

**UNIVERSITY OF CAPE TOWN  
FACULTY OF EDUCATION**

**A QUALITATIVE STUDY OF THE NEEDS OF PARENTS OF  
HANDICAPPED  
PRE-SCHOOLERS ATTENDING A SPECIAL SCHOOL**

A dissertation  
presented in fulfilment of the requirements for the  
Degree of  
Master of Education

by

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## SUMMARY

This thesis is an assessment of the needs of parents and families of handicapped preschoolers attending a special school. The focus is on school related needs.

An assessment of these needs could concentrate on child related needs or include needs relating to parent and family well-being. In chapter I this question is debated in light of literature on early intervention history and practice in the USA. The reciprocal interaction of handicap and family is seen to be important. This necessitates a family systems approach with a wider interpretation of family needs. In Chapter II background is given to the application of family systems theory to families with handicapped children. The importance of an ecosystemic viewpoint to special educational studies is explained and the role of support systems investigated. Theories pertaining to the processes of stress, coping and adaptation are introduced. The special contributions of authors such as Bronfenbrenner (1976 and 1977); Dunst (1985); Kazak (1987); McCubbin and Patterson (1983) and Turnbull and Turnbull (1986) are mentioned in this chapter. Chapters III and IV then give an overview of the rich literature pertaining to families with handicapped young children and their special needs.

The fieldwork for this thesis was done in the preschool section of the special school where I was teaching and comprised fourteen in-depth interviews with parents, open-ended parent questionnaires and twenty structured staff interviews. The methods followed were primarily inductive and qualitative. Analysis and interpretation of findings was guided by the grounded theory approach of Glaser and Strauss (1967). Data were classified and categorised by constantly comparing, selecting and relating dominant themes and looking for counterexamples, thereby developing a theoretical framework grounded in the data. Chapter V sets out the methods and procedures chosen and the theory underlying such choices.

The main fieldwork findings (Chapter VI) from the parent interviews indicated the comprehensive parental need to manage the impact of the handicap on themselves, on the family and especially on the child and its future. There was the

corresponding need to manage their support systems. Parental motivation and ability were determining characteristics of the managing process. Parents articulated this as their wish to "do their best for their child". The main attributes of parental motivation were their aims and attitudes. The nature of the skills needed to manage as well as the parents' capacity to apply skills contributed to their ability to manage. Circumstances such as the availability of information and support as well as the characteristics of handicap and family could enhance or impede the process of managing. The interplay between these circumstances and parental motivation and ability determined the choice and kind of the action strategies which they employed. These strategies played a role in the nature and consequences of the managing process and influenced subsequent needs of parents.

In Chapter VII the findings of the questionnaires and staff interviews are presented. These counterbalanced and illuminated the findings of the parent interviews as shown in Chapter VIII where the outcomes of the three research procedures are discussed against the background of the reviewed literature. This process led to the formulation of hypotheses, the central one being that PARENTS WANT TO MANAGE THE HANDICAP AND ITS IMPLICATIONS. In consequence it is recommended that professionals should respect the parents' need to be able to manage, and should seek ways to empower them to manage. Further recommendations explore ways in which this can be done in the present cadre of special schools. The importance of a family focused approach to early education and the need for early intervention services is emphasised. Although the fieldwork for this study was restricted to a single school, some of these recommendations may be applicable to other situations. The findings highlight problems associated with special schooling, and a search for viable alternatives is recommended.

Little research has been done in this particular field in South Africa and the present study may be regarded as an exploration into a rich and rewarding field. Educational structures are currently changing fundamentally and the need of handicapped young children and their parents for cost-effective comprehensive services as indicated by this study pleads for further research that can act as guideline for practice

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The Cape Department of Education is thanked for granting permission to conduct this research in a special school and for granting me study leave. The first study leave enabled me to spend some time in Toledo, Ohio where I could study the rich American literature on early childhood special education, get first-hand knowledge of early intervention practice (thanks to Zarifa Roashan) and take a course at the University of Toledo on "Parent, Teacher, Child" taught by Gary Cooper. My thanks to him for his inspiring introduction into this field.

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# CHAPTER 1

## INTRODUCTION

### 1. INTRODUCTORY REMARKS

This study represents a search for more insight into the needs of parents and families of handicapped children attending the preschool section of a special school for neurally impaired children. The more specific focus falls on the link between home and school. In section 2 I give a background to the field of study and its specific problems. Section 3 describes the aims of this study and gives a preview of its organisational structure. In section 4 the main concepts and conventions used, are defined.

### 2. BACKGROUND TO THE FIELD OF STUDY

The stimulus for this research came from parents at the school where I was teaching. During informal discussions with some parents, their need for more involvement in their child's schooling, for guidance in coping with their unique problems, or just for emotional support from teachers or other staff members, became evident. I was also aware of the problems teachers and other staff members experience in their relationship with parents and their need for circumstances enhancing home/school contact.

In any school good relations between home and school have always been regarded as an important cornerstone of the educational process. Often this is also the area where manifold problems can be found.

the area of relationship between the school and the community and more precisely the parents and teachers, is one fraught with difficulty. There is a wide literature which accepts the importance of home-school relationships. But there is little indisputable knowledge on which policy can be formulated (Lynch and Pimlott, 1976:79)

In early childhood education this link is even more important. The entrance of a child into preschool also

represents the entrance of his parents - actually the entrance of the whole family - into this vital relationship between home and school (Miller and Myers-Walls, 1983).

This applies even more to parents of handicapped children. Their children are usually more dependent on them and a special bond exists which makes this transition period traumatic. The stress is exacerbated by the fact that the handicap of the child becomes "public" at this stage. (Bray, Coleman and Bracken, 1981; Meyer, 1986; Suelzle and Keenan, 1981; Wikler, 1981).

The potential for problems as well as the importance of the link between home and school in the early years, is evident. In this context there are special needs on both sides but the focus of this study is on the special needs of the parents. The question arises which needs of the parents should be looked at in a study like this. Connected are questions on the boundaries of the school's involvement with parents/families and the boundaries of parental involvement in the school.

### 2.1. WHICH PARENTAL NEEDS ARE IMPORTANT FOR THIS STUDY?

The common ground between schools and parents is their shared educational task and need for circumstances that would promote the child's development and well-being. The debatable question is how to delineate parent need categories that are applicable in the special circumstances of parents of handicapped preschoolers. Which categories are relevant to the shared educational task of the school and the home?

Professionals in early education for the handicapped have the potential to play a unique role in the development of the child. While their traditional responsibility has been that of child training, early childhood teachers are among the first service providers to have an extended relationship with both child and parents. A natural outgrowth of this relationship should be assisting the parents in understanding how the child's handicap will influence his or her educational achievements, what provisions can be made to promote development, the range of problems parents typically face and the nature and availability of services likely to be required in future (Bray et al., 1981:33).

These authors recognise the needs parents have for information and guidance to advance child development and progress. The relationship between parents and teachers is significant in enhancing the process of information exchange

but seldom remains confined to child-directed needs, especially where parents are under stress related to the impact of the child's handicap.

Recognizing that one's child has a disability, whether short term or lifelong, is a staggering blow from which one adjusts slowly and seldom totally. This recognition in turn will have a profound effect on the functioning of the total family unit. Unfortunately there is a tendency on the part of the professionals to label parents as rejecting, overprotective, unrealistic or unaccepting, when parents are merely exhibiting normal reactions to stress (Lerner, Csudnowski and Goldenberg, 1981:231).

This quotation emphasises the importance of professional reaction to the emotional needs of parents. However, Winton (1986) points out that although professionals had ample evidence that parents had needs of their own and suffered from depression, marital discord and chronic sorrow their focus remained on the child except for the provision of parent support groups.

. . . the parent involvement trend of the 1970's did not incorporate an understanding of how parents' needs might interact with child needs or interfere or be at cross purposes with the professional desire to enlist parent support for the educational process (Winton, 1986:1).

Voluminous research results and practical experiences of professionals strengthened the realisation that parents' emotional well-being has a direct influence on child development (Dyson and Fewell, 1986). The school seems to be a natural source of support although this function is traditionally not part of its task. Feiring (1986) pleads the case for parent/mother support by teacher/interventionists thereby enhancing the quality of the mother's support system and indirectly the child's development.

Consequently, it is important to determine (through interviewing and discussion) whether the parents feel they are receiving enough support and attention from spouses, family, friends and child care workers in order to monitor the parents' level of self esteem and frustration. In addition to teaching the child and instructing parents in child rearing skills the interventionist's role may require providing support in terms of listening to parental frustrations, complaints, expectations, hopes and successes (Feiring, 1986:8).

Lerner et al. (1981) refer to the impact of the handicap on family functioning and the special support needs of the family system for its different members individually and collectively. Gradually there also came "a recognition of the

ongoing, pervasive, and complex influence of the family on child outcome" (Simeonsson and Bailey, 1986:67). Strong indications came from educators recognising the validity of the ecosystemic viewpoint that the child should be seen as part of his family system and the family's ecological background (Apter, 1982; Bronfenbrenner, 1976; Vadasy, Fewell, Meyer, Schell and Greenberg, 1984). According to Bradley, Rock, Caldwell and Brisby (1989) there has been increasing interest in detailed investigations and assessment of environment-development relations in these families. Children with handicaps seem to be especially vulnerable to environmental factors and often there is a wide variance in developmental outcome for children with the same handicapping condition.

. . . the recognition that the young child's social and emotional condition provide both the support and content of most early learning. Increasingly the focus on the social-emotional life of the child has expanded to the social and emotional life of the family because education during the first years of life has been almost exclusively in the family context. Moreover, the social and emotional health of the family has come to be seen as an important ingredient in not only the social emotional growth of the child, but in cognitive growth as well (Wright, Granger and Sameroff, 1984: 51-52).

Simeonsson (1991) goes further and recognises the family unit as an important context for intervention in its own right.

Among major factors that can be identified as contributing to changing views of the significance of the family in intervention efforts are the recognition of the bidirectional nature of caregiver-child interaction (Bell, 1968), the transactional model of developmental outcome (Fiese and Sameroff, 1989), and Bronfenbrenner's (1977) ecological model of child and family functioning (Simeonsson, 1991:124).

A strong emphasis developed on the study of the family and ways to incorporate this knowledge into family focused early intervention practices (Brümmer, 1990). In the USA this development has led to the promulgation of Public Law 99-457 (1986) which specifies that an Individual Family Service Plan (IFSP) with information about both children and families must be drawn up with a written statement of the family's strengths and needs and plans for the enhancement of both child and family outcomes (Dunst, Johanson, Trivette and Hamby, 1991; Mahoney, O'Sullivan and Dennebaum, 1990; Summers, Dell'Oliver, Turnbull, Benson, Santelli, Campbell and Siegel-Causey, (1990). This demonstrates the importance of going beyond the narrow

definition of child related parental needs and to include family needs in a study like this.

## 2.2. WHAT ARE THE BOUNDARIES OF THE SCHOOL'S INVOLVEMENT?

A strong case can be made for an investigation of the family's general needs but an investigation in itself already brings about a measure of responsibility. A handicap in the family has an impact on the social and economic functioning of the family which might create special needs. Unfulfilled needs could directly and indirectly influence the child and seriously impede any educational progress. Could the school ignore these needs or isolate specific needs and draw boundaries to limit responsibility? Does knowledge or awareness of needs imply responsibility or does it just have an influence on the shaping of the educational programme? Could partial intervention exacerbate parental needs and cause harm? (Brinker 1992).

Answers to these questions are partly provided by the way in which family focused intervention programmes have been implemented in the USA. This applies especially to programmes where a close link between research and practice exists. A vital component of these programmes is the accent placed on the amount of parental input required in the formulation of intervention goals (Bailey, 1987; Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, Donnell and Helm, 1986). To an extent parents could determine the boundaries of intervention. However, recent research results show that professionals still tend to play the major role in the making of decisions (Bailey, Buysse, Edmondson and Smith, 1992; Minke and Scott, 1993).

The extensive work of Dunst and his associates (Dunst et al. 1991; McWilliam and Dunst, 1986; Trivette, Dunst, Deal, Hamer and Propst, 1990) made it clear that the responsibility of professionals lies in the empowering of parents to meet their own needs. Until recently intervention practices have been primarily deficit oriented and reactive but should be strength oriented and proactive.

Knowledge of the family combined with knowledge of stress theories can play an important role in anticipating needs of families and providing timely support, thus enhancing family adjustment and preventing the development of maladjustment (Bray et al., 1981; Farran, Metzger and Sparling, 1986).

Given the often scant resources available for family intervention, it is imperative to know which coping resources are more likely to be influenced by intervention and which ones are likely to have the greatest impact on a particular domain (Frey, Greenberg and Fewell, 1989:248).

However, concern exists among professionals in the field about the dangers of raising false expectations, and confusing families on the purpose of early intervention (Slentz and Bricker, 1992). Brinker (1992) emphasises the necessity of a balance between child-directed and family-directed goals. The words of a school psychologist debating the same issue are applicable.

Focusing attention upon the child alone (as is the case in the medical model), but also a focus which is limited to only the family as was common during the zenith of the family-therapy approach (so-called 'family reductionism'), both lead to distortion of a complex reality (Käser, 1993:12).

Qualitative research of Able-Boone, Sandall, Loughry and Frederick (1990) as well as Summers et al. (1990) emphasises the need for sensitivity and the danger of intrusion. Families gave clear indications that the type of need they were prepared to share with professionals were child-related and family needs directly related to these rather than personal needs.

"Every time you answer a question about your family, you give up some of your privacy and uniqueness" and "professionals should get to know the family first and then ask questions. They have to be willing to let the family get to know them too in order to learn about families' concerns and priorities" (Able-Boone et al., 1990: 107-108).

Slentz et al. (1992) and Brinker (1992) stress the importance of forming relationships, only to the degree of intimacy that the family will allow, and understanding family dynamics before assessing needs. The importance of maintaining the "boundaries of expertise available" (Brinker, 1992:308) and the danger that interventionists can act upon insufficient knowledge of the particular family is emphasised.

### 2.3. WHAT ARE THE BOUNDARIES OF PARENT'S SCHOOL INVOLVEMENT

Up to now questions relating to the school's delineation of and responsibility for family needs have been discussed. However, parents also have needs in relation to the more narrowly defined educational task of the school. According to Turnbull and Turnbull (1986) parents have assumed or have been expected by professionals to assume various roles e.g. source

of their child's problems, organisation members, service developers, recipients of professional decisions, learners and teachers, advocates, educational decision-makers and family members. Both parental need for involvement and professional expectations and attitudes toward this need determine the nature and boundaries of the involvement. The history of parental involvement in the USA highlights several important guidelines to a study of parental needs. Research during the seventies indicated strongly that parental involvement with educational processes was beneficial for improved child outcome and there were indications that parents wanted more involvement (Bronfenbrenner, 1976). The assumed needs of parents for more involvement with their children's education and for more decision-making powers were met and even mandated by law P.L. 94-142, (1975) but the outcome did not necessarily lead to more involvement and improved child outcome. The sole concentration on child outcome goals negated the side-effects that these programmes could have on parents and families. The gradual realisation that the child is a member of a family system compelled professionals to take a broader look at family needs as far as parental involvement in education is concerned (Dunst, 1985; Foster, Berger & McLean, 1981; Hanline and Hanson, 1986; Turnbull and Turnbull, 1982; Winton, 1986).

Qualitative research emphasised the individual nature of parental needs for involvement and also the need of parents to sometimes be less involved (Turnbull and Winton, 1984; Turnbull, Winton, Blacher and Salkind, 1983; Winton and Turnbull, 1981). P.L. 99-457 (1986) acknowledged this need.

"The plan (IFSP) is the result of the process of interaction among families and professionals and is developed jointly by the family and appropriate qualified personnel. . . Contents are parent-driven" (Campbell, Strickland and La Forme, 1992:113).

The importance of parental rather than professionals' perception of needs become very important in the context of parental contribution to planning of services. One parent stated: "a need is not a need unless it's recognized by parents" (Summers et al., 1990:90). The question can therefore be posed whether parents are aware of their needs and always know what to ask and how far the method of needs assessment and the attitude of professionals play a role. Winton and Bailey (1990) state that the emphasis has shifted from giving

information about services to gathering information about needs, strengths, resources and preferences and from experts giving specialised knowledge to partners sharing knowledge.

From the above it is evident that in the USA parental involvement in the child's education is regarded as beneficial and encouraged. However, caution is taken to respect family needs and not to assume that all parents need involvement.

#### 2.4. WHAT ARE THE IMPLICATIONS FOR THE PRESENT RESEARCH?

I have discussed the general situation in the preschool/early intervention fields. The focus was especially on the USA where radical shifts in theory and practice have taken place over the last 20 years. How have these changes affected theory and practice in South Africa and what are the practical implications for the present research? Salient differences exist between the conditions of preschool special education in South Africa and the USA. Local theory and practice show few signs of the radical shift experienced in the United States. In many ways comparisons are precluded.

American early intervention services are provided for children from 0-5 and are home and centre-based while South African special educational services are mostly centre-based and provided from the age of three according to Biersteker (1987). However, there are reports of new initiatives for home and centre programmes for the younger group in some areas ({Botha, 1993; Kench, 1993; Louw, 1993 personal communication}; Rocher, 1993; Solarsh, Katz and Goodman, 1990) In stark contrast to practices in the USA and other countries South Africa has a separation of facilities for population groups and types of handicap and minimum facilities for handicapped children in mainstream schools (Nkabinde, 1993).

No legal provision is made in South Africa to mandate parental involvement in special education. Act 70 of 1988 recommends guidance to parents with a view to the instruction, teaching, training or treatment of their children. These needs are acknowledged in so far as this will directly benefit the

child. Most special schools were started through parental and other private enterprise but currently parents have no legal rights to participate in the government of the school. Once a child has been admitted to the school parents have little say in determining the type or direction of the child's education. However, in practice parents do have more rights. However, presently this country is moving rapidly into a transitional stage and vast changes are sweeping through mainstream education. As a result of the current economic backslide, parents in mainstream education have to pay much more for their children's schooling and thus have gained considerable governing powers. The situation in special education has not changed as yet except for real and threatened cutbacks in the provision of staff and other facilities. Another aspect of these changes is that the need for parent empowerment is mentioned more often in the literature on preschool education, especially in the case of culturally disadvantaged children (Biersteker, 1987; Govender, 1987).

In the USA an enormous volume of research has been conducted in this field especially during the last twenty years and research has directly influenced the practice and the legislation in this field. In South Africa little research has been done on special education. I could find little specific research on preschool special education except for the outstanding contribution of Solarsh (1986) on maternal participation in families with mentally handicapped preschool children. In a few other studies, preschool groups are included in the general study or as part of a comparative study (Berzon, 1987; Jansen, 1991; Lea, 1986; Poonsamy, 1985; Sillipp, 1987;). Parent/family needs are not directly researched but are given prominence in some special education research e.g. Dreyer, (1977) researched the influence of parents on the emotional adjustment of CP-children and recommended that special schools should provide intensive emotional support facilities to parents involving them more in the child's rehabilitation programme; Du Plessis (1991) stresses the importance of parent support and information in the preschool years; Vorster (1991) and Pelser (1986) worked on guidance programmes for parents of handicapped children; Van Rooyen (1989) concentrated on marital satisfaction and family stress in families with a pervasive developmental disorder and mental retardation; and De Wet

(1984) researched the psychosocial implications of the birth of a child with congenital anomalies emphasising parental needs. The need for guidance, support - especially psychotherapeutic support - and information is stressed throughout. Some researchers have studied the parents and their handicapped children as part of a family system e.g. Berzon, 1987; Jansen, 1991; Sillipp, 1987. The emphasis in the above research is on problems parents experience and resultant needs with less emphasis on family strengths and resources.

The differences cited above will give some guidelines in the interpretation of research findings against the background of the reviewed literature. Although theoretical viewpoints and the present nature of facilities for handicapped children and their families differ, some basic needs are shared. The need for research on preschool special education and specifically on parental and family needs is highlighted. The history of early intervention practices in other countries could sensitise South African researchers to parental needs, alert them to wrong assumptions and broaden the scope of the field thus giving direction to this research in this area.

### **3. AIMS AND PREVIEW OF THE PRESENT STUDY**

The conception of this project has been shaped by my practical experience, literature on early intervention and the current state of research and practice in South Africa. This exploration of parent/family needs is undertaken against the broader background of the whole family and its ecosystemic environment and not restricted to needs related to child outcome. Thus a study of the impact of the handicap on the family system and its subsystems i.e. family relationships, family functioning as well as the impact over the family's life cycle, is included. However, it is also necessary to study family interaction with other systems, e.g. school systems, and ways in which the handicap impacts on this interaction and creates special needs. As important is the study of family strengths and resources as these are closely interlinked with needs.

Differences between parents' and professionals' perception of parental needs can easily occur. This is partly due to the fact that parents do not always make their needs

known which could be owing to an inability to verbalise their needs, or misgivings about the appropriateness of mentioning a need, or resistance to sharing private needs. The search for insight into parental need perceptions is further complicated by different perceptions in the family and by the professional/researcher's own background which plays a role in the interpretation of parental need perceptions. As Brinker (1992) points out, extreme caution is necessary in a study like this and assumptions and interpretations should be made with care.

The investigation will take the form of an in-depth study of a small group of parents with children attending a special school. I aim to develop a tentative theoretical framework grounded in the insights that will be gathered from this project. Although the resulting theory will be substantive rather than general as it is restricted to one setting (Glaser and Strauss, 1967; Jacob, 1990) it could provide guidelines for further research in this area and for practical applications in the broader field of parent/school linkage in special education.

The research will involve the researcher, staff and parents. Inevitably research process as well as findings, will have an effect on all participants. An aim of this study will be to sensitise myself and other professionals to the needs of this group of people and to indicate ways in which this awareness could be used to create a sound base for planning to meet some of these needs. The process will inevitably open a discussion with parents on their school related needs and in some create a stronger awareness of needs and possibilities for fulfilment.

In chapter 2 I discuss basic theoretical concepts which guided this study. In chapter 3 and 4 I give an overview of relevant literature on families of handicapped preschoolers. Chapter 5 gives the rationale behind the choice of methodology and explains research procedures. Chapters 6 and 7 present research findings. In chapter 6 fourteen in-depth interviews are described, analysed and the main themes placed in a contextual framework. Chapter 7 presents research results from an open-ended parent questionnaire and twenty staff interviews. These results serve as triangulation of the main study and give

background and perspective. Chapter 8 presents conclusions and recommendations.

#### 4. DEFINITIONS AND CONVENTIONS

##### 4.1. NEEDS

The Penguin Dictionary of Psychology gives two alternative definitions of need:

1. Some thing or some state of affairs which, if present, would improve the well-being of any organism. A need, in this sense, may be something basic and biological (food) or it may involve social and personal factors and derive from complex forms of learning (achievement, prestige).
2. An internal state of an organism that is in need of the thing or state of affairs (Reber, 1985 : 465)

Reber (1985) states that these two fairly straightforward definitions mask the abundance of technicalities and subtleties found in psychological and related literature. He finds this symptomatic of the fact that "need" is one of those concepts whose underlying characteristics are essential for sound theory but whose connotations are so diverse that conceptual boundaries have not been agreed upon.

Springboard (1981) discusses need statements e.g. needs for something to satisfy a rule or to achieve a specific purpose; tangible or abstract needs; existing but unacknowledged or unverballed needs and needs that people are supposed to have. He warns against normative judgement of somebody else's need.

Maslow's theory that all human motives can be viewed as parts of a hierarchical need system is relevant to this study. The seven steps of this pyramid are: 1. Physiological needs; 2. Safety needs; 3. Belongingness and love needs; 4. Esteem needs; 5. Cognitive needs; 6. Esthetic needs; 7. Needs for self-actualisation (Reber, 1985; Leff, 1978)

Need hierarchy concepts are important as parents have to have their basic needs met before the fulfilment of higher needs become important. There is no sense in discussing lack of parent/school contact while parents are struggling for food.

## 4.2. HANDICAPPED CHILD

The term **handicapped** is defined as:

Having an encumbrance or disadvantage that produces a less-than-normal ability to perform. Usually the term refers to the physically impaired but may on occasion be used for the mentally retarded (Reber, 1985: 316).

A collection of often confusing terms is used for children with handicaps. In the USA the word handicap was discarded and disability introduced in legal documents but many authors prefer the term exceptional (Turnbull et al., 1986). Warnock (1978) had serious difficulty with the use and precision of these terms. They disliked the labelling effect of the terms and preferred to categorize children according to their educational needs.

To describe someone as handicapped conveys nothing of the type of educational help, and hence of provision that is required. We wish to see a more positive approach, and we have adopted the concept of **special educational need**, seen not in terms of a particular disability which a child may be judged to have, but in relation to everything about him, his abilities as well as his disabilities- indeed all the factors which have a bearing on his educational progress (Warnock, 1978:37).

In South Africa the word "handicapped" is used officially and I will use it in this study although I am aware that some people prefer terms like disabled or environmentally challenged. The legal definitions are:

'**handicapped child**' means a child who in the opinion of the Head of Education is able to benefit from a specialized education programme for handicapped children, but who deviates to such an extent from the majority of the children of his age in body, mind or behaviour that he-

(a) cannot benefit sufficiently from the instruction provided in the ordinary course of education; (b) needs specialized education to facilitate his adaptation in the community; or  
c) should not attend an ordinary class in an ordinary school, because such attendance may be harmful to himself or to the other pupils in such a class; (Act 70 of 1988- Education Affairs Act [House of Assembly] Chapter 1, Definitions).

## 4.3. SPECIALISED EDUCATION

Specialised education is legally defined as follows:-

'**specialized education**' means education of a specialized nature provided to suit the needs of handicapped children, as well as-

- (a) the psychological, medical, dental, paramedical and therapeutic treatment of, including the performance of operations on, handicapped children;
- (b) the provision of artificial medical aids and apparatus to handicapped children;
- (c) the care of handicapped children in a hospital, hostel or other institution;
- (d) the provision of transport, escort and such other services as the Minister may deem necessary to meet the needs of handicapped children; and
- (e) the provision of guidance to the parents of handicapped children, including handicapped children who are not yet subject to compulsory school attendance, with a view to the instruction, teaching, training or treatment of such children; (Act 70 of 1988- Education Affairs Act [House of Assembly] Chapter 1, Definitions).

Another definition is of importance here.

'education' means instruction, teaching or training provided to White pupils in terms of this Act. (Law 70 of 1988- Education Affairs Act [House of Assembly] Chapter 1, Definitions).

The bizarre definition of education seems to restrict this facility to white pupils but there are laws and institutions which provide for educational facilities for other racial groups. This definition does show the sad state of affairs which caused racial groups to be provided with different and mostly unequal educational facilities. This dispensation is now changing but was still in effect when the fieldwork was done and explains why this study is restricted to white pupils.

In the 1981 Handbook of the Department of National Education provision is made for different types of schools for different handicaps. Educable children whose main problem is disturbed function caused by a brain defect or brain damage, qualify for admittance to this specific type of special school where the study is conducted.

#### 4.4. PARENT

The legal definition of a parent used in this study is

'parent' in relation to a child, means the parent of such child or the person in whose custody the child has been lawfully placed (Law 70 of 1988- Education Affairs Act [House of Assembly] Chapter 1, Definitions).

#### 4.5. PRESCHOOL (SPECIAL EDUCATION)

In the Handbook of the Department of Education and Culture (House of Assembly) (1990) preprimary teaching is described as facilities for children who have not yet reached school going age. It is advised that they should start a formal specialised teaching programme as early as possible as this will enable them to attain the necessary communication skills, therapeutic and educational support to realise their potential. The Handbook of The Department of National Education (1981) advise the age of three. In special schools the age range of preprimary children is usually between 3 and 7 years.

#### 4.6. CONVENTIONS

The following conventions are adhered to in this study:

1. To simplify matters the pronoun he is used except where it is clear from the context that a girl is referred to.
2. For reasons of confidentiality fictitious names are used.
3. The following abbreviations have been introduced:
  - 3.1 Quotation = Q
  - 3.2 Questionnaire response = QR
  - 3.3 Mother = Pm
  - 3.4 Father = Pf
  - 3.5 Staff member = S

## CHAPTER 2

# THEORETICAL FRAMEWORK: SOCIAL SYSTEMS APPROACHES

### 1. INTRODUCTION

Although much research has been done on families of exceptional children, the complaint is often heard that the research is limited in scope and lacks theoretical structure (Crnic, Friedberg and Greenberg, 1983; Dunst and Trivette, 1988; Kazak, 1986; Lea, 1986). A growing group of researchers in this field have adopted social systems models in their search for a broader, holistic perspective with a sound theoretical foundation. These models include family systems theory, (Berger, 1986; Feiring and Lewis, 1978; Kopper-Roland, 1986; Turnbull et al., 1986) social ecology, (Apter, 1984; Bronfenbrenner, 1976 and 1977; Kazak, 1986) social network theory (Dunst, Trivette and Cross, 1986) and adaptational theory (Crnic et al., 1983; Farran et al., 1986).

The systems theoretical framework, especially as it applies to family systems theory, has caused a shift from the concentration of studies on child development or the mother-child dyad to a more family oriented field where the child is recognised as part of the family system. There is also an awareness that the family system is embedded in a social network system as part of their ecological environment. Thus inter-relationships, feedback processes and the context in which a phenomenon occurs are seen as vitally important (Bubolz and Whiren, 1984).

The physically handicapped child is only a focal point in an interrelated, dynamic system of parents, siblings, extended family, neighbors, friends, and health care professionals (Kazak, 1986:265).

As I will utilise some of the theoretical concepts of these social systems models, a closer look is taken at some of the underlying concepts in family and ecological systems; social support systems; and stress, coping and adaptation processes.

## 2. FAMILY SYSTEMS

The family is a social system with unique characteristics and needs. Minuchin (1985) describes the family as an open system constantly changing and adapting to demands made from internal and external sources. This system operates through transactional patterns determined by mutual expectations of members and is regulated by universal rules of family behaviour. There is a "wholeness" of the family that makes it more than a collection of individuals and gives it an "essence of its own that can be sensed and felt" (Miezio, 1983: 16-17). Successful family life, requires that the needs of all family members, including parents, be identified and addressed. Individual members of a family are so interrelated that any experience affecting one member will affect all (Turnbull et al., 1986; Miezio, 1983). Skrtic, Summers, Brotherson and Turnbull (1984) also warn that families differ widely in their make-up and these differences as well as the life-stage of the family, lead to endless variations in the ways in which they function to meet the needs of their individual members.

FIGURE 1 FAMILY SYSTEMS CONCEPTUAL FRAMEWORK

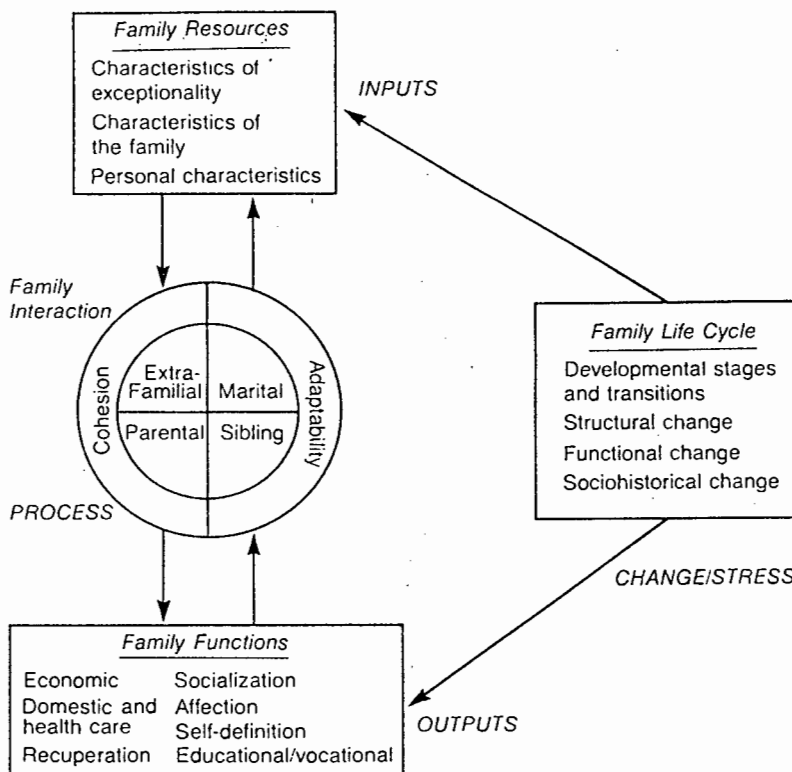


Figure 1-1  
FAMILY SYSTEMS CONCEPTUAL FRAMEWORK

In Figure 1 a framework is given which is a synthesis of the sociological literature on family systems theory and the literature in special education on the impact of children with exceptionalities on their families.

### 2.1. FAMILY RESOURCES

From a systems perspective, family resources are called input into family interaction. Applied to exceptional families this would be characteristics of the handicap (diagnosis, level of severity); characteristics of the family (size, culture, socio-economic background, geographic location etc.); personal capacity (health, intellectual capacity and coping styles.)

### 2.2. FAMILY INTERACTION

The family unit is an interactional system with family subsystems forming the components. Feiring et al. (1978) show that a system has a nonadditiv quality. Knowing everything about the subsystems is not equal to knowing the system as a whole because any subsystem behaves differently within the system from the way it does in isolation. This is vital to remember when working with parents. The picture of a mother and child's relationship when they are on their own might be completely different when they are operating within the whole family system. That is why parents may give different pictures of their child's needs or capabilities.

Within the traditional nuclear family there are usually major subsystems i.e. marital; parental; sibling; and extrafamilial. As the members of a family unit are interlocking parts of the system and connected by a continuous feedback loop, it is important to remember that behaviour of a person in a family is a stimulus for another person but also a response to that other person. A child's tantrum is a response to something that happened and at the same time it might trigger a tantrum from the parent. The communication connections are both verbal and non-verbal and tone of voice, body posture etc. can transmit very powerful messages. Children can be very sensitive to underlying messages conveyed by a frown or a sigh etc. (Kopper-Roland, 1986; Miezio, 1983; Turnbull et al., 1986).

Two important elements of family interaction are cohesion and adaptability. Cohesion has to do with the closeness of the emotional bonding and the independence of an individual within the

family system. The two extremes found in families are either enmeshment or disengagement. Adaptability is the term used for the family's ability to change in response to stress. Family adaptability can be viewed on a continuum ranging from rigidity to chaotic. Rigid families are unable or unwilling to change in response to situational or developmental stress while chaotic families change all the time whether it is necessary or not. The changes made are not consistent and often characterised by family instability. Power hierarchies and roles and rules in the family are important. The concepts of cohesion and adaptability can be extremely helpful in understanding the needs of parents. The way needs are expressed and interpreted will be influenced by these concepts (Berger, 1986; Miezio, 1986; Turnbull et al., 1986).

### 2.3. FAMILY FUNCTIONS

Family functions represent the different categories of needs the family is responsible for addressing. The purpose or "output" of family interaction is to produce responses to fulfill the needs associated with family functions (Turnbull et al., 1986: 20).

In a family with exceptional children many of these functions may become problematic and the family will focus more on certain areas. The family systems approach stresses the importance of being aware of all the different functions a family has to perform and all the needs that will exist in these different areas (Gentry and Olson, 1986; Turnbull et al., 1986).

### 2.4. FAMILY LIFE CYCLE

This is described as the sequence of developmental and non-developmental changes that affect families. There are the inevitable changes that every family experiences like birth, going to school, growing up, dying etc. Unexpected changes also occur like divorces, accidents, loss of employment or the birth of an exceptional child. For my study the early stages are the most important. Mallory (1986) discusses the concepts of individual, family and historical time as introduced by Haraven (1977). Asynchronicity between the three levels of time could occur in cases where there is a delayed development in one family member.

An important life cycle concept is the transition from one stage to another when the family is adjusting its interactional style and roles to meet new needs. Transitions to different stages

in the life cycle are characterised by stress especially if the change is unexpected and the family is unprepared for it as often happens with the birth of a handicapped child. An understanding of life cycles - the stage of the family and the individual cycles of its members and their changing perspectives, is important in the study of family needs (Berger, 1986; D'Amato and Yoshida, 1991; McCubbin, Patterson 1983b; Turnbull et al., 1986).

### 3. SOCIAL ECOLOGY

Ecological theory is concerned with the interaction between organisms and their environment. In a special educational context a child will be regarded as an inseparable part of a small social system. This system is an ecological unit made up of the child, his family, school, neighbourhood and community (Schmid, 1987). The family's environment furnishes the resources necessary for life and constitute the life and social support systems. Family members transform energy-matter and information from their environment to meet survival and higher level needs (Apter, 1982; Bubolz et al., 1984). The importance of a balanced ecosystem is emphasised.

The success with which a person meets life's challenges is dependent upon his ability to reach a desired functional balance between his physical and social habitats, and himself (Thomas and Marshall, 1977: 16).

The cause of a problem or disturbance can be viewed as a failure to match - a problem lying in the system rather than a deficit in the individual. Interventions must then be aimed at the points of discord in the system which cause failure to match. This can encompass a changing of the child, the environment or of attitudes and expectations. The nature of the child's environmental experiences has an important impact on biological problems of youngsters (Apter, 1982).

Bronfenbrenner (1976, 1977) with his social ecology model has introduced terminology and definitions which clarify how child and family fit into the educational environment as part of the total life system. His conception of the educational environment as a "nested arrangement of structures, each contained within the next" (Bronfenbrenner, 1976:5) forms a useful bridge between the general area of ecology and the application of its principles to the education of exceptional children (See figure 2).

FIGURE 2 - (BAILEY AND WOLERY, 1992: 66)

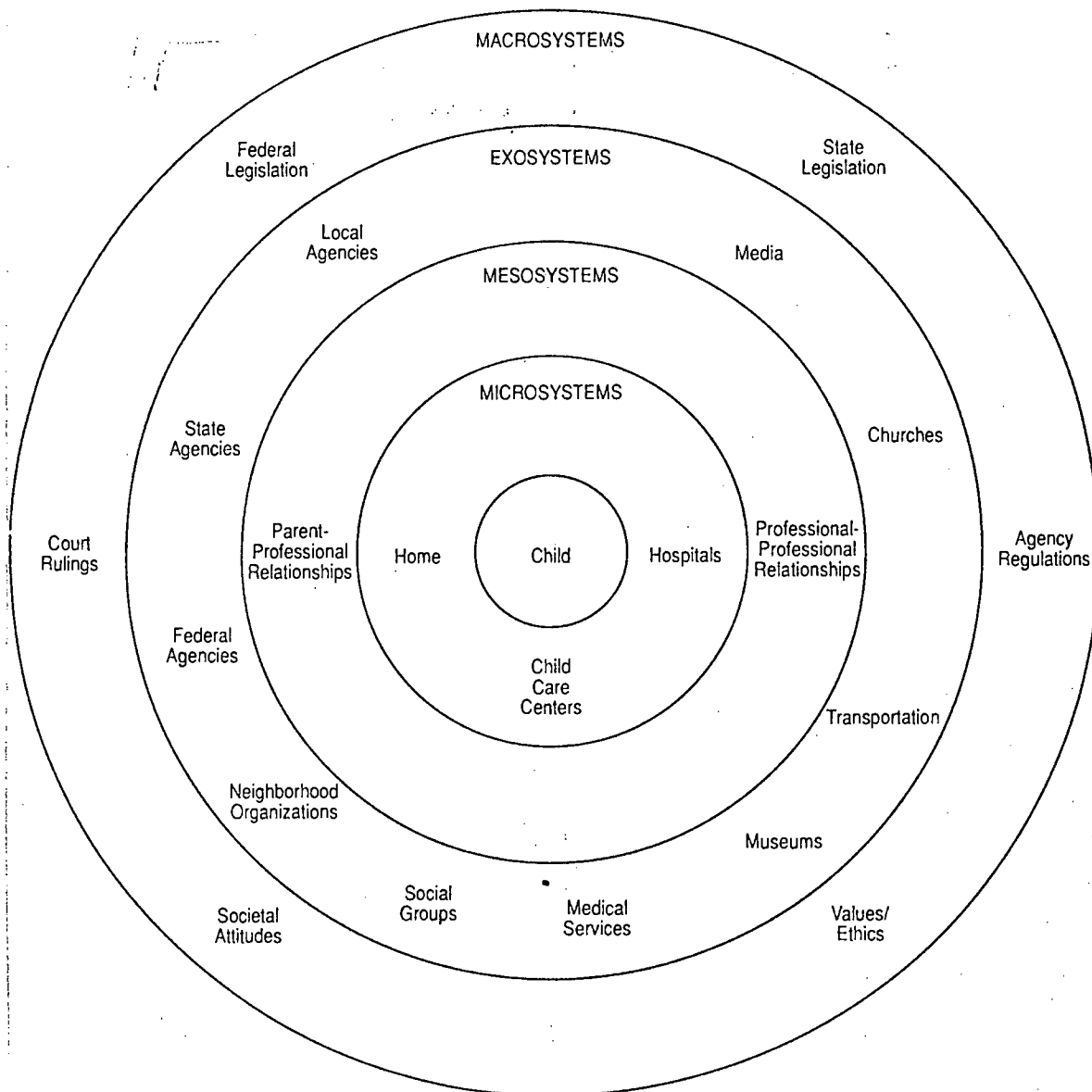


FIGURE  
Four nested levels of the environment

Note: Figure form and content by D. B. Bailey. Based on concepts presented in "The Experimental Ecology of Education" by U. Bronfenbrenner, 1976, *Educational Research*, 5(9), 5-15, and in "Toward an Experimental Ecology of Human Development" by U. Bronfenbrenner, 1977, *American Psychologist*, 32, 513-531.

**Microsystems-** an immediate setting containing the learner - e.g. home, school, neighbourhood - where he experiences patterns of activities, roles and interpersonal relationships. Place, time, activity and role form the elements of the setting.

**Mesosystems-** the interrelations among the major settings containing the learner at that stage- in this study it will mean the relationship between the home and the school or the home and the neighbourhood of the handicapped child.

**Exosystems-** this extension of the mesosystems embrace other specific social structures both formal and informal that do not

themselves contain the developing person but in which events happen that affect the child. These structures include the major institutions of society. Most relevant to this study, are the school and other parental or family social support networks.

**Macrosystems-** these are the general prototypes existing in the culture or subculture, that set the pattern for the structures and activities occurring at the concrete level (Apter, 1982; Bronfenbrenner, 1976 and 1977; Kazak, 1986).

Apter (1982) states that great advances have been made in the field of special education through the use of ecological principles and that this theory could be a useful basis for conceptualising issues in this field. According to Kazak (1986), Bronfenbrenner's social ecology is especially useful for understanding the ways in which families with handicapped children interact in general with other systems.

#### **4. SOCIAL SUPPORT AND SOCIAL NETWORK SYSTEMS**

This section focus on one facet of the exosystem namely the social support network systems which can play an important part in the adjustment process of the family. The social ecology model of Bronfenbrenner (1976) demonstrates the interdependence between different social networks. The provision of support in one area reverberates in other areas and affects the behaviour of members of other units (Dunst and Trivette, 1984). Cobb (1976) describes social support as information leading the person to believe that he is cared for and loved, esteemed and valued, and part of a network of mutual communication and obligation. He states that goods and services are not as central to the idea of social support as information and the meeting of relational needs. The amount and type of social support that families receive in times of stress can play a decisive role in the way in which their stress is alleviated and in the development of coping strategies (Dunst et al., 1986a), Dunst et al., 1984b; Kazak, 1987; Kazak and Marvin, 1984).

A closer look at social systems and the analysis of social network systems will provide a useful background for the study of parents' needs. These needs are often related to insufficient social support or a lack of organisation between the different systems which might lead to non-effective utilisation of existing systems.

Dunst, Jenkins and Trivette (1984) distinguish between various types of social support in their Family Support Scale - a scale devised for use with families of young handicapped children. The items of the scale make a distinction between the different types of support coming from friends, family both nuclear and extended, social organisations and general and specialised professional services. A further distinction is made between the different functions of support including emotional and psychological support, physical and instrumental assistance, resource and information sharing, appraisal, self-evaluation, attitude transmission and assistance with problem-solving (Dunst et al., 1986a; House, 1981; Kazak, 1987). According to Dunst et al. (1986a) social support networks also serve to nurture and sustain linkages among persons that are supportive on a daily basis and in times of need and crises.

In their discussion of the impact of personal social networks Cochran and Brassard (1979) draw a further distinction between network forces which influence the child's development directly and those which indirectly influence the child through the parents. However, clear distinctions between these categories are not possible.

Direct influences on the child are through people in the child's social support network which may or may not be part of the parent's network. The indirect influences on the child's development through the network of the parents could be as a result of demands on their time and energy that drain resources for the child; assistance to the parents in the fulfilling of their other functions i.e. better work opportunities, marriage enrichment, recreational facilities etc. through which the children benefit indirectly; assistance related to the parental role through the provisions of goods, affection, parenting advice, censoring of parental behaviour and role-modelling. However, the last category of assistance could be helpful or detrimental. Support accompanied by critical advice or censoring of parental practices can break down confidence.

One can safely state that these influences can be crucial during the first few years of a child's life, especially with a firstborn or an exceptional child, as this is the time when parents are still finding their feet in the parental role and are susceptible to outside influences.

The positive or negative effects social support systems can have, merit a further look at their significant characteristics.

**Network size** i.e. the quantity of persons available for help.

**Density** (Kazak, 1987) or personal interconnectedness (Cochran et al., 1979) i.e. the extent to which members of the network know and interact with each other. This is closely related to the concept of open and closed systems which is a measure of the ease with which information flows between networks. In systems theory terms information exchange is seen as a mutually affecting process between components. There is an ongoing feedback and each link is modified by its interaction with others constituting a feedback loop. A well-designed structure allows flexibility in the interlinking between subgroups creating an optimal information flow thus facilitating planning and decision making (Chinn, Winn and Walters, 1978; Dowling, 1985; Taylor, 1985).

**Boundary density** i.e. the proportion of possible network interconnections existing between two networks - mesosystem - or two segments within the network - microsystem linkages. This concept has importance for the understanding of the interaction between formal and informal support networks- i.e. school and family. The density of boundaries affects the receiving of information from divergent sources. According to Kazak (1987) the role of boundary density between systems is not yet fully understood in the process of information exchange. Families with handicapped children often receive information from diverse sources and it may be difficult to integrate the information constructively.

**Reciprocity** i.e. the degree and balance of aid given and received in a network. In the case of families with handicapped children there is a tendency towards non-reciprocal relationships which could cause stress on both sides or a draining of support networks. The ongoing series of reactions in this relationship will change the next cycle of interaction. Positive or negative feedback will shape reactions and help to retain a homeostatic balance (Kazak, 1987; Cochran et al., 1979). Kazak (1987) states that there has been no research aimed at understanding the sequence of interactions for families with handicapped children.

**Location in space and time** i.e. the geographic proximity of network members and the frequency and continuity of the contact (Cochran et al., 1979). Kazak (1987) stresses the developmental perspective causing changing needs of families over time.

Quality of the support i.e. the relevance or "goodness-of-fit" of the support and the perceived helpfulness of the support (Dunst, Trivette and Cross, 1986; Kazak, 1987; Lea, 1986). According to Kazak, 1987 research has indicated that network members providing multidimensional support are seen as being more helpful but it is unclear how this applies to formal support networks.

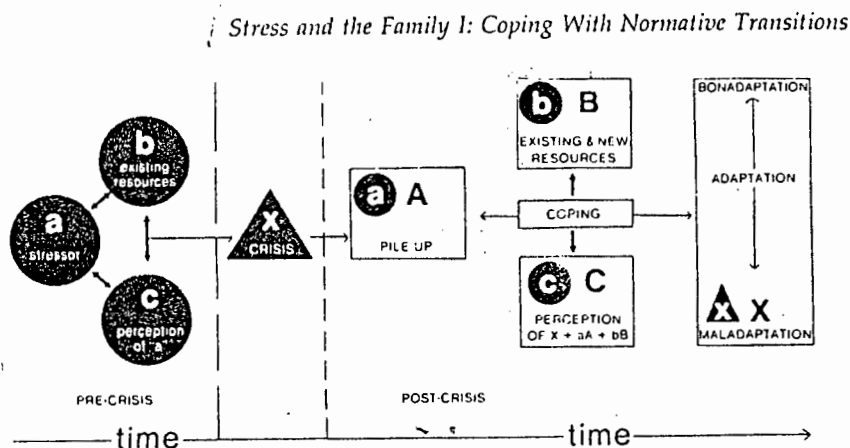
## 5. STRESS, COPING AND ADAPTATION

In this section I discuss the interactional processes between support systems and families of handicapped children. Intermingled with any study of families of handicapped children, is the interplay between stress and coping, the strengths that are conducive to successful family outcomes and the relative needs that arise on the way especially when the family is struggling. Wikler (1986) and Goodfriend, Bronicki and Turnbull (1986) underline the need for a conceptual framework to "tease out the interactions between stress and coping and to define operationally successful family outcomes" (Goodfriend et al., 1986:51). They recommend the ABCX model developed by Hill (1949) as used in the general arena of family studies. This model has the potential to identify key variables and to balance the focus on positive and negative impact of these variables on family functioning and family needs. Wikler summarises Hill's scheme.

A (The stressor event)- interacting with  
 B (The family's crisis-meeting resources)-interacting  
 with C (The definition the family makes of the event)-  
 procedure  
 X (The family crisis) (Wikler, 1986:169).

McCubbin and Patterson (1983a) added a new dimension to this model with their double ABCX model which focuses on the family efforts to recover from a crisis situation over time. This model as illustrated in figure 3 is an effort to incorporate additional concurrent stressors affecting recovery from the original crisis and takes the effect of the pile-up factor aA into consideration.

FIGURE. 3 THE DOUBLE ABCX MODEL (MCCUBBIN AND PATTERSON, 1983: 12)



The stressor event, A, is a problem situation i.e. life event or transition arising from a demand-capability imbalance that presents itself to the family for resolution with the potential of producing change in the family social system. A stressor is often a crisis-provoking event or situation for which the family has little preparation but sometimes it is a series of crises that undermine the person or family's coping abilities resulting in higher stress levels. The pile-up factor aA includes the initial stressor, the accompanying hardships, and the consequence of the family efforts to cope (Gallagher, Beckman and Cross, 1983; Jansen, 1990; McCubbin et al., 1983a; Wikler, 1986). Farran et al. (1986) emphasise the importance of the family's own description of the event, as there are often other crises which coincide with and exacerbate the effect of the birth or diagnosis of a handicapped child e.g. the loss of a job or illness in the family. The demands of the event itself can also have a significant effect on the amount and kind of stress that is produced. Of relevance here is the amount of stress-producing changes - both psychological and physical that are required - changing their perceptions of the child that was expected, adjusting to increased demands of caretaking, role adjustments etc.

The B factor is the family's adaptive resources and comprises the family member's personal resources, the family system's internal resources and social support. When these resources are insufficient a crisis may force a restructuring of the family and/or changes in their interactional patterns. New

resources are developed in response to the new demands caused by the pile-up of stressors i.e. the bB factor (McCubbin et al., 1983a; Jansen, 1991).

The C factor is the family's definition of the initial stressor. Families often see the event e.g. the diagnosis of a disability, as overwhelming and beyond their ability to manage. They might see the situation as a threat to family status, goals or objectives. The cC factor is the family's struggle to give new meaning to the situation through redefinition or passive appraisal. Ideally the aim is to clarify the issues and tasks to render them more manageable, decrease the intensity of the emotional burden associated with the crisis situation and encourage the family unit to go on with tasks like promoting the members' social and emotional development (Jansen, 1991; McCubbin et al., 1983a; Wikler, 1986).

The mourning process plays an important role in the definition of the crisis. However, the idea of mourning stages is related to the psycho-analytically -oriented theory that the parents have to mourn for the expected ideal child (McConachie 1986). Blacher (1984) reviewed the literature for evidence of the existence of these stages and concluded that professional inference has played a role in the description of the stages. An important methodological observation made is that parents are not eager to report reactions that imply weakness or anger in themselves. Blacher's conclusion is that the question whether parents do experience sequential stages remains to be answered but that it may provide a useful basis for determining helping strategies.

The stages generally include feelings of shock, denial, and disbelief; feelings of anger, guilt, and/or depression; reorganisation of thoughts from self to others and constructive attempts to seek services and otherwise incorporate the exceptionality into the reality of daily life (Blacher, 1984). However, "chronic sorrow" may stay with these parents for life (Olshansky, 1962).

The X factor is described as an ongoing variable indicating the amount of disruptiveness, disorganization, or incapacitation in the family social system. Stress is a demand-capability imbalance while a crisis is characterised by the family's inability to restore stability. Stress results from a perceived imbalance between the demands of an event and an appraisal of

one's skills to meet or contend with the event. The bB and cC factors are often major buffering variables which can protect the family from becoming dysfunctional and provide resilience against the stressor (Wikler, 1986). They can also increase a family's vulnerability and cause a crisis. Important to remember is that the individual's capacity to adapt does not remain static. There can either be growth adding new resources or too much strain on existing resources leaving the family in a weakened condition for handling new demands (Farran et al., 1986). The family and the environment are undergoing continual readjustments to each other regarding the individual's perception of the demands of the event and his ability to meet them. Family adaptation, or the xX factor, describes the outcome of family efforts to achieve a new level of balance after a family crisis. This process is illustrated in Figure 4.

FIGURE 4 (MCCUBBIN AND PATTERSON, 1983: 20)

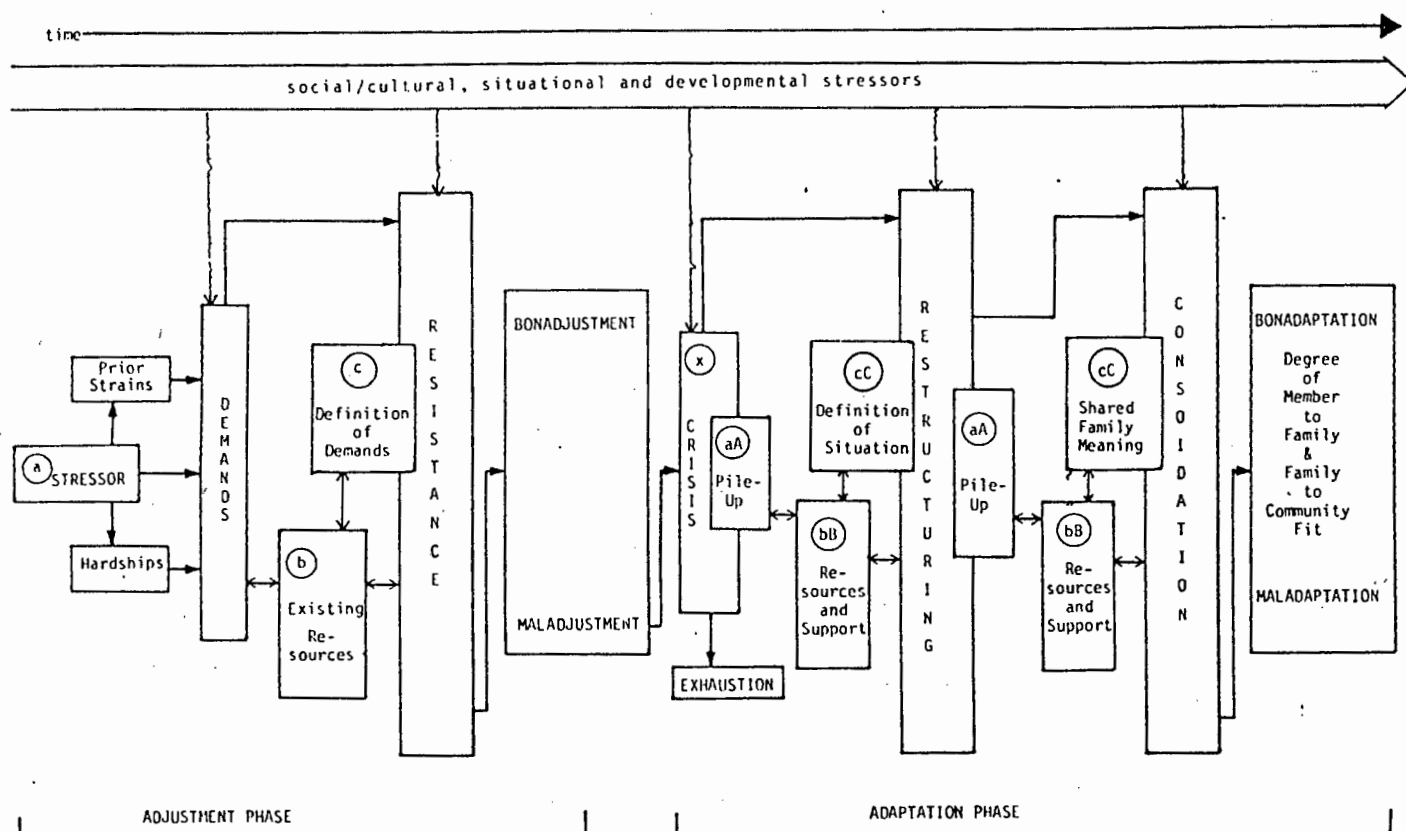


Figure F A A R—Family Adjustment and Adaptation Response

In their efforts to achieve a balance the family use coping resources which could be internal and/or external (Shapiro, 1983). A person's internal environment include personality attributes, such as self-concept, psychological hardiness and resilience. Past

experience with stressful situations plays a significant role (Farran et al., 1986). Crnic et al., (1983a) emphasise the importance of these resources and ecological environments as interactive systems that serve to mediate the family's response to stress. The resources that are available, as well as how and when they are used, are mediated by the various ecological contexts in which the family and its individual members interact. The authors postulate that the ecology of families with handicapped children will differ markedly from those of nonretarded children in the micro-, meso-, exo- and macro-systems.

Shapiro (1983) introduces the concept of family coping. She describes an effectively coping family as one able to attain a new adaptive equilibrium in relation to an individual member's handicap. Caution must be exercised however because it is still unclear in what sense it is possible to talk about family coping as more than an aggregate of the coping strategies of individual family members.

Farran et al. (1986) advocate the necessity of studying the stress associated with families living with handicapped children in a broader, stimulus-response ecological context because service delivery has focused on the end-state or the impact of demanding events on individuals and has little knowledge of the various ways in which they have reached the same end-state. This leads to insufficient understanding and an inability to develop anticipatory services. If service providers and policy makers understand the way an event exerts its influence they can intervene earlier in the process of adaptation. According to them there are two clear places for intervention :-

1. One can attempt to alter the demands of the events, reducing the number of changes families must undergo both immediately and through the years;
2. one can intervene at the level of individual adaptability through such efforts as parent support groups and individual counseling (Farran et al., 1986: p.151).

Bubolz et al. (1984) also plead that a broader, stimulus-response ecological context is necessary for the study of families under stress to understand the coping and adaptation processes. They underline the importance of physic and psychic energy supply and the danger of parental burnout when the energy supply is drained.

A minimum supply of energy is required for system maintenance and existence. . . Additional energy or more efficient use of energy is required for transactions with other systems - educational,

religious . . . Still higher levels of energy or more efficient use of energy are needed for adaptive, creative behavior to enable a system to cope with changing environments, internal stresses and unusual demands on the system. Information, money, goods, and services are other critical resources necessary for family functioning (Bubolz et al., 1984: 6).

In figures 5 and 6 the concept of the family ecosystem and the effect of various stress levels on the functioning of the system is aptly illustrated. The implication for timely intervention as advocated by Farran and associates is clear.

## 6. CONCLUSION

In this chapter an overview was given of some theoretical frameworks which can help with the interpretation of the research findings in this study. These frameworks all stress the importance of a holistic view of the family interacting and interrelating with its members and the outside world. This seems to be especially important in a study of handicapped children and their parents as the birth of a handicapped child can have a devastating effect on the family. The handicapped child can easily become the main focus point to the detriment of other members and family functioning. It is thus especially important that professionals in this field be able to see the handicapped child and his needs against the broader background of his whole family and their ecosystem.

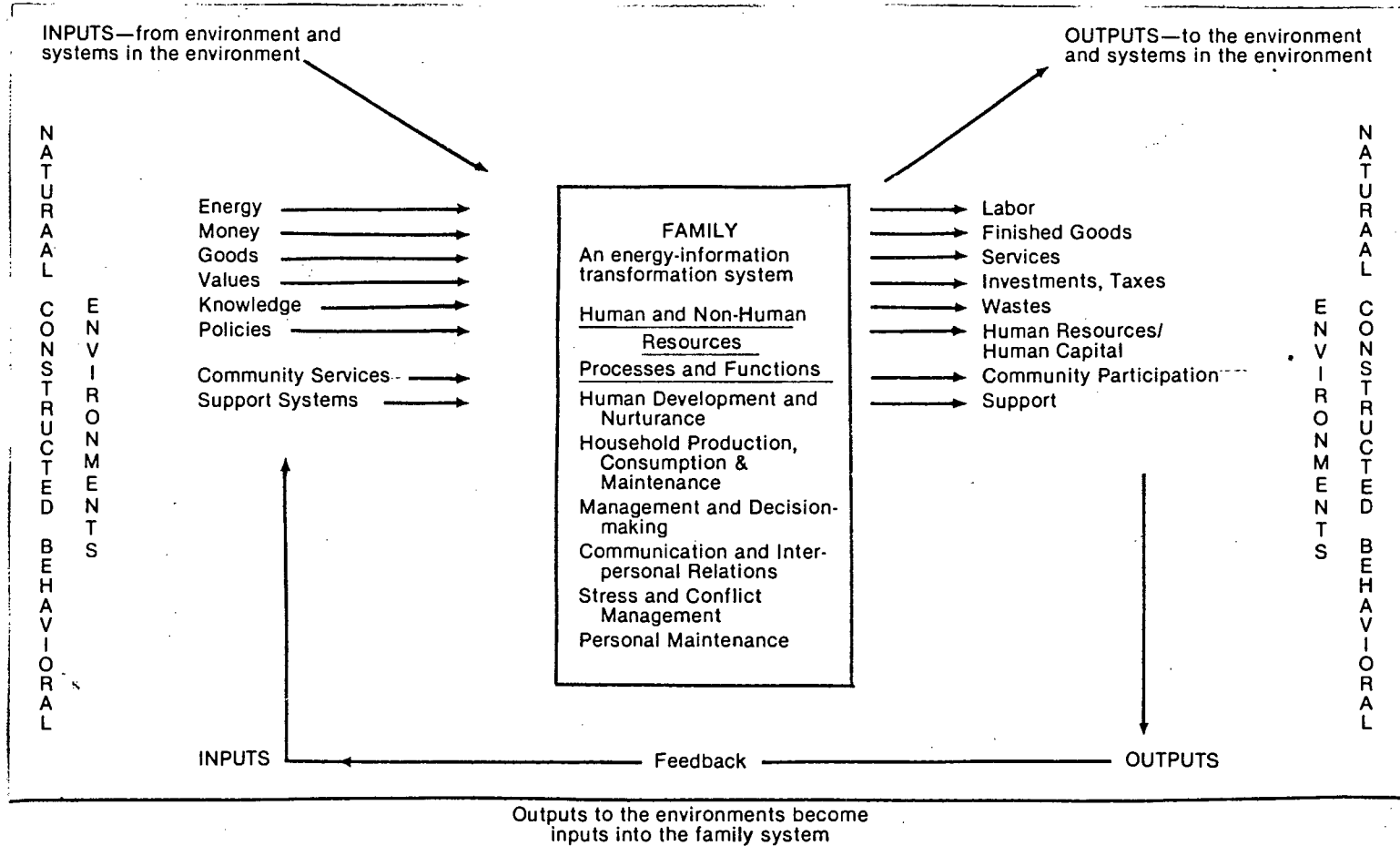
The above theoretical frameworks provide researchers with structures to relate different variables affecting and being affected by the impact of the handicap. This is extremely important as the study of isolated variables could easily lead to distortions which made a mother of a handicapped child ask:

"Who are these researchers and why are they saying these horrible things about me?" . . . they feel inclined to notify the world that my family is isolated, full of disharmony, and pessimistic. How can they say these things when they have never been in my home? (Gerdel, 1986:47).

However, even with the availability of these frameworks, the task still remains daunting as the interrelationships and mutual effect in families and even more so in those with the complicating factor of a handicap in their midst are myriad and difficult to capture. The overlapping nature of these frameworks and the often confusing terminology complicates matters even more. However, they serve the useful purpose of making researchers aware of multiple interpretations of single events, sensitising them to the need for

a holistic approach and to the dangers of oversimplification and generalisation of results.

Figure 5: CONCEPTUAL MODEL OF FAMILY ECOSYSTEM



Source: Dept. of Family and Child Ecology, College of Human Ecology, Michigan State University, Research, Extension and Public Service Review, 1975-1981, 1982

Figure 5. CONCEPTUAL MODEL OF FAMILY ECOSYSTEM

Figure 6: FAMILY SYSTEM FUNCTIONING AT VARIOIUS STRESS LEVELS

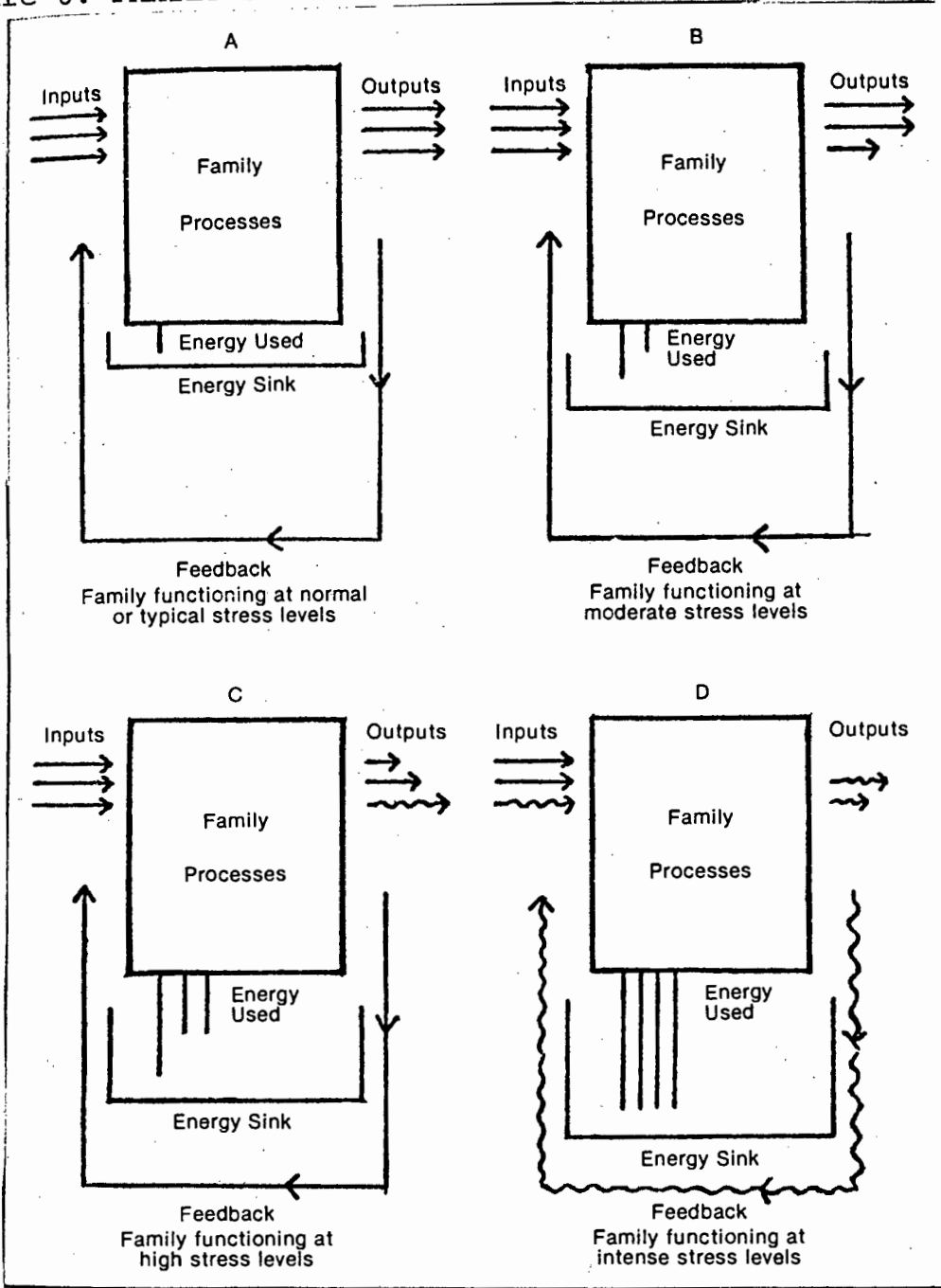


Figure Family System Functioning at Various Stress Levels

## CHAPTER III

# REVIEW OF RESEARCH LITERATURE ON YOUNG HANDICAPPED CHILDREN, THEIR FAMILIES AND THEIR SCHOOLS

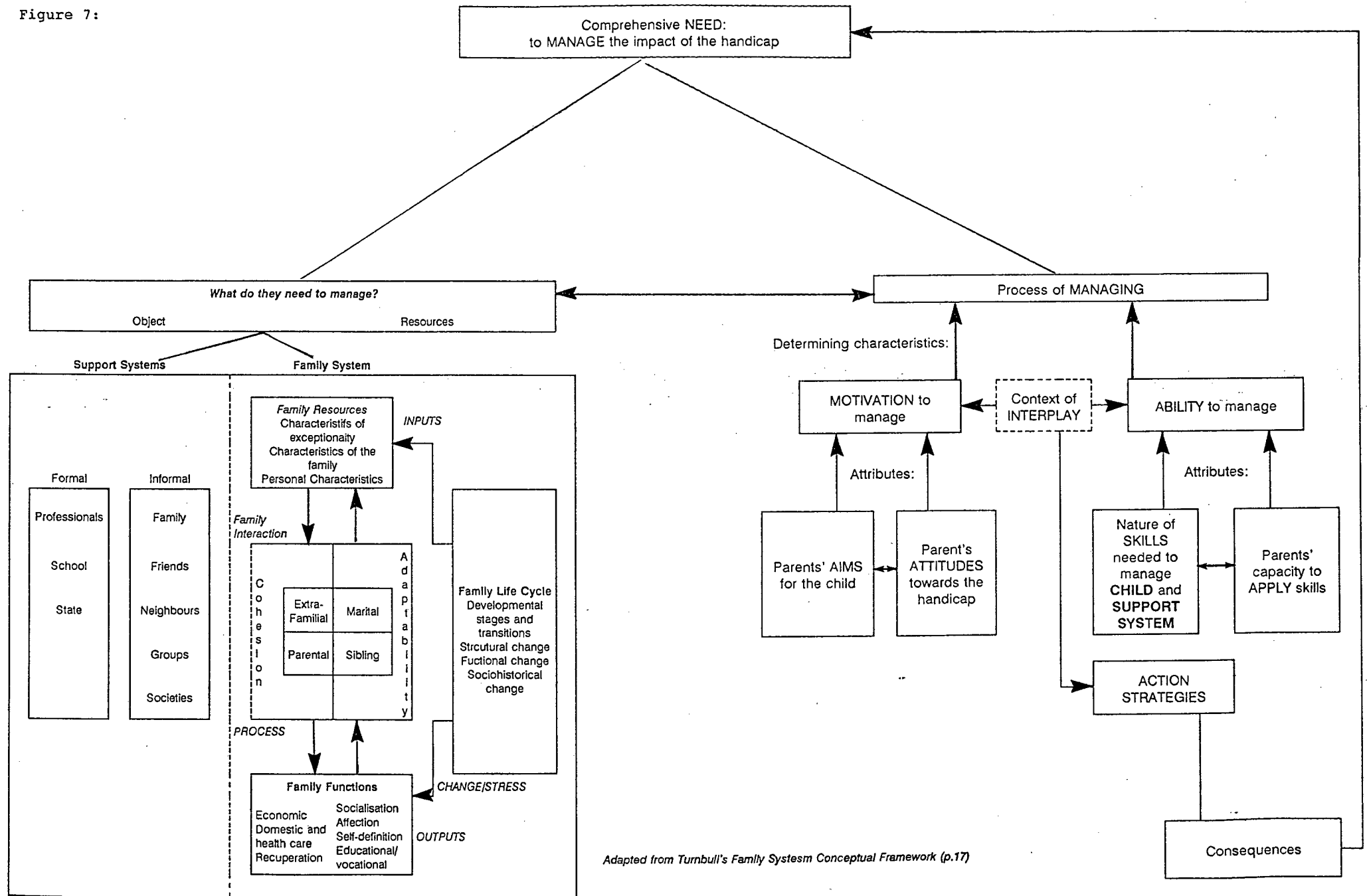
### 1. INTRODUCTION

In their discussion of the use of literature in grounded theory research, Strauss and Corbin (1990) state the importance of developing categories through the study of the research material and only then returning to the technical literature to determine if these categories are there, and if so what other researchers say about them. To facilitate this process I use the categories which emerged during the study of the research findings as a broad organisational pattern for the literature review. The intertwinement of categories necessitated adjustments to avoid overlapping and repetition and some sections e.g. the characteristics of support systems were expanded to provide the necessary background to the understanding of parental needs.

The previous chapter looked at theoretical frameworks fundamental to this research on families. The next two chapters take a closer look at research dealing more specifically with the impact of a handicap on families and the needs that consequently arise. Considerations which influenced this presentation are the vast amount of American literature on this subject which was available to this researcher and the dearth of research directly applicable to the South African situation (Jansen, 1991).

Special education practices in the USA differ from South African practice as indicated in chapter I. This has an influence on the composition of the research population as well as on the attitudes and expectations of the various groups of parents. These factors make comparison and in depth analysis of research results less satisfactory. Thus I give a general presentation of research literature with the aim of creating an awareness and sensitivity to relevant factors as a background to the findings of this study.

Figure 7:



The comprehensive need that emerged from the research findings was the parents' need to manage. The two main questions which arise are: What do they need to manage?; What does the process of managing entail? The first question will be dealt with in this chapter and the second is discussed in Chapter IV (See figure 7).

## **2. WHAT DO PARENTS NEED TO MANAGE?**

This question could be interpreted in two ways: 1. What needs to be managed? 2. What do parents need to enable them to manage? The characteristics of the family and support systems will define the nature of the managing task or the what that needs to be managed. These same characteristics are however, also the resources and/or constraints that determine what the parents need for the managing task. The answers to these two questions are closely intertwined because the resources required by the parents to manage and the impact of the handicap that needs managing, mutually affect each other.

In the following sections the relevant literature on family and support systems is discussed to show to what extent these factors need managing as a result of the impact of the handicap on the family. At the same time the question will be asked to what extent the above factors could act as enhancements or impediments to the managing process and thus determine the extent and nature of the family's need.

## **3. FAMILY RESOURCES**

The family resources are seen as the inputs in the system which will determine and be determined by family interactions and functions and which will vary over the family life cycle. The resources are the descriptive elements of the family and includes characteristics of the handicap, characteristics of the family and personal characteristics of individual family members. The range of reactions to the handicap shape the varying needs of families (Turnbull et al., 1986).

### 3.1. CHARACTERISTICS OF THE HANDICAP

The common denominator of the families in this study is the presence of a handicapped pre-schooler. In this section, research on the impact of the type and degree of the handicap, is presented.

Hewett (1970) in her study of C.P.-children and Salisbury (1987) in her study of young handicapped children both found that many family problems that are often blamed on the presence of a handicapped child are also found to the same or a lesser degree in families with normal children. Although research results suggest that there is a positive correlation between severity of stressful events and severity of the involvement, the correlation is only minimal. If the severity of the handicap is associated with other impeding factors like low socio-economic status it can play a determining role in family adjustment (Mahoney, O'Sullivan and Robinson, 1992). Enhancing factors determining the impact of the handicap are availability of coping resources and support systems (Frey et al., 1989; Friedrich, Wiltturner and Cohen, 1985; Mahoney et al., 1992a).

Stressful circumstances connected to the type and level of severity of the handicap are the amount of concern and pessimism caused by the handicapping condition (Dyson et al., 1986) as well as the nature and extent of the changes that the child's exceptionality requires (Farran et al., 1986). Fathers in particular, find it necessary to change their expectations and ideals for the handicapped child as well as for the family (Frey et al., 1989; Schell, 1981). Unusual caregiving demands, demands for intensive therapy and special schooling can all require non-trivial changes which affect the whole family (Beckman-Bell, 1981; Erickson and Upshur, 1989; Frey et al., 1989; Harris and McHale, 1989 Weinhouse, Weinhouse and Nelson, 1992). The number of demands made on families play an important role but this factor is frequently overlooked by professionals who judge the amount of stress caused by crisis events (Farren et al., 1986).

Characteristics of the specific handicap can play a more definitive role although not always in a predictable way. Characteristics of a child with cerebral palsy that may cause stress are poor intellectual functioning, multiple sensory and perceptual dysfunctions, the onset or fear of epilepsy, visual

and hearing defects, speech and feeding problems, enuresis, dribbling, hyperactivity, distractibility, impulsiveness and disinhibition, poor social skills, introversion, withdrawal and depression (Jansen, 1991).

Bonding problems, caused by long neo-natal periods in incubators, atypical reaction patterns or physical abnormalities often occur in these families (Kasari, 1986; Schell, 1981; Tulloch, 1983). A less severe condition like a learning disability may be difficult to identify, and this creates extensive tension which may be prolonged because of the vagueness and unpredictability of the condition and the resultant behaviour of the child (Turk, 1991; Turnbull et al., 1986).

Behavioral problems and hyperactivity can restrict the family's social life, cause anger, social shame and a sense of failure because of inability to discipline the child (Hewett, 1970; Turk, 1991; Turnbull et al., 1986; ). Conditions marked by a strong component of physical disabilities could demand more physical attention from the caregivers, specialised equipment and therapies and place a restraint on their ability to go places (Beckman-Bell, 1981; Dyson et al., 1986; McConachie, 1986; Turnbull et al., 1986; Weinhouse et al., 1992).

Further handicap related factors which might have a special impact on the family are the visibility of the handicap causing social rejection or special understanding and empathy (Turnbull, et al., 1986); the child's inability to communicate and the need for alternative communication strategies (Frey et al., 1989).

Crnic et al., (1983) give perspective to the relative influence of the characteristics of the handicap in their summary of results of Nihira, Meyers and Mink (1980):

Their results indicated that family adjustment and functioning were related not only to the severity of the child's retardation and degree of maladaptive behavior, but to family demographic characteristics, the psychosocial climate of the home .... and specific kinds of parental behavior toward their retarded children (Crnic et al., 1983a: 132).

### 3.2. CHARACTERISTICS OF THE FAMILY

The unique characteristics of each family, play a determining role in the way in which they manage the impact.

The importance of this is illustrated by the wealth of research on the influence of these characteristics on the ability of families to cope.

### 3.2.1. Family Size and Form

The changing structure of society has increased the number of children who have to grow up in single parent families. The target group of this study forms no exception as these families are in the high risk group for divorce and mothers are less likely to remarry (Bristol, Reichle and Thomas, 1986; Deiner, 1987; Vadasy, 1986; Vincent and Salisbury, 1988). Differences in the plight and needs of diverse single parent families namely widowed mothers or fathers, divorced mothers or fathers and unmarried mothers should be taken into consideration (Bristol et al., 1986b; Deiner, 1987).

Little research has been done specifically on the plight of single parents with disabled children (Deiner, 1987). This applies even more to the special needs of single fathers. I could find no research on this specific group. There are specific needs/and or problems indicating needs that single parent families with handicapped children are prone to.

Factors which could play a role are: financial needs forcing single parents to go to work and related respite care needs (Vadasy, 1986; Vincent et al., 1988); personal/social needs which are exacerbated by social isolation, lack of stable social networks, and emotional and family support (Dunst et al., 1986a; Turner, Gordon and Beavers, 1986; Vincent et al., 1988); and interactional problems like enmeshment and/or locus of control especially if single parents are dependent on their parents ((Bristol et al, 1986a; Ferrari, Matthews and Barabas, 1983).

Results on the effect of the number of children in the family seem to be inconclusive and more research is needed (Feiring et al., 1978). Factors mentioned are : "a larger number of siblings fosters a greater atmosphere of normalcy" (Trevini, 1979:489); the impact of the handicap is more destructive in the case of families with two children (Yura, 1987); the number of siblings has a direct influence on the amount of time available to each sibling (Hewett, 1970; Paget, 1991; Vadasy et al., 1984); more than four children in the

family is a risk factor for child development (Dunst, 1993); a first born or only handicapped child might cause more stress as the expectations of parents are focused just on this child (McConachie, 1986).

No conclusive results have been found on the influence of the ordinal position of the handicapped child in the family. Research on the impact of having one handicapped twin was remarkably absent from the literature studied. (Bryan,) 1992 describes instances of emotional problems parents and the healthy twin experience as a result of having a handicapped twin that develops atypically.

### 3.2.2. Cultural Background

Cultural sensitivity and knowledge of differences are necessary in early intervention programmes. Language, values, beliefs and attitudes toward disability and help seeking, cultural styles, strengths and support systems all affect the ways in which families will respond to programmes. Special care should be taken to accommodate these differences and to be aware of the danger of working with stereotyped ideas about certain cultures (Beckman and Bristol, 1991; Bruder, Anderson, Schutz and Caldera, 1991; Hanson and Lynch, 1990; Hanson, Lynch and Wayman, 1990; Harry, 1992; Lynch, 1986; Rocher, 1993; Turnbull et al., 1986). This is especially applicable to the South African situation with its diverse cultural groups and current integration process happening in the schools. Jansen (1991), Sillipp (1987) and Van Rooyen (1989) compared reactions of different cultural groups to certain aspects of the impact of a handicap in the family. They found significant differences in attitude and reactions and stressed the need for more research in this area.

### 3.2.3. Socio-economic Status

The research literature indicates that socio-economic status of the parents is an important determining factor. However, research findings are inconclusive. McConachie (1986) points out that although these findings indicate the importance of class differences, there are many exceptions to the rule.

The following factors have been found significant. The neighbourhood and its informal support systems shape the family's attitudes and expectations and provide instrumental

help (Crnic et al., 1983a; Rocher, 1993; Swick, 1984). Lack of finances force mothers back to work. According to Tavormina, Boll, Dunn, Luscomb and Taylor (1981) mothers employed outside the home exhibit less stress in coping with their physically handicapped children than non-working mothers. Other researchers highlight the problems of working mothers in terms of time and energy limitations leading to insufficient communication with the school, increased stress, neglect and even abuse of the child (Bristol et al, 1986b; Gallagher et al., 1983; Linder and Chitwood, 1984; McConachie, 1986; Vincent et al., 1988).

The higher academic expectations of upper SES groups make it harder to adjust to cognitively-based limitations while physical handicaps cause more stress in lower SES families (Bray et al., 1981; Lea, 1986; McConachie, 1986; Miller et al., 1983; Skrtic et al., 1984; Wikler, 1981). A good educational background and/or status in society enable parents to find and utilise services for their handicapped children (Friedrich et al, 1985; Schell, 1981; Vadasy et al., 1984). Intervention services are mostly geared to the needs of middle-class parents and handicapped children of lower SES-groups are identified at a much later stage, drop out rates are higher and these families experience motivational problems caused by need hierarchial factors (Beckman et al., 1991; Brinker, 1992; Gliedman and Roth, 1981).

Application of the ecological and basic needs hierarchy frameworks (Bronfenbrenner, 1979; Maslow, 1970) could assist the family and the practitioner in determining both the proximal and distal factors in the family ecology that affected the child, and could help prioritize ways to address them. . . A single parent with no job might not be able to take advantage of child development advice if he or she is stressed and overwhelmed by economic plight." (Le Laurin, 1992:96)

#### 3.2.4. Geographic Location

The basic need related to parents' geographical position is for enough schools and other support facilities so that the detrimental effects caused by large distances are minimised. Where these are lacking special consideration is needed for the problems that are experienced in these circumstances.

Specific effects of parents' geographic location highlighted in the literature are: time, money and energy spent on transport; concern over child safety and happiness on

busrides; curtailed communication possibilities with the school and lack of school friends in the neighbourhood (Fratini, 1992; Furneaux, 1988; McConachie, 1986).

Scarcity and inaccessibility of special schools could force the family to move. This in turn could affect the parents' job opportunities and their distance from sources of support i.e. extended family and friends (Gabel and Kotsch, 1981; Salisbury, 1987; Turnbull et al., 1986).

### 3.3. PERSONAL CHARACTERISTICS OF FAMILY MEMBERS

Characteristics which are discussed for their relevance to the special needs of families are: health of family members; disabilities of other family members; special characteristics of the handicapped child. Other personal characteristics e.g. attitudes to the handicap and coping styles are discussed in the next chapter.

#### 3.3.1. Family Health

The interplay between the characteristics of the child's handicap and the physical health and fitness of the prime caretakers has an obvious relationship to symptoms of over-exhaustion, back problems, headaches and psychosomatic problems. These symptoms cause irritability and incapacity in caretakers, which in turn cause adverse child behaviours which spiral into a vicious cycle of caretaking and health problems (Deiner, 1987; Turnbull et al., 1986; Vadasy et al., 1984).

The mental health of the family affects their ability to cope and handle stressful situations. Research findings have indicated a higher percentage of child abuse among the child handicap population showing that even within families, handicapped children will be more subject to abuse than other children. Bonding problems can be aggravated by lack of mental and psychological resources and substance abuse by parents (Meier and Sloan, 1984; Blacher, 1984, Tymchuk and Andron, 1986). Lea (1986) found that parents who had experienced serious psychological difficulties in the past (e.g. depression) reported greater stress in relation to the handicapped child while Farran et al. (1986) mention prior positive coping experiences as a factor which may increase parental confidence as well as parenting skills. A sense of

humour and resilience help tremendously in the coping process (Farran et al., 1986).

The onset of depression is very prevalent among parents of special children. The danger of not-recognising the inevitable process of mourning can lead to undifferentiated depression in the latter years of the parents' life (Yura, 1987). McConachie (1986) concludes from her study of the relevant literature that mothers of young children who have received some form of early services usually show fewer emotional and physical problems which highlights the importance/need of early intervention services.

### 3.3.2. Handicaps in other family members

Chazan, Laing, Bailey and Jones (1980) found that nearly 48% of families in their sample had more than one child with a problem. However, literature on the impact of more than one handicapped child in a family is scarce. Farran et al. (1986) emphasise the effect previous experiences have on the coping ability of a family. They present a case study illustrating how a family's adaptation to the presence of a second handicapped child was adversely and positively affected by their experience with their first child.

### 3.3.3. Personal characteristics of the handicapped child

At first Christina's presence made me feel less involved with life, for my dreams were no longer consistent with reality. The more she showed us her determination to do things, the easier it was to see that although she was different from ordinary children, she would have a positive impact on people. She showed a willingness to change, which prompted changes in me (Schell, 1981: 27).

This quotation is one of few which mention the specific characteristics of the handicapped child as a significant factor in the managing task. Discussions around bonding difficulties or behaviour problems resulting from characteristics of the handicap touch upon adverse child characteristics (Turnbull et al., 1986).

## 4. FAMILY INTERACTION

In this section the focus is on interactional and relational systems in families and ways in which handicaps impacts on these systems and affect individual and collective

family needs (Käser, 1993). Marital, sibling and extended family subsystems are dealt with. Parental subsystems are covered in the next chapter.

#### 4.1. THE MARITAL SUBSYSTEM

Marital satisfaction and positive spousal support is a significant predictor of family coping. Parents living in a cohesive, supportive family unit usually experience less stress (Crnic, Greenberg, Ragozin, Robinson and Basham, 1983; Deiner, 1987; Farran et al, 1986; Feiring, 1986; Friedrich et al., 1985; Gowen, Johnson-Martin, Goldman and Appelbaum, 1989; Kazak, 1987; Wikler, 1981). Where the father is not present or not supportive the mothers have consistently more problems coping and higher stress indexes (Beckman, 1983; Gallagher et al., 1983; Vincent et al., 1988).

Unfortunately many families experience increased conflict after the birth of a handicapped child (Erlank, 1985; Gallagher et al., 1983; Lea, 1986; Turnbull et al., 1986; Yura, 1987). The negative impact of the handicap on the marriage system is evident.

A child's handicap attacks the fabric of a marriage in four ways. 1. It excites powerful emotions in both parents. 2. It acts as a dispiriting symbol of shared failure. 3. It reshapes the organization of the family. 4. It creates fertile ground for conflict (Featherstone, 1980:91).

Additional and often prolonged stress and repeated crises drain mutual support and coping strengths and will leave little time and energy for the tasks of managing the handicapped child, family and support systems. (Erlank, 1985; Miezio, 1983; Yura, 1987). However, Turnbull et al. (1986) and Miezio (1983) warn that professionals should not assume automatically that there are marital problems. In many families the impact of the handicap has improved the quality of the marriage relationship.

Special needs that could arise in this section are sensitivity towards difficult adjustments in the marriage, awareness and respect for spousal as distinct from parental duties and help for both parents in easing their task through intervention efforts with sensitivity for the amount of involvement they require.

## 4.2. SIBLING SUBSYSTEM

As with marriage subsystems, sibling subsystems are very dependent on parental/mother's time and energy resources for their effective functioning. If the system functions well, the parents are free to apply their managing skills but if there are problems they will be less able to manage and land in a vicious circle of ever growing demands. The presence of a handicapped sibling could affect the subsystem negatively or positively (Crnic and Leconte, 1986; Yura, 1987). Researchers found the following factors could influence sibling adjustment and the functioning of the subsystem.

The specific temperament and behaviour of handicapped children as well as the nature of the handicapping condition were equally important in determining the impact of the handicap on siblings (Simeonsson and Bailey, 1986).

Changes in the individual time of siblings of handicapped children might affect them i.e. required caretaking roles which accelerate their social development and/or introduce them prematurely into adulthood (Crnic et al., 1986; Mallory, 1986). The danger of overinvolving older sisters with care duties is stressed (Lea, 1986; McConachie, 1986; Miezio, 1983) as well as siblings perception of competence in dealing with their handicapped brothers or sisters. This often helps older siblings to adjust better (Simeonsson et al., 1986).

Proportionally large amounts of parental time spent with the handicapped sibling might give rise to real or perceived neglects and feelings of jealousy and anger, but can also lead to growth of tolerance and understanding (Waggoner and Wilgosh, 1990). Younger and closer-aged siblings seem to have more difficulty adjusting. Two mothers described their problems and needs in this respect:

"My 5-year-old needs more attention. He feels neglected. I wish I could get my baby in school 4 or 5 hours so I could spend more time with the 5-year old." and "Our oldest son shouldn't be deprived because his brother has Down syndrome. We don't want him to suffer or have to sacrifice because of his brother" (Able-Boone et al., 1990).

The parents concern and worry over the handicapped child might make siblings feel less important or worthy or make them anxious or overly concerned for their siblings sake, especially if his treatment entails frequent hospital visits and frightening treatment or crisis episodes at home i.e. epileptic

fits or blocked shunts (Miezio, 1983). Parents are often unable to assist siblings in adjusting because of their own emotional involvement (Lea, 1986). Dyson, Edgar and Crnic (1989) found that children with younger handicapped siblings were at risk for problems with self-concept, social competence and asocial behaviour and this was linked with parental stress and some dimensions of the family social environment.

Researchers in this field stress the importance of an awareness of sibling needs and the danger of strengthening the mother/handicapped child dyad too much at the cost of siblings. Provision of information and counselling to parents and the provision of sibling support groups and training and information sessions have been very successful (Simeonsson et al., 1986; Turnbull et al., 1986).

#### 4.3. EXTENDED FAMILY SUBSYSTEM

The family's interaction with significant extended family members, especially the maternal grandmother, could play a vital role in families' ability to manage (Gabel et al., 1981; Goldberg, Marcovitch and Lojkaser, 1986; Schell, 1981; Sonnek, 1986). These interactions are usually characterised by the support function of the extended family e.g. provision of respite, helping with daily care duties and transport, and sharing the financial burden (Deiner, 1987; Gabel et al., 1981; Moore, Barsh and Hamerlynck, 1986; Vadasy et al., 1984; Wikler, 1981). Gabel et al. (1981) highlight problems caused by ignorance or fear which make grandparents incapable of caring for their handicapped grandchildren. Their role in the provision of emotional support is vital as they can provide the shoulder to cry on and the wisdom to accept. However, in some cases the grandparents cannot accept and withdraw or even impede parents in their process of adjustment or in their attempts to provide special education for the child (Cochran et al., 1979; Gowen et al., 1989; Hewett, 1970; Schell, 1981; Sonnek, 1986). The success of intervention programmes which make special provision for involvement of and information for grandparents or other extended family members shows that there is an important need in this area (Gabel et al.; Rocher, 1993; Sonnek, 1986).

## 5. FAMILY FUNCTIONS

Family functions are regarded as tasks or outputs of the family system to meet individual and collective needs of their members. Special needs created by the handicap have an impact on these outputs and the way in which the family functions. This in turn affects ways in which families meet these special needs (Turnbull et al., 1986).

The impact of a handicapped child on the economic functions of the family, might cause increased consumption and decreased earning power (Skrtic et al., 1984). Depending on the life cycle stage of parents, the impact of the handicap could effect parents efforts to establish themselves in their jobs and especially the mother's vocational ideals, earning power and time schedules (Feiring, 1986; Lea, 1986; Schell, 1981). Gallagher et al. (1983) describe increased financial demands as a source of anxiety and stress. A good income helps to ameliorate the stress because parents can afford the best medical, psychological and educational services and procure domestic help and/or other respite services (Beckman-Bell, 1981; Lea 1986; Turnbull et al., 1986.).

The extent to which the domestic and health care functions of the family is influenced by a handicap in the family will depend to a large extent on the characteristics of the handicap and the time, energy and type of skill they demand (Beckman-Bell, 1981; Deiner, 1987; Schell, 1981) although Hewett (1970) states that the degree to which a disability becomes a handicap depends to a certain extent on the surroundings of the person who is handicapped. This applies especially to the safety and accessibility of house and garden e.g the availability of ramps, push chairs, railings and proper toilet seats.

Other important factors influencing domestic and health care functions are the division of labour in the household, the availability of support (Parke, 1986; Skrtic et al., 1984; Vadasy et al. 1984) and information that can make life easier for parents i.e. skills training, practical hints on the care for the disabled and guidance on where to find affordable apparatus that can ease their task (Beckman-Bell, 1981; Berzon, 1987). Vadasy et al., (1984) summarise research findings indicating that families of handicapped children often

experience increased caretaking demands which result in fatigue, reduced time for individual family members, and emotional problems including depression.

The way in which the impact of a handicapped child could affect parents' self-identifying functions is described aptly by this mother.

Somehow, having one's handicapped child lumbering and clomping slowly behind oneself detracts from one's own image of oneself. [For me], it takes away from my feelings of being attractive or a relatively free person. In a sense I feel restricted, trapped, pulled on, and ugly. . . To confront those feelings makes one feel like a 'bad' person, a 'bad and unacceptable mother'. And if you don't like yourself, you are not much good to anyone (Miezio, 1983:23).

The above problems also affect socialisation functions causing withdrawal, embarrassment and inability to discuss the disability (Berger and Foster, 1981, Gabel et al., 1981; Kazak, 1987; Miezio, 1983; Skrtic et al., 1984).

Parents of handicapped children, for example, *experience an intense sense of isolation* from the usual life routine. It appears that they use so much energy in coping with the child's problem and their new life context that feelings of resentment and insecurity temporarily isolate them from their former friends and acquaintances. . . It is essential that all who work with parents in such situations establish some basis for helping them re-establish self confidence and social linkages with the outside world so they can foster constructive family living and be functional community participants (Swick, 1984: 17).

The above problems link closely with recreational functions and needs of the family. Problems parents experience in realising their recreational needs are mothers' hesitation to leave handicapped children with other people, their struggle to find suitable respite services and time and energy to relax (Bailey and Simeonsson, 1988; Beckman-Bell, 1981; Skrtic et al., 1984; Gallagher, Cross and Scharfman, 1981; Garshelis and McConnell, 1993). Further problems are described as follows:

We try to take him out but he's too fussy, so now we just stay at home with him. We never go out and do things together - one goes to the grocery, the other stays at home with the kids - we split ourselves all the time like that (Able-Boone et al., 1990).

The positive effects of relaxation is stressed.

With all the demands on their time- including those made by professionals- parents may feel guilty about taking time to get away occasionally. They may need to know that they have 'permission' to relax, and that professionals think it is important for parents to take some time just for themselves (Turnbull et al., 1986: 308).

Turnbull et al. (1986) describe families as providing an important environment for meeting the needs of physical intimacy, unconditional love and esteem by others. Problems might occur in the attachment process between the handicapped child and the parents because of characteristics associated with the handicap e.g. tenseness, limpness, lack of responsiveness. Parents often need help to understand the effect of these characteristics and to see the positive contributions the handicapped child can make to the family's needs for affection (Blacher, 1984; Turnbull et al., 1986).

Family functioning is greatly dependent on the parents feeling of competence to manage the daily demands. Trivette et al. (1990) stress the role of support systems in this respect. Professionals must create opportunities for competence to be displayed or learned and a sense of control regained over important aspects of parents' lives to improve family functioning (Dunst, 1985; Swick, 1984).

## **6. LIFE CYCLE**

An awareness of the stages of the family life cycle and possible asynchronicity which may occur, is vital for the understanding of the interactions described above and for the consequent effects this will have on the family's need to manage. (Berger et al., 1986; Suezle and Keenan, 1981; Turnbull et al., 1986). Fowler, Schwartz and Atwater, 1991 stress the importance and problems of transitions for these families.

Mallory (1986) points out that changes in historical time can have a major impact on the abilities of families to proactively manage the formal support systems they need. An awareness of this is especially important at the present time of radical actual and threatening changes in South Africa (Nkabinde, 1993).

## **7. CHARACTERISTICS OF SUPPORT FACILITIES**

In Chapter II it was stressed that the family is in constant interaction with and dependent on the environment for its resources. The characteristics of the support systems will

affect the family's ability to manage and the nature of their needs (Apter, 1982).

### 7.1. THE IMPACT OF SUPPORT

The need for support ranks very high in parental need hierarchies (Davidson and Dosser, 1982). Early intervention has been described as "the provision of support" (Dunst, 1985:179) to families of handicapped children from members of the informal and formal social network which impact upon parental, family and child functioning. Numerous studies have been done on the important role of support in the amelioration of stress and the ability to manage in families with handicapped children (Beckman, P.J., 1991; Crnic et al., 1983b; Dunst et al., 1986a,b; Erickson et al., 1989; Miezio, 1983; Schell, 1981; Wikler, 1986). The relevance is emphasised by the following quotation:

Support networks are currently being studied with an avid interest because interaction with a good support network when faced with acute stressors is so repeatedly and significantly correlated with better functioning (Wikler, 1986:171).

FIGURE 8 (DUNST AND TRIVETTE, 1988: 323)

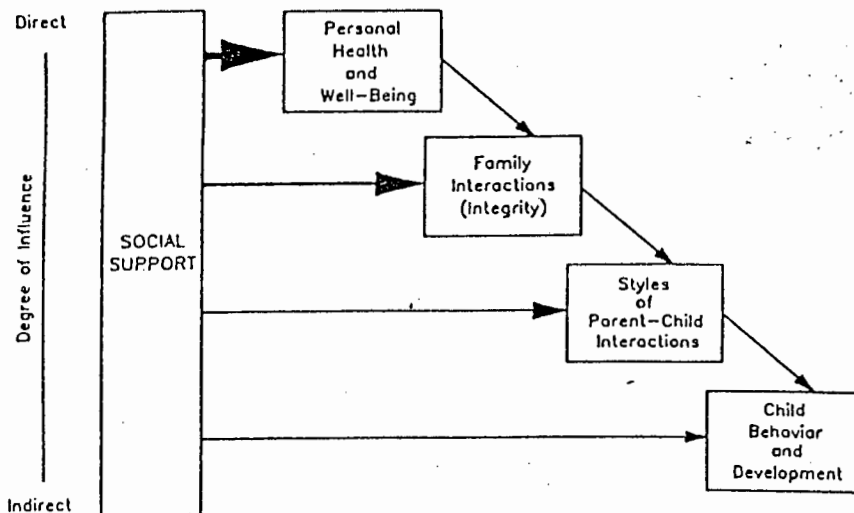


FIGURE . . . The hypothesized direct and indirect influences of social support on parent, family, parent-child, and child functioning.

Specific areas have been indicated where support has a decisive influence: 1. parents' perception of their child's behaviour (Dunst et al, 1986a); 2. parental attitudes toward

the child and his handicap i.e. parents with less support tend to be more overprotective and pessimistic (Crnic et al. 1983b; Dunst et al., 1986b; 3. parental styles and abilities (Crnic et al. 1983b; Dunst et al., 1986a,b) 4. personal well-being i.e. fewer physical and emotional problems (Dunst et al., 1986a); 5. child well-being and development gain (Crnic et al., 1986b; Dunst et al., 1986 a,b.). (See Figure 8)

The parental need for emotional/social support has been described as the need for a shoulder to cry on and a place to express periodic grieving without being considered pathological ((Dyson et al., 1986; Feiring, 1986; Wikler, 1981) or as aiding a "family's recovery and re-organization to a crisis such as the birth of a developmentally disabled child" (Davidson et al.: 296).

Parents have specific needs connected to the special parenting, caregiving and educational demands of the handicapped child. The impact of instrumental support in providing respite care helpers and/or facilities and educational and financial aid is emphasised strongly (Crnic et al., 1983b; Deiner, 1987; Deiner and Whitehead, 1988; Erickson et al., 1989; Gallagher et al., 1983; Gowen et al., 1989; Lea, 1986; Miezio, 1983).

## 7.2. SOURCES OF SUPPORT

The main distinction between formal/professional and informal support is that professionals are paid to help and that it is their job (Turnbull et al., 1986).

### 7.2.1. Informal sources

Extended family members, as well as friends and neighbors, can produce a powerful support network for a family with a developmentally disabled child when informed about and included in the development of that child (Moore et al., 1986:39).

Although it is never possible to determine the exact influence of the various sources of informal support, research findings give some indications. The decisive role of spousal support is dealt with in section 4.1. Siblings are mentioned less often as sources of support but Gallagher et al. (1983) and Farran et al., (1986) emphasise the supportive role they can play. In section 4.3 the important role of the extended family in providing acceptance, emotional and instrumental

support is emphasised. An interesting result from the study of Gowen et al. (1989) accentuates the importance of intrafamily support. They found that the mother's perception of the quality of her relationship with her husband and parents was more strongly associated with her feelings of depression and parenting competence than was her rating of the helpfulness of her overall support system.

Friends and acquaintances can play an important supporting role. Friends in general and especially those who are parents of handicapped children are described as being available, comforting and sharing in their struggles and pleasures (Farran et al.; Wikler, 1981). The need for contact with other parents of handicapped children, especially in the initial stage of the handicap trajectory is stressed (Bailey et al., 1988; Brookman, 1988; Farran et al.; Furneaux, 1988; Garshelis et al., 1993).

Support groups of parents with handicapped children can play a vital role in the provision of emotional, instrumental and informational support. Advantages of these groups are to be found in decreased isolation felt by parents and the provision of practical help with transport, appliances and information (Brookman, 1988; Davidson et al., 1982; Krauss, Upshur, Shonkoff and Hauser-Cram, 1993; Summers et al., 1990; Turnbull et al., 1986; Warnock, 1978). The initial help of a committed professional or experienced parent, capable group leaders and well coordinated referral services is advocated (Warnock et al., 1978).

Other organised groups can be a strong source of support. Fewell (1986) states that religious organisations offer many different types of support which could be utilised by parents as well as professionals interested in strengthening natural support systems. However, parents often indicate that for various reasons this source of support does not always fulfil their expectations (Farran et al., 1986; Fewell, 1986; Turnbull et al., 1986).

#### 7.2.2. Formal sources of support

Kazak (1987) emphasises the critical need for professional help to parents of handicapped children because of their special need for support and socialisation. Some support functions traditionally performed by friends must be augmented

by professional helpers. Health-care systems and educational institutions are the two main formal support systems that these families have to rely on. Mallory (1986) stresses the central role that health-care systems play throughout the family's life cycle. The focus of this discussion is mainly on the special education system and their potential and actual support role, although many of the issues are relevant to the health-care systems. Bronfenbrenner (1976) points out that the school and its broader structures i.e. meso- and exosystems have a vital role to play in the provision of support to the families in question.

Despite concern about the extent and types of parental involvement, no research has been conducted which addresses issues of how schools function as elements of the social network. Such work seems particularly critical as concerns families with handicapped children since it can be anticipated that developmental transitions centering on the educational experience (such as the transition from pre-school to elementary school) may be particularly difficult for the handicapped child as well as the family (Kazak, 1987: 188).

### 7.3. APPROPRIATENESS AND ACCESSIBILITY OF SUPPORT

With greater understanding of the relationship between social support and the diagnosis of mental handicap in a child, clearer guide-lines for ameliorating parental stress may become apparent. This may prove of greater benefit to families than the blind prescription of increasing all forms of social support in order to ameliorate stress (Lea, 1986: 37).

This quotation underlines the importance of the quality of support available to parents. Research findings indicate that the availability and appropriateness of informal support systems, play a determining role in helping families cope with the presence of a handicapped child (Beckman, 1991; Crnic et al. 1983b; Dunst et al., 1986a; McWilliam and Dunst, 1986). However, the recipients' perception of the support and the satisfaction they get out of it is of paramount importance (Frey et al.; Lea, 1986). According to Dunst et al., (1986a) social support could be defined in terms of perceived satisfaction with various sources of support.

The preschool program seemed to have an enormous impact on the family. Parents reported benefits such as improved family self-esteem, increased optimism and more positive attitudes about their child. They noted that the respite from demands and responsibilities enabled them to regain some of their own sense of self. They reported a reduction in their uncertainty about

their child's abilities and more confidence in their ability to make sense out of their child's behavior (Turner et al., 1986).

This is an example of satisfaction with the available formal source of support. However, Beckman (1991) found that in contrast to informal support, formal support was not significantly related to negative stress scores. She questions whether service providers are meeting the needs of the families. Bray et al. (1981) point out that support facilities are not automatically suitable or available and the extent to which they can alleviate the task of parents of handicapped pre-schoolers depends to a large extent on how these facilities are utilised or managed.

Warnock (1978) points to the problems parents experience in locating or utilising existing services because of their confusion or helplessness. They suggest the appointment of a "named person" to assist and advise families in identifying and utilising existing services. Mallory (1986) stresses the important relationship between the formal and informal support systems and points to the buffering role informal support systems can play in family-agency interactions. The importance of a healthy balance between the formal and informal support systems is stressed.

There must be an appreciation of the total developmental system. An inseparable part of that appreciation is the individual analysis of the kind of child, the kind of parent, and the kind of program. The role of the family is not an educational extension of the intervention program. Rather the opposite is true: The intervention program should be an extension of the family, recognizing the primacy of the parent-child relationship in fostering the development of the child. (Wright et al., 1984:85-86)

Families are at risk for reduced participation in informal networks and accelerated participation in formal systems, leading to early burnout, disenchantment among family members, and a sense of helplessness due to external locus of control and unequal relationships with service providers (Mallory, 1986: 326).

### 7.3.1. Parents and Professionals

We are parents who are either intimidated by professionals or angry with them, or both; parents who are reasonably awed by them; parents who intuitively know that we know our children better than the experts of any discipline and yet we persistently assume that the professionals know best; parents who carry so much attitudinal and emotional baggage around with us that we are unable to engage in any real dialogue with professionals, or psychologists - about our children (Gorham, 1975:521).

. . . traditional models of disability either promote pseudo-expertise or prevent the professional from establishing cooperative, non-oppressive relationships with the handicapped child and his parents" (Gliedman et al., 1981:227).

In recent years professionals have become increasingly aware and critical of the effect these traditional models of disability have on the parent professional relationship and changes have been suggested to improve this vital relationship (Bailey, Palsha, and Simeonsson; 1991; Berger, 1986; Carney, 1983, Foster et al., 1981; Turnbull, et al., 1986).

Mallory (1986) emphasises the need for the basic assumption that families with handicapped members are more similar to other families than they are different. Instead of an emphasis on guilt, signs of non-acceptance, rejection and pathology in parents the stages of grief should be regarded as important growing processes, natural reactions and constructive attempts to deal with traumatic events. The need for positive reinforcement and societal acceptance of the child and the family during this process is evident (Roos, 1985; Tulloch, 1983; Turnbull et al., 1986). The positive developmental approach as advocated by these professionals is strongly advocated in the following quotation:

Professional training programs and the short-sightedness of helping professionals who view handicapped people and their families as "patients" have perpetuated the notion that our goals should only be to diagnose and prescribe rather than understand and support. To enter into a helping relationship with a family with a prior expectation of pathology or deviance will create a sense of unjustifiable power in the helper, and a sense of dependence and helplessness in the "recipient." Instead of searching for pathology, helpers must search for the existing coping resources, which all families possess to some degree, and must strive to change the ecological conditions in which the family is enmeshed in order to free and bolster the existing strengths (Mallory, 1986:318).

Traditionally early intervention was based on a deficit model with the focus on intervention of the remediation of these deficits. The success of intervention is measured by the ability of the programme to bring the child closer to the norm of average test performances and normal patterns of behaviour. A more balanced approach to early intervention is advocated. The focus must be on the whole child and on his existing strengths rather than his weaknesses. A strong emphasis must be placed on the development of self-esteem (Dunst, 1985; Foster et al., 1981; Turnbull et al., 1985).

A further result of the adherence to the deficit/pathological model is that the locus of decision making lies mainly with the professionals. Usurpation of control over decision making which make families inadequate and ineffective as partners/parents, is often a common occurrence in early intervention programmes (McWilliam et al., 1986; McConachie, 1986).

Parents are told what is wrong with their child and family, what needs to be done to correct (inferred) deficits, when and how interventions ought to be done. . . Control over the child's life and sometimes the life of the family cannot but foster a sense of helplessness and powerlessness in the child's caregiver. (Dunst, 1985: 169).

Gliedman et al. (1981) feel that parents have a moral claim to authority over their child and enough expertise with their own child to match any professional expertise. The difference is that in contrast to the often narrow specialists view, parents are usually able to see the general picture of the child. This entitles parents to assume the authority of the manager.

The parents' need for empowerment and permission to exercise discretionary and coordinating powers in their encounters with professionals, as well as their need for services which are structured in ways which let them experience competence, control and recognition for their key role in their child's development, is underlined strongly by this group of professionals.

Scholars and practitioners from fields outside early intervention but also working in the field of family support services have basically come to the conclusion that families should play a major role in shaping the direction of the resources and supports they receive, and that resources and supports ought to be provided in ways that strengthen the capabilities of families (Dunst et al., 1991: 124).

The vast assymetry in need between parents and professionals and problems coming from issues of reciprocity is another area of concern. The expertise and the qualifications of the professionals, the scarcity of facilities for the handicapped and the fact that services are often provided by the state and that parents seldom pay directly for the services, exacerbates the situation. Professionals more or less expect parents to make the most of the services offered and do not expect them to evaluate the quality of those provided. Parents are at the receiving end and the system makes it

difficult or impossible to reciprocate and thus they are placed under obligations which can be very intimidating. They dare not criticise or disagree because they fear they can forfeit these all important services (Gliedman et al., 1981). Kazak (1987) explains this situation as follows:

However, by virtue of their nature, interactions with helping professionals are non-reciprocal . . . Even if professionals are seen as "doing their job" by helping the family, it is nonetheless a non-reciprocal relationship, with the family of the handicapped child to get, but probably not to give, help. A lack of reciprocity in parent-professional relationships may contribute to increased distance between the two parties, thereby contributing to dissatisfaction with the relationship, and decreased helpfulness (Kazak, 1987:185).

Qualitative findings on family and practitioner preferences for family services, indicated the need for professional sensitivity to families as paramount. The need was expressed for staff to be supportive, accepting, non-judgemental and unhurried in their interactions with families. The authors deducted that families regard the early intervention practitioner as an important source of emotional support and friendship. This suggests that families may need practitioners who can perform the dual functions of formal and informal support systems (Summers et al., 1990). The importance of personalised services and the need for professional capacity to form relationships are stressed (Gallagher et al., 1983; Mallory, 1986; Winton et al., 1981).

The need for professional acknowledgement of family diversity and individual family preferences is emphasised in research on family preferences (Garshelis et al., 1993; Summers et al., 1990), research on the adequacy of resources as related to personal well-being and the adherence to professionally prescribed child-regimens (Dunst, Leet and Trivette, 1988) and research on collaborative goal setting with families (Bailey, 1987; Garshelis et al., 1983).

Of further relevance to this need is research on the diverse needs of fathers and mothers (Bristol and Gallagher, 1986; Frey et al., 1989; Markowitz, 1984; Meyer, Vadasy, Fewell and Schell, 1982; Vadasy, Fewell, Meyer and Greenberg, 1985; Upshur, 1991); the special needs of single/working mothers (Landis, 1992; Vadasy, 1986; Vincent et al., 1988); the changing support needs over the family and child's life cycle (D'Amato et al., 1991; Suelzle et al., 1981); and the needs of

people with different cultural or language backgrounds (Bruder et al., 1991; Hanson et al., 1990; Lynch, 1986; Rocher, 1993; Wolery, 1992). These research findings emphasise the importance of family need hierarchies and the unique value systems of families. The need for individualised services is aptly stated by Trivette and Dunst (1992):

The results from our study indicate that different biocultural factors that, in part, define family diversity must be taken into consideration by early interventionists when developing Individualized Family Service Plans. . . . That is, the interventions must be designed so as to be compatible with the realities of a mother's life, including her work and marital status (Trivette and Dunst, 1992:382).

### 7.3.2. State policy on provision of services and training of professionals

The characteristics of the educational support system are determined to a certain extent by government policies and provisions. Examples of this can be seen in recent legislature on special education in the USA and UK. which has a strong impact on the characteristics of available educational support (Furneau, 1988; Mittler, 1990; Summers, et al., 1990; Turnbull et al., 1986) (See Chapter I)

In the Republic of South Africa state policy and educational legislation determines the nature of special educational services in the following ways:

\* The main characteristic of the special educational provision in South Africa is that facilities are provided in special schools for specific types of handicaps e.g. separate schools for blind, deaf, cerebral palsied. Schools are mainly segregated for different racial groups but due to political factors there is currently a gradual change in this state of affairs. Partly because of the segregation and mainstream policies the special educational provision is excellent in some of these schools. Du Plessis (1991) quotes Hamilton (1986) and Lemmer (1975) in stating that the special educational facilities in South Africa rate among the best in the world. This applies however mostly to the provision for white South Africans (Nkabinde, 1993).

The effectiveness of mainstream special education is also debated. According to Boonzaier and Jagoe (1992) the education of children with disabilities in the Republic of South Africa, is at least twenty years behind world trends in this respect.

However, Du Plessis, (1991) states that the provision of an atmosphere of emotional safety, a team of specialists that provides the necessary therapies and other services during school hours and smaller class groups are distinct advantages of special schools. Furneaux (1986) sees the main problems of special schools as social isolation, problems with the home/school link, greater costs and the long distances children often have to travel. There are many other aspects relevant to this debate on the advantages of the various systems, mentioned by the above authors and others (Chazan, Laing, Bailey and Jones, 1981; Guralnick, 1990; McClean and Hanline, 1990; Odom and McEvoy, 1990; Turnbull and Turnbull, 1990). However, the main issue at this point is that there are very few facilities for handicapped children in mainstream schools in South Africa. This leaves little choice for parents as they can often only get appropriate education in special schools.

\* The legislation regarding the provision of facilities for pre-school handicapped children is not clear. The Education Act dictates circumstances under which pre-schools must be registered and can be subsidised but makes no special mention of those attached to special schools. However, in the handbook for special schools compiled by the Department of National Education (1982) the importance of pre-school education for handicapped children from three years onwards is stressed and guidelines given for the admittance of these children to specialised schools. In a later handbook issued by the Department of Education and Culture (1990) the necessity for pre-primary education for handicapped kids as early as possible is underlined. No specific age is mentioned. In the earlier document the practice of providing support and guidance services at special schools for young children who cannot yet be admitted to the school is recommended and guidelines given for ways in which these services could be implemented to achieve maximum results. However, it is made clear, that these services should not interfere with the treatment of school age pupils. Although the possibility of early intervention centre-based services do exist, these services are not offered regularly and could definitely not be regarded as a right of parents. This applies to a lesser degree to the three to six year old school population where school admittance is strongly recommended but not guaranteed.

\* Although most special schools were founded through initial parent effort, the role of parents in special schools as prescribed by state legislation is currently very insignificant. These schools are governed by a Management Board which consists of members appointed by the sponsoring body and by the Minister of Education (Regulation 692, 1990). No mention is made of parent representation although it is customary to appoint a few parents or ex-parents to the Board ((Engelbrecht, 1975). This regulation contrasts sharply with the regulation for the Management Councils of mainstream public schools where parent representatives have to constitute the majority on the Council (Education Affairs Act, House of Assembly, Act 70 of 1988).

Apart from a few regulations ruling parental rights and obligations regarding the placement of school-aged children in special schools, the only mention that is made of parents and their role in the Education Act, is as recipients of guidance. This clause was added in 1982 (Act 16) to the definition of specialised education (Kitshoff, 1985).

(e) the provision of guidance to the parents of handicapped children, including handicapped children who are not yet subject to compulsory school attendance, with a view to the instruction, teaching, training or treatment of such children (Act 70 of 1988).

In this document the importance of parental attitudes toward the child and his handicap and their need for professional guidance support and services are emphasised. The focus is strongly on parents as recipients of services and parents in need of training to enable them to help their children. No mention is made of parents as partners, team members or managers of their children and it is explicitly stated that they are not specialists and thus need guidance. Provision is made for the appointment of a social worker at the school who has to liaise with the parents (Dept. of National Education, 1981) In practice this rarely happens (Personal communication Dr. Rocher, 1993).

\* The training of special educational personnel is generally stressed as an important factor in the provision of services (Bailey, Buysse and Palsha. 1990; Bailey, Simeonsson, Yoder, and Huntington, 1990; Du Plessis, 1991; Gentry and Olson, 1986; Mallory, 1983; Olson and Kroth, 1986). In South Africa only a few educational courses are offered that specialise in special

educational problems. Although these qualifications serve as an extra recommendation when teachers are appointed at special schools, they are not compulsory and most of the personnel at special schools have no special training (Du Plessis, 1991). As yet no courses exist that specialise in pre-school special education.

### 7.3.3. The nature of the school

Schools and their personnel often intimidate parents (Brümmer, 1989). When parents have to send their children to school, this event inevitably causes an upsurge of memories and emotions connected with their own experiences at school. To many parents school memories have strong connotations with authoritarian teachers and strict administrators (Michaelis, 1980). Factors exacerbating these attitudes of fear and helplessness with regard to special schools are: professional attitudes of "omniscience and omnipotence" (Roos, 1985:247); parental lack of confidence or anger associated with previous histories of unsatisfactory dealings with professionals (Dowling and Pound, 1985; Lindsey, 1985; Farran, et al., 1986; Osborne and Barrett, 1985; Sayler, 1971; Winton, 1986).

It is easy too, for parents to feel intimidated when they are forced to turn to highly trained individuals who use educational jargon and seem totally competent, particularly at a time when parents feel incompetent and insecure. One parent has stated that during her child's earliest years, all the successes belonged to professionals "only the failures were mine" (Scholl, 1986:53-54).

Apart from the general feelings that schools may evoke in parents, the goodness-of-fit of the particular school, the family and the child plays a role. The first requirement parents will have is that the programme of the school must fit their perception of the needs of the child and the family. Their need perception is shaped by available child diagnostic information, their aims for the child, and family needs. Each family represents a unique combination of distinctive strands e.g. child's handicap and personality and parents' coping abilities and living standards which will vary with time (Cordera, 1988; Warnock, 1978). Other factors that might complicate the goodness-of-fit between schools and families are differences in values, rules, hierarchies, tradition and language (Dowling, 1985; Lindsey, 1985). This can be a special problem in the beginning stages of a child's school career as

he has to adjust to different sets of rules and values which might complicate his initial adjustment to school - a circumstance which can affect the parents attitude toward the school (Lindsey, 1985). Because of the scarcity of special schools parents have comparatively little choice and misfits can occur.

The policy and organisation of the school can have determining effects on the appropriateness of the support it provides to the family. Schools have their own policy regarding parental involvement, staff responsibilities re parents and school organisation which can affect parents' attitudes and abilities. This is complicated by the fact that schools have histories of parent-school relationships, official policies and unofficial attitudes toward parents.

A main factor is the nature of the school's organisation of contact possibilities between school and home. Schools have regulations ruling formal feedback e.g. parent-teacher conferences, team meetings, written reports and optional measures such as home-school notebooks, telephonic contact, unscheduled meetings and home-visits (Bjorklund and Burger, 1987; Fuqua, Hegland and Karas, 1985; Kroth, 1975; Schmalz, 1987; Turnbull et al., 1986). The effectiveness of these contact mechanisms depend largely on the school's attitude and philosophy toward parent contact and the parents' ability to utilise them. Turnbull, Winton and their associates have done extensive research on parent's preferences for contact and involvement and found that obligations and regulations about parent involvement activities often do not work in situations where parents are already overburdened by the care of their exceptional child. (Goldstein, Strickland, Turnbull and Curry, 1980; Turnbull et al., 1984; Turnbull et al., 1983; Winton et al., 1981).

South African literature on school/parent contact mechanisms is scarce. A nursery school teacher at one school strongly advocated the use of home visits, regular telephonic and written communication (Ahrends, 1971). Two schools reported on the success of regular parent guidance group sessions (Kitshoff, 1982; Orner, 1981) and one parent reported on a very innovative meeting she had organised between a school therapist, family and friends- a procedure she recommended for

all prospective parents of handicapped pre-schoolers (Shirley, 1983).

There are various ways in which the internal organisation of schools can affect parents. Density of the network of helping professionals, all knowing and interacting with each other, can impede the ability of the family to maintain control and independent action (Kazak, 1987). Helping professionals at special schools work as part of a team. Special organisational problems are associated with team organisation (Bailey, 1884).

It is not only between systems but within systems that feelings of isolation and poor communication can occur. The staff of a school may find that there are few opportunities to meet, pool resources and work co-operatively on their difficult problems. There are sometime dynamic processes within staff groups that interfere with sharing and supporting behaviour between teachers (Dowling et al., 1985: 93).

The existence of subsystems in schools indicates that the organisation will be subject to group processes and group dynamics "as well as the power struggles and politics involved in any hierarchical structure" (Taylor, 1985:158). Dowling (1985) observes that the hierarchical organisation with its boundaries which characterise school systems is also a feature of family systems. In both systems there are to a lesser or greater degree, executive subsystems where decisions are made and carried out. When these systems interact it is important to know who constitutes the executive subsystem and what style of decision making and communication they have. Are there consultations, explicit rule making and open communication channels? Parents need clarity on hierarchial structures and their functioning as they have a definite effect on the way in which the school relate to parents and make information available (Dowling, 1985).

The initial contact with special schools usually coincides with an assessment of the child to determine whether he is an appropriate candidate. This is often an intimidating procedure for the parents especially in cases where the assessment is done within the framework of the deficit approach to disabilities (Gliedman et al., 1981). It is described as "a critical and emotional point in the development of the parent professional relationship" (Winton, 1986:6 ).

The importance of the testing process to the parents seems especially great when the problem presented is around schooling, but in all cases it can be a focus for anxiety and even the most

careful feedback of the results can be misunderstood, distorted or forgotten. Often the underlying parental feelings appear to be quite as intense as those of the child (Osborne, 1985:55).

An important characteristic of any school is the staff working at the school. Although this is not a stable characteristic there are some general trends in the composition of school staff and their attitudes which can be lifted out. Lack of training in working with parents, i.e. inability to listen and communicate and in delivering sensitive information often impede relationships (Bailey et al., 1990; Fuqua et al., 1985; Olson et al., 1986) Research conducted on teacher stress has implicated interactions with parents as a major source of concern (Turnbull et al., 1984). The traditional status of professionals makes it difficult for them to process criticism and to share power (Dowling et al., 1985; Gliedman et al., 1981; Mittler, 1990; Taylor, 1985). Previous histories with difficult parents can predispose staff in their dealings with other parents (Mittler, 1990). Internal organization of schools can significantly affect attitudes and expectations of teachers as well as time and energy available for parent contact activities (Beale, 1985; Fuqua et al., 1985; Taylor, 1985; Wiegerink, Hocutt, Posante-Loro and Bristol, 1980). The persistent belief among professionals that parents should play a passive role -"benign passivity" (Mittler, 1990:61) i.e. learner and audience, in the education of their child because they do not have the necessary expertise persists despite the intention of lawmakers to empower parents and thus ensure accountability of the school (Minke et al., 1993; Turnbull et al., 1984; Witt, Miller, McIntyre and Smith, 1984; Yoshida, Fenton, Kaufman and Maxwell, 1978). Teachers often see their primary task as the improvement of child-functioning and thus regard parental involvement as a strategy for improving child-outcome rather than parental or family outcome (Turnbull et al., 1984).

## 8. INFORMATION

The informational need is often classified as a subsection of support. This is a logical classification as the availability of information fulfils a vital support function. However, as this need is so important especially as indicated in parental need surveys, a separate section is devoted to its

discussion. This need encompasses the need for knowledge of their childrens' disabilities, for information on available services, child progress and school activities ((Able-Boone et al., 1990; Bailey et al., 1988; Becker, Bender and Kawabe. 1080; Burden and Thomas, 1986; Garshelis et al., 1993; Lusthaus, Lusthaus and Gibbs, 1981; Goldstein et al., 1980; Vincent, 1992).

### 8.1. REASONS WHY INFORMATION EXCHANGE IS IMPORTANT

Having a child with a handicapping condition is a unique parenting experience and, consequently, these parents continually must seek information regarding therapeutic, educational and vocational intervention. This ongoing need for information cannot be underestimated as a source of stress (D'Amato et al., 1991: 246).

On the one hand if parents are to support the efforts of the teachers they need information and advice from the school about its objectives and the provision being made for their child: on the other, a child's special needs cannot be adequately assessed and met in school without the insights that his parent from their more intimate experience of him are able to provide (Warnock, 1978:155).

The importance of the information exchange process is emphasised in the research literature for a variety of reasons. The birth of a handicapped child represents an uncontrolled event which may lead to loss of control by the family. This is accentuated by parental inability to work effectively with their youngster or to access needed community services and resources. "Not knowing what to do or whom to turn to is frustrating for parents, affects their feelings of competence, and results in additional stress" (Bailey and Simeonsson, 1984:41). Chinn et al., (1978) and Turk, (1991) point out that information can alleviate anxiety and depression. Parents need information to empower them to make responsible decisions and contributions (Able-Boone, Goodwin, Sandall, Gordon and Martin, 1992; Dunst, 1985; Jephson, 1992; Mahoney et al., 1992a; Taylor, 1985; Warnock, 1978). McConkey (1985) explains the role of two-way information exchanges in the enhancement of parental teaching skills and Schell (1981) stresses the importance of the interplay between the family's expectations about the child's development and the child's actual progress. He sees it as a vital need for parents to have access to educators or

other specialists willing to share information and assist them in developing realistic expectations.

## 8.2. TYPES OF INFORMATION EXCHANGE

For individual parents however there can be no substitute for personal access to the school whenever they require information about their child's education or wish to discuss his progress (Warnock, 1978:155).

The types of information exchange between parents of handicapped pre-schoolers and the professionals vary with the stages of the child's life cycle (D'Amato et al., 1991). Initially the most mentioned need is for medical information. The importance of an empathetic, honest and early diagnosis and prognosis of the condition is emphasised by many researchers and repeated in the personal stories of parents of handicapped children (Lipton and Svarstad, 1977; Miezio, 1983; Quine and Pahl, 1986; Roos, 1985; Turnbull et al., 1986; Vincent, 1992). Information on home carry-over activities is also important at this stage (D'Amato et al., 1991). As soon as the child starts school, the parents are eager for information on the type of programme followed and activities done at school, report back on progress especially in the area of gross motor skills and communication, and future prognosis (Kroth, 1975; McConachie, 1986; Turnbull et al., 1986). Behaviour management, and to a lesser degree lack of playmates, become more of a concern as the children get older (D'Amato et al., 1991).

The importance of the parents initial and ongoing contribution of their knowledge of the child and the beneficial influence this can have on assessment procedures and child progress in general is emphasised (Diamond, 1993; Gliedman et al., 1981; Mallory, 1986; Minke et al., 1993). According to research results parents mostly prefer informal, frequent and two-way contacts (Fuqua et al., 1985; Turnbull et al., 1983; Winton et al., 1981). Parent-teacher conferences were the mode used by the largest number of parents while home-visits were only moderately used. However, the latter proved to be more successful in the overall achievement of goals (Rocher, 1993; Upshur, 1991). Fuqua et al. (1985) found that written notes were most frequently used by teachers but often had negative effects on parents.

### 8.3. BARRIERS TO INFORMATION EXCHANGE

Factors which impede communication between parents and professionals are: logistic problems (Turnbull et al., 1986); lack of well-defined communication channels (Wiegerink et al., 1980); differences in perception between parents and professionals (Dowling et al., 1985); relative helplessness and vulnerability of the parent; lack of recognition and or respect on professional side for parental skills and information (Turnbull et al., 1986).

Another factor which impedes communication is the selectivity of professionals in imparting information. Parents often do not get the full information they need. An example of this is the procedure followed when a child is comprehensively assessed at a school or a hospital by a team of experts. The parents are usually excluded from this lengthy process. The team members confer together before one member interprets the results to the parents. Parents are usually not allowed to see the test results except in cases where parents are judged able to interpret the results (Du Plessis, 1993; Gliedman et al., 1981; Lamprecht, 1988; Warnock, 1978). I.Q. test results are traditionally kept confidential because they are believed to be prone to misinterpretation. This procedure can give parents the feeling that things are said and done behind their back, and that decisions and conclusions are made without their input (Gliedman et al., 1981).

These authors comment further on the selective sharing of knowledge and the role of socio-economic status in this process.

Parents often know more about their children than the experts whom they consult. While many professional acknowledge this fact, their training and ideology encourage them to ignore it in practice. All too often the only parents allowed relatively free give-and-take with professionals are parents who possess some independent professional standing as experts in a speciality that bears upon childhood - medicine, clinical psychology . . . to be taken seriously, the parents' claim to expertise about their own child must be backed by a socially recognized formal credential that "proves" that they are experts about children in general (Gliedman et al., 1981: 229).

Minke et al. (1993) did a thorough qualitative study on the roles of parents and staff in the development of the Individual Family Service Plan. They found that both parents and professionals choose to withhold certain information and

concerns from each other and more research was needed on this aspect. Parents who were actively involved in the assessment process e.g. completing assessment forms prior to discussions, contribute more during discussions. They postulate that the request from the staff to complete the assessment reflected the value staff members put on parent input.

Lack of professional training in delivering sensitive information and adherence to professional jargon are additional barriers to effective information exchange (Cranwell and Miller, 1987; Fuqua, 1985; Gliedman et al., 1981; Lea, 1986; Mallory, 1986; Olson et al., 1986; Winton and Bailey, 1990).

## 9. CONCLUSION

In this section the focus was on the question of the contents of the parental need to manage as well as factors which impede or enhance the process of managing. The research literature showed that the characteristics of the handicap could influence the ability of families to manage. However this factor could not be isolated as the main determining factor. There seems to be a continual interplay between the characteristics of the handicap, the characteristics of the families and the ways in which these families interact and function. Although some research results showed definite ways in which handicapped children affected family life e.g. increased marital problems, depressions etc. it also became clear that many families coped despite a handicap in their midst. The important role of support is stressed throughout the research literature as a factor that ameliorates stress. However, research results indicate that the impact of support on the managing ability of parents depends on the appropriateness and availability of this support.

Although it was impossible to go into finer details of analysis and discussion of research results, this overview is intended to illustrate the scope and variety of factors that can influence the extent of the impact a handicap can have on the family and how it can impede or enhance the managing ability of the parents. The complicity as well as the

reciprocity of variables affecting and being affected by the impact of the handicap on the family forced researchers to look at family systems rather than isolated variables and to interpret research results in the context of a specific framework rather than in isolation. A further trend is the frequency with which qualitative research methods are used which try to capture some of the complexity of family and professional perspectives (Davis, Brady and Anderson, 1993).

## CHAPTER IV

### THE MANAGING PROCESS AS PORTRAYED IN THE LITERATURE

#### 1. INTRODUCTION

In the previous chapter I looked at relevant research literature on circumstances created by the impact of a handicap on the family and how the individual circumstances of families and their support systems can influence the extent and nature of the impact and in turn be affected by them. These are the circumstances that need managing. In this chapter the reasons for this comprehensive need to manage and the nature of the process of managing are studied as it is portrayed in the literature.

According to Collins English Dictionary (1986: 934) the word manage means

1. to be in charge of;
2. to succeed in being able to despite obstacles;
3. to have room or time for;
4. to exercise control or domination over;
5. to contrive to carry on despite difficulties.

This selection of meanings give an idea of the scope of the word's general application referring to both the elements of effort to overcome obstacles and control over circumstances as well as the availability of the person who has to manage. In the research on parents of handicapped children the word cope is often used synonymously with manage. According to Collins (1986) cope could have the meaning of fighting/battling against or handling it successfully. The word manage includes these meanings of coping but accentuates the aspect of being in control rather than fighting as well as the aspect of availability. For the purposes of this study the word manage seems to be more appropriate.

In the research findings the determining characteristics of the managing process emerged as parental motivation and ability. The parents' aims for the child and their attitude towards the handicap proved to be the main attributes of parental motivation. The ability to manage is dependent on the nature of the skills needed to manage the child and the support

system and the nature of the parents' capacity to apply the managing skills. It was shown that the process of managing could be impeded or enhanced by the availability of information and support and by the characteristics of the handicap, the family and the support system. According to the findings all these factors determine the nature of the parents' managing strategies (See Chapter III, fig.6) In chapter 111 characteristics of the handicap, family and support systems have been dealt with. In this chapter research literature focusing on the following issues is portrayed.

- \* The reasons for the existence of the parents' need to manage the impact of the handicap.
- \* Parental motivation
- \* Parental aims
- \* Parental attitudes
- \* Nature of the skills needed to manage the child
- \* Nature of the skills needed to manage the support system
- \* The nature of the parents' capacity to apply their managing skills
- \* Action Strategies

## **2. THE PARENTAL NEED TO MANAGE THE IMPACT OF THE HANDICAP**

The stress of the transition to parenthood is often exacerbated if the child is born with a disability or is discovered having one in early childhood. Additional stress often involves uncertainty about the exact nature of the handicap and its implications for the child's future development, the effect this particular child will have on the family unit, and relationships with the community at large (Deiner, 1987: 197).

As stated above, initial and ongoing stress is a common characteristic in families with a handicapped child. This is confirmed by numerous research findings on the impact of the handicap on the family (Beckman, 1983; Hanson and Hanline, 1990; Dyson et al., 1986; Kazak et al., 1984). Significant differences exist in the way in which stress and its effect on families have been described and researched. According to Frey et al., (1989) children with disabilities are viewed as unique stressors who are likely to affect the patterns of functioning and psychological status of family members. Gallagher et al. (1983) emphasise the unpreparedness of families for this stressor event which then often becomes a crisis event. For

many years research studies focused on the impact of a handicap through measurement of signs of family stress and malfunctioning. Turnbull et al., (1985) point out that the belief that a handicap in the family causes stress and consequent malfunctioning sometimes forced researchers to give negative interpretations to positive results. This belief stemmed mainly from traditional psychoanalytical and/or pathological approaches which emphasise the maladaptive aspects in parenting a handicapped child and the prevalence of feelings of guilt and ambivalence (Blacher, 1984; Gerdel, 1986; Innocenti, Huh and Boyce, 1992; Turnbull et al. 1985).

A more recent trend in the research literature is to adopt developmental approaches or normality orientations which emphasise opportunities for growth and successful adaptation in parenting an exceptional child and seek to explore sources of stress and resources families use to mediate it or to manage ((Beckman et al., 1991; Frey et al., 1989; Innocenti et al., 1992; Trivette et al., 1990; Tulloch, 1983).

Wikler (1986) emphasises the importance of distinguishing between the stressor itself and changes caused by families' reaction to the stressor i.e. the results of the managing process. Families' reaction to the stressor is described as: a process requiring ongoing coping responses (Bailey et al., 1984; Blacher, 1984; Dyson et al., 1986; Friedrich et al., 1985; Tulloch, 1983;); a stress-provoking drive towards homeostasis (Miezio, 1983); the need for "control within an environment where the families perceive they have no control" (Bailey et al., 1984:40). In the study of Summers et al., (1990) a sense of being in control of the situation was rated by families as an important characteristic of success. Deiner (1987) states that most parents accept professional control initially. However, as they begin to search for alternative definitions and solutions to the problem, they take back the authority. McCubbin et al. (1983b) state that a stressor event produces tension which calls for management.

Family stress is defined as a state which arises from an actual or perceived imbalance between demand (e.g. challenge, threat) and capability (e.g. resources, coping) in the family functioning. It is characterised by a nonspecific demand for adjustment or adaptive behavior (McCubbin et al., 1983b:10).

The stress giving rise to this need to manage arises from the tension field between the demands of the handicap and the

family's capacity to meet it. Very relevant to this study are the various conceptual frameworks that have been developed to study the interaction between stress and coping and the factors that enhance positive family outcome. In the next sections the elements of the process of managing as they are portrayed in the literature are presented.

### 3. PARENTAL MOTIVATION

The existence, strength and importance of parental motivation are stressed in the literature in the following ways: parents must not be underestimated in their resilience and action-oriented efforts to manage and be portrayed as passive victims of stress (Frey et al., 1989; Friedrich et al., 1985); parents have a strong sense of responsibility for their handicapped children (Borsay, 1990); parents are driven to procure the best possible services and future for their children (Becker, Bender and Kawabe, 1980; Turnbull et al., 1986); parents are characterised by tenacious and goal oriented behaviour which shows a strong sense of motivation to manage the handicap trajectory (Summers et al., 1990). Vincent et al., (1988) quotes the findings of Laten (1981) stating that a majority of mothers cited their belief in themselves and their own motivation as their most important resource. Innovative research on ecocultural niches and the accommodation of developmentally delayed children showed that these parents have a central dynamic force in their lives.

They were driven by the task of *constructing and sustaining a daily routine* for themselves and their children and making that routine satisfying and coherent in terms of their view of family and child life. With respect to their developmentally delayed child, most parents wanted each day organized to provide what they believed was proper care, supervision and stimulation for their children. . . with preferred motives driving interaction (Gallimore, Weisner, Kaufman and Bernheimer, 1989: 219).

However, some of these families are particularly vulnerable to the experience of stress and statistical evidence of suicide and divorce and the greater risk for child abuse, show that the motivation to manage is not always strong enough (Gallagher et al., 1983).

An important facet of parental motivation relates to their willingness to be involved in the education of their children. An interesting feature of American early intervention

children. An interesting feature of American early intervention history is the strong drive and advocacy efforts that led to the inclusion in Public Law 94-142 of a clause requiring parents to be included as an integral part of the child's education programme (Bricker and Casuso, 1979). However, for various reasons parents did not make full use of this mandate and this led to professional frustration and the belief that parents were disinterested and not motivated enough (Bailey, 1987; Fuqua et al., 1985; Goldstein et al., 1980; Turnbull et al., 1984; Winton et al., 1981; Winton, 1986). Two relevant reasons for their apparent lack of motivation and the link between parental motivation and aims are described in the following quotations.

Most families are doing the best they can under circumstances; our task is to try and change the circumstances and not the families themselves (Bronfenbrenner, 1979:103).

However, what may be interpreted as either oppositional or apathetic behavior may have less to do with contempt for professional opinion and more to do with lack of consensus regarding the nature of the presenting problem, the need for treatment . . . and the course of action that should be taken. As noted by Merton (1976), people who occupy different positions in a social structure . . . tend to differ in their appraisal of the same situation, and consequently will differ in terms of what constitutes individual and family needs and how one should allocate time and effort to obtain resources to meet needs (Dunst et al., 1988a:108).

#### 4. AIMS

The aims of parents could be long term or short term and directed toward the child's well-being and/or the family and personal well-being of the parents. Formation of parental aims is in constant flux together with the growth and development of their own and society's attitudes toward the handicap.

The realisation that a child is abnormal violates the expectancies for achievement that most parents hold for their children. These parents often become dependent on professionals who assess the children, provide information on the children's potential and help with the formulation of realistic goals (Berger and Fowlkes, 1980; Cordero, 1988; Schell, 1981). Unrealistic goals may cause parents to give up or become negative and pessimistic and can even lead to child abuse (Dyson, 1991; Schell, 1981).

However, there are dangers inherent in outside people/professionals entering the scene. The tendency of professionals to assume that parents "require constant guidance and tutelage to act in the best interest of their children" (Gliedman et al., 1981:235) poses one of the biggest problems in the managing process. According to these authors professionals "exist to further the parents visions of the handicapped child's future" (Gliedman et al., 1989: 229). Only in the most extreme cases of parental incompetence may professionals use their immense moral and practical power to intimidate or manipulate the parent. In most other cases their assumption of a moral right to impose their own values disempowers parents.

Turnbull et al. (1985) discuss the effects of the "fix-it" approach prevalent among early interventionists, in the formation of goals. Basically the handicapped child is seen as "broken" and needing help to develop as far as possible toward normal standards or at least to his full potential. They point to the dangers of overconcentration on developmental goals and negating the importance of the development of self esteem and concentration on the whole child.

The importance of family goals rather than just child-centered goals are stressed (Bailey et al., 1986; Turnbull et al., 1986; Berger, 1986). In their dealings with early interventionists parents tend to focus more on child-centred goals (Summers et al., 1990). However, Gallimore et al., 1989 emphasise the interconnectedness of these goals and the necessity to balance child-centered ones against the general goals of the family. Often these goals are part of the parents cultural and personal belief system (See also Harry, 1992; Wayman, Lynch and Hanson, 1991). Examples of these are parental beliefs in the critical importance of early experience, the unique role of parents versus other caretakers, the absence of materialistic values, career-driven goals and sex-typed role-schemas (Gallimore et al., 1989). These authors found that

Most of the families in our cohort are actively constructing and refining a niche that they believe will make their child "more normal" or "as normal as possible", or "able to be all that my child can attain" (Gallimore et al., 1989:227).

A professional who became the father of a handicapped child names the aims he has for his child as "maximum

individual development, happiness, economic independence, emotional independence" (Roos, 1985:253). In a qualitative study to assess the service needs of parents of young handicapped children the following family goals were included:

independence, acceptance by other children, realization of the child's potential, ability to communicate, and becoming "potty-trained" (Able-Boone et al., 1990).

## 5. ATTITUDES

Construction of the daily routine and its activity settings is mediated by central family *themes* that give meaning to parents' decisions concerning their daily routine ; these themes determine the relative impact of niche features and whether they are viewed as resources, constraints, or simply ignored. (Gallimore et al., 1989:219-220)

This quotation illustrates the role of aims and attitudes in shaping the accommodation of the family to their special circumstances. The crucial importance of parental attitudes is further illustrated by the results of a path analysis of the findings of an investigation of the McCubbin et al., (1983a) double ABCX model which indicates that the causal link between the factors suggests an ACBX path because of the importance of the parental perceptions of the handicap and related needs (Orr, Cameron and Day (1991). Zeitlin, Williamson and Rosenblatt (1987) see beliefs and values as a filter through which stressors are processed. The perception of the stressor is seen as a mediator for the utilisation of internal and external resources.

According to Tulloch (1983) the birth of a handicapped child could lead to initial reactions like despair, confusion and fear. In most cases there is a gradual process toward the development of coping mechanisms and of coming to terms. Sometimes the process is compared with the stages of the mourning process which could lead to a final stage of acceptance. However, researchers warn against stereotyped ideas about eventual acceptance as some families do not accept the child's handicap but adjust to the reality of the handicap in various, often unique ways, keeping open the possibility of change or a cure. Often these processes are ongoing and could fluctuate with renewed crises in the life cycle of the

handicapped child (Blacher, 1984; Deiner, 1987; Wikler, Wasow and Hadfield, 1981).

Factors which enhance or impede the process of coming to terms are:-

\* The customary way in which parents approach problems or their coping styles can have a determining effect on the development of their attitude. Tackling, rather than avoiding problems and self-appraisal rather than excessive self-blaming, moderate stress and promote coping. The most effective intervention for parenting stress might be development of self-enhancing comparative frames of reference to cultivate greater perceived control on the part of parents (Frey et al., 1989). Turnbull et al. (1986) stress the importance of reframing a problem to make it more manageable. The research of Shapp, Thurman and DuCette (1992) emphasised the significance of attributions in relation to parental well-being, confirming that self-blaming is not conducive to the well-being of mothers. They found, however, that fathers who did not blame fate, the obstetrician or someone else had higher total well-being scores.

\* The role of religion and/or other spiritual beliefs has been shown to be an important factor in the interpretation of the event. Some regard a handicapped child as a special blessing or a special task that God has given them; others see it as a punishment for their sins and others do not hold God responsible for their misfortunes but turn to God for help and strength to manage this misfortune (Dyson, 1991; Frey et al.; Kushner, 1981; Lea, 1986; Turnbull et al., 1986; Weisner, Beizer, and Stolze, 1991). However, Fewell (1986) stresses the point that whatever the religious interpretation given to the event it helps the parents to deal with the fundamental questions of life.

By providing answers, regardless of their specificity or truth, these support sources help parents to get on with their lives, to attend to other things about themselves and their world. . . . For far too long, professionals . . . have failed to understand and realize the importance of these sources of religious support. . . it has not been overlooked by parents, and from these sources they often derive much of the strength they need to nurture their child with special needs (Fewell, 1986:314-315).

These conclusions of Fewell are consistent with results reported by Mahoney et al., (1992) and Weisner et al., (1991) who found that parents with strong religious beliefs are more

family oriented and see their children as an opportunity rather than a burden. Their religious interpretation may enhance family relationships and thus enable them to cope effectively with the stressful situations caused by the handicap.

\* The impact of the marital subsystem on the shaping of attitudes is underlined by Beckman, (1991); Gallagher et al., (1981); Jansen (1991); Miezio (1983) and Van Rooyen, (1989). Exacerbating factors are spousal inability to share deep seated anxieties and fears and differences in coping strategies and stages of acceptance. These factors can cause interpersonal stress, misunderstanding, conflict and estrangement which can drain mutual support and the development of positive attitudes and coping strategies (Shapp et al.; 1992). Extended family members can also play an important role through their acceptance or rejection of the handicapped child (Gabel et al., 1981; McConachie, 1986; Schell, 1981)

\* The importance of the larger societal framework against which the presence of a handicapped child is interpreted can influence the parents reaction and eventual adaptation considerably (Borsay, 1990; Tulloch, 1983). Middle class societal norms for the behaviour of children e.g. children must behave properly and do well in school, can influence parental attitudes. Negative societal reaction to the child's deviant behaviour may imply to parents that their capacity as parents and/or status in general is being questioned (Gallagher et al., 1983; Miller et al., 1983; Turk, 1991; Turnbull et al., 1986).

Miezio (1983) emphasises the role of society's responsibility for the care, treatment and education of children with special needs and blames some of the difficulties and uncertainties that families experience as the result of larger society's inconsistent and ambiguous values. Turk (1990) points out that current economic and political circumstances in South Africa make parents especially vulnerable to these uncertainties resulting in fearful or maladaptive attitudes.

\* The role professionals, especially school professionals, play in the shaping of parental attitudes can be a determining factor. These professionals have frequent contact with the family and form an important part of their support system (Crnic et al., 1983). However, parent-professional interactions can be a source of additional stress if parents feel that they are blamed or criticised when they do not live up to

professional expectations (Deiner, 1987; Gallagher et al., 1983; Mittler, 1990). Official policy regarding parental roles and the gap between official policy and existent professional attitudes often cause parents to feel excluded from discussion and decision-making. (Fuqua et al., 1985; Mittler, 1990; Turnbull et al., 1984; Yoshida et al., 1978). The importance of presenting the initial diagnosis in accurate, nonstigmatizing language is as another factor which "can have a profound effect on the adaptation process, including early bonding and attachment" (Mallory, 1986: 341).

The following statement by a mother of a handicapped child summarises the influence of professionals on parental attitudes.

[Early intervention] should not try to eliminate or deny pain and suffering. Part of the strength of families is that they have faced pain. People need permissions to feel sad. . . . However, early intervention should not add MORE pain. . . . Families don't have to go through pain of not having services, or the pain of being blamed for the child's handicap. . . . (Summers et al., 1990)

## 6. PARENTAL ABILITY : NATURE OF SKILLS

Having experienced the personal turmoil of emotions Christina precipitated, adjusting to those demands, then choosing to go beyond the psychological limitations a handicap can place on a person and family, I have come to a clearer understanding of and appreciation for the human ability to adapt to life-changing events. . . . we have the strengths, skills, and personal abilities to choose the best course for our child, the family, and very importantly for ourselves (Schell, 1981:27).

The above quotation shows the link between the attitude to the handicap and the development of skills to manage the impact of the handicap on the family. Special parenting, personal and social skills are needed to manage the handicapped child as well as the support systems and to integrate the special demands created by the handicap with the needs of the rest of the family.

### 6.1. MANAGING THE CHILD : PARENTING SKILLS

There is a strong interplay between the attitudes parents have toward their child and his handicap, and their managing skills in the area of parenting as can be seen in the following discussion of skills.

\* This interplay becomes evident in the need for balance. Yura (1987) states that the birth of a handicapped child can have a profound effect upon cohesion within a family. In some cases this event may result in the family becoming totally disengaged. The grieving, anger and depression may cause family members to nurse their own sorrows and not have much time left for the rest of the family. In other cases the family may move more towards enmeshment, concentrating fully on the handicapped child, often becoming overly protective of him. Lack of balance could lead to extreme attitudes i.e rejection of the child or total devotion leading to the subordination of all other family demands. In between there are variations of the two extremes, with the parents maintaining a sense of their own identity, a more normal life style and mutual support of each other and the child (Tavormina et al., 1978). Sillipp (1987) and Mahoney et al., (1992) found in their research that families of handicapped children compared favourably to the families of normal children in the areas of cohesion and adaptability. Sillipp et al., (1987) compared Afrikaans and English groups of children attending a special school and found that the Afrikaans mothers view themselves as more enmeshed as a family group.

Balance is also needed in the adaptation of parenting styles, roles and hierarchies to the demands of the handicap. The impact of the handicap may overthrow existing routines and necessitate the changing of rules and regulations which may lead to chaotic conditions in the family. Some parents' reaction could lean to the opposite direction and result in a rigid adherence to rules and regulations regardless of the fact that this might put unnecessary strain on the family (Turnbull et al., 1986).

Balance is needed between the drive to lead the child to independence and the special nurturing and care needs of the handicapped child. Miezio (1983) stresses the parental need for: information on normal child development; help to interpret possible milestones for their child; guidance to know how to encourage the child to achieve to his full potential without pressurising him too much and causing frustration and sadness to themselves.

\* The often overwhelming demands made on the emotional, financial, time and energy resources of these parents make

special demands on their problem-solving skills or the need for reflective parenting (Farran et al., 1986; Frey et al., 1989; Jansen, 1991). This is described by a father.

Because of Christina's handicap, my wife and I have different decisions to make than those of other parents. Possibly the most difficult problem is knowing what situations require more of us because of Christina's handicap and when she is simply needing normally attentive parents (Schell, 1981:24).

Frey et al. (1989) describe the problem of fathers who struggle to fulfil their traditional role of providing recreation for the child in the form of physical play. Lack of problem-solving abilities might cause withdrawal from the child. Turner et al., (1986) report on the creative adaptations, adjustments and resourcefulness they observed during video-sessions with a group of families with handicapped pre-schoolers which enabled these families to function better than expected. A sense of humour and resilience are invaluable parental skills (Dyson, 1991; Farran et al., 1986).

\* Bonding is another challenging area. Factors that play a role in this respect are early medical crises and hospitalisation during the critical bonding period as well as characteristics and behaviours of the infant that discourage attachment. Among these are negative responses to being handled e.g. tenseness or limpness, lack of responsiveness, irritable or prolonged crying, hyperactivity and impaired perceptual functions affecting the ability to communicate. The growing insight into the role of the infants in eliciting, programming and affecting responses and behaviours has special relevance for the families of handicapped children. Parents might be unable to interpret the infant's signals or the child may seem unresponsive to the parents' activities. The kind of stimulation and nurturing that the infant needs will be adversely affected and a negative interaction with increasing stress and frustration might develop. Parents then find it harder to form an attachment (Blacher, 1984; Miezio, 1983; Sameroff and Chandler, 1975; Schell, 1981; Tulloch, 1983). As a result of this parental burnout could become a serious possibility with the accompanying symptoms of feeling drained, irritable, always seeming to meet someone else's needs and becoming increasingly introspective and questioning of their own value systems. In extreme cases this may lead to abuse (Schell, 1981).

Enhancing and impeding factors which play a role in the bonding process are :inter- and intrafamily support; social networks and the parents' general attitude to the handicap; the stage at which the handicap is diagnosed (Blacher, 1984; Schell, 1981, Turnbull et al., 1986). Specific ways in which professionals can help to enhance bonding are by helping parents to realise the positive contribution a child with an exceptionality can make towards affectionate needs of the whole family (Schell, 1981; Turnbull et al., 1986).

Her ability to let us know of her enjoyment and dependency elicited positive responses of enjoyment and concern from us. Almost from the beginning she was able to be an infant first and then an infant with a handicap (Schell,1981:24).

Further ways to enhance bonding are by creating special circumstances and occasions for bonding (Miezio, 1983; Warnock 1978) and helping parents to interpret and react to their children's unusual ways of communicating (Warnock, 1978).

\* In the earliest years, parents should be regarded as the main educators of their children. This signifies a special need for parents who have children with marked difficulties and disabilities. They might need skilled support in developing behaviour and attitudes necessary to help their children to develop to their full potential (Mittler et al., 1990; Summers et al., 1990; Warnock et al., 1978).

The task of educating Glen to achieve his developmental milestones was performed by trial and error. Oh, how we needed that developmental psychology degree! Breaking down learning processes for simple tasks, step by step, was difficult for us. (Farran et al. : 156)

This quotation illustrates a few of the particular needs parents as educators have. The following needs are mentioned by Miezio (1983): information on the formulating and achieving of learning goals; a place where they can air their frustration with and concern over the child's slow progress; guidance on teaching and behaviour management skills to achieve optimum results; people who can help with teaching when parents feel that their own ambiguous feelings or overprotectiveness are in the way of the child's progress. Rodger (1986) emphasises that parents need external encouragement and continued support to become effective change agents for their children especially in the field of parent/child interaction. Mothers tend to act differently and to exercise more control in a

teaching/therapeutic situation. This may have a negative effect. The following quotation underscores this.

There has been fragmentation among programmes that focus on parents' educational skills, attitudes and emotions, and social-emotional interactions with the child. Each of these aspects has something to contribute to the intervention process, but each taken alone may reduce the parent's competence in other important developmental domains (Wright, Granger and Sameroff, 1984:52)

\* The impact of the handicap causes increased workloads and places heavy demands on the parental system and their ability to share tasks. Fortunately traditional role models and division of duties are changing and fathers are increasingly eager to explore new roles, helping more with the home and childcare. Father involvement is vital to helping families build internal networks of support which enable them to meet the added demands (Farran et al., 1986; Hewett, 1970; McConachie, 1983; Meyer et al., 1982; Parke, 1986; Turk 1991).

However, societal attitudes toward fathers' roles still hinder this process. Traditionally and even more so with the birth of an exceptional baby, fathers are pushed to the back seat and throughout the early years mothers are addressed as the prime caretakers. The danger is that the mother will become the "specialist" as she gets most of the instructions and father will withdraw more and more from the child-rearing activities. Often well meant intervention endeavours strengthen the mother/child dyad and result in greater distance between the parents (Berger, 1986; Foster et al., 1981; Sandler, Coren, and Thurman, 1983). This presents a special need which has been met successfully in some special programmes in the USA. Intervention activities are planned at times when fathers can attend and geared toward their special needs, thus encouraging and empowering them to play a more active role and thereby strengthening the sharing possibilities of parents (Gallagher et al., 1981; Lamb, 1986; Lea, 1986; Markowitz, 1984; Schell, 1981; Vadasy, Fewell, Greenberg, Dermond and Meyer, 1986).

## 6.2. MANAGING THE SUPPORT SYSTEM

Although we tend to dwell upon the dependence of many parents on professional support, we are well aware that professional help cannot be wholly effective - if at all so - unless it builds upon the parent's own understanding of their children's needs and upon the parents' capacity to be involved (Warnock, 1978:151).

This quotation highlights the intrinsic importance of interdependence between parents and their support systems. Summers et al., (1990) found that the skills to recruit help from others and to use social support, were ranked highly by parents. The nature of the skills necessary to manage especially the school support system is now investigated.

This involvement has different facets, depending on the role the parent plays i.e. recipient of services, advocate, negotiator, learner, teacher, partner, decision-maker, family member (Turnbull et al., 1986). There is a continual interplay between the roles parents are expected to play, those they wish to play and the skills necessary to manage the system. Fuqua et al. (1985) comments on this issue:

a special education teacher initially may need to "take the lead" in relationships with parents unfamiliar with special education processes and their particular roles. But hopefully as time passes and links between the home and the school become easier and more extensive, the parent will be able to assume a larger responsibility for the interactions between the two settings (Fuqua et al. : 308).

The managerial skills could be seen as sharing of responsibility; assuming the role of consumer; sharing of control and power.

\* Parents have a wide range of opinions about the sharing of responsibility with the school. Teachers often complain that parents are uncooperative, do not really care or lack responsibility. Orr (1974) remarks that the staff concerned seemed to be unaware that they have fostered this expectation by the assumption of the role of specialist or authority. A parent reacts to this in the following way:

I do not believe that lack of concern prevents parents from working with their children. Instead, lack of knowing "how to help" may be the obstacle that keeps the most natural of "teachers" from assisting in their children's education at home (Brixter, 1987:24).

The parents need the skill of sharing knowledge and insights with professionals but they also need opportunities and an encouraging atmosphere in which to do this. A mother of a handicapped child commented on the reluctance on the part of many teachers to accept the abilities of the parents:

I have a son who is retarded. I taught him to walk, to use the bathroom, to feed himself, to say his first words, to interact with the family. I know my son; I can help you to know him and to teach him (Schulz, 1985:5).

Fuqua et al. (1985) found that sharing of responsibility was relatively easy if the teacher had a favourable idea of the mother's teaching capabilities. However, often the parents who most needed contact and support, were labeled as lacking in responsibility and commitment and with them the teacher became easily frustrated, labeling them as denying or low-functioning. The need of these parents to be especially supported and encouraged to take responsibility is emphasised (Warnock, 1978; Gliedman et al., 1981).

However, some parents will not, for a variety of reasons, realise the value of reinforcing what is done in school, while other parents might feel diffident about offering their contributions to what they see as a matter for experts. It is for these reasons necessary to create a climate in which parents are encouraged to have an active share in meeting their child's special educational needs (Warnock, 1978:156).

A different aspect of this issue is presented by the findings of Turnbull, Winton and associates. A large majority of parents in their research emphasised their need for a preschool with competent professionals so that they could be relieved of the educational responsibility for their children. They indicated their preference for a more passive level of involvement from programme activities. Frequent informal give-and take contact and sharing of information with the teachers was the most preferred activity of these parents. (Turnbull et al., 1984; Turnbull et al., 1983; Winton et al., 1981).

A critical time for the development of these skills is when a child starts with pre-school. The educational and nurturing task of parent and teacher is closely interwoven at this stage. Teachers often have an important caretaking role during the school day and a sharing of information and responsibility is vital (Cordera, 1988; Lindsey, 1985). Winton (1986) emphasises the special skills parents need to redefine their boundaries to accommodate the professionals with whom they must form a relationship. In the case of handicapped children it is often harder for parents to release part of their responsibility as the child often needs special types of caretaking and vigilance.

\* The parents role in the partnership is that of a consumer with the professionals assuming accountability to them (Mittler, 1990; Turnbull et al., 1986). However, parents often find it hard or impossible to assume this role. This is partly

due to professional attitudes which regard parents as in need of help, patients, or part of the problem (Roos, 1985). These attitudes make parents vulnerable and help to create "the vast asymmetry in need between parent and professional" (Gliedman et al., 1981: 232) Some of the special skills demanded from parents is described by a mother of a handicapped son:

For Glen to reach his maximum potential in growth and development, close monitoring, open communication, and persistence are required of us. (Farran et al., 1986:157).

Families in the study of Summers et al., 1990 confirmed this and felt they required skills to access information and services as well as interpersonal communication skills to negotiate and problem-solve with professionals. They wanted to ensure that everything was done to further future possibilities for the child.

The ability to communicate is seen as a vital parental skill that helps parents to manage the role of consumer (Deiner, 1987; Schulz, 1985). Skills necessary for open communication channels are mainly the ability to define problems in system terms rather than holding specific people responsible for communication problems and the ability to form open friendly relationships with professionals and thereby preventing defensive reactions when problems arise (Dowling and Pound, 1985; Turnbull et al., 1986). Warnock (1978) emphasises that parents are basically eager to communicate with somebody who loves and understands their child. When problems arise they need patience and perseverance from professionals and an open system that facilitates communication.

Previously mentioned research results indicated parents strong preference for informal frequent and open communication shared in a relaxed give-and-take fashion. To them this type of involvement is far more important than volunteering time at the preschool, serving on policy boards or participating in training or counselling sessions (Turnbull et al., 1983; 1984; 1986; Winton et al., 1981; Winton, 1986). The question is whether parents are better able to assume the consumer role through these informal relationships. Gliedman et al. (1981) remark that often the client-professional relationship is transformed into a kind of friendship creating the danger that the preservation of this special bond can become an end in itself and make it harder to assume the consumer role. The

professional might then be denied essential feedback in the process. Parental ability to communicate respect and trust and to give positive and negative feedback to staff members are vital skills in this respect and it is surmised that only a few parents have the ability and influence to act like a consumer in relation to school system. They feel that only through self-help groups which can provide moral support, access to information and alternative services can parents practically exercise their power, strengthen the influence of individuals and force professionals to take parents seriously (Gliedman et al., 1981; Schulz, 1985).

\* The importance of skills to share control and power is stressed in the following quotation.

the parents should assume a managerial role. He must have power - the kind of power that comes with occupying a position of administrative authority in a large organization. Without it, even the best attempts to reform the way professionals deliver their services, risks frustration. Good intentions and a genuine desire to help are simply not enough if the deck remains stacked against the client. The parent, not the professional, should be the one to set the terms of the relationship (Gliedman et al., 1981: 237).

Gallagher (1992) basically agrees with the above authors when he discusses the parents' struggle to retain control in the light of their need and lack of expertise. Although the family is encouraged and has the responsibility to seek professional advice

the family is expected to maintain executive control over the important decisions and not cede that control to professionals, no matter how distinguished their credentials (Gallagher, 1992:8).

Summers et al. (1990) found that parents felt they needed more self-confidence in their own judgement. Mittler (1990) emphasises the parental need for mutual respect, trust, equality, understanding and shared decision-making in the family-professional partnership (Mittler, 1990).

Dunst and his colleagues emphasise the need for the empowerment of parents to enable them to manage. (Dunst, 1985 and 1986; Dunst et al., 1988; McWilliam et al., 1986; Trivette et al., 1990). Their approach is proactive, focusing on child and family strengths.

the things that children and families do well are used as foundation for meeting family-identified needs. . . FIPP enables and empowers parents to make informed decisions and take

control over their lives and the lives of their children by imparting information, skills and knowledge to the families. One major focus of intervention, therefore, is promoting a sense of both intra- and interpersonal efficacy in families (Dunst et al., 1988b:321).

The FIPP- programme is based on partnership with parents. The goals are based entirely on needs, determined by joint assessment procedures and selection of programme goals. The role of professionals in empowering parents is emphasised in the following quotation.

the more decisions are made by people outside the family without input from the families themselves regarding the types of services they need, the less likely they are to feel personally and interpersonally effective and to develop or maintain an internal locus of control. . . The role of the intervener is to provide families with the information, skills, and knowledge to affect their decision-making power. The more families are empowered , the greater the likelihood of their developing a sense of intrapersonal and interpersonal control (McWilliam et al., 1986: 79-80).

However, an international survey commissioned by Unesco (Mittler 1990) showed, that despite examples of good practice, many parents still feel excluded from discussions and decision-making and the development of educational programmes. In surveys on preferred levels of participation in decision making and preferred involvement activities, parents were satisfied with more passive role in decision-making but indicated a need to have control over some decisions e.g. medical services and child transfers to other schools (Lusthaus et al., 1981). The time needed for more active involvement often determined parents' involvement preferences.

## 7. THE NATURE OF THE PARENTS' CAPACITY TO APPLY THEIR SKILLS

*Enabling* families means creating opportunities and means for families to apply their present abilities and competencies and to acquire new ones as necessary to meet their needs and the needs of their children. . . Empowerment is both a process and an outcome that takes different forms in different families. . . Empowering families in early intervention. . . means interacting with families in such a way that they maintain or acquire a sense of control over their family life and attribute positive changes that result from early intervention to their own strengths, abilities and actions (Johnson et al., 1989:5 as quoted by McGonigel, Kaufmann and Johnson, 1991).

The allocation of the limited resources of time and energy is a source of stress for virtually all parents, especially during the early and middle phases of parenting (Miller et al., 1983: 67).

Parents often have the skills to manage or the basic ability to develop these skills but they do not have the capacity to apply these competencies. Many factors have been highlighted which could impede or enhance the families implementation of their skills. Parent's attitudes to the handicap were shown to have a determining influence on the emotional energy available to manage. When parents continuously struggle to cope there is the danger of parental burn-out. However, there is also potential for growth and empowerment when parents go "past the psychological limitations a handicap can place on a person and family" (Schell, 1981: 27).

As was shown in chapter III, the characteristics of the family could impede or enhance the implementation of management skills in term of the time and energy available for management of the handicap trajectory e.g. the needs of siblings, the work obligations of the parents etc.

Time is regarded as a fundamental resource and constraint for families with young handicapped children (Beckman, 1991; Brotherson et al., 1992; Harris et al., 1989; Morton, 1985). A mother stated her problems clearly.

I had a long talk with myself and finally came to the conclusion I can't do it all every day, so I just have to do what I can. All the exercises, all the little games, everything I am supposed to do, I am just constantly spending all my time trying to stimulate her or do physical therapy and I didn't have any time to do anything else or to enjoy her (Brotherson et al., 1992: 519).

The interaction between the resources of the family and the problems they experience in the application of their skills to manage is illustrated aptly in figure 5 and 6 (Chapter II). The ecological model indicates how families function at various stress levels. Under normal circumstances the family uses moderate amounts of energy and a large energy sink remains. However, as stress levels increase, the energy sink empties. Then the outputs decrease and eventually resources are affected by the lack of feedback. The family lands in a vicious circle of crises which could lead to parental burnout.

The presence of a handicapped member is a source of stress and may place excessive demands on the energy and other resources of the family. . . Depending on the type or degree of handicapping condition and the *real* amount of input into the microsystem, a particular family could be functioning with a relatively high energy expenditure and still remain intact. However, such a family would be extremely vulnerable to other sources of stress

as inflation, unemployment, or school problems of siblings (Bubolz et al., 1984:8).

The relevance of family systems and ecological approaches to the understanding of parental managing capacity is evident. (Dyson et al., 1989). Dunst et al. (1988a) demonstrate this by adding new perspectives to this question. Their focus was the relationship between the extent to which the adequacy of personal and family resources affected parental well-being (emotional and physical) and commitment (time, energy, and investment) to professionally prescribed child-level treatments. The concepts of "environmental press" and "need hierarchies" employed by them is relevant. Environmental press is defined as

. . . the combined influence of forces working in an environment to shape the behavior and development of individuals in that setting. It arises from the circumstances confronting and surrounding an individual that generate (needs and) psychosocial momentum, which tend to guide that individual in a particular direction (Gabarino, 1983:8).

Dunst et al. (1988) surmise that when self-identified needs go unmet, this acts as a force that presses one to invest energy in meeting these needs. If one accepts the family systems theory that individual and family needs form one set of forces that affect behaviour (Hartman and Laird, 1983) the concept of need hierarchies is applicable. Maslow, (1970) stipulated that unmet basic needs dominate behaviour and interfere with achievements of higher level needs. "When embedded within both human ecology and family systems theory, the notions of needs and needs hierarchies take on new meaning" (Dunst et al., 1988:109). These authors state that unmet family needs in basic areas e.g. nutrition, child care, affect parents' health and well-being and decrease the probability that they will attend to matters such as home therapy programmes. The results of their study showed that adequacy of resources is related to mothers' emotional and physical health and predicts the extent to which they have time, energy and personal investment to carry out professionally prescribed, child-level educational and therapeutic interventions.

Personal and family needs were found to be a set of forces shaping maternal beliefs, and unmet needs took precedence in terms of influencing parental attributions about the importance of child-level interventions (Dunst et al.:13).

An interesting further finding is that the families perception of the adequacy of their resources is related to their ability to manage these resources rather than to their actual socio-economic status. This finding underlines the importance of the interplay between attitudes, ability and resources.

These authors stress the importance of assessing family needs and taking basic need hierarchies into consideration from a broader based social perspective before any intervention is planned. A shift in professional role perception might be necessary with a stronger focus on helping parents with basic family needs. Parents should be strengthened pro-actively instead of being blamed or shamed for failing to subscribe to what professionals think is best for them and their children.

There are many factors and forces impacting on the parents' capacity to apply their managing skills forcing parents to continually balance needs and make voluntary or involuntary choices on where to apply available resources This will influence their choice of managing strategies.

## **8. MANAGING STRATEGIES**

The managing tasks that parents need to perform are directed toward themselves, the family, the child and his handicap and the support systems. The strategies they employ, are arranged on a sliding scale of effectiveness. Turner et al. (1986) conducted extensive qualitative research on the impact of the young handicapped child on the family system and possible strategies to prevent the development of a dysfunction in these families. They observed

. . . very creative adaptations and adjustments in these families as a group. In general they functioned better than you would expect. They demonstrated a level of resilience and resourcefulness that increased the respect and optimism of the school staff for them (Turner et al., 1986:15).

### **8.1. STRATEGIES TO MANAGE THEMSELVES**

Turnbull et al. (1986) stress the importance of developing effective internal coping strategies. Passive appraisal is often parent's first reaction to the stressor. They deny the event or refuse to think or talk about it. Turner

et al., (1986) found that parents often concentrate on the positive aspects of their parenting and regard the admittance of problems, irritations or worries as signs of weakness and rejection. However, avoidance and wishful thinking related to higher distress while the ability to admit more negative feelings enabled parents to deal realistically with their problems and develop positive feelings toward the child (Frey, et al., 1989; Turner et al., 1986). A more positive and necessary form of passive reappraisal is the taking of time off (Turnbull et al., 1986).

Reframing of the problem involves distinguishing between things that cannot be changed and are beyond control and those that can be changed through action. In dealing with the unalterable the ability to redefine the situation i.e. the fact of the handicap, and make it more acceptable and less stressful is needed. Typical ways of doing this are through positive comparisons or the "count your blessing"s process and to concentrate on the positive contributions of the handicapped child to the family (Schell, 1981; Turnbull et al., 1985).

However, research results often show that parents employ less effective managing strategies. Depression, concern about financial and other special needs of their children, non-acceptance, desertion or divorce are some of the managing strategies resorted to by fathers (Meyer et al. 1982, Yura, 1987). Other studies found that fathers reported fewer symptoms of distress, higher self-esteem and more internal locus of control than mothers (Goldberg et al., 1986; Beckman, 1991). but Frey et al. (1989) found that because mothers are often forced to engage more in problems-solving strategies necessitated by the increased child-caring demands this leads to healthier coping styles. They are often more personally invested in successful childrearing than fathers and more sensitive to troubled children but have less chances for developing their own intellectual and occupational resources. This might affect their sense of competence and resultant need for social support (Beckman, 1991; Harris et al., 1989).

The role of professionals in enabling parents to employ effective managing strategies through empowering has been dealt with extensively. Preventive intervention is emphasised in this respect.

. . . helping alleviate the depression after it has developed is almost too late. If service providers and policy-makers understand the way an event exerts its influence, they can intervene earlier in the process of adaptation (Farran et al., 1986: 151).

## 8.2. STRATEGIES TO MANAGE THE FAMILY

Surprisingly, each family member's active involvement in this ridiculous inconvenience [stringent diet] brought positive feelings. Personal contribution, personal effort. personal sacrifice raised the family's spirits. . . we cooperated willingly and understandingly with our silent partners, the pills and syrups. Participation in this common project bonded the family unit, making up for the "separated feeling" created by the duty system (Farran et al., 1986: 155).

Positive family managing strategies such as increased closeness, mutual helping and cooperation are described frequently in the literature (Gowen et al., 1989; Harris et al., 1989; Orr et al., 1991; Salisbury, 1987; Turner et al., (1986). However, some studies found signs of severe stress and/or maladaptation in the families who over concentrated on the affected child and or neglected siblings and other family members (Beckman, 1991; Dyson et al., 1986; Gallagher et al., 1983; Kazak et al., 1984; Turner et al., 1986).

The following section synthesises managing strategies employed by strong families. These strengths should be seen, not as isolated variables, but functioning as interrelated, dynamic clusters forming a unique family functioning style. The strengths include a sense of commitment toward promoting the well-being of family members and the family unit, appreciation and encouragement for things that family members do well, concentrated efforts to spend time together, a sense of purpose that enables them to continue in both bad and good times, congruence among family members regarding the value of efforts towards attaining goals and fulfilling needs, the ability to communicate in positive ways, a clear set of rules, values and beliefs, a varied repertoire of coping strategies, ability to engage in problem-solving activities when necessary, the ability to be positive and to see crises and problems as growing opportunities, flexibility and adaptability in procuring and using resources, balance between use of external and internal family resources for coping and adapting to life events and future planning (Trivette et al., 1990: 18-19).

### 8.3. STRATEGIES TO MANAGE THE CHILD AND HIS HANDICAP

We wanted to let Christina grow as normally as possible, but needed answers to many questions before we felt comfortable with her progress. . . . As these gaps in our knowledge were filled in, our confidence in ourselves as parents grew. We were able to start setting developmental goals for Christina that exceeded our original expectations. The future became a source of hope rather than an unknown to be dreaded (Schell, 1981:26).

Parents need information and understanding to empower them to tackle handicap related problems in a positive way. Turner et al., (1986) confirm this and describe how uncertainty about the child's abilities can create disciplining problems and undermine parenting confidence and satisfaction. Often this uncertainty caused chronic conflict between parents. Those who employed positive strategies to get more information and understanding through books and open discussions were able to adapt better to the parenting demands.

Some parents tend to be over-committed to the task of parenting the handicapped child, even to make martyrs of themselves for the sake of the child (Turk, 1991), while others find a new sense of fulfilment and direction through their involvement with the child (Farran et al., Schell, 1981)

She further crystalized ideas about my career . . . . She has motivated my wife and me to focus more sharply on our intentions about how we will contribute to our community (Schell, 1981:27).

### 8.4. STRATEGIES TO MANAGE THE SUPPORT SYSTEMS

when special education services increase, so do our responsibilities. . . . parents of handicapped children must become assertive, even obnoxious advocates for their children. Well we qualify. For Glen to reach his maximum potential in growth and development, close monitoring, open communication, and persistence are required of us. (Farran et al.:157)

High and/or unrealistic expectations of the educational support system sometimes cause reactions of disappointment, loss of confidence, anger and despair which lead to managing strategies characterised by passivity, distrust or aggressiveness (Cordera, 1988; Farran et al.; Turk, 1991;)

In their research review on parent involvement in handicapped children's early education programme projects Turnbull et al. (1984) found that involvement was the greatest in the more passive activities. Their choice of managing strategies should however be seen against the broader

background of parental abilities and motivation, school policy and practice and their personal need hierarchy.

## 9. CONCLUSION

In the previous sections the basic need of parents to manage the impact of a handicapped child in the family is portrayed. The characteristics of the situation that needs managing is discussed with special focus on the handicap, the family and the persons involved as well as the available support systems. A closer look is taken at the characteristics of the process of managing involving parental motivation, aims and attitudes as well as the nature of the required managing skills and the nature of parental capacity to apply these skills. To be able to manage parents need information, support and managing strategies.

What became clear throughout these discussions is that these different facets of the basic need overlap, intermingle and interact continually. In the literature various models have been introduced to organise and describe the interaction and interdependence of all the factors that have a bearing on parental need perspectives showing that there are definite causal links between the resources and the needs.

The most salient parental needs that emerged from this literature study are the need for support, information, professional sensitivity to individual needs and for respect and empowerment.

## CHAPTER V

### METHODOLOGY : CHOICES AND PROCEDURES

#### 1. THE CHOICE OF A RESEARCH METHOD

##### 1.1. INTRODUCTION

According to Burgess (1984) the shape, substance and style of educational research have undergone considerable change in the last ten years. He therefore stressed the importance of giving not only more detailed accounts of research procedures but also paying attention to the basic assumptions of researchers and their epistemological and theoretical concerns. As the process of research (in contrast to the product) is becoming more important the role of the researcher and the relation between research and researcher need also to be looked at. The importance of selecting a research design based on the goals of the research is stressed.

We must first understand our problem, and decide what questions we are asking, then select the mode of disciplined inquiry most appropriate to those questions (Shulman, 1988:15).

In deciding which way of disciplined inquiry is most appropriate there are choices to be considered. These choices have been presented as dichotomies, but in research practice, they resemble a sliding scale with a combination of various choices possible and a strength of focus oscillating between the two extremes.

##### 1.2. POINT OF DEPARTURE

The first choice will be between inductive or deductive methods of research. This study is conducted inductively. The point of departure is the collection of data without preconceived hypotheses; then allowing the data to lead on to the discovery of theories and hypotheses in the process of its collection. It is important to start the investigation with a

general question and from the initial information gradually develop theories/hypotheses that is grounded in the data. This should be followed by a further collection of information that will substantiate or disconfirm the theory. At this stage deduction and verification play an important role (Strauss, 1987).

My stance is that an inductive approach will suit the requirements of this specific study for the following reasons: this particular research field is mainly untapped in South Africa and therefore few guidelines exist for the choice and formulation of a specific research question. Under these circumstances one could easily base the research on inaccurate assumptions or choose a research question which might not be of intrinsic relevance to the needs of the parents of this study. I thus decided that the point of departure should rather be an open general question which leads to an exploratory inductive study. This approach could yield valuable indications for future research. Summers et al., (1990) emphasise the value of inductive research which could generate hypotheses for subsequent quantitative research.

Inductive research methods yield information on a wider field and can vary significantly on the level and depth of sharing. In the light of my position as teacher at the school, I felt that inductive research would be of more intrinsic value to me and the parents concerned. Researchers in this field emphasise the importance of using research methods which enable parents to share their perspectives of family needs rather than make assumptions about needs and services. They state that:

Unfortunately, policymakers and interventionists have often designed policies and intervention programs without getting parental views (Able-Boone et al., 1990:101)

### 1.3. THE CRITERIA FOR THE TYPE OF DATA COLLECTED

The choice of an inductive point of departure determined the choice that qualitative data was to be collected. The relevance of this choice is emphasised in the following discussion.

The assumptions basic to a choice of quantitative data is that objective, countable, measurable data exist apart from the

feelings or thoughts of people and that reality can be subdivided into stable measurable identifiable and isolated units or variables (Stainback and Stainback, 1984). According to these authors special education research has so far been dominated by this type of positivism.

Qualitative data collection is described as a concentration on holistic, subjective, difficult-to-measure-data, which exists within the minds of people. The meaning people give to events, behaviour, interaction is more important than the behaviour itself. Observable behaviour or objects may have different meanings to different people or in different contexts. In any situation there are potentially multiple realities, based on participants' perceptions. The changing, dynamic, nature of these realities is relevant and makes ongoing research imperative. Research which concentrates more on human beings as meaning makers is called interpretivistic research (Jacob, 1990:199; Stainback et al.:1984)).

In special education the use of qualitative data has special significance as disjunctions between meanings of the various participants in educational settings can lead to problems. Qualitative research results illustrate how conflict between parents' and teachers' views and goals can hinder teacher effectiveness (Erting, 1985 Jacob. 1990).

According to Hanline and Hanson (1986) research in early childhood special education should centre around the family and be able to reflect the unique needs and strengths of each family unit. Odum and Shuster (1986) point out that these changes have accentuated problems inherent to the traditional positivistic research methods in assessing matters like family functioning, family interactions and family belief and value systems. The need for alternative research designs and methods has become apparent and an interpretivistic approach to research seems to offer an appropriate alternative in this particular area.

The above is especially applicable to the concept of needs. Although family needs could be very basic in terms of the lower steps of Maslow's hierarchy and easily quantifiable they could also be variegated, rich and abstract with many dimensions which are impossible to capture in any

investigation. Qualitative data may bring one nearer to an understanding of some of these needs especially as the aim of this study was to obtain more insight into the needs of the parents/family. The needs concept is embedded in the context in which it operates. It is often a case of multiple realities changing with time and with changing contexts. Flexible methods of investigation are thus required to capture some of the complexities of the needs reality.

The ecosystem and family systems viewpoint adopted in this study made the context and meaning of behaviour important and put a special focus on the interaction between the various systems. This made it difficult or impossible to look at measurable quantifiable variables particularly within the limitations of such a small study. Qualitative data could at least provide a more overall picture with emerging themes highlighting significant areas for more detailed study. The generalisability of the findings to other settings or subjects could however, be questioned.

All settings and subjects are similar while retaining their uniqueness. This means that qualitative researchers can study general social processes in any single setting or through any single subject. They hope to observe and understand these general processes as they occur under specific circumstances (Bogdan and Taylor 1975:12).

#### 1.4. THE GATHERING OF THE DATA

Naturalistic procedures create opportunities for parents to share insights overlooked by traditional measures (Odum et al., 1986 :80).

Qualitative research data are collected as far as possible in a naturalistic manner, studying the phenomenon in its natural context and environment. Variables that naturally influence the data are seen as important and allowed to continue to operate without interference (Jacobs, 1880; Stainback et al., 1984). Bronfenbrenner (1976 and 1977) talks about the natural experiment and emphasises the importance of "maximising one's sensitivity to phenomena through the juxtaposition of contrasts" (Bronfenbrenner, 1976:6).

Keeping these principles in mind one has to decide on the choice and method of data gathering. The smallness and nature

of my study precludes any rigid sampling procedures and the method of "purposive sampling" as advocated by Lincoln and Guba (1985) seems to be appropriate for this particular study and an inevitable consequence of the choice to start inductively. Through subsequent constant comparison "confronting similarities, differences, and degrees of consistency of meaning" (Strauss, 1987:25) one progressively focuses on emerging key issues (Millar, 1983).

According to Odum et al. (1986) participant observation and interviewing are the two primary ways of gathering data in naturalistic inquiry. The type of data gathered in this way can be: extensive notes made during participant observation, recorded statements i.e. transcriptions of interviews; recollected statements from unrecorded conversations often being a natural follow up of the interview; observations made during interviews; observations of the setting; relevant documents i.e. reports, minutes of meetings.

#### 1.4.1. Interviewing

According to Odum et al. (1986) the purpose of the interview is to obtain information that is not available from observation. The assessment of family needs fall mainly into this category.

In depth interviewing formed the main thrust of my data-collection procedures as this method has more possibilities to investigate various need perceptions. (Bailey, 1987; Winton et al., 1981; Winton, 1986). The specific type of interview technique suitable for this study, is a combined open-ended and focused interviewing technique (Able-Boone et al., 1990; Bogdan and Biklen, 1982).

Guiding questions helped ensure that all families had similar opportunities to share information. This type of interviewing was used because certain types of information was desired from all parents but the particular phrasing and order of the questions varied in order to fit the characteristics of the individual families (Able-Boone et al., 1990:101).

This flexible ethnographic interview technique was found effective in gaining parental perceptions and enabling family interventionists to get a better understanding of both parents and their abilities to cope. A set of service goals was generated that differed substantially from those hypothesised

by the professionals prior to the interviews. Parents liked the openness and felt they could state their case without preconceived ideas about their needs (Winton et al., 1990). A parent expressed the effectiveness of these informal interview procedures.

It may not come out as, "I need this," or "I need that". It may come out like "I didn't get any sleep last night" (Summers et al., 1990:87).

In this study parents of handicapped pre-schooler as well as staff members of the school were interviewed. In some cases I made use of the "elite interview" as described by Marshall and Rossman (1989). Elites are considered to be the influential, well informed people in an organisation and they are selected for interviews on the basis of their special knowledge of the organisation, its policies, past histories and future plans.

#### 1.4.2. Participant Observation

The purpose of participant observation is described as "allowing the investigator to enter the lives of persons being studied as fully and naturally as possible" (Edgerton, 1985:498). I was to some extent in the position of participant observer, having been part of the school setting and having had numerous occasions for informal discussions with parents, discussions where explicit and implicit needs emerged in a natural way. I had opportunities for informal home visits where I saw the family functioning in their normal home setting and could observe interactions within the broader family - unfortunately mostly without the father being present. On the other hand I was part of the setting as part of the school establishment which immediately changed the setting in various ways- depending on the perspective of the parent- the most usual reaction was that it was a special occasion when a teacher came for a visit.

Although these informal occasions of observing and studying the parents were not intended as part of the formal data collection this definitely played a role both in the process of data collection and in the interpretation of the results.

#### 1.4.3. Open-ended questionnaire

A third research method used was an open-ended questionnaire. According to Blase (1986) a questionnaire can be a useful personal document in qualitative research addressing subjective perceptions when the research participant controls the wording of the answers. A questionnaire of this type can be an ideal supplementary source of information yielding additional information in a less time consuming way through a method where the effect of my position as teacher was less pronounced.

#### 1.4.4. Other relevant data

As teacher at the school I had access to and knowledge of background data on the parents and the children. This knowledge was inevitably used in the processes of data gathering and processing. Further relevant data used were the minutes of a contact group meeting and of a meeting of the Heads of Departments.

### 1.5. THE PROCESSING OF THE DATA

The type of data gathered will determine the ways of processing the data. In the case of naturalistic data as described above, statistical procedures are precluded. However, there are various ways in which naturalistic data could be processed alternating between content analysis and the search for grounded theory. In the case of grounded theory emphasis falls on studying the nature of relationships between emerging themes and placing them in a broader context. The process of data analysis thus entails the conceptualisation, categorisation and contextualisation of data rather than summarising results. In the process the researcher's cognitive background inevitably plays a role and this had to be taken into consideration. Methods used to enhance this process are constant questioning of the relevance, meaning and context of data; constant comparison of the data within the study and within broader contexts; the gradual development of hypotheses; testing and grounding of the hypotheses against the data; eventual development of a theory grounded in the data (Strauss and Corbin, 1990; Parker and Gehrke, 1986).

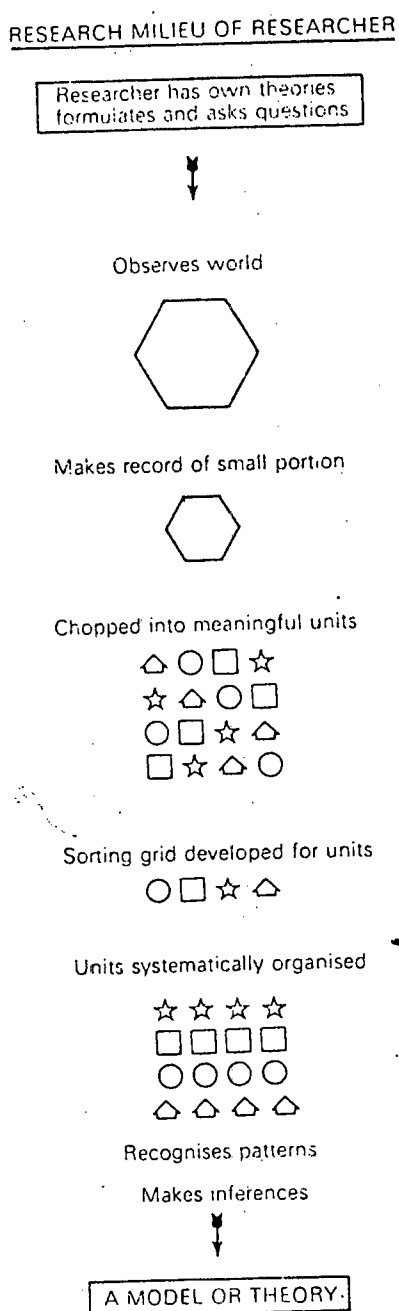
The first step is to analyse the contents of interviews in search for concepts.

"Conceptualizing our data becomes the first step in analysis. By breaking down and conceptualizing we mean taking apart an observation, a sentence, a paragraph, and giving each discrete incident, idea or event a name, something that stand for or represents a phenomenon. (Strauss et al., 1990:63)

Concepts tend to fall into groups indicating the existence of certain phenomena. This process is called categorisation. At this stage the categories are still provisional as further data could force reorganisation. These categories are then developed in terms of their characteristics. However, characteristics have dimensions varying in the way in which they appear in each particular context. For instance in this study a need could be intense or mild, child or parent directed and more intense at the beginning of the trajectory than at a later stage. The dimensions of a need could vary for each parent and in each particular incident.

The next step is to put the data back together in new ways by making connections between the categories and between categories and their sub-categories (See Figure 9). This process is called axial coding. A model or coding paradigm is used, involving conditions, context, action/interactional strategies and consequences.

FIGURE 9 (FLEET AND CAMBOURNE, 1989:9)



*Figure .* A schematic representation of the model-building process using a naturalistic research orientation

The context is the specific set of characteristics that pertain to a phenomenon- in other words the dimensional picture of the phenomenon or category as it appears in a specific incident. A young mother who brings her child for an assessment to the school will have a strong need for reassurance at that particular stage because of her own insecurity in a situation that she perceives as threatening. There are, however, intervening conditions which might facilitate or constrain the strategies taken within a specific context. These are the structural conditions bearing on the action/interactional strategies that pertain to a phenomenon. In the case of the mother cited above, the lack of information about the school caused ambivalence in the mother about her daughter's school placement. Added to this was the inexperience of the professional dealing with her. These circumstances impeded strategies she could have taken to get the reassurance she needed. The consequence of the resultant inaction was acute unhappiness and a strengthening of her self doubts. At a later stage in a different context this same mother was able to manage her need for reassurance in a positive way with better results. The investigation of intervening circumstances and their effect on the outcome is thus imperative. The complexity of these procedures reflect the complexity of the data and their relationships.

In developing a grounded theory we are trying to capture as much of the complexity and movement in the real world that is possible, while knowing we are never able to grasp all of it . . . The discovery and specification of differences among and within categories as well as similarities, is crucially important and at the heart of grounded theory (Strauss et al., 1990:111).

The process of constant comparison as described above includes a constant moving between inductive and deductive thinking. There is a "constant interplay between proposing and checking. This back and forth movement is what makes our theory grounded" (Strauss et al., 1990:111) These concepts and relationships arrived at through deductive thinking have to be verified against actual data. This process leads to further refinements of the initial hypotheses.

The last stage of the analysis entails the selecting of a core category, relating it to other categories and validating

those relationships. The process of selecting a core category basically follows the same steps as in axial coding but needs a more abstract level of analysis. The method Strauss et al. (1990) advise, is to write the basic story of the research data. This story helps to indicate, the centrality of the core category and indicate the relationship of other main categories to this core. Again this process has to be thoroughly validated against the data. Throughout the process it was necessary to place the data against the temporal and ecological background.

This theory could either be substantive or general depending on the setting(s) studied. There is no clear demarcation possible between the gathering and processing of data as the two processes are in constant interplay. In the process of the analysis of initial results and the development of provisional hypotheses, questions will arise which will determine the choice of subsequent data gathered. New data may confirm, limit or disprove the hypotheses. According to Strauss et al. (1990) this process could go on up to the final publication of results.

The aims of my research indicated strongly that the methodology of grounded theorists as expounded by Glaser, Strauss and associates (Glaser et al., 1967; Strauss, 1987; Strauss et al., 1990) would be the most appropriate choice. Practical considerations i.e the extensive claims on time and especially expertise made this a difficult choice to follow consistently. The final choice was a compromise between content analysis and grounded theory eventually leaning heavily towards the grounded theory alternative. However, the search for perceptions rather than facts, forced the research into the direction of broader conceptualisation. The interconnectedness of the emerging categories made it imperative to use a model which could accommodate the interplay and causal effects of the relevant categories. The exploratory aim of the study as well as the desire to get a global overview of the need structure were thus better served by the results obtained through a grounded theory study.

## 1.6. THE ROLE OF THE RESEARCHER IN THE INVESTIGATION

Investigating from an outside or an inside perspective is another basic choice for the researcher (Stainback et al., 1984). From the insider perspective the researcher is part of the setting, achieving first hand experiences from the procedures or activities she is investigating and in this way striving to get meaningful data. The process of investigation is as important as the results and the influence of the researcher on the process is a meaningful part of the investigation (Stainback et al., 1984). Bronfenbrenner (1976) talks about the principle of reciprocity which has special significance for educational research.

As a teacher I was inside the school setting and played an active part in the home/school relationship. Interviewing parents was in a way a natural extension of pre-primary teaching activities and the research process was part of a reciprocal educational process not only providing valuable feedback on teacher practice but also having the potential to change the teacher and the setting to some extent (Kincheloe, 1992).

However, serious problems were also inherent in the position of research from the inside as familiarity with a setting can cause blinded vision which can impede research processes or if sensitive matter is discussed it might place the interviewer in a difficult ethical position.

In matters of ethics, then, the researchers must counterbalance the multiple responsibilities they have to their profession, the pursuit of knowledge, the society, their subjects, and ultimately themselves. Each researcher must define what is ethical (Bogdan et al., 1975:29).

Circumstances inherent in the plural position of researcher and teacher which should be acknowledged were: an interest by a teacher in parental needs was an influential statement; in depth interviewing initiated processes in both interviewer and interviewees; existing relationships could have enhanced or impeded the process; the official relationship inevitably implicated a specific need context and placed a restriction on the type of data discussed. Merton (1968) emphasises the tendency of informants to make certain private views known to a disinterested outside observer - views which

would not be expressed were it thought that they would get back to management. Odum et al. (1986) discuss the importance of developing rapport with key informants and the dangers inherent in the situation of close involvement as the observer. In most cases I felt that my position as teacher helped establish an easy rapport with the parents but definitely influenced the events.

Special precautions are needed to make sure that these factors are taken into consideration. An awareness of the impact these factors can have is essential in the analysis of results. To a certain extent the research processes followed with a grounded theory analysis concentrate on procedures which sensitise the researcher to factors which might influence the research and analytical process. The procedure of constant comparison enables researchers to place these factors in context and to counteract subjectivity by forcing them back to the data to ground the theory. Methods for the triangulation of data provide further safeguards as discussed in the next section.

### 1.7. RELIABILITY AND VALIDITY OF RESEARCH RESULTS

According to Stainback et al (1984) researchers using quantitative research strategies focus more on achieving reliability. The data must be stable and consistent and research results should be replicable. Validity in terms of the interpretivistic focus relies more on the true understanding of the meanings of behaviours to the participants than on correctly measuring the behaviours (Jacob, 1990; Kincheloe, 1992). Thus the results of qualitative research strategies must give a true, full picture of what the researcher is attempting to investigate and the data must be "real", "rich" and "deep" (Stainback et al., 1984). Bronfenbrenner defined ecological validity as

the extent to which the environment experienced by the subjects in a scientific investigation has the properties it is supposed or assumed to have by the investigator (Bronfenbrenner, 1977:516).

In this definition the relevant features of the environment include the objective and the subjective properties

of the environment as perceived by the research subject. In the light of the argument thus far it is clear that my focus in this study was a search for validity rather than reliability in the traditional sense of replicable results. The focus on more qualitative methods should render results that are "real" and should give indications of the depth of the needs existing within the parent community. To ensure further trustworthiness multiple source data could be used as a measure for the triangulation of the conclusions (Brotherson and Goldstein, 1992; Minke et al., 1993; Odum et al. 1986). In this study parent questionnaires were used to complement the parent interviews. With this method of data gathering the impact of the teacher/researcher effect should be less pronounced. Staff interviews were used to provide contextual background and insight and to further counteract researcher subjectivity.

## **2. THE RESEARCH PROCESS**

### **2.1. THE SETTING AND THE RESEARCHER**

The research was conducted in the pre-primary section of a special school (renamed AP) between October 1989 and June 1992. It is a state-aided school for pupils with neurological or learning disorders subsidised by the Cerebral Palsied Association and provides education from pre-school level to matric. The main language is English but there are a few Afrikaans classes. During the time of the study only white pupils attended the school. This is in the process of changing. The number of pupils in the school vary between 320- 340 and the nursery section had between 40 and 45 pupils divided between 5 or 6 classes with 6- 10 pupils each.

The staff of the school includes administrative staff; teachers and their assistants; three medical doctors doing sessions; a full time nursing sister; three educational psychologists and physio-, speech- and occupational therapists. A bus service transports children to and from the school to fixed points near their homes. (Personal communication from principal, 1991).

The parents come from different socio-economic levels and are spread over a vast geographical area. Most of them make use of the bus system but during the early stages children are often lifted by parents. A relatively recent development at the school is the constitution of a parent-teacher association (PTA). Their main task is fundraising but they also organise area contact groups. The aim of these groups is to bring parents who live in the same area into contact with each other for practical and emotional support purposes. Although the groups were very successful in some areas, most of them were not functioning actively.

The following channels are available for contact between home and school. Initial contact is through the psychologists who arrange a pre-admission assessment at the school and discuss results with parents. After admission the pre-school teacher is usually the main link through her frequent informal contact with the parent. Formal contact channels are bi-annual written reports coffee-mornings where psychologists, therapists and teachers are available for discussion. On the request of staff or parents a team meeting could be held with the parents to discuss specific problems. An open door system invites parents to come to the school and discuss matters whenever they feel concerned. Parents transporting their children often drop in and use the opportunity for informal discussions and/or forming relationships. Staff members, especially teachers and speech therapists make extensive use of message books for regular or occasional messages. Some prefer intermittent phone calls or home visits. Parents can make phone calls to psychologists, the resident nurse and the administrative staff when available. Phone calls to teachers and therapist could be made during break time but in practice this seldom worked out. Some staff members provide their home numbers to parents and allow/encourage them to phone. Reports and meetings are obligatory activities for the school staff but other communication methods depend on parent/staff initiative.

My own position in the setting was that of a pre-school teacher with several years experience at the school, representative on the PTA committee and active in the organisation of and liaising with parent contact groups.

## 2.2. THE PROCESS OF DATA GATHERING

Qualitative research cannot be neatly fitted into well-planned phases which must be engaged in from the inception of the study to its final publication, since every step is typically executed side by side with the next one . . . The researcher does not follow refined and standardised rules but decides what to do next as problems in the field arise (Schurink and Schurink, 1988: 34).

### 2.2.1. The pilot study

The aim was to explore the possibilities for data-gathering through a focused interview procedure with the parents of five children from my class. I had to assess the suitability of this method, the interview format and my role. This also enabled me to sort out problems around data recording, transcribing and analysing. I also received an indication of emerging themes and categories to provide guidelines for further research.

The sampling of families for the pilot study was dictated by practical considerations. I took families from my own class as I had rapport with them, had been on home visits and knew the children well. The final choice was dictated by the availability of the parents for the interviews. These were conducted between October and December 1989 and lasted 45 to 90 minutes.

The following procedures were used. Appointments were made for interviews, the aim of the research explained and cooperation asked. I requested both parents to be present if possible. The interviews were held in the natural environment of their home where it was convenient and they could feel at ease. At the start I explained the context of the research, asked leave to audiotape the interview and reassured them on issues of confidentiality (See Appendix A).

The format of the interviews was focused as I asked some general open-ended questions. The aim of the questions was to lead them to give a more general picture of the impact of the handicapped child on their daily lives and not to concentrate on needs, especially school related needs, only. The general tendency in S.A to confine the role of schools to their educational task and my close association with the school necessitated an interview format which made my interest in a

broader needs spectrum clear and counteracted the tendency for verbalised needs to be too situation bound. The generality made the interviews longer, less focused and difficult to analyse but I felt it was necessary to obtain a picture of the whole family instead of a single focus on the handicapped child. McConachie (1986) stresses the value of minute details in the study of families of handicapped children. More insight was made possible into the impact of the handicapped child on family relationships, functioning and life cycle and I obtained feedback on family needs and strengths from a broader and a more specific school related perspective.

The Processing and analysis of the interview-data were done by listening repeatedly to each audiotape shortly after the interview and making short summaries of the emerging themes. The first half of each interview was then transcribed and the rest summarised in detail - focusing on theme contents and fully transcribing significant replies. I proceeded to analyse the transcripts, looking for themes and emerging categories. This enabled me to make a more in-depth need summary which gave a clearer idea of the emerging need categories. The data obtained were so rich and relevant that I decided to use them in the main study.

Important guidelines for the main study were indicated, showing me that I was on the right track with my aims and methods. The interviews produced "real" "rich" and "deep" data pertinent to the subject. Parents cooperated well. However, a shorter interview format was indicated. The initial questions took too much time to the detriment of more specific questions about needs. The use of the tape recorder did not seem to cause major problems.

My position as teacher gave me easy access to the homes of the families. Minimum time was necessary for preliminary questions. I was sensitive to the teacher intimidation factor but nevertheless felt that parents were comfortable enough to voice their opinions. However, the data should be qualified "as collected by a teacher". Keeping to the intended purpose of the interview with the teacher restricting herself to the role of researcher proved to be more difficult. Parents, especially fathers clearly had a need for prolonged and uninterrupted time

with a teacher to discuss their child. It became clear that it would be very unnatural to restrict the occasion to the purposes of the interview and I had to make compromises. An interesting side effect was a change in the relationship with these parents, mainly because parents had a chance to speak out and I had a chance to listen. Fathers' participation was especially fruitful as their perspectives are seldom heard.

### 2.2.2. The main study

The data collection for the main study involved three basic processes namely parent interviews, staff interviews and the employment of an open-ended questionnaire. Parent interviews formed the bulk of the research while the staff interviews and the questionnaire were employed for sensitising and triangulation purposes. Nine parent interviews took place over a period of 16 months from August 1990 to November 1991 and the audiotaped interview time ranged from 40 - 90 minutes.

Guided by the experience of the pilot study, I confined the choice of parents for the interviews to those of children in my class. The search for counterexamples and practical reasons determined further choices e.g. parents' invitations or responses to the questionnaire which indicated these parents' preference for verbal discussions.

The same basic interview format, with minor changes was used. (See Appendix B). In two cases the interview format changed radically, due to the parents' desire to discuss sensitive needs. However, these conversations flowed naturally, covering the desired ground without questioning. Parts of these interviews were not audiotaped due to the sensitivity of the contents.

Six of the nine tapes were fully transcribed. Gradually as the themes became clearer and according to the method of purposive sampling full transcription was unnecessary. Repeated listening and careful study enabled me to summarise the contents and transcribe only relevant sections.

Initial attempts at content analysis failed because the emerging themes were so interwoven. Eventually I was forced back to grounded theory methodology as expounded by Strauss et al. (1990). They used a model which could accommodate the data

to a greater extent and embed it in a broader framework. The nine new interviews as well as the initial five interviews from the pilot study were then analysed according to the procedure explained in 1.5.

The first step was reperusal of interview contents. Three interviews were sampled on the grounds of their context, especially in the light of the process of constant comparison. The contents of these interviews were analysed in a search for concepts. These concepts easily fell into groups indicating the existence of categories. Through the selective analysis of other interviews searching for examples and counter examples these provisional categories were tested and reorganised where necessary. At this stage the main categories and their sub-categories were selected, leading to the process of axial coding. Conditions, context, action/interactional strategies and consequences could now be sorted out with the help of further purposive sampling of data or in some cases going back to the parents to check perceptions.

The selection of a core category was now relatively easy with the help of the story writing technique. In this particular study the handicap trajectory and the family life cycle were relevant. It was also imperative to see the data against the ecological background i.e. the school; the larger family; the social environment; and the state provision for handicapped children.

As a method of triangulation I employed an open-ended parent questionnaire. This questionnaire was sent out in October 1991 to all the parents who had children in the pre-primary section. Forty-six questionnaires with an accompanying letter and a stamped self-addressed envelope with my home address were sent out. Copies of the questionnaire, the accompanying letter and two subsequent reminders are in Appendix C.

Twenty-three questionnaires were returned, one without any comment at all. Only a few parents made use of the post and of the option of anonymity. Many of the questionnaires were returned by hand at school. In six cases parents commented on their inability or reluctance to complete the questionnaire leading to five of the interviews.

Most of the returned questionnaires were filled in meticulously, using more than the provided space. Some parents included their telephone numbers and invited further discussion.

The replies to the questionnaires were analysed for content, using key words as guidelines and sorted according to themes. These themes were classified into broader categories or need concepts.

During 1991 and the 2nd term of 1992 I conducted interviews with the following staff members: 6 pre-school teachers, 5 psychologists, 5 therapists, a medical doctor, the resident nurse and two administrative heads. These numbers include the heads of department of the pre-school, psychology and occupational therapy department.

Two interview formats were used i.e. a focused interview format asking staff members for their perceptions of general and school related needs of pre-school parents. They were also asked to sketch their role in meeting these needs and how they thought parents could help themselves (Appendix D). The second format was added to the first and could fall into the category of "elite interviewing" (Marshall et al., 1989 :94). This part of the interview I used for Heads of Departments and the Administrative Heads of the School. In this section more general questions about the school's or the section's function, their policy and problems in relation to parents' needs were asked (Appendix E).

These interviews lasted from 20- 90 minutes. The first few were transcribed fully and the rest partly transcribed and/or summarised. They were meant to provide a different perspective on the needs of the parents and as a means of triangulating the information obtained from the parent interviews. Their purpose was to provide me with a broader insight into the needs of parents as seen by other staff members working with the same population. They also acted as a safeguard against too much subjectivity from my side. The questions on the role of staff members and/or elite in meeting the needs of the parents did not apply directly to the research question of identifying parental needs. Their purpose was to provide the ecological context in which these needs should be

seen. It was hoped that the understanding of attitudes and problems existing in the school system, and governing the process by which these needs were being met or not being met, would clarify the existence and satisfaction of these needs.

As the general purpose of the staff interviews was for providing background I did not analyse them in detail. The perceived parental needs mentioned by staff members were listed and then classified according to core words. However, these interviews also played a significant role in the analysis of the parent interviews as they were used in the process of selective sampling and constant comparison. When parents commented on a certain aspect of the school service this was checked against the circumstances and attitudes of relevant staff members through their interview protocols. This provided excellent contextual data and helped in the process of interpreting data in systems rather than personal terms.

### **3. CONCLUDING REMARKS**

The use of inductive, qualitative methods of research was new to me and proved to be a challenging task. However, the richness and depth of the research material and especially the wealth of insights provided by it, made this a worthwhile venture. I am convinced that this is a fruitful way of exploring special educational practices. This form of abstract categorisation and contextualisation of the results make it possible to compare these results with trends found in the literature survey.

## CHAPTER VI

### RESEARCH FINDINGS: THE NEED TO MANAGE

#### 1. INTRODUCTION

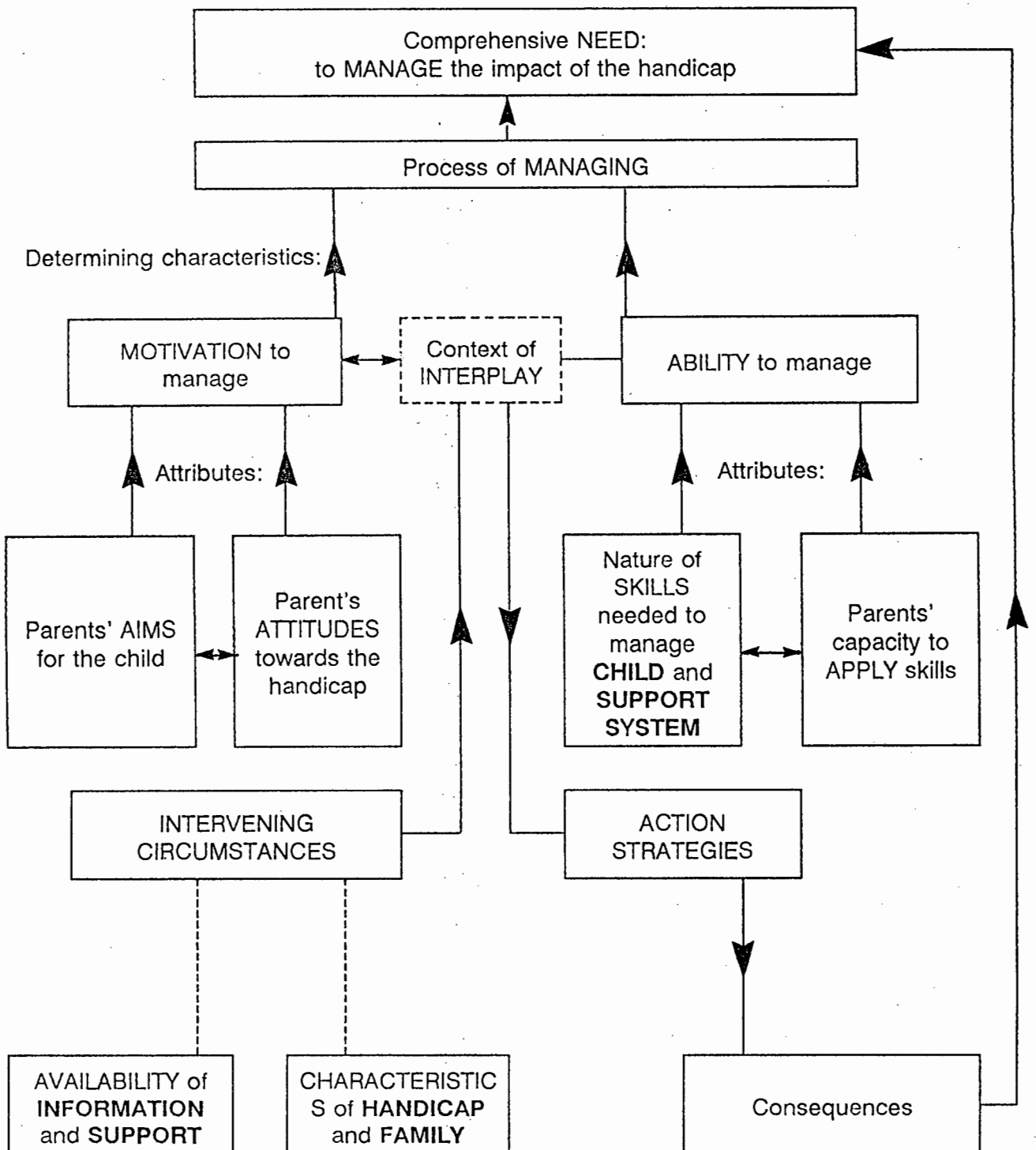
This chapter presents a qualitative analysis of the fourteen interviews conducted with parents of preschool handicapped children. In this study the parents' perception of their many needs are voiced, and needs implied or not mentioned at all. Some are not mentioned because of time and energy constraints. Some might not have been mentioned because the parents felt intimidated by a staff member interviewing them and some needs were still too vague to be articulated. Some states are not mentioned as needs but as strengths or factors for which to be thankful. Clearly they represented a section that could be named "fulfilled needs".

Needs covered a diverse field. In their classification and categorisation, some categories emerged as primary needs because of the frequency or emphasis with which they were mentioned. Main need categories were the need to know; the need for support; the need to come to terms; the need to do the best for the child. A closer analysis of these need categories indicated that they were all encompassed by the comprehensive need to manage.

Information and support enabled them to manage. The parents felt they had to come to terms with the handicap to enable them to manage themselves. Their main aim was to do their best for the child; to minimise the effect of the handicap and thus manage its trajectory and impact on their lives. The need to manage thus emerged as the core category. The task of relating it to the other categories and validate those relationships, remained.

The first step was to investigate the parents' perception of the need to manage and its dimensions i.e. intensity, direction and temporal factors. This is followed by an investigation of their perception of the process of managing in this particular context. The salient characteristics of this

Figure 10: M-Model



category emerged as the motivation to manage and the ability to manage. Motivation to manage was dependent on the nature of parental aims and attitudes. The ability to manage depended on the nature of the skills needed to manage and the parents' capacity to apply them. The interplay of these properties in the context of the study constituted the particular set of conditions within which the action/interaction strategies for managing took place.

There were intervening circumstances present in the broader structural context which either facilitated or constrained the strategies used within specific contexts. The main ones were the availability of support and information and the characteristics of the handicap and the family. Figure 10 illustrates the context and relationship of the different categories to the core category. The material is presented in the following sequence:

- \* Dimensions of the need to manage.
- \* The process of managing: Motivation to manage.
  - Parental aims
  - Parental attitudes
  - The context of the characteristics of motivation
- \* The process of managing: Ability to manage
  - The nature of the skills needed to manage child and support
  - The nature of their capacity to apply these skills
  - The context of the characteristics of the ability to manage
- \* The context of the process of managing
- \* Intervening Circumstances: Availability of information and support
- \* Intervening circumstances: The characteristic of the handicap and the family
- \* Managing strategies directed to parents, family and support
- \* Consequences
- \* Conclusions.

## 2. DIMENSIONS OF THE NEED TO MANAGE

Q1. It was not easy. Most of the time I was without help but I like to be in control-keep my finger on everything (P11m).

Q2. We all make our own decisions. . . You know you have to make judgements and if there are more people involved, it might be useful but it can also become very complex. You've got to call it a shot at some stage (P6f)..

Q3. Getting the indemnity form (*from the school*). . . I saw these paragraphs "Do you agree that it is entirely the responsibility of the school to retain her at AP till such time . . . yak yak yak' you know. Stands in there!!!" And I said: "This is absolutely outrageous. We are the ones who decide about our child, not the school" (P7f).

Q4. We need understanding of his problems, which I believe we have to a certain degree, and how to cope with it. We often do not know how to cope with him. Tell you quite honestly, we had to call a doctor to come and help before we murdered him. We just could not cope. It was so bad!. It was so bad!! (P5f).

In these quotations the words "control", "cope" and "making decisions" were used to indicate the managing need. In many instances the need was not verbalised directly but indicated strongly by the intensity of their questions, their concern and sometimes anger about impeding circumstances and their eagerness to do their best. The need to manage was expressed as something they were striving towards (Q1 and Q4), fighting for (Q3), or stated as something that was important to them and an accomplishment (Q2). Although the need to manage was comprehensive to the general needs of these families, the direction of the specific focus varied. In Q1 the mother of four small children, one of which was a hemiplegic, voiced her need to be in control of household and family. With the added burden of a handicapped child, her ability to manage was in jeopardy. In Q4 the need to manage was directed at themselves and at the behaviour of the child who had a serious handicap with related behaviour problems. In Q2 and Q3 the fathers wanted to make sure that the decision-making capacity stayed in their hands. In this study the parents mostly concentrated on managing needs related to the handicap trajectory and rarely mentioned their own or family needs directly. This may have been affected by the interviewer's position on the school staff, the common interest shared and/or because of the nature of other needs and the interview.

The intensity of the need to manage was affected by the nature and strength of the aims parents were striving toward. For these parents the consequences of not managing, ranged from not achieving their aims for the child, chaos in the household,

to disempowering by support services and loss of control over themselves with disastrous results.

The handicap trajectory as well as the progression of the family life cycle had a determining influence on the direction and intensity of the need to manage. During the interviews the influence of the temporal factor became obvious. Initially most of the parents directed this need to an intense quest for diagnostic information. Some parents described in detail their initial struggle to come to terms with the diagnosis. Problems concerning special school placement and related emotional issues indicated another period when managing efforts were intense and directed toward the child's school career and parents personal feelings.

The following analysis of research data took special cognisance of these basic elements of the need to manage starting with the process of managing. Parental motivation and ability emerged as the two most salient characteristics of the process.

### 3. MOTIVATIONS FOR THE PROCESS OF MANAGING

Q1. I often want to know whether I am doing the right thing. I do so want to do what is best for her (P4m).

Q2. Basically that you have got to make time for him and you have got to provide. Life moves around him (P12m).

Q3. Dis hoekom dit so belangrik is met altwee kinders- ons weet nie wat hulle potensiaal is nie maar ons weet wat die kinders vandag nodig het. Ek voel as mens net in staat kan wees om te voorsien wat nou die beste vir haar is (P14m).

These quotations illustrate the intensity of the parents wish to do what is best for their child; their strong motivation to manage. It also indicates the importance of parental aims as an integral part of motivation. The range and effect of these aims are discussed in 3.1. It is often difficult to distinguish between parental aims and attitudes as attitudes often shape the nature of aims chosen by parents. Parental attitudes are discussed in 3.2.

#### 3.1. PARENTAL AIMS

Q1. He can become anything. . . as long as he is happy and well-adjusted (P5). As long as she is a happy child- I cannot live

her life for her (P4m). I would like her to be happy- I mean if she can go far academically - well then fine (P6m). I just want my child to be happy where she is. As long as my child is happy and stimulated I'm satisfied (P3m).

The importance to the parents of the child's emotional well-being was clearly illustrated above. In discussing the eventual mainstreaming of his child a father remarked that they wanted her to stay in the special school as long as necessary and as long as she was happy. The predominance of this parental need was in stark contrast to the reaction of parents who stared blankly and struggled to react when asked to describe a "happy day" or "joyful occasions".

The desire for eventual mainstreaming was clearly voiced in many of the interviews. Although parents acknowledged the excellent services and the happiness of their children at AP, many used the occasion to discuss this possibility, indicating a strong desire for "normality". This sentiment was expressed from a different angle in the following quotation.

Q2. I think I would like her to have a good feeling about herself-and that she won't see herself - - - you know that she will see herself as a person- not a disabled person (P6m).

Independence was high on the list of aims and ideals. Parents were unanimous in encouraging self-help skills as early as possible. This was highlighted by the detailed reports on the early morning dressing scenes of frustration and accomplishment. A single mother commented on the importance of "giving the child her independence - to grow up - not tied to my apronstrings" (P4m).

The following quotations expressed the aims of independence; the wish for the development of potential; the juxtaposition of realism, hope, and wishful thinking and the belief that dreams can relieve the pain of unbearable truth. For some parents, future aims were risky to contemplate. Dreams, wishes or day by day survival tactics served instead.

Q3. I would like to feel that she can be - - - ? Depends on what her abilities are going to be. To exploit them as far as possible. To carry her through hopefully in that one day she is going to be self sufficient (P6f).

Q4. We would like him to be a self-sufficient, well rounded person that can basically look after himself. . . We hope he will be able to make matric. Sometimes I dream that he will be able to go to Varsity but we will never impose out ideals on him. Perhaps he might go to Bible School- that is my dream (P2m).

Q5. I always think that he will get right. And that he will be able to do what he wants to do. He will say: "I want to play rugby" and I will say "yes you will be able to". Let him think that. Let yourself also think that. But I mean you have got to think. You have got to be positive. Maybe he is going to be a lawyer, maybe he is going to be a doctor. You must be able to think. You can't say he'll never do that because he has got a problem. I think maybe. . . (P12m).

Q6. We have seen a lot of progress since he has been in your school but perhaps we had expected a bit more. Perhaps we had expected a miracle. But we worry a lot. How is he going to cope academically, socially. We do not have any ideals for him. He can become anything - motor mechanic or whatever as long as he is happy and well-adjusted. But we do not know if he will ever reach that stage. We have often thought of starting a trust for him so that somebody else can look after him if we are not there anymore (P5f).

The above statement- the cry for a cure or miracle was seldom voiced though it was implied by questions like "will she be able to walk properly one day?" (P13). In some cases it was expressed as the impossible dream as was so aptly articulated by the father of a hemiplegic:

Q7. I mean the realisation that the one thing you will never be able to do would be a fictitious person saying you know - "I'll cure your daughter right now- what will you give me " - and I know within myself, I'll have no hesitation- he can have my house, my car, he can have anything. Just to see that child walk perfectly -suddenly- and yet its not to be (P7f).

Q8. I always think that he will get better. We hope that they will be able to do more and more as they get more experienced. So that is an ideal that he is going to be - - - (P9f).

The little boy referred to in the above quotation had a serious congenital heart condition. The parents revealed that they had never been able to think far into the future because of his small chance of survival. His future health was their prime concern. For that they primarily had to depend on the advances in medical science. This was in sharp contrast to the active part the other parents wished to play to make these dreams and ideals come true. This was stressed by the following quotations.

Q9. Ons glo dis belangrik om jou kind by die beste neuroloog, beste pediater, beste skool ens. te hê. Daardie geloof is belangrik. As mens nie glo sy is by die beste plek nie sal jy nooit rus vir jou siel hê nie. . . Sy moet 'n regverdige kans in die lewe kry (P14f).

Q10. I would like to be able to fulfill her needs. To be there for her, to help her. That she could be a happy stable person - secure, happy (P4m).

Q11. It would be well if we can give her as much as we can (P6m).

The above quotations gave an insight into the way these parents saw their children's future and the role they wished to play in procuring the best options for them. Their expectations ranged from idealistic optimism to realistic pessimism, from an intense need to be instrumental in the child's future to the realisation that it was not in their hands. The types of aims mentioned, illustrated the scale of priorities in the parents value system. The time scale stretched from the immediate future through possible mainstreaming to the far removed future.

### 3.2. ATTITUDES TOWARDS THE CHILD AND HIS HANDICAP OR THE "NEED TO COME TO TERMS"

Q1. I just see her. She is normal. She's our - - - she is a normal part of our family. In some respects she is obviously of course not normal but. . . and to see your child in that environment and have to adjust to the fact that she is going to be one of them. Does she belong here? Does she really need to be here? You are feeling for that child, wondering whether she will be able to cope with it. It was just terrible. It really was. . . It was just from my side that I haven't really come to terms with it (P6m).

In this revealing quotation the mother described how the planned placement of her daughter in a special school affected and forced her to realise that she had not yet come to terms with the implications of the handicap for herself and her daughter. This highlighted the role of realistic information in the process of coming to terms because "you cannot come to terms with something you do not know" (See 6.1). Other parents related how the initial diagnosis, the school placement or the realisation that he was lagging behind other children more and more, forced them to face the fact that this child was not going to be normal - "set apart" (P2m). To others, the exposure of their child to mainstream activities like Sunday School, parties, ballet lessons etc. made them acutely aware of their children's problems and caused concern over their ability to cope (P7). It was interesting that the parents mostly chose to relate incidents of self acquired information in the context of information that forced realism on them. In one case especially, this contrasted strongly with their reaction of

disbelief and anger to realistic information given to them by professionals.

The process of coming to terms was described by the parents in various ways, highlighting the degree of activity involved, the time schedule, and the help they got along the way. In Q2 the mother attacked the process very actively describing it as something to get over as quickly as possible. She used a professional to facilitate the process, her aim being to be available to her children to do her best for them.

Q2. Ek was na 'n sielkundige - vier jaar terug en ek het vir hom gesê: "Hoor hier, ek wil dit nou verwerk. Ek moet nou die pad vat saam met my kinders". . . as die ouer dit self nog nie verwerk het nie, hoe kan daai kind sy beste potensiaal bereik. As dit by die huis - as sy ouer dit self nog moet verwerk dan gaan jy niks uitgevoer kry met die kind nie en sy ouer en die skool nie. Dan is daar geen spanwerk nie want dan het daai ouer dit nog nie verwerk nie. Jy het niks vir jou kinders te gee as jy so is nie. En jy is self 'n gestremde ouer (P14m).

In Q3 and Q4 the process was described as a more gradual but active process, stretching over a period of time with intermittent crises often triggering renewed effort to accept at a different level. Q4 and Q5 describe the initial resistance or denial experienced by these parents.

Q3. I cried for about a month after she was diagnosed. If someone looked at me I just dissolved. You know it is just a whole emotional adjustment. I started a diary at that time - thrash it out on paper. . . Maybe for me the thing was always the extra work aspect. Visualising myself in my old age pushing my child in a wheelchair and not lying on the Riviera. I think the only things that I can pinpoint really are all conflicts going on till eventually they all settle down and you come to terms with them (P6m).

Q4. . . . as you are learning the way into the situation and getting very strong recommendations . . . that she must go to special school and then realise that that is going to be on the cards. . . and I suppose inevitably if one is going to be very truthful dealing with things like snob value and the recognition that your child isn't main stream and normal but is one of them-type of thing. And O.K. you get past all that and it's no hassle now and when you get the chance you kind of give a blast of good solid propaganda for the special school- its the most amazing school you ???(P7f).

Q5. . . maar gedink dis stoutigheid. . . Dis nou net dat jy gedink het maar jy het klaar 'n probleemkind- jy wil nie nog moeite hê met jou ander een ook nie. (P8f).

Q6. Maar met haar het ons weer- dit was moeilik om weer van voor af te begin. . . ek was neuroties omdat ek reeds 'n gestremde kind gehad het (P14m).

Often there were factors impeding or enhancing this process. In Q5 and Q6 the child in question was the second and less affected handicapped child in the family. In both cases the parents found it extremely hard to accept that they had another handicapped child illustrating, the influence of familial factors on the attitude of the parents.

The interaction between the parents over the issue of acceptance, played an important role. In the above cases both the mothers reported problems in this respect, which contributed to marital conflict. In Q7 different routes parents took on the road to acceptance was positively described. Some parents consistently used the pronoun "we" in describing their state of acceptance.

Q7. I've never seen her as disabled though- totally diametric to my wife you know. People are often hampered by personalities. Maybe we are all hampered by something. . . I think that she will have to work harder in certain areas. . . I feel quite strongly that she must realise that there are certain things that she can do well and other things that she cannot do well. . . I mean it is a fact that she has a disability and she will struggle with certain things but- - - everybody struggles in certain areas-and I think it is a reasonable thing to try and teach them (P6f).

The influence of the characteristics of the handicap on this process of working through is highlighted below:

Q8. She's mild compared to other kids. She looks normal too - not obvious handicap- I don't feel embarrassed when I take her out. I rather use the word left-sided hemiplegic to describe her. C.P. sounds much worse (P11m).

At a later stage, this mother verbalised her concern over her daughter's intellectual potential. As problem areas became apparent, she realised that people treated this child differently. The younger sister started catching up and passing this little girl. She adjusted her mainstream expectations, adopting an attitude of "we will just have to see how things are going". In this case the sister's faster progress triggered the need to readjust attitudes towards the handicap.

Q9. I could take anything except them telling me that he has a low IQ (P2m). Intellectually I have never actually seen or noticed that he had much of a problem. He is deep-thoughted (P9m). wat my baie bly maak is dat sy so 'n goeie verstand het omdat- - - dit beteken daar is niks fout met haar verstand nie. Sy is ongeag van haar probleme wat sy het, is sy baie intelligent en ek dink dis 'n pluspunt vir haar. En dis iets wat vir my meer gerusstel, wat vir my by die gebrek laat kyk (P13f). there is nothing wrong with him mentally- he is just like handicapped (P12).

This cluster of quotations highlighted another way in which the characteristics of the handicap could affect the parental attitude. Intellectual impairment was hard to accept. This influenced their perception of the child's potential and the formulation of their aims. As can be seen in the case of the hemiplegic from Q5 parents often had to readjust their ideals.

An extreme case which illustrated the influence of the characteristics of the handicap on the parent's ability to "come to terms" was the case of a diplegic boy who developed normally till the age of three and then gradually started to regress.

Q10. I don't think he understands yet that he has got a problem because he was not like that from the beginning as we- - - You know I think that we accept it, that it- - - but we can't believe it. He was normal and he used to walk around and he did everything.- -So it is difficult to- - - you know. . . We just had to adapt. It is the fact that he might get worse. You don't know. His problem has not been diagnosed to a certain extent. . . What is waiting for us round the next corner. We just have got to go day for day. We can't let it change. We go along as we can (P12m).

Apart from "adjusting" as she called it, the parents had to live with the fear of what may yet come. In this case it was salient that the mother adjusted by adhering strictly to a set of dogmas she had adopted as guidelines. Throughout the interview she repeatedly said "I got to" even six times in one paragraph.

Q11. You have got to curb yourself. . . You have got to make time for him. . . You have got to be patient. . . I mean he is your child. You have got to.- You can't throw him outside and say stay there or whatever. I mean at times you get tired. I mean you have got a child who can't walk and things like that (P12m).

In this case, as in the next two, the ongoing stress of living with a severely handicapped child made it difficult to "come to terms" with the handicap and the handicapped child.

Q12. I think you just have to deal with your own problem because you have to. Either you are going to- - - - (*long silence*) just forget about it and not do anything for this child or just get on and do whatever you possibly can (P9m).

Q13. Nou party middae is ek net nie lus vir haar nie. Hier het ek dit nou gesê. Dis die waarheid. . . Partykeer dan is ek nie lus vir haar nie. Sy eet darem self en so aan, jy weet. Maar ek sal nog altyd verkies dat hul net 'n toets neem dat sy vir 'n tydjie weggaan (P13m).

In Q7 I got a strong feeling that the child was an active partner in the parents' process of "coming to terms" because she was working just as hard to overcome her handicaps. The characteristics of the child had a decisive influence on this process. Throughout the interviews the parents commented on the special nature of the child and how that had helped them.

Q14. . . how much one appreciates the other side of a child like that- whether it's story telling, or her exuberant vocabulary or in a sense to a degree its a kind of compensation (P7m). Fortunately she has got the type of personality that copes. Makes it easier for her. If she was a crabapple or something she would struggle a lot more. . . normally she has got a very sweet disposition - even at home (P6m). Nee, ek is baie trots op hom(.p8f) . . . and she'll hug and kiss, and mummy give me a hug. . You know and ag shame. She's sweet 99% of the time. That makes up for it (P4m).

A parent described how the school's attitude affected the child's and by implication the parent's attitude:

Q15. I think he accepts himself as being normal- every child at that school does because of the tender loving care they get. They feel normal. There is a unique atmosphere of acceptance at the school. Every child is so open, all happy, all content. They all know who they are. They all know they have a problem and everyone accepts the others as they are (P1f).

In Q16 as in Q2 the direct link between coming to terms or being strong for the sake of the child was stressed highlighting some parents' reason for tackling this process. No mention was made of the parents' own needs in this respect.

Q16. . . . no one else is going to take over. It is your child and if you don't show that you're strong or whatever it's got to have an impact on your child.- if they see that you are uptight , upset or whatever. . . you just have to accept the circumstances and get on with it. The easiest is actually to adapt to it because the less you accept it the more the child actually gets affected (P9m).

The results of this process of coming to terms varied with the parent's way of approach, the stage of the handicap trajectory and the parents' life cycle. In Q7 a father explained his active way of accepting his daughter's handicap, an attitude empowering him to "do his best for her." In Q17 the mother described a medical student's surprise when she interviewed them on their experience of having a handicapped child and the father described his pain and joy. Both parents gave a strong sense of control.

Q17. "Oh, what a gift. How absolutely special". . . She kind of felt an elation instead of a sense of heaviness. There was so much joy. It was so different from what she had expected (P7m).

There is a lot of pain at times recurring and moments where you just feel intensely emotional. I think, you know - that old enigma of - like making a pearl out of it (P7f).

Some other parents felt there was nothing they could do except to learn to live with the fact that their child is not normal. In a number of cases the parents advocated the "count your blessings" attitude and referred to other families where the child's handicap was more severe. Some felt that one should not concentrate on problems (P3). The level of awareness of this need "to come to terms" ranged from well-defined and discussed to not existing at all or being dealt with in very general terminology.

A father discussed men's problems in working through these processes because they don't have the easy access to occasions and people where these things were dealt with and were more reticent in dealing with emotions - often they didn't even know what their needs are. He felt that many parents have a whole series of undefined issues they have not faced about having a disabled child.

The process of "coming to terms" had varying dimensions which appeared in the context of each separate case. In some cases the process was seen as long, gradual and perhaps never-ending with intermittent crises along the way. Others saw it as a process which they had to go through and solve to empower them for the sake of their child. The process could be static at times or progressive, continuous or crisis-related. Some tackled this process actively, some even aggressively, while others waited passively for time to bring the desired result. The result could be: acceptance of this burden; the "just having to learn to live with it" attitude; not accepting; wishing it away; experiencing it as a challenge or a joy. The cases also varied from parents having an external locus of control that helped them bear this burden- often being uncritically and desperately dependent on the sources of support, to an internal locus of control - where they made their own decisions, adapted to the circumstances and use available sources of support when necessary.

### 3.3. THE CONTEXT OF THE CHARACTERISTICS OF MOTIVATION

The interplay between the aims and the attitudes of the parents formed the context of the parents' motivation to

manage. I found a definite link between the degree of realism displayed and the state of the process of coming to terms. In cases where parents found this an exceptionally difficult process, their ideals seemed to be fluctuating between pessimism and unrealistic optimism e.g. a miracle or a trust to provide for the future of the child. This fluctuation tended to dampen their motivation. In cases where parents had worked hard to achieve an equilibrium, they were more able to plan realistically for their child's future. They kept an eye on the reality of the child's development and adjusted their ideals when necessary but were strongly motivated to do whatever was best for the child. In the worst cases, the parents barely had ideals except for their wish for the child to become independent and able to look after himself. Their attitude toward the school's support system was often that they must either "fix" this child or take the child away, even if it could be "just for a short while" (P13).

The important role of the characteristics of the handicap as intervening circumstance was indicated by the fact that the parents who had serious problems in coming to terms in this study were also the parents whose children were the most seriously affected by their handicaps.

It was of prime importance to parents that their children should be happy (aim). This enhanced acceptance (attitude) and motivated parents. The role of the school in providing a happy atmosphere was a significant intervening factor. This facilitated the process of coming to terms especially in cases where parents struggled to accept special school placement. However, one mother stated that she was afraid that the child's happiness at school made her relax her efforts to monitor the child's well-being.

The interplay was significant in the case of the mainstreaming ideal which was also reflected in the problems parents had in accepting intellectual impairment. In most cases parents were able to adjust their time scale as their degree of acceptance grew. The following example of a specific context illustrates the interplay.

### 3.4. NICO

I visited the home of a diplegic for this interview. The mother seldom had a chance to talk to the staff of the special school and used this occasion to ask a number of questions. She made it clear that she just wanted to do the best for this child. Although the mother realised that this child most probably had a degenerative disease, she still hoped it would come right and "thinks positively" (Q5) that he might even become a lawyer or a doctor. This attitude restricted realistic thinking on the child's future. Perhaps in this case there was an inability to "come to terms" because the future was *too ghastly to contemplate*.

Circumstances impeding the good intention of the mother were a heavy work load; a husband who struggled to accept; the scarcity of transport and other communication facilities restricting information exchange and the undiagnosable progressive characteristics of the handicap. Her love and perception of her child and his special characteristics i.e. "very sunny, independent and full of jokes" (P12m) strengthened her motivation.

The interplay between the fairly unrealistic ideals of the mother and her inability to come to terms with this unknown condition paralysed the mother. She was unable to channel her scarce resources to tackle problems and struggled to initiate active proceedings like finding out what the physiotherapist was doing and what they expected of her. The impression she gave was of a mother who wanted to do far more for her child but found it very hard to actually do anything. Her admiration for the school's work encouraged the handing over of responsibility because "he is in such good hands at school. They are doing the best they can" (P12m). Consequently the mother seldom took action, the inaction disempowered her more and added to her already heavy burden.

### 4. "I WOULD LIKE TO BE ABLE TO"

"I should jolly well be able to" (P7f) "I would like to be able to" (P4m) "jy het niks vir jou kinders te gee as jy so is nie" (P14m).

These phrases expressed the importance of parental ability in their striving to manage the child and the handicap and indicated a difference between wanting to do something and being able to. Two significant attributes of this phenomenon of "being able", were the nature of the skills necessary to manage and the nature of the parents' capacity to apply these skills.

#### 4.1. THE NATURE OF THE SKILLS

This section looks at skills parents viewed as necessary in order to manage "if you are taking the upbringing of kids seriously" (P7f). The focus of these skills to manage were directed to managing themselves; managing the child or parenting skills; managing the support system and managing the family. Due to overlap the skills to manage themselves were discussed in 3.2 and the need for family skills is discussed in 4.2.

##### 4.1.1. Managing the child

Q1. "You just have to listen to their fears and accept". . . "I realised how very careful one has to be with a child with a disability.". . . "One has to practice the difficult concept of seeing them as human beings in their own right and respect them as you would respect any adult.". . . "Does she do that because she wants approval? - because I am a terrible approval seeker and it is such a burden." (P7m). . . "Perhaps she is just thinking about a story or something is happening in her imagination." (P7f) "You must not start projecting. She has no sustained concentration." (P7m)

Q2. I think that she will have to work harder in certain areas . . . I feel quite strongly that she must realise that there are certain things that she can do well and other things that she cannot do as well as her twin brother (P6f).

Q3. I try to be patient and tolerant but I'm not always successful. I try to be consistent. I do not want to confuse her (P4m).

In these quotations parents reflected on various aspects of their parenting and/or assessed their skills showing the importance of this parenting skill. Interaction between parents as illustrated in Q1 as well as the type of contact which promoted an awareness of the value of reflective parenting were of vital importance. It became clear that an awareness of the skills needed for parenting played a central role with some parents while in others these needs were fairly dormant and/or overshadowed by the demands of daily living.

Q4. You have to be patient and let him do things on his own. . . . You are always worried that something is going to happen to him and you are not there to help him but you have also not got to show him neither. Because you can't pity him (P12m).

Q5. I still helped him to get dressed then I realised it was time I stopped doing this. . . . Perhaps it is just that mum is expecting too much (P9m).

Q6. Well obviously there is a lot of bolstering so I sometimes think there is a slight danger that maybe we can overprotect and you can praise a child so much that you can really think she is a ??? in a particular area. And I realise the danger . . . . Yet there is also a sense at times that- how much one appreciates the other side of a child like that (P7f).

Q7. We probably have delayed a bit longer than normal in getting the kids to dress themselves. . . . Well it would probably have been better if they did but it is such a rush in the morning. . . . It puts a strain on you. So often it is finding the thing that works best for everybody in the long run (P6f).

Q8. She frustrates me when she gives up easily. She stamps her feet and does not want to try. Sometimes she frustrated me when she cannot do things other children her age can do. Little things irritate me. . . . She wants to eat chips with fingers instead of with a fork. . . . I feel strong about manners. It makes me mad at times (P4m).

Q9. "But when daddy comes home of course it is the highlight! When daddy comes they drop everything (Q5a)" "He won't even stand up to kiss me. I feel that's wrong and I insist that he gets up and stands up and kisses me" (P5f).

These are examples of the special demands parents made on themselves to do what is right. There was always a struggle for balance. Extra vigilance and care were demanded but without overanxiousness; the child needed bolstering but not overprotection; the child needed encouragement to be independent but not to be pushed beyond his abilities. Sometimes it was a question of being able to adapt standards of behaviour and conduct to the needs of the handicapped child, to be enabled to survive the stress of dealing with the impact of the handicap. Q6 and Q9 illustrated the problems fairly rigid standards of behaviour could cause while Q6 expressed a more adapting viewpoint.

One mother described problems experienced in dealing with a learning disabled child who often came home in a bad mood unwilling to discuss his day at school. Parents needed balance and a good understanding to enable them to handle this situation (P10m).

Q10. His first two years were terrible. I wouldn't wish them on my worst enemy. He was a very whiny, non-sleeping, non eating

child. He was a real pain to have around. He was no pleasure. I don't think I made it any easier because the tension was a bit too much. But he was no pleasure to have around. He was not somebody that anybody would want to look after or coo with or...He had his moments of being happy but they were very short (P9m).

Q11. You know she was quite a colicky baby- and apparently it is all related to her disability and - screaming - is actually part of their condition. For her to snuggle up- she finds it difficult. . . You know she was never affectionate. It might have been something to do with her condition, partly a physical thing, not wanting to be restrained, afraid it might hurt. . . In the last year she has become so affectionate - she just wants to be hugged and loved and cuddled and that's been very warming (P6m).

Q12. They'll get up and crawl into bed with me and I will tell stories. They love stories- both of them and we have lots of books. And they'll cuddle up and I'll read. That's tremendous fun, tremendous bonding time! (P2m).

Problems of bonding are highlighted above. Some children spent their first few weeks in an incubator or needed operations within the first few days, followed by many weeks of hospitalisation. In Q11 the father related how a teacher at the school was instrumental in helping the child to overcome her tactile defensiveness and promoted bonding with the parents.

The daily tension of living with a handicapped child also took its toll. In Q12 the child in question was a "lovely baby-cooing, contented, happy". But now the mother described their daily life as often filled with "shouting and screaming", especially at times when she was worried or anxious about progress. Only during holidays she relaxed when there was no need for the "frantic" rush to catch the "departing school bus".

Q13. You sometimes feel you need assurance. Sometimes I am quite strict with her and then I always wonder whether I have done the right thing (P4m).

Q13 shows the need for assurance that was necessary for confident parenting. Parenting a handicapped child brought special demands caused by the characteristics of the handicap, the inexperience combined with inadequate information and dependence on support. This often created a lack of confidence leading to doubting parenting. Guilt feelings could accompany or aggravate the situation. As can be seen in section 5.2 the parents often reacted strongly to the real or imagined suggestion that they were not doing their parenting task properly. In Q13 a single mother articulated a request for

reassurance and guidance indicating that parents do not always feel able to manage this task. The role of the spouse in giving appraisal support was evident in positive as well as negative cases.

Q14. Ek gebruik heeltyd met hulle in die huissituasie tel of kleure ens. .... Jy weet dit is amper 'n leefwyse vir ons (P14m).

Q15. As ek hom roep (*vir spraakterapie huiswerk*) begin klagtes en dan is hy ontsteld as ons dit nie reg doen nie. Ek kan dit nie hanteer nie. Ek voel die skool verwag van my ek moet dit reg doen en ek is mos nou die ouer en verantwoordelik. . . Die ouer kan nie 'n onderwyserhouding aanneem by die huis nie. Jy is sy ma. Die kind wil nie daai rol aanvaar by die ma nie (P10m).

The teaching and/or therapeutic role the parent often had to play is outlined above. Sometimes it was a very natural interaction between the mother and the child but as shown in Q14, it can cause problems especially if the school's expectations cause tension and doubt in the mother.

#### 4.1.2 Managing the support system

Q1. . . when I put him to school and I am also worried and things like that. I mean at school he is for that but - - - You still worry if they will really know what his needs will be etc. So in a way you are all the time tuned in to his safety and his needs (P12m).

Q2. Ek gaan laai hul af bedags by die skool. Ek het my 'job' gedoen. Hul kom huistoe. Ek hoef niks te doen nie (P14f). Omdat ouers dink dis die skool se werk. Selfsugtig basies. By gewone skole is dit ook so (P14m).

Q3. Parents need to take more responsibility. . . Parents must be educated to start asking if we want schools to change. . . They hand their children over to the school and they don't like to criticise (P7m).

Q4. You know like on Thursday, standing there, . . . I couldn't say anything because -- you mean- - I didn't know exactly what they said. . . She gave a long word to me- - - you don't know (P12m).

Q5. And I thought you don't have to go in as if you are criticising her. You are coming with everything that you are - as a mother, as a movement /music therapist, as a person, as an educator and saying: "We want a change" (P7m) I sometimes worry. Am I not seen as astrid or pushy?. . . I had a wonderful chat with her because that is how I go about all my dealings. I don't want to smooth her up. I really think she had a valid question that I wanted them to ask me. . . I think if there was any threat I have opened it- you have got to realise as a parent that you dare not wander in there - but of course I know where I am safe (P7m).

Q6. Ek voel heeltemal- genoeg vrymoedigheid - miskien meer "leef" as gewone ouer. Ek dink dis ook die ouers se verantwoordelikheid om nie net te wag en te sit tot - - - ek meen jy moet van jou kant ook inisiatief neem (P14m).

These quotations emphasised problems that arise in the parents' dealings with support systems and their perception of the skills they need to manage. In Q1 the mother told of her problems in sharing responsibility of the child with the school. Parents related their problems in releasing some responsibility knowing that the child was in good hands, while other parents stressed the importance of continued parental responsibility for the child and criticised parents handing over responsibility too easily (Q2 and Q3). A father felt he could relax when he realised that things were going well. A mother described this skill as being able to trust stressing her need for informed trust not blind trust.

The sharing skill is related to and dependent on the skills of judging and assessing the services of the support system. A father stressed the importance of this as no risks should be taken with a handicapped child. A mother felt that it was important to be able to "pick up the vibes" (P11m) and assess regularly whether the child was getting the services she needed.

A recurring theme was the need for skills to communicate with professionals and to make use of available facilities. In Q2 the mother described her problems in talking to doctors and understanding all the big words. The importance of knowledge to be able to discuss the child with professionals and to make informed decisions was stressed. One father praised his wife's skill in spotting problems. Another regarded his university background as an asset. Some parents complained that professionals did not seem to be interested in parental knowledge. They needed skills to interest professionals and/or force them to listen.

Parents stressed the importance of tact, wisdom, balance and interpersonal skills e.g. the ability to: see things from different perspectives; to form open relationships; to be open and honest with professionals (Q3). The need for tenacity and courage, assertiveness and self-confidence was stressed. However, some thought that the main skill parents should develop was to walk a tight rope (Q3 and Q4) knowing how much one could ask without offending or being regarded as a busy

body and thus harming the child's prospects. Parents felt vulnerable in relation to the support system especially as they were dependent on the system for the child's well-being. In this sample the parents who managed best were strong parents with resources of their own and positive experiences behind them.

#### 4.2 THE NATURE OF THE PARENTS' CAPACITY TO APPLY THESE SKILLS

Parents sometimes had the basic skills but did not always have the capacity to apply them fully. The main factors which influenced the capacity, centred on the characteristics of the family, the support system and the attitude of the parents. The interplay of these factors resulted in a constant balancing of priorities either deliberately or through the force of circumstances. The characteristics of the family determined to a large degree the scope parents have to apply their skills. The nature of the enhancing and impeding circumstances related to characteristics of the family is discussed in 7.2. The attitude of parents as it is influenced by the process of coming to terms was discussed in 3.2. Significant in this context was the fact that parents who had come to terms had more emotional freedom to apply these skills. Temporal factors as the learning process which enabled parents to become more adept through experience, active reflection and assessment, and the influence of the family life cycle, played a determining role.

Q1. If I feel very tired and irritable I will be shouting and screaming all the time and if I feel better they will have a good day (P2m).

Q2. If I am ratty everything they do irritate me. . .And you know it is also a case of feeling sorry for yourself because you had no time to be by yourself to unwind . . . You know it is just a bad time of the year- lots of work, lots of pressure (P5m).

Q3. Hy het vir my gesê hy is 'n hotnotjie. Sy kry al die aandag en liefde (P13m).

Q4. Maar een ding as hy so aangaan, as hy daardie aandag trek, ek weet net ek het dan geen geduld met hom nie. Hy verstaan so goed. Ek kan dit amper nie insien dat hy nou so jaloers moet wees dat sussie meer aandag kry nie. As daai gedrag nou voorkom - jy kan hom nie jammer kry amper nie. Hy verstaan. Hy ken haar probleem. Eintlik moet ek miskien 'n bietjie sagter wees. Hy is seker maar nog jonk en hy is nog kind (P8m).

Q5. . . . but you see it is a lot of things because you are busy and it is not fair on the children. The problem is that on Sunday is the only time that I really have to do these things - - and I have to give my undivided attention to the job. You know there are certain things I have to do. I would like just to be with the children but there again, the job's got to be done (P5f).

Q6. It upsets me when I cannot go on an outing. She would like me to be at school like the other parents. It upsets us both. During the week-end I spend as much time as I can with her . . . but you also need time for yourself (P4m).

Q7. . . and she was still in nappies at that stage. We have tried but she just took a very, very long time. And that was another thing that I was upset about because I was trying and it wasn't working. And I was made to feel that there was something wrong with the way that I was bringing her up. Her twin brother was out of nappies. He was fine (P6m).

Q8. Dis nie net dat hulle nie verstaan nie, maar hulle dink jy is die ouer- jy weet mos nou nie eintlik iets van die onderwys af nie. . . . Daai tipe ouerbetrokkenheid wil hulle nie hê nie. Hulle wil net hê: "Ja nee, ons kom gesels net so 'n bietjie" en "nee, jou kind gaan goed aan." Met ander woorde dat hulle vir jou kan sê" jy moet so en so maak. Of jou kind moet meer lees en jy moet maar net ja en amen sê" (P10f).

Q1 & Q2 above illustrate the effect of emotional or physical drain. The constant concern for the child as well as the extra demands on time and physical energy took their toll. Q3, Q4, Q5 and Q6 illustrate the process of balancing of priorities and the role it played in the parenting of the special child. In Q3 the mother was angry about the impact of the handicap on the sibling, stating that the handicapped child was normal and should be treated as such, totally diametric to reality. In Q4 an older sister was severely emotionally handicapped and attended a school for autistic children. The mother was so drained by the demands of the sister that she had little patience left for him although she realised her expectations were too high. Other parents felt that balancing for the sake of the other children was a real but manageable issue.

Parent's need hierarchies and value systems caused internal conflicts because of the tendency to blame themselves if the children were not the main priority. The parents quoted in Q5 felt they were too houseproud, not able to let go and enjoy time with the children. In Q6 the situation of a single mother trying to fulfil her child's and her own needs, was highlighted.

The interplay between professional attitude and personal attitudes and the doubts caused by this is illustrated in Q7 and Q8. The parents in Q8 had experiences in the mainstream system which left them with the impression that their knowledge of the child was not respected and their interest resented. This experience made them hesitant and resulted in a tentative attitude toward teachers of their children, a not knowing whether "they were allowed" to be involved. This "burnt finger" attitude disempowered them to a large extent. Their own suggestion to remedy this situation was a request for clear direct instructions from the school on what was expected of parents also in terms of teaching and therapy carry over activities.

This "waiting for instructions" attitude exacerbated by professional expertise was very prevalent among parents and kept them from spontaneously applying their skills. They often expressed the need for guidance and the willingness to be led by the school. In cases where this was accompanied by a desire to be part of the team and to share responsibility parents often felt hampered and disempowered by the above mentioned lack of clear cut demarcation of the expectations. This was exacerbated by a feeling that the school often blamed parents for not taking responsibility. However some parents related positive exchanges they had with staff members and related the empowering effect of their involvement with school activities.

The issues centering around the ultimate control over the child and the parents role in decision making is discussed in 9. The role of information is further discussed in 6.1.

#### 4.3 THE CONTEXT OF THE PROPERTIES OF THE NEED "TO BE ABLE TO"

The interplay between the nature of skills and the capacity to apply them, formed the context for this need "to be able to". The parents in this study showed a wide range of ability. At one end was the young inexperienced mother still struggling to come to terms with herself and still going through post adolescent crises; totally unskilled for the task of parenting or negotiating with support systems and too preoccupied with her own problems to be able to learn. She was barely aware of the spectrum of abilities that she needed to manage. At the other end of the range was the mature mother of

Annie. She had long teaching experience and actively acquired and desired more parenting and social skills. She made herself emotionally available for the child, through deliberate exposure to experiences geared to personal growth and development. Her social skills enabled her to utilise support without releasing responsibility. In between were a range of parents still in the process of acquiring parenting skills, some were moderately skilled but so overwhelmed by the demands of their family and/or the demands of another handicapped child in the family that they often know what they want to do but are not able to do it (Q15).

In 4.4 an incident taken from the interview with Annie's parents show how the context of the interplay between the nature of the skills to manage and the capacity of the mother to implement these skills resulted in a positive managing experience.

#### 4.4 ANNIE

A hemiplegic four year old needed an operation to ease the spasticity in her leg muscle. The parents were naturally very concerned. The mother decided to do her best to make this operation a positive experience for the child, through preparing her thoroughly and thereby diminishing anxiety and introducing the child and her school friends to the hospital world. This was done through stories, play and discussions and a ring conducted by the mother at school where she demonstrated how to plaster a dolls' leg. The class was very excited about this oncoming event and the little girl was envied rather than pitied.

The mother's attitude toward this crisis was to "make a pearl out of it". In this she was bolstered by the support of her husband, family and friends, the deep love and adoration they both had for this special child, her own teaching background and her experience in nurturing this child. She was active in her search for more insight, critical in assessing her own attitude and performance and she maintained an open relationship with the child's teacher which ensured her cooperation. The interplay between all the factors above led to a strong motivation to tackle this looming crisis actively.

## 5 THE CONTEXT OF THE PROCESS OF MANAGING

The context of the need to manage represents the specific set of characteristics that pertain to this phenomenon and within which the action or interaction strategies are taken. The interplay of the characteristics determines the character and dimension of the need and the strategies necessary to manage.

When the parents have a strong motivation to do their best for their child because they have realistic aims and a positive attitude they want to take initiative and to manage. The way in which they want to manage will be determined by their skills and their capacity to apply these skills at any given time. One parent told of her eagerness to discuss her child's progress with the teacher but how a language barrier and "burnt finger" attitude made her doubt her communication skills and dampened her motivation. Real and perceived lack of skills triggered a process of negative feedback which can lead to a state of diminished motivation and thus managing capacity. Walter's case further demonstrate the reciprocal influence of attitudes, aims and abilities.

### 5.1 WALTER

Walter had a diagnosis of neurological dysfunction and behaviour problems. He had one younger brother who was not affected. The brothers previously had had bad crèche experiences and Walter's first school experience was catastrophic and caused serious regression.

The parents were extremely anxious about Walter's strange behaviour and at this stage their only aim was that he should be happy and well-adjusted. They felt pessimistic about the child's future, even thinking in terms of a trust to provide for him. Both parents seemed to find it hard to come to terms. The mother felt that the child's behaviour was a reflection on her parenting skills and this caused resentment. The parents who had natural parenting skills, took their responsibility for the upbringing very seriously but their reflective capacity was impeded by feelings of guilt and defensive attitudes. The development of their parenting skills seemed to be further hampered by their own rigidity, the child's strange reactions,

the mother's volatile temperament and the strain of other responsibilities which made her unavailable to the children. They were able to process knowledge and to form relationships with most professionals but the mother had a block against psychologists, stemming from previous bad experiences.

The context of their need to manage was a wish for a miracle coupled with serious doubts about the existence of their own and professional abilities to do anything for this child - a combination which dampened their motivation for action. Circumstances impeding their managing ability were the strange character of the handicap which made the managing of the child a daunting task, their socio-economic circumstances which affected the parent's availability and ability to interact with the school. Lack of extended family support caused by the necessity to move near the school and their history of grossly inappropriate professional support added to their difficulties in managing, as did ignorance of the child's condition and behaviour control tactics. Enhancing circumstances were the success the parents had with the upbringing of their younger child, and the good contact they had with the teacher this year.

Action strategies employed to manage the child included lovely afternoons when all helped to clean the house; shouting and screaming; fighting and bribing; reasoning and "using hand"; threatening "to pack my bags and go"; phoning a doctor to prevent them from murdering the child. An illustrative excerpt follows:

Q2. Then also rightly or wrongly we will have a story three times a week. I know I should do it more. It's just such a pleasure to get them to bed. . . And then its constant screaming and shouting and then you end up saying: "I'll pack my bags and go." I know it's very bad but the kids know me (P5m)

Their strategies for seeking help at this stage included a cry for help and guidance, combined with statements expressing futility as all help to date was experienced as inappropriate. Their inaction included failure to contact the school psychologists or other suggested sources of help. Positive actions that were taken were the attendance of school functions and telephone contact with the teacher. This enabled the mother to "let off steam" when she was angry or disheartened. The consequences of the action/interaction taken

were an ongoing struggle to manage this child with the potential for further disempowerment of the parents. On the other hand, the actions they did take in areas where they felt safe contributed to the considerable progress the child had made.

In the following two sections circumstances which can impede or enhance the strategies taken to manage are discussed.

## **6 THE AVAILABILITY OF INFORMATION AND SUPPORT**

Judging by the frequency and intensity with which the need for information and support were mentioned the parents perceived these two categories as extremely important factors in the enhancing of the managing process.

### **6.1 "THE NEED TO KNOW"**

The need for information was a prominent theme in every interview. This need was tightly interwoven with the need to give information about their child. The characteristics of this need and its fulfilment influenced strategies taken by the parents to manage. Salient characteristics were the purpose, types, sources, appropriateness and accessibility of the information.

#### **6.1.1 The purposes for which they need information**

Parents indicated that the main reasons for wanting information were to enable them manage the trajectory of the handicap, the child and themselves as the following quotations demonstrate.

Q1. I would like to feel that she can be - depends on what her abilities are going to be - to exploit them as far as possible - to carry her through, hopefully in that one day she is going to be self-sufficient. I think this is one of our reasons why we think it is so important to have an open relationship with the school. That we can discuss this as with any other school (P6f).

Q2. One measure of really caring is in the realm of practical activities and another one is actually knowing what the whole thing is about. I feel that very strongly (P7f).

Q3. We do not need theories on how the situation evolved but we basically want to know from the experts what is wrong and what can we do to remedy it (P2f).

Q4. Ek dink dis ook hoekom baie ouers nie kan aanvaar hulle kind is in 'n hoë mate gestrem nie, omdat die dokters en die terapeute nie heeltemal eerlik is met hulle nie (P14m). Ek glo jy moet eerlik wees, want hoe gouer jy eerlik is met die ouer, hoë gouer kry hy perspektief(P14f). Hoe gouer kan daai ouer dit ook verwerk (P14m).

Q5. Contact with the school has certainly been a great strength for us- like for me its been a great relief- you feel you're child is in good hands and you can relax (P6f).

Q6. I knew something was wrong but at the same time I felt he was not trying hard enough. I did not realise the full extent of his physical problems. . . Had I realised the full extent of his problems I would not have been so impatient with him (P1m).

Q7. We need understanding on how his mind works and how to distract him when he is throwing a tantrum (P5f).

A dad emphasised the effect of ignorance when they were considering the special school placement of their daughter:

Q8. . . . feeling very uncertain because of plain ignorance about the so-called negative effects of less advantaged kids than her (P7f).

### 6.1.2 Sources of information

In the interviews the doctors and physiotherapists were cited in most cases as the first and also a continuing source of information. At a later stage the professionals at the school were regarded as the main source of information. Other interesting sources of information on the children's progress and daily activities at school are demonstrated in the following quotations:

Q1. Ons weet goed wat in die klas aangaan want sy kom vertel alles- ons het nie 'n probleem daarmee nie (P13f).

Q2. I would like to know more - the physiotherapist side .Teachingwise- I can hear what he is saying and judge (P12m).

Q3. . . and she is so immensely happy at school. It is such a joy to have that school experience with a child like her. She just loves going to school.(P7m)

Q4. . . . and that's another thing - I think, sometimes just watching her walk down the passage- the fact that she is so happy. It's nice to see (P6f).

Q5. Daardie skool het darem baie vir hom beteken. Jy kan dit sien (P9f).

One parent mentioned the need to see tangible progress e.g. a hemiplegic starting to use both hands. Others mentioned how pleased they were to see progress e.g. a three year old

suddenly becoming toilet trained or friends not noticing that their diplegic child was handicapped because her walking had improved so much. Another couple felt that they got invaluable although disheartening information from observing their daughter in situations where she mixed with mainstream children.

Q6. When I take her to ballet I get used to the way she copes there. But you know, sometimes you see her at a party and I just know she is not actually coping. At Sunday School she doesn't. She kind of cannot do much. . . She just - - - Then I think we are going to have problems with her. She does not have the ability to concentrate like other children (P7m).

The need for information from the following sources was also mentioned: 1. From other parents of the school with information on stages or crises that they had already gone through. 2. A parents' library with books on parenting and more specific books on handicapped children. 3. A newsletter informing parents of interesting workshops or lectures taking place.

### 6.1.3 Types of information needed

The first need was always for a diagnosis: naming the condition, spelling out implications for the future and advising the parents how to manage it. Vivid illustrations were provided by stories of struggles to get a diagnosis in spite of doctor's reassurances to the contrary. During this process and after the diagnosis there was a need for information on sources of professional support and information about the child's intellectual potential to enable parents to decide on suitable educational facilities. Acquiring knowledge about the availability of therapists and special educational facilities seemed not to be a serious problem to most parents but there were exceptions.

Q1. . . . dis 'n baie alleen pad - - voor ons by 'n skool eers uitkom. Jy is absoluut aangewese op jouself. Niemand sê vir jou - kom gaan na die mense of daai mense nie. Jy moet soek vir terapeute (P14f).

An interplay between the search for information on facilities and their suitability and a lack of knowledge of the child's potential, played a role.

Q2. . . toe het hy (neuroloog) vir my gesê: "sit haar by normale kinders". Ons het haar ingesit maar dit was 'n geweldige frustrasie- sy het nooit 'n woord gepraat nie. Sy was verlore (P14m).

Q3. Does she belong here? Does she really need to be here? . . .  
You think now, will they drag her down? (P6m)

A special informational need related to health care was mentioned by a mother who felt mothers needed more guidance on managing high temperatures because of the special danger of convulsions.

Once the child was in the school parents needed to know what the school was doing with their child and how was he coping.

Q4. Mens weet net nie hoe om te weet wat gaan in daai klaskamer aan nie. HOE moet jy as ouer optree en wat is jou aandeel eintlik. Jy weet nie wat in die klas aangaan nie. As jy kans kon kry om 'n dag in te sit in die klas sal dit nogals vir jou 'n goeie idee gee van wat aangaan. Is daar probleme- jy sien 'n ding van 'n ander kant af en jy weet nie hoe sy dit insien nie. Sy sien soms nie in dis 'n probleem nie (P10).

Q5. If we ever had any problems at the school it was to know what was going on- how is she getting on at OT and what can we do to help her at home (P6m).

The need to know what parents could do and what their rights and responsibilities were, was clear. A parent specifically inquired whether they had any part in decision making on important issues like eventual mainstreaming.

#### 6.1.4 The accessibility and appropriateness of the information

A situation where the accessibility of knowledge was of vital importance to the parents is illustrated here:

Q1. it is the fact that he might get worse. You don't know. His problem has not been diagnosed to a certain extent.- - - It is not knowing exactly what it is. Going - O.K. not from doctor to doctor but you know - - - hope - - - I don't know how. You know like on Thursday, standing there. They all try to do what they can but I couldn't say anything because you mean??- - - . I didn't know exactly what they said. . . And not knowing if there is a cure for him. O.K. he is getting the best treatment at school. . . They are doing the best they can. It is not knowing exactly what is wrong. If it can be cured or not (P12m).

In this case the medical profession did not have the information available. To a lesser extent the inability of the medical doctors and other professionals to diagnose minor conditions in children had caused serious managing mistakes on the parents part. In five cases parents suspected problems but were told to relax as the children were fine or might outgrow their problems. In four cases the parents then placed the child in an unsuitable educational setting which caused emotional trauma to parents and children.

A number of parents mentioned how appropriateness of the information giving process affected them. In Q2 and Q3 the need for honesty and directness in delivering news was stressed. However, some parents stated a need for open ended results leaving some hope.

Q2. The only big stress area for me was the process of diagnosis-getting the bad news in small increments which got worse and worse. . . You don't need to get that. You rather just have the facts. You don't want people to beat about the bush (P6f).

Q3. Jy kan partykeer voel die onderwyser wil vir jou iets sê maar sy sê dit nie en 'n ouer het nie nog tyd om te sit en raai raai speel nie. Jy wil graag weet hoe gedra die kind hom in die klas. Soms is daar so 'n groot verskil van sy gedrag by die huis (P10m).

Q4. I would like more detailed reports more often. I would like to get the whole picture. I would like to know what she is struggling with. . . even negative reports would be very helpful because people often say to me-"Why is she not going to normal school. Does she get what she needs there." Eventually you start worrying yourself- are you doing the right thing. If I go there and see what she needs and where she is lacking , what they are doing to help her, it helps me. It reinforces me to do what is right (P4m).

Q5. I think my need would be for guidance in the area of school-contact with people who are assessing her progress. . . having an open relationship with them that I can discuss things with them. That I think is important- including things like mainstreaming and so on. I think it is different from a normal school where you just get reports and so on (P6f).

The recurring need for open discussions and two-way communication was highlighted in Q5. A couple felt that better assessments could be made if parents had a chance to contribute their perceptions and a number of parents stressed the need for relationships and opportunities which would make free exchange of negative and positive information possible.

During the interviews parents had expressed appreciation for home visits and phone calls and to a lesser extent message books as sources of two-way information. Coffee-mornings were appreciated although some parents felt that these were not appropriate occasions for discussing sensitive issues. Working parents felt that attendance at these were costly. The open door policy of the psychologists was mentioned as a valuable but seldom used facility. Some felt they had easy access to therapists but many felt that they did not really know what was going on and wanted more information (Q4). Written reports were

appreciated but often felt to be too general. One father wanted more reports and specific facts about the child's progress and the aims the school were working towards.

It became clear that there was a need for information exchange where a teacher and parents could talk quietly and without interruptions as in the research interview set up. Although it was the stated aim to get information from the parents on their needs they had an intense need to discuss their children, their progress, prospects and problems with the interviewer. In most cases this was a natural extension of the interview which was very fruitful to all the parties.

#### 6.1.5 Discussion

During the interviews it emerged that there were circumstances which facilitated or constrained the gathering of information. 1. Parents living near the school or regularly transporting their children found it much easier to have regular communication with the teachers while those without transport or telephone as well as working mothers experienced problems. 2. Many parents felt that there were enough channels available for procuring information. However, it was up to the parents to take the initiative. Their ability to do this was influenced by the strength of their motivation as well as the characteristics of the family and the handicap. Parents in the higher socio-economic group in this study had much easier access to the sources of information.

### 6.2 "I NEED HELP" OR THE NEED FOR SUPPORT

In contrast to their outspokenness on informational needs parents seemed to be more reticent about their need for support although the need was obviously present. The most salient properties of this need were the purpose, types, sources and appropriateness of the available support as factors enhancing or impeding the parents' managing strategies.

#### 6.2.1 The Purpose of Support

The main purpose was to enable parents to manage themselves, the child and the rest of the family as well as the child's handicap trajectory. The direction of this need could be child-centered, handicap-centered or parent-centered. An interesting feature of the interview responses was that most of

the support needs mentioned were child and/or handicap centered while it was fairly obvious that the parents had needs of their own. One mother explained that "men had needs that are different from women and they might not even know what they are" (P7m). There was however an awareness that the parental mood or struggle to cope affected the children.

Q1. . . . well that is a bad day. Very much depends on my mood. But it does affect their behaviour because if I am ratty everything they do irritates me. . . And you know this is also a case of feeling sorry for yourself because you had no time to unwind (P5m).

Q2. It depends more on how I feel. If I feel very tired and irritable I will be screaming and shouting all the time and if I feel better they will have a good day (P2m).

A salient factor was the intensity of this need. Some parents feared disaster if their support need was not met.

Q3. I don't know how we would have coped without the support that we had - me from a time viewpoint. You also need some time. Also just knowing that they love the kids and- - you know. Just accept her as she is (P6m).

The nature of the parents' need perception influenced the intensity and direction of their need. A couple who had three handicapped children felt they were actually very lucky compared to some other parents whose kids were more involved and they stated no special needs.

### 6.2.2 The sources of support

The sources of support mentioned by the interviewed parents fell naturally into two groups: 1. Informal support from family and friends or organised groups; 2. support from professionals.

Q1. Then I fetch her or another member of the family. We are very fortunate in having the back-up of the family (P6m).

Q2. We have been very happy with people around us, giving lots of support, interest and help (P2m).

Q3. But he actually goes to Sunday School on a Sunday morning- there the people have really adapted that he must sit down etc. - they carry him for me - they are matric pupils. They are also like- how shall I say- with us. Very fine group (P12).

Q4. I may have appreciated perhaps having contact with another mother- maybe six months ahead of me progress wise, at the time when we were envisaging getting her in- very alone- and you almost didn't want to be part of AP - because I didn't want to be there- so it was a funny kind of ambivalence (P6m).

Q5. Ek het 'n vriendin wat ook 'n gestremde kind het. Jy weet ons is groot vriendinne want ons is in dieselfde situasie. Ons sit en huil saam en baklei saam en lag saam (P14m).

The role of informal sources of support was illustrated above. Domestic helpers were mentioned a few times in this respect. No direct referral was made to spouses except for a single mother who lamented the lack of spousal support. This might have been due to the nature of the interview. However, in some cases the way in which the parents related during the interview - sharing in joys and disasters and in discussions of parental issues - made it clear that there was considerable mutual support. The reverse was however also demonstrated.

The important supportive role of medical professionals was mentioned negatively and positively. The educational and para-medical professionals played extremely important supportive roles in the life of this group of parents.

Q6 We see her at school where she is also surrounded by a wonderful support network and she is so immensely happy at school (P7m).

Q7. Mens raak eintlik, - - - jy weet dis deel van jou span. Dis deel van jou netwerk om jou kind. Dit is vir ons belangrik dat dit nie net jy alleen met jou kind is nie maar al daai mense saam, saam met jou kind se toekoms (P14m).

Q8. I must say *the physio* has been a real help. She has really been a part of the family. I mean we don't know her that well but we feel as though she is part of the family (P6m).

The above examples refer to professionals in special schools but para-medical staff in private capacities were also mentioned.

### 6.2.3 Types of support

Types mentioned were informational, appraisal, emotional and instrumental. The need for information has been discussed. Applicable to this section is the need for professional information supporting and substantiating their perception of the child's need.

Q1. ek het altyd geweet daar is 'n probleem maar ek kon nie by iemand uitgekome het wat gesê het daar is 'n probleem nie (P9m).

Q2. I knew that something was wrong with him from age two. Every single year I went to the paediatrician for a check-up and told him something was wrong . . . and each time he said "Don't worry, it will come right" (P1m).

A quotation used before vividly describes the need for supportive information.

Q3. I would like more detailed reports more often. I would like to get the whole picture. I would like to know what she is struggling with. . . even negative reports would be very helpful because people often say to me-"Why is she not going to normal school. Does she get what she needs there." Eventually you start worrying yourself- are you doing the right thing.? If I go there and see what she needs and where she is lacking , what they are doing to help her? It helps me. It reinforces me to do what is right (P4m).

Closely akin to the above was the need for appraisal support. The same mother expressed her self-doubt and need for appraisal. This need was also emphasised by the reaction of parents when they felt they were blamed for deficiencies in their child's development.

Q4. I often want to know whether I am doing the right thing. I do so want to do what is best for her.*Int:*" Do you need guidance?" Well, I just want to know whether I am doing it right. Especially being a single parent I don't always know that I can do it right (P4m).

The tendency to be reticent about emotional needs was noted by one of the mothers.

Q5. I think I was overanxious, and I was aware of the fact that I was and I also felt that the circumstances were fairly abnormal. I don't actually think other mothers felt like that. The other mothers always seem all to cope fine and I feel that I- - - Either that or they are not prepared to communicate about the way they felt. And I find I'm always asking how they are and how they have got on and they never ask me how I felt. I don't really know anybody else who has traumatised the way I did (P6m).

A mother of a child with a serious congenital heart condition, felt the emotional support "a shoulder to cry on" so strongly that she started a support group for parents experiencing the same need. Some mothers needed emotional support from other mothers in the stage just after the assessment of their child.

Q6. In the very beginning it would have helped if I had contact with other parents of AP-school. Your friends are kind and sympathetic but they do not really realise what you are going through. I spoke to L's mother when she started at AP and she went through a similar experience and we could share our experiences and tears. It is in the initial stages just after the assessment that one really needs help and contact (P2m).

Q7. Nie een van daai ouers het dit nog verwerk nie. Dis ongelooflik. Daai ouers sit met daai kind en hulle sê hul aanvaar die kind maar hulle aanvaar nie sy gestremdheid nie. Hulle verwyder dit van mekaar. Hulle wil daai kind se liggaam

weg hê en hulle moet daai kind versorg- en dis elke dag se probleme- dis elke dag se probleme wat mens moet verwerk. . . So ek dink miskien kan sielkundiges dalk vroeg, vroeg, vroeg op 'n gedwonge basis kontak maak met daai ouers. . . Hulle bejammer hulself. Hul het dit nog nie verwerk nie. As 'n kind toegelaat word, moet die sielkundige afspraak met daai ouers maak wat hy moet nakom. Hy moet nie eers 'n keuse gegee word nie want op die ou end is dit net tot sy voordeel (P14m).

Q8. But there is a possibility of a perception. There is a whole series of undefined issues they have not faced about having a disabled child and not wanting to be involved." (P7f).

In Q7 and Q8 two couples discussed this need from different angles. Both pinpointed the problems of parents not being able to face issues around their emotional attitude toward the child's handicap which would explain to a certain extent the reticence people had to talk about emotional support needs. The second couple stressed the respect needed. From previous unrecorded discussions with mothers it was clear that there were serious emotional problems in the family partly connected to the impact of the handicap on the family. In two of the cases this resulted in a divorce.

The need for instrumental support from family, friends professionals and the state was more pronounced. Most fathers and occasionally other family members played a prominent part in the daily lifting to the school or bus and in providing some respite for the mothers especially over week-ends. The need for respite care was important especially where the handicap demanded special vigilance or lack of nearby schoolfriends due to the geographical spread of the pupils limited natural respite care opportunities.

Q9. Ja nee, dit is nogal 'n behoefte, want soos een van haar vriendinne het gesê sy sal graag wil help maar sy is te bang daar gebeur iets met die kind en so aan. Daai is 'n groot behoefte (P13f).

Q10. and I do find the friendship angle- not having people-friends close by is really - - - especially now that I'm working a bit and I really would like to find a wider circle of friends where she could stay. You know that I find I miss very much (P6m).

Very few parents mentioned financial needs - the most explicit need mentioned was for more money to be able to provide extra-mural activities like horse riding for the children. One family described vividly how lack of domestic help and the fact that the mother had to work part time affected their family life.

The most pronounced instrumental support needs lay in the realm of professional services: -medical, para-medical and educational. In most cases this need was expressed in a positive way. Parents felt that available services were sufficiently instrumental in fulfilling their support needs.

Q11. The self-serving advantage is that physio etc. they get on the spot. It suits us financially but also it is much better for her. . . I have a child that I adore and she is at a school that she is incredibly happy at and we have nothing but joy about the kind of teaching that she is getting. What more do you want. And to take a child from a school like that. No ways! No ways! (P7f).

Q12. She has always been very happy there. I always felt I did not want to stand in her way. If she was happy and got what she needed, I will not stand in her way (P4m).

#### 6.2.4 Appropriateness and accessibility

The question on the appropriateness and accessibility of parental support has been answered partially by the quotations in the previous sections. A few more aspects need highlighting for insight into the satisfaction gained from the available services.

Extended family support was mentioned as indispensable. However, it had the potential for locus of control problems.

Q1. If there are more people involved it might be useful but it can also get very complex. You've got to call it a shot at some stage (P6f).

Q2. She was too involved. She regarded her as a fourth child. She just wants everything for the best for her. . . She encourages her to try and do everything that her cousins of the same age can do. It is not always good for her. She looked after her from the time she was 3 months old. Mum was not ideal with her but she did a lot with her educationally. Maybe they need more from the school- more feedback. This would have helped me because they often ask why she is still there (P4m).

In both cases the parents mentioned the school's role in providing information to extended family and thus influencing the appropriateness of their support. In Q1 the parents appreciated the fact that the grandparents could regularly visit the school and share the school experience with them but indicated the necessity for clear boundaries in responsibility. Contrary to this the second mother needed direct information from the school to her parents to promote their understanding and thus gain effective cooperation and support.

Balance was needed between factors influencing appropriateness of support. A young mother with serious emotional problems associated with the acceptance and control of her severely handicapped daughter received counselling from a psychologist employed by her husbands' firm. He felt threatened by the counselling procedure and argued that she should use the school psychologist as he would be more experienced in dealing with handicapped families. The support was not suited to the husbands' needs and thus less appropriate for the family system.

Q3. I went to physio on that day and was very keen and very thrilled with the fact that she had walked - for even though they had said that she should walk by the time that she was four we wondered whether it would happen and I said to the physio "She took her first steps this morning". Her face dropped and she said "Oh, what did she look like". I thought when your'e child was one and took its first steps wouldn't you be excited. My child is disabled and I have been waiting for this day for so long and when it happens all that she can say to me is "and what did she look like?" I felt so deflated (P6m).

The parent's need for sensitivity on the part of the professionals was illustrated above. The physiotherapist was genuinely worried about a child starting to walk before her walking patterns were sufficiently developed. She concentrated on her specific field and missed the mother's intense need to share her joy with the person who was instrumental in bringing it about.

The following quotation illustrates how an unsuitable therapy situation turned into an unavailable one because the therapist was not sensitive to the need for appraisal.

Q4. Ek het haar privaat gevat vir terapie. Die spesifieke terapeut het my soos 'n misdadiger laat voel, asof ek nagelaat het om van hierdie kind 'n normale kind te maak. Ek het besluit ek gaan nie meer na hom toe nie. As hy my so laat voel gaan dit my ook nie goed doen die terapie nie (P14m).

Parents discussed the function of the school's support groups. They confirmed the existence of a need for support from "other people who have had the same experiences", "who know what it is all about", and can give some guidance. While some parents found the organised groups informative and supportive, others felt their group was not functioning properly and not providing appropriate support. Suggestions were made for occasions where people with similar problems or interests could meet e.g. meetings of parents from their child's class or

meetings with mothers whose children had had the same operation. The need for natural sharing opportunities like Saturday maintenance workparties was suggested by a father who felt that men might feel uncomfortable in situations where the focus was on feelings.

In two cases the parents perception of the goodness-of-fit of the available instrumental support affected the support value of the services. They felt that the current economic condition was to blame for the scarcity of funds available for special education. In one case the mother wanted an in-between facility (mainstream with special facilities). The father of a child who might have to go to a training centre discussed their provision of services.

Q7. Verdere frustrasie is dat skole vir gestremde kinders in die Kaap het nie die fasiliteite vir gestremde kinders nie. Wat ek daarby wil sê is geld: Poste word gevries ens. m.a.w. daar is geriewe vir jou kinders om bedags uit hul huise te gaan maar daar is nie geld vir die nodige terapie nie. Dis 'n groot frustrasie (P14f).

## 7 THE CHARACTERISTICS OF THE HANDICAP AND THE FAMILY

### 7.1 THE CHARACTERISTICS OF THE HANDICAP

These characteristics often played a decisive role in the ability of the parents to manage. In Section 3 Q6, Q7 and Q8 illustrated their effect on the parent's ability to come to terms. The problem of social stigmatising was mentioned in Q6 where the mother is thankful that the child "looks normal". A parent discussed the broader issues of society's acceptance of handicaps and how that would affect their child's future mainstreaming.

Q1. Sometimes another child can be very cruel. How cruel people can be towards handicapped children and that. I mean that is also another thing. You know what I mean. Other people you know always looking and saying nasty things. Like shield him to, like (P11m).

Q2. The biggest frustration, more than frustration, hurt, was to see him rejected by other children. We just wanted him to be accepted as he was, but there were other children ganging up on him, playing little tricks on him or just running away from him (P2m).

This last mother recounted how adults made remarks like "Why do you send him to that school", and told their children to "be nice to the handicapped child because he is brain-damaged." They voiced the need for more exposure of normal children to handicapped people and spreading of the school's attitude of acceptance. Other parents denied the impact of the social stigma on them, stating that one should realise that it was caused by ignorance. Other parents marvelled at the fact that their children only had positive experiences in the outside world but were concerned about the children's preparedness for future hurt.

Q3. One area of, I think, very valuable potential of sharing for parents would be dealing with things like --is the moment going to come when someone turns round and says "but gosh, you're a freak" or "you're kinked" or "what is the matter with you" and suddenly the child realises that not everybody that they have dealt with accepts (P7f).

The added burden of caring and constant concern and vigilance demanded by special health problems were experienced diversely by parents. One family with a diplegic child felt they could incorporate therapeutic measures, like sessions in the standing frame, naturally into family routines while another mother described the impact as follows:

Q4. I get up early in the morning because then I listen for him. I take him out of the bed. The first thing I do is take him to the toilet - make sure he is comfortable there and I carry on and I listen for him. Then I just carry him because he doesn't walk around like his- - just try to move around let say, but then I carry him. . . Basically that you have to make time for him and you have to provide. Life moves around him (P11m).

Another mother urgently requested relief from the burden of caring for a diplegic child with several other serious complications. The mother admitted that she often could not face the care of the child in the afternoon and wanted someone to take the child away for a period. In one case serious behavioural problems developed which was proabaly caused by treatment for an epileptic condition. Managing was definitely excacerbated by health complications as with behaviour related characteristics.

Q5. But we do worry a lot. How is he going to cope academically and socially. He is not a good mixer. He will for instance at a children's party go in there, grab cookies etc. and then go and sit at the door, staring outside. It is as if he does not need other kids. It is not normal. He has an aggressive streak in

Q1. A bad day is when his teacher phones me on a Sunday night talking for half an hour telling me my son is not shaping and on Monday I receive a letter from Alex's (brother) teacher saying he is not shaping. That was an extremely bad week (P2).

The position of the child in the family often enhanced or impeded the managing. Parents highlighted the role of experience in enhancing their abilities to cope with the handicapped child. The mother of twins explained the impact of the handicapped child's condition on his twin brother relating how traumatic the onset of epileptic fits and resultant treatment were to the twin.

The role of socio-economic circumstances was not stated clearly by parents but they gave indications of its importance. The influence of educational status and background was prominent in their need for and ability to process information. A couple described the satisfaction and perspective they received from being able to exchange ideas and information. This father regarded the quest for knowledge as his special task.

Q2. I feel for me particularly, having had the advantage of an excellent academic education and two degrees- no three degrees - and you name it and I should jolly well be able to get this thing together for myself (P7f).

One mother voiced her concern about the lack of "scientific" information presented suggesting that the school should make more effort to accommodate fathers and "career ladies" Other parents complained about the use of professional jargon. A mother explained how her medical background had helped her in relating to other medical professionals and with the care of her child. Her background made it harder to accept when professionals discussed a possible operation on her child's hand in her presence without including her. She stated that this incident had a detrimental effect on her feelings toward the school and professionals in general. Parents, who were teachers felt this gave them insight into and tolerance for problems in the area of home/school communication. Parents with tertiary education seemed to have a stronger need for the clearance of locus of control issues. The influence of economic circumstances was mentioned in connection with working status of mothers, ability to afford a servant and extra-mural activities for the children.

A family's geographic location affected them as follows: the area where they lived provided freedom and beauty to their

children; in certain areas neighbourhood children tended to tease the handicapped child; children had to travel long distances to school; or parents who had to move to be nearer the school. The school's bus system helped the parents but caused problems beginning with the early morning rush for the bus aggravated by handicap related problems. Mothers described the strain.

Q3. It's also not fair on the child to have to rush him. And then shovel through. . . that is the early morning- which is suicidal (P5).

Q4. "Astrid, get done! Get ready! We still have to eat our breakfast and we have to get the bus. I'm not riding after that bus again today" (P4).

Further problems were related to the bus not being on time thereby complicating tight time schedules and the effect of the long and often rowdy bus rides on the children.

Q5. Walter, you get from the bus- he's grumpy, he's grouchy, he has left his satchel or he is lethargic or he bitches at you because you are a little bit late. The bus arrives very erratic. . . . It's not the bus drivers fault. It's the parents on the previous stops who did not pitch up on time. "You're late! Why are you late." And that is all you get out of him (P5m).

In a report from a Support Group Meeting (1992) the comment was made that this particular group from the same geographical area as the school, was the most involved and committed group.

Q6. Mothers in this area tend to meet informally at the school when transporting the children. This highlights one of the great problems at *the school* - lack of parental socializing (because children are bused to school) makes it difficult for parents to interact, become involved in school activities and build up a community spirit. The difficulties of communicating with the school when parents seldom see teachers was discussed. This is a great concern for Nursery School parents particularly.

This quotation illustrated two frequently mentioned problems connected with the large area the school served. Parents who could lift their children to school had easy access to staff members and commented favourably on the communication facilities in stark contrast to the ones who had to use the bus system. The same applied to the available support from other parents as the early morning encounters at school often served an important purpose. A further need was voiced for school friends nearby, as children want to play with them in the afternoon. Often parents had to travel to the other end of town.

Q7. The need for more friends for Yvette in our neighbourhood. An almost insurmountable problem for A.P. parents and children - we do realise the reason for the problem, but often wish it didn't exist (P6).

Problems with school involvement were highlighted.

Q8. I think with *her brother's* school, part of it is that it is so much easier to become involved there because its part of the community, because the children all come from this area. With AP its again the geographical . . . you don't get so much of a feeling of - a - community is the only thing to use (P6).

Although not exhaustive, these were the most frequent circumstances mentioned or implied by the parents as factors that could enhance or impede the strategies which they employed or wanted to employ to fulfil their need to manage.

## 8 MANAGING STRATEGIES

This section examines parent's perception of strategies necessary for the process of managing, looking at the need to manage themselves, the family, the child and the support system.

### 8.1 MANAGING MYSELF

Q1. Parents need to be psychologically prepared. It is something to come to terms with that your child is going to a school like AP (P2m).

In 3.2 the process of coming to terms and some of the managing strategies employed by the parents was discussed. Active strategies mentioned were "working it through", "thrashing it out on paper" and going for professional help. More passive strategies were "learning to live with it", "having to accept" and "learning your way into the situation". A father related how a chance encounter at the school had helped him tremendously in this process. While watching his son's occupational therapy session he realised that this was serious business. He saw other children with bigger problems struggling and succeeding with little tasks. This helped to get perspective on his child's problems and the work being done at the school.

Coming to terms, form an integral part of daily managing the parents have to do and it was clear that the control they had over themselves influenced the way in which they succeeded in managing their nurturing and household duties and the support systems.

## 8.2 MANAGING THE CHILD AND THE FAMILY

The descriptions of a day in the life of the family gave a vivid picture of the managing strategies parents employ. The drama to get them to the "departing bus" or school on time seems to tax the parents' ability in most cases. Terms like "frantic" and "suicidal" (P5m) were used with intermittent comments on the ongoing conflict around expediency versus child independence. In contrast to this there were parents who seemed to be managing fine and could incorporate finer health care details in the early routine. Strategies they employed ranged from "screaming like a fishwife in the morning" (P11m), "you have got to curb yourself and you say like 'you're late' or whatever. You have got to make time for him" (P12m), to the reflective "finding the thing that works best for everybody in the long run" (P6f). Some of the strategies employed by parents are illustrated below.

Q1. Saans badtyd- ek probeer gewoonlik saans badtyd bietjie taal opkry. Bietjie liedjies sing, stories vertel en gesels. . . hulle moet my kyk, hoe ek my mond vorm, terwyl ons was, dat ons kan spraak gebruik (P14m).

Q2. He is very hardheaded. . . But I don't want to give in to him. You know you tend to feel sorry for him because he has got a handicap and things like that and then you think: " No! don't! You musn't". I said: "You can do the things, you must do it." I mean it is hard for you but you must give him the courage. . . He calls out sometimes and say's I can't but he musn't slip back. You don't want him to go further (P12m).

Q3. I try to be patient and tolerant but I'm not always successful. I try to be consistent. I do not want to confuse her. . . . She tends to be willful and very manipulative at times and then I am very strict. I feel that it is necessary that she should feel that there is someone stronger than her (P4m).

Q4. As die weer nie reg is nie dan sit sy daar. Dan sê ek gaan speel met jou speelgoed. Jy het 'n klomp speelgoed. Dan sit sy. . . Sy het genoeg goed maar sy sit net. Sy treiter my (P13m).

One couple resorted to physical punishment as nothing else helped. He just "switched off and looked blank" (P5f) when they tried reasoning.

Managing strategies to handle the impact of the handicap on the family especially as far as siblings were concerned varied from anger against the handicapped child causing the sibling suffering, to constant reflection on ways to diminish and even utilise the impact of the handicap on the siblings.

Q5. A little boy had said "he walks funny" so he (*brother*) was very upset. . . . So I sat and explained to him what he - - as best as a person can. I mean that he is different and things like that. . . . They tend to push him aside and don't play with him like attitude. I told him: "Don't do that. I mean he might not be able to run around with you and things like that, but you include him. If you don't play nicely with him you don't play.".... But I mean he (*the brother*) is also very worried about him and very concerned about him. He has lately become mature. But I suppose he will still learn to settle this one (P12m).

Q6. In some ways we have more stress with him (*twin brother*). That might perhaps be a point. You see with being disabled she gets far more attention and with somebody with that type of nature she just gets so much more attention. We better watch that actually, but you know, that he sees he is also special (P6f).

Q7. They don't think of her as a special kid that needs special things. I've heard them (*brothers*) say: "Where is your other hand?" (*helping with therapy*) (P11m).

Strategies for managing in the marriage relationship were not discussed but were demonstrated in some cases. This varied from openly fighting and blaming to whispered comments when the partner was on the phone or withdrawal of one partner because "that is the department of the other one" or "because he/she could not handle a discussion like this". In the most extreme case the father did not attend the interview but stood listening behind the door, sending signs to his wife when he did not like the conversation. Eventually he appeared, looked threateningly at his wife and me and then withdrew without saying a word. In some cases it was obvious that both partners shared in the care and nurturing of the child and that the father felt an extra responsibility to be more active because of the child's special problems. In a family with two handicapped children the father went through a process of initial rejection which also affected the marriage relationship. He gradually came to terms and shared and enjoyed the care of his son. This lightened his wife's burden and enhanced the marriage relationship.

### 8.3 MANAGING THE SUPPORT SYSTEMS

As indicated in previous sections dependence on support necessitated special managing strategies e.g. locating, assessing, monitoring and controlling.

#### 8.3.1 Locating and assessing services

Q1. Hy is besig om jou kind te evalueer op so 'n manier "maar daai kind behoort dit en dit te doen". Nie dat daai kind 'n probleem het hoekom sy dit nog nie kan doen nie. Dit het amper op jou geprojekteer as ouer. . . Dit het ek by baie terapeute ervaar. Ons het mense gesoek wat die kind raaksien. Maar jy moes so hard oortuig net om jou kind 'n kans te gee (P14m).

Q2. Ek het pal vir hom saamgeneem. . . net om seker te maak dat daar nie probleme is nie. Dan vat ek hom elke keer . . . na die dokter. Dan sê ek vir die dokter "Kyk sy arm. Hy lyk vir my so pap." "Nee, nee. Daar is niks verkeerd nie. Hy sal nog regkom." . . . Ek het altyd geweet daar is 'n probleem maar ek kon nie by iemand uitgekome het wat my gesê het daar is 'n probleem nie (P8m).

In the interviewed cases especially the parents of children with the more subtle handicaps described the tenacious and/or roundabout strategies they had used to manage the diagnostic process and the early search for therapists.

#### 8.3.2 School Placement and Attendance

This represents a managing decision which caused a major crisis to some parents while others accepted it as inevitable or a positive step. In most cases the advice of professionals played a major role but some parents wanted to actively assess the services of the school and investigate other possibilities.

Once the children were accepted in the school the parents' perception of managing strategies varied. One basic problem experienced by some was that the school tended to take over. Strategies parents employed varied from handing over the child to the school, hoping that they would achieve a miracle, to a partial release of responsibility with relief or with anxiety.

The strategies parents used to retain responsibility and thus some managing powers, amounted to assessing and monitoring child progress. Some described their strategies and frustrations.

Q1. Al gaan dinge rustig aan, mens het nie 'n idee wat daar aangaan nie. . . 'n Ouer moet betrokke wees by sy kind. . . Die ouer wil weet wat in die klas aangaan. Hulle is soort van buitestaanders wat deur 'n opgemiste venster kyk. Jy vee en vee,

dan mis dit weer op. Dis hoe ons begrip is van wat in die klaskamer aangaan. . . Jy kan seker gaan vir 'n dag of wat maar jy voel so of jy in die pad is (P10m).

Q2. The contact is much easier when you come to school regularly and can check on things. . . I feel you must be there to feel the vibes (P11m).

A father described how he progressed from active monitoring to gradual relaxation when he saw that things were going well. Another mother described how her initial anxiety about her daughter's progress at school- which seemed to be slower than at the crèche -changed to a feeling of relaxation because the child was obviously stimulated and happy. This same process was reversed in another case where relaxed monitoring changed to an anxious, nearly aggressive monitoring when things were not going well. The direction of the monitoring fluctuated according to the child's special needs or the parents special aims. In one case the mother's active monitoring was mainly directed at the state of the child's clothing.

Apart from monitoring through observation of the school, assessment of the child's accounts, behaviour, and the contents of his school satchel, some parents formed relationships with the professionals who were working with their children, through frequent visits or telephonic conversations. Parents felt that this enabled them to monitor but also to discuss progress or problems and in that way give information to the teacher and contribute their ideas thus having a more active managing role.

Q3. . . . having an open relationship with them. That I can discuss things with them. That I think is important (P6f).

Q4. Dit het ook darem baie frustrasies verminder. As mens bymekaar kan kom en die ding bespreek (P10m).

In the nursery section most parents said that they felt free to discuss things and thus empowered to manage on that level. Some parents however felt they wanted to be more involved in the process of caring and educating their child. They were eager to help in the class, go on outings or to carry on with therapies or teaching at home. Some of the mothers came to help with swimming because they were concerned about the safety aspect.

Q5. I would like to know more - the physiotherapists side. What are they doing and what can I do at home if anything (P12m).

Q6. I happen to enjoy preschool children, so I enjoy doing that. I think it is important from the other kind of view - for the

child's sake - show you are interested enough to come along - and for your sake and to be able to get to know the parents and the children and you a bit better. And just to spend a bit more quality time with you that one would not get otherwise (P6m).

The role of advocate or negotiator for their child's rights or for their own rights were filled hesitantly in the case of these parents in their dealings with the school. The father quoted in Section 2:Q3 was extremely upset over what he perceived as a violation of his right to decide the length of his daughter's stay at the school. He solved the problem not by direct negotiation or advocacy but by scrapping the relevant section of the indemnity form. Another father solved a similar problem by approaching a staff member with whom he felt safe to discuss the best procedures to follow to make sure that he would not tread on toes or place his daughter's schooling in jeopardy. There seemed to be a perception among parents that school establishments in general were very sensitive to criticism or even enquiries and that parents had to be very careful. A mother stated categorically: "If you open your mouth, you tread on toes. There is no question about that" (P11m). The parents of a child who was on the borderline between educability and trainability had problems getting the child into the special school. Their definition of their role in the process was described as "fighting" (Q12). Actual skills they used in their negotiations were friendly, relationship forming

Q7. Al frustrasie wat ons as ouers het is om *haar* in die regte skool te kry. Ons het al baie daaroor gepraat dat 'n gewone kind wat nie 'n probleem het nie, hy gaan sy lewe aan. Hy gaan net aan. Ons as ouers moet veg om 'n bestaansreg vir jou kind te kry (P14f). Ons aanvaar dit - maar die geveg is nog nie verby voor dit verby is nie . . . By altwee ons skole is die kontak met die skool met die onderwyseres so goed. Geen probleme daarmee nie. Baie goeie kontak en ek voel dit moet van albei se kant kom, dis nie net van die skool se kant nie. . . Dis belangrik om betrokke te wees bymekaar (P14m).

The importance of retaining responsibility was discussed frequently during the interviews. The temptation to "hand over your child" in the hands of the specialists and the desire to have at least some say in the decision making were stated.

Q9. I know they are going to make the ultimate decisions. I have to trust them. That is why I sent her here. . . It will depend entirely on how she is going to cope- academically as well. I feel the ultimate decision is mine. The problem in this city is that it is a closed community. If I go against the grain I have to be very careful. There are no other facilities to go back to.

. . . I am unsure how much support you will get if you don't go along with their decisions. That is always at the back of my mind (P11m).

Most parents accepted that the school had the right to make decisions about school related matters. The wonderful services the school was offering and the lack of other facilities acted as deterrents, restricting action in this context. In their enquiries about eventual mainstreaming they all stated in various degrees of submissiveness that they would be led by the school in this matter. The decisive role of realistic information in choosing the mode of managing was underlined by a mother stating that the primary need was perhaps not so much to take over the decision making but to have confidence which comes from informed trust not blind trust. Another mother consulted an outside professional on the advisability of keeping her child in the school indicating a confidence crisis.

Some expressed the need to retain part of the managing function by the desire to be part of the team and share in the information, work and decision making processes. One mother spoke about her team rather than the team working with her child..

Q10. Mens raak eintlik - jy weet dis deel van jou span - dis deel van jou netwerk om jou kind. Dit is vir ons belangrik dat dit nie net jy alleen met jou kind is nie maar al daai mense saam, saam met jou kind se toekoms- dis belangrik vir ons om betrokke te wees bymekaar - regtig waar ons het nog nooit ondervind dat ons enigsinds- ons was nog altyd baie gelukkig (P14m).

## 9 CONSEQUENCES

The consequences of the action/interactional strategies taken by the parents cover a wide spectrum as reflected in the quotations. The positive consequence of the successful managing strategies is a handicap trajectory that is on track allowing the parents to concentrate on doing their best for their child while reflecting on positive ways to empower them to manage. The negative consequence of action/interactional strategies that were unsuccessful or not taken at all was a family in crisis often with disastrous results to all concerned. This can perhaps be better illustrated by applying the paradigm to some instances discussed during the interviews.

## 9.1 YVETTE

Yvette was a bright five year old diplegic child, mildly affected, who attended the preschool section of a special school. She had a buoyant personality and a good sense of humour which gave much joy to her parents. She was one of twins who were born prematurely and spent their first weeks in an incubator. The brother was unaffected. They were the only children. Both the parents had a university background. The mother had just started to work part time with a flexible time schedule. They had a very supportive extended family, living close by.

Two incidents in Yvette's school life are discussed to show the interplay of the properties of this need to manage, the role of the intervening circumstances, the strategies that were used and the consequences of these strategies.

### 9.1.1 The able mother who could not (P6)

The context of this need to manage was the school's pre-admission assessment of Yvette, then not quite three. She was still in nappies and drinking from a bottle. Her mother felt ambiguous about this assessment because she was not sure whether her child really belonged in the school. She stated that she had not "come to terms" with it yet and was concerned about the intellectual level of her daughter's future class as her daughter seemed to be brighter. These parents had realistic aims for their daughter, wanting her to exploit her abilities - "whatever they might be" - as far as possible. Both the parents were motivated to "do their best for the child" and the father felt, contrary to the mother, that "she would be well provided for" in the school.

The parents were consciously working on their parenting skills, reflecting continuously on ways to improve and critically assessing their performance, while trying to be balanced in their approach. They both had warm, open personalities and generally found it easy to form relationships. At this stage the mother was not working and was available to and enjoying the children.

The interplay of the characteristics of the need to manage showed highly motivated and able parents at the beginning of the child's school career. The assessment and

possible school placement was causing a crisis in the process of adjustment.

Intervening circumstances which had played a role in enhancing the managing of this crisis was the strong supporting relationship between the parents and the extensive support from family, friends and the physiotherapist. Circumstances which had impeded the managing were the lack of information on this event from "somebody who was ahead of me", the immature image of the child and the school's lack of experience and skills in working with small children.

The assessment was described by the mother as "terrible".

Q1. So he expected her to go into this room with him. He closed the door and I was outside and he wondered why she screamed. If I had been there she would have done what he had asked her to do and I would not have interfered. She did her speech assessment that way. . . It was the fact that he was surprised that she cried and it was as if she and I had committed a crime, outcasts, because he had not succeeded in doing her assessment. He came out shaking his head and you know, rolling his eyes, and I felt like a worm (P6m).

She described the rest of the day at school as totally disastrous with Yvette falling and traumatising herself and screaming right through the physio-session. The mother nearly burst into tears and was upset and angry. The picture that emerged was of a mother who was usually well in control of the child and herself but was temporarily unable to manage the situation because of the anxiety caused by the conflict about the school placement. The mother might have been able to manage if her emotional energy had not been so depleted by her conflict. The consequence of this episode was that the child was only admitted to the school at a later stage. The parents were sensitised to the capacity for misunderstanding that existed in a school like that and took special care to form open relationships with the people who were working with their child.

#### 9.1.2 The parents who did not want to rock the boat

Yvette was now 5 years old and in her second year at the school. The parents were looking around for a possible future school for her twin brother and this had triggered a renewed concern for Yvette's eventual mainstreaming. They wanted to discuss this with the school without offending or rocking the

boat. However, they did not know when, where or whom to approach. Previous experiences with the school had made them aware of a potential for misunderstanding; they were confused about hierarchial structure and procedures; unsure about mainstreaming policy and parents' role in the decision making process.

The context of this need to manage the child's future schooling occurred at a stage when the parents were enthusiastic about special schooling. However, they felt it was realistic to prepare for mainstreaming in order to exploit her abilities fully.

Circumstances which had enhanced the action/interaction that they intended to take were: 1. The characteristics and especially the degree of the handicap which made future mainstreaming possible. 2. The parents lifted regularly and had ample opportunities for forming open relationships with staff members enabling them to get appropriate feedback on the child's progress and abilities. 3. The socio-economic background of the parents facilitated the processing of information and gave them confidence in approaching professionals. Impeding circumstances were: 1. The lack of opportunities to discuss sensitive matters. 2. Lack of accurate information on school procedures and policies. 3. Confusion about parental roles and responsibilities in relation to the school.

Their managing strategy was to invite the teacher to their home for an evening of discussion and ask advice on the correct procedures to follow to facilitate the child's future mainstreaming. The beneficial exchange of information removed misconceptions about the school's policy and provided guidelines for future discussions. This led to fruitful general discussions. The type of strategy that was used in this case was careful, non-confrontational and safe to ensure that no harm would be done to their daughter's future chances.

The consequences of the action initiated here led to the mainstreaming of Yvette. More immediate consequences were a relaxation on the part of the parents on this issue and valuable insights which were gained by the teacher and which enhanced her ability to work with this child and her parents.

## 9.2 ELKE

Elke was a five year old severely affected diplegic in her second year at the school. She was born prematurely with several congenital abnormalities which meant weeks in an incubator, several operations and seven months of her first year spent in hospital. This had made bonding extremely difficult. Further health complications caused intermittent hospital stays often in an emergency ward. Her condition had stabilised considerably except for the sudden onset of epileptic fits for which she needed regular medication. Her older brother was unaffected.

Her parents were young and inexperienced with no academic background. The mother did not work and the family struggled financially. The parents had unrealistic aims for Elke, and both struggled to accept their child's handicap. Sometimes this non-acceptance verged on rejection. The mother had an extremely hard time coping with her daughter's upbringing and managing the impact of the handicap and she had few skills to sustain her. She used the skills she had rigidly. The father was critical and unsupportive and the marriage was on the verge of breaking up. The mother depended on the father for transport and they seldom came to the school. Periods without a telephone impeded communication. The mother was very concerned about the state and completeness of her daughter's clothing, an area where she felt confident to manage. The parents were satisfied with their daughters' stories from school as their main source of information.

The context of this particular set of characteristics was a couple who struggled to manage themselves, their marriage and the upbringing of their children

The impeding circumstances were overwhelming. The characteristics of the handicap demanded constant vigilance and care and caused social stigmatisation in their area. Exacerbating this condition, was the lack of support from husband, family and friends and their socio-economic circumstances.

Managing strategies employed by the parents were desperate attempts to control the child's manipulative behaviour, attempts to organise alternative care for the child

(e.g. school hostel), and diligent attempts to dress her nicely.

Consequences of the above strategies and the lack of strategies were a strained relationship between the mother and the child, frequent health crises and the worsening of a bad marriage relationship. These parents had a need to manage but very little to empower them for this exceptional task.

### 9.3 ALICE WHOSE MOTHER MADE HER OWN DECISIONS

Alice was a four year old mildly affected hemiplegic; the third child of a family of four. Both parents were professionals, but the mother stayed at home. There was a strict division of labour and managing tasks with the father providing a comfortable income and the mother looking after the affairs of the children and the household. The father was not present at the interview and I am giving the mother's perceptions. The parents were adjusting their aims for their daughter as they watched her progress at school with some concern. The mother stressed the importance of being in control but found that it was not always possible. She was practical in her approach to mothering but could be reflective at times with strong opinions of right and wrong. She tried to be balanced, but admitted that she sometimes went overboard. Her professional as well as her mothering experience and her dedication to the children made her an able mother. The present incident happened in Alice's second year at school. Her mother was concerned about her class placement because she felt Alice did not get enough social and intellectual stimulation in that particular group. Most of the other children were younger and Alice's behaviour seemed to regress. Her mother felt something had to be done and was not satisfied with the school's reaction to her concern. She had a good relationship with most of the staff and easy access to information as she lifted regularly. Her experience of institutions and some specific incidents which had happened at school made her determined not to relinquish responsibility. She felt that the ultimate decision was hers but her impression was that the school expected unquestioning trust.

The context of this need to manage was a highly motivated and able mother who wanted the best for her child and family.

She felt the handicap trajectory was not quite on track at present and wanted to remedy this.

Enhancing circumstances were the mother's proximity to the school, the financial and emotional back-up from the father, the child's position in the family, easy access to information and the professional support at school. Impeding circumstances were the mother's perception of the school's attitude toward parental rights.

Managing strategies that she employed were increased active monitoring of the child's behaviour and progress followed by discussions with the child's teacher and therapists on her concern. The staff's reaction was sympathetic/noncommittal. The mother then independently decided to place the child for one day per week in a mainstream nursery school and informed the school of her decision. The interaction that followed this step consisted of concern from the school, careful monitoring from the mother and reports that the experiment seemed to be working well. After internal team discussions, the parents were called in and according to the mother, the school reluctantly agreed to the continuation of the experiment providing the child did not suffer in any way. The mother explained that she took the law in her own hands because she wanted to give this plan a chance and felt sure that had she asked, the school would have refused permission.

The consequence of the mother's managing strategies was that Alice benefited socially and intellectually from the experiment and the mother felt that the trajectory was back on track and she felt empowered to manage her child and the school

## 10. CONCLUSIONS

In the above study of interviews with parents of fourteen handicapped preschoolers the paramount need was to manage the impact of the handicap. The determining characteristics of the process of managing were seen as the motivation to manage and the ability to manage. Important attributes of the motivation to manage were the aims the parents had for their children and the attitudes they had towards the handicap. The attributes of the ability to manage were the nature of the skills necessary to manage, as well as the capacity to apply the skills. The context of this interplay between the properties of motivation

and ability determined the action strategies that the parents took to manage. Circumstances which might have intervened mainly consisted in the availability of information and support and in the characteristics of the handicap and the family. The managing strategies used by the parents were described as well as the consequences of these strategies or in some cases lack of strategies. Case studies were used to demonstrate the interplay of motivation and ability and the influence of the intervening circumstances showing how this need to manage was fulfilled.

The following section gives an overview of this process of managing. General patterns became clear through the study of the interviews.

1. In all the cases the intimate intertwinement of the characteristics of the managing became clear. No single characteristic can be singled out as being decisive. A continuous process of interaction often leading into a spiral of consequences is demonstrated. This makes it extremely difficult to discuss single characteristics as they can only be seen as embedded in their larger context. The use of the above model is an effort to capture some of the intricacies and vitality of this interaction.

2. The variability of the patterns of interaction between characteristics is demonstrated. Each case demonstrates an individual process of merging of characteristics changing continually with passage of time. Patterns that are described below should be seen in this context.

3. The main pattern that emerges shows a sliding scale. Parents who have relatively high ability and strong motivation to manage the impact of the handicap are also able to take initiative to get the necessary information and to maximise the available support. The effect of positive feedback amplifies their ability and motivation, empowering them further to manage. On the other hand the parents who have relatively low ability and motivation are less able to acquire or process information or to acquire or manage support systems. This weakens their abilities and motivation, leading to a process of negative feedback which disempowers them even more.

Most of the parents oscillate between these two poles. One mother was strongly motivated to help her child through active involvement in the school support system. Her eagerness

was not backed up by social and parenting skills and was sometimes counter-productive. In other cases relatively skilled parents were still so embroiled in their struggle to come to terms that anger and/or guilt arrested their skills to a large degree, making them less competent to use existing support systems.

4. The nature of the support system and its goodness-of-fit can play a decisive role in empowering parents to come to terms and to develop skills. The happiness and good adjustment of a child at school could ease the parental burden of care and concern, freeing them to attend to the tasks of managing themselves and developing skills rather than "frantically" or "suicidally" trying to cope. Alternatively it could lead to a vicious circle, disempowering parents further.

5. The importance of information as an empowering tool for utilising support systems and for developing skills, realistic aims and healthy attitudes emerged clearly.

6. The influence of the unique characteristics of the handicap and the family could play a decisive role in swaying the balance between managing and not managing. The presence of other handicapped children in the family was especially significant in this study. However, examples on both sides indicate that other factors like parental attitude and/or support systems can determine the outcome. This underlines the force of the continual interplay between these factors.

7. Temporal factors have to do with the stage in the handicap trajectory and in the family life cycle and with the effect of maturity and life experience on the abilities of the parents. Their importance can be seen in the intensity of the need for information especially in the early stages of the handicap trajectory and the child's school career, and in the strong influence of the managing history of the handicap, especially the "burnt finger" reaction which can impede or in some cases enhance the use of future managing strategies.

8. The level of consciousness of their needs is significant. The parents who are at the top of the managing scale are the ones who verbalise diversified and strong needs. To a certain extent the ability to verbalise needs coincides with the socio-economic status of the parents. However this is not true in all the cases. The attitude towards the handicap seems to suppress

the consciousness of needs in some cases or to direct it to less threatening areas.

9. The above considerations place the need hierarchies of this group of parents in context. The practical implications will be dicussed in Chapter VIII.

## CHAPTER VII

### THE SAME STORY FROM OTHER SOURCES OF INFORMATION

#### 1. INTRODUCTION

In the previous chapter the findings from a grounded analysis of interviews with the parents were presented and the emerging structure of needs discussed. Here a summary is given of questionnaire replies of 22 parents of handicapped pre-schoolers attending a special school and 20 interviews with staff members of this school.

#### 2. QUESTIONNAIRE ANALYSIS

The parents were asked to state three salient needs they experienced because of their child's problems and to what extent these needs were being met. The second section focused on the home/ school link. Parents were asked to list needs and give practical suggestions for ways in which the school could meet them. A specific question was asked about the role of the Parent Teachers Association and its contact groups in meeting these needs (See Appendix C ).

Some considerations regarding the analyses of these responses warrant explanation. The format of the questionnaire invited anonymity. The rationale behind this was to minimise the intimidation factor thus giving parents the freedom to voice sensitive or negative feelings. The reaction was different to the expectation. Only six parents sent anonymous returns and only two of these contained more critical remarks. However, these remarks were not more critical than remarks voiced during interviews. This could indicate that neither of these research methods allowed the parents sufficient freedom to criticise or that parents do not have an intense need to criticise and felt free to say what they felt.

As in the interviews, the tone of the responses was generally positive. Though many unmet needs or partly fulfilled needs were voiced most parents expressed positive feelings of

gratitude towards the school and other support systems. This did not prevent them from contributing positive suggestions for the improvement of these services and to indicate how some of their needs could be fulfilled in more appropriate ways.

In many cases the parents personally brought the responses or wrote messages inviting further discussion. This echoed a need which had become clear during the interviews. Parents were eager for occasions to discuss their needs with sympathetic staff members. In contrast to the trend in the interviews, the questionnaire need responses were more parent directed and parents actually asked for emotional support. The format of the questionnaire could have made it easier to express this sensitive need.

The children of the interviewed parents were all past or present pupils of mine. In the questionnaire group there were three who had children in my class. Among the pre-school teachers, there were differences in the amount of time and effort they were prepared to spend with parents. As my special interest was the link between home and school my efforts in this respect were consequently more pronounced. This factor should be kept in mind.

Completing the questionnaire was entirely optional while parents in the interview group may have felt more of an obligation to participate. Parents who complete questionnaires were selected in the sense that they were motivated and confident enough to complete the task. In the interview group there were parents who had specifically requested the interview because they felt hesitant to complete a questionnaire.

Although the interviews and questionnaire basically covered the same content matter their format differed. In the interview the context of the needs and their interconnectedness were obvious, while the questionnaire responses tended to be more a listing of needs. Comparison of the two necessarily focus more on content analysis.

## 2.1. PARENTAL AIMS AND ATTITUDES

The questions asked and the nature of the replies gave little scope for discussing the aims and attitudes of the parents. The need for mainstreaming and for the happiness of the children were not mentioned at all. Some parents verbalised

needs for the eventual independence, emotional adjustment and social acceptance of the children. The role of support from spouses, family and friends in enabling them to come to terms was stressed. In one case the spouse's inability to come to terms drove her from the family. The need for positive thinking and positive input was emphasised. The interplay of aims and attitudes leading to motivation was vague in the context of the questionnaire responses. However, the role of parent initiative and active parenting was stressed as important.

## 2.2. PARENTAL ABILITY

There were many entries in the questionnaires relating to the need "to be able to". The most mentioned need was the need for balance between spoiling and the drive for independence; in disciplining; in time spent with siblings and the handicapped child and on their own needs. The need for guidance in the handling of siblings was mentioned and the creation of a sibling support group suggested. The need for active, responsible parenting and for training in educational matters corresponded with the need for reflective parenting as seen in the interviews. Parents emphasised the problems they experienced when they had to teach things to their children. The need for more patience was mentioned explicitly. Conflict between parents over the disciplining of the child was a problem in at least one case.

The social skills needed for managing were mentioned in connection with information and support needs. Some questionnaire responses stressed the need to be in control of decisions.

Q1. A link which does not support ignorance but will approach a problem with our child not their pupil. The main problem we have encountered has been a misled "possessions" of school over pupil which tends to be autocratic (QR7).

The need "not to be blamed"; "seen as part of the problem"; or intimidated, was mentioned. The importance of an individualised approach to parents and an attitude of acceptance was stressed as well as the parents' need to be respected as able to contribute their knowledge.

Q2. I need to know that my "hunches" about my children are going to be taken seriously by i) the medical profession ii) the educational/psychological profession. Ever since *my child* was 3-4 days old, she has had feeding, bowel and sleeping

problems, which culminated in me being prescribed antidepressants, and *her* problems being entirely a figment of my imagination. To this day whenever I make a serious suggestion, it is laughed off (QR2).

Parents needed to feel available to their children. A number of parents; including two single fathers stated their need for time to spend with their child especially when there were siblings.

The general picture of parental need for empowering in their role as managers, especially as far as the upbringing of children was concerned, coincided with emerging need patterns in the interviews.

### 2.3. "THE NEED TO KNOW"

The need for information was emphasised in almost every questionnaire response. The range and the reasons correlated well with those mentioned in the interviews. The need to know about the child's future was especially emphasised. Parents wanted to know how secure the child's placement was at the school to enable them to plan for the future. Concern for the future of state funded special schools and the need to be informed of future educational strategies was aired. Information because: "we'd like to feel that we're the people in control of decisions taken for our daughter" (QR 14) was stated quite bluntly in some cases. The need for information that would enable parents to be involved in educational or therapeutic processes was also stressed.

The sources from which information was needed were mainly the teachers, therapists and the school in general. As in the interviews a special need was expressed for more feedback from the therapists, especially the occupational therapists.

Types of information needed were described as two-way, constant, day to day communication; as much as possible feedback on progress, problems, prognosis; reports on what "they are doing with my child all day"; and reports on the school's methods, aims and future plans for the child. Parents also asked for more general information on handicaps, child development and education.

Their judgement of the appropriateness and accessibility of information provided coincided mostly with points mentioned in the interviews. These parents also emphasised the need for direct and honest information, expressed their satisfaction

with the message book system used in the class and asked for an extension of this to the therapies. One mother mentioned the need for home visits. None commented on telephonic contact. The coffee mornings were appreciated but evening meetings with therapists and teachers and more individual meetings were requested urgently.

These parents also experienced more satisfaction from the school's information provision when they lifted children regularly. The parents' responsibility to take initiative in procuring information was stressed.

#### 2.4. THE NEED FOR SUPPORT

As with information, the need for support was mentioned in nearly all of the questionnaire replies. This group had the same reasons for wanting support but were more explicit in their need for parent directed support- i.e needing support in coping with themselves, needing counselling or needing a helpline.

The sources of support also coincided with those mentioned in the previous chapter with the addition of explicit references to the importance of spousal support, ; the state's role as supplier of support and the role of society in providing acceptance and special amenities. As in the interviews, the importance of support from other parents of handicapped children either in contact groups or as personal friends was heavily underlined.

The types of support needed, correlate with those mentioned in the interviews but the need for appraisal support was not mentioned at all while the need for emotional support was more pronounced. The need for respite was verbalised as

Q1. I need to have time on my hands, to myself, to be able to do things I enjoy without even slightly involving the family and thereby salving a guilty conscience of being selfish, or neglecting them etc.(QR2).

The need for a place where emotionally disturbed children can stay for a few days was stated. The need for special schooling and the services offered was strongly emphasised. Financial needs were verbalised explicitly as well as the need for affordable and functional apparatus.

The appropriateness and accessibility of the support was not discussed as fully as in the interviews. However, the

problem of inappropriate albeit indispensable support from family was described as well as the positive role of family and friends. The appropriateness of the PTA and their contact groups was discussed. Some parents felt that the PTA could serve as a negative force-"a battle ground for grievances" etc. Others felt the contact groups were indispensable and fulfilled a valuable role as givers of informative support, emotional support and social support and were thus a source of empowerment for parents.

The school's function as support system is widely appreciated but with the plea that parents be made partners and not treated as part of the problem.

## 2.5. THE CHARACTERISTICS OF THE HANDICAP AND THE FAMILY

These characteristics played an important role in determining the need hierarchy of the parents as was the case in the interviews. Emotional and behavioural problems caused special needs for managing. One mother stated that only counselling by a psychologist helped her to cope. The special medical and care needs of a spina-bifida and a diplegic were stressed. The need for special schooling and therapies and concern for the future of the child were all related to the special circumstances of the child.

The characteristics of the family and resulting needs were evident in the case of single father families and those who mentioned the impact of more than one disability in the family.

Q1. Lack of time. I am a single parent with insufficient time for my children or myself. The handicapped child takes up enough time for any 2 or 3 other children (QR11).

There was a strong emphasis on the problems brought about by the large geographical area which the school services. The large distances the children travel and the problems related to the school's bus service were highlighted. Problems in getting friends for the child as mentioned in the interviews were emphatically underlined.

The cultural background of the family influenced requests for more Christian input and an Afrikaans class. Socio-economic circumstances determined the type of need mentioned especially with respect to informational needs and the services offered.

Q2. It is very necessary for planning to be done by audit - or even better - for protocol and approaches to be based on research (QR7).

Q3. As the need of each child is needed through the various therapies it is necessary to be able to keep up dated on when extra work is needed to be done at home - if the child needs to have extra input at home if one is able to do so (QR4)

Q4. Definitely good, strong, reasonably priced apparatus. Medical Aid doesn't always pay for wheelchairs, walkers etc. and the price they are, many children will have to have a cheap make or go without until Mum and Dad can afford to buy (QR2).

## 2.6 CONCLUSIONS

Considering the circumstances mentioned above there was a remarkable correlation between the content of the questionnaires and that of the interviews. There were clear indications that the need to manage was as important there as in the interview group. In the questionnaire responses the focus was slanted toward the need to manage themselves and the rest of the family. In a few questionnaires the need to manage the support system was stated explicitly. The focus was on managing the services of extended family and sharing the responsibility at school.

## 3. STAFF INTERVIEWS

These interviews were conducted with 20 staff members working directly or indirectly with the pre-schoolers in question. They varied in length, depth and intensity and were generally shorter than the parental interviews. As the purpose of these interviews was for background rather than in-depth analysis both transcriptions and analysis were more superficial. Attention was given more to the structure of parental needs than to details.

I discussed some general trends and considerations before a detailed account of staff interviews are given. Although there were differences in degree and type of attitude toward parents, the general feeling emanated by the interviewed staff of this particular school was of deep and sincere empathy toward the parents for their plight. Sometimes it was difficult to judge whether staff members were giving their perception of parental needs or their views on what parents should need as

they slipped easily into the didactic mode. In some instances staff needs seemed to influence their perception of parental needs.

Amongst the elite, preponderance of school needs had a determining influence. Possible parental needs and their fulfillment were perceived in the context of their feasibility in the school system, especially with regard to responsibility toward pupils and staff members. Background and training of staff members showed a definite influence on their attitude toward parents. The most decisive factor came from the experience of parenthood.

Q1. You know, now that I am a mother myself it has just changed things so much because you realise that you know your child better than anybody else and you are the one that loves the child most and will do anything for that child (S17).

The background of preprimary teachers predisposed them toward frequent two-way communication and sharing of nurturing responsibility with parents as is customary in preprimary schools. In special schools the preprimary section forms an integral part of the school. In comparison, there is less parental involvement in the higher standards where the focus is more on teaching. According to teachers interviewed, this had a determining influence on policy and attitude towards parents.

Most staff members are not trained to work with parents. Some regarded this as a serious drawback while others argued that natural skills and empathy were more important. The traditional attitude toward parents in the special school often centred on the belief that parents of handicapped children were so enmeshed in their own and the children's problems that they needed help rather than involvement but one of the elite stated that the focus was gradually changing towards cautious parental involvement.

### 3.1. PARENTAL AIMS AND ATTITUDES

Some staff explicitly stated their view of parental aims for the children. An elite member stressed that parents had a great need for education equipping their children "the same as the child outside"- always with the hope of an independent career. This need for independence and also for the happiness of the child were often mentioned. A psychologist found the need for a miracle often among preschool parents. The school is

seen as an institution being able to "fix" their child. In another elite interview the extreme importance of realistic information on the child's future was stressed. Parents need a very clear conservative picture of what they can expect and the school must be careful not to raise false expectations.

Most of the staff interviews dealt extensively with the parental need for coming to terms. Although their definition of "acceptance" varied considerably staff perceptions were that this is the most prominent need among parents. Aspects highlighted were the problems parents experience, the nature of the process, the support facilities needed and the necessity for acceptance.

According to staff members the following factors impeded or enhanced acceptance: the nature and severity of the handicap, the time of the onset of the handicap and the personality and expectations of parents. A psychologist stated that from his experience the extent of the child's physical handicap is not necessarily a determining factor that impedes acceptance. Parents mostly had problems in accepting mental impairment. In a number of interviews staff felt that fathers experienced more difficulties with acceptance and that most parents experienced guilt feelings. One psychologist found a definite link between the parents' guilt feelings and their repression of and/or reluctance to acknowledge their needs. This tendency is described as the "brave front syndrome".

The nature of the process as seen by staff showed the same variation in the time schedule and levels of consciousness that are depicted in the parent interviews. This process were depicted as: "counting your blessings"; a task parents had to tackle actively and get done with; an ongoing process with various stage of mourning and acceptance or a process everybody had to tackle in his own way and time. A general attitude among staff members was that parents needed support and reinforcement to enable them to come to terms. Some advocated an active role for staff members and suggested various ways in which this could be facilitated, others advocated a more passive role of "being available" in the background and others felt they were not qualified and/or available to handle this.

The reasons stated why parents needed to come to terms were parent, child and school related. Some staff members saw it as a prerequisite for success during the child's school

career. The accepting, realistic parent was seen as constructive, action orientated and active in the child's school progress and thus motivated to do their best for the child. One staff member strongly identified with parents who are still hunting around for a miracle. She saw this is a parental right but which also constituted a threat to professionals who wanted parents to accept their realistic advice and have trust in their ability to help the child. This feeling was echoed by another staff member who queried the emphasis that is laid on the parents acceptance of "realistic information". She felt that it was more a need of the staff to work with "accepting parents" who are not too demanding, not too critical and not too hopeful. Some staff members commented on the tendency to describe active parents as non-accepting, over-involved and over-ambitious. The interplay between attitudes and aims as seen by a staff member was described as follows:

Q1. I think that the parents must be helped to accept the cold fact of the handicap realistically and not have any stupid thoughts or very real thoughts as to what is going to happen. Not that you can project exactly, but how often you get parents who are totally unrealistic and I think it is not fair on the child because their expectations are too high and I think this is where the school can help them in the kindest possible way to accept the limitations of the child (S4).

### 3.2. PARENTAL ABILITY

As the staff group who were interviewed, also represented the main support system these parents wanted to manage, their views on parental abilities and the ways in which the school was able to accommodate these abilities or lack of abilities, were significant.

#### 3.2.1. Parental skills

There were marked differences in the way in which the ability of parents to manage were seen. The psychologists stressed the parental need for understanding, guidance and information to enable them to manage the child. A member of the elite indicated the importance of the staff's role in educating the parents. Specific problems mentioned were : 1. the problem of looking past the handicap and seeing this child as a person in his own right. 2. The difficult task of disciplining/managing the child with the potential for

overindulging or rejecting, enmeshment or rigidity and the struggle of keeping a balanced approach. 3. The problems parents had in coping with outsiders or professionals who blame them for the behaviour of the child- defining the child as "spoiled brat". 4. The important role of parental guilt which complicates parental attitudes significantly.

### 3.2.2. On managing the support system

The views on the parents' ability to manage the support system varied even more and strong views were expressed. Some staff members felt adamant that parents did not share responsibility and tended to dump the child on the school. They based their views on the fact that parents did not carry on the work started at school, were not interested enough in the work of the school as was evident from non-attendance at meetings, not reacting to messages and not showing enough interest in the education of the child.

Other staff members felt as strongly that the attitude of the school did not make it easy for parents to realise their responsibilities. Factors mentioned as impeding circumstances were: 1. the attitude that some professionals radiated that they will fix the child, parents must hand over the child and professionals know best thus indicating their superior capabilities. This attitude tended to disempower parents and encouraged the "handing over". 2. Teachers felt that there were not enough occasions for parents to bring their side, providing teachers with information on home circumstances, giving feedback on the child's reaction to school and above all, sharing their views on the child's needs, problems and successful ways of handling him. A teacher stated that the attitude of schools in general is geared more to "pushing parents off" than to incorporating them as team members. Disempowered parents cannot take responsibility. 3. One teacher felt that the tone was already set during the assessment week with anxious parents and a collection of competent but secretive professionals who gave non-committal answers. 4. The fact that staff members easily felt threatened if parents took too much interest in the child's schooling or therapy and regarded these parents as "naggers" or "nuisances", discouraged parents 5. There were too many specialists who often did not see the child as a whole. Parents got confused about where they

must go and to whom they must talk. 6. Although parents had the major responsibility for the child, they had little or no say in intermediate decisions. The lack of mechanisms to ensure parental input of information and needs was an impeding factor. According to a staff member the attitude was that "the school will decide" rather than "let us sort this thing out together". 7. Lack of other facilities contributed to parents feeling intimidated/dependent and consequently disempowered.

Q1. They are feeling excluded from the process that is happening with their child at school- and at the same time it is a privilege because they are getting an awful lot for a very little money and everything is apparently being done. So they have no part to play in handling the problem - all under control (S19).

Thus some staff felt that parents could not realise their full responsibility to manage the support system because of the nature of the system rather because of their inabilities.

Other staff members felt that other needs of the parents overshadowed the need to manage the system. The official policy of the school on decision making was that the team who worked with the child had to discuss issues among themselves and come to a decision as it was better to present a united front to the parents. According to one of the elite, the rationale behind this was that parents needed to have confidence in the professionals and differences of opinion among team members was very confusing. He felt that confidence and trust in the school should be regarded as overriding needs for the parents as they already had to deal with enough uncertainties and confusion.

On parental involvement in the teaching or therapeutic activities in the school or even at home, the official school policy was cautious. It was felt that most parents had limited ability and/or training to help and understand the individualised nature of the teaching methods. Teachers and pupils needed protected against difficult situations and parents might not cope with the fact that their children struggled in class.

The official viewpoint on parental involvement and responsibility tended to be protective toward parents and staff not encouraging empowering or involvement of the parents especially with regard to the school's educational and

therapeutic task. This might explain some feelings verbalised by parents.

### 3.2.3. The nature of parents' capacity to apply their skills.

There was a general feeling of compassion and understanding for the many tasks parents have to perform. The plight of working and single parents was isolated as difficult. Staff members were fully aware of problems parents had in applying their skills. The need for time and care for siblings was also stressed. Some staff members had special understanding for the full schedules of parents and warned against giving "guilt provoking exercise drills" to be completed at home. Instead they advocated the giving of tasks that could be incorporated into daily routines. One psychologist emphasised the importance of spousal and vocational responsibilities and the danger of being too involved with the handicapped child. A few staff members mentioned the necessity for parents to have time out and had understanding for parents who felt like handing over their responsibilities.

### 3.3. THE NEED TO KNOW

The staff placed this parental need as high as the parents did in the hierarchy of needs. The reasons why parents needed information were according to staff members: 1. to know the implications the handicap would have on their child's, their own and family life now and in the future. The giving of a prognosis was discussed by a medical doctor who often found it necessary to curb parent expectations on the information doctors were able to give; 2. to know the origin of the handicap and if they did anything to cause it; 3. to help them to come to terms - here the role of realistic information was stressed; 4. to enable them to monitor the child's progress; 5. to plan for the future; 6. to empower them to play a role in the managing of the handicap projectory.

Q1. *The parents need information to make the decisions. The child is my responsibility. The repercussions would be the family's to handle so - feeling that I was the most important member of the team as far as decisions was concerned (S 19).*

The sources of information were basically the same as those the parents had mentioned. The medical doctor mentioned that parents were often intimidated by the status of medical

professionals and rather needed people with whom they felt at ease, to provide information. A general feeling among the staff members was that preschool teachers were a valuable source of information because of their close and frequent contact with parents. The importance of real-life experience for the child as a source of realistic information was mentioned by a physiotherapist. The staff perception of types of information needed coincided with those mentioned by the parents. The need for realistic, honest and positive information was stressed.

Accessibility and appropriateness of information were discussed comprehensively by staff members and covered a range of opinions. Staff regularly in contact with parents generally echoed the parental need for more information. The opinions of other staff members varied, some regarded this need as unrealistic or excessive. The ability of the parents to process the information was considered an important factor in the perception of the appropriateness of information. The shock of bad news, the emotional state of the parents and the technical nature of some information could influence the processing ability of parents. The necessity for sensitivity to parental needs was emphasised by staff members. The importance of sending a written report of sensitive discussions to parents was stated repeatedly.

Differences of opinion were expressed on the effectiveness of information giving mechanisms at the school. Teachers felt that more occasions for two-way communication were necessary. Telephonic contact and home visits would have answered this need to a certain extent but time constraints and the geographic spread of the parents made this impractical for most. The therapists discussed their problems in relation to private practice where routine contact with the parents was customary. Some felt that the parents should have taken more initiative in finding out what was being done. Others felt staff should have initiated contact. Psychologists and therapist experienced practical problems with an ever increasing case load which prohibited too much parental contact.

The need for professional sensitivity toward parents was echoed and some staff lamented their lack of training in this respect. A factor that impeded staff's ability to give appropriate information, was the lack of regular and systematic contact between members of the team due to the size of case

loads. Although channels for informal contact existed they were not always appropriate and feedback to parents was effected.

The impression that emerged was that staff were aware and sympathetic to this need for information but were not always able to fulfill the expectations due to problems in the school system.

### 3.4 THE NEED FOR SUPPORT

According to the staff's perception this parental need was extremely important. This could be deduced from the frequency with which it was mentioned, time spent on this issue and the importance staff members apportioned to this need. The reasons for needing this support mainly focused on the parental need for acceptance and understanding. The sources of support mentioned were other parents of handicapped children, the school's contact groups, teachers, psychologists and other staff members. Prominence was given to the role of the contact groups disregarding the fact that these groups were only functioning effectively in two or three areas. The need for a social worker at the school was mentioned by a psychologist.

Types of support needed were regarded mainly as emotional needs: sharing with other parents, counselling, a sounding board, reassurance, empathy and acceptance, guidance through stages of grief, help with working through unnecessary guilt or toward empowerment. Further needs mentioned were for practical help especially during a crisis and the need for sibling, partner and extended family support. One therapist stressed the special support need of fathers whom she described as "shadowy figures in the background" not getting a chance to speak out.

The appropriateness and accessibility of support were discussed at great length by staff members. The harmfulness of inappropriate support e.g from family and friends as opposed to appropriate professional support was mentioned in an elite interview. There was a general feeling that support, like information should be geared toward gaining realistic acceptance.

There were differences of opinion on the accessibility of staff members for the support role. On the one hand this task was seen as the prerogative of staff psychologists. However, some psychologists and other staff members felt that any staff

member who had had sufficient contact with a parent could have fulfilled this function. Preprimary teachers were regarded by many as appropriate but lack of training, time and energy constraints were seen as impediments.. The psychologists stated that their doors were open for this purpose but they could give their services only on request. For various reasons their services as support givers were not fully utilised. There were indications that barriers, such as heavy case loads, precluded intimate knowledge of children in the preschool school and thereby limited these services. One psychologist emphasised the necessity of round the clock support facilities. Some staff members were willing to supply parents with home telephone numbers and encouraged parents to make use of them in cases of need.

The policy of the school toward broader family support-preventive, crisis intervention, sibling and marriage support was cautious as this was not seen as the prime function of the school and could lead to further work overload, the danger of confrontation and alienation and intruding into the privacy of the home. In severe cases where the child was suffering, intervention was clearly justified according to one of the elite. The importance of referral to outside agencies was stressed. Conclusively, it seemed as if there was tremendous goodwill toward the support needs of parents but there were problems with the accessibility and appropriateness of support facilities.

### 3.5. CHARACTERISTICS OF THE HANDICAP AND THE FAMILY

Staff members did not dwell on the impact of the characteristics of the handicap or the family. The main entries showed a similarity to the problems and needs mentioned in the parent interviews. Impact related to handicap characteristics were: parental problems in accepting intellectual impairment; special problems experienced with diagnosing, understanding and living with learning disabled children; problems in coping with and accepting the physical side of the handicap i.e. cuddling an ever drooling child or taking the child to public places and coping with a tactless and curious public.

The characteristics of the family and the impact these had were seen to be relevant in the case of single parents,

especially single fathers, and working parents. There was an acute awareness of the need to accommodate their specific circumstances. Sibling needs and balancing of priorities in the family were mentioned as well as the special measures that should be taken to incorporate extended family members in the support services of the school.

One of the elite commented on the fact that the only real problems mentioned by preschool parents were problems in connection with the bus system. This underlined the prevalence of this need. Problems of social isolation due to the geographic spread of the school were also mentioned and the need stressed for parents of school friends to meet.

### 3.6. CONCLUSIONS

The interviews with staff members provided an interesting portrait of a group of people representing different statures, disciplines and backgrounds but all working with the common purpose of educating handicapped children. Dedication and commitment to the task were shared values, though expressed in different ways.

In the context of this study the differences lay mainly in attitudes toward parents or in the ways in which the parental roles were perceived in relation to the common aim of educating the children. As was expected and understandably, the staff in the elite category tended to be more protective of the school system and its workers. Attending to the school's needs for the achievement of maximum efficiency was seen as vital to the well-being of the children as well. They saw the parents as valuable co-workers in supplementing the school's income, helping with the essential service of giving emotional support to other parents and providing home circumstances that were conducive to the enhancement of the school's educational task. They preferred to restrict the parents to these roles although they realised the necessity for parental input in other sectors. In some cases a strong empathy toward parents was evident in a protectiveness toward them. This resulted in a confining of parents to "safe" exposures to school activities.

At the other side of the spectrum the preschool teachers were more aware of the role of parents as partners in the educational task. The sharing of the nurturing role with

parents as well as the pre-school children's relative dependency on parents and teachers made it essential for them to liaise closely. Frequent contact with parents sensitised these teachers to individual needs of parents. In some cases the teachers identified strongly with these needs and became advocates for parental rights, pleading for the empowering of parents.

The attitudes of other staff range between these two poles with degrees of empathy and/or identification with parental needs along with awareness of the practical complications of answering these needs.

Another salient difference was evident in the way in which staff members saw their duty in fulfilling some of the needs of the parents. The balancing of priorities played a role in this respect. A teacher described home visits as

Good, but not so practical. Parents live all over the place and it is time consuming. If one feels strongly about it one could do it. Sometimes it is of course necessary. (S16)

A warning was issued in one of the elite interviews that instructional time should never be used for parental support activities. Opinions also differed with regard to the role staff initiative should play. Some advocated an active role while others felt that they must only indicate their availability and leave the initiative to parents. Others were however careful not to intrude in any way. A teacher said that she did not want to be forward in inviting herself to the children's homes or even in phoning them. She felt she had to wait for them to indicate their need. This should be placed against the background of one of the questionnaire replies.

"But maybe the school staff can project to the parents that discussions are welcomed. That problems can be discussed without fear of rocking the boat. And above all the school has to work very hard helping parents with guilt feelings, fear of the future and feelings that they are part of the problem instead of the best informed team member as regards their own child." (QR1).

In the final analysis a picture emerged of a school where there was sympathy toward the parents and their needs and a parent body that was mainly satisfied with the services provided. However, a large field of unrealised needs remained. Both staff and parents were aware of these areas and comments coming from interviews and questionnaire responses indicated

that moves were being made from both sides to bridge these gaps.

## CHAPTER VIII

### CONCLUSIONS

#### 1. INTRODUCTION

In this chapter the research findings are discussed against the background of the literature review. In the process conclusions are reached and hypotheses presented. This is followed by some recommendations for practice and research.

The principal fieldwork results were grounded on the analysis of the fourteen parent interview transcripts. The comprehensive need to manage emerged as the main need of the parents. The overriding purpose of managing was to control/minimise the impact of the handicap on themselves, their family and especially on the affected child and his future. These parents wanted to be able to do their best for their child, they wanted to come to terms with the handicap, and they wanted support and information, all to enable them to manage. This finding led to an attempt to analyse the process of managing.

The open format of the interviews enabled me to get insight into parental motivations, attitudes and aims and parenting competencies. It was possible to get an idea of the impact of the handicap on the family. The presence of both parents at most interviews helped to give a more comprehensive picture of the family and their interrelationships. The relaxed atmosphere of the interview encouraged the telling of histories and anecdotes which added to the richness of the material and placed the events in the context of the family life cycle. This in turn gave insight into the sequence and causality of events and made the development of the management model (M-model) possible which provided a framework to incorporate and relate other need themes.

I was aware that my position as teacher and the wide focus of the interview could limit verbalisation of specific and or sensitive needs. However, the anonymity and need focus of the questionnaire format partly compensated for these

factors. Causality, motivation and attitudes were more difficult to assess. However, the need picture emerging from these research methods was fairly similar. In both sets, the need to take an active role in managing were emphasised by most parents. The unspoken or outspoken need for empowerment to enable them to fill this role was obvious.

The staff interviews provided the context of the parents' main support system; insight into staff need perceptions; and a safeguard against researcher subjectivity. The managing need did not emerge as clearly from these findings. A dominant theme perception was that parents needed information and support to be able to accept the situation. Diverse viewpoints among staff emerged. Some questioned the existence of parental motivation to manage, and quoted examples of parental neglect and apathy. Others underlined the professional tendency to take over and the resultant disempowerment of parents. These viewpoints forced me to re-check findings of parental perceptions and threw light on the nature of the educational support system.

I found the methods used to assess parental needs effective in providing rich and deep data, presenting a broad spectrum of perspectives as well as a measure of triangulation. In the next sections special attention is given to the relevance of theoretical concepts introduced in chapter II in relation to the fieldwork results and literature review. The characteristics of the family system; ecosystemic influences; and the importance of support systems are discussed. These mutually affecting factors form the object of the managing process and provide the resources required by parents to manage. I then looked at the processes of stress, coping and adaptation, including the managing process which forms an integral part of these last processes.

## **2. FAMILY SYSTEMS**

A shift has taken place in early intervention theory and practice toward a focus on family services. The question is whether my research findings reflect this trend. Do parents express the need for broader family involvement?

Considerations relevant to this question are: 1. Parents in South Africa do not expect family services. I expected their verbalised needs would concentrate on child-directed needs as

parents do not ask for things they do not regard as relevant or attainable. 2. Summers et al., (1990) found that even in family-focused programmes, parents tend to concentrate on specific child- needs. 3. Moore et al., (1986) found that families often needed help in identifying and verbalising needs and were reticent to verbalise needs, fearing it might reflect a negative impression of their ability to care for their children.

In light of the above it is not surprising that few family needs were actually verbalised during the interviews. Parental needs were directly linked to child needs in most cases. However, descriptions of a day in their life indicated family needs and implied a need for family services. This was confirmed by anecdotes in which they openly discussed their past needs - a trend also observed by Moore et al. (1986). In the questionnaire analysis family and personal needs were indeed stated more explicitly and in some instances requested from the school. Staff were aware of family needs but divided whether this implied a need for greater family involvement from the school. Examples of unutilised family services were given and the danger of intrusion mentioned.

In the literature, the need for family services is strongly emphasised through the results of need assessments as well as the history of special educational practice in some other countries (Gallagher, 1992; McCleary, 1985; Mittler, 1990). The shift from child directed services to family focused services is evident in the greater provision that is made for family needs. Examples of this are the individualisation of services to accommodate family differences and the broadening of the scope of the services to include family needs. The special needs of the family system and its individual members have become relevant and successful efforts have been initiated to involve fathers, siblings and extended family members.

The next question is to what extent the comprehensive need to manage as found in the research, indicates a need for broader family services? This question will be answered using the Turnbull family systems framework (Chapter II, fig. 1), looking at Family Resources (including characteristics of the handicap, the family and its members), Family Interaction, Functions And Life Cycle. Fieldwork results are discussed

against the background of the literature presented in Chapter III.

In the literature it is stressed that the severity of the handicap does not necessarily determine the strength of the impact of the handicap on the family. However, in association with other detrimental factors it can play a determining role. The amount of change demanded by the handicap is important.

In the fieldwork the following factors indicated needs for family- focused services: 1. Parents' sensitivity toward the possibility of mental impairment of the child. 2. The exhausting care needs of diplegic and spina bifida children. 3. Behaviour problems related to the handicap causing management problems and social stigmatisation. 4. Lack of a definite diagnosis and/or unclear indications of the handicap's prognosis causing fear, confusion and insecurity about the future in parents.

As described in the literature review the unique characteristics of each family and its individual members play a role in the way families manage and call for sensitivity toward their special needs. This was confirmed by findings of the fieldwork.

Single fathers and mothers complained about their limited time and the schools' lack of accommodation to their time schedules- a complaint echoed by working mothers. Single parents also had special needs for reassurance, guidance and understanding and voiced locus of control problems experienced through sharing child care with indispensable extended family. The staff were aware of these special problems. In all these families the number and age of siblings were relevant.

The geographic location of the parents was prominently mentioned as a significant factor in relation to the disruption in family life the spectre of the "departing bus" in the morning; the upsetting effect of long and unsettling bus rides on children; lack of school friends in the afternoon; and the prohibiting effect of long distances on the frequency with which parents could visit the school, or teachers the home.

A family characteristic which seemed to have a strong effect on the family's managing ability in this sample was the socioeconomic background of the family. Professional status and/or higher educational qualifications were enhancing factors which neutralised the effect of other impeding factors thus

enabling parents to manage. This trend is not generally confirmed by the literature studies although some authors mentioned teachers' problems in relating to parents with lower socioeconomic backgrounds. Problems mentioned by Afrikaans parents were the lack of an Afrikaans class in the pre-school and misunderstandings and/or reticence they had experienced because of language and cultural problems.

The presence of handicapped siblings in the family was a major factor in this group and affected parental attitudes and their capacity to manage. Parents clearly have special needs for sensitivity understanding and accommodation from staff members. This factor is rarely mentioned in the literature.

The nature of FAMILY INTERACTION could play a major role in the determining of parental needs for family focused services. In the literature the dangers of focusing on the mother-child dyad is stressed and the importance of family subsystems in relation to intervention services underlined. Parents in this group were not so aware of these dangers and mothers even requested more guidance on home activities. However, some fathers indicated their need to be more involved in the education processes of their children. Staff members showed a strong awareness of the special needs of fathers. One made the remark that fathers were too often "the shadowy figures in the background" (S 14).

No explicit needs were mentioned that had a bearing on the marital subsystem but the need for services which give support to spouses who are struggling to adjust, was evident. This was also true in the case of siblings and in this respect a special request was made by a mother for sibling support groups organised by the school. The inclusion of extended family members in support and informational activities of the school was requested by a mother and discussed by others. The interviewed psychologists all stressed the importance of support to fathers, siblings and extended family.

The demands made by other FAMILY FUNCTIONS (the outputs of the family) are important factors in the family's need hierarchy. According to the literature sources these can play a decisive role in dictating the type of individualised needs parents have. This was confirmed by the fieldwork results.

Although parents were reticent about financial needs they explained how their economic activities affected the time and

energy they had available for the child and his school activities. This was also the case with the domestic and health care functions of mothers. The interplay between the economic resources of the family, the care demanding characteristics of the handicap and family characteristics determined their output and their need for support and understanding from the school.

Parents described the socialisation needs of the family in respect to the lack of school related socialisation opportunities e.g. nearby schoolfriends and regular contact with mothers at the school. They also voiced needs for respite care facilities and time to do their own thing. These needs relate to the family functions of recreation and self-actualisation. A psychologist confirmed this as an important need and lamented the lack of available facilities.

In the literature the importance of stages and transitions in the FAMILY LIFE CYCLE was emphasised. In the fieldwork, the start of the child's schooling, placement in a special school and transition to formal schooling featured as times when support and informational needs as well as concern about locus of control and managing doubts were strong.

I found that the needs parents expressed or implied strongly indicated areas where individualised family-focused services had a role to play in the empowering of parents to manage.

### 3. ECOSYSTEMS

The relevance of an ecosystemic approach to special education was stressed in chapters I and II. The possibility that problems might stem from a failure of systems and individuals to match was underlined and thus also the necessity of studying the child's environment instead of exclusively focusing on the child's deficits. In this case the child's environment is his family system, neighbourhood, community and state with their informal and formal support systems which comprise the micro-, meso-, exo- and macro-systems. In section 2 the impact of the family system has been discussed and in section 4 the discussion focuses on the support function of the family, school and neighbourhood. Here the focus falls on the macro-system, especially the state provision of special

educational services and its effect on parental ability to manage.

On the whole, parents expressed deep gratitude for the amenities provided at special schools though serious concern was expressed by some about future provision of special educational services in the light of the evolutionary processes in the country. Concern was expressed in staff interviews about current curtailing of state provision which influenced the provision of services e.g. higher case loads and fewer amenities.

The philosophy behind the provision of special services as separate amenities was not criticised at all. None mentioned integration into the mainstream schools as a solution in spite of parents' paramount need for eventual mainstreaming. However, there is reason to believe that the expressed needs of the parents were situation bound in this case as there were indications of problems experienced within the system of special schools.

The child's intellectual potential proved to be a source of concern. Parents who felt that their children's mental capacity was above average were apprehensive about the potential for stimulation and intellectual development in a special school and some wished for "in-between facilities". Where placement in a special school was tentative because of doubts surrounding the educability of the child, parents were concerned about assessment and classification procedures and lack of comparable alternative facilities (P14b). Some parents talked about the realisation that their child would be "put apart" and be "away from the mainstream" (P2a) and many complained about the disadvantages related to geographical and social factors.

The need for more friends for her in our neighbourhood. An almost insurmountable problem for A.P. parents and children- we do realise the reason for the problem, but often wish it didn't exist (QR13).

Parents experienced the results of this "apartheid" when neighbourhood children ostracised their children or when neighbours or family criticised them for putting their child in a special school. The wish was expressed that the general public should be educated regarding disabilities and special schools to change prevailing attitudes. Parents saw it as their

task to give a "solid blast of propaganda" (P7b) for the school whenever they could.

The laws ruling the provision of special education give limited power to parents in governing the school. However, these parents did not voice desires to be more active in the governing of the school but expressed the need to have more control over assessment procedures and school placement decisions.

#### 4. SUPPORT SYSTEMS

In this section the focus is on support systems including informational support, which form an integral part of the ecosystem of the family.

##### 4.1. SUPPORT

Mahoney's (1992) statement that distress is often caused by unmet needs for support rather than by the severity of the handicap illustrates the emphasis on support in the literature. This emphasis has caused a wide interest in the nature and function of support systems and led to interesting work on the empowering of parents through utilisation of their natural support systems. The type and sources of support mentioned in the literature correspond broadly to those mentioned in the fieldwork. However, the focus is much stronger in the literature on the empowering function of support in contrast to the rescuing function stressed in the research findings.

Direct and indirect references accentuated parental support needs and important sources e.g. spouses, extended family, friends, especially parents of handicapped children, and professionals.

Staff members perceived the parents' need for emotional support e.g. empathy, understanding, counselling and acceptance, as important. The sources of support named were parents of other handicapped children including the school's system of support/contact groups, preprimary teachers, psychologists and other staff members in this order of importance. Some lamented their lack of training for providing these services.

Parents were outspoken about the appropriateness and availability of support. Characteristics of informal support systems mentioned had to do with density and boundary density of systems, location in space and time and perceived helpfulness of support.

The dangers of an enmeshed support system were mentioned where overinvolved extended family disempowered parents. The ability to draw boundaries helped others to retain control and to benefit. The support needs of families over time were illustrated e.g. in the beginning stages the family needed emotional support and at later stages instrumental support became more important. These findings are in agreement with findings in the literature.

School professionals were dominant in the provision of formal support in my study but the boundaries between formal and informal support were not clear. Kazak (1987) raised the question of the advisability of multi-dimensional support in the formal sector. Gliedman et al. (1981) warn against the development of friendship bonds as a disempowering factor. However, Summers et al. (1990) found in their assessment of parental needs that respondents strongly indicated that families look to the early intervention practitioner as an important source of emotional support and friendship, showing a strong preference for emotional sensitivity in this relationships which should preferably be "informal, unhurried, friendship-forming" (Summers et al., 1990:95). These authors argue that the importance of empowering and enabling families to become independent of the service system as propagated by Dunst and his associates (Dunst, 1985; Dunst et al., 1988b; McWilliam et al, 1986) is not negated by this finding but indicate that

. . . at least in the early stages of adjusting to the child's disability, families may need practitioners who can perform the *dual* functions of formal (i.e., knowledgeable, capable, and professional) and informal (i.e., emotionally responsive) support systems. The tenor of the comments more strongly endorsed interdependence than independence. . . Perhaps in the professional world of early intervention, we have viewed emotionalism and professionalism as incongruent; thus we describe formal support and informal support as entirely separate. Apparently, families do not make the difference (Summers et al., (1990:95).

The findings of this study confirms the last statement. Although parents were adamant that professional support should

not undermine their authority, they spoke about their need for an open relationship and friendship with staff members as this facilitated discussions and formal dealings with other professionals and thereby empowered them.

The appropriateness of support groups received extensive attention. This often requested type of support is extremely sensitive to variations in the nature of supply and need. Parental needs were not always realised in the present set-up of these groups. Staff members stressed their importance irrespective of their actual effectiveness. However, some warned against harmful support e.g. people who encourage unrealistic hopes and stressed the value of informed professional support.

Issues of reciprocity between the systems are stressed by Gliedman et al. (1981) and Kazak (1987) as important to parents. However, this did not play a prominent part in the fieldwork responses. Some parents positively mentioned their contributions of services but none mentioned lack of reciprocal opportunities as a restricting factor. Staff regarded the services parents rendered to the school as a positive sign of acceptance. Some commented that services rendered against direct payment were usually more efficient as both therapist and parent were more motivated to get good results.

#### 4.2. INFORMATION

The importance of information is stressed in the literature and seen as an empowering factor that enables the parents to manage and to know what they have to deal with now and in future. The availability of information is stressed as a factor that alleviates anxiety, frustration and depression.

The fieldwork accentuated the same points emphasising that information helped them in the process of coming to terms, gave them confidence and promoted relaxed attitudes. Questionnaire responses stressed the need to know about children's prospects at school and information on home programmes. Staff pointed to the necessity to curb parent expectations on the type and amount of information that are available and stressed the importance of information that could alleviate guilt feelings.

The main sources of information are medical and educational professionals but during parent interviews the child was mentioned as an alternative source of information. The happiness of the child, reports on daily activities as well as tangible progress the parents noticed gave them a clear idea of the school's programme and effectiveness. The importance of realistic information gained through observation and comparison of the child in mainstream settings was stressed by some parents and staff members as parents could easily develop unrealistic expectations with a child who copes well in a special school.

Parents expressed strong views on the appropriateness of the contents and ways of delivering information. The need for honest, straightforward information was emphasised but parents wanted to retain some hope. Problems with obtaining initial diagnostic information were common in this group. Parents expressed their preference for frequent two-way, discussions. This was confirmed by the interviewed group's appreciation for home visits and telephone calls. In the questionnaire group, message books were commended and their use by therapists requested. Staff members stressed the importance of open and honest information as vital to the parents but differed on the amount of information they could realistically expect. The elite felt that the information delivery system of the school was functioning well, within the bounds of feasibility. Impeding factors mentioned were the intimidating professional status of information givers, emotional inability of parents to process information, and the use of professional jargon or inappropriate levels of communication. Lack of time, energy and training hampered staff's ability in this respect.

Kazak (1987) sees a connection between the characteristics of social support networks and the flow of information. Factors which play a role are the density and boundary density of networks which can determine the ease with which information flows in and between networks (Chapter II:4.2,3). Open systems encourage fluid information exchange allowing the system to incorporate feedback. The fieldwork findings indicated the parents' strong need to contribute information to planning and decision making processes. Chinn et al. (1978), Dowling (1985) and Taylor (1985) connect the circular process of information exchange with these processes.

The common practice at A.P. school, as in similar institutions (Gliedman et al., 1981), is to have internal team meetings where children are discussed and consensus reached about recommendations or decisions before parents are informed of the unanimous decision or recommendation of the team. The school's main priority is to deliver optimal, well-coordinated, non-confusing services to parents, geared to professionally assessed needs of the child. The concept of boundary density of systems is applicable. Kazak (1987) states that receiving information from diverse sources might make it difficult to integrate the information constructively but she also speculates that a system that is too dense might impede the family's ability to maintain control. The school practice of presenting a "united front", with team members who all know and interact with each other, resembles a dense formal support network which seems to restrict the easy information flow as well as parental sharing of decision-making and control.

The boundary and system density could restrict the imparting of sensitive information. A complication mentioned by staff was that official restrictions and limited information flow within the school system caused by the increasing size of the school e.g. bigger case loads and less time for meetings, affected staff ability to give information to parents. The density within the school became less but adherence to the traditional policy of the school still made the school operate as a closed system. The present functioning of the information feedback loop could possibly disempower parents and staff members in the processes of information exchange.

## **5. STRESS, COPING AND ADAPTATION**

In Chapter II.5 the theoretical concepts of stress, coping and adaptation was presented. Conceptual frameworks proved to be helpful to identify key variables and to balance the focus on positive and negative impact on family functioning and needs. The process of managing as it emerged from an analysis of the interview protocols showed similarities to the double ABCX model on stress and coping as introduced by McCubbin and Patterson (1983). The managing-model (M-model) provided a framework for this study for the identification and organisation of key need concepts and for understanding some of

the interrelationships between these concepts (See chapter VI, fig. 9). In the following sections these concepts are compared with findings in the other fieldwork components and relevant literature as portrayed in chapter IV. To add more perspective my M-model and the double ABCX-model is then compared for similarities and differences in their treatment of this process of managing/coping.

### 5.1. THE NEED TO MANAGE

The impact of the handicap on the family has been described as a stressor that needs managing. This need to manage is referred to explicitly in the research literature. The stressor has been described as an unexpected crisis-provoking event (Gallagher et al., 1983) affecting the family system (Frey et al., 1989) and creating opportunity for growth (Innocenti et al., 1992; Tulloch, 1983). In the fieldwork this need to manage was verbalised in various ways but was most visible in the parents' eagerness to talk, to search for solutions to their managing problems and in their accounts of their daily activities.

### 5.2. PARENTAL AIMS

The fieldwork showed the importance of the nature of parental aims to parental motivation. Parents wanted and wished specific things for their child - some fully or partially attainable and others reflecting a wish for a miracle. The following needs/wishes for the child were paramount.

The child's happiness was of prime importance to interviewed parents. Often this was a fulfilled wish. The need for the child's eventual mainstreaming was mentioned with the same amount of regularity and intensity. These two wishes were not mentioned at all in the questionnaire responses. The staff saw the need for happiness as important but were less aware of the centrality of the wish for mainstreaming indicating the sensitivity of this issue. The actual wish for the happiness of the child received little prominence in the literature. The widespread wish for mainstreaming is well documented in the literature of the seventies and resulted in legislation mandating mainstreaming in some countries. Other wishes/aims mentioned by parents in the literature and fieldwork were for

health, the development of self-concept, future emotional well-being, independence, and the realisation the child's full potential.

Fieldwork responses reflected an awareness of the parent's role in achieving the above aims but none of them expressed the wish to have more say in determining the specific goals on which the school should concentrate - i.e. having decision making powers in the drafting of IEP's. This could partly be explained by the traditional attitudes concerning the respective role allocations prevalent among parents and educators and the absence of a system of formal IEP's in S.A. schools. Most staff members who were asked to comment on this felt that parents were not knowledgeable enough to have a say in child educational goals but emphasised the need of parents for realistic information to help them have realistic ideals. This contrasts strongly with the emphasis placed in the literature on collaborative goal setting.

### 5.3. PARENTAL ATTITUDES

The fieldwork and literature review strongly emphasised the importance of parental attitudes toward the handicap, both stressing the following salient factors which enhanced or impeded the process of coming to terms i.e.. the characteristics of the handicap; the availability of information and support from family members and professionals. A salient factor noticed in the interviews was the influence of the parents' level of awareness of their need to come to terms with the handicap. This had a direct bearing on their ability to work actively on various aspects of their attitudes. Parents discussed this in terms of the inability to face problems. Some staff members saw parental acceptance as a prerequisite for the ability to manage.

### 5.4. PARENTAL MOTIVATION

During the interviews many examples came to light of parents' motivation to do their best for their child. Often it was not so much what they said as the intensity of their discussions which indicated their high level of motivation. The questionnaire replies were focused on naming needs and thus the importance of parental input and initiative received less

emphasis. Yet the overall impression gained, was of a motivated group of people who needed certain things to enable them to do their best for their children. These findings are in agreement with the relevant literature where a strong plea, backed by research results, is made to professionals to recognise the strength of this parental drive/central dynamic to procure the best for their child (Frey et al., 1989; Friedrich et al., 1985; Gallimore et al., 1989; Summers et al., 1990; Turnbull et al., 1986).

The interview protocols indicated factors which suppressed parental motivation or caused fluctuations. Unrealistic expectations and parental attitudes shaped by previous bad experiences played a significant role indicating the importance of the interplay between parental attitudes and aims. Parents who were struggling to come to terms with the handicap had less energy and time to want to do things for their children. The majority of interviewed staff focused on problems of acceptance and malfunctioning prevalent among parents and deplored the resultant lack of motivation. In contrast to this, other staff members felt that the school system was dampening motivation and that many parents appeared to be quite passive because they did not want to rock the boat. According to this group the school expected parents to be fairly passive and accepting of the school's judgement and not to "shop around" for alternative ways of treating the child. The above difference of opinion is also reflective of stages of the history of early intervention.

#### 5.5. THE NATURE OF REQUIRED SKILLS

In the literature it is stressed that the birth of a handicapped child is usually an unprepared for event which violates expectations and causes parents to feel incompetent. This is exacerbated by special skills often demanded by characteristics of the handicap.

From the fieldwork results it was clear that the nature of child-rearing skills required, is not so different from ordinary skills but there is a difference in accent and intensity of need. The need for reflective parenting was stressed. To cope with unusual caretaking demands parents needed conscious and constant consideration, deliberation and

planning. Discussions with other parents and professionals enhanced these abilities. The need for balanced parenting, bonding problems and the difficulties some parents experienced in having to play the role of teacher/therapist, were stressed. In the questionnaire analysis special emphasis was placed on disciplining problems. This and the danger of overprotection, overindulgence and enmeshment were perceived as problems by some staff members.

In the literature importance was given to the same type of skills but with little emphasis on disciplining problems with the exception of some articles in the S.A. Cerebral Palsy Journal (du Plessis, 1982; Schoeman, 1984; Vermeulen, 1987). The need for behaviour modification skills was stressed in earlier publications. The need for problem-solving skills corresponded to the need for reflective parenting mentioned above. Special attention is given to bonding problems.

#### 5.6. SKILLS TO MANAGE SUPPORT SYSTEMS

In the literature the different roles parents are expected to play and consequently the varying nature of the skills required to manage support systems are discussed at length. (Chapter I). The skill of sharing responsibility with the school is emphasised as the preschool period is an important transitional time when boundaries are defined and adjustments made. The role of early interventionists in enabling parents to play their new roles, is stressed. Parents need to be encouraged to assume the role of consumer in relationship to support services. For that they need self-confidence in their own judgement; persistence; communication skills; ability to form relationships; and monitoring skills.

Interviewed parents saw the ability to form open relationships as important. None of them thought that open confrontation was wise and felt that tact was required in mentioning points of critique. The questionnaire responses stressed the need to be able to share control with the support systems; to demand the necessary respect for parental knowledge and decision making abilities; and the need for information and support to empower parents to manage rather than be managed. This corresponds to the skill of assuming the role of consumer.

Contrasting views were aired by staff. Some underlined the need for skills that will enable parents to take responsibility and comply with school requirements for the child's treatment. The ability to be loyal to the school was stressed. Others felt that parents needed skills to retain responsibility as the "fix it" approach of the school tended to disempower parents.

#### 5.7. THE CAPACITY TO APPLY THESE SKILLS

Many studies have been devoted to determining the impact of a handicap on the family system and the effect of family characteristics on their ability to manage. The role of restricted time (Beckman, 1991) and energy (Bubolz et al., 1986) is emphasised. The conceptual model of the family ecosystem (Chapter II:fig. 4,5) gives an excellent illustration of mutual interdependence of family outputs and inputs and the effect of prolonged stress on available energy. The danger of parental burn-out and the continual need to balance priorities are emphasised.

Recently the focus has shifted to the study of the characteristics of strong families who manage to apply their skills. The need for empowerment of families by strengthening their natural resources and support systems is strongly emphasised. Parental burn-out must be prevented rather than studied and treated (Farran et al., 1986). Professionals must work with the child in the context of his family system and be aware of the danger of draining family resources.

The story of the daily life of interviewed parents abounded with testimony that they were not able to do things for their child in the way they wanted or would have been able to do. Time and energy constraints played an important role. Concern over the child and other demands made on them by family functions and careers drained their resources and made them less effective as parents. The questionnaire replies highlighted the need for time to devote to siblings and for some time do things for themselves.

#### 5.8. PARENTAL ABILITY TO MANAGE

The interplay between the nature of the skills required to manage and the capacity of the parents to manage represents

their actual ability. From the protocols of the interviews it became clear that some parents were consciously aware of the need for special skills and actively developed these. This was closely related to their attitude toward their child's handicap and the way in which they had incorporated the family's unique set of values and central drive system into the need hierarchy created by the handicapped child's special needs. Part of the challenge was to balance the demands made by the impact of the handicap and their other responsibilities thus regulating their capacity to manage and preventing symptoms of parental burn-out or the drained energy sink. On the other end of the sliding scale were parents who were not able to develop skills and in some cases were scarcely aware of the need for these skills. They experienced the impact of the handicap as something they had to suffer rather than tackle. This did not necessarily mean that they did not want to do their best for their child but they tended to be overwhelmed by the demands made on them and had a reduced capacity to manage or to apply the skills they had. On the other hand their ability to manage affected their attitude toward the demands of the handicap.

#### 5.9. INTERVENING CIRCUMSTANCES

However, there are intervening circumstances which can further affect the managing processes. These constitute the characteristics of the family system and the availability of support as discussed in section 2, 3 and 4. Intervening factors can enhance or impede action strategies under specific circumstances. The parent's managing capacity is determined by the interplay between these intervening circumstances and parental motivation and ability. Family need hierarchies (Dunst et al., 1988a) and the central drive of families (Gallimore et al., 1989) play an important role in this interplay often determining the nature of the impact of family characteristics.

#### 5.10. STRATEGIES

The managing strategies employed by parents are the actual actions or in some cases lack of actions they take to manage. The fieldwork indicated that these managing strategies were mainly directed to the managing of themselves, the family, the affected child and the support systems.

Some parents vehemently stressed the importance of actively working to come to terms with the handicap because it was necessary to manage themselves to be able to do their best for the child. Strategies employed were passive and active i.e. "thrashing it out on paper", "crying my eyes out", "going for counselling" or "learning to live with it". Some parents mentioned that it was an ongoing process and employed strategies as attending support groups or having talks with other parents of handicapped children, actively seeking experiences for self-growth and enrichment and finding time for themselves to do their own thing. Staff members mostly stressed the importance of active strategies to come to terms and a psychologist emphasised the value of strategies that would enable parents to get some respite. In the literature the value of developing external and internal coping strategies i.e. active relaxation and reframing of the problem was stressed as well as the need for developing empowering strategies.

Managing strategies directed to the child and the family included shouting and screaming in the morning, quiet reflection on better ways to cope, and actively enjoying the child. Strategies to handle the impact of the handicap on the rest of the family were named as "watching out" that other children are not neglected, incorporating siblings in the treatment of the child and educating siblings to understand the nature of the handicap and the ways in which it affected the family. Staff emphasised the importance of educating siblings, employing strategies to avoid overinvolvement with the handicapped child. The importance of these strategies to manage is highlighted throughout the literature. The study of managing strategies promoting strengths and positive family outcomes received special emphasis in recent literature. Managing strategies that were singled out as successful were: employing a sense of humour, being resilient, creative adaptations and resourcefulness.

Parental managing strategies directed to the support systems included the retaining of responsibility, assessing and monitoring services actively or passively, and using round-about strategies rather than confrontational strategies. Staff members pointed to some non-active managing strategies e.g. not attending school meetings, not reacting to invitations to communicate and not doing exercises at home or following simple

instructions given for the benefit of the child. Other strategies mentioned were active participation in the activities of the school; the child's home programme; and strategies to help other parents cope. In the literature various studies highlighted the parental tendency to choose non-active managing strategies i.e. preferring to hand over responsibility when a child starts pre-school and preferring the role of listener and giver of information rather than being too involved with the school programme in governing or teaching activities. This tendency was explained in terms of the parental need to have time and energy to attend to other demands and feeling that the child was well cared for in the pre-school setting.

#### 5.11. CONSEQUENCES OF MANAGING

In the discussion of the findings, case studies have been used to illustrate the consequences of managing. These case studies showed a sliding scale. Parents who have relatively high ability, strong motivation and an awareness of their needs work actively to manage the impact of the handicap and are able to maximise the effectiveness of available support. Their successes give positive feedback which further enhances their ability and builds their strengths. On the other end of the scale are parents who are disempowered by negative feedback from their initial inability to manage. These parents often cannot utilise the available support and find it difficult to process information. The consequence is often an augmentation of the impact of the handicap on themselves, the family and the child. In the questionnaire analysis it was not possible to follow the managing path in the same way as in the interviews. However, there were cases where the parents reported their managing problems and the effect this had on their families- a case was reported where a mother left the family because she could not cope. Generally the parents were positive. Although they concentrated on needs, many reported their successes with gratitude. Staff members showed an acute awareness of parental managing problems but often focused on the pathological side of parents as patients. In the literature there is a clear distinction between strong families who are managing and those who struggle and the different coping strategies employed.

### 5.12. THE DOUBLE ABCX-MODEL AND THE M-MODEL

The double ABCX model (See Chapter II, figures 3 and 4) is a general model applicable to various types of stressors, although it has been applied frequently to the specific circumstances of families with a handicapped member (Turk 1991, Jansen 1991). My M-model focuses on a specific stressor, namely a handicap in the family, and was developed on a small sample of parents of pre-school handicapped children. The M-model is thus restricted to the specific circumstances of these parents and represents a substantive rather than general theory.

In both models the impact of the stressor is seen as a crisis-provoking event that causes stress and needs managing. Of special relevance is the family's attitude to and perception of both the demands made by the impact of the handicap and their ability to manage. According to Wikler (1986), stress is a demand-capability imbalance often caused by the family's perceived inability to restore balance. This is caused by the family's appraisal of their managing skills. The managing effort itself can be maladaptive or bonadaptive and their influence must be incorporated in further managing efforts. In the double ABCX- model this is called the aA or pile-up factor. In the M-model the life-cycle dimension draws attention to the historical causative aspects of the process. In both models the enhancing or impeding effects of parental attitudes (the cC factor) and the family members' personal resources, the family's internal resources and social support or adaptive resources (the bB factor) are regarded as significant. In the M-model more attention is given to the nature of the actual managing process, the skills necessary to manage and the actual managing strategies employed. The important role of parental aims and attitudes and the actual demands made by the stressor are incorporated as characteristics of the managing process rather than as buffering factors. Both these models see the result of these managing/coping efforts as positive or negative and as influencing further efforts to manage. Thus, the M-model derived from this particular study confirms to a certain extent the validity of the double ABCX-model also for this group of parents. As in the double ABCX-model the importance of subjective factors such as parental attitudes, and causative

factors influencing the adjustment process over a period of time, is underlined.

## **6. CONCLUSION : HYPOTHESIS AND RECOMMENDATIONS**

In this discussion of the fieldwork findings in relation to the literature some salient features have emerged which gave rise to the following hypotheses and recommendations for practice and research. Two questions need answering 1. What can be done in the practical reality of special school organisation to meet these needs of the parents? Many of the needs expressed in this investigation were expressed as fulfilled needs. Thus some of the recommendations are already implemented to a certain extent. Some of these recommendations have been suggested by parents or staff members. Although these recommendations are shaped on the expressed needs and the circumstances at the specific school that was studied, the recommendations are also based on general principles, problems, and needs discussed in the study and should therefore be generally applicable to other special schools and institutions. 2. What role can research play in relation to parental needs? The contribution of this study will be critically evaluated as well as suggestions given for further research in this area.

### **6.1. RECOMMENDATIONS FOR PRACTICE**

The main finding and also the central hypothesis of this study is that PARENTS WANT TO MANAGE THE HANDICAP AND ITS IMPLICATIONS. Professionals do not always seem to be sufficiently aware of the strength of parental motivation and the circumstances affecting motivation in relation to the school. Often this has to do with lack of open communication between parents and school and the restrictions and expectations imposed by the South African educational tradition. Professional activities are limited mainly to child outcome goals. The main recommendation of this study is that

\* Professionals should respect the parents' need to be able to manage. If parents seem to have problems in managing, professionals should seek ways to empower them to manage, believing their motivation to manage.

In the practical reality of special schools there are circumstances and problems which impede this empowering. These are now discussed and recommendations made on ways to enhance the empowering of parents.

Problems between the school and the home could be the result of a failure to fit caused by problems in the ecosystem rather than deficiencies in the parents or children. This necessitates assessment and continual awareness of the circumstances of the family which will entail a broadening of the present focus on child educational needs.

\* A shift is needed toward an ecosystemic/family systems approach in the education of handicapped preschoolers.

A further hypothesis is that **PROFESSIONALS' ATTITUDE TOWARD PARENTS CAN PLAY A DETERMINING ROLE IN THEIR ABILITY TO MANAGE.** The fieldwork findings indicated that parents are extremely sensitive to what they perceive as criticism, blaming or negative attitudes from professionals. Parents expressed their need for professional understanding and respect to enable them to believe in themselves when things were going roughly.

\* Professionals should take special cognisance of parental strengths and management successes and the parental need for appraisal.

The majority of staff members at special schools have natural empathetic dispositions according to the elite. This does not necessarily imply special knowledge and skills in working with parents and the need for these was expressed.

\* Teachers should get special training to equip them to work with parents. They need special skills and sensitising to the needs, problems and strengths of parents. In service-training at special schools could be used to supplement teacher training courses.

A major component of professional attitude toward parents is the nature of the recognition professionals give to parental knowledge and skills in decision-making processes. This is partly reflected by the school's policy and practice. Problem areas indicated by parents were the lack of time/weight given to parental perception of the child's abilities; and lack of or doubts about the appropriateness of avenues where they can contribute to decisions. Problem areas indicated by the school were the presence of parental bias toward their children and

their inability to be realistic about their child's handicapping condition- e.g. degree of mental impairment; lack of time to spend in meetings with parents; and the prescribed "united front" policy of the school. The following recommendations are suggested that could enhance the empowering of parents in the decision-making processes.

\* The provision of a child development questionnaire to parents where they can give their perception of the child's abilities. The differences in perception between parents and professionals can be compared and discussed to give parents more insight into the assessment processes and give recognition to their knowledge of the child.

\* When parents are not present at decision-making meetings, special care should be taken that parental views are known and expressed at the meeting. This could be done either by a written statement by the parents or by the delegation of a staff member to consult the parents before the meeting.

\* A combined meeting with parents and team members should be held a month or two after the child's admission to discuss plans for treatment- I.E.P. Parents could thus get more insight into realistic treatment options and contribute to the planning. Although this will be time-consuming, it might save time in the long run in preventing misconceptions and in enabling parents and staff to work toward a common goal.

The provision of support, especially emotional support is a strong empowering factor according to the fieldwork results and literature review. A further hypothesis is that **THE CURRENT WAY IN WHICH THE SPECIAL SCHOOL SYSTEM IS FUNCTIONING DOES NOT PROVIDE ENOUGH SCOPE FOR THE PROVISION OF EMOTIONAL SUPPORT TO PARENTS DESPITE STAFF RECOGNITION OF THIS NEED.**

Practical problems encountered at the school in the provision of emotional support were the lack of time, energy and occasions to provide support; professionals' real or perceived inadequacy to deal with parents' emotional needs; and the strong focus on educational needs which can cloud the awareness in parents of their own legitimate handicap related emotional needs. The importance of a conscious level of awareness as found in the fieldwork is relevant. Practical recommendations for meeting the emotional support needs of parents at the school are:

\* The recognition of the special role the pre-school teacher can play in the provision of support. This

recognition will entail special training sessions to equip them to help and refer parents; the provision of time, and recognition of time spent on these activities thereby creating circumstances for relaxed communication with parents. Examples of such occasions are home visits, telephone calls and informal discussion times at school.

\* The provision of general talks or hand-outs to the parents on the legitimacy of their need for emotional support, the importance of working through problems of acceptance and the development of positive managing strategies. Invitations to the counselling facilities of the school and/or directions to appropriate alternative facilities could be included.

The impact of the handicap on the family can be stressful and impede the family's ability to manage. A further hypothesis is that **THE SCHOOL COULD ENHANCE THE PARENTS' MANAGING ABILITY BY PROVIDING FAMILY SUPPORT**. Parents of young handicapped children need parenting support e.g occasions for discussions of special problems and airing of frustrations and skills training to help with bonding problems and/or behaviour management. The special emotional, informational and involvement needs and problems of fathers and siblings must be taken into consideration in the provision of services. The strengthening of natural resources of the nuclear and extended family, their friends and neighbourhood societies could enhance family functioning and their ability to manage the child. Practical suggestions for the meeting of these need within the current set up are

\* The encouragement of home visits by preschool teachers which can provide insight into home circumstances and parents' natural resources, and detect needs and avenues of support for the family.

\* Special efforts must be made to include the fathers in the activities of the school- e.g. meetings or interview times must be held at times when fathers can attend.

\* The organisation of Saturday morning work parties where the whole family is invited. This has proved a successful way to involve fathers and repetitions of this event have been specially requested.

\* Extended family members must be included in invitations to functions of the school e.g. open days and coffee mornings. The final decision to extend the invitation to these family members must rest with the parents to avoid augmentation of family problems.

\* Workshops and/or talks and books on the handling of family problems e.g. sibling rivalry must be available to parents.

\* Counselling facilities or referral possibilities for family problems must be available at the school. A sibling support group has been suggested by a parent.

Informational support to parents has been rated throughout as an important empowering factor. Parents seem to need consistently more information than professionals can provide and the effectiveness of the existent provision depends strongly on the parents' perception of the appropriateness of the information exchange. The importance of two-way information exchange has been stressed throughout but especially during the initial diagnostic processes. My hypothesis is that **MORE FREQUENT INDIVIDUAL INTERVIEW SESSIONS WITH PARENTS ALTHOUGH INITIALLY TIME CONSUMING, WILL EVENTUALLY SAVE TIME AND PRODUCE BETTER CHILD AND PARENT OUTCOME RESULTS.**

However, the success of these sessions might be dependent on the professionals' ability to shift the focus from the giving of information to the gathering of information about needs, strengths, resources and preferences and the shift from being an expert to becoming a partner. Apart from the initial IEP-meeting and the facilitation of home visits recommended above the following recommendations are made:

\* Individual parent interviews could replace or augment mid-year reports giving both parents and teachers the opportunity to discuss the child's school and home progress.

\* Telephonic contact should be facilitated as this is a time economic way of two-way communication. The breaktime slot is not regarded as suitable. Parents could be informed at the beginning of the year when teachers/therapists are available to receive phonecalls at school and with clear indication on their availability for home phonecalls.

The power of self-acquired information in empowering parents to shape realistic child outcome goals and to come to terms with the handicap was accentuated in the fieldwork findings giving rise to the hypothesis that **PARENTS NEED OPPORTUNITIES TO SEE THEIR CHILD FUNCTIONING IN A VARIETY OF SETTINGS, TO ENABLE THEM TO ACQUIRE REALISTIC INFORMATION.**

Practical recommendations to achieve this in the present special school set up are

- \* Ample occasions must be created at the school for the parents to see their children functioning either through parent involvement in the class e.g. outing supervision, class assistance, open days or through window watching.

- \* Special times for the observation of therapy sessions should be organised with the parents.

- \* Parents must be encouraged to involve their children in extra-mural mainstream activities i.e. Sunday School, ballet classes etc. Support groups are excellent sources of information on possible activities in the neighbourhood.

Parents have expressed strong needs around the contents and modes of the information exchange they require. Recommendations for meeting some of the parents' needs in this respect are:

- \* The creation of additional ways in which staff members can communicate with parents to keep them in touch with therapy and educational processes. To accommodate individual communication problems of therapists and parents a communication plan of action should be devised for each case e.g. intermittent attendance at therapy sessions, regular telephonic contact at prescribed times or a message book system.

- \* The compilation of a pre-school parent handbook with an introduction to the school, staff members and their functions and the procedures parents could use in communicating with the school. Included should be some indication of the nature of parents rights and responsibilities e.g. the type of services and feedback parents can expect, the type of services they must deliver and the type of information that staff members need from parents.

- \* Regular class newsletters keeping parents up-dated with class happenings, highlights in the programme and regular routines.

- \* Procedures should be devised to facilitate the system of internal information exchange between team members. Internal reports on the children could be circulated at regular intervals e.g. after a therapy reassessment, a teacher home visit or a psychological assessment. Regular short discussion sessions on all children, not just problem cases are advisable to enable staff members to give more authoritative feedback to parents. This could help to settle

some of their doubts on their child's progress and prospects at the school.

\* Video-programmes manufactured by the school could provide information on the school and handicapping conditions.

\* The development of parent libraries could provide some of the general information parents want.

The problems experienced with meeting some of the expressed parental needs have their origin in the inherent clash of interests that exist between parents and schools. Often the school's needs have to take precedence over individual needs. Schools usually cannot individualise their services too much for fear of creating precedents, or doing injustice to some. In small independent preschool structures more flexibility and individualisation is possible as well as adherence to the informal approach and philosophy of preschool education. In a preschool attached to a bigger institution the pre-school have to adjust their programme and philosophy to the needs of the institution as a whole often resulting in a more rigid approach which affects their ability to meet parental needs for flexibility and individualisation. These circumstances give rise to the hypothesis that **SPECIAL PRE-SCHOOLS ATTACHED TO A LARGER FORMAL SCHOOL INSTITUTION NEED SPECIAL RECOGNITION OF THEIR DISTINCTIVE CHARACTER AND FUNCTIONS AND NEED A FAIRLY INDEPENDENT ADMINISTRATIVE STRUCTURE.**

As indicated above, the larger societal structures, - macro systems - have a role to play in the empowering of parents to manage and especially the provision of services to handicapped pre-schoolers. The fieldwork findings showed the value of support provided through outpatient therapy treatment for babies and toddlers. This leads to the hypothesis that **THE PROVISION OF EARLY INTERVENTION SERVICES COULD PLAY AN IMPORTANT ROLE IN THE EMPOWERING OF PARENTS.**

Parents were pleased with the provision made for their children and none criticised the current special school policy of the government. However, some stated needs pointed to a need for facilities for handicapped children at mainstream schools e.g. the problems caused by long distance between home and school and the lack of neighbourhood socialisation

opportunities as well as the stigma associated with special schools. The uniqueness of the facilities at special schools tends to have an intimidating and disempowering effect on parents. This leads to the hypothesis that **MAINSTREAM SCHOOLS WITH SPECIAL FACILITIES FOR HANDICAPPED CHILDREN WOULD BE A VIABLE ALTERNATIVE FOR MANY PARENTS AS SOME OF THEIR CURRENT NEEDS COULD ONLY BE MET IN THIS WAY.** Added to the above considerations is the current financial crisis in the country and the equalisation of educational resources which are causing serious cutbacks in special education. A situation might develop where special schools still have the existing infrastructure and tradition of excellency but are without the necessary manpower and facilities to fulfill their role. A mainstreaming system with special facilities for handicapped children might then prove to be a more economic and efficient system. Recommendations regarding the mainstream issue are

\* That the present trend to mainstream children as soon as possible should be continued.

\* That the issue of the possible mainstreaming of children should be debated openly and the parents exposed to the pro's and con's of mainstreaming by exposure to parents of children who have been mainstreamed.

\* Staff members should be aware of the, in many cases unspoken, wish of the parents for the eventual mainstreaming of their children and provide opportunities to discuss this.

One could state that there are many ways in which the empowerment of parents could be enhanced under the current system. Perhaps the greatest need of parents is a greater awareness of their need to manage by all who are delivering services to them and a resultant willingness to devise ways in which parents could be empowered to increase their ability to manage the handicap and its implications on the whole family. A greater awareness of the inherent capabilities and strengths of the parents to do their best for their handicapped child is also necessary. One could hypothesise that **PARENTS WHO ARE EMPOWERED BY SUPPORT AND INFORMATION COULD BE VALUABLE PARTNERS IN THE TEAM AND EVENTUALLY SAVE TIME BY CONTRIBUTING TO THE EFFICIENCY AND EXPEDIENCY OF THE EDUCATIONAL PROCESSES.**

## 6.2. RESEARCH RECOMMENDATIONS

### 6.2.1. The present research evaluated

As little research has been done in South Africa in this particular area this study was seen as an exploration of methods and approaches which could serve as indicator of the feasibility and usefulness of this type and area of research.

The point of departure for this study was inductive i.e. starting with open questions rather than hypotheses and keeping the research process open and flexible, trying to share parents perceptions of their needs rather than making assumptions about parent/family needs. This approach proved to be worthwhile although exhaustive and still leaves many open questions. The method of constant comparison led to the development of hypotheses and substantive theory applicable to this particular group of people. In the research the importance of the impact of the nature of the educational setting on the needs of the parents was indicated. The question remains to what extent this theory is now applicable to other special educational settings in South Africa especially as these settings are in a process of drastic change? Further research could explore the generalisability of this theory to different settings and ways in which the processes of managing and therewith the needs of parents change according to the nature of the setting.

The type of data collected was qualitative with a concentration on holistic, subjective data, focusing more on people's perception of events than on the events themselves. In the light of the family systems/ecosystemic approach adopted, as well as the smallness of the sample this proved to be a correct choice as the collected data provided a holistic picture. It was possible to get more insight into the perceptions of the people and the meaning they gave to events. However, as pointed out in the discussion of the findings, these perceptions and meanings had to be interpreted/evaluated keeping in mind the nature of the data gathering processes and especially the impact of my double role as this probably placed some restrictions on the type of meanings vocalised but also created a natural setting which encouraged open discussions.

The staff interviews fell into the same category of relaxed discussion. The questionnaires were more formal but served a very important purpose in providing the chance for

anonymity as well as a different method of data collecting. In many cases strong opinions were verbalised which gave strong indications of parental perceptions and need hierarchies.

In the chapter on methodology it was stated that the research action itself has certain repercussions. The researcher's close involvement in the setting gave the research the character of action research where the research processes influence events and the researcher. In this case the research also involved staff members and parents. The effect of the interview process on the parents was in some instances the opening of an ongoing discussion between the parents and staff members. One of the contact group convenors reported back that the interviews and the questionnaires had created a stronger awareness of needs in the parents and/or a stronger wish for fulfilment of these needs. The danger is, however, that through a process such as the one mentioned above expectations might be raised which cannot be fulfilled under the current dispensation and this could lead to a growing frustration. In some cases I gave feedback on the findings of this research and this gave further stimulus to discussions as well as an awareness of the managing process for parents. Invitations from support groups have been extended to come and discuss these findings.

During the interview process, some parents and staff became aware of problem situations and made suggestions for solutions. Some of these suggestions have been partially or fully implemented already e.g. the establishment of a parents' library; a stronger focus on the organisation of parent support/contact groups; the creating of infrastructures to bring new parents in touch with contact group convenors in the period between the assessment and admission of their child to the school; the more frequent inclusion of extended family members in invitations to the school; a newsletter from the school on contact possibilities between home and school and the organisation of workshops on family matters.

The process had a profound influence on me in sensitising me more to the needs and especially the strengths of the parents; the importance of family focused intervention and the need for early intervention. I also experienced the usefulness of occasions where both the parents can be interviewed in a relaxed way. This is a procedure which could be very worthwhile as part of the normal parent/teacher contact programme. The

majority of staff members interviewed, welcomed the chance to focus their thoughts on parental needs and expressed a need for more conversations of this kind. On the whole the research proved to be a stimulating process which focused the participants attention on parental needs and generated some solutions to problems.

The processing of data aimed at a broader conceptualisation of the needs of these parents. Although the mass of information gathered was formidable and presented many kinds of needs, the sifting and organisational process eventually showed a fairly consistent unambiguous focus on the need to manage with indications on the parents perception of the prerequisites for managing. The determining characteristics of the managing process were not always as easy to demarcate because of the intimate intertwinement of these factors. The process of analysis showed that multiple interpretations of the material were possible. However, the interplay and the causative links between these factors and the combination of the three types of data gathering processes gave clear indications that the data combined in a natural way to form the substantive theory which eventually emerged. This theory was then thoroughly tested and validated through a process of constant comparison and verification as prescribed by Glaser and Strauss and their associates (Glaser and Strauss, 1967; Strauss, 1987; Strauss and Corbin, 1989).

My aim with this research was to get data that are "real" and "rich" and give an in-depth picture of the needs of the parents rather than a set of "reliable" and reproducible data. Despite all the obvious limitations of the study, this aim has been achieved and a fairly comprehensive set of data gathered and interpreted to give this in-depth picture.

#### 6.2.2. Indications for further research

Indications of needs for further research which were highlighted are:

\* A general need for more research on special education in South Africa. This is becoming increasingly important as the educational structures are rapidly changing and research could provide guidelines as to the efficiency of structures and teaching methods and ways of adapting current structures to become more economically viable.

\* A specific need for more research on the special needs of families who have more than one handicapped child, families with one handicapped twin and single father families.

\* The need for more family-oriented research which concentrates on the effects of intervention on family as well as child outcome goals.

\* The need for more qualitative research in the special educational field.

\* The need for more research on family strengths.

\* The need for more action research which could nurture a critical awareness of current teaching methods and a thirst for knowledge to improve efficiency in special education.

\* The need for avenues to disseminate research to teachers and parents in the special educational field. The establishment of a parent/professional journal which could disseminate research findings and other matters of mutual interest in the broader field of special education is strongly recommended.

Some of these needs are aptly summarised by an American mother pleading for easier access to research findings.

If I could make one request to the researchers it would be that they spend their time researching things that can help my child. If research must be done on my family, let's try to research the positive as well as the negative. Then perhaps we can get a true picture of what my family is really like. And then together we can continue the uphill journey towards success (Gerdel, 1986:49).

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## APPENDIX A

### PILOT INTERVIEW

Introductory remarks: I want to ask you some open questions which you may feel free to answer as you like. If you do not mind I would like to record your answers to enable me to attend fully to the interview itself. I would like to ensure you that the material will be fully confidential. and if I need to quote from your answers for my thesis I would make sure that no identifying particulars will be used.

1. Describe a typical school day in the life of your family?
  - 1a. Describe a bad day?
  - 1b. Describe a good day?
2. How would you picture the ideal set up you would wish for your child?
  - a. Now?
  - b. In the future?
3. Can you name some special ideals you have for your child?
4. Describe special frustrations you experience with your child.
5. Describe stressful situations?
6. Describe joyful occasions?
7. Are there any special needs you have as parents of a special child?
  - 7a. Do you feel you have special needs in relation to the school?

## APPENDIX B

### GUIDELINES FOR PARENT INTERVIEW

Introductory remarks: I want to ask you some open questions which you may feel free to answer as you like. If you do not mind I would like to record your answers to enable me to attend fully to the interview itself. I would like to ensure you that the material will be fully confidential. and if I need to quote from your answers for my thesis I would make sure that no identifying particulars will be used.

1. Could you describe a typical day in the life of your family?
2. What would you ideally wish for your child now and in the future?
3. Could you describe special frustrations and stressful situations that you have experienced with your child?
4. Could you describe specially joyful occasions?
5. Are there any special needs you have as parents of a special child?
6. Do you feel you have special needs in relation to the school?

## APPENDIX C

### QUESTIONNAIRE

October 1991

Dear Parents

I am doing research on the needs of parents of pre-school children attending a special school. This is for an M.Ed.-thesis at UXL. I would appreciate it if you could help me by completing this questionnaire. This would not only help me with my research but also help the school to become more aware and sensitised to your special needs and in this way help us all to help your children.

As this is a concern of both parents I would like you to complete this questionnaire together if possible or to indicate which parent has filled in the reply. Differences of opinion could be indicated.

Your replies may be anonymous and I hope this will encourage you to answer as openly and candidly as possible. I will treat all the answers as confidential. When writing the thesis, I might need to quote from your replies. I will however, eliminate any identifying particulars. If you nevertheless have objections, please state this on your reply and I will respect your wishes.

Please complete this questionnaire as soon as possible and return it to me before the end of October. For your convenience I have enclosed a self-addressed envelope.

I thank you sincerely for your cooperation.

Laetitia Brümmer  
(Nursery School Teacher)

HOME TELEPHONE: 000000

# QUESTIONNAIRE

Page one

Having an exceptional child often causes special problems in the family and creates special needs. Some of these needs are common to all parents but are just more deeply felt when you have a child with problems. I would like you to tell me about three of the most important needs you have experienced since becoming aware of your child's problems. To what extent are these needs being met?

- 1.
- 2.
- 3.

You may add more paper if you need more space.

Page 2

The link between home and school is always important but becomes even more so when your child has special problems. Could you describe to me what you think the most important needs are that you and your family have in this area?

Do you have any practical suggestions for ways in which the school could meet some of these needs?

Is there a role for the PTA and its contact groups in helping you with some of these needs?

Further questions, or remarks welcome- phone-000000 (evenings)

## REMINDERS

27 October 1991

Dear Parents

We are approaching the end of October and I have received only a small number of your completed questionnaires. I know that this is a busy time of the year and that many of you find it difficult to answer these questions but may I plead with you to complete and return them as soon as possible. It is very important for me to get your reactions as I cannot complete this study without them. Some parents have discussed their difficulties with the task with me. You really do not have to rack your brains to answer this. Just write down the thoughts that come to your mind when you read the questions. There are no right or wrong answers. If you have any problems please phone me at 0000 in the evenings. I am only to willing to discuss this with you. You can also give verbal answers over the phone if that will be easier. But remember if you do not want to be identified- you can write your answers without any name attached to it.

If you have mislaid your questionnaire- just send a note to your teacher. I will be only to willing to provide new ones. Thank you for your kind cooperation..

Laetitia Brümmer.

17 November 1991

Dear Parents

This is just a sincere thank you to all the parents who have so kindly completed my questionnaire. I was so grateful and impressed with the caring thoughtful way in which you have completed them- really taking time to think about and discuss the issues. I will make full use of this information and hope that everybody will benefit from this in the end.

Then a very special request- there are so many parents who have not yet returned the questionnaire. I know this is a busy time and I know a questionnaire is mostly a nuisance but please if you have intended to do it and mislaid it or just have not got down to it may I request a last special effort. I have got extra copies which I can supply to your child's teacher if necessary. I am also available on the phone most evenings at 000000 if you would rather just make a few comments on the phone.

Thank you again for your cooperation.

Laetitia Brümmer

## APPENDIX D

### GUIDELINES FOR STAFF INTERVIEW

Introductory remarks: I would like to ask you a few questions that I am using in a questionnaire to parents of children attending our nursery section. With your permission I am recording the interview to enable me to attend fully to your answers. The material will be fully confidential and if I need to quote from your answers for my thesis It will be anonymous.

1. Having a handicapped child often causes special problems in the family and creates special needs. What do you think the most important needs of these parents are?
2. The link between home and school is always important but becomes even more so when there is an exceptional child in the family. What are the special needs of the parents of the preschoolers in this respect?
3. What do you think the school and you as *therapist/teacher/administrator etc.* could do to improve the contact between home and school and to provide information, help and support to the parents?
4. What do you think the parents could do to improve the contact between home and school and to support other parents?

## APPENDIX E

### GUIDELINES FOR ELITE INTERVIEW

Introductory remarks: I would like to ask you a few questions that I am using in a questionnaire to parents of children attending our nursery section. With your permission I am recording the interview to enable me to attend fully to your answers. The material will be fully confidential and if I need to quote from your answers for my thesis it will be anonymous.

1. Having a handicapped child often causes special problems in the family and creates special needs. What do you think the most important needs of these parents are?
2. The link between home and school is always important but becomes even more so when there is an exceptional child in the family. What are the special needs of the parents of the preschoolers and what do you think they expect from the school?
3. What do you think the school and you as administrator could do to meet some of these needs? Do you experience barriers in the school system e.g. time, cost, official regulation or organisational requirements?
4. What role do you think the teachers, therapist, psychologists should play in this respect.
5. What do you think the role, responsibilities and rights of parents are in this school.
6. How involved should the school become with the families of the children? Does the school have responsibility for parent/family training, counselling and support.
7. Do you think we have been sufficiently prepared to work with parents in our training and in-service training?