Mothers with disabled children in Cyprus: experiences and support

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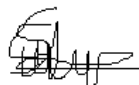## Institute of Education

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'I, Antigoni Stylianou confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

In a discernibly developed world, where the subject of disability and equal rights for disabled children is strongly discussed, it is expected that inclusive practices and service provision should be developed in smaller societies as well. There is evidence that mothers, and mothers of disabled children in particular, are the main care providers to their children. Lack of evidence for this however, in the context of Cyprus, was the main point of departure for this research.

By focusing on mothers with disabled children in Cyprus, this study aimed to gain an understanding of mothers' experiences and their perspectives on raising disabled children. An examination of the Cyprus context, its history and relation to disability, have been analysed in an attempt to contextualise the analysis of mothers' accounts.

Twenty-five mothers shared their personal experiences of their journeys with their disabled children. Data were collected via semi-structured interviews with mothers whose children ranged from the ages of six to twenty-two years. Mothers described their experiences and early feelings, from the time that their children were born, to the time that the mothers became aware of the disability.

Mothers were asked to describe the support that they received 'formally', with regards to state support and other public services, as well as the 'informal support' received from family members and friends. In addition the study aimed to establish an understanding of the experiences of stigma that the mothers encountered, and the ways used to manage and cope with stigma.

Data were analysed through thematic analysis. The study shows that mothers went through different stages of grief associated with their journeys with their children. Shock, disappointment and lack of trust in doctors and other professionals were the main feelings that characterised the different stages of their journeys. In terms of support, the results highlighted differences between the formal and informal support that they received. Mothers were much less satisfied with formal than informal support. All the mothers experienced stigma by 'courtesy' of having a child with a disability. The study concludes that in Cyprus there is still a huge gap between policy and practice.

Acknowledgements

'As you set out for Ithaca,
Hope the voyage is a long one
Full of adventure, full of discovery' (Cavafy, 1984)

Even though the destination might have been Ithaca, the journey was actually more important as the Greek poet emphasised in his poem when he talked about the journey of Odysseus returning back home after the Trojan War that lasted ten years.

I am also grateful to those 25 mothers. Though your names remain confidential, this work could not have been undertaken if it were not for you. Your deeply personal and emotional experiences and your lifelong journeys, made this journey pleasant and achievable at the same time. The opportunity I had to hear your stories was a privilege and I feel so lucky for this.

I can't remember my life without you even though you are younger than me. I have also passed through feelings of anxiety, denial, confusion, anger. After all these negative feelings, proudness is the one that has remained and prevailed. My beloved youngest sister Christina, I know that you won't be able to read this, but this work is dedicated to you. Thank you for everything. I love you and I promise that I will be there for you... forever.

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Chapter 1 – Introduction

1.1. <u>Background of the Study</u>

There is widespread concern about disabled children regarding theory and policy in many countries that emphasise the equal rights of every child, state the necessity of inclusive practices and criticise any form of marginalisation and discrimination (Great Britain, 2005; United Nations, 1989). The Convention on the Rights of the Child refers to any child without discrimination. More countries have ratified the Convention than any other human rights treaty, with 194 countries having ratified the Convention (UNESCO, 2014). The UK signed it in 1990, and it came into UK law in 1992. The Republic of Cyprus signed the Convention as well in 1990 and ratified it in1991.

At the same time, there is a general agreement that research around disability is growing (Barnes, 2007, Barton, Barnes & Oliver, 2002). Articles discussing theories of inclusion (Booth and Ainscow, 2002) and practices around the right of every child to be educated and treated equally are frequent topics in the contemporary disability literature (Armstrong, Armstrong and Barton, 2000; Goodley and Runswick-Cole, 2011).

According to the evidence, this increasing interest in the literature has not produced many changes in practices on the ground. Many disabled children in poor countries such as Zambia, Tanzania and Vietnam are still marginalised in their schools both socially and educationally (Booth and Ainscow, 1998; Degener and Koster-Dreese, 1995; Ford, 2012). Prejudice and injustice continue to exist (Petrou, Angelides and Leigh, 2009). On the contrary, many disabled people argue that they are not being treated equally in their communities (Burdekin, 1995; Irving, 1994).

There is also more interest in contemporary research about families with disabled children (Ellison, 2006; Maplethorpe, Chanfreau, Philo and Tait, 2010; Runswick-Cole, 2010) and some acknowledgement that development and progress has occurred. However, negative feelings and stigmatised experiences still prevail (Fleitas, 2000; Flexman, Berke & Settles, 1999; Rossiter & Sharpe, 2001; Van Riper, 2000; Main, Kaplan & Cassidy, 1985; Stalker *et. al.*; 2015).

What is happening in Cyprus raises an interesting discussion. Cyprus is considered to be a developed country especially after 2004 when the island became a member of the European Union (IMF, 2010). It is a developed island and according to Annan's definition of developed countries, all Cypriot citizens 'enjoy a free and healthy life in a safe environment' (Annan, 2000: 2). In addition, the cost of living in Cyprus is relatively high

and the vast majority of its citizens enjoys a relatively high standard of living with many facilities, for example, people build and own their own houses without having the need to rent, have their own cars and earn money that affords them a relatively wealthy lifestyle (Cyprus Tourism Organisation). However, developments in the way of life do not characterise the situation that prevails in Cyprus regarding disability. For example, according to the household budget survey that was conducted by the statistical service in Cyprus (Statistical Service, 2009), 86.2% of the households in Cyprus had one or more cars, 89.1% coloured TV, 89.6% mobile phone and 86.5% internet access.

It is important to note that disability in Cyprus is influenced by the experiences of many European countries and especially the United Kingdom as it used to be a British Colony (Symeonidou, 2009) for many years until 1960. British ideas and legislation have influenced the Cypriot education system as we can see from the literature (Phtiaka, 2003; Symeonidou, 2009) and the legislation (Ministry of Education and Culture, 1999). According to Phtiaka (2003: 147), 'education history and post–colonial dynamics suggest that today's UK policy is often tomorrow's Cypriot practice'. This is obvious, for example, in the legislation for disabled children and their education.

The legislation regarding the 'handicapped' as they used to be called in official documents which was introduced by Great Britain in 1944 was similar to the first Cypriot legislation that was established in 1979. The next piece of legislation about disabled children in Cyprus was later passed in 1999 and supported the societal integration of children with disabilities. It was similar to the British legislation of 1981. It is, on the other hand, still the case that old beliefs that connect disability with the charity model. A charity model of disability is an individualistic model which turns disability into the problems of disabled people and blames them for their problems or impairments. It is a traditional way of looking at disability together with the medical model which is analysed in the next section. Disabled people are in need of help, according to charity model and charities are needed to raise money (Symeonidou, 2009; Symeonidou and Beauchamp-Pryor, 2013). This model still exists in Cyprus among most of the population and, even worse, prevails in the actions of policy makers, for example the existing legislation for disabled people; even though the legislation talks about integration of disabled children in mainstream schools, many of them are still educated in special schools which is a characteristic of this model (Phtiaka, 2007). In this model the problem rests with the disabled person who is seen as a victim that is to be pitied and needs help, sympathy and money (Alison and Enfield, 2003). Disability is a "tragedy, a misfortune that must be tempered or erased by generous giving" (Clare, 2001: 360). Given that charity and charitable organisations play a very important role in the provision of services it is

inevitable that they are seen as a solution when people have a disability and are considered as in need (Oliver, 1996).

What is more, policy regulations and decisions about the future of disabled people are made without listening to the voices of those who interact with disabled people or, even worse, without listening to the accounts of disabled people themselves. Politicians and more specifically the Parliament in Cyprus are responsible for the adoption, amendment and repeal of legislation (House of Parliament, 2013). The members of the House, the representatives of citizens, are people that come from many backgrounds, educational levels and occupations. However, most politicians do not have any experience of disability or disabled people (House of Parliament, 2013b).

My interest in undertaking the specific study does not emerge from a totally detached position. It stems first from my personal background of being a sibling of a disabled sister, ten years younger than me. Watching my mother's journey with all the struggles, difficulties and achievements, developed in me a desire to understand the position and perspectives of mothers with disabled children in Cyprus, and at the same time to provide them with the opportunity to talk and share their thoughts and experiences. This is a significant group of people that, as we will see, has not been 'listened' to so far in the Cyprus context.

Secondly, my professional background as a special education teacher and a manager of a private inclusive school also inspired me to undertake the specific study. Based on the results of this study, I hope to be able to point to the need for the types of support required by mothers of disabled children. The significance of the study in a more general context is underlined in the following section.

1.2. <u>Purpose of the study</u>

Focusing on mothers with disabled children in Cyprus, this study aims to gain an understanding of the experiences of mothers who have disabled children living in Cyprus today. By interviewing mothers (in 2015) and analysing their personal accounts it seeks to understand how far disability theories and practices have changed the experiences of mothers caring for disabled children in Cyprus. What mothers expect to be provided is compared with what they actually experience and receive.

A goal of the study is also to explore mothers' experiences and feelings from the time of their disabled child's birth to the time they became aware of the disability, their assessments of the support they receive from the Cyprus government in terms of

benefits, and from sources of informal support during their journeys. How they experience the stigma of raising a disabled child in a nondisabled world and their accounts of their experiences will also be examined, together with the ways that mothers learned to cope and manage their lives in the context of Cyprus.

The study sample consists of mothers of disabled children in Cyprus. Mothers and mothers of disabled children in particular, are the primary caretakers: they have the main responsibility for raising their child (Borum, 2007; Brehaut et al. 2004; Crowe & Florez, 2006; Goodwin and Huppatz, 2010; Helflnger & Taylor-Richardson, 2004; Paroutsas, 2005; Read, 2000; Weiss, 2008). The families studied vary by their individual histories, by their structures – married or divorced for example, and by their cultures – the kinds of communities they belong to (Brannen and Moss, 1992; Goodwin and Huppatz 2010). At the same time, contemporary representations of motherhood are important in shaping how the mothers are perceived (Goodwin and Huppatz, 2010; Paroutsas, 2005; Wilson, 2012).

Put precisely, the study addresses three main questions:
A. What are the experiences and feelings of mothers following the child's birth until the time of awareness or diagnosis of a disability?
B. What kind of support did mothers have access to throughout their journeys of raising their disabled children, formal and informal? What support did they receive at time of interview and what were their assessments of support that they received?
C. How far did mothers experience stigmatisation related to their child's disability and how did they experience and cope with stigma?

1.3. Theoretical Framework – Overview

Based on the background of the study, its significance and purpose, the proposed conceptual framework was built from a combination of theoretical frameworks. Figure 1.1 below presents the conceptual framework of the study.

As mentioned, a range of theoretical perspectives around disabled children exist in the literature. How disability is understood and represented over the years is a vital component of the study. There are two main models of disability, the 'medical or individual model' and the 'social model' (Armstrong and Barton, 1999; Barnes, Mercer, and Shakespeare, 1999; Oliver, 1996). The 'individual model' emphasises the deficiencies of the person and is based on the dominance of medical knowledge, medical diagnosis and medical solutions (Brisenden, 1986; Fulcher, 1989). Disability activists criticised the medical or individual model and developed the idea of the 'social

model' in which the 'problem' is not the person or his or her impairment. Rather, the problem is the structures of the society that do not provide the disabled person with an equal quality of life.

Given   Cyprus's policy and practice that supports the social model of disability I considered it important to examine mothers' experiences over the life course of their disabled children. I examined how far changes in mothers' experiences and feelings along the journey constituted turning points. Turning points are defined in the sociological literature as the incidents that happen in a person's life and involve important changes to his/her life (Strauss, 1959). 'Turning points are perceptual road marks along life course. They represent individuals' subjective assessments of continuities and discontinuities over their lives' as Hareven and Masaoka (1988: 272) defined them. A very important addition to the framework is stigma: the extent to which mothers experienced it because of their children and the mechanisms they used to cope with it. Stigma is a concept defined by Goffman as discrimination that some people face because they deviate from the 'normal' (Goffman, 1963). All the concepts included in the process of the theoretical framework are presented in Chapter 4.

The approach of the study is informed also by the actual time and place of the implementation of the study; Cyprus in 2015. As mentioned earlier, there is lack of research around mothers of disabled children in Cyprus. The history of Cyprus and the history of disability, policy, and practice are important concepts that frame the research questions and the analysis.

Mothers with disabled children in Cyprus

Mothers
Main Care Providers

Disabled Children
Social Model of Disability

Cyprus
- Context
- Policy and Practice

Early Experiences and Feelings (Turning Point)
Support Provision: Formal and Informal
Stigma Experience and Coping Mechanisms
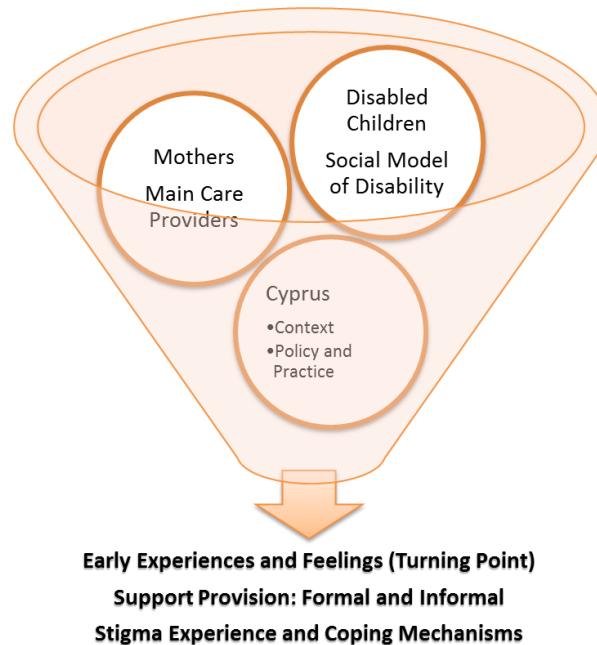
Figure 1.1. – Conceptual Framework of the Study

1.4. <u>Significance of the study</u>

There is a lack of research around family and disability in Cyprus. People who have worked on disability studies in Cyprus suggest that more research is needed and at the same time there is a need for inclusive policies and practices to be developed (Angelides, 2004; Phtiaka, 2007). In this sense, this study is an attempt to fill the gap that exists in the research about this topic, mothers with disabled children in Cyprus.

In this study, the focus is on mothers for several reasons. The literature suggests that mothers are the primary providers of care for children and children with a disability in particular (Koro-Ljungberg and Bussing, 2009; Paroutsas, 2005; Read, 2000; Wilson, 2012). A second reason is that mothers are absent from the political discourse about disability. Zoniou-Sideri, Deropoulou-Derou, Karagianni and Spandagou (2006), professors who work in childhood and inclusive educational programmes in Greek Universities, discuss the inclusive discourse of Greek society in a period of rapid change, a period in which Greece hosted two big international events (the Olympic and Paralympic games). In their article they argue that voices of people who interact with disability can be powerful and emotive, but lack a long-term political strategy for change.

Moreover, directions for change need to be discussed by the people who interact or engage actively with disabled children and their families. Experiences and the opinion of people who interact with disabled children are vital for change to occur. Mothers of disabled children are the most appropriate persons to speak about their children and need to be heard in order for the future of these children to change in Cyprus because they are in practice the main carers (Chapter 2). Mothers in Cyprus lack the opportunity to express their beliefs and ideas and, more importantly, the political channels to affect changes in the policy and practice for disabled children.

'Voice' has tremendous power and needs to be acknowledged in understanding current situations, taking decisions and changing thoughts and ideas. The voices of the mothers who look after disabled children are an important source of experience concerning support for disabled children. If mothers are given the opportunity to speak, share their experiences, and discuss the difficulties in their journeys of raising a disabled child, this will give insight into the kind and amount of support that is needed.

Media representations and international discourses are dominant in changing policies and practices concerning inclusive strategies. For example, the Greek media played an important role in changing inclusive strategies (Zoniou-Sideri, *et al.* 2006), notably arguing for the need for an elevator to be installed in the rock of the Acropolis in Athens at the time of the Olympic and Paralympic Games in 2004. Only after the media interfered and promoted the matter was the elevator installed.

Families can use their voice as a strategy for change since they experience disability first hand. At the moment in Cyprus, there are only a few parents' organisations that lobby for change and speak of an inclusive philosophy. There are parents' organisations that seek donations and subscribe to the charity model even though some would also regard inclusion as the ideal (Panos Foundation, 2014). As will be mentioned later, Cyprus lacks a strong discussion around disability in comparison to other countries. Thus, giving a voice to an unheard group makes the study significant. Mothers are the focus because of their important role as the main carers of their disabled children.

A further reason to undertake this study is because there is a need to understand more about how mothers perceive and experience social support - how socially integrated or isolated such families become when a disabled child arrives in a family and how parents access support in practice.

1.5. Outline of the Study

The thesis is composed of nine chapters. In this first introductory chapter, I have set out the background and the importance of the study, presented the purpose of the study and my reasons for pursuing the topic. I also pointed to some aspects of the conceptual framework which is discussed more fully in Chapter 4. Chapter 2 is a review of the relevant literature in the areas of motherhood, experiences and discourses, the notion of disability, studies of disability, the concept of stigma and inclusion. The literature also covers caring for disabled children, the emotional effects on mothers, childcare, maternal and marital satisfaction and satisfaction with social support, formal or informal.

Chapter 4 is devoted to methodology. In the first part of Chapter 4 I set out the research questions and develop the key concepts used in the study. Then, the research design, the sample, how I recruited my participants as well as the sample's characteristics, data collection procedures and data analysis methods are presented with a consideration given to the ethical issues of the study.

Chapter 3 offers a discussion around the Cyprus context in order to provide the reader with information relevant to the current study - Cyprus's history, the characteristics of the society, its policies and practices concerning disability. How stigma and disability are experienced in Cyprus and the theory that exists in policy as well as in practice are discussed. The healthcare system as well as the services that are provided to families of disabled children in Cyprus are examined, and a critical analysis of theory in comparison to practice is presented.

Chapters 5, 6, 7 and 8 are devoted to the analysis of the data and address the research questions. Mothers' first experiences of disability as well as their feelings and turning point are analysed in Chapter 5. Chapter 6 presents an analysis of mothers' accounts in regard to formal support, especially from the state, while Chapter 7 concerns an analysis of the support mothers received or did not receive informally. The last analysis chapter, Chapter 8, presents the findings concerning the ways in which mothers consider the issue of stigma that is associated with disability and how it affects them and their children; it discusses the different mechanisms that mothers employed in the face of stigmatisation. Chapter 9 seeks to draw the different threads of the thesis together and suggests its contribution to the field both substantively and theoretically. It considers the limitations of the study and makes suggestions for further research.

Chapter 2 - Literature Review

2.1. <u>Introduction</u>

Issues related to disability, inclusion and motherhood are multidimensional. They involve political, social, and economic aspects of families and the society. It is also to be expected that different families and children will have different experiences and journeys to describe.

After deciding on the research questions that I wanted to examine, I performed literature searches of the relevant literature beginning in the early stages of my study, in December 2012 until the completion of the thesis in December 2016. A comprehensive search, limited to articles in English and Greek was conducted in the wide range of databases that were available for use by UCL students such as Wiley Online Library, Explore, Taylor & Francis Social Science and Humanities library, ProQuest and PubMEd. I also used Google Scholar and Google Books where applicable. I limited the search by using keywords for each section of the lit review that I wanted to examine. For example, I used the keywords; 'stigma, 'stigma and disability', 'mothers being stigmatised' and other relevant keywords when I was searching literature on stigma. Books, Dissertations and Theses relevant to the topic of my study were borrowed from the Institute of Education Library. Legislations, documents from organisations in Cyprus about current legislation and administrative systems I have undertaken from Cyprus. I made visits to the specific places and people who provided this information.

The aim of this chapter is to draw on different literatures. These are divided into three basic categories. Firstly, I present a literature review of motherhood, mothers' experiences, practices and ideologies. In the next section I discuss the notion of disability in general, as well as the term stigma and how it is related to disability. Studies of people with disabilities and the models of disability are presented in this section as well as definitions of research concerning inclusion. The last section includes relevant research on mothers and other carers of disabled children, their experiences and feelings as well as the support the mothers received through their journeys of raising a disabled child.

2.2. <u>Motherhood</u>

How many prayers for each little white bed?
How many tears for her babes has she shed?
How many kisses for each curly head?
Nobody knows but Mother
(Morrison in Harrison and Stuart Clark, 2004)

Families have different characteristics that relate to the histories, structures and cultures of the society. When talking about matters to do with household work and care in family life, the role of the 'mother' continues to be central despite greater gender equality and rising rates of mothers' employment (Brannen and Moss, 1991; Goodwin and Huppatz 2010; Treas and Tsui-O, 2012). Many discussions on mothers and motherhood have been raised in the literature, emphasising the important role that mothers hold in the life of the child as the child grows (Cole, 2004, Sevón, 2005). The role of a mother is very important in shaping the personality of the child in many ways (Paroutsas, 2005; Wilson, 2013). The mother is the first person who the newborn baby encounters and the first to influence and foster the development of the child and its adaptation on the society.

The word 'mother' in the dictionary is defined as the female parent who is pregnant or gives birth to a child or the one who adopts or raises a child (Collins, 2003). 'Images of good mother persist in public theory, media, popular culture and workplaces, and saturate everyday practices and interactions' as Goodwin and Huppatz argue (2010: 1), not only in Australia as they analyse in their writing but in many countries. The one who learns from experiences and knows more than the various professionals also influence what it means to be a mother (Read, 2000). However, representations of the 'good mother' through the media or government policies and via work and educational institutions, shape women's lives and create an idealised image that few can live up to. A 'good mother' is not always the 'heterosexual, married, and monogamous ... white and native born' mother, as Arendell (1999: 3) claims. Contemporary representations of good mothers are not uniform (Goodwin and Huppatz, 2010). They change and, as Goodwin and Huppatz (2010: 3) point out, 'good mother ideals are produced and reproduced in a variety of ways: through media mis/representations, through government policy, via the organisation of institutions such as work and education, and as the result of deeply held cultural beliefs'.

In her study, Cole cites Kaplan's representations of mothers: 'the self-sacrificing, saintly carer in the house; the selfish, over-indulgent woman; and the sinister, evil, all possessing monster' (Cole, 2004: 53). Representations of motherhood are expressed to a great extent through the press, magazines, newspapers or television and radio.

Mothers are characterised as full–time parents and sensitive to a baby's needs, whereas fathers are regarded as part–time and usually less competent in taking care of a baby (Sunderland, 2006). Yulindrasari and McGregor argue that in the 1980s and 1990s, women were seen 'as wives and mothers and men as breadwinners and the decision-makers for the family'' (2011: 607). Nowadays parents are expected to undertake dual roles and thus work and rear the children at the same time. Super–mum and super–dad discourses where parents are able to balance their child–rearing life with their public activities are typical today in western countries and the US countries. Hays (1996) has talked about 'intensive mothering' where mothers are the central care givers to the children and who spend a lot of time to meet their children's needs giving their time and energy. Shirani, Henwood and Coltart (2012: 26), when examining this term in the UK, highlighted an assumption that exists where mothers in most of the cases 'have the ability to control and shape the lives of their children, … ensuring children are turned into responsible citizens'.

I continue with experiences of motherhood as they are discussed in the literature.

2.2.1. Motherhood Experiences

There is only one way to find out how women actually experience motherhood, and that's by listening to what they have to say (Oakley, 1997, p. xvi).

It is important to examine what mothers experience and how motherhood is practiced. In a study on working mothers, Sharpe in 1984 when full-time motherhood was common, observed that 'full-time mothering has never been accessible to all women in the same way at the same time' (1984: 22). 'Culture determines the specifics of attitudes towards motherhood' as Razina (2014: 101) suggested from the distinguish characteristics of attitudes towards motherhood in women from different cultures. Different cultures regard mothers as if they belong to a different religion as Razina examined through her study. Social class and the different cultures of motherhood reveal that experiences differ, for example when a baby is crying, one mother will pick it up but another mother will turn away, leaving the baby to cry himself or herself out (Chown Oved, 2013). Both mothers love their children.

Chown Oved examined the research of Bornstein, Putnick and Lansford (2011) who evaluated similarities and differences between parents' attributions regarding perceptions of causes of successes and failures in caregiving and attitudes in parenting in nine countries. In terms of attribution they did not differ. In terms of attitudes to the examination of progressive versus authoritarian childrearing attitudes, however, mothers

were more progressive and modern, and fathers were more authoritarian. Cultural differences were reported since mothers, as mentioned earlier, in different countries act differently in specific situations.

The limited time which mothers have for themselves because of their children's needs is not always easy to achieve as Thomson, Hadfield, Kehily and Sharpe (2012), for example, observed a small sample of mothers in the UK whom they followed from pregnancy into motherhood. The study focused on the active engagement of mothers with small babies within wider family narratives of mothers as they were followed from pregnancy into motherhood. Mothers were not able to talk for a long enough time in the interviews since they had to interrupt the interview in order to go to their babies. Moreover, through their longitudinal study, the authors focused on examples of interaction between researcher, mother and child relating to food and they found that the relationship between the mother and the researcher had been shaped by a number of factors such as the age and/ or the relationship that the child and the researcher developed during the researcher's visits.

Studies have shown that the lives of mothers differ before and after having a baby. Horne, Corr and Earle (2005) carried out a small-scale exploratory study on the changes in the employment lives of first time mothers. They used both quantitative and qualitative data: the Modified Interest Checklist and the Role Checklist and semi-structured interviews with a sample of six mothers, two and a half years post motherhood aged between 28 and 42. They found that before having their baby, mothers were able to have a shower, get dressed and eat breakfast without being in a hurry. This altered after their baby's arrival since they had to look after the baby first and then to spend time on themselves. Activities such as attending parties, pubs and concerts were not so frequent as mothers mentioned postnatally whereas post-motherhood they had to do the housecleaning, ironing, childcare and activities that were carried out in the home. Activities such as cooking, driving and shopping were reported both before and after motherhood. These experiences suggest that 'being a mother' needs dedication and putting the needs of the baby first (Horne et al, 2005). Difficulties in relation to taking on new roles and activities included a 'shell-shocked' feeling in relation to the baby's arrival (Kielhofner, 2008). How motherhood is represented in women's magazines and how the term motherhood is translated in different contexts through practices and ideologies is presented in the next section.

2.2.2. Motherhood discourses, practices and ideologies

Johnston and Swanson (2003) have studied motherhood ideologies and myths in women's magazines drawing on an analysis of twenty magazines. Among other things their analysis showed that mothers' work status is reported differently compared with reality. Some researchers have explored motherhood ideologies in relation to self-help literature (Zimmerman, Holm & Haddock, 2001) while others examined child-rearing (Ever, 1996). Dally (1982) worked on motherhood ideologies on both topics - raising children and cultural expectations on the construction of motherhood. Johnston and Swanson (2003) through their analysis of motherhood ideologies and myths in contemporary women's magazines, suggested that 'women's magazines persist in the promotion of traditional constructions of motherhood' (p. 29).

'The term motherhood refers to the context in which mothering is experienced' as Dedeoglu suggested (2010: 297). Factors such as race and class affect how the term motherhood is translated and practiced in different contexts (Miller, 2007). Reference is made by Dedeoglu to dominant 'Discourses of Motherhood' where a 'good mother is presumed to be child–centered and prioritizes the needs and wants of her children over those of her personal ones' (Dedeoglu, 2010: 298). Discourses around motherhood change; increasingly more emphasis is put on the fact that most mothers are in paid work (Van Hove, De Schauwer, Mortier, Bosteels, Desnerck and Van Loon, 2009). The literature also discusses the ways in which parenting differs between mothers and fathers considering that child–care and domestic responsibility can be done by fathers as well (Doucet, 2006). It also explores issues of who takes most responsibility: mothers are found to be the main caregivers (Bugental, Blue, & Lewis, 1990; Craig, 2006; Lorensen et al., 2004; Nyström & Öhrling, 2004) while fathers are there in a more symbolic representation (Brannen, 1990).

At the same time, we can observe that discourses of motherhood are shaped by others such as doctors (Cosslett, 1994). Also, parents are expected to professionalise themselves in the area of childrearing (Edwards and Gillies, 2004, Schaubroeck (2010). Ramaekers and Suissa (2012: 5) question these demands on modern parents and suggest that parenting is not an unreflective process:

> *Acting in appropriate ways, that is, in ways which are most appropriate to ensuring one's child's development is, on this account, not something that just happens, but something that requires a particular approach (Ramaekers and Suissa, 2012: 28).*

Parenting according to Ramaekers et.al is a process that is not natural but open to influence, notably that of experts who seek to professionalise and put the responsibility onto parents. Experiences of motherhood are often negative as analysed by feminist researchers. For example, motherhood in the postpartum period results in depression (Nicolson, 1998; Paradice, 1995). Oakley (1979: 6) found in her study that:

> *In some ways the picture is deliberately black. What many of the women who were interviewed said was that they were misled into thinking childbirth is a piece of cake and motherhood a bed of roses.*

According to Hays (1996), mothers have been positioned as all caring and self-sacrificing.

Unemployed mothers at home emphasised that they were accessible all the time to their children, while part-time employed mothers talked about the quality of communication that they had with their children. All mothers in practice reported that they tried to educate their children to be polite and well behaved; they set limits and had rules even if sometimes they lost their tempers (Johnston and Swanson, 2003).

Motherhood in Cyprus is translated as care, as in other contexts. Care and responsibility is what mothers believe to be their duty and how they translate it. According to a study that was undertaken in Rhodes, a Greek island, mothers with disabled children are overprotective towards their children and undertake multifunctional roles such as covering the on-going needs of the child, interest, love and continuous attention (Tsimpidaki, 2008); while fathers took part in the development of the child, mothers show more dedication and commitment.

Being a mother of a disabled child is similar to having a child without a disability but it is also different. There is a gap in the research concerning mothers' experiences of raising a disabled child and the support provided to them and other members of the family. In the next section I discuss disability and the studies related to it. I discuss two basic models of disability, medical and social, as well as the notion of stigma and inclusion.

2.3. <u>Disability</u>

2.3.1. The notion of disability

Disability was seen as a controversial issue in the past and we can observe this from the various approaches of how disability has been understood and represented over the years. "Models are merely ways to help us understand the world" (Oliver, 1996: 39) and

the models which I describe below are those that have been employed to examine disability, its causes and impacts on humans and on societies (Goodley, 1997; Wasserman, Asch, Blustein, and Putnam, (2013).

Two conceptualizations are evident in the literature, the individual or medical model and the social model. The individual model suggests that disability or illness is a result of a person's condition (WHO, 2011). People who support this model believe that the individual has the sole responsibility for his/ her disability. The individual model breaks down into further models, such as "the moral model, the deficit model, the survival-of-the-fittest model, the eugenics model, and the medical model" (Reid-Cunningham and Fleming, 2009: 11). Each model contains the main idea of the medical model, that is, that disability derives from the individual, the body and its impairment. Notions of rehabilitation are highlighted in these definitions carried out via professional power and authority (Fulcher, 1989; Söder, 2008). Doctors and therapists are regarded as experts and are considered fundamental to the rehabilitation of the child or the person with a disability. Disabled people in this model are regarded as passive receivers of services that aim to cure them (UKDHM, 2011). Brisenden (1986: 173), a disabled activist and writer, writes about the medical model that "our opinions, as disabled people, on the subject of disability are not generally rewarded with the same validity as the opinions of 'experts', particularly medical experts".

According to this individual model, people with disabilities are defined by their deficiencies, that is, in failing to live up to normative notions of being human; the solution is to assist them through charity or ostracization (Arneil, 2009; Mackelprang, 2010). Others following the medical model suggest a religious and spiritual necessity for helping people with disabilities (Reid-Cunningham & Fleming, 2009). People with disabilities should be passive without the possibility to contribute to the society, excluded from all spheres of social life, while any difficulties they have should be seen from the perspective of treatment for the 'patient' (Brisenden, 1986).

There were many critics of the medical/individual model including social activists or people with disabilities as I mention further down. Oliver (1996: 32) argues that the medical model of disability 'sees the causes of this problem as stemming from functional limitations or psychological losses which are assumed to arise from disability'. Being primarily a medical phenomenon, the individual model of disability highlights the importance of professionals and experts in order to help with the needs of these people. It "sees its diagnosis and solution in medical knowledge" and from this model terminologies such as "Autism" and "Mental Retardation" have emerged (Barnes,

Mercer, and Shakespeare, 1999; Reiss, 1997). 'The basic medical concern is to diagnose the bodily or intellectual 'abnormality' and advise on appropriate treatment' (Barnes, Mercer, and Shakespeare, 1999: 21). For the medical model, a child who cannot walk is disabled because he or she cannot walk (Dowling and Dolan, 2001).

On the other hand, a child who cannot walk is disabled because the society that he or she lives in is not able to accommodate the child's inability to walk (Dowling and Dolan, 2001). In this approach to the "problem" of disability we can find disabled activists that have tried to develop and present their own idea and their own model of disability, that is, the social model. According to the social model of disability, the disabled is not the child or the person itself that is the "problem", nor the impairment but the structures within the society that appear unable to provide him or her with a suitable quality of life in order to live in a healthy and "normal" environment (Armstrong and Barton, 1999; Oliver, 1996; Oliver and Barnes, 2008).

Environment and society constrain citizens who are different from the "norm", different from what society estimates to be "normal". For example, a person in a wheelchair is not "problematic" because he cannot access a building if there are only stairs. The "problem" exists in the society; access that is not provided as it should be. Society fails 'to take account and organise around difference' as Dowling and Dolan argue (2001: 23). Similarly, others who are also deemed different are those who come from a different race, migrants, a different class, people with different religious beliefs, those who are gay or lesbians, just as those identified as disabled (Ainscow, Booth, and Dyson, 2004; Corbett and Norwich, 1999; Burke, 2004; Hill and Cole, 1997).

The UK passed the Disability Discrimination Act in 1995 in order to ensure that disabled people are treated equally in the society. With this Act discrimination against disabled people was challenged and helped to remove the barriers for them. For the purposes of this study, I will use the definition given by The Disability Discrimination Act in the UK (DfES, 1995). The Act was established with the aim of ending discrimination against disabled people regarding employment and provision of goods, facilities and services. According to DfES (1995), the disabled person is 'someone who has a physical or mental impairment that has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities'. According to the Act:
- "substantial" means that the effect on the disability is neither minor nor trivial - it does not have to be a severe effect,
- "long-term" means that the effect of the impairment has lasted or is likely to last for at least 12 months and the effect must be a detrimental one - a person with a life

expectancy of less than twelve months is covered if the effect is likely to last for the whole of that time,

- "normal day-to-day activities" include everyday things like eating, washing, walking and going shopping (DfEs, 1995).

The Act talks about both the medical and social models of disability. In its use of the term 'disability', it is close to the medical model's definition since it states the impairment and the limited activities that disabled people can do. At the same time, when it mentions discrimination against disabled people and the barriers that disabled people face, it suggests the social model of disability. The specific Act was underlined under the Equality Act of 2010. Conditions that are not covered by the disability definition according to the Equality Act of 2010 include conditions such as addiction to drugs or alcohol. The social model is more straightforward in the fact that discrimination and disability are synonymous and can be translated with similar meanings since disability is defined as impairment and not as barriers placed on people with impairment (Shakespeare, 2004).

It is important to add that this study follows the notion of disability that was stated by the College of Social Work in order to develop a curriculum guide where disabled children are 'described as 'children first'' in order to avoid negative connotations but 'their identity as disabled children needs to be confident to convey clear expectations for their childhoods' (Lunn, 2013: 1). Disability in the Disability Act of 2000 in Cyprus is defined as the 'inability and handicap' that a person has and cause mental or psychological limitation to the person and reduces or excludes the ability to perform activities or functions that are considered as normal and essential for the quality of life of each person. The specific definition refers only to the medical model of disability and this encompasses the reason of not adopting the specific definition but following the Disability Discrimination Act of the UK for the definition used in this study which includes the social model as well.

Generally, the literature on disability and social class mentions the "discriminating tradition focus" where school produces discrimination against disabled children who are accorded lower social status because they have more difficulties in adapting to the school culture and demands (Bourdieu, 1977; Veland, Midthassel and Idsoe, 2009). Socioeconomic status which includes education level and occupation is a factor that influences the beliefs and attitudes that parents have on inclusion, as the literature suggests (Stoiber, Gettinger and Goetz, 1998; Leyser and Kirk, 2007).

Definitions of a typically developing child are usually underpinned by norms of what a normal child should do at particular ages. Piaget's cognitive development stages for example defined a norm 'where a child from birth to two years old should be able to move around, use his memory'; he described the four stages of the child's cognitive development (Piaget, 1964). The American Academy of paediatrics presented the developmental milestones that a child should reach from its birth until teen age (American Academy of Pediatrics, 2016). Medical model considerations and definitions are found in medical literature where children with disabilities are named as patients and where healthy and safe development is regarded as catholic (Shelov and Remer Altmann, 2009). Mothering manuals have been constructed during the years and prescriptions of how to be a good mother or statements about motherhood as 'ultimate fulfilment' have been expressed (Marshall in Phoenix, Woolett and Lloyd, 1991).

Normative development is the most appropriate form to describe a person or a child who does not receive treatments and has common characteristics based on behaviour, intellectual abilities and functional skills with other children of a certain age. A disabled person according to the definition followed for the specific study is 'someone who has a physical or mental impairment that has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities' (DfES, 1995). Normalising discourse by definition should name that children without disabilities are the children who can carry out normal day-to-day activities without relying on someone else. This case happens after the age of six where children can act on their own. This is what normal development includes. A child through his first steps needs the care of his parent which through the years this care is minimised until the time the child does not rely on his parent. This is not the case for the disabled child (Diamond, 1994, Phtiaka, 2007). The specific study as argued in the literature review is aware of the two dominant models of disability, the medical and the social, and adopted the social model of disability where disabled is not the person itself but the structures that prevail in the society and cannot provide to the person a decent quality of life (Armstrong and Barton, 1999; Oliver, 1996; Oliver and Barnes, 2008). Mothers according to the concept of 'normal development' or of "typically development" were expected to assess their child's progress. They realised that something like this was not possible either on their own, from a doctor straight after birth, after seeking a second opinion or from a doctor or other professional after some years from their child's birth.

Disability and disabled children are a different case. Curran and Runswick-Cole (2014) studied the conditions of disabled children's childhoods. They argued that these studies should be viewed with an approach which is premised on three distinct premises. Firstly,

disabled children offer a different starting point for discussion as the approach does not talk about impairment and inequalities. Secondly, the voice and experiences of disabled children are at the centre of inquiry and thirdly, this approach seeks to change the 'norm' that exists. My study is not about disabled children's childhoods but about the experiences and, support of their mothers and the stigma mothers encounter. In disabled children's childhoods, children described that their parents had an important role in their lives (Ryan and Runswick-Cole, 2008). The notion of disability is closely related with stigma. Who is stigmatised and what are the coping mechanisms are discussed in the next section after stigma has been conceptualised.

2.3.2. Stigma

2.3.2.1. Conceptualising stigma

The notion of stigma, an Ancient Greek word (στίγμα) was used in the past in Greece to indicate those who had markings on the body or displayed unacceptable behavior. Later, the usage of the above notion was included in the Christian dictionary as an indicator of holy grace or a physical disorder that a person might have (De Paoli, 2004).

Stigma according to those that have worked with this concept has various definitions (Link and Phelan, 2001). For instance, leprosy was a disease that attracted stigma leading to the complete ostracisation of lepers from society (Opala and Boillot, 1996), or it may arise in the context of mental illness (Phelan, Link, Stueve and Pescosolido, 2000).

Stigma is associated with prejudice or discrimination (Arboleda – Flórez, 2005; Stuber and Meyer, 2008). In order to aid the development of effective health strategies Stuber and Meyer (2008) examined the linkages between stigma, prejudice and discrimination. They linked stigma and prejudice to health, mentioning that stigma and prejudice "adversely impact health through five pathways". First, as Stuber and Meyer (2008) mentioned, discriminatory interactions cause stress and have negative implications for health and wellbeing. Secondly, stigmatised people are denied access to basic health and life resources. Often people perpetrate prejudice unconsciously. Studies have also shown that the "internalization" of stigma and prejudice by marginalized people is related to health problems such as depressive symptoms (Link, Streuening, Rahav, Phelan, & Nuttbrok in Stuber and Meyer, 2008) and unemployment (Link, in Stuber and Meyer, 2008).

A Recent National debate in 2014 about stigmatisation of disabled people was sparked in the UK by Lord Freud's suggestion that some disabled workers are not worthy of receiving the national minimum wage. Freud, the Welfare Reform minister, then apologised for the comment since his suggestion created criticism from disability charities and politicians. It was suggested that Freud should be removed from his post (Chakrabortty, 2014; McTague, 2014; Press Association – Mail Online, 2014; Press Association – The Guardian, 2014). After Lord Freud's comments, disabled people and organisations found the opportunity to express the stigmatisation and segregation that they felt in the society, emphasising that to be disabled nowadays in Britain is still a burden because of the uncertainty surrounding their benefits and all the welfare cuts and changes that prevail (Chakrabortty, 2014). Wahl (1999) suggests that stigmatisation occurs in educational settings and in the labour market, for example finding a job (Wahl, 1999, Scheid, 2005).

Prejudice against and isolation of disabled people are also developed through language. "Special Educational Needs" as a discourse to describe disabilities is not acceptable in my study because it locates the 'problem' within the child which has needs instead of rights (Runswick-Cole and Hodge, 2009). For the purposes of the specific study I use both terms *disabled children* and *children with disabilities* interchangeably because they are both used in Cyprus and are acceptable.

The language of "special educational needs" was first described by the Warnock Report which mentioned that 20% of children would experience those individual difficulties. The terminology has come to be seen as increasingly problematic almost forty years after the Warnock Report where it was introduced (DES, 1978).

Language is a barrier to inclusion and typically this discourse is underpinned by the medical model approach. In their article on challenging the discourse of special educational needs, Runswick-Cole and Hodge (2009: 199) argue that 'it is largely the medical establishment and other professions which pathologise individuals, by defining them, through a variety of negative and disempowering labels, such as "different", "deviant", "abnormal", "invalid" or "special"'. They provided an alternative discourse to the Warnock Report while they built on the work of other educators such as Tomlinson (1985) and Reggio Emilia (Philips, 2001; Vakil, Freeman & Swim, 2003) who also criticised the excluding language of "special educational needs". Their alternative approach is based on rights instead of needs for disabled children: "educational rights" instead of "educational needs" that "support all children in their education" (Runswick-

Cole and Hodge, 2009: 201). Moreover, the rights language that they introduced is a tool that reduces discrimination and stigma against disabled children and their families.

Erving Goffman was one of the first sociologists to conceptualise stigma (Goffman, 1963). According to Goffman, people 'believe the person with a stigma is not quite human' (p. 15); he or she possesses 'an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme, a person who is quite thoroughly bad, or dangerous, or weak' (Goffman, 1963: 12). Stigmatisation means lack of acceptance by society. Stigmatised people are the people who 'depart negatively from the particular expectations'; they are not "*normals"* as Goffman puts it (p. 15). Mental patients or physically deformed people are such stigmatised people.

Stigma, as Goffman (1963) stated, conceals a double perspective. On the one hand, "differentness" is linked to the notion of being "discredited". Here the extent to which differentness is visible varies and accordingly the extent to which the stigma is visible. Stigmatised people therefore face more or less prejudice against them.

An individual that is going to be 'more often faced with these situations than are we, [he] is likely to become the more adept at managing them' (Goffman, 1963: 31). On the other hand, a stigmatised person assumes or knows that his differentness is not always known or immediately perceivable by the people who are present. This perspective according to Goffman is called 'discreditable'. In this case a person faces 'unwitting acceptance by individuals that are prejudiced against persons of the kind he can be revealed to be' (Goffman in De Paoli, 2004: 8). Although there is an important difference, it is possible for a stigmatised person to experience both being *discredited* and being *discreditable*.

Goffman distinguished stigma in three types:
- Abominations of the body, where an individual is stigmatised because of an imperfection that he has in his appearance. In this type, disabilities such as having a facial 'abnormality' or any physical disability are included. Most of the time this type of stigmatisation is visible (Goffman, 1963; Olson, 2002)

- Blemishes of individual character include people who are perceived as weak willed. Stigmatised people in this group include criminals, alcoholics, unemployed or 'mentally ill'. In regards to the disabled people, in this group are children or adults with mental retardation, epilepsy or a disability that might not be visible to others from the beginning

- Tribal stigma is the case where people are stigmatised because of race, nation or religion, for example being an African American. This type of stigma can contaminate, as Goffman highlighted all the members of a family (Goffman, 1963) and in general it is associated with a less visible type of disability such as learning disabilities. Later in this section I discuss about visible and non-visible types of disability.

According to the third type of stigma above Goffman also suggested that stigma is not only perceived by those individuals or groups of individuals but also *by courtesy: it* affects people who interact and are in contact with those individuals, people who are 'close' to them. He characterised them as 'wise', and defined them, that they are normal persons who have a different situation which 'has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded a measure of acceptance, a measure of courtesy membership in the clan' (1963: 41). Parents of 'handicapped children' are included in the groups of people experiencing courtesy stigma. Studying ways of managing a courtesy stigma in an American context, Birenbaum (1970: 196) drew on Goffman's conceptualisation saying that courtesy stigma was experienced by a range of groups:

> *There are friends or relatives of those publicly identified as radicals, homosexuals, criminals, or mental patients; parents of handicapped children or children of divorced or handicapped parents; and, finally, friends or lovers of members of pariah groups in society, as "nigger lovers," who become branded as not fully competent.*

Courtesy stigma was reported by parents of children with physical, psychological and behavioural problems in Francis's study in Worcester, United States (Francis, (2012). On the basis of qualitative interviews Francis found parents experienced two types of stigma: courtesy stigma and stigma of being a 'bad parent' Bad parenting is experienced when parents 'perceived culpability for children's discrediting attributes' (Francis, 2012: 932). According to Francis (2012: 928), 'stigma is not a matter of children's discrediting attributes, but a matter of which parents, under what circumstances, are deemed worthy of blame, pity, or full acceptance in this era of medicalisation and anxious parenting'.

After Goffman's influential work on stigma, various investigators provided their own definitions. The variability that exists in the definitions 'is likely to lead investigators to conceptualise stigma in somewhat different way' (Link and Phelan, 2001: 365). Link and Phelan provided a conceptual observation in an attempt to conceptualise stigma

because according to them, the definition has been criticised as vague and individually focused. Their work is an extension of Goffman's work and more generally of social science research on stigma which highlights the fact that the stigmatising processes and circumstances that can affect people's lives are numerous. How mothers of disabled children understood stigma and how they experienced it is dependent on various factors and from various reasons. When, for example, people lack opportunities to socialise and to present themselves to others in healthy and non-stereotypical ways then labeling, 'difference', prejudice and discrimination come into play. In these situations disabled people become stigmatised (Pescosolido, 1992; Pescosolido, Martin, Lang and Olafsdottir, 2008).

2.3.2.2. Empirical evidence on stigma and disability

Researches in 2000s in the UK suggested that disabled people experience difficulties and unequal behavior compared with non–disabled people.   For example, in relation to employment, Smith and Tworney examined the characteristics of disabled people and the extent they fare in the labour market. They reported that in the United Kingdom in 2002, 81 per cent of the population of working age (that is defined as 16-64 for men and 16-59 for women) were in employment, whereas only 48 per cent of disabled people were in employment, meaning 52 per cent were not employed. In the previous years (1998, 1999, 2000), the percentages of employed disabled people in the United Kingdom were lower (45.2 per cent in 1998, 46.8 per cent in 1999, 46.9 per cent in 2000). In contrast, over 80 per cent of non-disabled people were in employment (80.3 per cent in 1998, 80.8 per cent in 1999, 81.1 per cent in 2000) (Smith and Tworney, 2002). Gingerbread, an organisation working for single parents in the UK, in one of their study findings pointed out that 34 per cent of single parents that were not working were parents that have a disabled child (Gingerbread, 2014).

The Department of Education in England has provided national statistics concerning education and 'special educational needs' for 2013. According to these data, 53 per cent of disabled pupils were attending mainstream schools in 2013, 39.6 per cent were attending state – funded special schools, 4.9 per cent independent schools, 1.8 per cent special schools and 0.7 per cent attended pupil referral units (Department of Education, 2013).

According to the studies above as well as other studies (described later in the section of families with disabled children) stigma still characterises disability since society does not fully accept people who either have a disability, for example an obvious genetic

condition, such as autism, downs syndrome or people in wheelchairs or a disability that may only be occasionally visible to others such as epilepsy. Both visible and non-visible types of disability reflect what Goffman (1963) referred to as discredited and discreditable conditions that disabled people may encounter.

It is clear, as Earle (2003) states, that society creates and establishes barriers which prevent the full participation of disabled people in their communities, both socially and economically. Culture, society, type of disability may influence whether a disabled person faces stigma and prejudice. Mitra, Posarac and Vick (2011) conducted empirical research on social and economic conditions of people with disabilities using data from the World Health Survey which were collected by the World Health Organisation in 2002-2004 in 30 developed and 40 developing countries. In the countries they examined, disabled people were significantly worse off economically and in most of them they experienced multiple deprivations. Thus, poverty and disability have been shown to be strongly related in Ghana, Bangladesh and Paraguay. A disabled person in a developing country may be treated differently or face marginalization, as Avoke found in his study about labelling in Ghana among people with disabilities. Disabled people in Ghana were put in a dependent position since 'they were considered to be incapable of fighting and protecting themselves' (Avoke, 2002: 771). Labelling in Ghana of disabled people was commonplace (Avoke, 2002).

In cases where stigma influences disabled people's lives, inevitably most of the time this affects their family too (Ainlay, Becker and Coleman, 1986; Earle, 2003). Murray (2000: 684) suggests that 'our relationships with our disabled children are subject to the huge pressures of prevailing prejudice towards disabled people in general'. Murray (2000) writes that even the loving emotions that a parent normally has for his/her child are perverted by people who believe that a disabled child is not capable of being loved. In the late 1950s, parents were advised to send their disabled children to hospitals and abandon them there. Dyer (1996) wrote that parents in the UK in the late 1950's took their children to the hospital because parents faced unbearable difficulties and that, by taking their children to the hospital, they believed the children would be in the hands of people who knew best how to treat them. For some parents this was a relief because of the stigma that they and their child suffered (Hevey, 1993; Murray, 2000). Since then the legislation in many countries such as the UK and Cyprus (Barton and Armstrong, 2007; DfES, 1995), and Sweden (Swedish Disability Act in Lewin, Westins and Lewin, 2008) has changed and perceptions around disability have changed also.

Mothers with disabled children also experience marginalization from people who criticise the behavior of their children, as Tina describes in her narrative (O'Connell *et. al.,* 2013). Tina is a mother with a disabled child who had the opportunity to tell her story and experiences in a study that O'Connell *et.al* (2013) undertook. She does not go out with her disabled son since she encounters intolerant, uncaring and unhelpful people on many occasions. In addition, Tina wrote about coming across religious people who said that children like her son are cursed or a gift from God. The frequent frustrations that mothers with disabled children experience in their daily routines from society tend to outweigh any positive feelings they have when their children achieve something:

> *Every tiny achievement creates a sense of extreme pride. When he first said 'Eddie loves Mum', it was my proudest moment. When he first offered to make me a cup of tea, I felt as proud as a parent watching their child graduate from university (O'Connell, et.al, 2013: 381).*

In Chapter 8, I discuss courtesy stigma that mothers with disabled children experience and provide evidence about mothers' ways of coping with stigma.

2.3.3. Inclusion

Inclusion is the notion that encompasses the right for every single child to be educated and treated equally. The concept of inclusion serves to integrate cultural, political, racial, ethnic, gender and linguistic diversity. Inclusion is the policy that was adopted in the 1994 conference that was held in Salamanca, Spain, organised by the Spanish government and UNESCO, with the purpose to further the objective of Education for All (UNESCO, 1994). Representatives of 92 governments and 25 international organisations (including policy makers, senior education officials, specialists, international governmental and non-governmental organisations and donor agencies) formed the World Conference on Special Needs Education. The Salamanca statement was the product of the meeting that introduced the concept of 'inclusion' and inclusive education.

Inclusive education more specifically is a commitment to Education for All, and at the same time is a constant ongoing process which respects diversity and the different needs of the students and their communities (UNESCO, 2008). Nillhom states that "schools should be organized on the basis of the fact that children are 'different'" and "diversity is celebrated within the classroom and that children have a right to participate, to learn and to build social relationships" (Nillhom, 2007: 436). Inclusive practice is

something that should be used in every country not only during school time. Every child has the right to live in an equal environment. Inclusion, as Corbett (1996) and Hollanders (2002: 66) argue, is 'more than being present in a place of education along with everyone else, being offered the same, or similar, content as offered to others'. In order to have active participation in a context such as school, inclusion should not be viewed as an option. It should be considered as a right.

The violence of disablism which is defined as 'the real, psycho emotional and systemic acts of violence against disabled children' is another experience that disabled children are enculturated into, as Goodley and Runswick-Cole argue (2011: 612). In order to explore the multi-faceted nature of violence focusing on the accounts of disabled children and their families, Goodley and Runswick–Cole identified four elements of the violence of disablism - the cultural, systemic, psycho emotional and real. Based on these elements, they suggest that through these elements of violence, 'we become more in tune with the everyday conditions of exclusion that lead, time and time again, to the ontological, cultural, community and physical exclusion of disabled children and their families' (Goodley and Runswick-Cole, 2011: 615).

Armstrong (2002), in her article on inclusion, performance and power and how these discourses are managed in the UK, highlighted how 'the term 'inclusion' has emerged as one of the most important signifiers of New Labour reconstruction encompassing the social, economic and educational spheres' (Armstrong, 2002: 53). However, in an agenda advanced under New Labour the term 'inclusion' has been reinterpreted as part of a coercive discourse and wider set of goals. Under these wider set of goals, discourses of poverty, panic, exclusion and crime are developed. In order for the successful management of education, a cross-disciplinary approach is suggested by Armstrong (2002).

Booth and Ainscow (2002) provide an inclusive approach to school development with their 'index for inclusion' as a resource to support inclusive development in schools. In an attempt to improve schools according to inclusive values, Booth and Ainscow worked with teachers, parents, governors, researchers and disability organisations in England and made recommendations about how their ideas should be used by schools in general.

Some research has shown that children with disabilities can be included in the mainstream educational system and in society in general (Norris and Closs, 1999; Peters, 2002). Norris and Closs (1999) discuss how inclusion can be implemented in

England if there is successful training for teachers. Peters talks about successful implementation of inclusion in the USA. However, there is always room for improvement. Waite, Bromfield, and McShane (2005), for example, suggest that the factors which facilitate inclusion are peer support and working in groups. Communication and teamwork are important for successful inclusion. It is important to have a common target and to work towards it (Walther-Thomas, Korinek, McLaughlin, Williams, 2000).

However, children and their families are still subject to marginalization in many cases even if they are included in the society in which they live (Murray, 2000). Teachers, for example, do not value all children equally mainly due to the fact that they do not have adequate knowledge about inclusive strategies (Murray, 2000). At the same time, 'assimilation practices, transmission pedagogy, and traditional curriculum may defeat the efforts to include all students' (Curcic, 2009: 532, Harry, 2005). Ryan (2005) explored the experiences of seventeen mothers of children with learning disabilities in the UK in public places. This study suggests that the inclusion of the children was unsatisfactory and incomplete with four areas impacting upon the experiences of mothers and their disabled children in public places: "the effects of the children's learning impairments, structural constraints, the attitudes of others and the attitudes of the mothers" (Ryan, 2005: 65). The following section is the third category that literature review covers. It includes caring for disabled children, care providers, mothers as the main care providers, parents and mothers' experiences in particular, emotional effects on mothers' effects, issues of mothers' satisfaction concerning services for disabled children and marital satisfaction, mothers' social support and satisfaction with formal and informal support.

2.4. <u>Caring for disabled children</u>

There is rather little research on mothers of disabled children; this group is missing from the literature on motherhood (Cole, 2004: 58). Some research has been undertaken in the UK (Ryan, 2005; Ryan and Runswick-Cole, 2008; Voysey, 1975), in the USA (Blum, 2007), in Australia (Keen, 2007), and in Belgium (Van Hove *et. al.* 2009). Thus far there is no research on mothers raising disabled children in Cyprus.

In a study of 21 parents of disabled children in the UK conducted in the 1960s, Voysey (1975) identified strategies that parents employed in order to manage. Becoming a parent of a disabled child, she found, involves dealing with the unexpected. Using normalising mechanisms or ways to 'cope' with problems such as stigma can legitimise mothers' own claims to the rights and obligations of motherhood (Voysey, 1970). Voysey (1972: 15) named this process of normalisation as 'the legitimation of suffering' where

different agencies and institutions offer a set of prescriptions with the aim to make the burden tolerable and acceptable. In order to maintain a 'normal life', parents accommodated to their child's disability through a framework of normalisation that had positive outcomes such as positive relationships with doctors or other specialists, or an improvement in their marital relationships (Voysey, 1975). As Voysey noted, 'because they do not choose their position, and far from being expected to refuse, are encouraged to welcome its responsibilities' (Voysey, 1970: 127).

Drawing on others' work, Keen (2007) aimed to examine how parents with disabled children form meaningful and productive partnerships in America. She found that family-professional partnerships can influence outcomes for all family members including the disabled child. She found that professionals are seen as the experts. However, she also found that professionals view parents as passive partners in parent-professional partnerships.

Parents of children diagnosed with an autistic spectrum disorder were the subject of Farrugia's study in Melbourne (2009). Farrugia interviewed twelve parents in an attempt to understand better the stigmatisation that parents faced. The results indicate that the medical diagnosis was critical for parents in order for them to resist stigmatisation. Chapter 8 provides an analysis of stigma and coping mechanisms that mothers used in my study after experiencing courtesy stigma.

Parents and mothers provide the majority of support and care during the lifetime of their disabled children. Most of the time, responsibility for the care of disabled children is provided by mothers (Judd, 2013; Maxwell and Barr, 2003). At the same time, however, it is assumed that a mother should have the appropriate support in order to help her child and herself (Glendinning, 1983; Roll-Petterson, 2001). Support provided to mothers and their disabled child is covered in Chapters 6 and 7.

Breslau (1983) examined housework and child care and suggested that having a disabled child at home increased the housework load of working wives as well as of homemakers to three hours more per week compared to mothers without disabled children. Furthermore, mothers spent four hours per week in addition with their children when they engaged with them in therapies at home and thirty hours every year taking their disabled children to therapy centres. These findings were reported more than 30 years ago. Nowadays, accompanying children to their therapies has increased a lot. Breslau, (1983: 629) suggested that 'the finding that mothers of disabled children spend more time on household work suggests that the care of the disabled child is not at the

expense of other family responsibilities (at least not entirely)'. The evidence from this study indicates the importance of the family regarding caring for the disabled child which most of the time is at the expense of the time that a mother has for herself. This raises issues concerning the importance of paid home care for disabled children that can substitute for mothers' care (see Chapter 3).

Leiter, Wyngaarden Krauss, Anderson and Wells (2004), in their study conducted in 1998-1999 in the USA, reported that almost one fifth of the mothers spent at least 20 hours a week in health care for their disabled children at home. More than half of the mothers in the sample mentioned the effects of having a child with a disability on their employment: cutting down their employment hours or stopping working in order to care for their child. The researchers examined the amount of time that mothers provided to their disabled children that included not only medical and therapeutic care but other forms of caregiving, such as feeding and bathing. They found that mothers developed new roles as health care providers to their disabled children at a formative stage of the children's lives which appeared to be intense and of long duration. This affected mothers' employment activity.

There is a large amount of evidence in many countries concerning the division of childcare between mothers and fathers but none that examines the division of caring work in families with disabled children. There is evidence from personal accounts. Maxwell and Barr (2003) examined a mother's reflections on her experience of raising a disabled child. This shows a disabled child lives at home longer than those children with no disability (Maxwell and Barr, 2003). This is also found by Taggart, Truesdale-Kennedy, Ryan and McConkey (2013) in their research on ageing carers' preferences for future care in the UK. Taggart et al (2013) examined through a mix method study the preferences of parents for their child's future care and the support systems that were required for those with intellectual disabilities. They found out that the majority of the carers preferred the disabled person to remain in the family home with a family member to support them instead of moving the person to the home of a sibling or to a residential facility.

We can see that in caring for disabled children mothers are typically the main care providers, and that they experience emotional effects from raising a disabled child. Their emotions and feelings of satisfaction – including mothering and marriage - are important. Of special interest is the work related to social support that is provided to mothers and to their disabled children and the satisfaction with support. These aspects are discussed in the sections 2.4.1 and 2.4.2 that follow.

2.4.1. Emotional effects on mothers

Runswick-Cole (2010) focused on three mothers with disabled children with the aim of examining the psycho-emotional aspects of living and dying with 'disablism' as well as to foreground the disadvantages of families with disabled children. 'Disablism' is defined as the 'discriminatory, oppressive or abusive behavior arising from the belief that disabled people are inferior to others' (Miller, Parker, Gillinson, 2004: 28). Runswick-Cole's data were taken from the findings of a wider research project in England funded by the Economic and Social Research Council 'Does Every Child Matter, post-Blair? The interconnections of disabled childhoods' (Goodley, McLaughlin, Runswick-Cole and Campbell, 2011). Based on the interview data, she found that families with disabled children and children with life-limiting and life-threatening impairments experienced isolation, unsatisfactory support from the various service providers and poverty. In her article, Runswick-Cole (2010: 824) suggested that it was the time 'to challenge the marginal position' of those children and thus families.

In a study conducted in New England communities, Blum (2007) examined mothers of children with invisible, social, emotional or/and behavioural disabilities with the aim of refining feminist theories that redress the idea that mothers are to blame for their children's troubles. Through in-depth interviews and fieldwork with mothers raising disabled children, Blum argued that mothers with children with invisible disabilities constitute a model of maternal valor, meaning that they are responsible for their children's future in a period of public stinginess and medicalization. She comes to this conclusion as more mothers 'are blamed as proximate causes if they do not make unrelenting efforts, paralleling "concerted cultivation," to resolve them' and because 'such mothers often exceed concerted cultivation, as they seize authority, as vigilantes, within educational and medical systems' (Blum, 2007: 202).

Some studies show that many mothers with disabled children are optimistic and enjoy life and are able to cope with disability (Moor, 2012; O'Connell, O'Halloran and Doody, 2013; Weis, 2008). For example, O'Connell, O'Halloran and Doody, a mother, a nurse and an academic (2013) respectively, wrote an article focusing on a mother's feelings and reflections on raising a child with autism. The study described the mother's story - from the difficulties that she had in the beginning to the better place that she arrived at during the study. Moor (2012) wrote an autobiographical account as a single mother trying to support her child who was diagnosed with Downs syndrome and then with autism. Weis (2008) also described her life journey in raising her disabled daughter. She

described the challenges that she had to face after the birth of her disabled child but also the blessings that she experienced every day. She talked about important lessons that she learned after the turning point of awareness of her child's disability.

In their qualitative study of parents of children with chronic illness in Australia, George, Vickers, Wilkes and Barton, (2007) showed that parents felt that their voices were not heard or valued by professionals and that they lost confidence and trust towards them. Parents' experiences, and mothers more specifically, are often undervalued as shown as well in the literature review of Ryan and Runswick-Cole (2008: 199); they suggest that mothers with disabled children 'occupy a liminal position because they are often not disabled and yet they can experience forms of disablism'.

Having a child diagnosed with a disability can be regarded as a reversal of normative expectations of what it means to have a 'normal child' that provokes a range of possible different feelings in parents such as crisis. For the purposes of this study the term crisis is defined as the first set of emotions that follows when a parent becomes aware of the disability of her or his child.

Raising a child is not an easy task. A parent has to find the time and energy to raise the child, to be there when he/she grows up and to manage the demands and stresses that are involved. A parent who raises a child with a disability 'must find additional resources to cope with the specific needs of that child' (Diamond, 1994: 168). Singh (2016: 1107) in a study of 23 families examined caring for and loving a child diagnosed with autism. He notes that this 'can be an emotional journey for parents' and that it 'leaves parents in a 'foreign' land with no guidebook on how to navigate the many twists and turns in the journey of parenting a child with autism':

> *[the parents in the study] 'embraced and resisted the medical model of disability by seeking and pushing for a clinical autism diagnosis and subsequent treatments, while at the same time challenging the limits the medical model places on their children by providing them opportunities, possible futures, and a sense of personhood'* (Singh, 2016: 1107).

When a child is diagnosed with a disability or chronic illness mothers experience various feelings. Feelings of anxiety, coping, loneliness, grieving process or advocacy have been identified (Blacher, 1984; Goldberg, Magrill, Hale, Damaskinidou, Paul and Tham, 1995; Landsman, 2009; Marshak & Seligman, 1993; Panitch, 2010; Runswick-Cole, 2007; Rutgers et al., 2007; Ryan, 2005).

Huang, Kellett and St. John (2010) in their study of the experiences of 15 mothers who learned that their child had cerebral palsy drew on the concept of crisis or stages of grief (Sicile-Kira, 2004) - the reactions and feelings of shock, anger, fear and uncertainty about the extent of disability and any other associated impairment.

As Morris, Blake, Stimson, Borek and Maguire (2016) wrote, being responsible to care for a disabled child is not something that any parent should expect or plan for. Even in cases where parents may know in advance of their child's disability, they hope for the 'typical development' right up to the birth. The time of awareness is something that empowers unexpected reactions such as shock and refusal.

McCauley (2010) in her study of the experiences of six parents of children diagnosed with autism found parents experienced intense feelings of loss that McCauley described as a 'grief' reaction, after their child was diagnosed. She suggested that these feelings were related to the fact that parents before the diagnosis was given would have 'envisioned' a life for their 'normal' child. McCauley argued that the sooner the grieving process can begin the quicker the acceptance of the child by the parents, which in turn leads to them seeking appropriate support for themselves and their child'. Grief stages, as they are described by Sicile-Kira (2004) and other researchers, are defined in Chapter 4 and are analysed in regard to my study in Chapter 5 where I analyse mothers' feelings and experiences of awareness of their child's disability.

Parents in Cyprus believe that they have to support their children for ever especially if their children are disabled (Symeonidou, 2009). They have a fear of dying before their children and wish to live longer in order to take care of them for the rest of their lives (Theofilou, 1980). Feelings and first experiences of mothers that follow their disabled child's birth until the time of awareness constitute the first research question as it is examined in chapter 4.

A sense of fear accompanies a lack of knowledge concerning disability that parents as 'others' experience (Goffman, 1963). However, not all the feelings and experiences are negative as it is suggested in the literature that characterised families of disabled children. Mothers 'adapt, adjust and develop a whole range of skills as they mediate and negotiate the world on behalf of their children' (Ryan and Runswick-Cole, 2008: 204, Green, 2001, Read, 2000).

Blum (2007) as mentioned in the beginning of the section, in her in-depth interviews with 45 mothers who raise children with invisible disabilities presented cases of mothers who

were vigilant of their children's future: they are 'vigilantes' acting on behalf of their children in a period of public stinginess and medicalisation. There are mothers that strengthen and 'try to help their children to develop resilience and coping strategies' (Read, 2000: 113) in a way to develop practices of 'normality' (Kelly, 2005). Read highlighted the anxiety of mothers but also how they became more outgoing and developed confidence.

Blum argued that mothers with children with invisible disabilities constitute a model of maternal valor, meaning that they are responsible for their children's future in a period of public stinginess and medicalization. She comes to this conclusion as more mothers 'are blamed as proximate causes if they do not make unrelenting efforts, paralleling "concerted cultivation," to resolve them' and because 'such mothers often exceed concerted cultivation, as they seize authority, as vigilantes, within educational and medical systems' (Blum, 2007: 202).

Trute and Hauch (1988: 191) conducted a study of families with disabled children in Canada. They highlighted the fact that mothers 'displayed a remarkable absence of symptoms of depression and scored within normal ranges of self-esteem'. Trute and Hauch talked about the existence of the positive family adjustments after the birth of a disabled child in the family.

It is obvious that a mixture of feelings both positive and negative is expressed in the literature. This is not something that has been much stressed in the literature on mothers in Cyprus who have children with disabilities.

2.4.2. Disability and maternal employment

A survey conducted by Maplethorpe, Chanfreau, Philo and Tait (2010) from the Department for Work and Pensions investigated the circumstances of British families with dependent children in Britain in 2008. The report covers topics such as family characteristics, health, work and income, child characteristics, childcare and child maintenance. Among other findings, mothers from families with disabled people compared to mothers without disabled family members were found to have fewer employment opportunities in the top three socioeconomic groups (managerial, professional and associated professional). Another important finding was the fact that 68 per cent of mothers in families with disabled members (one adult and one child at least) were more likely to stop working for more than two years than mothers without disabled

people in the family (54 per cent) in all socioeconomic groups. Families with at least one disabled child and one disabled adult were twice as likely as the others to be living on a low income because of caring responsibilities of the other members of the family as well as of the employment opportunities and trajectories.

The socioeconomic background of the family may affect mothers' ways of raising their disabled children. It may affect their jobs and the ways mothers give meaning to their experiences. For example, mothers with a lower socioeconomic status may be less satisfied with the support provided to them and to their disabled children. The socioeconomic position of mothers affects not only the chances for education and occupation but the way they encounter the unexpected events of life such as the birth of a disabled child.

Emerson, Hatton, Llewellyn, Blacker and Graham studied the extent to which the feelings of mothers with disabled children were different according to their socioeconomic position. They studied 6,954 British mothers with dependent children under the age of 17, of whom 514 were disabled. Among their findings, they found a statistically elevated risk of poorer well-being among mothers with disabled children in the UK who were from a poor socioeconomic background.

It is well documented that parents with sick children need time off from their employment. Smith and Kim (2010) mention that about half of U.S. employees do not receive any paid sick days that they can use to care for their family members. This can lead to them being fired or penalised if they take time off work in order to take care of their sick child, as Schuster and Chung suggest in an article in the New England Journal of Medicine (2014).

Heymann, Toomey and Furstengerg (1999) examined the working conditions that determined whether parents are able to take care of their children when they are sick. The survey used a sample of mixed-income urban parents aged between 26 and 29 years old who participated in the Baltimore Parenthood Study in the USA. Among the findings of their study, they found that 42 per cent of the parents had paid sick leave or vacation leave in order to care for their sick children. As they say, 'providing paid leave to any kind of parents significantly increases their availability to care for their children' (Heymann, Toomey and Furstengerg, 1999: 873).

Not all parents have this right. Forty-two per cent of the working parents in the study of Heymann et.al. (1999) in the USA cared for their sick children, while 58 per cent

continued to work and left their children to be cared for by others. More than half of the parents who were able to stay at home and provide care to their sick children mention that the reason they did so was that they received some type of paid leave. Only 14 per cent of those parents who stayed at home had paid leave to care for sick members in the family (Heymann, Earle and Egleston, 1996; Heymann et.al. 1999).

Employed mothers with disabled children face considerable pressure at work. Scott (2010) examined forty in-depth interviews with mothers' (and a few fathers') accounts of care for disabled children, in Oregon, USA. More specifically he interviewed 33 mothers alone, 3 fathers alone and four couples together. Mothers with disabled children faced great pressure in the face of care work demands to reduce their working hours or they had to stop working completely in order to handle the increasing care work that was a necessity for their children. Scott concludes that even more than in families with non–disabled children, mothers of disabled children experience a 'disproportionate burden of care' (Scott, 2010: 674) because of the lack of alternative care, the inflexibility of the employers or because their child had extraordinary needs. Her study underlined the results of other previous studies where mothers of disabled children have lower labour force participation than those whose children did not have a disability (Cohen and Petrescu-Prahova 2006, Porterfield, 2002). Poverty, segregation and abuse are more likely to be experienced by disabled children as research in the United Kingdom has shown (Read, Clements, and Ruebain, 2006).

2.4.3. Childcare and disabled children

Childcare is an issue for families with disabled children either as supplementary care or as the main care provider when both parents work. Moreover, if a mother works and at the same time raises a disabled child, the combination of work demands and care responsibilities is increased and mothers may experience greater work-family demands (Hauge *et.al.*, 2013; Spiess & Dunkelberg, 2009). Studies in the USA (DeRigne & Porterfield, 2010) and in Norway (Hauge et al., 2013) suggest that mothers with disabled children seek part-time work, work for fewer hours or return later than the norm after their maternity leave. Dillon-Wallace, McDonagh and Fordham (2016) recently compared the employment and work experiences of a group of 292 mothers with disabled children with mothers of children without disabilities in Australia. They found only few differences between the two groups studied regarding employment characteristics and job quality but significant differences concerning the overall work-family balance. Fewer mothers with disabled children mentioned that work had positive effects on their families'

functioning. For these mothers work-family balance was considered not as positive as for mothers without disabled children.

In a paper by Powers (2001) concerning the impact on mothers' work of children with serious health problems in America, there is evidence to suggest that in high–income families, mothers have more chances to purchase childcare in order for the mother to continue working, compared with mothers on low incomes. This is similar to families without disabled children.

2.4.4.   Maternal satisfaction with services for disabled children

One important aspect of maternal satisfaction concerns the contact between mothers and health care providers in therapy clinics. There is little research on this. An exception is Green's study (2001) in South Florida, USA, of seven mothers who showed interest in participating in extensive interactive interviews. These data were taken from a bigger survey of 81 mothers of children who were regularly treated at one of three therapy clinics. Green found that mothers who were more satisfied with the therapy clinics were mothers who interacted with 'wise' individuals; those 'whose special situation has made them intimately privy to the secret life of the stigmatised individual and sympathetic with it' (Goffman 1963: 28) as compared with those 'who have little or no personal experience' of the stigmatised (Green, 2001: 800). Another finding was that 'among mothers who do not prefer interactions with wise individuals, perceived stigma is inversely related to overall satisfaction and moderates the relationship between the social environment and satisfaction' (Green, 2001: 798).

Malacrida conducted a study with thirty-four mothers in Canada and England, and aimed to understand the stigma that they encountered from their experiences with medical, psychiatric and educational professionals. She suggested that the mothers, in their attempts to help their children achieve their full potential, faced stigmatisation and 'were named as over-protective, over-achieving, or simply in denial of their children's true limits' (Malacrida, 2001: 146).

2.4.5.   Marital satisfaction

Marital satisfaction is another relevant issue. The literature suggests that mothers with disabled children compared to mothers without disabled children are more likely to be divorced (Fischer, 1990; Jesser, 2003; Reyns, 2006; Shtayermman, 2013). Shtayermman (2013) conducted an online web survey of 253 parents of children diagnosed with autism. He identified a relationship between marital satisfaction and

being a parent of a child diagnosed with autism which was linked to parental stress. Jesser (2003) carried out a quantitative research project in California, US, of the parents of children diagnosed with autism. The object was to compare the level of autism and the effect that the child had on parental relationships and marital satisfaction. He found a relationship between the severity of autism and marital satisfaction. He suggested that child behaviours have a significant relationship on marital satisfaction. Children with more severe disabilities increased the level of marital dissatisfaction of their parents.

In this section we can see that mothers raising disabled children are, and are seen as the main carers of their children. Mothers adopt strategies in order to accommodate their children's disabilities and face stigmatisation. Issues of maternal and marital satisfaction are also involved. Mothers experience problems with their jobs, and talk about feelings of grief during the time they first become aware of their child's disability. In Chapters 6 and 7 I cover relevant literature on the support that mothers in this study mentioned that they receive. In the sections 2.4.7 and 2.4.8 I review the literature on satisfaction for both formal and informal support.

2.4.6. Social support for disabled children

According to Williams et al. (2004) social support has many definitions and generally it has been a concept difficult to conceptualise, define and measure. Hupcey (1998) conducted a critical analysis of studies of social support for the purpose of concept clarification. He focused on 200 studies published between 1978 and 1996. After carrying out the review he defined social support as 'a well-intentioned action that is given willingly to a person with whom there is a personal relationship and that produces an immediate or delayed positive response in the recipient' (Hupcey, 1998: 313). Social support is categorised into two basic types - instrumental and emotional (Veiel, 1985). Expanding the basic categorisation, House (1981) offered four different aspects of social support. Firstly, emotional support is about sharing life experiences. Secondly, instrumental support includes services that directly assist the person that needs the support. Another aspect is informational support that involves the provision of advice and information given to the person in need and, lastly, appraisal support which refers to useful information that is given for self-evaluation (Findler, 2000).

Instrumental support includes economic support according to House (1981). It concerns goods and services that individuals may provide to people in need. In terms of disabled children, social support includes early intervention programmes, for example, educational support that is offered when children with a disability go to school or need emotional support to face the barriers that are created by society. In their article on

educational support Mortier, Hunt, Desimpel and Van Hove (2009: 337) use the term 'support' in the plural and they define it as a 'variety of possible strategies and adaptations that are intended to facilitate the full engagement and optimized learning of a child with disabilities in a general education class and school setting'. They suggest that the collaboration between parents and teachers was successful when they implemented plans that increased the engagement of children in activities in the classroom, including their social interactions as well as their academic skills. The team process was evaluated by the team members as 'effective, unifying, creative, clear, and practical' (Mortier et. al. 2009: 337). Support is closely related to the concept of care (Tronto, 1993). Tronto defined the term as both a practice and a disposition. She identified four phases of care which are 'caring about, taking care of, care-giving and care-receiving' (Tronto, 1993: 106). According to Tronto, these phases are analytically separate but interconnected. Tronto's definition recognises the cultural variation of care and at the same time that care extends beyond the family.

Williams et.al (2004) reviewed thirty definitions of social support through a search of academic databases that could apply to the experience of being a parent. For example, they cited Cobb (1976) who undertook a dissertation and defined social support as 'information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligation' (Williams, et. al., 2004: 950). Williams et al reviewed the study of Gottlieb (1978) on informal helping behaviors in a sample of 40 single mothers who defined social support as emotional and problem-solving behaviours as well as indirect personal influence. Emotional and problem-solving behaviours according to Gottlieb include talking, providing clarification, and suggestions to others. Social support has also been translated as 'indirect personal influence' which according to Gottlieb consists in offering unconditional access and readiness to act. A more recent study that Williams et. al. reviewed was that of Coffman and Ray concerning high-risk pregnant African American women. Coffman and Ray (1999) use the phrase 'being there' as an indicator of how informants describe social support to cover various behaviours such as caring and respect. They summarise the definitions of support and identify a number of aspects concerning:

> *time (short or long term) and timing (when); relationships and social ties (structure, strength, type, nature); supportive resources (emotional, material, skill or labor, time, cognitive, information, feedback); intentionality of support; impact of support (positive or negative); recognition of support need; perception of support; actual support; satisfaction with support; characteristics of recipient; and characteristics of provider* (Williams et.al., 2004:947).

Williams et. al. (2004) suggest that the most effective way to develop a definition of social support is a qualitative and contextualized approach.

2.4.7. Parental satisfaction with formal support

Public support is provided in a country according to the characteristics and the priorities of the state. In Chapter 3 I discuss the formal support provided in the UK and Cyprus. The reason that I have chosen the specific countries is that the UK is the country where I am supervised and Cyprus is the country that I am undertaking my PhD. The two countries are related since Cyprus used to be a British colony in the past and, although it has been an independent country since 1960, it is still influenced by the UK in many aspects. Parental satisfaction with formal support provided to disabled children in the UK was studied in a national survey in government regions across the UK by Grant and Hamlyn (2009). They measured parental views on five elements with sub-indicators within three service areas one of which was education. Positive experiences of education were expressed by only 37 per cent of parents with disabled children and only an 11 per cent found the school supportive (Grant and Hamlyn, 2009).

Based on the same survey, Slade, Coulter and Joyce (2009) state that, inadequate knowledge about disability has led to misunderstandings and disagreements about how to manage and support children. Porter, Georgeson, Daniels, Martin and Feiler (2013) wrote about the support that parents with disabled children want for their children based on the *duty* that schools in England have towards children with disabilities. They found that parents thought that 'a standard one-size-fits-all' was not the appropriate approach (p. 17). Differentiation of practice, based on the abilities of each pupil, is essential according to the Index for Inclusion that Booth and Ainscow introduced (2002). They recommended that teachers should differentiate the material and job in order to be adjusted to the abilities of their children. They sought an inclusive philosophy and practice, the right for every child to be educated and treated equally in the school community and healthy co-operation with the educators for the development of their children.

In Cyprus, every disabled child receives an amount of money every month from the government according to the type of disability and needs of the child. For example, if a disabled child wears nappies or needs a special assistant every day, his or her family will receive more money than a child who does not need a carer every day at home (Ministry of Labour and Social Affairs, 2013). Parents' perception of support is likely to have some relation to the type of the school that their child attends. However, there is a lack of

literature on this in Cyprus, something I will examine in my study. Formal support and findings from other studies are analysed in Chapter 6.

2.4.8. Parental satisfaction with informal support

There is a vast literature on social networks. In my study I concentrate on social networks and disability which includes the people a mother knows and is supported by through her interactions.

Ellison (2006) studied 42 families with disabled children from four ethnic groups in the US (African American, European American, Latino and American Indian) in order to explore the nature and meaning of social support, perceptions regarding the disabled child and the extent to which social support and perceptions of the disabled child varied among different ethnographic and economic groups. Parents found their social networks, both formal and informal, to be supportive of the care of their disabled children. Ethnicity did not show any influence on families' perceptions of social support. Parental beliefs about the diagnoses given were shown to be influenced by the medical model of disability, views of normalcy, labelling or stigmatisation and discrimination.

More specifically, informal support networks, as Ellison (2006) writes, are comprised of individuals such as members of a family, friends and social organisations. Husbands and fathers are a vital part of informal support to children. There is research such as Ellison's work on the nature and meaning of social support for parents with disabled children in the US, or Craig's study in New South Wales (Craig, 2006) that compares the total child care time that mothers and fathers spend with their children. This study found that mothers with disabled children who talked about informal support did not mention their husbands; where they did mention instrumental help (services that directly assist the person that needs the support) this included their husbands' financial support and provision of transport to therapists of their disabled children (Ellison, 2006).

As indicated above, according to Coffman and Ray (1999), fathers' contribution was translated by behaviors such as caring and respect. As Brannen and Moss (1989) and Brannen (1990) argued, the contribution of fathers' support was in a way more ontological and symbolic. According to Brannen (1990: 274) 'rather they seemed to be central to individuals' sense of ontological security, giving them the feeling that someone is 'there' if they need them'.

Undoubtedly a father's role is important and there is evidence that shows its significance (Habib, 2007; Van Hove, et al., 2009). For example, from a nonacademic perspective Habib (2007) wrote about a father of a disabled boy who set up a project to build inclusive schools and communities. He funded this by making a film of his child's daily life and experiences and the family's hopes and struggles.

Grandparents can provide an important source of informal support (Lee and Gardner, 2010). Parents with disabled children ask for support from members that are not in the nuclear family as a matter of a necessity (Gardner, Scherman, Efthimiadis, & Schultz, 2004; Vadasy, Fewell & Meyer, 1986). The most common source is grandparents (Katz and Kessel, 2002). The literature relevant to informal support is analysed in Chapter 7.

2.5. <u>Summary</u>

In closing this chapter, I am adopting the position of Curran and Runswick-Cole (2014: 1618) that 'disabled children's childhood studies starts with childhood and disability but never ends here'. A study that engages with the experiences of mothers with disabled children, their experiences, support and stigmatisation, can contribute to a wider theoretical debate about motherhood and disabled children.

Representations of mothers nominated them as the central care givers and as those who have the ability to turn their children into responsible adults. The literature also finds that mothers experience motherhood differently based on different cultures and contexts. Big differences exist, as the literature makes clear, in mothers' experiences before and after motherhood. Discourses on motherhood still promote traditional representations of mothers as full-time carers that do not conform to reality although the negative aspects of motherhood are also expressed in the literature.

The literature highlights the importance of mothers in caring for a disabled child and that mothers bear most of this responsibility. Mothers' experiences include daily interactions with therapists and other professionals and encompass an emotional journey with a range of feelings. A key finding is the social support that becomes a necessity as care giving responsibilities become greater in cases of mothers with disabled children.

The literature on social support is divided into two main categories - formal and informal support. Formal support which is provided by the state services such as schools left the majority of parents with negative experiences or led to misunderstandings and disagreements between parents and the schools. Informal support included husbands in

providing financial support to mothers and children, with other types of support mainly ontological and symbolic.

As the literature suggests mothers' personal lives are influenced by their marital and employment status. Mothers with disabled children are more likely to be divorced or to express significant levels of marital dissatisfaction (Fischer, 1990; Jesser, 2003; Shtayermman, 2013). Another key finding is that mothers with disabled children experience changes in their employment status because of the caring needs of raising a disabled child. Although mothers' employment has increased in recent decades in countries such as Britain, this development has not occurred among mothers of disabled children. As studies found, mothers' support needs are more long-term compared to mothers of non-disabled children. On the contrary, mothers of disabled children are at risk of being fired or are penalised after taking frequent time off work in order to take care of their child.

Mothers and their disabled children face stigmatisation such as labelling and prejudice. Mothers face stigma by courtesy as they are close to their disabled children. As studies found, mothers adopt a range of coping mechanisms such as normalisation in order to cope with stigma.

The literature on mothers of disabled children in Cyprus in relation to the educational system and the implementation of policies of inclusion in the schools suggests that disabled children are not included fully in schools. Major problems such as limited opportunities in the subjects that disabled children can study at school, school timetables are not flexible for them and teachers who subscribe to inclusive practices but do not implement them in their teaching. Research on family collaboration with schools and the lack of involvement of parents who have disabled children in Cyprus' educational policies suggest that parents' voices are not taken into account even though parents have a vital role in their children's lives.

Cyprus lacks research on mothers' feelings and experiences on raising a disabled child. It requires more evidence about the support that mothers receive (or not) and their satisfaction with support, together with the stigma they face and how they cope with it. My study on mothers with disabled children in Cyprus sets out to examine mothers' feelings about having a child with a disability, their experiences of raising a disabled child including from the time of awareness of the disability, the stigmatisation the mothers face from society and the ways in which they cope with stigma. Through my study I intend to

build upon and add to the literature, both substantively for Cyprus and theoretically to contribute to the understanding of disability more generally.

It follows a presentation of the general context of the study. In the next chapter, I provide a description of the Cyprus context, in order to make the study's background more understandable and provide some answers to possible questions before I move into the methodology and analysis chapters.

Chapter 3 – Cyprus Context

3.1. <u>A short history of Cyprus</u>

"A discussion about disability and education in the Greek-Cypriot culture should have the long troubled political history of the country as a starting point" (Symeonidou, 2009: 565). In order to understand the current situation that exists in Cyprus with regards to disability and disabled children it is necessary to study the historical context of Cyprus and in particular, attitudes towards disabled people as well as the level of support that is provided to them.

Although Cyprus is just a small island in the Mediterranean, it has a long history, which has significantly influenced the development of the island, both socially and economically. Symeonidou (2009) states that the Church, the State and Society have been the links in a powerful triadic chain. This chain has affected Cyprus' development in every aspect. Disability is considered to be one of these aspects.

In an attempt to understand how disability is perceived in Cyprus today we need to go back many years. For 300 years (1571 – 1877) Cyprus was under the Ottoman sovereignty which could be characterised as an oppressive domination in Cyprus (Michael, Gavriel, and Kappler, 2009; Educational Institute, 1994). Rules were strict and there was very little freedom. Ottomans as Muslims, did not allow Cypriots the freedom to practice their own religion, namely, Orthodox Christianity. Thus Cypriots, in order to avoid persecution, kept their religion secret. They became Crypto-Christians to express their religious feelings (Richter, 2007). Crypto-Christians was a term used for Christians who were not allowed to express their religious beliefs. Instead, they pretended that they were Muslims but secretly practiced (crypto – κρυφά = hide) their Orthodox religion in underground churches, mainly during the night (Richter, 2007; Nicolaou, 2013).

With the British colonialism that followed (1878 – 1959), the Ottoman Empire Cypriots acquired more rights in terms of religious and societal matters. They could now practice Christianity and use and decorate their churches and could also conduct ceremonies without any restrictions, something that was not allowed during the Ottoman period as churches had remained closed. Any decisions that were made concerning political and societal issues were only taken after discussions were held with Archbishops and other priests. So the State was governed in part by the Church, unofficially. Members of parliament during colonialism were priests and Metropolitans. What is more, during the first serious uprising against British rule, which happened in October 1831, the leader was the Metropolitan Dionisios Kykkotis (Mavros, 2010; Pittaka, 2007).

The connection between the Church and the State was officially legalised when in 1960 Cyprus became an independent country. The first president of the Presidential Republic of Cyprus was Archbishop Makarios III. Having the same person as both president and Archbishop, it was obvious that the Church, the State, and Society, were inextricably connected. As Symeonidou states, 1960 was the time where 'the Church undertook the role of the State' (2009: 567). Only a couple of years after Makarios III's death, the State began to separate its role from the Greek Orthodox Church.

Three years after the independence of Cyprus the Cypriot dispute between Greek-Cypriots and Turkish-Cypriots began which rose to additional problems regarding the functioning of the government. The two communities before the independence of Cyprus lived in social harmony around the whole island (Papadakis, 1998). Their conflicts began after independence. Between 1963–1974, various peacemaking strategies were attempted however, without any substantial result.

In 1974 Turkey invaded Cyprus and occupied the northern part of the island. Since then, 36 per cent (36%) of the island is under Turkish control. Greek-Cypriots who lived in the northern part of the island moved to the south and became refugees. There were also Turkish-Cypriots who fled from the south to the north.

Since 1974 the two communities live separately with a ceasefire line dividing them, with two different governments and with different policies. Cyprus became a member of the European Union in 2004. The history of Cyprus is presented in the timeline in Figure 3.1.
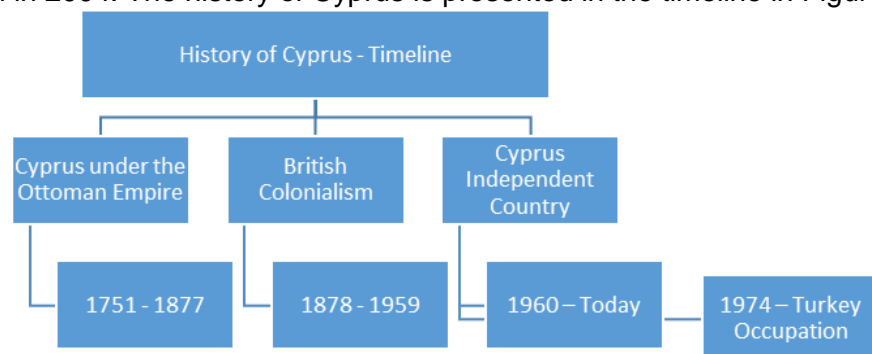
Figure 3.1 - Timeline of Cyprus History

As shown above, the history of the island is important in order to understand the situation that exists on the island regarding disability. After presenting some statistics and data in the next section I will examine the history of disability in Cyprus and I will also examine how disability is perceived in Cyprus today.

3.2. <u>Statistics and Data</u>

In this section I present demographic data and characteristics of the population in Cyprus and some data on disabled peopled that was taken from the demographic report on the population of Cyprus for general information (Statistical Service, 2014), as well as data from the social welfare services for disabled people in Cyprus as there is no statistical data for the population of disabled people in Cyprus.

Before the presentation of demographic data it is important to mention that the 2008 world economic recession has influenced Cyprus as well since in March 2013, 10 per cent was cut from the monthly allowance for the disabled. This continued for eight months until the government revoked its decision and disabled people's allowance was restored to the former amount. These cuts that the state imposed in almost every area of government funding and allowance together with the crisis of 2013 affected vulnerable citizens as well.

3.2.1. Demographic Data

According to the demographic report of 2014 the population of Cyprus is estimated at 938.400, with 74% being members of the Greek Cypriot community, 9.8% Turkey Cypriots and 16.2% foreign residents. The proportion of children below the age of fifteen years decreased to 16.4% of the population, while the proportion of elderly people over the age of sixty-five years increased to 14.6% in 2014 compared to 1992 and 1982 as presented below. The proportion of persons aged between 45-64 increased as well, indicating an ageing of the working age population. It has increased as we can see in Figure 3.2 below from 17.6% in 1982, to 19.3% in 1992, and to 24.5% in 2014. Men aged between 25-29 (35000 men) and women aged between 30-34 (35000 women) were the largest groups of the population in 2014.

Figure 3.2. presents the population by age and gender in 2014, in comparison to the same proportion of persons in 1992 and 1982 as taken from the Statistical Demographic data.
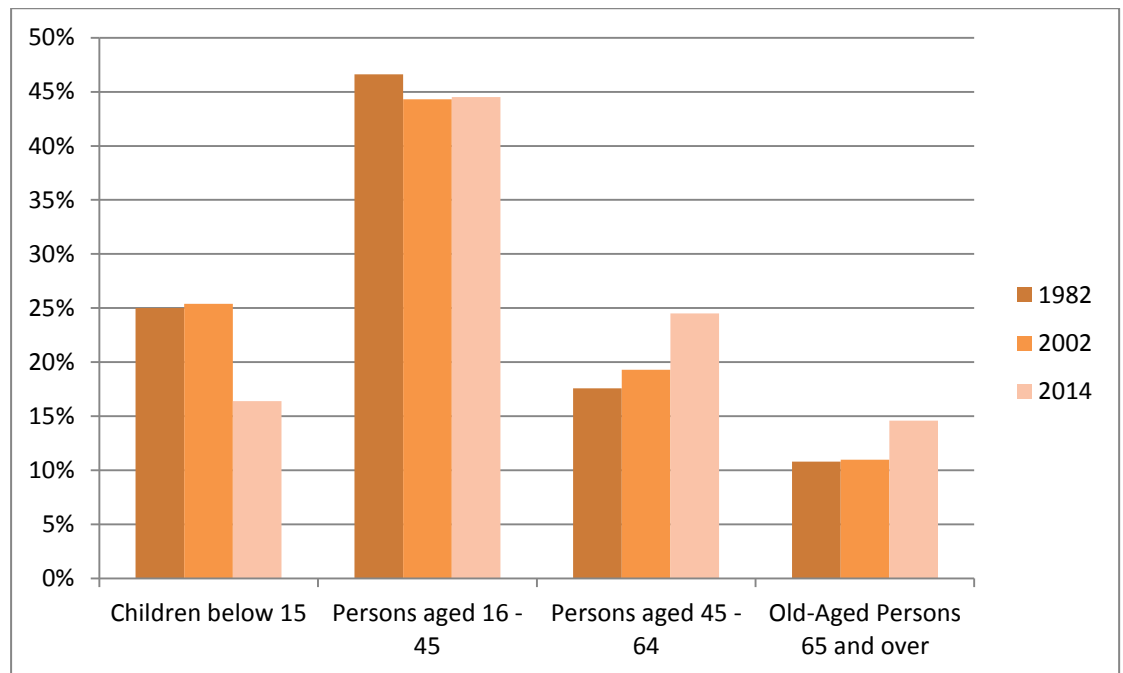
Figure 3.2 - Population in Cyprus 1982, 2002, 2014

Marital status and divorce rates shown in the Republic of Cyprus demographic report of 2014 show that the total number of marriages decreased between the years 1975 to 2014: the total number of marriages in 1975 was 10.6 per thousand population, in comparison to 2014 where 6.3 per thousand population got married. Cyprus has one of the highest marriage rates compared to most EU countries. While 6.3 per thousand of Cypriots got married in 2014, the European Union countries' mean rate was 4.2 per thousand, with Bulgaria and Slovenia being at the end of the table with a 3.0 rate per thousand population, and Lithuania being the only European Union country that comes before Cyprus' rates, with 6.9 per thousand population who got married in 2013. The mean age of male residents in Cyprus as a first marriage was calculated at 30.8 years, and for women at 29 years in 2014. Age at marriage in rural areas continues to be lower in Cyprus than in urban areas for both men and women. The Eurostat statistics show fewer marriages in line with more divorces: since 1965 the number of marriages has declined by nearly 50%, whereas during the same time period the divorce rate has increased from 0.8 in 1965 to 2.0 per thousand people in 2011 (Eurostat, 2016b).

The total divorce rate has increased as well in line with other EU countries. Demographic indicators in Cyprus reveal the divorce rates per 1000 population to be 2.21 in 2014 and 2.0 in 2011 in Europe. Almost half of the divorced couples in 2014 (48.6%) had no dependent children under the age of 18 years, 25% reported one dependent child, 18.9% two, and 4.2% reported three or more dependent children at the time of their divorce. The majority of married couples who were divorced lived in urban areas (78.6%).

The mean age of women when they gave birth to their first child was 28.8 years in 2014, while 30.4 years was the mean age of all mothers giving birth in 2014. Both numbers have gradually increased in the time period of 1975 to 2014.

3.2.2. Main industries and employment sectors for men and women

According to the Eurostat statistics (2014) the employment rate in Cyprus was 68% in 2015. This percentage was 8% below the national target of 75% which was needed in order to exclude the risk of poverty and social exclusion by 2020 (Eurostat, 2016). Regarding gender, men's employment status was not significantly different from women's employment rates. In 2014, the overall employment proportion was divided as 51% of men and 49% of women; 16.1% of men were unemployed while 17% of women did not have a job (Statistical Service, 2014).

According to the labour force survey of the Cyprus Statistical Service (Statistical Service, 2015) the population of employed people in Cyprus that work in the wholesale and retail trade is 17% of employed citizens. Those in education come next at 9%, and people working in services follow at 7.8%. Public government employees come next with 7.3% of employed people.

3.2.3. Rurality and Cyprus

Cyprus is an island and trade, in general terms, holds a significantly high position because the economies of smaller countries and small islands such as Cyprus are dependent on fewer sectors than are larger countries and tourism and trade are included in these (Katircioglu, 2009; Mehmet and Tahiroglu, 2002; Shan and Sun, 1998). Another characteristic of the workforce in Cyprus is the proportion engaged in agriculture. The European Union Farm Structure Survey in 2010 (FSS, 2010) collected information on the agricultural labour force. It shows that it decreased in Cyprus from 2003 to 2010, but it still represented 19% of the active population in 2010 and it was one of the highest proportions within the twenty-eight countries of the European Union. We can see these high proportions if we compare Cyprus' labour force to the European Union's countries where 5.2% of employed people were employed in the agriculture, forestry and fishing sectors (FSS, 2010).

Eurostat Statistics categorised areas and regions according to the degree of urbanization or the urban-rural typology. Areas or regions have three categories: rural areas or regions, intermediate regions and city or urban regions based on population

size and density. As we can see from the map provided by Eurostat and presented here in figure 4.3 (GISCO, 05/2013) the whole island is indicated as one intermediate region. However, comparing it to other countries Cyprus should be considered as a partly rural country. According to the World Bank (2014) 33% of the total population is rural.
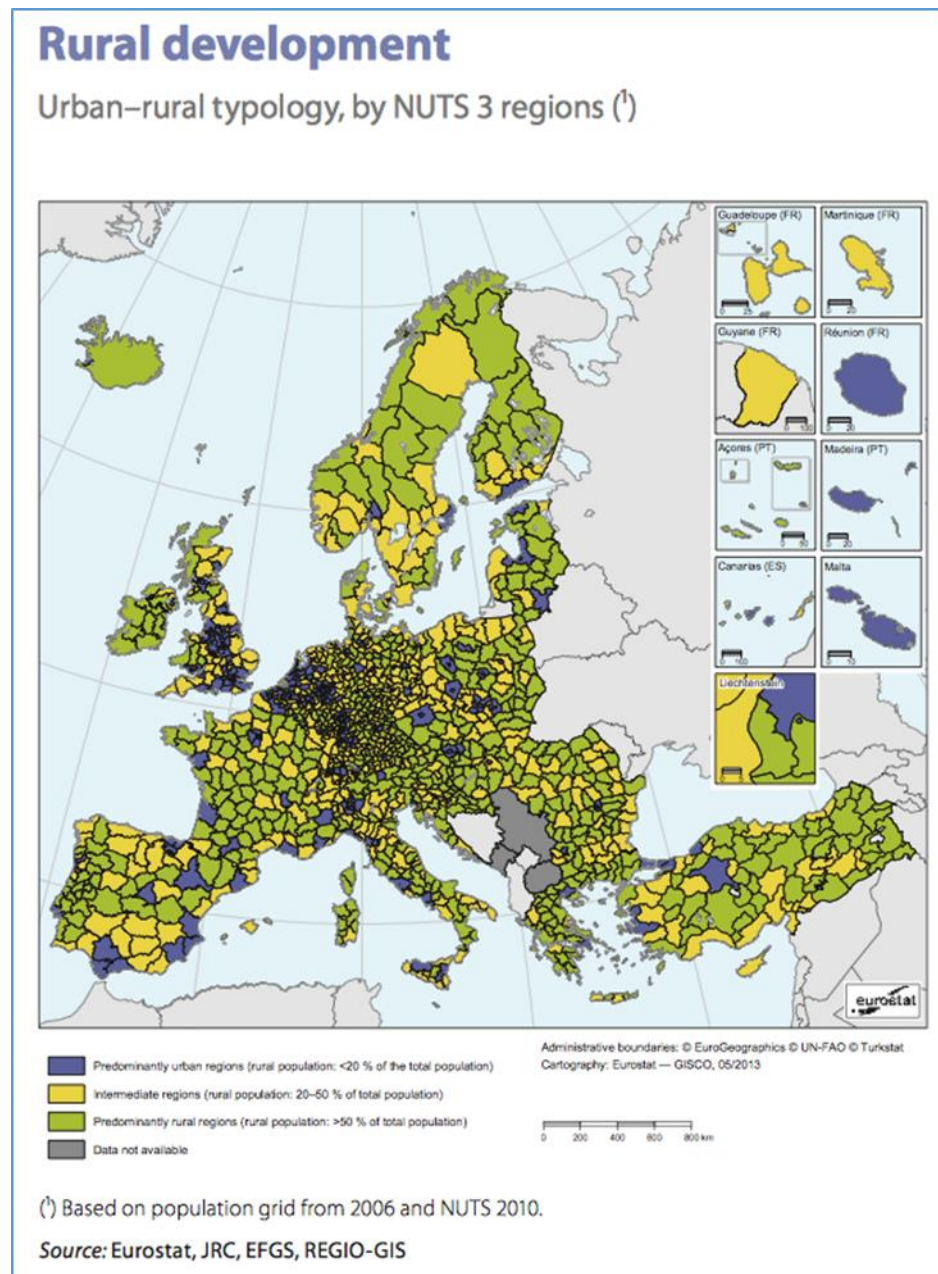
Figure 3.3 - Rural Development (GISCO, 05/2013)

Rurality in these terms is defined both as people living in rural areas as defined by national statistical offices (World Bank, 2014) as well as the high proportion of the workforce involved in agriculture and trade in comparison to other European countries (FSS, 2010). Cyprus' rural characteristics will be helpful to understand some stereotypical behaviours and mothers' accounts on these.

3.2.4. Data on Disabilities

The statistical service does not have any data for disabled people or more specifically, for children. Data on disabled people and the characteristics of disabled children in Cyprus are taken here from three annual reviews provided by the different services in Cyprus. Firstly, the social welfare services that are responsible for providing a monthly allowance for disabled children, 20558 people received a monthly allowance in 2014. The range is of 64.08% or 13174 people in 2014 in comparison to 64.43% or 13457 of 20886 people in 2013 that is, those who received an allowance for a disability or had a chronic illness (Social Welfare Services, 2013b). Other citizens that were eligible within the monthly allowance scheme were the unemployed, the elderly, or people with social problems such as orphaned children (Social Welfare Services, 2014).

Secondly, data for disabled people was taken from the unpublished annual review of 2015 regarding people with mental disabilities such as mental retardation or cerebral palsy (EPNKA, 2015). According to this data 2571 people were mentioned in 2015 as having mental disabilities, 601 people or 23% were people between the age of 0-20, 918 people or 36% were between 21 and 40 years, and 1052 people were above the age of 41.

The data presented in 2015 was not significantly different in comparison to the data presented in the Annual Review of 2004. In 2004, 2086 people were registered by the committee for people with mental disabilities. There is a slight change in the number of these people in regards to the age distribution over time: 28% of people between 0-20 years old compared with 23% in 2015, 37% of disabled people were 21-40 and 35% being more than 41 years old.

Out of the 2571 people with disabilities mentioned in 2015, 1564 people or 61% had multiple disabilities, 974 people or 38% had only mental disabilities, and for 33 people or 1%, their disabilities had not been diagnosed.

Furthermore, data are available on the types of occupations held by the parents of the 2571 disabled people. Rates of, and types of the parents' occupations are presented in figure 3.4 below.
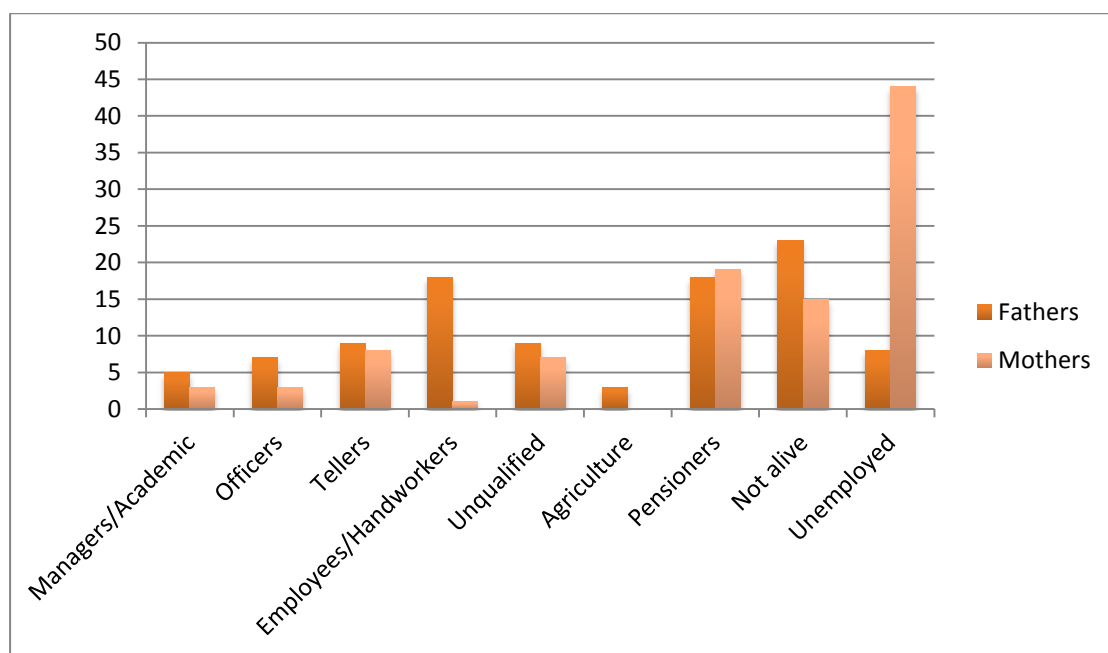
Figure 3.4 - Percentage distribution of parents with disabled people occupations in 2015

Forty-four per cent of mothers were housewives and/or unemployed mainly due to the fact that as mentioned in the annual review of 2015 they did not have any support or somewhere to leave their children. According to the data, 7% of the parents within this number of population of disabled people were divorced (EPNKA, 2015).

Data on the disabled children between the ages of 3-21 years were limited to the schools that they attended. Disabled children were registered as attending either mainstream or special schools. Sixty per cent (60%) of these children were attending mainstream schools, 22% special schools, and a percentage of 18% were not attending any school. The latter were probably children between the ages of 3-5 years that did not go to school, or children above the age of 18 years old (EPNKA, 2015).

And thirdly, some data has also been taken from the Early Intervention Liaison Service (2015). Early Intervention programmes provide services for children up to the age of six years who have presented problems or developmental disorders including physical, speech and cognitive development and self-care skills. According to the annual evaluation of these services there was a 21% increase in the number of children that took part in these early intervention programmes in 2015 (111 children), in comparison to 2014 (92 children). Figure 3.5 presents the number of families that were provided with early intervention programmes between the period of 2006 and 2015.

Number of families provided with support by Early Intervention programmes
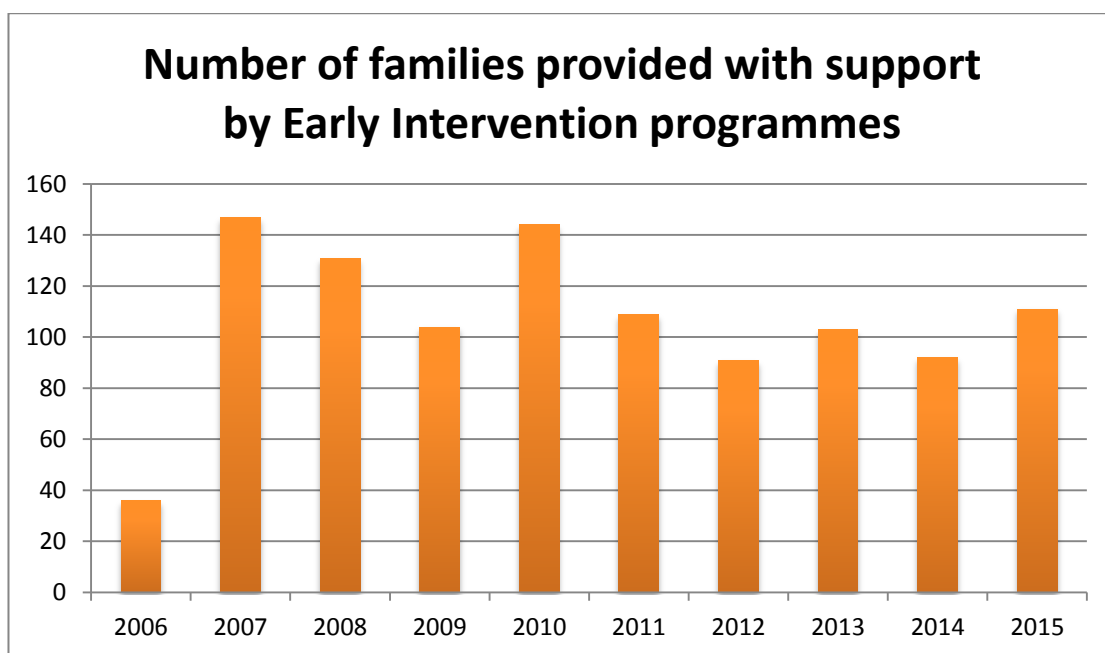
Figure 3.5 - Support to families between 2006 - 2015 by Early Intervention Programmes

Most of these children were diagnosed with developmental delays and lack of speech (86), ADHD syndrome (51), learning difficulties (50), Autism (44) and mental disabilities (43). Comparing data with the Cyprus annual review of 2004 Early Intervention Liaison Service (2004), 47 children out of 149 (32%) of that year were diagnosed as having 'mental retardation', 36 children or 24% were diagnosed with multiple disabilities, and 66 children or 44% were 'at risk'.

Out of the 111 children that received services in 2015, 25 were between 2-3 years old and 22 between the age of 4-5. The review shows that 25 of the children out of the 111 (23%) were above the maximum age of 6 years that the Early Intervention Liaison Service stipulates in order to be eligible to receive this support. This corroborates the absence of support from Cyprus' services to children older in age.

3.3. History of disability in Cyprus

Cyprus is an island that has experienced various political problems and these have been a main characteristic of Cyprus' background for many years. Symeonidou (2009: 565) shares Titchkosky's opinion on mapping culture's representations of disability as a way to move through culture, by stating that 'the mapping of disability in different cultures becomes central as it actually defines it'. The way disability is perceived in different cultures therefore explains the various responses towards disabled people.

Disabled people have always existed. Prejudice and isolation were characteristics associated with the lives of the disabled in ancient times. Labelling has always prevailed and disabled people were considered 'sick' or 'weak'. According to a myth in Cyprus' traditional literature the disabled should be thrown off a deadly cliff called Keadas or be hidden from society (Papadakos, 2009). They had no freedom and they were considered 'abnormal' (Trikkaliotis, 2001). Society in the past was not engaged with issues regarding disability and disabled people lived on the margins of society (Phtiaka, 2007).

Following a series of foreign invaders who tried to break Cyprus' connection with Greece, the Cypriots' ancestors had as their main priority opposition to Greek ideals, namely the Greek Orthodox religion, the Greek language and its culture. Their efforts led to an 'ethnocentric' and 'nationalistic' nation that developed over the last century and is clearly observed in some cases in Cyprus even today (Angelides, Stylianou and Leigh, 2003: 64).

On the other hand, it is worth noting that even though Cyprus is a nation with a comparatively long history it has only been an independent country since 1960, which is quite recent. The fact that 'it is a context that assimilates to a great extent, policies and practices from other dominant contexts, especially from the UK and Greece', is inescapable (Liasidou, 2008: 231).

The charity model, characterised by generosity and voluntary giving, derived from the time Cyprus was under the British colony. Cyprus followed the British system to a certain extent concerning disability. According to Phtiaka (2007: 149), 'education history and post – colonial dynamics suggest that today's UK policy is often tomorrow's Cypriot practice'. The UK's legislation of 1981 underlined the provision needed for children with special needs. This UK Education Act underlined the unacceptable nature of the use of words such as 'handicapped' and recommended their replacement with the term 'special educational needs'. It was legislation however with serious limitations and contradictions as Barton and Armstrong highlighted in the paper in which they presented a project that took place between 1999 and 2001 in Hillside, north England where they examined the nature and implications of policy in the context of attempts to rationalise resources. For example, as they mentioned, 'the looseness of the guidance resulted in local authorities interpreting the directives in ways which reflected different values and ideologies according to the dominant political complexion of decision makers at local government level'. Second, the recommendations were not enough to challenge the values and the priorities of the system while at the same time, the nature of 'special educational needs' as a label was applied to a wide range of children (Barton and Armstrong, 2003: 43).

According to the powerful influence that Cyprus experienced from Britain during the British colonial period, the history of special education began with the establishment of the first special school for blind people, "The school for the Blind" in 1929. This special school was established during the British colony in 1925 when Cyprus officially became a crown colony. Cypriots expected the UK to satisfy their biggest demand and to cede Cyprus to Greece, something that the UK has also done with the Ionian Islands in 1864 (Dodd, 2010; Tofallis, 2002). During the period that Cyprus was under British colonial rule, many things changed on the island. Citizens, as I have mentioned earlier, had more freedom and development was obvious in many areas. People began to study and to show interest in the public good, for example, they helped in the development of the island and they built roads and theatres, and also on other issues regarding the development of their country. Although there was not any particular philosophy regarding special education, the charity model began to make its appearance after 1929. It was the first model that prevailed, and years later, it remained the most dominant. The "School for the Blind" was initiated by the wife of the British governor who ruled at that time in Cyprus, Lady Storrs (Maratheutis and Koutselini, 2000).

Following the opening of the "School for the Blind", special schools were then established. They were all run as charitable institutions and were based on offering care rather than education. Focusing on care instead of education still remains even today as Moss highlights in his work on early childcare in British childcare provision (Moss, 1998). Thus, a benevolent philosophy that emanated from charity organisations and from contributions made by wealthy people characterised the beginning of policy and practice issues around disability and special education in Cyprus. Educational concerns came much later. Phtiaka (1999: 176) emphasised that 'the charity model has become well established in people's consciousness at the expense of a human rights model'. As I mentioned earlier, and according to Symeonidou's triad of 'State – Church – Society' (2009: 567) the three bodies were connected in such a strong link that each one was influenced by the others.

The charitable values characterised the Cypriot topic regarding disability for many years. Education was not considered to be a priority issue. Even disabled people's organisations encouraged the charity model (Stylianou, 1973).

The rhetoric began to change around the 1980s. By then, the first law for the education of disabled children was passed in 1979 (Ministry of Education and Culture, 1979), which followed the concept of the UK 1944 Education Act which categorised and defined

disabled children in medical terms, segregating them from other children. Segregation and medicalisation made their appearance in a more intensive way and together with the charity model, they characterised disability in both thinking and practice. According to Symeonidou (2009: 575), 'segregation and medicalisation were imported into Cyprus in the given culture from the West and shaped thinking accordingly'. It was argued that what is effective in one context could be implemented in another. Obviously Cyprus had its own peculiarities as a country. Taking into account the interaction of segregation, medicalisation and the charity model, these peculiarities developed an exclusionary and normalising civilisation.

Thus, even though the Special Education Law of 1979 was the first legislation for disabled people and unique for the Cyprus framework, its regulations were outdated compared with the international facts around disability. During that period the United States proclaimed the International Year of Disabled people and England also introduced the Education Act of 1981. Disabled children according to this law were divided into four categories which were based on the medical model of disability: "maladjusted", "trainable", "mentally retarded", "physically disabled" and "slow learners" (Ministry of Education and Culture, 1996). By being categorised and labelled, these children according to the legislation should be educated in special schools or in very special circumstances, in special units situated in mainstream schools. However, special units like these were very limited during those years (Makri, 2005). Special schools with this legislation had the opportunity to flourish as they were protected by the law.

Benevento, (in the 'Benevento' UNESCO report 1980) was critical of the 1979 law's separatist philosophy. She talked about more practical issues at several levels such as intervention techniques and the need for the acquisition of skills basic to effective learning. This should involve a variety of people such as teachers/interventionists, psychologists/interventionists and others as Benevento suggested. The International Year of Disabled People emphasised values such as equality in the rights for disabled and the rehabilitation of disabled people so that they could be part of mainstream society.

In the context of all these new ideas and concepts that were implemented in other countries, namely that disabled people should be educated together with their peers in mainstream schools and should be treated as equals, Cypriots began to ask for their own rights for equal opportunities in education and for development. The notion of integration has been emphasised more and more and the philosophy around disability has gradually begun to change. According to Phtiaka (1999: 178) 'a changing rhetoric is

a good sign if it takes us in the direction of a changing philosophy'. In the decade that followed, integration was adopted in philosophy by the Ministry of Education while the segregation law of 1979 was still in force. As Liasidou (2008: 232) said: "despite its importance the 1979 law was rather short-lived. Less than 10 years after its introduction the avowed, albeit unofficial, philosophy of the Ministry of Education was the integration of disabled children in mainstream schools". Disabled children began to attend lessons in mainstream schools unofficially, but in ways different from what the original separatist legislation had intended.

General debates around disability in Cyprus emerged based on educational initiatives and were discussed by people who had worked abroad and were aware of other countries' policies and practices (Kypriotakis, 2000; Phtiaka, 1999), by people who were actively engaged with disability issues and could criticise the charity model (Constandinides, 1992; Phtiaka, 2003) or from disabled people and their families. On a general discourse level, parents' associations began to ask for their children's rights and to apply pressure for integration. They became 'a driving force for integration' with their disagreement of the separatist environment that had prevailed with the 1979 law (Phtiaka, 2007: 153). In 1992, together with the Parents' Federation, the Constandinides Report was produced (Constantinides, 1992) which recommended the urgent need for a law related to integration and not segregation. The Ministry of Education and Culture with two publications in 1988 and 1996 underlined its support for the integration of children with special needs into mainstream schools. According to the publications, the purpose was to facilitate learning, to minimise differentiation, to enhance socialisation, and to reach the same level of educational development as the rest of Europe and as well as America had (Ministry of Education and Culture, 1996).

The conflict between legislation and philosophy and practice was clear. The reasons for this were obvious, based on social and historical conditions. International influences were one of the main reasons: via the Education Act 1996 in the UK and the US' introduction of the International Year of Disabled people. Chapter 2 of the 1996 Education Act in the UK legislated for the provision of special education not only in special schools, but also in mainstream schools. Earlier, the Department of Social Policy and Development in the US proclaimed 1981 as the International Year of Disabled Persons, highlighting full participation and equality including in school. What is more, parents, together with disabled activists, became aware of their rights and began their own attempts to bring about change in the norms and practices that characterised society (Symeonidou, 2005, 2007).

Implementing integration was not easy. Philosophy and practice were often in conflict. As Liasidou (2008: 232/3) highlighted, the attempts at integration,

were merely the result of the necessity to harmonise with the international trends and therefore integration took place in a wholly unprepared and unaltered education system.

Mainstream schools were ill-prepared to accept and include children who 'deviated from the norm'. Buildings did not have the basic necessary infrastructures, and educators, teachers and professors did not have the basic knowledge. Disabled children were attending lessons in special units, separated from the other classes, even though they were physically under the same roof.

All this came to an end with the introduction of the new special Education Law in 1999 (Ministry of Education and Culture, 1999). It was an important date for special education in Cyprus since it was the first time Cyprus had legislation that allowed children the right to go to a mainstream school in their neighbourhood. It was only at this time that conflict ceased and an agreement was reached on paper between policy, philosophy and practice. As we will see later the conflict between policy and practice has not yet come to an end.

3.4. <u>Stigma and disability in Cyprus</u>

As it is argued, the term 'stigma' is difficult to define as it concerns a notion that may be differently understood in different contexts. 'Stigma' is a term in its own right in Cyprus; laypeople attribute a particular meaning to it. The word stigma in Cyprus is usually used to refer to the term 'Mediterranean stigma', better known as beta thalassemia 'the underproduction of haemoglobin, the indispensable molecule in red blood cells that carries oxygen' (MedicineNet, 2013). It is a disorder in which the body does not have enough normal, healthy red blood cells. It is inherited and can be caused either by a genetic mutation, or by a deletion of certain key genes. Beta thalassemia can be life threatening with a variety of symptoms, such as fuzziness, pale skin, poor appetite and jaundice (Holm, 2012).

In Cyprus, every couple that intends to get married is obliged first to undertake specific blood tests in order to determine whether or not they are carriers of b-thalassemia. If both carry thalassaemia minor then their children may have thalassaemia minor or normal blood, which are both ok. There is a one in four chance though (25%) that their child might have thalassaemia major. In the past, couples where both were at risk of

having this condition, the lay word 'stigma' meant that they were not able to get married. Today, examinations for this condition are compulsory. However, couples are now allowed to marry but they must have additional examinations every time the woman becomes pregnant. This policy was established by the Cypriot government in an effort to reduce the incidence of new births with two mutations associated with beta thalassemia, as recommended by the World Health Organisation in 1973, and has since been supported by the Cyprus Orthodox Church in the years that followed. The role of the Church was crucial because marriage requires a blessing and a certificate from the Church (Beck, 2005; Ministry of Health, 2016).

'Social stigma' portrays a different understanding than the word 'stigma' that is commonly used within Greek society. Here stigma refers to the isolation of people within society. Like everywhere else, it refers to those with obvious physical disabilities, senility, psychological conditions including addiction to drugs, and socioeconomic groups, for example, those that live in poverty or unemployment (Zianni, 2009). Ignagni, Schormans, Liddiard & Runswick-Cole in their article where they analysed a discussion between self-advocates labelled with intellectual disabilities, academics and service providers, begun with the fact that people with the label of intellectual disabilities 'are experiencing urgent material threats to their well-being and, indeed, to their lives in a time of a global economic crisis' (2016: 131).

Although a significantly important social problem in Greece and even more so in Cyprus, stigma is not a topic of research. There are some references to this, such as the work of Azizi Kalantzi, Sideri Zoniou and Vlachou (1996). These researchers, who have an academic interest in disability studies examined stigma in relation to disability. They emphasised that stigma exists in schools and that teachers may also stigmatise students. Teachers often label children, as Azizi Kalantzi *et al.* (1996) wrote, and according to these labels, children often behave in school in accordance with the labels put upon them. According to the labelling theory, deviance is regarded as a social construction rather than as an objective property of behaviour. As presented in the models of disability, the labelling theory in the medical model derives from the disabled child whereas in the social model, labels are created by society (Armstrong and Barton, 1999; Chandler and Munday, 2011). Labels that teachers use are based either on the societal or on the learning characteristics of a child. For example, a teacher may typify one student as a genius and another as lazy. Although these labels are not used directly to address a child and are not mentioned to a student officially, the students can infer the expectations of their teacher and thus gradually understand whether their school will be a place that makes them feel included or segregated. In Cypriot society various social

groups are stigmatised, for example, Pakistanis and other migrants, or students coming from lower socioeconomic groups or disabled people. Disabled students are a social group that face marginalization in the Cyprus educational system (Lagios, 2008). In a small traditional society, stigmatisation flourishes (Sotiriou, 1977; Symeonidou, 2009).

The abolition of stigma is a subject that is somewhat underdeveloped in the Cyprus context. Policy and theory concerning disability are not strong enough to establish drastic and effective practices against stigma. Services that minimise stigmatising practices, behaviour and attitudes exist in Cyprus policies. Compulsory wheelchair access to public centres is one example. However, this is not enough and there are no strong or substantial stigma discussions as in more developed societies. Some discussions are taking place mainly in private initiatives such as the 'Cyprus Confederation of Organizations of the Disabled – CCOD' or 'Hug of Hope'. These organisations are trying to gain more rights for disabled people. There are also discussions in the media which documents cases of violations of disabled people's rights in Cyprus with the aim of eliminating stigma (Lambrianides, 2014; Pitsiali, 2014). Injustice and negative feelings are expressed in many quarters towards disabled people or towards parents of disabled children and policies are not being implemented. Demetriou (2014) wrote an article in Simerini, a Cyprus newspaper, discussing how disabled people are more disabled in Cyprus than they would be in other countries. He highlighted an experience that he had when wheelchair access was not available to enter the conference room at the Cyprus House of Parliament. 'Full wheelchair access is a right by the law and the same building that established the law has not got wheelchair access to all of its rooms' he argued, saying that 'having the conference discussion outside was not a solution' (Demetriou, 2014).

3.5. Theory of disability in Cyprus, Policy and Legislation

3.5.1. Legislation on Disability

There are various laws in Cyprus pertaining to the rights and provisions for disabled people in general, and also for specific disabilities. The basic and most recent Acts are presented in the Appendix 3. It is important to note that the various services provided by the government which are based on the relevant legislations are covered by different Ministries, departments and other services in Cyprus. This said, a disabled person or the main carer of the disabled person who in most cases is assumed to be the mother, must approach all the different departments and services in order to be informed about his/her rights.

The general 'Legislation on the Rights of Disabled People in Cyprus' (Ministry of Labour, Welfare and Social Insurance, 127(1)2000) highlights the equal rights that disabled people have as they too are citizens of the Republic of Cyprus, and does not accept discrimination against their right to equal employment. At the same time, it emphasises the State's responsibilities towards them. It names the services and facilities that the government has to provide in terms of equal justice. For example, the public transport service is obliged to have seats for disabled people to sit, and wheelchair access to all public vehicles such as buses. Also, 'blue cards' as they are termed, are allocated for all disabled person's vehicles or for the parents' vehicles in the cases of disabled children. The 'Right Transport Allowance for Disabled Persons' (Ministry of Transport, 36/1980) is an allowance that permits disabled people who live and work in Cyprus to use all public transport services without the obligation to pay.

With regards to persons with hearing impairments, the public telecommunication services have to provide a suitable telecommunication system. The ability to be hosted in institutional care is another facility that disabled people have. According to the Cyprus Annual Review of 2015, 261 children and adults or ten per cent (10%) of the population of disabled people were accommodated in houses for disabled people or institutions (EPNKA, 2015; Social Welfare Services, 2013b).

The only legislation regarding disabled children in Cyprus is the Act that was established in 1999 which mainly refers to children's rights to education (Ministry of Education and Culture, 113(1)1999).

Cyprus has accepted the conventions of the United Nations, the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). CRC, the convention that Cyprus ratified after 1990, emphasises that what is most important is the right of the child. According to the United Nations Committee for the Rights of Children early intervention is of great importance in order that children will be able to receive valuable help and support. Early detection however, requires that professionals who come into contact with the child, namely doctors and teachers, and their parents, are able to recognise the early signs of a disability and to refer the child for diagnosis and intervention (CRC Committee, 2006, paragraph 56).

Since Cyprus has ratified both UN conventions, UN members are required to take the necessary measures to ensure enforcement of the rights deriving therefrom. According to the Articles 2, 23, 28, all children, irrespective of their level of disability, have the right to develop their abilities to the highest level. The 1999 Special Education Act for the

Education of Children with Special Needs (113/1999) as well as the regulations that followed, include many suggestions for the ensuring of this right. However, as argued in the present chapter, the practice does not reflect the policy's statements.

3.5.2. Integration of Children with Special Needs Act[1]

As it has already been mentioned above, integration was unofficially implemented in schools for children with special needs while the 1979 segregation law still existed in policy, although it was recognised as being outdated and discriminatory (Phtiaka, 2007; UNESCO Report, 1980). With the establishment of the 1999 legislation for children with special needs, a new era began in Cyprus regarding disability.

This Act is comprised of seven parts and begins with terminology regarding the persons who are involved and mentioned in the legislation, such as the child, the parent, and the Ministries or committees that are responsible for the assessment or the provision of special education to the child. It defines 'special education' as the assistance that is given to a child with special needs to enhance its development in every aspect of its life, including education and social integration, as well as independence. 'Child' is defined as a person from the age of three until the end of his or her studies, and a 'child with special needs' is a person who has serious learning difficulties. These difficulties may be functional or adaptive and are caused by intellectual, literacy or psychological deficiencies that create the necessity for special education.

The second part of the Special Education Act describes the schools that can provide special education in Cyprus. According to the law, education for "children with special needs" should be provided within a mainstream school in general circumstances, unless it is stated otherwise. In such cases, a disabled child can attend lessons in a special unit within a mainstream school or he/she can go to a special school. Special schools must be fully equipped and suitable for the provision of equal and right education.

The third section of the Act defines the establishment of committees that should be responsible specifically for special education. With the current legislation two types of committees have been established: The Central Committee for special education and training, and the District Committees which cover the various provinces in Cyprus and which are accountable to the Central Committee. Therefore, if a child has been identified as having "special needs" by its teachers or by any other member of its educators, these persons have the responsibility to inform the District Committee. It is then the

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[1] Ministry of Education and Culture, 113(1), 1999

Committee's responsibility to identify the needs that the child has and to conduct an evaluation process.[2]

The procedure of identification and the evaluation of "children with special needs" is stated in the next part of the Act. Any person who interacts with the child on a daily basis (including the parent) has the right to inform the District Committee regarding any perceptions concerning disability that the child might have. The parent must be informed and the Committee then has the responsibility, as I noted earlier, to conduct an evaluation. In the case that a child is under the age of three, the parents have to give their assent. The assessment process includes evaluation made by different specialists (such as speech-therapists, child-psychologists). It is important to note here that the child's parents have the right to participate in this assessment process either on their own, or they can be accompanied by a specialist that they believe can contribute to the assessment process.

The examination process follows the above assessment process. Initially, the District Committee has the obligation to send a letter to the parents informing them about the purpose, the time and the location of the examination, and to advise the parents that they have the right to be present and to be accompanied by any specialist that they feel can help with the examination.

Thereafter, the District Committee writes a report which defines the special education and free treatment that will be provided to the child, as well as the facilities or exceptions such as no assessment in several school subjects or differentiation in assessment. If in the examination it is decided that special education should be provided in a place different from a mainstream school, the Committee is responsible for providing free transport from the child's house to this school and vice versa. In the case where special education is to be provided fully or partly within a mainstream school then the legislation states that the number of pupils who attend the specific class should be of a small size, according to the 'extent of the problem' that the child with "special educational needs" has. They justify this as with this facility, the disabled child will be able to have the

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[2] Each District Committee has one representative member of the Government who has the role as president of the Committee, one representative from the Ministry of Education, a special education teacher, a child psychologist, a clinical psychologist, a speech therapist, a social worker, a doctor and any other specialists that may be identified as necessary. The Central Committee for special education and training is also regulated by a multidisciplinary team, which also includes members of the Government, psychologists and doctors. The Ministry of Education, in co-operation with the administrative staff, is responsible for the persons/specialists that will constitute the Committee members.

attention needed. Depending on the 'type' of disability, the legislation provides various facilities such as the exceptions or the differentiation in the curriculum, the building facilities and the various therapies that the child might need. Twice a year, the District Committee is responsible for conducting a re-evaluation of the child with special needs.

The fifth part of the Special Needs Law refers to the special education and treatment that should be provided for free in mainstream schools. These schools are required to have suitable infrastructures that can be adapted to the specific programme of the child. On the other hand, special schools must provide special education and treatment in classes that are appropriate to the age and the disability of the child.

The last two parts of the Special Education Act state the establishment of a 'council around special education and treatment' as well as a 'function committee of special education and treatment'. The council is responsible for general topics regarding special education as well as plans for development. The function committee coordinates the special education that is provided in practice, in cooperation with the Department of Educational Psychology as well as with the Department of Curriculum Development. The committee also checks and evaluates the educational programmes of the schools that provide special education.

3.6. Healthcare System in Cyprus

In Cyprus, the healthcare system operates with eight public hospitals (Ministry of Health, 2016b)[3] and many other private clinics which are administered by private doctors or businessmen and not by the Government. With regards to childbirth, mothers have the option to choose where they can give birth to their child, either at a private clinic or at a public hospital.

Mothers can give birth to their child at a public hospital without having to pay, or with minimal expense. The cost of child birth is covered by taxes which are collected by the government from salaries. A family is eligible to give birth to their child cost free if they fulfil one of the below conditions:

- The mother is unemployed
- The annual income of the family is estimated as low (less than 7000 euros per year) or
- Either the mother or the father are government employees

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[3] Two public Hospitals in the capital Nicosia, one in each of the other four counties and two in the largest mountainous cities of Cyprus

In all other cases, parents have to pay to give birth at any of the public hospitals in Cyprus.

If mothers or parents choose to go to a private clinic they will have the option of choosing their own personal doctor rather than having a doctor that happens to be available or on call the day of the childbirth (as in public hospitals). However, they will have to pay a significant amount of money (2500-4000 euros for the parturition and three overnight stays of the mother and infant in the hospital included). Some mothers prefer private clinics as they receive more personal care since they have one doctor who sees them throughout the entire duration of their pregnancy and childbirth. However, only a few private clinics have Neonatal Intensive Care units or Special Care Baby Units. Therefore, mothers who have given birth to low birth weight babies or babies with medical needs at a private clinic, these babies are then transferred to a public General Hospital which has the facilities to provide long-term support to babies who are born with medical problems.

The same also applies when someone needs medical care for any other kind of health problem. There are private specialists that people can go to for approximately the amount of 50 euros per consultation and with an additional cost if they need to have an operation or any further treatment. Alternatively, there are general medical practitioners that people can see at a public hospital or at a district health centre (Ministry of Health, 2016b). Again, if someone belongs to one of the above categories that exempts them from payment, they are eligible to have their consultations for free. In all other instances, a person has to pay for medical care unless they have private health insurance. Vulnerable citizens such as some elderly people or disabled children are eligible to use the above facilities for free. The same conditions apply for some specialised therapies that they may need to attend.

3.7.   State Services for Disabled Children

The public services that are available to disabled people are financial, medical and educational. Financial support to disabled children in Cyprus begins from the amount of €420 per month for disabilities that have been assessed as mild, that is, where a child needs support for his or her daily needs and where therapies are not regarded as necessary for the development of the child. Children who usually receive this monthly allowance are children who have been diagnosed with 'mild mental retardation' or 'epilepsy'. In cases where children have been assessed as having greater needs and have been diagnosed with syndromes or disorders, then the public allowance increases to €820 per month. In the case where a child has been assessed and diagnosed with a

severe motor disability for example, 'cerebral palsy', the allowance scheme is then increased to the amount of €1000 per month. The type and level of disability is the first and only criterion of the monthly allowance which is meant to include the therapies that the disabled child might attend.

Mothers can also apply for other special allowance schemes which are available as extra support. These are:
-        Financial assistance scheme for the purchase of a wheelchair
-        Special allowance for blind persons
-        Financial assistance scheme for private carer

Children and disabled children in general are eligible to receive a monthly allowance for their entire life, but they are re-assessed every two years by Social Welfare Service officers and social workers who are responsible for examining and evaluating the extra facilities that a disabled child has received from the government. An officer visits the child's house every two years to conduct the assessment where she or he evaluates the progress of the child and whether the money has been spent according to the scheme.

The financial assistance scheme for a private, full-time carer is an extra monthly allowance available to mothers or to the main carers of disabled people and is provided by the social welfare services (Ministry of Labour, Welfare and Social Insurance, 95(1)/2006). According to the 'Public Allowance Act' a monthly allowance of 310 euros is provided to mothers to use towards the salary of the carer whose gross salary is 460 euros, based on the Department of Population from Social Welfare Services in Cyprus (2013), which is responsible for determining the carer's salary. In families with a low socio-economic background where both income earners in the family receive a monthly salary of less than 870 euros, which is the minimum wage in Cyprus (Ministry of Labour, Welfare and Social Insurance, 2012), the allowance is still provided to them even if they decide to use this money for other needs instead of having a full-time carer at home. Carers live in the house with the families and provide services such as supporting mothers with caring for their disabled children or with the general household cleaning.

The medical support provided to mothers of disabled children is the allowance of a free medical card that covers their children for:
-        Free medical appointments, examinations or surgery at any hospital
-        Free management/provision of technical means, instruments and other aids

The medical services include free consultations and treatments for disabled children in public hospitals, even if their parents do not fulfil the above criteria. Also covered within the medical services are the therapies offered to them, mainly physiotherapy, speech-therapy and occupational therapy. Therapies can be provided to children either as one to one or in group sessions. One to one services are the common therapy sessions disabled children have from their birth until the age of three, which are carried out either in public hospitals or at home. After the age of three the public therapies are carried out within the school context; children may have group therapy sessions depending on the type of disability they have or on the availability of therapists and time in the specific context. Therapies are usually offered to children twice a week, for a duration of one-hour each time.

Educational support covers the free education that all disabled child have the right to in Cyprus, according to the Special Education Act as presented above (Ministry of Education, 1999). According to this law on special education, children with 'special needs' have the right to attend a school in their district or a special unit that the public schools have.

The Department for Social Inclusion of Persons with Disabilities offers a holistic assessment of the needs and potential of each person with a disability and the appropriate support for intervention in every area of his/her life, in order to enhance social inclusion (Department for Social Inclusion of Persons with Disabilities, 2014). However, practices, as we will see in the next chapter on mothers' experiences on giving birth to a disabled child (Chapter 5) as well as on the support provided to families with disabled children (Chapter 6), do not comply with these policies.

3.8. Theory vs Practice: A Critical analysis

In the previous section, I presented the legislation regarding disabled people and in particular, disabled children. I demonstrated the main approaches of the current legislation regarding disabled children, explained how the health care system operates in Cyprus, and the services that the State offers to disabled children and their families. In this section, I will analyse the conflict that exists at a practical level, based on public debates mainly as we shall see, held by disabled people or by people with academic backgrounds providing in a way a critical assessment of the policy. Moreover, the analysis in the study will present the results as perceived by mothers' accounts adding up to this gap between policy and practice.

It is important to note that in Cyprus there is no specific legislation or policy concerning the services for parents when they give birth to a disabled child, as there are in other countries, for example the Children's Act in the UK (Children Act, 41/1989, Department for Education, 2015). In Cyprus, the various services and benefits provided to parents and to their disabled children fall under the responsibility of different Ministries and public services which the parents have to research and find out about, most of the time, on their own. Furthermore, there is no legislation regarding disabled children under the age of three years. These children are allowed to have their therapies and treatments for free in public hospitals or at their home up until the age of three, and from thereon, they continue their therapies within the school context as they then fall under the Ministry of Education's rules and legislation. However, as we will see later on, private medical services for treatments and therapies such as physio therapy or speech therapy are preferred by parents for various reasons.

As described already, the Integration for Children with Special Needs Act 1999 has many similarities to the 1981 Educational Act in the UK (DES, 1981). It introduces the terminology of 'special educational needs' and legitimises the integration of disabled children into mainstream schools, and also having as a second choice the option of special schooling. Although it could be characterised as legislation that respects the equal rights of disabled pupils, it appears to have one basic problem; the fact that 'most of the rhetoric for integration, or even inclusion, does not correspond to the existing practices' (Symeonidou, 2007b: 3).

In 2004, the Ministry of Education in Cyprus asked for a committee which included members from both the University of Cyprus (Helen Phtiaka) and the Cyprus Pedagogical Institute (Research Department) to evaluate the implementation of the integration law. At that time the law had already been implemented within the Cyprus educational system for three years. The evaluation team investigated the ways in which inclusion or integration was implemented and the degree of integration in schools, and whether the legislation achieved its aims and also the problems that emerged from it.

The evaluation was conducted in two stages. In the first stage, researchers provided a literature review that scoped all relevant resources of the history of integration in Cyprus. In the second stage, they undertook a survey which comprised of observations, interviews, and questionnaires of the people involved, such as teachers and parents, who were directly involved in the implementation of the existing legislation.

A year later, the evaluation team presented their results (Phtiaka, Michaelidou, Tsouris and Vlami, 2005). The results were rather negative and highlighted the gap between the policies and practice. Although the teachers that were observed and interviewed and according to their own statements, believed in the philosophy of integration, they held a different view regarding the actual implementation of integration in Cyprus. They did not implement inclusive or integrating practices, and their obsession with the segregation philosophy of the past characterised their practices.

Conflict between policy and practice exists not only with regards to the Special Education Act but also with other legislation for disabled people in Cyprus, as it has emerged from general discourses and people's articles in newspapers and in other media representations.

Integration in practice appeared to mean only the attendance of the child into a mainstream school, but nothing more substantial. This was obvious not only from the observations that were made, but also from the interviews that were conducted with the parents as well. The parents were both frustrated and disappointed as they realised that their children had not made any progress in learning. Priority was given to care (Moss, 1998) and basic socialisation skills such as personal care, visiting places and trying to make children feel 'happy', but even this appeared to have many gaps. Teachers were trapped in the medical and charity model (Symeonidou, 2009).

Also important to note is the language that is used in the various laws regarding disabled children. Children with 'special needs' or 'severely disabled' 'epileptic' or 'physically handicapped' are terms that are used in the legislation although they are considered as terms that are not appropriate in more developed societies (Office for Disability Issues and Department for Work and Pensions, 2014). Terminology within my study that is considered as not appropriate is used in inverted comas.

Injustice and the differences between theory and practice are emphasised in various articles in Cyprus newspapers, which are written mainly by disabled people or disabled activists. Lambrianides (2016) distinguished between 'equal' treatment and 'special' treatment, for example, a disabled citizen that goes to a theatre and is not able to enter it because it doesn't have wheelchair access; this is contrary to the regulations that state which facilities should be available in all public places. Conflict also appears in employment too. While according to the law every citizen has an equal right to be employed without any discrimination, newspaper statistics show that fifty percent (50%) of disabled citizens are unemployed. Statistics in Cyprus for unemployed disabled

people do not exist, but unemployment is also at a high rate in the general population too (Politis, 2014, Statistical Service, 2014).

The disappointment of disabled people and of their families is generally observed in Cyprus with regards to the services provided. Pitsiali, (2014) a mother and the president of a parent's association in Cyprus named 'Hug of hope' [Αγκαλιά Ελπίδας] wrote a letter to the General Manager of the Ministry of Health. She sent the letter in order to express the concerns that the parents as members of this association had about the suspension of a specific allowance for medication that disabled children with cerebral palsy and epilepsy were allowed in the past. State services stopped providing these medicines to parents for free because they no longer cooperated with the specialised doctor who previously provided the specific prescriptions to them. This doctor continued to work without cooperating with the public services, but instead, worked within the private sector. Mothers continued to visit this doctor although they now had to pay because this doctor was the only one available in this particular field. The mothers expressed their disappointment through Pitsiali's letter, as the General Hospital according to the letter did not have any other professionals with the same specialisation, and therefore, they had no other option than to use private medical services. These were concerns of mothers that were in conflict with what the legislation supposedly provided. Their disappointment also continued with other services provided to their disabled children. Through Pitsiali's letter, they expressed their concerns about the quality of the services provided and the need for a public centre accessible to all mothers and children for therapies or any other treatments needed - a centre that should be located within the General Hospital for children.

There is a lot of debate around people's opinions regarding whether to use private or public healthcare. Those who prefer private healthcare usually justify their arguments with the fact that by doing so they have their own privacy and appointments are made without waiting lists, while those who prefer public doctors and State hospitals argue that they do not have to pay and that most of the time (such as in child birth) public hospitals have better equipment and facilities. It has become common practice for people to visit a doctor privately, even when they do not have a lot of money. Lack of trust in the services provided by public doctors is a strong debate, while at the same time, many public doctors are choosing to leave the public sector and to work within the private sector because of a lack of satisfaction with their salary and excessive work loads and demands. This is a major problem as people want to have a doctor that they can trust, but without having to spend an enormous amount of money, and this subsequently influences many citizens' decisions (Panagi, 2015; Panagi, 2016).

As we can see from the critical analysis above, the gap between policy and practice in Cyprus emerges in many aspects. Firstly, in terms of legislation where, while the equal rights of disabled children are highlighted, at the same time integration is promoted and the option of special schooling is offered. Inclusion and equal rights however do not correspond to the reality of teachers in Cyprus. Teachers' practices are often not inclusive and reflect a segregation philosophy in their teaching and classrooms (Phtiaka, Michaelidou, Tsouris and Vlami, 2005).

The tension between medical and social models of disability in Cyprus appears to exist in the use of language. "Children with special needs" or "the physically handicapped" are terms that reflect the medical model of disability and are used not only by the society but in the legislation even where it supports the social model. In Cyprus, as Phtiaka rightly acknowledged (Phtiaka, H., 2007b: 154) 'the terminological and conceptual struggle between integration and inclusion still holds strong'.

Under the notion of integration, there is a debate though, that needs to be clarified concerning the integration of disabled children from special to mainstream schools and whether it is always the right decision or 'appropriate' for every individual child. Inclusion on the contrary does not demand 'appropriateness' for every child. It takes as a prerequisite that every child should be where his/her peers are and the creation of a supportive and effective environment are a necessity. Both terms of integration and inclusion support the social model of disability. Integration however has been criticised since it cannot achieve equality of opportunities between disabled children and those who are not disabled. Thus an inclusive approach is presented as the right approach but is not implemented in the Cyprus context.

3.9. Conclusion

In this chapter I have outlined a small part of the history of Cyprus regarding political and societal issues, as from 1751 till today. I emphasised the fact that during the long history of the island, the State, the Church and society were connected with strong links, and the aspects of these have influenced the development of important practices such as disability. I then presented some demographic data on the characteristics of the population – size, age profile, marital status / divorce rates, age at marriage, and mean ages of childbirth, and also some data on disabilities. I set out the main industries and employment sectors for both men and women according to the information provided by the Statistical Service in Cyprus. Lastly, I defined rurality in relation and concentration of the population.

I continued with the history of disability and how stigma is understood in the Cyprus context. I then presented legislations concerning disability, and introduced the legislation that exists in Cyprus for children with 'special needs'. The presentation of the healthcare system in Cyprus followed, and I then discussed the implementation in practice of the legislation through a critical analysis.

In discussing the case of Cyprus, major difficulties were observed when the introduction of a new theory or philosophy was put into practice. As I described, Cyprus until 1999, had segregation legislation regarding disabled children. Even if people at that time appeared to be progressive as influenced by other countries, they were sceptical when they were asked to make changes. Thus, we can observe that although the legislation emphasises integration, the idea of charity still prevails in some practitioners and Cypriots' minds, and philanthropic feelings diminish the possibility for the development of real inclusive practices. Symeonidou (2009: 574) states that:

> *Although segregation, medicalisation and charity are no longer at the centre of the political responses towards disabled children and adults, they are still behind socio-cultural notions of disability guiding everyday practice.*

The current legislation has many positive ideas. If these ideas could be fully implemented, inclusion may become a reality. Cyprus' history still acts as a barrier towards inclusion, especially with regards to issues on disability.

One can say that this is our history and that we should be proud of it. However, history can only have a positive impact if citizens use it for the development of their country. What we need to do is to work only with the positive characteristics of our culture, and thus, as a result, we could then benefit from these. It is always possible for people's minds and attitudes to change, as an inclusive society does not just have to exist as an idea of utopia. By using a country's history and the positive features of its culture, we would then be able to proceed towards an inclusive society. Phrases and terminology that are offensive, discriminatory attitudes and stigmatised behaviour, and the reinforcement of existing prejudice are still to be found. This behaviour and these attitudes come from a history preoccupied with charitable and philanthropic feelings, from a society where the term 'stigma' is still being used in everyday life, and from current legislation regarding disability that conflicts with actual practice. These attitudes become more understandable once we consider Cyprus as underdeveloped with regards to discourses on disability and its practices, rather than implying that citizens are 'bad' or have a bad attitude.

The way I undertook the research, the methodology of the study, the research questions, the concepts, and sample's characteristics are the topic of the next chapter.

Chapter 4 – Methodology

This chapter begins by setting out the research questions and concepts. It then provides a detailed description of the research design and the qualitative approach that was used and the sample. The next section discusses how the sample was approached and the characteristics of the sample. Following this, the methods of data collection, interviews and the documentary material that was used in the study are also presented, followed by a discussion of the ethical issues that arose in undertaking the study. Lastly, the approach to data analysis is set out.

4.1. Research Questions

As mentioned in the Introduction (Chapter 1), the study aims to show an understanding on the experiences of mothers with disabled children in Cyprus. More specifically, the interview process examined the perspectives and experiences of twenty-five mothers of disabled children with ages between 6-22 years old. The aim was to explore and understand the mothers' experiences and feelings over time - from when their disabled children were born until the time of their own awareness of the child's disability, and the point of medical diagnosis. I also set out to explore the support they had received up to the time of interview and instances of stigmatisation that they and their children faced from society. Put precisely, the study addresses three main questions:

A. What are the experiences and feelings of mothers following the child's birth until the time of awareness or diagnosis of a disability?
B. What kind of support did mothers have access to throughout their journeys of raising their disabled children, formal and informal? What support did they receive at time of interview and what were their assessments of support that they received?
C. How far did mothers experience stigmatisation related to their child's disability and how did they experience and cope with stigma?

4.2. Concepts

The concepts used in the study relate to concepts of disability and inclusion as well as mothers as care providers, conceptualisations of the process of awareness of disability as a temporal process or trajectory, as well as support provided to mothers, children and families with disabled children and stigma. Figure 1.1 in Chapter 1 presents the theoretical framework of the study and the ways in which the concepts link together.

The concepts of disability and inclusion are central to the study. The term inclusion relates to the ways in which the institutions of education and services in the society operate. Disability is a term applied to persons 'who have a physical or mental

impairment that has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities', a definition adopted under the Disability Discrimination Act in the UK (DfES, 1995). The definition is analysed in Chapter 2, section 1. In terms of the approach adopted here the study is premised on the social model of disability (Chapter 2, Section, 1). Children are understood as 'disabled' in the sense that they are prevented by society from achieving their potential rather than being defined only by their special needs (Armstrong, 2007; Corbett, 1996; Oliver, 1996). Disabled here does not mean 'less able'. It means preventing from functioning. The use of the term disabled people and not 'the disabled' means it is not a collective term (Office for disability Issues, 2014).

As Shakespeare (2004) suggests, every person is impaired in a different way and extent. As a consequence, some people's impairments are not subject to social exclusion or discrimination compared with those of others. People with mental disabilities faced stigmatised attitudes, for example, in job opportunities. Employers have stigmatising attitudes and discriminate against people diagnosed with mental disabilities. On the other hand, people with physical disabilities do not face the same extent of discrimination as Scheid (2005) presented in her study in the Southern metropolitan area of stigma as a barrier to employment. Scheid focused on the employment of individuals with mental disabilities and examined the role played by stigma through a survey of 190 employers concerning the 1990 Americans with Disability Act. She showed that stigma influenced employers in their recruiting policies when hiring those with 'mental disabilities'.

Another important term is 'inclusion' which has become a current trend in education for disabled children is their integration into education as a right of every child. Inclusion is defined as the right where disabled children are fully included into mainstream schools and mainstream classes just like other children (Friend & Bursuck, 2002, IDEA). Discourses of inclusion in general, as Armstrong (1999: 76) highlights, 'have multiple meanings, used by different people in different contexts, and are commonly used in ways which mask the attitudes, social structures and processes which produce and sustain exclusions'. Inclusion in this study means the right for every disabled child to be equally treated in his or her society without any discrimination or segregation.

A major concept in the study includes mothers and mothers of disabled children. Mothers are conceptualised in their role as carers because as based in the literature, mothers make the most significant contribution to children's care (Eker and Tuzun, 2004; Goodwin and Huppatz, 2010; Wilson, 2012). At the same time, mothers, as research suggested were more likely to accept their child's impairment and more likely to talk

about their child's disability than fathers (Fuligni, 1998; Panteliadou, Papadioti, Prokobas, & Sandrabelis, 1994; Soulis & Andreou, 2007).

The experience of giving birth to and caring for a disabled child is understood as a temporal process or trajectory in which mothers learn of their child's disability. As noted in Section 7 in Chapter 2 the trajectories of awareness of the child's disability that mothers experienced can be understood through the notion of turning points (Strauss, 1959; Elder, Johnson & Crosnoe, 2004). Turning points are defined in the sociological literature as the incidents that happen in a person's life and involve important changes to his/her life (Strauss, 1959).

In the Sociological literature turning points relate to decisions, actions and ways of thinking about the world. A turning point is another concept included in the conceptual framework of the study. Turning points for mothers giving birth to a disabled child can be seen as a set of experiences involving awareness and acceptance of a child's disability. The turning point can be experienced as a crisis (Hatton, Akram, Robertson, Shah and Emerson, 2003; Huang, Kellett and St John, 2010) and the feelings that accompany it may compare with the process of grief.

> *Learning a child's diagnosis of disability is a crisis for parents. Their reactions include shock, refusal to accept the diagnosis, anger, fear, and uncertainty about the extent of disability and associated impairment.* (Huang, Kellett and St John, 2010: 1223).

Mothers' awareness of their child's disability can also be understood in relation to the grief processes that were presented as far back as 1969 by Kubler-Ross (1969). She studied grief reactions to bereavement and loss and states five stages of the process: denial and isolation, anger, bargaining, depression, and finally acceptance. These stages do not only relate to responses to death. More recently researchers applied this concept of the grief process based on Kubler-Ross' work to other contexts. For example, Sicile-Kira (2004) described a grief cycle among parents raising a child who was diagnosed as having Autistic Spectrum Disorder. She mentioned that parents of children diagnosed as autistic appeared to follow similar stages of grief. These stages are presented in Chapter 2 and include feelings of shock and disbelief, denial, confusion, anger/rage, depression, guilt, shame, fear and panic, bargaining, hope, isolation and acceptance.

Another experience that mothers may indicate includes the concept of social comparison. Social Comparison theory has its origins in an American social psychologist, Leon Festinger (1954). According to social comparison theory and

Festinger's definition, people evaluate their own opinions and abilities by comparing themselves with others that have similar characteristics. After this original formulation, theory on social comparison in psychology has made many advances (Morrison et. al., 2004). For example, comparisons may occur in many aspects of the self such as appearance or eating habits (Lindner, Tantleff-Dunn; Jentsch, 2012; Wheeler and Miyake, 1992). The theory of how social comparison is relevant to mothers of children with disabilities will be discussed in the data. Mothers were asked about their first experiences and feelings when they had a disabled child; they compared themselves to other mothers or compared their children to other disabled children in a way to feel better. Downward or upward comparisons that are probably used by mothers might provide a way to make mothers aware of their children's disability or to feel better by this evaluation.

It is not my intention to analyse the various concepts and expanding motivations around social comparison. I briefly described some key concepts focusing on relative work on self-comparison and chronic illness in order to examine whether mothers accounts provide similar findings regarding social comparison. Issues of support and support that mothers received for themselves, for their disabled children and families in relation to other studies are discussed in the next section.

Mothering a disabled child raises issues of social support. Social support is another key concept presented in the theoretical framework and in examined in the study in depth (Chapter 2, Chapter 6 for formal support and Chapter 7 for informal support). It is what House (1981) defined as sharing life experiences, the provision of services, advice and information and appraisal support for self-evaluation such as provision of constructive feedback in order to help the person that needs the support (Findler, 2000). Social support can be categorised as formal support, the support provided by state services or other organisations in a more official way (Bridge, 2005; UK Government, 2013) and informal support that is comprised of support provided by members of the family, friends or social groups such as social organisations, for example afternoon activities and clubs (Ellison, 2006). Through the study, mothers had the opportunity to talk about their experiences of and degree of support provided to them in the Cyprus context. Support can be defined as what is offered in terms of services and other types of support and also in terms of what mothers find helpful, in this case emotional, respite care for the children, in-home and financial support (House 1981, Findler, 2000).

Goffman's influential concept of stigma and courtesy stigma is another key concept that is employed to understand mothers' experiences of discrimination concerning having a

disabled child. As Goffman suggests, stigma is activated when 'people [who] depart negatively from the particular expectations' (Goffman, 1963: 15). Moreover, he suggests that the focal person (the disabled person) is not the only one stigmatised but the members of his or her family as well who experience 'stigma by courtesy'. Mothers in the study are the members of the family, the 'wise' people as Goffman named them, who experience stigma by courtesy as they are affected by stigma through their daily interactions with disabled children as an extension of stigma discrimination (Goffman, 1963). The conceptualisation of the ways they coped with and responded to stigmatised behaviours is discussed in Chapter 8. The ways they coped with stigma and the coping mechanisms they used were also examined and analysed in Chapter 8.

The study in general will provide a clearer view of how disability and inclusion are perceived, the important role of mothers as care providers, the early experiences of mothers with disabled children, the support they receive and the experiences of stigma that they faced in raising a disabled child in the Cyprus context. This study should be undertaken using a qualitative approach as analysed in the section that follows section 4.3 which is the research design.

4.3. <u>Research design</u>

The focus in the study is mothers who care for their disabled children and not fathers or the children themselves. Mothers are the main care providers in Cyprus (Phtiaka, 2008; Zoniou-Sideri, Deropoulou-Derou, Karagianni and Spandagou, 2006), the context of the research. Lack of research generally on families with disabled children raises the necessity to focus on mothers, even though other members of the families including the disabled children themselves have been neglected as disability researchers and sociologists have identified (Shakespeare, Barnes, Priestley, Cunningham Birley, Davis, and Watson, 1999). The aim of the study is therefore to examine the experiences of mothers with disabled children and the support that they have access to in Cyprus.

The research design constitutes of a small group of mothers with a disabled child (N=25). Samples in qualitative research are usually small and non-probabilistic (Greswell, 2014; Guest, MacQueen, & Namey, 2012). I sought to select mothers who have a child or young adult with a disability in the region of Nicosia, the capital city of Cyprus because it was easily accessible to me as a Nicosia resident. Another reason was that 38.9 per cent of the population is located there (Cyprus Population Census, 2015). It was decided to select only mothers whose disabled children ranged in age from three years old to twenty-one, the age group that children are considered to be of school age (see also Chapter 4). A second rationale for this design was that the children were

living at home with their mothers rather than in institutions or with other people, something not usual to Cyprus but that happens at older ages. Omitting families whose children were in institutions was therefore justified as I was interested in mothers who were carers of their children.

The reason for including mothers whose children were aged three and older was that the study sought to examine mothers' experiences of support from the education system, the state and other services. In Cyprus, disabled children of school age are dependent both on their parents but are also under the Ministry of Education's rules and legislation; they receive funding from the government because they are considered 'dependent children' and they have the facilities offered by the state that include free services and treatments (Ministry of Education and Culture, 1999; Phtiaka, 2007). Before the age of three and after the age of twenty-one, children are under the Ministry of Labour and Social Affairs and thus legislation provides for their rights and needs (Ministry of Labour and Social Affairs, 2000). Children of school age have different needs from those aged over 21 or less than 3 years old. The government provides special-needs facilities for children from the ages of 3 to 21. A child over 21 is not a child anymore and is considered an adult that has to look for a job. Two children were 22 years old because they were allowed an extension to remain in school (Ministry of Education and Culture, 1999).

Children in both special schooling and those in mainstream schooling were selected. Disabled children attend mainstream or special schools according to the level of their disability and parental preference (Ministry of Education and Culture, 1999) (see Chapter 3). Parental preference plays an important role since parents are responsible for the selection of the school. It is important to know whether the child's attendance was a parent's preference, a teacher's suggestion or an agreement between both. The placement in the most appropriate educational setting according to the needs and abilities of the disabled child is emphasised in the Education and Training of Children with Special Needs Law 1999 [113(1)/1999)].

Given my own limited resources as a PhD student in terms of time and money and also that Cyprus has a relatively small population, together with the fact that mothers looking after disabled children at home are difficult to identify and may be reluctant to take part in research, the sample of mothers was likely to be relatively small (N=25). In the first instance, I set out to sample twenty to thirty cases of mothers having disabled children in Cyprus.

Individual differences and heterogeneity between disabled children raise difficulties theoretically in comparing mothers' situations in terms of the issues they face in caring for their children. In order to deal with this issue, mothers in the sample were chosen on the basis that their children had different types of disability, both 'visible' and 'invisible' (Goffman, 1963; Howlin, 2010; Jordan, 1999). The different range and types of disabilities are presented in the table 4.1 below. We can see that seven of the children were diagnosed as having 'cerebral palsy', two with 'autistic spectrum disorder' and two with a rare syndrome which are visible types of disability. Five children were diagnosed as having 'mild mental retardation' two with ADHD and two with 'epilepsy' which are 'invisible' types of disability. Some disabilities were not officially diagnosed at the time of the interview as shown in table 4.1, five out of twenty-five. Those five disabled children who did not have an official diagnosis were children identified as disabled based on the definition used for the disabled people but did not have an official diagnosis as the range of disability listed in table 4.1.

Range of disability	Number of children
Mild Mental Retardation	5
Autistic Spectrum Disorder	2
Cerebral Palsy	7
ADHD	2
Rare Syndrome	2
Epilepsy	2
Not diagnosed	5

Table 4.1 - Range of disability in relation to number of children

4.4.   A qualitative approach

Denzin & Lincoln (2005: 3) describe qualitative research as 'a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that makes the world visible. These practices transform the world'. A qualitative approach was also adopted because its aim is understanding the perspectives of others

as 'meaningful, knowable, and able to be made explicit' (Patton, 2003: 341). As Patton argued, the lack of power of qualitative research to generalise from this approach and sample does not invalidate it:

> *The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher rather than with the sample size (Patton, 2003: 245).*

Through qualitative interviews with mothers with disabled children, their own understandings and experiences of the world are better understood. I used qualitative methods to collect and analyse my data. The study is qualitative in the sense that it 'uses qualitative methods for both the gathering and analysis of the data, that is, visual and verbal (conceptual or thematic) rather than numerical data manipulation' (Long and Godfrey, 2004: 183). I sought to take account of the fact that the method 'constructs the means to think about the data, both in and through processes of data collection and conceptualization' (Brannen and Moss, 2012: 791).

Qualitative research uses words instead of numbers and focuses on meanings (Hammersley, 1992; Brannen, 2004). None the less qualitative researchers are expected to be rigorous and systematic in their research practice. Seale (1999: 476) discusses the ways in which concepts such as 'validity and reliability' are not adequate for assessing the quality of the qualitative research. According to qualitative researchers, 'trustworthiness' of the findings can be used instead (Denzin and Lincoln, 2005; Kvale, 2002; Noble and Smith, 2015; Hammersley, 2007).

Lincoln and Guba (1985) make reference to the terms credibility, transferability, dependability and confirmability. In my study, I address the validity of the data by recognising the multiple realities of mothers' personal experiences and viewpoints. I am not seeking the truth or the accuracy of the mothers' accounts but to capture mothers' meanings. Salmon (1985), Andrews, Squire and Tamboukou (2013) and other authors talk about the 'co-construction' of narrative between the interviewer and the interviewee, which in my study is myself as the interviewer and the questions that I asked as I engaged with the interviewees, the mothers. In that way, the interview accounts constituted both the meanings of respondents but are also the products of the methods used and the encounter between researcher and researched.

Another point that I used in order to enhance the validity of the data was that I asked a peer debriefing in order to help me reflect on taken for granted assumptions such as issues of support. Peer debriefing which has been defined as 'the process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind' (Lincoln and Guba, 1985: 308). I used this useful technique in a way to establish the credibility of my study. A friend of mine, an academic professor was the impartial peer who examined the transcripts, the general methodology and the data analysis. The purpose was as Lincoln and Guba (1985: 308) asserted, to 'keep the inquirer 'honest'' and provide 'an opportunity to test working hypotheses that may be emerging in the inquirer's mind'.

Overall it was a way to probe for meaning, bias and understanding. A granted bias should be for example the fact that mothers that receive the monthly allowance should be happy with the support received from the government. This was an assumption which came from the peer debriefing and helped me to view mothers' realities through a more holistic approach. In the context of this study, validity extends to the presentation of the mothers' accounts and perspectives without distortion by me. Among the different perspectives of validity, I support the view of Kvale (2002: 323) who mentioned that 'valid research would be research that makes question of validity superfluous' since the research procedures that I followed as described in this chapter were transparent, the results of the study were clearly presented through the analysis chapters that follow and the conclusions were justified. Under these circumstances, 'the need for external validation becomes less important' (Teusner, 2016: 88). Another way that helped with the issues of validity were the semi-structured audio recorded interviews which allowed me to revisit data in order to check emerging themes and remain true to mothers' accounts.

Noble and Smith (2015) replaced the term reliability with the term 'consistency' as more appropriate. Lincoln and Guba (1985) called 'dependability' and 'confirmability' with respect to 'reliability'.

I addressed issues of reliability, consistency or dependability by undertaking the methods of data collection and analysis in a clear and transparent way. At the same time, I used in a way what Ritchie and Lewis called a 'feministic research approach' by feeling free 'to step outside the formal role of the neutral asker of questions'. I did not express my own feelings and opinions as Ritchie and Lewis suggested but I showed to mothers that I understood them while they described their personal experiences. I felt

this was useful because mothers were not accustomed to providing interviews in formal ways especially about these sensitive topics. This step outside of the formal and structured interviewing provided me a way to address reliability of the data. The fact that I discussed the emerging themes with my supervisor challenged me and led to the achievement of greater consistency.

Together with validity and reliability, I addressed issues of reflexivity as it 'enhances the quality of research through its ability to extend our understanding of how our positions and interests as researchers affect all stages of the research process (Primeau, 2003: 9). My study involved a continuous process of reflection on my values and preconceptions and those of mothers as Parahoo (2014) highlighted when studying reflexivity.

I tried to make sure that I set aside any preconceptions that I had during the process, any suppositions and personal biases. In order to be aware of my potential judgments during data collection and data analysis, I explored my beliefs. As a teacher I was critical of much the current legislation and policy making in Cyprus concerning disability as well as assessment strategies that are followed in Cyprus's educational system. I had to set this criticism aside and approach the topic in an open minded way. Moreover, I expected that mothers were going to mention high levels of formal support since disabled children in Cyprus are a group who have been less affected by the economic crisis in Cyprus. After I acknowledged my own beliefs, I tried to separate them from those of the mothers (Manias and Street, 2001). Both the recordings and the transcription of the interviews helped me 'to raise awareness of the subtle ways in which data can be affected' by not being reflexive (Jootun, McGhee andz Marland, 2009: 43). The informal conversational style of the interviews also helped to avoid bias as they allowed mothers to reflect and communicate their experiences freely about support, feelings, stigma and any other issues encountered.

4.5. Recruiting the sample

Mothers were selected through purposive and snowball sampling techniques. Purposive sampling as Abrams, (2010: 538) mentions,

> *refers to strategies in which the researcher exercises his or her judgment about who will provide the best perspective on the phenomenon of interest, and then intentionally invites those specific perspectives into the study.*

Goodman (1961: 148) defined snowball sampling as the 'random sampling of individuals is drawn from a given finite population'.

My connection to the field of disability professionally is that I am a teacher for disabled children owning an afternoon inclusive school in the centre of Nicosia, the capital of Cyprus. In principle, I could have asked for mothers who had their children at my school to be participants in my study. However, I did not wish to interview mothers who were known to me because I sought to distance myself from my position as a teacher of their children and to adopt the position of a researcher.

In the beginning, I was going to choose mothers on the basis of their occupational status with a balance between those in higher and lower status jobs. In seeking to include both higher and lower socioeconomic groups I sought to take account of how financial resources and education may have an impact upon support. For example, mothers in families of higher socio-economic groups may have people that help them on a daily basis and so may take such support for granted, compared with mothers who do not have the same high economic resources.

During data collection, I added husbands' occupations as another criterion because nine out of twenty-five mothers were not working at the time of the interview. Six more had left their jobs at different points after the birth of their disabled children but later returned to work or found another job. The former group (the six mothers), were not working because of their care responsibilities. The last column of table 4.2 presents the employment status of mothers indicating the number of mothers who were employed from the birth of their disabled children to the time of the interview (ten mothers), the number of mothers who left their jobs after their disabled child's birth but had a job at the time of the interview (six mothers), and those who were still unemployed at the time of the interview (nine mothers).

In order to find mothers with disabled children I visited four services for disabled children (two special education centres and two occupational therapy centres) and two schools. I wanted to 'discover, understand, gain insight and therefore have a sample from which I was going to learn the most' as Merriam said when talking about purposive sampling (Merriam, 1998: 48). I informed the schools and centres about the purpose of the study. I asked their permission to give flyers about the study and consent forms to mothers that had disabled children in their schools and services.

Consent forms were given to twenty mothers who were found through the services and the schools and who met the criteria concerning the children's age groups and whose children lived with their mothers. Ten mothers who were interested in taking part wrote their names and addresses and phone numbers on the consent forms. These were returned to me by the schools and the services. The mothers who showed interest were then invited by me to be the participants in the study and were interviewed in their homes or in any place where they felt free to talk. The other ten mothers who were given consent forms declined to take part in the research so they did not sign and return the consent forms that were given to them. The reasons why mothers did not want to take part are not clear. I did not ask them as I did not want to put them in a position where they needed to find an excuse. Perhaps also the mothers were not used to participating in research studies or did not want to talk about their experiences or their disabled children. Through this purposive sampling strategy I was able to find ten mothers.

The other fifteen mothers were found through a snowball sample technique. Each participant recruited via the services or schools was asked to name other mothers who they thought might be interested in participating in the research. This method proved to be successful as those who referred me to other mothers were in a position to re-assure them that I was a PhD researcher and not part of the services or government or other organisation related to the state (Sapsford and Jupp, 2006). The fact that I was a teacher in an afternoon school for disabled children that is privately funded also meant that I was not seen as connected to the statutory services.

I asked the mothers who completed the consent forms or verbally agreed to take part to choose the place of interview. As Walker, Boddy and Phoenix (2014: 2) put it 'research thus needs to find ways to make the everyday visible and analyse it'. This proved to be useful for studying mothers since interruptions from children or any other duties that need to be done at the time of interviewing was something that mothers might want to avoid. The initial task included the possibility of conducting interviews in two short meetings instead of one long interview. I had to consider that mothers had limited time but in the end I conducted only one interview with all the mothers.

Consent to participation and agreement about the place of interview was reached through telephone communication. Some mothers decided to meet at a neutral place such as at a restaurant where we had lunch before the interview or at the private school that I am the head teacher. The five mothers who were interviewed at the private school said they felt more comfortable talking about their children without them being there at the time of the interview. Two mothers came to my house while I met one mother at a

restaurant during her break time from her work, and in the case of one mother I went to her workplace and we did the interview there. The other sixteen mothers were interviewed at their homes. Mothers wrote their phone numbers on the consent forms. The most convenient time and most comfortable setting for each participant was, I hoped, a way to help mothers speak freely.

4.6. <u>The sample and its characteristics</u>

Stake (2000) states that the cases that constitute a sample should be 'cases of something'. In this study the cases are not intended to be representative of Cypriot mothers with a disabled child but cases that exemplify both the particularity and diversity of experiences of this group of mothers.

Mothers who adopted disabled children or fostered them were not included in the sample. I did not exclude such cases. However, there were no mothers with adopted or fostered children interested in participating in the study. Table 4.2 below provides a summary of all mothers' profiles. In the beginning of the interview I asked mothers to give their demographic characteristics: ages, marital status, work status, job/occupation, number of children and name and age of their disabled child. Code names are used in the transcripts and data analysis instead of mothers' names, as well as those of their children in order to conceal their identities, something that was highlighted on the consent form provided to them before the interview as well as when I called them to arrange the interview.

Mother's Code Name	Age	Marital Status	Number of children	Disabled child's age	Employment Status of mother	Education
A.K	53	Married	2	22	Unemployed at interview	College
A.M.	41	Married	2	15	Unemployed in the past	College
A.Mav.	47	Married	3	19.5	Unemployed in the past	College
A.Kaz.	47	Married	6	18	Unemployed at interview	University
A.Y.	49	Divorced	3	11.5	Unemployed in the past	High School
C.H.	43	Divorced	1	18	Unemployed at interview	College
C.K.	50	Married	3	22	Unemployed at interview	High School
D.P.	48	Married	4	20	Unemployed in the past	High School
D.D.	31	Married	2	8	Unemployed at interview	High School
E.S.	42	Divorced	3	18	In paid work	College
E.Si.	50	Divorced	3	10	In paid work	College
G.P.	37	Married	1	10	Unemployed at interview	College
K.G.	50	Married	2	11.5	In paid work	College
K.K.	45	Divorced	4	18	In paid work	College
K.E.	50	Married	2	22	Unemployed in the past	High School
L.S.	50	Divorced	3	19	In paid work	College
M.K.	45	Married	2	7.5	Unemployed at interview	High School
M.S.	33	Married	1	9	Unemployed at interview	University
S.C.	45	Married	3	20	In paid work	College

T.K.	54	Married	3	20	In paid work	College
T. C.	35	Married	1	6	In paid work	College
T.X	47	Married	2	18	Unemployed at interview	University
V.H.	46	Married	2	11	Unemployed in the past	College
Y.O.	46	Married	2	15	In paid work	University (PhD)
Y.K.	42	Divorced	2	9	In paid work	University

Table 4.2 - Participant Profiles

Table 4.3 below provides the socioeconomic status of the families. I assessed families' socio economic status by asking the income of the family, both of the mother and her husband. Eleven mothers did not give this information either because they said they did not know the amount or because they did not want to share the information. For this reason, the socio-economic status of the family has been assessed on the basis of either mothers' and husbands' occupations, or mothers in cases that they were divorced and lived alone. In the table presented above (4.2), I illustrate the education level of mothers. Mothers who graduated high school had periods of unemployment either at the time of the interview or before. Most of the mothers/participants graduated college which means that their highest equivalent qualification was the degree they undertook from college.

Families were divided into three groups based on their socio-economic level. Their socio-economic level was estimated according to the occupation of both partners as well as to their educational level. The three levels, high, medium and low are presented in the table "Socio-economic status of the families". The household disposable income, which is defined as the sum of income of all household members from economic activity, property income and social benefits in cash has been divided by household's respective equivalised size. Four study families are in the high group, eleven in the medium group and ten in the low group. The study is biased therefore towards the low-income families (10/25). In my group of participants, ten families were estimated at low socio-economic condition based on the occupation of both husband and mother, as both of them were not working (G.P.), the mother was unemployed and divorced (such as A.Y) or one unemployed and the other one manual worker or in a part-time work position. This is rather more than the general Cyprus population; in 2014 28.9% of households were at risk of poverty or social exclusion. This is the percentage of the population who are at risk of poverty or are severely materially deprived or living in a household with a very low work intensity defined by Eurostat (2015): 'people of all ages (from 0-59 years) living in

households where the adults worked less than 20% of their potential during the previous 12 months' (D.D).

At the time of the interviews, mothers' ages ranged from 31 to 54 years old with a mean age of 45.04 years old. Disabled children had different diagnoses of disability that include chromosomal abnormalities, syndromes e.g. Aarskog-scott, mental retardation, autism, cerebral palsy and ADHD. Eighteen mothers were married while seven mothers were divorced. Ten mothers were unemployed. Out of the fifteen mothers who were employed, three were working part-time and one was employed only in term time as she worked as a SENCO in a primary school.

Based on the population Census of 2011, there are 291, 848 mothers in Cyprus (Statistical Service, 2011). Of these, 50, 189 were raising their children alone, roughly 17%. In my study seven mothers out of the twenty-five were divorced, roughly 28%. Thus, as the literature (Fischer, 1990; Jesser, 2003; Reyns, 2006; Shtayermman, 2013) suggests, mothers with disabled children are more likely to be divorced compared with those whose children are not disabled. For example, Jesser (2003) in his study examining marital satisfaction of parents with disabled children identified that as stereotypic behaviours increase, marital satisfaction decreases and the child's disability has a significant relationship to marital satisfaction.

According to the same Population Census (Statistical Service, 2011), the participation rate in the workforce of women aged 15 years and over was estimated at 54.8%. This means that 45.2% of women were non-employed or officially unemployed. Ten mothers were unemployed (40%) in my study.

Mother's Code Name	Mother's Work	Husband's Work	Socioeconomic Status of the Family
A.K	Unemployed	Shop worker	Medium
A.M.	Secretary - part time	Government Worker	Medium
A.Mav.	SENCO – Term Time	Officer in the Army	Low
A.Kaz.	Unemployed	Manual Worker in the Municipality of Nicosia	Low
A.Y.	House Maid (private employee)	Manual Worker in a private company	Low
C.H.	Unemployed	Manual Worker in a Government Position	Low
C.K.	Unemployed	Runs home bakery business for private occasions	Medium

		Unemployed, painter and builder occasionally	
D.P.	Carer and Florist - Part time	Unemployed, painter and builder occasionally	Low
D.D.	Unemployed	Private Employer (car engineer)	Low
E.S.	Government Officer - Full time	Government Worker	Medium
E.Si.	Teller in a bank - Full time	Manual worker in a private company	Medium
G.P.	Unemployed	Unemployed	Low
K.G.	Secretary - Government - Full time	Private Worker	Medium
K.K.	Secretary - Full time	Admin Officer in semi-government organisation	Low
K.E.	Unemployed	Owner of a small business (mini market)	Medium
L.S.	Government officer - Full time	Manual worker in semi-government organisation	Medium
M.K.	Unemployed	Worker in a Government Position - Full time And owner in a private small business	Low
M.S.	Unemployed	Worker in a private company	Low
S.C.	Medium Businesswoman	Medium business Man	High
T.K.	Nurse - Full time	Owner of a small business	Medium
T. C.	Secretary - Full time	Owner of a small business	High
T.X	Unemployed	Medical Doctor	Medium
V.H.	Artist - Cashier in an Organic Health Shop - Part Time	Private Hospital Owner	High
Y.O.	Academic Professor - Full time	X-Ray Doctor	High
Y.K.	Teller in a bank - Full time	Lawyer	Medium

Table 4.3. - Mothers' and Husbands' occupations and socio-economic status of the family

Another important characteristic that needs to be mentioned is the fact that Cyprus is considered a rural country based on the high proportion of the workforce involved in agriculture and trade (FSS, 2010) as it is mentioned in the previous Chapter (Chapter 3). Country's rural characteristics will be helpful to understand stigma behaviours associated with disability and mothers' accounts of and reactions to these. It is important to have in mind that my sample is considered as mothers living in a partly-rural country as 33% of the total population is rural. Even though mothers in my study live in Nicosia, they have strong ties to the countryside and this makes the above statement relevant. The parents

of most of the mothers lived in the countryside and the mothers visited them regularly or they relied on them to take care of their children.

4.7. <u>Methods of Data Collection</u>
4.7.1. The research interview

A semi- structured interview format was used that included both open – ended questions with some closed questions. One reason for choosing an in-depth interview approach was that it combines structure with flexibility (Legard, Keegan and Ward, 2003) and that it aims to generate new and unexpected phenomena (Kvale, 1996). Through in–depth interviews I expected to create a more detailed picture than I would obtain through a survey (Boyce and Neale, 2006). A more complete picture was expected to be gained through using an in–depth interview that takes the form of a conversation about everyday life (Kvale, 1996). This approach can be rewarding for both interviewer and interviewee, 'the unfolding of stories and new insights can be rewarding for both parties in the interview interaction' (Kvale and Brinkmann, 2009: 27).

The interview was of a sensitive nature because I was interviewing mothers about sensitive matters such as the time of awareness of their child's disability or experiences of stigma. Heptinstall, Bhopal and Brannen (2001) in their work about children adjusting to a foster family highlight the careful balance needed between probing and not pushing hard that needs to be maintained during the interview in order to avoid making the child upset. This was also necessary in approaching mothers in the interviews. I provided various opportunities to mothers to talk about their experiences through the different questions that I asked. However to some extent every mother was approached in a different way. In cases, for example, where a mother was less forthcoming, I tried first to make her feel comfortable by discussing more general topics before I raised the interview questions. As noted above, I planned to do the fieldwork in one or two meetings with each mother. In the end, all the mothers were interviewed in one meeting, which lasted between one and three hours.

It was opted to generate narratives of mothers' experiences of bringing up their children over time (Riessman, 2002). A narrative form is used in order to address temporality – stories about the past told in the present with an eye to the future. As Brannen highlighted, 'life stories tell us not only about how informants experienced, and continue to experience, the past, but also about how they experience the present and how they may live their lives in the future' (Brannen 2013). I tried to encourage the mothers to lead the discussion and describe their experiences and feelings as they changed over their

child's life. The interviews fall somewhere between a more structured and a narrative form.

Two mothers were interviewed for a pilot study. These were mothers of children from my school who had shown interest in participating in the research after I asked them. They were not included in the overall sample as I made changes to the interview structure and questions after these interviews. The main reason for not including them was that I did not want to include mothers that were known to me even though I tried to distance myself from my relationship with them as a professional with responsibility for their children. On the basis of the pilot, changes were made mainly in the first part of the interview that is presented in Appendix 1. I noted that the grid that mothers were asked to fill in concerning the people they had regular contact with was not seen by mothers as helpful as they talked about support and those that did or did not provide support throughout the interview. I therefore removed the grid.

The interview schedule (Appendix 1) was divided into three stages. In the first stage after outlining the study and its aims, I asked five structured questions about the mother's and child's networks in order to gain personal and demographic information about the mother and the family. I asked questions to ascertain their socio-economic background so that I could examine how the socio-economic status of the family affected the experiences and support that they received.

The second stage included open-ended questions about the feelings and first experiences of mothers from the time of their disabled child's birth to the time of their own awareness of the disability and the medical diagnosis. I also asked the mothers to recount particular stories concerning their experiences of living with a disabled child and feelings of stigma that they had encountered over the course of their children's lives.

In the third part, issues of support were asked. Mothers were asked to describe support and services that they and their children received from society and from the Cyprus government (formal support). At the same time I asked them about the lay support that they received from family friends and importantly their husbands/children's fathers, relatives and their other children (informal support). I asked various questions but also followed up with probes in order to achieve "depth of answer in terms of penetration, exploration and explanation" (Legard, Keegan and Ward, 2003: 141). The qualitative interviews provided data that would not have been gathered through the use of other methods such as standardised questionnaires. Mothers showed genuine interest in talking about their experiences in a relatively informal way; I tried to make mothers feel

comfortable by, as Kirk and Miller highlighted (1986: 9), 'interacting with them in their own language, their own terms'. During the interviews there were many times when I asked mothers to provide clarification and I asked further questions in order for them to elaborate their experiences and accounts.

4.7.2. Documentary data about services and schools

In order to set the context in which mothers' care for their disabled children in Cyprus, I collected documentary material about: legislation (Education and Training of Children with Special Needs Law 1999 [113(1)/1999)]), the services provided by the government, and the schools in relation to the ways they respond to disability and provide support to families with a disabled child in Cyprus. This includes data that related to both mainstream and special schools in the policies that schools have about the attendance of children in their schools, and documents about the inclusion and exclusion of disabled children (Phtiaka, 2007). At the same time, data were taken from institutions such as 'Radiomarathonios' (Radiomarathonios, 2013), the main charity organisation for people with disabilities in Cyprus (see chapter 4) as well as statistics from the statistical service of Cyprus.

It is very important to consult such documents in order to discover what resources exist and what are the meanings that underlie such documents that relate to the topic of inquiry. According to Scott (2014: 36), documents can be used as *resources* or as *topics*. In this study I used the documentary material as resources, for example, the information available on support from charity organisations, and as topics that provided an understanding of models of disability and of inclusive practices that exist in Cyprus.

Scott (2014) studied documentary sources in social research and created a typology. He classified documents on two dimensions based on authorship and access. The dimension of authorship referred to their origin, divided into 'personal', 'public' and 'official' categories. The dimension of 'access' has to do with the availability of the documents to other people, not only the authors. The first category is named 'closed' access. Secondly, there are 'restricted' documents that are accessible under specified conditions which Scott classified into personal and official, and divided the official documents into private and state. The third category relates to 'archival' documents which include documents lodged in a place where access is open if asked and finally 'published' documents that are accessible to all.

Table 4.4 presents the documentary material used in the study in relation to the classification made by John Scott (2014).

Document	Authorship	Access
Legislations e.g. The Education and Training of Children with Special Needs Law 1999 [113(1)/1999)].	Official – State	Open – archival
Radiomarathon (Is the largest charity organisation in Cyprus for fundraising to help children with 'special needs')	Official – Private	Open – published
Cyprus Statistical Data - Census	Official – State	Open – archival
Services for the disabled people e.g. Monthly allowance for disabled people	Official – State	Restricted
Public Discourses around disability e.g. Pitsiali, Y. (2014) *Letter to the General Manager of Ministry of Health*	Personal	Open – published
Official Reports e.g. Annual Review for disabled people	Official – State	Restricted

Table 4.4 - Classification of documentary material in relation to Scott's classification

Data that are not available in Cyprus concerns children with disabilities. I therefore identified data that includes disabled people and not only disabled children. Data are also collected in relation to the allowances to mothers and disabled children. In addition, I examined the legislation I was able to understand the rights of the disabled children to be educated. I also sought documents about Radiomarathon, the charity organisation for disabled children in Cyprus and the information that it provides economic support to mothers.

4.8. Ethical Issues

In order to gain permission for the doctoral study I made an application to the Ethics Committee of Institute of Education, University of London. The application included a summary of the research, as well as the ethical issues that were likely to arise in the course of my study and how I was going to address them. The study protocol was submitted to the ethics committee for approval before undertaking the research.

In a research study that concerns the recounting of personal and often difficult experiences relating to mothers' children I had to be careful in my research practice because of the fact that these are sensitive topics. While endeavouring to be sympathetic and understanding I sought to be non-interventionist and to remain in my role as a researcher (Boyce and Neale, 2006; Kvale, 1996; Swain, Heyman and Gillman, 1998). Should the interview raise issues in which mothers indicated they wanted support,

I prepared and offered them a list of organisations and the benefits available. The fact that I am also a teacher of children with disabilities put me in a strong position to provide this information. I made sure that mothers understood that I did not judge them. Research that is "conducted by sensitivity... becomes a process with benefits to both participants and researchers" (Corbin and Morse, 2003: 335).

In order to maximise confidentiality, I minimised the potential risks of exposing the mothers' personal information and that of their children to media or any organisations. Matters of confidentiality and anonymity were discussed with the mothers before and during the course of the research. The real names of mothers on the stored files and all other information regarding mothers, their child or any other member of the family that were mentioned in the research were changed and I used their code names as pseudonyms in any reporting of the research. In many cases mothers are mentioned in the thesis as 'the mother' while disabled children are mentioned as 'the child'. Organisations or institutions that mothers made reference to are named. On the other hand, names of the particular doctors, for example, are not mentioned in the thesis even if mothers named them, that is, in order that the study maintains the anonymity of individual professionals (Cyprus is a very small society). The interviews were recorded, transcribed and stored on a secure computer with passwords. Accuracy of the interview transcripts as well as my own interpretation of what mothers said were vital for the research. With the tape recordings I was able to listen back to everything that was said.

As noted above, I tried to create an environment where mothers felt comfortable to talk. The fact that the interviews were held in mothers' homes or in any place preferable to them was helpful. I took field notes from my observations before the implementation of the interview began in order to provide further contextual data for the analysis. Since the children were present in many interviews I had to be flexible, for example where necessary I offered mothers the opportunity of conducting the interview on more than one session. However there were no cases of interviews that were conducted in two sessions. I also offered 'walking interviews' (Jones, Bunce, Evans, Gibbs and Ricketts Hein, 2008) so that the participant and I were able to move and talk while undertaking the interview. This as well as the two-session interviewing was not taken up by any mothers.

With the form showing interest in participating in the research, mothers were asked to sign a consent form, which they were asked to fill in and return to me if they were interested in participating in my research. Hammersley (2014) argues that the expectations of the interviewees are shaped by what the researcher tells them about the

research. Therefore, mothers were informed about the aim of the project beforehand (Appendix 2), and what kinds of issues would be covered in the interview (Hammersley, 2014). My personal information such as contact details, address, email and telephone number were included in the consent form so that they were able to get back to me any time and also as a token of trust for communication purposes (Appendix 2).

In order to increase the trustworthiness of the data I tried to get close to the mothers' subjective experiences of raising a disabled child as Oakley describes in relation to her sample of women's experiences of becoming mothers (Oakley, 1981). It may not be considered helpful to disclose one's own personal issues in an interview, as Brannen (1988) argues, women may want all the attention to be on them. However, at least at the start of the interview when I told the mothers about my personal interest in disability, I preferred to take this risk.

Of equal importance was the issue of safeguarding mothers' emotional wellbeing during and after the course of interviews. Babbie (2001) has talked about the risk that social research entails in asking participants to dwell on behaviour, attitudes and experiences that may make people uncomfortable or may cause grief. In regards to this study, mothers were asked to describe their experiences through their journey from giving birth to a disabled child until the time of interview. I gave them the opportunity to decline to answer and to withdraw from the study at any time. I mentioned these possibilities on the consent form and repeated them at the beginning of the interview. None of them declined to answer any question or withdraw from the interview.

After we finished the interview, I informed mothers that at the end of the study I was going to provide them with a brief account of the results from the study. I also told mothers that they had the right to see their interviews before I was going to analyse them. None of the mothers asked for them. I gave them a document that sets out their rights to particular benefits in Cyprus and where and how to apply. I also provided them with a list of organisations that give support to mothers and to families of children with a disability.

4.9. <u>Data Analysis</u>

Thematic analysis is 'a method for systematically identifying, organizing, and offering insight into patterns of meaning (themes) across a data set' (Braun and Clarke, 2012: 57). I selected thematic analysis because, as Braun and Clarke highlighted, it 'is a way of identifying what is common to a way a topic is talked or written about and of making

sense of those commonalities'. In this way, I used thematic analysis in order to identify the experiences, the support that mothers reported and the stigma that they encountered and to try to make sense out of them in relation to the commonalities that existed in relevant references and studies. Accessibility and flexibility, the two main reasons to use thematic analysis as Braun and Clarke emphasised, justify my selection of this method as well.

I chose thematic analysis rather than for example, Interpretive Phenomenological Analysis (IPA) which tries to capture understandings of lived experiences and how participants make sense of their experiences themselves (Smith, Flowers, Larkin, 2009) although it is said that it is very close to some versions of thematic analysis (Pringle, McLafferty and Hentry, 2011). Grounded theory can be said to be similar to thematic analysis because it provides systematic, successive strategies in order to develop ideas to collect and analyse empirical data (Charmaz, 2008; Glaser and Strauss, 1967). It thus can be considered as part of my approach to analysis in which themes are identified as well as a deductive logic of inquiry based on questions asked (Glaser and Strauss, 1967).

Through this method of thematic analysis I was able to focus on the data in numerous different ways, for example, from mothers accounts to take the responses that provided me with the opportunity to conceptualise mothers' narratives about their feelings and first experiences of learning their child had a disability as 'journeys' and the different turning points that they went through. Inductive thematic analysis also helped me to understand that the experience had much in common with the grief process. At the same time, mothers' responses concerning support followed from the way I asked them about different types of support: state services and the voluntary sector (formal support) and family and friends (informal support).

In analysing mothers' accounts of feelings and experiences of having a disabled child, the support they received, their experiences concerning stigmatisation and mechanisms of coping with stigma, I used thematic approach in that analysis of mothers' responses were driven by the research questions and by the questions I asked them in the interviews. I coded them accordingly. The themes reflect my research questions and the questions that mothers were asked during the interviews. I also used an inductive approach to find 'emergent' themes from the data and coded them (Braun & Clarke, 2006; Braun and Clarke, 2012).

Firstly, I familiarised myself with the data by listening to the recordings two or three times. I then transcribed the recordings and read and reread them. While I was reading them I was able to create some basic headings based on the research questions. I made notes and wrote summaries around four main themes. The first theme was "Information about the family and its social network". All the personal information about the mother – her age, education, current job, employment hours, partner, number of children and ages, husband's education, job and employment hours. I also collected information about the disabled child: type of disability and the child's schooling chronology.

The second theme covered mothers' narratives of becoming a mother of a disabled child, their feelings and first experiences. Theme three covered their responses to the questions about services and the support provided to or sought by mothers in relation to their disabled children or their family in general. The last main theme concerned mothers' responses to the questions concerning stigma and stigmatisation.

I then generated some initial codes based on the main themes and then searched for sub themes. Thus for example, in relation to my research question concerning the experiences or pathways of mothers following the child's birth until the time of the mother's awareness of the child's disability and/or the medical diagnosis of disability, I identified a number of important distinctions concerning the time, persons and processes involved in mothers becoming aware of their child's 'problem' (Chapter 5).

In relation to the research question - 'What kind of support did mothers access through their journeys of raising disabled children, formal and informal?' I identified the type of support and the source of the support that mothers had recourse to. I treated separately the different types of support that mothers mentioned: I analysed formal support in chapter 6 and informal support in chapter 7. The former concerned state benefits, services and voluntary organisations and informal support refers to the support of their husbands, other household members, friends and other relatives.

The last research question - 'How is stigmatisation understood, experienced and coped by the mothers of disabled children?' - was analysed using inductive thematic approaches. For example, the mechanisms that the mothers used, in order to cope with stigma behaviours and their emotional responses to stigma, were analysed largely inductively although I also had recourse to the literature, based on Goffman's work on stigma (Chapter 8). The aim was to identify the common issues raised in mothers' accounts of their experiences of stigmatisation and explore their feelings about and their views and actions when they encountered stigmatised behaviour.

In reporting the findings I have stated how many mothers mentioned a particular theme. I did this in order to demonstrate that I have analysed the data thoroughly and rigorously. I am not suggesting any generalisations can be made from the sample of mothers. During the analysis I came across instances that did not fit into the 'common issues' that I identified. I was rigorous in my analysis as I analysed the data thoroughly as I was looking as each case separately. I looked at each interview as a specific case with the aim to use the data that each one provided me instead of cutting up and grouping responses. That is why I used numbers in the analysis to represent all the cases in which a particular theme was mentioned, both common and uncommon themes. For example, in the analysis of the second research question, specifically concerning formal support provision, there were mothers who were satisfied with the formal support they received. Even if this was not a 'common issue' as the majority of mothers talked about in negative terms, I presented these cases but also the three mothers that received the charity organisation funding who talked about it in positive terms.

After setting out the methodology of the study, I will analyse in the following chapters the data derived and based on the research questions, discuss the findings, and I will examine the importance of the points that emerged in understanding the mothers' unique journeys.

Chapter 5 – Mothers' feelings and learning about their children's disabilities: from the child's birth, to awareness

5.1. <u>Introduction</u>

In this chapter, the aim is to get an understanding of the feelings of the mothers about their children's disabilities, and the different pathways through which these mothers became aware of the disabilities. This chapter is related to the first research question:

- What are the experiences and feelings of mothers following the child's birth until the time of awareness or diagnosis of a disability?

As discussed in section 2.3 in Chapter 2, giving birth to a disabled child generates feelings and experiences that are not the same as raising a child without a disability (Phtiaka, 2007; Beresford, Rabiee and Sloper 2007). Having a child diagnosed with a disability is considerably more challenging because of the amount of time, energy and patience that is required by a mother or by the main carer than the amount needed for raising a typically developing child, and stress and anxiety are common feelings amongst mothers raising disabled children (Crowe, VanLeit, Berghams and Mann, 2007; Lawrence, 2011; Plant and Sanders, 2007). From the birth of the child to the time of becoming aware of the child's disability, irrespective of whether or not a mother is given an 'official' diagnosis, parents endure a stressful experience as reported in many studies (Gupta, Mehrotra and Mehrotra, 2012; Huang, Kellett and St John; 2010; Sicile-Kira 2004). For this reason, the stories, the explanations and the descriptions given by the mothers on learning about their child's disability, how they became aware of it, how they felt about it and what their first actions were, are analysed in this chapter. Work in relevant studies such as George, Vickers, Wilkes and Barton (2007) and Huang et. al. (2010) are discussed in chapter 2 – Literature review.

The first months and years of a child's life are very important and a mother's decisions and reactions can influence the child's progress and development (Paroutsas, 2005; Wilson, 2012). A mother's first reactions and experiences after giving birth to a disabled child may differ from the normative expectations of "celebrating a birth, maternal bonding, returning to work, a child's healthy body, speech and language, hearing, sight, socially appropriate behaviour, academic ability, mainstream schooling" (Rogers, 2011: 563). Mothers are obligated in a way to change their everyday life. For example, an important change in their daily routine is the communication with people such as doctors, therapists, specialist teachers and other professionals (Donzelot, 1979, Rogers, 2011). Mothers' reactions vary as they are influenced by expectations and assumptions

concerning what it means to have a 'normal child'. All these feelings and different reactions are analysed in this chapter.

The feelings that the mothers experienced and their reactions and the actions that they took after they realised that their children did not follow the typical developmental path that they hoped or thought their child would are examined here, because these factors are said to play an important role in how children subsequently develop and the consequences on how parents manage the disability. For example, Johansson and Ringsberg (2004) undertook a study on the experiences of parents whose children were born with a cleft lip or palate. They concluded that parents who had a positive attitude when they accepted that their child had a disability, had a positive effect on their children's future.

As presented in Chapter 3, Cyprus does not have specific legislation regarding disabled children that outlines the procedures that a parent or a specialist should follow from the beginning, that is to say, from the time of the awareness of the child's disability. There is a law regarding disabled people in general such as their right to equal opportunity in employment and the benefits that they are entitled to, for example, the disability parking card and some general matters concerning the monthly allowance that parents or main carers of a disabled child are eligible to receive (Ministry of Labour, Welfare and Social Insurance (L. 127 (I) 2000). There is no specific law regarding disabled children or the procedures that a parent should follow in order to help their child. Children have the right to be diagnosed and assessed without any personal expenses being incurred by their parents (Ministry of Labour, Welfare and Social Insurance, L. 127(I)/2000; Department for Social Inclusion of Persons with Disabilities, 2016). Furthermore, many families seek treatment abroad. In these cases, this includes an additional allowance, even if some expenses might be covered by the government (in cases where there is no relevant department, equipment or specialists in Cyprus).

During the interviews I asked the mothers to describe what happened when their child was born, and whether they experienced feelings of bonding with their child straight after the birth, and whether they celebrated the birth or not (Rogers, 2011). If mothers did not mention the disability of their child, I asked them at a later stage of the interview about the time that they found out about their child's disability, how they felt about it and what their feelings were. At that point, I went back to asking them to describe their experiences during their child's early years. Important to be mentioned here was the emphasis that I placed on the mothers. I did not ask about the fathers' feelings and involvement and this therefore, may have underestimated their importance to the

mothers. I asked about the mothers' feelings and the events that followed, and so I analysed their experiences when they spoke in the first person about themselves. However, I mentioned the cases where they referred to 'we', which included their husbands' feelings and experiences in their journey of awareness.

This chapter analyses mothers' narratives of their experiences over the life course of their child. It needs to be stressed that these mothers were reflecting over long periods of time. Disabled children in the study ranged in age from six to twenty-two years with a mean age of 16.25 years. The stories of the mothers' experiences and feelings are presented according to four main themes that I identified in analysing the data. The themes suggest the different pathways of the mothers' experiences, from the birth of the child, to finding out about the disability themselves or from it being diagnosed by a professional. The moment of acceptance of the diagnosis of a disability is also considered. These are 'pathways' of experience and some mothers proceeded through more than one pathway. Commonalities in the feelings that the mothers experienced are also analysed in the section that precedes and follows the analysis of the different pathways.

Finding out about their child's disability was for some a turning point. The concept which was included in the conceptual framework of the study was defined in chapter 4 and refers to an incident, event or experience that changes the way a person looks at life and which alters the direction of their life. In this study, becoming aware of a child's disability is a turning point in the sense that it is the transition from the idea of having a 'healthy child' to another set of understanding, which is the arrival of a child that is disabled or not healthy. It also signals that the child will be in need of and dependant on his or her parents for probably the rest of his or her life (Fischer, 2012; Miller, 2007, Shanaban & MacMillan, 2008). Goldberg *et al.* (1995) working with families with learning-disabled members in the UK suggested that parents on learning that they had given birth to a disabled child felt that they had just lost a healthy and 'normal' child that they expected to have.

Some mothers compared their children either with other children or with other disabled children. The concept of social comparison in psychology first originated by Festinger (Festinger, 1954) who defined social comparison as the ways in which people compare their own opinions or abilities in accordance with a group's standards and norms. For example, Schachter and Singer (1962) discussed how people compare their emotions to those of others, while Buunk and Gibbons (2007) examined how people compared their own characteristics to other people's characteristics.

As we will see in the presentation of the different pathways, some mothers in the study were aware of their child's disability from the beginning, whereas others were informed some years after the birth of their child, usually when the child went to school and was assessed by teachers and other professionals such as school psychologists. In Cyprus, in cases where a baby is born with a visible disability, a physical or mental condition that is usually easily observable (Matthews and Harrington, 2000) the baby is referred by his doctor or another specialist or by the parent for an assessment, to diagnose the possible disability. In the situation where the child is of school age, that is, three years and over,[4] the specialist who will be conducting the assessment is referred to the District Committee of the Ministry of Education (Desforges and Lindsay, 2010). After the age of three years children in Cyprus fall under the Ministry of Education's legislation (Ministry of Education 113/1999). According to the special education provision in Cyprus' educational system, if an assessment concludes that the child needs special education provision at school, then he/she is entitled to receive special education throughout his/her entire student life. If a child does not attend special education lessons whilst in primary school, then it is more difficult to receive the facilities needed at secondary school since he/she has to be assessed again and the whole procedure takes a lot of time (Angelides, 2004). A presentation and a critical analysis of the Special Education Act in Cyprus is described in Chapter 3 (Ministry of Education 113/1999) and in this section I also mention that there is no specific legislation for disabled children under the age of 3. Before this age, they are entitled to have their early intervention programmes either at home or in public hospitals.

The literature on the feelings of parents with disabled children suggests that parents go through different stages with their feelings until they acknowledge and accept the disability of their child (Knapp, Romeo & Beecham, 2007), a process that is akin to grieving (Kubler-Ross, 1969; McCauley, 2010; Sicile-Kira, 2004).

Huang, Kellett and St. John (2010), in their research about the experiences of fifteen mothers after learning about their child's diagnosis of cerebral palsy employ the concept of 'crisis' (Hatton et.al, 2003) to make sense of the mothers' responses after being given their child's diagnosis, which included feelings of shock, anger and fear, and uncertainty about the extent of their child's disability and of any other possible associated impairments.

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[4]Education level in Cyprus is obligatory from the age of 4 8/12 years old whereas children are accepted in education from the age of three years old.

Giving birth to a disabled child can be emotionally traumatic. Work on trauma was defined by Freud as a wound that occurs outside the range of normal human experience (Woolfork, 2000). Krystal (1978) distinguished "chronic stress trauma" and "acute shock trauma". Acute trauma can arise from a major event or experience that leads to depression and anxiety (Krystal, 1978; Murphy, 1961). Guilt, confusion and disappointment are some of the feelings that characterise a traumatic period in parents' and mothers' lives, in particular when they discover their child has a disability (McGill Smith, 2003). As Morris, Blake, Stimson, Borek and Maguire (2016) suggest, being responsible to care for a disabled child is not something that a parent expects or plans for. This is something that produces unexpected reactions such as trauma, shock and denial. In their qualitative research on the feelings and experiences of full-time parents of children with chronic illness, George, Vickers, Wilkes and Barton (2007) show that parents felt that their voices were not heard or valued by health specialists in relation to their actual experiences and concerns and that they lost confidence and trust in the professionals.

McCauley (2010) in her research on the experiences of six parents of children diagnosed with autism supported the results of other studies, such as Nissenbaum *et.al,* (2002) and Futagi and Yamamoto (2010). McCauley mentions that:

> *Parents by this stage would have already 'envisioned' a life for their 'normal' child and the sooner that a diagnosis can be made, the sooner the grieving process can begin, which leads to quicker acceptance of the child by the parents, which in turns leads to them seeking appropriate support for themselves and their child (p.30).*

McCauley also argued that grieving can begin as soon as the diagnosis is provided. This leads to a quicker acceptance of the child's disability, which in turn can lead to parents seeking the appropriate support both for themselves and for their child. According to Fletcher, a medical practitioner, there is a strong argument in favour of giving a parent clear information about their child's disability as soon as possible after the birth (Fletcher, 2004).

Feelings however are not only or always negative. As presented in the literature review, parents and mothers in general talk about positive feelings of happiness, energy and empowerment that follow the birth of their child. At the same time, becoming a mother and bringing a new life into world evoke positive feelings that mothers with disabled children experience as they give birth (Green, 2001, Read, 2000; Ryan and Runswick-Cole, 2008).

The findings of the study are divided into two sections in this chapter. Firstly, I present the findings based on the mothers' reported feelings of shock, disappointment, stress, anger, disbelief, panic and other feelings, and I then discuss the different pathways of the mothers learning about their children's disabilities from the time of birth to the time of awareness as I identified from their experiences.

5.2. <u>Mothers' feelings of learning about their children's disabilities</u>

The mothers in the study described going through different stages of feelings. The fact that they recalled so many years later the feelings that they first experienced is evidence of the significance of these feelings for them. Most of the mothers (fifteen out of twenty-five) described their feelings and reactions using narrative speech that usually involved accounts from five to ten minutes when answering to the question: 'what happened when your child was born and how did you feel about this?' Narrative or 'story-telling' is defined here as a form of communication whereby 'people recall what has happened, put experience into sequence, find possible explanations for, and play with the chain of events that shapes individual and social life' (Jovchelovitch and Bauer, 2000: 1). Narrative is defined as a form of communication which expresses individual experience and how this 'experience is shaped, constrained, or marked by society and culture' (Kelly, 2005: 185).

In addition, there were six mothers who recalled the time they gave birth, vividly described their experiences, almost as if they had experienced them the day before. The fact that those six mothers provided detailed information and vivid accounts, made this group specific. They were either younger mothers in age (on average 33 years old) and mothers whose children were aged between six to fourteen years and therefore did not need to think back many years (Y.O., M.S., T.H.), or they were mothers who had actively engaged in Parents Associations Groups in order to protect their children's rights at school and in society. (K.E., C.H., D.P.). This group of mothers was significant as this association with the public kept mothers more up to date with the development of disability in Cyprus as well as with the problems that they were or were not able to deal with.

Only two of the mothers provided short responses to the question. One was a mother who was from a low socio-economic background and had difficulty understanding the question posed and in general during the interview I had to repeat the questions two or three times in order for her to understand and to respond to them (D.D). The second

mother did not feel comfortable from the start of the interview and so her responses were brief initially (K.G).

Socio-economic background is not related to the feelings experienced by mothers since as all mothers reported negative feelings and feelings relevant to the stages of grief. Social class however is related to the time mothers acknowledged their child's disability, their turning point experience. Mothers from higher socioeconomic backgrounds reported turning point experiences when their children were younger in comparison with mothers from lower class backgrounds whose negative feelings and acknowledgment of their child's disability emerged when their children were older.

Although Cyprus is a different cultural context from the UK, and the interviews were in Greek, the mothers used words that have the exact parallels in English to name their feelings. Most commonly reported were feelings of 'shock', 'disappointment', 'stress' and 'anxiety', 'anger' as well as 'frustration' and 'disbelief'. Important to be noted though was the feeling of 'happiness' that mothers mentioned. Giving birth to their children, mothers highlighted the 'excitement' that they felt and 'enjoyment' as they brought a new life into world (M.S., E.Si., K.G).

5.2.1. Shock

All the mothers mentioned 'shock' (=σοκ) as one of the first feelings they experienced when they found out about their child's disability. This feeling was expressed by the mothers who 'envisioned' a 'normal' life for their child and now had to accept the fact that their dreams and their expectations for their child would probably encounter significant obstacles in life. Obviously, this was something unexpected for the mothers and they faced difficulties in accepting this from the one day to another. This feeling was common to all the mothers as mentioned, even among those who were informed of the disability immediately after the birth of their child, or some months or years later.

> *For the first years, I lived with this feeling of shock. I could not ask for specialised support as I had to pay for this and I could not afford it* (A.M. aged 41 at interview, married with two children, disabled child aged 15 at interview, part time secretary in a lawyer's office)

> *I was shocked. I knew that as of now on, many problems and difficulties would begin and they would be continuous and never-ending and I was not ready to accept this* (A.Mav. aged 47 at interview, disabled child aged 19.5 at interview, SENCO teacher).[5]

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[5] Throughout the thesis, mothers are presented with their code names and in most of the cases a short personal information is followed in brackets, helpful for understanding.

Mothers mentioned that the first years were more difficult compared to the years that followed. For one mother, M.S. (33 years old at the time of the interview, married with one child, disabled, aged 9 at interview, unemployed) who knew during her pregnancy that her child would be born with problems, her first feeling was still one of shock.

Ok, I didn't know what to expect. Everything happened suddenly, I was expecting to give birth on my due date, and from the one moment to another, everything changed. It was a very big shock, and the first days were dreadful.

5.2.2. Disappointment

Mothers said that the first months of realising their children's disabilities were the most difficult; they felt disappointed and alone especially when they felt nobody could help them. Feelings of helplessness were common to mothers in the study. Disappointment was mentioned by fifteen mothers when they realised their loss of a 'normal' or 'healthy' child (Miller, 2007). This was mentioned by mothers who were aware of their child's disability early on after their child's birth.

I was so disappointed. I just could not believe it. I felt that I was not able to trust any doctor, because they said that everything was fine before I gave birth and all of a sudden everything changed. I just felt disappointed and I only had negative feelings, what else was I supposed to feel? (L.S. aged 50 at the time of the interview, divorced with three children – Government administrative secretary).

The feeling of disappointment was expressed by the mothers as a lack of trust in doctors and other professionals in general: '*No, no I could not trust them*' (S.C.). The mothers' disappointment in these professionals led some of the parents, as I shall show further on, to seek medical help abroad.

5.2.3. Stress and anxiety

Fourteen of the mothers mentioned health problems or behavioural problems such as stress and anxiety. Y.O. talked about these feelings when she first realised that her disabled child could not eat properly and that this was life-threatening and a matter of survival. '*I had unbelievable stress and anxiety ... I was trying to feed my child in any way that I possibly could...*'

5.2.4. Anger and frustration

Ten mothers felt angry and related this feeling of anger to helplessness as they felt that professionals such as doctors were the reason for the delay in their child's diagnosis. The mothers thereby lost valuable time in helping their child, time that would have been saved if they were given an earlier diagnosis or sufficient information.

I went through all these feelings, disappointment, as nobody could help me, frustration, as the doctors were not doing their job properly, and confused, because the doctors did not agree with my opinions and expectations when I decided to seek medical advice abroad, and that I would find the answers I was looking for in the UK, and that I would receive the adequate support that I needed (T.H. aged 35 at the time of the interview, married, with one child aged 6, secretary).

5.2.5. Disbelief

Disbelief is another major feeling that the mothers experienced after the first consultations with the doctors, when they were given the diagnoses. It was a feeling that resulted in some cases, as I have noted above, to mothers going abroad to seek other medical opinions, because they found it difficult to trust doctors and other professionals in Cyprus. Ten mothers said that they did not believe the doctors' and other professionals' opinions such as school psychologists and teachers, while six mothers said that they became angry and frustrated with the doctors (S.C., A.K., E.S., V.H., E.Si, Y.K., G.P. C.H., T.H., D.P).

I did not believe them, I thought they made a mistake (E.Si. aged 50 at the time of the interview, divorced with three children, disabled child aged 10, employed at the Ministry of Finance).

After all these visits abroad I became more informed and I felt so frustrated with the doctors in Cyprus (she named a doctor) *and promised myself that I will never trust any of them again* (E.S., aged 42 at interview, divorced with three children, disabled child aged 18, multifunctional teller at a bank).

5.2.6. Happiness

There were mothers who reported happiness as one of their feelings on the birth of their child. The feeling of happiness was the main feeling M.S expressed she said after her baby was born. This was because during her pregnancy doctors did not give the baby any chance of survival.

For me it is a miracle that she is as you can see for yourself now. She could have been born blind, deaf or be confined to a wheel-chair. I was so happy that I was able to see my baby alive and so grateful that she was born.

E.Si. felt 'in love' with the birth of her daughter as she said in the beginning even though when the problems identified she shown disbelief to doctors as seen in the feelings above.

It was the unique feeling of falling in love with a new life, a new life that you gave birth, that was developing inside you for nine months. I was so happy.

K.G. was a mother who mentioned both feelings of happiness and sadness when she gave birth to her son.

> *It was mix feelings I could say. It was happiness as I was holding my son in my breast but I had a sad feeling that I translated as coming from the anxiety as having a baby means struggle to help him or her develop in the right way. But I was happy, I was very happy. Don't forget that I wanted a son, I only had a daughter.*

5.2.7. Other feelings

Four mothers developed depression and melancholy in response to the news of their child's disability.

> *I fell into depression and I felt helpless, I felt very isolated and I didn't want to see anyone* (K.K. aged 45 at the interview, divorced with four children, disabled child aged 18, secretary).

Two mothers said they sought professional advice and help for themselves a few days after the diagnosis (K.G., A.Y). One mother recalled trying to save some money in order to visit a psychiatrist and to buy antidepressant medication (A.M).

There were two mothers who said they felt guilt and tried to blame someone else or themselves for the fact that they had a child with a disability (A.M., L.S).

> *I thought that I was responsible, that I caused my child's disability, I asked my mother if we had any relatives that were disabled, and I wanted to have blood tests done. I could not understand where this 'problem' had come from.*

5.3.   Mothers' pathways to learning about their children's disabilities

The four pathways concerning the mothers learning about their children's disabilities that I identified concern both the context in how this information unfolded, and the feelings associated with this context. The four main pathways are:

- Mothers who identified the 'problem' themselves
- Mothers who were informed of their child's disability by a doctor straight after their child's birth
- Mothers who sought a second opinion after they realised that their child was not developing as expected or was poorly
- Mothers who were referred by a doctor or other professional because their child had physical or other problems which led to a diagnosis of the disability

The four pathways are presented in Figure 5.1. The distribution of the twenty-five mothers across the pathways is presented in Appendix 4. In the first pathway there were three mothers, and in the second eight mothers. Ten mothers experienced pathway three and six mothers pathway four. Two mothers took two different pathways.
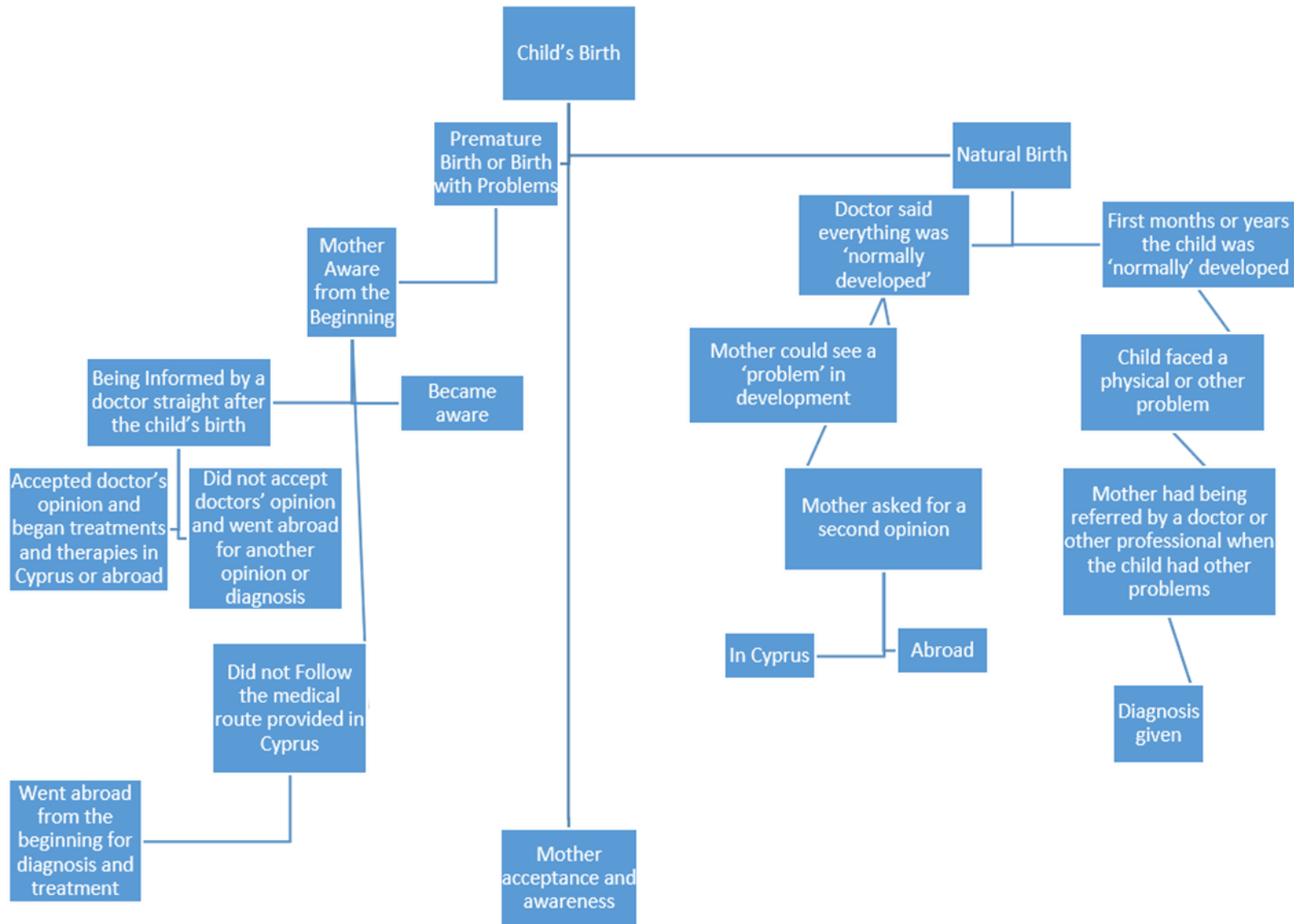
Figure 5.1 - Pathways followed by the mothers from the child's birth to awareness of the child's disability

5.3.1. Mothers identifying the 'problem' themselves

Only three mothers said they became aware of the 'problem' on their own just after the birth, from their own observation and intuition. They said that nobody (doctor or other professional) told them at that time about any possible developmental delays or difficulties that their child would face in the future. From these three mothers, two did not get an 'official diagnosis' (Y.O., K.E.) until the time of the interview or only received one many years after the birth of their child (A.Kaz). All three mothers were married and had other children. Two of these mothers went abroad in order to get more information once they realised that their child was not developing as expected and because the doctors in Cyprus were not helping them enough. Both mentioned disappointment and uncertainty and a lack of trust in doctors in Cyprus as some of their main feelings after the initial shock they experienced when they became aware of their child's disability.

In the case of Y.O. (aged 46 at the time of the interview, married with two children, disabled child aged 15 at interview, academic professor), both parents were medical doctors. The mother was an academic professor at a University. Her son was 15 years old at the time of the interview and till this time, no 'official diagnosis' was given although according to the mother, her child had cerebral palsy from birth. This was an unofficial diagnosis given by the mother after she read medical literature on the subject along with the medical knowledge provided by her husband. They went to America twice in order to receive treatments and to get information about how they could help their child because, according to the mother, in Cyprus there were no specialised centres that could offer support and therapy. This is true as we can see from the public debates around disability in Cyprus and highlighted in Chapter 3.

The mother (Y.O.) said she had a normal pregnancy and normal parturition, but the baby was a low birth weight baby weighing 900 grams below the average which according to statistical data on birth weights in Cyprus during the period 1998-2002 was 3152 grams (Vogazianos, Fiala & Vogazianos, 2005). The problems, she said, began when he was born and he did not gain any weight. Given that both parents were well-educated and the father was a paediatrician, they knew straight away that their child was not developing according to the norm. The mother described her feelings from the beginning and, as she said, she went through many of the feelings that the literature described,

> *I felt stressed and anxious throughout the first year as I was trying to feed my child in any way I could so that he would eat and gain some weight. It was a survival issue. His needs were substantial. …Feelings, well I went through all the*

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feelings that the literature calls common, such as negativity, anger and depression. I think… I got rid of the negative feelings quite early on. I am a positive person and I have a positive outlook on life.

A.Kaz was a mother aged 47, married with six children, (disabled child aged 18), and unemployed. She said that she realised from 'the beginning' that her child had developmental problems, but that nobody helped her to investigate the matter further and to get a proper diagnosis. When her son was born she was employed as a nursery school teacher at the time but after having health problems of her own for six years and when her child was aged six, she stopped working and stayed at home. A. Kaz. said she found out that her son was brain damaged at birth, when he was 17. She learnt about this when she took her son to hospital after he was injured by his classmates during a fight at school. She said that she could not accept the opinion of doctors in Cyprus and managed to get government funding in order to arrange for two overseas doctors to visit her son in Cyprus when he was 17 years old. The government covered the main doctors' expenses and the mother also contributed to the amount. For 17 years, she said she believed that her child only had 'learning difficulties' [μαθησιακές δυσκολίες] as doctors could not find anything else wrong with him. She normalised the diagnosis given by the doctors which she did not feel was as threatening as the concept or label of 'disability'.

Her narrative was sketchy in terms of describing the experiences of when her child was born and when she became aware of his disability. Nonetheless she described her disappointment with the whole system, especially with the people that worked in the government departments and with the doctors and specialists in the public hospitals,

Okay, I can't say that I didn't feel frustrated and that I hated all government employees. But the fact that I am a teacher helped me to acknowledge that he had this disability and to help him in any way that I could. However, if I knew or had a diagnosis earlier there were many more things that I could do.

5.3.2. Mothers informed of the child's disability by a doctor straight after birth

Seven mothers out of the twenty-five were informed straight after the birth of their child by professionals, mainly doctors, of their child's disability or about the difficulties that their child would face in the future. Most of these mothers gave birth prematurely. Some of them realised there was a problem when their babies were immediately transferred from the private clinic where they gave birth, to the General Hospital in the capital of Cyprus (the Makario Hospital). This is what usually happens in Cyprus (see

Chapter 3) when a baby is born with problems (as happened in the cases of G.P, M.S. and C.K who gave birth prematurely).

Mothers who knew from the beginning that their children were not going to develop "normally" made other efforts to help their children. The children were referred for further treatment by the General Hospital. Some mothers also went abroad for their child's treatments and for additional specialised care. These children included those diagnosed as having a motor and brain disability, mainly cerebral palsy and quadriplegia. Some mothers went abroad in the next pathway as well, but in these cases they went abroad in order to seek a second opinion, in comparison to the mothers in this pathway who went abroad for treatments and therapies.

M.S. (33 years old at the time of the interview, married with one child, a disabled daughter aged 9 at interview, unemployed) was previously a nursery school teacher but gave up her job after her child was born because, as she said, she had no one to help her and thus had no alternative,

> I had to stop work. Although I loved my job, I had no other option. It was extremely difficult to work and to care for a disabled child. When [child] was one-year old I stopped working. ... She needed somebody to pick her up from school, to take her for her therapies, and to take care of her in the afternoon.

Mothers like M.S. stressed that the economic crisis in Greece and in Cyprus had seriously affected the economic situation of her family. Her husband lost his job and for three months they had no income. At the time of the interview, her husband had found another job, but also had to work during the weekends. Even though the family had a low level of income, they travelled abroad in order to help their disabled child. They were entitled to the monthly allowance provided to families with disabled children and the unemployment benefit provided by the government, but it was not enough to cover the family's needs. Their child, aged 9 at the time of the interview, was diagnosed with hemiplegia in the lower limbs and cerebral palsy due to prematurity and lack of oxygen at birth. M.S. knew from before the birth that her child would be born with a disability. After the initial shock of hearing that her child would be born disabled, the fact that she was aware of her child's disability from beforehand made her mindful and happy when her daughter was born because as she said, she knew what to expect and was grateful that her baby survived,

> Ok, I didn't know what to expect. Everything happened suddenly, I was expecting to give birth on my due date and from the one moment to another everything changed. It was a very big shock and the first days were dreadful. At the end of

the day, the most important thing is that she survived and that she is healthy. For me it is a miracle that she is as you can see for yourself now. She could have been born blind, deaf or be confined to a wheel-chair.

While she emphasised that from the beginning everything was very difficult and that she felt stressed and anxious, she was content with everything that she had achieved over the years up till the time of the interview taking place.

Lack of trust in doctors and other professionals was a feeling expressed by other mothers too. Mothers such as M.S. and E.S. were informed from the beginning about their child's disability but felt safer to go abroad for treatments instead of staying in Cyprus. E.S. aged 42, said:

I did not believe what they said to me in the beginning. I was aware that my child's development could not be considered as 'normal' but I did not trust them. We (the mother mentioned that her husband accompanied her on this journey as they travelled abroad together) *went to England to see specialist doctors at the Great Ormond Street Hospital without any funding from the Cyprus government.*

After numerous visits to hospitals abroad, she became more aware of the issues involved in her child's disability and she made the decision that she would never trust the doctors in Cyprus again.

E.S. as well as C.H. were two mothers with many similarities. They both had daughters diagnosed with cerebral palsy and were both divorced (their children were aged five (E.S) and three years old (C.H) at the time of their divorce). They were energetic and proactive mothers, and were members of the Parents Association at their children's mainstream schools and they were very supportive of their disabled daughters' rights. C.H. was not working at the time of the interview because she had difficulty in finding a job with suitable working hours that would enable her to be with her daughter in the afternoons. E.S. worked in a bank at the time her child was born and continued to work there for four more years but had to stop in order to look after her child. She also said she was no longer in line for a promotion because she had been absent from work many times due to the circumstances she faced with her disabled child.

Hospital visits abroad for treatments and therapies were frequent for C.K. as well. C.K. was a mother with a son diagnosed with cerebral palsy (aged 50, married with three children who were living with her, disabled child aged 18, unemployed). She knew from the time of birth that her child was going to face developmental problems. At the birth the doctors said that the possibilities of her child surviving were slim. She described

her experiences and feelings during the first days after her child's birth, and said she felt that her son was 'different':

My son was born at a private hospital, and he was transferred immediately to the neonatal unit at the General Hospital. He was born premature, 8 months. .... He had many different operations even though he was just a baby. He was discharged from the hospital when he was one and a half months. I was very sad as I knew my baby was different from my other two children and I couldn't sleep...

Like E.S and M.S, C.K. also did not trust the doctors in Cyprus. She described her first consultation she had with the doctors at the public hospital in Cyprus; she said they were rude and unsupportive:

The doctor started shouting at me and said: "Nobody told you that your baby is epileptic?" ….. I had no idea! What did the doctor expect me to answer? I felt that I would collapse. I knew that my child had problems, I was aware of this. I wasn't in denial that my child had disabilities. Maybe it was the way the doctor spoke to me or maybe because every diagnosis given to me at the time made me feel helpless and depressed. But I did not give up.

C.K. went on to describe that, although with modest economic means, together with her husband they took their child abroad to receive treatment from doctors in Israel.

G.P.'s child, (37 at the time of the interview, with a disabled son aged 10, unemployed) was unofficially diagnosed with Aarskog-Scott syndrome by doctors in London when she went with her husband for their child's treatment when her son was one-year old. Her son was born prematurely and his neck was wrapped in the umbilical cord, which had affected his development. For five years, the parents travelled to London every three months for examinations, treatments and minor operations and they used money from their savings and money they were given by their parents. The mother mentioned her husband as well in her journey of becoming aware of their son's disability.

It was a shock for both of us. My pregnancy was normal, nothing unusual was seen throughout the pregnancy. The only thing we were told by the doctor was that I was going to have a small baby. This, as we now know, is a characteristic of the syndrome. From my experiences over the years, your reactions and the stages that you go through all depend on the kind of personality that you have. The first shock is inevitable. It is your reactions and actions that follow that matter. You have two options. You are either going to be strong as you go on, or you will just become lost.

There were two mothers that after being informed of their child's disability straight after the birth began treatment immediately in order to help their child. Another premature baby was T.K.'s child (mother was 54, married with two children, disabled child aged

20, a nurse), who was also diagnosed with cerebral palsy. The mother expressed the shock that she first experienced,

> *It was such a shock and it was so unexpected for us. I had symptoms of depression and feelings of fear and I felt isolated after my child's birth. My feelings then changed and I would not acknowledge that my child had a problem, I could not accept it. I had to stop working in order to help my child, and this did not help me ultimately. I stopped working and I began taking my son for his treatments immediately. I wanted to help him. I wanted to treat him.*

5.3.3. Seeking a second opinion

There were ten mothers who were aware of their children's disabilities some months or years later (from eight months to two years old) and from these ten mothers, some travelled abroad either for a second opinion or to get a diagnosis and some went to another doctor in Cyprus to seek a second opinion. All these mothers gave birth to their children unaware of their child's disability. In this group of mothers who sought a second opinion, the mothers did not receive advice or support for their children's problems and disabilities.

Because of the existing policies in Cyprus that state that children have the right to be diagnosed and assessed without any personal expenses being incurred by their parents (Ministry of Labour, Welfare and Social Insurance, L. 127/ 2000) and through the implementation for the assessment of disability and functioning (Department for Social Inclusion of Persons with Disabilities, 2016), many mothers therefore went abroad for a second medical opinion.

Four mothers went to America (S.C., E.Si., V.H., and Y.O. who was mentioned in the first pathway) because as they said, the USA has more specialised centres for children with disabilities and they wanted to provide the best possible treatments for their children.

S.C., (aged 45 at the time of the interview, disabled child 20, married with three children, a business woman) went to America '*five times with the majority of expenses funded by the government',* because at that time the hospitals in Cyprus could not provide the proper support and treatment that her daughter needed. They first went to Greece:

> *because it was nearer to Cyprus and had better hospital facilities and they could help us more.'* The doctors there recommended that they go to America, as she said *'they had more knowledge than the doctors in Greece and even more than in Cyprus. In Cyprus fifteen years ago, they didn't even know what 'Botox injections' were.*

Two mothers went to the UK for similar reasons. E.Si. for example, (aged 50 at the time of the interview, divorced with three children, disabled child aged 10, employee at the Ministry of Finance) said that when she was given her child's diagnosis in Cyprus she did not believe or trust the doctors' opinions. The mother included the father in her narrative speech of experiences:

> *Ok, the truth is that I did not believe the doctors' opinions in Cyprus. I thought, how is it possible that my child was examined and diagnosed after only one visit to the doctor* (she named the doctor) *and for the doctor to be able to give a diagnosis after just one consultation. We went to the Great Ormond Street Hospital when my daughter was only 9 months at the time. Doctors there were more specialised and even though they did not give us a different diagnosis, it was easier for me to become aware… they were more professional and they could provide us with the answers to our questions and this helped me to become aware of my child's disability.*

Mothers who went to Greece justified their decision in terms of it being the nearest country to Cyprus that they could visit and at the same time, the only country where they could communicate in Greek (C.K., A.Mav, E.Si.,Y.K.).

C.K. and A.Mav both visited Israel as well as Greece because the doctors there were more specialised than those in Cyprus. S.C. visited the USA, and the UK. E.Si. went to the USA, the UK, to Ukraine and to Russia because, as she said, she did not know how to help her child and she took every possible opportunity that could provide suitable treatments, that friends or other people who had similar experiences suggested to her.

Two mothers out of seven in this group sought a second opinion from another specialised doctor in Cyprus. D.P. and A.K challenged the initial doctors' opinions because they were told by them that they, the mothers were at fault, that they had not started their children at nursery school early enough with the result that the children failed to socialise and to learn new skills, for example one of the children had delayed speech and was still wearing nappies.

A.K. (aged 50 at interview, married with two children living with her, disabled child aged 22, unemployed) said that her child was diagnosed with mental retardation when she was three years old. A.K. said that her daughter would lean her head to one side when she was ten months old when ideally at this age, a typically developed child would be expected to hold their head up:

I was aware of my child's difficulties after seeking a second opinion from doctors since I could see that my child had developmental problems. The paediatrician said that everything seemed normal to him. The only suggestion he made was that I should take my child to a nursery school. When my daughter was two and a half I took her to nursery school but I faced difficulties with the nursery teachers as they were not co-operative or understanding towards my child's difficulties and as a result my daughter was negative too.

D.P. (aged 48 at the interview, married with four children, disabled child aged 20, worked part time as a carer of an elderly person and as a florist) identified that there was a 'problem' even though the paediatrician said there was nothing wrong with her child. The mother accepted the paediatrician's opinion but a few years later, she asked for a second opinion from a neurologist at the General Hospital in Nicosia. She requested this second opinion during an overnight stay at the hospital when her child was admitted for gastroenteritis.

I asked for a neurologist to come and see us in the hospital ward as we (mother used 'we' including herself and her disabled child) *were already in the hospital and it would have been more practical. She* (the neurologist*) came the next morning. She asked me some questions about my child and then she said: "Do you know that your child is retarded?" I was shocked and I panicked and for a moment I felt breathless, but I soon found myself and responded: "You are retarded!", "Listen" she said, "your child has a problem. You have three other children, you know what normal development is, how did you not realise that this child is different?"*
From that day on we did everything. We undertook an encephalogram, blood tests and anything else that was necessary. After the results of the first encephalogram they diagnosed epilepsy as well.

D.P. felt that she did not have the experience necessary to raise a disabled child and that she needed help and support. Therefore, for this mother the turning point in which she became aware of her child's disability came very late. She blamed her own lack of experience for this as well as the lack of support and information available.

I felt that I lacked experience, I could see that raising a 'normal' children and a child with disabilities was not the same… no one told me what to do or what dimensions the problem was going to take or how my life was going to change from that moment on.

Even though this mother had three other children and appeared to have a strong personality she did not know how to help her child, and her helplessness was compounded by the fact that the paediatrician did not identify the problem when her child was a year old.

Getting a second opinion was therefore often a key turning point in the mothers' awareness of their child's disability (Miller, 2007) and signified the loss of a healthy child and the arrival of one who was disabled.

K.K. (aged 45) was a mother who gave birth to triplets at the age of 27. They were born prematurely and with low birth weights but without any indication of disabilities. One of the triplets was described by the mother as the healthiest of the three because he was the heaviest. A medical problem arose when this baby was six months old and he was incubated and put on a ventilator. When he was taken off the ventilator he had trouble breathing and the doctors gave him more oxygen than was necessary and this resulted in a haematoma [αιμάτωμα] on the brain. The doctors informed K.K. and her husband that their child was going to have problems as he was growing up. The mother was not informed from the beginning of what kind of difficulties her child would face and she was worried as she could see that her child was not developing at the same pace as the other two were. However, looking back over the past eighteen years, the mother has come to terms with her son's disability:

> *I do believe that he has developed quite well now, he can communicate and you can understand what he wants, for example he can go to the toilet on his own and generally he has made some substantial progress. This progress has been the outcome of two things: the therapies that I used to take him to, and that I still take him to even now that he is 18 years old, and because I have accepted the problem that my child has.*

A.M. was another case of a mother (aged 41, married with two children, disabled child aged 15, part-time secretary in a lawyer's office) who went through the various stages of grief; in the beginning, she was shocked and did not believe the doctors in Cyprus who were rude and harsh and she was angry with them. She went abroad to seek a second opinion. When the doctors there provided a diagnosis, she became depressed and felt guilty. The transition from the 'normal' child that she thought she had to the child 'with problems' was a difficult period for her.

> *I tried to think what I had done wrong. My baby was full term, I did not smoke and I did not drink, I tried to remember whether I had an x-ray during my pregnancy but no, I hadn't, everything had gone smoothly during my pregnancy.*

This mother said that she went to Greece because it was near to Cyprus. She mentioned her husband at this point in order to highlight that he could not accept the difficulties his son was facing, and was unwilling to support his wife when she wanted to go to the UK. A.M. was a mother that mentioned her husband as well using the term 'we':

I knew that my child was disabled... I could see that his development was different in comparison to my older son…. Greece was nearby and not expensive to go to. When we went to Greece they told us that our son had "Autistic Spectrum Disorder".

The turning point for this mother in terms of how she viewed her life in the future took place when she visited the doctor in Greece:

From the one moment to another the future of my whole life flashed in front of my eyes. I felt so bad at that moment when I realised how my life was going to be. I knew that my child had some problems but I hadn't anticipated the scope of the situation.... until that moment. I was only 23 with two babies and I was about to begin a life full of anxiety and treatments.

T.X. was 47 years old at the interview, married and living with her husband and two children (their disabled child was 20 years old at the time of the interview). Her husband was a medical doctor and she was a dentist. The mother was not working at the time of the interview. She worked up until the time the family decided to leave Cyprus and emigrate to Greece. As she said:

We (husband and wife) *went to Greece in order to have a better quality of life. In the end, well, basically after two years, we faced economic difficulties as we could not earn as much as we did in Cyprus and we had more expenses there so we came back to Cyprus. When we returned though, I couldn't return to my practice since Cyprus was going through an economic crisis and it was very difficult to find a job.*

T.X. talked about past events, 20 years prior, and described the first days of her son's life and how they faced his disability. In the beginning, she thought that everything about her son was normal. '*Basically, up until he was around 7 months old it seemed that he was developing normally'.*

She used the normalising discourse of a 'child' as a basis for comparing her child with other 'normal' children. When her baby was 9 months old she realised that he could not sit properly as she thought he 'should' be sitting by that age (Sullivan, 2007). She was worried and discussed her concerns with her child's paediatrician who recommended that they should see a child neurologist, and at that time, there was only one child neurologist in Cyprus. After their consultation with the neurologist, their journey began. The mother together with her husband took their child to have blood tests conducted and other medical examinations in order to identify the 'problem'. The mother described her feelings in the beginning:

Worrying about what our son might have had turned into anxiety and we were in a state of shock day after day since regular blood tests, medical examinations and frequent hospital visits were things that we had never thought we (including

her husband) *would be facing, and of course did not want to define our lives forever.*

The mother described her experience regarding her feelings of anxiety and worrying about the 'unknown' as she did not know how to help her child. Frequent hospital visits acted as the turning point in the mother's realisation of her child's disability and after the initial shock she tried to help him as much as she could.

Most of the mothers in the study who faced similar problems in the early years of their children's lives were sceptical about trusting the services provided by the Cyprus government and about the medical diagnoses given and the support provided. Whereas the Department for Social Inclusion for Disabled People in Cyprus emphasises the holistic assessment of the needs of a disabled person, most of the mothers in the research appeared sceptical and believed that the assessment system, specialists and developments in Cyprus were unreliable and disrespectful.

5.3.4. Referral by a doctor or professional when child had physical or other problems leading to the diagnosis of a disability

Five out of twenty-five mothers did not notice any sign of disability for some months or years after the child's birth. It was only when the child appeared to have physical problems (K.G.), problems at school (D.D.), health problems (V.H.) or other problems that the doctors contemplated a possible disability. Four mothers who experienced this had children whose disability was not from a genetic condition such as Downs syndrome or cerebral palsy. They had a non-visible type of disability (Goffman, 1963). The fifth mother's child (A.Mav) had cerebral palsy, also a visible type of disability.

There were mothers whose children's slow development was recognised by their teachers. Both K.G. and M.K. said that their children's teachers suggested to the mothers to have their children assessed.

K.G. (50 years old, married and living with her husband and two children, stenographer at the Supreme Court of Cyprus) during the interview went back to a period of 12 years prior, in order to remember and talk about the experiences she had with her child. Her son was born premature. K.G. described both feelings of happiness and sadness at his birth. She was not aware from the first months of his developmental problems because as she explained, she could not compare her son with her older daughter because she too was a premature baby. Her daughter had no subsequent problems despite this:

> *I couldn't compare because my daughter was premature too, she was born at 33 weeks. My son was born at a private hospital but he was transferred to the neonatal unit at the General Hospital where he was kept in for several weeks.*

Her feelings in the beginning varied as she described:

> *I was not able to see that there was something wrong with him, there was no specific 'problem' although I had a bad feeling inside me which I could not explain or describe. ... The struggle began after my child started school and they suggested that my child should be assessed because they could see that there was a problem.*

Going back seven and a half years, M.K. described her feelings and the turning point experience of her child's disability when her child went to school at the age of six (her child was only seven and a half years old at the time of the interview). The mother was able to identify the symptoms because she could compare her son with his older sibling but she did not worry as she said, she knew that every child was different. For this reason, she was shocked when the school psychologist told her that her child had disabilities.

M.K. also talked about the other children that were at the same centre as her son for therapy and concluded that she felt 'lucky' when she compared her child to the other children with disabilities. She added that she felt distressed every time they went to the therapy sessions and she saw these children, but at the same time, she felt relieved because she realised that her child was in a better situation.

> *I saw children there that were three years old but had the abilities of a baby aged 5-6 months. They were "like a vegetable" (they were not able to do anything on their own). I could not stand something like this, honestly… how did I feel after this? …. I felt very lucky.*

M.K. was not aware of her child's problem and so did not take her child for assessment. Her son's school carried out an assessment via the school psychologist who informed her that her child was diagnosed with mental retardation.

V.H. (aged 46, living with her husband and two boys, disabled child aged 11, working part-time at an organic health store) followed the same pathway as she was referred by a doctor for her son's disability following a problem her child had which led to a diagnosis. V.H.'s pregnancy was full-term without any particular problem. When her son was 15 months, he had his first epileptic seizure. From then on he began facing difficulties in his everyday life. The mother and father went to Greece and to the USA to see other doctors because they wanted to get a second opinion, the opinion of specialists, as they were disappointed with the system in Cyprus. In response to the question to describe her first feelings and experiences, the mother said:

It was such a big shock. As you can see, I am a very calm and quiet person but during those times I wasn't. I had to 'fight' everyday against something unexpected. My child was in hospital ... it was a horrible experience. I remember holding my breath many times while I was given news by the doctors, I was stressed and anxious.

V.H., like M.K. mentioned above, said that she compared her son with other disabled children that she had seen. This helped her to feel better. She received support and guidance on how to deal with certain situations from the feedback and information that she got from others in similar situations. The meaning of the behaviour that somebody might have is able to reflect the meaning in understanding other standards (Stets and Burke, 2014; Stets and Harrod; 2004). Mothers like D.P. and K.K. who compared their disabled child with their other children were able to better understand their disabled child's behaviour. The feelings of denial, the negative feelings, stress and anxiety that the mothers went through in this pathway, depended on their turning points - the incidents in the mothers' lives that led to their awareness of their child's disability. Going through these stages and comparing their own situation with other disabled children provoked this awareness.

I was always aware, from the first time the doctor (she named the doctor) referred *us for our son's disability. I knew from the beginning that as of now on I was going to face difficulties in my life. For me it was a matter of* survival *after everything that I had seen. Having a child in intensive care and living in the hospital, you become more easily aware. You compare your situation with other cases and at the end of the day you just "Thank God, you realise that there are worse situations".*

Through the mothers' personal accounts, we can distinguish stories expressing survival issues. Mothers such as V.H. presented a story of survival in their journey to awareness of their child's disability. Other stories are descriptions of the mothers' acceptance of the disability, and others focus on the struggles or difficulties they faced in order to receive a proper diagnosis. This conclusion should be justified by the fact that some of the mothers' journeys combined more stages as in the grieving process, while others less until they became aware of their child's disability.

5.4. Conclusion

In this chapter I have analysed the mothers' feelings and experiences in relation to learning about their child's disability, from the period following the birth of their disabled child. The mothers went back from six to twenty-two years to recall their feelings and the events that occurred. The fact that they could recall these feelings and experiences many years later is evidence of their impact and significance.

The first main finding relates to the types of feelings that the mothers experienced that include shock and disbelief, disappointment, anger and depression. The main feeling that most of the mothers mentioned was that of their initial shock. Many of the mothers went through similar feelings during the different stages of the grieving process. Grief has been defined as the stages of emotions that are experienced by people who lose a person close to them (Melnyk, Feinstein, Moldenhouer, Small, 2002; Sicile-Kira, 2004). Happiness, gratefulness and excitement were important positive feelings mentioned by mothers mainly in the first days of the birth of their children. The last stage of grief, acceptance, is defined as the stage of awareness that the mothers reached at the end. Some of the findings are supported in the literature. Shock, for example, is described as a feeling that parents of children with autism experienced in McCauley's study (2010). Disappointment was also expressed as a feeling by Ajesh, et.al. (2007) and Fischer (2012), as well as happiness and relevant positive feelings (Read, 2001; Ryan and Runswick-Cole, 2008). Other feelings expressed in the grieving process that is presented earlier in this chapter and some feelings such as anxiety or frustration that are not found in the literature, specifically in the Cyprus context.

The second main finding of this chapter concerns the four different pathways that the mothers followed in their journeys towards awareness. They described the turning points in these pathways that led them to acknowledge their children's problems and disabilities and to help them.

The first concerned mothers who identified their child's disability on their own following the birth when they realised there was a 'problem'. The second pathway includes a group of mothers who were informed by doctors in Cyprus about the disability of their children (most were born premature) straight after their birth. In this pathway mothers took action quite early such as taking their child for treatments and participated in early intervention programmes in order to help their children. Most cases fell into pathway 3 in which mothers gave birth to full-term children and doctors declared their child was 'normal' – 'a typical child development'. Normalising discourses are suggested in literature as influential in shaping the experiences of mothers with disabled children (Fischer, 2012; Sullivan, 2007; Rogers, 2011). According to the literature there are 'normative expectations' such as celebrating the child's birth or the child's healthy body which if not met, mothers or parents of disabled children in general are obliged to change their daily life and routines (Donzelot, 1979, Rogers, 2011). However, mothers sought a second opinion, as they were not convinced their child's development was normal and they were worried. This group of mothers acknowledged their children's disabilities after they sought a second opinion, which constituted a turning point in their

lives in so far as it enabled them to help their children. The fourth pathway includes mothers with full term babies. They seemed not to have been aware of any kind of disability after the birth. Indeed, the children of the mothers in this group had 'invisible' types of disabilities and so the turning point for the mothers in this pathway was when they were informed by a doctor or other professional such as a teacher that their child had a disability some months or years after the child's birth.

As these women suggested, even for families with modest economic means, going abroad for a second opinion or for treatments was common. However, although support was provided by the government in full as stated by the law (Ministry of Labour, Welfare and Social Insurance, L. 127(I)/2000) for the mothers, the type of support mentioned in the law was not adequate or enough as they mentioned and as we can see in Chapter 6. However, the reasons for seeking medical advice abroad had less to do with the lack of available services in Cyprus and more to do with the lack of trust in doctors, or because the doctors had failed to provide a diagnosis or information regarding their child's disability.

Another key point from the analysis was the rudeness and lack of support and professionalism that mothers experienced from doctors and other professionals that made their 'learning journeys' even more painful. A further conclusion identified from the mothers' accounts was the fact that the initial years following the birth of their children were the most difficult compared to the years that followed. This statement applied to all the mothers at every socio-economic level. Acknowledging the situation and becoming aware from the one day to another was not something to be done easily. The mothers however managed to accept their child's disability because as most of them emphasised, they knew that they did not have any other choice if they were to help their children.

Chapter 6 – Formal Support: State Benefits, Services and the Voluntary Sector

6.1. <u>Introduction</u>

In the last chapter I presented that there is a variation among mothers in when they learned about their child's disability, which had consequences for when they accessed public services. In this context, there were many mothers who expressed their dissatisfaction with services, especially medical services. Families with disabled children need support for various reasons, in particular material provision in order to deal with the expenses incurred in raising a disabled child. At the same time, they require information, somebody to inform them about what they can expect to be provided with and how to access it. They also need to be able to trust the people that provide them with the information needed. Families of children with disabilities do not only have to anticipate the various economic and financial costs involved in helping a child with a disability, they also have to be able to meet the needs and expectations of the other members of the family (Florian and Findler, 2001; Papaeliou, et al, 2012). Of great importance also is the emotional support as families need to have a person or more that can help them emotionally when needed, in order for them not to feel helpless or alone (House, 1981; Findler, 2000; Read, 2000) (see Chapter 7). Mothers are typically the persons who provide the main care and support to children and have the main role in raising their children with or without disabilities (Brehaut et al. 2004; Crowe & Florez 2006; Goodwin and Huppatz, 2010; Paroutsas, 2005; Read, 2000). After giving birth to a disabled child, they are obliged to adapt, as McCauley (2010) highlighted, to the difficulties and to the new situation which will continue throughout their lives and those of their children (Wandersman, Wandersman & Kahn, 1980).

This and the following chapter examine the research question: "What kind of support did mothers access through their journeys of raising disabled children, formal and informal?"

Formal support is defined here in terms of the type of support provided to families and children by the government and professional services based on the legislation whereas informal support encompasses the support provided by members of the family namely husbands, siblings of mothers and / or their other children, grandparents of the children, friends and voluntary organisations (Raina et al, 2004; Twoy et al, 2007, Duvdevany and About, 2003).

The lack of support in the past is likely to affect their feelings in the present. In this chapter I focused on mothers' current access to and feelings about benefits and other

formal sources of support. It is important to mention that mothers' current feelings about the formal support they received, reflect their past experiences and feelings which were negatively expressed in the last chapter.

It should be noted that in this study, a distinction is made between received support and perceived support. This is because what people describe as 'supportive' does not necessarily correspond with what services a person is receiving. Received support is defined in terms of the institutional provision available while perceived support refers to what mothers regarded as helpful to them (Wethington and Kessler, 1986). Received support is defined as 'the quantity of supportive behaviours received by an individual' whereas perceived support is regarded 'as both the satisfaction with support and the availability of it' (Melrose, Brown and Mood, 2015: 97). Through mothers' accounts, received support and perceived support were not always the same as it will be shown later on (Haber, Cohen, Lucas, & Baltes, 2007; Sarason, Sarason, & Pierce, 1990).

The need for formal support to be provided to families of disabled children and for the children themselves has been generally acknowledged. It is suggested that the costs of raising a disabled child are about three times more than a non-disabled child (Dobson, et.al. 2001; Gordon, Parker, Loughran, & Heslop, 2000; Slade et. al. 2009). Furthermore, as previously said, mothers usually have the primary role of caregiver because raising a disabled child demands considerable attention to be given in regards to time and money to be spent (Florian and Findler, 2001; Jennings, Khanlou and Su, 2014; Read, 2000). Lack of sufficient support provided to mothers is emphasised in research in general in the USA (Lawrence, 2011) or in the UK (Read, 2000). At the same time, research has shown that mothers who face difficulties in their everyday life are not understood and sometimes their role is undervalued (Lawrence, 2011, Ryan & Runswick-Cole, 2008).

In the study, formal support is the support provided to mothers and families with disabled children in general from the government or from voluntary organisations. It includes the benefits that families receive from the state, and the services to which they are entitled. Also included here is the support provided by the voluntary sector such as charity organisations, which as noted in Chapter 3 are pervasive in Cyprus in providing support to families with disabled children. The government in Cyprus[6] provides financial support, medical and educational sources of support to families with disabled children. The different sources of support are set out in Chapter 3 – Cyprus Context.

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[6] Department for Social Inclusion of Persons with Disabilities, Ministry of Labour, Welfare and Social Insurance

The services such as monthly allowance, parking allowance, medical card for more severe disabilities are provided to disabled children in Cyprus for life. The children are assessed every two years and in the cases of the types of disabilities which, according to the legislation, are considered 'permanent conditions'.

The allowances to carers or to the children are renewed every two years. At the same time, the voluntary sector contributes another important role in support for families with disabled children. 'Radiomarathon', the main charity organisation that exclusively helps families with disabled children, offers financial support to cover therapies that children attend. This is another section analysed in Chapter 3 as well. Charity as a term in Cyprus has a long history. Cyprus was a society that used to be characterised by its charity movements. The first special schools for disabled children in Cyprus were established by private charity organisations (Phtiaka, 2000) and before Cyprus' independence, matters to do with education, rehabilitation and inclusion of disabled children were under private or charitable initiatives (Phtiaka, 2007, Symeonidou, 2008). Special schools were all run as charitable institutions based on a care rationality and practice instead of an educational approach. As Phtiaka (1999: 176) emphasised, 'the charity model has become well established in people's consciousness at the expense of a human rights model'. Only few people talked about it though because work in disability studies is only recently developed as shown in Chapter 3.

The financial costs of raising a disabled child are well documented (Carpenter, 2000; Dobson, Middleton and Beardsworth, 2001). Dobson, *et al.* (2001) explored the costs to 182 families with disabled children in the UK. They studied severely disabled children and highlighted the financial costs as an important element of bringing up a disabled child. They concluded that it was a challenge for policy to provide parents with the help and support they need in order to meet the needs of their disabled children.

Slade, Coulter and Joyce (2009), in their study on parental experience of services for disabled children in England, emphasised the insufficient resources that existed especially when a parent wanted to get a diagnosis and had budget constraints or because of the fact that social services were limited to those most in need.

Carpenter's study on six parents of children diagnosed with autism in the UK who participated in the EarlyBird Support Programme for parents and carers organised by the state and therefore offering a 'formal support' suggested that 'in order to provide effective services for our families, we must understand and respect them' because their needs are not always financial needs (Carpenter, 2000: 135).

Stalker, *et.al.* (2015: 1) found in their study between 2011 and 2013 effects from the economic recession on families with disabled children in Scotland. They describe how although the families 'appeared to be at "tipping point" they were not receiving the help they needed'. Similarly in Cyprus in 2013, the state imposed cuts in almost every area of government funding and allowance so this affected the monthly allowance for the disabled. In March 2013, 10 per cent was cut from the monthly allowance for the disabled. This continued for eight months until the government revoked its decision and disabled people's allowance was restored to the former amount.

In my study, mothers were asked the following general question about formal support:
- Do you receive any support from the government in Cyprus or any other official organisations in Cyprus? What source of support is it and how satisfied are you with it?

  In cases that mothers did not mention any particular types of support, I prompted them with the following direct questions:
- Do you receive any services from the government or organisations different from financial support?
- Do you have a carer at home? What type of support do you receive from him/her and how satisfied are you?
- Do you receive any support from the charity organisations in Cyprus?

  When mothers talked about the support they received or perceived from the government and other public services or voluntary organisations they mentioned whether they found the support helpful or not. They did not say 'formal support'. They used the terminology 'support from the state', 'support from the government' or 'services'.

6.2. <u>Formal Support to mothers and families with disabled children</u>

All mothers mentioned financial support they received through the monthly allowance as the support they estimated to perceive from the government. Services as shown from their responses were not an answer from the first general question as a support they perceived. This was a finding from their responses, as they did not directly mention the services they received. They answered about them after I prompted them with a direct question regarding these services.

All but two mothers were dissatisfied with the support perceived from the government. The two mothers who considered the formal support they received to be satisfactory were distinctive because they both were mothers who were living a life without a lot of

expenses, and were trying to make do with the basics. M.K.'s son was having speech therapy and occupational therapy lessons, where only speech therapy was private, while T.X. stopped all the therapies and other activities that cost a significant amount of money.

M.K. was a mother with two children who stopped working after the birth of her disabled child. Her husband had two jobs in order to manage the household expenses. M.K had low expectations of receiving support from the authorities and when she received the government allowance she was pleased. M.K was also not informed that she could have free medical consultations for her child. She answered to the general question highlighting the fact that she did not have any support in the past:

> *In the past I did not have any help, I did not know about that money. After my child went to primary school and the problem appeared to be bigger, the school's psychologist said "Mrs K why don't you visit 'Social Welfare Services'?" I did not know and my husband was negative about accepting any government money. … We sent the application and then a lady from the government came and met my child and then me. After a couple of months my application was accepted and we got the money. Every two years the government will assess my child and I will get the support in order to help him.*

She said she was able to live a more comfortable life due to this allowance. Although her husband in the beginning was negative this was because he thought the child did not have any kind of difficulty as well as being the kind of person who did not want to receive help. The mother mentioned that only because of this money she was able to buy her children the things they wanted, for example games and toys.

T.X. (married, unemployed, husband a doctor, full-time carer) also found the support given to her family helpful and expressed no disappointment or dissatisfaction. T.X stopped taking her child for therapies when her son was thirteen years old (at the time of the interview he was eighteen) because she believed that he did not need them anymore. Answering to the general question she mentioned the therapies he used to have in the past:

> *We were undertaking speech therapy lessons and occupational therapy when he was younger. One was private and the other one public. They were helpful, okay, but we stopped when there was no longer a need to go. The occupational therapist showed me some exercises that I had to do with my child and we then stopped going.*

She continued answering to the same question, justifying the fact that she was not dissatisfied with the state's support:

> *Ok, generally I am a person that doesn't spend a lot, ok I am not stingy but I am not a waster either… if I need something, I will buy it but ok. Regarding my son,*

we did not need something that cost a lot of money such as a wheelchair in order to say that money was not enough.

All the other mothers said they were not happy with the support the government provided to them when answering the general question. Talking about support that they received from the government mothers emphasised the monthly allowance they were entitled to through the Social Welfare Services.

Some included in their support their replies to questions about the support from the government the payment provided for carers. Paid carers[7] provide practical and in-home support to mothers and help to the children, sources of support that, as we will see, mothers refer to also in talking about informal support.

However, carers are included in this chapter as families were given some money for their salary, but they did not estimate this type of support as perceived from the government. Ytterhus, Wendelborg and Lundeby, (2008) in their longitudinal study of families with disabled children in Norway, emphasized the importance of 'support workers' who were included in the private-public mixed care system. The Cyprus government through its Social Welfare Services the Public Allowance Act (Ministry of Labour, Welfare and Social Insurance, 95(1)/2006), provides families with an extra monthly allowance for a private carer who is expected to live with them and provide services full-time. Mothers have to apply for this allowance in the case that they want to have a carer at home. The salary of the carer is 410 Euros per month. Social Welfare Services cover 310 Euros and the family pays the rest of the money. In cases where the monthly salary of the income earners in the family (parents) is less than 870 Euros which is the minimum household income in Cyprus (Ministry of Labour, Welfare and Social Insurance, 2012), then Social Welfare Services continue to provide the carer allowance even if the family decides to use the money for their own needs instead of having a full-time carer at home.

No mother mentioned the free educational provision that the children received. Perhaps this is because free education is the right of all children so they did not perceive education as support provided to them. The practical support provided to them through the medical card was not mentioned by mothers either. Mothers did not mention the voluntary sector as a source of support in reply to the question asked about the support they receive from the government or any organisation generally.

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[7] Using this term and not personal assistants that is preferred because they do not work for the disabled person exclusively

They only mentioned the voluntary sector when I asked them a direct question about voluntary organisations.

6.2.1. State benefits and services

Mothers highlighted their dissatisfaction with the formal support provided to them and their families by the government. The themes that I identified from this analysis of mothers' comments about formal support have been organised accordingly:

- Insufficient income including the monthly allowance for disabled people
- The economic crisis
- The high cost of private therapies
- Insufficient resources –need for something more than financial i.e. for emotional support
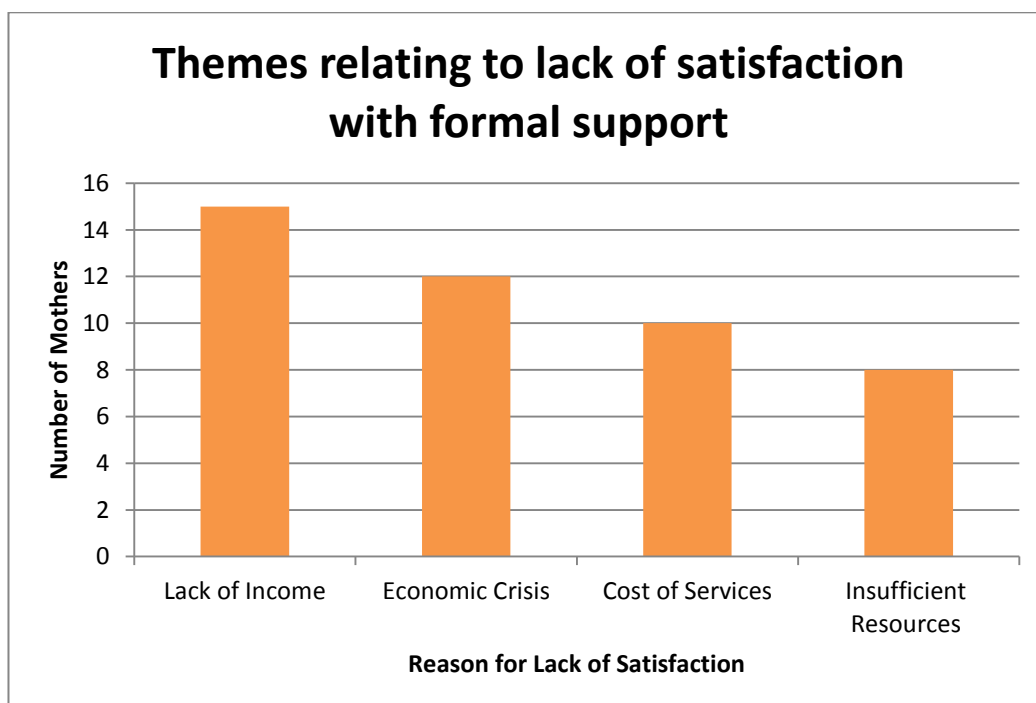
Figure 6.1 - Lack of Satisfaction from the Government by number of Mothers' comments

It is important to note that mothers reported lack of satisfaction with government provision under more than one theme (Braun and Clarke, 2006).

As we can see from Figure 6.1, fifteen mothers named lack of income as a reason for lack of satisfaction with support that they received from the government; twelve mothers mentioned that they were affected by the economic crisis in Cyprus and ten mothers reported high cost of services as a condition for a lack of satisfaction received by state benefits. There were eight mothers who mentioned insufficient resources. This last theme included mothers who would like to receive other resources from the state

than just the financial allowances, for example emotional or practical support. The four conditions of lack of satisfaction are analysed below.

6.2.1.1. Lack of income

Under this theme, mothers expressed low levels of satisfaction from the state saying that they did not have enough money to manage the needs of their children. Eleven out of twenty-five mothers stopped working in order to raise their child, either because they did not have any other member in their family to take care of her/ him or because they could not afford to pay a carer to look after their child even if they were able to have the allowance for this. A carer has her/his own personal needs and other expenses such as food or accommodation which most of the time are extra expenses for the family. A mother for example, who cooks for the family, will cook for the carer as well which is extra money. Some mothers just did not trust anyone else to look after their child; so stopping work was the only option they had, as they said. In other cases, mothers said that they did not earn enough money on their own in order for the state's financial support to be adequate, while at the same time their husband's income was not regarded as sufficient either.

Both G.P. (aged 37, married, unemployed, disabled child aged 10) and her husband left their jobs and never went back to work after the birth of their disabled child who suffered from Aarskog-scott syndrome. Frequent trips abroad together and the severe disabilities of the child were the main reasons that they decided to stay at home and be his full-time carers. The mother replying to the general question mentioned that the money they received from the government was not enough so she had to borrow money from her parents in order to be able to survive and support the needs of her child:

> *Government support is very low. It is only economic and this still is not enough. There is no type of support that in a way that we have to say "Thank you" to them and appreciate it. What do they expect? To appreciate something that is our right to have? We are not getting money that we are not entitled to or we should not have...They have to give us this money; it is their responsibility since they don't do anything else… actual provision of therapies is not provided, neither are examinations.*

Out of the eleven mothers who stopped working, seven never returned to their work or did not find new jobs until the time of the interview. The state monthly income was the only money that they received for their child together with the financial contribution of their husband's income. One mother of those who was unemployed was divorced. However this mother (C.H) had some financial support from her ex-husband.

A.Kaz (aged 47, married, unemployed, disabled child aged 18) was another case of a mother who did not work after the birth of her child; she lost her job. After her child's diagnosis of disability she faced some health problems of her own (cancer). So for both reasons she had to stay at home. It was a case of a mother who had to raise six children, one of which was disabled. She was disappointed because she expected more support from the state than she received. In her opinion the amount of money that the family received was not enough. Her account of disappointment and lack of support as an answer to the general question is evident in this quote:

> *We received nothing from the government…. only arrogance and humiliation. We received the funding from the government, we were allowed to take some money for nappies but they did not give me anything for 5 years. They owed me 5500 Euros. I called them every month. And all this was happening at a period where I had my own health problems. Everything we have done for our child was done privately. The government did not help at all.*

At the same time the mother talked about the support that the members of the family needed in order to 'accept' the disability:

> *My whole family needed support in order to accept and familiarise ourselves with the disability. What did the government do? Nothing at all! We went to a private psychologist. The government's help was absent when I needed it. When I wanted the medical papers that described the disability of my child in order to go abroad, the nurses* [from the government] *refused to give them to me. I went through the House of Parliament[8] and spoke to a member of Parliament about it, I was arguing with them every day. … There are many people in the government that hold high positions in social work. But they hold positions there only to take money, in order to get paid from the government. They do absolutely nothing. Nobody evaluates their work. It is unacceptable to have an officer from the social welfare services responsible to examine the case of your child and who visits your house only once… and your child is 22 years old! And when she* [the social welfare service officer] *came that day what do you think she did? She just filled in some papers and wrote that we didn't have a housemaid anymore.* [The officer got this information in order to stop the allowance for a housemaid that the mother used to have] *In order to get their money back! Only this!*

C.K (aged 50, married, unemployed, her husband was working as a baker at home for private occasions, disabled child aged 22) was the case of mother who clearly said that she could not trust anyone to take care of her child. She was responsible for the house although her husband helped her a lot. To my general question whether she received any help, she said:

> *My mother and my mother-in-law were willing to help me. I was allowed to have a carer as well. But I knew that in both cases I would be stressed if they did not do the right thing. To be honest, I do not trust any of them.*

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[8] It meant a lot to her, going through a member of the House of Parliament meant that she tried in any way to get her rights.

<u>6.2.1.2. Economic Crisis</u>

As mentioned in the introduction, even though the amount of monthly allowance did not change, the families experienced the effects of the economic crisis in Cyprus in other dimensions of their lives such as cuts in their salaries (T.H, A.Y). Some mothers mentioned their husbands' salary cuts (A.K., K.E., C.K) and husbands' loss of their jobs (M.S., D.P). M.S.'s husband lost his job as a result of the recession in Cyprus as the industry he used to work in was permanently closed. Answering to the question whether she was satisfied with the support she received from the government, she described this as the worst period of her life:

> *I am not satisfied with the economic support I had from the state. My husband due to the economic crisis lost his job and nobody helped us. Our household didn't have a monthly income from either of us* (similarly to the case of G.P above). *Our everyday life had been affected to a great extent and nobody helped us. People from the government or any support from them was absent at that difficult period of my family's life too.*

Two mothers out of the twenty-five stopped receiving the monthly allowance from the government as a result of the economic crisis. The government after the economic crisis of 2013 had made some cuts in monthly allowances to adults and children who were not regarded as having a serious type of disability. Some months later the monthly allowance was returned to the families. However, in some cases the government did not give the full allowance back. D.D and K.G were two such cases. D.D (aged 31, unemployed, husband repaired cars, disabled child aged 8) said that her child was not given a proper diagnosis of mental retardation and so the family was denied the allowance. She said that in the past she used to have a monthly allowance of 420 Euros but after the recession she stopped receiving it. She thought this was unfair and as she said: '*There was nothing that I could do because I could see that circumstances regarding the economic situation in Cyprus were not optimistic'.*

K.G. was the second mother (aged 50, married, a secretary working full-time, husband a worker with a private company, disabled child aged 11.5) whose family did not receive a monthly allowance since as she said she did not know that she had to make a case to the authorities in order to receive it. She was told that due to the high level of her household's income, she was not eligible to receive any money from the government and so she did not ask again.

C.H. (aged 43 at the interview, divorced and unemployed, disabled child aged 18) argued strongly for the rights of herself and her child to the officers of Social Welfare Services. She knew all the rules and regulations in Cyprus for disabled people and she disagreed with the cuts that the government made to the monthly allowance. Her

opinion was that the least that Social Welfare Services in Cyprus could do was to provide a decent amount of money to mothers and families in general for raising disabled children. When professional services reduced the allowance due to the economic crisis as mentioned earlier, the mother refused to accept it. She was angry and upset as she said when answering to the general question of how satisfied she was with the government's support:

> *My feelings of frustration came after they reduced the amount of the allowance. If they weren't going to make any more 'ridiculous' cuts to the allowance, then I wouldn't argue with them, but my frustration wasn't unfounded.... For a long time I was waiting and nothing came. I was calling them and they were telling me that I had to wait a bit more, a bit more. One day I prepared my child's bag and took her to the inspector of social welfare services' office. I opened the door, gave her my child and told her: "I am leaving, I have to go, and I finish work at 8pm. In her bag there is everything that you need, nappies, food, water ... When they realised that I was not joking, the inspector asked for my details and promised me that by the end of next week I was going to receive my allowance.*

6.2.1.3. High Cost of Private Services

Ten mothers mentioned the high cost of private services in Cyprus. As mentioned in Chapter 3, public services under the Ministry of Health in Cyprus are provided to disabled children from the time of their birth until the age of three in the General Hospital or in their homes. From the age of three until the age of eighteen, the child falls under the educational legislation (Ministry of Education, 113/1999), and is entitled to services provided at school. These services are special education, physiotherapy, speech therapy and occupational therapy. They can be provided either as one to one or in group sessions – this is mainly in the case for children of school age and with a frequency of once or twice per week.

Most mothers in the study did not take advantage of the public services and used private services for various reasons. They used private services either because they did not trust the public services or because the public services were not sufficient to meet their children's needs. Some of them referred to the fact that their children needed access to services more often than they were allowed. Others highlighted the lack of availability of specific services that were free, such as physiotherapy which was available for them to attend only once per week for example, whereas their children had to attend at least twice. Private services for therapies including visits to specialists which were costly, was a reason of mothers' dissatisfaction.

M.S. (aged 33, unemployed, married, disabled child aged 9) was a mother who stopped working when she gave birth to her daughter. She emphasised that the

monthly allowance was the only support the family had from the government, which was not enough. They used it to pay for various private therapies that her child attended. Her husband's income was not enough as he was working part-time as a cashier in a DIY store. She replied to my direct question whether they receive any services from the government negatively, adding that using private services which despite their high costs, was something inevitable to avoid:

> *Therapies cost a lot you know ... but I can't stop taking my child to them. As long as I see that my child is making some progress I can't stop these therapies.*

M.S talked about her child's medical card, which allowed free appointments at the hospital and for prescriptions. However, as she said, the procedure they had to follow in order to get them was not easy. Their daughter needed a device to support her legs which, according to the government's scheme for the provision of technical assistance, instruments and other aids that cost more than 100 Euros are eligible for free to the disabled persons (Department for Social Inclusion of Persons with Disabilities, 2016). This device according to the scheme was available for free to the family. However, as the mother said continuing her reply to the same question, in order to receive it, they had to visit a specific doctor in hospital with whom the mother had had an argument in the past concerning her daughter:

> *I will try to get the money for these leg support immobilisers but I do not want to go to this doctor again. I have my own doctor now in Greece and I don't mind paying for the travel costs in order to visit him instead of visiting this doctor in Cyprus here.*

C.H. (aged 43, divorced – unemployed, disabled child aged 18) talked about the insufficient support she perceived from the government in relation to the high cost of private services and generally the cost of living associated with a disabled child. As she said answering to the general question about what type of support she received from the government and her level of satisfaction or not:

> *We get the monthly allowance for disabled people plus another amount of money for severe motor disability and a special allowance for care. I give this money to her father since he pays for the carer I have at home and he also buys anything expensive that our child needs such as a wheelchair, bathroom seat etc. There are so many things that I could do if I had more support ...computer lessons, water therapy treatments for example. She is having computing lessons at school but it is not private and the equipment they have at school is not the same as the computer we have at home. We need to change her wheelchair now. It costs 13.500 Euros. The government will provide us with only 4000 Euros. Where will I find the rest of the money?*

Y.O. (aged 46, married, academic professor, husband a doctor, disabled child aged 15) lived in a high-income family. She mentioned that she did not have any financial problems but emphasised the high costs of looking after her disabled child and that the monthly allowance was not sufficient. Answering the general question of satisfaction she described her experience when she was refused the monthly allowance and her preparedness to fight for his rights:

> *That money (the monthly allowance) is not enough to cover his treatments but it is okay. We earn enough money to support our child. Now if our son as a citizen of the Republic of Cyprus is entitled to an allowance because he is disabled, then I was ready to fight for its acquisition.*
> After an argument with the Public Welfare services, her son was given the extra allowance for severely disabled children:
> *… then we got approved so now he receives 300 Euros plus the monthly allowance of 820 euros per month for this. This money only partly covers his needs. Again we need to pay a lot of money to cover for all these services but he is our child and anybody would do that even if he was without any disability.*

6.2.1.4. Insufficient resources –need for something more than financial i.e. for emotional support

There were eight mothers who said the services that they perceived to be insufficient as they expected more types of support other than financial. They felt that the monthly allowance was not the only support they expected from the state but also wanted other things, for example practical or emotional support.

L.S. (aged 50, secretarial position in the government, divorced, disabled child aged 19) was a mother with three children, two of whom were working. She translated the support she received from the state differently:

> *I don't want any other help. I wish I had a person for example a nurse or a teacher from the state that could be here when I needed to go out or when my child was sick and had to stay at home. Every time that there is an election and they want you to vote for them they call you and they show you that they are interested in your problem or your needs. But no one is really interested in helping you.*

One could say that there is a carer allowance. In the case of this mother for example, who was a divorced mother a carer was not a solution as she said, because she preferred to use the carer's allowance for the therapies. She was not satisfied with the state's support because she expected more practical support which she said she needed on a daily basis.

E.S. (aged 42, divorced, multifunctional teller in a bank – full-time, disabled child 18), was sarcastic about the government's support which was only financial, which is nothing as she said compared to other countries. She did not perceive the state's services as support because as she said she preferred for there to be emphasis on

other types of support. Answering to the question whether she is satisfied with the support provided to her family from the state she said:

> *No, no I am not. Things should have been so different. The current situation would function in a healthier and better manner, if our system had embraced several features from other developed countries. I wish we [Cyprus system] would adopt some of them. ... Let's say you live abroad, services will come to your house ... here in Cyprus you have to fill in a hundred forms in order to get the minimum amount of money. What does the government do? Let me tell you… Nothing... Their support is only the monthly allowances, nothing else. Even the educational system lacks essential mechanisms offering actual support…*

C.H. talked about the insufficient resources from the government and expressed her dissatisfaction when she asked about the objectives from her disabled child's teacher.

6.2.2. Carers

Eight mothers in the study had a private carer living with them. The carers were all women who were not Cypriot nationals. They came from Asian countries, Bangladesh, Singapore, Vietnam and the Philippines. Mothers emphasised the practical support, in-home support and respite care that the carers provided (see also Hartrey and Wells, 2003 in Ireland). It is assumed in Cyprus that this care is provided by women:

> *The maid care service offers personal care for the disabled child, care when parents are not at home, house cleaning, laundry, accompany to the hospital…*
> (Ministry of Labour, Welfare and Social Insurance, 2006)

The carer support was the only type of support from the government that mothers mentioned feeling satisfied with. C.H. emphasised the respite care and in-home support that the family perceived from the carer:

> *The carer sleeps in the same bedroom as my child because she might wake up during the night and want some water. She also helps me with house cleaning and any time I might want to go out she stays with my child while I am away. When my child goes to her father, the carer goes with her.*

E.S. (aged 42, divorced, multifunctional teller in a bank - full-time, disabled child aged 18) was another mother who had a carer living with them. Answering to the direct question whether she had a carer she said:

> *Oh, yes... I have a carer living with us at home. If I have to stay at home when my child is sick I will but this does not happen very often. Usually the carer stays with her. In the mornings when my child is at school she does the house cleaning, ironing and cooking. Somebody has to substitute at least the support I should have from my ex-husband. I am not a superhero!*

V.H. (aged 46, married, worked in a food shop - part-time, husband manager of a private hospital, disabled child aged 11) had a carer for six months before the

interview. She answered to the direct question as well where she talked about how not having a carer in the past was a big mistake:

I wish I had not been so stubborn in the past. The fact that I did not have a carer in the past because I wanted my privacy was the biggest mistake I made. I was wrong. The carer [from the Philippines] supports me with my child. She plays with him all the time. She does the housecleaning as due to a health problem that I have I can't do a lot. And she never disturbs us as a family. She is very polite and helpful.

Y.O. (aged 46, married, academic professor, husband a doctor, disabled child aged 15) said that she was fully dependent on her carer; answering to the same direct question she felt she had no other option than to trust her:

Because if I have to go to the supermarket, to church or to a party, I need to leave him at home, otherwise I cannot manage it. So at the end of the day you are dependent on this person, fully dependent... The feeling of responsibility you constantly have just because it's your problem and not anybody else's.

6.2.3. Voluntary Sector

The voluntary sector is treated here as part of formal source of support.

At the time of the interview, the charity organisations focusing on disabled children and people were few and their task was to organise charitable events and provide support to families and to mothers of disabled people more specifically. Radiomarathon was the only annual charity organisation exclusively for disabled people. It collected money for "children with special needs" using the slogan "Only love can". It developed a charitable culture the last twenty years of its establishment which influenced society in general (Phtiaka, 2007).

Mothers as noted above, did not estimate the support from the charity organisations as a perceived support. They only mentioned charity organisations after I prompted them with the direct question. When mothers were asked whether they received support from charitable organisations they all mentioned the money that Radiomarathon offered. However, the procedures for application are very bureaucratic. Mothers have to provide all the receipts from the therapies that their child attends. A confirmation letter is also needed from the therapist and a statement showing parents' income and socioeconomic condition. Then the organisation assesses whether the mother or the carer of the disabled child will receive the benefit. The amount of money is about twenty per cent (20%) of the money they pay throughout the whole year for the therapies or other needs (Radiomarathon, 2015). Socioeconomic background was relevant to mothers' responses to the question whether they received any support from voluntary organisations. Mothers with a lower socioeconomic status reported having

received this type of support in the past, although they were not satisfied with the amount received or with the procedures that they had to follow in order to get it.

Out of the twenty-five mothers that participated in the study, only three received financial support from charity organisations, from Radiomarathon. Two of them (C.K. and D.D.) were unemployed while the third mother (A.Mav.) was a carer for a disabled children in a primary school; during summer break and bank holidays she was not paid. Regarding voluntary support that the family got, the mother answering to the direct question of the support they receive from charity organisations said:

> *Charitable support? Hm… I do have support from Radiomarathon. Economic support. I cannot say that this is a high level of support. Not only regarding the amount of money that we get but from the source of support as well. We fill in the forms every year. Ok we get some money, I can't ignore that, but it is very little.*

Twelve out of twenty-five mothers responded positively to the question whether they used to receive financial support from Radiomarathon but at the time of the interview they had stopped. The main reason that was given by ten mothers was that it was a long and difficult procedure which only resulted in low levels of financial support.

T.X. said in regards to the same direct question: 'I *used to receive some money when he was younger but every year we had to take the receipts from the services to Radiomarathon and they gave us back the amount of money that was estimated. If we paid for example 1000 Euros we had an amount of 200 Euros returned. It was not worth it'.*

L.S. when asked whether she received any charitable support said she used to, and justified the fact that they stopped applying for support because of the increasing number of disabled children and the increasing demands for support:

> *Last time we received it, the amount was 150 Euros for the whole year, which was less than the previous year. The number of disabled children has increased and more and more children need this money. In the past, you would just take the receipts and it was enough. Now the procedure has changed. You have to fill in all the application forms and wait in order to be assessed. It is a time-consuming procedure…*

D.P. answering the same direct question added that the time that she had to wait in order to get the money from this charitable organisation was another reason to stop receiving the financial support:

> *I went there* [to Radiomarathon] *filled in all the papers and I only managed to get the money after a year and a half from the time that I made the application. I did not know that I had to wait for so long to get only this small amount of money...125 pounds twelve years ago* [before Cyprus become a member of the

euro zone]. *Nothing... At the moment, I don't get any money, I don't fill in any papers.*

Ten mothers gave a negative answer to the question about whether they perceived support from charitable organisations. Three mothers (Y.O., V.H. and Y.K) stated clearly that they did not want to take any money from charity organisations such as Radiomarathon, as they were working and were able to care for their children without this money. Y.O. added that some other children might need the money more than they did when asked whether she received this type of support:

> *We only receive the monthly allowance from the government that is by law our right. Even though it is not enough to cover my son's needs, we have never received any money from Radiomarathon, we don't think we should receive any charity money. We earn enough money to support our child. The charity should go to people that do not have the money to support their children.*

There were two mothers that did not receive any money because they did not know if they were allowed to get this financial support (M.K., E.Si).

6.3. <u>Conclusion</u>

This analysis of formal support focuses on the types of formal support that were available to mothers irrespective of whether they received them at the time of the interview or considered them helpful. These services include financial allowance for families with a disabled child, services such as physiotherapy and speech-therapy and the voluntary sector such as charity organisations. When asked about these benefits most mothers expressed considerable dissatisfaction. This finding confirmed the findings of other studies conducted regarding care for disabled children in the USA and in the UK (Lawrence, 2011; Read, 2000), while mothers in the study also complained that the costs of raising a disabled child are high, as other studies concluded (Dobson, et.al. 2001; Slade et. al. 2009).

The first theme in this analysis focused on lack of income; fifteen mothers said that the monthly allowance from the government was not enough to cover the needs of disabled children. This was particularly so for the eleven mothers who had to give up their work in order to raise their disabled children. Because these mothers either did not earn enough money or their husbands were low paid they were not able to afford the extra money needed to pay a carer or they did not have any parent or relative to take care of their disabled child if they were to get a job. On the other hand, four mothers said that they preferred to stay at home because they did not trust anyone else to look after their child.

The global economic crisis, which is considered as the most severe since the Great Depression of the 1930s, (Dezhao, n.d) has affected many societies adversely and in many aspects (Elder-Woodward, 2013). The cuts in welfare benefits and services provided by the government have particularly affected vulnerable people (Wood, 2012; Larkins *et.al, 2013,* Stalker *et. al,* 2015). In Cyprus families with disabled children have been affected. Unsurprisingly therefore, a second theme in mothers' accounts of formal support concerns the negative impact of the economic recession in Cyprus and the cuts imposed by the government on them and their families, in particular a temporary cut to the disability allowance for children and cuts to salaries.

The high cost of private services such as therapies and other treatments that mothers use for their children was a focus of dissatisfaction. As mentioned in the beginning, it is a common practice in Cyprus to visit a private doctor or therapist because of the insufficient services provided by the public sector. Lack of availability of therapists or specialised treatment, were the main reasons that mothers reported for going to the private sector. The cost of private lessons, visits or therapies however, was more than the monthly allowance as mothers highlighted in most of the cases. The problem of affording services is noted in other studies of families of disabled children such as those in the UK (Dobson, *et al.,* 2001), or Australia (Bourke-Taylor, Cotter, and Stephan, 2014).

Additionally, some mothers expected different types of support from the state, not only the financial scheme that was provided to them and their families through the monthly allowance. The lack of services for diagnosis is reported by parents in studies of parental experiences of the services provided to disabled children in England (Slade, *et.al. 2009*). Mothers in this study indicated of great importance the fact that economic or financial support that they received was not only what they really needed or willing to perceive from the public services. They emphasised the need for emotional support that was absent when they wanted someone to help them overcome their turning point, the event in their life that made them become aware of their child's disability (Hareven and Masaoka (1988) where they wanted the state to be there by a representative to offer them emotional support but was not. There were cases where mothers talked about the lack of practical help every time they needed a person to help them with their disabled child in an emergency for example. Only two mothers found the support from the government adequate to meet their needs. Those mothers who appeared to be a little more satisfied then the others who were very dissatisfied, were cases of mothers

with low expectations of the state and sought to provide help within their own means or no longer needed the help as mentioned.

The majority of mothers in the study expressed the need for more information regarding the services, financial support, or any supportive programmes, generally the provision of more information was a necessity (Canary, 2008), and the need for more services which should be helpful to families anytime they might need them such as in-home support in cases of an emergency, and for families who did not have a carer at home either because this required additional funding or because families did not want a carer on a daily basis and they would like this type of support occasionally (Burton-Smith, 2009).

The support provided by carers was another source of formal support available. These carers lived in the home and worked full-time. Mothers could apply for an extra allowance for this that the government was providing to them. Mothers did not mention carers' support as an answer to the general question and I needed to prompt them with the direct question of whether they had a carer at home. Carers were included in the formal type of support because of the fact that mothers paid them and their support was mainly focused on in-home support and respite care. This type of support was highly estimated from mothers who perceived it as indicated from their accounts.

Considering the support from charity organisations, mothers did not spontaneously mention voluntary support in the general question about formal support either. They were prompted with the direct question where they provided their negative response as only three mothers received the charitable support at the time of the interview. Voluntary support, the support provided to families with disabled children by non-profit organisations such as the well-known charity organisation in Cyprus 'Radiomarathon' was not used by many mothers at the time of the interview while none who had sought charitable support in the past spoke positively about it. Some of them said they stopped because of the bureaucratic procedures they had to follow, others stopped because of the insufficient amount they received. Some said that other children were more in need than their own disabled children, whereas two mothers did not know whether they were entitled to this type of support. The three mothers, who received support from charity organisations, came from low socio-economic levels, were unemployed or hourly paid employees but also said that this was not enough to cover their needs.

Chapter 7 - Informal support: Husbands, Family Members, Friends and Other Relatives

7.1. Introduction

Chapter 6 presented the findings that were identified from mothers' accounts in regard to formal support from the state, various government organisations and services or voluntary organisations. In general mothers highlighted their dissatisfaction with the support they perceived from the state. When they were asked to nominate people who provided them with support all the mothers named people from their families and friends. Therefore, this chapter focuses on the informal support that is provided to mothers from family members and friends.

Support to families becomes a necessity as mentioned in the literature. Several types and sources of support are mentioned in the literature, such as emotional support (Florian and Findler, 2001), practical support (Forde, *et. al,* 2004), financial support (Burton & Phipps, 2009) or social support, that is the support provided through social interaction with other people (Manuel, Naughton, Balkrishnan, Paterson-Smith, & Koman, 2003; Sepa, Frodi & Ludvigsson, 2004). In general, social support has been conceptualised in both formal and informal forms as an external resource to reduce the stress and difficulties experienced by families with disabled children (Kazak, 1986; Dunst, Trivette, Gordon, & Pletcher, 1989). As mothers felt they did not receive adequate support from the government and the various services in Cyprus, it is expected that informal forms of support will be important to them. To which extent and in what ways is examined in this current chapter, Chapter 7.

Duvdevany & Abboud (2003) undertook a study to examine the relationship between social support and the level of stress and personal well-being of Israeli Arab mothers of children with disabilities. They found a strong relationship between informal support resources and the level of marital and economic stress of the mothers, 'the higher the amount of the informal support resources, the lower the level of stress that was experienced by the mothers' while at the same time, the higher the amount of informal support resources, the higher the sense of well-being of the mothers' (p. 264). Several studies confirmed this relationship and the importance of support on the wellbeing of these mothers as it helped them to cope with a range of child related stressors such as health problems (Russo and Fallon, 2001; Sepa *et.al.* 2004; Sipal & Utku, 2013).

As research has shown, the social networks that are available to families have important relationships to parents' successful parenting (Gardner, 2003). The

networks, the connections that people have with other people usually offer mutual benefits (Harman, 2013; Putnam, 1995). People who have difficulties in their lives are in need of support. Not only disabled people but also the members of their families, and mothers in particular need to reduce stress and the difficulties they have through support (Sepa *et.al.* 2004; Sipal & Sayin, 2013). Informal support is recognised as one of the most important predictors of adjustments among these mothers who raise a disabled child (Findler, 2000; Manuel, Naughton, Balkrishnan, Paterson Smith, & Koman, 2003). It has been also considered that the informal support that mothers received through their social interactions can lead to happiness (Barth, Schneider, & von Kanel, 2010). Montes & Halterman (2007) concluded that mothers in their study through their social relations had feelings of safety and security in being able to rely on others.

Mothers in the study were asked the general question below:
- Nominate the people that provide you with the most support. How helpful or unhelpful is it?
  What type of support do these people provide you? How helpful or unhelpful is it?
  In order to obtain more information in cases where mothers did not refer to any people as informal support providers and the source of support they had from them, I prompted them with the direct questions below:
- Who is responsible for the care of the child when you are not able to take care of him?
- What happens in cases that the child has to stay at home because he or she is sick?
- Do you have any support from your husband/ex-husband? What type of support?
- Do you receive any support from your family or friends?

Mothers were asked about the support provided to them in the present but their replies often referred to support through their whole journey of raising their disabled child.

Husbands' support to mothers has received the most empirical attention in the literature on the relationship of women's role strain to social support. One hundred twenty-nine married and employed women who were mothers highlighted the support received from their husbands as an effect of enhancing their sense of being able to cope effectively with the demands of their everyday lives (Erdwins, Buffardi, Casper, and O'Brien, 2001). Several studies have examined the risk of divorce to parents with a disabled child after the birth. Some studies found higher divorce rates among parents with disabled children compared with parents without (Witt, Riley, & Coiro, 2003;

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Wymbs et al., 2008) while others have shown no relation between divorce and having a disabled child (Risdal & Singer, 2004).

Other studies examined husbands who were close to mothers from the beginning of pregnancy, meaning that they shared experiences such as going to doctor's appointments with their wives. These husbands reported strong marital adjustment after the birth of their disabled children as they supported mothers in several ways after their child's birth such as overall engagement, caregiving and positive affection. They were also aware of the disability of their children earlier than others who were not close to their wives during pregnancy (Belsky, Gilstrap, & Rovine, 1984; Goldberg & Easterbrooks, 1984). At the same time, poor marital adjustment was related to husbands' non-intervention and support for the disabled child and mother (Dickstein & Parke, 1988).

Abidin, Jenkins and McGaughey (1992) in their research on the relationship that child's behavioural adjustment has with child's gender, life-stress events, child characteristics, maternal characteristics and spousal support, found that the support that mothers received from their husbands was strongly related to their own characteristics and feelings of depression, and sense of competence. Nicholas (1997: 16) highlighted that 'fathers' involvement and support in the marital subsystem can have significant influences on each partner's parenting and the parent-child relationship and provide support for investigating fathers' adjustment to their children's diagnoses in the context of the family system'.

Grandparents can provide an informal source of support (Katz & Kessel, 2002; Lee & Gardner, 2010). As Lee and Gardner (2010: 482) write, 'in a variety of contexts, the relative emotional impact of becoming a grandparent of a child with a disability may have an effect on the development of the child's future involvement and support'. It is generally acknowledged that grandparents' support can be an important source for families with disabled children (Hastings 1997; Sandler 1998). Mothers in Eisenhower, Baker and Blacher's study (2005) on 215 disabled preschool children in the USA, showed that mothers received support not only from grandmothers but from their other children and from other relatives as well. Hastings, Thomas and Delwice (2002) in their study of sixty-one parents of children diagnosed with Down's syndrome in the UK, identified that grandparents' support was associated with mothers' ratings of stress. Grandparents, especially the maternal grandmothers, provided high levels of informal support (Hornby & Ashworth 1994; Glasberg & Harris 1997; Seligman *et al.* 1997).

Finch and Mason (1993) analysed which members of kin networks took on responsibilities when kin needed help. Their analysis suggests that this is not a normative matter, that is a question of role obligations, but one that is subject to negotiation over time. They suggest negotiations are 'embedded in concrete, particular and local situations' (Finch and Mason, 1993: 168) that occur in specific contexts, and that moral identities are constructed around the various support exchanges, for example, 'identities as a reliable son, a generous mother, a caring sister or whatever it might be' (Finch and Mason, 1993: 170). Different types of support are provided in different cultures. Brannen, Moss and Mooney in their study of family life across four generations, mentioned the importance of a particular family culture where (2004: 175) 'a particular culture could permeate families across the generations, for example the culture of duty, love and family mutuality'. As I argue in Chapter 3, in Cyprus there is a strong cultural link to the Church. This culture permeates family relations and shapes the ways in which people think about and act in relation to love and support. This Mediterranean culture also stresses the importance of mothers in family life (Palut, 2009; Moreno & Marí-Klose, 2013). Mediterranean culture is characterised as the traditional family culture 'where obedience, dependence, loyalty and empathy to others are important factors promoting interdependency among family members' (Palut, 2009: 246).

Sipal and Sayin in their study of 103 mothers of deaf children in Turkey, found that support from friends did not have a significant effect on parental attitudes in terms of negative attitudes. However, friends' social support was an important source of support in lowering depression levels among mothers (Sipal and Sayin, 2003).

Shang and Fisher (2014) carried out a study of parenting experiences and social support among mothers of children with disabilities in China. They found that some mothers were able to call upon their friends while others experienced rejection by friends. Mothers experienced rejection by their friends because, as they said, they were fearful that the mothers would ask them to provide financial or emotional support and to take care of their child. These were the reasons that as Shang and Fisher suggested in their research 'many of the mothers were protective of their emotional vulnerability and did not seek help from friends or people in the community' (Shang and Fisher, 2014: 584). When society is characterised by norms that support the medical model of disability and by characteristics that do not support any inclusive ideas and inclusive practices, then disability is regarded as a lack of ability of a disabled person, as it is characterised in the medical model, and the disabled child and his/her family

are therefore stigmatised. Rejection by friends then is an inevitable effect in a society that stigmatises disability (Oliver, 1996).

The themes that I identified through the thematic analysis that was undertaken concerning informal support are organised according to the persons who they said provided support.

- <u>Husbands' support to mothers</u>
- <u>Family members' support to mothers – parents and other children</u>
- <u>Friends' support to mothers</u>
- <u>Other informal support to mothers – other relatives</u>

As Tétreault *et. al.* (2014: 274) have suggested, there is a 'lack of consensus regarding definitions of support and its different forms'. Thus, the sources of informal support for the study were developed based on mothers' responses and from definitions used in different studies as there was not a generally agreed upon definition of support:

- Emotional support: 'expressions of care, concern, love, and interest, especially during times of stress or upset', (Burleson, 2003: 2), understanding, acceptance, encouragement (Manuel *et al.,* 2003). Under this type of support the person shows understanding to the mother and the mother feels she can trust him/her to talk about her problems or worries.
- In – home support: 'physical help with the demands of caring for the person with a disability, as well as assisting with general household chores' (Burton-Smith *et. al.*, 2009: 243). Under this type of support, the person offers help to the mother with house cleaning or provision of support through physical presence.
- Financial support: 'represents targeted *financial* contributions, direct or indirect, that are intended for the family' or the disabled child in particular (Tétreault *et. al.*, 2014: 276). Under this type, the person provides the mother or childwith financial support, for example, money for therapies or other needs.
- Respite care provided from family or friends: it is defined as the care provided to mothers as temporary relief for the mothers from their caretaking responsibilities by members of the family or friends (Cowen and Reed, 2002; Hartrey and Wells, 2003). It is the support related to the disabled child as in-home support but it is different as it involves overnight stays and caring for the disabled child on a regular basis in child's home or in their own home rather than mere physical presence (Chan & Sigafoos, 2000; Tétreault *et. al.*, 2014).

7.2. Findings

Mothers mentioned four different types of support provided to them by their husbands or ex-husbands, family members, parents, parents-in-law or other children, friends and other relatives. The following sources of support were the types mothers' referred to: emotional support, in-home support, financial support and respite care (taking care, overnight stay).

Cases	Themes (People that provide support)					
	Husband	Parents	Other children	Friends	Other support (relatives)	Overall Support
K.K.	1	1	1	1	1	5
A.Mav	1	1	1	1	1	5
S.C.	1	1	1	1	1	5
A. Kaz .	1	1	1	1	0	4
C.H.	1	1 /		1	1	4
Y.K.	1	1	1	0	1	4
Y.O.	1	1	1	1	0	4
V.H.	1	0	1	1	1	4
E.S.	0	1	1	1	1	4
A.M.	1	1	0	1	0	3
G.P.	1	1 /		1	0	3
T.K.	1	1	0	0	1	3
K.E.	1	0	1	0	1	3
E. Si.	0	1	1	1	0	3
L.S.	0	1	1	1	0	3
D.P.	1	1	0	0	0	2
D.D.	1	1	0	0	0	2
K.G.	1	1	0	0	0	2
M.S.	1	1 /		0	0	2
T.X	1	1	0	0	0	2
A.K	1	0	1	0	0	2
C.K.	1	0	0	1	0	2
T. H.	1	0 /		1	0	2
A.Y.	0	1	0	0	0	1
M.K.	1	0	0	0	0	1
Number of cases	21	17	13	14	8	

*Table 7.1 - Informal support relating to mothers' accounts*

Table 7.1 shows all the mothers and whether they received support from each source – husband, parents, other children, friends and/or other relatives. Number 1 in the table indicates where the mother mentioned support from the specific source, whereas the number 0 means that they did not mention or were negative in support received from the specific source. The "/" represents cases where mothers had no other children.

From Table 7.1 we can see who mentioned more sources of support and who mentioned less. At the top are those who mentioned that they received informal support from all five sources, then the mothers that mentioned four sources and moving down the cases of mothers who mentioned fewer sources of support.

Twenty one out of twenty-five mothers in the study named husbands or ex-husbands support. After husbands, the parents or parents-in-law receive more mentions, with more mentioning their own mothers, followed by seventeen mothers highlighting their parents' support. Friends and then their other children were next. Last are eight mothers who referred to other relatives' support such as their own siblings or other relatives.

Sources of support as already noted concern emotional support, respite care (taking care of the disabled child, overnight staying), in-home support and financial contribution. However, it is important to note here (see also chapter 6) that there were mothers who probably received support but did not estimate it as support and thus did not mention it in the first general question. They only named it after they were directly asked with the prompted questions or did not mention it in their interview at all.

The tables showing both types of support and persons providing it for each of the 25 mothers are in Appendix 5. In Figure 7.1, I present the number of mentions made by mothers for each type of support provided by each sources of support.

Number of mothers by person providing the support and types of support
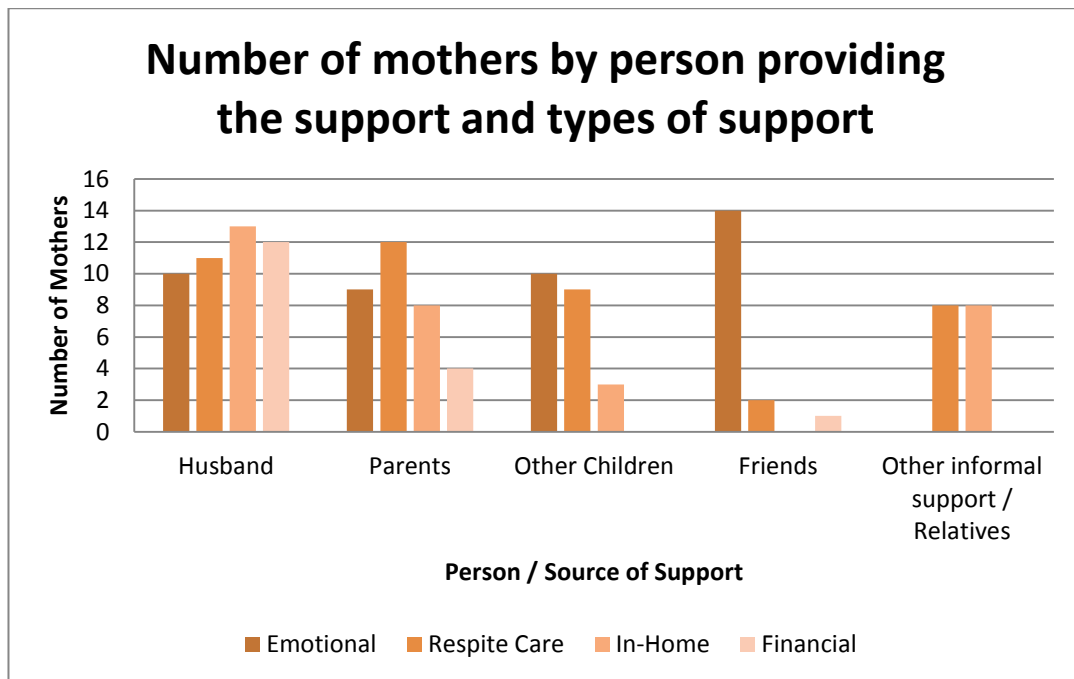
Figure 7.1 - Number of Mothers by person providing informal support and types of support mentioned

More mothers mentioned their husbands followed by support from parents, both of whom offered financial support. Mothers' other children provided emotional and in-home support in terms of physical presence and assistance in household chores.

Friends were mainly seen as offering emotional support. Relatives provided respite care (taking care of the disabled child, overnight staying, taking him/her to the therapies and other afternoon activities) and in-home support.

Another finding was the fact that every theme of support provider concentrated the responses from mothers in different sources of support as analysed in detailed in the next paragraph.

Friends' network support concentrated most in the emotional source of support as mothers mentioned that with their friends they discussed their problems, and friends were the people who mothers could trust and rely on. The support from their other children was mentioned by mothers as mostly emotional support; they said that their other children made them proud of their academic achievements or behaviour.

Mothers' parents or parents in law were nominated mostly as providing respite care such as caring for their disabled child through overnight stays on a regular basis in the parents' home or in the mothers' own home. Husbands are not included in this finding

as mothers referred to three or more sources of support provided to them such as in-home support, respite care (taking care, overnight staying) or emotional support, so there was not a distinct emphasis in one source.

7.2.1. Husbands' support to mothers

Overall twenty one out of twenty-five mothers mentioned that they perceived one type of support from their husbands or their ex-husbands.

Some mothers saw the support they received from their husbands as satisfactory naming one or two sources of support that they received from him. However, four mothers were not happy with their husbands' or ex-husbands' support in any respect.

Nine out of twenty-five mothers mentioned that they received emotional support, ten out of twenty-five that they received respite care (caring for the disabled child, overnight staying) and thirteen out of twenty-five said that they received in-home support such as help for the household and cleaning. Six of these mothers emphasised all three sources of support.

C.K (aged 50 at the time of the interview, married – informal support from husband and friends)*: My husband is with us in almost every activity we do, I mean he joins us to the places we go.*

A.Mav (aged 47 at the interview, married – informal support of all types, husband, family members, friends, and other relatives) emphasised the practical and emotional support that her husband provided to her and her disabled child:

> *He changes his nappies, he does the suction to child, he used to stay overnight in hospital with our child many times in the past in order for me to come home to our other children. When my son was sick, the first person that was on the list was me (herself). If not, my husband took a day off work and stayed with the child. He is my best friend I can talk to him, I can share my worries, and he is the only person that I feel confident with every single day.*

D.P (aged 48 at the time of the interview, married – informal support from husband and her parents) emphasised the good relationship that her child had with her husband mentioning the respite care (taking care, take her daughter to the afternoon activities) that she received from him and at the same time the in-home support, both valuable as she said:

> *My husband helps me a lot, now more than before since he hasn't got a job but ok. He helps me with the children, he does the gardening, he may go shopping and he is the person that I can count on. His support is so valuable to me!*

S.C. (aged 45 at the time of the interview, married– informal support of all types husband, family members, friends and other relatives) was the mother whose strong marital relationship helped her raise her disabled child. Her husband was the president of the Parents Association group for disabled people in Cyprus and they both tried to help their child in every way. The fact that they were close helped her as she said to be strong and powerful. She emphasised that her husband's presence was the most important fact in her life. Their child's disability as she said had brought them closer and answering to the question about who gave most support she named her husband:

> *If I am a strong character it is because of him. Generally, I could say that we are a family with members close to each other. The fact that I was so close with my husband was something that empowered both of us. I can't live without him. When I am not well he is there for me and when he is having his bad days, either because of our child or because of anything else I am there for him to support him as he does.*

Not surprisingly, mothers who said they did not highly value but had enough support from their husbands were mothers who could not rely on or trust them. Some of them justified this with the fact that their husband was probably working for many hours during the day and the week. In the case of D.D for example, there was no communication between the couple even if they were living in the same house and he did not help her with the daily responsibilities as house cleaning or taking care of the children. Six out of twenty-five mentioned financial support as the main source of support from husbands and from these six, two mentioned respite care. If they needed to leave the house for example, they knew that if their husband was at home he was going to be responsible for the child. These mothers did not nominate their husband as the first person in their list providing support to them.

A.M. (aged 41 at the time of the interview, married – informal support from husband, parents, friends) said that she did not receive any help from her husband other than financial support for the needs of the household. She nominated him in response to the general question about which persons provided her with the most support regarding her disabled son. However, she explained that they both had a different perspective of life:

> *We are two different people that are trying to co-exist in the same house. The good thing is that he respects my existence as I do his. Otherwise I would divorce him. There are times that I don't want to talk to anyone. He helped me with the child after I encouraged him to do it. He never visited our son's special school or had an appointment with his teachers. … I am the one that has to stay home when our child is sick. For the upcoming summer holidays, I asked my husband to take some days off work in order to be with our child at home since I can't take*

two months off work. He did not accept it. I will have to pay a carer then. My mother can't help, she has her own problems.

M.K. (aged 45 at the time of the interview, married – informal support from husband) said that her husband had two jobs in order to manage the economic expenses of the family. Thus, she did not receive any other support from him as he was not at home. However, she also mentioned that they did not sleep in the same bed during the night as her husband preferred to stay in the sitting room where he found the sofa more comfortable than their bed. The mother was sleeping with her disabled son because as she said he needed her in order to sleep. Answering the general question, which was to nominate the people who provided her with most support, she said that she only had some support from her husband but:

> *I feel that I am both a mother and a father for my children. I do not receive any support other than the money that he brings home. Ok and the fact that he is there that he contributes to the family with his presence. He works twelve hours per day in two jobs. He leaves home early and comes back late and tired. He was never the type of person who helped his wife for the housecleaning or in raising his children.*

C.H. (aged 43 at the time of the interview, divorced – informal support of all types husband, family members, friends, relatives) was the only divorced mother included in this group who mentioned that her husband supported her financially. He also helped her practically even though they were divorced. Twice a week the child was with her father where she stayed overnight at his house. She nominated her ex-husband's support after she mentioned support from friends and other relatives:

> *He (Ex-husband) supported me only after the child turned five years old. He knew about the disability after he left home. He did not help me at all while we were together, not even practically, not even to change her nappy. Now he helps financially, and practically as he takes the child two times per week and they go out and she stays with him too. When he takes her, the carer goes with her and they sleep at his house. He supports me sometimes emotionally. We are not friends but I know that if I have a problem regarding our child I will probably tell him.*

An important distinction can be detected between mothers who highly valued their husbands' support and those who said their husbands gave 'some support'. Mothers in the first group did not mention financial support because they took it for granted. On the other hand, mothers who mentioned their husbands' economic contributions were mothers who were not satisfied with other types of support provided by the husbands. They only reported the husbands' financial contribution or some respite care for example, caring for the disabled child when the mother needed some help. In cases where mothers mentioned that they received financial support from their husbands,

these cases related to mothers who were not satisfied overall with the support received from their husbands.

Five mothers said they did not feel supported at all by their husbands. All these mothers were divorced. The financial amount required by the law following divorce[9] (Cyprus Bar Association, 232/1991) was received by two of these five mothers and not by the other three. All five mothers did not perceive their ex-husbands to be supportive because of their lack of financial contributions. They also expected something more as we will see from their accounts below.

Y.K. (aged 42 at the time of the interview, divorced – informal support from ex-husband, parents, other children, other relatives) was married to a lawyer in a high employment position and he was earning a lot of money according to the mother. While he paid child maintenance according to the law, the mother was not satisfied because as she said it was not just the money that she wanted and expected from him to provide:

> *Financially we don't have problems. Every month he gives the money he has to give. But he is absent. Money is not what I would like to get. He has chosen the easiest path, leaving me alone. I don't perceive any actual support from him, no.*

K.K. (aged 45 at the interview, divorced – informal support from all cases) was negative in her answer when asked whether she received any help from her ex-husband. K.K. was a case of a mother like Y.K. who divorced her husband after she found out that he had another woman some years after the births of their disabled children.

> *Unfortunately, in cases where a couple gets divorced after a third person comes into the relationship and the husband marries a lady who has her own children, you do not expect any support.*

When asked whether her ex-husband provided her with the child maintenance that should be provided monthly to the main child carer of a divorced couple, she said she received the money but only after a struggle.

L.S. (aged 50 at the time of the interview, divorced – informal support from parents, other children, friends) and E.S. (aged 42 at the time of the interview, divorced – informal support from all types except husband) were not receiving the economic amount as their children were above the age of 18. Fathers are obliged to give this

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[9] The amount is between €200-€680 based on both parents' socioeconomic level and needs of the child.

monthly allowance up to the age of eighteen. If after the child's 18th year, fathers still want to contribute they are free to give the money as in the case of C.H. In the cases of L.S. and E.S, ex-husbands stopped providing the child maintenance to mothers. As E.S. said to the direct question whether she received any support from her ex-husband:

> *We don't even talk anymore after we divorced. He does not help me with my daughter. I receive no support. He does not want to see me, so he does not have any contact with my children. I know that my disabled daughter wants to see her father. Yesterday she was crying, shouting that she wanted to see her dad. What did I do? Nothing…He does not help me with the 'child maintenance' either.*

7.2.2. Family members' support to mothers

Other members of the family, mothers' parents, parents-in-law and other children have a vital role to play in the lives of mothers with disabled children and on disabled children themselves. Mothers in this study mentioned their parents and their other children as providers of support to them and their disabled children.

An important finding that mothers in this study underlined the support they received from their parents, a finding that is highlighted in the literature as shown above especially support from the maternal grandmothers (Glasberg & Harris, 1997; Hastings, Thomas, and Delwiche, 2002; Seligman, Goodwin, Paschal, Applegate, & Lehman, 1997). Twelve out of twenty-five mothers highly valued the support that they received from their mothers. They translated this source of support as being able to leave the child with their mothers when they had to go somewhere. They also valued them because they were 'there for them' even if mothers did not ask for help.

S.C. nominated her mother emphasising the support she received from her from the very first day that her twins were born:

> *From the very first day we received support from my mother. She was there from the day I gave birth to my children until today. She cooked for us, used to clean the house before we had the housecleaner, took the kids to their afternoon activities and looked after the other two children when we had to go abroad with the child. Now that she has grown up things are more difficult as she can't provide us practical support meaning that she can't help the child to have a bath. I can't say that I did not live my life because of the child since I had my mother always by my side.*

T.X. (aged 47 at the time of the interview, married – informal support from husband and parents) highlighted the important support she received from her mother when she was working, in the form of respite care such as doing baby sitting at the grandmother's own house and in-home support that is cleaning the mother's house for her:

When my children were younger she used to take them to their afternoon lessons, she used to take my son to his therapies. She was basically doing everything. Until today she helps me a lot. She helps me with the house cleaning too even if I don't ask her to do it.

There were three cases where mothers mentioned the support they received from their mothers-in-law. A.Mav said her mother-in-law helped her practically as she was looking after her child when everyone was at work.

After we decided to stop having a housemaid-carer I needed a person to be with my child when I was at work. It was going to be a disaster for me if I stopped work. My mother who used to be close to me passed away so my mother in law helps us for the moment. Probably in some months my mother in law won't be able to come. She is quite old and she can't do a lot. In that case I don't know what I will do; I might find a lady to come in the mornings.

Emotional support received from their parents, especially their mothers was mentioned by nine mothers.

D.D. (aged 31 at the time of the interview, married – informal support from husband and parents) emphasised that her mother is her best friend (Montes & Halterman, 2007).

No I do not have friends. My mother is the person who I can rely on every time I have an issue and want to speak to somebody. Even though I do not see her often, I know she is always there for me.

There were mothers who mentioned financial support that they received from parents. These were mothers with economic problems, mothers that were unemployed (G.P., M.S) or divorced (K.K).

G.P. (aged 37 at the interview, married – informal support from husband, parents, and friends) said:

Neither of us work at the moment. It was our choice to stay home and raise our child. But you come to a point where you need to get an income. My parents were always there for us. Until today they help us economically.

Y.O. (aged 42 at the time of the interview, married – informal support from all cases except other relatives) talked with great respect about her parents-in-law who gave lots of help - emotional, respite care (taking care of the disabled child, accompanying mother and child when they went abroad) and in-home care of the child and house.

They come every day since he [the child] *was born, they come every day! They do spend time with him and my father-in-law tries to say things with him, he has a tutorial with him every day and when they do this it's like a ritual, they've been doing it every day for as far as I can remember. …I am very appreciative of these*

people who are like my parents. … the other thing is, when I went to the States they came with me to help me out with N [the child]. I went three times, I could not go alone because my husband had to work so yes, I think I have received so much support from these people that I cannot pay back.

Another set of supportive persons mentioned were mothers' other children (Finch and Mason, 1993). Fourteen mothers highlighted the emotional support from their other children and also respite care (emphasised on taking care for the disabled child) and in-home support. Four mothers had no other children and seven mothers reported no support from their children (see table 7.1).

The support they received from their children, the siblings of their disabled child, was highly valued by mothers. Mothers who mentioned emotional support used phrases such as *'she makes me proud every day'* (K.E, aged 50 at the interview, married – informal support from husband, other children and other relatives), *she is so mature that we can chat and share our problems'* (Y.O) or *'she is the person I can trust more than any other. She has her own strong opinion about everything, she studied, she is a special education teacher and this on its own means a lot to me* (L.S).

Mothers who referred to the in-house support that they received from their children said: *Everyone has his own responsibilities at home. I am not working so my responsibility is to cook. I don't go shopping, my oldest son does this. My daughter is responsible for cleaning the bathroom. My child puts away the ironed clothes. My husband does the laundry.* (A.Kaz, aged 47 at the time of the interview, married – informal support from all cases except other relatives).

There were cases of mothers whose children gave both emotional help and help in the house and with care of the disabled child:

> *I receive support from my other two children. My child's twin brother helps me with practical things, he helps with bath time, and he knows that he has to do it, he has to help his father and obviously his sister. My youngest daughter helps me with house cleaning and emotionally. The fact that she is progressing in her life is the best source of support I would like to have* (S.C).

Two divorced mothers (K.K. and Y.K.) named their oldest sons as care providers to their children. K.K. said her son took on the role of the father in the family:

> *The absence of a father in the family is substituted by my oldest son who supports me practically and emotionally. E.P* (the disabled child) *asks for my oldest son more times than for his father. Every time he comes to Cyprus, as he studies in England, he spends time with him, he goes out for a coffee or watches television with E.P. This is very important to me as well as to my disabled child, who needs a parental figure in his life you know.*

Y.K. cried when speaking about her oldest son's practical and emotional support, who substituted as well the absence of her ex-husband:

> *I can't imagine my life without him. He was with me throughout this entire journey. He knows better than his father how to give the child his medicines and what to do in case of an epileptic crisis. He is a good student, has a good character, he's my best friend…. and so much more.*

D.P., T.X. and A.K. 'exempted' their children from helping (Finch and Mason 1993) on account of their age (too young or too old) saying that the latter (grown up children) had their own responsibilities and lives:

> *My daughter has her own job, and even though she is 28 years old, she lives with us but she is like a housemate. I won't ask her to take care of her sister or to help me when I might feel sad about something. Of course, I will never ask her to provide economic support. I am her mother you know!*

A.Y. (aged 49 at the time of the interview, divorced – informal support from parents) was the only mother who was disappointed with the behaviour of her children. She mentioned that her daughter aged 19, and not the disabled child, took all the monthly child maintenance from her ex-husband and used it for her own needs instead of helping with the expenses of the house. They were not officially divorced, so her ex-husband was not obliged by the law to pay. She said about her daughter:

> *Instead of providing the money to me in order to cover the needs that the household has, he gives the money towards raising his children to my daughter. My daughter uses it only for her own needs. If you want to give money for your daughter's studies it is ok! But who has to contribute to the house's expenses where your children live?*

From this section we can see that mothers valued the support provided by their parents, specifically their mothers. In particular, they valued the respite care they offered, for example, the practical support they received from them when raising their disabled children and that they received until the time of the interviews. Mothers-in-law were also mentioned by mothers whose own mothers lived far away or were not alive.

Mothers also mentioned support from their other children, both emotional and practical support to them and their siblings. Their children's own development made them proud of these children and they praised their children's maturity and kindness. Some did not expect support from their children because either they were seen as too young or they had their own lives and responsibilities.

7.2.3. Friends' support to mothers

There were eighteen out of the twenty-five mothers who nominated one or more friends as people who provided them with support. All mothers mentioned emotional support from their friends while two mothers said that the friends provided respite care that is caring for their disabled children or looking after their disabled children when mothers needed somebody to be with them.

A.M. was a case of a mother who nominated two friends as providers of support; she had met them through an association of families with autism in which she had enrolled after her disabled child's birth. She described them as 'not just ordinary friends'; they meant a lot more than that to her, she emphasised that the emotional support she had from them supplemented her husband's support.

> *I feel proud that I have these two people in my life. One of them has a brother with autism and the other one has a son, five years old diagnosed with autism. They are my angels. They are not just ordinary friends. We go out for a coffee, sometimes I take my child with me, they are the people I can trust in anything I might have. As I told you with my husband we have some communication problems. These two friends with their presence supplement my husband's support.*

In comparison to eleven mothers who mentioned that they received high support from friends, there were seven mothers who expressed low or insufficient levels of support from friends. There were four mothers who said they did not have any friends while three mothers defined as friends, members of their family.

A.Mav when asked whether she received any support from friends said that the birth of her disabled child resulted in the loss of many friends that as a family or as a person she used to have. The mother was disappointed about this as she said:

> *His godparents lost contact with us. It's been many years that we have talked to them. I was offended and their behaviour hurt my feelings.* She tried to justify their behaviour: *They were probably shocked and could not handle it that is why they left. Last year I saw them at a wedding but did not talk to them.*

She nominated one friend who lived close to her and they were colleagues as well, a friend that she could trust if there was an occasion, for example, to which the whole family had to go.

> *Generally I do not like to ask for help from anybody. I think the main reason that I do not want to is because I am afraid of a negative answer. I know that A (her friend) is always positive so in case I need her I will ask her for support but I will think twice before I ask, you know… I don't want there to be a barrier…*

Other mothers were like A. Mav.; they were sceptical about asking friends for practical support in case they lost their friendship and so relied on them for emotional support only. 'Friends' and 'good friends' were distinguished by C.H. who only mentioned two friends that she felt that they supported her. These were friends who either had similar problems or disabilities or were aware sympathetic to or understood about her daughter's disability. C.H's daughter was diagnosed with cerebral palsy and as she was not able to walk she was in a wheel-chair. The mother answered the direct question whether she received any help from her friends. She used the term 'good friends' to define friendships from the past that she kept in the present or friends that did have disabled children too.

> *I do have some friends from the past that we still meet or talk to each other. Friends that know my child and are aware of the situation. They are 'good friends' from the past or friends that we met after my child's birth that have similar cases in their lives. I don't visit them, since they might live in flats without elevators, they visit us here or we go out together. My child is part of my life so my friends are her friends. I don't look for friends. I do have enough. The fact that we spend time together and we share our problems is the best source of support.*

C.K. had lost friends after her disabled child's birth. She did not interact with the same people as she used to do in the past.

> *I get along more with people who have the same problem as me. The friends that I had before the birth of my son have been lost. Not because we had a disagreement but because they wanted different things, my mind was on my child whereas theirs was somewhere else… it was not the same. Slowly, slowly I stopped seeing them. I met mothers with disabled children and we go out with our families together. Mothers that I met from classmates of my son. I communicate more with them. They are my friends now. … It is not that I have any issues with my relatives, they love my child they bring him presents but a friend is different. Especially if it is a person who has got a disabled child.*

G.P. (aged 37 at the interview, married – informal support from husband, parents, and friends) had also lost touch with her friends after the birth of her child and only has a couple of 'true friends' now.

> *Friends… I have lost them all but I do not regret it. They were obviously not true friends. Two or three are family friends as I call them. We visit them and they visit us, they only support me in a way that they are there for me, I might not discuss my problems with them but yes their presence is what I find helpful* (G.P.)

D.D. said she did not have friends but saw her mother as her friend. She emphasised the emotional support she received from her mother as a friend:

> *No I do not have friends. My mother is the person who I can rely on every time I have something and want to speak to somebody. Even though I do not see her often, I know she is always there for me.*

E.Si said that after her daughter was three and when her difficulties became more obvious, she stopped visiting any friends and stopped interacting with them; she suggested they did not 'understand':

> *We did not go out for food or coffee after my daughter was three years old maybe since she was always seen as the 'naughty' girl. We prefer to go to places that I feel safe and where people will understand us, this happens mainly at my mother's house.*

C.H. said that the emotional support she received from her friends served as a replacement for the support that she rarely received from her ex-husband.

> *It is not that we don't ever talk with my ex-husband. But in cases that I need somebody to talk to, I don't feel ill-fated. I have my friends who are there for me anytime I need them.*

Mothers emphasised the changes that they had in their friendship networks after they gave birth to their disabled children. Some of them mentioned that it was their decision as they preferred to keep people as friends who understood what the mothers and children had been through (C.H, A.K, G.P). There were mothers who lost their friends, had been rejected by them or faced stigmatisation as it will be discussed later. Some mothers described rejection by their friends as friends were seen not to be able to cope with the mothers' children (A. Mav) or because friends preferred to interact with people who did not face such difficulties in their lives (A.Y). Another important finding was that mothers, although they did not expect their friends' practical support, they highly valued their emotional support (A.Mav, L.S., A.M).

7.2.4. Other informal support to mothers – other relatives

Eight mothers talked about the informal support they received from members of their extended family networks; their siblings and their nephews and nieces.

G.P. for example said that she received emotional and respite care (take care of the child) from her sister:

> *If we have somewhere to go with my husband my sister will take care of the child when my parents can't make it.*

T.K. (aged 54 at the time of the interview, married – informal support from husband, parents and other relatives) has a disabled child diagnosed with cerebral palsy. She mentioned her sister among the people who provided to her with most support:

> *I am a person that doesn't like to go out, I prefer to stay at home and relax. Rarely do we go out and if we go we might visit my sister. I do have one sister we are close to each other, with her husband and children. We don't have frequent visits to their house but there were a lot of times when I asked for her help and she was there for me.*

Two mothers, S.C. and A.K. said that they were trying to have relationships with their nieces and nephews since they were the people who were going to support their child in the future. S.C. said that she often invited to her house people who she hoped in the future would be able to have relationships with her disabled daughter. A.K. mentioned that there were times when she rang the cousins of her child asking them if they could take her child out for a coffee.

7.3. Comparison of two cases – S.C. and A.Y.

S.C. and A.Y. were two contrasting cases. S.C. received support from many sources while A.Y. gave mostly negative answers when asked about support. The differences that mothers gave are presented in the Table 7.2 below.

Mother	Age	Marital Status	Occupation	Number of Children	Age of Child	Socio-economic Level	Financial	Medical	Educational	Charity	Carer		Husband	Family members	Friends	Other relatives
									Formal Support					Informal Support		
A.Y.	49	Divorced	House cleaner	3	11.5	Low	Yes	Yes	Yes	No	No		No	No	No	No
												Emotional	No	No	No	No
												Respite Care	No	No	No	No
												In-Home	No	No	No	No
												Financial	Yes	No	No	No
S.C.	45	Married	Business Woman	3	20	High	Yes	No	Yes	No	Yes		Yes	Yes	Yes	Yes
												Emotional	Yes	Yes	Yes	No
												Respite Care	Yes	Yes	No	Yes
												In-Home	Yes	Yes	No	Yes
												Financial	Yes	No	No	No

Table 7.2 - A.Y. and S.C - two comparisons of cases: high VS low support

The mothers were of similar ages and had three children each. A.Y. was divorced while S.C. was married. A.Y. at the time of the interview was working as a house cleaner in a part time job while S.C. was a business woman who owned a travel agency with her husband. They were a family with a high socioeconomic level in comparison to A.Y. whose socio-economic level was low. Both families received the monthly allowance from the government. S.C.'s family received 820 Euros per month while A.Y.'s family received 420 euros because of the different type of disability of their child. Both mothers were not satisfied with the amount of money they received. A.Y. did not mention the financial support she received from the government and she was negative about the informal support she received. As we can see A.Y. did not mention any source of support provided to her informally, only the financial support she had from her ex-husband which she did not mention in the beginning, only after I asked her whether she received any support such as the 'child maintenance' that she received from her ex-husband as she was divorced. A.Y. complained about the insufficient support she received both formal and informal. She said she did not have any help from her family members, parents, children or extended family nor from friends.

S.C. was dissatisfied with the support she received from government services. However, she was happy with her husband's support, which included all the sources of support, emotional support and respite care as in terms of practical support, in-home and financial support. She emphasised as well on the important support she received from her family members which was emotional, respite care, in-home support and financial and on the emotional source of support she had from her friends, estimating all the informal support that she received of high importance to her and to her child.

A.Y. described being depressed; such negative feelings are likely to have resulted from a lack of support and loneliness - her experience of state benefits and services, her ex-husband's and family's lack of support members. On the other hand, S.C. characterised herself as feeling empowered. This is again unsurprising given the considerable support from her husband and the informal support she received from her social networks. The latter case supports findings in the international literature that suggests that mothers with disabled children experience high levels of depression that is associated with low social economic levels (Sicile-Kira, 2004; Link, Streuening, Rahav, Phelan, & Nuttbrok in Stuber, Meyer and Link, 2008). Socioeconomic status is another important factor in comparing the two mothers who differed greatly in their access to material resources and which was made worse by the fact that A.Y. was also

divorced. However she did not receive the material support as she was supposed to receive as the divorce was not official.

Similarly, there were mothers who, although they mentioned a lot of support services and sources provided to them, both formal and informal, were not satisfied. By contrast, there were mothers who did not receive much support but were happier overall. Socio-economic status contributed to this: mothers with a high socio-economic level who were dissatisfied were mothers who knew their children's rights and demanded equal treatment (K.K) and support, while mothers with a low socio-economic background were happier with even the smallest amount of support available (M.K).

This finding is supported by the literature that suggests that support and socio-economic status influence mothers' feelings of being supported (Russo and Fallon, 2001; Sepa *et.al.* 2004; Sipal & Sayin, 2013).

7.4. <u>Conclusion</u>

The interview data concerning mothers' perceptions of support suggests that most mothers report informal support rather than formal support. Regarding the informal support they mentioned several sources of support. This included support from their husbands or their ex-husbands and from members of their families of origin such as their parents or parents-in-law. In addition, they mentioned the help of their other, usually older or grown up, children, from their social networks of friends and from other relatives such as their own siblings. Four sources of informal support were mentioned by mothers: emotional support, in-home, financial contribution and respite care (taking care for the disabled child, overnight stays, taking the disabled child to the therapies and other afternoon activities).

Mothers were asked to nominate the people who provided them with most support. The majority of mothers named their husbands, their parents and then their friends. Husbands' support was the most highly valued in terms of the range of services they provided compared with other groups (three or four sources of support). It was interesting to note that mothers' family members - their parents or other children - often substituted for the absence of support from the husbands in cases where the husbands no longer lived with mothers or worked long hours.

Lone mothers, as the literature shows, face more difficulties in raising a child because of basic difficulties such as low income, poor housing or health (Rowlingson & McKay,

2002). Seven mothers in the study were divorced mothers. Most of them did not receive financial material support from their husbands while some did not receive any type of support such as in-home or practical support from their ex-husbands. According to mothers' accounts, the absence of husbands' emotional support was replaced in most of the cases by emotional support that they received from friends or their other children. In terms of respite care (taking care, overnight stays) and in-home support, divorced mothers mentioned their family members or carers, (the ladies who took care of their children, usually living with them and paid for their services as we saw in formal support) as the main providers of these sources of support.

Parents' support was mainly valued as respite care: they provided mothers with the temporary relief for taking care of their disabled children, staying with them when mothers or parents had to go out or for some hours during the day with them. Mothers said they could trust their children to their parents, highlighting the maternal grandmothers' support to take care of them each time they had to go out or needed the children to be looked after following the end of the school day. Some parents provided mothers with financial support. This happened in cases where mothers faced economic problems or were unemployed. Children provided mothers mainly with emotional and practical support. Mothers who mentioned that they did not expect their children's support justified this on account of their age; younger children were not seen as 'old enough' while older children were exempted on account of their responsibilities such as school work or jobs.

Mothers relied on emotional support from their friends but not practical support. They talked about the 'good friends' – those they felt were 'there' for them in the good and the bad times and with whom the mothers felt they could discuss the problems of their lives or seek advice. Several mothers mentioned that they did not have a lot of friends. Some of them emphasised rejection by their friends after their disabled child's birth. They justified the support received from their friends as they were able to share common experiences if they had disabled members in their families or simply because they felt their friends were closer to them than their other relatives. Few mentioned support from other relatives apart from their parents or other children. Friends' emotional support may complement the support they received from their husbands or was a substitute for the support that they did not receive from some family members.

As we were able to see from the two contrasting cases of mothers who received high levels of support and mothers who mentioned only one or two sources of support,

socio-economic status and material resources played an important part together with the presence of husbands in influencing the range and experience of support.

Chapter 8 – Experiences of stigmatisation through the mothers' journeys of raising a disabled child in Cyprus

8.1. <u>Introduction</u>

According to Goffman's influential analysis, stigma is used to refer to the attributes which signal the difference in relation to an assumed norm, and it is mostly interpreted as something negative. If an individual receives negative information during social interaction, then the effect is the creation of *'a virtual social identity',* in comparison to what that person 'is', his or her *'actual social identity'*. As Goffman suggested, this 'stranger' which in the case of this study represents the disabled child, *'is reduced in our minds from a whole and usual person to a tainted, discounted one'* (Goffman, 1963: 12)*.*

The double perspective concealed in the notion of stigma that Goffman presented in his work, is used in the categorisation of the cases in the study. The 'discredited' children are regarded in the study as those whose type of disability is visibly apparent, whereas the 'discreditable' children are those whose 'differentiated condition' is not visible. It is possible for a person to experience stigma in both situations.

Stigma is described as a result of various negative behaviours and stereotypes. Researchers have found that stigma encourages fear or a lack of trust towards disabled people, or labelling, since people may characterise disabled people as 'sick' (Jones, *et al*, 1984). The people who are stigmatised are 'discrediting and become more consequential when marks are perceived as persistent and central in comparison to the social norm' (Koro-Ljungberg and Bussing, 2009: 1176).

The effects of stigma not only have a powerful effect on the stigmatised person, but they also contaminate, as Goffman (1963) highlighted, the other members of the family. He named those persons as 'wise', borrowing as he said the term. This concept of 'wise' people is analysed by Goffman in relation to the term 'own' persons. The two adjectives - 'wise' and 'own' - used by Goffman, cover the two categories of people from whom the stigmatised individual can expect some support, and 'are ready to adopt his standpoint in the world and to share with him the feeling that he is human and 'essentially' normal in spite of appearances and in spite of his own self-doubts' (Goffman, 1963: 31). The 'own' persons are the people who share the individual's stigma, people who by virtue of this are defined or define themselves as persons with a particular stigma. In the case of this study, 'own' people include other disabled children. In regards to the concept of 'wise' persons as Goffman states, these include those 'who are normal but whose special situation has made them intimately privy to the

secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded to a measure of acceptance, a measure of courtesy membership in the clan' (1963: 41).

Stigma does not affect only the people who endure it, but by 'courtesy', it affects other people or groups of people that are in close association with these stigmatised persons. Goffman's point was vital to this term as courtesy members are not the members who make themselves available to the individual that is stigmatised, but are the people who are accepted by this individual. The concept of 'courtesy stigma' which is regarded as the extension of stigma discrimination is related to the aim of the analysis in this chapter. Stigma also impacts the lives of people who are close to the stigmatised person, and that in this study, encompass the disabled child. Additionally, as Voysey argued some years later (Voysey, 1970), parents should be distinguished from this category as they are different from the other people that experience courtesy stigma, because they do not choose their situation. They are obliged in a way to accept this new situation and to support their child. And since the people who were closest to the disabled children in the study were their mothers, they are the 'wise' people in this study who experience courtesy stigma.

This chapter is related to the following research question:
- How is stigmatisation understood, experienced and coped by the mothers of disabled children?

As Link and Phelan (2001) rightly mentioned, stigma, especially following Goffman's definition, has been defined in different ways by different researchers. Stigmatisation is a notion that might be differently understood or misunderstood by people in general and, as I will explain, there is an additional possibility of it being differently understood by Cypriot people. As it has been said, the term 'stigma' [στίγμα] was originally adopted by the Greeks when they referred to unusual bodily features of a person such as cuts or burns, and that indicate that the person is one to be avoided (Bos, Kok & Dijker, 2001, Falk, 2001, Goffman, 1963). Christians later added two layers of metaphor to the term. Firstly, they mentioned 'bodily signs of holy grace that took the form of eruptive blossoms on the skin' and, secondly, 'a medical allusion to this religious allusion, referred to bodily signs of physical disorder' (Goffman, 1963: 11). Because of the fact that Cypriots are both Greeks and Christians[10], the possibility of understanding the question regarding stigma in different ways was highly relevant in this study.

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[10] Greek Cypriots formed 80% of Cyprus population and 90% of Greek Cypriots are Christian Orthodox

For this reason, mothers were asked directly and indirectly whether they have been stigmatised or not, and in the cases where their responses were positive, I asked them to describe an experience that they had faced. The questions asked were:

Direct question:
- Have you ever felt that you have been stigmatised as a mother of a disabled child?

    Indirect questions:
- How easy or difficult is it to include your child in your everyday activities?
- Have you ever felt that you were treated differently as a mother of a disabled child? What happened to make you feel like this?
- Have you experienced any changes in your relationships with people since your child was born?
- Have you ever felt alienated from the people you knew or met because of your child?

For this chapter, thematic analysis was used. Firstly, the aim was to identify the common issues raised in the mothers' accounts of their experiences and their mechanisms of coping with courtesy stigma. And second, through the inductive approach used, I sought themes that emerged from the analysis of the data, as well as the themes that were deduced from the literature, in order to explore mothers' views and actions (Braun and Clarke, 2006) (Appendix 6).

8.2. <u>Coping mechanisms and stigma</u>

The aim of the study was not to examine the definitions mothers gave the notion of stigma, but to understand how they experienced and coped with stigmatising behaviour. As Pescosolido (2007) and Koro-Ljungberg, Bussing (2009) highlighted, an accurate definition of stigma or an investigation of the factors that shape the various perceptions around stigma are not sufficient. Mothers in the study experienced the notion of stigma in various ways and in different contexts. Coping mechanisms as Skinner, Edge, Altman, & Sherwood, (2003) suggested, can be broad, specific and based on individual differences. There are various subtypes of coping across different measures and studies and according to the work of Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, (2001: 5) on coping with stress during adulthood and adolescence, coping mechanisms are 'leading to considerable difficulty developing a cohesive picture of coping in childhood and adolescence'.

In studies in other context, Corrigan reviewed mental illness stigma with a summary of the different ways that researchers developed, implemented and evaluated various anti-stigma programs. He emphasised on the low levels of self-esteem that stigma creates and robs people of social opportunities. Thornicroft *et.al.* (2009) on their cross-sectional survey in twenty seven countries about the nature, direction, and severity of discrimination that people with schizophrenia faced, they mentioned social exclusion and isolation. Those were common feelings and actions that mothers faced in this particular theme.

Mothers experienced stigma in the study in several contexts: family, school, employment and social networks. There were mothers who experienced stigmatisation in more than one context. However, they were only asked to recount one experience in detail, they provided answers in more than one context (Appendix 6).

It is important to realise that all of the mothers - the 'wise' people (Goffman, 1963) – had an experience of stigma to share. Through their narratives, five themes emerged concerning the mechanisms that they used: 'Helping or defending their child', 'Isolating oneself', 'By being proactive', 'Minimising stigma' and 'Normalisation. (see Figure 8.1)

An interesting outcome of this study was the positive and negative consequences that emerged from the ways in which mothers experienced and coped with stigma. As we will see in the following section, the indications show that the themes were directly related to the consequences, positive or negative (Figure 8.3), whereas there were no indications that there was a direct relation between the context and the consequences of coping with courtesy stigma.

Mothers who experienced courtesy stigma from their family networks, included members of their family, nuclear and extended. Mothers who described an experience that happened within the context of school mentioned that their children were stigmatised by teachers or parents within the school context. And thirdly, some mothers experienced stigma within the context of employment, in which they described stigmatisation from their employers, or were stigmatised in their attempts to find a job. Another context was the context of other social networks such as those they met at their children's afternoon activities or when they went to church.

In their narratives mothers discussed their reactions to these behaviours, that is to say, coping with courtesy stigma as it is termed (Birenbaum, 1970; Koro-Ljungberg & Bussing, 2009). The mechanisms that they used are (see Figure 8.1):

- Helping or defending their child: mothers had arguments and disagreements with people after they felt that they were stigmatised, or acted in different ways in order to protect their child

- Isolating oneself: mothers avoided visiting certain places where they felt stigmatised, and stigma influenced their access to particular places or their access to care. Some of the mothers coped with stigma by hiding and covering up their child's disability and their 'problem', and they detached themselves both physically and emotionally

- By being proactive and communicating their knowledge to other people about their child or about disability, and by volunteering in various organisations to do with disability

- Minimising stigma: by saying that there were worse situations than their own, comparing their child's disability to other children's disabilities, and by suggesting that their situation 'was not such a big deal'

- Normalisation: by interacting with families or mothers with similar problems, or with people familiar with and unprejudiced towards disability issues.
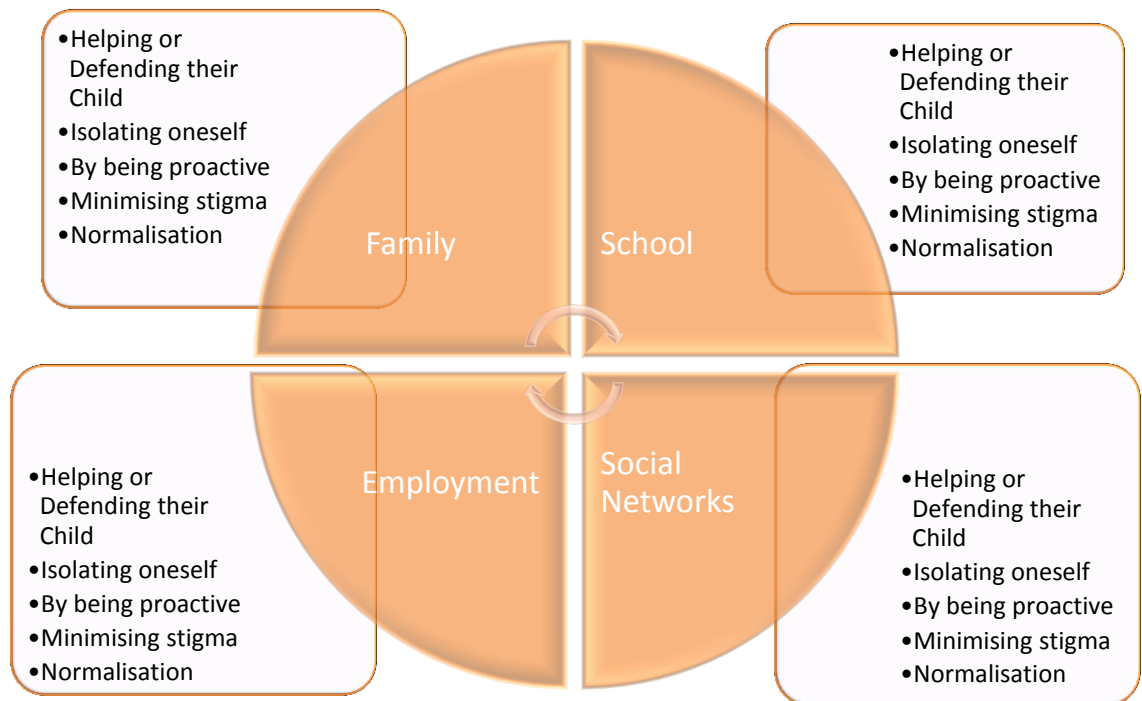

Figure 8.1 - Mothers' Context of Experience Courtesy Stigma and Coping Mechanisms

The number of mothers who mentioned mechanisms for coping with stigma is presented in Figure 8.2

From the analysis done in this chapter and from the themes developed on the basis of the mothers' frames of reference, their mechanisms of coping with courtesy stigma resulted in different consequences. For some mothers the result was positive, for others negative.

Figure 8.2 presents the positive and negative outcomes of stigma according to mothers' different mechanisms.

Mechanisms of Coping Courtesy Stigma and Consequences
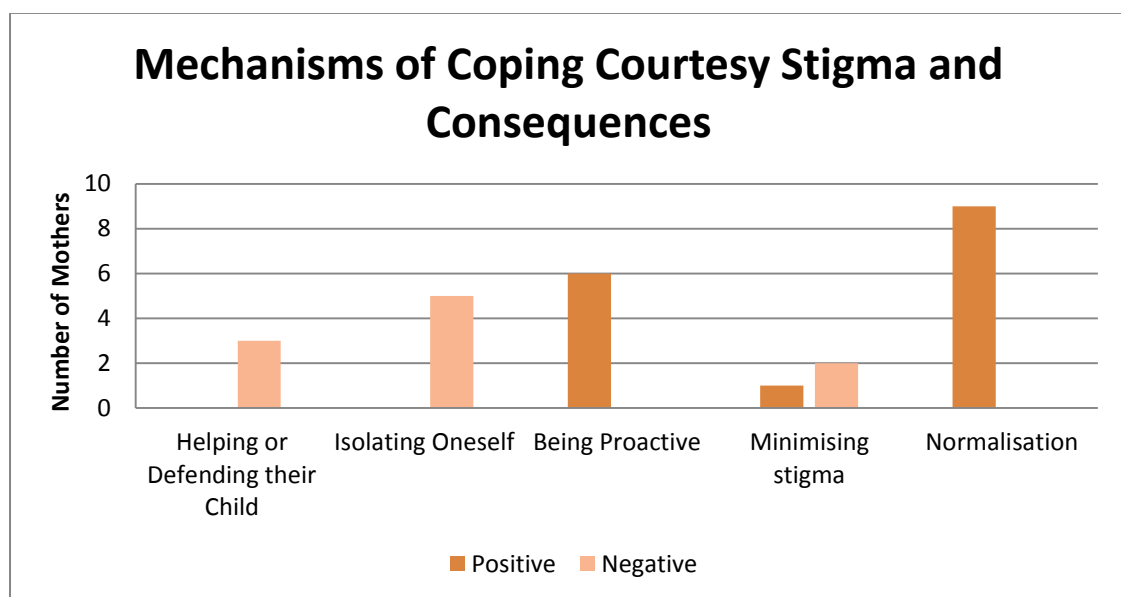
Figure 8.2 - Mechanisms of coping with Courtesy Stigma / Consequences according to the number of mothers described

Sixteen mothers who reported a positive outcome when experiencing stigma while nine out of twenty-five reported negative effects of courtesy stigma.

Mothers who coped with stigma with positive results in terms of making them feel positive were mothers who helped other disabled children or families with disabled children, or mothers who were volunteers in organisations or Parents' Associations for disabled children were six out of twenty-five. These mothers also normalised disability as they interacted mainly with families of other disabled children, or with people who adopted a positive attitude towards the stereotyping behaviours of people towards them and their children. Mothers who experienced courtesy stigma negatively described depression and social exclusion, or arguments with other people. Some mothers avoided certain places that they used to visit in the past, or who adopted

evasive behaviour such as hiding their child's 'problem'. The context in which stigma was experienced was not associated with negative or positive emotions. As shown in Figure 8.3, the contexts of 'Family' and 'Social Networks' were associated with both positive and negative ways of coping with courtesy stigma. The school context on the other hand, was only associated with negative experiences of and mechanisms of coping with stigma, while employment was only positive.

Context and Emotions of courtesy stigma
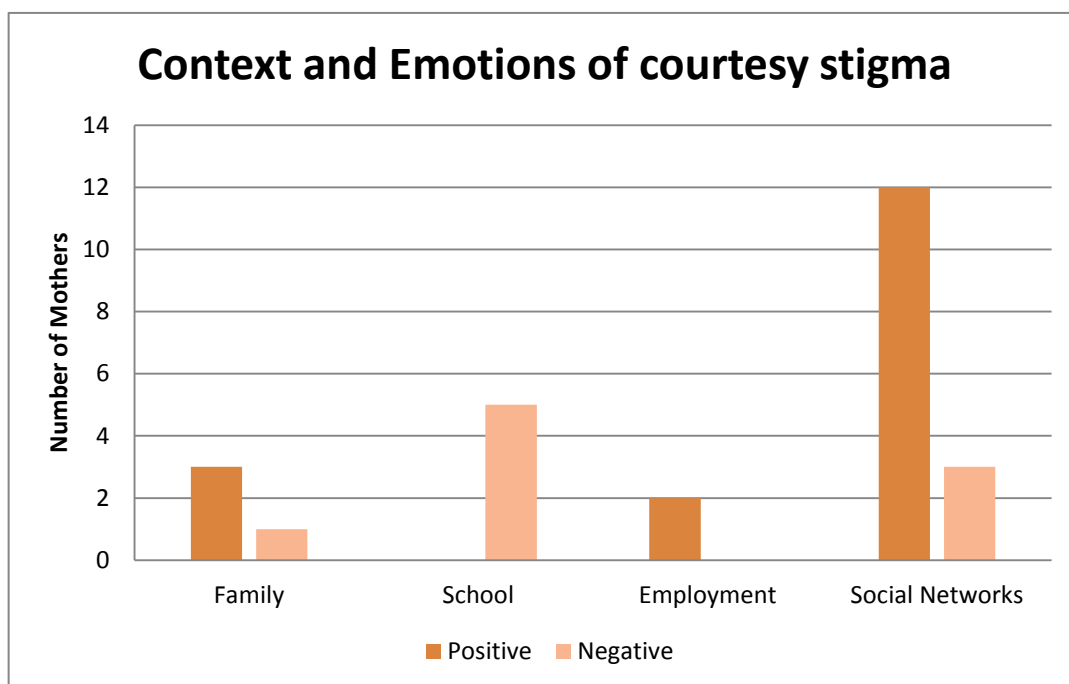
Figure 8.3 - Numbers of Mothers by the context of the stigma experiences

In addition, the context of 'School', a context that the 'wise' people in the study were not supposed to have direct interaction with as it was the children's context mainly, resulted in negative consequences for mothers, as they had arguments with educators or people interacting in that context of school, resulting in depressive feelings and reactions. On the other hand however, mothers in the context of 'Employment', a context where only mothers were present and not their children resulted in positive outcomes. In this context, mothers suggested that the difficulties and challenges that they faced in finding a job had empowered them and helped them to become more aware, and to reject any negative aspects of being a mother whose child had a disability. They said it also helped other people become more informed about disability. In the next section where I analyse the ways mothers reacted to stigmatised behaviours I provide relevant examples of the contexts that are mentioned above.

The types of disability were examined in relation to mothers' ways of coping with courtesy stigma. Sixteen mothers in the study had children with discredited condition of disability, a visible type, while nine mothers had children with discreditable condition, a non-visible type as categorised by Goffman (1963).

Figure 8.4 below, presents the relation between the type of disability and the ways in which mothers coped with stigma. The majority of mothers of children with visible or discredited types of disability (13/25) coped with courtesy stigma positively, whereas the majority of mothers with disabled children who had a discreditable type of disability (7/25) were negatively affected by the stigmatising behaviour of others. This suggests that visible appearance affects other people's responses to disability. Mothers of disabled children with visible or discredited condition of disability provided positive responses to stigmatised behaviours as they were used to stigmatised behaviours for example Y.O or T.X as we will see later. On the contrary, A.Mav or A.K. who had children with non-visible types of disability reported negative emotions for their coping mechanisms with stigma.
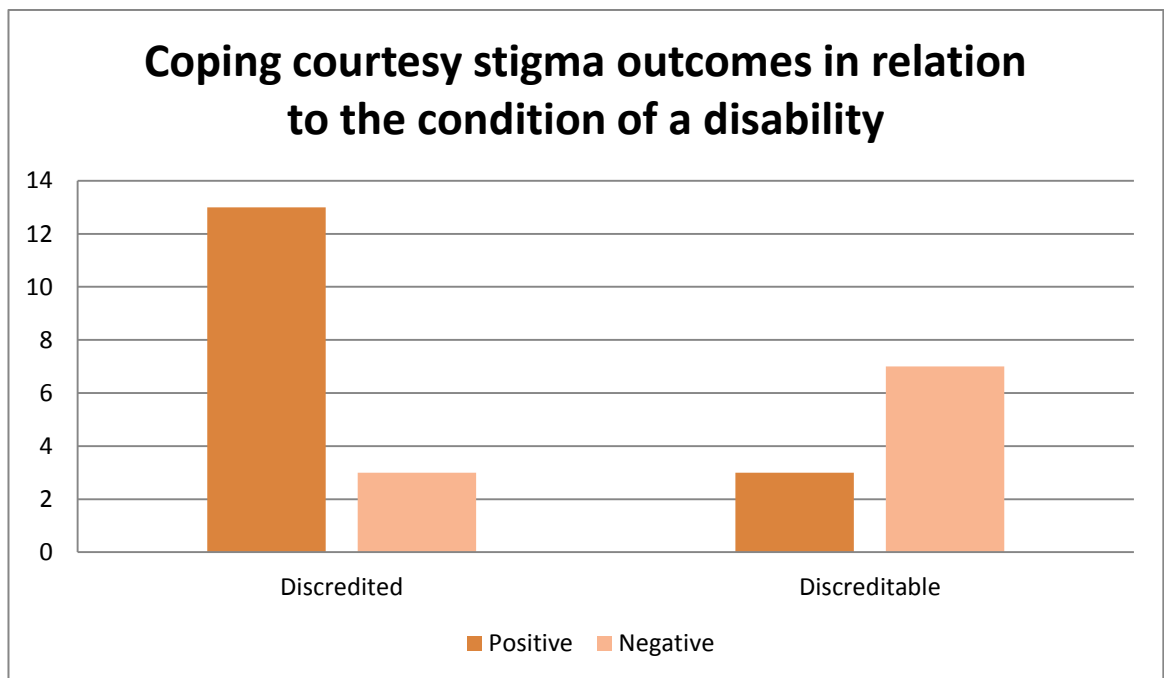
Figure 8.4 - Mothers' feelings by type of child's disability

In addition, mothers who attended church service reported experiencing stigma at church where they felt marginalised and excluded. Mothers' ways of coping with and responding to stigma are discussed below in details by providing relevant examples.

8.3. <u>Ways of responding to stigma</u>

8.3.1. Helping or defending their child

Three mothers out of the twenty-five (3/25) said that they coped with stigma resulting from their child's disability by being positive, notably by helping or defending their child. All three of these mothers (A.K., M.K., V.H.) mentioned that they encountered stigmatisation in the context of the school. These mothers tried to protect their children by standing up for their children's rights. V.H moved her child from the school he was attending to another school, in order to avoid any further stigmatisation.

A.K. (aged 53 at the time of the interview - child aged 22 with an invisible disability, Mild Mental Retardation), described an experience that she had with the 'specialists' that came to her child's school to assess her. The stigmatising behaviour the mother encountered included labelling of the child by the specialists on the day they visited the school to assess her daughter. They also asked her to move her child from the mainstream school the girl was attending at the time and to take her to an institution for 'children with special needs'. The attitudes that she encountered badly affected the mother, who went to the Ministry of Education to demand her child's rights. As she said, she demanded that her daughter had a Senco[11] teacher to help her while she tried to find ways to help and to protect her child in any way that she could.

> *…There they were, five women standing in front of my child telling her (my child) to write her name. My child was drawing circles instead of writing her name. They came upstairs and said "You know, your child is not capable of attending this school and you have to take her to the "Evangelismos" centre* [an institution for disabled people]. *I will never forget that day. I felt offended, I was a victim of stigma at that moment.*

M.K. (aged 45 at the time of the interview - child aged 7.5 with an invisible disability, Mild Mental Retardation) narrated a 'small story' (Bamberg, 2004) concerning an experience of stigma that she had in the past which happened at her child's school.

> [At nursery school, when the child was around 5 years old] *There was this particular mother ... well, at nursery school my child was a bit hyperactive and he sometimes touched or slightly pushed her daughter or pulled her hair. He behaved like this not only towards this child, but to other children too, but it was not every day behaviour though. I remember the incident almost as if it had happened yesterday. This mother would go to my child's school and argue with everyone, with the nursery teacher and with the head teacher* [about M.K.'s child]. *The head teacher kept explaining to her that my child was facing some*

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[11] Senco stands for the Special Educational Needs Co-ordinator - co-ordinates additional support for pupils with SEN and liaise with their parents, teachers and other professionals who are involved with them

difficulties and she asked her to show some understanding. The mother did not accept this, and demanded that the head teacher be more cautious and to pay more attention to my son's 'unacceptable' behaviour. I was very upset … I found another teacher and asked her whether we could move my child to another class as I knew that I could not put up with any more arguments with her. It was the best thing that I could do to avoid her and to protect ourselves [me and my child] and because if she continued I would have a proper fight with her for sure!

V.H., (aged 46 at the time of the interview – child aged 11 with an invisible disability, epilepsy with autistic characteristics) also faced stigmatisation in the school context, and in the end she moved her child to another school in order to help her child, after having unproductive arguments with many people.

I faced stigmatisation in the first years of primary school. My child did not have the type of disability that was obvious from the beginning, even though it was evident that he had not developed 'normally'. The teachers at his school could not see this. Anyway, his teacher would give him extra work that he hadn't completed during the lesson because, according to her, it was his choice not to participate during class! I argued with her so many times. She kept on giving my child extra work for homework. My son refused to cooperate as this was a normal reaction. At the end of the day, in order to protect my child, I changed his school.

All three mothers had children with invisible disabilities who faced stigmatisation in their schools and the mothers sought to protect their children from it.

8.3.2. Isolating oneself

Five mothers out of the twenty-five (5/25) coped with stigma experiences through isolating and detaching themselves both physically and emotionally from other people. All five of these cases reported negative consequences in terms of how they felt. Two of the mothers, (A.Mav. and D.D.) experienced stigma from members of their social networks; one (D.D.) at school, and the fourth mother (A.Y.) experienced stigma from her family, husband and the child's siblings. A.M. was the fifth case; she coped with stigma in the first years of her child's life through cutting herself off from other people but she subsequently changed her way of coping with stigma by talking to other people about what disability involves.

A.Mav. (aged 47 at the time of the interview - child aged 19.5 with a visible disability, Cerebral Palsy) emphasised that even up to the time when the interview was conducted, nearly 20 years after her son's birth, she was still not able to deal with people's judgemental attitudes:

I still can't manage this even today. I can't handle people looking at me and my child as if we are abnormal. My husband has overcome these judgemental attitudes, but I haven't. I can't take it when people judge me with their condescending looks and comments, as if we are not human. An example of

these experiences is when we attend church and we are frowned upon by people that know both of us very well! I could more easily accept this from someone that has just met us for the first time, but not from people that have known us since my son was born and see us again and again, or from when they push in front of us to receive Holy Communion, they show antipathy towards him, and it hurts me. Every time I go to the church I go home crying.

K.G. (aged 50 at the time of the interview - child aged 11.5 with an invisible disability, Mental Retardation), said that she stopped going out with her child because of the attitudes people had towards her and her disabled child.

I don't go out very often with my child, just in case my son has an accident and gets wet, as he has urinary incontinence, and then people will think that I am not a capable mother…this always makes me feel stressed so I prefer to stay at home.

Higher levels of stress were reported by both A.Mav and by K.G., as well as by D.D. (aged 31 at the interview - child aged 8 with an invisible disability, ADHD – hyperactivity and neurodevelopmental disorder) who experienced stigma at school. D.D. was rejected by the private nursery school where she went to register her child.

The first nursery school that we went to did not accept my son because they said that he was not ready as he had bad habits that might prove dangerous, such as swallowing dangerous objects. I felt very bad, it affected me a lot. When I went to pick him up he was shouting and I felt that people wanted to hurt my child. After this rejection I became depressed, I was not able to help either myself or my child.

A.Y. (aged 49 at the interview - child aged 11.5 with an invisible disability, ADHD and mild mental retardation) became depressed after experiencing stigma from her husband and her sisters:

They kept talking behind my back, and when I wasn't present, they gave my child food to eat that doctors said he should better avoid. I was in such a bad state psychologically and instead of helping me, they were prejudiced against me. My sisters and my husband thought that I was overreacting and that I was acting abnormally. But I was not! I had the doctors' recommendations that clearly stated what we should be doing. I was not doing very well and I became depressed, and after a while I filed for a divorce.

A.M. (aged 41 at the time of the interview - child aged 15 with a visible disability, Autistic Spectrum Disorder) highlighted that in the beginning her coping mechanism consisted in hiding the 'problem'. She said she felt depressed every time she faced stigmatisation within her social network. From the beginning she said she accepted that as a 'wise' person, she was never going to allow herself to experience stigmatising behaviour. But she also dealt with the problem by isolation. However, later on she overcame this and became active in a group for families whose children are autistic.

Up till the age of 6, wherever we went we had a problem, as my son could not sit still for a long period of time, he would throw everything off the table, and he would sit on the floor screaming and crying. Stigmatisation was obvious from the way people stared at us and whispered. In the beginning, I felt bad, as if it was my fault. They believed that we were different from them, and yes, I suppose we were. There were many times that we all stayed at home, or my husband went out with our oldest son, and I stayed at home with my other son. I was depressed. After all these years though, if we are now invited to go out, we will, because I don't care anymore. If I want to go out, I will, if you don't like us, don't look at us. I no longer have any inhibitions. On the contrary, I would say that I want to go out now and talk about autism, to inform people. This is why I registered as a member of Families with Autistic Children in Cyprus. People's glares and whispers will never stop; I now know that very well! It is my attitude that has changed, and this is the most important thing.

8.3.3. By being proactive

Six mothers out of the twenty-five (6/25) (A.M. included), used coping mechanisms for courtesy stigma by talking about their child's disability, or by interacting with other people or groups of people, in order to bring about awareness and in a way to avoid stigmatising behaviour and stereotypes. At the same time, they were mothers who were not afraid of or nervous to talk about disability. Within this theme, three mothers mentioned that they were members of volunteer organisations, which were mainly their children's schools' Parents Organisations.

Four mothers mentioned experiencing stigma in the context of social networks. T.X. (aged 47 at the time of the interview – child aged 20 with a visible disability, Agenesis of corpus callosum) said that she was not ashamed of her child and believed that acceptance and awareness are necessary when talking about disability, without hiding your problem or feeling depressed.

Oh yes… I experienced stigma… mostly in the past though, but nowadays too I would say that many people still look at us as if there is something wrong. In the past I would go and talk to these people, especially if they were younger people or children that were the same age as my child. I am not ashamed of my child and I am not trying to hide his disability. ...and if anyone asks me, I will talk about it. When you keep something like this to yourself it remains an unsolved problem, but if you talk about it, it will be resolved and you won't be affected by stigmatised behaviour. You have to accept it within yourself. If you don't, how do you expect others to accept it?

D.P.'s child had an invisible disability (mother aged 48 at the time of the interview; child aged 20, Mild Mental Retardation). The mother coped with stigma by talking about her child's disability. D.P. was also the president of the Parents' Association at her child's school. She said she faced stigma in her social network as well:

My child demonstrated a stubborn type of behaviour as a symptom of a malfunction of the brain. Every time we went out she would be stubborn, and she was insistent on getting whatever she wanted, the moment she wanted it. As people were not aware of her disability they just thought that she was a spoilt child and they spoke to me as if it was my fault. Each time, I had to force myself to explain to all these people why my child acted like this and that she had a disability. I still face this situation even today, since C.M.'s disability can be misinterpreted by people for two reasons, because of her appearance, and because of the lack of progress that she has made over the years.

C.H. (aged 43 at the time of interview – child aged 18 with an invisible disability, Cerebral Palsy in the motor sector and Quadriplegia) was the president at her daughter's school's Parents Association, and had the opportunity to talk to many people about disability, and to inform them about the services that are provided in Cyprus to families with disabled children. She was the 'wise' case who experienced stigma in her employment, and especially while she was trying to find a job where her work mates would be respectful of her own and her child's situation, as she said:

I had a lot of difficulties in trying to find the right job. When I say 'right job', I am not talking about the salary, but about acceptable interaction, behaviour and mutual respect. You may find employers that are interested in your qualifications, character or your communication skills, but when you tell them that you have a child with disabilities, their attitude immediately changes, not in a positive way but in a negative way. They believe that you will regularly ask for time off, well, this is what I understood. These are stereotypes of behaviour, and at the end of the day the only thing you can do is to accept that you are going to encounter them every day, and must just continue your life without letting them affect you. At the moment, I am trying to change things that I may have the power to, as I am the president of the Parents Association at the school my child attends, and I am trying to help her, because even though I have been stigmatised, I won't allow it to affect me in a negative way.

E.S. (aged 42 at the time of the interview – child aged 10 with a discredited disability, Cerebral Palsy and Spastic Quadriplegia) coped with courtesy stigma in the contexts of both employment and social networks using coping mechanisms of talking about disability and not allowing the situation to make her feel depressed. She also became a member of the Parents Association at her daughter's school.

I experienced stigmatisation at work because I should have been promoted, but I still have the same position that I did fifteen years ago. Due to the frequent overseas trips that we took in the past for our child's treatments, to America and to other countries, I did not get the promotion that I was eligible for. I don't mind though….

…and I don't mind if I lose any friendships because of my child's disability. What I don't like is all those people who stare at us every time we go out. I can justify this stereotype behaviour though because of the fact that they 'don't know'. I want to inform them, maybe not them but young children who are more likely to accept

a new situation and a different opinion. I have experienced children looking at us when we go out and my reaction was to go and talk to them, but their parents looked at me suspiciously. I am also a member of the Parents Association of my child's school, as I want to inform as many people as I possibly can.

Obviously experiencing stigma is not a desirable feeling. Mothers were disappointed as we saw from their accounts but those mothers coped with it with positive emotions after they experienced courtesy stigma. These mothers dealt with courtesy stigma by providing help and information to other people, in order to reduce the effects of stereotyping behaviours, or to avoid the judgemental attitudes from people who exercised them. D.P and E.S. were mothers that talked to children or young people about disability and inclusion and said they believed the younger generation was more 'willing to listen and to become aware'.

T.H. (aged 35 at the time of the interview – child aged 6 with a discredited type of disability, rare disease) mentioned stigmatisation from her parent-in-laws, who did not acknowledge their grandchild's disability. They came from a village, and according to the mother, they were people with a limited academic background:

When my child was born and they realised that there was a problem, the first thing they did was to ask me if during my pregnancy I had eaten something that had adversely affected me. When I told them that I hadn't, they then asked me whether I had some kind of a brain disorder when I was a child, because their son never had any kind of problem. I was furious, but there wasn't much I could do. They still blame me in a way for the late development of my child. For example, every time we visit them, they insist that my child has to hold both her knife and fork. But my child can't eat on her own, somebody has to help her! In the beginning I was very affected by their behaviour towards me, but now I just try to explain the situation to them. They will probably never understand, but at least I know that I have tried.

8.3.4. Minimising stigma

Three mothers out of the twenty-five (3/25) adopted the coping mechanism of minimising stigma. Having a strong belief that their children's disabilities were not 'such a big thing' and that there were worse situations to worry about, they managed stigma and stereotypes.

Koro-Ljungberg and Bussing (2009: 1185) quoted a mother's response to their study who said that her child's disability was not anything "*earth shattering*". Mothers in this study provided similar responses to his however some of them appeared to compare their child's disability to other disabilities or other children in particular as a way to cope with courtesy stigma experiences. There were mothers who compared their child with

immigrant children who were 'dirty and naughty' in comparison to their child. Two mothers compared their child's disability to other children who had disabilities.

Y.O. and K.K. were two cases of mothers who experienced stigmatisation in their social networks. They both had children with a discredited disability, and coped with courtesy stigma by minimising it. However, Y.O. experienced a positive consequence of stigma while K.K had a negative result.

Y.O. (aged 46 at the time of the interview – child aged 15 with a discredited disability, Cerebral Palsy an unofficial diagnosis) was a mother who was aware from the beginning of her child's disability and did not feel bad or ashamed about it. She had high self-esteem and she minimised her problem in a way that did not allow stigmatised behaviour to influence her. As she said, she felt good within herself and so she was not prepared to accommodate bad feelings:

> *'Sometimes I feel that people feel sorry for us. For example, yesterday we went to church, and we had only been inside the church for a couple of minutes when my son started shouting, so we had to go outside. From the time we had gone inside the church, I could see all these glaring looks of pity and people feeling sorry for us. I don't feel sorry for myself. Actually I am very proud of what I have accomplished, so I will not accommodate other people's feelings because I will not allow anyone to confront me with their own personal thoughts. I sense though that they probably feel bad for us, I mean they can see how I have to deal with this 'disaster' I have…'*

K.K. (aged 45 at the time of the interview – child aged 18 with a discredited disability, Spherical psychomotor growth retardation) emphasised that stigma was present in her everyday life. She struggled with the situation. But she compared her 'problem' with other people's situations.

> *I encounter stigmatisation every day. I will give you an example that happened yesterday. We went to the shopping centre with our child, as the temperature outside was very high and we had to go somewhere that was air conditioned. I was holding my child's hand while walking in the shopping centre, and who is taller than me, quite slim and handsome, and he was well dressed and looked very smart. There was nothing in his appearance that showed anything bad. However, people were looking at me as if I was walking with a monster or an alien. Yet there were two Bulgarian ladies with their children who were dirty and were behaving badly, and they were looking at us! I did not show it, but it hurt me, and when I went home I kept thinking all day about what had happened. I preferred to be in the situation that I was. My child was in a better condition than those of course.*

A.Kaz (aged 47 at the time of interview – child aged 20 with a discreditable disability, cerebral dysfunction and mild mental retardation) mentioned various experiences of

stigma, emphasising the context of school. Teachers and the Head Teacher of the school included her son in the special education lessons with disabled children that were from other countries and did not speak Greek. The mother believed that her son's 'problem' was not so severe as that of the other pupils because he was able to understand and communicate in Greek.

> *My child faced marginalisation and segregation at his school. The Head Teacher did not want to help me and I felt that they degraded both me and my child as they kept telling me that he was having special education lessons but in fact he wasn't, he was just in another class with some foreign children and he did nothing all day. I tried to explain that the other children were not in the same situation as my child, the only problem that the other children had was that they couldn't speak Greek and that my child only needed some special education lessons which wasn't so severe. They wanted special education lessons plus the fact that they were not able to speak our language! I became very angry, every day I went to the school to argue with the headmaster, but nothing happened.*

Both of the mothers K.K. and A.Kaz tried unsuccessfully to compare their children's situations with others' situation that they believed were worse. This coping mechanism did not help them though, because it had negative effects: the mothers got into arguments with other people or felt sad and tried to find explanations without getting any answers. On the contrary, Y.O., who believed that her problem was not actually a problem but a daily situation did not make any comparisons but did not take into consideration any stigmatised behaviours. Y.O.'s coping mechanisms can be understood under the next theme of normalisation.

8.3.5. Normalisation of disability and avoiding and ignoring stigmatising persons

Just over a third of mothers in the study (9/25) coped with courtesy stigma by normalising the behaviour of their children that provoked stigma and marginalisation and by avoiding and ignoring stigmatising persons. They tried only to interact with other 'wise' people, with families of other disabled children or with people familiar with disability. Notably, all these nine mothers felt positive. They experienced stigmatisation in two contexts, either in the context of family or social networks.

E.Si. (aged 50 at the time of the interview – child aged 10 with a discreditable disability, Mental Retardation) experienced stigma from her ex-husband who did not accept his child's disability and was prejudiced towards his ex-wife. E.Si got divorced in order to live 'a normal life' as she said by avoiding people that were stigmatising her even if this was her own husband.

Stigma… I don't mind experiencing it from other people, but I experienced stigma behaviour from my child's own father. During a difficult period in my life where I had to accept our child's disability, I had to experience my ex-husband's stigmatisation as well, since he kept confronting me about the way I was raising my child, and he would compare me to his mother's way of raising her children, and he degraded me many times. The result was that we got a divorce … at the end of the day I realised that having a person in your life that is aware of the notion of disability is better than living with a person who will never accept the child's disability, even if this person is the father of the child. I love my life and I have found a person that stands by me no matter what, and is happy because of the existence of my child. This is what I want, what I have always wanted. I did not mind. My child's disability for me was a normal condition and I got divorced since I wanted to continue my life as a normal life. Living with a husband that was not able to acknowledge his daughter's disability was not a normal life.

Y.K. (aged 42 at the time of the interview – child aged 9 with a discreditable disability, Epilepsy with mental retardation) also experienced stigma from within her family network, specifically from her ex-husband's relatives who did not accept her child's disability. Labelling and discrimination characterised their attitudes towards her, as the relatives compared the disabled child with their other grandchildren. In order to cope with this courtesy stigma experience the mother cut off relations with these relatives because she wanted to live her life in a 'normal way' as she said.

My ex-husband's relatives have never accepted the disability of our child and from the beginning they cut all ties with us. I did not care about them. I tried to interact with other people from school as I knew they would never degrade or label us. I was always open-minded and expressive, and looked at things from the 'actual' perspective. I have seen other mothers hiding or covering their children. I have never done this, we always go to birthday parties and socialise, and I have never allowed anyone to say that my child has special needs.

Both mothers were divorced and both mothers managed stigma with a positive outcome.

Furthermore, the other seven mothers in this group experienced stigma in their interactions with their social networks. Mothers emphasised the fact that they communicated mainly with people that also had disabled children or with people aware of disability issues. They justified this by saying that they did not have to explain anything to them, nor did they have to act differently, and that they could just 'be themselves'.

C.K. (aged 50 at the time of the interview – child aged 22 with a discredited disability, Cerebral Palsy), ended relations with people in her social network after the birth of her disabled son and stopped going to places that she previously went to, in order to be herself and to no longer pretend or have to explain anything: '*Today I interact mostly*

with other ['wise'] *people that have disabled children, because I feel that I can communicate better with them and at the same time I find their behaviour normal!'*

G.P. (aged 37 at the time of the interview – child aged 10 with a discredited disability, Aarskog-scott syndrome (unofficial diagnosis[12]) provided a very straightforward response to her coping mechanisms of stigma, saying that she refused to take any notice of these potentially stigmatising responses:

> *Ok, Listen. There will always be certain people who will look at you as if you are different compared to them, and probably feel sorry for you, as if you have asked for their pity. I don't mind, I don't pay attention to them, I will never interact with these kinds of people. I focus on my child and interact with my family who regard my child as a normal child and who lives a normal life. I am aware of the difficulties involved, but I won't accept marginalisation or pitiful feelings from anyone.*

K.E. (aged 50 at the time of the interview – child aged 19 with a discredited disability, Mobility disorder) talked about her decision to interact only with people whose reactions did not adversely affect her, and emphasised people's ignorance related to disability. Her response was 'not to care' about it:

> *Ok people who are not aware about disabilities exist everywhere. I remember once when I took my child to church and I could hear some awful people whispering … 'poor mum and poor child'… Ok, I am not going to die because some people were born without manners. I realise that they are not educated. So I don't care about them.*

L.S. (aged 50 at the time of the interview – child aged 22 with a disability, Chromosome syndrome – no speech, mental retardation) also talked about the stigma experiences she faced when she went to church and said that she ignored the way others stared at her and her child in public:

> *Church is a place where we face stigmatisation, and where we continue to be stigmatised every time we go. These people are simply not aware and they don't know what it's like to be different because they have never experienced this in their own families. But it's just a child, and even if you can see the difference that divides 'you' from 'us', just stop looking at 'us'! It is these kinds of negative stereotypes that I cannot accept, but I will continue going to church with my child, because I am doing this for me and for my family and I am trying to live a 'normal' life, even if they do not agree.*

An important outcome of the analysis of this chapter in general was the effect that church had on mothers and the stigmatisation mothers mentioned that they faced when they went to the church. Cyprus is considered as a very religious country, with the

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[12] A diagnosis given by people (specialised or not) without following an assessment

majority of Cypriot citizens being Christian Orthodox[13]. Every village or town has its own district church, to which many people go to in order to pray and to receive Holy Communion, every Sunday morning. The mothers in the study met people's negative attitudes when they went to church, or when their children behaved 'inappropriately'. Even though Church is the House of God, people's stereotyping of disability excludes mothers and their disabled children. The mothers in this study had different ways of managing this behaviour. There were five mothers from different themes that faced courtesy stigma whilst attending church. This link appeared to be a context were stigmatised behaviour exists and affects mothers of disabled children, and within this environment they developed feelings of disappointment and anxiety. Some mothers said they felt anxious and disappointed every time they went to church However, there were mothers such as Y.O., as they said, tried not to let stigma affect their daily lives and continued going to church.

M.S.'s (aged 33 at the time of the interview – child aged 9 with a discredited disability, Hemiplegia in legs and Cerebral Palsy) said that in the beginning she felt bad about stigmatising behaviour that she and her child experienced. However, she soon realised that she would not allow stigma to affect her life and she ignored the negative reactions of people, 'you get over it':

> *Have I been stigmatised? Oh yes… many times. Wherever you go there are people out there who are going to stare at you. Being different intrigues people, but in a negative way. There are people who take a step back and whisper something about you or your child. In the beginning I felt bad, but now I don't. We go anywhere we want. In the beginning, you're disturbed by it and you feel anxious, but then you get over it. I now say to myself, if they stare at me, so what?*

An interesting relation between the nine mothers under this theme was that of the different contexts. Two of the mothers whose children had a discreditable condition faced stigma under the context of their family networks, while the other seven mothers whose children had a visible disability did so within their social networks while interacting with people in the church for example or in social events, gatherings and other activities. Moreover, the experiences of stigma of all nine mothers in this group resulted in positive outcomes.

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[13] Christian Orthodox – 748 610/ Cyprus Population – 840 407 (Census of Population 2015, Statistical Service, Cyprus)

8.4.   Conclusion

The aim of this analysis was to investigate the ways in which the 'wise' mothers of disabled children in the study experienced courtesy stigma, and the mechanisms they used in order to cope with these experiences.

All twenty-five of the mothers in the study mentioned that they experienced stigma. Mothers reported experiencing stigma from family members, at their child's school, at the workplace, and in their social networks. Prejudice and marginalisation were experienced over the course of being a mother with a disabled child (Goffman, 1963; Koro-Ljungberg & Bussing, 2009).

The five coping mechanisms of mothers against stigma were visible in the four different contexts above. Some mothers' coping mechanisms produced or were associated with positive outcomes for the mothers, while others produced negative outcomes, for example feelings of depression and negativity.

Some mothers who were less negatively affected by stigma used coping mechanisms of avoiding and ignoring stigmatising persons and normalising disability. Others were proactive and took the initiative in providing others with information about disability or joined organisations set up to lobby for better conditions for children with disabilities in society. These mothers sought to provide help and information to other people with the aim of reducing stigmatisation. In this way they became members of parents associations and were not afraid to talk about their children's disabilities or about disability and inclusion in general.

The mothers who experienced stigma negatively were those who adopted strategies to 'defend their child' and had to isolate themselves from those who were the perpetrators of stigma. Some mothers sought to minimise disability and believed that their children's disabilities were not 'such a big thing'. Some compared their child's situation as being better than that of other (disabled) children, while some did not allow other people to confront them because they believed that their child's disability was not a problem. In this last group of minimising stigma, mothers tended to feel better about the situation.

The type of disability, which is related to 'discredited' and 'discreditable' types of disability was relevant to understanding how stigma is perpetrated (Figure 8.4 - more detailed in the Appendix 7). Whether a child's disability is visible or not influences people's responses and thus the coping mechanisms mothers adopted. Hence most of the mothers of children with a discredited condition of disability had positive outcomes

because their child's disability was obvious from his/her early years and they were used to stigmatised behaviours from the past, while the majority of mothers with children with non-visible disabilities were affected negatively because stigma isolated them from other people or caused depression and negative feelings.

The context in which mothers encountered stigma appeared not to be associated with how mothers felt: they were as likely to feel depressed as a result of negative reactions in different contexts as they were to feel positive. A mother who, for example, experienced stigma in her social networks was as likely to feel depressed as one who experienced stigma at her child's school or a mother who experienced stigmatisation from her family. These mothers coped by isolating themselves.

Furthermore, on the basis of the mothers' frames of reference, an important finding was that they frequently mentioned attending church as a context of their social networks. It was more difficult for mothers and children in some contexts, for example the context of church services which most families in Cyprus are expected to attend. Feelings of disappointment and anxiety characterised mothers within this context.

Chapter 9 – Conclusion

This study adds to the body of knowledge regarding the understanding of mother's feelings and experiences of raising a disabled child, their perceptions of support and their experiences of stigma. The findings of the study are important for the understanding of mothers and children's disability in the Cyprus context. The findings are consistent with the literature including that which exists in the Cyprus context. They provide a deep understanding of the research questions on mothers' own frame of references and they raise significant implications for further research.

This final chapter summarises and concludes the thesis. The first section discusses the results of the study in relation to findings from previous studies. The second section presents its contribution to theoretical knowledge. And the next section states the methodological limitations of the study. In addition, recommendations for further research are identified and some practical suggestions concerning mothers with disabled children are outlined based on the findings.

9.1. <u>Study results in the context of previous findings</u>

9.1.1. Research question 1: Mothers' feelings and learning about their children's disabilities: from the child's birth to awareness

To address the first research question, in Chapter 5 I analysed mothers' feelings and experiences concerning their mothering journeys from their children's birth until the time of their awareness of the disability including the diagnosis, whenever that happened and which varied considerably. The findings suggest that the mothers had negative feelings until the time of awareness, feelings which were similar to the different stages of grief, including feelings of shock, disappointment, stress and anxiety, anger as well as frustration and disbelief (Carbenter, 2000; Kubler-Ross, 1969; McCauley, 2010; Sicile-Kira, 2004). These findings are generally supported by the literature.

In the same chapter I analysed mothers' ways of learning about their children's disabilities. The findings of the different pathways that mothers followed were not found in the literature as this has not been a topic for research. Some mothers did not follow the medical route provided in Cyprus and went abroad at the beginning in order to get treatment for their child. Some were informed of their child's disability by a doctor straight after the child's birth. These mothers were aware from the beginning of the disability. Either they accepted the doctors' opinion and started therapies and

treatments in Cyprus or they did not accept the information or the diagnosis given and went abroad for another opinion. Mothers included in this pathway were mothers of children with invisible types of disability. What is found in the literature is that people with visible disabilities are more acceptable than disabled people with invisible disabilities (Gouvier *et al.*, 1991; Yuker, 1987). In the third pathway, mothers were not informed from the beginning about their child's disability. Some of these mothers asked for a second opinion in Cyprus but some went abroad for an expert opinion. Mothers who were unaware of any 'problem' in the first years of the child's life were found in the last theme. Mothers' in the study reported different turning points in their awareness of their children's disabilities. In the literature, the implications of not being able to resolve the loss entailed in coming to terms with a child's disability is referred to. Kaplan & Cassidy (1985), for example, exploring the intergenerational transmission of adjustment styles in families, highlighted such cases of mothers and found that they were at greater risk of depression later.

9.1.2. Research question 2: Support to mothers raising their disabled children – Formal and Informal

Chapters 6 and 7 addressed the second research question that aimed to understand the type of support provided to mothers through their journeys of raising their disabled children, the main support providers and the resources to which mothers had access. Mothers' accounts distinguished between the services and benefits provided by the state and by the voluntary sector and the support they received from the members of their family and from friends.

9.1.2.1. Formal Support

The first type of support was analysed and presented in Chapter 6. The state provides three sources of formal support; financial, medical and educational as presented also in Chapter 3. Mothers in the study mainly regarded support provided by the state in Cyprus as financial and the majority of mothers were not satisfied with the services provided: lack of sufficient income (divorce, lack of employment), lack of professionalism within the free state medical services which resulted in high costs of alternative private services, and insufficient financial benefits from the state for disabled children and their families.

These findings are supported by the literature, for example lack of income because of mothers non employment (Baldwin, 1985; Lewis, Kagan, Heaton and Cranshaw, 1999;

Heymann et.al. 1999; Scott, 2010); the high costs of services from government (Bourke-Taylor, et.al 2014; Dobson, *et.al.* 2001); insufficient financial benefits from the state for disabled children and their families (Slade *et. al.* 2009; Phtiaka, 2009).

Carers are included in the private-public mixed care system in Cyprus, as in other countries (Ytterhus *et.al*, 2008). Phtiaka, (1999b) argued that paid carers in Cyprus have an active role to play together with doctors and teachers. Mothers in this study, as we will see in the next section concerning the study's contribution criticised doctors and other professionals. Paid carers however were the only source of formal support that mothers in the study mentioned as helpful to them and their disabled children.

The voluntary sector was the other source of formal support provided to mothers. Mothers were not positive about it. The charity model that characterises the history of disability in Cyprus (Symeonidou, 2009) did not lead to mothers' satisfaction. Mothers in this study talked about the long and difficult procedures that the charities required them to follow and the low amount of benefit that was on offer. They judged that this was not worth the effort. Mothers who did not apply for or receive support from charity organisations were those who said they did not need it. Some considered that the money should be given to those in greater need then themselves. The findings suggest that mothers who received this type of formal support were mothers with a lower socioeconomic background.

9.1.2.2.   Informal support

Chapter 7 examined the provision of informal support. Four sources of informal support emerged that have been found in other studies. The first source of support was the emotional support mothers experienced from others, for example, understanding and encouragement (Burleson, 2003; Manuel *et al.,* 2003). Secondly, they valued in-home support with the care of their children and with household chores (see Burton-Smith *et. al.,* 2009). Third, they valued financial support, for example the provision of money for therapies or other needs (see Tétreault *et. al.*, 2014). The fourth source of support was respite care provided to mothers by family members or friends. This consisted in practical help and not just than just their physical presence (see Cowen & Reed, 2002; Chan & Sigafoos, 2000; Hartrey & Wells, 2003).

Husbands received most nominations from mothers as the people who provided them with support, mainly in the form of emotional help and practical help (see Erdwins, Buffardi, Casper, and O'Brien, 2001). This (emotional) type of support mothers said

made them feel happy and diminished stress and negative feelings (see Abidin, Jenkins and McGaughey (1992). Other studies have investigated the relation between the higher divorce among parents with disabled children, indicating the low support provision as a consequence of divorce (Risdal & Singer, 2004; Witt, *et al.,* 2003).

Mothers were asked about the support they received from their parents. The most common source of support mentioned was respite care which included practical support related to the disabled child. Most mothers mentioned their satisfaction with support from their parents and, as indicated in the literature, their support was associated with mothers' lower stress levels (Hastings 1997; Sandler 1998). Support from their mothers was especially highly valued (Hornby & Ashworth 1994; Glasberg & Harris 1997; Seligman *et al.* 1997).

The other children in the families were a further source of support, mainly emotional support, and were highly valued (see Finch and Mason, 1993). Children usually older or grown up were able to support mothers through their actions and attitudes which mothers mentioned and valued. On the other hand, there were mothers who mentioned no support from their other children. Some exempted children on account of their young age. Two divorced mothers relied on their older children who were acting as substitutes for the absent fathers absence.

Friends' support to mothers was another theme. Support from friends was highlighted in other studies (Shang and Fisher, 2014; Sipal and Sayin, 2003). Divorced mothers suggested that friends complemented the support they received from their husbands or substituted for other family members. Support from friends was mentioned by married mothers as well indicating that mothers overall were satisfied with the support they had from their friends even though they did not mention many sources provided by them for example financial and in-home support. Friends such as people with other disabled children were particularly valued as they were said to be able to understand and support them more than their family members and their contribution was highly estimated even though not mentioned in all the four sources of support.

Support from extended family members seemed to be rare. Some mothers said they had closer relationships with friends than with relatives.

The comparison between the two cases of mothers in section 7.3 show that the mother whose socioeconomic level was low was lacking support, mainly informal support, whereas the mother with a high socioeconomic level received higher informal support .

9.1.3. Research question 3: Experiences of stigmatisation through mothers' journeys of raising a disabled child in Cyprus and coping with stigma

Chapter 8 drew upon Goffman's approach to and analysis of stigma. Goffman's theory of 'courtesy' stigma and the term 'wise' were used to describe the 'normal' people who see the 'individual with a fault as an ordinary other' (Goffman, 2963: 41). The 'wise' are the people, the mothers of disabled children, who were in receipt of the experience of stigma as by 'courtesy' and were affected by it. As Voysey argues, mothers did not choose this situation nor did they have the option to reject it (Voysey, 1970).

The main finding of this chapter was that all mothers experienced stigma through their lives of raising their disabled children. Most mothers experienced stigmatised behaviours from their social networks (see Malacrida, 2001; Singh, 2004); from schools; from members of the extended family; and from employment. This position reflects to the social model of disability where the 'problem' lies within the society that is unable to provide their children the qualities of a 'normal' environment (Armstrong and Barton, 1999; Oliver, 1996).

Some mothers coped with courtesy stigma by being proactive and communicating their knowledge to other people about their child or about disability. Some coped by defending their children and taking issue with those who stigmatised them and their children. Some mothers coped by isolating themselves both physically and emotionally as a reaction to their experiences of stigma (see also Corrigan, 2004; Parle, 2012; Thornicroft *et. al*, 2009). Those mothers detached themselves and hid or tried to cover up their child's disability and their 'problem'. Others 'minimised stigma' by supporting that there were worse situations than their own and by comparing their child's disability to other children's disabilities (see also Koro-Ljungberg and Bussing (2009). The last group of mothers coped with courtesy stigma using 'normalisation' as they interacted with people familiar with disabilities and unprejudiced towards those issues. Outcomes from this study showed that some mothers' coping mechanisms produced or were associated with positive outcomes for the mothers, while others produced negative outcomes, for example feelings of depression and negativity. The results from the analysis of the chapter indicated that outcomes were related with the type of disability and the coping mechanisms that mothers used. Mothers who experienced stigma positively were not afraid to talk about their 'problem' and were proactive in order to inform people about disability and normalised their lives. The 'wise' mothers who experienced stigma negatively were the cases of mothers that adopted mechanisms to

defend their children, and isolated themselves from the perpetrators of stigma or minimised the disability. The context was not associated with how mothers felt.

9.2. <u>Contribution to knowledge</u>

This study delved into the world of mothers raising disabled children in the Cyprus context. The findings make an important contribution to knowledge, given the lack of research in Cyprus on families with disabled children overall and mothers in particular. A summary of the research findings was sent and shared with the mothers who contributed to my research as each mother provided an important source of knowledge and experience which together led to the accomplishment of the specific study (Appendix 8).

An important contribution of my study lies on the decision to focus on mothers' accounts, a group of people that have never been asked about their journeys as mothers of disabled children, in the hope of creating a stronger disability discussion in Cyprus. The concepts of disability and inclusion proved useful sensitising concepts, concepts that do not seem to coexist because, in practice, mothers lack formal support and experience stigma, while their children are not fully included in Cyprus society.

There was little evidence on mothers' satisfaction of the support provided by the state and by voluntary organisations in services that include the financial allowance for families with disabled children and services such as physiotherapy. Lack of satisfaction was expressed by mothers when referring to the support they received and disappointment with public services. Moreover, disappointment was expressed regarding the high costs that exist on raising a disabled child in Cyprus and the lack of information regarding services and supportive programmes. Negative was the response that mothers gave in regards to the voluntary support they receive. By contrast there was evidence of mothers' satisfaction with informal support, although only from friends, husbands, other children and parents of the mothers. The four sources of support that were mentioned by mothers, emotional support, in-home, financial contribution and respite care were the basic sources that mothers asked for and had support mainly from people within their social networks instead from the formal services. While Cyprus is a small society and kinship support is important this appears not to be the case for mothers with disabled children.

Another significant contribution concerned their medical help-seeking behaviour. Several mothers made frequent trips abroad to seek either another medical opinion or

in order to get treatment for their children. This resulted from the lack of trust in doctors and other professionals. Trips to Greece, Israel, UK and/or America, were mentioned. The mothers travelled either because Greece was close to Cyprus or because they believed that the professionals in those countries were more specialised in topics relevant to their children's disabilities.

The previous, leads to another not common contribution of the study from mothers' accounts was the criticism they kept on doing against doctors as well as against the government of Cyprus. Behaviour that was possibly came after the lack of support they had from both of parties and of the negative feelings that emerged after their 'cooperation' with the doctors and/or the people from the government. Island's history on disability as well as the fact that the current legislation for disabled children exists in almost two decades now, cultivates negative attitudes.

Regarding the concept of stigma, I have shown that mothers in Cyprus experience stigma by courtesy. Devaluation, prejudice and marginalisation as well as unacceptable behaviours were mentioned by most mothers in one context or another. Mechanisms for coping with courtesy stigma were related to the type of disability of the child. The relationship indicated was that whether a child's disability is visible or not influenced the coping mechanisms that mothers adopted against stigma. Most of the mothers with a discredited condition of disability had positive outcomes as their child's disability was obvious from their children's early years while most mothers of disabled children with invisible disabilities coped with stigma with negative feelings and expressions.

Last but not least, I find it important to note that this study has developed me personally and professionally. Mothers' accounts offered a welcome opportunity to ask many questions which challenged me as a 'special education' teacher as well as a sibling of a disabled child. I knew from early on that providing 'actual' support to mothers and families with disabled children in Cyprus is not an easy task. From the findings of this study I realise that I have to create my own framework for the provision of actual support to mothers. In the past I have had to present myself as a 'professional' among families that used to come to my school to ask for help and support. After the implementation of this study I have gained considerable insights into how to avoid being only a professional. In order to be trusted by them, I became more alert to the fact that I had to listen to them before I could offer support, support that will not only be seen as 'professional' educational support but emotional and practical as well.

9.3. <u>Recommendations</u>

Through listening to the voices of these twenty five mothers, the study produced some interesting results. These results have raised some recommendations for policymakers, practitioners and other organisations. Mothers, through their experiences and daily interactions with professionals encounter a variety of institutions whose policies and practices they were not happy. Their accounts suggest significant recommendations for change.

9.3.1. Public Policy

Legislation needs to be deconstructed and reconstructed in order for inclusion to be implemented successfully. In these terms, it is vital to make for example 'education for all' inclusive in practice as well as in theory. In any new legislation, there should be a collaboration of all interested parties and not only the Ministry of Education and Culture. The Mothers and Parents of disabled children, professors from the University of Cyprus, school teachers and other relevant organisations should be included in the discussions.

In all relevant contexts the definition of disabled children should be reviewed. From a critical analysis of the current legislation, definitions about disabled children and language that characterises them needs to be more inclusive as it uses notions such as 'special needs' and 'handicapped' which are not acceptable. All children should be included no matter what their level or type of disability. The world 'special' should be abolished in order for a gradual change of the minds of the society as well.

Last but not least is the necessity for the new legislation to indicate respect for the voice of mothers and parents of disabled children and their voices should be clearly stated as highly valued in the decisions for their children's future and development.

9.3.2. Support

Lack of satisfaction with formal support was evident among the majority of mothers/participants in the research. Mothers with disabled children highlighted the need not only for financial support but also for other types of support such as emotional and respite care. Mothers and parents more generally require emotional support from professionals to be available when needed. Public carers should be available to

provide respite care to disabled children in cases that need somebody to take care of their children.

Also, as has been found from the accounts of mothers, there is lack of information about disability and the services that are available. Social Welfare services for example, should inform parents about the rights and the services for them and their disabled children. Information regarding disability, disability organisations and associations that are able to offer support should be provided as well.

9.3.3. Educational System

Restructuring the educational system is a necessity in order to change the whole theory and practice around disability and disabled children. An inclusive society is central to democracy. Every teacher should implement inclusive practices to every pupil in his/ her class and in planning lessons. It is important that every special educator should work for every pupil as an individual and at the same time as equal to others.

General education should be provided to all educators from head teachers to school assistants about terms, policy, inclusion and practices with relation to disability. All educators should be listened to concerning the problems and difficulties that they face every day; recommendations should be taken into considerations and answers should be provided. The curriculum needs to be changed in order to be more flexible to adopt inclusive strategies. The number of pupils in mainstream classes should be reduced in order for every teacher to be able to give more time to every student. At the same time, links for inclusive practices and examples should be given to them.

9.3.4. Changing Attitudes

This study recommends the necessity of getting rid of language that is inappropriate and that creates stigma. The attitude that professionals know everything should also change. This is something that could happen if information was to be provided to every citizen, notably to mothers of disabled children who experience everything in first hand.

The results of this study strongly suggest every organisation and the society in general should reconsider its model regarding disability and adopt an inclusive approach based on the social model. In order for trust to be gained by mothers and families with disabled children, a social model should be implemented in every public service and in every practice relating to disability.

In addition, public hospitals should be equipped with more doctors in order for waiting evaluation procedures to be done more quickly and parents should be able to choose a doctor instead of having no choice. This would help prevent mothers being forced to go private or seek professional help abroad which is costly.

9.4. <u>Limitations of the Study</u>

Some limitations of the study concern design and methodology. I did not ask mothers to rate the satisfaction of the support they received. Based on open-ended questions I chose to focus on mothers' accounts and narratives. The use of a questionnaire may have added a further source of data that might have helped to address issues of social support.

On the other hand, it could be said that the vivid responses and in-depth answers of the twenty-five mothers that were interviewed gave a significant strength to the results. However, the small sample size is also a limitation. The results cannot be generalised to the population of Cypriot mothers. Although generalisation was not the aim of the study, nonetheless it offers some indications about the broader context of Cyprus which is indeed a small community.

The second limitation is the fact that I interviewed mothers only. Interviews with husbands, other children in the family and practitioners may have added to a more rounded picture of motherhood in the context of disability. I chose mothers because I wanted to give a voice to a very important group, the children's main carers, who has remained unheard.

Another limitation concerns the large number of mothers with disabled children older than 10 years old. Although the results of the study did not show that the age of the child was relevant to any of the research questions, it is unclear and hard to know if mothers of children younger in age may have different feelings and turning point experiences, perceptions of support and coping mechanisms against stigmatisation.

Finally, the disabled children in the current study varied considerably in their disabilities which may again be seen as a limitation. Sixteen out of twenty-five had 'visible' types of disabilities diagnosed, for example, with cerebral palsy or they were wheelchair users. The other nine had 'invisible' disabilities such as epilepsy or mild mental illness. The study showed some differences between these two groups. Results from earlier

studies reported the different feelings that mothers had according to their children's type of disabilities. Feher-Prout (1996), for example, in his study of family adaptation to the birth of a deaf child identified lower levels of stress and depression compared to mothers with disabled children with more severe disabilities. Hanson and Hanline (1990) in their longitudinal study of the feelings of mothers with disabled children, found lower levels of depression and stress in mothers with children with Down syndrome, a visible type of disability and higher levels of depression among groups of mothers of deaf children or children with neurological impairments such as cerebral palsy. Conclusions about the population in Cyprus of mothers with children with visible disabilities for example are not possible due to the different types of disabilities of the children in the study.

9.5. <u>Suggestions for further research</u>

The following discussion provides some ideas for future research based on the findings and on the limitations of the study.

Fathers of disabled children have a vital contribution to make (Nicholas, 1997; Meyer, 1995) and they have been neglected in this study and in the research in general. One consideration for future research should be to explore fathers' feelings and experiences from the birth of their disabled child until the time of awareness, the formal and informal support they receive and their mechanisms for coping with courtesy stigma. The results of a study of fathers should then be compared with those found in the current study.

The impact of disability among all the members of a family is of significance as well, such as for other children in the family (Fleitas, 2000; Flexman, Berke & Settles, 1999; Rossiter & Sharpe, 2001; Van Riper, 2000) or for grandparents (Hornby & Ashworth 1994; Glasberg & Harris 1997; Seligman *et al.* 1997). This research is lacking in Cyprus. A qualitative approach should be able to yield further insights into support patterns, experiences and management of stigma within the entire family. Additionally, exploring families as systems should be a way to understand mothers' accounts and roles better.

As mentioned in discussing the limitations of the research, most mothers had children older than ten years old. A qualitative research investigating mothers of disabled children of different ages should be able to examine the significance of the age of the child.

Generalisation was not an aim as I highlighted earlier. A larger scale research should provide some interesting results for the population of mothers with disabled children in Cyprus, providing insights into support provision. Designing a study based on the population of mothers of disabled children will contribute to the establishment of community support and from services and government.

In this study, the participants were required to have a child of school age (6-22 since disabled children are eligible to have extension in Cyprus) who was having a disability according to the Legislation for the disabled children in Cyprus (Ministry of Education, 113/1999). I could not take account of other factors in my research design although I tried to have as varied a sample as possible. Socioeconomic level, type of child disability, age of the mothers and marital status were not included specific requirements for the recruitment. From the findings however, a family's socioeconomic level and the type of disability of mothers' disabled children indicated some relationship with the support they received as well as to the experiences of stigma and the mechanisms of coping with courtesy stigma. Further research should use purposive sampling with the specific requirements in order to generalise the results.

9.6. <u>Conclusion</u>

Conducting research on mothers with disabled children in Cyprus was the focus of the study. Being a sibling of a disabled child, I always remember my mother trying to speak but nobody listened. The willingness to make her 'voice' heard was the motivation for undertaking this study.

This study adds to the body of knowledge regarding the understanding of mother's feelings and experiences of raising a disabled child, their perceptions of support and their experiences of stigma.

The study aimed to add to the body of knowledge on mothers with disabled children in Cyprus by examining three major topics: First, the study examined the feelings and experiences of mothers in Cyprus from the beginning of their disabled child's birth to awareness of the disability. Second, it explored the support that mothers received (or not) formally or informally. Third, it looked at stigmatisation and the mechanisms of coping with stigma in mothers' everyday lives.

Mothers' narratives were rich in providing information for analysis and discussion and they provided vivid accounts even though most had to go back many years (their

disabled children ranged in age from six to twenty two years old with the mean age of 16.25 years old). The use of thematic analysis provided a deep understanding of the lives of mothers with disabled children, their feelings and experiences, the support they perceived or not, and their lives in relation to the stigma associated with disabilities of their children.

Through this study a better understanding has been acquired of what it means to mother a disabled child in the context of Cyprus. A context with a long history of a charity model, with only one law concerning disabled children passed almost twenty years ago, and with theory and practice still very much in conflict among practitioners and services. By redefining the terms of disability and inclusion in the society, and by listening to mothers' accounts and providing them with what they 'actually' need, we may be able to positively change both theory and practice in Cyprus. Each mother in the current study, with her knowledge and experiences can contribute to this change. In a world full of general discourses about equal rights on disability and strong stigma discussion among disabled people and their families, change becomes a necessity.

The final words are taken from C.H, a 43 year old mother, divorced and unemployed at the time of the interview, with a disabled girl aged 18, diagnosed with cerebral palsy in the motor sector, quadriplegia:

> *Yes, I have divorced and I have no job. However, I wake up with a smile on my face… they are not problems, they are my reality. I live with them, I have accepted them. I am very well… my child made me strong and gave me confidence. What I can't accept is those people who have no idea how it is to be a mother of a disabled child, they believe they do and the worse thing is that they don't do anything to improve the current situation. Listen to us. Listen to us… Reality and needs have changed since the last legislation. How do you expect people's minds to change if you have stuck to the same legislation for 20 years now?*

Appendices

Appendix 1 – Interview Schedule

1ˢᵗ Stage

Information for the family – social network questionnaire			
(Mother)			
DATE:			
Time:			
Name			
Age			
Family type			
If divorced / widowed for how long?			
How many people do they live in the household?			
Who are they?			
Number and names of children in the family			
Ages of the other children			
Position in the family that the disabled child has			
Date of birth of the d.c.			

Education Level	Did not graduate high school	High school graduate	College graduate	University graduate	Postgraduate degree
Mother					
Father					
Current job of mother					
Employment hours of mother					
Current job of father					
Employment hours of father					
For how many days does the father work?					
Is mother's job permanent and full time?					
Is father's job permanent and full time?					
Have the income changed within the last years?					

Are there any other income earners in the household?	
(if divorced) Does the father contribute to this?	

Information for the disabled child	
Name of the child	
Type of disability	
Which school does he / she attends Get history of schooling chronology	

2ⁿᵈ Stage

NARRATIVE OF HAVING A CHILD WITH A DISABILITY AND MATERNAL EXPERIENCES AND FEELINGS

Narrative of becoming a mother of a disabled child

Describe to me **what happened when** your child was **born**. Was a unique feeling? Tell me the story.

If they do not mention: When did you find out about his/ her **disability**?
How did you feel then?
Did your feelings change?
Can you tell me a bit more about what happened and how you felt?

Tell me about your **experience as a mother of having a disabled child in his/her early years**.

Tell me about how if affected others in the family
      Child's father
      Other children in family
Effect on wanting to have another child.
How did things change as disabled child got older?

FAMILY RELATIONS AND SOCIAL NETWORK SUPPORT

Can you describe to me a **typical day** for you (if working describe a working day)
What about the **care** of your child?
In terms of physical care
Who is taking him/her to the school/services/afternoon activities?

What types of **support does the child's father** provide to him/her?

And to you (If not mentioned above)

Do you receive any **help from family and friends?**
Name people that disabled child has regular contact with

- **in the home**

- **with the child with a disability**

- **With your other children**?

What about at the **weekend**? How is the weekend different from the weekday?

How do you manage the household activities?
If the child is sick or has to stay home, who is taking care of him/her?
Tell me what happened the last time?

Do you think that you do more for this child **in comparison to your other children**?

Does his/ her disability make you feel differently about this child?
Are you closer to him / her than to other children in your family?
Do other children mind?
What is the relationship that his/her father has with the (disabled) child?
What do they do together?
Is he closer to him / her than to other children in your family?
Relationship with siblings
How easy / difficult is it to include your (disabled) child in family activities?
Tell me about this

If I ask you to **nominate the people that provide most support** to your child, whom would you mention?
ASK the same set of Questions for each Support person?
- Can you describe what support she/ he provides?

- How often?

How long on each occasion
- In what way do YOU find this helpful

- Any way unhelpful?

Experience of being a mother of a disabled child now

What is like being a mother of a disabled child in Cyprus and having the child live with you?

Have you ever felt you were **treated differently** in your community? as a mother of a disabled child?

Tell me what happened to make you feel like this?

Have you ever feel stigmatised as a mother of disabled child?

Do you feel your child is treated differently from other (nondisabled) children? Does this affect you?

Places that you prefer to go with the disabled child.

Have you experienced any changes in your relationships with people since your child was born?

> With family? Get stories
> with friends?
> With others?

Have you ever felt you have withdrawn from their company because of your child? Get story

SERVICES HISTORY AND PAST EXPERIENCE

Tell me about your contact with the services in the PAST because of your child, beginning with the first contact

When C was born?

Following that?

Which services?

Get story how felt as your relationship with different services developed – contact with doctors when child born and what happened after that?

Compare and contrast different experiences

Which **services** did you NOW have contact with for your d.c.?

Were any services you wanted but had no access to?

What was the reason you were denied access?

CHILD'S SOCIAL NETWORK

Does the child have **friends**? What are they doing together?

Does he have any friends there?

Do they visit or does your child visit them?

MOTHER'S VIEWS OF SOCIAL INCLUSION

Do you think your child is fully part **of Cypriot society**?

> Can you tell me why/ why not?
>
> How do you feel about this?

Do you feel he/she is fully a member **of her school**? (Is she participating in the school program as the rest of the students equally?) – Mother's feelings

If not mentioned: Do you find yourself as a mother or the disabled children are treated differently or badly?

3rd Stage

PUBLIC SUPPORT

What type of support do you receive from the government as a mother of a disabled child?

What other **types of support** does the government provide to you and your disabled child?

How feel about support provided by government?

What is your **opinion about charity organisations** such as "Radiomarathon"?

Do you receive support from this or any other organisations?

Is there any other voluntary **organisation that provides support to you and your disabled child?**

Is there any **religious** organisation that provides support to you and your disabled child?

Other questions – open structure

March, 2014

PARTICIPANT CONSENT FORM FOR RESEARCH

Dear participants,

My name is Antigoni Stylianou and I am a research student at the Institute of Education, University of London.

I am writing to invite you to take part in my research project for my PhD. The aim of my project is to talk to mothers of children with disabilities with the aim of investigating their situation and support in Cyprus.

If you agree to take part you will be asked to talk about being a mother of a child with a disability. The interviews will be completed at one or two meetings. With your consent, I will contact you in order to determine the place and date of the interview. Your participation does not involve any obligation neither by you, nor by your children.

The interviews will be recorded, transcribed and transferred to a secure computer. Your real name on the stored files will be changed and you will be given a different name in any reporting of the research. All other information regarding yourself, your child or any other member of your family that may be mentioned in the research will be altered so that you will not be identifiable. You can also withdraw from the study up to six weeks after the interview.

Your participation is vital to the accomplishment of the study, which I hope will create a deeper understanding about disability in Cyprus, and the experiences of those who care for children with disabilities. However, you participation is entirely voluntary.

For more information please do not hesitate to contact me at my number, 95185195 or my email address: goni_sty@hotmail.com

Kind Regards,

Antigoni Stylianou

Consent statement

By signing this document you consent to participate in the research.

You are not obliged to participate in the research and you can withdraw from the study at any time.

All of the answers you provide to me will be kept private. You should know that you have the right to see the results prior their presentation.

A copy of the consent form will be given to you.

I have read and understood the above and consent to participate

Name of participant _____

Age of participant   _____

Phone Number   _____

Email Address   _____

Home Address   _____

Signature   Date

_____   _____

Appendix 3 – Catalogue of the main Legislation Acts for disability in Cyprus [In Greek]

Σύμβαση ΟΗΕ για τα Δικαιώματα των Ατόμων με Αναπηρίες
Σύμβαση των Ηνωμένων Εθνών για τα Δικαιώματα του Παιδιού
http://www.childcom.org.cy/ccr/ccr.nsf/All/EC4B08A25498EE64C225746300267
0A7?OpenDocument
Σύμβαση της Διεθνούς Οργάνωσης Εργασίας αρ. 159
http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/All/A47315E7980A3E4DC2257AA100
48852B?OpenDocument
Οι περί Ατόμων με Αναπηρίες Νόμοι 2000-2007
http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/All/93E0AC1BD61BE111C2257AA100
47A3BF?OpenDocument
Ο περί της Διαδικασίας Διαβούλευσης Κρατικών και άλλων Υπηρεσιών σε
θέματα που αφορούν Άτομα με Αναπηρία Νόμος του 2006
http://www.kysoa.org.cy/kysoa/page.php?pageID=17&langID=13
Ο περί Καταπολέμησης των Φυλετικών και Ορισμένων Άλλων Διακρίσεων
(Επίτροπος) Νόμος του 2004
http://www.ombudsman.gov.cy/Ombudsman/Ombudsman.nsf/All/341F06F0809
843A6C22575B200444BBB/$file/Καταπολέμησης%20των%20Φυλετικών%20κ
αι%20Ορισμένων%20Άλλων%20Διακρίσεων%20(Επίτροπος)%20Νόμος%20το
υ%202004.pdf?OpenElement
Ο Περί Νοητικά Καθυστερημένων Ατόμων Νόμος 117/89
http://www.cpmental.com.cy/epnka/page.php?pageID=16
Ο Περί Πρόσληψης Ατόμων με Αναπηρίες στον Ευρύτερο Δημόσιο Τομέα
(Ειδικές Διατάξεις) Νόμος, Ν.146 (Ι)/2009
http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/All/5E5F3AD92A3FA954C2257AA100
466BA1?OpenDocument
Ο περί του Ειδικού Ταμείου του Κέντρου Επαγγελματικής Αποκατάστασης
Ατόμων με Αναπηρία Νόμος του 2000 και Τροποποιητικός Νόμος 102 (Ι) 2010
http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/All/F36D497467D94AD6C2257B44003
E8CEF?OpenDocument
Ο περί Παροχής Επιδόματος Διακινήσεως εις Αναπήρους Νόμος του 1980
http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/All/57271588CBA96B6CC2257AA100
47BBAA?OpenDocument
Ο περί Παροχής Ειδικής Χορηγίας σε Τυφλούς Νόμος του 2011
http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/06F37D2067C298D4C2257A7C002CF
E84/$file/N.11(I)2011_pdf.pdf
Ο περί Λαχείου Προνοίας Νόμος του 1992
http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/All/6A88404BEC1C790DC2257B4400
3249FC?OpenDocument
Ο περί Διαχείρισης της Περιουσίας Ανίκανων Προσώπων Νόμος του 1996
(23(I)/1996)
http://www.cylaw.org/nomoi/enop/non-ind/1996_1_23/index.html
Ο περί Προσλήψεως Τυφλών Εκπαιδευμένων Τηλεφωνητών στη Δημόσια και
Εκπαιδευτική Υπηρεσία Νόμος του 1988 (Ν.17/1988)
http://www.cylaw.org/nomoi/enop/non-ind/1988_1_17/index.html
Ο περί Σχολής για τους Τυφλούς Άγιος Βαρνάβας (Μεταβίβαση) Νόμος
(ΚΕΦ.168) http://www.cylaw.org/nomoi/enop/non-ind/0_168/full.html
Κανονισμός 61.Η δυνάμει του άρθρου 19 του Περί Οδών και Οικοδομών Νόμου
για την χρήση κτηρίων από ανάπηρα πρόσωπα

http://www.mcw.gov.cy/mcw/dbpd/disabledaccess.nsf/All/3BC82DF3DA86360BC22572A6004A620D

Οι περί Ελαχίστων Προδιαγραφών Ασφάλειας και Υγείας στους Χώρους Εργασίας Κανονισμοί του 2002 και 2004

http://www.mlsi.gov.cy/mlsi/dli/dli.nsf/All/452777F82089C055C2256E4D002551A9/$file/KDP%20174_2002.pdf

http://www.mlsi.gov.cy/mlsi/dli/dli.nsf/All/D9CA728A82D3FD4FC2256F3C003D5117/$file/KDP%20494_2004.pdf

Οι περί Ξενοδοχείων και Τουριστικών Καταλυμάτων (Γενικοί) Κανονισμοί του 1985 έως 2005.

http://www.visitcyprus.com/media/b2b_gr/Tourism_Services/Accommodation/Oi_peri_Xenodoxeion_kai_Touristikon_Katalymaton_Genikoi_Kanonismoi_tou_1985_kai_tou_2005.pdf

Οι περί Άδειας Οδήγησης Νόμοι του 2001 μέχρι 2012

http://www.mcw.gov.cy/mcw/RTD/rtd.nsf/All/48440FE4678BEBABC22578C50035CC8D/$file/N94(I)2001.pdf?Openelement

Οι περί Μηχανοκινήτων Οχημάτων και Τροχαίας Κινήσεως Νόμοι του 1972 μέχρι 2012

http://www.mcw.gov.cy/mcw/rtd/rtd.nsf/All/3E86D96E9921981DC2257824004BEB7B/$file/ΠΕΡΙ%20ΜΗΧΑΝΟΚΙΝΗΤΩΝ%20ΟΧΗΜΑΤΩΝ%20ΚΑΙ%20ΤΡΟΧΑΙΑΣ%20ΚΙΝΗΣΕΩΣ%20ΝΟΜΟΣ%20ΙΑΝΟΥΑΡΙΟΣ%202012.pdf?Openelement

Ο περί Έγκρισης Τύπου Οχημάτων Νόμος του 2005

http://www.mcw.gov.cy/mcw/RTD/rtd.nsf/All/278CDA2CD3A85808C225788D001EDC5F/$file/Type_Approval_N61_I_2005_160605.pdf?Openelement

Οι περί Αγωγής και Εκπαίδευσης Παιδιών με Ειδικές Ανάγκες Νόμοι 1999 – 2001

http://www.moec.gov.cy/eidiki/nomothesia/Nomothesia_N%20_13(I)_99.pdf

http://www.moec.gov.cy/eidiki/nomothesia/Nomothesia_N_69(I)_2001.pdf

Οι περί της Αναγνώρισης της Κυπριακής Νοηματικής Γλώσσας Νόμοι 2006-2008

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http://www.moh.gov.cy/MOH/MOH.nsf/0/94A15074C2FBD34742257909003C916D/$file/%CE%A3%CE%97%CE%9C%CE%95%CE%99%CE%A9%CE%9C%CE%91%20%CE%9F%20%CE%A0%CE%95%CE%A1%CE%99%20%CE%A4%CE%97%CE%A3%20%CE%9A%CE%91%CE%A4%CE%9F%CE%A7%CE%A5%CE%A1%CE%A9%CE%A3%CE%97%CE%A3.pdf

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Οι Περί Κέντρων Ενηλίκων Νόμοι 1997-2011
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Appendix 4 – Mothers' pathways towards awareness of their child's disability

Theme 1: Mothers who became aware themselves of the 'problem'	Theme 2: Mothers being informed of the disability of their child straight after birth	Theme 3: Mothers seeking a second opinion from another professional in Cyprus or abroad	Theme 4: Mothers being referred by a doctor or professional when child had physical or other problems leading to the diagnosis of a disability
A.Kaz	C.H.	A.K.	A.Mav.
K.E.	C.K.	A.M.	A.Y.
Y.O.	E.S.	D.P.	D.D.
	G.P.	E.Si.	K.G.
	H.S.	K.K.	M.K.
	M.S.	S.C.	V.H.
	T.K.	T.H.	
	A.Mav	T.X.	
		V.H.	
		Y.K.	

Appendix 5 – Support provided to mothers

Cases	Themes (People or organisations that provide support)					
	Husband	Parents	Other children	Friends	Charity Organisations	Carers
A.K	1	0	1	0	0	0
A.M.	1	1	0	1	0	0
A.Mav.	1	1	1	1	1	1
A.Kaz.	1	1	1	1	0	0
A.Y.	0	1	0	0	0	0
C.H.	1	1	/	1	0	1
C.K.	1	0	0	1	0	0
D.P.	1	1	0	0	0	0
D.D.	1	1	0	0	1	0
E.S.	0	1	1	1	0	1
E.Si.	0	1	1	1	0	0
G.P.	1	1	/	1	0	0
K.G.	1	1	0	0	0	0
K.K.	1	1	1	1	0	1
K.E.	1	0	1	0	0	1
L.S.	0	1	1	1	0	0
M.K.	1	0	0	0	0	0
M.S.	1	1	/	0	0	0
S.C.	1	1	1	1	0	1
T.K.	1	1	1	0	0	0
T. H.	1	0	/	1	0	0
T.X	1	1	0	0	0	0
V.H.	1	0	1	1	0	1
Y.O.	1	1	1	1	0	0
Y.K.	1	1	1	0	0	1
Number of cases	**21**	**17**	**13**	**14**	**2**	**8**

Appendix 6 – Themes of stigma experiences mothers' mentioned and theme dercribed

Code Name	Themes Mentioned					Theme Described
	Helping or Defending their Child	Isolating oneself	Minimising stigma	Normalisation	By being proactive	
A.K	1	1	1			Helping or Defending their Child
A.M.		1		1	1	By being proactive
A.Mav.	1	1				Isolating oneself
A.Kaz.	1		1			Minimising stigma
A.Y.	1	1				Isolating oneself
C.H.				1	1	By being proactive
C.K.				1	1	Normalisation
D.P.	1			1	1	By being proactive
D.D.		1				Isolating oneself
E.S.				1	1	By being proactive
E.Si.				1		Normalisation
G.P.			1	1		Normalisation
K.G.	1	1	1			Isolating oneself
K.K.	1		1			Minimising stigma

K.E.				1		Normalisation
L.S.				1	1	Normalisation
M.K.	1					Helping or Defending their Child
M.S.			1	1		Normalisation
S.C.				1	1	Normalisation
T.K.				1		Normalisation
T. H.					1	By being proactive
T.X		1			1	By being proactive
V.H.	1					Helping or Defending their Child
Y.O.			1	1		Minimising stigma
Y.K.			1	1		Normalisation
	9	7	8	14	9	

Appendix 7 – Type of child's disability in relation to mothers' positive or negative influences after stigmatising experiences

Code Name	Child with Discredited or Discreditable condition	Coping mechanisms	
		Positive	Negative
A.K	Discreditable		1
A.M.	Discredited	1	
A.Mav.	Discredited		1
A.Kaz.	Discreditable		1
A.Y.	Discreditable		1
C.H.	Discredited	1	
C.K.	Discredited	1	
D.P.	Discreditable	1	
D.D.	Discreditable		1
E.S.	Discredited	1	
E.Si.	Discreditable	1	
G.P.	Discredited	1	
K.G.	Discreditable		1
K.K.	Discredited		1
K.E.	Discredited	1	
L.S.	Discredited	1	
M.K.	Discreditable		1
M.S.	Discredited	1	
S.C.	Discredited	1	
T.K.	Discredited	1	
T. H.	Discredited	1	
T.X	Discredited	1	
V.H.	Discreditable		1
Y.O.	Discredited	1	
Y.K.	Discreditable	1	
		16	9

Discreditable			Discredited	
Positive	**Negative**		**Positive**	**Negative**
3	7		13	3

Appendix 8 – Letter to Mothers providing information for the results of the study

Dear mothers,

Thank you again for your willingness to participate in my study on the experiences and support that you have in your lives as mothers of disabled children in Cyprus. I greatly appreciate your willingness to meet with me and to share your thoughts and experiences which were very informative and useful.

This letter is written in order to inform you about the results that were the outcomes of your valuable responses. The main results are presented based on the three main research questions of the study.

Research Question 1: What are the experiences and feelings of mothers following the child's birth until the time of awareness or diagnosis of a disability?

The first research question resulted with the outcome of the feelings that you have had in the beginning of your child's birth until the time of awareness of his/her disability. A sense of shock was the main feeling mentioned by most of you. Disappointment, anxiety, happiness and excitement at the new life were some others. Based on the early experiences that you had in the beginning, going abroad for another opinion or for treatment was a common outcome no matter the economic status of the family. The initial years were the most difficult compared to the years that followed and lastly, acceptance of the disability was something that came with awareness of the child's disability or diagnosis.

Research Question 2: What kind of support did mothers have access to throughout their journeys of raising their disabled children, formal and informal? What support did they receive at time of interview and what were their assessments of support that they received?

The second research question was related with the type of support that you received. The type of support has been divided into support from the state, voluntary sector, carers, paid support (formal support) and support from husbands, parents, friends, other children, and social networks (informal support). Most of you reported more satisfaction towards informal rather than formal support and that the most support received was from your husbands, parents and friends. Lack of satisfaction from formal

support was justified coming from insufficient income, the economic crisis, the high cost of private services and the insufficient resources meaning that you highlighted the need for something more than financial support such as emotional support. Informal support sources included emotional support, in-home help, respite care and financial support. Socio-economic status and material resources played an important part together with the presence of husbands in influencing the range and experience of support.

<u>Research Question 3: How far did mothers experience stigmatisation related to their child's disability and how did they experience and cope with stigma?</u>

The last research question was an attempt to examine whether you experienced stigmatisation during your lives of having a disabled child and how you coped with it. The result was that all of you experienced stigma in various contexts, in the family, in the school of your child, in the environment of your employment and in social networks. You also used different coping mechanisms some of them providing positive and some negative impact on you. Positive impact had coping mechanisms of being proactive, in cases when you communicate your knowledge to other people and by volunteering, when you minimise stigma by saying that there were worse situations than yours and by normalisation in cases where you interacted with families with similar experiences or with unprejudiced people. Those of you who coped with stigma in negative ways had arguments and disagreements with the people that made you feel stigmatised or isolated yourselves by stop visiting those places and covering up or hiding your 'problem'.

Generally from the findings of the study, it has been concluded that medicalization and frequent trips abroad resulted from the lack of trust and disappointment in terms of the support from the public services and from the doctors and other professionals in Cyprus. The charity model that characterises the history of the island as well as the legislation for disabled children that is now almost twenty years old cultivates negative attitudes. Paid carers have an active role to play in Cyprus and positive accounts were reported about them in terms of informal support. Theory and practice concerning disability are still in conflict among practitioners and services in Cyprus. Through this study a better understanding has been acquired of what it means to be a mother of a disabled child in the context of Cyprus.

By redefining the terms disability and inclusion in the society and by listening to your accounts and providing you with what you 'actually' need, we may be able to positively change both theory and practice in Cyprus.

Each one of you with your knowledge and experiences can contribute to this change.

In a world full of general discourses about equal rights on disability and a strong stigma discussion among disabled people and their families, change becomes a necessity.

Once again, thank you so much for your time and effort that made this research study possible. If you have any questions or concerns, do not hesitate to contact me, it will be my pleasure to answer and discuss.

Warm regards,
Antigoni Stylianou

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