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ABSTRACT

Five models for respite care services for families of developmentally disabled persons were developed, including use of a sitter or in-home companion, week-end day care, and boarding and/or group homes. A needs survey of 11 counties in Alabama identified 300 eligible persons and included information on behavior patterns, diagnosis, range and severity of disability (large numbers manifested severe physical or behavioral problems), preferences for types of services (out-of-home care was favored), cost figures, and client satisfaction. Findings suggested that the population was at risk of institutionalization and that efforts to recruit qualified providers for respite care were largely successful, due to the existence of a pool of previously trained local talent. (CL)

RESPITE CARE WHICH MEETS COMMUNITY NEEDS

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RESPITE CARE WHICH MEETS COMMUNITY NEEDS

Introduction

Respite care has only recently emerged as a service modality for developmentally disabled persons and their families. The concept first appeared in the professional literature about 16 years ago (Paige, 1977). Over the past 10 years it has gained increased recognition as concerted efforts have been made to sustain developmentally disabled persons in the community rather than in institutions.

Proponents of respite care are generally in agreement about both the need for and the value of respite care (Upsur, 1978). Care of the severely or profoundly handicapped individual involves a great deal of stress for the family. Brief periods of respite or relief from that stress provide the opportunity for revitalization and strengthening of family members as a resource for care of the handicapped person. Such revitalization enables the family to continue to function effectively as the major caregiver for a longer, if not indefinite, period of time. The quality of care is likely improved in the family which has an occasional respite. Such improvement may lead to an upward spiral of improved functioning in the handicapped individual, lessened stress on the family, and improved care etc.

The research literature provides some support for the commonly held position that mentally retarded persons achieve and maintain a higher level of adjustment when they reside at home as opposed to an institution (Stedman & Eichorn, 1969; Carr, 1970; Eyman & Borthwick, 1980). Hence programs which strengthen or enhance their chances of living with the family would seem beneficial. The cost of care for state and federal governments would seem to be lessened considerably if the individual resides at home. The mental and physical strain of providing continuous unrelieved care of a handicapped person is a major factor contributing to institutionalization and thus in maintaining costly traditional institutional settings (Upshur, 1982; Townsend & Flanagan, 1976). In summary, respite care is seen as offering not only a valuable addition to services for the developmentally disabled from the humanitarian, legal, and ethical perspective, but also offering cost savings to state and federal governments financing institutional care.

There are numerous models for the provision of respite care. Upshur (1982a) identified ten different program models. These models may be categorized generally as follows:

(1) Programs in which the care giver goes into the handicapped person's home, e.g. sitter service, homemaker service, companion aide.

(2) Programs in which the handicapped person goes into the care giver's home, e.g. foster family, respite family.

(3) Programs in which the handicapped person goes into a specialized group care setting, e.g. institution, boarding or group home, camp, or day care.

Experience of respite care providers suggests that families of handicapped children utilize respite care in a variety of situations, in part, contingent on utilization criteria established by the provider: emergencies, vacations, special family commitments, brief family recreational activities, or simply running errands (Hagan, 1980; Upshur, 1978).

A review of the respite care literature suggests that many models of respite care have sprung from groups of concerned citizens endeavoring to provide a service with very limited or no funds. Providers were often parents of handicapped children themselves and/or volunteers with very little training or experience in the care of handicapped persons. Such financial and technical skill limitations may have impeded the development of viable models. Respite care is thus seen by many as a program to be offered by volunteers rather than a service to be financed and provided by governmental agencies.

Many significant questions about the impact and utility of respite care remain unanswered. The research literature is notably lacking in any systematic attempt to address these questions. Literature available presents primarily a popularized description of how to do it, rather than documentation of effectiveness.

Whether or not respite care really enables the institutional candidate to reside in the community for a longer period of time is a major unanswered question. The logic seems compelling, however we have little evidence to date. A related issue concerns the true risk factors for many individuals to whom respite care is provided. Many respite care programs seem to provide care for only the mildly or moderately retarded individual whose likelihood of being institutionalized is quite low (Upshur, 1978; Hagan, 1980). Many respite care providers report that they are unable to provide care for the severely and/or moderately handicapped person and/or the behaviorally aggressive. Difficulties in recruiting and training providers for the care of severely handicapped individuals is understandable, none-the-less, it is these individuals who are most at risk for institutionalization.

Assuming the validity of the case for respite care, it follows that state and federal governments responsible for the care of the developmentally disabled could wisely invest state and federal money in the provision of respite care.

The Program

The program to be reported represents an attempt to begin to address the concerns expressed above. This project was initiated when the Alabama Department of Mental Health made a progressive decision to utilize a share of its federal developmental disabilities monies to develop a respite care program in one of the state's regions in which community resources had been somewhat underdeveloped. These funds were allocated to the University Affiliated Facility in Alabama (Center for Developmental and Learning Disorders at the University of Alabama in Birmingham). The University was charged with the responsibility to develop a respite care program for the 992,000 residents of an eleven county region which includes the Birmingham metropolitan area. The population in need was defined as a subgroup of those residents of this region who met the federal definition of a developmental disability: approximately 14,880. Of these, approximately 9,400 live within the Birmingham vicinity. Careful attempts were made to systematically collect data on the functional level of persons who would use respite care. Resources were developed based on the specific advice of several local parent groups and of professionals who dealt with the concerns of such families on a daily basis. Multiple kinds (models) of service delivery were investigated. The report which follows presents the program and some preliminary data.

Program staff for the project include a full-time respite care coordinator and a one-half time secretary. Two or three hours per week were contributed by each of several other CDLD faculty. The operational plan called for a reduction in staff time once the program was established.

Five different models of respite care were actually developed:

(1) Sitter or companion aide (in home).

(2) Respite family (out of home).

(3) Summer and week-end camping.

(4) Week-end day care.

(5) Boarding and/or group home.

In most cases these programs were developed through subcontracts with local providers who had already developed related expertise. Federal funds supporting the project were interpreted as restricted to service programs only, hence they could not be used to train prospective providers. Extensive orientation was offered to some of the respite families; however, other providers were selected based on an organizational guarantee to provide qualified personnel. The Center was also responsible for staff orientation.

During the initial phase of the project, staff planned to develop a free-standing respite care group home as the primary out-of-home resource. As the expense and long-range commitment of funds necessary for such a group home were clarified it was determined that this was not a financially sound decision and this plan was abandoned.

Results

Approximately 350 persons were determined eligible for services from among about 400 applicants. Only those who met the federal developmental disabilities definition were accepted. Families of persons eligible for services were provided 10 days of free care. In addition respite care was provided on an emergency basis depending on family need as determined by the respite care coordinator.

Fairly comprehensive information was solicited on each applicant as part of the admission process. Behavioral descriptors were provided by parents. The diagnostic information came from agencies who had provided services to these individuals. This information provides an extensive description of the population as portrayed in summary fashion in Tables I-IV. As can be seen from Table I, a large number of those served fell in the school-age bracket. Table II, reporting the principle diagnosis, shows the range of disability served. The severity of the disability is well established in this population, since all met the federal definition of a developmental disability. It should be noted that Table II gives only the principle diagnosis. In most

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Insert Table I about here

Insert Table II about here

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cases a secondary diagnosis was also present. Table III

Insert Table III about here

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provides some insight into the severity of the disability for this group. A sizeable number were quite disabled physically and a large percentage manifested severe behavioral disorders. Table IV is a summary of the parent's

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Insert Table IV about here

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assessments of their children's functional levels in five critical self-help areas.

Table V summarizes by age of the client the general category of service requested. As can be seen, out-of-home care was generally preferred over in-home care. Actual utilization paralleled requests.

Insert Table V about here

Costs for various program components are presented in Table VI. These figures represent amounts actually

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Insert Table VI about here

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reimbursed to contractors and do not represent total costs for the service. Approximately 10% should be added to cover administrative costs.

Extensive client satisfaction and follow-up evaluation forms were developed and distributed on each occasion the service was utilized. A representative sample is summarized in Table VII. The overwhelmingly positive response was

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Insert Table VII about here

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extremely gratifying though hardly surprising to staff who were in frequent contact with these parents.

Discussion

The severity of the disability of those served is apparent from the data presented in Tables III and IV. These data combined with the diagnosis of a developmental disability strongly suggest that this population is at risk for institutionalization. Obviously there is no foolproof way to demonstrate that all, or even any, of these individuals would have been placed in an institution were it not for this program. None of those served during the time frame of this study were placed in such an environment. A sizeable number of those served were behaviorally aggressive; however, providers capable of caring for them had been identified and were matched with them so as to accommodate their needs.

Success in identifying qualified providers for this project was reassuring. Previous attempts to recruit such providers by other community agencies had been largely unsuccessful in the Birmingham community, primarily because of the lack of financial resources. The adults and the behaviorally aggressive members of the group had been particularly hard to serve because providers had not been identified and/or trained who could meet their needs. The project was able to offer financial incentives for the development of a cadre of qualified providers. The availability of a pool of local talent which already had many of the prerequisite skills to provide these services was particularly fortunate. Most metropolitan areas should be able to identify similar talent.

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TABLE I

AGE DISTRIBUTION OF RESPITE CARE CLIENTS

AGE	FREQUENCY
0- 5	15%
6-17	62%
18-48	23%

TABLE II

PRINCIPAL DIAGNOSIS OF RESPITE CARE CLIENTS

DIAGNOSIS	FREQUENCY
SPINA BIFIDA	15%
MENTAL RETARDATION	42%
CEREBRAL PALSY	22%
EMOTIONAL DISTURBANCE (SEVERE)	13%
DEAF	5%
BLIND	3%

TABLE III

OTHER BEHAVIORAL DESCRIPTIONS OF RESPITE CARE CLIENTS

DESCRIPTOR	FREQUENCY
SEVERE BEHAVIORAL DISORDERS	32%
REGULAR SEIZURES	20%
IN WHEELCHAIR	30%
USE WALKER	12%

TABLE IV

FUNCTIONAL LEVELS IN FIVE CRITICAL SELF HELP AREAS

AREA	DESCRIPTOR	FREQUENCY
LANGUAGE	- NO LANGUAGE SKILLS	42%
	- CAN CONVERSE	29%
DRESSING	- REQUIRE ASSISTANCE	90%
FEEDING	- TOTALLY UNABLE TO FEED SELF	13%
BATHING	- REQUIRE CONSIDERABLE ASSISTANCE	78%
	- BATHE WITHOUT ASSISTANCE	10%
TOILETING	- GO BY SELF WHEN TOLD AND RARELY HAVE ACCIDENT	56%

TABLE V

RESPITE SERVICES REQUESTED BY AGE OF CLIENT*

	TYPE OF SERVICE		
AGE	IN HOME	OUT OF HOME	BOTH
0- 5	15%	23%	62%
6-17	18%	24%	56%
18+	12%	41%	47%
ALL AGES	15%	28%	57%

*16% UNCERTAIN

TABLE VI

RESPITE CARE COSTS BY TYPE OF CARE

SERVICE	COST/UNIT
SITTER/COMPANION AIDE	$ 5.35 PER HR
RESPITE FAMILY	40.00 PER DAY
BOARDING/GROUP HOME	30-40.00 PER DAY
CAMPING	20-26.00 PER DAY
WEEKEND DAY CARE	4- 4.50 PER HR

TABLE VII

PARENT EVALUATION OF RESPITE CARE SERVICES
N = 79

	EVALUATION QUESTION	% YES	NO
1.	DID YOU FEEL THAT THE SERVICES MET YOUR NEED?	100	0
2.	DID YOU EXPERIENCE ANY DIFFICULTY SCHEDULING RESPITE CARE SERVICES?	1	99
3.	DID THE PROVIDER SHOW UP ON TIME?	100	0
4.	DID THE PROVIDER FOLLOW YOUR INSTRUCTIONS?	100	0
5.	DID THE PROVIDER SHOW AN INTEREST IN YOUR SON OR DAUGHTER?	100	0
6.	WAS THE PROVIDER NEAT IN APPEARANCE?	100	0
7.	WOULD YOU USE THE RESPITE SERVICES AGAIN?	100	0
8.	WOULD YOU WANT TO USE THIS PROVIDER AGAIN?	100	0
9.	WAS THE PROVIDER COURTEOUS TO YOU AND YOUR FAMILY?	100	0