

THE UNIVERSITY OF HULL

**Exploring the Impact of having a Child with a Disability in
Saudi Arabia: Implications for Family Support Services**

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By

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Abstract

This study explores the impact of having a child with a disability in Saudi Arabia, with a focus on the challenges involved and the implications for the development of relevant family support services. A qualitative approach was employed for the study, using individual interviews and focus groups, with a total of 42 parents, both fathers and mothers. A total of twenty individual semi-structured interviews were conducted in Riyadh, the capital of Saudi Arabia, in Jeddah, its second largest city and in two rural areas. Three focus groups were also held in each city, two of which comprised four mothers and the third three fathers.

Data analysis suggests that having a child with disability often profoundly affects the perceptions of parents about disability, their feelings, and their way of life. In addition, many face particular challenges in relation to education, health care, regulations and the community. Finally, the study highlights that the current provision of services for people with disability and their families in Saudi Arabia is modest and that many parents lack awareness about the existing as well as potential services. Overall, the views of parents reflect the medical model of disability, which is also reflected in the position of Saudi Arabia as a whole, as illustrated by official policies. Religion and culture were found to be instrumental in shaping such attitudes and should therefore be factored into the design of related services.

The study outcomes suggest that the development of a more inclusive approach for these children will require the perceptions of disability to change among parents and the wider society. Education on disability with regards to religious and cultural issues, supplemented by the provision of appropriate services through family support services centres, can enable the development of awareness and knowledge to better meet the rights and needs of children with disability and their families.

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Table of abbreviations	
AIHW	Australian Institute of Health and Welfare
DCFS	Department for Children, Schools and Families
DDA	Disability Discrimination Act
EHC	Education, Health and Care
EI	Early Intervention
KSCDR	King Salman Center for Disability Research
MOE	Ministry of Education
SEN	Special Educational Needs
WHO	World Health Organisation
UK	United Kingdom
UNESCO	United Nations Educational, Scientific, and Cultural Organization
USA	United States of America

Chapter 1: Introduction

1.1 Introduction

Family support services have comprised an indispensable element of service quality since the mid-1980s in the USA, when the US federal government funded the Child and Adolescent Service System Programme (Stroul, 1996). Family participation is also perceived to be vital to service quality due to the significant role that parents and caregivers play in the lives of children with disability. The parents of children with disability are often able to assist through the provision of support, as well as playing an important role in service engagement and the delivery of the treatment that their children require (Friesen and Koroloff, 1990; Heller et al., 2007). The family has a greater impact on the well-being of children than any other single factor (DCFS, 2010b).

In the context of inclusive education, parents play a fundamental role, since they can be the advocates for ensuring their children's rights to education, as well as encourage and evaluate the process of inclusive education (Tisdall and Riddell, 2006). However, parents may require some degree of support to most effectively play their role in this process, especially in countries where progress towards inclusion is slow or even not widely available, as is the case in Saudi Arabia. In respect of human rights, inclusive education can be described as a system of educational reform that supports and welcomes the diversity of all learners (UNESCO, 2001).

It is possible that family support services may help to extend the experience of parents and make them more aware of the options that exist, empowering them to provide the

best quality of life to children with disability and overcome the challenges involved. However, the official provision of these kinds of services is currently limited in the kingdom of Saudi Arabia. At the present time, the first and the only centre offering specialised family support is situated in Jeddah. This centre, the ‘Saudi Association for Parents of People with a Disability’, was established in October 2010. Given the considerable size of the country, it will be a challenge to offer the comprehensive family support services that would meet the needs of the population with disabilities, particularly in more remote areas. Clearly, there are myriad factors that could potentially complicate the delivery of support and these need to be properly understood in order to encourage national development in this field.

1.2 Research Motivation

Having worked as a teacher and parents trainer in centres for children with disabilities in Saudi Arabia for four years, I have had the opportunity to deal with hundreds of mothers of children with disability. This experience informed my decision to study a master’s degree in the UK, in an attempt to develop myself and to contribute to the progress of Saudi Arabia in the provision of services for people with disability.

The dissertation that I undertook on this programme focused on an exploration of the role that mothers play in inclusive education in Saudi Arabia. The main findings of the thesis indicated that none of the participants understood the meaning of inclusive education and that neither the mothers nor officials believed in the value of inclusive education. A high level of misinterpretation was identified among the study participants, however the inherently limited scope of Master’s dissertations resulted in the findings failing to take proper account of the awareness of both parents and officials regarding the kinds and levels of services that they need (Alariefy, 2011).

It is worth mentioning that, working with children with disabilities and their mothers for five years in Saudi gave me the opportunity to touch some of the shortage in different levels in their life. This was a great motivation for me to study their needs in depth throughout this research.

As a female researcher in a conservative society where gender segregation is applied to almost all aspects of life and the domination is in favour to males, it was necessary for me to limit my participants in my Master's dissertation to mothers. Due to the absence of public transport, and the prohibition of women from driving in Saudi Arabia, all participants came from Jeddah, the city where I live. Therefore, in my PhD, I overcame the very real obstacle of transportation and was able to conduct interviews in two cities and two rural areas. Also I challenged the stereotype of the Saudi female researcher which expects women to interview only women, in my effort to increase the value of my research and to expand the scope of participants' involvement I interviewed both mothers and fathers within the constraints of the limitations set by society. This was not easy.

Since males dominate over females in Saudi, I have also needed to be careful with interviewing fathers by showing the right amount of my power such as knowledge in the topic. Indeed, I showed my gratitude for parents [both mothers and fathers] to help me in my research and also confirmed that we are as a researcher and participants collaborating to improve the situation of children with disability and their families in the Saudi society. In other words, my study relates to the ideas of activist research which focuses on "challenging inequality by empowering the powerless, exposing the inequities of the status quo, and promoting social changes that equalize the distribution of resources" (Cancian, 1993: 92). In activist research, the researcher is committed to supporting change within a particular community (Smeltzer, 2016). In

my study I was looking for a real change and improvement in the life of children with disability and their families in the Saudi society.

Successful activist research should highlight major changes in balancing power as opposed to improving services for the vulnerable group within the present power structure (Cancian, 1993). This research after presenting the voice of parents, it can be useful for parents, decision makers and services providers in Saudi in order to improve the life of children with disabilities and their families within the Saudi society.

This PhD study is considered to be a continuation of the research that I previously conducted during my master's degree. This specific subject has been chosen in recognition of the paucity of studies that have investigated the impacts and challenges faced by parents with children having disability in Saudi Arabia. This was the main motivation to conduct research, with the ultimate aim being to address the gap that currently exists in the Saudi context. In addition, little is known regarding the position of these parents with respect to family support services as a separate service in Saudi Arabia. This may be because the idea of family support is a relatively new phenomenon in the kingdom. As a result, this study offers a highly relevant and topical investigation of the ways in which this service can be improved and developed with respect to the particular needs of Saudi Arabia. It is also expected that the outcomes of this study will help to pave the way for future research and development in this field. Additionally, the findings of this project might assist policy implementation and play a critical role in guiding and empowering the parents of children with disabilities to learn about and then to more effectively utilise their rights.

Therefore, the aim of this study is to explore the impacts of having a child with a disability in Saudi Arabia, with a particular focus on the challenges faced by parents. The implications of these understandings on family support services in Saudi Arabia are also explored. The study seeks to act as an opportunity to map the way for Saudi to achieve suitable family support services in the near future, by taking into account parents' views and the cultural context of Saudi Arabia.

1.3 Research Questions

This study will address the following questions:

- What are the impacts of having a child with disability on the family?
- What are the challenges faced by parents who have a child with disability?
- What are the parents' views of family support services?

In order to address these questions with detailed, personal information, this research has adopted a qualitative approach. This enables the researcher to prioritise more intimate, in-depth data in an attempt to collect the personal insights of individuals that have first-hand experience of the subject matter.

Given that this research aims to explore the views of adults, my study adopts a data collection paradigm that holds that the fairest, richest data should be obtained by asking participants direct questions about their perspectives and insights (Plowright, 2011). The chosen data collection method is interviewing, which were conducted in two rural areas as well as in the two largest cities in Saudi Arabia, the capital city of Riyadh and Jeddah, a major port city 950 km to the west. I have chosen semi-structured interviews, both with individuals and focus groups. This approach seeks to maximise the quantity of data obtained from conversations with each participant,

giving them freedom to talk while ensuring that the direction of the conversation can be kept on appropriate matters.

The snowball sampling method was used to reach the 42 participants: 20 individual interviews and 6 focus groups, each comprising multiple members. The participants in my sample are mothers and fathers of children with disability.

1.4 Thesis Structure

Chapter One sets out the primary aims and intentions of the thesis and the research questions to be addressed, along with a preliminary explanation of the approach that was adopted.

In Chapter Two a review of the literature is made by presenting, explaining, and evaluating the findings from previous studies conducted on this subject. The chapter provides an overview and explanation of disability in general. It then addresses the literature about the families of the children with a disability in terms of what family means, why it matters, the impact of having child with disability, and theories about parental attitudes. The chapter finishes by discussing family theories and the kinds of support services that can be offered to such parents.

Chapter Three provides a description of the Saudi society with a particular focus on education and health care. It also attempts to shed light on the main welfare rights that exist for people with disability in Saudi Arabia.

Chapter Four outlines the specific research approaches and methods that have been applied to the study. In addition, a discussion is provided of the underlying research philosophy, outlining the relation between the methodological theory and the practical

aspects of the study. Finally, this chapter highlights the important ethical issues that have informed the research process.

The following three chapters, (Five, Six and Seven) present the findings from the fieldwork that was conducted in Saudi Arabia. The findings are organised into three chapters that present the main themes that emerged from the data analysis. Each of the chapters relates to each of the research questions: Findings A: The Impacts of Having a Child with a Disability on the Family: These issues include parents' perceptions of disability, parents' feelings, the impact of having a child with a disability on their family's way of life, and the positive impact that this experience can have on parents.

Findings B: Challenges Faced by Parents: this section explains the challenges faced by parents of children with disability. Four themes are discussed: treatment, education, regulations, and officials and community.

Findings C: Parents' Views of Family Support Services: this section presents the views that parents have of the family support services that are offered in Saudi Arabia, as well as those of other countries. A discussion is also provided of the kind of services favoured by parents.

Chapter Six discusses the meaning of the research findings and explains their value in light of the literature. It critically examines the findings and presents what has been learnt from the work.

The final chapter, Chapter Seven provides and justifies certain key recommendations to be made for children with disability in Saudi Arabia, on the basis of both the historical and current practices. A description is provided of key findings and the achievements of the current study, with reference to the research aims. This is

followed by a brief outline of the limitations inherent to this research and potential opportunities for future work.

Chapter 2: Literature Review

2.1 Introduction

The topic of ensuring universal provision of quality education has been recognised at the highest international level. This can be clearly seen during discussions of education and disability held in Spain, over 20 years ago:

More than 300 participants representing 92 governments and 25 international organisations met in Salamanca, Spain... All concerned must now rise to the challenge and work to ensure that Education for All effectively means FOR ALL, particularly those who are most vulnerable and most in need.
(Salamanca, 1994: iii)

This demonstrates a great interest in this area from the international governments and organisations, who took the time to meet in Spain to discuss the issue of education and its provision for all irrespective of ability.

After the publication of the Salamanca statement in 1994, a move towards inclusive education became obligatory for the signatory states, including Saudi Arabia.

The move towards inclusive education has been in the process of development for the past decade. More rapid progress has been made in developed than developing countries.
(UNESCO Bangkok, 2009: 12).

However, this progress is not reflected in the current reality of Saudi Arabian life in terms of either the governmental policies or the acceptance of individuals for inclusive education (Weber, 2012). Perhaps due to the fact that it is still a relatively new state, Saudi Arabia lacks support centres for families of children with disabilities that meet their needs and empower them to fulfil their role; the first centre was only opened in 2010, which is ‘Saudi Association for Parents of People with a Disability’.

In order to serve the families of children with disabilities, the associations that support them have to take into account their particular preferences. In order to understand these wants and needs, it is important to take note of the disability and the understanding that the families themselves have of it, as well as their individual needs, awareness and beliefs. Regarding family support services, it is important to ensure the understanding of family support and to consider the extent to which the preferences of families are compatible with the services provided in countries that have a relatively large amount of experience in the provision of support for families of children with a disability. Therefore, this chapter covers three topics: disability, the family, and family support.

Initially, a definition will be provided of inclusive education for more understanding; detailed definitions of disability, family, and family support will be given later. A discussion will be provided of the historical background of the rights of people with a disability, as well as the extent to which there has been movement from medical to social models. This is important as the disability models can be used to explore and understand the views of parents. The mothers and fathers in this research are referred to as caregivers in the context of family. In order to achieve the aim of this study, the importance of family will be underlined in the context of having a child with a disability. A discussion will also be provided of the impact of having a child with a disability and the needs that may arise from this situation. Highlighting the history of family support and the relationship between parents and professionals, will then enable the significance of family support services to be explored. A number of theories will be discussed in an attempt to facilitate a deeper understanding of the features of families and those issues that may impact on them. Examples of these include the Family Systems Theory, The Theory of Family Stress, and Adaptation and

Resiliency Theory. The final section of this chapter will discuss the types of family support services that are commonly available.

2.2 What is inclusive education?

Inclusive education is a term that can be defined in a variety of ways. However, the majority of publications do not give an explicit definition, instead leaving the reader to make their own inferences about the meaning of inclusion (Ainscow et al., 2006). A useful general definition might be the following:

Inclusive education means that schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions. This should include disabled and gifted children, street and working children, children from remote or nomadic populations, children from linguistic, ethnic or cultural minorities and children from other disadvantaged or marginalised areas or groups.
(UNESCO, 2003: 4)

This definition highlights the responsibility of schools to accommodate all children, noting that inclusive education should be a consideration for all children, rather than being limited to those with disabilities.

From a rights and justice viewpoint, it is part of the human rights movement towards social integration. Barton gave a broad definition for inclusive education:

Inclusive education is about responding to diversity; it is about listening to unfamiliar voices, being open, empowering all members and about celebrating 'difference' in dignified ways... it is about how, where and why, and with what consequences, we educate all pupils
(Barton, 1997: 233, 234).

While this definition talks about the education of all pupils, it does not mention schools; it refuses any limitations being placed upon inclusive education and gives a wide perception of this concept. That enables this definition to be applied to a society because of its broadness. It perceives the 'difference' as points of strength and positives that are worthy of celebration and respect.

A formal definition of this term was approved at the 48th Session of the International Conference on Education in 2008, based on the Salamanca Statement and Framework for Action on Special Needs Education:

An ongoing process aimed at offering quality education for all while respecting diversity and the different needs and abilities, characteristics and learning expectations of the students and communities, eliminating all forms of discrimination.
(UNESCO et al., 2009: 126).

The focus on inclusive education moved from the vision of inclusion as a state to seeing inclusion as an ongoing and endless process (Mittler, 2000). There is increasingly unanimous support for the idea of inclusive education, although there is still no universal agreement about the specific actions that ought to be taken to push this idea forward in terms of policy or practice (Ainscow and Miles, 2008)

It is difficult to identify a single perspective on inclusion within one country or school (Ainscow and Booth, 1998). Ainscow et al. (2006: 15) developed a typology of six ways of thinking about inclusion: the first of these is “Inclusion as concerned with disability and ‘special educational needs’”, the second is “Inclusion as a response to disciplinary exclusion”, the third is “Inclusion in relation to all groups seen as being vulnerable to exclusion”, then “Inclusion as developing the school for all”, and “Inclusion as ‘Education for All’”, the last one is “Inclusion as a principled approach to education and society”. There are a number of limitations with these conceptualisations, however, as the authors themselves highlight. For example, the first and second views serve to limit inclusive education to specific types of student, rather than ensuring provision for all, which is inconsistent the core idea of inclusive education. The third includes all vulnerable groups, but it focuses on the student and dividing them into vulnerable and invulnerable individuals in the education system. This division can potentially act as a barrier to the development of a broader view of

inclusion. However, this typology provides an indication of the link between inclusive education and disability, since the first one indicates inclusion is connected with disability and special educational needs.

In many cases, inclusive education can be understood as a term that is generally limited to the education of children with a disability (Ainscow et al., 2006). Even though, the meaning of inclusive education is typically much wider than this, the current research context concentrates on inclusive education for children with disabilities as this focus is related to my previous experience in the work field and to my master's study. As inclusive education is a core right for children with disability, it is necessary to provide a cogent definition of disability and an overview of the rights of those with disabilities throughout history, which reflect people's understanding of disability and the rights that people should be given.

2.3 Disability

2.3.1 Definitions of disability

Although the word 'disabled' is commonly associated with the image of a person in a wheelchair, a large variety of disabilities exist (Hume, 1994). Consequently, it should be unsurprising that there are many definitions of disability; one of the most popular of which is from the World Health Organisation (WHO), which identifies a disability as "any restriction or lack 'resulting from any impairment' of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1976: 8). However, as luminaries such as Helen Keller have demonstrated, the scale of achievement that people have managed to attain relates to the quality of achievement rather than the way in which it is achieved. Accordingly, the Disability Discrimination Act (DDA) of 1995 in the UK describes disability as "A physical or

mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities” (DDA, 1995: 2). The definition provided by the Equality Act 2010 is extremely similar:

A person ‘P’ has a disability if—
a- P has a physical or mental impairment, and
b- the impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities.
(EA, 2010: 4)

The DDA definition states three principles for defining disability: mental or physical impairment, which affects the ability to carry out normal day-to-day activities and the effect has to be substantial and long-term. However, it should be understood that what is meant by ‘normal’ day-to-day activities can vary by era, environment, or the needs of the person. In the context of Saudi, according to the King Salman Center for Disability Research (KSCDR), the Disability Code provides the following understanding of disability:

A person with a disability is one who is totally or partially disabled with respect to his/her bodily, material, mental, communicative, academic or psychological capabilities, to the extent that it compromises the ability of that person to meet his/her normal needs as compared to his/her non-disabled counterparts.
(KSCDR, 2000: 20)

In addition to the use of the word ‘normal’, which can be deemed unacceptable due to its vagueness and because it cannot be measured or evaluated, the Saudi Disability code omitted the stipulation for disability to be substantial and long-term in nature. Therefore, this research adopts the DDA definition. The language that is used in definitions is crucially important, not only because it shapes and limits meaning, but also because it illustrates the particular thoughts and beliefs at that time that it was coined. As Hume notes, “language is critical in shaping and reflecting our thoughts, beliefs, feelings and concepts. Some words by their very nature degrade and diminish people with a disability” (Hume, 1994: 3).

A debate also exists regarding the most appropriate way in which to identify people with disabilities. As an academic with disability, Oliver (1990) argues that the term 'people with disability' is a linguistic trick to negate the reality of disability and their struggles with governments and agencies. Oliver instead demands the use of the term 'disabled people'. This view defines 'disability' as a form of social oppression, rather than as a physical disability, meaning that individuals are disabled by society as opposed to their bodies (Shakespeare and Watson, 2002). Some activists have rejected this idea, however. Birke (1986) argues that persons are not simply disabled by society but that they have inherent impairments and that ignoring these will therefore necessarily entail ignoring a major part of their biographies. Shakespeare and Watson (2002) claim that most of the activists who advocate for the use of the term 'disabled person' in their campaigns do so in order to emphasise that their disability is from the society rather than because of their impairment. However, they argue that these activists are talking about "aches and pains and urinary tract infections" behind closed doors (Shakespeare and Watson, 2002: 6). Hume (1994) believes that the phrase 'disabled person' tends to send the message that the most important thing that is worth mentioning about a person is their disability, whereas the phrase 'person with a disability' stresses the person first, without denying the reality of their disability.

With deep respect to Oliver's opinion, as well as to the others who adopt the term 'disabled person', as well as ignoring a major part of the person with disability, namely their disability, and prioritising the disability over the person, the act of conceptualising the disability in 'disabled person' as being caused by the society may imply the existence of a conflict between the disabled and their societies. The term 'disabled person' suggests that the disabled constantly blame their society in causing this disability. This may have been more acceptable in the past, when the disabled

began to fight for recognition of their rights; however, nowadays, with the recognition of the rights of the disabled in most societies, I think that working in harmony and with consensus is a more efficient approach than one based on blame. However, this is often not the case in Saudi Arabia, as people with disability in the kingdom do not gain recognition of their rights, as will be clarified later. Indeed, agencies in Saudi Arabia, such as media and universities, view the term ‘disabled person’ as being inappropriate and therefore tend to avoid its use (Al-Jadid, 2013). Based on the above and in an attempt to make this study more acceptable to Saudi society, as well as making it clear to readers in Saudi Arabia which group of people I am focusing on, I have elected to use the term ‘person with disability’ in my research.

Despite the efforts to define disability, the interpretations that families have are useful as a reflection of the societal attitudes toward people with disability (Ferguson, 2002). The language of a society may give an indication of its attitude. Since the families of children with disability are a part of their society, it can therefore be expected that they will adopt the same attitudes of the community, which can be inferred through the vernacular phrases that are used. Some societies use terms that reflect undesirable perceptions, such as crippled, lame, invalid, retarded, and moron, all of which suggest inferiority of the subject, or evoke pity or fear of the person with disability (Roush, 1986). Supporting this position, Graham (2006) argues that terms such as cripple, lame and invalid may have been acceptable in the past, but are now considered to be insensitive and hurtful. Graham adds that terms like handicap and handicapped should also no longer be used unless in citation for laws. This evolution of terms can result in confusion regarding the correct ways with which to describe individuals. For example, research suggests that efforts by the British government to define ‘disability’ have not completely addressed confusion among parents regarding ‘disability’ and ‘special

educational needs', and whether or not these terms apply to their children (Lewis et al., 2007).

Besides the definition of disability, it can be useful to understand disability through a review of the evolution of the concept through time. In any society, the current concept of disability will necessarily be the result of accumulations and developments that have arisen from previous understandings.

2.3.2 Historical background

People with disability and the rights to which they are entitled have passed through difficult times such as oppression, marginalisation or segregation. The ancient Greek treatise, *The Republic*, provides one of the earliest known discussions of this topic, stating that "those who are diseased in their bodies they will leave to die, corrupt and incurable souls they will put an end to themselves" (Plato, 360 B.C.: 200). This demonstrates a clear neglect for people with disability during Plato's time, in terms of the culture of that region. Myriad differences have been observed between cultures in respect to people with disability, with individuals with disabilities being rejected in some cultures, like India; exiled, as occurred in some Greek city states in the sixth century; or kept alive by their families, but perceived as economic burdens, as occurs in some Eskimo communities (Hanks, 1948). In some cultures they were tolerated and treated in incidental ways, such as in Northern Blackfoot of the North American Plains, whereas other cultures have long respected people with disability and have given them the right to fully participate in society to the full extent of their capability, as is the case among the Bathonga, a group of tribal units living in Portuguese East Africa or Natal (ibid).

In the Western world, during the 17th and early 18th centuries, people with disabilities were normally rejected from society and did not have the right to participate in life (Barnes, 1991). They were often hidden away and could even be disowned by their families, eventually being allowed to die because the means to properly support a person with disability were rarely available (Fleischer and Zames, 2011). This seemed to be the survival of the strongest. However, in Arab countries, justice for people with disability can be traced back as far as the seventh century. One of the most famous Islamic stories tells of Allah admonishing his Prophet Muhammad, because of how he treated a blind man. People used to consider the limping and blind people as being repulsive, leading them to avoid sharing food with them (Al-Jadid, 2013). When Prophet Muhammad was busy inviting some highly positioned men to Islam, a blind poor man approached the prophet and asked him a question about Islam. Muhammad turned his head and did not answer the blind man's question because he was busy with the other men. In the holy Quran, this is written as follows:

-1- The Prophet frowned and turned away -2- Because there came to him the blind man, [interrupting]. -3- But what would make you perceive, [O Muhammad], that perhaps he might be purified -4- Or be reminded and the remembrance would benefit him? -5- As for he who thinks himself without need, -6- To him you give attention.

Allah's castigation of his prophet, Muhammad, can still be read from the holy Quran today. At that time, the instructions from the holy Quran and the prophet Muhammad, were sufficient to create an inclusive community in the Hejaz region of the Arabian Peninsula, which contains the city of Jeddah. This community was compatible with the needs of life at that time, which did not have the complexity of requirements and luxuries as modern society.

In the era of the Umayyad dynasty (662-750AD), which began in the Hejaz region and expanded as far as Andalusia in Spain, there was an organised renaissance regarding

the care of people with disability. Caliph al-Walid bin Abdul Malik, appointed a server for each person with physical disability and a leader for each person with visual disability. Later, one his successors, Caliph Omar bin Abdul Aziz decreed that the number of people with disability in the Umayyad state be counted. The State Treasury was also responsible for the expenses of people with disability at that time and hospitals were built for people with mental disabilities (Hamed, 2007). Over time, with the disintegration of the strong Islamic State, these privileges eventually disappeared. Perhaps one of the reasons for stopping such a service was the absence of its creator, since the support was established by the Caliphs, rather than because of the pressure from the families of people with disability.

In the Western world, the 19th century saw a very slow movement towards the rights of people with disability and their families. In the 1850s, reformers began to open large institutions for people with severe learning disabilities, which were very popular for almost a century (Leiter, 2004). This created complete segregation for many people with disability, with their families having little choice except to leave them in those institutions in order to enable them to benefit from the services that were being offered. Professionals, such as doctors, educators, social workers, and psychologists typically advised families to put their children in either a state or private institution, as it was generally believed that these specialised centres would be better able to provide the care required by children with disability (Skarnulis, 1979; Trent, 1994).

Disability also came to the forefront in the 1930s, with the inception and spread of the euthanasia movement around the United Kingdom and the United States. This approach to disability was inspired by Nazi doctors, who executed two hundred thousand people with disability because of their physical and mental impairments (Fleischer and Zames, 2011). Looking back at the situation in the nineteenth century it

seems evident that people with disability were perceived as being a burden on their families and their communities. In addition, the desire to isolate them from society and limit their numbers were common and even dominant views, to the extent that euthanasia was accepted. However, from the second half of 20th century, the development of services and support systems for people with disability experienced a profound shift, from taking those with disability from their family and leaving them in institutions, to empowering the same individuals to participate in society by working and living like any other citizen (Braddock, 2002).

2.3.3 Disability models

An examination of the historical perceptions of disabilities suggests that there has been a shift of emphasis from the individual to the social, which has enabled a wide-ranging critique of the ways in which society views people with disability (Priestley, 2003). This has led to the development of various disability models, to describe and understand the presence of different attitudes with regards to disability (ibid). The models are a way of conceptualising a situation.

The focus of the medical model has classically been on diagnosing and attempting to cure disability. In this model, a disability was regarded as a tragedy (Johnstone, 1998; Marks, 1998). In order to meet this objective, this model divides people with disability into categories and gives them labels according to their diagnoses and abilities. According to this model, services and support were aimed to 'fix' the individual and to eliminate the disability. In the medical model, it is not the responsibility of the society to adapt to the potential of a given individual (Oliver, 1996). Professionals isolated each behaviour or syndrome in the most positive way in order to study it, typically through examination, in controlled settings, such as hospitals or clinics

(Mary, 1998). In this model, there is a focus on what was needed to 'fix' the person with disability, often through instruction from physicians, which was motivated by developments in science and medicine (Turnbull and Turnbull, 1990).

Some went beyond this stance and linked disability with punishment from God (Thornton, 1987). This view may be old and may still be believed by superstitious people, by those who have a simple view of causation, or those who believe in fatalism (Sandow, 1994). However, it is almost certainly a much rarer belief in the modern world (Avoke, 2002).

During the mid-twentieth century, there was a deviation from the medical model of disability, with the shift moving towards the view of disability within a societal context. The medical model was gradually replaced by the social model, known as 'the big idea' in the UK (Hasler, 1993). In this model, social context plays a crucial role in understanding the disability, meaning that the environment has to be reformed (Marks, 1998) and societal barriers have to be fixed or changed, rather than the individuals with disability (Braddock, 2002; Shakespeare, 1997). The social model places the duty of supporting those people with a disability on the community, in terms of both the physical environment and general social behaviour (Brandon and Pritchard, 2011). Marchant and Jones (1999) think that many of the difficulties facing people with disabilities arise due to society's beliefs, the arrangements of services and the behaviour of adults. Many studies emphasise the importance of news media in the social construction of reality (Gamson, 1992), as well as in the induction of societal worldview of any matter (Cohen and Young, 1981). In fact, Haller et al., (2010) go so far as to argue that the news media act as an obstacle for inclusion, since reporting typically presents disability in relation to the medical model. However, in the modern context, the service system has evolved and people with disability and their families

are no longer viewed as needing to be fixed, instead needing to be supported (Samuel et al., 2012).

Ultimately, in the Western world, the beginning of the provision of systematic services for people with disabilities was considerably later than the renaissance in the Umayyad era in the Arab world, which took place in 662-750, whereas the first special schools in western world opened in the 1700s (Adams et al., 2007). However, unlike Umayyad's renaissance, the western beginning continued to form and improve until this day. In contrast, the situation in the Arabian Peninsula, which is now Saudi Arabia, did not provide any systematic services until 1960, when the first school opened for people with visual impairment (Almosa, 2007). Regarding family support, the push towards recognising the role of the family of children with disability and ensuring the provision of support has resulted in the steady growth of provision of services for people with disabilities in the Western world. In contrast, the position in Saudi Arabia is more limited, with the first independent centre to support families of people with disabilities only opening in 2010.

However, in order to be in a position to discuss the topic of family support, we need first to identify what is actually meant by family and to then underline the important issues that can relate to family support.

2.4 Family

2.4.1 Family Meaning

'Family' has no fixed definition, serving as "both an ambiguous and emotive" term (Hill and Tisdall, 1997: 65). In most parts of the world, the stereotypical family comprises two married people, of opposite sexes, with children; the mother is a

housewife and the father goes to work (Roll, 1991). Despite this picture of a traditional family being the reality in many countries for many years, it is now becoming out-dated in many places around the world. A large number of types of family exist, sometimes without any blood relation, and so the term has been interpreted widely by some academics:

Families are big, small, extended, nuclear, multi- generational, with one parent, two parents, and grandparents. Live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. A family is a culture unto itself, with different values and unique ways of realising its dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighbourhoods, communities, states and nations.

(Winton, 1990: 4)

The importance of family not only depends on its form, but also on its functions and the impact that it has on its members. While many concerns were raised about the destruction of the traditional form of the family, studies have shown that more changes tend to occur in the types of the family than in its function (Mann, 2003).

In recent decades, significant economic, social and demographic factors have influenced family forms and life, contributing to the reshaping of public attitudes (Cabinet Office and DCSF, 2008). Attempts have been made to confirm a connection between the traditional form of family and positive outcomes (Home Office, 1998). Some academics have argued that a link exists between the quality and the stability of life and the type of family; Ermisch and Francesconi (2000) claim that marriage has a better chance at providing a stable home for children than cohabitation

However, Arab countries have less fear about the destruction of family functions because of the changing family forms. In Saudi Arabia, the only form accepted by law and society is the traditional form of the family: a single mother can only exist through divorce or the death of her husband. By law, a single mother is the legal

responsibility of her father or brother, while her children are the responsibility of their father or his relatives. The extended family is also still extremely common in Saudi Arabia, especially in the countryside. Despite the potentially varied form of the family, it is still internationally perceived to be the main vehicle in child rearing (Leskinen, 1994); even in European countries, the family plays a crucial role in raising children (Dahlstrom, 1989).

2.4.2 Why family matters

A family can be considered to be the initial structure for the running and ruling of all human societies (Brown and Brown, 2003). Crow and Allan (2000) emphasise the central place occupied by the family as an organisation that delivers social care for its members within a civil society. The reality of the kind of support that is typically associated with the family does not require blood-relations, it can be found in any type of family, including “a self-defined family: a family comprising non-blood relatives, but carrying out the functions, traditionally associated with the patriarchal, blood-related family” (Carpenter, 1998: 181). Family is important for its members of all ages, but for children this importance becomes obvious and exigent because of the great impact that family has on the child’s well-being which is more than any other single factor (DCFS, 2010b). According to Shakespeare (1997), it is widely recognised that the relationships that parents have with their offspring are strongly linked with the children’s eventual outcomes. This is predicated upon the idea that strong families provide love, identity and security to their children, meaning that as they grow up, they explore, enjoy and get the most out of their lives (DCFS, 2010b). The impact on a child’s well-being is not limited to the relationship between the child and their parents. The relationships between children and other members of the family, such as step-parents, siblings and grandparents, will also often have an impact

on their well-being. Moreover, the quality of relationships among the grownups in a particular family has been shown to have a pronounced impact on the children in that household (Coleman et al., 2009).

It can be argued that the importance of family and its impact on their children are even more significant in the Saudi society than any western society, at least in the modern context. The family in Saudi society continues to maintain its cohesion in the traditional form. Even small families that live away from their extended family tend to still offer obedience and loyalty to the senior family due to cultural and religious reasons. In fact, in some communities the power of the family is greater than the power of law. Moreover, unlike in modern Western society, there are not many civil rights organisations in Saudi Arabia that can ensure the rights of the individual, so many families exert a very high level of power over their members.

Carpenter (1998) has argued that having a child with disability makes it even more important for the family to be part of an effective social structure. In addition to being the representative of the child in claiming their rights, the family of a child with disability also provides day-to-day support and plays a crucial role in arranging opportunities for their children, helping them to take decisions, and in interpreting their aims and hopes (Neely-Barnes et al., 2008; O'Brien et al., 1997). The role of the family transcends the role of ensuring the importance of the child's voice, as it may also select the suitable services for their child and claim those services, or petition for new options when they cannot find the right one.

From the perspective of inclusive education, the involvement of a family in their children's education is a requirement. In the case of children with disability, families are playing an increasingly important role in educational issues (Riddell and Brown, 1994; Vincent and Tomlinson, 1997). It may even extend until the family has a role in

developing legislative context of inclusive education (Tisdall and Riddell, 2006). The expectation from parents is that they should play the role of a sergeant to preserve their children's rights and insert their perceptions into the political changes (Symeonidou, 2007). Dee (2006) argues that before parents reach this level of involvement, they should use some powers that include economic and practical support. She adds that parents can also have influence through social groups in which the families are involved. For instance, the first special school in Saudi Arabia, serving people with visual impairment, was opened in 1960 as a consequence of the pressure put on the government by their parents and themselves (Almosa, 2007). Nowadays, I think social networks such as Twitter and Facebook can play an integral role in giving those concerned with disability a voice. Social media widely used in Saudi, with the most popular applications being Twitter, with one out of three Saudis tweeting (Aarts et al., 2015), and smartphone applications like WhatsApp, which can be used to create groups for different purposes (Hamdan, 2015). The effective use of social networks as a means to achieve rights is effectively illustrated through the so called Arab Spring. During this movement, social networks like Facebook and Twitter were employed by the populations of countries like Tunisia and Egypt to call for freedom and justice, which enabled the public to bring down governments.

In the UK, parents have the right to impact on decisions of educational provision in four key areas: "formal educational assessment, appeals, non-statement special provision, and participation or otherwise in the National Curriculum" (Lewis, 1993: 296). Legislation still emphasises the importance of parental involvement, the Special Educational Needs and Disability Code of Practice 2015 emphasises the importance of the involvement of parents in decision-making, also:

Early years providers, schools and colleges should also take steps to ensure that young people and parents are actively supported in contributing to needs assessments, developing and reviewing Education, Health and Care (EHC) plans (Department for Education, 2015: 20).

In some situations, the decisions made by parents are especially important because they directly impact upon the future of young people. The decisions taken by parents on behalf of their children can be particularly important when the youngsters have learning difficulties (Dee, 2006). This is the reality in many cases, regardless of the morals of this procedure. At this stage, it should be stressed that parents should always have the ability to take an informed decision on behalf of their children.

Family matters because it is a unit structure of society, the main source of support to all its members, especially the children, and one of the most important ways to achieve inclusive education and ultimately an inclusive society. In addition to family playing a major role in the life of children, those youngsters also affect the lives of their families, as will be explored in the next section.

2.4.3 The impact of a child's disability on the family

The most important thing that happens when a child with disabilities is born is that a child is born. The most important thing that happens when a couple becomes parents of a child with disabilities is that a couple becomes parents (Ferguson and Asch, 1989: 108).

This states the position that a responsibility exists between parents and their children, irrespective of the abilities of either party. This responsibility that providing for a disability entails will very likely have an impact on the whole family (Turnbull et al., 2006). This impact can be understood in a variety of ways. For example, Summers et al. (2005) place the impact that a child's disability has on their family into three categories:

1- The effect of a child with a disability on the functions of families: this focuses on the various interactions within the family, taking into account considerations that

include communication, unity, flexibility, roles and coping procedures (Olson and Gorall, 2003).

2- Eco-cultural modifications to the family's routine caused by the disability: this refers to the fact that in many cases, the family of a child with a disability has to reorganise their daily living and working routine to accommodate the new situation (Diamond and Kontos, 2004).

3- Stress, depression or the burden of providing care: this is the major category that affects the family, because it refers to a set of potential symptoms that can have a profound impact on the life of the family (Crnjc et al., 1983; Gallimore et al., 1996).

However, the impact of disability may not be limited to only three categories. As each family has its different circumstances, the presence of a child with a disability may have other effects that cannot be confined or generalised. It is not necessary that all of the three categories have an impact on all families, but they should all be taken into account due to the possibility that they might occur at some point for any given family.

Indeed, in my opinion, it is hard to isolate the third category from the other two: the stress, depression and burden inherent in the provision of care may arise from an inability to cope with the challenging situation of having a child with a disability, perhaps through family functions or the through the family routine. The opposite line of causation might also be true, with stress, depression and the burden of providing care leading to individuals coping badly with their new situation.

2.4.3.1 Impact on the family's functions

This category originates from the family systems theory (Olson and Gorall, 2003). In this context, the term 'system' is defined as:

A set of objects together with the relationships between the objects and their attributes. The objects are the component parts of the system, the attributes are the properties of the objects and the relationships tie the system together.
(Patterson, 2002: 18)

By viewing a family as a system, it is possible to shift the analysis from a focus on the child to a focus on their family as a whole (Bailey et al., 1998; Turnbull et al., 2006). This theory is grounded in the features of the family as a single unit that includes its size, type of family form, the culture that has an impact on it, as well as its specific socioeconomic position and geographic location (Turnbull et al., 2006).

In applying this theory to the family of a child with disability, the family systems theory must be able to provide a perception of how the family deals with and adapts to the situation of being a group that has a child with disability throughout the rest of their lifespan. In this theory, the historical social context is informed by, and to a large degree influenced by, the reactions of the family towards the arrival of a child with a disability (Ferguson, 2002).

Regardless of the type of family and the nature of the potentially diverse relations within it, the presence of a child with disability in any society may add other dimensions and complexity to the family's responsibility. One study conducted in the US found that all parents struggled to meet the needs of their children with disability, spending less on themselves and trying to make savings whenever they could (Dobson et al., 2001). These results were supported by the findings of a later study conducted in the UK (Woolley, 2004). This is important as studies have shown that the parents of children with disability typically spend at least twice as much on their children as parents of children without disability in order to ensure a reasonable standard of living (Dobson et al., 2001). That being said, some academics have argued that the birth of a child with disability creates distinct, life-transforming experiences for the family (Meyer, 1995).

2.4.3.2 Eco-cultural modifications to the family's routine

Generally speaking, mothers are usually an essential part of families. Classically, their role involves doing most household chores and taking care of children, although the diversity of their roles has been widely researched (Carpenter, 1998). Katz et al., (2007) argue that childcare in Britain now is still widely considered as a 'women's work' and organisations and services in society tend to emphasise this. A cross-Nordic study by Hautamaki (1997) found that mothers of children with 'Down's Syndrome' often change the focus of their own lives after giving birth due to the greater sense of responsibility that they report feeling for the care of their children. These mothers were found to take part in limited leisure activities and to choose types of work that afford them a high level of sick leave (ibid). My previous experience with mothers has shown that many have dedicated their lives to serve their children with disabilities and to take care of them. This perceived role of mothers is similar around the world, as they are typically considered to be the main carers in most families (Mittler, 1995).

Regarding fathers, the concept of fatherhood began to evolve in the last century, moving away from the stereotype of the Victorian vision; the strict patriarchal model began to be replaced by a softer picture, depicting men as being more open-minded and capable of getting in touch with his feminine side (Carpenter, 2002). The fathers of children with disabilities have also been the specific focus of investigatory studies. Fathers have been referred to as 'hard-to-reach parents' because of the difficulty to get their approval (McConkey, 1994). Meanwhile, in their study of the family as a system, Booth and Edwards (1980) found while the father and mother are supposed to share the rearing of their children, but it is most of the time not the reality and the father is invisible call fathers 'the invisible parent'. Fathers have also been referred to as the 'peripheral parent', to describe the common case in which fathers are not involved in

everything, whether this is by his choice or not (Herbert and Carpenter, 1994). West (2000) describes the father as 'just a shadow', with her study finding that fathers were often not satisfied with the support services, adding that these services were more suitable for their partner than for themselves.

These labels do not always apply to all fathers and do not mean that a father is not interested in being involved in the life of his child. This lack of concrete evidence suggests that more studies should be conducted into the role of fathers, in order to find the suitable way for the father to become involved in the collaboration. Meyer (1995) showed that having a child with disability has a great impact on the working life of fathers, who are often unable to obtain the flexible conditions required to combine employment and caregiving. Fathers were also shown to be negatively impacted by their choice of work and the loss of opportunities and earnings. Despite this, fathers were found to receive comparatively little formal support, which made it harder for them to spend time with their children, even in emergencies (ibid).

There has also been recognition of the need for some degree of reorganisation of the services in order to fit the life patterns of fathers (Herbert and Carpenter, 1994). Ideally, this would increase the opportunity for these men to access the services and obtain the information and support that they require, in addition to providing them with the chance to meet other fathers and exchange their experiences.

Having a child with a disability is a challenging experience that will be ultimately life-transforming for most fathers. As a consequence, this event could evoke some features of their personality that they had not acknowledged before, such as 'relentless stress', which could adversely affect their daily life pattern, including their work (Meyer, 1995).

In terms of education, however, it is recognised that the involvement of the father improves exam results, attendance, and behaviour of children, as well as helping the youngsters to form better quality relationships in the future (Goldman, 2005).

2.4.3.3 Stress, depression or the burden of providing care

Having a child with a disability has been shown to put parents under an incredible range of stresses. In extreme cases, exposure to extreme sadness, guilt, shock and pain can develop a state of ‘chronic sorrow’ for parents of these children (Wikler et al., 1981). Studies have shown a significantly higher level of stress among parents of children with intellectual disabilities in comparison to the parents of children without a disability (Hassall and Rose, 2005). Furthermore, some disabilities add a level of additional complexity to the parents’ life, such as in the case of intellectual disability. If parents have a child with autism, for example, parents will also have to deal with their child’s limited social interaction, communication difficulties and stereotypical behaviours (Shu et al., 2002). Sandler (2001) argues that parents of children with chronic illnesses are more likely to experience psychological problems, including anxiety or depression. This can exacerbate problems in the family further, as people who have depression have been shown to often be more likely to be frustrated, less harmonious, and ultimately less effective in their family than individuals without depression (Lemmens et al., 2007).

In 2006, a survey was carried out with 350 families in the UK. It addressed the breaking point in families of a child with disability and the need for the provision of effective respite (MENCAP, 2006). This study defined ‘breaking point’ as a:

Physical and emotional crisis, where the persistent lack of short break services and the endless pressure of providing intensive care finally take their toll. It is a

dreadful situation for families, which causes pain and despair and, often, irreparable damage.
(MENCAP, 2006: 5)

A significant proportion (70%) of the sample reached or came close to breaking point, 70% spend more than 15 hours providing care every day, 50% of the sample provide care during the night, and 50% do not receive any care assistance. In addition to this, 60% thought that their poor physical health could be attributed to the amount of care that they needed to provide, while almost all (90%) blamed their poor mental health on the amount of care they were required to give. The study showed the intensity of the pressures on families of children with disability; Mandy, a mother of a girl with a disability, described her feelings “When I reached breaking point I could see no future, no way I could go on” (MENCAP, 2006: 2). Another mother said: “I felt as if I was losing control of my life, like I couldn’t go on anymore. I really wanted to just be a ‘normal’ family” (MENCAP, 2006: 5). According to MENCAP (2006), the breaking point is not unavoidable and results from a lack of appropriate help during the caring process.

If the situation described above is the case in the UK, where there are various support services and a wealth of research in this field, it is unlikely that a better situation exists for the families of children with disability in countries such as Saudi Arabia, where the family support trend has only just begun.

With specific reference to the investigation of parents, one study conducted in Saudi Arabia collected data from a sample of 102 fathers and 102 mothers of children with learning disabilities. The study found higher levels of stress among mothers than fathers (Aldosari, 2013). Some studies have indicated that women tend to experience a higher rate of depression than men (Nolen-Hoeksema, 1990), they are also prone to the emergence and development of new symptoms as a result of physiological

changes such as the menopause (Woods et al., 2008). Compared with men, women tend to battle depression by drawing upon their relationship with their partners and families (Lemmens et al., 2007; Thompson and Heller, 1990). The high levels of family support arguably have a greater impact on women than on men, so women have a quicker recovery from depression (Kamen et al., 2011). In contrast, men tend to rely less on family support services, often due to the belief that those services are not relevant to or intended for them (Ghate et al., 2000; O'Brien et al., 2004). Despite a shift in the image of 'masculinity', a traditional outlook still exists in many contexts. This image stresses self-sufficiency and independence over the seeking help and accessing services (O'Brien et al., 2004). The weak engagement of fathers is a well-known problem and the progress made in addressing it has been very slow (Ghate et al., 2000). O'Brien et al. (2004) claim that individual psychological features, as well as social and institutional aspects, play a crucial role in the unwillingness of men to engage with support services. However, when fathers receive support, their depression shows a rapid improvement (Leskela et al., 2008). In other words, although men do not rely as heavily on family support, it does not necessarily mean they do not want or need it. It may instead suggest reasons like an inability to find appropriate services for them.

Bray et al. (1995) found that fathers of children with disabilities tended to be very worried about the future of their children. Perhaps as a consequence, they often consumed more alcohol in an attempt to deal with emotional trauma (ibid). In studies in the UK, fathers have often been shown to try to 'keep some normality' in their lives by returning back to their work early after the birth of their children, despite their disability, and to work for long hours (Herbert and Carpenter, 1994). This may be a strategy that allows them to be emotionally detached from the situation at home (ibid).

The use of the word 'normality' indicates that those fathers think there is something wrong and that their lives have deviated from the norm, which is a sign of their inability to cope. Carpenter (2002) thinks that the social network of fathers of children with disabilities gets smaller with time, which can be understood as the result of the extra effort that many of them need to spend in their work.

The impact that a child with a disability has on the life of fathers is profound. I think that there is strong evidence that the unsuitability of support services may make the situation worse. Also by failing to support men, the situation is worse for both sexes since women may have to do more work with the children. The fathers may need the opportunity to participate in a manner appropriate to them; professionals have to facilitate that, in order to achieve the best for parents and their children. Another British study shows that fathers are often seeking a high level of involvement in all aspects of their children's life, ranging from day-to-day activities to decision-making (Carpenter and Towers, 2008). However, the study stresses that this objective is often difficult to reach.

2.4.4 Parents' Attitudes

According to the World Health Organisation, attitudes are:

The observable consequences of customs, practices, ideologies, values, norms, factual beliefs, and religious beliefs. These attitudes influence individual behaviour and social life at all levels, from interpersonal relationships and community associations to political, economic, and legal structures. (WHO, 2007: 207).

The life of children with disability can be significantly affected by the attitudes of the others, not least because children with disability will be living with others and not live alone in a different world. The attitudes of others may create many obstacles or facilitators that influence the life of people with disability (Guscia et al., 2006).

The parents are the closest people to children with disability, often living together with them in the same house and therefore sharing the same life circumstances. Because of this, the attitudes of these parents can affect significantly the lives of the children due to reasons that include the implicit relationship between them. However, parents' attitude can be changed (Rose, 2010).

In general, The knowledge of role models with disability can profoundly impact the attitudes and life course pathways of people (Priestley, 2001). However, it is important to bear in mind that parents may have a range of reactions towards their child having a disability, such as rejection, blame shifting, guilt, unhappiness, withdrawal, and acceptance (Drew et al., 1984). This final reaction, acceptance, can have a particularly profound impact on the way in which children understand and perceive their disability. Thus, their pessimism, anger and shame may be good reasons for suffering (Rangaswamy, 1989). Some parents may blame themselves or experience weakness, feelings of insufficiency, anger, shock and guilt, whereas others may go through periods of doubt, depression or frustration (Chandramuki et al., 2012; Bhan, 1995). These kinds of feelings and reactions can spread to affect siblings because they will share the same life conditions and will usually live in the same house. For this reason, many siblings have also been shown to feel guilt, shame, or embarrassment (Frude, 1991).

In terms of education, the attitude of parents are critical, since they are often among the most sceptical and hesitant about moving their children from special schools to mainstream schools (Rose, 2010). Regarding academic performance, gender can have a great effect on the expectations that families have of their children in general. Male children with disability are often under higher pressure than female children, due to an expectation of higher levels of achievement in education, as well as better positions in

work and consequently higher levels of financial security (Chandramuki et al., 2012). Although this study was conducted in India, male children with disability in Saudi Arabia may live under the same kind of pressure as both Saudi and India are eastern countries and may therefore share some beliefs.

As mentioned previously, parental attitudes may vary, with common attitudes including over-protection (Perosa and Perosa, 1982) and rejection (Minuchin et al., 1978; Nabuzoka and Smith, 1993). Parents who tend to over-protect their offspring or reject them were primarily unaware about the nature of the disturbances in their children (Chandramuki et al., 2012). Cultural beliefs about disability can play a key role in determining the perceptions that a family has about disability and the type of prevention, treatment, and rehabilitation that they will seek or accept (Sen, 1988). Therefore, families from some cultures may think of disability as a barrier of living and being involved in their societies.

To conclude, parents play a crucial role in supporting children with disabilities, which means that the best setting in which to support a child is in the context of their family life (Parish et al., 2001). Moreover, collaboration with parents in supporting children with disabilities can be invaluable for professionals in ensuring the provision of the best support services. Dunst (1997) claims that this approach can help professionals who work in partnership with families to obtain better outcomes from the child and be better able to meet the needs of children with disabilities. Accordingly, the family support must work with all family members and the community as a network, striving to acknowledge the family as a complete system instead of individual, isolated individuals.

2.5 Family support

Some families can cope with the situation of having a child with a disability quite well, whereas others cannot strike the right balance (Koller et al., 1992; Taanila et al., 2002). Although it is likely that some families need more support and help than others, I believe that all families could potentially benefit from support. Even when they do not need direct support to address their difficulties, the availability of options will offer them a better quality of life, which does not have an upper limit.

The most obvious way to learn what someone needs is to ask them. According to Moorman et al. (2001), studies that explore the views of parents tend to show that parents believe that they need more information and advice. In addition, other research found that training and early interventions can improve the skill shortages experienced by parents and address issues related to raising children (Moorman et al., 2001). In my opinion, direct communication with the individual or group who is receiving the service is not the only way to identify their needs, because they are likely to only ask for what they already know. For example, when famine occurs in poor countries, mothers cannot be expected to ask for intravenous care for their children without having had previous experience with this option. Instead, a mother will only ask for food and drink. In countries such as Saudi Arabia, where the concept of inclusive education is still missing, the expectations of the mothers is not to ask for inclusive education. Therefore, the information and advice available from experts can help families to better understand what options are available to support them and the appropriate ways to claim their children's rights.

It is important for parents to take the initiative to join services and that this effort is reciprocated by the services themselves (Featherstone and Broadhurst, 2003). Engaging parents as active help seekers instead of passive receivers of services is the

key issue (Katz et al., 2007). This means that a lack of knowledge on the part of parents about the available services and how they could help should be considered to be an important reason for limited engagement (Gibbons and Thorpe, 1989; Cragg et al., 2002). There is a range of possible reasons that may hinder the engagement of parents in the services. In some cases, even physically accessing a particular service can be a challenge, due to a lack of available public transport, the high cost (Katz et al., 2007), or perhaps the large distances involved. Time pressure can also prevent services from being accessed, particularly among single parents and parents in employment (Barauski et al., 2003). However, Smith (1996) argues that even services that are supposed to welcome all parents are often limited in relation to geographical location. Realistically it cannot reasonably be expected that parents will join services unless they are located in their own community or neighbourhood. As an illustration of this, families in rural communities in the UK were found to be failing to join the services due to issues of physical inaccessibility (Frost, 2001). Frost believes that because of assumptions among policy makers that the majority of needy families live in urban communities, support services are often set up in a way that does not give proper consideration to other contexts (ibid).

Regarding my own research, I assume that there are many helpful services for family support in some countries that Saudi parents will not know about or easily understand because they will not have experienced them. Examples include consultancy or advice, which are uncommon services in Saudi and therefore need to be explored further. Parents need to be given explanations about some of them to give their opinion about the unknown services. Reynolds (2011) suggests that the voice of parents has to be heard, so they need training for their capacity for participation. These types of training programmes need to have clear objectives and their effect

needs to be evaluated, thereby helping to ensure the continuation of the services and that the family needs are met.

2.5.1 The Meaning of Family Support

Although the definition of inclusive education is debatable and complex, the description of family support is somewhat less complex.

Family support services draw on a continuum of intervention, it includes pre-natal classes, early childhood education, parent education, day-care, family centres, after school clubs, home and school liaison, child abuse and neglect prevention programmes, neighbourhood-based resource centres and mutual help support groups.

(Katz and Pinkerton, 2003: 10)

While this description provides a good understanding of family support services as a continuum of intervention, it limits the family support into several services that may not necessarily be able to meet the continually evolving needs of the family, due to the myriad social and economic developments in society. These changes may alter the frequency of problems or even give rise to need that did not exist in the past. For example, 30 years ago there were no housemaids or drivers in many homes in Saudi Arabia; now these are present in most homes, as discussed later in the research context, meaning that it is important for housemaids and drivers to be taken into account during the design and provision of services for the family. However, the comprehensive definition for the support of parents should not exclude any service that family may need. The best way to ensure this is to not limit the term to a single fixed definition, as this can include or exclude some activities or programmes (Katz and Pinkerton, 2003). Katz and Pinkerton (2003) argue that the best approach is to deal with the term of family support as a unit of issues, such as definition; level of need; possible capacity of informal social care in a specific society; the provided

services or the services which could be developed; and the followed overall social policy at any given time and place (ibid).

Those clarifications about family support open broad possibilities to introduce other types of services as forms of family support. However, one senior social services practitioner takes the pragmatic position that “family support is whatever supports families” (Pinkerton et al., 2000: 11).

The Audit Commission in England and Wales have given the more detailed definition of family support as:

Any activity or facility provided either by statutory agencies or by community groups or individuals, aimed at providing advice and support to parents to help them in bringing up their children.

(Audit Commission for Local Authorities in England and Wales, 1994: 39)

Most parents consider extended family and friends as being informal support systems and even rely on them more than the formal organisations (Ghate and Hazel, 2002; National Autistic Society, 2009). Similarly, in societies like Saudi Arabia, we can add the extended family as an important resource for the provision of advice and support to the parents of children with disability.

Brennan and Rosenzweig (2008) assume that a formal and informal constellation of services is usually included in a family support package. This includes the tangible goods that are outlined by families. In effect, this means that family support describes whatever might be needed in order to provide the recipient, whether they are an adult or a child, with the full opportunity to participate in society. This supports the statement by Pinkerton at the top of the page.

Regardless of the exact definition of the term, family support centres have been shown to have better outcomes than more traditional way of serving families (Dunst and Bruder, 2002; Summers et al., 2005). Where the family support centres offer multiple

services in a unified, harmonious package in one location, the traditional way enables the provision of each service separately. The term 'family support centres' refers to the integration and coordination of services, rather than to the traditional, non-integrated manner in which services are provided (Dunst and Bruder, 2002; Summers et al., 2005). In family support centres, as families can receive all their required support under one roof, they do not need to find training centres for appropriate courses or to visit psychological counselling centres to make an appointment for advice.

There is an overlap of the state and civil society because both of them can provide family support services. Even in a situation in which the services that are provided from informal social care are sufficient to optimise the quality of life for the family members, there may still be a need to rely on more formal social care as required (Katz and Pinkerton, 2003). Therefore the challenge that faces formal social care is to improve their services based upon an understanding of the family's needs and the best ways to respond to them. Therefore, in order for individuals with disability to get the most out of life, it is necessary for the formal social care, represented by the state, to take advantage of the relations and resources within the informal networks. When this is achieved, the formal services benefit from the relationships within the informal networks, while informal services benefit from the facilities available from the officially funded services. This cooperation between formal and informal social care is likely to be in the best interest of the family and can be considered as a valuable source of support to the family.

Regardless of the service provider, it is known that caregivers (parents in this case) are the key to service access (Costello et al., 1996; Farmer et al., 1997). Therefore, it seems important to focus most of the attention on meeting the needs of parents and

their preferences for support (Hoagwood et al., 2010). There are diverse views about the identity and role of the important people in the lives of children with disabilities. Mittler (1995) thinks that the available support for families provided by their neighbourhood is critical for improving and shaping their quality of life. Others argue that the support has to be defined by the families themselves, along with definition and design done by family, and they must therefore contain whatever is needed to achieve comprehensive care for a child with a disability (Brennan and Rosenzweig, 2008).

2.5.2 Background of family support in relation to disability

In early 20th century America and Europe there was no overlap between families and professionals in the care of the child with a disability, since the family had to choose from keeping their child with disability at home without any support from professionals and placing them into residential institutions (Leiter, 2004). Until the 1960s, parents had to make the difficult decision about whether to keep their child with disability at home and lose access to all formal services, or to obtain those services by enrolling them in residential institutions (Scheerenberger, 1976). At that time, there was a residential assumption, which means “a person is assumed to need residential facilities simply because he or she is mentally retarded” (Skarnulis, 1979: 67).

Nevertheless, it was the parents of children with severe learning disabilities that pioneered the creation of disability rights organisations. These groups started to grow in the 1940s, becoming a dominant voice on behalf of children with disability by the 1950s (Leiter, 2004). In both the UK and the US, the family movement can be divided into three waves. The first wave was organised by the parents of children with

physical, sensory, and developmental disabilities; it succeeded in narrowing the gap between parents of children with disability and professionals in the care sector (Cooley and Olson, 1996). Some parents volunteered to run charities for children with disabilities (Leiter, 2004), so parent organisations started locally, although they eventually grew to national and even international levels (Dybwad, 1983). At the beginning of the 1960s, parent organisations started to form in order to support a wide range of disabilities (Leiter, 2004). As those organisations grew and collaborated with one another, their missions also improved. The early parent movements received pity and charity for their disabled children's institutions through telethons and fundraising drives (Fleischer and Zames, 2011). However, their demands changed in the 1950s through to the 1970s, when parents started to support the development of services and programmes to benefit children with disability (Pizzo, 1990). In so doing, parents became primary advocates of the rights of children with disabilities, being involved in activities from fundraising to claiming their rights to services. They were "the advance troops of a new consumer movement" (Boggs, 1994: 47). Parents in the first wave of movement strove to obtain community-based services for their children with disability. The result of this was that by the late 1960s and 1970s parents no longer had to choose between keeping their children at home or sending them away to get the services that they needed (Pizzo, 1987). Furthermore, during this time, parents also fought on behalf of their children to provide public education for young people with disabilities (Leiter, 2004). This wave confirmed the essential role that families of children with special needs play in the inception and development of disability support services. This process started with the efforts of individuals towards simple targets like the collection of donations to support their children. However, with the

formation of organisations to clarify and fulfil their needs, parents became stronger and their demands evolved to requesting services, helping their voice to be heard.

The second wave involved adults with disabilities. This was a major movement from charity to confrontation, which was led by the adults with disability themselves (Fleischer and Zames, 2011). This wave started in the US and was called the independent living movement. Fleischer and Zames (2011) wrote in detail about this movement in the US; when people with disability grew increasingly frustrated about the services being provided, they started to fight for their rights through lawsuits, demonstrations, and sit-ins. In the late 1970s people with a disability in the UK felt the services were more paternalistic, institutional, second-class, reliant on medicine, and did not meet their needs. This perception ultimately led to the inception of the independent living movement (Evans, 2003). Some members of this British group reached to the US for the success of their movement, importing expertise from their North American predecessors (Evans, 2003).

The third wave refers to the period during which the social model of disability was shaped and clarified. It describes a collaboration between adults with disabilities, parents of children with disabilities and professional constituencies (Powers, 1996). After securing the provision of community-based services in the 1970s, parents sought to improve their relationship with the professionals. This led both groups to realise and recognise their mutual interests: parents wanted to provide the services that the professionals can offer for their children. However, some of the professionals went beyond that and collaborated with parents to work directly on behalf of the children with disabilities (Shapiro, 1994, cited in Leiter, 2004). In the 1980s, the alliance between the parents and the professionals produced the Early Intervention 'EI' programme, which extended the scope in two dimensions: they started with children

with disability from birth, and later included the child's parents and eventually the whole family in the programme (Leiter, 2004).

The three waves of gaining rights clearly demonstrate the resilience of people with disability and their families. For over thirty years, these movements in Europe and North America challenged pre-existing cultural and professional assumptions about underestimating people with disability (Albrecht et al., 2001).

Social movements typically challenge the historical and cultural tradition related to groups of disadvantaged people (Risdal and Singer, 2004). For example, the disability rights movement challenged the pre-existing cultural and professional assumption regarding the devalued status of people with disabilities, leading social science research to change accordingly (Albrecht et al., 2001). Pressure from popular movements can be a reason for issuing policies and accelerating their application. In the UK, general family centres were first mentioned in 1963, with the Children and Young Person Act. However, family centres gained full sanction in 1989 with the Children Act (Ryden and Smith, 1998), which emphasised the importance of providing services to children with special needs or the provision of suitable alternative centres for them. Paragraph 9 of schedule 2 of Children Act 1989 stipulates that family centres should be places for the parents of the child, any individual that has parental responsibility for them, or any person who is in charge of looking after the child. Any of these caregivers can attend for occupational, social, cultural, or recreational activities, as well as to seek advice, guidance, or counselling. Family centres are also able to provide accommodation for the beneficiaries while they are receiving advice, guidance or counselling (Gyamfi et al., 2009). In addition, this Act committed all local authorities to "provide such family centres as they consider appropriate in relation to children within their area" (ibid: 228).

In 2010, according to the Department of Education, which was then known as the Department for Children, Schools and Families, even family support services look different in every area, with only shared basics, “all local authorities now offer a Family Information Services, parenting programmes, one-to-one support and intensive family intervention services” (DCFS, 2010a: 10).

In the US, family support services have spread rapidly and more families have become keen to engage in them. As an example of this, the New York State Office of Mental Health launched a network of family support programmes in 2002. This network was intended to reduce family stress and increase each family’s capacity to care for their child with disability; in 2008 there were 400 family support programmes, with a plan to double the figure of some programmes, such as family peer advocates, within 2 years (New York State Office of Mental Health, 2008). A survey from the MacArthur Foundation and the Robert Wood Johnson Foundation confirmed that over 4 million parents are members of national associations for parents of children with disability (Hoagwood et al., 2010). This underlines certain key issues that should be considered in this area, such as the amount of support services that the families of children with disability might need. It also highlights the awareness of parents and demonstrates their desire to receive realistic, structured support from organisations that seek to serve the families of children with disability. Access to services through organisations requires an effective relationship between the professionals and the parents as the family’s representatives. This relationship may play a crucial role in the extent to which the families are able to participate and how motivated they are to join the programs.

2.5.3 The relationship between parents and family professionals

Some authors have argued that

The news that a child has, or is at risk from, a developmental disability is often among the most frightening and confusing pieces of information that parents will ever receive.

(Beckman and Boyes, 1993: 1)

What is almost certain is that this will signal the beginning of a lifelong relationship between parents and the professionals (Carpenter, 2002).

Covert (1992) emphasises the sharp change in what professionals expect from parents. For example, in earlier times physicians and other health care professionals encouraged parents to obtain residential institutional placements for their children when they had a disability. In contrast, parents in the modern context often want to influence the planning of the services, as well as how they are designed and run (DCFS, 2010a). The professionals have to see this enthusiasm to participate as a success of the programmes (Golden et al., 2004). This supersedes the idea of conducting a survey and asks about the satisfaction of the family with the services provided, however they are supposed to be participants and effective throughout all stages. The Department for Children, Schools and Families (DCFS, 2010a) suggests that one way to make this a reality and controllable is to ensure the development of a set of standards for family participation in the formation of services.

The relationship between parents and professionals is highly dependent on which party has more power and authority: power tends to lead to greater influence, while authority can be employed in order to channel this influence in a specific direction. It can also be used to maintain the status quo. Effectively, this means that the group with the most power is in “the driving seat” of the relationship between parents and professionals (Dale, 1996: 5). Although the relationship between parents and

professionals is complex and changeable, parents as individuals or groups are generally considered to have less power than professionals. This may not be the case in certain circumstances, however, such as the parents having a position in the committee managing a service or when they have enough funds to launch their own services independently (Dale, 1996).

However, the power of parental influence started to evolve in response to their growing knowledge and the corresponding expansion of their role in the decision-making process (Dale, 1996). The 1990s saw significant reinvestment in the family support sector (Tomison, 2001), which highlighted the need for a working strategy to get a response from the families in order to improve the health and the wellbeing (Tomison, 2003). However, many studies have found that parents still feel powerless in the decision-making processes, for example in terms of the activities that are planned by schools (Weiss and Edwards, 1992). In the case of Saudi Arabia, the relationship between professionals and parents is still an authoritarian relationship one for the majority of the time. I think that if the balance of authority is not protected by policies, it is hard to get this right. In Saudi Arabia, evidence shows us that this protection is missing and that parents are therefore marginalised. For example in the National Report on Education Development in the Kingdom of Saudi Arabia, the Ministry of Education MOE (2008) did not mention any role or support to the parents or the family. Alanazi (2012) studied the relationship between parents and schools in Saudi Arabia. The study showed that general teachers, special needs teachers, and head teachers in three of the five participating schools perceive parents to be a barrier to the delivery of effective education. Meanwhile, the parents in these studied institutes were requesting communication channels between the school and their family (ibid). Indeed, the findings in my previous master's research suggest officials

look at mothers as a means to implement instructions, not as participants in decision-making (Alariefy, 2011).

2.5.4 Types of Family Support Services

To make sense of how to generate services in family support centres, Katz and Pinkerton (2003) suggest a conceptual framework that can be applied to any child welfare matter. This framework involves the interaction between four aspects: needs, services, processes and outcomes. In a civil society, the family is a critical organisation that has ‘needs’ which are met by social care ‘services’ that are provided by programmes and projects, delivered directly or indirectly by the state. The needs and services go through ‘processes’ and ultimately end with the ‘outcomes’. The state, in this context means “a set of agencies claiming supreme authority for the co-ordination and continuity of a population within a particular territory, backed by a virtual monopoly of force” (McLennan et al., 1984: 3). Civil society describes “all those social institutions and relationships which arise, through voluntary association, outside the sphere of direct state control” (McLennan et al., 1984: 20).

In addition to the dynamic interaction between the four aspects, each has to be clarified. Regarding needs, some important questions have to be asked, such as why those particular issues are considered as needs and why they require support. Katz and Pinkerton (2003) explain that social care was provided by the family itself, in the past, but the growing pressures involved in modern society, including the need for most households to have multiple incomes and so no stay-at-home parent, means that many families are now incapable of doing it alone. Social care, as it is described by Barclay and National Institute for Social Work (1982), is a cluster of assistances that utilise the resources that are available, delivering them to the family informally by means of

community networking or formally through public services. Should a family be unable to meet its need exclusively from social care, then the state should launch processes to provide the required care through programmes.

Families of children with a disability usually have a number of demands, ranging from psychological and financial, through to physical and social, which they are likely to have not had before the diagnoses of their children (Gallimore et al., 1996; Itzhaky and Schwartz, 2000; Mak and Ho, 2007). In order to help fulfil these demands, there are many ways to support the family, which are on the rise due to the complexity of modern working situations, housing, transport, and even the changes in the type of leisure time available to people (Katz and Pinkerton, 2003).

Family support services can be divided in different ways. For example, they can be differentiated according to the setting, with services being delivered outside the family support centre, in locations like homes, hospitals, schools, places of worship, or other community sites (Thompson and Uyeda, 2004), or it can be done remotely, online or by phone. However, the two main ways of dividing family support services are according to the type of the service and who is delivering that service.

2.5.4.1 Family support services according to the provider or the leader

Family support services can be offered by a professional, a peer, or a team of professionals and parents (Cavaleri et al., 2011). The more traditional model is for services to be led by a clinician or another professional, whereas newer models may be led by family members or peers, with those being led by a team as the most recent model (Hoagwood et al., 2010).

Despite the comparatively short life of the formal peer-led model in comparison to the professional-led model, government-funded studies of families that have enrolled in

the largest service programme in children's mental health, have found that approximately one third of the enrolling families are in services provided by peer families (Gyamfi et al., 2009). The short life of the formal peer-led model can be considered as a disadvantage, which comes back to nature of their work as volunteers.

However, the model led by family members or peers is rapidly developing as an adjunctive service, in which current or former parents of children with a disability provide emotional support, information about disability services, or even direct advocacy (Hoagwood, 2005; Osher et al., 2008). This approach results in both current and former parents of children with a disability gaining credibility, which develops trust between them and among other parents based on similarities in their personal experience (Gyamfi et al., 2009; Hoagwood, 2005; Osher et al., 2008; Robbins, 2008).

In fact, the importance and effectiveness of the peer-led model as a way of delivering services led to the development of a new model called the professional family peer model, which is increasingly being employed to assist families (Gyamfi et al., 2010). This shortage is filled by a new method of workforce, which is known as 'professional family peer' approach (Hoge and Morris, 2007).

Another provider of support services are support groups. Studies have shown that support groups can be an easier place at which to share experiences and obtain support from support groups than from their friends or extended families (Chandramuki et al., 2012). One of the most important ways that these groups help children is in the development of realistic expectations for children with disabilities, which in turn helps parents to feel more competent (Wong et al., 2004). It could be argued that this is because parents can share a lot of experiences and obstacles related to their children or to themselves and their families. Network support groups can build the confidence, self-esteem and assertiveness of participants. The associated feelings of control and

positive psychological well-being may positively affect the attitude of parents towards children (Turnbull and Turnbull, 1990; McGaw et al., 2002; Kroese et al., 2002).

2.5.4.2 Family support services according to type of service

Reynolds (2011) categorises family support services into three types: Instrumental, Emotional and Informational. Instrumental support is for day-to-day needs, which includes childcare, facilitating more or better leisure time, assistance with finance, and therapy support (Bailey et al., 1992). Formal emotional support is typically provided by professionals, such as mental health specialists. However, informal emotional support is also available from relatives, friends or parent-to-parent. The informational support includes educational support and training, which is very important to help families to understand the disability and the issues around it. This support also enables them to effectively ask for rights and services, as well as to choose the appropriate opportunity for their children (Friesen and Koroloff, 1990; Heller et al., 2007).

Like Reynolds' categories, Hoagwood et al. (2010) also divides the service according to the following types: 1- instruction and skill development, which can be training for caregivers or for the family on communication, problem-solving, crisis management, and child-rearing strategies, irritation management and stress reduction techniques; 2- information and education about child behaviour and development, health conditions, treatment options and about the system of family service and resources; 3- emotional support to promote parents' feelings of being understood and respected; 4- instrumental services such as transportation, babysitting and flexible funds for emergencies; 5- advocacy, including awareness of rights and resources, improving skills to advocate for the child's services and providing a direct advocacy to gain services for a parent or a child.

The Australian Institute of Health and Welfare (AIHW, 2001) has its own major categories of family support services: 1- information and referral such as media information, Parent Lines 24 hours, a family centre which is like information centre and sources for family matters; 2- education/skills development, such as research, family relationships education, which is intended to help family to develop stable and positive relationships; parenting education which aims to support in parents or family members in fulfilling their family roles; 3- counselling, mediation or therapy; 4- residential and in-home support; and 5- advocacy, which aims to foster greater access to particular benefits, to negotiate on behalf of the recipient when required, and a catchall category called 'other family support services', which includes any service that is not described by the main categories, such as playgroups.

As with Hoagwood's et al (2010) categories, the AIHW focuses on three main categories; education/skills development, information, and advocacy including the awareness of rights and resources and fostering greater access to particular benefits. Meanwhile, Hoagwood's et al (2010) categories include emotional support, the AIHW has counselling, mediation or therapy.

Hoagwood's et al (2010) categories have instrumental services that include services at home as the AIHW suggested. Moreover, these facilities can be extended to services such as transportation and flexible funds (ibid). Correspondingly, the AIHW has catchall category called 'other family support services', which includes any service that is not described by the main categories.

A US report that was conducted as part of a Cooperative Agreement between the National Center for Infant and Early Childhood Health Policy and the Health Resources and Services Administration (HRSA) and the Maternal and Child Health Bureau (MCHB), did not categorise the services of family support (Thompson and

Uyeda, 2004). Thompson and Uyed (2004: 12) listed services that family support should include but are not limited to:

Health care, public assistance, child care, employment development, transportation, translation, family court services, family advocacy, and legal assistance, case management, parent support groups and parenting education, mental health, domestic violence & substance abuse counselling, family and adult literacy, resource and referral services

Indeed, Morrill (1992) states that the family support service should be made up of health, education, and social services, out of which all required services can be drawn. Morrill promotes the linking or integration of the three components to ensure that families are dealt with effectively and holistically (ibid).

2.6 Summary

The important role played by families in the call for inclusion, as well as in encouraging and evaluating its process, has been evident throughout the history of disability. This role is especially evident through the three waves of the family movement. However, this is not the case in modern Saudi Arabia, where the voice of families of children with disability is still often missing. To play the role that is expected of them, families need support. There are many factors that may have an influence on families' preferences for particular support services, such as the impact of having a child with a disability on the family, the attitude of parents towards disability, their understanding of their child's disability, and their relationship with professionals. There is a high degree of diversity in terms of family support services provided around the world, which variation from one community to another. However, any family support service can be categorised in different ways, such as according to the provider or the leader, or according to the type of service. As illustrated in this review of the literature, which is based primarily from sources in the

West, it seems that family services have a crucial role to play in supporting families who have children with disabilities. However, these are not widely available in Saudi Arabia and this study therefore aims to address the following questions:

- **What are the impacts of having a child with disability on the family?**
- **What are the challenges faced by parents who have a child with disability?**
- **What are the parents' views of family support services?**

Chapter 3: Research Context; Saudi Arabia

3.1 Introduction

Due to its position in the Islamic world, as well as its preeminent oil production capacity, Saudi Arabia is considered to be an important country in the Middle East. Saudi Arabia was established as a country in 1932, after the tribes of the region were united by King Abdul-Aziz (Shoult, 2006). Saudi Arabia is an Arab Islamic State and therefore Islam is the primary and state religion. Despite having gone through dramatic developments after the discovery of oil, the authorities of Saudi Arabia have always tried to maintain the traditions and culture of the society. Saudi Arabia occupies a total land area of approximately 2,200,000 square kilometres. In 2014, the Central Department of Statistics and Information estimated the total population of the country to be almost 30 million (29.99), as many as 8% of whom are believed to be persons with some form of disability. However, at this time, there is an absence of solid official data on the numbers and types of disabilities, or on their geographical distribution in the kingdom (Japan International Cooperation Agency, 2002). For a deeper understanding of the research, it is important to shed a light on some of the aspects in Saudi Arabia such as the nature of Saudi society, education, health, and particularly on the services that are currently being provided to persons with disabilities in the kingdom.

3.2 Saudi society

Islamic religion is the primary legislation of the state and all segments of society do not show any kind of objection to that fact. In these kinds of religious societies,

religious men play a crucial role in influencing people (Obaid, 1999). Folklore and traditions can even be considered as a non-formal legislation of the Saudi society; people respect them and even the government gives them due consideration when issuing legislation. There are many examples of the power of traditions. Perhaps the most well-known in the Saudi context are the traditions governing the outdoors costumes for men and women. As women have to wear black cloaks in Saudi society, public schools do not allow girls to wear another colour but black. Also the traditional costume for men is a white vestment and a head cover and a lot of government departments do not provide services unless the person is wearing the white vestment and the head cover (Alnasar, 2001).

Saudi society is a conservative one; it mainly consists of tribes, which give the society a high level of cohesion and support (Determann, 2014). For instance, most Saudis tend to live in joint family systems that enable them to more effectively support each other: they take care of their spouse and consider them to be their pride, take care of their neighbours, and so on. The tribe is considered to be the main component in these aspects and most families belong to tribes, or big families, and so fall under their authority (Determann, 2014). Even if the family is living far away, people keep their loyalty to their tribe. There are dozens of separate tribes, although they vary considerably in terms of their size and power, and the members of these tribes often consider their families to be the most powerful source of authority over their lives. However, some families do not belong to a tribe (Determann, 2014). This can mean that their descendants do not come from the Arabian Peninsula and that their family have obtained Saudi nationality in the past (Al-Rasheed, 2010)..

One of the most prominent social issues in Saudi Arabia at the time of writing is the right of women to drive, which is currently forbidden. Although there is no religious

reason for women to be prohibited from driving cars, the legislation respects the desire of the conservative majority, both men and women, who do not wish women to drive. In fact, all women in the kingdom are not allowed to move in society without a male guardian, irrespective of their age. For this reason, Saudi Arabia is the only country in the world where it is against the law for women to drive. Saudis seem to generally believe that allowing women to drive will weaken their moral fibre and cause social damage to society (Snowdon, 2015). In the absence of a proper public transportation system in all Saudi cities, the streets are crowded with cars, driven exclusively by men and private drivers (Taher and Hajjar, 2014). Having a private driver in Saudi Arabia is therefore not considered a luxury. In fact, it might be a necessity in cases such as when a lady is an employee or when children go to different schools (Al-Rasheed, 2013). Even middle-income families can afford a private driver. The presence of housemaids is similarly universal, because of the house's size, the family's size, and the generosity of Arabs, it is imperative for many families to bring a foreign housemaid to Saudi Arabia to help with the housework (Al-Rasheed, 2013). However, poor families cannot hire private drivers or housemaids, which can create numerous problems for them.

Some of the most noticeable differences between Saudi Arabia and other nations are traditional dress and the existence of clear gender segregation (Abadeer, 2015). The clothing worn by Saudi women has a traditional and religious basis, with a black cloak being worn to cover the hair and body; additionally, the majority of Saudi women cover their faces with a veil (Marsh, 2015). Gender separation can be found in many sectors, including schools, universities, government departments, and even some public places (North and Tripp, 2006). These rules are kept by religious police, who monitor the separation of the genders and ensure that demure dress is always

maintained in public places. For instance, women are observed by police and other responsible authorities, in order to ensure that they are dressed in a proper manner, which complies with the dress code. The dress code has been set in accordance with the Islamic law that is enforced throughout the country, although variations do exist. All women must comply with this code, including high profile individuals like female television presenters, in compliance with the code laid down by the king's advisory body, the Shoura Council (Ammar, 2016).

Relatives tend to live side by side in the same neighbourhood and so in some cases the residents of an entire district may share the same last name (CultureGrams, 1975). The extended family system is common in Saudi society. Married sons often live with their parents in the same house, or in separate apartments in the same building (Yamani, 2008). This is especially common for sons who are newly married and who therefore have small families. Financial and social solidarity exists among members of most extended families, although the specifics of these arrangements are different from one family and to the next. There are sons who are financially dependent on their parents even after marriage, while some are more independent. It is important to note that the extended family system still exists, although it is decreasing because of changes in society and the workplace.

In Saudi Arabia, the father is responsible for all of the members of the family and all their expenses (Shoult, 2006). Regardless of whether the mother is employed or has any personal wealth, the father must also cover her expenses and take responsibility for some of her affairs (Haykel et al., 2015). For example, many hospitals ask for permission from men before doing a surgery for the women (Abadeer, 2015). Also it is common to hear women saying 'I have to get permission from my husband' even for something as simple as accepting an invitation for a dinner. Boys become

independent when they reach eighteen, however women of all ages have to be under the guardianship of a man, such as her father, husband, brother, or even an adult son when the husband is not available (Abadeer, 2015). This means that the law occasionally requires women to obtain written permission from a man for activities that include marriage, travelling abroad, accepting a scholarship to study abroad, or when applying for a job (Wynbrandt, 2010). However, this practice was recently dropped with respect to the employment field, meaning that women can now get a job without obtaining the permission of a man.

A man might be responsible for more than one wife, as he is entitled to have up to four at the same time. No one can oppose this law because it is derived from the Islamic religion and it is therefore commonplace for men to have more than one wife. There are no official statistics for the incidence of polygamy in Saudi Arabia, but the evidence suggests that it is fairly common (Abadeer, 2015). It should be noted that while polygamy is not confined to a particular class in Saudi society, it is less common among young educated newlyweds and more common among older, more financially stable couples. The financial situation seems likely to play a role in promoting polygamy, since the financial responsibilities on the man will increase considerably if he has more than one wife. It is noticeable that many of the wealthy men have more than one wife, as well as religious men, who often follow the example of the Prophet Muhammad. In any case, men are not asked to present reasons when they want to have another wife, it is their decision.

Husbands also control divorce in Saudi Arabia. In fact, men can get a divorce by saying 'you are divorced' to the wife, whereas the wife has to go to the court if she wants to have a divorce (Kelly and Breslin, 2010). After the divorce, the mother automatically gets custody of the children until they reach the age of seven, on the

condition that she does not get married again. However, if the mother marries again, the custody of the children is transferred to the father, even if he is married to another woman. After children reach seven years old, boys are given the choice between staying with his mother or going with his father; however, once they reach the age of nine, girls must live with their fathers, unless the father gives permission for her to stay with her mother (Moghissi, 2005).

The previous examples clearly illustrate the male domination of Saudi society, based on religious and traditional grounds. All segments of society often agree about the aspects related to religion, such as polygamy, tutelage, the financial responsibility of the man, and custody (Al-Rasheed, 2013). However, acceptance of male dominance based on traditions is less universal, with some voicing disagreement with rules such as men having the last word of all aspects of life.

3.3 Education

The Ministry of Education is responsible for all the educational systems in the state, including the education of people with disabilities. According to the Saudi disability code, the government shall guarantee to provide services such as education to persons with disabilities (KSCDR, 2000):

This includes all phases of education ‘pre-school, general, vocational and higher education’ that are suitable to the abilities of the disabled and that are commensurate with their various categories and needs, including the continuous updating of curricula and services provided in this field.
(Article 2)

However, there are very few references to the concept of inclusive education in Saudi literature or in any education policies. The term was not present in the national report on education (MOE, 2008). The alternative in Saudi literature was ‘mainstreaming’, with the literature stating that:

There is an increasing support for the concept of mainstreaming and inclusive educational teaching practices, whereby students with special educational needs are placed into regular public education schools and are taught alongside their non-disabled peers.

(Al-Mousa, 2010: 9)

Al-Mousa, who was instrumental in the development of special education in Saudi Arabia, deals with the two terms, mainstreaming and inclusive education, as if they mean the same thing. However, the Saudi Ministry of Education has adopted the following definition: “Mainstreaming, operationally, means educating children with special educational needs in regular education schools, and providing them with special education services.” (MOE, 2002).

In response to the 2008 UNESCO report, ‘Education for All’, the Kingdom of Saudi Arabia clarified in the Education for All Global Monitoring Report paper that:

‘Education for All’ in the Kingdom of Saudi Arabia means the provision of basic education to those of suitable age. It includes all categories determined by the International Declaration on Education for All and International Conference on Education for All namely, early childhood, basic education, adult education, the education of those from deprived environments and girls’ education.

(Shaer, 2007)

Without clearly mentioning children with disability, this paper was presented as background to assist in the drafting of the 2008 report. Indeed, it seems a fair reflection of reality to state that inclusive education is in its infancy in the nations of the Arabian Gulf, including Saudi Arabia.

There is no GCC [Gulf Cooperation Council] wide common strategy for dealing with special needs students and each individual nation has adopted a spectrum of responses from segregation to partial, to ‘theoretically’ full integration.

(Weber, 2012)

Among Arab countries, Saudi Arabia is the first to begin implementing mainstreaming in its schools on a scientific basis (Al-Mousa, 2010). This process began in 1990, when the Ministry of Education started implementing mainstreaming on a narrow scale. The first theme of the educational strategy of the Ministry of Education, which

was presented in 1996, pertained to the role of mainstream schools in the education of 'exceptional children' alongside their 'normal peers' (Al-Mousa et al., 2008).

In Saudi Arabia, the Resource Rooms is the most used programme in mainstreaming as a 'full integration' as they name it. Beneficiary students of this programme are mainstream school students who face some difficulties such as in reading or maths. In this programme students take extra classes individually or in small groups in rooms called Resource Rooms. The second most commonly used programme is Specialised Classrooms, which is considered as being partial integration. The main targets for this kind of programme are special classes, run for children with disability by specialist teachers inside mainstream schools and for students in special schools (Al-Mousa, 2007). In order for a child with disability to be integrated into a class in mainstream schools, the student must meet some specific requirements. One of these is that their intelligence must be tested as at least 73 on the Stanford–Binet scale or 75 on the Wechsler scale, both of which are internationally recognised intelligence tests. The child should also not have a disability that hinders their education in the mainstream class, such as being completely blind or deaf, or having severe behavioural disorders. In big cities, there are special schools called Noor Institutes, which are for students with visual disabilities; schools for students with hearing disabilities, which are called Alamal Institutes; and schools for learning disabilities, which are called Intellectual Education Schools.

Gaad (2010) labelled the two types of programmes in Saudi Arabia as 'full inclusion' and 'partial inclusion'. I think the terms, used by Al-Mousa, are more accurate than the terms put forward by Gaad, since 'inclusive' does not have as many types as Gaad suggests [partial and full]. I think that the Ministry of Education implements

integration on many levels and cannot be described as inclusive education. As mentioned before, the Salamanca statement describes inclusive education as follows:

An ongoing process aimed at offering quality education for all while respecting diversity and the different needs and abilities, characteristics and learning expectations of the students and communities, eliminating all forms of discrimination.
(UNESCO et al., 2009: 126).

In addition to these levels of integration, in Saudi Arabia, there is still segregated provision. In fact, “according to the Ministry of Education in Saudi Arabia 2008, 96% of students with multiple and severe disabilities received their education in separate institutes in 2007–08” (Alquraini, 2011:3). This is the situation in many countries, where the special education setting is the preferred option for dealing with educational challenges (Mittler, 2000). In the Gulf region, this approach to formal educational systems is relatively new and this is reflected in the limited presence of special schools, which have only just been introduced to these nations (Weber, 2012). Consequently, there are often long waiting lists for these special education schools or institutes, meaning that many parents of children with disability in Saudi Arabia struggle to obtain places.

Besides partial integration, special institutes exist to separately cater for people with visual and hearing disabilities and people with mild and moderate learning difficulties. However, these kinds of specialised institutes are typically only found in major cities, although some of these offer internal accommodation in an attempt to include students from remote areas. In the case of children with motor disabilities, integration into mainstream schools requires them to have no difficulties in speech, writing or learning. Meanwhile, children with autism are treated the same as those children with learning difficulties, so if they meet the requirements of the centre then they will be placed in a special class alongside students with learning disabilities.

People with severe mental disabilities and multiple disabilities have no state special schools or institutes available for them, unless they want to be in residential centres. However, it should be noted that there are private centres and some charity centres that can provide the required support for them.

Indeed, rather than prioritising training or education, the current focus in Saudi Arabia is on ensuring the good health of people with disability. There is also relatively little support for people with disabilities in securing employment (Japan International Cooperation Agency, 2002).

3.4 Health

According to the WHO (2014), the recommended density of physicians per 10000 population is 23 or above. The World Health Statistics of 2014, showed that the density of physician per 10000 populations in Saudi Arabia is 7.7, compared to 27.9 physician per 10000 population in the United Kingdom (WHO, 2014).

These figures demonstrate that while the government, through the Ministry of Health, is ostensibly responsible for the health of all its citizens, actually getting access to proper care remains difficult for some of the populace.

3.5 Main Welfare Rights for People with Disability

The statistics show that the distribution of facilities for people with disabilities offers much better support for those living in or near major population centres, where schools and specialised centres are more commonly situated (Japan International Cooperation Agency, 2002). There is a number of welfare rights for people with disability such as:

- Monthly or half annually subsidy for parents of people with disability in order to take care of them. The subsidy will be cut off if the person with disability is in a residential centre.
- 50% discount on Saudi Arabian Airlines tickets and trains for the person with a disability and one person with him.
- 50% discount on Saudi Telecom Company bills for internal calls in the network. The person with a disability can benefit from this after they apply for an identity card, which can be obtained after the age of fifteen.
- Free equipment for people with disabilities, such as wheelchairs, hearing aids and vision aids.
- Car parking spaces for people with disability.
- The person with a disability is treated as an adult even if they are a child when it comes to the right to obtain a land grant. Land granting is a right for any Saudi male adult and a right for divorced and widowed women and females who have exceeded the twenty-fifth year without marriage. Similarly, any child with disability is entitled to apply for a land grant.
- Some people with physical disabilities have the right to receive a suitable car. Even children with physical disability above six years old can apply for a car.
- There are facilities in visas in order to hire maids, drivers or nurses, according to the specific needs of the particular disability (Al rubiyea, 2010).

From the previous list, there is evidently a focus on welfare rights for people with disabilities. Of these benefits, the subsidy is undoubtedly the most well-known, while the right to apply for a land grant is the least. However, not all of these facilities are as beneficial as the ability to obtain the visas required in order to hire home help, such as fulltime maids, drivers or nurses. This visa costs 2000 Riyals [£348] and is paid at most once every two years, whereas there is no support given for the recruitment fees, which typically exceed 10,000 Riyals [£1,742], or the monthly salary of the driver or maid, approximately 1500 Riyals [£261].

3.6 Summary

Despite the relative youth of Saudi Arabia, the state has experienced a period of rapid development in areas that include education and health, facilitated by the economic revolution driven by the discovery of oil. Strict adherence to the Islamic religion and loyalty to the tribal system has enabled the country to retain its national identity and traditions, although its development has been inhibited in some areas as a consequence. However, hopefully the populace of Saudi Arabia will gradually realise the importance of education and health for people with disability, enabling rapid and necessary development to be undertaken in the near future. Having looked at the research context, the next chapter is the methodological framework.

Chapter 4: Methodological Framework

4.1 Introduction

The selection and use of an appropriate research methodology plays a vital role in managing the research, in determining how data will be collected, and in ensuring that data will address the aims of the research (Salehi and Golafshani, 2010). Therefore, informed by the aims of the research, this chapter provides an overview of the reasons for the selection of the methodological approach that has been adopted in this study. The discussion then offers an overview of the main features of qualitative research, particularly as these pertain to this research and my role as a researcher. Details are provided with regards to the data collection process and the chosen methods. These approaches have been selected with consideration of factors that include salient ethical issues, sampling, trustworthiness, neutrality, triangulation and generalisation, and so these choices are outlined below. Finally, a discussion is provided of the strategies chosen for qualitative data analysis.

This research seeks to explore the impact and challenges of having a child with disability in Saudi Arabia, with particular focus on the implication for family support services. The study took place in Riyadh and Jeddah, the two biggest cities in Saudi Arabia (MEP, 2010). In addition to being the largest cities in Saudi Arabia, Riyadh and Jeddah were chosen for this study because the former belongs to the Middle Region and the latter to the Western Region the two most populous regions. The geographical distance between the two cities means that there are many differences in their demographics, culture, and their level of openness to the world. Jeddah is known as the most liberal and cosmopolitan Saudi city, perhaps due to its location on the Red

Sea and its historic role as a port and gateway to the holy city of Makkah, which receives millions of pilgrims of different ethnicities and backgrounds every year (Jeddah Urban Observatory, 2011). Moreover, given that I live in Jeddah, while the majority of my relatives live in Riyadh, it was convenient to convey movement and communication between the cities. Additionally, I had access to several useful contacts, without which it would have been considerably more difficult to collect in-depth data.

With regard to the narrative of the research, there are advocates for the use of both the first and the third person. Van Maanen (1988) supports the use of the third person, principally focusing on the avoidance of 'I', arguing that this will increase the authority of the research and at least partially alleviate concerns about subjectivity. However, Holloway and Wheeler (2010: 136) claim that this approach is "pompous and dull" when the research states "the researcher has found...the author does...the writer considers...etc."

On the other hand, Alvesson and Deetz (2000) believe that first person pronouns can reduce authoritarianism in the relationship between the researcher and the reader. Nevertheless, Holloway and Wheeler (2010) strongly recommend the use of the first person during the introduction and when describing the chosen methodology, such as 'I chose' or 'I collected', since this approach shows the accountability of the researchers for their actions. However, it is important to be particularly careful when using the first person in actions such as think, believe or feel, as it is not appropriate for use in these actions (Holloway and Wheeler, 2010). Many scholars believe that the materials generated in qualitative research are co-constructions from collaborative processes between the researchers and the researched (Gilgun, 2005). In this case, the use of the first person can foster diverse interpretations through the inclusion of the

researcher in the text (Alvesson and Deetz, 2000), which integrates the roles of the researchers more fully into the study (Gilgun, 2005). Wolcott (2001) advocates the use of the first person as the rule rather than the exception in qualitative research. This is because of the critical nature of the researcher's role and influence, which the reader has to be aware of through the narrative of the writing. Based on the views of the scholars who advocate the use of first person and due to the specific nature of my role in the research, as discussed later in greater detail, I have decided to use the first person in the narrative in this research. This approach has encouraged me to integrate and involve my opinion, as well as better enabling the inclusion of my previous experience.

4.2 Research approaches

The two main types of research are quantitative research and qualitative research. Quantitative and qualitative data are sometimes known as numerical and narrative research, respectively (Plowright, 2011). It is viable to apply either of these approaches independently, or to use both in combination, in an approach that is known as mixed methods. Denzin and Lincoln (2000: 3) explain qualitative research as follows:

This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them.

The role of humans' understanding in qualitative research is very clear in this definition. It shows two layers of interpretation: that of the researcher and the interpretation of the participants themselves, with an emphasis on the natural settings. With respect to settings, qualitative studies typically examine phenomena within particular settings in an attempt to understand them naturally, whereas quantitative

research uses numerical analysis that reduces data into numbers for a broader and more impartial analysis. Quantitative analysis is “...supported by the positivist or scientific paradigm, leads us to regard the world as made up of observable, measurable facts” (Glesne and Peshkin, 1992: 6).

According to Silverman (2006), quantitative research was widespread in many Western countries because it was more trusted. At the end of the 20th century, quantitative research showed inaccurate results in important surveys. For example, in the British general election in 1992, quantitative research failed in the surveys regarding voting intention (Silverman, 2006). It also failed in the telephone poll studies for the Truman–Dewey US presidential race of 1948. These failures led the beginnings of public doubt with regards to quantitative research approaches, resulting in a clear shift towards the use of qualitative studies, particularly in social research (Silverman, 2006). Nevertheless, deciding the research approach is an important step that must be derived from the philosophy of the research in question.

4.3 Research Philosophy

In any research philosophy, the development of knowledge (its ‘epistemology’) and the nature of being (its ‘ontology’) inform the reader of the way in which the researcher perceives the world (Saunders et al., 2009). This perception influences the ways in which a researcher plans their study and interacts with the world. This section discusses the ways that I have conceptualised my research philosophy, highlighting the influence that my epistemology and ontology have had on this research.

According to Burrell and Morgan (1979), epistemological assumptions are about knowledge; specifically, the agreeable knowledge in the field of research. Sikes (2004) claims that epistemology is very important and that it is impossible to carry out

research without considering it. The epistemology on the development of knowledge can be grouped into opposing views; positivism or interpretivism (Saunders et al., 2009). Positivism is the stance more commonly adopted with regards to research that deals with the world as external and objective. Consequently, Saunders et al. (2009) argue that research that adopts the viewpoint of natural science is often positivist. In this philosophy, research places a focus on facts rather than meanings. Because of this, positivist research typically prefers quantitative methods and includes large samples that enable the findings to be measured accurately (Easterby-Smith et al., 1991). In contrast, interpretivist research focuses more on meaning than facts. It aims to understand the role of humans as actors in social life and the humans themselves (Saunders et al., 2009). The main belief in interpretivist research is that the world is socially constructed and subjective. This means that the researcher will necessarily be a part of the observation process and that humans are the main focus of the science (Easterby-Smith et al., 1991). The epistemological approach of interpretivism focuses on the importance of interpretation in social science (Lazar, 1998). This sort of research focuses on meaning more than facts, so benefits from the adoption of a qualitative approach.

If the epistemology is the nature of knowledge, the ontology is the nature of being. Both of these concepts are important to understanding the philosophy of a given piece of research. Ontological assumptions are concerned with the social phenomena under examination, with the goal of describing the social reality (Burrell and Morgan, 1979; Saunders et al., 2009). Some aspects of the ontology are objectivism, which examines the social entity independently from social actors, and subjectivism, which is centred on the belief that social phenomena are generated from the perceptions and actions of social actors (Saunders et al., 2009).

My research aims to provide an in-depth exploration of the views of adults, in their real context. From the above research philosophy, and based on the nature of the research, the essential approach to this investigation is to be deemed interpretive. Therefore, this research takes a qualitative approach, based upon an interpretivist epistemology and a subjective ontological perspective.

4.4 Qualitative Research and the Role of the Researcher

4.4.1 Qualitative Research

Adopting qualitative methods for collection and analysis of data allows an in-depth investigation of research questions and phenomena, enabling them to be understood through discovering, exploring, developing and testing various assumptions about social reality (Miles and Huberman, 1994). Regardless of the method of data collection, Onwuegbuzie and Leech (2004) argue that qualitative research is dependent on constructivism, interpretation and the effective involvement of the participants, whereas quantitative research is primarily reliant upon the importance of neutrality. Quantitative research insists on the importance of neutralizing human relations, nevertheless qualitative research advocates argue that human relations do not always clash with neutrality, as they can be used to support a study if used carefully (ibid).

Usually qualitative research typically emphasises natural settings and studies phenomena within particular situations, in order to understand them logically (Denzin and Lincoln, 1994). The emphasis on natural settings is due to the impact that they have on behaviour and so the events that happen naturally will tend to carry interpretations for an individual for the normal course of their life. Qualitative research has been described as a “real world setting [where] the researcher does not

attempt to manipulate the phenomenon of interest” (Patton, 2002: 39). However, Woods (1999) argues that research requires some assumptions, preferably to be made far in advance, which are often obtained through the literature review.

Qualitative research investigates the construction of the socio-cultural and the process of the political in the social world, as well as the particular events and structures, as well as the relationship between them. It also explores the outcomes of these processes on the roles and relations of different actors, in addition to the perceptions and interpretations of the actors toward these processes (Silverman, 1993; Seale, 1998; May, 2011). This type of approach enables the researcher to gain a deep understanding of how the participants understand their worlds, which enables a realistic story to be presented of the complex social system (Marshall and Rossman, 2006). However, the complexity and variability of social life has different levels and has “many layers of meaning” (Berger, 1966: 34). Therefore, the research has to “lift veils” and realise the covert meaning (Blumer, 1976: 15). One of the main features of qualitative research is the focus on meanings, views and understandings. It is necessary for a researcher to distinguish and understand the behaviour of participants, as well as their understanding of situations and their opinions towards issues. These observations must be made while taking into account the time, since things may have different meanings on different occasions (Woods, 1999; Mason, 1996). The process is also very important in qualitative research. In the 1950s and 1960s, the focus in education research was on input and its relation to output, while the processes between them were ignored (Woods, 2012). However, qualitative research became popular in the 1970s, with a focus being placed on processes and the way in which things happen (Woods, 1999). It should be noted that this approach may require a substantial investment in time and effort on the part of the researcher.

In qualitative research, the term generalisability denotes the ability for the findings of one study to be applied to a much wider population or to other circumstances (Campbell, 1957). Studies that seek to draw generalised conclusions tend to use questionnaires in order to reach large sample sizes and consequently to generate generalisable data (Neuman, 2000), although it has been said that “The only generalisation is: there is no generalisation” (Lincoln and Guba, 1985: 110). Cronbach (1975: 124) argues that social phenomena are too context-specific to promise generalisability, which means that the priority of qualitative research should be to “appraise a practice or proposition... in context”. Denzin (1983: 133) also refuses generalisability as a goal, stating that “every instance of social interaction, if thickly described, represents a slice from the life world”. However, a level of generalisability can be attained by providing readers with an adequately detailed report that enables them to evaluate whether or not the findings are applicable to similar situations (Mays and Pope, 2000). Thus, rich description plays a vital role in enhancing the generalisability because it shows “that the researcher was immersed in the setting and giving the reader enough detail to ‘make sense’ of the situation” (Firestone, 1987: 16), which enables readers to make their own judgement.

One of the most important terms in the lexicon of qualitative research is the concept of ‘thick description’, which is a way of generating rich material. Denzin (1989: 83) defines ‘thick description’ as something that,

...does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion and the webs of social relationships that join persons to one another. Thick description evokes emotionality and self-feelings. It inserts history into experience. It establishes the significance of an experience, or the sequence of events, for the person or persons in question. In thick description, the voices, feelings, actions and meanings of interacting individuals are heard.

Effectively, this is a way of presenting multiple layers of information from the various angles that are involved in the research. In addition to meaning and interpretations of people in a culture, a thick description also deals with their intentions. This enables the technique to be used to create “a clear picture of the individuals and groups in the context of their culture and the setting in which they live” (Holloway, 1997: 154). Ponterotto and Grieger (2007) think it is impossible to have ‘thick interpretation’ without ‘thick description’, as thick interpretation is required for the written report to possess credibility and resonance among the research society, the participants, and its readers. Therefore, because this approach involves much more than amassing great detail, it is the task of qualitative researchers to produce thick interpretations of the actions or behaviours that are seen in the thick description and then to present these interpretations in written form, thereby making them available to the reader.

It is clear that the role of a researcher in the qualitative research is absolutely the most important factor in the research process.

4.4.2 Role of Researcher

Mason (1996) believes that the best descriptions of the qualitative research process are ‘exciting and ‘challenging’. Qualitative research is an active process that requires decisions to be made about every aspect of the investigation. There are two main features or considerations of this kind of research: the impact of the researcher on the study and reflexivity.

In addition to good planning, the ability and personality of the researcher are vital in the success of qualitative research (Holloway, 2005). This endeavour is dependent on the expectation that the researcher will be able to identify the key issues, suggest solutions, and understand the intellectual, practical, moral and political implications of

different ways of addressing those issues (Mason, 1996). However, given that it is not always possible to provide or suggest solutions to all problems, I think that an emphasis should be placed on understanding a research issue and making recommendations based upon that understanding.

The first aspect of qualitative research, which was the researcher's ability and personality, impacts on reflexivity, which is the second aspect of qualitative research. Reflexivity is related to the researcher's awareness of various influences on the processes of the study (Costello et al., 1996). It is essential for qualitative research to involve the critical self-scrutiny of the researcher, or at least the reflections of this self-reflection through the analysis and the findings (Mason, 1996). However, it is not enough for researchers to be aware of the influences that affect their studies. Instead, they may need to be flexible and to be able to make selected changes in order to cope with unanticipated issues. However, not everyone agrees that flexibility is in favour of research. While some people think this encourages researchers to be innovative, some see flexibility as indicative of a lack of structure (Silverman, 2006), which may decrease the strength of the research. Mason (1996: 5) stresses that qualitative research has to be "systematically and rigorously conducted", in order to avoid casualties or an "ad hoc approach". This means that a researcher needs to think and plan, then to follow a systematic and exact approach in order to achieve a high quality qualitative research. However, being systematic and rigorous does not necessarily entail a shortage of flexibility. In qualitative research, flexibility denotes the ability to make decisions in response to any unexpected changes in contexts and situations, instead of being constrained by the research strategy (Mason, 1996). In particular, understanding the culture of the participants may play an important role in dealing with unexpected situations.

Fielding (1994) believes that participants respond more favourably if they have things in common with the interviewer. Therefore, I believe that conducting research will be easier if I belong to the society in which the study is conducted. Sharing and respecting the same culture as the participants may help to minimise misunderstandings or potential sources of conflict between the researcher and the participants. In my research, the participants and I are from the same community, meaning that we therefore share the same culture. Additionally, my previous experience of working with parents of children with disabilities for four years has contributed to my communication skills and an awareness of how to phrase issues for clarity and minimal offense.

Nevertheless, it could be a challenge for the researcher when he or she is a part of the community of participants. This is because researchers need the ability to derive valuable information from familiar behaviour, such as everyday activities that seem normal to them (Woods, 1999). Therefore, researchers have to be able to disregard some of their pre-existing beliefs and opinions about their society, as these can affect their neutrality or hamper the discovery of some variables. As mentioned earlier, my research took place in Jeddah and Riyadh. I am from one society, Riyadh; I have lived in the other society, Jeddah; and I am studying in a different society, Hull, in the UK. This may have helped me to notice actions or moments that might more commonly be overlooked. However, I relied on the ‘thick description’ to present a clear picture of my study and to get the opportunity to receive comments in the first place from my supervisor. Although it is potentially time consuming, as I reviewed all of the data at least seven times, at different times, in order to make sense of it and to minimise the risk of missing important emergent data points. Moreover, I discussed a selection of

my analyses with my colleagues, who are from different backgrounds, to ensure its accuracy.

4.5 Data Collection Methods

Two main methods are used in the exploration of the attitudes and views of adults; questionnaires and interviews, both of which involve ‘asking questions’ (Plowright, 2011). As this study aims to explore the impact and challenges of having a child with disability in Saudi Arabia, the decision has been made to dismiss the questionnaire method for several reasons. Firstly, questionnaires are typically used to gather quantitative data, as the philosophy of my research is qualitative in nature. In addition, it is important to bear in mind that the concept of family support services is relatively new and no research has been conducted on this topic in Saudi Arabia. This is clear because the first family support organisation, namely the ‘The Saudi Association for Parents of People with a Disability’, only opened in October 2010. Creswell (2003: 22) argues that if “a concept or phenomenon needs to be understood because little research has been done on it, then it merits a qualitative approach”. Therefore, the qualitative research method chosen for my research is interviewing. This approach has been chosen to gain as much information as possible, to enable the research questions to be investigated in-depth and to therefore better understand the real situation.

4.5.1 Types of Interview

In qualitative research, individual interviews are considered the most widely-used data collection approach (Nunkoosing, 2005). Research interviews with individuals are usually divided into three types: structured interviews; semi-structured interviews; and unstructured or in-depth interviews (Saunders et al., 2009). Structured interviews use prearranged or identical sets of questions, with the researcher recording the answer

given for each question according to a standardised schedule that often uses pre-coded answers. Semi-structured interviews, also occasionally referred to as ‘themed conversation’, utilise pre-prepared open-ended questions that provide interviewees with the opportunity to express themselves while simultaneously retaining faithfulness to the overarching themes of the study. In this type of interview, it is more important to maintain fluency and ensure that all the themes are addressed than it is to rigidly follow the sequence of questions. The third type of approach, unstructured interviews, have one theme for the interview and the interviewees are given the freedom to speak openly about feelings, events, behaviour and beliefs related to the theme (Saunders et al., 2009).

In order to ensure a deeper understanding of opinions and views about all the considered themes, but while ensuring that control of the interview is not lost, this research utilised the semi-structured interview strategy with the participants. Each interview consisted of a number of carefully chosen set of closed questions, gathering important but predictable information, such as the age of the child or the education level of the parent. These are followed by open-ended questions, giving the opportunity for new questions to be raised during the course of the interview.

Semi-structured interviews can provide important and sensitive data (Fielding, 1993; Hall and Hall, 1996). Besides the sensitive data, the information can be rich and detailed due to the presence of the open-ended questions. Moreover, it is a flexible method in questioning and answering because the interviewer has the opportunity to ask for clarification and the interviewer can stimulate discussion and extend some points (Frankfort-Nachmias and Nachmias, 1996; Morgan, 1997). However, interviews are recognised as a time consuming approach (Weinberg, 1983).

It has been argued that the practical application of semi-structured interviews means that they are as viable to use with groups as they are with individuals (Merton, 1956).

Morgan (1997: 23) also states:

Focus groups and individual interviews can be complementary techniques across a variety of different research design in particular, either of them can be used in either a preliminary or a follow-up capacity with the other. This illustrates the larger point that the goal of combining research methods is to strengthen the total research project, regardless of which method is the primary means of data collection.

The combination of interviewing methods, such as individual interviews and focus groups, has to be for a reason, that is, to strengthen the research, but it does not matter how it is conducted in the first place as long as the decision is justified. The combination of methods helps to enable the creation of a wide image and to address some gaps in knowledge that cannot be filled through the use of one method (Morgan, 1997). This use of multiple methods enables the use of triangulation, which is when more than one method is used to gain the same information to increase the reliability of the research and strength the trustworthiness of the findings (Kvale, 1996; Denzin and Lincoln, 2005).

Triangulation appears in many forms, such as methodological, theoretical, investigator, and data (Briller et al., 2008; Denzin, 1970). Data triangulation refers to the use of multiple sources of information on the same subject. According to Denzin (1978) there are three main types of data triangulation: time, space and person. With regards to the third type, person, there are many sources for data in my research: one-to-one interviews with mothers; one-to-one interviews with fathers; focus group interviews with mothers; focus group interviews with fathers. The interviews took place in two cities, Riyadh and Jeddah, in addition to two remote rural areas, one close to Jeddah the other close to Riyadh. In addition, parents of children with a disability can be viewed as multiple sources in themselves, due to the differences in their

communities, the range in their children's disabilities, they were both men and women and of different age ranges.

So, in order to increase the trustworthiness of the results, I conducted another method of interviewing alongside the individual interviews: a group interview, which is called a 'group focus interview'. Moreover, the combination of individual interviews and focus groups can be used for data completeness (Adami and Kiger, 2005; Halcomb and Andrew, 2005)

Krueger (1994: 6) defines focus groups as "a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment". This shares certain characteristics with the definition proposed by Marczak and Sewell (1999), who describe focus group as:

A group of interacting individuals having some common interest or characteristics, brought together by a moderator, who uses the group and its interactions as a way to gain information about a specific or focused issue.

Focus groups can be useful in understanding people's opinions of a programme, event, or service and to explore the underlying motivation behind the thoughts or behaviours of the participants in a relaxed structure. This enables the researcher to effectively investigate cognitive and emotional responses of the participants (Heary and Hennessy, 2002). Basch (1987) has advocated that focus groups are a potentially effective way to realise the ideas and views of homogeneous members, which can often produce a varied range of information. This study focused upon the views of the groups with regards to particular points that were emphasised by the participants in the individual interviews, such as type of service or particular challenge. Some of the questions that were asked without prior planning arose from the discussions that occurred, in accordance with the semi-structured interview approach.

In addition to the large quantity of data that can be produced from focus groups, this method is flexible and can be combined well with other qualitative and quantitative methods (Morgan, 1997; Vaughn et al., 1996). Lewis (1992) also indicates that, unlike individual interview, focus groups can continue even if one participant does not respond. This means that this approach does not put as much pressure on one individual, which could be a motivation and a catalyst for returning to participate. I faced this challenge in some of the groups; some participants needed longer to participate in the discussion, so the information provided by other participants could motivate them to participate. This could be attributable to the two-way transmission of information, meaning that each participant receives and sends information, as well as reacts towards the information that is received. Almost all of the groups in the current study provided useful information to at least one of their members, especially with respect to information about available services that they may not have been aware of before attending the group. Although the interaction among a focus group is generally considered an advantage, there is the possibility of domination within the group setting which may reduce interaction (Lewis, 1992). I faced this challenge during some interviews, which required me to quickly and tactfully intervene in order to provide the opportunity for all participants to speak freely on each topic.

Comparing individual interviews with focus groups, focus groups are difficult to arrange as a time and place for the meeting must be suitable for multiple parties. This was different from the individual interviews, which only required an agreement to be made between the researcher and the particular interviewee. Kitzinger (1994) adds that a problem can arise in group settings, when the discussion turns to some sensitive personal matters and members of a group can become unwilling to participate further, out of a wish to avoid sharing about those issues with the group. In contrast, Fern

(1982) argues that participants tend to feel more anonymous in individual interviews than in focus groups. In the focus group in this study, while no personal topics were raised, many parents were willing to share personal issues with other participants.

Finally, the quality of the findings in a focus group is closely tied to the moderator's skills (Festervand, 1985). It could be better for the researcher to be the moderator, based upon knowledge about the aims of the research and enthusiasm to obtain the best results.

4.5.2 Data Collection Process

Since my research involves semi-structured interviews with individuals and focus group interviews, there was a need for audio-recording to ensure the smoothness of the conversations. This equipment was also invaluable in enabling the researcher to react to the need of generating new questions or responding to the participants' questions through the progress of the interview, instead of being distracted by note-taking. Moreover, audio-recording keeps the researcher focused on the discussion and perceiving the dynamics of the interview instead of getting distracted by taking notes (Kvale, 1996; Barrett and Cason, 1997; May, 2011).

We could not be certain that all participants would agree to the recording of the interview, perhaps because of the personality of the participants and their culture. Regarding Saudi culture, some mothers were initially worried about using audio-recording, because they did not received explicit permission about this from their husbands. I was able to somewhat reassure the participants that there would be no breaches of tradition or protocol, however, as no one would listen to the recordings except me. An additional obstacle was the fact that audio-recording can be confusing with focus groups, since there are many voices and interruptions. I insisted on the use

of the tape-recorder after gaining the participants' consent. However, a few mothers refused the use of audio-recording and I therefore did not conduct an interview with them. The use of a recording device for interviews was invaluable, as it offered me the chance to listen to the interviews multiple times, in order to transcribe the interviews and ensure that the comments of interviewees were properly reported.

Besides the tape-recording, the researcher should not miss the opportunity to record any critical ideas or any observations that may occur during the data collection process. These can be extremely beneficial to the reflexive monitoring of the research and for provoking recollection or organizing idea to clarify the research's direction (Silverman, 1993; Miles and Huberman, 1994; Bryman, 2004; Punch, 2006). I took notes, 'memos', during the meetings, as well as before and after the meetings. Taking notes can be more important in focus groups as this can help to distinguish the participants' voices, which may be indistinguishable when later listening to audio recording. It is important to take notes on the reactions of participants that are not displayed in the audio-recording, such as facial expressions. This approach also enabled me to recognise individual speakers when they were talking more quietly. However, taking notes during the individual interviews was much more difficult, given the active role that I needed to take in the conversation with the interviewee. Therefore, in the case of individual interviews, I tended to record the majority of my notes immediately after the interview. In fact, my memos took me back to the meetings time, thus ensuring that I was better able to reflect holistically and act as a more effective moderator.

Additionally, the interviewer has to be ready to capture any action that may generate data through meetings (Morgan, 1997). Fontana and Frey (1994: 365) advise that the interviewer should strive to be "flexible, objective, empathic, persuasive, a good

listener”. It is important for the moderator to display objectivity, while managing the interview and enabling all interviewees in the focus group to express their opinions freely, avoid hegemony by some participants, and ensure that the interview topic is sufficiently covered (Flick, 2006).

The effectiveness of interviews relies heavily on the researcher’s role and therefore on their skill and knowledge (Morgan, 1997). Kvale (1996: 103) argues that “good interviewers require expertise – in both subject matter and human interaction”. I think that a researcher has to be able to put participants at ease, creating an environment in which people feel comfortable to speak. This role also requires a sensitivity and awareness of the interview’s theme, as well as the methodology that has been selected for the research.

No matter how much the researcher plans the research, there is likely to be non-controllable and unexpected issue, such as the personality of participants. Problematic interviewees can take different forms (Marsiglio, n.d.). These might include non-talkers, who give short and deficient answers, or ramblers, who talk about topics that are not related to the research and who must be brought on topic without losing their cooperation. Some participants may be uncomfortable about some questions, which would require the researcher to be able to evaluate the situation and make spur of the moment decisions to reword or even ignore some questions. In addition, some participants may inadvertently contradict themselves in their answers, which entails the researcher being able to recall previous statements and deduce truthfulness without questioning the credibility of the participant. It is not only contradictions that the researcher may face, but participants may also refuse to give clear descriptions or may wish to embellish themselves, if the truth defiles their self-image or if they are trying to impress the interviewer (Fielding, 1994). The chance of meeting participants who

misunderstand the purposes of the study is also possible, they may look for solutions from the research (Marshall, 2007).

In fact, during this research process I encountered all of these types of interviewees to varying degrees. For example, some mothers were ramblers and strayed off the subject, while fathers -especially the activists- seemed to be keener to enhance their image and demonstrate their knowledge, meaning that it often took time to elicit the truth due to the contradiction in their answers. Although mentioning the research's objective, I met parents who expected some benefit from me. This was understandable, since I was dealing with parents of children with disabilities who suffer from a lack of services, so the researcher who discusses those shortages presents the hope for these individuals to gain a payment for their contribution. Although this point was clarified at the beginning of every interview and all the participants signed the consent form, some of the interviewees required me to clarify it again several times during the interview to remind them and make sure they understand the purpose of their involvement in the research. Finally, during the interviews it is necessary to strike a balance between formality and informality, thereby ensuring that the participants feel comfortable and that they are able to cooperate effectively without asking the researcher personal questions or opinions before they answer. This reinforces the importance of interviewer skill in creating a balance and responding effectively to the questions of interviewees.

Taking into account the previous issues and how to deal with them, I was able to deal with unexpected situations in a professional manner. This was partially reliant upon my understanding of the social and political context of the study's field and my reading. Furthermore, I was able to overcome some emergent issues by drawing upon my particular professional skills and my previous experience as a teacher of children

with disability, as well as my experience as a trainer for mothers of children with disability. For example, when a mother refused to be interviewed because of the audio-recording, I told her that:

Yes you are right, I understand your refusal, it is not even easy for me to be audio-recorded. However, this research is an attempt from me to be a tool in improving the services for parents which will reflect on their children. In fact, according to the ethics of research, I have to delete the recording once I transcript it, even if you do not mind if I keep the recording, I cannot ignore the research ethics. Finally it is up to you if you want to participate in this research for children with disabilities or not.

Most of the mothers changed their mind and agreed to be recorded during the interview. Of course, awareness of types of bias and potential problems helps to avoid them, which I discuss later in more detail.

4.5.3 Interviews

One of the researcher's preparations for the interview, is what should he or she focus on. Beside the importance of facts and information, Kvale (1996) states that a clear understanding of the meaning of what an interviewee says is more important. Additionally, the selection and design of good quality questions can make responding and understanding much easier. In order to design suitable questions, there are three main guiding principles: to have a direct link to the study's subject, to ensure that they are easy to answer, and to select the right sample (ERIC/AE, 1997).

With a view to extract vital information from the interviewees in a non-threatening way, the personal abilities and skills of the researcher play a crucial role. It is particularly important to ensure that the confidentiality of information is respected, not least because this is key to obtain the trust and maintain the flow of answers from the participant (Lindlof and Taylor, 2002). Consequently, the formulation of comprehensive questions of the interview can have a great influence on the success of an interview. Broad questions have to be translated into hypotheses or into sub-

questions that are easy to answer (ERIC/AE, 1997). This has become a fundamental requirement, with some questions that are difficult to answer, such as a direct question asking about a particular concept (Morgan, 2002). In this situation, a question can be divided into a series of simple questions.

In order to ensure the quality of the questions asked during the interview process, each of them should be piloted before they are presented to the interviewees. In my research, I adopted a three stage review process: firstly, a consultation with my supervisor; secondly, the questions were piloted with a person who belongs to the same society and sample group as the interviewees; and thirdly, I conducted a personal evaluation of each interview. This means that I will be flexible and modify the questions according to individuals, but without adjusting the meaning of the questions. However, for me to choose the appropriate time for the question to be raised is more important than the exact sequence of the questions to be asked, as the smoothness of the conversation needed to be maintained in order for participants to feel at ease, speaking about personal matters (Appendix A, B).

Broadly speaking, it is possible to categorise interview questions into six general areas: background, behaviour, beliefs and opinions, feelings, knowledge, and information (McNamara, 1999). In my research I used various questions to ensure that the interview covers all aspects of the study. However, most of the questions deal with opinions and beliefs, while sensitive questions such as income or family problems were excluded, although many parents were willing to share this particular type of information. Optional questions were included to gather data about factors that may affect the kind of family support services available to each participant, such as age and education. Additionally, care was taken to ensure proper wording of the question to

help each interviewee to think about and respond to the topic matter in a clear and logical way.

McNamara (1999) suggests that some strategies be followed to support the clarity of the interviews, which was taken into account in designing the interview questions in my research. Firstly, the main topics such as issues in education and health were discussed as an introduction in the first question, which was about the parent's story with his/her child, from pregnancy until today. Spreading questions about the facts throughout the interview can help to minimise the likelihood of an interviewee feeling anxious or scrutinised because of the successive personal factual questions. Furthermore, the use of a timeline can help to structure an interview and facilitate recollection, with questions about the present being asked first, to motivate them to share their ideas about a time that is easy to remember, after which questions can deal with events or emotions from the past and thoughts about the future (ibid). Finally, the last question of the interview will be open, offering the participants the opportunity to discuss any issues that they think are important. Indeed, the wording of my questions differed from one parent to another, according to area since the dialect is different from Jeddah to Riyadh. It was also important to consider that wording of the questions should also vary depending on the age of the parent and their level of education.

4.5.4 Time and Location

Conducting interviews can be an extremely time-consuming process, which adds a major challenge to the research process. James and Busher (2006) advise the researcher to use allotted response times, to enable them to better control the discussion and avoid unwanted conversation. Creighton (2005) claims that a typical interview should take at least 30 minutes and, in this study, the actual duration for an

average interview was between 60 to 90 minutes. However, up to three hours was allocated for the interview and its arrangement in this research, which includes waiting time before the interview and the social requirement to chat after it, the low value of time in Arab culture, and the consideration of potential transportation issues, such as travel times or the need to wait for drivers. For the focus groups, the actual duration was 90 to 120 minutes. However, it was felt that setting an allotted response time in both types of interview could potentially have a negative effect on the comfort of some participants, so the time was left open and the duration determined by the direction of the conversation.

Where and when the researcher conducts an interview plays a crucial role in its success, which heavily depends on the individuals involved. Lindlof and Taylor (2002) advise that busy days should be avoided, adding that a comfortable and calm place should be found for the meeting. I was looking for a neutral zone like a school or a public area, such as a coffee shop or restaurant, since the shops are very quiet in the morning. In fact, it was easier with individual interviews, I set the time in accordance with the wants and needs of parents, with mothers all being met in the public places of their choice. However, the decision was made to avoid conducting interviews in the houses of the participants, because a stranger should not typically enter a home and, when they do, Arab etiquette may have resulted in the hosts giving priority to hospitality over the interview. I met the fathers as individuals or groups in my brother's office, since I cannot meet them in public places because it is not acceptable in the community or with the religious police. Even in my brother's office, I cannot be alone with a man due to cultural and religious reasons, so I brought a lady with me from Philippines [my housemaid] who cannot speak Arabic to maintain the privacy of the father. Each of the fathers was asked for permission for this in advance

of the interview. My brother was also in the office, although he stayed in a different room.

Time and place in focus groups were very difficult to agree upon. To encourage mothers to attend, I invited them to dinner in a nice, quiet restaurant that had rooms available to enable us to remove the veils covering our faces to see facial expressions.

4.6 Participants

4.6.1 Number of Interviews and Size of Groups

Kvale (1996: 101) advises researchers to “interview as many subjects as necessary to find out what you need to know”. The number of participants in qualitative research can be small or large, depending on the research subject and the point at which further interviews will not offer additional information (ibid). Barrett and Cason (1997: 106) add that “when you begin hearing (and believing) the same answers over and over again”, this should signal the end of the data collection task. This point, at which data does not add any depth to the topic, is known as ‘saturation’ (Strauss and Cobrin, 1998: 212). Regarding focus groups, Vaughn et al. (1996) suggest that groups be kept small and manageable, typically comprising 6-12 members.

In my research, I have 42 participants, 20 of whom participated in one-to-one interviews. In Jeddah, I talked with 4 mothers and 4 fathers; a further 4 mothers and 4 fathers were interviewed in Riyadh; and 2 mothers and 2 fathers from more remote regions also took part. I then conducted six focus groups. Four of these were groups of mothers: 2 in Jeddah and 2 in Riyadh, each with 4 participants. The remaining two focus groups contained fathers: the first in Jeddah and the remaining group in Riyadh, each with 3 participants. In fact, I was planning to have 4 fathers in each group, but

was unable to find sufficient willing participants, so I decided to conduct the focus groups with 3 fathers.

Some researchers elect to begin with individual interview data, then use the focus groups to confirm their findings (Plack, 2006). Conversely, some researchers start by collecting data from focus groups, then verify the findings with individual interview data (Dick and Frazier, 2006). For my research, I decided to conduct individual interviews first, then to use ideas that emerged from the individual interviews to inform the discussion in focus groups, in order to obtain more details and views about key topics. To make the best use of the time that I have, I conducted interviews first in Jeddah, where I live, and then in Riyadh. This meant that so I was able to arrange the Riyadh interviews and trips to more remote areas while conducting the Jeddah interviews. My first data collection trip involved conducting the individual interviews, after which I returned to the UK to transcribe the interviews and prepare the questions for the focus groups. The focus groups were conducted during my second trip to Saudi. Again, I held the focus groups of mothers in Jeddah, then moved to Riyadh to interview groups of mothers and fathers, then returned to Jeddah to conduct the focus group of fathers that I had not been able to arrange in the beginning. After evaluating the situation and the collected data, I decided that there was no need for further interviews, because the point of saturation had been reached.

4.6.2 Participants Selection

I used the snowball sampling technique (May, 2011; Miles and Huberman, 1994), since I needed to rely on social contacts, interviewees, and professional networks in Saudi Arabia to act as intermediaries to contact resource persons and potential informants.

Some of my participants were "good informants" (Morse, 1996: 228), meaning people with knowledge, experience and information that they were willing to share that with the researcher. This type of informant has important information about the research topic and can serve as a valuable resource upon which the researcher can rely heavily (Lindlof and Taylor, 2002). However, I tried to have a variety of participants, in terms of their knowledge, education and interest in the subject of family support. In my research, a good informant is any person who has a reputation among members of the community as being culturally knowledgeable, willing to be interviewed, and accessible to me. Most importantly, a good informant has to be seen to be seeking out the interest of their child. Since many families of children with a disability in Saudi Arabia rely on nannies for full time care, the activist parents were deemed to be 'good informants' in my research.

The challenge for me was to gain collaboration with those participants who were not looking for any real support for their family from any organisations. I reached many of these individuals through mediators and attempted to open communication with them, but unfortunately they refused to collaborate, primarily due to existing commitments and scheduling difficulties. Another type of parent that I heard about from my participants but could not reach were those who felt ashamed of being parents of children with disability.

In my participants, there were no requirements for the level of education or the social class and I was able to achieve a very good level of variation, as mentioned in the aforementioned section on triangulation. In the focus groups, Vaughn et al. (1996) argue that one of the core elements of a focus group is that its members should be relatively homogeneous, such as in terms of the ages or types of disability of children. The members of each focus group in my research came from the same city and all

have children with disabilities; moreover, due to the uniqueness of each culture, each focus group consisted only of individuals of the same sex.

There are significant differences between Middle Eastern countries and the Western world in the power dynamic and typical kinds of communication between males and females. For instance, Marshall (2007) explains that females defer to males in many developing countries, whether these men are husbands, fathers, or brothers. In these contexts, mothers are less likely to give their views in the presence of the father, due to the expectation that women should remain silent out of respect for the man's words, or at least to agree with him (Marshall, 2007). This subordination may have an influence on the credibility of the outcomes. Therefore, it is unwise to hold an interview with a mother in the presence of the father. Likewise, interviewing a man in the presence of his wife may adversely affect the trustworthiness of the information being provided, as he may be more likely to show his dominance and idealism in her presence. The formation of mixed focus groups is therefore often an inappropriate option. For me, there were no issues with interviewing mothers, either individually or in a focus group, because we are the same gender. However, the cultural and religious considerations inherent in Saudi society make the process of a female interviewer working with male participants complex and delicate. It is unacceptable for a female researcher to be alone with an unknown man, for example. So, individual interviews required a third party to be present. Therefore, as I mentioned previously, I was attended by a lady from the Philippines in every meeting; as she cannot speak Arabic, the privacy of the fathers was maintained. The presence of the interviewee's wife was dismissed an option, because it is inappropriate, the conversation may touch on the husband's opinion of the support provided by his wife or his extended family, which could potentially limit his willingness to express his opinion. For the same reason,

while I interviewed two couples, I did so separately. However, due to Saudi cultural expectations, conducting focus group interview with fathers required extensive communication, consideration and hard work to make possible.

Regarding triangulation, I interviewed 42 parents; there were parents of children with Down's Syndrome, autism, learning disability, physical disability, hearing disability, visual disability, and children with multi-disability. There were also parents of children with mild, moderate and severe disability. The age of the children in the sample ranged from 4 months to 17 years [see table 1, 2]. Additionally, there were parents of children with disability as the only child, first child, last child, middle child, those with a twin, those with a sibling who has the same disability, and children who have a sibling with a different disability.

Table 1: a list of fathers that were interviewed

The fathers: F=fathers, R=Riyadh, J=Jeddah U=rural area G=group, I=individual

Code	Type of interview	Child Gender/age	Type on disability	Any comment
FRI-1	Individual	G/15	Spina bifida	The only girl between boys
FRI-2	Individual	B/13 B/10 B/8	Visual disability	They have one big brother without disability. Their mother is [MRG-6]
FRI-3 Activist	Individual	B/11	Cerebral palsy caused quadriplegia	In the middle
FRI-4 Activist	Individual	B/9	Autism	In the middle
FRG-5	Focus group	B/7	Autism	The only child
FRG-6	Focus group	G/5	Autism	In the middle
FRG-7	Focus group	B/13	Hemiplegia at the age of five as a result of	In the middle

The fathers: F=fathers, R=Riyadh, J=Jeddah U=rural area G=group, I=individual

Code	Type of interview	Child Gender/age	Type on disability	Any comment
			infection	
FJI-1	Individual	G/7	Atrophy of the brain	Her eldest sister died, she has younger sister
FJI-2	Individual	B/9	Atrophy of the brain and Quadriplegia	He is the eldest
FJI-3	Individual	G/8	Spina bifida	In the middle
FJI-4	Individual	G/11	Cerebral palsy	The only child. Her mother is [MJI-4]
FJG-5	Focus group	G/9	Cerebral palsy	Has twin without disability
FJG-6	Focus group	B/9	Brain edema, weak bones, spine deviation, Speech difficulties and learning disability	The last child
FJG-7	Focus group	G/13	Complete paralysis after car accident when she was 3 months	Her mother and sister died in the accident, she has sisters from step mother
FUI-1	Individual	B/6	Autism	The only child
FUI-2	Individual	G/4	Home accident caused damage in brain	The only girl between boys

Table 2: a list of mothers that were interviewed

The mothers: M=mothers, R=Riyadh, J=Jeddah U=rural area G=group, I=individual

Code	Type of interview	Child Gender/age	Type on disability	Any comment
MRI-1 Activist	Individual	B/11	Down's Syndrome	The last child
MRI-2	Individual	B/17 G/11	Hearing disability	The last two children
MRI-3	Individual	B/6	Down's Syndrome	The last child
MRI-4	Individual	G/9 G/4months	Visual disability Spina bifida	Have two sisters without disability

The mothers: M=mothers, R=Riyadh, J=Jeddah U=rural area G=group, I=individual

Code	Type of interview	Child Gender/age	Type on disability	Any comment
MRG-5	Focus group1	G/10	Down's Syndrome	The last child
MRG-6	Focus group1	B/13 B/10 B/8	Visual disability	They have one big brother without disability
MRG-7	Focus group1	B/7	Down's Syndrome	The last child
MRG-8	Focus group1	G/10 B/4	The girl muscular atrophy and learning difficulties. The boy Cerebral palsy	They have a sister without disability
MRG-9	Focus group2	B/13	Spina bifida	The last child
MRG-10	Focus group2	B/10	Spina bifida	In the middle
MRG11	Focus group2	B/4	Spina bifida	The only child
MRG12	Focus group2	B/12	Cerebral palsy	In the middle
MJI-1	Individual	B6	Cerebral palsy	The last one
MJI-2	Individual	B/16	Learning disability	The last one
MJI-3	Individual	B/8 B/20months	White matter disease	They have big brother without disability
MJI-4	Individual	G/11	Cerebral palsy	The only child
MJG-5	Focus group1	B/4	Cerebral palsy	The first child and has brother without disability
MJG-6	Focus group1	B/2	Cerebral palsy	The first child and has brother without disability
MJG-7	Focus group1	B/6	Cerebral palsy	The only child
MJG-8	Focus group1	B/4	Cerebral palsy	In the middle
MJG-9	Focus group2	G/14	Down's Syndrome	In the middle and has twin without disability

The mothers: M=mothers, R=Riyadh, J=Jeddah U=rural area G=group, I=individual

Code	Type of interview	Child Gender/age	Type on disability	Any comment
MJG-10 Activist	Focus group2	B/12	Autism	The last child
MJG-11	Focus group2	G/11	Hearing disability	The first child
MJG-12	Focus group2	B/6	Down's Syndrome	The first child
MUI-1	Individual	G/6	Atrophy of the brain	In the middle
MUI-2	Individual	G/8	Atrophy of the brain	She has younger sister

Table 2: a list of mothers that were interviewed

There were also parents of children in special schools, in mainstream schools with full or partial integration, children who did not go to school at all, and some went for a short period then they stayed at home. There were young parents who are still university students, retired parents, resigned parents, mothers as housewives, parents working in the government sector, those working in the private sectors, and those working as businessperson. The education of parents spanned from uneducated parents, including some with limited education, to those with graduate degrees. Some from wealthy families, the most were from average families and there were families with low income. Although a few parents belong to a tribe, others do not. I interviewed two couples but separately. I interviewed divorced mothers, mothers in the process of divorce, wives of men who have more than one wife and I interviewed single parents due to the death of the wife or because the husband was in prison.

4.7 Ethical issues

The ethical consideration in any professional research is very important, especially if the research involves humans. There are a number of ways to conform to ensure that a

given research project is giving due consideration to ethical issues, some of which are independent. Marshal (2007) explains that the main goal of independent Research Ethics Committees (RECs) is to offer supervision and approval of research proposals, in an attempt to ensure that each piece of research meets the desired ethical requirements. However, even if an organisation is independent, they may have additional goals besides ensuring ethical compliance. As a consequence of this, some RECs in developing countries are not very efficient, due to a desire to gain a financial benefit from the implementation of research. In addition, when the REC is not independently managed, or lacks authority, it can simply serve as a formality (NBAC, 2001). In this research, while gaining the formal authorisation is the first step, the personal ethics of the researcher play an important role in monitoring this process.

There are major principles that are associated with ethical conduct: firstly, do no harm. This means that if the researcher notices any participant is having an adverse reaction, the researcher should stop the study, even during the actual research process and after gaining informed consent (Lichtman, 2010). However, in my research, there is no harm of this kind, although the potential risks will be discussed later. It is also essential to ensure privacy and anonymity (BERA, 2011): the researcher should remove identifying information, such as names of people or organisations from the records, and use pseudonyms for quotations. In addition to considerations of privacy and anonymity, it is important to maintain confidentiality with the information and results. When conducting the interview, a line must also be drawn between good rapport and friendship. While rapport is important to encourage the disclosure of information by participants, the researcher should avoid playing the role of a friend, thereby tricking or coercing participants to give more information than they might wish to provide (Lichtman, 2010). I attempted to be aware of these factors, based on

my knowledge of Saudi mothers. Therefore, I avoided exaggerating sympathy with their situation, so that they would not give more information than they want. Similarly, the researcher has to avoid intrusiveness and not abuse the power held over participants in an attempt to extract more information than required by the research. Participants should feel comfortable that a researcher will behave appropriately, despite the fact that “there are documented examples of inappropriate behaviours between teachers and their minor students, between therapists and their patients, and between researchers and their participants” (ibid: 57). According to Saudi culture and the tenets of Islam, it is not acceptable for the researcher to be alone with a participant from the other sex. It is expected that all individuals respect that, with the religious police being responsible for monitoring the public behaviour, which reduces the possibility of exhibiting behaviour that is not culturally accepted. The researcher is responsible for dealing with data in a manner that avoids or minimises the opportunity for misquotes, misinterpretations, or fake analysis, and has to provide evidence for that. Finally, a researcher has the responsibility to ensure that all the participants are informed and that informed consent is explicitly given (BERA, 2011).

4.7.1 Informed Participation

In order to respect the principles of research ethics, all participants must give their informed consent. This means they must have clear information about the nature and purpose of the study. In addition, they have to be knowledgeable about aspects that include the specific objectives of the study, sources of funding, and any potential advantages or disadvantages involved in their participation. All participants should be provided with clear notification about their right of cooperation or withdrawal at any point through the research without being subjected to pressure or reprisal (NBAC, 2001). Informed consent requires an official document to be presented at the start of

the research process. This document should outline that freedom of choice will be provided to the participant throughout the progress of the research.

In some cases, language differences between a researcher and study participants can be an obstacle to real informed consent. However, even when the researcher and the participants share the same language, it can be difficult for many participants to understand the information, conditions and terms that are often found in informed consent letters (Marshall, 2007).

This research went through the Ethics Committee to gain the ethical approval from the Faculty of Education (Appendix C), which granted permission for me to present the ethical approval to the interviewees. Since the ethical approval is written in English, I supported the ethical approval with a written, plain language version of the statement in Arabic, to help participants understand their rights and the specific nature of the research (Appendix D).

Potential risks are very important and have to be clarified to gain informed consent. However, potential risks often cannot be measured, which may become hard to grasp (Marshall, 2007). Additionally, potential risks may have different meanings from the viewpoint of the researcher and the understanding of the public, which can be exacerbated by the researcher's language, becoming more confusing for participants (Morgan, 2002). However the direct exposure of potential risks may scare, upset, or worry participants (NBAC, 2001). Furthermore, the concept of risk is understood in different ways by different communities. For example, some communities think that discussing bad experiences is a potential risk because it may lead to negative feelings and hurt emotions, while it may be common in other societies to discuss all experiences, even those that are negative or personal.

In my research, supported by my knowledge about Saudi society, there is little that could be considered as a potential risk, except three possible issues. Firstly, the privacy and anonymity in focus groups, which cannot be guaranteed because there are other participants (Gibbs, 1997); this can be addressed by avoiding questions about very personal issues. The second issue is that some mothers think they have to have their husband's permission to participate, to avoid causing family troubles, I respected that decision and offered the option for easy withdrawal with thanks to those mothers. The third issue is talking about political issues, potentially a risk to both any researcher and participant alike, which may create some troubles with the government. Political views in interviews can be considered to be a sensitive topic (McCosker et al., 2001). In an attempt to avoid panicking participants, I decided to avoid raising these risks with participants apart from in those cases where the conversation had turned onto potentially problematic ground. For example, if an interviewee seemed to be about to express unacceptable criticism of the government or state, I intended to warn them of the implications of their choice and to steer the conversation back onto the topic of family support.

4.8 Trustworthiness

Lincoln and Guba (1985: 296) suggest that the trustworthiness of qualitative research is essential to evaluate its worth, meaning that findings are “worth paying attention to”. Trustworthiness involves four issues: credibility, transferability, dependability, and confirmability (ibid). They add that credibility denotes the traditional term ‘internal validity’, meaning that the results of the research should be credible or believable from the viewpoint of its participant. Generally speaking, this can be achieved by means of prolonged engagement and persistent observation in the field of

the study, as well as by discussing elements of the data that do not support or contradict the data that emerges from the research (ibid). Transferability describes the concept of 'external validity', which means showing that the findings can be applied to other contexts. When done well, this can be achieved by thick description. Dependability corresponds with 'reliability', showing that the findings are consistent and reproducible. This is often achieved by evaluating the accuracy through external audits that are not distinct from the examination of process and product that takes place during the research. The consideration of confirmability parallels 'objectivity', meaning the maintenance of a level of neutrality and the extent to which the respondents generate the findings and researcher bias, motivation, or interest. This can be achieved by triangulation and reflexivity. Crucially, it should be noted that there are generally "no procedures that will regularly (or always) yield either sound data or true conclusions" (Phillips, 1987: 21).

Indeed, it is important to bear in mind that researchers are fallible. Like any person, they may make mistakes and occasionally get things wrong (Norris, 1997). Regarding my research, I endeavoured to do my best, using insights gained from my belonging to the same society as the participants and my prior experience in the field of families of children with disability, both of which helps to check the accuracy of my findings. I am well versed in the vernacular in both Riyadh and Jeddah, including the meaning of some indirect terms and some well-known exaggerations. Some of the questions were rephrased in different settings and in different ways to check the information without offending the participants by questioning their credibility. Moreover, I employed several techniques to increase the trustworthiness of my findings, such as discussing the different perspectives offered in the literature review, having the work reviewed

by my supervisor and colleagues, or my use of the thick description approach in the presentation of data.

Regarding neutrality, some human relations can be supportive of the study if they are used carefully, although this raises the threat of interviewer bias and personal influence (Frankfort-Nachmias and Nachmias, 1996). Onwuegbuzie and Leech (2004) argue that neutrality does not necessarily have to clash with human relations. Identifying potential sources of bias is possible; however, the difficulties lie in constructing rules by which to achieve neutrality. Bias can come in different forms, such as through the way in which researchers behave with participants or through particular sources of information. Another common risk is selection bias, which can occur when choosing the participants, times, places and questions. There is also potential bias in the accessibility and reliability of various sources or data; bias in the affinity of researchers with certain types of participants, data, theories, concepts, explanations; or bias due to the personal qualities of researchers, such as their personal capacity for concentration and patience (Norris, 1997).

Beside triangulation and the reflectivity I sought to achieve neutrality in the semi-structured interview through leveraging my existing professional knowledge, my previous experience in interviewing, the awareness of potential threats and my understanding of the participants' culture. For example, I introduced myself by my first and middle name, without mentioning the last name. This was intentional due to the fact that I share my last name with a famous and respected religious man, we call him sheikh. As I do not know the opinion that the parents have of him and I want to prevent any positive or negative impact that their presumption of a familial relationship might have on their behaviour. I tried to ensure that I have suitable participants in terms of the type, size, place and time. In terms of interview questions,

after consulting my supervisor, I tested the interview questions with two people to ensure their quality and clarity. Moreover, I did not take unusual responses into account, even if they are interesting, unless they were echoed by multiple participants. Due to the limitation of human memory, which can be biased because of its tendency to preserve the most interesting information, I attempted to increase validity by taking an audio recording of the interviews. I supplemented this by taking notes for some issues that were absent from the audio recordings, such as facial expressions or body language, as well as transcribing the recordings. This enabled the use of strategies such as recasting some interviewees' responses to help in ensuring that their meanings were correctly understood. Finally, I tried to adjust my reactions, including my body language and facial expressions, and to focus on the words that I used while interacting so as to not carry any overtones or hints for specific answers.

4.9 Qualitative Data Analysis

The analysis of data typically involves its exploration, description and interpretation (Miles and Huberman, 1994). Data analysis can also be defined as a:

...process of piecing together data, of making the invisible obvious, of recognising significance from insignificance, of linking seemingly unrelated facts logically, of fitting categories one with another and of attributing consequence to antecedents.
(Morse, 1999: 25)

The aim of collecting data in any research is to answer the research questions. However, there are “few agreed-on canons for qualitative data analysis, in the sense of shared ground rules for drawing conclusions and verifying their sturdiness” (Miles and Huberman, 1994: 16). Therefore, the adoption of a systematic approach to data analysis can reduce the impact of inevitable human deficiencies (Robson, 1993), thereby increasing the focus on the research questions.

4.9.1 Preparing Data for Analysis

The first stage of data analysis in this context was the transcription of the interviews from audio-recordings or memos to written forms using 'Microsoft Word'. This phase was extremely time consuming, since I had more than 40 hours of recordings. However, it is important that the researcher prepares transcripts in as much detail as possible and that they attempt to gain a better grasp of the data by doing individually, rather than relying on an assistant. This latter point was particularly important in my context as I promised the mothers that no one else would listen to their interviews. To distinguish between the comments or notes of the researcher and the words of the participants it is useful to use some tags like CAPITAL letters, **colours**, square brackets [], **highlighting**, **bold**, *italics* or underline (Saunders et al., 2009). However, doing the transcription is not enough to prepare data for analysis. I also carefully read and re-read the interviews, in order to understand and analyse the data in the context of the research questions. In this study, all the interviews were conducted in Arabic, for reasons of time efficiency and to ensure complete understanding of the data. I did not translate the interviews from Arabic to English. I read each interview at least seven times. In addition, I used square brackets to comment on things such as facial expressions, the tones or body language of the participants, all of which were recorded by notes taken during the course of the interviews or immediately upon their completion. To ensure clarity, I used many colours of highlighting, using each colour to refer to a specific subject (Appendix E).

4.9.2 Coding, Creating Categories and Developing a Matrix

Coding is the first step to making analysis easier. Miles and Huberman (1994) recommend two levels of coding: the first is to attach symbols or labels to words or

groups of words, which is helpful in writing and prevents dispersion with labels while reading; and the second one is pattern coding, which describes the process of giving codes to words or sentences based on their themes, which serves to locate the meaning of segments according to the themes.

The second step is to categorise the data into meaningful categories, which can arise from the data itself or from theoretical frameworks (Saunders et al., 2009). Categories can be created from the research questions even before the coding, or they can be generated after a thorough reading of the data. The categories can be divided into sub-groups, which may need to be re-sorted until the sub-groups lead to the main list (Taylor-Powell and Renner, 2003).

The last step requires the linking of findings by uniting and developing a matrix that contains specific cells for all of the categories (Miles and Huberman, 1994). This step helps to modify the categories and to continue the rearrangement of the data. It is possible to “subdivide or integrate categories as ways of refining or focusing analysis” (Dey, 1993: 95). An extensive range of software exists to assist with analysis. Perhaps the most famous of these is NVIVO, but I dismissed this option for two reasons: firstly, most of these software programmes are not suitable for the Arabic language and my data was in Arabic since my participants are from Saudi Arabia. The second reason is due to personal preferences; I prefer to deal with my data manually as a hard copy and I only used some software such as the mind mapping programme ‘Simple Mind’ to organise the codes and themes (Appendix F). Appendix F includes two mind maps that have been chosen randomly and translated from Arabic to English.

4.9.3 General Observations

Interviews and focus groups were used in the research for triangulation purposes. As general observations, no major differences were noted in the levels of openness that were provided between the individuals and the groups. The themes that were discussed in the groups did not raise issues of privacy, so most of the participants were welcome to share their experiences with others. The most obvious difference in privacy between the individuals and the groups may be that almost every parent who took part in an individual interview decided to show me their child, either by bringing them to me after the interview or by presenting a photo using their smart phones. In contrast, none of the focus group parents presented any photos. The fathers seemed to be more comfortable with talking and laughing in focus groups, but were notably more formal during the individual interviews. This behaviour might be connected to the pre-existing cultural expectations about gender, because of the fact that the interviewer was female. In any case, the fathers were also more conservative in discussing the negative aspects associated with their wives. When talking about negatives, they spoke about mothers in general rather than the mother of their own children. In contrast, even on a general subject, the mothers tended to give examples using their own husband and even to criticise them. The focus groups of mothers had more side chatting, which made the interviews much longer and harder to control than the groups of fathers.

4.10 Chapter summary

This research used a qualitative approach to obtain data from related adults and create a thick description. The study relied on semi-structured interviews conducted with a study population gathered from snowball sampling. A total of 42 participants took part

in individual interviews and focus groups, which were held in the cities of Riyadh and Jeddah, as well as two remote areas of Saudi Arabia. These two cities were selected because they are the biggest cities in Saudi Arabia and for the large variation between them in the nature of the population, as well as to facilitate movement and communication for myself. All ethical issues were considered, including informed participation and I employed some select strategies to increase the trustworthiness of the findings. Data analysis passed through various stages, starting with the preparation of the data for analysis through the creation of transcripts and then tagging them. The data was coded, after which I created categories and developed a matrix to generate the themes. Finally, the findings were prepared for presentation manually, because no software is appropriate for use with Arabic quantitative data. The following three chapters present the findings of the study.

Findings

Chapter 5: The Impact of Having a Child with a Disability on Family

5.1 Introduction

This chapter discusses the impact of having a child with a disability on a family. I will begin by discussing the parents' perceptions of disability in terms of the following:

- The use of language.
- Parents' attitudes.
- Religious outlook.
- Exploitation of disability.

Then, I will provide an in-depth consideration of the findings regarding the parents' feelings, namely uncertainty and despair, anger and frustration, unimportance and emotional stress.

After this, I will focus on the impact that having a child with a disability has on their family's way of life, such as the impact on the career path of parents, on the lifestyle of the family, and on the role of each parent. Finally, I will highlight the positive impact that having a child with a disability can have on their parents.

5.2 Parents' Perceptions of Disability

In this section, I will explore the perceptions of parents regarding disability through the use of language. In other words, I will analyse and discuss the parents' use of language in an attempt to understand how parents perceive disability.

5.2.1 The use of language

Almost all participants, both mothers and fathers, refused to use the terms 'disabled' or 'child with a disability', although a small number of parents used the term 'children with disability' during the interview. However, these uses only occurred when they referred to other children and not their own, which will not be taken into account because it is clear it was a reflection of the phrases that I used as an interviewer. However, they did not perceive any difference between the terms 'child with disability' and 'disabled child'. A father [FRG-7] said "are we fooling each other? This is only a play on words". The reasons that they provided for the refusal of the two terms varied to an extent. For example, some parents showed a lack of understanding of the word disabled. As one mother [MJG-6] said:

The word 'disabled' cannot be used to describe our children. It means a person who is not fully capable mentally and physically. I used to have a sister and she passed away; she was disabled, not my son.

Although her son is in a wheelchair and the centre that her son attends contains 'disabled children' in its name, this mother never told him that he could be considered disabled. Similarly, one father [FJG-6] stated that "my son is not disabled, he can walk, disabled is just a word for people in wheelchairs". His 9-year-old son can hardly walk; has splints on his feet; cannot move one of his hands and only moves the other with difficulty; cannot talk; and has learning difficulties. However, these parents seemed to believe that the term 'disabled' does not apply to their children. A number of other parents refuse to use the term without giving reasons. One mother [MRG-7]

said “I will not accept the word disabled, I consider my son to be normal, and I do not care what the others think”.

The use of the word ‘normal’ by the mother gives the impression that she believes that children with disabilities are abnormal and that she is therefore afraid that her son will be classified in this category. This fear makes her insist on continuing to refer to her son as being ‘normal’ regardless of the opinion of others.

Some of the parents thought it was an insult to the child. For example, one mother [MJI-1] said:

Thank God I haven’t met anyone who said my son is disabled, despite the fact that some of the mothers told me that there are people who call their children disabled. What a shame.

She was talking about the term as being a bad word, even though her son is in a centre that has the words ‘disabled children’ in its name. Another mother [MRI-3] expressed her feelings by saying: “the word disabled is harmful to the child and his parents. When I see centres with the word disabled, I feel pain”. The son of this woman has Down’s syndrome and goes to a special school, however the name of the school does not contain the word disabled as most of the private centres. One of the mothers [MRG-11] raised a point worth considering:

I used to refuse the word disabled, but after a conversation with Muhammad Alsheref, who is active on Twitter and has a disability, I changed my mind. I think that the term ‘person with disability’ is acceptable, but you know the problem is the use of the word disabled in our society. A broken chair we call a disabled chair, a stupid idea is a disabled idea, when we gather as a family they say to the one who wasn’t sitting properly: correct this disabled pose. Often I get annoyed.

In this comment, she shed light on an important aspect of the linguistic culture of Saudi society. Since I belong to this society, I can confirm that in the vernacular, anything faulty can be referred to as disabled. In fact, it is extremely common to use

the word disabled in ironic comments and jokes, while the use of this term to a person with a disability is often intended to underestimate him or her.

Indeed, all of the parents refused to consider the use of the term ‘disabled’, although they did not agree on an alternative. Many prefer ‘child with special needs’, but there are other labels such as ‘gifts of God’. On this matter, a mother [MRG-5] of a daughter with Down’s Syndrome said:

We, as a group of mothers, decided to call our children Gifts of God because we think they are gifts that bring happiness and blessing to our lives.

One father [FRG-7] prefers the name chosen by his son, explaining that “my son is 13 years old, he has an Instagram account on which he introduces himself as a person with special features”. One mother [MRG-11] thinks the best term is “challenged children”, in reference to the numerous challenges that she believes will fill their lives. Another mother [MRG-9] refused all of the terms and said, “He has a name and people can call him by his name, no need for those terms at all”. A father [FRI-2] said “they can use phrases such as ‘integration children.’ They are not disabled or special needs”. This father has three children with vision disabilities and no learning difficulties. It may therefore be that the father chose the terms that are linked to education because it is a reflection of the most important concern for the father, which is teaching his sons and preparing them for life. He believes in their capability, but complains about the educational services available to them.

It is clear that there is no agreed-upon name for individuals with disability, although most of the participants prefer ‘people with special needs’. Many of the parents refer to their children by saying that they are tired or ill; some of them used the phrase ‘not normal’. Ironically, a mother [MUI-1] who refuses the word disabled used “Mongolian child” when she talked about a child with Down’s Syndrome. I think that there is a strong argument to suggest that the media plays a big role in promoting

‘people with special needs’ as a way to respect people with disabilities. On other hand, they consider using ‘disabled person’ or ‘person with disability’ as disrespectful way of treating them. On World Disabled Day 2013, the debates in social media in Saudi Arabia principally concentrated on two topics: what name should be used to refer to people with disabilities and parking issues. Despite persons with disabilities themselves being present on social media, asking for more important discussion, such as about the creation of a suitable work environment for them, the aforementioned topics received the largest share of attention. Moreover, programmes in the official media also typically promote the medical model by presenting special schools as being the best place for the child with disability.

Indeed, this attitude of parents towards disability is influenced by a number of factors. These will be raised in the next section.

5.2.2 Parents’ Attitudes

5.2.2.1 Cure and Abortion of a disabled Foetus

The issue of which term to use was not the only one that preoccupied the interviewees. Many parents were not convinced that their child’s disability is permanent, which had potentially far reaching consequences for the way in which they behaved.

In the interviews, most of the parents referred to disability as a disease, using phrases such as [FJG-6] “my son has had this disease since birth” or [FJI-2] “medical error is causing this disease in my child”. One parent [MRG-12] even said, “When someone asks me about my son, I tell them he is ill, just pray for him”. The use of words like ‘disease’ and ‘ill’ may be due to more than one reason. In the Saudi Arabian context, linguistic culture is one likely reason, as it is popular in the kingdom to use ‘disease’

and ‘ill’ in many cases where they are not technically correct. All types of disability can be referred to as illnesses. This term is also used for psychiatric disorders, even when the community believes they are cursed by evil eye, bewitching or even possession. Moreover, because parents avoid the use of ‘disability’ and ‘disabled’, the easiest alternative may be using common terms such as ‘disease’ and ‘ill’. After all, it is important not to marginalise the concept of the word ‘disease’ and its association with healing, as well as its potential impact on parents’ understanding of disability.

A father [FUI-1] of a child with autism said: “I did not leave out any hospital in Riyadh; I went to all of them. I want a cure for my son”. This family live in a small town about an hour and a half from Riyadh by car. His search for a cure for his son obligates him go to visit Riyadh daily for consecutive weeks. “Why does my child have to be disabled all her life? I need someone to tell me where I can get a cure in any country”. This father [FJI-4] was speaking about his belief that a cure for his daughter must exist somewhere in the world. His daughter has cerebral palsy due to a lack of oxygen at birth. Her father has travelled to Jordan, the Czech Republic, and Dubai; now he is preparing to visit America. This idea was not exclusive to this father; many shared this idea from a religious perspective. One mother [MUI-1] said the following:

Prophet Muhammad said, ‘Allah does not send down any disease, but He also sends down the cure for it.’ I know there is a treatment for my daughter; it is my responsibility to look for it.

All Muslims believe in this Hadith [Hadith means all the words of the Prophet Muhammad], so if parents consider disability to be a disease, it is reasonable that they would search for a cure.

In fact, even those parents who are aware of the difference between disease and disability may still be controlled by the idea of the pursuit of a cure as a solution. An

activist father [FRI-3] of a child with quadriplegia said, “Now my obsession is stem cells; it seems to solve everything”. I think that this interest is acceptable in situations in which it does not negatively impact upon the family or the child. Parents of children with Down’s Syndrome did not mention a cure in their interviews; none of them were looking for a cure, but they had other concerns relating to behaviour modification and skills development. This may be explained by the nature of the disability, since it is a defect in chromosomes and thus it is evident that it cannot be altered.

When asked, parents showed acceptance of the idea of aborting a foetus if it was found to have a disability, but only under two conditions: that there is no religious impediment and it would have to be done in secret. From the religious perspective, parents claim to have often asked holy leaders about their children when they were a ‘foetus’. The answers may vary from person to person, according to differing views. Usually, the answer is that it is possible to abort a foetus if the Spirit does not yet exist in it, which is estimated to happen at 12 weeks into a pregnancy. One mother [MRI-4] said, “my husband asked several religious men and all of them said ‘no it is too late,’ since I was in the 16th week of pregnancy”. The mother emphasised the importance of confidentiality before she confessed that, “of course if I did it, no one would know except my husband and me. People want to give their opinion on everything”. In fact, the subject of abortion is unusual in the community because extensive opposition exists from a religious perspective, which can put pressure on parents. One father [FJI-3] talking about his opinion on abortion explicitly said:

Unfortunately, we discovered a disability in the advanced stages of pregnancy. If it had been earlier, we would not have hesitated to abort the foetus, for the child himself and his family, but also for the society as a whole. The fire burns just the foot of he that stands on it [famous aphorism]; no one can imagine life with a disabled child except his parents.

This father explained that a child with a disability is a burden on different levels, while he thinks that nobody will understand the tragedy that his family are experiencing except for the family itself. Therefore, it can be anticipated that the father will not wait for support because he is convinced that no one understands the situation enough to provide it.

5.2.2.2 The Shock of Having a Child with a Disability

All parents spoke of their shock when a disability was discovered in their first child and how long time it took them to believe it. One mother [MRG-11] said “it was a shock to me, in particular because it was my first child”. In fact, when the radiologist told her that a problem existed with the child, she tried to see the doctor. However, that was not possible because she did not have an appointment, so she entered the doctor’s room in the presence of another patient. The issue of being the first child was raised by another father [FJI-2], who has a nine-year-old child with a disability. He said:

In fact, if the woe occurred in the first child, it will be very difficult, for us the situation was very bad until God gave us the second child and he was a healthy child.

Despite the use of the word ‘woe’ in the description of disability, the father clearly showed his reaction of shock when he learned that he would be having a child with a disability, noting the surprise and the factors that helped to relieve this shock. He considered having a healthy child as a relief. This may be due to the parents feeling like a failure with their first child, so giving birth to a healthy child restores their confidence in themselves and before society. One mother [MRG-5] told the focus group:

I know a family, the grandma put a pillow on the face of a newborn child [with Down’s Syndrome] until he died. She said ‘how can the first child of my daughter be like that, what will people say about her?’

A sense of failure and the fear about what society might think about the parents are stronger when the child with a disability is the parents' first child.

Not all of the parents who had a child with disability -but not a first child- talked about the shock, however some of the interviewees recounted bad experiences due to the way in which their doctors had delivering the information. One father [FRG-7] said:

My son was walking normally, he felt tired and we went to the hospital after two days. The doctor moved my son's feet up, then threw them and said he is disabled. I could not control myself; I beat the doctor until he was bleeding.

The father was laughing at the end of his story; he thought the doctor had deserved his punishment. One mother of a child with Down's Syndrome knew nothing about this disability, so the doctor began to explain her youngest daughter's condition. The doctor explained that she would have heart problems, the tongue would not stop growing and so would grow until it protruded from her mouth, there would be runny saliva, her weight would be above normal, and she would have mental and physical disabilities. The mother said [MRG-5] "when I came out of the clinic, I could not even cry from the shock. I thought I was carrying a monster in my hands". Then she added later "at home we could not see what the doctor said, she is a normal child". In general, the parents of children with disabilities who already had older children seemed to have been quicker to overcome this shock.

5.2.2.3 Parents' understanding of their children's attitude towards their own disability

According to the parents, some children showed an obvious dissatisfaction with their disability, which the parents noted had a negative effect on their own mood and perceptions. One mother [MJG-6] interpreted her son's looks in the following way,

“my son is two years old. When he sees his brothers walking, he looks at me as if he wants to ask why he’s not like them”. This may be a projection of what the mother feels more than what her child wants to say, however. One father [FJG-5] said:

My daughter keeps saying to me ‘why can’t I walk like my sisters and go with them to their school?’, since all her sisters including her twin go to the same school. She says ‘do exercises for me so I can walk.’ My poor daughter is nine years old and she cannot walk or even sit; if she wants something, she rolls to get it. Her sisters watch this sad situation every day.

Although the girl expressed her feelings with words rather than merely with looks, from the details that the father provided, the type of words that he used in telling the story, and his sad facial expression, it may be inferred that the father’s emotions had an effect on the attitude of his daughter. Another father [FRI-2] of three children with visual disabilities said:

My children are hurt by the word ‘disabled.’ They are right; they are able to walk and speak, they are not disabled. One of them told me that his cousin called him ‘disabled,’ so I asked ‘what did you do?’ He answered: ‘I hit him.’ I encouraged my son to fight for himself.

It is notable that the father’s understanding of the word ‘disabled’ influenced his son’s understanding of the word. Another mother [MJI-1] who spoke on behalf of her child said:

I am in trouble; I cannot use a wheelchair for my son because I feel he is ashamed of it, so I am always carrying him. He does not socialise because he knows he is different from others.

Her six year old son has never said to his mother that he does not want the wheelchair. I think that the mother’s words reflect her feelings about the wheelchair, rather than her son’s, however. In fact, parents are not the only factor that affects the degree of acceptance that children have of their disability. One mother [MRI-4] said:

When I reprint school text books in a large size so they become suitable for my daughter, she screams and cries, saying ‘I do not want this, I want to be like the rest of the girls.’ I talked with her teacher and I think it is a little better now.

Teachers and pupils can play a crucial role in the perception of children, especially in integration schools where there is a scope for comparison.

All of the parents who talked about their children not accepting their disability expressed varying degrees of dissatisfaction regarding their child's disability. On the other hand, a few parents seemed to have no problem accepting disability and neither did their children. This is a dialogue that took place between a father [FJI-3] and his daughter in front of me when we talked about his daughter's understanding of her disability:

Father: What is this? [pointing to her wheelchair]

Daughter: My chair.

Father: For what?

Girl [laughing]: Instead of my legs.

5.2.2.4 Impact of Seeing Other Children with Disability

Almost all parents talked about this point and how it had a positive impact on the acceptance of the child's disability and had helped them to overcome the shock. Some added that their children also have good feelings after communicating with other children with disability, whom they usually meet in special centres for the disabled.

My first problem was with the mother; she did not accept the situation of our son. But she changed completely after entering a treatment centre with our son for eight weeks. Now she has fully accepted our son's disability after seeing children similar to our son and worse. If you see others' disasters, your disaster will be eased.

The last part of the father's words [FJI-2] is a very famous aphorism that was mentioned by many of the parents in their interviews. This expression means that they need to see children with more severe disabilities than their children have before they will be able to properly accept their own children. One mother [MUI-1] said:

I used to say that my daughter is ill and she needs treatment, until my niece suggested a centre for the disabled where she works. It was a very shocking moment when I realised that people see my daughter as disabled. I went there and I saw children worse than my daughter. I gave up and accepted the reality.

From the words of this mother, it is clear that people around the mother avoid using the word 'disabled'. In fact, this word was shocking for the mother, despite being in the name of a centre, and so seeing other children with disabilities eased the shock.

Disability acceptance also extends to the children. A father [FRG-7] said that: “my son has improved so much emotionally after meeting with people with physical disabilities. He is becoming much more accepting of using a wheelchair”. One mother [MJG-6], who was speaking on behalf of her son, said, “After registering in the centre, my son became very happy because he saw kids like him. Now he does not feel strange”. Whether or not this is the real feeling of the son, who is only two years old, it is highly likely that these words reflect the feelings of the mother towards her son’s disability. Another mother [MJG-7] gave advice based on her experience:

Every mother who is tired or shocked by her child’s condition needs to visit centres and hospitals to see other children like her child because even if a thousand doctors were to speak to her, she would still not be convinced until she sees it with her own eyes.

However, not all of the participating parents seem to believe that seeing other children with disabilities has a positive impact on their own child.

To be present in a place with those children sends negative energy to anyone. Can you imagine that, when I am waiting in this environment for five hours a day with my child, I become depressed.

This father [FJI-2] refuses to meet children with disabilities as a group in general.

However, others place restrictions on people with disability that they meet. One mother [MRG-8] said:

I asked the doctor what muscular atrophy was; I wanted to know how the situation would be if my daughter grew up. He asked me to go see a receptionist who has muscular atrophy. I went there and I wish I had not; his life is miserable. I wish the doctor had not given me this advice.

The mother went to see the receptionist and only took a look at him from afar. Without taking the time to talk to the adult about his situation, life, and the difficulties that the man faces, she decided that he was miserable using only his appearance. Even meeting people with the same disability as the child is a method of supporting parents, but even though this case was only a suggestion from the doctor, it argues that this

type of service or exposure can have a negative impact if it is not delivered in the right way.

Many of the parents mentioned famous people from Saudi Arabia who have disabilities and some [MRG-10] [FRI-3] noted that they had “challenged their disability and succeeded”. Some parents saw these individuals and spoke to them directly, while others got to know them through the media; all agreed that their stories tended to have a positive impact on parents. This indicates that the parents need to have a successful model in order to create hope for the future.

5.2.2.5 Negativity in claiming rights

Regarding the process of claiming rights for children with disabilities, parents can be divided into four groups. The first group is comprised of non-educated parents with low incomes who think that they have everything that they are entitled to receive and have no need to claim rights. Although ‘non-educated’ is a relatively small proportion of the sample in my study, they have similar attitudes. Since I am from the same community, I can tell that these individuals represent most of the non-educated people in Saudi Arabia. One [FUI-2] of them said that “everything is available, and thankfully, God cherishes us and the government did not fall short”. Although this man’s daughter has been waiting for a wheelchair for more than two years, he does not see many of the services as a right.

The second group, which is also the most numerous group, believes that there is no benefit to be gained from making rights claims because it is likely that no one will take such claims seriously. Although she had not tried to claim any rights, one mother [MJI-2] expressed her opinion:

I never claim and in this country I will not claim anything. The activists as they call themselves are just a few newspaper writers who write one article on the disability day...there is no useful TV shows or even a good article.

Another mother [MJI-3] shared this view of hopelessness, saying:

There are many rights we did not have. There are many rights we did not think of claiming. There are a few rights we took as a favour from the government, but in fact, they are our rights. I have not tried to claim any right, because I know it is useless.

This particular quotation touches on the reality of the situation. Although this woman is a young mother studying at the university, and regardless of the hopelessness that she feels, she gave a summary of her perception of the situation regarding the rights of persons with disabilities in Saudi Arabia. In fact, there may be another reason for her not claiming rights: she is from a wealthy family and has the ability to respond to all financial needs of her child.

The third group comprised those who had tried to claim their rights but failed, so they had given up. A mother [MJI-4] who had had a bad experience said:

My husband wrote a letter to the Prince and a letter to the director of the centre. Nothing happened and we have no time to lose in claims. God suffices us, for He is the best disposer of affairs.

She concluded with the religious words that are uttered when an injustice is committed and the person cannot take revenge for himself.

The last group, which included the activists, had tried and most of the time had failed. However, they had not lost hope. An activist mother [MRI-1] said “yes, there are many claims and almost all have failed. We get painful responses, but we will continue”. An activist father [FRI-3] said: “when the opportunity comes, I try, although I am often sure it will not succeed, but it may, one day, succeed”. There is a new approach to rights claims, which is to seek to encourage international pressure to be placed on the Saudi government. For example, there is an international demand that women to be allowed to drive. However, questions are often raised about the

patriotism of the people involved in such movements because it is deemed unacceptable to ask for help from foreign organisations in obtaining rights by putting pressure on the government. This issue was raised by one of the mothers [MJG-5], who said:

We know that the quickest way to achieve the rights of the disabled is a claim from abroad, from countries that support the rights of the disabled, but this method may cause trouble for us. The simplest response is to question our loyalty to our state and it may lead to prison.

In fact, the words of this mother are not greatly exaggerated because going to the embassies of foreign countries or making demands in a language other than Arabic may stir up public opinion. This could lead to the person being considered an agent of a foreign country, with potentially disastrous consequences. It should be noted that there is no group of people who had already successfully made lots of claims.

In any case, most of the claims were made individually and often for the personal goals of the claimant. Simple attempts have been led by activists, in which they collect parents' signatures and attach them to a letter, which is then directed to one of the country's officials. These claims often ask for tangible assistance, such as cars for the disabled or to raise the disabled subsidy.

5.2.3 Religious outlook

All parents mentioned the importance of religion in accepting the disability at least twice in their talk; they all agreed upon the need to accept that the disability had been sent by God. "I believe in God, she is from God, and I am satisfied with that", these were the words of one of the parents [FRI-1], which were repeated by almost all of the participants, although often in different words. However, while some considered the disability a gift from God, others considered it to be a test. One mother [MJI-4] said, "God would not put this disability in my way unless it is good for me". This idea has a

religious basis, as Islam holds that all things, whether good or bad, are in the interest of the believer. One father [FJI-3] said, “We counted the awards from God. She is a blessing; when she came to us, our condition improved financially and emotionally”. This is one of the core tenets of the Islamic religion: namely that God will reward good conduct in such situations as the afterlife. Many parents cited this Hadith, which comes from the word of the Prophet Muhammad, “When God loves a certain people He tests them”. They think God is testing their patience and satisfaction by giving them a child with a disability. [MJG-8] “My son is of God and I am satisfied, but people bother me when they look piteously to him and think he is a misfortune”. In fact, religious people may be harsher in their beliefs and judgement on the child and his parents.

People around me think that my son is a punishment from God because they believe that I have oppressed my uncle’s wife by assisting her husband to have another wife... but I know myself, I even did not laugh at any one with a disability or taunted him... I just say All praise is due to Allah who saved me from that which He has afflicted you with.

As the mother [MJG-5] explained, people around this mother attributed this belief to this reason only. In addition, they believed that her divorce from her husband had occurred due to the same reason. However, it must be taken into account that this mother used to live in a village with a closed society where most of the residents are from the same family and have limited education, as is the case in most Saudi villages.

Another mother [MJG-6] said:

People bother me when they see my child as a scourge of God, but the reality is that he is light and a blessing of God in my life, even at the level of my relationship with my husband.

It may be that the words of this mother are slightly exaggerated, as she is the first wife. Because her husband has another wife, he only visits her home once a week. As mentioned earlier, men in Saudi Arabia can have up to four wives at one time. She said that except the financial support, she marginalised him from her life and the lives

of her children. This may not be incompatible with her first words: the woman was going to divorce, but she preferred to continue the marriage after having a child with a disability, as she believed that this would result in an improvement in her relationship with her husband.

However, it is hard for her to show that the situation was unpleasing. In the religious culture of Saudi society, one must show satisfaction in front of others, because acting the opposite may make people sceptical with regards to the degree of your religiosity.

Because of this, fatalism plays a big role in the parents' beliefs. Even if they do not believe in something, they cannot say so because objection and discontent of fate and destiny are unacceptable in the religious Saudi society. Thirteen years after a traffic accident, a father [FJG-7] said:

Having a baby born with disability is different from having your child become disabled due to a traffic accident. This accident also took my wife and my lovely oldest daughter; they died. My situation is different from the rest, but thank God, it is our fate; I do not want to talk about that.

In fact, he was the only father who confessed to being uncomfortable talking about his daughter. Even when he participated in the discussion with the focus group, he expressed this idea by saying, "this wound inside me and talking about it will open it again and cause me pain". Perhaps because of this, he ended up leaving the group a little earlier than the others.

5.2.4 Exploitation of disability

Exploitation of disabilities can appear in several forms and to achieve multiple objectives. These may seem to be moral objectives, but in reality they are the exploitation of the disability. An example of this might be showing support for disability issues in order to gain status from telling stories of one's own compassion in

the media. The following sections will discuss the incidences of exploitation by certain specific groups.

5.2.4.1 By parents

Even though this was not a common phenomenon in my interviewees, the idea of parental exploitation of the disability of their children is worth highlighting due to its importance. The interviews demonstrated that this could occur as the use of a child with a disability as a ‘trump card’ in family problems and financial exploitation.

A dialogue between mothers in a focus group presents the occurrence of the exploitation of children with disabilities by the parents and the extent to which the idea is recognised:

Mother A [MJG-5]: He has not seen my child since the divorce, not even once, despite the fact that his home is close to my family’s home. He wants to annoy me. I know how he thinks.

Mother B [MJG-6]: No need for him, your father and your brothers can take his place. Your son does not need a father like him.

Mother A [MJG-5]: But my family is tired of my son’s expenses.

Mother C [MJG-7]: What do you mean! The father does not bear the expenses of his son?

Mother A [MJG-5]: No, not at all, and my father tries to avoid trouble with him. I asked my father to talk to him, but he refused and said “I will do my best with your child without his father”.

Mother D [MJG-8]: But the subsidy will help, of course.

Mother A [MJG-5]: You will never believe me; I did not know about the subsidy from the beginning, but nearly five months ago I found out. I prepared all the required papers and my father went to ask about it. They said the father of the child started receiving the subsidy two years ago and he has received payment for his child every month since.

Mother C [MJG-7]: Are you serious! You should complain to the court.

Mother A [MJG-5]: I cannot, my father does not want people to talk about us. I tried to communicate with him via mobile phone messages in order to reach an agreement, but he said that I want to spoil his life, because he is preparing to marry again and if I do not cease in this, he will take my son by law. He said he had reports from doctors to prove that my child needs treatment and this treatment is not available in my area. So it is his right to take my son for the interest of the child and to ensure follow-up treatment.

Mother B [MJG-6]: Terrible, just throw the child on him, he won’t bear it.

Mother C [MJG-7]: Yes, you are right; he will do whatever you want to get rid of the child, especially as he is newly married [laughing].

Mother A [MJG-5]: I do not think this will work. Before the divorce he convinced me that we should put our son in a centre in Jordan. I do not rule out that he will do that if he takes my son.

Mother C [MJG-7]: We cannot say anything. God help you.

Through this dialogue, it is clear that the idea of exploiting a child with a disability is acknowledged by everyone. While the mothers did not accept the financial exploitation by the father, they nevertheless advised the mother to use her child in order to put pressure on the father and to obtain access to the expenses entitled to the parent raising the child. It is worth noting that none of the mothers touched on the feelings of their children. Their reactions may also have varied if they belonged to wealthy families, where financial matters are not a concern.

Unfortunately, people are interested in free stuff. If there is an announcement of free hair ties, you will find that even the bald stand in the queue. This is the case with parents of children with special needs. They want anything free, even if their child does not need it, hoping to sell it and take advantage of its proceeds.

This was the opinion of one of the activists [MRI-1] on the behaviour of parents of children with disabilities, which she considered to be negative. The activists recounted many real life stories in which they had been witnesses to the financial exploitation of children with disability. One of them [FRI-3] said:

Philanthropists donated wheelchairs for the disabled worth 5,000 Riyals [£851]. I was in a store of medical devices and a father took the chair then sold it to the store immediately at a price of 3,000 Riyals [£510]. He put 2,000 [£340] in his pocket and left the store. Do not think this is the only father who did this; this act is very common when the father is financially in need.

Another example of an opportunity to exploit a disabled child is that a child with a disability and one companion get a fifty percent discount on tickets for internal flights on Saudi Arabian Airlines. An activist [FRI-4] said:

I spoke with an employee at the airlines. He said that we are facing many frauds by the parents of children with special needs, where the parent books two seats for him and his child, so he gets a discount. Then he cancels the reservation of his child and travels alone for half the value of the ticket.

Another activist [MRI-1] said “many mothers complain to me that their husbands take the child’s subsidy and do not provide even a wheelchair for him or her”. There are

many stories about the financial exploitation of children with disabilities. However, it is noticeable in the words of this activist mother, as well as in the previous quotes from activist fathers, that financial exploitation of a child's disability is more commonly done by fathers than mothers. The reason for this may be that the law stipulates that Saudi Arabian fathers are financially responsible for the entire family. However, perhaps the worst stories of exploitation recount the deeds of mothers. I am familiar with this because I am Saudi and these stories are relatively well known. The exploitation of a child with a disability for begging in the streets is a notorious example in big cities. Although this behaviour is not socially acceptable, whether the person is alone or with a child with a disability, the dress of women may play a role in this as the veil covers their entire face, stopping people from identifying them and therefore enabling the mothers to avoid embarrassment in front of the community.

5.2.4.2 By media

Whoever knows Saudi affairs and is familiar with disabled issues realises that children with disabilities are commonly exploited in the media. Several forms of media exploitation were discussed in the interviews. An example of this phenomenon is the common announcement with an attractive title such as “humanitarian needs help from the owners of white hands”, as stated by one father [FRI-4]. They display a photo of a child with a disability and their medical report, where the image is often sad. After this, another announcement will detail the philanthropist who guaranteed the cost of treatment. The advert then names and thanks the philanthropist, who is usually a well-known person, such as an actor, football player, prince, or businessman.

This scenario is often repeated multiple times a day on social media, such as Twitter, Facebook, and Instagram, as well as in official newspapers. Some of the programmes

on TV channels are about the suffering of some people with disabilities. Communications through phone and fax coming on the air to the programme come from the one who will bear the expenses of treatment or living.

Another type of exploitation of disability is displaying these children in the media in order to raise funds for charities or for a centre. Famous people may also visit centres for disability in order to take photos with children, which are then broadcast in the media to present the humane side of these visitors. In my experience, having worked for four years in a centre for the disabled, it was common for us to be asked to prepare attractive children with severe disabilities for visitors. Children who have jovial faces, are friendly and wear nice clothes are preferred, while some children are excluded because the centre thinks that they do not look suitable. This practice has mutual benefits: the centre aims to encourage visitors to donate and visitors are keen to take photos with children for later publication.

A discrepancy was found between parents in terms of their acceptance of these kinds of exploitation. However, the majority totally rejected the appearance of their children in the media for any purpose. One mother [MRG-8] said about her son, “he will blame me when he grows up if I used him like that”. Another [MJG-6] commented, “I cannot allow my son to be in the media. They show children with special needs as miserable in order to stimulate others’ pity”. Many parents agree with the position put forward by this mother. However, some of them changed their minds after discussion with others in a focus group. On the other hand, some parents have certain conditions. One mother [MRG-7] said:

My son was on posters around the city, in order to collect donations for the centre where he goes. It is a charity centre so it is acceptable because it contributes to fundraising.

This was the only case in which the mother agreed that she would allow her son to be visible in the media. Another mother [MJG-7] said:

If there is a direct interest for my son, I may accept. For example, my son was in a photo with the football team; he got a free subscription to the club for a year and a gold membership.

She was against immediate monetary benefit, however, as she feels that this is insulting. Another view agreed upon by some parents in different interviews is this argument, articulated by one mother [MJG-10]:

I will not let my son be in the media in order to raise money, whether it is for a centre or for himself, not even to take a photo with a prince or football team. But I may accept if it is an awareness programme about disability, on the condition that my child appear among a group of children in their daily lives, such as playing or studying.

A mother [MJG-12] who agreed with her emphasised the importance of anonymity in the programme without providing a clear reason; maybe she is unsure that her community would accept that. To highlight the power of the community, a mother [MJI-2] who used to be a teacher for children with disability recounted a case that happened at the centre where she used to work:

The parents agreed to put their daughter's photo on a poster around the city. Two weeks later a group of their tribe came from the south of the country 1,000 kilometres away to refuse putting the tribe's daughter's photo on a poster around the city. They won and the face of the daughter was covered on all the posters.

In fact, this story took place in my city and I still remember the reaction of many people. There was widespread sympathy with the tribesmen against the centre and the girl's parents. Respect for the traditions of the community and adherence to the rules of the tribe system is still important for the majority of people in Saudi Arabia.

In contrast, some parents seemed to seek attention in the media. A father [FRG-7] said: "my son is talented; I hope that his appearance in the media increases his self-confidence". However, another father [FJI-1] said:

A journalist promised that my daughter would be in his newspaper. He asked me to send her medical reports and photos of her, and I did. But he did not fulfil his promise.

The family was middle-class: the father is an employee and the mother is a housewife. According to the father, his wife does not work because they do not need her to do so. Even though he was looking for a philanthropist to take care of his daughter's treatment abroad. However, the financial situation of the family may play a role in the acceptance of her making appearances in the media. One mother [MJG-11] said, “I refuse the appearance of my daughter in the media, but there are poor families who are forced to accept that”. One of the activists talked about a mother whose son had appeared in a miserable situation in the media in an attempt to raise funds for a centre. Many other mothers interacted with her and tried to complain to the court against the centre. The mother agreed with them, but she had a different view when the activist talked to her individually. The activist [MRI-1] said:

She told me that she cannot pay the fees of the centre and they made a deal with her, that if her son appeared in the media, they would drop the current year's fees.

One mother [MRG-12] said, “Life is hard and my husband does not help me. I do not mind if my son appears in the media if that helps”.

In general, the fathers in the sample opposed the idea of their children appearing in the media, whereas mothers tended to put conditions on this appearance. This may refer to the nature of a Saudi man, who is financially responsible for his family and it is not appropriate to show weakness in this aspect. Men are also keener to ensure the satisfaction of the community. A father [FRG-5] in a focus group said, “even if I have no objection, it is impossible to go for it; my tribe would kill me”. The others laughed and another father [FRG-6] said to him, “they will renounce you forever, but my tribe would even come from the north with guns”.

5.2.4.3 By hospitals and schools

Many parents feel exploited by schools, hospitals, and centres. The cost of these places is “astronomical,” according to the words of one father [FJI-3]. The difficulty inherent in obtaining free and appropriate treatment forces some parents to go to private hospitals. In addition to the high cost of such hospitals, some parents believe they cannot trust the service provided and may be asked to do unimportant tests and x-rays just for the profit. One mother [MJI-4] said:

We are treasure for doctors. Even when he asks me to do examinations for my daughter and I am sure it is not important, I cannot refuse; I am afraid to regret later.

There also seems to be a belief that exploitation exists in stores that sell medical devices. Because there is only a small number of stores, which are only found in the big cities, the prices of the devices that they sell are much higher than world prices.

One father [FJI-2] said:

My brother bought a wheelchair for my son from Britain; with shipping it cost 3,000 Riyals [£510]. When I found it here, it cost 7,000 Riyals [£1,192]. They are thieves.

Due to inadequate government funding of special schools, the private schools raise their fees to take advantage of the need of parents to have their children taught. One mother [MJG-12] said:

The fees of private schools for the disabled are three times the fees of schools for normal children although there are no distinctive services worth that amount. But we have no choice.

Almost all of the parents agree on the previous opinion.

Exploitation has been also been noted in sports clubs. One of the mothers [MRG-8] said:

All sport clubs refused to accept my daughter, except one club. I was asked to pay 3,000 Riyals [£511] as subscription fees for my daughter. My cost is 800 Riyals [£136], although my daughter will be with me all the time and I will take care of her one hundred percent.

The participants told many stories regarding exploitation. This seems to suggest that the absence of free services has created a monopoly, allowing greedy traders to exploit people with disabilities by exaggerating the price of their goods.

5.2.4.4 By Traditional Healers and Spirituality

Saudi society is a religious society and so spiritual therapy is religious in nature. All of the parents had tried this option, although the majority tried it themselves without an intermediary, while the remainder went to religious men. A father [FRI-4] of a child with autism said:

We have tried to read specific parts of the Holy Quran. It was very helpful for our son, then we tried to disseminate the idea to parents. There was a great response.

As this father is educated and spent many years in the United States, the approach of treatment by Quran is not limited to a specific group. One mother [MUI-1] said: “I went to approximately seven remote areas for Quran’s therapists. Currently I am reading the Quran to my child at home”. What the mother did in travelling to search for therapists by Quran is a common and acceptable method that is used by many people when formal medical treatment is unable to help. Even some traditional treatments, such as cauterizing with fire, have religious origins, as the Prophet Muhammad recommended cauterizing with fire as the last option for treatment. This approach involves heating a thin iron rod on fire until it becomes red from extreme heat. The rod is then placed on specific areas of the child's body, according to the traditional healer’s knowledge. Several parents from the interviews have tried cauterizing their children with fire as recommended by traditional healers, a father [FRI-1] said “at least 16 cauterizing spots in her body [laugh]... Zamzam for all of us, but I try to give it to her in the morning”. Although the children had not benefited, the parents were unrepentant. In a focus group a father was trying to convince another

father to try the cauterizing technique with his child because he did it for his non-speaking daughter and she can talk now. This approach is very common and not limited to a specific group. Furthermore, no one can openly doubt its efficacy due to its religious origin.

Despite traditional healers and some spiritual therapists charging for their services and the parents feeling that they did not get any benefit from their use, the parents did not consider traditional healing or spiritual therapy to be exploitation or try to complain. The reason may be that this type of therapy is an extra treatment they go to it beside the hospitals, which is very important to them. Therefore, parents can dispense the traditional and spiritual therapy but not the medical treatment. In addition, the healers of traditional and spiritual therapy are usually religious men, meaning that it is not acceptable to criticise or accuse them of exploitation in Saudi Arabia.

5.3 Parents' Feelings

It is easy to anticipate the feelings of the parents who have a new baby and how these feelings progress and develop with the child's growth. However, this is often more complex when discussing a child with a disability. The feelings of parents of these children varied and was influenced by many consideration. In the following sections, the most prominent feelings that emerged among parents will be discussed.

5.3.1 Uncertainty and despair

When they talked about treatment or education, the most noticeable expression among parents was a general feeling of confusion and, specifically, a sense of becoming bewildered and lost. One mother [MJI-3] spoke on behalf of others:

Mother: Any mother of a child with a disability has become confused and wandering in many aspects, between searching for an accurate diagnosis and

searching for appropriate treatment with a fear of being late so the child may miss something or an opportunity.

Interviewer: What about education?

Mother: This comes at a late stage. Do not talk to me about my son's education before he is diagnosed and treated.

This mother laid out some of the priorities for many parents. The first of these priorities was to obtain an accurate medical diagnosis, then medical treatment, followed by education. This sequence was agreed upon by almost all of the parents of children with either moderate or severe learning disabilities. In cases where the children did not have learning disabilities, or suffered from mild learning disabilities, the parents were keen to pursue education and ranked it as highly as treatment in terms of importance.

Parents often used the following expressions: “I don’t know what to do or where to go”; “I have no idea if I’m right or wrong”; “I have experienced years of confusion”, etc. These feelings were articulated by both mothers and fathers. However, they appeared more often in discussions with mothers, especially those who did not have the support of the child’s father. These feelings were also found to be more prevalent amongst parents who did not enjoy good communication with other parents of disabled children. One mother [MRI-1] said:

I sit alone and cry, I felt crazy. I ran up to any mother with a Down’s Syndrome child in order to ask her what did she do and where did she go, whether I met this mother in a shopping mall or at a wedding ceremony.

This mother talked about the early years of her child’s life before she established links with many other mothers and then became a rights activist. There was less confusion expressed by non-educated parents with low-incomes. These parents were satisfied with their child’s situation and expressed their confidence in the officials. A father [FRI-1] described the situation of his daughter with a smile on his face:

Everything is great. She is in her wheelchair and her brothers push her, there is no treatment for her, the doctor told us that... no school can accept her, her mind is very small as a child of 2 years old.

The age and disability of the child did not seem to have any impact on the outlook of parents. The mother [MRI-2] of a teenager aged seventeen, whose husband had been in prison for ten years, said:

I was, and still am, floundering. I am the mother and I am the father who should make all the decisions. I know that my son missed a lot because of my ignorance, but I swear to God I was trying. He now cannot hear and did not learn sign language. He is introverted.

This mother was very religious and her words reveal a profound sense of guilt. In the Islamic religion, children are considered to be a deposit and God will judge parents for their children.

According to the views of the parents, there are many reasons for feeling uncertain and lost, such as delayed diagnosis of the child's disability. A father [FRG-5] of a child with autism blames the doctors for his confusion because his son was not diagnosed until he was five years old. When the child was aged three, the doctors even performed an operation on his ears, because they thought he had a hearing problem. In fact, the father was more annoyed about the delayed diagnosis than he was about the diagnosis being incorrect, despite the fact that his child had been exposed to anaesthesia at a young age.

On this subject, one mother [MJI-3] said:

The situation is still vague. Every doctor says 'I can diagnose your kids' and we start a series of examinations and tests with large amounts of money until we get to a dead-end, then we start again with another doctor, and so on. No doctor told me not to have more children and no doctor also told me I can have more children.

This question was very important to one of the mothers. She has three children and two of them 'one aged 8 years and one aged 20 months' have a white matter disease [a progressive disorder caused by age-related decline in the white matter of the nerves that connect different areas of brain to each other and to the spinal cord]. This woman is from a society in which there is a relatively high number of children in a family.

Her husband is her cousin and they have four other cousins with white matter disease. Although this woman wants to hear the answer from the doctor, this situation clearly illustrates the difficulty of making the decision to not have more children in some Saudi families.

The conflicting views of specialists can also result in uncertainty for many families. The mother [MRI-1] of an 11-year-old child with Down's Syndrome described her suffering when she made the decision to accept and deal with her child's disability. The doctor made her go back to her starting point:

Doctors say that my son seems to be normal and he may just look like one of his grandparents. They renew the hope inside me and make me cancel all the plans for my son and start from scratch with a hope that perhaps my son is normal. He seems to be normal - a word that makes me very tired.

This scenario happened with more than three doctors. However, while there were doctors who told the mother that her son has Down's Syndrome, the expectation was that she should cling to whichever doctor offered her the best diagnosis. Effectively, the onus is on the mother to prove that her child does not have a disability. Another mother [MRI-2] with conflicting views, but this time with a school, said:

The school did not explain to me what is best for my son. In fact, I cannot go to them because they are a male school. A teacher from outside the school told me that my son must learn sign language, but the school refused. They said he does not need it, but sometimes they said 'we will try.' He is now 17 years old and cannot read or write and they said it is too late for him to learn sign language. I regret deeply that I did not listen to the words of the first teacher.

As part of the policy of separation in Saudi Arabia between the genders, there are only male teachers in boys' schools and females are not allowed to enter the school, even the mothers of the students, and the opposite is true in girls' schools. This mother was therefore forbidden from entering her son's school; she was the most uncertain parent in the group that I interviewed. She did not feel confident about the validity of her choices with regard to the education of her children with disabilities. In fact, a significant proportion of her speech patterns indicated a sense of guilt and an attempt

to excuse herself from the dereliction of duty to her son. Throughout the interview, it was clear that she carried a heavy emotional weight due to the absence of the father, saying, “For ten years I have been alone, facing everything by myself. The absence of my husband breaks me”. This was compounded by the conflicting opinions about what was best for her son. For some women, things may be much worse than this. With tears in her eyes, one mother [MJG-7] said:

I wish they had told me what my child had clearly from the beginning; for a period of time I did not know who spoke the truth and who did not. I cried every day and I thought of killing my son and then killing myself to relieve me from this puzzle.

As this mother explained later, she is deterred from suicide by fear of God. However, Saudi society is a religious society in general and suicide is considered as killing of another person because life belongs to God.

Also, the lack of a future plan for the child makes parents uncertain:

I panicked and started flapping when my son reached 12 years old. I do not have a plan for him; how will his life be when I die and who will take care of him?

This was how one mother [MJI-2] expressed her feelings. Her son is now sixteen and has a moderate mental disability. Approximately a year ago, he stopped going to school, although he did not have any supplementary vocational training. The mother still has no plan for her son’s future, believing that it will ultimately be decided by God. Another mother [MRI-3] said:

I wish I could have stopped time [laugh], I do not want my child to be up to the stage of adolescence, I want him to always be a child. I hope there is a medicine that helps me in this without side effects.

A father [FRI-2] talked about the future of his son:

I do not have time to waste. I have three blind boys. I have to be reassured about their future and they must not be a burden on anyone. All my trials and blunders were with the first child.

The father told me that he was aggressive towards the school in situations related to the education of his sons. This father talked about how much confusion and fatigue he

has to endure in order to secure the future of his sons. Even mothers [MJG-6] of young children are haunted by the same fear:

I need a doctor to explain to me how my child will be when he grows up, what his degree of disability will be, and whether his potential is good.

In general, fears about the future of children among parents appeared more clearly in parents with boys rather than girls. It may be possible to explain this finding because of the effect of Saudi culture and society, which stipulates that females -regardless of their capabilities- must generally be within the confines of males. Males have a greater social responsibility and so it is possible to see how parents might become more concerned for the future of male children.

Parents showed lack of learning from similar experiences. One of the points that a lot of parents touched on was that they do not have a person with the same disability as their child in their immediate circle, which prevents them from learning from experience. “My wife and I educated ourselves. Our family did not have anyone disabled to learn from or to ask”, stated the father [FJI-4] of an 11-year-old daughter with cerebral palsy. He considered any other family who had a child with a disability to be a potential source of information. In addition, another mother [MRI-3] said:

I was shy in the past, but not anymore. After I had my child I used to ask any mother of a child with Down’s Syndrome. Particularly during my visit to the hospital I asked the mother about everything [mothers of children with Down’s Syndrome]. Even now I am performing this role without being asked. When I find a mother with a small child with Down’s Syndrome, I initiate conversation with her. I am still remembering my suffering.

This is not the only mother who has been inspired to help others. In fact, most of the mothers and fathers are like her. A young mother [MJI-3] who has two children with severe disabilities said, “I do not want to start from scratch. I want any mother of a child with a disability to start from where others have ended”. She made this statement after reporting her difficulties and suffering in the search for answers to her questions.

In addition to this, the absence of a guide or advisor can play a crucial role in the uncertainty of parents. This is exacerbated by the lack of an entity in Saudi Arabia to offer counselling and advice to parents of children with disabilities. A mother [MUI-2] described her situation one day:

Where to go? I came out of the hospital with the medical report for my daughter in my hands. I did not know where to go and what is the next step.

There does not even seem to be guidance for parents from paediatricians. In the best case scenarios, when the doctors diagnosed the condition of the children, they would say that the child needed physical therapy or speech therapy, but did not specify where the parents should go. One mother [MJG-6] said:

The neurologist told me that my child needed physical therapy and he also told me the physical therapy in this hospital is bad. I asked him where to go and he said 'I do not know'. I think he considered using me as a kind of advertisement for another hospital.

This mother did not blame the doctor and it might in fact be possible to read her words from a different perspective. Her statement may actually be an implicit recognition from the mother that the responsibility to guide parents does not rest with the doctor.

In the Saudi context, the decisions of parents, even the important ones, may be taken using non-official routes. These routes is especially likely to include asking other parents of children with disabilities when they meet them accidentally in public places, as this was found to be the most common practice amongst the parents who participated. Parents may also find information online or in newspapers.

Most of the parents mentioned Istikhara during their talk as a last step in deciding their choice. Istikhara prayer is a common religious practice, to seek goodness from God, which is conducted when the person does not know which choice is good for them. This prayer was mentioned by the parents in such statements as "I pray Istikhara and trust in God" and "Even after the doctor's words, I pray Istikhara for more relief".

5.3.2 Anger and Frustration

It is noticeable that frustration is experienced by most parents for a number of reasons, including feelings of injustice. It may be that their sense of injustice is the most painful experience for parents. The medical errors that caused the disability of their children and have not been treated fairly are at the top of the list of incidents that result in feelings of injustice. An activist [FRI-3] said:

Did you know that my son had a disability because of a medical error? At the time I did not know how to act. I tried to complain to the hospital and they said 'we ended the doctor's contract and he travelled to his country.' If this happened now, I am now strong and have experience. I would catch this doctor and not leave him until he had departed.

Of course he was not intending to commit a crime, but his words are an expression of his great anger. "I could not take up rights for my son, but I hope that one day my son will become a lawyer and take up his rights for himself". These are the words of one father [FJI-2] who had tears in his eyes, tapping on the table with frustration as he recounted a medical error that had occurred nine years ago. Fathers were more inclined to talk about medical errors and despite the passage of years, these memories of injustice were evidently still fresh in their minds.

For most of the parents, another source of injustice is the privileges that some families are able to obtain due to their kinship or friendship with officials. A father [FRI-4] expressed his sense of injustice:

It is not fair that an autistic child has 100.000 Riyals [£17,000] from the government, because he is in a centre in Jordan, and not a penny is available for our children here... do not think that going to Jordan is easy, you need to have strong relationships with officials.

This practice deprives other children and, as a result, parents are convinced that the best way to ensure that their needs are met is through a relationship with a person in a high position: a "magic wand" was how one father [FRG-6] described it. There is no exaggeration in this matter; one of the mothers [MJI-3] said:

My mother-in-law went to a comprehensive rehabilitation centre in order to obtain devices for my son, such as a chair or table, along with a verbal recommendation from one of her friends. So they opened the storage for her and told her to take what she wanted. She returned to us that day with five new devices. She said the store is huge and is filled up with massive amounts of devices.

This account simply describes the situation of knowing one of the staff. Should a person know an important official or a manager, or if they have a kinship with one of them, it is easy to imagine that certain opportunities will become available at the expense of others.

Frustration with Saudi Arabia as a whole may be the predictable outcome of the previous frustrations expressed by many parents who wish to travel abroad. One mother [MJ1-2] said:

I do not want anyone to tell me what my rights are because it only causes me frustration and creates a sense of oppression. I know that whilst I am in this country, I will not get anything.

This comment shows the level of frustration experienced by this mother. Another mother [MJ1-4] said “Saudi Arabia, it does not matter how developed it becomes, they cannot reach what other countries have”. This might be a pessimistic view. The interview data show that mothers tended to criticise the general lack of provisions in Saudi Arabia, whereas fathers tended to criticise the situation more precisely. In a focus group of fathers, one [FRG-6] said, “In this country, if you want to educate your son or treat them, you have to know someone important, this is the law”. The other two men supported his opinion and one of them [FRG-7] added, “You often need bribery. Put five hundred Riyals [£85] in your file and your papers will be done in half an hour instead of a week”. The need to have a contact who has status or importance, in addition to the use of bribery, were issues agreed upon by all parents. However, these comments were made in an interview with fathers only. This may be attributable to the role played by men, who know the procedures and are more familiar with the

functions of the ministries than the women. An activist father [FRI-3] gave the following example of the Saudi system:

We are in a country where the disabled should live a velvet lifestyle. There is a considerable disruption and I will give you an example: in 1402 [the father used Islamic calendar, which matches 1982] when I was in grade two at primary school, a decision was issued to reconstruct all buildings and roads so that they would be suitable for the disabled. But they did not apply anything. For this building where we are in now [points out the main entrance], I need three people to help me carry my son in his wheelchair because of the sidewalk. There are systems, but corruption is in the ministries.

Whenever parents are more educated and knowledgeable about current trends, their expectations for Saudi Arabia were found to be negative. Parents who have travelled outside Saudi Arabia tend to compare Saudi Arabia to other countries, however their comparisons always favour the provision for the disabled in public places and health centres abroad, rather than in Saudi Arabia. A father [FRI-4] of a child with autism said:

I have enrolled my son in a school and I do not know anything about the school. In America, by pushing a button you can get any information you need, even if it is about McDonald's.

Another [FRG-7] presents his experience in Germany:

My son in Germany goes alone with his wheelchair, brings us dinner, and comes back to the apartment alone; moreover he does not speak the German language. Here he cannot even go to school alone; nothing is suitable.

Even parents who have not travelled abroad often believe that other countries are better than Saudi Arabia. One father [FJI-1] said, "I have not gone outside the country, but I am sure it is amazing". A mother [MJI-1] had the same idea: "I know it is another world. I have not seen it with my own eyes, but they told me". Almost all the parents want to obtain treatment by travelling outside the country, but most of them cannot due to financial issues or other reasons, such as their pre-existing commitments. One father [FJG-6] said:

I do not want to travel, I want to emigrate. But I cannot because of my responsibility in this country. If I become free I will not stay one minute more here.

There may have been some exaggeration in his words because he followed it with a laugh, the tone of which suggested that it may have reflected his frustration. Even mothers [MUI-1] from the villages want to travel. “Oh, I hope I can travel, but how? Now I do not have money even to try the ‘tingling bees’ treatment”. Instead of travelling, some parents send the medical reports of their children to famous clinics abroad, such as those in America, Germany, the Czech Republic, the Netherlands, and Jordan.

5.3.3 Unimportance

In general mothers and fathers have a feeling of being underappreciated and unimportant, a father [FRG-5] said:

No one cares about us, there is no lectures and courses or even TV shows, if you are lucky you will meet one of the fathers and he will give you tips, that is it... if there is a session Why don't they announce it, how can we know?

However, this feeling appeared clearly in the interviews with mothers. Some of the mothers feel there is insufficient respect for them amongst officials. In fact, one activist [MRI-1] reported having a bad experience with officials:

They see us as nothing. When I spoke with an official about our need for sport clubs, he said, ‘it is not our fault that you did not take your folic acid during pregnancy.

Despite the mother knowing that his information was wrong, she felt insulted at the time because her son has Down’s Syndrome and not spina bifida. Feeling insulted, she left immediately. Another mother [MJI-1] said:

Employees deal tough with us. Sometimes I need to speak to someone, but all the employees do not care and do not even give me ten minutes of their time.

It may be that the mother did not approach the right person, instead attempting to talk with the physiotherapy specialists and nurses. She interpreted their actions as revealing a lack of interest. It is worth mentioning that after the interview she said,

“There was a stone on my chest and it dissipated after talking to you”, which reflects her need to talk frankly about this issue.

Many of the other mothers also reported having had bad experiences regarding the way in which the doctors speak to them or about the type of information that they are provided. One mother [MJG-6] said, “They despise us. They speak to us as if we are ignorant”. This mother used very strong phrases that may have been a little exaggerated, but nevertheless indicate the intensity of her displeasure. Another example of a negative experience at a centre was the mother who travelled for three hours to attend a physiotherapy session with her daughter. The mother [MRG-8] said:

When I arrived, my daughter was tired from traveling. The specialist refused to give her the session because she was crying and she said, ‘come next week, we have a lot of patients and we have no time to lose.’ She did not appreciate my circumstances and did not respect me.

This experience was repeated multiple times and resulted in the mother moving to Riyadh to ensure that she was able to provide care for her daughter without suffering exhaustion or being insulted. Many mothers have reported similarly bad experiences in hospitals. The factor that is similar between the bad experiences of these mothers is that they all took place with doctors in government hospitals. The experiences of mothers in private hospitals are much better in terms of the respect shown for the parents and their opinions. A mother [MJI-4] talking about private hospitals said:

They serve me for my money. It is important to them to make me happy, so I do not go to another hospital. While in government hospitals where I used to go, the situation is very bad. It is like I beg for treatment from them.

Even in school, the mothers do not expect the authorities to pay heed to their opinions or to inform them clearly and respectfully about their children, especially in the case of government schools. A mother [MJG-9] who is also a teacher said, “I tell them I want my daughter to study the alphabet so she can read and write, but no one listens to me”. Despite her being a teacher who knows the regulations of the Ministry of

Education, this mother cannot make the school respond to her wishes regarding her daughter's learning.

Many of the mothers talked about the family support services as though they were thought of as a favour from the officials, which meant that it was inappropriate for them to choose the way in which they would receive the services. However, it is clear that this decision should be up to the provider. With a laugh, one mother [MUI-1] said, "I cannot tell the right time for me, I do not want to be beggar with his terms". This is a famous saying in Saudi Arabia used to describe a situation in which you ask for something that is not yours by right and you state your terms.

5.3.4 Emotional stress

Many parents expressed similar views to this father [FJI-2]:

What can I tell, no one helps, or even understands our circumstances, not the government, school and even my work, we take everything on our shoulders alone.

Mothers were more open in talking about their emotional stress, while fathers were noticeably more reluctant to talk about this aspect. Many of the mothers who were interviewed emphasised that their husbands suffer, but that they are unwilling to admit it, especially publically. One mother [MJI-1] said: "my husband is kind of secretive, does not disclose his feelings, and I know that he is tired emotionally because of our son". Most of the fathers confirmed that their wives are suffering and that they need help. One father [FRI-3] said:

I must be strong in front of my wife, because she derives her strength from me. I do not remember if I cried even if I am alone. In fact, mothers need support, while fathers flee from the house so they do not see this child.

One father [FJI-2] spoke on behalf of his wife, saying:

What is the mothers' sin to spend years of their youth in caring for people with disabilities they are not even able to move. Who will offset these mothers for the twenty or thirty years that they lost? We are suffering in his education, we are

suffering in his shopping. A disabled child means all the family is disabled, not only him.

Although the words of the father were referring to the mother and family, they actually reflect his high level of personal emotional stress, which made him see things from this angle and to consider the disability as a burden. This became especially clear when I asked him about his feelings. He replied:

I do not have time to think about whether or not I had a feeling. I am as a machine working all day. I have two jobs in order to provide for the needs of my son.

Financial situations may create emotional pressure on the parents, particularly on the fathers because of the cultural expectation that they will manage all financial issues.

Most of the mothers suffered from emotional stress at around the time of the initial diagnosis of a disability, however some lasted for years afterwards. One mother [MJG-7] said, “For three years I used to be alone in my room and cry”. This mother contemplated killing her son and then committing suicide, but religious faith was a deterrent for her. Another mother confessed to feeling guilty about her son, who is 17 years old, because she is not sure that her choices were successful. She [MRI-2] said, “When I see my son sitting in the living room alone I cannot stop my tears... I wish him a better life, unfortunately that is what I can do”.

In addition, the community can be a source of emotional stress for parents. One mother [MJG-5] said:

What hurt me was the questions from my relatives, which can be every day. They ask the same questions: do you think you will find a cure, what doctors say, he will walk or not, and so on.

Relatives may ask questions because of their curiosity or to show concern. However, it was certain that the mother had not developed skills to deal with such situations, so she was bothered by their questioning.

Another mother [MUI-2] complained:

My husband blames me too much in the way I treat my daughter; also my sister-in-law blames me for the same reason. They said I spoil her younger sister in front of her without taking her feelings into account. They make me sceptical about myself.

The mother began to tell me examples of some occasions and asked me if she had been right or wrong. It is clear that there is a difference in the style of child-rearing among parents, with the pressure often being placed on the mother since fathers have the power in the Saudi family. The interventions of relatives in the parenting of children may cause pressure, especially in the Saudi society where it is difficult to prevent these interventions.

Many mothers' lives revolve around their children with disabilities. They accompany them throughout the day and therefore have no time for themselves. A father [FUI-1] of a child with autism said:

My wife goes with my son to school. She stays with him all day long because she fears any danger. At home he must also remain under her observation, not to miss a single moment. There is no one who can help.

Many mothers quit their jobs so they could stay with their children, as some schools and health centres require the presence of a person with the child. Some parents talked about the number of hours, often as many as eight, that their children are at home after school. Since the task of following up on children's education often falls on mothers, this leaves barely enough time for the child and mother to eat and drink. One mother [MJG-8] in a focus group said:

What friends are you talking about, friends and hanging out are from the past, My ambitions now are to find time for a bath or to put oil on my hair [laughing].

All mothers in the focus group agreed with her. Each one gave an example of her daily routine, which almost consists solely of accommodating their children with disability and fulfilling some household chores. Most of the mothers ended their talk by stating that they have no other choice and that they hope to be rewarded by God for their behaviour. It is clear that children with disabilities are draining in terms of both

the emotional and physical energy of their mothers, putting pressure on them and the whole family.

5.4 The impact of having a child with a disability on his/her family's way of life.

Every member of the family has needs. Meeting the needs of one individual can potentially have a significant influence on the remaining members of the family. In light of the lack of services, a child with a disability can significantly impact on many aspects of the family's way of life. Important aspects will be discussed in the following sections.

5.4.1 The Impact of having the Child on Parents' Career Path

After having a child with a disability, many mothers reported that they had experienced a very big change in the path of career and study. However, this was not the case for fathers. Only a few fathers looked for additional work in order to meet the expenses of the child with a disability, but this did not require them to change their original job.

There were mothers who resigned for their children with disabilities. A satisfied mother [MJG-6] said, "Yes, I resigned and I do not regret it; my son needs me more than I need the job". On the other hand, not all mothers who have resigned from their jobs are happy with this decision. One mother [MUI-1] said: "I tried to continue in my work, but I could not. I had to resign with regret".

In addition to the mothers who tendered their resignations, one mother [MRI-2] said that she is aware of mothers who were looking for early retirement:

According to the system, there is still one and half years, then I will be allowed to take early retirement. It will be the longest year of my life.

Due to the needs of this single mother, she cannot resign, so she preferred to elect for early retirement in order to receive a part of her salary on a monthly basis.

Some other mothers stated that they were not able to leave work due to their needs and that it was too early for retirement, which meant that they tried to use vacation days as much as possible. One mother [MJG-7] said, “I think that my manager and my colleagues hate me because of my vacations; I barely go to work”. The mother has the same number of vacation days as the others, but she is asking for more by bringing medical reports for her child from the hospital. Where that is insufficient, she sometimes takes unpaid leave.

Others sought to change the nature of their work. For example, they moved to a new job close to the field of disability. One mother [MJI-2] said: “I moved to teach in a special centre for the disabled in order to understand this hidden world of the disabled”. A student mother [MJI-3] said, “I am now studying special education for my children”. The satisfaction that these mothers felt with their decision was noted.

Some mothers moved to a new job with fewer work hours or a location closer to their home. One mother [MJG-12] said:

I never thought of that before, working in the laboratory of a small health unit. My aspirations were to be in a large hospital, but I moved to this job because it is fewer hours and I have commitments to my son.

With sadness, she talked about her ambitions in the field of work and having given them up because she is in this little unit. “I lost the pleasure of teaching after moving to this school. The only good is that it is close to home”. A mother [MRG-8], who is a teacher, talked with indifference about her decision to move to a new school because of her belief that the time involved in transporting would be better spent with her children with disabilities.

5.4.2 The Impact of having the Child on the Lifestyle of the Family

Many of the parents who participated in this study stated that they had moved from small cities and villages to live in larger cities, such as Riyadh and Jeddah. They were looking for adequate hospitals and schools. One mother [MRG-7] said:

I was in Khafji and decided to move to Riyadh for my son, since there are no suitable schools in Khafji. My husband asked me cynically: 'will this make him a normal child?' I left my husband in Khafji and moved to Riyadh; he joined us after several years.

This mother is a businesswoman who appeared to be in her late forties. It seems possible that her maturity and financial independence helped her to act independently of her husband. Another mother [MJI-1] who moved from Taif to Jeddah said:

There are no suitable schools for my son in Taif. My husband asked me to go to Jeddah and he will join us when his work allows him to move to Jeddah.

Many parents' stories are similar, with the main differences being the names of cities and villages they came from.

Since there is a lack of adequate provision for children with disabilities in the villages and small cities, many of the parents who still live in villages complain about transportation issues. The driving duration can be up to 12 hours round-trip. One mother [MUI-1] said:

We stay in the car more than we stay at home. It is six hours and we need to go twice a week to Jeddah, so I try to review lessons with my oldest daughter during the journey...we did not claim for services here, you know it is impossible.

Even the eldest daughter suffers. In addition to being tired from the journey, she has to miss school for an average of two days a week. A single mother [MJG-5] said:

My children are scattered. I leave the youngest one with my mother in the village where I used to live and go to stay with my relatives in Jeddah with my child with a disability for his appointments. Sometimes a full month passes without seeing my baby. Even though my relatives are very nice, I feel embarrassed and tied in their home.

A father [FUI-1] of a child with autism whose hometown is two hours away from Riyadh said:

I know a lot of fathers who have moved to work in Riyadh for their children, and there are some who have hired a private driver to drive their children back and forth to Riyadh every day. For me, I cannot move or hire a private driver. I do not know how I will deal with the situation when my son grows up and needs to be in school.

Fathers have two choices, neither of which is ideal: either the child remains at home or they spend four hours a day on the highway where the vehicle speeds often exceed 150 kilometres per hour, travelling alone with a strange man.

5.4.3 The Impact of having the Child on the Role of Each Parent

The division of roles between the parents and the father's withdrawal may be the most important consideration in terms of parental responsibilities. The culture of the community has a significant impact on the roles of parents, as explained below:

5.4.3.1 The Division of Roles between Mothers and Fathers

"The full responsibility is on me, my husband does not do anything," one mother [MRG-12] said with a whimper. Many of the mothers supported this statement, though expressing themselves with different phrases. In fact, when mothers continued to talk, they admitted that fathers also had some roles but that they wanted to explain that mothers typically perform the everyday tasks at home. Even fathers agreed that the biggest responsibility for the care of children rested on the mothers. They present reasons for that, such as that the mother is in the house, so she is expected to be responsible for any children's matter. One father [FJG-7] said:

We are an Eastern community and this is our nature: the mother is responsible and the man is the man of the home. In fact, mothers want this responsibility.

The father's words not only reflected his opinion about the division of roles, but also the dominance of the eastern man. He spoke on behalf of the mothers and the assumption that women need to have all the responsibilities. He even claimed that

working mothers should bear the biggest responsibility because she is the one who is likely to be most affectionate and familiar with the children's staff. He said:

The mother is responsible even if she is working. She has the compassionate heart; it is the mother's nature. Some have been recently affected by what is written on the Internet and want to change the situation, but this is impossible.

It is worth mentioning that the father's wife died when his daughter was 3 months old. Since that time, he has been dependent on a nanny to help with raising his daughter. His opinion therefore reflects the male dominated culture in the community rather than his personal experience.

The main task of the Saudi father, which almost all of the mothers and fathers agreed upon, is to cover the expenses for the whole family, including the additional costs incurred by the child with a disability. Fathers who are not fulfilling this role often do not have enough money. One father [FJG-6] said "thus our God divides roles, the mother inside home and the father outside. He works hard to provide for their needs".

The participation of fathers in the rest of the tasks is limited, often being confined to those tasks that cannot be fulfilled by the mother. An example of this is carrying the child with a disability when they are older or heavier: one mother [MUI-1] said, "In the park, I cannot carry her, he has to be with us for that". Fathers also typically have responsibility for driving the car or hiring a driver. One mother [MRI-3] even stated that, "my husband does not contribute anything. He gave me the freedom and bought a car with a driver for me". This statement sheds light on a side of Saudi society culture wherein women do not enjoy a high degree of independence and instead act under the will of men. This occurs whether they are husband and wife, father and daughter, or brother and sister. By law, in the absence of the father, even a mother can be under the authority of her adult son.

One of the tasks expected of fathers is visiting the school of his son or sons if needed, as women are not allowed into male educational institutes. Despite this, follow-up lessons at home are usually the task of the mother. One mother [MRI-2] complained:

My husband is in prison and I have no one who can go to follow-up with my son at school. A teacher from outside the school tried to help me, but the school refused to brief him on the level of my son except with written consent from my husband. Even when I want to follow-up his lessons at home, I do not know the requirements.

In an attempt to overcome this recognised challenge, most boys' schools currently offer a direct phone line for parents. This can enable mothers to communicate with teachers, even though visits are still prohibited.

These rules mean that the role played by a father is larger when his child is a boy than if he has a girl, especially when the boy grows up. Beside the duty of visiting boys' schools, children of 12 years old or above have to be in the company of men when in hospitals. No women are not allowed to be in this section, even mothers, unless as a visitor. One mother [MRG-11] said:

After some years, if my son enters the hospital, his father should be with him. How will the situation be if the father does not know how to feed the child or change his clothes? The father must get used to this.

Additionally, the Saudi rules on gender segregation make it imperative for teenage boys to join his father or to stay at home, because he would be unwelcomed in the women's community. A father [FRI-2] of three children with visual disabilities said "they need to be with me, to get used to sitting with men. I want them to be useful for themselves and for their country".

Most fathers claim that they collaborate with the mothers of their children with regards to decision-making. One father [FRG-6] said, "My wife asks me before taking any action". Interestingly, only a few mothers said that they share these kinds of decisions with the father. One mother [MJI-2] said:

I make all the decisions. My friends might help me, but not my husband. Then I ask him ‘what do you think if we do this,’ and I know that he will say OK.

Another mother [MJI-1] said: “he has no opinion. He said I know better than him in this stuff, but I am interested in telling him everything”. According to this mother, she is telling her husband about her decisions because she is afraid of this responsibility and from the blame that may result in her making the wrong choice. Indeed, it therefore seems likely that there may be differences in the understanding of decision-making that makes most fathers think they share the role with mothers, while few mothers have this belief and claim to simply tell their partner what decision has been made.

5.4.3.2 Withdrawal of Fathers

Most parents thought that the majority of fathers withdraw from some or all their responsibilities towards their children with disabilities. However, the activists did note that a small number of fathers actually contribute more to the raising of the children than their mothers. One mother [MJG-7] said “not all fathers are neglectful. There are those who care and help, but they are few”. Parents offered several possible reasons for the withdrawal of fathers; some with regard to the father, some to the mother, and others referencing the culture of the wider community.

“The selfish father does not care, except for himself and his friends who he hangs out with,” commented one mother [MRI-1] immediately. Her opinion may be rather blunt and bitter in response to her personal situation, due to the fact that her husband refused to accept his son's disability, blaming her for their child having Down's Syndrome. This father told his wife, “You brought this baby into the world and will be bearing him alone”.

“Boring” was the answer one father [FJI-2] immediately gave. He then explained:

It is not a day or a week, it is years and years for nothing. There is no hope. This child will never be a doctor or engineer, so why do I pay effort to him?

The father was describing the perspective that he believed some fathers to have, although his view may be reflected in society's perception of the relative importance of a child with a disability. This idea was raised in focus group of mothers, who agreed that this may be the reason that some fathers do not want to pay too much for a child with a disability. A mother said “there is no future for this child, but he cares about his other children”. Some felt that this may be attributable to the father being so busy outside the home, with father [FRG-5] explaining that “if he has the time, he may do what the mother does and more”. This father he did not take into account the culture of the community, which generally forbids the father from doing tasks deemed to be for women. One father [FJG-7] believed that the reason is that employers do not typically cooperate with fathers, explaining that “it is not the work’s fault that you have this child, so you ask for permission to leave early every day. The work should be completed”. Another father [FJG-6] agreed and added that “you leave work to take your son to the school, who cannot get any benefit from school anyway”. In his statement, the speaker does not blame the employer, but the father for wasting time. This may reflect the general value of a child with a disability in society, including among some parents whose children have a disability. Shame may be another plausible reason for the lack of cooperation among some fathers. An activist [FRI-3] said:

Recently I found out that my neighbour has a child with special needs, ten years old. He keeps him in a room and does not let anybody see him. Do you expect any cooperation from a father like this?

Activists recounted numerous stories about fathers who deny the existence of a child with a disability. A mother [MJI-2] who is in the process of divorce said:

Do you know that my son is twelve years old and there is no one among my husband's friends who knows that he has a child of special needs? I know that he is ashamed of him.

Although this mother changed her job in order to be close to the field of disability and to keep abreast of new advances that could benefit her child, it was obvious that she lacked intellectual compatibility with her estranged husband, the father of her child.

Some mothers mentioned reasons referring to the mother. They criticised the mother's attitude in the debate with the father in matters that related to their child. One mother [MJG-11] said:

To be fair, some mothers cause the father's aversion to the home because of her way with him; she always blames and reprimands him. She should encourage the man in order to improve his tenderness.

Also, she may not select the right time to talk. One mother said: "Father returns from work tired, wife must choose the right time to talk in order to obtain his approval of the cooperation with her". A third mother [MRG-10] stated that these issues should be a matter of habit, in which the wife has to accustom her husband to sharing everything with her from the beginning, stating:

From the start when I was pregnant, I refused to see the doctor on my own. I told him, 'you must be with me, one day I may die and you will take the responsibility of this coming baby.' Now my husband got used to be with me in everything.

The reasons cited by mothers may be logical in Saudi society, but the common theme in their statements is that children are the responsibility of the mother and that she has to convince the father to share the responsibility with her. This may reflect the culture of the community and the way of thinking about the division of roles between parents.

Parents also added reasons related to Saudi society culture and its lifestyle. One father [FRG-5] thought that the presence of a private driver is an important reason for the withdrawal of some fathers.

Almost every house has a driver. The husband will ask his wife to go with the driver and do what she has to do, but if there is no driver, the husband will be forced to pick up his wife and child.

Though not in all cases, the absence of the driver sometimes makes a father more cooperative. One mother [MRG-8] said: “he takes me to the hospital, waits for me in the car, he even does not ask me which doctor I will see”. In fact, the presence of a driver instead of the father may even be preferable for many mothers. One mother [MJG-6] said “this is what we want; a driver and money, so he can go anywhere he wants”. Some of the mothers agreed with this opinion and stated that they were looking for this situation, although some merely because they conceded that it is the best choice typically available. Another reason given by a mother [MJG-10] was that “the father does not exist in the normal life; he is the guest of honour at home”. Another [MJG-11] mother from the same focus group had the same view but with more acceptance:

Let us be honest. This is the Saudi man; he does not follow the affairs of his normal children. Why would we expect him to follow the ill child? The man often does not get involved unless there is a serious matter.

Regardless of the use of the word ‘normal’ the mothers talked as this situation as the expected way of life. One father [FJG-5] raised an opinion that may reflect the mindset of some Saudi men “the father may say to his wife: who are you to give me instructions and tell me what I should do?” Instructions within a lot of Saudi families are one-way, passing from the father to the mother or the children, but not in the other direction.

5.5 Positive impact of a child on his/her parents:

Almost all of the parents agreed that their faith in God had grown after having a child who has a disability. Some stated a belief that this child was the reason for the rapprochement between the couple and, in a few cases, the birth had even been the

reason for the continuation of the marriage. One mother [MJ1-1] said, “My relationship with my husband has improved. In fact, we no longer have time for problems and bickering”. One father [FJ1-2] said:

Despite the existence of problems, my son was the reason for not getting a divorce. If my wife returned to her parents’ home, who would take care of him or carry him up the stairs?

On a personal level, some parents confessed to having undergone a major change. They cited developments like becoming stronger, caring more for themselves or others, and even becoming popular and loved. One mother [MJ1-1], who asked God for death after she learned that her baby would be born with Down’s Syndrome, said:

No, I am a new person. In the past I was waiting for death; then I accepted the challenge with my son. Now I am a businesswoman. I dye my hair, put on makeup, wear coloured contact lenses, and put on fake eyelashes. I became more confident talking with doctors and athletes. I can even travel alone; in the past it was heinous crime.

One father [FJ1-3] said “I became an activist and famous. Now I have thousands of children with special needs, not just one child”. One mother [MJ1-4] said:

I became loved by everyone. There were dozens waiting for us at the airport; they came for my daughter and brought gifts with them. In the past there had been no one at the airport except the driver.

Although some of these impacts from the presence of a child with a disability are not truly positive, such as the continuation of unsuccessful marriages, the most important outcome is the positive thoughts of the parents, who become happier and more willing to find positive outcomes for their family.

5.6 Summary

Through interviews, in light of the culture of the community, the impact of having a child with a disability on the family was clear in several aspects. The perceptions of parents about disability, and any changes arising from their own child having a disability, can be inferred by their use of language. Parents’ rejection of ‘child with

disability' and 'disabled' appeared clearly for both terms. However, the participants failed to agree on an alternative term.

Perceptions about disability were found to create certain attitudes towards disability, such as an obsession with searching for medical, traditional or spiritual cures, the last of which is often closely linked to religious thoughts. Their shock of having a child with disability and how they portray the situation by strong expressions, such as woe or disaster, also sheds light on their true feelings. However, their understanding of how their children accept their disability may give the clearest indication about the degree of acceptance that parents have for the disability.

Their attitude towards disability and their understanding of the community around them also played an important role in the negativity shown by some parents for claiming their children's rights. Their religious outlook toward disability is also of paramount importance, given that all of the participants touched on this topic several times and many of them claimed that their beliefs gave them a measure of solace.

One of the more unexpected results regarding attitudes towards disabilities in society as a whole pertains to the exploitation of disability, by parents, the media, specialist centres, hospitals, schools, and even by traditional and spiritual healers. I exclude the very common treatment by the Quran, which involves parents reading selected verses of the holy text to the child and praying for better health. This method does not provide any demonstrable rewards, except peace of mind for some parents.

The second aspect of the impact of the child with a disability on the family is the feelings of the parents. Many interviewees spoke about their uncertainty about options and their feelings of despair. Anger and frustration were also clearly expressed when discussing available services. In fact, parents were openly sceptical about the

importance of these issues for the government and the officials. Emotional stress was evident among many of the mothers when talking about these issues.

The impact of having a child with a disability also expands to the family's way of life. In term of parents' career, some fathers have taken on extra jobs, while some mothers had resigned, retired or changed their jobs in order to provide the care required by their children with disabilities. Maybe the biggest impact is that many of the families had needed to move to major cities in order to gain access to some available services.

Parental roles were found to have been significantly affected by culture; this may also have created the situation in which some fathers demonstrate a low level of participation that is sometimes limited to only financial support only. However, some parents commented on the positive impact that their children with disability had had on the family, such as improving the relationship between the parents.

Having looked in general at the impact of having child with disability on the family, the next chapter will now explore the specific challenges faced by parents when caring for their children with disabilities.

Chapter 6: Challenges faced by parents

6.1 Introduction

According to data analysis, parents of children with disabilities face a wide range of challenges in areas that include education, health care, issues with systems and staff, and even problems from or exacerbated by the community. The obstacles arising with regards to education and health care tended to relate to the trouble in finding suitable, free schools and hospitals. This could be made worse by the modest skills of many parents and poor relations that they have with officials, as shown in the analysis. There are financial challenges and others in integrating children with disabilities in mainstream schools.

Challenges faced by parents of children with disabilities in the community are similar in some aspects. For example, while certain positive impacts were shown in terms of the effect on the extended family, the analysis also uncovered some negative effects experienced by the parents of children with disabilities, in addition to obstacles like discrimination or inadequate transportation. These challenges are discussed individually and in much greater detail in the following sections.

6.2 Education

A significant disparity was observed in terms of the interest shown by parents in educating their children. Whenever the learning difficulty of the child is greater, the parents expressed less interest in educating their child and correspondingly more interest when the child learned more easily. One mother [MJI-3] of a child with severe

learning difficulties stated: “I want him to enjoy his life as much as possible, I do not want my child to learn, I know his condition worsens”. Nevertheless, parents prioritise education and are keen for integration in mainstream schools if their child has minor or no learning difficulties. One father [FRI-2] of children with a visual disability reported:

It is important for me that my sons’ school develops them so that they will be like normal people, if they are less than others, it means that I did not take advantage of this school, except training in behaviour.

The father’s point of view is understandable if we take into account that his children have a visual disability but no learning difficulties. This enables them to have partial integration in one of the two mainstream schools in Riyadh that accept this level of integration of children with visual disabilities.

Analysis of the data shows that challenges in education appeared in four key areas: suitable schools, parents’ skills, education costs, and integration.

6.2.1 Finding schools

Most parents in cities, regardless of whether their children are in special schools or they have been merged into mainstream schools, complain about the general paucity of appropriate schooling options for their children.

A mother [MRI-3] of a child with Down’s Syndrome stated: “I went to visit the Intellectual Education School, a scary thing, a mixture of Down’s with the mentally retarded, I cannot put my son there”. Although the mother eventually decided not send her son to this school and therefore had no experience of what the school is like in practice, she complained that “it has a bad name, they do not have education or even care, how come they put Down’s with others”. She was highly sceptical about the quality of available education and believes that children with Down’s Syndrome

education must be separated from other students. In fact, the responses of many parents showed an agreement with this mother regarding the low quality of the majority of government Intellectual Education schools, which have branches in many cities around the country and are devoted to children with learning difficulties. One father [FRI-4] stated “The Intellectual Education School needs an Intellectual Education school itself”. This father meant that the quality of education provided is poor. The judgement about the school may be influenced through the word of others, as one mother [MJI-2] reported: “It is not necessary to visit an Intellectual Education school; their bad reputation is enough, mothers complain about them”. In recalling a bad experience with an official, one mother [MRI-1] recounted the following:

I registered my son in a school, they said it is good, but unfortunately I found it bad. When he comes back I ask him about today's lesson, he tells me how he has been hit and belittled. Unfortunately, I do not have an alternative, they said there is another school but it is too far away and I do not have a driver.

With a laugh, she added:

My son does not know how to write or read even a single character. Today his homework was to write two lines about honouring one's parents and citations from the Quran or Hadith.

Other mothers echoed this complaint about the contents of lessons and the quality of individual plans provided for children. Another mother [MJG-9] reported:

They marginalised reading and writing, focused only on how to wear and care for herself. My daughter has the ability to learn, I try at home but she listens to the teacher more than me. I told them more than once, I want her to learn to read and write but they do not care.

Her daughter is 14 years old and has Down's Syndrome. Her attempts to ensure a better outcome for her child were unsuccessful because the school has a unified curriculum provided by the Ministry of Education. This curriculum is designed according to the child's age, without considering the views of parents or the students.

In addition to commenting about the quality of government schools, parents also complained about the shortage of schools. This has led many of them to enrol their

children in private schools, despite the fact that many feel that the education quality of these private institutes is very similar to that offered by government schools. In one of the focus groups, a mother [MRG-5] stated:

There is no appropriate government school for my daughter, so she is now in a private school. I registered her on a waiting list when she was one year old at a private centre that has a good reputation. Now she is ten years old and still waiting for acceptance.

Another mother [MJG-12] has a similar experience “I registered my son when I was pregnant after I realised that my baby has Down’s Syndrome; now he is six years old and still waiting”. Those schools are located in Riyadh and Jeddah. Like any school with a good reputation, they have a very long waiting list. As an example, the most famous centre in Jeddah, according to the word of several of the parents, does not accept children after they are three months old. One father [FJG-6] recalled:

A doctor told me about this centre that is good, they refused because my son was two years old, they required the child not to be older than three months. Well, no one told me about your centre before, so what shall I do?

It is also worth mentioning that these centres are among the most expensive options available.

Looking at remote areas, few locations have special schools or integration programmes for children with disabilities. This means that parents in remote areas do not have many choices: essentially, they must leave their child at home or, if their child reaches a certain level of ability, they can enrol in mainstream school. Theoretically, the choice of integration is up to the school, which is subject to the regulations of Ministry of Education, rather than the parents. However, social contacts can play a crucial role in remote areas, enabling the integration conditions set by the Ministry of Education to be sidestepped, since a degree of discretion is available as to their application. One father [FUI-2] from a village stated: “My wife works as a cleaner in a school, I do not think that the head teacher will refuse my daughter if we

wish to educate her... The head teacher is a relative of my wife”. One mother [MUI-1] gave several examples of how her village’s schools cooperate in the process of enrolling children who have a disability in mainstream schools, without obtaining strict permission from the Ministry of Education:

Of course, children cannot pass the year easily, they stay in the same grade for two or three years, until their parents are bored and take them out of school.

It is difficult for a school head teacher to refuse to take children from the village because of the influence of the tribe and considerations relating to their neighbours. Unlike urban areas, there is also less official monitoring from the Ministry of Education in rural schools, which makes this kind of locational integration possible even when it is not strictly in compliance with the rules of the ministry.

However, even when parents are able to find schools for their children, they may face other serious challenges, such as the cost of education.

6.2.2 Education costs

Given the absence of sufficient and appropriate free education, many parents have resorted to enrolling their children in private centres. As a consequence of this, the high prices of private centres was a complaint cited by almost all of the parents interviewed. While private centres are widely used, even parents whose children attend government or charity centres expressed complaints about the high cost of private centres, which often acted as a barrier to the enrolment of their children. One father [FJG-6] asked: “Do you know how much disabled schools’ fees increased last year? Three hundred per cent!”. Given the secrecy that exists with regards to school fees in Saudi Arabia, it is impossible to refute or verify this claim. Regardless of whether this claim is accurate, the discussion of the consensus among parents regarding higher fees is potentially valuable. One mother [MRG-5] reported: “I know

a lot of families have their children at home because they cannot afford to pay private school fees”. This point was universally agreed upon by the participants. One mother [MJG-12] posed a rhetorical question about the pricing systems currently used:

Does it make sense that the fees for a normal child are 7,000 Riyals [£1,210] and a child with special needs is 20,000 [£3,455] and 30,000 [£5,184] and sometimes up to 100,000 Riyals [£17,278]?

The financial costs might even burden parents who enrol their children in government schools. A father [FRI-2] of children with a visual disability stated:

A computer for the blind costs 20,000 Riyals [£3,455], I cannot get it and there is no entity that will help me. The Braille Writers device that is provided by the school is old and has a disturbing voice... It weighs up to 7 kg and my child has to carry it back and forth to school every day. There are new devices on the market, but they are expensive.

School budgets are limited and, a more important issue, do not always extend to provide the specialist school supplies required by children with disabilities. On these occasions, parents have to provide them personally or ask for financial assistance. One participant [FRI-3] stated: “The government pays just 5,000 Riyals [£864] from the school fees and I pay the rest”. Although no system stipulates that the government should contribute to the payment of fees in private schools, the social relations of this participant and his own individual efforts led to an official contribution towards the school fees for his son.

In addition to education costs, integration is another of the challenges for parents, as discussed below.

6.2.3 Integration of children into mainstream schools

In the absence of inclusive education even on the level of policies, integration is widely considered to be the best option currently available for children with disability. It may be that the most important challenge facing parents with regards to integration is their proper understanding of it. Furthermore, many parents believe that their

children are unsuitable for integration, occasionally leading them to reject the option outright, because of their belief that schools are ineligible for this approach. One father [FJI-1] disclosed the following:

I hope that my daughter is integrated, but her abilities are still weak and she forgets a lot, they asked me, do you want to integrate her, I told them not now.

The father sees integration as it is limited to children who can cope with school's curriculum. However, in the absence of a flexible curriculum and system of educational assessment for effectively measuring the success or failure of a child, the father preferred not to integrate his daughter. Another father [FRI-1] supported this idea:

My sons told me that they have disabled boys in wheelchairs at school, but they are better than my daughter. She has very weak hands, cannot even hold the pen, as well as her mind goes and comes. It is impossible for her to learn.

Limiting integration and education in general with regards to the cognitive aspect or physical weakness was an attitude expressed by many of the parents of children with disabilities, but which seems likely to be more widespread. This is because the current system judges the success of any child in school through a system of passing tests and moving to the next grade.

Parents may be wary of integrating their children due to a lack of confidence about the school's efficiency or effectiveness in terms of integration. One mother [MRG-8] answered:

I do not think about integration at all for my children. I am a teacher and I know how the situation is in schools. Our integration is not regulated. Instead, the first step should be to train teachers or change them.

In the same focus group, one mother [MRG-7] replied by commenting: "The path of integration is very long, needs awareness at all levels, mothers, children, teachers, supervisors". Additionally, this mother described her previous experience, talking

about the time that she worked as a teacher. One mother [MJG-11], sceptical about the acceptance of integration by the schools themselves, stated:

If there is a decision from the ministry to integrate my daughter, but the school refuses, I will not make a complaint against them. I will go to another school, because if they are forced to accept her, they will not cooperate.

Some believe that other children would not accept a child with a disability among them, complicating the process of integrating. They gave examples of when other children have stared at their child who has a disability. One father [FJG-5] recounted:

I carry my daughter every day to pick up my kids from school. Other children stare at her foot splint and how she moves her head, then they laugh at her.

The father believes that this is sufficient reason to avoid integrating his daughter in mainstream schools.

Despite many parents desiring to integrate their children, there are challenges. For example, some were unable to find a school to accept their children. A father [FRG-5] of a child with autism reported that “I tried, but no school accepted him because he is hyperactive. He cannot sit on a chair”. A mother [MJG-12] looking for integration stated “I visited all the schools around us. They said no we cannot accept him, we do not have an integration programme”.

Transportation can be a further challenge to integration. One father [FJI-1] commented:

My daughter is in a charity for children with disability, I found a school where I can integrate her, but it is far away...my work will not let me leave early every day to pick up my daughter.

It should be noted that this father had previously expressed an interest in integration but that he had noted that the ability of his daughter is weak. After discussion, he instead said that transportation is the main reason for refusing the option to integrate her.

In the absence of public transport and the ban on women driving, transportation can be a particularly problematic issue. However, even those parents without transportation problems often cited other challenges, such as the fees to attend appropriate schools.

One mother [MJG-12] recounted:

I took time off from work for three months to look for a suitable school integration for my son. I found the perfect one, it was an international school...but its fees are 90,000 Riyals [£15,850] per annum. I cannot afford this.

Even after integration, parents may face a lot of difficulties. One mother [MRI-4] stated:

My daughter is enrolled in a nearby school because my mother was a teacher in it, but the school was not cooperative, they call me every day, they say ‘do you see your daughter, she feels inferior, she has a disability’, they were trying to convince me to move my daughter to a school for the blind...of course, they were not able to reject her from the school because she is still considered as sighted, but they kept asking me for a copy of her medical reports, I think they are trying to convince the ministry that my daughter is not suitable for integration.

The mother believes that the officials at the nearby school chose the word ‘disability’ in order to discourage her from continuing to send her daughter to them, explaining that “They emphasise on the word ‘disabled’ several times to convince me that this school is not suitable for her”. So far, the child has spent three years studying there, but the mother still complains about a lack of cooperation with the school. Since the grandmother of the child has retired, the child’s eldest sister, who is in the same school, has helped the mother to look after her sister. However, the eldest sister confirms that her younger sister spends all of her time alone at lunchtime or during breaks. The mother stated: “I do not know why she spends her time alone, I think because she cannot see the girls”. It seems evident that the school has not managed or attempted to effectively adapt to accommodate the child, nor to cooperate with the mother in helping the child to acclimatise to life at the school.

The most successful form of integration in Saudi Arabia is currently in kindergartens, since the strict governmental rules regarding integration do not apply at this stage of education. There is also no use of pass or fail systems in kindergarten, which makes school principals more likely to accept children with a disability. Unfortunately, many children who were integrated in kindergarten then go on to experience segregation in special schools. One mother [MRI-3] reported this about her son:

He was integrated in kindergarten and he was very happy, all of his friends and his teachers loved him. All of this has changed now, after kindergarten we did not find an integrated school so I put him in a special school.

All of these challenges were faced by parents in the education of their children, despite the governmental system being based upon a set of rights that state that education should be provided to all citizens, regardless of their situation or ability. Reality proves that this has not been achieved.

Another potential challenge facing many parents is their lack of awareness regarding the educational process.

6.2.4 Parents' lack of awareness of children's education

Most parents do not know the contents of their children's lessons and did not contribute to their child's individual plan since some schools provide individual plans for each child that include certain goals, which are based on assessments conducted with the child at the beginning of the year or at the beginning of the term. When they were asked about their children's plans and lessons, they made comments such as "I do not know, is it necessary?", "they send homework", or "They did not tell me about a plan or anything". Even educated parents did not show a high level of awareness about their children's lessons, despite most being dissatisfied with the standard of education being provided. The only scale for evaluating the quality of teaching is a child's progress and achievement. I asked a mother [MRG-8] who works as a teacher

and who had complained about the quality of teaching about her daughter's lessons and individual plan. She informed me:

In fact I did not know, I think they sent it to me at the beginning of the year, however I did not need to know about the lessons or plan, I need to see the progress of my daughter and I did not see anything.

On this topic, another mother [MJG-12] said:

I do not know if there is a specific plan for my son, however they just send homework and ask me to help him. Their requests are not logical; the level of homework is much higher than the level of my son and they did not listen to me when I told them that.

As they mentioned, the most prominent role played by parents, is to follow the daily homework of their children, which is a task usually fulfilled by mothers. With a laugh, a mother [MRG-5] said: "Sometimes, I do the homework on behalf of my daughter, she cannot do it and they insist on it". This demonstrates that she is actually unaware of her daughter's individual plan and her targets, or the way in which homework plays a part in meeting those goals. Instead, she just deals with the homework as a task that must be completed by or for her daughter. A mother [MRG-6] of children with a visual disability reported:

They keep asking me to follow-up my children's homework, which is written in Braille and I do not know this language. I started to teach myself through the Internet and now somehow I can follow their homework.

This mother resigned from her job in order to dedicate herself to teaching her children. Initially, the parents hired a private teacher to visit their home to review the lessons with the children, however the mother now performs this task. Her accounts make it clear that the school was uncooperative and that it did not contribute to the development of the mother's ability to help her children. It must also be taken into consideration that no governmental or private centres currently teach Braille to parents. One mother [MRI-2] stated, with a wry laugh:

How do you want me to follow his study while I cannot communicate with him? When I want to say something to him my eldest son is a translator between us, they invented their own sign language.

Through the experience of this mother, we can discern the strength of the influence of the school and the weakness of the parents. The boy is 17 years old with hearing impairment and the mother claims that the school is refusing to teach him sign language. Instead, the school apparently reassures the mother by telling her not to worry, that he will still pass primary school and can then learn sign language in secondary school, although the mother argues that her son still “does not know how to read [written language], not even one character”. This mother cannot communicate face-to-face with the teacher or the educational supervisor since it is a male school, meaning that the only form of communication that is available is via telephone calls. The mother believes that her son's education needs time and effort, but that “This is what the school does not want, they want to throw the load on the secondary school”. It is clear that the mother does not trust the school her son attends and that this seems to be illustrative of a general lack of transparency between parents and schools.

On the other hand, some mothers accompany their children to school and stay with them throughout the day, as some schools require the child to be accompanied. These parents may be better informed about the educational process than other mothers, although it is important to note that the school still does not take their opinions or recommendations into consideration. One mother [MUI-2] recalled:

I go with her every day, sometimes I stay in the class if she needs help and sometimes I wait outside. They study lessons that exceed her ability and yet the teacher blames me because she thinks I do not teach my daughter at home.

Despite the presence of the mother in school every day, in addition to her ability to continually assess the capabilities of her daughter and the appropriateness of the lessons, she has no influence on decision making. This mother said “I do not know how to convince them, it is really hard for my daughter”. The teacher stated an explicit expectation that the child be taught at home. This approach was mirrored in

the experience of other parents, some of whom feel that this is the only task available for them with regard to the education of their children. A mother [MJ1-2] said:

I am as a mother of a child who has a problem. My duty is to follow his homework at home, the rest is supposed to be the school's role. How do I know about plans and other stuff, I did not study for four years in the university as she did [she meant the teacher in the special school].

Even though, she used to be a teacher in a mainstream school, it is interesting that she sees her role as only to follow the homework. This gives an indication that the idea that the role of parents is to follow homework at home is relatively widespread. In addition, as long as parents are able to afford the cost, most of the children's companions will be babysitters from different nationalities, who will therefore speak different languages and are not expected to be aware of a child's lessons.

Many schools seem to limit the parental role to following homework at home. A diligent mother may review lessons with her child, despite parents often lacking clear avenues of communication with the school and the skills to improve this state. The experiences recounted by the parents suggests little or no cooperation between many of them and the schools that their children attend, with educators behaving as though parents do not have the right to be involved in the contents of lessons or the particular teaching methods used.

Another of the areas in which provision is promised but where challenges are still faced by parents is in the area of health care, which will be discussed below.

6.3 Health care

The suffering and views of parents are fairly similar with regards to the free health care their children receive, as well as in terms of the level of satisfaction that they express with regards to the medical profession. This may be expected given the ratio of physicians to patients, which appeared in statistics compiled by the World Health

Organisation. According to the World Health Organisation the recommended density of physicians per 10000 population is 23 or above. The World Health Statistics of 2014, showed that the density of physician per 10000 populations in Saudi Arabia is 7.7, compared to 27.9 physician per 10000 population in the United Kingdom (WHO, 2014). There are also expected to be more shortages in remote areas than in big cities, which was confirmed by the parents.

6.3.1 Medical support

A mother [MUI-1] from a remote area stated:

I need to travel for six hours to Jeddah every six months to meet the brain and nerve doctor... I need to travel for three hours to Abha every month to see a speech specialist... Therefore, I have missed many sessions [with doctors].

By reviewing a sample of specific experiences recounted by interviewees, the difficulty in getting adequate health care can be clarified and discussed. One father [FJI-3], whose child has Spina bifida and lives in Jeddah, reported the following:

My wife gave birth in a private hospital, where my daughter remained in intensive care for 20 days. Each day cost 2,500 Riyals [£438]. I could not pay the costs, so the hospital director cooperated with me and asked just for the cost of the caesarean section. Then they tried to transfer my daughter to a government hospital for an operation on her back. After two months she had this surgery, but her head began to swell as a result of the increase of fluid. They did not put the spinal fluid shunt in until she was six months old. Now, two years later, we are in great suffering, as her back arched because she is growing up. The wound reopened and we have not been able to have surgery to close it so far.

Delays in the provision of necessary medical care are a common theme touched upon by parents in the interviews. The parents of the girl discussed above have been taking care of their daughter's open wound for two years, while they wait for the required surgical intervention.

The difficulty involved in obtaining an appointment with a doctor was cited by many of the parents. One mother [MJG-8] stated:

The doctor told me that my child needs physiotherapy and spoke at length about the importance of physical therapy for kids like my child. They gave me an

appointment for physiotherapy for half an hour each month, saying that this is the best the hospital can do.

The mother believes that the doctor wants to send an indirect message to her: she has to go to a private hospital in order to obtain the proper treatment for her child. Therefore, this mother made the decision to have her child treated privately and left the government hospital. Another mother [MRG-8] commented that “Prince Sultan Medical City has only one speech specialist, I tried to meet her four year ago but I could not”. Regardless of whether or not this information about the number of speech specialists is accurate, the mother was unable to meet a speech therapist, despite the size of the Prince Sultan Medical City in Riyadh. This mother was not the only parent to complain about the ability to access free speech therapy; many of the interviewees mentioned having the same issue, which suggests that there is a shortage of this specialty in most government centres.

As a result of the small number of hospitals that parents believe to be good, exacerbated by the scarcity of medical specialists related to disability, many parents use private hospitals or try to have their child treated in some of the government hospitals that are not typically open to members of the public. These types of centres include designated hospitals for the military or the National Guard. Many of the participants mentioned that, after numerous claims and many letters, they had received a letter from people in high positions granting permission for their children to be treated in such hospitals. However, this permission is often only valid for a certain period of time, after which the parents must then obtain another letter.

For parents who chose the easiest way, which is the treatment in private hospitals, the costs may present an extreme burden for the family. One mother [MRG-5] talked about speech therapy, saying that this costs “300 Riyals [£52] per session, I am no longer able to pay, so now I am looking for another specialist with lower prices”. One

father [FJG-5] reported: “They told me my daughter needs intensive physiotherapy sessions, each session is half an hour and costs 150 Riyals. How can I pay these huge amounts of money?” The father calculated that the costs of treating his daughter are more than his monthly salary.

One mother [MJI-1], after reviewing the difficulties that she faced, took a deep breath and said: “anyway, they said this kind of children have short lives, is that right?” By this she meant that the death of her child will be the end of the difficulties her family were facing.

6.3.2 Parents’ Relationship with Doctors

The analysis of the experiences of the parents that took part in this study indicates that they do not seem to be satisfied with the relationship that they have with doctors. Some believe that the doctors do not give them enough time or that they fail to provide sufficient information regarding the situation of their child. One father [FRI-4] remarked:

The psychologist in a single session decided that my child is autistic. He described a group of drugs and said the next appointment would be after three months. He did not clarify anything to me and did not give me any guidance.

Another father [FJI-1] commented:

After two visits, the neuroscientist told me not to bring my daughter to him again, saying there is no cure. He did not tell me where to go or explain my daughter’s condition.

A mother [MRG-12] said:

The doctor decided everything. He did not ask me what I need or what I want, even my son's pelvic surgery. The doctor got angry and said he will remove my son's name from the list when I asked him to delay the surgery for two weeks.

In the previous examples, time constraints may have caused the doctors to treat the mother in this way since they are in a government hospital. However, irrespective of the reasons, this behaviour represents unacceptable treatment.

Some parents believe that the doctors are not cooperating with them as parents of children with a disability. One father [FRI-4] stated:

When my son gets the flu I cannot find a doctor for him, as well as his teeth, no doctor agrees to do it. I tell them that he is autistic and it is not an infectious disease, they say we know but we cannot deal with autism.

The same problem can even be an issue for children with Down's Syndrome. The mother [MRI-3] of a child with this disability commented:

My son has tooth decay and the doctor refused to treat him, telling us to go to a clinic which specialises in such conditions. I told him he can use laughing gas, but he did not cooperate.

Another mother [MJG-6] said "they [doctor and nurses] talked for more than ten minutes about my son's x-ray, when I asked the doctor, he said 'nothing' they were talking in English".

The anecdotes outlined above show a lack of regulation within government health facilities, which can potentially prevent children with disabilities from receiving proper health care. Indeed, these experiences resulted in both of the parents who gave their accounts going to private clinics. These experiences relate to the next of the challenges faced by parents: obstacles relating to regulations and officials.

6.4 Regulations and officials

In comparison with the systems existing in many other countries, much of the legislation governing people with disabilities in Saudi Arabia is relatively new. The first code for people with a disability was issued in December 2000. This is exacerbated by the absence of a specific entity specializing in disability issues, although one of the functions of the Ministry of Social Affairs is to oversee matters relating to people with disabilities.

6.4.1 Ministry of Social Affairs

The Ministry of Social Affairs is a government entity that has a diverse range of functions. One of these responsibilities is to govern the affairs of people with disabilities. The ministry provides services for people with disabilities in conjunction with other agencies, although it has the primary say in actions taken. The headquarters of this ministry are in Riyadh, although it has branches in several cities, each of which has a male and a female section. There is also a ministry website [<http://www.mosa.gov.sa>].

The ministry website does not provide an abundance of information. Most of the parents had not visited it and even those who had claimed that the relatively limited amount of content available meant that it would only be useful for one or two visits. One participant [FRI-3] stated: “Yes I previously opened the ministry's website and did not get anything from it except a headache”. Parents noted that procedures and services are not shown clearly on the website and some are even missing. In addition, the methods for communicating with the ministry are limited, with the website only showing a clear address for the headquarters in Riyadh, plus an online enquiry field. I attempted to use an online contact form, which enables questions to be asked about the services they provide, but have still not received a response three months later.

In order to obtain services, every person with a disability has to visit the ministry at least once. The impressions that parents had about this visit to the ministry varied to a large degree, with both acceptable and negative experiences being mentioned by interview participants. One father [FUI-I] commented:

They told me what is needed and asked for the presence of my son. Next time I brought all the papers and photos. I also brought my son with me. They issued the card after six months.

Although six months might be considered a long time to issue a card to someone who is disabled, the father made no comment and showed no concern about the delay. However, it should be borne in mind that people with a disability are unable to receive any services until they receive this card. One mother [MJ1-3] gave the following account of her visit to the ministry:

Only once, I went to the women's section. Now I go to the men's section because they are better. If they ask me to go to the women's section, I refuse and tell them I do not have time to waste four hours waiting.

This mother was not the only one to complain about the women's section, where mothers of children with disability should go. In fact, most of the mothers claimed to have had poor experiences with this facility. Because of this, many of them prefer their husbands to go to the men's section, where the service is superior. That said, a number of fathers made complaints about the lack of clarity in terms of the required procedures, as well as having to visit several times in order to complete the paperwork. In addition to this, the ministry does not explain to the parents about the services that are available for their children unless they are directly asked about them. One mother [MRI-3] remarked: "They did not say anything about housemaids or tickets, only the card and they said wait for a subsidy". One father [FJG-6] expressed his shock at the available services, stating:

Are you serious? Can I apply for a land grant for my son? I swear to God that I just know that from you, even though I was in the ministry last week. From where and how?

Unfortunately, this was not the only parent who was unaware of the available services that can be provided for children with disabilities. Only a few of the parents knew, for example, about the available discounts on airline tickets and mobile phone bills. In addition, a significant number were not aware of the availability of vehicles for those with disabilities or about the granting of land. Although actually obtaining some of these services, such as the access to vehicles and land grants, can be extremely time

intensive and require years, it is still unacceptable that parents were not aware of their rights in this area.

6.4.2 Officials and the system

Parents also recounted difficulties that they had experienced with the inefficiency of officials, as well as with the lack of clarity in the system as a whole. A single mother [MJG-5] commented:

Do not talk to me about my son's rights. Now I need someone to help me with transportation, to open a file for my son. I need to go back and forth at least four times to complete all the paperwork; every time there is a paper or a photo missing.

In the absence of public transport, she has had to organise her own transport to visit the same offices on several occasions because of the unclear system in the ministry. Parents also complained on numerous occasions that officials are ignorant about regulations, stressing that their negligence and absenteeism from work disrupts the transactions for parents. One mother [MJI-4] said:

My daughter suffered a lot of injustice in integration, especially from the lady who is responsible for facilitating integration in the centre where my daughter used to go. She refused to integrate my daughter because she thought it was not suitable for her. When I insisted, she asked me to sign a statement to say that I am the only one responsible for integrating my daughter. When my daughter fails in integration, I do not have the right to appeal to have her put back in the centre.

This type of behaviour may be considered a form of intimidation that seeks to force mothers to be subservient to the opinions given by a specialist. On this occasion, this mother accepted the challenge and was able to have her daughter integrated. It is worth mentioning that the daughter is now in fourth grade, studying the national curriculum and succeeding in all subjects. One father [FRI-4] reported: “I went to the employee [in the ministry] and told him that the system says so and so. He said I do not know about that but we do it like this”. The child of this father is autistic and, according to a new regulation, a child with autism should be given priority in seeing a

doctor. This rule seeks to remove the need to wait, which can be as long as four hours in some hospitals. To fulfil this, the ministry should give the child a card that enables them to make a priority to see the doctor, but the employee did not know anything about this regulation. One participant [FRI-3] stated:

It is very common to see an illiterate father [cannot read or write], walking around in the corridors of the ministry, looking for help to fill in his paper.

Some parents have difficulty in understanding what is required of them due to the style of writing, which is often extremely formal and is not easy to understand despite the fact that the parents are literate.

6.4.3 Subsidy

Perhaps the most well-known and controversial service provided to people with disabilities is the subsidy. In fact, some believe that this form of support is the only service provided for people with disabilities. The complaints voiced by parents about the financial subsidy focused on two main points: belated knowledge and the small amount offered.

Almost all the parents had learned about the subsidy late and by chance, while all of them agreed on it not being enough. One mother [MJG-12] remarked:

I went to six centres, but nobody told me about the subsidy. When my son reached the age of seven, I met some mothers who told me about it.

One father [FJI-3] said:

I learned about the subsidy from some fathers when my daughter was five years old. I applied for it but it took two years. Of course, there is no pay retroactively for the delay.

Another mother [MJG-10] said:

For years the government and we knew that my child is autistic, but I did not know about the subsidy until two years ago when he was 10 years old, through some of the mothers... the subsidy for my son is 830 Riyals [£141] per month and I pay 6,000 Riyals [£1,023] per month for special teachers, in addition to school fees. Also I pay 1,500 Riyals [£256] per month for my son's driver.

When most of the parents were talking about the subsidy, they started calculating their children's expenses and comparing them with their subsidy to demonstrate that it is insufficient to meet their costs: [MJI-3] “My son’s subsidy is 1,200 Riyals [£205] and I pay 5,000 Riyals [£852] for physical therapy centres, in addition to the aid devices for my son”; and [MRI-1] “I take the subsidy and add 300 Riyals [£51] to it then give it to the driver”. There were many examples regarding children's expenses, all of which agreed that there are no adequate free services and that the subsidy is too small.

Although the subsidy is a sum of money that the government provides to support parents in caring for a child with a disability, some parents attached a different understanding to this payment. One father [FRG-7] stated:

I knew about the subsidy five years ago, but I think there are some who deserve this money more than me. I can bear the expenses of my son. Recently, I realised that it is a right for my son and I do not have the option of refusing after someone said to me: are you richer than the government? It is for your child, not for you.

Some still believe the subsidy is for the poor and they therefore find it embarrassing to accept it. One father [FRG-5] remarked: “My niece has severe disability and her parents are refusing to take the subsidy, they say we do not need alms [religious charity] from the government”. During the interviews, I noticed that the parents did not talk about subsidies of their own volition. When they were asked a direct question about subsidies, most hesitated before answering and their answers often contained a justification of why they receive a subsidy. This may be attributable to the previous point, namely that parents often do not want to be seen to be taking alms from the government.

6.4.4 Aid devices

Although the Ministry of Social Affairs is able to provide some important devices, such as hearing aids and wheelchairs, many of the parents were unaware of this. The

following dialogue occurred during a focus group for mothers, when they were asked if they received any free devices from the ministry:

Mother [MJG-5] 1: I buy all the devices; I did not know until today that the ministry gives free devices.

Mother [MJG-7] 2: I never took anything from them, in fact I just know that from you [from the interviewer].

Mother [MJG-8] 3: Do not be so optimistic, the complications upon receiving the devices make you prefer to buy them.

This means that some parents know about the free devices, but that they prefer not to use this option due to a perception that the procedure will be complex or inefficient, or that the free devices will be of poor quality. One father [FJI-3] reported:

They gave me a very heavy, large wheelchair, when I put my daughter in it you could not even see her head. I went to them and put my daughter in the wheelchair in front of them and I asked them: Is this appropriate? They said this is what we have. I had to buy a suitable wheelchair.

The complaint regarding the weight and size of the wheelchair was repeated from almost all of the parents who had received a wheelchair from the ministry for their child. Some of the parents returned the wheelchair to the ministry, others donated it to charity, while some of the interviewees confessed to have kept it as a toy for their children at home.

A key disadvantage associated with these devices is that their delivery may be slow.

One of the participants [FRI-3] stated:

I buy all the devices for my son, but I know what is happening in the ministry. When you apply for a wheelchair you may have to wait a whole month and if you need maintenance for the wheelchair you will remain without a wheelchair for two or three months.

One mother [MRI-2] remarked: “We have tried hearing aids from the ministry, my children refused to use them, they are not comfortable at all and caused headaches”.

As a consequence of this, this mother relies on the generosity of philanthropists to buy hearing aids for her children.

Above all, the devices provided by the ministry are very limited in range, number and functions. This leads most parents to buy devices or even to obtain them from charities or philanthropic donations.

6.5 Community

There are many unique aspects of the structure of Saudi society. These sometimes affect people with disabilities in a plethora of different ways. It should be noted that the conservative nature of the society also produces specific needs and imposes special approaches on the provision of services. Perhaps the most important aspect of Saudi society is the existence and continued relevance of the extended family, as illustrated below.

6.5.1 Extended family

When the parents were asked about the source of their support for, it was noticeable that almost all of the participants claimed to rely only on themselves. However, it became apparent through the interviews that extended families play a fundamental support role with almost all of the parents. This attitude of the parents may be attributable to this support being the expecting role of the extended family; namely that the extended families do what is supposed of them and so this kind of help is not seen as a favour or noteworthy. One of the mothers [MUI-1] complained that neither her family nor her husband's family helps her. However, I realised during the interview that her mother was taking care of her children while she was with me. She also confessed to leaving her children with her mother-in-law as often as twice a week in order to allow her to go on social visits or shopping trips. When I asked her if this could be considered as support, she answered with astonishment: "They are their children, they have to look after them sometimes, but they never helped me with my

daughter's exercises". It is important to note that according to the culture of Saudi society, as well as to the law, children belong to the father and his family, not to the mother's family.

In practice, the extended family do not necessarily always play a positive role in the life of children with disability. The extended family may even pose a challenge and put pressure on some parents, with many possible interventions, especially from the father's side, which can constitute a challenge to the choices made by parents. One young mother [MJI-3] commented:

My mother-in-law takes all decisions that are related to my son. Sometimes I am not convinced of her opinion, but my husband asked me not to undermine the opinion of his mother.

In addition to interventions from mothers-in-law, the father's authority to issue orders is clear. Another young mother [MRG-11] stated:

I cannot raise my child as I want because of my parents-in-law. They are spoiling him by pampering, they pity him so much, I do not want to make them upset.

Interventions may be broad in nature, as previously reported for the extended family in the case of the intervention by the tribe to prevent the media appearance of the child. Pressure can also be placed on the mother by actions such as the spreading of rumours like the disability of her child is punishment from God for the mother's bad behaviour.

The data suggest that a common pattern for the type of parents who most commonly enjoy the support of an extended family, but who also suffer most from their interventions, is that they are young parents who still live close to their relatives. Increased maturity of parents, particularly when supported by experience and financial independence, effectively limits the interventions of extended families. In fact, many of the more mature parents who participated in the interviews did not mention any positive or negative role being played by their extended families.

6.5.2 Abuse and pity

Although all the parents had been subjected to abuse or at least pitying looks, many of the interviewees made light of the effect that this had had on them, stating that this was a temporary impact. One mother commented:

I always hear annoying questions about the condition of my son, deliberately they stand in front of me in order to pray to God to heal my son... or to say 'All praise is due to Allah who saved me from that which He has afflicted you with' It is mostly the elderly who do that. They are poor, I cannot tell them anything. Just saying may God reward you well.

This comment supports the assertions of many parents, who note that most of the pity seems to come from elderly people. Many of these older individuals have limited education and knowledge, so are felt to have some excuse for their behaviour. One mother [MRI-2] remarked:

In the games area, some children, not all of them, do not care for my daughter's case. They may push her from the back or not respect her turn because she cannot talk. I think it is ill breeding: they did not learn how to respect others.

When the mother was asked about the places where her daughter had been abused, she stated that this occurred in lower-income areas. However, the majority of the anecdotes from the interviewees described good experiences with other children in public places being helpful and positive, such as giving them priority in queue, or offering them treats. Ideally, this may be seen as a good indicator that the awareness of the coming generations will be more in favour of and sensitive to individuals with disabilities.

The parents of children with Down's Syndrome and some parents of children with autism, however, recounted less positive experiences. They stated that some people may feel scared and try to avoid a child with Down's Syndrome; meanwhile, children with autism are also often accused of misconduct. A mother [MRI-1] of another child with Down's Syndrome stated:

One day a child tried to play with my son, but his mother came and stopped him and asked him to be away from my child. I came and told her that it is not an infectious disease to take away her son, then I took my son and went out. I cannot blame this mother. My mother is afraid of my son. I talked with her a lot and she is trying to please me, but I know she does not want him to be close to her.

Although this mother talked with other mothers, many of the parents of children with disabilities have experienced negative reactions from others. A mother [MJG-10] of a child with autism had the opinion that such people are “Not polite, spoiled, I heard them thousands of times, but what can I do?” One participant [MJI-2] asked:

How do we expect others to respect our children when the government does not respect them and give them their rights. If they received all their rights, as is happening in other countries, the respect would be imposed on everyone.

Perhaps there is an element of truth in this. The majority of shopping and entertainment centres, streets and buildings in Saudi Arabia are unsuitable for people with disabilities, potentially giving the general public the impression that people with disabilities are less important.

I should also note that some of the parents were happy and grateful to others as a result of the kindness and pity that they had shown for their children. Awareness may have a role in this, since all of the parents who expressed happiness at the pitying looks had received a low level of education. One father [FRI-1] stated:

They are very nice people, when they see my daughter they pray for her and caress her head. Some of them give her some candy... may Allah listen to their prayers.

6.5.3 Transportation

As the centres for children with disabilities are limited and because there is no public transport, which is exacerbated by the prohibition of women from driving in Saudi Arabia, children with disabilities may miss many opportunities for education and treatment. As previously mentioned the challenge of transportation may also constitute an obstacle to the integration of children. One mother [MRG-5]

commented: “My daughter stayed at home for one year because we do not have a driver”. A single mother [MJG-5] remarked: “I used to be against women driving, but not anymore. After I had my child, I realised the importance of women driving”. This mother lives in a village, 500 km from Jeddah, the city where she found treatment for her son. As she does not work, she is unable to hire a driver and her father is an old man from an average-income class. This meant that gaining access to treatment required her to move to Jeddah temporarily, to stay with her relatives.

Even the parents living in cities can suffer from a lack of suitable transportation. One mother [MRG-12] stated: “When I wave for a taxi, he does not stop if he sees my child in a wheelchair”. This may have been because the taxi driver did not want to waste his time in picking up and dropping off a wheelchair.

The Ministry of Social Affairs provides an option for people with disabilities that exempts them from paying the visa fees involved in hiring a foreign driver. A father [FRI-3] commented on this regulation:

The driver’s visa is just 2,000 Riyals [£341] every two years, we need the ministry to pay the driver’s salary, which is at least 1,500 Riyals [£256] each month.

It is clear that this regulation does not solve the problem of transportation, although it may provide limited financial support that enables the option to be considered. Another possible option that can be available from the government is the provision of a car suitable for people with physical disabilities. One mother [MRG9] commented: “If I have the car, who will drive it? Who will pay for the driver?” The car may constitute support for parents in their transportation difficulties than a driver's visa, but the problems may remain.

6.6 Summary

The challenges faced by parents of children with disabilities are often similar; such as teaching their children or doing their homework with them, or dealing with the regulations and entities that are related to disability provision. There are other more general challenges that that may have no specific link to disability, such as health care or transportation, but which may nevertheless profoundly impact upon the quality of life of children with disability and their families.

For example, in the area of education, parents may have limited access to adequate special schools or suffer problems integrating their children into mainstream schools. The private sector can cover some of this shortage, however the fees for private schooling can be prohibitive for many parents. The lack of awareness among parents themselves may also have a negative impact on the education of their children.

In terms of health care, deficiencies in the provision of care can adversely affect all segments of society. However, people with disabilities are often much more vulnerable due to their particular health considerations. In addition, the Ministry of Social Affairs, as the entity that is responsible for people with disabilities and the services provided to them, have been shown to create challenges and to be providing an unsatisfactory service in many respects. At the community level, transportation has been cited as the most prominent issue. Finally, in addition to the discrimination and pity that people with disabilities can sometimes encounter, the data show that even extended families do not necessarily have a universally positive impact on the parents and their children with disabilities.

Having looked at the most important challenges for parents of children with disability, the next chapter will focus on family support services.

Chapter 7: Parents' views of Family Support Services

7.1 Introduction

This research aimed to provide parents with the opportunity to express their preferences for family support services. Initially, many of the parents were unsure about the specific meaning of family support services. Moreover, they had no idea about the support services that were available for them in Saudi Arabia, or the kinds of support services that are often available for parents of children with disability around the world. The study also showed the limited imagination of parents regarding the kinds of support that could be offered with regards to disability, which may be due to this being a new concept for many of these parents. After being given examples, however, the parents were able to give their opinions and suggestions for family support services that might be useful in Saudi Arabia, the modest array that is currently available, and the kinds of services associated with the private and charity sectors.

Five main types of services around the world were raised in the interviews. These selected examples were derived from the literature review: first, the support and advice provided by specialists, from parents to parents, and by parent support groups; second, the education of parents and raising awareness; third, the provision of reliable information; fourth, services to be provided at home; and fifth, entertainment based services. It should be borne in mind that services can differ markedly in application from one society to another and therefore the interviewees gave their opinions about services around the world in light of the Saudi culture.

Finally, parents gave more suggestions for easing some of the difficulties that they personally encounter as parents of children with disabilities living in Saudi Arabia.

7.2 Parents' views regarding family support services in Saudi Arabia

The initial reactions from parents about 'family support services' in Saudi Arabia suggested that this was a new phrase for them, as the majority of the parents needed a few moments of consideration before answering. The answers ranged from [MJ1-1] "What do you mean?" or, [MRI-4] "I do not know" and [FJI-1] "I have not heard such a thing" to [FRI-4] "There are no services at all". Although the last answer came from an activist, a few of the parents offered similar answers to his.

Upon asking the parents if they had heard about organisations that provide support services to parents of children with disability, only two of the parents were aware of these kinds of groups. One mother [MJ1-4] from Jeddah stated:

I think that one of my friends has told me that there are associations for parents that will be opened, but I do not know if they have opened or not.

An activist father [FRI-3] from Riyadh reported:

Yes, I know the one in Jeddah. I communicated with them in order to collaborate with them, to be their representative in Riyadh or anything else, but they do not want this. In fact they do not provide any services, what they have are just foggy statements, nothing on the ground.

Through the interview, it became clear that the two parents referred to the same organisation, which is the Saudi Association for Parents of People with Disabilities. Having originally opened in Jeddah in October 2010, this was the first and until now the only association in Saudi Arabia that claims to be interested in supporting the parents of people with disability. Although almost five years have passed since this association opened, it was unknown to most of the parents, including those from

Jeddah. This may indicate that the services provided by this association, if there are any, are still not concrete and are certainly not well publicised.

Despite the reaction of parents to the phrase ‘family support services’, they still may in the receipt of some services. For example, the Ministry of Social Affairs states that a subsidy is offered to parents to help them in taking care of any of their children who has a disability. However, all of the parents in this study saw the subsidy as a right for their child, rather than as a means of support for themselves.

Some parents have obtained scattered services, primarily from the private or charitable sector. One father [FJI-3] commented: “This association visits homes and evaluates everything; doors, bathrooms, carpets, toys, everything, but they did not come to my home, because they just visited the nearby homes”. Here, this father was describing a charitable association in Jeddah that visits families and provides free advice on how to tailor the home environment to make it more suitable for a child with a disability. One mother [MRI-1] talked about a different private centre in Riyadh: “They came to my home and told me where to put the knife drawer and the level of the door lock, something like that, of course nothing for free”. She explained that this service is expensive and that there is a waiting list, but that they decided to collaborate with her because her 11 year old son, who has Down’s Syndrome, set a fire in her home that cost her 800,000 Riyals [£141,000]. They did not put her on the waiting list but she had to pay for the consultation.

In terms of education, the majority of the parents had not attended any training courses or specialist lectures provided by either the private or charitable sector. One mother [MRI-3] stated:

I took a training course for a term, an hour each week, we were a group of around 15 mothers... topics are good, although I did not take advantage of many things, mostly because I knew them before, such as how to train your child to go to the

bathroom or to feed him... The price of the course was very expensive, 8,000 Riyals [£1,382], and it was just 12 hours, they do not deserve this amount.

This mother has a child, the youngest of twelve, with Down's Syndrome. Twelve children is a large family in Saudi Arabia, but not exceptional. Although the fees were high for this course, it was clearly unsuitable for her, because she has raised 11 children and therefore has a wealth of parenting experience. Another mother [MJ1-4] had attended a number of lectures in a charity association and reported:

The mother: If they say there is a lecture and I have time I go, why not?

Interviewer: When was the last lecture?

The mother: (after thinking) I think last year.

Interviewer: About what?

The mother: I do not remember.

Interviewer: What are the lectures that you attended and were they helpful to you?

The mother: (laughing) I do not remember any of them; they bring a doctor who speaks and sometimes people I think might be specialists.

The fact that the mother had not chosen the topics makes it unsurprising that she had forgotten about the lectures. She explained that she only attends the lectures that are held at the same association that her child goes to every day and she has to be with him. During the lessons she has to wait outside the classroom and the association staff sometimes asks all of the mothers to go to the lecture room. This mother explained that she prefers to attend any activity in the association, regardless of the topic, rather than sit waiting and do nothing.

There can also sometimes be informal support services for parents. These will be addressed in the next section, along with a discussion of the views of parents about the family support services provided in other countries.

7.3 Parents' views regarding family support services provided in other countries

In addition to the phrase 'family support services' being fairly new to the parents, it was clear that it was difficult for the parents to imagine what hypothetical services

could exist. Many of the parents were also unable to give an outlook upon, or examples of, services in other countries. One father [FJI-4] stated: “I have no idea” and a number of other parents gave a similar response. Many provided one or two examples, which were usually related to the last subject we had been discussing in the interview before the question was asked; responses such as “maybe lectures and courses”, “aid devices”, “good schools for our children”, and “integrating those children”. However, there were some reactions worthy of consideration after participants had the opportunity to review some of the services, such as advice and support offered through hotlines, parent-to-parent support and services at home, which are services that are commonly offered in the UK. For example, after explaining the hotline for supporting parents, one mother [MJI-1] asked, “Where is this? Is it possible that this is a reality?” Another mother felt that “it is a dream”. Even one activist father [FRI-4] commented: “By the way, almost all the services you mentioned exist in the group that I manage. We provide these services without a government umbrella”. However, during the interview, the father tried to exaggerate the achievements of his group on multiple occasions, talking about their effort in supporting the families of children with autism, which is limited to only those families who use Facebook. According to the father, most of the families are from Egypt and only a small percentage is Saudi families [Facebook is not popular in Saudi Arabia]. However, when I asked the activists and parents of children with autism about this group, no one knew about it. Indeed, it is worth mentioning that after the interview, this father asked for a letter of thanks addressed to him and his group from my supervisor without any consideration to his anonymity, he may wish to use the letter as credit for him, either by displaying it on his website or adding it to his CV.

7.3.1 Support and advice

There are three most common ways of supporting and advising parents: by a specialist, parent-to-parent support, and by parent support groups. All the interviewees stated their belief that each of these three methods of support and advice is positive and important. However, they expressed different preferences and opinions about each of the three, as will be discussed below.

7.3.1.1 Support and advice by specialists

In general, most of the parents gave priority to support and advice by specialists. This may be a return to the uncertainty that they suffer and their feeling that many of their questions are still waiting for answers. One father [FJI-2] commented: “I think the most important is the specialist, I need an expert to get benefit from him [/her]”. Furthermore, many mothers showed a desire to receive moral, emotional or psychological support from a specialist, unlike the fathers who were much less willing to acknowledge the importance of this kind of support. However, some of the fathers agreed that mothers need moral, emotional or psychological support. One mother [MUI-1] stated: “Husband, sisters, friends are bored of listening, I need someone to hear me and relieve me. It would be great if it is a specialist”. One father [FRI-3] had this view:

I do not think I need one in order to support me morally. Thank God I am a believer and satisfied, but I think it might be useful to mothers because of their sensitive nature.

Another father [FJG-6] laughed and answered, “No, not for me, but it is a good idea for my wife. She suffered a lot in the beginning”. It was not necessarily the case that the fathers who were interviewed rejected the idea of moral or emotional support because they do not need it; rather, this rejection may be attributable to the stereotype

of the Middle Eastern man, who is supposed to be strong and there for the rest of his family to depend upon.

The majority of the parents stated that they would not mind if the specialist was a woman or a man, although the majority would also prefer a specialist who has their own child with a disability. One mother [MJ1-3] asserted:

It does not make any difference to me if the specialist is a woman or a man; the most important thing for me is he knows his job and does it correctly... if he has a child with a disability, great, he will appreciate my position and understand my situation.

Most of the parents echoed the same reason in different forms.

However, a few of the parents were conservative and would prefer a female specialist if the services were to be provided for the mother. One mother [MRI-4] stated

If I meet the specialist to talk about issues around my child, then it is OK [for the specialist] to be a man, but if I want to talk about myself, I need a woman. I cannot talk about that with a man

As not everyone gave this reason, religion or tradition may play a role in this. One father [FRI-1] held the following view “I will go with her, I cannot let my wife meet a man on her own. If this meeting is important, I will go with her”. This father’s words reflect the cultural relationship between husband and wife, in which the last word goes to the man of the house, even in matters directly related to his wife. Another father [FRI-4] stated:

I prefer to be with my wife, do not get me wrong, but women do not have time management, they may spend the whole meeting on unimportant points, so I have to be there just to keep control.

It was not only the case that the fathers would prefer to go to a specialist with their wives; most of the fathers would prefer to have their wives with them, but for different reasons. Examples of these reasons include [FJI-3] “If I did not understand, she can”, [FRI-3] “Better to be with me, I cannot focus, but she can”, and [FRG-5] “It is important that the mother attends the meeting, in fact it is the mothers who are

dealing with the child most of the time”. The importance of the role played by mothers with regard to their children may be another reason for fathers to be keen that the mother attends meetings with a specialist: the mother needs to understand the specialist directly without a mediator, which would otherwise be the father in this case.

For cultural reasons, some of the parents mentioned that they would prefer a Saudi specialist, as he would be better able to understand them and provide advice that is most suitable for their society. One mother [MRI-1] stated: “What I would have to explain to a non-Saudi specialist in 30 minutes, I could explain to a Saudi specialist in five minutes”, and one father [FJI-4] felt that “if he is a Saudi, he will understand many things without telling him”. However, the majority of the parents did not care about the nationality of the specialist, although they cared about ways of communication. Most of the parents would prefer to meet a specialist face-to-face as their first choice, or otherwise to communicate through a social media application like WhatsApp, which is a smartphone application that is very popular in Saudi Arabia. One father [FJI-3] stated:

Of course I want to meet him [her] face-to-face, but not every time. I think WhatsApp will be useful since I can even send him a photo.

A few of the parents thought a hotline service would be very important for them, while the majority of the remaining parents stated that their needs would be met by the specialist answering the phone during working hours. One mother [MUI-1] commented:

During the day, I am busy with the children. Thoughts and ideas do not come to my head until midnight. If there is a 24-hour phone, I will call immediately.

Another mother [MRI-4] had a different opinion:

It is too much, no need for a 24-hour phone. In fact, it is unacceptable for a woman to call in the night, even if she wants to ask about her child. She can wait until the morning.

This mother reflected the view of the conservative community, where there are many restrictions on the behaviour of women.

Nevertheless, despite the absence of this service on an official level, examples of remote support can be found on a small scale as a result of some of the efforts of some parents. One mother [MRG-5] commented:

We have a group of mothers on WhatsApp. Not only mothers, there is a volunteer doctor and some specialists with us. We can ask them what they want.

This facilitation of communication with specialists may be one of the most useful aspects of technology for parents, especially in remote areas. More of the benefits of WhatsApp will appear in the sections with regards to parent-to-parent support services and parent group support services.

7.3.1.2 Parent-to-parent support

Overall, mothers were keener on this kind of support than fathers. Some of the fathers questioned the usefulness of this kind of support. One father [FJI-2] commented:

I do not think it is a useful way, because I will be ashamed to ask him about affairs with his son. He is also not necessarily wanting to say everything.

Another father [FJG-7] stated: “Why do I meet another father, to complain to him and he complains to me? Each one of us knows what he suffers from”. Perhaps the stereotypical image of the strong Eastern man has impacted upon this father, who does not want to be in a position to need another father like him. This was confirmed by the words of one activist [FRI-3], who laughed and stated:

In the past, I did not think I would meet another father to ask him and get benefit from him, my pride and dignity did not allow me, but now I know it is very important, especially for mothers.

Also this activist father [FRI-3] stated:

I am now registered as a volunteer consultant in a charity association. They will provide the parents with my email and if they have any questions or need support they can communicate with me.

Although this is a good initiative from the father, it also entails certain risks, especially given that this father did not have any training that qualified him as an advisor.

Other fathers believed that while their wives could meet other mothers, there was no need for men to meet other fathers. One father [FJI-3] commented: “My wife can meet another mother and she will understand what she wants, I do not think meetings between fathers are important”. This suggests that the level of responsibility for childcare expected from mothers is greater than it is for fathers.

Almost everyone agreed that the meetings should be mother to mother or father to father and rejected the idea of meeting as couples. A mother [MRI-4] said:

I am shy. I do not think I am able to talk to a man. I prefer meeting the mother only, so I can speak freely.

An activist [MRI-1] mother commented:

For me, yes I can sit with the mother and father together [laugh], but I know my husband will refuse to come with me. However, almost all of the mothers do not prefer fathers in the meeting, and most of the fathers are not very different from my husband.

She laughed because it is generally deemed unacceptable for a woman to sit with a man and talk. Through the interview, she classified herself as a strong woman and stated that she challenged many issues in the Saudi community. Meeting directly with fathers would be one of those issues in a conservative Islamic society. However, a few parents from Jeddah who believed that the meetings could be as couples, perhaps because the community in Jeddah is more open-minded than that in Riyadh. A mother [MJI-4] said:

I think it is important for the mother and the father to meet at the same time. If one of them forgets something, the other can remember it... it will be excellent if there is a specialist with us.

Most of the parents would prefer the presence of a specialist in the meeting, in order to provide or verify information and to perhaps add more to what the parents know. One mother [MJ1-3] asked: “Who can guarantee to me that all the mothers’ information is correct? I think a specialist could correct any wrong information”. It should be noted that during the interview many of the parents spoke words that carried the meaning of the famous phrase, ‘Ask an experimenter, do not ask a physician’, as an expression of their greater confidence in parents than in specialists. However, they showed here that their trust is not absolute and that they therefore preferred to meet other parents at the same time as meeting with a specialist.

In order to make this kind of support more effective, however, many parents were not able to easily visualise this type of service. For example, many of them commented that they wanted to meet a parent whose child is of the same age as their own children. However, after discussing the kinds of services that might be available, many changed their mind and claimed that it might be better if the other child were older than their children to gain more benefit from the parent’s experience. One mother [MJ1-2] added:

I cannot answer, I need to try this service first, then I will tell you what is best, I now only expect it, but I may change my mind if I tried.

Some parents had suggestions, such as “If the mother brought medical reports, photos and video clips of her child, I could compare between the two children”. Another mother [MRG-8] suggested:

I do not think one meeting is enough. I want to continue to communicate with the mother to follow her child’s condition, for example, to exchange phone numbers and communicate through WhatsApp.

Some parents agreed with this mother and others had additional comments, such as this father [FRG-5]:

It may be better if I meet two or three fathers separately, not just one, then choose which one is helpful for me and I will keep in contact with him.

One group of parents liked the idea of this service but thought that they did not need it at this point in time. The common factor between these parents was that their children were all over the age of nine. One father [FJG-6] stated:

It is a good idea for parents who have just learned about their child's disability. My son is now 9 years old and I do not think it will add anything for me.

However, there were exceptions to this stance, including parents who confessed to still feeling uncertain. These parents wanted this service even though their children are already older than nine. One mother [MRI-2] felt:

I wish I could meet a mother with a son the same age as my son, I want to know how she deals with her son and which school he goes to.

This mother's son is 17 years old and she still feels unsure about the choices she has made for him. One mother [MRI-3] was more confident about her choices "Where was this brilliant idea when my child was small? Now I will be the mother who supports the new mothers". Without exception, all of the parents, even those who thought that the service was of no use, showed their willingness to support the idea if they were asked to do so. For example, they offered comments such as the following: "My pleasure to offer a service to one of the mothers", "We did not get this service when our children were young, it is not fair to stand idly by if one needs us now", and "I will certainly support any father, despite my lack of belief in its usefulness, but I respect the needs and views of the other father".

In addition to the parents' willingness to provide support to others through official channels, the majority of the parents, particularly the mothers, were positively inclined towards the idea of offering informal support. Throughout the interviews they mentioned incidents where they had already provided parent-to-parent support. For example, one mother [MJG-12] reported: "When I see a mother with a small child, I

cannot pass without talking to her. She may need help but does not know whom to ask”. One father [FRG-5] commented: “Many fathers know about the subsidy from me. Even if I do not know the father, I create a subject to talk with him and then move to our children”. One activist mother [MRI-1] stated:

I told people around me to give my phone number to any mother who needs help or has a question. Some mothers content themselves with chatting via WhatsApp, some ask for a meeting, we usually meet in a coffee shop.

In compliance with the norms of a conservative Islamic society, it was noticeable that mothers offered their support to mothers and fathers offered their support to fathers. Some might go further than offering advice, as one activist father [FRI-4] reported:

My wife opens our home to suffering mothers. The mother can spend all day with my wife and the children to see how life is with an autistic child. One of the mothers spent the night at our home because she came from an area far away.

This experience would likely be considered as a bold experiment in a conservative society. When I asked the focus groups their opinion about this experience, they expressed their admiration, while confessing that many of them would find it difficult to apply such standards themselves. One father [FJI-3] felt it was “Too much, the whole day. I think three hours is more than enough for the mother and it can be anywhere”. One mother [MRG-9] stated that: “It is a great idea and I have a willingness to host mothers in my house, but I do not think my husband would agree”. Another mother [MJG-7] commented: “I hope I can visit a mother in her home to see everything related to her child, but it is impossible, my husband will not let me go to a house of strangers”. This statement once again underlines the control that men have over women, as well as their concern for the norms of the community.

7.3.1.3 Parent support groups

In general, most of the participants wanted to become involved in parent support groups, especially for the exchange of information and experiences. However, the

fathers tended to prefer groups that aimed to improve or strive towards better conditions for children with disability. One father [FJI-4] asserted:

I am not sure I will attend this kind of meeting every time, I do not have time for chatting... if it is for claiming rights for our children, you will find my name at the top of the list and I will sign for anything, even if my child does not need it but others do.

Another father [FJI-2] stated:

Good idea but they should have minutes and arrange who will speak and about what, at the end we need a summary of the discussion in hard copy. It has to be an organised meeting with goals.

It was clear that the fathers placed great importance on time and organisation, although he arrived half an hour late for the interview, which perhaps serves as a practical illustration of the relative unimportance of punctuality in Saudi culture. Many of the fathers believed that their existing work and other commitments might also limit their participation in groups. However, many of the mothers stated that they would prefer that someone be present to direct the talk, while also ensuring that they had space to chat.

In general, the mothers expressed greater enthusiasm for groups that offer moral support. The following discussion took place in one focus group:

Mother [MJG-5] 1: It is the first time that I sit with the mothers and talk about our suffering. I think it is a great experience; even if we are here for your interview [talking to me].

Mother [MJG-8] 2: Yes [talking to mother [MJG-7] 3], I saw you a few times and our conversation did not exceed simple words, I think after this meeting, I will ask for your phone number [laughs].

Mother [MJG-7] 3: Especially as it is the case that my son and yours are similar.

Mother [MJG-5] 1: [talking to mother [MJG-6] 4] And we are both single mothers, we can put our hands together and get our rights from our husbands by force [laughs].

As seen in this extract, mothers organically created links during their time together in the focus group. In addition, the creation of links and support networks also took place in other group, with many of the fathers exchanging business cards after the interview. This could be considered as a viable and successful start for the formation of informal

parent support groups and underlines the importance of providing a simple forum for communication. This dialogue is taken from a mothers' focus group:

Mother [MRG-5] 1: We have WhatsApp groups. A month ago we established a family support group. Every three days is for one case; one mother talks about her child from day one until now, what did she do with him and she can put photos and video clips of her child in the group. During these three days, we discuss her experiences with the mother, we may get benefit from her and vice versa... the group has around 30 mothers... All of them have children with Down's Syndrome.

Mother [MRG-8] 2: [talking to mother 1] OK, such as me, my children are not Down's, where should I go? I do not have a group.

Mother [MRG-6] 3: [talking to the group] Me too, I do not have a group, frankly I did not look.

Mother [MRG-7] 4: [talking to mother 1] Can you add me to the group please?

Mother [MRG-8] 2: [talking to mother 1] God bless you, please add me to this group.

Mother [MRG-5] 1: I will add you all, God willing, benefits for all... even [she named a famous specialist in disability] will be with us.

Me: [talking to mother 1] Is it OK to be with you?

Mother [MRG-5] 1: Our pleasure and I am sure you will add something to the group.

Mother [MRG-6] 3: [talking to mother 1] What about me, my children have a visual disability.

Mother [MRG-5] 1: I will add you too.

Two days later we were all in this support group on WhatsApp. It is an active group and the conversation is supplemented by the regular exchange of links and posts for activities. It is worth mentioning that the mothers [MRG-5] and [MRG-7] have children with Down's Syndrome, the children of the mother [MRG6] have only visual disabilities, while the children of the mother [MRG-8] have multiple disabilities, although they attend a private school that specialises in children with Down's Syndrome. Two weeks later, mother [MRG6] 3, who has children with a visual disability, talked privately to me via WhatsApp. She told me that she wanted to leave the group, after feeling heartbroken over the stories and photographs that the group had shared. She wanted me to apologise to mother 1 on her behalf. The mother said: "their children are really disabled, but my boys are not. It is painful to see their photos and read their stories". The mother left the group, however this decision emphasises the importance of homogeneity in groups and most importantly stresses the relevance

of the medical model, because the mother felt pity towards the children she had not met.

By reviewing the interaction among the focus groups of both the mothers and the fathers, an apparent harmony seems to exist between parents when their children's disabilities were similar. The parents of children with different disabilities showed less interaction and often waited for a direct question before speaking. In addition, they marked their differences more clearly through oft-repeated phrases, such as, "I have a different situation" or "I am not like you".

Notwithstanding the above, some of the parents stated belief that a parent support group could even be more useful if the parents had children with diverse disabilities, whereas others argued that each support group should primarily contain parents of children with similar disabilities to enable a fruitful discussion. It should be borne in mind, however, that the majority had not tried a meeting with parents of children with different disabilities, while meetings with parents of children with similar disabilities had taken place. These meetings typically take place through the WhatsApp application on smartphones, which is a very common way to communicate in Saudi Arabia, perhaps in response to the size of the country and the relative difficulty of travelling for some people. However, a few mothers had succeeded in meeting face-to-face. One activist mother [MRI-1] stated:

We have many groups on WhatsApp, each group has approximately 150 mothers. There is a group for moral support, a consulting group, a group of mothers outside Riyadh, a chat group, and so on. All of them mothers of children with Down's Syndrome... once a month we have a face-to-face meeting, we rent a place and meet there...of course, not all of the groups, but some of them where we feel we are close to each other.

One father [FRG-5] added: "I have a group on WhatsApp, all fathers of autistic children, from different cities, we have not met face-to-face yet, but I hope".

Almost everyone agreed that the groups should be single sex, even the few parents who support the idea of mixed groups, as they recognise that this is difficult to apply in Saudi society. One father [FRI-3] explained: “I do not see anything wrong in a mixed group, it is for the child’s benefit, but it is impossible. We respect society”. One mother [MJI-3] added: “I hope for a mixed group, because mothers are talkative, so the presence of fathers will balance that, but it is not acceptable yet”. This division also included WhatsApp groups, as no one thought that it would be appropriate to have groups of mothers and fathers in the same group at the same time. One activist mother [MRI-1] who is a moderator for a number of groups stated the following:

I may accept a group of mothers and fathers in the meeting room, but I will not accept that or allow it in my WhatsApp groups. In the meeting room, it is just one or two hours and the talk will be in front of everybody, but on WhatsApp any father can talk to any mother privately at any time. I will not be the cause of a situation like that.

This demonstrates a kind of trusteeship of mothers and fathers. In Saudi society, the activist could be severely criticised for allowing a mixed group because she would be violating the wider norms and traditions of the community.

Many parents expressed confusion about the difference between parent support groups and educating parents and raising awareness.

7.3.2 Educating parents and raising awareness

A common service provided to parents of children with disability around the world is education and awareness raising. Therefore, this study examined the current state of affairs regarding this dissemination of vital knowledge in Saudi Arabia.

7.3.2.1 The current situation

The interviews gave some indication of the level of information and awareness among parents in terms of matters related to disability. For example, many parents did not

know the rights of their children except in the matter of the subsidy, despite the fact that many had even found out about this provision too late for it to benefit them. When asking parents about the rights of their children aside from the subsidy, they responded in the following ways. One father [FUI-1] exclaimed: “Are you sure, are there land grants for our children? Tell me where I can apply”. One mother [MRG-12] stated: “I know just now from you that there are free wheelchairs for our children”.

The following debate arose in the fathers’ focus group:

Father [FRG-5] 1: I just learned about the Saudi Telecom Company discounts from you.

Father [FRG-6] 2: [talking to father 3] Is it just for you as a Saudi Telecom Company employee?

Father [FRG-7] 3: [laugh] No, it is for any disabled person if they have an ID card.

This issue may be more critical for those parents who are unaware of their rights or have the wrong information when they are activists, because these individuals may pass incomplete or incorrect information to other parents. In one focus group:

Interviewer: Did you know about the land grants for children with disability?

Mother [MJG-9] 1: I heard something like that but I’m not sure if it is included... [mother 2 interrupts her]

Mother [MJG-10] 2: No, no, it is just for 18 years and older.

Mother 2 is an activist in a group of 200 mothers of children with autism. In the conversation above, she only just learned about the land grants for children with disability from me, yet was commenting on the subject as though she was acquainted with all of the facts. One activist father who shares his thoughts through Twitter talked about the most well-known charity association for children with multi-disabilities in Saudi Arabia:

Father [FRI-3]: The admission term of this association is that the intelligence of the child has to be 70 or above.

Interviewer: I think the Education Department requires 50 on the Stanford–Binet Intelligence Scales.

Father [FRI-3]: I am telling you now, the two departments, Education and Medical, require 70.

It should be noted that this father is registered as a volunteer consultant for parents with another association, however I worked for this association for four years and know the regulations there. Another activist father who shares his thoughts through Facebook used the term 'autism spectrum' as a type of autism disorder in order to refer to children who have some 'autistic traits'. According to the National Autistic Society (2009), autism is a spectrum condition, meaning that all individuals with autism share certain difficulties, but that their disorder affects them in different ways. However, using the term 'autism spectrum' instead of 'autistic traits' is a common mistake in Saudi Arabia. I have heard this used by academic people in Saudi Arabian universities. More importantly with respect to this activist father [FRI-4] is that some of his views are not based on studies. For example, he stated:

Geographic area has an impact on parents accepting their children's disability. For example, 80 per cent of the Northern Region rejects disability. Coastline also does not accept the disabled, except the Jeddah area which has increased awareness to 70 per cent, and then begins to decline towards the south. I can tell in the far south of Coastline that caring for the disabled does not exceed 2 per cent and the rest chain their children. They are tough, the disabled are outcasts. It is possible to leave a child alone in the desert.

This father and his wife run many groups on WhatsApp and Facebook, each with hundreds of members. The possibility that these views will be transferred to the parents in the group is therefore high. This erroneous and incomplete information provides an indication of the educational needs of the parents, who may not be aware of their lack of knowledge. This is exacerbated by the fact that the majority of the parents had not received any training or education to raise their awareness, as previously reported in the first chapter regarding the findings.

After asking the parents about education and training services, they expressed a number of needs and ways that this service would ideally be delivered.

7.3.2.2 What the parents wish to have

The parents listed a number of courses and lectures that they felt that they needed. First and foremost, they stressed the need for instruction on taking care of a child with a disability from the early stages. One father [FJI-1] stated: “I need to know how to deal with this disability”. One mother [MJI-2] commented: “I taught myself, it was not easy at all, it is important to have these kinds of courses to minimise mothers’ fatigue”. The parents of older children expressed a desire for specialised training courses on the stages of adolescence and adulthood. They suggested that lectures be given on updates in medicine and devices, as well as talks about enhance the ability of parents to look after their child with disability. Training courses in computing and English were also needed to develop parental skills. The mothers emphasised the value of courses on the management of stress, on how to integrate children with disability into the community, and those on sign language and Braille, the last of which were suggested by parents of children with visual and hearing disabilities. Parents also suggested training courses on early intervention and pre-marriage education. This gives the impression that parents have a desire for greater education and awareness.

Many parents needed reminding of some of the types of training courses in order to give their views, so I used some leading questions. For example:

Interviewer: What else do you suggest?

Father [FJI-3]: [still] Nothing in my mind now.

...[silent]...

Interviewer: What do you think about training on how to control stress?

Father [FJI-3]: Great idea, I hope it exists, sometimes parents get tired, especially in the beginning, it’s important for mothers.

Interviewer: Courses such as computing or English?

Father [FJI-3]: Yes, yes, English is very important, at least we need courses in terminology such as the medical devices, words such as ‘deformity’ or the name of the disease, nerves and others. Also, computing is very important for searching on the Internet and seeing the evolution of the world and what they have. If we know English and computing, we can even buy via the Internet.

Interestingly, this suggests the control of the medical model, since the goal of the father in learning English and computer skills is to more effectively search for medical terminology, such as the names of diseases and devices. As I previously mentioned in the introduction of this chapter, the interviewees had a relatively limited imagination regarding family support services. I had to give them examples to encourage them to talk about this topic. This limited imagination might be due to a lack of family support services on the ground, especially as lectures and training courses on disability support are extremely uncommon in Saudi Arabia. This could make it difficult for parents to initiate when they talk about family support services.

One activist father [FRI-3] talked about the quality of lectures, stating:

Better to have a Saudi lecturer to understand parents' culture, he has to choose the lecture content carefully to meet the needs. The information should be up-to-date, not from a book he read 15 years ago. He should use a suitable language, for example, not use English terms while parents do not speak English. And he has to take into account the parents' economic situation and not advise them to buy expensive devices when they do not have the money.

Even if he was the only parent to mention the importance of a lecturer from the same community, this advice was important because it was based on his experience of attending many more lectures and training courses than other parents.

Many parents believed that the training courses and lectures should also be provided for the children with disability themselves. One father [FJI-3] commented:

For two years I have been looking for someone to train my daughter in how to sit in her wheelchair and how to get out of it, but I could not find anyone. I wish there was a family support centre that could train my daughter.

Another father [FRG-7] stated: "The family centre can provide courses for children to help them in facing society". Many parents also noted that courses should be provided for teachers about how best to treat children with disability and how to integrate them in the classroom. One mother [MRI-4] had the following opinion:

It will be a great support for me if this centre trains the teachers and all the staff at my daughter's school. They do not know what integration even means.

Many of the parents made suggestions that people with disability could present lectures and talk about the difficulties they faced, as well as discussing how they overcame them. One mother [MRG-14] felt "You will shorten hours of education and motivation if the lecturer was a person with disability". One father [FJI-4] stated: "We have great people with disability, with a great lesson to parents if they talked about their experience". It is also possible that seeing a successful person would bring hope to parents regarding their children's future and be motivating for the children. One mother suggested showing documentary films about successful people with disabilities, such as Helen Keller.

The point that was agreed upon by all the parents was that the lectures and training courses should not be mixed sex, although some granted that should this be necessary then partitions must be placed between the two groups. This is a typical stance in Saudi society.

Many parents claimed that a family support centre should raise community awareness in order to better integrate children with disability into the wider society. They suggested many ways of doing this, such as giving lessons about disability in mainstream schools, posters in the street, presentations on television, or even text messages delivered to mobile phones saying information and advices. There was a particularly rich discussion in one focus group about how to raise community awareness:

Father [FRG-6] 1: Most people sit in front of TV. They can offer awareness messages in the advertising strip [commercial ticker].

Father [FRG-5] 2: Also Twitter

Father [FRG-7] 3: In large hospitals they can distribute leaflets.

Father [FRG-5] 2: However, people in the provinces do not have anything, they are poor. But you are right, TV reaches all people everywhere.

Father [FRG-6] 1: Also, many people do not have a background in computers or mobile phones but there is a TV in every house.

Father [FRG-5] 2: It is possible to have a database and send messages to mobiles.

Father [FRG-7] 3: Or leaflets in schools, children can pass them to their parents.

Many parents mentioned the use of Twitter and specialised forums as viable sources of information. One mother [MRG-11] said “I used Twitter to communicate with many people, they answer my questions. There are also useful topics in some specialised forums”. Forums often constitute the personal effort of individuals who are interested in the field of disability and, as such, could provide a rich, if unreliable source of information.

7.3.3 Providing reliable information

As mentioned previously in the first and second chapters of the findings, it was clear that the parents were suffering from a lack of information. They did not know the choices available regarding schools, centres, or services; there was also a difficulty in accessing information about disabilities and aid devices. Many of the parents had therefore had to resort to limited sources of information. Other parents and the Internet were the most popular list of information sources. Regardless of whether the material was sufficient or correct, most of the information that parents relied upon had come directly from other parents or the Internet. One father [FRI-2] reported:

When I need any information, I search the Internet first, or ask parents I am in touch with. They have often looked before me and they have an answer... I wish I could get the information from a specialist, but unfortunately this is very difficult, who should I ask?

This procedure is the same approach taken by many of the parents. However, despite the preference for using the Internet, few parents admitted to using the Ministry of Social Affairs website as it lacks any useful information as they said.

Some of the parents who did not know how to use the Internet relied upon their adult sons and daughters to search on their behalf. One mother [MRI-3] stated:

I do not know how to use a computer, but my daughters can, they look for everything I need... I have to ask them, they will not do it by themselves.

One father [FJI-3] commented:

I get onto the Internet to read about my child's case, epilepsy, and about problems that we face. My wife also goes onto the Internet to look up how to train a child to use the bathroom and more... I prefer to look through the Internet than use books, it is easier to find the information. I tried to read books before but there are no useful Arabic books.

This father may be one of the few who claims to have tried to read books. From the participants, only one father [FJI-2] said he had read a book that was very useful:

I read a book seven years ago and it was great. I made copies of it and gave them to any father I met at that time... I read just that book, now I do not have time to read a book while I have the Internet.

Some believed that even brochures are difficult to read. In one focus group they said:

Mother [MJG-6] 1: Any information I need I can find on the Internet.

Mother [MJG-5] 2: I do not have time to read.

Mother [MJG-7] 3: If the brochures do not have colours and photos, I cannot read it.

Mother [MJG-5] 2: But still, brochures will be useful to make an air fan in this horrible weather [everybody laughs].

None of the parents seemed worried about the reliability of information, despite most of them using Google. Despite this, they expressed a preference to get the information that they needed from a specialist. One mother [MJG-12] stated:

I use Google search for what I want, open approximately 10 sites and read them, compare them, then I can decide which information is right... absolutely, if I found a specialist answers my questions accurately that would be better.

This clearly indicates the preference of most parents for obtaining information: either directly from a specialist or through reliable information from the Internet.

One father [FJG-6] stated:

I want to get information in every way possible, but sitting with a specialist and having a discussion with him would be better, I may read something on the Internet and I need someone to explain it to me.

Another father [FRI-4] commented:

The Internet is very important. The parents' support centre website should be a reference for all the information needed by parents, in addition specialists have to

be available. Not all parents have the Internet and not all parents can read and write.

Parents who are young or who live outside cities preferred the use of the Internet instead of consulting a specialist. One mother [MUI-1] remarked: “All the world now uses the Internet. I need the information to come to me, not vice versa”. One father [FUI-1] stated that it was “easier for me to have everything on the Internet, so I do not have to drive many hours for this information”.

Despite the lack of acceptance of information found in books or brochures, the parents largely agreed on the importance of hard copy guides for parents when they hear a diagnosis of a disability. One father [FRI-3] made the following suggestion:

The hospital that diagnoses the disability should give a file as a guideline to the parents. This file should contain all of the information that parents need: information about the disability, treatment, available centres, appropriate schools, the rights of the child and anything else you may need. When they discover the disability, the parents will be in a shock, getting on the Internet or talking to many parents may confuse them more. They need papers to look at when at home with a cup of tea... do not just put a list of schools and centres. There should be a brief note about each centre and each school, such as their prices, an evaluation, cases they accept, their locations and ways to communicate with them... at the end of this file there should be numbers, parents can use these to communicate with a family support centre if they still have questions.

I can confirm that this activist father summarised what the other parents had stated about this point. However, the questions that seemed to most confound the parents were those about the kind of support services that they needed at home.

7.3.4 Services at home

Many parents looked at me with astonishment when I asked about services at home. A mother [MJI-4] said: "do you mean services provided by a centre in my home?" Most of the participants were not able to comment about services at home until they had been given examples.

Many of the parents were not keen on the idea of evaluations being made of the home environment and its suitability for a child with a disability. Some thought this service was unimportant due to the nature of their child's disability. One mother [MJI-2] stated that these were "good services, but not for my child. He does not need any special arrangement". One father [FJI-2] stated that it was "too late, if you asked me eight years ago I would have said yes, but now we learn from trial and error". This process of learning by trial and error may be the reality for many families in Saudi Arabia in the absence of evaluations by home environment services. One father [FRG-7] remarked:

If they come just to evaluate the home environment without providing anything, such as a ramp or a chair for the bathroom, I do not need them. I can learn by myself.

This father's opinion may be more closely related to the financial difficulties that parents usually face rather than his opinion about home environment evaluation. As evidence for this, the father thought that he could make the evaluation himself but needed someone to support him with what the home needed to make it suitable for the child. Many parents had a similar opinion, thinking that such a visit would not be useful if it did not support the required modification of the environment to make it suitable for the child. Another father [FJI-3] commented:

After they leave, who will help me to make all the arrangements that they suggested in my home? There is no need for some men to be in my home for nothing, with my wife and daughter.

This father reflected another issue in addition to financial difficulties: the required privacy of the Saudi house. In Saudi culture, it is not acceptable to let strangers into your house without a good reason.

With regard to privacy, one mother [MRG-12] stated:

Good idea if they evaluate my home environment, but I want them to be ladies so I can stay with them and discuss it. If they are men, my husband has to be with them and I will not be comfortable discussing issues with them.

The mothers were able to accept the idea of discussing matters with a male specialist in a centre, as mentioned earlier; however, privacy issues made them much less keen if this discussion were to take place in their homes.

Regarding the privacy of the home, almost all the parents refused to have a home assistant or a short term babysitter for precisely the same reason. Instead, they preferred the current situation, which is a visa option that enables a foreign housemaid to be hired, after which she lives with the family for a period of at least two years.

One mother [MRG-11] commented about this option:

No, I do not like this service, a strange woman coming to my house for a few hours, even if she is a babysitter. I prefer to have a housemaid and I will train her in how to become a babysitter.

However, the parents hoped to have more support than the option to apply for a housemaid's visa. They also stated the need for support in paying the salary of that housemaid. One father [FJG-5] commented: "Unfortunately, we cannot get rid of the housemaid, but we hope the government will help us with the salary, not just the visa".

One of the mothers raised the idea of offering formal training for housemaids in how to take care of their child. When this idea was raised in all the focus groups, it received a strong support from everyone. One mother thought it was a "brilliant idea, we can pay for this service, but we need a guarantee that the housemaid gets a good training in how to treat our children". One father [FJI-2] stated:

You go for physiotherapy for a month and then with a wrong movement from the housemaid your child loses all the benefit from the physiotherapy. It would be good if the housemaid had received training before holding the child.

The mothers also talked about their need for a private teacher to come to their house to teach their children. One mother [MJG-10] reported that "Six hours in school are not enough for him, I hope I can find a private teacher to help me at home". Her child

has autism and so she spends hours at home teaching him. Another mother [MRI-2] stated: “I hope for someone to come to my home to train my son in sign language, but for free. I cannot afford the cost of a teacher”. It was noted that the mothers were particularly interested in the option of hiring private teachers, which may be due to the task of teaching children at home falling to the mothers.

Given the many pressures on parents, this study looked at the value of entertainment for parents.

7.3.5 Entertainment

Most of the parents showed no enthusiasm for entertainment. One mother [MRI-2], who was still struggling with making choices in her son’s life, commented that “I do not think about this stuff now, I have more important things”. A father [FJI-2] stated: “In fact, I am not sure, if there is a suitable free activity we may go and we may not. I do not know”. He already has two jobs in order to provide for his family’s needs, so time and cost strongly influenced the father’s views. Another father [FJI-3] remarked: “I may drop off my wife and the kids at the activity then pick them up later, if they want to go”. He felt that such social activity is unsuitable for him as it is designed for mothers and children, which reflects the Middle Eastern image of what is an appropriate activity for men.

However, while many of the mothers thought they would join any activity if it seemed interesting, they were nevertheless critical of who else would join. The following are some of the mothers’ opinions: “I just want families of children with disability to be in this activity, fathers, mothers and all their children, there is no need for families of normal children”; “It is a great chance to integrate our children, but the families of normal children have to be aware about our children”; and “They can invite anyone

who wants to come to the activity, but with special treatment provided for our children, so others know that they are important”. Although the opinions of each of the mothers were different, they reflected a lack of confidence regarding the reactions of society towards their children. However, it should be noted that the father has the last word about going to an event in most Saudi families, regardless of their stated preferences. This is important because most of the fathers stated a preference for independence. One father [FRI-4] gave the following opinion:

It is better if the family support centre provides a discount for us as a family for theme park rides or resorts. Then I can go any time I want with my family without being tied to a group.

Almost all of the fathers agreed with this opinion, strongly resisting the idea of relinquishing direct control over their family to a group that contained external leaders, such as a group guide.

7.4 Parents’ suggestions

The participants in this study offered many suggestions. This section addresses on their recommendations, focusing on the most common services that have not been mentioned in previous sections. Differences were particularly pronounced between the suggestions of activists and non-activists parents, as explained below.

7.4.1 An entity speaking on behalf of the disabled

This idea was raised by the activists and then widely accepted by the other parents. In fact, most of the activists offered the same suggestion, albeit in different words. One of them [FRI-3] stated:

We do not want to be affiliated to the Ministry of Social Affairs; they are a failure. We want an independent body linked directly to the government just for the disabled and their affairs. For example, in the issue of the delay in disabled vehicles, we do not want every father appearing on TV in order to implore the public, we want this body to speak on behalf of everyone, based on power, not

propitiation. The first task for this body is to assess the number of disabled people in Saudi Arabia so that they can distribute services correctly.

Another activist [FRI-4] stated:

An independent body, that we can rely on to follow up the royal decisions that are related to the disabled to be applied, I do not care if it is called the Family Support Centre, or any other name. Also, they should stand on our side when we face a problem with any employee.

One father [FRG-5] asked: “Why should our children wait for a charity or a philanthropist? Why is there no government entity responsible for us and our children?” One mother [MJI-3] remarked:

I want a file for me and my son in this centre, so that I don’t have to carry my papers and medical reports every time. I just want to give them my number and they bring all my information from their system.

Another mother [MRG-9] suggested:

This centre should have the mobile numbers of all the parents, so that if there is any update about disability issues, they can send text messages to all the parents telling them what is new and what they should do.

All the parents’ hopes for this independent body could be attributed to specific challenges that they had experienced in their lives, as parents of children with disabilities. An activist father [FRI-3] spoke on this topic, saying:

Disabled in Saudi Arabia need a big leap, the staff in their offices is not enough to bring this shift: there must be an uprising in the media, social networking sites and among the people themselves... it is important to reach the disabled and give them assistance, do not wait until they ask for it, there are simple people who do not know their own good.

Many activists expressed the same idea, however some parents considered an alternative approach, as discussed below.

7.4.2 Advisors and mediators

“We need someone who knows the corridors of the ministry”, commented one activist mother [MRI-1]. Perhaps the word ‘corridors’ is the correct description for the required procedures in the Ministry, as almost all of the parents agreed about its

processes. The parents suggested allocating a mediator between them and the Ministry of Social Affairs. One mother [MRG-10] commented:

I do not want to go to the Ministry. I want to deal with a family support centre, someone from the centre to help me to fill out the forms and complete the missing paperwork. It would be great if he passes them to the ministry on my behalf.

Even this mother, who is educated, was looking for someone to help her deal with the Ministry. One father [FJI-3] stated:

Very important to have someone who knows about all the regulations in the ministry to help parents and minimise the time for them, especially parents who cannot read and write, they need someone to read to them and write on their behalf and they may need this person to go with them to the Ministry.

One mother [MJG-11] commented: “If this person existed, I would have applied for the subsidy a long time ago”. It seems likely that other parents also failed to receive a subsidy because of the ministry’s reputed complexities.

The parents were also keen to have an ‘educational advisor’. Those mothers who had sons with disability were more interested in the idea of this advisor because they are forbidden from entering male schools themselves. They do not want tips and guidance; instead, they need an advisor and representative to visit their child’s school in order to evaluate the situation and to talk on behalf of the parents. The following discussion occurred in one focus group:

Mother [MJG-10] 1: I will give him a mandate and he has to go to my son’s school to make sure everything is right.

Mother [MJG-11] 2: [laughs] He will play the father’s role.

Mother [MJG-12] 3: I will trust him more than my husband, because of his educational background.

Mother 4 [MJG-9]: Even mothers of girls need an expert to go with them to the school.

Mother [MJG-11] 2: For me, I do not think I need the advisor should go with me to the school, but of course I would consult her about my daughter’s education to learn from her... some mothers I think they need an advisor with them. Some of the mothers are illiterate or shy about discussing issues with teachers.

Many of the parents showed their need for a coordinator. One mother [FJI-4] remarked:

I hope there is a coordinator between any overseas services and me, whether they are buying devices or booking in centres or hospitals. A coordinator with the outside world; since I do not speak English it is difficult to rely on myself. Added to this, I may know one company that I can buy from, but due to his experience the coordinator will know a dozen companies and know the advantages and disadvantages of each one.

The idea of this service appealed to parents with limited incomes and to those with high incomes who are able to travel abroad. One father [FJI-1], who had complained about his economic situation, stated:

I hope to find someone who offers me this service. I am afraid of purchasing through the Internet because of fraud. The centre may also have a discount from companies, so it is worth buying through them.

According to many of the fathers, it can be cheaper to buy devices online than on the Saudi market. Given the lack of suitable free devices, the idea of obtaining cheap, high quality products was appealing to almost all of the parents.

A number of the interviewees expressed the feeling that they had been wronged at some time, but that they did not know where to go or how to gain access to a ‘legal advisor’. One father [FRI-3] commented:

Medical errors, no one pays for it, because parents do not make a complaint, they do not know how. They also cannot afford lawyer costs. This will be a great favour from the family support centre to parents.

Another father [FJG-6] stated: “If anyone helps me at that time, I will sue the centre because they did not accept my child”.

One activist mother [MRI-1] added the following:

We need a ‘family problems advisor’. I know many cases where people get divorced after having a child with disability. I think if they had had an advisor at that time they may be together now.

However, when the parents were asked about the importance of a family problems advisor, the majority stated that they did not need one. An opinion worth mentioning came from a father [FRI-1] who stated:

Thank God, I can deal with all my family problems. It is difficult to go to a stranger and talk about your personal issues. Maybe some can do it, but not me.

This illustrates the importance of privacy in Saudi family culture, which is reinforced by the belief that the man of the house should be responsible for all family issues and the resolution of all problems. This type of family may find it hard to seek external advice on personal matters.

7.4.3 Transportation alternatives

Some of the parents offered suggestions about how to overcome difficulties in transportation, such as the provision of one car with a driver for each residential quarter. One father [FJI-2] suggested the following:

It is impossible to provide a car with a driver for each family and a car without a driver does not help. I think one car with a driver for each residential quarter would be a good solution. The car would be available for important things, such as school or hospital.

Not all the parents liked this suggestion, with some insisting on a car with a driver for each family. The common factor among those parents was that their economic situation was at least average, meaning that they were in a position to hire a private driver.

One mother [MRG-9] offered a suggestion situated between sharing a car and having a private vehicle:

There are companies that provide cars with a driver for rent. If family support centres cooperate with these companies to nominate guaranteed and honest companies for parents, then help with the costs, it would be a wonderful thing. This would solve most of the problems that mothers have with transportation.

One group of parents were looking for an appropriate public transport. One mother [MRG-12] commented: "If they provide school buses for our children, it would be great. We do not need anything else from them".

It is evident from the above that financial issues complicated matters of transportation and featured in many of the earlier concerns. In fact, the provision of financial support was the demand most commonly mentioned by parents.

7.4.4 Financial support

Although all parents complained about financial costs with regard to their children with disability, none of them suggested that financial aid should be given to parents by family support centres. Instead, the parents spoke of the need to increase the quantity provided by the subsidy from the ministry. Even knowing that it is not a universal solution for the problems being faced, one activist [FRI-3] asked for it:

The first step is to raise the subsidy as a temporary solution. Parents have many needs that are unmet, the improvements in education and health need a long time, so raising the subsidy is a temporary solution until the improvements are done. After that, they can cancel the subsidy because there will be no need for it.

However, a few parents suggested the use of money and tangible aid as a way to gain the cooperation of parents. One activist [MRI-1] reported:

They are mostly poor people, if they know that there is a distribution of gifts, aid, money or even discount coupons, they will come. Family support centres should bear this in mind if they want to gain parents' collaboration.

Most of the parents agreed that this method would attract most parents, although some argued against using the needs of families to attract them. Others stated that they thought that incentives could be a very good idea but that the centre could not offer this each time and so should look for another way to attract families to visit.

7.5 Summary

The services provided to parents of children with disability in Saudi Arabia are modest and almost all are provided by the private and charity sectors. The parents showed their acceptance of and their need for all the common services that provided globally, with some modifications and additions to suit the Saudi community.

The majority of the parents in the focus groups talked about what they need, while the activists were more inclusive and talk on behalf of others and discussed Saudi parents of children with disability in general.

Chapter 8: Discussion

8.1 Introduction

The main aim of this research is to provide a cogent exploration of the impact and challenges that arise from having a child with a disability in Saudi Arabia, with particular reference to the implications that this has for family support services. It investigates the views of 42 parents. This chapter discusses the findings of the study in the light of the literature. A number of other interesting results emerged from the data that do not directly relate to the research questions. While these are not directly related to the research question, they are legitimate and relevant to the overall theme of this project and will therefore be mentioned.

The comments and suggestions made by parents were deeply rooted in the beliefs of the parents, which seem to be intimately related to the medical model of disability. This reflects the deficit way of thinking about disability within the Saudi society. In addition, some suggestions are provided in light of the findings and informed by the literature. These suggestions seek to facilitate the dissemination of knowledge to any individual or entity interested in supporting families, such as family support centres.

The different sections of this chapter and their organisational flow are illustrated in Figure 1. The chart has been provided to make it easier for the reader to follow the progress of the discussion.

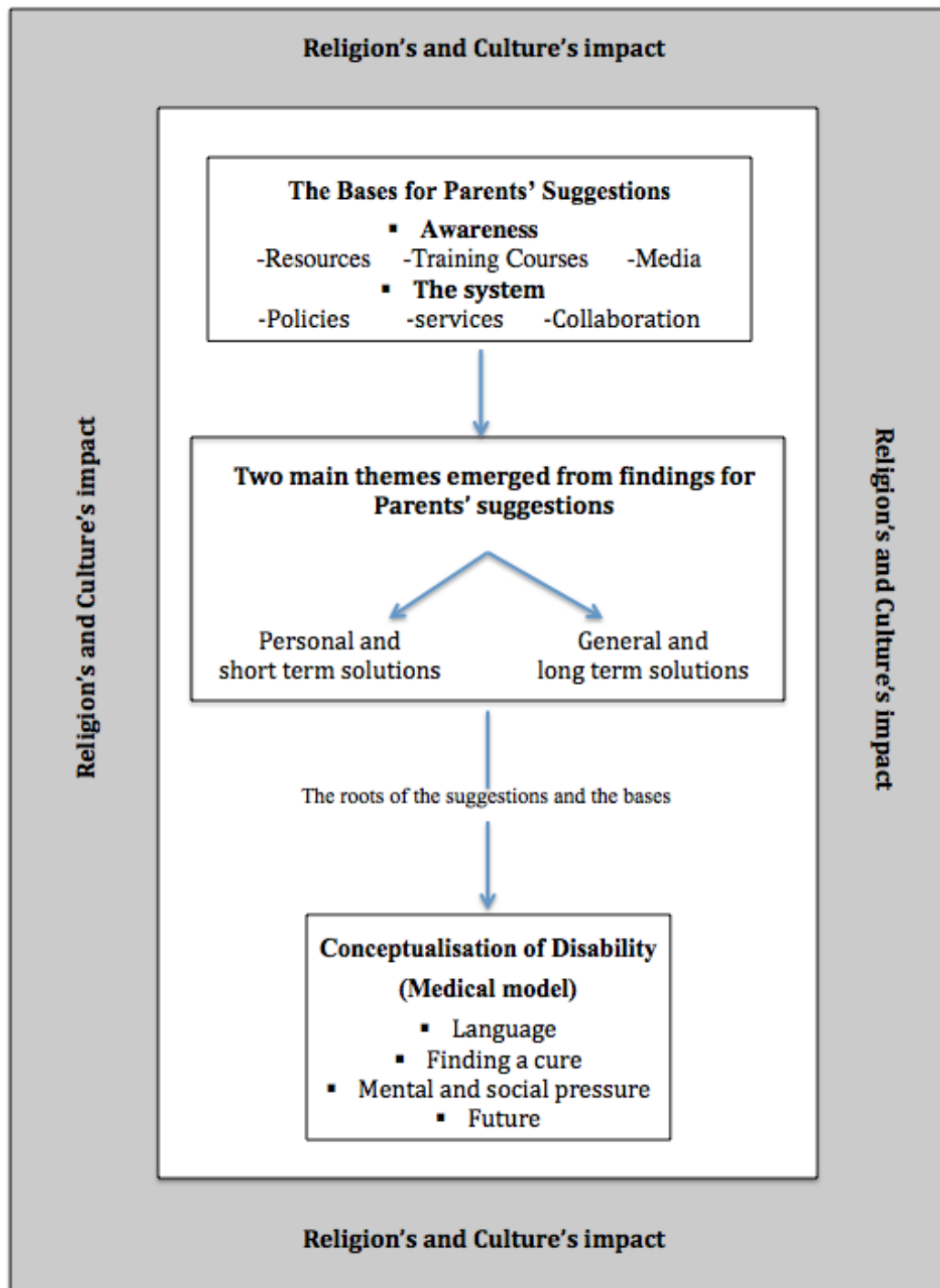


Figure 1: A representation of the different sections of this chapter, illustrating the structure of the discussion.

8.2 Parents' Suggestions and Preferences

As mentioned previously in the literature review, having a child with a disability can profoundly change the demands and needs of a family; the diverse needs of the families of children with disabilities can include the demand for support in psychological, financial, physical, or social issues (Gallimore et al., 1996; Itzhaky and Schwartz, 2000; Mak and Ho, 2007). For example, Brennan and Rosenzweig (2008) state that family support services should include formal and informal provision, in addition to the tangible goods that are defined by families. Indeed, family support effectively describes the meeting of any needs required to give them the full opportunity to participate in the society for all of its members.

The findings of this study provide an insight into the preferences voiced by parents of children with a disability and the suggestions that they have for improving this provision. Taking into account the differences in their preferences, the findings show that the parents expressed two patterns of demands and suggestions, which will be discussed in detail below.

8.2.1 Personal and Short Term Suggestions

Most parents asked for increased financial support through increases to the subsidy. This is because most claim what they currently receive is insufficient to meet the needs of children with a disability. A US study by Dobson et al. (2000) also found that all parents struggled to meet the needs of their children with disability, consequently spending less on themselves and trying to make savings wherever possible. Parents were also shown to spend almost twice as much on items than parents of children without disabilities and so they were only able to spend half of what they thought was necessary to ensure a reasonable standard of living (Dobson et al., 2001). In the

current research, most parents wanted money in order to provide for the basic needs of their children, such as appropriate healthcare and educational services, suitable aid devices and, in some cases, housemaids for their children [see page 195]. This can be classified as a personal demand because it is likely to benefit individuals, rather than to achieve benefits for children with disability in the society. Moreover, these demands are relatively short term in nature, because money to achieve a certain purpose will have a temporary effect. In other words, when this money is spent people may need to ask for more. For example, participants sought treatment from private hospitals for their children, rather than calling for the improvement of health services for all people with disabilities. This shows the reduced and somewhat minimalistic vision of the parents, indicating that they are focused on short term solutions to immediate problems.

Moorman et al. (2001) state that a number of studies have shown that parents believe that they need more information and advice. This is supported by other studies that show that training and interventions have the potential to develop parental skills, enabling them to better manage issues related to rearing children (ibid). Similarly, most parents in this study suggested that offering training courses to them on how to deal with children with disability could be beneficial, although this request was secondary to the plea for an increased subsidy. Although this is a logical demand if the parents believe that their skills in dealing with their children are limited. Parents have not demanded for courses to raise awareness in the community regarding the disability, or even courses about the disability rights, without encouragement questions from me during the interview or after I gave examples.

In respect of challenges they face in their dealings with various sectors, most of the parents request mediators between them and the other sector, whether it is the

Ministry of Social Affairs, schools or others [see page 233]. These kinds of solutions go again under the personal solutions because all people are focused on their immediate problems and how to get the service they need, instead of asking for reducing bureaucracy, which could potentially achieve benefits for other parents. This demand can also be considered as being a temporary solution because every time the parents need to deal with the official or social sectors they need to consider getting mediators to help them.

The majority of parents offered these kinds of short-term, personal solutions. Most of these were neither activists nor interacting with disability issues on social networking sites. On the other hand, the activist minority sought general, long term solutions. The demands of the activists are discussed in the next section.

8.2.2 General and Long Term Suggestions

Activists [two mothers and two fathers], who are considered to be the minority, did not raise personal or short-term demands, even if the question was directed to them in a personal way. However, they strongly suggested raising the subsidy, despite recognising that this would likely be a short-term solution. They still considered this a temporary solution, despite the potential value to parents, as this approach would take time to enhance the services required by parents of children with disabilities and their children [see page 237].

The activities of the rights activists in disability are often focussed on social media, striving to promote their ideas and opinions on a larger scale. Their activities have also involved a limited number of attempts to claim better disability rights through official channels, such as the ministries [see page 135]. This is due to many restrictions from the government on the formation of units to demand rights. In

comparison with the demands of the group of parents who were not activists, the claims of the activists were often found to be general in nature, rather than being personal demands. This helps to create long-term solutions that could be beneficial to all parents of children with a disability.

The group of parents who had become activists were able to offer a variety of choices for approaches that could support parents since they are more aware of the services provided for those with a disability in other countries. Examples of these include professional support services, support by peers, or assistance by teams of professionals and parents (Cavaleri et al., 2011). The activist group were interested in the diversity of the service provider, unlike the first group in which parents believe that their support should only be obtained from specialists [see page 233].

In terms of raising awareness, the activists had plenty of suggestions about how to build a greater awareness of the rights of people with disability in the society, such as attending conferences and seminars abroad to gain a better understanding from developed countries on how to implement ideas in Saudi. They also highlighted the importance of awareness activities and improving parents' skills in order to help families to cope more effectively with the difficulties that their children may have. This finding matches the results from the previous group, which is comprised of parents who are non-activists.

Regarding dealing with various sectors, activists suggested the idea of an entity speaking on their behalf, who facilitates all of the challenges that they face. This idea was also suggested by parents who are non-activists [see page 232].

To conclude, the parents interviewed had numerous different preferences, however some of the solutions that they offered were common to all participants, such as

increasing the subsidy and building public awareness. The analysis shows the underlying thinking of parents' suggestions, as well as their short-term and long-term approaches. Although I believe that the activists had some potentially valuable suggestions, their views missed depth in terms of vision, as they made suggestions according to their personal experiences and their opinions could therefore be further developed

8.3 The Bases for Parents' Suggestions

I found that the needs of parents are dependent on many factors, the most important of which are limitations to their personal knowledge (lack of awareness, lack of resources, lack of training courses and media) and the current system in Saudi Arabia (the system policies, services and the lack of collaboration). These factors are explained in greater detail in the following sections.

8.3.1 Lack of awareness

Despite the remarkable progress it has made in many areas, the society in Saudi Arabia is in need of development in terms of the rights of the disabled, including the awareness of issues among members of the public and even families. The findings of this study show that the lack of awareness among parents was one of the salient points. A lack of awareness includes knowledge of available services, which can limit the benefit from those services. A lack of knowledge about available services and how they could help has been found to be an important reason for the limited engagement that the parents have shown in those services in other countries (Gibbons and Thorpe, 1989; Cragg et al., 2002).

However, what applies to the parents of children with disability can be applied to the society as a whole. For example, cultural beliefs regarding disability often have a great impact on determining the way in which families perceive disability and the type of prevention, treatment, and rehabilitation they seek (Sen, 1988). Since parents of children with disability are a part of the Saudi society, they can be expected to be more engaged in disability related issues due to their children. So if the parents of children with disability lack awareness of disability issues themselves, it is not reasonable to expect greater levels of awareness among people that do not have first-hand experience of disability. From the findings, there are many aspects that play a crucial role in the formulation of the awareness within the community; these include:

8.3.1.1 Lack of resources

Hard copy and electronic resources are the most common sources of information. Very few parents tried to find appropriate books, without success [see page 227]. Since I belong in the same community, I understand this situation because I have encountered a paucity of high quality resources in Arabic during the course of this study. However, it is clear that the value of reading is very low because almost all parents have not read any books, or have any desire to read, even as they acknowledged their lack of information. In fact, the unwillingness of parents to read not only involves books, but also other hard copy resources such as leaflets. In other words, parents have shown no desire to read as long as simply presented options, like pictorial leaflets, have the potential to direct them in the right way [see page 227]. However, after numerous visits to centres and the government associations that deal with the affairs of persons with disabilities, a lack of leaflets and posters is evident.

These facts and observations show that both parents and centres are not interested in building the awareness through reading books, leaflets or posters

The Internet was shown to one of the most important sources of information for parents. Most of the parents mentioned it as their first and preferred choice. However, they realised that the Internet can be a non-reliable source [see page 227]. This is due to the poor quality and the degree to which untrustworthy information is made available on most of the Arabic websites. Browsing some of the Arabic websites demonstrates an evident lack of resources, with the available options typically being of poor quality. Not mastering the English language can be considered as another barrier to parents, as it prevents their use of the vast majority of online resources.

Parents' preferences and solutions will be influenced by, and reflect their knowledge and understanding of, their child's disability. An example of this is a father who insists on finding a cure for his daughter's disability, in an attempt to enable her to live without any disability. With greater awareness and knowledge about his daughter's disability and the possible treatments available, his demands may change [see page 127]. Nevertheless, the lack of resources influenced the awareness of parents in a negative way. In other words, a lack of reliable information may affect the parents' perceptions of their children's disability, as well as having the potential to affect their ability to specify their needs.

8.3.1.2 Lack of training courses

Training courses, lectures and interactive workshops can be a good way to raise awareness in the community. Among the interviewed parents, many expressed a wish to occasionally spend a few hours listening to experts talking about their children's disability, or even to discuss related issues with them [see page 227]. Unfortunately,

many parents stated that they were unable to find such activities, which could be helpful for sharing information and encouraging parents to face different challenges [see page 157].

Indeed, there may be some available activities, but parents may not know how to find them [see page 157]. This demonstrates a lack of advertising for such activities or suggests that the advertising did not reach the targeted group. Few parents had the chance to attend some sessions, which are often provided by the private sector. However, most of them were not satisfied with the training sessions in terms of content and fees [see page 206]. Surprisingly, the Ministry of Social Affairs does not offer any training courses or awareness raising activities.

8.3.1.3 Media

As mentioned in the findings, none of the parents mentioned a useful television channel or a radio programme, nor reported any benefit from articles in newspapers or magazines [see page 135]. Gamson (1992) notes that the importance of news media on the reality of social construction has been mentioned by many studies. The role of the news media in the creation of societal worldview is well recognised (Cohen and Young, 1981). As mentioned previously, since I belong to this community, I have noted this scarcity of appropriate programmes and articles. The most common topic that was over talked in the media is the use of disabled parking by people with no disability. In fact, they are often associated with occasions like the ‘International Day of Persons with Disabilities’ in the third of December. Therefore, I found that the contribution of the official media in educating and building the awareness among parents to be weak in Saudi Arabia. Haller et al. (2010) argue that when the news media present the disability it acts as an obstacle for inclusion, as they typically

present disability from the perspective of the medical model. In Saudi Arabia, I observed a media focus on many issues related to the medical model of disability. For example, once the media want to highlight and show the value of the services that are provided for the children with disability in Saudi Arabia, they start describing the high quality services provided by the special schools, rather than inclusion or integrated schools. Therefore, when I asked the parents about their requirements, they mentioned that they need good special schools to support their children. They focused on the quality and specifications of such schools instead of asking for inclusion [see page 178]. While the media will sometimes talk about inclusion, this topic is often discussed in an arbitrary manner or is potentially under-discussed. Therefore, this relates to the view that the media can act as an obstacle for inclusion (Haller et al., 2010). Moreover, regarding to the effect of media on the parents, when parents were asked about the rights of people with disabilities in Saudi Arabia, they generally talked about the lack of respect for disabled parking before they mentioned rights to education, health care, or sharing their life with others. This arguably demonstrates the profound impact of the media on developing the views of the public, even among parents who know better. The media has therefore been shown to have a crucial role in affecting the way people are thinking about disability and therefore on building their views about this disability. The impact of the media can transcend this level, potentially even exploiting disability in several forms for the fulfilment of a variety of goals. These could include the ability to highlight certain individuals and their deeds, enabling them to be presented as philanthropists or to achieve financial gain through fundraising [see page 141].

On the other hand, unofficial media, such as social media programmes have been shown to have an even greater influence. The options shown to have most influence

were Twitter and some specialised forums that were mentioned by many parents, who stated that they obtain most of their information from these sources [see page 226]. The presence of activists in social media and their interaction attracted parents to this type of media. In recent years, Twitter has exploded in popularity in Saudi Arabia (Aarts et al., 2015). In fact, I used Twitter to reach some of the activists who have children with disability. Surfing Twitter and forums it is evident that a wealth of information is available, although it is not necessarily correct. The inaccuracy of information has the potential to negatively impact upon the awareness of parents [see page 221, 222]. However, such available information may be helpful when less specialised topics are discussed, such as the respect for disabled parking or the use of the term ‘people with special needs’. Indeed, we should not ignore those parents who do not use social media, as delivering awareness to this segment is particularly important. Therefore, other methods should be found to do so.

However, as mentioned in the findings [see page 141], there is a degree of exploitation that exists on social media. This exploitation discredits the issue of disability and confirms the medical model, with the Internet acting as a platform for anyone to beg for money by posting child photos and copies of medical reports in order to seek help. Interestingly, some parents excused this behaviour because of the difficult circumstances experienced by parents of children with disabilities [see page 142].

An application that is available for smart phones named ‘WhatsApp’ was found to be the most popular way for parents to communicate, even among parents who are not familiar with the Internet. This application enabled multiple parents to liaise and share data through so-called ‘WhatsApp Groups’. This programme effectively enables individuals to be grouped together into private communication communities that may

have been created for a range of different purposes (Hamdan, 2015). ‘WhatsApp’ is even used in Saudi Arabia for communication between schools, centres and parents, as well as for some advertisements [see page 212]. The results of the study showed that many parents are members of at least one WhatsApp group [see page 219]. In fact, most of the parents prefer to arrange for the interview through WhatsApp. It should also be noted that they demonstrated a willingness to easily expand their groups, by inviting me to join the parents group on WhatsApp.

The above discussion demonstrates the effect of the alternative media and its superiority over the official media in influencing parents of children with a disability. As a consequence of these findings, it might be effective to use social media to educate parents. Moreover, the findings of the study seem to inform mass-media experts about the need to carefully reconsider the content and messages to be delivered to people through both official and unofficial media, in order to raise awareness of disability in society.

Given that the level of awareness has had an impact on parents’ suggestions and preferences for services, the system features have also been shown to have impacted upon the lives of families with disability. The effects of these features and their relevance to the research topic will be expounded upon in the following section.

8.3.2 Government System features

The system may have a crucial role in people's understanding and perceptions of disability. This can be explained through the effect of different policies and services provided by the system on the national level, as discussed in detail in the following sections.

8.3.2.1 Policies

Despite the fact that Saudi Arabia was among the first signatories of the Salamanca Agreement to implement inclusive education in 1994, the findings of the current study indicate that parents believed that neither adequate healthcare nor suitable education is provided for many children with disabilities. Furthermore, parents did not have any training in order to help them to take care of their children. Public facilities are commonly not designed for people with disabilities, thereby hindering engaging them with the community [see page 156, 166]. It is even the case that many leisure options and sport clubs do not accept children with disabilities.

Some policies marginalise certain categories or certain areas. In the UK, policy-making assumes that families in need live in urban communities, so families in rural communities often fail to join the services due to the physical inaccessibility (Frost, 2001). The same situation can be found in Saudi Arabia, where children with disability are unable to access the services provided for them because they live away from the urban centres where such services are almost always located [see page 188].

Indeed, it is worth mentioning that, according to the Saudi Arabia Disability Code of 2000, the government guarantees prevention, welfare and habitation services to persons with disabilities and their families (KSCDR, 2000). This code contains some excellent sentiments about health, education, sport, and information that should be implemented in reality. For example, the government promises to ensure medical, preventive and habitation services for all people with disability, as well as to train families about how best to take care of their children. The government has also committed to the provision of education for all people with disability from pre-school to higher education. Regarding the issue of social support, the government has to provide programmes in order to enable people with disability to integrate naturally

into various facets of public life. In terms of health and sport, people with disability have the right to utilise cultural and sporting facilities. Finally, the media has to play a crucial role in educating the community. Although the disability code has all of these clauses, it remains as a theoretical base and the actual implementation of these statements is evidently less than ideal, as shown by the findings of this investigation.

8.3.2.2 Services

The government centres for persons with disabilities in Saudi Arabia only exist in big cities. This pushes many parents of children with disabilities to move to live in bigger cities [see page 164]. Smith (1996) states that parents should not be expected to join services unless they are located in their own community or neighbourhood. Even when those services ostensibly welcome all parents, in reality they are limited to parents in their geographical location. Many parents claimed to see moving to a big city as a solution, instead of trying to claim services in their small cities [see page 164].

In Saudi Arabia, there is an uneven distribution of facilities, with schools and centres for people with disabilities being more common in urban than rural areas (Japan International Cooperation Agency, 2002). For example, the province that I come from has a population of 127,000. The estimated number of people officially registered with disability within this province is 1300, in addition to those who have not been registered. There are no official statistics on the numbers and types of disabilities in Saudi Arabia, nor about their geographical distribution (Japan International Cooperation Agency, 2002). In this province, there are no government centres, schools, or services to support people with disability.

However, the services provided by the government in terms of reachability and quality suggest that less value is given to children with disability by the government. Conversely, because Saudi Arabia pays great attention to the subject of compulsory education and literacy, it is common to find some schools in small villages with a total number of 15 pupils. According to the system, the government has to provide appropriate transportation to take small groups (under 15 pupils) to the nearest school, or to pay an 'alienation reward' to arrange transportation. At the same time, there are thousands of children with disability without appropriate health or education services, some of whom have been waiting lists for years to gain a place in a centre [see page 178, 188]. However, the greater focus in Saudi Arabia is on the health care of people with disability rather than education and training, with only little help given to persons with disabilities in finding a job (Japan International Cooperation Agency, 2002). This may reflect the medical model on government policy.

In terms of the quality of the provided services, the findings showed that parents complained about the poor governmental services in comparison with the private or the charitable sectors, especially with regards to education [see page 158]. So physically accessing a service such as transportation can be a challenge, like the lack of available public transport or the high cost (Katz et al., 2007). While the parents argued that mainstream schools are not bad, they are unsatisfied with the governmental disabled centres of integration programmes that exist within mainstream schools [see page 181].

The poor services for people with disability can reflect the value that the community as a whole gives to children with disabilities, the deficient way of thinking about disability in Saudi Arabia, and a failure to ensure proper assimilation of individuals

with disability into the Saudi society, as well as endemic failures to support disabled people at the system level such as polices and community level.

Sometimes a lack of engagement in services occurs as a result of parents' lifestyle, which service providers do not often take into account [see page 160, 217]. Time pressures can be a major hurdle to parents, preventing them from accessing services; this is particularly problematic for single parents and parents in full-time employment (Barauski et al., 2003). Additionally, financial pressures on parents can force fathers to work more hours or take on a second job [see page 160], which also lowers engagement with the child or support services intended to benefit the family.

The idea of providing support to parents was unclear to most of the interviewed parents, who largely believed that support can only be provided to them through supporting their children. However, the parents had low expectations and needs, pointing to the words of the Prophet Muhammad who said that "all of you are guardians and are responsible for your subjects". As a consequence, many of the parents feel that only they bear the responsibility for their children. On the other hand, there are words of Prophet Mohammed:

The believers in their mutual kindness, compassion and sympathy are just like one body. When one of the limbs suffers, the whole body responds to it with wakefulness and fever.

These words can be understood as placing the responsibility for care on the society as a whole, rather than only on parents. However, only one parent had come across these words. It is interesting to note that, the first words of the prophet, which state that all people are guardians and are responsible for their subjects, are more commonly known and cited than the second words, perhaps due to the traditional character of Saudi men, who are likely to take sole responsibility.

8.3.2.3 Lack of Collaboration with parents

As parents are the most attached to the child and they are responsible for their care they are the most affected by the presence of a child with a disability. Indeed, there is almost certainly a lifelong relationship that will be established between parents and professionals (Carpenter, 2002). In those communities that adopt the medical model, such as the Saudi community, the relationship between parents and specialists is typically marked by a pronounced discrepancy in terms of power, which is overwhelmingly concentrated in the hands of specialists [see page 194, 150].

As might be expected, the relationship between parents and professionals is usually controlled by the side that has more power and authority; power can direct the influence and authority can be used to drive this influence in a particular direction or to keep the situation (Dale, 1996). Because of this, parents and professionals have a complicated and changeable relationship, usually parents as individuals or groups have less power than professionals, unless there is a situation in which parents have power in the committee service, for example, or set their own services independently by their funds (Dale, 1996). In the case of Saudi parents, the findings showed that a significant proportion do not have to be in power of a committee service to meet their needs, it is usually enough to know someone in a high position who can facilitate their affairs [see page 199]. The power of knowing someone in a high position is an undeniable advantage across all areas of Saudi society, but this issue becomes ugly if it is related to essential rights for vulnerable group, such as with regards to the rights of children with disability. In regard of the power of money, wealthy parents usually travel abroad to seek medical treatment [see page 127].

The findings show that there is a lack of awareness among parents at many levels regarding educational and medical issues, as well as their general rights [see page

221]. However, their portion of decision-making is typically modest [see page 184, 190]. The strength of parental influence has been shown to have a direct link with their knowledge and the corresponding increase of their portion of decision-making, which gives them some official power (Dale, 1996). As a result, it is not expected that parents will be able to exercise any influence over the collaboration with experts, at least in comparison with specialists, at the current time. In fact, Alanazi (2012) showed that general teachers, special needs teachers and head teachers in 3 of the 5 Saudi schools perceive parents to be a barrier to the effective delivery of services. This position was in response to parents asking for communication channels between the school and their family. This suggests that parental involvement is not only inhibited by a lack of awareness among parents, as was clear in the findings, but potentially by a number of other factors such as teacher resistance to their participation.

This attitude among experts can be seen in anecdotes from parents, who mentioned that specialists in both hospitals and schools dismiss them, electing not to explain the situation to many parents, or not even offering parents a role in decision making regarding their own children [see page 150, 152]. This led many parents to acknowledge their low value in the government and that no official listens to them [see page 157].

Parents' suggestions and underlying understanding of their situation seem to be rooted in the beliefs arising out of the medical model of disability, which is discussed below.

8.4 Conceptualisation of Disability and medical model in Saudi Arabia

Parents' views reflected the ideas of the medical model of disability, such as seeing the disability as a disaster [see page 132], or believing that the responsibility for the

disability should be carried solely by parents rather than the whole society. [see page 169], which places emphasis on disability as a tragedy (Johnstone, 1998; Marks, 1998) or as the responsibility of the individual (Oliver, 1996). It could be argued that such views may effectively prevent them from developing a wider and a better understanding of what needs to change in society in order to include children with disability. This conceptualisation has the potential to be applicable to other societies that share the same traditions, beliefs, culture, religion and customs with Saudi Arabia, such as the other countries of the Arabian Gulf. By understanding the conceptualisation of disability in Saudi Arabia, plans can be developed to guide its society towards a more effective social model. The following are the most prominent features of the medical model in Saudi.

8.4.1 Disability Meaning and the Used Language

This study found that while most of the parents realise that their children have a disability, all of the participants oppose the use of the term ‘disabled’ and most of them also refused the use of other alternatives, such as the term ‘with disability’. Some parents state that their child is ‘normal’ [see page 124], while others associated the term disability with someone being on a wheelchair and so refused its use for their own son or daughter [see page 123]. Hume (1994) supports this assertion, having widely identified that although there are many different disabilities, the word ‘disabled’ is generally associated with the image of a person in a wheelchair.

In order to clarify to the extent to which the community refuses the use of the term ‘disabled’, some parents of children who use wheelchairs think that this word only can describe those with severe physical and mental disabilities, rather than simply describing children in wheelchairs [see page 123]. This contradicts Hume’s view

above. Therefore, many parents seem to believe that this term is like a stain and they are trying to avoid the use of this label for their children.

Parents who believe that their children have a disability still refused to use the terms 'disabled' or 'with disability'. They believe that those terms are insulting and the majority tend to use the term 'with special needs' instead [see page 124]. It should be noted that using terms such as crippled, lame, invalid, retarded and moron is thought to reflect undesirable perceptions in some societies, which may lead to inferiority, or evoke pity or fear of the people with disability (Roush, 1986). In the Saudi society, the word 'disabled' can also be added to the list of unacceptable words.

The language of scholars and the media may have contributed to this idea. The concept of refusing terms can be affected by the language used publically or by scholars, although in some cases these authorities have emphasised that the use of such terms can be inappropriate. Moreover, the colloquial Arabic use the words 'disabled' and 'with disability' by linking them with being unsuccessful, whether or not they are tangible objects, ideas or behaviours [see page 124]. This gives the impression to casual listeners that these words should be considered offensive.

Islam can be considered as the primary guidance of Saudi society. I found that the words 'disabled and with disability' were not mentioned in the holy Quran or in the words of the Prophet Muhammad, which is a likely reason for some Saudi parents to avoid using the term. However, none of the participants mentioned any part of the Quran that uses the word 'disability', meaning that neither of these terms 'disabled and disability' derives legitimacy from religion. However, the words 'blind', 'lame' and 'weak' can be found in the context of some religious commitments, such as praying in the mosque. This has a few different interpretations in Islam and is

typically referenced with respect to the suffering and pain that the disability may experience, which entitles them to a greater reward in the hereafter.

On the system level, it is interesting to note that the Ministry of Social Affairs, which has the primary responsibility for people with disabilities, uses the word 'disabled' in their official publications and on their website. The official website of the Ministry includes 'Disabled Care' as one of the main sections, for example, while the travel card is entitled the 'Discount Card for Disabled Passengers'. However, although these words do occur, most of the news written on the ministry website uses the term 'with special needs' (MOSA, 2015).

It can be concluded that the influence of the community and media has even shaped the language used by the editors at the Ministry of Social Affairs. The ministry has failed to influence its employees and even the parents, since all of the papers sent to parents by the ministry still utilise the term 'disabled', as in the case of the registration form in the ministry or a form of social research. The paper required by parents to prove their case also uses the word 'disabled' in its title, although this word is widely rejected by parents.

Parents tend to use words such as 'disease' and 'ill' in reference to both the disability and their child who has that disability [see page 126]. However, this is not merely a linguistic device, the data show that many parents continue to deal with disability as a disease and that they therefore give the issues of medical treatment a priority [see page 127]. This behaviour, which reflects the dominance of the medical model of disability in Saudi society, is discussed more in the next section.

The strong expressions used by parents to talk about the situation provide an interesting insight into their perceptions. Some of the mothers and fathers claimed to

see the situation of having a child with a disability as a fire, explaining that nobody will understand their difficulties except those who stand in that fire as they do [see page 128]. Others think of it as a lamentable situation, using terms such as ‘woe’ and mentioning that having another child without disability can provide a measure of solace for the parents [see page 129]. The reason may be that parents could regain confidence in themselves when they find that they are able to give birth to a child without a disability. In the US, it was common in the 1800s to see a child with a disability as the fault of parents, however this view became less prevalent in the early 20th century (Ferguson, 2002). Apparently this way of thinking about disability still exists among some parents in modern day Saudi Arabia. Some families are suffering from feelings of shame from having had a child with a disability. I found that such parents were extremely difficult to reach for the study, however their beliefs were mentioned in the interviews by other parents [see page 169].

From the religious perspective, many parents are devout Muslims and therefore see their child with a disability as being a message from God. This message can sometimes serve as a ‘test’ or a ‘punishment’, or even as a ‘gift’. In any case, in order to not question their faith in God’s will, these parents can only show their satisfaction with having this child [see page 136]. Fatalism is one of the pillars of the Islamic religion. It stresses the importance of accepting all events or actions, such as marriage and death, including the disability of oneself or a family member. Because of this, parents cannot show their anger or dissatisfaction in front of others, because this would be unacceptable behaviour that demonstrates the weakness of their faith.

The more religious believe in the sayings of the Messenger of Allah, who said: “Wondrous is the affair of the believer for there is good for him in every matter and this is not the case with anyone except the believer. If he is happy, he thanks Allah

and there is good for him. If he is harmed, he shows patience and there is good for him” [see page 136]. These parents believe that their child has been given their condition for the good of the family, ensuring a reward from God for their patience and the care that they give to them. Many parents mentioned the idea of patience and divine reward during their interviews.

This correlates with the findings about the general beliefs that parents have about disability. In the Saudi context, a disability is believed to be a punishment, a test or a blessing. Avoke (2002) thinks that the concept of disability as punishment is generally an outdated one, although this concept still exists in communities that believe in superstitions, who have unsophisticated view of causation, or fatalistic communities (Sandow, 1994). The findings of this study suggest that this way of thinking is still widespread in rural Saudi Arabia [see page 137]. Moreover, some Saudi people think that making fun of a person with a disability can be a logical reason to be with a disability as this person, or to have a child with a disability [see pages 137, 200]. A very common prayer exists for this, which people usually say when they see a person with a condition that they do not like, such as a disability, diseases such as leprosy, or even bad behaviour. Prophet Muhammad said: “Whoever sees an afflicted person then says: ‘All praise is due to Allah who saved me from that which He has afflicted you with and blessed me greatly over many of those whom He has created’” [see page 137]. While a large number of hadith scholars have questioned the credibility of this source, it remains very popular at all levels, and has been mentioned on numerous occasions in the interviews [see page 200]. Those parents who see disability as a test of their patience from God derive conviction from the former words of the Prophet, who said: “he shows patience and there is good for him”. This conviction is often linked to the belief that God has chosen the family to have a child with a disability

because He knows that they are able to afford it, in the words of the Quran: “Allah does not charge a soul except ‘with that within’ its capacity”. Therefore, some parents stated that they see the child with a disability as a blessing from God because of the positive changes that they have experienced in their life, such as improved economic situation or increasing convergence between parents [see page 136].

In addition to the religious effect of accepting a child with a disability, the decisions that parents make about keeping a foetus with a disability is also affected by the religion. This means that the idea of aborting or keeping a foetus with a disability is also subject to the standards of religion, so parents may only pursue abortion when it does not interfere with religious rules, namely that the foetus should be less than 12 weeks old. After this age, abortion is considered to be murder. Perhaps because of this, parents who accept abortion often did not want others to know about this belief without giving clear reasons. This reflects the culture of the community, as such behaviour is likely to be widely deemed unacceptable.

This also gives an indication about a lack of acceptance of the situation. This is a tragedy from the viewpoint of parents and requires a medical solution, which again reflects the dominance of the medical model.

8.4.2 Finding a Cure

The focus of the medical model is on diagnosing the disability and struggling to find a cure for it, which means that disability is necessarily a tragedy (Johnstone, 1998; Marks, 1998). Medical treatment is the biggest concern for the participants of this study, with many expressing concerns that medical treatment may be available somewhere for their children but that they cannot reach it. This leads parents to wish for the ability to seek treatment options abroad.

Regarding the importance of diagnosis, parents in this study emphasised the importance of finding a medical diagnosis for their children, regardless of how difficult that might be to obtain. Many parents were also interested in the IQ scores, mentioning this many times without being questioned. This is likely at least partially due to the education system, which focuses on the mental ability, since the admission to mainstream schools or special education schools is based on the IQ scores of the child [see page 74].

The issue of treatment from a religious perspective is influenced by such scripture as, “Allah does not send down any disease, but He also sends down the cure for it” [see page 127]. In the case that some parents believed that disability is a disease, describing their children as ‘ill’, it can be expected that they would believe that a cure should be available for it, even if one is not currently available in modern medicine [see page 127]. To convince parents that disability is not a disease may be the first step in stopping their fruitless search for a cure.

In Saudi society, treatment also includes spiritual and folk options. Every single parent mentioned that they had experimented with spiritual treatment of some kind. Examples of these had been religious men, whereas others had said phrases for healing or simply at least to feel peace. In addition, there is a belief that the blessed ‘Zamzam’ water, which comes from the Grand Mosque in Makkah, can cure any diseases. This belief is based on the words of the Prophet Muhammad talk and supported by many stories. The Prophet Muhammad said: “The water of Zamzam is for whatever it is drunk for”. Some parents also described their experiences with folk treatment, such as cupping or cauterizing. None of the participants spoke out against these practices because they all have a religious basis, as the Prophet Muhammad

said: “Healing is in three things: A drink of honey, the glass of the cupper, and cauterizing with fire” [see page 146].

Despite the refusal of the words of mercy and compassion directed to their children with disabilities, many parents nevertheless welcomed the prayer of others. This act was welcomed, even when it is said in front of the child and their parents, because they did not know which prayer would cause a cure and bring God’s response from the gates of heaven [see page 201]. This demonstrates a profound and unshakeable belief in the ability and the power of God, which the Quran explains as “Be and it is”. This means that anything God says “to be” will happen, even if that thing contradicts reason and logic.

8.4.3 Mental and social pressure

Having a child with a disability can result in many changes being made in the family life. As an illustration of this, many of the parents talked about the changes in their roles and family responsibility that had occurred after having a child with a disability. They also mentioned changes in relation to their partner, both in positive and negative ways [see page 168, 172]. This relates to the findings of Olson and Gorall (2003) with regards to the effect of disability on the family’s functions.

Parents specified many other larger changes that had occurred to their families as a result of their child having a disability. These included the need to move to bigger cities in order to access services to their children [see page 164]; changes also occurred professionally, with many mothers deciding to resign, retire or change the nature of their work in order to better deal with the raising of a child with a disability [see page 162]. These are eco-cultural adjustments to the family’s routine and is supported by the literature, which has often found that the family of a child with a

disability has to rearrange their daily living and working routines to suit their new situation (Diamond and Kontos, 2004).

In fact all the previous changes and the burden of providing care can lead to major effects on the family, such as stress or depression (Crnjc et al., 1983; Gallimore et al., 1996). Many parents, especially mothers, talked about different levels of stress and depression, sometimes even displaying symptoms of these during discussions [see page 160]. Other parents mentioned that they are feeling alone in facing the challenge of having a child with a disability and its consequences [see page 148]. This may have been compounded by the overall lack of awareness regarding the available medical options and services among parents of disabled children. This may have contributed to parents continuing to think about anything except the medical issues and may have caused remorse due to a lack of certainty about their medical choices [see page 147]. In addition, the fact that these parents must shoulder the whole burden of the situation, without support from the government or local organisations, was one of the most common reasons for stress and depression [see page 159]. Despite this, many do not expect any support from the community, believing that the pressure to deal with the disability should be borne by the family alone [see page 169]. As a result of this, their demands are limited and often focus on medical treatment, again reflecting the existing medical model in Saudi Arabia. In contrast, parents will have less stress when they believe the community shares the responsibility for their children, which is a feature of the social model of disability (Brandon and Pritchard, 2011).

The findings of this study indicated that mothers showed a high degree of stress and that many of them struggled with depression. It is not inconceivable that their feelings and experiences are mirrored in other families across Saudi Arabia, as they are largely attributable to factors that include isolation, from an inability to travel or access

support services, and ignorance, about the services that exist to support them and even the intricacies of their children's disabilities. Therefore, parents welcomed ideas such as having a psychologist to help them [see page 209]. In contrast, fathers showed composure and were resistant to the idea of having access to a psychological specialist [see page 209]. This opinion may reflect the image of the Eastern man who must be strong more than reflecting fathers' feelings, especially because they were speaking to a woman in the interviews.

In general, the Saudi family still maintains its typical, traditional form, comprising two people, of opposite sexes, with children; the father goes to work and the mother is a housewife (Roll, 1991). Although Saudi mothers now often rely on a household servant to do the household chores under her supervision, this does not exempt her from many other tasks within home. For example, the task of following up homework for the children inside the house is primarily that of the mother. This supports the findings of many researchers who have investigated the roles of mother within families in countries all around the world, where they are almost always considered to be the main carers (Carpenter, 1998; Mittler, 1995). It is noteworthy, however, that both fathers and mothers in the Saudi family stated that it is not the father's responsibility to contribute to the housework, the child care, or even to follow up children with their homework, despite grumbling from some mothers about this situation [see page 165, 171]. Mothers were dissatisfied about the non-participation of fathers, but were unable to persuade them to participate [see page 171]. It is expected that the mother will be the one to sacrifice her job and her leisure time in order to meet the changes in the family, but this does not apply to the father, almost certainly placing more pressure on mothers in the absence of extensive support from the community.

According to Nolen-Hoeksema (1990), studies have shown that there are some important differences that exist between women and men, such as the likelihood that women will have a higher rate of depression than men. Moreover, women tend to be heavily reliant on their relationship with their partners and families (Lemmens et al., 2007) and on family support (Thompson and Heller, 1990). Men on the other hand, rely less on family support services, but are receiving support that can help to reduce the incidence of depression (Leskela et al., 2008). Through the interviews mothers have mentioned the support that they receive from their families, but they still stated a need for further support from mothers in the same conditions, while fathers did not show the need for support. Indeed, when discussing their objective in their communication with other fathers, men stated that they were attempting to gain information not support, which conforms to the expected image of a Saudi men. Even though they were not seeking support, if they can spend time talking with other men, this may actually be support even if they don't think of it as support. As Herbert and Carpenter (1994) highlighted the need for reorganisation of the services to suit fathers' life patterns and to give them the opportunity to gain information and support through those services. This would, in turn, increase their opportunities to meet other fathers and exchange their experiences. In the context of Saudi Arabia, it could be argued that in order to help Saudi fathers effectively, the organisations will need to take into account the local attitudes of men and the culture that informs this [see page 165].

With respect to the daily care of the child, as the findings of the study suggest, the load is often principally or even exclusively on the mother, who may have some assistance from a housemaid from a foreign country. In many cases, there is little or no actual participation of the father at home, which is widely perceived to be part of

the eastern culture and which is taken as a given by a large proportion of mothers and fathers.

Perhaps due to the lack of availability of consulting services, a common practice in all things is Istikhara [see page 153]. Parents pray Istikhara in an attempt to relax and to remove, or lessen the stress associated with, the decision making responsibility, as they think that Istikhara enables them to consult with God. This means that the choice arising from Istikhara will be considered to be the best choice, as God lead them to it, which may release a big part of the stress that they are under.

8.4.4 Future

Although parents are engaged with meeting the immediate needs of their children, they expressed concerns about what the future would bring. Previous studies have found that fathers of children with disabilities tend to be very worried about their children's future and, as a way to deal with emotional trauma, they may consume more alcohol (Bray et al., 1995). Alcohol consumption is unthinkable for the majority in Saudi Arabia because it is forbidden and only enters the country through smuggling. However, there are many methods to escape from reality, such as the habit of men in Saudi Arabia to spend hours every day playing card games, such as 'Baloot'. Indeed, further research should be done on the methods that fathers use to manage stress or escape from reality. The fact Saudi fathers are solely responsible for the family can exacerbate their concerns over the future of their children. The findings also suggested that parents are more concerned about the future of their male children, especially if they do not have learning difficulties [see page 151]. Chandramuki et al. (2012) found that male children feel under more pressure than female children, perhaps due to the fact that parents expect a higher levels of achievement in education

from boys than girls, as well as better positions in work and financial security. In Saudi society, this is simply because males are supposed to be responsible for their families in the future, as well as for themselves. In contrast, even when girls do not have any disability, they are not supposed to be responsible for themselves. Instead, there will be a male guardian who takes care of their affairs. The biggest challenge for parents is how to prepare the male children with a physical disability to take the responsibility of themselves in the future.

The father is responsible for the members of his family and all their expenses. Regardless of whether the mother has a job or has any form of personal wealth, the father is also responsible for her expenses. He is also responsible for some of her affairs, for example, many hospitals ask for permission from a male guardian before performing surgery on women. Furthermore, it is common to hear women saying that she must get permission from her husband, even for something simple like an invitation for a dinner [see page 210]. Boys become independent when they reach eighteen, however women must always be protected by a man, whether he is her father, husband, brother, or even her adult son. This reflects male dominance in Saudi society and sometimes leads men to underestimate women, such as believing that women do not have as developed time management skills as men [see page 210].

On the other hand, parents' visions are not clear regarding the future of those children who have learning difficulties. Essentially, the parents expressed a lack of belief in their children's ability and have no real expectation that the child will be able to support themselves as an adult. This even led some parents to state that the time and money expended on a child with learning difficulties could be better used elsewhere. In particular, they did not want to waste money on education, because he "will not become a doctor or an engineer" as it mentioned in the interviews by on father [FJI-2].

The stereotypical, idealised bright future, which is a successful person with a decent job, is controlling the view of parents and affecting their approach to their children with disability.

Some parents touched on the potentially shorter lifespan of their children and some even indirectly considered that the passing of their child would signal the end of the challenges that they face [see page 190]. Some wished to stop time, so that the child does not reach the puberty stage because of the uncertainty of the later stages [see page 151]. Most of the parents repeated some religious phrases that state that God would not abandon their child. However, the most commonly held position among parents is that their children will be fine while they themselves are alive, but they are concerned about what will happen to their children after they [see page 151].

Their feelings may portray part of the truth. The children can be extremely reliant on their parents in a situation where the parents do not receive information about the available options or any support from the community, they have a legitimate concern that the community will take care of their children. Parents in the Saudi community live in isolation, as can be expected from parents who live in a community that adopts the medical model, as this model holds that it is not the duty of a society to adapt any persons' abilities (Oliver, 1996).

8.5 Recommendations about family support services

The voice of families of children with disability is still largely absent in Saudi Arabia. In order to properly play the role that is expected from them, families therefore need some support. There are many factors that can potentially influence the preferences of families for particular support services, including the impact of having a child with a disability on the family, the attitude of parents toward disability, their relationship

with professionals, and their understanding of their child's specific disability. Under the types of family support services, which may vary from one community to another, a great diversity exists with regards to the services provided around the world. However, any family support service can be categorised in different ways, such as according to the provider, or the type of service being provided. This has enabled this study to explore the impact and challenges inherent in having a child with a disability in Saudi Arabia and the implication that this has for the design and delivery of family support services. Ultimately, these findings are based on parents' preferences, aiming to be in a position to provide advice to the Saudi associations that serve parents of children with a disability. The revelations and insights gained through this study take into account the common family support services available in other countries, as well as the specifics of the Saudi context that are currently non-existent to a high standard.

The Islamic religion and tribal system have profoundly affected the identity of the country and its traditions, some of which have held the development of the country back in some regards. Nevertheless, the citizens of Saudi Arabia have started to realise the importance of education and health for people with disability and this area can therefore be expected to develop rapidly in the immediate future.

Based on this study, these are some of the recommendations related to the providing of family support services in Saudi Arabia:

8.5.1 Issues to be considered

1- Although family support centres are not a new concept, they are not well known among parents in Saudi Arabia [see page 205]. The concept of family support services therefore needs to be spread through the community by means of all available sources.

This should enable support providers to secure the cooperation of parents, allowing their goals of supporting families to be met.

2- Parents are not only unaware of the meaning of family support centres, but many are also unaware of the services that are currently available to them, such as land grants and discounts for people with disability [see pages 197, 193]. Therefore, family support centres should raise the awareness of parents about existing services and how to best access them. According to Gibbons and Thorpe (1989) and Cragg et al., (2002), a lack of knowledge among parents about available services and the way that these services can help is a common and important reason for limited engagement in those services.

3- When providing services, centres in Saudi Arabia must be aware that it is a religious and conservative society, which places great emphasis on gender separation. Therefore, there is limited or no mixing of genders in schools, universities, government departments, and even some public places (North and Tripp, 2006). The findings showed that the majority of participants are therefore unwilling to accept the idea of collaboration with the opposite sex in services such as parent-to-parent support, parental support groups, or even in lectures and workshops [see page 213]. However, they were more flexible with respect to activities like excursions or festivals [see page 231]. In general, parents from Jeddah were more open, with some of them accepting the idea of collaboration with individuals from the opposite gender [see page 220, 213]. This result was anticipated, since Jeddah is known as the most liberal and cosmopolitan Saudi city (Jeddah Urban Observatory, 2011).

It should be noted that this preference excludes specialists, since most parents did not mind if a specialist was male or female [see page 210], although a few of the

participants stated a preference for female specialists when talking with the mothers [see page 210].

4- The dominance of men in Saudi society is an issue that the centres should take into account [see page 231, 210]. This supports the commentary of Marshall (2007), who explains that females often defer to males in many developing countries. I think that a balance should be sought between avoiding collisions with the culture of the community, while attempting to avoid marginalising women.

5- Transportation in Saudi Arabia is an important issue for centres when they arrange their services, since women in Saudi Arabia cannot drive and there is no public transportation as an alternative. Many mothers are experiencing this issue [see page 202] and so centres should attempt to find solutions or alternatives, which would be likely to raise the cooperation of mothers with family support centres. The lack of available public transport can also mean that there is a high cost for some parents to engage in a particular service (Ilan et al., 2007),

6- Rural areas and small cities suffer from a general lack of services [see page 164], since most of the provision for individuals with disabilities are only found in the largest cities (Japan International Cooperation Agency, 2002). Ultimately, family support centres should try to cover all areas, regardless of the distances involved.

7- The preferences of parents regarding appropriate services should be taken into consideration, because they will typically originate from their need: “Family support is whatever supports families” (Pinkerton et al., 2000: 11). The things that parents need do not necessarily have to be common services, however. There may also be differences between the nature and needs of particular communities, which should be taken into account. The findings highlighted this difficulty and the complexity of the

governmental procedures, which remain an issue for parents [see page 194]. This presents an opportunity for family support centres to support and assist parents, such as through mediators, as the participating parents suggested.

8.5.2 Useful tools for family support centres

1- Collaboration with activists can be great tool for centres, since they are typically more willing to help and collaborate [see pages 172, 205]. Cooperation between professionals and parents on behalf of the children with disabilities is an important attribute of the social model (Shapiro, 1994, cited in Leiter, 2004).

2- Religious men play a crucial role in influencing people in religious societies (Obaid, 1999) [see page 128]. This means that family support centres should consider cooperating with religious leaders, for example in correcting some religious concepts related to disability [see page 127].

3- Successful people with disability were mentioned by many parents as being very influential in the lives of their children [see page 225]. Having knowledge of role models with disability can profoundly impact people's attitudes and life course pathways (Priestley, 2001). Family support centres can use those successful people as role models for the families, in an attempt to motivate them and change parents' attitude toward disability, since parents' attitude can be changed according to Rose (2010).

4- An aspect of family support centres that should not be overlooked is the existence of housemaids and nannies in most homes. The presence of housemaids is nearly universal in Saudi Arabia (Al-Rasheed, 2013). Many parents asked for courses to provide training for their housemaids about how best to manage children with disability [see page 230]. I think this might provide an excellent opportunity for

family support centres to raise awareness in this area, since they have direct contact with the children and their parents.

5- Despite the multiplicity of ways of communicating, WhatsApp should be highlighted. This application is very common in Saudi Arabia [see pages 212, 214] and can be used to create highly functional communication groups for different purposes (Hamdan, 2015). This means that family support centres can take advantage of what I can call the ‘WhatsApp Revolution’ to access a wider population of parents.

8.6 Summary

The beliefs of parents about the causes and the treatment of disability clearly reflect the medical model of disability. The main features of the medical model in this context are issues relating to language, cure, stress and concerns about the future.

The underlying reasons for the suggestions being made by parents about services were classified under the awareness and the system. Parents think that the provided services are insufficient to engage their children with the community. Furthermore, while some policies may be helpful to an extent, poor application can nevertheless build a closed, dark wall that hinders the involvement of people with disability within the community as a whole. This position seems likely to be exacerbated by the specific cultural and religious beliefs that govern the way in which most Saudi communities think, unless it is remedied by the government and family support centres. Since these centres are a relevantly new phenomenon in Saudi Arabia, further research would be useful in providing suggestions and recommendations to make them more effective, such as the work conducted in the current study.

Chapter 9: Conclusion

9.1 Conclusion

In order to find significant answers to its research questions, this research adopted a qualitative approach. In order to explore the views of adults on a personal, sensitive subject, semi-structured interview were conducted with 42 participants selected using a snowball sampling technique. Interviews were held with individuals and focus groups in cities of Riyadh and Jeddah, as well as two rural areas. All ethical issues were considered, including informed participation. I utilised specific strategies to increase the trustworthiness of the data, which was analysed to provide reliable evidence through the various stages, in turn enabling the research questions to be addressed. The findings of the research have covered three main areas:

1. The impact of having a child with a disability on family.
2. Challenges faced by parents.
3. Parents' views of family support services.

The three main areas were explored by examining the different perceptions of the parents of children with disability in Saudi Arabia, with particular focus on the use of language, parents' attitudes, and religion and culture. The study found that there is a great lack of awareness within the Saudi society regarding children with disability. It was evident that while the parents were willing to discuss their children's disability and problems they were facing, most of them had not yet accepted the disability itself. Limited awareness of the rights of children is also clear, as it has shown that no powerful authority is willing to listen to their call. Consequently, these families have

been extremely dependent on the strength of the connections they enjoy with authorities who have a greater level of power than themselves, such as someone working for the government. Others depend on individual movements. The culture of the country inhibits the creation of new connections and especially limits the movements of female carers or parents, which can potentially delay their ability to get help quickly and when required.

Another aspect of the findings showed that the media have sometimes proven willing to exploit disabilities in Saudi Arabia. It is also clear that some in the media have delivered the wrong message to the parents, by providing them with cultural and spiritual solutions rather than clarifying the concept of disability.

One of the key findings of this research has been that religion has had the largest impact on the parents. It has been their main driver for them to find solutions for the problems that these families are facing. Another of the most important influential aspects was the impact of culture, particularly as male parents are so dominant in securing the help needed. Any action that needed to be carried out therefore needs to be carried out by a dominant male figure, in accordance with the traditional widespread culture of the country. However it was well-defined during the period of research that the female parents were more honest and open about the problems they were facing, as well as better able to express their issues and difficulties. This was in contrast to the male parents who would try and hide problem issues as they may be considered a highly sensitive topic that they do not wish to exploit.

Another important challenge identified by this study is the absence of appropriate public schools for children with disabilities to attend. Only a very limited number of public schools were found to be accepting of children with disability. This means that parents are often forced to pay high fees for their child to attend a private school that

best suits their children needs. A large gap was seen in terms of awareness about exclusive education that should be provided to children with a disability in both private and public schools. Integration was amongst the best option available.

In terms of existing infrastructure, another area that was deemed to be insufficient was the provision of transport. This obstacle to the movement of children with disabilities was shown to be exacerbated by the ban on women driving in Saudi Arabia. It has also been difficult to obtain funding for other necessities, such as wheel chairs. This is a problem caused by the Ministry of Social Care, as they have failed to provide clear guidance or direction on what can be done. More worryingly, the services provided by this ministry have proven to be biased, creating a system riddled with inequality. Although the existence of extended families in the Saudi society has helped parents who have a child with a disability, there are cases where they have also added pressure. The concrete elements of the findings regarding the challenges faced by the parents can be summarised in the following: lack of public awareness on the rights of a child with disability in having access to, transportation, limited access to public schools, and limited access to public spaces. This provides a strong overall impression that children with disabilities are not considered to be an important part of the society. Another emergent finding was that parents in Saudi Arabia are often feeling a number of negative emotions, the clearest of which are uncertainty, despair, anger and frustration, unimportance, and general emotional stress. In addition, other parents commented on the difficulties of access to good health services and focused on the impact of a child with a disability on the family's way of life. These difficulties included considerations like the impact of the child on a parents' career path, on the lifestyle of the family, and on the role of each parent.

9.2 Limitations and Difficulties

As with any research this study was inhibited by a number of limiting factors. The first was the relatively limited time available for the research, which required extensive work in order to attain the best possible outcomes. Moreover, there was only a limited body of references discussing the topic within the Saudi context.

Regarding the difficulties experienced, travelling between cities and urban areas constituted a major barrier to a female researcher in such a conservative society, given that women are not allowed to drive in Saudi Arabia. There were also some difficulties associated with the translation of material from Arabic into English, which required extra care to ensure that meaning was retained and properly conveyed. In the Saudi context, I faced many difficulties as a female researcher who had chosen to interview male participants. This decision narrowed the available sample and skewed the findings, as many religious men or parents were unwilling to participate due to a perception that children with disability shame them and their families.

Having reviewed the nature of the research topic and the methods adopted to address it, as well as the challenges inherent to an investigation of this nature, the recommendations for future work will now be outlined in the following section.

9.3 Recommendations

The aforementioned discussion and the key findings of this study have informed the design of the following recommendations for the decision makers in Saudi:

1- Recognise the need for a professional body to run family support services, in consultation with specialist bodies, such as universities, organisations representing the associated professions, and leading figures in both the sciences and the arts. Most

importantly, these services should be informed by consultation with the parents of children with disability. This suggestion is intended to improve both the effectiveness of the services and system in delivering the best practice.

2- Sufficient governmental funding must be made available at all levels, in order to cover the costs associated with the provision of family support services, such as the use of public services to represent the highest standards of service in the field.

3- Recognise the need to ensure emotional support for parents and direct specialist bodies from the government sector and community sector to cooperate in the provision of such support.

4- Increase awareness of the Rights of Children with disability, including the assessment of how far the implementation of the United Nations' Convention on the Rights of the Child has progressed.

5- Establish Family Support Services in Saudi, in light of recommendations from related studies.

6- Family support centres should develop plans to help in helping the community to transition from the medical model of disability to a social model.

9.4 Suggestions for Future Research

Future studies could consider addressing the following areas of interest that have emerged from the current investigation:

1- A study of how the latest technology can be employed to benefit Family Support Services in Saudi and the ways in which children with disability would benefit from these options, such as the sharing of information or experience between countries via the internet.

- 2- An assessment of the risks and benefits involved in the use of the media in developing awareness about family support services in the Saudi community. An investigation of this area should seek to ascertain whether the use of such media would be useful to family and their children in better understanding the subject.
- 3- A study of how best to involve the public in a debate about Family Support Services, with the goal of determining the kinds of improvements that could be made to the present form of this kind of service.
- 4- A comprehensive study of the family support services in Saudi Arabia, examining the areas of the kingdom not covered by the current study, such as population centres in the northern, southern, or eastern regions of Saudi Arabia.

9.5 Summary

This chapter has concluded the thesis, highlighting the key findings with respect to the research questions and outlining the salient limitations and the difficulties experienced through the research process. An attempt has also been made to provide some recommendations in this area for the decision makers in Saudi Arabia. The study has highlighted the impact, with a focus on the challenges of having a child with disability in Saudi society. It seems that the biggest barrier for developing family support services in Saudi Arabia, in order to ensure the inclusion of children with disability, is the adherence to the medical model of disability, as this was illustrated on parents' views. The research suggests that family support services can play a crucial role in this process, by raising awareness among parents and society as a whole.

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Appendix:

A: individual interview questions:

Part One

1. In the beginning, can you tell me your story with your child, from pregnancy until today, the significant issues?
 - The medical diagnosis (when did you know, how did you know, what are the causes, who told you that, how and do you still have questions about it)
 - What did you do, where did you go (hospitals, schools...etc.)
 - The first person you resort to him when advice of support are needed?
 - The parties (people, schools, hospitals, centres, ministries...etc.) that offer you support (Type of support, The result)
2. To what extent does your child's disability have an impact on you?
(Financial, physical, emotional and your role...etc.)
 - As a mother or a father
 - As a wife or husband
 - As a member of the society
 - Courses or lectures in order to develop skills or expand knowledge, whether in the field of disability or other
(What were they, where, how and what was the motivation)
3. What do you think of the communication between families of children with disability?
 - The positive and negative sides, if any
 - The parent's evaluation of their experience of contact with other families of children with disability, if any
 - Type of organized activities with other families, if any
4. Regarding the activity in the disability field and the rights of children with disability, how do you see the rights of people with disability in Saudi Arabia?
 - Knowing activists in the field of disability (Who, nature and evaluation of the activity)
 - Involving in any activities (on the Internet or in reality, nature, duration and evaluation of this activity)

- Her/his opinion in their child's rights (receiving and missing rights, the way of claiming for those rights)
 - The impact of parent's voice in the child life's choices
5. About centres that support families of children with disability, are you aware about any of them in Saudi Arabia or in any other country?
- The name and location of the center
(How did you know them, any communicate with them, for what, what was the result)
 - The services and programs that the parent expects or wishes to be in the family support centre
 - The extent of accepting the services if they are provided by volunteers

Part Two

I will present some of the services that are widespread in many countries, I want to get your opinion about these services and their suitability for applying them in Saudi Arabia:

Question one:

There are three popular ways to get support and advice; 1. Advices and consultations from specialist, 2. Parent-to-parent support, 3. Parent support groups. (Give a brief explanation of each service).

These three cards present those services, Put them in order according to your preferences, then match them with the small cards that present how you want to receive those services (the small cards will be used in batches)

The cards

A. There are 16 cards for Advices and consultations from specialist:

- **Provider:** 1. Specialized Man; 2. Specialized Woman; 3. Specialized parent of a child with disability

- **Participants:** 1. Alone; 2. With your partner

- **Methods:** 1. Online chat; 2. E-mail; 3. SMS; 4. Telephone call; 5. Face-to-face; 6. Inside the centre; 7. Outside the centre; 8. By name; 9. Anonymous 10. Arabic; 11. English,

B. There are 17 cards for Parent Support Groups:

- Participants: 1. Mothers or fathers; 2. Mothers and fathers; 3. Parents of children with similar disabilities; 4. Parents of children with different disabilities; 5. Parents of children of similar ages; 6. parents of children of different ages; 7. By names; 8. Anonymous; 9. Supervision by specialist; 10. Supervision by a participant; 11. Without Supervision

Methods: 1. Online such as Skype; 2. Online forums; 3. Face-to-face; 4. Through a collective conference call; 5. Outside the centre; 6. Inside the centre

C. There are 14 cards for Parent-to-parent:

Participants: 1. Parent to parent; 2. Mother and father to mother and father; 3. In the presence of a specialist; 4. The children in same age; 5. The children are not in same age; 6. The children have the same disability; 7. The children have different disability; 8. By names; 9. Anonymous

Methods: 1. Inside the centre; 2. Outside the centre; 3. Online; 4. Telephone; 5. Face-to-face

Talk a little bit about these services and what are your suggestions for further improvement.

Question two

I will present three photos of places where parents can receive services from the family support services centres, and tell me what type of service may be useful for you in this place; 1- Photo of a classroom, 2- Photo of a home, 3- Photo of a park.

The discussion will involve some of the common services such as:

Classroom: formal education, job skill development, lectures in health, disability and rights

Home: respite care services, a visit to evaluate the home environment and the family to provide advice and training for caring and rearing the child.

Park: some events like sports day, barbeque day, visit tourist attractions, festivals, trips...etc.

Question three

Finally, due to the disability of the child, its family may need a lot of information, such as information about the available services in any support organisation, information about reliable internet sites, schools, hospitals, specialists, medical devices shops...etc.

- Where do you get this information from, if needed?

- If most of this information is available at the family support services centre, how do you like to obtain them? (Online, face to face, by phone, leaflet...etc.)
- When you take an advice from the centre about the places that might be useful for your situation, do you prefer a mediator (Referral and linkage)?

Do you want to add anything?

B: Focus group questions:

I will present issues facing the parents, which emerged from individual interviews without influencing the group by any suggestion that I already gathered from the individual interview. Although, I will manage to raise the related suggestions that, I have collected from the individual interviews to stimulate and activate the discussion. (I will attach the suggestions again)




As a start, I will ask this question to encourage parents to be engaged to the discussion:

- What is the best term to describe children with disability (children with disability, disabled children, children with special needs...etc.)?
1. The main issue that I have noticed is that, the parents used to get lost right after knowing that their child has a disability, in your opinion how can a family support centre help? Will consider the following points:
 - a) The main issues that need to be taken care of immediately after the diagnosis of disability
 - b) The appropriate treatment for the child
 - c) The best education plan for the child
 - d) How to know and secure the exiting rights of the child
 2. Based on my individual interviews, most mothers have many responsibilities compared to fathers. It is the mothers' responsibility to take care of the child, such as child day care and monitoring education progress. Therefore, mothers may face a lot of stress and obstacles, how can family support centre help those mothers in the following points?
 - a) Difficulties in accepting disability and psychological pressure
 - b) Difficulties in transportation
 - c) Difficulties in monitoring their children's education
 - d) Difficulty in continuing in their job

3. Parents in the individual interviews indicated their concern regarding the issue of communication. How can the family support centre help to alleviate them?
 - a) Communication with the integration school's staff
 - b) Communication with the doctors hospital
 - c) Communication with the Social Affairs employees
 - d) Communication with centres abroad for treatment
 - e) Communication between the families themselves
4. Some parents declared that, they are suffering from financial pressures, how can the centre help them to ease financial pressures?
 - a) In treatment costs
 - b) In education fees
 - c) In the costs of medical equipment
 - d) In the cost of maid house
5. It was clear in the individual interviews that many of parents are negative in pursuing their rights, how can family support centre empower them?
6. Most of the mothers in the interview, claiming that the father does not help, as well as most fathers admit that. Let us discuss this point, and how can the family support centre help?
7. In term of educating and informing, from the interviews, most parents rely on the internet and they listed a lot of courses and lectures that they think they may need, what are the best ways for family support centre to deliver information and avoid unreliable information sources?
8. In individual interviews, I noted considerable variation in the responses to the appearance of children in the media in order to stimulate the community to donate. Some of the parents were strongly agree, some were strongly disagree and some were agree with conditions, what do you think?

Do you want to add anything?

C: The Ethical Requirements:

	
Centre for Educational Studies T 01482 465031 E c.m.mckinlay@hull.ac.uk	
ETHICAL PROCEDURES FOR RESEARCH AND TEACHING IN THE FACULTY OF EDUCATION	
FORMAL NOTIFICATION OF ETHICAL APPROVAL	
Reference Number:	12/340
Name:	Mashaël Alariefy
Programme of Study:	Doctor of Philosophy (PhD)
Research Area/Title:	Exploring the family support services preferred by parents of children with a disability in Saudi Arabia
Image Permission Form	N/A
Name of Supervisor:	Dr Kiki Messiou
Date Approved by Supervisor:	31 st May 2013
Date Approved by Ethics Committee:	14 th June 2013
	
Faculty of Education Ethics Committee	
	
University of Hull Hull, HU6 7RX United Kingdom +44 (0) 1482 346311 www.hull.ac.uk	

D: Informed Consent Participates:

THE FACULTY OF EDUCATION ETHICS COMMITTEE
CONSENT FORM: (INTERVIEWS)

I, of

Hereby agree to be a participant in this study to be undertaken by **Mashael Suliman Alariefy**, and I understand that the purpose of the research is to explore the family support services preferred by parents of children with a disability in Saudi Arabia and to provide advice to the Saudi associations that serve parents of children with a disability, based on parents' preferences. The understandings gained through the study will take into account common family support services available in other countries as well as the specifics of the Saudi context.

I understand that

1. The aims, methods, and anticipated benefits, and possible risks/hazards of the research study, have been explained to me.
2. I voluntarily and freely give my consent to my participation in such research study.
3. I understand that aggregated results will be used for research purposes and may be reported in scientific and academic journals.
4. Individual results will not be released to any person except at my request and on my authorisation.
5. I am free to withdraw my consent at any time during the study, in which event my participation in the research study will immediately cease and any information obtained from me will not be used.

Signature: Date:

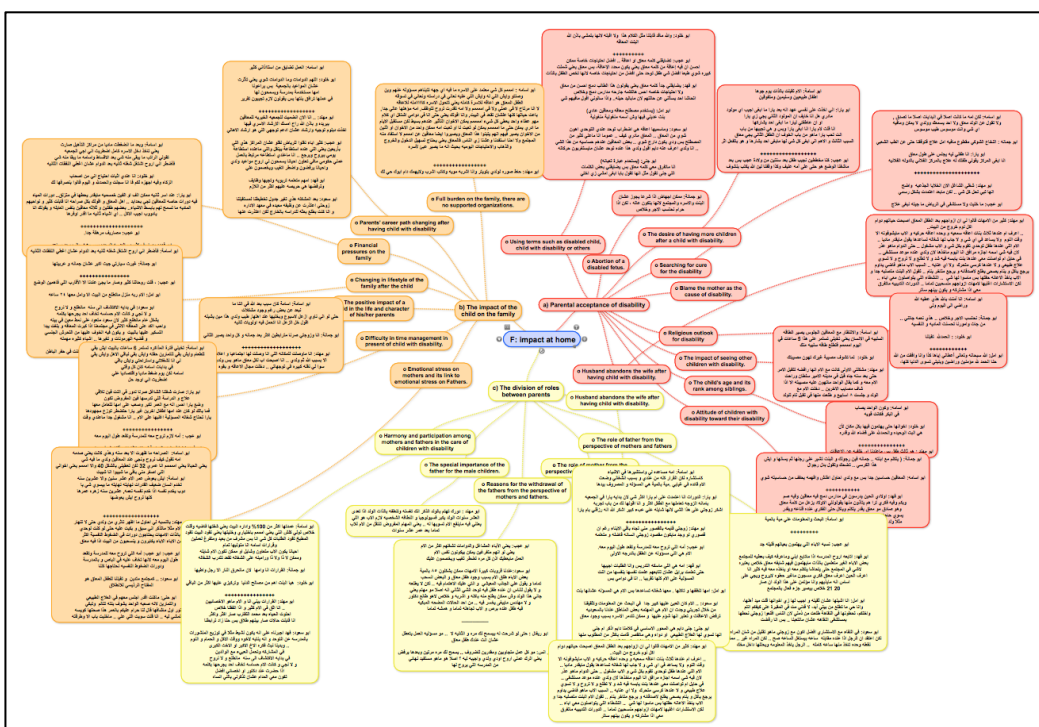
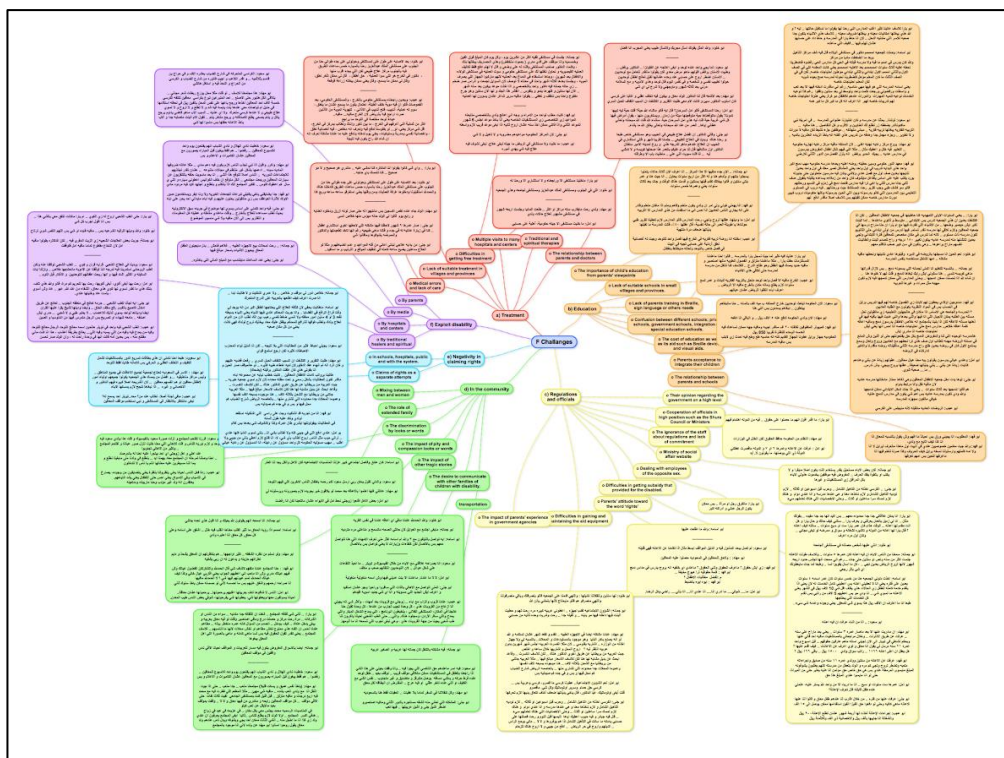
The contact details of the researcher are:

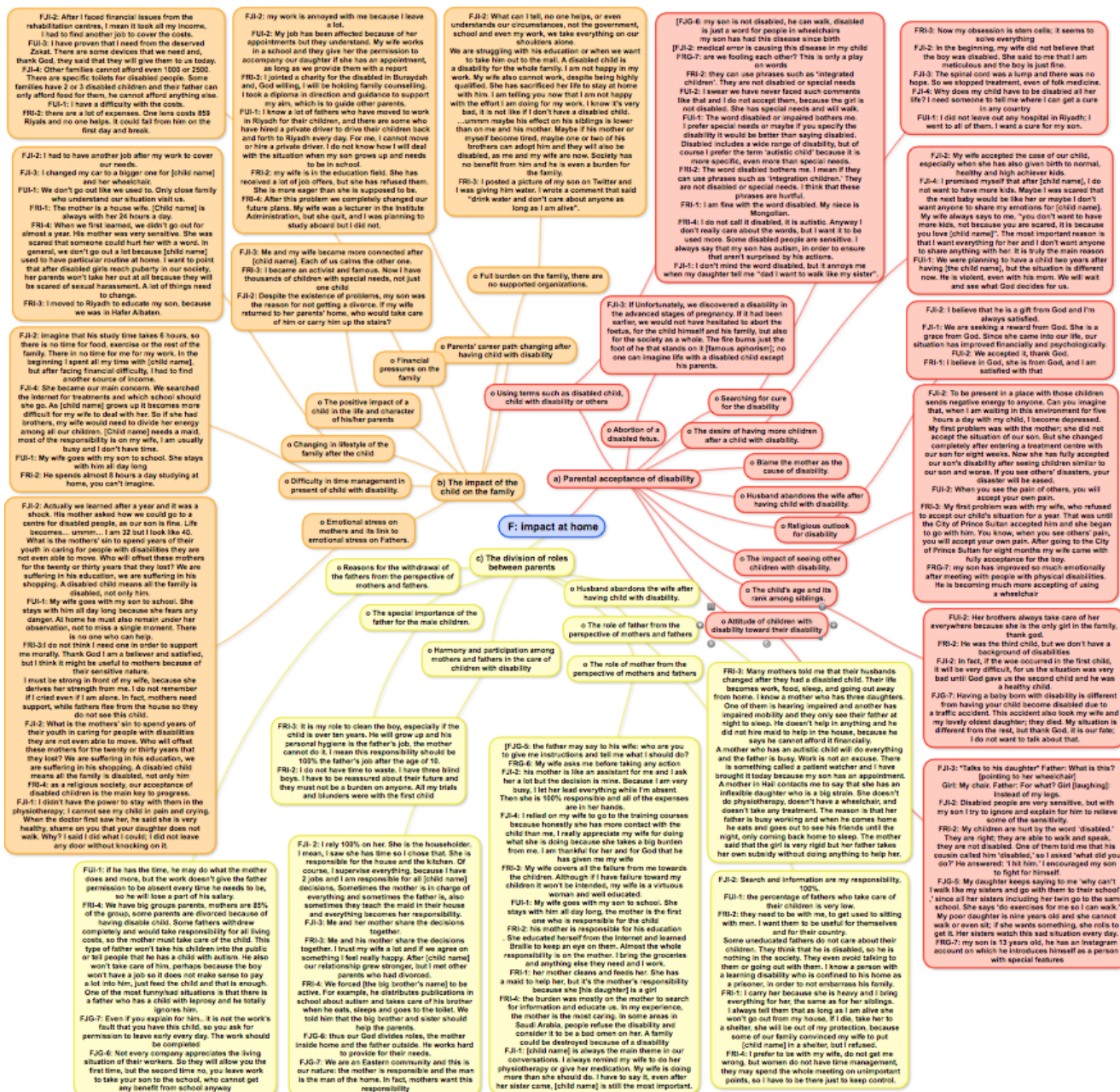
The contact details of the secretary to the Faculty of Education Ethics Committee are Mrs J.Lison, Centre for Educational Studies, University of Hull, Cottingham Road, Hull, HU6 7RX. Email: J.Lison@hull.ac.uk tel. 01482-465988.

E: Example of transcription:

<p>From group No. 1 in Jeddah (mothers)</p> <p>Mother A [MJG-5]: He has not seen my child since the divorce, not even once, despite the fact that his home is close to my family's home. He wants to annoy me. I know how he thinks.</p> <p>Mother B [MJG-6]: No need for him, your father and your brothers can take his place. Your son does not need a father like him.</p> <p>Mother A [MJG-5]: But my family is tired of my son's expenses.</p> <p>Mother C [MJG-7]: What do you mean! The father does not bear the expenses of his son?</p> <p>Mother A [MJG-5]: No, not at all, and my father tries to avoid trouble with him. I asked my father to talk to him, but he refused and said "I will do my best with your child without his father".</p> <p>Mother D [MJG-8]: But the subsidy will help, of course.</p> <p>Mother A [MJG-5]: You will never believe me; I did not know about the subsidy from the beginning, but nearly five months ago I found out. I prepared all the required papers, and my father went to ask about it. They said the father of the child started receiving the subsidy two years ago and he has received payment for his child every month since.</p> <p>Mother C [MJG-7]: Are you serious! You should complain to the court.</p> <p>Mother A [MJG-5]: I cannot, my father does not want people to talk about us. I tried to communicate with him via mobile phone messages in order to reach an agreement, but he said that I want to spoil his life, because he is preparing to marry again, and if I do not cease in this, he will take my son by law. He said he had reports from doctors</p>	<p>Masha3el 24/3/2016 16:05 Comment [1]: Parents' exploitation</p> <p>Masha3el 24/3/2016 16:06 Comment [2]: Male dominance</p> <p>Masha3el 24/3/2016 16:07 Comment [3]: Father's responsibility</p> <p>Masha3el 24/3/2016 16:23 Comment [4]: Guardianship of a man</p> <p>Masha3el 24/3/2016 16:21 Comment [5]: Parents' exploitation</p> <p>Masha3el 26/3/2016 07:41 Comment [6]: Society's authority</p> <p>Masha3el 24/3/2016 16:24 Comment [7]: Parents' exploitation</p>
<p>to prove that my child needs treatment and this treatment is not available in my area. So it is his right to take my son for the interest of the child and to ensure follow-up treatment.</p> <p>Mother B [MJG-6]: Terrible, just throw the child on him, he won't bear it.</p> <p>Mother C [MJG-7]: Yes, you are right; he will do whatever you want to get rid of the child, especially as he is newly married [laughing].</p> <p>Mother A [MJG-5]: I do not think this will work. Before the divorce he convinced me that we should put our son in a centre in Jordan. I do not rule out that he will do that if he takes my son.</p> <p>Mother C [MJG-7]: We cannot say anything. God help you.</p>	<p>Masha3el 24/3/2016 16:24 Comment [8]: Parents' exploitation</p> <p>Masha3el 26/3/2016 07:41 Comment [9]: Travel abroad</p> <p>Masha3el 24/3/2016 16:25 Comment [10]: Religious phrase</p>

F: Examples of coding by SimpleMind:





because the interview extracts cannot be read, they are provided in the next Appendix.

Challenges

A- treatment

1- Medical errors and lack of care

FJI-4: we did anything that the Doctors told us, although we did not know if it was the right thing to do or not. We would try anything.

FRI-3: The boy had a lack of oxygen, but the doctors did not pay attention until his colour started turning blue. They took him to the intensive care and on the fourth day they told me that his situation is hopeless

FJI-1: We went on a family visit to my brother in Jeddah. He is a child consultant. My brother noticed that she is not a normal person and told us that something is wrong with her. Although we took her to the hospital to be vaccinated, so the doctor and the nurse saw her, they did not tell us anything.

FUI-1: The doctor performed an operation for my son, then told me that it is possible for his talking to be delayed, and that he cannot hear and he may also need cochlear implants, but we found out is autistic.

FJI-1: From the beginning of my daughters' treatment, I suffered from a lack of appointments, and lack of discipline. For example, if I have a two hour treatment appointment, I will lose a full hour to clean up the place and I won't get any benefit.

2- Lack of suitable treatment in villages and provinces

FUI-2: After the injury we went to the hospital but they cannot do anything to her, so they transferred us to King Abdulaziz Hospital in Jeddah. We drove all the way from the south of Saudi Arabia to the west, almost 7 hours. When we arrived at the hospital they took her immediately to the operation room for one hour or one hour and 15 minutes.

FRG-5: I know more than eight children with autism in Al-Kharj, between males and females. We have demanded a clinic in Al-Kharj, at least a clinic, even if it is a private clinic. We will pay if we know that this clinic is specialised in autism and has specialist pronunciation experts, psychologists, and behavioural trainers. Meaning if we go to this clinic, I won't mind paying because we know that he will benefit from this clinic.

3- Difficulties in getting free treatment

FJI-3 My wife gave birth in a private hospital, where my daughter remained in intensive care for 20 days. Each day cost 2,500 Riyals. I could not pay the costs, so the hospital director cooperated with me and asked just for the cost of the caesarean section. Then they tried to transfer my daughter to a government hospital for an operation on her back. After two months she had this surgery, but her head began to swell as a result of the increase of fluid. They did not put the spinal fluid shunt in until

she was six months old. Now, two years later, we are in great suffering, as her back arched because she is growing up. The wound reopened, and we have not been able to have surgery to close it so far.

FRI-2 I wrote a letter to the Prince and I was directed to treat my son in King Faisal Hospital and to follow up his appointments at the King Faisal Hospital. Sadly, King Faisal Hospital is like any other private hospital. I wait 6 months for an appointment and if I missed it, I will have to wait a year for another appointment. If I want an early appointment, I have to have a good relationship within the organisation.

FJI-1 all the appointments in the public centres are bad and not qualified.

FRI-4: to treat his teeth I am forced to go to private dentist because it is the only one that will deal with autistic children

FJG-5: They told me my daughter needs intensive physiotherapy sessions, each session is half an hour and costs 150 Riyals. How can I pay these huge amounts of money

FUI-1: I went to all hospitals in Riyadh searching for appropriate treatment for my son, I want to know if there is a good treatment to him.

4- Multiple visits to many hospitals and centres

FJI-4: We went to all hospitals and all specialised doctors.

FUI-2: The one in the South, King Abdulaziz Hospital, University Hospital and this association.

FRI-3: I went to almost six centres or more. I also went to Germany for four months to a hospital that is famous for treating cases like my son's case.

FRI-1: I went to all hospitals, both public and private hospitals.

5- The relationship between parents and doctors

FUI-2: As the saying goes, asking an experienced person is better than asking a doctor, and I prefer to ask the experienced person.

FRI-4 When my son gets the flu I cannot find a doctor for him, as well as his teeth, no doctor agrees to do it. I tell them that he is autistic and it is not an infectious disease, they say we know but we cannot deal with autism.

The psychologist in a single session decided that my child is autistic. He described a group of drugs and said the next appointment would be after three months. He did not clarify anything to me and did not give me any guidance.

FRG-7: My son was walking normally, he felt tired and we went to the hospital after two days. The doctor moved my son's feet up, then threw them and said he is disabled. I could not control myself; I beat the doctor until he was bleeding.

FRI-3: After the X-ray the doctor told us that the boy will suffer from disabilities and mental retardation and that he will need a wheelchair. The doctor told us in a really

bad way. The mother was with me. We asked for the report and discovered that the reason was cord wrap.

FRI-1: We went to the hospital and they asked “is [his daughter name] still living?”. I said, “yes, she is still alive. Do you want her to die?”. The doctor said we did not expect her to live, we expected her death a long time ago. They were surprised. The doctor said that she suffers from diseases so it is surprising that she is still alive. I said, “yes this is [his daughter’s name] and she is alive, God bless her”.

FJI-1: After two visits, the neuroscientist told me not to bring my daughter to him again, saying there is no cure. He did not tell me where to go or explain my daughter’s condition.

People told us that the best physiotherapy is in Al-Habeeb Hospital, which is a private hospital of course. We went there and after one month a consultant in Al-Habeeb Hospital told us that the treatment they have is not that good so we should go to the City of Prince Sultan. In Prince Sultan City, the doctor said she is very healthy, shame on you that your daughter does not walk. Why? I said I did what I could; I did not leave any door without knocking on it.

FRI-4: The psychologist in a single session decided that my child is autistic. He described a group of drugs and said the next appointment would be after three months. He did not clarify anything to me and did not give me any guidance.

B- Education

1- The importance of child's education from parents’ viewpoints

FJI-3: Jeddah does not have any centre except this one. I know three families who wish to register their daughter or their son here. They have been trying for more than four years to register. I came here when my daughter was two years old. They said that it will take two years to register. Eventually, they accepted my daughter three years later, which means when she was five years old.

FRI-2: A It is important for me that my sons’ school develops them so that they will be like normal people, if they are less than others, it means that I did not take advantage of this school, except training in behaviour.

FJG-6: A doctor told me about this centre that is good, they refused because my son was two years old, they required the child not to be older than three months. Well, no one told me about your centre before, so what shall I do?

FRI-1: I did not take her to school, she is not stable. I went to some schools and they asked for a medical report. We took her to a therapist. She said that only 40 percent of her mind is working. The schools said that they won’t accept her because her hands are very weak.

FUI-1 I took him to a kindergarten that has one classroom for autism only. I also hired a Jordanian speech specialist who sits with him at home.

FJI-4 We suffered when we were looking for a school to register [name]. They do not have the facilities that she needs, for example, they do not have a ramp and there are no lifts for the upper classes. They do not have anything for the child to hold when she is going upstairs. Unfortunately, we went to many schools, but they were not suitable.

FRG-5: I tried, but no school accepted him because he is hyperactive. He cannot sit on a chair

2- Lack of suitable schools in small villages and provinces.

FUI-1 There is only one classroom for autism in Al-Kharj. It is in the Intellectual Education School for girls, and at the age of nine children need to leave the school. The only place that they can go to then is in Riyadh. I know parents who moved to Riyadh because of their children.

3- Confusion between different schools; private schools, government schools, integration or special education schools.

FJI-4: Unfortunately, we suffered a lot with schools that we visited to register her. They told us that we could not register her in the school because they need to have certain capabilities and certain conditions. Unfortunately, these things are often very difficult for low-income families. To register [name] at a school, I have to hire babysitter to care for her at school. What will the low-income families do in this situation?

[FJI-1: My daughter is in a charity for children with disability, I found a school where I can integrate her, but it is far away...my work will not let me leave early every day to pick up my daughter.

FJI-2: I learned about this association from a doctor in The Maternity Hospital, I went to it after I encountered financial difficulties from the private centres where he was studying. Since no public school in our neighbourhood accepted him, we had to register him in a private school for three years. The teachers at the private school were qualified in the first and second grade, but in the third grade the teacher was not qualified so we had to change his school to one that was further from our home but which had a special needs teacher. The school is not good, although I struggled to register him there. They only accepted him after I talked to someone to convince the school. They accepted him after two years.

FRI-4: I have enrolled my son in a school and I do not know anything about the school. In America, by pushing a button you can get any information you need, even if it is about McDonald's.

The Intellectual Education School needs an Intellectual Education school itself. The building is rickety, some employees are active but they are not given any training.

Other employees are very careless and their goal of teaching these children is the 20% that will increase their salary.

FRI-3: he goes to a private day care because we do not have a public day care centre in Saudi Arabia. There is a problem in education and I'll give an example. For example, children with paralysis cannot study in a normal school, because the principal refuses to move the class from the second floor to the ground floor.

FRI-2: Noor Institute in a public institute and it is bad. I registered my son in a private kindergarten and after that he went to a public school, but it is not an integration school. I'm talking about my oldest son. We were trained on him and all the problems happen to you with the first child. He was in a normal class in first grade and the teachers were collaborating with him. They gave him a board to write on, so he become more active, but he cannot see. One of his friends was helping him and wrote for him. In the second grade, the teacher told me that some schools have become integration schools in Zamzam and in Al-Naseem. I went to them and they asked for the medical report. There is a drop in the level of education among teachers who taught him and the teachers who are now teaching him, a huge drop, although both are public schools. I searched for private schools that they may accept them, but unfortunately I cannot afford to put them in a private school.

4- The cost of education as well as its aid such as Braille device and visual aids

FRI-4: It is not fair that an autistic child has 100.000 Riyals from the government, because he is in a centre in Jordan, and not a penny for our children here... do not think that going to Jordan is easy, you need to have strong relationships with officials.

[FJG-6: Do you know how much disabled schools' fees increased last year? Three hundred per cent!

FRI-3 The government pays just 5,000 Riyals from the school fees, and I pay the rest

FRI-2 A computer for the blind costs 20,000 Riyals, I cannot get it and there is no entity that will help me. The Braille Writers device that is provided by the school is old and has a disturbing voice

It weighs up to 7 kg and my child has to carry it back and forth to school every day. There are new devices on the market, but they are expensive.

5- Parents' acceptance to integrate their children

FJI-4: at first she was in the Association of Disabled Children, but I discovered that this association is only for primary school, they do not have secondary or high school. What will be the situation when she grow up? The mother and I agreed to put [name] in a good school, where she can stay from first grade to high school, because if she finishes her primary in a school that is only for disabled children, then we take her to a school for normal people, everything will change. The girl will be in shock. Also the girls in her class won't help her and it will be hard for her to adapt to the school.

FUI-2: yes, I registered her in a kindergarten in our village and they accepted her. We carry her and put her on a chair in the class room. We have no problem. Her mother works as a maid in the same school.

FJI-3: for education I wish for [name] what they call integration, but her capacity is still low. She forgets a lot. They asked me here if I want to put her in an integrated school but I refused. If God is willing, if she improves, I will move her to an integrated school. The school must have ramp for her wheelchair though.

FRI-1: I hope that my daughter is integrated, but her abilities are still weak and she forgets a lot, they asked me, do you want to integrate her, I told them not now.

My sons told me that they have disabled boys in wheelchairs at school, but they are better than my daughter. She has very weak hands, cannot even hold the pen, as well as her mind goes and comes. It is impossible for her to learn.

FJI-1: My daughter is in a charity for children with disability, I found a school where I can integrate her, but it is far away...my work will not let me leave early every day to pick up my daughter.

I hope that my daughter is integrated, but her abilities are still weak and she forgets a lot, they asked me, do you want to integrate her, I told them not now.

FUI-2: Normal kindergartens do not accept him because he cannot sit.

6- The relationship between parents and schools

FRI-2: Sometimes my child brings a paper from his school but I cannot understand it. How can I follow up with my son? I hired a teacher who comes to my home because I do not know how to read Braille and my wife also does not know Braille. I talked to the school and they sent us a paper that has all the letters in Braille and my wife started to learn. Now I do not know Braille, but my wife does.

C- Regulations and officials

1- Their opinion regarding the government on a high level

FJI-4: I cannot say they aren't given their rights. There is attention given to them by the government.

FRI-3: The system from the government maintains the rights, but the problem is the ministries

We are in a country where the disabled should live a velvet lifestyle. There is a considerable disruption and I will give you an example: in 1402 when I was in grade two at primary school, a decision was issued to reconstruct all buildings and roads so that they would be suitable for the disabled. But they did not apply anything. For this building where we are in now [points out the main entrance], I need three people to help me carry my son in his wheelchair because of the sidewalk. There are systems, but corruption is in the ministries.

FUI-2: everything is available, and thankfully, God cherishes us and the government did not fall short

FRI-1: I learned about the subsidy when she was 6-7 years old and the government gave it to me. As long as you can reach the government, they won't say no at all

2- The ignorance of the staff about regulations and lack of commitment

FRI-4: I went to the employee [in the ministry] and told him that the system says so and so. He said I do not know about that but we do it like this"

FRI-3: It is very common to see an illiterate father [cannot read or write], walking around in the corridors of the ministry, looking for help to fill in his paper.

FRG-6: In this country, if you want to educate your son or treat them, you have to know someone important, this is the law

FRG-7: You often need bribery. Put five hundred Riyals [£85] in your file and your papers will be done in half an hour instead of a week

3- Ministry of social affair website

FRI-3: Yes I previously opened the ministry's website, and did not get anything from it except a headache

FJI-3: Very important to have someone who knows about all the regulations in the ministry to help parents and minimise the time for them, especially parents who cannot read and write, they need someone to read to them and write on their behalf and they may need this person to go with them to the Ministry.

FJI-1: I took the chair from the Comprehensive Rehabilitation Centre, but we really struggled. After 3 weeks we had to take my daughter to the Comprehensive Rehabilitation Centre, but at the same time she has school and I have work. The queue there took 2 or 3 hours and even the specialists there treated us badly.

4- Dealing with employees of the opposite sex.

FJI-4: There is no real difference between them, but maybe men are more serious and aware

FRI-1: I will go with her, I cannot let my wife meet a man on her own. If this meeting is important, I will go with her

5- Difficulties in getting subsidy that provided for the disabled.

FJI-4: My relationships could be very limited, but it is very useful. For example, I met my co-worker who knows [his daughter name] and he asked me how I'm doing, how she is and if I applied for a subsidy. At that time she was 6-7 years old. I asked him what he meant by subsidy. He said that she is entitled to have a subsidy from the government, plus a visa for a driver, maid and a nurse, all for free. I hadn't known about the subsidy before.

FUI-2: Someone at the university hospital told me about it

FJI-3: I learned about the subsidy from some fathers when my daughter was five years old. I applied for it but it took two years. Of course, there is no pay retroactively for the delay.

FRG-7: I knew about the subsidy five years ago, but I think there are some who deserve this money more than me. I can bear the expenses of my son. Recently, I realised that it is a right for my son and I do not have the option of refusing after someone said to me: are you richer than the government? It is for your child, not for you.

FRG-5: My niece has severe disability, and her parents are refusing to take the subsidy, they say we do not need alms from the government. Many fathers know about the subsidy from me. Even if I do not know the father, I create a subject to talk with him and then move to our children

FJI-2: When [name] was 4 years, the association of disabled children told me about the subsidy. By the way, I don't want the subsidy. I want them to provide me with all the services my son needs, because if they provide all the services for my son's case, it will cost around 10 thousand. The subsidy is nothing compared to 10 thousand. I want to give them 5 thousand from my salary in order to provide me all the services. I don't believe that 1 thousand could do anything for a disabled child, it's nothing.

FRI-4: I learned about the subsidy from the Internet.

FRI-3: When my son was 3 years old, I learned about the subsidy. I learned about it from the Internet. I am active on Twitter and I received a lot of questions about their rights. A week ago, a 21 year old boy sent me a message saying "I am disabled and I just learned about the subsidy, how can I apply for it?". Also, is it acceptable that the highest subsidy is 1166 Riyals and my son's driver has a salary of 1500 Riyals? I will end up with 166 Riyals!

FRI-2: I learned about the subsidy 2 years ago. My friend told me about it and my son was 11 years old. But the process is very hard. My son missed school for several days because they asked to see him. I think that the subsidy isn't really worth the struggle to get it, but it is my son's right not mine, so I have to get it for him.

FRI-1: When she was 6-7 years old, I met a father of a child with a disability and he asked me if I knew about the subsidy.

FJI-1: I learned about the subsidy a while ago from a relative who has a disabled child. The subsidy is not enough. Even if they pay 2 thousand for the visa, the total cost to bring a maid could be 15 thousand.

FUI-1: The subsidy process took 4 months and it is 900 Riyals. I paid 1000 Riyals to have a maid and 1800 Riyals to see a specialist.

6- Parents' attitude toward the word 'rights'

FJI-2: To be honest I didn't look for it.

FRI-4: It is still less than what we need. For example, the subsidy is not enough for the parking issue.

FRI-3: No one disabled in Saudi took all his rights.

FRI-2: Rights like what? I don't know what are rights? I didn't know that there are integration schools to attend. By the way, 'rights' is a huge word. Much better if you use children claims.

FRI-1: Ummm ... look... I don't know... Ummm... I have my child and I am satisfied.

7- Difficulties in gaining and maintaining the aid equipment

FUI-2: We have been carrying her for 2 years now. We applied to the association of disabled children and they accepted our application, but they still did not give us anything. I think that they said that we don't need anything because the child will walk.

FJI-3: They gave me a very heavy, large wheelchair, when I put my daughter in it you could not even see her head. I went to them and put my daughter in the wheelchair in front of them and I asked them: Is this appropriate? They said this is what we have. I had to buy a suitable wheelchair.

FRI-3: I buy all the devices for my son, but I know what is happening in the ministry. When you apply for a wheelchair you may have to wait a whole month, and if you need maintenance for the wheelchair you will remain without a wheelchair for two or three months.

My brother bought a wheelchair for my son from Britain; with shipping it cost 3,000 Riyals [£510]. When I found it here, it cost 7,000 Riyals [£1,192]. They are thieves.

FRI-1: Social Affairs gave us chair, a wheelchair, a toilet chair and an automatic bed. I am very satisfied. I told them that I want everything automatic but the doctor didn't like the idea. He said her hands are very weak and if everything is automatic her hands will be weaker, so she will barely be able to move them.

FJI-1: I took the chair from the Comprehensive Rehabilitation Centre, but we really struggled. After 3 weeks we had to take my daughter to the Comprehensive Rehabilitation Centre, but at the same time she has school and I have work. The queue there took 2 or 3 hours and even the specialists there treated us badly. I bought many things from my own pocket, I don't want the headache of applying for them.

8- The impact of parents' experience in government agencies

D- In the community

1- The role of extended family

FJI-2: [child name] was an obstacle and a big barrier to our social life, but our family excuses us.

FRI-4: My mother told me that it is possible that God sent us [name] as mercy for people with autism.

FRI-3: After [child name], if anyone from our family saw something in the newspaper that is related to disability they would capture it and send it to me. Now they all care about all disabled children.

In all events [child name] stays with me, at a family gathering or at a wedding, he is always with me. My goal is to be in the society. People have to see the boy and I want them to know that I have a disabled son and that I am not shy about him. People might also guide other families with disabled children to me.

FRI-1: some of our family tried to convince my wife to put [child name] in a shelter, but I refused.

FRG-5: even if I have no objection, it is impossible to go for it; my tribe would kill me. (all laughing) [FRG-6] said to FRG-5: they will renounce you forever, but my tribe would even come from the north with guns (about present their children in media).

2- The discrimination by looks or words

FRI-4: We decided to break into the society. I uploaded a picture of [child name] on Facebook. I wrote that this is my son and he has autism and people have to see him. I also asked the families that are with us to upload pictures of their children. Let's break into society. Many families did what I did. We don't let anyone from my family or my wife's family say anything bad to him or about him. My wife and I do not care about the society anymore. We go out with our son at the time that we want and to the places that we want. If we have control of him, people should not say anything.

FUI-1: some people react negatively. They look at us as though he is annoying them. He shouts in malls, he even draws the kids' attention. They think that we do not discipline him.

FJG-5: I carry my daughter every day to pick up my kids from school. Other children stare at her foot splint and how she moves her head, then they laugh at her.

3- The impact of pity and compassion looks or words

FJI-3: when people say to me "may God help you" I let them hear me saying "she is a blessing from God"

FJI-2: If seeing a disabled child doesn't make you sad for him, this means that there is a problem in your heart. I feel sad for [child name] and every disabled person. I feel that every disabled person is my child.

FRI-3: I hope they don't give us a sad look. They think that all disabled people are always asking for money and have sad looks. They ask God to help them in front of us.

FRI-2: Our society understands, when they see a disabled person they thank God. But they have to leave their curiosity. They ask what is wrong with your children, but I hate to answer them. For example, some relatives ask me “how are your children? Are their eyes ok?”. I say that everything is good. To be honest, I feel sad for my children, but I don’t let them feel it. They may behave differently if I let them know that I am sad for them.

FRI-1: They are very nice people, when they see my daughter they pray for her and caress her head. Some of them give her some candy... may Allah listen to their prayers.

4- The impact of other tragic stories

FUI-2: Thank God, my daughter is the only disabled person in our village.

FJI-2: Yes, I communicate with 3 fathers by phone, but the mother know mothers more than I do. We only talk over the phone, though, we don’t meet.

FRI-4: To be honest, my relationship with other parents is only through Facebook and Twitter. I don’t like family gatherings because it is hard for autistic children to go from place to another.

FRI-1: No no, we don’t have any other disabled people. We only have one Mongolian girl in my family.

FJI-1: I wish to communicate with other families, especially the ones who travelled abroad, so I can learn from their experiences. I will tell them everything I do so they can benefit as well.

FUI-1: I have a group on WhatsApp, all fathers of autistic children, from different cities, we have not met face-to-face yet, but I hope

my wife also has some groups with mothers. I sometimes get annoyed by these groups, because everyone tells us what they did or what hospital they are using. They mix up our plans. Some think that Early Intervention is a good idea and some tell us to travel to Jordan. Some also think that traditional medicine is good. My wife wants to do everything and I do not blame her.

5- The desire to communicate with other families of children with disability

FRI-3 (laughing): In the past, I did not think I would meet another father to ask him and get benefit from him, my pride and dignity did not allow me, but now I know it is very important, especially for mothers

FJI-2: I do not think it is a useful way, because I will be ashamed to ask him about affairs with his son. He is also not necessarily wanting to say everything.

FJG-7: Why do I meet another father, to complain to him and he complains to me? Each one of us knows what he suffers from.

FJI-3: My wife can meet another mother and she will understand what she wants, I do not think meetings between fathers are important. In fact I do not want to meet with other families because my health is not good.

FJG-6: It is a good idea for parents who have just learned about their child's disability. My son is now 9 years old and I do not think it will add anything for me.

FRG-5: It may be better if I meet two or three fathers separately, not just one, then choose which one is helpful for me and I will keep in contact with him.

FJI-4: I am not sure I will attend this kind of meeting every time, I do not have time for chatting... if it is for claiming rights for our children, you will find my name at the top of the list and I will sign for anything, even if my child does not need it but others do.

FJI-2: Good idea but they should have minutes and arrange who will speak and about what, at the end we need a summary of the discussion in hard copy. It has to be an organised meeting with goals

6- Transportation

FRI-3: The driver's visa is just 2,000 Riyals every two years, we need the ministry to pay the driver's salary, which is at least 1,500 Riyals each month.

When we travel we don't have any transportation problems, but here we have problems.

(he takes a breath and waits) our society is tiring, so tiring. Even if I want to go somewhere with my son I get tired. Nothing is suitable for him. For example, the place where we had breakfast has four stairs, but no access for the wheelchair. Earlier today I was in the University Hospital. I drove three times around the hospital car park in order to find a free parking space. All disabled parking spaces were full but we don't know if they are disabled or not. The free parking that I found is too far away. It's almost half a kilometre from the hospital.

FJI-3: we have a problem in transportation because [child name] has a wheelchair and we also have a baby with a pushchair.

Also, in malls we want paths for wheelchairs. We have parking for the disabled, but sometimes I see other people parking in them.

FRI-4: some families do not have money for taxis. I saw this myself. When we go to hospitals, sometimes I cannot find a parking spot near the hospital so we have to park far away. When you have an autistic kid and you let him walk a lot, he gets tired and he will not be active with the doctor. This also applies to blind people. This ticket should be for all disabled people.

FJI-1: the problem that we have is that our apartment is on the second floor and there are no lifts. I carry [child name] and her wheelchair upstairs. It's really tiring.

FJI-4: I discovered that society's awareness is very low, both people and companies. Once I went to a centre and they had stairs but they do not have lifts. I asked them if a

disabled person comes here how can he go upstairs? The man was shocked, like he had never thought about disabled people. Disabled people are not even able to enter many restaurants or shops. Unfortunately disabled people only have some of their rights, not all of them.

E- Negativity in claiming rights

1- In schools, hospitals, public and with the system.

FJI-3: No, I just look for a parking space and that is it. I haven't claimed anything in my life. I know how to take her up in the escalator with her wheelchair.

FJI-2: I did not claim anything because I don't have time for the court. I do have some small cases in the court, but they have been ongoing for 3 or 4 years and we are still not done yet. They still aren't solved. Don't forget the pressure involved in leaving work to go to the court, which meant that I would not have time for my son. It was hard in all ways.

FRI-3: I asked for the medical report and I discovered that the reason was that the cord wrapped around his neck. I sued them and they told me that they fired the doctor because he had made many medical mistakes. But if this happened now, if I was as strong as now I'd hang the doctor from his neck (he laughs). We demanded salaries for the disabled children's mothers. I wrote a letter on behalf of a number of fathers. The claims are not official, though, because I would have to start a charity. I bought a wheelchair from the UK through my brother, who is a doctor there. Unfortunately it is broken now, so I am looking for a similar alternative, but the prices are too high. For example I bought the wheelchair from the UK and it cost me 3000SR with the shipping. Here it is 7000SR and we don't have many shops that I can buy it from.

FRI-2: from experience, I did claim once, it affected my son negatively. The one that I claimed did not leave my son alone for one year. Some tell us that they will do everything, but they don't, they only talk.

FRI-1: for me I rather pay all my money than request anything. My daughter means the world to me. I am not the kind of person who will go and demand things. No, I am satisfied that I have to care for my daughter from my pocket. She is not the government's responsibility. Every person is responsible for their own children and my children are my responsibility.

2- Claims of rights as separate attempts

FRI-3: when the opportunity comes, I try, although I am often sure it will not succeed, but it may, one day, succeed

FRI-4: I am disappointed with the number of claims that have no positive outcome. I am holding the warrior brigade. There are a lot of disappointments, but I try to be strong.

FRI-1: of course we wish the fast track for appointments at the hospital includes treatment for blindness and mental and motor retardation, but to be honest we only demand it for autism.

FRI-3: The families in Saudi Arabia need an association for all disabilities in every region in Saudi. It would be better if the parents of disabled children were in charge of it, or someone who is disabled, because they are a huge part of the society. Some are even doctors.

FUI-1: there is no committee, who should we ask? Does anyone take Twitter seriously? We don't want to stay on the waiting list in the hospital and we want to use the disabled parking.

F- Exploit disability

1- By parents

FRI-3: Philanthropists donated wheelchairs for the disabled worth 5,000 Riyals. I was in a store of medical devices and a father took the chair then sold it to the store immediately at a price of 3,000 Riyals. He put 2,000 in his pocket and left the store. Do not think this is the only father who did this; this act is very common when the father is financially in need.

Sadly, this is our society. A mother called me and told me that her disabled daughter doesn't have any treatment. She doesn't have a wheelchair and she never goes out at all. The reason is because her father is always busy. He goes out with his friends and only comes back home to sleep. She said that her husband always take her daughter's subsidy without doing anything for her.

FRI-4: The wheelchair from Al-Dhabab Street costs 10 thousand Riyals and the one in Ibn Qasem shop costs 300 Riyals. Parents can take a receipt from Al-Dhabab Street and buy a chair from Ibn Qasem. Then they could walk around with the receipt to show others and receive their sympathy, perhaps even receive money from them.

I spoke with an employee at the airlines. He said that we are facing many frauds by the parents of children with special needs, where the parent books two seats for him and his child, so he gets a discount. Then he cancels the reservation of his child and travels alone for half the value of the ticket

2- By media

FRI-4: I have spoken to AlHilal and AlAhli club, asking them to open one day a week for people with disability. They refused. They just want to take pictures with them before the game, but it's only for the cameras and the media.

FRI-3: I always say that if you want to encourage someone you have to give him financial support. People expect that, for example, after I talked on TV about the cars for disabled people everyone asked me if they gave me a car and how much money

they gave me. That is how people in our society think. If you go in public to talk and to try to do everything you can, you have to get a financial reward.

FRI-2: It really annoys me when a charity wants to collect donations. They use pictures of disabled children to get peoples sympathy. Some parents hate the idea that someone might feel sympathy for their child.

FJI-1: A journalist promised that my daughter would be in his newspaper. He asked me to send her medical reports and photos of her, and I did. But he did not fulfil his promise.

3- By hospitals and centres

FJI-3: Medical devices are very expensive. Instead of helping disabled children, companies sell things at a very high price.

FJI-1: The amount of money I pay should get more hours than they offer. I mean the hour is very expensive.

4- By traditional healers and spiritual

FRI-1: at least 16 cauterizing spots in her body [laugh]

Zamzam for all of us, but I try to give it to her in the morning

FJI-4: I tried the traditional healers. My wife didn't agree with me on this point, but I always say that we have to try everything.

FUI-2: I took her to try spiritual medication, but she didn't get any benefit. I still feel happy that I took her there.

FJI-3: I tried traditional healers, but the doctors said that there is no chance that the girl will improve because her bone is completely broken, so I stopped.

FRI-4: We start going to traditional healers and reading the Quran. Then we stopped going to them, but we continued doing spiritual medication at home. We really benefitted from the spiritual medicine. We even stopped all his medications because we don't need them anymore. Many people told me that Ayat Alsakena and reading Azkar before bedtime really made their children (Autistic children) more relaxed.

FRI-1: I took my daughter to a woman who does cauterization. She said that your girl is disabled, I cannot do anything with her, so hopefully Allah will heal her hopefully. Rhey refused and I gave up.

FJI-1: Yes, we went to traditional healers. We went to a woman in the south and we also took her to a Sheikh who read the Quran to her. I also took her to someone who does nerve massage. He doesn't have a certificate or anything, but he has experience from Indonesia and China

FUI-1: There is someone on Twitter who does traditional medication. He does treatments for people who have autism and he only does herbal medicine. I wasn't sure that I wanted to take my son to him, but my wife told me that she knows a mother who has an autistic child and he improved after going to that guy.

Impact at home

A- Parental acceptance of disability

1- Using terms such as disabled child, child with disability or others

FJG-6: my son is not disabled, he can walk, disabled is just a word for people in wheelchairs

my son has had this disease since birth

FJI-2: medical error is causing this disease in my child

FRG-7: are we fooling each other? This is only a play on words

FRI-2: they can use phrases such as 'integrated children'. They are not disabled or special needs

FUI-2: I swear we have never faced such comments like that and I do not accept them, because the girl is not disabled. She has special needs and will walk.

FUI-1: The word disabled or impaired bothers me. I prefer special needs or maybe if you specify the disability it would be better than saying disabled. Disabled includes a wide range of disability, but of course I prefer the term 'autistic child' because it is more specific, even more than special needs.

FRI-2: The word disabled bothers me. I mean if they can use phrases such as 'integration children.' They are not disabled or special needs. I think that these phrases are hurtful.

FRI-1: I am fine with the word disabled. My niece is Mongolian.

FRI-4: I do not call it disabled, it is autistic. Anyway I don't really care about the words, but I want it to be used more. Some disabled people are sensitive. I always say that my son has autism, in order to ensure that aren't surprised by his actions.

FJI-1: I don't mind the word disabled, but it annoys me when my daughter tell me "dad I want to walk like my sister".

2- Abortion of a disabled foetus.

FJI-3: If Unfortunately, we discovered a disability in the advanced stages of pregnancy. If it had been earlier, we would not have hesitated to abort the foetus, for the child himself and his family, but also for the society as a whole. The fire burns just the foot of he that stands on it [famous aphorism]; no one can imagine life with a disabled child except his parents.

3- The desire of having more children after a child with disability.

FJI-2: My wife accepted the case of our child, especially when she has also given birth to normal, healthy and high achiever kids.

FJI-4: I promised myself that after [child name], I do not want to have more kids. Maybe I was scared that the next baby would be like her or maybe I don't want anyone to share my emotions for [child name]. My wife always says to me, "you don't want to have more kids, not because you are scared, it is because you love [child name]". The most important reason is that I want everything for her and I don't want anyone to share anything with her. It is truly the main reason

FUI-1: We were planning to have a child two years after having [the child name], but the situation is different now. He is violent, even with his mom. We will wait and see what God decides for us.

4- Searching for cure for the disability

FRI-3: Now my obsession is stem cells; it seems to solve everything

FJI-2: In the beginning, my wife did not believe that the boy was disabled. She said to me that I am meticulous and the boy is just fine.

FJI-3: The spinal cord was a lump and there was no hope. So we stopped treatment, even of folk medicine.

FJI-4: Why does my child have to be disabled all her life? I need someone to tell me where I can get a cure in any country

FUI-1: I did not leave out any hospital in Riyadh; I went to all of them. I want a cure for my son.

5- Blame the mother as the cause of disability.

6- Religious outlook for disability

FJI-2: I believe that he is a gift from God and I'm always satisfied.

FJI-1: We are seeking a reward from God. She is a grace from God. Since she came into our life, our situation has improved financially and psychologically.

FUI-2: We accepted it, thank God.

FRI-1: I believe in God, she is from God, and I am satisfied with that

7- The impact of seeing other children with disability.

FJI-2: To be present in a place with those children sends negative energy to anyone. Can you imagine that, when I am waiting in this environment for five hours a day with my child, I become depressed.

My first problem was with the mother; she did not accept the situation of our son. But she changed completely after entering a treatment centre with our son for eight weeks. Now she has fully accepted our son's disability after seeing children similar to our son and worse. If you see others' disasters, your disaster will be eased.

FUI-2: When you see the pain of others, you will accept your own pain.

FRI-3: My first problem was with my wife, who refused to accept our child's situation for a year. That was until the City of Prince Sultan accepted him and she began to go with him. You know, when you see others' pain, you will accept your own pain. After going to the City of Prince Sultan for eight months my wife came with fully acceptance for the boy.

FRG-7: my son has improved so much emotionally after meeting with people with physical disabilities. He is becoming much more accepting of using a wheelchair

8- The child's age and its rank among siblings.

FUI-2: Her brothers always take care of her everywhere because she is the only girl in the family, thank god.

FRI-2: He was the third child, but we don't have a background of disabilities

FJI-2: In fact, if the woe occurred in the first child, it will be very difficult, for us the situation was very bad until God gave us the second child and he was a healthy child.

FJG-7: Having a baby born with disability is different from having your child become disabled due to a traffic accident. This accident also took my wife and my lovely oldest daughter; they died. My situation is different from the rest, but thank God, it is our fate; I do not want to talk about that.

9- Attitude of children with disability toward their disability

FJI-3: *Talks to his daughter* Father: What is this? [pointing to her wheelchair]

Girl: My chair. Father: For what? Girl [laughing]: Instead of my legs.

FJI-2: Disabled people are very sensitive, but with my son I try to ignore and explain for him to relieve some of the sensitivity.

FRI-2: My children are hurt by the word 'disabled.' They are right; they are able to walk and speak, they are not disabled. One of them told me that his cousin called him 'disabled,' so I asked 'what did you do?' He answered: 'I hit him.' I encouraged my son to fight for himself.

FJG-5: My daughter keeps saying to me 'why can't I walk like my sisters and go with them to their school?,' since all her sisters including her twin go to the same school. She says 'do exercises for me so I can walk.' My poor daughter is nine years old and she cannot walk or even sit; if she wants something, she rolls to get it. Her sisters watch this sad situation every day.

FRG-7: my son is 13 years old, he has an Instagram account on which he introduces himself as a person with special features

B- The impact of the child on the family

1- Full burden on the family, there are no supported organisations.

FJI-2: What can I tell, no one helps, or even understands our circumstances, not the government, school and even my work, we take everything on our shoulders alone.

We are struggling with his education or when we want to take him out to the mall. A disabled child is a disability for the whole family. I am not happy in my work. My wife also cannot work, despite being highly qualified. She has sacrificed her life to stay at home with him. I am telling you now that I am not happy with the effort I am doing for my work. I know it's very bad, it is not like if I don't have a disabled child.

...ummm maybe his effect on his siblings is lower than on me and his mother. Maybe if his mother or myself become tired, maybe one or two of his brothers can adopt him and they will also be disabled, as me and my wife are now. Society has no benefit from him and he is even a burden for the family.

FRI-3: I posted a picture of my son on Twitter and I was giving him water. I wrote a comment that said "drink water and don't care about anyone as long as I am alive".

2- Parents' career path changing after having child with disability

FJI-2: my work is annoyed with me because I leave a lot.

FUI-2: My job has been affected because of her appointments but they understand. My wife works in a school and they give her the permission to accompany our daughter if she has an appointment, as long as we provide them with a report

FRI-3: I jointed a charity for the disabled in Buraydah and, God willing, I will be holding family counselling. I took a diploma in direction and guidance to support my aim, which is to guide other parents.

FUI-1: I know a lot of fathers who have moved to work in Riyadh for their children, and there are some who have hired a private driver to drive their children back and forth to Riyadh every day. For me, I cannot move or hire a private driver. I do not know how I will deal with the situation when my son grows up and needs to be in school.

FRI-2: my wife is in the education field. She has received a lot of job offers, but she has refused them. She is more eager than she is supposed to be.

FRI-4: After this problem we completely changed our future plans. My wife was a lecturer in the Institute Administration, but she quit, and I was planning to study abroad but I did not.

3- Financial pressures on the family

FJI-2: After I faced financial issues from the rehabilitation centres, I mean it took all my income, I had to find another job to cover the costs.

FUI-3: I have proven that I need from the deserved Zakat. There are some devices that we need and, thank God, they said that they will give them to us today.

FJI-4: Other families cannot afford even 1000 or 2500. There are specific toilets for disabled people. Some families have 2 or 3 disabled children and their father can only afford food for them, he cannot afford anything else.

FUI-1: I have a difficulty with the costs.

FRI-2: there are a lot of expenses. One lens costs 859 Riyals and no one helps. It could fall from him on the first day and break.

4- Changing in lifestyle of the family after the child

FJI-2: I had to have another job after my work to cover our needs.

FJI-3: I changed my car to a bigger one for [child name] and her wheelchair.

FUI-1: We don't go out like we used to. Only close family who understand our situation visit us.

FRI-1: The mother is a house wife. [Child name] is always with her 24 hours a day.

FRI-4: When we first learned, we didn't go out for almost a year. His mother was very sensitive. She was scared that someone could hurt her with a word. In general, we don't go out a lot because [child name] used to have particular routine at home. I want to point that after disabled girls reach puberty in our society, her parents won't take her out at all because they will be scared of sexual harassment. A lot of things need to change.

FRI-3: I moved to Riyadh to educate my son, because we was in Hafer Albaten.

5- The positive impact of a child in the life and character of his/her parents

FJI-3: Me and my wife became more connected after [child name]. Each of us calms the other one.

FRI-3: I became an activist and famous. Now I have thousands of children with special needs, not just one child

FJI-2: Despite the existence of problems, my son was the reason for not getting a divorce. If my wife returned to her parents' home, who would take care of him or carry him up the stairs?

6- Difficulty in time management in present of child with disability.

FJI-2: imagine that his study time takes 6 hours, so there is no time for food, exercise or the rest of the family. There in no time for me for my work. In the beginning I spent all my time with [child name], but after facing financial difficulty, I had to find another source of income.

FJI-4: She became our main concern. We searched the Internet for treatments and which school should she go. As [child name] grows up it becomes more difficult for my wife to deal with her. So if she had brothers, my wife would need to divide her energy among all our children. [Child name] needs a maid, most of the responsibility is on my wife, I am usually busy and I don't have time.

FUI-1: My wife goes with my son to school. She stays with him all day long

FRI-2: He spends almost 8 hours a day studying at home, you can't imagine.

7- Emotional stress on mothers and its link to emotional stress on fathers.

FJI-2: Actually we learned after a year and it was a shock. His mother asked how we could go to a centre for disabled people, as our son is fine. Life becomes... ummm... I am 32 but I look like 40.

What is the mothers' sin to spend years of their youth in caring for people with disabilities they are not even able to move. Who will offset these mothers for the twenty or thirty years that they lost? We are suffering in his education, we are suffering in his shopping. A disabled child means all the family is disabled, not only him.

FUI-1: My wife goes with my son to school. She stays with him all day long because she fears any danger. At home he must also remain under her observation, not to miss a single moment. There is no one who can help.

FRI-3: I do not think I need one in order to support me morally. Thank God I am a believer and satisfied, but I think it might be useful to mothers because of their sensitive nature.

I must be strong in front of my wife, because she derives her strength from me. I do not remember if I cried even if I am alone. In fact, mothers need support, while fathers flee from the house so they do not see this child.

FJI-2: What is the mothers' sin to spend years of their youth in caring for people with disabilities they are not even able to move. Who will offset these mothers for the twenty or thirty years that they lost? We are suffering in his education, we are suffering in his shopping. A disabled child means all the family is disabled, not only him

FRI-4: as a religious society, our acceptance of disabled children is the main key to progress.

FJI-1: I didn't have the power to stay with them in the physiotherapy; I cannot see my child in pain and crying.

When the doctor first saw her, he said she is very healthy, shame on you that your daughter does not walk. Why? I said I did what I could; I did not leave any door without knocking on it.

C- The division of roles between parents

1- Harmony and participation among mothers and fathers in the care of children with disability

FJI- 2: I rely 100% on her. She is the householder. I mean, I saw she has time so I chose that. She is responsible for the house and the kitchen. Of course, I supervise everything, because I have 2 jobs and I am responsible for all [child name] decisions, Sometimes the mother is in charge of everything and sometimes the father is, also

sometimes they teach the maid in their house and everything becomes her responsibility.

FJI-3: Me and her mother share the decisions together.

FRI-3: Me and his mother share the decisions together. I trust my wife a lot and if we agree on something I feel really happy. After [child name] our relationship grew stronger, but I met other parents who had divorced.

FRI-4: We forced [the big brother's name] to be active. For example, he distributes publications in school about autism and takes care of his brother when he eats, sleeps and goes to the toilet. We told him that the big brother and sister should help the parents.

FJG-6: thus our God divides roles, the mother inside home and the father outside. He works hard to provide for their needs.

FJG-7: We are an Eastern community and this is our nature: the mother is responsible and the man is the man of the home. In fact, mothers want this responsibility

2- The special importance of the father for the male children.

FRI-3: It is my role to clean the boy, especially if the child is over ten years. He will grow up and his personal hygiene is the father's job, the mother cannot do it. I mean this responsibility should be 100% the father's job after the age of 10.

FRI-2: I do not have time to waste. I have three blind boys. I have to be reassured about their future and they must not be a burden on anyone. All my trials and blunders were with the first child

3- Reasons for the withdrawal of the fathers from the perspective of mothers and fathers.

FUI-1: if he has the time, he may do what the mother does and more, but the work doesn't give the father permission to be absent every time he needs to be, so he will lose a part of his salary.

FRI-4: We have big groups parents, mothers are 85% of the group, some parents are divorced because of having disable child. Some fathers withdrew completely and would take responsibility for all living costs, so the mother must take care of the child. This type of father won't take his children into the public or tell people that he has a child with autism. He also won't take care of him, perhaps because the boy won't have a job so it does not make sense to pay a lot into him, just feed the child and that is enough. One of the most funny/sad situations is that there is a father who has a child with leprosy and he totally ignores him.

FJG-7: Even if you explain for him.. it is not the work's fault that you have this child, so you ask for permission to leave early every day. The work should be completed

FJG-6: Not every company appreciates the living situation of their workers. So they will allow you the first time, but the second time no, you leave work to take your son to the school, who cannot get any benefit from school anyway

4- The role of mother from the perspective of mothers and fathers

[FJG-5: the father may say to his wife: who are you to give me instructions and tell me what I should do?

FRG-6: My wife asks me before taking any action

FJI-2: his mother is like an assistant for me and I ask her a lot but the decision is mine. Because I am very busy, I let her lead everything while I'm absent. Then she is 100% responsible and all of the expenses are in her hands.

FJI-4: I relied on my wife to go to the training courses because honestly she has more contact with the child than me, I really appreciate my wife for doing what she is doing because she takes a big burden from me. I am thankful for her and for God that he has given me my wife

FRI-3: My wife covers all the failure from me towards the children. Although if I have failure toward my children it won't be intended, my wife is a virtuous woman and well educated.

FUI-1: My wife goes with my son to school. She stays with him all day long, the mother is the first one who is responsible for the child

FRI-2: his mother is responsible for his education. She educated herself from the Internet and learned Braille to keep an eye on them. Almost the whole responsibility is on the mother. I bring the groceries and anything else they need and I work.

FRI-1: her mother cleans and feeds her. She has a maid to help her, but it's the mother's responsibility because she [his daughter] is a girl

FRI-4: the burden was mostly on the mother to search for information and educate us. In my experience, the mother is the most caring. In some areas in Saudi Arabia, people refuse the disability and consider it to be a bad omen on her. A family could be destroyed because of a disability

FJI-1: [child name] is always the main theme in our conversations. I always remind my wife to do her physiotherapy or give her medication. My wife is doing more than she should do. I have to say it, even after her sister came, [child name] is still the most important.

5- The role of father from the perspective of mothers and fathers:

FJI-2: Search and information are my responsibility, 100%.

FUI-1: the percentage of fathers who take care of their children is very low.

FRI-2: they need to be with me, to get used to sitting with men. I want them to be useful for themselves and for their country.

Some uneducated fathers do not care about their children. They think that he is disabled, so he is nothing in the society. They even avoid talking to them or going out with them. I know a person with a learning disability who is confined to his home as a prisoner, in order to not embarrass his family.

FRI-1: I carry her because she is heavy and I bring everything for her, the same as for her siblings. I always tell them that as long as I am alive she won't go out from my house, If I die, take her to a shelter, she will be out of my protection, because some of our family convinced my wife to put [child name] in a shelter, but I refused.

FRI-4: I prefer to be with my wife, do not get me wrong, but women do not have time management, they may spend the whole meeting on unimportant points, so I have to be there just to keep control.

6- Husband abandons the wife after having child with disability

FRI-3: Many mothers told me that their husbands changed after they had a disabled child. Their life becomes work, food, sleep, and going out away from home. I know a mother who has three daughters. One of them is hearing impaired and another has impaired mobility and they only see their father at night to sleep. He doesn't help in anything and he did not hire maid to help in the house, because he says he cannot afford it financially.

A mother who has an autistic child will do everything and the father is busy. Work is not an excuse. There is something called a patient watcher and I have brought it today because my son has an appointment.

A mother in Hail contacts me to say that she has an inflexible daughter who is a big strain. She doesn't do physiotherapy, doesn't have a wheelchair, and doesn't take any treatment. The reason is that her father is busy working and when he comes home he eats and goes out to see his friends until the night, only coming back home to sleep. The mother said that the girl is very rigid but her father takes her own subsidy without doing anything to help her.