THE DEVELOPMENT OF FAMILY SUPPORT PROGRAMS

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by

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Murphy's Law 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. For the purpose of this paper, four major laws and thirteen corollaries patterned after Murphy's Law have been postulated.

The four major sections of the paper are: (1) definitions, (2) impetus for chance, (3) barriers to family care, and (4) future. Each section will be prefaced by a law and each subsection by a corollary.

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

This paper will not 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.

Cobb (1976) defined social support as information exchanged at the interpersonal level which provides emotional support (care and love), esteem support (value as a person), and network support (mutual obligation and understanding). Support can occur in neighborhoods, family,

and self-help groups. Neighborhoods tend to provide short-term assistance. Families provide longer term support such as information, feedback, guidance, help, rest, identity, and an emotional base. Self-help groups form because of a mutual problem or situation.

Various taxonomies of family services have been offered. For example, Bates (1983) suggested the following:

- Subsidized adoption;
- Direct subsidies to families;
- Respite care;
- Training; and
- Technical assistance.

Loop and Hitzing (1980) offer a more comprehensive and graphic representation (Figure 1).

(INSERT FIGURE 1)

The common stereotype 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 an "employed husband, age 38; a wife not employed outside the home; an 8-year-old girl; and a 13-year-old boy" (p. 21). In contrast, the Census Bureau has abandoned the term family and adopted the term household to denote the range of living arrangements that currently exists.

In the background paper produced by Human Services Research Institute (HSRI), the authors (1984) adopted a very traditional view of the family as a "fundamental social or mating group found within human society." HSRI included such words as "marriage," "offspring," and "relations." Demographers suggest that society is moving away from these traditional concepts.

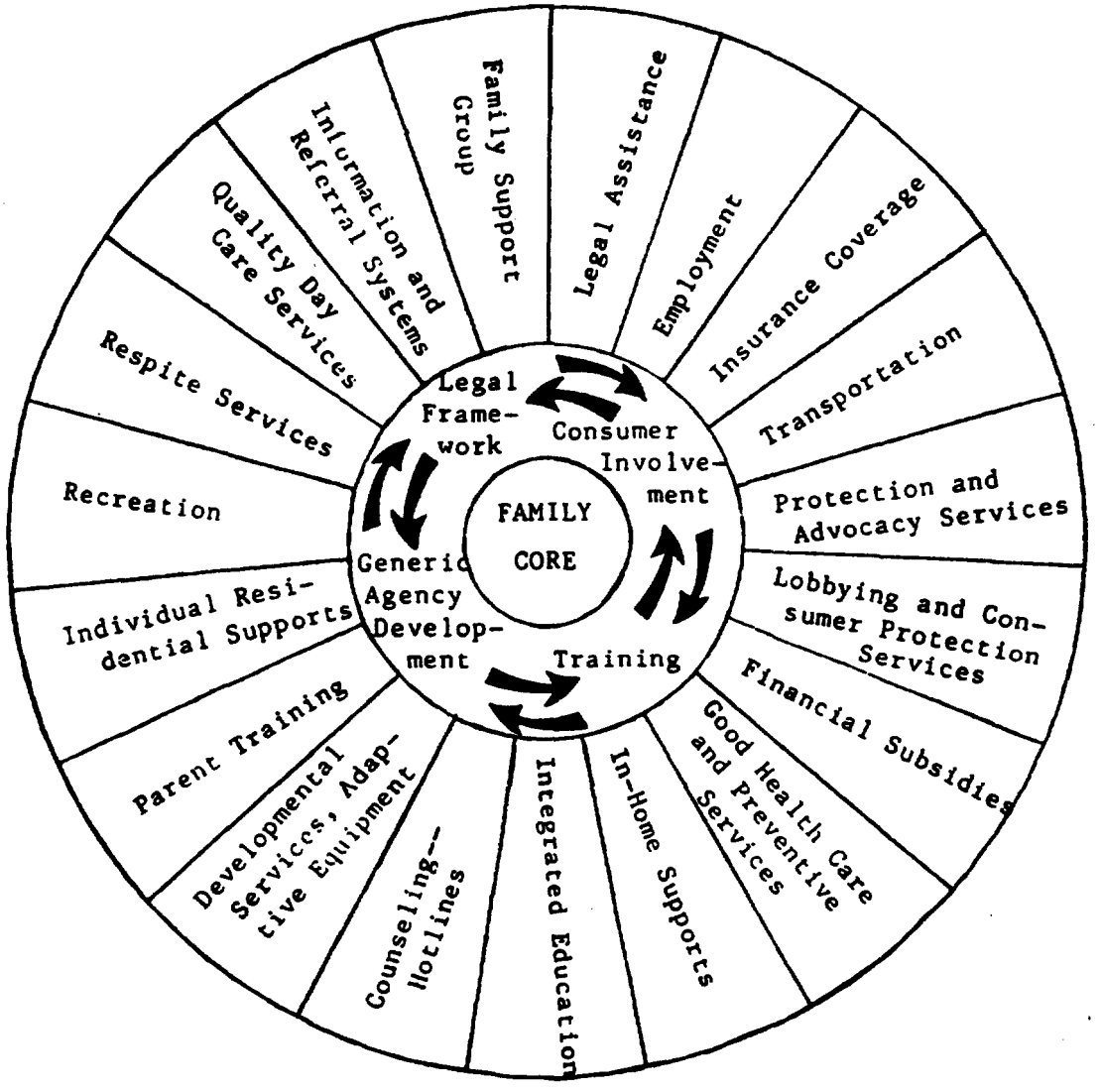

Figure 1: Model Array of Family Resource Systems and Support Services for Handicapped Children and Their Families

Of greater importance to this paper are the functions of the family delineated by the HSRI paper. The fundamental issue of family support programs is "who shall care for the members of the family, particularly those individuals with handicapping conditions?" This question leads to several others:

- What are the conditions which allow one family to care for its handicapped member and another to place the handicapped person out of the home?
- What are the reasons why there is family support for mentally retarded persons but not for Alzheimer's disease, head trauma, or hundreds of other conditions that place chronic stress on families?
- Why do family support programs tend to focus on children and not young adults, middle-aged adults or elderly adults with disabilities who might be living in a household unit?
- Is family support an anticapitalist concept?

Corollary 1.1: Service systems will occasionally stumble over the truth, but most of the time, the system will move on quickly. (Service goals.)

What are the goals of family support programs? The goals differ according to perspective. The government's perspective is to care for the child and save money. The family's perspective is to receive necessary assistance to prevent out-of-home placement. For the person with a disability, it is not a goal if the term maximizing potential is not mentioned.

The goal of providing stable family support occurs in the unstable context of society. There are dozens of political, economic, social, cultural, technological, psychological, and demographic variables

affecting living arrangements:

1. Family functions have shifted outside the household unit.
2. Marriage patterns have changed with delays in marriage (Duvall, 1977).
3. Divorce has increased and is not regarded as a stigma.
4. Family authority has shifted to women.
5. Older and younger family members are treated differently than in the past with care given outside the family.
6. The number and size of families have changed (Beck & Bradshaw, 1976).
7. Individualism has replaced familism.
8. New types of households are formed consisting of one person, more than one person not conventionally related, or single parents with children especially female-headed households (Bradbury, Bishop, Garfinkel, Middleton, & Skidmore, 1977).
9. Women are participating in the work force in greater proportions which affects fertility rate and the increased demand for child care (McDonald & Nye, 1979).
10. Two-paycheck families have created a new level of consumerism (Bird, 1979).

President Carter initiated a series of state and national White House Conferences on the Family. The stimuli for such an initiative came from several statistics, according to Dworkin (1978):

- Increase in juvenile crime;
- Increase in teenage pregnancy;
- Increase in suicide among children and youth;
- Increase in physical abuse of children; and
- Increase in domestic violence.

One of the purposes of the conferences was to define a national policy on families that could alleviate the problems previously mentioned. According to McDonald and Nye (1979), the problems in forming a national policy on the family include: (1) definitions, (2) unexpected consequences of government actions, and (3) tax laws. There is also growing interest in defining the domain of rights from government interventions. The rights of families were described in a special issue of the *Harvard*

Law Review (1980):

- Form a family and marry;
- Childbearing decisions;
- Custody of children; and
- Upbringing of children while recognizing the child's constitutional rights.

As expected, one group of policy analysts (Berger & Neuhaus, 1977) argue for less government intervention and increased reliance on families, neighborhoods, churches, and voluntary associations to address family issues. On the other side is the plea for more government assistance in the area of income and jobs (Featherstone, 1979). While no national policy on families has emerged, there seems to be greater recognition of the broader societal factors affecting families such as individualism, little government interference in private lives, and consumerism.

> *Corollary 1.2: All parents should give up their own handicapped children, become foster parents for another handicapped child, and at night, shift the children back to the natural parents. In that way, families can receive needed services and keep their own children.* (Service objectives.)

Brown, Johnson, and Vernier (1983) have defined objectives for income support programs, some of which are also appropriate for family support:

1. Adequacy: The program must allow every recipient to receive sufficient help to meet minimum needs.
2. Horizontal Equity: Those families in similar circumstances should be treated similarly.
3. Vertical Equity: Families in different positions in the income distribution are treated differently according to financial position.
4. Target Efficiency: Plan and execute programs to meet the needs of those who are to be assisted.

5. Family Stability: Policies and benefits should encourage families to remain intact and avoid incentives toward family breakup.

There is little doubt that family support programs attempt to meet the objectives of adequacy, target efficiency, and family stability. The two objectives that result in problems in some states are vertical and horizontal equity.

VERTICAL EQUITY: Those in greater need should benefit more than those in lesser need.

Point: Why is family subsidy provided to "rich" families when "poor" families 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 18 states provide family support, and 32 states do not. 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?
- Does family support help those families already receiving income support, or is family support a program for middle class families?
- Is family support designed to alter the distribution of funds from state institutions to families?
- Will family support be an entitlement program assuring benefits to all who meet the established criteria?
- Will family support continue to 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?

LAW #2: If your handicapped child only needs 10 minutes of assistance, you can only receive 24 hours of care, usually out of the home. (Impetus for change.)

There are three major sets of resons why states adopted family support programs: (1) moral reasons (it is the right thing to do), (2) habilitation reasons (it helps families and children), and (3) fiscal reasons (it is cost-effective).

> *Corollary 2.1: When the government's remedies do not match the problem, you modify the problem not the remedy.* (Moral imperatives.)

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).

Corollary 2.2: Unmet need is always greater than need. (Family needs.)

Reviews (McCubbin & Figley, 1983) of the traditional research in the area of family stress reveals 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 paradigm for 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 crisis meeting resources 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 the paradigm since 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:

1--Internal vs. external?
2--Pervasive vs. bounded?
3--Precipitous vs. gradual onset?
4--Intense vs. mild?
5--Transitory vs. chronic?
6--Random vs. expectable?
7--Natural vs. artificial generation?
8--Perceived insolvability vs. solvability?

There have been several studies on the effect of handicapped children on families, particularly, structure (Fotheringham & Creal, 1974; Beckman-Bell, 1981; Paul & Porter, 1981; Willer & Intagliata, 1984; McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980; Turnbull, Summers, & Brotherson, in press), stress (Wikler, 1981; Shapiro, 1983), and coping (Wright, 1970; McDaniel, 1969; Neff & Weiss, 1965). According to several investigators (Gruppo, 1978; Minde, Hackett, Killon, & Sliver, 1972; Heisler, 1972), families of handicapped children progress through stages similar to reaction to death: (1) shock, (2) disbelief, (3), rage, (4) guilt, (5) denial, and (6) adjustment.

As Farber (1979) observed, "Despite the vast increases in services to developmentally disabled people over the past 30 years, the major family problems remain the same." Loop and Hitzing (1980) admonish readers that "services focusing on supporting the family and the disabled child in the natural home have finished last when compared to other thrusts of deinstitutionalization."

Disabilities create financial hardships for families because of costs incurred for adaptive equipment, medication, therapies, and lost income due to caregiving responsibilities. Family subsidy can be helpful in meeting these costs (Turnbull and Turnbull, in press; Patterson and McCubbin, 1983; Boggs, 1979; Moroney, 1981). Traditionally, however,

"resources are available once the handicapped child leaves home" (Horejsi, 1979). Moroney (1979) also observed that traditionally the state provides substitute care and not supplemental care.

Intertwined with the issue of family resources and capacity is the pattern of out-of-home placements. According to an early 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 (1983b) 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).

Of specific concern to this paper is the utility of family support programs. Since 1976, Minnesota has had a family subsidy program. It was authorized by Minn. Stat. § 252.37, Subd. 4, and defined by DPW Rule 12 MCAR § 2.019:

> The program shall be for those children who, at the time of application, are residing in Minnesota and (a) who are living at home, or (b) who are residing in a state hospital or in a licensed community residential facility for the mentally retarded who, under this program, would return to their own home. Those children living at home must also be determined by the local board eligible for placement in a state hospital or a licensed community residential facility for the mentally retarded. [12 MCAR § 2.019, B(1)]

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

The program provides grants to parent(s) in an amount equal to the direct cost of the services outlined in a service agreement. Grants are to assist in the payment of:

> . . . diagnotic assessments, homemaker services, training expenses including specialized equipment, visiting nurses' or other pertinent theraptists' costs, preschool program costs, related transportation expenses, and parental relief or child car costs not to exceed $250 per month per family. (MINN. STAT. § 252.27, Subd. 4)

In 1983, the Minnesota Developmental Disabilities Council sponsored an evaluation of the family subsidy program. A sample of 70 families was selected, and 38 families participated.

The following results were reported in the area of program usefulness:

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

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

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

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

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

Corollary 2.3: Even after refined diagnosis, there is no change in treatment. (Needs of disabled person.)

As noted earlier, the HSRI summary (1984) defined several family functions such as serving as an economic unit, providing care, and transmitting social values. This list of functions was recently expanded by Turnbull, Summers, and Brotherson (in press) to include the following functions: economic, physical caregiving, rest and recuperation, socialization, self-definition, affection, guidance, education, and vocational.

The range, utility, and benefits of family care can be expressed very simply:

- Development at home is better (Poznanski, 1973);
- A family provides social development and emotional security (Schield, 1976);
- Disabled children have a right to be a member of a family (Vitello, 1976); and
- Habilitative family care includes care, training, and supervision of the developmentally disabled person in a planful manner (Horejski, 1979).

In addition, a child with a disability may be in a family home because it is the least restrictive environment. As Trace and Davis (undated) have operationalized least restrictive environment:

> When there is a need for intervention, the intervention should be no more drastic than that required to meet the needs of the disabled person.

To test whether family care is restrictive, both liberty and developmental potential must be examined. The Trace and Davis approach assesses whether the person with a disability is competent and is

prevented from performing the activity in the setting. There are three basic reasons for overrestrictiveness. First, a caregiver performs the activity for the individual. Second, a caregiver prevents the individual from doing the activity. And third, the caregiver may require additional training that is unnecessary for the consumer.

> *Corollary 2.4: 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 family.* (Fiscal imperatives.)

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 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 was $182; in 1978, it was $18,286. In Minnesota, the current annual cost is $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 5 percent of the mentally retarded people institutionalized than the 95 percent who are not. 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 institutions and 18 percent on community facilities. According to very rough calculations based on the HSRI summary of family support programs, over $24 million was spent in 1982-1983 on family subsidy (excluding California). Compared to the billions spent on out-of-home placements, less than 1 percent of funding is designated for family support.

In 1982, there were over 60,000 children (birth to 21 years old) in out-of-home placements which is a reduction of 30,000 children since 1977. The reduction is attributed to aging, reduced admissions, and transfers. According to the HSRI summary of family support programs, there were 5,250 families by family support programs with an additional 11,548 families in Pennsylvania and an unknown number in California.

In comparing the average daily costs of various options in 1982, there is a wide range of cost:

TYPE OF PLACEMENT	COST
Family support	$ 8.33 (est.)
Board and room	$15.97
Foster care	$16.15
Personal care	$17.05
Semi-independdent living	$27.40
Group home (1 to 15)	$38.31
Group home (16 or more)	$45.15
Nursing home	$49.81
Public group home (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.

LAW #3: Learning disability is to mental retardation as family support is to welfare. (Barriers to family care.)

Will there ever be federal support of a national family subsidy program? Is the idea of more government programs out of date? Will there ever be another entitlement program? Will the existing entitlements remain untouched?

Corollary 3.1: In society treat constants as variables. (Societal barriers.)

It is difficult to predict dramatic shifts in government policies when constants are really variables. In reviewing events of the past three decades, let us recall what we thought were constants:

- Marriage--no marriage--marriage;
- Baby boom--zero population growth--baby boom baby boom;
- Big cars--little cars--big cars; and
- Low inflation--high inflation--low inflation.

The adoption of family support programs is determined, in part, by the trendiness of the topic given the cyclical nature of society.

There are authors who argue that helping families preserves human dignity (Featherstone, 1979), while others counter that a family is the responsibility of its members, not government (Berger & Neuhaus, 1977).

To the latter group, family support can be perceived as an anti-capitalist idea since those who do not participate in economic development should not receive benefits. In addition, benefits to people with

disabilities should not exceed what "working poor" receive in benefits (Ozawa, 1982).

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?

The specter of socialism rises when any large outlay of funds to serve more families is discussed. Some authors (Ozawa, 1982) argue that serving more families would be an uneconomic use of resources and that other programs should be made more efficient to prevent out-of-home placements.

> *Corollary 3.2: You can fool all of the people some of the time and some of the people all of the time, but you can't fool mothers.* (Family barriers.)

In Australia, 116 mothers of handicapped children were interviewed in a study published by McAndrew (1976). The findings indicate that parents want prompt, accurate information that is factual. The problems faced the parents of handicapped children are complex and call for on-going support (Jefferson & Baker, 1964; Kendall & Calmann, 1964; Younghusband, Birchall, Davie, & Kellmar, 1970).

The strain on the family for physical care of the children was

considerable:

> The main brunt of the care was carried by the mother and probably accounts for the considerably bigger proportion of mothers compared with fathers who were in poor physical health. (McAndrew, 1976, p. 244; Freedman, Fox-Kolenda, & Brown, 1977)

The single largest expense was travel costs. Only a minority of the 116 families were experiencing financial problems. In Australia, the following types of assistance were mentioned:

> 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 on 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.

Of particular concern to siblings is the lifelong care and responsibilities for the handicapped person. Several others 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).

- Although programs are accessible to mentally retarded, few are accessible to autistic individuals. I feel very trapped because I know about all of these services and they're not interested in people like my brother (Daphne Greenberg, 21, whose brother is 23 years old).

Many siblings expressed a desire to understand guardianship, placement, and how to deal with guilt.

Corollary 3.2: The best family subsidy program works only one-fourth as well as the administrator says it is. (Fiscal disincentives.)

In the survey conducted of Minnesota family subsidy participants, 34 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).

Corollary 3.4: For every person who avoids institutionalization, two people will be imprisoned--usually out of state. (Residual policy biases.)

In July, 1984, a noted psychiatrist was quoted by the *New York Times* regarding two major social indicators--the number of institutionalized mentally ill people and the number of prisoners. Lunde stated that in 1970, 400,000 mentally ill people were institutionalized and 168,000 people were imprisoned. Within 10 years, there were 147,000 mentally ill people in institutions and 300,000 prisoners. Does the shift in population reflect a residual policy bias of reinstitutionalization?

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.

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 programs, legislators are faced

with several questions:

- Who should receive benefits?
- Should benefits be related to characteristics of the family or level of functioning of the child with a disability?
- Can benefits be coordinated with tax treatment or tax policy?
- Can family support benefits be coordinated with other income maintenance programs?
- Can family support financing ever make great gains when competing against state institutions and well-established community services and programs?

LAW #4: Family support programs that require no professional training today will soon require certification, accreditation, annual national surveys, federal grants, public service announcements, and a history by Richard Scheerenberger. (Future.)

There is predictability in human service programs such as state institutions, community residential facilities, day programs, and waivered services. The tendency is to professionalize a program; form a national organization that can splinter the Association for Retarded Citizens (ARC) even further; and require national surveys so that counts can be tabulated and progress can be proclaimed. The ultimate criterion is, of course, a historical account by Richard Scheerenberger published by the American Association on Mental Deficiency (AAMD). Federal involvement comes in the form of demonstration grants which usually results in dissemination of voluminous reports and taped public service announcements applicable only to the demonstration project. Can we prevent family support programs from becoming professionalized?

Corollary 4.1: We can predict the number of family support

programs. In even-numbered years, there will be an even number of states with programs. Given the current rate of development, by the year 2004, all states will have family support programs.

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 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 states because of the waiver.

Corollary 4.2: The only way to change paradigms is to legislate, litigate, agitate, and bury the dinosaurs.

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. Inappropriate placements are common.

In a consumer-powered system, the clients' needs are assessed; case managers are brokers, advocates, and creators of services to meet individual needs. Evaluation is systematic and based on outcomes.

The resource-powered system is common in states when individual

needs must contend with perverse fiscal incentives that favor placement in the most restrictive and most expensive settings. In Minnesota, the Intermediate Care Facilities for Mentally Retarded (ICF-MRs) is the most common residential option. While $200 million is spent on ICF-MR facilities, less than $1 million is earmarked for family support.

In 1984, the Minnesota Developmental Disabilities Council pursued a policy agenda including several goals in the area of supporting families:

> Increasingly, public policy supports the idea that the place for people with disabilities to build their futures is in the community. (p. 7)

A vision of the future must involve supporting communities to act responsibly, to be competent, to recognize and support the citizenship of people with disabilities. This vision of a responsive community includes:

- A community where children can grow up as members of families;
- A community where children and adults can be part of loving and caring relationships;
- A community where all children can learn together and from each other; and
- A community where people can turn not only to community services but their friends and neighbors for support.

At the federal level, President Reagan could proclaim a new initiative to move 13,000 children from state institutions to less restrictive settings. The approximate cost of out-of-home placement can be 8 to 16 times greater than family support program. 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, Australian, 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. Traditionalists 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 should not have excessive security but a balance between reasonable security and reasonable exposure to the risks in life. (Ozawa, 1982, p. 206)

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

> . . . ultimate right of every child irrespective of background, place of living, income of parents, and so on, to be welcomed, to have an economically and socially secure childhood and adolescence, with equal opportunities for a good

start in life and equal access to educational opportunities in order to develop his/her full potentialities. (p. 14)

Finally, initiatives that states should consider include:

- A checkoff on tax returns to "Save the Children" similar to checkoffs for political parties;
- Adoption of a version of S. 2053 at a state level to place emphasis on smaller living arrangements and alternatives to institutions; and
- Fund Individual Service Plans rather than buildings and programs.

REFERENCES

Allen, J. (1981). 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, 87-107.

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

Bates, M. (1983). State family support/cash subsidy programs. Madison, WI: Wisconsin Developmental Disabilities Council.

Baumeister, A. (1970). The American residential institution: Its history and character. In A. Baumeister & E. Butterfield (Eds.), Residential facilities for the mentally retarded. Chicago: Aldine Publishing.

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

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

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

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

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

Bradbury, K., Bishop, J., Garfinkel, I., Middleton, R. & Skidmore, F. (1977). Effects of welfare reform alternatives on the family. Washington, DC: Office of Income Security Policy, Department of Health and Human Services.

Braddock, D. (1984). Testimony before Senate Subcommittee on Health, February 28, 1984.

Brown, P., Johnson, C. & Vernier, P. (Eds.). Income support conceptual and policy issues. University of Maryland: Rowman and Littlefield.

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

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

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

Cianci, V. (1951). Home training for retarded children in New Jersey. The Training School Bulletin, 48, 131-139.

Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 300-314.

Daniels, M. (1981). 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, 147-164.

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

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

Dworkin, S. (1978). 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, 7(61), 61-63.

Farber, B. (1963). Interaction with retarded siblings and life goals of children. Marriage and Family Living, 25, 96-98.

Farber, B. (1979). Sociological ambivalence and family care. In R. Bruininks & G. Krantz (Eds.), Family care of developmentally disabled members: Conference proceedings. Minneapolis: University of Minnesota.

Featherstone, J. (1979). Family matters. Harvard Educational Review, 4(1), 20-52.

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

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

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

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

Graliker, B., Fishler, K. & Koch, R. (1962). Teenage reaction to a mentally retarded sibling. American Journal on Mental Deficiency, 67(5), 740-747.

Grossman, F. (1972). Brothers and sisters of retarded children. Syracuse, NY: Syracuse University Press.

Gruppo, P. (1978). Helping the handicapped child. Journal of Practical Nursing, 30-37.

Heifetz, L. (1977). Professional preciousness and the evaluation of parent training strategies. In. P. Mittler (Ed.), Research to practice in mental retardation, 1. Baltimore: University Press, 205-212.

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

Hill, B. & Lakin, K. C. (1984). 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.

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

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

Jefferson, E. & Baker, D. (1964). The needs of the handicapped child in the Sheffield area. Handicapped children and their families. Dun fermline, Scotland.

Johnson, C. (1981). Equity: Its scope and its relation to other objectives. In P. Brown, C. Johnson, & P. Vernier (Eds.), Income support conceptual and policy issues. University of Maryland: Rowman and Littlefield, 125-145.

Kendall, D. & Calmann, E. (1964). Handicapped children and their families. A survey based on Shropshire and West Midland Counties. Handicapped children and their families. Dun fermline, Scotland.

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

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

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

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

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

McAndrew, I. (1976). Children with a handicap and their families. Child: Care, Health and Development, 2, 213-237.

McCubbin, H. & Figley, C. (1983). Stress and the family, Volume 1: Coping with normative transitions. New York: Brunner/Mazel, Inc.

McCubbin, H., Joy, C., Cauble A., Comeau, J., Patterson, J. & Needle, R. (1980). Family stress and coping: A decade review. Journal of Marriage and the Family, 42(4), 855-871.

McDaniel, J. (1969). Physical disability and human behavior. New York: Pergamon Press.

McDonald, G. & Nye, F. (1979). Family policy. Minneapolis: National Council on Family Relations.

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

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

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

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

Moroney, R. (1981). Public social policy: Impact on families with handicapped children. In J. Paul (Ed.), Understanding and working with parents of children with special needs. New York: Holt, Rinehart, and Winston.

Neff, W. & Weiss, S. (1965). In B. Wolman (Ed.), Handbook of clinical psychology. New York: McGraw-Hill.

New York Times (July 8, 1984). Doctor assails Reagan on care of mentally ill.

New York Times (July 9, 1984). Who'll pay the bills for Baby Doe?

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

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

Patterson, J. & McCubbin, H. (1983). 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., 21-36.

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

Poznanski, E. (1973). Emotional issues in raising handicapped children. Rehabilitation Literature, 34, 322-326.

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

Scheerenberger, R. (1979). Public residential services for the mentally retarded in 1979. Madison, WI: Central Wisconsin Center for the Developmentally Disabled.

Schield, S. (1976). The family of the retarded child. In R. Koch & J. Dobson (Eds.), The mentally retarded child and his family: A multidisciplinary handbook. New York: Brunner/Mazel, Inc.

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

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

Thorsson, I. (1968). Children's allowance in Sweden. In E. Burns (Ed.), Children's allowances and the economic welfare of children. New York: Citizen's Committee for Children of New York City, 115-120.

Trace, M. & Davis, M. (undated). Restrictiveness in the doctrine of the least restrictive alternative: An operational approach. Unpublished manuscript, Ellsworth College.

Turnbull, A. & Strickland, B. (1981). Parents and the education system. In. J. Paul (Ed.), Understanding and working with parents of children with special needs. New York: Holt, Rinehart, and Winston.

Turnbull, A., Summers, J. & Brotherson, M. (in press). Family life cycle: Theoretical and empirical implications and future directions for families with mentally retarded members. In J. Gallagher & P. Vietze (Eds.), Research on families with retarded children. Baltimore: University Park Press.

Turnbull, H. R. (1981). Parents and the law. In J. Paul (Ed.), Understanding and working with parents of children with special needs. New York: Holt, Rinehart, and Winston.

Vitello, S. (1976). 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.

Wieck, C. & Bruininks, R. (1980). The cost of public and community residential care for mentally retarded people in the United States. Minneapolis: University of Minnesota.

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

Willer, B. & Intagliata, J. (1984). Promises and realities for mentally retarded citizens: Life in the community. Baltimore: University Park Press.

Wright, L. (1970). Counseling with parents of chronically ill children. Postgraduate Medicine, 173-176.

Younghusband, E., Birchall, D., Davie, R. & Kellmar, M. (Eds.) (1970). Living with handicap. London: National Bureau for Cooperation in Child Care.