PARENTS OF CHILDREN WITH DISABILITIES: ENVIRONMENT AND ACTIVITY

by

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ABSTRACT

Occupational therapy in Canada is guided by several models that describe an interconnectedness between the individual, his/her occupations and the environment (Canadian Association of Occupational Therapy, 1997, Law et al. 1996). Occupational therapists have also expanded their conceptualization of the client of occupational therapy services, from the individual to include groups, organizations and families (Fearing, Law & Clark, 1997). Yet little research has been conducted, in occupational therapy, to explore the issues faced by the family or family members of a child with a disability and how they experience daily life. The purpose of this qualitative research is to explore and describe parents' experiences raising their child with a disability, with a focus on their participation in activities outside the home environment.

In-depth interviews were conducted with seventeen parents from nine families who were recruited from suburbs surrounding Vancouver, British Columbia. The parents all had one child with a disability between 3 and 5 years of age. The diagnoses and abilities of the children varied, however they were all unable to walk unaided. The interviews were transcribed and a computer aided interpretive analysis was used to identify common themes.

The parents spoke of their emotions for their children. The parents relied on others, especially family members, for emotional, practical and financial support. Many parents drew a connection between participating in activities and their perceptions of what it is to be a normal family. The parents explained their strategies, such as planning ahead, and the conditions, such as the right equipment, necessary for them to decide to take their children out and to participate in activities. When the strategies and conditions were not in place, they stayed home. Parents also spoke of the social attitudes they encountered.

This research validates the concept of the dynamic and interconnected relationship among the person, occupation and environment. An individual's roles, activities and occupations both
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influence and are influenced by the environment. It also illustrates that fathers and mothers participate differently in the lives of their children, and that sometimes grandmothers are significant care givers. The term, family-member centred service is proposed, to incorporate two components of client-centred occupational therapy, that of individualized service and the family as a client.
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Chapter One: INTRODUCTION

This research is about parents raising children with disabilities with a particular focus on experiences outside of their home. My interest in the experience of parents stems from my background working as an occupational therapist with children with disabilities, their parents and other family members in their home. Initially, I started this research to explore two questions. First, how can the family be conceptualized, as the client, at the centre of the traditionally individualistic, client-centred model of occupational performance [Canadian Association of Occupational Therapists (CAOT), 1991]? Second, what are the experiences of parents with their children when they leave their home environment? These questions are relevant, because models in occupational therapy assert an interconnectedness between an individual and their environment (CAOT, 1991 & 1997, Law et al. 1996). I was interested in where they go, how they get there, what they do and who in the family goes along. Qualitative research is well suited to explore these questions, as it is concerned with the process and meaning of social experiences (Denzin & Lincoln, 1994). I also learned much more than I anticipated about the parents' such as their struggles, emotions and how they make decisions.

This chapter begins with the statement of the problem and the purpose of this research. Next, a significant about of space is devoted to explaining the Canadian model of occupational therapy (CAOT, 1997) and how the concept of the environment has evolved and recently been described in occupational therapy literature. Client-centred practice in occupational therapy is also defined. Lastly the significance of this research is described, and the organization of the following chapters is outlined.

Statement of the Problem

Most of my ten years of clinical experience has been in community-based practice, seeing clients in their homes, preschool, respite settings and other places. Employment as an
occupational therapist has provided two valuable opportunities. First, to establish a close working relationship with the parents, and second, to observe families create a home environment that suits their needs. As I spent more time in community settings, I became more inquisitive and empathetic about the parents’ issues and struggles raising their children. One of the reasons I became more concerned about parental issues is because my employing agency was shifting to a "family-centred" service. A public law in the United States which mandates family-centred service delivery has lead to a proliferation of literature on this topic (Dunst, Johanson, Trivette & Hamby, 1991, Education of the Handicapped Act Amendments, 1986). Although many people would concur with the main underpinning of family-centredness in practice, to view the family as central to a disabled child’s life, in Canada we do not have a law mandating service delivery. Occupational therapy in Canada, however, has utilized a client-centred model in practice since the 1980’s. The client has historically been conceptualized as an individual and there is current recognition that the client could be "the family" (Fearing, Law & Clark, 1997). The issue is, how do occupational therapists conceptualize the family as the client? What does it imply for clinical practice of occupational therapy?

Very little research has explored the issues associated with considering the family as the client in the occupational therapy literature. I chose to focus on parents because I believe in many situations they are the most important family members in a disabled child’s life. Parents are usually the people who define the child’s needs, provide hands-on assistance to the child with self-care activities, structure the child’s daily activities and organize paid child care. As a result of my belief in the significance of parents to a child’s life, this research is underpinned by the essential and broad question, what is it like to be a parent with a child who has a disability?

Lack in understanding the family as the client, in part, stems from the paucity of research on parents’ experiences in environments other than the home environment. This is a gap within
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the literature. I would consider it a problematic gap because in occupational therapy the environment is viewed as integral to occupational performance (CAOT, 1997). Occupational therapists have defined occupational performance as: "the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after one's self, enjoying life, and contributing to the social and economic fabric of a community" (p. 30). The literature provides a view, like a snapshot, of parents' concerns regarding activities with their disabled children. The literature in occupational therapy is largely focused on mothers' experiences caring for and managing their disabled children's needs. Mothers are primarily responsible for providing and organizing child care and performing household work regardless if their children are disabled or not (Dyck, 1992, Primeau, 1992). While research in the social science literature covers the experience of having a child with a disability more broadly, there is very little research describing parents' experiences going out of the home environment. Thus, I chose to focus on parents' experiences with their child in out-of-home environments for two reasons; one, to address a significant gap in the literature on this theme and two, to explore how the environment is implicated in the lives of parents with children who have disabilities.

The Purpose of the Research

The purpose of this research is to describe parents' experiences with their disabled children with a specific focus on their activities outside of their home environment. In doing this, it intends to enhance understanding of, firstly, the different family members involvement with the child, and secondly, of the relationship between person and environment. This research was initially guided by the model of occupational performance (CAOT, 1991) and subsequently by the Canadian Model of Occupational Performance (CMOP) (CAOT, 1997), which clarifies the core concepts of occupational therapy practice. The publication of CMOP has been timely to
explain the concepts of the client and the environment in this research.

The CMOP (CAOT, 1997), shown in Figure 1, illustrates the dynamic relationship between the person, occupation and environment. It demonstrates, by shapes and a three dimensional orientation, the interaction of concepts over the person's lifetime. The study of the interaction between the environment and the individual has lead to various categorizations of the environment such as by location and/or by attribute. The model defines the environment as "having cultural, institutional, physical, and social elements" (p. 45). The institutional environment encompasses the economic, legal and political elements influential in everyday life. The relationship between the individual and the environment is dynamic and inseparable, and not viewed as a cause and effect relationship. The environment influences the individual and, conversely the individual affects the environment (CAOT, 1997). Over a lifetime, the individual and the environment will change and balance in response to each other.

The Definition of the Environment

For the purpose of this research, the components of the environment of primary interest are the physical and social. I am specifically, but not exclusively, interested in the physical and social environment outside of the home. My definition of the environment includes, for example, the neighbourhood, friends' homes, the pre-school or day care, the community centre, the grocery store and other services, places of religion and other locales where parents go with their children. This definition is not restricted by geography or distance. I am including in the social environment people such as family members, friends, neighbours, acquaintances and strangers. This definition affected my interviews with parents.

In the interviews, I asked the parents to describe their children, family members who live in the household, and other significant people in their lives. I tried to uncover the contextual influences shaping the parents' choices of activities, such as their sources of social, emotional and
financial support. I inquired about what activities the parents did or did not do with their children and why they made particular choices. I purposefully wanted to hear both the fathers' and mothers' perspectives so I could write about "parents" and be inclusive to both groups of parents. My inquiry in the environment originates from my clinical experience as well as from the concepts within the models underpinning occupational therapy in Canada.

Figure 1: Canadian Model of Occupational Performance

The Conceptual Approach

The model of occupational performance has guided occupational therapy practice in Canada (CAOT, 1991), but the concept of client-centred practice and the relationship between the client and the environment have been evolving since the initial development of guidelines for practice in the 1980's. The Occupational Therapy Guidelines for Client-Centred Practice, often referred to as the "Guidelines" were published in 1991. Since then, the concepts within the Guidelines have been further developed, including the document, Enabling Occupation: An Occupational Therapy Perspective (CAOT, 1997), which will guide clinical practice into the twenty-first century. The following discussion will include brief description of how the environment has been conceptualized in occupational therapy and how the client and client centred practice have been defined.

The Environment

Various scholars have influenced how occupational therapists understand the environment. Specifically, the descriptive work of Kielhofner (1995) and the integrative work by Law (1991, 1992) are used to show how the conceptualization of the environment in occupational therapy has evolved. Occupational therapy has also been influenced by the critical work of those in other disciplines, such as, Hahn (1985) and Oliver (1991), political scientists. Each of these authors, and others who write with them, provide a perspective on the person-environment dynamic. Kielhofner (1995) labels and describes the environment and how humans behave within it. His view is relatively individualistic. Hahn's (1985) view is from a political perspective and is concerned with how the environment and the experience of disability intersect. Oliver (1990) proposes a social theory of disability. Law has been influenced by the work of Kielhofner, Hahn, and others in her writing on disabling environments (Law, 1991, Law, 1992, Law & Dunn, 1993).
Kielhofner (1995) describes how the environment influences behaviour by providing opportunities (affords) and expecting specific behaviour (presses). Kielhofner is specific about what environments include. He describes the physical environment as "... the material environment including natural and fabricated spaces and objects" (Kielhofner, 1995, p.95). The natural environment refers to outside spaces, including mountains, forests and the weather such as rain or snow. Fabricated spaces refer to the environment made by people. The built environment includes places such as houses, community centres and shops, as well as the sidewalks and roads that connect these places. There are also objects in both the natural and built environments which "can make an environment arousing, comfortable, practical, safe, interesting and aesthetically pleasing" (p.97) or depressing, dangerous and dull. The objects of one's surroundings vary in complexity and through their properties can influence behaviour. They symbolize and show to others an individual's or a group's interests and values. Objects are also significant because they hold meaning that is very personal or group specific.

Kielhofner (1995) also discusses the social environment. There are many places that social groups organize, and the formality of the arrangement varies. Places for social groups include households, schools and community clubs. Social groups have rules, traditions and values that organize people, spaces, and interests. Kielhofner discusses how an individual in different environments would display different occupational behaviours, called occupational behaviour settings, depending on what the environment affords or presses. For a simple example, a preschooler's home could allow opportunities for play and eating as well as for socialization by the parents in terms of the kinds of toys available and the type of food provided. Although Kielhofner describes the social and physical environment in detail and makes the connection of how the environment influences behaviour, his model is relatively individualistic and he does not write about how his model relates to disability.
In contrast, Hahn (1985) provides a political view of how the environment impacts disability. Hahn (1984, 1985) asserts the physical environment is the way it is because of social policy, and social policy is created as a result of social attitudes and values. He makes his argument by comparing and contrasting three definitions of disability: the medical, the economic and the socio-political. The medical definition views disability as a problem within the individual and asserts the person must adapt to his/her surroundings. Medicine has not been equipped to deal with this definition of disability because its focus has been on finding cures and therefore has been better suited to acute conditions. The economic definition of disability is similar to the medical one in that the individual is viewed in terms of his/her limitations and inabilities to do activities as a normal individual would. The economic definition assumes that if individuals were working then they could "return" money to society. This view led to the creation of rehabilitation programs and public policies aimed at returning people with disabilities to work. The main problem with these programs and policies is the focus on changing the person's skills rather than changing the environment in which they function.

The socio-political definition of disability (Hahn, 1985) is different in that the locus of the problem has shifted from the limitations and inabilities of the individual to society's attitudes and behaviours. In his discussion of the definition of disability, he links social structures to the experience of disability:

Fundamentally, this model implies that disability stems from the failure of a structured social environment to adjust to the needs and aspirations of disabled citizens rather than from the inability of a disabled individual to adapt to the demands of society (p. 93).

And:

Rather than concentrating on the economic or functional implications of disability, attention is focused on the attitudinal and behavioral significance of perceptions which are formed on the basis of visible and permanent characteristics (p. 93).
Hahn points out the dynamic influence between a change in attitudes, policies and the physical environment. Not that these characteristics follow each others as a natural sequence of change but rather they all influence one another and can lead to change over time.

Hahn (1985) promotes research from the socio-political perspective of disability. He encourages persons with disabilities to organize and advocate for change in the physical environment, "that their surrounding eventually may acquire the strength and the resilience to sustain a powerful and continuing movement" (p. 100). In the past, research was focused on the individual’s limitations and "neglected the common experience of disabling environments" (p.101). Hahn and other social scientists with a socio-political view of disability provide occupational therapists with a theoretical rationale to use the environment as a avenue for intervention and change.

Oliver (1990) is critical of personal tragedy theories of disability, which he espouses underpin definitions of disability. He developed a social theory of disability, by analyzing historical meanings ascribed to disability. Not all historical meanings of disability were negative. Oliver attributes the experience of disability to the relationships between the mode of production and core values of a particular society. He explains our current meaning of disability evolved concurrently with the rise of capitalism. A person’s "worth" was proportional to his/her ability to leave the family environment and earn a wage. Thus, Oliver postulates a social theory of disability which asserts that disability is the result of social organization and not individual deficit. Recently, Oliver (1996) suggests there has been a paradigm shift amongst professionals, from the individual tragedy view to the social model of disability. Yet the question of how this has impacted on practice, he states, is still open for debate.

Law (1991) integrates the work of social scientists, philosophers and the occupational therapy literature. She discusses influences that have created restrictive or disabling
environments, including "the built environment, production of space, increased classification, the perception of disability as deviance, distribution of power and bureaucracy" (p. 172). The production of space refers to the larger organization of cities and towns as well as the separation of private and public space. Increased classification refers to how people are marginalized. This marginalization of persons with disabilities evolves from the use of the word 'normal' as a reference for judging those with disability. Power and bureaucracy address the larger issues of how decisions are made for or about people with disabilities via public policy, organization rules and diffusion of responsibility. Disabling environments include the physical and social environment as well as the political, cultural, and economic milieu.

Law (1991) is also interested in how occupation and the issues of the environment discussed above can fit together and be addressed by occupational therapy. She stresses the need for theories in occupational therapy that are founded in social and political research. Law systematically goes through each of the areas contributing to disabling environments and suggests ways occupational therapists can work to effect a change. The power and decision making is with the client and therapist as opposed to the bureaucracy. Law sets the stage for developing the Person-Environment-Occupation Model (Law et al., 1996). The model draws from the work of occupational therapists and socio-political theorists such as Hahn.

**Person-Environment-Occupation Model of Occupational Performance**

Law et al. (1996) explain that although the relationship between the individual and the environment has been recognized in occupational therapy for a long time not much has been written on the theoretical and clinical application of this relationship to practice. Over time, occupational therapists have changed their thinking about the relationship between the individual and the environment. The profession has moved away from a biomedical view of cause and effect to a transactional approach. The transactional approach recognizes:
Occupational performance may be better described as the product of a dynamic interwoven relationship that exists among people, their occupations and roles, and cannot be separated from contextual influences, temporal factors, and physical and psychological characteristics (p. 10).

This view allows for the interdependence between the person and environment to shift and change as the context or individual changes. Occupational therapists have also been influenced by disability advocates who have pointed out that disability can and does stem from the environment. Law et al. (1996) present the Person-Environment-Occupation Model of occupational performance to bridge the gap in occupational therapy between our recognition of person-environment interdependence and the model of occupational performance. The purpose of their paper "is to discuss the Person-Environment-Occupation Model of occupational performance which can form the basis of a clinical model of practice for occupational therapists" (p.10). The Person-Environment-Occupation Model (Law et.al, 1996) represents the dynamic interplay between the person, the environment and the occupations. Diagrammatically, the model is represented in two ways. One depicts three rings (person, occupation, environment) in a three dimensional intersection to represent the dynamic relationship between the concepts. Occupational performance is the outcome and is represented in the centre of the overlapping circles. The second model is a linear presentation of the first; this shows development of the individual over time, and demonstrates the overlap, or fit, of the four concepts (person, environment, occupations and occupational performance) can change in time. Each of the concepts in the model including the person, environment, activity, task and occupation(s), temporal aspects and occupational performance are defined.

Enabling Occupation (CAOT, 1997) has adopted an adapted version of the three overlapping rings (person-environment-occupation) with occupational performance depicted as the middle at the centre of the overlapping circles. Enabling occupation has also taken on the
developmental perspective, similarly discussed in Law et al. (1996), stating there can be a change in the fit of the person-occupation-environment and occupational performance over time.

**Definition of Terms.** The following section briefly defines the terms of the person, environment, activity, task and occupations and occupational performance. Law et al. (1996) define the person as being a unique individual who carries out many dynamic roles simultaneously and over time. The roles may vary in importance, significance and duration depending on the context. As well:

The person is seen holistically as a composite of mind, body and spiritual qualities. The person brings a set of attributes (performance components) and life experiences to bear on the transaction described as occupational performance, including self-concept, personality style, cultural background and personal competencies. This last factor incorporates abilities related to motor performance, sensory capabilities, cognitive aptitude and general health (Lawton & Nahemow, 1973). Finally, each person calls upon a set of skills, both learned and innate, in order to engage in occupational performance (p. 16).

Time is an important aspect of this model. As described in the previous section, the model is conceptualized over time; hours, weeks or even longer to embrace the life span.

The definition of the environment is broad and concurs with the scope of the model of occupational performance (Law et al., 1996). In addition, the Person-Environment-Occupation Model of occupational performance considers the perspective of the person and his/her unique environment. Consider my example. A particular person could be very involved in their church. The definition points out that a person's behaviour at a particular time is cued by the environment. Elaborating on the example above, the church hall could be used by parishioners for a social coffee gathering one day and for voting by the same people on another day. The change in their role changes their behaviour, i.e., socializing to voting. Yet the physical environment, the church hall, is the same.

The definition of activity, task and occupation can be visualized as three nesting cups with
activity neatly fitting into task and tasks into occupations. Law et al. (1996) define activity as "the basic unit of a task" and a "singular pursuit" (p. 16). My example is sewing. "Task is defined as a set of purposeful activities in which a person engages" (p. 16). An example is sewing a jacket. Lastly, occupation is defined as "groups of self-directed, functional tasks and activities in which a person engages in over the lifespan and in which the person engages in order to meet his/her intrinsic needs for self-maintenance, expression and fulfilment" (p. 16). Continuing with my example of sewing a jacket, a tailor could run his/her own business. The roles and demands may change over time depending on the context of the individual and the environment. The tailor could be involved in sewing, selling garments, managing staff and accounting.

Lastly, Law et al. (1996) define occupational performance as:

...the outcome of the transaction of the person, environment and occupation. It is defined as the dynamic experience of a person engaged in purposeful activities and tasks within an environment (p. 16).

In the model, occupational performance is represented as the middle area of the overlapping rings of environment, person and occupation. Occupational performance is dynamic, meaning it can fluctuate with a change to any of the contributing components or over time.

The assumptions of the model include the constant interaction and influence between the person and the environment (Law et al., 1996). The environment is influenced by the individual and the individual can have an impact on the environment. Occupations are assumed to be "pluralistic and complex, and necessary function of living" (p. 17). The model assumes occupational performance is a phenomenon influenced by the dynamic transactions between the individual, environment, occupations and over time. Lastly, the model assumes a fit between the three concepts of person, environment and occupation with occupational performance. The closer the fit between the first three, the more optimal the occupational performance. As an example of person-environment-occupation fit let's look again at the tailor sewing the jacket. Regarding
the person, the tailor may have talents for blending colour combinations, paying attention to detail and designing clothes. Addressing the environment, perhaps the tailor lived in Italy where there is a history of designing well-made clothes and consumers expect and pay for quality hand-made clothes. Considering the occupation, the tailor might even come from a long family tradition of tailors and have inherited the shop. This combination of person-environment-occupation may lead to a good person-environment-occupation fit thus maximizing the tailor’s occupational performance.

This model has important implications for occupational therapy practice and this thesis. Law, et al. (1996) summarize:

In short, the model can be used to enrich and expand the clinical approach of occupational therapy. For example, instead of treating the person as a single entity in the institution or home, the person can be considered in multiple ways: as an individual, as part of a family living in a particular community of a province or state. At each of these levels, the person’s occupational performance can be appraised as influenced by cultural, economic, institutional, physical and social environmental factors as well as by personal occupational factors (p. 19).

The model validates the practice of considering the client in many environments and the dynamic interplay between the client and those different environments. The model endorses evaluation of occupational performance in light of a broad conceptualization of the environment that includes the influence of culture, economics, institutions, the physical and social environment in combination with what the client brings to that setting (occupational factors).

Enabling Occupation (CAOT, 1997) defines the elements of an environment in four broad categories as mentioned previously. They include:

Cultural: ethnic, racial, ceremonial and routine practices, based on ethos and value system of a particular groups.
Institutional: societal institutions and practices, including policies, decision-making processes, procedures, accessibility and other organizational practices. Includes economic components such as economic services, financial priorities, funding arrangements and employment support; legal components such as legal processes and legal services, legislation and political practices.
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Physical: natural and built surroundings that consist of buildings, roads, gardens, vehicles for transportation, technology, weather, and other materials.
Social: social priorities about all elements of the environment, patterns of relationships of people living in an organized community, social groupings based on common interests, values, attitudes and beliefs (p. 46).

The environment is one of several core concepts described in theory. Although the elements defined above appear succinct, they are only elements to describe an environment and do not reflect the dynamic interaction of the person-environment-occupation and occupational performance discussed perviously.

**Client-Centred Practice.** The second core concept significant for this research is client-centred practice. Law, Baptiste and Mills (1995) initially define client-centred practice as follows:

Client-centred practice is an approach to providing occupational therapy, which embraces a philosophy of respect for, and partnership with, people receiving services. Client-centred practice recognizes the autonomy of individuals, the need for client choice in making decisions about occupational needs, the strengths clients bring to a therapy encounter, the benefits of client-therapist partnership and the need to ensure that services are accessible and fit the context in which a client lives (p.253).

The chapter on the core concepts in occupational therapy (Law, Polatajko, Baptiste & Townsend, 1997) in Enabling Occupation: An Occupational Therapy Perspective (Canadian Association of Occupational Therapy, 1997) define client-centred practice as:

Client-centred practice refers to collaborative approaches aimed at enabling occupation with clients who may be individuals, groups, agencies, governments, corporations or others. Occupational therapists demonstrate respect for clients, involve clients in decision making, advocate with and for clients in meeting clients’ needs, and otherwise recognize clients’ experience and knowledge (p. 49).

Both definitions encompass elements of respect for the client’s autonomy, experience, values and for the relationship between the therapist and client to be one of partnership and enablement. A question that arises from these definitions is identifying who is the client. Law, Baptiste and Mills (1995) state:
It is also important to note that a client of occupational therapy may not always be an individual. Clients can include other family members or be communities, private companies, or organizations (p. 253).

While the definition by Law, Polatajko, Baptiste & Townsend (1997), specifies individuals, groups, agencies etc., it is unclear whether a family would be considered a group. In the following chapter the authors (Stanton, Thompson-Franson & Kramer, 1997) refer to the need for a partnership with family members of the client and that the term client can also mean a representative of the client and not necessarily the "actual client" (p.60). This concept of a representative of the client is vague. Later on in this chapter, family members are included as a resource, in terms of support, for the client. Lastly, in yet another chapter, (Brintnell, Clark, Kramer & Thompson-Franson, 1997) vignettes are used to illustrate the process of intervention; the authors describe a child with the disability as the primary client and the child’s mother, who also has occupational performance issues, as a secondary client (p.166). Why have this distinction? While the importance of families and family members is being acknowledged, it is not articulated adequately as to how to describe the family as the client in practice.

The definition of client-centred practice and the concepts underpinning it may be supported from a philosophical perspective, but whether or not it makes a difference to practice is still open to debate (Law, Baptiste & Mills, 1995). Fearing, Law & Clark (1997) present the occupational performance process model and discuss the alliance formed between the client and the occupational therapist. They too suggest the client can be a family or family member and the authors concur with the concept of client-centred practice. The previous discussion has shown that occupational therapists consider the family as the client, however, my analysis of recent literature that guides occupational therapy (Canadian Association of Occupational Therapy, 1997) reveals several possible views of how to describe the family members, i.e.: as a secondary client, as a representative of the client and as a resource to the client. On the one hand, we need further
clarification of what occupational therapist mean when they describe the family as the client. On the other hand, the term, *family-centred* service delivery is often used to describe services to children in the United States and in British Columbia. I have included the following description of family-centred to avoid confusion between what is evolving in occupational therapy and what has been described as family-centred service delivery.

**Family-Centred Service Delivery.** Family-centred service delivery is a trend that has emerged from the United States of America (USA) policies regarding provision of services to children with disabilities (Dunst, Johanson, Trivett & Hamby, 1991). From a historical perspective, services to children with disabilities in the USA formed a patchwork of programs provided through departments of health and education until Public Law 99-457 was passed in 1986 (Hanft, 1988). The Public Law 99-457 attempted to coordinate services to families with children from birth to five years old.

The task of supporting families is outlined in Part H of the Public Law and it further specifies an interdisciplinary team working with a family and outlines the sequence of intervention from assessment, planning and intervention. Thus this law validates and initiates two important ingredients for family-centred services, the importance of including the family in service provision and utilization of an interdisciplinary team.

Hanft (1988) describes how, in the US, occupational therapists traditionally have been child-centred. Public Law 99-457 implies occupational therapists need to consider what family-centred care means to them and their clients. There is a change in the occupational therapist role, which now includes collaboration with families and work with other agencies. The shift to family-centred means three partners are recognized; the child, the family and the service provider. Thus, potentially, the occupational therapist is not only providing programming for the child but also offering support and education to the parents. The families as partners have the power to
Parents of children with disabilities choose what kind of services they want and need. It is understood within the definition of family-centred that each family is different and has unique needs in order to provide for their child. This sets up a challenge to provide various kinds of services, such as direct service, monitoring and consultation, to meet different families’ needs as well as fit in with what other agencies may offer.

Although the Public Law 99-457 validates the inclusion of the families for services to children with disabilities the definition of family-centred can encompass stronger values. Dunst, Johanson, Trivette and Hamby (1991) define family-centred models of practice as:

Practices are consumer-driven; that is families’ needs and desires determine all aspects of service delivery and resource provision. Professionals are seen as agents and instruments of families, and intervene in ways that maximally promote family decision making, capabilities, and competencies. Intervention practices are almost entirely strength-and-competency-based, and the provision of resources and supports aim primarily to strengthen a family’s capacity to build both informal and formal networks of resources to meet needs (p. 118).

This definition places families in a position of doing advocacy and making decisions focused on their needs. It addresses the power relationship between professionals and families, describing professionals as "agents and instruments" of the families. Conceptualizations of family-centredness specify recognition and support of the family’s cultural values and lifestyle, thus the team members are not to impose their values on the family.

In British Columbia, children with disabilities and their families are the responsibility of province and programs are the responsibility of the Ministry of Family and Children (personal communication, Straathof, September 1997). The Children’s Early Intervention Program (Child Development and Rehabilitation Section of Ministry of Health and Ministry Responsible for Seniors, 1995) incorporates many services aimed at identification of children with special needs, providing services to the children, supporting integration in community programs and education to those programs, and supporting the parents and caregivers of children with special needs.
Early intervention includes children from birth to age of school entrance. The Ministry uses the term "special needs" children. Its definition includes children who have disabling condition and those at risk for disabling conditions because of either social or biological factors. Early intervention services can be provided by a number of places including, for example, child development centres or hospitals. An occupational therapist is one member of the team to provide direct service to children and their families.

In addition, the British Columbia government has several other programs to assist families caring for a child who has special needs, one of which is the At Home Program (Child Development and Rehabilitation Section of Ministry of Health and Ministry Responsible for Seniors, 1995). The At Home Program assists parents with the financial costs associated with having a child with a special need. Parents apply for their children. The parent(s) are interviewed by a professional who, based on the interview, describes the child’s ability to perform self care tasks. The child’s level of independence, or lack of independence, is an important criteria for acceptance onto the At Home Program. They are not assessed for financial need to qualify for assistance. The program benefits include: medical services plan coverage, dental coverage, pharmacare, extended therapies, hearing aids, durable medical equipment (i.e.; wheelchair, crutches, hospital bed etc.), custom medical equipment, equipment rental equipment repairs, medical supplies, non-nursing respite and for children who require nursing, nursing respite. The philosophy of the At Home Program is that families provide the best care for their children and need financial and service support to do so. A recent document (Child Development and Rehabilitation Section Ministry of Health and Ministry Responsible for Seniors, 1996) describing 'best practices' within early intervention included family-centred service as an effective way to provide service to children with disabilities.

There is no one definition of family-centred, but rather various descriptions stemming from
a value of having the family involved in the provision of services to children with disabilities. This is significant for this research in two ways. First, it implies the need to define the meaning of family-centred in relationship to the models already established in occupational therapy. Secondly, to understand who the family members are and what is important to know about them.

Significance of the Research

This research is important to two main groups of people, parents of children with disabilities and health care professionals, specifically occupational therapists working with families. It is my hope this research is important to the parents who participated in the study. It provided them with the opportunity to share their experiences. I believe it is important to parents of children with disabilities generally because it adds to the written mosaic of what it is like to be a parent of a child with a disability. Indirectly, this research is important to parents because it contributes to the literature and has the potential to influence professionals' understanding of families who are raising a children with a disabilities. This research also contributes to the conceptual development in occupational therapy by expanding knowledge of the influence of the environment on everyday activities and by furthering the conceptualization of the client.

Organization of the Thesis

This thesis is organized in six chapters. Chapter two presents the literature review of research descriptive of parents of children with disabilities. The methodology of this research project and the participants are described in Chapter Three. Chapter four begins the presentation of the data with a description of the parents' emotions towards their child, the kinds of support the parents receive, and their perceptions of being a normal family. Chapter five continues the presentation of the data. It covers the conditions parents require and the strategies they use, to participate in activities outside the home environment. Chapter six links the interpretation of the
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research findings with the literature, concepts in the model of occupational performance and practice in occupational therapy.


Footnote

1 The word "disability" according to the International Classification of Impairments, Disabilities and Handicaps (1980), in terms of health, means a restriction of the ability to perform activities at an age appropriate level. If a person is old enough to walk, feed themselves and communicate and is unable to do so, the person is considered to have a disability or disabilities. Impairment is considered a physical, psychological or anatomical loss or abnormality. For example, all of the children in this study have an impairment since they have abnormal muscle tone. A person with a disability may have a handicap when he/she experiences a loss of roles that would otherwise be expected for their social and cultural status. In this study all the children have impairments and disabilities. They also have handicaps depending on the context in which they perform activities and on what is expected from their role as a child. I have chosen to use the word disability throughout this text to be consistent and to acknowledge that the children in this study do experience lack of abilities that would otherwise be expected for their age.

In this text, my first preference is to use the phrases "children with disabilities" or "child with a disability(ies)" to reflect the sentiment of viewing the child first and the disability second. Unfortunately it is wordy. At times I have used the words "disabled child," to produce a less wordy sentence.
Chapter Two: LITERATURE REVIEW

Much has been written about parents' experiences with their disabled children in the social sciences, medical, and rehabilitation literature. The literature review is organized in six sections. The first is about what I describe as the "extra work" of having a child with a disability. This includes research on parents' experiences of stress, their responsibilities and time use. The second section explores caregiving, how it is defined and manifested in the daily lives of parents. The research shows children with disabilities constrain parents' daily lives. The following three sections discuss how parents are constrained in terms of their housing and transportation, employment and leisure. Lastly, there is a discussion about the social attitudes. In the conclusion, a summary critiques some of the problems within the research and identifies the gaps in the literature that are significant to this study.

Before reading the main body of this literature review, I want to briefly summarize what is written in the rehabilitation literature regarding parents of children with disabilities, what is reviewed and what is not. Many of the studies in this review are from the occupational therapy literature (Cant, 1993, Crowe, 1993, Dyck, 1992, Johnson & Deitz, 1985a, Johnson & Deitz, 1985b, Law & Dunn, 1993, Pierce & Frank, 1992, Primeau, 1992, Primm, 1996, Tetreault, 1994). The following studies are from the rehabilitation literature, but not reviewed because it was felt they were not relevant to the main themes of this thesis. These include studies on mothers' perceptions of occupational therapy services (Case-Smith & Nastro, 1993), parent expectations for professionals (Redman-Bentley, 1982), mothers’ perceptions of home programs (Hinojosa & Anderson, 1989, Hinojosa, 1990) and parents’ knowledge of cerebral palsy (Zissermann, 1978). In addition, literature reviews, drawing on knowledge from various disciplines are not covered in this review, such as the relationship between parents and professionals (Anderson & Hinojosa, 1984), counselling for parents (Ziolko, 1991), the interaction between a caregiver and infant with
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a disability (O’Sullivan, 1985, Calhoun, Rose, Hanft & Sturkey, 1991) and respite care (Short-DeGraff and Kolognisky, 1988). In the review on respite care the authors define several types of respite and describe how therapists can play a role in administration, providing information, supporting parents, training respite workers and researching the efficacy of respite programs. The following literature review focuses on research in the rehabilitation, medical and social sciences that describes parents’ caring and other issues in their daily lives.

The Extra Work of having a Child with a Disability

That a child with a disability is "extra work" for the parents is not overtly researched in the literature. The literature suggests, however, that 'extra work' is likely one of several reasons why parents experience stress. Many studies or parts of studies have found that parents of children with disabilities experience stress and develop ways to cope and adapt to daily life (Gallagher, Beckman & Cross, 1983, Primm 1996, Shapiro, 1983, Wallander & Noojin, 1995). One reason the parents experience stress is because of the amount of work they must do in order to meet their children’s needs within the family. Wallander and Noojin (1995) attempted to describe the problems of mothers of children with physical disabilities by using a mail out questionnaire. The 119 mothers who participated were asked to describe "bothersome" things that had happened to them in the last two months. Unfortunately, the categories Wallander and Noojin developed from the mothers’ responses were not very specific. Nevertheless, they found nearly 50% of the mothers identified child characteristics such as the child’s communication (or lack of communication), school experiences, social skill and behaviour and attitude as problems. The researchers did not describe in detail how these areas were problems for the mothers. Almost a quarter of the problems were in the areas of medical and legal concerns such as the worsening of the child’s illness or negative experiences with health professionals. Lastly the mothers reported about 13% of their problems in both the areas of concerns for their family and
for themselves. Wallander and Noojin did not find a correlation between the child's disability and maternal health.

Gallagher, Beckman and Cross (1983) found, in their review of the literature on the source of family stress, that multiple factors were significant to the parents' feeling of stress. Older children were more stressful for their parents than younger ones in terms of needing hands-on care. Child characteristics such as "difficult temperament, less social responsiveness, more stereotyped behaviour patterns and the presence of additional or unusual care-giving demands" (p. 12) were experienced as stressful for the parents. These authors also found studies which indicated variations, in the overall feeling of stress, between parents of children with different diagnoses. Parent characteristics were also significant, and parents who had a variety of defenses and more experiences handled stress better than those who did not have those qualities. The authors reviewed a number of studies that investigated support, generally, spouses, extended family members and professionals could be sources of support. They did not discuss studies reviewing other kinds of support such as financial or respite.

Primm (1996) conducted semi-structured interviews to find out about parents' experiences caring for a child with a disability and their satisfaction with health professionals. Almost equal numbers of mothers and fathers participated in the study. They asked many questions and quantified the frequency of responses. One question was about the mothers' ability to cope. The mothers identified five areas that were difficult to cope with, including: physical dependency, lack of mobility, lack of communication, disruptive behaviour and supervision requirements. The most difficult of these was the physical dependency because it was unrelenting. The children did not grow out of their dependency on their mothers for physical help. Equipment and aids sometimes alleviated the problems with mobility and communication. While these studies have identified what is stressful, other studies have been more descriptive of what the extra work
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comprises and what it means for parents.

Johnson and Deitz (1985a) conducted a questionnaire asking mothers of physically handicapped children and mothers of typical children about their activity patterns. They found that mothers of physically handicapped children spent less time away from home doing activities such as taking a course or shopping in comparison to the mothers of typical children. Crowe (1993) and Johnson and Deitz (1985b) carried out time use studies with mothers and found that mothers of children with physical handicaps spend more time doing child care than mothers of typical children or mothers of children with Down Syndrome.

Glendinning (1983) conducted a qualitative study with seventeen families in Britain using three in-depth interviews over an eight month period. The children varied in their age and disability; some had "behaviour problems" and some had a diagnosis such as spina bifida or cerebral palsy, but all of them lived at home with their family. The families who participated were a small sample from a larger survey study. The purpose of the larger study was to document "... the extent and character of the children’s disabilities, the families’ socio-economic circumstances, their use of services... (and) to explore the variations in the levels of stress reported by the mothers of the disabled children" (p.4). Glendinning chose to do a qualitative study to clarify why there were different experiences of stress among the families identified in the larger study. Fathers were included in some cases in the smaller study.

Glendinning’s (1983) study focused on the day to day experiences of both mothers and fathers. She pointed out that the parents are involved with daily care activities such as toileting, bathing, dressing, feeding and supervising for much longer than parents of typical children and that it is less rewarding. The parents in her interviews discussed the issues with their child’s incontinence, how it is unpleasant and led to more laundry. Another daily issue for parents was how to amuse and supervise the child because many of the children in the study had short
attention spans. This demanded time and energy of parents who may be physically tired. The parents reported having disturbed nights because some children were frequently sick and the parents would wake up and needed to deal with their child’s coughing. Another reason for disturbed nights was that children with behavioural problems would not sleep and would run around the house. Some parents expressed anxiety about their child’s health because the child’s pattern of sickness was unpredictable and fearful. Some children, with communication difficulties, could not report their pain or sickness. Social restrictions, as a result of not being able to get out and about with the child, was also cited as a problem. The main reason why it was difficult to get out was because the child lacked independent mobility. This led to difficulties using public transportation. Other problems related to getting out included the amount of planning involved, dealing with the equipment the child requires and managing the child’s disruptive behaviour in social situations. Featherstone (1980), wrote to an audience including parents and professionals. Her book provides insight into the care given by parents of children with a disability. She gathered her data from mothers involved in a mothers group, previous research on parents of children with disabilities, and her personal experiences of being a mother of a disabled child. The topic areas include emotions (fear, anger, loneliness, guilt and self-doubt), marital stress, siblings, and support: both giving and receiving. Although much of her book is about daily life experiences and the extra work of caring for a child with a disability, she includes a small section near the beginning specifically addressed to the issue of extra work, "the daily grind" (p.76). She stated that a mother’s self-esteem as a mother comes from the daily experiences and rewards of parenting, but when the child had a disability feeling success as a mother was more difficult:

The mother of a handicapped boy or girl faces even larger difficulties. Her child’s needs are often more numerous, more taxing, and more insistent than those of able-bodied peers. In addition to appropriately timed helpings of food, sleep, approval,
love, discipline, encouragement, and surveillance, the child may require physical therapy, transportation to distant schools and medical people, and special home teaching. Care and therapy tax the mother's time and energy. Tasks like dressing, bathing, and toileting, which most children manage unaided after the first few years, may challenge a disabled child for a long time (p. 77).

Her main point is that parents, especially mothers, must deal with all the things typical parents deal with but it is more difficult. Decisions about what to do with the child and the rest of the family are always balanced with the demands stemming from the disability.

Primeau (1992) pointed out the historical context of why women are at home providing household chores and child care. It has only been recently, through gender studies, that "household work" has been a worthy area of study. The division of labour, with the woman at home and the man at another work environment has happened as a result of the rise of industrialization. Before that time, although there were divisions between man's work and woman's work, the environment was essentially similar. Industrialization changed where men worked, and men started to work for a wage. The woman stayed at home. Post WWII, mechanization was changing the amount of time woman need to spend on household chores, thus eventually, freeing up some time to participate in work away from the home environment and for a wage. Yet their responsibilities for the household work and child care remained the same. The relevance of Primeau's article to this research, and particularly this section of the literature on "extra work", is to acknowledge that women are usually the providers of household work and child care. Thus if the child is disabled it is likely the mother will become the expert on providing care for that child and experience demands on her time as a result of organizing and planning for the child's needs.

Dyck (1992) investigated mothers of young children and the relationship between the environment, their mothering role and daily routines. Dyck found structures in society, for example the expectations of society for the mothering role from mothers and economic demands
within a household, were constraining influences on the mothering role. Yet the mothers who worked full time or part time used the environment and the connections they made with other people with similar values, to care for their children. This enabled the mothers to combine paid employment and mothering congruent with their conception of the mother role. Dyck suggest further research to understand how the mothering role is shaped and woven in the broader context of societal structuring.

The fathers of children with disabilities are not completely invisible in the literature, but almost. Fathers have written and published their personal stories, Hornby (1992) reviews and analyses eight of these. He includes each father’s description of his child and how the father came to understand his child’s disability. The accounts are different which suggests a wide range of emotions and experiences. The similarities between their stories are salient and revealing. Hornby outlines seven common themes: the intensity of a father’s reaction to his child’s diagnosis, the father’s process of adapting to his child, negative feelings towards professionals and others in the general public who do not understand the father’s situation, the negative and stressful effect the relationship with a spouse, the problem of finding suitable care, his intense feelings, both positive and negative towards his child, and the acknowledgement of personal growth as a result of having a child with a disability. The limits to Hornby’s review is that the fathers were well educated and likely not representative of fathers generally. Nonetheless, Hornby’s findings are interesting.

Meyer (1995) edited a book in which nineteen fathers contributed their stories. Meyer arranged the chapters according to the ages of the children, starting with chapters by fathers of young children and ending with a chapter by a father of a twenty-eight-year-old son with Down Syndrome. The stories are written from the heart and are moving accounts by fathers about their children. Although Meyer did not analyze their accounts the work is significant because it
contributes to the literature about fathers of children with disabilities.

In summary, the literature reveals the impact of a child with a disability upon a household and for parents is notable. Stress and extra work is related to the seemingly relentlessness "daily grind" of providing child care activities. Parents of children with disabilities spend more time daily on self care tasks than the parents of typical children. The child's physical dependency in terms of physical mobility, communication and social responsiveness or disruptive behaviour also compose, what I have termed, "extra work". There is also evidence in some studies that the extra work constrains the parents from going out of the home environment with their children. In addition, it is known and recognized that much of the work of caring for children and household chores are the responsibility of women, and typically mothers are the ones who manage and organize their children's activities. Yet there has been little research on the experiences of fathers of children with disabilities. The following sections looks at the demands of providing care for a children with disabilities more closely.

Care Giving

How is care giving defined differently from day to day care all children receive from their parents? Traustadottir (1991) investigated the understanding of care giving of mothers' of children with a disability. Her research illuminates three aspects of care giving: hands on caring for a child, i.e the mother doing the care giving herself, caring about a child, i.e. the mother managing and hiring person to provide hands-on caring, and the extended role of caring. The extended role of caring refers to situations where mothers extend their caring to children and families other than their own. Traustadottir (1991) discusses how families of children with disability tend to follow a traditional pattern of the father working, because he earns more, and the mother staying home, because there is social pressure to do so. She argues these are socially constructed roles. Traustadottir identifies themes from interviews: how the women were
empowered by their experience of care giving, and how it also could disrupt their life. For some mothers care giving became a central aspect to their life.

Care giving tasks for a child with a disability can be very different from care giving for a typical child. Pierce and Frank (1992) describe one mother’s experience of caring for her child in a neonatal intensive care unit and at home. The authors use a feminist theoretical frame of reference to analyze the mother’s experience of family-centred care and her redefinition of motherhood. The authors interpret her experiences from both an emic and etic perspective. Emic interpretation is concerned with personal experience of a phenomenon of interest, while etic interpretation focuses on the observer’s analysis of the larger, sociocultural influences on a phenomenon of interest.

The emic analysis of this case study (Frank & Pierce, 1992) evolved from how one mother defined her relationship with her child. This included: her responsibility, the meaning of her child’s illness, and daily care giving. Her definition and role as a mother was reshaped and thus changed her life. She became skilled at medical procedures, managed the medical supplies and health professionals for her child, engaged in public speaking, and organized resources for other parents caring for their child at home. The etic analysis critiques home care, unpaid care (being the mother), and the costs of paid care such as from nurses and therapists. This analysis illustrates how technology, changes in social care for chronically ill and technology dependent children, and how economic considerations transform the experience of motherhood for mothers of severely involved children. The authors recognize both the contemporary dilemma of work and caregiving demands for mothers and the social/political experience for the mother in the study.

The story of the mother in this article (Pierce and Frank, 1992) is a testimony to the complexity of the mother’s role and the demands in her daily experience of motherhood. The
mothers role was complex because she became a manager of health care, a provider of direct services, an advocate, and a speaker. She incorporated all these tasks in her description and understanding of motherhood. The authors do not define or explain what they understand as family-centred care. They do however, refer to Public Law 99-457 which mandates parent and family involvement in the care of children with disabilities as the rational for family-centred care.

These two studies, Traustadottir (1991) and Pierce & Frank (1992), do not talk about the problems of caring for a child with a disability but rather how the mothers conceptualize their care-giving role. The mother's role in the family is shaped in part by factors such as the family economics, the mother's feelings of responsibility to her child and the demands of the child's medical needs. In some situations, the mother takes on what Traustadottir refers to as the extended role of care giving, or advocacy work, to affect change in organizations outside of the home. The mother in Pierce and Frank's (1992) study did this by making speeches and organizing resource materials. An important point to make is that parents of children with disabilities can not be lumped together as one homogeneous group. Some parents will describe their situation in negative terms or as problems. These two studies show how some parents are inspired and empowered by their experiences with their child.

Beresford (1994) also studied parents from a positive view of caring. She conducted a qualitative study with 20 parents of severely disabled children. This represented 20 families. The model that underpins her study has three important assumptions. She states:

...it does not assume that caring invariably has an adverse effect on the carer. Secondly, the fact that many carers do adapt and cope with their situation is emphasised. Thirdly, carers are redefined as active agents as opposed to passive recipients of an onslaught of carer-related stress (p.2).

These assumptions cast a positive light on this study that views the parents as active, perhaps proactive, people. She interviewed each parent in depth on two occasions and asked questions about
their daily life and how they coped. Only one of the twenty parents interviewed was a father, as the norm in Britain was for mothers to be the main carers of children Beresford stated. She investigated how parents managed their difficult situations. Beresford assumes parents have their own perceptions of what is stressful and that they use resources as a way of coping with stress. Resources can be both personal such as financial resources, or social such as public programs.

Beresford (1994) identifies how informal networks are an important resource for parents. The care-giving parent's partner in many instances is important for practical help around the house, providing care, and for emotional support. Beresford states why:

First, the fact that the partner is living in the household and is with the parent for a considerable part of the day, facilitates the extent to which the partner can help with child care and provide emotional support...Secondly, the nature of the relationship introduces other factors. Most fundamental is the fact the child is theirs, and that the couple have a commitment to the child. Also the parents have a commitment to each other which no other relationship can match or imitate (p. 22).

In addition, other children in the family and extended family were also important sources of support. The amount and range of support from extended family varied between families. Friends and neighbours in many situations were not a source of support, and in some situations their support decreased over time.

Beresford (1994) discussed the barriers to parents' access to informal sources of support. This includes physical distance between extended family members who would otherwise provide practical help. In some situations, the grandparents were frail and not able to help. Partners' employment was also a factor; the fathers who were not employed were able to participate in child care more than fathers who were working. Mothers were not as demanding of the fathers for help if the fathers were employed and had to work the next day. Lastly, and as found in Cant's (1992) study, the issue of reciprocation influenced the parents' willingness to participate in informal networking with neighbours and friends:
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Parents were aware that they would be unlikely to be able to return favours. Feeling unable to reciprocate was a very commonly expressed barrier to asking for help from all sources of informal support. It prevented some parents going for help unless they were in a crisis (p. 29).

Some parents joined a support group, but the decision to join or not join varied widely between parents.

Parents also used formal resources such as health professionals and the educational system (Beresford, 1994). Formal sources of support could be significant to parents if they perceived they needed those services. In addition to providing a service, it was the relationship between the professional and the parent that the parent perceived as supportive. Schools were a valued part of the older child’s day because it provided a break for the caregiver and was a source of people who were also involved in caring for the child. Respite care was another important source of formal support. Parents could spend more time with their other children and have a break for themselves from their disabled child. Another source of support were programs that provided financial assistance. If formal sources of support did not work out or parents were unsatisfied it became a source of stress rather than support. Lastly, some parents perceived using respite or social work support as a failure on their part as a parent so they chose not to use these resources.

Beresford (1994) asked parents about how they "keep going" in the face of many difficulties. The parents expressed how they integrated their children’s needs into their lives and that their children are their responsibility. They are motivated by love, "...the love parents have for their children is the fundamental reason why parents continued to care for the child" (p. 71). The parents wanted their children to reach their potential and to be happy individuals. And they enjoyed their children’s success and their parenting role. As Featherstone (1980) realized, "...I began to look at Jody’s disabilities a little differently. They became part of the pattern of my life, rather than the dominant motif" (p.221). Beresford also found a difference between the
parents of younger children and older children. The parents of younger children were new at parenting and their children still had the endearing qualities of young children. The parents of older children separated their roles more decisively, viewing themselves as care givers and parents. Thus, they distinctly acknowledged that they were parents but they also had a large responsibility of caring for a child who was not developing independence, especially in self-care areas such as toileting.

The parents in Beresford’s (1994) study also used a number of family-specific strategies to help them get through the day. The strategies depended on the characteristics of the family and what worked for them. Sometimes having information and understanding the child’s diagnosis was very important to the parents. Some parents relied on formal supports to help them manage their child’s behaviour. For example, if they could brainstorm strategies to manage behaviour with the professional on the phone, that was valuable. For other parents, becoming an advocate and being involved in decisions about education or other services was important. Personal strategies such as a treat at the end of the day, such as watching the news and having a cup of tea, or maintaining a hobby were significant for the parent to cope. Beresford makes the point that parents use all kinds of ways to help themselves cope and enjoy their children.

Tetreault’s (1994) qualitative research stands alone in the Canadian occupational therapy literature on mothers of children with a physical handicap. She conducted qualitative research by interviewing 67 Québécois mothers of children who have physical disabilities. Her focus of concern was the daily realities for these mothers. Tetreault’s analysis of the interviews revealed four major themes which comprised these women’s experiences. First, the behaviour of the medical profession was mostly a negative experience because of: misinformation from doctors, a long waiting period before receiving a diagnosis, and the negative attitudes of hospital personnel. Secondly, attributes of the child were also identified by these women as a source of
stress, including: the number of surgeries, the abilities of the child, the care giving responsibilities especially as the child grows and becomes heavier to move, and the anxiety about their child’s future. Thirdly, mothers identified access to and delivery of services as a struggle. For example: the lack of information about public services, the difficulty finding babysitters, and the transition into school. The last theme revolved around the mothers’ experiences with the negative attitudes of others, including, in some cases, the spouse, and other family members. The negative attitudes were experienced as negative comments from others, lack of help with care giving demands, and inflexible employment situations.

In summary, the daily experiences for parents, whether it is called caregiving, the daily grind, daily realities or parenting comprise the description of what it is to raise a child with a disability. And, usually, mothers are responsible for and do child care tasks. The parents acknowledge they do similar tasks as parents of typical children, such as bathing, dressing, toileting, feeding, taking child to school, but the time frame for doing these tasks and the nature of the experiences, are different. Beresford’s (1994) study is significant to this study because she discusses in detail how parents cope. Informal supports, especially those of the spouse and other children in the family, play a significant role in helping the care giver cope with the child. Formal supports, such as professionals and services such as respite, also play an important role. They provide information, and the relationship between the professional and care giver is perceived as supportive. If services are not helpful, this adds to parents’ perception of stress they feel about their child. Parents use many family specific strategies to help them cope with the difficult times and many express love, caring and a sense of responsibility for their child. Research shows that some mothers, because of their experiences with their disabled children, have changed their conceptualization of motherhood. Parents also expressed how their experiences and opportunities for paid employment were changed, the following section looks at studies that
Parents of children with disabilities investigated employment.

**Employment**

Philp and Duckworth (1982) reviewed research conducted for the government in Britain in 1978. The research discussed was concerned with information systems, service delivery, the role of voluntary services, and the link between children with disability and the social and emotional difficulties of the children and their families. To narrow the scope of their review, "material relating to sensory impairments, mental retardation and educational handicaps...(were) excluded from the review" (p.xi). In their review they discuss definitions of disablement, practical issues faced by families and the social and emotional problems of parents. They also discuss service delivery and recommendations. Practical issues include: housing, the effect of lack of mobility, equipment, transportation, leisure, employment of parents, incontinence of the child, and financial implications and are described in this review.

Philp & Duckworth's (1982) research review concerned employment of mothers of children with disabilities, who were found to work less than other mothers of children without a disability. As well, studies indicated mothers wished they could work. The reasons given by the mothers for wanting to work were the desire for social contact and increased income. This finding is consistent with the study by Traustadottir (1991), who found only one of the mothers she interviewed was employed. In Traustadottir's analysis of this mother's management of employment and child care responsibilities, she states "combining a career with having a child with severe disabilities requires an extraordinary amount of work. To do both, (she) had to organize her time extremely well and get by with very limited amounts of sleep" (p. 178).

Breslau, Salkever and Staruch (1982) used structured questionnaires to see if a disabled child in the family affected the mother's participation in the work force. They found that married white mothers were significantly less likely to engage in work outside of the home than white
mothers of typical children. Black and low-income married mothers were even more likely than white married mothers not to engage in work outside of the home. They did not find a significant difference for single mothers. Mothers of older children were more likely to employed outside of home than mothers of younger children.

Philp and Duckworth (1982) state there is less research on fathers’ employment. The first of the two studies they identified suggested that fathers were negatively affected regarding employment, and the second study found that fathers of children with spina bifida made changes with their job or career to be at home more than they would have otherwise. The mothers in Tetreault’s (1994) study were not emotionally supported by their husbands, who engaged in work and leisure activities. The fathers, from the mother’s perspective, did not make changes to their work situation to be available to provide care giving to the child.

In summary, parents participation in paid employment outside of the home is influenced by the presence of a child with a disability. Generally, mothers of children with disabilities would be employed less than mothers of typical children, but not necessarily. Other factors, such as race, level of income, marital status and age of the child, shape the opportunity and necessity for paid employment. Fathers’ participation in paid employment may mean they are less available or less asked by the mothers to provide hands on help caring for the child. The presence of a child with a disability may be constraining for both mothers and fathers participation in paid employment in various ways, but there are very few studies on this topic.

Housing and Transportation

Housing and transportation are discussed, not as a subtopic of the theme of extra work but rather as a continuation of the theme of constraints experienced by parents of children with disabilities. Philp & Duckworth’s (1982) summary of this research suggests, generally, housing is often inadequate and the family makes changes in accommodation to suit the needs of the child
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with disability. Housing was found to be a problem if the child was not independently mobile. The most common problem cited was the inability to manage stairs. Lack of mobility is cited as the major problem in connection with transportation; public transportation was not being used by the families, and some families stated the use of a car would not eliminate problems. A child’s lack of independent mobility, in addition to problems of incontinence, is suggested as being problematic for engaging in leisure activities, but the authors did not explore the reasons why transportation is a problem.

Philp & Duckworth’s (1982) main point concerning the issue of equipment is the lack of research conducted on accessibility, funding and storage of equipment. They cite one study that identified design flaws and environmental barriers as the reasons for a wheelchair not being suitable for a child. Philp and Duckworth also discuss why parents experience increased financial obligations. From their review of the literature they suggest increased costs arise from the cost of special foods, clothing, washing and equipment. Extra costs were also found to be incurred by the family for transportation.

Leisure

Another area affected by the presence of a child with a disability and indicates further constraints on parents everyday activities is parents participation in leisure activities. The reason to include this sections is because leisure ties closely to the parents’ experiences of time use, which was discussed previously, and of social experiences, which is discussed in the next section. Cant (1993) conducted qualitative research with 73 Australian mothers of children with disabilities regarding their "perceptions of difficulties with enjoying leisure and social activities" (p. 115). Her study is part of a larger study that evaluated time use of mothers of children with disabilities to time use of typical mothers. Although the amount of time spent on activities was similar, the nature of the activities chosen by parents of disabled children was different. Two
main themes emerged.

The first theme is that circumstances excluded the care givers from participating in leisure activities (Cant, 1993). Circumstances which seemed to exclude care givers from socializing included: "polite disattention" from neighbours, fear of the reactions of others to the child’s disability, and a reluctance to ask friends or neighbours to help with the care giving tasks. Parents were concerned about not being able to reciprocate resources with friends who did not have children with disabilities. Friendships were often formed between two mothers of children with disabilities because their children’s needs were a shared interest as well as other issues that stemmed from having a disabled child. The second theme in Cant’s (1993) study is about the difficulties with resources, such as lack of time to go to leisure activities. As a result the mothers chose places close to home such as the street, park or playground to engage in leisure activities. These choices also suited the needs of their child. Another difficulty was that the home was not suitable for socializing with friends. Cant outlines how the home is often the place where people meet with friends, but the mothers in this study were anxious about friends coming over because of the child’s equipment being in the entertaining space or because the child was incontinent or destructive. Cant (1992) states that the families, and specifically the mother, of children with disabilities are isolated in terms of individual friendships and networks of friends.

The mothers of Traustadottir’s (1991) study organized their time around caring for their children. Although the mothers did not express their caring role as limiting, Traustadottir’s interpretation was that it was in fact limiting:

Thus the majority of parents did not seem to define it as limiting to have a child with a disability if it only limited the mother’s life; only if it limited other family members or if it prevented their family from doing things "as a family" was it seen as limiting. Most of the parent seemed to interpret the restrictions placed on the mother as a "normal" part of the traditional mothering role. (p. 180).

Featherstone (1980) also points out the loneliness and isolation of families that have a disabled
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child. She refers to both the individual feeling of loneliness and the very practical issue of trying to get out of the house:

Disability may isolate families in a variety of ways. Most concretely, it often interferes with ordinary social activities. Young children always complicate their parents' effort to get out of the house, whether to a laundromat, a park, or a movie. A disability adds to the difficulty of organizing expeditions and recreation. It also creates invisible social barriers. Many people feel awkward with pain and difference. They avoid a disabled person and sometimes his or her family as well (p. 50-51).

Featherstone refers to "invisible social barriers" whereas Cant (1993) writes of "polite disattention" from neighbours. These are descriptions of dimensions of the social attitude that shape the experiences of parents of children with disabilities. The next section describes two seminal pieces in the literature concerning attitudes to 'deviance' and a study on perceptions of "being a normal family," which illustrate the concept of being different and managing that difference.

Social Attitudes

Irving Goffman (1963) wrote a seminal analysis of how persons who are stigmatized, such as criminals, the mentally ill or the disabled, manage their personal identities and act in social contexts. Goffman draws together and makes sense of the subtleties of how people with differences are systematically stigmatized by others who use the norm as a reference for acceptance. Goffman's analysis, although dated, explores how persons with a difference manage in social attitudes, how they need to explain, hide or deal with their difference. He describes how persons with a difference are often discredited of their "virtual" personality because they are being categorized by a distorted image of who they are.

Davis (1972) describes a sequence of social interactions that a person with a visible disability experiences, based on his research interviewing a small number of people with visible disabilities. All the participants were articulate and, in his words, "socially skilled". He does not
further describe the participants or process of the study. Davis points out the struggles and awkwardness in social interactions between people when one has a disability. He explains how social rules, assumptions and concepts of "normal," are a "threat" to social interaction. Finally, Davis describes how some individuals with a disability, "disavow" deviance to be a person who knows his/her difference, yet it is not central to every social situation. Davis proposes that then, "normal" interactions can occur. Davis’ perspective is from the individual with a disability, Gray (1997) studies parents conceptualization of "normal family life" (p. 1097).

Gray (1997) researched 53 parents (21 fathers and 32 mothers), of children who were high functioning and had autism, and asked them about their "normal family life" (p. 1097). The expression "normal family life" he states, is problematic because of its elusive definition, a meaning that changes with different families. He states that the study of the family in sociology has been diverse. Gray’s assumptions are that the meaning of "normal" is constructed and shared by family members. He states:

Its reality is not given, but rather exists as a kind of "collective representation" or series of meanings shared by its members. As a representation, it is part of the discourse of domesticity that defines issues such as the boundary between public and private, membership in the family and the rights and responsibilities of family members. This reality is based on ordinary social processes that give rise to such meanings and sustains them through the experience of daily interaction (p.1098).

An issue is how the family views itself differently in private and in public. The family, when presented with a challenge such as a child with a disability, must respond in some way. It is then, Gray suggests, the idea of a "normal family" is important.

Gray (1997) found that many of the parents in his research did not view themselves as normal families, although there were diverse reasons between the families as to why. Although Gray’s study is about parents of children with autism, the issue of normal is relevant to this study. It is the only study investigating the conceptualization of normal by parents of children
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Research on how people with disabilities or other perceived differences manage social experiences provided insight into the experience of disability. People, disabled or not, experience social attitudes in a multitude of ways. The theme of dealing with social attitudes is a part of this review because parents of children with disabilities, the children themselves and other family members experience the behaviour resulting from social attitudes every time they leave their own home. These studies (Davis, 1972, Gray, 1997) show how social attitudes and concepts of normality colour the social experience for persons with a disability and parents of children with disabilities.

Summary
This literature review provides a synopsis of how a child with a disability shapes, influences and constrains parents' experiences of raising his/her child. The parents may experience stress due to the extra work. Extra work for the parents of a disabled child is comprised of caring for and dealing with their child's physical and behavioral need. Taking care of the child places a greater demand on the parents' time in comparison to parents of typical children. Parents, to cope, utilize support which can be informal, such as help from other family members or formal, such as services from professionals. Although caring for a child with a disability is demanding on parents in terms of the number of care giving demands and time, some literature describes how mothers have re-conceptualized their concept of motherhood to fit with their experiences. Literature and studies in occupational therapy have recognized that it is usually mothers who provide child care and do household work. Part of the mothering role, whether she is working or not, is to organize and plan activities for her child. It is also shown that typical mothers use the environment and connections they have with other people to support ability to be, what they conceptualize as, "good mothers".
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The presence of a child with a disability in the home also constrains parents in several ways. Paid employment opportunities for the mother are shaped by the larger context of race, income and marital status. White upper and middle class mothers are more likely to be at home providing child care than other groups of mothers. Paid employment for fathers may not be flexible enough to provide time for care giving, and mothers may not ask for care giving support if the father is employed. Housing may become inadequate in terms of space for equipment or because it has physical obstacles such as stairs. And lastly, the child with a disability can constrain parents in terms of their friendships and socializing. The parents can feel isolated from socializing with friends and family in their own home or out in the community. Persons with a disability can also experience the behaviour of others as a result of their attitudes towards those with a difference and their concept of being normal.

Although the research covers many themes relevant to this research, there are gaps within the literature. A significant number of studies investigate mothers only (Breslau, Salkever & Staruch, 1982, Cant, 1992, Cant, 1993, Crowe, 1993, Featherstone, 1980, Johnson & Deitz, 1985a, Johnson & Deitz, 1985b, Pierce & Frank, 1992, Tetreault, 1994, Traustadottir, 1991, Wallander & Noojin, 1995). In comparison to mothers of children with disabilities, very little research has investigated the fathers' issues or experiences raising a child with a disability (Hornby, 1992). The reason that mother are usually the subject of research is likely because mothers traditionally are the main care givers for their children. Yet, if in occupational therapy we are to understand "the family" as our client in a client centred practice, or the family as in a family centred practice, we need to know about the experiences of both fathers and mothers raising their disabled child.

Another topic identified in the literature, but not researched, is the issue of participating in activities outside of the home environment. The literature does point to the problems parents
have with inaccessible transportation (Philp & Duckworth, 1982) and that families can feel isolated in their neighbourhood (Cant, 1992). Yet no studies have specifically researched parents or family experiences of going out into the community. Also, how the physical, social or political environments shape the decisions parents make about how, when and where to go in the community is completely unexplored in the literature. This is a gap within the literature. If occupational therapists assert an interconnectedness between individuals and the environment, then it is essential to research it, to understand, to critique, to evaluate and to analyze this relationship.
Chapter Three: RESEARCH METHODOLOGY

This chapter introduces qualitative research and the method used for this study. The research design is explained and includes a description of how the participants were recruited. The parents and their families are portrayed. How the data were collected, organized and analyzed is described in detail. This chapter concludes with a description of with how I came to understand the themes of this research and used them in organizing the following chapters.

Qualitative Research

Bogdan and Biklen (1992) describe five characteristics of qualitative methods that provide an overview of the methodology used in this study. They state, "qualitative research has the natural setting as the direct source of data and the researcher is the key instrument" (p.29). The qualitative researcher is concerned with context and assumes it is important for the researcher to be on location; to learn and to understand the context of the place and people they are studying. The qualitative researcher ". . . assumes that human behaviour is significantly influenced by the setting in which it occurs, and wherever possible, go there" (p.28). Data collection is carried out by the researcher, who uses a pencil and paper, a video camera, or a tape recorder to record the data.

Secondly, "qualitative research is descriptive" (Bogdan & Biklen, 1992, p.30). Qualitative research involves using words, pictures, narration, text and quotes to present the data, although tables and numbers may be used. The transcribed interviews or documents collected as part of the data are not reduced to numbers. Thirdly, "qualitative researchers are concerned with process rather than simply with outcomes or products" (p. 31). The researchers are constantly asking questions about the data such as, "How do people negotiate meaning? How do certain terms and labels come to be applied?" (p.31). By asking questions, they pursue how things have come to be as opposed to a primary concern with the end result. This ties in with the fourth
characteristic, which is that "qualitative researchers tend to analyze their data inductively" (p.31). Qualitative research is not intended to test an hypotheses or to prove or disprove something. The analysis in qualitative research attempts to show a picture, which is created as the study progresses.

Lastly, "meaning is of essential concern to the qualitative approach" (Bogdan & Biklen, 1992, p. 32). The qualitative researcher is concerned with "the ways different people make sense out of their lives" (p.32). Qualitative researchers are interested in gleaning this knowledge from the participants themselves. The use of tape recorder or video camera provides the qualitative researcher with an accurate way to record data, from which to portray the participant's perspective. The interest qualitative researcher have for uncovering meaning leads to the importance of a theoretical underpinning. A set of assumptions from which to ground the research and perspective of the participants. Bogdan and Biklen (1992) describe several theoretical underpinnings, that have evolved from research in anthropology and sociology, including the phenomenological approach, symbolic interaction and culture. Historically, anthropologists have held a cultural orientation, and traditionally the study of culture is called ethnography.

**Ethnography**

Hammersley and Atkinson (1993) assert that ethnography describes what the researcher does; the researcher spends time in the field. Simply, the field can be broadly understood as the place and people of interest to the researcher. By doing field work the researcher collects data. Field work is characterized by the researcher trying to understand or make sense of everyday life through observation and talking to people. Participant-observation is about observing and participating in the social world and reflecting upon the product of those observations. The ethnographer is interested in discovering the meaning of everyday activities and uses description
to convey the research findings. Currently, ethnographers are also reflexive about the research process, including their role in the research and the findings. The underlying assumption is that the researcher is part of the research: "There is no way in which we can escape the social world in order to study it; nor, fortunately, is that necessary" (p. 15).

Atkinson and Hammersley (1994) are cautious of too much emphasis being placed on what people say or the forms of language they use as opposed to a holistic approach to what and who is being studied. They categorize ethnography as a form of social science research having several of the following features:

- a strong emphasis on exploring the nature of particular social phenomena, rather than setting out to test a hypotheses about them
- a tendency to work primarily with "unstructured" data, that have not been coded at the point of data collection in terms of a closed set of analytic categories
- investigation of a small number of cases, perhaps just one case, in detail
- analysis of data that involves explicit interpretation of the means and functions of human actions, the product of which mainly take the form of verbal descriptions and explanations, playing a subordinate role at most (p. 248).

Atkinson and Hammersley go on to discuss how ethnography in the twentieth century has evolved from the tradition of the researcher directly observing the people they are studying. The founders of modern ethnography spent years in the field collecting volumes of written description. Although there has been much debate and discussion on whether or not ethnography is science or not, it has been utilized in many areas of study, including, for example, education and rehabilitation. Consequently, the methods and the focus of study have changed, to include, for example analysis of spoken language. The authors continue to make the point that such detail, as required in spoken language analysis, may negate the background and social context, the major contributions of participant observation. Atkinson and Hammersley conclude, "It is not the case that all ethnography has been undertaken under the auspices of one epistemological orthodoxy."
Instead, the distinctive characteristics of ethnographic work have been differentially appealed to by different disciplines and tendencies" (p.258).

Ethnographies are not new to occupational therapy. Krefting (1989) advocates for ethnographies as a useful method to research disability. She asserts that research in health has been dominated by the medical professions. The underlying assumption in traditional medical research is that the professional is the expert. Ethnography, she explains, is appropriate for studying disability, because it places the individual with the illness or disability as the expert. Krefting also makes the point that ethnographic research shows a picture of the person in his/her environment in contrast to the researcher’s environment. The process of ethnographic research facilitates the health professional to examine the influence of their biases on the research. Lastly, Krefting argues that since ethnography studies everyday life and creates a picture of what it is like to have a disability, it is significant information, in addition to statistical research, for professionals health or social policy makers.

While this study is not an ethnography in the traditional sense of spending a lengthy amount of time in the field as in participant observation, it is ethnographic in approach, encompassing all of the features outlined by Atkinson and Hammersley (1994). The purpose of the in-depth interview was to glean the participant’s perspective and understanding of his/her life and to obtain data for analysis. The researcher plays a key role in all phases of the research process.

The Role of the Researcher

The researcher is the key instrument in qualitative research (Bogdan and Biklen, 1992). The role of the researcher includes thinking, creating, observing, note taking, interpreting and, perhaps most importantly, writing. Because the researcher’s role is inherently connected to the text, social scientists have been judged by others and within their own community, regarding their
interpretations of what they have researched. Within social sciences, they have challenged the results and credibility of qualitative research. Denzin (1994) explains there is a "crisis in interpretation" because the criteria for evaluating research is now being challenged. He states the resolution of this crisis needs to come from within the social sciences and each community within the social sciences is best equipped to judge themselves. We are in a postmodern time. It is understood that research is not meant to reflect or be a profound statement of "truth." Richardson (1994) explains:

The core of postmodernism is the doubt that any method or theory, discourse or genre, tradition or novelty, has a universal and general claim as the "right" or the privileged form of authoritative knowledge. Postmodernism suspects all truth claims of masking and serving particular interests in local, cultural, and political struggles. But postmodernism does not automatically reject conventional methods of knowing and telling as false or archaic. Rather, it opens those standard methods to inquiry and introduces new methods, which are also then subject to critique (p. 517-518).

In a sense, no one can claim to be "right," and any method to understand something should be questioned or critiqued. Denzin (1994) states: "The age of putative value-free social science appears to be over" (p. 501). The researcher's values are present in his/her written work. The researcher is intimately intertwined in the research, the research is personal, it could be political or experimental in form. In the following paragraphs, I will share some of my personal views that shaped this research project and eventually, the text presented here.

I chose to research parents of children with disabilities, both fathers and mothers. This choice makes me an "outsider" researcher. I am outside the experience of being a parent, because I am not a parent. If I was an "insider," I would have a child with a disability. I have worked with many families that have a children with a disability. In this sense, I feel that I know some of the issues, problems, and delights a family faces. From this perspective, I feel like an insider. Aguilar (1981) advocates for insider research, because insiders can blend into situations and in
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a sense, know how to act. The insider, because of his/her knowledge about the culture, can ask meaningful questions in a comfortable way. Indeed, I did feel comfortable with my participants and I felt I could keep the conversation moving by asking relevant, thought-provoking questions. In some situations, siblings or other family members were present during the interviews. Because I am familiar with the "business" of a household with children, I was able to attend to the interview yet handle the interruptions that occurred with children.

Despite my comfort level, I know I was an "outsider" in the eyes of the parents. Aguilar (1981) states that outsiders lack 'member knowledge'. This was blatant on one occasion when a mother said: "Wish I was single and living in Vancouver or something." Since this mother knows I live in Vancouver and she assumes I am single, I believe this mother implied life as a single person is easy and free. How could I possibly know what her life is about? I also knew I was an outsider when one father, Ned, started to talk about how his marriage was starting to dissolve. He described stress in his marriage using fishing line as a metaphor: "So the stress between us is just a two pound test line right now and getting close to the spider web line. It will crack." Although Ned and I had covered most of the interview topics, after he finished talking here, I ended the interview. I was uncomfortable with him talking about his marriage, even though this could have been a very important issue for him and significant to his experience of raising a child with a disability. I may have missed or minimized a difficult and emotional aspect of his experience as a parent. It was my judgement call to end the interview, squelching any exploration of this topic. Aguilar states, "...that insiders are better equipped to get past the ideal side of social behaviour and opinion and into the area of real life" (p. 19). In this example, being an outsider, I was uncomfortable with this facet of family disharmony.

Another concern is that of representation. In other words, how well I interpret and write about the interviews between me and the participant. In the social sciences, part of this concern
is the issue of "self" and "other." In the past, social scientists have been criticized for writing about others out of context and ignoring personal bias (Fine, 1994). Richardson (1994) states:

Representation, of course, is always self-presentation. That is, the Other's presence is directly connected to the writer's self-presence in the text. The Other who is presented in the text is always a version of the researcher's self (p. 503).

On this issue, I am distinctly aware that I have "packaged" this text, from interviews to categories. Even though I have endeavoured to have the participant's "voice" as much as possible (i.e: direct quotations) I understand the very act of categorizing is a way of making the participants "others." I have in effect, changed their way of saying what they have said, into a representation I believe readers will understand. Most importantly, I have learned, by categorizing and writing of their experiences, that my representation is not the only way to view the data. Denzin (1994) writes, the researcher "fashions meaning and interpretation out of an ongoing experience" (p. 501). In this postmodern time, researchers should include themselves in the text, learn from writing, and create something interesting to read (Denzin, 1994). The legitimacy of the text is ultimately evaluated by those who read it.

The Issue of Credibility

Janesick (1994) states "In responding to the issues of validity, generalizability, and reliability, I rely on experience and the literature" (p. 216). She continues her discussion of how these terms have evolved from the positivist evaluation of research and are inappropriate for qualitative research. Until qualitative research became more widely accepted as a way of research, it was often misjudged by the positivist rules of validity, generalizability and reliability. The results of qualitative research are not intended to be generalized in a statistical sense, but rather to bring insight, depth of understanding and clarity to issues raised by the researcher. Altheide and Johnson (1994) present five dimensions which have been unspoken cannons or the ethic of qualitative research. During the process of qualitative research the researcher must...
reflexively account for the following: the relationship between what is observed and the larger social context; the relationship of the observer to the participants and setting; the point of view of the researcher and participants; the researcher’s investment in the final product; and, the representation of the research. An assumption underpinning these dimensions is "based on the view that the social world is an interpreted world, not a literal world" (p.488). Each can be problematic for validity.

Altheide and Johnson (1994) point out that since ethnographic research has become reflexive, ethnographers themselves have become critical of their own work. They say, "this reflexive turn has added much to our understanding of how qualitative research is actually done, but has additionally raised the hitherto unanticipated dilemmas about representation and legitimation (standpoint or voice)" (p. 485). They also discuss how qualitative research is interpretative, both in analysis and writing. I will address each of the five dimensions Altheide and Johnson discussed, illustrating the credibility and validity of this research.

First I describe the participants of this research, I describe them in the cultural context of British Columbia as I am also. Secondly, my relationship with the participants is essentially that of a stranger. I introduce myself as a graduate student and some realized I was an occupational therapist. I used my skills as a therapist to create a relaxed atmosphere during the interview, to build rapport and trust. Most of the interviews took place in the participants’ homes which provided a familiar and conducive setting for the participants to talk about their experiences. Three parents initially choose not to be interviewed at home. One parent was interviewed at the public library, another at a cafe, and one in the cab of his truck. Thirdly, my experience working with families helped me gain a sense of authenticity in the parents accounts. At times, my view as an occupational therapist may have clouded my glasses as a researcher. Since my occupation, experiences and personal experiences are so entwined it is difficult to pull these roles, or views
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apart. I have attempted to be reflexive in the text. Fourthly, this text is for my Master of Science. I believe this adds to the credibility. My thesis committee contributed their expertise and experience regarding qualitative research methods and provided feedback on the analyzed data and subsequent written drafts. By asking questions, probing assumptions and encouraging depth, they inspired better writing. Lastly, the issue of representational style is complicated. The data were collected immediately and accurately as the interviews were audiotaped and transcribed. Accurate data are critical for the analysis and writing work. As well, using the computer to assist in categorizing and organizing the interviews provided a consistent and thorough way to handle the data. These strategies along with editing and improving the style of the written account, I believe add to a credible representation of what was studied.

Research Design

This section reviews the interviewing approach I used and describes how participants were recruited. The participants and their families are described. Finally, the data analysis is discussed.

Interviews

Interviewing is one way to gather data when conducting qualitative research. Mishler (1986) proposed the concept that interviews are jointly constructed between the interviewer and participant. He asserts "...both questions and responses are formulated in, developed through, and shaped by the discourse between the interviewers and respondents" (p. 54). Considering this concept, the interview questions are a framework for the interview but not a rigid structure. The interview is a process that involves a smooth transition from one phase to the next. Spradley (1980) discusses the process of rapport between the ethnographer and respondent as movement from "apprehension to exploration to cooperation to participation" (p. 79). As the research progresses, the participant becomes more willing to provide the researcher with information and
ultimately at the stage of participation, the respondent knows what the researcher "wants." Fontanta and Frey (1994) discuss how "gaining trust is essential to an interview's success..." (p. 367) and how establishing rapport is necessary for the researcher "...to see the situation from their (the respondent's) perspective..." (p. 367). Listening to respondents and asking good questions are an important part of the interview process (Merriam, 1988). Characteristics of a good interviewer are that he/she "... refrains from arguing, is sensitive to the verbal and nonverbal messages being conveyed, and is a good reflective listener" (p. 75).

This research utilized in-depth semi-structured interviews. In-depth means the interview was a detailed discussion about the topic. Semi-structured implies there were research questions posed by the researcher during the interview (Appendix A), but there was flexibility in the order of how the questions were asked. I tried to encourage parents to be interviewed individually. My intent having individual interviews was so each person would have equal opportunity to speak and not be influenced by the other. Five of the eight couples were interviewed separately for the initial interview, three preferred to be interviewed together. Generally, I tried to follow the parents' lead in the interview by following up on concerns they raised in response to the questions asked. All of the interviews were with the parents only, except for the interview with Sue and Trent in which the grandmother was also present and participated in the interview. Children were also present in several interviews. The interviews were audiotaped and lasted between 30 minutes and an hour and a half. Most of the follow-up interviews were very short relative to the initial interview. Eleven of the follow-up interviews were in person, five were conducted on the phone and one father missed the follow up interview. The follow-up interviews were read by myself and stories that clarified the categories from the initial interviews were highlighted. The second interview was just used to verify the initial interviews. No new questions were asked, only clarification of what we had already talked about during the initial
interview. I wrote notes about the interview immediately after it and later transcribed the field notes on the computer. The notes included the following: interview code, time and length, summary of the household, who was present during the interview, how the interview progressed and the main subjects or items covered in the interview. I called my interview notes the "interview profile". I drew a family tree of the household members in my field note for reference.

Recruitment of Participants

The parents were recruited from three centres serving the needs of children with disabilities; the centres were in Abbotsford, Surrey and Vancouver. I approached the directors of therapy at the centres and asked if they were willing to identify families who fit the inclusion/exclusion criteria and deliver, to the parents, a letter introducing the research. Included with the introductory letter was a form parents could return to me if they wanted to volunteer. I was following ethical procedures set out by the University of British Columbia (UBC). The Vancouver centre decided to have the letters sent out to families. No participants volunteered from this site. At the Abbotsford and Surrey centres therapists hand delivered the letters and return forms. I am unsure of the exact number of letters that were given to eligible families as I provided each centre with 10-20 letters to distribute. In total eleven forms from eleven family households were returned. Nine mothers and eight fathers, eight couples and one single mother participated in the study. Two families volunteered later than the other participants, but I felt I had enough participants and therefore they were not included. Each parent signed a consent form prior to the interview in accordance with the UBC ethical procedures.

The criteria developed in the proposal to recruit parents included: their child with a disability needed to be three to five years old and use augmented mobility, and the family include both a father and mother, although in one family the parents were separated and only the mother
Parents of children with disabilities participated. Augmented mobility means the use of a stroller, wheelchair or powered mobility as the primary means of mobility for the child. I wanted parents who were new to the experience of having a child who were physically dependent for mobility. I wanted to hear fathers’ experiences as well as mothers. I did not want to investigate parents’ experiences with the school system. Families excluded from the study included foster parents, as their relationship and length of time with the child varies widely. Families with more than one child with a disability were excluded because it was thought the issues facing these parents would be quite different from parents with one child with a disability. And lastly, the child could not have an acquired disability, by trauma or disease, after normal development. Parents were not included or excluded from the study based on their child’s medical diagnosis or cognitive abilities.

Descriptions of the Participants in the Study

At the beginning of each initial interview, with the exception of the first three, the parents were asked to fill out a sheet that listed demographic questions. The information requested on the sheet included: age, education, area where they lived, whether they owned or rented their home, occupation, ethnic identification and the length of time they had lived in BC. The first three participants were asked this information verbally, and I filled in the sheet after I had the transcribed interview.

The participants as a group were similar in many ways. Their ages ranged from 29 to 44 years old with the group average at 35 years. All but one family owned their home. The size and style of the owned homes varied from a new rancher style to a two bedroom apartment condominium. The home that was rented was a modest size split level. Three two-level homes had stairs inside, two bungalows had stairs to get in the front and one family had a ramp built to get in their backyard that was level with the back entry to their bungalow. All but two parents chose Canadian as their ethnic identification, the other two chose British. Lastly, most of these
parents are lifetime British Columbians. Five of the seventeen parents did not grow up in BC, of these the length of time in BC was between eight to 29 years (average of 18 years). They all live in suburban or bedroom communities outside the city of Vancouver.

Regarding the participants’ education and occupations there were differences between the fathers and mothers. The eight fathers had different levels of education, two had grade ten, two had finished highschool, two had technical school diplomas, one had some university and some technical courses, and one had some university and a technical diploma. Their employment also varies. One father works as a director in a video and TV production company, two were self-employed, one in the construction and logging industries, and the other owns his own furniture assembly business. The remainder of the fathers are employed in technical or trades occupations, such as a telephone lineman, a plane re-fueller, a gas and oil technologist and a shipper at a dairy.

Most of the mothers were similar to each other regarding their education. One has a teacher’s training and one completed grade nine, the rest had completed highschool. In addition to grade twelve, two have taken technical school courses and one wrote ‘college’ as her level of education. Six of the mothers are currently home full-time. In all but 2 cases, I inquired what occupation they had prior to having children. One worked in a bank, one as a secretary, one as a teacher’s assistant for children with special needs and one had several small businesses including a hair-dressing shop. Two of the mothers worked part time, one as a restaurant hostess and one as a teacher of the deaf. Both of these mothers had these jobs prior to having children. Only one mother worked full-time, as a coordinator in a factory.

I have summarized the family composition and the ages of the children in Table 1 (pp. 62). There are two households that include the paternal grandmother. In both situations, the grandmothers lived in basement suites. One disabled child lived in the basement with the grandmother, they both shared the same kitchen and bath with the family. The other grandmother
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had a self-contained suite. In both situations the grandmothers were important caregivers to the child with the disability.

The children of the parents in the study are evenly divided in age and gender. Of the nine children, three are three years old, four are four years old and two are five years old. There is almost an even gender split with five girls and four boys. None of the children walk independently. One child is learning to use a walker. Three children use supportive walkers that they are strapped into, as an alternative position to their wheelchair. All the other children use a wheelchair or stroller for mobility. Three of the nine children could be described as only motor impaired, the other six had two or more impairments.

They are a diverse group because they have various functional abilities. Many parents described their child’s difficulty with communication, feeding, vision, seizures and sleeping habits. This information was volunteered by the parents, I did not have any kind of checklist. Six of the nine children are non-verbal and two of these are fed through a tube. Four of the parents mentioned their child had some kind of visual impairment. Three children have seizure disorders, and all three parents mentioned that their children’s seizures were under control by medication or diet. Four parents spoke about their child’s poor or erratic sleeping patterns and two of these children were on melatonin, a hormone prescribed to regulate sleeping patterns.

Data Analysis

The main purpose of analysis in qualitative research is categorization of the data (Hammersley & Atkinson, 1994). Qualitative data analysis is a process which attempts to uncover meaning (Dey, 1993). The researcher attempts to discover the meaning by managing the data, reading, thinking and writing. Managing the data is the way the researcher physically handles and organizes the data. Wiseman (1974) writes about the "constant interplay of data
Table 1. **Description of the Participants**

<table>
<thead>
<tr>
<th>Family</th>
<th>Mother's employment</th>
<th>Home</th>
<th>Assistance Needed/Grandmother support</th>
<th>Transport</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marie\textsuperscript{a}, Jim, Jason (8), \textsuperscript{a}Kate\textsuperscript{b}, (3)</td>
<td>part time teacher</td>
<td>bungalow</td>
<td>total assistance needed in all areas of self care, non-verbal support</td>
<td>van</td>
</tr>
<tr>
<td>Rhonda, Ned, Rose (5), Jane (3)\textsuperscript{c}</td>
<td>works full time in a factory</td>
<td>bungalow</td>
<td>needed total assistance in all areas of self care, tube fed, non-verbal, grandmother provided care while parents worked</td>
<td>van, father had a work truck</td>
</tr>
<tr>
<td>Cindy, Sam, Brad (6), Thomas (4), Charlene (1)</td>
<td>at home full time</td>
<td>bungalow</td>
<td>needed total assistance in all areas of self care, tube fed, communicated with sounds and laughing</td>
<td>car</td>
</tr>
</tbody>
</table>
Parents of children with disabilities

<table>
<thead>
<tr>
<th>Name(s)</th>
<th>Placement</th>
<th>Type of Residence</th>
<th>Needs</th>
<th>Device/Transportation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betty, Lee, Richard (5), Dan (4)</td>
<td>at home full time</td>
<td>rancher</td>
<td>needed total assistance in all areas of self care, communicated by crying, screaming and gesturing, grandmother provided respite care</td>
<td>truck, van, equipped power lift</td>
</tr>
<tr>
<td>Sue, Trent, Joan (6), Patty (5), Steve (3), Kurt (17 months)</td>
<td>worked part time as a waitress</td>
<td>split level</td>
<td>needed assistance for self care, starting to communicate using words and switch, accessed communication devices, grandmother provides daily care full time</td>
<td>car, grand-mother took Patty on public transit</td>
</tr>
<tr>
<td>Carla, Ted, Nic (8), Sarah (5)</td>
<td>at home full time</td>
<td>two story house</td>
<td>needed assistance for mobility inside the home, used power wheelchair outside of home, she assisted with her own self care, verbal</td>
<td>van with ramp access</td>
</tr>
</tbody>
</table>
Parents of children with disabilities

<table>
<thead>
<tr>
<th>Name</th>
<th>Living Situation</th>
<th>Type of Home</th>
<th>Assistance Required</th>
<th>Mode of Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann, Fred, Irene (14), Wendy (4), Cameron (3)</td>
<td>at home full time</td>
<td>bungalow built into a hill with garage underneath the house</td>
<td>needed total assistance with self care, communicated by laughing and other sounds</td>
<td>car and truck</td>
</tr>
<tr>
<td>Pamela, Pete (4), Lori (2)</td>
<td>at home full time</td>
<td>townhouse on two levels</td>
<td>needed assistance primarily with mobility, verbal</td>
<td>car</td>
</tr>
<tr>
<td>Marlene, Jon, Jessica (4), Jen (3)</td>
<td>at home full time</td>
<td>apartment condominium on second floor</td>
<td>needed assistance primarily for mobility</td>
<td>van</td>
</tr>
</tbody>
</table>

*a All names used in this thesis are pseudonyms.
*b The underlined name is the child who has the disability.
*c The paternal grandmother lives in the basement of the home.

gathering and data analysis" (p.317). She describes how she carries out the interplay between data gathering and data analysis. Initially she organizes the data by interview topic then she begins to expand and revise her list of topics. The topics are her initial codes for the data. By asking a series of questions about the data, and answering those questions by ongoing data collection and developing codes, Wiseman illustrates how the data gathering and analysis
processes overlap. In essence, the overlapping process facilitates addressing the purpose, the theoretical concerns, the organization of data and the writing. Her method of analysis follows a logical sequence of underlining, coding, cutting, sub-coding and pasting the text. All of the text is accounted for in the analysis. I followed a similar computer aided process as described in the next section. The emphasis in analysis is on theoretically relevant characteristics that may be relevant to other situations, in this case to parents of a child with a disability, in a logical and coherent way (Mitchell, 1983), rather than statistical generalization.

The purpose of this section is to describe how the data were managed for this research project. Reading and thinking about the data were concurrent functions that constantly shaped and modified how I organized and wrote about the data. Ultimately, it is the written description or research narrative that shares the meaning of the research with the reader. My analysis involves understanding the parents' experiences as shaped within their particular social and physical environment. The following sections pertain to this research project and describe the data, data management, storage and retrieval of coded text, connecting categories and data display.

The Data Management

The data for this research were collected by audio taping the interviews. The audiotapes were then transcribed, one by myself and the rest by a secretary I paid with funds from a grant. The transcription was formatted with hard returns every two or three sentences, and in between speakers, single spaced and a three-and-a-half inch margin on the right hand side. The large margin on the right provided enough space for writing notes and codes on the hard copy, therefore double spaces were unnecessary. The transcribed data were on a hard copy in both real and pseudonym names and on a computer disc. The hard-copy data were duplicated and
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organized separately into two binders with each interview text filed under the family name. One binder was left unmarked, a clean text, and the other one was written on, such as corrected typos, comments and codes. The field notes from both initial and follow-up interviews were typed into the computer, printed and filed in the binder under the family name. The field notes for each interview were a page to a page-and-a-half of single spaced text. The field notes reminded me of descriptive information about the family, their home, the tone and topic(s) of the interview, for comparison with other families and during the writing phase of this research. The disc copy of the interview was cleaned up of any typing and transcription mistakes, then loaded as an on-line document into the QRS NUD:IST (QRS NUD:IST, 1996) program on the computer.

NUD:IST

Storage and retrieval of data for this project was facilitated by the use of the computer program QRS NUD:IST (NUD:IST) (1996). NUD:IST is a relatively new computer program to assist a researcher with data analysis. It has its own terms to describe qualitative data analysis functions. The program and the terms are described in this section, followed by the process of how NUD:IST was used for this research project.

NUD:IST (1996), Non-numerical Unstructured Data Indexing Searching and Theorizing, is designed for data that are non-numerical or not numbers, and are unstructured i.e. text, pictures, videos and other data. Data can either be on-line, meaning the document is put on the computer, or off-line, meaning the data are described on-line but are not actually on the computer. In this research project all the initial interviews were on-line. Each on line interview is called a document. I identified each document with the interviewee's initials, and numbered it one or two to indicate the initial or follow-up interview, and with an abbreviated date. For example, JN1.J15 represented Joe Normal, initial interview, on January 15th. All the indexed data
could be traced back to the original interview by the header.

Indexing refers to what is often called **coding the data**. The researcher assigns a code to a chunk of text, or text unit, and files that unit and all other units with the same code in the same place or in NUD:IST (1996) terms, in the same "node." The nodes are organized in a tree structure. Each node has a name (category or theme) and numerical address (code) that describes where it is on the tree. Indexing is essentially deducing a document into coded units. In stating this, it must be understood that the on-line document is always intact. Any coded text is automatically copied and sent to the node address(s) the researcher has indicated. At any time the researcher can retrieve a node to read all the text that has been sent to that node. Retrieving a document or node text is called in NUD:IST terms "investigating." Each time I started indexing a new interview I would investigate all the nodes to check to see if the text in the node was consistently on the same theme and to make changes as necessary. The node title, in some cases, was clarified.

Searching refers to the process of being able to call up or retrieve text, by code, by word or by category and other ways. In NUD:IST (1996) both the on-line document and the index system of nodes can be investigated and searched. This means you can retrieve very specific information to read and index or change the indexing. NUD:IST allows for consistent, thorough, organized and detailed data indexing. It provided me with structure to categorize the data. Yet the flexibility to change and expand categories ensures a dynamic data analysis process.

**Storage and Retrieval**

In this research project I read through all the interviews and wrote notes in the margin or on the back page before I started indexing them. Categorization involves being familiar with the
data to be able to make decisions about themes. Before I indexed an interview, I had read through it a least three times. I choose the three interviews that I thought were the most complex to index first. I created the first 15 nodes from my notes. This gave me a skeleton to start the indexing. I indexed the first two interviews adding nodes as I read the themes in the text. Initially I used key words from the text as the node title, then as more text was assigned to that node I changed the name to be more representative or generic of all the text in that node, for example "proud: he is my son" became "love/pride/acceptance." I compared each of the interviews to each other and went back to see if I missed themes that were newly created with interviews I had previously indexed. Some nodes I deleted or left empty as the relevance of the categories evolved and the number of categories expanded. After the 14 initial interviews were indexed, 57 nodes represented the data and five of those nodes were only titles for a tree structure and did not have text in them. Since each node had a node address I assigned the node address as the code. I simultaneously coded the on-line document and the hard copy text.

After all the documents were indexed into nodes, each node was printed out. The amount of text in each node varies from one to two pages up to thirteen pages of text. Each section of text in a node is identified by the header and the inclusive line numbers from the document. NUD:IST does provide quantitative information such as the percentage of a particular interview in a node and the percentage of the total number of interviews in a node. This information was not utilized in this research project. The follow-up interviews were not indexed using NUD:IST since the follow-up information was only to clarify the information gained in the initial interview. In the case when the follow up interview was relevant to the indexed nodes the follow-up text was added.
Advantages and Disadvantages of using a Computer for Data Analysis

The computer has a number of distinct advantages and disadvantages for the qualitative researcher. In this section I will briefly review these and provide specific examples I encountered using NUD:IST (1996) during this research project.

One of the most obvious advantages is the ease in which text can be indexed, stored and retrieved. In most cases it is a matter of a few specific key strokes on the computer. And not only is it easy to do but also it is significantly faster than trying to cut and paste photocopied text into different piles. Another advantage is the capability to edit the text at any point, in the document and in the node. Printing all the nodes from the computer was convenient and neat.

The disadvantages pale in comparison to the advantages, however, two main problems with using the NUD:IST (1996) software stand out. First, because the text is on-line the researcher physically handles the text less than, I assume, using a cut and paste method of categorizing text. I concurrently coded the hard-copy text and the on-line text and I printed out a list of the nodes and addresses. I preferred to see the text on the paper to make decisions about how to index it. I assume researchers' preferences vary.

The second disadvantage is how the tree structure is organized on the NUD:IST (1996) software. There are two disadvantages. The tree structure is like a family tree. The names of family members and their children are nodes. Each node is a category and each node can have, in NUD:IST terms, children and the children can have more children. The researcher creates and names the children. NUD:IST provides the numbers to identify the children or the node addresses. It is very simple, the first node is 1 and all the children of one are 1:1, 1:2 etc. and the children of 1:1 are 1:1:1, 1:1:2 and so on. The researcher can create as many nodes and
children as they see appropriate. The first disadvantage of the tree structure is that if the researcher deletes a node in the middle of the tree structure all the node addresses in the remaining structure are assigned new addresses by NUD:IST. The NUD:IST program does this automatically so that all the numbers (addresses) are in numerical order. Since I wanted to keep all the node address consistent as codes on the hard copy I preferred to leave nodes that I wanted to delete as "empty" nodes on the tree structure. This does not effect the storage and retrieval functions but it does clutter the tree structure.

The second problem with the tree structure is that it only arranges the data in a hierarchial model. This is a disadvantage if the researcher does not visualize a hierarchial model for their data. As a result, there is a mismatch between the tree structure on the computer and the researcher’s final representation of the data.

In this research project the final tree structure was wide and shallow. On paper, I rearranged the flat hierarchy into several links with sub categories radiating outwards like spokes on a hub. Ultimately, the links and connections became one big web with the parents in the middle surrounded by all the issues they identified. This fit with my conceptualization of the parents being the centre of attention. Then I grouped the issues in two broad categories. The first is about the parents’ descriptions and feelings about their children and the kinds of support they receive. The second is about their experiences of participating in activities, going out of their home and meeting people. These broad categories provided the basis for the organization of Chapters Four and Five.
Chapter Four: PRESENTATION OF THE DATA

THE FOUNDATION

This chapter is about the parents' descriptions of their emotions about their children: discovering the difference, of the support they receive, and their perception of being a "normal family". These themes comprise what I understand as the foundation for parents' decisions about participating in activities outside their home with their children. As with a house built on a foundation, neither the construction nor the transition from foundation to house are necessarily obvious. The first theme, 'discovering the difference', is about the feeling parents experienced after their child was born or diagnosed. Three sub-themes, 'searching for answers', 'proud parents' and 'emotional work', are also about the parents' knowledge of what their children's differences mean to them. At the same time, each theme involves different emotions occurring from daily life of parents of children with disabilities.

Support, the second major theme, comprises the parents' descriptions of what is important in terms of information and who the significant people are to enable them to do activities with their children. Parents utilized various programs and sought information to access caregiving and emotional and financial support. However, parents expressed frustration with the difficulties of accessing information or the lack of information, as well as the incidental way they found services that supported them. For many families, kin provided the most important source of support. The spouse, the siblings, the grandparents, especially grandmothers, and friends all gave practical, caregiving, emotional, financial and other kinds of support.

The last theme examines the parents' descriptions of their desire to be a "normal family". To many parents this meant being able to participate in activities outside of the home. Going to the rink to watch hockey or going to the swimming pool held value as normal family activities. Although the parents in this study spoke of all types of outings, for example doctor appointments,
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therapy appointments, holidays and trips to the park, it is the usual family activities carried out in the community they referred to when they spoke of being a normal family. The desire to be normal underscores the concept of these themes as the foundation from which the parents venture. And, by dealing with what they understand normal to be, the parents showed how they view their families as not only similar to other families but also as different.

Discovering a Difference

You don't give birth to a baby who is 4 years old in a wheelchair, that is something that happens gradually. (Betty)

I have chosen the word "discovering" to imply the action and movement of the parents' emotions towards an understanding of what their children's 'differences' mean to them. Many of the parents described what happened when their child was born or when the child was being diagnosed. Although each parent's situation and circumstances around the diagnosis was unique, commonalities exist in their descriptions of this time. In most situations there is a time lapse between the parents' feeling of knowing something is wrong with their child to actually hearing the diagnosis.

All the parents expressed strong emotions around the time the diagnosis was made or when the realization that something was wrong with their child became clear. Betty said, "I felt like somebody had kicked me in the throat" when the public health nurse suggested, before they had a diagnosis from a doctor, her son might be "mentally retarded." Carla expressed her feelings, "When she was diagnosed, of course I was devastated."

Lee is the father of two boys, Richard and Dan. He told me about how they had moved to a townhouse as a temporary arrangement before building a house. It was during this time when their second son was born and six months later, diagnosed with cerebral palsy. Lee, in the following quote describes the process of coming to know that something was not right with his
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We didn’t find out for 6 months... So when he (Dan) came home everything was fine but we noticed, I noticed, he was a little bit stiff. You know, he was very tense and then we noticed he was very, very colicky. He cried and he cried and he cried and he cried and he never stopped, and it got to the point, well, it was getting worse that when he was awake he wouldn’t stop crying... we just about lost it between the two of us, I mean, it was just hell. So we thought you know he’s a colicky baby and I had no sleep at all... and same with her (Betty). And then we had to look after Richard and he was one. I mean he was flying around too and we’re in this little place and it was just, it was hell. Anyway, we went a long, long time and I mean if you put Dan in the car and you drove... he would scream to the point that his face would be as red as a tomato and he was ready to blow up... there was something wrong. This is not right... So finally it got to the point that we were going to lose our marbles between the two of us because we just couldn’t handle it, I mean life was just awful. I mean this is just not normal... We got to get him checked out. So we went to the specialist that was there, Dr. (Name),... he said you know I’m really sorry to say this but your boy has cerebral palsy. Right away, of course, you are devastated and along with that he has all these other problems, epilepsy, you just don’t know. I mean what went through our minds was, 'Oh my God.’ (Lee)

For Lee the whole context of his situation is complex, characterized by small, temporary housing, an energetic typical young child, lack of sleep and going to work. Dan’s crying made this time "hell". Another father said:

I think that the toughest thing for me was when he was first born, and it’s a pride thing, you always want to have a healthy child, and a child to be, I don’t know, you want to be able to boast about your kid. And it was a little bit of a difficult thing for me to basically acknowledge, not really tough like I probably didn’t show it but on the inside I was wondering, you know, having to accept that I have a special needs child and declare that to people if they ask me. I won’t tell people unless I feel close to them, not even that but in the right discussion. Just to be able to say I have a special needs child and to actually be proud of him. I found that tough. (Sam)

Sam described his acceptance of his child's difference as a tough thing to do. His comments reveal an emotional struggle "inside" to understand what his child's disability and difference means and as well as how other people will see him.

Marie, who works with children with special needs, reflected on the time when her child was diagnosed and how important it was for her to make contact with other parents of children
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I knew, like once she was diagnosed with the disability or we knew that something was really wrong with her, I knew the process that I had to go through before I could sort of accept it. So I just went, 'Okay I have to do this, I have to do that, okay I’m allowed to grieve now and like get on with it, okay now we’re done.' So I think that really helped. I think it helped because I had immediate contacts with parents with special needs kids...I would knock on the door of the lady down the street, I would have no idea who she is but I know that her son is very special and he’s older but I just knew who he was and so I just knocked on the door. Sort of on my way home from the doctor, it was sort of like, oh, something is wrong with my baby. And she was really helpful. (Marie)

Rhonda and Cindy who both have children with multiple disabilities, describe their experience of realizing there were problems, but not receiving a diagnosis following a normal pregnancy and birth. Rhonda said:

Okay, well she was a surprise, she was a term baby, there were no problems with my pregnancy and when she was born she was a Cesarian birth so there was no problem with birth. And when she was born there didn’t seem to be any thing wrong. And then that first night they (hospital staff) realized that things were, she was just not reacting as a typical child would... it just started them looking at her and then they found that there had been severe brain damage. They (doctors) still have never... given me, the title or name of as to what her you know, ailment is...it didn’t take long, about six months, they (doctors) realized it (the extend of Jane’s impairments) was going to be way more (than just motor skill loss). (Rhonda)

Cindy describes her situation:

He was born two weeks over due and he was born not very healthy. We knew that there was something wrong right away, but we didn’t know what it was. And then they did all sorts of tests. It basically started at the top of his head and went to the base of his feet, that’s where they covered every test they possibly could. There was obviously something really wrong...that was the worst scenario for us having him having a handicap. I guess gradually the test results were coming in and we went to Children’s Hospital and I guess he was 2 months old when he got really sick. He got pneumonia. Then we were in a hospital for 10 days. And then we found out that there was something wrong with his brain and we wouldn’t probably ever know what the diagnosis was. He had 2 bouts of pneumonia within one month. Then we thought, well, we got him home in March or April, and then he started getting better health-wise. But it was very apparent that his brain wasn’t working the way it should be and he wasn’t, his goals and all that stuff, he wasn’t meeting any of the goals...we don’t have a diagnosis for him and he (has) developed incredibly (compared) to what he started out like. (Cindy)
For Marie, Cindy and Rhonda there were 'unknowns' about their children's diagnosis. Marie went to the woman down the street, a stranger, who she knew also had a "special child." Rhonda had never been given a diagnosis for Jane. Cindy's "worst scenario" was having a child with a handicap. The parents' stories describe their response to the discovery of difference. They reveal that this is an emotionally charged and painful time for parents. Cindy is also amazed at her child now. This points to the acceptance and realization of her child's difference.

Searching for Answers

Many of the parents talked about a variety of feelings they experienced because of their child's disability. What characterizes the following sections is how the mothers asked questions: such as why and how did this happen to my child and to us? All but one mother made a comment on guilt. Yet their comments and questions express not only feeling guilty, but also a deeper sense of wonderment, of searching for answers:

And I am exhausted at night...I'll look at Jane and just check myself. I can't blame her it's not her fault. It is not really anyone's fault. I went through the fault and guilt thing for a long time, like: 'What did I do? What, why has this happened to her? What could I have done different?' All of those things, but I realize it is nothing I did. It is just something that has happened. (Rhonda)

If it weren't for things that went wrong at birth he wouldn't be this way. So sometimes you find yourself feeling guilty, other times you feel yourself feeling frustrated, angry, it's not fair. And other times you think that you are really lucky because you have learned so much from him. (Pamela)

Betty retold the conversation she had with her doctor when he gave the diagnosis of cerebral palsy and she told her fears to her husband Lee that maybe she did something to cause the disability.

Then he (doctor) said 'No, it's brain damage,' and I said, 'What did I do? I did something?'
He said, 'No you didn't.'
The whole summer I'd wake up in the middle of the night and say to Lee, 'Do you remember when I was pregnant and we went bike riding and I fell?' And he said, 'Betty, nothing would have happened.' And then a year later I'd be laying in bed
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and I’d go, ‘Oh, you know, maybe I didn’t do this or maybe I didn’t do that, maybe when I didn’t go to the doctor right away when my membranes broke maybe infection, maybe that’s when it happened.’ So I would say for a good three years I blamed myself...(Betty)

Marlene recalled her situation:

When we first found out that, when she was diagnosed, of course I was devastated. I thought, ‘Oh what did I do?’ You know, the typical thing. First of all you feel guilty because she was born early, and then when I found out that she has cerebral palsy it was like, ‘Now what have I done? You know, what did I do that caused this?’ I got to the point actually, instead of dwelling on it, I always looked at the positive. (Marlene)

Marie spoke about not wanting to assign blame to anything or any person. She did not feel guilty about her daughters’ disability because she knew she would never have meant to cause any harm. Unlike Betty, she was not searching for something or someone to be the cause of her child’s disability:

There is nothing that we did to cause her disability and I’m glad for that. I know that when we went to medical genetics they wanted to find a reason for her delay and I didn’t. Cause I thought if it was something that we did we would never have meant to do it, like there was no way that we would have meant to do something. Like they were saying, ‘Well, did you take any extra pills or did you use a cream for your legs or what, think, think, think?’ We just didn’t want to. And as it turned out it is genetic and is absolutely nothing that I did and I didn’t want to find blame in anybody, in the doctor, in us, or anybody, because there is nothing that can be done anyway. (Marie)

Mothers were the ones who asked themselves ‘why’. Their emotions were layered with fear, guilt and frustration. However, the sentiment is not necessarily to find blame in any thing or any person. The mothers also spoke in past tense about these feeling and questions. Many parents, both fathers and mothers, spoke of their love and pride for their children.

Proud Parents

Thomas is my son, he was my son before he was handicapped. (Cindy)

The parents voiced pride and love for their child in many ways. Rhonda is the mother of two children. Her youngest child, Jane, has a severe disability and does not communicate.
Rhonda told me about going bowling; she did not usually take Jane, but on this occasion she did and Jane cried the whole time:

The last night there were a couple of people who came up and started asking questions about her and wondering what her problems were and stuff like that. It is interesting people are quick to, you know, 'oh you know you are just you’re incredible, and I’m not incredible. I’m just doing what I have to do. She’s my child and you would do the same thing if it was your child you just do what you have to do. (Rhonda)

Rhonda assumes all parents would accept their children. She does not want extra credit for herself just because her child happens to have a disability. Other parents considered how far their children had progressed and were proud of their child for that reason. Lee and Betty are the parents of Dan who has Cerebral Palsy and communicates primarily by crying. They both express their pride in their child, and Betty eloquently talked about how she is proud but it is still very difficult to take Dan out. Lee said:

I’m very proud of him by all kinds of ways...the way he is and what he gives to me, gives love to me and what he gives to the rest of us. That is the most important thing and he doesn’t ask for much and I don’t expect a lot. When I see little tiny things that he has achieved, it is such a big thing compared to a normal person...But when Dan does a little something special or a little something to be achieved or to move ahead it’s unbelievable. Everybody knows, the phones are ringing off the hook because we have to tell everybody. (Lee)

Betty says she is proud and she would not want her child to be any different or "placid." Betty talked about trying to understand Dan from his point of view and that as a parent she has to, become intuitive to her child. Betty is accepting Dan just the way he is, but she acknowledged it is still difficult to take him on outings:

But as far as going out I try and avoid it. I’m so proud of him when I’m out there. It’s not because I don’t want to take Dan out... And in saying that I would not want Dan to be placid, like put him in a chair, and he has no emotion or you know, just okay all the time...But you just have to, I think and you develop that because you are the parents and you just have like a labour of love. You just, you know, it’s part of Dan and you accept that. But still it’s still difficult to go on outings. (Betty)

Cindy and Sam are the parents of Thomas who was frequently ill after he was born. Cindy
described how she now appreciates her son. He is non-verbal, fed with a tube, has just learned
to stand and he does not cry anymore when positioned in the sunlight:

He’s a funny, happy, loving, tough kid. (Sam)

And we have started appreciating more him for who he is now than we did before (the younger sister was born). So when we go out now it’s different than it used to be. We are more, I guess we are prouder of him now, and now that he has come out of his sickness now we don’t have to be in a hospital all the time. He’s older and he’s not afraid of the sunshine and he doesn’t mind it so much anymore. (Cindy)

Ann spoke about the difficult times. For her these times are taking her son to the hospital and feeling mad because her mother-in-law did not want to hold him, and she concluded that "it’s all worth it." In conversation, Ann and Fred spoke of how they felt when Cameron first learned to roll over, a milestone they waited a long time to see achieved:

...every time he smiles at you, you forget all that. It’s worth it when he makes a little bit of a goal or achievement. It’s great, it’s worth it all. (Anne)

Like the first time he rolled over. (Fred)

Like he was a vegetable for a year and a half. He did nothing but lay there. And before the surgery he was like normal. He wasn’t happy and laughing and stuff like that, he was crying but you know after he was a vegetable for so long. And then the smiling came back and the voice came back, it makes it still worth it over all...(Ann)

Two parents, of children who have the ability to talk and feed themselves, spoke of their children’s personality. Marlene is the mother of Jessica who is just starting to use a walker. Jessica has been able to move around the house by crawling:

But yet when you look at her and you see her struggling and the determination that she has it really makes you feel good inside to know that she is that determined to do something. And she doesn’t give up easy and she has a really bubbly personality which really helps. (Marlene)

Carla, like Marlene, is proud of her daughter because of her outgoing personality. Sarah is talkative and uses a power wheelchair at preschool and outside in their neighbourhood:

She has determination and personality that will carry her through it. I can’t always
be there but she is an outgoing, outdoor person. And I think that will carry her through it. (Carla)

Marie spoke of how they really wanted to have another child after their first child. She struggled to get pregnant and feels lucky to have her daughter:

We had Jason (brother) and I got pregnant very easily having him and for two years we struggled to have another child and I think even though she has a handicap I feel lucky to have her. I think that if we hadn't ever had her that I would always still want her...there is alot to deal with her, like she's a lot of work. I'm happier having her than not. (Marie)

The parents have different reasons for accepting and being proud of their children. Parents were proud of their children because the children had overcome illness and are now healthy and stable. Two mothers spoke of their children’s personality and what will help to overcome the problems the children might face. Betty’s "a labour of love" signifies the dual connection between the "work" of her child and the love she has for him. Marie too, "...she’s a lot of work. I’m happier having her than not," recounts how her child is a lot of work but she is happy to have her. Some parents spoke of the physical work.

Although this study was not directly exploring the theme of physical work, it is an implicit issue for most of the parents of this study because some of their children are totally dependent for all areas of self-care. Thus every task, moving, dressing, playing, eating, drinking, coughing, toileting and communicating is layered with different amounts of caregiver intervention and hands-on care. Every action with the child demands a physical response from the caregiver, who in many situations, is the parent. Table 1 on page 60 briefly describes the amount of assistance required by the children in this study. The physical work, I would suggest, is part of the experience of raising a child with a disability. As the parents described, this work is closely connected to the emotional experience of raising a disabled child.
Emotional Work

All the parents discussed what I categorize as "emotional work". Emotional work is what the parents themselves described as emotional or emotionally hard, stressful and tough in their daily life. Ann described why she feels a mental strain; she is angry for many reasons. Her son is non-verbal as well as physically disabled. She explained why going out is difficult for her:

I hate getting out of bed sometimes. But you hear him awake and you have to get up right away otherwise he’s going to roll all over and get caught in something. I don’t know it’s a lot of physical work but I think it is more mental...You have no life anymore. It’s hard to go out and have fun with other people because they don’t help you so much with him (disabled child), but they will with the normal kids. Of course they play with her (sister) where as they won’t with him. You are sick of explaining it to people, you know, and his (husband’s) mother, you get pissed off sometimes with people, like family especially. If his mother can’t take time to hold him, or some kind of contact, you get mad. (Ann)

Again, Ann spoke of the physical work and the emotional work of having a child with a disability. She expressed resentment towards others, including her mother-in-law, who do not help or play with her disabled child. She relies on her husband to help with the work required in taking their son to the hospital:

I get tired of calling the doctors all the time, every time you go to the hospital you have to remember to tell them everything. You tell them over and over again, and you get sick of that. I always have to go. I try, when his shunt is blocked and I know it, like with the last time I waited to take him in, so it would be a weekend to have surgery so Fred could stay, because I can’t stand going to the hospitals anymore. I just can’t take it. It just, as soon as I know I have to go I just start getting stressed. I can’t stand staying overnight, so I try and go on the weekends so he (husband) can stay overnight because I just can’t stand that anymore. (Ann)

Lee indicated that now they can handle any problem because they have been "through hell." He described the rough emotional times:

I think you could pretty well put anything on our plate...nothing would fizz us. Nothing would bother us...we have gone through hell and came out of it. We have coped with things on a daily basis where people would probably lose their marbles and snap and you know I mean there has been rough times for myself and her (wife) in different ways, emotionally, and hard on the two of us to keep together, and everything is going to be okay and we have beat that. (Lee)
Rhonda related the emotional struggle of having a child with a disability:

Like she is struggling to breathe to put air in. I mean her tummy is rumbling and it’s and she is uncomfortable and she is vomiting and she has got diarrhea...I struggle you know I’ve even, and this might be the worst thing anyone could ever say about their child, there’s even times I pray to God when she is really sick this is going to be the time. He’s just finally going to put her out of her suffering. You know and I can’t believe I think about that with my own kid but it’s because she is just existing, she is not living, you know, and that’s hard for me. (Rhonda)

Parents vary. A child’s lack of communication contributed to the parent’s emotional work. The parents, of children who do not communicate verbally, experienced the added and complex issues of trying to understand their children’s needs and wants. The parents of children who were often ill, found the frequent trips to the hospital very stressful as well as the emotions of watching their children suffer. Jim reflected on the emotions. His story illustrates how the lack of communication impacts various aspects of daily care as well as his relationship with his child:

It’s difficult from an emotional point of view, you know you always want to hear and be able to communicate with your children and that’s the thing I guess I miss the most with Katy is not being able to effectively communicate. We are always sort of guessing. That is particularly true when she’s sick. Like when she had the bout of seizures and not to be able to console her and tell what is happening, or I mean yes, you do, you talk to her, you console her as best you can but you don’t know what she’s getting out of that. And for her not to be able to tell you her feelings and what’s happening and where it hurts, if it hurts, that’s really hard...so you are always trying to guess and double guess. And there is really no one to tell you what the answer is. And so messages are very subtle and conflicting and that’s really difficult not having a clear understanding of knowing where she’s at. And you know not being able to hear "I love you daddy" or something...But you know she has a great smile and a great laugh so you accept that as her telling you that. (Jim)

Ned spoke about the amount of care his daughter needs because she is not moving, feeding herself and not communicating. That added stress on his daily life. He is empathetic about her inability to communicate:

So now she’s a 24-hour care because she can’t do anything on her own. Twenty-four hour care is one thing but not being able to tell anybody or ask anybody questions, or statements, or what you want or what you don’t want, or what you like and don’t like...that makes it very tough. (Ned)
Betty spoke about one occasion that illustrated the emotional experience an outing can be. Dan cries to communicate his needs; he is impatient to listen to specific music. Music has a calming affect on him. They always carry a tape recorder with headset, music tapes and extra batteries on every outing. When the batteries in the cassette player die and he does not have music to listen to the situation can be unpredictable. Betty explained:

Sometimes he’s really mad and he’s really screaming and it’s just, it’s frustrating...like why am I out, why do I make things hard on myself, why don’t I just stay home and wait until Lee can look after Dan. If he was patient and didn’t constantly have to have the music on all the time I think it would be a pleasure to go out but it’s unpredictable. I don’t know. Even when we go for a walk all of a sudden he’ll decide he wants the other music he doesn’t want to hear it any more or you know, we try, we have so many tapes, we try all the time different music...I would have to say it’s because emotionally and mentally so much work. The physical part I’m physically able to do all that, you know. It’s not really an issue, the physical part, it’s the emotional part. The mental strain...(Betty)

Dan became impatient, unpredictable and frustrated and as a result, Betty experienced what she called "mental strain". Her story of trying to find Dan the right tapes at the right time illustrates why lack of communication was emotional work. In contrast, Carla spoke of how Sarah’s physical dependency had led them to a close relationship because they talked to each other when Sarah was being held. Carla feels their relationship will change when Sarah spends more time in her power wheelchair as opposed to being carried:

I’m kind of dreading it (being away from Sarah), I think she does too because I think part of the closeness that we have will be gone too...when I have her on my hip, we’ll just stand there and talk...

In summary, the parents of children who have disabilities experience what I have called emotional work. The emotional work makes their day to day life "tough" and/or "stressful." A few parents described the emotional work as being more difficult than the physical work of caring for their children. Of all the parents in the study, only Sue and Trent did not speak of their emotions. For them, Trent’s mother was the primary care giver, the whole family was present
for the interview and there were many interruptions. These factors may have limited the depth
of the interview. For many parents, their children’s medical and self care needs were complex
and multifaceted. The parents of these children talked more about the emotional work, especially
that caused by the lack of communication.

Both fathers and mothers spoke of the time around their children’s diagnosis, the feelings
of guilt, the love they have for their children and also about the tough times. In most situations,
the mothers had more to say and would give either more details, or more examples of a particular
situation or feeling. For example, several mothers questioned themselves about why their
children had disabilities, and none of the fathers spoke of guilt the same way the mothers did.
One father felt awkward taking his son out, and another father found it difficult to acknowledge
his disabled son and be proud of him. Many parents in this study expressed intense feelings of
pride and love for their disabled children and discussed the physical work as well as the
emotional work or "mental strain" in caring for their children.

Support

I find that as we have gone with Jane from day one right through until now that, that
it is really good to have more people helping us with the child. (Ned)

Parents used support, both formal and informal. I categorized support as deriving from two
main types of resources: first, agencies and information, and second, people who enabled parents
to participate in activities on their own or with their child. In many situations, the support
benefits both the child and the parent. The child received caregiving support and the ability to
participate in programs, while the parent gained peace of mind knowing the child was well cared
for. Opportunities were provided to take up employment or have leisure time. Parents went to
resource places to seek out information on funding to pay for a person to provide extra support.
Resource places for parents of children with disabilities include child development centres, health
departments, social services, hospitals and other specialized organizations. Children with multiple disabilities require more help than typical children. This influenced how the parents sought out and organized respite. The parents voiced frustration in and concern for the process of finding information, especially for respite and funding programs. The following sections will describe parents’ descriptions on accessing information and people who support them. People, or social support, is sub-divided into the following issues: finding and trusting people for support, spousal support including financial support, grandparents’ support and sibling support.

Accessing Information

You don’t know, nobody comes and tells you. You find out through trial and error and somebody saying, well hey, how come you don’t have this. (Betty)
And if you do have a special needs kid and you want to find out anything, it takes years. (Fred)

Resource places, information and support are closely linked together. Many of the parents viewed resource places as a source of information but often expressed frustration with the haphazard way the information was passed on to them. Access to information about funding for respite and equipment, programs, or even medical information is especially important to the parents because it often had implications on their daily life. Marie explained how she and her husband acquired information to build a ramp from their backyard to the back lane, and how her parents-in-law paid for the expenses of the ramp:

I went to the child development centre and I asked her if they knew of any books or anything that I could get out of the library or whatever and they just photocopied some information for me and gave it to me. And the funding came from our parents. It isn’t funded at all. Anything, like the walker the wheelchair, anything that is specifically for her...is paid for (by the government program called the At Home Program), but the things that are sort of aiding me, like getting her up the stairs or into the van, those kinds of things aren’t paid for.

Lee sought funding from a charitable organization because van lifts, as Marie states, are not covered by the provincial At Home Program. Charitable organizations that provide funding
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include, for example, The Lions Club, The Variety Club and CKNW Orphans Fund. Charitable organizations vary in their criteria and willingness to provide funding:

(Charitable organization) has a great fund for disabled equipment...I can't afford a lift to be putting that in a van...different equipment, like his wheel chair, came from California, quite a few thousand bucks for a wheel chair and you look at it and you go, how can that be worth it, but they are. Every little thing that he has is a lot of money. (Lee)

Lee recognized that all his child's equipment is expensive. However in the following quote, he described the discrepancies between organizations' willingness to help them with funding. The first agency, a disability association, refused their request. A radio station completely funded the lift:

We asked them...we (said) have a severe boy with (diagnosis), we need help, we need some funding for some different equipment and different things like that. And they haven't given us a dime...(The other charitable organization) why would they want to (donate funding)? But they do. And they have, they replied back, they said 'Listen we are working on funds and we'll get back to you.' They wanted to know, have an interview...And they said no problem we'll get to you. We have this lift... (Lee)

Lee is perplexed at why the association representing his child's diagnosis was unwilling to provide them with funding, and why the radio station with funds for charity, would provide the funds. Jim and Marie, at the time of the interview, were trying to seek extra funding to put a lift on their van. Their story shows the incidental way in which they have accessed information on a funding source. Marie had walked her oldest child, Jason, to school once a week during the last two years. On their way, they crossed a street at which there was a crossing guard. The guard, who had some experience with persons with disabilities, took an interest in Katy and suggested they get a lift, although initially Marie did not think she needed one. She had some connections with the fire department and knew they had funds for children with special needs. The crossing guard told Marie she was willing to see if the fire fighters would be willing to fund a van lift. Marie went to her therapist to ask if this was something she should pursue. The
therapist said yes. Marie provided some information to the crossing guard about her family. A fire fighter came and interviewed Jim and Marie. Marie had heard, unofficially from the crossing guard, that they were to receive $2,000.00. Marie concluded:

You never know where your connections are and you never know whether this person is going to come through with it or not. I mean, I could have just said, 'No thank-you' thinking she had no connections. But she did.

In the following quote, Betty found out by coincidence that extra funding is available to her for respite:

...the social worker met with me last January and she said, 'How come you are not getting your respite?' I said, 'I didn’t realize that I qualified because I also get Respite dollars from the At Home Program from which we pay Lee’s mom because she looks after Dan.’ So I found out through the social worker, and within a couple of weeks it was happening and it was great. (Betty)

Fred and Ann are frustrated by the lack of equipment supplied through the government program. They can seek funding through a charitable organization, however, the organization would want recognition for what they have given to the family:

Yeah, another thing they at the At Home Program will not pay for is the stair lift, there is no way that you can have lifts paid for and they are very expensive. You can try the (organization) and all that but there are very few places. (Fred)

See the (charitable organization), nobody will help you unless they get a really good recognition...it’s really sad. (Ann)

Marlene expressed confusion because the criteria for who is eligible for funding seems to be biased towards single mothers:

Before we got on to the At Home Program, I actually had people say to me, 'well if you were a single mom, we (charitable organization) could help you.’ And it’s very frustrating and it’s, I mean it was to the point where a lot of times I was in tears because I just think to myself it’s so unfair. Like where do you go for help? (Marlene)

Marlene’s comment reveals her frustration and questioning of where to go for help; that sentiment is evident in many of the parents’ comments. All these parents discussed frustrations with
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accessing information, programs and/or funding. They point out that: it is time consuming, organizations are not always willing to help and sometimes they want recognition, and some are biased as to who they will fund.

Of the nine families, two mothers and one father were involved in organizations: one as a director in a diagnosis specific association, one on a parent committee at the school and one on a committee associated with the Infant Development Program. For two of them, the reason for taking on that role has to do with accessing information. They all felt a responsibility that information is passed on to other families who also have a child with a disability:

So it has always been our (their) feeling that if you are going to deal with this the best way is to get involved, and as a director, you are even more able to get information than if you are on your own. So that’s why I decided to do that. (Jim)

So this way, if we (the association) can put the information into the hands of the parents, then they of take that information back to their doctors in order to ask for more specific information, medically how things should be treated etc. At least that way the parents have as much information as they can to take to their doctors, whether that is asking questions or helping them sort out what medication for seizures works best for (diagnosis) kids, that sort of thing. (Jim)

Lee explained why Betty is on a committee. Part of the reason is because Betty and Lee do not want programs to be discontinued because people are not using them. Part of the reason people might not be using a program is because they do not know about it. He was emphatic about the importance of parents knowing what is available:

My wife, she’s part of a committee to do with disabled kids as well, helping out in different things in that. She got involved in that, I think you almost have no choice in a lot of ways, but Betty has gone a little further. She wants to be part of that because it is important that we don’t let things slip away because if things are not used, and people don’t know, then the government will take them away because they are not used. (Lee)

Information is important to parents. Valuable information includes more about the child’s diagnosis or how to find funding for equipment or respite. Information is important to lead parents to the right kind of programs such as daycare or preschool. Many of the parents in this
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study were upset with the lack of availability of information and the conditions surrounding what was available, for example, funding was available if the mother was single or a charitable organization might recognition. The frustration with finding information led three parents to become more involved in organizations serving their children. This served two general purposes: first, to find things out themselves or second, to ensure something was done to address a situation. For example, one mother was on a committee to make sure the playground at the new school was wheelchair accessible. Two parents felt very strongly that their role on the committee was important to make sure information was available to other parents. Both fathers and mothers were involved in accessing information. In Sue and Trent’s family, the grandmother was the person who accessed information from doctors and a preschool. One father, Ted, accessed plans to build a ramp into their home through the association representing his child’s syndrome. Another father, Fred, approached the drug store to see if they were willing to sell pear juice, the only kind of juice Cameron would drink, for a discounted price. Although accessing information may be a shared endeavour between parents, mothers were more involved in planning child care.

Finding and Trusting People for Support

This theme of support is about the mothers’ efforts to organize and hire a person to provide paid care-giving to their child:

And that is all that is important to me is I know they’ll (respite worker) make the decision if she needs to go to Children’s (Hospital) they know, they just do it. (Rhonda)

This quote reflects the trust Rhonda has in a person who is paid to care for her child. For the mothers, the issues of finding someone suitable to do the work and trusting them to care for their child was paramount. Two mothers told me about how they organized respite after their maternity leaves. Five of the families in the study needed paid care-giving support.

Rhonda told of her experience of going back to work and then needing more time to
organize an alternative caregiver in addition to her mother-in-law who was providing care during the day. Rhonda used a non-profit organization that matched families needing caregivers and people who wanted to do that kind of work. Rhonda found Judy, the respite worker. Later in the interview she stated that unfortunately, the funding for this matching program was cut, although that did not effect Rhonda now. Initially, for Rhonda the issue was recognizing that she needed to have extra support in addition to the time and support her mother-in-law could provide.

She said:

I had gone back to work, I think it was September and then I went off again at the end of October and I was off for November, December, and January, went back to work at the beginning of February. And it was exactly what I needed. It gave me the opportunity to get Judy organized. I just wasn’t comfortable leaving her with mom (mother in law) all the time. (Rhonda)

Marie did not find a respite worker through an organization. She had difficulty finding a person she could trust and who would have realistic expectations of her daughter. Her comments point to the reality that a caregiver needs to understand what it is like to care for a child with a disability:

But when I was first looking for people they saw Katy as a baby and couldn’t see that she was a child with a disability that needed to be treated a little differently than a baby. One lady said, 'You’ve got to push her a little more, why aren’t you pushing her?' Thank you very much (sarcastically). I found it hard to find somebody that I trusted her with, that would actually push her a little bit, but have realistic expectations of her too. (Marie)

Marie found a mother who was operating a home daycare to provide respite for Katy and Marie’s older son Jason. The respite worker took Jason to school, fed Katy breakfast and cared for her the rest of the day while Marie and Jim were working. The respite worker had her own children, other children and Katy and Jason in her daycare.

In addition to finding someone to provide respite, the parents also needed to be satisfied with that person’s work once he/she has started caregiving. Betty and Ann spoke about not being
happy with the care their child received:

We had a lady here for a couple of months and she was really nice. She was great but she would bring a book and I didn’t want a baby-sitter for Dan, I wanted somebody to keep him company. (Betty)

But most of the people are actually good for the first little while and then as the months go on they just, you can tell it when you come home. He’s laying in the corner. His diapers haven’t been changed. We’ve had a lot of care like that, that just after so many months you have to finally just say that’s it. We’ll find somebody new for awhile. You know you have to constantly keep changing because they’ll sit, on comes the TV, he’ll sit on the floor, and then that’s it. (Ann)

Mothers were the coordinators of arranging paid care. Eight of the nine families were on the At Home Program which would provide them with funding for equipment and, for five families, funding to hire a person to provide respite. In addition, the mothers accessed other people, who had various experience such as nursing or child care, to provide respite. Two sets of parents had ongoing frustrations with the people they hired, and were not satisfied with the kind of care provided. For example, the respite worker would read or watch TV instead of interacting with the children. The other three sets of parents were satisfied with the person they had hired. For one family, an extended family member provided respite and it was not an issue for this family to find her or to be concerned about the quality of care provided.

In conclusion, the mothers of children with more severe disabilities need to hire a person to provide respite. For mothers who are hiring someone to provide respite, the issues are twofold; they need to trust the person to provide quality care and to make responsible decisions for example, taking the child to the hospital. Five of the nine families in the study hired someone to provide respite have children that have multiple needs such as, in the areas of feeding, toileting, communication, sleeping in addition to a movement disability. Sue and Trent were an exception in that although their daughter has multiple needs they did not hire someone for respite. In their family the grandmother was the main caregiver for their daughter. The
remaining three families did not hire someone for respite, perhaps because their children did not have multiple needs.

**Spousal Support**

Since almost all of the parents in the study were in partnerships it is not surprising that in many interviews the parents talked about the support they receive from each other. One mother was separated from her husband. In all the families the mothers were the main caregiver and/or coordinator of paid child care, but the fathers in many situations were involved in caregiving and playing with the child as well as financially supporting the family. Some fathers were involved in several areas of the child’s life while some participated less. All of the fathers in the study were employed.

Ann expressed her sense of relief when Fred came home, knowing someone else was there to deal with Cameron. They both communicated a sense of shared responsibility for their child. Fred, too, acknowledged that he helps. Even though he is employed, he knows Cameron’s routine and will help, for example by giving him his medications:

I like it when he comes home, not even when he plays with him or not but I just get this feeling of, ‘Oh, somebody else.’ If I don’t want to look at him (Cameron), Fred can go and deal with him. (Ann)

I come home and Ann says, ‘I’m leaving, I’m going here, there, or whatever.’ I still give him his medication at night and I know when those are due. Like on the weekends, like this morning, I got up with him and fed him, and give him his medications. (Fred)

Jim spoke about how he helps out with self-care activities, not as much as Marie, and how he wants to participate:

Probably diapers, feeding, and I have to say that I don’t do as much of that as Marie but I do do it and want to do it. And certainly helping out with the feeding. (Jim)

Jon gave credit to Marlene for caring for the children every day. He made these comments after I asked him to describe what it is like to be the parent of his child with a disability. These two
parents communicate their feelings with each other. Marlene is home full time with the children and Jon works full time. Jon conveyed a sense that they share their responsibility of caring for their children through their feelings and communication although their activities and participation in the daily lives of their children were different:

Marlene and I have conversations at night time...she pretty well said it. She knows the way I feel and I know the way she feels and we see everything the same way. There is not really much more to add to it except that she is a special mom and I can honestly say this that I couldn't be home everyday doing this day after day. I couldn't do it. (Jon)

Jon talked about how he spent time with the children after work and on the weekend:

...And then I come in and lately its been a monster; I have to be a monster. I have to crawl around, they can jump on me, chase them around, throw the ball and that's the start of it. For a while there I was just coming home and being beat and I really wasn't doing a whole lot with them when I first come home but now I have just kind of changed that around a little bit. (Jon)

Jon had a routine of coming home and spending time with both his children. Spouses provided emotional support to each other by caring for, playing with and knowing their child’s needs. By doing these activities and communicating with each other about their child, some spouses expressed a sense of shared responsibility for their child, yet their individual roles with the child and in the family were different. One explanation for the different roles between parents certainly can be the influence of child rearing traditions, i.e. mothers traditionally have been providers of child care. Another explanation can be the amount of time available to spend with the child. In this study, the fathers were spending a significant amount of time at paid employment away from the home.

Employment and Paying the Bills

Employment led to two issues for fathers. First, dealing with the amount of time they were away from their families thus and are unable to provide care-giving help. Second, their responsibility of financially supporting the family. Fathers spoke about how they spend time with
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Well I see her every morning. I don’t spend time with her because she’s just sleeping or her machine is going, feeding her...so you know I just see her and hold her hand, but she’s dead sleep when I go in. I just talk to her, give her a kiss and check her and make sure everything is okay and then go. So I don’t spend any time there. But there are days when I’m home, and on the weekends I see her and at night time. Not very often because I have my own business and I’m trying to get it going and I’m just at a stage where if I want to get to the next step...I have to work longer hours... (Ned)

When I get home from work I usually, if Sue is not home I get mom (grandmother). Between us we get dinners and then we basically just play with the kids. Just take them for walks and that. But basically, it’s pretty well the same routine everyday. I usually, if Sue is working, I take care of the work and that. Come home and just play with the kids in the evenings until they go to bed, 7:00. (Trent)

Lee spoke of his responsibility to pay the bills and how that compromises his time available to provide care-giving support:

I mean I’m there, I’m there as much as I can in the day time, I’m there every day off I have, but I have to go to work. Somebody has to pay bills and keep everything going. And that’s where I leave and they have to take over. So there is a lot, you know, I have to give her the biggest credit of all because she’s had to hold together. (Lee)

These fathers, to varying extent, have a presence in the children’s daily lives. Their role and activities within the family included employment and some child care. In most families the fathers were the main or sole source of financial income, and having enough money was voiced as a concern for two fathers. Fred and Jim voiced concerns about making enough money, which is stressful for them:

Yeah, that’s it, lots of work. Like it’s not just work with him but it’s work for me finding out where the next dollars are coming for him because he needs this, this and this. So you are constantly stressed out worrying about where that’s coming from, where this is coming from, how am I going to do that. Or I know we need this but I know we can’t afford it for another year but we still really need it. (Fred)

So it’s stressful. (Anne)

And a lot of work. (Fred)
Jim wanted to make sure his daughter's needs are well cared for. He understood this meant more paid work for him to be able to afford what she needs. This translation of her needs into the amount of work for him is both stressful and worrisome. In addition, working long hours at the workplace means less time at home:

And I want her to have more than what she just needs. And so that is a concern and that gets back to working like a dog to try and get ahead in the world and it all sort of goes around and around in a circle. So that is a worry and a stress, so I try and deal with it as best I can in a day to day way that relates to working long stupid hours... (Jim)

And one father acknowledged that his salary allowed them to provide for their daughter in the way they wanted:

I know we are in a good situation because I have a good job. We are pretty fortunate that way to have things available for Sarah that she needs. (Ted)

Only one father spoke about the conflict between his hobbies and time he could be spending with his family:

It's having my own time. It's really hard because I work so much and then I just want...to be able to go and do something...there are times when I have to go and do what I need to do. And I do it. And I don't let a whole lot get in the way. Although I should, there should be more priorities but it's too bad, I do what I have to do sometimes. (Ned)

The parents in the study follow traditional roles. The fathers provided the main financial support and the mothers, at home, cared for the children and coordinated paid care-givers. The spouses supported each other and their families in different ways: by sharing responsibility, caregiving, and providing financially for the family. Many of the fathers actively participated in child care and played with their children when they were not at the workplace. Some fathers expressed concerns about needing to work to bring home an income because they had experienced the extra costs associated with their disabled children's needs. This was a source of stress both for the present and in thinking about the future. Fathers who were employed full time also had
less time to spend with their children than mothers who were either employed part time or not at all. Thus the available time for outings with the father or both father and mother was, in most cases, in the evening or on weekends. Mothers, in contrast, took the children to activities or to appointments during the day. The mothers were the primary caregivers and/or organized paid care, even the mother who worked full time.

The fathers also spoke about the stress of the responsibility to financially support the family. More than the mothers, fathers had concerns about earning enough money, spending time at paid employment to earn more, and one father spoke of fitting in leisure time. However, the fathers recognized the significance of their partners role in the family (for example, Jon, Jim and Lee’s comments). Spouses are important sources of support, and grandparents also are very significant to some parents.

**Grandparents**

And my in-laws are fabulous. I mean they will come over at the blink of an eye if we need them to come over right away. (Marie)

Four of the families in the study had involved extended family member(s), in most cases grandparents, who provided both respite (paid work) and emotional support to the parents. The involved grandparents in this study often provided support in many ways. For example, they would provide care or respite, take the child to appointments, give practical help around the house and give emotional support to the parents.

Katy recently received a wheelchair. The family home was inaccessible and they needed a ramp. Marie acknowledges the extra help her in-laws provided:

...they (grandparents) came over and built this ramp a couple of weeks ago because we got this wheelchair and we needed to be able to get out of the yard. So they have been helpful not with just taking care of the her, but just helping us with the things that need to be done. Or like my father-in-law came over and picked up our van because it needed some work done. So they just have been helpful with other daily things so that I can spend more time with her. (Marie)
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Several grandparents, specifically grandmothers, provided respite care to their disabled grandchildren. Respite consists of hands-on caregiving and the respite caregivers must be competent to care for a child with special needs and for longer periods of time (i.e.: from a few hours to several weeks). The respite that grandparents gave in many situations was more than just in-home caregiving, including activities such as taking the child to medical appointments. Betty described how both her parents and in-laws are important people for respite, emotional support and help with appointments:

I have a really close relationship with my parents. We just spent a month up there (out of town), the boys and myself. And even when we said good-bye it was like it wasn’t enough time... and my mom she is physically able to help me with Dan, and for emotional support I phone her...Lee’s family, his mom and dad live in Surrey and his mom is very instrumental in helping me with Dan. She’s our Respite worker because she does a lot of caring for Dan. She will come out and help me. Help me with the appointments, taking the kids to appointments because they are all in Vancouver. (Betty)

Two of the nine families had the paternal grandmothers living with them in the same house. Both children are severely disabled, both are non-ambulatory and non-verbal, Jane had a gastro tube for feeding. Rhonda described the importance of her mother-in-law for hands-on caregiving while she is at work:

I am actually really lucky my mother-in-law lives with me and you know she’s pretty much the major caregiver when I’m at work...there is no way that I could deal with work full time and deal with Jane and you know the rest of the family without having her help there. There is just no way. (Rhonda)

In the second household the grandmother is the primary caregiver. She and Patty live in the basement although they have mealtimes and bathing upstairs with the rest of the family. I asked how this arrangement evolved. Sue explained:

Well, I think it was six months after she was born I had a nervous break down so I moved out for four months. And so, I kept the kids with Trent (partner) and his mom (grandmother) because they were better off with them there. And, so at this time grandma was taking care of her so they bonded. (Sue)
I’m in the background so she knows who I am but she knows more as Nanny. So I don’t do too much with her. I’ll play with her, I’ll sit with her, I’ll feed her and chips or whatever but mainly Trent’s mom is the one who takes care of her. So I don’t know too much. Even with the doctors, I don’t know even half of the doctors that she goes to see...I’m just the back seat driver. (Sue)

In both these families the grandmother freed up the parents’ time to care for the other children and/or for paid employment. Both Sue and Rhonda are employed, part-time and full-time respectively. Other family members who were briefly talked about as important to baby sit were aunts of the child, cousin of the parent and an older sibling of the child.

In one family, the grandparents were involved with the siblings but not with the child who has a disability. It made Cindy angry, she wanted her in-laws to love her son as she does:

Seeing how family responds to my son and not loving him the way I want them to love him, like I love him. (They are) having a hard time getting close to him because he is not very bondable, he’s not easy...every Monday they (older sibling and paternal grandparents) go out all day together. And why I’m concerned is when Thomas came along there was nothing there. And so I couldn’t believe that, I thought, it was hard enough for me to be dealing with this the last thing I need is a family member not, but then, I had this, bitterness and anger to people who didn’t open up their hearts to Thomas like I did. (Cindy)

Cindy is not the only parent who described a negative response from grandparents, but she expressed the most anger. The grandparents were important sources of support for the parents. The support takes the form of practical "hands-on" caregiving and emotional support for the parents. Not all grandparents are involved with their grandchildren. The most common reason given by the parents for grandparents not being involved was because they lived out of town.

**Siblings of the Disabled Child**

Lori just adores Pete, she dotes on him. (Pamela)

Siblings were also a source of support to the parents. Lori is two years old. She knew that Pete, her bother, cannot walk so she would get snacks from the kitchen and feed him while they were watching TV. Pamela said she dotes on him. Since most of the siblings are young, the
support to the parents is in terms of emotional support and some practical help. Many parents described the patience and love of the sibling for the disabled child. The parents also recognize that the siblings experience their own stress and anxiety about their disabled sibling:

It was hard on him (Richard, Dan’s sibling) too because he felt stressed because of the stress that we are all going through and he had to go through it too. He had to be there and listen to it (reference to Dan’s crying) and he does to this day have a lot of patience for Dan and he helps Dan out and he helps Betty out a lot. (Lee)

Richard is five years old. He helps Betty out by pushing Dan’s wheelchair. Lee also spoke about the sacrifices Richard experienced, as a small child, in terms of the amount of attention and energy they as parents could provide.

Carla spoke about Nick, their oldest son, going to an integrated camp:

It was an integrated one and it helped him too, to realize he isn’t the only one with a special needs (sibling). (Carla)

Carla’s comment illustrates she recognizes Nick’s needs. That the experience of having a sister with a disability is challenging for him too. Rhonda spoke of how Rose, her five-year-old daughter, tries to help with exercise and recognizes when Jane is having feeding problems. Rhonda thinks Rose is incredible for her age. Rhonda credited Rose as being a very strong person, but also thinks that she keeps her "sane." Ann’s oldest daughter is 14 and provided some babysitting support.

The siblings in this study were described by their parents as an important source of emotional and caregiving support to them. The sibling’s presence in the family was also an important part of being a "normal" family. The siblings want to do typical things and by their presence they are a reminder of what "normal" activities and desires of children are.

Being Normal

...I thought they understood our situation and how we try and be as typical as we can as a family...(Betty)

Sam and I, it doesn’t bother us to have people stare at us because we know we are
different and we know we have dealt with all that. (Cindy)

The two quotes above draw attention to the contradiction these families negotiate when they go into the community, that of being a typical family as well as being a different family. Similarity, being typical or being "normal" are part of a construct created by comparison of themselves to other families. The word "normal" was used by the parents in this study to describe themselves. Thus it is used in this text, although the connotations given to the word by the parents is not fully explored. "Going out and doing stuff" is, in some sense, "being normal" and not doing that is part of being a family with a difference.

**Difference: "That's part of life"**

In virtually all the interviews the parent or parents made some reference to being normal or, in contrast, how they were different from other families. Sam spoke of how Thomas is included in the family and that his personality characteristics are like other children, but importantly, he has more difficulties:

Basically Thomas is included in normal family life. (Sam)

He's a funny, happy, loving, tough kid. He's everything that a normal kid would be and has obviously more difficulties. (Sam)

Lee articulated the disjuncture between their family and other families. The difference is the "easiness" of "doing." Another issue that Lee identified that may be a different from other families is being able to look ahead or perhaps dream about his child's future:

...no matter how we look at it, it's not as easy as any other family. I mean we accept that, we are not asking and we aren't complaining or whining, we are very happy with a lot of the stuff that we have and the equipment to get us through these things. That's part of life...We don't look to the future, we can't. Maybe other people can but we don't do that because sometimes it's too overwhelming. (Lee)

Pamela and Marlene identified the additional concerns they have about their children in comparison to parents of typical children:
Parents of children with disabilities

You spend a lot of time worrying, afraid, being afraid and struggling. A lot of things that you wouldn’t normally do with your typical child. (Pamela)

I think being a parent of a special needs child, I think that it gives you a greater outlook on things. You know, people that have what you call typical children have no idea of really how lucky they are in the sense that their child is potty trained on time and does everything at a typical time or a normal time in a child’s life. (Marlene)

These parents’ statements are about difference and how that is part of their family and future. Their tone is accepting of their children. Marlene speaks of the "greater outlook" it has given her. Lee is accepting when he stated "that’s part of life." Other parents linked doing things with their child with being a normal family.

**Doing things: "...as normal as we can"**

We’ll pack her up and go off, do whatever, try to be as normal as we can. (Rhonda)

Rhonda’s statement reflects a link between going out and doing activities with being a normal. Rhonda’s daughter Jane, is non-verbal, non-ambulatory and is fed through gastrotomy tube. Jane easily becomes ill and when she is sick she is difficult to manage. Rhonda, despite all of Jane’s needs and difficulties, linked what it is to be normal with going out.

Carla told me their family philosophy:

So basically the fact that where there is a will, there is a way. We try to be as normal as possible. (Carla)

Carla associates being able to do things, even if they need to be adapted and changed, with being normal. Then she went on to tell me how they adapted a tricycle and a toboggan so that Sarah could participate in the those activities. Carla recognizes that they need to think and change situations so that Sarah can participate. Carla concluded by saying, "So like I said we work things out as normal as we can."

Marie and Jim were insightful about what going out and being a normal family meant to them. Marie gives credit to their son, Jason, for making them a typical family:
I think for us we wouldn't want Katy to stop us from doing things and we see other families that are just really busy and involved with their kids and that is what we want to do and that is what we do. I think Jason has made us the typical family because he forces us to go out, he forces us to, like he's involved in hockey or whatever and so we go out with all the other parents and we're just the typical family sitting out there in the stands just like everybody else. (Marie)

We were just talking about that. We went camping this summer and it wasn't all that easy because we have to take her wheel chair, and the walker and all this equipment with us, the van was stuffed full. You have all this stuff, so it probably would have been a whole lot easier to say, 'Oh no, let's just go for a day trip and we'll do a picnic or something,' but you know we thought, 'No, we could make this work.' (Jim)

And we do enjoy it. It isn't all just for Jason. That's not what I mean. It's just that I think he helps us be more typical. (Marie)

And I think all of those experiences are really good for Katy too, not just for us and not just for Jason but for Katy as well rather than just doing the safe or the easy thing by just staying home. (Jim)

Jim and Marie's discussion emphasizes many of the points discussed in research findings. They gave their reason why going out into the community is important. Being busy and involved with their children is what being a typical family is to them. They acknowledged that they want to be like everyone else, with difference. They were frank about the amount of equipment and the physical work to deal with it. The easy thing is to stay home, but it was not what they chose.

In summary, this chapter comprises the parent's descriptions of their emotions about their child, the support they receive and their understanding of what participating in activities means. The parents in this study were supported by their spouses, their parents, their other children and by other extended family members. Almost half the parents in this study had ongoing daily support from grandparents for both their emotional and physical needs. Grandparent support and other family support, when it was available and suitable, was valuable.

In contrast, outside help for respite care is hard to find and cannot always be trusted to continue to provide quality care to the child. Three families did not organize any extra help
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above what would be considered typical babysitting. The children (Sarah, Jessica and Pete) of these families were high functioning in comparison to the rest of those in the research group. The three children could talk, eat independently and have some independent movement (two could crawl around the house, one used a power wheel chair outside the home). For families who did not have involved grandparents, or needed extra help in addition to grandparents, it was the mother who organized respite care and hired a person to help care for their child. Generally, the more areas of care (for example, mobility, feeding, toileting, communication) the more organized support was required (for example, paid respite help) and the more this was an important issue for the parent during the interview. The siblings, even though most of them were very young, were a source of emotional and practical support.

Striking differences existed between the role and activities of fathers and mothers. Mothers were the primary providers of child care and organizers of paid care giving support. Fathers' roles involved financially supporting the family. Although these roles and activities are traditional they are not exclusive. Many of the fathers did participate in some child care and several parents expressed a sense of shared responsibility for their children. One mother also was employed full-time and two were engaged in part-time employment thus also likely contributing to the finances of the household.

The parents in this study recognized not only that they were families with a difference but also, by doing activities, they were creating experiences they considered to be a part of normal family life. Some parents recognized that to be able to do activities they needed to adapt the activity or have the proper equipment. In contrast to studies that link families of children with a disability as being "isolated" (Cant, 1992, Gallagher, Beckman, Cross, 1983, Gray, 1997), isolation was not a theme for these parents. I believe this theme of being a "normal family" is very important to this study. The parents conceptualize being a normal family as being able to
go out and to participate in activities.
Participating in Activities

The parents in this research described how they and their children participated in activities. Parents had to consider the feasibility of an outing within the context of their family, in terms of their family size, health of the children and need for extra help. The first section deals with the conditions parents need to participate in activities outside of the home. These are the proper equipment such as wheelchairs and walkers, an accessible destination and appropriate transportation. The second section covers the strategies and adaptations to the activities to make the outing successful for the disabled child as well as other family members. These include having a person to provide extra help, planning both time and materials, and adapting the activity to make it suitable for both their child with disability and the rest of the family member.

Seeing and hearing the attitudes of others is also part of the experience of going out of the home. The third section is composed of parents descriptions of the attitudes of others. Many parents told stories of being stared at or their child being stared at. Both strangers and people who know them well have made insensitive comments. Dealing with social attitudes explains and builds on what parents have identified as the mental strain of going out of the home. Lastly, when the conditions are not all in place parents often make the choice for their child to stay home. Parents said it was easier to stay home because all the child’s equipment and anything else he/she needed was there. Staying at home was less physical work for the parents. The parents point out it is hard for them to discern the impact of their disabled child on the family’s participation in activities outside of the home environment.

Briefly I will set the scene of daily life for the families in this study. The lives of these families are composed of all the activity that comes with young children. All of the families in this study had at least one other young child in the household in addition to the child with the
disability. Having a child or two in the household who are dependent on help from an adult in all areas of self care, and other components of daily life, is not new to these families. Because the children with disabilities are between 3 and 5 years old, most of the parents, instead of their child growing out of equipment, are on the cusp of having to deal with "bigger" daily equipment such as wheelchairs and large car seats. In addition activities such as preschool or kindergarten, are happening if not for the disabled child then for his/her sibling. Living in suburban communities, places such as preschool, shopping centres, community centres, child development centres and other places were not within walking distance or were inconvenient to walk to. Thus the conditions needed and the strategies they used to participate in activities are like strings on a marionette. Each needs to be in place to be able to move and to participate in environments outside of the home. Thus the following themes describe each "string" that are part of parents daily lives. The first is about equipment.

**Equipment**

I never go anywhere without a bag full of stuff. (Marie)

All the participants except for one father had something to say about equipment. Their comments reveal how equipment is not only central to getting out in the community with their child but also demands a significant amount of physical work:

Whenever we go to a friend's house I feel we are packing to go for a weekend. We always take her walker because she does like to stand up now. If we'll be eating there, we'll take her little portable high chair, or maybe we'll be eating outside so maybe we better take the wheel chair, or maybe we'd better take the tray. Loading takes about 20 minutes or so with both of us helping. (Marie)

...always having to think about having the right food grinder, like a truck load of stuff if we need to take Thomas anywhere. (Cindy)

The amount of equipment makes it difficult to manage and organize:

I take him to the mall once in awhile. It's just such a pain because his stroller is so heavy. You have to take it in and out and every time you go to different store it's
the same thing, it’s so heavy. You put him in the car, take the thing apart, put it in the trunk. (Ann)

Handling equipment was also physically demanding. Three fathers expressed concern for their spouses’ physical well being, specifically their backs, due to the amount they had to lift and to carry their children:

(Equipment) makes our lives easier, but it sometimes, you know everyday it’s haul out the wheel chair, haul out the walker, haul out this. For a guy those things aren’t so bad, but I worry a little bit about Marie’s back and stuff like that, constantly lifting things in and out. Even lifting Katy, because Marie will typically be carrying her a lot more than I will or lifting her or whatever. So those things are a bit of a worry too, like what if something did happen to her back, what then? (Jim)

He’s (Dan) big enough and heavy enough that you just can’t go picking him up and putting him in and out (of equipment such as a wheelchair). Betty can’t pick him up as much anymore and stick him in different positions, as I can. Where I’m more of his arms and legs when I’m around. But for her (Betty), she needs this equipment in order to go through everyday life. (Lee)

She’s (Jane) getting a little heavy now and the women are having a hard time lifting her up so it’s better if I can carry her around a bit...there is times when I can spend alot of time with her. You know an hour here and there when she’s up, but there is a lot more times than not that I can’t and don’t do it. (Ned)

Mothers voiced concern for their physical well being:

I can’t let Pete go out in the front play ground because that means I have to accompany him, and he crawls or I have to strap him into the walker. So it’s not easy because Pete, he’s too heavy to lift all the time, my back just can’t cope, and he’s too old to just sit here and watch TV all the time. (Pamela)

There’s times it’s challenging and it’s hard. She always wants to be picked up and carried, and that’s tough to do because she is getting heavier. I don’t need to lift weights I have two kids I pack around a lot. (Marlene)

One reason for much work in many situations is the amount of equipment. Parents mentioned packing a range of items: food grinders, special food, tube feeding equipment, medication, standing frames, braces, wheelchairs and strollers, walkers and crutches, play pens, highchairs, toys and clean-up cloths.

Two of the families have lifts in their vans, everyone else lifted their children in and out
of the vehicle. Having a lift does not eliminate all the work of getting a child into a vehicle; however, it is relatively easier than the process Rhonda describes prior to having a car seat. Before she had the car seat, the seat on her stroller was also used as a car seat. One seat for two purposes meant more lifting than having two seats, one for each purpose:

She has this Snug Seat that fits onto a stroller frame, but it is also the car seat. But when you get it into the van it sits quite high in the van. So you get in the van, and then you have to lift her even higher to get her in and with her weight it was just really hard. If I was alone, I have to take her out of the seat, lay her on her back, take the car seat out of the van put it together (on the stroller base), and put her in the chair. Coming back is the reverse. Now at least the car seat is in the van you know I just take the seat apart and take it, at least its (transferring) from one seat to another. (Rhonda)

A strategy for one mother was to leave the wheelchair in the car trunk for storage as this meant less lifting for her and less equipment in the house.

Managing equipment presents a predicament. Parents need the equipment to be able to go out with their child but the very fact of having the extra physical work is bothersome. Parents expressed concern for the health of their backs.

**Accessibility**

The world is really in tune to people with disabilities now, I mean you have all your handicapped spots, you have wheelchair accessibility and that kind of stuff. I have never had a problem with taking Jane public. (Rhonda)

This quote reflects the positive tone most of the parents have when questioned about physical accessibility in the community. Like Rhonda, they stated that many buildings are accessible. However, most parents also had experienced a place that was physically inaccessible. In the following two quotes mothers described how they managed physical access to buildings:

If we are going out with friends, just making sure that it is somewhere where she’s going to fit into. We just went to ice cream the other day and there was about a million stairs up to the ice cream place. That was special. Dragging her up. Most restaurants are wheelchair accessible now so it’s not a big deal. (Marie)

...we were at a school and it wasn’t wheelchair accessible so she couldn’t get in, we
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couldn’t take the chair in so we had to carry her. A few of the older buildings aren’t changed. If you go downtown (town) there are some buildings that I can’t get into because they have stairs and so for the power chair forget it. But that’s because they were built before the code or whatever came in. So there is still a few of those around. (Carla)

These two parents point out that when they encounter a building with stairs they are able to either "bump" the wheelchair or carry their child up and down. In fact, three families lived in houses which had stairs to the main living areas and the parents regularly carried their children up and down. Ann said the thought of having to carry Cameron down to the garage, which was on ground level, and up again would deter her from taking him out. Carla and Ted lived in a two story home in which the bedrooms were on the second level, thus necessitated some carrying up stairs every day. Lastly, Rhonda and Ned’s home had five steps up to the front porch. Nonetheless, carrying or bumping up a wheelchair is a relatively easy strategies with a small child.

In the following interview segment, Betty describes Dan’s doctor’s office as inaccessible due to stairs. In this situation she describes how someone who happened to be there at the same time as she carried Dan up the stairs, then the doctor carried him down. For the next appointment her husband Lee was planning to come so he could carry Dan:

This is so crazy. Dan’s pediatrician, his neo-natal specialist has no ramp into his building, it’s all stairs. You know it’s crazy. (Betty)

How do you get him in, do you bump him up the whole way? (SM)

Well the last time the doctor carried him upstairs and carried him down. And his insert, you have to take his insert out and then collapse it, that’s not easy. (Betty)

How did that happen, that he (the doctor) came down, and is it 20 stairs or is it 5? (SM)

About 10. (Betty)

It’s about 10. (SM)
And they’re steep. This one time I had Dan, not his wheelchair (he was in) his stroller, a special stroller, and I couldn’t believe it, there just so happened to be a guy there at the time and he carried Dan up for me. That was really nice. (Betty)

Like another patient? (SM)

Yeah. It’s an office with a lot of different businesses and what not. So the first thing I said to the doctor was, ‘How come there is no ramp?’ He said, ‘Well, I’ll walk you out.’ And that’s when he carried Dan down. We have to see him at the end of this month and Lee is coming with me so he’ll probably carry Dan or I’ll carry Dan and it’s easy to do it that way. (Betty)

Again, Betty uses strategies to overcome barriers in the environment. She plans her schedule to make sure she has extra help. Lee will carry Dan up and down the stairs on their next visit.

Many parents mentioned specific situations when they had problems with accessibility, such as stairs or being places where the wheelchair areas did not suit their child’s needs:

You can’t take the wheelchair across the Suspension Bridge. There is the outside area on the one side of the bridge and I’m not going to pay only to see a third of the site. The Aquarium is nice, but it’s still very hard to get around there with a wheelchair because there are so many people and all of the things are way up here. (Pamela)

Marie describes a situation at the movie theatre where there is a wheelchair accessible spot but it is not in the right place for Katy:

They have this lovely little wheelchair spot at the back (of the theatre), but she can’t go back there. She’d never figure out where the screen is because it’s too far away. (Marie)

Marlene and Jon talked about how the playroom at McDonald’s was a distressing experience for Jessica because she got in the ballroom and literally sank in the balls, not being able to move:

Well, we went to a birthday party that she was invited to at McDonald’s last October, and of course, it was right in the play area. So she went in and she was playing in, with those balls. Because she can’t stand she just sunk and... (Marlene)

She just lost it. (Jon)

The poor thing she was in there crying, just sobbing. (Marlene)

Now you are an adult, and you have to try and get inside that thing and get her out.
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It's a job. (Jon)

The experiences of Marie, Marlene and Jon are specific to their children. Katy could not see a theatre screen from the back and Jessica could not move in the ball room. Jon and Marlene made the choice not to go back to McDonald’s because it is too difficult physically for Jessica and for them. Potentially, another child with a disability could enjoy being in the ball room or sitting in the designated spot at the theatre.

Carla describes an experience at a stadium where accessibility was problematic on one occasion because a large number of people were crowding the space in the elevator. The attendants acted indifferently and did not manage the crowd:

We were standing in line, and people were cutting in and going into the wheelchairs (space). The attendants are looking. And then when we finally get in (the elevator was) over-loaded and people were hanging over Sarah. I said, 'No more we can’t.' We go down the next level and people were cramming in, nobody is saying a word. And poor Sarah, I’m trying to give her some air, and when we finally got out of there I said, 'There is no way that she is going back there again.' (Carla)

In general physical accessibility into and around buildings is not a problem but many of them could think of a place or a situation that was inaccessible for their child. Parents also made choices about what activities they wanted to do and where. I only asked one father after he said they had not had any problems with accessibility so far if he consciously chose places that were accessible and he said "I think so, that’s true" (Ted). Marie’s comment at the beginning of this sections also indicated she made the choice, that was to "bump" Kate up the stairs. Cindy spoke about her family and how Thomas influences where they go but her other children have an influence as well. The deterrent to hiking is not just about accessibility:

We are very active people, we love hiking and stuff like that. We haven’t done a lot of that, unfortunately, because of Thomas, and I don’t like to blame him. It’s not really blaming him, but we have had to change our life style. That is frustrating because we love to be in the mountains, and we love to do that kind of stuff. Thomas just can’t do it. There is no way unless we hire a horse or something and pack him on the horse because he is big. I couldn’t carry him up a mountain. Sam
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could, but then we would have to pack Brad too. So we have changed some things. I think everybody does change things when they have kids... (Cindy)

Perhaps more parents thought this way and did not voice that perspective. I have more questions than answers about the parents’ descriptions of accessibility, for example: how do they feel about receiving help, do they expect every place to be accessible, do they feel excluded and what would they change?

Transportation

We often don’t get to do much...She (Lori) sees Pete riding (in his wheelchair) and so she has to ride as well, not walk. She wants to ride in the stroller, or even sitting on Pete’s lap, or she wants to be carried. She’s too big to be carried. Often times she climbs up on his lap, (I) push the two of them...There is so much close by here that I try and walk to everything. I go to the bank, or walk to the stores, sometimes to the market. (Pamela)

Transportation is an important part of being able to go out of the home. Like Pamela, Marlene explains why it is difficult for her to walk with her daughters, Jessica and Jen. They live across the street from the mall:

...with Jessica it’s tough because she likes to go over to the mall, and the malls are close but Jessica can’t walk that far with her walker so she has to be in her stroller...Well I have a backpack for Jen but she won’t stay in it... she won’t hold my hand, she won’t wear the harness, she just wants to go on her own. This is Jen. It’s too difficult for me to take both of them out unfortunately. (Marlene)

One of the reasons a vehicle is important was because parents need to respond to all the children’s needs. The rest of the families in this study used some form of transportation to leave their homes. All the families have their own vehicle; this was the most frequently cited mode of transportation. The issues that were important to families about their vehicle included accessibility into the vehicle, the size of the vehicle and parking.

Betty and Lee had a commercial lift put on their van. They decided to purchase a lift for themselves after they saw another family using a lift in the parking lot of the Child Development Centre. Betty and Lee contacted several agencies via letters and finally received funding through
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a radio station. They were interviewed before they received the funding. Yet even though the lift was valuable to Betty and Lee, Lee described how it was not an easy process:

This lift is beautiful, but they have to modify these straps (tie downs). Betty has to bend herself in and out to hook him to the front of the wheelchair and to the back. I mean if it’s raining out it’s awful, she’s a mess. It’s hard, he (Dan) only has so much patience, he gives you that time and then he starts to get upset because he doesn’t know what is going on. So all of a sudden you are racing to beat the clock. You get the van running to get some music on so he’s familiar in his own thing... It’s like going in (the garage), opening up the door to the car, hopping in (and saying), "hey lets go." (Lee)

One father built a ramp himself to fit on their van. All the other families lifted their children in and out of the vehicles.

An issue for Fred and Ann was the size of their vehicle:

So virtually when you have a handicapped kid, you have to have a big expensive van because you have to take so much (stuff with you). (Fred)

His stroller takes up my whole trunk of the car. It’s an ’88 (model), so when we go grocery shopping we have to either go without everybody, so I can put the groceries in the back seat, or we have to put them on the top of everybody. (Ann)

Parents, since they were mainly using their cars, also expressed the need for accessible parking. Two parents spoke about the problem with people who do not have a disability using handicapped parking and the insufficiency of handicapped spots:

A couple of times I’ve pulled up to a place to use the handicap spot and one of the two handicap spots is used by someone who is not handicapped...somebody stays in the car and somebody goes inside....I think that is pretty rude. (Pamala)

People are so bad at parking in the handicap spots, and they just don’t realize that when you have a lift you need it for the width. It’s not so much that you need to be close to the building, I just need that space. (Betty)

There was less consistency in terms of use of other modes of public transit such as buses, taxies, HandiDART, ferries and planes. HandiDART is a publicly funded, accessible, door-to-door transportation service for persons with disabilities. Most families did not use public buses; however one family used them regularly without difficulty. Marie described a difficult situation
when she rode the bus with Katy:

I had her in a stroller, I thought, 'Oh, I’ll just leave her in her stroller, because she was really hard to get in and out because she is really long, getting her out of the stroller was kind of difficult.' So we just got on the bus and on the way there the driver said, "You will put the breaks on that won’t you." 'Oh, yes I will.' But he didn’t help me at all, he just sat there and watching me struggle up the stairs and stuff. On the way back the guy (driver) said, 'You can’t bring that on the bus. You can’t have her in that stroller on the bus.' I said, 'Well, I came with her like this.' He said, 'No, these rules are the correct rules the other guy let you get away with something, and I won’t.' And I just thought, 'Oh,' and he waited until I got her out and sat her down on my knee. I thought, 'This is something that I wouldn’t do again.' (Marie)

Patty, who was cared for by her grandmother, regularly used public transportation. They lived on a wheelchair accessible route and this made it possible to use the bus often enough to become comfortable with it. Patty and her grandmother took HandiDART everyday to the preschool. However, Patty’s mother recounted an occasion with a handicapped accessible taxi. The driver did not know how to use the lift:

...we asked for a handicapped cab, the guy (driver) comes up and he doesn’t know how to work the lever to make the thing (lift) go down. He has it half way down, and we (parents) had to lift Patty up onto the thing(lift platform), then push her up (into the van). He didn’t know how to put the seat back up. It was the worst time that we have ever had. (Sue)

To a certain extent the parents' bad experiences, at least in these two situations, are not because the transportation is inaccessible but rather because other people are not helpful or do not know how to use the equipment.

Riding a ferry was a less routine trip than going shopping. Nonetheless, parents shared their experiences. One family had a positive experience and one family had a negative experience. In the positive experience the parents told the ferry personnel that they had a child with a disability when they bought their ticket. The ferry personnel then instructed them to put on their four way flashers and to line up in a specific lane. When they boarded the ferry in their van, a ferry staff person was there to help them. The family who went as foot passengers had
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a negative experience. The terminal was under construction and when they disembarked they had a long walk due to construction and it was night time. The combination of the long walk and the darkness was difficult for this family. I am not sure if they told ferry personnel that they had a child with a disability. Only one family sent their child on a plane, a positive experience for them.

In summary, parents use what is easy, flexible and the most familiar to them, that is the family vehicle. When they used their own vehicle, accessibility into the vehicle, the size the vehicle and parking are important issues. Most parents could describe a situation that was frustrating about inaccessibility and/or poor transportation but the overall tone and the amount of time parents talked about these event was much less than the strategies they used to actually go out and about with their children. The issues of transportation and accessibility are however, two factors that contribute to the parents considerations of when, why and where to take their child out of home. Like the strings on a marionette, all of the factors must be in place and work together to allow going out of the home to be successful. In saying the parents talked about transportation and accessibility less than the strategies they used to actually go out of the home, I do not want to minimize the overall importance of transportation and physical accessibility for parents going out with their children.

Strategies and Adaptations

I take him in the wheelchair and I’ll zip him around in the wheelchair. If it’s too hard then I’ll carry him, but I make sure he gets out and he does what we have to do. (Lee)

The families in this study are typical families in the sense that; some families went out often and others chose to stay home. Table 2 lists all the places parents mentioned going and, roughly, how frequently it was mentioned by parents. When I started to analyze the data I read through and listed the situations that positively or negatively influenced a parent to take their
## Table 2. Places Parents take their Children

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Over half of the parents stated they went to these places for an outing.</td>
<td>Child Development Centre&lt;br&gt;Homes of family or friends&lt;br&gt;Preschool or Daycare&lt;br&gt;Parks/Beach&lt;br&gt;Mall/shops&lt;br&gt;Hospital/medical appointments</td>
</tr>
<tr>
<td>Five or less parents mentioned these places as outings.</td>
<td>Swimming pool&lt;br&gt;Restaurants&lt;br&gt;Camping</td>
</tr>
<tr>
<td>One or two parents mentioned these places as outings.</td>
<td>Grocery store&lt;br&gt;Horseback riding&lt;br&gt;Bicycle riding&lt;br&gt;Bowling&lt;br&gt;Science World&lt;br&gt;GM Place/Aquarium&lt;br&gt;Church&lt;br&gt;Water slides&lt;br&gt;Baby sitter’s home</td>
</tr>
</tbody>
</table>

"Parents" includes the outings of one family described by both or either the father and the mother.
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child out of the home which Table 3 summarizes. Some went to many places, some to just a few. Each family had a set of conditions they considered before they made the decision to go out with their child with a disability, a trip that perhaps included other children in the family.

The following sections categorize the strategies that make it possible and/or desirable for parents to take their children out of their home. The strategies include having extra help, planning, and/or adapting the activity.

Extra Help

I often think that if I won the lottery, the first thing that I would do is have an aide come stay (with us). (Betty)

One of the most common themes that eased going out was if there was extra help. Extra help means more people available than just one parent to attend to the child with the disability and/or the other children. This could be both parents, or a grandparent and parent, or an older sibling and parent. The rationale for having more people is to have more help to manage the child and equipment. The grandmother of Patty, who was present during the interview, explained how they all went swimming. Patty, who has cerebral palsy is the second oldest in a family with four children under the age of six. Trent and Brenda are Patty’s parents. They mainly care for the other children and the grandmother cares for Patty.

Two other families also described how they take their children swimming:

We have gone to the swimming pool once this summer. That was a bit too much effort. I have to take another girl with me, a teenager. Pete was in a life jacket just to make sure (he was safe). It was okay, but it was an ordeal. (Pamala)

Betty commented that they try to do as many family things as they can because then both she and her husband are available to help with their two children; swimming is just one of several family activities:
Table 3. Situations which Positively or Negatively Influence Parents to take their Children Out of the Home

<table>
<thead>
<tr>
<th>Positive Situations</th>
<th>Negative Situations</th>
</tr>
</thead>
<tbody>
<tr>
<td>- equipment that makes the process easier, such as van lifts, wheelchairs</td>
<td>- no transportation</td>
</tr>
<tr>
<td>- extra help, such as both parents, grandparents, hired help</td>
<td>- other children in the family</td>
</tr>
<tr>
<td>- extra help and physical accessibility at the end of the destination, such as a one to one worker and barrier free preschool</td>
<td>- the child’s vulnerability to getting sick</td>
</tr>
<tr>
<td>- physical accessibility, such as the mall</td>
<td>- thinking the child does not benefit from that outing</td>
</tr>
<tr>
<td>- wanting the child to have a change in their day</td>
<td>- considering the cost of the outing versus the child’s participation</td>
</tr>
<tr>
<td>- when people at the destination have a positive and inclusive attitude</td>
<td>- the physical work of carrying/transferring the child and dealing with equipment</td>
</tr>
<tr>
<td>- when another child in the family is going somewhere and the sibling with a disability joins him/her</td>
<td>- individual child characteristics, such as the child’s weight, the child’s impatience and the child’s crying spells</td>
</tr>
</tbody>
</table>

Taking Dan with us is a challenge. We try as hard as we can, like we’ll go to family skating. As long as Dan is moving he’s fine. We’ll go swimming too, as a family. We try and do as many family things as we can. (Betty)

These comments indicate how important extra help is. In contrast to these comments, Betty describes how her husband took both of their children swimming on his own, only to find out
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about a change room designed for persons with a disability, as they were leaving the pool. Betty said "so apparent" in an exasperated tone, implying that people do not understand the "work" of having two small children, one with a disability:

This isn’t too long ago, he (Lee) took Dan swimming...So Lee took him with Richard and of course Dan’s batteries ran out (for his tape recorder), and he was crying and Lee is trying to change him and himself and Richard. Lee said, 'You know all these men are standing there and nobody is helping me. You know you get flustered.’ After all this he’s dressed and Lee looks at Richard and his shirts inside out but Lee don’t care. We are just leaving the building. The lady (at the pool reception) said, 'You know there is a handicap change room that you could use.’ Then Lee said to me, 'She told me when I was walking out, couldn’t she have told me that (when I was going in)? I mean it’s so apparent.’ (Betty)

Parents also referred to the frequent outings such as going grocery shopping and why they would or would not take their child:

Pete loves to go grocery shopping. I put him in the cart and Lori (sister) sits on the other side. (Pamela)

While Pete loves to go shopping, many parents did not want to take their children shopping:

So the usual weekend is probably made up of all the usual stuff that everybody does from going to the mall, to getting groceries. For those trips we might go more where Marie or I can go instead of going as a family just because we can get in and out faster. Like going to the grocery store isn’t much fun for anybody so it’s not the kids are missing anything. So we’ll probably do that more on our own than we might typically. (Jim)

Like going grocery shopping, if Thomas was a normal 3-1/2, 4 year old it wouldn’t be that hard because you wouldn’t have to put him in a walker or you wouldn’t have to put him in a wheelchair or a buggy or anything. Charlene has to be carried and Thomas has to be carried, so one person can’t go grocery shopping. In a normal family you probably could. (Sam)

I can’t go grocery shopping with Dan or anything like that. I can’t do errands, it’s just much too difficult. And with Lee working afternoon shift it makes more sense to wait until he wakes up, and then I can go do errands on my own. So, other than going for walks or to school, I usually wait until Lee’s around so we can go out as a family. (Betty)

Having help on an outing obviously makes it easier. Two of the fathers above imply they might do these activities more if their children were not disabled. Parents may organize the schedule
to facilitate having another person, usually the spouse, available. Betty says she plans times to shop when Lee is available to be at home with Dan. Planning is a strategy other parents use too.

**Planning: Time and Materials**

...as far as taking her out, if you have the right equipment and you have the right support and you are able to plan, I mean you just don’t go out, you have a plan, but if you plan properly, you can do all the things that you need to (do). (Rhonda)

Rhonda’s comments highlight the point that the parents plan and organize for outings. Planning involves organizing equipment, time for feeding, time for exercises and other situations. Time management seems all the more critical to some of these parents because, for example, they know their child cannot feed him/herself or indicate that he/she is hungry. The parents must make time to ensure that they feed their child.

Rhonda described how she spent time at the mall with a friend and then, at home, combined Jane’s morning and lunch gastro tube feedings into one. Tube feeding can take hours depending on the amount of food and rate of feeding, many children are fed their main meal during the night. By combining the two feedings she was able to stay out longer than she could have otherwise. Rhonda said she would have been able to stay out even longer than they did but because Jane was getting irritable, they needed to go home. Rhonda asked her friend to go to McDonald’s to get lunch and she took Jane home to start her tube feeding. The plan was for their other children to play in the backyard:

... a girl friend met us at the mall and we went shopping...then we all went back to the house so Jane ended up on a, a juice feed from 1:30 to 4:00. So instead of getting two juice feeds I gave her one, and we kinda got all the juice in one sort of stretch. And it worked out just fine. But I had planned to meet that girl friend too so it was all in the plan. We would have stayed out longer except Jane was starting to cough, and she was getting irritated sitting in her chair. And so it was just okay look, ’You (friend) go drive through McDonald’s and get lunch and I’ll go back to the house and the girls can play in the back. And this one (Jane) can go on her feed.’ (Rhonda)

Rhonda planned the outing with her friend in advance, organized who would get lunch and
changed Jane's feeding schedule to be able to spend time with her friend at the mall.

Ann spoke about how it is difficult to stay in a routine on holidays because time seems to go so fast. Ann's strategy is to not do the things she normally would do at home:

When we go (on a holiday) he usually never gets the splints on. He doesn't do any standing. We totally go off a lot of stuff when we go on holidays because it is just too much to remember. Time goes by and it's different when you are at home and you know your routine. (Ann)

In Ann's situation, she decided not to include activities she normally would have done at home because it is too much to remember, and there is not enough time. Several of the parents spoke about how important planning at home was for an outing later on. Planning facilitates 'more time' later on:

What I'm doing now is planning the night before. I think a lot of it, especially with a child with a disability, is if you are organized it will make things go that much easier. (Betty)

When we are getting up to go, I have to make sure there is enough time because if she hasn't been fed properly then obviously the day has been lost. And she can't just eat in the car because she can't feed herself. So I have to stay home until she is fed. So that is a priority. So we usually get up fairly early if we have to go out. About an hour an a half before we are leaving. (Marie)

Marie describes how they feel their life pace has "slowed down" because they need to take time to attend to Katy's needs, especially feeding. Both Marie and Jim are aware that they cannot rush like they normally could. Getting ready takes "extra time":

I feel that we have slowed down a lot in our life style since she has been born. You realize that things have to take longer, and if you are late, you're late. Like that is just the way it is and you don't get stressed about it because there is too many other things to worry about. I mean we try not to be really late for things that we should be on time for but things are a slower pace. And she doesn't deal well with rushing, like she does get a little bit frantic when you try and rush her too much, like when you try and get her clothes on too quickly or rushing around with her, she doesn't like that. She seems a bit frantic, so we try to allow extra time so that she doesn't have to be rushed around. (Marie)

So you are rushing from one place to another and Katy can't be rushed like that and certainly at noon or whatever she needs to eat. And you can't like a normal 3 year
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old just throw her a snack in the car and say, 'Here have a snack bar or a muffin, you can eat this and we'll get some lunch later or this will tie you over till dinner.' Because obviously she can't feed herself and it will probably be a long time before she can. (Jim)

Parents change the schedule and plan to meet their needs as well as their child's, for example allowing more time to prepare the child for an outing. Parents also emphasized the importance of planning ahead and managing their time to facilitate going out with their child. Carla spoke about planning ahead for several reasons, i.e. where they go out in terms of washroom accessibility and what equipment to use on a school outing. She needed or had information before she went out with Sarah:

I won't go into a store downtown because the washrooms are down stairs and there is no way that I'm carrying her upstairs. So I won't go there... they have one accessible washroom... Some of the stalls aren't wide enough to get her and her wheelchair in. You just have to plan ahead. Like she's going to the apple farm on Thursday and it's supposed to be gum boots (the teacher requested the children wear gum boots). She wanted to take her power chair, and I said, 'If they (teachers) are asking of gum boots I don't think we are going to take the power chair.' (Carla)

In some situations the type of activity may determine how the child participates or how the parent plans for the activity to work for their child.

**Adapting Activities**

Parents make choices about the kind of activities they do with their child. Often past experiences have taught them to pick activities that can fit or can be adapted to fit their child's needs. By adapting the activity the children with disabilities can participate with other family members or be involved in the activity themselves. Two fathers explain how their families chose the activity to include their child with a disability:

...we go to the back road places... places up in these mountains that you can go to... where Jessica can get out and throw rocks and do that type of things because she likes doing that... We improvise different things. (Jon)

But most places we sort of just adapt. Like if we go for a walk down at the (Quay) or something down at (Town) Jason will take his bike or his roller blades, and I have
roller blades too, so we’ll do that. Katy will just be in her wheel chair, and we’ll all just sort of go. But so we try and adapt, I guess, what would be a normal walk. (Jim)

Jim explains how they make some changes in how they go camping to include Katy:

This summer we’ll go camping...that changes things a little bit because you have to be very aware of Katy and you have to find a place to put her in the shade, again because she is not running around so you have to find a place that is cool for her to sit...you adapt but that doesn’t mean that we don’t go camping it just means that we have to take more (equipment) with us and be aware of all of her needs. (Jim)

Being aware of the child’s needs is essential to being able to plan where the family goes and what kind of equipment to take along:

We have a special floatation device that we have for her and she sits in that thing and goes out in the lake and stuff like that. (Ted)

Planning includes organizing time, equipment, where to go and who goes along. Who participates in the family activity is not straight forward. Parents must balance out the needs of the other children in the family as well as the needs of the child with a disability. The following three descriptions are of situations when the family has decided to split up to allow everyone to participate in an outing. In the first situation Jim explains how Katy goes to the grandparents to allow Marie and himself to go to the water slides with their older son, Jason. Jim says that it would be "inconvenient" to take Katy so she spends time with her grandparents. Although Katy is not going on an outing with her parents and siblings she is going to her grandparents’ house:

There is places like...the water slides with Jason once a year and we have done that the last couple of years. We have left Katy with her grandma and grandpa on those days because it would probably slow Jason down. Jason is not at the age where we can just sort of leave him to go off on his own. And Katy can’t go on the slides obviously, so that’s a little bit inconvenient. (Jim)

Carla explains how Sarah and she stayed at their campsite when others went hiking. Although Sarah is not participating in the hike she is participating in their camping experience:

Oh, when we were camping they went on a hike up to a water fall, well her and I just stayed home (at the campsite) and we wrote post cards. (Carla)
Cindy, who has three children, explains why going to church is an "ordeal:"

Okay, because we have to get them all ready, nicely dressed, sort of, or somewhat dressed nicely. That's the big part...usually we sleep in, like 8:00 or whatever, 8:30 so it's kind of stressful because we have to feed everybody, and then dress everybody, and then get the wheelchair in the car, and throw the kids in the car and get to church by 10:00...Then at church, anybody with kids, you've got Charlene who wants to jump around, and Brad wants to go and play with his friends, and Thomas doesn't really care, he just sits in the wheelchair and is happy. But, by the time we get home it's lunch time again and then we have to pump food into them all and get them down for naps. Then the day is almost over. (Cindy)

Parents made their choices on where to go based on the child's needs as well as those of other family members and the equipment required. For example, Jon and Marlene decided that throwing rocks in a brook is a better choice for an outing than going to a park with play structures. For her parents and Jessica, climbing on play structures is too frustrating and not an enjoyable outing. Where to go is important. One family chose to go camping, and to do that they needed to find a spot that was shady for their child to be comfortable. When they go for a walk they need to have her wheelchair and a flat walking surface. The quay is that place. Equipment is also necessary. For another family, including their child in boating and swimming meant they needed to have the right seat and floatation device. Lastly, parents make decisions about who does what to include everyone in the available activities. The needs of all those in the family need to be balanced.

The process of deciding how to include the child with disability is complex. In the above examples the parents need to consider many things: the child, the siblings, the place where they go, how they get there and who goes along. They need to consider the child's health. In deciding where to go they need to consider the equipment they need to take and the accessibility for using that equipment. Additional planning needs to happen if not everyone is going on the same outing. Other conditions not necessarily born out of these examples, include such things as being able to afford to go out, or accessibility to the right equipment. The complex task of
trying to figure out where to go and how to include their child with a disability might totally squelch all the energy needed to actually get out of the house. Going out does require physical work and just the thought of all the work involved to go out might, sometimes, be a deterrent.

Social Attitudes

"I look at it this way, who’s the ignorant one?" (Marlene)

This quote reflects two of the main themes in the parents’ experiences with people when they are out in the community with their child. For Marlene, "ignorant one" was the person who did not know what disability meant. Gestures such as staring or in some way reacting to the child reveal a person’s attitude. The parents in this research describe how, in some situations, they experience the reactions of other people, mainly strangers. The parents see people staring at their child. They answer people’s, especially children’s, questions about their child. They also sense or know peoples’ fears because they have felt that way themselves but have changed as a result of their child. The insensitive comments are hurtful. Other peoples’ ignorance is sometimes, but not necessarily, viewed as a negative experience.

Cindy spoke about the attitude of others, as did two other fathers. They feel other people view their child, not on an individual basis, but rather as the collective response to persons with a disability. Cindy told me how she was trying to explain to a family member: Thomas is her son and she does not have a preference for her other children or for Thomas because he is handicapped:

I tried to explain it and I said, 'If there was a burning building and they were both (Thomas and Brad) in it, I wouldn’t go to Thomas before the others because Thomas is handicapped.' I think our society thinks is that they are less people than the normal person.

Jon shared his thoughts when we were talking about physical accessibility:

Disabled people will always be disabled from everything really. Their life will never be easy unless they fight for it. I don’t think, whether it be the provincial
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government or the federal government to make disabled child’s or adult’s life easier. I really don’t. I think you are looked down upon if you are disabled...we didn’t catch the whole thing (news item) on the news the other night, but they were talking about that class room that they want to put into a school...something about disabled kids going to be in this one classroom because it had an elevator in it. And they don’t really want it. The normal kids, like the parents of normal kids, they don’t want disabled kids around them. So it will never be, it will always be a fight for disabled persons, forever. Well that’s my opinion. You never know.

Ned too, who does not take his daughter out to participate in activities, shared his thoughts about persons with disabilities and how he questions his own role with his daughter:

See, when I grew up as a kid, I avoided people like that, that had disabilities. The reasons were probably selfish because it wasn’t from the lack of love or interest of these people...it was because I didn’t have time. I didn’t have time to be involved. I was too busy doing things...But with Jane, I love her dearly, but there is just that part of me that said I never wanted it in my lifetime, unfortunately it’s been forced onto me but how far do I have to go to deal with this?...does that mean I have to shut out my entire life and completely change everything I have worked so very very hard to do, and change all my ideas and everything to deal with this situation now? Is that fair to the rest of my family, relatives and friends and business and employees and everybody else?...Is that unfair to Jane that I don’t do this? (Ned)

Parents have different notions of how other people should respond to their children. Cindy spoke of the values others attribute to persons with a disability. Jon’s opinion echoed Cindy’s point and added the concept of persons with a disability having to fight for their place in society. Ned speaks for himself. I will take this opportunity to inject some of my own thoughts, to be introspective. Although I believe there are many people in society who would say something like what Ned has said, I cannot help but feel angry. As an occupational therapist, and as a person, it is very difficult for me to think someone would not be patient or understanding of someone who is disabled. I often view a child with a disability as a mystery, someone to discover and enjoy. My view is of "the other". I do not have to deal with the concept of, "I never wanted this to happen in my life, will I have to change everything?" My anger prevents me to see and understand the depth of Ned’s own anger and resentment. Ned statements and others have shown me the range of responses by parents.
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Parents see, hear and interpret the actions of others towards their children:

Most people look at him like... (Ann)

What a weirdo. (Fred)

Like a freak. (Ann)

Okay so they know (he has a disability). (SM)

I think so because he screams a lot when he’s in his stroller, he’s so excited. All he does is scream. (Ann)

And you get a lot of dirty looks. (Fred)

And people like look at you like (they are thinking), 'Shut up your kid.' There is a few people that will smile, but it’s mostly people that know. (Ann)

Elderly people. (Fred)

Cerebral palsy. Well I don’t know there has been a couple of old ladies there. (Ann)

And they’ll (old ladies) say, 'Oh my isn’t he having fun.' Well yeah he is. (Fred)

These quotes highlight that people stare because they are looking at something different, in this case the screaming child’s. Fred and Ann interpreted the stare of people who look at their son as "freak" or "weirdo". Being stared at is part of what makes their family different. Many of the parents spoke of other people staring at their child:

If you are going to sit and stare fine, go ahead, like if you have nothing better to do but to sit and stare at a child or whatever that has a handicap, I know, I guess ... (Marlene)

If it makes your day to stare at her I mean. (Jon)

Yeah. (Marlene)

That’s just the way people are. (Jon)

Yeah. They do, but it doesn’t bother me anymore, not at all. (Marlene)

Marlene stated people’s stares did not bother her anymore, it implies that at one time it did. Over time parents might become more skilled in responding to others. Rhonda describes in more
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detail how she changed over time:

If it was three years ago, when she was really young, I found it very hard to take her out. I was very conscious of her. I didn’t want people to look at her, I didn’t want people to feel sorry for her....And its like, 'Poor little girl.’ She is not a poor little girl you know she is Jane. I mean you know it is funny how my attitude has changed within this span. That would have really bugged me way back when she was really little. And I am not even afraid to hook her up to her feeds if we are out now, it doesn’t phase me at all. (Rhonda)

Rhonda does not appreciate people who look at her child with sympathy. She has overcome her self-consciousness or fear of feeding Jane through the gastro tube in public:

We don’t feel embarrassed or feel bad...say we are pushing Dan along in a wheel chair and people are gawking at Dan and wondering what his problem is and, 'Oh we feel sorry,' that doesn’t even fizz us any more. We don’t even think of him as a problem, there is no problem, there is nothing wrong with him. Like that is the way we feel, he lives with us and he’s a part of our lives and no big deal. I mean at one time there was a little bit of that, where you felt very awkward. (Lee)

Lee, like Rhonda, does not want people to feel sorry for his son. Both parents, over time, had learned to "manage" the stares and reaction of other people towards their children. Other parents also commented on how their attitudes have changed about seeing people with a disability. They are more accepting of other people and their child. They do not want people to feel sorry for them or their child. Betty made two significant points in the following quote. First, how children, more than adults, come to ask her questions about her son. Secondly, how she continued to have an underlying fear of other children with disabilities. Her fear is not knowing how to respond to a person with a disability:

I’ll take Richard and Dan to McDonald’s because Richard can play with the kids in the ball room. So many little kids will come up and say, ’What’s wrong with that kid?’ and it’s so nice because you can tell them. After you tell them that they want to know what he is listening to because he always has his head phones on. You’ll tell them and they think it’s neat and then they walk away. I just love kids because they are so honest and straight forward. I find parents, I don’t blame people because maybe I did the same thing, people stare because they don’t know. And you know if you see a child that is disabled, even though I have Dan and I see another child, it’s scary. You know, you just don’t know what, because every child is different. I don’t know if I went up to another child and said, 'Hi' if that would upset him.
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It’s not so much ignorance I think it’s fear. I think of that a lot when I’m out. (Betty)

Carla tells the story about when her two nephews came to visit and they noticed the number of people staring at them. She is very straight forward about her preference to have people ask questions rather than stare. This again is an example of the assumption that people stare because they do not understand and/or are curious. Carla, similar to Betty, noticed that children ask questions more frequently than adults:

I have two nephews who are 13 and 14, we went to a camp, a Provincial Park, (they) come up to me and (said), 'The number of people who are staring at us.' And out of the ones that ask most of them were little kids. They come up and say, 'Why is she in that chair?' And even the boys (nephews) said, 'Doesn’t that bother you?' I said, 'No, I’m used to it now. In fact I’d rather have them (other people) come up and ask me than stand there and stare. And then if they have the nerve to ask me then I’ll just tell them.’ Especially for adults. But for kids if they have the nerve, I’d rather have them come up and ask me than stand there and stare and point. (Carla)

Parents not only responded to others’ stares and questions but also to others’ insensitive comments. Jim relates the story of being at a school concert where a woman makes an insensitive comment about their child not being able to run around and how that must be nice. Jim says even though this comment could hurt their feelings because of what "running around" means, they accept this comment as ignorance "she certainly never intended to make that comment."

We were at a school concert I think it was one of Jason’s. We had been holding Katy through the concert, this was before she had her wheel chair. One of the other moms was talking to us afterwards and I guess lamenting that her son had been running all over and she had been trying to corral him. She made the comment that, 'Oh it must be so nice to have Katy that she doesn’t that she doesn’t do that.' And it’s like, 'Oh if you only knew what we would give to have Katy running around, causing trouble at something like that.’ Those sort of comments, sort of hurt and yet nobody really knows. And there is no real point of making a big deal out of that because she certainly never intended to make that comment. (Jim)

Betty also described a situation at a school picnic, when a few mothers made an comment about
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her family. I did not inquire what was the comment. Betty is hurt and emotional about the comment, she thought these women knew her situation and about her family. She talks about her "guard" being down, as if in most situations she is protecting herself from insensitive comments that could hurt her feelings. Similar to Jim in the previous quote, Betty believes the hurtful comment was unintentional:

All the families are there and these two ladies that I had talked to throughout the whole year. I thought they understood our situation and how we try and be as typical as we can as a family. They had said something. It hurt so much, that I just broke down. It was a good thing that I had my sun glasses on because nobody was aware that it had upset me. I said to my mother-in-law later, 'I think because my guard was down. Usually I'm prepared and I'm ready for it but I just wasn't expecting to be hurt that day.' It was awful...It took a long time to get over that. And I don't know why, why I get so hurt? I don't think they meant to, I think they would feel bad if they thought that they hurt me. (Betty)

Lastly, Cindy is eloquent and accepting about people's stares as inquisitiveness about difference. Their son looks different, therefore, people stare. Again she, like the other parents, talked about what she knows, she knows there is a difference between her family and other families and because she knows she is accepting peoples stares:

You know he has a gastro tube and it sticks out of his stomach and I give him water through it and people would be staring at us and I don't care it doesn't bother me at all. Sam and I, it doesn't bother us to have people stare at us because we know we are different and we know we have dealt with all that. (Cindy)

The parents spoke of situations when they experienced people being rude or insensitive to them. These parents experience other people staring and insensitive comments because some characteristic of their child sets them apart from "normal" whether that be the child screaming, riding in a wheelchair or being fed by a gastric tube. These characteristics of disability are what people stare at or ask questions about or seem fearful of. And, therefore I would describe the parents' experience of being stared at or people's insensitive comments as part of their experience of being out of their home environment with their disabled child.
In addition, I think it is important to recognize that the parents in this study acknowledged that people stare; they might have done that too in similar circumstances; they recognize their family as different from typical families. The parents attribute other people's actions as ignorance because other people do not know about disability, and they could be curious. Children are often the ones to ask questions which are welcomed by several parents. If people ask questions, it give the parents an opportunity to explain their child and dispel obvious assumptions.

Staying Home

Participants in the study recounted many situations in which, because of the conditions surrounding the child with the disability, staying home is the best choice for them. There are family specific reasons for not taking the child with a disability out. For example, Jon and Marlene had only one vehicle which Jon took to work. If Marlene needed to use the vehicle, they all packed up in the morning and she drove Jon to his workplace. She then spent the day doing errands and stayed at her mothers home, which was closer to Jon's workplace, and picked Jon up at the end of the day. Since Jon did not always have the same workplace this arrangement was only suitable on specific days. Sam and Cindy and Trent and Sue did not go out because of the number of children they had to manage, three and four respectively. There are also child specific reason why the child with a disability is not taken out of the home. For example, Ned mentioned just the potential of Jane getting sick is enough of a reason for them to keep her at home.

Betty described several times how Dan's impatience and crying deterred her from taking him out on her own. The conditions surrounding the child, such as the support from extra help, the right equipment, the available transportation, the accessible environment, the suitable or adapted activity and the plan need to fit together, like the strings on a marionette, to allow going
out to happen.

When the conditions surrounding the child are not all in place staying home is the choice of parents. By staying home, parents do not need to deal with transportation and the demands of a different environment (stairs, where to park the wheelchair). The equipment is all present and known to the child and the parents.

In fact, staying home is a strong theme. Many of the parents, even those who described themselves as going out often, described how in some situations staying home is the sensible choice, mainly because the equipment is at home and does not have to be hauled around. Lee, Jim, Cindy and Sam describes how they socialize:

Our visiting with other people is harder, we would rather have people come here, it’s a lot easier for us. We have everything here for Dan, and it’s not a problem. (Lee)

If you go with friends you have to try and remember to lay her down and let her get some rest because she gets over tired. It’s just a whole lot easier if friends come to our house as opposed to us going to their house just because of all the equipment we have to drag around with her, her walker or her wheel chair. (Jim)

We stay home an awful lot. So going out with the three of them, sometimes we go to the mall. It’s a lot of (work), we have to pack the wheel chair and buggies and all that stuff if we go to the mall. Not very often. (Cindy)

Normally Thomas doesn’t impact where we are going to go. Maybe that’s not true, I guess we could do other things, but we don’t know any different. If we didn’t have Thomas we might go out more, it’s easier at home. (Sam)

Having one family vehicle, which the father takes to his place of employment, impacted on how much the mother and her children went out:

Grocery shopping, we take them with us when we go, but it’s hard with only one vehicle. I don’t get out a lot during the week with the kids. (Marlene)

Rhonda describes how staying home with Jane while her husband Ned and daughter Rose go out to the beach is a "sacrifice". She struggles with balancing the needs of both her children. Rhonda also points out that she need to plan for a baby sitter if she wants to go out with Rose
and Ned. Although Rhonda see the benefits of being able to get other things done around the house that she might not have accomplished otherwise, staying home is still a "sacrifice". In this quote Rhonda is conscious of Rose’s needs and the need to balance Rose’s wants in addition to the other needs within the family:

So I mean I sacrifice a lot. A lot of times I’ll just say to Ned, 'Okay you and Rose go and do that’...Because its not fair to Rose. And that is really hard sometimes is balancing it out because it is always, 'Well, no Rose, we can’t because of Jane.' You know and she struggles with that. And so I try sometimes or most of the time to say, 'Well, okay, you guys just go ahead seeing we can’t get the baby sitter...' (Rhonda)

Staying home is the choice of parents when they weigh the factors involved in taking their child out. The conditions need to be right to take the child out of the home; when they are not in place, staying home is the choice of parents. Staying home is easier because equipment does not need to be hauled around; transportation is not needed; or physical accessibility or needing extra help to supervise other children in the family are not necessary. Staying home also eliminates the "emotional work" of going out discussed earlier in this thesis.

In summary, taking a child out of the home to participate in activities is a complicated endeavour. Child specific conditions such as the child’s health or need to be fed may also constrain the family from going out of the home. As well, family specific conditions may impact on going out such as having a large family, balancing the siblings’ needs or the availability of one family vehicle. The level of enjoyment varies between a trip to the hospital or a trip to the swimming pool but the conditions essentially need to be the same: case in point, Ann, who waited until the weekend to take Cameron to the hospital because on the weekend Fred was available to help and possibly stay over night at the hospital with the child. For many parents the physical work and planning involved to take their child out of the home is not the difficult part, although it is an important part of an outing. The emotional work is the most difficult. The participants’
accounts show that participation in activities demands both physical work and emotional work.

Social and physical environments are interwoven. The social attitudes are complex. Not only do society's values seem to permeate their lives, but the parents themselves have their own values and concepts of how others, and they themselves, view children with disabilities. Other people stare and make insensitive comments. These parents of children with disabilities manage others' responses to their children by justifying the comments and ignoring the stares. Stares and insensitive comments cause mental strain or emotional work when going out. Some parents know that people were staring at a behaviour and characteristics of their child, for example crying, screaming or being fed through a gastro tube. Many parents also spoke about how staying home was easier. By staying home parents did not have to deal with the physical work or emotional work required when going out of the home to participate in activities. Several parents mentioned that it is easier for friends to come over to their house. Thus socializing with friends continues to be possible. Going out of the home, to other physical environments, includes a response to "others", their attitudes, stares and comments.
Chapter Six: CONCLUSIONS AND IMPLICATIONS

Summary of this Research

Initially, this research set out to explore the broad questions of what it is like to be a parent of a child with a disability? To narrow this topic, the focus was specifically on the parents’ experiences of participation in activities in environments other than the home. The rationale for choosing this theme was that occupational therapy models see the environment as integral to occupations and interconnected with a person’s occupational performance. In addition, since occupational therapists are considering broadening their concept of 'the client' to include groups such as families, exploring issues connected to families seemed appropriate and important. The parents, both mothers and fathers, were considered the most important family members for a child with a disability, and the literature review revealed the paucity of research exploring the experiences of fathers who have children with disabilities. Thus both fathers and mothers were recruited to participate in this study. The research questions posed were appropriate for qualitative methods which are descriptive, exploratory and aims for an understanding of negotiated meanings created by the researcher and the participants.

The research findings have been organized into two broad themes. The first, like a foundation, consists of the parents’ descriptions of their discovery of their child’s difference, support and being a normal family. The discovery of the child’s difference sets the framework for how parents describe their feelings and their children. For many of the parents, support is important, for practical help with their children and for accessing agencies and information. Underlying their concept of their family as different, many families desire and understand themselves as being "normal families". Part of their description of being normal includes being able to participate in activities in the community.

The second broad theme concentrates on parents’ descriptions of the conditions necessary
to go out and the strategies parents develop to go into the community. The conditions include issues about equipment, an accessible destination and transportation. In addition, parents use strategies and adaptations to do activities. These include ensuring the parent has 'extra' help, planning for outings and adapting the activity. When the conditions and strategies do not fit, parents chose to stay home. It is easier to stay home where the environment is suited to their needs. People in the community, these parents explained, are not necessarily knowledgeable about disability. The parents recognize why other people stare and sometimes make comments, none the less it comprises part of the mental strain or emotional work participating in activities outside of the home.

This chapter begins with a section which compares the literature to the research findings. Next the two concepts introduced in Chapter 1, that of the environment and the client are discussed in light of the research findings. Following this is a section on the limitations of the study. Lastly the implications for occupational therapy are addressed.

Comparison of the Research Findings with the Literature

The literature review outlines the major themes identified in the research about parents of children with disabilities. The following sections explore the similarities and differences of this study with the themes in the literature. The themes and sub-themes presented here correspond to the themes in Chapters Four and Five. First the research findings are summarized then compared and contrasted to the literature. Many similarities exist between the themes identified in the literature and the themes that emerged from this study.

The Foundations

Emotions

Many parents describe how they came to understand their child’s difference. Over time the parents come to understand their child for who he/she is. Along the way, they learn of their
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The parents express how they had feelings of guilt about their child's disability, but they have overcome those feelings. As a result, as a group, they express love and pride for their disabled children. Yet their affirmative feelings for their children do not negate the reality of the stressful and tough times parents experience. For some parents, lack of being able to communicate with their child is a significant difficulty. Both fathers and mothers speak of their emotions, although mothers tend to speak more specifically about the guilt.

Studies that have investigated parents' stress concur with the finding that parents experience many complex emotions (Beresford, 1994, Featherstone, 1980, Gallagher, Beckman & Cross, 1983, Hornby, 1992, Tetreault, 1994). The idea that lack of communication is problematic for the parents of disabled children is also reiterated in these studies. One issue discussed in the literature but was not a theme that emerged in this study is that of the child having disruptive behaviour, and that this would restrict social experiences (Gallagher, Beckman & Cross, 1983, Glendinning, 1983, Wallander & Noojin, 1995).

Support and Care Giving

Support is an important issue for the parents of this study. It comes in many forms. Information is an important source of support. Information leads to a better understanding of the child's diagnosis, as well as knowledge about funding resources for equipment or respite care. Generally, these parents express frustration with how they found information. Some of the reasons for frustration are finding information only by chance, or that accessing information or funding through a charitable organization is confusing, or discovering that charitable organizations want recognition for their support.

People, such as extended family members and hired help, provide hands on care giving support. For parents who have to hire people, finding and trusting someone is an important issue. Spouses, both husbands and wives, are a source of emotional support to each other, as well as
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care giving and financial support. One issue for the fathers regarding support is how they divide
time between paid employment and time at home. The fathers recognize their financial support
is necessary. That means for some that more time at paid employment is necessary to earn
more. Two fathers in this study discussed that they felt they needed to work more to be able to
provide for their child's financial needs, now and for the future. Many of the fathers are
involved in their children's care, but to a lesser extent than the mothers. Some fathers recognize
they could not spend as much time with their children as the mother could, but validate their
wife's mothering role. Several of the parents, even though they had different supportive roles
and spent different amounts time with their children, express a sense of shared responsibility.

The discussions around support were very similar in this study to the issues identified in
the literature. Like the parents in Beresford's (1994) research, the parents of this study describe
the importance of their partner and extended family for care giving and emotional support. No
studies in the literature identify the importance of grandmothers as primary care givers, as
identified by two families in this study. The parents of this study, and Beresford's, identify that
agencies are important sources of support as well, especially in terms of providing funding for
respite. Comparable to the sentiments of the mothers in Tetreault's (1994) study, if access to or
delivery of services is not adequate, confusing or poorly provided, it is stressful to parents. Not
only do the parents have to contend with the original problem that moved them to consult with
an agency, but also they must figure out the system. These are the concerns identified in this
research and in the literature. When intended support is unacceptable to the parents it is stressful.
Featherstone (1980) described the significance of parents both receiving and giving support.
Traustadottir (1991) discussed the concept of the extended role of caring meaning the parent takes
on a role of caring about other families in addition to their own. Frank and Pierce's (1992) in
depth analysis of one mother also identifies this in describing how she takes on an advocacy role.
The mother’s advocacy role included making speeches and organizing resource material. In this study, three parents took on an extended role, one as a director of a national association, one as a member of a committee designing an accessible school playground and one as a member of an advisory committee to an early intervention program. Each of these parents felt motivated to make a change that would also help parents like themselves.

**Employment**

The parents who participated in this study carry out traditional roles in the family. The fathers were employed and spent more time away from the home than the mothers, with one exception. Financial needs were a concern and stressful. Two of the three mothers in this study who worked, one full time and one part time, had the paternal grandmother living in and providing significant hands-on care giving. The employment patterns of these two parents might have been influenced by the grandmother’s support.

The parents’ employment pattern in this research is similar to those in other studies on parents of disabled children (Traustadottir, 1991, Beresford, 1994, and Pierce & Frank, 1992) and the research review conducted by Philp and Duckworth (1982). Indeed, this is traditional division of tasks typical for most families (Primeau, 1992). However, there are exceptions, for example one father, in Beresford’s study of 20 families, was the primary care giver and in Traustadottir’s (1991) study one mother worked full time, as in this study. In some studies (Tetreault, 1992, Philp & Duckworth, 1982) a theme identified, interviewing mothers, was about fathers not having flexible work arrangements to help with care giving. This theme was not reiterated in this study.

**Normal Family Life**

The last theme is about the parents descriptions of being a "normal" family. Some parents linked "being normal" to being able to participate in activities such as an outing. There is an underlying understanding that their family was different; yet they strived to pursue typical family
activities, to be a "normal" family. Several parents recognized that to do activities took an extra effort and was emotionally and physically demanding.

Gray (1997) investigated parents of children who were high functioning and had autism. His conclusion was essentially that each family had a construct of normal, which changed in private and public domains. Although Gray's research and this study cover two different topics, the conjecture of families having notions of what is normal to them is similar.

Participating in Activities

Equipment and Accessibility

The parents described and explained how they experienced going out of the home to participate in activities. One of the conditions necessary for parents to take their children out of the home is having the right equipment. Yet at the same time, many parents were concerned and almost resented the amount of physical work managing equipment entailed. It is a constraint. Physically handling the equipment is strenuous work. The parents expressed concern for their own and spouses' backs lifting and carrying not only equipment but also the children.

Philp and Duckworth (1982) noted the lack of research on equipment. They cite one study described design flaws in the equipment and that equipment was expensive for parents. Primm (1996) linked the issue of the child's physical dependency on the parent with the parents feeling stressed. In addition, and along with Glendining (1983) and Featherstone (1980) the physical work of caring for a child with a disability is extra because of the time frame. Johnson & Deitz (1985b) and Crowe (1993) show that parents of children with physical disabilities spend more time providing child care than mothers of typical children. The theme of children with disabilities being work for their parents is consistent in the literature, however the impact of the children's equipment on the parents experience of parenting has not been studied.

Physical accessibility was not a strong theme identified by the parents in this study,
although the parents could usually identify a building that was not accessible. The parents identified several strategies to deal with buildings that were not accessible such as not going to those places, bumping up stair with the child up in the wheelchair or carrying the child up stairs. Several parents said their homes were not easily accessible for their children. Stairs were the main problem. The literature does not cover the topic of physical accessibility in many environments for parents of disabled children, except Philp and Duckworth (1982). Their finding were similar to this study.

Transportation

Regarding transportation, the parents in this study all have their own vehicle. As a result, important issues were accessible parking and access into the vehicle such as by physically lifting the child in or having a mechanical lift or ramp. The parents described various experiences on public transportation. Only one family regularly used the public bus. They were on a wheelchair accessible route. In addition, the one family which does use public services, begs the question: if wheelchair accessible transportation were available, would parents use it? In the literature it is unclear whether authors refer to public or private vehicles for transportation. Philp and Duckworth (1982) reviewed one study on transportation. A reason, quoted in the study, for not using any form of transportation was because of the child's incontinence. Incontinence was not a theme in this study.

Social Attitudes and Leisure

The social attitudes of others adds another dimension to the experience of participating in physical environments other than the home. The attitudes of others are revealed, in part, by their behaviour. Parents out of the home need to respond to the stares and comments of others. This component of going out of the home comprises what is described as "mental strain". Although Goffman (1963) and Davis (1972) write about how adults with disabilities feel stigmatized and
how adults managing social situations so as to minimize the influence of their disability on a social interaction, I am not sure that parents in this study felt stigmatized or that they must manage every social situation.

The literature on leisure (Cant, 1993) and other studies (Traustadottir, 1991, Featherstone, 1980) highlight the social experiences for parents of children with disabilities. Themes such as being isolated from other families (Cant, 1993, Featherstone, 1980) and having limited participation in activities, especially the mothers (Traustadottir, 1991) were not predominate themes in this study. Isolation was not a theme identified in this study, although one mother spoke about the sacrifices she made by staying home with her disabled daughter while the father and other daughter went out to participate in activities. These studies also refer to attitudes of others such as "invisible social barriers" (Featherstone, 1980, p. 51) and polite disattention (Cant, 1993). This may be similar to what parents in this study experienced when they describe the behaviour of others in terms of their comments and stares.

Staying Home

The last theme identified in this study is that of staying home. Going out of the home to participate in activities is a complicated event. Parents must consider the needs of the child and other children in the family, they must have transportation and a suitable activity. Cant (1993) describes how parents' leisure time is negatively affected by having a child with a disability. Parents tend to stay closer to home and engage in activities their child can do as well as they themselves. A child's incontinence is mentioned as a barrier to going out or having friends over in some studies (Cant, 1993, Glendining, 1983, Philp & Duckworth, 1982). None of the parents in this study mentioned incontinence as a reason for not wanting to take their child out or to entertain at home. There are reasons why incontinence may not have been mentioned in this study. First, the children in this study are all under five and the parents might not have the
expectation that they should be toilet trained. Second, and perhaps more significantly, new disposable diapers are very absorbent; therefore the issues of the child smelling unpleasantly might not be a factor in going out or having friends over.

**Summary**

Comparing and contrasting the literature with the findings of this study reveals both similarities and differences. Gallagher, Beckman and Cross (1983) point out two limitations when comparing the literature, the age and complexity of the children. Their review of the research suggests that parents of children with complex needs, because of individual characteristics, experience more stress. Complex needs could arise from the child’s slow rate of development, temperament, social behaviour and/or care giving demands. Another point they make is that parents of older, school-aged children experience more stress than parents of younger children, possibly because the gap in development widens between children with disabilities in comparison to their peers as they grow older. Many of the studies in the literature are of parents of school aged children. In this study, significant variation among the children in terms of their physical, social, developmental and personality characteristics results in a diversity of themes and issues identified by the parents. Since much of the literature does not specify exactly what kinds of characteristics the children have, it is difficult to know how if children in the literature are similar to the children in this study.

Another consideration is that the literature represents research from several different countries including the United States of America, Britain and Australia in addition to Canada. Services to families of children with disabilities might vary considerably from country to country and thus influence the parents’ experiences of care giving and financial support, access to equipment, transportation and other areas in daily life. Thus issues relevant in one area may not be relevant in another.
In conclusion, this research contributes four new issues that have not been previously identified. First, parents link ability to participate in activities outside of the home and what it is to be a normal family. Being able to participate in activities out of the home has value and meaning. Secondly, participating in activities out of the home is, what I termed, emotional work. The emotional work, for some, is more demanding on the parent than the physical work. Thirdly, to go out of the home parents must haul their children's equipment. While parents recognize the need for equipment, it is physically demanding and takes time to pack into a vehicle. Equipment, although it is a major source of 'extra work', is both an important conditions that facilitates the parents taking their children out. However, it also constrains them. Lastly, this research show the importance of equipment, physical accessibility into buildings and transportation for parents to participate in activities outside of the home. It illustrates how the physical environment is intimately connected with the ability to participate in activities outside of the home.

The Concept of the Environment in light of the Research Findings

In chapter one I discussed how the environment has been conceptualized in occupational therapy and political science. Essentially three approaches were covered. First, I described how Kielhofner (1995) categorized the environment. Second, I discussed the socio-political perspective and models outlined by Hahn (1984, 1985) and Oliver (1990, 1996). Lastly, work primarily by Law (Law, 1991, Law & Dunn, 1993) including the Person-Environment-Occupations model of occupational performance (Law et al., 1996) was introduced. The model representing the person, environment, occupation and occupational performance in Enabling Occupation (CAOT, 1997) is essentially the same as Person-Environment-Occupation model of occupational performance (Law et al., 1996). The purpose of the discussion in chapter one was to provide a rationale for investigating parents experiences of participation in activities, focusing on environments outside of the home. Thus the following discussions comprise my critique and
analysis of how the environment has been described and conceptualized in light of the research findings.

Kielhofner’s (1995) work is largely descriptive of what environments are composed of and that environments can influence behaviour. His categorizations are useful to some extent. Kielhofner’s idea that the environment provides opportunities or affords and presses behaviour eludes to a cause and effect relationship. Law et al. (1996) suggest we have moved away from cause and effect models because they do not adequately describe dynamic and interwoven relationships. Indeed, this research shows how parents decision making about participating in activities includes many factors and is complex and multifaceted. The findings of this research also show how larger structures such as policies about wheelchair accessible public transportation could have an impact on the experiences of family members. Although Kielhofner states that different environments would result in different occupational behaviours, his work lacks a model from which one could analyze why a person or group of persons experience a particular environment and what the components are that would shape it.

The socio-political theorists locate the definition and experience of disability in society (Oliver, 1990, Hahn, 1985). Disability is not equated to individual deficit rather they assert structures in society, such as attitudes, policies, organization and physical environments, create what disability means. In this study, there are many examples of how social structures impact the parents. The parents experienced social attitudes, both inclusive and negative, from family members, strangers and friends. It is difficult to pinpoint a salient negative attitude. It is easier to describe the behaviour of others which included stares, insensitive or naive comments and reluctance to play or help with the child. The parents themselves were keenly aware of both their normality and difference in comparison to other families. Attitudes that maintain the prevailing hegemony of fathers as primary income earners in a family and mothers as care givers and
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responsible for household work is a structure that influences these parents lives. Indeed, attitudes, policies and organization all function together to produce the division of work between men and women.

The socio-political perspective (Hahn, 1984, 1985, Oliver, 1990, 1996) is valuable to understand the experience of disability. This study shows, for example, how policies influenced the parents in this study. Many parents utilized funding through a government program that paid for equipment and wages for respite care givers. In addition, policies requiring buildings to be physical accessible have increased access to those in a wheelchair. Similarly, transportation that is made accessible may be utilized, and for those who drive their own vehicle, designated parking spots are important. These examples illustrate how policies can lead to changes in the physical environment and hence people’s experiences.

From a socio-political perspective, Law (1991) discusses the elements that create disabling environments. Law and Dunn (1993) show children with disabilities are limited by their environment. They advocate for social change as a way to transform disabling environments to encourage people’s, including children’s, participation in their community. Law’s contributions to the occupational therapy literature not only adds depth to understanding disability from a socio-political perspective but also strengthens our knowledge of a relationship and connection between the individual, environment, occupation and occupational performance. Law’s work leads up to the Person-Environment-Occupations Model and the concept of fit with occupational performance.

Application of the Person-Environment-Occupations Model of Occupational Performance

The following discussion considers each concept within the Person-Environment-Occupations Model of Occupational Performance (Law et al., 1996) from the perspective of the parents of the disabled children in this study. The concepts are person, environment, occupation
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and occupational performance, and are defined in Chapter One. First, the parents, as persons, experienced various new roles. For some parents, both mothers and fathers became advocates for services or programs serving their child's need. The mothers' roles, in particular, included being recruiters, managers and coordinators of paid care for their child. Some parents' self-concept changed as a result of having a child with a disability, specially overcoming their self-consciousness about their child's disability and having an accepting attitude towards others who have a disability. One father, in particular, commented on how their competencies as a married couple changed. His attitude was that they could "go through" anything as a result of their experiences with their child.

Secondly, the research findings show the interconnectedness of the person, the environment and occupation. Although my initial intent was to focus on physical and social environments, the findings show the complexity of this endeavour. The physical structures in the environment, such as transportation and using equipment, did shape the parents decision making process. A person can and does change the physical environment. One parent in this study was actively pursuing a physical change in the school playground by sitting on a committee to recommend the changes. This would correspond with the idea or assumption that the environment impacts on the individual. Yet it was not only physical structures but also social, cultural, institutional environments that influenced their decisions. For example, the availability of persons to help depended on social factors such as the parent's relationships with family members or friends. The institutional environment became evident through the parents' stories about access to information and access to equipment. In all situations the parents relied on equipment to go out of the home with their children, such as a wheelchair or large size stroller. In British Columbia the At Home Program pays for equipment such as wheelchairs and large size strollers. In addition, because the At Home Program does not pay for some items, such as lifts for vans, some
parents chose to access funding through charities. Access to funding is complicated and in some cases involves many groups of people. Thus it can be stated that parents' ability to go out of the home with their children is influenced by attitudes and processes in all categories of the environment, social, cultural, physical and institutional. Although the categories of the environment (CAOT, 1997) as outlined in chapter one are helpful in identifying components of the environment, the research findings show how they are inseparable.

Thirdly, these parents were influenced by their children in terms of their activities, tasks and occupations. Engaging in activities and tasks were shaped, in many situations, by the children's physical care needs. For example, for several families, their child's feeding needs shaped the day. The mother explained how she needed to get up earlier to have time to feed her child, how they could not feed her in the car, and that on an outing they must remember to feed her because she cannot ask for food herself. Managing the child's equipment highly influenced how the parents prepared for an outing. Parents spent time packing equipment into their vehicle and often this was physically demanding as well as time consuming.

In terms of a change in occupations over time, the fathers in this study clearly identified several issues. First, they identified the dilemma of having to spend time at work and spend time with their families. It could be argued that all employed fathers have to divide their time, however these fathers were conscious of their children's care giving demands on the mothers. In several situations they felt a sense of shared responsibility and wanted to help with caregiving or playing with the child. Secondly, these fathers, as primary income earners, felt a responsibility to earn enough to support their child's needs, for the present and the future. This was a concern and stress for the fathers. I would suggest that these issues for the fathers would have an impact over time on their roles as caregiving fathers and wage earners for their families. This may impact on how they make choices about work, for example working long hours or taking extra
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to play in making decisions about their child’s care, such as going to the hospital or administering medication. The occupation of child care and home making for the mothers is, I would suggest, intensified by the experiences of having a child with a disability, in terms of physical demands and emotional stress.

Although it is relatively easy to find examples of how these parents have been changed or influenced by their children in personal, environmental, occupational terms, their occupational performance it is more difficult to evaluate. The purpose of this study did not include evaluating occupational performance. There are two definitions of occupational performance presented in this thesis. The most current definition, (CAOT, 1997) states occupational performance is "the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after one's self, enjoying life and contributing to the social and economic fabric of the community" (p. 30). From my brief interaction with all the parents in the study I observed them parenting and heard their stories of employment, personal and family joys and meaningful relationships. I also heard of hardships, pain and breakdowns. Our conversations went back in time and to the present, some into the future. I concur with Law's et al. (1996) recognition of occupational performance being "the product of a dynamic interwoven relationship...and cannot be separated for contextual influences, temporal factors, and physical and psychological characteristics" (p.10). I also concur with the idea that a fit between person-occupation-environment exists and influences occupational performance, but I think there needs to be further research on the parents’ sense of choice, meaningful occupations, and contribution to their community and other aspects described in definitions of occupational performance. Do parents have choices raising their child with a disability? How do fathers of children with disabilities construct the meaning of fatherhood? How do financial resources and
responsibilities influence the families of children with disabilities?

In summary, the findings of this study can be understood using many of the concepts and assumptions presented in the Person-Environment-Occupations Model of Occupational Performance (Law et al., 1996) and concepts of the environment and occupational performance contained in the Canadian Model of Occupational Performance (CAOT, 1997). Further research will be needed to cover topics introduced but not explored in depth in this study. For example, interaction with the institutional environment were only alluded to. Social attitudes and how they unfold in public policy is an important issue which surfaced in this research. This study does not directly analyze the cultural environment, although cultural norms about the family are pervasive in how these families organized their lives. Furthermore, if we understand occupational performance to be dynamic and recognize the temporal factors, studies need to investigate an individual’s or family’s change over time with respect to their interaction with respect to the concept of fit between occupation, environment, person and occupational performance.

Considering the Family as the Client in Client-Centred Practice

The findings of this study point to three main factors when considering the family as the client. First, despite the impression of these families being a homogeneous group, describing who the family is presents a challenge. For example, from the analysis of the findings, grandparents, especially grandmothers, play an important role in providing care giving and emotional support. In one family the grandmother was the coordinator of medical appointments and knew more about the child in terms of daily care, equipment and medical appointments than either of the parents. In two other families the grandmothers were providing paid respite for the parents and were also involved in taking the children to medical appointments. These findings indicate that parents are not always the primary person(s) in the child’s life. In other families, grandparents were not involved for a variety of reasons.
Second, the concept of individualized service and viewing the family as the client seem contradictory. One of the concepts within the definition of client-centred practice (Law, Baptiste & Mills, 1995) is that of individualized service. The findings of this study reveal numerous implications for the parents when their children are disabled, especially when they take their children out of the home to participate in activities. The parents need to plan and organize; they need to ensure the transportation is available; they need to consider where they are going and adapt situations that do not "work" for their child. Parents need to manage the many aspects of their children's equipment. The parents need access to resources and information to make decisions and receive support. It makes sense that a parent of a disabled child would be the receiver of individualized service, recognizing that the reason he/she require services is because of the presence of the disabled child in his/her life (personal communication, May 1997, Sue Stanton).

And, lastly, the findings suggest that the potential needs of individual family members could be distinct. Most of the parents in this study carried out traditional roles with the father employed away from the home and the mother responsible for child care and household chores. This impacted the amount of time each had to spend with the child. Some parents had a sense of shared responsibility, communicating between each other about their child's needs, others did not. The main point taken from this study is that the parents' roles and participation in the daily lives of the children varies. Some of the reasons for the differences in roles and participation include, the amount of grandparent support, the sense of shared responsibility between the parents and the amount of time available for both mothers and fathers to be with their child. If occupational therapy considers the family as the client, an appreciation of the very different individual roles of family members is needed.

Considering how the definition of family-centred service delivery evolved and the many
definitions describing what it means, perhaps for the occupational therapist, the term "family member-centred" service is more reflective of what the "family as the client" means to occupational therapy. This research suggests that family members vary in their roles within the family. It also shows that parents, as individuals, have a number of different needs as a result of having a child with a disability. Perhaps considering the term family member-centred service would better reflect the understanding of different individuals, their roles within the family and the concept of individualized service.

Limitations of the Study

This is a descriptive study of parents' experiences with a child with a disability. Its broad and general focus on questions such as where families go in the environment and the process of getting there, perhaps neglected to consider the parents underlying values of why going out is meaningful for them and for their child. The parents' comment that going out is a part of being a normal family hints at values and meanings that were not adequately explored in the one or two interviews with parents. Although, the purpose of this study was not to explore the meaning of being a normal family, the study is limited by this omission.

One issue identified in the review of the literature is that parents of children of different ages and varying needs can have diverse concerns. It seems obvious that a parent of a school aged child would have different concerns than a parent of a preschooler. In this study the issue was not the age of the children, since they were all between 3 and 5 years of age, but rather their disparate needs. Most children in this study have a mix of what I would categorize as complex needs, meaning the child may have needs in all or several areas including feeding, toiletting, playing, communicating and sleeping in addition to a mobility. The diversity of the children's needs did add depth to the study, yet the study is limited by the relatively small size of participants. In addition, the small study size means the research is limited by lack of diversity
among the participants. For example their are no participants who are high income earners, or from dual-earner families, or low income families. Also, since all of the families lived in suburban communities, issues for families in rural and urban communities, are not addressed by this research. Lastly, the participants in this study were of similar ethnic background thus this study lacks a multicultural perspective. The lack of cultural diversity may be due to the recruitment process which relied on parents volunteering in response to a letter, and because I did not specifically target families of different ethnic backgrounds in developing the inclusion criteria. There may be cultural differences in how children with disabilities are raised which this research did not address. For example, from my experience working with families in a multicultural community, I have observed that there is a diversity of values concerning the family and different modes of household organization, among different cultural groups. It may be that the family life also differs, including the nature and extent of participation in activities outside of the home environment that are seen as constituting a "normal" family.

Implications for Occupational Therapy

The model of occupational performance (Canadian Association of Occupational Therapist, 1991) and the literature that describes how occupational therapists conceptualize the client and the environment guided my thinking and analysis throughout the research process. The implications of this research for occupational therapy are understanding the family, specifically parents, as the client and how the environment can be implicated in their daily lives.

Client-centred practice acknowledges that the client can be the family and that the client has strengths and resources to solve occupational performance problems (Fearing, Law & Clark, 1997):

Many clients are adept at problem solving and there is so much to learn from them. As well, clients have individual, social, familial and community supports that are long-standing, and whether or not they appear to be ideal, they may work very well.
In client-centred practice, the therapist and client together identify client strengths, skills and resources that can assist in resolving occupational performance problems (p. 11)

If occupational therapists consider the child with a disability as the client, then parents, siblings, grandparent and other family members are the resource and supports to solving the child’s occupational performance problems. In addition, this research shows that it is conceivable that the parent, grandparent or sibling do have occupational performance problems as a result of having a child with a disability.

In this research the parents frequently commented on the impact of the amount of equipment their child required and how that influenced going on an outing. Since occupational therapists are often prescribing equipment, this research implies that we need to assess and evaluate the impact of these choices for the parents as well as for the child. Another consideration is the lifting/carrying and how that effects the physical health of one’s back. Several parents commented on how they were concerned about their backs because they are lifting and carrying their child often. Occupational therapists, viewing the parent or grandparent as the client need to consider the physical demands of caring for a child with a disability and provide relevant information. There are many other examples of issues parents identified in this study. We can identify who the client is by evaluating the occupational performance problems as a consequence of the child with a disability being present in the family. For some problems the client could be a family member, for other problems the client could be the child with a disability.

Occupational performance problems for either family members or the children with disabilities exist within a unique environment:

Environmental conditions are cultural, economic, institutional, physical or social factor outside the individual. Environmental conditions are important not only because they influence performance, and our understanding of that performance, but
also because they have the potential to become resources rather than barriers (Fearing, Law & Clark, 1997, p.13).

The parents in this research hinted at conditions in each environmental area that influenced their experiences. For example, funding for equipment and respite is the result of changing policies in institutions, a cultural value to assign money to this need and economic climate. This study demonstrates the complexity of the parents’ considerations and decision making to enter many different physical and social environments. Although the focus was on the physical environment, the parents spoke about the cultural, economic, institutional and social environment in terms of peoples attitudes, funding and access to information, support and services. The implication from this study is that more research needs to take place investigating a holistic view of how the environments are connected with and experienced in the lives of parents of disabled children. What government policies are instrumental to assist parents to not only care for their children at home, but also to participate in many environments? How does accessible transportation impact on the daily lives of persons with a disability and their care givers? What impact does the environment have on children who have cognitive or behavioral disabilities? Do families of children with disabilities and typical families have a similar construct of what is normal family life?

This study explores and describes the experiences of parents participating in activities with their children in various environments. The themes were identified by listening to audiotaped interviews, reading transcripts, describing themes, categorizing text, analyzing categories, thinking about how themes fit together and writing. The process of qualitative research can be overwhelming. In the end, it is easy to have moments of self-doubt and, alas, more questions than answers. I have been challenged in my thinking and understanding of 'the client' and have gained a new appreciation for the complexity of the environment in which our clients live. In
addition, I have learned more intimately how the Canadian Model of Occupational Performance (CAOT, 1997) can be integrated into my understanding of occupational therapy practice. The participants in this study had so much to share. I was moved by their sincerity and serious approach to the interview process and topic.
REFERENCES


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Sample Interview Questions

Introduction: introduce myself, purpose of the research, assure confidentiality, describe who has access to the data, explain if they are interested they can read the final research findings (thesis or summary of findings), gain permission to use the tape recorder, express my interest in their experiences and opinions.

Preamble as to why I need demographic information—to be able to describe the group of parents in the study. Demographic information is to be collected on a separate sheet.

1. Since I don't know your child could you tell me about _________?
   probes: age, personality, physical ability and disability, etc.
   Yield: description of child

Preamble to the next two questions—daily schedule, activities.

2. What about the rest of your family, who lives here at your home and others who are here often?
   Probes: siblings, grandparents and other relatives
   Yield: household composition

3. I am interested in your daily activities. I would like to start with your description of your day to day activities. Could you describe a typical week for you.
   Probes: Tell me who does what kinds of things with your child...what kinds of things would you like to do but can't for some reason or another? ...what have your experiences been that have lead you to these decisions?
   Yield: description of weekly schedule, decision making strategies
description of activities that are excluded and rationale

4. I am interested in activities you do outside your home. (list different places you go and tell me a bit about them) Could you describe a typical day's outing (perhaps choosing one)?
   Probes: Start from planning, include the transportation you use and, what you do when you arrive? How long does it take? Who else is involved?
   Yield: sequence of events, information about the built and social environment, barriers
Preamble, this next question may be a little be more difficult ...
5. I am interested in what it is like for you to be a parent of [Blank], including both the joys and the difficulties parenting [Blank].
Probes: what you like to do together, fun times, positive or rewarding moments, difficult times, what do you dread to do, what concerns you
Yield: positive and difficult experiences, particular concerns

6. If you could imagine things differently...what would be your wish list...what things would make a difference to the things you can or do do? Could you tell me about activities that you have excluded from your schedule and how you came to making those decisions?
Probes: If you had more help would you have been able to [Blank], if the physical environment was more conducive to [Blank] would you participate in the activity?
Yield: decision making strategies, rationale for choices regarding activities.