastically, thereby making placement out of the home desirable, at least temporarily.

> Nicky, age two and a half, was severely retarded, suffered seizures and required a gastrostomy tube due to severe digestive difficulties. Her parents separated and the mother felt unable to cope with the additional stress. Nicky was placed in a residential facility. The family had received $100 per month primarily for medical and equipment expenses.
>
> Richard, age six, was also severely retarded and had suffered from cerebral palsy and blindness. He was under the guardian. ship of his grandparents after his mother died and his father was sentenced to a reformatory. Placement at a state hospital was made after the grandfather was killed in an automobile accident. The family received $250 per month, covering basically respite care, babysitting and special equipment expenses.
>
> Barbara, a two and a half year old child with moderate retardation, was placed in a foster home after her mother suffered an emotional breakdown. The county welfare department seriously questioned whether the natural home was the most appropriate alternative for Barbara. It was reported by several medical and social service personnel that the home environment may have retarded her psychomotor development.

In the two remaining situations, the child's handicaps appeared to be the decisive criteria for placement.

> Kevin, age 15, was mildly retarded, suffered from some seizure activity, was hyperactive, and had extreme behavior problems (his disposition vacillated from being cooperative and polite to violent outbursts). The school and the parents were unable to control his extreme behavior. The social worker noted that, at one point, Kevin "threw his father half-way across the bedroom." After five months in the program, Kevin was placed in a residential facility. The MR-FSP provided $250 per month which covered primarily medical, babysitting costs and summer tutoring tuition. The financial aspects were not the dominant reasons for placement in a residential facility. The emotional strain of caring for a young man with severe behavior problems was reported as the reason for placement.

> Lisa, age eight, experienced multiple handicaps, including retardation, blindness, and seizures for which she needed to wear a helmet at all tines. She required total care from the family because her basic skills were minimal. She was not toilet trained. Lisa's parents and five older siblings were extremely nurturing and included her in their activities. The parents had always been concerned, however, that eventually placement would probably be necessary. After three months in the program, she was placed in a residential facility. Factors leading to placement included the family's concern that placement in a residential facility be made as soon as an opening existed because of limited availability of space, and the increasing difficulty in securing respite parental relief on occasional weekends.

The first entry into the program was March, 1976. This evaluation report is based on data compiled from that date through December, 1976, and is based on families who had participated in the program for an average of six months. Table 1 shows length of time in program for 51 families.

Table 1

MONTHS PARTICIPATED IN MR-FSP

Months in Program	Number of Families
1	0
2	0
3	3
4	3
5	8
6	13
7	13
8	6
9	5
Mean = 6 mos.	Total = 51

Twenty-eight counties in Minnesota were represented in the program. Table 2 provides the number of participants per county:

Table 2

COUNTY OF RESIDENCE

County	Number	Percent
Metro Area		
Anoka	1	2
Carver	2	4
Dakota	2	4
Hennepin	14	26
Ramsey	6	11
Scott	1	2
Washington	1	2
TOTAL	27	51
Southeast		
Goodhue	1	2
Olmsted	3	6
Rice	1	2
Steele .	1	2
Winona	1	2
TOTAL	7	14
Southwest		
Kandiyohi	1	2
Lincoln	1	2
Lyon	1	2
McLeod	1	2
Martin	2	4
Pipestone	1	2
Rock	1	2
TOTAL	8	16

(Table 2 con't.)

Northeast		
St. Louis	2	4
Northwest		
Becker	2	4
Benton	1	2
Crow Wing	1	2
Otter Tail	1	2
Red Lake	1	2
Stearns	1	2
Todd	1	2
Wright	1	2
TOTAL	9	18
GRAND TOTAL	53	99*

*Reflects rounding error.

As shown on Table 2, approximately 50% of the families reside in the metropolitan area.

The socioeconomic data obtained on the participating families includes family size, number of parents in the household, income, and outstanding bills solely related to the MR child's care. Tables 3, 4, 5, and 6 show the data elements respectively.

Table 3

FAMILY SIZE

Number of Family Members	Number of Families	Percent
2	1	2
3	12	23
4	14	26
5	13	25
6	4	8
7	3	6
8	2	4
10	1	2
11	2	4
15	1	2
TOTAL	53	102*

Mean = 5

Mode = 4

*Reflects rounding error.

"Family size" refers to those members of the family living at home, including the parent(s). The average (Mean) family size is 5. The family size of highest frequency (Mode) is 4.

Table 4

NUMBER OF PARENTS

Single Parent	Two Parents	Total
6	47	53

Families were categorized by the number of parents living at home at the onset of the program. Two of the single-parent families are recipients of AFDC (Aid to Families With Dependent Children).

Table 5

FAMILY INCOME

Income	Number	Percent
Less than 5,000	6	12
5,000 - 10,000	11	21
10,000 - 15,000	16	30
15,000 - 20,000	16	30
20,000 - 25.000	4	8
TOTAL	53	101*

Mean = $10,000 - 15,000
*Reflects rounding error.

The average gross annual income per family at point of entry into the program is between $10,000 and $15,000.

Also computed was the dollar amount of outstanding bills solely related to the MR child's health and care. The bills were primarily medical and had been incurred prior to the family's participation in the program. Monthly medical payments were considered to be a financial burden on

families who care for their handicapped child; subsequently, reasonable payments on outstanding medical bills were included, when possible, in the monthly financial subsidy. Table 6 provides data in this regard.

Table 6

OUTSTANDING BILLS

Dollar Amount	Number	Percent
Less than $300	22	45
$ 300 - 600	16	33
$ 600 - 900	4	8
$ 900 - 1,200	2	4
$1,200 - 1,500	1	2
$1,500 - 2,000	1	2
$2,000 - 3,000	1	2
$3,000 - 4,000	0	0
$4,000 - and up	1	2
TOTAL	48	98*

Mean = $300

*Reflects rounding error.

Descriptors: The MR Children

Extensive data continues to be collected on the MB children involved. In this report, the children are described by age, sex, "intelligence" test results, diagnostic information, and functional levels of performance.

The socio-environmental response to the children may be interpreted from

the data pertaining to any history of placements out of the home, the child's current educational program, the qualitative and quantitative description of educational objectives for the children, and the review of progress towards meeting the objectives.

Finally, a comparison of environmental responses to the same type of child in two extreme situations, specifically the state institution and the home-based MR-FSP, is made in Table 12.

Table 7

AGE AND SEX

Years of Age	Frequency	Female	Male
1-5	16	17	36
6-10	22		
11-15	11		
16	4		
TOTAL	53	53	
Mean Age = 8			

The age was determined as of 1976. The MR-FSP is designed to include MR children to the age of 18 years.

Table 8

"INTELLIGENCE" TEST SCORES

I.Q. Range		Number	Percent
Borderline	70 - 85	2	4
Mild	50 - 69	5	10
Moderate	35 - 49	6	12
Severe	below 35	19	38
Untestable		17	34
TOTAL		49	98*

*Reflects rounding error.

I.Q. scores were available on 49 children. Of significance in Table 8 is the large percentage (38%) of individuals identified as "severely - profoundly" retarded. "Untestable" refers primarily to preschool children who have not been tested due to their age which, very often, invalidates psychological testing. Also, in a number of cases, testing was impossible because of psychoneurological problems associated with hyperactive and/or "autistic" type children.

The degree of mental retardation, as suggested by I.Q. scores, does not, in itself, provide an adequate description of the children. A more comprehensive profile was compiled and includes data on the multiplicity of handicapping conditions in addition to mental retardation. Information was obtained from medical records and the parents. Tables 9 and 10 display the types and frequencies of additional handicaps experienced by these children.

Table 9

ADDITIONAL DIAGNOSES

Condition	Number
Physiological dysfunction	6
Severe hearing impairment	3
Severe vision impairment	5
Cerebral palsy	17
Uncontrolled seizures	10
Hyperactivity	12
"Autism"	8
Extreme behavior problems	6
Severe sleep problems	6
Mobile, nonambulatory	12
Nonmobile	16
"Other"	6

Categories in some cases were defined arbitrarily; therefore, the following definitions are presented:

Physiological dysfunction refers to severe upper respiratory problems, digestive and excretory abnormalities. It does not include muscular dysfunctions.

Uncontrolled seizures refers to seizure activity not eliminated thru the use of medication.

"Autism" refers to "psychotic" types of behavior, including a preoccupation with order, self-mutilating and self-stimulating behaviors, unintelligible speech, and inability to show affection.

Extreme behavior problems refers to antisocial behaviors which interfere with other's functioning and which teachers and parents are unable to control or eliminate without constant control techniques.

Severe sleep problems refers to the child who either cannot sleep for more than a few hours at a time, or to the child who awakens as early as 4:30 a.m. for the day.

Mobile, nonambulatory refers to the ability to walk with the assistance of crutches, or holding onto furniture for support.

Nonmobile refers to the inability to move about at all in an upright position, at an age when walking is expected of the average child.

"Other" refers to degenerative and terminal diseases and, in one case, to paralysis of one side of the body.

The multiplicity of handicapping conditions can be considered an important variable when analyzing the physical and emotional strain on family members. Many professionals believe that the stress on the family increases considerably, proportionate to the type and number of additional handicapping conditions beyond the diagnosis of "rental retardation".

Table 10

NUMBER OF ADDITIONAL HANDICAPS

Number of Handicaps	Number of Children
0	1
1	20
2	20
3	11
4	1
TOTAL	53

As noted in Table 10, in only one case is the child diagnosed as "mentally retarded" only. The percentage of MR children experiencing one, two and three additional handicaps is 37%, 37% and 20%, respectively.

A functional analysis of behavior completes the children's profile. The MDPS includes 18 behavioral scales, subdivided into 20 levels of mastery.

The assessment results provide an estimate of the child's skills. Table 11 gives examples of "level 5" mastery. The MDPS will be administered on a pre-post basis. Table 12 provides the behavioral categories and the mastery levels from the pretest scores. The descriptive statistics include the average level of mastery (Mean), the level at which 50% of the 53 children fall below (Median) and the most frequent level of mastery (Mode). The "mean" performance of 580 institutionalized individuals, in Minnesota's state hospitals, is also included for comparison. The population is comparable in age in that the data refers to individuals 18 years of age and younger.

Table 11

EXAMPLES OF LEVEL FIVE MASTERY ON MDPS

Scale	Level Five Behaviors
Gross Motor	Changes from lying on stomach to a sitting position.
Fine Motor	Turns a doorknob and opens the door.
Eating	Picks up a glass and drinks from it.
Dressing	Undresses self completely (may need help with belt or bra).
Grooming	Places a toothbrush in mouth and begins brushing motion.
Toileting	Goes to the bathroom with a reminder.
Receptive Language	Performs the appropriate action when the word "me" is used, such as, "Give me the ball."
Expressive Language	Imitates five words heard.
Social Interaction	Spends time alone with toys or objects for two minutes.
Reading	Identifies different sounds, such as bell ringing, hands clapping, whispering, keys jingling.
Writing	Marks on a chalkboard or paper in circles and lines.
Numbers	Counts to ten.
Time	Indicates own age.
Money	Selects a penny, nickel, dime and quarter from a group of. coins.
Domestic Behavior	Straightens bed.
Community Orientation	Chooses the correct restroom in a familiar public place.
Recreation, Leisure-Time Activities	Brush paints.
Vocational	Attends to an assigned task or activity for one-half hour (may need to be encouraged).

Table 12

MEAN GROUP PERFORMANCE BY MDPS BEHAVIORAL DOMAINS

	MR-FSP (N=53)			State Hospital (N=580)
Scale	Mean	Median	Mode	Means
Gross Motor	10	7	19	11
Fine Motor	7	5	0	7
Eating	3	6	2	8
Dressing	5	2	1	7
Grooming	6	4	1	6
Toileting	7	2	1	7
Receptive	8	7	2	7
Expressive	6	4	3	6
Social Interaction	9	9	7	6
Reading	5	3	0	4
Writing	4	2	0	5
Numbers	4	0	0	3
Time	3	1	0	3
Money	2	0	0	2
Domestic	3	0	0	3
Community Orientation	3	1	0	3
Recreation	5	4	0	3
Vocational	5	3	0	4

The scales in Table 12 are developmentally sequenced, beginning with the most rudimentary, i.e., gross motor skills. As to be expected, therefore, both the MR-FSP and State hospital population means decrease inversely proportionate to the increased mastery requirements. It appears that a discriminating skill area is "Social Interaction." The MR-FSP population's

Mean of nine exceeds the institutionalized population's Mean of six. From this discrepancy, one might infer that social interaction is more frequent in the home and, therefore, is learned more readily.

Information was obtained from the parents as to previous placement of their mentally retarded child out of the home. Table 13 summarizes this data.

Table 13

PLACEMENT HISTORY

Placement	Number
None	45
State Institution	
0-6 months	1
0-4 years	1
Residential	
0-6 months	1
1-2 years	1
5 or more years	2
Foster Home	
0-6 months	1
1-2 years	1
TOTAL	53

The majority (85%) of mentally retarded children had never experienced placement in a residential program. Two children were institutionalized in a state hospital, and four in a residential facility. A foster home placement was made in two cases.

At the point of entry into the program, data were also collected on the child's current educational program. The public school is responsible for providing the primary program for children over five years of age. However, the financial subsidy very often allowed the child access to therapy

or skill instruction which supplemented the primary educational program such as speech, physical and occupational therapy and additional self-help or academic instruction. For the MR behavior problem, hyperactive, and "autistic" children, the MR-FSP facilitated essential consultation and direct services in behavior management.

The county has the option of providing an educational or therapeutic program through the day activity centers to the preschool child. In seven out of the 14 children four years and younger, the county either did not pay for services or did so only partially. Therefore, in these cases, the subsidy program provided for their educational and therapeutic needs. Table 14 shows the distribution of children by primary and Supplemental distribution.

Table 14

CURRENT EDUCATIONAL PROGRAM

	Primary Number	Program Percent	Supplemental Number	Program Percent
Homebound	8	15	9	17
DAC	16	30	1	2
Special School or Class	29	55	3	6
TOTAL	53	100	13	25

All 53 of the MR children were enrolled in an educational program designed to meet the child's particular educational needs. The children's education was provided through homebound therapy, day activity centers (DACs), specialized schools, or public school special education classes.

Homebound therapy was very often provided by the multicounty nursing ser-

vice available through the county, or by a person specially trained, such as a DAC teacher. The therapies included physical, sensorimotor, and speech. Homebound therapy was provided for preschool children or for multiply-handicapped children who did not have access to adequate transportation, In eight cases, homebound therapy was the total program and, in nine cases, it served to supplement partial—day programs.

A total of 16 children were enrolled in DACs as the primary educational program, and one child utilized the DAC facility as an additional program.

Special schools or special education classes in the public schools provided educational programs to 29 children and a partial-day program to three children.

Following the administration of the MDPS, educational objectives were established and recorded. The data in Table 15 refers to the number and percentage of children with objectives identified in the various skill areas.

Table 15

EDUCATIONAL
OBJECTIVES (N=53)

Educational Domain	Number	Percent
Gross Motor	45	84
Fine Motor	44	83
Eating	43	81
Dressing	37	69
Grooming	36	67
Toileting	33	62
Receptive	40	75
Expressive	33	71
Social Interaction	41	77
Reading	22	41
Writing	23	43
Numbers	18	33
Time	9	16
Money	9	16
Domestic	16	30
Community Orientation	13	24
Recreation	17	32
Vocational	15	28

The educational domains are listed in a developmental sequence with the most elementary skill area "Gross Motor" listed first. As might be expected from the diagnostic data and MDPS scores, the major emphasis in the educational programs for these children is in the motor, self-help and communication areas. It is interesting to note the expectations of

these children in areas beyond basic self—help.

The child's progress in meeting the objectives is reviewed quarterly. Data from the December mid-year reviews were translated into "importance value" figures by multiplying the "number of educational areas" by the "number of children" in each of three criterion situations: (1) no progress, (2) progress, and (3) objective met. Thus, "no progress" yielded a value of 94, whereas "progress" yielded a value of 322, and "objective met" yielded a value of 31. These figures indicate significant progress towards the educational objectives in spite of the fact that the children have been involved in the program on the average of six months.

MR Family Subsidy Program Efficacy

At the onset of the program, an attempt was made by the programming team to project a monthly grant amount which would adequately cover the family's expanses incurred in caring for their retarded child. Due to the fixed limit of $250 per month, high cost items and services which would exceed the limit for a given month had been prorated. Parents would then "save" money in order to cover these expenses. The grant was provided on the basis of needs identified by the fallowing categories:

> Medical refers to all physician, clinic, and related hospital expenses for the child, prorated on a monthly basis, not covered by insurance. It also includes monthly payments on outstanding medical bills for the child.
>
> Medication refers to prescription and excessive over-the-counter drugs.
>
> Educational Program refers to therapies, tutoring, and special programs which supplement the public school or day activity center programs; educational services to the preschool child when unavailable otherwise; consultation and direct service fees for

behavioral therapists and developmental disabilities specialists; tutoring and special programs during summer vacations; and to special educational summer camps.

Babysitting refers to paid supervision of the child during the day and for occasional evenings. In two instances, the baby-sitter is a family member because of the expertise required and the inability to locate another provider.

Respite Care refers to paid supervision of the child for an occasional weekend or family vacation. It includes either the total charge for a person coming into the home, or the 10% charge to the parents when a county or state facility is used under the "Cost of Care" program.

Special Clothing and Diet: refers to all clothing and food costs exceeding what is normally expected with a child the same age. "Unusual clothing" includes items such as disposable diapers, rubber pants, extra clothes, and extra bedding for the child with uncontrolled bowel activity (the diapers and rubber pants are subsidized expenses for the older child only); and items such as orthopedic shoes.

Special Equipment refers to all medical devices, such as hearing aids, helmets, body casts, braces; special furniture, such as bean bag chairs, wheelchairs, car seats, commodes, hospital beds; recommended teaching materials and physical therapy apparati for home use and for school use if unavailable otherwise; recreational equipment, such as swing sets, three-wheeled bicycles; and miscellaneous items including fences and stairway ramps.

Transportation refers to gasoline expenses in transporting the child to clinics for medical evaluations or for special therapies, to recreational programs, to educational programs for the preschool child, and to summer school programs. It also includes overnight lodging for parents of children, undergoing periodic medical examinations quite a distance from home, for two or more consecutive days.

Counseling refers to parent or family counseling for emotional problems either as a result of caring for a multiply-handicapped child or directly affecting the child's emotional well-being.

Other refers to expenses incurred which have not been previously included.

Estimated monthly expenses were projected for families as they entered the program. Adjustments were made mid-year in December, 1976. Table 16 shows: CD data on the number of families who projected the use of various categories initially and after the adjustment, (2) data on the number of families spending money within dollar amount intervals per category, and

(3) the average (mean) amount of money spent per category for those families utilizing that category.

TABLE16

PROJECTED MONTHLY EXPENSES

Category	Families Using Category				$1- 25		$26-50		$51-75		$76-100		$101-150		$151-200		$201-250		Mean	
	Int.		Adj.		Int	Adj	Int	Adj	Int	Adj	Int	Adj	Int	Adj	Int	Adj	Int	Adj	Int	Adj
	N*	%	N**	%	N*	N**	N*	N**	N*	N**	N*	N**	N*	N**	N*	N**	N*	N**	$	$
Medical	35	68	37	74	15	14	11	13	3	4	4	4	2	2			1		48	40
Medication	34	64	38	76	25	35	8	3			1								19	16
Ed. Program	36	68	27	54	11	9	5	3	3	3	4	3	4	4	5	3	4	2	87	79
Babysitting	46	87	48	96	14	14	15	16	4	9	5	6	5	2	2	1	1		60	49
Respite Care	22	42	22	44	18	15	4	5		1		1							18	25
Special Clothing	23	43	31	62	15	22	7	7	1	2									24	24
Special Diet	8	15	20	40	6	13	1	2		4	1			1					23	23
Special Equipment	35	66	42	84	16	22	9	12	5	6	3	1	2	1					38	32
Transportation	36	68	42	84	25	28	9	9		3	1	1		1	1				24	28
Counseling	5	9	4	8	3	3	1			1			1						34	34
Other	2	4	3	6	1	3			1										36	5

* Calculations based on N=53;all data entered

** Calculations based on N=50; all data entered

The mid-year financial adjustment resulted in projected expenditures approximating the previous estimates. First of all, approximately the same categories are being utilized throughout the duration of the program. Secondly, the average dollar amount per category is relatively the same throughout the first and latter half of the program. The only significant exception is that families are using $31 less per month in the catch-all category of "other" in the last half of the year. This latter discrepancy can be explained by the fact that during the first half of the program, the "other" category was sometimes used to include educational and health programming needs. During the latter half of the program, these expenses were more appropriately itemized under "educational program" or "medical".

The significance of specific categories to the family's needs can be interpreted based on (l) the number of families utilizing the category and (2) the average projected dollar amount per category. Therefore, the categories of highest significance appear to be, in order of priority: (1) educational programming at $79 per month and utilized by 54% of the families, (2) babysitting at $49 per month and utilized by 96%, (3) medical at $40 per month and utilized by 74%, and (4) special equipment at $32 per month and utilized by 84%.

The monthly totals are tabulated in Table 17.

Table 17

PROJECTED TOTAL MONTHLY SUBSIDY

	Initial		Adjusted	
	N	%	N	%
$100-125	2	4	1	2
$126-150	1	2	2	4
$151-175	5	10	3	6
$176-200	8	16	10	20
$201-225	3	6	8	16
$226-250	34	64	26	52
TOTAL	53	102*	50	100
Mean	$224		$223	

*Reflects rounding error.

In establishing optimal programs for the families, the families have required, on the average, $224 per month.

At the time the initial projected estimates were made, data were collected on the number of families needing monthly grants in excess of $250 per month. It was determined that 12 families would ideally need between $150 and $200 above the ceiling of $250.

Information was also gathered regarding medical insurance coverage for the MR child. Of the 53 families, 44 (or 85%) utilized medical insurance. In a few cases, the child's portion of the insurance premium was reimbursed. The MR-FSP also provided medical expense reimbursement for items not covered under the insurance policies.

In a November, 1976 questionnaire, the parents were requested to race the various categories subsidized as to "importance" in alleviating problems

in their particular situation. All families participating at that time responded and the data are summarized in Table 18.

Table 18

PARENT RATING
(N=51)

Category	Most Important	Moderate	Least	NA*
	N	N	N	N
Medical	28	8	3	12
Medication	17	13	5	11
Educational Program	21	8	5	17
Babysitting	30	14	4	3
Respite Care	13	10	11	17
Special Clothing	11	11	6	23
Special Foods	6	7	4	34
Special Equipment	23	17	6	5
Transportation	11	20	7	13
Counseling	7	5	5	34
Other	0	2	1	48

*Refers to categories not applicable.

According to Table 18, the categories rated as most important were (1) babysitting for 30 families, (2) medical for 28 families, (3) special equipment for 23 families, and (4) educational programs for 21 families.

In the same November questionnaire, parents were asked to indicate whether they had seriously considered placement of their child out of the home. Those parents responding in the affirmative were then asked to rate the MR-FSP's effect on altering this decision. The results are tabulated in Table 19.

Table 19

MR-FSP's EFFECT ON FUTURE INSTITUTIONALIZATION

Effect	Number
MR-FSP completely altered decision to place	4
MR-FSP altered somewhat decision to place	7
MR-FSP did not alter decision to place	1
TOTAL	12

At the onset of the program, 12 families had seriously considered making placement arrangements out of the home. As a result of participation in the MR-FSP, four families were no longer considering such an alternative, seven had somewhat altered their decision, and one family's decision was unchanged.

Summary of Findings

1. On the average, families have participated in the program for six months.

2. The families are equally distributed between the metropolitan and out-state areas.

3. The "typical" family has two parents with five family members, an annual gross income from $10,000 to $15,000, and $300 in outstanding medical bills on their MS child. Approximately $224 per month from the MR-FSP adequately covers the expenses incurred while caring for the child in their home.

4. The "typical" MR child appears to be eight years old, with an I.Q. below 35, suffering from one or two additional handicapping conditions of which cerebral palsy, seizures, difficulties in mobility and hyperactivity are the most frequent. In spite of the fact that the average MR child's behavioral functioning is comparable to that of the institutionalized child in the state hospitals, the child has not had a history of placement out of the home. The child, for the most part, is enrolled in a special school or special education class and is progressing well in the basic skill areas of motor development, self-help and communication.

5. The categories of significant need to the families as measured by the frequency of use, by the amount expended, and by the parent ratings, are:

   a. educational programming
   b. babysitting
   c. medical
   d. special equipment

6. With regard to the MR-FSP's effect on future institutionalization, the program appears to have (a) altered "somewhat" seven out of 12 families' decisions to place their child out of the home, and (b) completely altered the decisions of four of the 12 families. As to the two families who withdrew from the program and placed their child in an institution, severe behavior problems and a lack of self-help skills were the decisive criteria.

Recommendations

Based on the findings, the following recommendations are made:

I. Grants need to be provided on a flexible basis rather than arbitrarily limited to $250 per month. The individual needs of families vary, due to the uniqueness of each situation. Twelve of the participating families had documented needs beyond the $250 per month maximum. Because of this limit, it was necessary to prorate high cost items and services over 12 months, rather than immediately paying for then as they occur. That process has been extremely cumbersome both for the county welfare staffs and the families,

II. Expenses can be prevented from becoming excessive with adequate guidelines dictating appropriate use of MR-FSP funds. A very difficult decision must be made as to whether items and services purchased by families of normally functioning children should be subsidized to families with retarded children. If such a decision favors cost coverage of only unusual expenses, the following definitions of "appropriate" expenses may be used to establish more conservative guidelines:

1. Medical - All medical and dental costs not covered by medical insurance, Medical Assistance, or social service monies; payment on previously incurred medical bills, up to a limit of $1,000, for the child; costs of medical personnel, such as county nurses providing special services to the child and consultation to the parents.

2. Medication - All prescription drugs, not to include over-the-counter drugs.

3. Educational Program - All programming costs not covered by the county, for children under the age of four years and for whom special education programming is not mandated by the public educational system; consultation and direct service fees for behavior therapists and supplementary special programs for MR behavior problem, hyperactive, and "autistic" children; summer tutoring and/or therapy costs when not provided by special or public education; and summer camp tuition.

4. Babysitting - All babysitting expenses paid to a provider.

5. Respite Care - Cost coverage to be paid a provider coining into the home for an occasional weekend and for family vacation time, not to include the minimal 10% charge to the family under the "Cost of Care" program.

6. Special Clothing - All extra clothing and bed linens used for the no toilet-trained child, and medically prescribed articles such as orthopedic shoes.

7. Special Diet - All special food costs which exceed that for an average child.

8. Special Equipment - All medical devices as prescribed by a physician; special furniture required for basic maintenance, such as wheelchairs, car seats, commodes, hospital beds; physical therapy equipment as prescribed by a physician for home use only; recreational equipment and backyard fences for the older mentally retarded child and for the severe behavior problem, hyperactive, and autistic child of all ages; stairway ramps and special lifts.

9. Transportation - Gasoline expenses in transporting the child more than 50 miles one way to medical facilities for evaluations and/or special therapies.

III. Finally, continue the MR-FSP at the experimental level of 50 families for two years so as to provide longitudinal data on the MR children and their families. The child's progress will be measured against pre-set goals, treads will be noted, and program efficacy determined.

A P P E N D I X

1975 DPW Policy Bulletin #120

Minnesota Rule DPW 19

Department of Public Welfare

Program for Home Care and Training of Menially Retarded Children

DWP 19 Experimental program for the home care and training of children who are mentally retarded.

A. Introduction.

1. This rule governs the administration of reimbursement to local boards for the cost of home care and training of children who are menially retarded pursuant to this program of family subsidy [[.]], as provided in Minn. Stat. i; 252.27. subd. 4.

2. Definitions.

a. Child. Any person under the chronological age of 18 years.

b. Home. The home of the natural, adoptive or step parents(s), or legal guardian, in which the child is or would be living for purposes of this experimental program.

c. Licensed community residential facility for mentally retarded persons. A facility which is licensed under DPW 34 (Minn. Stat. .252.28), and the Minnesota Department of Health Rule for supervised living facilities[[.]] (Minn. Stat. 144.56).

d. Local board. A county welfare/human service board established under the authority of Minn. Stat., chs. 393 or 402, as amended.

e. Mentally retarded person. A mentally retarded person refers to any person who has been diagnosed as having significantly subaverage intellectual functioning existing concurrently with demonstrated deficits in adaptive behavior [[such as to require supervision and protection for his welfare or the public welfare.]] and manifested during the developmental period.

(1) Intellectual functioning shall be assessed by one or more of the professionally recognized standardized tests developed for that purpose: significantly subaverage refers to performance which is approximately two or more standard deviations from the mean or average of the tests. [[Mental retardation under this rule includes manifestation during the developmental period to 18 years of age and brain injuries occurring in adult life.]]

(2) Adaptive behavior shall be determined through the use of published scales, or by a combination of pertinent test data, professional observations, and the utilization of all available sources of information regarding the person's behavior which indicates the degree with which the individual meets the standards of personal independence and social responsibilities expected of his age and peer group.

f. Minnesota developmental programming system (MDPS) behavioral scales. A tool used in assessing mentally retarded persons to assess their behavioral skills, provide a basis for planning programs to increase their skills and consequently their independence, and determine what new behavioral skills have been acquired over a period of time.

g. Parent. A natural, adoptive or step father or mother or a legal guardian.

h. State agency. The Minnesota Department of Public Welfare.

B. Eligibility for participation in the program.

1. This program shall be for those children who at the time of application, are residing in Minnesota and (a) who are living at home, or (b) who are residing in a state hospital or in a licensed community residential facility for the mentally retarded who under this program would return to their own home. Those children living at home must also be determined by the local board eligible for placement in a state hospital or a licensed community residential facility for the mentally retarded.

2. Each child considered for participation shall have been diagnosed as mentally retarded.

3. Parent(s) of children participating in this program shall be informed by the local board that this program is experimental in nature, and that due to its experimental nature, those parents must consent, in writing, to the following conditions:

a. Participation in the behavioral assessment of the child by means of the Minnesota Developmental

Programming System which will be provided by the local board.

b. Furnishing sociodermographic data about the home environment.

c. Participation in evaluating the child's progress toward meeting his goals in the individualized treatment plan on a quarterly schedule.

Parent(s) shall also be informed by the local board that the program is financed through June 30, 1977, and that continuation will be contingent upon success of the program and further appropriations by the Minnesota Legislature.

The state agency and local board shall assure in writing to the parent(s) that his participation and furnishing information for the purposes of evaluation will be solely for the purposes of evaluating the program and that all data collected will be rigorously safeguarded with regard to confidentiality of data. All data accumulated on the child, his program and his environment will be available to the parent(s).

4. Acceptance and approval of applications by the state agency with priority given on the basis of the following factors:

a. Severely handicapped persons.

b. Degree of need in family environment (i.e. single parent families).

c. Potential for greatest benefit i.e. degree of developmental advancement as measured by the Minnesota Developmental Programming System.

C. Procedures.

1. Application is submitted by the local board to the Commissioner. Department of Public Welfare, Mental Retardation Division. Centennial Office Building, St. Paul, Minnesota 55155, ATTENTION: Director.

Application must include:

a. Application for social services, DPW-1400

b. Service plan and agreement, DPW-1950

c. Diagnostic data

d. Evidence of eligibility for institutionalization

e. Grant amount requested for services specified in C.1.b.

Forms DPW-1400 and 1950 are not to be used to determine financial eligibility for grants but for identifying <u>name and address</u> information and defining needed services.

2. The local board shall provide the state agency with quarterly progress reports concerning progress of the child. Quarterly progress report forms will be furnished by the state agency upon acceptance of the child into the program.

3. Upon approval by the state agency, the local board shall make grants to the parent(s) of the mentally retarded child. The grant shall be an amount equal in the direct costs of the services outlined in the service agreement subject to a maximum of $250 per month. The costs shall include one or more of the services pro vided in Minn. Stat. 252.27. subd. 4, or related services stipulated in the individual program plan. Reimbursable costs shall not include resources already available such as special education classes, daytime activity center programs, or medical costs covered by insurance if these resources are available at no cost to the child or parent(s).

D. Payment.

1. Local boards shall receive quarterly reimbursements from the state agency by filing the prescribed claim forms.

KEY: New rules and material proposes to be added to an existing rule are printed in boldface. Material proposed to be deleted from an existing rule is printed in[single brackets]. <u>Underlining</u> indicates additions to proposed rules, while [[double brackets]] indicate matter stricken from proposed rules. Existing material is printed in standard type face.

B. The local social service agency shall provide the State Agency with quarterly progress reports concerning progress of the child. Quarterly progress report forms will be furnished the local social service agency upon acceptance of the child into the program.

C. Upon approval by the State Agency, the local social service agency shall make grants to the parents of the primary client. The grant shall be an amount equal to the direct costs of the services outlined in the service agreement subject to a maximum of $250 per month.

Local agencies shall receive quarterly allowances from DPW for the costs via filing claim forms prescribed by DPW.

Any questions regarding this bulletin should be addressed to Ardo Wrobel, Director, Mental Retardation Division, Department of Public Welfare (296-2160).

Very, truly yours,

Vera J. Likins
Commissioner

STATE OF MINNESOTA
DEPARTMENT OF PUBLIC WELFARE
CENTENNIAL OFFICE BUILDING
ST. PAUL, MINNESOTA 55155

OFFICE OF THE
COMMISSIONER
612/196-2701

GENERAL
INFORMATION
612/296-6117

1975 POLICY BULLETIN #120 December 8, 1975

TO: Chairperson, County Welfare Board
Attention: Welfare Director

Chairperson, Area Board
Attention: Program Director

State Hospital
Attention: Chief Executive Officer/Medical Director

Chairperson, Human Services Board
Attention: Director

SUBJECT: Experimental Program for Home Care and Training for Children Who are Mentally Retarded - FAMILY SUBSIDY PROGRAM

This bulletin is to be used to initiate and carry out the provisions of U.S. 252.27, Subdivision 4, which establishes an experimental program for home care and training for children who are mentally retarded. This program will be called MR Family Subsidy Program. During F. Y. 1976-77, this program is limited to 50 families as selected by DPW.

Application may be submitted upon receipt of the bulletin.

MR FAMILY SUBSIDY PROGRAM

Minnesota Statutes, Section 252.27, Subd. 4, provides:

> In order to determine the effectiveness of the family unit in providing alternate living arrangements and providing or arranging for the training and developmental opportunities provided in a state hospital or a licensed community residential facility, the commissioner of public welfare may establish an experimental program to subsidize selected families who agree to carry out a planned program of home care and training for their minor dependents who are mentally retarded.
>
> This program shall be limited to children who otherwise would require and be eligible for placement in state hospitals or licensed community residential facilities.

Grants to families shall be determined by the commissioner of public welfare. In determining the grants, the commissioner shall consider the cost of diagnostic assessments, homemaker services, training expenses including specialized equipment, visiting nurses' or other pertinent therapists' costs, preschool program costs, related transportation expenses, and parental relief or child care costs not to exceed $250 per month per family.

An individual care and training plan for the child shall be established and agreed upon by the parents receiving the subsidy and the appropriate local welfare agency. Periods of parental relief, including vacations, may be included in the plan and do not require the approval of the local welfare agency. The plan shall be periodically evaluated to determine the progress of the child.

This policy governs the administration of reimbursement to county welfare boards or human service boards for the cost of home care and training for children who are mentally retarded pursuant to this program of family subsidy.

I. Definitions

A. Child - any person under the chronological age of 18 years.

B. Mentally Retarded - shall mean a person who has significantly subaverage intellectual functioning existing concurrently with demon-strated deficits in adaptive behavior such as to require supervision and protection for the individual with this disability.

1) The diagnosis of mental retardation shall be made by a licensed psychologist as defined in U.S. 148.88 to U.S. 148.99.

2) When psychological examination is not possible because of the severity of mental retardation, the combined diagnosis of a psychologist or a physician knowledgeable in the area of mental retardation and the local social service agency social worker shall be required.

C. Local Social Service Agency - local agency which is under the authority of the county welfare board or human service board, which is responsible for social Services.

D. State Agency - Minnesota Department of Public Welfare.

E. Parent - shall mean a father or mother, natural or adoptive. It also includes a legal guardian.

F. Primary Client - mentally retarded child who is the primary benefactor of the family subsidy grant.

G. Social Worker - shall mean any qualified person who is paid on a full or part-time basis to render professional social service to individuals, families, groups or communities.

H. Cost of Home Care and Training - may include the costs of one or more of the services provided in M.S. 252,27, Subd. 4, or any other services provided in the individual program plan as approved by the State Agency. Such cost shall not include resources available to the child or parent(s) at no cost to then.

I. Home Care - shall mean the home of the natural or adoptive parents, or legal guardian, In which the child is or would be living for purposes of this experimental program.

J. Minnesota Developmental Programming System (MDPS)Behavioral Scales - available from Outreach Training Program, 301 Health Services Building, University of Minnesota, St, Paul, Minnesota 55108.

II, Eligibility for Participation in the Program

A. This program shall be for those children, residing in Minnesota, who are under the age of 18 years, and, who are living at home, or, who are residing at a state hospital or in a licensed community residential program for the mentally retarded who, under this program, could return to their own hose. Those children living at home must also be determined eligible for placement: in a state hospital or a licensed community residential facility for the mentally retarded.

B. Each child considered for participation shall have been diagnosed as mentally retarded (as defined in Section I, B, Definitions),

C. Parents of children participating in this program shall be informed by the local social service agency that this program is experimental in nature and that due to its experimental nature, those parents must consent in writing to the following conditions:

1) Participation in the behavioral assessment of the child by means of the Minnesota Developmental Programming System.

2) Furnishing certain socio-demographic data about the home environment.

3) Participation in evaluating the child's progress toward meeting his goals on a quarterly schedule.

Parents shall also be informed that the program is financed through June 30, 1977, and that continuation will be contingent upon success of the program and further appropriations by the Minnesota Legislature.

The State Agency shall assure the parents that their participation and furnishing information for the purposes of evaluation will be solely for the purposes of evaluating the program and that all data collected will be rigorously safeguarded with regard to confidentiality of data. All data accumulated on the child, his program, and his environment will be available to the parents.

D. Acceptance and approval of applications by the State Agency (DPW) will be based upon the following factors with priority considerations given to the following:

1) Age of child (youngest given highest priority).

2) Severity of handicapping conditions.

3) Degree of need in family environment (i.e., single parent families).

4) Potential for greatest benefit (i.e., degree of improvement over present condition expected by social service agency).

5) Degree of comprehensiveness and appropriateness of the Individual Program Plan.

E. Participation will be limited to 50 children of whom approximately one-half are currently residing in state hospitals.

F. The first closing of applications will be January 15, 1976, and the second closing March 15, 1976.

III. Procedures

A. Application is submitted by the local social service agency to the Commissioner, Department of Public Welfare, Attention: Director, Mental Retardation Division, Centennial Building, St. Paul, Minnesota 55155.

Application should include:

1.) Application for Social Services, DPW-1400.

2.) Service Plan and Agreement, DPW-1950.

3.) Diagnostic data.

4.) Evidence of eligibility and need for institutionalization.

5.) Grant amount requested for services specified in III, A, 2 above.