SUPPORT SYSTEMS FOR PARENTS
OF CHILDREN WITH DOWN SYNDROME
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We accept this thesis as conforming
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This study investigated the sources of support available to mothers of children with Down syndrome. Three levels of social interaction were examined: family support; informal support (friends and neighbours), and; formal support (professionals and social institutions). A questionnaire was circulated to thirty-two mothers of children with Down syndrome. The questionnaire surveyed those formal and informal systems which were potential sources of support for mothers. Findings indicated that mothers' experiences were differentially affected by their setting. Mothers were generally satisfied with their sources of informal support. In two-parent families fathers were perceived as very supportive of their spouses, while in one-parent families the mothers relied on other sources such as friends, neighbours, and extended family for their support.

Urban mothers expressed less satisfaction with formal systems of support than did mothers living in non-urban areas. Findings indicated that perceiving systems of support as supportive may relate to the quality of the services as well as to the availability.
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CHAPTER ONE: INTRODUCTION

I. Introduction

A. Reasons for the Study

There are more than eight hundred children with Down syndrome living in British Columbia. As parents try to cope and adapt to the needs of their children, they realize that handicapped individuals present challenges which consume energies and resources over and above the demands made by typical youngsters. Parents may also experience anxiety and grief. Consequently, families require support in order to maintain and nurture their offspring with Down syndrome. This thesis addresses two questions:

(1) Who is supporting parents in their caregiving roles?

(2) What is the perceived quality of these supports?

Support has been defined in many ways. This study defines support as "a system of community-based resources which assist families in the provision of care to their handicapped children". There is a wide spectrum of behaviors which is characterized as supportive. This study was conducted to identify and describe community resources which parents find helpful. Parents were surveyed on their sources of support.

Support will take many forms. This study examined
the assistance given to parents at three levels of social interaction: family support; informal support (friends and neighbours), and; formal support (professionals and social institutions). The concept of support as it relates to families with handicapped children is an emerging area of study. The catalyst in British Columbia has been the decision to close provincial institutions and to re-allocate resources to the community.

Families of children who have handicapping conditions are often faced with a unique set of problems. In addition to the many psychological and emotional difficulties and adjustments that are frequently associated with the birth of a handicapped child, families also are confronted with economic and management challenges. These include increased medical and other extraordinary expenses for health-related conditions and child-care, and time management difficulties resulting from unusual care demands. Nor are the families exempt from the pressures and tensions that all families experience to one degree or another in contemporary Canadian society. Stresses and pressures combine and interact and take their toll on the parents of handicapped children.

Families derive support and assistance in diverse ways and from various sources. There are both formal and informal networks that provide support. The extended family and friends form an informal network. Societal
institutions such as churches, schools, and family service agencies are formal networks which include physicians, teachers, therapists, and other professionals as an additional source of support and assistance. These support networks contribute to the abilities of families to cope.

When these support systems work well, they provide encouragement and specific forms of assistance. This author believes that families who are informed that their children face serious handicaps such as Down syndrome benefit from knowing that there are those outside of the family who can assist them to appropriately care for their children. Not only do they need information and therapeutic intervention, they need to feel that their children have a future and a place in society. Awareness of the existence of support reinforces the interactions which are a part of a family life and part of the community life. Furthermore, support that is provided in the form of services such as physiotherapy, after-school care, and an infant development program assists families in their roles as caregivers of persons with Down syndrome. The encouragement and assistance offered by family, friends, volunteers, and professionals all function in the network of support.
II. The Concept of Support

A. Support as a Construct

Support is a multi-dimensional construct which encompasses a wide spectrum of behaviors and resources, and relates to many fields of professional endeavor, and/or individual commitment and activity (Morris, 1977; Gallagher, Beckman, and Cross, 1983; Cobb, 1976; Wickler, Wasow, and Hatfield, 1983; Marcus, 1977). The concept of support is rooted in the provision of care for persons in a society, and the supportive activities give sustenance and aid to individuals both on a day-to-day basis and in times of crisis. Those variables which have a positive influence on attitudes and behavior are also seen as supportive.

The concept of support and services to families has a long history. In particular, the literature on adaptation to illness or crisis is rich with documentation. Gallagher, Beckman, and Cross (1983) have reviewed the historical development of the concept of support as it relates to illness. The concept of support as it relates to disability is emerging as a new trend in service delivery for persons with handicapping conditions and their families.
B. Theoretical Basis for the Present Study

Two theoretical frameworks provide the basis for this study of support: the ecological theory articulated by Bronfenbrenner (1979) and the social network theory postulated by Caplan (1976). These theories will be briefly explained below.

1. Ecological Theory of Family Function

Bronfenbrenner postulates an ecological system where the nuclear family is represented as the inner circle in a series of concentric circles. Neighbourhoods, schools, workplaces, and agencies form an ecological system in which a family functions. The nuclear family is affected in a number of ways by the society of which it is a part. Values, attitudes and opportunities are created to a great extent by the larger society. No unit of society can operate in complete isolation from another part.

Bronfenbrenner has identified a series of large contexts which influence events within the immediate family or microsystem. Outside this immediate environment a larger system exists. In the mesosystem there are complex interactions between the developing person and the environment. The mesosystem involves the interrelations among the major settings containing the developing person, for example, interactions among family, school, and peer group. Outside the mesosystem is the exosystem. The exosystem
represents formal and informal social structures which impinge upon the individual's immediate environment, such as the neighbourhood, and agencies of government. The macrosystem represents the overarching institutional patterns or general prototypes of the culture of which the micro-, meso-, and exosystems are concrete manifestations.

2. Social Network Theory

Social network theory describes linkages among individuals and groups. These interactions between individuals influence expectations, behavior, attitudes, and knowledge. Linkages are operationally defined in terms of network characteristics, including size, satisfaction, density, connectedness, and frequency of contact (Mitchell and Trickett, 1980). Social support networks function to nurture and sustain linkages among persons that are supportive on both a day-to-day basis and in times of need and crisis (Caplan, 1974; Cobb, 1976; Brim, 1975). Both the ecological and network theories share a great deal in common and focus attention on interpersonal relationships as a source of support.

C. Other Relevant Concepts of Support

1. Cobb's Concept of Social Support

Support has been described in other ways. Cobb (1976) used the term "social support" to describe the meaningful
interchange between people which is based on information rather than on goods or services. This information, it is suggested, enhances the individual's belief that he is loved and cared for, that he is esteemed and valued, and that he belongs to a social network. Cobb argues that social support facilitates coping with crisis and adaptation to change, and that the moderating effects of social support are found when major transitions of life or when unexpected crises arise.

2. **House's Concept of Support**

House (1981) has identified four types of support behaviors: emotional support which involves caring, trust and empathy; instrumental support which provides resources for the individual in carrying out his role; informational support which includes giving information or teaching a skill; and appraisal support which involves information which helps one in evaluating personal performance. Emotional, instrumental, informational, and appraisal support help families to maintain and encourage their children's development.

3. **Personal Social Services**

"Personal social services" (Hepworth, 1982) is a concept developed to facilitate a caring environment for the delivery of social services in the community. Hepworth defined personal social services as "professional
and voluntary services which complement, supplement, or are in the place of services and care rendered by families or friends on an individual basis to relations, friends, or other individuals.\(^2\) A distinguishing characteristic of this concept of support, as portrayed by the author, is that effective services demand personal delivery, with people responding to the needs of others in a sensitive and appropriate way, preferably in familiar or home surroundings. Both formal and informal systems of support can be given in personal ways.

D. The Need For Support For Families

The nature of the support for families of handicapped children may determine the ways in which a family perceives and enacts distinctive areas of family function. The availability of support helps to form the attitudes and perceptions of the family and strengthens the ability to cope with time commitments, pressures, and unfamiliar situations. When stress is high and when there is an underlying lack of control over the factors which govern one's life, or when there is a lack of information which needs to be either tapped or accommodated, there is usually not time available for positive interaction between family members. Parent-child interactions, family structure, social climate, interpersonal relationships, family harmony and quality of parenting roles are powerful influences
in socializing the child. In addition, parent-child play opportunities, educational and cognitive stimulation available in the home, emotional support for learning, and cohesiveness of family members (Nihara, Mink, and Meyers (1981); Dunst, Trivette, and Cross (1986)) influence social, psychological and educational growth of children. With support, parents of handicapped children learn to manage the time and energy demands of their role and they also learn to enhance their parenting activities.

1. **ComServ Plan - A Support Plan For Families with Handicapped Members**

The specific model of support proposed to meet the long-term needs of persons with developmental disabilities was conceptualized by The Canadian Association for Community Living, formerly The Canadian Association for the Mentally Retarded. The model, named the Comprehensive Community-Based Service Delivery Systems Plan (ComServ Plan, 1972), outlines the requirements for appropriate services for mentally handicapped people in community settings. This concept of support suggests strategies for service delivery. Community-based services provided close to the home of the handicapped person, comprehensive services which ensure that all types of needs will be met, and continuous services which would be available as needed throughout the lives of handicapped people are key features of this model. Also, an important component
is a system of delivery which ensures that a wide range of individualized services will function as a coordinated unit.

As part of the ComServ Plan, families are allocated services and resources which would enhance their abilities to maintain their children in their own homes. This notion is central to the discussion of support services which collectively are the subject of this thesis. The appropriate services are determined by the individual needs of the handicapped person and his family. Although the nature of services may vary over the life-span of the handicapped individual, the quality of services must be maintained in order to be useful to the individuals.
I. Family Support

A. Family Acceptance of the Child

Parents of handicapped children differ in their acceptance of the diagnosis of their child's condition. Watson and Midlarsky (1979) and Ferrara (1979) suggest that prevailing socio-cultural attitudes influence parental attitudes and behavior toward their mentally handicapped children.

Molsa and Ikonen-Molsa (1985) examined the ability of family members to accept a mentally handicapped child into a family. They found that 83% of mothers and 86% of siblings adapted well to the presence of a mentally handicapped child. Sixty-seven percent of fathers and 75% of grandparents were able to accept a child who had a mental handicap.

B. Successful Adjustment Factors

Gallagher, Cross, and Scharfman (1981) studied the characteristics of parents who have made successful adjustment to the birth of a handicapped child. The data from this study indicated that major sources of strength were the personal characteristics of the parents and the quality of the husband-wife relationship. Personal characteristics associated with success were maternal ego
strength and self-confidence, and commitment to a set of supporting values (i.e. strong religious beliefs).

Farber (1959) studied the relationship between marital integration and the frequency of contact with the maternal grandmother. In parents where there was close contact between the mother of the child and the maternal grandmother, the relationship was found to be supportive to the family. Emotional support was seen as the powerful factor which encouraged the mothers to adapt to the role of parent of a handicapped child.

C. The Effects of Family Environment on the Child's Growth

Nuclear families approach the care of their mentally handicapped offspring in various ways. Nevin, McClubbin and Birkebak (1983) found that low conflict families with handicapped children possessed greater family strengths in mastery of family events and outcomes. They also showed better physical and mental health. High conflict families, however, were found to have many more stressors which continued over time as chronic strain.

Nihara, Meyers, and Mink (1980) studied families of mentally handicapped children living at home. They examined the home environment, family adjustment, and child characteristics. Family adjustment and functioning were found to relate not only to the severity of the child's mental handicap and behavior, but also to family demographic characteristics, the climate of the home
(harmony, expressiveness, and family cohesion) and specific kinds of parental behavior toward their mentally handicapped child. This study demonstrated the interactional nature of the family and the functioning of the child with a mental handicap. The child's adaptive functioning was related to the parents' abilities to successfully cope with the challenges of mental handicap.

II. Informal Support

A. Parent to Parent Support

Meadow and Meadow (1971) suggest that parents of handicapped children are re-socialized into the new role of caregiver for a handicapped child. Individuals who may help in this process include other parents of handicapped children and handicapped adults.

Scott and Doyle (1984) describe a parent to parent support network offered to parents of newly diagnosed handicapped children. This program provides new parents with an opportunity to discuss problems and to expand their network of support. Featherstone (1980) suggests that parent to parent support encourages new parents to redefine the image of themselves as parents of exceptional children in a more positive way.

B. Neighbourhood Support

Riger and Lavrakas (1981) maintain that people's life circumstances, particularly their stage in the life
cycle, may play a critical role in determining their degree of attachment to local community settings. Age, in particular, appears to distinguish among levels of physical attachment, while the presence of children distinguishes among those who are socially involved within a neighbourhood. Children serve as important information links among neighbours (Keller, 1968) and their presence may facilitate the development of functional as well as communicative ties. Fischer (1977) found that people with children were less emotionally attached to their neighbourhoods, but more strongly connected in terms of local organizational and social ties.

C. The Value of Informal Support

German and Maisto (1982) studied the relationship of a perceived family support system to the institutional placement of handicapped children. One hundred twelve mothers were interviewed to assess the relationship of the placement of the child (home, respite care or residential care) to the mother's perception of the extent of her support system and of the stresses acting on the family. The results of this study indicated that families derive emotional support from a variety of sources, and that a major source of emotional support that enables a family to maintain the mentally handicapped child in the home is the presence of both parents in the home. In addition, the mothers of families who
chose to retain their children at home perceived that they received more support from their own parents, extended family members, and had greater availability of sitters.

Gallagher, Beckman, and Cross, (1983) describe a study by Bristol (1979) in which the mother's informal support networks were found to have significant impact on maternal stress. Mothers who reported the least stress were receiving more help from all sources, including their spouse, friends, relatives, and parents of other handicapped children.

Dunst, Trivette, and Cross (1986) examined the role of social support on parental attitudes toward their mentally handicapped child, family integrity, and the child's behavior, development and functioning. Results showed that family support and resources make a difference in a handicapped child's opportunity for growth and development. Several areas of family functioning were significantly related to support and resources. Respondents who indicated more satisfaction with their social support networks indicated being less protective of their children.¹ Overprotection increased with increasing age of the child for respondents with low support but not for respondents with high support.² When social supports are available, the child has more
opportunity for social interaction. Results indicated that the effects of diagnosis, physical problems and limitations of the child could be mediated by social support. Respondents with children who had low developmental quotients or with children who were physically impaired indicated that their offspring had more limitations in both intra- and extra-family opportunities. However, families with larger social support networks had fewer limitations placed on them in terms of intra- and extra-family opportunities. Limitations increased with increasing child age among families with limited social support. Financial resources strengthen family integrity and have impact on the cognitive development of the child. Respondents from high socio-economic status families with larger incomes indicated that they had more integrated family units, more family opportunities and fewer financial problems. Children from high income families showed smaller developmental quotient losses between measurements. Children were more likely to show smaller developmental quotient losses if they were offspring of parents with supportive social networks.

D. Parental Concerns Which Informal Supports Cannot Address

When a child is born with, or acquires a handicapping condition, many stressors are present in the family.
In addition to the potentially stressful changes which occur as a result of responsibility for the well-being of another person, reallocation of financial resources, and shifts in the communication system to accommodate the new person in the family (Wandersman, Wandersman, and Kahn, 1980), other stressful changes occur for the couple. Often there is a need to interact with medical professionals with more frequency than would be expected with a typical infant; decisions regarding medical intervention must be made; changes in values are required; social supports may break down, and; time demands for infant care may increase beyond typical or expected requirements. The usual physical isolation of a couple with a newborn may be exacerbated by the situation where the network is too dissimilar in the experience and attitudes are too dissimilar to alleviate the uncertainty of the new parents (Wandersman, Wandersman, and Kahn, 1980).

Stress may be present around issues of care for the child throughout his/her life cycle. A table provided by Nevin, McCubbin, and Birkebak (1983) summarizes these concerns.5 (See Table 1.)
TABLE I
RESPONSIBILITIES AND CHALLENGES IN THE STAGES OF THE FAMILY LIFE CYCLE

<table>
<thead>
<tr>
<th>Infant</th>
<th>Pre-School 3—5 years</th>
<th>School Age 6—12 years</th>
<th>Adolescent 13—20 years</th>
<th>Young Adult 21</th>
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Issues of parent-child interaction, sibling development, parental adjustment, and coping abilities have been discussed in the literature. A comprehensive review of the literature by McNeill (1981) reveals many sources of concern for parents of a handicapped child.

III. Formal Support

A. The Need for Professional Help

Brown (1978) addressed the question, "What group seeks professional help?". The data suggested that help-seekers experienced more troublesome events than individuals who did not seek help. The magnitude of stressful episodes in the lives of this group was greater than in the other groups studied. The author suggested that professionals were contacted in situations where stressful events and higher levels of role strain were exhibited. For this group, the reliance on formal support systems seemed to reflect the inadequacies of informal supports, and a reluctance to keep asking informal associates for assistance.

Lloyd-Bostock (1976) suggested that the perceptions of parents regarding services are closely tied to their relationship with the individuals acting as agents of those services. She noted that the individuals with whom the parents came in contact had importance in parents' experiences of the service. Often contact with
a particularly helpful of sympathetic individual marked a turning point in understanding and coping with the child and family problems. As well as the help they offered, professionals were praised when their attitudes were positive, their acceptance of and sometimes affection for the child as an individual were shown, and their encouragement to the family was such that the parents were helped to feel that the problems, though great, were not unique and insuperable.6

B. The Quality of Professional Services

1. Program Evaluation

Program evaluators often recognize the need to include consumer information in an assessment of how well a service is being employed (Sommers et al., 1979). Within the general population, the majority of people who seek help from professional services are satisfied with what they obtain (Gurin et al., 1960; Hill, 1969). Rosenblatt and Mayer (1972), in fact, found that for educated women needing assistance with family problems, the help received from professionals was more satisfying than that received from friends and relatives. Several studies have evaluated the consumer satisfaction of programs for mentally handicapped children and their families. These studies will be reported below.
2. **Counselling Practices**

Pueschel and Murphy (1976) assessed the counselling practices of physicians at the birth of a child with Down syndrome. Four hundred fourteen parents were asked to respond to a questionnaire on the professional counselling practices at the birth of their child. Nearly one half of the parents reported that professionals had presented the diagnosis in a sympathetic manner, while twenty-five percent of parents said that their physicians were abrupt and blunt. Some parents commented that they were given very little information and that their physicians were evasive; two parents were told of their child's condition by mail. The authors stressed the need for an awareness of counselling techniques at this sensitive period of parental adjustment.

3. **Clinical Services**

Sommers and Nycz (1978) monitored consumer satisfaction with the clinical services provided to exceptional children. Parents and case coordinators were asked to rate the level of satisfaction with clinical services received at a comprehensive medical child care centre. Most parents indicated overall satisfaction with the service, however, specific suggestions included that there was a need to improve communication, clinical follow-up, and to provide more educational advice on the children assessed.
4. **Respite Care**

Ptacek et al. (1982) evaluated parental satisfaction with respite care facilities for families of children with severe handicaps. These services gave parents the opportunity to have time away from their children. A variety of respite options were evaluated. The data from a follow-up questionnaire indicated that the parents felt extremely positive about the service.

5. **Educational Services**

Norman and Mullin (1983) reported the results of two studies which assessed parents' attitudes and perceptions of their severely mentally handicapped child and that child's involvement in education. The first study, the Pennsylvania Survey, examined the attitudes toward school placement by families of children either living at home or living in institutional settings. For the families with children residing at home, the opportunity for school programming gave parents their first consistent, regular time away from their children. Parents reported improvement in parent-child interactions as a result of this "release time". Interactions between other family members were also generally perceived to be improved. Eighty-two percent of these parents felt that the family had adjusted well to the child's attendance in public school.7

Skill-development on the part of the child was also
reported. Eighty-two percent of the parents or guardians reported improvement in at least one of the child's functional areas. The greatest improvement (49% of the responses) was shown in areas of communication skills, followed by appropriate behavior (39% of the responses) and play skills (34% of the responses). 8

In the second study reported, the Alberta Study, two groups of parents were interviewed: parents with children remaining in the home, and parents whose children had been previously institutionalized. The questionnaires asked for demographic data, parents' perceptions of changes in their child's functional ability, parents' understanding of the goals and objectives of the program, and the parents' perceptions concerning the impact of the school program on individual family members as well as on the family dynamics. Of the parents with children living at home, sixty-four percent reported that this was the first time their child had been away from home for any extended period (except in hospital). Sixty-seven percent of the parents reported that the attendance of their child in the educational program positively influenced their interactions with their child, increased positive family dynamics, and sixty percent indicated that the school experience better met the needs of their child. 9 Eighty-two percent of the parents felt the program, despite a perceived absence
of performance changes, was beneficial for the child in relation to general family attitude and better presentation of their child. The major outcome of the program for the parents whose child had been institutionalized was in the area of improved care and increased parent-child interactions (visits).

C. Changes in Service Needs Over Time

Suelzle and Keenan (1981) examined the availability of family support networks over the life changes of children. Four stages of childhood were analyzed: preschool, elementary school, teenage years, and young adulthood. Utilization of personal and professional support networks by parents varied over the life stages of their mentally handicapped children. In general, parents of younger children utilized more services and support networks, while parents of older children were less supported, more isolated, and more in need of expanded services.
CHAPTER THREE: METHODOLOGY AND RESULTS

I. Methodology

A. Statement of Problem

This study addresses the questions of availability and quality of support for families who have a child with Down syndrome. The specific question addressed was: "What are the major sources of informal and formal support for families?" This study investigated the following categories of support:

1. Family support
2. Informal support systems
3. Formal support systems

B. Definitions

1. Family Support

Family support is defined as support coming from the spouse, other children in the family, and extended family members.

2. Informal Support

Informal social support is that which is the result of interpersonal relationships with significant persons other than relatives, who are within the family's social contacts. Neighbours, babysitters, co-workers, friends, and other parents of children with handicapping conditions would act as informal social supports.
3. **Formal Support**

Formal social support comes from relationships with a social agency, institution, and/or individual professionals such as physicians, therapists, or teachers who may or may not work out of a social agency. The professional person may function as administrator of a program which employs other staff members to carry out a particular task, or as a direct service provider.

C. **The Present Study**

This study was modelled after the American study by Fewell, Belmonte, and Ahlersmeyer (1982). Questionnaires were distributed to mothers of children with Down syndrome throughout British Columbia. This section will describe the population surveyed, the questionnaire, methods of data analysis, and the results obtained.

1. **Method**

a. **Subjects**

The population was mothers of children with Down syndrome. The participants were contacted through British Columbians for Mentally Handicapped People. The data was based on the responses to the questionnaires.

b. **Procedure**

The questionnaire was adapted from the Fewell, Belmonte and Ahlersmeyer study (1982) who used this questionnaire to survey four hundred families of children with
Down syndrome in United States. Data pertaining to reliability and validity were not available in the American study. The Vancouver-Richmond Association's Research Committee suggested slight revision to the Fewell et al. questionnaire in order to accommodate the British Columbian population. The questionnaire was revised to be relevant to the British Columbian population. See Appendix I for the questionnaire.

c. Distribution of Questionnaire
   An envelope containing a cover letter, the questionnaire, and a stamped return envelope was sent to each subject. Most questionnaires were returned to the researcher by mail. Of the one hundred questionnaires distributed thirty-two were returned. Data are based on these replies.

d. Data Analysis
   The data from the questionnaires were analyzed for the following information: demography, family support systems, informal support systems, and formal support systems. The researcher attempted to discover what supports were available to families and how important these supports were perceived to be. The number of respondents choosing each alternative in a question was tallied, totals were converted to percentages. A chi square test was carried out to discern the general perception of informal and formal support systems. A chi square test
was also used to evaluate the general satisfaction with support systems in the urban and non urban populations.

II. Results

A. Demography

Thirty-two mothers responded to the questionnaire. Fifteen of these parents resided in the urban area, eleven in small cities, and six in rural areas. Of the thirty-two families, twenty-nine families were two parent families and three were single parent families. In twenty-seven of the families the father was employed full-time; in ten of the families the mother had full-time employment. Six mothers were employed part-time. Twenty of the fathers and twenty-two of the mothers were high school graduates. In seventeen of the families the child with Down syndrome was male; in fifteen of the families the child with Down syndrome was female. See Table II for the demographic information of families who participated in the study.
TABLE II
DEMOGRAPHIC INFORMATION OF FAMILIES WHO PARTICIPATED IN THE STUDY

<table>
<thead>
<tr>
<th></th>
<th>Urban</th>
<th>Small City</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Number of Families</td>
<td>15</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>2. Two Parents in the Home</td>
<td>12</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>3. One Parent in the Home</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4. Father Employed Fulltime</td>
<td>11</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>5. Mother Employed Fulltime</td>
<td>6</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>7. Father High School Graduate or Above</td>
<td>11</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>8. Mother High School Graduate or Above</td>
<td>12</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>9. Child With D.S. Male</td>
<td>8</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>10. Child with D.S. Female</td>
<td>7</td>
<td>6</td>
<td>2</td>
</tr>
</tbody>
</table>

B. Family Support

Data regarding family support was classified into two groups: non-urban and urban populations. See Tables III through VI for the tabular data described below. Seventeen (100%) mothers from the non-urban areas reported that they were highly supported by their spouses. Thirteen (76%) reported that their other children were very supportive, one parent (6%) reported that siblings were not available, and three parents (18%) indicated that the siblings were neither very supportive nor unsupportive. Nine (53%) respondents reported that their extended families were very supportive, two respondents (12%) stated that their extended families were not
available, and six respondents (35%) indicated that their extended families were neither very supportive nor unsupportive.

**TABLE III**

NUMBERS OF MOTHERS WHO RESIDE IN NON-URBAN AREAS WHO PERCEIVE FAMILY AS SUPPORTIVE, NOT SUPPORTIVE

<table>
<thead>
<tr>
<th></th>
<th>Spouse</th>
<th>Siblings</th>
<th>Extended Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Supportive</td>
<td>17</td>
<td>13</td>
<td>9</td>
</tr>
<tr>
<td>Not Supportive</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not Available</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>

**TABLE IV**

PERCENTAGE OF MOTHERS WHO RESIDE IN NON-URBAN AREAS WHO PERCEIVE FAMILY AS SUPPORTIVE, NOT SUPPORTIVE

<table>
<thead>
<tr>
<th></th>
<th>Spouse</th>
<th>Siblings</th>
<th>Extended Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Supportive</td>
<td>100%</td>
<td>76%</td>
<td>53%</td>
</tr>
<tr>
<td>Not Supportive</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Not Available</td>
<td>0%</td>
<td>6%</td>
<td>12%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>18%</td>
<td>35%</td>
</tr>
</tbody>
</table>

In the urban population twelve mothers (80%) reported that their spouses were very supportive in the parenting role. Three mothers (20%) reported that they did not
live with their spouses. Ten of the mothers (67%) reported that their other children were very supportive, one mother (7%) reported that her other children were not supportive, and four mothers (26%) indicated that their other children were neither very supportive nor unsupportive. Eight families (53%) indicated that their extended families were very supportive, four mothers (27%) indicated that their extended families were not available, and three mothers (20%) indicated that their extended families were neither very supportive nor unsupportive.

TABLE V

NUMBER OF MOTHERS WHO RESIDE IN URBAN AREAS
WHO PERCEIVE FAMILY AS SUPPORTIVE, NOT SUPPORTIVE

<table>
<thead>
<tr>
<th></th>
<th>Spouse Frequency</th>
<th>Siblings Frequency</th>
<th>Extended Family Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Supportive</td>
<td>12</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Not Supportive</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Not Available</td>
<td>2</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>
TABLE VI

PERCENTAGE OF MOTHERS WHO RESIDE IN URBAN AREA WHO PERCEIVE FAMILY AS SUPPORTIVE, NOT SUPPORTIVE

<table>
<thead>
<tr>
<th></th>
<th>Spouse</th>
<th>Siblings</th>
<th>Extended Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Supportive</td>
<td>80%</td>
<td>67%</td>
<td>53%</td>
</tr>
<tr>
<td>Not Supportive</td>
<td>0%</td>
<td>7%</td>
<td>0%</td>
</tr>
<tr>
<td>Not Available</td>
<td>13%</td>
<td>0%</td>
<td>27%</td>
</tr>
<tr>
<td>Other</td>
<td>7%</td>
<td>26%</td>
<td>20%</td>
</tr>
</tbody>
</table>

C. Informal Support Systems

Twenty-six of the mothers (81%) reported that friends were very supportive of their parenting role, six mothers (19%) indicated that their friends were neither very supportive nor unsupportive. Twenty-one respondents (66%) indicated that other parents were very supportive, eleven mothers (34%) indicated that other parents were neither very supportive nor unsupportive. Fourteen mothers (44%) indicated that parent groups were very supportive, one mother (3%) reported that parent groups were unsupportive, and seventeen mothers (53%) indicated that parent groups were neither very supportive nor unsupportive. Sixteen mothers (50%) reported that neighbours were very supportive, five mothers (16%) indicated that neighbours were unsupportive, and eleven mothers (34%) indicated that they were neither very supportive nor unsupportive. Fifteen respondents (47%) reported
that babysitters were very supportive, two mothers (6%) reported that their babysitters were not supportive, and fifteen mothers (47%) reported that their babysitters were neither very supportive nor unsupportive. See Tables VII and VIII for the tabular data on informal support systems.

**TABLE VII**

**FREQUENCY OF PERCEIVED INFORMAL SUPPORTS FROM SOURCES OTHER THAN FAMILY**

<table>
<thead>
<tr>
<th></th>
<th>Friends</th>
<th>Other Parents</th>
<th>Parent Groups</th>
<th>Neighbours</th>
<th>Babysitters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Supportive</td>
<td>26</td>
<td>21</td>
<td>14</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td>Not Supportive</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>11</td>
<td>17</td>
<td>11</td>
<td>15</td>
</tr>
</tbody>
</table>

**TABLE VIII**

**PERCENTAGE OF PERCEIVED INFORMAL SUPPORTS FROM SOURCES OTHER THAN FAMILY**

<table>
<thead>
<tr>
<th></th>
<th>Friends</th>
<th>Other Parents</th>
<th>Parent Groups</th>
<th>Neighbours</th>
<th>Babysitters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Supportive</td>
<td>81%</td>
<td>66%</td>
<td>44%</td>
<td>50%</td>
<td>47%</td>
</tr>
<tr>
<td>Not Supportive</td>
<td>0%</td>
<td>0%</td>
<td>3%</td>
<td>16%</td>
<td>6%</td>
</tr>
<tr>
<td>Other</td>
<td>19%</td>
<td>34%</td>
<td>53%</td>
<td>34%</td>
<td>47%</td>
</tr>
</tbody>
</table>
D. **Formal Support Systems**

Twenty-four mothers (75%) reported that the child's physician was very supportive, two mothers (6%) reported that the physicians were not supportive, and six mothers (19%) indicated that their physicians were neither very supportive nor unsupportive. Twenty-four respondents (78%) indicated that teachers were very supportive, seven mothers (22%) indicated the teachers were neither very supportive nor unsupportive. Twelve mothers (38%) reported that their clergy were very supportive, two mothers (6%) indicated that the clergy were unsupportive, and eighteen mothers (56%) did not use the service or did not feel either very supported or unsupported. Twelve mothers (38%) reported that professional agencies were very supportive in their parenting role, two mothers (6%) reported that they did not feel supported by professional agencies, and eighteen mothers (56%) did not use the service or did not feel either very supported or unsupported. See Tables IX and X for the data reported on formal support systems.
TABLE IX
FREQUENCY OF PERCEIVED FORMAL SUPPORT
FOR MOTHERS WITH A CHILD WITH DOWN SYNDROME

<table>
<thead>
<tr>
<th></th>
<th>Physicians</th>
<th>Teachers</th>
<th>Clergy</th>
<th>Professional Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Supportive</td>
<td>24</td>
<td>25</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Not Supportive</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Perceived Effect</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown or Service</td>
<td>6</td>
<td>7</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>Not Used</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TABLE X
PERCENTAGE OF PERCEIVED FORMAL SUPPORT
FOR MOTHERS WITH A CHILD WITH DOWN SYNDROME

<table>
<thead>
<tr>
<th></th>
<th>Physicians</th>
<th>Teachers</th>
<th>Clergy</th>
<th>Professional Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Supportive</td>
<td>75%</td>
<td>78%</td>
<td>38%</td>
<td>38%</td>
</tr>
<tr>
<td>Not Supportive</td>
<td>6%</td>
<td>0%</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Perceived Effect</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown or Service</td>
<td>19%</td>
<td>22%</td>
<td>56%</td>
<td>56%</td>
</tr>
<tr>
<td>Not Used</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

E. General Satisfaction with Informal and Formal Support
Table XI indicates the frequencies of response to questions pertaining to general satisfaction with informal and formal supports. Thirty-one of the respondents were satisfied with general informal supports for their parenting role. One respondent was not satisfied. Fourteen respondents were satisfied with general formal support.
Fifteen respondents were not satisfied with the general formal support they received. When a chi square was calculated on this data, the difference between the groups was significant ($p < .01$).

**TABLE XI**

FREQUENCIES OF RESPONSE TO GENERAL PERCEPTION OF INFORMAL AND FORMAL SUPPORT SYSTEMS

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Satisfaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With Informal Support</td>
<td>31</td>
<td>1</td>
</tr>
<tr>
<td>General Satisfaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With Formal Support</td>
<td>14</td>
<td>15</td>
</tr>
</tbody>
</table>

F. **Urban and Non-Urban Satisfaction with General Support Systems Available**

Within the urban population two respondents indicated general satisfaction with the support systems available to them. Thirteen respondents indicated a lack of satisfaction with the support systems available to them. In the non-urban population, ten respondents reported general satisfaction with the support systems available. Seven respondents indicated a lack of satisfaction with the support systems available to them. See Table XII. A chi square was calculated on this data. The difference between the responses of the two groups was significant ($p < .01$).
TABLE XII
FREQUENCIES OF EXPRESSED SATISFACTION/DISSATISFACTION WITH THE GENERAL SUPPORT SYSTEMS FOR THE URBAN AND NON URBAN POPULATIONS

<table>
<thead>
<tr>
<th></th>
<th>General Satisfaction With Support</th>
<th>General Dissatisfaction With Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban Population</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Non-Urban Population</td>
<td>10</td>
<td>7</td>
</tr>
</tbody>
</table>
I. Discussion

A. Introductory Statement

In this study the author examined the availability and perceived quality of support provided to mothers of children with Down syndrome. Three areas of support were considered: family support, informal support, and formal support. The results of this research lend support to the position advanced by Wandersman et al. (1980) which suggests that an analysis of the network of support must include the many relationships a family experiences in a family's social environment.

B. Similarities in Formal and Informal Support

In both formal and informal support systems there is an underlying principle of provision of care for persons in a society. Supportive activities, behaviors, attitudes, and procedures give sustenance, opportunity, and aid to individuals on a day-to-day basis and in times of crisis. The support and resources offered to an individual or family may be provided through many channels, and it is the composite impact of many sources of positive comment, helpful behavior, and general acceptance which enables parents to feel supported. The multidimensional nature of the concept of support is apparent
in both the informal and formal systems of support. House's (1981) four types of support are present in both systems: emotional support, instrumental support, informational support, and appraisal support.

C. Differences Between Formal and Informal Support

Formal support is based upon provision of care in specific areas of need. The requests and expectations made of professionals are inherently dissimilar from requests and expectations made of relatives and friends. The professional or agency is responsible for the provision of a service to the individual. This service is defined in terms of the discipline of the professional or the mandate of the agency. The scope of behavior is usually narrow, and is often performed with an element of professional distance. The services rendered are placed within time parameters, and the relationship between the client and the professional /agency is placed within the same time constraints.

The scope of behavior in informal support is not defined to the same extent as in formal support. Because there is not a mandate or discipline to define the interaction, the relationship may take any course. There is not an element of distancing beyond that of interactive constraints found in any relationship. Therefore, both persons in the relationship have the opportunity for mutual satisfaction. Time restrictions are not placed
on the interaction in an informal relationship. The opportunities for an ongoing interaction are present, with factors determining longevity of a relationship open to the same sources of mutual satisfaction or dissatisfaction as in any relationship. The underlying cohesive factor is the bond of the relationship, which, when it is strong, will enable the relationship to be maintained indefinitely.

D. Family Support

This study demonstrated that support from family is offered to mothers of children with Down syndrome, and that there are several factors which determine the availability and quality of support. The presence in the home of a spouse, the presence of other accepting children in the home, and the opportunity to interact with extended family members are factors which give support to mothers.

1. Two-Parent Families

In two-parent families mothers receive considerable support from their spouses. When fathers are available, there is a natural sharing of responsibility for the child's well-being. Fathers may provide an active adult involvement with the child, an opportunity for the presence of a mutual interest in the offspring, role division, and, in some cases, access to monetary and
social resources. It is helpful to mothers to know that there is another adult who is deeply interested in the life events, health, and development of the handicapped child.

2. **One-Parent Families**

In one-parent families mothers receive support from sources other than a spouse. Involvement with friends, family, acquaintances, church, and community resources may have a meaningful role in the life of a single mother of a handicapped child. There are vast differences in the personal strengths and resources in single parents and it is necessary to consider the opportunities available when evaluating the support system. Women who have financial resources are often able to gain access to respite and assistance, information, and services which women who live in poverty cannot afford. The lack of shared responsibility, especially financial responsibility may, as Holroyd (1974) suggested, be a source of stress to single mothers.

3. **Siblings**

Siblings are generally very supportive of their mothers. However, family circumstance may dictate the degree of involvement a sibling has with the family. In several cases the child with Down syndrome was the youngest family member and often there was a considerable
age difference between the youngest and oldest child. Also, in some instances the children in the family were all young and would not be considered either supportive or unsupportive. In the situation where the sibling was reported as unsupportive, the mother indicated that there was sibling rivalry related to the closeness in age of the two children.

4. Extended Family Members

This study demonstrated that extended family members may not have the personal resources necessary to be very supportive to families raising a handicapped child. Many families reported that their extended families lived at considerable distance from them or were not available to the family. Older parents often reported that their own parents were deceased. In one case the mother's parent was chronically ill and the family members needed support for their own situation. In another case the contact with the husband's extended family had been withdrawn after the couple had divorced. Those families who reported that their extended families were supportive indicated a wide spectrum of behaviors which were described as helpful. Some extended family members exhibited attitudes and caring gestures which showed their understanding and empathy for the situation. Other family members provided babysitting opportunities for the parents. In one case a large extended family provided
many social opportunities for the handicapped child. Fotheringham and Creal (1974) suggest that it is through outside relationships that parents perceive acceptance or rejection, and receive assistance and encouragement for the ways in which various situations are handled.

E. **Informal Support**

Results of this study indicated that mothers of children with Down syndrome received support from informal sources such as friends, other parents, parent groups, neighbours, and babysitters. Dunst, Trivette, and Cross (1986) suggest that personal, family, and child functioning in families with a handicapped child are mediated by social support. Personal well-being and parental attitudes are influenced by the social support a family receives.

1. **Friends**

   The respondents indicated that friends were very supportive of them in their role as parent of a handicapped child. Friendships provided a wide variety of supportive actions such as babysitting, advocacy, social opportunities for the mother and the handicapped child, and demonstration of acceptance of the situation. Many friends acted as confidants. Some individuals participated in helpful acts such as transporting the other children, sharing material items, or introducing the
family to new social contacts. Those respondents who indicated that the perceived effect was other than "very supportive" had friendships through work or in situations which were not family oriented. The friendships were outside the realm of family function and children were not a main topic of conversation.

2. Other Parents

Other parents were also very supportive of the respondents. The mothers indicated that other parents were willing to share some of the responsibilities inherent in the parenting role. They would pick-up or drop-off children at school in an emergency situation, or cooperate with babysitting. Also, there was a willingness to share toys and other resources such as books or articles of interest, and to give information on services which would be helpful to the family. Those respondents who indicated that the perceived effect was other than "very supportive" were parents of older individuals who were more socially isolated, or were parents in one-child families who did not have contacts in the community. Many of the respondents indicated that other parents were sometimes helpful but that they did not perceive them as "very supportive".

3. Parent Groups

The majority of respondents did not perceive parent
groups as very supportive. The results of this finding were confounded because of a lack of definition of "parent groups". The author intended this category to include only parent groups for parents of exceptional children such as the local association for mentally handicapped persons, a parent group for mutual support, or a group initiated to teach a specific skill for working with the handicapped youngster. However, the category was interpreted more broadly by some respondents to include school consultative meetings, preschool meetings and other general groups. The findings cannot be interpreted as a result.

4. Neighbours

Neighbours were perceived as very supportive in one half of the respondents. Some neighbours were willing to befriend the child and to support the parents in their role. Many respondents indicated that neighbours were sometimes helpful, but often urban dwellers had less opportunity for interaction with their neighbours. Three of the respondents indicated that there was no interchange between themselves and their neighbours. While the urban population had less interaction with their neighbours, the rural population did not have neighbours available to them.
5. Babysitters

Many babysitters were very supportive of the parents, however some were considered only somewhat helpful. The babysitters who were very supportive showed care for the child, and were available when required. They were willing to undertake the extraordinary demands of caring for an exceptional child. Those babysitters who were described as unsupportive were less flexible and more reluctant to carry out atypical requests. Some parents reported difficulties in finding a suitable babysitter, especially for older children.

6. The Influence of an Informal Support Network

Positive attitudes in friends and family members influence the degree of support a family may experience. The informal supports which are present in a network strengthen the resolve to encourage and guide the child's development (German and Maisto, 1982). This support helps parents to carry through in the therapeutic procedures and medical treatments, and to make the personal sacrifices necessary to ensure adequate care for the child. Friends, family, and neighbours, in their supporting roles, encourage the parents to sustain growth in the child, and they may also assist in basic care requirements. In addition, babysitters offer respite to the parents.

Parents in the study were adequately supported by
their informal support system. The respondents indicated a general satisfaction with the informal supports available to them.

F. Formal Support

1. Characteristics of Positive Professional Support

In making the adjustment to parenting a handicapped child, specific kinds of support are required for each area of adjustment to be made. Professionals may be very helpful in bridging the gap between the known and the unknown (Peuschel and Murphy, 1976; Sommers and Nycz, 1978). With this knowledge comes a broader understanding of the special needs of the child. In addition to their role requirements within their disciplines, supportive personnel are able to alleviate fears, clear misconceptions, and focus parental actions. Professionals may assist parents in acquiring the resources, skills, and positive attitudes and supports to maintain and enrich the life of the handicapped child. An encouraging word, an enquiry about family concerns, or a positive attitude toward the child will make considerable difference to a parent who is adjusting to the new challenges a handicapped child may bring (McAndrew, 1976).

2. Hindrances to Professional Functioning

Professionals often are forced to function in an unresponsive milieu. If the resources are not available
within a system, professionals feel unable to adequately support their client. This lack of resources often results in frustration for the parents and role conflict for the professional who is trying to appropriately meet the needs of the child.

3. Support by Physicians

Parents perceived physicians as very supportive in most situations. Those physicians who were described as very supportive showed interest and concern for the well-being of the child. Positive comments were made about the child's growth and development or the child's achievements. The emotional needs as well as the physical needs were addressed. Very supportive physicians made appropriate referrals when necessary, and did not question the child's right to access to medical procedures. Very supportive physicians assisted parents in their requests for appropriate medical services for their child.

Some physicians were described as unsupportive. These professionals indicated to parents a lack of interest in children with Down syndrome. One physician suggested to the parent that the only appropriate setting for a child with Down syndrome was in an institution. Some parents reported that referrals for important medical procedures, those which are recommended for all children with Down syndrome such as screening for hearing problems, were not made. Parents felt that unsupportive physicians
made their role as caregiver far more difficult.

Physicians who were neither very supportive nor unsupportive were usually described as "generally helpful". They followed through with procedures in ways that maintained the health of the child, but did not exhibit the additional qualities which made families feel particularly supported by them.

4. Support by Teachers

Teachers were generally perceived to be very supportive. The teachers were described as knowledgeable in their discipline and were able to communicate well with the parents. The teachers took the responsibility for educating the children seriously and provided appropriate learning opportunities for them.

In some cases the children were not of school age and did not experience "teachers". Also, some parents described their children's teachers as "sometimes helpful". In other cases the school system did not educate the children in the way that the parents expected. One parent stated that she had been requesting an integrated setting for her child for nine years.

5. Support by Clergy

Several respondents indicated that they were very supported by their clergymen. Some respondents wrote in great detail about the distinction between the support
they received from their belief in their religion and that from their church leaders. It was indicated that for some individuals a strong belief in a religion assisted them to put the birth of their handicapped child into a perspective that was helpful in sustaining their efforts for their child. However, one respondent complained that there was no place on the questionnaire to register her loss of faith as a result of the circumstance of her handicapped offspring.

Many respondents did not have a religious affiliation and indicated that a religious leader was neither supportive nor unsupportive. One respondent indicated that she wished that she had had a strong faith at the time of her child's birth. Some respondents indicated that their clergyman was "sometimes helpful" in the adjustment to the role of parent of a handicapped child.

6. Support by Professional Agencies

Professional agencies were not available or were not used by most respondents of the questionnaire. Many of the parents reported that they did not have contact with professional agencies such as health centres, social services, or mental health services. Some parents did not realize that the services were available to them. Parents who reported that these agencies were unsupportive had not had their requests for services met.
For the respondents who described the services as very supportive, there had been considerable effort made by the professionals to meet the needs of the child. One parent reported that she had been given access to a drug her daughter required for maintenance of health. Another parent had used speech therapy services for her child through public health.

G. General Perception of Support

1. Informal and Formal Support Differences

When the general perception of overall informal and formal systems was examined, maternal response clearly indicated a satisfaction with the informal system, but did not indicate that this satisfaction extended to the formal system as well. Many respondents felt unsupported by the formal system. It is the opinion of the author that the necessary services parents need to feel supported by the formal system are not presently in place, or if they are available, parents do not know how to gain access to them.

2. Urban and Non Urban Population Differences

Urban and non urban populations had very different perceptions of their general support systems. The majority of the urban population had a general dissatisfaction with support, whereas the non urban population indicated a general satisfaction with their support.
It is the opinion of the author that the families in the urban area are often not familiar with neighbours, and must utilize more complex systems in order to gain access to formal support networks. More effort on the part of the family must be made to have the social, educational, emotional, and health needs met in the urban area, and this may influence the attitudes of the mother in how she perceives her support systems.

II. Limitations and Conclusions

A. Limitations of the Study

The study was limited by the nature of the population surveyed. The parents who join support groups are those who already have resources and personal skills which enable them to seek out sources of support. Association members would also have personal resources available which the majority of parents of children with Down syndrome may not possess. The researcher was unable to locate parents of children who were not affiliated with a parent organization. There is not a method available to reach families who are not members of an organized group.

The population size was very small. The respondents reported that their informal supports were adequate. A larger, more diverse population is required in order to analyze the support available to families who do not
have the personal and financial resources necessary to maintain a child with Down syndrome.

The study was also limited by the lack of consistency and availability of services to parents throughout the province. Services which are available in the metropolitan area of Vancouver may not be available to parents in other regions of the province, particularly the opportunity for medical consultation and access to facilities.

Information of the validity and reliability of the questionnaire was unavailable to the researcher. The research tool was also altered to accommodate the Canadian population.

B. Implications for Further Research

An area of research which is necessary is the study of individuality of families in their perception of support systems. What characteristics in individuals and in families help them to perceive gestures, services, and systems as supportive? Also, what life experiences shape the individuals so that they perceive their support systems in either positive or negative ways? Are there ways that formal systems deliver services which parents perceive as being unsupportive? Are there critical periods when formal support is necessary for families?

The role of parent associations in facilitating
access to services must be addressed. Do presently established parent associations give direction to parents regarding the availability of services in the community? How do parents learn about services and resources that are available to their children? Who is lobbying for the co-ordination of services and for the services to be made accessible to the families of children with special needs?

C. Conclusions

Although families feel generally supported by their informal systems of support, there is a general dissatisfaction with the formal system of support. There is a great need to assess what services are presently available, to catalogue these services, to examine the ways in which parents are made aware of these services, and to help parents find the services they require. Systems which co-ordinate professional effort, such as a provincial clinic for persons with Down syndrome, would be a direct way to provide appropriate care for the children. There may also be gaps in service which need to be addressed. Parents of children with handicapping conditions require the support of the community to make the role of caregiver a manageable task.
Reference Notes

Chapter 1


2 Hepworth, P. Formal and informal community support services: The elderly in Canada. The Social Worker, 1982, 50, 1, 10.

Chapter 2


2 Ibid., 409.

3 Ibid., 411.

4 Ibid., 413.


8 Ibid., 98.

9 Ibid., 98.

10 Ibid., 99.
References


Holroyd, J. The Questionnaire on resources and stress: An instrument to measure family response to a handicapped family member. *Journal of Community Psychology*, 1974, 2, 92-94.


Questionnaire on Family Support Systems

Demographics

1. Date this form was completed: ___/___/___
   mo. day year

2. Child's sex: male ____ female ____

3. Child's birthdate: ___/___/___

4. Mother's birthdate: ___/___/___

5. Father's birthdate: ___/___/___

6. Ethnic/Racial Background:

   Father or  
   male guardian | Mother or 
   female guardian

   Black ____  ____
   Caucasian ____  ____
   Oriental ____  ____
   Other (please state) ____  ____

7. Type of area:

   Inner city ____ Urban (population of 50,000) ____
   Small city (population 2,500 to 49,999) ____
   Rural (2, 500 or less) ____ Other (population ____)

8. Indicate the guardians in the home of the child:

   Female  Male
   None ____  ____
   Natural parent ____  ____
   Adoptive parent ____  ____
   Foster parent ____  ____
   Other relative ____  ____
   (Please state relationship) ____
9. **Parents' / Guardians' Education:**

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<th>Check highest attained</th>
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<th>Mother</th>
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</tr>
<tr>
<td>some college</td>
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<tr>
<td>diploma</td>
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<tr>
<td>bachelor's degree</td>
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<tr>
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10. **Employment and Income of Parents / Guardians:**

**Employment Status**

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<td>____</td>
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<tr>
<td>full time</td>
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<td>part time</td>
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<tr>
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11. Occupation

<table>
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<td>professional</td>
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<tr>
<td>clerical</td>
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<tr>
<td>sales</td>
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<td>craftsman</td>
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<tr>
<td>blue collar</td>
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<tr>
<td>service worker</td>
<td></td>
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<tr>
<td>not applicable</td>
<td></td>
</tr>
<tr>
<td>other</td>
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</tbody>
</table>

12. How many siblings does the child have?  ____

13. The child's health in general is:

- good
- fair
- poor

State the health problems your child has (which you consider serious)

_____________________________________________________

_____________________________________________________

14. At what age did your child begin receiving educational services at least once a week?

- 0-6 months
- 7-12 months
- 13-24 months
- 25-36 months
- 37-48 months
- 49-60 months
- after 60 months
15. Please list the age and sex of your child's other siblings:

   ____ yrs.  ____ mos.  ____ brother  ____ sister
   ____ yrs.  ____ mos.  ____ brother  ____ sister
   ____ yrs.  ____ mos.  ____ brother  ____ sister
   ____ yrs.  ____ mos.  ____ brother  ____ sister

16. Check the following services your child has received from specialized personnel in educational programs:

   ___ physical therapy
   ___ occupational therapy
   ___ language therapy
   ___ health care services
   ___ other __________________________
   ___ none

17. In how many educational programs has your child been enrolled?

   ___ none
   ___ one
   ___ two
   ___ three
   ___ four or more

18. In our family, discipline is:

   ___ very strict
   ___ strict
   ___ sometimes strict, sometimes easy
   ___ easy going
   ___ very easy going
Religious Affiliation

19. Do you have a religious affiliation?
   Yes ___  No ___

   If you answered question 19 with "No", please do not answer
   questions 20, 21, 22, 23.

20. What is your current religious affiliation?
   ___ Catholic
   ___ Jewish
   ___ Protestant, Please specify denomination
   ________________________________
   ___ Other, Please specify
   ________________________________

21. I was raised:
   ___ With no religion
   ___ Catholic
   ___ Jewish
   ___ Protestant (please specify denomination ____________________)
   ___ Other (please specify _________________________)

22. How often do you participate in religious services?
   ___ not at all
   ___ less than once a month
   ___ at least once a month
   ___ weekly
   ___ more than once a week

23. I am satisfied with the support I receive from this religious
    group as it pertains to my handicapped child:
   ___ not at all  ___ very helpful
   ___ sometimes helpful ___ extremely helpful
   _________________________  _________________________
**FAMILY SUPPORT**

Listed below are sources of support that often are helpful to members of families raising a young child. Please circle the response that best describes how helpful these sources have been to your family during the past three to six months.

**Key:**
- 1 Not applicable
- 0 Not available to us
- 1 Not at all helpful
- 2 Sometimes helpful
- 3 Generally helpful
- 4 Very helpful
- 5 Extremely helpful

1. My parents
2. My spouse's parents
3. My relatives / kin
4. My spouse's relatives / kin
5. Husband or wife
6. My friends
7. My spouse's friends
8. My own children
9. Other parents
10. Professional helpers
11. My family or child's physician
12. Co-workers

<table>
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<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<td>My spouse's parents</td>
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<td>My relatives / kin</td>
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<td>My spouse's relatives / kin</td>
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<td>Husband or wife</td>
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<td>My friends</td>
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<tr>
<td>My spouse's friends</td>
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<td>My own children</td>
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<tr>
<td>Other parents</td>
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<tr>
<td>Co-workers</td>
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</tbody>
</table>
13. Parent groups -1 0 1 2 3 4 5
14. School / day care centre -1 0 1 2 3 4 5
15. Professional agencies (public health, social services, mental health) -1 0 1 2 3 4 5
16. Family, Infant, or Preschool Program -1 0 1 2 3 4 5
17. Social groups / clubs -1 0 1 2 3 4 5
18. Church -1 0 1 2 3 4 5
19. Neighbours -1 0 1 2 3 4 5
20. Babysitters -1 0 1 2 3 4 5

EDUCATIONAL

For these items, consider your "family" as the individual(s) with whom you usually live. If you live alone, consider family as those with whom you have the strongest emotional ties.

Key: 0 Not applicable
1 Strongly disagree
2 Moderately disagree
3 Neither agree nor disagree
4 Moderately agree
5 Strongly agree

Please circle the answer that best describes your situation.

1. It has been difficult to obtain the educational services my child needs.  0 1 2 3 4 5
2. It has been difficult to obtain the extra therapy services my child needs.  0 1 2 3 4 5
3. I was not provided the information and training necessary to work with my child at home during my child's early life. 0 1 2 3 4 5

4. It has been my experience that I have difficulty in communicating with my child's teachers. 0 1 2 3 4 5

5. Educational personnel have been supportive in nurturing and providing guidance for my child. 0 1 2 3 4 5

6. Outside of my spouse, members of my family are not helpful or involved in my child's education. 0 1 2 3 4 5

7. I worry about my child's education, particularly the type and quality of programs available to my child in the future. 0 1 2 3 4 5

8. If I could choose my child's teacher, I would select one who is very strict with the students. 0 1 2 3 4 5

9. I feel that integration of handicapped and non-handicapped children is an unimportant issue facing the educational system. 0 1 2 3 4 5

10. I need to have close contact with my child's teacher in order to ensure skill development. 0 1 2 3 4 5

11. A major contribution to my family has been the opportunities for me to get to know other parents with similar concerns. 0 1 2 3 4 5

12. In my child's case, educational involvement and program participation is primarily the mother's responsibility. 0 1 2 3 4 5
13. If given the opportunity, I would work with my child and his/her teacher in my child's educational program.

14. A focus in the public school system should be a knowledge and awareness of handicapping conditions by non-handicapped students.
SPECIAL EDUCATIONAL CONCERNS

1. If I had had a better understanding of skill development, teaching techniques, and reasons for methods employed, I would have worked more effectively with my child during the early years. 0 1 2 3 4 5

2. My child's teachers do not believe me when I tell them what my child does at home. 0 1 2 3 4 5

3. Members of the educational staff help us get the services we feel our child needs. 0 1 2 3 4 5

4. I worry about the type and quality of the educational programs available to my child in the future. 0 1 2 3 4 5

5. If I could choose my child's teacher, I would select one who has a strong background in child development and progression of skills. 0 1 2 3 4 5

6. I will be very disappointed if non-handicapped classmates are not included in my child's educational program. 0 1 2 3 4 5

7. I will need to have closer contact with my child's teacher than I would if my child were not handicapped. 0 1 2 3 4 5

8. A major contribution of my child's educational program has been the opportunities it provides parents to get to know parents with similar concerns. 0 1 2 3 4 5
RELIGION

If you do not have a religious affiliation, please do not answer these questions. Please go on to the next page.

1. My clergyman was helpful to me when my child was born.

2. My religion has helped me to understand and accept my child.

3. I am satisfied that my religion is fulfilling my family's spiritual needs.

4. Having this child has brought me closer to God and my religion.

5. I am satisfied with availability of religious instruction for my child.

6. I feel comfortable in taking my child to church.

7. I am more active in my church since my child was born.

8. If I had problems associated with my child, I would seek help and guidance from members of my church or clergy.

9. I seek comfort through prayer.

10. My faith continues to be a source of help and support in raising my child.

11. The church has been more supportive to me than other agencies in our community by providing the help I need as the parent of this child.

12. My church is a source of personal and family strength in everyday living.

13. Most of my social activities involve members of my church.
FAMILY'S SOCIAL SUPPORT

1. I am satisfied that I can turn to my family for help when something is troubling me. 0 1 2 3 4 5
2. I am satisfied with the way my family talks things over with me and shares problems with me. 0 1 2 3 4 5
3. I am satisfied that my family accepts and supports my wishes to take on new activities or directions. 0 1 2 3 4 5
4. I am satisfied with the way my family expresses affection and responds to my emotions, such as anger, sorrow, or love. 0 1 2 3 4 5
5. I am satisfied with the way my family and I share time together. 0 1 2 3 4 5
6. Often I feel very lonely. 0 1 2 3 4 5
7. I visit my friends whenever I want. 0 1 2 3 4 5
8. I am satisfied with the relationships I have with my neighbours. 0 1 2 3 4 5
9. I am satisfied with the amount of time I spend away from my child, for social reasons (example: movies, visiting friends, concerts). 0 1 2 3 4 5
10. My neighbours and I socialize a great deal together. 0 1 2 3 4 5
11. My co-workers are a large part of my social life. 0 1 2 3 4 5
12. I am satisfied with the availability of professional persons (counselors, doctors, teachers) to talk to about my child. 0 1 2 3 4 5
13. I feel better after I talk to a professional about my child. 0 1 2 3 4 5
14. I don't feel the professionals I have dealt with understand my problems or concerns.  
   0 1 2 3 4 5

15. I am satisfied with the amount and quality of services provided to my child in my community.  
   0 1 2 3 4 5

16. I think the support services in my community adequately meet the needs of myself and my child.  
   0 1 2 3 4 5

17. I am satisfied with the relationships I have with my co-workers.  
   0 1 2 3 4 5
OPTIONAL INFORMATION

Please do not fill in this page unless you feel comfortable in doing so. If you do provide the information, the researcher will endeavour to send you a summary of research findings.

Name: __________________________________________

Address: _______________________________________

Telephone Number: ______________________________

Comments:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________