FAMILY CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: A GROWING COMMITMENT

May 20, 1985

This project was supported by the U.S. Department of Health and Human Services primarily through the Office of the Assistant Secretary for Planning and Evaluation (Grant Number: 123A-A3). In addition, because the goals of this project were complemented by those pursued as part of another project, it should be noted that the Administration on Developmental Disabilities also helped to support portions of this effort (ADD Grant Number: 90DD0049/01).

Project Officer:

Jerry Silverman
ASPE/DHHS
Hubert H. Humphrey Building (room 447F)
200 Independence Avenue, SW
Washington, DC 20201

FAMILY CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: A GROWING COMMITMENT

PROJECT STAFF

HUMAN SERVICES RESEARCH INSTITUTE	NATIONAL ASSOCIATION OF STATE MENTAL RETARDATION PROGRAM DIRECTORS
phone: 617-542-1812	phone: 703-683-4202
VALERIE BRADLEY (PROJECT DIRECTOR) JOHN AGOSTA	ROBERT GETTINGS BERYL FEINBERG DEBBIE JENNINGS RUTH KATZ

PROJECT STAFF ASSISTANTS

SAM AUSTIN
KAREN HARTFIELD
PAUL NURCZYNSKI
ANNE RUGG

CONCEPT PAPER AUTHORS

PAUL CASTELLANI	POLICY OPTIONS FOR FAMILY SUPPORT SERVICES
ADDIE COMEGYS	A PARENT'S PERSPECTIVE
SUSAN LAMB	THE PERSPECTIVE OF A PERSON WITH DISABILITIES
ROBERT PERLMAN. . . .	FAMILY SUPPORT OPTIONS: A POLICY PERSPECTIVE
COLLEEN WIECK	THE DEVELOPMENT OF FAMILY SUPPORT PROGRAMS

THE RECOMMENDED CITATION FOR THIS ENTIRE PUBLICATION IS AS FOLLOWS:

Agosta, J.M. & Bradley, V.J. (Eds.)(1985) Family care for persons with developmental disabilities: A growing commitment. Boston, MA: Human Services Research Institute.

ADDITIONAL COPIES OF THIS PUBLICATION MAY BE OBTAINED, POSTPAID AT $19 PER COPY, CHECK PAYABLE TO HUMAN SERVICES RESEARCH INSTITUTE, FROM

HUMAN SERVICES RESEARCH INSTITUTE
FAMILY CARE REPORT
2336 MASSACHUSETTS AVENUE
CAMBRIDGE, MA 02140

ACKNOWLEDGEMENTS

The authors recognize and appreciate the significant contributions made by many throughout the course of this project. Thanks are due those who responded to our requests for information on family support programs operating around the country, the conference participants who sharpened and broadened our understanding of the many issues involved with supporting families, and members of the National Advisory Committee who reviewed initial project materials.

Special thanks are extended to Gunnar Dywbad, Ph.D., Dorothy Lipski, Ph.D., and Kris Slentz, Ph.D., for the guidance they provided regarding various aspects of the final report. In addition, we would like to thank staff in the office of the Assistant Secretary for Program Evaluation, and especially Jerry Silverman, who reviewed drafts of our work and provided us direction.

This report is dedicated to all those families who provide or have ever provided home care to persons with developmental disabilities.

TABLE OF CONTENTS

PREFACE

In the past two decades, we have watched as an increasing number of disavantaged and disenfranchised groups moved to the forefront to assert their rights to participate as full members of the society. The move was begun by black civil rights groups but later grew to encompass women, and more recently, persons with disabilities. The common aspiration of all of these movements is a desire to control one's own destiny and to gain the power to affect one's immediate circumstances. This spirit is also present today in attempts to move the control of human services programs closer to local communities and in the explosion of self-help and self-advocacy groups around the country. It is within this context that the following report on the enhancement of the capacity of families to care for developmentally disabled family members should be viewed.

Historically, the families of persons with developmental disabilities have been viewed as more of an impediment to the habilititation of their family member than as a potential care-giving resource. The author of a relatively recent article in a reputable academic journal epitomized the condescending attitude that some professionals have traditionally reserved for parents: "We cannot assume that families have the intelligence, values, education, motivation or interest to enable them as a unit to proceed as a cooperative member in decision-making." Instead of assisting families to understand the nature of their child's needs and the steps they might take to help them, many professionals counselled out-of-home placement and forgetting.

Today, the families of persons with developmental disabilities are asking that their role as caretaker be acknowledged and are requesting the information and support necessary to provide such assistance. At the same time, more and more families are coping with increasingly disabled infants whose survival is made possible by advances in neonatal care. These families are faced with enormous responsibilities and family stresses. The material in the ensuing report is meant to assist in the "empowerment" of families and to suggest concrete ways in which both the public and private sectors can facilitate the maintenance of the family unit while improving of the life chances of the family member with developmental disabilities.

The preparation of the following report was a joint venture between the Human Services Research Institute and the National Association of State Mental Retardation Programs (NASMRPD). The support of the staff of NASMRPD -- Robert Gettings, Deborah Jennings, Beryl Feinberg, and Ruth Katz -- throughout the project was deeply appreciated.

Valerie J. Bradley
President
Human Services Research
Institute

OVERVIEW

Parents of sons or daughters with developmental disabilities face a variety of dilemmas and choices regarding the long term needs of their offspring. Traditionally, such families have been accorded few supports and have often been encouraged to seek residential placement for their child with disabilities away from the family home. Policy initiatives, however, have focused increasingly on establishing statewide programs of systematic support to care-giving families.

Pursuant to a grant from the Department of Health and Human Services, the Human Services Research Institute (HSRI) cooperated with the National Association of State Mental Retardation Program Directors (NASMRPD) to acquire an improved understanding of this movement. To achieve this goal, the following three objectives were set:

- To identify new and creative ways of involving families in caring for their relatives with developmental disabilities and to determine the barriers to growth and acceptance of these new approaches;
- To identify new approaches for encouraging families to plan financially for the future of their relatives with developmental disabilities; and
- To examine the fiscal incentives and disincentives that influence parental choices regarding the placement of family members with developmental disabilities and to identify innovative ways of countering incentives that favor out-of-home placement.

These objectives were achieved through a variety of activities, including:

- Solicitation of information from knowledgeable officials in 50 states. This survey provided information on the status and character of family support programs around the country.

of the number of states that have initiated extensive family support programs. However, there is still more to be done and we hope that this report will spur the further development of programs for persons with developmental disabilities and their families.

This report's major chapters are as follows:

PART I: THE FAMILY

I. THE FAMILY AND ITS NEEDS:

This chapter presents key definitions of terms along with information on the prevalence of family-based care, the problems families have with coping with the advent of disability, and their overall service needs.

II. A PARENT'S PERSPECTIVE:

This portion of the report is written by a parent of a daughter with developmental disabilities and includes thoughtful insights regarding family needs.

III. THE PERSPECTIVE OF A PERSON WITH DEVELOPMENTAL DISABILITIES:

This section is written by a person with disabilities and provides information regarding the needs of the family member with a disability.

PART II: RESPONDING TO THE NEEDS OF FAMILIES

I. HISTORICAL AND CONTEMPORARY RESPONSES TO DISABILITY:

This chapter describes the tension between society's responsibility to care for persons with disabilities on the one hand, and the family's responsibility on the other. It also includes a discussion of present barriers to increased public support for families, factors spurring increased demand for family support, and the challenges to professionals in developing such services.

II. THE DEVELOPMENT OF FAMILY SUPPORT PROGRAMS:

This portion of the report, written by the director of a state developmental disabilities council, offers information regarding what can be done on a policy level to support families.

III. STATEWIDE FAMILY SUPPORT PROGRAMS: NATIONAL SURVEY RESULTS:

In this chapter results of a national survey of existing family support programs are presented.

PART I: THE FAMILY

Chapter 1: The Family and Its Needs

Chapter 2: A Parent's Perspective

Chapter 3: The Perspective of a Person with Developmental Disabilities

THE FAMILY AND ITS NEEDS

During the past twenty years, the norms and mores affecting American family life have undergone rapid changes. Parents of children with developmental disabilities have also endured these changes and additionally have experienced significant shifts in the way society responds to persons with developmental disabilities. Until recently parents of such children were afforded only two residential service options: parents could forego traditional parental functions by placing their child in an institution or they could provide care at home with little or no external support. A third option, however, is slowly evolving. This option is symbolized by the rapid growth of community-based services that increasingly serve as an alternative to institutionalization. Among these services are those that provide assistance to families who choose to maintain persons with developmental disabilities within the family. Prior to designing or implementing family assistance programs, however, the needs of families must be clearly understood.

The Family and Family-Based Care

Any discussion of care provided by families to members with developmental disabilities must begin with definitions of three fundamental terms: family, developmental disability, and family-based care.

- Family. In the simplest sense, "family" can be defined in terms of its composition. As such, the notion of "family" is viewed traditionally as a group of two or more persons who live together and who are related by blood, marriage or adoption. In her chapter

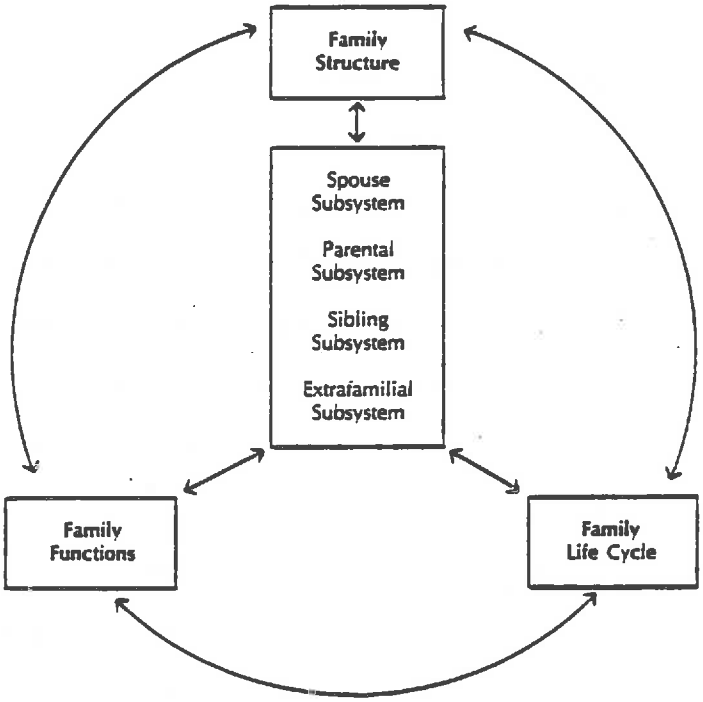


Figure 1: The Family Systems Model*

*Source: Turnbull et al., 1985

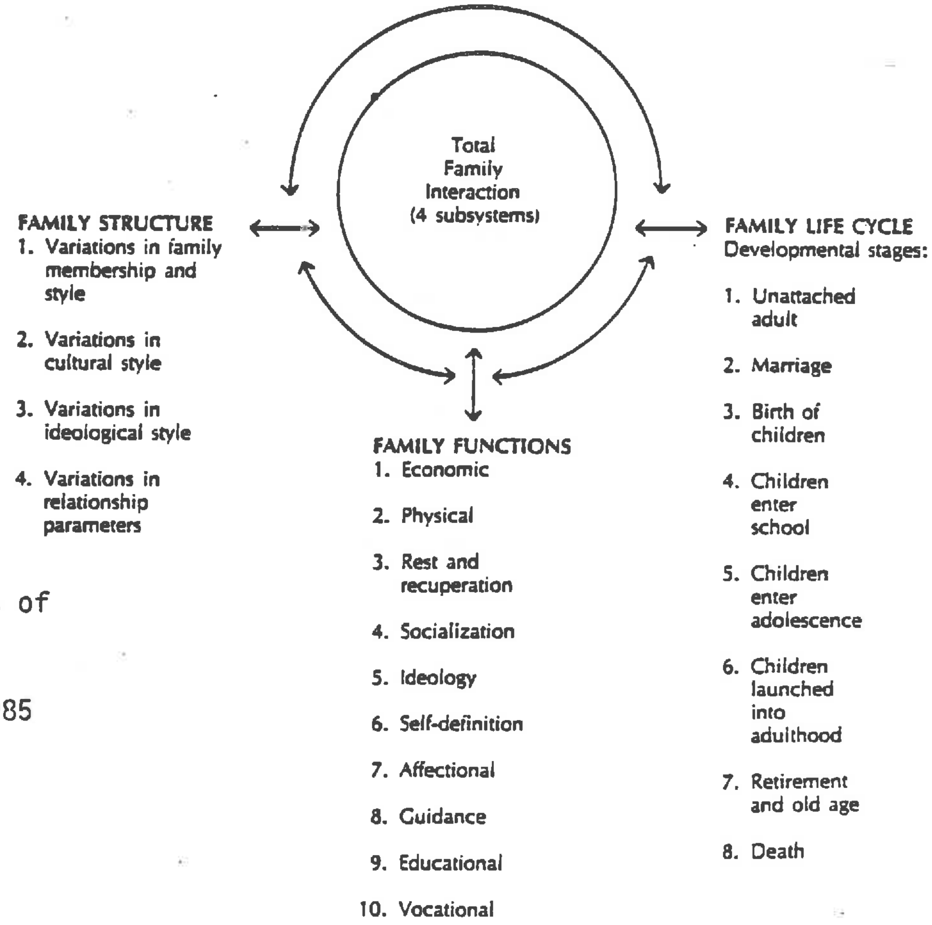


Figure 2: Three Perspectives of Family Dynamics*

Source: Turnbull et al., 1985

developmental disability is taken from the Comprehensive Services and Developmental Disabilities Amendments of 1978 (P.L. 95-602) and is as follows: "the term `developmental disability' means a severe chronic disability of a person which

a) Is attributable to a mental or physical impairment or combination of mental and physical impairments;

b) Is manifested before the person(s) attains age 22;

c) Is likely to continue indefinitely;

d) Results in substantial functional limitations in three or more of the following areas of life activity;

    1. Self Care
    2. Receptive-expressive language
    3. Learning
    4. Mobility
    5. Self-direction
    6. Capacity for independent living; and
    7. Economic self-sufficiency; and

e) Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are individually planned and coordinated." [Sec. 102(7)]

- <u>Family-Based Care</u>. Family-based care is provided when a person with developmental disabilities lives with his/her natural family (i.e., parents, siblings, other relatives). Expanding this basic definition, Horejsi (1979) notes two types of family-based care: habilitative and ordinary. Habilitative family care occurs primarily in the family home and is carried out by family members who assume major responsibility for ordinary parenting duties and some responsibility for providing more therapeutic or habilitative care. This type of care is planned systematically and is augmented by family assistance services to strengthen the family and integrate the person with developmental disabilities into the family unit (Bryce, 1979; Horejsi, 1979). In contrast, ordinary family-based care refers to situations where persons with developmental disabilities remain at characteristics of caregiving families remains a concern of policy planners, much has been learned about the effects of disability on a family and the needs of persons with disabilities. Such information can be used to gain an understanding of what support families require to provide effective family-based care.

Families and the Presence of a Member with a Developmental Disability

The presence of a person with developmental disabilities in the home can present the family with a variety of extraordinary challenges. There are, however, inconsistent and contradictory findings regarding the nature and severity of such challenges. In general, available research suggests that any problems individual families experience are related to multiple factors including the seriousness of the family member's disability, the presence of maladaptive behavior, family characteristics, the family's emotional status, specific parenting patterns, the family's capacity for coping with adversity, and the availability of community support services (Crnic, Friedrich & Greenberg, 1983; Nihira, Mink & Meyers, 1980; Mink, Meyers & Nihira, 1984). As a result, Moroney (1983) notes that though not all families experience extraordinary problems, all are "at risk" because they are more likely to have difficulties than families without members with disabilities.

For many families the initial recognition that a severe disability exists persents an immediate crisis that evolves into a life crisis. Several of the problems families can experience include:

- Adverse reactions to the discovery that a family member has a developmental disability including a sense of shock or numbness, denial, grief, shame, guilt and depression (Fortier & Wanlass, 1984; English & Olson, 1978);

Needs of Persons with Developmental Disabilities

As defined in greater detail earlier, persons with developmental disabilities require special care due to physical and/or mental impairments that occur before age 22, and that result in severe functional limitations in a variety of life skills. This definition is stated in such broad terms that it encompasses a variety of handicapping conditions including, but not limited to, mental retardation, cerebral palsy, epilepsy, and autism. The advantage of using a definition based on functioning level is that it groups together a variety of persons requiring comparable long-term care and results in fewer persons "falling through the cracks" of rigid service eligibility criteria. The primary disadvantage is that it is difficult to compile precise demographic information on the entire population with developmental disabilities.

Review of available information, however, suggests that:

- Mental retardation is the primary disability listed for the great majority of persons with developmental disabilities (Lubin, Jacobson, & Kiley, 1982);
- Persons with developmental disabilities have severe functional limitations due to inadequate skills, maladaptive behavior, or extraordinary medical needs; and
- Persons with developmental disabilities often possess multiple handicaps (Moroney, 1983; Lubin *et al*., 1982; Lea, Reed & Hansen, 1978).

Given these considerations, persons with developmental disabilities can have extraordinary needs pertaining to:

- Health status: Several types of disabling conditions require frequent monitoring of biological functions. Moreover, they require that caretakers be knowledgeable about the means for coping with medical emergencies.
- Health maintenance: Many health professionals are not trained to cope with extraordinary health needs of persons with developmental disabilities. Consequently, many routine health maintenance tasks are greatly complicated. A child with a severe reverse tongue thrust and little voluntary muscle control may need to see a special dentist. Likewise, a person

Participants at HSRI's working conference on family support noted the following problems with the way such services are currently provided.

- Lack of <u>individualization</u> of services received. Because family situations are unique, services must be flexible enough to accommodate each family's individual needs. Existing family support services, however, are often designed with an insufficient capacity for such flexibility, resulting in an unsatisfactory match between services and family needs;
- Insufficient <u>control</u> over services received. When available support services do not match family service needs, families often have little leverage to modify the services they are offered;
- Inadequate <u>information</u> regarding the present and future needs of the family member with disabilities as well as the implications these needs have for family care providers. Such information also includes systematic instruction for family members regarding contemporary habilitative practices. The need for such information begins at the time of birth of the person with disabilities and continues throughout his/her life;
- Shortage of <u>time</u> to care for the person with disabilities, perform normal household routines, undertake productive activities such as attending school or working, and cope with other aspects of one's personal and familial life;
- Insufficient number and range of <u>direct services</u> for the person with disabilities. For persons with disabilities of school age this often includes the availability of habilitative activities during evenings and/or weekends. For adults with disabilities this can involve a need for daily vocational instruction, alternative community living arrangements, a variety of age-appropriate social and recreational activities, and suitable transportation services to enhance the accessibility of various community resources;
- Lack of <u>instrumental and environmental</u> supports. These supports include proper adaptive equipment for the person with disabilities as well as the provision of a living environment that is barrier free for both the person with disabilities and the family caretakers;
- Inadequate specialized <u>health care</u> to meet extraordinary needs regarding medical and/or dental care;
- Needs for a <u>support network</u> for and run by parents to provide informal support, share information, and overcome the social isolation many families experience; and
- Insufficient means to ensure the <u>future well-being</u> of the person with disabilities. This issue pertains primarily to guardianship and financial planning.

A PARENT'S PERSPECTIVE

By

Addie Comegys

With both support from her husband and interruptions from Kate!

Every family is different from the next, whether it includes a person with handicaps or not. But families with a member having a developmental disability share a number of goals and concerns.

We all have problems of one kind or another. That is life, a challenge to be sure. But, persons with developmental disabilities, in addition, eventually have to prove that they can contribute to society in both competitive productivity and in winning ways. To achieve this they need the supportive consistency and sustenance of their own flesh and blood from birth through death. Society must, and can, increase its desire and capacity for assimilating this population. But it must move more quickly and supportively in the immediate future then it has in the past.

I would like to see the end of placements in nursing homes or institutions for developmentally disabled individuals needing long term total care. Instead, I would like to see each person with a disability able to be cared for in their own home, just as our great great grandparents cared for their elderly family members.

Those of us who participated in the HSRI conference can provide some creative and corrective momentum by addressing accurately the genuine needs of all types of households, present and future, that are actively caring for, or considering caring for, developmentally disabled members.

directing your (natural) anger towards the doctors who (usually) informed you. Family members often progress through emotional stages similar to those experienced in response to a death in the family.

Let me tell you about our own experiences with our second daughter, Kate. It was only thirteen years ago in a hospital office in our nation's capital, that my husband and I were advised by medical personnel to institutionalize our daughter who was approximately eighteen months old. Kate, we were told, was multiply handicapped. She had cerebral palsy. She was very retarded, and so, the doctor went on to say, we would be wasting our love on her. "Why not adopt another child in Katie's place," she suggested. One who could return our love.

I hugged my child all the way home. I worried that she had "sensed" the abrasive consultation. I worried about my husband's reactions and those of our older daughter. I could feel a ghastly hollow detachment and isolation envelope me from head to toe and side to side, but not before we stubbornly and from the gut answered that ugly challenge with a loud and firm "No!" as we arrived in our driveway.

There was no early intervention as we know it today. I think that family caregivers do what comes instinctively in that situation. But the added knowledge of various therapies and techniques are crucial because it can possibly save a marriage from divorce or desertion or noninteraction. Or it can give parents courage to hang on, not to institutionalize, and something constructive to do with their hands and minds.

A parent of an involved child becomes afraid of the unknown; isolated with his or her own strange emotions. I remember asking my

I still wonder (guilt) what happened during my pregnancy that caused our much wanted child to be born with handicaps. No doctor has an answer. (As the March of Dimes TV ad says: Parents of handicapped children aren't evil nor do they deliberately have babies with handicaps.) When we learned in August, 1983, (Kate was 14) that she had also been deaf since birth, all my old fears and questions resurfaced. Did I do something wrong Maybe my ancestors are to blame. Maybe my husband's. All of these are natural reactions. My point is that relevant information from the very beginning is the key. It is the cement that can glue a family together in horrendously stressful times, not to mention Faith and Hope.

Implications for Families Providing Habilitative Care

Today when a family is presented with the knowledge of any disability, all sorts of supporting arms should be available to swoop around the family, arms from physicians, social service agencies, religious institutions and the local communities alike. These attitudes should promote confidence, hope and a "we'll learn to live constructively together" attitude. This must happen in those first hours, days, months and years. Service providers (e.g., case managers, parent trainers) must be trained to provide expert consultation and quality care for that child and its family, which will be in a state of shock and then confusion, perhaps for several years.

Services That Families Require

Kate needs partial assistance and partial independence in every phase of her daily life --dressing, toilet schedule, washing, eating, leisure activities, positioning, stairs, and nonverbal communications (She does not need assistance to either give or vacation with and without family. The problem is fitting in to the mold of a sitter -- her hours, her constraints, her transportation. Sometimes I feel as though I am being freed to leave the home only on the sitter's terms: her free time and her rate.

Respite Care is a term I dislike. In many states it is hard to get. It is bureaucratic. It is unreliable. It is insufficient. It is not immediate. When I feel exhausted, I must know that I can anticipate relief tomorrow at 10 A.M. That very knowledge is, in itself, one of the controls I have learned to use constructively. I do not plan my frantic moments. Currently, in my state, the Department of Social Services may authorize ten days of Respite for each six month period. Parents may choose to use half days (five hours or less) or a combination of full and half days. A "full" day is ten hours only. At my house, a full day is 24 hours!

Our primary preference is to find someone, living in our community, who could simply become a welcomed member of our family when here. If I can find a person who has been exposed in a personal way to handicaps so much the better. I prefer a person who will continue my routine. I do not require fancy training. I think I can provide that myself. Fancy training can create preconceived misconceptions about a child's abilities and how s/he should be treated. Often those preconceived notions do not fit, but are difficult to correct.

I do require an individual, male or female, who will talk with Kate, as a sibling might, constantly commenting on the happenings of the moment. This, I have discovered, is hard for some people to do. Maybe it reflects their own insecurities. I need someone who will help Kate to fill her day with quality activities even if Kate can for better positioning and adjustments.

Our bathroom has grab bars installed around the tub. I found them in a catalog which now will not accept individual orders -only institutional ones.

We have made numerous adaptations to several bicycles along the way -training wheels, welded handlebars, banana seats, velcroed foot straps.

When we buy a new car, the seat's accessibility is a major factor. Those needing vans and lifts endure tremendous expense. And what about resaleability.

I am not knowledgeable about Medications because Kate does not need them. I wonder how families who do purchase many medicines pay for them. I do know they are increasingly expensive.

My husband has put together, with the guidance of a professional, several electronic Leisure and Educational Activities for Kate. For instance, consider a Kodak Ectagraphic Slide Projector with synchronized tape cassettes. It has an on/off switch operated by Kate and a push panel wired to the projector's screen that enables her to change the slides by pressing the panel. The slides are pictures we have taken of family occasions and pages of favorite books. Our voice on the tape reads the text. Both projector and tape are fixed to a timer so that Kate must press the panel to activate the slide and hear the next part of the story.

He has also organized a tape recorder with a timer and a color organ (Radio Shack) so that when Kate presses the on/off switch a cassette tells the story of Louisa May Alcott's Little Women. For instance, colors are flashed to vocalizations for as long as the timer is set. Both slide projector and tape recorder are precursors this youth and his frantic parents in his own home environment. How can we help?

In many states, like Massachusetts, Home and Health Services are being utilized more and more by parents who cannot find regular sitters and whose health insurance plans or Medicaid will cover the extremely high cost. But these services can be expensive (e.g., $80 a day). The Home Health Aides are medically trained, and serve a real need. But the cost is outrageous and not all families need the medical input.

When my widowed mother became ill, sold her house and was hospitalized, I would have liked very much to have her stay with us during her recuperation and subsequent housing decision. Her interactions with Kate and us would have been very valued. But my prior experience locating sitters for Kate scared me. And I was uncertain about the close quarters, nurses aides she would require, and my questionable ability to calmly juggle husband and child, mother and constant outsiders in our house. I should have taken the chance. But I did not know of a definite safety valve I could turn for me. I would like to see changes in the current support system which would help others instinctively struggling to hold families together.

Family Well Being

Some families disintegrate but many solidify when they learn they have a disabled member amongst them. Much depends on communication, that old buggaboo and hangup. Egos have become damaged. Guilt and anger and confusion are pervasive. Parents must communicate with themselves and other siblings. If that is difficult, the strongest must reach out to a trusted friend, sharing is there. I like to envision each sibling leaving the nest as an ambassador to the world outside. I am happy to report that Kate's older sister, who is 28 and a reporter for United Press International in New York City, is not only an ambassador but a great support to Katie, who blossoms when she comes home, and to my husband and me.

Siblings may benefit from genetic counseling. Siblings need time of their own. They need to be recognized for their own achievements. There is a trend to feature "Sibling Panels" at conferences today. We have much to learn about their joys, fears and frustrations. Siblings may often be found in professions related to the special needs field.

The <u>extended family</u> should also be considered. Aunts and uncles, grandparents, in-laws, a particular neighbor, a peer buddy from the community, a peer tutor are all the kinds of arrangements which are homespun and community-based. TV ads proclaim Adopt-a-Grandparent, and Big Brother/Big Sister programs. A good example is a television show hosted by Jack Williams on Boston's TV Channel 4. This program, called "Wednesday's Child," promotes the adoption of children with a wide range of handicaps in Massachusetts who need a family to live with. He received a Media Award from T.A.S.H. at its 11th Annual Conference in Chicago, November, 1984.

Recommendations for Improving Support Services

The support services available in many states are a great help to families. They can, however, be improved. Please consider the following recommendations:

7. High School Peer Tutors are noted by name in town newspaper columns. Perhaps, more of them could be enlisted to act as skill instructors, care attendants or just plain friends

8. Responsive and sufficient Respite Care is virtually nonexistent. I am aware of two current projects to document the situation. Standards vary greatly. Rates are subminimal. The need is acute. Parent cooperative arrangements are one answer.

9. Families need Financial Reimbursement for educational litigation. Poor and minority families are unable to upgrade an educational placement. Advocates are scarce. Lawyers are expensive. Parents are not reimbursed for their efforts, school systems are.

10. Early Intervention must be maintained and creatively expanded.

11. Integrated Recreational Programs that are run by local townships are needed by persons with severe handicaps.

12. Expanded involvement of Churches and Community Organizations in the lives of persons with disabilities would be welcomed.

13. There is a need for development of Accredited Summer Camps appropriate for all handicaps. Camperships. Both are in minimal supply. Both are so important in social development.

Support Networks

14. I believe that parents need outlets to tell and write their stories in order to communicate their experiences to other parents and to spur changes in the system.

15. Parent Advisory Committees (PAC) in school systems are mandated but not enforced. These committees should be strengthened to reduce the costs of appeals and out-of-school placements prompted by inadequate local services.

In conclusion, professionals, bureaucrats and others committed to helping families should be reminded that parents really do want to treat their child with disabilities like their other children. That is, they seek to be primarily in charge of shaping the course of their children's early life; that is their parental responsibility. Moreover, those wishing to support family efforts must realize that no two families are alike. Each responds to the advent of disability differently, and requires different types and amounts of services.

THE PERSPECTIVE OF A PERSON WITH DISABILITIES

by

Susan F. Lamb

Call me Susan. Call me Matthew. Call me your daughter or son. Call me pupil or client. Call me cripple or dummy. Call me developmentally disabled. Whatever your label, I am, I live. And your attitudes about my limitations and future determine the fullness or paucity of this life I have been given. I was not born with an awareness of the meaning of "severely disabled." I didn't understand why the dreams my parents had for me had been shattered. I had not been excluded yet from schools, libraries, museums, parks or a place in society. When I was small, nestled in the soft padding of my special stroller and a child shrilled as he passed: "Why is she bent that way?," "look she's got no legs;" or "Mommy I don't like ugly people like her." I couldn't understand why the "Sh-h-h-h" of the child's mother sounded so angry at me. I had been introduced into the harsh reality of attitudinal and architectural barriers. For a person who is moderately or severely disabled, these barriers create the loneliness and isolation that is ever present in our lives.

Whatever the disability, race, sex, religion, nationality or income group attitudinal and architectural barriers frustrate the life of the individual and his/her family. Consequently, the purpose of this paper is to personalize the consequences of these barriers on the life of the individual with the disabling condition and his/her family. It is divided into three parts:

communicating with the child, what IS happening or what MIGHT happen. To not inform a child of what is happening makes the child vulnerable to unneccessary fears.

> *I don't like being alone because it gives me a feeling of loss. I think it all started when I went to the hospital and was separated from my family. There was almost no communication. I think I have been alone for so long and for so many years that I hate the idea. -- Lois, deafness*

Many disabled persons believe that only their families care enough to help them or are interested in them. Inactivity of the body and passivity of mind during a young child's early years will atrophy the spirit as well as the body. Even a young child needs to understand and be encouraged to assert him/her self, to ask questions or to seek help from those outside the family. Because, for so many professionals you are just another case and you are assumed to have no need for privacy nor a sense of modesty, a child needs to know the answer to "Why?" and "What for?" and "What is it?"

> *We had monthly visits by an orthopedist, who would come like a circuit judge to the school. . .I would have to get out there in my underwear in front of the doctor, the physical therapist, a couple of teachers, maybe the principal, other kids and parents. I'd be paraded around and had to listen to my case being discussed. -- Vickie, cerebral palsy*

Disabled persons must also cope with stress stemming from a recognition of the inordinate demands made upon parents and siblings for their time, their patience and their physical endurance. If left unchecked, this condition can frustrate a disabled child and promote guilt. Likewise, the family may resent the extraordinary caretaking responsibilities. It takes time to realize that alternate care arrangements can help.

WHY DON'T FAMILIES RECEIVE SOME HELP FROM THEIR COMMUNITY OR THEIR GOVERNMENT? Why isn't there a uniformity in the scope of community based services programs from state to state? Why does a family often have to reach poverty level before they can qualify for medical care or other services like homemaker assistance, respite care, personal care, medical equipment, physical or occupational therapy or adult day care? It has been shown time after time that when home health aides and services are available to families caring for a disabled member, the savings to the taxpayers and to the fiber of the family is staggering. Families need these support services in order to maintain their self sufficiency -- both economically and emotionally.

Having a disability is only a part of a disabled person's life. To the individual and those who care and love for him/her there are other sides to that person. It's the life of the disabled person that matters. How to preserve, respect and enhance that life is the ultimate goal of both the parents and that individual with the less than perfect body or mind. Nondisabled and disabled family members need to interact with their environment. They must be able to explore, manipulate and enjoy their world together. Architectural and attitudinal barriers must be eliminated within communities. Within our nation's special-needs families, the integrity of these families and the self respect of EACH member of the family depend upon the elimination of those barriers.

> *feelings of inadequacy. It might bring out your protective father or mother instinct. It is sometimes hard to conceive that someone who is really screwed up physically with the speech of a drunk or no speech at all has the same needs as you and perhaps in some cases a higher intelligence than yourself. --- Elizabeth, cerebral palsy*

I can assure you that people are looking at Elizabeth wondering what will become of her or rejoicing that God didn't zap them. She is wondering: Am I somebody? Do I look that grotesque? Will anyone marry me? Will I ever work? These are all questions asked by anyone who searches for meaning to their life.

Where do you build the self-confidence to know what you are capable of doing? Within the home is where it begins.

> *Because of my physical condition, I was given limits by people. They assumed that they knew all about me because they read about cerebral palsy in their college textbook. -- Lauren, cerebral palsy*

Family schedules are hectic. A disabled young person wants to do his or her part to help out. However, everyone, including parents, is preoccupied with how long it takes to accomplish a task or the awkwardness demonstrated to carry out the task. Attempts to assert ourselves are too often dismissed with "You'll tire yourself, let me do it." This is a mistake. The emphasis should be on self sufficiency whether the child is disabled or nondisabled. The more dependent you are on your parents -- when you believe you can do something for yourself -- the more surly you become. Your family become servants.

A recent example of this concerned a young man I know. He was ashamed that his mother still helped him bathe. He didn't need help but was afraid he would break the glass shampoo bottle. Finally he told his mom. She substituted a plastic interest.

This assertiveness is revealed by statements such as: "Thank you, I can tie my shoes." "I can push my chair." "I can pick up the book." "Thank you, I can make my own decisions."

One of the earliest ways a young disabled person learns how to be assertive and to practice cooperation is in school. About ten years ago, handicapped children were routinely excluded from school or placed in inappropriate classes. With the enactment in 1975 and enforcement of the Education for All Handicapped Children Act (P.L. 94-142), handicapped children now have access to a vast array of educational services. With P.L. 94-142 each child has his her individual needs met in the least restrictive environment. Issues relevant to placing moderately or severely handicapped children in special or mainstreamed classes are vigorously debated by educators and parents. Whether the child is in a segragated classroom or taking his or her chances with nondisabled children in integrated settings, the school experience is deeply felt.

> *When people ask me if I'm in special ed, I get embarrassed. I'm afraid they're going to make fun of me or laugh. Sometimes I just say "Yeah." They ask why and I say because I'm slow. I used to get laughed at. -- Cheri, learning disabled*
>
> *I don't like it in this school. I would prefer to be with deaf people. I don't try out for sports and I would in a deaf school. -- Becky, deaf*
>
> *I remember interacting in school with other kids who were disabled kids. . . We were all the butt of everyone's ridicule and exclusion. There was a camaraderie among us because we were mutually hurt... That's had an influence on my life. -- Ann, blind*
>
> *Our little girl is 2½ years old. Thanks to infant stimulation, she is going far beyond the doctor's*

how resourceful their disabled child is. Educators should be aware of which tests are best suited for which students.

Lastly, there is a great gap in educational opportunities for autistic children. For preschoolers, programs are few and far between. Occasionally, these children are served in community preschool programs sponsored by associations for retarded citizens or Head Start. They are, almost always, placed inappropriately. They never receive the year round services they need. Twenty-four hour, year long educational and treatment programs are scarce. Those programs that do exist are expensive and most families lack the resources. The bottom line is that it is the rare autistic child who receives appropriate services. Consequently, a great many adults with autism become institutionalized for life. Why can't these children receive what they need to stay with their families?

Section 504 of the Rehabilitation Act of 1973 (PL 93-112) is considered by many of us, who have struggled all our lives to be first class citizens, to be our civil rights act. The basic goals of this legislation and other recent legislative initiatives [e.g., 1978 Amendments to the Rehabilitation Act of 1973 (PL 95-602); Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103); Developmental Disabilities Amendments (PL 98-527)] grows out of such principles such as self help, self direction, deinstitutionalization and a rejection of the medical environment. Self help groups and federally funded Protection and Advocacy projects have become the catalyst for these goals.

developmentally disabled person receive all the rights and services to which they are entitled. Protection and Advocacy programs, as established in PL 95-602, are required in all states. P and A's can provide supportive, investigative and legal assistance to enhance the welfare of developmentally disabled children and adults.

> *When she moved into this neighborhood, I was the only one trying to help her... And her parents are not trying to keep her in proper care. They take all her money and spend and drink it up in liquor and beer... They are the ones trying to mess up her life by trying to put her in a home that she really doesn't need to be in. All she wants is to have a free life... She knows how to dress herself, and cook, and wash but when it comes to business things she comes to me for help -- a neighbor.*

This is part of a letter received by the Alabama Developmental Disabilities Advocacy Program. Hundreds of similar letters are received each year.

Helping developmentally disabled people to accomplish their ultimate objective, independence, requires effort on the part of the disabled individual, their parents and the community. The individual must put effort into becoming self-motivated. The parents must teach their disabled child daily living skills to foster the self-confidence needed for independence. And the community must support these efforts through integration of the disabled into the community.

Some Crucial Concerns

After reviewing the relevant literature and speaking to a number of persons with disabilities, it is clear that a variety of service needs exist. My purpose here is not to elaborate on each service, rather, I want to highlight five service needs of ambulance attendants, police, etc), with disabled people and their needs. People who have responsibility for assisting others need to know about different disabilities.

Day Care

Day care and home safety go hand in hand. In many states school services are designed to serve disabled children younger than five. In addition, Head Start serves some children in some areas. But from state to state the quality of existing services varies and they are not uniformly available. Severely retarded children/adults may be forced to wait three to four years for limited space in adult activity programs. Summer programs for severely disabled children are virtually non-existent except at parental expense. If the majority of households with children are headed by women, and society says it's better to work than be on "AFDC," and a good percentage of those women headed households that have one of those 2,000,000 chronic physically or mentally disabled children, where is that mother supposed to put her child when she goes to work?

> *Sue, my daughter, age 6, goes to East Elementary School Special Education Class. Before she was six, she went to the Cerebral Palsy School here all year long. I checked about her going there when school is out for the summer and the CP school said if they didn't get funded for extra children they would not be able to take her. Sue needs to continue her speech and physical therapy all the time, three months is too long to be without help. Day care does not take handicapped kids, so if I can't put her in the CP center this summer, I really don't know what I can do. I work and I need to have her taken care of just for the summer.*

Transportation and Architectural Barriers

If you use a wheelchair, crutches or have sensory limitations, transportation and architectural barriers are giant expectation of fulfillment. Many people, parents, teachers, counselors and medical personnel included, ignore the sexuality of the disabled adolescent and adult. We are assumed to be either asexual or impotent. This denial of sexuality is the cruelest attitudinal barrier faced by someone with severe disabilities.

> *I was born without legs and with a right arm that ends where most people have an elbow. It's an unusual body but it is a body. It houses a living person and lets me do many of the things I want to do to fullfill my life.*
> *-- Sara, amputee*

What you see in your mirror affects the decisions you make regarding: How to take care of yourself; what you think you can do, can't do, won't do, want to do; and what kinds of relationships you choose to have. The reflection you see tells you how to look to those who love you, the way you need to look, the way you look to strangers. The scars, the curvatures, the spasms, the slowness makes you appear physically different from those images on TV or people around you. From these sources it appears that loving depends on body fitness. The implicit message is that it is unnatural or pathetically unrealistic to expect to experience various relationships with other disabled persons, or even more maladjusted, a nondisabled individual. It is hammered into your head by parents, rehabilitation and medical personnel, as well as architectural and attitudinal barriers found in communites, that you are incapable of having a deep relationship with anyone other than your parents. After all, who else but your parents might love someone so different and dependent.

adjust. However, there is one inevitable situation few parents actually plan for: What will happen if I can no longer take care of Mary, Jimmy, Sally? Or worse, when I die, where will they go? How will they manage?

Coping with aging can precipitate changes and stress within the family of a developmentally disabled person. Growing older is difficult for all of us. We are reminded with the weakening of our body and senses that in American society the aging process represents a change in status from being a responsible adult to becoming a dependent adult.

For the parent who has the responsibility of caring for a developmentally disabled adult, aging has frightening implications for their lives. Having once accepted the obligation of parenthood for a moderately or severely disabled child (i.e., the physical and emotional care giving and financial support), surrendering those obligations to another is out of the question. It is terrifying for most aged parents when it is suggested after 50 or 60 years of providing food, clothes, grooming, protection, and so forth that other arrangements need to be made to insure the well being of their loved one. Many aged parents are painfully aware that the majority of moderately or severely handicapped children and aged adults are inappropriately placed in institutions when they can't care for them. Opportunities for the severely physically disabled to live independently in group homes are virtually nonexistent. Also, Medicaid, the primary source of payment for disabled individuals in nursing homes, does not pay for any disabled person to reside therefore, must be made of wills, trust instruments, guardianships, receipts of insurance proceeds and their impact on the maximization of government benefits.

The last hurdle, which is the most difficult to accomplish, is for the parents to communicate to their loved one, a sense of well being toward their future. My legacy for any severely disabled adult is that parents believe in their child's capabilities, respect his/her dignity and have confidence that he/she is capable of some measure of self-direction.

Conclusion

Throughout this paper I have attempted to highlight major points during a lifetime of living with disabilities. With that focus I chose the personal approach, "the human touch," to draw attention to the people whose abilities are inhibited by some arbitrary malfunction. Within that different body, the essence of life within demands the right to live that life to the fullest.

Disability is an irrational, irreconcilable fluke that occurs. But it happens everyday to many people. There is no natural or human law that decrees that any of us must or should live disabled, immobile, or misshapened. To ourselves we aren't demographic statistics. We aren't an unfortunate set of lamentable cause and effects from which to draw rational and objective conclusions. We are not separate and apart from anyone or anything else. We have pain but we also have pleasures. We have frustrations, disapointments but we also have victories. We struggle but we learn. Cerebral palsy. Autism. Mental or Sensory Disability. Whatever the disabling condition, the persepective is the same: Here is LIFE. Now, what can be done with it!

PART II: RESPONDING TO THE NEEDS OF FAMILIES

Chapter 1: Historical and Contemporary Responses to Disability

Chapter 2: The Development of Family Support Programs

Chapter 3: Statewide Family Support Programs: National Survey Results

HISTORICAL AND CONTEMPORARY RESPONSES TO DISABILITY

The occurrence of disability in society challenges both families and the greater community to provide adequate care for persons with disabilities. The efficiency and effectiveness of such care would be enhanced if there were a clear division of labor between families and publicly supported efforts (Caro, 1980). However, notions about the relative roles of society and families in providing care to persons with disabilities have fluctuated over the past several years.

Conflict in Roles Over Time

Demos (1983) notes that in any historical period the caregiving roles played by the greater society and by individual families are related to the interaction of five factors:

- The cultural context defines what segments of the population will be considered vulnerable or disadvantaged. For instance, Demos (1983) speculates that in earlier times the societal position held by elderly persons and persons with mild retardation was more favorable than today; life was less complex and more managable, and marginal employment was more easily obtained. As a result, these persons were, on the average, less vulnerable than persons today with similar disabilities.
- Demographic and biomedical considerations influence the numbers of persons with special needs present in any population. Given recent technological advances, we are growing older than ever and many children, who were at risk of dying just a few years ago, are surviving their early life crises. Moreover, just as the proportion of persons with disabilities is expanding within the population, the potential pool of family-based caretakers is shrinking due, in part, to increased numbers of women in the work force.
- Societal attitudes toward disability reflect the capacity and willingness of a given society to respond with care and concern to those in need.

the number of institutional settings for persons with developmental disabilities and other vulnerable persons. The advent of such settings reflects a dramatic shift in the locus of responsibility for the care of persons with disabilities. Families were no longer automatically viewed as the caregiver of choice. Instead, despite the good intentions of many proponents of publicly supported services, these services often involved isolation of the person with disabilities from the family and the prevention of the "injudicious interference" of family members. Additionally, early in this period many believed that persons with disabilities should be segregated from the mainstream of society to protect these persons from the hardships of everyday life and to provide them with needed supervision and care. Later in the period, however, placing persons with disabilities into isolated settings was also premised on the belief that these persons were a menace to society (Wolfensberger, 1975).

To be sure, during this stage the great majority of persons with disabilities remained at home in the care of family members. What must be noted, however, is the increased role of society in providing care for persons with disabilities and the advent of the "residential assumption." That is, a person is assumed to require specialized residential services just because s/he has a developmental disability (Skarnulis, 1976). These changes in the balance of interests surrounding persons with disabilities resulted in an inconsistent and often conflicting division of labor between families and publicly sponsored service efforts. Whereas in the pre-modern stage families were viewed as competent and preferred caregivers, during this stage the capacity of families to provide suitable care was questioned and

Attitudinal Biases

Three types of attitudinal barriers persist. First, professionals in the developmental disabilities field are far from reaching consensus over the role of the family in the provision of care. Some professionals discount the family's capacity for making sound decisions about the welfare of their child or adult with disabilities. The legitimacy of this claim is underscored by individual cases where parents decide against life saving or enhancing medical care for their offspring with disabilities, spurring calls from professionals to overturn parental decisions. Often, this issue is put before the courts in dramatic fashion where complex concepts pertaining to the rights of persons with disabilities, the bounds of parental autonomy, and the role of government in family affairs are discussed vigorously to no clear and final end (Skarnulis, 1974; Annas, 1979; Herr, 1984). Likewise, even where the medical status of the person with disabilities is not at stake, there is intermittent disagreement between professionals and parents concerning the most appropriate approach to habilitation. Some professionals go so far as to view the family as part of the problem, due to purported tendencies for overprotection and inherent attitudes that deter skill development (Crnic, Friedrich & Greenberg, 1983; Tapper, 1979). Given these considerations, professionals sometimes presume family incompetence and pursue out-of-home placement as a matter of course.

Second, society has not reached consensus over the public's role in private family affairs. This dilemma is both moral and political. Some believe, for instance, that parents themselves are responsible for any problems they encounter in bearing children and

On one hand, current lifestyles emphasize independence, self-actualization, and employment outside the home for women. Running counter to these values is a renewed interest in family-based care and a need to cope with the extraordinary demands such care entails. Consideration of these contradictory perpectives can create for many families an unsettling sense of ambivalence regarding their future and the future of their child.

Demographic Trends

In the future, persons with developmental disabilities may be increasingly vulnerable to out-of-home placement due to at least three population trends. First, in comparison to past census information, families, in general, are getting smaller; there are greater numbers of single parent families, and couples are having fewer children. This suggests that the family's capacity for providing long-term care may diminish because there will be fewer family members on which to rely. Supporting this speculation, Giele (1981) found that disproportionate numbers of elderly persons in institutions who need personal care are there only because they have no family with whom to live.

Second, the number of women entering the labor force is increasing (Keniston, 1977). This trend adversely affects the caregiving capacity of families because, in the United States, it is primarily women who have responsibility for providing such care. With this pool of caretakers shrinking, increasing numbers of persons with disabilities may be faced with out-of-home placement.

Finally, more and more persons are living in urban settings. In some ways this trend appears advantageous because, when compared to more rural settings, urban settings have more services and they are institutional and inpatient settings -- also known as the "co-location principle" (Noble, 1981), 2) the severity of the disabilities of persons in institutions compared to those living in the community (Bruininks, Hauber & Kudla, 1979), and 3) the pressure brought to bear on policy makers by special interest groups intent on maintaining institutional services (Blatt, 1981).

Recent information indicates that skewed funding patterns are being slowly corrected. Braddock et al. (1984) show that the ratio of dollars spent in institutional settings versus community settings was reduced from 3.46 to 1.0 in 1977 to an estimated 1.47 to 1.0 in 1984. Though these findings are encouraging, the disproportionate allocation of available funds remains a formidable impediment to an expanded and improved community-based service system.

Even the expenditure patterns within the community system are skewed. Examination of current spending reveals that a majority of community dollars are allocated to the development and maintenance of vocational training sites (e.g., sheltered workshops and activity centers), supervised living arrangements (e.g., group homes and apartment settings), and specialized evaluation and therapeutic clinics (Morell, 1983). Observing these trends, Tapper (1979) concludes that "as a matter of public policy, we grossly undersubsidize family care of the handicapped person, while at the same time lavishly support care outside the family setting" (p. 80).

Review of present policy suggests that community services are primarily designed to deliver habilitative services to individuals in settings external to the family rather than within the family unit (Morell, 1983). Though some persons with disabilities are helped by these policies, they do little to encourage or enhance family care.

1977). Mothers of children with disabilities may be inhibited from seeking employment due to the demands of providing care (Turnbull, Brotherson & Summer, 1985). As a result, these mothers may grow to resent their caretaking role and their families are denied access to a second income.

The opportunity costs associated with home-based care can lead many parents to conclude that the interests of the entire family can be best served through out-of-home placement. Consequently, a strong need exists to examine the effects of opportunity costs on the provision of family-based care and to develop policies that counter such disincentives.

Factors Spurring Increased Demand for Family Support

The impetus for family-based care stems from two major ideological tides. The first is "normalization." This notion began in Scandanavia (Nirje, 1969) and was later expanded upon in North America. The philosophy of normalization presumes that persons with developmental disabilities should be served within programs and residences that are as normal as possible and that they be taught skills necessary for life in the community (Wolfensberger, 1972).

The second major movement, which is also premised on the integration of persons with disabilities into community life, is "mainstreaming." Supporters of this concept advocate that children with disabilities be educated in public school classrooms, and placed in non-segregated or "mainstream" classrooms to the extent possible. This notion led directly to litigation to secure free and appropriate education for children with disabilities and ultimately to the passage of the Education for All Handicapped Children Act in 1975 (PL 94-142).

providing necessary services in the community has been clearly established within the service system as a guiding philosophy and factual reality (Lakin, Bruininks, Doth, Hill and Hauber, 1982).

The effects of this movement on state-wide service systems are well documented. Recent information indicates that the total population of state institutions for mentally retarded persons declined from about 195,000 in 1967 to just over 125,000 in 1981 and the number of persons receiving community residential services increased from 26,000 in 1967 to an estimated 90,000 by 1982 (Lakin, et al., 1982). Likewise, comparison of Children's Bureau Survey results of 1961 and 1977 reveals that the absolute number of children with handicaps (emotional disturbance, mental retardation and physical handicaps) receiving public school services has more than doubled (MacEachron and Krauss, 1983). Finally, many states now offer parents of persons with a developmental disability a variety of supportive services including case management, parent education, financial assistance, respite care and family therapy .

Present services, however, are not yet adequate. Many persons with developmental disabilities remain within settings that are too restrictive. Moreover, much still can be done to provide families with suitable types and amounts of specialized assistance.

The Current Challenge

Developing suitable policies to respond to the occurrence of disability is a complex undertaking burdened by historical, philosophical, methodological, and political considerations. To be sure, the increasing recognition of the crucial caretaking role families can and should play is encouraging. Proponents of

THE DEVELOPMENT OF FAMILY SUPPORT PROGRAMS

by

Colleen Wieck, Ph.D.

Murphy's Law[1] is as familiar to all of us as the Law of Gravity. Although human services are not governed by the same types of laws, rules, or principles as physical sciences, there are some common themes that do allow us to humorously reflect on current professional practice. In this paper, four major laws and seven corollaries patterned after Murphy's Law have been postulated to provide a framework for discussion of family support programs.

Law # 1: Human problems tend to be defined in terms that require professional solutions thus rendering them insoluble.

This paper will provide definitive answers to the question, "what are family support services?" Definitions of "social support," "services," and "family" continue to be difficult for researchers, parents, and providers. The debate over programs and policies affecting families including family support programs, has been complicated by a lack of consensus regarding these definitions. The common stereotypic definition of family is "mother, father, and two children." The Bureau of Labor Statistics (1979) has published a cost of living index for census regions based on a hypothetical urban family of four consisting of "employed husband, age 38; a wife not employed outside the

---

[1] "Anything that can go wrong, will..."

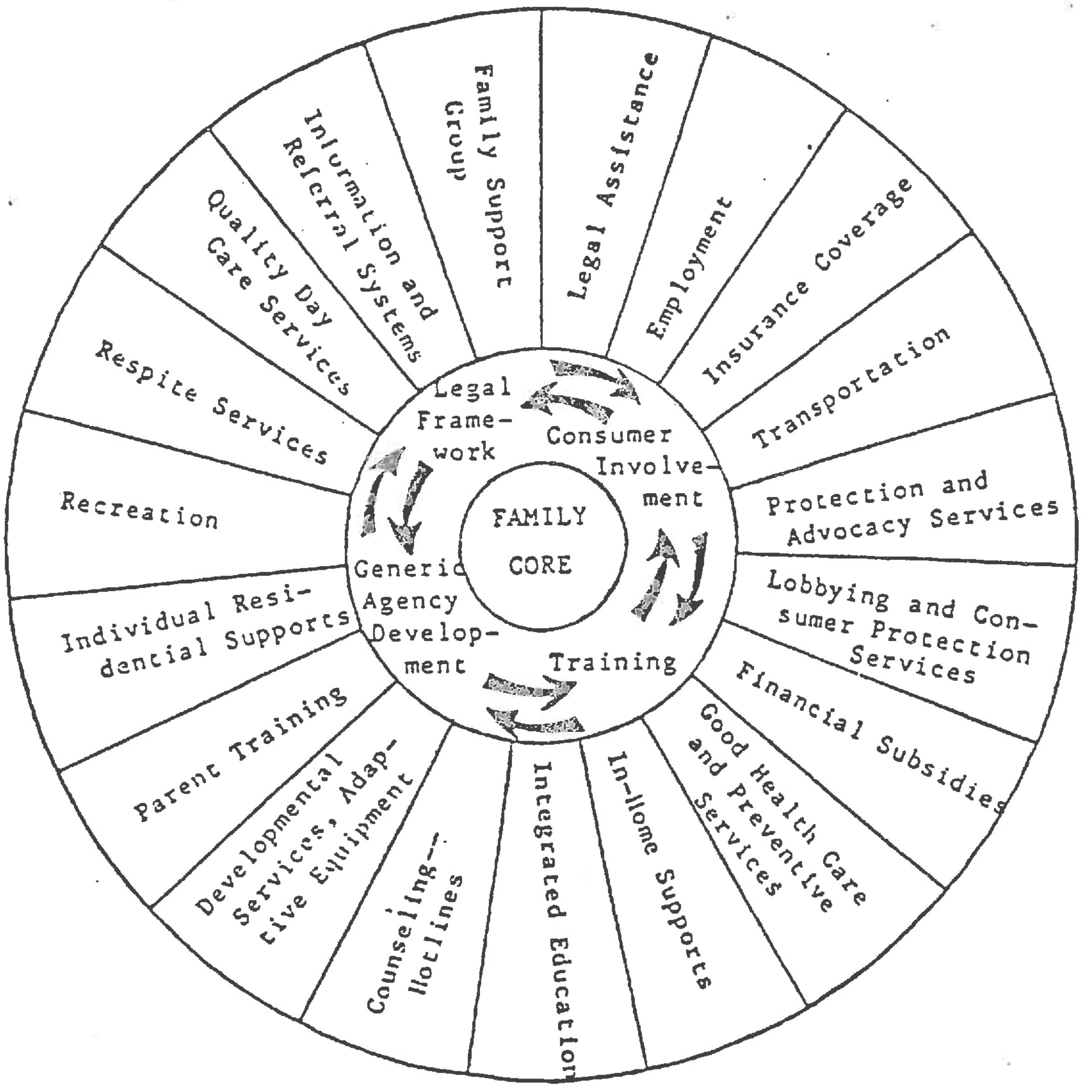


Figure 1: Model Array of Family Resource Systems and Support Services for Children with Disabilities and their Families*

* Source: Loop and Hitzing, 1980

All families are currently feeling the impact of a combination of cultural, technological, psychological and demographic changes which have altered both the structure of the family and the roles filled by individual family members.

<u>LAW # 2:</u> If your handicapped child only needs 10 minutes of assistance, you can only receive 24 hours of care, usually out of the home.

Reviews (McCubbin & Figley, 1983) of the traditional research in the area of family stress reveal emphasis on typical topics such as:

Marriage, sexuality, parenthood;
Divorce, step-relations;
Careers, economic stress, retirement;
Illness, death; and
Natural disasters, war.

Usually, the topic of handicapped children is combined with illness.

A simple way of understanding family stress was first advanced by Hill (1949) and has been modified since:

A,B,C, -X.

A = the event and related hardship interacting with

B = the family's resources for meeting crisis interacting with

C = the definition the family makes of the event produces

X = the crisis.

The Philip Becker case provides an excellent example of the flexibility of this formula. This case ended up in the courts because the natural and adoptive families of a child with Down's Syndrome reached different decisions about whether the child should have heart surgery. In this case, the natural and adoptive families faced the same event (A) but had different resources (B) and definitions (C) of the crisis (X).

Another approach to assessing family crises comes from a set of eight questions developed by Lipman-Bluman (1975) who asked whether the crisis is:

The single largest expense was travel costs. Only a minority of the 116 families was experiencing financial problems. The Australian study noted that in addition to prompt accurate information families required the following types of assistance:

> Many of the families who used their car would be eligible for free travel vouchers from the State Health Department if they were able to make use of public transportation. A subsidy or tax deduction for travelling expenses would be a help to these parents. Financial assistance for home conversions was needed by a small number. A government subsidy would also assist these families. (Senate Standing Committee of Health and Welfare, 1971).

In addition to the parental view, siblings are beginning to speak out. A search of the literature revealed little work on siblings, although the need for professional aid for siblings has been noted by several authors (Carver, 1956; Caldwell & Guze, 1960; Graliker, Fishler, & Koch, 1962; Farber, 1963).

Gaiter (1984) summarized views of several adult siblings. As one sibling recounted:

> Sharing the pain, the anguish, the shame and the guilt of having a handicapped person is a family affair; it is not just a parents' affair (p. 18)

Of particular concern to siblings is the lifelong care and responsibilities for the handicapped person. Several siblings interviewed by Gaiter offered their own personal accounts about responsibilities:

> I may have passed up marriage a couple of times because of my sister (Rita Haahn, 52-year-old sister of Grace who is 48 and mentally retarded).
>
> I feel guilty for saying that I really didn't want the responsibility. Although I have an older brother, it is implied that I will inherit the care of our sister (a 58-year-old woman whose 53-year-old sister is mentally retarded. Their mother is 85 years old).

study of admission, Saenger (1960) identified two factors leading to out-of-home placement: (1) level of mental retardation and (2) behavior problems combined with families' capacity to cope. According to Lakin, Hill, Hauber, Bruininks, and Heal (1983), 11.9 percent admissions and 30.0 percent readmissions are related to family capabilities.

To prevent out-of-home placements, agencies must shift attention to the family. Lash (1983) explained:

> ...Agencies tend to focus exclusively on the needs of the developmentally disabled individual rather than looking at the entire family system . . . The first response of an agency must be, "How can we keep your family intact? (p. 19)

Paul and Porter (1981) argued for an even broader understanding of the family:

> An isolated view of persons with handicapping conditions can be superficial and inappropriate. No real understanding of the deficits, assets, and needs of the exceptional person can be achieved without comprehensive, in-depth attention to the values, expectations, resources, and circumstances of that person's social and physical environment. (p. 19)

There have been several demonstration projects that focus on home intervention to prevent placements. These projects have changed parents' attitudes toward institutionalization (Cianci, 1951, 1967); avoided large expenditures of money per client for out-of-home placements (Kinney, 1977, Pullo & Hahn, 1979); eliminated problem behaviors of children at home (O'Leary 1967; Allin and Allin, undated); and increased levels of confidence in handling children (Heifetz, 1977).

are on a waiting list? Why isn't this program based on income?

Counterpoint: A "rich" family can place their handicapped child out of the home as easily as a "poor" family. The purpose is to prevent out-of-home placements regardless of income.

HORIZONTAL EQUITY: Those with equivalent needs should receive equal benefits.

Existing Problems: Some groups of needy families are excluded, particularly if the subsidy is designated for children with the most severe handicaps.

Some groups receive favorable treatment over others (parents of mentally retarded children compared to parents of children with cerebral palsy, autism, head trauma, and others).

Geographic inequities exist in the United States since only about 25 states provide family support. In addition, states vary in how programs are operated, the level of benefits, and the standards of eligibility for benefits.

There are several questions that remain unanswered regarding the effectiveness of family support programs in meeting service goals and objectives. These areas include:

Is there any evidence to suggest that family support programs negatively affect the family structure and function?

Should family support help those families already receiving income support, or should family support include middle class families?

Should family support be an entitlement program assuring benefits to all who meet the established criteria?

Should family support be a needs-based, limited service with benefits rationed to those among the eligible who are deemed most in need according to some defined criteria?

additional training that is unnecessary for the consumer.

Corollary 3.2: In order to have a family support program, you must first spend billions of dollars on bricks and mortar in remote rural areas so that you can rediscover the efficiency of the familiy.

Over 100 years ago, there were fewer than 2,500 mentally retarded people in state institutions in the United States. The number increased to 195,000 in 1967 and has declined to 130,000 in 1982. In combination with the decline of state institutions, there has been a large increase in the number of community/ residential alternatives. From 1977 to 1982, the number increased from 4,427 to over 15,000 (Hill & Lakin, 1984).

During the same time period, the cost of providing state institution services has continued to increase dramatically. In 1915, the annual per capita cost per client was $45,000. In 1916, Cornell observed that until the cost of institutions was reduced to under $100, the public would object to segregation on the ground of expense (Wieck, 1980). In 1970, Baumeister said that "more money is spent on the five percent [of mentally retarded people who are institutionalized than on the 95 percent] who are not [in institutions]" (p. 22). Scheerenberger (1980) estimated that during the decade of the 1970s, the per diem rate increased over 450 percent.

Most recently, Braddock (1984) analyzed federal and state expenditures for institutions and community services. Between 1977 and 1984, the United States government spent $13 billion on ICF-MR (Intermediate Care Facilities for Mentally Retarded) reimbursement. Of that amount, 82 percent was spent on state

Type of Placement	Cost
Family support	$8.33 (est.)
Board and room	$15.97
Foster care	$16.15
Personal care	$17.05
Semi-independent living	$27.50
Group home (1 to 15)	$38.31
Group home (16 or more)	$45.15
Nursing home	$49.81
Public group homes (16 or more)	$85.84
Average out-of-home placement	$61.89

The rising cost of residential placements has intensified the search for alternatives to out-of-home placements and the emphasis on families. While some argue that by focusing on cost, attention is shifted from civil rights and humanitarian concerns, economics cannot be dismissed.

<u>Corollary 3.3</u>: The best family subsidy program works only one-fourth as well as the administrator says it does.

Of specific concern to this paper is the utility of family support programs. Since 1976, Minnesota has had a family subsidy program for children who are Minnesota residents and living at home or residing in a state hospital or in a licensed community residential facility for the mentally retarded who, under this program, would return to their own home.

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

While the families reported that the program enables them to function better and to care for their disabled child at home, the subsidy does not cover all of the expenses entailed in the child's care. Almost two-thirds of the families (n=24) reported additional expenses in the categories covered by the subsidy.

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

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

- Yearly applications rather than every six months;
- Optional phone renewal of the applications;
- Education of local social and health services staffs about the program;
- Use parents to publicize the program;
- Increase benefits for families with greater needs; and
- Increase allowed benefits to include long distance medical calls and emergency respite care. (Minnesota Developmental Disabilities Program, 1983a).

Florida has conducted two evaluations of their family support program. Initial problems were noted with staffing and reimbursement schedule. In the second evaluation, the payment method remained a problem to families (Bates, 1983).

In an attempt to define a national policy on families that could alleviate such problems as juvenile crime, teenage argue that serving more families would be an uneconomical use of resources and that other programs should be made more efficient to prevent out-of-home placements.

On the other side, there are authors who argue that helping families preserves human dignity and that there should be more government assistance in the area of income and jobs (Featherstone, 1979).

The controversy over government assistance to families extends beyond questions of whether and how much government should assist families to questions about limited resources and complicated moral dilemmas.

As Moroney (1979, 1981) has described in several publications, there is competition among several groups (elderly, mentally ill, mentally retarded, chemically dependent, children and others) for scarce resources.

The Baby Doe cases have raised several questions about a society that wants children's lives saved but may not be willing to support the child after discharge from the hospital. A _New York Times_ editorial (1984) pursued the questions of support:

> A society that understandably wants doubtful cases resolved on the side of life also has an obligation to those for whom such a life may be extremely painful: the infants and their immediate families. Pending amendments in Congress ask for study of the best ways to provide federal financial support for the treatment of disabled infants. But who will pay for an adequate level of _continuing_ care?

In reviewing the policy biases that remain against family support, one of the largest concerns is that state legislators are torn between the desire of providing for needy persons and the fear of creating uncontrolled programs. With family support

Based on the careful work of Bates (1983) at the Wisconsin Developmental Disabilities Council, we have an annual status report on the number and type of family support programs. Some simple estimates suggest that while family support programs are expanding, the rate of increase does not match the need of families. It seems absolutely essential to move away from the experimental or demonstration approach to a larger-based adoption of programs. The Medicaid community services waiver may be one alternative to the limited state-supported family support program. Further analyses will be needed to determine the extent of family support in the state because of the waiver.

Several authors have described the empowerment of families because of legislation and litigation. Institutions and segregated placements are no longer accepted remedies given changes in philosophy, P.L. 94-142, and judicial principles such as least restrictive environments (Paul & Porter, 1981; Beckman-Bell, 1981; Turnbull, 1981; Turnbull & Strickland, 1981).

The Minnesota Developmental Disabilities Council published two policy briefing documents in 1983 and 1984. In 1983, two paradigms were described: the consumer-powered system and the resource-powered system. In a resource-powered system, services are based on funding availability and a general estimate of need. Clients are placed depending on availability of slots with clients fitting the system. The result is inappropriate placements.

In a consumer-powered system, the client's needs are assessed, and case managers function as brokers, advocates, and of out-of-home placement can be 8 to 16 times greater than family support programs. While some children may be in appropriate placements, others should be transferred without dumping and without hardship to families.

The federal government could also consider helping children through an allowance program regardless of parental status or family income. At this time, 69 nations (28 European, 24 African, 2 Asian, 3 Middle East, 10 South American, Australia, and New Zealand) have family allowance programs. In Bolivia, there is a housing allowance, birth grant, nursing allowance, burial allowance, and monthly cash payments. The positive outcome of a children's allowance program is elimination of current income maintenance programs that regulate and coerce parents. If all children receive an allowance, there is no stigma because of handicapping condition. Some analysts oppose children's allowances for several reasons:

> First, children's allowances, like any governmental intervention in economic activities, would impede free competition and eventually result in uneconomic utilization of resources. Second, children's allowances would conflict with the basic principles of the capitalistic system, in which all are to be rewarded, not according to their needs but according to their contribution to the general economy. Third, children's allowances would create a powerful drive toward socialism. Fourth, if financed by progressive taxation, children's allowances would reduce the capacity and the incentive for the rich to save and invest. This in turn would discourage innovation and invention, which are real sources of economic progress, and consequently, could adversely affect standards of living. Fifth, for advance in economy, human beings shold not have excessive security but a balance between reasonable security and resonable exposure to the risks in life. (Ozawa, 1982, p. 206)

On the other hand, Thorsson (1968) argued that children's allowances are an:

STATEWIDE FAMILY SUPPORT PROGRAMS: NATIONAL SURVEY RESULTS

by

John Agosta, Ph.D., Debbie Jennings and Valerie Bradley

Families of persons with developmental disabilities face a variety of dilemmas and choices regarding the provision of long term care. Tradtionally, such families are accorded few, if any, services to support their efforts and often are encouraged to seek residential placement for their child with disabilities away from the family home (Perlman, 1983; Skarnulis, 1976; Bruininks & Krantz, 1979). Recent policy initiatives, however, have focused increasingly on establishing statewide programs to provide systematic support to families with developmentally disabled members (Bates, 1984; Bird, 1984; Michigan Association of Community Mental Health Boards, 1983; Nebraska Legislative and Advocacy Committes, 1980).

The fundamental goals of these programs are to strengthen the family's capactiy to provide care, prevent undue out-of-home placement, and promote development of a family life that is as close as possible to that experienced by families without members with disabilities. To acquire an improved understanding of this movement, the Human Services Research Institute and the National Association of State Mental Retardation Program Directors undertook a national survey of existing statewide family support programs. The purpose of this paper is to report the results of that survey.

Method

Approach Taken

Information was solicited from officials in the 50 states during a survey period beginning in November, 1983 and continuing through under a "family support" rubric in one state may not be listed as such in other states.

Second, discussions with numerous state officials revealed that several states operate a variety of family support services but that various services may be administerd by different state level divisions. Thus, directors of developmental disabilities programs may have neglected to mention relevant services administered by other state level agencies.

Third, the comprehensiveness of the responses secured varied considerably. Some state officials cooperated fully and forwarded much useful information. In contrast, others provided little information. As a result, survey results may underestimate the family support efforts in some states.

Results

Service Types by State

All states but Oklahoma indicated the presence of some type of family support program. These programs were sorted into three administrative categories. First, Cash Assistance Programs provide money to families to offset the costs of habilitative materials or services. In such programs, families either receive a periodic subsidy or stipend to pay for future expenses or are reimbursed for costs of care incurred. Second, Supportive Programs provide families free inkind habilitative materials or services. In these programs states fund various agencies which in turn provide specified services. Finally, Combination Programs offer families both cash assistance and inkind support services.

Table 1 displays the 49 states that report the existance of a family support program according to the administrative category that best exemplifies each state's support system. Review of this table shows that nine states operate cash programs primarily, 33 provide in-kind supportive services, and seven operate combination programs.

These findings, however, must be considered in light of two factors. First, though nearly all states report the presence of a family support program, fewer than 25 have developed "extensive" initiatives that are well coordinated and available statewide. Many other states recognize the importance of supporting family efforts but offer few services to few families or administer programs in restricted areas.

Second, statewide initiatives often are complemented by services made available through sources other than the state mental retardation or developmental disabilities service system. Examples include programs sponsored by:

- the public schools. Due in great part to the Education for all Handicapped Children Act (Public Law 94-142), public schools in all 50 states offer special education to children and young adults with developmental disabilities. Though the age range served varies somewhat by state, about four million persons with disabilities received special education services during the 1982-83 school year (Division of Education Services, 1984). In addition, some school districts offer outreach services to the families of these persons (e.g., parent education). The positive impacts of these services on persons with disabilities and on the family's capacity to provide care cannot be overlooked;

- advocacy organizations. Numerous national and locally based advocacy organizations sponsor a variety of services to family members (e.g, information and referral, parent education, mutual support groups) and to persons with disabilities (e.g., recreational activities). Some of these organizations serve persons with a specific type of disability (e.g., downs syndrome, autism, prader-willi syndrome), while others are not so specialized (e.g., American Coalition of Citizens with Disabilities) (See Office of Information and Resources for the Handicapped, 1982);

- specialized family service agencies. These organizations offer one or more useful services to family members or persons with disabilities and often charge a fee. For instance, these agencies may provide parents assistance with financial

Table 2: Eight Cash Assistance Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
Connecticut	1981	Cash Program	$2,000 per year	15	$23,106	developmental disabilities	sliding scale based on income and family size; no other public assistance received	at risk of out-of-home placement or returning from such placement
Idaho	1981	Cash Program	$250.00 per month ($3,000 per year)	138	$47,000	developmental disabilities; under age 21		priority to those at risk out-of-home placement or returning from such placement
Indiana	1982	Cash Program	Determined by casemanger, maximum of $500 per month for respite	191 65 families	$185,000 (FY 1985)	developmental disabilities		priority to those at risk of out-of-home placement
Louisiana	1983	Cash Program	$375.00 per month ($4,500 per year)	25 15	$112,500	mental retardation		
Minnesota	1975	Cash Program	$250.00 per month (3,000 per year)	190	$525,000	primary diagnosis of mental retardation; under age 18; priority to severest disability	priority to greatest resource needs	
Nevada	1981	Cash Program	$286.00 per month ($3,432 per year)	67	$110,000 (FY 82)	profound mental retardation	insufficient income to cover costs of care; sliding scale based on family income & size	
North Dakota	1981	Cash Program	$15/week for basic care; $35/week for services/ treatment ($2,600 per year)	200 161 families	$200,000 (3 year pilot)	developmental disabilities; under age 21		
South Carolina	1974	Cash Program	150.00 per month ($1,800 per year)	15	$23,000	mental retardation	insufficient income to cover costs of care	

Table 4: Seven Combination Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
Florida	1978	Combination Program	Based on need; no maximum	~~8,227~~ (210 in Cash Program)	$21,000,000 (1,200,000 for Cash Program)	developmental disabilities 60,226		at risk of out-of-home placement if services not received
Maryland	1984	Combination Program	No set limit; based on need within reason	103 56 family	$197,000	developmental disabilities under age 22		at risk of an out-of-home placement
Michigan	1984	Cash Program	$225.00 per month ($2,700 per year)	Estimated at 2,000	$5,700,000 (est. FY 1985) 4,000,000	severe mental or multiple impairment, autism; under age 18	family taxable income for year preceding application cannot exceed $60,000	
	1983	Support Services	No set limit; limited by budget	355	$495,000	developmental disabilities		
Montana	1975	Combination Program	$1,385 per year	600	$1,125,000	No set priority but preference to young and severe disabilities		
Nebraska	1982	Combination Program	$300.00 per month averaged over one year	115 (31)	$200,000	developmental disabilities	insufficient income to cover costs of care	
Rhode Island	1981	Combination Program	$60/week for basic care, $15/week for training ($3,900/year)	65	$256,000	mental retardation; mental illness; chronic impairments		resident of state residential facility for 90 days to receive a cash subsidy
Wisconsin	1984	Combination but varies across the state	$3,000 per year	197 420	$125,000 900,000	severe disabilities; children	no access to sufficient funds to cover costs of care	at risk of an out-of-home placement or returning home from such placement

FY 85-87

This figure is considered by many to be unsatisfactorily low when it is considered that: 1) the overwhelming majority of persons with developmental disabilities live at home with their natural families (Perlman, 1983; Maroney, 1981; Bruininks, 1979), and 2) 243,669 persons with developmental disabilities are served in out-of-home residential alternatives, including institutions and community-based arrangements (Hauber, Bruininks, Hill, Lakin & White, 1982).

Appropriation Levels. As expected, the amount of funds appropriated varies with the number of clients/families served. Appropriation levels ranged from $21,000,000 for a combination program in Florida serving 8,229 families to $23,000 for cash assistance programs serving 15 families in both Connecticut and South Carolina. Moreover, survey findings show that cash programs are generally funded at lower levels than either support or combination programs with combination programs generally receiving the most fiscal support.

Table 5 lists all 22 states and illustrates what services are permissible besides case management. In addition to these services, at least 11 states have provisions for families to acquire services that are not regularly permitted. For example, families in Pennsylvania can present extaordinary service needs to local review boards. Though state guidelines influence decisions, these boards are at some liberty to ratify the provision of unique services. Likewise, Michigan will allow any service the family views as contributing to its capacity to provide care.

Review of Table 5, however, suggests significant variance among states regarding the range of services offered. The services noted most frequently are temporary relief or respite care (21 states) and adaptive equipment (20 states). The least noted services are information and referral and room and board for family members (two states). Maryland and Nebraska offer the most comprehensive array of services (14 services), while Indiana offers the fewest (three services).

Discussion

It is encouraging that nearly all states have initiated family support programs of some kind. Though conclusive evidence is not presently available, the worth of these programs is not easily denied in terms of their benefits to the child with developmental disabilities and his/her family. Moreover, many states argue that family support programs can result in significant long term cost savings to taxpayers (e.g., Florida and Michigan). But much more still needs to be achieved. Recall that the majority of states lack extensive family support services. Additionally, survey results suggest that even where extensive service systems exist, surprisingly few families are served.

Establishing an effective state-wide family support program, however, is a complicated task requiring consideration of several philosophical and programmatic concerns. The substantial variance among existing programs demonstrated by this survey suggests that little consensus has emerged regarding the most efficient and effective means of administering such programs. Among the several issues that must be resolved are: The role of the family, program eligibility, means of service administration, permissible services, and the potential for consolidating resources across various disability groupings.

Program Eligibility

States cannot afford to provide comprehensive services to all families who have members with developmental disabilities. Consequently, service planners must devise equitable criteria for restricting the number and/or type of persons served. In structuring such criteria, several hard choices must be made. For instance, all states require that a family member have a "developmental disability." However, should the functional definition of developmental disabilities in the federal law be applied or should eligibility be restricted to conditions such as mental retardation, autism, or multiple impairments? Many states have chosen to restrict the definition, while others have adopted more lenient criteria. Certainly this aspect of eligibility raises the spectre of competition among various disability groups (See Part III; Chapter 1). Likewise, states must decide whether families confronting similar problems should be treated similarly or whether families should be served based on their amount of financial income (Brown, Johnson, & Vernier, 1983).

Who should receive services is a preplexing issue that severely tests a society's capacity for equitably distributing scarce resources to those in need. The existing variance among state eligibility criteria reflects each state's own solution to the problem. Such variance, however, has resulted in an inequitable national response to providing family support since families are treated differently from state to state.

Means of Service Administration

Survey results suggest that services can be made available to families through at least three administrative formats: cash consultant services and parent education to provide parents with the knowledge they need to choose appropriate services.

Supportive services programs. Most states with family support programs elect to provide supportive services primarily. The advantage of this approach is that the locus of control rests with the state and various service providers. As a result, a cohesive service structure can develop throughout the state that can be directed and monitored centrally.

Ironically, this asset is considered by some analysts to be a liability. Though families help decide which services they receive in this scheme, the types of services and the service providers are pre-determined by the state. Consequently, families take a secondary role in deciding which services are needed and which services should be funded. Additionally, because the state contracts with service providers, providers are accountable primarily to the state and secondarily to parents.

Combination programs. These programs offer an opportunity to develop a system that maximizes the relative strengths of cash assistance and supportive administrative styles, while minimizing their weaknesses. There are at least two unique advantages to this approach. The first pertains to funding. Review of existing cash assistance programs shows that the funding source is often state revenue. By adopting a combination approach, however, available resources can be expanded by acquiring federal Title XIX dollars (through the Community-based Waiver Program) to fund certain supportive services like parent education or respite services. Rhode Island is one state that has pursued this course.

Second, if the primary service goal is to promote family programs "crosscut" disability categories. Exemplifying this point, Abels (1984) describes a Wisconsin based family support program that provides a variety of services including case management, consumer training, and cash subsidies to families with members of four disabilty categories (elderly, developmental disabilities, physical disabilities, and mental illness).

Many believe that this type approach is superior to those that result in separate systems for each disability type because it is cost efficient and encourages coalition building among various disability interests. Designing these programs, however, will not be an easy task. Difficulties can be expected with regard to establishing equitable eligibility criteria between groupings and gaining consensus over the type and level of resources that should be expended for each participating group. In addition, even if these problems were overcome, program administrators would be faced with ongoing difficulties related to writing and implementing program standards that cut across disability categories.

PART III: CONTEMPORARY SERVICE DIRECTIONS

POLICY OPTIONS FOR FAMILY SUPPORT SERVICES*

by

Paul J. Castellani, Ph.D.

Family support services have become the focus of a great deal of attention in the field of services to people with mental retardation and developmental disabilities. A number of new programs in this area are being developed in several states. Other states are reconfiguring service options to more explicitly identify and manage the family support services they have provided. Overall, there is a wide variety and diversity of approaches in these programs across the states. As states seek to broaden existing programs, develop new ones, or to look for indicators of national trends and federal policy affecting family support services, the diversity provides an intriguing array of experiments which may suggest policy choices. Additionally, there have been several legislative and regulatory initiatives at the federal level which may affect the availability of family support sources.

The purposes of this paper are to examine the major dimensions of existing family support service programs and to review the several policy options that are central to the development of such programs. Specifically, discussion will focus on four emerging issues pertaining to the underlying goals and administration of family support programs including: 1) What

---

* The positions expressed in this paper are solely those of the author and do not represent those of the New York State Office of Mental Retardation and Developmental Disabilities.

frameworks (OMRDD, 1983).

The history of the development of family support services explains some of the definitional ambiguity. The need for support services first became apparent when they became linked to deinstitutionalization and success in community living (Gollay, et al., 1978; Intagliata, et al., 1980; Braddock, 1981; Bachrach, 1981). Persons leaving institutions have been the primary focus for the development of these services, although the overwhelming majority of people with developmental disabilities live at home with their families and often need the same type of services. To a large degree, support services to this latter group have been developed subsequent to and with less resources than those for the former group. Thus, the services that have become widely known as "family" support services were initially and largely developed as "placement" support services. An understanding of the evolution of such services, therefore, is important in order to clarify who the intended recipients of family support services should be, and how the objectives for such services should be characterized.

Current State Family Support Services

The conceptual and historical ambiguities are also compounded when we examine the experience of states with family support service programs. Figure 1 shows the array of family support services in 17 states gathered from a survey of these programs by the New York State Office of Mental Retardation and

Developmental Disabilities (Bird, 1984).* There have been other recent reviews of state family support services (e.g., NASMRPD, 1979; Bates, 1983 and the survey results presented in Part II, Chapter 3). Before commenting on Figure 1 it is important to note two things about these surveys. First, while every effort is made to ensure the accuracy of the information, many states operate more than one family support service program and/or subsume them under other programs. Therefore, there are occasional discrepancies between surveys. Second, family support services are developing and changing so rapidly that surveys of this sort tend to become out-dated rather quickly. Nonetheless, these recent surveys do provide an important insight into what various states have defined as family support services. As shown in Figure 1, virtually the entire range of therapeutic services are being offered as family support services.

Policy Options and Implications.

The historical and conceptual ambiguity surrounding the development of family support services is reflected in the considerable variation in what states see as family support services. Thus, the question of what options should be pursued is ultimately dependent on what is politically and fiscally prudent within a particular state context.

---

* In this paper Dr. Castellani uses information gathered from a survey of 17 states with family support services conducted by William Bird of the New York State Office of Mental Retardation and Developmental Disabilities. Though the survey of family support programs described earlier (Part II; Chapter 3) presents information of a similar nature, the reader may note that the results of these two surveys differ somewhat.

of family support services may be helpful in closing the gap.

The major goals are: 1) to strengthen the family structure in order to enhance the quality of care families provide to a developmentally disabled member, and 2) to prevent undue out-of-home placement? To what extent do family support services strengthen family structure, and secondarily, prevent placement. Addressing the question in this way should help to determine what services should be encompassed in family support service programs and who the recipients should be.

If we return to the starting point of what families need, the range of services that would be encompassed within the framework of family support services narrows. Many of the services listed in Figure 1 are core habilitative services provided for the person with a developmental disability in the home setting. These are typically provided by someone who comes into the home. While these services may be clinically necessary or more convenient for families, they do not directly strengthen the family structure. Indeed, a careful review of the services in Figure 1 from the perspective of strengthening the family structure, or enhancing the family's capacity to provide care, would result in a narrowing of the range of family support services.

With the exclusion of Basic Care Subsidy, which is not actually a service in this context, and with some collapsing of categories such as family counseling and individual counseling into counseling, the following is a list of family support services that directly strengthen or enhance a family's capacity these goals with respect to eligibility for family support services reveals a major problem. That is, if we choose to strengthen families, this would seem to argue for a very broad definition of who should be the service recipients. Indeed, Moroney (1981) proposes the universal provision of support services to families caring for a developmentally disabled family member at home. The most obvious problem with this approach is the political infeasibility of an entitlement strategy at a time when existing social welfare entitlements are being reconsidered.

Another problem with a universal approach towards eligibility is the lack of certainty regarding the magnitude of need among certain segements of the developmentally disabled population. Estimates for autism, neurological impairment, and learning disability for instance, are problematic. Advocates for these groups of disabled people have often argued that their numbers are substantially larger than estimates used by government agencies. Moreover, they have been especially vociferous in demanding services for unserved and underserved persons who typically live at home or in other independent community settings. This is especially important since advocates for these disability groups view family support services as a vehicle for access into the developmental services system and a mechanism for expansion of services overall (Castellani & Puccio, 1984).

Further, a more inclusive elgibility standard may generate tension among disability groups. It has been shown that access to family support services is highly dependent on enrollment in resources available for the unserved and underserved.

Clearly, providing a modicum of services to all families to strengthen their capacity to care for a developmentally disabled member can be very costly. At the core is the question of whether: 1) few services are to be provided to virtually all families, 2) whether more services are to be provided to all families, or 3) whether more services are to be provided to those most in need. The problems inherent in the more universal approach have been described. The alternative, focusing on those in need, also involves problems.

The first question concerns what constitutes need. The second goal of family support services, preventing unnecessary out-of-home placements, represents one way of determining need. However, that criterion obviously does not represent either the most extreme or exclusive measures of need for family support services. The overwhelming majority of families caring for a disabled member at home are not likely to request an out-of-home placement, but many may need family support services. However, when we consider needs in a more individually oriented context, a variety of problems arise.

The criteria for services have, to this point, been almost exclusively based on the disabled person's needs. A wide variety of assessment tools is available to ascertain a person's functional and service requirements. To determine the level of need of a family is more complicated. Designing services that enhance a family's capacity to provide care at home and/or that prevent out-of-home placement requires a knowledge of specific underserved, and families with low incomes or who are geographically and socially isolated from MRDD services.

Although these family and situational characteristics have been suggested as factors that affect a family's ability to care for a developmentally disabled member at home, it is extremely difficult to measure their impact and use them to establish service priorities.

Eligibility Criteria in Current State Programs

Figure 2 shows the eligibility criteria currently employed in state family support services programs. It is apparent that many of the factors that have been suggested as important in creating needs or, conversely, strengthening families and preventing out-of-home placements, have not been explicitly included. Eight of the 17 states surveyed require that risk of out-home-placement be established, which can of course encompass other factors. Income level, used by nine of the 17 states as a criterion, can also be a surrogate measure of some of the other factors indicated in the literature. The other two eligibility criteria, age and level of disability, are obviously specific to the individual with the developmental disability. There seems to be no direct inclusion of criteria that are linked to such specific needs of other family members such as number of siblings, others in the family in need for care, capacities of parents or other family members to give care, or housing configuration.

Policy Options for Eligiblity Criteria

It is clear that as states develop and expand family support services, they must deal more explicitly with the strategic and practical issues involved in the central problem of who is to receive family support services. Continuing experience with these programs should provide an enhanced capacity to measure needs more accurately and link appropriate services to those needs. That will depend, in part, on undertaking well-designed evaluations of those efforts. Nonetheless, practical problems as well as the strategic issues (e.g., who is to be served by family support services) are likely to be resolved politically rather than through some process of rational planning and evaluation. There simply are no objective measures of need on which to base service determinations for individuals or groups when the standard is to enhance a family's capacity to provide quality care. Capacity is both relative to others' situations and to society's changing expectations of what constitutes an acceptable or desirable standard of living. Given the political character of such determinations, it seems unlikely in light of fundamental reconsiderations of entitlement programs at federal and state levels, that a broad and inclusive approach to eligibility will be a policy option that will emerge.

How Should We Deliver Family Support Services?

Policy Issues and Current Options

The question of how family support services are to be delivered raises several important policy issues. These include:

- the level of government best suited to manage these services;
- the extent to which family support services conform to or compensate for community conditions;
- the relationship of public and private sectors (voluntary and proprietary) in delivering family support services;

area. At stake here is a basic question of equity within and among locales. In the first instance, much more needs to be known about the environment in which we expect family support services programs to operate. We are aware that family support services are related to such community resources as the availability and accessibility of public transportation, recreational facilities, medical, dental, and other professional services. It is also apparent that these services and resources vary widely by locale. In one respect, local management of family support services can best take into account local needs and resources. On the other hand, the intimate link between family support services and often widely varying community resources raises the question of whether family support services should equalize the differences in availability and accessibility that are likely to result. Clearly, institutional models, especially those supported in part through Medicaid funding, are operated on the principles of "statewideness" and equal access. Placement support services, as pointed out earlier, were in many instances initially built around community residences for deinstitutionalized persons and served as models for family support services for individuals who had never resided in an institution. This creates a strong precedent for equalizing the availability and accessibility of family support services across local governments to compensate for comparative deficits in resources and services.

The relationship between the public and private sectors, including voluntary and proprietary, is another concern that must

(OMRDD, 1983). However, state government-operated services tend to be the most expensive and may be limited by an institutional bias and historical perspective that may inhibit delivery of family support services to unserved and underserved populations (Commission on Quality of Care, 1984). In addition, difficulties with maintaining an acceptable level of operating flexibility in a large bureaucratic structure must also be considered. The use of public non-profit agencies established for the purpose of managing the delivery of family support services is another structural option. Here a key issue is the degree of authority that type of agency might exercise vis-a-vis other governmental agencies in coordinating and gaining access to services for its clientele.

No one model need be selected to the exclusion of others across an entire state, nor is this discussion intended to suggest that services cannot function conjointly or collaboratively. It is intended to indicate that family support services represent a substantially distinct type of service, and we should not assume that management models derived from institutional perspectives or even community residential and day program services are appropriately or easily adapted for family support services.

Another major issue of service delivery and management is the extent to which we create specialized family support services or integrate these services into social welfare, education, health, mental health, and other service domains. We are all familiar with the problems associated with gaining access to issues in this area. While there are many aspects of this issue, the basic question concerns the structure of services and the mechanisms families can use to gain access to those services.

As was pointed out earlier, many states began support services programs when it became apparent that people who had been placed out of institutions were returning or having problems because the so-called generic services that were expected to be available were not. It has often been only secondarily that states provided support services to families as spin-offs of placement support services or in belated recognition of the needs of families caring for a developmentally disabled member at home. Thus, the progression has been to first ensure that those services that had been available in institutions were provided to individuals placed in the community and then attempt to make those services available to people living at home with their families. In many instances, these family support services are provided as direct service adjuncts to core residential and day programs (OMRDD, 1983).

The increasing demand for and use of family support services has raised several problems and concerns with the direct provision of services model. As experience grows, it is becoming increasingly apparent that families are radically different than institutions, even those that are community-based. The structure of service delivery is primarily institutional, and the problems and opportunities families present seem to confound or be confounded by that structure.

The family is often the setting where family support

Summary

The answer to the question of how we should deliver family support services is obviously complex, as the discussion of the several issues encompassed in that question suggests. These issues, perhaps more than any of the others involved in the entire area of family support services, are highly conditioned by each state's experience in delivering services to people with developmental disabilities and the political-economic environment in each state. New York State, for example, has a large state-operated system of services complemented by services provided by large voluntary agencies. Local governments play a very limited role in the direct provision of developmental services, and there has been virtually no experience with vouchers or cash subsidies and little apparent movement in that direction. Pennsylvania has had a very large family support services programs for a number of years which operates largely through provision of services through county government. Other states are likewise conditioned by their history in this area.

Nevertheless, there are factors that seem either inherent in the nature of family support services or at work in the political-economic environment that will shape the direction of delivery of these services. Family support services are closely linked to the communities in which the needs arise, and it would appear that local governments will have to play an important role in managing and/or delivering family support services. The continuing pressure to contain government spending on social programs seems likely to create more pressure to increase the

-- the so called Chaffe Bill. An appreciation of these issues will be enhanced by examining them from the following basic perspectives:

- What are the current sources of funding for family support services in the future?
- What will be the sources of funding for additional family support services?

<u>Current Sources</u>

Much of the discussion about family support services concerns strategies for increasing funding. To some extent it ignores the current bases of funding that are usually the best predictors of the future (Wildavsky, 1964). Moreover, this discussion also ignores some problems which threaten the current bases of funding family support services.

The answer to the first question about funding sources is that state tax level dollars constitute the largest source of funding for family support services (Braddock, 1984). Despite the importance of the issues raised in the debates on S. 873 and the Home and Community Care Waiver, arguments for increasing the amounts of funding for these services should take into account the fiscal commitment made in each of the states to these services. Figure 3 indicates that for those states surveyed by Bird (1984), the levels of funding varied widely and also represented a relatively small proportion of the states' total spending for developmental services. Another important aspect of the issue that was pointed out by a study of family support services in New York State was that funds for these services were often not specifically identified or budgeted (OMRDD, 1983).

Figure 3: Program Characteristics of 17 Family Support Programs

STATES	REPORTED NUMBER SERVED	BUDGET	MAXIMUM ANNUAL COST/CLIENT	METHOD OF DELIVERY	LOCUS OF MANAGEMENT/ CONTROL	PROGRAM SCOPE
CA	102,400	$288,639,000	$2,900*	Individual providers	County	Statewide
CT	10+	20,000	2,000	Cash subsidy	State	Pilot
FL	216	500,000	2,300*	Reimbursement	Region	Statewide
ID	130	45,000	3,000	Cash subsidy	Region	Statewide
IL	n/a	n/a	4,200	Cash subsidy	State	Pilot
MD	60	120,000	2,000	Cash subsidy	State	Pilot
MI	2,140	5,700,000	2,600	Cash subsidy	County	Statewide
MN	187	525,000	2,800	Cash subsidy	State	Statewide
MT	600	1,125,000	1,880*	Services & subsidy	Region	Statewide
NB	90	500,000	3,600	Cash subsidy	State	Proposed pilot
NV	57	110,000	3,400	Cash subsidy	State	Statewide
ND	124	200,000	2,600	Cash subsidy	State	Statewide
OH	n/a	2,000,000	2,500	Services & reimbursement	County	Statewide
PA	15,630	4,887,000	2,000*	Direct services	County/Region	Statewide
RI	66	256,000	2,600 - 3,900	Cash subsidy	State	Statewide
SC	16	22,063	1,800	Reimbursement	State	Statewide
WA	1,900	1,052,000	554*	Direct services	Region	Statewide

*average cost/client

Source: Bird, W. A. A Survey of Family Support Programs in Seventeen States (Albany, NY, New York State OMRDD, 1984) radical change in the states' fiscal incentives to use Medicaid funds for community vis-a-vis institutional services. In summary, the intent of the so-called Chafee Bill would be to remove and/or create substantial fiscal penalties over time in the federal financial support for residential facilities serving over 15 persons. Since the initial introduction of the legislation there have been a variety of modifications and counter proposals that would generally soften the immediate impact on states with substantial institutional populations. Nonetheless, the intent of the proposal remains substantially the same. Supporters of the proposal argue that the impact of the passage of this legislation would be to force the phase-out of large institutions and conversely provide a large financial incentive for states to develop community and family support services programs. Opponents of the proposal have argued that size alone is not an adequate measure of quality of care and that the provisions for implementation create a differential and inequitable impact on states. Most opponents of the specific proposal, S. 873, do tend to acknowledge the desirability of a community-based rather than institutional system of care.

Major public policy changes such as those involved in the Community and Family Living Amendments typically take place over a period of time; often several years. Nonetheless, there seems to be considerable energy within the developmental disabilities field for changes in the general direction of the Chafee Bill. Moreover, there is substantial pressure being exerted by the federal government to contain Medicaid costs, and proposals such the one hand, it is generally assumed that governments at this level which depend in large measure on property and sales taxes for revenues have neither the capacity or willingness to themselves fund family support services programs. However, some core family support services such as transportation and recreation are typically services provided by local governments. Voluntary agencies which provide substantial amounts of these services such as respite, counseling, and information and referral also rely in part on funding from local government sources. Moreover, school districts either as independent local entities or as components of municipal governments are being pressed to provide more family support services as adjuncts to special education services mandated by PL 94-142. Thus, the role of local government in funding family support services has not been particularly prominent in discussion on this topic, but it seems that closer attention must be paid to the problems and opportunities of financing at this level of government.

Some attention has been paid to private sources of funding for family support services (See Part III; Chapter 4 on use of private sector resources). Most of that effort has focused on the possibilities for inclusion of family support services in either privately purchased or employer provided health insurance programs. The potentially large and usually long-term costs associated with services (including family support services) for persons with developmental disabilities tend to either confound basic insurance principles or prove to be prohibitively expensive in an increase in their number and size.

The opportunity for the use of Medicaid funds for community and family support services has become an overriding issue in the developmental disabilities field. While advocacy for overall expansion of these programs continues, it seems that the major political energy is devoted to efforts to reallocate the institutional and community services shares of the Medicaid "pie." In light of the possibility that Medicaid funding will contract, the energy devoted to reallocating what is now available for developmental services may dissipate the political momentum needed to increase funds available for all services, including family support services.

One final overarching concern in the area of funding family support services is the extent to which these services are items on the agenda for long term care reform. Gettings (1980) and others have pointed to the need to broaden the base of funding services (including family supports) beyond a health base. Boggs (1981) points towards that direction in observing:

> ...a newly emerging constituency for long-term care, as earlier defined, appears to be making headway toward legislative reform, what is sought is an alternative funding stream for non-institutional support services in which it will not be necessary to differentiate between homemakers or personal care givers by whether they earn health dollars or social service dollars. (p. 76)

It is apparent that most of the core family support services identified earlier, such as transportation, recreation, counseling, homemaker services and information and referral are not especially disability-specific. It is likely, therefore, that funding for family support services may indeed be an developmental disabilities community as cleavages surface and become resolved among advocates for previously and never institutionalized persons, individuals with various developmental disabilities, and groups that have been traditionally unserved and underserved by formal developmental services. The issue of how family support services are to be delivered may result in basic restructuring of the provision and use of social services and relationships between government and its clientele as families seek greater empowerment. Finally, the question of how family support services are to be funded will likely be part of a major reform of federal, state, and local fiscal responsibilities for long term care.

The discussions surrounding the Home and Community Care Waiver and the Community and Family Living Amendments have pushed some of these concerns to the forefront. However, very few of the issues discussed in this paper have been explicitly dealt with in the federal, state, and local policy process. We can be sure that the political energy that put family support services on these various policy agendas is sufficient to ensure that these policy choices will be made in the relatively near future.

FAMILIES AND FUTURE FINANCIAL PLANNING: NATIONAL SURVEY RESULTS

by

John Agosta, Ph.D., Beryl Feinberg and Valerie Bradley

Every parent wonders, at some point in his child's life, "What will happen to my child if I die or am permanently incapacitated?" In most instances the response depends on the child's age and family situation. Parents normally expect that as a child approaches adulthood, s/he will be competent to manage his/her personal and financial affairs. For parents that have sons or daughters with developmental disabilities, however, responsibilities do not necessarily diminish with the passage of time. Unique issues must be faced to protect and maintain the health, welfare and financial well-being of persons with developmental disabilities for the duration of their lives.

Several traditional means exist for coping with this problem. Families can:

- Create and contribute to savings accounts and investments in the name of their son or daughter with disabilities under the Model Uniform Gift to Minors Act;
- List their child with disabilities as a primary or contingent beneficiary under a life insurance or pension plan;
- Establish an Individual Retirement Account (IRA) account in the name of the person with disabilities; or
- Establish a will whereby the person with disabilities inherits specified assets.

These alternatives, however, are flawed because they each set conditions whereby assets flow directly to the person with disabilities. This event is undesirable for at least three reasons. First, the person with disabilities may be incapable of managing his

Numerous types of trust arrangements exist (see Russel, 1983; ARC National Insurance and Benefits Committee, 1984; Stuemke, 1984), each carrying with it specific terms to govern the circumstances and means by which assets are disbursed. Three commonly referenced trusts are:

- Testamentary trusts are established by the terms of the creator's will and go into effect at his or her death. Russel (1983) notes that these trusts are less common today than in the past but can be appropriate in some cases. They are most useful for parent's who cannot afford to establish a living or "inter-vivos" trust that requires periodic contributions. If these parents hold a life insurance policy, they can state in their wills that in the event of their death, all their assets, including proceeds from their insurance policy, will be placed in trust for the benefit of their child with disabilities;

- Inter-vivos trusts are established and go into effect during the creator's lifetime. Russel (1983) observes that they can be created with relatively small amounts of money, while the bulk of parental assets flow into the trust when the creator dies according to the terms of a will. These trusts, however, require periodic contributions from parents so that they may retain control of assets that could otherwise be tied up in the trust.

  Stuemke (1984) argues that this type trust offers at least four advantages over a testamentary trust. First, assets that flow into the trust at the parent's death are not subject to a probate fee or the time delay of probate. Second, inter-vivos trusts assure some level of privacy, in contrast to probate records. Third, it accords parents valuable time to evaluate the performance of the trustee. Finally, it can provide parents with flexibility and adaptability to future events by granting discretionary powers to others. Thus, in the event of serious illness or diminished capacity to function, parents can count on the trust continuing to operate; and

- Master or joint trusts are arrangements whereby parents pool a portion of their assets in the name of their son or daughter with disabilities with assets contributed by other parents. Because many financial institutions refuse to manage small trusts (i.e., trusts under $50,000), many parents of low to middle income cannot easily arrange an appropriate trust. Thus, master trusts serve a useful purpose by allowing parents of varying incomes to benefit from a trust arrangement. These trusts, however, represent a cooperative agreement and cannot be easily customized to accommodate the needs of individual families. As a result, planning or establishing trust arrangements for persons with diabilities.

Subsequently, interview guides were forwarded to any identified persons or organizations. These guides sought information in a variety of areas including: year of program initiation, corporate status, affiliate organization, number of clients served, eligibility criteria, sources of income, and services provided. In some cases, telephone inquiries were used to contact persons who failed to respond to the mailed survey or to clarify information received.

Results

Information was gathered from persons around the country describing numerous worthwhile efforts. In many cases, however, the organization described provided advocacy or guardianship services but not financial planning. These programs were not reviewed. Likewise, materials were received from other groups that offered some financial guidance but primarily provided advocacy services. It was decided to review a limited number of these advocacy-oriented programs for purposes of comparison with those primarily directed at financial planning. Thus, the full range of these programs was not profiled.

Based on these decisions, 19 programs were identified that provide systematic estate planning and/or trust arrangements on behalf of persons with disabilities. Detailed descriptive information, however, could be acquired on just 11 of these programs. Table 1 displays these 11 programs according to seven primary information areas and reveals several findings of note:

Date initiated. The oldest program profiled was begun in 1963 (Foundation for the Handicapped). Most programs, however, were initiated in the late 1970's or early 1980's.

Corporate status. Only Star Systems Consultation and Training Services operates as a "for profit" organization. All other organizations have a nonprofit corporate status.

Affiliate organization. Five programs are not affiliated with any other organization. Of the six that are, two are associated with local Associations for Retarded Citizens, two with government offices, and two with a provider agency.

Service area. Only the National Continuity Foundation is available across the country. Of the remaining ten programs, one is available in multiple states, two are available statewide, four are available in sub-state regions, and two in urban areas. No information of this kind was available on the Bridge Foundation.

Number of clients. The Foundation for the Handicapped serves the largest number of clients (n=500), while the Virginia Beach Community Trust serves the fewest (n=25). (The National Continuity Foundation was just begun and presently has no clients.) These figures, however, can be misleading because the programs profiled offer services that are not necessarily comparable.

Eligibility criteria. All programs except the National Continuity Foundation have residency requirements related to the program's service area. Regarding the disability categories of clients served, all but one program specifies developmental disability as a satisfactory precondition. The exception, Sentry Fund, confines its service to persons with mental retardation. In addition, many will serve persons with other disabling conditions (e.g., mental illness, physical disability, functional incompetence, aging). Only Star Systems serves parents of children without disabilities.

Table 2: Services Offered in 11 Financial Planning Programs

PROGRAM NAME	GUARDIANSHIP	ADVOCACY	FINANCIAL PLANNING	TRUST FUNDS	MASTER OR JOINT TRUST	ADDITIONAL SERVICES
GUARDIANSHIP ADVOCACY AND PROTECTIVE SERVICES PROGRAM OF OREGON	X	X	X			
PACT OF CHICAGO, ILLINOIS	X	X				CASE MANAGEMENT PROGRAM ASSESSMENT ESTATE PLAN REVIEW INFORMATION SPECIAL SERVICES
VIRGINIA BEACH COMMUNITY TRUST				X		CASE MANAGEMENT FAMILY COUNSELING ON FUTURE NEEDS
STAR SYSTEMS CONSULTATION AND TRAINING			X			CASE MANAGEMENT TECHNICAL ASSISTANCE SPECIAL SERVICES FOR A FEE
PLANNED LIFETIME ASSISTANCE NETWORK (PLAN) OF VIRGINIA			X		X	SURROGATE FAMILY ROLE
BRIDGE FOUNDATION						MANAGEMENT OF FINANCES LIFE INSURANCE POLICY
SENTRY FUND (MICHIGAN)		X			X	CASE MANAGEMENT
INLAND COUNTIES MASTER TRUST (CALIFORNIA)					X	
FOUNDATION FOR THE HANDICAPPED (WASHINGTON)	X		X		X	ACT AS REPRESENTATIVE PAYEE LEGAL ADVICE STATEWIDE REGISTRY OF PERSONS WITH SEVERE DISABILITIES
PERMANENT PLANNING INC. (IOWA)	X		X			
NATIONAL CONTINUITY FOUNDATION	X	X	X		X	USES EXISTING LOCAL SERVICE AGENCIES TO RENDER SERVICES $50,000 DEATH BENEFIT PLAN

programs offer little time-tested guidance.

As a result, those concerned with establishing financial planning or trust programs must depend on a review of relevant literature, the present experience of others, and careful consideration of numerous issues. Apolloni (1984) and the Association of Retarded Citizens of Colorado (1983) note several issues that must be examined:

- Corporate Status. What should be the organization's corporate stutus: profit or nonprofit?
- Corporate Affiliation. Should the organization act as a separate, free-standing corporation, or should it function as a subsidiary of some other established corporation?
- Board Membership. Who should serve on the board? What expertise should be represented? Should the board include persons with developmental disabilities, members of subscribing families, service providers, lawyers, trust management and investment experts? Should there be a membership outside of the board? How many people should serve on the board? What officers are needed and what should be their duties and powers? What committees are needed and what should their roles and responsibilities be?
- Board Selection. How should board members be selected (membership vote; board member vote; appointment by outside bodies such as advocacy organizations, elected officials, judges, etc.)?
- Board Responsibility and Powers. In what capacity should the board function? Should it be appointed as a guardian of its clients with disabilities or simply facilitate guardianship arrangements with volunteers as needed? What decisions must the board make and which could be delegated to staff? Should committees be established to carry out or oversee activities such as long range planning or trust investment?
- Funding. How much funding is needed to assure program stability and how will it be obtained? What sources of funds should be pursued in the long term and how should resources be allocated to secure such funds? How should the organization's services be marketed?
- Services Provided. What services should the organization provide? Should these services be provided directly or should the organization simply coordinate and monitor service provision by establishing contractual arrangements

Similarly, when establishing trust arrangements, parents presume that their assets are safe from unforseen loss. This may be true in nearly all cases but the possibility exists that the terms of a trust or the organization administering a trust could fail. This could occur if a trust is not properly prepared or through organizational mismanagement. Ordinarily, the enduring success of a program could be taken as proof of its potential for long term stability and effectiveness. The newness of so many financial planning and trust programs, however, does not allow parents to judge programs based on their past performance and leaves them vulnerable. Thus, there may also be a need to safeguard parental assets against loss due to mismanagement or fraud and/or to develop standards for establishing sound and effective trusts.

The role government should play, if any, in addressing these and similar issues is open to discussion. Some argue that because the state has a long term interest in the well-being of its citizens with disabilities, it should establish standards or regulations to govern financial planning and trust initiatives. Others argue that government should steer clear of these programs because public money is not often involved, government has a conflict of interest due to its role as service provider and funder, and involvement might result in states being held liable for any financial losses incurred by parents.

Adminstrators of financial planning and trust programs may do well to establish their own commonly accepted quality assurance formats. Other organizations facing similar issues have shown that such systems can be developed and have some effect on programs (Human Services Research Insitute, 1984). Examples include the Commission

Similarly, on a systems level, a financial planning and trust program could have a significant impact on the substance and course of services in an area. This could occur if the program assumed guardianship responsibilites for numerous clients and/or held significant amounts of assets in their behalfs. Given these conditions, programs could broker with the state and provider agencies to provide the type and amount of services needed to serve all clients in an area. Of course, the more clients a program served, the greater its influence could be.

Additionally, it must be understood that these programs presume that parents have resources available to invest in the future well-being of their son or daughter with a disability. For numerous families of middle or low income, however, this will not be the case. Moreover, families of any income who are faced with extraordinary costs related to providing care may be incapable of investing in financial planning programs. Thus, while these programs will be useful to some families, many will be unable to participate due to insufficient resources.

Though the above issues are particularly relevant to those concerned with establishing worthwhile financial planning mechanisms, the future viability of such programs will be determined by how effective they are in the long term. Due to the recent inception of most specialized financial planning programs, however, no longitudinal perspective is available. Consequently, assessing the efficacy of various means for capitalizing assets to provide future benefits for program enrollees is a difficult process. Take, for example, the Sentry Fund, established ten years ago. Currently, only two trusts are considered activated as a result of parents' deaths.

USING TAX POLICY IN SUPPORT OF FAMILIES WHO HAVE A MEMBER WITH DEVLOPMENTAL DISABILITIES

Current financial supports for many families who have members with developmental disabilities are insufficient. In response, several policy options have been suggested for complementing existing family support programs, including modification of state and/or federal tax policy. The primary intent of such policy would be to provide parents with a financial incentive for caring for their offspring with developmental disabilities at home. The purpose of this chapter is to: 1) examine the various modifications of tax policy that could be made; 2) review what tax incentives presently exist on the federal and state levels; and 3) offer discussion pertaining to the use of tax policy for supporting families.

Potential Tax Policy Options

Though federal and state tax policy can be altered in a number of ways, attention has centered on three basic policy options: tax exemptions, tax credits, and specialized tax relief.

Tax Exemptions

Tax exemptions allow reductions in the taxpayer's taxable income. The amount of the reduction can be standardized or can fluctuate up to some maximum limit depending on the taxpayer's costs providing care to a dependent with disabilities. In addition, to offset the costs of care, Piccione (1982a) suggests that tax exemptions could be used in at least two other ways.

First, one parent could be offered a standardized deduction for remaining at home to provide care. If used in tandem with post hoc

Specialized Tax Relief

This category refers to tax relief options not directly pertinent to income-related tax structures. Tax relief can be provided through exemptions or credits for a variety of taxes including real estate or property taxes, sales tax, taxes on investment dividends and interest, and excise taxes for telephone usage. In addition, as discussed below, special Individual Retirement Accounts (IRA) established for the benefit of a family member with disabilities would also fall into this category.

Present Federal Level Tax Policy

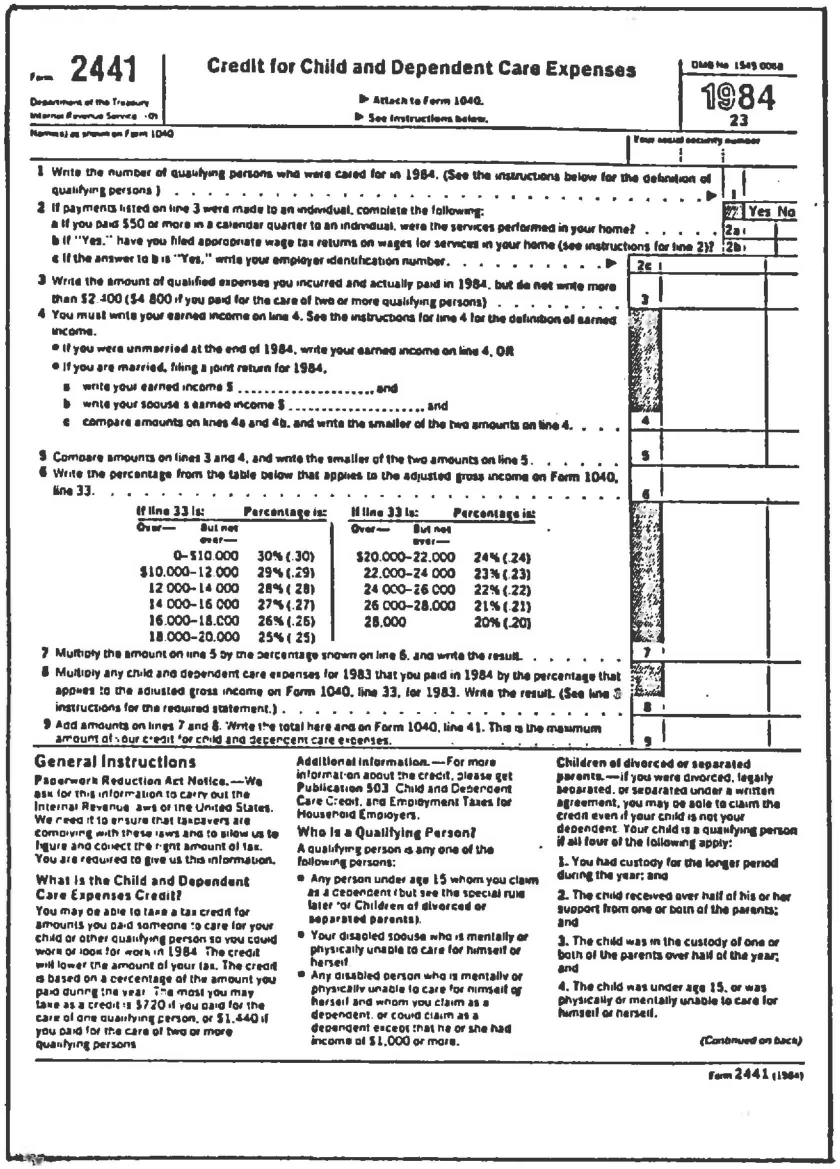
At present, the federal government offers several mechanisms for caregiving families to reduce their tax liability. Four such options are: deductions associated with reporting income, tax credits for child and dependent care expenses, employer related flexible spending accounts, and Individual Retirement Accounts.

Standard Deductions

When computing one's income the Internal Revenue Service allows several expenses to be exempted from the income of persons with disabilities or their parents. These deductions, however, are not always available to all persons with disabilities; several are restricted to specific disability categories (e.g., blind, deaf, physical disabilities). The Office of Information and Resources for the Handicapped (1983) notes the following allowable deductions:

- Special equipment such as motorized wheelchair, special equipped automobile, and special telephone for deaf persons;
- Special items, including artificial teeth, artificial limbs, eyeglasses, hearing aids and their component parts, crutches, and dogs for blind or deaf persons;
- The cost and repair of special telephone equipment that enables a deaf person to communicate effectively over a regular telephone by means of converted teletype signals;

Figure 1: Form Used to Claim Tax Credit for Child and Dependent Care Expenses



Form **2441**

Department of the Treasury
Internal Revenue Service (0)

Credit for Child and Dependent Care Expenses

▶ Attach to Form 1040.
▶ See Instructions below.

OMB No. 1545-0068

1984
23

Name(s) as shown on Form 1040

Your social security number

1 Write the number of qualifying persons who were cared for in 1984. (See the instructions below for the definition of qualifying persons.) ▶ 1

2 If payments listed on line 3 were made to an individual, complete the following: Yes No

a If you paid $50 or more in a calendar quarter to an individual, were the services performed in your home? 2a

b If "Yes," have you filed appropriate wage tax returns on wages for services in your home (see instructions for line 2)? 2b

c If the answer to b is "Yes," write your employer identification number. ▶ 2c

3 Write the amount of qualified expenses you incurred and actually paid in 1984, but do not write more than $2,400 ($4,800 if you paid for the care of two or more qualifying persons) 3

4 You must write your earned income on line 4. See the instructions for line 4 for the definition of earned income.

- If you were unmarried at the end of 1984, write your earned income on line 4, OR
- If you are married, filing a joint return for 1984,
  - a write your earned income $ .... and
  - b write your spouse's earned income $ .... and
  - c compare amounts on lines 4a and 4b, and write the smaller of the two amounts on line 4. 4

5 Compare amounts on lines 3 and 4, and write the smaller of the two amounts on line 5. 5

6 Write the percentage from the table below that applies to the adjusted gross income on Form 1040, line 33. 6

If line 33 is: Over—	But not over—	Percentage is:	If line 33 is: Over—	But not over—	Percentage is:
0–	$10,000	30% (.30)	$20,000–	22,000	24% (.24)
$10,000–	12,000	29% (.29)	22,000–	24,000	23% (.23)
12,000–	14,000	28% (.28)	24,000–	26,000	22% (.22)
14,000–	16,000	27% (.27)	26,000–	28,000	21% (.21)
16,000–	18,000	26% (.26)	28,000		20% (.20)
18,000–	20,000	25% (.25)			

7 Multiply the amount on line 5 by the percentage shown on line 6, and write the result. 7

8 Multiply any child and dependent care expenses for 1983 that you paid in 1984 by the percentage that applies to the adjusted gross income on Form 1040, line 33, for 1983. Write the result. (See line 8 instructions for the required statement.) 8

9 Add amounts on lines 7 and 8. Write the total here and on Form 1040, line 41. This is the maximum amount of your credit for child and dependent care expenses. 9

General Instructions

Paperwork Reduction Act Notice.—We ask for this information to carry out the Internal Revenue laws of the United States. We need it to ensure that taxpayers are complying with these laws and to allow us to figure and collect the right amount of tax. You are required to give us this information.

What Is the Child and Dependent Care Expenses Credit?

You may be able to take a tax credit for amounts you paid someone to care for your child or other qualifying person so you could work or look for work in 1984. The credit will lower the amount of your tax. The credit is based on a percentage of the amount you paid during the year. The most you may take as a credit is $720 if you paid for the care of one qualifying person, or $1,440 if you paid for the care of two or more qualifying persons.

Additional information.—For more information about the credit, please get Publication 503, Child and Dependent Care Credit, and Employment Taxes for Household Employers.

Who Is a Qualifying Person?

A qualifying person is any one of the following persons:

- Any person under age 15 whom you claim as a dependent (but see the special rule later for Children of divorced or separated parents).
- Your disabled spouse who is mentally or physically unable to care for himself or herself.
- Any disabled person who is mentally or physically unable to care for himself or herself and whom you claim as a dependent, or could claim as a dependent except that he or she had income of $1,000 or more.

Children of divorced or separated parents.—If you were divorced, legally separated, or separated under a written agreement, you may be able to claim the credit even if your child is not your dependent. Your child is a qualifying person if all four of the following apply:

1. You had custody for the longer period during the year; and

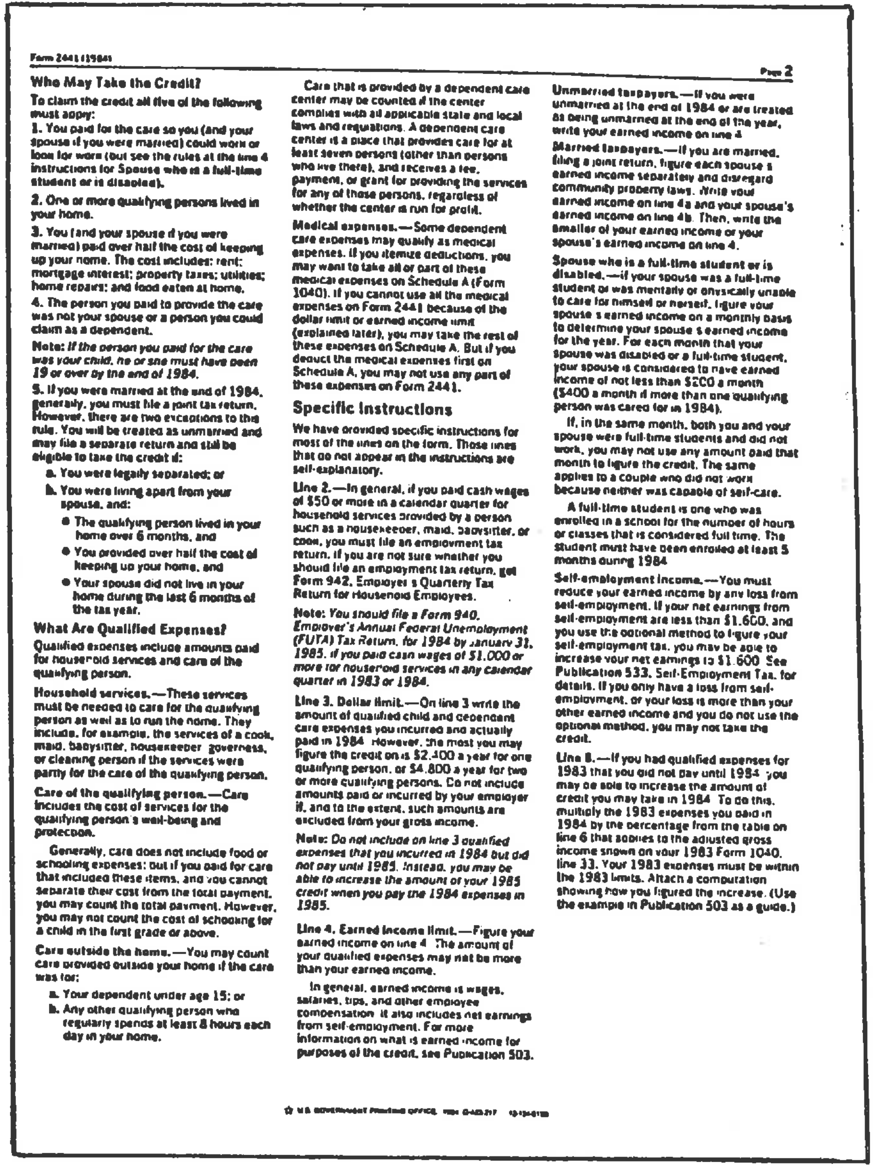
2. The child received over half of his or her support from one or both of the parents; and

3. The child was in the custody of one or both of the parents over half of the year; and

4. The child was under age 15, or was physically or mentally unable to care for himself or herself.

(Continued on back)

Form **2441** (1984)



Form 2441 (1984) Page **2**

Who May Take the Credit?

To claim the credit all five of the following must apply:

1. You paid for the care so you (and your spouse if you were married) could work or look for work (but see the rules at the line 4 instructions for Spouse who is a full-time student or is disabled).

2. One or more qualifying persons lived in your home.

3. You (and your spouse if you were married) paid over half the cost of keeping up your home. The cost includes: rent; mortgage interest; property taxes; utilities; home repairs; and food eaten at home.

4. The person you paid to provide the care was not your spouse or a person you could claim as a dependent.

Note: *If the person you paid for the care was your child, he or she must have been 19 or over by the end of 1984.*

5. If you were married at the end of 1984, generally, you must file a joint tax return. However, there are two exceptions to the rule. You will be treated as unmarried and may file a separate return and still be eligible to take the credit if:

  a. You were legally separated; or

  b. You were living apart from your spouse, and:

  - The qualifying person lived in your home over 6 months, and
  - You provided over half the cost of keeping up your home, and
  - Your spouse did not live in your home during the last 6 months of the tax year.

What Are Qualified Expenses?

Qualified expenses include amounts paid for household services and care of the qualifying person.

Household services.—These services must be needed to care for the qualifying person as well as to run the home. They include, for example, the services of a cook, maid, babysitter, housekeeper, governess, or cleaning person if the services were partly for the care of the qualifying person.

Care of the qualifying person.—Care includes the cost of services for the qualifying person's well-being and protection.

Generally, care does not include food or schooling expenses; but if you paid for care that included these items, and you cannot separate their cost from the total payment, you may count the total payment. However, you may not count the cost of schooling for a child in the first grade or above.

Care outside the home.—You may count care provided outside your home if the care was for:

  a. Your dependent under age 15; or

  b. Any other qualifying person who regularly spends at least 8 hours each day in your home.

Care that is provided by a dependent care center may be counted if the center complies with all applicable state and local laws and regulations. A dependent care center is a place that provides care for at least seven persons (other than persons who live there), and receives a fee, payment, or grant for providing the services for any of those persons, regardless of whether the center is run for profit.

Medical expenses.—Some dependent care expenses may qualify as medical expenses. If you itemize deductions, you may want to take all or part of these medical expenses on Schedule A (Form 1040). If you cannot use all the medical expenses on Form 2441 because of the dollar limit or earned income limit (explained later), you may take the rest of these expenses on Schedule A. But if you deduct the medical expenses first on Schedule A, you may not use any part of these expenses on Form 2441.

Specific Instructions

We have provided specific instructions for most of the lines on the form. Those lines that do not appear in the instructions are self-explanatory.

Line 2.—In general, if you paid cash wages of $50 or more in a calendar quarter for household services provided by a person such as a housekeeper, maid, babysitter, or cook, you must file an employment tax return. If you are not sure whether you should file an employment tax return, get Form 942, Employer's Quarterly Tax Return for Household Employees.

Note: *You should file a Form 940, Employer's Annual Federal Unemployment (FUTA) Tax Return, for 1984 by January 31, 1985, if you paid cash wages of $1,000 or more for household services in any calendar quarter in 1983 or 1984.*

Line 3. Dollar limit.—On line 3 write the amount of qualified child and dependent care expenses you incurred and actually paid in 1984. However, the most you may figure the credit on is $2,400 a year for one qualifying person, or $4,800 a year for two or more qualifying persons. Do not include amounts paid or incurred by your employer if, and to the extent, such amounts are excluded from your gross income.

Note: *Do not include on line 3 qualified expenses that you incurred in 1984 but did not pay until 1985. Instead, you may be able to increase the amount of your 1985 credit when you pay the 1984 expenses in 1985.*

Line 4. Earned income limit.—Figure your earned income on line 4. The amount of your qualified expenses may not be more than your earned income.

In general, earned income is wages, salaries, tips, and other employee compensation. It also includes net earnings from self-employment. For more information on what is earned income for purposes of the credit, see Publication 503.

Unmarried taxpayers.—If you were unmarried at the end of 1984 or are treated as being unmarried at the end of the year, write your earned income on line 4.

Married taxpayers.—If you are married, filing a joint return, figure each spouse's earned income separately and disregard community property laws. Write your earned income on line 4a and your spouse's earned income on line 4b. Then, write the smaller of your earned income or your spouse's earned income on line 4.

Spouse who is a full-time student or is disabled.—If your spouse was a full-time student or was mentally or physically unable to care for himself or herself, figure your spouse's earned income on a monthly basis to determine your spouse's earned income for the year. For each month that your spouse was disabled or a full-time student, your spouse is considered to have earned income of not less than $200 a month ($400 a month if more than one qualifying person was cared for in 1984).

If, in the same month, both you and your spouse were full-time students and did not work, you may not use any amount paid that month to figure the credit. The same applies to a couple who did not work because neither was capable of self-care.

A full-time student is one who was enrolled in a school for the number of hours or classes that is considered full time. The student must have been enrolled at least 5 months during 1984.

Self-employment income.—You must reduce your earned income by any loss from self-employment. If your net earnings from self-employment are less than $1,600, and you use the optional method to figure your self-employment tax, you may be able to increase your net earnings to $1,600. See Publication 533, Self-Employment Tax, for details. If you only have a loss from self-employment, or your loss is more than your other earned income and you do not use the optional method, you may not take the credit.

Line 8.—If you had qualified expenses for 1983 that you did not pay until 1984, you may be able to increase the amount of credit you may take in 1984. To do this, multiply the 1983 expenses you paid in 1984 by the percentage from the table on line 6 that applies to the adjusted gross income shown on your 1983 Form 1040, line 33. Your 1983 expenses must be within the 1983 limits. Attach a computation showing how you figured the increase. (Use the example in Publication 503 as a guide.)

☆ U.S. GOVERNMENT PRINTING OFFICE: 1984 [illegible]

The primary reason is that taxpayers providing care to dependent persons without disabilities are also eligible for the credit and their numbers are not distinguished from those providing care to persons with disabilities. Perlman (1983) writes that he pursued this matter with the Office of Tax Analysis (in the Office of the Secretary of the Treasury) and was advised that when reviewing aggregated summary statistics that "10% of the expenses claimed and 10% of the tax credit be attributed to home care and 90% to child care" (p. 281).

Based on this advice, Perlman (1983) estimates that: 1) the number of families who have members with disabilities who claim this credit has risen from about 100,000 before 1971 to 300,000 in 1978; 2) the combined expense claimed by families increased from $125 million in 1973 to $263 million in 1977; 3) the average amount claimed per family during the years 1971-1977 ranged from $700 to $1400; and 4) the loss in tax revenue rose from about $18 million before 1971 to $66 million in 1978.

These figures, however, must be interpreted with caution because they are based on rough percent <u>estimates</u> of families providing care to members with disabilities. If taken on face value, however, at least three observations can be made:

- Comparing the number of families claiming the tax credit (around 300,000 in 1978) with estimates of the prevalence of family-based care, it can be concluded that relatively few families take advantage of this tax credit option. Perlman (1983) estimates that under 10% of those eligible claim the credit. Reasons for this surprisingly low estimate are unknown. It can be speculated, however, that: 1) requiring taxpayers to obtain and complete additional tax forms may deter some from taking advantage of the program, and 2) many parents may be unaware of the program.

- The dollar amounts claimed by all families for care averages between $700 to $1400. If this range is an accurate representation of expenses claimed by families who have allocated only after a covered expense is incurred. Usually, the employee is reimbursed by the employer by subtracting the total amount of covered expenses from the employee's taxable income at the end of the tax year.

Because flexible spending accounts require that an agreement be reached between the employer and employees regarding the nature of the account, these arrangements vary by worksite. In general, however, the following conditions apply:

- Any employee eligible for benefits qualifies to arrange a flexible spending account. There are, however, restrictions placed on "highly compensated employees" such as those who: act as an agency officer during the plan year or any of the four preceding plan years, are one of the ten employees owning the largest interest in the agency, own five percent of the agency, or own one percent of the agency and earn more than $150,000 per year;

- The flexible spending arrangement can cover a variety of expenses including certain <u>legal expenses</u>, <u>medical/dental expenses</u> (e.g., vitamins, drugs, visits to medical doctors, dentists, physical therapists, psychiatrists), rehabilitative aids (e.g., eyeglasses, contact lenses, crutches, false teeth, braces, hearing aids), <u>transportation services</u> associated with obtaining medical care, and expenses for providing <u>care to a dependent</u> child under age 15 or person with disabilities who is incapable of self care (e.g., day care, sitter services). There is no maximum limit for expenses incurred, though individual employers may set limits.

- Reimbursed expenses cannot be claimed elsewhere by the employee with the intention of further reducing his or her tax liability. For instance, the taxpayer cannot be reimbursed for dependent care expenses as part of a flexible spending arrangement and then use the expense to participate in the tax credit for child and dependent care program;

- The employer assumes the costs associated with administering the flexible spending program. However, some of these costs are offset because: 1) employers may place the money allocated to the program by employees into a bank account that earns interest for the employer, and 2) the amount of social security tax (FICA) paid by the employer for workers participating in the program is reduced. This occurs because the each worker's gross taxable income is reduced commensurate with the amount he or she allocates to the program;

- Employers maintaining a flexible spending arrangement are required to file a return showing: 1) the number of employees of the employer, 2) the number of employees participating in such as a family member with disabilities. (In 1981 the National Association for Retarded Citizens proposed to Congress that a provision be adopted to permit parents to establish an additional account for their offspring with disabilities, but it was not passed.)

Based on changes in tax laws adopted in 1982, Boggs (1984) suggests that there are at least two ways for parents to use an IRA to benefit their offspring with disabilities. First, if a parent already possesses a sufficient retirement plan, s/he can set up an IRA in the name of the person with disabilities, deposit up to $2,000 per year to the account, and name the person with disabilities as a beneficiary at the death of the parent. Second, while the parent(s) help pay for daily living expenses, the person with disabilities could establish his/her own IRA account.

Though reasonable, using IRAs can be problematic for at least three reasons. First, by establishing arrangements whereby the person with disabilities is granted a sum of money later in life, s/he inadvertently may forfeit eligibility to federal entitlement programs such as Supplemental Security Income (SSI) and Medicaid or may be held liable for the costs of care provided by the state (Davis, 1983; Russel, 1983). As a result, long-term costs of care may soon deplete whatever savings were set aside. To avoid this undesireable consequence, Boggs (1984) suggests that parents make arrangements to have assets maintained in the IRA transferred into a trust account at the death of the IRA contributor. A carefully worded trust account will hold and disburse funds in the name of the person with disabilities without risking loss of federal benefits or being held liable for services received. (See Part III; Chapter 2)

Disabilities (Edwards & Mandeville, 1982). In this study, directors of state councils on developmental disabilities, protection and advocacy agencies and departments of revenue were queried to determine: 1) which states provided an exemption on state income tax for a disabled person, 2) whether a given exemption is based on the severity of the disability or on a specific disability category, and 3) the amount of a given exemption. Survey results are not fully applicable to families who have members with developmental disabilities because the information obtained does not distinguish clearly between exemptions that can be claimed by disabled taxpayers, taxpayers with disabled dependents, or both. Moreover, no clear distinction is made between tax exemptions claimed on the basis of developmental disabilities and those stemming from other disabling conditions. In addition, the authors note that caution is warranted in interpreting survey findings because the information may be dated and/or not fully reliable. Though these limitations are worth noting, the survey resulted in several instructive findings:

- Seven states do not have a personal income tax. These states include:

  Alaska
  Nevada
  South Dakota
  Tennessee
  Texas
  Washington
  Wyoming

- Three states do not have a personal income tax, but provide exemptions for persons with disabilities on other types of state tax. These states are listed below:
  - Connecticut: provides limited exemption by category of tax (e.g., telephone).
  - Florida: provides exemptions on property tax.
  - New Hampshire: taxes real estate and income earned through interest and investment dividends. Some persons with disabilities receive exemptions on these taxes.

structures. These survey results, however, do not offer evidence regarding the overall utility of various state tax policies. What is needed is additional information that: 1) separates taxpayers with disabled dependents from taxpayers with disabilities, 2) distinguishes between disabling conditions (e.g., developmental disabilities, physical handicaps), 3) shows how often available tax options are used, 4) specifies the dollar costs to the state for a tax program in terms of administrative costs and lost revenues, and 5) sheds light on the benefits accrued by those who make use of available tax options. Based on this type of information, initial conclusions can be drawn regarding the relative utility of various tax policy options. Moreover, the role of state tax policy in the greater scheme of publicly sponsored family support can be more easily determined.

Relevant Issues

Review of current federal and state tax policy reveals that several options exist for families who have members with disabilities to reduce their tax liability. Moreover, it is clear that existing tax codes could be further modified to ecourage familiy based care. Examples include:

- Extending the double exemption pertaining to the calculation of federal tax liability to disabilities other than blindness and to taxpayers who claim a dependent with disabilities;
- Modify present rules governing use of the dependent care tax credit by increasing the amount of the credit, allowing care provided by other dependents of the taxpayer who are under age 19 to be claimed as an expense, and making it "refundable" to increase its utility for low income families;
- Expand specialized tax relief programs (egs., reduce or eliminate sales taxes on care related purchases made by qualifying parents, reduce or eliminate property taxes incurred by caregiving taxpayers);

must be made to monitor the use of existing programs, uncover abuses, and recommend improvements in the program;

- Cost. The GAO (1982) notes several difficulties with estimating the costs (i.e., administrative costs and lost revenue) of tax relief programs. These difficulties include uncertainties regarding: 1) the number of taxpayers who will use the programs, 2) the prevailing eligibility criteria, 3) the mechanisms put in place to reduce misuses of the programs, and 4) the provisions that place limits on the dollar amounts taxpayers can gain from using a given program. Consequently, tax relief programs should be pursued with caution since other means of promoting family-based care may be more cost efficient and effective, such as providing families direct cash assistance or access to a comprehensive array of free supportive services (Michigan House Legislative Analysis Section, 1983);

- Evaluation of the Effects of Tax Relief Programs. The ongoing evaluation of the effects of tax relief programs on the capacity of families to provide care is crucial for determining the efficacy of such programs. This suggests that governmental tax analysts should coordinate with those providing other types of family support to collect information that will be of use to all concerned parties. In this way, systematic and longitudinal evaluation of all family support efforts can be pursued with the intent of enhancing the entire family support system.

- Equity. When tax policy is proposed as a means of supporting families, its utility for benefiting all types of families must be considered. A policy that benefits only certain types of parents (e.g., upper income, employed), does little to contribute to an effective national strategy for encouraging family-based care. This point grows especially salient in view of evidence showing that a significant number of families who have a member with developmental disabilities have lower incomes than the general population. In fact, Robert Perlman (See Part III; Chapter 6) shows through analysis of information collected during the 1976 Survey of Income and Education that 45% of those families providing care to persons with developmental disabilities had incomes below $10,000 in 1976, compared with 33% of all United States families; and

- Ease of Use for Families. Parents providing care to persons with disabilities cannot and should not be expected to keep abreast of the array of tax saving strategies available at various levels of government. Recall that providing care to persons with developmental disabilities is not an altogether easy task, given the potential effects of such care on the family, the ongoing needs of the person with disabilities, and the effort that must be exerted to obtain and/or participate in available services. Government officials concerned with promoting family care should be commited to simplifying the

These considerations suggest that though using the tax system to support families may benefit some families, it will not be sufficient nor may it be necessarily or desirable. Program planners may well prefer to encourage and support familiy efforts through more explicit approaches that delineate the role of government more clearly, treat families more equitably, and provide support in a more systematic fashion.

USING PRIVATE SECTOR RESOURCES TO SUPPORT FAMILIES WHO HAVE A MEMBER WITH DEVELOPMENTAL DISABILITIES

Much recent discussion regarding funding for human services has focused on utilizing private sector resources (Meyers, 1982). Business and industry can get involved in the initiation of programs to support families in a variety ways. For instance, businesses can make financial contributions directly to existing service providers. Citibank/CitiCorp has pursued this course by granting $50,000 to the Metropolitan Child and Family Support Program (MCFSP) in Baltimore, Maryland (NASMRPD, 1984). With these funds, MCFSP provides services to families with children with disabilities from birth through seven years that accommodate socio-emotional, parent training, medical, and specialized programming needs.

The private sector can also initiate family support programs that are independent of existing public sector services. This can be achieved by: 1) involving segments of the for-profit service industry with family support efforts, and 2) prompting individual employers -- or organized labor unions -- to initiate services that benefit their workers who provide care to family members with developmental disabilities. The purpose of this chapter is to examine the utility of these two alternatives and to discuss relevant issues pertaining to private sector involvement in family support.

Family Care and the For-Profit Sector

Numerous for-profit businesses are in a position to support families who have relatives with disabilities. For example, banks can initiate special low-interest loans to qualifying families for

- Part B: Medical Insurance. This program helps pay for doctor's bills and other health services not covered or covered only in part under the terms of Part A (e.g., home health visits, physical therapy, speech pathology, outpatient hospital services, X rays, laboratory tests, certain ambulance services, purchase or rental of medical equipment). If a person is enrolled in the Part A program, she or he automatically is enrolled in Part B -- but participants can elect to terminate their enrollment in Part B. In 1984 participants in the Part B medical insurance program were required to pay a basic premium of $14.70 a month.

Though the Medicare program offers numerous useful services, its utility for families who have members with developmental disabilities is severely limited. To qualify parents must themselves be eligible for retirement, disability or survivor's benefits under the Social Security Act. Relatively few parents, however, satisfy this eligibility standard, requiring that other means for obtaining health care coverage be considered.

Medicaid Benefits

Medicaid is a joint federal and state program available in all states but Arizona that provides physical and related health care services. Persons eligible for Medicaid are classified into three groups:

- Categorically needy: These persons receive or are eligible to receive Aid to Families with Dependent Children (AFDC). In addition, recipients of Social Security Income (SSI) generally are eligible. (Those who reside in Guam, Puerto Rico, or the Virgin Islands can qualify for Medicaid if they receive Old Age Assistance, Aid to the Blind, Aid to the Permanently and Totally Disabled, or Aid to the Aged, Blind, and Disabled.);

- Medically needy families: These persons have an income high enough to disqualify them from receiving public assistance, but who could not meet their basic needs in order to pay their medical bills. These persons can become eligible for Medicaid if they pay a premium (usually a nominal fee) and have an income that is less than the "state standard." This standard varies by state; and

- Medically needy children: persons 21 years of age or under who qualify on the basis of financial eligibility but do not qualify as a dependent under the state's AFDC plan.

present deeming requirements. Likewise, high income families may be able to absorb additional medical costs without assistance from public programs. Middle income families, however, are caught in the unenviable position of having too few resources to cover medical costs without hardship but too many resources to qualify for government benefits.

To help ameliorate this crucial disincentive to family-based care, the federal government initiated a temporary review board in 1981 to consider specific cases. This board was established after President Reagan granted a special waiver of federal Supplemental Security Income (SSI) regulations in the case of a three year old child with severe disabilities named Katie Beckett. Following this special waiver, the Secretary of the US Department of Health and Human Services established a review board to consider applications from state Medicaid agencies on behalf of persons who could be served appropriately in the home, but due to existing eligibility criteria were found ineligible for Medicaid services. This board operated until December 31, 1984. During its tenure, 200 cases were submitted for consideration with about 150 cases approved (estimates provided the National Association of State Mental Retardation Program Directors by a member of the review board). In addition, the board's authority was extended to allow it to decide on 40 remaining applications. Of those cases submitted, most were initiated by the same six states, with about 25 states making use of the board altogether.

At present, individual states may pursue any of three options for negating disincentives to family-based care growing out of Medicaid policy. These option are: the community-based waiver program, the

Figure 1: Three Options for Countering Medicaid Income Eligibility Criteria and Utilization Pattern by State

STATE	COMMUNITY BASED WAIVER (PL 97-35) DEEMING CRITERIA WAIVED	TAX EQUITY AND FISCAL RESPONSIBILITY ACT OF 1982	MODEL WAIVER PROGRAM	STATE	COMMUNITY BASED WAIVER (PL 97-35) DEEMING CRITERIA WAIVED	TAX EQUITY AND FISCAL RESPONSIBILITY ACT OF 1982	MODEL WAIVER PROGRAM
Alabama				Montana	X		
Alaska				Nebraska		X	
Arizona				Nevada		X	
Arkansas				New Hampshire	X		X
California				New Jersey	X		
Colorado				New Mexico	X		
Connecticut			X	New York			
Delaware	X			North Carolina	X		X
Florida	X			North Dakota	X		
Georgia		X	X	Ohio			X
Hawaii				Oklahoma			
Idaho		X	X	Oregon	X		
Illinois				Pennsylvania	X		
Indiana				Rhode Island	X	X	
Iowa			X	South Carolina	X		
Kansas				South Dakota	X		
Kentucky				Tennessee	X		
Louisiana	X			Texas			
Maine		X		Utah			
Maryland				Vermont			
Massachusetts	X			Virginia	X		
Michigan			X	Washington	X		
Minnesota	X			West Virginia	X		
Mississippi			X	Wisconsin		X	
Missouri				Wyoming		X	

While the bill would not necessarily close all institutions, it would encourage states to emphasize community living by making available a variety of services such as habilitative programs, personal aides or attendants, medical care and family support services. Though Congress has not as yet passed S. 873, its proponents continue to press for its adoption in some form.

Private Insurance Plans

Many believe that comprehensive private insurance plans for families who have members with disabilities could obviate the necessity of public funding. At present, however, this approach is considered unrealistic by some analysts since many persons with disabilities do not qualify for private or group medical plans (Davis, 1983). Meiners (1982) notes that private coverage often is unavailable for a variety of reasons including: 1) insufficient family income for covering the costs of premiums, 2) the ongoing availability of public long-term residential options that diminish the pressure for establishing private insurance, and 3) a variety of traditional insurance concerns such as administrative diseconomies, premium pricing difficulties, and fear of incurring an open-ended liability.

There is, however, a growing recognition among private insurers that the cost of home health care is far cheaper than the cost of hospital care. Figure 2 shows the estimated savings from health care provided in the home in relation to four disability categories. Due in great part to findings such as these, many private insurers and hospitals have made home health care a crucial element of their cost containment strategies. Moreover, at least 17 states have mandated the inclusion of home care in private health insurance programs.

may well be within the range of many parents. In addition, Meiners (1982) argues that if marginal adjustments were made to the existing private insurance system, the feasibility of having private insurers underwrite home health care for persons with disabilities would be enhanced. Examples of some of the changes that could be made include: 1) offering families who have members with disabilities an opportunity to share the cost of insurance with other families in similar circumstances (i.e., a group plan for the person with disabilities), 2) using the tax system to provide caregiving families with refundable tax credits with which they can purchase available insurance, and 3) using the tax system to provide employers with tax subsidies to defray any additional costs associated with including family members with developmental disabilities on existing group plans.

Coordinating Public and Private Sector Efforts

The present health care system does not actively encourage family-based care. Given extraordinary medical costs, families who cannot obtain coverage through a private insurance company realistically are presented with five options:

- Families can acquire needed funds by borrowing money or selling off assets. These approaches further reduce the family's financial resources.
- Families can expend available resources until they meet the income eligibility requirements of Medicaid and become eligible for Medicaid benefits.
- Families can acquire financial or direct medical assistance from a variety of charitable foundations such as the March of Dimes, Easter Seals and the Shriners. Unfortunately, this option does not reach all of those in need.
- Families can elect not to pay for incurred expenses. Indeed, this option is often used by families who then run the risk of being sued. It has been suggested that many hospitals no longer seriously expect some families to pay. In effect, hospitals pass on these costs to other clients who can pay for

serious discussion among all concerned parties to set eligibility standards and to coordinate the efforts of government and private insurers. Likewise, public policy makers committed to encouraging family care must make publicly financed medical assistance plans, such as Medicaid, available to all families with insufficient resources to pay for private insurance.

Employer Centered Independent Initiatives.

Current federal fiscal policy is designed to encourage businesses and industry to make capital investments that will spur increased employment and production. Some speculate that such conditions will prompt the private sector to allocate additional resources for the benefit of workers (e.g., initiating day care programs for working mothers).

Review of the evolving relationship between employers and workers lends some credence to this view. Akabas and Krauskopf (1984) note that employers can no longer count on a continuing supply of devoted workers and therefore must endeavor to make employment attractive. Most often, these considerations prompt initiation of benefits that reinforce the relationship between employment and the well-being of the worker and his or her family.

Several analysts have documented the growing number of family-oriented benefits initiated over the years including fiscal benefits such as financing health care, flexible spending accounts, pension programs and disability retirement programs, and service benefits such as child care and counseling (McKinnon, Samors & Sullivan, 1982; Weiner, 1972; Akabas and Kurzman, 1982). These findings show that "a significant occupational social welfare system [has] developed within the worksite, with families as well as private sector resources, equity, long term program stability, and quality assurance.

Realistic Estimates of Private Sector Involvement

Underlying any argument for increased private sector involvement in family services is the belief that businesses are capable and willing to make such investments. To a great extent, the capability of businesses to make substantial contributions to human services is related to the performance of the national economy; if the economy begins to fail, or if the present federal deficit is not reduced, businesses will be less apt to allocate additional resources for human services (Penner, 1982).

But even if the economy were to perform well, Boggs (1984) warns that surveys of private businesses do not reveal substantial plans for contributing to human services initiatives. Further, proponents of family services must consider that they will be competing for private sector resources with numerous other deserving groups. Thus, though businesses represent a viable source of additional support, employer-sponsored programs are not a panacea for solving chronic funding shortages.

Coordinating Private and Public Sector Resources

Systematic evaluation may disclose that certain types of services are most effective when financed through the public sector. Likewise, other service types may be especially suited to the private sector. Consequently, the goal of family service proponents should be to weave both public and private sector resources into the most comprehensive and effective service network possible. Thus, business and industry could best accommodate the needs of families by finding ways to complement -- not compete with -- already existing family assurance of quality services (HSRI, 1984). Assuring quality in the public sector is already a difficult process that would likely grow more complicated by the addition of services funded through the private sector. Given a desire to assure quality across all services, formats that are equally applicable to public as well as private services should be developed. Of course, the source of authority for planning and implementing such procedures, and enforcing any resulting recommendations for program improvement remains open to discussion.

Though the above issues are significant, they should not be used to discount the potential utility of private sector resources for supporting family efforts. Insufficient attention has been paid to the potential benefits and mechanics of encouraging local businesses to help support caregiving families. By becoming involved, business can help integrate willing caregivers into the labor force and further enhance their capacity to provide care. Such participation also could help integrate business into the mainstream of community life (Piccione, 1982b). Moreover, many argue that encouraging private sector involvement with service delivery may well result in a greater variety of services for families to choose from and in services that are more responsive to individual family needs. Thus, program planners are challenged to investigate this option and develop means for integrating business into systematic family support systems.

EVALUATING FAMILY SUPPORT PROGRAMS

Family support programs present unique challenges to professionals regarding the development of evaluation mechanisms to monitor activities, measure program outcomes, and provide direction for service improvement. Ultimately, such knowledge is necessary to justify future levels of investment in family support programs. However, to date, little effort has been made to examine administrative processes and program outcomes associated with existing family support programs. The purpose of this chapter is to examine what types of evaluation are needed, to review the difficulties involved in conducting such evaluations, and to present some of the findings from the few evaluations that have been undertaken.

Types of Evaluation Needed

Though nearly 25 states operate what may be termed "extensive" family support programs, surprisingly few of these programs have been evaluated. At least two types of evaluation are possible: process and outcome. Process evaluation is generally used to improve the efficiency, responsiveness or relevancy of an existing program, especially during its early stages of development. In contrast, outcome evaluation is designed to present conclusions regarding the overall effects or worth of a program, and often includes recommendations about whether it should be retained, modified, or eliminated.

Figure 1 shows these two types of evaluation, process and outcome, in relation to the social service system and individual families. As shown, evaluation that focuses on the process of

Evaluation that focuses on the outcome of services is also useful. Such evaluation can be used to determine if various system level program objectives have been met. One example of such an objective includes realizing cost savings to the state due to diminished demand for residential services. On the family level, one telling outcome pertains to the effect of services on family placement decisions. Other outcomes of interest include aggregated tabulations of skill gains made by parents and persons with disabilities, or the family's satisfaction with services.

The evaluation of family support services can take numerous directions given the complex interactions among family service needs, the resources available to program planners, the service process, and service outcomes. Figure 2 displays the multiple factors associated with each of these evaluation targets. This outline suggests some of the many areas of inquiry that evaluation of family support service might take.

- What is the relationship between the needs of families and persons with disabilities? What client needs (e.g., daily insulin injections, special diets, reducing maladaptive behavior) can be best accommodated by meeting certain family needs (e.g., specialized information and education)? What client needs are best met by professionals outside the family home and which are best met by family members?

- How are client and family needs related to the service delivery process? Are certain administrative practices (eg., cash subsidies) more responsive to some service needs than others? What role should the private sector play in service delivery?

- What administrative practices are most time or cost efficient? Should cash subsidies utilize sliding fee schedules? How should services provided by multiple providers be monitored and coordinated?

- What types and levels of service should be made available? How can specific family needs be identified? How can the type and level of services provided to families be determined?

- How do services affect a family's capacity to provide care? How are interactions between family members altered? How do services affect the family structure, its functions, and its lifecycles? Is the caregiving capacity of a family really enhanced?
- What are the outcomes of service delivery? Are cost savings realized by the state? Are parental placement decisions altered? Is the quality of life of individual families improved? Are families satisfied with services provided? To what extent do services satisfy the needs of families?
- What is the relationship between specific service delivery processes and program outcomes? Do certain administrative practices make a difference? Do certain services have a greater impact than others?

Of course, it will take several years to collect sufficient information to answer these and other relevant questions. However, evaluation is an evolutionary process that builds on assessment efforts over time. The intention is to develop a growing understanding of how to maximize the positive effects of family support programs.

Difficulties in Conducting Program Evaluations

Current efforts to evaluate the efficacy of family support services are plagued by two problems: 1) variation in program objectives, and 2) methodological problems.

Variation in Program Objectives

There is little disagreement that the two goals of family support services are to enhance the family's caregiving capacity and to prevent unnecessary out-of-home placement. Most would also agree that achieving these goals is in the interests of persons with developmental disabilities, their families and society. Operationalizing these goals in terms of specific program objectives, however, is another matter. There is a striking lack of consensus family expect)? Not all service planners agree on the best means for resolving these questions. Consequently, there is substantial variance in the services families can receive around the country.

On the family level, specific program objectives are equally difficult to operationalize. This is in part due to the growing recognition that each family is unique and needs varying types and amounts of services. As a result, "programs have increasingly moved from a pre-set pattern of giving the same services to everyone, to a more individualized approach in which parents have more control over both the length and extent of their program involvement" (Weiss, 1983, p. 10). Illustrating this point are recent survey findings regarding the service utilization patterns of 101 families in five Maryland counties who participated in the first year of the state's Family Support Services Consortium (Gardner and Markowitz, 1984). Figure 3 shows the distribution of the number of families receiving various types of services at least once and suggests that families make periodic use of a variety of services.

Likewise, the amount of services provided to individual Maryland families varies. Figure 4 shows the percentage of families categorized by annualized costs of service in five counties. Though situational variables (e.g., availability of services, differing administrative practices) may explain some of the variance, these findings suggest that some attempt was made to allocate resources according to varying levels of need.

The current trend to establish programs can accommodate unique family situations is encouraging. The resulting variance in the services families receive, however, impedes comparison of program strategies and effects.

Methodological Problems

Evaluation of family support programs is also complicated by methodological difficulties involved in the measurement of program processes and outcomes. Examples of such problems include:

- The insensitivity of measures to program effects: Due to the nature of developmental disabilities, service benefits are not always easily or promptly observed. Consequently, Halpern (1984) suggests that current measures may underestimate program effects. Moreover, Weiss (1983) notes that intervention efforts centering on the entire family require that measures be capable of monitoring changes within family dynamics. Such measures have yet to be perfected.

- The absence of longitudinal evaluation: The lack of immediately observable program effects also suggests that evaluation models should be designed to view change over time. Longitudinal evaluation, however, is burdened by a variety of difficulties, including the attrition of participating families, keeping service packages received by families constant, and determining the proper statistical means for assessing change over time (Cronbach & Furby, 1970).

- Sampling related problems: Halpern (1984) notes a variety of sampling-related problems including small sample sizes, the difficulty in employing random assignment of families to service groupings, and variability in the characteristics of families and persons with disabilities.

- Mitigating circumstances: Evaluation efforts can be adversely affected by a variety of uncontrollable circumstances. For example, Tausig (1983) and Herman (1983) note that several states have initiated policies whereby out-of-home placement into institutional settings is actively discouraged. The obvious impact of such policies on parental placement decisions greatly complicates the process by which family support programs are evaluated.

- Inadequate causal models: Due to many of the problems noted above it is extremely difficult to employ group-based research techniques within a causal model. Consequently, the effectiveness of family support strategies remains largely untested in a quantitative sense.

  An effective alternative strategy involves use of single subject design methodology to establish cause-effect relationships. This type of design generates information at a slower rate than group designs because it utilizes few subjects per study. It is, however, especially suited to coping with research problems where there is great variance in program objectives and practices.

eligibility). Examination of this practice revealed that it cost the state more to collect information and allocate services according to a sliding scale than the state was saving through its use.

Similarly, the Minnesota Developmental Disabilities Council sponsored an evaluation of the state's cash subsidy program. Thirty-eight families participating in the program were asked a series of questions regarding how administrative practices could be improved. Respondents suggested that:

- the program be expanded to include adults,
- yearly rather than twice a year applications be required,
- local social and health service staff be educated about the program,
- parents be used to publicize the program,
- benefits be increased for families with extraordinary needs, and
- benefits be increased for emergency respite care and long distance medical phone calls (Minnesota Developmental Disabilities Program, 1983a).

Findings such as those above are useful in making administrative practices more efficient and services more responsive to families. However, our search of available literature yielded few examples of this type evaluation. Consequently, much more study needs to be done at the system level to improve services.

Family level findings. Present evidence suggests that family support services do enhance the family's caregiving capacity. Families receiving services report:

- Reduced overall stress levels (Moore, Hamerlynck, Barsh, Spieker & Jones, 1982);
- Increased time spent away from the demands of care giving resulting in an improved capacity to keep up with household routines, pursue hobbies and seek employment outside the home (Zimmerman, 1984; Moore et al., 1982);

system of services. One popular claim is that family support services are cost effective because they diminish the need for funding expensive out-of-home residential arrangements by making it possible for families either to keep their member with a disability at home or have him/her return home from an out-of-home placement. Surely, as illustrated by relative costs of care in Michigan (Figure 5), family support services cost the state less than alternative residential arrangements. Michigan officials estimate that by serving one person at home instead of at a state residential facility, the state saves about $47,000 annually.

Figure 5: Daily Costs of Care in Various Residential Settings in Michigan*

Residential Setting	Cost Per Day
Institution for persons with developmental disabilities	$136.90
AIS/MR Residential Care	67.45
Intensive Foster Care	61.70
Group Foster Care	50.06
Family Foster Care	23.05
Family Support Subsidy	7.41

---

* Source: Stabenow, 1983

Though the accuracy of this type information cannot be disputed, it must be weighed against two other findings. First, the overwelming majority of families do not place their sons or daughters with disabilities out of the home. Thus, unless family services are successfully targeted <u>only</u> to families likely to seek an out-of-home placement, the cost savings realized by states would not be substantial. In fact, in the short term at least, the costs of funding an extensive family support program may even <u>add</u> to the intellectually, and emotionally. Likewise, a comparison between children with disabilities living with families receiving support services and children living with non-participating families reveals that children living with participating families show significant increases in adaptive skills and decreases in maladaptive skills, whereas children living with non-participating families do not (Rosenau, 1983). The difficulty with this type evaluation, however, pertains to the need for time to pass before sizeable effects can be expected. Thus, snapshot studies or longitudinal studies of short duration are insufficient.

Regarding family placement decisions, available information suggests that among parents who seek out-of-home placements there is no one overriding factor that cuts across all families. Rather, there are numerous factors that vary from family to family, and change as the family member with a disability ages and as the family's composition, characteristics, resources, and perception of the problem are altered (Tausig, 1985).

Sherman and Cocozza (1984) present an extensive review of the literature on this matter and show that when families do decide to place their son or daughter with disabilities out-of-home, their decision is related to four factors:

1. Characteristics of the child with disabilities such as level of disability, IQ, and functioning level (Allen, 1972; Downey, 1965; Janicki, 1981; Shellhaas & Nihira, 1969);

2. Characteristics of the family such as family size, age of the parents, socioeconomic level, marital and family relations, and the presence of other family problems (Fotheringham, Skelton & Hoddinott, 1972; Hobbs, 1974; Culver, 1967; Shellhaas & Nihira, 1969);

3. Perception of the problem as related to the level of stress family members experience. Such stress can be chronic and stem from a variety of sources including financial burdens, difficulty with phsycial management of the child, lack of parenting skills, and strained family relationships (Wikler,

- Herman (1983) describes a meta-evaluation of family support services that served 252 families for two years in three counties of Michigan. [Note that the 13 families involved in the Rosenau (1983) study are included in this evaluation.] Services varied somewhat by county and four models of family support emerged from the meta-analysis: intensified services through case management, intense in-home intervention with out-of-home respite, cash subsidy, and case management with respite care and cash assistance. Study results indicate that, for the most part, families retained their disabled member at home throughout the course of the projects but that the placement decisions of these families did not differ markedly from those of parents not participating in the projects. Further analysis, however, reveals that significant numbers of participating families would have sought out-of-home placements if not for the projects' services, and that families with past histories of repeated use of out-of-home options used these options less. Thus, family support services appear to have had some positive effect on family placement decisions.

- Zimmerman (1984) presents findings of a telephone survey of a stratified random sample of 38 families receiving financial subsidies ranging between $76 and $250 per month in Minnesota. Half the families had received the subsidy for less than two years with only four families participating in the subsidy program since its inception (4-6 years). Results indicate that, in part due to the program, 36 of the families had no present plan for seeking an out-of-home placement. Moreover, the program had helped make it possible for one family to bring home one of its members with a disability.

Findings like those presented above suggest that family support services can forestall out-of-home placement decisions. It is equally clear, however, that the utility of support services with regard to placement decisions has not been definitively demonstrated. What is needed is additional longitudinal research that examines service effects over longer periods of time. Given some level of variation regarding the <u>duration</u> of family-based care, related variables can be identified. With such knowledge, efforts can be made to modify services so that their positive effects on placement decisions are maximized.

In sum, it is apparent that much of the qualitative evidence that has been collected documents the efficacy of family services.

Second, evaluation findings could be used to spur increased investment in family support programs. It must be understood that though nearly 25 states have extensive family support programs, the total budgets for these programs pale in comparison to what is spent on out-of-home residential services. Convincing state legislatures and other potential funding sources to invest in family support services will not be easy. But securing additional funds can be made easier if reliable information is available to document increasing administrative efficiency and positive program effects.

All in all, however, the biggest problem facing policy makers and program evaluators is the lack of clarity regarding the goals of family support services. Should services be justified solely on their ability to save tax dollars for the cost of out-of-home placement, or is the goal of improved quality of life for the family as a whole and the person with disabilities in particular a sufficient public good? The weight of all the discussion that has preceded this chapter suggests that the enhancement of the quality of life of the family -- though not directly related to cost savings -- does result in substantial benefits to the larger society including increased family self reliance, maxmization of family cohesiveness, and improvements in the productivity of individual family members including the person with disabilities. Though these gains are somewhat more ineffable, they should likewise be part of any systematic exploration of family support services.

FAMILY SUPPORT OPTIONS: A POLICY PERSPECTIVE

by

Robert Perlman, Ph.D.

Policy making requires making a choice of ends and means for the future. It rests on values and goals interwoven with analyses of forces that are shaping future possibilities and requirements. In this paper we consider policies that seem desirable, likely, and feasible with regard to family care of developmentally disabled people.* We take as our points of departure a value judgment and a fact. The fact is that family-based care of developmentally disabled people is a much larger part of the care system than institutional and community care combined. The judgment is that social policy ought to support the families who provide this care. Our purpose here is to examine current trends and developments that bear on this policy and to suggest a framework for family support in the next five or ten years.

Given our goal, the challenge is to achieve a reasonable balance among the programs that will:

1. Strengthen the ability of families of different types and capacities to care for a developmentally disabled person at home;
2. Maximize the quality of life for the disabled person;
3. Maximize the quality of life for the family as a whole;
4. Prevent inappropriate out-of-home placements; and
5. Develop a system of supports that is politically and economically feasible.

These objectives are not presented in any order of importance. They

---

* The assistance of Gunnar Dybwad, Professor Emeritus of the Heller School at Brandeis University, in preparing this paper is gratefully acknowledged.

prevent what hitherto have been severe handicaps (e.g., phenylketonuria) and can reduce the extent of disability and dependency.

On balance, the number of children requiring long-term care will "increase slightly in the next 10 years" according to one study (Callahan, Plough & Wisensale, 1981). Moroney (1979) foresees even more of an increase: "The prevalence of disabilities is increasing and will continue to grow at an accelerated rate over the next 25 years." We shall assume in this paper a moderate increase in the number of children who are disabled.

Factors For and Against Family-Based Care

At present the great majority of families care for their developmentally disabled children at home. In projecting what is likely to happen to this large but vulnerable family-care system in the next decade, we begin with those factors that tend to diminish the size and effectiveness of family based care. We group them under three categories: demographics, attitudes and ideological factors, and political and economic tendencies.

Demographics

One must always wonder whether today's population trends are likely to persist or are only temporary. Bearing that caution in mind, there are a number of changes now under way that seem likely in the near future to have the effect of shrinking the pool of available caretakers, most of whom have traditionally been women (U.S. Bureau of the Census, 1984).

1. The size of families is decreasing and the number and proportion of persons not living with any relatives is increasing. Non-family households rose from 19 percent of

6. The implications of the movement of people away from central cities is unclear. The greater accessibility of services in urban areas may be offset by greater family and neighborly involvement in the caring function in rural and suburban areas.

Attitudes and Ideology

1. As life-styles change there appears to be a greater interest in self-fulfillment and individual freedom among family members. This can militate against taking on the responsibilities of family based care.
2. On the other hand, there is a strong belief among many people that parents should be responsible for the care of their children, including those who are disabled. Some believe, moreover, that since parents for the most part are already providing care at home for disabled children, there is no need to spend public money, -- especially if there is a risk that public support might erode parents' sense of responsibility.
3. There is another current of belief on the part of some people that parents of children with developmental disabilities are somehow deficient or patholoical and, therefore, not worthy of public support.
4. As part of a general disenchantment or rejection of "the Welfare State" there is ideological and political resistance to the costs of supporting family based care and to the growth of services and bureaucracy that greater public support might entail.

of a "woodwork effect." That is, will so many additional families "come out of the woodwork" and claim assistance if it is more readily available, that the total cost in tax dollars will be increased?

2. Additional research may help to document the advantages of family care for the disabled person, their families, and society. For example, studies indicate that parents can be taught specialized caretaking skills that, otherwise would be performed by highly paid professionals.
3. The continued growth of community services that serve the aged and other groups can be a positive development.
4. A Princeton University study reports that the states have "embraced and preserved" most of the social programs that Congress turned over to them in recent years. The states have "replaced more of the Federal money than had been generally expected" following the cuts made by the Reagan administration (The New York Times, June 1984). Whether policy-making in this specific area at the state level will be supportive of families remains to be seen.
5. As a result of legislation, the public schools have become a significant resource for family support.
6. The concern about the American family and the view that its sense of responsibility is being undermined can be made to work for family support as a way of saving families from going under. The facts cited above that indicate a shrinking pool of caretakers can be used to justify offering compensatory assistance to enable families to continue carrying out their caring function.

is a set of longitudinal studies that track these elements over time in relation to each other.

With regard to item (f), the characteristics of families who are providing care at home, a crude description can be gleaned from the Survey of Income and Education conducted by the U.S. Bureau of the Census in 1976. Several questions about disability and the need for personal care were included in the survey of 181,000 families. We have identified 1,270 families in the SIE data who are caring for a mentally retarded person at home.

This information is subject to several qualifications. The respondent was asked in each family whether there was someone living at home who was mentally retarded. The designation was thus made by a family member and could well be under-reported, though it should be noted that half the respondents said the condition of retardation was diagnosed by a professional. The survey estimated that there were 866,000 persons categorized as retarded in the United States living outside of state institutions. This is lower than most other studies suggest. Second, the data refer only to mentally retarded people and not to the total developmentally disabled population, though the former constitute a high proportion of the latter. Bearing these caveats in mind, a national sample of 1270 families with a disabled member living at home is still useful in an area where so little is known.

1270 Families Engaged in Family Care

The Survey of Income and Education (SIE) asked two questions that permit an estimate of the degree to which mentally retarded persons living at home depend on others for assistance. The respondents were asked (1) does this person "need help from others in to work, thereby reducing the time and energy available for the caring role. We turn first, therefore, to compare family income for the United States with the SIE sample, as shown in Table 1.

Table 1: Income of Families Giving Care and All U.S.Families, 1975-1976 (in percent)

	U.S.	SIE Sample
Income Under $10,000	33.2	45.1
$10,000 - 14,999	22.8	22.4
$15,000 - 24,999	30.4	22.2
$25,000 or more	14.1	10.3
	100.0	100.0

Sources: Author's tabulation of unpublished data, U.S. Department of Commerce. Bureau of the Census, Survey of Income and Education, 1976, and Statistical Abstract of the United States, 1981, Table 725, Family Income for 1975.

It is clear that families caring for a retarded person at home had, on the whole, lower incomes than the general population. The data show that 45 percent of the SIE families had incomes under $10,000 in contrast to 33 percent of all families. Conversely, 45 percent of all families had incomes over $15,000, while only 33 percent of the SIE families exceeded that income level.

This comparison is even more stark when one considers that in 1975 only 9.1 percent of all U.S. families were living below the official poverty level, while 17.3 percent of the care-giving families were poor by this definition.

In 1976 one-fourth (24.2 percent) of all U.S. families were headed by women. The same proportion (24.2 percent) of the SIE sample were female-headed families. As we pointed out earlier, this

The SIE data are limited in several respects and certainly there is a need for follow-up studies to determine trends since 1976. But these two findings -- concerning income and female-headed households -- strengthen the case that care-giving families face greater obstacles and burdens in maintaining a mentally retarded member at home than "the average American family" would if it were in the same situation. For the many, many families who want to provide care, despite their disadvantages, the argument for support from the rest of society seems strong and in keeping with concerns for the viability of American families.

As we look ahead into the near-term future, our projections of public support for these families need not be based entirely on speculation. Using the old saw that the best predictor of future behavior is past behavior, we can get some idea of the directions that are likely and possible by looking at what is now being done at the state level.

The very fact that at least 22 states have taken some action in the past decade to develop programs of family support (and several others are considering new programs) demonstrates the political feasibility of moving toward the goal enunciated at the outset. The information on these programs (See Part II; Chapter 3), provides a preliminary picture of state activity in this field. These data are subject to several qualifications. It is not clear how much of what was reported by respondents was "what is on the books" as distinct from what is in operation. Nearly all states in their survey reported some program in existence, though less than 25 can be said to be extensive. In any case, the available information indicates what the states aspire to achieve.

Age. Sixteen states set no age requirement. Three refer to children, two to persons under 18, and three to persons under 22.

Living arrangements: Most states gear their programs to people living with their families. Three states consider eligible those presently living in a state facility but who will return home. Six programs give priority to persons "at risk of out-of-home placement."

Income: Fourteen states do not specify income limits; eight are geared to lower-income families or those who cannot bear the costs of care.

Overall, disabilities are not tightly defined as a basis for being eligible for these state programs; only four of them are limited to the most severely disabled. Only five of the programs specifically say that they are addressed to children (under 18 years of age). Only eight target families with insufficient resources. Three programs are aimed at disabled people living away from home.

Some notion of the relative emphasis given by the states to different types of services can be obtained from a review of permissible services. Table 2 displays those services available in the 22 states.

It should be noted that one important need is not addressed in these state programs and it concerns provisions for care of the disabled child after the death or incapacity of the parents or other relatives. This is a major source of concern to parents. In an earlier chapter, data from a national survey are presented that describe 11 programs that provide future planning services (See Part III; Chapter 2). They are quite new programs and their efficacy is not yet clear, but the argument is made that they should be

Possible Directions for Family Care Policy

The following discussion of future policy is divided into four parts. First, we return to the objectives set at the outset and raise the thorny question of priorities among them, using models of family support that emphasize one or another objective. Second, we take up some issues of equity affecting sub-populations among families providing care. Third, we look at mechanisms for delivering programs, and, fourth, we touch on the matter of finances. The paper concludes with a suggested framework for a future program of family support.

Using Theoretical/Programmatic Models

At the beginning of this paper we said that the objectives of family based care should be: to strenthen the capacity of care-giving families, to maximize the quality of life for the developmentally disabled person and/or the family; and to prevent inappropriate out-of-home placements -- all within a system that is economically and politically feasible.

But whose needs rank first. . .second. . .third? Those of the disabled individual. . .the family. . .society? Should priority be given to services that parents want most or to those that appear to have the greatest impact on costs to the public? Or should we give highest place to services that make the greatest difference in the life of the disabled person?

Only by trying (with no guarantee of success) to sort out these questions can we establish criteria for determining which services are crucial and which are peripheral. It may help in this search if we have before us a number of models or points of emphasis, which we can examine in the light of the demographic and political recreation came out near the bottom of the list of services provided by the new state programs. Yet, as Gunnar Dybwad persuasively argues, recreational services -- especially those involving a disabled child in physical and, therefore, social contact with other children -- contribute not only to quality of life, but to the disabled child's development and ultimately to the outcome of family based care.

<u>The Medical Model</u>. Much criticism has been hurled at those who view developmental disabilities as diseases to be cured and who build service programs on that basis. The critics charge that this perspective is myopic and self-defeating. However, there seems to be little doubt that medical and other health-related services are crucial to families engaged in home care. These services become a terrible drain on finances when families must pay for them out-of-pocket. Hence, some provision for health services as one element in a "floor of support" for care-giving families must be made.

<u>The "Daily Grind" Model</u>. Much of the literature hammers home the point that, perhaps even more than financial aid, parents want help with the practical, daily demands of living when they are carrying the responsibilities of home care. Assistance with meals, shopping, bathing, house cleaning, transportation and the like is critical for many families, especially those whose children are severely disabled. To what extent this goal can be met through community services, such as those addressed primarily to the frail elderly, remains to be seen. The degree to which practical help of this kind can be obtained through volunteers, other relatives, or by exchange with other care-giving families should be tested by agencies

a country as richly endowed as this, to pit two such programs against each other. In relative terms, however, it can be argued that family support has been under-funded and will in the future require considerably more resources than it has hitherto been accorded.

The Service Model vs. The Cash Model. Boggs (1979) cautions against putting too much emphasis on cashing out benefits "unless dollars can be translated into something else perceived as critical." She cites studies to the effect that the cost of home care is not the main problem for families; the biggest problem is "the amount of care and supervision" they are required to give. Some of their sense of strain has to do with the single issue of time, time to do what is necessary for the family as a whole and for the disabled child. In part, this can be alleviated by having someone on hand to share the responsibilities on a daily or weekly basis, as is true with difficult tasks such as lifting and bathing some children.

To a considerble extent cash and services are interchangeable. In the example mentioned above, a homemaker could be sent in or the family could use some of a cash subsidy to hire someone to take part of the burden. But not all services can be easily purchased and some would be financially beyond the reach of most families, hence the preference of many for a mix of services and cash.

Obviously, none of these models is valid as a sole guide for policy, but each contributes considerations and cautions that must be taken into account. Disabled individuals, their families, and the community at large all have legitimate claims on the resources that must go into supporting families. Policy-makers will have the difficult job of balancing these claims and making trade-offs that are both humane and reasonable. For example, there is no answer to care-giving families who cannot participate in such financial planning programs.

Some care-giving families are qualified for assistance under Medicaid and SSI. On the other hand, families slightly above the income limits set for these programs often are not eligible for services without paying, thereby creating a serious inequity. The same is probably the case in some of the state programs.

Future programs should redress this inequity by making some benefits accessible without cost to all families involved in family based care. At the upper end of the income scale, it seems justifiable to expect more affluent families to bear a larger share of the cost of public services for family based care. In all instances we would opt for counting cash subsidies and other services as benefits and not as taxable income. Above all, the incredible anomaly in establishing eligibility for public support, that is, counting the income of parents when the child is at home but not when the child is institutionalized, should be corrected since the present situation creates great inequities.

Extent of Dependency and Disability. What is the proper allocation of resources among different levels of disability? Moroney (1979) has pointed to the competition for resources between the families of severely retarded and moderately retarded children. Clearly, the former need more assistance and resources than the latter. But there is a minimum amount of support that should go to all families not only as a sign of society's recognition of their situation, but as a preventive measure to minimize strains in even those families with the least disabled children. Our analysis of the SIE data suggested that the families of "Independent" persons were, of the advantages and disadvantages of each, is the distribution of differential benefits according to categories that reflect the degree of dependency of the disabled person, the family's income, and perhaps other criteria. Such a system does recognize differences among families, but guarantees some assistance to all families providing care, at the same time that it restrains the size of the service establishment and presumably the cost.

Another program device that requires consideration for the future is the mechanism for dividing responsibility between the family and the community. One arrangement is for the community to furnish a certain amount of services and/or cash to all families, with the families expected to supply whatever is needed beyond that amount. The inequities that would ensue, however, in terms of levels of need, are too obvious to require comment.

The reverse strategy is also possible. Each family could be required to provide some basic amount of care, perhaps measured in time units, with community agencies supplementing in cash or services what is needed beyond the family's input. This device acknowledges that ideological position that expects families to shoulder their responsibilities for their children. It could, however, create a situation in which more affluent families could buy themselves out of the responsibility by employing outside help, while lower income families would have to invest their energies and time in direct care-giving activities.

Under most arrangements for shared responsibility, questions of accountability, control, and decision-making arise. Should a service plan be negotiated case-by-case, thus setting the framework for payments or service delivery? Or, within some limits, should the

It is beyond the scope of this paper to go into these complexities in any detail, but a few general comments are in order. The efforts of about 22 states to date to mount extensive programs of family support are encouraging signs of forward movement. But the very limited and tentative nature of those programs -- both in terms of assistance and coverage of families -- argues for an underpinning of nation-wide financial support from the federal government.

As we pointed out earlier, there is a concern about the "woodwork effect" of broadening programs of family support. But this calls for a closer look, since there are two kinds of outcomes under this rubric. If utilization of services and cash subsidies skyrocket, thereby vastly increasing public expenditures (wherever they come from), it may indeed mean that there is some over-use and inappropriate use of the program by those people who do not conform to the eliibility criteria. This is a legitimate concern and one that will require prudent and reasonable measures to restrain improper exploitation of public funds.

However, there is another kind of "woodwork effect" that ought to be welcome, despite the fact that it will increase costs. Many families now struggle to maintain a developmentally disabled person at home with little or no outside help. Some are able to sustain this for longer or shorter periods of time; some understandably collapse under the weight and the human consequences for all concerned are serious and, in financial terms, costly. If families such as these come forward to make claims on an expanded program of family support, we must reconize both the legitimacy and the desirability of expenditures on their behalf. In this connection, it should be recalled that Sager (1983), cited above, found no evidence

Table 3: Demographic and Political Considerations and their Political Implications

1. Low income status of many families caring for disabled members	Benefits must be accessible to all income levels and must be seen to be fair
2. Differences in degree of disability	Programs must provide assistance in relation to disability but must also serve the least disabled, and be flexible as conditions change.
3. Shrinking pool of care-givers (more female-headed families,etc.)	Assistance should be scaled to size and composition of families
4. Disabled children outliving parents.	Build in care and security for disabled children when parents are unable to provide it.
5. Rising costs of medical and other health services	Assurance that these extraordinary expenses for care will be covered.
6. Concern that parental responsibilities not be eroded.	Programs should supplement not replace family effort, but also recognize parents' rights in decision-making.
7. Growth in state financing and community-based programs for the elderly and others.	Tap into these for family support, and utilize states for administration
8. Increasing questions about the Welfare State.	Programs should restrain growth of unnecessary bureaucracy and balance self-help against over-professionalism.
9. Resistance to rising costs of social programs.	Build accountability and reasonable controls into family support programs

scheme be financed by federal funds, but that only the survivor's insurance be federally administered. The supplementary budget program and case consultation would be state-financed and the latter administered locally. Thus, except for survivors' insurance and case consultation, the program would be state-administered. This proposal assumes the continued phasing out of state institutions and the shifting of funds to family support and community-based care.

This proposal is advanced here not as a blue-print for a new program, but as a means of articulating the policy considerations that have been developed in this paper and, hopefully, as a stimulus to discussion, disagreement, and better planning to support the families about whom we are concerned.

PART IV: RECOMMENDATIONS

Chapter 1: Family Base Care and Social Policy: Recommendations for Change

FAMILY BASED CARE AND SOCIAL POLICY: RECOMMENDATIONS FOR CHANGE

The primary goals of this project were to explore factors that constrain family involvement in the care of a family member with a developmental disability and to identify new and improved means for overcoming such barriers. Findings stemming from various project activities strongly suggest that numerous aspects of present social policy* must be altered to encourage family-based care.

In this light, recommendations and proposals emerging from this project reflect a variety of ideas and concerns for improving present policy, examining unresolved conceptual issues, and securing needed information. The following recommendations are not in any particular order of priority:

1. **Family support programs should be designed to empower families and persons with developmental disabilities.**

An underlying theme of family support pertains to the role that consumers can play in the provision of care. A primary finding of this project is that family support programs should be designed in ways that:

- recognize the family's underlying commitment to care for their family member with a disability;
- embrace practices that promote, not discourage, increased family independence from the formal service system;

---

* As used here, a social policy option is defined as:

Something that could be done as a matter of national policy by way of position statement, set of principles, law, regulations, pattern of apropriation, or similar action on the part of any branch of government or a national public or private group so as to bring about more, more effective, better quality, easier, or more rewarding (to all parties) life as a family member by developmentally disabled persons. (Krantz, 1979; p. 104-105).

disabilities, and professionals that empower service consumers to the maximum feasible extent.

Of course, there are limits to the emotional, physical and financial resources of parents and their expertise. When first confronted with the advent of disability, many family members will have little understanding of what overall needs they will have. Moreover, even as time passes, some families will be unable or unwilling to accept an empowered role. Similarly, many persons with developmental disabilities will be unable to make responsible decisions in their own behalf. The eventual goal of the system, however, must be to equip service consumers, whether they are family members or persons with developmental disabilities, to provide and/or obtain competent care, not to ensnare them in bureaucratic mazes and to make them dependent on professional judgements.

2. Family support programs should provide families with multiple service options.

No two persons with developmental disabilities or two families are alike. Considerable variation exists regarding disability types and severity, family characteristics and resources, and family perceptions of the caregiving situation. Moreover, these factors are not static but evolve over time. These considerations suggest that responsive family support programs must permit a wide array of services and encourage each family to select those services that are most appropriate for its needs.

3. Family support programs should make greater use of cash programs.

Many states presently operate cash programs that provide families with money to offset the costs of providing care. To some extent, however, shown some interest in allocating resources to complement services offered through the public sector. This interest could be promoted by: 1) establishing systematic procedures for businesses to contribute money to existing family support programs; 2) encouraging initiation of additional employer sponsored cash or fringe benefit programs for employees who have family members with disabilities; and 3) encouraging businesses to offer certain family support services of their own to complement existing public programs.

This latter suggestion is especially relevant to the health care industry. Government should act to encourage private health insurers to underwrite coverage for home health care. This could involve mandating that such coverage be made available as part of individual and/or group risk plans and establishing tax policy that provides incentives to insurers for providing such plans. It must be understood that the provision of suitable and affordable health care for persons with disabilities is an essential element of any family support system. To achieve this end, government and private insurers must work together as partners so that needed medical care will be within reach of all families.

6. Using tax policy to support families should be pursued with caution.

Though numerous incentives to encourage family based care could be provided through tax policy, these incentives must be viewed in light of their efficiency, effectiveness, and fairness. Using tax credits, tax exemptions or specialized tax relief to support individual families is questionable due to problems associated with: coordinating multiple levels of government, enforcing regulations, estimating costs in lost government revenue, establishing programs special needs a person with disabilities may have, and other professionals whose services families may require. In addition, such networks could be used to manage information on special equipment or toys parents may wish to share or exchange with one another.

On a state or national level existing information systems, such as Project SHARE, could be utilized to foster more effective means of providing families with information pertaining to state-of-the-art instructional practices, useful state and federal tax relief programs, and novel private sector initiatives. This type information would help keep parents aware of what is available on a broader systems level as well as promote greater cooperation among caregiving families around the country.

Likewise, service planners and administrators could make greater use of computer based information systems. Computer technology can be used to guide development of resource allocation plans pertaining to family support, to track expenditures for such services, and to monitor the processes and outcomes of service provision.

8. Development of parent-run mutual help organizations should be encouraged.

Encouraging the development of parent-led mutual help groups will complement efforts to structure family support programs within a family empowerment model. Examples of such groups include those offering ongoing social support and advocacy training, and others involving joint estate planning. In addition, the need for providing support and information to other members of the immediate (e.g., siblings) and extended (e.g., grandparents) family should not be overlooked.

family support programs, eligibility criteria, means of administration, and sources of funds. One outcome of such structured discussion could be the preparation of model legislation that could be used by states to guide development or improvement of family support programs.

11. <u>A national study should be undertaken to identify the social and economic characteristics of families with members with developmental disabilities and to estimate their numbers.</u>

Such information would benefit service planners by providing an improved understanding of the composition of caregiving families and knowledge regarding the overall number of families that could benefit from support services. This type of information could be acquired by surveying a systematic <u>sample</u> of families with members with developmental disabilities and could be achieved by adding a series of relevant questions to already planned federal surveys such as the Annual Housing Survey administered by the US Department of Housing and Urban Development. This type information, however, should not be collected in a sporadic or disjointed manner. Rather, there is a need for longitudinal studies that track these types of information over time and in relation to one another.

12. <u>A study should be made of sociological and demographic trends related to the family's caregiving capability</u>.

These trends include the number and type of surviving infants with disabilities, the size of families, and the number of women entering the work force. These trends should then be taken into account when outlining family support policy.

13. <u>Ongoing evaluations of family support programs should be made a high priority</u>.

assessment and evaluation, oversight, resource organization, and fund raising. In essence, research efforts must be directed at documenting the most efficient, effective, and equitable means for delivering family support services.

Conclusion

Findings emerging from this project reflect a growing concern with discovering ways to assist families who have a member with a developmental disability. This concern is expressed in efforts to understand more fully the varying and complex needs of families, and to implement comprehensive strategies for satisfying such needs. The above recommendations suggest that building an effective family support system will require the cooperation of many, including parents, immediate and extended family members, neighbors, government officials at all levels, and professionals working both in the public and private sector.

At the core of any effective family support system must be a firm societal resolve to actively encourage, rather than discourage, family care. This report presents evidence that such a commitment is emerging and that past biases in social policy and professional philosophy favoring out-of-home placement are coming under increasing scrutiny. Still in question are the respective roles families, persons with disabilities, and government should play in directing the course of family support services. History reveals that these roles seldom remain static but evolve continually with the social values of the times.

In addition, much must still be done to clarify the objectives of present family support initiatives, estimate the number of families

COMPOSITE BIBLIOGRAPHY

Abels, M. *Wisconsin voucher system initiative for long term support -- The consumer directed services project*. Materials Presented at a Research Update for the Office of Human Development Services of the Department of Health and Human Services, February 9, 1984.

Akabas, S.H. Workers are parents, too. *Child Welfare*, 1984, *63* (5), 387-399.

Akabas, S.H. & Krauskoff, M.S. *Families and work: Creative workplace responses to employees with disabled children*. New York, NY: Industrial Social Welfare Center, Columbia University, 1984.

Akabas, S.H. & Kurzman, P.A. *Work, workers and work organizations*. Englewood Cliffs, NJ: Prentice-Hall, Inc., 1982.

Allen, J. The concept of vertical equity and its application to social program design. In P. Brown, C. Johnson, & P. Vernier (Eds.), *Income support: Conceptual and policy issues*. University of Maryland, Rowman and Littlefield, 1981.

Allen, M.K. Persistent factors leading to application for admission to a residential institution. *Mental Retardation*, 1972, *10*, 25-29.

Allin, R. & Allin, D. *The home intervention program*. Chesterfield, VA: Chesterfield Mental Health and Mental Retardation Services, undated.

ALMA Matters. Special toy libraries for children with disabilities. *Official Newsletter of the Alternative Living Managers Association* (1642 North Winchester Avenue, Suite 100, Chicago, IL), 1985, *1*(4), 1-2.

American Bar Association. *Guardianship and conservatorship: Statutory survey, model statue*. Paper presented by the Developmental Disabilities State Legislative Project of the American Bar Association Commission on the Mentally Disabled, June, 1979.

American Health Planning Association. *The complex cube of long term care: A national working conference*. Washington, DC: AHRA, 1984.

Annas, G. Denying the rights of the retarded: The Phillip Becker Case. *Hastings Center Report*, 1979, *9* (Dec.), 18-20.

Bayley, M. *Mental handicap and community care*. London, United Kingdom: Routledge and Kegan Paul, 1973.

Beatrice, D. F. *Case management: A policy option for long term care*. Washington, DC: Health Care Financing Administration, 1980.

Beck, D. & Bradshaw, E. *Marriage and the family under challenge: An outline of issues, trends, and alternatives*. New York: Family Service Association of America, 1976.

Beckman-Bell, P. Parent perspectives. In J. Paul (Ed.), *Understanding and working with parents of children with special needs*. New York: Holt Rinehart, and Winston, 1981.

Berger, P. & Neuhaus, R. *To empower people: The role of mediating structures in public policy*. Washington, DC: American Enterprise Institute for Public Policy Research, 1977.

Birenbaum, A. On managing courtesy stigma. *Journal of Health and Social Behavior*, 1970, *11*, 196-206.

Bird, C. *Two-paycheck marriage: How women at work are changing life in America*. New York: Rawson/Wade, 1979.

Bird, W.A. *A survey of family support programs in seventeen states*. Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities, 1984.

Blatt, B. *In and out of mental retardation*. Baltimore, MD: University Park Press, 1981.

Boggs, E.M. Feds and families: Some observations on the impact of federal economic policies on families with children who have disabilities. In M.A. Slater & P. Mitchell (Eds.), *Family support services: A parent/professional partnership*. Stillwater, OK: National Clearinghouse of Rehabilitation Training Materials, 1984.

Boggs, E.M. Behavioral fisics. in J.J. Bevilacqua (Ed.) *Changing government policies for the mentally disabled*. Cambridge, MA: Ballinger Publishing Co., 1981.

Boggs, E.M. Economic factors in family care. In R.H. Bruininks & G.C. Krantz (Eds.), *Family care of developmentally disabled members: Conferences proceedings*. Minneapolis, MN: University of Minnesota, 1979.

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

Bryce, M. Home-based care: Development and rationale. In S. Maybanks & M. Bryce (Eds.), *Home-based services for children and families*. Springfield, IL: Charles C. Thomas, 1979.

Bureau of Labor Statistics. *Autumn 1978 urban family budgets and comparative indexes for selected urban areas*. Washington, DC: U.S. Department of Labor, 1979.

Buscaglia, L. *The disabled and their parents. A counseling challenge*. Thorofare, NJ: Charles B. Slack, Inc. 1975.

Business Week. *The insurer's big push for home health care*. May 28, 1984, p. 128-130.

Caldwell, B. & Guze, S. A study of the adjustment of parents and siblings of institutionalized and noninstitutionalized retarded children. *American Journal of Mental Deficiency*, 1960, *64*, 845-861.

Callahan, J., Diamond, L. Giele, J. & Morris, R. Responsibilities of families for their severely disabled elders. *Health Care Financing Review*, 1980, *1*, 29-48.

Callahan, J.J., Plough, A.L. & Wisensale, S. *Long-term care of children*, University Health Policy Consortium. Waltham, MA: Brandeis University, 1981.

Carillo, A.C., Corbett, K. & Lewis V. *No more stares*. Berkeley, CA: Disability Rights Education and Defense Fund, Inc. 1983.

Carr, C. *Independent living and advocacy base of service provider*. Rehabilitation Gazette, 1983, *25*, 42-43.

Caro, F.G. *Care for the disabled: Family and public responsibilities*. New York, NY: Institute for Social Welfare Research, Community Service Society, 1980.

Carver, J. *Reactions of parents of severely retarded children at a state training school*. Unpublished doctoral dissertation, Yale University, 1956.

Castellani, P.J. and Puccio, P.S. *The Development of Family Support Services for the Developmentally Disabled: An Administrative and Political Perspective*. Paper Presented at the American Society for Public Administration National Conference, Denver, CO, 1984.

Center for Life Independent Living, Inc. & Closer Look (Ed.) *Taking charge of your life*, Washington, DC: Closer Look, 1981.

Culver, M. Intergenerational social mobility among families with a severely mentally retarded child. Unpublished doctoral dissertation, University of Illinois, 1967 (available from University of Illinois library).

Daniels, M. Conflicting objectives and the priorities problem. In P. Brown, C. Johnson, & P. Vernier (Eds.), Income support conceptual and policy issues. University of Maryland: Rowman and Littlefield, 1981.

Davidson, B. & Dosser, D. A support system for families with developmentally disabled infants. Family Relations, 1982, 31, 295-299.

Davis, C.G. Financial and estate planning for parents of a child with handicaps. Western New England Law Review, 1983 5(3), 495-535.

de Bevoir, S. The coming age. New York, NY: G.P. Putnams & Sons, 1972.

Demos, J. Family home care: Historical notes and reflections. In R. Perlman (Ed.), Family home care: Critical issues for services and policies. New York: The Haworth Press, 1983.

Developments in the law--the Constitution and the family. Harvard Law Review, 1980, 93(6), 1-229.

Division of Educational Services. Sixth annual report to Congress on the implementation of Public Law 94-142. Washington, DC: U.S Department of Education, Office of Special Education and Rehabilitation Services, 1984.

Doll, W. Family coping with the mentally ill: An unanticipated problem of deinstitutionalization. Hospital and Community Psychiatry, 1976, 27, 183-185.

Downey, K.J. Parent's reasons for institutionalizing severely mentally retarded children. Journal of Health and Human Behavior, 1965, 6, 163-169.

Dunlap, W.R. Services for families of the developmentally disabled. Social Work, 1976, 21, 220-223.

Dunlap, W.R. & Hollingsworth, J.S. How does a handicapped child affect the family? Implications for pratitioners. The Family Coordinator, 1977, 26, 286-293.

Duvall, E. Marriage and family development. New York: Harper and Row, 1977.

Dworkin, S. Notes on Carter's family policy: How it got that way, what happened to his White House conference, and some warnings for the future. MS, 1978, 7(61), 61-63.

Fotheringham, J. & Creal, D. Handicapped children and handicapped families. International Review of Education, 1974, 20, 355-373.

Freedman, D., Fox-Kolenda, B. & Brown, S. A multihandicapped rubella baby: The first eighteen months. Journal of the American Academy of Child Psychiatry, 1970, 9, 298-317.

Friedman, W. Winning the real war. Rehabilitation Gazette, 1980, 23, 13-14.

Friedrich, W. Predictors of the coping behaviors of mothers of handicapped children. Journal of Consulting and Clinical Psychology, 1979, 47, 1140-1141.

Gaiter, D. Siblings who help disabled. The New York Times, July 2, 1984, p. 18.

Gardner, J.F. & Markowitz, R.K. Maryland family support services consortium: Data analysis summary, year one report. Baltimore, MD: Maryland Developmental Disabilities Council, 1984.

General Accounting Office. Assessment of the use of tax credits for families who provide health care to disabled elderly relatives. Washington, D.C.: GAO, Document Handling and Information Services Facility: IPE-82-7, 1982.

Gettings R.M. Federal financing of services to mentally retarded persons: Current issues and policy options. Paper prepared for U.S. Office of Human Development Services, 1980.

Giele, J.Z. A review of selected data sources on the family's role in long-term care. Waltham, MA: Brandeis University, Levinsion Policy Institute, 1981.

Gilbert, N. Special issue of family policy. Social Work, 1979, 24,(6), 445-572.

Gliedman, J. & Roth, W. The unexpected minority: Handicapped children in America (Summary). New York, NY: Harcourt, Brace and Javanovich, 1980.

Goldman, H.H. Mental illness and family burden: A public health perspective. Hospital and Community Psychiatry, 1982, 33, 557-560.

Gollay, E., Freedman, R. Wyngaarden, M. & Kurtz, N.R. Coming Back. Cambridge, MA: Abt Books, 1978.

Goode, W.J. The family. Englewood Cliffs, NJ: Prentice-Hall, 1964.

Heifetz, L. Professional preciousness and the evaluation of parent training strategies. In P. Mittler (Ed.), Research to practice in mental retardation, 1. Baltimore: University Press, 1977.

Heisler, V. A handicapped child in the family. New York: Grune & Stratton, 1972.

Herman, S.E. Family support services: Reports on meta-evaluation study. Lansing, MI: Michigan Department of Mental Health, 1983.

Herr, S.S. The Phillip Becker case resolved: A chance for habilitation. Mental Retardation, 1984, 22, 30-35.

Hill B., & Lakin, K.C. Trends in residential services for mentally retarded people: 1977-1982 (Brief # 23). Minneapolis: Center for Residential and Community Services, University of Minnesota, Department of Educational Psychology, 1984.

Hill R. Families under stress. New York: Harper & Row, 1949.

Hobbs, N. The future of children. San Francisco, CA: Jossey-Bass, 1974.

Horejsi, C.R. Social and psychological factors in family care. In R.H. Bruininks & G.C. Krantz (Eds.), Family care of developmentally disabled members: Conference proceedings. Minneapolis, MN: University of Minnesota, 1979.

Horejsi, C.R. Social and psychological factors in family care. In Perlman, R. (Ed.), Family home care: Criteria issues for services and policies. New York, NY: The Haworth Press, 1983.

Human Services Research Institute. Assessing and enhancing the quality of human services. Boston, MA: Human Services Research Institute, 1984.

Intagliata, J. Improving the quality of community care for the chronically mentally disabled: The role of case management. Schizophrenia Bulletin, 1982 8(4), 655-674.

Intagliata, J., Kraus, S., & Willer, B. The Impact of Deinstitutionalization on a Community-Based Service System. Mental Retardation, 305-307, 1980.

Ivie, P. A right, not a favor- a legal right handbook for the developmentally disabled. Tuscaloosa, AL: Alabama Department of Disabilities Advocacy Programs, 1978.

Kinney, J., Madsen, B., Fleming, T. & Hacipoila, D. Homebuilders: Keeping families together. Journal of Consulting and Clinical Psychology, 1977, 45, 667-673.

Klerman, L.V. Adolescent mothers and their children: Another population that requires family care. In R. Perlman (Ed.), Family home care: Critical issues for services and policies. New York, NY: The Harworth Press, 1983.

Konanc, J.T. & Warren, N.J. Graduation: Transitional crisis for mildly developmentally disabled adolescents and their families. Family Relations, 1984, 33(1), 135-142.

Kozak, A.E. & Marvin, R.S. Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. Family Relations, 1984, 33(1), 67-78.

Lakin, K.C., Hill, B., Hauber, F., Bruininks, R. & Heal, L. New admissions and readmissions to a national sample of public residential facilities. American Journal on Mental Deficiency, 1983, 88, 13-20.

Lakin, C.K., Bruininks, R.H., Doth, D., Hill, B. & Hauber, F. Sourcebook on long term care for developmentally disabled people. Minneapolis, MN: University of Minnesota, Department of Psychology, 1982.

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

Laswell, H.D. Politics: Who gets what, when, how. New York, NY: McGraw-Hill, 1936.

Lea, S., Reed, R.R. & Hansen, R.F. Developmentally disabled persons of normal intelligence: Need assessment findings. San Mateo, CA: UCPA of California, 1978.

Legislative Commission on Expenditure Review (New York State) LCER. Mental Health Community Support System, Albany, NY: Program Audit, October, 1983.

Leslie, G.R. The family in social context (4th Ed.) New York: Oxford University Press, 1976.

Lipman-Bluman, J. A crisis framework applied to macrosociological family changes. Journal of Marriage and the Family, 1975, 27, 889-902.

Lonsdale, G. Family life with a handicapped child: The parents speak. Child Care, Health and Development, 1978, 4, (2), 99-120.

McGrath, M. Give us the knife -- carving a lifestyle. Nashville, TN: Ashlar Press, 1978.

McKinnon, V.R., Samors, P.W. & Sullivan, S. Business initiatives in the private sector. In J.A. Meyers (Ed.), Meeting human needs: Toward a new public philosophy. Washington, DC: American Enterprise Institute for Public Policy Research, 1982.

Meiners, M.R. Private coverage of services not covered by medicare: The case for long term care insurance. Paper presented at the 110th annual meeting of the American Public Health Association, 1982.

Meyers, J.A. Meeting human needs: Toward a new public philosophy. Washington, DC: American Enterprise Institute for Public Policy Research, 1982.

Michigan House Legislature Analysis Section. Second analysis of House Bill 4488: Mental health, family support subsidy. Michigan State Legislature, 1983.

Minde, K., Hackett, J., Killou, D. & Sliver, S. How they grow up: 41 handicapped and their families. American Journal of Psychiatry, 1972, 128, 1554-1560.

Mink, I.T., Meyers, C.E. & Nihara, K. Taxonomy of familiy styles: II. Homes with slow children. American Journal of Mental Deficiency, 1984, 89, 111-123.

Minnesota Developmental Disabilities Council. Policy analysis no. 18: The Minnesota family subsidy programs: Its effects on families with a developmentally disabled child. St. Paul, MN: Minnesota Developmental Disabilities Planning Council, 1983a.

Minnesota Developmental Disabilities Council. Developmental disabilities and public policy: A review for policymakers. St. Paul, MN: Minnesota Developmental Disabilities Planning Council, 1983b.

Minnesota Developmental Disabilities Council. Toward a developmental disabilities policy agenda: Assuring futures of quality. St. Paul, MN: Minnesota Developmental Disabilities Planning Council, 1984.

Moore, J.A., Hamerlynck, L.A., Barsh, E.T., Spieker, S. & Jones, R. Extending family resources (2nd Ed.). Seattle, WA: Children Clinic and Preschool, 1982.

Moroney, R.M. Allocation of resources for family care. In R.H. Bruininks & G.C. Krantz (Eds.), Family care of developmentally disabled members: Conference proceedings. Minneapolis, MN: University of Minnesota, 1979.

Nihira, K., Meyers, C.E., & Mink, I.T. Relationship between home environment and school adjustment of TMR children. American Journal of Mental Deficiency, 1981, 86, 8-15.

Nihira, K., Meyers, C.E. & Mink, I.T. Reciprocal relationship between home environment and development of TMR adolescents. American Journal of Mental Deficiency, 1983, 88, 139-149.

Nijre, B. (1969). The principle of normalization and its human management implications. In R. Kugel & W. Wolfensberger (Eds.), Changing patterns in residential services, for the mentally retarded. Washington, DC: Government Printing Office, 255-287, 1981.

Noble, J.H. New directions for public policies affecting the mentally disabled. In J.J. Bevilacqua (Ed.), Changing government policies for the mentally disabled. Cambridge, MA: Ballinger Publishing Company, 1981.

Office of Information and Resources for the Handicapped. Directory of national information sources on handicapping conditions and related services. Washington, DC: Superintendent of Documents, U.S. Government Printing Office (Publication No. E-82-22007), 1982.

O'Leary, K., O'Leary, S. & Becker, W. Modification of a deviant sibling interaction pattern in the home. Behavior Research and Therapy, 1967, 5, 113-120.

Ozawa, M. Income maintenance and work incentives. New York: Praeger Publishers, 1982.

Patterson, J. & McCubbin, H. Chronic illness: Family stress and coping. In C. Figley & H. McCubbin (Eds.), Stress and the family: Volume II. Coping with catastrophy. New York: Brunner/Mazel, Inc., 1983.

Paul, J. & Porter P. Parents of handicapped children. In J. Paul (Ed.), Understanding and working with parents of children with special needs. New York: Holt, Rinehart, and Winston, 1981.

Penner, R.G. Macroeconomic and tax policy environment for private sector initiatives. In J.A. Meyer (Ed.), Meeting human needs: Toward a new public philosophy. Washington, DC: American Enterprise Institute for Public Policy Research, 1982.

Perlman, R. (Ed.) Family home care: Critical issues for services and policies. New York, NY: The Haworth Press, 1983.

Senate Standing Commitee on Health and Welfare. *Report on mentally and physically handicapped persons in Australia*. Commonwealth Government Printing Office, Canberra, 1971.

Shapiro, J. Family reactions and coping strategies in response to the physically ill or handicapped child: A review. *Social Science Medicine*, 1983, *17*(14), 913-931.

Shellhaas, M.D. & Nihira, K. Factor analysis of reasons retardate are referred to an institution. *American Journal of Mental Deficiency*, 1969, *74*, 171-179.

Sherman, B.R. & Cocozza, J.J. Stress in families of the developmentally disabled: A literature review of factors affecting the decision to seek out-of-home placements. *Family Relations*, 1984, *33*,(1), 95-104.

Skarnulis, E. Noncitizen: Plight of the mentally retarded. *Social Work*, 1974, *Jan*., 56-72.

Skarnulis, E. Less restrictive alternatives in residential services. *AAESPH Review*, 1976 *1*(3), 40-84.

Snell, M.E. & Beckman-Brindley, S. Family involvement in intervention with children having severe handicaps. *TASH*, 1984, 9, 213-230.

Sokol-Kessler, L., Conroy, J., Feinstein, C., Lemanowicz, J., & McGurrin, M. Development progress in institutional and community settings. *TASH*, 1983, *8*, 43-48.

Stabenow, D. *The family support subsidy, act: Questions and answers on P.A. 249 of 1983 (H.B. 4448)*. Lansing, MI: 412 Roosevelt Building, State Capitol, 1983.

Stuemke, J.E. Estate planning for families with developmentally disabled children. In T. Apolloni & T. Cooke (Eds.), *A new look at guardianship*. Baltimore, MD: Paul Brookes Publishing, 1984.

Suelzle, M. & Keenan, V. Changes in family support networks over the life cycle of mentally retarded persons. *American Journal of Mental Deficiency*, 1981, *86*, 267-274.

Surrey, S.S. *Pathways to tax reform: The concept of tax expenditures*. Cambridge, MA: Harvard University Press, 1973.

Symposium on Living Independently With Severe Disability, *Personal Assistants*. Paper presented at the second Post Polio Conference, May 1983.

Turnbull, H.R., Brotherson, M.J. & Summers, J.A. The impact of deinstitutionalization on families: A family systems approach. In R.H. Bruininks and K.C. Lakin (Eds.), Living and learning in the least restrictive environment. Baltimore, MD: Paul Brookes Co., 1985.

U.S. Bureau of the Census. Population profile of the United Stats: 1982, Current Population Reports, Special Studies, Series P-23, No. 130, 1984.

U.S Bureau of the Census. Statistical Abstract of the United States: 1978 and 1981.

Vitello, S. The institutionalization and deinstitutionalization of the mentally retarded in the United States. In L. Mann & D. Sabatino (Eds.), The third review of special education. New York: Grune & Stratton, 1976.

Waisbren, S. Parent reactions after the birth of a developmentally disabled child. American Journal of Mental Deficiency, 1980, 34, 345-351.

Warren, R.D. & Dickman, I.R. For this relief (respite), much thanks . . . New York, NY: United Cerebral Palsy Associations, Inc., 1981.

Wares, M. & Bentley, A. Report on the evaluation of the Alabama developmental disabilities advocacy program. Tuscolosa, AL: Alabama Developmental Disabilities Advocacy Programs, 1982.

Weiner, H., et al. The world of work and social welfare policy. New York, NY: Industrial Social Welfare Center, Columbia University, 1972.

Weiss, H. Issues in the evaluation of family support and education programs. Family Resource Coalition Report, 1983, 2(4), 10-11.

Wieck, C.A. & Bruininks, R.H. The cost of public and community residential care for mentally retarded people in the United States. Minneapolis, MN: University of Minnesota, Department of Psychoeducational Studies, 1980.

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

Wikler, L. & Hanusa, D. The impact of respite care on stress in families of mentally retarded children. Paper presented at Amercian Association of Mental Deficiency, San Francisco, May, 1980.

APPENDIX A: LIST OF CONFERENCE PARTICIPANTS

John Agosta, Ph.D.
Research Associate
Human Services Research Institute
120 Milk Street (8th Floor)
Boston, MA 02109

Mary Ann Allard
Research Associate
Human Services Research Institute
120 Milk Street (8th Floor)
Boston, MA 02109

Tony Apolloni, Ph.D.
Executive Director
California Institute on Human Services
Sonoma State University
Rohnert Park, CA 94928

Allan Bergman
Executive Director
Colorado Association for
Retarded Citizens
2727 Bryant Street, Suite L-3
Denver, CO 80211

Joseph Bevilacqua, Ph.D.
Commissioner
Department of Mental Health
and Mental Retardation
PO Box 1797
Richmond, VA 23214

Valerie J. Bradley
President
Human Services Research Institute
120 Milk Street (8th Floor)
Boston, MA 02109

Allan Carlson, Ph.D.
Rockford Institute
934 North Main Street
Rockford, IL 61103

Mitchell Carrier
165 Essex Street
Beverly, MA 01915

Paul Castellani, Ph.D.
Local Services Project
Office of MR/DD
44 Holland Ave.
Albany, NY 12229

Addie Comegys
PO Box 491
Wenham, MA 01984

Charlie Diertele
People First Representative
PO Box 7337
Boulder, CO 80306

Mrs. Irene Dixon
Route #1
Box 41
Leonardtown, MD 20695

Gunnar Dywbad, Ph.D.
Professor Emeritus of
Social Welfare
Florence Heller School
Brandeis University
Waltham, MA 02154

Rosemary Dywbad
Florence Heller School
Brandeis University
Waltham, MA 02154

Jean Elder, Ph.D.
Commissioner
Administration on Developmental
Disabilities
Room 336-E
200 Independence Avenue SW
Washington, DC 20201

Susan Epstein
Project SERVE
101 Tremont Street
Boston, MA 02108

JoAnn Gasper
Deputy Asst. Secretary for
Social Services Policy
ASPE/DHHS
200 Independence Avenue SW
Washington, DC 20201

Robert Gettings
Executive Director
National Association of State Mental
Retardation Program Directors
113 Oronoco Street
Alexandria, VA 22314

Kris Slentz, Ph.D.
Center on Human Development
University of Oregon
901 East 18th Street
Eugene, OR 97403

Rebecca Spence
Human Services Research Institute
120 Milk Street (Eighth Floor)
Boston, MA 02109

Warren G. Stambaugh
Virginia State Legislator
Suite 323
2425 Wilson Blvd.
Arlington, VA 22201

Alice Wells
Autism Services Association
36 Pleasant Street
Watertown, MA 02172

Joel West, Ph.D.
Department of Education
Seventh and D Streets, SW
Room 3915, ROB-3
Washington, D.C. 20202

Colleen Wieck, Ph.D.
State Council on Developmental
Disabilities
101 Capital Square Building
550 Cedar Street
St. Paul, MN 55101

NEBRASKA

Disabled Persons and Family Support Program
Aged and Disabled Services Unit
Department of Social Services
PO Box 95026
Lincoln, NB 68509

(402) 471-3121

NEVADA

Family Preservation Program
Division of Mental Health and Mental Retardation
Frontier Plaza (Suite 244)
1937 North Carson Street
Carson City, NV 89710

(702) 885-5943

NEW JERSEY

Home Assistance Program
Division of Mental Retardation
222 South Warren Street
Trenton, NJ 08625

(609) 984-0152

NORTH DAKOTA

Family Subsidy Program
Division of Developmental Disabilities
Department of Human Services
State Capitol
Bismark, ND 58501

(701) 224-3243

OHIO

Family Resources Services Program
Department of Mental Retardation and Developmental Disabilities
30 East Broad Street (Room 1220)
Columbus, OH 43215

(614) 466-6670

OREGON

Mental Retardation and Developmental Disabilities Program Office
2575 Bittern NE
Salem, OR 97310

(503) 378-2429

PENNSYLVANIA

Mental Retardation Family Support Services Program
Div. of Community Day and Support Programs
Office of Mental Retardation
302 Health and Welfare Building
Harrisburg, PA 17120

(717) 787-5102

RHODE ISLAND

Parent Deinstitutionalization Subsidy Aid Program
Division of Mental Health, Retardation and Hospitals
600 New London Avenue
Cranston, RI 02920

(401) 464-3235

SOUTH CAROLINA

Family Care Program
Department of Mental Retardation
PO Box 4706
Columbia, SC 29240

(803) 758-3671

VERMONT

Family Support Services Program
Community Mental Retardation Programs
Department of Mental Health
Center Building
103 South Main Street
Waterbury, VT 05676

(802) 241-2636

APPENDIX C: DIRECTORY OF FINANCIAL PLANNING AGENCIES

BRIDGE FOUNDATION

The Bridge Foundation
1790 Broadway
New York, NY 10019

(212) 399-0407

FOUNDATION FOR THE HANDICAPPED

Foundation for the Handicapped
1600 West Amory Way
Seattle, WA 98119

(206) 283-4520

GUARDIANSHIP, ADVOCACY AND PROTECTIVE SERVICES (GAPS)

Guardianship, Advocacy and
Protective Services
Oregon Association for Retarded
Citizens
1745 State Street
Salem, OR 97301

(503) 581-2726

INLAND COUNTIES MASTER TRUST

Inland Counties Master Trust
PO Box 2664
San Bernadino, CA 92406

(714) 888-6631

NATIONAL CONTINUITY FOUNDATION

The National Continuity Foundation
co/ Donald Sappern
253 Riverside Avenue
Westport, CT 06880

(203) 226-1288

PACT

Pact
6 North Michigan (Suite 1700)
Chicago, IL 60602

(312) 853-0226

PERMANENT PLANNING

Permanent Planning
co/ Exceptional Persons
2530 University Avenue
Waterloo, IA 50701

(319) 232-6671

PLANNED LIFETIME ASSISTANCE NETWORK

Planned Lifetime Assistance Network
Network (PLAN)
PO Box 323
Charlottesville, VA 22902

(804) 977-9002

SENTRY FUND

Sentry Fund
Kent County Association for
Retarded Citizens
1225-37 Lake Drive, SE
Grand Rapids, MI 49506

(616) 459-3339

STAR SYSTEMS CONSULTATION AND TRAINING

Star Systems Consultation and Training
1011 -70th Avenue
Philadelphia, PA 19126

(215) 549-5440

VIRGINIA BEACH COMMUNITY TRUST

Virginia Beach Community Trust
MR/DD Programs
Pembroke Six (Suite 218)
Virginia Beach, VA 23462

(804) 499-7619