

EVALUATING CONSUMER PERCEPTIONS  
OF HEALTH AND SOCIAL SERVICES:  
A SURVEY OF FAMILIES SUCCESSFULLY CARING  
FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

BY

CARMEN MARGINET

Report of a Practicum

Presented to

The Faculty of Graduate Studies

School of Social Work

University of Manitoba



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CARMEN MARGINET

A practicum submitted to the Faculty of Graduate Studies  
of the University of Manitoba in partial fulfillment of the  
requirements of the degree of

MASTER OF SOCIAL WORK

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## PREFACE

Prior to entering university in the fall of 1985, I was employed as a Case Co-ordinator for the provincial Continuing Care Program. It was during my last job evaluation that I realized that I knew pitifully little about program evaluation, planning, and research. One of my long-term goals was to undertake a study of spouses left alone at home after their wives or husbands entered a Personal Care Home. It was only in thinking about this goal that I realized that I did not know how to select a sample, design a questionnaire or interview research guide, conduct interviews, code data, analyze the results, or indicate the significance of the study for program development. It was my broad interest in social policy, a conviction that programs which advocate family-based care such as Continuing Care and some components of the provincial Mental Retardation program should elicit the comments and suggestions of their clients, and my desire to gain practical research skills that led to a practicum rather than a thesis.

I had several expectations of the practicum. It was to provide me with the opportunity to develop a beginning competence in the formation and implementation of a study and was to familiarize me with some of the measures used to assess family and individual functioning. Moreover, because I was in the Social Administration stream of the

program, I wanted to learn how to interpret the results of research for the purpose of improving service delivery.

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## CHAPTER I

### LITERATURE REVIEW

Because the practicum consists of a research study of "successful" families who have adjusted well to having an infant with a developmental disability, the literature review will focus on two main topics: the services which have been designed to support family-based care and client satisfaction with community-based human services. The former section will use a model of coping to explain the stress associated with raising a developmentally disabled child and the consequential value of supportive services. The latter will include the history of client satisfaction surveys and their contemporary utility to program evaluation. It will also review the methodological problems associated with consumer satisfaction research and will outline the solutions suggested by other researchers.

#### Family Support Programs

One major ideology advocates family-based care for developmentally disabled children (Agosta, Bradley, Rugg, Spence, & Covert, 1985). Termed, "normalization", it was proposed in Scandinavia (Nirje, 1969) and later developed in North America. It implies that the developmentally disabled should live and attend programs in normative settings and can learn the skills and behaviors essential for



community living (Wolfensberger, 1972). Its adjunct, "mainstreaming", refers to the education of disabled children in non-segregated classrooms and regular schools.

The major goals that should guide any family support program from a normalization theory perspective are: (1) to prevent unnecessary out-of-home placement, (2) to augment the caregiving capacity of families, and (3) to return persons residing in institutions to a family environment (Agosta et al., 1985).

After conducting an extensive literature review, Agosta et al. (1985) determined that several findings in particular supported the ideological shift toward family-based care: (1) literature based on the "developmental model" indicated that developmentally disabled children have the ability to grow and learn, (2) the debilitating effects of institutionalization and the positive effects of community and home-based care were illustrated in several studies (e.g. Shroeder & Henes, 1978; Nihira, Meyers, & Mink, 1983), (3) there was continuing improvement in instructional methodologies for individuals with developmental disabilities, (4) evidence arose indicating that parents can be taught specialized skills to meet the needs of their developmentally disabled children, and (5) a growing body of literature indicated that home and community-based care is less expensive than institutional care (e.g. Smith, 1981). Agosta et al. (1985) also argue that family-based care was supported, in part, by a burgeoning

consumer movement which resulted in the organization of politically active parent groups and self-advocacy organizations.

As can be expected, there are also several obstacles to family support programs. Attitudinal barriers exist. Agosta et al. (1985) state that there is no consensus regarding the role of the family in the provision of care to a disabled family member. Some professionals disregard the family's ability to make decisions and consequently recommend out-of-home placement. Families are caught in a crossfire of conflicting interests and social role expectations (Agosta et al., 1985). Contemporary lifestyles emphasize employment outside of the home for women, independence, and self-actualization. These expectations are in conflict with a renewed interest in family-based care and the reluctance of some families to use an alternative form of child care. A lack of consensus exists regarding the public's role in what is perceived as a private family affair (Agosta et al., 1985). Some believe that the family is responsible for disabled children and that the public should provide limited assistance. Others believe that public monies should address the special needs of family caregivers and persons with disabilities.

Agosta et al. (1985) argue that political realities have hindered family support programs. Although most individuals with developmental disabilities live at home during childhood (Bruininks, 1979), the majority of service

dollars are most frequently spent on institutional care. Providing families with comprehensive support services either requires more money and/or a reallocation of existing resources. Because of fiscal restraint and the tendency to maintain current allocation patterns, many politicians are reluctant to approve of additional family support programs. Some fail to see the necessity of providing public funds to a service, family care, that is provided free of charge. Others argue that a decrease in financial support to families caring for a member with a developmental disability will eventually result in huge financial burdens.

Agosta et al. (1985) also argue that family support programs have been plagued with administrative uncertainties. They explain that the establishment of a comprehensive family support program is politically and programmatically complex and, as a result, family support programs have developed slowly. Decisions to be made include "What department should administer the program? How many families have disabled members living at home? What are their characteristics and level of need? Should the programs be provincially funded? Is federal cost-sharing available and if so, under what conditions will it be provided? What services should be permissible?" These questions are further complicated by the fact that the composition of the traditional family has changed (Agosta et al., 1985). Program decisions need to acknowledge the increase in female labour force participation, the declining

size of contemporary families, and the increasing number of single-parent families.

### Crisis Theory and the Importance of Family Support Programs

In crisis theory, formal and informal supports can be helpful to individuals attempting to cope with stress. If we consider raising a disabled child as stressful, crisis theory is useful in understanding the importance of family support programs.

The development of crisis theory began shortly after World War II. Present-day crisis theory is the amalgamation of concepts and hypotheses that have been drawn from psychodynamic personality theory, child development theory, experimental psychology, sociological studies on families experiencing stress and communities experiencing large-scale disasters, findings in military and civilian psychiatry, and developments in learning and behavioral psychology (Golan, 1978).

A conceptual model of stress is proposed by Dohrenwend (1978). She describes a process in which stress, unless alleviated by professional intervention or personal supports, can result in psychopathology (see Appendix A). This model suggests that both the formal support provided by programs and services and the informal support offered by natural helpers can contribute to a family's ability to be "successful" in its attempts to cope with the stresses associated with raising a child with a developmental

disability. This model also acknowledges that individuals have different values and aspirations and vary in their ability to cope with adversity. It recognizes that some people cope without relying on a support network.

Crisis is usually seen to begin with a stressful life event. The individual's perception of this event is affected by the extent to which this recent stress is determined by the environment or caused by his or her psychological characteristics. Dohrenwend (1978) uses the example of an employee who is laid off from work. If the entire office has been closed, the individual's unemployment is caused by environmental factors. If the employee has been fired, the event is seen to have been determined by some failing of that person and is attributed to his or her psychological characteristics.

As the model indicates, a person may develop transient psychological symptoms immediately after a stressful life event. For example, families who discover that a family member has a developmental disability have a number of reactions including shock, numbness, denial, grief, shame, guilt, and depression (Fortier & Wanless, 1984). The outcome which follows this transient stress reaction depends on the situational and psychological mediators available to the individual. Situational mediators include material and social supports. Psychological mediators include aspirations, values, and coping abilities.

The transient stress reaction is moderated by situational

and psychological factors to produce three outcomes: (1) psychological growth, (2) the resumption of life without noticeable change, and (3) psychopathology. Dohrenwend (1985) advances two hypotheses regarding individuals who successfully cope with a stressful event. An individual whose financial resources are strained by the demands of a crisis is likely to have a worse outcome than someone with adequate financial means. A lack of social support will increase the likelihood of a negative outcome. Although there does not appear to be any empirical evidence for the first hypothesis, there is evidence that high social support enables high-stressed families to cope with stress better than similarly stressed families with low social support (Johnson & Sarason, 1978).

Preventing the use of successful families in many studies has been the fact that there is no consensus as to how to define successful adjustment to a crisis (Kessler, Price, & Wortman, 1985). One approach has been to identify characteristics which indicate mastery of a stressful situation (Hamburg & Adams, 1967). These characteristics include keeping one's distress within manageable limits, maintaining self-esteem, restoring former relationships with significant other people, and being able to function in major life roles. Kessler et al. (1985) maintain that this approach may not be satisfactory. Spinal cord injured patients who were the most upset with their disability were later rated as making the most progress in

rehabilitation (Goldsmith, 1955). Coyne, Kahn, and Gotlib (cited in Kessler et al., 1985) note that some people cope with a life crisis in a manner which reduces distress at someone else's expense.

Stress is a perceptual phenomena. For some, raising a child with a disability is perceived as a crisis and results in illness. Lonsdale (1978) found that 33% of the mothers that she interviewed had suffered with an illness attributable to caring for a handicapped child. Other people easily accept and cope with the situation. A crisis theory perspective suggests that the stresses associated with raising a disabled child may lead to a crisis.

The stresses associated with raising a developmentally disabled child are well documented. To determine the types of stress which are exhibited by families caring for members with disabilities and the degree of their children's disabilities, Holroyd (1974) developed a 285 item questionnaire with 15 scales: (1) poor health mood, (2) excess time demands, (3) negative attitude toward the person with the disability, (4) overprotection/dependency, (5) lack of social support, (6) overcommitment (martyrdom), (7) pessimism, (8) lack of family integration, (9) limits on family opportunity, (10) financial problems, (11) physical incapacitation, (12) lack of activities for the person with the disability, (13) occupational limitations for the person with the disability, (14) social obtrusiveness, and (15) difficult personality characteristics.

He determined that mothers of retarded children differed from mothers of nonretarded in only two respects. They perceived their children as overdependent and themselves as overprotective and they were painfully aware of the fact that their children would have limited access to school, occupational, and community opportunities. Also of interest is Holroyd's (1974) finding that mothers of retarded children differed from their spouses. They had excessive demands on their time, suffered poorer health and/or poorer overall mood, experienced less personal development, were more aware of the child's acceptance into the community, and showed greater sensitivity to family problems. Unfortunately, the fact that Holroyd (1974) administered his questionnaire to parents of only 43 children evaluated in one outpatient clinic in California brings into question the generalizability of his findings.

There are other stresses associated with raising a developmentally disabled child. Friedrich, Wilturner, and Cohen (1985) studied a sample of 140 mothers to determine if coping resources are related to coping outcome. They determined that marital satisfaction, maternal depression, locus of control, and the quality of the family social environment were significant predictors of coping ability. Using the same sample, they conducted a second study eight months after the initial data-collection. Maternal depression, as measured by the Beck Depression Inventory, increased. From these results, the researchers suggest that



parents' depression gradually increases as their disabled children grow older. Their findings are supported by Wikler, Wasow, and Hatfield (1981) who suggest that, despite popular conception, parents do not gradually adjust to the fact that their child is retarded but experience periodic crises during the child's development. Specific developmental crisis points include (1) diagnosis, (2) the age at which the child should have begun walking (12-15 months), (3) the age at which the child should have begun talking (24-30 months), (4) the point at which a younger sibling overtakes the retarded child's abilities, (5) serious discussion regarding the placement of the child outside the home (or actual placement), and (6) the entry of the child into the public school system.

Beckman-Bell (1981), too, supports the notion of chronic stress. She states that parental stress is affected by both unalterable and alterable characteristics of the child. Whereas little can be done to change such characteristics as gender, chronological age, diagnostic category, or physical appearance, intervention can reduce stress by influencing the child's temperament, rate of development, social responsiveness, and problematic behavior. If these characteristics persist, stress is chronic.

Raising a developmentally disabled child interferes with household duties, the time spent with other family members, and socialization (Lonsdale, 1978; McAndrew, 1976).

In the study conducted by McAndrew (1976), parents perceived an adverse change in their relationships with their friends after the birth of the child. Former friends were said to be "embarrassed", "frightened", and awkward. Lonsdale (1978) noted that more mothers than fathers felt that their social life had been affected. Although Lonsdale (1978) does not elaborate on this statement, findings in McAndrew's (1976) study suggest that mothers bear an unequal responsibility for child care and experience social isolation to a greater extent than their husbands.

The family member may be socially disruptive and require assistance with physical management (Agosta et al., 1985). As indicated in Holroyd's (1974) study, the family is faced with extraordinary time demands involved in providing personal care to the disabled family member. In a study on respite services in California, Apollini & Triest (1983) find that the most common reason for respite utilization was "sheer relief for overworked family members" (p. 241). Gliedman and Roth (1980) point to the financial costs and lost opportunities that the parents of a disabled family member encounter.

Friedrich (1979) determined that the problems that a family with a developmentally disabled child experience are dependent upon marital satisfaction, the child's residence, and the child's gender. Mothers of institutionalized children reported more stress than mothers of children who lived at home and mothers of female children reported more stress

than mothers of male children. Friedrich, Greenberg, & Crnic (1983) determined that family problems are related to the extent of the child's physical disabilities and the presence of socially maladaptive behavior. Friedrich & Friedrich (1981) found that parents with handicapped children reported less social support, less religiosity, and less psychological well-being than parents with nonhandicapped children. Mink, Meyers, and Nihira (1984) used cluster analysis to form seven distinctive family types of families with slow-learning children. They found that families who had a positive view of the child's impact on the home and reported few stressful life events tended to be cohesive, independent and organized, open and aware, and harmonious in their quality of home life and parenting.

### Locus of Control

Locus of control has been an important research question in regard to coping and findings have been equivocal. Rotter (1966) derived his assumptions pertaining to internal-external control from social learning theory. He purported that individuals who attribute the success of an event to their own skill and expertise exhibit an internal locus of control and, because of the positive reinforcement, will take responsibility for the outcome of future events. Those who attribute the outcome to luck, chance, or the intervention of powerful others have an external locus of control and will accept very little

responsibility for future events, either successful or unsuccessful.

As with many other researchers, Friedrich et al. (1985) used the concept of locus of control as a predictor variable in their research. Results from their study indicate that mothers who felt that they had the capacity and the ability to make changes in their situation were better able to cope with having a retarded child. Although support for their findings is found in the literature (Lefcourt, 1976; Johnson and Sarason, 1977), it is tempered by several cautions.

Lefcourt (1976) and Rotter (1975) admonish that: (a) locus of control is not a specific personality trait but indicates an individual's response to a particular situation and depends upon the value and the expectation of the perceived reinforcement, (b) other interacting variables may be as equally, if not more important, than locus of control in predicting the criterion variable, (c) experimenters have designed their instrumentation to emphasize the importance of internal-external control of reinforcement, and (d) the measurement typically used in research to measure internal-external control of reinforcement, the Rotter I-E scale (Rotter, 1966) was developed to allow for low prediction across a variety of situations, not to indicate high prediction in specific situations. Social desirability effects cloud the effectiveness of the instrument in different situations.

Of interest is the observation by Friedrich et al.

(1985) that the child and parental variables associated with stress are interrelated. For example, mothers who are depressed and who do not feel support in their marriages or in their friendships will be less able to encourage their children to act in a socially acceptable manner. Disruptive children will affect their mothers' sense of well-being and make it more difficult for them to invest time in their marriages and families. Four variables--depression, marital satisfaction, the presence of socially maladaptive behavior, and social support--interact. This implies that interventions which target only one of the family's coping resources, or focus on only one stressor such as the child's behavior, are not as effective as interventions which target on multiple foci (Friedrich et al., 1985).

### Services

Family support programs are designed to assist families caring for a family member by addressing the needs of their developmentally disabled children. Children with physical and/or mental impairments have specific needs relating to their disability and require assistance with the acquisition of adaptive skills, the maintenance of their physical and emotional health, and the learning of socially appropriate behaviors (Agosta et al., 1985). Families have multiple needs in such diverse areas as information, specialized services for the developmentally disabled person, social networking, and assistance in providing direct care (Agosta et al., 1985).

Because the menu of services available to families is lengthy, only four services--self-advocacy groups, politically active parent groups, cash subsidies, and respite care--will be discussed. These services exemplify the range and diversity of family support services. Parents join the first two groups for support, information, and advocacy. The third service, the provision of cash subsidies, is controversial and as yet, not provided in Manitoba. The fourth service, respite, is presently provided and recognized as essential in the literature (Apolloni & Triest, 1983).

Joining a self-advocacy group gives a parent the opportunity to discuss the experience of raising a developmentally disabled child with others. Not every parent, however, recognizes a need for either the emotional support or for the information provided by such groups. Many of the 45.3% of the parents in Lonsdale's (1978) study who claimed that support groups were unnecessary said that they found it depressing to be with other parents in a similar situation. Those parents who did belong to support groups cited information about resources rather than emotional support as their reason for attendance. It is interesting to recall the finding (Gourash, 1978) that those who seek help from self-help groups tend to be young, white, educated, middle-class, and female.

Politically active parent groups have been responsible for instigating most of the advances in programming for the

developmentally disabled. Agosta et al. (1985) surveyed family support programs in the 50 U.S. states from November, 1983 until November, 1984 and found "almost without exception" that it was organized family groups that pressed the case for the passage of family support legislation in state legislatures.

Although many of the services in Manitoba are provided free of charge, there appears to be benefit in cash subsidies. In the study conducted by Agosta et al. (1985) family members rated cash subsidies highly because of their individualized character. Subsidies allowed the families to choose their own services, rather than being limited to a predetermined menu of services. They also had the advantage of being easily and efficiently implemented.

Families require respite and other forms of parental assistance to cope with seriously disabled family members. In a study of respite services in California, almost half of the parents stated that they would consider out-of-home placement if respite was not available (Apollini & Triest, 1983). They cited relief from the emotional stress associated with caring for a family member as the primary reason for the service. Practical needs such as care during emergencies and illness and care before and after school rated second. Recreational needs such as care during holidays came last. Although respite services appear to be particularly valuable to families with young children, Boggs (1979) argues that it also helps young adults with

developmental disabilities achieve independence from their parents.

Bubolz and Whiren (1984) propose an ecological model that considers the impact of raising a child with disabilities on the whole family. The "family ecological systems model" is based on the concept of ecosystem, that is, the notion that all living things interact with the environment that surrounds them. Underlying this perspective is the belief that a change in any part of the system affects the system as a whole and requires system adaptation. To function, families require physical and psychic energy in the form of money, goods, values, knowledge, policies, community services, and support systems. As illustrated in Appendix B, the family is a cybernetic input-output system. It requires information in the form of feedback to adapt its behavior to the external environment. Any change to the system or environment creates stress and requires counterbalancing. When stress is overwhelming, it may exhaust physical and psychic energy and result in system failure. The following assumptions are made in an ecosystem model of the family:

1. Any alteration in the flow of energy, information, and other resources through the family system requires adaptive change.
2. Supplies of human energy--physical and psychic--are limited.
3. Behavior of individual family members creates stress



which requires additional energy inputs by other family members or from external supports, as well as energy input for obtaining these supports.

4. Undue energy demands create "energy sinks"--where adaptive, creative behavior may no longer be possible, resulting in still greater stresses on the family. (p.6-7)

The family unit can function with high resource expenditures repeatedly, and for brief periods if it has adequate inputs. However, caring for a family member for a long period of time can exhaust the family's resources. In addition, nuclear families with developmentally disabled children run the risk of separation. This lessens the coping capacity of the remaining caregivers.

Society has a stake in the family's decision regarding a handicapped member. Family members have societal roles and are expected to go to work, to school, and to participate in the community. If family resources are depleted with the care of a handicapped member, society is affected. Acknowledging the needs of the family as a whole does not detract from the right of the handicapped to receive humane care and services that enable them to achieve their fullest possible development.

Using the ecological model, Bubolz and Whiren (1984) outline several implications for policy and practice:

1. The total family should be considered in the development of a plan for a handicapped member to ensure

that benefits to the entire family are maximized and costs minimized.

2. Support and services should be provided to the entire family unit and not just one specific member. Because parents concentrate their care on a disabled member, healthy children run the risk of developmental delays. Little research has been done on the costs and benefits to nonhandicapped family members.

3. Policies and programs should consider the issue of longevity. Parents typically provide care to handicapped members until either their death or the death of their offspring. The question of sibling responsibility for care after the death of one or both parents needs to be considered.

4. The development of external systems of support should consider the total energy needs of the family. The energy flow into the family (goods, money, and labour) should equal the energy demands created by the handicapped member.

5. Easily accessible information retrieval systems and advocacy systems which include material on stress management and effective resource utilization should be provided so that families can receive the information that they need.

6. The design and implementation of delivery systems should adhere to an ecological model. There should be communication and coordination between public and private services. Services should interface to provide support to

the person with the disability and his or her family.

7. Although the current emphasis is on family or community placement, some families do not have the resource base sufficient for either maintenance or successful role performance in the community. Community support services, self-help voluntary groups, and public supported services should acknowledge and provide supportive services to those families that are incapable of providing care. As indicated in the study by Friedrich (1979), mothers of an institutionalized child experience more stress than mothers who care for their child at home.

8. Agencies which arrange the adoption of handicapped individuals should follow an ecological perspective. Information, counseling, respite services, and financial aid may need to be offered to adoptive parents.

When designing a family support program, several other factors need to be considered. Service needs of the family change as children with developmental disabilities move from one developmental plateau to another. Suelzle and Keenan (1981) administered a pretested 57-page mail survey questionnaire to 330 families. Four stages were recognized in the life cycle of the retarded child: "preschool (birth to 5 years old), elementary (6 to 12 years old), teenage (13 to 18 years old), and young adult (19 to 21 years old)" (p. 269). They comment that because the general public has had little experience interacting with retarded persons, the networks of information available to parents of non-

handicapped children (i.e. family, friends, neighbours) are often not available to parents of handicapped children. Because of their need to rely on professionals for information in regard to children's services, parents of younger handicapped children tend to utilize services and support networks to a greater extent than parents of older disabled children. Although all families are in need of some type of support regardless of the age of the person with disabilities (Agosta et al., 1985), Suelzle and Keenan (1981) determined that parents of older children have less support and are more isolated than parents of younger children. This is partially explained by the decline in their utilization of personal networks for support and babysitting as the child grows older.

The needs of the family unit change as it, too, passes from one life stage to another. A critical time for many families is when siblings of the developmentally delayed child mature and leave the family unit. The departure of these formerly dependable caregivers weakens the family's capacity to provide care and places the caregiving burden on aging parents (Agosta et al., 1985).

In the study conducted by Suelzle and Keenan (1981), the life-course planning essential to the concepts of mainstreaming and normalization did not occur. Although a plethora of services were available for the younger disabled child, the older child was faced with a limited choice of occupational, residential, and educational alternatives.

The researchers found that parents requested living alternatives for their children were often at two transitional crises. The first was when the child entered the age-graded structure of the school system and the second was when the young adult was forced to accept limited life choices.

From their findings, the researchers contest that parents do not gradually accept a child's disability but rather become acutely aware of his or her limitations at certain stages in the life cycle. Their hypothesis is supported by the findings of Folkman and Lazarus (1980) who determined that in situations in which there are few possibilities for beneficial change, individuals resort to emotion-focused rather than problem-focused strategies. Strategies such as avoidance, detachment, assignment of blame, and fatalism would be typical of parents faced with the reality of limited alternatives for their disabled children.

There are several implications, then, for service provision. First, families should be provided with a range of health and social services designed to meet the changing needs of both the child and the family. Second, in situations where families have only limited alternatives, family counseling should be provided to ameliorate the chronic stress associated with raising a disabled child. Third, along with the diagnosis and prognosis, health care professionals should provide practical information to the

family that emphasizes the gains, however small, that the child can achieve. Fourth, both families and communities should be encouraged to accept the principles of normalization. At a certain age, all children are expected to leave home. Through public relations and counseling, professionals should encourage families to prepare their disabled children for independence and the community to accept disabled adults. Parents who see an "end in sight" will tolerate the temporary demands of caring for a disabled child.

#### Client Satisfaction / Consumer Feedback

Marin (1980) best summed up consumer feedback when she noted that while much has been done, little has been done well. Although she was referring to attitudinal surveys and personal interviews, many of their problems have plagued all such surveys. Improvement is possible though. Through the use of questionnaire items related to concrete, manipulable aspects of service delivery, precoded response categories, computers and data analysis, consumer feedback can be used for public relations, to identify service delivery problems, to evaluate solutions to problems, and to measure the impact of service changes and innovations (Marin, 1980).

Lebow (1983) defines consumer satisfaction as "all inquiries into the extent to which services gratify the client's wants, wishes, or desires for treatment" (p. 212). He extends this definition to include the perceived adequacy

of treatment and surrounding milieu, reactions to the quality of care and to its helpfulness, the cost and continuity of service, and the availability and accessibility of the service provider. Consumer satisfaction is typically collected through two methods: self-report (i.e. questionnaires, surveys, and interviews) and program indices (i.e. rates of service utilization) (Lebow, 1982). Although it has not been extensively used, it is invaluable as an outcome variable in service evaluation.

In the marketplace, manufacturers conduct extensive consumer tests before a product is introduced. They note consumers' likes and dislikes, the appeal of the advertising strategy, and improvements which need to be made to the product before it is mass produced. Moreover, consumers who are dissatisfied with a product have the option of purchasing a similar product manufactured by a competitor.

In contrast to purchased goods or services, clients are unable to cast their vote on public and government services by exercising their purchasing power and are expected to unequivocally accept the services which are offered. Even the groups which have organized to advise policy makers and lobby on behalf of clients appear to have limited success in the design and implementation of services. The accomplishments of organizations such as the Manitoba League of the Physically Handicapped have been limited to the areas of human rights, employment, and transportation (LeBlanc,

Gingras, Mann, & Roeher, 1981). It is not surprising to note that the two recent reviews of services in Manitoba (Schaefer, Robson, & Steinkopf, 1982) and in Canada (Smith, 1981) comment on the absence of consumer input in the formation, implementation, and evaluation of services directed at persons with disabilities.

Consumer satisfaction should be used in service evaluation for a number of reasons. For programs which provide consumers with a variety of service choices, it determines the most effective services chosen by the majority of clients and indicates the specific services which families use at particular points in their child's development.

Evaluators are now accountable to two decision makers-- administrators and citizen groups (Kaufmann, Sorensen, & Raeburn, 1979). Media coverage of agency business, particularly of those with a high public profile such as child welfare agencies, informs the populace and exposes the agency to public scrutiny.

Although a study by Bredemeier (cited in Margolis, Sorensen, & Galano, 1977) indicates that the administrative structure of a health delivery system downplays the involvement of consumers because service providers are more dependent on their employers than on clients, consumers remain a valuable source of information. Through self-report measures, they can comment on service accessibility and needs unmet by available services (Margolis et al.,



1977).

Consumer feedback recognizes families as the key caregivers in the lives of their children. Although the literature recognizes that parents are the people best able to care for children with disabilities (Buscaglia, 1983), many professionals are reluctant to relinquish their authority and responsibility. Consumer feedback reinforces the rhetoric that the parents, rather than the professionals, should make the final decision in regard to the services that their children receive.

On a more practical note, consumer feedback can enhance cost efficiency. It can pinpoint unsatisfactory programs and identify needed programs which require "beefing up". It prevents the misallocation of limited funds and resources. Despite its utility however, practical and methodological difficulties abound.

One practical difficulty with consumer satisfaction surveys is mentioned by Larsen, Attkisson, Hargreaves, and Nguyen (1979). The lack of a standard satisfaction scale and the corresponding lack of meaningful comparison bases prevents comparison either across programs or within programs. The researchers use this example: A satisfaction score for one service setting of 70 on a scale of 1 to 100 with a standard deviation of 10 indicates only that the clients appear to be satisfied. If, however, the mean satisfaction score on the same scale in a sample of comparable settings is 85, we can safely say that the

clients in the program under study are less satisfied than the clients in the other programs. Comparing different time periods, different groups of clients, or clients receiving different service combinations within a program requires a standardized measurement. To date, investigators have invented their own questionnaires or have modified existing scales.

Two highly rated scales have been designed by Attkisson and Zwick (1982) and by Attkisson, Roberts, and Pascoe (1983). The former, the Client Satisfaction Questionnaire, is highly internally consistent and has little variance between questions. Three of the eight questions operate well as a smaller global measure of evaluation. The latter, the Evaluation Ranking Scale, is preferable to such global measures for several reasons. It is equally acceptable to patients, produces more normal score distributions, and provides comparative information about specific services.

Another practical difficulty with consumer satisfaction surveys is the high reported levels of client satisfaction. Clients appear to be satisfied regardless of the services that they have received. In a study conducted by Kaufmann et al. (1979), 87 percent of the clients who had received service from a metropolitan mental health program claimed to be satisfied. In a telephone survey of ex-patients from a community mental health center (Denner & Halprin, 1974), three questions were asked. The first was a global evaluation, "How satisfied were you with the services you

received?" 71 percent of the respondents were satisfied with the clinic's services.

The one exception to the high levels of client satisfaction was reported in a study conducted by Woodward, Santa-Barbara, Levin, and Epstein (1978). Although 64 percent of families with a child between the ages of 6 and 16 who had presented with academic and/or behavioral difficulties were satisfied with the total services received from a mental health centre in southern Ontario, widely varying degrees of satisfaction were reported with specific aspects of the service. For example, 44 percent of the respondents indicated that they had not received all the services for which they were eligible. Unlike other studies in which clients reported that they were satisfied with the service although they did not feel better about their original problems (McPhee, Zussman, & Joss, 1975), clients in this study expressed dissatisfaction even when their original problems showed improvement.

Gutek (1978) points out that respondents often report satisfaction in areas in which it is common knowledge that dissatisfaction is quite high. For example, 85 percent of assembly line workers claim to be satisfied with their jobs, and in a study on marriages, 92 percent reported satisfaction. She suggests that the high reported rates of satisfaction are due to the fact that people rate their own life experiences more highly than they rate the same experiences of others. Although respondents frequently

state that most government bureaucracies do not meet the needs of the public, they rate their own experiences with the government quite highly (Katz, Gutek, Kahn, & Barton, 1975). Lebow (1983) suggests that reports of satisfaction may be unrealistically high because of reactivity, social desirability, the clients' attempts to pursue their self-interests, and selection in the responding sample.

Methodological difficulties are prevalent. Nguyen, Attkisson, and Stegner (1983) note that client satisfaction findings are influenced by a number of social-psychological artifacts which skew the results. These include researcher bias, the Hawthorn effect, and social desirability bias. Orne (1962) determined that experimental subjects are not passive responders to stimuli, but recognize the purposes of experiments and act in such a way as to prove the experimental hypothesis. Similarly, asking service recipients for an evaluation places them in a demand situation and produces a halo effect in judgements of outcome.

Many client satisfaction surveys have had difficulty avoiding sampling biases. Nguyen et al. (1983) and Lebow (1982) state that the timing of data collection is especially important. A respondent interviewed shortly after he or she has been registered on the program has not experienced the full range of services. Evaluations which collect data at termination may have difficulty locating departed clients and, if found, the clients may be unable to

remember details of the service experience. Since most dissatisfied clients will likely drop out of a program, the timing of data collection may determine the extent and direction of bias in the study. Moreover, timing an evaluation may be imprecise. In some agencies, cases remain open long after the final treatment session. To address the problem of timing, Larsen et al. (1979) advocate the use of cross-sectional studies.

Because of methodological problems, several approaches to assessment have been attempted (Gutek, 1978). Some researchers have abandoned subjective measures of satisfaction in favor of such objective measures as the number of cases processed or recidivism rates. This has proven unsatisfactory because only a weak relationship exists between subjective and objective measures of satisfaction. Others have attempted to develop a better measure of satisfaction than the commonly used single-item measures. This, too, has proven unsatisfactory. Most of the attempts to improve consumer satisfaction surveys have involved questionnaire construction.

Locker and Dunt (1978) state that global evaluations are inadequate measures of consumer opinion. Their alternative is to separate aspects of the program into discrete items, attribute a value to each item, calculate a composite score of these individual items for each respondent, and determine if the respondent is satisfied or dissatisfied by looking at their total score. They argue

that the validity of the rating can be improved if the respondents are asked to share their experience with each service before they give it a rating. They suggest that the ratings should use a multi-dimensional scale with a equal weighting given to each point on the scale rather than a dichotomous (satisfied--dissatisfied) scale.

Unstructured and direct questions should be used in the questionnaire. Direct questions are a better measure of satisfaction and dissatisfaction than open-ended, or unstructured questions (Locker & Dunt, 1978; Marin, 1980). Respondents tend to be more critical when asked specific questions about the care that they have received. Moreover, the questionnaire technique facilitates recall and enables respondents to elaborate on the services which they feel are priorities and comment on the services which they feel are less important.

Larsen (1979) advocates the use of inexpensive data collection methods and cautions that the researcher should ensure that the results of the research will be used for program planning and decision making. He mentions that a small number of items included on the questionnaire will minimize the costs associated with data collection, tabulation, and analysis. (For example, the previously mentioned Client Satisfaction Questionnaire had a total of only eight items and took an average of three to eight minutes for a client to complete.) As do other researchers (Rocheleau & Mackesay, 1980; Locker & Dunt, 1978), he

suggests that only a few items be devoted to overall client satisfaction. The remainder should relate to concerns of managerial interest and program effectiveness. Moreover, comparison should be built into the study by using questions in the local survey which have been used in other studies (Rocheleau & Mackesey, 1980).

Locker and Dunt (1978) suggest that the researcher focus on task related services rather than on particular services and examine respondent satisfaction with arrangements made for performing various tasks such as personal care, mobility, medical and nursing care. The advantage of this method of item construction is that the questions will be applicable to all respondents although they may have received different combinations of service. Using this method also has the advantage of disassociating a particular service from a particular service provider. Cohen's (1971) study of retarded mothers indicates that clients are reluctant to express dissatisfaction with a service if they like the individual who delivers it.

Although there is consensus that the items on the questionnaire should be related to manipulable aspects of care and generated by the staff or administrators (Marin, 1980), the method used by Kaufmann et al. (1979) insures that the items included on a consumer feedback questionnaire are also of importance to the consumers. After conducting an extensive literature review, the researchers created a menu of 38 sample questions. They distributed this menu of

questions to the three groups identified as the stakeholders: consumers, the advisory board, and administrators, and asked them to circle five of the questions. Of interest is the finding that the three groups were concerned about different aspects of the program. The clients were concerned with confidentiality and the program's links with other agencies. The board wanted to know how clients felt about the location of services and the administrators were interested in the ethnic matching of the therapist and the client. Kaufmann's method indicates that in order to truly involve consumers in an evaluation of the services that they have received, they need to be queried on those aspects of the program that they find relevant.

The way in which the survey is presented to the consumers is important (Lebow, 1982). The survey will receive different responses depending on whether it is internally or externally generated, whether anonymity is guaranteed, the stated purpose of the survey, and possible ramifications of the survey for clients and staff. Lebow (1982) argues that it is better to reduce the consequences of the survey and increase respondent anonymity.

The response rate is also affected by the way in which the questionnaire is administered to the client. Lebow (1983) reviewed 49 studies reporting satisfaction data and determined that in comparison to mailed questionnaires, interviews with a carefully selected sample immediately after service results in a high response rate.



Unfortunately, this method is also the most reactive and/or costly.

Descriptive statistics appear to be the most useful way in which to present the findings of consumer research to managers and practitioners. Rocheleau and Mackesey (1980) point out that "there exists an inverse relationship between the sophistication of the statistical technique used in an evaluation and the impact that this statistical information had on practitioners" (p. 412).

In the literature, numerous variables predict satisfaction. Predictors include client expectation (Locker & Dunt, 1978; Lebow, 1983; Larsen & Rootman, 1976); diagnostic and history variables, the length of treatment, the manner of termination, and the degree to which the treatment is viewed as supportive (Lebow, 1983); the number of counseling sessions and the extent to which the client improves with therapy (Attkisson & Zwick, 1982); world view (Gutek 1978); the extent to which counselors contacted other agencies on behalf of the client and the client's satisfaction with the amount of time spent with the counselor (Rocheleau & Mackesey, 1980). Demographic variables such as age, sex, race, marital status, income, social class, or education are not good predictors of satisfaction (Lebow, 1983).

### Conclusion

The concept of normalization, although widely espoused

and readily accepted, is not the norm for services designed for persons with developmental disabilities. Although the rights of those with physical or mental disabilities seem assured by Section 15 in the Canadian Charter of Rights and Freedoms, inequalities and impediments to community living are catalogued in the Report of the Special Committee on the Disabled and the Handicapped (Smith, 1981).

Disabled children, especially those with learning difficulties, do not have equal access to education. Unlike parents in European countries, parents in Canada continue to purchase, or rely on charity for aids and devices for their children. Those who modify their homes are saddled with the full cost of the renovation and do not receive the benefit of a tax concession. Although respite relieves the burnout which accompanies the provision of care to a family member, it is offered to a time limit of only two weeks per year in Manitoba (Arnold, Baumann, & Lowther, 1982). As previously mentioned, consumers have not been consulted in the design and implementation of services which are directed at them.

There are four reasons for the inadequate implementation of the normalization principle. First, persons with disabilities continue to be stigmatized. As aptly stated by one of the twelve persons profiled in the Report, Canada "is basically a materialistic society which is very hung up with money, and with visual beauty" (p. 120). Those who cannot contribute to society in the form of paid employment or who are physically unattractive are not

valued members of society and are not ensured equal rights.

Second, the medical profession continues to control access to services. Arnold et al. (1982) note that most of the services which are provided to families require a diagnosis and referral. The diagnostic process places the individual in the "sick role" and legitimizes the provision of well-meaning but often inappropriate services.

Third, politics interferes with the concept of independent living. This was exemplified by a recent article in the Winnipeg Free Press (21 May 1986, p. 10) which outlined the controversy which has arisen over the closing of the psychiatric nursing school at the Manitoba Developmental Centre in Portage. The manager of the Portage la Prairie Chamber of Commerce claimed that 30 out of 64 people that the Manitoba branch of the Association for Community Living (ACL) relocated have died. Her allegation, dismissed as "absolute hogwash" by the ACL, appears to be a smoke screen for the underlying community concern that closing the school and deinstitutionalizing residents will mean a loss of jobs.

Fourth, the professions which have arisen to deal with the problem of persons with disabilities are reluctant to relinquish their authority and responsibility. Although Schaefer et al. (1982) advocate that infant development services and respite services for children from birth to the age of three be delivered by generic sources (eg. Public Health Nursing and Continuing Care), specialized agencies,

programs, and departments have detailed eligibility criteria and appear reluctant to advocate individualized, comprehensive planning.

Schaefer et al. (1982) argue that current program planning is largely an attempt to fit individuals into existing program "slots". They suggest that the provision of cash subsidies to families for the purchase of services and the establishment of community boards which would identify local needs and supplement available resources are ideas which would further the concept of normalization.

The discussion on stress and coping indicated the importance of family-support services. Of particular importance is the observation that a family's service needs change as their child reaches different developmental plateaus and the importance of self-advocacy groups.

Consumer satisfaction surveys are a first step in acknowledging that families should have input into the services which are designed to assist them and their children.

## CHAPTER II

### METHOD

#### Practicum Organization and Study Site

My interest in consumer satisfaction and evaluative research led to my involvement in a study commissioned by the Department of Community Services and conducted under the aegis of the Child and Family Research Group at the University of Manitoba. The Principal Investigator, Dr. Barry Trute, drew up the initial proposal and in negotiations with the Department, determined the terms of reference of the study and obtained the Department's permission to interview the recipients of provincially funded medical and social services.

The site of the practicum was province wide. Because we were interested in families which cared for children with developmental disabilities and were particularly interested in those which were perceived as successful, we chose the provincial Winnipeg-based service which diagnoses developmental disabilities, the Child Development Clinic (CDC), and its ancillary service, Family Support Services (FSS) to serve as the co-ordinators of family identification for this study. The sample for our study consisted of 40 families located throughout the province who were chosen by

the Co-ordinator of FSS and the childrens' pediatricians using three criteria: 1) the child is happy, 2) the child is functioning at maximum given his or her developmental disability, and 3) the family has adjusted well to the child's disability.

The study sample consisted of families who had contact with FSS since its inception in 1982. Considering the fact that FSS receives approximately 120 referrals annually (Strutinsky, Note 1) the sample made up 10% of the total number of families seen by FSS since 1982.

### Procedure

The purpose of the study was to formulate hypotheses about the needs of families with children with developmental disabilities and the services which they require to be successful in their attempts to cope with the stress associated with raising such children. Consequently, we used a cross-sectional group study rather than a more rigorous experimental design. The cross-sectional survey design, described in full by Tripodi (1983), uses a purposive rather than a representative sample. It collects observations after the sample has experienced program services. To generate "hypothetical-developmental" knowledge, it describes what has occurred with program participants at one specific point in time.

After the interview guide had been designed and the study sample chosen, a response card, a pre-stamped return

envelope and two covering letters signed by the Co-ordinator of FSS and the Director of Special Children's Services were sent to the families. Overall, we were unable to interview only 5 families. One family refused to participate in the study. Another left for Europe. One of the members of a third family had a serious illness. A fourth family spoke very little English and we were unable to locate a fifth family. In total, 35 families--88% of our sample--agreed to participate in the study and completed the survey interview.

To ensure confidentiality, FSS would not release any of the families' names until they agreed to participate in the study. Once received, we kept systematic records of the respondents.

Appointments were arranged by each of four interviewers. During the initial telephone contact, the interviewer explained that the interview took approximately two hours, indicated that it involved both the father and the mother for the first hour and only the mother for the second hour, and offered reimbursement for child care if the parents felt that they would be interrupted during the course of the interview. At the beginning of the actual interview, interviewers assured the respondents of confidentiality, explained the purpose of the study, and mentioned that the results would be shared with the participating families either by mail or in a group meeting.

We attempted to familiarize each interviewer with the interview guide. Each question was thoroughly explained and

each interviewer delivered the study to a relative or friend before doing an actual interview. It was stressed that this was an interview and not a questionnaire. Respondents' comments were noted in page margins. We attempted to record the exact wording of respondents' answers to open-ended questions. The completed interview guides were collected and stored at the university research office.

### Instrumentation

The Family Survey was designed to provide qualitative and quantitative information in regard to families perceived as successful in their efforts to raise a child with a developmental disability. It included several sections: Information on Child(ren) in Family with a Disability, Information on Family Needs, Services Received (by both the child and the family), Impact of Child Disability on Family, and Family Information. Many of the items were adapted from the recent study conducted by Agosta, Bradley, Rugg, Spence, and Covert (1985). The section, Information on Family Needs, comes directly from their study.

The section, Information on Child(ren) in Family with a Disability, identified the child by first name, disability, gender, and birth date and measured the extent of the child's disability by asking four questions related to physical impairment, intellectual impairment, the amount of specialized medical attention that the child would require, and the amount of ongoing assistance that the child would



need with such daily activities as bathing, eating, and dressing.

The 16 items in the section, Information on Family Needs, identified the family needs which had arisen as a result of the child's disability. Needs such as comprehensive information, crisis and regular respite, quality care for the child at night, parent support groups, day activity centers, more time, specialized services like speech or physical therapy, transportation, specialized equipment, and modifications to the house were included.

In the Services section, parents were asked to list, rate, and indicate whether they had had to pay for the services that they had received. Services received by the family included day care, homemaking, genetic counseling, counseling or psychotherapy, respite care and/or sitter service, training in parenting skills, and information and referral. Services received by the child included early intervention preschool (defined as educational stimulation provided to a child under the age of five either at home or in a setting resembling a school), regular school, special education, physical therapy, speech or hearing therapy, recreation, medical services, dental services, transportation, home health care, attendant care, medication, diagnosis and assessment, counseling in regard to a special diet, special clothing, and equipment and/or modifications to the house. Those mentioned by families and later included in our list were infant stimulation, regular

nursery school, occupational therapy, assessments provided by an optometrist or an opthamologist, hearing assessments, and music therapy.

The section, Impact of Child Disability, consisted of 19 questions which measured both the positive and the negative impacts of raising a child with a developmental disability. Included were such diverse queries as "The situation has led to tension with spouse" and "Raising a disabled child has made life more meaningful for family members".

The section, Family Information, gathered basic demographic information. Included were the ages, educational level, and occupational status of family members, the family type, the family's postal code and annual income, and the opportunity losses attributable to the child's disability.

Other questions in the survey concerned the family's service priorities, the extent of their involvement in self-advocacy groups, their experience with other disabled family members, and the impact of the disabled child on their decision to have more children.

Although the cross-sectional group study does not control for internal validity (Tripodi, 1983), we attempted to enhance criterion based validity by using items that had been used in a previous study (Agosta et al., 1985), and by reviewing the scope of the information gathered with local service experts.

Questions were checked for clarity and appropriateness during a pretest with relatives and parents of children with disabilities who were not included in the original sample derived for this survey.

### CHAPTER III

#### RESULTS

##### Who were the successful families?

The successful families had several characteristics. Our first finding was that none of the families were single parent families. All had two parents, or in one instance two grandparents, caring for the child with the developmental disability. The majority were urban (80%), nuclear (86%), and biological (97%). In two families the parents were over the age of 40, but the rest were younger and most were in their 30's and late 20's. The average maternal age was 32 years; fathers averaged 35 years of age. In the one instance where grandparents provided care to the disabled child, the grandfather was 62 and the grandmother was 55.

On the average (46%), families in this study had two children. In 29% of the families, the child with the disability was the only child and in 17% of the families, the handicapped child was the youngest child. The children were predominantly male (63%). They ranged in age from six months to nine years; the average age of the handicapped child for the total sample was 3.4 years.

Of significance is the fact that these children were

often severely impaired. Forty-three percent of the families had a child with more than one disability. The response for the question concerning the extent to which the child's disability would affect intellectual development was: 3%-not at all; 40%-mildly; 37%-moderately; 20%-severely. Of the 91% of parents who claimed that the disability would affect their child's physical development, 43% specified that physical development would be affected to a moderate degree. The figures for the question which determined the extent to which ongoing specialized medical attention would be required were: 23%-no need; 37%-some need; 29%-moderate need; 11%-severe need. Seventeen percent of the families felt that their child would require long-term assistance with such everyday activities as eating, bathing, and toileting.

Down's syndrome was the disability most often mentioned (37%). Others listed were Fragile X syndrome, Alobar Holoprosencephaly, Robineau syndrome, Rubenstein-Taybi syndrome, tuberous sclerosis syndrome, mucopolysaccharidosis, and myochonic seizures.

These families were well educated. Eighty-six percent of the mothers and 80% of the fathers had at least a Grade 12 education. Almost two-thirds (60%) of the fathers had an university education.

The total taxable incomes of these successful families for the 1985 tax year ranged from \$0--9,999 to \$50,000 or more. Most of the families earned between \$30,000 and

\$39,999 (29%). Many (20%) earned more than \$50,000.

According to the 1981 census, 30% of the general population could be considered as middle-income earners (\$20,000--\$29,999). If the income categories of the families in our study are converted to 1981 dollars, most of the families would be included in this middle-income category. Because we did not ask for the families' exact incomes, this is only an approximate comparison. Direct comparison could have been made only by converting each family's income to 1981 dollars and calculating the percentage of families which fell within each income category as defined by Statistics Canada.

Almost half (46%) of the mothers worked; one quarter of these worked full-time. Almost all (91%) of the fathers were employed full-time.

### Services Received

Parents were asked which services they had ever received, which services they felt were not applicable to either their situation or the situation of their child (e.g. in the one situation where foster parents provided care for the disabled child, genetic counseling was an inappropriate service), the type of payment required for each of the services that they had received, and the services which they were presently receiving. The results are in Table 1.

Table 1

Percentage of Families Who Have Ever Received Service, Paid  
for Service, and are Currently Receiving Service  
That Family Has Received

Service	% of Families Ever Receiving Service		Not App	% of Families Ever Rec'g Service by Payment Category			% of Families Presently Receiving Service
	No	Yes		Pay	Partly Pay	No Pay	
Day Care	51%	46%	3%	50%	50%	*	37%
Homemaker	97%	3%	*	100%	*	*	3%
Genetic Counseling	37%	57%	6%	*	*	100%	11%
Counseling or Psychotherapy	86%	11%	3%	*	*	100%	3%
Respite Care/ Sitter Service	40%	57%	3%	5%	15%	80%	43%
Training in Parenting Skills	97%	3%	*	*	*	100%	3%
Information and Referral	11%	89%	*	*	*	100%	57%

\* Blank areas in the columns indicate no families.

Parents were asked to give an overall rating beside each of the services that they had received, indicating whether they had been "very satisfied" (VS), "satisfied" (S), "dissatisfied" (D), or "very dissatisfied". The results are in Table 2.

Table 2  
Parents' Rating of Services That Family Has Received

Service	Number of Parents Ever Rec'g Service	very satisfied	satisfied	dissatisfied	very dissat- isfied
Day Care	16	69% (n=11)	31% (n=5)		
Homemaker	1		100% (n=1)		
Genetic Counseling*	20	37% (n=7)	42% (n=8)	16% (n=3)	5% (n=1)
Counseling or Psycho- therapy	4	25% (n=1)	25% (n=1)	25% (n=1)	25%(n=1)
Respite Care Sitter Service	20	40% (n=8)	40% (n=8)	15% (n=3)	5% (n=1)
Training in Parenting Skills	1	100%(n=1)			
Information and Referral	31	52% (n=16)	39% (n=12)	10% (n=3)	

Note. Totals may not equal 100% because of rounding.

\* The total number of those rating a service may differ from the total number of families who have ever received a service because of missing data. In these instances, percentages were calculated using available data.

The figures in these tables indicate that day care, respite care/sitter service, information and referral, and genetic counseling are the four most common services. Thirty-seven percent of the families are presently receiving day care, 11% of the families are receiving genetic counseling, 43% of the families are receiving respite care or sitter service and 57% of the families are receiving information and referral. Although the majority of services



were provided without charge, half of the families who received day care needed to pay the full cost and the other half partially paid for the service. This is explained by the fact that payment for licensed day care is calculated on the basis of family income and varies from family to family.

Parents were either satisfied or very satisfied with the majority of services. The only services which received as many negative ratings as positive were counseling and psychotherapy. It should be noted that because only four families received these services, the ratings of only two of the families affected the distribution.

Many of those who expressed dissatisfaction with a particular service commented on the reason for their dissatisfaction. One couple said that, in their experience with genetic counseling, their needs were secondary to those of medical students. After they had been summoned to the hospital to receive genetic counseling, they discovered that the counseling session was in fact a training session in "ostensible pathology". Another commented that the physicians treated their child like a specimen. Even though they pushed for practical information, they received many different diagnoses. A third dissatisfied couple said that although the information that they received was helpful, the way in which they received it was too clinical and patronizing.

Although one couple was satisfied with the psychological counseling that they received, they

commented that it was not practical, and the counselor's suggestions were difficult to implement.

Respite care received the bulk of comments. Parents commented that the high staff turnover prevents the staff from developing long-term working relationships with the families. At least 11% of the families who received the service said that it was inconvenient. The need to arrange it one week in advance and the scarcity of evening coverage reduced its utility. Another family decried the qualifications of the respite workers. Their experience with respite had been extremely negative and they questioned the professionalism of the service.

Besides listing the services which they had received as a family, parents were also asked to list, and rate, the services which their child had received. The results are in Tables 3 and 4.

Table 3

Percentage of Families Who Have Ever Received Service, Paid  
for Service and are Currently Receiving Service  
That Child Has Received

Service	<u>% of Families Ever Receiving Service</u>		<u>Not App</u>	<u>% of Families Ever Rec'g Service by Payment Category</u>			<u>% of Families Presently Receiving Service</u>
	No	Yes		Pay	Part Pay	No Pay	
Early Intervention Preschool	26%	74%	***	12%	15%	73%	54%
Regular School*	54%	14%	31%	20%	***	80%	6%
Special Education*	46%	26%	29%	33%	11%	55%	20%
Physical Therapy	37%	57%	6%	***	5%	95%	31%
Speech or Hearing	49%	43%	9%	***	7%	93%	31%
Recreation Program	80%	14%	6%	20%	***	80%	9%
Medical Services	11%	89%	***	***	10%**	90%	77%
Dental Services	51%	40%	9%	43%	14%	43%	37%
Transportation	69%	26%	6%	22%	66%	11%	26%
Home Health Care	74%	26%	***	***	***	100%	11%
Medication	57%	40%	3%	36%	36%	29%	34%
Diagnosis and Assessment	6%	94%	***	3%	6%	91%	69%
Special Clothing	83%	9%	9%	100%	***	***	9%
Equipment/Modify	69%	26%	6%	***	11%	89%	23%
Montessori School	89%	11%	***	75%	25%	***	3%
Infant Stimulation	54%	46%	***	***	***	100%	29%
Occupational Therapy	77%	23%	***	***	***	100%	17%

\* Interviewer included Montessori school in this category.

\*\* Parents either moved to Manitoba from another province and needed to initially pay medical costs until they were eligible for the provincial medical insurance program or, in one instance, the parents decided to obtain specialized medical attention in another province.

\*\*\* Blank areas in the columns indicate no families.

Table 4  
Parents' Rating of Services That Child Has Received

Service	Number of Parents Ever Rec'g Service	very sat- isfied	satisfied	dissat- isfied	very dissat- isfied
Early Intervention Preschool	26	42%(n=11)	42%(n=11)	12%(n=3)	4% (n=1)
Regular School	5	60%(n=3)	40%(n=2)		
Special Education	9	67%(n=6)	33%(n=3)		
Physical Therapy	20	45%(n=9)	45%(n=9)	5% (n=1)	5% (n=1)
Speech or Hearing Therapy	15	40%(n=6)	40%(n=6)	7% (n=1)	13%(n=2)
Recreation Program	5	20%(n=1)	60%(n=3)	20%(n=1)	
Medical Services	31	39%(n=12)	55%(n=17)	3% (n=1)	3% (n=1)
Dental Services	14	57%(n=8)	43%(n=6)		
Transportation	9	67%(n=6)	22%(n=2)	11%(n=1)	
Home Health Care	9	33%(n=3)	67%(n=6)		
Medication	14	21%(n=3)	71%(n=10)	7% (n=1)	
Diagnosis and Assessment	33	27%(n=9)	58%(n=19)	6% (n=2)	9% (n=3)
Special Clothing	3		100%(n=3)		
Equipment/ Modifications to House	9	44%(n=4)	44%(n=4)	11%(n=1)	
Montessori School	14	75%(n=3)	25%(n=1)		
Infant Stimulation	16	31%(n=5)	50%(n=8)	13%(n=2)	6% (n=1)
Occupational Therapy	8	63%(n=5)	38%(n=3)		

Note. Totals may not equal 100% because of rounding.

As is evident from these tables, early intervention preschool, infant stimulation, physical therapy, speech or hearing therapy, medical services, dental services, transportation, medication, and diagnosis and assessment are the most common services. The percentage of the total number of families which are presently receiving these services are: 54%-early intervention preschool, 29%-infant stimulation, 31%-physical therapy, 31%-speech or hearing therapy, 77%-medical services, 37%-dental services, 26%-transportation, 34%-medication, and 69%-diagnosis and assessment. As with the services that the family received, parents indicated overall satisfaction with the services that the child received.

However, parents indicated a wide discrepancy in the quality of infant stimulation and speech therapy. In the 2 1/2 years that one child attended infant stimulation, there were three workers. One was described as excellent, one as unsatisfactory, and one as average. The rural families complained that the infant stimulation workers were untrained, arrived at unsatisfactory hours, and attempted to apply a program that the parents had difficulty implementing. One family received infant stimulation only once every several months.

In one northern community, speech therapy is available only twice a year and in another community, it is delivered by a paraprofessional in the day care program, rather than by a qualified speech therapist. Urban parents reiterated

that speech therapy is insufficient.

Regular school appears to have similar problems. Handicapped children who attend regular school are very reliant on teachers' aides. The inconsistency in teachers' aides, noted one family, flawed an otherwise satisfactory program.

Two families stated that they were not able to receive enough physical therapy, and what was offered, did not come soon enough. Another family, living in rural Manitoba, said that there is no occupational therapy in their community. They need to bring their son to Winnipeg every three months to receive therapy. Most of the criticism was aimed at the diagnostic and assessment services. Comments included, "It is slow and doesn't reflect the child's abilities", "The doctors are insensitive", "Being an atypical setting, the (diagnostic setting) elicits atypical behavior. It relies on a clinical approach rather than acknowledging the parents' impressions of their child's development", "Although a comprehensive assessment is done annually, the results are not used to inform any of the service providers. The assessment serves a bureaucratic function", and "The assessments are based on statistical norms and are of no use insofar as understanding (the child's) likely progress."

### Family Needs

This section measured the families' perceptions of their unmet needs at the present. It did not measure the needs currently being met by service provision.

### Information

Families' need for information varies. Although 49% indicated that they have no present need for information on the type of disability that their child has, need was indicated for information on how they should best care for their disabled child (66%), on how they should deal with behavior problems displayed by their disabled child (57%), and on how or where they could get services (66%).

Almost all of the parents said that they had found out everything possible about their child's disability. Those who indicated extreme need (14%) often stated that little was known about their child's particular syndrome, and although what is known is available, not nearly enough has been published. Only one family felt that this question was not applicable to their situation. The mother, fearing that her son would be labeled, asked that she not be told his syndrome type.

Whereas the amount of information regarding disability type is limited, families have an ongoing need for information regarding services. Services are much more accessible to urban families, but it takes contact with an individual knowledgeable about the system, the child, and

the services which are available to take advantage of the range of health and social services.

One of the most common responses was that families felt that they had "lucked in" to someone who was able to refer them to the appropriate services. In contrast, the family most distant from Winnipeg indicated extreme need, with the explanation, "There are no services here." Extreme need for information in regard to services was expressed by 11% of the families.

Information on how to best care for the disabled child and information on how to deal with behavior problems were considered needs by the majority of families. The latter need for information depends on the particular behavioral problems that the child displays and is related more to the type of the syndrome than the age of the child. Many parents, especially those with Down syndrome children, viewed their children's behavior as appropriate and typical for a child their age.

### Respite

Respite in Manitoba is allowed to a maximum of two weeks or \$1200.00. For ongoing respite that is arranged during the summer, workers advise that the families give them at least two weeks notice. Co-ordinators attempt to arrange crisis respite in the event of a death or emergency in the family, but are dependent on the availability of respite workers. Both in-home and out-of-home respite are



available. The type depends on the family's needs.

The need for respite--both crisis and ongoing--was evident in the survey. Twenty percent of the families indicated an extreme need for someone who could come to their house and care for their children on short notice; 17% were desperate for a qualified person to care for their child overnight. Twenty-six percent of the families indicated extreme need for regular, temporary, respite.

Those who indicated that they did not need crisis respite (46%), overnight in-home respite (60%), or regular respite (54%) often commented that their family or friends are available if they need child care on either an emergency basis or for several days. This appears to be substantiated by the fact that, although we offered parents reimbursement for arranging child care for the duration of the interview, only six families accepted our offer. The rest, if their children required care, made arrangements with either a family member or a neighbor.

#### Self-advocacy Groups

Some individuals benefit from joining a group consisting of other people with similar concerns and experiences. The emotional support and the information which they receive from these self-advocacy groups help them to cope with their problems. Others prefer to handle their difficulties alone. Almost two-thirds (63%) of the families in our sample recognized participation in a self-advocacy

group as a need; 37% indicated "no need" for this type of involvement.

Of those who had participated in self-help groups, most belonged to either "Parent to Parent" or the "Parent's Group of the Canadian National Institute for the Blind". Other groups mentioned were the "Fort Garry Group", the "Canadian Association for the Mentally Retarded", the "Integration Action Group", the parental lobby group set up to reestablish funding for physiotherapy outpatients, the "National Society for Mucopolysaccharide Diseases", the rural program of the "Society for Manitobans with Disabilities Inc.", and "Parents of Exceptional Children".

#### Day Care

In regard to day care, 49% of the parents indicated "no need", 23% of the parents indicated "extreme need", and 26% of the parents saw their need as between these two extremes. The clearly polarized responses indicated that although only 11% of the mothers in our sample were employed full time and required alternate care for their child throughout the day, day care was seen as a priority by most parents.

#### Time

In regard to the need for more time to complete household chores, 49% of the parents indicated "no need", 9% of the parents indicated "extreme need", and 40% of the parents saw their need as between these two extremes. In

contrast is the need for more personal time. Twenty percent of the parents acknowledged an "extreme need" for time alone. These questions, although answered by both of the spouses, largely represented the views of the mother and often required negotiation. After reminding their husbands that they spend a disproportionate amount of time with the disabled child, the mothers' initial responses usually held.

#### Specialized Services (Speech or Physical Therapy)

Of all of families' needs, the need for specialized services, especially speech therapy, was one of the most apparent. Eleven percent of the parents indicated "no need", 51% indicated "extreme need", and 34% of the parents saw their need as between these two extremes. Not only is there a one year waiting period for speech therapy, several parents commented that speech therapy is "rationed" and offered only to those children who require it the most.

#### Money

The need for financial assistance was not widely supported by the parents. Because many of the services for children with disabilities are either subsidized, or provided free of charge, the majority (60%) of parents had "no need" for money to take care of their disabled child. There was a significant minority (14%), however, who indicated "extreme need". This group did not appear to be in financial straits. Their taxable family income for 1985

ranged from the income categories \$20,000 - 29,999 to \$40,000 - 49,999 and averaged between \$30,000 and \$39,999. Rather, it tended to be rural. More than a quarter (29%) of the rural families remarked that they needed to pay for the costs involved in travelling to Winnipeg for medical and nonmedical appointments.

#### Transportation

The fact that the need for transportation was recognized by only 20% of the sample indicates that urban families do not require transportation. Although families need to drive their children to appointments, other services such as regular school and the day care programs at both the St. Amant Centre and the Society for Manitobans with Disabilities provide transportation. It is in rural Manitoba, especially in northern rural Manitoba, that transportation is a problem. Because of the scarcity of services, families need to travel to Winnipeg for regular medical assessments, physiotherapy, and occupational therapy. They receive reimbursement only if the appointments are authorized by a physician. For services which are not authorized by a physician, parents pay the travel, hotel, and food costs associated with the lengthy trip themselves.

#### Special Equipment

Although some need was noted for such special equipment

as arm or leg braces, wheelchairs, special shoes, or toys, the majority of parents (54%) indicated "no need". The need for equipment was specific to the child. A child with Down's syndrome, for example, required very little specialized equipment in comparison to a child with a physical disability. Only 14% of the parents indicated an "extreme need" for this type of service.

#### Modifications to the House

There was no need for household modifications to enable the childrens' motility. Eighty-nine percent of the parents indicated "no need"; 11% of the parents remarked that the question was "not applicable". If the children had been older, more need could conceivably have been identified. In this study, the children who were physically disabled were still small enough to be carried, and those who were wheelchair dependent could still wheel through average width doorways.

Parents were asked to prioritize the services which they had received in terms of those which they had found to be the most helpful. These were the four most helpful services, in rank order:

- infant stimulation (n=11)
- respite care (n=11)
- occupational therapy (n=8)
- medical services (n=8)

Several other services merit mention. For one family, day care was only made possible through the availability of a special needs grant. The interviewer understood that this grant took the form of a subsidy given directly to the parents rather than a grant given to the day care provider for more equipment or staff. It was the provision of this practical service, rather than the availability of a more specialized service, that the parents found to be the most helpful. Another family appreciated the fact that the association to which they belonged functioned as an advocate for their concerns. A third family praised the benefits of a music therapy program. A fourth family found the local summer recreation program to be invaluable for their nine year old son.

When asked to prioritize the services which they had found to be the least helpful, parents listed the following in rank order:

- diagnosis and assessment (n=12)
- speech therapy (n=4)

- genetic counseling (n=3)
- physical therapy (n=3)

Two points are relevant. Nine parents - 26% of our sample - did not respond to this question. They stated that they had found all of the services that they received to be helpful. Although diagnosis and assessment were the most common services, received by 94% of the families, they were also seen as being the least helpful of all of the services by 20% of the surveyed families.

In looking at these lists of the services which the families rated as the most important and the least important, several observations can be made. Parents appeared to favour such practical, skill-building services as infant stimulation and occupational therapy. Physical therapy, with its emphasis on the treatment of physical disorders through such physical methods as exercises and massage, may have been seen as a least helpful service because of the child's relatively slow rate of progress.

Parents rated medical services in general as a helpful service, but rated two specific medical services--diagnosis and assessment and genetic counseling--as least helpful services. Diagnosis and assessment and genetic counseling provide technical information. Parents appear to have a need for practical and understandable information.

The availability of respite services was highly rated. Speech therapy was poorly rated. The former may indicate that parents, at times, need time away from their child.

The latter rating points to the parents' comments that speech therapy is insufficient and has a long waiting list.

### Ranking of Services

Families were asked to prioritize a list of services according to those that they would find the most useful in caring for their disabled child at this point in time. Each family was given a list of fourteen services and asked to rate these services in descending order of preference. A list of services was compiled, starting with the most useful and ending with the least useful, by averaging the ratings given by the 35 couples for each of the 14 services. The services, ranked by parents in order of importance, were:

- advice regarding access to services for your disabled child (mean=3.52)
- counselling in regard to your child's future (mean=3.86)
- regular respite services (mean=4.09)
- information about your child's disability (mean=4.19)
- crisis respite services (mean=6.30)
- transportation assistance (mean=6.45)
- cash assistance program (mean=8.41)
- professional advice in regard to financial planning for child(ren) (mean=8.74)
- family counselling to help home situation (mean=8.76)
- housekeeping service to help with household chores (mean=8.85)
- aid in obtaining special equipment for your disabled



child (mean=9.13)

- marital counselling to assist parents (mean=10.34)
- assistance with chores done outside the home  
(mean=10.45)
- improvement grant to meet needs of disabled child  
(mean=10.53)

### Recommendations

One of the most interesting and thought provoking questions in the interview guide was, "What would you do different than what is currently being done to help families like yours with a disabled child?" Although this was an open-ended question, many families voiced the same concerns and offered similar suggestions. The major recommendations were:

1. More information sooner. Over a third (34%) of the families stated that parents should be provided information in regard to the child's disability, the name of a person who they can contact, and a comprehensive list of services immediately after the child's diagnosis. For those parents who learn of their child's disability at birth, information should be provided in the hospital. Information in regard to services should be available in book form and updated on a yearly basis. Several mothers felt that women who want to help their children at home should be provided with the instructional material used by their child's infant stimulation worker and speech

therapist. Several families suggested that parents receive a copy of the physician's report after their child attends an assessment.

2. Earlier diagnosis and referral. Twenty percent of the sample argued for more medical information "right from the start"; 9% of the parents argued for earlier diagnosis and suggested that physicians inform families as soon as a developmental delay is suspected. Although it appears that many physicians are hesitant to inform the parents that they suspect a developmental disability, access to services seems to be denied until the parents receive a firm diagnosis. Delaying the diagnosis is seen by parents as hurtful to the developmental progress of the child.

Families suggested earlier referral (without their needing to "pressure" professionals) to occupational therapy, physiotherapy, self-advocacy groups, and most importantly to a consistent, central referral person. Two families indicated that parents who learn of their child's disability at birth should be immediately referred to a support group while the mother is still in the hospital. One family recalled that, because of their physician, they were introduced to another parent of a child with Down's syndrome shortly after their son's birth. It was by looking at her family pictures that they realized that raising a disabled child was possible, and even enjoyable. Another family suggested that parents should be referred to a support person as soon as a developmental disability is

suspected. They felt that parents, from the time that they suspect that their child is developmentally disabled to the time that they actually receive services, undergo a great deal of stress and require the understanding and experience of a confidant.

3. Sensitive and competent medical treatment.

Fifty-four percent of the families made recommendations in regard to the service areas of diagnosis, assessment, and medical treatment. Each parent that we interviewed was able to clearly recall the circumstances surrounding their child's diagnosis. The time of day, the physician's wording, and their reactions upon hearing the diagnoses were vivid. They also recounted their childrens' regular assessments with the same detail. Unfortunately, many of their experiences with health care professionals have been less than satisfactory. Twenty-three percent of the families insisted that health care professionals should be more sensitive to the needs of the disabled child and the family. Several families said that nurses and interns should receive specific training in regard to the psychosocial aspects of a mental disability and the range of social services which are available. One family stated that health care professionals should provide more comprehensive medical information in regard to the child's disability and should treat the disabled child as a member of a family, rather than as a medical anomaly.

These statements suggest that qualified family

counselors should be employed to provide therapeutic support and practical advice during the period of stress and depression which follow the diagnosis.

4. Normalization and public awareness. Fourteen percent (n=5) of the parents suggested an increase in programs which adhere to the concept of "normalization". Two programs, in particular, were mentioned: daycare and recreation. Day care should follow the same principles as an integrated school program. One family suggested that it should provide speech and hearing therapy and advocate the Montessori teaching method. Children with developmental disabilities should have the opportunity to join a recreation program. Because of their developmental delays, they are presently unable to join sports teams with children their own age and need to rely on the recreation that is provided by the school. An event such as father and son baseball was given as an example of the types of programs that could be available.

5. Tax rebate. The implementation of a tax rebate for the expenses associated with raising a child with a developmental disability was suggested by 9% of the parents. Two of the rural families mentioned that a tax rebate should be available for transportation. One family calculated that they spend between \$300 and \$500 on gas transporting their child to various appointments in Winnipeg. This expense is not recognized by either the provincial or federal government.

6. Expanded community-based services. Parents

recognized a need for more infant stimulation, speech therapy, respite, and counseling in regard to parenting skills. Specific comments were made about each of these services. It was suggested that the infant stimulation program should be appropriate to the child's developmental stage and should begin before the child is five months old. It was also suggested that infant stimulation workers should be provided with more equipment, such as toys. One of the rural families commented that, "Rural infant stimulation workers are chosen because they are good with children but they should receive ongoing training and orientations. At present, infant stimulation workers do not have the experience."

One couple told the interviewer that speech therapy is rationed and offered only to those children most desperately in need. Because their son was denied speech therapy, even after three different assessments, they plan on hiring a speech therapist privately. Two families mentioned that speech therapy is unavailable to children under the age of three. They suggested that it should be offered to children one year of age and older.

Community respite, on the whole, is understaffed, receives sporadic funding, and is unable to accomodate parents who require it on short notice. More workers could be hired if it was better funded, and consequently, parents could utilize it more often and more spontaneously throughout the year. Eleven percent of the families

recognized a need for crisis respite. They were critical of the fact that respite requires several weeks notice. One family said that respite should be offered twice a month and should be delivered by the same worker so that the child becomes familiar with the worker. Another said that a sitter service should be provided for the siblings who are not disabled to permit parents to attend appointments with the disabled child.

7. Specially planned rural services. Parents who live in rural Manitoba are in an unique position. They either need to travel to Winnipeg or to push for local services. One family realizes that because their child is the only child with a disability in their area, they will need to press for and initiate services that are already well established in Winnipeg. These parents have faced difficult experiences in securing medical services, day care programs, and infant stimulation. They anticipate the eventual difficulties that they will encounter with the local school board when their child is of school age.

Like urban families, rural families advocate integrated programs and normalization. What they see lacking in the rural services, though, is an awareness of children with disabilities and the specialized training which will enable these children to reach their potential. For example, infant stimulation workers are seen as being not as well trained and do not seem to gather the experience of workers in Winnipeg. Consequently, the infant stimulation program,

although appreciated by the parents, is seen as being of dubious benefit to the child. The services seen as priorities by the rural families were: specialized education and specialized day care, support groups, transportation, advice, information, and appropriate mental health counseling.

Several specific requests were voiced by families during the course of survey interviews: (a) all diagnostic tests should be done at the Children's Hospital, (b) special recreational programs like horseback therapy (currently available to adults) should be available to children, and (c) day care operators should be actively recruited and adequately remunerated.

#### Impact of Child Disability on Family

Although families have experienced both positive and negative consequences as a result of raising a child with a developmental disability, the results indicate that this study's "successful families" report less stress, more marital satisfaction, less family disruption, less financial strain, and less social isolation than families of handicapped children in general (for description of usual family adjustment see Lonsdale, 1978).

The majority of families (77%) (n=27) indicated that chronic stress either had not been a consequence, or had only been a mild consequence, of raising a child with a disability. Only 11% of the families indicated that chronic

stress had been a consequence "to a substantial degree". Although families acknowledged that there had been unwelcomed disruption to "normal" family routines (29%-"not at all"; 40%-"to a mild degree"; 17%-"to a moderate degree"; 14%-"to a substantial degree"), 63% of the families claimed that raising a disabled child had either not had any impact, or had had only a mild impact, on the amount of time that they were able to spend with other children. Families seemed to have remained cohesive. Ninety-four percent of the families stated that the child's disability did not affect the degree to which family members discussed family problems unrelated to the disability.

Of the total, 71% of the parents noted that there has been no physical management problems requiring special equipment or modifications to the house. Only two families acknowledged the presence of this problem "to a substantial degree".

When asked if raising the handicapped child had led to additional financial costs, 34% of the parents said "not at all" and the majority (40%) of the parents said only "to a mild degree". This was substantiated in a later question which determined if parents had had to cancel holidays or postpone a major purchase because of the costs associated with raising a handicapped child. Eighty-three percent of the parents have not had to cancel or postpone major holidays nor delay a major purchase.

Almost all of the parents (97%) indicated that there



has been extraordinary time demands created in looking after the needs of the disabled child. Thirty-one percent of the families recognized this problem "to a substantial degree"--only one family said that having a disabled child had not made any difference in terms of time. Of interest is the finding that the increase in time demands did not lead to a reduction in the time parents were able to spend with their friends. Fully 60% of the families claimed that they spent as much time with their friends now as they did before. The rest of the figures for this question were: 26%-"to a mild degree"; 3%-"to a moderate degree; 11%-to a substantial degree.

The negative effects of raising a disabled child on the parent's marriage was of important research concern. Forty-six percent of the families in this study, however, claimed that the situation either had not led to marital tension or had led to marital tension only "to a mild degree" (37%). Many of these spouses appear to have had a solid relationship before the birth of the disabled child. Although many (89%) recognized an improved marital relationship, 11% denied that the success of their relationship was due to the fact that they had raised a child with a developmental disability. The common remark was, "But it (the marriage) was good before we had the child."

Social contacts, although affected, have not been a notable consequence of raising a disabled child. When asked

if the child's disability had led to limitations in social contacts, 54% of the parents responded "not at all", 29% responded "to a mild degree", and 17% responded either "to a moderate degree" or "to a substantial degree". Eighty-nine percent of the families have not hesitated to phone friends and acquaintances. Rather than voicing family isolation, parents (74%) indicated that they had made valuable friends through sharing the experience of a disabled child. In fact, 37% stated that they had experienced this consequence "to a substantial degree".

Two of the positive benefits of raising a disabled child that are seldom mentioned in the literature are that other family members become more understanding of people with developmental disabilities, and in appreciating normality and in developing patience, experience a more meaningful life. Ninety-four percent of the parents in this study acknowledged that other members of the family had become more understanding. The figures were: 6%-"not at all"; 17%-"to a mild degree"; 34%-"to a moderate degree"; 43%-"to a substantial degree". Eighty-nine percent acknowledged that raising a disabled child had made life more meaningful for family members.

This finding is reflected in the results regarding positive personal development. All but 11% of the parents acknowledged personal growth as a result of having a child with a disability.

Have the parents' views of government services in

general become more positive because of their experience with services for disabled children? The findings for this question are inconclusive. Many (23%) have not developed a more positive view of government services, but the same number (23%) indicated that their impressions of government services had improved "to a substantial degree". On the whole, since they have become familiar with services for disabled children, parents have developed a more positive view of government services. From the comments which accompanied this question, it appears that it was those who experienced a scarcity of services, or who had had a particularly bad experience with one of the services who indicated dissatisfaction.

### Summary

The "successful families" had several characteristics. They tended to be two-parent, urban, nuclear, biological, relatively young, well-educated, and financially comfortable. The children in our sample were also relatively young (mean=3.4 years) and often severely impaired.

### Services

Parents were asked to list the services which they had ever received, the services which they were presently receiving, the type of payment required for each each service, and their rating of each of the services. Those services which required full or partial payment by the

majority of parents who had received them included: Montessori schooling, day care, dental services, transportation, medication, special clothing, and a homemaker. Some parents paid for services which are normally provided free of charge in Manitoba. Out-of-province medical services, specialized education, and private speech therapy were three examples.

Overall, the parents were either satisfied or very satisfied with the services. In those instances where dissatisfaction was expressed, the small sample size lent caution to the findings.

The services which were presently being received by over a third of the total sample included: day care, respite care/sitter service, information and referral, early intervention preschool, medical services, dental services, medication, and diagnosis and assessment.

Parents were queried about unmet need. Day care, one of the most widely received services, was seen as being sufficient. The provision of respite--both crisis and ongoing--was seen as being insufficient. Although families listed information and referral as a common service, they continued to recognize a need for practical information in regard to how they should care for their child, on how they should deal with behavior problems, and on how or where they could get services. Need was also recognized for more personal time and more specialized services such as speech therapy. Rural families acknowledged that transportation

was a problem and requested the provision of either transportation or a subsidy to defray the costs of travelling to Winnipeg to attend appointments.

The services perceived as being the most helpful included infant stimulation, respite, occupational therapy, and medical services. The services perceived as the least helpful were diagnosis and assessment, genetic counseling, physical therapy, and speech therapy. The last service appears to have received an unfavorable rating because of its unavailability and long waiting lists.

When asked to rank services, parents prioritized these services in order of importance: advice regarding access to services for their disabled child, counseling in regard to the child's future, regular respite services, information about the child's disability, and crisis respite services.

It appears from this data that the most important services that can be provided to parents raising a child with a developmental disability are practical information, regular and crisis respite, speech therapy, occupational therapy, infant stimulation, medical services, and psychological counseling.

#### Impact of Child's Disability on Family

The families in our study appeared to be coping well with the responsibility of caring for a disabled child. They reported little stress, seemed to be cohesive, had few physical management problems, and had not experienced

burdensome financial costs.

Raising a disabled child does not seem to have been detrimental to these families. In some respects, the families appear to have benefitted from the experience. Rather than indicating marital tension, the majority of spouses stated that their marital relationship had improved. Social contacts were maintained despite the fact that caring for the disabled child involved extraordinary time demands. Most parents said that they had made valuable friends through sharing the experience of raising a disabled child. Parents reported positive personal growth. Family members were said to have become more understanding of people with developmental disabilities and were finding life more meaningful.

## CHAPTER IV

### DISCUSSION

The results of this research study indicate that successful families are homogeneous. Each shows an ability to cope with the disability of the child that is independent of the extent of the child's disabilities, the age and gender of the child, and the family's annual income. In this respect, research findings support the hypothesis forwarded by Mink, Meyers, and Nihira (1976) that there is homology in the types of families which provide care to disabled children that is independent of the degree of the child's retardation.

To determine the effect of the aforementioned variables on the family's ability to cope, each was correlated with the Negative Impact Scale which identified the parents' perception of the impact of the child's disability on the family. The scale consisted of the questions included in the section, Impact of Child Disability on Family. Ratings on the positive items were reversed, and the one question which proved inappropriate, "There has been less time for parents to spend with other children in the family" was deleted. (We realized that this question was inapplicable to those families with only one child only after we scanned the computer readout. The number of missing cases (n=10) justified its deletion).

In their shortened form of the Questionnaire on Resources and Stress (QRS, Holroyd, 1974), Friedrich, Greenberg, and Crnic (1983) included a question on the extent of the child's physical and intellectual disabilities. They reasoned that parents with a severely disabled child would report different difficulties than parents with a mildly disabled child. Although 43% of the sample had a child with more than one disability, it was found that there was no significant relationship ( $\chi^2 = 3.69, df=4, p<.45$ ) between the extent of the child's disability and the perceived impact of the child's disability on the family.

The literature suggests that the type of disability affects the parents' ability to cope. Findings by Nihira, Meyers, and Mink (1983) reveal that providing care to a Down's syndrome child is less stressful than providing care to a non-Down's syndrome child. Despite the fact that children with Down's syndrome make up 37% of our sample, there is no significant relationship ( $\chi^2=2.52, df=2, p<.28$ ) between the occurrence of Down's syndrome and the family's ability to cope.

Some researchers have suggested that the age of the child affects the parent's ability to cope. Wikler, Wasow, and Hatfield (1981) noted that parents experience periodic crises during the developmental stages of their child's life. For example, parents who realized that their child would not walk at the usual age of 12 to 15 months may



experience a period of grieving. Although 40% of the children in our study were at the ages at which normal children would have met two important developmental milestones--walking and talking--the age of the child was not found to be related to the Negative Impact Scale ( $r=0.1, n=33, p<.29$ ).

The findings in regard to the impact of the child's gender on the parent's ability to cope are equivocal. In a study conducted by Friedrich (1979), mothers of female children reported more stress than mothers of male children. One of the reasons for this finding may be that female children, in comparison to male children, tend to be socially maladapted (Nihira et al., 1983). In a much earlier study (Farber, 1959), parents of handicapped boys reported more stress and indicated that raising a disabled son had adversely affected their marital relationship. We found that there was no significant relationship ( $\chi^2=1.37, df=2, p<.50$ ) between the gender of the child and the perceived impact of the child's disability on the family.

One might anticipate that families with adequate financial means will tend to cope with stress better than those families who are poor. Findings indicate that there is no significant relationship ( $\chi^2=0.84, df=4, p<.93$ ) between family income and the family's ability to cope with the child's disability.

#### Needs

Families recognize a need for practical information, respite, day care, self-advocacy groups, speech therapy, and personal time. The need for more practical information, acknowledged by approximately two-thirds of the sample, was cited by Agosta, Bradley, Rugg, Spence, & Covert (1985), listed as a priority by parents interviewed by the Minnesota State Planning Agency (cited in Bruininks, 1979), recognized by Wikler et al. (1981), and considered essential and/or important by 95% of the parents interviewed in a study conducted by Lonsdale (1978).

Findings in regard to the need for emergency, in-home, and ongoing respite, recognized by 49%, 34%, and 43% of our sample respectively, are equivocal. Although 45% of the parents stated that short-term hostel care was unnecessary In Lonsdale's (1978), the average age of the handicapped children was a relatively young 6.9 years and, when pressed to consider situations in which they would use crisis respite, parents could not foresee exigencies that could not be met within the family network. These results suggest that the need for respite services depends on the age of the child and the support network available to the parents. Other findings and recommendations (Apollini & Triest, 1983; Agosta et al., 1985; Arnold, Baumann, & Lowther, 1982; Bruininks, 1979; Schaefer, Robson, & Steinkopf, 1982) point to the importance of respite care.

The need for both day care and participation in a self-advocacy group was recognized by the parents interviewed by

Lonsdale (1978). The need for more personal time, indicated by 60% of our sample, was also identified as a need by Holroyd (1974).

Recognizing that families caring for disabled children often had financial difficulties (Holroyd, 1974), Schaefer et al. (1982) recommended in their review of mental retardation services in Manitoba that families be provided with direct financial subsidies for special needs and equipment. Although the majority of families (60%) who were successful in their adjustment indicated "no need" for financial assistance, need was indicated for such specialized services as speech therapy. This need could be met by: (a) providing families with direct financial subsidies to purchase the service on the open market, (b) providing the service free of charge, and (c) providing the service with a fee and an offsetting income-tested subsidy.

### Services

From the ratings on the Information on Family Needs Scale, comments that accompanied the Services Received section, and the discussion that stemmed from the open-ended question, "What would you do different than what is currently being done to help families like yours with a disabled child?", several themes emerged.

Parents would like health care professionals to deal with the psychosocial, as well as the behavioral aspects of the child. Although they acknowledged that receiving the

diagnosis is important, and an essential first step, parents wanted information in regard to their child's functioning at home, in the school, and in the community. They commented that health care professionals should indeed practice "family practice" and recognize the child as a family member, rather than as a physical anomaly. They worried about their child's acceptance in the community, applauded integrated schools, and recognized the scarcity of recreational opportunities for their children.

This emphasis on the child's interaction with his or her environment is recognized by Beckman-Bell (1981). She hypothesizes that professionals can reduce parental stress by acknowledging the psychosocial functioning of the child and appropriately intervening in the ongoing interaction between the child and the environment.

Parents want a central referral person who is aware of the services and resources that are available and who will offer ongoing advice. Their complaint that they often accessed services by accident could be remedied by the availability of a directory listing relevant professionals and resources. The provision of information should be ongoing and age related. The fact that parents recognized "counseling in regard to their child's future" as a service priority reveals that they need to make difficult decisions at different stages in their child's life and rely on the appropriate information. This need for advice concerning the child's future could be acknowledged in the child's,

or the family's initial service plan and implemented through regular service contact. Conscientious case management would increase the likelihood of parents receiving the appropriate counseling.

Parents need emotional support and practical help from both professionals and self-advocacy groups at crisis periods to cope with the child's disability. They recalled that the first crisis was hearing the family physician voice a concern in regard to the child's development. Another was having the child tested to determine if the problem was in fact a developmental delay. A third was hearing the actual diagnosis. Many of the parents who had learned of the child's disability at birth regretted that they had not been immediately referred to a self-advocacy group. Others felt that a professional could aptly provide emotional support at these critical times.

Our findings support the results of McAndrew (1976). She suggests that parents should have contact with a social worker in the days immediately following the child's birth or as soon as the parents suspect a developmental delay. Because parents often lack the energy during these periods of depression and crisis to seek help she feels that social workers should take the initiative and actively reach out to provide timely assistance.

Although 49% of the sample indicated that their need for information in regard to their child's disability type had been met, 20% of the parents recommended that more

medical information should be available "right from the start" and 9% advocated earlier diagnosis. This is important for two reasons. First, hearing the diagnosis enables the family to first grieve, but then cope with the fact that their child is disabled. Second, access to many of the services seems to be denied until a diagnosis has been made.

Families decried the fact that health professionals were largely uncompassionate and insensitive. Comments like, "Genetics people seemed to be too cold and routine" and "(we) often felt to be guinea pigs for interns who looked very bored" were common. Parents' suggestions included better and more comprehensive training for interns and nurses in regard to developmental disabilities and the services which are available to families with disabled children, more linkages between social and health services, the provision of a list of specialists knowledgeable about the child's disability so parents know who to contact, and the close association of a social worker with the facilities that provide diagnosis and assessment.

The large number of parents who felt a need for family counseling suggests that services should be directed to the family as a whole and should not only focus on the child. This finding reflects the ecological model of the family forwarded by Bubolz and Whiren (1984). The total family should be considered in the development of a plan for a handicapped member to ensure that benefits to the entire

family are maximized and costs minimized.

Three of the variables that we did not measure, but which appear to have had an impact on the family's ability to cope with a disabled child were optimism, openness, and a sense of humour. In recounting their experiences, families could almost always refer to another's situation that was more desperate. "That's life" and "You can always look around and see people who are worse off" were typical remarks. When we first started interviewing, we were surprised at the bluntness and openness of the many of the parents, especially the mothers. The families appeared to be extremely realistic and practical. Almost all of the researchers interviewed a couple who had difficulty agreeing on the appropriate answers, and who would engage in a vociferous argument in defense of their viewpoints. Although we were at first surprised that these families were considered successful, we later realized that healthy arguments had probably abetted their ability to cope.

Two articles support these findings. Lonsdale (1978), too, commented on the parents' optimism and their philosophical attitude towards raising a child with a developmental delay. In the taxonomy of family life styles formed by Mink et al. (1984), openness and awareness of the respondent were common to families who had good parent-child relations and a low occurrence of stressful life events.

Many of the parents had been in contact with self-advocacy groups and a small percentage (17%) remained

actively involved. Two had been past presidents of "Parent to Parent", another was an active board member of the "Association for Community Living", and a fourth who was in need of the support of such an organization, formed the "National Society for Mucopolysaccharide Diseases". It appears that advocacy plays an important part in the family's attempt to successfully cope with their child's disability. The rural families which did not have an advocate in the form of a social worker, physician, or self-advocacy group had difficulty receiving emotional support, practical advice, and relevant services.

The fact that the parents were generally satisfied with the services that they had received indicates that a reorganization of the service system is unnecessary. However, there does appear to be room for improvement. Parents indicated a need for more speech therapy; rural parents indicated a need for transportation. These needs could be met through either expanding or developing the service, by providing a direct financial subsidy to parents that would enable them to purchase the service on the open market, or by charging a fee for the service that would be offset by an income-tested subsidy.

Respite care should receive ongoing funding and be more convenient. Maintaining qualified staff, attempting to reduce the waiting period needed to access respite, and providing readily accessible evening coverage should be priorities.



Other recommendations involve service delivery and do not involve financial expenditures. There should be more linkage between the health professionals working with parents of disabled children and the social service professionals. For example, the results of ongoing assessments would benefit the child's infant stimulation worker and speech therapist. Health care professionals should receive training in regard to the psychosocial aspects of a mental disability and the range of social services which are available. Parents should be provided with practical, age-related information, should receive ongoing counseling in regard to the child's future, should be offered family counseling, and should be provided with emotional support at crisis points. Health care professionals should offer to refer parents to a self-advocacy group immediately after diagnosis.

## CHAPTER V

### CONCLUSION

#### Research

The needs identified by the families in this study were more practical medical information, a focus on the psychosocial aspects of the child, earlier diagnosis, a central referral person who could provide information at different stages of the child's life, family-focused as well as child-focused services, the compassionate delivery of medical information, and professionals and/or self-advocacy groups who could offer practical information and emotional support at crisis periods. Of the services which parents had received, four were found to be the most helpful: infant stimulation, respite care, occupational therapy, and medical services. Parents indicated a need for practical information, respite, and speech therapy. A notable minority (23%) had need for day care. Rural parents indicated a need for transportation.

#### Practicum

In my Practicum Proposal, I forwarded several goals. I wanted to become familiar with the methodology and the analysis associated with applied research, use research as an evaluation procedure, become familiar with instruments

that measure family and individual functioning, and interpret research results. Now, 500 hours and several months later, I can safely say that I have accomplished these goals. My learning can be summarized in several categories:

1. Research design. Our first task was choosing a design for the study that would produce the appropriate information. We decided on a comparative case study of families who had been deemed successful by the Co-ordinator of Family Support Services and the childrens' pediatricians. Earlier in the report, I elaborated on the study design by referring to Tripodi (1983). The cross-sectional group study, as he described it, aptly suited our purposes. We were interested in developing hypotheses in regard to families with developmentally disabled children and were particularly interested in the factors which had contributed to their ability to cope. The design, I learned, had one drawback. By using a purposive sample, we were unable to use inferential statistics. However, it also had one significant advantage. The Co-ordinator who chose the sample had a personal investment in the completion of the study and was very helpful with our questions, problems, and occasional demands.

2. Literature review. Doing a literature review helped in the construction of the questionnaire, identified methodological difficulties, and provided relevance to the research findings. Although the literature review was the

most onerous and the most time-consuming aspect of the research, it was useful and necessary.

Before I became involved in the practicum, I thought that researchers designed their own questionnaires, from scratch, before they conducted a study. We drew our interview guide from an American study done by Agosta, Bradley, Rugg, Spence, and Covert (1985) and supplemented it with items which we felt were more relevant to the families in Manitoba.

Using items from another study has a number of advantages. Criterion based validity is supported. Second, by using items which have been previously used and which yield a standard score, the findings can be compared to those in the previous study. Third, it saves time both in the construction of the questionnaire and in pretesting.

The literature also suggests hypotheses which can be tested in the final analysis. For example, although the literature suggests that the family's ability to cope is dependent on the gender of the child, maternal education, the type of disability, the age of the child, family income, and the extent of the child's disabilities, our research findings suggest that the coping ability of families who are perceived as successful is independent of these factors.

3. Instrumentation. Through the practicum, I learned several lessons in regard to questionnaire and scale construction. The first lesson was in regard to the value of pretesting. We discussed each one of the items at length

among ourselves and pretested the questionnaire with friends, relatives, and parents of disabled children who were not included in the study. Each of the pretests was timed. The relevance and the wording of the items were checked. Double-barreled questions were noted and modified. The pretesting produced an interview guide that had surprisingly few problems in the field.

The second lesson was in regard to scale construction. One of the scales that we used initially measured only the negative consequences of the child's disability on the family. Because we felt that this scale presented a negative bias, we added positive items. When we analyzed the data, we reversed the ratings on the positive items on the scale to produce a consistent negative measure.

I also became familiar with some of the instruments that measure family functioning. Because I was in the Social Administration stream of the program, I was ignorant of such clinical measures as the Dyadic Adjustment Scale, the Family Assessment Measure III, the Beck Depression Inventory, the Tennessee Self-Concept Scale, the Marlowe Crowne Social Desirability Index, and the Psychological Social Support index (PSS-Fa). Although they were not used in my analysis, I did become familiar with their names, purpose, and the order in which they should be presented to families.

4. Data analysis. Analyzing the results of a practicum is different, and much more difficult than

analyzing "dummy data" in a research course. One of the most valuable lessons that I learned was that data should be entered into a computer in a logical and consistent pattern and the researcher should check for errors at the beginning, not at the end of analysis. Through my practicum experience, and by much trial and error, I have become computer literate and will be able to comfortably use and produce descriptive and inferential statistics in the future.

5. Interviewing. Who would have thought that interviewing was so difficult? I thoroughly enjoyed the interviews. Because of my rural background and rural work experience, I especially enjoyed interviewing families who lived outside of Winnipeg. However, although I tried desperately to be impartial and speak in a monotone as not to influence the subject's answers, I inevitably would get into a conversation, be asked to settle an argument, or be enticed into clarifying a question. My role as an interviewer often clashed with my previous role as a social worker. Several of the families were frustrated. One family in particular, wanted to know why they had been chosen as a successful family because they were fraught with service problems, marital difficulties, and grief. Although my instinct was to listen and provide counseling, I needed to remind myself that I was there as an interviewer.

I learned the importance of guaranteeing confidentiality and assuring the families that they would

receive, in a meeting or by mail, the results of the study.

6. Time and attention to detail. Research takes time. and good research takes even more time. Through doing some of the "housekeeping" tasks associated with the study such as licking stamps, collecting the returned response cards, assigning each subject a number and an interviewer, and keeping a record of the subjects who agreed to participate, I learned the value of paying attention to detail. I have learned that the time spent in such seemingly trivial tasks as stuffing envelopes, ensuring that the correct name and address is on the envelope, and keeping up-to-date records can mean the difference between a successful and an unsuccessful study. We were very conscious of the fact that the loss of a subject would decrease the size of our already small sample and seriously affect our research findings. Consequently, we attempted to ensure that the maximum number of subjects were interviewed.

All in all, the practicum was a valuable experience. It provided me the skills necessary to pursue my interest, and career, in research.

## Reference Notes

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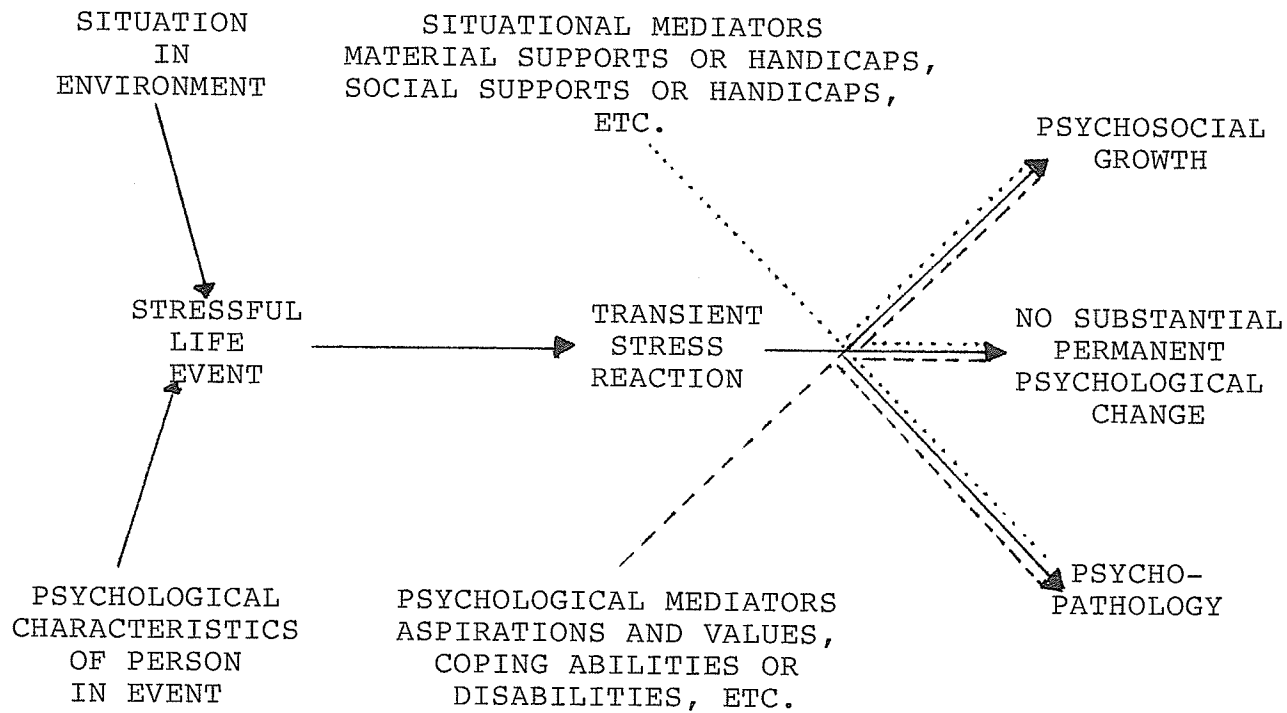
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Appendix A: A Model of the Process by which  
Psychosocial Stress induces Psychopathology

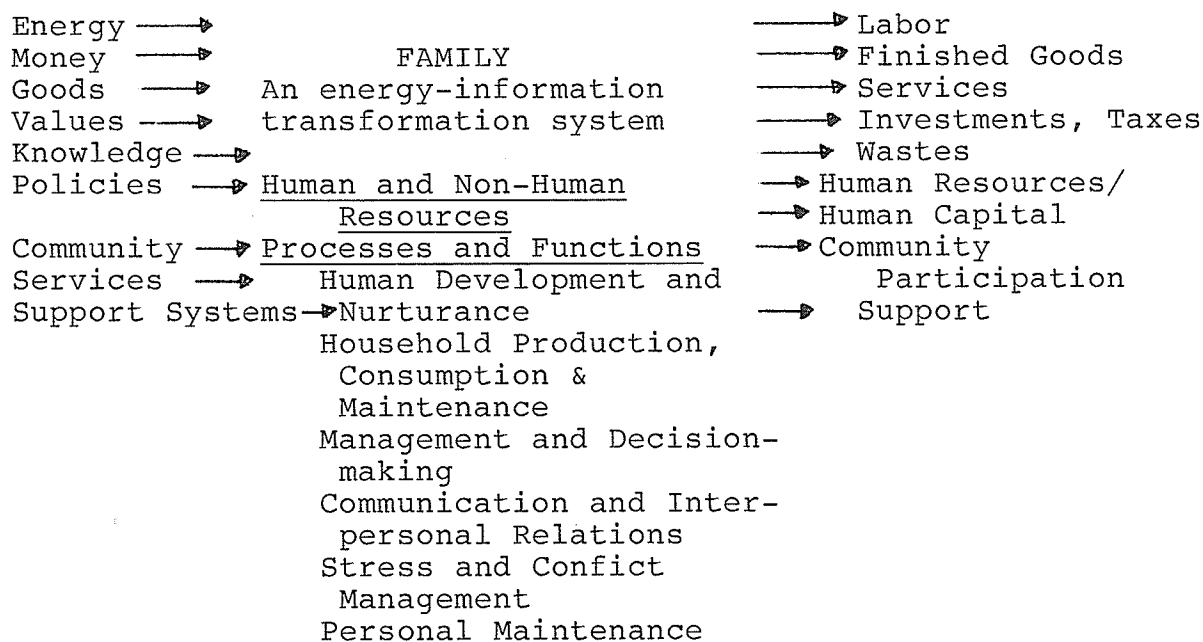


Note. From "Social Stress and Community Psychology"  
by B. S. Dohrenwend, American Journal of Community Psychology,  
1978, 6, 1-14.

## Appendix B: A Conceptual Model of Family Ecosystem

INPUTS—from environment and  
systems in the environment

OUTPUTS—to the environment  
and systems in the  
environment



INPUTS

Feedback

OUTPUTS

Outputs to the environments become  
inputs into the family system

Note. From "The family of the handicapped: An ecological model for policy and practice" by M. Bubolz and A. Whiren, Family Relations, 1984, 33, 5-12.

Appendix C: Family Survey

INFORMATION ON CHILD(REN) IN FAMILY WITH A DISABILITY

First name of child \_\_\_\_\_ dob yy/mm/dd/ sex \_\_\_\_\_

What disability best describes this child?

\_\_\_\_\_ developmental delay

\_\_\_\_\_ cerebral palsy

\_\_\_\_\_ emotional disturbance (e.g. hyperkinetic)

\_\_\_\_\_ epilepsy \_\_\_\_\_ other... specify \_\_\_\_\_

\_\_\_\_\_ hearing loss \_\_\_\_\_

\_\_\_\_\_ vision loss \_\_\_\_\_

\_\_\_\_\_ autism \_\_\_\_\_ don't know

\_\_\_\_\_ mental retardation

\_\_\_\_\_ physical disability

In your view:

our view:  
To what extent will this child's disability affect his/her mental or intellectual development?

not at all	mildly	moderately	severely
1	2	3	4

To what extent will the disability affect physical development?

not at all	mildly	moderately	severely
1	2	3	4

To what extent will ongoing specialized medical attention be required?

no need	some need	moderate need	severe need
1	2	3	4

How much assistance will this child require over the years to perform everyday activities like eating, bathing, toileting?

very little	a moderate amount	frequent	constant
1	2	3	4

# INFORMATION ON FAMILY NEEDS

Below is a list of needs some families have in caring for their family member with a disability. Please rate from 1-5 YOUR family's PRESENT level of need by CIRCLING THE APPROPRIATE NUMBER. The lower the number you circle, the less need your family has. The higher the number you circle, the greater your family's need.

	NO NEED			EXTREME NEED		NOT APPL	DN/ NR
1. Information on the type of disability my disabled child has.....	1	2	3	4	5	8	9
2. Information on how or where to get services.....	1	2	3	4	5	8	9
3. Information on how to best care for my disabled child.....	1	2	3	4	5	8	9
4. Information on how to deal with behavior problems displayed by my disabled child.....	1	2	3	4	5	8	9
5. People who can come to my house and help me care for my disabled child on short notice.....	1	2	3	4	5	8	9
6. Qualified persons to care for my disabled child overnight.....	1	2	3	4	5	8	9
7. Other families with a disabled child with whom I can talk to about raising my disabled child.....	1	2	3	4	5	8	9
8. A place where my disabled child can go during the day while I do something else like go to work, school or shop.....	1	2	3	4	5	8	9
9. Time for me or my spouse to complete household chores or routines (shopping, house cleaning....).....	1	2	3	4	5	8	9
10. More time just for myself.....	1	2	3	4	5	8	9
11. Specialized services for my disabled child like speech or physical therapy.....	1	2	3	4	5	8	9
12. Money to use to care for my disabled child.....	1	2	3	4	5	8	9
13. Temporary relief from caring for my disabled child.....	1	2	3	4	5	8	9
14. A way to transport my disabled child around town when needed.....	1	2	3	4	5	8	9
15. Special equipment for my disabled child (like arm or leg braces, a wheelchair, special shoes or toys).....	1	2	3	4	5	8	9
16. Modifications to our house to make it easier for my disabled child to get around (like grab bars, ramp, wider doorways).....	1	2	3	4	5	8	9

Services received

Please specify below which of the listed services have been received first by YOUR FAMILY and then by YOUR CHILD WITH A DISABILITY. If a specific service has not been received, place a CHECK in the column marked "NO". If the service has been received, place a check in the column marked "YES". If either you or your child are/were ineligible for the service, place a check in the column marked "NOT APPLICABLE".

## SERVICES RECEIVED BY YOUR FAMILY

SERVICE	SERVICE RECEIVED		PAYMENT CATEGORY			BEING RECEIVED	
	NO	YES	PAY	PARTLY PAY	NO PAY	NOT APP	NOW
DAY CARE							
HOMEMAKER							
GENETIC COUNSELING							
COUNSELING OR PSYCHOTHERAPY							
RESPITE CARE/SITTER SERVICE							
TRAINING IN PARENTING SKILLS							
INFORMATION AND REFERRAL							
OTHER							

Please give an OVERALL RATING beside each of the services that you have received, indicating whether you are VERY SATISFIED (VS), SATISFIED (S), DISSATISFIED (D), OR VERY DISSATISFIED (VD).

SERVICE	RATING OF SERVICES			
	VS	S	D	VD
DAY CARE				
HOMEMAKER				
GENETIC COUNSELLING				
COUNSELING OR PSYCHOTHERAPY				
RESPITE CARE/SITTER SERVICE				
TRAINING IN PARENTING SKILLS				
INFORMATION AND REFERRAL				
OTHER (specify)				

## SERVICES RECEIVED BY YOUR CHILD

SERVICE	SERVICE RECEIVED		PAYMENT CATEGORY			NOT APP
	NO	YES	PAY	PARTLY PAY	NO PAY	
EARLY INTERVENTION PRE-SCHOOL						
REGULAR SCHOOL						
SPECIAL EDUCATION						
PHYSICAL THERAPY						
SPEECH OR HEARING THERAPY						
RECREATION PROGRAM						
MEDICAL SERVICES						
DENTAL SERVICES						
TRANSPORTATION						
HOME HEALTH CARE						
ATTENDANT CARE						
MEDICATION						
DIAGNOSIS AND ASSESSMENT						
SPECIAL DIETS						
SPECIAL CLOTHING						
EQUIPMENT/MODIFICATIONS TO HOUSE						
OTHER (specify)						

Please give an OVERALL RATING beside each of the services that you have received, indicating whether you are VERY SATISFIED (VS), SATISFIED (S), DISSATISFIED (D), or VERY DISSATISFIED (VD).

SERVICE	RATING OF SERVICES			
	VS	S	D	VD
EARLY INTERVENTION PRE-SCHOOL				
REGULAR SCHOOL				
SPECIAL EDUCATION				
PHYSICAL THERAPY				
SPEECH OR HEARING THERAPY				
RECREATION PROGRAM				
MEDICAL SERVICES				
DENTAL SERVICES				
TRANSPORTATION				
HOME HEALTH CARE				
ATTENDANT CARE				
MEDICATION				
DIAGNOSIS AND ASSESSMENT				
SPECIAL DIETS				
SPECIAL CLOTHING				
EQUIPMENT/MODIFICATIONS TO HOUSE				

Of all of these services that you have received, which have been the most helpful? \_\_\_\_\_

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Of all of these services that you have received, which have been the least helpful? \_\_\_\_\_

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What would you do different than what is currently being done to help families like yours with a disabled child?

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IMPACT OF CHILD DISABILITY ON FAMILY

In your view, what consequences have resulted from having a child with a disability in your family:

There have been extraordinary time demands created in looking after the needs of the disabled child:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

There have been physical management problems requiring special equipment or modifications to home:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

We have made valuable friends through sharing the experience of a disabled child:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

There has been unwelcomed disruption to "normal" family routines:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

It has led to additional financial costs:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

Having a disabled child has led to an improved relationship with spouse:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

It has led to limitations in social contacts (family isolation):

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

Chronic stress in family has been a consequence:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

We have had to postpone or cancel major holidays:

Not at all 1	To a mild degree 2	To a moderate degree 3	To a substantial degree 4
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Other members of the family have become more understanding of people with developmental disabilities:

Not at all 1	To a mild degree 2	To a moderate degree 3	To a substantial degree 4
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There has been less time for parents to spend with other children in the family:

Not at all 1	To a mild degree 2	To a moderate degree 3	To a substantial degree 4
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It has led to a reluctance in family members to discuss family problems unrelated to the disability:

Not at all 1	To a mild degree 2	To a moderate degree 3	To a substantial degree 4
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It has led to a reduction in time parents could spend with their friends:

Not at all 1	To a mild degree 2	To a moderate degree 3	To a substantial degree 4
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The child's disability has led to positive personal development in mother and/or father:

Not at all 1	To a mild degree 2	To a moderate degree 3	To a substantial degree 4
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Because of the situation, parents have hesitated to phone friends and acquaintances:

Not at all 1	To a mild degree 2	To a moderate degree 3	To a substantial degree 4
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Because of our experience with services for disabled children, we have developed a more positive view of government services in general:

Not at all 1	To a mild degree 2	To a moderate degree 3	To a substantial degree 4
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The situation has led to tension with spouse:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

Because of the circumstances surrounding the child's disability, there has been a postponement of major purchases:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

Raising a disabled child has made life more meaningful for family members:

Not at all	To a mild degree	To a moderate degree	To a substantial degree
1	2	3	4

Please rank these alternative choices according to what would be highest priority to lowest priority for you right now in taking care of your disabled child:

- \_\_\_\_\_ transportation assistance
- \_\_\_\_\_ cash assistance program
- \_\_\_\_\_ crisis respite services
- \_\_\_\_\_ regular respite services
- \_\_\_\_\_ advice regarding access to services for your disabled child
- \_\_\_\_\_ information about your child's disability
- \_\_\_\_\_ aid in obtaining special equipment for your disabled child
- \_\_\_\_\_ home improvement grant to meet needs of disabled child
- \_\_\_\_\_ marital counselling to assist parents
- \_\_\_\_\_ family counselling to help home situation
- \_\_\_\_\_ housekeeping service to help with household chores
- \_\_\_\_\_ professional advice in regard to financial planning for child(ren)
- \_\_\_\_\_ assistance with chores done outside the home
- \_\_\_\_\_ counselling in regard to your child's future

Have you and/or your spouse participated in any self-help groups for parents of disabled children?

If "yes", please identify group and indicate extent of participation: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

If "no", do you have interest in joining such a mutual help group of parents? yes \_\_\_\_\_ no \_\_\_\_\_

FAMILY INFORMATION:

Family type: ☐ two parent ☐ single parent  
☐ nuclear ☐ blended ☐ extended ☐  
☐ biological ☐ adoptive

Please list ALL FAMILY MEMBERS living in your house, their AGES, EDUCATION and whether or not they are EMPLOYED.

DO NOT COUNT YOUR FAMILY MEMBER WITH A DISABILITY IN THIS LIST BUT REMEMBER TO INCLUDE YOURSELF. Please only write down the family member's relationship to the disabled person (mother, father, aunt, brother, grandmother, etc.) NO NAMES PLEASE

Relationship	Age	Education	Employment Status		
			Employed Full Time	Employed Part Time	Not Employed
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					

What was the TOTAL taxable family income last year (1985) of primary wage earners in your household (please check one only)

☐ \$0 - 9,999      ☐ \$30,000 - 39,999  
☐ \$10,000 - 19,999      ☐ \$40,000 - 49,999  
☐ \$20,000 - 29,999      ☐ \$50,000 or more

What is the postal code area of your home? \_\_\_\_\_

To meet the needs of the disabled child(ren), has anyone in your household:

(a) given up a paying job? yes \_\_\_\_\_ no \_\_\_\_\_ (if yes, mom \_\_\_\_\_ dad \_\_\_\_\_ other \_\_\_\_\_)  
 (b) not taken a paying job? yes \_\_\_\_\_ no \_\_\_\_\_ (if yes, mom \_\_\_\_\_ dad \_\_\_\_\_ other \_\_\_\_\_)  
 (c) refused a job transfer  
     or promotion      yes \_\_\_\_\_ no \_\_\_\_\_ (if yes, mom \_\_\_\_\_ dad \_\_\_\_\_ other \_\_\_\_\_)  
 (d) postponed work      yes \_\_\_\_\_ no \_\_\_\_\_ (if yes, mom \_\_\_\_\_ dad \_\_\_\_\_ other \_\_\_\_\_)

1. Were there any relatives in either of your families with a physical or mental disability?

father's family \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

mother's family \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. At what age was your child when you were told he/she had a disability? \_\_\_\_\_
3. Do you plan to have more children? yes \_\_\_\_\_ no \_\_\_\_\_  
If no, was this because of your experience with your disabled child? yes \_\_\_\_\_ no \_\_\_\_\_