GREEK FAMILIES WITH A DISABLED CHILD: PARENTAL PERSPECTIVES AND PERCEPTIONS OF NEED FOR SERVICES

By

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To my beloved mother, my husband and my new-born baby boy who showed me what means loving and caring

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ABSTRACT

The aim of the present study was to explore the perspectives of families with disabled child in Greece and their perceived needs for services. One hundred and ten families were interviewed in Athens. The study provides an insight of the positive aspects of caring for a disabled child but also of the difficulties that parents face in their everyday life. It is a first attempt to reveal how Greek parents with a disabled child construct their world. Additionally the similarities and differences to other studies in England and America are pinpointed. The daily difficulties found were the caregiving activities, the externalising behaviour problems and the difficulties with communication and mobility. The perceived support from spouse and the positive marital relationship were associated with positive family functioning. Greek parents used religion, comparative appraisals and positive contributions as coping strategies. Their perceived needs for services included the establishment of special schools, of information centres, better social provision from the State for the disabled, and counselling intervention for the parents of the disabled children. It is suggested before that any attempts for parental participation and empowerment of parents should proceed knowledge of parents' stresses, strengths, belief systems, coping abilities and perceived needs for services.

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INTRODUCTION

Throughout history the family has been vital to the well-being of individuals and nations. It is the cornerstone that hold a civilisation alive and is the mean for any values and attitudes transfer to other generations.

The birth of a child signalises the continuation of the particular family. The diagnosis of a child's disability forces the family to mobilise resources in order to adapt to this painful and traumatic event. A considerable number of studies in England and America were conducted to understand the way of parents' coping under such circumstances. The basic assumption was that all areas of individual and family functioning would be affected negatively. Later, however, researchers discovered that not all families react pathologically and there were families able to find ways to cope. The concept of adaptation to a child with a disability can now be seen as an ongoing process. Nowadays, the effective planning and delivery of services for disabled children and their families is given a greater emphasis than before. It is realised that intervention could be effective when parents of disabled children or even the disabled individual express their own needs in the creation and delivery of services.

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 English/American. 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, it was hoped, 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 through the literature review the reader to 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 (Findings and 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 section 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 fourth chapter of the present study are discussed the implications of the results of the study for intervention and service planning and delivery.

CHAPTER 1

LITERATURE REVIEW

LITERATURE REVIEW

1. **Introduction**

2. **Stress, coping and adaptation**

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1. INTRODUCTION

The birth of a child for most parents is an event eagerly awaited, an occasion for the celebration of life's renewal. Parenthood is considered a transitional point, a phase or space of time (McBride,1989), but also a learning process of experimentation enacted daily in the laboratory of homes and communities. Prospective parents entertain fantasies about what their child might accomplish in its future life and endow their offspring with limitless potentials and possibilities. As Gath (1985) suggested:

> *'The very success of family planning has meant that each child is planned to be perfect, embodying more of the parental aspirations than a generation or two ago, when many families could expect to lose a child through early death.' (p.393).*

The birth of a child arouses ambivalent feelings in parents who not only feel the joy of having produced a new life, but also the sombre acknowledgement of new challenges and responsibilities for which there has been little preparation (Brooks, 1987). The baby forces the family system into a period of disorganisation. In order to restore equilibrium, the parents must learn new coping methods and establish new patterns of relationships. The resolution of the discrepancy between the ideal image and the actual appearance of the child is one of the early tasks of parenting (Bristor,1984).

If the child is diagnosed with a disability, then parents have to face additional stress and greater discrepancy. Dreams are readjusted with the realisation of the disability and a period of extreme psychological vulnerability begins, as the child fails to reach critical developmental milestones and discrepancies persist. Parents of new-born exceptional children have to face additional challenges and responsibilities laid on them when in fact they may feel powerless and are required to become super parents in order to cope with internal feelings and external pressures (Hanson and Hanline,1990).

The diagnosis that a child has a disability confronts families with many practical and emotional challenges as they come to terms with their child's limitations and begin to cope with an uncertain future and also may place excessive demands on the energy and resources of the family. Additional care and exertion are often necessary and continuous. Locating and obtaining access to educational, social, medical, and other support services place demands which deplete from the family's energy supply.

The researcher wanted to introduce readers to what is the experience of parents bringing up 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 such 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 latter 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. Coping and adaptation would be of particular significance in order to explain the reality of Greek families with a disabled child. 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 pinpointed. A separate eighth section introduces the unique characteristics of the Greek family to the readers.

2. STRESS, COPING AND ADAPTATION

2.1. Process of Adaptation

A gradual awareness of the loss of the perfect child they have dreamed of, brings to parents sadness and sorrow and they must begin the grieving process in order to continue with their lives. They may deny the existence of the disability, yet denial can be an important step to a successful grieving process. It gives parents time to gain the inner strength and external support necessary to cope. Through this process, personal growth is facilitated, and the re-evaluation of the values and attitudes of the parents is stimulated (Pueschel, 1986). Bruce and Schultz (1994) concluded that grieving is an ongoing feature of caring for a disabled child.

Analysis of the literature on families of disabled children revealed contradictory views of how these families react to their predicament. Byrne and Cunningham (1985) delineated three assumptions that guided stress research in families with disabled children.

2.1.1. Pathological Approach

The first assumption described research up to the mid-1970s which examined the impact of disabled children upon family functioning, and adopted the 'pathological' approach. This approach assumed that such families experience higher stress, which in most of the cases led to psychological impairment on family functioning. At that time, researchers like McMichael (1971) claimed that all families with a disabled child were disabled families. Literature beginning around the 1960s focused on how the birth of a disabled child created a discrepancy between reality and the wished for child. The initial reaction, or 'novelty shock' as Wolfensberger and Menolascino (1970) have suggested, could hamper the flow of encouragement that parents were prepared to offer their offspring. Parents faced a 'narcissistic blow' (Cohen, 1962, p.138) detrimental to their self-esteem, their ability to produce a normal infant, their opportunity to live a fuller life through a child. For Schneider (1983) the loss of the perfect child also forced parents into an awareness of their own mortality. The parents encountered a roller-coaster of emotions that ranged from guilt, denial, and anger to adaptation and reorganisation (Drotar et al, 1975). As an example of this approach, Michaels and Schucman (1962) characterised parents of mental disability as suffering from emotional disorders and depicted the husband and wife as 'blaming each other', and with mutual support relative rare (p.570).

Buck (1950) on the birth of her exceptional child wrote 'All the brightness of life is gone, all the pride in parenthood' (p.27) verifying the notion that children represent for parents extensions of themselves and affirmations of successful self-fulfilment. Theories of chronic sorrow and mourning were derived from this deficit model of approaching families with disabled children.

2.1.1.1. Chronic sorrow

Olshansky (1962) writing from a psychoanalytical perspective, believed that parents were frequently held in lower esteem for having an exceptional child. Consequently, they were unable to get rid themselves of the guilt that became internalised as 'chronic sorrow' and carried out throughout life by the whole family. Olshansky (1962) advised professionals 'to increase the parent's comfort in living with and managing their 'defective child' (p.193) rather than spend time helping them reach an arbitrary level of acceptance of their situation. He maintained that this 'chronic sorrow' was an 'understandable, non-neurotic response' and in describing denial, viewed it as a way for the parent to better tolerate, the terrible reality that confronted him/her each day. In a more recent study, Wilker et al. (1981) and Fraley (1988) noted that although Olshansky's views were held by a minority of professionals, as a concept 'chronic sorrow' is still a valid one. Their results indicated that parents experienced grief in transitional periods. In this scheme, rather than having a predetermined outcome, adjustment was seen as ongoing. Davis (1987) elaborated upon the theme of recurrent grief and stressed the importance of the external environment in the grieving patterns of parents with disabled children. He warned professionals not to 'overestimate the impact of the initial crisis and to underestimate that of later grief episodes, even though, they are sensitive to the chronic nature of parental sorrow' (p.354). These findings are important, because they stress the need for providing assistance to those who lack the necessary resources and explain why some families who are supported by services, still experience problems. Dunst and Trivette (1986) stressed that greater resources such as physical help and social and emotional support could increase the sense of personal well-being for parents with disabled children.

2.1.1.2. Mourning

Like Olshansky, Solnit and Stark (1961) build on Freud's formulation of mourning but they differ from Olshansky in that they felt that grief could and should be resolved. Three stages of crisis following diagnosis of disability were listed: numbness, disappointment, and re-experience. Parents experienced an intense feeling of loss of the desired child and resistance to the alternative attachment. Mourning could not be as effective as in the death of a child because of the child's need for daily care. Hurley and Hurley (1987) noted that parents experience their feelings of sorrow as a 'peak and valley phenomenon', rather than as 'chronic' unchanging sadness. Solnit and Stark (1961) concluded that mourning might be manifested by a vacillation between obsessive dedication to rejection of their child's atypical traits.

2.1.1.3. Stage Theories

From about the 1950s to the 1970s most articles dealing with understanding parents of disabled children were based on conceptualisations of bereavement (Kubler-Ross 1969; Bowlby, 1960). Within this context parent adaptation was assumed would move through a predictable series of stages which include an initial phase, often labelled as shock, followed by a period of disorganisation. During this stage, parents experienced an array of emotional states. In a review of 24 different stage theories, Blacker (1984) concluded that most of them could be summarised into a three-phase model:

1. Denial reactions were experienced by parents when they initially learned that their child had a disability. Denial to accept the diagnosis, denial to see the child, and denial which might also take the form of wishful thinking (Fortier and Wanlass,1984). Denial has been viewed negatively, however, it could be considered as positive since it is necessary to the process of moving on (Burden,1991).

2. During the disorganisation stage, parents' feelings include shame, ambivalence, disappointment, anger, hopelessness. A common reaction associated with this stage was that of guilt (Garguilo, 1985). Borrowing from the literature on grief, some models included a bargaining phase, where parents sought a better diagnosis by 'shopping' around for different professionals opinions.

3. Eventually, resolution of the above feelings were expected to bring parents to a plateau of reorganisation and acceptance (Gath, 1985; Bristor, 1984; Drotar et al., 1975).

Moses and Van Hecke-Wulatin (1981) have proposed that parents of disabled children proceeded through stages of grief in no specific order while Ellis (1989) added that the phases varied in length and intensity.

Logic dictates that the discovery of a child's disability represents a crisis for the parents, however, it has been argued that a sequential pattern of reaction to having a disabled child might not actually exist for many families. Allen and Affleck (1985) found 'that individual mothers differed considerably in the degree and direction of their mood changes' (p.201). In fact, the stage approach presented valuable insights into various reactions of parents which were considered as entirely natural and even essential towards adaptation (Burden, 1991). As well, it provided a heuristic reference upon which the professional could assessed and categorised, and make judgements regarding the parents' level of coping. However, as Blacker (1984) noted imposing the stage concept onto parents might unfairly stereotype their responses and should not be accepted without expansion or revision.

2.1.1.4. Existential conflicts

Roos (1986) suggested that parents without being precluded from reactions following the stage theory, might be affected by existential conflicts which were exacerbated by the disability of a child such as *disillusionment* (for fulfilment of parental expectations by the child), *aloneness* (due to difficulty to establish intimacy with the child), *vulnerability* (by the realisation of the minimum control over life), *inequality, insignificance* (due to difficulty to achieve meaning in life*), past orientation* (focus on present or past than the future), and *loss of immortality.*

This theory on the one hand, gave some clues of what parents of the disabled might experience but on the other hand, followed a pathological point of how parents react to the disability without giving suggestions how and which of the parents reach adaptation and through what ways.

2.1.1.5. Developmental tasks

Mitchell (1985) suggested that another way to view the adaptation process was by seeing parents as reaching stages which were characterised by a set of developmental tasks. These tasks should be mastered or partially achieved if they were to adapt to the caring of a disabled child, and were associated with initial diagnosis, infancy and toddlerhood, childhood and early adolescence, and with late adolescence and adulthood. This theory could be of help for professionals by giving them the tasks involved at various developmental stages of the child, so they could inform parents of what to expect. However, did not give any explanations of how the parents adapt to the disabled child.

The majority of studies which followed the traditional psychoanalytical orientation emphasised the maladaptive aspects of parents' seemingly futile attempts to overcome the shock and to adequately raise their children (Glimps, 1984; McMichael,1971). Problems such as depression (Burden,1980), and marital problems or divorce (Gath,1977; Price-Bonham and Addison,1978) in these families have been well documented. Jaffe-Ruiz (1984) stated that 'early conceptualisations of the parental response to the developmentally disabled were psychoanalytically oriented ... focused on guilt denial projection and rejection' (p.65). This may be reflected in professional views which tended to predict more negative effects on families rather than on the parents' own perceptions (Blackard and Barsch, 1982; Sloper and Turner, 1991). The research derived from these assumptions contained methodological shortcomings. Often variables such as socio-economic status, family size, age, and type of disability were not considered as potential sources of differences in the response of the family system to a disabled child.

This static deficit outlook failed to recognise the importance of identifying areas of family functioning which were not affected by the child's disability. Studies following this orientation adopted a relatively simple course and effect relationship between stress and dysfunction. However, they failed:

1) to explain the process of adaptation which presumes coping, and factors that influence the parents' ability to adapt;
2) to identify areas of family functioning that are not affected and
3) to note the specific processes through which family functioning may be altered.

These omissions together with the lack of control groups and a focused view that psychological impairment was an inevitable consequence for families, due to problems and difficulties experienced from caring for a disabled child, contributed to the self-fulfilling nature of the assumption of homogeneity and pathology among families (Byrne and Cunningham, 1985), and has led in turn to the generalisation that families of disabled children have similar resources and needs (Lipsky, 1985).

2.1.2. Unmet Needs for Services Approach

The second assumption discarded the first assumption, but suggested that high levels of stress were caused by the unmet family's needs for services (Beckman, 1983; Gallagher et al., 1983; McKinney and Peterson, 1987). Burden and Thomas (1986) regarded the concept of *need*, as a more constructive point to start understanding families with a disabled child. The difference between a positive and a negative resolution of each crisis period was considered to 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. Much earlier, Mechanic (1970) had argued that from a sociological point of view, stress arose when the social system failed to provide adequate support systems and preparatory institutions (such as families, schools, peer groups).

An interesting point came from Darling (1979) who strongly rejected the 'victim-blaming ideology' (p.222) and concluded that access to adequate community resources and acceptance by close family and other contacts were crucial for adaptation. Her position was that when successful parenting and family interactions were not possible, it might be due to a deficiency of societal resources and not to inherent family pathology. Andersson, (1993) and Byrne and Cunningham (1985) also identified the lack of unmet service needs of families, rather than the simple presence of a disabled child as a stressor leading to family problems. Darling's work seemed to present a fundamental and powerful contribution with its persistent emphasis on the similarities between the experiences of parenting disabled or non-disabled children. Nonetheless, the focus should not be only on recognising the needs of the child but also on identifying the needs of the whole family system which change over time because the family with a disabled child passes through a series of 'transitions' (Viney, 1980). Certain potentially troublesome life events, such as beginning school and the onset of puberty, give rise to individual and family needs. Transitions might be more demanding on parents with disabled children, because they are unexpected and might last longer than anticipated. So it would be better to consider that the needs of the families change over time and the need for support is exacerbated at periods of transition.

Conclusions from this body of research presented some difficulties because of its a theoretical nature. Control groups were rarely included and conclusions drawn tended to be related to the locality in which the families live and the specific time during which the study took place.

2.1.3. Comprehensive Approach

The third assumption suggests a comprehensive approach which highlights the strengths as well as the difficulties among parents of disabled children. The present study, will follow this approach for understanding families with disabled child and explore their experiences. It is a more flexible approach observed now by professionals, where parents of disabled children are thought to progress through a multitude of perspectives with successful adaptation and personal satisfaction as an ultimately realistic possibility (Lipsky, 1985; Seligman, 1985). Wilker et al. (1983) acknowledged that in spite of feelings of chronic sorrow 'being the parent of a retarded child has been a strengthening rather than a debilitating experience' (p.313). Earlier Begab (1967) identified in his research findings that parents and siblings of disabled children could develop 'tolerance, patience and understanding which strengthens rather than weakens family relationships' (p.3). Current perspectives do not presume parental response to the birth of a disabled child to be always that of a grieving process. 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). 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 adaptation through various stages of adaptation, culminating in a stage of 'acceptance'. The island of isolation on which many parents of disabled children find themselves, may be abridged when it would be understood that acceptance and rejection are not universal parental responses.

As Dreikurs stated:

> *'Each handicapped child formulates our response to his disability. His lifestyle is developed early in childhood through the interpretation that the child makes of all the experiences and*

> *difficulties with which he is confronted. The disability is one experience. What he does with it is all important.'(1976, p.52)*

Summarising, the variability of approaches for the study of the family with a disabled child has gone on for more than forty years, and provides us with a deeper insight of what the caring for a disabled child involves for the family because the reviewed approaches focused on different elements of the process to adaptation. In the beginning, research adopted a pathological approach, to reach a point where it was realised that families adapt to the disability of a member in different ways. All the above frameworks, could be of help to the professionals working with the families and provide them with a variety of approaches that they could adopt in order to create their own framework that suit their theoretical background and could be of maximum help for parents. The professional could then efficiently recognise malfunction but also effective adaptation. By focusing on and understanding the family functioning and needs, the professionals could help the family mobilise the use of its own coping skills and resources, and prevent the results of stress in the family.

3. ADAPTATION MODELS

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.

It is clear from past research that parents of disabled children reported high levels of stress (Hanson and Hanline, 1990), thus, most parents come to value their child despite his/her disability. Families experience periods of growth and integration, periods of relative balance and stability, as well as periods of disorder and disorganisation. In fact, stressful adaptive struggles led not only to disequilibrium but also influenced growth and development. Concluding, Allen and Affleck (1985) suggested that adaptation should be as a life long process.

The viewpoint that has guided the vast majority of research on coping was that of Lazarus and Folkman (1984) who defined coping as:

> *'the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person (p.283).'*

This definition encapsulated three key concepts. First coping was a *process* or interaction between the person and the environment. So coping efforts attempted to alter this relationship and were influenced by the characteristics of the person and of the stressor. Second, coping was viewed in terms of *management* (Beresford, 1994) as opposed to mastery. Third, the definition included the notion of an individual's *appraisal* of the situation. The emphasis was shifted from objective appraisal to one that phenomena are 'perceived, interpreted and cognitively represented in the minds of the individuals' (Magnusson, 1982, p.231). The appraisal of a stressful event was considered an important determinant of how a person will respond (Litt, 1988). There are three related aspects to this appraisal: 1) evaluations of the situation's implications for the individual (primary appraisal), 2) evaluation of the resources and options for handling the stressful event (secondary appraisal) which may lead to direct action for acquiring additional resources or maintaining existing ones (Sarafino,1994), and 3) the reappraisal of the event by the individual which provides a feedback on the consequences of the event on the individual well-being (Tunali and Power,1993).

Lazarus and Folkman's (1984) definition of coping has an important feature. Coping was defined independently of its outcome and did not imply that managing leads to success, whereas, failure follows not effective coping. It implied that a person would make some conscious choices to respond to stress. It was a definition where action taken by an individual resulted from the feedback that received from his/her environment, and from within.

The appraisal of an event by an individual is in part associated with the utilisation and availability of resources and coping strategies (Folkman,1984). 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).

The coping strategies are characterised as *problem-focused* and *emotional focused.* The first are the attempts to change the environment and reduce stress by using problem-solving, direct action and decision taking, while, the second are the attempts to manage the emotional results of stress (Folkman,1984). Thoits (1986) added a third category called *perception-focused* coping which consists of attempts to alter the meaning of a stressful situation to a less threatening one by changing the meaning, making positive comparisons, and/or focusing on the positive aspects of the experience. Specific coping strategies such as active problem solving (information seeking, use of professional services) were related with to adaptation, whereas blaming oneself for the disability, avoidance, and wishful thinking were associated with distress (Tunali and Power,1993).

Lazarus and Folkman (1984) formulated a model of coping in which individual differences and environmental factors were subsumed under the global construct of appraisal rather than threatened as separate entities.

One of the advantages of the model of coping and adaptation (Lazarus and Folkman,1984) was its focus on the strengths of individuals, their persistence to overcome difficulties, and their will to live a normal life.

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 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*. This particular theory suggests that the individual could overcome the stressful event and find positive contributions of the experience to his life, and benefit from it.

The *search for meaning*, is a kind of appraisal, a search for *meaningfulness* and involves the need to understand why a crisis occurred and what its impact is (Thompson and Janigian,1988). Lazarus (1990) and Sloper and Turner (1993) contend that the psychological meaning of the event is most relevant to the coping process which the individual will employ. By understanding the cause of an event, the individual understands what it symbolises in his/her life and what its significance is, so he/she can re-establish a sense of control over the environment and a sense of order in life. One way in which meaning is addressed is through *causal attributions* (Taylor, 1983). People make attributions in order to understand and control their environment after a stressful event. These attributions result from personal experiences and the individual's socialisation over their course of his/her life (Kawanishi,1995). Beliefs and values provide a structure for a person's perception of the world, and shape personal expectations for the outcome by helping individuals to redefine or 'reframe' the stressful event in order to make it manageable, as Cameron et al. (1991) suggested.

Folkman (1984) suggested that another way to transform the meaning of a stressful event is to abandon old goals and priorities and create new ones. The creation of new goals promotes positive morale and a general sense of control over the threatening event and facilitates efforts to adaptation.

Mastery involves gaining a feeling of control over the threatening event so as to manage it or keep it from occurring again (Taylor,1983, p.1163). The sense of control over events has been associated with effective coping (Hanline,1991). Affleck et al.(1982) found that parents with internal locus of control tended to adjust better, to actively seek services, and to actively participate in intervention programs. Taylor (1983) suggested that finding *positive contributions* could help the individual in the establishment of control over an event. Researchers found that families with disabled children were benefited from the experience and reported parents being strengthened, having learned greater tolerance, having found meaning in life, and having got closer as a family (Behr,1990; Murphy et al.,1990; Stainton and Besser,1998) after caring for a disabled child.

Another theme of adjustment was *self-enhancement*. It was generated by social comparisons which have been the chief vehicle for self-enhancement. Similar comparisons (perceiving yourself as equal) might also be effective coping strategies (Murphy et al.,1990). Turnbull, Summers and Brotherson (1983) found that parents of children with disabilities who compared their children favourably to others without disabilities coped more effectively.

In some cases attributions, beliefs and control or social comparisons functionally overlap as well as serve several needs simultaneously. So, a causal explanation could simultaneously provide an individual with a meaning for the experience, increase his/her sense of mastery and enhance his/her self -esteem.

Thus, little is known about the degree to which this may be useful to individuals, the underlying dimensions of these strategies, and/or the difference in their use between men and women. For the latter, one answer came from Rosario et al. (1988) who found that when men and women were acting similar social roles they did not have different way of coping with stress.

The **Double ABCX** model was formed after an expansion of the original ABCX by Hill (1949) and served as a framework to realise which families, under what conditions, using which coping resources reach a new balance after a family crisis (McCubbin and Patterson,1983). The model has as its central concept, the family adaptation, and refers to the family's efforts to find equilibrium after a crisis. The outcome of the family is influenced by the previous experiences, the use of resources, and cognitive appraisals (Kazak,1987).

Later, McCubbin and McCubbin (1987) introduced, four additional factors to the double ABCX model and formed the **T-ABCX** model. In the model, adaptation and coping represent both process and outcome variables related to the impact of stress. The added factors were: family vulnerability, family type, adaptive coping, and family regenerativity.

Coping cannot be understood as a single, static response to a single demand. Most previous research has not reflected a transactional perspective where determinants and consequences of stress would be assessed together. Parkes (1986) demonstrated that coping was not determined solely by intra-individual processes related to individual differences but also by external factors, particularly the nature of the environment in which the episode occurs. He independently assessed variables representing the major determinants of cognitive appraisal and directly evaluated their main and interactive effects of coping.

In sum, it is essential to consider coping as a function of the developmental level of the individual, as well as a function of situational and temporal factors related to the stressors. Coping may involve the attempt to change a crisis situation either by altering the problematic person-environment relation or by changing the way the situation is perceived. Secondly, coping may involve the attempt to regulate the psychological and physiological effects of stress. The communality among different models of coping (Lazarus and Folkman,1984; Zeitlin et al.,1987; Taylor, 1983; Thompson et al.,1992; Crnic et al.,1983; McConachie,1994) was their emphasis on the definition, appraisal, evaluation of the stressor, and the need for use of personal and social resources.

In the literature it was often suggested that individuals' ability to cope and adapt to a stressful encounter was influenced by the resources available to them. Recently, researchers have emphasised the importance of resources and social support which may moderate or mediate the effects of stress (e.g. Donovan, 1988; Friedrich, Witurner and Cohen, 1985). The availability of resources can help the individual to redefine a situation and to develop alternative means of adaptation. We will explore the importance of these resources in the next section.

4. RESOURCES AND SOCIAL SUPPORT

'Resources refer not to what people do but to what is available to them in developing their coping repertoires.' (Cameron et al.,1991,p.302)

4.1.Resources

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.

Resources are defined as 'those objects, personal characteristics, conditions or energies that are valued by the individual or that serve as a means for attainment of these objects, personal characteristics, conditions or energies' (Hobfoll,1989, p.516). Availability of resources affect the appraisal of a situation or an event and determine the strategies the person will employ (Fong, 1991). Thus, Sloper et al. (1991) conceived coping resources as both resistance and risk factors in relation to vulnerability to stress. If a person could not have access to a particular resource, there was a risk for the individual to become more vulnerable. Sloper and Turner (1993) found that possession of resources mediated the effects of life events and negative child characteristics. In contrast, if resources were available to the person, then he/she was more resistant to the adverse effects of stress. For parents of a disabled child, resources, were as closely related to adaptation as to the severity of disability (Bristol, 1987). Coping resources consist of personal and socio-ecological (refer to attributes of the social environment) factors (Beresford, 1994).

4.1.1. Personal Resources

Some of the important personal resources that may be used by the family to meet demands included: 1) physical and emotional health, 2) intelligence, 3) personality traits, 4) parenting skills, 5) ideological beliefs, 6) previous coping experiences, and 5) problem-solving skills (Beresford, 1994).

4.1.1.1 Physical Health

Physical health is considered an important coping resource for parents of a disabled child (Brown and Hepple, 1989). It is a resource that when absent can lead to vulnerability (Carr, 1988). The tasks of caring are long-term, physically demanding, and therefore tiredness may deprive parents of quality 'time out' periods. For instance, they may be too tired to go out with partner or friends (Gogh, Li and Wroblewska, 1993). In a national survey of parents caring for a disabled child in Great Britain, 37% of mothers reported their health been affected by caring for their disabled child (Meltzer et al., 1989). Earlier, other researchers having used the Malaise Inventory showed again that parents of disabled children scored higher on the measure of physical and mental health than the general population (Bradshaw and Lawton, 1978; Quine and Paul, 1986). Though, given the measures used, it is not possible to distinguish the direct effects of caring for a disabled child on physical health and the extent to which the parents reports of physical symptoms were affected by poor emotional well-being.

4.1.1.2. Beliefs and Ideologies

Two approaches to life have been positively associated with adjustment. Parents' approach to life and their religious or ideological beliefs have been shown to be important resources.

First, the parents' ability to focus on the positive aspects of the situation and their child (Venters,1981; Turnbull et al., 1985). Five ways of re-evaluating an experience as positive were proposed by Thompson (1985): 1) finding side benefits, 2) social comparison, 3) imagining worse situations, 4) forgetting the negative, and 5) redefining. He suggested that focusing on the positive was related to the avoidance of negative psychological consequences. Having a disabled child forces massive changes within the family so the second coping resource is not the existing philosophy of the parents but their flexibility to alter previous life philosophies and to adapt to the dramatic change (Copeland, 1988). They have to adopt a day to day approach to life rather than to plan for the future. Focusing upon non-materialistic achievements was significantly related to positive family functioning (Venters, 1981; Deaton, 1985).

Religious beliefs may correlate positively with mental health in part because they reflect the optimum socialised behaviours of the culture (Hess et al., 1991). Religion provides meaning, a way for parents to interpret their child's disability (Selway and Ashman,1998). When a situation is viewed as uncontrollable, religion may be used as a means of gaining 'secondary control' understanding and thereby of adjusting to the event rather than trying to change it (Rothbaum et al., 1982).

Mahoney et al. (1992) and Weisner et al. (1991) found that parents of disabled children were more religious and family oriented, and saw their child as an opportunity rather than a burden. For example, parents had certain beliefs that they had been specially selected for the task (Venters, 1981; Libow, 1989) and that they would be given the strength to perform it (Fewell, 1986). Reliance on religion was found to be an important aspect of coping as it enhances family relationships (Mahoney et al.,1992), and enables parents to generate their own explanations for the stressful event (Barbarian et al., 1985).

Religious beliefs may, however, create vulnerabilities in other ways. The outset of disability may lead parents to question their pre-existing beliefs (Burden, 1991), and beliefs may lead to self-blame for the child's condition (Copeland, 1988).

In sum, coping efforts were highly related to beliefs and to the appraisals held by the parents. It becomes clear that parents differ dramatically in the way they view their child's disability. This difference is reflected in the use of parents' belief systems and comparative standards of appraisal which were found self-enhancing and linked to adaptive functioning (Taylor and Brown, 1988).So, intervention aiming at beliefs and appraisal might enhance family functioning by reducing distress (Frey et al., 1989).

Optimism is another personality characteristic, giving parents a hope for the future which enables them to bear the burden of care. Scheier et al. (1986) found interesting differences on coping strategies used by optimists and pessimists. They found that optimists used more often problem-solving coping and social support than pessimists who used strategies such as denial. Having a sense of optimism enables parents to adopt strategies such as focusing on the positive aspects of their child's disability which is related to positive adaptation (Baxter et al., 1995; Beresford and Lawton, 1993).

4.1.1.3. Previous Coping Experiences

There is little research on the effects of prior experiences on how parents cope with caring for a disabled child (Farran et al., 1986). In families with healthy children parental confidence was increased due to a history of positive coping experiences (Heinricke et al., 1983). In this sense previous experience with coping, affects the appraisal of the event and as reported earlier, appraisal and parents' perceptions of their coping efficacy are positively associated with low distress. Pueschel (1986) suggested that, if parents were able to cope with previous major stressful situations they would be more successful in dealing with adapting to the disability of a child. This issue appears important but methodologically problematic since it would require a longitudinal model to consider of the person's history of coping.

4.1.1.4. Parenting Skills

Parenting skills include discipline, supervision, communication and negotiation with their child (Webster-Stratton, 1992). They are the competencies or behaviours which enable parents to manage or deal with their child (Backett, 1982). Parents of a disabled child with behaviour problems need to be supported both with strategies to minimise these difficulties, and strategies to enhance the parents' sense of competence. This increased competence affects their belief of being in control over life which has been found to be associated with adaptation (Lefcourt,1982). However, it is not clear whether adaptation results from the teaching of the new skills or if parents perform their tasks effectively when they have increased comparative frames of reference and/or greater perceived control over their lives.

4.1.1.5. Problem -Solving Skills

Problem-solving skill is considered a preferred style of effective coping with disability. Avoidance, wishful thinking and self-blame were associated with distress in parents (Frey et al.,1989). Mechanic (1974) believed that effective problem-solvers seek information and services as soon as possible, take on tasks that they can handle, plan and anticipate problems, and protect themselves against defeat. It seems that problem-solving has as its components the appraisal of the event, and the use of previous experiences which can help the individual to have a repertoire of alternative ways of responding. Furthermore, taking time to assist parents to change issues related to their disabled child and to establish a broader base of social support may be invaluable in adaptation.

The use and importance of social support in adaptation will be discussed next.

4.2. Social Support

> *'Attachments among individuals or between individuals and groups that serve to promote competence in dealing with short term crises and life transitions, as well as long term stress.'*
>
> *(Caplan and Killea, 1976, p.41).*

The marital relationship, social networks, and economic circumstances form another group of coping resources found in an individual's environment that can act as risk and resistance factors and have a profound influence on a person's adaptation to a stressful event.

Social support research has joined two areas of inquiry, coping and stress. The stress-buffering and health promoting influences of social support have been well documented (Cohn and Syme,1985; Sarason and Sarason,1985; Beresford, 1994). It is almost axiomatic to state that social support enhances well-being and lessens the likelihood of emotional and physical distress, bolsters self-esteem, and the sense of control over the environment. (Mitchell and Trickett, 1980; Thoits,1986).

Florian and Krulik (1991) defined social support as the availability of social resources to which people have access to counteract demands in their lives. It is a definition that regards social support as a 'personal experience rather than a set of objective circumstances or even a set of inter-actional processes' (Turner et al., 1983, p.74).

Ecological and social network theories (Bronfenbrenner,1979; Caplan, 1974; Cochran and Brassard, 1979; Mitchell and Trickett, 1980) have been used as a framework for generating predictions related to the mediating influences of social support. A fundamental tenet of the social systems theory is that ecological units do not occur in isolation but interact both within and between levels so that alterations in one unit have an impact upon other units.

Another tenet of the social systems theory is the contention that the behaviour of individuals is affected by a host of forces emanating from different systems and units. Social systems theory postulates that the support provided by people both directly and indirectly influences the behaviour, attitudes, expectations of parents and their children as well as other network members.

Sarason et al. (1983) concluded that people with high social support seemed to experience more positive events in their lives, had higher self-esteem, and had a more optimistic view of life than did people low in social support. The extent to which aspects of social support and personal resources influence the family and parent and disabled child functioning has been a focus of research efforts since lack of support could be a factor which could jeopardise their coping ability (Dunst et al., 1986; Hanline,1991).

Previous literature on families with a disabled child indicated that social isolation or lack of informal social support can be one of the most stressful themes related to caring for a disabled child (Quine and Pahl, 1985). Featherstone (1980) noted that :

> *'a special loneliness is the most pervasive theme in the stories told by parents with disabled children. This loneliness is nourished from within and without ... The two most prominent ingredients of a parent's loneliness are difference-his own and the child's and isolation (p.50).'*

The isolation that parents experience may be self-imposed. Suelzle and Keenan (1981) suggested that social isolation resulted more from the family's withdrawal than from community's avoidance of the family. Parents may try to defend themselves from the reactions of others or may be afraid to leave their child, while friends and relatives may contribute to a sense of social abundance because they are unsure how to offer help (Cherry,1989; Parke, 1981). Exhaustion from caring for the child may preclude parents from maintaining friendships (Gough et al., 1993) since they are unable to participate frequently in recreational or sporting activities as other families are. Additionally, parents may experience social isolation because of their perceptions of the acceptance or rejection of their child mainly due to behaviour problems exhibited by the child (Szukula,1991). Moreover, the behavioural problems in children were found more important at determining stress in parents than the type of disability (Floyd et al.,1997).

The emphasis on social support suggests that imbedded in social ties are basic social processes that could enhance general adaptation and assure adjustment to particular stressful events. Research studies suggest that the use of personal coping resources and social support are associated with family strength and proved crucial determinants of the capacity of parents to cope with their disabled child (Judge,1998). Turning to functional rather than structural types of support five basic dimensions have appeared in most models of social support: 1) tangible aid, 2) informational support, 3) emotional support, 4) esteem support (sense of competence and value), and 5) social integration (sense of belonging).

The importance of informal caring networks was emphasised in the White Paper 'Better Services for the Mentally Handicapped' (DHSS, 1971) by stating that help from friends and community members are

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The importance of informal caring networks was emphasised in the White Paper 'Better Services for the Mentally Handicapped' (DHSS, 1971) by stating that help from friends and community members are necessary to accommodate the needs of families for normality in their life as well as the child's. As Mechanic (1974) has stated:

> *'Finally the ability of persons to maintain psychological comfort will depend not only on intra-psychic resources, but also .... on the social support available or absent in the environment' (p.33).*

Informal social support networks can be defined in terms of their structure, and described in terms of linkages among individuals and groups (Mueller, 1980; Bolt, 1971). Cobb (1976) defined a network as a 'set of individuals who provide information leading the subject to belief he/she is cared for and loved, esteemed and a member of a network of mutual obligations.'(p.300). For Caplan (1974) a social network provides a person with 'psychological supplies' for the maintenance of mental and emotional health. An analysis of these networks is one of the most popular methodological means for providing a 'framework' in which social isolation and utilisation of potential resources can be understood. The field of social network analysis includes many complex characteristics with network size, density and the boundary density of each individual network being the most significant factors.

Network size is a frequently investigated variable and refers to the numbers of people with whom the focal person has direct contact (Mitchell and Trickett, 1980). Research mostly associated larger networks with a greater likelihood of successful coping and positive psychological adjustment (Wilcox,1981; Hirch, 1980). Kazak and her colleagues found that compared to parents of children without disabilities, parents of children with disabilities (specially physical) had more dense, bi-dimensional networks, and smaller friendship network sizes (Kazak, 1987; Kazak and Marvin, 1984; Kazak and Wilcox, 1984). Kazak (1986) suggested that this type of support may be adaptive for parents of children with physical disabilities because it enables parents to rely on those persons who fill their needs, yet require less support in return. Finally, studies found that social networks of parents with mentally disabled children are smaller. Smaller networks were also found among mothers of hearing-impaired children (Quittner, 1992). While smaller networks indicate less available help, this does not necessarily provide an indication of the quality of network support (Veroff et al., 1981). Seybold et al. (1991) suggested that the perception of support is more important to self-esteem than the size of the network. These results indicate that it might not be social isolation per se, but underdevelopment of particular types of relationships that characterise families with disabled children.

Network density is the extent to which members of an individual's social network know and interact with one another, independently of the focal person, (Mitchell and Trickett, 1980). Density can be thought of as the member of 'alkalised' relationships among members of a network compared with the entire number of relationships possible (Wilcox, 1981). As such, density, could be considered a measure of the interrelation of the network where lower-density networks are believed to provide the individual with diverse coping strategies and believed to enhance more successful adaptation (Hirch, 1980; Wilcox, 1981). High density networks may foster extreme closeness and a sense of togetherness or they may become groups in which high degrees of consensus stifle independent action (Kazak and Marvin, 1984). Kazak and Wilcox (1984) found that higher density was associated with higher stress in families with disabled children than in comparison families.

Boundary density is the proportion of possible network interconnections between two or more individual social networks or between segments within a network (Neimeijer, 1973). Sociological research of marital satisfaction and kin relationships have indicated that network overlap is associated with stability in marriage (Bott, 1971; Lee, 1979). High levels of boundary density in families of disabled children may be related to relatively small and dense networks of spouses as individuals (Karak and Wilcox, 1984).

Network reciprocity is defined as the degree to which affective and instrumental aid is both given and received (Mitchell and Trickett, 1980). Reciprocity highlights the balance (or imbalance) inherent in social network interactions as needs for support are balanced with demands or help for others.

Network dimensionality is defined as the number of functions served by a relationship and has been found to be a strong predictor of adjustment and coping as well as satisfaction with one's social network (Hirsch, 1980).

Despite more than a decade of studies associating social support and well- being, we still lack a basic understanding of how and under what conditions social ties are health protective. Bristol and Schopler's (1984) work found that the family's adaptation to a disabled child was more related to the perceived adequacy of both professional services and informal social support than to the actual severity of the disability. A model developed by Heller et al. (1986) suggested that it is not social activity *per se* that is health protective but also how this activity is perceived and interpreted. The term *perceived* support used by Procidano and Heller (1983) referred to a generalised appraisal that individuals develop in the various role domains of their lives, in which they believe that they are cared for and valued, that other significant people are available to them in times of need, and that they are satisfied with the relationships they have.

If social support is a 'personal experience' then the type and availability of formal and informal systems and what a person regards as support, and how satisfied he/she is from this support, is more important than the network size (Frey et al.;1989).

The work of Florian and Krulik (1991) further supports the argument that there may exist discrepancies between parent's perceptions of support and its objective availability. Schilling et al. (1986) showed that parents of children with physical disabilities received less support and felt less satisfaction with support than comparison groups. They suggested that appraisal of availability of social support is mediated by other factors. Personality variables affect the ability of individuals to set out or perceive the availability of social support (Monroe and Steiner, 1986). Another factor might be the increased needs of parents of children with disabilities. Mahoney et al. (1992) concluded that the mothers' unmet needs for support rather than those of the child contributed to increased distress.

4.2.1. Social support as a coping measure

Psychological research suggests that social support is a significant coping resource (Holahan and Moos, 1985) and affects the ways parents cope with a disabled child in a number of ways. Quittner (1992) indicate that the perception of the availability of support rather than the number of social contacts were associated with psychological benefits. Friedrich (1979) found that mothers who reported more supportive social networks and enhanced well-being experienced less stress related to their child's disabilities, a finding which became more important after Fisman's and Wolf's (1991) conclusion which associated the psychological well-being of the mother with the well-being of the siblings and the disabled child. Parents with more supportive social networks had also reported being less over protective of their disabled child regardless of their child's diagnosis. These parents indicated that their children were more accepted and integrated into the society (Dunst et al., 1986) probably due to the reduced over protection. Furthermore, mothers of children with spina bifida have been shown to be more confident in their care of their child, if they had social support (Havermans and Eiser, 1991).

Thoits (1986) pointed out that in this sense social support can be reconceptualised as an aid to coping by assisting the person to change the situation, the meaning and the emotional reactions to this situation.

4.2.2. Spouse Support

An emphasis on spouse support reflects the findings that mothers usually take over responsibility for the child's care (Parker, 1990; Bristol et al., 1988). Spouse support and marital status are seen as coping resources. Sloper et al. (1991) reviewed studies of families with disabled children, and found that spouse support was related to a positive outcome in mothers and fathers. Empirical evidence suggests that effective support from spouses can be crucial in functioning in parenting roles (Reddon et al., 1992; Dunst et al., 1986). However, a difficulty with much of the research is that spouse support has been treated as a single construct and the components of the particular support have not been separately assessed. So, the most important aspects of spouse support remain unclear. Probably this explains the conflicting research findings regarding the importance of spouse support. Although there is evidence to suggest the primacy of spouse support in intact families (Weber and Clark, 1986; Karak and Marvin, 1984), other investigators have reported no relationship between spouse instrumental support and adjustment (Cronenwett, 1985; Wandersman et al., 1980). The perceived availability of spouse support is again as important as its existence. Glenndinning (1983) found that mothers were affected more by their perceptions of the willingness of their husbands to help than by the actual amount of tasks carried out by them. Further, Barbarin et al. (1985) found that husbands who actually took an active role in child care were perceived by their wives as being highly supportive.

In sum, the type and availability of formal and informal systems are thought to contribute to family adaptation since the support and understanding could help to lessen the chance of pathological response. Research studies suggested that personal coping resources and social support could be crucial in determining the ability of parents to cope with their disabled child (Dunst et al., 1986; Mink et al., 1983). Results of studies also highlighted the importance of measuring the perceptions of support since the availability of specific support could be linked to more stress than the network size. Social support is a multidimensional construction that includes attitude transmission, physical and instrumental assistance, emotional and psychological support, and information sharing. There is evidence that emotional support and instrumental support in the form of assistance with child care could enhance parenting attitudes and behaviour (McConnell, 1988). In a later study, Crnic and Greenberg (1990) found that hassles and maternal support interacted to affect mother's interactions with their infants. A research study conducted by Parkes et al. (1992) indicated a positive relationship between social support and the quality of stimulation for pre-schoolers. Higher levels of support were associated with better locomotion and general development. Overall, continued support for parents might create a social environment which could help children to achieve their maximum developmental potential. It could also provide physical and emotional well-being, fewer time demands on parents, and more family integration (Dunst et al., 1985).

4.2.3. Benefits of Social Support

Social support can be viewed as beneficial, because it provides people with consistent positive experiences and a set of stable rewarding roles, and buffers individuals from the effect of stressful events (Cohen and Wills, 1985). In the latter case, social support is hypothesised to 'buffer' or moderate the negative effects of the presence of a disability. Thoits (1986) concluded that when practical help is combined with self-esteem enhancement or empathetic listening and understanding, it could be an important pre-condition for effective coping. Parents who reported satisfaction with their support resources were less likely to develop psychological or physical symptoms. Higher levels of social support could be associated with better adjustment and maintenance of the psychological and physical integrity of the individual over time. Interestingly, the beneficial effects of social support seem to be related to perceptions of availability rather than actual receipt (Kessler, 1991).

Despite the plethora of research on stressful life events and the association between social support and well-being and self-esteem, very little is known about the mechanisms underlying these effects. The concept of social support was not based on theory, there was a lack of contextual specificity, and there was little agreement about the definition and methods of assessing social support.

The methodology used in the majority of social support studies was questionnaires. However, no matter how well they are designed, this is a challenging method for capturing relationships that are flexible and subject to change over time. More research is needed to specify how social support works, what types of support are effective, and who benefits from it at what time (Quittner, 1992). This conclusion, however, does not necessarily provide us with an indication of the quality of the network. It could be helpful if future studies used questionnaires in the form of standardised tests similar to a semi-structured interview, where parents could openly express their opinion about social support and its value in their lives. It could be also useful to gather information on the daily parenting demands of disabled children in order to understand the role and meaning of supportive social relationships for parents with disabled children.

5. FAMILY FUNCTIONING AND THE DISABLED CHILD

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.

There are three main models of family functioning for families with disabled children 1) the transactional, 2) the ecological, and 3) the family systems model.

The *transactional* model believes that parents affect and are affected by the disabled child. The type, the severity of the disability, and the developmental stage that the disabled child is in but also the life-cycle stage of parents, have an effect on how parents will respond to the disability of the child (Hornby,1994).

The *ecological* model suggests that the social environment influences the parents' reaction to a disabled child. Four different social systems exert impact on the family, the *microsystem (*family, kins*)*, the *mesosystem (*school, society*)*, the *microsystem* (formal support services*)*, and the *macrosystem* (beliefs,culture*)*. The interaction within family members but also all systems have impact on the reaction of the family to a disabled child (Hornby,1994).

Recent attempts to understand how families work, suggests that it is useful to construe families as systems and suggested the *Family Systems Model*. In order to maintain itself and function, the system must have a set of needs and will require resources to meet these needs (Hornby,1994). The intervention programs following this perspective emphasise the unique coping capabilities of the families.

According to this model, the family act as an agent of change and recipient of influences of others factors. In the past decades, Minuchin (1974), Whitaker (1977), and Haley (1973) have all discussed family structure in relation to a system and the interaction of its members. During the ecologically aware 1980s more people recognised the family as a valuable asset in the care of disabled members, and acknowledged the need to support family caregivers in their demanding task. Within the last decade the focus for intervention within the family with a disabled child has shifted from the child to the family. The family was recognised as an interactive, dynamic system where changes in any part of the system reciprocally affect the whole (Trout and Foley, 1989; Marshak and Seligman, 1993). A basic tenet of the family systems approach is that a change in any part of the system, affects the system as a whole and its other sub-parts, creating the need for system-adaptation rather than simply attending to a single part. The systems approach investigates factors that may exacerbate feelings of stress and those that may serve as mediators or buffers to the stressful events imposed on individuals and the family unit (Margalit, 1990). Turnbull, Summers and Brotherson (1983) elucidated various elements of the family system with the development of the Family Systems Conceptual Framework which is made up of four components. That are:

The Parental Subsystem, which includes the interaction of the parents with the children, the disabled, as well as, other children in the family.

The Marital/Spousal Subsystem, which includes all types of interaction between marital partners.

The Sibling Subsystem, which examines the interactions among siblings.

The Extra family Subsystem, which refers to the interaction the family has with other people such as the extended family, friends, and the community.

The use of a systems model of the family is an attempt to identify the ways and means that families use to maintain a balance, and to function in meeting the needs of individual members.

6. EFFECTS OF DISABILITY ON THE FAMILY

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.

6.1. PARENTAL SUBSUSTEM

6.1.1. Mothers

Mothers and their psychological functioning have been the focus of studies concerning parental responses to the birth of a disabled child. Many studies concluded finding higher stress levels for 'parents' when they actually meant for 'mothers'. This is understandable, bearing in mind that mothers are usually the primary caretakers of a disabled child (Chetwynd, 1985; Paul and Quine, 1985; Frey et al.,1989; Saddler et al.,1993; Andersson,1993). Sex role differentiation of family duties tends to be more traditionally oriented in parents of disabled children (Breslau et al., 1982). For many couples a disabled child will polarise parental roles in which the mother provides special care, while the father is the sole financial provider for the family (Schilling et al., 1985). Disabled children show inordinately increased child-care demands and this could place mothers at higher risk for stress tied to extensive child care demands (Singer and Farkas, 1989;

Trute, 1995). Aneshensel et al. (1981) suggested that women who carry the heaviest burden in role obligations, particularly those related to child care in the house, would show higher levels of depression than their male partners. Holroyd (1974) indicated that mothers of disabled children had poorer health, limited personal use of time, less freedom, and more awareness of discord in the house. In a study of 30 mothers of disabled children by Harris and McHale (1989) the concern over the present and for their future well-being of their child, and the excessive time demands associated with care giving were the most predictive features resulting to stress. It seems that the way in which care giving responsibilities were distributed and the ambiguity associated with child-related problems, especially the uncertainty about the future, were the most important factors in the stress experienced by mothers (Golberg et al., 1986). Mothers perceived their family life as quite stressful (Quitter et al., 1990), however, the stresses which were reported tended to be specific to care giving demands rather than global in nature (Quitter et al., 1992). Pearlin et al. (1981) found that life strains could erode self-esteem and this reduction in self-esteem and sense of personal mastery might lead to heightened psychological stress. Mothers of children with disabilities show diminished self-esteem which recovers as the child gets older. Bristol (1987) found that increased age was associated with better family functioning. Probably, as mothers became more familiar with daily routines there was an easing of 'novelty shock' (Wolfensberger and Menolascino, 1970) and parents felt more competent in meeting the demands of the child's disability (Trute, 1995).

Moreover, not only the care giving demands of a disabled child are those factors which could jeopardise the physical and psychological health of mothers and consequently their adaptation.

The work of Wallander et al. (1989) concluded that the social environment strongly is related to the functioning of these mothers. When mothers perceived that they could refer to a supporting social network, they were more likely to experience less difficulty with adapting (Trute, 1995). This may explain the finding of Singer and Farkas (1989) who suggested that many mothers of young disabled children found meaning and enhanced self-esteem with care giving, despite the stresses involved. Probably, these mothers were more supported from their environment. Some studies suggested that women had larger social networks (McFarlane et al., 1983), whereas, other results found no differences in the size of the social network between men and women (Trute, 1995). Mothers reported receiving more social (especially emotional) support than did fathers (Stokes and Wilson, 1984; Burda et al., 1984). Burda et al. (1984) concluded that gender differences in social support might be partly a function of socialisation where stereotyped patterns place emphasis on warmth and expressiveness for women, while for men the emphasis is on autonomy, independence, and self-reliance which hinder the use of emotional support. These data, however, compatible with the socialisation theory, do not help to determine whether women are more ready to perceive and accept available support and seek more often support or whether others offer more support to them (Rosario et al., 1988). In any case, the studies do not provide support for the notion that women cope less effectively than men when both are in the same roles. When men and women occupied the same social roles, they used similar strategies for adaptation (Rosario, 1988).

Satisfaction with support from family members was equally important for the adaptation of both mothers and fathers (Trute, 1995). The most significant factor for mothers' adaptation was the feeling of security in the marital relationship (Belsky, 1984; Friedrich, 1979). Previous research indicated that greater paternal support was related to decreased maternal stress (Bristol, 1987; Friedrich et al., 1985). Vanfossen (1981) suggested that 'expressive and equitable relationships with a spouse do provide some protection against the experiencing of depression'(p.136). The importance of the husband is further affirmed by the strong relation between maternal well-being and spousal support (Crnie et al., 1983; Levitt et al., 1986). The intensity of excessive child-care demands may enhance partners' need for emotional support and their sensitivity to each other's psychological state (Trute,1995). However, mothers reported also higher levels of satisfaction with social support from friends (Burda et al., 1984; Trute, 1995). Mothers may turn to friends for support when the marital relationship is strained, but support from friends may not overcome the dissatisfaction experienced by a mother from her marital relationship (Levitt et al., 1986). Furthermore, the child's level of disability was not significantly associated with maternal adaptation. Wallander et al. (1989) found no relationship between the child's functional independence or physical condition and the mothers' adaptation. It was, however, the behavioural problems of the child which were directly associated with poor adaptation in mothers (Hanson and Hanline, 1990; Chetwynd, 1985; Singer and Farkas, 1989).

In sum, adaptation in mothers of disabled children is affected by their feeling of self-worth and competence, the strength of the marital relationships, and the perception of available resources to them. Mothers who did not blame themselves, reported happier marriages, and were rated as having better levels of adaptation. In cases where mothers did not perceive the resources from provided information, support, and guidance efficient, were more likely to experience stress. Bristol (1987) found that maternal beliefs and resources were more closely related to adaptation than the severity of the child's disability.

6.1.2. Fathers

Societal changes during the last two decades have necessitated parental role changes which requires more paternal involvement. More mothers are nowadays working outside the home. Given the increased workload, the involvement of fathers in child care becomes very important. Around the mid-80s research started to focus on the role of fathers in the development of a child. The findings showed that the involvement of fathers could influence children's development (cognitive and internal), encourage positive psychological adjustments, and shape their children's gender-role identification (cited in McBride and Barragh, 1995). Fathers, however, are not given opportunities to develop skills necessary to became a nurturing parent. This lack of preparation and the lack of support contributes to the stress fathers experience in their parental role (McBride, 1989).

Furthermore, additional research examined the father's role in families with a disabled child. Similarly to mothers, fathers have reported the parenting of a disabled child to be stressful, to be related to role confusion, social isolation, and marital difficulties (Belsky et al., 1983; Ventura, 1987). Fathers were found to report less stress related to a disabled child than mothers probably because men were less likely to disclose their inner thoughts and experience (West,1998). The traditional role of fathers as providers, perceived as having to be strong and supportive to their partners rather than caregivers may serve to mask their underlying feelings about having a disabled child, and restrain them from close participation in their care and interaction with them (Saddler et al., 1993). Sloper and Turner (1993) found that fathers as well as mothers earlier, reported also increased distress compared to fathers of normal children.

The strengthening of the parental subsystem should be of primary concern to those who wish to assist the family to maintain a stable and nurturing home environment for their child, to meet the developmental needs of the child, and to develop resilient kinds of relationships (Turnbull,1988).

6.2. MARITAL/SPOUSE SUBSYSTEM

There is a long-standing notion that the marital relationship in families with disabled children is particularly vulnerable, although, close scrutiny of this literature provides an ambiguous picture (Sabbeth and Leventhal, 1984).

Some investigators have quoted divorce or separation rates higher than those of the normal population (Zuckman, 1982; Gath, 1977). Featherstone (1980) observed that a disabled child might expose pre-existing unresolved problems in a marriage. She described some ways marriages could be affected by the disability: 1) it might produce powerful emotional responses, 2) the disabled child might be perceived as a symbol of shared failure, and 3) the organisation of the family system might be reshaped and 4) might generate a potential area of conflict. Sloper and Turner (1993) suggested that the quality of the marital relationship before the birth of the disabled child could be an important predictor of adaptation. Trute and Hauch (1988) found that there was a high correlation between the strength of couple adaptation and the strength of family functioning. This was true regardless of the child's disability, the level of family income or the age of the child.

Despite the stress, other investigators found that many marriages were strengthened by sharing the care of a disabled child (Kazak and Marvin, 1874; Waisbren, 1980; Gilbert et al., 1982). Methodological considerations account for some of the confusion. There is a lack of measures of consistency in operational definitions as well as in the use of different constructs. These constructs vary from marital satisfaction, marital adjustment, marital quality, and/or marital intimacy. In addition, studies have used different instruments of assessment. The Locke Wallace Marital Adjustment Scale (Bristol et al., 1988) and the Spanier Dyadic Adjustment Scale (Kazak and Marvin, 1984) are measures designed specially for a particular study (Tew and Lawrence, 1974). None of these scales contained measures that take into account the effects of social desirability in the given responses (Hansen, 1981). Other studies have not used control groups (Fisman and Wolf, 1991) and included the mother's perception of marital intimacy but not the father's. Inferences from one spouse, however, may be unreliable as well as biased. Using a marital assessment instrument which includes a social desirability scale (Waring Intimacy Questionnaire), Fisman and Wolf (1991) undertook a study investigating both mothers' and fathers' perception of marital intimacy and linked those to parenting stress and depression. Mothers of autistic children scored significantly lower on total intimacy than mothers of normal children. When demographic variables (such as parents' age, education, income, and family size), however, were controlled, differences were no longer significant for total intimacy. The father's education and the existence of other children in the family were found positive factors in the measurement of intimacy across all groups of parents (Fisman and Wolf,1991). Similarly, Trute (1990) has found that fathers who were highly educated, facilitated more positive adaptation in the family.

Peterson (1980) and Goldberg and Easterbrooks (1984) suggested that the marital relationship had a supportive function in relation to the satisfaction of parenting, the mothers' sensitivity to infants' cues, and particularly to the wife's morale and sense of competence as a mother. Satisfaction with life was associated for with the quality of the marital relationship (Sloper et al., 1991). The marriage quality was correlated with the perceived marital stability (Bradley et al., 1991). 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).

Further, Goldberg and Easterbooks (1984) found a relation between marital quality and child-parent attachment. They showed that secure child-parent attachments were most likely to occur in families in which wives and husbands were highly satisfied with their marriages. It seems that satisfying marriages meet parents' emotional and affection needs and enhance the parent's relationship with the child. Both conditions help parents to feel more competent, having higher self-esteem, and this perceived higher competence helps them to adapt to the disability of their child. Mothers who did not blame themselves for the disability of the child reported happier marriages (Bristol,1987).

Viewing the family as a dynamic system, the child-parent relationship and wife-husband relationship are interdependent. A strained marriage impacts on the parent-child relationship, the child becomes more difficult, stress escalates further, and so a vicious circle is perpetuated. Similarly, there is reciprocal influence within the husband-wife relationship. A depressed spouse is likely to affect the quality of the marital relationship, and the escalating tension in the marriage may further affect the psychological health of the spouse.

Additionally, family characteristics such as communication, cohesion, integration, and adaptability were seen as making parents better able to adapt to the disability of their child. Parents living in cohesive and supporting family units were more likely to adjust to stressors (Gowen et al., 1989; Prieto-Bayard, 1993). Seligman and Darling (1989) suggested that spouses need to develop skills to function as a co-ordinated team, and maintain their sense of cohesion as a couple. Viewed collectively, family adaptation cannot be reduced to a psychological construct such as denial or mourning. It can be regarded as a process, as a 'peak and valley phenomenon' which changes as the family passes into new experiences (e.g. beginning of school, puberty etc.). The financial and physical burden of caring for a disabled child cannot adequately explain differential family acceptance. The once unexpected findings regarding positive outcomes in adaptation are no longer surprising.

In conclusion, it seems that an intimate, supportive spouse subsystem can function as the foundation for an effective, collaborative parenting subsystem. Rather than reflecting a family structure where fathers are peripheral to the family, it may be a more accurate reflection of family structure to perceive fathers with a central role in the spouse system. The presence of a disabled child in the family creates additional life stress but, as Dyson (1987) suggested, this does not necessarily impair the general family functioning. The increased documentation of diversity in family adaptation indicated that parental appraisal of the situation, spouse support and the involvement of fathers, the availability of social resources, and the parental beliefs and values may be important. These variables may form a parental team where both fathers and mothers experience a stable, and satisfactory relationship which in turn is the best predictor for a family's adaptation to a child's disability. It is evident that despite the added strain imposed on the family by a disabled child couples have competencies as well as deficits in their functioning, and are able to keep their marriages intact, and satisfactory as Naseef (1989) suggested.

6.3. SIBLING SUB-SYSTEM

> This is *'the first social laboratory in which children can experiment with peer relationships. Within this context children support, isolate, scapegoat and learn from each other. In the sibling world children learn how to negotiate, co-operate and compete. They learn how to make friends and allies, how to save face while submitting and how to achieve recognition of their skills. They may take different positions in their jockeying with one another and those positions, taken early in the sibling sub-group, can be significant in the subsequent course of their lives.' (Minuchin, 1974, p.59)*

The interest in sibling relationships emerged from two theoretical perspectives. The first is the attachment theory, which suggests that there is a coherence in close personal relationships that is based on the quality of early attachment to parents (Sroufe and Fleeson, 1988). The second theoretical base emerged from a family systems theory, which maintains that family members are part of an interactive network in which the behaviour of each individual modifies that of other individuals in the family (Minuchin, 1974). Interaction among brothers and sisters is an important dimension of family dynamics which may contribute to both the normal social development of the child and to the incubation of mental health problems. Siblings serve major functions for each other such as: 1) giving reflected self-appraisal, 2) forming cohesive groups, 3) provide support (Cicirelli, 1991), 4) be agents and receptors of socialisation process, and 5) controlling behaviour (McKeever, 1983).

Sibling relationships are not static, but change as children move through different developmental periods. They are not played out in a social vacuum and have been described as:

> *'multiplicity of bonds that arrange themselves into a finite number of predictable patterns; it is a fitting of two peoples' identities' (Bank and Kahn, 1982, p.15).*

Factors other than birth order or age-spaces can be important in describing and explaining the nature of sibling relationships. Differences in sibling relationships are linked to the emotional climate in the family (Brody and Stoneman, 1988) and parents' overt message about sibling roles (Einstein and Moos, 1967).

Given the long-lasting persistence of sibling relationships, it seems reasonable to posit that substantial changes in the health or functioning of a sibling will affect the other.

In families with disabled children, relationships between siblings are complex and may be mediated by a number of variables. Crnic and Lecoute (1986) suggested care-taking responsibilities, age, birth order, individual temperament, socio-economic status, and severity of disability may determine whether siblings will be negatively or positively affected by the presence of a sibling with disabilities. Other factors, should be considered as well, such as the family size, gender, parental attitude, sibling perceptions, and emotions (Correa et al., 1986; Seligman, 1983).

The search for factors mediating the influence of disabled children on siblings has led to a focus on effects rather than processes. These effects are of three kinds. First, by starting from the premise that the presence of a disabled child causes a great deal of stress research has focused on the negative effects (Breslau et al., 1982; Tew and Laurence, 1975). Second, attention has focused on the problems of living and growing up with disabled children (Gath, 1985). Finally, studies have explored the therapeutic and teaching roles of siblings (Lobato et al.,1988).

Although some studies found negative effects, a number of other studies showed that not all siblings of disabled children will develop problems of adjustment or exhibit higher rates of stress (Wilson et al, 1989; Dyson et al., 1989; Lynch et al., 1993; McKeever, 1983; Hannah and Midlarsky, 1985; Gayton et al., 1977). Crnic and Lecoute (1986) suggested that siblings of disabled children develop tolerance, are more certain about their goals and aspirations, and achieve maturity beyond their years. Since a child is not a passive recipient in his/her system and is being constantly affected and affecting other members of the system, it is helpful to view the effects of a disabled child on the sibling as a continuum. At one end, are the very positive outcomes and at the other, the negative outcomes.

Interpreting the available data on siblings of disabled children is difficult due to the variety of methodological problems such as lack of appropriate control groups, non-comparable samples, and non-equivalent methods or assessment techniques. The most significant limitation of the existing research has been the failure to identify and evaluate specific aspects of the non-disabled children's experiences that may engender stress or those personal characteristics and/or response strategies that contribute to susceptibility to stress. Consistent with the focus on effects rather than processes, some studies used retrospective reports by questionnaires or interviews. Usually, studies have attempted to explain the sibling relationships of disabled children solely through what one interacting member, the sibling, thinks of the relationship. This has been investigated by recording the siblings' recollections of interactions with their disabled brothers or sisters. Older siblings may have been able to look back at their disabled sibling with greater maturity than they would have as children. Furthermore, participation in the research was voluntary and it is possible that only those adults who felt comfortable discussing it, participated in the research projects.

Maternal reports and ratings have been utilised in other studies concerning sibling relationships which again may be subject to bias. In addition, mothers' views may be influenced by her own adjustment to the presence of the disabled child (Breslau et al., 1982).

In an attempt to introduce objectivity, some researchers have used the reports and ratings of teachers, in order to enhance the external validity of their findings (Tew and Laurence, 1975). Blackard and Barsh (1982) however, reported that teachers' responses can be biased by the fact that they know the children being assessed have a disabled sibling. They concluded that teachers tend to overestimate the negative impact of disabled children, and therefore, had lower expectations for children's adjustment.

Typically, few studies of sibling interactions have collected observational data in naturalistic settings. Again in this case, it is difficult to have unbiased responses since the very presence of the researcher may impose obstacles on the interaction. Additionally, however, observation in laboratory playrooms provides a degree of validity, which can be lost when children are observed in widely different home environments.

In sum, early researchers assumed that the sibling is harmed by the experience of growing up with a disabled brother or sister (Cohen, 1962). More recent work, by taking a broader view, recognises that while some siblings appeared to be harmed, others seemed to benefit (Wilson et al., 1989). These discrepancies in research results may also be related to the fact that the adjustment of the healthy sibling is dependent on the family's system characteristics, on the non-disabled child's characteristics, and/or on the characteristics of the disabled child (Lobato, 1983; McHale et al., 1984).

6.3.1. Family structure characteristics and the psycho-social adjustment of siblings of disabled children

Specific family variables have been examined in association with sibling adjustment such as family size, socio-economic status, and parental attitudes.

Family size is a family structure characteristic that may impact the psycho-social adjustment of siblings. Some investigators assert that larger families provide the best outcome for non-disabled siblings because as Trevino (1979) noted when more children are present, an atmosphere of normality prevails and the burden of the disability and the child care responsibilities are distributed among several children. Additionally in large families there were more children to meet the expectation of parents.

Cadman et al. (1988) conducting research with normal siblings of chronically ill children, and Mates (1990) conducting research with normal siblings of autistic children, found that family size had no significant effect on normal siblings' social adjustment mental health. The investigators offered no explanation for this result.

The **socio-economic status** of the family may also affect sibling responses to a disabled child which enable or impede families to procure important resources that aid in adaptation. According to Farber (1972) socio-economic status is related to the way in which the disability of a family member is interpreted. He suggested that middle class, achievement-oriented parents perceived the disability as a 'tragic crisis' in which parental goals for the child could not be achieved. In contrast, lower class families perceived the disability as a 'role organisation crisis' in which the burden of the disabled child was superimposed on already heavy family demands. Middle-class families, when compared with working class ones, tend to be more financially secure and better prepared to utilise outside resources such as respite care services. This may influence families positively by reducing the amount of stress experienced and by increasing the amount of time that siblings spend with their parents. Financial resources may also decrease the amount of time siblings have to spend with their disabled brothers or sisters for physical care.

6.3.2. Parental attitudes and expectations

Before the birth of a child, parents have expectations that the child will achieve in ways valued by the culture of a particular society. However, children with disabilities are often not able to meet parental expectations. As a compensation for the disabled child's different than expected achievements, parents may press other children to attain higher levels of achievement. On the other hand other, studies have found that non-disabled children described their parents as being overprotective, more lenient in discipline, and as providing more attention to their disabled child (Bendor, 1990; Freeman and Hagan, 1990).

The results of the studies stabilise the bi-directional model of socialisation demonstrated by Mink and Nihira (1987) where children are not simply passive recipients of parental influences, but also exert influence to them. So, it seems logical to assume that the parents' attitudes toward their disabled child would affect the attitudes of the siblings in the family.

Lawenius (1988) found that in families where parents accepted the disabled child, siblings responded similarly. Furthermore, Dyson et al. (1989) concluded that the probable harmful effects on siblings may be mediated by 'psychological' resources in the family system. They found that family cohesion, openness (Gogan and Slavin,1981; Bearslee, 1981), and communication about the disability associated negatively with behavioural problems in siblings, while family conflict was positively correlated with lower social competence. Family cohesion, as measured by Lynch et al. (1993) was also found in both the clinical and comparison groups to enhance self-concept. The closeness and mutual support found in cohesive families contributed to the child's positive self-evaluation. Lower organisation and structure in families with a disabled child appear to have a negative impact in contrast to comparison families where levels of family conflict and organisation had little effect on their siblings' social competence and self-concept. Maybe the resources and resiliency of families with a disabled member were further taxed by conflict and disorganisation, and as a result the adaptation of siblings was detrimentally affected.

In sum, it appears that family conflict and disorganisation are particularly disruptive in these families while family cohesion, where open communication can flourish, is of the utmost importance. So, harmful effects may be minimised through early intervention to guide parents regarding the importance of family organisation and conflict resolution skills in facilitating healthy sibling development.

6.3.3. Characteristics of the Non-disabled child and the psycho-social adjustment of the sibling

Helen Featherstone (1980) noted that:

> *'a handicap inevitably changes the experiences of each child in the family but exceptional families offer normal children unusual opportunities as well as unusual problems' (p.163).*

A sibling relationship fosters familiarity and strong affectionate ties between siblings are both essential features for the formation and perpetuation of attachment between siblings. A large proportion of older children act as subsidiary attachment figures for their younger sibling by showing care giving behaviour in distressing conditions and by providing a secure base for exploration (Senapati and Hayes, 1988). As a result, much of the research has reached the conclusion that older, especially female, siblings are most likely to be affected negatively by the presence of a disabled child (Lobato et al., 1987; Seligman,1983; Breslau,1982) perhaps, due to the likelihood of their taking on greater child-care responsibilities. In contrast, Howlin (1988), Simeonsson and Bailey (1983) and Gallo et al. (1992) felt that siblings younger than, or closer in age to, the disabled child have poor adjustment, which can be attributed to identity problems. Although, the younger child is expected to be the focus of concern and caring from the parents, instead, he/she becomes the older child who would take care of the disabled sibling and would perform more responsibilities (Simeonsson and McHale, 1981) that may not receive much time or attention. The need for a younger sibling to take on 'pseudo-adult' behaviour is likely to cause additional stress on the relationship. Younger sibling may develop behavioural problems in order to gain some attention. In contrast to the bulk of the research on sex differences, which find that females are more adversely affected by the disabled sibling, some contradictory results have been obtained. Nagel and Begun (1982) found that young boys are more affected, probably, because males are more susceptible to environmental stresses (Hetherington and Martin, 1986). Furthermore, studies with teenage siblings found that older siblings were reported as being more socially adaptive than siblings younger than the disabled one (Simeonsson and Bailey, 1983; McHale et al., 1984). Abramovitch et al. (1987) found no evidence that non-disabled females were put into more active roles or that birth order gave evidence of particular risk. This particular result might be influenced by the small sample consisting of 31 families who were following an infant stimulation program.

Birth order and the gender of the non-disabled child have been the most frequently investigated variables with contradictory findings. While these contradictory results may be attributed to the confounds of age with birth order, it seems that birth order is a variable with some influence on the adaptation of normal siblings. Shedding light on factors that influence sibling outcome may not only enhance our understanding of family functioning in general, but also improve our effectiveness in counselling parents regarding the practical and emotional matters concerning disability for all family members.

6.3.4. Characteristics of the disabled child and the psycho-social adjustment of the sibling

6.3.4.1. Type of disability

It appears that factors other than the diagnosis may be more important in determining how normal siblings experience the physical and developmental problems of their brothers and sisters. Simeonsson and Bailey (1983), and Dunn (1983) suggested that factors, such as individual characteristics and the temperament of the disabled child, might transcend the influence of any particular disability and influence sibling relationships.

6.3.4.2. Severity of disability

There is no simple linear relation between the severity of a sibling's disability and the adjustment of the non-disabled child. The state of the family's financial resources interacts with the severity of the disability. In families where there are no financial resources for baby-sitters or teachers, siblings typically have more responsibilities. The impact of a disabled child on a non-disabled sibling is a process not simple to trace. Past research has not considerably indicated either positive or negative effects on siblings. Higher levels of stress, low self-esteem, and behavioural problems have been described as symptoms listed under 'psychological effects' among the siblings of disabled children (Tew and Lawrence1975). However, more recent research reports no negative reaction (Lobato et al., 1987; McHale et al., 1986; Lynch et al., 1993; Thompson et al., 1994).

On the negative side, worries about the disabled child's future, parental favouritism toward the disabled child, and higher expectations of the healthy sibling are all associated with more negative siblings relationships. Thus, inquiries should be made about the tasks siblings are expected to perform, and the level of expectations of the non-disabled children.

Regardless of the level of adjustment in siblings, open communication about the disability seems to facilitate positive sibling functioning (Seligman, 1983). However, Featherstone (1980) noted that family members have particular difficulty discussing the disabled child with each other. Consequently, siblings may often lack information about their disabled sibling or an opportunity to express their own worries.

Simeonsson and Bailey (1986) suggested that the temperament and functional behaviour of the disabled child might be of major significance in examining the relationship between two siblings and they suggested looking at individual differences in sibling adjustment.

The setting in which the sibling interaction takes place is the family. The family is a matrix shaping the personalities of its members. The understanding of a disabled child of a non-disabled sibling and the relationship between them involves an understanding of the entire family. Families differ in their structure and needs and these differences lead to endless variations in the way in which they approaches their functional tasks at different stages in their life span. In particular, when parents react positively to the disability of the sibling, the reaction of the sibling tends to be more positive, as well too.

Family structure and organisation plays a critical role in defining how ideologies are actualised through the functions families perform, as well as, determining the family's responses to life-cycle transitions. The factors that appear to have a powerful influence on sibling behaviours are the activities in which siblings participate and the presence of other people.

Future research could also consider the development of sibling relationship in natural environments probably in the context of the family system. An examination of these interactional factors could be the focus for the next phase of research on sibling relationships Questions such as how a disabled sibling influence families with different values, religion, and culture also need to be addressed.

6.4. THE EXTENDED FAMILY AND FRIENDS SUBSYSTEM

Sonnek (1986) suggested that a primary role of grandparents is to provide support to the nuclear family. Such a support network can enhance family functioning, reduce stress as well as influence the well-being of the children in the family (Byrne et al., 1988). The grandparents are often the first people contacted after the parents learn of the disability, therefore, may be a key element of the support network available to parents. Grandparents overwhelmed by the event of the disability may be unable to offer support to parents because of their own grief over the child's disability. Additionally, 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. In contrast, there are many supportive grandparents with more support provided by maternal than paternal grandparents (Byrne et al., 1988; Golberg et al., 1986; Harris et al., 1985). 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) found that maternal grandparents were more supported but interestingly when mothers perceived also their in-laws to be supportive, they had a more positive relationship with their disabled child than those who were viewed as unsupportive.

Parents have reported feeling that their relationships with friends was also affected by the birth of a disabled child (Friedrich and Friedrich, 1981). Neighbours are often perceived as being reserved towards the family and when they made an offer of help it was for the able child in the family rather than the disabled. This perceived rejection may be painful for the parents. As a result, feelings of alienation may further minimise contacts and possibly heighten the effects of intra-family stress. Finally, the development and maintenance of friends is based on the sharing of common interests and activities. The disability of a child seems to reduce opportunities for developing friendship bonds (Karak and Marvin, 1984). Again, the old dictum ' blood is thicker than water' reflects the tendency for the extended family to be more accepting of a disability than friends (Kazak and Wilcox, 1984). Cooke and Lawton (1984) found that relatives rather than friends offered to look after the children. Friends and neighbours provided help with the shopping or transportation or help in the form of moral support or company.

7. SUMMARY

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, however, 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, could find ways to adapt to the disabled child and 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, needs for services, and similarities and differences to other research work in England and America on this topic will be pinpointed.

Coping 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's (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 rather 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 through 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 and reported a satisfying marriage. 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 more 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 literature 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 which 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.

8. THEORETICAL FORMULATIONS SUGGESTED BY THE LITERATURE REVIEW

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 and not only limitations. 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.

9. THE FAMILY IN GREECE

An understanding of the form of the Greek family and the intrafamiliar relations can not occur in a vacuum. The ancient Greeks gave to the family the name of 'ESTIA' which means that functioned as a respite from physical and social strains where people could find personal fulfilment. The Greek family as well as the theoretical frames in which it belongs, is under reformation.

Since the fall of Byzantium until recently the agricultural economy was dominated by family cultivation. The lay out of the land and the climatological conditions acted in favour of the formulation of different, small, local communities.

The farmers grouped in these assemblies had autonomy while their only responsibility to the state was only to pay taxes. The smallest unit for taxation purposes was the 'community' and in the case an individual was unable to pay, the others in the community paid his share (Katakis,1998).

It was the very autonomy of these populations that helped the need for togetherness and the development of the collaboration between their members since the survival of one person was related to the other (Vergopoulos, 1975).

During the Turkish occupation, which lasted for more than 400 years, the family and religion belief formulated a strong core which kept alive the spirit of liberty, tradition,and morale. The bond within these communities was so powerful, so decisive, that it was almost identical with the affiliation between the members of an individual family.

After the constitution of the new independent state, in 1831, community life began to decay.The administrative and legislative framework of the new state were influenced by those of Western Europeans which were consistent with a culture where the primary agency for survival was the community.

The period that followed was a process of readjustment from the dwindling of community life to the extended family. At the end of the 19th century, the well established phenomenon of immigration (20's and 60's) increased at escalating rate. Greek agricultural workers followed the wide-spread immigration wave to the New World but in comparison with other societies always kept their country and their family as a point of reference (Tsoukalas, 1977).

Over the last three decades Greek society is passing from the *traditional* way of living, to the *nuclear* family and recently the new form, the *couple*. These constant, rapid changes formed a mosaic of values, attitudes and ways of behaviour but also brought the new generation a dilemma between individuality and self-actualisation or collaboration.

Greek families, like Greek society are under transition and the complete picture can be developed only by exploring the three consecutive stages of its change: the traditional-rural family, the nuclear-urban family and the new form, the couple.

The Traditional Family

This form of family organisation resembled community life in many ways. The traditional way of living gave priority to joint effort, solidarity and collaboration between the members of a group and considered these as prerequisites for a creative life. The traditional family part of this society has as a part of its own reality and as psycho-social base, the extended family.

In the early seventies, Katakis conducted a research where couples aged 35-45 years old answered to the question 'why did you get married'. The majority of answers showed that their aim was to educate their offspring and give to society worthwhile individuals. Through their progenies' success, parents were fulfilling psychological needs. Maybe this artificial common goal prolonged the psychological survival of the members of the family (Katakis, 1998). Actually, parents were given the chance to validate the values the principles which they themselves internalised in their own childhood and growth.

In a later study Katakis (1980) explored the views of couples engaged to be married on their future life together. The absence of a common goal for the evolution of their family was transparently clear.

Nuclear family

Though, the aims of the individual in the traditional family were related with the aims of the group he/she was a part of, in the nuclear family, the fulfilment of expectations were not based on the wider family but on one member, the child. Basic needs for security and communication were provided within the family. Main concern of parents was the development of the child which was accomplished through education. The child was considered the mean for the social upgrading of the family and fulfilment of parents expectations.

The birth of the boy was related with social upgrading of the family, the security and stability. The success of the boy was related with pleasu young people confess nowadays that would have a degree for the sake of their parents and later they would follow what they really like to do in life (Katakis,1998).

The Couple

Within two generations, marriage and procreation was not the aim of an individual any longer. Urbanisation diverted the route of family life and partners find there are discrepancies between their own personal norms and the norms which they believe prevail in their social group. They are fluctuating between self-actualisation and the collaboration and reciprocity in human relationships.

It seems that young people are interested in the a smaller unit, the couple (Katakis, 1998) but the equal relationship that they dreamed of exploded when the discussion turned to on arrival of a new child, the event that for most parents is an eagerly awaited event.The only realistic solution which they suggested was that the grandparents would undertake the children's care.

On the one hand, young couples are striving to find a balance between the fulfillment of personal goals and consider grandparents help of primary importance and on the other hand, they realise that by following this attitude are stereotyping norms they want to avoid where the mother take care of the children and the father is the breadwinner and distant from child caring tasks.

Woman's Position

Another basic presupposition for understanding changes within the intra-familiar support is the awareness of a woman's position in the three dimensions of the Greek family.

Greek mothers are facing the demands of a new era but are carrying influences of a pre-industrial culture. The picture of the urban woman who tries to keep the members of the family connected by creating affection, is totally different from the rural-traditional woman who was able to keep the family united without being the centre of interest and with the role to fortify and dissolve any disputes among the members. She was the shelter against the harshness of nature, as well as, of society, and was the history and continuation of the family (Katakis,1998). Her main trait was to be aware of everything and received respect from everyone. The identity of the traditional woman was based upon two factors: giving and power. From giving was gaining strength and from strength was acquiring the courage to continue giving. She had a definite, clear role and purpose in life, that of *giving* (Katakis, 1984). For the woman in the nuclear family the predominant occupation was to help the child with his/her homework, her ultimate purpose in life is the future of her child. For the woman in the nuclear family the predominant occupation was to help the child with his/her homework, and her ultimate purpose in life was the future of her child. Social forces exert impact upon the woman's satisfaction for her mothering role.

They value the bond between mother-child as the closest and more important intra-familiar relationship, while in the rural areas women were investing more in the male-female bond. However, they were also considering the mother-child link as the closest (Katakis,1998).

For Doumanis (1983) the behavioural characteristics which distinguish the urban mother from her rural counterpart are: (1) the preoccupation of the urban mother with household activities, the sudden change of her attention from housework to child-minding, (2) the profound verbalisation and the restricted observation, and (3) the extreme preoccupation with her child. The woman in the nuclear family is educating her child without the help of the extended family. It is striking that she is holding her child more than traditional women did and she teaches her child how to play (Katakis, 1998).

In today's society, the family cannot any longer neither cover the spiritual, intellectual, interpersonal relationship, nor the social status which once was accredited to the woman of rural areas. Mothers, have to choose the correct forms for establishing their families, not to create new ones. The modern Greek woman is divided between deciding if she is strong, or not, and if she wants to fulfill her personal aims or to satisfy the needs of others (katakis,1998).

Religion and Family

Certainly, the last few years the structure of the family institution is being modified its structure. One of the most important influences on the family was imposed by the Greek Orthodox Church. During all the hardships, the wars, the poverty, people referred to God for help and the Church was providing a shelter for individuals.

The Church considered the family as an intellectual, holy establishment for personal and social growth, and for the preservation of tradition. The Orthodox Church gives an eminent place to the matrimony blessed by God. It considers the marriage as a sacrosanct mystery which is to imply that does not involve only the two heterosexual people who decide to upgrade their relationship to a permanent one but also entails the presence of God. This mediation of the holy element reinforced the viability and effective functioning of the family throughout the years.

In summary, within framework of the Greek consumer society there prevails the isolation and rivalry between people. Some of the main roles of the family are declining but the family network continues to be a social unit which has internal, as well as external functions. Doumanis (1983) who stated that since the new family without any resources to defend its existence, cannot fulfill all the needs of its members it should not absorb all its energy.

Maybe the family fluctuates between reciprocity and self-actualisation of its members but is the only means for the psychological survival of its human components. The duration of a family as a social institution is based upon the human needs for identification, and the maintenance of existence. Without the emotional charge which only close familiar relationships can generate, it is not fulfilled. A solution would be to reinvent family forms and to define the nature of the family in the context of a society under progression. Parents are dealing with a discrepancy which require realism and adaptability to make the task of parenting effective. Equally, they realise that marriage is a dynamic process not static one and given favourable conditions for growth can be closer to their relationship potential. In a study by Katakis et al. (under publication) young couples emphasised on the need for satisfaction from the marital relationship, expressed intentions for more efficient communication. They were more optimistic on future development of their marriage and their intention to keep the family ties. The child was not the centre of the family but still parents wanted to provide the best for their child. Greek society is under transition. Living in an era of domination of computers and knowledge more than the rate of a person can absorb, young people realise more the worth of the family and try to find better communication ways between men and women. Parents are doing their best for their children either for their economic security or their education.

CHAPTER 2

METHODOLOGY

METHODOLOGY

1. Introduction

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

3. Possible approaches to research-quantitative or qualitative

4. Data collection method

  4.1. *Use of interviews in family research*

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5. Procedure

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  5.2.4. Interview

6. Data analysis method

1. INTRODUCTION

Behr (1990) suggested future research to investigate the effect of a disabled child on different cultures than the English/American. 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) mentioned that before effective service planning and delivery is professionals need to be aware of parents' strengths, coping strategies, and 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.

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),and 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 Questions 1-5.

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 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.

<u>Research question 3</u>.

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 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?

<u>Research question 4.</u>

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 resources helping parents to adapt, as in the literature review religion enhanced family relationships (Mahoney et al.,1992) and 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 Question 15.

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

Interview Question 14.

Which persons were perceived as supportive to your family?

Research Question 6.

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.

3. Possible approaches to research-quantitative or qualitative?

> *'Research is a process of seeking, by means of methodical enquiry, to solve problems and to add to one's own body of knowledge and that of others by the discovery of significant facts and insights.'*
>
> *(Herbert, 1990, p. 1)*

The last decade has witnessed changes in the scale, substance and strategy of research designs. By and large, two research traditions can be viewed as contributing to the understanding of different aspects of the phenomenon in question, the qualitative and the quantitative approach. The debate reflects a tendency to treat quantitative and qualitative research as antagonistic ideal methods of the research process. For many years, the quantitative approach was the predominant method thought to provide an objective knowledge base to guide practice. It was the process which was said to serve the term 'scientific' (Clark and Hackey, 1989). This idea was supported by Burns and Grove (1987) who defined quantitative research as 'a formal, objective, systematic process in which numerical data are utilised to obtain information about the world' (p.140). Quantitative research was often conceptualised by its practitioners as having a logical structure in which theories determine the problems to which researchers address themselves in the form of hypotheses derived from general theories (Bryman, 1988). Qualitative, is the study of the social world which seeks to describe and analyse the culture and behaviour of those being studied from their own point of view (Bryman, 1988).

The researcher, the discipline, the culture to be translated and the cultures into which it is translated form an interwoven amalgam of elements. Any attempt to capture social reality must be grounded in people's experience of it. Failure to recognise and encapsulate the significant nature of everyday experience runs the risk of losing touch with social reality and imposing instead 'a fictional non-existing world constructed by the scientific observer' (Schutz, 1964, p.8).

Leininger (1985) pointed out:

> *'the goal of qualitative research is to document and interpret as fully as possible the totality of whatever is being studied in particular contexts from the people's viewpoint or frame of reference. This includes identification, study analysis of subjective*

> *and objective data in order to understand the internal and external worlds of people.' (p.5)*

Qualitative researchers stress the change and interconnection of the socially constructed nature of reality by keeping an open mind and fostering new lines of enquiry. Quantitative studies establish regularities in social life by emphasising the measurement and analysis of causal relationships between variables. So far, much of the discussion concerning these two main research traditions has given an exaggerated picture of their differences.

The critics of quantitative research stressed that this positivism was not only a poor way of undertaking the study of social reality but also a poor account of the nature of science (Guba, 1985) thus, inappropriate to the study of people (Filmer et al., 1972). Couchman and Dawson (1990) encapsulated these views and further described qualitative methods as less concerned with establishing causality, regarded as being less 'scientific', working from the particular to the general, whereas, quantitative methods work from the general to the particular with high dependence on statistical significance of findings.

Supporters of qualitative research, describe qualitative data as a source of well-grounded, rich descriptions and explanations of processes employed by local contexts (Miles and Huberman, 1994). In much qualitative research the symptom and course of an undertaking to view social life is seen as a process, rather than static (Bryman, 1988). By focusing on naturally occurring ordinary events in natural settings, Miles and Huberman (1994) believe that we can have a strong handle on what 'real life' is like. Qualitative researchers tend to espouse an approach in which theory and empirical investigation are interwoven. The prior field work specification of theory tends to be excluded because of the possibility of introducing a premature closure on the issues to be investigated. (Bryman, 1988). Consequently, qualitative researchers go to the particular setting to make sure they capture perspectives accurately. Such a strategy involves a readiness to empathise with those being studied and also entails the penetration in the frames of meaning with which they operate. The subjective realities of the investigator and his respondent are recognised as part of the data set. Through their relationship can be gained access to the data which reflect the subjective communicated meaning of the participant as well as the selective interpretation of the investigator (Lincoln and Guba, 1985).

Many quantitative researchers express reservations about this lack of objectivity since they themselves apply a pre-ordained framework on the subjects investigated reaching the field of their study with tight rules, pre-structured questions, instruments, coding, and analytical techniques. However, this approach conveys a static view of social reality which tends to neglect the impact and role of change, a view totally incompatible with the study of people and their environments.

Field and Morse (1985) pointed out that the basic distinction between qualitative and quantitative approaches is that the former aims to develop theory inductively from the data without presupposing in advance what the important dimensions will be, while the latter's intention is to generate and test theories deductively from existing knowledge through developing hypothesised relationships, and proposed outcomes for the study before data collection begins.

The initial concept in the present study followed Filstead's (1979) remark that qualitative research 'is marked by a concern with the discovery of theory rather than the verification of theory' (p.38). Secondly, over-reliance upon theory testing can lead to the neglect of the formulation of a new theory which is necessary since we describe a different frame of social reality with unanticipated facets. The researcher in the present study, followed Pyke and Agnew's (1991) suggestion that qualitative methods may be most appropriate when the purpose of research is to describe or understand rather than to predict and control because their purpose is to 'see through the eyes of' the participants (Bryman,1988). So a qualitative research design was selected for this study since the point of using it was to understand phenomena in terms of the meanings people bring to them (Denzin and Lincoln, 1994) in their naturally occurring states (Patton, 1990). Taylor (1988) has stressed the strength of qualitative research methodologies when using descriptive data from the parents' own experiences. It was believed that since qualitative design explore relations within a system or culture (Janesick,1994) this was the appropriate way to reach the study of a social world which differs from British/American reality. Qualitative methodology was selected because it rejects the formulation of theories and concepts in advance of beginning the fieldwork due to the possibility of introducing a premature closure on the issues to be investigated and of prejudicing the researcher' ability to see through the eyes of the parents, its favours unstructured research designs, it understands actions and meanings in the social context they occur, and provides the researcher with a framework to cope with the unstructured complexity of the Greek social reality and so render it manageable.

The aim of the present study was to collect information, and 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, or 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.

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. The researcher always asked parents if they minded being tape-recorded. She indicated that their anonymity would be kept and that she 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, she 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, she thanked the parents for giving me their time, and agreeing to speak to me. Additionally, she wrote to all the families a 'thank you' note and at a later date she phoned them to ask how the children were.

5. PROCEDURE

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. It was thought that this was best achieved using a semi-structured interview schedule. In order to minimise the imposition of predetermined responses, the researcher 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 the researcher was interested in understanding the parent' subjective experience she 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 open-ended 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. As these pilot interviews worked well, data emerging and 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.

5.2. Conducting the study

5.2.1. *Inclusion of fathers*

In the original design of the research, it was considered to be extremely important to include fathers in this study. It was soon made apparent that most fathers were unable to participate because they were working at two jobs, were operating businesses and no effort was made to intrude upon their limited free time. At the end, twenty-five fathers were present at the interviews.

5.2.2. *Recruitment of the sample*

The most difficult thing in conducting this study was the recruitment of the families. Gatekeepers range from absolutely legitimate to self-declared. A really surprising response from a social worker was:

> *'You want to find out about the parents' needs? You don't have to go to parents themselves, I will tell you what they want. You know the theory but I know the reality.'*

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 assessment 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 five (5) 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 nine more parents completed the sample from different agencies approached.

From the schools, the researcher was provided with a list of parents' names. She knew that it was unlikely that all parents whose names she had would agree to take part , so to avoid the final sample being too small 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 and establishing generality of results to other populations presents problems. 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.

5.2.3. The demography of the population

The background to the interpretation of these data must be sketched on a canvas of demographic characteristics for both the parents and the children. Mothers mostly participated, although the fathers were also invited. Twenty-five fathers accompanied the mothers to the interview. The families were living in rich, middle or underdeveloped areas of Athens. The educational level of parents ranged from Grades 1-4 to University degree holders. The grades 1-4 stand for those who finished primary school (year 6 to year 12), Grades 5-6 stand for those who finished high school (year 13 to year 15), grades 7-9 stand for those who finished a Lyceum (year 16 to year 18), Grades 10-12 for those who have a degree from a higher, technical education institute (year 18 to year 20), and, lastly, those who hold University degrees (year 18 to year 22). The following tables illustrate the educational status of fathers and mothers.

Table 1. The educational status of fathers

EDUCATIONAL STATUS OF FATHER	N	%
Grades 1-4	5	5%
Grades 5-6	23	23%
Grades 7-9	24	22%
Grades 10-12	20	18%
Degree	36	33%

Table 2. The educational status of mothers

EDUCATIONAL STATUS OF MOTHER	N	%
Grades 1-4	5	5%
Grades 5-6	28	25%
Grades 7-9	28	25%
Grades 10-12	29	26%
Degree	20	18%

Thirty six fathers (33%) had University degrees, 18% held a degree from a technical institute, 22% had finished a Lyceum, 23% had finished high school, and 5% had finished primary school. Of the participating mothers, 18% held University degrees, 26% held a technical institution degree, 25% had finished the Lyceum, 25% had finished high school, and 5% had finished primary school. The age of the fathers and mothers is presented in the following tables:

Table 3. The age of fathers

AGE OF FATHER	N	%
20-30	2	2%
31-40	65	59%
41+	40	36%
Father absent	3	3%

Table 4. The age of mothers

AGE OF MOTHER	N	%
20-30	15	14%
31-40	72	65%
41+	23	21%

The majority of parents was aged between 31-40 (59% of fathers, 65% of mothers). Over 40 years of age was represented by 21% of mothers and 36% of fathers. Parents between 20-30 years were few in the present study and were represented by 2% of fathers and 14% of mothers. In three (3%) cases the father was absent (2 divorced, 1 separated).

The principal demographic variables in the present study are derived through the particular traits of the children. The age of the children ranged between 5-15 years of age. This span was selected for a number of reasons. Firstly, it permitted a coverage of the early years of schooling through to adolescence and suggested that all parents were probably fully aware of the diagnosis by that time. The majority of studies, specially those following the deficit model have chosen children and parents who have just received a diagnosis and have presented the reaction of parents, relatives and friends. In the present study the children were older and parents were about to face a transition in their lives. Those parents who had children 5-6 were in the process of finding a special school, those between 7-10 were in the first year of a special school and those 11-15 were at the onset of puberty. The parents were all facing transitions, which may have caused stress in their lives. The participating children were 37% (n=41) physically disabled, 48% (n=53) mentally disabled, and 15% (n=16) hearing disabled. The following tables give a representation of numbers and percentages of the children's impairments and age.

Table 5. The type of impairment of children

TYPE OF IMPAIRMENT	N	%
Physical impairment	41	37%
Mental impairment	53	40%
Hearing impairment	16	15%

Table 6. The age of children

AGE OF CHILDREN	N	%
5-6 years	19	17%
7-10 years	63	57%
11-15 years	28	25%

The majority of the children were male 57% (n=63) as compared to 43% (n=47) female. The participant physical impaired children were: 38% male (n=24) and 36% female (n=17), the mentally impaired were: 44% male (n=28) and 53% female (n=25), and the hearing impaired children were: 17% male (n=11) and 11% female (n=5). The distribution of type of impairment by gender is represented in the following table (Table 7).

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 family size in the participating families was: 56% two children (n=61), 16% three children (n=18), 7% four children (n=8), and in 21% (n=23) of the cases the disabled child was an only child. In this study, families mostly had two children, the disabled and a non disabled child and other families had the disabled as the only child in the family. The birth order of the disabled child was the following: 28% first child (n=25), 50% second child (n=45), 13% third child (n=12), 1% twins (n=1), 4% fourth child (n=4), and 21% (n=23) of the cases the disabled child was an only child. In half of the cases the disabled child was the second child in the family.

The age of diagnosis was the following: 6% from birth (n=7), 19% at 3-6 months (n=21), 6% at 7-8 months (n=7), 28% at 11-12 months (n=31), 18% after the first year (n=20), 18% after the second year (n=20), and 4% at entering elementary school (n=4).

Parents identified as the cause of the disability the following: 45% unknown cause (n=41), 20% difficult delivery (n=18), 6% otitis media (n=5), 22% prematurity (n=20), 2% post term delivery (n=2), 4% icterus (n=4), 6% a virus (n=5), 3% inherited (n=3), 10% anoxia during delivery (n=9), 28% use of incubator (n=25), 3% use of breech (n=3), 1% epileptic fit (n=1), and 7% other problems (n=6).

5.2.4. Interview

Data gathering took place from November1993 to May1994 in Greece and particularly in the busy and crowded capital of Athens. Though, the recruitment of participants proved to be a difficult task when I contacted the parents, they were usually more than willing to participate and express their problems and needs. The reply of a father illustrated their welcome:

> *'We speak to you because you come from abroad and you may do something. If you were a Greek social worker we would not say anything, because until today, these people in Greece have not help us at all.'*

Telephoning was the first step in making contact and consisted of a brief introduction, an explanation of how the interviewer gained access to them and setting up an appointment to meet, and the reassurance that they would remain anonymous. Usually, the mother was my first contact with the family and at every telephone call the father of the family was invited to participate. Then, a date was decided upon always at the convenience of the parents. The same day of the visit to the family, the researcher confirmed by a telephone call that nothing had changed from the day the appointment has been booked.

The establishment of rapport was the second most important task of the interview. Measor (1985) stressed that access to informants was not only finding them but mainly involved being accepted by them and obtaining their trust. Establishment of rapport was an exciting and fulfilling feeling not only at the beginning of the study but throughout it. Every time, the researcher had to deal with a different family but the more she was conducting interviews, the more confident she was becoming, and was enjoying the process of interviewing. Once the interview was under way, the researcher tried to keep a balance between respecting what the parent was saying and taking advantage of opportunities to ask difficult questions.

A tape-recorder was used to assure of the accuracy of data collection. Walker (1985) regards tape recording as a safeguard for interviewer bias (when using semi-structured interviewing) in the responses by deciding which answers to follow up on. Parents quickly became accustomed to the presence of the tape-recorder, actually most of them seemed to forget it was there. For those parents who found the tape recorder inhibiting and they did not want it, she kept hand-written notes, after receiving their permission. Full note-taking was difficult at the speed of normal discourse. As a result, there were times that intruded upon the flow of the respondent's answers and upon the interviewer's concentration and lead quite frequently to the selection of a fraction of the data accrued from an interaction although, the researcher didn't have any other option. A valuable piece of data were lost because the parent talked too fast, pouring forth multiple paragraphs to express a particular thought at a pace which the interviewer could not transcribe. Apart from the tape recorder, the researcher 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 responses tapped areas of unrehearsed thought and represented the first plunge into feelings which were not so readily verbalised. Each question was chosen to probe more deeply into the personal dynamics of the parent relying upon the growing relationship of confidence, trust and intimacy between the interviewer and the parent, to free the parents for a more intimate exploration of themselves and their feelings. The analysis of the interview tapes, transcription indicated that this progressive phenomenon did, in fact, take place. The relationship between the interviewer-researcher and the parent did become stronger, more confidential, and trusting as the interviewer went deeper and bonds of empathy grew between them.

For many of the parents, the perceptual set of giving information in a research project became a secondary consideration to the personal dynamics, to the excitement and the treat of systematic self-appraisal, to the revelations being experienced in relation to their own feelings. Parents differ greatly in their recall of memories, their understanding of the wording of questions, their emphasis on the social desirability, their interest in the given study. In a sense, each interview was a study in itself. None of the parents openly refused to answer a question in the entire sample. Interviews lasted at a the minimum three quarters of an hour, each time. One and a half hours was the optimum amount of time for me in conducting the interviews where probes increased the richness of the data being obtained.

There were times where interviews became confessions and hidden things were revealed. They regarded my interest in their way of life as a sign of empathy and understanding. Some parents expressed this release or unfolding by commenting that they had ‘never been so confidential with anyone’, or ‘I have never told this to anyone before.’

The co-operative attitude of the parents was impressive. The parents gave freely of their time and appeared to be interested in providing information. Some of them expressed their motivation to contribute to a better understanding in the future. Others expressed interest in the findings of this study whereas others were willing to participate and openly declared that because the researcher wasn’t representing any Greek agency services and felt that this independent research project could be used to gather a strong parental perspective that could be used to develop support structures according to the expressed views and needs of parents.

Several parents expressed the feeling that the interview had served to 'recharge their own batteries.' From time to time, the parents were reassured about the nature, direction and duration of the interview. Each successive stage was structured to probe more deeply into the personal dynamics of the parent relying upon the growing relationship of confidence between parent and interviewer. The researcher tried throughout the interviews to monitor my own comments, gestures and actions as these may have conveyed particular meanings to those who were being interviewed which might have advanced or impeded the interview. The researcher became more experienced in conducting interviews and was able to be more successful in doing so.

In conducting the interviews, the researcher tried to retain a critical alertness of what was being said, ready to explore some issues in greater depth and to veer the discussion to a topic which had been omitted.

It was not surprising that the interesting material emerged when the recorder was switched off. This released a flood of ideas or comments such as 'We finished already? What a pity! And it was really nice talking to you.' There were times that parents were offering me sweets or flowers to take home.

5.3. After the interview

My intuitive reaction was that the responses were real and spontaneous. The parents appreciated the connotation that there was a set of questions that had to be answered.

The use of a tape-recorder promoted the fluent progress of the interview, and enabled accurate, reliable and comprehensive recording of answers important part of qualitative research. The transcription of the tapes provided an excellent record of 'naturally occurring' interaction (Silverman,1993, p.10) but it was proved to be a time-consuming activity. The ratio of transcribing time to tape-time was typically 5:1. The raw data of interview were quotations from which only the ones that were particularly important for data analysis and reporting were translated.

By using quotes I found a useful way of bringing the text alive to make the study interesting and richer. Before transcribing the tapes, the researcher listened to them at least twice: first time to get a glimpse of the whole interview and the second, to examine the data in more detail; to search for emerging themes. She found that a way of presenting interview data was to organise excerpts from the transcripts into categories and she indexed the data accordingly. She was engaged in several pilot categorising exercises which involved trying out categories on transcriptions, developing new categories or redefining existing ones. On the second listening of the tapes, the categories and emerging themes were recognised and the appropriate data were put under the appropriate categories. These descriptive categories were used to index the transcripts so that all mention of any of the topics were readily retrievable.

Parents, in their discourse, very rarely use the precise words with which the researcher have chosen to label the analytical categories. There is a limitation there: these excerpts have been removed from the contexts from which they originated although they have some meaning in themselves. Yet, for qualitative researchers the context is usually relevant to understanding and validation (Mason, 1994). However, how to understand relationships between themes in the data are matters of intellectual judgement which form the process of analysis of the data.

6. Data Analysis Method

The analysis of data should be considered a highly personal activity (Jones,1985).It is a process of making sense, of structuring the data. It is an effort of giving meaning to the transcript which accurately convey what the participant perceived as important The principle of following similar themes in different data sets is a way of linking the data (Mason, 1994). Silverman (1984) emphasised this interconnection mainly by presenting the qualitative data in his research employing quantitative information as a means of establishing the generality of his observations. The present study used quantitative information and qualitative to enrich data analysis.

For the analysis of the data about the variables, the researcher chose to use the Statistical Package for Social Sciences SPSS (Norvsis,1992). The guiding principle was to present different forms of data and explore the relationships between them. For this purpose, she followed the use of one method of bivariate analysis: cross-tabulations. Crosstabulation is a way of displaying data so that we can predict association between the variables involved (DeVaus, 1991) and aid the task of exploration.

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. A significant level smaller than 0.05 ($p =< 0.05$) is considered statistically significant in 2x2 contingency tables. The researcher used coded labels of each variable and each category within each variable but this task was very time-consuming. But these results of crosstabulations elucidated the important findings of the study. Through constant comparisons between categories and themes she have explored the complexities of the data corpus. After all, this was the only way to produce meaningful results.

Another difficulty was to decide which way of describing each variable would be used. There are three different ways to calculate percentage, the total, the column and the row percentage. In trying to find the association between variables row and column percentages are usually used. For this reason, the variables were characterised as independent and dependent. The variables derived from demographic information were characterised as independent and the variables derived from the data were the dependent since they could be influenced by the demographic or by other biases. DeVaus (1991) suggested that if the independent variables were across the top of the table and the dependent variables on the side, then the column percentage should be used. The examination of crosstabulations should be across the line of the table. In the present study, while the information, gleaned from the interviews was coded and represented as quantitative data, we employed verbatim quotations from parents replies in order to illustrate general points supporting the finding. It was thought that incorporating quantitative and appropriate qualitative material into the thesis would strengthened the qualitative conclusions derived from the data.

CHAPTER 3

FINDINGS AND DATA ANALYSIS

'Before you impose your theories on the people you study, find out how those people define the world.' (Spradley, 1979, p.11)

FINDINGS AND DATA ANALYSIS

A. Introduction

B. Findings and data analysis

Section 1. Difficulties in everyday life

Section 2: Aims for the future

Section 3: Changes in life

Section 4: Parents' belief systems

a) parents' source of strength

b)comparison with other families

Section 5: Positive contributions of the disabled child to the family

Section 6: Needs for services

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

SECTION 1

DIFFICULTIES IN EVERYDAY LIFE

1.1. Introduction

1.2. Effects of children's type of impairment on reported everyday difficulties

1.3. Effects of children's gender on the reported everyday difficulties

1.4. Effects of children's age on reported everyday difficulties

1.5. Summary of results and discussion

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 ($p=<0.05$).

A mother with a physically disabled girl commented that her child due to physical problems needs all the time someone to help her:

> *'She wants everything in front of her. The other two children are young and they cannot help. Everything is difficult in physical and*

psychological means. Because she has a mobility problem (uses a wheelchair), she needs a person to care for her all the time. I have two more children (pregnant with another), I don't have any personal time to spare for myself and I face difficulties.'

Another couple with a mentally disabled child said:

> *'You need to spend a lot of time with our daughter. She cannot understand everyday routines. She cannot go to the toilet alone, to eat or to get dressed. She always needs somebody to take care of her. We can be close to her for her education, in order to learn something.'*

Table 8 shows the relation of the type of impairment of children on the reported difficulties in everyday life.

Table 8. Difficulties in everyday life by the type of impairment of children

	TYPE OF IMPAIRMENT					
	Physical Impairment (N=41)		**Mental Impairment (N=53)**		**Hearing Impairment (N=16)**	
	N	**%**	**N**	**%**	**N**	**%**
All day with child (N=36)	17	37%	16	27%	3	19%
Mobility (N=17)	16	35%	1	2%		
Behaviour (N=21)	3	7%	18	30%		
Communication(N=26)	1	2%	14	23%	11	69%
Non mentioned (N=17)	7	17%	8	18%	2	13%
Problems of other nature(N=5)	2	5%	2	5%		

PS. Parents gave more than one answers in this question.

A couple, both teachers with a physically disabled girl responded:

> *'Our problem is that she can not move by herself and all the time needs something which we have to give to her. All the time she says 'give me that or give me the other'; 'I can not reach my toy etc.' She is also spoiled and though she can do a few things she does not do them because she knows that we will provide it for her. I think it is like working as a helper in the house. You have your job (at school) and then you have another full-time job, to take care of the child. You don't have any personal time. From the minute that you wake up till you go to sleep, you work. And it is not easy for somebody to work from dawn to dusk. If she could be independent she would not need the care of her parents or, of the helper at anytime. Our other child can stay and play alone, she can eat alone but when you have a child with special needs you can not do that. You can not say to your child that you will take her to the toilet when you finish your job.'*

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).

A couple with a mentally impaired child answered:

> *'Our problem is toilet training and the visits of guests. He goes round and round, he does not sit anywhere when visitors come, he is over-active. When he senses that he is accepted, he feels secure and does not disturb us, but when relatives come and they hug the other children, a storm starts coming.'*

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).

The mother of a mentally disabled boy with no speech said :

> *'My major problem is the difficulty in communication. I have found a way to understand what he wants. He will take me and show me what he wants. We, the family, have found a way to communicate with him. The problem with communication becomes more obvious with relatives and other people. For us everyday routine helps us to understand. For the others it is very difficult.'*

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.

The mother of a physically disabled girl said:

> *'My difficulties have no relation to my child. I have a problem with my husband's relatives because my husband does not take my side in our conflicts. If I stayed alone with my husband, away from his relatives, I wouldn't have any problem. My problems start with the attitude of my husband's family and his reaction to it.'*

Another mother of a mentally disabled girl replied:

> *'My major difficulty is the stares of other people. I don't like it, when I see them pity me, I feel upset and sad.'*

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.

Table 9. Difficulties in everyday life by the gender of children

	GENDER OF CHILDREN			
	Male (N=63)		**Female (N=47)**	
DIFFICULTIES IN EVERYDAY LIFE	**N**	**%**	**N**	**%**
All day with child (N=36)	17	24%	19	37%
Mobility (N=17)	12	17%	5	10%
Behaviour (N=21)	13	19%	8	15%
Communication (N=26)	16	23%	10	19%
Not mentioned (N=17)	10	14%	7	13%
Problems of another nature (N=5)	2	3%	3	6%

Ps. Parents gave more than one answer to this question.

A couple with a physically disabled boy answered:

> *'The difficulties are somehow more than those other children have because, in order to do something, he has to be next to me or sitting in his chair'.*
>
> *The father said: You cannot leave him because somebody has to be with the child, you have to pick him up and walk some distance, if you want to find a taxi to visit a friend or a relative. His needs are greater than those of other children. You have to be always near him. You cannot leave him even for five minutes. He is young, he can fall and hit his head.*
>
> *Mother: Now he is heavy and I cannot carry him in my arms and, if I don't have somebody, I cannot use his carriage so we can not even leave our apartment. One day I walked three quarters of an hour carrying my son in my arms. It took me a week to recover.'*

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%).

A mother with a physically disabled girl gave the following reply of how her own behaviour made the care of the child very difficult:

> '*She gave me a hard time. It is something that happens to all mothers caring for a disabled child. We suddenly become the experts, the only ones who know how to feed, carry or change the child's diaper. There was a time that I did not trust anybody to carry her, if he didn't know (in my opinion) how to hold her, to give her food. There came a time that I was overwhelmed and exhausted from her care. We (the mothers) feel exhausted while at the same time we do not give others the chance to do something to help us. I held my daughter as if she were a bag, always carrying her with me. I could not leave my child anywhere. At some point I felt I was irrational so I left my daughter for the first time with my husband. I went shopping, I returned and I saw that nothing had happened to her and from that time on my life became normal.*'

Another mother with a mentally disabled child said:

> '*She does not eat much, she does not collect her toys and she leaves everything in a mess. I get furious because she does not listen to me, so at home we are always uptight and stressed.*'

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.

Table 10. Difficulties in everyday life by the age of the children

DIFFICULTIES IN EVERYDAY LIFE	**5-6 years (N=19)**		**7-10 years (N=63)**		**11-15 years (N=28)**	
	N	**%**	**N**	**%**	**N**	**%**
All day with child (N=36)	9	41%	21	30%	6	20%
Mobility (N=17)	4	18%	11	16%	2	7%
Behaviour (N=21)	3	14%	11	16%	7	23%
Communication (N=26)	6	27%	15	21%	5	17%
Not mentioned (N=17)			10	14%	7	23%
Problems of another nature (N=5)			2	3%	3	10%

Ps. Parents gave more than one answer to this question

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.

The mother of a physically disabled boy reported:

> *'I lift him all the time, I wash him, feed him, dress him. He is toilet trained but my most difficult task is carrying him, he cannot move by himself '.*

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.

A mother with a mentally disabled girl replied:

> *'My biggest problem is her behaviour and the second is mobility or speech. With the ten words she knows, she can communicate perfectly.' (at the time of the interview she bit the researcher once)*

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):

> '.... *I can say that she does not give us a hard time. I got accustomed to everything that has to do with my daughter. My sister and my mother adore her, but people ask me how I can stand it. I'm used to everything to do with her and I feel sad with the reaction of others when we go to the park, when they stare at her. She is a difficult child but I do not feel overwhelmed or tired or think something bad about her ... we are very attached to our girl, we her father and I, but if we weren't overprotective of her we could help her more. Now her personality is formed. It would be better to start asking her to do things earlier. Our emotions do not help us. My husband and I argue about that. I persistently ask my daughter to do something, though my husband does not agree with me. He thinks that she will do whatever she can do.*'

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

2.2. Effects of children's type of impairment on reported aims for the future

2.3. Effects of children's gender on reported aims for the future

2.4. Effects of children's age on reported aims for the future

2.5. Summary of the results and discussion

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.

Table 11. Aims for the future by the type of impairment of children

AIMS FOR FUTURE	TYPE OF IMPAIRMENT					
	Physical impairment (N =41)		Mental impairment (N=53)		Hearing impairment (N=16)	
	N	%	N	%	N	%
To become more calm (N=10)	2	4%	6	9%	2	11%
To reach his/her potential (N=35)	14	25%	15	23%	6	33%
To secure economically him/her (N=15)	2	4%	12	18%		
To become educated (N=15)	10	18%	2	3%	3	17%
To become sociable (N=9)	1	2%	5	8%	3	17%
Non mentioned/I don't know (N=9)	3	5%	6	9%		
To be independent (N=40)	20	36%	17	26%	3	17%
To have balanced personality (N=8)	4	7%	3	5%	1	6%

Ps. Parents gave more than one answer to this question.

A mother illustrated clearly the importance she is giving on independent living:

'When I think of his future, I do not think of his marrying as his father does. For me it would be enough for him to find a job to support himself, to be able to defend himself and not to be the victim of opportunists, not even his

siblings. Today they are happy together but when their interests change, the relationship between them will alter, also. I don't want him to be the 'dumb', one who will be taken advantage of by every one because of his condition. I don't care if he becomes an intellectual, but I want him to have a job of his own. By securing him economically the problem would be partially solved. I want him to be independent so as not to be a burden for anyone. If his siblings want to help him they should do it because they want to and not because they are obliged to do so. The fact that he has siblings doesn't make things easier. I'd like him to be independent with his own money.'

Another mother strongly elucidated the importance of independence as follows:

'I have had awful thoughts. There are times where death seems a catharsis. I was thinking that I don't want my death to come suddenly but to give me notice, maybe a disease. If until then my son can not lead an independent life and be at ease with himself ... Yes we are a family in which problems are shared but the care of my child is my responsibility and not that of my other son. He has his own life to live. So, I was thinking that if my son cannot accommodate himself, I would like to give him freedom by euthanasia. Our society is very peculiar. It seems that it progresses but becomes more self-centred and I wouldn't like my child to live to be pelted with stones. It is selfish but still I recall something that I heard while I was a student. 'Since I cannot give my son a respectable way of living, I would give him a respectable way of dying.'

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.

The mother of a mentally impaired child replied:

> *'I wish him to finish school and I believe he will be able to learn a craft. The problem is his speech because it shows that there is something wrong but I believe he will learn more than 10 words, he should learn more than those.'*

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.

A mother commented:

> *'I should like to create such conditions such that my oldest daughter would be the least possible burden for her siblings. It may sound selfish but my daughter hasn't realised her condition and, as long as conditions don't change, she is very comfortable. But the present conditions will change and I cannot impose her care upon the other children. The first thing on mind is her economic security...'*

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.

Table 12. Aims for the future by the gender of children

AIMS FOR THE FUTURE	GENDER OF CHILDREN			
	Male(N=63)		Female(N=47)	
	N	%	N	%
To become more calm (N=10)	9	11%	1	2%
To reach his/her potential (N=35)	19	23%	16	27%
To secure him/her economically (N=15)	4	5%	11	18%
To become educated (N=15)	8	10%	7	12%
To become sociable (N=9)	8	10%	1	2%
Not mentioned/I don't know (N=9)	3	4%	6	10%
To be independent (N=40)	28	35%	12	20%
To have a balanced personality (N=8)	2	2%	6	10%

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.

A couple with a mentally impaired boy commented:

> *'We don't have any dreams for our son but only for him to be independent, to have a job, a minor one, to be able to travel on a bus and reach home, but not to get married. I have thought where I want him to be. I am not allowed (said the mother) consciously or unconsciously to think that something awful might happen to him.'*

The father of an autistic boy confessed:

> *'If my son progresses, I will resign from the Army and I will open a bakery. People will always eat bread. I have a personal private insurance for my son so he won't be a problem to the other children (twin boys). I don't have ambitions to become a General, if my child won't be OK. I will do whatever I can to help my son live independently.'*

Another mother added that her son earning his own living can feel that life is worth living:

> *'I would like for my son to become independent, to earn a living and to be sure about his abilities. I wish him to be able to live without my help, in order to live his life at its best for his own sake, to say that life is wonderful, it's worth living.'*

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.

The mother of a daughter commented:

> *'These two years we will do the best we can for our child. People say that we have money to spend but it is not that. I will do the best for my child, to have the best prospective in order to reach her potential. Another thought is for her to finish high school and become a hairdresser. But even for that she needs to know how to read. The other thing I have on my mind is if she will be able to recognise danger and*

> *not be used by other people. I don't want other people to take advantage of her.'*

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.

The parents of a daughter replied:

> *'We will try to secure her economically because we (the parents) will die one day and we don't want her to depend on her brothers. Not that the other children will deny any help but we don't want her to be a burden for her brothers. (Father): I changed my job in order to gain more money, I changed my habits (I was spending a lot of money though now I'm saving). I will try as long as I live for her in order to have everything she wants.'*

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.

The mother of a disabled boy commented:

> *'I wish him to be independent, to sit without disturbing someone or something, to sit with his brother in our shop and not be in the streets or in an asylum. I don't care if he learns a craft. I wish him to be able to go to a house of his own next to his brother and to be able to eat by himself, to become more calm and more sociable because if we don't manage that I don't know what will happen to him.'*

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

The mother of a physically disabled boy responded:

> *'I will do anything possible for him to finish school and learn a craft. I'm sure my son will continue his education. He then will be able to have a job. It would be unfair to be unable to take two steps*

alone, not to be able to do something on his own, since he is so clever. It would be unfair to feel that for every step he takes he needs someone.'

A couple with a boy with mental disability commented:

'We care about his education because no matter where he goes and what he does in his life we want him to be self-content. Some basic education is necessary and is part of self-sufficiency. To know how to read, to know the time, money, the date. What we want for him is to be self-sufficient and sociable. The onset of puberty concerns us what he will do, if he could have a job not so much for earning money, but more for being occupied with something. Is he going to be with us always? We will die one day and here in Greece reality is different from abroad. Society has not yet accepted these children. Information about them is non existent.'

The mother of a mentally disabled girl pointed out:

'I don't know yet what she will do with her school. I went to enrol her in a school but the headmaster didn't accept her. I can see the difficulties. I don't think she will continue high-school. We will see where we are headed. God will show us. If you ask me, I'm afraid of what the future will bring.'

The mother of a mentally disabled boy commented:

'I cannot foresee. I don't know what he will do later. The future will show us.'

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.

The mother of a girl pointed out:

'I really care how she'll react to her problem, if and how she is going to accept it. Because she is very sensitive and I don't know how she'll react, if somebody makes a comment about her. I don't know how much she'll progress, but I really care for her to be psychologically balanced.'

Another couple said about their daughter that they wanted to be balanced psychologically and accept her disability:

> *'I do not ask for much. To be educated, or to earn a lot of money but mainly to be happy, satisfied, to be balanced and accept her difficulty. This is a way to reach her goals.' (Her father): 'I want her to be balanced psychologically. Now she is young and she meets and get in touch with few people but later, as she gets older, she will meet more people and I don't know how she will react to their comments or stares. Now she is reacting well. But my basic worry is how will she react later?'*

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 mother of a young boy replied:

> *'I have got used to the idea that his problem (physical) will remain, but I wish for him to be independent, to live his life knowing what he can do and what aims he can reach. To live without needing me in order to live well, to realise that life is worth living and that life is beautiful and, for himself, is worth living.'*

Table 13 shows the interdependence of the age of children on the parents aims for the future.

Table 13. Aims for the future by the age of children

	AGE OF CHILDREN					
	5-6 years (N=19)		**7-10 years (N=63)**		**11-15 years (N=28)**	
AIMS FOR THE FUTURE	**N**	**%**	**N**	**%**	**N**	**%**
To become more calm (N=10)	2	10%	6	7%	2	6%
To reach his/her potential (N=35)	6	30%	22	26%	7	19%
To secure him/her economically (N=15)	1	5%	12	19%	2	6%
To become educated (N=15)	5	25%	8	9%	2	6%
To become sociable (N=9)	1	5%	4	5%	4	11%
Non mentioned/I don't know (N=9)	2	10%	4	5%	3	8%
To be independent (N=41)	3	15%	23	26%	15	42%
To have a balanced personality (N=8)			7	8%	1	3%

Ps. Parents gave more than one answer to this question.

A couple with a mentally disabled teenage boy said:

> *'Our aim for the future is whatever will help our son to become integrated in society and live independently. We function as a family with our son together at visits, at work, on holidays. Ever since pregnancy, we do everything with him. We wish him to be good, to be integrated, to have the means to survive independently. To reach a point that he will not need the help of others.'*

Another couple commented on their teenage boy:

> (Father): *'We don't have any other dream for our son than to be independent, to have a job, to be able to take a bus but not to get married. We have thought where our son wants to be. But until now our dream is for his spasms to stop.' (Mother): 'I do not permit myself to think that something will happen to him.'*

A mother of a 10 year old girl said:

> *'My goal for my child is for her to become independent. I, myself, live independently and I don't depend on anybody for help. That is my dream for my daughter. She can be independent through education and learning.'*

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).

The parents of a mentally disabled boy commented:

(Mother)

> *'I wonder what he will do when we aren't by him. My husband does not think of that. He does not express his thoughts as I do. His father does not press him to study, though I do.'*

A mother of a 7-10 year old boy said:

> *'I wish him to finish school and have a job. The problem is the lack of speech because it shows that something is wrong. But I think he will learn more than the 10 words he knows now.'*

Another mother said:

> *'Thank God, he progresses well. He can read, write and walk (with a walking aid). I wish to see him as independent as other children, because I have cried tears of sorrow and I'm still taking care of him.'*

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

3.2. Effects of children's type of impairment on perceived life changes

3.3. Effects of children's gender on perceived life changes

3.4.Effects of children's age on perceived life changes

3.5. Summary of results and discussion

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.

Table14a. Perceived life changes by the type of impairment of children (Social activities)

LIFE CHANGES	TYPE OF IMPAIRMENT					
	Physical impairment (N=41).		Mental impairment (N=53)		Hearing impairment (N=16)	
	N	%	N	%	N	%
Social activities reduced (N=57)	18	44%	32	60%	7	44%
Social activities haven't changed (N=53)	23	56%	21	40%	9	56%

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.

Many parents perceived that their life changed because they had given birth to children and not only because their child had a disability.

A couple with a mentally disabled daughter answered:

> *'Our life changed after the birth of our children. For the sake of our daughter, we had to leave the school we were working in (away from Athens), to change our friends, to change way of living. Most of the changes happened then. We lost our friends, our social environment. The change was better for our daughter but worse for us. We cannot find here in Athens, the friendships and the social contacts we had in the small city we were living. We have to say that our social contacts are limited or even eliminated because in Athens the way of thinking is different. In Athens, social contacts are not as easy as they are in rural areas. You can not feel close to others in Athens. You can meet your colleagues, your neighbour everyday in a city but in the Capital, even if you see someone, they are indifferent. In the beginning we were shocked. They didn't want to know us, as new comers from another city, it was a shock to us. We were used to a different way of living, different way of showing interest to other peoples' problems. Our decision to go on holiday is not influenced by our daughter. We just chose places near to Athens in order not to disturb her routines. Now we go everywhere together, on visits or holidays.'*

Another mother with a disabled boy replied:

> *'Our life changed after giving birth to our first child (the second is the disabled). It is not marriage which kills love, but the children. The first two years after the birth of the child what happens in the house is what the child wants. He/she has his/her own needs and the couple's relationship is forgotten for a while. Then the change of life comes. My husband was looked after our boy and everyone told us to care more for our first child. We haven't avoided taking our boy out, we go on holidays and camping. Now more than before, I trust him to go out to buy bread from the bakery and do it alone. He returns back, though he has an attention deficit.'*

Other parents were selective of the people they wanted to have a relationship with.

The mother of a mentally disabled daughter commented:

> *'At the beginning I was very tired and stressed. Probably God gave me the strength to continue. I get very disturbed when other people look at her with pity. I get furious even now. We do not go to an*

> *environment with people who we don't know. With familiar people our daughter is easy to go because they accept her, but in an unknown environment some child can mock her. They don't accept her and she feels uneasy. I avoid, as much as possible, social visits and when it is necessary, I go alone. We go on holiday but we chose places familiar to us.'*

The mother of a physically disabled daughter answered:

> *'My life changed because I'm the mother of a young child and everyday she has physiotherapy sessions. Everyday we go to the park. The children have accepted her. Other parents look at me or stare at me ,and old ladies make the sign of the cross and say 'Oh, the poor one'. This upsets me. I do not see my child as miserable and needing the pity of others. She is not the first or the last child with difficulties. I could wish my child to be the last one having difficulties but there will be other children with difficulties too.'*

The mother of a physically disabled boy replied:

> *'Just I have an additional course of tiredness. I can not say that I won't go somewhere because of my boy. I have three children and I can not behave as if I were alone. It wasn't the disability of my son that reduced my outings but the care of my other children as well.'*
>
> *'My son is a very good boy. He does not constantly ask for things, does not disturb you, you can pass one or two hours as if he was not in the room.'*

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.

Table14b. Perceived life changes by the type of impairment of children (Economic Burden)

LIFE CHANGES	TYPE OF IMPAIRMENT					
	Physical impairment (N=41)		Mental impairment (N=53)		Hearing impairment (N=16)	
	N	%	N	%	N	%
Economic burden (N=78)	26	63%	41	77%	11	69%
No economic burden (N=32)	15	37%	12	23%	5	31%

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.

The answer of a couple with a disabled boy illustrated the difficulties resulted from the economic demands:

> *'Economic demands overwhelm parents. We don't know where to go to find the money needed for therapy. We are not supported in the right way because social benefits are too small to cover expenses. Every centre asks for so much money and the burden is unbearable for the parent.'*

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.

A couple with a physically disabled daughter replied:

> *'For us the money required for therapy is not a problem. We want her health to be OK. This is our problem.'*

Table14c. Perceived life changes by the type of impairment of children (Marital Relationship)

	TYPE OF IMPAIRMENT					
	Physical impairment (N=41)		Mental impairment (N=53)		Hearing impairment (N=16)	
	N	%	N	%	N	%
Marital relationshi negative (N=26)	7	17%	16	30%	3	19%
Marital relationshi positive (N=84)	34	83%	37	70%	13	81%

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 influence the perception of a positive marital relationship.

A couple gave the following answer:

> *'Our relationship (between husband and wife) has not changed. It was influenced in the beginning, we were uptight, getting upset easily because we had many problems and we had to bring up another child, too. Now I must say that the problem brought us together and we are closer to each other. Nowadays, though, we still have many problems, I feel my husband supports me. Yesterday he was away and I felt that I was lost without him - I don't know if I am right about making such confessions in front of him. We are joined together, we support each other in this problem. I'm more sensitive and when I reach moments of pessimism, my husband supports me. He is the strong one, or he shows strength to me.'*

The mother of a hearing disabled boy added:

> *'I feel we are more close to each other with my husband now. Our friends and relatives ask us what we say to each other on holidays all those 20 days and long hours just being alone with each other. Though for us all this time is not enough and we want more.'*

Another couple with a physically disabled girl replied:

> *'Our relationship hasn't changed. We have a bigger problem than other couples but we support each other and we try to understand the needs of each other. Of course our social contacts have been reduced because, you cannot take out the two children and leave our daughter behind.'*

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.

The mother of a mentally disabled child answered in an illustrative way:

> *'My husband is indifferent. He cannot understand the problem. He does not care. Because his sister gave birth to two children and within two months they were 10 kilos he turned and said to me that I'm worthless because I have this child I was alone after the death of my mother. I had to face economic difficulties with the shop I owned and I found this man to lean on, but now he asks me what I offer him and I answer two children. He is indifferent. He does not pay for the therapy of our girl or the school outings. I pay for all the expenses alone without his economic support.'*

Another mother admitted that she gives more time to her child than to her husband:

> *'My relationship with my husband has changed because I care too much for my child and he feels neglected. Still I care overly for her.'*

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

The following tables (15a,b,c) give the relation of the gender of children on reported life changes (social activities, economic burden and marital relationship).

Table 15a. Perceived life changes by the gender of children (Social Activities)

	GENDER OF CHILDREN			
	Male (N=63)		**Female (N=47)**	
LIFE CHANGES	**N**	**%**	**N**	**%**
Social activities reduced (N=57)	31	49%	26	55%
Social activities haven't changed (N=53)	32	51%	21	45%

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.

A couple with a physically disabled girl replied:

> *'Our life changed from day to night. Our life changed dramatically because she had this problem. It's impossible not to change when a child with special needs is born in the family, because you have to be with her all the time. She needs you all the time, you cannot do anything else. You cannot close her in a room. Of course our life changed. Now we don't go anywhere, how can we go out when we have to carry 20 kilos in our hands. You don't feel in the mood to go anywhere. It's not that you isolate the child. Conditions don't allow you*

> *to do things. The transport of the child, the difficulties in the place you're going, the difficulty to get a taxi ... She goes to an ordinary school, she has physiotherapy. She goes to the sea for swimming. Wherever we go she comes with us, but conditions make everything difficult.'*

Another couple described the changes in the following way:

> *'Our initial reaction was to isolate ourselves from friends and relatives because our psychological mood was not good. Later, we changed our minds (said the father) and we realised that we had to do something. The instinct for life, to continue your life, gives you strength to overcome this initial stage.'*

The mother of an autistic teenager observed:

> *'My life has changed very much. I think that I do not have the experience of a mother that has two normal children. I also have worries that mothers of normal children don't have. Of course, the relationship with my husband has been influenced because everyday life creates tensions between us. In social matters our life hasn't changed. Our friends remained our friends. We go out, my colleagues know about it. I haven't talked very much, not because I feel ashamed, but because I believe that when you spread the news it is like using the problem you have to get better treatment. I used to discuss it with people who do not care to gossip about it, with those who were thoughtful, or those who were good listeners or who could support me. Calmness in the other person who doesn't have your problem can help you to overcome difficulties. I haven't felt socially rejected. What really worries me is that after having a difficult life as a child (my mother died, my father remarried) now, above all, my son has this problem. When can I rest for a while?'*

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.

The mother of a mentally disabled boy who may not go out very often but the house is open to friends and gave the following description:

> *'We have an open house, day in day out we have friends at home. Our life hasn't changed dramatically. We ourselves tried not to change, because in a sense our life changed since we care for a disabled teenager. I cannot go somewhere with my husband because we have the problem where to leave our boy. He doesn't feel comfortable with many people. So we can not go out, but we invite friends at home in order to have company for ourselves. Our boy is more of a problem to us, the others accept him. We don't want him to disturb a friend's house or to react abruptly. In this way our life changed.'*

The mother of a mentally disabled boy reflected:

> *'I didn't stop any of my activities, though I felt hurt many times, I went everywhere. There were so many times I hurt because my son didn't talk or play with other children. There were children who were taunting my son, parents who rejected me or felt pity for me but I didn't stop. At weddings or christenings I didn't use my child as an obstacle not to go. For my husband it is still difficult to accept. We go everywhere together. I don't care if they will make comments about my child. I will feel upset for a moment and that is all. I haven't isolated my child or myself. That's why I think I've helped my son a lot.'*

Table 15b. Perceived life changes by the gender of children (Economic Burden)

	GENDER OF CHILDREN			
	Male (N=63)		**Female (N=47)**	
LIFE CHANGES	**N**	**%**	**N**	**%**
Economic burden (N=78)	50	79%	28	60%
No economic burden (N=32)	13	21%	19	40%

The mother of a mentally disabled teenager noted:

> *'Economic demands are very high. From the moment we found out that something was wrong, God help him and keep him healthy, I realised that without these expenses we could have had a house which we don't have now. Our son represents money that we could have spent to buy a house if he didn't have this problem.'*

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.

Table 15c. Perceived life changes by the gender of children (Marital relationship)

	GENDER OF CHILDREN			
	Male (N=63)		Female (N=47)	
LIFE CHANGES	N	%	N	%
Marital relationship negative (N=26)	13	21%	13	28%
Marital relationship positive (N=84)	50	79%	34	72%

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.

A couple presented the negative influence of the disabled boy on their marriage:

Mother:

> *'In the beginning my husband blamed me for what happened. I felt guilty because I was married for seven years but I didn't want a child, because I was having the time of my life. We went out every night with friends, we had a big social circle. Now my husband is ashamed of our child. My child is an angel as are the other children, but he is an angel who misses a few wings.'*

Father:

> *'My wife and I are a lost case as a couple. I like desirable women. When I come home and she is covered with a woollen blanket instead of a negligée that does it for me. I tell her that she is spoiling*

> *our son, she is the one to be blamed. With me my son is more obedient. Many times I tell her that I want a divorce.'*

Another mother with a mentally disabled girl presented the influence on the marriage as follows:

> *'Our relationship was influenced negatively. Our girl was difficult to manage, did not stay put anywhere, cried a lot. My husband didn't talk about his work. We still argue about her. We cannot communicate with each other, we are always fighting. I want one thing for the child, he wants another. Generally, he is not interested in our daughter. When I'm not at home, he may not think to give her something to eat. When I go out I have to tell him what to give our girl to eat, or hours may pass and he does not talk to her. I'm not supported by my husband because he wants everything easy for himself. We went on holiday and he didn't give her space, or initiatives. There are times when we argue and he tells me that I'm the one to blame, because I don't let her do what she wants.'*

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.

The mother of a physically disabled girl replied:

> *'Thank God I have a good relationship with my husband which has grown despite the difficulties. He supports me, I can lean on him and he lean on me when we feel psychologically down. He cares for us and provides the best he can for us.'*

A couple with a disabled boy with a mental disability responded:

> *'When we realised the problem, I was desperate because my father had the same disease. It was my husband who supported me and together we faced and facing the multiple difficulties of our child.'*

The father's reply was astonishing:

Father:

> *'I love my boy and because of his problem I love him more.'*

Another mother with a hearing disabled boy answered:

> *'There is a bond between me and my husband. We now have a better understanding of each other. Previously we used to shout when we were in disagree. Now we agree with each other. We don't have alternatives. We sit and discuss all our problems with my son and my other child, or between ourselves.'*

The mother of a girl with a disability confessed:

> *'I have a good relationship with my husband. We struggle together. We discuss our problems and though I suppress him sometimes he can stand it. He is a counterpoise for me and our relationship. He supports me.'*

The only father participating in the study without the presence of his wife said:

> *'In the beginning we had problems accepting it ourselves. We now have problems with relatives. They do not say anything, but you feel that they don't want you. So together with my wife we went everywhere accepting every invitation. If they accepted us, we went again. If not, we did not go again. So we have friends that accept our child and let their child play with our son.'*

The mother of a mentally disabled girl agreed with the above comments by admitting:

> *'Now we go to good friends of ours who accept us and are not bothered by something that our daughter does. If I don't know somebody, I don't visit him. Our life is in accordance with our child's programme.'*

Among the changes reported by parents were those cases in which the father(s) changed working status. Also few a mothers (4) left their job, as well, and stayed at home or they chose different jobs so they could care for the disabled offspring.

The mother of a mentally disabled adult replied:

> *'I changed my job for the sake of the child. I was working freelance and I was going or leaving from work whatever time I*

wanted. I was obliged to restrict myself to an ordinary job in a bank and to follow rules that I didn't know till I was 26. The uncertainty of the future and what will happen later made me want to leave the ambivalence of the private sector so that I might, at some point in time, not have to work and be ready to respond to my child's needs. Now, in the public sector I can cover the expenses of trips abroad, and therapy through my National Insurance.'

A couple caring for a physically impaired girl replied:

> *'Mother: 'Generally life changes when you have children. Before my son I had 5 miscarriages and a lot of misfortune. When you are single you are different and when you have children again different. For us the problem is not very serious. Life would be different if my daughter didn't have this problem. It would be different because we were living in a city, Alexandroupolis and had a first class life. It was more beautiful, better quality of life for the children and for us. After this problem we were obliged to return to the Capital which we didn't want to do.' Father: 'I was working in the Army and I was obliged to change jobs and now I have a business because in the Army I had to be transferred every 2 years and this was difficult since my girl has this problem.'*

The mother with a girl with a physical disability replied:

> *'Of course we go everywhere with our daughter. I don't think that nowadays there are families who do not take their disabled children out. Maybe there are a few in villages that are socially isolated.'*

Another mother who did not feel that her life had changed, said:

> *'Till now my life hasn't changed. I would not have done something more or less because of my son. My social activities have not been reduced. Sometimes, I shout because I'm stressed and tired. We both have a job and two children. My husband can understand my behaviour better than I do.'*

Another mother with a boy with mental disability also stated:

> *'My husband faced more difficulty accepting the disability of our son. Of course he does not show anything to our son. They do homework together, play, go out. My husband and I try to solve problems by discussing them.'*

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.

Table 16a. Perceived life changes by the age of children (Social activities)

AGE OF CHILDREN						
	5-6 Years (N=19)		**7-10Years (N=63)**		**11-15 Years (N=28)**	
LIFE CHANGES						
	N	**%**	**N**	**%**	**N**	**%**
Social activities reduced (N=57)	10	53%	35	56%	12	43%
Social activities haven't changed (N=53)	9	47%	28	44%	16	57%

The mother of a 7 years old physically impaired boy stated:

> *'My social life stopped seven years ago. When I was without a child, I was free to go anywhere. Now I cannot leave the child, even for a while, even to go to my mother, because I'm afraid. Even if we go out with my husband, after a while we return back. From the time we realised that something was wrong (when the child was 11 months old), I have been isolated. We go everywhere with my son. I don't go anywhere alone. I don't care that I do not go out because I feel sad when he is not near me. We are very close to each other. The 2 months that we are on holiday he is always with us.'*

The mother of a mentally disabled 13 years old noted:

> *'Our life changed a lot. My husband is very sociable. It is his style to walk down the street and say good morning to everybody. He doesn't like to be without friends or isolated. After giving birth to our son our social activities were minimised. We used to invite friends to our home two or three times a week. With the passing years we realised that this was not feasible because the programme of the child changed and he was becoming nervous and uptight. So we decided not to have friends mid-week. We have a vacation house where we go every weekend. We celebrate birthdays rarely now because nobody invites our son, but I celebrate my son's birthday and I invite neighbours at the last minute, so they won't be obliged to bring a present but just to come and have fun with my child and their children (together).'*

Other parents noted that their life changed because they were not going out as a couple anymore.

The mother of a 10 years old mentally disabled boy answered:

> *'We invite people home, and we go out, but not as a couple anymore, because someone has to stay with the children. We respond to all invitations, weddings, social activities. We have our problems but we do not exploit them and we try to overcome them. We go on holidays for two months at our places of birth and nowhere else because our money is not enough to rent a hotel room elsewhere.'*

A couple with a physically disabled girl aged 10 years stated:

> Father: *'Our life changed a lot because we cannot go out as before. We do not isolate the child but due to her physical problem, she is getting heavy and we cannot have her in our arms all the time. We cannot leave her alone and go out. We play a whole play so to be able to go out as a couple. This is not easy all the time.'*
>
> Mother: *'We cannot say 'you' stay here for a while because we want to go to the supermarket. I have to take her with me and it is not easy when I have to carry the child and the shopping. After all I have no one to help me. I have to do everything alone.'*

Another couple with a physically impaired 6 years old boy responded similarly:

> *'I cannot go out, because someone has to stay at home with him. It is not easy to trust somebody else. I cannot go to the bakery and leave him alone as I could with my other 2 children. He is young. He can step over, he can lock and unlock doors. Now he is heavy and when I have to go somewhere I have to carry him if I don't have somebody to open and close the carrier. One day I carried him three quarters of an hour trying to find a taxi. It took me a week to recover. We take our boy out (father: 'I on the weekend'), we behave towards him as to a normal child but the situation is difficult. I need help but I do not restrict his outings. We go on holiday for a month at least to his grandparents. We respond as normally as possible.'*

Another mother with a physically disabled girl argued:

> *'Maybe at the expense of us as a couple we do not go out alone. We haven't left the children alone at any time (2 more children). We go*

> *to weddings, christenings all together. We try not to spoil them. We try to keep a balance between discipline and care.'*

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.

The mother of an 8 years old physically disabled girl responded:

> *'Our life hasn't changed at all. It is more full now. I have more obligations but I do not think that influenced us negatively. We go out, we go on holiday more than before. The school ends and after 2 days we leave for our holidays and we return 2 days before the opening of the school. She is very sociable, she hasn't influenced our life. We returned to Athens from Samos (an island in the Aegean Sea) but I do not feel sad. I have lived all my life in Athens. I am glad I am back. In summertime, it was OK but in winter there was no life at all .My husband didn't like the change because Samos is his birth place and he wanted to be there. Our days are more full now. I could complain because I don't have any leisure time but now I'm getting used to it. If I was mourning because of what happened to me I wouldn't have done anything of what I've managed up to now. Thank God the problem is not a mental one. That would hurt me more. I don't think that her problem is serious.'*

Another couple with a mentally disabled boy commented:

> *'You are very lucky, you've found us at home. Usually every weekend we go somewhere. We go on short trips for 2 or 3 days. Last year we went to New York and we reached Florida by car that means 24 hours of travel. Our son was excellent. Other couples who do not face such problems are more isolated than we are because they also have children to care for. I don't know if we are a phenomenon or not but we haven't faced problems with our friends. We always feel welcome. We had invitations for both our children. They try to share their holidays with us. We don't have such a problem. We haven't stopped socialising with anybody. Of course we don't often go out because our friends also have children to care for and mid-week with school and homework I don't think anybody can go out and leave the children. With family work and children's homework it is not easy. I don't think that the problem influenced us negatively and I say that sincerely.'*

Table 16b. Perceived life changes by the age of children (Economic Burden)

AGE OF CHILDREN						
	5-6 Years (N=19)		7-10Years (N=63)		11-15 Years (N=28)	
LIFE CHANGES						
	N	%	N	%	N	%
Economic burden(N=78)	13	68%	43	68%	22	79%
Not economic burden(N=32)	6	32%	20	32%	6	21%

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.

A couple with a young physically impaired child answered:

> Father: *'It is not only that our social life has changed, but economic demands have, also. Having 2 more children who also need a lot, it is difficult to manage.'*
>
> Mother: *'I was working before but now with the problem of my son I cannot leave home. So the money is even less now. He needs additional therapy. We are always taking a taxi to go somewhere though when I had my other 2 children we took the bus. Now it is difficult to carry the child on the bus and nobody gives us a seat. He needs additional equipment in the house and toys, visits to private doctors who need to be paid.'*

Another mother with a mentally disabled boy mentioned:

> *'Now I don't have as many friends as before. My life has definitely changed in terms of economic means because, he needs*

> *additional therapy. Now I've started working at home, because with my husband's income only ,we couldn't manage the cost of living.'*

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.

A mother with a physically impaired girl noted:

> *'Economically the demands were higher, we needed more money, so we opened our own business to respond to the needs of our daughter for additional therapy, equipment, toys.'*

Another family also opened a business, a step that they wouldn't have taken if there was not a problem with their daughter.

They commented:

> *'Our life in economic terms is better. We organised and established a business. Everyday she has to go for therapy and we have to take our car to go anywhere. Generally, she doesn't bring us any difficulty. She maybe unlucky for herself, but she has brought luck to our family.'*

Another mother with a physically disabled girl replied:

> *'My case is exceptional. I'm not working, and I can afford the expense of therapy. I can buy her and provide her with everything and compared to others, she has only a mild problem.'*

Table 16c. Perceived life changes by the age of children (Marital Relationship)

AGE OF CHILDREN						
	5-6 Years (N=19)		**7-10Years (N=63)**		**11-15 Years (N=28)**	
LIFE CHANGES						
	N	%	N	%	N	%
Marital relationship negative(N=26)	5	26%	17	27%	4	14%
Marital relationship positive(N=84)	14	74%	46	73%	24	86%

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.

The mother of a 10 year old mentally disabled boy stated:

> *'The problems with my husband still exist. We haven't overcome them. It is not that he doesn't love the child but he does not accept the child as he is. Our son is provocative, he is persistent, if he wants something, he becomes violent. He is a very difficult child. We don't know how to behave towards him. He is violent towards his sister. Our daughter hides under tables to escape his grasp. He breaks things and doesn't leave anything in its place. When my husband returns from work, he tries to discipline him. My son reacts violently and at the end everybody is shouting at me.'*

The mother of an 8 years old hearing impaired boy reflected:

> *'My relationship with my husband was influenced a lot because of the child. We were about to get a divorce but eventually we overcame it, but even then the relationship is in danger. Our son is difficult. He does not sit still even for a while, so, in order not to exhaust myself I prefer not to go anywhere and to remain inside.'*

The father with a 10 year old autistic child answered:

> *'Our relationship passed through a lot of turbulence. My wife needed a lot of time to acknowledge the problem. She wouldn't accept that something had happened to her. I hadn't realised it also and I continued to placed a lot of demands on her. Though I realised it earlier, I didn't help my wife to overcome it. I remained demanding the same as before. Though my wife had serious problems, I continued my life as before. As a husband I was very demanding about what had to be done at home. This was a big mistake. It hurt our relationship a lot. I could have helped her more.'*

A lot of the tension in spouse relationship was due to the difficult behaviour of the child. Other mothers mentioned that their relationship had not changed because they had a helpful husband.

The mother of an 8 year old tetraplegic girl confessed:

> *'In the beginning, I was depressed. I was taking pills to sleep and I wanted to commit suicide. I was feeling guilty that I'd done something wrong during the pregnancy. I overcame it due to my husband's support of who is a very good person and who helped me to act towards our daughter as normal as possible, not to spoil her, and without being too strict on her. Now, I have given birth to my second child and I feel that my life is normal again.'*

Another mother with an 8 year old mentally disabled girl similarly replied:

> *'I suffered from depression. I used to return from work and was lethargic until the next morning. My husband had taken over everything. He is stronger and though we began to fight over who was to be blamed,, he reacted positively. We found out that it wasn't inherited and we tried for another child. So I gave birth to another daughter and a few months ago I gave birth to our third child, a son. We planned the second pregnancy as a way to overcome the disability of our daughter, because I*

felt I was drowning. We haven't plan the third pregnancy, it happened accidentally.'

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 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.It seems that twochildren in the family are bringing greater balance in the family 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. Probably, this happened because the number of boys in the study is bigger than those of girls.

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

4.2. Effects of children's type of impairment on parents' source of strength

4.3. Effects of children's gender on parents' source of strength

4.4. Effects of children's age on parents' source of strength

4.5. Summary of results and discussion

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.

Table 17. Source of parents' strength by the type of impairment of children

SOURCE OF STRENGTH	TYPE OF IMPAIRMENT					
	Physical impairment (N=41)		Mental impairment (N=53)		Hearing impairment (N=16)	
	N	%	N	%	N	%
Myself (N=34)	15	22%	16	20%	3	12%
My child (N=30)	12	17%	12	15%	6	24%
Myself and my child (N=23)	10	14%	11	14%	2	8%
My faith in God (N=62)	22	32%	30	38%	10	40%
My family (N=22)	10	14%	9	11%	3	12%
No relation with God (N=2)			1	1%	1	4%
My doctor (N=1)			1	1%		

Ps. Parents gave more than one answer to this question.

The mother of a mentally disabled child replied:

> *'I have a lot of faith, I pray a lot and I believe that Mother Mary won't abandon us and will help my son a lot. Along with my Faith in God, my character, which is strong, also helped me. If your character is not strong you cannot overcome such a difficulty. That's why I've decided to have another child. I love children. Could I leave my son alone? My character helped me but, also, as my son progresses, this helps us and gives us strength.'*

Another mother with a mentally disabled girl commented:

> *'I believe that she will progress in the school she is attending now. Mainly I believe in God. I believe that He won't abandon her. I have faith and strength inside me. My mother used to teach my child to make an effort in everything. It is my character and, of course, my*

faith in God that gives me strength. We go to Church very often. I've led my daughter to be religious, also.'

Similarly, the mother of a mentally disabled girl replied:

'I have hope. I believe in God more now than before. There was a time when I was unclear as to what exists and what not. There was a period that I did not believe that anything exists because of what happened to me. Later, I've decided that God 'was testing' me and I've found my faith again.'

Other mothers mentioned that their own temperament was a source of strength for them. Of those 22% had physically disabled, 20% with mentally disabled, and 12% a child 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.

The mother of a hearing impaired teenager said:

'I am not the type of woman who gives up and declaims her calamity over and over again. I had, of course, forgotten how the outside world was. I had three years to visit my sister because the child was either in hospital, or had a virus and was sick.'

Another mother with a mentally impaired boy replied:

'I'm a person with a lot of energy and dynamism. I'm very organised and I do not leave anything to fate. I face whatever difficulty comes up. My aim is to see everything on its bright side but I do not succeed every time. Maybe trying to see things positively gives me strength. When I was younger I was dynamic, leaving nothing to luck, and this helped me a lot. Despite the problem I'm facing, I try to be organised, to care for my children, to cook and keep up my appearance. I'm optimistic and I feel that I will successfully manage any difficulty.'

Another mother with a mentally disabled boy similarly stated:

'Ever since I was young I had to face many difficulties. So, when I had to face my son's problem, I had strength and the experience of facing difficulties, thus, I didn't react very badly. My character gave me strength and the use of my past experiences helped me to overcome the problem.'

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).

A couple with a physically disabled girl replied:

> Father: *'In the beginning we lost our courage but later things improved.'*
>
> Mother: *'Our daughter has so many positive traits so why look at it negatively (her physical impairment)? I do not say this because it is my child but I think she is charismatic and that she will be able to be independent and do something with her life.'*

The mother of a hearing impaired boy commented:

> *'My child gives me strength. When I'm down psychologically I reconsider and say to myself to 'calm down' because I have to bring up my child. I wish for him to be healthy regardless of the fact that he is deaf.'*

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.

Parents with mentally disabled children also perceived that their own child was their source of strength.

A couple with a mentally disabled girl replied:

> Mother: *'Your child's problem gives you strength. Wherever we go we take into consideration what we can do together with our child. You find solutions and you become stronger, better at your work. Of course there are the ups and downs, especially when we visit doctors and hospitals. The future of our daughter is a little better because we have the other children. Our character and our educational status helped us to overcome the difficulty.'*
>
> Father: *'I was sensitive about the disability because in our neighbourhood when I was young we had a boy with a disability and I was one who behaved without pity towards him.'*

A couple with a mentally disabled boy answered that their boy helped them to go against the prognosis of the disability:

> Mother: *'Our son gives us hope and strength. I won't give up easily. I've struggled against all odds and all given diagnoses, in order*

to prove to them that love and mutual support play the most important roles. At the hospital they told me that he would be at best a ' vegetable' and advised me to let him die and not try to keep him alive. I took him home a nothing and I've made him into a child. I had promised myself and my child to take him one day to the hospital on foot. And it happened. When he was three years old he walked. Before then I struggled because he could not keep his head up straight. A doctor helped me. I was holding his head for hours because for 4 months he was on a bed and the nerves were unpractised. I had backaches from holding his head. Although everybody told me that he would never be able to walk I kept my faith and at last <u>we</u> did it. In all this effort my son helped me, it is as if he understood my struggle and was helping me. If his condition was static I might not have had the courage to go on. One step led to another and the more he progressed, the harder we tried.'

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.

The mother of a mentally disabled girl stated:

'My own faith in life helps me a lot. It's I that helps, but also my daughter who is a happy child, who is always smiling, has humour and is not a difficult child.'

Another mother with a physically disabled boy answered similarly:

'I was always a dynamic person, but my child helped me a lot to overcome my initial disappointment by being very sociable, by being attractive to other people. He helps me with his personality.'

The mother of a physically disabled girl gave the following answer:

'I believe that everything will be OK. Though I'm worried about her progress in school, my child herself helps me. She is a good and independent girl. Some people told me that I taught her to be independent. Even if you do not walk very well, you can have a job and you can educate yourself. I tell her often: You don't have a problem and you can decide to do whatever you want to in your life.'

Another mother of a physically disabled girl answered:

'I had a strong desire to give birth to a child. I thank God that I have this child without thinking about her disability. While pregnant, I promised to name her Maria after Mother Mary, if it was a girl. God

gave me a child and I'm happy that I'm her mother. On the other hand, my daughter is so good, happy, wilful, sociable, easy going as a child and these traits of hers give me strength, because I believe that she will find her way in life.'

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.

A couple with a physically disabled girl replied:

> *'We believe in God. He gives us strength. But my husband supports me also. We understand each other and we manage to be close to each other and to find courage to continue our efforts for our child and our two other children.'*

The mother of a mentally disabled teenager replied:

> *'My husband is my major support and also my faith in God. I am optimistic and I try to face and overcome difficulties.'*

A couple with an autistic girl answered:

> *'We think our faith and our hope for a better future helps us a lot. Mainly, it helps that we support each other, one gives strength to the other.'*

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.

Table 18. Source of parents' strength by the gender of children

	GENDER OF CHILDEN			
	Male (N=63)		Female (N=47)	
SOURCE OF STRENGTH	N	%	N	%
Myself (N=34)	20	20%	14	19%
My child (N=30)	18	18%	12	16%
Myself and my child(N=23)	12	12%	11	15%
My faith in God (N=62)	35	35%	27	36%
My family (N=22)	12	12%	10	13%
No relation with God (N=2)	1	1%	1	1%
My doctor (N=1)	1	1%		

Ps. Parents gave more than one answer to this question.

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.

Table 19. Source of parents' strength by the age of children

	AGE OF CHILDREN					
SOURCE OF STRENGTH	**5-6 years (N=19)**		**7-10 years (N=63)**		**11-15 years (N=28)**	
	N	**%**	**N**	**%**	**N**	**%**
Myself (N=34)	3	11%	22	21%	9	21%
My child (N=30)	5	18%	20	19%	5	12%
Myself and my child (N=23)	8	29%	13	13%	2	5%
My faith in God (N=62)	9	32%	35	34%	18	43%
My family (N=22)	3	11%	12	12%	7	17%
No relation with God Faith (N=2)			1	1%	1	2%
My doctor (N=1)			1	1%		

Ps. Parents gave more than one answer to this question.

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

The mother of a 6 years old hearing impaired boy replied:

> *'I believe in God and in fate. Whatever is meant to be will happen.'*

The mother of a 10 years old mentally disabled boy answered:

> *'I believe in God who gives me strength. Though we were sad at the beginning, we didn't place the disability of the child as an obstacle to our activities. By believing I find the courage to overcome difficulties and don't look back, though I'm worried about his life, not ours.'*

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.

The mother of a mentally disabled boy in the younger age group replied:

> *'Our son motivates us to find solutions for his problem. I will do whatever is possible for all my children (2 more children). I think about their future, but for my son it is a necessity to do everything for his protection. Thank God, economically we can afford to find solutions for his future.'*

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 mother of a teenage mentally disabled boy responded:

> *'I don't know how to explain it but I feel a power inside me and I struggle and support both my children. I believe in children and, generally, young people. I haven't done anything extraordinary for my*

> *son. It relaxes me and gives me strength, when I can provide something for him. I'm optimistic and I think I will manage to face any difficulty. Other times I cry for my child, but I overcome it. If I were different we wouldn't be a family, we would be separated. I keep the family close together. Together with my husband we keep the family together. If he were not as good as he is, I don't think that I could keep the family together.'*

Another couple with a mentally disabled boy stated:

> *'Together as a couple we face difficulties and we behave towards our son as if he didn't have a problem. We have two other children and we try our best for all of them. People have strength, they don't know about it until the time comes when they need it. No matter the level of difficulty you find the strength, the power to overcome every thing. All of us have power but we don't know it exists. By realising what has happened, you find the power to face the unpleasant event.'*

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:

> *'A doctor's speech in a seminar helped me a lot. He said I should love my child and accept him as he is. He turned my whole life and my philosophy around. As a next step I found ways to fill my batteries and not to pay attention to what other people say. I do not know, if I'm lucky, but my child is lucky having my husband as a father, who cares for him and hasn't left our 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

4.2. Effects of the children's type of impairment on the comparison with other families

4.3. Effects of the children's gender on the comparison with other families

4.4. Effects of the children's age on the comparison with other families

4.5. Summary of results and discussion

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.

Table 20. The comparison with other families by the type of impairment of children

	TYPE OF IMPAIRMENT					
	Physical impairment (N=41)		**Mental impairment (N=53)**		**Hearing impairment (N=16)**	
COMPARISON WITH OTHER FAMILIES	**N**	**%**	**N**	**%**	**N**	**%**
We are different compared to other families (N=35)	14	34%	18	34%	3	19%
We are similar compared to other families (N=55)	22	54%	21	40%	12	75%
We are different but in positive way (N=12)	3	7%	7	15%	1	6%
There are differences and similarities (N=7)	1	2%	6	11%		
I don't know (N=1)	1	2%				

The mother of a hearing impaired boy said:

> *'Comparing my family to other families close to us, I think that we do not differ. Maybe, the others think that we have differences, but I don't care at all. We don't have fights, separations, problems with my husband. I have a very close relationship with my husband and together we discuss our difficulties.'*

The mother of a mentally disabled boy replied:

> *'We are a very close family, we face difficulties together and we think that everything will turn out OK. I don't know if other families are as happy as we are.'*

A couple with a mentally disabled girl answered:

> *'I don't think that we are different to other families. We have a bigger problem to face. Our difference is that we have to care more for our disabled daughter than for our other child. There are no children without problems.'*

Another mother with a boy with mental disability replied that although the disability of their child the family members are close to each other and this makes them different from other families:

> *'You might laugh when I tell you that my family is extraordinary, but in a positive way. Although we have the disability of my child, we are very close to each other, and we understand the needs of each other. We are friends with my child and we talk about everything. There is a trust between us and I tell him to talk to me about everything and to not hesitate for a minute. Not many parents have so good a relationship. We have something exceptional.'*

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.

The mother of a mentally disabled girl stated:

> *'We are different from families which aren't dealing with a disability. Precisely this disability makes us different from others.'*

A couple with a physically disabled girl replied:

> *'The families I think are different. I'm very stressed and I pray to God for health and strength to overcome difficulties.'*

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.

Table 21. Comparison with other families by the gender of children

	GENDER OF CHILDREN			
	Male (N=63)		Female (N=47)	
COMPARISON WITH OTHER FAMILIES	**N**	**%**	**N**	**%**
We are different compared to other families (N=35)	19	30%	16	34%
We are similar compared to other families (N=55)	32	51%	23	49%
We are different but in positive way (N=12)	8	13%	4	9%
There are differences and similarities (N=7)	4	6%	3	6%
I don't know (N=1)			1	2%

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.

Table 22. Comparison with other families by the age of children

	AGE OF CHILDREN					
	5-6years (N=19)		7-10years (N=63)		11-15years (N=28)	
COMPARISON WITH OTHER FAMILIES	**N**	**%**	**N**	**%**	**N**	**%**
We are different compared to other families (N=35)	5	26%	18	29%	12	43%
We are similar compared to other families (N=55)	12	63%	34	54%	9	32%
We are different but in positive way (N=12)	1	5%	6	10%	5	18%
There are differences and similarities (N=7)	1	5%	5	8%	1	4%
I don't know (N=1)					1	4%

The mother of a young teenage boy stated:

> *'I had to raise three children together with my son who had a disability. In the beginning I was working outside the house. After the birth of my son I didn't think I would work again because I couldn't imagine a stranger would care for my children in the same way as I do. We are very close to each other within the family. We have the children with us at celebrations and vacations even though they are 18 and 17 years old. Other*

> *families don't have this closeness and harmony. Maybe the problem brought us together.'*

Another mother of an 8 years old girl replied:

> *'We are similar to other families. We have just tried not to be influenced by situations outside our family. We don't interfere or snoop around other people's lives. If we can help, we try our best to comfort and support each other because of this problem. I'm not different, I just have a more correct way of thinking about the problem I'm facing.'*

Lastly, a couple with a 10 years old girl answered:

> *'We are very similar to others. We have similar anxieties, similar problems when we compare ourselves to our friends' families. When you care for your children, you always have worries.'*

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). 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 13, 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. The families more often perceived themselves as similar to other families when they had more than one child, tended more often to have intact social activities, had no economic burden ($p=0.01$), and tended more often to report a positive relationship with their spouse.

SECTION 5

POSITIVE CONTRIBUTIONS OF THE DISABLED CHILD TO THE FAMILY

5.1. Introduction

5.2. Effects of children's type of impairment on perceived positive contributions of the child to the family

5.3. Effects of children's gender on perceived positive contributions of the child to the family

5.4. Effects of children's age on perceived positive contributions of the child to the family

5.5. Summary of results and discussion

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).

Table 23. Positive contributions by type of impairment of the children

TYPE OF IMPAIRMENT						
	Physical impairment (N=41)		Mental impairment (N=53)		Hearing impairment (N=16)	
POSITIVE CONTRIBUTIONS	**N**	**%**	**N**	**%**	**N**	**%**
Brought us together (N=50)	19	32%	20	25%	11	42%
Change in personality (N=71)	25	42%	38	47%	8	31%
I have a child (N=29)	10	17%	13	16%	6	23%
Found real friends (N=2)	1	2%	1	1%		
Non reported (N=14)	4	7%	9	11%	1	4%

Ps .Parents gave more than one answer to this question.

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.

A mother with a hearing impaired child replied:

> *'There are positive and negative points that my disabled son brought to our lives. Among the positive ones, firstly he brought us together both as a family me and my husband. We can*

> *go on holidays for one month alone and we don't get bored. On the contrary, we always want more time together.'*

The mother of a mentally disabled girl answered:

> *'Our daughter brings the smile to our faces when things are difficult for us. She helps us with her humour and that naive laughter of hers. Even though, in the beginning, we had to face the difficulty of caring for her and to find help. In the end, I believe that she helped us to stay united as a family.'*

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.

The mother with an autistic teenage boy replied:

> *'You realise that calamities happen not only to other people but to you as well. You become more sensitive as a human being and you recognise the real problems in life. Your theory about the world changes dramatically.'*

The father of a physically disabled girl answered:

> *'For me there is no bad thing in life and there is no need to blame God for everything. Even though, we have to face difficulties we have to Praise the Lord, because through the difficulties you get to know yourself better, how much you can bear, you find reasons to offer something to another person and with all these you go beyond the ordinary as a human being.'*

Another mother with a mentally disabled girl answered:

> *'I was stronger in character than my husband. Through the pain, I realised the true value of things in life. I realised that life is not easy, but has many problems and I had to become stronger to overcome them.'*

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.

The mother of a mentally disabled girl added:

> *'You have something to gain from all your problems. I used to care about little things. Now, I try to be realistic, not to care about details. Now I see everything from a new perspective. It is more real my life now. I'm more humanitarian and not materialistic. As an educator, I used to think that 'poor' students have parents who don't care for them. Now I know. All people have rights in life.'*

Other parents, perceived that their personality changed because they became more sensitive.

The father of an autistic girl replied:

> *'I became more sensitive to the difficulties people have to face. As a teacher in a high school I feel the enormous joy of a 'poor' student when I give him or her a higher grade and help himself to pass the class. If you are not generous in life you're a failure.'*

The mother of a hearing impaired boy answered:

> *'I became sensitive to people's problems. Sensitivity exists but we do not show it often, but it is this sensitivity that makes you human.'*

A couple with a physically disabled daughter explained:

> *'In the time before we faced our daughter's disability we were sensitive about problems, but we dealt with them logically. We believed in the integration of the disabled child in general, but in practice we didn't want him/her in our class (both elementary teachers). Now we have come to realise the subtlety of the problem. Our way of thinking has changed because it was very wrong. Unfortunately, we learned our lesson the hard way.'*

Other parents, on the other hand, became stronger due to the disability and the care of their offspring. They learned to live every single day of their lives.

The mother of a mentally disabled boy replied:

> *'I have changed very much. You deal with people, life or my needs in a different way. I became stronger to reactions and actions of people. I became more receptive to my friends. I'm visiting friends not because I'm obliged to be, but because I want them and they want me. I became more persistent. I want more things from people, I do not complain about my problems. I live for today and I try not to make plans for the future.'*

Another mother with a teenage mentally disabled boy answered similarly:

> *'The disability of my son hasn't changed the course of my life. It was the same before the birth of my son and after. It changed my psychological world. It made me not more delicate but stronger.'*

There were parents who responded that the very existence of the child in the family was a positive contribution.

The mother of a mentally disabled boy stated:

> *'He brought so much joy and happiness to us, the happiness that a child brings to a family. If he had a more serious problem maybe we would not have the courage to deal with it, we would decide not to have another child because we would be more afraid.'*

The mother of a physically disabled boy answered:

> *'A child came into my life and I love him because he is my 'blood' even though he has a problem. I cannot give birth to other children and not only love him but I adore him.'*

The mother of a physically disabled girl replied:

> *'The happiness that my daughter brings to us I couldn't change for anything in the world even though she has a problem. I tell her that she made me enormously happy, that life without her is unthinkable and my daughter replies: 'I know that because from our life together, all mothers don't love their children the same way.'*

Another mother with a mentally disabled boy responded:

> *'The prospects for my son were negative. It was a challenge to keep him alive despite his problems. The doctors couldn't say anything, after all they are not God. A force kept me trying. The development is totally different from the beginning.*

> *My son is alive. I should be brimming over with happiness, shouldn't I ?'*

Similarly another mother with a mentally disabled boy answered:

> *'It is good that my son is alive. I'm glad I have him despite his disability. I love him and he will always be my child and I'm happy with his progress.'*

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.

Table 24. Positive contributions by the gender of children

	GENDER OF CHILDREN			
	Male (N=63)		**Female (N=47)**	
POSITIVE CONTRIBUTIONS	**N**	**%**	**N**	**%**
Brought us together (N=50)	28	45%	22	47%
Change in personality (N=71)	41	44%	30	41%
I have a child (N=29)	18	19%	11	15%
Found real friends (N=2)	1	1%	1	1%
Non reported (N=14)	5	5%	9	12%

Ps .Parents gave more than one answer to this question.

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). However, the difference was not found statistically significant.

Table 25. Positive contributions by the age of children

	AGE OF CHILDREN					
	5-6 years (N=19)		**7-10 years (N=63)**		**11-15 years (N=28)**	
POSITIVE CONTRIBUTIONS	**N**	**%**	**N**	**%**	**N**	**%**
Brought us together (N=50)	7	24%	27	28%	16	38%
Change in personality (N=71)	11	38%	43	46%	16	38%
I have a child (N=29)	8	28%	15	16%	6	14%
Found real friends (N=2)			2	2%		
Non reported (N=14)	3	10%	7	7%	4	10%

Ps .Parents gave more than one answer to this question.

The mother of a mentally disabled teenager replied:

> *'I believe that as a family we united and used our strength to solve the problem with my son. If we didn't have this problem*

> *maybe we would have other problems or start habits, which aren't good for the family. All families pass through stages and transitions. I have been married 20 years. Ten years of marriage routine and boredom bring difficulties into the marriage. For us the positive thing is that we are very united, maybe due to our son's problem. We have a problem and our attention is focused on this problem. We don't have time to feel bored and to start bad habits which can 'kill' a relationship.'*

The mother of a mentally disabled girl replied:

> *'I show more patience now. My relationship with my husband improved, and we communicate with each other better. My husband was never at home before the birth of our daughter. Now he does not play cards any more, he plays with her. He is very close to me and our family.'*

The father of this girl described his girl 'as the beauty of the home.'

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.

The father of a physically disabled girl confessed:

> *'I feel more human and I'm happy about it. I'm not saying that because our child face this problem but for another reason, too. We had another girl who died and we were unhappy because we missed her childhood. Maybe the prolonged care that our daughter needs will compensate for what we missed. Maybe God takes something and gives you something in return to compensate. With our daughter the part which was missing came and made our life more complete.'*

The mother of a mentally disabled girl reflected:

> *'I had a belief that in my life everything would be OK. The problem of my daughter made me see many things differently. I became more sensitive, more human. I was left to feel the pain, the sickness, the child. I must confess that I came to love my other children through my disabled daughter. It was my first child (I have 3 more) and because she had a problem I'm now more ready to find excuses for people's actions and to be more forgiving. My husband loves children and he is sensitive. I must confess that I wasn't. Everybody should be ready to deal with difficult circumstances and should learn to live with his/her problems.'*

Other parents realised what things truly have value in life. A couple with a physically disabled daughter answered:

> *'We found the true value of things in life. We have hope and are thinking of the future. We have 2 more children (pregnant with another). The thought was that if we had more children they will share the burden of caring for their sister.'*
> Mother: *'We decided to have other children not only for this reason but also because the pain is easier to bear when you have other children.'*

Another mother with a boy with mental disability replied:

> *'I became more down to earth. In the past, (I got married when I was fourteen) I thought beauty and entertainment were important. From the time I had to face my son's difficulties, I've realised that the most important thing in life is health.'*

The mother of an autistic teenager was revealing in her statement that her past experiences helped her to deal with her son's disability:

> *'I knew about problems in life because I've lost my mother very early. Very early I came to distinguish reality from illusion. I became more sensitive, wiser and stronger. I don't allow myself to be sad about anything. I've learned to consider health as a gift, a very important gift, to live each and every moment of my life and not make plans for the future. I've learned that I can control very few things in my life and I don't feel guilty about my son's condition.'*

Similarly, a couple with an autistic girl answered that they realised the joy of giving and enjoying simple things in life :

> *'As individuals we realised how much simple things are important in life. The ones which we don't pay any attention to, under ordinary circumstances. We realised how much people need each other. How many things you can offer to a person and the joy of giving.'*

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.

The mother of a mentally disabled teenager replied:

> *'There is a good thing about these children. My son in particular has shown great love to me, more even than my*

> *mother. You cannot understand what I'm telling you as a mother, woman, individual. I feel that this child not only loves me but that I'm his oxygen. It is the most astonishing feeling that a person can experience and (cries).'*

Another mother with a mentally disabled boy similarly stated:

> *'My son gives true love, too much love. You love the children and they love you and it is the most important thing in a mother's life. Through fire and iron you are formed as a person.'*

Finally, the father of an autistic boy concluded:

> *'My son taught me what the meaning of love is, what love consists of. It is the everyday 'I love you' that you get when you try to communicate with an autistic child. The attempts to get him out his isolated world. He gave me a dream come true - to become a teacher. I'm teaching my own child.'*

The mother of a mentally disabled girl perceived that she learned how a child should be brought up:

> *'I've learned how a child should be brought up. Because most of the children grow up by chance. I became more patient and don't say 'never' because everything is possible. The substance of things is not always apparent, to the bare eye. I want to be (psychologically) calm, to feel good about myself and I believe in God, something that before was an abstract. I enjoy small pleasures in life. Sometimes, I deliberately leave a problem unsolved or don't even want to see that there is a problem. Maybe this helps me to cope and have the courage to continue. I'm not interested in money.'*

The father of an autistic girl similarly answered:

> *'We learned how a child should be brought up. I think parents do not care for children as much as the child needs. They think the child does not need them and they provide care through their own needs and demands and not their child's. They care about their being a good student and not that much about, for example, his/her emotional stability or sociability.'*

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.

SECTION 6

NEEDS FOR SERVICES

6.1. Introduction

6.2. Effects of children's type of impairment on perceived needs

6.3. Effects of children's gender on perceived needs

6.4. Effects of children's age on perceived needs

6.5. Effects of children's age on perceived needs

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.

Table 26. Perceived needs for services by the type of impairment of children

SERVICES	TYPE OF IMPAIRMENT					
	Physical impairment (N=41)		Mental impairment (N=53)		Hearing impairment (N=16)	
	N	%	N	%	N	%
Special schools (N=52)	9	7%	33	21%	11	26%
Multidisciplinary centres (N=41)	27	22%	13	8%	1	2%
Trained specialists in disability (N=34)	12	10%	15	10%	7	17%
Support for parents (N=87)	29	24%	46	30%	12	29%
People with positive attitudes on disability (N=33)	16	13%	12	8%	5	12%
Sex education (N=4)			4	3%		
Support from the State (N=13)	6	5%	6	4%	1	2%
Information Centres (N=42)	17	14%	20	13%	5	12%
Respite Service (N=11)	6	5%	6	4%		

Ps. Parents gave more than one answer to this question.

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).

The mother of a mentally disabled girl replied:

> *'More schools, more special schools. These schools should have a gym and all the necessary equipment for a special school. A place where the children can be occupied with drawing, clay, etc. A place that children would work for more hours.'*

The mother of a hearing impaired boy explained:

> *'When you go to a special school, the children should be in the category responding to their disability. You cannot have a child with a mental disability and a child with a physical disability and work with both children in the same class. Also you cannot have an autistic child with a child with physical disability. These children are difficult to match in a group. Now I'm thinking about the future of my child. I should like it if there was a private school equipped with all the necessary instruments, team, programs. I don't care how much it would cost me, I'm not wealthy, but I care that my child should receive the maximum help. Now I'm able to pay for private lessons in speech therapy but I don't know if I shall be always be able to take her there, because I have another child who needs my care too. I would prefer to be able to have all the therapies at school, each day, for the hours needed. Unfortunately, the help comes from the family and not from the school.'*

Another mother similarly stated that there should be special schools for each disability:

> *'The school that my son goes to, is a school appropriate for him but it is very far from home. I wish that there were more schools like that so that a six year old, like my son, would not be obliged to go so far to his school. It is needed the establishment of schools according to the child's disability. My son cannot go in a school with physically disabled children or with Down Syndrome children. George cannot go to a school where children have severe problems but should go to a school for children with mild disabilities.'*

The mother of a mentally disabled boy expressed her own problem with special schools:

> *'In schools there are children with different problems. My son is distracted by noise and in his class there are behaviourally disturbed children and this is very bad for my boy. I don't trust anybody to care for him. We need a school with all disciplines, speech therapy, physiotherapy etc. and where the child would have a full program. But for a school like*

that you have to pay a lot of money. There are not a lot of special schools for these children and not appropriate trainers, teachers or programs.'

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 physically impaired girl replied:

> *'A multidisciplinary team is needed where the parents may get all the available information and not go from place to place to find what they can do for their child. This team would give information not only for the disabled child but also for the parent.'*

The mother of a mentally disabled boy answered:

> *'There is a need for a public foundation with appropriate professionals and paramedics where the parent would get all the answers and not 'shopping around' to find what is wrong with their child. The people in such a foundation would offer suggestions for solutions to problems concerning the particular special child. But the State only promises. You try to find somebody to help you, to tell you what to do. Everybody is an expert but nobody helps.'*

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

> *'Everything depends on parents, on our strength because we are open to the problems and listen to given suggestions. We try to find solutions for ourselves and learn a few things, and generally we try our best for our child. Nobody, otherwise, will come and tell you that you have to send the child to a special school, or to be advised by a psychologist, or how social security will help you. We have to search for everything by ourselves. If there was an information centre it would be so different for us. A more responsible solution to our problems.'*

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

> *'We are searching by ourselves to find what services or financial aid we are entitled to have. We are not given appropriate information. The parent with such problems doesn't know where to go. There is not one information centre to guide you concerning the condition of your child. The State does not provide what is needed. We live in uncertainty all the time. Along with the need of a centre with a variety of specialities for the care of the child, it would also be helpful for an information or advisory centre for parents with psychologists and teachers who would follow the progress of the child and give answers to parents' questions.'*

The mother of a mentally disabled boy agreed by stating:

> *'From the day the child is born, it would have been good if there were people to support parents and advise them where to go so they would not become victims of irresponsible doctors, who take advantage of us, who let time pass without a reason and allow the problem to become bigger. My paediatrician didn't advise me what to do. We need to be told where to go for the child, if we have any hopes, and so that we don't make mistakes. We need information.'*

Parents asked for information on how to behave to their child. The mother of a mentally disabled boy revealed:

> *'It is very difficult bringing up a child with special needs. We need information on the disability, we need support as parents on how we should treat the child. Nobody helps, neither psychologists nor educators. They see the child as a source of money. I don't know if society later will take advantage of him. That's why I want him to be independent and have a job.'*

The mother of a physically disabled girl explained:

> *'We need information on how to behave with our special child. Many children are taking advantage of their problem and behave as they wish.'*

Education for parents

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

> *'What we need is a school for parents. Something like the Open University. I need to be taught about my child, not something general. She is young and I can be taught and show her things. It is very important*

> *for the parent to know how and what to teach to his child. It would be very effective also to have collaboration between parents and teachers.'*

The mother of a mentally disabled girl further commented on the idea of an Open University:

> *'And, of course, parents have special needs, too. Something like an Open University with flexible timetable for those who are working or not and where parents could get advice on practical matters. As an example, what can teach him to do. These meetings could be held all year round, periodically, so that parents would be supported. We face different problems at different periods in the life of our child and so feedback from professionals should be continuous. Then, the support would be available in a sequence of time. The parent would, then decide when a circle of knowledge is complete and stop attending.'*

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:

> *' For the parents there should exist support by counselling, also. We need to talk, exchange ideas. Though you have a child with special needs, you should not always be with parents of children with special needs. You need to talk with people who don't face this problem.'*

The mother of a physically disabled boy replied:

> *'It would be good if there were an association or group where we could meet each other and talk about our problems.'*

The mother of a physically disabled girl expressed the need for the formulation of parents' groups:

> *'We need groups for parents.I don't know how I would be involved but I would like to hear advice or ideas. Instead of hiding and isolating yourself, it is better to hear some other ideas. You adopt what you need the most.'*

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 ($p=<0.05$). The mother of a physically disabled girl replied:

> *'It would be good if there was a centre covering different therapies such as speech therapy, physiotherapy and swimming pool, a place that she could move easily with her wheelchair, properly built for children with physical difficulties. In the school she is attending, I've argued with the head- master to change the classroom to another on the first floor but again I have to carry her to her class because there are steps that she cannot walk up. Every school-break I'm carrying her to the playground or the toilet otherwise I have to restrain her. I cannot leave her in the class. In the afternoon paying for private lessons for speech therapy and physiotherapy.'*

The mother of a mentally disabled daughter added:

> *'There is a need for a public centre where the child could have physiotherapy, speech therapy etc. Not all parents have money for private lessons at home.'*

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:

> *'Generally in Greece people are prejudiced towards disabled people because they don't know much about them. In schools, children from elementary to high school, should know about disabled people, should learn what they can offer to others and not only what to take from them. If they learn this, we will become more humane and civilised.'*

A couple with a physically disabled girl argued:

> *'All these efforts for people with special needs make for a great imbalance in equality, and do lead to inclusion. There should be a change in attitudes in the relationship between the doctor and the patient. Our experience is that they of deal with us and look at us as resource of money and nothing more. When you have such a problem you need a*

> *different approach, more humanitarian, most of the time this doesn't exist.'*

The mother of a mentally disabled girl further target the problem:

> *'Nothing exists. Since I found out about my daughter's problem I didn't find anything to help me. Society should start realising that there are people with disabilities around them and that they are not there to be pitied. They are people with needs and feelings. They are not there to deserve the pity of others as they show on TV.'*

The mother of a hearing-impaired boy added:

> *'There is a need for trained people on deafness who could help deaf children and appropriate schools for them.'*

The mother of a physically disabled boy similarly answered:

> *'There is nothing in Greece. From every aspect there are a lot missing from professionals, doctors but more importantly from organisations. You cannot find your rights anywhere, you are not treated properly.'*

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.

The mother of a physically disabled boy replied:

> *'The State should give us a pension that would help the child and cover all his/her needs. So I would be able to hire a baby-sitter when I'm not feeling well and need help. I have 4 children and many economic problems. I needed a carrier for him but I didn't have the money to buy it. My husband has been unemployed 4 months now. It's not that we need the money for us but for our children. We got used to live without a lot of money but what about the children who have their own needs?'*

A couple with a physically disabled daughter added that it would be better to design programmes to help the child and the family instead of giving to each family such a minimum financial aid:

> *'The economic aid that the State offers is not enough, just a pittance. It is too little to receive one hundred drachmas per month. It is the least you can do for the family. It would be better if the State gave money for good programs that support the child and the parents.'*

Another couple with a physically disabled boy expressed their complaints that parents who receive financial aid from the State usually are treated with suspicion:

> *'They treat you suspiciously when you want to take the aid which the State gives to parents with special children. I got so furious on day that nowadays I'm not going to accept the aid. They treat you as if you want to take advantage of your problem. I left crying and saying to an employee 'I hope God does not give you such a problem.'*

The mother of a mentally disabled boy responded:

> *'I think that the State has rather abandoned the children with special needs. My son receives financial aid of 21.000 drachmas per month. What can I do with this money? My son has had 3 operations and needs 5 more. With the money we are receiving we cannot cover any of the expenses. We are obliged to pay for the child, God keep him well, for his whole life but if the State offered more money it would be better. The State should be involved more in a financial sense because a child with disabilities has many needs.'*

Parents asked for respite care (5% and 4%) though, the term does not exist in the Greek language.

The mother of a mentally disabled boy stated:

> *'There are so many things the State can offer. Programs of help within neighbourhoods, athletic centres, respite care when I'm sick. Because when I'm sick, my husband has to leave his work and stay at home. I need someplace where I can leave my child in cases of emergency. I cannot leave with just anybody because he has spasms. But on the State's part there isn't anything. Help may exist somewhere but I, myself, haven't discovered it yet. If I want to say it in the correct words, only on a personal level can somebody help you.'*

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.

> *'Nothing exists for the care of the child or parent. Parents with a disabled child are desperate. Nothing organised exists. The parent has to seek by himself what is best for his child. And, of course, you don't know what is best. Your perception of his needs will guide you to make wrong or right decisions.'*

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

> *'It would be good if there were evening classes for the children. Many parents pay for private lessons but it is not feasible to pay money all the time.'*

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.

Table 27. Perceived needs for services by the gender of children

SERVICES	GENDER OF CHILDREN			
	Male (N=63)		Female (N=47)	
	N	%	N	%
Special schools (N=52)	31	49%	21	45%
Multidisciplinary centres (N=41)	24	38%	17	36%
Trained specialists in disability (N=34)	22	35%	12	26%
Support for parents (N=87)	49	78%	38	81%
People with positive attitudes on disability (N=33)	16	26%	17	36%
Sex education (N=4)	2	3%	2	4%
Support from the State (N=13)	24	38%	18	38%
Information Centres (N=42)	8	13%	5	11%
Respite Service (N=11)	6	10%	5	11%

Ps. Parents gave more than one answer to this question.

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. The next table(28) shows the effect of age on parents needs.

Table 28. Perceived needs for services by the age of children

SERVICES	AGE OF CHILDREN					
	5-6 years (N=19)		7-10 years (N=63)		11-15 years (N=28)	
	N	%	N	%	N	%
Special schools (N=52)	10	17%	26	14%	17	23%
Multidisciplinary centres (N=41)	9	16%	25	13%	7	9%
Trained specialists in disability (N=34)	7	12%	22	12%	5	7%
Support for parents (N=87)	15	26%	50	27%	22	29%
People with positive attitudes on disability (N=33)	5	9%	22	12%	6	8%
Sex education (N=4)			1	1%	3	4%
Support from the State (N=13)	1	2%	9	5%	3	4%
Information Centres (N=42)	11	19%	23	12%	8	11%
Respite service (N=12)			8	4%	4	5%

Ps. Parents gave more than one answer to this question

Special schools

A mother with a mentally disabled child aged 8 years gave a challenging reply:

> *'There is a need for schools for each disability. I do not like my daughter to attend a school for physically disabled children because she*

> *might imitate the behaviour of others and have more problems. Teachers should have more training about the problem of these children.'*

Another mother with a 10 year old mentally disabled boy added:

> *'We need schools for mild disabilities or ordinary schools to accept our children.'*

The mother of an autistic 13 year old teenager pinpointed the need for schools or independent units for autistic children:

> *'There does not exist an independent unit or school which deal with autism and can take care of a child from kindergarten to the point that he/she would reach the optimum of his/her potential. There should be training for independent living and training for a job even in sheltered workshops since the possibility of finding a job in the open market is impossible.'*

Finally, the mother of a mentally disabled teenager also required the establishment of units for independent living:

> *'We will strive for our son to have everything in his life. But if he cannot live independently, what's his future? In an asylum such as Dafni which is hell? I've visited these places. There is a need for the establishment of units for independent living. A place that I could leave my boy, or sheltered workshops. I don't want asylums, no more storage of people. The personnel should care for them, not tie them up, not leave them naked, no more horrible things like the Leros institution.'*

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. As a father commented:

> *'Everything should be organised with greater responsibility because in hospitals and schools the one that has connections gets better treatment, and the one that does not have connections cannot do anything.'*

Multidisciplinary centres

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

> *'There is a need for a centre that has all specialities for dealing with the whole spectrum of difficulties which the child is facing.'*

The father of a 6 year old boy added the need for organised centres:

> *'There is a need for organised centres with school classes in the morning and therapy in the afternoon. My son does not have mental problems. It could be good if there were these centres where children would be occupied for a longer time, without parents being obliged to pay private lessons at home. Parents could then use the money for other purposes ways.'*

Information centres

Parents requested the establishment of information centres also regardless the age of their offsprings. The mother of a 7 year old mentally disabled boy stated:

> *'We need information as parents. There are parents who keep their disabled children at home until they have to send them to school at the age of six or seven. They are enrolling the child in an ordinary school and they are shocked when they are told that their child should follow the program of a special school. There should be information given at the hospitals when the child is born advising parents where to go.'*

A couple with a 6 year old physically disabled boy replied that parents need training through seminars on various matters concerning the disabled child:

> *'We parents need seminars concerning our children. We have learned so many things that we didn't know at a seminar that we attended recently.'*

A mother with an 8 year old boy with mental disability commented that parents need instructions and advice on behavioural management techniques:

> *'There is a need for parents to have information about the condition and development of their child. Many parents are searching for*

> *answers and solutions all alone. I need somebody to give me instructions and advice on how to behave towards my son.'*

The mother of a 10 year old mentally disabled child suggested as important the need for psychological support:

> *'We need support for families with disabled children and not only financial support but also psychological one. There are families, indeed, with great economic problems and they need financial support. I have sometimes reached a point when I faced economic problems and I know what these families have to deal with, but mostly we need psychological support.'*

The mother of a 15 year old mentally disabled teenager added the need of receiving advises on various matters:

> *'I have the need to receive advice from professionals of different disciplines concerning my child. There are many times that I give up. No matter what my will and strength I giving up. Problems are getting harder to deal with and when I think about puberty, what will I do then with my son? There is no provision or social security. If I want to help the development of my son to develop I have to pay a lot of money and when I don't have it I understand how the mother feels who doesn't have money at all. I can offer to help my son but later on ..... People caring for my son have to be paid and paid well. When people, professionals, are not paid they lack the initiative to work and offer to the child the very best opportunities.'*

Similarly, a mother of an 8 year old physically disabled daughter replied:

> *'There is nothing for the parents. A place where one can get information and advice. They should learn how to behave to a child with special needs. Here, it is not like abroad. There are children from rural areas, whose parents do not have any support. They cannot offer anything to their child and they come to Athens leaving their lives behind. Sometimes the family is divided. The one parent and the disabled child are living in Athens and the other parent with the other child are in another city.'*

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:

> *'In the public sector they employ disabled people, especially physically disabled, who are taken advantage of because of their problem or they are given a low position that has no prospects. I want the State to give jobs to disabled people not out of pity but because they can do the job as well as a normal individuals. It is not good to live with other people's pity. I want my child to be independent and I want her to do the best she can. If the State provide appropriate training to these children then they can become efficient employees.'*

Another mother with a 10 year old girl pinpointed the need of vocational training:

> *'These children should be employed later on in a job and should be trained for the demands of this job. There is a need for social policy, more understanding and care for these children.'*

Finally, the reply of a couple with a 7 year old boy with a physical disability represented the view of many parents on the social provision:

> *'Help from the State? Unfortunately the State keep giving promises without keeping them. Just words. The State does not doing anything for children with special needs. If you need anything special then you are pitied. And if you don't live in Athens and you have a special child, it is a disaster, your hands are tied.'*

And a couple with a 9 year old mentally disabled girl complained:

> *'The State treat the parents with indifference. There is nothing for parents or children. Parents are tired of searching; its like swimming in an ocean.'*

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 and11-15 years required respite care.

The mother of a 13 year old autistic boy replied:

> *'A place for respite care. My husband needed an operation and I didn't have a place to leave my son. If I get sick who is going to care for him? Even if you are dying you need to be awake. My son has autism and*

> *when I am ill and I'm in bed, my son asks me to get up because he is accustomed to seeing me awake.'*

And the mother of a 9 year old mentally disabled boy added:

> *'We need respite care. We don't have anywhere to leave the child and so consequently we become isolated.'*

Parents of older children inquired after the possibility of sex education, a finding significant ($p=<0.05$). A mother with a 15 year old teenager with mental disability suggested:

> *'These children should have sex education or should be sterilised so they may have joy in their life, because sex is a form of pleasure and satisfaction. I told that to a group of parents and this caused disagreement. They told me to shut my mouth and say no more. But the truth is that if this cannot be controlled there is a need for education on these matters. We asked for units of independent living, we dream our children could live together in an independent house and not in an asylum but we don't want to talk about sex education. It is like hiding behind our fingers.'*

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

CONCLUSIONS

1. Introduction

2. Critical review of the methodology used

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3.1. *Daily difficulties*

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5. Contributions of the Study to Research and Further Developments Needed

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.

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.

3. Summary of the findings

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 influenced 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 the 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 were 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 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 influence 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.

4. Implications for Intervention

In Greece, there are not many studies exploring the world of parents with disabled children. Knowledge of family functioning in Greece could provide the necessary basis for promoting the acquisition of new competencies, building upon existing capabilities and the mobilisation of resources to meet the needs of each family as Trivette et al. (1990) and Hornby (1994) suggested. Following the family systems approach it is necessary intervention attempts to focus toward the whole family if we want to create a balanced family functioning. In family intervention programs parents could develop communication competence between spouses, maintain family flexibility and family boundaries, balance the disability with other family needs, and engage in active coping efforts (Cooley,1994). Bailey and Simmeonsson (1988) stressed the need for clinicians to be aware of the differences between their own values and those of the parents in order to plan effective intervention. Usually professionals come to partnership with the parents of disabled children holding stereotyped views of how they respond to the disability. Thus, such a relationship holds no respect and reciprocity between the partners, so intervention can not efficiently target the needs and consequently the service delivery does not respond effectively to the actual needs of the families. If we want to work collaboratively, share information, and develop a partnership with parents and professionals should be more responsive to the needs of the family as perceived by the family members themselves. Wolfendale (1997) pinpointed that an assessment of the child, parent and professional could create a partnership based on the '*reciprocal exchange of information on the base of equality*'(p.21). The present study could suggest that intervention aiming at beliefs and appraisal might enhance family functioning by reducing distress.

This study similarly with major studies in England and America suggested that the quality of marital relationship and the support from the husband to the mother were crucial factors in functioning competently in parenting roles, in acquiring self-esteem, in having efficient and productive child-parent relationships. So a consideration of interventionists in Greece would be the enhancement of the marital relationship which could bring the enhancement of the parent-child relationship. It was found that counselling intervention could increase parents' feelings of support and satisfaction with their relationship with the child and other members of the family (Davis and Rustin,1991). One way to achieve this could be, by focusing on the positive traits of the marital relationship, the spouses and the child.

In the present research, behavioural problems caused a reduction of efficacy and satisfaction with parenting and decrease the positive parent-child interaction and alter discipline strategies a finding similar with DeKlyen et al.(1998). Also younger mothers, mothers of mentally disabled children and only children should be the focus of intervention since they were found to experience more stress. The use of support resources might serve to increase family autonomy because it reduces the dependence upon the professional (Hanline,1991). Short parenting courses could be beneficial to increase the parents' self-esteem, to develop family relationships and deal with behavioural management of children (Davis and Spurr,1998). The participation of fathers should also be the focus of intervention since fathers who were involved in care giving provided enhanced stimulation at home, could provided the couple with shared experiences which could contribute to greater satisfaction from parenting and greater marital satisfaction (Harris and Morgan,1991; Parks et al.,1997). Support programs of fathers could enhance their confidence in dealing for a disabled child. Additionally, it would be of help the creation of support groups for parents and for siblings. They may exist now privately but the information is not easily accessible to individuals.

The results of this study suggest the need for a collaboration between parent and the professional in order to design effective intervention programs. The idea of empowering people with disabilities and their families conceived without sufficient knowledge of their felt needs and the potential of those directly affected could be ineffective as Bischoff et al. (1996) suggested. Social workers and health visitors should be trained in the basic skills of family counselling and know how to assess and be sensitive to family needs, resources and strengths and to free themselves from stereotypes about the effects of a disabled child on the family before deciding about intervention goals or introducing support groups for parents and sibling of disabled children.

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).

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APPENDIX I

INTERVIEW SCHEDULE

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?

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

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

8.Describe the behaviour of the child at home.

9.Describe how you behave/discipline your disabled child.

10.Describe siblings' acceptance of the disabled child.

11.Did you seek advice abroad?

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

(social activities, finance, marital relationship)

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

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

15.How you consider your family compared to families without disabled child?

16.Do you feel lucky for having the child ?

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

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

APPENDIX II

A. LIST AND PRESENTATION OF TABLES

The tables in this appendix were calculated and the relationship between variables was found statistical significant.

Table 1. The difficulties of everyday life by the educational status of mother
Table 2. The difficulties of everyday life by the age of mother
Table 3a. The social activities by the educational status of father
Table 3b. The social activities by the educational status of mother
Table 4a. The social activities by the age of father
Table 4b. The social activities by the age of mother
Table 5. The marital relationship by the family size
Table 6. The economic burden by the social activities
Table 7a.The economic burden by the family size
Table 7b. The economic burden by the social activities
Table 8. The source of strength by the educational status of mother
Table 9. The source of strength by the marital relationship
Table 10. The comparison with other families by the social activities
Table 11. The comparison with other families by the economic burden
Table 12. The comparison with other families by the parents' construct of luck
Table 13. The comparison with other families by the marital relationship
Table 14. The positive contributions by the persons supportive to mother
Table 15. The positive contributions by the marital relationship

TABLE 1. THE DIFFICULTIES OF EVERYDAY LIFE
BY THE EDUCATIONAL STATUS OF MOTHER

	EDUCATIONAL STATUS OF MOTHER									
	Grades1-4		Grades 5-6		Grades 7-9		Grades10-12		Degree	
	N	%	N	%	N	%	N	%	N	%
DIFFICULTIES IN EVERYDAY LIFE										
All day with child	1	20%	12	39%	8	24%	7	22%	8	38%
Mobility			4	13%	7	21%	5	16%	1	5%
Behaviour	2	40%	9	29%	3	9%	4	13%	3	14%
Communication	2	40%	2	6%	8	24%	10	31%	4	19%
Non mentioned			3	10%	5	15%	6	19%	3	14%
Problems of other nature			1	3%	2	6%			2	10%

Table 2. THE DIFFICULTIES OF EVERYDAY LIFE BY THE AGE OF MOTHER

	AGE OF MOTHER					
	20-30		31-40		40+	
	N	%	N	%	N	%
DIFFICULTIES IN EVERYDAY LIFE						
All day with child	3	18%	22	28%	11	44%
Mobility	4	24%	9	11%	4	16%
Behaviour			19	24%	2	8%
Communication	7	41%	16	20%	3	12%
Non mentioned	2	12%	11	14%	4	16%
Problems of other nature	1	6%	3	4%	1	4%

Table 3a. THE SOCIAL ACTIVITIES
BY THE EDUCATIONAL STATUS OF FATHER

	EDUCATIONAL STATUS OF FATHER									
	Grades 1-4		Grages 5-6		Grades7-9		Grades10-12		Degree	
	N	Col %	N	Col %	N	Col %	N	Col %	N	Col %
SOCIAL ACTIVITIES										
Social activities reduced	1	20%	18	72%	14	58%	10	50%	14	39%
Social activities haven't changed	4	80%	7	28%	10	42%	10	50%	22	61%

TABLE 3B. THE SOCIAL ACTIVITIES BY THE EDUCATIONAL STATUS OF MOTHER

	EDUCATIONAL STATUS OF MOTHER									
	Grades1-4		Grades 5-6		Grades 7-9		Grades10-12		Degree	
	N	%	N	%	N	%	N	%	N	%
SOCIAL ACTIVITIES										
Social activities reduced	2	40%	19	68%	18	64%	8	28%	10	50%
Social activities haven't changed	3	60%	9	32%	10	36%	21	72%	10	50%

TABLE 4A. THE SOCIAL ACTIVITIES BY THE AGE OF FATHER

	AGE OF FATHER							
	20-30		31-40		41+		Father absent	
	N	%	N	%	N	%	N	%
SOCIAL ACTIVITIES								
Social activities reduced			41	63%	15	38%	1	33%
Social activities haven't changed	2	100%	24	37%	25	63%	2	67%

TABLE 4B. THE SOCIAL ACTIVITIES BY THE AGE OF MOTHER

	AGE OF MOTHER					
	20-30		31-40		41+	
	N	%	N	%	N	%
SOCIAL ACTIVITIES						
Social activities reduced	10	67%	42	58%	5	22%
Social activities haven't changed	5	33%	30	42%	18	78%

TABLE 5. THE MARITAL RELATIONSHIP BY THE FAMILY SIZE

	FAMILY SIZE							
	two children		three children		four children		only child	
	N	%	N	%	N	%	N	%
MARITAL RELATIONSHIP								
Marital relationship negative	12	20%	2	11%	1	13%	11	48%
Marital relationship positive	49	80%	16	89%	7	88%	12	52%

Table 6. THE ECONOMIC BURDEN BY THE SOCIAL ACTIVITIES

	ECONOMIC BURDEN			
	Economic burden		Not economic burden	
	N	%	N	%
SOCIAL ACTIVITIES				
Social activities reduced	50	64%	7	22%
Social activities haven't changed	28	36%	25	78%

TABLE 7a .THE ECONOMIC BURDEN BY THE SOCIAL ACTIVITIES

	SOCIAL ACTIVITIES			
	Social activities reduced		Social activities haven't changed	
	N	%	N	%
ECONOMIC BURDEN				
Economic burden	50	88%	28	53%
Not economic burden	7	12%	25	47%

TABLE 7B. THE ECONOMIC BURDEN BY THE FAMILY SIZE

	FAMILY SIZE							
	two children		three children		four children		only child	
	N	%	N	%	N	%	N	%
ECONOMIC BURDEN								
Economic burden	44	72%	12	67%	2	25%	20	87%
Not economic burden	17	28%	6	33%	6	75%	3	13%

TABLE 8.THE SOURCE OF STRENGTH BY THE EDUCATIONAL STATUS OF MOTHER

	EDUCATIONAL STATUS OF MOTHER									
	Grades1-4		Grades 5-6		Grades 7-9		Grades10-12		Degree	
	N	%	N	%	N	%	N	%	N	%
SOURCE OF STRENGTH										
Myself	2	29%	6	13%	8	16%	14	35%	4	13%
My child	1	14%	9	20%	7	14%	6	15%	7	23%
Myself and my child			3	7%	7	14%	7	18%	6	20%
My faith to God	4	57%	25	56%	20	40%	7	18%	5	17%
My family			2	4%	7	14%	6	15%	6	20%
No relation with God					1	2%			1	3%
My doctor									1	3%

9.THE SOURCE OF STRENGTH BY THE MARITAL RELATIONSHIP

	MARITAL RELATIONSHIP			
	Marital relationship negative		Marital relationship positive	
	N	%	N	%
SOURCE OF STRENGTH				
Myself	5	13%	29	21%
My child	10	26%	20	15%
Myself and my child	8	21%	15	11%
My faith to God	12	31%	51	38%
My family	3	8%	19	14%
No relation with God	1	3%	1	1%
My doctor			1	1%

TABLE 10. THE COMPARISON WITH OTHER FAMILIES BY THE SOCIAL ACTIVITIES

	SOCIAL ACTIVITIES			
	Social activities reduced		Social activities haven't changed	
	N	%	N	%
COMPARISON WITH OTHER FAMILIES				
We are different compared to other families	26	46%	9	17%
We are similar compared to other families	23	40%	32	60%
We are different but positively	3	5%	9	17%
there are differences and similarities	5	9%	2	4%
I don't know			1	2%

TABLE 11. THE COMPARISON WITH OTHER FAMILIES BY THE ECONOMIC BURDEN

	ECONOMIC BURDEN			
	Economic burden		Not economic burden	
	N	%	N	%
COMPARISON WITH OTHER FAMILIES				
We are different compared to other families	30	38%	5	16%
We are similar compared to other families	32	41%	23	72%
We are different but positively	10	13%	2	6%
there are differences and similarities	6	8%	1	3%
I don't know			1	3%

TABLE 12.THE COMPARISON WITH OTHER FAMILIES BY PARENTS CONSTRUCTION OF LUCK

	PARENTS CONSTRUCTION OF LUCK					
	I'm lucky in my misfortune		I'm proud of my child		I don't feel lucky	
	N	%	N	%	N	%
COMPARISON WITH OTHER FAMILIES						
We are different compared to other families	24	31%	1	7%	10	56%
We are similar compared to other families	37	47%	11	79%	7	39%
We are different but positively	11	14%	1	7%		
there are differences and similarities	6	8%			1	6%
I don't know			1	7%		

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TABLE 13.THE COMPARISON WITH OTHER FAMILIES BY THE MARITAL RELATIONSHIP

	MARITAL RELATIONSHIP			
	Marital relationship negative		Marital relationship positive	
	N	%	N	%
COMPARISON WITH OTHER FAMILIES				
We are different compared to other families	13	50%	22	26%
We are similar compared to other families	7	27%	48	57%
We are different but positively	2	8%	10	12%
there are differences and similarities	4	15%	3	4%
I don't know			1	1%

TABLE 14. THE POSITIVE CONTRIBUTIONS BY THE PERSONS SUPPORTIVE TO MOTHER

	PERSONS SUPPORTIVE TO MOTHER															
	Husband		maternal mother		Mother-In-Law		Sister/ Brother		Relatives		Children		Alone (Mother)		Alone (Father)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
POSITIVE CONTRIBUTIONS AS PERCEIVED BY MOTHERS																
Brought us together	46	34%	2	10%							3	27%	2	14%		
Change in personality	55	41%	13	65%	1	100%	2	67%	3	38%	5	45%	7	50%	1	100%
I have a child	21	16%	5	25%			1	33%	3	38%	2	18%	3	21%		
Found real friends	2	1%							1	13%	1	9%				
Non reported	11	8%							1	13%			2	14%		

TABLE 15.THE POSITIVE CONTRIBUTIONS BY THE MARITAL RELATIONSHIP

	MARITAL RELATIONSHIP			
	Marital relationship negative		Marital relationship positive	
	N	%	N	%
POSITIVE CONTRIBUTIONS AS PERCEIVED BY MOTHERS				
Brought us together			50	36%
Change in personality	14	52%	57	41%
I have a child	3	11%	26	19%
Found real friends			2	1%
Non reported	10	37%	4	3%

B. LIST OF TABLES

The tables in this appendix were calculated but the relationship between variables was not statistical significant.