POLICY ANALYSIS SERIES

ISSUES RELATED TO WELSCH v. LEVINE / NO. 20

RESPITE CARE: A SUPPORTIVE AND PREVENTIVE SERVICE FOR FAMILIES

I. INTRODUCTION

In 1980, the Minnesota Governor's Planning Council on Developmental Disabilities selected alternative community living arrangements as its first priority of activity for its three-year State Plan (1981). The specific objective within this federal priority area was to demonstrate creative alternatives to out-of-home placements by encouraging the development of respite care services throughout the state. Such services were viewed as a means for providing support to families, which could possibly prevent or forestall placement of developmentally disabled persons into more restrictive settings, such as community or state residential facilities.

The term "respite care" has been defined in many different ways with little general agreement. Salisbury and Griggs (1983) offered the following definition of respite care:

> . . . planned or emergency care provided to the disabled individual, in or out of the home, for the purpose of providing relief to the family from the daily responsibilities of caring for a developmentally disabled family member. Such services should be delivered by trained providers and should occur within the context of a coordinated service network. (p. 51)

The mechanism used for developing alternative models of respite care services in Minnesota was through the demonstration grant program that was administered by the Developmental Disabilities Program of the State Planning Agency. Sixteen respite care projects were funded during a three-year period. The summary and analysis of these projects will be presented in *Policy Analysis Paper No. 21*. The primary focus of this paper is to present a review of the literature and to identify available resources which Minnesota might draw upon when planning and implementing future respite care services in this state.

DEVELOPMENTAL DISABILITIES PROGRAM • MINNESOTA STATE PLANNING AGENCY
201 CAPITOL SQUARE BLDG. • 550 CEDAR STREET • ST. PAUL, MN 55101 • 612/296-4018

II. REVIEW OF LITERATURE

A. Status of Respite Care Services in Minnesota

In Minnesota, as well as throughout the country,

> 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. (Bates, 1983, p. 1)

In 1980, the Metropolitan Council/Health Board studied the need for respite care services in the seven-county metropolitan area. Families who had substantially handicapped family members (N = 765) were asked about their preference for respite care delivery. While most (70 percent; N = 536) preferred care in the family's own home (p. 1), there was frequent reliance on foster care homes, group homes, or state hospitals for respite care purposes (p. 8). Where respite care was provided in the home setting, such care was usually provided by siblings, untrained sitters, relatives, neighbors, and friends (p. 9).

Although the extent of in-home respite care is not known, out-of-home placements in community and state Intermediate Care Facilities for the Mentally Retarded (ICF-MR) are known. It appears that state residential facilities have provided a large volume of respite care services in Minnesota. A study of the number of people admitted or readmitted to state hospitals between September 1, 1980, and December 31, 1981, revealed that the largest number was for respite care/parent relief purposes (*Policy Analysis Paper No. 5*, 1981; *Policy Analysis Paper No. 10*, 1982). Admission reports indicated that approximately 8 out of 10 admissions from family homes were for respite care/parental relief purposes. Specifically, "more than two-thirds (67.5 percent; N = 102) of the 151 admissions recorded were for respite care/parent relief" (*Policy Analysis Paper No. 10*, 1983, p. 11). Regarding readmissions, "Ninety-two percent (N = 23) of the readmissions from natural homes were for respite care purposes" (*Policy Analysis Paper No. 10*, 1983, p. 4).

The reasons for temporary placements in state hospitals were numerous and varied. "Family emergencies were the most frequently cited reasons for requesting a respite care admission" (*Policy Analysis Paper No. 5*, 1981, p. 11). Other reasons included: "family trips or activities, recent or prolonged hospitalization of a parent, illnesses in the family, and unavailability of community respite care services."

The above studies concluded that, "It is apparent that many families and community care providers rely upon state hospitals for respite care services. The admission reports suggest that had these services been available in the community, many short-term, informal admissions might have been avoided" (*Policy Analysis Paper No. 5*, 1981, p. 13).

For a relatively small number of families, the Minnesota Mental Retardation Family Subsidy Program, begun in 1976, has "greatly enabled families to care for their mentally handicapped child at home" (*Policy Analysis Paper No. 18*, 1983, p. 9). This has been an experimental attempt to provide financial incentives and home-based services to families with handicapped children in their own homes. The intent has been to prevent or forestall out-of-home placement in foster care homes or institutions.

B. The Need for Respite Care

Respite care has been considered to be unique among human services in that "it was intended to benefit the family or caregiver. It has been a service for those who give care, rather than for those who normally receive care" (United Cerebral Palsy Associations, 1981, p. 3). This primary emphasis was implied in its title, "respite" being synonymous with "relief" and its definition, as stated in the introductory section of this report.

Prior to the movement of deinstitutionalization, parents who chose to keep their developmentally disabled children at home "usually did so from choice, and there is considerable evidence to show that these families were expected to cope with the consequences of their choice on their own" (United Cerebral Palsy Associations, 1981, p. 2). Today, however, there has been increased awareness of how families and caregivers coped with the many responsibilities and stresses experienced by them when assuming total care of a person with a developmental disability (Bavolek & Keene, 1980; Wikler & Hanusa, 1980; Moore et al., 1982; and McCubbin et al., 1981). These studies and several others emphasized the need for addressing and providing social and economic supports to families. To prevent social isolation, which frequently occurred, there was a need to expand and strengthen social support networks, such as relatives, neighbors, and friends (Moore, 1982), and to encourage interaction between parents facing similar circumstances (Rueveni, 1979; Porter & Coleman, 1978). Failure to recognize and deal with stress could result in parent (caregiver) "burnout" (Shaw et al., 1981), increased occurrence of child abuse (Newberger, 1982), and other types of family problems, from school failure of nondisabled siblings to marital disharmony and divorce.

Respite care, as a relatively new service, has been proven "effective in reducing stress experienced by these families" (Wikler & Hanusa, 1980, p. 4). Probably no one stated the importance of and

need for respite care better than Moore and Seashore (1977):

> Respite care cannot be considered a luxury; it is a necessity if families are to stay together and function well together. Parents deserve relief from their daily responsibilities; their handicapped children must learn to know and trust people outside their immediate families. The long range effects of this vital supportive service can only produce happier, freer, and less anxiety-ridden people. (p. 2)

Lash (1983b) went a step further by stating, "Respite care services, therefore, are not only a supportive service to families, but must be viewed as a preventive service as well" (p. 21).

C. Respite Care as an Essential Component within an Array of Family Support Services

Loop and Hitzing (1980) noted that, ". . . services focusing on supporting the family and the disabled child in the natural home have finished last when compared to other thrusts of deinstitutionalization" (p. 20). Lash (1983b) observed,

> Too often, but understandably, when there are limited funds for limited services, agencies tend to focus exclusively on the needs of the developmentally disabled individual rather than looking at the entire family system. If the service system is committed to maintaining the home and family environment for a developmentally disabled person as the norm, then the first response of an agency must be, "How can we keep your family intact?" (p. 19)

Several parent support services were identified in the *CAIR* report (*Community Alternatives and Institutional Reform*) in 1975, which outlined an array of services for future development in Minnesota:

- Crises assistance;
- Family planning;
- Genetic counseling;
- Homemaker services;
- Medical support;
- Parent education programs;
- Respite care (short term):
  - — Weekend and vacation relief,
  - — Crises relief;
- Sibling counseling;
- Special funding:
  - — Home care,
  - — Transportation,
  - — Special diets,
  - — Babysitting and day nurseries. (p. 25)

Another and more recent version of the array of family support services was provided by Loop and Hitzing (1980) regarding services in Omaha, Nebraska, which is graphically illustrated in Figure 1.

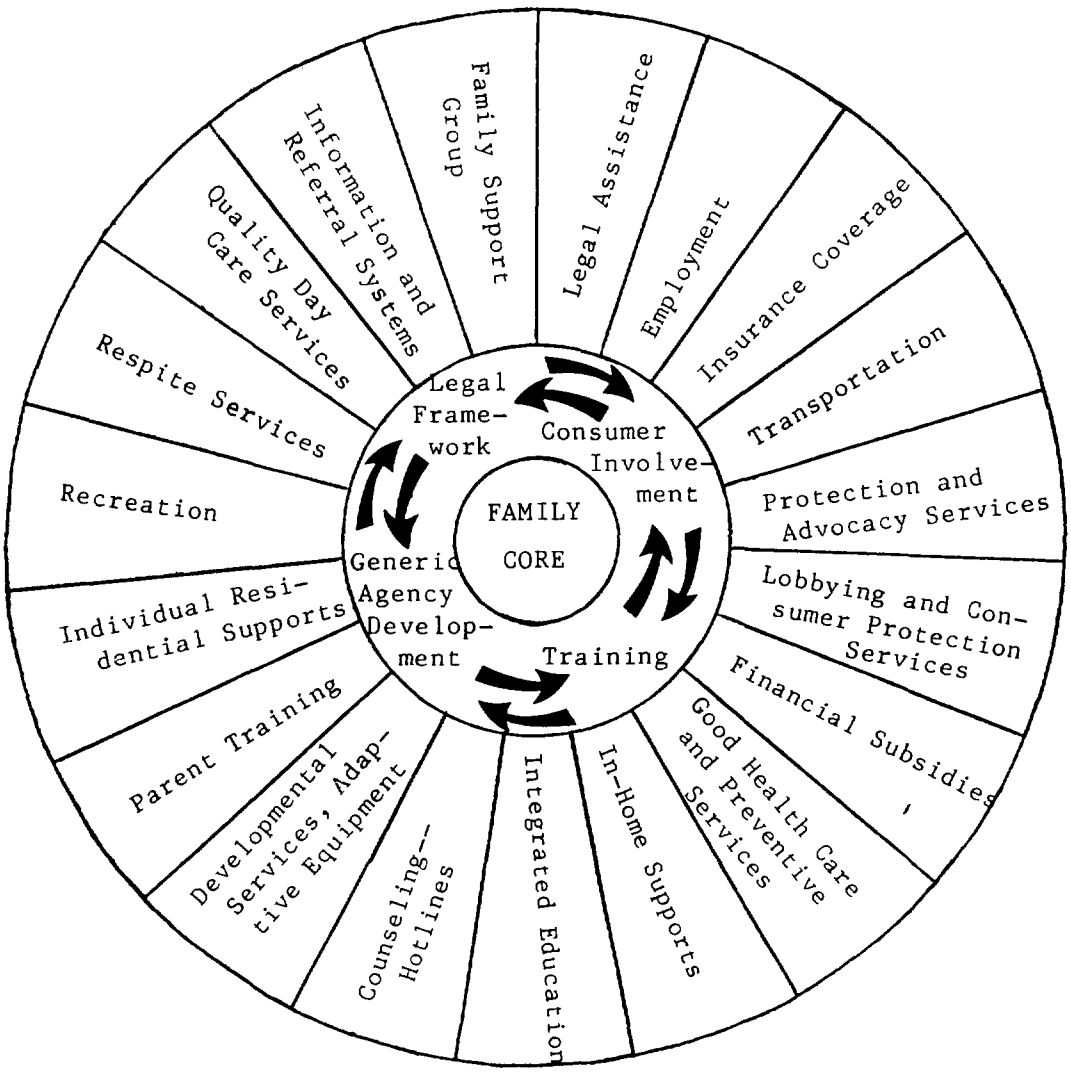

Figure 1: Model Array of Family Resource Systems and Support Services for Handicapped Children and Their Families

"The existence and characteristics of a support system are critical in determining whether or not the developmentally disabled individual is integrated into the community" (Lash, 1983b, p. 19). "For integration to occur, there must be an array of community services appropriate to the individual's *and family's needs* (*emphasis added*). These services must be:

- Integrated into the mainstream of the community;
- Provided in-home as well as out-of-home;
- Planned as well as crisis-oriented;
- Part of a comprehensive community service network;
- Short-term as well as long-term;
- Individualized and responsive to the changing needs and resources of the family or family needs." (Loop & Hitzing, 1980, p. 21)

The relationship between respite care and other family support services was further stressed by Wikler (1982) at a conference in Minnesota on "Preventing Harm to Children with Disabilities." Wikler noted that parents often have to learn how to use respite care and leisure time. In Madison, Wisconsin, parents have been instructed on how to use leisure time through parent training, and parents have been reinforced by other parents through support groups to take time out for themselves. Wikler cited several studies which revealed that families with a developmentally disabled member tended to be socially isolated. Other studies have correlated the high incidence of child abuse with social isolation.

"There is no best form of respite care," observed Cohen (1982, p. 8). As early as 1971, Paige described the following locations and types of respite care arrangements (pp. 1-4):

SERVICES IN THE HOME	SERVICES OUTSIDE THE HOME
Homemaker services	Foster home
Nursing services	Temporary-care home
Qualified babysitting	Family-group home
	Group home
	Halfway house
	Specialized nursing service
	State residential facilities.

A more recent description was provided by Upshur (1982b) based on a study of existing programs in Massachusetts where ten different types or models of respite care were identified (see Table 1). Information and referral services were also needed "in order to promote the availability of respite care services" (Upshur, 1982b, p. 6).

Table 1
Models of Respite Care Currently in Use (Massachusetts)

Respite Placement Agencies:
Agencies recruit and train community providers (similar to foster parent recruitment) and match client requests with providers. Care is provided in client's home or provider's home for a few hours up to two weeks overnight.

Group Day Care:
Respite care is provided in the form of group daytime care where children are brought to a facility to relieve families of constant care.

Community Residences:
Some residences for mentally retarded adolescents and adults reserve one or two beds for overnight respite, or will take clients in an emergency.

Group Care or Residential Treatment Facility:
Programs primarily set up as long or short-term treatment facilities reserve one or two beds for overnight respite. Some provide all beds for respite when the regregular treatment program closes for vacations, etc.

Group Respite Provider:
These are group residential programs operated solely as respite care, separate from other types of longer term treatment services.

Pediatric Nursing Homes/Hospitals:
These primarily serve as long term nursing care facilities or acute hospitals, but will also provide overnight respite in an emergency for children with medical needs.

Private Respite Provider:
This model involves nurses and others who provide overnight care for 1 to 4 children in their own homes, but are not affiliated with any agency.

State Institutions:
Some state institutions provide overnight care to older children and adults when no other alternative exists. Most prefer to serve only former in-patients.

Funding Conduit:
This model allows families to select their own caregiver for daytime or overnight services in their own home or that of the caregiver. The agency merely reimburses the family (within agreed limites) for the costs incurred in obtaining respite care.

Camperships:
This model allows daytime or overnight camp experience to be considered respite care. In some cases, parents select the camp; in others the agency does.

Great care must be given to the taxonomy and design of family support services and to the definition of respite care services. When defining respite care, the National Respite Care Advisory Committee of the United Cerebral Palsy Associations noted that, "It should be recognized that many other services provide relief but it is not

their primary function" (1981, p. 3). Ross added these words of caution:

> Public policy makers design programs and establish arbitrary boundaries around them in order to have workable funding guidelines and parameters and insure (*sic*) accountability, integrity, and control. This fact of public financing implies that respite care should be narrowly defined so it is understandable and operational. To define respite care as all services required by families not currently being offered, ignores the potential and mandates of existing programs, creates confusion regarding its mission, and implies uncontrollable budgetary implications. (1980, p. 20)

D. Review of Respite Care Programs in Other States

This section will highlight respite care programs that have been developed in two selected states: Massachusetts and Wisconsin. Products and experiences of additional states may be noted in the above text and in the list of references. Although literature and research is relatively underdeveloped regarding respite care, there are several training curricula and other resources that may prove helpful. A listing of such resources are presented in the Appendix.

Massachusetts

Massachusetts was among the earliest developers of respite care services in the country (Upshur, 1978). In 1977, the Massachusetts Developmental Disabilities Council recognized the need for "a comprehensive, integrated approach to the provision of respite care services" and created The Respite Care Policy Development Project with an advisory committee consisting of six state agencies, providers, and consumer groups (p. 1). The results of this project and subsequent grant projects through Developmental Disabilities led to several accomplishments in developing respite care services in Massachusetts.

A Respite Care Interagency Policy Committee was established to coordinate efforts and facilitate communication between the major funding agencies: the Department of Mental Health, the Department of Social Services, and the Department of Public Health (Massachusetts Developmental Disabilities Council, 1982, p. 1). Each agency has defined respite care, established regulations or service standards guided by the recommendations made by The Respite Care Policy Development Project and The Respite Care Interagency Policy Committee. Program standards have been enforced by way of funding mechanisms rather than licensure (Upshur, 1978, p. 58; Upshur, 1982,

p. 2). Providers of respite care services were reimbursed for services rendered through "Purchase of Service Agreements" with a state agency (Massachusetts Department of Social Services, 1983a, p. 1). Unit rates for services were negotiated by each state department through the Massachusetts Rate Setting Commission procedures. Each state department has monitored the performance of respite care providers from whom services were purchased in order to assure compliance with Purchase Agreement terms, state and federal regulations, service standards, and licensing requirements. Monitoring activities have included desk reviews, desk audits, and site visits. The latter has included consumer billing verification, compliance monitoring, and interviews with the respite care provider (p. 2).

The Massachusetts Department of Mental Health established a set of regulations regarding four service models that had been classified and defined by the Respite Care Policy Development Project (Upshur, 1978, pp. 56-58):

- Group Respite Providers: Group homes set up solely for providing short-term placements;

  Licensed Providers: Programs/facilities that were already licensed for other purposes, e.g., day care centers, family day care homes, group care facilities, temporary shelter facilities, and nursing homes;

  Community Respite Providers: Persons who were recruited by respite placement agencies and provided respite care in their own homes or in the homes of clients; and

  Respite Placement Agencies: Programs that recruited, trained, monitored community providers, and placed clients with community providers. (Massachusetts Department of Mental Health, Chapter 400, pp. 11-12)

The above classifications assisted the state agencies in establishing standards for respite care service providers who were not licensed and provided "add on" regulations for already licensed programs (Upshur, 1978, p. 59).

Between the three major funding agencies in Massachusetts, a considerable amount of public funds have been allocated for purchase of respite care services. The following allocations were made

for fiscal year 1983 (United Community Planning Corporation, 1982c, p. 1).

DEPARTMENT	ALLOCATION
Mental Health	$5,504,124
Public Health	241,800
Social Services	1,000,000
TOTAL	$6,745,924

In fiscal year 1982, there were approximately 15,500 people who received respite care services through these three state agencies in Massachusetts (p. 2).

Wisconsin

Wisconsin demonstrated the generic nature of respite care services. In addition to the population with developmental disabilities, respite care demonstration projects were designed to serve persons with mental illness, physical disabilities, elderly persons, and children. The latter included children who were not necessarily physically, emotionally, or developmentally disabled but were in stressful family environments where there was a risk of abuse or neglect (Wisconsin Department of Health and Social Services, 1981, p. 1).

Cretney (1983) stressed the importance of how a state defines respite care at the onset of designing and planning for respite care services. "Most policy decisions and discussion seem to revert back to how respite care is defined in the first place," Cretney commented. In Wisconsin, respite care was broadly defined as:

> . . . the temporary or periodic provision of a range of services which helps prevent individual and family breakdown or institutionalization by relieving the usual (primary) caregiver of stress resulting from giving continuous support and care to a dependent individual. (Wisconsin Department of Health and Social Services, p. 1)

In 1980 and 1981, ten demonstration projects were state-funded by the Wisconsin Division of Community Services. The use of respite care as a family service to relieve stress was the basic goal of all the projects regardless of the nature of the dependency.

During the two years of demonstrating respite care services in Wisconsin, 458 families were served (p. 4). Developmentally disabled individuals and elderly persons were the two major groups using respite services (see Table 2). Care in the individual's own home was the setting by choice in 80 percent of the cases. The only exception to the trend of care in the individual's home was for

children at risk of abuse and neglect who received care in the respite workers' homes. Other sites of care available were foster families, group homes, or institutional services.

Table 2
Wisconsin: Target Population
for Respite Care for CY 1980-1981

TYPE OF INDIVIDUALS USING RESPITE SERVICES	NUMBER OF INDIVIDUALS SERVED CY 1980	CY 1981
Children at risk of abuse or neglect	107	62
Developmentally disabled persons	187	236
Elderly persons	197	191
Mentally ill persons	11	16
Physically disabled persons	47	43
TOTAL	549	548

Wisconsin attempted to identify the factors that either facilitated or hindered the provision of respite services. Community awareness and understanding of the respite care program had a definite impact on the appropriateness and timeliness of referrals. As families and agencies better understood the service, families were better able to plan for service requests, which, in turn, facilitated better scheduling and assignment of respite care workers. Interagency coordination for planning as well as implementation was critical both in reducing costs and duplication of efforts as well as meeting families' needs more effectively (p. 17).

E. Financing Respite Care Services

There have not been enough respite care services available because of "an absence of a stable funding base" (Cohen, 1982, p. 10). Temporary funding, mostly for demonstration purposes, has been provided by Developmental Disabilities such as in Wisconsin, Maryland, Massachusetts, and Missouri. Long-range funding has been difficult to obtain and has been fraught with restrictions due to income tests and other eligibility requirements.

In a review of possible federal funding sources for respite care programs, Ross (1980) concluded that utilization of generic funding programs (i.e., funding programs not limited to those with disabilities) seemed to be the key to financing respite care (p. 21). Federal programs seen as accessible were Title XIX Medicaid, Title XVIII Medicare, Crippled Children's Services, Maternal and Child Health Services, SSI Disabled Children's Program, Title IV(B) Child Welfare Services, and Title XX Social Services. "The long-range solution . . . is to liberalize the generic funding programs so that respite and related family support services may be financed" (p. 21).

Additional federal programs explored by Ross in 1980 were: Title XX Training, ACTION volunteer programs (VISTA and Foster Grandparent Program), Title III of the Older Americans Act, and The Cooperative Extension Service of the United States Department of Agriculture.

Cohen (1982) noted that, "Clearly, a highly desirable addition to these systems (federal programs) would be legislation aimed at providing support for a variety of community-based, noninstitutional services, including respite care" (p. 10). In part, such a program was created when the U.S. Congress passed The Omnibus Budget Reconciliation Act of 1981. Under Section 2176, states were provided the opportunity to apply for a waiver of certain Medicaid statutory limitations in order to allow the states to develop home and community-based services for eligible persons who would otherwise require placement into Intermediate Care Facilities and other costly long-term care facilities. Many states have applied and been approved under this waiver (Intergovernmental Health Policy Project, 1983).

In the 1983 legislative session in Minnesota, authorization was given to the Department of Public Welfare (MINN. STAT. Chapter 312) to apply for such a waiver. Waivered services at a minimum, included "case management, family training and support, developmental training homes, supervised living arrangements, semi-independent living services, *respite care*, and training and habilitation services" (*emphasis added*). State Representative Ann Wynia, St. Paul, a chief advocate behind the bill, commented on what she hoped would be accomplished through this enabling legislation: "I hope that this is going to give us a more rational system of services, a system that will reflect individual needs as well as sensitivity to the cost of services" (*Information Exchange--State Supplement*, July 1983, p. 1).

III. DISCUSSION

A review of literature about respite care services revealed that it is a supportive as well as a preventive service for families. Aimed at providing relief to the primary caregivers, or parents, respite care services may not

only help in reducing stress that often accompanies the responsibilities of caring for a severely disabled/dependent family member, but it may also prevent or forestall permanent out-of-home placement that would be more costly and more restrictive of individual freedoms.

Because respite care services have not been available in most communities in Minnesota, there has been an overreliance on the use of state hospital facilities by families seeking temporary relief from or care for their disabled family members. In view of the spiraling costs of out-of-home placements and a heightened awareness of the service functions that families perform for their members, human service planners and policy makers must address the question, "How can we help to keep families intact?"

An array of family support services must be conceptualized and implemented among which respite care should be an integral part. Through support groups and specialized training, parents must not only learn the value of using leisure time for themselves, but they must recognize the danger signals and effects of stress in their daily lives. Besides the provision of temporary relief, qualified respite care providers could also help to imrpove and/or reinforce parenting and homemaking skills.

If respite care services are to become an established social service in Minnesota, several key elements must be addressed, of which a few include: (a) arriving at a consensus on a definition of respite care; (b) the establishment of a sound funding base; (c) the possibility of providing respite care as a generic service that would broaden the scope of clientele to be served and the consolidation of categorical funds; (d) the provision of training of respite care service developers/providers and parents; and e) the involvement of parents throughout the planning and implementation phases of creating a coordinated network of support services to families.

A continuation of this discussion is contained in *Policy Analysis Paper No. 21*, entitled *Summary and Analysis of Minnesota Developmental Disabilities Respite Care Demonstration Projects (Federal Fiscal Years 1981-1983)*.

IV. REFERENCES

Bates, M. V. State family support/cash subsidy programs. Madison: Wisconsin Council on Developmental Disabilities, 1983.

Bavolek, S. J. & Keene, R. Primary prevention of child abuse: The identification of high risk parents. Eau Claire: University of Wisconsin, 1980.

Beckman-Bell, P. Child-related stress in families of handicapped children. Topics in Early Childhood Special Education, 1981, 1(3), 45-53.

Bruininks, R. H. & Krantz, G. C. (Eds.). Family care of developmentally disabled members: Conference proceedings. Minneapolis: University of Minnesota, 1979.

California Institute on Human Services. Respite services for Californians with special developmental needs. Rohnert Park: Sonoma State University, 1982.

Center for the Development of Community Alternative Service Systems. Community-based systems of temporary family supports and integrated respite service systems: A resource bibliography. Omaha, Nebraska: Author, 1979.

Center for the Development of Community Alternative Service Systems. Respite services community development project: Project description. Omaha, Nebraska: Author, 1976.

Cohen, S. Supporting families through respite care. Rehabilitation Literature, 1982, 43(1-2), 7-11.

Cretney, L. Personal communication, May 23, 1983.

Cretney, L. Respite care and institutionalization. Madison: Division of Community Services, Wisconsin Department of Health and Social Services, 1982.

Fredericks, M. A review of respite care services and needs. Dallas: Association for Retarded Citizens--Dallas, 1980.

Hahn, S. & Pullo, M. L. Respite care: A family support service. Madison: United Cerebral Palsy of Wisconsin, 1979.

Hagen, J. Report on respite care services in Indiana. South Bend: Northern Indiana Health Systems Agency, Inc., 1980.

Hill, R. B. Thoughts on the history and future of purchase-of-service in Massachusetts. New England Journal of Human Services, Winter 1983, 36-49.

Intergovernmental Health Policy Project. Medicaid waivers. State Health Notes, July 1983.

Judd, E. & Crouch, P. Early intervention for families: Respite, training and integration (CAIR); Interim report. Denver: Colorado Department of Institutions, 1975.

Kennedy, M. Giving families a break: Strategies for respite care. Omaha: University of Nebraska Medical Center, 1982.

Kline, D. F. The disabled child and child abuse. Chicago: National Committee for Prevention of Child Abuse, 1982.

Lash, M. Personal communication, August 4, 1983. (a)

Lash, M. Respite care: The development of a preventive support service for families under stress. Boston: Massachusetts Department of Social Services, May 1983. (b)

Loop, B. & Hitzing, W. Family resource service and support systems for families with handicapped children. Omaha: Meyer Children's Rehabilitation Institute, 1980.

Massachusetts Department of Mental Health. Title 104 CMR, Chapter 400.000, Section 400.001. Respite Care Program Regulations. Boston: Author, undated.

Massachusetts Department of Social Services. Program description package: respite care, fiscal year 1984. Boston: Author, June 1983. (a)

Massachusetts Department of Social Services. Provider reference manual: respite care, fiscal year 1984. Boston: Author, 1983. (b)

Massachusetts Department of Social Services. Respite care program for the developmentally disabled: An overview. Boston: Author, June 1982.

Massachusetts Department of Social Services. Standards for the provision of respite care services. Boston: Author, June 1983. (c)

Massachusetts Developmental Disabilities Council. The future of respite care in Massachusetts: Proceedings of the respite care conference--October 5, 1982. MDDC Newsletter, December 1982.

Massachusetts Developmental Disabilities Council. Respite care studied in Massachusetts. Boston: Author, 1978.

McCubbin, H. I., Nevin, R. S., Larson, A., Comeau, J., Patterson, J., Cauble, A., & Striker, K. Families coping with cerebral palsy. St. Paul: Department of Family Social Science, University of Minnesota, 1981.

McCubbin, H. I. & Patterson, J. M. Systematic assessment of family stress, resources and coping: Tools for research, education, and clinical intervention. St. Paul: Department of Family Social Science, University of Minnesota, 1981.

Metropolitan Council/Metropolitan Health Board. Respite care for handicapped people in the Twin Cities area: A report of the seven-county ad hoc committee on respite care. St. Paul: Author, 1980.

Metropolitan Council/Metropolitan Health Board. What families with handicapped members living at home are saying about respite care: Comments extracted from metropolitan respite care survey--1980. St. Paul: Author, January 1981.

Minnesota Developmental Disabilities Program. CAIR: Community alternatives and institutional reform: Planning alternatives for the developmentally disabled individual. St. Paul: Minnesota State Planning Agency, January 1975.

Minnesota Developmental Disabilities Program. Legislature allows changes in services for retarded persons. Information Exchange--State Supplement, July 1983, pp. 1-4.

Minnesota Developmental Disabilities Program. Policy analysis paper no. 5: Admissions/readmissions to state hospitals September 1, 1980 to May 31, 1981: The behavior problem issue. St. Paul: Department of Energy, Planning and Development, August 1981.

Minnesota Developmental Disabilities Program. Policy analysis paper no. 10: An update to policy analysis series no. 5: Admissions/readmissions to state hospitals June 1, 1981 to December 31, 1981: The behavior problem issue. St. Paul: Department of Energy, Planning and Development, April 1982.

Minnesota Developmental Disabilities Program. Policy analysis paper no. 18: The Minnesota family subsidy program: Its effect on families with a developmentally disabled child. St. Paul: Department of Energy, Planning and Development, May 1983.

Minnesota Governor's Planning Council on Developmental Disabilities. Developmental disabilities state plan--1981. St. Paul: Minnesota State Planning Agency, 1981.

Moore, C. A coalition approach to respite care. Silver Spring, Maryland: Montgomery County Association for Retarded Citizens, 1977.

Moore, C. & Seashore, C. N. Why do families need respite care? Building a support system. Silver Spring, Maryland: Montgomery County Association for Retarded Citizens, 1977.

Moore, J. A., Hamerlynck, L. A., Bartsh, E., Spieker, S., & Jones, R. Extending family resources. Seattle: Children's Clinic and Preschool, December 1982.

National Association of State Mental Retardation Program Directors. The minimal array of essential services for mentally retarded persons: An analysis of consumer and provider opinions. Alexandria, Virginia: Author, 1979.

Newberger, E. Understanding the dimensions of abuse and neglect in 1982. Paper presented at a conference: "Preventing Harm to Children with Disabilities," Coon Rapids, Minnesota, May 21, 1982.

Paige, M. Respite care for the retarded: An interval of relief for families. Washington, DC: U.S. Department of Health, Education and Welfare, 1971.

Perske, M. & Perske, R. Hope for the families: New directions for parents of persons with retardation or other disabilities. Nashville: Abingdon, 1981.

Porter, F. & Coleman, R. Pilot parent program: A design for developing a program for parents of handicapped children. Omaha: Greater Omaha Association for Retarded Citizens, 1978.

Ross, E. C. Financing respite care services: An initial exploration. Word from Washington (Analysis). Washington, DC: United Cerebral Palsy Associations, Inc., February 1980.

Rueveni, U. Networking families in crises: Intervention strategies with families and social networks. New York: Human Sciences Press, 1979.

Salisbury, C. & Griggs, P. A. Developing respite care services for families of handicapped persons. The Journal of the Association for the Severely Handicapped, Spring 1983, 8, 50-57.

Shaw, S. F., Bensky, J. M., & Dixon, B. Stress and burnout: A primer for special education and special services personnel. Reston, Virginia: Council for Exceptional Children, 1981.

United Cerebral Palsy Associations. For this respite, much thanks . . . concepts, guidelines and issues in the development of community respite care services. New York: Author, 1981.

United Community Planning Corporation. Basic principles of respite care for developmentally disabled persons. Boston: Author, 1982. (a)

United Community Planning Corporation. Providing respite care: A training program for respite care providers and home health aids. Boston: Author, 1982. (b)

United Community Planning Corporation. Respite care dollars. Boston: Author, 1982. (c)

Upshur, C. C. An evaluation of home-based respite care. Mental Retardation, April 1982, 20(2), 58-62. (a)

Upshur, C. C. Respite care for mentally retarded and other disabled populations: Program models and family needs. Mental Retardation, February 1982, 20(1), 2-6. (b)

Upshur, C. C. Respite care policy development project: Summary of final report. Boston: Massachusetts Developmental Disabilities Council, 1978.

Upshur, C. C. & Schmickel, A. F. Basic principles of respite care for developmentally disabled persons. Boston: Respite Care Interagency Policy Committee, 1982.

Wikler, L. Chronic stresses of families of mentally retarded children. Family Relations, April 1981, 30, 281-288.

Wikler, L. Stress plus stress: Living/working with disabled children. Presentation at "Preventing Harm to Children with Disabilities Conference," Coon Rapids, Minnesota, May 21, 1982.

Wikler, L. & Hanusa, D. Impact of respite care on stress in families of developmentally disabled people. Paper presented at the American Association of Mental Deficiency Annual Conference, San Francisco, May 13, 1980.

Wikler, L., Wasow, M., & Hatfield, E. Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. American Journal of Orthopsychiatry, 1981, 51, 63-70.

Wisconsin Department of Health and Social Services. Respite care projects: 1980 final report. Madison: The Bureau of Aging, 1981.

APPENDIX: RESPITE CARE TRAINING RESOURCES

*Arizona Department of Economic Security. Family support services: Respite sitter, in-home program handbook. Phoenix: Division of Developmental Disabilities, 1979.

*Andress, J. J., Jolliffe, N., McNees, M., Meier, H., & Warner, D. Manual of the parent respite care cooperative. Kalamazoo, Michigan: Association for Retarded Citizens, Kalamazoo, 1977.

*Association for Retarded Citizens--San Diego. Sitter service for the handicapped: Respite worker training manual. San Diego: Author, 1982.

Balthazar, E. E. Training the retarded at home or in school: A manual for parents, home trainers, teachers and others. Palo Alto: Consulting Psychologists Press, 1976.

*Calhoun, M. L. & Duncan, T. M. The helping hand of respite care . . . A training manual for providers of respite care. Columbia, South Carolina: Respite Care Project, Circa 1982.

*Kenney, M. Giving families a break: Strategies for respite care. Omaha: Meyer Children's Rehabilitation Institute, University of Nebraska Medical Center, 1982.

Kenney, M. Handbook for home-based services. Des Moines: Iowa Civil Rights Commission, Protection and Advocacy Division, 1979.

*Meyer's Children's Rehabilitation Institute. Respite care fact packet. Omaha: University of Nebraska Medical Center, 1982.

*National Council for Homemaker-Home Health Aide Services. Working with the developmentally disabled person and family: A manual for instruction of the homemaker--Home health aide. New York: Author, 1979.

National HomeCaring Council. A better answer . . . Homemaker-home health aide services for the person with developmental disabilities and family series: No. 1, A community guide; No. 2, A manual for instructors; No. 3, A handbook for aides; No. 4, Guidelines. New York: Author, 1983.

*National HomeCaring Council. 1982-83 Publications and audiovisual aids list. New York: Author, 1982.

National HomeCaring Council. Someone I can trust. New York: Author, 1981.

---

*These resources may be borrowed from the Minnesota Developmental Disabilities Program, State Planning Agency, 550 Cedar Street, St. Paul, Minnesota 55101.

*National Institute on Mental Retardation. Residential services: Community housing options for handicapped people. Downsview, Ontario: Author, 1978.

*Nisonger Center for Mental Retardation and Developmental Disabilities. Operating manual for residential service personnel. Columbus, Ohio: Author, 1974.

*Perske, R., Clifton, A., McLean, B., & Stein, J. Mealtimes for severely and profoundly handicapped persons. Baltimore: University Park Press, 1978.

Powell, T. H. & Hecimovic, A. Respite care for the handicapped: Helping individuals and their families. Springfield, Illinois: Charles C. Thomas Publishers, 1981.

*Pullo, M. & Hahn, S. Respite care: A family support service. Madison: United Cerebral Palsy of Wisconsin, 1979.

*Respite Care Program, Inc. Respite care training manual. Crookston, Minnesota: Author, 1983.

*Shoob, Deanne. A community respite care program for mentally retarded and/or physically handicapped. Springfield, Virginia: Child Care Assistance Program for Special Children, Inc., November 1976.

South Carolina Department of Social Services. Love in the world--A manual for foster parents. Columbia: Author, undated.

*United Cerebral Palsy Associations. For this respite, much thanks . . . Concepts, guidelines and issues in the development of community respite care services. New York: Author, 1981

United Community Planning Corporation. Providing respite care: A training program for respite care providers and home health aids (handbook for trainers, core curriculum; and specialized modules in severe behavior problems; recreation and leisure; and stress and burnout). Boston: Author, 1982.

*Wehman, P. & Schleien, S. Leisure programs for handicapped persons: Adaptations, techniques and curriculum. Baltimore: University Park Press, 1981.

---

*These resources may be borrowed from the Minnesota Developmental Disabilities Program, State Planning Agency, 550 Cedar Street, St. Paul, Minnesota 55101.