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HOW THE PARENTS OF HANDICAPPED CHILDREN EXPERIENCED HELPFUL BEHAVIOURS:

A Phenomenological Study

by

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ABSTRACT

The purpose of this study was to investigate how the parents of handicapped children experienced helping behaviours, using a phenomenological approach. The parents were asked to describe behaviours that were helpful to them when interacting with professionals and when interacting with family and friends. The participants were also asked to describe the ways in which they had helped themselves.

Three couples with one handicapped child over the age of three were recruited and interviewed individually. The data generated from the audiotaped interviews were analyzed according to the steps outlined by Colaizzi, Hyener, and Rose. Seventeen themes were identified from the parents' interaction with professionals; nine from the parents' interaction with family and friends; and eleven from the parents' own self-help behaviours. These themes complement and build upon the existing literature focused on professional intervention with the families of handicapped children by providing more detailed information on what specific behaviours were helpful to the parents and why. These behaviours and their impact on the parents are summarized in table form. A list of guidelines for helpers is offered.

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INTRODUCTION

The birth of a child often introduces the beginning of change within a family unit. Family members usually need to make some adjustments in their lives in order to accommodate the new member, and for the most part they do so successfully in their own unique fashion. When a child has a disability, the parents must not only adjust to the presence of another demanding human being, they must also adapt to the fact that this is not the perfect child they had hoped for. It is an emotional time for the parents, when they must not only come to terms with their feelings, but must also process technical information about their child's condition, as well as deal with the variety of professionals who will likely be involved with their child.

Although arguably the intent of these professionals is to help the child and the parents, many parents report that most of their interactions with professionals were intensely negative (Featherstone, 1980; Turnbull & Turnbull, 1978, Lipskey, 1985). Parents generally seem to find more support in informal contacts such as family and friends. Yet, as Featherstone (1980) observes, many parents will state that there was one professional who was helpful to them.

The impetus for this present research was to closely examine some of the positive interactions that occurred between the parents of a handicapped child with professionals as well as with family and friends, and learn from them. It is hoped that detailing these positive contacts, and elucidating why they were helpful to the parents, will be useful to helpers in guiding their own interactions with parents of handicapped children.

PURPOSE

The purpose of this study is to explore how three families experienced being helped in three areas: (1) when interacting with professionals, (2) when interacting with family and friends, (3) and how the parents help themselves through the emotionally difficult times. The negative experiences that many parents of a handicapped child have when interacting with others, such as prejudice, staring, or insensitive comments, have been frequently investigated by researchers such as Philps & Duckworth, 1982; Fewell & Vadasy, 1986. However the positive interactions are less frequently reported or examined, yet as Featherstone (1980) observed, they do occur.

This research project sought to examine these positive experiences by seeking answers to the following questions:

> In relation to suggestions and assistance in the care of your child, and your own needs:
>
> 1. Who was especially helpful? A friend, relative, professional, or acquaintance?
>
> 2. What did that person say or do that was helpful to you?

This study also examined the parents' own coping mechanisms by asking the parents how they help themselves through the emotionally difficult times.

The detailed information gathered led to the formation of a list of the behaviours that the parents found helpful when interacting with others and why.

Helpers can use this list to check their own interactions with families of handicapped children.

LITERATURE REVIEW

A great deal has been written about the reaction of parents to the birth, or later diagnosis of a handicapped child, and many aspects have been studied: stress levels in mothers, fathers, siblings, grandparents; effects on the marital relationship; grief reactions; coping styles; institutionalization versus non-institutionalization; as well as effects on self-esteem, to name but a few.

However, in spite of this abundance in research, few conclusions or generalizations can be made regarding the impact that the presence of a handicapped child has on the family. Contradictions abound in the literature. While some studies report a highly negative effect bordering on the pathological (e.g., Evans, Carter, 1954; Worchell & Worchell, 1961), others report only a slight increase in stress levels (Kazak & Marvin, 1984). Yet others report no differences between families with a handicapped child and those with "normal" children (Busch-Rossnagel, Peters & Daly, 1984). Still, others have found that having a handicapped child sometimes has some positive effects (Burden, 1980; Gath, 1977; Simeonson & Simeonson, 1981).

In their literature review, Byrne and Cunningham (1985) offered several possible explanations for these varied findings. One reason they suggest is the

inconsistent way in which the information is gathered. Studies use different measuring tools or different combinations of tools and thus arrive at different conclusions. Another reason offered is that the samples often vary greatly in composition. There are differences in nature of handicap, age of target child, age of parents, marital integrity, birth order of target child, presence or absence of support systems, pre-morbid personality and functioning, age of the child when the disability was diagnosed, SES, and financial security. All of these variables have been found to influence the impact the handicapped child will have on the parents, although it has yet to be determined which are more important.

To account for and control every one of these variables is an awesome task. In addition, just as individuals react uniquely to a crisis, families react idiosyncratically to their handicapped child (Longo & Bond, 1984; Fewell & Vadasy, 1986). It is erroneous to try and simplify such a complex situation by assuming that all families of handicapped children are similarly affected, possess similar characteristics, or are in need of similar types of assistance (Lyon & Preis, 1983).

Although the presence of a handicapped child may not be the cause of severe psychological impairment, it does incur an added burden on the family, both emotional and physical (Lyon & Preis, 1983), which is bound to challenge a family's resources financially, emotionally, and physically (Burden, 1980; Lyon & Preis, 1983; Featherstone, 1980; Fewell & Vadasy, 1985). This challenge is an ongoing phenomena. It is not one that the family can meet and then forget; they must meet this challenge on a daily basis (Featherstone, 1980). For example, the

grief that parents experience on discovering that their child is handicapped is often addressed in terms of stages in the literature, with the expectation that once the parents have passed through these stages, the grieving is over (Bristor, 1985). However, there is evidence that the grieving process is not finite but recurs throughout the child's life. Olshansky first described this phenomena as Chronic Sorrow in 1962, and Wickler, Wasow and Hatfield, replicated the findings in 1981.

According to Byrne & Cunningham (1985), until the mid-seventies, most of the researchers who report their findings in literature examining the effects of a handicapped child on the family used a pathological approach. This approach assumed that families with a handicapped child experience high levels of stress which cause psychological impairment. The belief that psychological impairment is an inevitable consequence of having a handicapped child has resulted in the stereotyping of these families, and some of the problems that parents have experienced with professionals can often be traced to this stereotyping (Lipskey, 1985; Lyon & Preis, 1983; Sabbeth, 1984).

The most recent literature has been more positive when examining the family with a handicapped child. It stresses the essential normality of the families rather than assuming pathology, and rejects the idea of homogeneity. Byrne and Cunningham (1985) organized this emerging research into three areas based on the underlying assumptions guiding it.

The first approach seeks to identify which families and which family members are most vulnerable to the presumed stress of having a handicapped child (Beckman, 1983; Wishart, Bidder & Gray, 1981; McCormick, Charney, Stemmler,

1986). The idea of some possible positive effects of having a handicapped child is introduced in addition to the often reported negative consequences, and sources of stress other than the handicapped child are considered (Burden, 1980). This approach provides some understanding of which families are most vulnerable to stress, but it does not explain why they are vulnerable nor does it give suggestions on how these stresses might be relieved or avoided.

The assumption of the second approach is that the main source of stress is not the handicapped child *per se*, but suggests instead that the presence of such a child creates needs within the family which are not met. The emphasis of the research is on identifying the material and practical problems faced by the families, and possible solutions are offered (Schild, 1982; Lloyd & Bostock, 1976; Lonsdale, 1978). These surveys have provided some useful information on what the families themselves consider to be their practical, material and service needs; there does seem to be some consensus among the families regarding which needs are most pressing. However, although large groups may express certain needs, there are many individuals who do not, and thus the conclusion is reached that families must be considered individually.

The emphasis of the third and most recent approach is on the fact that many families cope successfully with the stress of having a handicapped child. The research tries to find out how they do so, and models have evolved describing potential psychological and social resources such families use, and the coping strategies they develop (Crnic, Freiderich & Greenberg, 1983; Buboltz & Whiren, 1984; Drotar, Baskiewicz, Kennell, Irvin, Kennell & Klaus, 1975; Longo & Bond,

1984). It is upon this last approach that the present research is based, and therefore it will be discussed in more detail.

Family resources, those attributes manipulated by the family "to control and direct change within the family system and decrease vulnerability to stress" (Byrne & Cunningham, 1985, p. 854), are a dominant subject in this third category of research. Resources which may be considered include health, potential energy, family members, problem-solving skills, the family members' perceptions and definitions of the situation, the intra-familial relationships and role division, and the family's social and support network (McCubbin, 1979; Stagg & Catron, 1986; Dunst, Trivette & Cross, 1986). Factors which can influence the resources described above such as cultural variations and ideological styles of families are also attended to (DeLucas & Salermo, 1984). However, no one model has emerged which considers all of the factors listed.

Of particular concern to this recent research is the area of social support, both formal and informal. The notion that there is a positive relationship between support, both perceived as available and actually received, and an individual's well-being has been well researched (Cohen & Wills, 1985; Gottlieb, 1983; Wethington & Kessler, 1986; Dakof & Taylor, 1990). Some of the research pertaining specifically to social support and the family with a handicapped child has indicated that social relationships and support available from a variety of sources has a positive impact on parental functioning and attitudes (Crnic, Friederich & Greenberg, 1983; Blatcher, 1984; Dundst, Trivette & Cross, 1986).

Further, it has been shown that social support can influence how the parents of a handicapped child perceive their child. For example, the research of Dundst, Trivette & Cross (1986) indicated that when parents report more satisfaction with their support system, they also report that their child has fewer physical limitations, is more socially accepted by others, has fewer behavioural problems and difficult personality characteristics than when they report less satisfaction with support systems, regardless of the child's actual limitations.

The marital relationship is one source of support which has been investigated numerous times with conflicting results. While one researcher reported a higher rate of divorce among couples with a handicapped child (Love, 1973), others reported no difference with national averages (Waisbren, 1980; Longo & Bond, 1984). As indicated by Byrne and Cunningham (1985), one explanation for this could be the variance in the sample compositions.

More pertinent to the area of coping and social support, Freiderich (1979) and Beckman (1983) reported that mothers verbalized significantly less stress when the marriage was intact. In addition, Freiderich's research (1979) indicated that marital satisfaction or the degree of security the mother felt in the marriage was positively related to coping.

It is difficult to determine the effect of professional contact on the parents of handicapped children. There are many different professionals who become involved with a handicapped child and his or her family, and each of these professionals interacts with the family in his or her own unique fashion according to his or her role. Which professionals the families will relate to varies over the life-cycle as the

needs of the child change (Fewell & Vadasy, 1986), with the family with a younger child being more likely to enlist the services of the medical profession, whereas the family of the older child is more likely to be in contact with teachers, physiotherapists, occupational therapists, and speech therapists. Suelsle and Keenan (1981) also found that use of both formal and informal supports varies over the life-cycle with families of younger children using more of the available services.

Burden (1980), in his evaluation of an early intervention program in England, found that professional contact is helpful. He reported that after two years, those participating in the program had made better progress in adjustment and were more positive about their child than those parents who had not participated. Unfortunately, the participants were not asked what it was about the program that had been helpful to them, nor were the variety of professionals involved identified.

In view of the idea that social support increases well-being, one might think that when more services are available, the parents will show a higher level of adjustment. However, Waisbren's (1980) study indicated that this was not necessarily the case. He studied a group of parents from Denmark, where support services are more readily available than in North America, and compared them with an American group of parents. The study found no differences in adjustment between the Danish group and the American group.

Thus far the studies reviewed determined the presence or absence of support but they neglect the actual transactions, and do not address how support affects the parents. Yet, it is those issues that are most germane to practitioners.

There are many books written for the helping professional on how to help families of handicapped children. Some of these such as Heward, Dardig and Rossett (1979) are mainly concerned with the behaviour management of the child, and they focus on teaching the helper to teach the parents to teach and manage their child, with little if any reference to the parents' emotions.

Others such Seligman (1983), Paul and Beckman-Bell (1981), Delucas and Salermo (1984) concern themselves with the parents' emotional world. The parents' possible emotional reactions are discussed, and helping strategies are suggested, case examples are used to illustrate the problem and the authors' successful intervention strategies. Others still, of which Mori (1983) is an example, combine the two approaches.

However, most of the literature designed to guide the clinician in helping the parents of a handicapped child makes little use of the points of view of the parents themselves, their experiences and perceptions of what has been helpful to them. Some exceptions to this are Paul and Beckman-Bell (1981), Delucas and Salermo (1984), and Fewell and Vadasy (1986).

Paul and Beckman-Bell asked several parents with a handicapped child to respond in writing to questions regarding the impact their handicapped child had on them and their community. They were also asked to describe their experiences with various professionals and the public school system. A variety of handicaps were represented. Some of the parents' responses were printed; however, there was no summary, analysis or synthesis of those responses.

DeLucas and Salermo taped a group interview with an ongoing therapy group asking the members about their relationships with professionals, their own coping mechanisms, and their support networks. The group consisted of families of hearing impaired children. Some of the participants were mothers, some were fathers, and there was one grandmother. A brief summary of the group members' comments was presented at the end of the chapter, but again, there was no systematic analysis of the information gathered.

Fewell and Vadasy's book (1986) presents a combination of qualitative and quantitative data addressing a variety of issues concerning the needs and supports of the family with a handicapped child over the life span of the child. This is one of the most useful books for practitioners since it combines the presentation of the current quantitative research regarding the needs of the handicapped child and his family, both emotional and physical, with the actual experiences of what it is like to parent such a child.

The chapter written by Moeller, herself the mother of a son with Down's Syndrome, gives a vivid description of her reaction to the birth of her son and the effects that a variety of professionals have had on her and her family. Her own experience is supplemented with anecdotes taken from her conversations with other parents over the years. However, again the interactions with the professionals do not go beyond the descriptions; they are not systematically analyzed.

RATIONALE FOR THE STUDY

The intent of the present research was to build on the existing information provided by Paul and Beckman-Bell (1981), DeLucas and Salermo (1984), and Moeller (1986), by providing more detail on the actual positive experience of having been helped. Although professionals have available guidelines and advice on how to work with families of handicapped children, parents themselves report few positive or helpful contacts with professionals (Featherstone, 1980). By obtaining more information on the positive interactions between parents of handicapped children and helpers--both professional and non-professional--as well as how the parents help themselves, potential helpers can then use that information to guide their own interactions.

In view of the evidence that positive social supports improve parent-child relationships, it is important that helpers understand as fully as possible those positive interactions in order to promote and increase their frequency.

METHODOLOGICAL CONSIDERATIONS

Some authors recognize that implementing effective intervention programs for families of handicapped children is contingent upon a more thorough understanding of how parents think and feel (Bristol & Schopher, 1984; Fewell & Vadasy, 1986). However, much of the existing research involving families of

handicapped children has been primarily experimental in nature, striving to measure and quantify the experience of having a handicapped child, in an attempt to predict how families will react to the stress. Such an approach generally obscures the individual's experience, yet the response to any stressor is a subjective experience, unique to the individual.

The effort to control the myriad of variables involved when studying such a complex situation as parenting a handicapped child has provided a wealth of information; however, this multivariate approach has also often narrowed the scope of many studies, as well as contributing to the many contradictions existing in the research literature.

For the information to be of practical value to the clinician, it now needs to be balanced by more research depicting how the parents themselves experience help. Dunkell-Schetter, Folkman and Lazarus (1987) indicated a need to determine what happens in a helpful transaction that makes the parent feel helped.

The phenomenological approach examining data arising from an interview with participants seems ideally suited to elicit such information. I felt that the face-to-face interview would enable me to obtain detailed descriptions of the way the parents of handicapped children experienced helping behaviour, by allowing me to probe more deeply or to ask for clarification when necessary. Further the phenomenological analysis of that dialogue offers the reader an opportunity to come to a better understanding of the "deeper meaning or significance" (Van Manen, 1990, p. 62) of the parents' experience by drawing out and making explicit the descriptions central to that experience.

CONTRIBUTION

The contribution made by this study is that it complements and builds upon the existing literature focussed on professional intervention with the families of handicapped children. It provides the practitioner with more detailed information on what specific behaviours are helpful to parents, and what it is about these behaviours that makes them helpful. Helpers can use the guidelines which evolve from the data to check their own interactions with families of handicapped children.

ASSUMPTIONS

I assumed that people in a shared cultural and linguistic community can name and identify their experiences in a consistent manner (Von Ekartsberg 1986) and that there is value in detailing those experiences.

I assumed that the gathering of other peoples' experiences allows us to become more experienced ourselves.

I assumed that I was able to form a sufficiently trusting relationship with the participants so that they will consequently confide in me.

I assumed that I was sufficiently able to suspend judgement during the interviews and while analyzing the data to allow the phenomena to speak for itself (Hyener, 1985).

LIMITATIONS

This study is limited by three main considerations. One, it was limited by my ability to develop a trusting relationship with the participants so that they would confide in me.

Two, this research was also limited by my ability to remain unbiased in interpreting the data and in extracting meaningful information from the participants' descriptions.

A third limitation of this study is that the findings are derived from the experiences of a six individuals and thus cannot be generalized to the general population. However, the intent here was not to generalize but rather to illuminate a human phenomenon or the world of the participants. By so doing, we may learn about the phenomenology of human beings in general (Hyener, 1985). In other words, the findings may be plausible to others and thus provide useful guidelines for understanding how the parents of handicapped children experienced helpful behaviours.

METHOD

Selection of Participants

There were four criteria for the recruitment of the participants. One, the family was to be intact. Two, only one child in the family was to be disabled. The third criterion was that the child had to be over three years of age since some researchers, such as Gath (1977) and Busch-Rossnagel, Peters and Daly (1984), have found that the stresses of parenting a very young child with a handicap are not so very different from those of other families with young children. The fourth criterion was that the exceptional child had to have a developmental delay which was diagnosed as moderate to severe.

Three intact families, each with one handicapped child, participated in this study. The participants were recruited with the help of a social worker at a local out-patient clinic which provides a variety of services to families with handicapped children. A written purpose and rationale of the study was given to the social worker (see Appendix A), who circulated it among his clients. He then gave me the names and telephone numbers of the parents who had expressed an interest in participating in the study. I then contacted the interested parents by telephone and further discussed the research project with them. Interviews were then set up with the parents who agreed to participate.

Research Procedures

1. The research project began with a conversation with a professor interested and knowledgeable in phenomenologically oriented research for the purpose of discussing and developing interview questions suitable for obtaining personal comments from parents. This led to the formation and approval of a research proposal.

2. The families to be included in the study were then contacted by me and interviews were scheduled. All of the participants chose to be interviewed in their own homes.

3. Each parent was interviewed once separately. Fathers are often ignored in the research involving parents of handicapped children; thus, this study will consider the experience of each parent individually. I allowed each interview to continue until the participant felt that he or she completely described their experiences. The interviews ranged in length from one half hour to three hours long. Although research questions had been developed to guide the interviews (see Appendix B), I remained attuned to each person's experience and allowed the participant's responses to guide the interviews as much as possible.

Throughout the interview, I strived to remain attentive to the participants' nuances of speech and gestures, and listen with my "whole being" (Colaizzi, 1978).

Although the focus of the study was to learn about positive experiences, participants were allowed to described all experiences negative and positive, so as not to restrict the flow of ideas. The interviews were audiotaped. A consent form (see Appendix C) was signed at the start of each interview.

4. The tapes were transcribed by a typist.

5. Meaning units were extracted from the tapes and themes were extracted (see data analysis steps 1 through 10 for details, p. 19).

6. A summary of the interviews incorporating the identified themes were then sent to the 6 participants. A letter accompanied the transcripts, asking the participants to carefully read the summary for accuracy and to answer any questions asked for the purpose of clarification (see Appendix D). Comments were invited and included in the analysis.

7. I contacted the participants by telephone one week later to discuss concerns and answer any questions they might have had concerning the content of the summary sent to them or the research study itself. The participants were asked to return the summary in the stamped, self-addressed envelope provided.

Data Analysis

The transcripts and audiotaped interviews were analyzed according to the procedure outlined by Colaizzi (1978) and Hyener (1985) and Rose (1990) and further enhanced by the philosophy of Van Manen (1990) and Von Eckartsberg (1986). The analytic steps used were as follows:

1. All six audiotapes were transcribed verbatim by a typist.

2. I listened to each tape to ascertain the accuracy of the transcripts.

3. I listened to the audiotapes again to familiarize myself with each participant's expressed and implied meanings.

4. I reflected on each participant's transcript separately to get a feeling for the uniqueness of each experience.

5. The written transcript of the first participant was read and re-read, and significant statements or meaning units pertinent to the research questions were extracted.

6. The meaning units were read over carefully to allow implied meanings as well as explicit ones to evolve and be noted.

7. I then determined which of the meaning units naturally clustered together; that is, I identified some common threads or essences that united several meaning units together.

8. The clusters of meaning units were examined to determine if there was one or more central themes which expressed the essence of those clusters.

9. Significant statements and verbatim quotes were organized around the themes to provide support for them from the data.

10. A summary of the first participant's interview was then written incorporating the themes. This summary "gives a sense of the whole as well as providing the context for the emergence of the themes" (Hyener, 1985, p. 291).

11. Steps 5 to 10 were repeated for each participant.

12. I then looked for themes that were common to most or all of the descriptions in order to write a composite summary, as well as identifying individual variations.

Throughout this process, I returned to the original transcripts time and time again to ascertain their full understanding and to allow the phenomenon to direct and guide my analysis.

PRESENTATION OF DATA

First I will briefly introduce each couple to the reader and provide a short description of the child's disability. I will then present a summary of each participant's unique experience, incorporating the themes extracted from their interactions with professionals, family and friends and from their own self-help mechanisms. Following the summaries will be a composite of the themes originating from the interactions of all the participants. These will be organized into three sections beginning with the themes originating from interactions with professionals, followed by the themes originating from interactions with family and friends, and ending with the themes originating from self-help mechanisms. Verbatim quotes are included with each theme so as not to loose sight of the theme's origin. A discussion will follow offering a composite impression of how these parents experienced helping behaviours.

Four tables are included which summarize the identified themes, outlining the behaviours associated with each theme, and delineating how those behaviours affected the parents.

Table 1 (p. 66), lists the themes derived from the parents' interactions with professionals, and what professionals were involved. Table 2 (p. 83) lists the themes originating from interactions with family and friends. Table 3 (p. 85) presents a list of the themes which were common to both the professional and personal contacts.

Table 4 (p. 93) lists the themes originating from the parents' own self-help mechanisms and the specific behaviours they utilized.

Summary of the Parents' Experience

Mary and John

Mary and John are a young professional couple in their mid-twenties. Their only child, a daughter, was three and a half years old at the time of the interview. She is considered developmentally delayed. She had no speech, was just learning to feed herself, could not walk or crawl, and needed a special chair in order to sit up properly.

Mary

Mary is a very articulate and energetic lady who was eager to talk about her experience. Help or support to her means someone assisting her to define what and where a problem is, and defining how best to resolve the problem according to the person involved. It also means allowing the person the freedom to express him or herself without preaching, assuming or judging, and accepting the person's final solution to a problem, regardless of the helpers' own viewpoint.

Mary's child is the youngest of the participants and Mary's experience following the birth of her daughter is still very vivid in her memory. Many aspects of it are still very painful to her and Mary seemed to need to talk about and relive that experience with a willing and sympathetic ear.

The period immediately following a baby's birth is generally a very emotional one for any parent. When that child is not the perfect one that was hoped for, the emotions become more intense and are complicated by grief. Further complicating Mary's particular situation was the fact that she had had an emergency Caesarian Section and was thus receiving narcotic analgesics, which numbed and confused her emotions. Mary felt helpless and out of control. She desperately needed to regain control of her life by taking some action and by reaffirming her sense of self and competence. She also needed to feel a sense of normalcy in her situation. The most vivid experiences that Mary had with both professionals and personal relationships were those whose behaviours either helped her to fulfil those needs or impeded her efforts. Her own self-help behaviours were also geared to reclaiming control over her life and reaffirming her sense of identity.

The lack of and the ambiguity of the information she received concerning her baby's condition did much to increase Mary's sense of dread, helplessness and incompetence. Without concrete information about her baby's condition, she could not act nor could she make decisions about herself or her baby. In addition, she could not be herself. She could not feel free to express emotions or frustrations for fear that she might alienate someone and thus more information would be withheld from her.

So she would hide in the bathroom to cry. Further, Mary's exclusion from the major decisions concerning her baby contributed to her feeling incompetent and out of control.

By contrast, when the baby was admitted to another institution where she was treated as an important part of the child's care team, Mary's spirits were lifted considerably. The staff there, nurses and nurses aides, treated her as a competent person and expected her to cope with her baby's care and needs. She felt a sense of mastery and she lived up to those expectations.

Another theme central to Mary's experience is respect for her as an individual and for her child. The situations where she felt the most despair were those when her individuality was obscured and she was treated as a statistic or "just" the mother of a handicapped child. It was important to Mary that she be treated as the mother of a child not just a handicapped one. Thus she resented being told globally that she was wonderful. She wanted recognition for specific parenting skills that would be important in raising any child, not just a handicapped one.

To this end, she helped herself by telling herself that all parents have problems when raising children. Her problems may be different than those of most parents but not necessarily worse.

It was also very important to Mary that her life return to "normal" as much as possible. Thus she felt very good when she and her child were treated like any other mother and child, such as being invited to places where a "normal" child would be invited. To help herself regain a sense of "normalcy," Mary resumed some of the

activities that had been important to her before the birth of her child, such as taking courses and going back to work. This helped her to reaffirm her sense of self, and boosted her confidence as a functioning human being. When engaged in these activities, she was Mary, a competent adult, not just the mother of this handicapped child. She may have had a handicapped child but she was still the same person. She also found that by spending time alone she was able to put her situation in perspective and refocus her concentration.

Mary loves her child very much and she longs for her to be accepted and loved by others as well. Therefore, it hurt her a great deal when that did not happen. For instance, when the nurses at the hospital did not cuddle her, even when feeding her, or did not provide adequate physical care. Or when her friends avoided the baby and did not pick her up. On the other hand, when professionals expressed delight with the child and saw her as cute and cuddly, or when friends picked her up and reacted with friendly interest, then she felt her spirits lift considerably. When her child was valued as a person then her own ego was boosted.

Before a helpful experience, Mary would be feeling desperate and haggard, not sleeping or eating, and unable to concentrate on anything. Knowing that something had to be done, but not having enough energy to follow through, rendered her frustrated and panicky. Afterwards it was like a wave of relief. She felt almost invincible, like she could conquer anything. Her confidence was boosted, and that would be enough to sustain her until the next time.

Reading a summary of her experience was educational for Mary. Seeing her thoughts and feelings written down illustrated for her how far she had come mentally, emotionally and physically since those first months. It also made her realize more concretely that in "one form or another it will be around forever." This is a problem she cannot escape, but one she will have to face for a very long time.

John

John is a soft-spoken, sensitive man whose love and concern for his daughter was very evident. He was very thoughtful and articulate through the interview but needed encouragement to express his feelings and experiences.

Help to him encompasses actual practical help such as helping to feed his daughter, lending a car, or taking care of his daughter as well as psychological support, such as helping him to understand the stress involved when parenting a handicapped child, and helping him through the emotionally tough times.

His daughter's condition at birth was difficult for John to accept; it came as a complete surprise. There was a great deal of ambiguity concerning her diagnosis and thus there was no definitive information for him to work with. John does not feel that he received help from anyone during the early shock period. The pain he felt was something he had to work through himself. He sensed a wall between himself and his friends; they had problems dealing with their own feelings and were thus unable to help him and he felt isolated.

Similarly, he feels that on the whole he experienced no emotional support from the doctors involved in his daughter's care. He felt misunderstood and ignored by them.

John needed to feel like a person, a father, with the ability to exercise some control over his and his daughter's life. He had ideas and opinions concerning her care and he wanted to discuss those with the professionals as an equal. When that did not happen, he felt diminished as a person and as a father. On the other hand, when he felt that the professionals involved in his daughter's care listened to his ideas and discussed them with him intelligently and involved him actively in the decision-making process, then his sense of self-worth was restored. He felt that he had more control over his life again.

When John sensed that their was some warmth in his relationship with a professional, when that professional did not remain cold and distant but was open and showed some vulnerability, then he felt more relaxed with them and could trust his or her judgement regarding his daughter's treatments more easily. He was also able to accept less progress than he had hoped for because he knew that that person was doing the very best job they could possibly do.

John wanted to talk about his feelings regarding his daughter, but he did not feel comfortable doing so unless he sensed that the people with whom he was interacting were really interested in him and his feelings. Thus, if a professional initiated contact and asked him about his feelings, it helped him to open up. Similarly, when his friends were comfortable enough with their own feelings and

asked him matter-of-fact questions about his daughter and her care, their friendly interest let him know that they were ready to listen to him if he wanted to talk. John also felt more comfortable in a non-judgemental atmosphere where he felt no expectations to feel differently.

John loves his child very much and it hurts him to know that she will not develop normally. That hurt is lessened somewhat when the people involved in their lives professionally or personally demonstrate that they like his daughter for who she is regardless of her disabilities, and thus respond to her in the same way that they would towards any child. Conversely, when that does not happen, the hurt is exacerbated.

He found it helpful to know that people or programs were there for him if he needed them, but were not pushed on him. There were so many people involved in his daughter's care and treatments who just did what they felt needed to be done without ever soliciting his wants that John frequently felt that he had lost control over his life. However, when allowed to just be, or when presented with options leaving the final choice for him to make, he regained a sense of mastery.

Linda and Sam

Linda and Sam are in their fifties. They adopted their daughter when she was a baby, and were aware of her special needs status at the time of the adoption. She became infected with meningitis as an infant with the residual effects of left-sided

weakness and mental retardation. She can feed and dress herself and do some small chores around the house, but because of severe memory deficits she must be constantly reminded of what needs to be done. Linda has grown children from a previous marriage. This is Sam's first marriage and he has no other children. Their daughter was 10 years old at the time of the interview.

Linda

Linda is a very giving person who tends to take on too much in trying to please others. When describing what help meant to her, she described it in terms of how she helps others, not how others can help her: "to do my best to ease a burden to anyone who is in need of my help. Be it caring for or giving." Linda was recovering from a severe episode of bronchitis when interviewed and seemed tired. Yet, she was eager to talk about her experience. She talked a great deal about what life was like in general with her daughter.

Linda is a very busy person. She works full time and enjoys many interests. Her daughter is at an age where were she normal she would be relatively independent in terms of self-care as well as being of some help around the house. However, her daughter's disabilities are such that Linda must always be around to supervise and remind her daughter of what needs to be done. Therefore, she has always been grateful for any practical help given to her that lightened her burden and made every-day life easier.

In this Linda has found that the occupational therapists and the physiotherapists have always been helpful to her. They give her concrete methods to help her child such as feeding techniques, proper sitting, and specific exercises that can be done at home to promote her development. With these techniques, certain tasks such as feeding and dressing are made easier. In addition, Linda is empowered to contribute positively to her daughter's progress. Being able to act gives her some control over her life and her situation.

Other circumstances that have made life easier for Linda is her daughter's new school. Just the fact that the school provides lunch twice a week, and provides transportation to and from school has taken some of the weight off her shoulders. In addition, Linda has been particularly grateful for the extra pair of hands around the house since her husband has been off work waiting for elective surgery. The morning rush trying to get her daughter ready for school is shared, taking some of the pressure off her when she also needs to get herself ready for work.

Obtaining pertinent and appropriate information concerning various aspects of her daughter's behaviour and development has been helpful to Linda. When properly informed about her daughter's medical condition, she understands her daughter's condition more thoroughly and can thus make more realistic plans for her future care. Similarly, when informed of her daughter's behaviour at school, Linda can judge more accurately what kinds of environments are suitable for her.

Linda loves her daughter and wants others to have respect for her humanity and to treat her well. Thus it is distressing to her when she and her daughter find

themselves in a situation where this does not happen, such as in an early day care, where the child did not receive adequate care and supervision, or at her previous school where her daughter's individual needs were not considered and again adequate supervision was not provided.

On the other hand, when her daughter is liked and accepted and included in the types of activities any other child would be involved in, such as in her new school or with community organizations such as Brownies, then Linda feels good and hopeful that her daughter will have a place in society even when they are no longer able to care for her.

Linda wants her daughter to experience as much of a normal childhood as her disabilities will allow, and she wants her to learn as many life skills as possible. The more independent she can become, the more accepted she will be by the community. Thus, Linda finds that the programs that support those goals are helpful to her: the physiotherapists and the occupational therapists who give her ideas to improve her daughter's functioning; the school program that teaches life skills and incorporates the disabled children as a part of the school's community; Brownies, who like her daughter and take her on all kinds of outings that any normal child would participate in. Linda finds these helpful because her daughter is treated with respect and she is being taught important skills while she is having fun.

Linda has found that she needs a break from her daughter from time to time. She needs to nurture herself if she is to continue to function. However, she often needs permission to do this and it is helpful to her when someone such as her general

practitioner tells her that this is what she must do. Yet, before she can take time for herself Linda also needs to know that her daughter will be happy and well cared for in her absence. Thus, it is helpful to Linda to have competent people who look after her daughter lovingly whenever she needs to be away such as her neighbour, babysitters and Brownies. With these resources, Linda can enjoy her time away secure in the knowledge that her daughter is loved, safe and happy.

Linda has built good support systems around her and she is able to reach out to different people when she needs emotional support or advice such as her general practitioner, her co-workers, her neighbour, her husband, and her social worker.

These people help her by encouraging her to confide in them, by asking questions and thus showing their interest. They help her to clarify her ideas, and to get started on an appropriate solution to her problem. She knows that they are there for her and care for her and she does not feel so alone.

When Linda suspects that something is wrong with her child or with a program with which she is involved, she wants someone to listen to her concerns and help her do something about it. She knows her daughter better than anyone else and she feels good when that is acknowledged.

Linda does several things to help herself. Very important to her at the time of the interview was her developing assertive skills. Learning to say "no" to too many demands made on her time so that she can nurture herself, and learning to question professionals and to be persistent in pursuing change when she senses that something is not quite right. Recent successes in this endeavour have really buoyed Linda and

she feels energized. She feels that now she has more control over her life and what can be obtained for her daughter.

Developing this assertiveness is not easy for Linda. Thus, it is helpful to her when others such as her co-workers and a neighbour encourage her to trust her instincts and persist in pursuing her goals. Knowing that they think she is right gives her the extra courage she needs to do what she thinks is necessary. She likes to have her own opinion and she feels good about herself when she makes the decision to say "no" when she really wants to.

Linda has not turned to her family for help. Her grown children all keep in close contact and frequently offer to take her daughter to give her a break. She knows that they love their disabled sister and that feels good. However, she rarely turns to her family for help. She feels that she took on this responsibility, and she must cope with it without troubling them because they have their own concerns.

Before a helpful experience, Linda is besieged by gloomy thoughts and wonders what she is going to do. Following a helpful experience, she feels relief, particularly, if her daily routine has been made easier or her daughter is happier.

Although living with her daughter has been a source of frustration and hard work, as well as a financial hardship for Linda, and although she feels that she did not fully understand the challenges that raising a handicapped child would bring when she adopted her, Linda's outlook remains positive. She finds that her child is a source of great joy for her, and that her presence keeps her young.

Sam

Sam is a very private person who tends to work out his problems on his own. Help to him meant someone who will listen, offer advice or alternatives and suggestions. He was not eager to discuss his experiences and needed encouragement to elaborate and describe his experiences more fully.

Sam has had very little contact with the professionals involved in his daughter's care because his wife usually deals with them. He sees the contact with professionals as more the mother's role, and she keeps him informed of whatever was discussed or done.

An exception to this is a recent contact with a paediatrician whom he perceived as helpful. When his daughter's behaviour became very difficult due to stress at school, this professional was helpful to Sam by listening to his concerns and then thoroughly assessing his daughter. This assessment confirmed his suspicions that the problem was not medical in origin but was rooted in the school program. This paediatrician then supported Sam in his struggle with the school Board to transfer his daughter to a more appropriate program in mid-term. Sam feels that the paediatrician's willingness to back up his efforts gave him more power to achieve his goal.

The interaction itself was not important to Sam, "he was a busy physician," what mattered was that he obtained results for his child.

His daughter's behaviour towards others is inappropriate at times and Sam finds that this can be embarrassing. He senses that the other people may not know how to react, thus, he tends to avoid certain situations. He finds that it is helpful to him when he can discuss his daughter's behaviour with friends, because then he can be more open and relaxed with them and better able to enjoy their company. However, Sam is unable to pinpoint why he feels comfortable with some people and able to discuss his daughter's behaviour and their reactions but not with others. He just feels it intuitively.

Sam's main source of support is his wife. He can discuss what is troubling him with her. When he talks with his wife, he feels less alone since she often shares his concerns. He also gets a different perspective of the situation and together they can often solve whatever was causing the problem.

To help himself, Sam will reach out to his wife or possibly his family physician. Otherwise, he engages in activities that remove him from his immediate situation and either distract him, such as reading a book or tackling a project on his workbench, or one that gives him a chance to think and possibly arrive at a solution, such as a drive by himself. Getting away from the situation relieves the tension and renews his energy.

Sam seemed to take a cognitive approach to life which enabled him to accept, understand and create meaning in his world in general. He does not blame people for their often insensitive attitudes towards the disabled; he understands that their attitude is due to a lack of exposure and thus not really their fault.

Jane and Marc

Jane and Marc are in their early thirties. They have two daughters aged eight and ten. The eldest was diagnosed as having Cerebral Palsy in infancy. She has right-sided weakness and is considered moderately retarded. She speaks and can do self-care but she has poor judgement and is considered a behaviour problem. Their second daughter is developing normally. The marriage broke up shortly after the interviews and Jane and Marc did not return their summaries to me. I chose to include their experiences regardless because of their unique contributions to the study, and since each of them had concurred with the content of their summaries in my telephone conversations with them and at that time voiced no concerns or objections.

Jane

Jane seemed to be very intense during the interview, like a tight ball of energy ready to explode. She was eager to talk about her experiences, and at three hours her interview was the longest.

Help to Jane means someone who will help her understand her daughter a little better and help her manage her behaviour. Jane seeks help when she is feeling at the end of her rope. Afterwards she feels empty. She has obtained immediate relief because she has ventilated some of her feelings, but her problems are still there.

It takes a while to implement solutions (in itself a stressful process) and the results may not show up for some time, or there may not be any results.

She has found that although her situation is actually more difficult now that her daughter is older because her disability is more visible, and her younger sister is passing her and leaving her behind developmentally, Jane thinks that she is handling it better because she has learned how to deal with her feelings and how to obtain the help that she needs from the community.

Accepting her daughter's disability was central to Jane's ability to help herself and to accept help from others. Accepting and seeking help meant admitting that her child would not meet her idealized expectations. It also meant giving up some control over her daughter and her life. This was a difficult step for Jane to take. However, once she did accomplish this, every day life was easier for her because the burden of caring for her child was shared, giving her more time for herself. The staff at the out-patients clinic where her daughter is in attendance could have been more helpful to her in the early days of their association by being more sensitive to her need to seek other opinions until she was satisfied that no mistakes had been made in terms of diagnosis and prognosis, and that this particular clinic was the most appropriate place for her daughter's needs. Their disapproval increased Jane's resistance to accept their help and impeded the early development of trust.

Trust is an important factor to Jane when interacting with professionals, and it does not come easily to her. She found it difficult to trust the staff at a local general hospital in the early diagnostic days because she perceived that information was being

withheld from her. She was better able to trust the staff in a Vancouver hospital where her daughter was sent for assessment, where they would tell her what they were doing and what they knew or did not know.

It is also important to Jane that the professional who is trying to help her be familiar with her daughter and her behaviour. She feels that only then can they really understand what she is going through.

This theme is also important to Jane in her personal relationships. When talking with friends, Jane finds that one couple in particular really understands her thoughts and feelings about living with a disabled child because a member of their family is disabled and she feels an affinity to them. In spite of this, Jane does not wish to participate in support groups with the parents of other handicapped children. When she did try, she found that these other parents' problems were similar to hers and they had no solutions for her. This she found depressing. She prefers discussing her problems one-on-one with a professional; she has more trust in what they have to say because she feels they are more knowledgeable and can offer more solutions.

Trust in professionals and thus their ability to help Jane has increased over time. Once she knew the staff at the outpatient clinic, and they had proved their expertise by often being correct in their assessments and treatment plans, Jane could then have more faith in their suggestions for treatment.

Practical help that can make everyday life easier for Jane was appreciated from both professionals and friends. Professionals help her the most by giving her specific suggestions to help manage her daughter's behaviour, or by helping her

identify, locate and use available community resources. Friends help her by offering to care for her children once in a while to give her a break.

It is important to Jane that she not feel alone in her daughter's behaviour management and in how she perceives her daughter's place in the family. Jane is acutely aware of this because of the lack of support she has felt from her family in this respect. Their opposition to behaviour management plans and in Jane's realistic perception of her daughter's abilities is a source of stress for her and she feels isolated from her family.

Similarly, it is Jane's perception that her husband has had difficulty accepting the severity and permanence of their daughter's condition. According to Jane, he thought that she would just outgrow it and thus did not adhere to the behaviour management programs designed for their daughter. This impeded their child's progress and as a result Jane was feeling alone and frustrated. However, she feels that since Marc has come to terms with his daughter's disability, and they are now battling the behaviour problems together, they back each other up instead of fighting each other with happier results.

It is helpful to Jane when she senses that she is in a caring environment where people are interested in her and her problems, in both her professional and personal relationships. When interacting with the professionals at the out-patient clinic where her daughter is in attendance, this atmosphere comes to life for her. They ask her how she is feeling, or how her daughter is doing. In addition, they have always shown her that they are never too busy to talk with her if she needs to even without a scheduled appointment. She is important enough to them that they will make an effort

to fit her into their busy schedules. They encourage her to phone them at home if she becomes overwhelmed, and they look into things for her. These behaviours let her know that help is available; she is not alone. Also, she never feels judged by these professionals. She can feel free to express any feelings, both negative and positive, and still feel accepted by them.

Her friends let her know that she is welcome to express herself with them by inviting her to phone them or to visit them when she feels the need to talk. They have made themselves available to her if she needs them.

Jane seems to be acutely experiencing chronic grief. The stress and the hard work of parenting a handicapped child overwhelm her on a regular basis and she finds herself being depressed. Over the years, Jane has developed several strategies to help her through the day-to-day stresses and the recurring episodes of grief.

Paramount in her coping strategies has been achieving more control over her life. One way she has done this has been to develop more assertive skills. She has learned to be persistent when she needs something for her daughter, and to more effectively use the available community resources or create some where none exist

Another way that Jane has learned to gain control is by owning her feelings. She reasons that they are her feelings and thus can only be changed by her. Further, Jane prevents herself from being overwhelmed by her situation by looking at her life in small manageable chunks. Jane also tries to focus on her daughter's positive attributes rather than dwell on the negatives. By appreciating and enhancing the positives, Jane's relationship with her daughter has improved.

Jane has also recognized the importance of taking care of herself and her own needs. When she recognizes that her grief is adversely affecting her behaviour towards her daughter, she distances herself from her daughter for a short while until she can work through her negative feelings.

Working has been helpful to Jane in this respect. At work not only is she forced to concentrate on something else which takes her mind off herself and her situation, but also at work she is a functioning adult who is in control of her situation.

Another strategy that has been effective for Jane is to set goals for herself and her child. This gives her something positive to work towards. But she has also learned to remain flexible if the desired goals cannot be achieved, thus she avoids disappointment.

These strategies are helpful to Jane but still the grief is ever present. Sometimes Jane wishes that she could "wake up and find out it was all a bad dream. When I wake up I wish that it would just be gone."

Marc

Marc is a quiet man who needed encouragement to describe his experiences. The word "help" to him means relief, someone he can turn to if he has a problem, someone to help him gain better insight. When he makes the decision to seek help from the clinic where his daughter is the recipient of a variety of services, he is usually feeling nervous, and also hopeful that he will be hearing great words of

wisdom. However, afterwards he often feels confused. Some of the things he heard were not the answers he wanted to hear. He thinks that perhaps he was looking for something a little too easy. He goes in expecting more help than he actually gets. He does not blame the professionals for that; he thinks that he was probably expecting too much. They do not have all the answers and sometimes that is disappointing.

The familiarity with professionals associated with the clinic which has developed over the years has been helpful to Marc. It is comforting to know what to expect from someone or a facility and when, particularly, since he is content with the help that he receives there. He is satisfied that the professionals at the clinic are well trained and competent. He knows that the facility is well staffed and able to deal effectively with any behaviour that his daughter might engage in. These factors all contribute to his feeling that this clinic is helpful to him. When his daughter is in attendance there, he is confident that she is receiving good care and he does not worry about her.

This familiarity is all the more poignant now that his daughter will be entering the public school system. There are many unknowns associated with that transition and it is causing him much anxiety. He worries that some of the factors that contribute to the overall helpfulness of the clinic, such as the amply trained staff, will not be available. He is concerned about the possible disruption this could cause, such as receiving calls at home or at work to come and get his daughter because they cannot handle her. This transition to the public school system could have been a less anxious process for Marc if he had been familiarized with some of these unknowns.

His questions about class size, the training of the staff and procedures regarding disruptive behaviour could have been explained. Some idea of what to expect of his daughter's new environment would have alleviated some of his anxiety and would have helped him to prepare mentally and practically for this important transition.

For someone to be helpful to Marc, it is important to him that they be familiar with his daughter. He feels understood by the staff at the clinic because they interact with his daughter daily and they know what she is like and they can truly empathize with the problems that Marc may be having with her.

A professional is also helpful to Marc when they give him information. When he senses that the professionals are telling him what they know and are answering his questions fully, then he can trust their judgement. This trust becomes very important in the child's treatment at times when a controversial procedure or treatment, such as medication, is being advised, which invokes negative feelings for Marc. If the professionals can explain clearly what they are wanting to do, in a way that makes sense to him, then Marc is more willing to put aside his fears and trust the professionals' judgement. This trust helps him to make a difficult decision.

An important part of the professional relationship was the practical help that was given. Helping Marc to find alternate ways to manage his daughter's behaviour, or locate appropriate community resources, made his everyday life easier. In addition, having some positive action to takes removes some of the helplessness.

The helpfulness of his personal relationships follow some similar themes. Close friends stand out as being particularly helpful because he finds them so easy to

talk to. Although it was difficult for him to pinpoint exactly why this was so, one factor was that these friends would invite the children over on their own. This action on their part was helpful for several reasons. Although the obvious practical consequence of giving Marc and his wife a break was present, this was not the most significant reason why this was helpful to Marc. Rather it was the fact that they enjoyed having the children around. They like the children and this makes him feel good. In addition, because they have had the children around so much, they know intimately what it is like to live with them. Thus, Marc feels understood by them and therefore more comfortable discussing his situation with them.

Marc's parents are also very helpful to him by providing hands-on practical help. They take the kids away to give himself and Jane a break, a chance to be alone. In addition, they help in the everyday living, such as transportation to and from school and being available for unforseen contingencies such as their daughter being ill and needing to be picked up early from school. His mind is at ease with his mom taking care of these details for him and he can concentrate on his work.

In spite of his parents close contact with his daughter, they do not seem to really understand the permanence and severity of her disability. This prevents Marc from feeling truly emotionally supported by his parents. He senses their disapproval of some of his plans for his daughter and this is hurtful to Marc. He worries about his daughter's future and what will happen to her if her behaviour does not improve. His parents' approval and support of his goals would facilitate his decision making.

Themes

Themes Originating from Interactions with Professionals

1. Receiving clear, honest and pertinent information.

Mary:

"I found them very evasive about the baby . . . . I knew there was something very wrong . . . . They wouldn't let me hold her . . . . It was just like pulling teeth trying to know anything . . . . I kept asking and asking and there was no doctor--I needed to know what I was going to do and what we needed to expect and then I could sort of plan my life around that."

John:

"It would have been nice for them to be honest about it though and say, 'we really don't know' . . . . I felt that I was a real idiot myself and that they thought they shouldn't tell you anything because you wouldn't understand anyways. Either that or they didn't feel that they could communicate with you and tell you what was going on for some reason, you couldn't handle the stress."

"They are normally honest with you, they will tell you whether your expectations are too high . . . which is nice because it let's you get going also."

Jane:

"They don't tell you a great deal half the time anyway."

Jane recalls of the early days when a clear diagnosis of her daughter's condition was still being determined.

Marc:

"I haven't had too many encounters with the professional side of it . . . . My wife has been to most of the meetings . . . . They are quite helpful out there . . . . They tend to answer your questions

> pretty well . . . what you are curious about . . . what to expect . . . . There are psychologists out there, I found them to be fairly helpful . . . . I wouldn't say they are holding anything back."
>
> "Not enough communication between what goes on in the class and at home. It was just a couple of weeks ago that they mentioned to send a little book and it will be written in the book whether the behaviour was good or poor or any other problems, but I kind of wonder why wasn't it done before."
>
> **Linda:**
>
> "When [daughter's name] was 6 years old she had a psychological assessment and it was explained to us in a way we could understand what had happened during the brain damage and what we should expect with her advancement."
>
> "I can't believe the difference between the two schools, the difference in information that comes home . . . from the principal, mostly from the teacher, the nice notes that come home that concerns the whole school . . . . We are now not worried. Already, from going to this other school, we know that for the next few years that [daughter's name] will be at [school's name]. We know the class that she is going into in September and all about it. We know the teacher already. We also know that when she is old enough to go to another school, she will go to [name of school]. They get the child used to that different environment . . . to see if they are suffering in any way. It's such a relief because we were thinking, 'what's going to happen in September?'"

Receiving information was a theme important to five of the participants. Sometimes it was the paucity of information that stood out in their minds such as with Mary, Jane and John, following the birth of their baby. The anxiety, confusion and helplessness felt by these parents increased when they sensed that information was being withheld from them. It was demeaning for the parents. They felt that they were not trusted to respond in a mature fashion. They needed to act to make sense of their situation but without adequate information they felt powerless to do so.

Linda's experience in this regard reflects those feelings in a positive way. When she received some accurate and pertinent information addressing her daughter's medical condition and potential development, she was better able to make realistic plans for the future for herself and for her daughter.

The proffering of honest information can contribute to the building of trust between the parents and the professionals. Jane experienced this when her daughter was taken to a hospital in Vancouver for assessment. There the parents were kept informed and the staff were honest about their uncertainty concerning a definitive diagnosis. Sensing their openness and honesty made it easier for Jane to communicate with them--a sentiment shared by John. It was helpful to him when the professionals shared their perception of his daughter's potential development. Their honesty helped him to get on with his life and make plans for his daughter in a more realistic way.

Communication from the school informing the parents of the child's progress and behaviour at school as well as ongoing activities was helpful to both Marc and Linda. They are concerned about their child's behaviour, and they like to be informed of how their children are behaving when they aren't around to observe them themselves. The communications books and notes from the school are a link between them and the school. They feel less isolated from their child's daily life.

Information can also alleviated anxiety concerning future events and help ease important transition times such as changing schools. This was Linda's experience and it was a great relief to her to know what to expect the following year. It was one less worry for her, freeing her to focus on other things.

2. Sensing that the child and parent were important to the professional.

Mary:

"It was horrible . . . but I found that they were sort of palliative care with her. They were just feeding her and keeping her dry. She was having these horrible loose stools, and she was burned all over. She still has scars on her buttocks from them. But when they found out she was going to the [another institution], then and only then did professional pride come into play and they started 'lamping' her bottom and feeding her properly and these kinds of things."

"She [the dietician, who finally realized the baby was allergic to her formula and administered an appropriate one] was great. She [child] retained her only feed in weeks and started to thrive."

Re a new feeding program:

"One RN and she was as stubborn as [daughter] and she came in on her days off. She worked seven to seven. She would come in at midnight to feed her."

"He [GP] felt almost as strongly as we did . . . . He just said nice normal things. He sat there. He was very caring. He would say, 'This is going to be tough but we will get through it.' He knew what I needed then."

John:

"The nurses took a real interest in her [daughter]. There was one nurse who came in every day just to do her feeding, on her days off and everything."

Linda:

"When she was in daycare . . . . She always had colds then, sometimes I'd go and she would be outside playing with no sweater on and the wind was so cold and these people that you trust to look after your children, she had tubes in her ears, she was always having ear infections . . . when I would go her nose would be running and she would be cold. Those kind of things used to drive me nuts."

"I went to school, and this is a special needs program, one little girl was sitting out in the hallway because she wouldn't eat her lunch that

> was more handicapped than [daughter's name]. They have two monitors everyday with the children, helping them with their lunch, no adults . . . [daughter] fell on her face in the school yard a week before Christmas, such a bad fall, that she was bruised behind her ears, her face still has the scar. Two special needs children brought her in, there was no adult again."

Sam:

> "He [pediatrician] wanted to be in on any meeting for which class she was to go into."

Jane:

> "They phone you at home to see how you are doing, and they encourage you to phone them on week-ends if you run into problems . . . . They look into things for you . . . . They phone you at home and say 'we can arrange this for you.'"

Marc:

> "I guess over the years, I have felt a lot of comfort with [daughter] going there because there are so many professionals. I guess that takes a lot of the stress and worry away because you know she is somewhere where there are people there who are trained to deal with and help her."

As parents who love their children these parents want them to be well cared for and happy in their absence. When the care their child receives is less than adequate, it is as if the professionals involved do not consider or her important enough to care for or her properly. Her humanity is diminished and the parents feel angry and helpless and they worry about their child's well-being. On the other hand, when their child receives competent care, and when the parents sense that the professionals are doing their jobs properly, or when they seem to be making an extra effort and obviously doing their best, the parents can relax and go about their day

worry free, secure in the knowledge that their child is receiving the best care possible by committed individuals.

3. Sensing that the person's individual circumstances were being considered.

Mary:

> "She [social worker] stood their and said, 'I just want you to know we are there if you need us because parents of handicapped children have a much higher potential of abusing their children than other parents.' She didn't try to find out how we are going to cope or if we needed help. I was going to abuse this child so I'd better watch it."
>
> "They seemed to assume that I wasn't going to take the baby home."

Mary's individual situation was not assessed in these two encounters. The archaic assumption that the baby would be institutionalized was made without first discussing it with Mary, and she was lumped with statistics on child abuse in families with handicapped children. Mary was outraged.

A more positive experience was an RN who "came in for coffee because I wasn't sleeping through the night and put her feet up on the bed and bitched about the other patients. I thought, "This is great, she recognizes that I'm a person that I'm not this jelly person over here who is going to fall apart."

This encounter also distanced Mary from the situation as well as validating the negative feelings she had about the other mothers on the ward, "I hated those mothers with their perfect babies."

A negative encounter where Mary did not feel recognized as an individual was an RN who explained the most fundamental medical terms to her even though she

knew Mary was a nurse. "Suddenly my skills as a nurse were gone." Mary felt she had been belittled and patronized.

4. Achieving reciprocal familiarity with the involved professionals and the child and her needs.

Marc:

> "I guess that is why next year we are looking at being a little more worried, because we don't know what to expect . . . . I don't know how big the classes are. I don't imagine that they will have the same amount of time to deal with the individual kids. It is a worry with her behaviour problem at school . . . . that they won't have the time to handle it."

Jane:

> "Now most of the professional contact is more positive . . . . I think that the difference is in me rather than in them. I think that now I have grown along with it and faced the reality of the way she is . . . . I'm more willing to listen to what they have to say . . . most of the time they are right."

Mary:

> "Like the RNs on Peds, now she goes in quite frequently for surgery, they were quite horrendous the first two times I was there but now they're great. They know [child's name] and they know what to expect from her and they are very, very good. And I think the farther you get from that shocky, sort of initial time, when you don't know each other the better things are. Because the professionals I meet now are much better able to give me what I want than they were initially."

The interaction and help received from professionals improved over time for Mary and Jane. When the family and the staff are more familiar with each other, expectations of each other are more clearly defined and communication improves.

For Marc, the importance of that familiarity is more acutely perceived now that he is about to lose it. His daughter will be attending a different school. He is leaving a familiar situation where he knows the people and what to expect from them, to an unknown one where he knows nothing of the people or the system. He has to wait and see until the fall when school starts to know more and it is not a comfortable feeling.

5. Sensing that the professionals are interested in the parents as individuals and their feelings.

John:

> "The doctors that we dealt with were virtually no support at all . . . on the medical side they did the surgery, but as far as any support for feelings and that, there was virtually none. The nurses I didn't find helpful at all . . . most were just professional . . . . They did what they were supposed to do, the physical stuff, give medication and stuff like that but they were not supportive at all."

By contrast:

> "The caring nurses made an attempt to get to know you as a person, they made an attempt to come and speak to you when you were in there with [daughter] . . . and spent time with you. They were more concerned with your feelings or at least they appeared to be than with what the actual treatment, it was important, but it was secondary to what your thoughts and feelings were."

> "They [the physio and speech therapists] seemed to set their time, it wasn't like they had to do this thing today, if we have time at the end of that procedure we might sit and talk for a few minutes . . . with them, they went through that stuff with you first and even during the physiotherapy or during speech or something, you could take a break and chat if you wanted . . . they seemed to take a lot more concern about your feelings and stuff than just the clinical aspects of what was going on."

John felt supported by professionals when they talked with and seemed interested in him as an individual. In those instances he felt that he counted as a person and that his feelings were important. These professionals let him know that they were never too busy to listen to him and talk with him. This made him feel like he was part of his daughter's treatment and he did not feel so isolated. On the other hand, when the opposite happened, when the professionals performed their duties in silence without considering him, then he felt isolated.

6. Knowing that support is available for family members.

Mary: Mary appreciated one of the nurses in the special care nursery who was supportive with her dad. She was very worried about him in this situation and the support this nurse gave her dad took some of the pressure off her. "She wasn't good for me, but she was good for my dad. I really appreciated that."

7. Having needs anticipated accurately.

Although Mary emphatically resented decisions being made for her and her child, there were some circumstances where she actually appreciated the initiative of others.

Mary's roommate who had had several healthy babies was unable to curb her delight at having had yet another one. This was irritating for Mary as well as

accentuating her grief. One of the nurses on the ward recognized Mary's distress and moved her to a private ward at the earliest opportunity. This was a tremendous relief for her.

Another example was when the child was at home. The hospital staff ordered a special feeding device for the child and initiated a program to help Mary use it.

> "She was six months old and still being tube fed. It just was not working and they phoned and said they had this marvellous bottle from Toronto, they had ordered it from a catalog, it was brand new and did I want to try it. They were always thinking about you. Just when you had reached the end of your rope, something came in. There was some relief in sight. I didn't have to go searching because it was there."

In both these situations Mary didn't have to go searching for help, someone thought about her and took some appropriate action. This made her feel understood and less alone.

8. Sensing that their child is liked and valued.

Mary:

> "She was very positive about my child and positive that we could do something. She said, 'we have so much potential here.'"

Part of Mary's unhappiness with the general hospital was the lack of hugging and stroking given to her child, devaluing her in a way. However with her first encounter with another institution, she felt a difference right away. "We just came through the door--and there they were with [daughter's name] and wasn't she cute and

wonderful!" The same institution would always express their delight when her child was admitted. "Their total acceptance of the way the children looked--these were little people and they may have some difficulties---but they were worth something too."

John:

> "I know that when a person opens themselves up like that it probably has more of a toll on them personally . . . because they have become attached. It certainly makes a big difference, even the way [daughter] deals with them, it's not such a clinical thing . . . . It's nice to know that [daughter] likes who she is going to see . . . if she is not happy--then it will also have an effect on her physio . . . . She is not going to perform well."

These parents love their children and hope for their future. Thus when the professionals pointed out positive traits and expressed future potential, the hope was kept alive. It also feels good when others perceive their child as cute and attractive just like they did, and it was comforting to observe how the staff at one institution accepted all their charges with special needs. The parents were reassured that their child was valued and would be treated well. In addition, when the professional treating their daughter cares for her and likes her, she in turn is comfortable in that environment, more cooperative with her therapy, and thus more likely to benefit from it.

9. Sensing that their child is accepted and respected as a normal child would be.

John:

> "I know that the doctors spent very little time with [daughter], they'd just briefly look at her."

"People were really interested, not just on a piece type basis, all of a sudden [daughter] is a person again."

Linda:

"It is so integrated that she is involved in everything that she can be, and without feeling that she can't do anything . . . whereas the other school they had their sports day, but not for the special needs children . . . . They had the Christmas Concert . . . the special needs children were only allowed to perform in the dress rehearsals for the school in the afternoon and not for the Christmas Concert. They were devastated over that. Now they are involved in everything . . . . The special needs kids are part of the lives of the other children in the school . . . . It's just so wonderful I can't believe the difference in [daughter's name]."

These parents love and value their children and would like others to feel the same way. It hurts them when they witness their child experiencing discrimination because of their special needs, particularly if the child is aware of the discrimination. In addition, when in an accepting environment the child is happier and more likely to thrive which is very satisfying for the parents.

10. Having their ideas concerning their child's treatment listened to and being involved in their child's care.

Mary:

"The staff at the [institution] were the most helpful to me because they treated me like they expected me to be able to handle it . . . an equal, strong . . . and that was very important."

"When I came in they handed me the tubes . . . . There was no question of me not being able to feed her. They gave me a choice. They didn't hover making sure I didn't make a mistake."

There was a feeling that "we were going to handle things together and decide what was best for this baby." The physiotherapist gave Mary some things to do with her child, "even if nothing comes of it, it has given you something."

By contrast:

> "I think that they [the staff at another institution] take advantage of the fact that you are numb by deciding all the things for you as a favour to you. I really think they should have to ask you and involve you more in the baby's care. It is your child. It may be tough but things just get tougher."

John:

> "I would have liked a chance to discuss [daughter's] care with the doctors and nurses . . . bounce some ideas off them too, ideas I had about [daughter's name] and stuff like that. It would have been nice to bring that up and discuss that with them. They could have been more receptive to some of the ideas that we tried to put forward . . . . We were kind of out of the picture while this stuff was going on . . . . We weren't included in any of the plans and treatments. Our opinion wasn't solicited for anything. Whatever the doctors or nurses decided to do that was done. When [daughter] was readmitted to the hospital she was having feeding problems and stuff and I made suggestions to the doctor, I wanted them to change formulas and stuff like that, it was just ignored. I even had the nurse put it down on the chart once, it was still ignored. No one ever said anything back, no action was ever taken. They didn't even come back and say, 'you're an idiot, that's not worthwhile.' I would like to get some feedback anyway."

Jane:

> "It started three years ago [behaviour problem] . . . . I went to them a few times and said 'this and this is happening and I don't know what to do about it.' Nothing was done about it because she is cute and she is tiny and you wouldn't expect that she could do something like that . . . . I don't think they thought it was as bad as what I said it was. So now it has gotten into full scale. It should have been corrected a few years ago until now it has got to the point where she is unmanageable at times."

Parents have ideas and opinions concerning their children's care. When these are listened to and acknowledged they feel good as parents as well as feeling that they have some control over their and their child's life. On the other hand, when their input is unsolicited or ignored they feel angry, powerless and ineffectual.

These parents are capable adults who wish to fulfil their parenting role by caring for their child. Thus it is helpful to them when professionals provide opportunities for them to be actively involved in their child's day-to-day care.

11. Having one's parenting skills acknowledged.

Mary: Mary mentioned the physiotherapist whom she felt treated her as someone who knew about the child and would be good for the child. She also mentioned the aids and the LPNs at one institution who gave her credit for her competence as a mother by telling her that she would probably do a better job than them. "You are better suited to do this because you are the mother." She liked being told that what she had done was noticeable and worthwhile, "not just saying 'you are wonderful' but saying something specific about what you are doing that is good. Pointing out good mothering behaviours important to any child not just handicapped one." Those kind of comments were real ego-boosters for Mary.

12. Feeling comfortable enough in the presence of others to discuss situation.

Mary:

"I wanted to be treated like I was going to be this strong person and they could give me this information that I needed . . . . You are scared to offend people in that situation too . . . . I thought I don't want to make enemies, I don't want to be seen as somebody they are not going to come to easily."

"Say anything and everything . . . . You could just open up and just rail against anybody you felt like and they were perfectly accepting . . . . Nothing was off limits."

Jane: *Re staff at outpatient clinic; the social worker, psychologist, and teacher:*

"Have always been more than willing to, whenever you need to see them, they are always more than willing to see you. They are taking the time to listen to you. Even if you think: If I told them that they'd think, 'this woman is right off the wall.'" You can go and tell them that and they'll say, 'Yes, you are not the only one out there who thinks that they are crazy.' You always have someone to talk to . . . or if there is a time if you go out there and you don't have an appointment to see anybody, they always make the time to see you, even if they are busy they will say, 'Can you wait a few minutes?' They will take the time to talk to you and help you."

Linda:

"I will sit in his office and I'll cry and he'll say, 'Okay now, what has been happening?' So then we have a really good talk. It's just the way he talks, the way he comes through. He is so much a part of our family. We call him by his first name, his wife is his receptionist too, they feel more like really good friends than a doctor."

In an atmosphere where they didn't feel judged, parents could express their feelings freely without fear of alienating anyone. An informal atmosphere, and an

invitation to share feelings did much to make the parents feel that they mattered, that they were cared for, and that they always had someone to talk to.

13. Receiving practical help.

Mary:

> "I wanted to take her home and that was going to be a problem. Then all of a sudden it wasn't a problem, that was great, that was dandy, and they didn't make sure that I knew how to tube feed this child. They didn't make sure that I had a suction machine at home or that I had the right formula or that I had a phone number that I could call if . . . ."

By contrast when it was time for her to take the baby home from the other institution, it was a completely different situation. A list was made of the things she would need at home. "What if?" scenario's were played with her to prepare her for a variety of situations, further allaying her anxieties. She was also told to call whenever she felt the need. These actions consolidated her skills in caring for her child, and increased her confidence and feeling of security.

John:

> "It was just nice, they let you know they were there. They had a program where we could leave [daughter] over the weekend if we wanted to get away. It was never pushed on us, but we were made aware that it was there, and it was available."

Linda:

> "The physiotherapists, we've always been thankful for, and the occupational therapist, always. All along the line they have been wonderful . . . . They would give us ideas of what to do to help our

child and things that you had never even dreamed of because of not being a physiotherapist or being an occupational therapist . . . . Things that without them advising us, we would never have thought."

"Another thing that has really helped us too, apart from the swimming which she goes to every Monday, they have on Tuesdays they don't take lunch, they make their own lunch at school . . . . On Thursdays they don't take a lunch either . . . . They cook it and they go shopping so they learn how to shop and how to handle money . . . . Another thing is that she is picked up by the bus every morning . . . and she is brought home every afternoon."

Marc:

"I mean the times that we have been in are when she has been having behaviour management problems, and we have gone in and discussed the problems, and they have given us their thoughts on it . . . . They give us ideas of what can maybe be done, that is where [respite care] came up and a few other things . . . and they let you know what types. There are groups that are happening and courses that you can take . . . because without going in to talk to them, you'd never hear about it . . . ."

Re a behaviour management course:

"There have been a few things that I've picked up on that make sense, and that I hadn't thought of before. There are a lot of things in it that I guess you don't really think about, not unless they are pointed out to you."

Jane:

"They sort of offer you a way out. Some sort of help which is okay like maybe we should try just doing something a little bit different . . . . They offer suggestions to you . . . . Her teacher helps her a lot, she has learned a great deal in the last two years with [teacher]. She has done wonders with her. Stuff that I thought [daughter] would never learn and she does."

Practical help included different actions on the part of the professional. It could be actual physical help, such as making lunches or providing transportation or simply the awareness that some sort of physical help was available should they want

it, such as respite care. Practical help could also involve teaching the parents and giving them ideas on how to manage their child's behaviour, and teaching the child endeavouring to develop skills and thus improve her level of functioning.

Practical help also included finding out and making the parents aware of available community resources which increased the parents' choices, such as respite care, or educational programs. With that sort of help the parents felt less overwhelmed, there was comfort in knowing that they had options. They were not trapped in a situation with no choices.

14. Feeling understood and not alone.

Mary: They [the staff at one institution] acknowledged that she looked tired and that her situation was very difficult and they suggested that she go home and have dinner.

> "I want to sit here and just scream and throw things at the wall and curse, and hate all the other mothers on the floor who have well babies . . . and feel horrible because of that . . . . I could have really used another parent . . . . Somebody coming in saying, 'This is hell, but it passes and you are going to feel like this.' You know because I was feeling like a warped person, because I was hating these other moms, I was hating those healthy babies crying . . . . I felt guilty, I'm not a nice person."

> "You are hurting so badly yourself that you don't have time for anybody else, and you feel guilty about that and I think that there wasn't anyone who addressed that until we hit [out patient clinic] and the social worker up there was great. She said, 'You know, you might come in and have a talk.' And the social worker at the [name of institution] was also very good about that when we brought her in for the first time. She had John and I in together and she said, 'You

> are going to run into this, this and this. You can handle it anyway you want, but be prepared. And if you are looking for it, you may not hit it dead on. You may be able to circumvent it, or find a way to handle it.' But I thought that was really good to know. Because you do. At every stage you hit another set of problems. She was good. She laid it right on the line."

Linda:

> "Then he [GP] starts telling me, 'Well, this is how it should be. You have just taken on too much and you have to remember you have got [daughter's name] and she is a handful so what else is going to go?' He'll say 'you should take a week off work, and just relax.' Things like this he tells me to do which is really great!"

Some of the professionals interacting with Mary and Linda let them know that they understood how they were feeling. In Linda's case having someone understand the pressure she was under and her tendency to take on too much was helpful. Not only did her GP understand this but he gave her permission to take it easy for a while, something she was wanting to do but felt she shouldn't.

Similarly, some of the helpful professionals involved with Mary understood her fatigue and gave her permission to go and have a break. They also understood some of her negative feelings and let her know that others in her situation shared those feelings. Knowing that she was not alone diffused some of the guilt that she felt.

Conversely, following her baby's birth Mary felt overwhelmed by negative feelings, without anyone to share or understand those feelings, Mary felt guilty, like she was a bad person. In retrospect, Mary felt that some of that guilt could have been alleviated by talking with another parent of a special needs child.

15. Professional having contact with the child.

Jane:

"They [the professionals at the outpatients clinic] are in that kind of a setting where they work with those kids everyday, but if you took them out and put them in an office, they are not having the contact with the kids every day, so they don't, or I'd get the impression that they didn't really understand what the kids were all about and like every day when they were not in that kind of a setting."

Marc:

"It helps to talk about it . . . like at the clinic . . . . They are a little better that way because they know what you are talking about."

It is helpful to both Marc and Jane when the professionals from whom they are seeking help are familiar with their child. When the professional has had contact with their child on a daily basis they know exactly what the parents are talking about and Marc and Jane feel better understood.

16. Having an ally in meeting objectives and needs.

Linda:

"I talked to the psychologist who was wonderful . . . . She was very open with us and said that she had viewed [daughter's name] in that classroom and it was definitely wrong for her. She saw that she was under stress, that she didn't think the teacher was right, and something should be done right away to get her out of that situation. We had been sensing this, but we didn't know what to do. Two days later she was accepted at the other school. She confirmed it and carried on right through and worked on it."

Sam:

> "It helped having the backing of a specialist . . . without that, I don't think the school board would have listened, well they would have listened, but not pushed anything through."

When the professionals involved confirmed Sam and Linda's suspicions of the origins of their daughter's problem, they felt more confidence in their struggle for a solution. The support of the professionals also gave them more power; they were not alone against an intransigent bureaucracy.

17. Not sensing other's discomfort with their own feelings.

Mary:

> "I think that they are terribly uncomfortable and feeling they are going to say the wrong thing. I know how they feel I've been there . . . but I don't want to be saddled with trying to make them feel better . . . . I thought, 'Oh they are uncomfortable, I better stop what I'm saying.'"

John:

> "The nurses I didn't find helpful at all. I don't know whether it was because they were too busy or they just didn't know how to handle that stress, the stress of the family, how to communicate with people going through something like that."

John and Mary understood that some professionals had difficulty with their own feelings of inadequacy when interacting with them, that they were afraid to say the wrong thing. However, this was no help to them at all, they had enough to worry about without being on their guard and worrying about the feelings of others.

Table 1

Themes Derived from Interactions with Professionals, the Behaviours Associated with that Theme and How Those Behaviours Affected the Parents

Behaviour	Professional	Effect on Parent
1. Receiving clear, honest and pertinent information.		
• Gave honest information re child's medical condition and potential development.	• Physicians • Psychologist • Physio-therapist	• Parents were able to realistically plan for future, and thus have some control. • Parents felt trusted.
• Communicated daily events and behaviours.	• Teachers	• Continuity between home and school was maintained.
• Revealed plans for the future.	• Social worker	• Parents felt a sense of security from familiar surrounding. The change in environment during times of transition can cause anxiety. This anxiety can be lessened if the parents are made aware of future plans and introduced to a new environment.
2. Sensing that the child and parent were important to the professionals.		
• Provided adequate care and super-vision.	• Nurses • Therapists • Dietician • Teachers • Day-care workers • Physicians	• When absent, parents felt that their child is not valued. • When present, parents were able to relax knowing that their child was well cared for.

Behaviour	Professional	Effect on Parents
2. cont'd		
• Professional seemed to be making an extra effort to help the family and not just putting in an 8-hour day.		• The parents felt that they and their child were cared for and were not alone. • The parents felt secure that their child was receiving the best care possible.
3. Sensing that the person's individual circumstances were being considered.		
• Looked at person's individual needs, and situation.	• Nurses • Social worker	• When the parent wasn't treated as an individual, she or he felt patronized and belittled.
4. Achieving reciprocal familiarity with the involved professionals and the child's needs.		
• When the staff became more familiar with the child and her needs the care improved.	• Nurses • Therapists • Social worker	• Parents knew what to expect from the staff and were better able to voice their needs and receive help.
5. Sensing that the professionals are interested in the parents as individuals and their feelings.		
• Asked how the parent felt about treatments or surgery. • Considered the whole person, not just the problem being treated.	• Doctors • Nurses • Therapists • Social worker	• Gave parents a chance to talk about their feelings. • Decreased their sense of isolation. • Parents felt that they counted as people and that their feelings were important.

Behaviour	Professional	Effect on Parent
6. Knowing that support is available for family members.		
• Aware that other family members were suffering and offered support.	• Nurse	• The parent worried less about a significant other when they knew that there were other sources of support for them.
7. Having needs anticipated accurately.		
• Accurately assessed a situation and took appropriate action.	• Nurses	• Person didn't have to go looking for help. Someone was thinking of them. They felt understood and less alone.
8. Sensing that the child is liked and valued.		
• Commented on the child's positive traits and potential. • Expressed enjoyment of child's presence.	• Nurses • Therapists	• Parents felt proud of their child. • Child would respond better and thus benefitted more from treatment when liked.
9. Sensing that their child is accepted and respected as a normal child would be.		
• Talked to child when giving treatments. • Included child in as many activities as possible. • Didn't belittle child's contribution.	• Nurses • Doctors • Teachers	• Parents loved their child and wanted others to value them. • Child would be happier in an environment where she was valued.

Behaviour	Professionals	Effect on Parents
10. Having their ideas concerning their child's treatment listened to and being involved in their child's care.		
• Listened to the parents when they had ideas concerning their child's care; they know their child better than anyone. • Allowed the parents to participate in the decision making and actual care when that was their wish.	• Teachers • Nurses • Doctors • Physiotherapists	• Parents felt that they were a part of their child's life and treatment. • Gave parents some power and control over their situation. • Parents felt more competent when they were actively involved.
11. Having one's parenting skills acknowledged.		
• Pointed out the parents' specific behaviours that were good for the child. Good, parenting behaviours important to any child.	• Physiotherapists • LPNs • Aids	• Restored feeling of parental expertise. • Reassured parents that they were important to the child's life and that they were doing a good job as parents.
12. Feeling comfortable enough in the presence of others to discuss situation.		
• Invited parents to express their feelings. • Conveyed a non-judgemental attitude.	• Nurses • Therapists • Family physician • Social worker	• Parents felt free to express themselves without fear of alienating anyone.

Behaviours	Professionals	Effect on Parents
13. Receiving practical help.		
• Taught parents to teach life skills to the child. • Taught the parents to manage the child's behaviour. • Informed parents of available community resources. • Provided hands-on care. • Provided lunches, transportation.	• Teachers • Therapists • Social worker	• Parents became more knowledgeable and were empowered to help their child. • Parents were given choices and didn't feel trapped. • Parents' workload was lightened.
14. Feeling understood and not alone.		
• Named feelings. • Let parents know that their feelings were shared by others in similar circumstances.	• Social worker • Nurses • Family physician	• Parents felt understood and cared for. • Guilt diffused.
15. Professionals having contact with the child.		
• Involved in the child's program.	• Therapists • Psychologists	• Parents really felt understood because the professionals knew exactly what they were talking about when problems were discussed.

Behaviour	Professional	Affect on Parent

16. Having an ally in meeting objectives and needs.

• Assisted parent in struggle for services or rights. • Accepted the person's view-point.	• Pediatrician • Psychologist	• Parents felt empowered with a professional on their side. • Self-confidence increased.

17. Not sensing other's discomfort with their own feelings.

• Awkwardness when interacting with parents.	• Physicians • Nurses	• Parents sensed the professional's discomfort and were afraid to express feelings.

Themes Originating when Interacting with Family and Friends

1. Having an ally when meeting objectives and needs.

Mary:

"My mother who is an RN . . . went storming into the Special Care Nursery and said that both she and her daughter knew that there was something wrong with the child, and we demanded that somebody come down, so, all of a sudden the pediatrician was there with a number of x-rays."

Linda: Linda has found that co-workers and a neighbour have been very supportive in her attempt to become more assertive,

"One of the speech pathologists I work with . . . and my boss, they are wonderful, they have helped me by saying, 'It's okay to say no.' They have me practice saying it."

"Or [when discussing a problem with her daughter] they'll say, 'Something has to be done. It is always the noisy cog in the wheel that gets listened to. So you have to be the one to be assertive.' And so I was assertive."

Jane:

"We have two families that can see the disabilities . . . but they think that she should be treated like she is normal . . . . We should go on with our life and our family as if there was nothing wrong with her . . . . It causes an awful lot of tension, an awful lot . . . . They think . . . . We should gear our life to the way she is, and we should never be able to do the things, like with [second daughter] that we would do if [daughter] is normal. We have had to say, 'sorry, but what about [second daughter]?' They don't agree with that at all, not at all . . . . I don't think they have got to the point yet where they can admit that she is the way she is, this is the way it is going to be . . . . That's been a big tension between us all . . . . I don't put myself into that situation where I take her over there a great deal . . . . Then you get to the point where you don't get to see your family any more."

Marc:

> "I find a lot with parents, maybe they are not looking at it as outright as they should in admitting that she has a bigger disability than what she really does . . . . They tend to look at it [behaviour problem] more as a growing trend that she is in, a phase . . . . They tend not to agree with a few things [re behaviour management] . . . things like that I find to be a problem."

It is helpful for these parents to feel that they are not alone in a particular situation, that they have the support of significant others.

Mary found her mother's actions helpful for two reasons. One, she finally began to receive some of the information she so craved. And two, her feelings of being entitled to that information were validated.

Marc and Jane experienced this negatively. Their families' differing attitudes toward their child's disability causes tension between them. Sensing their disapproval increases some of the guilt they might feel concerning certain decisions, and undermines their confidence when making plans.

Linda is better able to develop a skill that doesn't come easily to her, being more assertive, knowing that she is supported in her endeavours and doesn't run the risk of losing important friendships when she is more assertive. It also boosts her confidence in her efforts to obtain services to meet her daughter's needs.

2. Sensing that child is accepted and respected as a normal child would be.

Mary:

"You really drop friends very quickly. People grab their children away from touching the baby. It's not like it's a contagious disease. They wouldn't pick the baby up, this kind of thing."

By contrast:

"I have two really good friends that just came in and picked the baby up and . . . both RNs . . . took her into the room and tube fed her for me. And I thought, 'this is great!' Came out and sat the baby down and this was normal. Touched the baby the way they treated their own children. I thought, 'This is just such an ego lifter.' But people accepting her like a normal little person, you know, and sort of inviting you to places where you would go anyhow."

John:

"With our helpful friends [daughter] was just accepted as she was and that was that. They just came in and grabbed her and picked her up, it was just like she was a normal kid."

Whereas unhelpful friends:

"Were really hesitant to pick her up, I think maybe it was just a fear on her part that she didn't know how to handle her . . . . We really picked up on it because we wanted to treat [daughter] like a normal kid. It hurt that they would treat her like that . . . especially being close friends, we thought that they would just accept her as she was, and that would be it. It was disappointing and it hurt that they didn't."

Linda:

"She goes to Brownies, and usually I go and cook at Brownie Camp, but now I've done my turn and so now the other mothers are taking over and people have gotten to know [daughter]. Everybody will just take her. She is really involved . . . . We got a note from the Brownies, she is going up to Guides, and we have wondered, 'Will they take her in Guides?' But they will because they have seen her so many times in Brownies that they can't wait to have [daughter's

> name]. We got a note, tomorrow night the leader is taking them out for pizza and to a show. It's like a normal child."

Mary and John love their baby very much and it hurts them when they sense that others, especially friends, are rejecting of her, or afraid to touch her. On the other hand, when others accept her like they would a "normal" baby then they feel good as parents.

Similarly Linda finds the actions of these community groups helpful because they include her daughter and offer her the opportunity to participate in typical activities that any other child would participate in. It is very gratifying to Linda when her daughter is accepted and invited to take part in age appropriate community activities.

3. Sensing non-judgemental acceptance.

Mary:

> "Maybe it was the guilt aspect because I felt quite guilty that this had ever occurred, but you know that they [friends] were quite accepting of me and that they didn't feel it was my fault. Because this doesn't happen to people who take care of themselves and have prenatal care . . . . This was the total prejudice I went in with . . . just being treated like somebody . . . like you are the parent of a normal child . . . . You are not a total subspecies because you have had a handicapped child."

Mary felt some guilt concerning her child's disabilities and it was helpful to her when others reassured her that she was not to blame and treated her like a mother, not just the mother of a handicapped child.

John:

John felt this with his parents in law, "they weren't demanding, i.e., didn't try to push you to get over certain stages . . . . if you were depressed they didn't try to push you to get out of that depression."

John felt he wasn't being judged. Whatever his feelings were they were accepted without any pressure to feel differently.

4. Feeling comfortable enough in the presence of others to discuss the situation.

Mary:

"My mother and I are very close and I knew that she would be very very good . . . . She goes at things much the same way I do."

John:

"Parents are there when you needed to talk. Family is understanding they seem to understand what we were going through . . . shared feelings."

Marc:

"I guess supportive as far as problems when you are talking, both families are willing to listen and discuss with you as best as they can about what is going on anyway . . . . They are always there to listen . . . . I guess I feel that she will always be there if there is anything that you really need her for."

"We have our best friends,they have been helpful . . . . They seem very understanding . . . . The girl . . . when you talk to her that she knows the right thing to say . . . . I think I just feel more comfortable talking to them is all it boils down to. I can't think of any incident really where they have saved the day with anything . . . just that they are there and easy to talk to."

Jane:

> "Some of our close friends know how it is, and you can sit and talk with them and tell them what we have been doing and everything, they understand . . . some of them will say, 'When you feel like this, why don't you phone us, come over.' One couple . . . I think that they would understand more because she has a brother who is disabled . . . . I think she sort of understands a little more."

Sam: Sam feels that having a handicapped child puts him on a different footing with friends. Some of his daughter's behaviour is inappropriate for her age and can be embarrassing and this makes him uneasy with some of his friends because he is not sure how they are going to react.

With some friends he can be open and discuss his daughter's behaviour and then he is able to relax and enjoy their company more; however, he is unable to specify why. He can talk to some people but not to others. "I guess it is just a feeling you have about certain people."

Sam's main source of support is his wife. He can freely discuss feelings with her.

> "It brings things out into the open, somebody else's opinion . . . . I can find out whether other people have the same ideas as you have."

Linda:

> "We do talk a lot John and I about . . . . We are open about anything that is bothering us . . . whatever concerns me concerns him, and the same goes for him, we are very close."

> "If there is something really upsetting me I'll go to [next door neighbour], talk to her, usually the girls I work with, there are a couple of them I can talk to, my boss, I can really talk to her. She is just lovely, and one of the speech pathologists I work with is really

> down to earth. She is right on the line . . . . She will say, 'Okay, tell me all about it.'

Some people are easy to talk to, although it is not always easy to pinpoint just why that is. John and Mary find comfort in interacting with their family because of their history of closeness and their shared feelings of grief.

However, sometimes as in Jane's case it is because she feels that her friends understand her because they have had a similar experience. Often simply inviting the parents to share their feelings lets the parents know that the person is interested in them and care about them, giving the parents permission to talk.

Sam and Linda was the only couple that used each other for emotional support. Sharing ideas and frustrations with each other brings things out in the open. They can get a different perspective on the situation and don't feel so alone.

5. Receiving practical help.

Mary:

> "I fit it [work] in with my mother and sister babysitting. I wouldn't have left her with anyone but family. That made me confident enough to go back to work."

John:

> "Parents are always there if we need them to do something."

Linda:

> "I have a lot of help from my neighbour though with [daughter's name]. She always says, 'If you need help with [daughter's name], ask me, ask me.' If I am out shopping or if I'm late coming home from work, this was before Sam was off work, I'd just phone her.

She loves [daughter] and she'd say she could go there. 'I'll go get her from school.' She has really helped me out a lot . . . . I can always count on [friend's name]. She is there all the time."

"We are really put to trial I feel, [in] the mornings. Maybe if I wasn't working it would be easier, but it is just the pressure of knowing I have to get to work, and getting her ready for school . . . . Dad has had surgery and is home now and I can't believe how wonderful and stress free it is to have him there to organize the morning rush."

"It has been helpful being friendly with another mother, who has this handicapped child, that is assertive and does know a lot of resources . . . . She finds out all these things and as soon as she does find out something she phones me right away. She'll say, 'Do you know this? . . . Do you know that?'"

Jane:

"Some of them [friends] will say, 'Send [daughter] over for the weekend.' So they will take her or they will take both of them so Marc and I will have some time to go out and spend some time together."

Marc:

"Well one thing they are supportive in is giving us time on our own maybe. My mom and dad are good at once a month or every two months, they will ask if they can have the kids for a weekend just to give us a break, which is nice . . . because it helps relieve a little bit of the stress. I think it does [daughter] good too because they treat her well and make her happy . . . . I think that they realize that there is a little bit of added burden with her, so it is nice that they realize that part of it . . . . My mom has helped out quite a bit when Jane has been working and I've been working, if [daughter] is not well at school or feels sick, she is the one who usually goes and picks her up, all in all very helpful."

Actual hands on practical help that makes the day-to-day living easier has been helpful to these parents, picking the kids up from school, help with the morning rush, or taking the children away to give the parents a break. Having someone the parents

can count on to care for the children in their absence and help handle unforseen events such as the child's illness is very helpful. Knowing that a loving, capable person is there to care for the child means that the parents needn't worry about their child's welfare. They can carry on with their scheduled activities and don't have to choose between their job or their child.

For Linda it is also helpful to have someone share information with her. She doesn't have the time or the energy to keep informed of new developments or services so she appreciates someone who does. She feels less isolated and doesn't feel like she is missing something.

6. Sensing that their child is liked.

Marc:

> "The only thing is that they like to invite them over, just the kids . . . . It is more of them wanting them as company."

These friends invite the children over, not just to give these parents a break, but because they like the children and like to be around them. That makes Marc feel good. In addition, since they are around the children so much they have a better understanding of what it is like for Marc to live with a handicapped child, and this in turn facilitates dialogue with them.

7. Being distanced from situation.

Linda:

> "I walk every day with my neighbour, I really enjoy it . . . . We talk and walk and look at gardens and flowers. In the winter we still walk. We've done a lot of exchanging of opinions . . . or my daughter will phone once in a while and say, 'Let's go to Sears and let's walk around.' So off we go."

Getting away from the situation with her friend or with her daughter, thinking and talking about other things refreshes and relaxes Linda. She then finds herself looking forward to getting back, and she enjoys her daughter more when she had a bit of a breather.

8. Sensing a friendly interest in child's condition and needs.

Mary:

> "Or being matter-of-fact and saying, 'What's that?' and 'What do you do now?' without making judgements."

John:

> "There was no hesitation on their part to talk about what was wrong with her. They didn't tip toe around the problem, they were direct and that felt good. They didn't ignore the fact that there was a problem, but didn't treat it like it was something weird or unusual. They treated it like it was a problem and how are you going to deal with it. But they didn't dwell on it either. It hurts when they are afraid and don't ask direct questions."

Friendly interest on the part of their friends enabled John and Mary to talk about their daughter's problems. Openly discussing her needs with them, helped to clarify and demystify some of what was happening.

9. Not sensing other's discomfort with their own feelings.

John:

> "They felt a bit alienated too . . . . They didn't know how to deal with their own feelings so that made me feel uncomfortable and didn't feel I could go to them . . . . I just don't think that they knew how to deal with their own feelings, so I can't blame them for what they did but it certainly wasn't any help to us."

John sensed that some of his friends were uncomfortable with his situation and he did not feel comfortable talking about his troubles with them. There seemed to be a wall between them and he felt isolated.

Table 2

Themes Derived from Interactions with Family and Friends,

the Behaviours Associated with that Theme, and

How Those Behaviours Affect the Parents

Behaviour	Effect on Parents
1. Having an ally in meeting objectives and needs.	
• Let parents know they agreed with their actions.	• Parents' confidence in their decisions and plans increased.
• Encouraged parents to pursue personal goals while ensuring continuing support and friendship.	• Parents felt free to experiment.
2. Sensing that child is accepted and respected as a normal child would be.	
• Invited parent and child where they would normally be invited. • Included in age-appropriate or developmentally appropriate activities.	• Parents felt good about their child. • Parents felt hurt and disappointed when this didn't happen.
3. Sensing non-judgemental acceptance.	
• Let parents know that child's disability wasn't their fault. • Treated parents like they would the parent of any child. • Accepted mood of parents without pressure to feel differently.	• Guilt alleviated. • Parents kept sense of identity, not just the parents of a handicapped child. • Parents felt comfortable expressing themselves.

Behaviour	Effect on Parents
4. Feeling comfortable enough in the presence of others to discuss situation.	
• Invited the parents to talk about their problems and their feelings. • Conveyed an understanding of the parents' situation.	• Parents felt that others were interested in their feelings and problems and they felt free to relax and express themselves. • Parents got a different perspective. • Parents felt understood.
5. Receiving practical help.	
• Took care of the child. • Helped with transportation. • Was available to assist in emergencies. • Shared information.	• Burden lessened for parents. • Lessened worry for parents. • Provided parents with choices and options.
6. Sensing that child is liked.	
• Demonstrated they enjoyed child's company.	• Parents felt good about their child.
7. Being distanced from situation.	
• Invited parent to a fun activity.	• Parents thought about something else and felt refreshed.
8. Sensing an interest in the child's condition and needs.	
• Asked matter-of-fact questions.	• Encouraged the parents to talk. • Clarified and demystified situation.
9. Not sensing other's discomfort with their own feelings.	
• Aware of own feelings and how this was affecting interaction with the parents.	• When others are uncomfortable, the parents sense this and feel isolated and unable to communicate.

Table 3

Themes that Were Shared when the Parents Described Interactions with Professionals and Family and Friends

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1. Having an ally when meeting objectives and needs.

2. Sensing that their child is accepted and respected as a normal child would be.

3. Feeling comfortable enough in the presence of others to discuss situation.

4. Receiving practical help.

5. Sensing that their child is liked.

6. Not sensing others' discomfort with their own feelings.

Themes Originating from the Participants' Own Coping Mechanisms

1. Developing assertive skills.

Jane:

"You learn you have to fight for everything you want because if you don't you are never going to get it . . . . You learn to use the system . . . . You ask 'What are my options? What kinds of thing are open to me?' If you don't think there is enough you have to push harder . . . ask if something is available in the community . . . or make things happen yourself . . . if you don't like what is happening you have to change that yourself too, no one else can do that for you . . . . You can ask for help and they can help you but you pretty well need to know what you want yourself, I think . . . . I do things as I please, I don't ask any more . . . . You have to be involved and stick your nose sometimes where you think it doesn't belong, but you have to . . . . You don't get anything unless you ask for it, or if you demand it . . . . You have to be more demanding, and you have to fight more, and you have to fight more for your kid's rights, because they are the way they are."

Linda:

"I tend to take on too much, at work and at home . . . . I've taken this on now to say 'no' and be assertive and to think of myself and what is important to me so that I know that I can function properly for Sam and [daughter]. I'm learning to say, 'This isn't right, and I'm not a bit pleased with the way this is handled.' You can sit back and the experts will say, 'Oh, this can be done, and that can be done,' but you know, when you are not a professional, it's hard to even understand even what they are talking about . . . . What does it all mean? . . . Now I want to know what everything is. What everything is about."

Mary:

"I think because you know this little person is so dependent upon you, you are their only hope, you get to be a lot more aggressive than you thought, because it is not you any more . . . . It is another person . . . . I am more confident and may be able to verbalize more definitely what I want."

Developing some assertive skills has helped these mothers regain some control over their lives by being more active participants in the helping process. They are acutely aware of the total dependence of their child on them, and that it is up to them to make sure that they receive appropriate services. They cannot allow themselves to be at the mercy of others.

2. Being aware of the way people around them react to emotions and modify behaviour accordingly.

Mary: Mary was acutely aware of the way others were reacting to her and her situation. She perceived that some people were afraid to set off an emotional reaction and thus either avoided her or withheld information from her. Because she so craved information she hid her emotions.

> "I was embarrassed to have them find me crying because they are going to start treating me with kid gloves and they are going to withdraw even farther. So I go into the bathroom and I'd stand in the shower and cry and cry and cry, then I'd come out and everything would be fine, because they couldn't know I was crying and that I wasn't a strong person."

3. Developing a personal philosophy of normalcy.

Mary: Mary tells herself that she is:

> "Just this normal person raising a child . . . . Every parent has problems with children but your sort of problems are a lot different than mine you just can't equate the two."

Mary needed to feel a certain sense of the normal, of the ordinary, and it helped her to find the essentially normal elements of her situation.

4. Focusing on the positives.

Mary:

> "When it does get overwhelming I think of the positive aspects of the situation . . . . You learn to appreciate the little things such as smiles."

Jane:

> "About once a month, or once every couple of months, I really get down in the dumps about her . . . . I get to the point where you sit back, 'Okay, these are the good things about her.' Maybe you work on those a little more and forget the bad stuff . . . just go day to day on the good things that happen."

Mary and Jane find that by focusing on their daughters' positive attributes, and accentuating the good things helps them to appreciate their daughters for the little human beings that they are.

5. Taking time out for self.

Mary:

> "I do things for myself now because I figure I'm entitled, sitting in a bath, reading. It's a lone time to get myself together again. It shows me that I can actually concentrate on something for more than fifteen minutes, because initially I couldn't read . . . . I also take courses. I go to work."

> "[At work] I'm not just [child's name] mom any more. My thought processes can actually handle something a little more involved. I'm a confident person who has this whole other sphere that I can work in. Work is good. It boosts my confidence. It shows me that I'm quite

> capable of handling something else. It also gets your mind off yourself. There are a lot of other people out there with worse problems than you have . . . . I need this little bit of out, get out and expand my horizons."

John:

> "I am a quiet person . . . if I have a problem I go to the park or go sit somewhere and just think it through and it may take a while but eventually I work out many problems."

Sam:

> "I sometimes turn to a book to read. I have a workbench downstairs, I go out and cut the grass or do something like that . . . . I think about it [his situation]. I take a drive sometimes."
>
> "Usually I can come to a solution or an idea. I guess it relieves the tension to get away from it and then come back to it."

Jane: When she finds herself becoming irritated with her daughter's behaviour because of her own feelings of grief, Jane tries to distance herself from her for a while so that she doesn't take it out on her daughter. "It's not her fault." She will find an activity in another room or send her daughter outside for a while until she feels better. Jane realizes that her gloomy feelings could be reflected in her behaviour towards her daughter and thus seeks solitude to vent her feelings without taking it out on others.

> "Work has been good. It gets me away and I have to concentrate on something else. It feels good to be doing something else."

Getting away from the situation relieves the stress for these parents. It gives them a chance to think things through and make some sense out of what is troubling them, and reaffirms their sense of self.

Work has furthered this process for Jane and Mary. It forces them to concentrate on other matters and they regain a sense of mastery. At work they are capable, functioning adults again.

6. Accepting disability.

Jane:

> "You have to grow along with the disability until you get to the point where it is just the way it is, and then accept it, because accepting it I think is the hardest part of all. You sort of just have to go, 'Okay, this is the way she is and now what are you going to do to correct it?'"

Once Jane was able to accept her daughter's disability and look at her potential development realistically, then she was able to engage in some positive action, and begin problem solving.

7. Setting goals but remaining flexible.

Jane:

> "You need to know what you want . . . and set goals for yourself and for your kid . . . . and sometimes you get knocked down [by your expectations]. So you have to lower them."

Jane finds that it is helpful to have something to work towards like teaching her daughter a particular skill, but she has to be prepared to alter her expectations if she needs to so that she doesn't become too disappointed if the goals cannot be met.

8. Obtaining education.

Jane:

> "We need help desperately . . . . We are taking a parenting course now . . . a behaviour management . . . . It has helped us join together in what we are going to do with her, instead of one doing one thing and one doing the other . . . so it has helped the both of us and her, because now she knows . . . . We are working together."

Jane realized that she needed help in managing her daughter's behaviour, and is now taking a parenting course with her husband. This has helped her and her husband come together on issues of discipline instead of working at odds with each other. Their discipline has since been more consistent and thus, more successful.

9. Looking at situation in small manageable chunks.

Jane:

> "Shut out a lot of things and ignore such things as thoughts about the future as what are you going to do for the rest of your life . . . . You can only plan for so much."

Jane finds that she could become overwhelmed by gloomy thoughts and worries about the future, so she wills herself to take it one day at a time. She thinks about the future and makes plans, but she does not allow herself to become obsessed by it.

10. Accepting and owning feelings and responsibility for change.

Jane:

> "You have your time of getting down in the dumps and teary eyed about the situation and then you have to slap yourself and say, 'enough of this.' They are your feelings, no one else can change those. You have to do that yourself."

Jane does not deny her down times, she allows herself to grieve, but she doesn't wallow in self-pity either. She faces her feelings and then gets on with her life. She owns her feelings and realizes that she is the only one that can change them if that is what she wants. She is in control of how she feels.

11. Learning to use the resources available.

Jane:

> "I got to the point where I thought that she should be at home, that I should do that, I thought that I should carry all that on my shoulders, and that I should do everything for her because she was the way she was. That's wrong, I don't agree with that any more. Those resources are there and you should use them and use them to the fullest."

Jane was reluctant to accept help when her daughter was younger. She felt that she alone should be responsible for her daughter's treatment but the task became overwhelming. Everyday life became easier for Jane when she allowed herself to use the community resources available. The pressure was off her somewhat and the responsibility for her daughter's development was shared.

Table 4

Themes Originating From Parents' Own Self-Help Mechanisms

Behaviour	Effect on Parents
1. Developing assertive skills.	
• Learned to say "no."	• Set limits on activities and parent was better able to take care of self.
• Became more questioning of professional's opinions.	• Had more control over child's life and programs.
• Verbalized needs more confidently.	• Parents were better able to obtain needed services. They had more control.
2. Being aware of the way people around them react and alter behaviour accordingly.	
• Contained emotions when aware that people in environment would withdraw further if confronted with strong feelings.	• Avoided alienation of others.
3. Developing personal philosophy of normalcy.	
• Told self that all parents have problems and no two parents have identical problems--they are all different.	• Felt less isolated from other parents.
4. Focusing on the positive.	
• Identified the child's positive traits and worked to enhance those.	• Parents appreciated the child more and felt proud of him or her.
• Learned to appreciate the little things such as smiles.	

Behaviour	Effect on Parents
5. Taking time out for self.	
• Reading • Gardening • Walking • Driving • Working	• Diverted attention away from problems. • Getting away relieved stress. • Gave parent the opportunity to think quietly and arrive at a solution. • Reaffirmed sense of self.
6. Accepting disability.	
• Realistically evaluated child's condition and potential.	• Was able to begin problem-solving and planning for future.
7. Setting goals but remain flexible.	
• Had some concrete action to engage in but was realistic about expectations.	• Action towards goals gave the parents some control, however flexibility avoided disappointment.
8. Obtaining education.	
• Recognized that help was needed and took courses to learn other ways of coping.	• Increased options in handling behaviour problems.
9. Looking at situation in small manageable chunks.	
• Concentrated on day-to-day issues.	• Avoided becoming overwhelmed by the complexity of the situation.
10. Accepting and owning feelings and responsibility for change.	
• Allowed self to grieve but didn't get lost in self-pity. • Recognized own responsibility for self-change.	• Parents had control over their feelings.

Behaviour	Effect on Parents
11. Learning to use the resources available.	
• Educated self re help available in the community and made use of it.	• Responsibility for the child's care and development was shared and parent had more time for self.

DISCUSSION

Sartre believed that the "person is the totality of his or her life choices for which he or she is fully responsible" (Von Eckartsberg, 1986, p. 29) and that his/her essence is "linked to existential choices and radical freedom to make commitments to choose our future. Sartre's key notion in this context is the way a person chooses his or her long-range life commitments and life direction in and through all particular acts of involvement" (Von Eckartsberg, 1986, p. 15).

When a parent learns that his/her child has a disability, the known reality of that person's existence is thrust in a state of disequilibrium. The goals and plans made for the family during the pregnancy are suddenly rendered irrelevant, and the hopes and aspirations for that child's future need to be readdressed.

There is a loss of agency and autonomy. The parents have no control over the handicap itself, and in addition seem to have no control over the child's life either. They are having to deal with a variety of professionals who have their own sphere of jurisdiction concerning their child's care. The experience of the participants in this study, was that frequently, these professionals often busily go about their business and exclude the parents in the process. They are seen by the parents as having more control over the life of their child than they do.

In our society this is contrary to the norm. Our culture dictates that parents should have the primary responsibility for the nurturing, protecting and teaching of their children. When they lose control of that responsibility the parents feel

inadequate, lost and guilty. The professionals perceived as helpful by the parents of this study were often the ones who returned some of the control back to the parents enabling them to make choices and plan for their and their child's future.

Crucial to that process for the parents in this study was information. The paucity of information was a predominant theme with these parents. In the diagnostic phase the parents need medical information. That information decreases the ambiguity of their situation and allows the parents to understand their new reality and get on top of it. Later in the child's life, information continues that process by giving the parents a realistic assessment of their child's potential progress.

The parents in this study were not alone in their thirst for more information from the medical profession. Waitzkin (1984), in his study of doctor-patient communication, found that 65% of doctors underestimated their patients' need for information. Fewell and Vadasy's (1986) survey of the parents of handicapped children uncovered similar findings.

However, when they did receive adequate and pertinent information, the parents regained some of the lost control. The information helped them to understand from the beginning what they were likely to face in the future, enabling them to make new plans for their child and re-organize their lives.

Similarly, sometimes the parents viewed as unhelpful some clearly helpful medical interventions such as putting on a cast or initiating tube feedings. Coates, Nemzaglia, and Embree (1983), postulate that sometimes helping can backfire by increasing the helplessness of the client whose responsibility for the solution has been

minimized. Keeping the parents informed of what the professional is doing, and including them in any decision regarding their child's treatment, can do much to reduce that sense of helplessness and return some of the traditional parental control.

One study by Strull, Lo and Charles (1984), found that even though patients wanted information concerning their medical conditions they preferred to leave the final decision up to the physician. This finding is not supported by Fewell and Vadasy (1986), nor by the parents in this study.

In an effort to regain control of their lives, all the women in this study mentioned becoming more assertive since having a handicapped child. The development of assertive skills helped them reaffirm their sense of self by enabling them to reclaim some responsibility over their and their child's life. These skills helped them to articulate and obtain what they wanted for their child and they no longer felt as though they were at the mercy of others.

The parents' relationships with their family and friends as well as with professionals could further enhance this process of regaining control. When the parents were able to talk about their situation, their thoughts and feelings were brought out in the open. Once verbalized, their thoughts and feelings were clarified, enabling the parents to identify and then priorize the difficulties in order to begin problem-solving. When engaged in the act of problem solving they are no longer at the mercy of events.

Further, as stated by Van Manen (1990) dialogue with someone is itself grounding and confirming of a reality beyond one's immediate reality. It gives the

reassurance that one matters, or is cared for and accepted. There is a sense of connectedness with others; we are not alone. The participants in this study often reached out to someone perceived as understanding or responded to an invitation to talk. The connectedness was further enhanced when others obviously had thought about the participants and were involved with them and their child, by continuing to problem solve even in the absence of the participants, such as a solution to a feeding problem, or phoning the participants at home to say they had arranged a service. Parents often seemed to need an invitation to express feelings and ask questions, and were more likely to open up when they sensed a nonjudgemental attitude in their environment.

Acceptance of the child by others was often a helpful experience for the participants. Van Manen (1990), talks about the notion of lived time, "through hopes and expectations we have a perspective on life to come" (p. 104), and further his notion of lived body where "we experience our children as separate from ourselves yet physically close. For many people there is a deep significance in the knowledge that parents and children are one flesh" (p. 105).

This notion came to life for some of the parents in this study in both negative and positive ways when interacting with family and friends and professionals. When others treated their child well, showed liking for her, delighted in the child's company, and cared for her competently as they would any other child, then the parents felt good about being a parent and about their child. When the positive traits and accomplishments were pointed out they could feel proud of their child. Moeller

(1986) also found this to be true in her conversations with parents. However, when the child was treated simply as a medical problem, or when friends were hesitant and seemingly rejecting of their child, the parents were personally affronted, and felt angry and isolated. Their own identity was threatened. Rejection of their child meant rejection of the parents as well.

The parents of the two older children of this study had concerns about the future. Van Manen (1990) mentions that there is a "modality of hope which I cherish for my child's happiness and becoming" (p. 105). Current societal attitudes towards the handicapped often threatens that hope. The parents are very concerned about what will happen to their children when they can no longer look after them. A more accepting community which includes the disabled in its every day functioning would do much to ease the parents' minds. When this in fact did happen, when the children were included in "normal" activities with friends or with community organizations, the parents felt satisfied and hope for their child's future happiness and of finding a place in society was kept alive.

The professional and personal relationships shared many similar themes perceived as helpful or unhelpful to parents. Liking the child and treating him or her as one would any other child was already mentioned, as was the connectedness felt by the parents when they were able to talk to someone. Another shared theme is others comfort with their own feelings. The experience of some of the parents in this study is similar to the findings of Dakof and Taylor's (1990) study of social support and cancer patients in this respect. That study found that the events often create

conflicting reactions in others such as feelings of fear, aversion, and produces anxiety when interacting with the person. Often they are afraid of saying the wrong thing. Thus people will often exhibit signs of physical avoidance of the affected person and will often shun open communication about the event and its consequences, resulting in the person feeling rejected and abandoned. Dakof and Taylor's study only examined social supports, but the participants in the present study felt that avoidance from professionals as well. On the other hand, when the opposite happened, when the professionals and family and friends had their own feelings under control and communicated openly and honestly with the parents, then the parents felt helped. They didn't have to worry about the feelings of the others. They could concentrate on their own.

In this study, the children's disability were such that every day life was more complicated for the parents. The children needed more supervision and tasks taken for granted by most of us such as dressing and eating were more difficult. In addition, the child's special needs made it more difficult for the parents to obtain adequate and appropriate child care. Both professionals and personal relationships were seen as helpful in this regard by their concrete actions such as providing transportation, meal preparation, or competent and loving child care, or by providing options or choices such as knowledge of respite care programs, or by simply being available in case they were needed.

Just the knowledge that help was available if needed was perceived as helpful. This is supported by the research of Wethington and Kessler (1986), who found that practical activity was not necessarily required. When practical problems have the

potential to develop, awareness of sources of help provide parents with a safety valve. They are not trapped in a difficult situation, but have access to different options from which they can make choices.

The literature suggests that traditionally fathers are less involved than mothers in the care and treatment of their handicapped child (Gallagher et al., 1986). This would seem to hold true for the participants in the present study. One dad was involved with his child's treatment right from the start. However, one father had recently become more involved. The literature has tried to include various demographic variables in an effort to explain the underinvolvement of fathers with their disabled child such as age and class, with little success. Our society's attitudes are in the process of change in this respect. More fathers are becoming increasingly involved in their child's day to day care. It is reasonable to assume that this could be happening with the families of handicapped children as well.

Working was important to all the women in the present study. It reaffirmed their sense of self and increased their self-esteem.

The theme of others supporting the parents in their pursuit of objectives and needs was another one that was shared by both professional and personal relationships, but not one that was found elsewhere in the literature. When others shared the parents' ideas or objectives, the parents felt more confident in their quest and in their right to the aspired end. However, when there was opposition to their endeavors, their confidence was shaken and the decision-making process was impeded.

Parents want different things from professionals. They want competent medical care as well as an open relationship with them (although this did not hold true for Sam), where the professional shows some vulnerability. They also want to feel that they and their child matter to the professional providing care. In addition, parents want answers or solutions from the professionals that the professional might not be in a position to provide. Thus, the expectations that the parent has of the professional could be instrumental in the parents' perception that they have or have not been helped by that professional.

The experience of Jane and Marc illustrated this. Although all the participants shared gloomy thoughts of despair before having been helped, only Jane and Marc did not feel relief following a helpful experience. Instead they felt confusion and emptiness. Both admit that their expectations of the professionals had been too high. They craved something from them that the professional could not provide. Conversely, the disappointment over unmet high expectations can be mitigated if a relationship akin to friendship bonds has developed between the parent and the professional, as was experienced by John.

Although not all themes were present for all the participants, many were shared by at least one other person. However, themes were never contradicted. In other words, what had been helpful to one was never perceived as unhelpful to another. Helpful behaviours were often the opposite of unhelpful behaviours and seemed to come alive for the participants when they experienced both.

While many of the themes originating from the interaction with both professional personal relationships were usually shared by more than one of the participants, themes originating from self-help mechanisms generally were not. Of the eleven themes outlined, only three were shared by others, developing assertive skills, focusing on the positives and taking time out for self. Six of the unique themes were derived from Jane's experience. It was she who seemed the most affected by the concept of recurring grief, and those mechanisms were her way of coping with this.

CONCLUSION AND SUGGESTIONS FOR THE FUTURE

While it is true that the volume of literature addressing a variety of concerns pertaining to the handicapped child and his or her family is considerable, there remains a general dissatisfaction among such families with the services they receive from professionals. For four of the participants of the present study, their first reaction when asked to describe helpful behaviours on the part of professionals, was that there were not any. After further discussion and reflection, helpful behaviours were remembered and described, but the very first impression was that of dissatisfaction. Further, the two participants whose initial reaction was more positive still related many negative experiences when interacting with service providers. The dissatisfaction of the research participants reflects the negative experiences with professionals that have been described by other writers such as Featherstone (1980), Fewell and Vadasy (1986), Turnbull and Turnbull (1978).

Yet presumably, most professionals providing services for these families are endeavouring to be helpful. Further research is necessary to identify why the helpful intent of the professional is so often perceived as unhelpful by parents. Some of the themes which emerged from the experiences of the research participants could be used as a springboard for such research.

For example, two of the parents in this study sensed the discomfort of the professionals with whom they were interacting. It is reasonable to assume that this discomfort led to some of the behaviours identified as unhelpful, such as infrequent

direct interaction with the child when providing care or performing examinations, or cold and distant interaction with the parents. It is possible that these behaviours, interpreted as disinterest, and lack of value for the child by the parents, were rather a result of the professional's own feelings of helplessness when confronted with such a grief-laden situation. Dakof and Taylor (1990) found this to be true in their study of social support with cancer patients. A similar study involving helpers in contact with families of handicapped children would be valuable in providing more detail about this issue.

Advances in medical technology have enabled more children to survive premature and difficult births, as well as other medical emergencies, resulting in the survival of more children with disabilities. Professionals are now more frequently in contact with disabled children than they were in the past. We need to examine the training of the variety of professionals likely to provide services to handicapped children and their families to determine if the curriculum has kept pace with this phenomena. We need to determine if students are sufficiently exposed to and adequately informed of the unique circumstances of the family with the special needs child. A deficit in this area could account for the parental dissatisfaction with professional contact.

The helpful behaviours identified in the study could be used to develop a questionnaire to be circulated to a larger number of parents of special needs children to (a) determine if other parents concur with the findings of this study, and

(b) priorize the concerns identified. The additional information gathered from such a survey could be used to evaluate existing services or develop new ones.

Finally, it would be useful to examine in more detail the vast literature on support and counselling, in general, in relation to the findings of the present study. Identification of similarities and discrepancies with the experiences of the research participants would be useful to practitioners and researchers alike.

IMPLICATIONS FOR HELPERS

While the findings of a phenomenological study are considered specific to the participants in the research project, and therefore not generalizable, they do tell us something about the human condition. We can learn about the phenomenology of human beings in general by examining in detail the world of a few individuals (Hyener, 1985).

The findings of the current study tells us something about how the parents of handicapped children experienced helpful behaviours; what was helpful and why. Although more needs to be learned about how the the parents handicapped children are helped, the data generated in the present study do identify certain behaviours that could be helpful to other parents in similar situations. Therefore, helpers involved in providing services for families of handicapped children may wish to keep the following guidelines in mind when interacting with such families.

These guidelines derived from the themes are relevant for any of the many professionals frequently in contact with parents of handicapped children: physicians, nurses, teachers, physiotherapists, speech therapists, occupational therapists, social workers, dieticians, LPNs and aides. These are not exhaustive. For more detail, refer to Tables 1 (p. 66), 2 (p. 83) and 4 (p. 93).

1. Give as much information as possible to the parents regarding their child's medical condition, potential development and available community resources so that the parents will have some idea of what to expect and can make plans for the future (p. 45).

2. Include the parents in the decisions regarding the child's treatment and care so that they will feel a part of their child's life, and be able to fulfil the cultural expectations of parents being primarily responsible for their child's care and well-being (p. 56).

3. Encourage the parents to develop assertive skills so that they can participate in the helping process, verbalize their needs, and obtain necessary services for their child (p. 86).

4. Emphasize the child's positive traits as a way of comforting the parents. Every child has potential and it is important for the parents to know this so that they can feel proud of their child (p. 54).

5. Show respect for the child and his/her humanity. This boosts the parents' ego; they feel good about themselves and their child (p. 55).

6. Encourage the parents to take care of themselves, to learn to be a little selfish and make time for the things they want to do instead of only the things they ought to do, so that they can reaffirm their sense of self and renew their energy (p. 88).

7. Encourage the parents to develop and maintain their relationship with their spouse so that they can use each other for ongoing support (p. 76).

8. View parent as an ally in the care of the child. The professional's best asset could be the parents. They live with the child and know him or her best and can help the professional to understand and help the child (Fewell & Vadasy, 1986).

9. Let the parents know that you value their unique insight so that the parents will share what they know, and feel good about contributing to their child's care (p. 56).

10. Make a point of noticing that what the parent is doing is right and good for the child so that he or she can feel proud of their parenting skills (p. 58).

11. Be aware of the recurrence of grief and stress particularly during transition times and be sensitive to the possible need of extra support during those times (Fewell & Vadasy, 1986; Olshansky (1962).

12. Encourage the parents to develop their social supports and provide information re community resources so that they can have choices when problem solving (pp. 60 and 78).

13. Encourage and invite parents to verbalize their needs so that the parents feel the helper is interested in them as individuals and in their problems (pp. 48, 52 and 59).

14. Be aware of your own reactions to the presence of a disabled child. The parents can sense discomfort in others and will not communicate as easily (pp. 65 and 82.

15. Be aware of the importance of familiarity, particularly in times of transition when the family needs to relate to a new system. Give parents as much information as possible. The more they know of the new system, the people, and how it works, the less fear and anxiety will be experienced (pp. 45 and 51; Marc's Summary, pp. 41-44).

16. Most important, helpers must never lose sight of the uniqueness of each individual's situation and his or her reaction to the added challenge of parenting a disabled child, and assess and respond according to that individual's needs.

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APPENDICES

Appendix A

Purpose and Rationale of Study for Social Worker

The purpose of this research is to explore the experience of being helped. In general, I will want to know who has been helpful in the participants' lives--a professional, friend, or relative?--And what was it about that person that was helpful? There are approximately thirteen questions.

The interview will be approximately one and one-half hours in length and will be audiotaped. Confidentiality will be strictly maintained. Personal identifying characteristics such as names or addresses will either be changed or not used. I will want to interview both parents separately.

Participation is strictly voluntary, and participants who agree to be involved may withdraw at any time without any unfavourable consequences.

I will be happy to provide more details on request.

Appendix B

Interview Guide

1. Help, or support as a term means many things to many people. In order to understand your point of view, can you please tell me what these terms mean to you.

2. Think back on your contacts with professionals since the birth of your special child. Can you recall feeling that you were helped by some of these professionals?

3. If yes, who was the professional?

4. Can you recall what you were thinking and feeling before the helpful incident?

5. What did the person say or do that was helpful?

6. How did you feel afterwards?

7. What had been your expectations of that person? Were you seeking the help you received?

8. What about the other people in your life, family, friends and neighbours?

9. If yes, from whom?

10. What did that person say or do that was helpful?

11. What were you thinking and feeling before, afterwards?

12. Had you been seeking help from that person?

13. What kind of things do you do to help yourself?

14. What are you thinking and feeling before, and after?

Appendix C

Consent Form

I, _____, consent to participate in the research project conducted by Maryse M. Ridley, Master's candidate at the University of Victoria, examining the experience of being helped.

I am aware that I will be asked questions about my experience during an in-depth audiotaped interview with the researcher.

I understand that my involvement in this study will be kept in the strictest confidence. In order to ensure this, resulting transcripts will not include any information that will reveal my identity, such as my name, that of my employer, my address, description of physical characteristics, etc.

I am aware that my participation in this study is strictly voluntary, and that I may withdraw from the project at any time without any unfavourable consequences.

I understand that I will be given a description of the full purpose of the study, as well as an opportunity to debrief my personal reactions to the project.

I understand that the tape will be erased following its transcription.

_____

Signed

_____

Date

Appendix D

Letter to Participant

Maryse Ridley
1216 Montrose Avenue
Victoria, B.C.
V8T 2K4

Dear _____:

Enclosed is the summary of our conversation dated June ____, 1987. Please read it over carefully. Feel free to write any comments as you are reading. I have included some questions within the summary for clarification; please use the back of the sheet for your comments. I will contact you in a few days by telephone to answer any questions.

Thank you for taking the time to help me in this project.

Sincerely,

Maryse M. Ridley

VITA

Surname: RIDLEY **Given Names:** MARYSE MARCELLE

Place of Birth: FRANCE **Date of Birth:** December 6, 1949

Educational Institutions Attended:

Royal Jubilee School of Nursing	1969-1972
University of Victoria	1981-1983
University of Victoria	1986-1991

Degrees Awarded:

RN	Royal Jubilee School of Nursing	1972
BSN (with distinction)	University of Victoria	1983
MA	University of Victoria	1991

Honours and Awards:

n/a

Publications:

n/a

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HOW THE PARENTS OF HANDICAPPED CHILDREN

EXPERIENCED HELPFUL BEHAVIOURS:

A Phenomenological Study

Author [redacted]

(Signature)

MARYSE MARCELLE RIDLEY

Feb. 28/91

(Date)