

POLICY ANALYSIS SERIES

ISSUES RELATED TO WELSCH v. LEVINE / NO. 18

THE MINNESOTA FAMILY SUBSIDY PROGRAM: ITS EFFECT ON FAMILIES
WITH A DEVELOPMENTALLY DISABLED CHILD

I. INTRODUCTION

The provision of financial incentives and home-based services to assist families with developmentally disabled children is a fairly recent policy development. Support for families has emerged as a response to the spiraling costs of out-of-home placements and to a heightened awareness of the service functions that families perform for their members. The effectiveness of financial incentives and home-based services is being demonstrated and tested throughout the United States by both voluntary and public agencies (Wisconsin Council on Developmental Disabilities, 1983).

The purpose of this study is to describe the effect of the Minnesota Family Subsidy Program on families with a developmentally disabled child. The Minnesota Department of Public Welfare began the program in 1976. It was authorized by Minn. Stat. § 252.37, Subd. 4, and defined by DPW Rule 12 MCAR § 2.019:

The 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. [12 MCAR § 2.019, B(1)]

Priority is given to families of severely and multiply handicapped children who are experiencing a high degree of family stress and show the greatest potential for benefiting from the program.

The program provides grants to parent(s) in an amount equal to the direct cost of the services outlined in a service agreement. Grants are to assist in the payment 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.
(MINN. STAT. § 252.27, Subd. 4)

The program is designed to complement, not duplicate, other community services and programs. Initially, the program included only 50 families; but in fiscal year 1982-83, it was expanded to include up to 200 families throughout Minnesota. The current legislative appropriation of \$525,800 for fiscal year 1982-83 is expended in grants to 187 families. There is a lengthy waiting list for the program.

II. METHODOLOGY

A sample of 70 families was selected. Letters were sent requesting their participation in the study. Staff attempted to obtain a balanced representation of county residency and length of involvement in the program. Of the sample of 70, 38 families agreed to participate. A telephone survey was conducted with the individual identified as the primary caretaker of the developmentally disabled child in these families. In 37 cases, this was the mother; in one instance, it was the child's grandmother. The telephone interviews were completed in less than one hour. The small sample size (n = 38) means that caution should be taken in generalizing the findings to the study's total population.

The questionnaire was comprised of three sections. The first section contained 177 structured items regarding demographic information, program use, and program evaluation. The second section included four open-ended questions regarding strengths and limitations of the program. These questions provided a reliability check on the first section and allowed respondents to expand on the perceived positive aspects and shortcomings of the program. The final section consisted of information from public (DPW) records on four environmental factors: county size, county mean income, number of county residents with mental retardation, and number of residential placements (beds) for persons with developmental disabilities in the county.

III. RESULTS

A. Family Characteristics

An examination of family characteristics reveals a generally homogeneous group. Of the 38 families in the survey, 36 (95 percent) have two parents who have not been divorced nor separated. The number of children actually living at home ranges from 1 to 6. Overall, there is a total of 68 boys and 54 girls represented among the families, or approximately 20 percent more boys than girls. The sex distribution of the children with developmental disabilities reflects a similar pattern: 24 boys (63 percent) and 14 girls (37 percent).

Ages of the sample parents range from their late twenties to their fifties. None of those surveyed are over 60 years old. The average age category of the children with developmental disabilities is 5 to 9 years. Nineteen of the children (50 percent) are in this age group. The remaining children are distributed among the other categories as follows: five preschoolers (13 percent), aged 2 to 4 years; ten preadolescents (26 percent), aged 10 to 12 years; and four adolescents (11 percent), aged 13 to 17 years.

Annual family income ranges from the income categories of \$5,000 or less to a high of \$40,000 to \$49,000. The majority of family incomes (84 percent) are distributed between \$10,000 and \$24,000.

All of the 36 fathers in the study are employed; almost all (94 percent) work full time. The remaining 6 percent (N = 2) are employed part time. Mothers tend to be employed outside the home far less frequently. Of those mothers who do work outside the home, 10 are employed (26 percent) part time and 6 full time (16 percent). The other 22 are full-time homemakers (58 percent).

In terms of the developmentally disabled child for whom the family receives a subsidy, the effect of the child's handicapping condition on his or her ability to function is severe. Over three-fourths (n = 29) of the families reported that the child's condition greatly affects his or her ability to toilet independently. Of those persons responding to the question regarding the child's ability for self-care, such as self-feeding and self-dressing, 23 (93 percent) responded that the disability affected these skills. Twenty-two (58 percent) reported that the child's handicapping conditions also greatly affect his or her ability to relate to adults, while twenty-one (55 percent) reported it greatly affects the child's ability to walk. The only functioning abilities which were not greatly affected in a majority of children were the ability to see and hear. Of the 37 respondents, 23 (62 percent) indicated that the disabling condition does not greatly affect the child's sight or hearing (see Table 1).

Table 1
 The Effect of the Developmentally Disabled
 Child's Condition on Ability to Function
 (Minnesota Family Subsidy
 Study: 1982; n = 38)

| AFFECTED FUNCTIONAL ABILITY | NUMBER OF RESPONDENTS | L E V E L O F E F F E C T | | |
|--------------------------------|-----------------------------|---------------------------|-------------------|-------------------------------|
| | | None/Small (percent) | Some (percent) | Great/Very Great (percent) |
| Toilet independently | 38 | 18% | 5% | 77% |
| Walk | 38 | 34% | 11% | 55% |
| See | 37 | 62% | 11% | 27% |
| Hear | 37 | 62% | 27% | 11% |
| Play with other children | 38 | 8% | 16% | 76% |
| Relate to adults | 38 | 13% | 29% | 58% |
| Other ^a | 25 | 0% | 8% | 92% |

^aOther includes self-feeding, self-dressing, and self-control.

B. Family Resources

Family and community resources identified by respondents as being most helpful to them with respect to the care of their developmentally disabled children are the public school, their other children, and county welfare departments (see Table 2).

Table 2
 Extent to Which Identified Resources Are Helpful to Respondents
 (Minnesota Family Subsidy Study: 1982; n = 38)

| TYPE OF RESOURCES | NUMBER OF RESPONDENTS | E X T E N T O F H E L P | | |
|----------------------------------|-----------------------|-------------------------|----------------|----------------------------|
| | | None/Small (percent) | Some (percent) | Great/Very Great (percent) |
| Schools | 37 | 11% | 22% | 67% |
| Children | 34 | 29% | 24% | 47% |
| County welfare agency | 37 | 54% | 11% | 35% |
| Parents | 36 | 58% | 25% | 17% |
| State hospital | 35 | 80% | 3% | 17% |
| Sisters | 31 | 78% | 6% | 16% |
| Parents-in-law | 35 | 78% | 11% | 11% |
| Friends | 38 | 68% | 21% | 11% |
| Developmental Achievement Center | 32 | 85% | 6% | 9% |
| Brothers | 31 | 91% | 3% | 6% |
| Sisters-in-law | 35 | 88% | 6% | 6% |
| Public health center | 35 | 88% | 6% | 6% |
| Religious organization | 38 | 84% | 13% | 3% |
| Mental health center | 33 | 94% | 3% | 3% |

C. Subsidy Benefits

Families receive payments ranging from \$76 to \$250 per month with over two-thirds (n = 26) receiving the maximum allowable amount of \$250. Most of the families (n = 19, 49 percent) have participated in the program for less than two years, reflecting the program's recent expansion. Only 4 families (10 percent) have participated in the program since its inception or very early years, while the remaining 15 have participated in the program from two to three years.

D. Out-of-Home Placement Plans

Almost none of the families (n = 37, 97 percent) have ever placed their developmentally disabled child out of the home. The family who had a previous placement did so primarily because of the child's low functional level. The child subsequently returned home because

of improved functioning and because the subsidy had become available. Although only two families indicated they presently plan to place their child in long-term care in a foster home or institution, one-half of the families (n = 19) stated that they anticipated making such plans in the future.

E. Program Usefulness

Thirty-seven of the respondents (97 percent) reported that the Family Subsidy Program is of "great or very great help." One family (3 percent) rated the program as being of "some help."

Respondents indicated that the subsidy program assists in relieving financial, psychological, and social stresses. Participating families felt that the subsidy was of great or very great help in the following activities: purchasing special items needed by the child (n = 36, 95 percent); attending to the needs of the developmentally disabled child (n = 35, 92 percent); purchasing babysitter services or respite care (n = 27, 71 percent); doing things outside the home, such as going to movies or taking walks (n = 23, 61 percent); doing things with other children in the family and their spouse (n = 22, 58 percent); and attending to the needs of other family members (n = 21, 55 percent).

With regard to other dimensions of family functioning and coping, comparison of respondents' perceptions of their situation before and after program participation leaves little doubt as to the positive effects of the program. For example, only two respondents (5 percent) said they were able to purchase special items needed by the developmentally disabled child to a great or very great extent before receiving the subsidy, contrasted with 36 (95 percent) after receiving the subsidy. Other purchases and activities were affected similarly; only one family (3 percent) said they were able to purchase respite care to a great or very great extent before, contrasted with 27 (71 percent) after; attend to the needs of the developmentally disabled child, 2 families (5 percent) before, 35 (92 percent) after; and attend to the needs of other family members, 6 families (16 percent) before, 21 (55 percent) after.

The subsidy was not perceived as having a great impact on ability to keep up with household chores for 24 respondents (63 percent) or ability to work outside the home for 14 mothers (37 percent). At the same time, respondents felt that they did manage better along these dimensions after they received the subsidy than before.

While the program enables families to cope and function better and to care for their developmentally disabled child at home, the subsidy does not cover all of the expenses entailed in the child's care. Almost two-thirds (n = 24) of the families reported additional expenses in the categories covered by the subsidy. These costs include: medications, education, special equipment, baby

sitting, special clothing, respite care, special food, and transportation.

F. Ratings of Services

When asked to rate the services purchased by the subsidy grants in terms of quality, availability, accessibility, convenience, and cost, such services were rated highly on all five counts. Indeed, comparing the overall mean ratings of subsidy purchased services with those of services provided by family and friends, and community agencies, subsidy purchased services were more highly rated (see Table 3).

G. Possible Program Improvements

Thirty-four families (89 percent) said they thought the program should be expanded to include young adults. One respondent, however, felt the program should not be expanded while there are families with young children waiting to be served by the program.

Respondents offered suggestions to improve the application process, increase the program's publicity, and improve the benefits provided. The suggestions included:

1. Yearly applications (rather than every six months);
2. Optional phone renewal of the applications;
3. Education of local social and health service staffs about the program;
4. Use parents to publicize the program;
5. Increase benefits for families with greater needs;
and
6. Increase allowed benefits to include long distance medical calls and emergency respite care.

Table 3
 Family Rating of Subsidy Purchased Services (SPS), Services Provided
 by Family and Friends (F&F), and Community Agencies (CA)
 (Minnesota Family Subsidy Study: 1982; n = 38)

| SERVICE CRITERIA | F A M I L Y R A T I N G | | | | | | | | |
|------------------|---------------------------|------------------|-----------------|------------------|------------------|-----------------|------------------|------------------|-----------------|
| | Very Poor/Poor | | | Fair | | | Good/Excellent | | |
| | SPS (percent) | F&F (percent) | CA (percent) | SPS (percent) | F&F (percent) | CA (percent) | SPS (percent) | F&F (percent) | CA (percent) |
| Quality | 0% | 8% | 13% | 5% | 14% | 11% | 95% | 78% | 76% |
| Availability | 11% | 35% | 13% | 16% | 27% | 16% | 74% | 38% | 71% |
| Accessibility | 11% | 30% | 21% | 22% | 30% | 16% | 68% | 40% | 63% |
| Convenience | 8% | 43% | 16% | 24% | 22% | 16% | 68% | 35% | 68% |
| Cost | 19% | 9% | 13% | 3% | 11% | 3% | 79% | 81% | 84% |

IV. SUMMARY

In summary, the study's findings show that the effects of the subsidy are considerable on all of the measures used: (a) enabling families to care for their developmentally disabled child at home; (b) degree of general helpfulness of the subsidy to families; (c) families' functioning and coping capacities (financial, social, and psychological); and (d) changes or improvements in families' functioning and coping capacities (financial, social, and psychological).

The subsidy increased the families' ability to: (a) purchase items needed by the child; (b) attend to the developmentally disabled child's needs; (c) purchase respite care and baby sitting services for the child; (d) do things outside the home they enjoy; (e) do things with other family members; (f) enjoy the company of family members; (g) be with friends occasionally; and (h) attend to the needs of family members. Dimensions of the family functioning on which the subsidy seems to have had the least effect include enabling mothers to: (a) work outside the home; (b) do things at home they enjoy; and (c) keep up with household chores. All of these are activities that compete with the needs of the developmentally disabled child and family members for parents' time and energies. At the same time, it should be noted that although the program has not had a tremendous effect on the employment status of the study's mothers, it has enabled some mothers to work outside the home.

Respondents suggested that the program might be improved by simplifying the application process, increasing publicity about the program, and increasing the maximum level of benefits.

The process of deinstitutionalization includes prevention of institutional admissions as well as returning institutionalized residents to the community (National Association of Superintendents of Public Residential Facilities, 1974). Support services for families who care for disabled members at home are an essential component of a comprehensive deinstitutionalization policy. As Representative John Brandl noted in a recent *Corporate Report* article, such services can be a cost-effective as well as a humane alternative to institutional care in a period of fiscal cutbacks (Brandl, 1982).

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