DOCUMENT RESUME

ED 181 687 EC 122 821

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TITLE Respite Care: A Survey of State Regulations and Family Options.
PUB DATE Sep 79
NOTE 31p.; Paper presented at the Annual Convention of the American Psychological Association (87th, New York, NY, September, 1979)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Community Services; Day Care Services; *Delivery Systems; *Developmental Disabilities; Family (Sociological Unit); *Family Resources; *Home Programs; Models; Program Evaluation; Residential Care; *Respite Care; *State Agencies; State Programs; Surveys
IDENTIFIERS Massachusetts

ABSTRACT

The findings of a 1978 project of the Massachusetts Developmental Disabilities Council on the need for respite care services and the various models for delivery of respite care are reported. Methodology included review of respite care regulations in 12 states, site visits and a survey of Massachusetts programs, and a survey of 339 families with developmentally disabled members. The project found that respite care is not well developed as a support service to families in any state although recognition of respite care as a necessary community service component is growing. Ten program models for delivery respite care were identified: respite placement agencies, group day care, community residences, residential treatment facilities, group residential care, nursing homes, private in home care, state facilities camperships, and funding conduit. The majority of families (70%), however, reported preferring home based care over other models. Obstacles to respite care identified by families included reluctance to leave their family member with a stranger and lack of knowledge of what types of services were available at what cost leading to the recommendation that more publicity and community education about respite care should be conducted. Problems with quality of care were identified for most program models and recommendations are made for improving services. (Author)

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RESPITE CARE: A SURVEY OF STATE REGULATIONS AND FAMILY OPTIONS

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Respite Care: A Survey of State Regulations and Family Options[1]

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Respite care, the provision of temporary relief to the families of the developmentally disabled living at home, is a relatively new concept. It has grown out of the national movement of the early 1970's to deinstitutionalize and provide treatment settings for the mentally ill and retarded that are the "least restrictive", e.g. the most like normal community living. The concept of deinstitutionalization has been established firmly in public policy starting with the Developmental Disabilities Act of 1970 and further supported by the Rehabilitation Act of 1973 (29 U.S.C. 794), the Education for All Handicapped Children Act (P.L. 92-142), Title XX of the Social Security Act (1974) and the Developmental Disabilities Act of 1975. Along with deinstitutionalization, however, came the necessity to design new treatment methods and delivery systems. With many disabled persons now remaining at home or in home-like community settings, the need for home-based service models became apparent.

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[1] The research for this article was completed through Grant Number 77-977-6 from the Massachusetts Developmental Disabilities Council to Provider's Management, Inc. to conduct a Respite Care Policy Development Project. The article represents a summary of the Project's final report also written by this author. Those wishing a copy of the report should write to the Massachusetts Developmental Disabilities Council, 1 Ashburton Place, Boston, Mass., 02108. The author is grateful to project staff who carried out a large part of the day to day activities particularly Judith Oppenheim, Project Director; Martha Cleary, Staff Assistant; Barry L. Mintzer, Legal Consultant; and Rachel Crystal, Research Consultant.

Among the first definitions of respite care comes from a 1972 publication of the Department of Health, Education and Welfare:

> "appropriate services in a variety of settings, providing for the care of individuals with developmental disabilities through temporary separation from his/her family, in or outside the home for the short, specified purpose of relieving the family of his/her care to: 1) meet planned or emergency needs; 2) restore or maintain his/her physical and mental well-being; and 3) initiate training procedures in or out of the home"[2]

Respite care was seen as one of a variety of community programs and services that would become part of individualized treatment plans for disabled children and adults. Where families with normal children have a range of babysitting and day care options in most communities, the behavioral and medical problems of the developmentally disabled child or adult often prevents families from being able to leave them at all. The mental and physical strain for a family of providing constant care for a disabled person, sometimes for the entire lifetime of the person, continues to be a major factor in support of maintaining traditional institutional settings.[3] It is thus clear that if deinstitutionalization and the policy of home-based treatment is to be successful, the families of the disabled must be provided a variety of supports.

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[2] p. 1, Respite Care for the Retarded, Marianne Paige, U.S. Department of Health, Education and Welfare, Social and Rehabilitation Services Administration, Division of Mental Retardation, 1972.

[3] See P.W. Townsend and J.J. Flanagan, "Experimental Pre-Admission Program to Encourage Home-Care for Severely and Profoundly Retarded Children", American Journal of Mental Deficiency, 80, 5 (1976): 562-569.

The Massachusetts Respite Care Policy Development Project

As with many other states, the process of deinstitutionalization of mental health and retardation services and services to other disabled populations has been moving slowly in Massachusetts. However, due to attempts to reduce the populations at state institutions starting in the late 60's and early 70's, many disabled persons had been returned or remained at home by the mid 1970's. The problems of family and other community-based care in the light of sparsely developed community services began to surface. Local parents associations, in particular associations for retarded citizens began to lobby the Department of Mental Health for more services and began to establish small programs to help out families of the disabled. State agencies dealing with the disabled began responding to pressure and to family crisis by providing temporary institutionalization of a few children and small amounts of funding for community-based babysitting-type services.[4] By 1976 respite care was surfacing as a crucial unmet need for the families of disabled persons, while at the same time the makeshift arrangements that had developed over the previous three or four years were being questioned as to adequacy and quality.

In this context, the Massachusetts Developmental Disabilities Council funded the Respite Care Policy Development Project to provide a comprehensive look at respite care.

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[4] see pp 19-26, Final Report of the Respite Care Policy Development Project, Carole Upshur, Provider's Management, Inc., Boston, Mass., 1978.

The tasks of the Project included proposing a definition of respite care services, descriptions of the variety of models for respite care, developing program standards for the various models, making recommendations as to state policy, and researching funding mechanisms and cost. A fulltime project director and staff assistant administered the project while a team of consultants provided program legal, fiscal and research help.

Methodology

The project undertook a number of tasks during its one year duration. These included reviewing respite care programs and policies of twelve states; conducting site visits of 19 Massachusetts programs; conducting a mail survey of 55 Massachusetts programs; and conducting a mail survey of 339 client families.

The review of respite care programs in other states was conducted by requesting information of appropriate state agencies in 24 states where Project staff had knowledge of existing respite programs.[5] A total of twelve states returned information. In some cases, written correspondence was supplemented by telephone contact with individuals involved with respite programs.

The mailed survey and site visits conducted for Massachusetts programs were initiated by identifying existing programs listed in a state directory of services.[6] A total of 42 out of 55 programs returned the survey questionnaires, or 76%. Of these 42, seven stated they did not currently or previously provide respite care.

Site visits, initially planned for only a small portion of operating programs eventually resulted in 19 programs being visited, half of the operating programs in the state. The survey questionnaire and site visit checklists were developed by project staff and consultants along with a review by members of the Developmental Disabilities Council. Questions covered a variety of areas including:

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[5] A valuable resource was the "Project Description" and "Second Year Project Proposal" from the Respite Services Community Development Project, Community Alternative Service Systems, Omaha, Nebraska.

[6] Office of Federal/State Resources. Directory of Residential and Non-Residential Service Providers in Massachusetts, 1975.

Numbers and types of disabilities of clients served; response for the respite service; the model of service delivery; length of time of respite services; problems in delivering service; service procedures; staff training and qualifications; publicity and client recruitment; and sources of funding.

The client survey was not originally intended to be part of the project and so funding for a sophisticated needs assessment was not available. Project staff had to rely on direct care staff of the various state agencies to distribute questionnaires to families. (In addition some local parents associations were utilized). This procedure enabled the survey to be conducted with a small project staff but it also assured complete confidentiality for participating parents and families.

A 30-item questionnaire was prepared and pre-tested with a number of families, professionals and providers of respite care. The questionnaire requested information on the age and disability of the disabled family member; the relationship to the disabled person of the person filling out the questionnaire; whether families had used day or overnight respite care; under what circumstances; what problems they had in utilizing the service; and how it was funded. (See Figure 1. for a sample question.)

Figure 1. Sample Question from Family Survey

What problems did you encounter the last time you wanted or needed to leave the client overnight and were unable to do so? (Check as many as apply).

____1. no services available
____2. didn't know where to find help
____3. not enough time to make adequate arrangements
____4. too much paper work required
____5. client had too many problems for the type of care available
____6. not satisfied with quality of services available
____7. reluctant to leave client with stranger
____8. couldn't afford it
____9. client too upset
____10. no transportation and/or placement too far away
____11. didn't want to interrupt client's daily routine
____12. other, specify: ________________________________

Packets of questionnaires were prepared so that staff in local offices could themselves mail the questionnaires to their clients, thus assuring complete confidentiality of respondents from the project staff. Packets contained five to fifteen questionnaires and specific instructions including a simple formula for random selection of clients (except for the Society For Autistic Children which did a direct mailing to their total Massachusetts membership). Staff were asked to return a pre-addressed postcard after they had put all their questionnaires in the mail.

A total of 1,265 questionnaires were sent from the project office to be distributed from the local agencies. It is estimated that a little more than half of the questionnaires actually reached client families due to failure of local agency staff to send out the questionnaires while others sent out only part of the packet received. However, if we received four-fifths of the questionnaires back from a packet, it was assumed the entire group was mailed out even if no postcard had been returned. (Packets and individual questionnaires were pre-numbered so that such a tracking system could be set up.) Using this system it is estimated that a return rate of at least 52% was obtained for questionnaires that actually reached client families. Data from 339 questionnaires were coded and analyzed. Cross tabulations were run to compare experiences of rural, suburban and urban families with respite care and experiences of the various disability groups and level of disability.

Results

The results of the project will be reported in three major categories:

1) Survey of other states;
2) Service delivery and models of care; and
3) Family experiences and preferences.

Survey of Other States

As a general statement, it is safe to say that respite care is a new, developing and emerging service for the developmentally disabled, and is far from being fully developed and regulated in any state. In fact, as the project staff learned what other states were doing, it became clear that Massachusetts has one of the most extensively developed respite care networks in the country.

The information obtained from 12 states (California, Connecticut, Delaware, Idaho, Maine, Montana, Nebraska, North Carolina, Ohio, Oregon, Pennsylvania and Virginia) indicates that only three have developed separate licensing or regulatory procedures for respite care as a distinct service. However, these procedures do not give programmatic guidelines for respite services, but rather focus on procedures for obtaining care, definition of care and funding mechanisms. The state of California, for example, has separate guidelines for respite care and specific rates set for various types of care, from in-home care by a community respite worker to nursing home care. These guidelines say very little about how respite programs are to operate except to state that if a community worker is utilized to deliver care, the worker must have training in an overview of developmental disabilities, a Red Cross course, and previous experience with the disabled population.

Idaho provides a definition of respite care and allows respite care to be provided in a number of different settings (i.e. foster homes, day care centers, respite care centers, shelter homes, skilled nursing care facilities and in-home). The standards for care specify, in addition, that the families of the disabled person must in all except emergency cases select and arrange for care from a list of providers provided by the state Department of Health and Safety; or they may arrange for their own caregiver, providing the person is not a relative of the family. The families must assume the responsibility for determining that the setting is adequate and safe for their family member, and they must release the department from any liability in the selection or provision of care. The Idaho regulations state a list of information which the family must give the provider and require an emergency medical release form, but no other guidelines or standards are stated to be followed by the caregiving person or program. Respite care cannot be used to provide care while parents are working. Care is limited to 18 days a quarter or 36 days a six-month period.

Pennsylvania defines respite care as one component of a "Family Resource Services Program" which also includes a range of other services available to developmentally disabled persons living in community settings or with their families. Respite care can be offered in the family's home, in a "host" family home approved by the County Mental Health/Mental Retardation Office, or in a medical facility if needed. Respite care is limited to four weeks, and any care given for under a 24-hour period (even if overnight) is separately defined as a "family aid" service. No other program standards are given for respite care, although the family aid standards require an approved training program and a written report by the

Aide provided to the County office describing the care given. Family aid may be provided up to four times per month, or more if approved, however, it cannot be provided daily. Family aid services take place in the client's home or the home of the family aid.

The other three states where respite care is recognized at the state policy level are <u>Delaware</u>, <u>Montana</u>, and <u>Ohio</u>. <u>Delaware</u> has a respite program operating out of its state hospital for the mentally retarded but does not provide funds or guidelines for other types of respite care. The <u>Montana Administrative Code</u> requires respite care to be available to the developmentally disabled population but provides no guidelines or regulations with the result that each county in the state has gone its own direction, some using foster care guidelines to implement home-based respite services. In <u>Ohio</u>, various private programs have developed to provide respite care using public funding, but without an overall state policy or set of guidelines. Ohio, however, has recently proposed state licensing regulations for the developmentally disabled and mentally retarded which include a definition of out-of-home respite care which could be provided by a residential facility.

The state of <u>Nebraska</u> includes respite care as one of the continuum of community services available to developmentally disabled clients. However, state officials have indicated that separate definition or regulation would limit the flexibility needed to respond to individual family support needs.

Service Delivery and Models of Care

The site visits and suevey of respite care agencies in Massachusetts provided information on major dimensions of Service Delivery and revealed a total of ten different models for delivering respite care. The service delivery characteristics explored included what type of clients are served, under what circumstances, for how long, at what cost provided what services, with what model of care and what problems have been encountered.

It was found that care is provided most often to the mentally retarded population and while care is primarily provided to clients under age 36, at least half of the programs would serve any age. (See Tables I and II for more specific results on disabilities served.) The majority of the programs (63%) provide care in the homes of the clients through use of trained aides rather than any type of group or institutional setting.

Further, contrary to assumptions about how programs operated, agencies surveyed reported a wide range of family needs were considered appropriate to receive services, i.e., there did not have to be a severe family emergency or crisis. In fact, when the figures for the most frequent use of care are noted, family emergencies counted for only 16% of the care, with 44% of respite care being provided for "relief from the physical or emotional strain of care" (See Chart I.)

TABLE I: Percentage of Programs Serving 4 Major Disabilities

Disability	%
Mental Retardation	94
Epilepsy	57
Cerebral Palsy	63
Autism	37

TABLE II: Percentage of Programs Serving Other Handicapping Conditions

Condition	%
Visually Impaired	43
Hearing Impaired	43
Language Impaired	43
Seizures	51
Other Physical	34
Other Neurological	31
Other Emotional	26

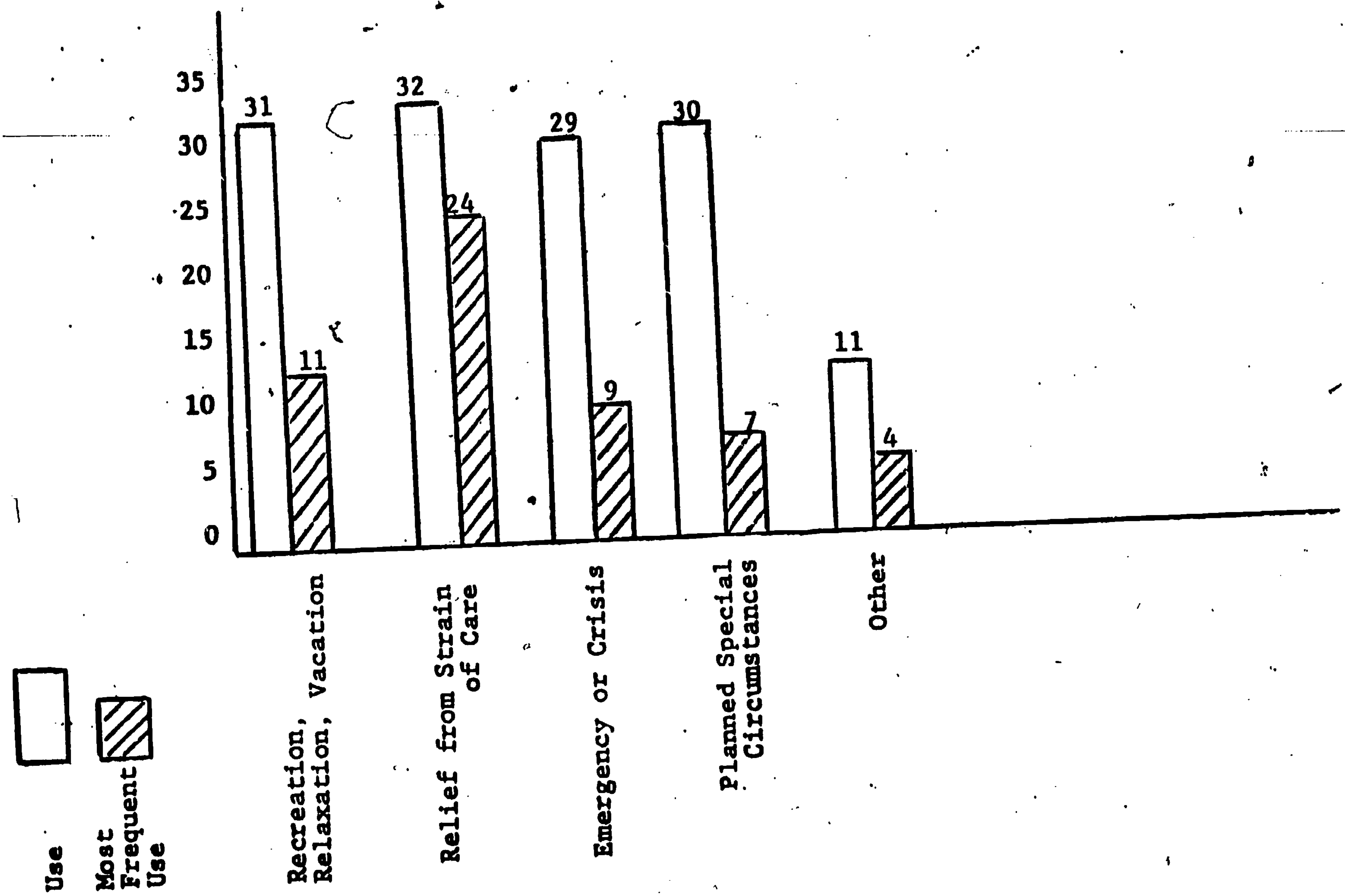

CHART 1. Uses of Respite Care and Most Frequent Use as Reported by 35 Agencies.

In addition to describing in general terms which families and clients would be served, the agencies were asked what family situations and what client characteristics would be specifically excluded from eligibility. (See Chart 2.) The results indicate lack of services for autistic clients and others with severe emotional/behavior problems. A large number of agencies (46%) also indicated that "too severe medical needs" would prevent services. The two most frequently mentioned family issues which result in denial of services were "too many requests" (for service) and "inappropriate reason for care" (ten agencies mentioned each of these.)

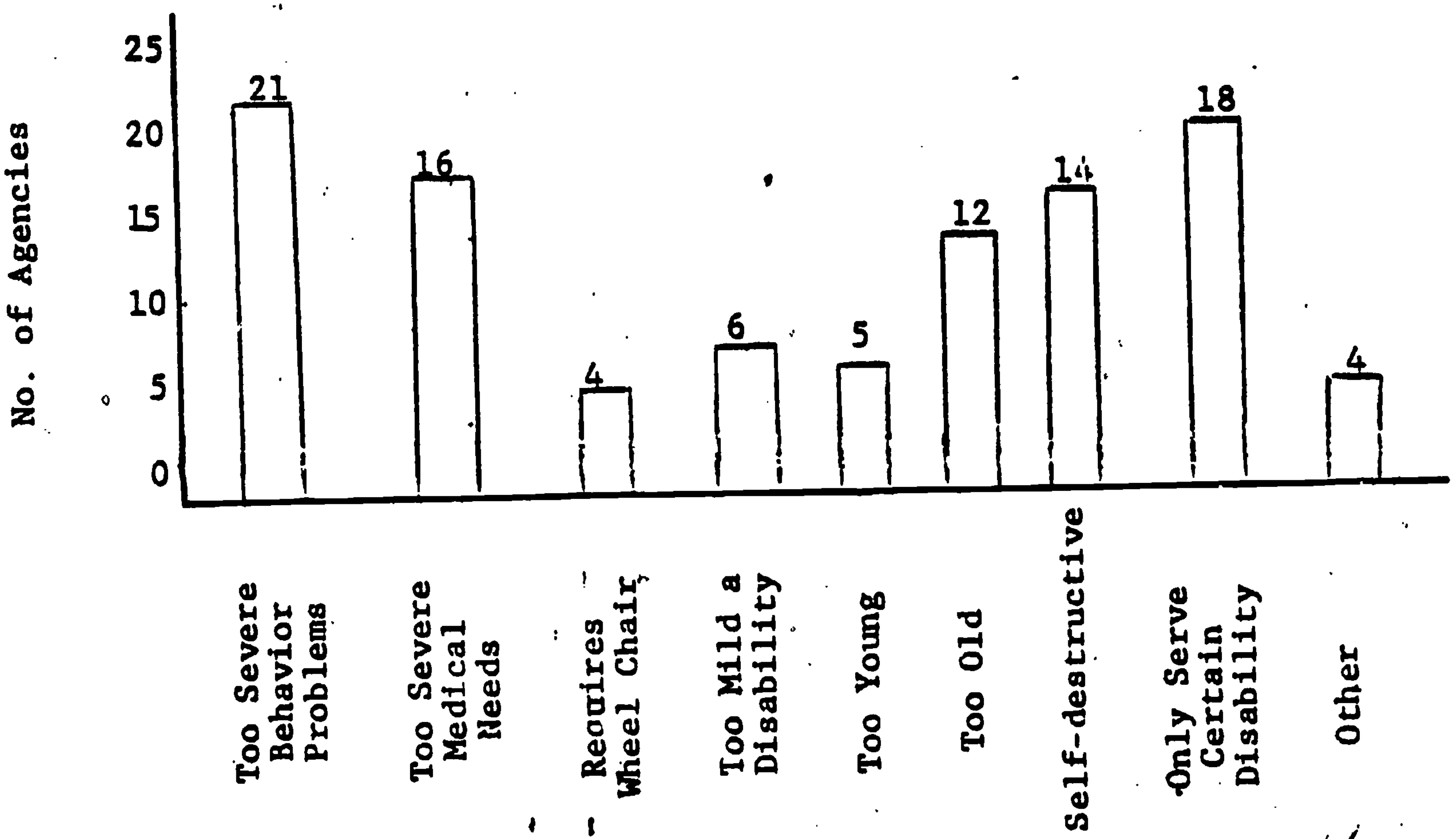

CHART 2. Client Characteristics Which Result in Denial of Services

Data on length of services shows that 69% of the agencies provide care for several hours through 14 days of overnight care, while 43% can provide overnight care up to 30 days and only 23% for up to three months. The most frequently used length of care is day or evening care (less than overnight), with weekends, two weeks and then overnight following in that order. (See Tables III and IV).

TABLE III: Length of Services Available N=35

Length of Service	No. of Programs	% of Programs
Several hours day/evening	27	77
Overnight	27	77
Weekend	27	77
3-7 days	28	80
8-14 days	29	69
15-30 days	15	43
2-3 months	8	23

TABLE IV: Most Frequent Length of Respite Care Services N=31

Length of Care	No of Programs
Several hours day/evening	14
Weekend	8
Two weeks	5
Overnight	4

The cost of services varies greatly depending on whether a group or institutional setting is utilized or the model of home based care where a trained aide provides care in the home of the client or their own home. Group/institutional fees for overnight care range from less than $10 a night to $65. Hourly fees paid a trained aide (hereafter called a community provider) range from $1 to $4.50; overnight rates for community providers range from $10. to $40. for a 24 hour period. Sixty-five percent of the community providers receive between $2. and $2.99 per hour; 60% receive between $20. and $29. for a 24-hour period.

Services provided to clients during respite care are rarely very specialized. Almost two-thirds of reporting agencies noted "recreation", "opportunity to mix with peers" and "continuation of school work" as the major services provided. While 54% report that follow-up contracts are made with families, less than half provide family counseling concerning the respite service and only 28% provide any special programming for clients during respite care. As far as problems identified in providing respite care, the most common problem indicated by agencies was "client reluctant to leave other members of the family" (34% of agencies reporting with family does not return at agreed time" (31%) second and "lack of transportation for client to or from care" (26%) third. A variety of other problems were cited by at least one agency, however, including client problems after the respite care service was delivered, families reluctant to leave the client, and families placing unreasonable demands or harassing providers.

Results on the major models of care in operation revealed that the majority of programs operate as "respite placement agencies" (51% of agencies surveyed), while nursing homes (11%) group day care and group respite facilities (each 8.5%) are the next most common in Massachusetts. A brief description of all ten models follows.

1. Respite Placement Agencies

The most common model of respite care currently operating in the state. These agencies have been labeled respite placement agencies since their primary mode of operation is to identify and recruit community providers (similar to the way foster parents are recruited) and to match a client family with a particular community provider who seems appropriate to care for the client involved. This care is provided in the client's own home or in the home of the community providers for a few hours a day up to a week or two overnight. The community provider is usually paid by the agency from agency funds, although sometimes the families pay part or all of the cost to the agency. The community providers are provided a range of training opportunities, varying from program to program, including no training, CPR courses, homemaker courses, general seminars on developmental disabilities and behavior management, or participation in specialized home care training programs. There is a wide range of paperwork, applications and agreements utilized by the programs. Often there is only one part-time or volunteer coordinator who carries out the entire program.

2. Group Day Care

Several programs provide respite care in the form of group daytime care where children (in no case was this model provided to adults) are brought to a facility or family day care home for the purposes of allowing daytime relief for the family. Usually, this model is part of an agency service system which provides other developmental services to the child and family.

3. Community Residences

Existing community residences for the retarded across the state either reserve one or two beds for respite care or will take in clients in emergency situations. These are always overnight respite situations and in all but one case were for teenagers or adults, not children under 12. Most of the community residences worked closely with a respite care placement agency to receive referrals rather than operate independently to recruit and serve respite clients; however, one residence visited would provide respite care to anyone requesting it if they felt the client was appropriate and they had the room.

4. Group Care or Residential Treatment Facility

This model involves the provision of respite care by a program which is primarily set up as a long- or short-term treatment facility. Programs reserve a bed or two for overnight respite care, and at certain times of the year when the regular treatment program is closed, may provide all its beds for respite care.

5. Group Respite Provider

   These programs operate as a group residential programs which provide respite care in a separate facility from other types of longer term treatment services.

6. Pediatric Nursing Homes-Hospitals

   These programs primarily serve as long-term nursing care facilities or acute hospitals, but will also provide overnight respite care to children with medical needs.

7. Private Respite Provider

   This model involves nurses who open their own homes to provide overnight respite care from a few nights to three months to 1-4 children at a time who have medical needs.

8. State Facility

   This model involves a state residential facility which provides overnight respite care to older children and adults, but where the primary service is long- or short-term residential care and treatment.

9. Funding Conduit

   This model of respite care allows families to select their own care provider for daytime or overnight services in their own home or in the provider's home. The agency merely reimburses the family (within previously-agreed limits) on a monthly basis for the costs the family incurs in obtaining respite care. The agency does not become involved at all in recruiting care providers or matching them with families. A part-time staff person serves to coordinate the program.

10. Camperships

   This model allows daytime or overnight camp experience to be considered respite care. In some cases the family picks its own camp: in others, the agency helps in identification of an appropriate camp.

Family Preferences

The 339 respondents to the family questionnaire indicated that 68% of the clients were mentally retarded, 25% cerebral palsyed, 20% epileptic, and 20% autistic (totals more than 100% indicating multiple handicaps). The three most frequently encountered accompanying disabilities were language impaired, seizures, and other physically handicapping conditions. One-half of all the clients were identified as being language impaired, and half of this group falls in the severe level. One-third of all the clients had some other physically handicapping condition, and one-third had some seizures.

Questionnaires were completed about clients of all ages, but half were about children under twelve years of age (the mode was nine years), and only a little over 10% were about clients over the age of twenty-six. There are almost twice as many male clients as females and most (87%) have always lived at home. Out of the 339 questionnaires, 322 of the respondents identified themselves as parents of the client (including adoptive and foster parents). Over three-quarters of the clients are living in two-parent households, and 13% living in rural areas.

Families reported that day time or evening care (less than overnight) was most often (58%) provided by other family members or relatives, neighbors, or friends with no special training. A total of 14% of respondents report that they do not even have untrained day care and ostensibly, get no relief from care of the disabled family member. Care, whether by relative, neighbor or respite worker, almost always takes place in the client's own home during the day or evening (70%). A total of 5% of care not in the client's home takes place in the sitter's home and 12% of the clients receive day care in group homes or institutions.

When asked to state their preference for care during the day or evening, 37% of the families specifically stated they wanted a sitter with training, or that the client be placed in a group setting. More than two-thirds prefer that care during the day be at their own home. If not in their own home, they would prefer a group setting to the home or a relative, neighbor or friend. (See Table V).

TABLE V: Where Families Would Prefer Day or Evening Respite Care to Take Place:

	No.	%
Client's home with sitter, relative, neighbor, friend	162	47.8
Client's home with trained homemaker/ aide	69	20.4
Neighbor, relative or friend's home	7	2.1
Foster home	1	0.3
Group home/community residence	29	8.6
Nursing home/hospital/other health care facility	8	2.4
Residential school	12	3.5
State school/facility	3	0.9
Other	6	1.8
No response	42	12.4

As far as overnight respite care, while almost 34% of the families gave no response (most likely indicating that they do not have overnight care available), 37.8% reported using a sitter, neighbor, relative or friend (23.6% in their own home). One quarter of the families report having used a group or institutional setting for their most recent respite care experience. Overnight care thus takes place out of the client's home much more frequently than day or evening care. Families, over 57%, however, prefer overnight care to take place in their own home (40.4% with a sitter, relative, neighbor, or friend and 17.4% with a trained homemaker/aide/worker). Over 13% would prefer overnight care in a group home or community residence. (See Table VI).

TABLE VI: Where Families Prefer Overnight Respite Care to Take Place

	No.	%
Client's home with sitter, relative, neighbor, friend	137	40.4
Client's home with trained homemaker/ aide/worker	59	17.4
Neighbor, relative or friend's home	11	3.2
Foster home	10	2.9
Group home/community residence	45	13.3
Nursing home/hospital/other health care facility	14	4.1
Residential school	14	4.1
State school/facility	2	0.6
Other	4	1.2
No response	43	12.7

The reasons for using respite care reported by families indicate a range of needs. The most common for day or evening care being relief time; the most common for overnight care is recreation or vacation. However, family and medical emergencies and personal needs of the care giving family member were both frequently mentioned as reasons for needing day or evening respite care services. (See Tables VII and VIII).

TABLE VII: Reason for Use of Day or Evening Respite Services

	No.	%
Emergency (medical, family)	169	49.9
Relief time	191	56.3
Planned day care for working families	23	6.8
Other family members' needs	118	34.8
Personal needs	154	45.4

TABLE VIII: Reason for Most Recent Use of Overnight Respite Service

	No.	%
Emergency	30	8.8
Relief from strain of care	57	16.8
Recreation, vacation	83	24.5
Planned special circumstance	33	9.7
Other	15	4.4
No response	121	35.7

Families were asked what problems they encountered in obtaining day or overnight respite care. For day care, the problem most noted was not knowing where to find help to obtain the service at all (30.7%), but almost as many (28.3%) indicated that they felt reluctant to leave the client with a stranger. Over 20% indicated not having time to make arrangements while close to 20% felt care was too expensive for them. As far as overnight care, the largest obstacle indicated by families was "no services available" (25.1%) although 20.6% indicated cost was a problem and 20.1% "didn't know where to find help." (See Tables IX and X).

TABLE IX: Obstacles to Use of Day or Evening Respite Services

	No.	%
Didn't know where to find help	104	30.7
Waiting list too long	13	3.8
Not enough time to make adequate arrangements	74	21.8
Client had too many problems for type of care available	41	12.1
Not satisfied with quality of services available	24	7.1
Reluctant to leave client with stranger	96	28.3
Couldn't afford it	66	19.5
Client too upset	12	3.5
Lack of transportation	23	6.8
Placement too far away	13	3.8
Didn't want to interrupt client's daily routine	23	6.8
Other	33	9.7

TABLE X: Obstacles to Use of Overnight Respite Care Services

	No.	%
No services available	85	25.1
Didn't know where to find help	68	20.1
Not enough time to make adequate arrangements	44	13.0
Too much paper work required	6	1.8
Client had too many problems for type of care available	27	8.0
Not satisfied with quality of services available	22	6.5
Reluctant to leave client with stranger	70	20.6
Couldn't afford it	46	13.6
Client too upset	6	1.8
No transportation/placement too far away	17	5.0
Didn't want to interrupt client's daily routine	18	5.3
Other	20	5.9

Families also asked whether they are satisfied with respite care services they have received. For day or evening care, over 50% of the families indicated they are "always" satisfied, 25% indicated they are satisfied "sometimes". For overnight care, 43% reported being "always" satisfied, 15% "sometimes". The most frequently mentioned reason for dissatisfaction for both day and overnight care is that the person providing care is not adequately trained. Other reasons noted for day care include its cost and "lack of opportunity to mix with peers" (indicating care most often is home based). Other reasons for overnight care were the placement being too far away, lack of activities and recreational programs, reluctance of client to leave their family and the cost of care.

Data on cost of care was collected. The range indicated by families included no cost(for use of other family members, friends) up to $3.00 an hour for day or evening care and $4.00 to $190. a day for overnight care (mean of $24.61). Almost 40% of the families contribute at least some of the cost of day or evening services; 20.9% contribute toward the cost of overnight care. Other funding most frequently comes from state agencies.

Cross tabulations were run to see if urban, suburban and rural families experienced similar problems in utilizing respite care and whether the level or type of disability of the client affected the ability of families to obtain services. No statistically significant results were found, however, trends indicate that suburban families had problems with travel distances and waiting lists for day or evening care and felt there was more "red tape" for overnight care. Families with more severely involved clients tended to experience more obstacles and tend to utilize more out-of-home care for overnight respite.

Conclusion

The national review of state policy and programs concerning respite care for the developmentally disabled found that there are very few programs and that there is limited support both at the policy and funding levels of state governments for respite care. In addition, the position of state officials in Nebraska in opposition to a separate definition of respite programs is another view that must be taken into consideration. However, the development of a variety of models of respite care in the absense of either national or more local policy and guidelines indicate a significant need on the part of families maintaining developmentally disabled clients at home.

It appears to be appropriate to encourage the development of respite care as a service directed to periodic relief of families from the daily care activities for a disabled family member. Both at the national level and in Massachusetts a variety of program models are in operation which are directed to such relief services. It does not appear that families must have an extreme emergency in order to receive respite services. In fact, only 16% of Massachusetts agencies report respite care being delivered most frequently for emergency situations. While most agencies report providing emergency care, a number of families also reported not having enough time to arrange for services. Contrary to the initial assumption of project staff that respite care would most frequently be offered and utilized by families for emergency situations, lack of emergency response on the part of respite care services and in particular respite placement agencies (the most commonly operating program model) does seem to be an issue arising from this study. On the other hand, the use of respite care to introduce home-based treatment was mentioned by only one agency and a handful of families. Thus respite care is seen primarily as a service to provide relief for families to enable them to shop, run errands, attend functions or take vacations without the constant burden of providing care for a disabled family member.

Families most frequently report prefering respite care to take place in their own homes. This supports increasing the availability of the already most common model of care, that of a respite placement agency. Family concerns about the adequacy of training of the community provider, however, as well as findings that recruitment, training, administrative procedures, back-up services and supervision are often informal or lacking altogether in this model of care indicate that considerable improvements to the quality of service are needed. Other models of care, however, were also found lacking.

The primary areas of concern for all models of care are administrative procedures such as securing signed medical consent forms from families; establishing written agreements with families concerning the services to be provided and their duration (note that 31% of the agencies surveyed reported one problem with delivering services was that families did not return at the agreed upon time); having pre-placement visits and evaluation of services. Fees for service for most models except institutions and nursing homes also seem to be too low to support quality care on an on-going basis. The lack of consistent training programs for community providers and lack of back-up plans for medical and behavioral emergencies raises serious questions of risk to clients, especially the more severely disabled. The failure of community residences to orient respite clients adequately to emergency evacuation routes and other such procedures and the similar lack of back-up services for private respite providers are equally serious.

If the glaring issues of inadequate procedures, fees and lack of back-up supports are corrected in the various models of care it does seem appropriate, however, to advocate for the current range of models. The respite placement agency is a cost effective model (even with increasing fees to pay community providers at least minimum wage) which provides care where families most desire it, in their own or someone else's home. Increased training can make such a model available to even the most severely disabled clients. The use of community providers helps to eliminate transportation problems associated with a centralized facility and makes it easier to serve rural and suburban communities. Emergency response will continue to be a problem, however, as long as when to provide care is left to the option of an individual community provider.

Group models of care using a special respite facility and institution or as a adjunct service to an on-going program provide the advantage of more easy emergency response; better trained staff; ability to deal with more severely involved clients; and ability to provide more activities and peer contact for clients. However, transportation problems, cost and family biases against some institutional settings will remain disadvantages of these settings. Finally, the funding conduit model is seen as a viable option only for families who can find their own caregivers and who, most likely, have less severely involved clients. Potential for problems and poor quality service is greatest with this model, but it should not be completely ruled out at least until there are enough other home-based models available to meet family needs.

The optimum frequency of availability of respite care services to an individual family is difficult to discuss since so few services are currently available. Regular day care for working families probably ought to be considered a different category of service than respite care. However, regular weekly respite care to allow the primary caregiver personal time for shopping or other family errands is a common use at present. One weekend a month throughout the year is one model for older clients (20 and up). Thus respite care must be an individualized service and decisions for frequency of service must be made separately for each family.

One might assume that the demand for respite care could become overwhelming once families learned about it. However, the project found both families and agencies reporting reluctance to leave clients with strangers.

This, compiled with a large number of family responses that they did not know were to obtain services when they needed them, points to another major conclusion of the project, that information and referral services are also needed to promote the availability of respite care. It is not enough to merely have care available. Families must know it exists, feel confident that their family member will receive quality services, and not feel guilty using the service for relief, vacations or personal errands rather than only in extreme emergencies.

References

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