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Additions and amendments to PhD thesis following Viva on 20th July 1999...
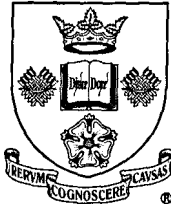External Examiner – Prof. S. Wolfendale.

1. List of additions and amendments

2. The additions and amendments in full.

12th March 2001.

Additions/Amendments to the thesis following viva on 20 July 1999

<u>**Additions and Amendments to Contents, Pages**</u> l – √

Section A changed to chapter 1.

A page was added with the title <u>Literature Review.</u>

<u>**Literature Review**</u>

A page was added with the titles of the sections in the literature chapter.

The title   of section **5. Stress, Coping and Adaptation** becomes title of section 2.

The section **2. Process of adaptation** became section 2.1

Numbers of the remaining sections of this chapter follows consecutively after.

The section **3. Unmet needs for services** became section 2.1.2. The section **4.**

Comprehensive Approach became section 2.1.3.

The section 5 do not exist any more. Finally, section 5.1 became section2.2.

The section **6. Resources** became section 3 and under new title **Resources and Social**

Support.

Numbers of the remaining sections of this chapter follows consecutively after.

Section 7 became section 3.2. Numbers of the remaining sections of this chapter

follows consecutively after.

Numbers of the remaining sections of this chapter follows consecutively after.

Methodology

The section B changed to chapter 2. A page was added with the titles of the sections in methodology chapter.

In the methodology a new section (1) was added. The previous1 becomes 2.

1. Introduction.

Another section (2) has been added. The previous (2) becomes 3.

2. Key Issues of the study and the design of the interview questions

The section 3 has changed title and instead of 'Method of research' becomes 'Possible Approaches to Research: Quantitative-Qualitative'

3.Possible Approaches to Research: Quantitative-Qualitative

The previous section 2 becomes section 4.

4. Data Collection Method

The previous 3 becomes 4.

The section changed to include:

4.1. Use of interviews in family research

4.2. Method of analysis used in this study

4.3. Anticipated unique contribution of the study

4.4. Ethical elements of the study

5. Procedure

The previous 3.1 becomes 5.1. The title changed from 'Preliminary Steps' to

'Preliminary Steps- construction of interview, and pilot-study'

5.1. Preliminary Steps- construction of interview, and pilot-study

The previous 3.2 becomes 5.2.

5.2.Conducting the study

The section 5.2. changed to include:

5.2.1.Inclusion of fathers
5.2.2.Recruitment of the sample
5.2.3.Demography of the population
5.2.4.Interview

The previous section 3.3. becomes 5.3.

5.3.After the Interview

The previous section 3.4 becomes 6

6. Data Analysis Method

CHAPTER 3: DATA ANALYSIS

Section c changed title to chapter 3.

A page was added with the titles of the sections in the Findings and Data Analysis' chapter.

The title has changed to 'Findings and Data Analysis' and has two parts. Part A is the 'Introduction' and Part B contains the findings of the study under six sections. In each section there is the 'Summary of the Results and Discussion'.

CHAPTER 4: CONCLUSIONS

A page was added with the titles of the sections in the conclusion chapter

A new section was added under the title ' **Introduction'**

A new section was and under the title **'Critical Review of the Methodology Used'**

The existing findings of the study are all now under a section with the title **'Summary of the Findings'**

A new section was added under the title **'5. Contributions of the Study to Research and Further Developments Needed'**

List of amended paragraphs and chapters under the same headings.

A page was added with the titles of the sections in the literature review chapter.

The existing section **INTRODUCTION** has been amended, under the same heading, to include the aims of the study and a preamble to guide the reader through the study.

LITERATURE REVIEW

1. Introduction
2. Stress, coping and adaptation
3. Adaptational models
4. Resources and social support
5. Family functioning and the disabled child
6. Effects of disability on the family
7. Summary
8. Theoretical formulations for the present study
9. The family in Greece

The existing section **1.INTRODUCTION** has been amended, under the same heading, to include preamble to guide the reader through the literature review.

The existing section **3.ADAPTATIONAL MODELS** has been extended, under the same heading, to include a brief introduction to say what relevance this section is to the aims of the study.

The existing section **4.RESOURCES AND SOCIAL SUPPORT** has been amended, under the same heading, to include a brief introduction to say what relevance this section is to the aims of the study.

The existing section **5.FAMILY FUNCTIONING AND THE DISABLED CHILD** has been amended, under the same heading, to include a brief introduction to say what relevance this section is to the aims of the study.

The existing section **6.EFFECTS OF DISABILITY ON THE FAMILY** has been amended, under the same heading, to include a brief introduction to say what relevance this section is to the aims of the study.

A new section was added **7.SUMMARY** to present the summary of the finding in the literature review.

A new section was added **8.THEORETICAL FORMULATIONS FOR THE PRESENT STUDY** to explain the philosophy which guided the present study.

METHODOLOGY

A page was added to include the sections included in the methodology section.

A new section was added under the title **'1. Introduction'** in order to highlight the aims of the study and clarify them.

Another section was added focusing on the key issues of the study and the rationale for the interview schedule of the study under the title **'2. Key Issues of the study and the design of the interview questions'**

Each research question was made to refer to one or more interview questions and a clear reference to the literature review was added. Also the aims of the study were clarified by also quoting the key research issues.

In the existing section **4.'Data collection method'** paragraghs were added to expand on the use of observation ,interviews for research purposes. Different types of interviews were presented and possible errors in interviews were discussed. The

anticipated contribution of the study is stressed and the ethical elements of the study are highlighted.

In the existing section **5.1** with changed title to **'Preliminary steps- construction of interview, and pilot-study'** was expanded to include the rationale for the pilot study and the construction of the interview schedule.

The existing section **'5.2.2.Recruitment of the sample'** was expanded, under the same title, to include more information the criteria for obtaining the sample, the schools that were contacted and the rationale for having in the sample parents children attending special schools.

The existing section **5.2.3. 'Demography of the population'** that was presented in the data analysis section was removed from the latter section in order to be included in the methodology section. Also was added the table with the distribution of gender by the disability of the children.

The existing section **5.2.4 'Interview'** was amended, under the same title, to include information for the processing of the interviews.

FINDINGS AND DATA ANALYSIS

A page was added with the titles of the sections in the findings and data analysis chapter.

The existing section **'Data analysis'** changed to chapter 3 and was expanded, under a different title 'Findings and Data Analysis'.

The introduction (Part A) gives information of how the statistical significance was declared and part B includes the findings of the study.

CHAPTER 4: CONCLUSIONS

A page was added with the titles of the sections in the conclusion chapter and the conclusions are now a chapter with the title 'Chapter 4'

A new section was added under the title ' **Introduction**' to clear state the aims of the study

A new section was and under the title '**Critical Review of the Methodology Used**' to expand on the critical reflective review of the methodology used in the research study.

The existing findings of the study are all now under a section with the title '**Summary of the Findings**'

A new section was added under the title '**5. Contributions of the Study to Research and Further Developments Needed**'. In this section was stated the possible contributions of the present study to research and suggestions for further research.

FULL TEXT OF AMENDED OR ADDITIONAL PARAGRAPHS

The existing section **INTRODUCTION** has been amended, under the same heading, to include the aims of the study and a preamble to guide the reader through the study (p.1).

AIMS OF THE STUDY

The present study was conducted in an attempt to understand how the Greek family with a disabled child construe their reality. Behr (1990) suggested future research to investigate the effect of a disabled child on different cultures than the American/English. It was an aim of the present study to explore the difficulties strengths, coping strategies and to acknowledge the needs for services concerning Greek families with disabled child specifically in the capital of Athens. Additionally, this information would encourage professionals not to stereotype the reaction of parents after the birth of a disabled child, and to be aware that families do not form a homogenous group but each one would have individual competencies and needs.

The study is divided in four chapters. The first chapter of the present study introduces the reader through the literature review on research studies on stress, coping and adaptation of families with disabled children in England and America. Different adaptation models are presented and the results of the impact of a disabled child in the family and the parents are discussed. The main elements in the formation the Greek family are presented in a separate section. In the second chapter the methodology of the study is discussed. Issues are explored such as: the aims and the chosen method of the study, the data collection method, the procedure for conducting the study, from the preliminary steps to the data analysis method. The third chapter (Data Analysis) gives the results of the data analysis and is divided into six sections. In the first section of the data analysis an account of parents difficulties are discussed, in the second section are discussed the aims for the children's future. In the third are explored the perceived life changes after caring for a disabled child on social activities, finance and marital relationship. The fourth presents the parental belief systems such as the source of strengths of parents and, the use of comparative appraisal as coping strategies that parents in Greece use for dealing with a disabled child. The fifth section gives an

account of positive contributions of the disabled child to the family as a coping strategy. The last section of the data analysis presents the perceived needs for services for the disabled child and his/her family. Finally, in the four chapter of the present study, are discussed the implications of the results of the study for intervention and service planning.

LITERATURE REVIEW

The existing section 1.INTRODUCTION has been amended, under the same heading, to include preample to guide the reader through the literature review(p.5).

The researcher wanted to introduce readers to what is the experience of parents bringing up a disabled child. Coping and adaptation would be of particular significance in order to explain the reality of Greek families with a disabled child. So the literature review begins with an exploration of what is stress and adaptation for families with a disabled child. The different approaches of this process will be extended from the pathology based approach of mid-70s to the up to date comprehensive approach. Other theories as the stage theories, existential conflicts, developmental tasks and the unmet needs for services approach will be also examined. The different approaches to adaptation would be explored to explain why the particular study followed a positive approach to disability, which is the later trend in dealing with families with a disabled child. It is an approach which do not presume parental response to the birth of a disabled child to be always that of a grieving process but rather adaptation is a life long process. Studies thus far, have not agreed on whether the cause of the stress is related to parental, family and/or to child factors and have questioned the progression through various stages of adaptation, culminating in a stage of 'acceptance'. Rather, stress and adaptation is affected by a variety of factors such as the child's and the parents' characteristics; the families' appraisal of the situation; parental beliefs about the cause of disability and family and individual family members' coping resources. Accordingly, in the third section of the review the adaptational models are explored including the importance of the appraisal in adapting to the disability of a child to the families. The fourth section examines different types of resources characterised as

important factor in the adaptation process and secondly examines the social support and its benefits for an individual who is adapting to a stressful event. The fifth section explores the family functioning when one of its members is disabled. Next in the sixth section the effects of the disability on the family's subsystems are presented. Separately are explored the effects on the parental subsystem (mothers and the fathers), on the marital/spouse subsystem, the siblings subsystem and the extended and friends subsystem. Lastly, a summary for the whole of the literature review is provided. In the seventh section the theoretical formulations of the study are be pinpointed. A separate eighth section introduces the unique characteristics of the Greek family to the readers.

The existing section **3.ADAPTATIONAL MODELS** has been extended, under the same heading, to include a brief introduction to say what relevance this section is to the aims of the study(p.17).

It seems, that families fluctuate through periods of strength and weakness depending on the situational context in which they live in and on how family members respond to the birth of a disabled child. This section will explore the different coping strategies related with adaptation.

The existing section **4.RESOURCES AND SOCIAL SUPPORT** has been amended, under the same heading, to include a brief introduction to say what relevance this section is to the aims of the study (p.24).

Individuals' reactions to challenges from the environment can be seen as a function of their personality, perceptions, and resources. The ability of families to cope with a disabled child will be related in part to the personal and social resources that the family has. This section will look at some of the links between coping strategies and resources.

The existing section **5.FAMILY FUNCTIONING AND THE DISABLED CHILD** has been amended, under the same heading, to include a brief introduction to say what relevance this section is to the aims of the study (p.39).

Family functioning is influenced by different factors depending on the dymanics of the family and the context where the family with a disabled child live. In this section will be explored the different models of family functioning.

The existing section **6.EFFECTS OF DISABILITY ON THE FAMILY** has been amended, under the same heading, to include a brief introduction to say what relevance this section is to the aims of the study (p.41).

The demands of the disabled child is central issue related with the adaptation of the family. In this section will be explored the effects of a disabled child on the different subsystems of the family system and which are the best predictors of family adaptation.

A new section was added **7.SUMMARY** to present the summary of the arguments in the literature review and the relation with the aims of this study (p.61).

Early research examining the effect of childhood disability has viewed disabled children as a source of extreme stress in the family which affected the psychological status of the members of the family and, generally, the family functioning. Parental stress was associated with a number of factors, though studies have not agreed whether the source of stress was parent related or child related. It was realised that parents, although perceiving family life as quite stressful and with more demands, they could find ways to adapt to the disabled child and to have positive family functioning and satisfaction from parenting.

The aim of the present study was to explore the experience of Greek parents with disabled children. Without denying the difficulties of parenting a disabled child, this study has also focused on the positive aspects of the experience, trying to find what is the Greek reality related to families caring for a disabled child. The study aimed to understand how Greek families grapple with the disability of their children and how they construe the main issues influencing their lives. Then will be explored the difficulties, coping resources and needs for services and similarities and differences to other research work in England and America on this topic will be pinpointed.

Coping as an important feature, it implies that a person would make conscious choices resulted from feedback from within or his/her social environment to respond to stress. According to Lazarus and Folkman (1984) model for coping the appraisal of a stressful event was considered an important determinant of how a person will respond (Litt, 1988). This appraisal was associated and influenced by the evaluation of the situation, the availability of resources and coping strategies. These strategies are problem-focused (attempts to change the environment), emotional (attempts to alter the emotional results of stress) and perception-focused strategies (attempts to alter the meaning of the stressful situation). The coping resources include the physical, social, psychological, utilitarian resources and the structural characteristics of the family.

The Cognitive adaptation model (Taylor, 1983) suggested that the readjustment process focuses around three themes: 1) the *search for meaning* in the experience, 2) an attempt to *regain mastery* over the event and 3) an effort to *enhance one's self-esteem*. By understanding the cause of an event and what its signifies, the individual can reestablish a sense of control which is associated with effective coping. The feeling of control increases the mastery over the event and help parents to adjust better, actively seek services and participate in intervention programs (Affleck et al.,1982). Another way to establish sense of control is by finding positive contributions and making favourable comparisons with others, strategies that are also associated with positive coping (Murphy et al.,1990). So crucial determinants of the capacity to cope with the disabled child were considered to be the personal coping resources and social support of parents (Judge,1998).

The marital relationship, social networks, and economic circumstances form another group of coping resources. Thoits (1986) stated that social support enhances well being, bolsters self esteem and the sense of control over the environment.

Research on families with a disabled child concluded that lack of informal social support can jeopardise family's coping ability. The reported isolation of families was suggested that may be self-imposed and may be due to underdevelopment of particular relationships. Parents may experience social isolation due to behavioral problems of their child (Szukula,1991), exhaustion of caring, minimise the ability to maintain friendships, or parents try to defend themselves from the reactions of others. Overall, not only the type and availability of social support but also the way individuals regard that in various domains of their lives are supported and satisfied with the relationships that they have, influence their appraisal of how supported they are.

Social support is a significant coping resource, it is associated with enhanced well being on behalf of parents, maintenance of the psychological and physical integrity over time and less demonstration of overprotection on disabled children. Social support is assisting the parent to change the situation, the emotional reactions resulting and the meaning of the situation (Thoits,1986). Also there is an evidence that emotional and instrumental support in the form of assistance in child caring enhance parenting attitudes and mother -child interactions and quality of stimulation for children (McConnell,1988; Crnic and Greenberg,1990; Parks et al.,1992). Interestingly, the positive effects of social support seem to be related to perceptions of availability than actual receipt of support (Kessler,1991). Quittner (1992) indicated that the perception of the availability of support rather than the number of social contacts were associated with psychological benefits. Those with satisfying social relationships reported high levels of stress probably due to altered appraisals of stressor and maintenance of self -esteem which may facilitated the use of adaptive coping strategies.

Overall, higher levels of support could create a social environment which could help children to achieve the maximum of their developmental potential. The family system model (Hornby,1994) guided us though this research in the exploration of the findings. According to this model, the family is considered to be an interactive system where changes in any part of the system reciprocally affect the whole. The model is consisted of four components the parental, the marital, the sibling and the extra family subsystem. Its use can help us to identify the ways and means that families use to function and maintain equilibrium in meeting the individual needs of its members. The main focus of studies exploring parental responses to a disabled child

was on the response of the mother, similar to this study. These mothers were found experiencing more stress than other mothers of normal children, and were involved with increased child-care demands. As a result those mothers were reported having poorer physical health, less personal use of time, less freedom and more awareness of conflict in the house. Moreover, the functioning of these mothers was related with the support from the social environment. The feeling of security in the marital relationship was the most significant factor in the adaptation of mothers. The more supported the mothers were, the less they were experiencing stress. For both mothers and fathers the support from the family was important. Men and women used the same coping strategies when they were occupied in the same social roles. The behavioural problems of the disabled child were associated with poorer adaptation (Hanson and Hanline,1990) and were more associated with stress than the type of disability (Floyd et al.,1997). As the child gets older, mothers show higher self-esteem, probably because as the time is going by, they feel more competent in meeting the demands of the child. In later research the role of fathers in the development of the child started to be investigated. In response, the reaction of fathers of disabled children was also examined. It was found that similarly to mothers, fathers also reported more stress, role confusion, social isolation and marital difficulties (Ventura,1987). Comparing the stress between mothers and fathers of disabled children, fathers were found to experience less stress. Probably the role of fathers as providers rather than caregivers may serve to mask their feelings and prevent them from disclosure of their feelings (West,1998).This traditional perception for the role of fathers also may restrain them from close participation and interaction with disabled children. The focus on greater paternal involvement may provide the couple with shared experience which may contribute to satisfaction with parental roles and consequently the couple may experience marital satisfaction (Harris and Morgan,1991). McConachie (1997) pinpointed that before effective service planning and delivery is needed professionals to be aware of parents' strengths, coping strategies, needs and aims for the future of the family. Since parents do not form a homogenous group it is rational to have different resources and consequently needs. The availability of medical and support services to meet these needs were considered critical in mobilising family's resources (Mahoney et al.,1991). The social environment which fails to provide adequate support and is unprepared to meet service needs could be identified as stressor leading

to family problems more than the presence of a child with disability (Andersson,1993).The focus should be not only on recognising the child's needs but · the needs of the whole family. Services should be in the direction to meet the individual needs of parents and to complement the family's own structure of coping in order to identify and encourage the usage of adaptive strategies.

The results of the literatyre review indicated the need to identify the strengths and difficulties of these families and to highlight which aspects of parenting a disabled child were generating more stress. Intervention efforts that have treated families as a homogenous group with similar resources and needs were not effective. The existence of a disability was not the sole determinant of family functioning. Child characteristics were found not sufficient to explain family adaptation. An understanding of the family structure was required, and the need for the exploration of dynamic and reciprocal interaction between its members was suggested. The coping efforts associated with adaptation were the appraisal of the event, beliefs, perceptions about control over the environment, and the influence of previous experiences. The use of comparative appraisals, utilisation and use of personal and social resources could help adaptation to a stressful event and cultivate greater perceived control on the part of parents.

The availability of appropriate community services can be critical in mobilizing the family's resources. We should try to mobilize the existing strengths of parents. Parents by getting involved and contributing to their child's development they experience a sense of satisfaction that fulfills their own needs while at the same time respond to the child's needs. Intervention should focus on the needs and strengths of the families than try to change families and children (Wilgosh1990). Professionals who foster cooperative partnerships with parents informally enhance the family's self- confidence and feelings of mastery and control (Cooley,1994). Services should be in the direction of meeting the individual needs of parents and to complement the family's own structure of coping in order to identify and encourage the usage of adaptive strategies. These conclusions from the literature review formed the background of the present study.

A new section was added **8.Theoretical formulations for the present study** to explain the philosophy which guided the present study (p.66).

The study of the family with a disabled child has gone on for more than forty years. The variability of approaches for dealing with the family with a disabled child provided us with a deeper insight of what means the caring of a disabled child. In the beginning, research adopted a pathological approach. This approach assumed that in most of the cases such families experience higher stress, which led to psychological impairment on family functioning. The second approach believed that the lack of unmet service needs of families rather than the simple presence of a disabled child was a stressor to the family. The approach considered that the difference between a positive and a negative resolution of each crisis period was be largely dependent upon the availability of medical and support services to meet these needs (Mahoney et al.,1991) which were critical in mobilising family resources. The most recent approach to understand the family with a disabled child is the comprehensive approach. In this approach the difficulties are not overestimated and the followers of this approach believe that the family has also strengths. Rather stress and adaptation is affected by a variety of factors such as the child's and the parents' characteristics; the family's appraisal of the situation; parental beliefs about the cause of disability and family and individual family members' coping resources (Hanline,1991). The appraisal of an event by an individual for Folkman (1984) is in part be associated with the utilisation and availability of resources and coping strategies. The coping resources include: physical (health, energy, stamina), social (support systems, social networks) psychological (personality, belief systems, problem-solving skills) and utilitarian resources, structural characteristics of the family such as employment, mothers age and education, family size, housing, and finance which can help families to deal with disability problems (Sloper et al.,1991). On the other hand, research in the area of cognitive adaptation suggested that strategies like the ability to identify a perceived cause, make favourable comparisons with others, perceive positive contributions, and enhance the perception of mastery over the event, all are associated with positive coping (Murphy et al.,1990).

The present study followed the approach of cognitive adaptation to form the research questions and the data analysis. This approach was considered more flexible and giving the possibility for families to reveal not only their stresses but also their capabilities.

In a context, where the family ties are still very strong and trustworthy, a comprehensive approach, would give to the families the opportunity to deal with their difficulties more effectively by discovering their hidden strengths and further by suggesting needs and services. But first, we need to examine which are the characteristics of the Greek family before we start to impose any theories on how the Greek parents respond on a stressful event in their life.

METHODOLOGY

A new section was added under the title '1. Introduction' in order to highlight the aims of the study and clarify them (p.77).

1.INTRODUCTION

Behr (1990) suggested future research to investigate the effect of a disabled child on different cultures than the American/English. The present study was conducted in an attempt to understand the Greek family with a disabled child and provide to them effective services related to their needs for whom little is known. Due to the cultural differences mentioned above, it can not be assumed that Greek families react to their disabled children in the same way as English and American families do. McConachie (1997) pinpointed that before effective service planning and delivery is needed professionals to be aware of parents' strengths, coping strategies, needs and aims for the future of the family. Similarly, it was an aim of the present study to explore the difficulties strengths, coping strategies and needs of the parents in Greece and specifically in the capital of Athens. The researcher hoped to provide evidence of a wide variety of coping strategies in families in order to convince professionals not regard stereotype the reaction of the families, and treat families as individual families with different competencies and needs, not as homogenous group.

Another section was added focusing on the key issues of the study and the rationale for the interview schedule of the study under the title '2. **Key Issues of the study and the design of the interview questions**'.

Each research question was made to refer to one or more interview questions and a clear reference to the literature review was added. Also the aims of the study were clarified by also quoting the key research issues (p.77).

2. KEY ISSUES OF THE STUDY AND THE DESIGH OF THE INTERVIEW QUESTIONS

In order to find answers which fulfil the aims of the research, this descriptive study as Carter (1985) suggested, was guided by research questions rather than a research hypothesis.

Few studies have been held on the Greek population and little is known about the stressors parents of disabled children are experiencing and which personal resources they use.

The key research issues were identified as follows, and from these the specific interview questions were identified below. Alongside each interview question are presented findings from research in the UK and USA which may be relevant for interpretation of the answers given by the Greek families.

Research Questions

Research question 1.

Impact of diagnosis-How did the family learn of the diagnosis and how did they react?

The nature of the diagnosis, the way it is given and the attitudes of other members of the family might influence the attitude of parents towards their child. Relatives who deny the child's disability in an attempt to avoid the pain, often become a burden for parents (Ebert et al., 1989) and lead them to isolate themselves from the

extended family. The disability of a child seems to reduce opportunities for developing friendship bonds (Kazak and Marvin, 1984). In contrast, there are many supportive grandparents with more support provided by maternal than paternal. Seligman (1991) suggested that there are two types of grandparents, those who intensify the stress of the family and those who provide support to the family and act as a social resource for them. Similar findings were reported by Hornby and Ashworth (1994) too. Breslau et al. (1982); Byrne et al.(1988); Golberg et al.(1986); Harris et al. (1985) found that maternal grandparents were more supported than paternal ones but interestingly when mothers perceived also their in-laws to be supportive, they had a more positive relationship with their disabled child.

Interview Question1-5

1.How was like your initial reaction on hearing on the diagnosis of the disability?

2.At what age the diagnosis was given and from whom?

3.Are there any identified causes for the disability?

4.How was like the reaction from relatives, grandparents and others?

5.Was the father present at diagnosis, and what his reaction?

Research question 2.

What are the difficulties of caring for a disabled child, and how have these influenced family life.

It is suggested that characteristics of the children (type of disability, gender and age) or the parents'(educational status and age) exert an impact on adaptation. For example, the behavioural problems would cause reduction of sense of efficacy and satisfaction with parenting and decreased positive parent-child interaction similarly with the suggestions of DeKlyen et al. (1998). Moreover, the behavioural problems in children were found more important at determining stress in parents than the type of the disability (Floyd et al.,1997). Additionally, the communication problems of the child would be perceived as a difficulty of every day life. Accordingly with Sloper and Turner (1993) these problems would be related with adaptation. The child's communication competence rather the severity of impairment would be central to the quality of family transactions similarly with Frey's et al.(1989). The younger children would generate more stress in mothers consistent with Trute (1995). Older mothers would be found more adapted to living with a disabled child similarly with

Trute(1995). The type of impairment, age or gender of the child and/or other variables may or may not influence the parents' answer in Greece.

Interview Question 6.

Which are the difficulties in everyday life due to caring for your disabled child that influence family functioning?

Interview Question 14.

Which persons were/are perceived as supportive to your family?

Interview Question 8.

Describe the behaviour of the child at home.

Interview Question 9.

Describe how you behave/discipline your disabled child.

Interview Question 10.

Describe siblings' acceptance of the disabled child.

Research question 3.

How much did parents wish to encourage independence and competence in their children?

The independence in life may be one of the reported aims for the future. The financial security may be another referred aim similarly with Cameron et al.(1991). Parents would do their best for their children's education as we mentioned earlier in the section about the Greek family either for their education as we mentioned earlier in the chapter about the Greek family, but they may interpret this in a different way from parents in UK or in America. The type of impairment, age or gender of the child and/or other variables may influence the parents' answer in Greece.

Interview Question 7.

Which are the anticipated aims to be achieved in the future concerning your child?

Research question 4.

How did behaviour and possibly limited development of the disabled child influenced family life?

The social activities of parents might be reduced or remained the same as mentioned by bibliographic references from England and America. The type of impairment, age or gender of the child might influence their answer. The parents might report financial burden and the quality of their marital relationship as elements of their life that changed after caring for a disabled child. The positive marital relationship might be an important factor in parents' coping. The disabled child might put strain on marriage. The security, satisfaction and quality of a marriage can serve as a potential buffer to stress allowing for more successful family adaptation (Saddler et al., 1993). In the present study the satisfaction from support and the marital relationship might be factors related to positive family functioning and adaptation with the disability of their child). The type of impairment, age or gender of the child, family size and/or parents' characteristics might influence the parents' answer in Greece.

Interview Question 12.

Has your life changed after caring for a disabled child and in what ways?

Interview Question 14.

Which persons were/are perceived as supportive to your family?

Interview Question 8.

Describe the behaviour of the child at home.

Interview Question 9.

Describe how you behave/discipline your disabled child.

Interview Question 10.

Describe siblings' acceptance of the disabled child.

<u>*Research Question 5.*</u>

How did parents maintain their motivation to keep in caring for their disabled child and how they compare their family to other families?

Social comparisons is the chief vehicle for self-enhancement when people compare themselves favourably to others according to Murphy et al.(1990). The use of

comparative standards of appraisal was found self-enhancing and linked to adaptive functioning (Taylor and Brown, 1988). Parents in the present study might use downward or upward comparisons to cope with the stressful event of caring for a disabled child. The type of impairment, age or gender of the child and/or other variables might influence the parents' answer in Greece. The religion might be one of the resource helping them to adapt referred by parents, as in the literature religion enhance family relationships (Mahoney et al.,1992), has been regarded as a coping strategy associated with better management of daily hassles (Hathaway and Pargament,1991). The type of impairment, age or gender of the child and/or the characteristics of the parents (age and educational status) and family size might influence the parents' answer in Greece.

Interview Questions 13.

How you consider your family compared to other families without a disabled child?

Interview Question15.

What gives you strength to continue your efforts with your child?

Interview Question 14.

Which persons were perceived as supportive to your family?

<u>Research Question 6.</u>

How much do parents feel that caring for a disabled child has brought benefits?

Taylor (1983) suggested that finding *positive contributions* could help the individual in the establishment of control over an event. Thompson (1985) suggested that focusing on the positive was related to the avoidance of negative psychological consequences. The unity of the family might one positive contribution to the family as mentioned in international research(see for example Stainton and Besser,1998). The type of impairment, age or gender of the child, family size and/or other characteristics might influence the parents' answer in Greece.

Interview Question 16.

Do you feel lucky for having the child ?

Interview Question 17.

Are there any positive contributions of the disabled child to your family and which are these?

Research Question 7.

What services should be developed to help parents raise their disabled child and why?

The parents might ask for information centres, support from the State and counselling for parents similarly with Burden (1991).The type of impairment, age or gender of the child, family size and/or other variables might influence the parents' expressed needs for services in Greece.

Interview Question 18.

What sort of services do you think are needed in Greece that do not exist or are not adequate in their current form for the disabled child and his/her family?

From the research questions, it is clear that information is needed on a range of topics from the parents. Much of the information is specific to the experience of the individual. The two possible approaches to gathering this information are the questionnaires(using quantitative, descriptive approach) or by interviews(using qualitative, descriptive approach). These two approaches have been written about in some detail, and the differences between these two are important in the methods of gathering the information, in the way the information is interpreted and in how the information relates to the theoretical ideas.

The aim of the present study was to collect information, describe new facts about the situation, parents and their activities. It was an exploration of the impact of disability on Greek parents about which little is known. The present study followed an descriptive design. Carter (1985) suggested that the focus of the descriptive study is on conditions that exist, ongoing processes, beliefs that are held.

The focus of this study was on the situation as it is, the discovery of what there is, and the meanings of the results. There was no attempt to introduce anything new or to modify or control the situation being studied. Without denying the difficulties of

parenting a disabled child most often found in the literature review, this study has also aimed to include the positive aspects of the experience, trying to find what is the Greek reality related to families caring for a disabled child and to pinpoint similarities and differences to other research work in England and America on this topic.

The present study has been guided by a social model about the disability rather a medical one. This model requires the consideration of the context in which the people live and is not enough to translate research findings from other cultures and settings. The contribution of this study, would be the derived information on how the Greek families construct the disability and how they describe the main issues that influence their lives. If we could determine the variables that influence their adaptation to a disabled child then we could understand the construct of their world and we could plan services appropriate to their unique needs. The present study explores also what the parents' needs are and if the perceptions of these needs are influenced by the age, gender or the type of disability of the child of other variables. The data obtained could be used by professional in the field of disability to justify and access current conditions or to make plans to improve them.

In the existing section '4.Data collection method' paragraghs were added to expand on the use of observation,interviews for research purposes. Different types of interviews were presented and possible erros in interviews were discussed,the conrtribution of the study to research and the ethical elements involved in the study (p.89-96)

4. DATA COLLECTION METHOD

The research questions described above could be investigated using a range of interview methods. The most obvious ones are observation, questionnaires, and interviews of different types. In qualitative research, investigators try to get closer to

the individual's perspective through detailed *interviewing* and *observation* (Denzin and Lincoln, 1994).

The types of observation methods which could be possibly used are field observation methods, where the observer is not involved with the activities of the people being observed, and the participant observation, where the observer attempts to make their prescience less disturbing to those being observed and hence cause less distortion to the events by actively participating in the activities going on. Participant observation also might produce more insight in the researcher because they experiencing the same events as those being observed but presents also the problem that the participant observer may manipulate by his presence the actual behaviour of parents and that he/she can hardly study past events.

However, both these styles of data gathering would be likely to influence the behaviour of the parents whist they were caring for their children, and in addition these key research questions depend heavily on describing the meanings of events given by the parents, and observation methodologies do not give data directly related to the meanings of the participants, although they give data which can help to interpret the meanings given by the participants by relating those meanings to significant activities of the parents. In addition, observation methods require a considerable amount of time and prolonged access to families in order to have an in-depth account of the experience of the parents, and as this study aimed to gather data from a wide range of families to enable as much generalisation as possible, it was decided not to use them on these grounds.

On the other hand, interviews are social encounters and not simply a passive means of gaining information. Interviews can yield rich sources of data on people's experiences, opinions, aspirations and feelings and can be completed in shorter time than participant observation. They are a resource for understanding how individuals make sense of their social world and act within it (May, 1993). Interview data reports not on an external reality displayed in the respondent's utterances but on the internal reality constructed as both parties contrive to produce the appearances of a recognisable interview (Silverman, 1985 p.165). Interviewing contributes in data collection of different sources in a effort to describe a culture. 'Culture' this sense in is the act of how people interpret their experience and generate social behaviour.

The most common type of interviewing is the face-to-face interview, or the group interviewing. Similar but simpler information can be also be sought using mailed or self-administered questionnaires and surveys (Fontana and Frey, 1994). May (1993) said that questionnaires self-administered, mailed or in the form of surveys provide a rapid and relatively inexpensive way of discovering the characteristics of a population, though, they provide us with a simplification of a complex social world. Till now, studies mostly used questionnaires to assess the impact of the disability on family members, on family functioning or the marital cohesion. The use of an 'objective' measure in the form of standardised tests, reduces the possibility of bias by the researcher but also reduces the range of information obtained (Behr,1990). In the present study, the use of existing attitude scales was not possible since there was not a adapted version for Greek population. The use of questionnaires did not seem advisable because of the uncertainty as to whether the families in Greece would report similar difficulties and ways of dealing with them to those difficulties reported by earlier UK and USA based research. Without this knowledge, it would be very difficult to design questions for a questionnaire approach.

4.1. Use of interviews in family research

There are different types of interviews. There are the structured interview, the semi-structured interview, the group interview, and the unstructured (focused, or informal) interview (May,1993). The use of structured interviews is related with survey research. It is a method that allows comparability since it relies upon a uniform structure and consequently achieves a reduction of variation in responses and reduction of the possibility of bias. Because the researcher can not use probes to expand on issues raised, flexibility is minimised and the emotional dimension is overlooked or minimised. Group interviews help in the gathering of data in limited time, but they may produce different answers on the same issues since the interaction with others affects the respondents in terms of actions and opinions(May,1993). On the other hand, the unstructured interview has an open character and is characterise by its flexibility and the discovery of meaning. Generalisation of the results, or a concern to compare the answers of the participants with those of others is much more difficult because the data from each person interviewed would be different. This study did wish to seek some

generalisation as far as possible, so unstructured interviews alone seems less appropriate for the study. The unstructured interview could be used in combination with participant observation to permit the researcher to understand reactions of individuals to what is happening, but in this study there was not enough time for participant observation, as discussed above. Since the aim of the research was not only to find out what happened to the participant parent but also to gain insight into the perceptions of the parents living with a disabled child, the semi-structured interview was considered the appropriate interview method. As May (1993) suggested semi-structured interviews allow to the participants to answer in terms of their own construct of the world. This particular interview method allows the design of the interview schedule with specific questions as in structured interview but the researcher or interviewer is able to probe seeking *clarification* and *elaboration*. During the interview there was an attempt to help parent to express his/her concerns and interests without feeling unduly hampered. Therefore, each interview in the present study, ended to be characterised as a unique record of social interaction.

4.2. Methods of analysis used in this study

A further advantage of using semi-structured interviews is that they can also be used to collect simple quantitative data. In this study, were used to collect information, given by the interviewees, on the type of disability, the demographic aspects of the family, age of the child, the gender of the children, the principal difficulties in everyday life reported by each family, the principal aims for the future, the main life changes reported by the families, sources of strength and support for the family (including comparison with other families), extent of positive contributions made by the disabled child, and the improvements of services felt necessary. These categories of information were asked for specifically during the interview as they had been demonstrated to be relevant to the issues in research carried out in the UK and USA, and the responses to all such questions were available from all interviews. The information was recorded for each family, and then part of the data analysis was to analyse whether any variables tented to be associated with other variables in the Greek population. The level of quantitative data analysis was kept at a descriptive, associative level rather the than hypothesis-testing or theory-building level. The quantitative and qualitative data are

reported together when considering each of the key research questions, the qualitative data to illustrate the meaning given by the families and the quantitative to show how general these meanings were across the families studied and to investigate whether they were any statistically significant associations between variables. All interviews were transcribed, and the specific quantitative data identified in the interviews. Then a sample was identified to illustrate the meanings given by the families to the information requested in the interviews. Then, other relevant specific themes were looked for in the rest of the transcripts using a content analysis approach and where these were relevant to the central set of information looked for, these 'extra' themes are reported. However, it was judged beyond the scope of this thesis to also report on a full content analysis of all the large number of the interviews and so this has to be left to a later date. It would be very interesting to give such a report as much of the data available in the interviews has had to be left out of this thesis.

Research question one, which explores the impact of the diagnosis, was also not content analysed, as the answers turned out to be not centrally relevant to the main aims of the thesis. These questions helped the researcher to establish rapport with the parents and was an opportunity for the researcher to show empathy for what the parents were revealing about the difficult time of the discovery of the disability.

4.3. Anticipated unique contribution of the study

The study became interesting because it focused on Greek parents for whom little is known about what impact disability of their child has on them. We know nothing of how they respond, react, what resources or coping behaviour they use. This study investigates ways of thinking which determine how parents cope with the disability of a child. The interview elicited parents' stories in a way that shows each person to be interesting no matter how anonymous. It also allowed us to have a glimpse into the feelings, attitudes and perceptions of family members. If we could determine which variables influence parents' stress and coping, if we could listen to their needs for the successful care of a disabled child, then support services could use this information to construct intervention strategies suitable for them. Instead of searching for pathology, I have appreciated the difficulties of caring for a disabled child and searched for the

coping resources of Greek parents, which variables affected the caring of their child and what were their perceived needs for services.

The experience of the each family was captured in depth so two possibilities for making connections were developed. First, the researcher might find connections among parents whose lives were quite different but were affected by common social forces and so see patterns in this experience. Second, by presenting the experience of parents with disabled child in Greece, the researcher might open up for readers the possibility of connecting their understandings of disabilities in families to those explored in the study and the readers might extend their own understandings from this study. These connections would be the researcher's alternative to generalisability (Lincoln and Guba,1985). Additionally, following suggestions of Henwood and Pidgeon (1992) the use of quantification it was taken as a crucial condition for the findings of the study to be replicable and generalisable and for predictions upon observed regularities to be made. Thus, both the quantitative and the qualitative data could be used together.

4.4. Ethical elements of the study

In order to achieve the aim of this study, it was thought that participants should be able to talk freely and openly about themselves and express their concerns without feeling unduly hampered. The pilot study showed that parents understood the purpose of the study and were willing to support this effort. During the first contact by the phone the researcher explained to the parents how the access was gained, the purpose of the study and reassurance of anonymity was given. Once the interview was under way the relationship between the parent and the interviewer was marked with respect, interest and attention. There was no apparent perception that the questions represented an invasion of privacy. I've always asked parents if they minded being tape-recorded. I indicated that their anonymity would be kept and that I wanted to tape-record the interview in order to have accurate account of what they had said. For those parents who found the tape recorder inhibiting and they did not want it, I kept hand-written notes, after receiving their permission. It was found worthwhile to ask the parents if they had any questions or if they wished to add information and comments to the ones that had already made. This not only provided the researcher with some unexpected gems of insight but in some cases with a summary of parental needs. Of course, the

amount of time available was a real constraint in building relationships but most of the times, the researcher left the homes of the participants, feeling as if she had left a friend's house. A rule of thumb was to smile, show interest and always have a packet of tissues to offer to parents when they were crying. Once the interviews were completed, I thanked the parents for giving me their time and agreeing to speak to me. Additionally, I wrote to all the families a 'thank you' note and at a later date I phoned them to ask how the children were.

5. PROCEDURE

In the existing section 5.1 with changed title to **'Preliminary steps- construction of interview, and pilot-study'** was expanded to include the rationale for the pilot study and the construction of the interview schedule (p.96).

5.1. Preliminary Steps-construction of interview, and pilot-study

The interview schedule had to include questions designed to obtain factual information about a wide variety of events which affected both the disabled child and its family. In order to minimise the imposition of predetermined responses, I tried to include mostly open-ended questions which permitted the respondents to answer in their own terms and not to presume an answer as a correct one. Silverman (1993) suggested the open-ended questions as the most effective route towards the gathering of 'authentic' understanding of peoples' experiences, concluding that 'authenticity' rather reliability was the issue in qualitative research. Since I was interested in understanding the parent' subjective experience I did not want mothers and fathers to feel that there were any right answers, that they were expected to answer in any particular way or that one answer would meet with the interviewer's approval more than another. The researcher wanted to give the chance to parents to reconstruct their experience according to their own sense of what was important. With the exception of

the demographic information questions, all others were open-ended questions which is an important means of gathering information pertinent to each family's unique situation (Bailey and Simeonsson, 1988). The demographic information questions were: the date of birth of the disabled child, the type of impairment, the age of the child, the gender of the disabled child, the educational status of father, the educational status of mother, the age of father, the age of mother, the family size, the birth order of the disabled child, and the occupation of parents. Since an interview question is a stimulus whose purpose is to create or generate a response, special attention was given to the wording of questions. The aim was to elicit the responses which accurately reflected the behaviour, attitudes, beliefs and values of the participants. The questions were single and straightforward to avoid tension and confusion and probes were used to deepen the response to a question. An important part of the actual design of the questions was to construct them ambiguously and to be clear what the question was for, who was to be answered and how the researcher was intended to interpret them. The questions how?, what? and which? were asked in the quest for understanding of behaviour and in an attempt to assess problems. The Appendix1 provides the reader with the interview schedule. A pilot study was conducted in Athens with ten(10)families with disabled children. The interviews were tape-recorded (after receiving parents' permission to do so) and the information obtained showed that parents had a very good understanding of the purpose of the study and welcomed the whole effort. These pilot interviews were analysed using the same approach as that used for the main study. As these pilot interviews worked well, the themes occurring were added to the main study data. The questions did not change as a result of the pilot-study but the researcher was provided by the answers with useful probes for latter use in the main study. When the participants parents were beginning to talk about different subject, I tried to guide them back to the focus of the interview, which was to provide contextual background of their life with a disabled child.

The existing section '5.2.2.Recruitment of the sample' was expanded,under the same title, to include more information the criteria for obtaining the sample, the schools that were contacted and the rationale for having in the sample parents children attending special schools (p.98).

In Greece, the education for disabled children in the elementary level could be provided in special schools, special classes and in integrated classes in mainstream schools. The sample in this study was from special schools. The children were defined as disabled after an official referral from a multidisciplinary team recognised by the State. This multidisciplinary asessment gave a clear definition of 'disabled' for this study. Those children with mental disability and/or hearing disability were all following special schools. Fortunately, nowadays, there is an effort to integrated more children with disabilities in ordinary schools. The aim for the sample, therefore was to find families with disabled children aged 5-15 years covering the nursery, elementary and the pre-vocational level of the special educational system.

Many special schools were contacted but not all agreed to provide help by giving to the researcher a list with parents names. The schools which were approached and provided me with a list of parents' names were: The public elementary special school for the mentally disabled of 'Pamakaristos' (12 positions for teachers, population of students 76,16 parents agreed to participate out of 23), the public elementary special school for the deaf of Filothei (6 positions for teachers, population of students 13, 9 parents agreed to participate), the public elementary special school for the deaf of Argiroupolis (12 positions for teachers, population of students 68, 5 parents participated), the public elementary special school for the mentally disabled of 'Maraslios' (6 positions for teachers, population of students 42, 8 parents participated), the public elementary special school for the physically disabled 'ELEPAP'(10 positions for teachers, population of students 75, 10 parents participated out of 19), the elementary special school for the mentally disabled 'Theotokos' (6 positions for teachers, population of students 40,16 parents participated), the public special school for mentally disabled teenagers of Holargos (3 positions for teachers, population of students 25, 8 parents participated out of 14). All those public schools not only were willing to help the researcher but also had as common characteristic that were big schools having over 5(five) positions for teachers except the school of 'Holargos' which had three positions. The centres for physically disabled 'KASP' (20 parents participated) and 'KEHAGIA' (9 parents participated out of 14) were not public and children were visiting the centres for physiotherapy sessions. Those children recruited from the above centres were going to integrated

classes and/or following special classes and were all physically disabled. Additionally 9 more parents completed the sample from different agencies approached. From the schools, I was provided with a list of parents' names. I knew that it was unlikely that all parents whose names I had would agree to take part , so to avoid the final sample being too low I decided to aim for a total population sample, and approached all parents whose names I had. As, expected not all parents agreed to participate after being approached by telephone and eventually 110 families (including the 10 families used in the pilot study) was the final number of participants. The proportions of families with children with different disabilities, and the families from richer or poorer backgrounds in the final sample did not appear different from the proportions expected in the total population sample from the schools participating. This was true even for those parents contacted through the private centres. The fact that there were private did not made them unsuitable for poorer families since the therapies were covered by the social security of the parents. In this sense, the sample of families interviewed was approximately the same as a random sample from the schools participating, with regard to disability and social class variables as well as other minor variables. Though the sample was representative of the total school sample, a necessary condition for establishing generalisation of the total school sample, the results to a wider population of which the sample is representative there are still problems of establishing generality of results to other populations. The fact that the participated parents agreed to open their houses and be interviewed means that they volunteered and this condition prevents generalisation of results. For example, this may mean they were more confident than other parents, or that they were dealing more successfully with their disabled children than parents who did not volunteered.

The existing section '**5.2.3.Demography of the population**' that was presented in the data analysis section was removed from the latter section in order to be included in the methodology section. Also was added the table with the distribution of gender by the disability of the children(p.101).

Table 7. Gender of the children by type of impairment

	GENDER			
	MALE (N=63)		FEMALE (N=47)	
TYPE OF IMPAIRMENT	N	%	N	%
Physical impairment (N=41)	24	38	17	36
Mental impairment (N=53)	28	44	25	53
Hearing impairment (N=16)	11	17	5	11

The existing section *5.2.4. Interview* was amended,under the same title, to include information for the processing of the interviews (p. 105).

Apart from the tape recorder, I was taking notes of gestures, face and body movements related to an answer as May (1993) suggested since the outcome of the interview depends not only on the wording and content of the interview but also the non-verbal cues.

The existing section '**6.Data analysis**' was expanded,under the different title(Data analysis method), to include the way that was used to declare the statistical significant findings (p.110).

The Pearson chi-square test were used in the analysis for significance. Cramer(1994) suggested this test when we want to compare two or more unrelated samples on a variable which may have two of more categories. The categories in each category were not more than seven or eight as DeVaus (1991) had stressed. Though, the value for Fisher's exact test is given for 2x2 contingency tables. A significant level smaller than 0.05 ($p = < 0.05$) is considered statistically significant. I used coded labels of each variable and each category within each variable but this task was very time-

consuming. But these results of cross tabulations elucidated the important findings of the study.

Chapter 3- Findings and data analysis

The chapter is divided in two parts . In part A there is general information on the test used to find statistical significance and in part B the aqual findings are presented.

The existing chapter with different title (Findings and data analysis) present the findings of the study. The use of statistical significance changed the significant from the non significant findings(p.114).

PART A. INTRODUCTION

In this chapter the results of the data gathering are reported. The statistically significant relationships between variables arising from the interviews are reported, and these findings are related to the context of the families and to some of the literature discussed in the literature review chapter. The relationships looked for in the data are generally those which have been seen in other studies reported earlier from the cultural contexts outside Greece. As many of the variables are 'categorical variables', where the variable is related to two or more separate categories (such as 'boy' or 'girl'), non-parametric statistics are used to look for statistical significance in the differences between the frequencies obtained. Chi-square is the statistical test used to establish significance, with at the probability level set at $p<0.5$ and/or the $p<=0.1$ level. The statistical relationships established in this way are of course only associations, as cause and effect relationships cannot by established by such statistical terms. The relationships observed have to be interpreted through our knowledge of family dynamics from other settings.

Every time the researcher says that the differences in percentages or numerical data illustrated in the tables are statistically significant, this means that there was a statistically significant difference between the frequency of the most reported alternative and the next most frequently reported alternative. The actual numbers of parents, not the percentages, were used in the statistical calculations. In the main

corpus of the data analysis the tables presented, show the relationship between the characteristics of children (type of impairment, age, and gender of children) and the themes revealed from the answers of parents on the interview schedule. The percentages calculated were the column percentages. In the appendix II A are presented the tables showing the statistically significant relationship between the answers of parents and other variables such as educational status and age of parents, family size, birth order, behaviour of children, and other variables. In appendix II B the relationships between variables calculated but was not found statistical significance were presented.

PART B- FINDINGS AND DATA ANALYSIS

1.1. INTRODUCTION

Research studies which followed one approach that pinpoints normalities as well as changes in families with a disabled child emphasised also the need to explore the tasks that arise in the context of everyday life (Brown and Gordon, 1987;Quitter,1992). Kazak and Wilcox (1984) suggested that in order to determine the stress level of parents with disabled children it would be useful to gather information on their daily parenting demands. Bristol (1984) suggested that when families coped with the stress of daily living they were more able to respond to the child's needs. It was the daily care of the child about which mothers needed more information (Pelletier et al, 1994). So it seemed important in the present study to have parents' accounts of the difficulties they faced in their day to day care of their disabled offspring. From their replies the following difficulties emerged: 1) mobility (14%); 2) behaviour (17%); 3) communication (21%), and 4) that they had to have constant attendance (30%). The effects of the type of impairment on the reported difficulties will be discussed next.

1.2. EFFECTS OF CHILDREN'S TYPE OF IMPAIRMENT ON REPORTED EVERYDAY DIFFICULTIES

The findings reported here look at the associations between everyday difficulties (problems of daily care, mobility, communication, and behaviour) and the type of impairment of children.

The daily care of the child was reported as the most popular difficulty for those parents with physically disabled children (37%). As expected, mobility was their main difficulty (35%), a finding which was found statistically significant ($p=<0.05$).

Parents with a mentally disabled child were more likely to report difficulties related to the behaviour of the child (30%). A finding found as statistically significant ($p=<0.01$).

Another problem mentioned by the parents was the difficulty in communication. This answer was the most popular among parents with a hearing impaired child (69%) and it was found statistically significant ($p=<0.01$).

There were parents who reported problems of another nature. They had difficulties caused by their relatives or by the stares of pity from other people on the street or in the playground.

Summarising, it seems that the type of impairment was an influential factor in the reports of parents concerning their daily difficulties with their child. Next we will examine if the gender of the children influenced the parents' reports of daily difficulties.

1.3. EFFECTS OF CHLDREN'S GENDER ON THE REPORTED EVERYDAY DIFFICULTIES

The findings reported here look at the associations between everyday difficulties (problems of daily care, mobility, communication, and behaviour) and the gender of children. Table 9 shows the association between the difficulties reported by parents and the gender of the child. Although, it is seems that girls (37%) were more likely to cause difficulties for their parents on a daily basis than boys (24%) this difference was not found statistically significant.

Behavioural problems in everyday life were more frequently reported for male disabled children (19%) than female ones (15%). In addition, boys (23%) were more likely to cause difficulties in communication than girls (19%) but both these differences were not found statistically significant. It seems that the gender of the disabled children was not influential variable related to behavioural and/or communication problems reported by the parents.

Parents who reported problems of a different nature were caring either for a girl (6%) or for a boy (3%).

Summarising, we could suggest that the gender of disabled children did not influence the reports of parents on their daily difficulties of their children. Next we will examine if the age of the children was influential variable on the reports of the parents.

1.4. THE EFFECTS OF CHILDREN'S AGE ON REPORTED EVERYDAY DIFFICULTIES

The findings reported here look at the associations between everyday difficulties (problems of daily care, mobility, communication, and behaviour) and the age of children. Parents of young children were those who mainly reported as their major difficulty the care of the child (41%). At the age of 7-10 years the percentage got lower (30%) to reach its lowest point when the child was 11-15 years old (20%). Table 10 illustrates the findings as reported by parents. The observed differences do not reach statistical significance and this may be due to the distribution of the sample between age groups. The majority of parents interviewed had children between 7-10 years of age were the dilemmas were more and the demands multidimensional. When we focused only on the differences between the first and the latter age group then the variable of age was found statistically significant (p=<0.05). It showed that younger children needed more daily care from their parents.

Mobility, at all ages remained difficulty in every day life of parents but the differences did not reach the level of statistical significance. Focusing on the first and the latter age group then the difference was statistically significant (p=<0.05). A

finding which showed that younger children with mobility difficulties brought more problems to their parents.

Difficulties caused by the behaviour of the child were reported to be most distressing when the child was between 11-15 years (23%). For the other two age groups these were almost equal (16% and 14% respectively). When we focused only on the first and the latter age group then the difference was statistically significant (p=<0.05). It seemed that parents with older children reported more frequently the behaviour of the child as their daily difficulty.

Communication was reported most difficult when the child was young in age (5-6 years) (27%). As the child got older, communication was reported less of a problem (21% and 17% respectively). Again in this case, when we focused on the youngest and the older age group then the difference had statistical significance bringing the parents of younger children to face more problems with communication on a daily basis (p=<0.05). Those who did not mention any problem had older children (23%) between 11-15 years old. Lastly, those who were facing other problems, had children older in age between 11-15 years (10%).

A couple with an mentally disabled child mentioned how overprotection of the child and stares of other people brought difficulties on everyday life (the mother answered, the father was present):

It seems that the age of children had an influence on parents' perceived demands of everyday care.

1.5. SUMMARY OF RESULTS AND DISCUSSION-*Everyday life difficulties*

The age, type of impairment, but not the gender, family size, and birth order of the child influenced parents' perceptions of difficulties. It was found, that the younger rather than the older children, tended to be more demanding in their care according to parents' reports. Among, disabled children, statistically significant was the finding that those with physical disabilities had the greater caregiving demands related to difficulties in mobility.

Girls and only children were not perceived as needing greater everyday care. Birth order also, did not show more demanding the caregiving when the disabled child was the second child in the family. An unexpected finding was that having the disabled child as the only child in the family was also not perceived as producing more caregiving demands.

Another problem reported in everyday life was the behaviour of the disabled child. Cameron et al.(1991) found that mothers of children with behavioural problems reported more stress. In the present study, children who were perceived as being very difficult to manage, were mostly mentally disabled children who were found in all age groups but were more likely to be found in the group of older children (11-15 years). Both findings were statistically important. The birth order of the child was not influential in the perception of child's behaviour by the parent, a finding similar to Corter et al.(1992).

The birth order of the child was not influential in the perception of behaviour by the parent, a finding similar with Corter et al.(1992). Another finding which was not statistically important related to the difficulties of everyday living was the family size. Those parents with two children did not perceive the behaviour of the child to be more demanding and causing more daily problems to them. The mothers who answered that the behaviour of their child was their greatest difficulty, were of all educational levels except those with degree and were between the age of 31-40. Both these findings were statistically significant (p=<0.05)(see table 1, 2, Appendix II A). We could suggest that those parents might lacked the means to help their child interact socially, so is needed to help parents to accept their child, teach them problem-solving techniques or behaviour management skills which could minimise these difficulties and could enhance the parents' sense of competence which is low maybe due their young age. This increased competence could affect their belief of being in control over life which has been found to be associated with adaptation (Lefcourt,1982). Furthermore, maybe the apparent visibility of the disability evoked the curiosity of others and might brought to parents difficulties and caused them more stress.

Another difficulty for parents was the communication problems between parent and child, especially with children young with hearing disabilities, findings statistically significant (p=<0.01).

Lastly, parents who did not mention difficulties in their every day life had older children regardless of disability groups or gender. These parents were represented in all age groups and all educational levels.

Summarising, in the present study, similarly with other studies, parental difficulties in everyday life were mainly associated with caregiving demands (Harris and McHale, 1989; Erickson and Upshur, 1989; Quitter et al., 1992), demanding behaviour, and low communication skill of the disabled child (Carr, 1990; Szykyla et al., 1991; Frey et al., 1989). Type of impairment, and age of the children but not birth order, family size or gender of the child exerted an impact on parents perceptions of the child's behaviour. The younger the child, the more overtaxed, parents felt. Furthermore, the demanding behaviour of the child and the difficulty in communication placed a lot of pressure on the everyday life of parents. Low communication skills was perceived as a difficulty for younger hearing impaired children. In conclusion, it seemed that child characteristics such as the type of disability, age of the disabled child played a crucial role in parents' perceptions of everyday difficulties. The mothers' characteristics which influenced perceptions of difficulties in everyday life were their age (p=<0.05) and their educational status except those with degrees (p=<0.01). The younger the mother, the greater were the difficulties experienced in everyday living with a disabled child with communication and the behaviour of the child.

SECTION 2

AIMS FOR THE FUTURE

2.1. INTRODUCTION

The findings presented here look at the relationships between parents' aims for their child's future and the background factors of type of disability, gender and age. Another key question addressed to parents was their concerns about their child's future. The categories were formed after a careful analysis of verbatim responses to a general question about aims for the future. Parents had the following aims for their children's future: 1) to become more calm (7%), 2) to reach his/her potential (25%), 3) to be secured financially (11%), 4) to become educated (11%), 5) to become sociable (6%), 6) to be independent (28%), and 7) to have a balanced personality (6%). The effects of child variables on the parents aims for the children's future will be discussed next.

2.2. EFFECTS OF CHILDREN'S TYPE OF IMPAIRMENT ON REPORTED AIMS FOR THE FUTURE

The type of impairment was significantly associated with the reported aims for the future ($p => 0.05$). The most popular answer of parents was the importance of independence when thinking of the future of their child. We can assume, that this aim for the future was in response to their fear of what will happen to their children after they were gone. Of these, parents who had physically disabled children (36%) and parents who had mentally disabled children (26%) were most concerned about the possibility of an independent life for their child but the difference was not found statistically important. This finding showed that equally parents of mental and physical impaired children were aiming for independence for their children. Table 11 shows the influence of the type of disability of children to the aims for the future.

It became obvious that parents of physically, hearing impaired children more than parents with mentally disabled children reported as their aim the development

of child's potential (25% and 33% respectively). However, the observed differences did not reach statistical significance and showed that parents reported this aim for the future regardless the type of impairment of their child.

Those parents with physically impaired children, wished for the completion of their offspring's education (18%). Only in 2% of cases with mentally impaired children did respondents hope for the same. This difference reached the levels of statistical significance ($p=<0.05$), and showed that parents of physically impaired children believed as more possible their child to be educated than parents of mentally disabled children.

It was apparent that mothers of hearing and mentally impaired offsprings, mostly thought that it was important for their child to become sociable (19%, 11% respectively). Only 2% of cases with a physically disabled child responded similarly, however, the difference was not found statistically significant. It seems that the ability to socialise more effectively is an aim for the parents regardless the impairment of the child.

Of those parents who recognised the need to build a secure economic future for their offspring, most had children with mental disability (18%) while only the 4% of those with physically impaired children replied similarly. The differences observed were statistically significant ($p=<0.05$) and showed that parents of children with mental impairment were more concerned to secure their child economically than parents of children with other disabilities.

Essentially, those who didn't mention any thought about the future had mentally impaired children (9%).

It seems that, regardless of the type of impairment, parents aimed for an independent life for their children, the development of their potential, and the effective socialisation of the child. The type of impairment was found statistically significant variable regarding the aims for the economic security and the education of their children. Next we will examine if the gender of the children imposed impact on the reported aims for the future by the parents.

2.3. EFFECTS OF CHILDREN'S GENDER ON REPORTED AIMS FOR THE FUTURE

The variable of gender was found to be statistically significant related with the parents' aims for the child's future (p=<0.05). Table 12 illustrates the relation of the disabled child's gender on aims for the future as reported by parents.
Ps. Parents gave more than one answer to this question.

Although, it seemed that mothers of boys were more concerned for an independent life for their child than mothers of daughters (35% compared to 20% for girls) the observed difference did not reach levels of statistical significance (p=0.05) showing that for this particular aim, gender was not influential factor.

Chiefly, both the mothers of daughters and sons were concerned with the development of child's potential (27% and 23% respectively). The difference was not found statistically significant showing that regardless the gender of the child the parents were aiming for the maximum development of child's potential.

An aim more often reported by Parents who had daughters (18%) than sons (5%) was their child's economic security. Interestingly, the difference reached levels of statistical significance (p=<0.05) showing that in this case the gender was influential variable, bringing the disabled girls to be perceived as more vulnerable and needing economic security than boys.

Mothers with male disabled children (11%) more often wished in the future their children to become more calm and, as expected, were mostly parents with boys (10%) hoped their child to become more sociable. Both findings that were found statistically significant.

Equally important was for parents of boys (10%) and girls (12%) to become educated. Education was considered a way for independent living.

Parents who had as their goal for the future of their child to have a balanced personality regardless the gender of the child. The observed differences did not reach level of statistical significance.

Summarising, it seems that gender was a variable that influenced parents' aims for the future. Both parents with boys and girls wished for independence in personal life, to reach their potential, and become educated. Interestingly, more often parents of girls had as a basic aim the financial security of their children and more parents of boys aimed to become their child more sociable. Next we will examine if the age of the children influenced the reported aims for the future.

2.4. EFFECTS OF CHILDREN'S AGE ON REPORTED AIMS FOR THE FUTURE

As the children got older, independence became a more important issue for parents. It was15% for children from 5-6 years, then 26% for children from 7-10 years old, and 42% for children from 11-15 years. The observed differences did not reach levels of statistical significance and this may be due to the distribution of the sample among age groups. The majority of parents interviewed had children between the age of 7-10 were the dilemmas were bigger and the answers were more than one. When we focus only on the differences between the first and the latter age group, then we found significant difference related to the choice of independence as major aim for the future. The difference showed that parents of older children were more frequently chose this aim for their children's future. The older the child, the stronger the parents viewed that their child should lead an independent life.

The goal of an education became less pressing as the child got older (26%, 13%, 7% respectively). Focusing on the younger and the older age group, the difference was found statistical significant and showed that the aim of education was stronger when the child was younger ($p = <0.05$). Equal for all ages was the aim for the child to reach to the maximum of his/her potential (30%, 26%, 19% respectively).

Another interesting finding which was significant in statistical terms was that parents of older children more frequently chose as aim for the future their child's economic security ($p = <0.05$), and to become more sociable ($p = <0.05$).

Summarising, we could suggest that another variable that influenced parents' replies was the age of the children, if we focus on the older and the youngest age

group. As the children got older, their parents became concerned about the future and wished for an independent life for their offspring, to secure them economically, and to become their children more sociable. The younger the child, the more parents strove for educational achievements.

2.5. SUMMARY OF RESULTS AND DISCUSSION-*Parents aims for the future*

All parents wanted their child to live independently, regardless the type of impairment and the gender of the child. Maybe the strongest variable related to this answer was the age of the child. Those parents with older children more often answered that independence was their aim for the future. For those couples the questions of what will happen to their children after their death and how their children will live independently without being burden to anybody, was their main thought for the future. Those couples were both older (over 30 years). As for the educational status of mother and father who aimed for independence, they were from all grades but, interestingly fewer from those with degrees. We hypothesised that they realised that their child wouldn't be able to live independently. But both the age and educational status of parents were not statistically significant related to the aims for the future. The parents uncertainty about the future became more apparent when it was found that mainly economic security was an aim for mentally disabled children. Furthermore, regardless of their birth order, mainly parents of girls perceived economic security as a necessary aim for the future more than for boys, a finding statistically significant (p=<0.05).

In this respect, gender and type of impairment influenced the perceived goals for independence and economic security. As the family was getting bigger, greater was the expressed need for an independent life for the disabled child but the observed differences were not statistically significant.

There were parents who were more concerned about their child's education. Mostly those had young hearing and/or physically disabled children, a finding found statistically significant (p=<0.05). Regardless of the child's gender or the birth order parents saw independence as being achieved through education. In Greece, many

hold the point of view that a 'certificate' or 'diploma' gives one an opportunity to find a job and, consequently, to live independently. It seems that this perception apply to families with a disabled offspring.

Development of the child's potential was an aim wished, regardless of their type of impairment, gender, and age or their parents own age and educational status.

Those parents who had older in age impaired children were concerned more about the behaviour of their child, and wanted them to become more calm and/or sociable, a relationship significant in statistically terms ($p=<0.05$).

Finally, parents who were most concerned that their children acquire a balanced personality, regardless of their age, type of impairment, family size, birth order and gender, and regardless of the parents' age and educational status. As parents mentioned, the children live in a social world and as they get older they have to come to terms with their disability, and even though they are disabled they still need to form friendships without feeling inferior to their able-bodied peers and friends. It seems that again the development of social skills could be of assistance to those children.

In summary, parents' aims for the future were the independence, the economic security, the education, the development of potential, the change in behaviour and the balanced personality of their children. An aim, which was influenced by the age of the disabled child, was independence. The older a child was, the more independence was mentioned as an aim for the future. Economic security was an aim for females and mentally disabled, mostly the older in age and firstborns. The change in behaviour was an aim for parents with older children, regardless of the birth order and the family size. The aim for education was mentioned more often for hearing/physically disabled, young in age children regardless of the family size, and/or birth order. Balanced personality for their children was reported as an aim for the future regardless of the age, type of impairment, gender, family size, and birth order. On the reported aims for their offspring future had an effect particular characteristics of the children but not the educational status and age of the parents, the birth order, and the family size. As it was mentioned in the chapter about the Greek family, the parents are doing their best for

their children either for their economic security or their education regardless the existence of disability or not.

SECTION   3

CHANGES IN LIFE AS PERCEIVED BY PARENTS

3.1. INTRODUCTION

In this section, findings will be reported which relate to the associations between parents' perceptions of life changes and the type of impairment, gender, and age of the children. The care of a disabled child at home can evoke a range of emotional responses in parents and constitute a prolonged and serious stressor for some parents. When the child is disabled, the changes in the organisation of the family system are even greater. Parents in the present study were asked to articulate these changes in their life after the birth of their child. The various life changes perceived by the parents over time in the marital relationship, the economic impact of having a disabled child, and the extent of changes inthe parents' social life. The following categories for the variable 'Life Changes' were derived from parents' answers: 1) social activities reduced (17%); 2) social activities remained the same (16%); 3) economic burden (24%); 4) no economic burden (10%); 5) marital relationship negative (8%); 6) marital relationship positive (26%).

3.2. EFFECTS OF CHILDREN'S TYPE OF IMPAIRMENT ON PERCEIVED LIFE CHANGES

The following tables (Table14a,b,c) present the relationship between the life changes (social activities, economic burden, and marital relationship) and the type of impairment of the children.   The percentages calculated were the column percentages as in all other tables.

The largest percentage of parents who replied that their social activities were reduced (60%) were caring either for mentally disabled child and/or a physically or a hearing disabled child (44% respectively). The observed differences did not reach levels of statistical significance. It seems that parents regardless the type of the disability of their child reported that their social activities were reduced.

Parents not only answered that their life had changed negatively after the birth of a disabled child. There were also those parents who said that their social activities remained the same. Parents of physically disabled children (56%) and hearing impaired children (56%) were equally represented into this category and the mentally disabled children were represented by the 40% but the observed differences were not statistically significant. So it seems, that the perception that the social life had not changed was not influenced by the type of disability.

In summation, we may suggest that the type of impairment did not influence the reported life changes on social activities. The next set of changes refers to the reported changes of the economic status of the family.

Most families reported that were facing economic burden due to the care of a disabled child (N=78) but regardless the gender of the child.

Mostly parents found that the money which were receiving from Social Security, was not enough to do the necessary therapies for their child. They asked for better economic support from the State. This finding was expected since Social Security usually do not covers the expenses for adequate physiotherapy sessions, but for other therapies too.

Those parents who didn't face economic problems had children with physical (37%) or hearing (31%) disabilities. The observed difference was found not statistically significant.

The majority of parents answered that their marital relationship was positive, even though caring for a disabled child (N=84). This reply was given by 83% of those parents with physically disabled children, 70% of those with mentally disabled children, and 71% of those with hearing disabled children. However, the observed

differences did not reach levels of statistical significance. So, it seems that the type of impairment did not influenced the perception of a positive marital relationship.

Of those parents who regarded their relationship with their spouse as negative after caring for a disabled child, 30% had a mentally disabled child, 17% had children with physical and 19% children with hearing impairments. Also these differences did not reach levels of statistical significance. It seems that the type of disability was not influential factor in the perception of a negative marital relationship.

Summarising, it seems that the type of impairment was not influential factor for the reported life changes on the social activities, economic burden, and marital relationship. Next we will examine if the gender of the children imposed an impact on the reported life changes.

3.3. EFFECTS OF CHILDREN'S GENDER ON THE PERCEIVED LIFE CHANGES

Of those parents, who reported that social activities were reduced, 49% had boys and 55% had girls. The observed difference was not found statistically significant.

Those parents with disabled boys replied that their social contacts have not changed (51%), and parents with girls with disabilities gave this answer in 45% of the cases. The differences were not found statistically significant. It seems that the social activities of the family were not influenced by the gender of the disabled child.

Relating the economic burden with the gender of the child it was found that boys were seen as presenting an economic burden in 79% of cases, while girls 60% of cases. The observed differences reached levels of statistical significance (p=<0.05) showing that boys were representing greater economic burden for their parents.

The marital relationship was negatively influenced (N=26) after the birth and care of girls (28%) and boys (21%) with disabled conditions but the difference did

not reach levels of statistical significance showing that the gender of the child did not influence the negative perception of the marital relationship.

On the other hand, there were parents who replied that their relationship with their spouse was positive, despite caring for a disabled offspring. This reply was given in 79% of those having boys and in 72% of those having a girl. Also in this case the difference was not found statistically significant.

Obviously, parents who mentioned that their relationship with their spouse was positive, commented about the communication and support between them regardless the gender of the disabled child.

In sum, the gender of the disabled children did not influence the given answers on the life changes, but only in regard of economic burden, where boys were perceived as bringing greater economic demands. Next, we will examine the effects of age on the reported life changes.

3.4. EFFECTS OF CHILDREN'S AGE ON PERCEIVED LIFE CHANGES

Social activities

The relation between the age of the children and perceived life changes is given in tables 16a,b,c. Parents who mostly had children aged 5-6 and 7-10 comment on the reduction of their social activities (53%) and (56%) respectively. Parents having children 11-15 years answered that their social activities had changed in 43% of the cases. The observed differences did not reach levels of statistical significance showing that the age of the children was not associated with the social activities of the family.

Parents who had children aged 11-15 perceived that their social activities had not changed (43%) after caring for a disabled member, however, parents with younger children replied that their activities had not altered in 53% and 56% of cases respectively.

Interestingly, parents who had older children (11-15 years) estimated that the economic burden was very high (79%). For parents with younger aged children the burden was equally difficult to manage (68% and 68% respectively). The differences between older and younger children did not reach levels of statistical significance showing that the age of the children was not influenced the perception of the economic burden.

Of those parents who were not facing economic demands, which they could afford, more had younger children 7-10 (32%) than young adults (21%). Again, here the differences were not found statistically significant.

The marital relationship was reported more often as positive for parents who had older children (86%), while for parents with younger offspring the same reply was given for the two age groups in a comparatively lower percentage but almost equal (73% and 74% respectively). As expected, the spouse relationship was more often negative for parents with younger children (26% and 27% respectively for each group) than for parents with children aged 11-15 years where it was perceived negative in 14% of the cases. However, the differences were not found statistically significant.

In summary, it seems that the age of the disabled children was not influential factor on the reported life changes either the positive or/and the negative ones.

3.5. SUMMARY OF RESULTS AND DISCUSSION-*Life changes*

In this section, parents gave an account of changes in their family life after the birth of their disabled child.

Parents in this study perceived either that their social activities were reduced or that they remain the same. However, neither the type of impairment, gender, and age of the child or the perceived behaviour of the child, and family size were influential factors on the reports on social activities. This study was inconsistent with the finding of Baxter et al. (1995) that parents of mentally disabled children were more stressed and isolated. The variables found to have statistical significance

regarded with the reported by the parents changes in social activities were their educational status and their age (p=<0.05) (see table3a,b,4a,b, Appendix II A). Mothers of lower educational status and those parents younger in age perceived more often than others that their social activities were reduced.

A finding with statistical importance (p=<0.05) was that in families with intact social activities, the father had a higher degree of education (see table 3a, Appendix II A). We could hypothesise for the present study, that when fathers were more educated were more ready or willing to help and support their wife and therefore most of the other activities of the family remained the same as before. Furthermore, another finding statistically significant (p=<0.05) was that when mothers were older in age, perceived less changes on their social lives. Further, as Reddon et al.(1992) suggested, maybe the spouse support was the crucial factor for the perception of more satisfying parenting roles.

The present study, similarly with Sloper et al.(1991), found that the support from the spouse influenced positively the mother's reports of the changes on social activities, and also her reports about the status of marital relationship. When the mother was supported by her spouse, reported more often a positive marital relationship (see table 6, Appendix II A). As we expected those parents with a negative marital relationship answered that they were unsupported by their spouse. In the present study, participants reported a positive marital relationship regardless of their age or educational status. The family size was found statistical significant related with the marital relationship (p=<0.01) (see table 5, Appendix II A). Inconsistent, with Bristol (1987) it was not found in this study, that older children help more than younger children towards better family functioning or that boys have a positive effect on the marriage more than girls. Those parents who reported negative marital relationship had the disabled child as the only child in the family, a finding which was statistically significant (p=<0.01). It seems that only children brought more negative influence in parents' marital relationship. Maybe the existence of a child without disability could bring balance to the family life since the parental expectations could become true from the other child.

Lastly, mainly parents felt that the economic demands for the care of their children were excessive. The type of impairment and the age of the children had no impact on parents' replies. The family size and the gender were statistical significant (p=<0.01) showing the family had two children, one normal and the disabled child or when the disabled child was the only child, facing greater economic demands were reported (see table7b, Appendix II A). Additionally, boys were considered as having greater economic demands. After further exploration, it was revealed that those parents with reported economic burden had also reduced social activities, and those parents with no economic burden had no reduction of their social activities, both findings reached statistical significance (p=<0.01) (See table 7a, Appendix II A).

Summarising, neither the type of impairment, gender, age of the children, the child's behaviour, and the family size had statistical importance exploring the influential variables on social activities. Age, behaviour, gender and were also characteristics with no statistical significance on the marital relationship. Family size was significant variable showing only children to influence negatively the marital relationship and bringing more economic burden to parents. Parents of two children, with one the disabled, reported more often economic burden but more positive marital relationship. The majority of parents reported a positive marital relationship regardless of their age or educational status. Those who reported a positive marital relationship were more often reported a considerable support from their spouse. It seems that parents' emotional and affection needs were met through satisfying marriages.

The type of impairment, the birth order and the age of the children had no impact on parents' replies on economic demands. The family size was statistical important showing that in cases where the family had two children or the disabled child the only child, the economic demands were reported greater. Also the gender of the child was influential making boys bringing more economic burden to the family.

In sum, characteristics of the disabled child such as age, gender, the type of impairment, and the parents' perception of child's behaviour did not influence

parents' accounts of changes in family life. Family size was influential variable on marital relationship and the economic burden. Also were statistically significant, characteristics of parents' such as their educational status and their age. The support from the husband and the positive marital relationship were the main factors for parents to report less changes in their lives.

SECTION 4:PARENTS' BELIEF SUSTEMS

A: Parents' source of strength

4.1. INTRODUCTION

In this section parents were asked to give an account of their source of strength and how they perceived their family as compared to other families. The parents' answers formed the categories used for description.

First, the finding presented here look at relationships between the parents' source of strength which was used to adapt to the existence and care of a disabled offspring in their family and background factors of type of impairment, gender, and age of children.

4.2. EFFECTS OF CHILDRENS' TYPE OF IMPAIRMENT ON PARENTS' SOURCE OF STRENGTH

Mostly this question was answered by mothers or, in some cases, as well as by the fathers who, when present, agreed with the mothers' perception. The main source of strength for mothers was their faith in God. Regardless of the children's type of impairment, mothers revealed that they turned to God and generally to religion as a way to find support, guidance and strength (32%, 38%, 40% respectively). The next table (17) presents the relation between the type of impairment and the parents' source of strength.

Other mothers mentioned that their own temperament was a source of strength for them. Of those 22% had physically disabled, 20% with mentally

disabled, 12% with a hearing impairment. The observed differences were not statistically significant, showing that the type of disability did not influence the temperament of the mothers.

Other parents perceived their own child as a source of strength. More often those parents were caring for physically and hearing disabled offsprings (17% and 24% respectively).

The mother mentioned above had reduced social activities and her relationship with her husband went through a critical period because of the child's disability, but she still perceives the child as a source of strength.

Other mothers perceived that the combination of their own traits and their child's gave them strength to continue, regardless the child's type of impairment (14%, 14% and 8% respectively). Those children were sociable, and easygoing ones.

Also parents mentioned that their family gave them strength. The family included both the husband and the children. The support from their husband was mentioned as an important factor for overcoming difficulties.

Mostly mothers found strength and hope in their faith in God and from their husband's support. The type of impairment of their child was not associated their answers. Next we will examine the effects of children's gender on parents' source of strength.

4.3. EFFECTS OF CHILDREN'S GENDER ON PARENTS' SOURCE OF STRENTH

Generally, the parents' answers concerning their source of strength to continue making efforts on behalf of their children were not influenced by the gender of the child. The majority of parents, regardless of the child's gender, found strength, as they stated, by having faith in God (35% and 36% respectively). The next table (18) gives the inter-relationship between the gender of children and the source of strength.

It was not only their faith in God but also the mother's personality that helped them to find the strength to continue their efforts regardless the child's gender (20% for boys, and 19% for girls respectively).

Other parents perceived the existence of their child as their source of strength, regardless of the gender of their offspring (18% and 16% respectively). There were parents who answered that their own traits and their child gave them strength and courage regardless of gender (12% and 13% respectively), and finally, those who found strength in the support of their family (12% and 13% respectively).

It seems that the gender of the disabled child was not an influential factor on the mothers' reported source of strength. Next we will examine the effect of the age of the disabled children on participants' replies to the same question.

4.4. EFFECTS OF CHILDREN'S AGE ON PARENTS' SOURCE OF STRENGTH

In examining the effects of children's age on parents' answers, again the majority replied that their faith in God helped them face the difficulties of bringing up a disabled child. The next table (19) gives the presentation of the inter-relationship between the age of the children and the parents' reported source of strength.

Interestingly, the older the child, the more parents reported faith in God but this finding was not found statistically significant.

Of those parents who had children between 7-10 and 11-15 years more frequently reported as their source of strength their own personality (21% respectively). Those who perceived their child as their source of power mostly had children aged 5-6 and 7-10 years (18% and19% respectively) than older ones (12%). This finding was found statistically significant (p=<0.01) showing that when children were younger, were more frequently source of strength for their parents.

Although, mostly mothers who perceived their family as a source of strength had older children aged 11-15 years (17%) than younger ones (11% and 12% respectively), the observed differences were not found statistically significant.

The couple who mentioned a doctor as their source of strength, had a mentally disabled male child aged between 7-10 years. The mother described herself as very active, who changed her work for the sake of her child. She stressed that her boy is lucky because he has a good father who haven't left the family:

4.5. SUMMARY OF RESULTS AND DISCUSSION- Parents' belief systems -Parents' source of strength

One of the parents' belief systems in which were found significant elements associated with family adjustment to a disabled child (Flagg-Wilkins, 1991) was religion.

The present study similarly with Bennett et al. (1995) and Weisner et al. (1991) found that religious orientation gave parents with disabled children a source of support, hope and strength. In the present study, it was found that mainly parents turn to God for support and comfort. Their belief in God helped them find ways to lessen their perceived difficulties of caring for a disabled child. Regardless of the child's gender, type of impairment, and family size, the most reported source of strength for mothers was their faith in God. The age of the child and the age of mother did not influence the responses. Interestingly, the educational status of the mother was related to their faith in God (see table 8, Appendix II A). The lower the educational status of the mother, the more likely she was to believe in God.

The other relationship found statistically significant was between the source of strength and the perception of support (p=<0.05). Those mothers who were supported by their husbands were more frequently able to find strength from their own personality. The mothers who had faith in God were no more able to maintain a positive relationship with their spouse than the others. Also, was not found statistically significant that mothers who perceived themselves and their character traits to provide them with strength, were more likely than others to report fewer changes in social activities of the family, and a positive marital relationship.

In summary, the majority of parents turn to God for support and comfort. Neither the gender, age of the child nor the type of impairment and the family size

had any effect on which sources of strength parents reported as important. Regardless of the child's age, gender and type of impairment and family size, faith in God was the main source of strength for mothers. Interestingly, the educational status of the mother but not her age was related to the use of religion as coping strategy. The less educated the mother was, the more likely she was to believe in God. When mothers were supported by their husbands, more often reported that were able to find a source of strength in their own self in order to cope. Mainly, mothers when they needed to cope with a stressful event turned to religion or to inner personality characteristics.

SECTION 4

B: Comparison with other families

4.1. INTRODUCTION

The finding presented here look at relationships between the parents' comparison with other families and background factors of the type of impairment, gender, and age of children. Flagg-Williams (1991) found that parents' belief systems such as how they made comparison of their family to others was an important factor associated to family adjustment. Parents differ dramatically in the way in which they view their child's disability. This difference was reflected in the importance given to comparative appraisal (Frey et al., 1989). In the present study, parents were asked to give an account of the result of a comparison between themselves and families with non-disabled children. Their replies will be discussed in this section.

4.2. THE EFFECTS OF THE CHILDREN'S TYPE OF IMPAIRMENT ON THE COMPARISON WITH OTHER FAMILIES

The participant parents answered that they perceived their family as similar to families without disabled children. Those who found greater similarity were parents with a hearing impaired (75%) or a physically impaired child (54%)

compared with only 40% for mental disabled children. The observed differences reached levels of statistical significance (p=<0.05) showing that parents with mentally disabled children perceived their families more frequently different than families with non-disabled children. In the next table (20) we depict the relationship between the type of impairment and a comparison with other families.

Those parents who mentioned that there were differences between families that had disabled children and those that did not, used the existence of the disability as a starting point for this difference.

All parents who replied that their families are different from others, but in a positive way, perceived that they were very close to every other family member, having harmony in their inter-relationships and communication among the members of the family.

It seems that the type of impairment influenced perceptions of similarity with families having non-disabled children but not the perceptions of difference. Next we will examine the effects of the children's gender on parents' answers.

4.3. EFFECTS OF CHILDREN'S GENDER ON THE COMPARISON WITH OTHER FAMILIES

Again more often parents perceived their families as similar to other families regardless of the gender of the child. Although, mostly parents who perceived that their family was different compared to others were caring for a girl (34%) than a boy (30%) the observed difference was not statistically significant.

The next table (21) illustrates the inter-relationship between gender and parents' answers concerning their comparison with other families.

It seems that the gender of the disabled child had no impact upon the perception of difference or similarity with other families without disabled offspring. Next we will explore the effect of the age of children on the comparison with other families.

4.4. EFFECTS OF CHILDREN'S AGE ON THE COMPARISON WITH OTHER FAMILIES

The interesting finding in this set of inter-relationships is that the older the child was, the less families perceived themselves as similar with others (32%), finding found statistical significant ($p=<0.05$). The next table (22) illustrates the influence of the variable age of disabled children on parents accounts of comparison. The observed differences did not reach statistical significance and this may be due to the distribution of the sample between age groups. When we focus only on the differences between the first and the latter age group then the variable of age was related with perception of similarity and was found statistically significant ($p=<0.05$). It showed that those who perceived their family similar to others, had younger children between 5-6 years old (63%) and 7-10 years old (54%) than older ones.

We could hypothesise that parents with young children, perceived no difference with families of non-disabled children because they pass similar stages of child development with them. A thumb rule for parents of non-disabled children is that their child becomes more independent as it gets older. This is not the case with a disabled child. Perhaps for this reason parents of older disabled children perceived less their family as similar to others.

In sum, it seems that the age of the child as well as type of impairment were variables, which had an impact on parents' answers.

4.5. SUMMARY OF RESULTS AND DISCUSSION- Parents' belief systems-comparison with other families

Asking parents to consider their family in terms of other people formed another set of questions in the present study. The similar social comparisons were related to less stress and positive adaptation while downward social comparisons were related with more stress and negative effects on adaptation (Murphy et al.,1990). The majority of parents in the present study, considered themselves similar to other families with no effect of gender. The type of impairment and the age of the disabled children had an effect on the participants' answers. Those with a younger child perceived more often their family as similar to others. Additionally,

families with physical and hearing impaired child regarded more often that they were similar to other families. Probably, when the child was younger the differences in development were not as apparent, so parents more easily perceived themselves similar to families without disabled children. The behaviour of the children was not statistically significant variable on the comparison with other families. Another reason for the perception of similarity, might be that those families were tended to have intact social activities, finding statistically significant ($p=<0.05$), to report no economic burden ($p=<0.01$), and tended more often to report a positive relationship with their spouse, findings also significant ($p=<0.01$) (see tables 10,11,12 Appendix II A). Comparing the educational status and the age of parents to the result of the appraisal, neither of the two variables influenced the answer. Further, it was found significant the relationship of comparison with other families and the parents' construct of luck ($p=<0.05$). Those who reported lucky despite the disability of their child more often regarded their family similar to others (see table 13, Appendix II A). It was statistically significant the family size of the family ($p=<0.05$) (see table 14, Appendix II A). Those families with two children more often reported that perceived their family similar to others.

On the contrary, those parents who perceived their family as different from others, had older children. The type of disability of the child and family size but not the gender influenced the result, because mothers of mentally disabled children and those with only children perceived more often their family as different compared to others. But might not be only the disability of the children that influenced the report but the fact that those families were found to experience reduction of their social activities, finding significant ($p=<0.05$) (see table 10, Appendix II A). Also, was statistical significant ($p=<0.05$) that the relationship with their spouse was reported negative (see table 12, Appendix II A). Probably, the diminished social activities and the negative marital relationship made mothers to perceive more often that they were different to other families and not only the type of impairment of their child.

In sum, the type of impairment and the age of the disabled children and family size had an effect on the participants' answers. It was found that the age and the education of the father and the mother did not influence the answer. Those families which more often perceived themselves similar to other families had more than one child and tended more often to have intact social activities, had no

economic burden (p=0.01) and tended to report a positive relationship with their spouse.

SECTION 5

POSITIVE CONTRIBUTIONS OF THE DISABLED CHILD TO THE FAMILY

5.1. INTRODUCTION

In the present section we will explore the relationships that show association of the positive contributions of the disabled child to the family as perceived by the parents with the background factors of the type of impairment, gender, and age of children.

Current research does not deny the stress experienced by parents of a disabled child but emphasis is also placed on the reasons and on the coping ability of parents to overcome difficulties of caring for a disabled offspring. Following this research line of individuals with disabilities they are often perceived as making positive contributions to their families. This perception can be viewed as an adaptive strategy (Behr, 1990).

In the present study, the main positive contributions of the disabled child as reported by parents were the unity of the family (30%), the change in personality (43%), and the existence itself of the child (17%).

5.2. EFFECTS OF CHILDREN'S TYPE OF IMPAIRMENT ON PERCEIVED POSITIVE CONTRIBUTIONS OF THE CHILD TO THE FAMILY

The responses of parents showed that they thought the disability of their child brought them together rather than separated them as a family, and that their personality changed with the very fact of the disability of their child and their parenting of the child. When they were asked to specify the change in their personality, they replied the following: that they had become more sensitive (n=27), they valued things differently (n=37), they believed more in God (n=5), they 'seize

the day' (n=2), they were content with details (n=5), and that they became less selfish (n=2).

The perceived contributions of the disabled child to the family according to the disability of the child are shown in the next table (23).

The most frequent answer of parents was that their family remained united despite the disability, while only 25% of those with mentally disabled offspring mentioned family unity as a positive contribution of the impaired child to the family. However, the observed differences did not reach levels of statistical significance showing that the type of disability did not influence their answer.

Parents very often reported the change in their own personality, as a positive contribution of their disabled child. The parents reported becoming more sensitive to other peoples' problems, stronger in order to face difficulties and understanding themselves better. The percentage reporting this change did not depend on the disability 42% of parents had a physically disabled child and 47% had a mentally disabled child. Parents with hearing impaired children less often reported a change in their personality (31%). Also in this case the differences were not found statistically significant. Of those parents who perceived that their personality changed from parenting a disabled child, a number of them reported that they had realised the value of simple things in life.

It seems that the type of impairment did not influence the parents' perceived positive contributions of the disabled child to the family. Next we will examine the effect of the gender of children on their views.

5.3. EFFECTS OF GENDER ON PERCEIVED POSITIVE CONTRIBUTIONS

The gender of the child did not seem to influence the proportion of parents perceiving their family as remaining united, despite the disability of their child (45% for boys and 47% for girls). Similarly, regardless of the gender of the child, parents perceived a change in their own personality (44% for boys and 41% for girls). The next table (24) illustrates the relationship between the gender of the child and parents' perceived positive contributions.

Next we will explore the effects of the age of children on parents' replies.

5.4. EFFECTS OF THE AGE OF CHILDREN ON PERCEIVED POSITIVE CONTRIBUTIONS

Mainly, parents of older children more often (11-15 years) perceived as a positive contribution of their child that they were brought together as a family (38%), while only 24% of those parents with children aged 5-6 felt the same (see Table 25). Though, the difference was not found statistically significant.

Of those who felt that their personality changed due to the disability of their child, many felt that they became more sensitive and responsive to other people's needs. Others felt that they realised the valuable elements of their life.

Some of the parents, regardless of the age of the child, commented that the positive contribution of the disabled child was the expression of true love shown by the disabled offspring to the members of the family.

Generally, those who had older children were the ones who mostly reported the unity of the family as a positive contribution while those with younger children felt that the change in their own personality was the major positive contribution of their disabled child to them. However, it seems that the contributions of the disabled child to the family were not related on the age of the child in statistical terms.

5.5. SUMMARY OF RESULTS AND DISCUSSION-Positive contributions of the disabled child to the family

Similarly with other studies (see above), in the present study the unity of the family was found as one perceived positive contribution. However, the type of disability, gender, age, family size and the perception of child's behaviour were not influential variables to this perception. Another finding was that also the age and educational status of the mother and father did not influence in statistical terms the reported positive contributions of the child to the family. It was not also found statistically significant the relationship between the positive contributions and the perceived social activities changes, or the economic demands reported by the parents. Interestingly, it was found statistical important that mothers who perceived the family unity as a positive contribution had also reported that their spouses support them (p=0.00) and reported a positive marital relationship (p=0.00) (see table 14,15, Appendix II A). This study similarly with Sloper et al.(1991) and Reddon et al.(1992) could suggest that the spouse support might be a crucial factor for positive outcome for parents and for better functioning in parenting roles. This finding showed that the result could be influenced from two ways. The support from

the husband might helped the mother to perceive herself satisfied with her roles since was able to balance the burden. This helped her to have a positive marital relationship with her spouse and consequently was more ready to maintain the family together. On the other way round, the need to do the best for the child, as we mentioned in an earlier section, reinforced her efforts to keep the family together and consequently to find ways to have a positive relationship with her husband.

Another positive contribution was the parents' perception of positive change on their personality. Parents reported that parenting a disabled child helped them to realise what the important things in life were, a finding similar with Nassef (1989). Others became more sensitive to people's problems or they became stronger through the experience. Mothers and fathers seem to have reconsidered their value system and to have adopted new attitudes in life regardless their age or educational status. Again the type of impairment, gender and age of the child was not found significant related to reported changes in personality.

Those parents who perceived the existence of the child as positive, despite his/her disability had mostly the disabled child as their only child. They had a low educational status with no obvious affect of their age or the child's type of impairment and gender on the matter. Also, non of those parents reported a change in personality or the family unity as a positive contribution, findings statistically significant (p=0.00).

Summarising, it was found that the type of impairment, gender, age and behaviour of child did as well as the family size and the educational status and age of parents did not influence perceived positive contributions of the disabled child to the family. It was found statistically significant that those mothers who reported the family unity as a positive contribution had perceived the husband as supportive and regarded their marital relationship as positive. Interestingly, the main finding in this section was that the quality of the marital relationship and the mothers' perception of support was influential factor for those mothers who perceived as a positive contribution the unity of the family.

CHAPTER 6

NEEDS FOR SERVICES

6.1. INTROCUCTION

The unique needs of Greek parents with disabled children have been inferred from studies in other countries and are mainly unknown or misunderstood.

Thorin and Irvin (1992) noted that :

'common sense suggest(s) the importance of listening to the perceptions of families about their members with disability and the effects on the family before making assumptions about support services' (p.35)

Following this suggestion, in the present study, after exploring the effect of a disabled child on the family, we tried to explore what were the needs of the Greek family with a disabled offspring. After a careful examination of the data, we found that parents needed mainly 17% more special schools (N=53), 13% specialised centres for each disability (N=41), 11% more professionals and paramedics trained on disability matters (N=34), 27% counselling for parents (N=87), 4% more support from the State (N=13), 13% information centres (N=42), 4% respite care (N=11), 1% sex education(N=4), and 10% change in attitudes against the disabled (N=33).

Next we will explore if the type of impairment had an impact on the perceived needs reported by the parents.

6.2. EFFECTS OF CHILDREN'S TYPE OF IMPAIRMENT ON PERCEIVED NEEDS

The disability of the child seemed to have an influence on the expressed needs of parents. The next table(26) shows the needs of parents according to the disability of the child.

Special schools

Parents with mentally, and hearing children required more special schools (21% and 26% respectively). The observed difference was found statistically significant (p=<0.05).

Information centres

Parents, regardless of the type of disability of their child had, expressed the need for information centres. In these centres, parents would ask for information about the child's disability, how to handle his/her behaviour, how to teach their child new skills, and would also receive information about services available.

The mother of a mentally disabled boy expressed her disappointment and the need for an information centre:

The mother of a physically disabled boy requested an information centre where one could find available services for the child and the parent:

Education for parents

Other parents asked to have information on how to teach their child. A couple with a mentally disabled daughter stressed:

Support and Counselling

Nearly 90% of parents, regardless of the type of impairment of their child, required counselling. The mother of a mentally disabled girl suggested:

Multi-disciplinary centres

Parents, mainly with physically disabled children, expressed the need for organised centres within which their child could have physiotherapy, other therapies and school lessons (22%) which was a significant finding in statistical means (p=<0.05).

Positive attitudes to disability

Parents regardless of the type of impairment expressed the need for more people with understanding and generally changes in attitudes towards disabled people

Support from the State

Parents mostly with physical (5%) required more help from the State not only in the form of economic aid but also in the form of programs for the family.

It seems that parents of disabled children were not satisfied with the State provision for them. They perceived the help of the State minimum, if not existent. The reply of a couple with a mentally disabled daughter illustrated the opinion of the majority of parents in this study.

Lastly, four parents asked for evening occupation regardless of the disability of their child. The following quotations are representative of the answers given:

Concluding, it seems that parents of mentally and physically disabled children were influenced by the type of impairment on their perceptions of needs for their children. Those parents with mentally disabled children mostly asked for the establishment of more special schools and those parents with physically disabled

children asked for more multi-disciplinary centres. The type of impairment partly influential factor for the expressed needs for services.

6.3. EFFECTS OF CHILDREN'S GENDER ON THE PERCEIVED NEEDS

It seems from the next table(27) that gender did not influence parents needs. Either for girls or for boys the needs of parents were the same.

6.4. EFFECTS OF CHILDREN'S AGE ON PERCEIVED NEEDS

It seems that the age of their children influenced the needs expressed by the parents. Parents with older children 7-10 and 11-15 years of age were more likely to require more special schools for each disability but the finding was not statistically significant.

Special schools

As the child reaches age of school entry, parents face the big problem of finding a school to accept their child. The older he/she gets, the more difficult is the attainment of a formal education due to the lack of schools or independent living establishments.

Multidisciplinary centres

Parents who asked for multidisciplinary centres regardless the age of their children. A mother of an 8 year old girl replied:

Information centres

Parents requested the establishment of information centres also regardless the age of

Support from the State

Parents regardless age of children expressed the need for more help from the State. A mother with an 8 year old physically disabled girl stressed:

Positive attitudes to disability

Regardless of the age of their child, parents asked for a change in attitudes towards disabled people. Parents of older children aged 7-10 and 11-15 years required respite care.

Parents of older children inquired after the possibility of sex education, a finding significant (p=<0.05).

Concluding, firstly, there were these needs shared by the majority of parents irrespective of age, gender and type of disability of the child, the need for support from the State, professionals specialised on disability matters, information centres and counselling for parents. Secondly, there was the need for certain services depending on the disability of the child-the need for special schools for mentally disabled children and multidisciplinary centres for physically disabled children. Thirdly, there were those needs arising from the unique circumstances of each family.

6.5. SUMMARY OF RESULTS AND DISCUSSION-Needs for services

The views expressed by parents in this study could be used to help and to stimulate professionals on how to usefully consult with and cooperate with parents in designing, planning and developing services that would meet the expressed needs of parents.

A large proportion of parents with mentally or hearing disabled children were those who mainly requested special schools designed for each disability.

The type of disability of the disabled children exerted an impact on perceived needs for services. As disabled children became older, the need for special schools becomes more pressing, in parents needs. This may be explained by the apparent minimal existence of services and special schools able to accommodate the needs of older children. The existing vocational training centres are very few and the need for vocational and independent living units was reported as a necessity. The needs of older and younger mentally disabled children (12-18) are usually accommodated in the primary special schools which do not always applying programs according to their needs.

Parents with physically disabled children expressed the need for multi-disciplinary centres where their offspring could have their therapies without obliged to go from one place to the other for therapy as was the case up to now or to pay for private lessons at home. Such places do not exist in Greece or in Athens.

Parents focused on the need for more trained professionals on disability and further pinpointed the need for change in attitudes against disabled people. Their replies were not influenced by the impairment, gender or age of the child.

Among the needs of parents, the availability of information was mentioned more often by parents. It is interesting to note the existence of medico-pedagogical

units in Greece responsible to diagnose, support the child and the family. However, as Stathopoulos (1995) noted in these units the idea of multi-disciplinary team is not yet a reality. Some of these units do not employ psychologists or social workers. This may explain why regardless the type of impairment, gender, and age of the child, parents expressed the need for information centres that would provide information on the disability, available services, and teaching techniques for their child. Lack of information may restrict parents' expectations of services (Orlowska, 1995). Lukes (1974) suggested that the most effective way to exert power is the one which people do not recognise that they have needs which are unmet. Earlier, Gibson and Young-Brockopp (1982) suggested that the primary importance given to information is often based on the belief that lack of knowledge creates much anxiety on the part of parents. They continued that information is certainly a necessity which would clear up misconceptions and confusion, but that it is only a beginning.

In the present study, parents asked for support programs for themselves dealing more directly with the feelings of parents and their experiences, the organisation of parent groups where they could exchange advice and ideas, regardless of the type of impairment or the age of the child.

In the present study, parents asked for greater financial aid from the State more organisation in the services and financing of programs for the disabled and their families. Parents felt that the State had abandoned disabled children and their families. As their children were getting older, the need for support from the State more evident and the lack of services more obvious. The apparent requests for special schools should not be viewed as being against the ideals of inclusive education. The parents are asking for effective services for their children, and they assume this can only be provided in special schools rather than in mainstream schools. Their requests for changes in attitudes towards disabled people shows they recognise that their children will be living in a society which needs to change to include them effectively.

Summarising, the type of impairment was influential factor for the parents of mentally and physically disabled children. The expressed needs by the parents were not influenced by the gender of the children. Mainly parents of older children required more special schools, and the possibility of sex education at schools. The other needs expressed by the parents were not influenced by the age, gender, and type of child's impairment.

CHAPTER 4

CONCLUSIONS

A page was added with the titles of the sections in the conclusion chapter

A new section was added under the title ' **Introduction**' to clear state the aims of the study(p.241)

1.Introduction

The aim of the present study was to explore the experience of Greek parents with disabled children. At the demands of the comprehensive approach, this study has focused on the positive aspects of the experience without denying the difficulties of parenting a disabled child. The study was conducted trying to find what is the Greek reality related to families caring for a disabled child, how Greek families grapple with the disability of their children, and how they construe the main issues influencing their lives. In the present study, were explored the parents' difficulties, aims, coping

strategies and needs and they were pinpointed similarities and differences to other research work in England and America on this topic.

A new section was and under the tittle 'Critical Review of the Methodology Used' to expand on the critical reflective review of the methodology used in the research study (p.241).

2.Critical Review of the Methodology used

The present study was descriptive and used a qualitative and quantitative methodologies. It was guided by research questions rather than a research hypothesis, without theory development before the field study. Possible links between the data presented and theoretical ideas used in earlier research in other countries were explored in the discussion. In Greece, the research on families with a disabled child is rare and the professionals usually are making interventions following results from studies in other countries. However, each population is influenced by the unique context they live. So, it would be helpful professionals in order to design effective intervention and services for families with a disabled child to have reports of the individual characteristics of Greek families. In this way, the answers of this study would be useful and add to knowledge.

Unfortunately, the time for data collection was limited. The use of questionnaire would be helpful to gather very quickly information but might fail to grasp a complex social reality. So interviewing was decided to be the method for data collection. The interview schedule was structured with semi-structured questions. Mostly families were represented by mothers, although in nearly a quarter of cases fathers were present also. It was proved a successful method of data gathering because helped the researcher to understand how individuals make sense of their social world in Greece and to act within through the collection of parents' experiences, opinions, aspirations and feelings The wording of each question was given careful consideration in order to minimise the interviewer's effect by asking the same question of each parent and to reduce the necessity of the interviewer judgement during the interview. By using semi-structured interview schedule organisation and analysis of the data was facilitated.

However, the interviews reports on the internal reality of each family and the researcher knows little about a reality external to the interview and how parents adopt particular opinions and values for leading their lives. A fuller understanding could be achieved by witnessing the context of the event or the circumstances to which parents refer and this could be explored during observation of the families over time. For such observation to be realistic, however, it should be participant observation, where the researcher could stay with the family for a period of time and add from field notes to the interview data gathered. In this way, the researcher could understand in a more complete way the conditions and events that made the families to act in a particular way. This would take considerable time, which was not possible for this study, but could be part of a future study with much smaller sample. If the researcher could stay with the family for about one week, the situation of each family and possible factors influencing the interview answers could be described.

Even though, the parents did not felt pressured to adapt their responses according to demands of social acceptability or social aquiescence a possible bias could be the presence of the researcher. Now matter the responses the researcher could use to demonstrate that there was no bias in the interviews someone could doubt the accuracy of the information by arguing that the researcher chose the responses that were more convenient for showing the limited bias in the research process. After all, the researchers that are opposing the qualitative research they argue they even the presence of the researcher can be a bias in the information.

The data analysis was proved to be successful by using both qualitative and quantitative methods. The qualitative data provided the richness of information and helped in the construction of Greek reality whereas, the quantitative data established regularities in social life by focusing on the measurement and analysis of important interrelationships between variables.

The choice of open-ended questions provided the researcher with a lot of information on the related subjects. Though, in the data analysis was not always easy to find statistical significance because the information were too many to be qualitatively treated and for this plurality of answers on each research question probably the sample was small. If the parents had to choose between two possible answers then probably it would be easy to find statistical significance in most of the research questions.

The sample of the study was sufficient to reveal relationships between variables. Even in those cases where the group of parents was small the general conclusions were true because the number of schools approached was bigger than the number of schools for other disabilities.

It would be questionable if the results would be the same with smaller sample. If the sample was small then it would be better the interview to be unstructured in order to explore in greater depth the issues involved, and base the analysis much more on qualitative methods. From another point of view if the sample was from a general sweep of parents then the results would be questionable because it would be difficult to decide on the representativess of the sample. Using schools as a starting point for did give a good initial range of families to contact.

The use of other methodologies in order to gain more information and adding to the reliability of the information would be advisable. It would have achieved a total, complete picture of the phenomenon investigated. But according to Silverman (1985) ' What goes on in one setting is not a simple corrective to what happens elsewhere- each must be understood in its own term (p.21).' Equally, the researcher's role is not to decide which is the real account but to describe and understand the situation.

The present study was descriptive and the results derived from the study should be interpreted in view of several methodological limitations. First, the parents represented a limited sample thus, limiting data generalisability. Information, was gathered from interviewing parents, mainly mothers. It would be very helpful if the same interview schedule was administered also to fathers. In this way we could examine any existing differences in their answers.

Another shortcoming of the research was the sampling. It would be more easy to find statistical significance between variables if the characteristics of the children (type of impairment, gender and age) were balanced, to give groups equal size, and to give larger groups of the families with children who had disabilities relatively more rarely. This would have needed a much more widespread sampling at the beginning of the study, and then families selected from this wide range to give the groups sizes required.

The study did not assess with standardised tests family functioning, the coping strategies and the satisfaction from social support (informal or formal). In the study, we did not explore if behavioural problems in children could be directly associated with

poor physical health in mothers. It was suggested that similarly to mothers, fathers also reported more stress, role confusion, social isolation and marital difficulties (Ventura,1987). Although, comparing the stress between mothers and fathers of disabled children, fathers were found to experience less stress though, mainly mothers were interviewed in this study and the reaction of fathers of disabled children was not explored. In the literature review, was suggested that men and women used the same coping strategies when they were occupied in the same social roles. This finding was not examined in the present study. The impact of siblings in the adaptation of the family was not assessed, and also not a lot of fathers participated in the study, though from research studies abroad was found valuable their contributions to the functioning of the family. We did not explore the coping strategies of younger and older mothers to see if their age impact the use of different strategies to cope. Also we did not explore which factors helped parents in having sense of competence and satisfaction for parenting and marriage. We did not explore elements of parent-child interaction and how the parents define this interaction.

In further research would be important to use standartised tests to evaluate the reports of the families especially for the ways that parents discipline their children and the reaction of sibling toward the disabled child. Additionally the views of professionals about the family with a disabled child were not explored. The results of this study can be characteristic only for the sample of parents involved in the study, as although they were from a range of schools and reflected a range of features, they were all volunteers, and this limits how far the information they gave is typical for all parents. It is likely, though, that because those parents will probably be more successful and confident as parents than those who did not volunteer, any services needed by parents volunteering in this study will also be needed for parents who did not volunteer, as they are likely to need more help to care for their disabled child.

The existing findings of the study are all now under a section with the title 'Summary of the Findings'. The findings are different from the original thesis because the test for statistical significance changed the findings and now are more concrete(p.245).

3. Summary of the findings

This study explored the daily difficulties that parents face after caring for a disabled child, their aims for the child's future, their perceived changes in family life, the parents' belief systems such as the perceived source of strength and the parents' perception of similarities with other families as coping strategies, the positive contributions of the disabled child to the family, and, finally, the parents' perceived needs for services.

3.1.Daily difficulties

In the present study, after following Crinc and Greenberg's (1990) and Krech and Johnston's (1992) suggestions that daily hassles were more powerful than major life events in predicting child, parent and family functioning, we explored parents' perceptions of daily difficulties with their child. In the present study, the most reported everyday difficulties were caregiving, demanding behaviour and low communication skills. The age, type of impairment, but not the gender, family size and birth order of the child influenced parents' perceptions of difficulties. Similarly with other studies, parental stress in Greece was associated with the caregiving demands of a disabled offspring. (Erickson and Upshur, 1989; Frey et al., 1989; Harris and McHale, 1989). It was found, that the younger rather than the older children, tended to be more demanding in their care according to parents' reports. This is a finding similar with Trute (1995) who found that young children are causing more stress in mothers. Among, disabled children, statistically significant was the finding that those with physical disabilities had the greater caregiving demands related to difficulties in mobility. In the present study, similarly with others, it was found that the diminished functional independence of the child caused increased caregiving demands on the parent (Breslau et al., 1982; Leonard et al., 1993; and Tangri and Verma, 1992) but this finding is in opposition to Wallander et al. (1989) who found that the functional independence of the child did not influence mothers' adaptational abilities as much the perception of support from the social environment.

Girls and only children were not perceived as needing greater everyday care. This finding is inconsistent with Tangri and Verma(1992) who found that the care of a female disabled child was more overwhelming task than caring for a boy. Birth order also, showed that when the disabled child was the second child or the only child in the family, the caregiving was not perceived as more demanding.

The demanding behaviour of the child, was another daily difficulty reported by parents. Problematic behaviour has been directly associated with poor physical health in mothers and has been found as one factor which has a pronounced effect on family function (Carr, 1990; Wallander et al. 1989; Stainton and Besser,1998; Floyd et al.,1997). Similarly with Cameron et al.(1991) and Hagborg (1989), in the present study, the child with behavioural problem caused more stress to mothers. According to DeKlyen et al. (1998) behavioural problems cause also reduction of sense of efficacy and satisfaction with parenting and decreased positive parent-child interaction. In the present study, children who were perceived as being very difficult to manage, were mostly mentally disabled children. The gender was not significant, finding which did not support the suggestion of Maccoby and Jacklin (1974) that boys were frequently exceeded girls in the frequency of acting out and non-compliance. These children were found in all age groups but were more likely to be found in the group of older children (11-15 years), a finding statistically significant. The birth order of the child was not influential in the perception of behaviour by the parent, a finding similar with Corter et al. (1992). Another finding which was not statistically important was the family size. Those parents with two children did not perceive the behaviour of the child to be demanding and causing more daily problems to them. Those parents who perceived the behaviour of the child as a daily difficulty also reported reduced social activities and negative effect on their marital relationship. The relationship between behaviour and social activities and/or marital relationship might not be one way. Maybe demanding behaviour had an impact on those variables but maybe the reduced social activities due to reluctance of parents to socialise influenced the behaviour of the child since the opportunities for experiences out of the house were minimised. Szykula et al. (1991) suggested that when social support patterns fail to develop child-rearing attitudes, this result in the diminished pleasure of mothers in their children and bring an increase in aversive aggressive parent-child interactions. Additionally, the negative marital relationship might influence parents who perceived the behaviour more demanding than it was, or possibly the child was exhibiting more active-out behaviour influenced by the general negative atmosphere in the house. All these could made parents fell less competent in their roles, or the combination of the above might influenced their moods and evaluations of their children's behaviour. Studies by Patterson (1982), Dix (1991) and Jouriles and Thompson (1993) suggested that

mothers' moods could influence their evaluations of their children's behaviour but were unclear whether positive or negative moods had similar effects, on the mothers' evaluation of the child's behaviour. We do not know if the behaviour was actually demanding or if it was perceived as such by the parents. The particular point becomes important after one takes under consideration the suggestion of Rimmerman and Portowicz (1987), where the greater the perception of behavioural problems in children, the greater the parent's perception of the child's limitations in physical abilities and self-help skills. So, maybe, the parents got into a vicious circle, spending more time on the care of the child, because they perceived their child as unable to perform tasks. The mothers who answered that the behaviour of their child was their greatest difficulty, were from all educational levels except those with degree and were between the age of 31-40. These findings were statistically significant (p=<0.05). We could suggest that they might lack the means to help their child interact socially due to their young age, so they need to find ways to expand their social lives. Since Patterson (1985) and Szykula (1991) found that children who were aggressive were more likely to be rejected by their parents, it becomes important to help parents to accept their child, teach them problem-solving techniques or behaviour management skills. Taking under consideration that the educational status of the parents was from all educational status except those with degrees, we could hypothesise that those parents felt less pleasure with their children and they had poorer health. In the present study, we did not assess mothers' moods by standardised tests as suggested by studies reviewed, studies (used mothers with depression) which failed to support the hypothesis that depression distorts mothers' reports of children behavioural problems (Conrad and Hammen,1989; Richters and Pellegrini,1989).They concluded that mothers may negatively perceive the behaviour of their child regardless of their moods. Maybe exhaustion from caring influenced their perceptions of their child's behaviour. Mothers in the present study, who reported a demanding child's behaviour as an everyday difficulty, also asked for support and information on how to behave towards their child. We may suggest that there is a need for intervention techniques focused on the enrichment of mother-child interaction, enhancement of the self-esteem of parents and the teaching of behaviour modification techniques so they might feel more competent to face the behavioural problems of their child. Carr (1990) found that parents were successful in dealing with behavioural problems more than with teaching

skills. According to Carr (1990), parents could be taught basic and straightforward methods for the management of demanding behaviour such as reinforcement of more desirable behaviour, time out, desensitisation and 'ignoring'. Though, intervention focusing only on children is not enough. Sloper et al.(1991) stressed that intervention which targets only the behaviour of the child is less likely to be successful. More importantly, the relationship between spouses should be put on new grounds, where the mother would receive more support from the father, and also the father and the siblings would be able to deal with the demanding behaviour of the disabled child more effectively. Apart from the teaching of methods for the management of demanding behaviour, parents could be taught stress management and relaxation techniques. A model of stress management was suggested by Hornby (1994). The model consists of strategies related to the interpersonal, cognitive, physical, organisational and task-related factors which have to be assessed from the professional and the individual in order to effectively manage stress.

Thus, it would be more effective when planning intervention, to think about and empower the whole family and help the family to discover its own personal and social support resources.

Another difficulty for parents was the communication problem between parent and child, especially in children with hearing disabilities, finding statistically important (p=<0.01). These children were mainly young in age, and the parents were young in age, both findings were found with statistical significance (p=<0.05). The older mothers seemed to be more competent in the performance of their roles. The present study consistent with Trute (1995) found that as mothers were becoming more familiar with daily demands were feeling more competent. So, an aim for interventionists should be the support of younger parents to face the everyday care of the child.

Consistent with other research designs in the present study when the child's communication skills were low, the parents experienced more stress (Frey, Fewell and Vadasy, 1989; Frey, Greenberg and Fewell, 1989; Sloper and Turner,1993). Similarly with Frey et al. (1989) and Frey, Fewell and Vadasy (1989) in the present study, we found that when the child's communication skill was low, the parents felt

more stressed. Sloper and Turner (1991) suggested that communication problems were related to the parents' adaptation. Disabled children have greater difficulties in communicating their wants and needs (Nihira et al., 1980) and as a result parents tend to provide less stimulation and structure. It seems that reduction in the ability to express and negotiate intentions and/or interpret each other meanings or intentions, resulted in more stress. Probably, parents of young children lack skills of alternative communication patterns, so they face more difficulties with the basics of communicating. Because communication problems were related to adaptation as Sloper and Turner (1991,1993) suggested, there is a need for greater focus on mother-child interaction. Furthermore, Corter et al. (1992) found that the gender of the disabled child did not affect mother-child interaction, what did was the disability of the child. It seems important that intervention should serve to explain to the parents the characteristics of their child, how to observe the existence of cues and how to develop those characteristics of children, which affect interaction. Additionally, intervention strategies would help parents through the teaching of sign language, or alternative means of communication to have better communication with their children and consequently, to provide their children with a higher level of stimulation and support, since they would be more able to understand their wants. Bradley et al. (1989) reported that parents who provided stimulation and other kinds of material and structure for their disabled children, helped them to function more competently.

One way to accomplish this task would be by enhancing the parent-child interaction. Goldberg and Easterbrooks (1984) stressed that effective parent-child interaction could help mothers to feel more competent and adapted better to the disabled child. Another helpful provision that would be helpful is the provision of respite care for these families. If the mothers had the money to pay for someone to care for their child or could pay for respite care, then might the burden of care not be so overwhelming on her. Additionally, if the fathers could help mothers in the task of caregiving, then the mothers could feel more able to provide care. According to Parks et al.(1997) when fathers were involved in care giving activities, the quality of stimulation at home was enhanced. Glendinning (1983) found that actually the mothers' perception of the willingness on behalf of their husbands to help affected

them more than the actual number of tasks carried out by them. Paternal involvement could also provide the couple with shared experiences which could contribute to greater satisfaction from parenting and greater marital satisfaction as Harris and Morgan (1991) suggested. Finally, it is necessary if we want a participating father to enhance the father-child interaction by developing skills in play interactions, teaching them how that child develop and how to observe the cues of the child in communicating with him/her. Relationship enhancement should also focus on the enhancement of the marital relationship which is related to the sense of competence, satisfaction from parenting, sensitivity of mothers to children cues and more effective adaptation (Peterson,1980; Goldberg and Easterbrooks,1984).

Summary of discussion of parents' difficulties in everyday life

Summarising, in the present study, similarly with other studies, parental difficulties in everyday life were mainly associated with caregiving demands demanding behaviour and low communication skill of the disabled child. It seems that child characteristics such as the type of disability, age of the disabled child played a crucial role in parents' perceptions of everyday difficulties. Furthermore, the demanding behaviour of the child and the difficulty in communication placed a lot of pressure on the everyday life of parents. The mothers' characteristics which influenced perceptions of difficulties in everyday life were their age ($p=<0.05$) and their educational status except those with degrees ($p=<0.01$). The younger the mother, the greater were the difficulties experienced in everyday living with a disabled child.

3.2. Aims for the future

It seems that the most important goal for the child's future was independence. This independence in the present study was thought to be achieved through economic security, education, the ability to socialise, having a balanced personality, and reaching or expanding their child's potential.

All parents wanted their child to live independently, regardless the type of impairment, the gender of the child, the birth order and the family size. Maybe the strongest influential variable related to this answer was the age of the child. Those parents with older children more often answered that independence was their aim for

the future. Those couples were both older (over 30 years). As for the educational status of mother and father who aimed for independence, they were from all grades but, interestingly fewer from those with degrees. We can hypothesise that their education helped them to understand and realise that the type of impairment of their children could prevent them from living an independent life. Indeed, these parents were caring mainly for mentally disabled children. The parents' uncertainty about the future became more apparent when it was found that mainly one main aim for mentally disabled children was economic security. This explains why these parents perceived that they should secure them financially. Perhaps, the fact that they were degree holders may also help them to have a higher social status and, consequently, to have the money to help their child compared to others of a lower educational status.

Furthermore, regardless of their birth order, mainly parents of girls perceived economic security as a necessary aim for the future more than for boys, a finding statistically significant (p=<0.05). Similarly, with Pfeifer and Sussman (1991) in Greece sex stereotypes lead to differing priorities for parents' responsibilities. In regard to a son, the generally held view is that mainly parents should foster their son's independence and ensure the basis for his future socially and economically. Sons, in Greece, carry the family name, through sons the family may be socially upgraded and they are considered the family's breadwinners. Mainly, fathers socialise their sons and share the male world with them. Daughters were seen as rather vulnerable. Thus, a parent's foremost responsibility is to protect his daughter and to ensure her welfare. In this respect, gender and type of impairment influenced the perceived goals for independence and economic security. It seems that in Greece the socialisation of males, developmentally normal and disabled as well, follows stereotypic patterns with emphasis on autonomy, self-reliance and independence. On the contrary, parents of girls perceived economic security as an important aim for them more than for boys. Those parents with older children asked for independent life units, and vocational training centres. In Athens, there is only one public unit of independent living directed by the child-psychologist Tsiantis, and a private one called 'Margarita'. Both found difficulties in their establishment of the buildings because of the great reaction of neighbours in the area. Vocational training centres in Athens under the authority of the Ministry of Education are only three and one under the authority of the Ministry of Work (Information for special education, Ministry of Education ,1995).

There were parents who were more concerned about their child's education. More often those parents had young hearing and/or physically disabled children, a finding statistically important (p=<0.05). Regardless of the child's gender or the birth order, parents saw independence as being achieved through education. During, the early 1950 and onwards education was perceived as the most secure way to achieve higher social status in Greece. Nowadays, many people believe that holding a 'certificate' or 'diploma' gives to the individual an opportunity to find a job and consequently he/she have the economic security to lead their lives independently (Katakis,1998). It seems that this perception applies also to families with a disabled offspring. Another reason to support this finding could be that in Greece exist more vocational training centres for the hearing and physically disabled, more opportunities for the child to be educated in mainstream schools and more chances for people with these type of disabilities to find work placements.

Development of the child's potential was a desired aim, regardless of their type of impairment, gender and age or their parents own age and educational status. Mainly, parents with only children aimed for development of their child's potential.

A relationship significant in statistically means (p=<0.05) was the relationship between the type of impairment and the aim to become the children calm/sociable. In the previous chapter we revealed that those parents with mentally and hearing disabled child perceived the behaviour of their child as demanding and faced difficulties with communication. In addition, they wanted their child to become more socially competent. Those parents between 31-40 who had older in age hearing or mentally impaired boys were concerned more about the behaviour of their child and wanted them to become more calm and/or sociable. We can surmise that behaviour was a matter with an effect on all domains of family life. These parents do not have any other aim, but only for their child to became calmer. We can hypothesise, firstly, that parents lack the means for the behavioural management of the child and so maybe these parents would be helped by teaching them behavioural management techniques. Maybe the perception of behaviour was influenced by the apparent difficulties with communication, and this leads to a need to find ways which would improve interaction between parents and children. At the same time, we should also help the family to restore the relationships between its members, and to help parents learn stress management skills. In cases that we can teach disabled children to interact with their

environment in a more adaptive way by teaching them social skills, we could decrease aversive behaviour and consequently increase the responsiveness of parents to the child. Schlundt and McFall (1985) defined social skill as 'the specific component processes that enable an individual to behave in a manner that will be judged as competent'(p.23) Michelson et al. (1983) noted that social skills were: 1) primarily acquired through learning, 2) comprised of verbal and non-verbal behaviours, 3) entailed appropriate responses and initiations, 4) maximised social reinforcement from others, 5) were interactive in nature and required timing and reciprocity of specific behaviours, and 6) influenced by variables such as the age, gender and status of the individual. The above suggestions would be of help only when combined with the support of the parents so they might be able to care for their children but without overprotecting them.

Finally, parents were most concerned that their children acquire a balanced personality, regardless of their age, type of impairment, birth order, family size and gender and regardless of the parents' age and educational status. As parents mentioned, the children live in a social world and as they get older they have to come to terms with their disability and even though they are disabled they still need to form friendships without feeling inferior to their able-bodied peers and friends. It seems again that the development of social skills could be of assistance to those children. A hypothesis of why parents aimed for a balanced personality could be the parents' own feelings and the effect of other individuals' reactions and stares on their child. If this is true, then parents should be helped to resolve their own feelings about the disability and intervention should focus on the enhancement of parents' coping strategies. If this aim is related to the children's future personality development, then, it seems important to give parents information about the personality development of disabled children and even better to form groups for the enhancement of the self -esteem of disabled children and teenagers.

Summary of discussion of parents' aims for the future

In summary, parents' aims for the future were the independence, the economic security, the education, the development of potential, the change in behaviour and the balanced personality of their children. The aim which was

influenced by the age of children, was independence. The older a child was, the more independence was mentioned as an aim for the future. Economic security was an aim for females and mentally disabled mostly the older in age and firstborns. The change in behaviour was an aim for parents with older mentally disabled boys, regardless of the birth order and the family size. The aim for education was mentioned for hearing/physically disabled, young in age children regardless of family size and birth order. Balanced personality was reported regardless of their age, type of impairment, gender, family size and birth order. On the reported aims for their offspring future had an effect particular characteristics of the children but not the educational status and age of the parents. Both the age and educational status of parents was not statistically significant related to the aims for the future.

3.3. Life changes

In this section, parents gave an account of changes in their family life after the birth of their disabled child. None of the characteristics of the disabled children or the perceived child's behaviour were statistical significant related to whether or not parents perceived their social activities the same or different since the birth of a disabled child. In opposition to findings of Chetwynd (1985) and Baxter et al.(1995), in this study mothers of children with mentally disabled child were not reported more often facing difficulties and changes in their life. In the present study, were more influential on the perceived changes on the social activities were the educational status and age of parents than the type of impairment of their child. Mothers of lower educational status and those younger in age more often reported that their social activities have been reduced. Their social isolation appeared to be self-imposed. These parents might were afraid to leave their child to grandparents or friends, or might tried to keep away people who could reject themselves or their children. Probably the parents' perception of limitations in social activities, rather than the actual behaviour of the child, caused by their low educational status and the young of their age led them to spend all day on their care, and then because of exhaustion as well as self perception of appropriateness, they socialised less. Tiredness might precluded parents from maintaining friendships, since they were

unable to participate as frequently in social or recreational activities as other families, a finding consistent with Gough et al. (1993).

It was interesting that in families with intact social activities the father had a higher degree of education, finding with significant significance (p=<0.05). We could hypothesise for the present study that the educated fathers supported more often their wives, and as a result most of the other activities of the family remained the same as before. This study similarly with Carr (1990) found that fathers with degrees facilitated more positive adaptation in their families, because they were supportive to their wife. Further, those mothers who did not report changes in their social lives were older in age, another finding statistically significant (p=<0.05). Maybe similar with Trute (1995) as the mother was getting older, became more familiar with daily demands, felt more competent and satisfied with her role and better adapted and kept her social activities as normal as before the birth of the disabled child. A further explanation could be that the mother who was supported by her spouse reported less changes in her life.

Indeed, in the present study, parents who had intact social activities mostly reported a positive marital relationship regardless of their age, or their educational status. We could hypothesise one the one hand, a satisfying marriage could support the sense of competence and satisfaction from parenting, a finding similar with the suggestions of Peterson (1980) and Goldberg and Easterbrooks (1984). The literature indicated that the quality of the marital relationship was the most important predictor of family adaptation (Sloper and Turner,1993; Sloper et al., 1991; Saddle et al.,1993;Bradley et al.,1991). On the other hand, maybe these parents who had more opportunities to socialise and to enjoy recreational activities were more likely to provide intimacy and companionship in their marriage and to receive support by their spouse. The finding is important because Goldberg and Easterbooks (1984) found a relation between marital quality and child-parent attachment. They showed that in families in which wives and husbands were highly satisfied with their marriages, secure child-parent attachments were most likely to occur. Both conditions could have helped parents to have higher self-esteem, to feel more competent and this perceived higher competence helps them to adapt to the

disability of their child. Child characteristics did not influence the reported quality of the marital relationship. Contrary to the findings of Bristol (1987) and Murphy et al. (1990), it was found in this study, that older children did not help better family functioning. The family size was found statistical significant related with the marital relationship (p=<0.01). The present study similarly with Fisman (1991) found that those families with more than one child more often reported positive marital relationship. Maybe families with more than one child without disability were more able to find stability and balance and feel more competent as parents. As a result they kept their social activities intact, probably for the sake of the other child. It seems that only children brought more often negative effects on parents' marital relationship, a finding statistically significant (p=<0.01). For those parents who reported a negative marital relationship neither of the characteristics of the children were statistically significant. Maybe exhaustion from caring for one disabled child had a negative effect on the parents' marital relationship since parents could not have recreational or social activities due to lack of time. Sabbeth and Leventhal (1984) suggested that time demands due to physical care and socialisation, limits the time for intimacy, privacy and the companionship needed in a marriage. Maybe mothers who reported a negative marital relationship were not supported by their husbands. Indeed, in the present study, these parents who had a negative relationship were not supported from their spouses.

Lastly, the majority of parents felt that the economic demands for the care of their children were excessive. The type of impairment and the age of the children had no impact on parents' replies. When the family had two children, one normal and the disabled child or when the disabled child was the only child then the economic demands were reported greater, a finding statistical significant (p=<0.01). Further exploration revealed that those parents with economic burden reported also reduced social activities and those parents with no economic burden had no reduction of their social activities, both findings reach statistical significance (p=<0.01).

Summary of discussion of parents' life changes

Summarising, characteristics of the disabled child such as age, gender, the type of impairment, and the perception of child's behaviour by the parents did not influence parental accounts of changes in family life. Neither the type of impairment gender, age and family size nor the behaviour of the child were found to have statistical significance related to reduction or not of social activities. In the present study, the educational status and age of parents were more influential on the perceived changes on the social activities. Mothers of lower educational status and those younger in age were more to see their social activities being reduced. Family size was a significant variable showing only children to influence negatively the marital relationship and bringing more economic burden to parents. Parents of two children, with one the disabled one, reported more often economic burden but also reported more often positive marital relationship. The majority of parents reported a positive marital relationship regardless of their age or educational status. It was statistically significant that the mothers who were supported by their spouses were more often reported a positive marital relationship.

3.4. Parents beliefs systems

In this section we explored the parents belief systems in which we found significant elements associated with family adjustment to a disabled child (Flagg-Wilkins, 1991). Murphy et al. (1990) found that families, which experience less stress and higher family well being, were more religious. Religious belief plays an important role in the life of millions of people and is used by parents of disabled children as a coping strategy in their life (Selway and Ashman, 1998). Rothbaum et al. (1982) suggested that when a situation is viewed as uncontrollable, religion may be used as a means of gaining 'secondary control' understanding and thereby accepting the event rather than focusing on ways to change it (p.25). There is another reason why religion is an important factor for coping. It may be used to handle daily hassles (Compas et al., 1988) which in the case of the care of a disabled child demands are overwhelming.

The present study, similarly with Bennett et al (1995) and Weisner et al (1991), found that religious orientation gave to parents with disabled children a source of support, hope and strength regardless of the child's gender, age and type of

impairment. Their belief in God helped them find ways to lessen their perceived difficulties of caring for a disabled child. Mahoney et al.(1992) suggested that religion could enhance family relationships, and thus enable the family to cope effectively with stress related to caring for a disabled offspring. Neither the gender of the child, age nor the type of impairment and the family size had any effect on which sources of strength parents reported as important. Regardless of the child's gender and type of impairment and family size, the main source of strength for mothers was their faith in God. The age of mother did not influence the responses. It was statistically significant the educational status of mother. The less educated the mother, the more used religion as coping strategy. The other statistically significant relationship was between the source of strength and the perception of support (p=<0,05). Those mothers who were supported by their husbands were more frequently able to find strength from their own personality.

Asking parents to consider their family in terms of other people formed another set of questions in the present study. The use of comparative standards of appraisal has been linked with adaptive functioning (Taylor and Brown, 1988; Wood et al, 1985). The similar social comparisons were related to less stress and positive adaptation while downward social comparisons were related with more stress and negative effects on adaptation (Murphy, et al.1990). The majority of parents in the present study consider themselves similar to other families with no effect of gender and family size. The type of impairment, the age of the disabled children, and the family size had an effect on the participants' answers. Those with a younger child perceived more often their family as similar to others. Additionally families with physical and hearing impaired child regarded more often that they were similar to other families. Probably, when the child was younger the differences in development were not as apparent, so parents more easily perceived themselves similar to families without disabled children. Probably was not only the age of the child which helped towards a similar comparison with other families. When the family had more than one child, perceived more often that were similar with other families since there was a balance and equilibrium in the family as they perceived existed in other families. These families tended more often to have intact social activities, finding statistically significant (p=<0.05), had no economic burden (p=<0.01) and tended more often to report a positive relationship with their spouse, a finding also significant (p=<0.01). Goldberg and Easterbooks (1984) found a

relation between marital quality and child-parent attachment. They showed that in families in which wives and husbands were highly satisfied with their marriages, secure child-parent attachments were most likely to occur. Earlier we found that parents with positive marital relationship perceived no dramatic changes in their lives after the birth of their disabled child. Both conditions could have helped parents to have higher self-esteem, to feel more competent and this higher competence helped them to adapt to the disability of their child and as a result those parents considered more often that they are similar to other families. Comparing the educational status of the parents to the result of the appraisal, it was found that the age and the education of the father and the mother did not influence the answer. Those who reported lucky despite the disability of their child more often regarded their family similar to others($p=<0.05$).

On the contrary, those parents who perceived their family as different from others had older children. The type of disability of the child but not the gender influenced the result, because mothers of mentally disabled children perceived more their family as different compared to others. These families experienced reduction of their social activities, finding significant ($p=<0.05$). Further, the relationship with their spouse was reported negative, finding also significant ($p=<0.05$). Probably, the diminished social activities and the negative marital relationship encourage mothers to perceive more often that they were different to other families.

Summary of the discussion on parents' belief systems

In sum, regardless of the child's gender and type of impairment and family size, the main source of strength for mothers was their faith in God. The age of the child and mother did not influence the responses but the educational status of mother was statistically significant ($p=<0.05$). The less educated the mother, the more used religion as a coring strategy. The other relationship found statistically significant was between the source of strength and the perception of support ($p=<0.05$). Those mothers who reported that were able to find strength from their own personality mainly were supported by their husbands.

Those families which more often perceived themselves similar to other families had younger physical and/or hearing impaired children, tended more often to have intact social activities, had no economic burden ($p=<0.01$) and tended to report a positive relationship with their spouse. The type of impairment, age and family size had an effect on the comparison with other families but not the age and educational status

of parents. Most importantly, the support from spouse and the positive quality of marriage were determinants of parents' use of coping efforts.

3.5. Positive contributions

Earlier research mentioned the experience of positive benefits from the presence of a disabled child in the family as evidence of denial and attempts to hide their real feelings (Wilker et al., 1983; Darling, 1979). Contemporary family research suggested that finding positive contributions in an experience was an active effort to cope with the situation and find a meaning for this experience. The search for meaning which could help the individual to understand what it symbolised this event to his/her life could help him/her to regain a sense of control. The cognitive adaptation theory suggested that finding positive contributions in an experience is an active effort to cope with the situation and to find a meaning for this experience. It is a source of stability for overcoming crisis in a family system (Taylor, 1983) and may reinforce the goals of normalisation (Behr, 1990). But studies didn't explain what influenced these perceptions. An aim in the present study was to examine if variables such as type of impairment, gender, or age of the child, or the age and educational status of the parents, had an impact on the positive contributions of the disabled child to the family. Hanline (1991) had associated the regain of sense of control with positive coping. It was considered a source of stability for overcoming crisis in a family system (Taylor, 1983).

The present study, similarly with studies in Britain and America (Affleck et al., 1985; Turnbull et al., 1988; Abbott and Meredith, 1986; Glidden et al., 1988; Naseef,1989; Murphy et al.,1990; Stainton and Besser,1998) found the family's unity and the change in parents' personality were perceived as positive contributions of a disabled child to the family system. Neither the type of impairment, gender, age nor the perception of child's behaviour and family size was found statistically important variables related to positive contributions. Also the age of the mother did not influence reported positive contributions of the child to the family.

It was found statistically significant that mothers who perceived the family unity as a positive contribution had also reported that their spouses support them (p=0,00) and reported a positive marital relationship (p=0,00).

A finding similar with Nassef (1989), was that parenting a disabled child helped parents to realise what the important things in life were. From those others

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became more sensitive to people's problems or they became stronger through the experience. Mothers and fathers seem to have reconsidered their value system and to have adopted new attitudes in life regardless their age or educational status.

Those parents who perceived the existence of the child as positive, despite his/her disability had mostly a disabled child as their only child. They had a low educational status with no obvious affect of their age or the child's type of impairment and gender on the matter. Also, non of those parents reported a change in personality or family unity as a positive contribution, findings statistically significant (p=0.00).

Summary of discussion on positive contributions

Summarising, the perceived positive contributions of the disabled child to the family were not influenced by the age, gender, the type of impairment of the child, the perception of child's behaviour, the family size, and the age and educational status of the mother.

Finally, it was important that the quality of the marital relationship and the mothers' perception of support by her spouse was influential for those who perceived the unity of the family as a positive contribution.

3.6. Needs for services ·

The views expressed by parents in this study could be used to stimulate professionals on how to usefully consult with and cooperate with parents in designing, planning, and developing services that would meet the expressed needs of parents. Such information would form the basis for improved personnel training and service delivery and it may also emerge as a salient step in establishing *parent-related programming* (p.46).

Traditionally, attempts to meet the needs of parents with disabled children have been based on a) assumptions regarding the needs of parents with non-disabled children (Simpson,1988), b) theoretical ecological models of the needs of parents with disabled children (Bronfenbrenner, 1979; Crnic, Friedrich and Greenberg, 1983), and c) the responses of parents of impaired offspring regarding their perceived needs (Cunningham and Davis,1985; Fewell and Vadasy,1986; Burden,1991). In general, society's predominant image of the needs of disabled persons is based on a 'medical' rather than a social model of disability (McConachie, 1997). The medical model is based on the definition of need which sees problems centred on disabled people arising

from their impairments, in contrast to the social model which sees their problems stemming from significant barriers in the social and built environment (Sim et al., 1998). Sim et al. (1998) suggested that until the social model of disability is more widely accepted, disabled people will continue to face difficulties in receiving a successful response their needs. With the medical model of disability dominating services the needs and concerns of parents have been usually inferred through circuitous means (Simpson, 1988).

According to Dale (1992) and Simpson (1988) it is ineffective to respond to problems in isolation from the settings in which they occur and suggested that for services which could efficiently target resources to meet the needs of parents with disabled children, would be important to have a firm database on consumer needs and wants. McConachie(1997) stressed that the social and community context should be the point of exploration of how more effectively we will respond to disability.

The United Nations report(1994) was explicit and in these words stressed:

> '*Services need to be planned and delivered in order to respond to these individual needs. Services must not be delivered in inflexible packages or be based on a stereotype of family needs and priorities. These have to be discussed and negotiated.*'(p.26)

In the present study, similarly with Baxter et al. (1995), was found that the perception of needs changed in relation with the child's age. The abilities might became apparent with age so different services became relevant. Orlowska (1995) agreed that when services are planned, there should be flexibility for parents to alter preferences and tailor the services according to their needs. So one suggestion would be that services in Greece should be tailored according to the needs of the families that should be taken under consideration during planning, and development of services for disabled children.

In Greece, with services under development and these that do exist controlled by professionals with stereotyped views about families with a disabled child, the views of parents were not sought by service providers and there is no law on parent participation.

The present study provides a insight and was the first attempt to identify the needs of Greek parents with a disabled child. The suggestions derived from other research studies (Sim et al., 1998; Orlowska, 1995) stressed the need for careful

identification and assessment of family needs when developing services for disabled children and their families and before applying the concept of parent participation.

A large proportion of parents with mentally or hearing disabled children were those who mainly requested special schools designed for each disability. The existing Special Education schools and units in Athens, under the jurisdiction of the Ministry of Education according to the Statistics of Greek Ministry of Education for the academic year 1996-1997 is illustrated in the following table.

Table 29. Special Education Units in Athens

	Kindergartens	Primary	Gymnasium Lyceum	Vocational training centres
Physically disabled	2	4	4	1
Deaf	3	2	4	2
Mentally disabled	2	30	-	2
Blind	1	1		
Special classes in ordinary schools		176		

The type of disability of the disabled children exerted an impact on perceived needs for services. As disabled children became older, the need for special schools becomes more pressing, in parents needs. This may be explained by the apparent minimal existence of services and special schools able to accommodate the needs of older children. The existing vocational training centres are very few and the need for vocational and independent living units was reported as a necessity. The needs of older and younger mentally disabled children (12-18) are usually accommodated in the primary special schools which do not always applying programs according to their needs. Recently the preparation of a curriculum for special schools has initiated which till now the curriculum for the ordinary schools with some adaptations for the disabled children was followed. This year a programme financed by the E.E.C. has began which aims at the vocational and independent living training of mentally disabled teenagers

and adults. In the programme three schools for the mentally disabled located in Athens participate.

Parents with physically disabled children expressed the need for multi-disciplinary centres where their offspring could have their therapies without obliged to go from one place to the other for therapy as was the case up to now , or to pay for private lessons at home. Such places do not exist in Greece or in Athens. There are private centres for physiotherapy, and recently some private multi-disciplinary centres (two as far as the researcher knows in Athens) were established but is not known how they operate, how well-equipped they are and what children they accepting. They follow requirements designated by the State for their licence but the level of offered help can not be assessed. The state could establish such centres with the cooperation of the Ministry of Education and the Ministry of Health and Social Affairs. The level of offered services in such establishments could be assessed and their help evaluated. Thus, a lot of preparation and organisation is needed to decide the aims, the requirements and the professionals involved in the task of providing these services. Finally some local authorities provide programmes for the disabled child but no general information is available about them.

Parents focused on the need for more trained professionals on disability and further pinpointed the need for change in attitudes against disabled people. Their replies were not influenced by the impairment, gender or age of the child.

Among the needs of parents, the availability of information was mentioned more often by parents. It is interesting to note the existence of medico-pedagogical units in Greece responsible to diagnose, support the child and the family. However, as Stathopoulos (1995) noted in these units the idea of multi-disciplinary team is not yet a reality. Some of these units do not employ psychologists or social workers. This may explain why regardless the type of impairment, gender, and age of the child, parents expressed the need for information centres that would provide information on the disability, available services, and teaching techniques for their child. Similarly, Sloper and Turner (1993) found that information about services was a important theme in the requests of parents in their research. In Hanline and Halvorsen (1989) research also was stressed the need for ongoing accurate information. Indeed, looking generally at the role of information in society, Moore and Steele (1991) stated:

'increasingly it is being recognised that information is, in fact, an essential element of citizenship; without information people cannot play their full part as citizens, nor can they take advantage of the benefits which citizenship can offer.' (p.2)

There is no reason why this should not apply to families with disabled people. Lack of information may restrict parents' expectations of services (Orlowska, 1995). Lukes (1974) suggested that the most effective way to exert power is the one which people do not recognise that they have needs which are unmet. Earlier, Gibson and Young-Brockopp (1982) suggested that the primary importance given to information is often based on the belief that lack of knowledge creates much anxiety on the part of parents. They continued that information is certainly a necessity which would clear up misconceptions and confusion, but that it is only a beginning.

In the present study, parents asked for support programs for themselves dealing more directly with the feelings of parents and their experiences, the organisation of parent groups where they could exchange advice and ideas, regardless of the type of impairment or the age of the child. Gibson and Young-Brockopp (1982) stressed the need of parents to share common concerns and feelings. They assumed that sharing helps people get in touch with their own feelings and learn that others may have similar feelings and experiences- a discovery which in itself helps acceptance.

In the present study, parents asked for greater financial aid from the State more organisation in the services and financing of programs for the disabled and their families. According to Stathopoulos (1995) the financial aid from the State is the following: blind (employed 22.800drachmas, not employed 63.000 drachmas) deaf (21.000 drachmas), mentally disabled (40.000 or 36.000 drachmas), physically disabled (38.500drachmas), tetraplegics/paraplegics (106.760 drachmas) and characterised as 67% disabled (30.500 drachmas). Parents felt that the State had abandoned disabled children and their families. As their children were getting older, the need for support from the State more evident and the lack of services more obvious. The apparent requests for special schools should not be viewed as being against the ideals of inclusive education. The parents are asking for effective services for their children, and they assume this can only be provided in special schools rather than in mainstream schools. Their requests for changes in attitudes towards disabled people shows they

recognise that their children will be living in a society which needs to change to include them effectively.

The existing services in Greece were found disorganised and fragmented, a finding similar with Leonard et al.(1993). 'Usually the one that shouts louder gets better treatment', a father complained. Current services are often constrained by a narrow medical and educational conception of their purpose. Families were found in the present study to need consistency and coordination of services. McDonnell(1997) considering the support provided to families stressed the importance of coordinated services which they had to become comprehensive, flexible and responsive as possible to the needs of families. The responsibility of child care, teaching, and management falls on parents who need a consistent group of specialists able to formulate an individual plan of family's needs and priorities and would monitor and revise the progress. Consistent with Dale (1990) parents in the present study expressed the need that services to be delivered locally and to be accessible to all children and families that utilise community facilities. Lastly, parents of older children, mainly mentally disabled, expressed the need for independent living units (only one exists in Athens) and sex education for these children and teenagers. It should be noted that the establishment of these units necessitates also the preparation of disabled children by teaching them independent living skills and the preparation of professionals who would supervise the disabled adults. Additionally, these units should keep contact with other professionals such as social workers, doctors, psychologists and vocational training experts and must also include sheltered workshops with equipment, personnel and a specialist involved in vocational placements. Parents in this study, requested social provision and a State with social welfare for the disabled and those of need. Hutton (1996) stressed the importance of social welfare in the following statement:

> 'At the heart of the welfare state lies a conception of the just society
> ...the vitality of the welfare state is a badge of the healthy society. It is a
> symbol of our capacity to act together morally, to share and to recognise the
> mutuality of rights and obligations that underpin all human associations. It is
> an expression of social citizenship '(p.306).

The availability of appropriate community services could be critical in mobilizing the family's resources. It was proved that professionals who foster cooperative partnerships with parents informally enhance the family's self-confidence and feelings of mastery and control (Cooley,1994). Parents by getting involved and

contributing to their child's development, they experience a sense of satisfaction that fulfills their own needs while at the same time respond to the child's needs. The best way to provide effective intervention should be to focus on the needs and mobilisation of the existing strengths of the families than try to change families and children (Wilgosh,1990). Additionally services could be closer to the parents' needs if they were designed to meet the individual needs of parents and to complement the family's own structure of coping in order to identify and encourage the usage of adaptive strategies. In England, with the introduction of the Community Care Act in April 1993, the user participation in services planning and delivery was emphasised. In other countries, like England and America with over 20 years of research on parent participation, the meaning of the term and how it is best applied, is still questionable. According to Sim et al. (1998) the Community Act 1993 has failed to reconcile the needs defined by the users and the needs defined by professionals. Blacker and Baker (1992) suggested that this is an area in which there is much work still to be done, both on process and outcome levels because there is an uncertainty about the type, level and patterns of participation desirable. Additionally, Allen and Hudd (1987) argued that the participation of parents should be considered from the perspective of parent needs and also of professional responsibilities so that parents were not expected to take on tasks which are the responsibility of professionals. Middleton (1998) suggested that since partnership has been far from realisation, it would be more effective to advocate family support and services rather than *family policing*.

Summary of discussion on parents' expressed needs for services

Recent research has emphasised the need to have a database on parents needs if we want to plan and deliver appropriate services that would accommodate these needs. The needs of parents, in the present study, changed according to the age of the child but the most interesting finding was the similarity of parents' perceived needs within disability groups. Parents expressed the need for counselling, support from the State and information centres a similar request found also in Burden (1991). They asked for coordination of services, which could be delivered locally, and professionals more understanding towards the disabled. The coordination of services could help to reduce parents' confusion, the incidence of contradictory advice and information and could improve access to unfamiliar facilities. There were parents who asked for special

schools and multidisciplinary centres. Most of all they asked for organisation and availability of services depended upon finance and policy.

A new section was added under the title '5. **Contributions of the Study to Research and Further Developments Needed'.** In this section the possible contributions of the present study to research and suggestions for further research are presented (p.258).

5. Contributions of the Study to Research and further Developments needed

The aim of the study was to explore the theories and empirical findings of research from the UK and USA on the experiences of families bringing up a child with disabilities and to try to discover if these ideas would reflect the realities of that situation as discovered by the Greek families. The present study's unique contribution was to provide professionals involved with disability matters with necessary knowledge about family functioning of Greek parents with a disabled child so they can easier identify the strengths, the weaknesses, the coping strategies, the support networks, the needs and satisfaction from services. The study followed a family system approach and a social model of disability focusing not only on deficits but also the strengths of the families. The sharing of knowledge, skills and experiences could develop an effective partnership between professionals and parents and could eventually lead to parents' empowerment. When the professionals would understand how the Greek families construct their world, they could understand what makes an event a crisis for one and not the other and they would be more ready to enable them and help them to live more satisfying lives. The study has demonstrated that many of the theoretical ideas could be used in Greece. In particular, the concept of coping and the theoretical ideas around it were of particular significance in explaining the reality of the Greek families having a disabled child to care for.

Research on families in Greece are scant, so a lot of studies should be conducted. Future research should use longitudinal designs to assess the impact of the disability of a child on the family for longer periods of time; observation studies should be conducted to determine upon the family functioning in relation to parenting skills

and discipline strategies; the incidence of mental and physical health in mothers caring for a disabled child; the impact of disability on normal siblings; to describe what Greek couples' mean of quality and satisfaction from marital relationship and parenting; to measure if the amount of caregiving tasks performed or the perception of the psychological support to her by the father could reduce stress in mothers; to determine if religion or the inner traits of parents leads to effective adaptation; and would be helpful a comparison studies with families having a disabled child and healthy children; to find ways to develop parent-child interaction and determine which methods are more effective for the Greek parents; to examine if the positive effects of social support are related to perceptions of availability rather than actual receipt and appropriate and explorations of parents' and professionals' perceptions about the effect of a disabled child in the family functioning. Future research could develop also measurement tests in a adapted form for Greek population assessing family functioning, the coping strategies and the satisfaction from social support (informal or formal). The most important thing would be to use the findings of research in England and America and thus save time when we start creating intervention plans for the family with a disabled child and not to use concepts like parent participation, which is still questionable, before empowering the families and recognising their uniqueness.

During the last months reactions of joy and frustration have swung like a pendulum. The effort was worthwhile because through this research, I reached a deeper understanding and appreciation of the intricacies and yet coherence of parents' experiences. I took pleasure in sharing their stories and gaining access into their lives because this lead me to appreciate the possibilities and difficulties in changing the present status quo for Greek families with a disabled child. The parents expressed the notion that they had learned from the process of being interviewed. Most of them, openly expressed their motivation to contribute to a more efficient understanding for the future. I was led to an understanding of the issues and processes that imbue subjects' stories and most importantly to relish the understanding that I gained from them. In a more practical way, the research helped to have the best possible relationship with the parents of my students in the school I was working.

This research presents a gap between the field study and the writing-up stage because after the collection of the data, I was offered a full-time position as a teacher in a school for mentally disabled children back in my country. Definitely, I could not

stop my PhD but it was also not eager to leave a permanent working position. Looking back, it would be better to complete the thesis first and find a job later, as there is little time to write up the report when working full-time and bringing up a young family. As a Greek proverb says 'Always you have to try hard if you want to gain something worthwhile'.

This study painfully, joyfully and courageously moved through its life course and it has being shaped by criticism, praise and much persistence. It has been a learning experience which started with a single step. It showed me that *care and education are inseparable-quality care is educational and quality education is caring* (White,1997, p.24).