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Disability, Social Work and Social Exclusion: New Strategies for Achieving Social Inclusion of People with Physical Disabilities in the Kingdom of Saudi Arabia

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ABSTRACT

INTRODUCTION: Recent statistics estimate that 15.3% of the world population (978 million people) have moderate to severe disabilities, with this figure is set to rise dramatically in the near future.

OBJECTIVES: The primary objective of the study was to identify and characterise barriers (financial, social, cultural, socioeconomic) to social inclusion, to investigate the role of social work and social workers working with people with disabilities in the Kingdom of Saudi Arabia (**KSA**), and to provide evidence for future disability social inclusion policies.

METHODS: The study undertook literature reviews of relevant aspects of the domestic, regional and international legislative and social policy framework relating to people with disabilities in the KSA. Qualitative semi-structured interviews (n=20) were undertaken with people with disabilities and social workers (n=2) from within the Rehabilitation Centre in the **White Hospital** based in Jeddah.

RESULTS: The study identified ten themes: the nature of medical support; financial assistance; mobility; (5) religion and disability; gender and disability; quality of life; perceptions and problems; social support services and social workers; and Saudi law and policy implementation.

CONCLUSION: The findings indicate there still exists a large implementation gap, as there is a disparity between the rights people with disabilities have on paper, and the rights people with disabilities have in practice in the KSA. People with disabilities interviewed within the research study encountered a multitude of problems and challenges both within the **White Hospital** and in Jeddah. These related to areas such as potential medical negligence, non-payment of financial support (benefits), lack of high-quality medical care, services, and provisions, problems with mobility, and negative perceptions and attitudes from society. Overall, the research participants continue to suffer from a low quality of life and there is still a huge amount of work remaining if people with disabilities are to enjoy full social inclusion.

CHAPTER 1
INTRODUCTION AND BACKGROUND

AN INTRODUCTION TO THE RESEARCH STUDY

This research study analyses the current barriers confronting people with physical disabilities in the Kingdom of Saudi Arabia (**KSA**). The study highlights the difficulties and barriers faced by people with disabilities in the KSA and provides evidence that there is an urgent and compelling need to offer them support people. The chapter starts by presenting the research aim, objectives, and questions. It then proceeds to define disability, types of disability, and describing the influence of disability on self-identity of people with disabilities, the different types of disability, including the number of people with disabilities, characteristics of disability, and a general background of disability in the KSA.

The chapter will also introduce the significance of focusing on social inclusion of people with disabilities. Coverage of social work and the role of social workers and people with disabilities is a funding requirement for the Doctor of Philosophy (**PhD**) grant from the Saudi Ministry of Education (**MoE**). Consequently, the nature of social work and the nature and interaction of social workers in the KSA will be discussed. The section also presents positionality, the rationale behind the choice of hospital, and a brief discussion of how the study evolved.

It should be noted that although this research study relates to people with disabilities in the KSA, there is very little in the way of research studies in the existing literature covering people with disabilities and disability issues in the KSA. Consequently, references to disability issues in other countries will be incorporated to provide a comparative context within which to view disability issues in the KSA. However, the comparison and subsequent interpretation should always be subject to caution. That is because the way issues or ideas are viewed within one particular country or context may be different in another country, which gives rise to contextual interpretation. Therefore, any use of materials from other countries to highlight disability issue or idea, should not automatically be assumed the case in the KSA.

AIM AND OBJECTIVES OF THE STUDY

Aim

The study aims to identify and characterise the barriers to social inclusion and to provide initial evidence for future social inclusion policies targeted at people with physical disabilities in the KSA.

Objectives

The aim of the study will be supported by several research objectives listed below.

- To carry out a literature review of relevant aspects of the domestic, regional and international legislative and social policy framework relating to people with disabilities within the KSA.
- To carry out a literature review of the cultural and socioeconomic barriers faced by people with disabilities in the KSA
- To undertake interviews with a sample of people with disabilities from within the **White Hospital** located in Jeddah
- To investigate the role of social work and social workers working with people with disabilities in the KSA.
- To make recommendations for policies and nurturing aimed at improving social inclusion for people with disabilities within KSA using the findings from the data.

RESEARCH QUESTIONS

The research questions for this research study are:

(1)   Are there barriers to social inclusion for people with physical disabilities in the medical setting in the KSA?

(2)   If there are barriers, what are they, and how do they impact on the people with disabilities?

(3)   What steps can be taken to overcome any barriers in the medical setting in KSA?

Definition of disability

The term disability lacks a universally accepted definition because its meaning varies depending on culture, traditions, and contexts such as rural and urban (Aiden and McCarthy, 2014). However, most international literature tends to use the World Health Organisation (**WHO**) definition, which describes disability as a physical or psychological impairment that affects an individual's ability to perform and complete tasks in the same way as the rest of the population within the same age range (WHO, 2014). The WHO asserts that disabilities are not simply a health problem, but a rather complex phenomenon that reflects: "The interaction between features of a person's body and features of the society in which he or she lives (WHO, 2014, online)."

However, other authors provide important distinctions. Oliver and Barnes (2012) suggest that disability is an umbrella term that refers to three distinct areas: *impairments* (i.e., problems in body function or structure); *limitations of activity* (i.e., difficulties encountered by individuals executing tasks or actions); and *Participation restrictions* (i.e., problems experienced by individuals involved in life situations). Disability includes physical, psychological and psychosomatic ailments that stop an individual from being able to have full and healthy participation in society (Papworth Trust, 2017). Thus, both health (medical) and social aspects apply when assessing and an individual's disability in practice.

Types of disability

There are two majorly discussed categories of disabilities: mental and physical disabilities (WHO, 2014). Mental disabilities refer to a wide range of mental health conditions or disorders that affect a person's thinking, mood, and behaviour (Green *et al.*, 2005). Mental disorders include depression, mood disorders, personality disorders, psychotic disorders such as schizophrenia, bipolar disorder, body dysmorphic disorder, borderline personality disorder, obsessive-compulsive disorder, and post-traumatic stress disorder (Oliver and Barnes, 2012; WHO, 2014). There are also other cognitive disabilities such as dementia, autism, and intellectual disability (WHO, 2014). Intellectual disability refers to "a disability which occurs in the developmental period of life (i.e. before the age of 18) and is characterised by below average intellectual functioning" (Intellectual Disability Rights Service, 2009, p.2). It is often difficult to classify precisely when a mental disorder becomes a mental disability. Thus, in

practice, a mental disability may depend on the unique situation of a particular individual, and not simply a clinical diagnosis of a mental disorder.

Physical disabilities refer to impairments that affect a person's mobility, physical capacity, and/or dexterity temporarily or permanently (Al-Jadid, 2013). Physical impairment affects individuals' ability to use part of their body because of stiffness, paralysis, or pain. There are many kinds of physical disability experienced including arthritis, amputation, multiple sclerosis, spina bifida, muscular dystrophy, post-polio syndrome, cerebral palsy, acquired spinal injury, and others. Besides mental and physical disability, other disabilities include acquired brain injury, blindness and vision impairment, deafness and vision impairment, learning disabilities, and neurological disabilities.

In reality, people with disabilities are very diverse and heterogeneous. Thus, in practice, people with disabilities may often differ significantly. For example, visual impairment may take the form of full blindness, partial blindness, colour blindness, or cataracts while hearing impairment may incorporate full or partial hearing loss, Ménière's Disease, and Tinnitus (WHO, 2011a; WHO, 2011b; Aiden and McCarthy, 2014; United Nations, 2015). Mobility impairment may take the form of Stroke, Paralysis, Arthritis, Cerebral Palsy, Multiple Sclerosis, and Muscular Dystrophy (WHO, 2011a; WHO, 2011b; Aiden and McCarthy, 2014; United Nations, 2015). All these spectrums affect individuals to different extents.

However, it should be noted that although people with disabilities may fall within a particular definition of disability, it might be the case that individuals themselves do not see themselves as having a disability (Gannon and Nolan 2006). That introduces the notion that disability is an external social perspective that is applied to individuals whereas an individual's internal perspective may be that they do not regard themselves as having a disability because they can cope well in their daily lives. Indeed, although a person has an impairment, technological advancement may offer a restoration such that the affected persons will not view themselves as having a disability.

DISABILITY AND SELF-IDENTITY

Because the definition of disabilities aligns with contexts such as culture, individual perceptions, and those of others, social description has a considerable effect on self-

identity and the behaviour of those with disabilities. The impact of the social description of disability has been discussed using Labelling Theory. Labelling theory is a sociological approach that focuses on the role of the social description of individuals on their behaviour and self-identity (Bernburg, 2009). The theory proposes the belief that labelling individuals based on their characteristics or behaviour causes negative stereotypes and stigmatisation because of how others react to the identity of those labelled (Becker, 1963; Lemert, 1967; Bernburg, 2009). Eventually, the stereotyping and stigmatisation worsens the relationship between the labeller and the labelled (Bernburg, 2009).

Thus, the way society describes disabilities may reinforce negative behavioural patterns or trends of those with disabilities. For example, Hilbourne (1973) observed that to be labelled as handicapped assigns a category of deviance to an individual, thereby excluding that individual from the full social acceptance that they would otherwise receive. Indeed, Watson (2006) suggests that labelling diagnostics of people with disability as 'disabled' could affect the individual's sense of identity. Hilbourne (1973) also suggests that a blind man may be treated as if he is deaf, dumb, stupid or lame, notwithstanding that the person is only blind.

The present study is influenced by labelling in attempting to elaborate the social issues attached to describing disability in society. It draws on the labelling perspective because it has a dominant effect on the social and emotional adjustment in a community and explains why most of the people with disabilities do not passively accept labels. Labelling causes behavioural and emotional challenges to people with disabilities because of the values that the rest of society attaches to labels (Hughes *et al.*, 1997). Understanding a situation from the context of labelling helps to disclose that the assignment of social import to people with disability significantly affects their behaviour and identity whether in health practice or other social contexts (Green *et al.*, 2005).

Labelling is associated with the definitions of disability, whether formal or informal, especially when relating to eligibility. Labelling is a concern because it can cause people with disabilities to feel singled out, ridiculed, treated unkindly, affect their self-perception, cause low-esteem, and fail to capture the strengths and limitations of people with disabilities (Green *et al.*, 2005; Hughes *et al.*, 1997). Li and Moore (2010) found that perceived discrimination against persons with disabilities is significantly associated with disability acceptance.

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Therefore, while analysing disabilities in the KSA, it would be important to recognise the consequences of how its institutions perceive people with disabilities. Furthermore, since the KSA is strongly influenced by political, cultural, and religious factors, the underlying social descriptions of disability may reflect a judgement of the social worth assigned persons with disabilities. In practice, the KSA demonstrates a prevailing collectivist culture with a 'top-down' hierarchical structure. Thus, the social labelling of disabilities influences the treatment, views, and attitudes of people with disabilities at various levels of hierarchy in the KSA.

BACKGROUND TO DISABILITY WORLDWIDE AND IN THE KINGDOM OF SAUDI ARABIA

Disability is a universal problem that affects people of all kinds from all nations. It is therefore important to discuss disability from a global perspective, and then to narrow down to disability within the context of the KSA.

DISABILITY AROUND THE WORLD

The WHO, based on 2010 global estimates, claims that more than a billion people are living with some form of disability around the world and the majority come from low-income and middle-income countries (WHO, 2011a; 2011b). The WHO estimated that the mean prevalence rate in the adult population aged 18 years and over was 15% (650 million people of the estimated 4.2 billion adults aged 18 and older in 2004) (WHO, 2011a; 2011b) (**Appendix 1**). It also estimated that 15.3% of the world population (978 million people of the estimated 6.4 billion in 2004) had a moderate or severe disability, and 2.9% (185 million) experienced severe disability (WHO, 2011a; 2011b) (**Appendix 2**).

Importantly, the world prevalence rate of people with disabilities is growing because of populations are ageing (older people have a high risk of disability), increasing chronic health conditions such as diabetes, growing number of accidents, infectious diseases, child abuse, congenital disabilities, and violence (Albrecht and Seelman, 2012). The WHO (2016) suggests that people with disabilities around the world face limited access to health and rehabilitation services, unemployment, lack of education, discrimination

and other challenges. In developing nations, some people with disabilities live in extreme poverty, are widely discriminated against, and have difficulty accessing services because of poor infrastructure.

DISABILITY IN THE KINGDOM OF SAUDI ARABIA

The definition of disability affects the number of individuals reporting disabilities (i.e. because some definitions exclude certain types of impairments that may be included in other definitions of disability) (Albrithen and Briskman, 2015). In the KSA, a person with a disability is one who "is totally or partially disabled concerning bodily, material, mental, communicative, academic, or psychological capabilities, to the extent that it compromises the ability of that person to meet normal needs (Article 1 of Disability Code 2000). The Saudi General Authority for Statistics (GAStat) (2016) survey defines disability as:

> individuals who suffered disability by genetic and environmental factors that
> resulted in a physical or mental impairment that makes it difficult for them to
> successfully carry out business or physical and mental activities which might
> be made by normal persons.

Therefore, the definition of disability in the KSA involves both medical and social aspects and recognises that it can be psychological or physical. Presently, there is no actual record of the number of people with disabilities in the KSA, For example, it has been estimated that it could be 1.06 million (GAStat, 2016), or 4.07 million (WHO, 2014). There are estimates of disability statistics based on government statistics. It is surprising that modern-day Saudi government with annual government revenues of 519,448 million Saudi Arabian Riyals (**SAR**) (approximately £98,749.59 million sterling) has no idea of the total number of people with disabilities in the country. In 2012, the Social Affairs representative in Madinah suggested that there were approximately 720,000 people with disabilities in the KSA (Arab News, 2012). Previous KSA surveys estimated a 3.73% disability rate, which translates to an estimated 1,012,209 people suffering from some form of disability in the KSA (Al-Jadid, 2014).

GAStat (2016) suggest that people with disabilities make up 3.3% of the KSA population. In 2016, the KSA population was about 32.28 million according to the World Bank, which implies that 3.3% represents approximately 1.06 million people with

disabilities in the KSA. However, based on an estimation of 15% of the global population suffering from physical, sensory, intellectual, or mental disability made by the WHO, it has been estimated that 4,070,546 people in the KSA require rehabilitation services (WHO, 2011a; WHO, 2011b; Al-Jadid, 2014). The rate of functional disability was estimated at 0.8% of the population by a door-to-door survey conducted nationwide (CDSI, 2010).

The Saudi Demography Surveys on Disability 2016 and 2017
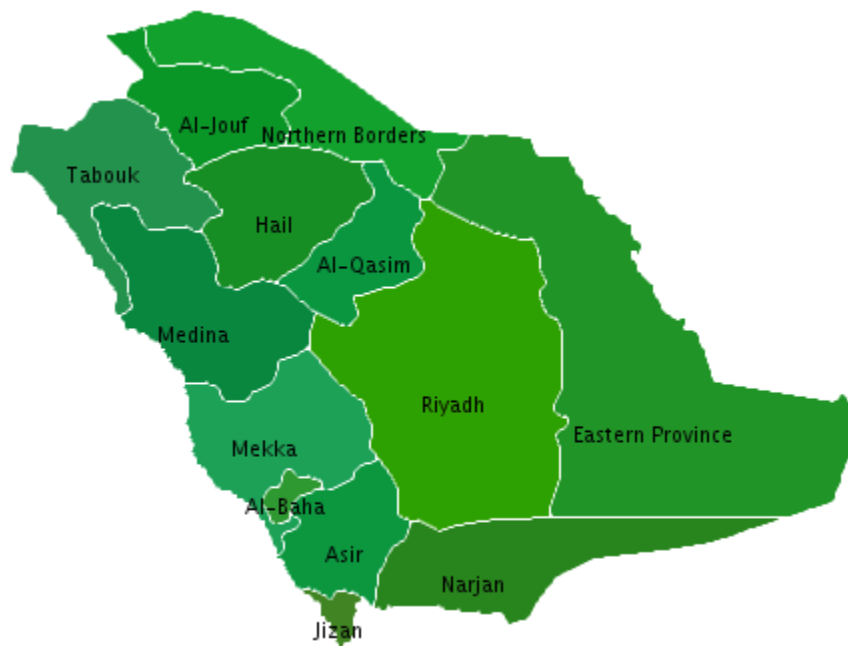
Figure 1: KSA Demography
Source: Adapted from (AlMubarak, 2014)

It is important to explore the perspective of disability in the KSA by broadly putting its demography in context. The KSA is the largest country in the Middle East, with a reported population of more than 30,770,375 people (CDSI, 2010). There are 13 provinces in the KSA with 150 cities, more than 2000 villages, and vast distances between cities (AlMubarak, 2014) (**Figure 1**). More than 65% of the KSA population lives in the three urban and semi-urban provinces: Riyadh, Eastern Province, and Makkah (CDSI, 2010). The disparity might be explained by the large income gap between provinces in the KSA. However, it has been observed that more people with disabilities live in rural areas (JICAPED, 2002). The KSA population is homogenous

because the people share common linguistic, religious, and cultural values (AlMubarak, 2014).

The GAStat 'Disability Survey 2017' is the latest survey of disability statistics that covers a random sample of (33,575) households in a way that is nationally representative. The figures are based on what people report and may not actually be fact. For the 2017 survey, the percentage of the population in the KSA reporting difficulties (mild, severe, extreme) in the KSA is 7.1% of the total population in the KSA (Male=3.7%, Female=3.4%) (GAStat, 2017). Similar to the 2016 findings, the 2017 survey found that overall slightly more males reported disabilities than females (GAStat, 2016). The number of the population in the KSA who suffer middle, severe, or extreme degrees of difficulty was 1,445,723 in 2017 (GAStat, 2017). In 2017, the greatest concentration of people with disabilities across the KSA was in Riyadh (**Table 1**).

Table 1: Distribution of People with Disabilities in the KSA

Description	Total	Males	Females	Location
People with Disabilities	100%	52.2%	47.8%	KSA
Highest Percentage	25.13%	54%	46%	Riyadh
Lowest Percentage	0.87%	4.2%	45.8%	Najran

Source: Adapted from: GAStat (2017)

The 2017 survey also provided a percentage distribution of people with disabilities across the KSA. The heat map shows that the areas with the highest concentration (red) of people with disabilities are Riyadh and Mekka, both areas that are generally highly developed. However, there is a distribution of people with disabilities across the whole of the KSA.
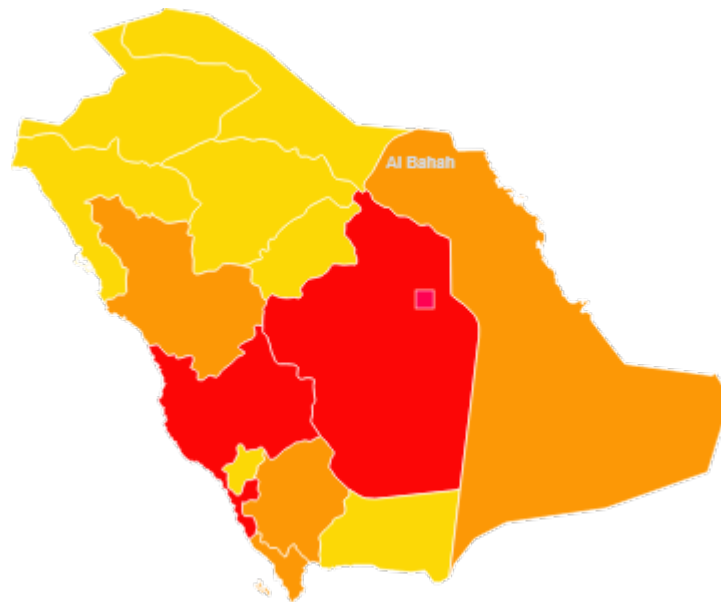
Figure 2: Heat Map of Percentage Distribution of Saudi Population by Administrative Region and Difficulty Status.

Key: Red (High percentage distribution); Orange (medium percentage distribution); and yellow (low percentage distribution)

Source: Adapted from GAStat (2017)

Regarding disability and age, the 2016 survey found that the ratio varies according to age, with a higher ratio of 9.1% for 65-69 year olds, 11.6% for 70-74 year olds, 14.6% for 75-79 year olds, and 27.6% for those greater than 80 years (GAStat, 2016). The results of the 2017 survey are similar to those of the 2016 survey. Regarding age groups, the lowest percentage of disability was reported in the 5-19 years age group (11.6%), and the highest percentage of disability was reported in the 20-65 years age group (55.86%) (GAStat, 2017). It was observed that difficulties markedly increased among the older (65+) population in the KSA, owing to their health conditions which could lead to multiple difficulties regarding mobility, seeing and hearing, as well as the result of chronic diseases (e.g. diabetes, stress, heart diseases) (GAStat, 2017).

Mobility disability (38.2%) was the largest type of disability present in the KSA in 2016 (GAStat, 2016) while in 2017 mobility disability came second (37.6%) after visual difficulty (46.02%) (GAStat, 2017). The above-discussed survey findings help to provide the disability context in the KSA and promote the need to address issues affecting people with disabilities. The findings are important because they can help to guide future disability policies in the KSA. For example, if mobility and sight disability have been identified as the largest types of disability present in the KSA, then it is essential that future disability policies in the KSA have at least implemented the most basic disability aids for people. That includes providing wheelchairs (e.g. building

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access ramps, accessible lifts, accessible parking spaces, and accessible public shopping centres) and for those with sight impairments (e.g. sight impaired aids, Braille access in buildings and lifts).

Challenges facing people with disabilities in the KSA

Studies suggest that people with disabilities continue to face a large number of societal and cultural barriers to full and active participation in society in the KSA (Al-Odaib and Al-Sedairy, 2014). Al-Jadid (2014) has argued that there has been a disregard of due process when dealing with people with physical disabilities in the KSA. Indeed, government policy makers in the KSA have done comparatively little to improve the quality of services needed by people with disabilities (Al-Jadid, 2013). There is no central government helpline for people with disabilities in the KSA. There is no central and publicly available document that sets out the rights of people with disabilities in the KSA. Furthermore, there is no central and publicly available register outlining the financial and social support services that people with disabilities in the KSA may be entitled to access. Therefore, the government in the KSA should be making tackling disability a national priority given the massive discrepancies between disability prevalence levels in the KSA compared to other high-income countries.

Limited research on disability in the KSA

There are very few studies on disabilities conducted in the KSA by government agencies, non-governmental organisations, or individuals. Previous studies have also acknowledged that there is a paucity of documented knowledge regarding various and important aspects of disability. AlMubarak (2014) has argued that there is no single source of national data for disability in the KSA, there is no formal data collection approach for the country, and there are very limited publications that have addressed the prevalence of disability in the KSA. There is emergent evidence in the literature that reveals heightened social injustice for people with disabilities in the KSA (Al-Odaib and Al-Sedairy, 2014; Al-Jadid, 2014).

Hemdi's (2010) study noted that there is a limited number of studies that explore crucial disability topics such as disability affecting the growth and development of children in the KSA. Montagu's (2010) study on civil society and voluntary sector in the KSA reported that overall there is a lack of documented knowledge and facts about disability and its effect on society in the KSA. Albagmi (2016), who examine physical disability

in the KSA, also acknowledged that there is a challenge of accessing theory focusing on physical disability or related disability topics in the KSA. Indeed, I faced a similar challenge. Very few studies discussed disability and social exclusion in the KSA. Some of the available studies were published a few decades ago, and therefore their contribution of knowledge could not reflect the present situation in the KSA. As a result, I applied some of the studies from the Middle East, developing countries, and the UK in relevant sections.

DISABILITY AND SOCIAL EXCLUSION

This study widely engages with the notion of social inclusion and contests exclusion. Therefore, it is imperative to describe social exclusion and inclusion at this level. The social debate (inclusion and exclusion) is essential in study of disability because it touches on reciprocal relationships, appropriate living accommodations, employment, informal and formal supports, welfare, and community involvement in disability issues (Simplican *et al.*, 2015). Social inclusion covers the ability of a person with disabilities to participate effectively in economic, social, political, and cultural life, leading to participation in mainstream society.

Social exclusion is "the dynamic process of being shut out…from any of the social, economic, political and cultural systems which determine the social integration of a person in society (Walker and Walker, 1997, p.8)." Social inclusion or exclusion concepts are crucial, specifically, for national policy development. They can guide the government in the KSA to develop effective social inclusion policies, and it is essential that social exclusion is capable of being precisely defined, precisely measured and precisely monitored, in order to identify whether or not such policies are actually working in practice (Stone, 1999; Gannon and Nolan, 2006; Rohwerder, 2015).

Often, social inclusion is viewed as the interaction between two major life domains, namely interpersonal relationships and community participation (Gannon and Nolan, 2006; Rohwerder, 2015; Simplican *et al.*, 2015). Interpersonal relationships covers: categories (e.g. family members, friends, partners); structure (e.g. length, origin, frequency, reciprocity, intensity); and function (e.g. emotional, instrumental, informational) (Gannon and Nolan, 2006; Rohwerder, 2015; Simplican *et al.*, 2015). Community participation covers: categories (e.g. leisure activities, employment, school, cultural activities); structure (e.g. segregated, semi-segregated, mainstream);

and function (e.g. presence, encounter, participation) (Gannon and Nolan, 2006; Rohwerder, 2015; Simplican *et al.*, 2015).

Thus, when this study pursues social inclusion, it is analysing how people with disabilities in the KSA should have both strong interpersonal relationships as well as active community participation to feel socially included within society in the KSA. By having stronger interpersonal relationships and community participation, people with disabilities will feel more strongly connected to and supported by others. Social exclusion, therefore, occurs where the elements of social inclusion are not met. Factors that contribute to social exclusion include lack or limited access to social environment and services, unemployment, stigmatisation, lack of adequate training and specialised services, and inadequate education systems (European Disability Forum, 2002).

In principle, the social inclusion discussion applied here aims to highlight the need for the government in the KSA to specifically tailor policies. Disability and social exclusion policies not only must address a country's particular culture and traditions but must also be integrated across national governmental to provide more cost-effective support for people with disabilities institutions. This may in practice be a very difficult task for many developing countries around the world and this is especially the case for the KSA. Social services provided by the KSA are therefore the cornerstone of the disability framework in the KSA. In order to fully understand the social services framework in the KSA the nature of social work and the role of social workers and people with disabilities will be discussed.

SOCIAL WORK

Some consideration of social work is essential to this thesis as, owing to the complexity of disability laws and policies in the KSA, as well as the complexity of obtaining disability support services, social workers are ideally placed to help and support people with disabilities with their daily needs. Albrithen and Briskman (2015) observe that social work in the KSA did not develop from Western constructs, rather in 1953 social experts from Arab countries were instrumental in its development, with a gradual evolution of Arab social work. Factors that influenced the development and practice of social work in the KSA include significant economic growth, cultural change, rapid social transformation leading to changes in life patterns (Albrithen and Briskman, 2015). Albrithen and Briskaman (2015, p.2196) state:

The programmes of social welfare provided by Saudi Arabian society stem from Islamic philosophy, which places on the shoulders of the author-ities [sic] responsibility for taking care of every weak and need person in the society who cannot find assistance within the family setting.

Consequently, social welfare programmes and social workers are driven by the philosophy of Islam in the KSA. Yet, a chief difficulty to date has been that social work has been very slow to develop in the KSA, with Albrithen and Briskman (2015, p.2195) noting that it is "at a relatively embryonic stage of development", with no formal professional association to take the lead on ethics development. Megahead (2017) has also identified a number of factors that have resulted in a paucity of published research on social work practice throughout the Arab world.

These include most social work practitioners not having sufficient time to conduct research or write about their interventions and a lack of formal support for scientific writing (Megahead, 2017). It also includes a lack of any formal mechanism for receiving credit for practice-based research, and a lack of mechanisms for distributing practice-based research (Megahead, 2017). Given this lack of social work research Megahead (2017, p.362) has argued that:

There exists a need to support social work practitioners in learning how to evaluate and how to communicate their eva-luation **[sic]** findings clearly in writing… There is also a critical need to ground social work practice in established the-ories **[sic]** and tested models.

Social work research is therefore crucial in the KSA, as it will help to develop both policy and practice. In fact, Albrithen and Briskman (2015, p.2195) argue that although social workers aim to enhance social work in the KSA, "they are relatively powerless and cannot develop new policy approaches without support from administrators, educators and researchers." Consequently, the nature and role of social work will be discussed, as well as the role of social workers and people with disabilities, followed by the role of social work and social workers in the KSA.

Moriarty, Baginsky, and Manthorpe (2015) observe that defining social work in practice has been complex and controversial. There are distinctions made between social work as an activity and as a profession, which blur the boundaries of theory and practice (Moriarty *et al.*, 2015). Social workers' roles and responsibilities have been greatly

influenced by the welfare regime in which they are located, and therefore contextual definitions are often required (Moriarty *et al.*, 2015).

Furthermore, the views of stakeholders (e.g. the media, politicians, service users, carers, employers, practitioners, educators) about the meaning of social work may not coincide, which makes defining social work difficult (Moriarty *et al.*, 2015). Also, the changing nature of social work in the 21st century reflects the evolving and dynamic definitions of social work (Moriarty *et al.*, 2015). Notwithstanding such difficulties, the International Federation of Social Workers (**IFSW**) and the International Association of Schools of Social Work (**IASSW**) have provided a global definition of social work:

> Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing (IFSW and IASSW, 2014).

Social work has been described as a discipline within human services, with the main goal being to assist individuals and families with their needs, as well as being used to solve their problems using a multidisciplinary approach (UNESCO, 2000). Social workers typically work closely with other professionals depending on the nature of the social work services provided. For example, they may work with medical professionals to provide medical care for clients, with school personnel to identify children in need of help, and with counsellors and psychologists to provide psychological counselling (UNESCO, 2000).

Adults with disabilities still continue to experience negative attitudes, discrimination, oppression, hostility and abuse, and therefore social workers must be sensitive to these additional difficulties (BASW, 2012). Trevithick (2005) notes that social work is located within some of the most complex problems and perplexing areas of human experience, and because of this it is by its nature a highly skilled activity. Trevithick (2005) adds that the social work is complex because it involves working across differences of class, race, gender, age, disability, sexual orientation, religion, culture, health, geography, expectations, and outlook on life.

In practice social workers must not only have the relevant skills and qualifications, but they must also have or develop certain behavioural characteristics or traits. For example, these may include sensitivity, patience, trustworthiness, a high level of communication skills, and someone who is approachable, genuine, and warm. Because of the broad range of areas that social workers cover, social work is often seen as a continual learning experience. Social work can be viewed as a professional activity that aims to realise social functioning, and to help to develop or repair the capacity of individuals, groups and communities, in order to produce appropriate social conditions (Daniş and Kirbaç, 2013).

Social workers must be able to provide welfare services when an individual's capacity for responding to the demands of life may be strained, when capacity for growth may seem like it is unattainable, and also when important decisions may elude resolution (UNESCO, 2000). In practice social work is influenced not only by the underlying social work theory, but also by the particular context within which social work takes place, i.e. legal and political framework. Social work theory covers a number of different objectives. It can provide the system of rules, assumptions, and logical bases that help social workers to understand a number of issues related to the field of human relationships (UNESCO, 2000). It can also provide a framework for general ideas and facilitates a broad and cohesive view of complexities that may be involved in any given human interaction (UNESCO, 2000). Because social workers work with doctors, teachers, sociologists, and other professionals, they must be able to demonstrate a theoretical understanding of their field so that their contribution is not ignored (UNESCO, 2000).

Social workers constantly find themselves faced with a need to predict a situation, and theory facilitates the capacity to predict (UNESCO, 2000). The British Association of Social Workers (**BASW**) has defined social work theory and social work practice. The BASW (2012, p.7) notes that in terms of social work theory social work derives its methodology from a systemic body of evidence informed knowledge, this has been developed through research and evaluation of practices. Social work theory therefore recognises the complexity of interactions between human beings and their environment, and also the capacity of people to be affected by, as well as to altering the multiple influences action upon them (e.g. bio-psychosocial factors) (BASW, 2012).

In terms of social work practice, this seeks to address barriers, inequities and injustices that exist in society, as well as responding to crises, emergencies, and everyday

personal and social problems (BASW, 2012). Social work interventions range from primary person-focused psychosocial processes, to involvement in social policy, planning and development (BASW, 2012). Social work methods may cover counselling, clinical social work, group work, social pedagogical work, and family treatment and therapy, and efforts to help people obtain services and resources in the community (BASW, 2012). The holistic focus of social work is universal, but the priorities of social work practice will vary from country to country and from time to time depending on cultural, historical, legal and socio-economic conditions (BASW, 2012).

Social work theory is guided by a number of underlying theories. These include: 'cognitive theory' which seeks to provide a greater understanding of how an individual's thinking and beliefs affect their actions; 'humanistic theory' which provides an encouraging vision of the goals of human development; and 'psychoanalytic theory' which helps individuals awareness of the importance of early childhood experiences and shows the effect the immediate environment has on behaviour (UNESCO, 2000). Trevithick (2005) however, argues that whether social work can lay claim to any *distinct* theories in its own right, independent of other disciplines, is debatable, and if it can it is still not clear what a social work theory would consist of in terms of its distinct characteristics.

Trevithick (2005) believes that social work has its own unique theory base which is built on knowledge-in-practice, and this identifies how certain theories are applied and adapted to specific practice situations. The findings of practice can then be used as a basis for new hypotheses to develop and further theory-building (Trevithick, 2005). Gordon (1962) set out the basic principles underlying social work, namely that the individual is society's primary concern, and that there exists an interdependence between individuals and society. There is also the notion that there is a belief that individuals have social responsibility for each other, and that each person has human needs, but each person is unique and different from others (Gordon, 1962).

Social work refers to the provision of social welfare services, these are typically formally organised and socially sponsored institutions, agencies, and programmes that aim to maintain or improve economic and social conditions, and health or personal competence in the population (UNESCO, 2000). In practice social work services seek to assist children, young people and adults with social problems; enhance problem-solving and capacities of people to cope; assist the community to initiate programmes for people using community resources; provide rehabilitation services for individuals in

prison, people with disabilities, parents, and their communities; link people with systems that provide them with services, resources, and opportunities; promote the efficacy of such systems; carry out research; and contribute to the improvement and development of social policy (UNESCO, 2000)..

The College of Social Work (**TCSW**) (2014, p.3) has described the role of social work in detail. Social workers use a distinctive range of legal and social work knowledge and skills to help people to make changes in their lives and get the outcomes needed (TCSW, 2014). Social workers are often uniquely skilled in accessing a wide range of practical and emotional support and services to meet individuals' needs and aspirations (Lechman and Duder, 2009; TCSW, 2014). They are a collaborative profession, working alongside other professionals but taking the lead in helping children, adults and families improve and gain control of their lives when their safety or ability to participate in their communities is restricted (Lechman and Duder, 2009; TCSW, 2014).

In practice social workers have a lead role in safeguarding people who may be socially excluded, at risk of abuse or neglect, or who become vulnerable for other reasons (TCSW, 2014). They balance support and protection/safeguarding roles carefully and in keeping with the specific needs and circumstances of the person or family, taking protective action as needed and within the context of legal roles and frameworks (TCSW, 2014). Furthermore, social workers are educated and trained to engage with people whose age, mental incapacity or ill-health constrains their ability to protect themselves or others (TCSW, 2014).

Within the hospital context, social workers can be involved with discharge planning, cost-containment, and working as change agents by participating and developing projects while working to create key roles on multidisciplinary teams (Judd and Sheffield, 2010). Other studies have found that hospital social workers are highly valued by service users, especially in terms of their responsiveness, emotional support, and practical help during the hospitalisation process (McLaughlin, 2016).

In adult social care they endorse and act in accordance with the principles of personalisation, ensuring that care and support are person-centred and as far as possible put the people with whom they work in control of their lives (TCSW, 2014). The BASW (n.d.) has defined 'Social Work Level Capabilities' and 'Values and Ethical Principles'. The Social Work Level Capabilities include professionalism; values and

ethics; diversity; rights, justice and economic wellbeing; knowledge; critical reflection and analysis; intervention skills; contexts and organisations; and professional leadership (**Appendix 3**).

SOCIAL WORKERS AND PEOPLE WITH DISABILITIES

Social work can be seen as an organised professional activity that is carried out on behalf of individuals or groups of people (Oliver *et al.,* 2012). This activity is geared towards the provision of services on an individual, group, or community basis (Oliver *et al.*, 2012). Social work is said to involve the matching of need with resources, as well as requiring professionals to work in partnership with people with disabilities in order to help them ascertain what their needs are, and to argue for adequate resources to meet those needs. Typically, social workers used a broad range of methods in order to try to help people with disabilities. These include casework, community work, and group work, and they can be applied within the home setting, day care, sheltered accommodation, and residential care (Oliver *et al.*, 2012).

According to the General Social Care Council, social work seeks to promote social change and apply problem solving in human relationships with a view to empowerment and liberation of people and enhancement of their well-being (McLaughlin, 2007). In practice social workers seek to overcome problems of disability, to help to negotiate the transition to adulthood and achieve independent living, to secure personal assistance (e.g. equipment and employment adjustments), and to access direct payments, individual budgets and other funding sources (McLaughlin, 2007). At the same time social workers also play a role in welfare provision by helping to ensure that public resources are allocated and any changes are applied fairly (McLaughlin, 2007).

Simcock and Castle (2016) note that social workers may need to draw on relationship-based skills that have been traditional in social work and on assessment and support-planning skills, including advocacy with service users, and promoting self-advocacy and independent living. In addition to helping individuals, Simcock and Castle (2016) believe that social workers should be prepared to engage with collective issues identifying by firms working with people with disabilities. They also believe that social workers should be prepared to raise questions about traditional assumptions and conventional approaches within the agencies that employ social workers.

The role of the social worker when working with people with disabilities may therefore vary greatly. Social workers may be dealing with day-to-day issues, as well as helping people with disabilities obtain support (e.g. financial, counselling), and caring for people with disabilities. In practice, social workers may play a crucial role in the lives of people with disabilities and may be a key facilitator in empowering people with disabilities to live full and independent lives. However, it should also be noted that given the broad range of disabilities and different approaches employed by different social workers and different institutions, the actual role of social workers will be dictated by the particular context within which the social worker operates.

HEALTH AND SOCIAL SERVICES IN THE KSA

In the KSA social services are overseen jointly between the Ministry of Social Affairs, the Ministry of Labor, and the General Organization for Social Insurance (**GOSI**). Social service programmes address a broad range of social needs such as the unemployed, widows and widowers, social security pensions, orphans, victims of natural disasters, females with no living family members to support them, as well as persons with disability, and disability resulting from occupational hazards (AlMubarak, 2014). The Royal Embassy of Saudi Arabia (2018) notes that "The establishment of a modern health care and social services system has been one of Saudi Arabia's most stunning successes." The government sponsors a wide range of social service programmes that seek to ensure that every citizen has a decent standard of living (The Royal Embassy of Saudi Arabia, 2018).

It is noted that the transformation of the health care system in the KSA since 1970 has been astonishing, as in 1970 there were 74 hospitals with 9,039 beds, but by 2005 there were 350 hospitals with nearly 48,000 beds (The Royal Embassy of Saudi Arabia, 2018). The KSA's health service plan consists of two tiers. The first tier consists of a network of primary health care centres and clinics that provide preventative, prenatal, emergency and basic services across the country (The Royal Embassy of Saudi Arabia, 2018). There is also a fleet of mobile clinics that provide remote rural areas with services such as vaccinations and basic medical care (The Royal Embassy of Saudi Arabia, 2018).

The second tier consists of a network of advanced hospitals and specialized treatment facilities located in major urban areas and accessible to all (The Royal Embassy of

Saudi Arabia, 2018). Social services programmes in the KSA include the provision of benefits and relief assistance to people with disabilities, with monthly stipends of social security recipients depending on individual status and need (The Royal Embassy of Saudi Arabia, 2018). There are currently 18 centres in the KSA operated or supervised by the Ministry of Health to treat and rehabilitate the mentally and physically disabled (The Royal Embassy of Saudi Arabia, 2018). Centres throughout the KSA also teach the mentally and physically impaired social, educational, and vocational skills so that they can enter society as independent, productive individuals (The Royal Embassy of Saudi Arabia, 2018).

Social work, social workers and disability in the Middle East and the KSA

Soliman (2017) observes that in the Middle East, a combination of religious, historical, ideological, cultural, and geographical factors have influenced the emergence of social work. Soliman (2017) adds that the religion of Islam has to a large degree contributed to the acceptance of social work instruction in the Middle East. At the same time Soliman (2017) states that social work in some countries in the Middle East has been a major player in the social welfare system. However, in other countries social work was marginalized and continued for years to provide typical social assistant services, without expansion of its mission or services (Soliman, 2017).

Historically in the KSA, traditional forms of welfare included providing food, clothing, and subsidies to vulnerable groups of the community such as the poor, the disabled, orphans, and people with no source of assistance (Soliman, 2017). There are a number of factors which have facilitated the development of a well-structured welfare system in the KSA (Soliman, 2017). These include a rapid growth of resources owing to the discovery of oil and the government's commitment to play a major role in the provision of social and humanitarian services to its citizens in the KSA (Soliman, 2017).

In addition, the KSA has relied on the experience of social work practitioners from neighbouring countries, through employment and research, who have contributed to the growth of social services in fields such as health care, social welfare, and schools and care for people with disabilities (Soliman, 2017). The influence of academia in the KSA has also contributed to the development of social welfare. There has been an increase in the number of universities which has led to the integration of social work education in the higher education system, and social work educators have sought to modernize social work education (Soliman, 2017).

The Ministry of Social Affairs oversees the practice of social work and runs a number of social welfare agencies (Albrithen and Briskman, 2015). In addition, the Ministry of Health deals with social work departments in hospital and health fields, with other Ministries (e.g. Ministry of Education, Ministry of Interior) that have social work departments that plan and supervise the practice of social work in various social sectors (Albrithen and Briskman, 2015). In the KSA, qualified social workers are individuals that have obtained a relevant qualification in social work or social care, and have trained professionally on the job either in hospitals or within special care clinics.

Albrithen and Yalli (2015) have identified that social work in the KSA is not a well-developed profession, and therefore this affects three areas of social work, namely: how it is practiced; the education of practitioners; and the quality of professional publications. There are also other problems identified including that social work is largely unregulated, there is no professional body, social work education is neither developed nor organised by any professional body, and social work publications are of poor quality in the KSA because the profession is so poorly defined (Albrithen and Yalli, 2015).

In the KSA hospital social workers are employed in both the private and public sectors, with approximately 80% of social workers employed by the Saudi Ministry of Health in hospitals, 11% employed by semi-governmental hospitals, and 7% employed by other governmental agencies (Albrithen and Yalli, 2015; Albrithen and Dziegielewski, 2016). In hospitals in the KSA social workers take on a range of responsibilities, including daily visits to wards, outpatient areas, assessments of psychosocial aspects of health, counselling and therapeutic services, advocacy services, planning services, and consulting with other care providers about psychosocial factors and implications for health (Albrithen and Yalli, 2015; Albrithen and Dziegielewski, 2016). They can also be involved in community organising and capacity building, training in psychosocial aspects of illness and intervention strategies, and preventative services (Albrithen and Yalli, 2015; Albrithen and Dziegielewski, 2016).

In the KSA the Department of Social Services was established by the Ministry of Health to supervise social work practitioners and to provide them with infrastructural support. Although theoretically this is how social work is structured, in practice it has been observed that owing to the hierarchal structures emphasised by culture in the KSA, social work units operate within an implicit hierarchal model whereby the relevant medical authority controls the specification of job qualifications, salaries and work

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processes (e.g. resources, promotional systems, training, development) (Lymbery and Bulter, 2004; Yalli and Albrithen, 2011). In practice this means that the role of social workers may significantly vary from hospital to hospital.

It has been observed that in the KSA, the minimum qualification required for social workers is a bachelor's degree, but that this does not have to relate to social work (Al-Saif, 1991; Yalli and Albrithen, 2011). They note that this relates to the lack of availability of higher education programmes in the field of social work in the KSA, and that the demand for health care social workers far exceeds the current supply (Al-Shammari and Khoja, 1992; Yalli and Albrithen, 2011). They stress that "It may be concluded, therefore, that a number of social workers in the hospital environment lack the necessary skills to perform their jobs effectively" (Yalli and Albrithen, 2011, pp.846-847).

In health care in the KSA, decision making remains in the hands of the physician, so nurses, junior medical staff and patients have a very limited role in the process of decision making (Yalli and Albrithen, 2011; Shammari and Khoja, 1992). In addition to this, it has been identified that the extent of the role played by hospital social workers with client decisions is very limited, and that this can be attributed to family ties, and the willingness and readiness of family members to look after the patient and safeguard his or her interests (Yalli and Albrithen, 2011; Yalli and Albrithen, 2015a; Yalli and Albrithen, 2015b). This means that the power of social workers within the context of public hospitals is severely limited. Yalli and Albrithen (2011, p.847) comment that people in the KSA "are reluctant to accept, and may resent the notion that a complete stranger can help patients to determine their care, and the right of self-determination, even if this stranger is from the same community and has similar religious beliefs".

A qualitative study of ten social workers in the KSA found that social work practitioners identified real limitations to performing their tasks in the hospital setting within the KSA (Yalli and Albrithen, 2011; Yalli and Albrithen, 2015a; Yalli and Albrithen, 2015b). These limitations were linked to: job-related skills upgrading; quality of support within the social work department; and personal health and well being in the workplace (Al-Saif, 1991; Acker 2004; Yalli and Albrithen, 2011). The participants felt that the hospital was not overly caring for the personal and professional qualities of social workers, and that they felt de-valued by hospital management (Yalli and Albrithen, 2011; Yalli and Albrithen, 2015a; Yalli and Albrithen, 2015b). Another issue was the supervision of

social workers by supervisors who possessed non-social work qualifications (Yalli and Albrithen, 2011; Yalli and Albrithen, 2015a; Yalli and Albrithen, 2015b).

One of the social worker research participants highlighted the unfavourable experience they found in the workplace. The individual noted that the social work services were not part of the hospital budget and they did not receive funding, and they were denied access to organisational resources to help clients (Al-Saif, 1991; Shammari and Khoja, 1992; Yalli and Albrithen, 2011). The individual also noted that they lacked ongoing training opportunities; they were employed on temporary or short-term contracts so they lacked job security; and they received less payments and less benefits (Yalli and Albrithen, 2011).

Albrithen and Yalli (2013) subsequently undertook a more comprehensive research study using 260 social work practitioners working within all of the state hospitals in the western region of the KSA. The study highlighted a number of perceived difficulties for social work practitioners. It identified that a large number of respondents criticized the hospital administration for being less caring about the personal and professional qualities of social workers (Albrithen and Yalli, 2013). It was also noted that there existed deficiencies in supervisory support and problems with job skills updating requirements (Albrithen and Yalli, 2013). The study corroborated their earlier study that hospital social workers in the KSA experienced negative perceptions of their role, and encountered a number of operational challenges in practice. It also corroborated earlier studies conducted on this particular area (Albrithen and Yalli, 2013; Albrithen and Yalli, 2015a; Albrithen and Yalli, 2015b).

The Disability Convention Code 2008 (**DCC**) suggests that individuals, both disabled and non-disabled, should have support services and participate in a fair and just society. The stipulations of the policy frameworks, such as the disability discrimination laws and more specifically the human rights acts of the UN echo these important views. The KSA's Disability Code stresses the importance of equal rights for people with disabilities, which necessitates at the very least basic rights for services required by people with disabilities in order to participate in society. Under Article 2 of the Disability Code, the Government shall guarantee to provide services to persons with disabilities in a number of different areas.

This includes all phases of education (pre-school, general, vocational, higher education) that are suitable to the abilities of the disabled, and are commensurate with

their categories and needs (Article 2(2), Disability Code). However, the existing literature has highlighted unfortunate barriers to obtaining adequate support services. For example, barriers might relate to several impediments to enjoying similar equal opportunities to non-people with disabilities or inaccessible public infrastructures (i.e., transport, buildings) (Al-Jadid, 2013). They could also relate to negative social and cultural beliefs and attitudes; and income barriers (Al-Jadid, 2013).

POSITIONALITY

When examining the experiences of people with disabilities, it is important to discuss positionality of the researcher to provide the reader with background information, which can help in the reader's assessment of the research. According to Denzin (1986, p.12) "Interpretative research begins and ends with the biography and self of the researcher." Indeed, to undertake ethical research, it is essential to consider positionality, reflexivity, the production of knowledge, and power relations that are inherent in the research process (Sultana, 2007). Positionality describes both an individual's world-view and the position they have chosen to adopt about a specific research task (Foote and Bartell, 2011; Savin-Baden and Howell Major, 2013; Holmes, 2014). A researcher's world-view incorporates ontological assumptions (i.e. the nature of social reality), epistemological assumptions (i.e. the nature of knowledge), and assumptions concerning human nature and agency (Sikes, 2004; Holmes, 2014). These may, in turn, be influenced by values and beliefs (e.g. gender, sexuality, religion, race, social class, disabilities (Sikes, 2004; Holmes, 2014).

In essence, positioning theory proposes that researchers are also agents and authors in our social participation (Foote and Bartell, 2011). Our positions in research are informed by the duties and expectations particular to the roles and social discourses we inhabit (Acevedo, 2015). Positioning can also allow for the subjective histories of individuals (i.e. identities, personal attributes, experiences) as well as preconceived narratives and understandings of our social locations, to play a critical function in the production of interpersonal behaviour (Sikes, 2004; Holmes, 2014). Positioning can, therefore, reflect my subjective history and experiences with disability and with people with disabilities in general.

Thus, positionality refers to the position I have adopted about people with disabilities in the KSA and people with disabilities in the **White Hospital**, Jeddah. My background

shapes the lenses through which I view the research with people with disabilities in the KSA. I have people with disabilities in my family, and so I have been involved with disability throughout my life. I have also met many people with disabilities in the KSA, and I have discussed with them at length their experiences with disabilities, and their views on disability in their daily lives. I have also seen a broad range of problems that people with disabilities face, regarding lack of social, financial, and mobility support in the KSA. I see disability as a challenge in the KSA, and although I view it as a challenge, I have aimed to approach this research study as objectively as possible. These personal experiences with people with disabilities in the KSA could have influenced the choice of processes, expression of sentiments, and interpretations of outcomes in my research. It is also possible that my beliefs, political stance, cultural background (i.e. gender, race, class, socioeconomic status, and educational background) importantly influenced this current study.

Potential influences on the research

My background with disability in the KSA may have influenced my choice of research questions, my review and critique of the literature, my review and critique of disability legislation and policies in the KSA, and my findings based on the research data, my interpretation of the research data, and the conclusions that I reached based on the findings and interpretation. Although my background with disability in the KSA may have influenced the research, I have at all times aimed to provide a balanced viewpoint and perspective. I have identified both positive and negative aspects of disability issues in the KSA, and I have aimed to provide a realistic account of disability issues present in the KSA as possible.

Positionality in relation to the research participants

The predetermined position that I chose about the research participants was one of neutrality. I was very wary of the potential for research bias, and so I aimed throughout to ensure that I was not pushing a 'disability agenda' in any way towards the research participants. I also tried to ensure any questions that I asked the research participants were neutral and that they were not intended to solicit solely negative responses or criticisms. I would add that although I aimed to adopt a position of neutrality, it was very difficult not to empathise with the research participants and the difficulties, problems, and challenges they faced in their daily lives. The interviews with the research participants were emotionally difficult for me.

Personal influence on the research process

My influence on the research process is notable because I have chosen the type of research methods to be used, I have developed the research questions, I have undertaken the interviews with the research participants, and I have undertaken the qualitative analysis of the research transcripts. Throughout the research study, however, I have aimed to ensure that I have received feedback from my research supervisors on all my choices that I have made. I feel that this has helped to keep the research study balanced and reflexive, as the commentary and feedback that I have received from my supervisors has been highly beneficial and informative. That has helped to ensure that my critique or commentary at times has not been too speculative or critical, and has allowed me to develop a more balanced approach to the research process.

RATIONALE BEHIND THE CHOICE OF HOSPITAL FOR THE RESEARCH STUDY

Many of the choices that I made concerning obtaining research data were based on practical challenges I faced during the research process. For example, because I was not able to obtain a list of people with disabilities in the KSA. Therefore, I was not able to obtain the names and addresses of people with disabilities, and not able to send out invitation letters or interview people in their homes. Trying to undertake a quantitative research study of people with disabilities across the whole of the KSA would have been too difficult for me, regarding both costs and time. Therefore, identifying sites with people with disabilities was a key priority for me.

To undertake this type of research into people with disabilities, it was, therefore, necessary to obtain approval from the relevant Ministries in the KSA. These Ministries would be the ones that could authorise me to access people with disabilities in the KSA and who were resident in hospitals or other rehabilitation centres in the KSA. The process of obtaining authorisation from Ministries in the KSA was long and difficult. The final choice of providing access to the **White Hospital** in Jeddah was governed by the Saudi Ministry of Health, which granted me access to this particular institution. It is acknowledged that because the research study was carried out within a hospital and a medical setting, the findings that I obtained may have been very different if a research study would have been carried out in the private residences of people with disabilities.

This research study will, therefore, focus on researching people with physical disabilities in the KSA. One of the reasons behind this choice is the difficulty of defining mental disability in practice and of identifying research participants that are suffering from a mental disability but are still competent enough to be able to provide their informed consent to the research project. A second reason is that acquiring access to people with mental disabilities is very difficult in the KSA, as there is no official reporting of statistics of people with disabilities in the KSA.

In addition, acquiring access to a hospital with people with mental disabilities would require the researcher to undertake a very long and detailed application process (that might ultimately not be successful). It is acknowledged that a research study, which included people with disabilities (both physical and mental), would be ideal. However, the current study has conceded to balance what can be achieved in practice, with the overall aim of the study.

HOW THE RESEARCH STUDY EVOLVED AND THE CHALLENGES INVOLVED

There are some challenges that I faced through the research study that shaped how the research study evolved. Firstly, there are no official statistics for people with disabilities in the KSA or Jeddah available. Therefore, I had no way to identify people with disabilities. That shaped the source of research participants. In my first year, the research study aimed to cover all people with disabilities based in Jeddah. However, after undertaking research, I found that there was no way to identify sufficiently large numbers of people with disabilities in Jeddah to form a statistically representative sample of the target population. I had no idea of the number of people with disabilities in Jeddah, and I was not able to access lists or databases listing the contact details of people with disabilities in Jeddah.

In the beginning, I also found it difficult to identify which Saudi Ministry dealt specifically with people with disabilities. The roles of the Ministry of Health and the Ministry of Affairs were not clear on the relevant websites. Therefore, I had to contact these Ministries directly, and this took some time. I was originally aiming to get approval from the Ministry of Education to collect data at the **White Hospital** in Jeddah, in order to research physically disabled students at the Ladies Campus within the King Abdulaziz University in Jeddah where I was working. However, I found that it was a highly complex process to obtain access and ultimately I was not able to obtain access.

Ultimately, I obtained approval from the Ministry of Health to collect data at the **White Hospital** in Jeddah. Access was provided to the Hospital's Rehabilitation Center because it receives the highest number of car accidents victims in the Western area in the KSA every year.

In the first year, I was aiming to undertake a mixed methods research study using both qualitative and quantitative methods. However, as I was not able to identify a source, which would provide me with access to a large number of people with disabilities based in Jeddah, I was only able to undertake a qualitative study with smaller numbers of research participants. I had to wait a long time to undertake the research study as obtaining approval for the research from the Saudi Cultural Bureau in London and the Ministry of Health in the KSA took a long time. In addition, obtaining ethical approval from the University of Salford took over two months, and the application had to be resubmitted in response to comments from reviewers.

The research aim, objectives, and research questions have been changed and refined several times. Initially, the research study was going to explore barriers to accessing higher education that young people with physical disabilities faced. However, in the final year of the PhD, the research question was changed to the social barriers that people with disabilities faced because of the difficulty accessing an educational establishment in the KSA. There were also problems I faced when in the KSA. When in the KSA, it took around three weeks to get access to the Hospital, as they had first to authorise me to collect data after first presenting them with my approval letter from the Ministry of Health.

I was also aiming to interview the Head of the Hospital or the Head of the Rehabilitation Centre, but because my time was limited, I was only able to carry out the interviews with the research participants. It was also difficult for me to carry out the interviews as I could only do one interview in the morning and one interview in the afternoon. Every day that I had to carry out interviews, I had to travel by car from my home to the Hospital, which took me around 50 minutes each way, driving in temperatures higher than 40 degrees Celsius.

CHAPTER SUMMARY

This chapter has introduced and set out the background to the thesis. As highlighted in the section covering disability in the KSA, disability poses some challenges in KSA, not least regarding social inclusion. The chapter identified the percentage distribution of people with disabilities in the KSA. It was identified that the distribution of people with disabilities is spread across the whole of the KSA, and this presents a logistical challenge for the government in the KSA as it is difficult to provide high-quality care and medical support for the thousands of small towns and villages located across the KSA. It has also been seen that the social exclusion of people with disabilities is a key challenge that needs to be addressed with effective social exclusion policies at a national level. Disability is, therefore, a key issue in the KSA as there are many barriers for people with disabilities that still exist throughout the KSA. This thesis will aim to identify and characterise the barriers to social inclusion that exist in the KSA and to provide initial evidence for future social inclusion policies targeted at people with physical disabilities in the KSA.

CHAPTER 2
REVIEW OF THE ACADEMIC LITERATURE

INTRODUCTION

This chapter critically reviews the literature on disability to identify factors affecting people living with disability in the context of KSA. However, an initial review revealed that literature on disability in KSA was extremely scarce. The chapter will commence with a review of the different types of literature review and their application. It will then disclose the literature search process and search results. After that, it will analyse the leading models of health and disability, suggesting that while the psychosocial is beneficial to understand disability in KSA, it is important not to disregard the bio-medical model completely. Subsequently, issues relating to disability, barriers, and social exclusion will be discussed. Finally, it will evaluate the literature, revealing that most studies analysed disability in broad perspectives including health, education, employment, cultural, and more.

TYPES OF LITERATURE REVIEW

Literature review refers to the search for and evaluation of available publications related to the chosen topic of study to help understand the phenomena under study (Webster and Watson, 2002). Randolph (2009) asserts that literature review includes the presentation of current knowledge, substantive findings, theoretical, and methodological contributions regarding a topic under study. Thus, reviewing the literature on disability helped to highlight and document the state of social inclusion of people with disability in KSA. Adams *et al.* (2007) argue that there are four main types of literature reviews, namely: evaluative, exploratory, instrumental, and systematic reviews.

The evaluative review focuses on providing a discussion of the literature concerning coverage and contribution to knowledge in a particular topic (Randolph, 2009). The exploratory review seeks to establish what theory, empirical evidence, and research methods applied in academic literature related to the specific research topic and its wider subject area (Grant and Booth, 2009). The instrumental review helps a study to establish how to research a highly specific research problem (Adams *et al.*, 2007). A systematic review uses research questions to identify, appraise, select, and synthesise

all high-quality research evidence and arguments about a study topic (Randolph, 2009).

Therefore, each type of literature search fits specific research needs. According to Adams *et al.* (2007), a study applies an evaluative review approach if it intends to compare research findings directly with others when their findings are available. Seemingly, the exploratory review is deployed to investigate further, sharpen, focus, and identify findings for unanswered research questions on a specific topic (Randolph, 2009). An exploratory approach is crucial in topics faced with limited research because this can be used to gather knowledge from existing empirical studies regarding the topic under study (Adams *et al.*, 2007).

Thus, since the initial review identified scarcity of materials available relating to disability in the KSA, for this study I selected the exploratory literature review approach. Moreover, the choice of literature review reflected the objectives of the research study and enabled me to identify key areas relating to disability in KSA and to gather knowledge based on existing literature. However, this literature review does not include a comprehensive quality assessment owing to the sparse availability of materials. The aim was to survey the literature, to describe its characteristics, and to provide a narrative synthesis wherever possible.

SEARCH PROCEDURE

The search procedure applied was aimed at filtering the most relevant publications. The procedure involved undertaking some keyword Boolean searches across databases. The search targeted articles discussing disability around the world, disability in the Middle East, and disability in the KSA. The Boolean search excluded any articles that were medical, i.e., articles that covered medical research studies or medical analysis of disabilities. The search focused on articles that covered adults with medical disabilities. However, I drew on a few research studies covering children and disabilities as these were relevant to describing the prevalence of disability in the KSA. Overall, over a hundred relevant articles were identified and used in this current study's literature review.

Search criteria

The search for articles involved the application of Boolean commands (AND, OR) along with keywords to filter the most relevant research studies. The language used for search strings comprised of English and Arabic. Additionally, the search did not apply a date limitation during filtering of relevant articles given the significant lack of research studies and information relating to disability in the KSA.

Key words

Keywords that were used for the search in databases and Google are listed below.

Disability AND Saudi Arabia

Disability AND The Kingdom of Saudi Arabia

Disability AND The KSA

Disability AND The Middle East

Disability AND Human Rights

Disability AND Policies

Disability AND Legislation

Disability AND "Saudi government"

Disability AND the Middle East

Disability AND Women

Disability OR People with disabilities OR Disabled people

Disability AND Culture

Disability AND Islam

Disability AND Religion

Disability AND Barriers OR Social Exclusion

"Social model of disability."

"Medical model of disability."

"WHO and disability."\

"People with disabilities."

Databases searched

The search for relevant literature started in June 2016. The database search was conducted on different online databases including the *Salford University Library System, Emerald Insight*, *Ingenta Connect*, and *NCBI*. The search was then narrowed to focus on online journal databases that were specifically related to disability, such as *Disability and Society*, *Disability and Health Journal*, and the *British Journal of Learning Disabilities*. Those searches allowed this study to identify some good quality articles relating to disability, disability in the Middle East, and disability and gender. I then conducted Boolean searches across other sources of information to broaden gathering of facts given the paucity of studies on disability in the KSA. These extra sources include the *BBC*, the *Guardian*, the *World Health Organization*, Google *Scholar*, and *Aljazeera*.

Table 2: Databases searched

Name	Type	Website
British Journal of Learning Disabilities	Searchable Journal	http://www.bild.org.uk/our-services/journals/bjld/
Disability and Society	Searchable Journal	http://www.tandfonline.com/toc/cdso20/current
Disability and Health Journal	Searchable Journal	http://www.disabilityandhealthjnl.com/
Disability Studies Quarterly	Searchable Journal	http://dsq-sds.org/
Emerald Insight	Database	http://www.emeraldinsight.com/
Ingenta Connect	Database	http://www.ingentaconnect.com/content
International Journal of Disability, Development, and Education	Searchable Journal	http://www.tandfonline.com/toc/cijd20/current

Name	Type	Website
Journal of Disability Policy Studies	Searchable Journal	http://dps.sagepub.com/
Journal of Intellectual Disabilities	Searchable Journal	http://jid.sagepub.com/
Journal of Religion, Disability, and Health	Searchable Journal	http://www.tandfonline.com/doi/abs/10.1300/J095v06n02_16
Middle Eastern Journal Disability Studies	Searchable Journal	http://www.jdisabilstud.ir/index.php?slc_lang=en&sid=1
NCBI	Database	http://www.ncbi.nlm.nih.gov/pubmed/27471664
Science Direct	Database	http://www.sciencedirect.com/
Science Open	Database	http://about.scienceopen.com/
Taylor & Francis Online	Searchable Journal	http://www.tandfonline.com/

Media and other institution sources searched

Table 3: Media and other institution sources searched

Name	Website
Aljazeera	www.aljazeera.com
Amazon	www.amazon.com
Comment Middle East	www.commentmideast.com
Global Disability Inclusion	http://www.globaldisabilityinclusion.com
Global Disability Watch (Middle East)	http://globaldisability.org/middle-east
Google Scholar	http://scholar.google.co.uk/
Independent Living Institute	www.independentliving.org
Middle East Health	www.middleeasthealthmag.com
The BBC	www.bbc.co.uk

Name	Website
The Guardian	www.theguardian.com
The World Health Organization	www.who.org
United Nations Human Rights Office of the High Commissioner	www.ohchr.org.com

Search results

The manual search using the above keywords resulted in more than 400 articles, websites, and uncategorised documents. However, of these less than 150 were found to be relevant for further review. The literature identified from the search procedure was further analysed to establish the themes that they contribute towards the disability debate. That included models of disability along with disability barriers, social exclusion, disability and the environment, disability and poverty, cost of disability, disability, and quality of life, the perception of disability, culture or religion and disability. These themes provide the framework for this literature review.

MODELS OF DISABILITY AND SOCIAL EXCLUSION

By definition, a 'model' is an abstract method used to describe and analyse the relationships between different factors that contribute to the outcome of interest (Wade, 2009). It has been widely argued that models are crucial for understanding phenomena and validating professional practices (e.g., Bantinx and Schalock, 2010). In the context of disability, models offer relevant frames of reference relative to medical, social, and behavioural aspects that are imperative for good professional practice. Wade (2009) explains that within the context of health and illness, a model aims to specify what factors are important for determining whether a person is ill, and establish the nature of the inter-relationships between those factors and being ill.

Models assist us in understanding multiple perspectives and the multiple dimensions of disability and inclusion in society. However, Scullion (2010) asserts that the use of models must acknowledge that disability is not homogenous, and every story is different relative to circumstances, type of disability, environmental factors, and care.

Literature analysis indicates that there are two distinct models of health associated with disability, namely the biomedical model (medical) and the psychosocial model (social). Researchers have pointed out that both models are important in describing the way people living with a disability, or particular categories of disability, are viewed or treated (Deutsch, 1952; Lave and March, 1993; Trifiletti *et al.*, 2005). For example, the biomedical model of disability focuses nearly exclusively on the medical or biological aspects of disability, the particular medical condition an individual has, or the particular impairment that the individual develops (Wade, 2009). On the contrary, the psychosocial model seeks to understand societal attitudes and environmental issues that limit disabled people's life activities (Scullion, 2010). Thus, examining the models can significantly contribute to understanding disability and professional practices.

The biomedical model of health and disability

As the name Biomedical implies, the model draws its premises from both biological and medical concepts. The Biomedical Model defines health as the absence of disease and focuses on identifying and treating the biological cause of illness in the body (Reindal, 2008). It aims to classify and objectively treat illness, based on provable facts and scientific theory (Taylor and Hawley, 2010), by use of sciences (i.e., physiology, pharmacology, biology, biochemistry), to diagnose symptoms and clinically treat human illness or disease (Hosking, 2008). As such, it views disability as a disease but frequently does so by adopting a body-mind dualism (vanTeijlingen, 2005).

Wade and Halligan (2004) assert that the biomedical model is prone to separating the body and mind such that mental phenomena, such as emotional disturbances, are separate from, and unrelated to other disturbances of bodily functions. This dualism has led to it being termed reductionist because it seeks biological explanations of disease (Hardey, 1998; Adibi, 2014). Taylor and Hawley (2010) call it empirical, because knowledge is generated by observation, and tested through experimentation; and Shah and Mountain (2007) call it interventionist because medical knowledge is applied to repair damaged biological systems. It is, therefore, a strongly explored and applied model in health and disability.

The biomedical model can be seen in health processes in which doctors, acting on the best available evidence, advise on, coordinate or deliver interventions for improving the health of people with disability (Smart and Smart, 2006). Other experts also

commend the biomedical model as the important framework that has enabled advances in technology and research in health including the introduction of antibiotics, anaesthetics, x-ray and more (vanTeijlingen, 2005). Taylor and Hawley (2010) argue that the biomedical model has also enabled many common health problems to be effectively treated. Critics have argued, however, that the biomedical model considers disability as impairments or differences that require medical procedures or treatments to fix or modify them even when the identified impairment does not cause pain or illness (Reindal, 2008).

Indeed, it has been suggested that the biomedical model creates low expectations for people living with disability and results in them losing independence, control, and choice in their lives (Scullion, 2010). Thus, when applied to disability, the biomedical model of health views disability as an illness or disease, which must be cured or treated to alleviate the symptoms to restore health to the greatest extent possible. That way, the disability in question is viewed as a deviation from the normal healthy state, or as an anomaly. That makes the biomedical model attract significant criticism (e.g., Oliver, 1990; Shah and Mountain, 2007).

For instance, Adibi (2014) remarks that the use of the biomedical model in disability practice equates victim blaming, while Mitra (2006) argues that it results in individuals blaming themselves for the illness, disease, or impairment. Significantly, some researchers have pointed out that illness and disability are not the same thing even if some illnesses may have disabling consequences (Shah and Mountain, 2007). Rather, disability is a long-term social state that doctors cannot use their knowledge and skills to treat, and which does not need medical intervention (Reindal, 2008). Thus, the biomedical model should only focus on treating an illness that may cause or be related to a disability.

Despite these criticisms, it is important to note that research based on this approach can aid our understanding of disability. For example, some studies have used the biomedical theory in identifying disability trends in the KSA regarding prevalence and causes, or medical aspects of children with disabilities in Saudi hospitals and clinics (Al-Jadid, 2014, Al-Hazmy *et al.*, 2004; Al-Turaiki, 2000; Shawky *et al.*, 2002). Still, the criticisms do suggest that this approach is by itself insufficient.

The psychosocial model of health and disability

The psychosocial model is seen as contrasting with the biomedical model as it incorporates psychological and social factors (e.g., Haegele and Hodge, 2016; Bantinx and Schalock, 2010). Taylor and Hawley (2010) explain that the environment or a wide range of additional social, economic, geographic, and cultural factors affect the health of an individual. Indeed, the perception of health in a remote village in the KSA will differ from that in Riyadh, the capital city. Besides, Haegele and Hodge (2016) highlight that biological factors (e.g., age, gender, illness), with psychological factors (e.g., beliefs, perceptions, mental health), and social factors (e.g., community, housing, country, location) significantly affect the health of any individual.

In this way, the psychosocial model seeks to move beyond the neutrality and scientific position of the biomedical model, which it sees as only one aspect to viewed alongside the social determinants of health (i.e., gender, ethnicity, social class, income, and occupation affect health and illness of individuals) (Adibi, 2014). Psychosocial issues are increasingly seen as at the centre of health. For example, according to the WHO health is "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 1984).

In the context of disability, the psychosocial model is a significant model because it draws on the idea that society disables people through a focus on addressing the needs of the majority of people who are not disabled. However, there are a lot of things that society can do to reduce, if not remove the disabling barriers (Wally, 2009; Alquraini, 2010; Al-Jadid, 2013; Kavanagh *et al.*, 2015; Corrigan and Watson, 2002). Thus, the psychosocial model argues that disability is a responsibility of society and not that of the person(s) living with a disability.

The psychosocial model is a crucial framework regarding disability because it emphasises the equal and proactive involvement of people living with disabilities (Ewles and Simnett, 2003; Bantinx and Schalock, 2010). Thus, it offers a more holistic view of health, and it can more realistically incorporate both intrinsic forces (e.g., culture, behaviour, genetics, habits, lifestyles) and extrinsic forces (e.g., preventative, curative, promotional aspects of the health sector) (Rolland, 1994; WHO, 2016). The psychosocial model of disability, therefore, aims to empower people with disabilities so that they can challenge disabling barriers, stereotyping and stigma and seek full participation in economic, political, and social life (Corrigan and Watson, 2002;

Kavanagh *et al.*, 2015; Taylor and Hawley, 2010; Wally, 2009). It does this without denying that persons living with a disability have a difference or that the differences affect their life.

In the KSA, some studies have applied the psychosocial model in analysing psychosocial contexts of disability affecting people living with a disability. For example, Al-Hano (2006) investigated representations of learning difficulties in nine KSA elementary schools and revealed the contexts that surround the disability identification process. Al-Saif (2008) also explored the rights of people with disabilities and discrimination by comparing British, American, and disability laws in the KSA and revealed inadequacies in the existing KSA disability framework. Thus, the psychosocial model can provide a helpful framework for analysing social issues related to disability in KSA. Similarly, the psychosocial model has also been applied in neighbouring Oman; Al-Mawali (2004) broadly analyses the life experiences of the physically disabled young people with their families and the wider community (including public and professionals).

Overall, the biomedical and psychosocial models take distinct approaches to disability. The above analysis indicates that each of the models has a significant role in the health of people living with a disability. Since this study is pragmatic, I accept that both models of disability have a role because health, social services, community, and the affected person can combine to support and attain a meaningful life. Besides, the biomedical model is crucial if the disabled person has an injury caused by illness or any other factors. However, helping the person recover is not just about healing the wound or disease, it involves the comfort experience particularly when the society wants to change and become less limiting.

In the KSA, Madi (2014) pragmatically applied the two models in examining the situation regarding children with cerebral palsy and their mothers and presented significant findings of their experiences. Seemingly, Elsheikh and Alqurashi (2013) employed both models to analyse the future of people living with disability in KSA. The studies depended on the principles from the two models to facilitate a holistic approach in analysing disability. Consequently, the biomedical model of disability can help to highlight the impact a particular physical impairment has on an individual while the psychosocial model of disability considers the impact of social and environmental factors on a person with disabilities.

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BARRIERS AND SOCIAL EXCLUSION OF PEOPLE WITH DISABILITIES

In life, every person faces hardships, but for people with disabilities, barriers are more frequent and usually have greater impacts on their life. For example, Wally (2009) reported that about 10% of the world's population has some form of disability and 80% live in low-income countries where they face more barriers and challenges. That implies barriers are a significant issue for people with disability. Barriers include aspects such as a physical environment that is inaccessible, expressed negative attitudes towards disability, lack of important assistive technology, the existence of policies, services, and systems that hinder the involvement of all people with disability or health conditions in normal life (Kavanagh *et al.*, 2015).

Significantly, these barriers can deny people living with a disability the opportunities that define a quality life such as good job, safe housing, satisfactory health care, affiliation with adverse people (Corrigan and Watson, 2002). Therefore, barriers can make it extremely challenging or even impossible for people with disabilities to function or lead a normal life. Several studies highlight the implications of barriers to people with disabilities. The common barriers are associated with communication, physical, attitude, policy, social, transportation, or programmatic (Al-Saif, 2008; Kavanagh *et al.*, 2015; Ramesh, 2010). In the UK, a survey engaged 18,000 people about eight areas of their lives regarding social barriers to participation that they experienced daily (Ramesh, 2010). The survey showed that 19% of people with disabilities believed anxiety and lack of confidence to be a major barrier to employment, and insecurity prevented 13% of people with disabilities from using buses, and 15% from using trains (Ramesh, 2010).

A quantitative survey study on disability that involved over a hundred nationals (including Saudi nationals) indicated that people with disabilities face physical barriers that curb their mobility into crucial facilities such as education, equipment that require them to do the impossible given such as standing regardless of their impairment to stand and more (Madans *et al.*, 2011). The studies indicate that because of the obstacles, people with disability may develop anxiety and lack of confidence required to secure employment. While in developed countries like the UK, the government is committed to ensuring non-discrimination (Kavanagh *et al.*, 2015), in countries like

KSA, the government has not put in place adequate protections from discrimination for the disabled (Al-Saif, 2008).

People with disabilities in developing states face several barriers that make their daily life challenging, but the most common are physical and social barriers that are common even in government institutions (Al-Jadid, 2014). In the KSA for example, people with disability face structural obstacles in natural (such as land terrain) and human-made (such as transport, buildings) that block their mobility or access to crucial services such as healthcare (Alquraini, 2010). Getting on to buses and trains in KSA is difficult since there are no special accommodations available for people in wheelchairs to use (Frye, 2013). Most, if not all building lifts in the KSA have no braille markings on them for the visually impaired to use, and some buildings have no lifts or ramps for wheelchairs access (Hartblay, 2017; Hasanzada, 2002).

Indeed, mobility adaptations in towns and villages in the KSA are rare, if any exist at all, which poses a significant physical barrier to people with disabilities in KSA. The limitation of such obstacles implies that people with disability cannot use important infrastructures such as trains or buses. Such social and environmental barriers not only limit functioning but may also create disability (CDC, 2016). People in society may also hold negative attitudes towards people with disabilities, which may result in services, systems, and policies that hinder the involvement of people with disabilities (CDC, 2016). These attitudes may include or lead to stigma, prejudice, discrimination, and stereotyping (Corrigan and Watson, 2002).

Therefore, not only do people with disabilities have to cope with the physical barriers, but also face mental challenges such as stigma and prejudice. Indeed, such attitudes and behaviours have been found to exacerbate the effects of impairments on individuals, leading to feelings of oppression, anxiety, depression, anger, and bitterness, or they may feel resentful and even suicidal (Yanagita *et al.*, 2006; Brown, 2010). Significantly, however, attitude related barriers have been found to contribute to other barriers because they underpin the perception of the society towards removing or imposing limitations on people with disability.

According to Al-Jadid (2014), stereotyping of people with disability is common in KSA such that people will assume that their quality of life is poor or regard them as unhealthy because of their impairment. However, Alquraini (2010) asserts that the KSA society is increasingly getting educated and enlightened that disability is not a personal

tragedy or inability or unhealthy but a status. People with disabilities also face communication barriers that hinder interactions with others in the society. For example, those with hearing impairments may not hear auditory health messages while those with vision impairment may not also read small print writing (e.g., written terms and agreement).

As such, communication of social support to people living with disability in KSA becomes a challenge because some people with disabilities do not have access to communication channels, or their impairment makes it difficult for them to receive messages (Almalki *et al.*, 2012). Alquraini (2010) asserts that at health facilities professionals argued that they would find it challenging to communicate directly to people with disability mainly if they had hearing or vision challenges. The use of kin to pass the communication was the most applied method in hospitals. Indeed, there are not many sign language professionals or braille scripts available in health facilities or education institutions to facilitate affluent communication with people with disabilities. As the CDC (2016) noted, the use of braille version captioning, and sign language can significantly help to break down communication barriers for people with disabilities.

The barriers facing people with disabilities entangle with the social activities resulting in exclusion or inclusion. A UK study by Abbott and McConkey (2006) on social inclusion of people with intellectual disabilities (some being tenants in support living or shared homes), suggests four main barriers to associate with inclusion. First is the role of support staff and service managers. Second is the location of the house. The third is the lack of necessary knowledge and skills, and fourth are community factors (e.g., lack of amenities, attitudes). The study concluded that greater advocacy of social solutions is an essential element in reducing the social isolation of other marginalised groups.

Similarly, Grewal *et al.*'s (2004) analysis in six UK local authorities found that people with disabilities had trouble making transitions in their lives, including delays and even not receiving the service they required. Even though these studies highlight the situation in the developed world, they disclose the complex interaction between barriers, organisation or structural issues or social issues to further challenge people with disabilities. Moreover, the existence of such challenges in a developed country like the UK may imply that they greatly affect people with disabilities in a developing country such as the KSA. They suggest that this can have significant personal consequences. For example, a child with a disability moving to a new school loses on-

site provision of a specialist therapy; an adult moving home to a new local authority ends giving up equipment provided to them (as an adaptation to their former home); and a person starting a new job may lack necessary IT equipment in place when required.

In the KSA, organisations servicing the disabled face budgetary and procedural problems that worsen the social exclusion of people with disability because they do not adequately receive the required support services (Alquraini, 2010). That builds on earlier studies identifying barriers to the full social integration of people with disabilities, including information; counselling; housing; technical aids; personal assistance; transport; and access (Davis, 1990). Although these barriers have been identified, it is difficult to operationalise such information and translate this disability 'need' into working policies (Zaidi and Burchardt, 2005). Even more complex is identifying who qualifies for such support, such as is if a person without a hand is entitled to housing for his or her entire life (Al-Jadid, 2014).

Alternatively, regarding personal assistance, are all people with disabilities entitled to personal assistance, or only people with certain types of disabilities? Regarding access, does every single public or private building have to be accessible for people with disabilities? Adopting a social model of disability or attaining full social inclusion may cost a huge amount of money and may take a very long time (Shepherd and Parsonage, 2011). Therefore, from a rational perspective, although the social model of disability is desirable and more equitable, there is a question to be asked as to where to draw the line. A government can only operate with an annual national budget, and therefore any implementation of a social model of disability within a country such as the KSA will be constrained by national allocated budgets and resources.

Nevertheless, the KSA government and others around the world are making an effort to support people with disabilities to gain considerable and adequate equality (WHO, 2011a; 2011b; Al-Saif, 2008). Some experts, however, blame the commitment of government and politics as the ultimate barriers to realising social inclusion. Laurin-Bowie (2005) argued that current initiatives to combat poverty through international financial institutions and governments have not effectively evaluated the exclusion of people with disabilities from economic and social participation in the construction of policies. A systematic review of 97 epidemiological studies from low and middle-income studies showed that the majority of the studies (78 of 97, 80%) found a positive, statistically significant association between disability and economic poverty (Banks and

Pollack, 2014). It has been argued that a model of social and economic development has proven unsustainable and ineffective because the real barriers to inclusion are in the structure and implementation of policies and programmes, including the training of social workers (Al-Saif, 2008; Swain, 2004). As such, there have been calls for strategies to help governments and donor agencies to develop inclusive policy approaches (Laurin-Bowie, 2005).

However, in other countries such as the UK, there have been some legislative efforts to improve the quality of life of people with disabilities. The Education Act 1981 aimed to better integrate children with 'special needs' within the school and classroom setting. In 1991, the 'Disability Living Allowance' and the 'Disability Working Allowance' were introduced to help people with disabilities pay for the additional costs that people with disabilities incur (Doyle, 1996a; 1996b). Further, The *Disability Discrimination Act* 1995 made discrimination against people with disabilities illegal for the first time in the UK, thereby securing legal rights for people with disabilities (Zaidi and Burchardt, 2005). In 2000, the Disability Rights Commission was established to support people with disabilities.

The Disability Rights Commission seeks to establish a society where all people with disabilities can participate fully as equal citizens (Purdam *et al.* 2008). It provides education, employment, health and living, and services and transport support services and information. There are also some charities that exist which seek to aid people with disabilities, such as '*Scope*,' '*Mencap*,' '*Leonard Cheshire'*,' '*Motivation*,' '*The Children's Trust*,' '*Sue Ryder*,' and '*The Disabilities Trust*.' However, the way disability issues such as social barriers are approached in low and middle-income countries may differ from the way such issues are approached in Western developed countries. Thus, the UK case is a testimony that though attaining full inclusion of the people with disabilities is complex, there is a possibility of attaining a considerable level of social inclusion. Therefore, the KSA can benchmark and adapt to successful national context, such as those applied in the UK, to improve the lives of her citizen with disabilities.

ENVIRONMENTAL FACTORS AFFECTING DISABILITY

As already established from the analysis of models associated with disability, disability is not inherent in persons but emerges from their interactions with society. The social model implies that the degree of disability a person experience emerges from the

extent of disabling conditions or limiting factors in the environment (Al-Gain and Al-Abdulwahab, 2002). That makes it crucial to examine some environmental factors that affect people with disabilities. This view is supported by the WHO, which has adopted the International Classification of Functioning, Disability, and Health (**ICF**). The ICF emphasises the role of the environment in enabling or disabling people with health conditions, thus indicating the significance of environmental factors for people with disabilities.

The implication of a focus on limiting factors in the environment is that eliminating them can create a better environment for people with disabilities. Seemingly, the WHO (2011a; WHO 2011b) believes that the environment can be changed to improve health conditions, to prevent impairments, and to improve long-term outcomes for people with disabilities. Al-Gain and Al-Abdulwahab (2002) suggest that willing countries can achieve such changes through policy changes, legislative changes, capacity building, or technological developments (e.g., built environment and accessible transport design, accessible health, rehabilitation, education, and support services). Perhaps, the KSA can also make a more significant effort in both policy and legislation change in making the environment less limiting.

Poverty and disability

Poverty is a limiting factor that significantly affects people with disabilities. A lack of resources or finances can adversely affect the ability of persons to function or acquire support or adoptive technology meant to improve their disabling condition (Mitra *et al.*, 2006; Braithwaite and Mont, 2009). In some contexts, poverty can limit an individual's access to appropriate rehabilitation that would minimise the impact of their disability or affect social opportunity such as employment because of the cost of specialised transport. There is also evidence that people with disabilities have worse educational and labour market outcomes than those without disabilities (WHO, 2011a; WHO 2011b). In addition to this, people with disabilities are more likely to be poorer and unemployed, in-part-time employment or on low-incomes (WHO, 2011a; WHO 2011b; Mitra *et al.*, 2013). Regarding children, the WHO (2011a; 2011b) reports that children with disabilities tend to have lower school attendance than those children without disabilities. Thus, in KSA where the majority of people have limited resources, people with disability face more difficulties owing to economic conditions.

Costs of disability

Cost of disability is important because it reflects the economic level explanation of disability expenditures or possible cost-effective approaches associated with disability programmes that countries apply to preserve equity and adequacy. Indeed, in most cases, the cost to sustain the personal needs of people with disabilities such as transport, health fees, or more, has a potential influence on their well-being (Hosking, 2008). However, the cost of disability differs relative to philosophies around disability. This is for several reasons, including varying definitions of disability, different data collection instruments, and different public programmes for disability (WHO, 2011a; 2011b). As such, Stapleton *et al.* (2006) noted that comprehensive estimates of the cost of disability are scarce and fragmented.

What is important to note though, is that disability expenditures create a significant part of the programmes and policies towards benefiting those with disabilities. Rubaii-Barrett and Wise (2008) argue that some programme costs are ameliorative because they provide payment as a form of income support or for medical care. On the contrary, corrective programmes apply when the intention is to assist the affected person with the ability to return to work or remove the disabling effects for them (Rubaii-Barrett and Wise, 2008). Nevertheless, the WHO (2011a; 2011b) notes that though the economic and social costs of disability are significant, they are difficult to quantify because they consist of direct and indirect costs, as well as costs borne by family and friends, employers, and by society (**Appendix 4**).

Quality of life and people with disabilities

Quality of life is an imperative factor when discussing disability because people with disability require health attributes that affect how they enjoy and maintain a good life. Nevertheless, a significant number of people with a disability face serious health issues. Almalki *et al.* (2012) reported that different underlying ailments, conditions, and types of impairment affect the quality of life of people with disability. Indeed, Hägg *et al.* (2010) interviewed 100 patients with chronic lower back pain that were due for surgery, 99 patients who have fibromyalgia, and 268 randomly selected adults from the general Swedish population. They found that persons with chronic lower back pain, whether surgical candidates or in the general population, suffered decreases in their

quality of life that were similar to patients with fibromyalgia (Hägg *et al.*, 2010). Similarly, Viemerö and Krause (1998) investigated the quality of life of 45 adults with severe physical disabilities from both Sweden and Finland. They found that satisfaction with one's life situation was a function of the person's occupation or meaningful occupational activities, social integration, and the individual's sense of the meaning of life (Viemerö and Krause, 1998).

Both Hägg *et al.* (2010), and Viemerö and Krause's (1998) studies critically reveal that different factors influence the quality of life that people with disability can lead. However, according to Hägg *et al.* (2010), the most significant is the severity of their depressive symptoms, which was most predictive of their quality of life. They argued so because their study results revealed that that where individuals are dealing with a condition, the severity of their depressive symptoms tended to indicate the quality of life they were leading (Hägg *et al.,* 2010). However, for Viemerö and Krause's (1998) study, the length of time since the onset of the disability was a risk factor for the person's feeling of satisfaction with the life they were leading (Viemerö and Krause, 1998). Thus, even in KSA, it is likely that depressive symptoms or one's life situation can be predictive of the quality of life that people with disability lead.

Apart from examining the quality of life of people with disability from both social and health aspects, some studies have focussed on health-related quality of life. For instance, Bennett *et al.* (2005) aimed to understand the impact of fibromyalgia pain on health-related quality of life for 313 men and women (ages 18-75 years) who suffered moderate-to-severe pain from fibromyalgia, before and after treatment with Tramadol/Acetaminophen. They found that moderate-to-severe fibromyalgia pain significantly impairs health-related quality of life and that effective pain relief in those patients significantly increased health-related quality of life (Bennett *et al.*, 2005).

Matarán-Peñarrocha (2011) undertook a longitudinal study of 104 individuals that had fibromyalgia to investigate the influence of craniosacral therapy on anxiety, depression, and quality of life in patients. The outcomes measured included the state anxiety, trait anxiety, pain, quality of life, and Pittsburgh sleep index quality levels (Matarán-Peñarrocha, 2011). They concluded that approaching fibromyalgia using craniosacral therapy contributes to improving anxiety and quality of life levels in studied patients. Thus, conditions causing pain can significantly influence the quality of life of people with disability. Conditions such as fibromyalgia can cause people to suffer a vicious cycle of pain, poor sleep, fatigue, and increased pain in overt fibromyalgia (Shaver *et*

al., 1997), which affects their health-related quality of life. Nevertheless, approaching these painful conditions with effective pain relief or therapy methods can contribute towards improving the quality of life of people living with a disability (Matarán-Peñarrocha, 2011; Bennett *et al.*, 2005). As such, the health conditions of people with disability in KSA can be a determinant of the quality of life level, which can be improved by applying effective pain-relieving approaches to uplift their health-quality of life.

It is important to note that an individual's capacity to cope with everyday life and occupation, meaningful occupational activities, as well as social integration at different stage of life, were factors to take into account when planning intervention programmes (Hägg *et al.,* 2010; Bennett *et al.*, 2005; Viemerö and Krause, 1998). The research studies related to the quality of life analysed above reveal that some physical intervention can often help to alleviate pain and depression and that alleviating depression can help to increase the overall quality of life experienced. It would seem to be that if individuals with disabilities become depressed, then they subjectively experience an overall lower quality of life than would otherwise be the case. As such, the WHO (2011a; 2011b) argues that a public health approach to the prevention of health conditions associated with disability is vital to help to reduce the incidence of health conditions leading to disability. Three types of action can be taken: primary prevention; secondary prevention; and tertiary prevention.

Primary prevention consists of actions that may be taken to remove or avoid causes of a health problem in an individual or a population before they arise (e.g., health promotion and specific protection such as HIV education (WHO, 2011a; 2011b). Secondary prevention consists of actions that are taken to detect a health problem at an early stage, or creating a cure, or reducing or preventing the spread or reducing or preventing long-term effects (e.g., supporting women with intellectual disability to access breast cancer screening) (WHO, 2011a; 2011b). Finally, tertiary prevention consists of any actions taken to reduce the impact of a disease that is already established by restoring function and reducing disease-related complications (e.g., rehabilitation for children with musculoskeletal impairment) (WHO, 2011a; 2011b). In this way, public health policies have an increased probability of successfully combating and reducing the incidence of health conditions leading to disability, e.g., polio, leprosy, and trachoma.

Cultural beliefs and disability

Cultural and religious beliefs affect perceptions of disability around the world and the attitudes that society expresses to people with disability (Ravindran and Myers, 2012). Choruma (2007) indicated that negative attitudes fostered by cultural beliefs toward people with disabilities are still prevalent in Zimbabwe and across Africa. Snyder and Mitchell (2010) also explain that there is still a lot of misunderstanding and lack of knowledge in some communities about disabilities, there are cultural misgivings about disabilities, and disability is still an issue that is surrounded by myths. For example, people in Zimbabwe may view disability in a very different way compared with those in the UK or USA.

For example, Choruma (2007) reported that the Zimbabwe community had negative beliefs on the causes of disability including associating disability with witchcraft or maternal promiscuity and curses. Snyder and Mitchell (2010) add that communities view the birth of a child with a disability as a taboo that is likely to bring bad omen to the family and the fathers of such children would usually blame the disability on the mother. As such, it means that disabled people experience limited social acceptance by the community and families.

Such negative beliefs toward people with disabilities hinder efforts to remove barriers. Al-Gain and Al-Abdulwahab (2002) argue that where culture is negative about those with disabilities, the social amenities are often not structured in a way that is inclusive for people with disabilities. According to Choruma (2007, p.8), "Society's attitude towards people with disabilities reflects a view that people with disabilities are useless liabilities who have no role to play in society." Once a society considers people with disabilities as a liability, then addressing their considerable needs will not be a priority.

Though traditions are the natural source of cultural beliefs, some modern sources are also significantly contributing to the negative culture experiences for people with disability. A UN investigation in Africa observed that factors that could contribute to the formation and perpetuation of negative beliefs about disability included misconceptions or social constructions regarding the causes of disability, ill-informed and insensitive coverage by the media that perpetuates negative views, reinforcement of prejudice and fears through policies and laws that might reinforce harmful beliefs (UN, n.d.). The UN also noted that in general, a lack of understanding and awareness about disability could perpetuate negative beliefs (UN, n.d.).

Some of the negative cultural perpetuations against people with disability include causes of childhood disability such as 'sin' or 'promiscuity' of the mother, an ancestral curse, and demonic possession (Al-Gain and Al-Abdulwahab, 2002). Other supposed causes of disability included ancestral violations of societal norms, offences against the gods and land, witches and wizards, adultery, bad spirits, and a curse from God (Snyder and Mitchell, 2010). These may support ongoing discrimination. For example, people with a disability cannot work or learn but only beg (Ravindra and Myers, 2012).

As can be seen, predominant cultural and religious beliefs may often strongly affect overall perceptions of disability within a particular country or context. The harmful beliefs about disability result in some consequences including stigma, discrimination, and physical and sexual violence and other abuses (UN, n.d.). The UN recommended some measures to combat harmful beliefs, including empowering people with disabilities, developing community-based sensitisation and education campaigns, strengthening documentation and reporting, and undertaking law and policy reform efforts to combat stigma (UN, n.d.).

Cultural beliefs and perceptions of disability in the KSA

Some studies and publications indicate the effect of culture on people with disabilities in the KSA. For example, Al-Jadid's (2013) study observed that many people with disabilities in the KSA suffer from some marginalisation. Some of the reasons included lack of understanding of the nature of the disability, fear of dealing with disability, being ashamed of the involvement with their community, lack of understanding of ways of dealing with such cases, and ignorance of the role assigned to health facilities. Al-Aoufi *et al.* (2012) raise the conservative nature of society in the KSA as a contributing factor to these views continuing. Indeed, conservatism is common in smaller rural villages, towns, and provinces, where Bedouin influences may still dominate (Madhi and Barrientos, 2003).

Another factor is the top-down approach to national development, stemming from the KSA collectivist culture (Al-Jadid 2013). Al-Gain and Al-Abdulwahab (2002) suggest that the KSA society is strongly guided by the views and actions of the government and change and reform will only occur if dictated or commanded by the government. Whereas in certain developed countries such as the UK where there are a large

number of public demonstrations, and freedom of expression and equality movements (facilitating bottom-up cultural changes), this is not the case in the KSA (Al-Jadid 2014). Al-Gain and Al-Abdulwahab (2002) assert that close-knit family nature of society in the KSA translates to large extended families, often living under one household, and there often being less focus on the importance of individual independence and autonomy. Thus, having bottom-up cultural changes that may benefit the disabled is highly unlikely. Existing cultural and Islamic perspectives on disabilities are also crucial factors contributing to limiting perceptions of the disabled. Culture, religion and the factors above directly interact to protect the status quo that exists for people with disabilities in the KSA (Al-Jadid 2013; Al-Aoufi *et al.*, 2012).

This approach towards people with disabilities appears to extend into some organisations' culture, specifically, those in the field of disability. Al Thani (2007) noted that there is often a lack of transparency in organisations working within the field of disability. For example, the King Salman Center for Disability Research (**PSCDR**) is one of the main organisations in the KSA working in this area. It aims to be a recognised centre of excellence in disability research with global impact and to improve the quality of life for the disabled through research. However, in its current research listings, none of the research areas covers anything to do with compiling disability statistics – something vitally needed in the KSA.

Thus, the PSCDR research listing appears likely to extend the existing status quo because it does not show any effort to identify the affected population, commonly experienced issues, and causes as a way towards improving their quality of life. PSCDR also lacks public transparency since annual reports ceased to be published after 2008. This calls into question the accountability of the PSCDR. In the KSA, cultural issues are more complex for women with a disability because of the gender issues that are rampant in the Arab community (Hamdan, 2015). Al Thani (2007) makes some alarming comments about Arab community as relates to disability:

> The general condition of persons with disabilities in Arab societies is invisibility. In particular, persons with intellectual, developmental, or psychosocial disabilities are considered as a source of shame and a burden on their families. Nevertheless, none more so, than women with disabilities. If women with disabilities in other parts of the world suffer double discrimination, once based on gender and again on their disability, then it is safe to say, if such a thing is possible, that women with disabilities in the

Arab region suffer triple discrimination… Persons with disabilities are a source of shame, a financial burden, even sees as a curse on their families; the words used to describe or denote disability are derogatory and pejorative; people are often identified by their disability, or their disability replaces their given name (Al Thani, 2007).

In this context, it is not surprising that there are very few programmes targeting women with disabilities specifically. In communities where a woman's status is dependent on concepts such as "a good marriage," "a good wife," and "a good mother", women with disabilities do not stand a chance (Hamdan, 2015, p.33). Instead, they are likely to suffer violence and sexual abuse, without access to rehabilitation, education, accessibility, or any number of services available to men with disabilities (Al Thani, 2007).

Islam, religion, and disability

The concepts of disability and inclusion are culturally constructed such that they need to be understood within the particular context (Hassanein, 2015). That implies that when discussing Islam, religion, and disability, it is important to understand what Islam means for Muslims. Islam (submission to the will of Allah) is not simply a moral philosophy of life or a system of belief, but a way of life for Muslims (Al-Aoufi *et al.*, 2012; Hassanein, 2015). Consequently, the treatment of disabled people in Islamic societies is strongly linked to the five pillars of Islam. These are: the Shahada (i.e. declaration of faith that Allah is God and Muhammad is the Messenger of God); the Salat (i.e. the five daily prayers); fasting (i.e. during the month of Ramadan); Zakat (i.e. annual alms tax of 2.5% of one's wealth); and Hajj (i.e. pilgrimage to Mecca during the Muslim's lifetime) (Hassanein, 2015).

Adherence to the five pillars depends on each person's ability (e.g., prayer may be modified if a person is physically unable to pray due to disability) (Hassanein, 2015). This suggests that Islam recognises the challenges of people with disability and accommodates them. According to Al-Aoufi *et al.* (2012), Islamic philosophy has a positive attitude towards needy individuals, and the Qur'an and the Hadith provide principles and practical suggestions for caring for people with disabilities. Islam, in general, gives a great deal of attention to all groups within society, with each having their rights, including people with disabilities (Hassanein, 2015; Al-Aoufi *et al.*, 2012).

Significantly, the word "disability" cannot be found within the Qur'an or Hadiths (religious texts of Islam). Nevertheless, the Qur'an illustrates society's civic responsibility to care for people with disabilities and for improving the conditions in which they live, which are believed to be a result of barriers produced by society (Al-Aoufi *et al.*, 2012). They also note that the Sunnah supports the notion of social responsibility towards individuals, and they provide two Hadith in support of this (Al-Aoufi *et al.*, 2012). 'Sunnah,' in Islam comprise of the teachings, actions, sayings (*hadith*), virtues, opinions, and ways of life of the Prophet Mohammed (PBUH), which are the second source of Sharia Law after the Qur'an (Hassanein, 2015).

Thus, religious texts of Islam bear generic terms that have been used (*Al-Daeīf*, the weak; *Aṣhāb al-aāhāt*, people with impairments or defects; *Ahl al-balāa*, people of affliction; *Aṣhāb al-aadhār*, people with excuses) (Al-Aoufi *et al.*, 2012). The most common Arabic equivalents used for disability now are *iaāqa*, *awaq*, and *tawīq* (Hassanein, 2015). Although the word disability is not explicitly mentioned in the Qur'an, Hassanein (2015) explains that the Muslim holy books demand that human life is to be valued within Islam and every Muslim regardless of their abilities or disabilities should be regarded as valued members of the community. He notes that ten Ayat of the Qur'an indicates that people with disabilities are to be treated with full regard, and they are to have the same person-to-person relations granted to non-disabled people (Hassanein, 2015).

The Qur'an refers to 'weak-minded' which is a generic term that could include mentally disabled and mentally ill individuals. More specifically, the Qur'an sets out an idea of 'guardianship' of disadvantaged individuals, out of a sense of duty, fairness, and kindness (Al-Aoufi *et al.*, 2012). This includes social responsibilities and duties to provide disadvantaged individuals with their basic needs such as food, safety, care, and shelter (Al-Aoufi *et al.*, 2012). The Qur'an is also concerned with distributive justice and requires Muslims to give a small percentage of their income to charity or Zakat, to which people with disabilities are considered as having a rightful share (Al-Aoufi *et al.*, 2012). Thus, the Muslim religion does offer a caring framework for the disabled by setting out the requirements for those in Islam.

However, the charitable response that is fostered in Islamic tradition has been criticised by those who believe that the approach may lead to a paternalistic view of disability that may discourage self-motivation amongst individuals with disabilities (Oliver and Barnes, 1998). Nevertheless, Hagrass (2006) argues that this view of disability in

Islamic countries is appropriate because it encourages a sense of social responsibility. While the teaching of the Qur'an, the Sunnah, and the Hadith indicate tolerance and acceptance of people with disabilities, This teaching may often not influence cultural attitudes and beliefs.

Hasnain *et al.* (2008) noted that Muslim families with children with disabilities might often encounter a range of attitudes ranging from pity to downright hostility and fear. They note that some families had forbidden their children from playing with other children with disabilities, and some parents had been asked if they were scared of their child's unpredictability resulting from a disability. Indeed, Al Thani (2007) also comments that cultural factors can both limit and facilitate attitudinal factors that affect the life of Muslims with disabilities. That is, for some Muslim families, a prevailing culture of social 'inclusiveness' will mean that children and family members with disabilities are included regarding education, employment, and community living decisions (Hasnain *et al.*, 2008). However, in some Muslim countries, children with disabilities may miss attending school (Hasnain *et al.*, 2008).

Disability in some Muslim countries has also been seen to have some moral or religious significance (Al-Aoufi *et al.*, 2012). For instance, it is observed that some cultures view disability as a blessing while others view it as a curse or a test of faith under the will of Allah. Al-Aoufi *et al.* (2012) therefore believe that when cultural perspectives are mixed with religious values, this can sometimes lead to a number of different courses of action, which in turn may be falsely attributed to religious faith, e.g., embarrassment at having a child with a disability, attempting to explain the cause of disability, and looking for fast solutions.

Blanks and Smith (2009) have argued that Islamic law and the Qu'ran explicitly call for the inclusion of people with disabilities in social life, and accommodations should be offered to make their participation in religious life possible to the greatest extent possible. They also argue that special educators have a responsibility to inquire about and consider ways in which faith traditions influence the beliefs, feelings, and behaviours of individuals with developmental and intellectual disabilities (Blanks and Smith, 2009). Similarly, Bazna and Hatab (2005) argue that the Qur'an emphasises the notion of a Muslim society rectifying inequality by recognising the plight of the disadvantaged and improving their conditions. Consequently, the way Islam and culture influence perceptions of disability is highly complex and nuanced, and perhaps significantly shaped by national cultures, and the particular local context within which

people with disabilities live. Therefore, consideration of the perception of disability in Islam is imperative when discussing or reviewing special education policies, facilities, or services.

Blanks and Smith (2009) also note that Islamic law and the Qu'ran explicitly provide for the inclusion of people with disabilities in social life via emphatic denials of ideas about contagion or pollution associated with disability. It is also stated that accommodations may be offered to people with disabilities to allow their participation in religious life to the greatest extent possible (Blanks and Smith, 2009). There are also links between religion and healing that have been noted in Islamic teachings. For example, Ghaly (2008) believes that Muslim law writers have spoken of both physical and spiritual means of treating disabilities.

Early jurists gave a general preference to the spiritual treatment of disabilities whereas modern jurists prefer the physical treatment of disabilities (Ghaly, 2008). Ghaly (2008) notes that under Muslim religious scholarship, *'Al-tibb al rûhânî'* (spiritual medicine) has two meanings. The first is what has been referred to as 'medicine of the heart,' which refers to managing, maintaining, and healing a person's spirit, soul, or heart. Ghaly (2008) remarks that for Muslim scholars this type of medicine can only be provided by the Messengers of God and it is only through their teachings that it can be obtained.

The second meaning is that spiritual means are used rather than physical means to combat and cure diseases (Ghaly, 2008). Ghaly (2008) explains that under Islam prayers and religious formulae are covered by the broad Arabic term *'ta'wîdh'* which means guaranteeing a refuge, protection, or preservation. Under this term, three spiritual medicines can be applied. These are *ruqya*, *tamîma*, and *nushra*. In essence, *ruqya* means spiritual medicine based on spoken language such as prayer, *tamîma* means spiritual medicine based on writings and written documents, and *nushra* means spiritual medicine based on the use of water to wash and cleanse written materials.

BARRIERS AND PEOPLE WITH DISABILITY IN THE KSA

The debate about the barriers facing people with disabilities indicated how relations or interaction with society could disable or empower individuals. Since barriers directly

link with the community or society, they are different from one country to another. It is imperative to focus now on barriers related to the context of this study in the KSA.

Saudi disability services

The literature shows that services offered to people with disability in KSA have a significant impact on their life. The services include both health and social services and have a substantive influence on the routine life of people with disability in KSA (Al-Jadid, 2014; Aleisa *et al.,* 2014). Al-Jadid (2014) posits that the KSA government has established several disability services, but most of these services only offer medical and therapeutic services within the existing health care system. Seemingly, Aleisa *et al.* (2014) argue that the government has claimed to be making the access to higher education for people with disabilities an integral part of its educational policies and developments.

However, many people with physical disabilities still face difficulties in attending higher education, including problems related to accessing buildings, using the transport system and financial support (Al-Jadid, 2014). Aleisa *et al.* (2014) observe that rehabilitation covers a wide range of activities that include rehabilitative medical care, physical, psychological, speech, and occupational therapy and support services. It has been suggested that people with disabilities in KSA should have access to both general medical care and appropriate rehabilitation services, but physical barriers such as lack of suitable public transport impact upon access to services (Al-Gain and Al-Abdulwahab, 2002).

Rehabilitation is provided to enable people with health conditions experiencing or likely to experience disability, to achieve and maintain good functioning and interaction with the environment (Aleisa *et al*., 2014). Aleisa *et al.* (2014) noted that the King Khalid University Hospital and the King Abdul-Aziz University Hospital are the two major rehabilitation service providers in Riyadh. There are also other hospitals such as Sultan Bin Abdulaziz Humanitarian City and King Fahad Medical City (Aleisa *et al*., 2014). However, Al-Jadid (2014) complains that although the MoH compiles medical statistics for its annual reports, there are no regular and reliable reports on the distribution of people with disabilities in such facilities (even though this could be done).

In addition, the rehabilitation statistics do not show the types of cases and treatment by rehabilitation specialists, they do not show how patients are referred for

rehabilitation, the selection criteria, what factors may influence the number of patients treated, the number of visits, or the therapist/patient ratio (Aleisa *et al.*, 2014). Consequently, for a country that believes itself to be progressive, it can be argued that it is less developed than it might be regarding public rehabilitation statistics and information. These types of statistics and information are vital to develop effective social inclusion policies for people with disabilities in the KSA.

Moreover, the disability services offered in the KSA appear to face some structural and resource-based challenges. Almalki *et al.* (2012) argue that the KSA has limited staff training programmes and disability campaigns for the country to improve the lives of people with disabilities. Similarly, Aleisa *et al.* (2014) notes the weaknesses of KKUH as including a lack of established patient safety standards; limited capacity; minimum level staff qualifications; limited communication between rehabilitation staff and other departments; limited and/or undefined rehabilitation research; a weak IT system; weak administrative and organisational environment; and limited financial incentives for staff. As can be seen, if these are the weakness of one of the major hospitals in Riyadh, one can imagine what problems and standards exist at smaller hospitals in smaller cities and rural provinces in the KSA.

Education and people with disabilities

Another important theme emerging from the literature is education. Education for people living with a disability is highly emphasised as an important empowering tool. For example, the WHO (2011a; 2011b) suggests that Higher education and qualifications can help people with disabilities to secure employment, and can lead to higher levels of social inclusion. However, it is notable that there are no universally agreed concepts of inclusive education and special needs education (Al-Saif, 2008; Choruma, 2007). There are two common models of inclusive education. A general model of inclusive education, which focuses on adhering to the 'least restrictive environment' where individuals are educated regardless of the settings or adaptations required (WHO, 2011a; 2011b). Alternatively, there is a model with a stricter sense of inclusion that adheres to the notion that all individuals with disabilities should be educated with their peers in normal classrooms (Al-Jadid, 2013; WHO, 2011a; WHO 2011b).

In the KSA, the central government manages the education system through the activities of the Ministry of Education (**MoE**). Currently, the total number of Higher Education institutions in KSA has reached 28, with 21 public universities and 7 private universities (Hamdan, 2015). Among these higher education institutions, some institutes exist, which are managed by the MoE through its regional government sectors. The requirement for educational services is vital for people with disability to improve their enrolment and engagement in the higher education system (Al-Jadid, 2013). This important service often cuts across all age groups irrespective of type, level, and goal of educational services.

Al-Ajmi (2006) suggests that younger people with a physical disability have different goals and often require different degrees of support to succeed in the higher education environment of KSA. Gender should also be considered when performing a needs assessment because of the important role of gender in a Muslim community. Unfortunately, there is a lack of statistics and information on the distribution and availability of such educational services. The KSA relies on special education services in the effort to assist people with disabilities to attend and acquire high education training, which has characteristics of inclusive education (Alquraini, 2010).

The WHO (2011a; 2011b) claims that inclusive education means identifying and removing barriers, providing reasonable accommodation, and enabling every learner to participate and achieve within mainstream settings. The MoE supervises the Special Education Department (**SED**) that specialises in the care and education of people with disabilities. The SED implements the care and education under three programmes: the Education of Blind Students, the Education of Deaf Students, and the Education of Retarded Students. However, there are still areas of these special services that have a negative impact on people with disabilities. Alsaif (2008) reported that students with disabilities often share classrooms with their peers during elementary school and middle school.

They also participate in non-curricular activities with non-disabled students during this time (Al-Ajmi, 2006). Unfortunately, most of the disabled students have limited opportunity to advance their education beyond high school. The exception to this is when they attend vocational training institutes, which are special education centres that bring about the challenging environment (Alsaif, 2008). Although these centres are targeted at providing people with disabilities with the skills and support needed for independent living, it often results in significant segregation (Al-Ajmi, 2006).

Segregation limits the ability of such students to interact with their peers. Moreover, these training centres are located in places where students have little interaction with their family and friends (Alsaif, 2008).

In addition, Alquraini (2010) indicates that the disabled students receive separate education programs from the general curriculum, which are developed from the special education curriculum by the MOE. The modified curriculum often fails to meet the individual needs of the students because they receive training based on a general curriculum for people with disabilities (Alquraini, 2010). Finally, some private schools provide related services in a more inclusive environment but lack important services such as physical therapists that should enable the physically disabled student to benefit from the special education training (Al-Ajmi, 2006). In summary, the educational setting of special services for disabled students often fails to recognise their human rights and the importance of social inclusion for disabled students.

Mobility

Mobility of people with physical disabilities is also highly debated in KSA. In particular, mobility is a significant topic in the social model of disability debate, which focuses on challenging and removing barriers that may prevent people with disabilities from living full and active lives (Aiden and McCarthey, 2014). Mobility addresses physical barriers relating to people with disability such as inaccessible buildings and a lack of accessible transportation. Ungar (2017) believes that the built environment is probably the most potent symbol of the exclusion of people with disabilities from society.

In the KSA, Article 3 of the Disability Convention addresses mobility under 'accessibility' as a general principle. Article 9 of the Disability Convention aims to put in place accessibility provisions that are orientated towards enabling persons with disabilities to live independently and to participate fully in all aspects of life. However as noted by Ungar (2017), barriers to mobility for wheelchair users can often be quite varied in practice, and this makes it difficult to adequately address mobility issues for particular areas, cities, or countries. Article 9(1) specifies that States Parties are required to take appropriate measures to ensure that people with disabilities can access the physical environment on an equal basis with others.

It also specifies that they are required to take appropriate measures to ensure that people with disabilities are also able to access transportation, information, and communications (including information and communications technologies), and other facilities and services open or provided to the public (in both urban and rural areas). Despite Articles 3 and 9, and efforts to increase accessibility (mobility), there are environmental barriers, which impede mobility mainly in urban areas. These include barriers such as uneven paving slabs, narrow pavements, rough or cobbled surfaces, congested pavements, steep gradients, or ramps, high kerbs and/or lack of dropped kerbs (Ungar, 2017).

Article 9 measures apply to buildings, roads, transportation, and other indoor and outdoor facilities, including schools, housing, medical facilities, and workplaces. Al-Jadid (2013) noted that people with disabilities in the KSA still experience challenges with mobility on the streets as well as accessibility problems when in buildings or rural areas. Nevertheless, Madhi and Barrientos (2003) suggest that there are also challenges related to roads such as street furniture that has been poorly placed and therefore restricts access, deep gutters along the roadside impeding crossing, busy roads, raised utility hole covers at road-crossing points, and insufficient designated road-crossing places. Consequently, because of the difficulty of travelling and access to rehabilitation services, people with disabilities lead restricted professional and social lives, with little opportunity for social inclusion, thereby leading to social isolation (WHO, 2011a; 2011b). Moreover, these effects may be economic, social, cultural, and political.

Article 9 also specifies that State Parties be required to take appropriate measures stated previously relating to the development of minimum standards and guidelines. One of the difficulties with this requirement is that it is very difficult to identify what kind of measures that the government in the KSA has to put into place to ensure that it has fulfilled its obligations under the Disability Convention. For instance, Al-Jadid (2013) argues that counters in banks and post offices have been designed for the height of a standing adult and this makes it impossible for people in wheelchairs to be served on an equal basis in the KSA.

According to Alsaif's (2008) study problems relating to mobility or access such as the height of fixtures (e.g., lift buttons, cash machines, telephones, door handles) remain a barrier for people in wheelchairs. Hamdan (2015) observes that toilets are also a major concern. Similarly, Alsaif (2008) claims there are extremely few public transport

vehicles with wide aisles, flat entrances, or dedicated wheelchair space. Thus, even though the Disability Convention states obligations owed to people with disabilities, the implementation of the measures has not been effective.

Regarding personal mobility, Article 20 of the Disability Convention sets out that State Parties should establish effective measures that ensure personal mobility with the greatest possible independence for persons with disabilities. This includes taking effective measures relating to mobility, costs, mobility aids, devices, assistive technologies, forms of live assistance, and training in mobility skills. While the aims and objectives of the independent living movement are worthwhile, it is also essential to note the socioeconomic status of the country in which a person with disabilities lives, and other relevant cultural factors as well. For example, the focus of the independent living movement is on independent living, but in the KSA, there is a predominant collectivist culture which means extended family cohabitation arrangements are very common, i.e., all the family living under one roof. In this type of situation, the objectives of the independent living movement may not fit well with the lifestyles of some people with disabilities in the KSA.

DISABILITY AND GENDER

The literature makes it clear that gender issues affect people with disability. Meekosha (2004, p.3) argues that people with disabilities "have often been represented as *without gender*, as *asexual* creatures, as freaks of nature, monstrous, the 'Other' to the social norm." Asfar *et al.* (2007) also assert that the image of disability may be intensified by gender, for example for women a sense of intensified passivity and helplessness. Meekosha (2004, p.4) believes that these images may have consequences for women with disabilities regarding "education, employment, living arrangements, and personal relationships, victimisation, and abuse that then, in turn, reinforce the images in the public sphere."

According to Meekosha (2004), gendered studies of disability in Western countries show clear patterns in public and private arenas that women with disabilities fare less well than men with disabilities. For example, in the public arena, it has been identified that more women than men are classified as disabled, women with disabilities are more likely to live in poverty, and younger women with disabilities achieve lower educational outcomes than men (Rousso, 2003). Hamdan (2015) also reported that women with

disabilities are less likely to have access to rehabilitation and are more likely to experience degenerative conditions. Regarding employment, Meekosha (2004) suggests that women with disabilities are less likely to be in the paid workforce compared with men with disabilities, and overall they have lower incomes from employment. Rousso (2003) reported that poverty is also linked with a disability because women and girls with disabilities are more likely than males to be deprived of necessities such as food and medicine.

Rousso (2003) adds that women with disabilities are more likely to be divorced and less likely to marry compared to men with disabilities. They are also more likely to face medical interventions to control their fertility, and they are more likely to experience sexual violence in relationships and institutions (Meekosha, 2004). They are more likely to be living on their own, or in their parental family compared with men with disabilities, and experience more extreme social categorisation than men experience with disabilities experience. Thus, women with disability face more barriers compared with men.

A report by UN Women (2015, p.1) states "For far too long, women and girls with disabilities have been invisible, both to the advocates of women's rights and of disability rights, and this has increased their vulnerability." The report notes that the global literacy rate is as low as 3% for all adults with disabilities, and 1% for women with disabilities (UN Women, 2015). Stapleton *et al.*'s (2006) study indicated that men with disabilities are almost twice as likely to be employed as women with disabilities and that women and girls with disabilities experience higher rates of gender-based violence, sexual abuse, neglect, maltreatment, and exploitation, than women and girls without disabilities.

Rousso (2003) argues that gender patterns about disability indicate that women with disabilities are more vulnerable to domestic violence, are more likely to find their access to education more limited, and are likely to have few if any social supports or options if sexually abused. Asfar *et al.* (2007) add that in the Middle East, girls with disabilities also face numerous barriers to gaining access to primary and secondary schools, such as attitudinal barriers (gender bias compounded by disability bias), transportation barriers, and architectural barriers.

Similarly, Rousso (2003) states that widespread cultural biases based on gender and disability have led to a greater limitation of educational opportunities for women with

disabilities. Women and girls with disabilities are three times more likely to experience gender-based violence compared to women without disabilities (UN Women, 2015). Rousso (2003, p.2) continues to say "Those committed to gender equity, by failing to consider disability, and those committed to disability equity, by failing to consider gender, have unwittingly rendered disabled girls invisible."

There is a dearth of policies and programmes that focus on the education needs of females with disabilities. In the KSA, the gender issue becomes more critical to women with disabilities because of the cultural practices that motivate gender inequality. The UN Women (2015) report recommends increasing the leadership and participation in decision-making of women and girls with disabilities and identifying key factors, strategies, or approaches that might be shared to establish equality. It further advocates for increased cooperation, partnerships, and synergies between entities and organisations of women and girls with disabilities, to provide sustained and sustainable support for the empowerment of women with disabilities (UN Women, 2015).

However, Sheldon (2014) explains that the marginalisation of women with disabilities has led to research that has borrowed heavily from feminist scholarship and insisted on the primacy of personal experience. Sheldon (2014) notes that this trend has often been criticised (e.g. Finkelstein, 1996), because it may hamper the development of the faction of people with disabilities. However, Sheldon (2014) argues that it is not enough for women from oppressed groups to simply argue for equal rights with men, because women without disabilities are still unequal. Consequently, women with disabilities also need to challenge societal structures that create and perpetuate disability and other forms of oppression (Sheldon, 2014). Sheldon (2014, p.75) concludes that:

> To eliminate all kinds of oppression, we need to transform society…The Key to all our liberation is unity among oppressed people. Rather than 'competing for "our" piece of a reduced pie … what we need to do is demand a transformation that delivers a different pie – one big enough for all of us'.

LEARNING FROM ELSEWHERE AND POLICY TRANSFER

It can be argued that developed countries such as the UK and the US have implemented more advanced regulatory and supportive frameworks for people with disabilities. Therefore, this does raise the question of whether the government in the

KSA and government institutions might be able to take policy developments and learning from elsewhere (e.g., the WHO, the Council of Europe) to adapt existing disability frameworks. Traditional attempts to explain policy change have focused on domestic factors (e.g., the role of political institutions, partisan structures, socioeconomic conditions) (Bender *et al.*, 2014).

Bender *et al.* (2014) believe that policy change can also be attributed to international influences and interdependencies (e.g., international policy networks, supranational institutions, global development partners, and other 'soft governance' processes). Dolowitz and Marsh (2000, p.5) further explain policy transfer as "the process, by which knowledge about policies, administrative arrangements, institutions and ideas in one political system (past or present) is used in the development of policies administrative arrangements, institutions and ideas in another political system." As noted by Park *et al.* (2017), public policies, in general, suffer from complexity, uncertainty, and lack of feedback throughout the policy process. Consequently, transferred policies may often become distorted owing to lack of adaptation to context (Park *et al.*, 2017).

It is therefore essential that the basis of policy change and policy transfer is understood, in order to ensure that policy recommendations rest not only on knowledge of what works in developed Western countries, but also of how components of these policies could be adapted to the context within the KSA. Hall (1993, p.278) identifies three variables in the policymaking process: "…the overarching goals that guide policy in a particular field, the techniques or policy instruments used to attain those goals, and the precise settings of these instruments." Hall (1993) also identified three orders of change, which were first order change, second-order change, and third order change.

In first order change, the focus is on changing instrument settings in light of new knowledge and experience, although the overall goals and policy instruments remain the same (Hall, 1993). In second-order change, the instruments of policy in addition to their settings are changed, in response to previous experience, although the overall goals of policy remain the same (Hall, 1993). Finally, in third order change, there are simultaneous changes in the policy instrument settings, the policy instruments, and the hierarchy of goals behind policy (Hall, 1993).

When applied within the context of the KSA, it may be that the KSA has experienced first order change through the introduction of the Disability Convention into national

legislation. Therefore, the overall policy framework is already in place in the KSA. However, as has been seen over time, this overall policy framework has been scrutinised, and it can be seen that there are still elements of the policy framework that are not functioning correctly or could be improved to ensure that the overall goals of policy are achieved in the long term. Consequently, within the KSA it would seem to be the case that it is the second-order change that is now required. It is likely the case that third order change will come in time in order to bring about an approach to disability that better reflects the social model of disability, rather than the medical model of disability which currently exists in the KSA.

The socioeconomic status of a country is also important because the objectives that are set out by the Disability Convention have to be applied proportionately in practice. Along with religion and culture, how a country does this may vary according to the level of economic development. It is important to look beyond Gross Domestic Product (**GDP**) or GDP per capita, however, to broader issues that may have a more direct impact on people's experiences, such as health, work status, living conditions, command of material resources, and the subjective perception of those factors (i.e., quality of life').

For instance, although the KSA has high levels of national revenues from the sale of its vast reserves of oil, this may not provide an accurate assessment of the lives of people living in the KSA. It does not highlight that the bus and train systems in the KSA are not yet well developed. It does not highlight that the living conditions of people living in the KSA vary significantly depending on the particular area they are living, i.e., people living in rural areas have a lower overall quality of life than people living in cities or other developed urban areas. There are greater numbers of schools and hospitals in cities and developed urban areas than there are in rural areas and villages. In practice, developed countries may be able to provide higher levels of assistance than developing countries with smaller national budgets. In addition, levels of assistance provided may differ at regional and local levels.

STRENGTHS AND LIMITATIONS OF STUDIES IN THE LITERATURE REVIEW

Strengths

The variety of studies applied in this research offered important benefits to the current study. A significant number of the reviewed studies established their findings upon analysing samples of between 100 to 400 taken from the target population (Al-Jadid, 2014; Aleisa *et al.*, 2014; Al-Saif, 2008; Al-Hano, 2006; Hamdan, 2015; Al-Mawali, 2004). There was a balanced analysis between the experience of people with disability and society's wider views through the involvement of people with disabilities where the studies examined disability experience and non-disabled people where studies analysed society's views about disability (Corrigan and Watson, 2002; Al-Jadid, 2014; Madi, 2014; Alquraini, 2010).

A considerable number of the studies applied interviews in collecting data, which allowed the studies to document first-hand experience views of people with disability (Kavanagh *et al.*, 2015; Ramesh, 2010; Wally, 2009; Al-Saif, 2008; Al-Hano, 2006). Moreover, the interviews were primarily crucial because they allowed researchers to probe participants and seek clarification implying that their findings are non-fictional. Importantly, the studies covered broad participant demographics regarding disabilities that included different age categories including children, youth, and the elderly (Elsheikh and Alqurashi, 2013; Al-Aoufi *et al.,* 2012; Taylor and Hawley, 2010).

In addition, the studies analysed disability using a variety of perspectives mainly education, health conditions, employment, culture, social attitudes and behaviours, and barriers (Wally, 2009; Hamdan, 2015; Madhi and Barrientos, 2003). The wide approach crucially underpinned the effects of living with disability and the importance of social inclusion. Lastly, but not least, some of the studies apply theoretical models such as labeling theory, biomedical model of disability, and psychosocial models of disability to analyse social inclusion of people with disabilities (Taylor and Hawley, 2010; Buntinx and Schalock, 2010; Trifiletti *et al.*, 2005; Lave and March, 1993).

Limitations

There were also notable limitations in the reviewed studies which may affect how they contribute knowledge to the current study. The most significant limitation in the analysed studies was the scarcity of studies specific to the burden of disability in the KSA (Al-Jadid, 2014; Alquraini, 2010; Almalki *et al.*, 2012; Al Thani, 2007). Most of the studies that focused in the KSA mainly analysed a specific region such as Riyadh resulting in scarce, incomplete, and likely underestimation of the KSA national

incidence and prevalence of impairment and disability along with the social demographic characteristics of people with disabilities (Hartblay, 2017; Hasanzada, 2002; Hägg *et al.*, 2010).

Consequently, available studies in the KSA attempted to make inferences or facts from systematic reviews or data from administrative registries, which do not present the actual burden of disability in the KSA (Al-Jadid, 2013; Brown, 2010; Yanagita *et al.*, 2006). The paucity of studies on disability specific to KSA warranted the use of studies conducted in a sociocultural environment or economic status different from that of the KSA, which is mainly Islamic-based (Al-Aoufi *et al.,* 2012; Madans *et al.*, 2010; Abbott and McConkey, 2006; Grewal *et al.*, 2004). Lastly, some of the KSA studies on disability were decades old and therefore may not represent the current situation of disability in the KSA (Al Thani, 2007; Hamdan, 2015; Al-Gain and Al-Abdulwahab, 2002; Hasanzada, 2002).

CHAPTER SUMMARY

The chapter has carried out an analysis of different types of literature review that can be identified in practice. It has also set out the search procedure that was used to review the academic literature and the databases that were searched. After that the chapter has undertaken an analysis of disability, barriers, and social exclusions, as well as disability in the Western developed world. The chapter reviewed the role and influence of cultural and religious beliefs on perceptions of disability, as well as barriers and people with disabilities in the KSA, and disability and gender. The chapter also touched upon developing appropriate policies and standards as well as issues relating to policy transfer. It has identified a range of barriers that continue to exist for people with disabilities.

CHAPTER 3

REVIEW OF INTERNATIONAL STANDARDS AND POLICY IN THE KINGDOM OF SAUDI ARABIA

INTRODUCTION

Although the Kingdom of Saudi Arabia (**KSA**) has on paper ratified a number of international treaties relating to international human rights and disability, in practice the implementation of these at a national level has often been criticised (Amnesty, 2018). Although such criticisms have identified a range of problems that do exist, they do little to examine *why* such problems exist. Therefore, a comprehensive analysis of this area requires analysis of multiple layers of factors that contribute to the existing human rights and disability framework in the KSA.

This includes an analysis of the complex framework of laws and policies relating to healthcare and disability rights that has been developed in piecemeal fashion periodically. It also includes examination of the role and influence of cultural and religious beliefs on disability in the KSA, as well as politics and policy making in the KSA. In practice this means that understanding disability rights in the KSA is incredibly difficult, not only for those wishing to research and understand this area, but also for the thousands of people with disabilities across the whole of the KSA.

In order to develop such understanding, this chapter will discuss issues relating to the policy theories of historical institutionalism and implementation, as well as Islamic *Shari'ah*. Existing international standards relating to human rights and disability will be reviewed in the context of KSA (including the *International Covenant on Civil and Political Rights*, the *International Covenant on Economic, Social, and Cultural Rights*, and the *Convention on the Rights of People with Disabilities*). The chapter will also review disability legislation and policies in the KSA. It will be argued that while there have been considerable policy improvements for people with disabilities in KSA, and some movement towards an appreciation of the social as well as medical model of disability, these have been limited due to the particular cultural and religious context present in the KSA.

POLICY THEORIES

There are a number of policy theories which may help us to understand why the policy framework for people with disabilities in the KSA has not developed at the same pace as it has internationally, or as recommended in the conventions and frameworks of the United Nations (**UN**). Theoretical approaches such as policy diffusion at their most simplistic might be interpreted as suggesting that it is only a matter of time before developments and best practices cascade down to political units which have been slower to adopt the latest policy trends (Walker, 1969). However, policy change is frequently a much more complex process, which requires agency and taking domestic factors such as the political, cultural, religious, and social context into consideration.

Furthermore, even after policy change has been made, this does not mean that the implementation process is smooth and without unintended consequences. It has been observed that "institutions and policies have a tendency towards inertia; once particular paths have been forged, it requires a significant effort to divert them on to another course" (Greener, 2005, p.62). This section further investigates: historical institutionalism (Pierson, 1994); and implementation studies (Smith, 1973; Van Meter and Van Horn, 1975; DeGroff and Cargo, 2009; Rahmat, 2015), in order to try to understand why there has not been dramatic change in terms of disability policy in KSA and, in instances where there has been policy change, why this has not always been effective in achieving its goals.

Historical Institutionalism (Path Dependency)

Historical institutionalism has been referred to as a social science theory that focuses on the creation, persistence and change of institutions over time (Sorensen, 2015). It refers to a loose collection of writings by authors that have tended to mix elements of rationalistic and constructivist explanations (Immergut, 2006). The idea is that choices that are formed during the time of creation of an institution, or during the formulation of policy, can have a constraining effect in the future (Koelble, 1995; Peters, 2001; Greener, 2005). Historical institutionalist (**HI**) approaches to the understanding of institutions, path dependency, positive feedback effects in public policy, and patterned processes of institutional change can offer social sciences a robust theoretical framework for the analysis of continuity and change in public policy (Sorensen, 2015). Institutions have been defined to be the formal rules, compliance procedures, and

standard operating practices that can structure the relationship between individuals that exist in different units of polity and the economy (Thelen and Steinmo, 1992; Hall, 1993).

At a narrower level, institutions have been defined as collectively enforced expectations with regards to the behaviour of specific categories of actors, or to the performance of certain activities (Thelen and Steinmo, 1992). At a primary level the literature has identified that states continue down a particular path, in terms of policy choices, unless their trajectory is interrupted for some reason (Peters, 1999; Pierson; 1994). Policies also exist within a particular environment, which means that dramatic change can be difficult (Smith, 1973; Van Meter and Van Horn, 1975). It has been observed that developing country governments tends to formulate broad, sweeping policies, and governmental bureaucracies often lack the capacity required for practical implementation (Smith, 1973).

Consequently, while in practice there can be dramatic change, this is often an accident of timing and circumstance (Smith, 1973; Van Meter and Van Horn, 1975; Immergut, 2006). The term path dependence refers to the notion that, once established, some institutions tend to become increasingly difficult to change over time, and therefore small choices early on can have significant long-term impacts (Sorensen, 2015). The idea of path dependency leads to the claim that a suboptimal arrangement (i.e., a policy problem) can continue over time, because even though multiple possibilities initially existed, contingent events that led to one approach gaining an early lead and increasing returns to scale ensured continuing dominance (Sorensen, 2015). It has been observed that path-dependence has at its heart an economic bearing, because it was originally used to define why sub-optimal or inefficient technologies attain strong market positions (Davis, 2015). Prime examples of such path dependency include the 'QWERTY' keyboard and the 'VHS' versus 'Betamax' video formats (Sorensen, 2015).

In practice claims of path dependence must demonstrate that other alternatives are available, as well as explaining how the positive feedback effects generate continuity (Sorensen, 2015). Applied to the field of political and policy processes, this means identifying those who benefit from a particular institution, and who support continuation or will fight a change that will disadvantage them (Sorensen, 2015). It has been argued that there are four characteristics of political systems that make them even more subject to positive feedback effects than in economics (Pierson, 2004). These are: the central role of collective action; the high density of institutions; the possibilities for using

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political authority to enhance asymmetries of power; and its intrinsic complexity and opacity (Pierson 2004).

Models of path dependency may be able to provide a rigorous way to illustrate why history matters, and that these models are applicable under conditions that are quite common for a range of political phenomena (Pierson, 2000). However, there are inherent challenges that have been identified in the literature. One of these is the difficulty of explaining institutional change. In order to be able to explain institutional origins and development, a theory must account for institutional change and for institutional stability (Immergut, 2006).

It is noted that formulations such as 'punctuated equilibrium', 'critical junctures', and 'exogenous shocks' have been used to explain change, however they have been criticised for being incomplete, and not being able to fully convince as to what causes the switch from stability to instability (Immergut, 2006). Greener (2005) argues that we have a mechanism for change in a path-dependent system, and that this is located not in the cultural or structural spheres, nor in human agency, but in the interactions between all three. Viewed in this way, formulations such as punctuated equilibrium, critical junctures, and exogenous shocks should not each be seen to be the definitive model to explain change, but as possibilities when examining particular situations.

Consequently, although the KSA does follow a number of international standards, it may be the case that it does so to the extent that this fits in with what is acceptable within state institutions in the KSA. In this sense it may be guided to a great extent by religion and culture (including *Shari'ah* law), as well as the conservative nature of the Saudi state, for example, as illustrated by attitudes towards gender (discussed in the literature review chapter). This proposition will be explored further below. In practice, policy change may be only half the battle, as even after policies have been introduced, they will still need to be implemented.

IMPLEMENTATION OF POLICY

Implementation studies have for several decades been concerned with examining how policies are put into practice (Winter, 2006). The implementation of policy may cover the formulation of high-level political objectives which are translated into practical implementation goals such as primary and secondary legislation, policy

implementation committees, oversight committees, and operational projects (Winter, 2006). Studies have examined how these policies are implemented in practice at a national and local level, and the diverse range of stakeholders involved (Pressmen and Wildavsky, 1973; Kirst and Jung, 1982; Winter, 2006). The implementation of policy may also include a review of how effective policy implementation is over time.

The pioneers of policy implementation focused on what was called 'complexity of joint action' by showing how stakeholders (i.e. federal, regional, state, local government actors, interest groups, courts, private firms, media) had a role and stake in putting policy into practice (Pressman and Wildavsky, 1973). The top-down approach advocated the structuring of the implementation process from the very top of an objective (e.g. legislation) and followed the implementation process down the chain and through the system in order to minimise the number of decision points that could be vetoed (Mazmanian and Sabatier, 1981; Kirst and Jung, 1982; Sabatier, 1986).

Critics of this approach believed that it ignored the ability of policy opponents to interfere in the structuring process (Moe, 1989; Winter, 2006). In contrast, advocates of the bottom-up approach believed that it was the front-line workers that had the real power to shape policy because of their discretionary role in delivering services or enforcing regulations (Lipsky, 1980; Winter, 1986). In addition to evaluating the role of front-line workers, the bottom-up approach tended to undertake network analysis in order to map the informal, empirical implementation structure around a given problem to map the interaction between both public and private actors (Winter, 2006). Thereafter there were attempts to synthesise both perspectives with varying degrees of success (Hull and Hjern, 1987; Winter, 1990; Winter 1994).

Implementation studies are relevant to this thesis as they provide tools to analyse the implementation of disability policies in the KSA. Crucially, the top-down and bottom-up approaches allow us to critically analyse to what extent the formulation and implementation of disability policy in the KSA has been successful, as well as potentially providing a way to identify characteristics and stakeholders that may inhibit or restrict the effective implementation of disability policies in the KSA. This is essential if we are to analyse to what extent international human rights and disability conventions adopted in the KSA have the potential to shape policy and improve the conditions for thousands of people with disabilities in the KSA today.

THE ROLE OF ISLAMIC *SHARI'AH*

As noted in the literature review, the primary source of the divine law is said to be the Holy *Qur'ān*, and *Sunnah*. By studying the *Qur'ān* and the *Sunnah*, a number of basic socio-economic rights have been identified (Ayub, 2007). These include: the right to safety; the right to be informed; the right to choose; the right to be heard; the right to satisfaction of basic needs: the right to redress; the right to education; and the right to a healthy environment (Ayub, 2007). It is these fundamental rights that have been identified that are then required to be implemented through relevant and apposite government policies. For example, it has argued that:

> Islam requires rulers and various regulators in the system to protect the masses from harm and hardship caused by unscrupulous factors in society through strong and effective laws, and they should be respected in the sense of fulfilment of all socio-economic rights. The State must also curb institutional and other malpractices (Ayub, 2007, p.25).

In the Arab world there is no single approach to the embodiment of *Shari'ah*. Unlike Western legal systems which have long since separated canon and secular laws, *Shari'ah* principles still continue to constitute an important source of legislation in the majority of Arab countries (Al-Rimawi, 2011). *Shari'ah* as a constitutional source operates in a variety of ways. At one end of the spectrum it may be an overall constitutional source and the embodiment of the state, while at the other end it may have no constitutional role in some Arab countries (Al Rimawi, 2011). There is a variety of positions in between, including being the principal source of legislation. Consequently, as can be seen, that extent to which *Shari'ah* is embodied within a particular Arab country, many in turn significantly influence the prominence of *Shari'ah* from a constitutional perspective.

In this respect Vogel (2012) observes that *Shari'ah* holds a unique position in the KSA, as it is the constitution of the state, the sole formal source of political legitimacy, and the law of the land. This means it is the solitary source of binding norms for civil and private spheres, thereby shaping and justifying social, communal, and family mores, as well as individual morality (Vogel, 2012). It is "the central conception of the religion to which every Saudi citizen formally belongs, laying down the intricate rules of ritual practices, among them pilgrimage to the hold place which the Kingdom administers"

(Vogel, 2012, p.18). Article 1 of the Basic Law describes the role of *Shari'ah* in the KSA:

> The Kingdom of Saudi Arabia is a fully sovereign Arab Islamic State. Its religion shall be Islam and its constitution shall be the Book of God and the *Sunnah* (Traditions) of His Messenger, may God's blessings and peace be upon him (**PBUH**). Its language shall be Arabic and its capital shall be the city of Riyadh.

This commitment to *Shari'ah* can be contrasted to much watered-down or non-commitment to *Shari'ah* as a legislative source by other Arab constitutions (e.g. Algeria, Jordan, Lebanon, Libya, Morocco, Tunisia) (Al-Rimawi, 2011). In practice the KSA stands apart from other Muslim-majority countries in that it consciously preserves the Sunni constitutional system that has prevailed in most of the Muslim world for the last 1000 years (Vogel, 2012). The system is called *siyasashar'iyya* (governance in accordance with *Shari'ah*), which divides the finding and applying of law into two modes under the aegis of *Shari'ah* (Vogel, 2012). The first mode represents law as found by religious-legal scholars and then applied by them in religious-legal courts (Vogel, 2012). This is the *fiqh* or Islamic jurisprudence constituted by the opinions of scholars (Vogel, 2012). The second mode is that of laws and tribunals that obtain their authority from the ruler and the political establishment (Vogel, 2012).

The King exercises power, called *siyasa* (governance) delegated to him by *Shari'ah*, to make laws to serve the public interest (*maslaha*), subject only to the requirement that such laws do not contradict basic *Shari'ah* principles (Vogel, 2012). Law in the KSA derives from the opinions of scholars and the King appoints scholars to all judicial and fatwa-issuing positions (Vogel, 2012). However, owing to strong group loyalty and solidarity among scholars, this appointment power does not translate into control over the substance of the law (Vogel, 2012). Consequently, the basic common law remains outside the state's control and can be learned only from the study of pre-modern Hanbali treaties and modern Saudi juristic opinions (Vogel, 2012). It is observed that since *fiqh* encompasses the most basic rules governing business and investment, this places heavy burdens and costs on Saudi and foreign business (Vogel, 2012).

The embodiment of *Shari'ah* within the Saudi constitution has significant ramifications for the political system and human rights, rule of law, and civil society activists. Whereas other countries in the Middle East region have developed more

democratically-focused political and legal systems, the KSA has preserved the conservative *Shari'ah* law governed political and legal system. Because of the different Islamic Schools, *Shari'ah* principles in one Arab country may be very different to *Shari'ah* principles in another Arab country. At the same time any government reforms or the implementation of human rights frameworks must be undertaken in a way which upholds *Shari'ah* law. They will not be automatically transferred from the international sphere to the domestic sphere.

Therefore, ratifying and implementing international human rights frameworks has proved to be inherently complex and difficult in practice for the KSA. This is because any reforms must be developed nationally by a legal system that is governed by *Shari'ah* law, and implemented by *fiqh* scholars in a piecemeal way. In addition, unlike some other countries where human rights and disability reforms have been driven and promoted by human rights activists and disability activists, the conservative nature of the King and the Wahhabi scholarly establishment has translated into practice to historically suppress political activism in the country (Vogel, 2012). Consequently, analysing the implementation of international human rights and disability frameworks in the KSA is an inherently complex process that requires consideration of a vast array of different legal, religious, cultural, social, and socio-economic perspectives. In order to undertake such analysis, it is necessary to first understand the international human rights framework in place across the world.

INTERNATIONAL HUMAN RIGHTS AND DISABILITY

A framework of international treaties and conventions enacted around the world sets out human and disability rights. It is essential to understand this core framework as it allows us to benchmark the strength of a country's human rights and disability framework implemented nationally. On 10th December 1948 the UN General Assembly adopted the Universal Declaration of Human Rights (**UDHR**). This was intended to be universal in order to protect individuals from any type of violation and included the right to live in dignity; the right to liberty and security; the right to freedom of movement; the right to nationality and education; and the just treatment of human rights and respect; and economic, social and cultural rights (Fanack, 2018).

Although the Declaration was not legally binding, two binding UN covenants were formed because of it, namely the International Covenant on Civil and Political Rights (**ICCPR**), and the International Covenant on Economic, Social and Cultural Rights (**ICESCR**) (Fanack, 2018). Over time this body of international law has been ratified and implemented to varying degrees by countries around the world. However, disparities between international law frameworks and national frameworks relating to human rights and disability still remain. This is because different countries may have ratified some but not all international human rights treaties, or they may have implemented them slowly, or they may have implemented them in a minimal way.

The KSA's approach to accepting international human rights is complex. The KSA has previously rejected crucial recommendations that would ratify core international treaties, including those that would safeguard the rights of women and grant victims access to justice (Amnesty, 2018). Given the religious, political, cultural, and social context in which the institutions of Saudi government operate (outlined above), this is not surprising. Indeed, it may be argued that it would require a strong departure from the current path for this to take place. However, the KSA is a signatory state to certain international human rights treaties. The international treaties relevant to human rights and disability that the KSA has ratified are: 'The Universal Declaration of Human Rights 1948'; and 'The International Convention for the Rights of Persons with Disabilities 2006'. This last Convention was implemented via the domestic Disability Code Convention of 2008 (**DCC 2008**).

The ICCPR is a multilateral treaty adopted by the UN General Assembly and opened for signature, ratification and accession on 16th December 1966 (entering into force on 23rd March 1976) (**Appendix 5**). The ICCPR commits the parties to respect the civil and political rights of individuals, including the right to life, freedom of religion, freedom of speech, freedom of assembly, electoral rights and rights to due process and a fair trial. Although these are basic rights that are recognised globally, they do pose somewhat of a challenge within the context of the KSA. For instance, freedom of religion is a right that is in conflict with Article 1 of the Saudi Basic Law, which stipulates that Islam is the religion of the State. Civil and political rights such as freedom of speech and freedom of assembly have historically been politically suppressed in the KSA (Hamzawy, 2005; Chatham House, 2011; Beck and Hüser, 2012; Menoret 2016). Article 18(1) of the ICCPR states that everyone has the right to freedom of thought,

conscience and religion, including the freedom to have or to adopt a religion or belief of his choice.

The Saudi government has argued that this right of an individual to change their faith is incompatible with the teachings of the Islamic *Shari'ah*, as it forbids Muslims from ever changing their religion (Al-Hargan, 2005). The Holy *Qur'an*, verse 3:85 states "if anyone desires a religion other than Islam, never will it be accepted of him; and in the hereafter he will be among the losers." This prohibition of apostasy under *Shari'ah* is punishable by the death penalty (Al-Hargan, 2005). Some *Shari'ah* rules also set out rules which discriminate against women (e.g. in terms of marriage rights, inheritance rights) and which are in direct conflict with rights set out under Article 2(1) and Article 3 of the ICCPR (Al-Hargan, 2005). Al-Hargan (2005, p.502) observes:

> It seems to me that the Government of Saudi Arabia is placed in an impossible situation, by which it cannot ratify and honour the ICCPR without violating the *Shari'ah*, which is still to date central to both the Saudi Arabian constitution and the Saudis' way of life, or to modify is obligations under the ICCPR without violating the object and purpose of the Covenant, i.e. a stalemate situation.

The ICESCR is a multilateral treaty drafted by the UN General Assembly, which was adopted on 16th December 1966, and entered into force on 3rd January 1976 (**Appendix 6**). It serves to commit the engaged parties to work together toward the granting of economic, social, and cultural rights to the Non-Self-Governing and Trust Territories and individuals (e.g. labour rights, the right to health, the right to education, the right to an adequate standard of living). The Covenant follows the structure of the UDHR and the ICCPR. Article 2(2) of the ICCPR states:

> The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Whilst some of these rights are compatible with the rights stipulated under *Shari'ah* (e.g. the right to a healthy environment, the right to education), there are other rights

which lead to debate regarding their practical adoption and implementation. For example, under *Shari'ah* there is a right to the satisfaction of basic needs, but this might be interpreted differently to the right to an adequate standard of living (Ayub, 2007). The right to an adequate standard of living might be judged objectively from a socio-economic perspective in Western democratic countries, but would theoretically be judged from a religious *Shari'ah* perspective in the KSA (Ayub, 2007).

Simmons (2008) has argued that the ratification of human rights agreements can stimulate domestic demands for their realization that certain governments might find costly to recognise or cope with. Moreover, groups then begin to form to demand their rights once a government has formally acknowledged them through ratification (Simmons, 2008). Still, it is recognised that the incentives to mobilize will differ predictably across different kinds of political regimes (Simmons, 2008). However, the greater group's ability to monitor a government, the greater will be the pressures for the government to comply with international legal obligations protecting civil rights (Simmons, 2008).

Simmons (2008, p.2) comments that "Ratification stimulates demand for compliance, making it harder than it would otherwise be for a government to ignore international civil right norms." In the KSA it has been argued that the Saudi government prefers an obedient society, one that expresses gratitude to it, while tolerating its absence when deprived of it (Al-Saif, 2014). It is said that this relationship is practically depicted through the religious language used in the *Baya'h* (the pledge of loyalty to the King), which includes 'obedience in fortune and adversity', i.e. under all consequences (Al-Saif, 2014).

This cultural notion translates into practice to mean that the Saudi government preserves the traditions that safeguard it and defends the traditional groups within society who uphold it, and who consider this active factor as integral to their political culture (Al-Saif, 2014). In practice it has been identified that Saudi legislation has banned all public demonstrations, and those who participate are penalised (Almutairi, 2018). Furthermore, trade unions have been prohibited and collective organisation of workers and workers' strikes have been banned (Almutairi, 2018). With these kinds of public policy developments it is difficult to envisage how a framework of human rights can be effectively developed in the KSA. If certain human rights are granted and certain

rights are restricted, how can this be said to be comprehensive and effective implementation of international human rights standards? It has also been noted that obedience has been a focal point in the religious groups' discourse to the public, based on emotional and cultural unity among the people of the faith (Al-Saif, 2014). Consequently, traditional *Shari'ah* religious culture revolves around obligations and formalities, *rather than rights*, and entirely overlooks the *civil rights* of individuals, as well as society as a whole (Al-Saif, 2014).

The Saudi religious narrative does not talk about individual and civil rights, nor about citizenship as a basis for a relationship between citizens and state (Al-Saif, 2014). Consequently, it does not consider the individual as owner of his or her right to individual choice, or personal priorities and lifestyle, or alternatively as a partner in deciding the present and future of political society to which he or she might belong (Al-Saif, 2014). Viewed from this perspective, implementation of a 'rights-based framework' is not consistent with the religious historical *Shari'ah* based culture that has existed in the KSA. Implementation of a formal legal rights-based framework as advocated by the ICESCR, could potentially lead to a cessation of power by the Saudi government to a new generation of individuals more highly influenced by Western democratic rights-based frameworks (Al-Saif, 2014).

It has been argued that a country wishing to implement the UDHR would be required to make legislative and constitutional changes to allow precedence of international human rights law over its national laws, as well as ensuring respect for *all* human rights and the active role of women in the process of development (Iqbal, 2010; Baderin, 2005). Historically, this has been contrary to *Shari'ah* principles (Iqbal, 2010; Baderin, 2005). Indeed, it has been argued that *Shari'ah* is incompatible with human rights law (Baderin, 2005). Modern human rights are secular in nature and derived from natural law, whereas the Islamic concept of human rights is based on divine scripture (Iqbal, 2010). Secular modern human rights are based on the state-individual relationship which has nothing to do with race, religion, colour and sex, with the individual having the right to be protected from abuses of state authority (Iqbal, 2010).

The differences between international human rights law and Islamic law can certainly pose a challenge for the implementation of international human rights conventions, especially in areas relating to the equality rights of women and minorities and the

criminal laws (Iqbal, 2010). Under *Shari'ah* in the KSA females were, until recently, prohibited from driving cars, and male relatives wield legal powers over female's persons, children, activities, work and movements under Saudi administrative and family law, i.e. men's *qiwama* (Vogel, 2012). Saudi females also need permission from a male relative in order to conduct ordinary activities such as travelling alone, opening a child's bank account, or leaving the home for study or work (Vogel, 2012).

Under *Shari'ah,* Saudi women are required to cover their entire bodies (Al-Atawneh, 2009). Females are prohibited from working in hotels, and services that are provided by men to women in these places are prohibited (Al-Atawneh, 2009). Women can visit clothing stores and tailors only when they are accompanied by a *mahram* (male guardian) (Al-Atawneh, 2009). Also, work is permitted for females so long as there is no contact between a female and an unrelated male, and the occupation must be 'appropriate to a woman's nature', i.e. similar to a woman's role and job within the home (Al-Atawneh, 2009).

Because of a range of disparities between males and females under *Shari'ah,* it has been argued that certain provisions under the ICCPR are incompatible with *Shari'ah* law (Alwasil, 2010; Vogel, 2012). Article 3 of the ICCPR provides that: "The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights set forth in the present Covenant." As has been noted, men and women still have unequal rights under *Shari'ah* law and therefore this provision is incompatible. In addition, Article 10 of the ICCPR states that the widest possible protection and assistance should be accorded to the family, and that marriage must be entered into with the free consent of the intending spouses.

This provision is also incompatible with the tradition of arranged marriages in the KSA, especially within Bedouin tribes (Chaleby, 1985; Al Tamimi, 2009; Bravo, Martínez, Ruiz, 2014; Al-Hakami and McLaughlin, 2016). A note on human rights in the KSA published by the DG External Policies of the Union (2004) cited the government's human rights record as remaining poor. It stated that there was still discrimination against women in place as women were prohibited from taking part in public elections and they were not permitted to move freely without the company of an immediate male relative (*Mahram*), even to seek urgent medical attention (DG External Policies of the

Union, 2004). There was also no freedom of religion recognised in the KSA, and it was even noted that members of the *Shi'a* minority were discriminated against in government employment (DG External Policies of the Union, 2004).

The inherent conflicts in the ICCPR have to date seemingly prevented the KSA from ratifying and acceding the ICCPR and upholding the rights enumerated within it in national law. However, it has also been noted that regardless of the influence of *Shari'ah* on the ratification practices of Muslim states, there are still many ambiguous reasons, other than Islamic law, why a Muslim state may or may not ratify a particular human rights treaty (Baderin, 2015). Overall, it has been acknowledged that the issues of international human rights in the KSA are extremely complicated and controversial, and that the KSA has encountered difficulties because the legal system provides insufficient protection (Almutairi, 2018).

THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The Convention on the Rights of Persons with Disabilities (**CRPD**) is an international treaty that has 160 signatories and came into force on 3rd May 2008. Accession of the CRPD in the KSA took place on 24th June 2008. A brief history can be seen at (**Appendix 7**). The CRPD aims to set out in detail and protect the rights and dignity of persons with disabilities, as well as a number of General Principles and General Obligations which states must adhere to when implementing it at a national level (**Appendix 8**). It prohibits discrimination based on disability and ensures that people with disabilities are able to exercise rights in political, economic, social, cultural, civil, or any other field (Kinker, 2014). The General Principles of the Convention (Article 3) endorse the social model of disability by emphasising that the rights and opportunities provided to people with disabilities should be equal to what is offered to individuals who are not impaired (Lee, 2011).

These general principles include individual autonomy, equality of opportunity, non-discrimination, full societal participation, and respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (Lee, 2011). Article 1 CRPD states that it aims to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and also to promote respect for their inherent dignity. The definition of a person with disability is

"those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (CRPD, Article 1).

This definition clearly seeks to set out a psychosocial view of disability which identifies the fact that barriers in society may hinder the full and effective participation of people with disabilities in society on an equal basis. Article 3 specifies the general principles under the Convention and Article 4 specifies the general obligations. Article 5 recognises that persons with disabilities should enjoy the right of equality, right of non-discrimination, and prohibits discrimination on the basis of disability. The right of equality and non-discrimination enumerated in the CRPD requires States Parties to prohibit all discrimination on the basis of disability, and to guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

This right also requires States Parties to take all appropriate steps to ensure that reasonable accommodation is provided. It recognises that women and girls with disabilities may be subject to multiple discrimination and requires that States Parties take appropriate measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms (CRPD, Article 6). The CRPD requires States Parties to take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children (CRPD, Article 7(1)). Under Article 8 States Parties are also required to undertake to adopt, immediate, effective and appropriate measures to raise awareness of issues relating to people with disabilities, including combating stereotypes and prejudices, and helping to promote awareness and capabilities of persons with disabilities. These consist of a number of different awareness-raising Primary Measures and Practical Measures (**Appendix 9**).

The CRPD provides States Parties with the option of 'progressive realisation', which means that they are given time to apply some of the articles covering economic, social, and cultural rights, but this does not apply to civil and political rights (Jolly, n.d.). Apart from articles covering civil and political rights, all articles are subject to the existence of 'available resources' (Jolly, n.d.). This presents a familiar story to the implementation of equal rights for people with disabilities, especially in 'third countries' where such articles are urgently needed because basic disability civil rights infrastructures may be

absent (Jolly, n.d.). The implementation and monitoring opportunities in the CRPD will need to be powerfully activated for independent living and the other CRPD rights in order to avoid being diffused and deflected by alternative agendas (Collingbourne, 2009).

Article 12 of the CRPD (Equal recognition before the law) states that persons with disabilities are recognised as persons at law, and they enjoy legal capacity on an equal basis. Legal capacity has been understood to mean the construct which gives our decisions and transactions legal significance, it is essentially how we give effect to our preferences and choices in the real world (Pearl, 2013). This means people are able to enter into contracts, consent to medical treatment, marry, and control the course of their own life in many ways (Pearl, 2013). Historically people with disabilities have been systematically denied the ability to make their own decision, or have control over their lives (Quinn, 2009; Pearl, 2013).

Article 12 is the most controversial provision, but also the most important and revolutionary provision (Pearl, 2013). The CRPD aims to transform attitudes towards persons with disabilities so that they are viewed, not as objects of charity, but as individuals with equal rights, capable of making informed decisions, and being active members of society (Loza and Omar, 2017). In the General Comment on Article 12 made by the UN Committee for the CRPD, it is noted that persons with disabilities will have capacity at all times, and dismisses all kinds of substituted decision-making, including involuntary admission and treatment under any circumstances (Loza and Omar, 2017).

Without legal capacity under Article 12, the other rights contained in the CRPD become meaningless (Pearl, 2017). Without such legal capacity people with disabilities cannot make fundamental life choices such as where to work, where to live, whether to marry, and how to make healthcare decisions (Pearl, 2017). Without the protections of Article 12 people with disabilities may be denied access to justice, and from participating in political and cultural life (Pearl, 2017). In the context of Arab culture, the family often participates in decision-making on matters related to health and social welfare, this forms a doctor-patient-family relationship as opposed to a doctor-patient relationship (Al-Amoudi, 2017; Loza and Omar, 2017).

During the drafting of the CRPD 20 Arab countries included a reservation to Article 12 which provided that the concept of capacity pertains to holding this right and not exercising it (Pearl, 2013). By incorporating this reservation this effectively reduces the General Comment to empty rhetoric (Loza and Omar, 2017). The General Comment interprets human rights provisions from a narrow perspective and alienates families in many cultures (Loza and Omar, 2017). The CRPD's concept of legal capacity fundamentally challenges the current medico-juridical conceptualisations of the rights and duties owned to individuals with impairments (Kong, 2015).

The normative and practical import of the CRPD is undeniable (Kong, 2015). Article 12 symbolises a move away from a protectionist perspective towards people with disabilities and moves towards a rights-based framework which demands policies that respect autonomous choices of people with disabilities (Kong, 2015). It has been said that Article 12 "is to recognise the "dignity of risk" so that individuals with impairments are allowed to make unwise choices without paternalistic incursions into their lives" (Kong, 2015, p.710). The rights envisaged by Article 12, the General Comment to Article 12, and the reservation to Article 12 by the Arab countries together bring about a difficult situation regarding understanding the nature of the CRPD.

On the one hand Article 12 reflects a shift towards stronger rights for people with disabilities, so that they can be heard and operate autonomously and with dignity. At the same time the reservation made by the Arab countries essentially makes the provisions of Article 12 essentially worthless. However, at the same time the impetus behind Article 12 does not resonate clearly with Saudi society and cultural traditions. It is true that there is more involvement of family in decision-making regarding people with disabilities (Del Pozo *et al.*, 2017; Loza and Omar, 2017). However, at times this may be to the detriment of people with disabilities in the KSA who may feel that their voice has been taken away from them, or who feel that they can say little within the confines of a doctor-patient relationship based strongly on the medical model of disability.

The CRPD considers legal capacity as a human rights issue, meaning that it is critical to ensure effective exercise of civil, political, economic, social and cultural rights (De Pozo *et al.*, 2017). It also means that it requires the treatment of people with disabilities according to the values that animate human rights (i.e. dignity, autonomy, equality,

liberty to make one's own decisions) (De Pozo *et al.*, 2017). The regulation of legal capacity should be undertaken in accordance with the CRPD's social model of disability (De Pozo *et al.*, 2017). Therefore, under the CRPD paradigm, national legislation should move away from a model of substituted decision-making, towards assisted decision-making (De Pozo *et al.*, 2017). However, the Article 12 social model approach is in direct contrast with the medical model of disability treatment approach that exists in Saudi hospitals (Elsheikh and Alqurashi, 2013). This means that if the CRPD is to truly reach its potential in the KSA, the Saudi Government must expressly make a move towards implementing the social model of disability approach contained within the CRPD.

DISABILITY LEGISLATION AND POLICIES IN THE KSA

There are a number of laws and regulations that relate to disability in the KSA. Some of the laws and policies are only peripherally related to disability, while others are more directly focused on disability. Historically, there are also a number of developments in the KSA that have addressed the provision of services and support to people with disabilities. Disability legislation, regulations and policies are outlined below (**Table 4**), and a summary description of each of these is included in **Appendix 10**.

Table 4: Disability Legislation and Policies Timeline

DISABILITY LEGISLATION AND POLICIES
The Universal Declaration of Human Rights (1948)
Labor Code (Royal Decree No. M/21) (1969)
Council of Ministers Resolution No. 407 (1973)
Council of Ministers Resolution No. 715 (1974)
The Kingdom of Saudi Arabia Royal Decree No. 715 (1974)
The Kingdom of Saudi Arabia Royal Decree No. 1355 (1974)
The Regulation for Rehabilitation Program No. 1355 (N.D.)
The Kingdom of Saudi Arabia Royal Decree No. 1219 (1976)
The International Covenant on Civil and Political Rights (1976)
The International Covenant on Economic, Social and Cultural Rights (1976)
The Kingdom of Saudi Arabia Royal Decree No. 1219 (1976)

DISABILITY LEGISLATION AND POLICIES
Council of Ministers Resolution No. 219 (1980)
The Kingdom of Saudi Arabia Royal Decree No. 34 (1980)
Council of Ministers Resolution No. 187 (1981)
The United Nations Convention on the Rights of the Child (1990)
The Kingdom of Saudi Arabia Basic Law of Governance (Royal Order No. A/91) 1992
Council of Ministers Resolution No. 85 (1997)
Council of Ministers Resolution No. 7 (1999)
The Kingdom of Saudi Arabia Disability Code (2000)
The International Convention for the Rights of People with Disabilities (2006)
The Convention on the Rights of Persons with Disabilities (2008)
The Disability Code Convention of (2008)

Disability legislation in the KSA

In order to understand disability legislation in KSA, it is first of all important to discuss The Basic Law of Governance (Royal Order No. A/91) (**Basic Law**). The Basic Law of the KSA underpins the legal foundation regarding the rights and duties of people with disabilities with respect to social welfare, rehabilitation, and the provision of healthcare services. Part Five of the Basic Law (Articles 23-43) sets out provisions governing rights and duties in the KSA. Article 26 of the Basic Law provides that "The State shall protect human rights in accordance with the Islamic *Shari'ah*." Consequently, in principle the Saudi government is committed to protecting all human rights that are consistent with the rules and obligations contained within Islamic *Shari'ah* law in the KSA. Article 27 of the Basic Law also states:

> The government guarantees the rights of the citizen and his family in case of emergency, illness, disability and mental retardation, and supports the Social Security System and encourages institutions and individuals to voluntarily participate in the welfare programmes.

Article 28 states "The State shall facilitate the provision of job opportunities to every able person, and shall enact laws that protect the workman and the employer." The use of gendered language can be seen throughout the Basic Law, not only in Articles 27 and 28, and reflects not only the dominant masculine society in the KSA, but the historical approach of the government towards framing legislation and laws from a masculine perspective. In addition. As can be seen with these provisions, although the Basic Law sets out high level rights and duties, in practice it is the implementation of these provisions that is important. For example, it is difficult to understand whether the obligations of Article 28 exclude people with disabilities or not, because it is not clear whether this obligation requires the Saudi government to provide adaptations for persons with disabilities within the workplace.

In practice it is through Codes, Resolutions, and Decrees that Basic Law obligations and additional provisions are implemented. For example, in 1962 the Ministry of Education (**MoE**) set up an administrative body for special education to develop social, vocational, and educational services for people that were blind, mute, or what the Saudi government at the time labelled as "retarded" (Alsaif, 2008). Consequently, early legal provision focused to a large extent on vocational rehabilitation and developed in a piecemeal fashion. These policies approached disability from an exclusively medical perspective, focusing on changes for the individual rather than society more generally. Labor Code (Royal Decree No. M/21) of 1969 (1389H) initially provided details relating to labour rights and also set out provisions facilitating vocational rehabilitation for persons with disabilities (JICAPED, 2002). This was followed by the Council of Ministers Resolution No. 407 of 1973 (1393H) which established a framework for allocating monthly allowances to people with disabilities who participated at 'Disabled Training Centres' (JICAPED, 2002).

A specialised centre for rehabilitating people with disabilities was established under Council of Ministers Resolution No. 715 of 1974 (1394H) (JICAPED, 2002). This included rehabilitation for those who required medical care under the supervision of the MoSA, e.g. paraplegics, epilepsy patients (JICAPED, 2002). Under the Regulation for Rehabilitation Program No. 1355, the MoSA established a career rehabilitation department that aimed to prepare persons with disabilities for employment, and suggested means of rehabilitation and services for persons with disabilities (JICAPED, 2002). In addition, the department implemented career rehabilitation programmes, drew up general policies, undertook research on the development of such

programmes, and recorded the types of services provided (JICAPED, 2002). This emphasis on rehabilitation continued with Decree No. 1219 of 1976 (1394H), which set out the Policy of the General Department of Rehabilitation which set out special vocational training programmes, as well as other programmes (i.e. medical and psychological rehabilitation) for those individuals who were not fit to work (JICAPED, 2002).

Measures to address medical and mobility disabilities, including the provision of medical treatment or health care were introduced by Decree No. 715 (1974), which also established specialized centres to provide care for people with disabilities (Alsaif, 2008). Under this Decree, the MoE was charged with treating and training those individuals with a mental disability who were still capable of training, and the rehabilitation and social care of those who were not (Alsaif, 2008). These measures were extended by setting up a department for vocational rehabilitation in the MoSA under Decree No. 1355 (1974) (Alsaif, 2008). The department aimed to set out and enforce vocational rehabilitation policies, programmes, preparing people with disabilities for work, suggesting services for people with disabilities, and gathering statistical information about people with disabilities (Alsaif, 2008).

Discounts were set up by the Saudi government to promote rehabilitation. Council of Ministers Resolution No. 219 of 1980 (1400H) provided that the General Department of Rehabilitation could offer an annual donation of Saudi Arabian Riyals (**SAR**) 30,000 (approximately £6,017) to projects related to people with disabilities and that were initiated by people with disabilities or groups of people with disabilities (JICAPED, 2002). This figure was increased to SAR 50,000 (approximately £10,028) under Council of Ministers Resolution No. 7 of 1999 (1420H) (JICAPED, 2002). Financial benefits were extended to people with disabilities themselves under Council of Ministers Resolution No. 187 of 1981 (1401H).

This provided that people with disabilities, as well as their companions, were to receive 50% discounts on all government owned transportation (i.e. aeroplanes, ships, trains, buses) (JICAPED, 2002). Council of Ministers Resolution No. 85 of 1997 (1418H) provided that a 'Person with Disabilities Services Coordination Committee' was to be established (with members from King Saud University and Presidency of Girls' Education) that was empowered to donate to the families of people with disabilities, and that would prepare publicity plans for raising disability awareness and to find ways of preventing disability (JICAPED, 2002).

Decree No. 1219 (1976) which, along with rehabilitation programmes for individuals who are vocationally qualified, made provisions relating to the granting of subsidies to the families of people with disabilities who were not eligible for social rehabilitation centres (Alsaif, 2008). The regulations relating to rehabilitation programmes and the process for providing essential subsidies to support the families of people with disabilities were subsequently ratified under Decree No. 34 (1980) (Alsaif, 2008). It would seem to be the case that there is a lack of cohesion between these decrees and regulations which in practice undermines their effectiveness as directives and recommendations (Alsaif, 2008). In fact, as tools they are weak in that they cannot readily obtain services people with disabilities, owing to their lack of legal process (Alsaif, 2008).

Consequently, it can be argued that they need to be assembled in a comprehensive legal code, as special legislation for the rights of people with disabilities. Such type of recommended codification, while probably the most suitable and efficient method of improving their effectiveness, is unlikely to come about any time soon. It could be argued that the historical path dependency of the way that the Saudi government operates through myriad ministries and working groups would preclude any such codification from being enacted. At the same time, some commentators believe the progress outlined above by the Saudi government has been significant (Alsaif, 2008).

The Disability Code 2000

In 2000, the Saudi government passed the Disability Code which was a law that sought to protect the rights of people with disabilities (**Appendix 11**). As there is a Monarchy governmental system in the KSA, and in Arab countries normally the citizens following the Monarch without a Parliament to guide the King, a *Shari'ah* Council has instead been established to guide the implementation of *Shari'ah* law. In principle the Disability Code only serves as a pledge in principle that people with disabilities will be provided with appropriate rehabilitation, medical, social and education programmes by the state (Al-Jadid, 2013). Under Article 1 of the Disability Code, 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".

This is a broad definition of disability, as it incorporates mental, psychological and academic abilities. Article 2 of the Disability Code states that the Government shall guarantee the prevention, welfare and habilitation services to persons with disabilities and their families. This can be seen as drawing on both the psychosocial biomedical models of disability. For example, prevention is defined as:

> The set of medical, psychological, social, educational, informational and regulatory procedures, which aim at preventing or limiting the effect of disabilities and at pre-empting and easing the consequences thereof.

Similarly, welfare refers to not only providing 'care services to persons with disabilities dependent on the degree of their disability', but also 'their medical and social situation'. Habilitation also takes a more holistic perspective, to 'utilize medical, social, psychological, educational, and professional services to enable the disabled to achieve the maximum feasible degree of functional efficiency'. One of the main difficulties that can be seen with the Disability Code is that although it has lofty aims, there is no precise detail in terms of what shall actually be done in practice. The Saudi government did not issue interpretational regulations that would support the implementation of the Disability Code in practice. Therefore, the Disability Code lacks real practical impact. While the language has changed, there is no mechanism for more substantive change in government institutions, which has meant inadequate implementation.

From a path dependency perspective, it could be argued that the Saudi government needed to be seen to introduce disability policy and legislation to support people with disabilities at that time. However, a lack of political will owing to the conservative nature of the Saudi state may have caused path dependency to favour the status quo. Since there were no exogenous shocks (e.g. domestic human rights and disability movements) to continue and support change at such time, the development of disability policy and secondary legislation was hindered. At the same time the Saudi bureaucracy may have led to the development of secondary legislation never being authorised or auctioned because of more pressing matters to be attended to at such time.

The broad definitions of prevention, welfare, and habilitation are also open to a wide range of interpretations. For example, prevention including procedures which are

aimed at, preventing or limiting, the effect of disabilities, and at pre-empting and easing the consequences of these disabilities. Without implementing regulations to direct the high level obligations, the Disability Code provisions are somewhat meaningless. In the KSA, two of the main causes of disability are road traffic accidents and cerebral palsy (King Salman Center for Disability Research, 2018). According to the Disability Code then, the Saudi government is under an obligation to put in place procedures which aim to prevent or limit disabilities arising from these causes. In practice for road traffic accidents this should, for example, mean that the Saudi government should invest in national road safety measures, enforcing stricter driving tests, implementing road safety laws, making sure the roads were policed and monitored.

In practice for cerebral palsy this should mean that the Saudi government should invest in better healthcare for pregnant women, it should ensure that pregnant women in rural towns and villages are able to access healthcare and are instructed in natal procedures, pregnancy healthcare and giving birth. These are just two areas which in theory should be covered by the Disability Code. But as can be seen, the broad nature of the Disability Code in reality makes it very difficult to interpret and practically implement. It can be interpreted in many different ways, and there is no way for individuals to understand exactly what their rights are under the Disability Code. This makes its application and enforcement extremely difficult.

A research study undertaken by Alsaif (2008) aimed to identify shortcomings in the Disability Code and previous Disability Regulations. Many of the limitations identified relate to the absence of sufficient protections or rights for people with disabilities. For example, there is no mention of insurance systems, practical norms or enforcement, nor legislative mechanisms (Al-Maghlooth, 1999; Alsaif, 2008). There are no legal definitions concerning the actual rights of people with disabilities and discrimination (Al-Maghlooth, 1999; Alsaif, 2008). This lack of specificity in the primary legislation not only makes it difficult for people with disabilities to enforce the Code, but it makes it very hard for people with disabilities to actually understand what their rights are.

What is more, there is an absence of implementation guarantees, and also of any stipulations about a punishment system and pursuit of offenders (Al-Maghlooth, 1999; Alsaif, 2008). Therefore, not only do people with disabilities not understand what their rights are under the Code, but they do not know what system is actually in place in order to punish any people who might break any provisions of the Code. The Code

does not identify any judicial channels that may be available to restore the rights of people with disabilities (e.g. through a disability rights commission) (Alsaif, 2008).

There is a general deficiency in the legal framework for the Disability Code and previous Regulations (Al-Maghlooth, 1999; Alsaif, 2008). The text of the Disability Code is very general, it contains deficiencies in terms of definitions of disabled, education, employment, public services, techniques for their legal treatment, transport, housing, telecommunications, as well as enforcement mechanisms (Al-Maghlooth, 1999; Alsaif, 2008). There are further problems including no clear reference to the degree of impairment, and the period of impairment needed to qualify as a disability (Al-Maghlooth, 1999; Alsaif, 2008). There is no time frame specified for impairment and no specific characteristics of disability are defined (Al-Maghlooth, 1999; Alsaif, 2008).

The Disability Code does not specify any direct obligations upon the private sector, which may supply goods and services to people with disabilities (Al-Maghlooth, 1999; Alsaif, 2008). There is inadequate treatment of people with disabilities' housing issues, and there is no recommendation of positive discrimination in order to uphold this right (e.g. the prioritisation of people with disabilities and a prohibition of discriminating against them) (Al-Maghlooth, 1999; Alsaif, 2008). The Code does not contain any express affirmation of any rights of people with disabilities in terms of education, employment, and public services without discrimination (Al-Maghlooth, 1999; Alsaif, 2008). Essentially, this stops the Code from being an anti-discriminatory measure to ensure that the rights of people with disabilities and also to prohibit discrimination against them.

There are however, some worthwhile aims incorporated into the Disability Code. For example, Article 2(1) states that the government shall guarantee health services to persons with disabilities. This includes services such as genetic counselling, laboratory testing and analyses for the early detection of disease and necessary intervention. It also includes registering children who are at risk or born with a disability, and conducting follow-up monitoring of their condition(s), and communicating relevant information to the appropriate authorities. This means that in theory the Saudi government should have the information necessary to create national disability registers as well as publishing national disability statistics.

The government must guarantee enriching the health care of people with disabilities

and taking the necessary steps to achieve this (Article 2(1)). As can be seen, it is very unclear exactly what 'enriching' the health care of people with disabilities means in real life, and it is very difficult for people with disabilities to say to othe rs that they have been guaranteed by the Saudi government that they have the right of enriched health care. This again raises questions about how this can be implemented. The Disability Code also sets out a number of guarantees regarding training, habilitation, and education.

The government is required to guarantee the training of the families of people with disabilities in terms of handling and care (Article 2(1)). The government will guarantee their education, including all phases of education (pre-school, general, vocational, higher education) that are suitable to the particular abilities of people with disabilities, and that are commensurate with their various categories and needs (Article 2(2)). So, at the very least this should include a classification of people with disabilities, and a categorisation of the particular educational needs of those classes of people with disabilities. The government must also guarantee the training and habilitation of people with disabilities (Article 2(3)).

This includes the provision of training and habilitation services as required by the labour market, so that people with disabilities can be employable. It also includes the provision of vocational and social habilitation centres and adequate training aids. The transparency of the Disability Code is very limited, and it is very difficult to see how it should be interpreted, how it is actually interpreted in practice, and what actions have been taken on each particular provision. Under the Disability Code the Government is required to guarantee to provide for the recruitment and employment of people with disabilities in order to provide them with an opportunity to discover their personal capabilities and potential (Article 2(4)). This is to be provided by the Government in order for them to earn and generate an income like other community members. The Government is also required to enhance the performance of employed persons with disabilities by providing further ongoing training.

The government must guarantee the provision of programmes that contribute to developing the capabilities of people with disabilities, and which enable them to integrate naturally into various areas of public life, without hindrance from the nature of their disability (Article 2(5)). This obligation therefore reflects a social model of disability perspective. The Government is also required to provide people with

disabilities the right to utilise cultural and sporting facilities, and that it is required to adapt such facilities in order to allow them to participate (indoors and outdoors) in a manner that is suitable to their abilities (Article 2(7)).

In practice the government must guarantee providing information services, including using the mass media to enlighten and educate the community (Article 2(7)). This may be done by defining the types and causes of disability, by educating the public in the role of persons with disabilities in society, and by identifying their rights, needs, abilities and their contribution to services available. It also includes educating people with disabilities about their duties towards themselves and their role in society. The government must also encourage institutions and individuals to contribute to charitable activities within the field of disability (Article 2). The Disability Code states that the Government will provide services to people with disabilities in the areas of health, education, training and habilitation, work, social, cultural and sports, information, and complementary services.

These policies and commitments should in principle support the notion of equal rights for every Saudi citizen. However, it is contended that the fundamental treatment of people with disabilities in Saudi society still remains at discord with the rights specified in the Disability Code. It has not been reviewed in the past 10 years, and therefore may not reflect current societal norms, views, trends, and practices. It can be strongly argued that there is still a lack of substantive and effective implementation of the Disability Code. In reality this creates a huge discrepancy between what has been pledged by the Saudi government to be the rights of people with disabilities, and what problems and obstacles people with disabilities in the KSA face in everyday life.

There have noteworthy efforts to implement the Code. For example, a Supreme Council for the Affairs of Persons with Disabilities (**The Supreme Council**) was originally established which aimed to oversee provisions for people with special needs. Under the Provision Code for Persons with Disabilities in the Kingdom of Saudi Arabia, 1421H. Representation on the Supreme Council includes high level members such as the Ministers for Labor and Social Affairs; Health; Education; Higher Education; Finance and the National Economy; and Municipal and Rural Affairs. There is also representation from the General President of 'Girls' Education, businessman and specialists in the field of disability, as well as two persons with disabilities' (Al Rubiyea, 2010).

The Supreme Council was required to coordinate with authorities in order to develop architectural specifications to provide access and accommodate persons with disabilities in all centers for habilitation, training, education, medical, welfare and public places (Al Rubiyea, 2010). The Supreme Council was also required to provide access and accommodate persons with disabilities in all other areas in order to allow them easy access of movement and transportation (Al Rubiyea, 2010). In addition, the Supreme Council was required to coordinate with authorities in order to provide manpower to be educated and trained (nationally and internationally) in the field of disability, and also to promote the exchange of experience with other countries (Al Rubiyea, 2010).

Under the Disability Code the Supreme Council was authorised to organise the affairs of people with disabilities. This included the issuing of policies and procedures, as well as decisions required to implement the Disability Code. It also proposed modifications to regulations relating to the affairs of persons with disabilities in different areas and proposing basic standards as to what was offered to them, or to whoever took care of them (i.e. financial benefits). Article 9 of the Disability Code also provided that the Supreme Council was required to ensure implementation of the Code and its regulations, including other policies and procedures related to the affairs of people with disabilities. The Supreme Council was also required to coordinate between the Government and private sectors in relation to services that were provided to people with disabilities.

The Ministry of Health (**MoH**) that deals with people with disabilities currently does not have reliable information on types of disabilities, geographical distribution and, more specifically to this study, the exact population of people with physical disabilities. Most specialised organisations fail to report the statistics on people with disabilities, whilst the reported data are vastly underestimated (Al-Jadid, 2013). The Constitution in the KSA does not adopt any specific approach to equality across disability. Neither does the Constitution guarantee any type of protection against discrimination at work for people with disabilities. There is a general right of education which includes people with disabilities. In general, there are no, or limited income support benefits available to families with children with disabilities. There are also no specific family financial benefits for families with one child with severe disabilities.

In practice it would seem to be the case that the vast majority of provisions under the Disability Code have not been fully implemented, and areas governed by the Disability Code have been implemented in a piecemeal way. It is very difficult for people with disabilities to find out the rights that they have at law or under the Disability Code, and there is no centralised way of finding this information either online, or by telephone. The bureaucratic nature of the Saudi government has led to a very fractured implementation of disability rights, in practice hindered further owing to the diverse range of fractured legislation relating to disability rights. The current state of legislation and policies relating to disability clearly is in need of consolidation and overhaul to ensure that there is a harmonised approach to disability law and rights that people with disabilities in the KSA can actually understand.

Disability-related central government organisations

It is also important to discuss government organisations, as these are key players in rolling out policies and programmes in practice. Disability-related central government organisations in the KSA are the MoH, the MoE, and the Ministry of Labor and Social Affairs (**MoLSA**) (JICAPED, 2002). The MoE, the MoLSA, and the MoH have oversight of a number of institutes that have been set up to help to care for people with disabilities (**Table 5**).

Table 5: Institutes operated by the MoE, the MoLSA, and the MoH
Source: Adapted from (JICPED, 2002, p.10)

MoE	MoLSA	MoH
Noor Institute for the Blind.	Career Rehabilitation Centre, Riyadh.	King Faisal Specialist Hospital and Research Centre
Amal Institute for the Deaf.	Career Rehabilitation Centre, Taif.	King Khalid Eye Hospital
Institute for the Intellectually Disabled.	Career Rehabilitation Centre, Damman.	Prince Sultan City for Humanitarian Services
	Social Rehabilitation Centre for the Severely Disabled, Riyadh.	Physical, occupational, speech and hearing therapy, prosthetic, orthotic services.
	Social Rehabilitation Centre for the Severely Disabled, Al-Ahsa.	Rehabilitation programmes and facilities.

MoE	MoLSA	MoH
	Social Rehabilitation Centre for the Severely Disabled, Medinah.	
	Comprehensive Rehabilitation Centres in 5 regions.	
	Institute for Paraplegic Children, Riyadh.	
	Institute for Paraplegic Children, Taif.	
	Social Welfare Centres for the elderly in 7 major cities.	

In practice, there have been a number of disability projects and programmes that have been implemented in the KSA with the help of institutions such as the King Salman Center for Disability Research. This includes projects such as the national research project to study childrens' disability in the KSA; a genetic diagnosis for the prevention of genetic diseases project; spinal muscular atrophy (heterozygote (carrier)) screening; stroke in Saudi children (clinical features, etiology, risk factors, prognosis) study; a longitudinal study of prenatal and postnatal lead exposure and early cognitive development in Al-Kharj); and a study on the characterisation of the molecular basis of hereditary hearing loss in the KSA (Al-Odaib and Al-Sedairy, 2014).

Therefore, it is not the case that there are few or very little disability studies, projects or programmes in place in the KSA. However, it is the fact that nearly twenty years after the Disability Code was implemented there are still so many problems and challenges relating to disability and people with disabilities remaining in the KSA. This illustrates the extent to which there have been widespread policy implementation failures and arguably path dependency at play within the development of disability policies in the KSA. It has been identified that almost all services and programmes were concentrated in metropolitan areas, and therefore they were not easily accessible to the rural population and nomadic tribes (JICAPED, 2002).

Significantly, a lack of services in rural areas has been observed, where 58.7% of people with disabilities were reported to live, and therefore it was recommended that the Saudi government should take into account accessibility considerations for rural and nomadic people with disabilities in future endeavours (JICAPED, 2002). In terms

of policies on disability, it was seen that the Saudi Sixth Development Plan (1995-2000) intensified the follow-up and provision of health care for the most vulnerable, including people with disabilities, the elderly, and people with chronic illnesses (JICAPED, 2002).

In addition, the Saudi Seventh Development Plan (2001-2005) encouraged charities and cooperatives to develop economic and social projects which could help people with disabilities, e.g. hospitals, disability centres, private clinics (JICAPED, 2002). Areas identified as priorities under prevention, identification and early intervention included genetic counselling; parental care, mental nutrition, growth retardation, and low birth weight; nutrition support of inherited metabolic diseases; and international legislative action to ban land mines (JICAPED, 2002). Other priorities included disability prevention for the elderly; measures to prevent vehicle accidents; child safety and injury prevention; sport safety; substance abuse; terrorism; and mass media and public awareness (JICAPED, 2002).

Disability welfare and social services

From a social welfare perspective, the Saudi government seeks to train and help people with disabilities to equip themselves with suitable knowledge, experience and skills, as well as removing obstacles that could affect their integration and participation in society (Al-Maghlooth 2000). The government seeks to provide relevant psychological, health and social services that may allow people with disabilities to integrate with society, and also to enable them to understand their rights and duties (Al-Maghlooth, 2000). There are a number of welfare rights that have been identified that are in theory potentially available for people with disabilities.

These include the provision of artificial limbs, daily meals, free entertainment, free medical services (including free medicines), open access to vocational training, appropriate equipment for people with special needs, and a monthly remuneration or training allowance (Ministry of Social Affairs, 2007; JICAPED, 2002; Al Rubiyea, 2010). People with disabilities are also entitled to discounts for all public transport (as discussed above), special parking spaces at various institutions, access to public roads, parks, and gardens (Ministry of Social Affairs, 2007; JICAPED, 2002; Al Rubiyea, 2010). In theory, educational institutions are available for people with

disabilities, they can avail themselves of a SR 10,000 (approximately £1,892) to modify their cars (Ministry of Social Affairs, 2007; JICAPED, 2002; Al Rubiyea, 2010).

The authorities also provide accommodation such as special housing units for people with disabilities who live far away from special needs centres. These Social Rehabilitation Centres seek to provide shelter to people with severe disabilities who are not able to benefit from vocational rehabilitation programmes because they have multiple disabilities, severe intellectual disabilities, or severe disabilities (JICAPED, 2002). There are Social Rehabilitation Centres located in Riyadh, Madinah and Ahsa (JICAPED, 2002). If people with disabilities are cared for at home by their families, they can seek help from an aid programme that provides a maximum of SAR 100,000 (approximately £18,928) per year for severe cases, and SAR 6,000 (approximately £1,135) if they cannot benefit from vocational rehabilitation programmes (JICAPED, 2002).

The authorities also provide awards of SAR 50,000 (approximately £9,464) to every vocationally qualified person with disability to carry out individual or group projects under the Supervision of the Administration of Social Affairs (Ministry of Social Affairs, 2007; JICAPED, 2002; Al Rubiyea, 2010). There are financial benefits for people with disabilities who are undertaking undergraduate or postgraduate studies, and educational opportunities for persons with visual, hearing, or speech impairments and intellectual disability at special institutions under the supervision of the Ministry of Education and General Presidency for Girls' Education (Ministry of Social Affairs, 2007; JICAPED, 2002; Al Rubiyea, 2010).

Alariefy (2016) has identified that the ability to obtain visas needed in order to hire home help (e.g. drivers, nurses, maids) are highly beneficial in practice. However, there are some administrative difficulties involved. For example, the visa costs SAR 2,000 (approximately £378.33), which is paid at most, every two years, also there is no support given for recruitment fees which are estimated to exceed SAR 10,000 (approximately £1,892), or any other support for the monthly salary which is estimated at SAR 1,500 (approximately £283.93) (Alariefy, 2016). This is one of the main difficulties that people with severe disabilities face, as they invariably require domestic support but may not have the financial revenues needed to put such support in place.

Policy implementation

Official reviews of disability policy in the KSA have identified a range of implementation failures, which go beyond the shortcomings discussed above. The Human Rights Council (**HRC**) Working Group on the Universal Periodic Review prepared the first report (first review) that compiled information relating to the implementation of human rights in the KSA (Human Rights Council, 2013a). A number of observations and recommendations were made. The Special Rapporteur on violence against women noted that there was no written law governing cases relating to personal and family issues, there was no penal code, and there was no provision or code for criminalizing violence against women (e.g. rape or other forms of sexual violence) (Human Rights Council, 2013a). Without implementation of laws governing these areas, individuals cannot enforce their rights, and overall guidance policies cannot be implemented.

It was recommended that the KSA adopt a Penal Code that clearly defined and penalised criminal offences such as rape and cruel, inhuman and degrading treatment or punishment (Human Rights Council, 2013a). The Special Rapporteur also noted that *Mahram* (the legal guardianship of women by a male) was practiced in the KSA (Human Rights Council, 2013a), which strongly restricts women's freedom of movement and legal rights in relation to marriage, children and property ownership/control, as well as their education and employment (Human Rights Council, 2013a). It was also recommended that the KSA incorporate the principle of equality between women and men in law; define discrimination based on sex; take measures to end the practice of guardianship; abolish existing legal provisions requiring a guardian's authorisation; and facilitate the procedure for women to obtain an identity card (Human Rights Council, 2013a). However, there was no express mention of the rights of people with disabilities within the first review.

Again, without implementation of laws governing these areas, individuals cannot enforce their rights, and overall guidance policies cannot be implemented. The HRC prepared a second report (second review) that compiled information relating to the implementation of human rights in the KSA (Human Rights Council, 2013b). The KSA stated that Islamic *Shari'ah* guarantees gender equality and the State's legislation does not differentiate between men and women (Human Rights Council, 2013b). The KSA stated that Article 8 of the Basic Law of Governance sets out that the KSA is based on

justice and equality in accordance with Islamic *Shari'ah*, therefore women are full citizens and endowed with independent financial and full legal capacity (Human Rights Council, 2013b). This also allows them to freely dispose of property, and manage their affairs in a totally independent way, without seeking permission from others (Human Rights Council, 2013b).

The KSA noted that since the first review it had taken steps to protect women and children from violence and abuse by adopting a number of different measures, including a new 'Protection from Harm Act' (Human Rights Council, 2013b). The KSA also noted that it provides general and higher education free of charge and had now established an independent commission to evaluate general education (Human Rights Council, 2013b). This was done in order to improve its quality and to increase its output (Human Rights Council, 2013b). It was also stated that the KSA "has shown concern for social welfare by supporting needy families and providing assistance through programmes targeting all sections of society, especially persons with disabilities" (Human Rights Council, 2013b, p.5). However, there were a number of criticisms of the KSA:

> The United Kingdom of Great Britain and Northern Ireland expressed disappointment that Saudi Arabia has not implemented recommendations from the previous UPR cycle. It regretted Saudi Arabia's failure to meet treaty body reporting deadlines and the lack of access for several Special Rapporteurs (Human Rights Council, 2013b, p.5).

The KSA's approach to issues surrounding women's rights in the second review can be seen as somewhat disappointing (Human Rights Council, 2013b). In the first review the Special Rapporteur has made an express reference to the lack of clearly established legal rights (Human Rights Council, 2013b). In many other countries these legal rights exist in legislation or can be expressly identified in a constitution or other legal framework. In addition, there are guidance policies in place to shape their interpretation and development. The whole reason the Special Rapporteur identified this deficiency was because it leaves the rights of women obscure (Human Rights Council, 2013b). By specifying that *Shari'ah* law preserves the rights of equality the KSA has sought to hide behind *Shari'ah* law, and there is an argument to be made that

the difficulty with *Shari'ah* law is in its interpretation, and this was expressly stated in the second review (Human Rights Council, 2013b).

The courts must interpret *Shari'ah* through different texts and sayings and therefore there is a lack of clarity to ordinary women in the KSA. It is not until there is a ruling in the Islamic courts that a particular area will be clarified. It can be argued that the KSA understands this situation (Human Rights Council, 2013b). However, it would seem to be the case that, in a highly male dominated country, the KSA government is unwilling to expressly set out rights for females because this will provide females with a clear and easy way to protect their rights. Indeed, this may set a precedent that the KSA government is not willing to accept. By stipulating that female rights exist, but that they must take to the courts and argue a complicated case before male populated courts, the KSA government has sought to keep the status quo and has failed to empower females in the KSA. Otherwise, what would be the harm in simply setting out in law what the KSA government says already exists?

There is some hope that the situation for human rights and females and persons with disabilities may improve in the future. The Committee on the Rights of Persons with Disabilities (**the Committee**) created new 'Draft Guidelines for periodic reporting to the Committee on the Rights of Persons with Disabilities' (20 April 2016) (**the 2016 Guidelines**). The 2016 Guidelines are intended to be used as of 2017 to update existing guidelines from 2009. They are important because they expressly refer to a number of provisions that are highly relevant (**Appendix 12**). They also aim to provide guidance to States parties when reporting to the Committee, particularly in those areas where no general comments have been developed by the Committee yet.

By specifying particular areas in which the State has to comment, it pushes responsibility onto the State to either: identify particular areas which it has developed in practice; or justify why it has not done anything to develop particular areas. Indeed, the extent of the reporting Articles (Articles 1 to 33) and the specificity of the reporting requirements that are detailed, means that from 2017 onwards it will be very transparent what a State has and has not done in each particular area. This transparency is important, because it will expose any weaknesses that State parties have in terms of their national accommodation for persons with disabilities. For the KSA, areas such as awareness-raising and statistics and data collection may likely

show significant deficiencies in terms of the requirements of the 2016 Guidelines. This type of reporting required at a more granular level is to be welcomed, as it increases the transparency of States parties with regards to their own national frameworks for people with disabilities.

The first report submitted by the KSA to the Committee on the implementation on the Rights of Persons with Disabilities (**the Convention Report**) sets out the progress the KSA has made with regards to Convention obligations (Human Rights Council, 2013). The Convention Report states that the KSA has established a Human Rights Commission; a National Assembly on Human Rights; a National Society for Human Rights; a Committee for the Coordination of Services for People with Disabilities (Human Rights Council, 2013). It also notes a number of institutions exist that work to aid people with disabilities such as charities, Non-Governmental Organisations, the King Salman Center for Disability Research, the King Salman Center for Care of Older Persons, the Disabled Children's Association, institutions for the care of children with paralysis, the Saudi Autistic Society, the Saudi Society for Hearing Impairment, and centres for early intervention for women with disabilities (Human Rights Council, 2013)..

The Convention Report also praised the government's use of the medical and social models of disability, which seeks to provide a more balanced view of disability (Human Rights Council, 2013). In 2010 the UN Human Rights Commission established a special unit for the human rights of persons with disabilities which was staffed by persons with disabilities and by activists in that field. The Unit aims to ensure that the authorities responsible for providing services to persons with disabilities implement the provisions set out in the CRPD. The KSA has also enacted a number of positive discrimination reforms that seek to aid people with disabilities. These include requiring every employer that has 25 or more workers to allocate 4% of jobs to people with disabilities; providing financial support for small projects launched by people with disabilities; and providing prosthetic devices and equipment (i.e. audio and video) for people with disabilities.

The KSA has set up a number of institutions that are dedicated to helping to take care of the medical, health, and social care of children with disabilities. They work in areas such as paralyzed children, children with birth defects or pathological impediments.

Children outside of day care receive subsidies and there are paralyzed children programme subsidies. There is a national project which aims to deal with autistic disorders and inclusive growth. There is a national centre to prevent ill hearing, deafness, and control in children. There is a national programme for the detection of genetic metabolic diseases, and shortages in secretion of hypothyroidism in newborns.

The KSA has developed policies and programmes that seek to raise awareness of, and to promote respect for, the rights of persons with disabilities. Under Article 2 of the Disability Care Act the media have a number of obligations concerning awareness-raising. They are required to promote the social status of persons with disabilities, and educate the public about their rights, needs, abilities, and contributions. The media are also required to provide information on the services available.

The media are also required to produce special programmes that target persons with disabilities to help them to live in harmony with wider society, and they are also required to encourage individuals and organisations to provide material and moral support for persons with disabilities, and to engage in voluntary work for their benefit. The KSA adopted a Programme Culture of Human Rights in 2009 which is a programme aimed at raising awareness of human rights guaranteed by Islam among members of Saudi society and includes preparation of a matrix of human rights concepts in the school curriculum. The aim of the Programme was to develop social awareness of human rights and of the laws, directives and procedures enforced in the KSA for the purpose of protecting and promoting human rights.

A COMPARISON OF WESTERN AND SAUDI DISABILITY POLICIES AND FRAMEWORKS

While there are a number of limitations to disability policies in the KSA, there has also been some progress (as discussed above). It is important to situate developments in the KSA within the wider international context, however, in order to benchmark progress and compare approaches to disability policy. Historically, the focus on disability around the world has been towards the medical conditions affecting the ability of people with disabilities to participate in the society. However, in the case of the UK, Barnes (1991) suggested that disability should be viewed as a civil rights issue, rather than service provision and community care.

Oliver and Barnes (1998) also highlighted the change in social policy approaches regarding people with disabilities during the 1980s, from one of exclusion of people with disabilities, to one of greater inclusion of people with disabilities in terms of economic, social, political, and cultural initiatives. Occasionally it may be that people with disabilities have no social voice, suggesting that society as a whole has moral, social, and economic obligations towards them in meeting their needs. But in reality one of the difficulties with developing and implementing suitable and effective inclusive social policies for people with disabilities, is the limited national resources available.

For people with disabilities in developed countries like the UK, this may be more about allocating the size of national budgets, whereas in the KSA it may be a case of whether there is enough money for a 'people with disabilities' budget (Scheid and Anderson, 1995). In the UK, social policies for people with disabilities have been directed towards supporting what has been called 'Independent Living'. This is essentially the ability of people with disabilities to live independently, to provide for themselves, and to play their full part in the society (Oliver and Campbell, 1996). Campbell (2010, p.1) even noted that financial support for people with disabilities was under threat because it was being withdrawn, and that if this was not stopped "widespread abuse of human rights will take place routinely behind closed doors."

Perhaps the existing reality for many people with disabilities in the UK and in other developed countries is that they are also subjected to many social, economic, and cultural barriers. For example, people with disabilities have problems obtaining housing (Theakstone, 2012). They also face problems relating to social exclusion from work (Barnes and Mercer, 2005). They continue to face much prejudice, discrimination and hatred, including violence and hate crimes committed against them (Quarmby, 2011).

Indeed, Swain (2004) noted that despite major changes in legislation, "the dominant picture remains one of discrimination prejudice, injustice and poverty, often rationalised on the grounds of supposed progress for people with disabilities". Swain (2004) also suggested that many proposed changes for a better quality of life for people with disabilities come from people with disabilities. Which made the authors conclude that the challenge faced by people with disabilities is majorly based on developing their

view of disability, their demands for change, their individual and collective activism and their identity within a disabling society" (Swain, 2004).

Given the difficulties faced in the UK, where there is a longer history of policies seeking to support and protect people with disabilities, it is hardly surprising that Saudi Arabia continues to face difficulties. On the one hand, there has been considerable progress, primarily through the Disability Code and the DCC 2008. Still, at present this is not enough to protect and provide for people with disabilities in the KSA. The broad range of Royal Decrees and laws is not only complex, but highly fragmented. It is very difficult to navigate.

Saudi society is still developing and in a state of flux. For example, previously it was the case that it was against the law for females in the KSA to drive (BBC News, 2011). It was the case that females were required to be escorted everywhere by males (i.e. *Mahram*). Because of a very undeveloped transportation system across the KSA, this made it difficult for females with disabilities to travel, as they had to be escorted and/or driven by males (Taher and Hajjar, 2014).

Therefore, the notion of independence and social inclusion inherent in the social model of disability, clashes to a certain extent, with the existing traditional societal norms that exist for females, especially for females with disabilities who may feel even more vulnerable and powerless because of their disability. For example, previously the law required females to obtain written permission for certain activities, such as applying for a job or marriage (Wynbrandt, 2010). This male domination or unbalance that seemingly exists between males and females in the KSA is traditional and means that females are viewed as less empowered than men in the KSA. For example, females must go to court to obtain a divorce from their husbands, whereas males can simply divorce their wives by stating "you are divorced" to their wives (Kelly and Breslin, 2010).

CHAPTER SUMMARY

This chapter reviewed the idea of historical institutionalism (path dependency) which focused on the creation, persistence and change of institutions over time, and the notion that over time some institutions tend to become increasingly difficult to change, and therefore small choices can have significant impacts early on (Sorensen, 2015). A proposed mechanism for change in a path-dependent system is located in the

interactions between cultural spheres, structural spheres, and human agency (Greener, 2005). In the KSA the early laws and policies that enumerated the rights of people with disabilities put in place a path-dependent system which was not cohesive, and did not fully realise and enforce the rights of people with disabilities.

Over time, the rights of people with disabilities have been set out in multiple legislative frameworks and policies, which has led to a fragmented understanding and enforcing the rights of people with disabilities in the KSA. In theory it could be argued that the ratification of the Disability Convention in the KSA might represent an exogenous shock that could disrupt and bring about new change for the rights of people with disabilities. However, in practice it has been seen that this is not the case. There are far too many cultural and bureaucratic influences governing not only the rights of people with disabilities, but also attitudes towards people with disabilities.

Moreover, there is a strong influence of *Shari'ah* law in the KSA, which in theory should benefit people with disabilities (i.e. social equality and inclusion), but which in practice does not. It has been seen that international standards governing human rights and disability are comprehensive and have been in place for quite a while now. These international standards set out a broad range of rights, including rights of persons with disabilities. The Periodic Reviews of these frameworks have noted a number of shortcomings in these frameworks. The First Report on the Disability Code Convention of 2008 noted a number of shortcomings in the disability framework that existed in the KSA. In practice although disability legislation and policies in the KSA exist, it has been identified that they lack clarity and are sometimes vague in nature.

In addition, it has been noted that the particular cultural and religious beliefs that exist in the KSA may significantly influence the way disability and persons with disability are viewed in the KSA. In practice there are also barriers for people with disabilities that have been identified in the KSA. In the nearly twenty years since the Disability Code 2000 was implemented, there have certainly been a broad range of disability studies, projects, and programmes that have been implemented. However, overall it can be seen that given the current state of Saudi disability frameworks, there have been clear national disability policy implementation failures across many different areas. Whilst on paper the Saudi government has committed itself to enabling the social model of disability, in practice this has not been implemented.

CHAPTER 4
RESEARCH DESIGN AND METHODOLOGY

INTRODUCTION

This chapter will begin with an overview of epistemology and reflexivity to provide a framework within which to approach the research design and methodology chapter. The chapter will then review the meaning of research design, the researcher's choice of research design, the research aims, objectives, and questions, as well as the precise nature of the qualitative research that was undertaken. It will also discuss issues relating to the choice of semi-structured interviews as a research method, and the development of the semi-structured interview schedule.

The chapter will review issues that may arise when translating interview recordings and the different methods of data collection that were used, namely literature review, analysis of Saudi government legislation on disability rights, and semi-structured interviews with the research participants and social workers. It will also provide an overview of sampling methods and describe the purposive sampling that was undertaken in the research study. The chapter will touch upon thematic content analysis and will then cover research ethics and principles in social sciences research. Finally, the chapter will provide an overview of the framework used to protect the data obtained.

EPISTEMOLOGY

Epistemology covers the theory of knowledge and justification. It is essentially about understanding what and how an individual can know reality and knowledge. It is important in relation to this Doctor of Philosophy (**PhD**) research study as it will influence the methodological strategies that the study may use to discover reality and knowledge. Ultimately the knowledge and truth that this research study seeks to find is both objective fact and subjective knowledge. In relation to the former it is the objective facts relating to disability in the Kingdom of Saudi Arabia (**KSA**), i.e. what disability policies, legislation, and rules are in place, as well as how these policies, legislation, and rules have been implemented in practice. In relation to the latter, the study seeks to identify the subject knowledge, perceptions and beliefs of the research participants.

In answering the research questions, it is necessary to consider epistemology because the study needs to address the question of how and what we can know about reality and knowledge in relation to people with disabilities in the KSA. Awareness of the philosophical assumptions underlying this reality and knowledge can also increase the quality of the research. Epistemology is therefore all about 'how we know' (Pollock, 1968; Tennis, 2008; Demont-Biaggi, 2014). In life we all make implicit epistemic statements about knowledge of concepts, acts, entities, and systems (Pollock, 1968; Tennis, 2008; Demont-Biaggi, 2014). By doing this, we are all creating knowledge, and an individual's epistemic stance will then inform what kind of knowledge it is that that individual has created (Pollock, 1968; Tennis, 2008; Demont-Biaggi, 2014).

For example, there are different types of epistemic stances such as pragmatic, positivistic, operationalist, referential, empiricist, rationalist, and realist (Tennis, 2008). Each of these approaches make claims as to the type of knowledge that can be created through research, as well as how it is gathered and presented (Tennis, 2008). These epistemic perspectives are systematically presenting a view of reality, our knowledge of it, and the meaning that we give it (Tennis, 2008). It has been argued that that the mission of epistemology is to clarify what the conception of knowledge involves, how it is applied, and to explain what features it has and why (Rescher, 2003; Sosa, 2008; Audi, 2010).

This includes rational belief, probability, plausibility, evidentiation, and erotetics (the business of raising and resolving issues). From a high-level perspective, Rescher (2003) states that knowledge claims can be seen from two perspectives, these are 'internally and committally' and 'externally and detachedly'. The first relates to accepting a knowledge claim as correct and authentic from an individual's internal perspective, for example, I know who I am, I know my name, or I know I am male or female. The second relates to viewing a knowledge claim from an 'epistemic distance' without actually committing your belief to acceptance of that knowledge claim, but only as merely representing purported knowledge.

For example, we can see the sun exists and we can measure the amount of its solar radiation, but we have never actually touched the sun, or we may know Australia exists, but we may never have actually been there and confirmed its existence. Viewed from this perspective, it is argued that we cannot actually claim acceptance of knowledge until we have acquired personal physical proof of such knowledge, by for example,

touching the sun or setting foot in Australia. Rescher (2003, p.xiv) adds that in practice there are a range of cognitive involvements:

> …one can know, believe or accept (disbelieve or reject), conjecture or surmise or suspect, imagine or think about, assume or suppose, deem likely or unlikely, and so on. And there is also a wide variety of cognitive performances: realizing, noticing, remembering, wondering–and sometimes also their negatives: ignoring, forgetting, and so on.

Individuals can obtain knowledge in different ways, such as knowledge that something or other is the case (i.e. facts), adverbial knowledge (e.g. knowing when, what, how, why), knowledge by acquaintance with individuals or things, and performatory knowledge (e.g. I know how to skate, ride a bike, swim, surf) (Rescher, 2003). What is referred to as 'propositional knowledge', is also relevant to an individual's ability to answer questions, and can be classified in different ways, for example, by subject matter, source, mode of justification or validation, cognitive status of the matters at issue, or the mode of formulation (Rescher, 2003).

Indeed, there are a number of fundamental features of propositional knowledge which are said to be inherent in the *modus operandi* of knowledge discourse (Rescher, 2003). The first has been labelled as the 'truth commitment'. Essentially this proposes that only the truth can be known (Rescher, 2003; Hart *et al.*, 2017). There cannot exist both the truth and a lie, because this defies logic, and therefore there can be only one truth, whether or not we have discovered it yet or not (Rescher, 2003; Hart *et al*, 2017). For example, a person may believe that God created the Universe, but ultimately, there is only one truth, that either God did, or did not, create the Universe.

The second is that of 'grounding', in that knowledge must be appropriately grounded, so a person may accept something without a reason but cannot then be said to know it (Rescher, 2003). So, for example, if a family member discusses their holiday with you, you may accept their version of their account of their holiday, but you cannot be said to know such account, even if they show you pictures and videos, as you will never truly personally know all of their account. The third is that of 'coherence', essentially, it is proposed that since all items of

propositional knowledge must be true, they must be in consequence be collectively coherent (Rescher, 2003; Hansson, 2006; Olsson, 2017).

Finally, the fourth is that of 'reflexivity', essentially that in order to attribute a specific item of propositional knowledge to another individual, this is the same as claiming it for oneself (Rescher, 2003; Audi, 2010). Epistemology within the context of social sciences will invariably affect differences in the epistemological starting points of quantitative and qualitative research approaches. For example, my epistemological positioning will affect what I as a researcher will accept as constituting valid knowledge, and also in the way I go about obtaining such knowledge. If I as a researcher accept a positivist epistemological positioning, then I would seek to be guided by a deductive or theory-testing approach that seeks to obtain objective knowledge (Dancy, 1985; Audi, 2010; Raddon, 2010).

On the other hand, if I adopt an interpretivist epistemological positioning, then I would tend to adopt an inductive or theory-building approach, that is underpinned by a subjectivist ontology and seeks subjective knowledge (Dancy, 1985; Audi, 2010; Raddon, 2010). Typical methodological approaches include analytical approaches, ethnographies, and in-depth interviews (Dancy, 1985; Audi, 2010; Raddon, 2010). Interpretivism facilitates the understanding of the how and why, it enables the researcher to be alive to changes which occur, it is helpful when trying to make sense of social processes and can take on board complexity and contextual factors (Raddon, 2010). However, drawbacks often include that data collection can be time consuming, data analysis can be challenging and complex, and the researcher has to live with the uncertainty that clear patterns may not actually emerge from the data, i.e. no viable results obtained (Raddon, 2010).

This means that sometimes interpretivism offers a potential 'hit and miss' approach, which may lack scientific robustness with regards to social science research. Nevertheless, interpretivism facilitates subjectivism, and an ability to acknowledge that people are people and that whilst complex, the truth is out there (Dancy, 1985; Audi, 2010; Raddon, 2010). In addition, interpretivism can provide knowledge and understanding of interpretations, meanings, motivations, and values of social actors, structures, and patterns (Audi, 2010; Raddon, 2010). Because of the research study's fundamental objective, namely to understand and explain the subjective feelings, beliefs, and narratives of the research

participants, epistemological positioning would tend towards an interpretivist approach as being the most suitable for the research study (Audi, 2010; Raddon, 2010). At this stage, it is helpful to provide for a more granular analysis of reflexivity set against the background of epistemology.

REFLEXIVITY

Because of my own positioning in relation to the research study, I aimed to fully understand the importance of reflexivity when undertaking the research study. I felt that this was necessary for a number of reasons. First, I wanted to be aware of and understand my own journey throughout the research study, this included my initial thoughts on the study, as well as how I felt after the research study had been completed. This review of my journey took place across a number of years, and I therefore wanted to identify and document any intellectual and emotional changes that I might experience along the way. Given the nature of the research topic, as well as the potential complexity, I was certain that it was necessary to document my personal approach and development in order to better understand both how the research developed, and also how I as a researcher developed.

Second, I wanted to make sure that I remained professional throughout the research study. I wanted to ensure that I approached the research study in as objective a way as possible given my interpretive perspective, and to ensure that I treated all research participants in a similar way. I felt that undertaking research at a PhD level required a highly professional approach. This had to be reflected in the research methodology, my dedication to the research study, as well as my personal development. It was also important for me to accurately obtain the views of the research participants, therefore I wanted to ensure that I did not phrase any questions in ways that were suggestive or biased towards a certain response.

In practice the term reflexivity covers several fields of knowledge, including adult learning, work-based practice, and qualitative research (Jarvis, 1995; Carolan, 2003; D'Cruz *et al.*, 2007). It is interesting to note that reflexivity is an umbrella term which can cover a broad range of types of reflexivity. For example, general reflexivity describes an awareness of a specific perception, meaning or behaviour (Jarvis, 1995; Carolan, 2003; D'Cruz *et al.*, 2007). Affective reflexivity is an awareness of how an individual feels about they may be perceived, or thought about, or acted upon (Jarvis,

1995; Hand, 2003). Discriminant reflexivity describes an assessment of the efficacy of the perception of an individual, for example, how accurately a researcher is able to assess how effective the researcher's own perception is (Jarvis, 1995; Hand, 2003).

Theoretical reflexivity describes having an awareness of why one set of perspectives is more or less adequate to explain a personal experience, whereas conceptual reflexivity relates to the assessment of the extent to which concepts employed are adequate for the judgment that has been made (Jarvis, 1995; Hand, 2003). Judgmental reflexivity is all about becoming aware of the value of judgments that have been made, and psychic reflexivity is recognising the habit of making percipient judgments that are made on the basis of limited information (Jarvis, 1995; Hand, 2003).

In sociology, reflexivity comes to mean an act of self-reference, whereby examination or action "bends back on", refers to, and affects the entity instigating the action or examination. Within and as part of social research, reflexivity is the process by which the researcher reflects upon the data collection and interpretation process (Finlay, 2003; Rinaldi, 2013). Reflexivity includes both a subjective process of self-consciousness inquiry and the study of social behaviour with reference to theories about social relationships (Finlay, 2003; Rinaldi, 2013). Reflexivity has been taken up as the issue of "reflexive prediction" in economic science by Grunberg and Modigliani (1954) and Simon (1954). It has been debated as a major issue in relation to the 'Lucas Critique' and has been raised as a methodological issue in economic science arising from the issue of reflexivity in the Sociology of Scientific Knowledge literature (Simon, 1954).

Reflexivity in research may involve two key considerations. First, it requires that researchers reflect upon the research process in order to assess the effect of their presence and their research techniques on the nature and extent of the data collected (Finlay, 2003). Researchers must consider to what extent respondents were telling them what they wanted to hear; did the researcher(s) inhibit respondents; did the format of the data collection restrict the kind of data being collected etc. (Rinaldi, 2013) The principle of reflexivity was perhaps first enunciated by the sociologist William Thomas (1923) as the Thomas theorem: that 'the situations that men define as true, become true for them.'

By way of practical example, reflexivity requires that researchers critically reflect upon the theoretical structures they have drawn out of their analysis (Crumley, 1999; Finlay,

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2003; Rinaldi, 2013). Researchers are expected to reconceptualise their evidence using other possible models, and to think laterally. A researcher should not just fit details into a preformed schema, but instead should try to reform the schema to see if the details have different meanings (Crumley, 1999; Finlay, 2003; Rinaldi, 2013). In this way the researcher is said to shape the development of the research and advance it forward. Some commentators expect this dual reflexive process to be overtly discussed in the reporting of a research study. Giddens (1984; 1991) for example, noted that constitutive reflexivity is possible in any social system, and that this presents a distinct methodological problem for the social sciences.

Giddens accentuated this theme with his notion of "reflexive modernity" – the argument that, over time, society is becoming increasingly more self-aware, reflective and reflexive (Giddens, 1984; 1991). In practice, reflexivity applies to all forms of first-hand research, so that all researchers should adopt a reflexive approach to the data they collect (Dancy, 1985; Crumley, 1999; Huemer, 2002). This is often overlooked in quantitative research, where the data takes on an objectivist existence once converted to statistics that are open to manipulation (Finlay, 2003). Another level of reflexivity operates at a simple philosophical level, that of the self-referring paradox of the type 'this sentence is false' (Finlay, 2003).

A further level is a more complex philosophical one, namely the idea of reflexivity as self-awareness (i.e. reflecting back on oneself). The problem of possibility and implications of self-awareness is as old as philosophy. However, reflexivity, in this sense, has emerged as a major concern more recently. The modern denial of the possibility of knowledge (as in structuralism, semiotics, cultural relativism, the theory dependence of observation, etc.) raises a reflexive problem, namely how may one know that knowledge is not possible? (Finlay, 2003). A level beyond this is where reflexivity is used as a means of critique. Such critique adopts an approach that tries to show that the theory presented in a text itself reflexively denies the possibility of the theory. The different models of reflexivity are therefore helpful when analysing and composing the overall design of the research, as will be noted in the next section.

RESEARCH DESIGN

There are a number of different approaches to understanding research design that can be identified in the literature. Research design is essentially how the overall research

study will be carried out, as well as justification of the research methods used (Creswell, 2012). This includes what research framework will be adopted, what research methodology will be used, what research questions the research will seek to answer, what sampling may be used, what data gathering method will be used, how data will be analysed, and what research ethics procedures will be put in place (Gorard, 2013). However, there are other issues that may influence the nature of a research design. Research design is also about how to convince sceptical people that research conclusions are safe (Leavy, 2017). Therefore, research design should also aim to incorporate justification of choice of research methods, as well as covering areas such as validity and reliability or equivalent qualitative concepts like credibility (Creswell and Creswell, 2018).

Research design is created by the researcher, and it is moulded rather than dictated by the method (Richards, 2006). Research design is also responsive to the context of the research study as well as the participants (Creswell, 2012). Viewed in this way, research design is not a static blueprint, it is something that may change and be re-shaped, refined, and improved by the researcher as the research study progresses. There are a number of other issues that must be considered when deliberating research design. According to Eriksson and Kovalainen (2015), research design must also consider what types of data will be required for the research study, as well as what evidence will be required to answer any research question posed.

It is important to note that a research design is not simply just a work plan, as the work plan will flow from a project's research design (NYU, n.d.; Gorard, 2013; Leavy, 2017). A research design is therefore a way of designing a research study so that any evidence that is obtained will allow a researcher to answer the research question as unambiguously as possible (NYU, n.d.; Gorard, 2013; Leavy, 2017). So, in practice, in social research areas such as sampling, methods of data collection (e.g. questionnaire, observation, document analysis) and research questions, should all be viewed as subsidiary to the main issue of the evidence that needs to be collected for the research study (NYU, n.d.; Gorard, 2013; Leavy, 2017). The research study question and evidence are therefore vital elements of any research design. It has been observed that:

> …obtaining relevant evidence entails specifying the type of evidence
> needed to answer the research question, to test a theory, to evaluate a

programme or to accurately describe some phenomenon. In other words, when designing research we need to ask: given this research question (or theory), what type of evidence is needed to answer the question (or test the theory) *in a convincing way*? (NYU, n.d.).

A research design must therefore first locate the project methodologically, it must then design the pacing of processes, the strategies to be used, and the project needs to be seen as a whole (Richards, 2006; Creswell, 2012). So, in practice areas that will inform the overall research design will include the researcher's worldview assumptions, as well as data collection methods, type of analysis, interpretation, and procedures of inquiry (Creswell, 2008a; Creswell, 2008b; Creswell and Creswell, 2018). It must be noted however, that research design should not be viewed as a mode of data collection, but rather as a logical structure of inquiry (NYU, n.d.; Gorard, 2013; Leavy, 2017). Otherwise the researcher may encounter problems with the research study:

> Failing to distinguish between design and method leads to poor evaluation of designs. Equating cross-sectional designs with questionnaires, or case studies with participant observation means that the designs are often evaluated against the strengths and weaknesses of the method rather than their ability to draw relatively unambiguous conclusions or to select between rival plausible hypotheses (NUY, n.d.).

The research design will therefore both fit, and be obtained from, the research question, the chosen method, the selected area, and the research goals (Creswell, 2018). The research design is a problem that is carefully considered at the beginning of a study and reconsidered throughout (Richards, 2006; Gorard, 2013). The choice of research design will be developed taking into consideration the aim and underlying objectives of the research study.

AIM AND OBJECTIVES OF THE STUDY

Aim

The aim of the research study is to identify and characterise the barriers to social inclusion, and to provide initial evidence for future social inclusion polices targeted at people with physical disabilities in the KSA.

Objectives

The aim of the study will be supported by several research objectives listed below.

- To carry out a literature review of relevant aspects of the domestic, regional and international legislative and social policy framework relating to people with disabilities within the KSA.

- To carry out a literature review of the cultural and socioeconomic barriers faced by people with disabilities in the KSA.

- To undertake interviews with a sample of people with disabilities from within the **White Hospital**, Jeddah, KSA.

- To investigate the role of social work and social workers working with people with disabilities in the KSA.

- To make recommendations for polices aimed at improving social inclusion for people with disabilities within KSA using the findings from the data.

In order to facilitate the aim and objectives of the research study, a number of research questions will be posed in order to direct the nature of the research study.

RESEARCH QUESTIONS

The research questions for this research study are:

(1) Are there barriers to social inclusion for people with physical disabilities in the medical setting in the KSA?

(2) If there are barriers, what are they, and how do they impact on the people with disabilities?

(3) What steps can be taken to overcome any barriers in the medical setting in KSA?

CHOICE OF RESEARCH DESIGN

The research question and aim will both frame and guide the choice of research design (Gorard, 2013; Leavy, 2017). In practice social researchers ask two fundamental types of research questions, namely: *what* is going on (descriptive research)? and *why* is it going on (explanatory research)? (NYU, n.d.; Gorard, 2013; Leavy, 2017). Whether the research question is descriptive, or explanatory, will fundamentally affect the way in which researchers develop the research design (NYU, n.d.; Gorard, 2013; Leavy, 2017). The current research question combines both descriptive research (i.e. identifying the barriers (if any) to social inclusion *and* explanatory research (i.e. exploring why social exclusion exists). Therefore, ideally the research design should seek to identify the barriers to social inclusion, as well as exploring different types of moderating relationships that may exist.

In much the same way, elements of inquiry may directly affect approaches to the research study undertaken. For example, Creswell (2003) notes that elements of inquiry can combine to form different approaches to research, and that these approaches are in turn translated into processes in the design of research. Creswell (2003) explains that the first steps in a research design are assessing the knowledge claims brought to the study, considering the strategy of inquiry to be used, and identifying specific methods. Knowledge claims relate to areas such as post-positive knowledge claims, socially constructed knowledge claims, advocacy/participatory knowledge claims (e.g. feminist perspectives, critical theory), or pragmatic knowledge claims (Creswell, 2003).

Strategies of inquiry are associated with: a quantitative approach (i.e. experimental designs, non-experimental designs); a qualitative approach (i.e. narratives, phenomenologies, ethnographies, grounded theory, case studies); and a mixed methods approach which combines both qualitative and quantitative methods (i.e. sequential, concurrent, transformative) (Creswell, 2003). The approaches to the research are then effectively translated in practice and incorporated within the design process of the research.

Applied to the research study, owing to the distinct lack of information and literature relating to people with disabilities in the KSA, it was not possible to apply a knowledge claim prior to undertaking the research study. The study adopted an exploratory approach which therefore shaped the initial elements of inquiry. I was unable to obtain

access to a large sample of people with disabilities. This, together with the fact that the research study aimed to identify the barriers to social inclusion that may exist for people with disabilities, meant that a quantitative approach was rejected.

This decision was made on the basis that a qualitative research approach would provide richer and deeper insights into the barriers to social inclusion that people with disabilities may face in the KSA. A qualitative approach was selected as I believed this would allow me to explore in depth one or more individuals with a common element (Creswell, 2003; Creswell 2012). Applied in practice, this also helped to shape the design process, in terms of the qualitative research interviews adopted and the data collection and data analysis techniques used. Therefore, my research design was developed through a mixture of practical choices and avenues of enquiry that were available to me in the KSA.

Qualitative research approach

Several research paradigms have been used to investigate the complexities of world reality (Long and Johnson, 2000). The research method allows for the structuring of a research study, the determination of the data needed to answer a specific research question, and the collection and analysis of the data (Creswell, 2012). Qualitative and quantitative approaches are the two major types of research approaches, where the first investigates subjective reality and the latter commonly assumes an unequivocal objective reality (Joubish *et al.*, 2011; Creswell, 2012). Qualitative research aims to solve a problem using tools such as the case study, historical analysis, and phenomenology (Creswell, 2013; Creswell and Creswell, 2018).

Qualitative research methods adopt emerging methods, typically with open-ended questions, interview data, observation data, and document data (Creswell, 2003; Creswell and Creswell, 2018). A qualitative research approach is one where the inquirer makes knowledge claims based primarily on advocacy and/or participatory perspectives, and uses strategies of inquiry such as case studies (Creswell, 2003; Creswell and Creswell, 2018). Creswell (2003, p.18) notes that "The researcher collects open-ended, emerging data with the primary intent of developing themes from the data." For the qualitative approach, Creswell (2003, pp.20-21) further adds that:

…the researcher seeks to establish the meaning of a phenomenon from the views of participants. This means identifying a culture-sharing group and studying how it developed shared patterns of behaviour over time (i.e. ethnography). One of the key elements of collecting data is to observe participants' behaviours by participating in their activities.

A qualitative approach should be adopted when a concept or phenomenon needs to be understood, because little research has been done on it (Creswell, 2003). A qualitative approach is also useful when the researcher does not know which important variables to examine, e.g. a subject that has been rarely studied. It is also useful when a topic is new (e.g. new technologies that have only recently been developed) or has never been addressed with a certain sample or group of people before (Creswell and Creswell, 2018). The qualitative approach is therefore well suited to the context of the current research study, where there exists very little research undertaken on people with disabilities in the KSA. The current study will therefore adopt a qualitative research approach, using qualitative semi-structured interviews.

Semi-structured interviews

In qualitative research, interviews are a well-established method of obtaining relevant information (Creswell, 2013). The data obtained from interviews can often be rich, deep, and pertinent to the line of enquiry adopted in the research study (Creswell, 2013). Generally, an interview is simply a conversation between an interviewer and an interviewee where the interviewer seeks to acquire information from the interviewee (Moser and Kalton, 1971; Qu, 2011; Edwards and Holland, 2013). The type of interview format will often reflect both the skills of the researcher and the required data. For instance, interviews can be structured, semi-structured, or unstructured (Santiago, 2009). Structured interviews typically employ a set of pre-determined questions which the interviewer asks all the participants in the same manner and format (Block *et al.*, 2011).

This allows the interviewer to more accurately and effectively compare the responses of the participants, as there is little to no deviation from the interview questions. Naturally, a disadvantage of this type of interview is that the interviewer is not able to probe deeper into the responses that are given, nor is the interviewer able to follow up on any particular line of enquiry that may arise during the interview (Alshenqeeti, 2014).

Unstructured interviews do provide the interviewer with a great deal more latitude regarding questions or lines of enquiry. In unstructured interviews the interviewer does not rely on an interview guide but rather relies on his or her own professional skill, expertise, and experience to shape the format of the interview, and to ask the interviewee relevant questions (Cohen and Crabtree, 2006).

The advantage of this type of interview is that a skilled interviewer can often obtain rich and deep data from the interviewee (Alshenqeeti, 2014; Cohen and Crabtree, 2006). However, a disadvantage of this technique is that it may be difficult for the researcher to accurately and effectively compare the responses of the different respondents in a research study, because the responses given by participants may vary widely (Cohen and Crabtree, 2006). In addition, failure to recognise the special requirements of a qualitative interview can result in the interviewer obtaining data that seriously limits the research study (King and Horrocks, 2010).

For example, if an interviewer is too deferential to the interviewee, the interview may be too superficial and shallow (King and Horrocks, 2010). Alternatively, if an interviewer is too aggressive with an interviewee, the interviewee may ultimately clam up during the interview and no relevant data will be obtained (King and Horrocks, 2010). There are three main defining characteristics of the qualitative interview. These are: the interview is flexible and open-ended in style; the interview will tend to focus on a person's actual experiences rather than a person's general beliefs and experiences; and the relationship between the interviewee and the interviewer is crucial to the method (Alshenqeeti, 2014). Brinkmann (2014, p.3) explains the objective of a qualitative interview:

> The qualitative interview attempts to understand the world from the subject's point of view, to unfold the meaning of their experiences, to uncover their lived world prior to scientific explanations.

Semi-structured interviews can often be used to allow the researcher to adopt a standard interview guide, whilst also providing the interviewer with flexibility in terms of asking follow-up questions (Kvale and Brinkmann, 2008). This allows the researcher to obtain data that is both reliable and comparable (Bernard, 1988). Semi-structured interviews can provide the researcher with other advantages. For example, they can allow the interviewer to ask follow-up questions, to elicit emotional responses, and to explore the beliefs and opinions of interviewees in greater depth (Block *et al.*, 2011).

In semi-structured interviews the interviewer and the interviewee often understand the role that each will play, and this may often make the interview easier to undertake on the part of the interviewer (Kvale and Brinkmann, 2008). Semi-structured interviews were chosen for this research study as they provided me with the flexibility that I needed to obtain data that was comparable, but at the same time I had the flexibility to follow up with other questions if the research participants said something that was interesting (Blanford, 2013; Creswell and Creswell, 2018). In order to produce standardised questions I chose to develop an interview schedule for the semi-structured interviews.

DEVELOPMENT OF THE INTERVIEW SCHEDULE

I developed the final Interview Schedule by splitting the interview into two parts. The first part of the Interview Schedule covered the opening section. This was done in order to provide each interview with a structure. This structure was:

(1)   **Background** (to the research study and to me as a researcher);

(2)   **Purpose** (informing the research participant about what types of questions I will be asking in the interview);

(3)   **Motivation** (this covered the objective of the research study); and

(4)   **Time Line** (this provided the research participant with an idea of how long the interview would take. The second part of the Interview Schedule covered the main body of the interview.

What I aimed to do was to write down a number of different questions that covered a range of different topics and areas that were relevant to the interview. This included areas such as: a description of events from the onset of disability; what the research participant understood about his or her disability; views about accessing social services and higher education; if there were any particular issues about accessing higher education; views about his or her ability to perform work, and leisure and other activities; views about social and support services; disability services; and what it is like living with a disability. By covering these main areas I hoped to set a basic framework for the interviews.

After that I aimed to build a relationship and rapport with the interview participant, so that I could potentially discuss personal and family issues that the interview participant might be facing. Unfortunately, because of restricted access issues relating to the research participants, I was not able to undertake a pilot interview in order to test the interview schedule. However, my supervisors reviewed the interview schedule and the final interview schedule was developed in accordance with commentary and feedback which helped to improve the final interview schedule I used.

OVERVIEW OF DATA COLLECTION METHODS

Collection of data for the research study was undertaken in four ways:

(1)   a review of the existing literature on disability, disability in the KSA, and human rights and disability;

(2)   an analysis of Saudi government legislation on disability rights and international human rights legislation (e.g. international treaties and conventions);

(3)   semi-structured interviews with people with disabilities (n=22) based in the KSA and semi-structured interviews with social workers (n=2) based in the KSA.

DATA COLLECTION PROCEDURE

Data collection process at the White Hospital

I will set out the practical data collection process that I undertook in the KSA. I went to the KSA in order to collect data at the **White Hospital** in Jeddah city. This hospital has the largest rehabilitation centre in the region of Jeddah city, and the Western part of the KSA. The Rehabilitation centre can also accept patients transferring from other hospitals, either from Jeddah or from another other part of the KSA. This is the reason why the Saudi Embassy Cultural Bureau in London advised me to collect my data at this hospital, because in reality this hospital was receiving the highest number of car accidents in the Western part of the KSA. Essentially, all car accident victims were transferred to the **White Hospital** after their recovery. They were transferred to the rehabilitation centre there. The hospital is a public non-paid hospital operated by the Saudi Ministry of Health.

All devices which people with disabilities need are provided by the hospital via a Saudi charity, 'Alreaya Alawalia', which is established under the Ministry of Affairs (e.g. wheelchairs, commodes). This charity also provides services for people with disabilities when they request that they need, for example, a bed in their homes so the charity can then arrange with the patients and put a special bed in the patient's home free of charge. One of the difficulties I encountered in the KSA, was that when I went to the hospital I had to wait more than two weeks to get an additional approval to enter the hospital to collect data from the Director of the hospital. This second approval was necessary, despite the fact that I had already secured an approval letter from the Ministry of Health. This approval letter stated my name and the period for collecting data, the research topic, the research question, and also provided a copy of the research information sheet and the research participant consent form.

I started my first week by going around the hospital to check which department had received my letter of approval which had been sent directly to them from the Ministry of Health. After that, I received a response from the Director of the hospital informing me that I was to make arrangements with the Training and Research Department at the hospital. They apologised to me for the delay, and they informed me that it was not my responsibility as a researcher to go around. They said that everything was supposed to have been arranged for me. After that the Director of the Department provided me with a researcher Identification Document with a specific period of research time allocated to me. This was eight weeks.

The director of the hospital then transferred me to the Director of Training and Research Department because I was not authorised to collect data from the main building of the hospital on the recovery ward which housed people with disabilities and other serious health problems. I was then transferred to the Director of the Rehabilitation Centre which then transferred me so as to make arrangements with the Social Work department which was based at the Rehabilitation Centre. Each department had a copy of my Approval Letter from the Ministry of Health and copies of all the research documents.

The Head of the Rehabilitation Centre then took me around the Centre and apologised for the delay, and for the slow bureaucratic way that the hospital had send me around all the other departments around the building. The Head then guided me round the Rehabilitation Centre and I saw the outpatient area and the Hall of the centre. I visited

the Male section which was separated by a door and a hall from the Female section for people who were staying a long time at the hospital in the Rehabilitation Centre. I then went with her into the patient room which had approximately 6 or 8 beds in each room with curtains between each patient.

She informed me that the Female section was closed at that time for maintenance, and that the centre received females as outpatient only at that time until maintenance was completed. The Rehabilitation Centre was clean and tidy at the front and hall and entrance. However, there was no coffee shop to buy drinks or water if the visitors needed any refreshments. This made it difficult for visitors because the only other way to find refreshments was to go outside when the temperature was over 40 degrees centigrade with a high humidity.

Sampling

The target population is the population which is to be studied in a research study. In general, if the target population is very large then it is possible to take a sample of the target population which is then used as a statistically representative of the population, i.e. instead of actually studying all of the target population (Thompson, 2012). This means that any findings relating to the sample can then be generalised to the target population because the sample is statistically representative of all of the population (Emmel, 2013). For example, if a research study found that within a sample of 300 research participants if it was found that the average body weight within the sample was overweight, then this finding could then be generalised to the target population from which the sample was drawn (Thompson, 2012).

There are two types of sampling, namely: probability sampling (representative samples); and non-probability sampling (non-representative samples). Probability sampling is statistically the best type of sampling because there is a greater probability that the samples will be representative of the target population (Emmel, 2013). Two examples of probability sampling are random sampling and stratified sampling (Thompson, 2012). In random sampling each individual within a population has an equal chance of being selected (Emmel, 2013). In stratified sampling the population is divided into categories or stratum, and then a random sample is taken from within each stratum (Thompson, 2012).

The idea behind stratified sampling is that it ensures that the sample contains the target or required characteristics of the population. For example, there could be an unequal division among the target population and so stratified sampling is used to ensure that the specific characteristics of the population are actually targeted. By way of practical example, if the target population of a research study was a small island, and most of the islanders lived in the South of the Island, and most of the Islanders were men, a random sample of the population might not obtain the required proportion of women required for the research study. Therefore, stratified sampling could be used to sample across the island in order to ensure that the sample contained proportionally representative numbers of women.

For non-probability sampling there are two examples that illustrate different methods of sampling. The first is purposive sampling which is not representative of the population but is built up in a way that contains characteristics required for the research study (Thompson, 2012). A convenience sample is where the researcher obtains a sample that is convenient and accessible to the researcher (Emmel, 2013). In the research study purposive sampling was used, where participants are allocated to data collection and a predetermined group was used to conduct 22 interviews with people with disabilities at the **White Hospital** in city of Jeddah (Barnes and Mercer, 1997). Additionally, convenience sampling was used to carry out semi-structured interviews with two social worker that were present at the **White Hospital**. Purposive sampling will facilitate the collection of relevant information about the current research question (Creswell, 2013; Creswell and Creswell, 2018).

Purposive sample procedure

When the Director of the Rehabilitation Centre transferred me to the Social Worker Department she informed me that they knew the patients' situation and background information on them. This way I could use my research purposive sample criteria to identify patients to interview. The following criteria were used at the **White Hospital**:

• Include all nationalities not only Saudi nationals.

• Include all people aged between 18 and 40 years of age.

• Include both genders.

• Include people with physical disabilities.

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- Include people who were literate (i.e. had attended primary school).

- Balanced sample in terms of social economic criteria (i.e. participants with low income and high income status).

The exclusion criteria were:

- Exclude Children (aged 17 years or less).

- Exclude people over 45 years of age.

- Exclude people with a mental disability.

- Exclude people who were illiterate.

I aimed to include all nationalities in the sample. I excluded children (aged 17 years or less) because the research study focused on adults with disabilities. I originally included people between the ages of 18 and 40 because the original research objectives also included an objective about accessing education. I therefore included this group because I believed that this group would most likely still want to access education. This is also the reason I excluded people aged over 45 years of age, i.e. because they were likely to have a low probability of still wanting to access education (Carter and Beresford, 2000; Friebe and Schmidt-Hertha, 2013). I included people who were literate as the research study was originally intended to research access to education, and therefore I included only those that had been educated to primary school level.

I included both genders in the sample in order to make the sample as representative as possible. I included only people with physical disabilities because from personal experience I knew that trying to obtain access to people with intellectual disabilities would be very difficult in the KSA. This is also why I excluded people who had a mental disability. I aimed to have a balanced sample in terms of socioeconomic criteria as I wanted to try to make the sample as representative as possible. I excluded children because I knew from personal experience that trying to obtain access to children with disabilities would be very difficult. I commenced searching with the social worker to identify the sample. However, one difficulty that I encountered was that the social worker had no information about education levels for the patients.

Because of this I changed my sample to include people who were literate at any level of education. The literate criterion was initially used in order to identify people who would potentially be interested in improving their education and therefore accessing education. We then discussed how I would commence the interview process, and what time would be best to commence the interviews. In the morning the patients did physiotherapy exercises, and after that they had a rest - some of them could sleep or took prayer time. In practice, I was not able to obtain information about the patients relating to their socioeconomic status, their income, or their income status prior to the interviews.

On the third week of my collection data period I went with the social worker to the Male section at the Rehabilitation Centre and I introduced myself to the patients. I chatted with the patients and I smiled and tried to be polite and approachable. I told the patients about the research study and what the research study was about, and what I was trying to achieve. After that I asked some of the patients if they would agree to take part in the research study as research participants. If they agreed I asked each one what would be the best time I could come to the ward and carry out the interview. I made a schedule of interviews and carried out 2 interviews every day. This was done in order to have enough time to carry out the interview, and then listen to the recording afterwards and also write comments while the interview was fresh in my mind.

Before starting each interview, I made sure that the ward was quiet and also I spoke to the nurses that I was doing an interview with the patient on the ward, so I could be sure that there would be no interruption or loud voices during the interview. I then gave each research participant a research information sheet and explained to them if they needed more information. After the participant had signed the information sheet I then gave them the research consent sheet to sign. I confirmed that they had signed the sheet. Some of them could not because they had quadriplegia. In that case I asked a brother of his to sign, or they asked me to sign on their behalf. In that case I read the information on the sheet and I wrote the participant's name and my signature, and also I wrote a note so that I could remember the reason that I signed on their behalf. Before starting the interviews I had the research information sheet and also the research participant's informed consent from translated from English to Arabic.

Data analysis

After I finished collecting data I started to transcribe the interviews. I stayed in a quiet room in the hospital and used my recording device with a headset so I could be sure that I could listen to every word that was said during the interviews. I started the interview transcripts with initial information for research participants such as name, gender, age, education level, and income. I then translated all the interview transcripts and carried out a full manual Thematic Content Analysis (**TCA**) on all the transcripts. This involved me reading through the transcripts a number of times and familiarising myself with the content of the transcripts. After I had read through the transcripts a number of times and made notes, I looked at my notes in order to try to identify common issues that the participants were referring to. I narrowed down these issues further in order to identify preliminary themes.

The research study used qualitative content analysis (**QCA**) approach. The study performed 'thematic analysis' within different aspects of the data collection. In the context of the semi-structured interview, the Elo and Kyngäs (2008) three-step approach was utilised. The steps involved: preparation (mining information); organising (extracting themes and patterns within a particular context and counting words); and reporting (interpreting the themes and patterns) (Elo and Kyngäs, 2008). This approach provided contextual meaning to the barriers that people with disabilities face (Elo and Kyngäs, 2008).

It has been noted that QCA can be used in either an inductive or deductive way (Elo *et al.*, 2014; Mayring, 2014). Deductive reasoning begins from a more general theory and works towards narrowing and identifying a more specific explanation, and it seeks to test theories or hypotheses. Inductive reasoning begins with specific observations and works towards developing broader theories and generalisations. During the preparation phase, suitable data are collected for content analysis and the researcher makes sense of the data. When using an inductive approach, the organisation phase will consist of open coding, the creation of categories, and abstraction of data. The reporting phase consists of describing the results according to the content of the categories that have been chosen to describe the phenomenon being studied.

THEMATIC ANALYSIS

Content analysis is a widely used research process that can either use qualitative or quantitative data, using inductive or deductive approaches. This type of analysis provides an opportunity to understand the potential of any issue more widely (Marks and Yardley, 2004). It can be described as a methodology for determining the content of written, recorded, or published communications which is done using a systemic, objective, and qualitative procedure (The Texas State Auditor's Office, 1995). Both the inductive and deductive analysis processes can be represented as three main phases: preparation, organizing and reporting (Elo and Kyngäs, 2008).

However, whereas concepts are derived from the actual data within inductive content analysis, deductive content analysis is structured on the basis of previous knowledge (Elo and Kyngäs, 2008). In this way, inductive content analysis is used where there is no previous data, and the deductive approach is applied when comparisons in categories at different time periods are available (Elo and Kyngäs, 2008). This flexibility allows a researcher to deal with the observational data that has been collected in the research study (Alhojailan, 2012). The processes within thematic content analysis involve the identification of themes and categories that eventually emerge from the actual data (Burnard *et al.*, 2008).

These themes and categories are then verified, confirmed and qualified by searching through the data repeatedly and executing the process again (Burnard *et al.*, 2008). The themes then need to be evaluated by the researcher in order to ensure that they represent the whole of the text (Alhojailan, 2012). This repetition will hopefully identify even further themes within the data. In relation to the importance of developing coding categories, the quality of content analysis depends much upon the categories used (The Texas State Auditor's Office, 1995). Open coding involves a first stage of creating summaries for elements that are used or occur within the transcripts, and creating short theories, margins or phrases or what is being said within the transcripts (Alhojailan, 2012). The main purpose of coding in thematic analysis is to make connections between different parts of the data within the research study (Alhojailan, 2012).

The application of this process is important to the approach, as research using qualitative content analysis focuses heavily on the characteristics of language as communication with added attention to the content itself, or the contextual meaning of the text (Hsieh and Shannon, 2005). In this way, the aim of the process is to offer a

summary word for each element present within the transcripts, and so provides the opportunity to code and categorise data into themes (Alhojailan, 2012). This is except for when and where the discussions have wandered off track away from the relevant topic. These types of deviations are known as 'off the topic' materials and can be uncoded (Alhojailan, 2012). The second stage within the process involves the collection of all the words, summaries, phrases etc. from all the interview transcript material, into a separate area for examination (Alhojailan, 2012).

The information collected does not itself provide the explanations, and it is up to the researcher to then make sense of the data by exploring and interpreting it (Burnard *et al.*, 2008. Through a thorough examination of the material, all duplications are reduced. Data reduction refers to the process of selecting, simplifying and transforming the data (Alhojailan, 2012). Essentially, it is a form of analysis that can sharpen, sort out, and focus the data, as well as discarding and organising the data in such a way that a final conclusion can be drawn and verified (Miles and Huberman, 1994). So, the reduction of data results in highlighting the numbers of categories that are present, and also produces a workable coding framework for interpretation.

Of course, being a widely used technique, content analysis is adopted in various ways. Content analysis has been referred to a range of analytical approaches that can range from impressionistic, intuitive, interpretive analyses to systematic, strict textual analyses (Rosengren, 1981). The application of content analysis has also produced different types of approaches, and the specific type used or chosen, varies due to the theoretical and substantive interests and the problem being studied (Weber, 1990). The objective of content analysis is to provide comprehensive knowledge and understanding of the phenomenon that is being studied (Downe-Wamboldt, 1992). This statement correctly reflects that content analysis is a widely flexible analytical method for research and remains a commonly used procedure employed in critical studies.

Within its application, Hsieh and Shannon (2005) have come to identify three distinct techniques that are widely utilized within content analysis, those being conventional, directed, and summative. All three are applied for the interpretation of context within data, and are predominantly from a naturalistic paradigm. Through examination of all three, qualitative content analysis is essentially a research method for the subjective

interpretation of the content of text data, as well as a systematic classification process of coding and identifying themes of patterns (Hsieh and Shannon, 2005).

A conventional content analysis approach is generally used within a study design that is aimed at describing a phenomenon. This type of approach is particularly appropriate when existing theory or research literature on the phenomenon is quite limited (Hsieh and Shannon, 2005). Preconceived categories are avoided within this approach, and the focus is maintained on allowing new categories and names to emerge directly from the data, allowing for new insights and appropriate category development (Kondracki and Wellman, 2002). In this content analysis method, coding categories are derived directly from the text data, and this process also allows for other relevant theories to be addressed, within the discussion, in a compare and contrast contribution to the findings (Kondracki and Wellman, 2002).

The advantage of conventional content analysis is that direct knowledge is gained without preconceived categories or other theoretical perspectives, and the findings are grounded in the actual data used (Hsieh and Shannon, 2005). However, this approach does raise its own challenges. One is that it is open to failure to identify key categories within the data, due to not developing a complete understanding of the context (Hsieh and Shannon, 2005). This can result in the findings not representing the data accurately. Another challenge is that this process can be often confused with other similar qualitative methods such as phenomenology. Analysis procedures can sometimes make the theoretical relationships between concepts difficult to infer from the findings (Hsieh and Shannon, 2005).

Directed content analysis (**DCA**) is sometimes used when there may be existing theories or previous research about a phenomenon that is incomplete and needs further study (Assarroudi et al., 2018). The aim of this type of content analysis approach is to validate and extend a theoretical framework and helps to focus and produce predictive information around the variables, or relationships among the variables, and so contributes towards determination of coding schemes present (Hsieh and Shannon, 2005; Assarroudi et al., 2018). DCA uses a more structured process, and this type of analysis starts with a theory or relevant research findings as guidance for initial codes to be used. Using existing or previous research, the process begins with identification of key concepts or variables as initial coding categories and then

next the operational definitions for each category are determined (Potter and Levine-Donnerstein, 1999).

Data, which cannot be coded using the existing or previous research then creates new coding schemes that can be identified. Findings from this type of process offer both supporting and non-supporting evidence for a theory (Hsieh and Shannon, 2005). The challenges in this approach appear as inherent limitations to this theory. Findings may be biased in the way that evidence could be seen to be more supportive rather than non-supportive of a theory, because of the initial approach to the data from a previous perspective (Hsieh and Shannon, 2005). Also, this approach may also present an overemphasis on some aspects of the theory, which can cloud the ability to recognize other contextual aspects present in the phenomenon.

A summative content analysis approach typically starts with the identification and quantification of certain words or content, with the specific purpose of understanding the contextual use of those words or content. This is done in order to explore the usage, and to analyse the appearance, of words and content within the textual material, and is known as 'manifest content analysis' (Potter and Levine-Donnerstein, 1999). The summative approach then moves on to include latent content analysis, which involves the process of interpreting the content, and the interpretation of the context associated with the usage, which also focuses on discovering the underlying meaning of the words or content (Potter and Levine-Donnerstein, 1999).

This process involves counting of content and keywords, as well as comparisons, followed by interpretation of underlying context. There are advantages to this approach, in the way that the process is non-reactive and unobtrusive to the study of the chosen phenomenon, and it can provide insights into how words are actually used within the data. However, there may also be challenges in the way that this approach is limited by lack of attention to the broader implications or meanings present in the data.

Although the development of coding categories, within content analysis processes, along with the actual coding of content information, is the most important part of the process (Texas State Auditors Office, 1995), there must also be evidence of trustworthiness in all these approaches for them to be used as appropriate analysis techniques, and credibility is key. A mechanism to demonstrate internal consistency or credibility, is to show that the textual evidence is then consistent with the interpretation

(Weber, 1990). Additionally, it is important to that no single method of analysis can be used for all types of interview data (Burnard, 1991).

NVivo thematic analysis

NVivo software was used in organising, managing, and coding of the data obtained. NVivo has become a corner stone for social science research because it allows a researcher to edit text, take notes, retrieve information and manipulate categories of given data sets. NVivo is designed to facilitate a number of qualitative techniques for organising, analysing, and sharing data (QSR International, 2014). Key concepts that are used in NVivo to facilitate the qualitative research analysis include: sources (e.g. audio and video files); coding (i.e. gathering material together by topic, theme, or case); nodes (i.e. containers for the coding); source classifications (i.e. classifying information about the sources); and node c

Classifications (i.e. classifying information about people or places) (QSR International, 2014, p.7). NVivo allows the researcher to import existing Microsoft Word translated and transcribed interview files. NVivo also allows the researcher to import other items such as audio recordings, video recordings, pictures, web pages or social media content (QSR International, 2014). This allows the researcher to 'build up' a research project in NVivo and helps the researcher to better analyse patterns and themes that may emerge from the interview data (QSR International, 2014). The NVivo workspace is efficiently organised so that the researcher can organise and access interview transcripts from one location.

The NVivo navigation view allows the researcher to quickly access external materials that have been imported into NVivo, and to view sources, nodes, classifications, collections, queries, reports, models, and folders (QSR International, 2014). Sources are the source items such as videos, photos, transcripts, or other datasets. Nodes are the codes that are typically used in TCA, such as 'Culture'. Classifications refer to either source classifications or node classifications. Source classifications allow the researcher to record source information, e.g. particular database (QSR International, 2014). Node classifications can be used by the researcher to record information about people and places, and sources can be coded in order to gather material about particular themes or topics (QSR International, 2014). All references to the node can

then be coded in any sources that are analysed. NVivo also allows researchers to code to gather all material about a person, place or other case in one location (QSR International, 2014).

The way a researcher approaches coding will depend on the methodology that is employed, and the overall research design (QSR International, 2014). However, there are different types of coding that the researcher can use. For example, topic coding can relate to a particular topic such as real estate or tourism (QSR International, 2014). Analytical coding relates to what the content is really about, why it is interesting or relevant, and what is the particular context of the data (QSR International, 2014). Descriptive or case coding relates to people who are speaking, or anything that is being observed (QSR International, 2014).

Researchers may begin with a 'broad-brush' coding approach in order to organise the data into broad topic areas, and then do more detailed coding (QSR International, 2014). If we apply this NVivo approach to the research study I first aimed to identify broad-brush codes so that I could organise the transcripts into general patterns. This included codes such as 'pity', 'inequality', 'mobility', 'religion', 'culture', 'subsidy', and 'quality of life'. These codes helped me to start to make sense of the transcripts and allowed me to compare across the transcripts.

RELIABILITY AND VALIDITY

Reliability and validity are important considerations when undertaking research studies. The way in which they are approached will change depending on whether the researcher is undertaking a quantitative or qualitative research study. Reliability is important because people who may read the thesis may want to know and understand how they can trust the accuracy of the findings represented in the study. Validity is important because people who may read the thesis may want to know and understand whether my research findings are truly representative of the facts that exist at the **White Hospital** in Jeddah. Joppe (2000, p.1) has defined reliability as:

> The extent to which results are consistent over time and an accurate representation of the total population under study is referred to as reliability and if the results of a study can be reproduced under a similar methodology, then the research instrument is considered to be reliable.

Validity is defined as:

> Validity determines whether the research truly measures that which it was intended to measure or how truthful the results are. In other words, does the research instrument allow you to hit "the bull's eye" of your research object? Researchers generally determine validity by asking a series of questions, and will often look for the answers in the research of others (Joppe, 2000, p.1).

Reliability relates to whether the research study result is replicable or not, and for validity, whether the means of measurement used are accurate and whether they are actually measuring what they intended to measure (Golafshani, 2003). For quantitative researchers, validity and reliability are important because this verifies the truth of the scientific research (Golafshani, 2003). However, these concepts are viewed differently by qualitative researchers who believe these concepts to be inadequate and not suitable for the qualitative paradigm (Altheide and Johnson, 1998; Leininger, 1994; Golafshani, 2003).

Other researchers have proposed adopting alternative criteria for determining reliability and validity and therefore ensuring rigour, in qualitative inquiry (Lincoln and Guba, 1985; Leininger, 1994; Rubin and Rubin, 1995). The qualitative constructs used in this research study are: credibility (in preference to internal validity); transferability (in preference to external validity); dependability (in preference to reliability); and confirmability (in preference to objectivity) (Guba, 1981; Guba and Lincoln, 1981; Lincoln and Guba, 1985).

Credibility

For example, in terms of establishing credibility in a qualitative research study this might involve the use of triangulation, iterative questioning, random sampling of individuals to serve as informants, negative case analysis, and tactics to help ensure honesty in informants when contributing data (Shenton, 2004). The idea behind establishing credibility is that readers have more confidence and faith in the researcher when the researcher can establish and evidence the credibility of the research study. The strategies that were employed in this research study to establish credibility were regular checking of the research thesis and peer scrutiny of the research project by

University supervisors, the researcher's reflective commentary, thick descriptions of the phenomenon under scrutiny (Shenton, 2004).

Credibility can also be derived from the trustworthiness of the research study. This has been defined to encapsulate quality, authenticity, and truthfulness of findings in qualitative research (Cypress, 2017). This means that it relates to the degree of trust or confidence that readers have in qualitative research (Cypress, 2017). In a qualitative research study, it is the researcher that is often the data-gathering instrument, and this means that questions of research bias and researcher competency, if unchecked, may influence the overall trustworthiness of the data (Brink, 1993). For example, the status position of the researcher, as either an outsider or a group member, can prevent the researcher from obtaining certain information (Brink, 1993). This in turn may feed into the interpretation of data if the researcher is unaware of this (Brink, 1993). Alternatively, if the researcher becomes too intertwined within the participant group, the researcher runs the risk of "going native", and thereby assuming the attitudes and behaviours of those under study (Brink, 1993).

If this occurs the researcher may lose the ability to look upon the research study objectively, and therefore the trustworthiness of the study may be lost (Brink, 1993). By undertaking rigorous and extensive training as interviewers and observers prior to carrying out qualitative studies, researchers can be trained to develop a manner that encourages an objective view of the phenomena under study (Brink, 1993). In addition, a researcher can examine and declare his or her underlying values and assumptions in light of the research situation, in order to allow readers to consider them when reading the research (Brink, 1993). In this research study my personal positioning to the research study was set out for the reader in chapter 1.

Qualitative researchers aim to design and incorporate methodological strategies to ensure the 'trustworthiness' of the findings (Brink, 1993; Morse *et al.*, 2002; Golafshani, 2003; Noble and Smith, 2015). Indeed, Morse *et al.* (2002, p.14) argue that "Without rigor, research is worthless, becomes fiction, and loses its utility." Over the past two decades the criteria of reliability and validity have been slowly replaced by criteria and standards for evaluation of the overall significance, impact, relevance, and utility of completed qualitative research (Morse *et al.*, 2002).

There were nine strategies for establishing trustworthiness of findings that can be used in practice, and which were incorporated into my research study in order to ensure the

trustworthiness of the research study findings (Noble and Smith, 2015). These include accounting for personal biases which may influence findings (e.g. my personal views on people with disabilities) and acknowledging biases in sampling and ongoing critical reflection of methods (i.e. to ensure depth and relevance of data collection) (Noble and Smith, 2015). Another strategy is stringent record keeping and identification of a clear decision trail to ensure consistent and transparent interpretation of data by third parties (Noble and Smith, 2015). Also, a researcher can aim to seek out similarities and differences across accounts to ensure different perspectives are represented (Noble and Smith, 2015).

The researcher may also seek to include rich and thick verbatim descriptions of participants' accounts to support research findings (e.g. research themes), and by demonstrating clarity of thought processes during data analysis and interpretation (e.g. arguments supported by the literature) (Noble and Smith, 2015). The researcher may also engage with other researchers to reduce research bias (e.g. consulting with research supervisors) (Noble and Smith, 2015). There may also be respondent validation (of interview transcripts and final themes and concepts), and data triangulation (using different methods and perspectives) (Noble and Smith, 2015). The reliability and validity of a research study is also supported by a strong and robust approach to research ethics throughout the period of the research study.

Transferability

The second characteristic adopted is transferability. Transferability within the context of this qualitative research study involved the researcher providing information on the number of institutions taking part in the study, where they are based, the number of research study participants involved, the data collection methods that were used, and the time period over which the data was collected (Shenton, 2004). Other information used to establish transferability include any restrictions in the type of people who contribute to the data (i.e. the research sampling criteria), and the number and length of the data collection sessions which were set out earlier (Shenton, 2004). By providing as much information about the qualitative research study methodology, the researcher can aim to establish transferability in terms of the extent to which the findings can be generalised or transferred to other situations (Shenton, 2004).

Dependability

Dependability in terms of a qualitative research study, refers to the research design and its implementation, the operational details regarding the gathering of data, and reflective appraisal of the project (Shenton, 2004). By providing rich and deep data relating to dependability, the reader of the research study has a much better grasp of the approach that the researcher adopted (Shenton, 2004). The aim of this research chapter was to set out in as much detail as possible the overall approach to the research study, and comprehensive details of how the research study was undertaken. This was done in order to increase the dependability of the research study. By doing this, the reader is therefore in a better position to be able to judge for himself or herself the dependability of this research study (Shenton, 2004).

Confirmability

In terms of confirmability, a researcher might seek to reduce investigator bias, to use triangulation in order to reduce the effect of investigator bias (Shenton, 2004). In this research study I aimed to provide confirmability by justifying all decisions that were taken through the use of reflective commentary, I disclosed all of my predispositions, and I sought to provide an audit trail for the research project (Shenton, 2004). Overall, I aimed to put in place procedures to ensure the research findings are the results of the experiences and ideas of the informants (as opposed to characteristic preferences of the researcher) (Shenton, 2004). One view is that for a quantitative study whether the study is good or bad will depend on how reliability and validity are determined, whereas for qualitative inquiries, it would mean determining rigor (Cypress, 2017).

Rigour has been defined as the quality or state of being very exact, careful, or with strict precision or the quality of being thorough and accurate (Cypress, 2017). Means of establishing rigour include, audit of the decision trail and triangulation, self-description and reflective journal-keeping, respondent validation, prolonged involvement, persistent observation, peer debriefing, and triangulation (Long and Johnson, 2000). As noted by Long and Johnson (2000, p.35) "There is a clear imperative for rigour to be pursued in qualitative research so that findings may carry conviction and strength." In qualitative research, a comprehensive description of the research process which allows for intersubjectivity is something that can indicate good quality (Cypress, 2017). In addition, consistency and care in the application of research practices, reflected in the visibility of research practices, analysis, conclusion and

research limitations, can contribute to demonstrating reliability in qualitative studies (Cypress, 2017).

RESEARCH ETHICS

The research study involved researching and working with people with disabilities and social workers. In order to uphold the empowerment of the individual disabled participants and observe research ethics principles, I put in place a number of procedures in order to ensure respect for the autonomy of all the participants. The research ethics procedures that were put in place for the research study included a Project Information Sheet (**Appendix 13**); an Informed Consent Form (**Appendix 14**); approval from the Saudi Ministry of Health (**Appendix 15**); research ethics approval from the School of Nursing, Midwifery, Social Work and Social Sciences (now called the School of Health and Society) Ethical Approval Panel at the University of Salford; protection of research data; protection of research participants; and observing relevant codes of research ethics.

I developed a Project Information Sheet that provided comprehensive information about the research study to be administered to the research participants. The Project Information Sheet was subject to a process of refinement. It was updated and amended following suggested revisions and feedback provided by my supervisors. It included details regarding the background about the researcher; the involvement of the Saudi Ministry of Health; the aim of the research study; the research questions; the institution or institutions being researched; the number of research participants; an explanation of the research procedure and research methodology; and an explanation of the types of questions that will be asked. For the research study a research risk assessment was carried out and submitted as part of the overall research ethics research approval process (**Appendix 16**).

There is also an Informed Consent Form that provides written details regarding the research study and a detailed written form that the research participants signed prior to commencing any part of the research. The Informed Consent Form has been refined, with suggested revisions and feedback implemented. It included details explaining that the informed consent form was based on, and adapted, from a template form provided by the University of Salford. It stipulated that the research participant

has been provided with sufficient information to be able to give valid informed consent. It stipulated that the research participant has been provided with sufficient opportunity to ask me any questions that he or she might have about the research study. It also included a form which allowed the research participant to print and sign their name, as well as a space to write the date in order to ensure that there was no retrospective informed consent in place in the research study. Research ethics approval was sought and obtained from The Salford University Research Ethics Committee prior to commencement of any part of the field research (**Appendix 17**).

I also put in place and adhered to research security procedures that ensured that all research data was stored securely and in accordance with all legal requirements and obligations. I used a secured location for storing the interview recordings and transcripts that were collected in the KSA. I used a security password with digital encryption for any computer and/or laptop that was used in the research study. I only used trusted and reliable sources (i.e. people who can provide appropriate references or who the researcher knows personally to be trustworthy) for transcribing the interview recordings from Arabic to English. I observed and adhered to all legal requirements for the storing of personal data in the United Kingdom under the provisions of the Data Protection Act 1998.

I ensured that all the participants' rights to privacy and confidentiality were respected at all times. I ensured the anonymity of all the research participants by using pre–determined "codes" to refer to all the participants in all research documents. I ensured that all the research participants were informed of the potential future use of the research data, e.g. for publications and/or conferences. I also informed all the research participants that there will be no risks to being identified in the final written research thesis, or in any subsequent publications based on the findings of the research study. I later assigned pseudonyms to all the research participants. These were names that are used frequently in the Middle East region. I randomly assigned colours to the names of all the hospitals cited within the research study. The **White Hospital** was the hospital at which I carried out the research study. Other hospitals were hospitals that were referred to by the research participants. These were the **Red Hospital, the Green Hospital, the Blue Hospital, the Yellow Hospital, the Pink Hospital, the Purple Hospital, and the Orange Hospital**.

I read and applied two codes of ethics listed and recommended on the University of Salford Postgraduate Research webpage. This is located online at: http://www.pg.salford.ac.uk/page/codes_of_ethics. The codes of ethics were The British Psychological Society Code of Ethics and Conduct (August 2009) and The British Psychological Society Code of Human Research Ethics (2010). The British Psychological Society Code of Human Research Ethics (2010) notes four Code of Ethics Principles which I used and adapted to guide my research study, these are respect, competence, responsibility, and integrity.

Relevant code of ethics principles applied to the research study

When discussing respect in relation to carrying out a research study, this means respect for the overall autonomy of the research participants, including respecting the wishes of the research participants. In practice this meant explaining to the research participants that they could stop or withdraw from the interview at any time. It also meant ensuring that the Project Information Sheet provided all the information they needed about the research study so that I could obtain an Informed Consent form from legally competent research participants.

Respect also means respecting individual, cultural and role differences (e.g. disability, ethnicity, religion, socio-economic status). I aimed to avoid unfair or prejudiced practices, I kept appropriate records of meetings and interviews, and I carefully and securely stored confidential information. I made audio recordings of the research participants only with their explicit permission. I also ensured that the research participants were given every opportunity to understand the nature, purpose, and anticipated consequences of the research study. Finally, I ensured that the Research Participants were made expressly aware of their right to withdraw at any time from their participation in the research study.

In terms of competence, I developed and maintained a comprehensive awareness of professional ethics. I also aimed to integrate ethical considerations into the research study itself. I sought and obtained supervision and peer review to guide the process of ethical decision making wherever possible, including within the design of the research study and development of the written thesis. I was also able to justify my actions on ethical grounds, and I remained aware of, and acknowledged, the limits of research

methods used, as well as the limits of the conclusions that are drawn from the research methods under different circumstances and for different purposes.

In terms of responsibility for my research study, I aimed to avoid harming the research participants in any way at all times. I aimed to avoid personal and professional misconduct and I also aimed to consider all research from the view of the research participants in order to eliminate all potential risks to psychological well-being, physical health, personal values, or dignity of the research participants. When interviewing the research participants I informed them that they could at any time decline to answer any questions put to them, whilst also stating that this may lead to termination of their participation, especially where safety issues are implicated. I acted with integrity at all times and valued honesty, accuracy, clarity, and fairness in my interactions with the research participants. I aimed to be honest and accurate in representing my professional affiliations and qualifications, including such matters as knowledge, skill, training, education, and experience. I also aimed to refrain from abusing professional relationships with the research participants in order to advance their sexual, personal, financial, or other interests.

DATA PROTECTION ACT 1998

The UK's Data Protection Act (1998) (**DPA 1998**) was used as a framework for confidentiality, where all personal information will be coded and anonymised. The data generated was considered confidential and handled in a way that protects the anonymity and dignity of the research participants. Section 1 of the DPA 1998 states that 'data' means any information which is being processed by means of equipment operating automatically in response to instructions given for that purpose and is recorded with the intention that it should be processed by means of such equipment. This would therefore include data that is recorded by means of audio equipment such as the recording of an interview transcript. Schedule 1 of the DPA 1998 sets out eight 'Data Protection Principles' that data processors must adhere to when processing data.

There are a broad range of principles specified that data processors must adhere to. These include that personal data is be processed fairly and lawfully and, in particular, shall not be processed unless the data subject has given his consent to the processing. In the case of 'sensitive personal data' (i.e. his physical or mental health or condition) the data subject must give his explicit consent to the processing of the personal data.

Personal data is required to be obtained only for one or more specified and lawful purposes and is not be further processed in any manner incompatible with that purpose or those purposes.

Personal data is required to be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed. Personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes. Personal data is required to be processed in accordance with the rights of data subjects under the DPA 1998. Finally, appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.

CHAPTER SUMMARY

This chapter described the importance of epistemology within the research study, and highlighted the reasons for drawing on both positivist and interpretivist approaches. The discussion of epistemology was essential in order to contextualise the aim of the research study and the gathering of knowledge required to facilitate the research study. It identified the idea of reflexivity and how reflexivity was embedded within the research study in order to increase the overall. The concept of research design was discussed along with its importance in relation to the research aim, objective, research questions, and factors that may influence the choice of research design.

The chapter described the qualitative research approach that was adopted within the research study, including the use of semi-structured interviews and the development of an interview schedule. An overview of the data collection methods was provided (i.e. literature review, legislation and policy analysis, interviews) and the practical data collection procedure that was used in the KSA was set out, including sampling and data analysis. In terms of data analysis, the chapter described the nature of thematic analysis and the use of NVivo software to carry out thematic analysis on the research data. The importance of validity and reliability in research studies was discussed, as well as how validity and reliability within the context of this qualitative research study (i.e. credibility, transferability, dependability, and confirmability) were established. The chapter also discussed research ethics and the Data Protection Act 1998.

CHAPTER 5

INDUCTIVE FINDINGS – PART I

INTRODUCTION

The primary inductive findings are set out in two chapters in order to allow for more detailed coverage. This chapter sets out the inductive findings part 1, and chapter 6 sets out the inductive findings part 2. This chapter summarises the themes that were identified from the data obtained at the **White Hospital** in Jeddah, in the Kingdom of Saudi Arabia (**KSA**). This chapter will also set out the Initial Coding Framework that was used for all the transcribed and translated interviews. The findings were put together via a two-stage process. The first stage of the process involved an analysis of five of the research study transcripts in order to identify if there were any preliminary themes that emerged from the data. This stage facilitated a better understanding about the ideas and concepts that affected the research participants.

The themes that emerged from this analysis were labeled the 'preliminary themes'. Thereafter, during the second stage, a complete analysis of all the interview transcripts was undertaken, and this identified the 'final themes' that emerged from the data. The chapter will set out summary data for all the interviewees in order to provide an overview of the types of people who were interviewed. It will also set out the inductive findings and will put together the final themes that emerged from the Content Analysis that was carried out on all twenty-four transcripts.

Overall, the chapter will show that the research participants face a range of difficult issues that they encounter and have to deal with in their daily lives. For instance, there are difficulties with the overall quality of medical support that they receive, and issues with the level of social support services they can access. There are also a number of difficulties they face in terms of perceptions of them by others and their overall quality of life. Other issues that will be identified include the generally low levels of financial assistance they obtain, as well as what problems they believe they may face accessing education.

FINDINGS

The findings identified nine themes from the data: (1) the nature of medical support; (2) financial assistance; (3) mobility; (4) social support services and social workers; (5) access to education; (6) quality of life; (7) perceptions and problems; (8) religion and disability; and (9) gender and disability.

PRELIMINARY FINDINGS

The mean length of the interview transcripts was 25 pages long, and I was therefore able to obtain a rich, deep quality of data within the transcripts. There were many interesting insights that I was able to obtain from the research participants. I was able to draw together a few preliminary themes from the transcripts, based on five of the research participants that had been interviewed. I believe this initial analysis was helpful as it allowed me to highlight what areas the research participants had found challenging, and also what perspectives and insights they can offer into their lives, for example, in terms of how disability has affected them. In addition to this, I have to say that I was shocked by many of the stories that the research participants told me.

It was difficult for me to listen to their stories because many of the research participants had previously had to cope with such difficult situations that I really felt for them and what they were going through. For example, LULU noted that she had been travelling from Jazan to Tabuk to attend her marriage. Her father and mother and her ten sisters and a brother had been travelling with them. They had been involved in a car crash and two of her sisters died and her mother had injured her leg and now walked on crutches. Her father was a in a coma for three months at the **White Hospital** in Jeddah but had then died. She had not finalised the marriage subsequent to her injury.

It is so difficult to imagine the emotional impact that this kind of horrific ordeal had on LULU. Her life being instantly devastated. She lost two sisters and ultimately also lost her father. If we apply the medical model of disability to LULU, then we would say that LULU has a physical disability originating from a car accident (Wade, 2004; Smart and Smart, 2006). This is helpful to us in terms of identifying the medical treatment or potential rehabilitation services that might be relevant for her. However, the social model is better able to incorporate wider influences on the perception and meaning of disability felt by the research participants. For example, a social model is more able to

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incorporate the emotional horror that LULU has had to endure, seeing her sisters die and her mother injured, on top of having to come to terms with dealing with her own disability (Deutsch, 1952; Lave and March, 1993; Trifiletti *et al.*, 2005). The medical model of disability does not particularly take into account the fact that she was not able to marry after the car accident, and what effect this had on her emotionally (Deutsch, 1952; Lave and March, 1993; Trifiletti *et al.*, 2005).

In reality, disability is more than simply physical impairment. It incorporates so many different emotions, behaviour, and attitudes. Disability is both physical and emotional and is constantly changing. An individual may have a disability and over time may learn to accept and cope with that disability, but at any second, a negative social encounter (e.g. harassment because of a disability) may leave that individual feeling vulnerable (Oliver, 1990; Adibi, 2014). The social model of disability helps us to perceive how wider society in the KSA may view LULU now – a thirty four year old separated female with physical disabilities. Consequently, whilst the medical model of disability was important for the respondents, the respondents tended to view their disability more from a social model of disability (Taylor and Hawley, 2010; Adibi, 2014).

For example, they described their lives and the challenges they faced from a social model perspective, in terms of how society viewed them and the challenges they faced with, for example, mobility. Indeed, the social model of disability is better able to grasp the emotional turmoil that the participants have faced, and often continue to face, in their daily lives (Taylor and Hawley, 2010; WHO, 2016). Another practical example is the case of YASMINE. For example, YASMINE noted that her father died in the same month that she was planning to get married, and that she was not able to get married because she was experiencing serious conditions.

Having a father die, not being able to get married, and becoming paraplegic is an enormous emotionally difficult challenge. It can potentially bring the onset of depression, fear, worry, anxiety, bitterness, and helplessness. At the onset, a disability is emotionally draining (Carson, 2009). Indeed, these types of emotional difficulties faced by the participants would be hard enough to cope with by themselves, yet when coupled with physical disabilities, it is not hard to imagine how incredibly difficult it is for the participants to deal with the physical and emotional turmoil in their lives on a daily basis (Carson, 2009). The social model of disability is better able to capture this

turmoil which surrounds many people with disabilities (Swain and French, 2008; French and Swain, 2011).

However, even when dealing with the medical model of disabilities there are still problems that can be identified. For example, DOHA noted that she was irritated because she had been without physiotherapy for three months. She had asked the staff when she would next have physiotherapy and they had told her it would be soon. When I asked the social worker at the hospital why the hospital had stopped physiotherapy for DOHA, the social worker informed me that DOHA had hemiplegia and that she had not accepted her disability. In addition to coping with their disability, these individuals have had to adjust to quite traumatizing experiences and sometimes when discussing issues of disability and social inclusion, we often may somewhat overlook these highly important psychological and emotional aspects of disability (Yanagita *et al.*, 2006). Therefore, when developing the Initial Coding Framework, I endeavoured to try to capture these psychological and emotional aspects of disability, wherever I felt they were relevant.

INITIAL CODING FRAMEWORK

The Initial Coding Framework was developed for the first five transcripts that were transcribed. The Initial Coding Framework is set out below (**Table 6**). As can be seen, it uses Codes and Descriptors to identify feelings, emotions, behaviours, views and activities. In this way the Initial Coding Framework was developed to capture a broad range of descriptors that might apply to the research participants.

Table 6: Initial coding framework

Code	Descriptors
Acceptance	Acceptance of condition. Acceptance of situation.
Access to education	Issues relating to access to education. Information about access to education. Knowledge about access to education. Views about access to education.
Daily life	Description of daily life.

Code	Descriptors
	Positive and negative views of daily life.
Helplessness	Feelings of helplessness.
	Views of others towards participants.
Inequality	Views of participants regarding medical care and support.
Isolation	Feelings of isolation.
Loneliness	Feelings of loneliness.
Medical support	Level and quality of medical support provided.
	Lack of proper medical support.
	Bad medical support.
Mobility	Level of mobility of research participants.
Motivation	Feelings about condition.
	Feelings about life.
	Feelings about support.
Oppression	Feelings of oppression felt by the research participants.
Physiotherapy	Views towards physiotherapy.
	Provision of physiotherapy by hospital.
Pity	Views of others towards research participants.
Quality of life	Overall quality of life for research participants.
Religion	Aspects of religion affecting research participants.
	Practice of religion by research participants.
Social services	Social services provided to research participants.
	Availability of social services provided to research participants.
Social workers	Views of social workers.
	Conflicting information provided by social workers.
Subsidy	Subsidies available to research participants.
	Availability of subsidies to research participants.

Code	Descriptors
Support	What support research participants obtain from family, friends, and other people.
Women and disabilities	What problems women with disabilities face.

THEMES

Following on from undertaking TCA on five of the transcripts, there were seven themes that emerged from the transcripts. These themes were basic themes that I was able to ascertain from the transcripts. They were based on the issues that some of the participants were interested in talking about with me. There were some themes that were founded on more data than others. For example, themes such as quality of medical support, financial assistance, and mobility were all issues that were discussed in depth by the participants. Other themes such as access to education were mentioned by a few of the participants. However, there were different perspectives mentioned with regards to access to education, so it was not possible to identify a commonality behind this theme.

Generally, I identified issues that the participants were anxious about or issues which the participants wanted to talk about in greater detail compared to other issues. These themes are set out in **Table 7**.

Table 7: Themes

No	Theme
1	Nature of Medical Support.
2	Financial Assistance.
3	Mobility.
4	Social Support Services and Social Workers.
5	Access to Education.
6	Quality of Life.
7	Perceptions and Problems.

I have also summarised key characteristics of all interviewees in order to indicate their particular background. The key characteristics include details as to their disability,

gender, age, length of stay in hospital and other relevant demographic characteristics. These are listed in **Table 8**. I believe these key characteristics will help the reader to build up a 'mental picture' of the research participants, and to connect with the particular context of their situation.

INTERVIEW SUMMARIES

Table 8: Interview Summaries

Name	Condition	Injuries	Age	Occupation	Gender	Income	Education	Status	Family	Time Spent in Hospital
AAFIA	Limb nerve disease.	Unknown.	20.	None.	Female.	1000 Riyals (social insurance) 1000 Riyals (Aid) **MONTHLY TOTAL** **2000 SAR** **(£411.28)**	Middle stage education.	Unknown.	4 brothers, 1 sister, both parents.	4 years in different hospitals.
AASIA	Hemiparesis.	Fracture in spinal vertebra, cut in spinal cord.	25.	None.	Female.	None. Help from brother who works as a government employee. **MONTHLY TOTAL** **None.**	General secondary.	Unknown.	Divorced. No children. One brother and sister.	2 years in different hospitals.
ATIF	Hemiplegic.	Car accident.	18.	None.	Male.	Unknown. **MONTHLY TOTAL** **Unknown.**	Unknown.	Single.	Mother, father, four brothers, six sisters.	Unknown.
AWAD	Bank injury spinal cord intact.	Car accident, injured five lumbar vertebrae.	32.	None. Ex government employee.	Male.	900 Saudi Riyals (**SAR**) per month. **MONTHLY TOTAL** **900 SAR** **(£194)**	Bachelors Degree.	Single.	Five brothers and sisters.	Six years.
AWADI	Disability in limbs for 13 years.	Bullet penetrated the chest forming injury in spinal cord.	28.	Ex Solider.	Male.	None. **MONTHLY TOTAL** **0 SAR** **(£0)**	Second middle year.	Single.	Two sisters, four brothers.	One year.

Name	Condition	Injuries	Age	Occupation	Gender	Income	Education	Status	Family	Time Spent in Hospital
DOHA	Hemiplegia.	Car accident.	40.	None.	Female.	800 SAR per month. **MONTHLY TOTAL 800 SAR (£172)**	Average third.	Widow.	Two married siblings.	Unknown.
HANI	Parapleiga.	Fractures of the T12 and T13 vertebrae and compression of the spinal cord.	Unknown.	Unknown.	Male.	800 SAR per month. **MONTHLY TOTAL 800 SAR (£172)**	Secondary school certificate.	Unknown.	Unknown.	One year and five months.
INAM	Back injury.	Car accident, injured in the back on left side, from the seventh to the eleventh Lumbar vertebrae.	32	None. Ex government employee.	Male.	900 SAR per month. **MONTHLY TOTAL 900 SAR (£194)**	Bachelors Degree.	Single.	Five brothers and sisters, mother. Father is deceased.	Unknown.
KAMAL	Paralysis.	Disease in bone, tuberculosis.	35.	None.	Male.	1,800 SAR per month. **MONTHLY TOTAL 1,800 SAR (£388)**	Unknown.	Single.	Seven sisters, mother.	Four years.
LUCAS	Inflexibility in limbs, uses wheel chair.	Brain membrane inflammation.	36.	None.	Male.	Unknown. **MONTHLY TOTAL Unknown.**	Bachelor Degree in Administration.	Single.	Father, mother, brother, two sisters.	One week.
LULU	Physical disability.	Car accident.	34.	Unknown.	Female.	4,000 SAR per month. **MONTHLY TOTAL 4,000 SAR (£860)**	Bachelors Degree in Engineering.	Divorced.	Mother, five brothers and five sisters (two died).	Two months.

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Name	Condition	Injuries	Age	Occupation	Gender	Income	Education	Status	Family	Time Spent in Hospital
MALIK	Ataxia.	Car accident leading to brain injury.	33.	None. Ex administrative clerk.	Male.	7,900 SAR per month. **MONTHLY TOTAL** **7,900 SAR** **(£1,699)**	Unknown.	Single.	Father.	Ten years.
MOHAMMED	Tetraplegia.	Injuries in the vertebral column, spinal disc herniation.	26.	None.	Male.	Father is retired. No monthly income. No subsidy from Ministry of Social Affairs. **MONTHLY TOTAL** **0 SAR** **(£0)**	General Secondary.	Single.	3 sisters and parents.	4 years in the Rehabilitation Department. Before that 3 months in the admission department at King Fahad Hospital.
NANA	Quadriplegia in hands and legs.	Vehicle crash by drunk driver causing internal bleeding and fracture.	Unknown.	Ex Hospital Worker.	Female.	1,600 SAR. **MONTHLY TOTAL** **1,600 SAR** **(£344)**	College of Education (English literature department and translation).	Married.	Mother, father, two brothers.	Five years.
OMAR.	Disabled, paralyzed for 3 years.	Electricity column fell on his chest and spine and crushed him. He was also electrified and burned.	22.	None.	Male	800 SAR per month. **MONTHLY TOTAL** **800 SAR** **(£172)**	High school graduate.	Single.	Mother, brother, and four sisters.	3 months in Rehabilitation Department. 3 years in King

Name	Condition	Injuries	Age	Occupation	Gender	Income	Education	Status	Family	Time Spent in Hospital
										Fahad Hospital.
SAAD	Paralysis.		40.	Retired aircraft engineer.	Male.	4232 Riyals (£870.27). **MONTHLY TOTAL 4,232 SAR (£870.27)**	Diploma degree in Air Engineering (Pakistan).	Unknown.	3 children and wife.	6 months in Rehabilitation Department.
SAIF	Quadriplegic.	Car accident leading to broken neck and spinal cord compression.	23.	None.	Male.	800 SAR per month. **MONTHLY TOTAL 800 SAR (£172)**	Third grade secondary.	Single.	Father, mother, six sisters, five brothers.	Unknown.
SHAMZ	Unknown.	Unknown.	Unknown.	Unknown.	Male.	Unknown.	Unknown.	Unknown.	Unknown.	One week.
YASER	Quadriplegia.	Driving car, crashed into a tree, car overturned, spinal cord injured in the fifth and sixth vertebra of the spinal cord.	20.	None.	Male	1000 SAR per month. **MONTHLY TOTAL 1,000 SAR (£215)**	Secondary school.	Single.	Parents, five girls, and three boys.	Unknown.
YASMINE	Paraplegic.	Osteomyelitis	18.	None.	Female.	None. **MONTHLY TOTAL 0 SAR (£0)**	Second level intermediate education.	Single.	Uncle, father.	One month. Third time at the hospital.
ZEEK	Limited movement.	Tumour in spinal cord.	18.	None.	Male.	None. **MONTHLY TOTAL 0 SAR (£0)**	Unknown.	Single.	Nine siblings.	One month.

Name	Condition	Injuries	Age	Occupation	Gender	Income	Education	Status	Family	Time Spent in Hospital
ZEINA	Stiff dystrophy unable to walk.	Unknown.	Unknown.	None.	Female.	1,000 SAR per month. **MONTHLY TOTAL 1,000 SAR (£215)**	Second year in University.	Single.	Father, mother, sisters.	Unknown.
ZISHWAN	Hemiplegic.	Fell 10 metres and injured spinal cord and head resulting in paralysis.	39.	Air conditioning engineer.	Male.	Unknown. **MONTHLY TOTAL Unknown.**	Diploma in Industry.	Widower.	Wife and children (one boy and one girl) died. All family died in chemical bombardment from Syria.	Unknown.

FINAL THEMES

Following on from undertaking TCA on all the transcripts I was able clearly to identify nine distinct themes that emerged from the transcripts. The TCA on all the transcripts was undertaken using the NVivo software package. Four of the themes will be dealt with in this chapter. These are: (1) the nature of medical support; (2) financial assistance; (3) mobility; and (4) social support services and social workers. The other themes will be dealt with in the next chapter. These are: (5) access to education; (6) quality of life; (7) perceptions and problems; (8) religion and disability; and (9) gender and disability. The data from the full set of transcripts showed significant similarities from the first batch of transcripts that were analysed. In general, the answers from the respondents tended to fall within one of the pre-identified themes. These tended to relate to issues regarding mobility, quality of medical support, and financial assistance.

There were numerous problems that were discussed in practice and there was also commentary regarding the availability of social support services. The theme of religion and disability was added because it became clear that a number of research participants seemed to view religion as deeply integral to their lives. The theme of gender was also added because I felt there were many issues particular to gender and disability that were relevant to the research participants within the context of the KSA. It also seemed to be the case that the Islamic faith seemed to provide support for a number of the research participants, in terms of their ability to cope in their daily lives. This interaction between religion and disability is developed further in the discussion regarding the theme.

THEME 1: THE NATURE OF MEDICAL SUPPORT

There were a number of issues that were identified by the research participants that related to the overall nature of medical support that was provided to the research participants. The findings are presented thematically under three sub-themes: (1) problems with hospitals in the KSA; (2) problems with long term medical support; and (3) lack of high quality treatment and medical devices.

Problems with hospitals in the KSA

Several participants noted problems with hospitals in KSA. One participant, SAAD told me that although his case was well known, six hospitals said that he could not be treated there. He stated **"I don't request charity, but I request my right."** [SAAD Transcript, p.6] Indeed, it is difficult to understand why SAAD was turned away from six hospitals, even though in principle the Saudi government healthcare system is a national health care system that is supposed to provide free healthcare services for all members of society. Why is it the case that six hospitals refused to treat an individual with paralysis?

Saad believed that this might be connected to the way in which he had become paralysed. He entered a German hospital to have an operation on his fourth and fifth lumbar vertebrae. He said he had asked the doctor if there was anything dangerous about the operation, or if any difficulty would arise from the operation. The doctor informed SAAD that medicine had advanced and there would be no negative effects. However, after the operation SAAD was unable to move his leg. He stated **"… they don't want to write a medical report about the operation… this is due to a conspiracy between doctors"** [SAAD Transcript, p.5]

In the United Kingdom (**UK**) the law has established a general duty to take reasonable care to avoid foreseeable injury to a neighbour (*Donoghue v Stevenson, 1932*) (Bryden and Storey, 2011). Where a duty of care is breached, liability for negligence may arise (Bryden and Storey, 2011). In the UK the doctors would owe SAAD a duty to disclose all the risks that such a medical procedure would involve, in order for SAAD to be able to make an informed decision about the surgery (Bryden and Storey, 2011). In this instance it seems to be the case that SAAD was not informed about the risks of the operation, and he was not provided with a medical report about the operation.

The overall poor quality of medical support was also noted in a number of other participants. The data highlighted that this did seem to be an issue for many of the interview participants. For example, AASIA noted that the quality of medical care and support in some hospitals was quite bad. AASIA stated: **"I had the physical therapy in the Blue Hospital. My experience there was bad; the devices were poor, rusty, broken and dusty and tightened in ropes."** [AASIA Transcript, p.3] This seems to indicate a very bad level of overall quality of medical care and support, with medical equipment which could expose patients to harm and infection (Eaton, 2012). AASIA

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commented on the poor quality of medical support that she believed the hospitals were providing: **"I think that this is negligence from hospitals that are careless towards conditions of a patient like me who want to get the medical report or its seal."** [AASIA Transcript, p.5] AASIA said that she felt a lack of support from hospitals in Jeddah. She noted that one of the doctors at the Red Hospital even once told her to have physiotherapy because of her paralysis, which was frustrating for her.

In this day and age, it is quite startling to hear that a professionally trained doctor at Red Hospital told AASIA to have physiotherapy that she would not benefit from because of her particular type of paralysis. One might ask how does that kind of treatment fit into the medical model of disability? Instead of providing medical care and support AASIA's needs are misdiagnosed. KAMAL noted that he had been visiting hospitals for quite a while so that doctors could examine his back pain. The doctors provided him with medication and caffeine for several years and they finally diagnosed tuberculosis in his bones. He then went to the Green Hospital where they informed him that he had to have surgery. The surgery failed and KAMAL developed paralysis and a weakness in his muscles. He then had an operation to have a plate fixed to his back. But then the doctors discovered that the plate which was fixed on his back was bigger than what was expected as it did not match his size, and the installed plate was not the same as had been recommended in the medical report about his case.

In the UK, the maxim 'res ipsa loquitur', or 'the thing speaks for itself' is a long-standing rule of evidence commonly utilised in personal injury law (Moloney, 2017). Three conditions are required, namely: (1) the event is one that would ordinarily not occur in the absence of negligence/fault; (2) the thing causing the damage must have been under the control of the defendant; and (3) there is no evidence as to why or how the accident occurred (*Scott and Bennett v Chemical Construction (GB) Ltd*, [1971 3 All ER 822) (Moloney, 2017). Based on this test the information provided by KAMAL would seem to indicate that a degree of medical negligence took place, as KAMAL had the wrong type of plate inserted on his back during medical surgery, despite the fact that a recommended size of medical plate had been specifically stated in the medical report.

The potential medical negligence that was identified would tend to support the lack of good quality of medical care that has been provided to the research participants (Bryden and Storey, 2011). I asked KAMAL whether he believed that it was because

of the negligence in the place and he replied **"Yes many times we suffer from lack of medicines, especially diabetic medications."** [KAMAL Transcript, p.5]. I asked KAMAL whether he meant that they did not cover the needs of the patients in the hospital, to which he responded **"Yes due to the low budget, as the staff tell us, we have no right to complain."** [KAMAL Transcript, p.5]

If what KAMAL told me is true, how can hospital staff telling a hospital patient that they have no right to complain be in any way seen as providing good quality medical care and support? KAMAL continued by saying that he felt that no one had told him the right information about his case, no one had supported him socially, no one had provided him with a specific programme for physiotherapy, and he had received no indication about the development of his case. Despite the problems there, KAMAL noted that admission to the hospital was not easy, and one time he had sworn by God that he would not leave the hospital and so he was transferred to the current hospital and he threatened that he would throw himself off the bed.

The behaviour displayed by KAMAL was somewhat difficult to understand. On the one hand KAMAL was attending the hospital in order to obtain rehabilitation services so that he could be rehabilitated and be able to cope better in the outside world. However, his behaviour showed that he did not want to leave the hospital. He seemed to believe that the best place for him was to stay in the hospital and that KAMAL was lucky that he was admitted to hospital. Because of this behaviour and attitude the medical staff at the hospital seemed to find it difficult to cope with his case.   With regards to the attitudes and behaviour of the staff, KAMAL noted:

> **Yes, one of them works hard and the other is too lazy and they ask me to do back exercises to be freed from tension, but I can't move my legs up.** [KAMAL Transcript, p.4]

KAMAL believed that the staff aimed to make it look to the outside world that they were doing their jobs competently, but in reality this was not true:

> **I've found everyone imitates the other they don't care about patients and they are kidding until twelve o'clock, but they try to let people think that they are doing their job well.** [KAMAL Transcript, p.4]

If what KAMAL is saying is true, then this might merit further investigation.

Problems with long term medical support

From the data, there seemed to be real problems with the type, level, and quality of medical support that was provided to the research participants. For example, MOHAMMED had been in the Rehabilitation Centre for 4 years and in his first year he received no physiotherapy at all. MOHAMMED stated that he had many times asked for physiotherapy sessions with a physiotherapy specialist, but he was never provided with one. He acknowledged that physiotherapy sessions helped his condition but whilst other patients had been provided with sessions, he was not. MOHAMMED noted:

> **"…so there is no equality among patients in exercises." [MOHAMMED Transcript, p.9]**

MOHAMMED said that he perceived a lack of equal medical support:

> **"Because everything other patients take isn't provided to me, especially physical therapy." [MOHAMMED Transcript, p.9]**

MOHAMMED believed that the quality of medical support that was provided to him had deteriorated. He noted that in the past if he needed anything it was found for him, and the quality of nursing was better. But now MOHAMMED felt as if when he asked for a cup of water, the nurses only came after he had rung the bell multiple times, and **"they provided service with a sense of being 'pissed off'. I even only change the diaper once a day in order not to make them feel tired." [MOHAMMED Transcript, p.21]** In the hospital, even if it is the medical model of disability that is being implemented, patient medical care and attention should be of paramount importance. That is what the doctors and nurses are there for in a hospital, to treat the patients and those in rehabilitation. This overall quality and level of medical care and attention should be consistent, it should not deteriorate over time. MOHAMMED now even felt as if he was imprisoned because of his life and his treatment in the hospital:

> **I don't know. Suddenly, the management prevented me from going out through a report from the doctors, so this is like imprisoning me… In other words, the manager of the rehabilitation centre told us that we were not allowed to be out of the hospital, and only in the outpatient clinic. This is imprisoning. [MOHAMMED Transcript, p.8]**

Lack of high quality treatment, medical devices, and services

After reviewing the transcripts it also seemed to be the case that many of the participants felt that they had difficulties securing high quality treatment and medical devices such as wheelchairs or good quality diapers. The lack of good quality medicines and other items provided by the hospital was also made apparent:

> **I mean diapers which are given to patients here, the very coarse type is not fit for use where once used then odours quickly leak, because it is very weak because of the lack of quality, also about vitamins it is very few because of negligence with the pharmacy [KAMAL Transcript, p.5]**

HANI noted that he was in need of a new wheelchair but the Ministry of Social Affairs would only provide one every three years. HANI is paraplegic and therefore his impairment necessitates a wheelchair for mobility and access purposes. The Disability Code 2000 made provisions for people with disabilities across the whole of the KSA. However, HANI's situation shows how the provisions of the Disability Code 2000 do not really protect the rights of people with disabilities across the KSA. How can it be the case that a person with disabilities has to wait three years for a wheelchair? This situation is not protecting the rights of people with disabilities, and it is not even helping to facilitate a medical model of disabilities within the hospital environment.

YASMINE told me how she had become paraplegic and it was a difficult story to hear. She noted that when she was eighteen years old she had a surgery and soon after her feet were swollen and injured. She was tired and stayed in bed and her father was too busy to take her to the hospital. Although she went to the dispensary the doctor was not able to find a cause of the wound. She stayed in that condition for between three to four months and the pain stayed as it was. She was therefore in pain for a long period of time. A doctor was finally able to get her transferred to a hospital in Makkah and there the doctor told YASMINE that an infection had reached the bones and it was necessary to do an operation.

YASMINE had this surgery and was then able to walk but afterwards she said that the medication that she was taking caused her to burn up and have headaches which affected her vision. Thereafter she fell into a coma and went to the **Yellow Hospital**

for two months. It would therefore seem to be a combination of a lack of good quality medical support, often combined with careless attitudes that often led to the onset of disability in some of the research participants. Unfortunately, this is a really distressing situation to note in the research participants. ZISHWAN also believed that the services that were available were somewhat lacking:

> **Yes, there are many services and activities, that should be done, but the hospital does not have enough staff. For example, we need recreational services, let's consider it as leisure services, but the existing staff is not quite enough, and the staff must be specialists, the place must also have many means to provide treatment in a modern way. [ZISHWAN transcript, p.7]**

THEME 2: FINANCIAL ASSISTANCE

As discussed in the literature reviewed set out in chapter 2, it is clear that that there is a direct relationship between poverty and disability. People with disabilities also require greater financial assistance because they often have to purchase additional equipment and medications to support them in their daily lives. They often also have to buy wheelchairs, hearing aids, or other medical support aids, and may require some form of mobility support (e.g. electric wheelchairs or specially adapted cars) for travel purposes. In practice this means that people with disabilities often require additional financial assistance above and beyond their daily living costs in order to be able to cope with disability in their daily lives. From the interview transcripts, it was seen that people with disabilities were entitled to a wide range of disability benefits, i.e. there was a wide variation in benefits. The findings are presented thematically under three Sub-Themes: (1) lack of significant financial assistance; (2) delays in financial assistance; and (3) no financial assistance received.

Lack of significant financial assistance

There were a number of participants that were not receiving any financial assistance at all. In addition, where participants were receiving financial assistance, at a minimum these participants showed that at the bottom of the scale some were receiving

approximately 1000 SAR per month (£150) in terms of disability support. That works out to approximately £37.50 a week which means it is highly likely that they struggle to get by. In contrast, MALIK noted that he received 7,900 SAR (£2,249.11) every month. The Labor Office paid him 2,500 SAR (£600,028.), Social Insurance paid him 4,100 SAR (£1,024), and Social Affairs paid him 1,300 SAR (£234.66). MALIK seemed to be an outlier and the only research participant that received this amount. The amount he received positively impacted his life as he was better able to manage his disability and medical needs every month.

ZEEK was an example of a participant that was not receiving any financial assistance. When I asked ZEEK about whether he had his own income he replied that he no longer received any, even from insurance. In the KSA people with disabilities received monetary discounts from flights that are booked, and sometimes they are provided with complimentary flights. ZEEK said to me:

> **No, only from hospitals, the Airlines brought me here without giving me anything, but my father talked with them, so they gave me one month dues in the hospital and he talked with them once again to give me aid for another month** **[ZEEK Transcript, p.1]**

The interview transcripts revealed a clear theme relating to a lack of significant financial assistance. A number of participants noted that they received some financial assistance, but that it was not very substantial. For example, NANA said that she received Social Insurance every month of 1,300 SAR (£534.66) which would increase in the future to 1,650 SAR (£678.61) (because of complete paralysis). SAIF received 800 SAR (£172) from Social Affairs. ZEINA said that the family income was based on the retirement allowance of her father which she took from the government. She also noted that she had an allowance from the Social Affairs Department which was 1,000 SAR (£211.28) every month. ZEINA said that she was currently paying for physiotherapy in private sector hospitals in order to obtain good physiotherapy treatment, and that all of her family members were trying to find a way to help her pay for the treatment charges. She also said that she wanted to obtain a car for people with disabilities as she needed to go easily to many places.

Another research participant, DOHA, noted that she received 800 SAR (£172) from Social Affairs every month and 200 (£43) from her siblings every month. She had been lucky as her brother was a government employee and so he was able to obtain it for

her quite quickly after she gave him power of attorney. ATIF told me that he had his own income and he also had income from the government, but he still said that was still not enough. He believed that his income was more than 5,000 SAR (£1,056.40). He noted that he was able to obtain a social insurance allowance of 500 SAR (£105.64), which he thought to be a good allowance. These larger amounts of financial assistance received by MALIK and ATIF seemed to be an exception, and in general the research participants tended to receive much smaller amounts of financial assistance every month.

Another research participant AASIA, told me that she needed financial assistance because she requires physical therapy and it is expensive and the special centres in Jeddah where she can obtain it have limited availability. She also said that wheelchairs cost up to 25,000 SAR (£5,450), so if she had no money, she asked what she was to do about obtaining a wheelchair? Under the medical model of disability if a participant cannot walk or needs a wheelchair to get around that physical disability requires medical treatment or support in the form of a wheelchair. It is therefore difficult to understand why it is the case that the research participants were required to personally buy a wheelchair. How can it be the case that the KSA has enacted the Disability Code 2000 and the Disability Convention, yet people with disabilities who need a wheelchair are not provided with them by the Saudi government or the Saudi hospitals?

HANI noted that although he received some financial support it was not enough because of the treatment that he needed:

> **Also, the social affairs give me 800 riyal but it isn't enough per month. The treatment consists of one medicine that costs me 200 riyal and medical supplies which cost me 500 riyal. Also, nothing remains to spend on my personal requirements. [HANI Transcript, p.4]**

Although ZISHWAN was receiving some financial assistance, he noted that because of his disabilities and his need for medical treatment the financial assistance he was receiving was not enough:

> **For example, I should take compensation of SR 200 for 60 months, which means that I would earn about 12 thousand Saudi Riyals for five months. That isn't enough, because when I go to get treatment in any hospital I pay about twenty five thousand Saudi Riyals per month. Also**

we must count the transportation charges, and therapy fees, also I go to many hospitals in order to find the best place for my case. [ZISHWAN Transcript, p.4]

The issues relating to financial assistance seem to relate to an overall lack of significant financial assistance, and also of significant delays in obtaining financial assistance due to bureaucratic procedures in place. OMAR said he was relatively lucky. He noted that his brother, a soldier at the Ministry of Interior, applied on his behalf to obtain a monthly subsidy from the government. He noted that he received 800 SAR a month (£164.50) and that he believed it was still not enough. Other research participants noted that they received no monthly income at all.

See, indeed I am disabled with a difficult financial situation, but they made me feel that I'm not disabled. They ask my opinion in everything without saying that I have disability. [AWADI Transcript, p.9]

Delays in financial assistance

Many of the research participants noted that they had experienced delays in receiving financial assistance, or delays when applying for financial assistance. These delays were perceived to be because of problems with the bureaucratic financial assistance process. AASIA noted delays in financial assistance as well as problems in accessing the money that she was supposed to receive from the government. AASIA noted that she had previously had difficulties relating to finance. She noted that she submitted a request for treatment to the Ministry of Interior and had to wait for 7 months.

Her father did not pay her anything including pocket money, and the social insurance aid that she was supposed to receive was given to her dad instead, so she could not control her spending and she felt an indescribable type of humiliation. She said that her father brings the employee to her in the car for her to sign the form and that he takes the money, even though she has seen other girls with disabilities who receive the aid themselves. She confided in me that she believed that if she talked no one would listen so she needed **"someone to help me and know about this issue"** [AASIA Transcript, p.8]

Another research participant told me that he received 900 SAR (£194) as well as a specially adapted car and a specially adapted bed, and AWAD also told me that the costs of the medical operation had been provided by the rehabilitation authority. Another research participant told me that about one year ago King Salman had ordered by Royal Decree that every person with disabilities must be paid a one-off payment of 150,000 SAR (£30,289), but to date HANI said that nothing had been paid out (lifeinsaudiarabia, 2015). In terms of assistance received, HANI said that he receives 800 SAR (£172) every month from Social Affairs, but that it was not enough. HANI added that his treatment consisted of medicine that costs him 200 SAR (£43), and other medical supplies which cost him 500 SAR (£205.64).

Another research participant said that that his father helped him but his father's salary did not cover his needs, so ATIF had been forced to obtain a loan from the bank. When I asked ATIF how his parents spending money on him made him feel, he replied that he did not want to talk about it. LULU noted that she received 4000 SAR (£1000) a month in financial support. KAMAL told me that he had no income and that although he was previously employed, he left his job as a government employee and quit. KAMAL noted that he did not receive a monthly pension from the government and only received a rehabilitation and social security allowance which amounted to 1800 SAR (£388).

One of the research participants, KAMAL, told me that there were many difficulties that people with disabilities faced when trying to take advantage of a car donation worth about 150,000 SAR (£32,692). He said that people faced many difficulties in extracting such cars from both Social Affairs or Rehabilitation. He said that if they gave it to you it might deprive Social Affairs from getting 150,000 SAR (£32,692) even if it was your right. He noted that they might provide you with driving tools and then suspend the cheque money, claiming that you got the financial aid. He noted that he might be delayed for five years without any effective benefits, because those things were not guaranteed to be obtained.

No financial assistance received

Other research participants noted that they did not receive any financial assistance at all. When I asked YASMINE about whether or not she received financial benefits she

did not understand the question, and then noted that she did not receive this benefit. YASMINE noted that **Yellow Hospital** had asked her to pay 50,000 SAR (£11,564) for treatment and care that she had received to date, but she was not able to as she had no money and no job. She had never received any financial benefit from the government either. YASMINE is paraplegic and is 18 years old. How is it possible that she will be able to pay the **Yellow Hospital** 50,000 SAR for her treatment? Under the Disability Code 2000 and the Disability Convention, people with disabilities are supposed to receive medical care and attention. Why is it then that the **Yellow Hospital** would ask YASMINE to pay for her medical care and treatment?

ATIF noted that he did know about the financial assistance he could receive from the government related to discounted rates for air tickets. For example, he said that if an air ticket was 400 SAR (£45.82), he would receive a discount of 50 SAR (£30.56). KAMAL noted that there were some people who had applied for financial aid as long as ten years ago, and they had still not received anything. He noted that it was not easy to obtain a residence even though it was considered to be one of the duties of Social Affairs, but those duties were not carried out by any one.

When discussing discount card services or visiting his parents for holidays, KAMAL stated that he was not entitled to them and if he tried to breach that, his file in the hospital would be closed. I then asked KAMAL why he did not complain to the director of the hospital regarding these violations. He told me that he had informed him before and the director had tried to force him out of the hospital. He had tried to close the air conditioning in his room for a couple of days to try to force him out. KAMAL told me that they had tried to force him from his room and out of the hospital but he had refused.

THEME 3: MOBILITY

Having mobility is important for people with disabilities and supports their quality of life. Mobility enables them to go out shopping, to go to work or school, and to engage in recreational activities. It was seen in the literature review in chapter 2 that mobility plays an essential role in terms of social inclusion for people with disabilities. From the transcripts, it was identified that mobility plays a huge part in the lives of the research participants. Most of them cited problems that they faced because of their disability in terms of their mobility. This included problems accessing wheelchairs, mobility issues and problems relating to accessing malls, restaurants, and accessing other

recreational activities. The findings are presented thematically under three Sub-Themes: (1) access to wheelchairs; (2) mobility in Jeddah; and (3) access to special needs cars and mobility.

Access to wheelchairs

There were several problems that were cited by the respondents relating to accessing wheelchairs. Some noted that they were not able to have access to a high quality wheelchair. Others noted that it was only the charities that provided access to wheelchairs. Given the physical condition for some of the respondents, difficulties with mobility and wheelchairs could play a fundamental role in the lives of some of the participants (Ungar, 2017). For example, MOHAMMED stated that basically he could not move or go anywhere:

> **Since my injury and disability, I have not been out to public places. I was just going out of the hospital to home only, but most pavements of the hospital, are broken and cannot be ascended with a wheelchair. In addition, sidewalks of the hospital, despite having wheelchair ramps, they have a sharp height that is difficult to ascend by wheelchair. [MOHAMMED Transcript, p.19]**

OMAR noted that the hospital had provided him with a wheelchair but it was quite heavy and so he had asked for a lighter one. OMAR provided his views on mobility:

> **[In Jeddah] There are walkways but in public places such as shopping centres it is hard to cross the streets alone or get into shopping centres by using stairs. [OMAR Transcript, p.5]**

> **Yeah, it is hard for me to go up the stairs, but I can easily come down the stairs by using chair, so I can go up but have a problem with going down. Ok, if the electric elevators would be here, it would be okay. In this case, I can go down easily. I can climb up with electric chair, but I cannot do this with the normal chair. [OMAR Transcript, p.8]**

He had been in hospital three months but they had still not provided him with a lighter chair. This highlights the administrative and bureaucratic problems that are present at Orange Hospital. OMAR is 22 years old, and has been paralyzed for three years, ever

since an electricity column fell on his chest and spine, crushed him, electrified him, and burned him. Under the medical model of disability as OMAR is unable to move, having a wheelchair that he can use is absolutely essential to his mobility and to living day-to-day with his disability. Under the medical model of disability OMAR would be provided with a wheelchair that he can manage. But despite having asked for such a wheelchair, he was not provided with one thereby restricting his mobility and affecting his overall quality of life.

Mobility in Jeddah

Several participants noted problems with mobility in Jeddah. AASIA found that she had problems in relation to mobility and access in Jeddah, which impacted on the extent to which she was able to engage in activities that she wanted to do:

> **For example, I love to eat pizza. There's a Pizza Hut restaurant next to the house that contains a ramp for wheelchairs but a very small elevator that does not allow a wheelchair to enter. [AASIA Transcript, p.9]**

AASIA also noted that lifts (or 'elevators' in the US) and moving walkways (or 'sliders' in the US) were only available in the market and the large malls, so visiting any other area would be difficult in practice. AASIA said that even if she wanted to install an elevator in her house it was too expensive, as it cost approximately 150,000 SAR (£32,692). AAFIA commented that she once went to Abha with her family on holiday, and whilst she was there she had to stay for more than one hour in the car in order to find a car park with sufficient space, so she could get out of the car and use her wheelchair. AASIA said that in general in Jeddah, travelling to entertainment sites or other public places was tiring, as the walkways were not designed for people with special needs and it was tiring for her.

She also noted that people with disabilities could not play in the amusement park in Jeddah all the games that were played by healthy people. She said that when she tried to buy ice cream in the Jeddah City Park, she could not reach the seller because of the high counter, so the seller needed to walk around the counter to take her money. ZEINA noted that when she went to restaurants she did not find any services for people with disabilities. She did note that the people there helped her by carrying her

wheelchair. This highlights problems that remain in Jeddah with regards to special needs access and adaptation of existing public infrastructures. If the situation is like this in Jeddah then it is likely the same in smaller and more rural provinces and towns. AWAD also commented about how he had difficulties going outside:

> **…when I go out of the house, I must be accompanied by a companion, to help me in using my wheelchair [and] also to help me in driving my car, here in the house I can move alone, without any help, between the wheelchair and between the bed, praise be to Allah my life is normal like before suffering from disability. [AWAD Transcript, p.4]**

AWAD noted that there were some restaurants and markets that had paths and sliders that were convenient for people with special needs. AWAD also noted that next to the seashore there were also special paths for wheelchair users. AWAD noted that his muscle strain did not allow him to drive:

> **"…because it could result in a car accident because suddenly my leg nerves relax and I can't control it… Because in the crowds, maybe my feet touch the accelerator pedal, it is possible to cause an accident, because I can't concentrate with other cars around while I am concentrating on driving." [AWAD Transcript, p.6]**

ATIF told me that he had heard about this assistance from one of his father's friends who was an employee with a disability. ATIF also told me that at home he did not have an elevator and he was living on the second floor. Therefore, every time he wanted to go outside a family member had to carry him, this was usually his father or brother. He said:

> **I can't move alone, I can't leave my bed, but only through assistance, I can go and sit on my wheel chair and move by assistance of my wheelchair in the apartment without needed help from anyone. [ATIF Transcript, p.5]**

ATIF also noted that he needed assistance to go to the toilet, and so his brothers helped him to go to the toilet. In terms of mobility he did not find any problems using his wheelchair outside. He said **"I find that the streets are prepared well to be used easily by disabled people" [ATIF Transcript, p.8]** He also noted that when he visited the hospital he also found many facilities that were prepared for people with disabilities.

However, he stated that when he visited restaurants that he encountered mobility problems because the restaurants did not offer corridors or special paths for people with disabilities. ATIF noted that when he visited them the staff had to come and carry him inside the restaurant. This meant that he was unable to visit restaurants alone. He did comment that the sea shore was paved in a suitable way for people in wheelchairs.

Access to special needs cars and mobility

AWAD said that he had applied to obtain a car which was designed for people with special needs provided by the Ministry of Social Affairs. However, he noted that the system had now changed so that there were no cars currently available. He added that the price for the car was 150,000 SAR (£30,289), so if he was able to obtain the money he would be able to design a car according to his needs as a person with special needs. ATIF informed me that he had previously applied to the government for a car but that he was not able to secure a car for people with disabilities as his application was refused.

KAMAL said that he was still waiting to obtain approval for a special needs car, and commented that **"I must try to communicate with anyone who is responsible to provide cheques, to help me to get the approval for getting the car, after submitting application to get a car."** [KAMAL Transcript, p.7] When I asked KAMAL to explain what he meant by this he responded:

> **I mean that bribes paid to get those cheques and I saw myself people who got those cheques paid to them after paying for those bribes, but I must be confident in that person that [*an individual*] can give me cheques before giving the bribe to [*an individual*] and ensure [*an individual's*] ability to provide me by cheques, and I know people who got those cheques in less than two years and people who got these cars. [KAMAL Transcript, p.7]**

HANI noted that in the reign of King Abdullah, the King had signed an order granting a car for every person with disabilities. HANI had applied for a car five months ago but had still not heard anything back. AWADI said that he had been given a car that had been provided by the Ministry of Health that cost 150,000 SAR (£30,289). It would seem to be the case that people with disabilities that have applied for a car currently

face a very long administrative application process that could take years. This is because cars are being distributed in batches and each batch is distributed only after a long administrative process. This is a highly important issue because travelling around in the KSA is mostly done by private transportation. There are few public trains and buses available therefore mobility is a highly important issue for people with disabilities in the KSA.

ZEINA noted that the thing she found most difficult was going outside the home because of transportation problems, as she had to have a special car prepared for people with disabilities. She also said she had problems accessing malls because there was a lack of special passageways for people with disabilities. LUCAS noted that he found difficulties in finding parking spaces, and also difficulties when trying to access elevators, malls, shops, and restaurants. In light of the lack of public transport available in Saudi Arabia, mobility can be identified as a major challenge for people with disabilities in Saudi Arabia.

THEME 4: SOCIAL SUPPORT SERVICES AND SOCIAL WORKERS

The literature has highlighted that social support services, and in particular social workers, can play a vital role in the lives of people with disabilities. They can help people with disabilities to cope better emotionally, and also to help people with disabilities in their day-to-day lives (McLaughlin, 2007; Oliver *et al.*, 2012). This issue of social support services is something that is of real importance to the research participants. Some of the research participants noted that they had received some social support, whilst other research participants noted that they had not received any support. The findings are presented thematically under four Sub-Themes: (1) the role of the social worker; (2) the benefits of social support services; (3) negative perceptions of social support services; and (4) social care system, subsidies, and medical support.

The role of the social worker

It is helpful to understand the role of the social worker in the hospital practice in order to see what kinds of social support services people with disabilities can receive. Social Worker 1 (**SW1**) explained the role of the social worker to me in more depth:

As social workers, our role is to make daily visits and follow new cases. Of course, at the beginning, a social worker introduces himself/herself and starts studying the patient's case. If a patient with special needs, a social worker facilitates his appointments and looks for a way to communicate from his companion, receives the patient, facilitates his medical appointments and bring him free medicine from the state. As for insuring the patient's in kind needs: I.e. the need of a patient with special needs for an electric chair, sport wheelchair according to the patient's weight and also moving the patient from the house to hospital.

There is a private car equipped to transport people with special needs due to the difficulty of going to and from the hospital. Some patients complain that they do not have relatives or people they know to help them drive the car and some of them had no money to pay for a taxi so that they can attend to the dates of the hospital that provide them. This car is assigned for them and is fully qualified for ascending, descending the car and ascending the wheelchair for people with special needs. The goal is to make the disabled person not need people to help him/her and to be able to live a normal life. [SW1 Transcript, p.1]

SW1 explained to me that some of the patients had complained that they did not have relatives or people they knew to help them drive the car, and some did not even have money to pay for a taxi so that that could attend on the dates required. SW1 also explained that every day the social worker made daily visits with the medical team consisting of a physician, a physiotherapist, a specialist of functional therapy, a specialist of psychological therapy, and a specialist of social therapy. SW1 said that sometimes it was the case that the patient did not accept the therapist and sometimes that the patient would say that the nurse did not treat him well. In these situations, the social worker could interfere and transfer the case to another doctor.

In practice SW1 noted that when individuals were admitted to the rehabilitation centre, the person with disabilities would be provided with medical, rehabilitative, functional therapy, social therapy, and psychiatric treatment according to his or her needs. SW1 said that within the role of social worker, they aimed to provide for the needs of the

disabled, such as providing medical shoes, crutches, and other relevant equipment. Commenting on the patients, SW1 stated:

> **For example you met the patient named "[HOSPITAL PATIENT]" who refuses to leave the hospital as he doesn't want to make a burden for his family although he is excellent in the skill of using computers and tries to be a self-productive person, but, unfortunately, he understands disability as the hospital is the place where he will spend the rest of his life. In addition, most people with special needs are non-productive and some of them are found to be drug abusers from their blood tests, so they negatively affect each other due to psychological problems as a result of not accepting the disability or maybe due to other reasons. A social worker tries to help them, such as those who do not have a monthly subsidy from the state, facilitate receiving social insurance and registration in Ministry of Social Affairs. [SW1 Transcript, p.5]**

When I asked SW2 what the role of the social worker was SW2 replied **"The role of the social worker at the hospital is completely different of course from his role here, about the patients under treatment here, they are treated by specific means." [SW2 Transcript, p.1]** SW2 also noted that when patients are admitted to the hospital they informed them about the chance to get financial support from the country for the overall rehabilitation after getting full information about his as possible after two or three weeks. SW2 added:

> **"We also define to him about our role as a social worker, that we make necessary arrangement with colleagues in government departments to let him easily get a financial support, as social worker, we must have relations in all government departments such as the security man who must deal with audience, and we act in the same way. [SW2 Transcript, p.2]**

The findings from some of the research participants would seem to contradict this assertion by SW2. For example, KAMAL had noted that there were some people who had applied for financial aid as long as ten years ago, and they had still not received anything. SW2 confirmed that applying for subsidies takes a while. SW2 stated **"As social workers dealing with them, because the subsidy isn't collected as soon**

as applied, but it comes after two or three or four months…" [SW2 Transcript, p.3] SW2 also confirmed that material assistance such as beds and wheelchairs were not provided by rehabilitation at the hospital. SW2 stated:

> **"Rehabilitation centres may provide you a car for people with special needs, but we don't provide such material assistance (beds or wheelchairs) and I don't have any information on this point."** [SW2 Transcript, p.3]

So, it seemed to be the case that the social worker, whose very role was to obtain and find information that is relevant for people with disabilities, in order to support them, had insufficient knowledge of the provision of these services that were so very crucial to people with disabilities.

The benefits of social support services

The research participants that were interviewed in general had some positive comments to say regarding social support services. OMAR said that he had received a wheelchair, a bathroom chair, and subventions because of the social worker. AASIA did note that she had received social support at the **White Hospital** Rehabilitation Center. She noted that the social worker there had assisted and supported her by providing the medical equipment that she needed such as a bathroom chair and a wheelchair.

AASIA also noted that the social worker had helped her by identifying the procedures for the application to receive the monthly subsidy from the Ministry of Social Affairs. The social worker had also helped her to receive assistance from charities for items such as bathroom napkins, which were too expensive for her to buy herself. AASIA noted that social services and social workers were not the same everywhere, and that she had only found them in the **White Hospital**:

> **I went to several hospitals and these services were not explained to me by social workers and how the role of the social worker should be explained to the patient, what the services are, and how to receive them.** [AASIA Transcript, p.5]

SAAD also had positive things to say about social workers, she commented: **"Social workers talk to us as friend they're nice people we talk laugh I asked them for wheelchair and they gave me a chair."** [OMAR Transcript, p.9] The benefits of access to social workers were identified by SAAD and seemed to improve her psychological status: **"My spirits before coming here was 8%, but at this moment, it becomes 100%."** [OMAR Transcript, p.9] More specifically, SAAD commented that: **"I have acquired a great advance in my case, due to the high care addressed from the social workers here and the medical staff towards the patient."** [SAAD Transcript, p.2] However, he felt that the social support services he could access were limited. He noted that:

> **"Abroad if anyone gets injured he can request a good treatment, and he can find it easily, but here after submitting many requests to the concerned authorities we don't receive any replies to our request."** [SAAD Transcript, p.7]

AWAD noted that the services he was provided with were sufficient, and he seemed to be content with the delivery of equipment and resources to his home. He also noted **"Yes, praise be to Allah, and the country always supports."** [AWAD Transcript, p.4] LUCAS noted that he had been provided with two cards, one card was used to book parking places for people with disabilities and one card was used as a discount card for car parking places. DOHA noted that a charity had called her and asked her if she would need an electric chair and a bed. They had asked DOHA some further questions and had informed her that they would be secured for her soon.

Negative perceptions of social support services

It is important to note that there were some outliers, however, but in small numbers. For example, MOHAMMED commented that: **"No one spoke to me from the social workers."** [MOHAMMED Transcript, p.14] MALIK noted that he believed that in the KSA there were many places that provided facilities for people with disabilities such as elevators and special corridors. MALIK also noted that in Makkah there were many places provided for people with special disabilities, and in Medina there were many services provided for parking places for people with special disabilities. Therefore, MALIK believed that the government provided good social support services for people

with disabilities. AASIA also believed that more could be done in terms of social support services. For example, AASIA said that there were sport centres available but that these were for men only, and that there were no women's clubs that she could attend, i.e. no female sports clubs or swimming pools. She asked:

"Why don't we in Saudi Arabia have clubs, sports for people with special needs for women? Why are they only available for men? I'm a human being too. Before my disability I loved swimming and now, after becoming handicapped, is my life supposed to stop?" **[AASIA Transcript, pp.10-11]**

ZEINA said that she did not receive any other benefits or services, and this was the case in all the hospitals she had visited. ATIF was not offered a wheelchair by the hospital or any other authority, he noted that he had had to pay for it himself. He said that he had asked the social insurance to provide the wheelchair but they had not done so. KAMAL discussed the services that he received from Social Affairs in more depth with me. He noted that rehabilitation services were only provided to him upon request, and that he was not officially entitled to them because of his case, which was paraplegia.

He also noted that he was not entitled to obtain an electric wheelchair. He noted that if he requested a wheelchair to support him whilst he was going to enter the bathroom, they would provide him with the worst wheelchair which was not made well, and which would quickly be affected by rust. LULU noted that she lived with her family in a separate apartment in Tabuk. I asked LULU whether she was in need of social services and public services such as education, healthcare, housing services, and transportation services. LULU responded that she never thought about this and she did not know anything about this. When I asked LULU what services the hospital had offered her, she replied that they had not offered her any services.

When I asked SHAMZ if the hospital and helped to improve his mental health and adapt to his life he noted that he had received no help from the hospital. ATIF told me that the social workers had not talked with him about his disability, or how his disability made him feel. ZEEK said that he had tried to access social insurance, but he had not received anything back from them. However, ZEEK noted that his stress had now mitigated after the social worker had helped him to recover. ZEEK said that a social worker named **[ABDUL]** had helped him and now he felt better.

SW1 commented that **"…unfortunately when some patients see their colleagues have a sportive electric chair, they ask for it although the case is totally different to each person according to the disability."** [SW1 Transcript, p.6] I informed SW1 that people with special needs had stated to me that restaurants and public places were not prepared for them. However, SW1 did not agree. SW1 stated: **"Not true, now all restaurants in the Kingdom are prepared for the disabled except for few, I think 70% of them were prepared for disabled persons."** [SW1 Transcript, p.8] SW1 also added:

> **Now all the new buildings are provided with sliders for disabled persons and in the hospitals there's a walk line for them, they don't have to stop in a queue and they have the service priority, also there's private cars parking lots for disabled persons in hospitals and public places.** [SW1 Transcript, p.8]

This seemed to be quite a strong assertion about all new buildings and hospitals throughout the KSA. From my personal experience there are many buildings that do not have these facilities therefore I found this generalisation to be somewhat misleading. I therefore stated, **"With all due respect to all the opinions, but this is not true."** [SW1 Transcript, p.8] From my perspective what SW1 was saying did not seem to be completely accurate. The views and viewpoints put forward by SW1 seemed to be a view of people with disabilities being able to find every kind of support they need throughout the Kingdom, and of the current system being highly efficient and effective.

However, the evidence from the research participants evidenced that this was not the case and that what SW1 was not accurate. With regards to education SW1 stated **"as specialists we recommend whoever wants to join the university, he must register by distance learning, in other words the student goes to the university just at the exam time…"** [SW1 Transcript, p.8] This seemed to indicate that the social worker was recommending that people with disabilities study by distance learning. One issue with this recommendation is that if people with disabilities access education via distance learning, then they are not able to interact with others, and so they will not benefit from the full interactive and social university experience. SW1 added:

> **…the others don't want us to help them in his rehabilitation and see the hospital as an accommodation or lodging place and free**

**medicine, some patients have a wrong concept about disability
and don't want to get out of the hospital. [SW1 Transcript, p.11]**

Given that many of the views of the research participants noted that they did want to
get out of the hospital, to get better, to be treated better, and to actually receive good
medicine and treatment, it seemed to be the case that the view of disability in the
hospital held by SW1 was different to that of the respondents.

Social care system, subsidies, and medical support

SW2 also clarified a very important point about subsidies for people receiving in-patient
care at hospitals:

> **"If he mentioned exactly his case, the government will not give him
> subsidy, due to my experience, because many social workers now are
> working in the comprehensive rehabilitation told us that the Ministry
> of Social Affairs does not give subsidy for the patient if he is treated
> in the hospital. I was ignorant of this point but colleagues in the
> comprehensive rehabilitation has informed me about it to be aware
> about the systems. [SW2 Transcript, p.3]**

It seemed to be the case that the current social care system for people with disabilities
is set up so that only people with disabilities who are living at home are entitled to claim
a subsidy. All the people with disabilities that are staying in the hospital are not entitled
to claim a subsidy. Nor are they entitled to claim for a bed or a wheelchair from the
rehabilitation centre at the hospital. So, if they are in hospital they cannot claim a
subsidy and they will have no money to pay for a wheelchair or a bed for themselves.
SW2 noted that they followed up with patients by asking the doctor about the patient's
needs, such as wheelchairs, electrical beds, and electrical wheelchairs. SW2
confirmed that all items such as wheelchairs, electrical wheelchairs, diapers, gloves,
and bedspreads were all provided by charities.

SW2 noted that if the patient was in the hospital they were not entitled to receive these
items from the charity, because it was being provided by the hospital. SW2 noted
**"because some of the patients sell that stuff after receiving it from the hospital.
Because some patients are needy, so that they sell some of the stuff provided**

to them from the charity." **[SW2 Transcript, p.4]** I informed SW2 that when I met with a patient from the research sample, he had told me that he required a medical report to be translated so that he could submit it to Social Affairs, and he had told me that the social worker had not helped him. SW2 replied:

> **"No, it is isn't impossible to obstruct the patient. Because we provide the patient with a signed medical report. As you see, the social worker role here is provided on a full basis." [SW2 Transcript, p.13]**

When I asked SW2 about the activities provided to the patients, SW2 replied:

> **"About patients who are sitting here in the hospital for four or six years, and refusing to go out, for example, we don't reward them by providing them with trips, but about the patients who cooperate with the hospital, of course we provide them with trips." [SW2 Transcript, p.11]**

CHAPTER SUMMARY

The four themes that have been discussed have demonstrated that the research participants continue to face problems and challenges in their daily lives in addition to living with their impairment. This is consistent with the findings in the literature review in chapter 2. The findings showed that many of the research participants identified problems with the nature of the medical support that was provided. There were general problems in hospitals in the KSA that were identified, and also a general lack of high quality treatment and medical devices was identified. These themes highlight the problems that still exist in Saudi hospitals, notwithstanding the Saudi government's commitment to provide high quality medical services for people with disabilities.

In addition, financial assistance was found to be a problem for a majority of the research participants. The findings highlighted that the financial assistance that many of the research participants received was insufficient. The research participants needed greater financial assistance to help them live and cope with their impairment. In addition, many of the research participants did not know that they could receive financial assistance, or how to go about trying to obtain it. The findings also showed that there were problems with social support services. Some of the research participants had not been informed of the social support services they could receive.

Other research participants noted that the social support services they could draw upon were limited.

This shows that there is a clear need to improve the social support services for people with disabilities so they can better understand what financial and other social support services they can receive from the Saudi government. Mobility was also a problematic issue for the research participants. Several of the research participants said that they had problems with wheelchairs, either that they had not been provided with one, or that the one that had been provided to them was not suitable. The findings identified mobility problems, not only within the institution, but in Jeddah as well. For example, the research participants noted that they had difficulties when trying to go to restaurants and when trying to get a taxi. Therefore, even though the Saudi government's commitment to provide access for people with disabilities is set out in the Disability Convention, it still seems to be a significant challenge for people in hospital with disabilities in the KSA. The next chapter will cover the remaining themes that could be identified from the data.

CHAPTER 6
INDUCTIVE FINDINGS – PART II

CHAPTER OVERVIEW

This chapter will continue the review the of the inductive findings. More specifically, the following themes identified in the research data will be reviewed: (5) access to education; (6) quality of life; (7) perceptions and problems; (8) religion and disability; and (9) gender and disability. Each theme also has a number of sub-themes.

THEME 5: ACCESS TO EDUCATION

The research participants highlighted that lack of access to education is an issue that they face. Access to education is essential for people with disabilities. As discussed in the literature review in chapter 2, people with disabilities who are employed generally have a better quality of life than people with disabilities who are not employed. They are able to purchase items that they need in their daily lives with relative ease. Having a good education and qualifications is typically what is required to secure a normal day job. If people with disabilities lack education, or are not able effectively to access education, then they may face greater difficulties in life. Lack of access to education can therefore act as a social barrier for people with disabilities. The findings are presented thematically under the following sub-themes: (1) the importance of education; (2) the primacy of accessing education; and (3) barriers to accessing education.

The importance of education

The research participants generally felt that it was important for people with disabilities to obtain an education in order to improve their living standard and life. For example, OMAR noted that it was very important for people with disabilities to be able to access education, it was important to learn and to get a job. OMAR said that first he wanted to complete his rehabilitation therapy, and then after that would think about further study. AASIA noted that in theory accessing education would not be an issue:

> **Currently, nothing is difficult. It is possible 10 or 15 years ago that it was difficult but now everything has become available online, as you**

can study online or use the distance education system, so it is easy for a person to learn. [AASIA Transcript, p.9]

Although DOHA recognised the importance of education, however she did not wish to continue her education at present. She noted that in her village in the South of the KSA, education was not seen as an important objective. HANI did not believe that education would benefit him. He said that one of his contacts had passed the Baccalaureate and he had not been able to get a job in the Southern sector because they did not give any jobs for people with disabilities. Therefore, HANI was convinced that because one of his connections had completed education and had not been able to secure a job, he would not be able to secure a job either even if he completed further education. LUCAS also noted this:

Because I have a bachelor's degree, and I will not get any job better than what I got before, because a bachelor degree offers for me many opportunities to get good jobs. I will not get better jobs even if I get master degree or doctorate degree. [LUCAS Transcript, p.2]

LUCAS was therefore convinced that undertaking further education, in terms of undertaking a master's degree or even a doctorate degree, would not enhance his chances of obtaining a job. Therefore, for LUCAS it was not worthwhile pursuing further education as it would not benefit him. In terms of amenities, ATIF noted that at his school there were facilities that were provided for people with disabilities, including private corridors and also spaces for wheelchairs in class. ATIF also said to me that he believed that education would offer him a good chance of being employed by a reputable establishment, and this would then help him to get married after that. I asked ATIF how important education was to him. ATIF responded that he believed that education was quite important to him.

Not all the research participants viewed education this way. The importance of education seemed to be influenced somewhat by age and also the stage of rehabilitation that the research participants were at. For example, although many of the respondents saw the importance of education, it was not a priority for them. Because undertaking further education would involve quite a lot of time (e.g. researching institutions, undertaking applications, etc.), many of the research participants did not see it as important for them right now. Some of the research participants expressly noted that instead they wanted to concentrate on improving and

getting better. Since the participants were in a rehabilitation hospital, it is understandable that they held this view of education. However, it seemed to be the case that many of the participants viewed education in an instrumental way, i.e. as a means to obtain a job.

The primacy of accessing education

The findings identified that it was often the case that some of the research participants were potentially interested in continuing their education, but that they wanted to direct their attention on their rehabilitation first. This showed that although the participants understood the importance of accessing education in terms of securing a job and improving their quality of life, it was not currently the most important issue for them. For example, AWADI noted **"I'm very interested, but the current situation doesn't help me to complete my education." [AWADI Transcript, p.5]** ZEEK noted that he was not interested in studying but would try to improve his condition in the future. MALIK noted that education was difficult because of housing and trying to get to University because of traffic jams. MALIK also wanted to concentrate on his rehabilitation first:

> **Yes, there are many people who told me that, but I don't have energy to study in University through online learning, because I don't like to read any books, while I am in disturbance, I like to read a book while I am free from problems. [MALIK Transcript, p.3]**

LULU did not think education was important for her after the accident. She said **"I expect that it doesn't matter for my case." [LULU Transcript, p.5]** ATIF noted that he was currently completing his studies. He had visited a school to complete his exams he studied on his own at home. When I asked him if he knew how to apply to obtain education services for people with disabilities in the University, he told me that he did not know how to apply.

Barriers to accessing education

There were a number of barriers that were identified that stopped the research participants from accessing education in practice. AAFIA noted that she had wanted

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to access education, but that in practice there were barriers that had stopped her from accessing it. AAFIA noted that she had received an offer to start a university medical course from Al Farabi Medical School, and that the people there were respectful people. The Medical School informed her that she could study and work at the same time with a salary of 5,000 SAR per month (£1,028). However, her manager had informed her that if she was employed she would not be able to receive state aid, so her father had refused to allow her to continue her education. She said that because of this she had become depressed and had developed a bad psychological condition. In this case even though AAFIA wanted to undertake further studies, and the Medical School offered her a place on the medical course which would allow her to study and work at the same time, her father had refused to allow her to attend the course because she would lose her state benefits which her father was receiving and using.

One respondent (AAFIA) also noted that she had previously had problems in school. At school it was hard for her to descend the steps and she had once cried. She noted that at the school they had thrown water on her and she could not speak for fear. She had asked for help from a friend and her friend had left her. Another time she had fallen to the ground during the break and everyone went to classes without helping her. A teacher had told her to get up and she was unable to in front of the others so she was embarrassed. The girls had laughed at her and she had continued to cry and said that she was left with psychological scars.

Another respondent (ZEINA) also wanted to apply for a course at University, but she was not able to complete her studies because the building at the University did not have places for people with disabilities. It was also in part due to the difficult circumstances she currently faced. When she was studying in University she noted that she did not find any services that were offered for people with disabilities. She recognised the importance of education, and she said that she would benefit by learning courses in computer programmes or even languages. However, she noted:

> **"Of course, disability is a reason for leaving education, but there are many disabled people who completed their education, and now they are teaching in the university, but we need the support of the country to raise our education level."** **[ZEINA Transcript, p.4]**

In a similar position to ZEINA, NANA noted that she really wanted to complete her studies, but that it was very difficult for her to do so. She saw quite a number of

difficulties that she would have to overcome in order for her to continue her studies. This was also noted by SHAMZ, who said that the education system did not accept people with disabilities, and not all specialties could accept people with special needs. Another respondent, YASMINE believed that education was important because it would help people to understand everything. She believed that it would help her to understand religion and the Holy Qur'aan. She said that she held a real passion for learning religion and that she would love to work teaching religion. On the other hand, SAIF noted that he believed that universities in the cities were actually prepared for people with disabilities, however he believed that in the villages they were not prepared, for example in terms of stairs, lifts, and other things. This showed that there were potential mobility barriers to accessing education for people with disabilities located in rural areas in the KSA.

THEME 6: QUALITY OF LIFE

Overall, the quality of life experienced by some of the research participants seemed to be quite low. Some of the difficulties that presented themselves included a lack of access to social and recreational activities. Without regular access to a range of social and recreational activities and family support, people with disabilities are likely to feel isolated and lonely. This can turn into a cycle whereby the less social and recreational activities they take part in, the more isolated and lonely they feel. The findings are presented thematically under the following Sub-Themes: (1) access to social and recreational activities; and (2) family life.

Access to social and recreational activities

A number of participants noted that they had difficulties regularly accessing social and recreational activities. For example, MOHAMMED noted that he was not able to go down to the lounge in the hospital where the rest of the patients were staying because of his catheter. When I asked MOHAMMED about sport activities he replied there was nothing offered by the hospital. When I asked him about what his usual entertainment and activities were, he replied: **"Nothing, I just sit and work on the laptop or sleep."** **[MOHAMMED Transcript, p.13]** MOHAMMED had been in the Rehabilitation Centre

for 4 years, and this was what his life consisted of every day. What he told me in the interview was quite moving:

> **Everything in my life I am unable to do it by myself, such as entering the bathroom and unable to drive a wheelchair. If I sat on the wheelchair, I use electric one because I cannot push wheels of the chair until the descent of the wheelchair and ascending I cannot do that. I should be lifted by a crane to get in the car.** [MOHAMMED Transcript, p.13]

OMAR noted that in many hospitals there were big halls where patients could play basketball or other activities, but that in the Rehabilitation Centre there was only television. It seemed to be the case that the social and recreational activities in the hospital were limited. OMAR said that he spent about 6 to 7 hours playing PlayStation. His daily life consisted of him having three one-hour sessions of exercise every day, eating meals, playing PlayStation, or watching television. This would tend to suggest a sedentary lifestyle which involved little to no daily movement and exercise, and could be seen as unhealthy in the long term. There were no elevators at the hospital, and although he could come down the long ramps at the hospital easily, he had problems going up the long ramps at the hospital. This was because in order to climb up the long ramps he had to go up multiple ramps from the bottom floor and this was very tiring in practice. In theory if he had an electric chair he said he would not have any problems. He had not been supplied with an electric chair.

OMAR had previously asked for a lighter wheelchair three months prior but had still not received one. It seemed to be the case that the hospital was effectively restricting his mobility as well as access to social and recreational activities. In terms of recreational television, AWAD noted that he sometimes watched programmes on the television or on the internet at the hospital. DOHA also said that she had asked the staff to install a television to provide entertainment but none had been installed yet. Similar to DOHA's position, YASMINE noted that there was no entertainment available for her at the hospital. She only exercised in the morning. DOHA noted that she paid a Somali assistant 1000 SAR (£211.28) a month to help her and to be her companion, and that this friendship was very helpful to her. DOHA noted that other patients had informed her that there had previously been trips in the hospital, for example trips to the sea or to Umrah or to Mecca to meet with supervisors and specialists.

ATIF told me that for entertainment he played games, or played on his mobile, or went outside. I had asked a social worker about entertainment, and the social worker had told me that the building was new and that television sets would be provided for the patients and that a request would be raised to management which permits recreational trips. Given that the **White Hospital** Rehabilitation Center was established in 1990, it was not a new building as the social worker contended. From what I witnessed, I think it is highly unlikely that new television sets will be provided or recreational trips will be planned in the near future.

Family life

There were different aspects of family life that were discussed by the participants. Some of them related to the support that the participants received from their families, and some of them related to the lack of support that they received. I have provided an example of each of these two scenarios. For instance, SAAD noted in the interview that having the support of his wife was absolutely essential to the quality of life he was leading. This showed that he really valued the support that he received from his family and it was fundamental to his ability to cope with his disabilities on a daily basis. This support provided by his family showed the real need to focus on the support provided to people with disabilities as posited under a social model of disability. SAAD disclosed to me his comments on his wife's support:

> **People always find that serving patients is considered to be a hard service. I can't go to the bathroom, but she helps me always, and she was sleeping next to me during day and night, next to my bed on the ground, and she often doesn't sleep in order to take care of me, and sometimes I am ashamed to awake her until the morning, so that she becomes sad asking me why I left her sleeping? [SAAD Transcript, p.2]**

In terms of a lack of support there were other difficult aspects of life that were touched upon by the research participants. For example, AASIA discussed different aspects about her quality of life. The first was to do with her ability to work. She said that it was impossible to work because of her disability. She said that she could not go back to her previous role at the bank because she could not do anything without the help of her sister, and it was the bank's policy to prohibit any companions in the bank. There

was also a problem because of a lack of special bathrooms for people with disabilities, and so she would have to go home to change her diapers because of her problem of incontinence. This meant that it was an uphill struggle for AASIA to try to find work and to try to seek out her life independently.

The second aspect of her life that she discussed was about her not being able to entertain herself, as there were no places of entertainment available to her, and there were no places to enjoy, as she had difficulties in all places without the help of others. The final aspect of her life that she discussed was her personal life. She noted that she was divorced because of her disability. She said that she was psychologically tired at that time because her husband did not appreciate her case after she became disabled. He knew that she was disabled and was not able to become pregnant on clinical grounds because of her condition, and therefore he divorced her.

From what I could see, AASIA seemed to feel isolated and faced a lack of personal support. In reality this type of family and personal support is vital for people with disabilities, as it not only helps them to cope, but it can be a way to lower feelings of isolation and loneliness. ATIF felt quite positive about the way he was viewed by his family. He did not think they had changed their opinions about him. He felt very grateful for the support that they provided for him. He noted that his brother came home at 12 pm to help him, and he had many other people who cared for him. ATIF also noted that in general he believed that there were many people caring for people with disabilities in Jeddah, and that in general people treated him in a good way. LUCAS also felt he received strong support from his family:

> **All of my friends and family are supporting me, even my sister is caring for me because she helps in my shower, also she cares for me, also my older brother supports me so much. I feel like he is acting same like King Fahd… My brother responds to my requests, he gives me everything, car, money, everything, he encourages me to marry. He says to me that he would support me financially if I want to marry** [LUCAS Transcript, p.5]

The research participants highlighted many difficulties that they faced in practice, difficulties which lowered the quality of their lives. It was seen that having the support of family significantly helped the research participants cope with their disability on a daily basis.

THEME 7: PERCEPTIONS AND PROBLEMS

There were a number of other problems that the participants discussed during the interviews. There were several areas that these touched upon and which were identified. The research participants also noted a number of different views regarding perceptions people had towards them (as people with disabilities), and problems that they or others with disabilities encountered. The findings are presented thematically under two Sub-Themes: (1) negative treatment of people with disabilities; and (2) living with disability.

Negative treatment of people with disabilities

Many of the stories shared by the research participants related to different time and circumstances in which they had encountered negative treatment in their daily lives in different ways. As has been identified in the literature in chapter 2, many people with disabilities face challenges relating to the way they are negatively treated by others in their daily lives. Some people with disabilities may be mocked, and other people with disabilities may even have violence inflicted on them. In line with the findings in the literature, many of the research participants noted negative experiences and negative perceptions of them by others. Some of these experiences and perceptions were common among the research participants. This included the way people with disabilities were viewed in the KSA (e.g. with pity). For example, SAAD remembered one time that he had encountered a particular problem in public:

> **I remember one time that I stayed in my wheelchair for one hour because the entrance of the supermarket does not have a handicapped entrance… So people thought that I was a beggar. [SAAD Transcript, p.6]**

SAAD was not even able to carry out his regular shopping because his mobility was restricted. He stayed at the supermarket entrance for one hour and no one helped him to get inside the supermarket, people even thought because he was in a wheelchair then he must be a beggar because they offered him money. Similar to SAAD, SHAMZ noted that he encountered problems when he went out. He said that when he went shopping people thought he was a beggar and they gave him 5 SAR (£1.10) or 10 SAR

(£2.20). SHAMZ noted that this had happened in Jeddah and Tabuk. SHAMZ said that his life had become too difficult for him because he was alone, and there were no entertainment centres in the hospital. He did however note that his family and friends provided good support for him, as they all provided moral, psychological, and material support for him. SAIF also noted that when he went to the shopping mall, people looked at him in a strange way and they gave him 10 SAR (£2.20) (as if he was a beggar).

Several research participants highlighted that some people in the KSA viewed disability as some kind of disease. For example, OMAR noted: **"Yes, some people think that the disabled man is mentally ill"**, **before adding** that: **"…I see many people who think that I'm needy and poor because I was sitting in my wheelchair."** **[OMAR Transcript, p.10]** These views of people with disabilities as having some kind of disease, being mentally ill, or poor, strike completely against the social model of disability which seeks to break down social barriers for people with disabilities and to fully integrate them into society. Some of the research participants felt that they were treated differently, either in the way they were perceived by others, and sometimes even in the way they were treated by their family. For example, AAFIA commented that:

> **"Even now I am disabled since 14 years [*for fourteen years*], but I don't like the way my family has treated me or the way how they look at me as a poor person!"** **[AAFIA Transcript, p.14]**

> **"While I'm walking, I swear I feel annoyed and a burden on my family, society and people get mad at me."** **[AAFIA Transcript, p.5]**

Some of the research participants highlighted that they had often encountered feelings of pity from others. For example, OMAR stated: **"Old people in the village pity me, and I felt their perception of my situation."** **[OMAR Transcript, p.9]** MOHAMMED even noted that it was to be expected:

> **Of course, I encounter this and it is most annoying sometimes when I sit in a wheelchair, but at home I feel pathetic looks from some people as if I am poor and feel pity on my situation and I do not like this look… Sometimes I do not accept this look, and sometimes it really hurts.** **[MOHAMMED Transcript, p.19]**

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There were other comments made by other research participants that highlighted problems they had faced or were still facing in their lives. For example, AAFIA said that she had learned that there is a car available for people with disabilities. When AAFIA told her father to pay for the car from her money he had told her that he did not have any money and that she should walk on foot. She said:

> **I was crying because I was unable to walk and there were places where people with disabilities were allowed to enter even if there is no place or car. [AAFIA Transcript, p.12]**

MOHAMMED said that his disability affected his religious practices. He noted: **"I don't go to the mosque because my brothers must lift me and I don't want to make them feel tired." [MOHAMMED Transcript, p.20]** AAFIA said that she faced negative perceptions when other people dealt with her, commenting that **"I hate Saudi female employees because they are talking to me in a very offensive and bad way." [AAFIA Transcript, p.6]** It is important to note, however, that this negative treatment of people with disabilities was not felt by everyone that was interviewed. There were some outliers in the interviews. For example, when AASIA was asked how society looked at her in public places she responded:

> **Nothing, I never felt sympathy looks. On the contrary, many people help with open arms and a smile. I did not feel the negative outlook - there are humanitarian principles of community. [AASIA Transcript, p.10]**

Living with disability

There were a number of different perspectives that were identified with regards to how the participants coped with disability in their daily lives. This included views about living with disability in Saudi society, as well as practical difficulties that many of the research participants encountered on a daily basis. When I asked KAMAL what he believed disability to mean from his point of view he replied:

> **Disability means for me inability to marry and bear its responsibilities, I can't get a job here in this country while I am disabled… Meaning that I would never be able to marry because who accept to marry me would**

concede the dignity or the right of his rights in exchange for approval to marry one in my case? [KAMAL Transcript, p.7]

When I asked KAMAL why he believed it was hard to live with disability in the KSA, he replied that driving the car was difficult because of potholes and bumps, and some roads were not paved well. He added that he could not go to the grocery store, and when he was living with one of his family members, there was no elevator to reach the third floor. He noted that he could not climb the stairs at all so all he could do was to stay at home. Living with disability in this way was therefore not only frustrating for KAMAL, but also alienating. KAMAL was also quite frustrated at the lack of services that were provided by the Saudi Government:

There are no public services provided by the Government, either at their own expense or even at my own expense. There is no respect for our health conditions in streets or parking or sidewalks [KAMAL Transcript, p.9]

When I asked ZEINA what it meant for her to live with disability she answered:

It means for me to be fully isolated. I was loving walking and moving, but now Praise be to Allah, I got familiar with my disability. Sure, my family supported me to overcome my case. [ZEINA Transcript, p.7]

There were several participants that had encountered attitudes that demonstrated pity. For instance, ZEINA felt that she was viewed by society in a different way and pitied:

Because, the community views disabled people in a pitiful way, and the disabled people don't like to be watched in this way. I find people outside my family members looking at me with pitiful stares when I go outside my home [ZEINA Transcript, pp.4-5]

Another participant (HANI) also said:

You are talking about us, so when we go out, we see pity in people's eyes. We wish [there were] suitable places for us and [we] don't find pity in people's eyes. [HANI Transcript, p.5]

But very often it was a case of the research participants being treated in a negative way with either pity or, even worse, with anger. One of the research participants (NANA) stated that she had encountered sympathy, pity, and had been mocked:

I mean that, during my first time after the accident, I wasn't familiar with the way people were dealing with me, such as looking with sympathy and pity, while sometimes, some people were behaving in a mocking manner with us. [NANA Transcript, p.3]

NANA also said that she had been insulted on previous occasions:

I mean, if I am crossing the road, or walking, some cars don't want to stop for me, to cross the road, they refuse to let me pass or cross the road, insulting me, saying to me, that isn't your place to use it… [NANA Transcript, p.3]

She provided me with her views on why she thought people mocked her or were angry at her:

I think their bad behaviour is due to lack of awareness. We must promote awareness about disabled people's rights, all people must respect disabled people's rights. In our community, to be respected, you must respect people's rights. It is a corresponding respect, but some people mock us when we ask to park in the disabled parking bay. Once that happened, I started to cry, and asked my father to go away from that place and not to return to it again. I think that people are behaving in such a way due to ignorance and lack of awareness. [NANA Transcript, p.5]

This general feeling of helplessness and lack of support and services was also evident in other research participants. For example, YASMINE considered that she needed help when she wanted to go to the bathroom or to exercise. LUCAS told me: **"I feel now that I am considered to be a load or burden for my family." [LUCAS Transcript, p.4]** ZEINA also commented about physiotherapy treatment: **"About the physiotherapy, we didn't find any physiotherapy treatment. Also, there is no awareness about disability issues." [ZEINA Transcript, p.11]** ZEEK said that he felt deeply disappointed because he had expected his friend **[JAMAL]** to visit him but he did not. ZEEK said he was greatly affected because of the close relationship they previously had and he did not even call him. LUCAS described his feelings about the support he used to receive previously:

There are many factors, such as relatives, they don't know what the name of my disability is, they don't support me at all… No friends are visiting me at all. Before for [the first] five months, my friends were supporting me, but now, there are no friends at all supporting me. [LUCAS Transcript, p.5]

This lack of support tends away from the social model of disability which seeks to empower people with disabilities by providing them with ways of breaking down social barriers and helping them to be better integrated into society. There were a number of other daily issues that could be identified in the research transcripts that affected the way people lived with disability. For instance, HANI noted that when he went to the hospital he had difficulties. Whenever he told anyone there that he was physically disabled they would ask him for his hospital disability parking card in order to open the parking bay. However, in addition to that, on one occasion he was required to bring an approval letter from the hospital in order to be able to enter the disabled parking bay, which meant that he was unable to do so, due to not having the letter.

Instead, he had to park approximately 500 - 600 metres away. This was in the **Purple Hospital**. When I asked SAIF if he could access his rights and services that he was theoretically entitled to after becoming disabled, he responded by saying that:

Unfortunately, there is no such thing, and I never expect that. Also, there aren't any sufficient rights for the disabled people and we are lagging behind overseas countries where the disabled people are dedicated to study and housing. [SAIF Transcript, p.3]

THEME 8: RELIGION AND DISABILITY

From a full review of the interview transcripts it became apparent that many of the research participants held strong views on religion and disability. Overall, the interviews showed that a number of research participants felt comforted by their religion and this helped to support them in dealing with their disability. Although *Shari'ah* is a way of life in the KSA for Muslims, there are some individuals who do question traditional beliefs. Religion is a sensitive issue in the KSA, and I had not fully anticipated the interaction of religion and disability in the research participants. Looking back, I think it would have been very interesting to add some additional questions

regarding the interview participants' views of religion, and whether they viewed religion in a positive or negative way.

It would also have been insightful to have the views of all the research participants regarding the extent to which they believed that religion helped to support them on a daily basis. Although the concept of social inclusion in the Western literature focuses on societal aspects of inclusion (e.g. physical and non-physical barriers), if we adapt the concept of social inclusion to Saudi culture then it can be argued that social inclusion must include religious and *Shari'ah* perspectives, i.e. *Shari'ah* is a Muslim's way of life. The findings are presented thematically under the following Sub-Themes: (1) the role of religion in the lives of people with disabilities; and (2) religious support for people with disabilities.

The role of religion in the lives of people with disabilities

The review of the literature in chapter 2 identified that religion, and especially *Shari'ah*, may often play a significant role in the lives of people with disabilities. This can be seen in the way that it may sometimes impact on their ability as practising Muslims to undertake prayer and to visit Mosques, as well as how it impacts the way they view their disability. The findings also identified some of these types of religious connections with disability. Some of the research participants strongly believed that it was the will of Allah that they had become disabled; sometimes because they believed that they were being tested by Allah. For example, NANA said:

> **"I praise Allah that my injury is less severe than what I thought I praise Allah that I can talk and my eye sense are well, I praise Allah that I am doing well." [NANA Transcript, p.4]**

This seemed to show that religion played a deep role in NANA's life. Not only did religion seemingly help NANA to cope, but also at the same time she viewed the impairmetnt not as a bad thing, but as something that could have been much worse but for Allah. NANA also said:

> **"So I got nervous, but after I adapted to my situation, praise be to Allah, also thanks to the social workers who were supporting me, praise be to Allah that I am now familiar with my case. I think it is a**

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grant from Allah to raise my degree as a religious person and forgive me." [NANA Transcript, p.4]

What NANA meant by this statement was that at the first onset of disability she felt nervous and it was difficult for her to accept her situation. Over time she came to believe that what had happened was the will of Allah, whether good or bad. She believed that it was possible that Allah did this to forgive her of her past mistakes or if she had done something wrong in her life. As a consequence, because of her disability Allah had raised her degree as a religious person believing in Allah and had found greater peace in her life.

Religion seemed to play a crucial role in the lives of some of those that had physical disabilities. For example, DOHA noted that she had only been married one month when she was involved in a car crash that killed her husband. This was a terrible ordeal for DOHA to go through. She noted that she was depressed at first, her mother and father were dead, and her siblings left her in the hospital and did not visit her. These circumstances are incredibly difficult for an individual to cope with. Not only was DOHA physically impaired, but she had to deal with the grief of having lost a husband she had just married. She had to cope with the loss of a future life she had envisaged together and how she had been left alone to cope with it all by herself, with no support from her siblings.

Notwithstanding these psychological and emotional pressures, DOHA believed this to be the work of Allah. She said **"Thank God, it's Allah's fate"** and **"my God guides their ways, it's all written."** [DOHA Transcript, p.7] She seemed to find comfort and reassurance from her religious beliefs:

> **…but I was mentally depressed because I lost my husband and my siblings left me alone without visiting me, however I believe it's Allah's fate, thank God!** [DOHA Transcript, p.6]

This role of religion and its contribution to the lives of people with disabilities was not one that I had originally planned for in the interview schedule. It is an area that I would have liked to explore in further depth, but owing to time constraints when attending the interviews, I was limited in the number of follow-up questions I could ask. Clearly, since *Shari'ah* is a Muslim's way of life, religion will be part of the lives of all Saudi people. However, it would have been interesting to find out to what extent the participants took comfort in religion when dealing with their disability on a daily basis.

Religious support for people with disabilities

The interviews revealed that religion was clearly very important for some of the research participants. More specifically, religion seemed to provide a type of spiritual support for some of the participants. For example, DOHA's devotion to religion seemed to help her to cope with her disability:

> **…Thank God, I am a believer. I read the Qu'ran all the time. My God gave me the strength and power. [DOHA Transcript, p.8]**

When I asked LULU how she would cope with her disability she replied **"All this is God's will, I couldn't go against God's will" [LULU Transcript, p.6]** This response therefore meant that LULU seemed to be accepting her condition because she believed it to be the will of Allah. This does however, raise an important point about determinism and human agency. More specifically, if LULU believed that her disability was the will of Allah, could trying to improve her condition be seen as going against the will of Allah? Islamic religious support for people with disabilities is clearly very personal in nature, and dependant on the personal views of the individual in question.

When I asked LULU about the man she had been engaged to marry she noted **"He left me and took all my gold and married, thank God! [LULU Transcript, p.7]** I found this to be quite a surprising response. It seemed to be the opposite reaction of what would have been expected if someone left you after you became disabled and also took all your money. However, in light of LULU's belief in Allah, it seemed to be the case that she saw this as a good thing, because even though her fiancé had left her and taken her money, he would be happy and would have money to take care of himself, and not have to worry about taking care of LULU. There is also a gender dynamic at play here as well. For example, taking into account Saudi culture it would likely be considered not socially acceptable if a female had done this to a male with disabilities.

As can be seen, when dealing with religious support for people with disabilities in the KSA, it is important to take into account not only the particular context, but also if required, the particular person being discussed in relation to religious support. When YASMINE talked about her disability she said:

> **Subhan Allah, it's a disability and trial from our God, but I can't show appreciation for people by their looks or their disability…. I submit my self to Allah, and you know that when Allah loves people, he would test them.** **[YASMINE Transcript, p.6]**

In this paragraph, the phrase "Subhan Allah" (praise to be Allah who made this beautiful thin) means that YASMINE believed that her disability was because of Allah and that she accepted her disability because everything in her life happened because of Allah, good or bad, and that this was a test from Allah to see if she was a religious person. YASMINE believed that when Allah loves a person Allah tests them to see if that person has strong religious beliefs, and so Allah had tested her with the accident and in response YASMINE thanked Allah for everything that had happened in her life.

Therefore, for YASMINE her disability was seen as a trial, a trial set by Allah because he loves his people and tests them to see if they are worthy of his love. By accepting her disability and overcoming her disability every day, YASMINE seemed to believe that this is what would allow her to succeed in her trial. For others, religious belief was not enough to overcome challenges. Acceptance of a disability was difficult for SAIF but he was helped by his religious beliefs:

> **Thank God, our Islamic Religion taught us we must thank Allah for everything, but this matter is difficult in our society.** **[SAIF Transcript, p10]**

ATIF noted **"Praise is to Allah, I think that my life is easy, my life did not stop at all."** **[ATIF Transcript, p.7]** ZEEK stated **"Faith in Allah and regular prayers after I was neglecting it and made me psychologically relieved."** **[ZEEK Transcript, p.9]** When discussing his disability MALIK noted that he was lucky to be alive:

> **A car hit me, which lead to brain injury. But bless Allah, that Allah saved me, where bones and senses are not affected, but only what was affected is brain and nerves.** **[MALIK Transcript, p.1]**

Viewed in this way, MALIK saw his disability as not being as bad as it could have been because Allah saved him. In this way MALIK's religious beliefs provided him with support by helping him to accept his impairment more. MALIK also noted that he had adapted to his disability with the help of Allah:

First of all, I was frustrated, but now praise be to Allah that I have been adapted to my situation, I feel no problem now with my case at all. [MALIK Transcript, p.5]

THEME 9: GENDER AND DISABILITY

The findings from the research participants tended to highlight certain areas that were previously subtly hidden. The research participants collectively identified that there were clear, but subtle, links between gender and disability, and that these connections required further analysis in order to try to identify how the links operate in practice. Consequently, the findings here will summarise characteristics of those links and the next chapter will investigate these links in greater depth. It seemed to be the case that disability caused difficulties for participants of both genders, with males feeling emasculated and females feeling doubly disabled. The findings are presented thematically under the following Sub-Themes: (1) Saudi males and disability; and (2) Saudi females and disability.

Saudi males and disability

As discussed in the introduction and literature review chapters, the KSA has a dominant masculine society, whereby fathers are seen as leaders, of the tribe and the family. Males have traditionally and culturally exercised power over the family to the extent that females often have to seek prior permission for certain types of activities before being able to undertake such activities. Outside of the family, this dominant masculine society model is replicated in the political structure of the country, which has an absolute monarchy with the King as both the head of state and of government. Taking this into account, it is therefore interesting to note the effect that this may have on disability in the KSA. For example, the patriarchal approach by OMAR's family meant that even though he was a young adult, he was still treated as a child by his family:

Yes even my family treat me as a child. I am 22 years old, I am not a child any more. I am happy here at the hospital. [OMAR Transcript, p.11]

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In this instance, the fact that he was male seemed to have no impact on the way he was treated by his family. They did not seem to treat him as a man in his own right, able to assert his own rights independently, but rather as a child with a disability that still needed to be taken care of by his family. However, there is another way in which disability seems to be linked with gender. Many of the male research participants indicated that they had had negative experiences when out in public, ranging from reactions of pity to reactions of anger. These experiences seemed to have left some of the male respondents feeling bitter and sometimes hurt.

In particular in light of Saudi society whereby the male is seen as powerful and often a leader of the family, if not the tribe, the onset of a disability for male individuals might be seen in some ways as reducing his sense of masculinity and dominance in some way. It might be as if the disability has reduced his stature in society and thereby the male individual is now one to be looked at in pity. AWAD noted that the onset of disability changed his life. He noted that he had lost everything, including his job and marriage. Although he had to start his life again, he was thankful to Allah that he was still alive. He talked at length about how he had struggled to cope emotionally.

AWAD explained that after the incident that caused his disability he did not speak with anyone for seven months. It was clearly a very difficult time for AWAD trying to come to grips with his disability. After that his father died, as did two of his elder brothers, so this significantly affected him emotionally. He then decided to speak with his uncle to tell him that he should tell the girl to which he was engaged (his cousin), that he was not able to continue with the marriage because of his disability. AWAD said that he wanted to be fair with the girl, and that he could not let her wait for five or six years to see if he would recover or not. AWAD also noted that he had experienced some positive experiences with members of the public. He noted:

> **Even people who don't know me come to me and tell me this speech and comfort me and say prayers for me, asking Allah to grant me health, and well-being. Always people who meet me in the street pay pray for Allah to heal me. [AWAD Transcript, p.8]**

The phrase "tell me this speech" meant that in Muslim philosophy every Muslim must always say this speech: "Thanks Allah for everything that is happening in my life, I accept what is happening in my life good or bad, I believe Allah controls my life, and I accept everything Allah does in my life." In effect, this meant that

AWAD did not question or ask Allah why Allah had done this to him, he accepted what had happened as the will of Allah.

At the same time, AWAD noted that he had also had some negative experiences with members of the public. He noted that he was not able to go to restaurants to eat because he was not able to walk up and down stairs, and he also saw that people looked at him differently when he went out. He explained that it was not a pathetic look that they gave him, but that he was thought to be "needy". This shows that disability can have a traumatising effect on people with disabilities, and it takes time for them to come to grips with it. Moreover, dealing with a disability on a day-to-day basis continues to be hard for many of the research participants as they continue to encounter feelings of pity.

Saudi females and disability

There were a number of insights that were identified by the research participants which highlighted how females with disabilities in the KSA faced particularly difficult challenges. SAAD made some insightful comments about the position of women with disabilities, which appear to capture the treatment of many females with disabilities by men in Saudi Arabia:

> **…many can suffer due to disabilities, such as girls in terms of marriage, as I have debated with some young people in the Pink Hospital The youth said that they do not want to get married with disabled girls, to serve her, they want a wife who is able to support them. There are those men who marry a disabled girl for her money, one of my friends did so, so that he resigned from his company, and he established many companies from his wife's wealth, and divorced his wife… This is an important issue for women with disabilities because all women want the joy of marriage and children. [SAAD Transcript, p.13]**

In the male dominated society in the KSA, females typically play a subservient role to their husbands. Their focus tends to be on caring for the family and attending to their husbands. Females tend to marry earlier or have marriages arranged for them early on. Females are also restricted in terms of their daily

attire and on travel, as they must be accompanied by males and must dress conservatively. The research participants highlighted that disability can stigmatise females as young men in the KSA might not wish to marry females with disabilities because they believe they would not be able to support the males and for other personal reasons. Without a husband, or family, or an extended personal network, females with disabilities are more likely to feel alienated and isolated in the KSA.

For instance, another research participant (LULU) stated that in her first year of disability she had felt shocked and alone. She told me that at first her friends had visited her but later they had stopped doing so:

> **Some of them were my best friends ever, but after the accident they left me and never remembered me, the same thing with my husband. Unluckily I always feel alone. [DOHA Transcript, p.6]**

This is particularly difficult for females as in Saudi culture females tend to create strong familial bonds and so they rely on each other as a group collectively. To have this social bonding and support taken away, in addition to having to deal with a disability, must be particularly onerous for females with disabilities in the KSA. For females in the KSA the onset of disability might be viewed as a type of 'double disability', as being female in certain ways disables females in Saudi society whilst being physically disabled also disables females in Saudi society.

There was a range of scenarios set out by the female participants that I spoke to. One of them felt helpless and at the mercy of her father who seemed to be stealing her financial support and she had no one she could turn to for help. Her double disability seemed to be a burden that was causing her great pain and suffering. For other females it was the sense of isolation that hurt them in addition to their disability. It seemed to me when I talked to them that they felt alone and invisible to the outside world. For example, DOHA noted:

> **I am feeling annoyed, I can't move and my siblings don't visit me, I can't do anything by myself, it must be done with someone's help… Before the accident I didn't think about anything or have any responsibilities, in the village we are kind and simple people, now.. oh God I am alone in another city. [DOHA Transcript, p.8]**

For other participants the onset of disability had been a type of double disability, as they had lost a husband and the previous life they had been living. The impairment seemed to have ripped their lives away, leaving them to cope with the difficulties of the impairment and the emotional and behavioural problems by themselves. For other women, the onset of disability seemed to be a curse in that they now believed they would never marry again as no one would want to marry them. The female participants were well aware of Saudi culture and traditions, and also about the traditional tribal views held of females marrying young and to healthy males. In light of these views it is difficult to see how a social model of disability could be effectively implemented in the KSA at present. Overcoming extremely strong cultural beliefs and traditions regarding females, and challenging existing prevailing views about females with disabilities would seem to be an extremely difficult thing to do in practice.

CHAPTER SUMMARY

This chapter has addressed themes relating to access to education, quality of life for the research participants, perceptions and problems, religion and disability, and gender and disability. The chapter identified that access to education was important for participants, but that for many of them rehabilitating and recuperating was the most immediate priority for them at the moment. The social model of disability seeks to empower people with disabilities to take control of their lives, to fully integrate with society, and to be a productive member of society. The literature has identified that accessing education helps people with disabilities obtain better jobs and therefore they can earn more and have an overall better quality of life. Although some of the research participants understood and acknowledged this, their focus for the time being seemed to be on rehabilitating themselves first.

Overall, in terms of quality of life, many of the research participants felt that much could be improved. They did not have regular access to a range of social and recreational activities, nor financial and family support. This clearly lowered the overall quality of life they were experiencing. From a social model of disability perspective, rehabilitation should be not only about physically rehabilitating the research participants, but also helping them to reintegrate themselves with society and to fully interact with others. The lower overall quality of life demonstrated by some of the research participants

highlighted a pressing need to improve their situation to allow them to positively experience life on a daily basis.

Other respondents showed that they encountered many different types of treatment by the public, from attitudes of pity, and even sometimes viewing them as beggars, to negative attitudes of anger. The respondents demonstrated that living with a disability was very difficult for many of them, and simply coming to terms with the disability was hard enough for a number of the participants. Moreover, some of the research participants were particularly badly hit by the loss of their old friends and the social support that they had previously provided. This reinforced the findings in the literature that show that social support for people with disabilities is vital in order for them to fully integrated back into society.

Other difficulties in terms of family life and mobility also lowered the overall quality of life that the research participants experienced. The theme of perceptions and problems highlighted negative experiences that they had experienced or encountered in their daily lives. The theme of religion and disability highlighted that religion sometimes played a key role in the lives of the research participants by providing them with comfort, strength, and reassurance. The impact of gender on disability was also discussed in terms of both Saudi males and Saudi females.

CHAPTER 7
DISCUSSION

INTRODUCTION

This chapter will provide a critical analysis and discussion of the research findings, in light of developments in the literature and organised by theme. From a high level perspective, the research findings identify a large number of problems, obstacles, and challenges that the research participants face on a daily basis. However, the chapter also aims to explicate how the findings can inform our understanding of the experiences of people with disabilities in the Kingdom of Saudi Arabia (**KSA**) more generally.

THE NATURE OF MEDICAL SUPPORT

As discussed in the literature review, the medical model of disability views a person as having a medical impairment such as the loss of a limb, partial blindness, or deafness (Taylor and Hawley, 2010). Disability is seen as a condition which impairs the individual's quality of life (vanTeijlingen, 2005). A medical diagnosis of the condition therefore seeks not only to precisely identify the impairment, but to treat the impairment in any way possible. However, such treatment relies, not solely on the underlying impairment, but also on the overall quality of care available within any hospital or treatment centre. It is also reflected by the type of social welfare system that exists in any particular country.

In the United Kingdom (**UK**) the social welfare system provides for a system of free healthcare for UK residents except for fixed charges for prescriptions. It is useful to refer to the UK National Health Service here as the system in the UK can be used as a benchmark for the purposes of comparing systems. Nevertheless, when considering such a comparison or transfer of policy, it is essential to ensure that policy transfer does not become distorted (i.e., misinterpreted or misused) (Park *et al.*, 2017). Rather, policy transfer should be set within a historically and institutionally sensitive framework. A focus on communication, both between lender and borrower governments and between borrower governments and their target populations, can help to ensure that appropriate adaptations are (Park *et al.*, 2017).

In theory the quality of healthcare that should be provided to individuals with physical disabilities residing at the **White Hospital** should be good. However, in practice what I encountered seemed to be a broad range of problems that existed. These were not only problems relating to the individual research participants, but also problems relating to existing medical support frameworks. From my discussions with the research participants in some instances they seemed to indicate that they had even suffered some type of medical negligence at hospitals in the KSA. Many of the research participants indicated that they would have liked a better quality of medical support to be provided to them. The research participants seemed to embrace a social model of disability that would empower them in their daily lives.

If I ask myself if I believe that the social model of disability is being applied at the **White Hospital** then I would have to say no. Also, if I ask myself if I believe that overall, the research participants exhibited a loss of independence, choice and control in their own lives, then I would have to answer yes. The findings would seem to indicate that it is principally the medical model of disability that exists in the **White Hospital**. Based on my encounters and interviews with the research participants, the evidence seemed to indicate that the nature of medical support provided by **White Hospital** was below that specified in the medical model of disability.

Some research participants stayed in bed all day long. Other research participants wanted to socialise more but were unable to because they could not move their wheelchair up the hospital ramps. Other research participants had requested access to a television but had not been provided with such access. The system of healthcare that has been identified in the research data would seem to be that individuals who are in attendance at a hospital are not entitled to claim subsidies from the Government. In practice this means that individuals who had been in attendance at a hospital for four years, or in some cases even six years, had not been able to claim subsidies whilst there. The research participants noted that they had to rely on charities to provide them with wheelchairs and diapers. Indeed, some research participants told me that they felt "imprisoned" by the **White Hospital**. This may not simply be the case at **White Hospital** but it may also exist in other hospitals across the KSA.

Although there have been criticisms previously levelled at the UK NHS, it is useful to show a healthcare system that is free at the point of delivery, paid for from taxing the public, and that provides healthcare services to the entire country. In the KSA the Ministry of Health (**MoH**) is the government agency that is entrusted with providing

preventative, curative, and rehabilitative health care services to the population. In 2002 the Saudi health system was established by a Royal Decree in order to provide comprehensive healthcare for all the population in Saudi Arabia. In theory the quality of healthcare that should be provided to individuals with medical conditions or with other medical impairments in the KSA should be good.

In reality in relation to subsidies, the current Government policy is negatively impacting the individual research participants. Some of them are not able to claim financial subsidies to help to support their disability even though they clearly need as much financial support as they can get. This situation would seem to be clearly contrary to what is stated in Saudi laws and what the Saudi Government committed itself to when signing up to the Convention on the Rights of Persons with Disabilities (**Disability Convention**). For example, it was seen in the literature review that Article 5 (Equality and non-discrimination) of the Disability Convention upholds the rights of individuals to equal protection and equal benefit of the law without discrimination. This includes a prohibition against discrimination on the basis of disability.

Currently the situation in the KSA would seem to be that if you are a person with a disability and live at home you can seek disability financial subsidies. But if you are a person with disability who happens to be in hospital, then you are not entitled to disability financial subsidies. From an objective perspective both individuals are persons who have to cope with a disability in their daily lives and who would benefit from financial support. If the disability system in the KSA is supposed to provide sufficient financial support to people with disabilities, why is it the case that the majority of the research participants noted that they required more financial support in order to cope with their disability.

It is accepted that a person with disabilities that is resident in a hospital is also avoiding other home costs such as food, air conditioning, water and utilities supply, and homecare costs. However, the findings clearly demonstrated that the majority of the research participants did not receive sufficient financial assistance. The social model of disability seeks to find ways of removing barriers in order to allow people with disabilities to live their lives independently and equally in society (Hardey, 1998; Taylor and Hawley, 2010; Adibi, 2014). The social model of disability seeks to develop more inclusive ways of living for people with disabilities (Taylor and Hawley, 2010). In order to be able to cope with their disability in their daily lives, invariably people with

disabilities need financial support in order to pay for the additional costs, medications, adaptations, etc. that they require on a daily basis.

However, the current Saudi government policies are not sufficiently providing for the care of people with disabilities. They require more care and assistance than people without disabilities and therefore it would seem to be logical and fair to provide them with financial assistance, notwithstanding that they are in hospital. This might help to alleviate the current difficulties they face with financial support. When we are dealing with people with disabilities, is it not fair to say that any treatment a person with disabilities receives should be completely separate to the entitlement to receive disability financial subsidies? Currently it would seem that practices contradict the requirements of the Disability Convention. Although it may not be intentional, it t could be suggested that the Saudi Government is breaking its obligations under the Disability Convention. Indeed, the range of problems that were identified in the research data highlights that the KSA disability framework is not fully effective.

Clearly many of the research participants do not receive enough money to meet their needs. For example, some participants were receiving 800 Saudi Riyals (**SAR**) a month (£140.55), which translates to £35.38 every week with which they have to obtain medical supplies, medicines, diapers, rehabilitation services, wheelchairs, physiotherapy services, travel, etc. Realistically that would seem to be insufficient to support these people with disabilities, and the research participants were unanimous in stating to me that what they received was not enough.

By signing the Disability Convention the Saudi Government wishes to proclaim to the world and its population that it is acting to uphold the rights of people with disabilities and to provide them with a fairer system within which they can live. In theory this is a system whereby their rights as persons with disabilities are upheld, and a system in which the Saudi Government is committed to helping them to provide healthcare and social support for people with disabilities. But given the findings this would not seem to be the system that exists for the research participants. Taking into account all the information I obtained from the research participants, this would seem to be nothing like the situation that the research participants find themselves in.

Medical support services provided in a rehabilitation centre have been proven to lead to better health outcomes for people with disabilities, as they help to provide greater self-reliance with consequential cost savings (Momin, 2005). According to Social

worker SW2, all the research participants were well taken care of and everything was provided for people with disabilities that they needed. However, in reality the findings from the research participants contradicted this and identified a range of problems that the research participants identified that they still faced. At times the type of medical support provided seemed to defy the objectives of the medical model of disability, never mind the social model of disability.

FINANCIAL ASSISTANCE

With regards to adequate training, counselling, and respite care, as has been seen from the interviews with the research participants, all of these obligations are clearly lacking. In 2015 the Custodian of the Two Holy Mosques, King Salman gave the order to give financial aid to those people who have any sort of physical ailment or deformity (Saudi Arabia Blogspot, 2015). If a person with disabilities does not receive enough money to obtain sufficient food, clothing and housing, not only for themselves, but for their families, can it really be believed that the Saudi Government has fulfilled its obligation under the Disability Convention? Indeed, the £35.38 every week in subsidies is also supposed to cover the continuous improvement of living conditions for people with disabilities. People with disabilities who are staying in hospital may not even receive this sum.

The justification that is given is that an individual receives everything they can need in the rehabilitation centre, so they do not need these financial subsidies. However, as I have seen in the case of the research participants, this is not always true, and therefore the existing policy is flawed because it does not take into account the fact that sometimes the policy may not be implemented correctly or to the required standards. In addition, the research participants are not provided with wheelchairs or diapers of a good quality by the rehabilitation centre, instead they have to be provided by charities in the KSA. The implementation of the medical model of disability in the **White Hospital** is therefore flawed.

While in some cases the Saudi Government is breaching its obligations under the Disability Convention, because none of the people with disabilities are able to do anything about it, no one would seem to know. It is a case not only of the issue being overlooked, but also people with disabilities being told that they do not have the right to complain. According to the Social Affairs Minister the financial aid rules were

changed in 2015 in order to allow financial aid to be disbursed, and it would start to be given out by the end of 2015 to people with disabilities to buy their own cars (Saudi Arabia Blogspot, 2015). Yet near the end of 2016 when I asked the research participants about the 150,000 Saudi Arabian Riyals (£30,603) assistance to purchase a car, not one research participant had been able to secure this financial aid.

The more social assistance that is provided to people with disabilities, the more enabling such assistance is, and the more such assistance contributes to upholding a social model of disability. Marriott and Gooding (2007) note that social assistance can also contribute in the form of income replacement, i.e. relating to the frequent exclusion of people with disabilities from employment. We may ask what kind of a future do research participants who complain of being locked away or imprisoned in the hospital have, particularly in terms of employment potential. It would seem to be the case that the answer is virtually none. So social assistance viewed in this way would be provided to the research participant as a form of income replacement. But under the current system that research participant is prevented from receiving social assistance. He is, in his own words, imprisoned in a system which he is forced to endure, with no form of financial social assistance provided to him. Is this really the form of social assistance that the Saudi Government has committed itself to under the Disability Convention?

ACCESS TO EDUCATION

There are a number of issues that are required to be discussed in relation to this theme of education that has emerged from the interviews with the research participants. In general, most of the research participants felt that education was an important enabler for them. It was identified that it would help them to have a better chance of getting a job and it would allow them to potentially earn more money in the future, so that they would be in a better position to be able to take care of themselves. However, for most of the research participants the idea of education was far removed from their current circumstances. Because the **White Hospital** engendered a medical model of disability that focused primarily on the treatment and rehabilitation of the medical impairment, this is what tended to dominate the views of the research participants.

That is why many of the research participants noted that education was important but that at present they wanted to focus on getting better and completing their rehabilitation services. It might also have been the case that because many of the research

participants were older, education was less of an important motivating factor for them. For example, AWAD was 32 years old, AWADI was 28 years old, DOHA was 40 years old, INAM was 32 years old, KAMAL was 35 years old, LUCAS was 36 years old, LULU was 34 years old, MALIK was 33 years old, SAAD was 40 years old, and ZISHWAN was 39 years old.

At the same time it could be argued that such a medical approach to rehabilitation is less than what the research participants truly require. For example, if we engender a social model of disability approach within the **White Hospital** then it can be argued that rehabilitation would be a concept that would be reformulated to address a broader idea of rehabilitation. This would be one where a research participant would be rehabilitated to be able to not only cope with his or her disability on a daily basis, but to have prepared for his or her future as well.

It can be argued that rehabilitation of a medical impairment is insufficient, because the literature has established that people with disabilities face much greater challenges in terms of education and employment, than those without disabilities. If a social model of disability focuses on the broader rehabilitation of a research participant, this would mean that it would help the research participant to better prepare for his or her future. By having a more comprehensive understanding of the choices regarding further education that he or she could undertake, the research participant would be better enabled to navigate his or her future in society when he or she would be finally rehabilitated.

For example, AAFIA was aged 20 years old, ATFI was aged 18 years old, OMAR was aged 22 years old, SAIF was aged 23 years old, YASER was aged 18 years old, YASMINE was aged 18, and ZEEK was aged 18 years old. All these young research participants are at the start of their lives, and face having to navigate the same challenges and obstacles as people without disabilities. Issues such as writing a Curriculum Vitae, applying for a job, preparing for an interview, attending the interview, and securing a job. All of these areas are difficult enough for people without disabilities, and for people with disabilities they will be even more challenging. Yet education seemed to be far removed from the thoughts of all of these research participants. The importance of education and the level of education of a person with disabilities has been shown to be highly relevant in the literature (WHO, 2011a; WHO, 2011b).

In this day and age it is striking to think that such young people are not being guided as to the range of benefits that accessing education could provide, and in helping them to make informed choices. Article 3 (General Principles) of the Disability Convention states that the principles include equality of opportunity and accessibility. Article 24 (Education) sets out a number of obligations of States Parties with regards to the education rights of people with disabilities. They must recognise the right of people with disabilities to education, without discrimination, and on an equal opportunity basis. They must put in place an inclusive education system and lifelong learning (Article 24(1)). This is aimed at developing people with disabilities in terms of their personality, talents, creativity, and their mental and physical abilities to their fullest potential. The system should also enable persons with disabilities to participate effectively in a free society.

These rights for people with disabilities to access education cannot be acted upon if people with disabilities are not provided with information regarding potential future education, and encouraged to actively pursue further education in order to improve the overall life outcomes. Yet, rehabilitation, in which the research participants could potentially have so much time to be able to effectively consider and review such issues, is not being leveraged for such purposes. The WHO notes that there are many barriers to education for children with disabilities (WHO, 2011a; 2011b). These include system wide problems such as divided ministerial responsibility, lack of legislation, policy, targets, and plans, and inadequate resources (WHO, 2011a; 2011b). There can also be problems within a particular educational establishment. These include issues such as curriculum and pedagogy, inadequate training and support for teachers, physical barriers, labelling, attitudinal barriers, and violence, bullying, and abuse (WHO, 2011a; 2011b). Although these findings relate principally to children, there are many issues here which are equally applicable to adult education.

MOBILITY

The data that were obtained from the research participants would, taken together, seem to indicate that in general many of them encountered numerous challenges and difficulties associated with mobility in practice. One of the research participants noted that moving around was challenging because the wheelchair that they had been allocated was far too heavy to operate. The research participants noted that electric

wheelchairs were very expensive and that it was unlikely that they would be allocated such a wheelchair. Other research participants noted that they found moving around parts of Jeddah difficult.

Other participants noted that they had to have help in some restaurants, and at other times were not able to access restaurants because the building had not been adjusted to facilitate wheelchair access. Some participants noted that certain locations were accessible (e.g. certain public malls) but that this was not always the case. Many of the participants had identified and noted the proclamation that had been pronounced that people with disabilities could apply for new cars. However, many of the participants also noted that they had not been able to secure such a car in practice. Some of them noted that there were administrative difficulties that they had encountered, and others noted that they were not going to apply because they believed that they would not really get a car in practice.

Whilst the aims and objectives of the independent living movement are clearly worthwhile, it is also essential to note the socioeconomic status of the country in which a person with disabilities lives, and other relevant cultural factors as well. For example, the focus of the independent living movement is on independent living, but in the KSA there is a predominant collectivist culture which means extended family cohabitation arrangements are very common, i.e. all the family living under one roof. In this type of situation, the objectives of the independent living movement may not fit well with the Saudi lifestyles of some people with disabilities. However, the research data identified a broad range of obstacles and challenges that still continue to exist for people with disabilities in the KSA in terms of mobility.

The social model of disability focuses on challenging and removing barriers which may prevent people with disabilities from living full and active lives (Aiden and McCarthy, 2014). These can include not only societal and emotional barriers, but also physical barriers such as inaccessible buildings and a lack of accessible transportation. The social model of disability therefore focuses on trying to address these physical barriers through social policies such as building design and transportation design (Aiden and McCarthy, 2014). Article 20 of the United Nations Convention on the Rights of Persons with Disabilities sets out a number of obligations relating to personal mobility. These include that State Parties are required to take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities.

State Parties are required to facilitate the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost (Article 20). As was seen in the findings, some of the research participants were still awaiting wheelchairs and so had limited mobility. A majority of the research participants also identified barriers to mobility that they continued to encounter in their daily lives when going to places such as restaurants and the mall (Nakamura and Ooie, 2017. State Parties are also required to facilitate access to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost (Article 20). It was clear that some of the research participants would have significantly benefitted from electric wheelchairs, but they were not provided because they were not authorised to provide them, or they were too expensive.

The built environment is probably the most potent symbol of the exclusion of people with disabilities from society (Ungar, 2017). The findings noted that many of the research participants still continued to encounter problems when attending restaurants, or when trying to find parking spaces. Article 3 of the Disability Convention includes 'accessibility' as a general principle. Article 9 of the Disability Convention aims to put in place accessibility provisions that are orientated towards enabling persons with disabilities to live independently and to participate fully in all aspects of life. States Parties are required to take appropriate measures to ensure that people with disabilities are able to access the physical environment on an equal basis with others (Article 9(1)).

It also specifies that they are required to take appropriate measures to ensure that people with disabilities are also able to access transportation, information and communications (including information and communications technologies), and other facilities and services open or provided to the public (in both urban and rural areas) (Article 9(1)). Such measures apply to buildings, roads, transportation, and other indoor and outdoor facilities, including schools, housing, medical facilities, and workplaces. Article 9 also specifies that State Parties are required to take appropriate measures to develop and implement minimum standards and guidelines for the accessibility of public facilities and services. State Parties are required to ensure that private entities offering public facilities or services must take into account all aspects of accessibility for persons with disabilities.

In addition, State Parties are required to provide forms of live assistance and intermediaries (including guides, readers, and professional sign language interpreters) to facilitate accessibility to buildings and other facilities open to the public. One of the challenges with this requirement is that it is very difficult to identify what kind of measures that the Saudi government has to put into place to ensure that it has fulfilled its obligations under the Disability Convention. The Disability Convention states that these obligations apply both to urban and rural areas. However, the difficulty that the KSA currently faces is implementing accessibility measures across all rural areas, as there are a huge number of smaller rural centres across the KSA that would require a huge investment in order to effectively adapt them in terms of mobility requirements (Roberts and Babinard, 2004).

RELIGION AND DISABILITY

Notwithstanding their existing physical disabilities, many of the interview participants often repeated their thanks to Allah, or gave thanks to Allah that their condition was not worse, or that at least they were coping in their daily lives. In this way their belief in Allah and in Islam helped to support them not only in adjusting to their impairment, but also in coping in their daily lives with all the challenges they faced. Some of the research participants believed that their condition was the will of Allah and so this acceptance of a higher power in some way helped them to accept their impairment and to mentally cope with the challenge of their condition. Islamic philosophy has a positive attitude towards needy individuals and those individuals that may find themselves in a disadvantaged situation (Al-Aoufi *et al.*, 2012). It has been observed that:

> The Qur'an and the Hadith not only declared the existence of disabilities as a natural part of human nature, but also provided principles and practical suggestions for caring for disabled people, as well as discussing the significance of such caring (Al-Aoufi *et al.*, 2012, p.206).

However, it is also noted that disability in some Muslim countries has also been seen to have some kind of moral or religious significance (Al-Aoufi *et al.*, 2012). For instance, it is observed that some cultures view disabilities as a blessing whilst others view it as a curse, or alternatively a testing of faith under the will of Allah (Al-Aoufi *et al.*, 2012). When cultural perspectives are mixed with religious values, this can sometimes lead to a number of different courses of action, which in turn may be falsely attributed to

religious faith, e.g. embarrassment at having a child with a disability, attempting to explain the cause of disability, and looking for fast solutions (Al-Aoufi *et al.,* 2012).

Islamic law and the Qu'ran explicitly provide for the inclusion of people with disabilities in social life via emphatic denials of ideas about contagion or pollution associated with disability (Blanks and Smith, 2009). Accommodations may be offered to people with disabilities to allow their participation in religious life to the greatest extent possible (Blanks and Smith, 2009). The findings from the interviews in general tended to indicate or highlight the importance of religion and of Islam in the lives of the people with disabilities that I interviewed. In general, most of the individuals that I spoke with believed that Islam enriched their lives and their faith provided them with some measure of comfort, guidance, and support.

It is interesting to note the extent to which it can be argued that this type of religious support that the research participants experienced constitutes what has been called 'spiritual medicine' in the literature (Ghaly, 2008). Muslim jurists have spoken of both physical and spiritual means of treating disabilities, with early jurists giving a general preference to spiritual treatment of disabilities whereas modern jurists prefer the physical treatment of disabilities (Ghaly, 2008). So, it would seem to be the case, particularly in the KSA, that the issue of religion and disability is a very nuanced and complex issue. Religious views differ among Muslims, for example Sunni or Shia Muslims. In addition, the views of Islamic jurists also differ and may influence the beliefs of Muslims in a number of different practical ways.

Consequently, it may be the case that Muslim views of disability may vary depending on the particular region in the KSA, or particular town, village, or city. The Islamic faith is also deeply intertwined with the lives of Muslims across the KSA. The findings reveal that many of the participants found some measure of comfort in their faith in Allah and religion. In practice what this meant was that it seemed to be the case that their religion and their faith helped them to better cope with the difficulties they faced in their daily lives owing to their impairments.

The importance of the Islamic faith and an individual's belief in religion means that people with disabilities in the KSA should be helped and encouraged to participate as fully as possible in all Islamic religious rituals and prayers. This would not only help people with disabilities to continue to feel strongly about their religion and faith, but it would also carry the potential to support them in their daily lives by giving them religious

strength and hope. This is an aspect of the social model of disability which has not been fully developed in the literature relating to the social model of disability in Islamic countries. However, it is an aspect which I believe to be important and which is worthy of future discussion.

GENDER AND DISABILITY

Gender and disability together form an area which the literature has highlighted as raising a broad range of issues. For example, it has been argued that disability intensifies the sense of passivity and helplessness for women (Meekosha, 2004). The findings have shown that this argument is justified as a number of the research participants told me of the way they felt, or had previously felt, helpless. One of the research participants (AASIA) wanted someone to help her, she felt an indescribable type of humiliation because her father was taking her money. The literature also demonstrated that studies have indicated patterns that show that women with disabilities fare less well than men with disabilities (Meekosha, 2004). This included women with disabilities more likely to live in poverty, achieving lower educational outcomes, more likely to experience degenerative conditions, less likely to be in the paid workforce, and lower incomes from employment (Meekosha, 2004).

In the KSA these negative outcomes are amplified owing to the prevailing dominant masculine culture, together with the male guardianship system (i.e. Mahram). The findings showed that some of the female research participants found that their male companions no longer wanted to be with them subsequent to the onset of their disability. One of the research participants found that she was divorced by her husband who then took all her money away from her. These findings reinforce the findings in the literature, that women with disabilities are more likely to be divorced and less likely to marry compared to men with disabilities (Meekosha, 2004). The descriptions provided by the research participants tended to confirm the findings in the literature that females with disabilities were more likely to face extreme social categorisation in the sense that they were seen more as de-sexualised and inert (Meekohsa, 2004).

In practice then the findings showed that attitudinal barriers towards females with disabilities led disability bias to be compounded by gender bias. Given the medical model of disability that was encountered at the **White Hospital**, it is difficult to see how such societal attitudinal barriers can be effectively addressed. Moreover, without

addressing such societal attitudinal barriers, females with disabilities may find themselves the victims of a cycle of negativity. Perhaps the first step in addressing these difficulties faced by females with disabilities in the KSA is to first acknowledge that they exist. In practice it is difficult for females to assert their rights in a male dominated society in which they find themselves subject to a male guardianship system.

It has previously been identified in the literature that the United Nations (**UN**) had recommended that normative instruments could be used to positively impact the rights of females with disabilities, in order to achieve gender equality, and in order to end physical and sexual violence experienced by females with disabilities (UN Women, 2015). Increasing the leadership and participation in decision-making of females with disabilities was cited as a way to empower them and is a step in the right direction towards implementing a social model of disability in the KSA (UN Women, 2015). Widespread cultural biases in the KSA must be tackled by the Saudi government if the rights enshrined in the Disability Convention are to be upheld in the KSA (Rousso, 2003).

QUALITY OF LIFE

Quality of life is an area that has been widely discussed in the literature. It is an area that covers many different underlying ailments, conditions, and types of impairment. Where individuals are dealing with a condition, the severity of their depressive symptoms tended to indicate the quality of live they were leading (Hägg *et al.*, 2010). When applied to the research participants the broad range of problems that the research participants identified and discussed in depth, showed that they continued to have negative experiences and feelings in their daily lives. One of the research participants had seen two of her sisters and her father die in a car crash, and had not finalised a marriage subsequent to her injury. Many of the research participants experienced problems with the overall quality of medical support provided. Many of the research participants experienced problems with the overall financial support provided to them. Overall, it was clear that many of the research participants showed depressive symptoms and therefore according to the research study this meant that their quality of life was negatively impacted.

Satisfaction with one's life situation can be used as an indicator of overall quality of life. This would mean that quality of life is affected by a person's occupation, meaningful occupational activities, social integration, and an individual's sense of the meaning of life (Viemerö and Krause, 1998). Used in this way and applied to the situation of the research participants, this tool would seem to indicate overall low quality of life for the research participants. Some of them noted that they could not go down to socialise with others because they were restricted owing to mobility challenges. Others noted that they could not access recreational activities such as watching television. Some of the research participants noted that they had very little social interaction as they stayed in bed all day long.

It was identified that many of the research participants did not undertake meaningful occupational activities and there were low levels of social integration identified overall. These factors would tend to indicate that the research participants were experiencing a lower quality of life overall. Taken together, these research studies are very helpful when we apply them to the situation of the research participants. The research studies show that some type of physical intervention can often help to alleviate pain and/or depression, and that alleviating depression can help to increase the overall quality of life experienced (Adair, 2015). It would seem to be a cycle whereby if individuals with disabilities become depressed, then they subjectively experience an overall lower quality of life than would otherwise be the case.

However, if people with disabilities have an occupation, undertake meaningful occupational activities, or experience better social integration, then they are able to develop a better capacity to cope with everyday life. These individuals are also likely to perceive themselves to subjectively experience an overall higher quality of life than would otherwise be the case. Now, we can apply this framework to the situation that the research participants are experiencing daily, if a social model of disability was implemented for the research participants. We can see that in theory those individuals that are able to have an occupation, undertake meaningful occupational activities, or are able to experience better social integration, would more likely find themselves subjectively experiencing a higher quality of life than would otherwise be the case.

If they were undergoing rehabilitation and believed that when they were rehabilitated, they might be able to find employment that might be something that could help them to focus their energies. Alternatively, if the research participants were undertaking meaningful occupational activities, or activities that were training them for future

occupational activities, that might be something that might engage the research participants. The same can be said of the research participants experiencing better social integration. All these types of activities, and potentially similar activities, might contribute to the research participants finding some meaning in their daily lives and to viewing their overall quality of life as being higher than would otherwise be the case.

However, the findings generally tended to support the view that many of the research participants were not experiencing a high quality of life. There was a range of problems, difficulties, and challenges that the research participants were facing in their daily lives and which seemed to have been overlooked. It was because of this that the research participants often said that they felt "imprisoned" or could not socialise. A number of the other research participants noted that all they did was watch television or sleep.

The research findings tended to indicate that there were still problems remaining within the rehabilitation system that had been put in place at the **White Hospital**. It was noted that some individuals were not "rewarded" with external trips because of the nature of their behaviour. Other individuals had regularly asked for physiotherapy services but had not been granted access to these services. Other individuals had difficulty moving around because wheelchairs were too heavy but nothing had been done to alleviate this situation. Other individuals could not access the social lounge at all. A number of other individuals informed me that essentially all they did all day was to sit in bed and watch television or sleep. If that is all an individual is doing for 4 years I can see that it must be difficult to envisage a higher quality of life from arising at any time in the future.

PERCEPTIONS AND PROBLEMS

It was clear from the interviews with the research participants that many of them had faced similar public perceptions and experienced similar problems. Many of the research participants noted that they had encountered some form of negative treatment by members of the public, whether in the form of hostility or pity. Some of the research participants noted that some members of the public had thought that they were beggars. Other research participants noted that they encountered problems with transport, as they said that many taxi drivers did not want to transport them as they believed it would be too much trouble to take them, e.g. folding up the wheelchair, helping them inside the car, putting the wheelchair in the boot, and repeating at the destination.

Some of the research participants had noted that often members of the public viewed people with disabilities as being diseased, and they noted that they were treated differently because of this. Many of the research participants also noted that they were treated differently by members of their family. These findings highlight some of the difficulties that people with disabilities face in Jeddah. Although the findings are not statistically generalizable, the likelihood is that these findings are broadly representative of general behaviour to people with disabilities. At this stage it is not possible to say with certainty whether this is a cultural or social issue, or a mixture of both. However, if these types of negative perceptions and behaviour displayed to people with disabilities are common in Jeddah, then it is likely that the social model of disability is not widely recognised in Jeddah.

From my prior experiences, I have seen first-hand that even families of people with disabilities often 'hide' them away because of embarrassment or feelings of shame. They are often not taken to parties (e.g. weddings) because of the same type of feelings. So, from my personal experience I believe it to be a mixture of culture and society in general. Given the collectivist and hierarchical structure of Saudi society, it is highly likely that in order to change the way members of the public and society in general in the KSA view people with disabilities, a fundamental change from the top is required. Without such a fundamental change, rights that are entrenched in the Disability Convention will be difficult to enforce in practice.

The way that people with disabilities in the KSA are viewed and treated may also be viewed in terms of Labelling Theory. Labelling Theory asserts that labelling individuals based on their characteristics or behaviour causes negative stereotypes and stigmatisation owing to how other people may react to the identity of those individuals that are labelled (Becker, 1963; Lemert, 1967; Bernburg, 2009). In the KSA it can be argued that the effects of Labelling Theory are amplified owing to the collectivist nature of Saudi society. Because all Saudi society is Islamic and highly culturally influenced, any negative stereotypes or stigmatisation that may arise may very quickly be perpetuated among Saudi society, i.e. once certain segments of Saudi society view an issue or something as negative, the rest of Saudi society may quickly latch on to such view.

The literature has previously asserted that to be labelled as handicapped may assign a category of deviance to an individual, and thereby excludes that individual from the full social acceptance that they would otherwise receive (Hilbourne, 1973; Watson,

2006). The effects of Labelling Theory can be identified in the stories discussed by the research participants, i.e. how owing to their disability or particular impairment, they are labelled as disabled and viewed negatively by others. In much the same way as people with disabilities may be publicly labelled by others in the KSA, people with disabilities may also be privately labelled by others in the KSA. Such private labelling may take many forms and it may be very difficult to identify. From my personal experience I have witnessed how people with disabilities may be labelled in private by their families owing to embarrassment or feelings of shame within the family.

So, for example, instead of allowing people with disabilities to be present at a wedding celebration, they may be hidden way so that they do not taint the festivities in any way. The findings from the research participants also identified that Labelling Theory may also apply in particular in relation to females. For example, some of the females research participants believed or had accepted that because of their disability they would no longer be attractive to a male, or would no longer be a viable partner for a husband owing to their condition. The husband of one research participant had divorced her and taken all her money, and she still praised him as she wanted him to be happy. The extent to which labelling may led to negative feelings of low self-worth or low self-esteem in people with disabilities in the KSA is still unknown.

The Disability Convention seeks to protect the rights of people with disabilities to participate freely in society without discrimination. However, the findings from the research participants tend to support the notion that they are not able to participate freely in society without discrimination. Some of the research participants noted that they were not able to eat at restaurants because they had difficulty accessing the restaurant or had difficulties parking. There are three basic elements for exclusion that can be identified in practice. These are: relativity (i.e. comparing circumstances of individuals and communities relative to others at a given place and time); agency (i.e. the act of an agent, identifying the cause of exclusion); and dynamics (i.e. based on bleak future prospects and not simply on existing (UNICEF, 2006).

Based on these basic elements, it is likely that the research participants will continue to face social exclusion for the foreseeable future. On the whole, the participants all encounter similar circumstances in terms of medical care and support, financial assistance, access to education, mobility, religion and disability, quality of life, perceptions and problems, and social support services. In terms of agency we can identify agents as doctors, nurses, healthcare workers, and other members of the

public that the research participants come into contact with on a regular basis. In terms of dynamics, from the findings it would seem to be the case that most of the participants face bleak future prospects, some more than others.

Consequently, we can see that without fundamental changes to the three basic elements of exclusion, the research participants will continue to face social exclusion in their daily lives. Current initiatives to combat poverty through international financial institutions and governments have not effectively evaluated the exclusion of people with disabilities from economic and social participation in the construction of policies (Laurin-Bowie, 2005). It is because of this that such a model of social and economic development has proven unsustainable and ineffective because the real barriers to inclusion lie in the structure and implementation of social and economic policies.

We now know that rights are not enough, and that what is actually needed is strategies to help governments and donor agencies to develop inclusive policy approaches (Laurin-Bowie, 2005). A three-step process that has been proposed is: (1) persuasion and awareness raising; (2) education and knowledge development; and (3) collaboration and policy engagement. In terms of persuasion and awareness raising this involves making disability a priority for governments, donors, and international agencies (Laurin-Bowie, 2005). This requires carrying out research studies that are able to convince these institutions that inclusion for people with disabilities should be a priority.

I believe the findings provided by this present study are very important because it demonstrates that inclusion policies for people with disabilities should be made a priority for people with disabilities in the KSA. The research data have shown that rights in the Disability Convention are not enough. We need a better understanding of the knowledge of people with disabilities in the KSA have about their families, their communities, and the social, economic, and political structures with which they interact (Laurin-Bowie, 2005). Yet the literature review demonstrated the paucity of research undertaken in this field. The research study and the findings are important because they significantly add to the literature in this area.

SOCIAL SUPPORT SERVICES AND SOCIAL WORKERS

The findings show that social support services are essential to people with disabilities. They can enhance the quality of life of people with disabilities through social connections. Social interaction can also help to maintain the person's independence and wellbeing. Social support services can cover a wide range of services. They can include things such as disability equipment, adaptations to homes, support groups, individual support programmes, and home care help with things such as shopping, cleaning, physiotherapy. These types of services are vital for people with disabilities because they help them to become more independent and they facilitate social inclusion.

The findings showed that some of the research participants felt supported by their family and friends. However, many other research participants still felt they faced a difficult life and were short of money and support. Many of them wished for additional support and services. It is acknowledged that in reality the overall level and quality of social support services received by people with disabilities will be governed by the applicable healthcare system, government framework, and level of a country's socioeconomic development. However, given that the research participants were attending a rehabilitative centre in Jeddah, it would have been logical to presume that the level of social support services they could count on would be at a reasonable level.

It has been identified that social care users who are disabled view support as necessary in order to achieve things that are important to them, i.e. being part of social and economic life (Grayston, 2015). Day-to-day living needs are also more likely to be met through support services than needs around independent living (Grayston, 2015). Social support can be vital in helping people with disabilities in their daily lives and also in fully participating in society. However, the findings highlighted that there were both positive and negative views about the level and quality of social support services they received. Some of the research participants noted that they did not know what social support services were available. Other research participants identified that they had not received any social support services.

Some of the research participants said that the social support services that they had received from the social worker had really helped them. However, it seemed to be the case that the overall level and quality of social support by the research participants was not consistent. This was an issue because from my perspective many of the

research participants could have significantly benefitted from more social support. This could benefit them practically and also might significantly improve their outlook and daily lives. The social workers noted that they provided for the needs of the research participants by providing them with medical shoes, crutches, and equipment, and as well as services that help them to stand. However, what the research participants noted contradicted this.

Some of them noted that they had not been provided with a wheelchair or that the wheelchair that they had was too heavy to use. Other research participants noted that they were not provided with good quality diapers. Another research participant noted that he felt imprisoned. Another research participant noted that he could not access the social area. For a number of the research participants the response of the patients was very negative, patients had told me that the social workers did not provide any services to them. When I informed SW2 about this, SW2 replied **"Of course that isn't true, we are very interested in providing patients services" [SW2 Transcript, p.10]**

I think this is important to mention because from what I saw and heard, a number of the research participants said that they had not been provided with social support services. In contrast, SW2 asserted this was not the case and provided a different perspective on the situation. The point is that for people with physical disabilities rehabilitation is absolutely vital to enable them to re-enter society and live an independent life. From a social model of disability perspective, rehabilitation should therefore be not only about physical and mental rehabilitation, but also about preparing those individuals and supporting those individuals as fully as possible.

This includes things like being involved in the community, which no research participant told me they did, or doing enjoyable things locally, which some of the research participants wanted to do but said they could not because of mobility problems. It also includes other things such as accessing information and advice which some of the research participants noted that they had not been provided with information regarding the social support services of financial assistance they could receive. Given the fact that some of the research participants did not have friends or family that they could call on, social interaction and taking part in recreational activities is vital for their self-development and rehabilitation. Yet it would seem to be the case that the types of social support that are most needed by the respondents with physical disabilities are not being provided consistently to the respondents.

SAUDI LAW AND POLICY IMPLEMENTATION

In theory the Saudi Disability Code aims to empower people with disabilities by providing them with rights regarding welfare, habilitation, and health. The Saudi government has also committed itself to implementing the Convention on the Rights of People with Disabilities in the KSA. However, the research findings would seem to indicate that there still exists a large disparity between the rights that people with disabilities have on paper, and the rights that people with disabilities have in practice in their daily lives. One of the difficulties that exists today in the KSA is that there is a range of different laws relating to disability that all work separately. For example, the Labor Code (Royal Decree No. M/21) (1969), the Council of Ministers Resolution No. 407 (1973 and 715 (1974), the KSA Royal Decree No. 715 (1974) and No. 1355 (1974), and the Regulation for Rehabilitation Program No. 1355 (N.D.).

All of these laws operate in different ways and are governed by different government institutions. In much the same way, there is a number of different institutions governed by different government branches. Therefore, we have the Noor Institute for the Blind, the Amal Institute for the Deaf, and the Institute for the Intellectually Disabled operated by the Ministry of Education. We have the Career Rehabilitation Centres in Riyadh, Taif, and Damman, and the Social Rehabilitation Centres in Riyadh, Al-Ahsa, and Medinah run by the Ministry of Labor and Social Affairs. We also have the King Faisal Specialist Hospital and Research Centre and the King Khalid Eye Hospital run by the Ministry of Health. Consequently, there are many different stakeholders involved in running institutions and services for people with disabilities in the KSA. This makes it that much more complex in terms of the interaction of different disability frameworks in the KSA. Moreover, there is no centralised disability centre, institute or organisation that provides centralised information on disability to people across the KSA.

As the findings showed, people with disabilities find it difficult and complex to try to find out information regarding social and financial support for people with disabilities. The Saudi government makes announcements such as the proclamation that every person with disabilities is to be provided with a specially adapted car, but in practice the bureaucracy of the process has meant that this has not happened, and people with disabilities that need specially adapted cars are still waiting for them. In practice the findings showed that the research participants were still waiting for wheelchairs, or they

had to continue to use wheelchairs that were ill suited for them and in practice restricted their mobility and lowered their overall quality of life.

The findings have demonstrated that many of the research participants continued to face difficulties in terms of mobility, travelling around Jeddah, and accessing restaurants and shopping malls in the KSA. The findings have also showed how difficult and challenging the research participants found their daily lives to be, facing problems with mobility, problems with the quality of healthcare provided, and problems with negative attitudes and perceptions from others towards them. The prevailing Saudi culture of top down hierarchy from the ruling Saudi Royal family means that in practice, path dependency, remains strong in the KSA. Policy implementation in the KSA, and in particular the issue of complexity of joint action, means that, in practice, achieving across-the-board change is extremely difficult in the KSA owing to the broad range of stakeholders involved.

Taking into account the Government Ministries, the disability institutes, the disability charities, and the broad range of Saudi hospitals and rehabilitation centres involved with disability in the KSA, effectively implementing the rights enumerated in the Disability Code Convention of 2008 is an enormously difficult and complex challenge for the Saudi government. Nevertheless, it is an objective which the Saudi government has committed itself to. This therefore means that the Saudi government needs to put in place a framework which can effectively review whether or not it is complying with this implementation in order to effectively address all of the problems and challenges identified by the research participants at the **White Hospital**.

CHAPTER SUMMARY

There were ten themes that were identified from the research data. Many of the research participants identified that access to education was important, but they seemed to acknowledge that getting better was their first priority. Although religion and disability was identified as a theme that emerged, it was not initially addressed in the interview questions and interview schedule. Therefore, it was not an area that was discussed in depth with any of the research participants. However, it is certainly an area that would merit further discussion and research in the future. The theme of quality of life grouped together different viewpoints about different areas affecting the overall quality of life of the research participants. The theme of perceptions and problems in

principle is important, however there were a wide range of negative perceptions and problems that were identified. The nature of medical support is a theme because it was an area that the research participants discussed a lot.

The general indication was that the quality of medical support received was much less than what the research participants needed and wanted. The nature of medical support provided to the research participants has been seen to be of low quality and the overall quality of life of the research participants would seem to be low. The research participants have highlighted a number of problems that they have encountered in their daily lives and also negative perceptions of them by other people and by members of their own family.

In theory the Saudi Disability Code aims to empower people with disabilities by providing them with rights regarding welfare, habilitation, and health. The Saudi government has also committed itself to implementing the Convention on the Rights of People with Disabilities in the KSA. However, the research findings would seem to indicate that there still exists a large disparity between the rights that people with disabilities have on paper, and the rights that people with disabilities have in practice in their daily lives. People with disabilities interviewed within the research study would seem to continue to suffer from a low quality of life. This would seem to indicate that there is still a huge amount of work to be done if people with disabilities are to enjoy full social inclusion in the KSA.

CHAPTER 8
CONLUSIONS

CHAPTER OUTLINE

This chapter will set out the overall conclusions of the research study. It will draw together the ten themes that were identified in the findings and interpretation chapters and will link these themes together. It will also set out my perspective on the study. This will include reflections on my journey as a researcher through the various stages that I have gone through and also my views on the process and the outcomes. The chapter will subsequently identify research limitations and will then discuss issues relating to policy change. Finally, the chapter will set out recommendations for practice, research, and education following on from the research findings and interpretation chapters.

PEOPLE WITH DISABILITIES IN HOSPITALS IN THE KSA: TOWARD A BETTER FUTURE

The original aim of the study was to identify and characterise the barriers to social inclusion, and to provide initial evidence for social inclusion polices for people with disabilities in the Kingdom of Saudi Arabia (**KSA**). This section will focus on summarising the barriers to social inclusion that were identified and characterized, and initial evidence for social inclusion policies will be presented later in the chapter.

The significance of the research study

Based on the research findings to date, this research study has uncovered real problems in the disability framework that exists in the Kingdom of Saudi Arabia (**KSA**). The research is an original study that has identified real difficulties that people with disabilities in the KSA are encountering in their daily lives. The study sought to contribute to the existing literature covering people with disabilities in the KSA and aimed to provide a real voice for people with disabilities across the KSA. However, I believe that the research findings also go well beyond the existing literature. This is because there is very little literature that covers this area or examines it in any depth. For example, there were four unpublished research theses that provided insights into

disability frameworks in the KSA. Other studies provided some valuable insights such as Al-Jadid (2014) which identified disability trends in the KSA in terms of prevalence and causes. Other studies focused on medical aspects of children with disabilities in Saudi hospitals and clinics (Al-Hazmy *et al.*, 2004; Al-Turaiki, 2000; Shawky *et al.*, 2002).

It was identified that taken together these studies were not sufficiently comprehensive in nature to allow a researcher to have a thorough insight into disability in the KSA. These studies focus on specific medical aspects of people with disabilities in Saudi hospital and clinics, without consideration of social aspects such as mobility, social inclusion, and the subjective views and perspectives of people with disabilities. These studies have not provided a comprehensive insight into the problems faced by people with disabilities across the whole of the KSA, or about the real life challenges they encounter on a daily basis.

This research study has sought to identify the real life challenges faced by people with disabilities. It has identified a number of themes which highlight a range of problems that people with disabilities still face in the KSA. It has identified potential deficiencies in the Saudi legal system with regards to the social, financial, and medical support that has been pledged by the Saudi government in theory, and the social, financial, and medical support that people with disabilities actually receive in practice. It has been able to consolidate a wide range of articles relating to disability to highlight the legal, social, and medical framework applicable to people with disabilities in the KSA. It therefore significantly adds to the literature covering these areas. It can be concluded that the research findings provide real and important insights into the lives of people with disabilities cared for in hospital in the KSA.

The research study findings

The research findings show that although the Disability Convention sets out rights for people with disabilities in the KSA, this is clearly not enough. The themes that have been identified demonstrate significant problems for the research study participants. In addition to suffering from a disability, these research participants have disclosed saddening and sometimes appalling situations and behaviour that they have had to tolerate and handle. There are a number of unusual issues that were identified,

including situations which seemed to indicate medical negligence, non-payment of financial support (benefits), and forsaking the opportunity of employment so that the subsidies paid to family members would not be stopped.

There are many other problems that the research participants have identified that affect them in their daily lives. The research participants have highlighted that they have had problems in accessing financial assistance, and many said that the financial assistance they received was insufficient. Some of the research participants have highlighted that they had not received the medical support equipment that they needed to cope with their disability. Other research participants highlighted the problems they had in terms of mobility and accessing recreational areas and restaurants in Jeddah.

Although the research study only focused on a selected number of participants at one particular hospital in the KSA, the difficulties and problems they encountered highlighted the potential application to other people with disabilities in the KSA. For example, many of the research participants highlighted problems with obtaining financial assistance or relevant information. If this is the case for people who are attending a rehabilitation hospital with social workers there who are supposed to provide social care and assistance, then it raises questions about how many other people with disabilities in Jeddah and across the KSA encounter the same problems.

The negative perceptions and significant problems highlighted by the findings are troubling. They indicate that the participants face real problems in their daily lives in terms of discrimination or stigmatisation in addition to having to cope with their disabilities. People in the KSA have viewed the research participants with pity. They have sometimes been shunned by members of the public or have been treated badly. They are sometimes viewed as being diseased or even as beggars. Clearly it is not known to what extent this reflects the views and experiences of all of the people with disabilities living in Jeddah. But the fact that a majority of the research participants noted and identified these types of negative perceptions and significant problems shows that they continue to exist in Saudi society today.

The research questions for this study were:

(1)   **Are there barriers to social inclusion for people with physical disabilities in the medical setting in the KSA?**

(2)   **If there are barriers, what are they, and how do they impact on the people with disabilities?**

(3) What steps can be taken to overcome any barriers in the medical setting in KSA?

The research findings identified a wide range of barriers to social inclusion in practice, including barriers that have been widely identified in the literature (Raesh, 2010; Al-Odaib and Al-Sedairy, 2014; Aldabas, 2015; Hadidi and Al Khateeb 2015). One of the most important barriers was financial assistance. The general consensus from the research participants was they lacked financial assistance, or they lacked sufficient financial assistance. Indeed, it was noted by the majority of participants that the financial subsidies they received were insufficient.

The literature has identified that barriers such as financial issues, technical aids and personal assistance can cause real problems for people with disabilities (Davis, 1990; Grewal *et al.*, 2004). Indeed, the research study also found that the financial assistance the research participants received was not enough to allow them to purchase the right equipment, or good quality medical care products, or other medical support products. This in turn negatively affected the overall quality of life experienced by the research participants. This therefore supports the findings in the literature review (Swain, 2004). These are people with disabilities who are trying to lead normal lives but who cannot because they do not have sufficient money to be able to buy the medical equipment or support that they need on a daily or regular basis.

Mobility was another significant barrier to social inclusion that was identified in the research findings and has previously been identified in the literature (Al-Jadid, 2013). Many of the participants cited mobility problems, which negatively impacted their daily lives. Many of them noted that they had problems getting around the city. This included not having specially adapted cars despite promises made by the Saudi government to provide all people with disabilities with such adapted cars. The bus transportation system is very undeveloped in Jeddah and so people with disabilities cannot really use this system. This leaves them with a choice of being transported by family and friends or by taxis. Many of the research participants noted that taxis regularly did not want to transport them as it took too long to help them to get in and out of taxis.

The taxis in Jeddah are not all specially adapted to be able to accommodate people in wheelchairs. However, my interviews with the research participants suggest that their difficulties mainly resulted from the attitudes of the taxi drivers. So, it would also seem

to be a societal factor that influenced the situation. These kinds of attitudes and perceptions are ones that can be changed over time if the government provides the right kind of social awareness support in the media and elsewhere. But for now, it would seem to be the case that in some parts of Jeddah at least, people with disabilities are viewed as problematic by taxi drivers and this makes it difficult for them in terms of mobility.

In practice as many of the research participants did not have family and friends who could regularly provide transport for them, this left them unable to travel around in the city. They could not visit shopping malls, or restaurants, or cinemas, or parks, or carry out other recreational activities. In effect, problems with mobility directly led to their social exclusion. A number of research participants noted that they had not been provided with social support services or good quality social support services. Some of them noted that they had not been informed of financial assistance that they could receive, and they had not applied for financial assistance. The social workers also noted that the research participants were not provided with medical equipment or support, and that these items were only provided by local charities.

In practice this led to social exclusion in particular cases. Examples include individuals that were provided with wheelchairs that were too heavy to move and that prevented them from attaining full mobility, or individuals having to pay for wheelchairs themselves, or individuals that were not offered any social services or had not been informed about the availability of relevant social services. The findings showed that rehabilitation centres might provide people with disabilities a special needs car or other material assistance such as beds or wheelchairs but that this information was not known by the social workers. From the information obtained from the research participants it seemed to be the case that many of the research participants had not received social support, or sufficient good quality social support, and that this in turn had negatively impacted their social inclusion. They had not been able to apply for financial assistance and they were not helped in learning about what social support services they might be able to obtain.

The application of Labelling Theory within the context of the research participants identified further social barriers that affected the research participants in practice. In practice Saudi collectivist culture served to reinforce and amplify labelling of people with disabilities in the KSA. For example, the labelling of the research participants as handicapped seemed to fortify their sense of isolation and fears over their future. In

some instances this was particularly true for certain female research participants who, because they were labelled as disabled, believed that they would forever lead a single life without a husband. Although it had not been proved that this would be the case, certain research participants believed that because certain segments of Saudi society view females with disabilities as being unable to marry (e.g. because Saudi males wanted someone who would be able to take care of them), they too would be unable to marry.

The labelling of people as disabled also affected private relationships. For example, a few of the research participants now felt lonely and isolated because they considered that because of their impairment their friends no longer continued to keep in touch with them as they once had. In practice labelling causes behavioural and emotional challenges to people with disabilities owing to the values that the rest of society attaches to particular labels (Hughes *et al.*, 1997). Within the context of the KSA, labelling may be applied to people with disabilities in different ways, in public and in private, and with different effects in the urban and rural environments.

This is what makes the labelling of people with disabilities in the KSA particularly difficult to address. In terms of steps that can be taken to overcome barriers in practice, given the strong collectivist culture that is present throughout the KSA, it would seem to be the case that a multi-channel approach is required. For example, this would require a great deal more commitment from those at the top and in government to bring the disability agenda more strongly to the attention of the public. This has to be done consistently and on an ongoing basis. This would require increased financial commitment from government in order to ensure that Saudi societal views towards people with disabilities, where negative, might potentially be changed over time.

So, for example, this would require a renewed commitment from the Saudi government to invest in public educational programmes that promote social inclusion for people with disabilities across multiple media channels such as television, radio, and social media. It would also require increased engagement from people with disabilities across the KS in order for them to be able to showcase they views and experiences to inform and teach people in the KSA about the difficulties, challenges, and negative experiences that have experienced, and continue to experience, often on a daily basis. By providing an ongoing emotional public connection with people with disabilities, the Saudi government could help to significantly change negative perceptions of people with disabilities in the KSA that continue to exist today.

PERSONAL DEVELOPMENT

I feel it is important to the research to set out my journey and personal development through this research study. I believe this will help to guide the reader through the whole experience and to help them to understand my decision making throughout the period of the study. I think it is also important because it helps to disentangle theory from practice. What I mean by this is that when first starting out on my PhD study reading the theory behind research design and research methods led me to understand concepts such as reliability and validity. These concepts can be interpreted in different ways depending on the particular context. However, sometimes it is difficult to apply theory in practice.

For example, within the context of research that adopts a quantitative methodology, then concepts such as reliability and validity have firm established meanings, and have statistical tests that can be used to establish the reliability of research methods and data that has been collected (Tavakol and Dennick, 2011; Heale and Twycross, 2015). The idea behind this is that a PhD researcher undertaking PhD research should seek to ensure that their data and findings are reliable and valid in order to 'prove' to others that the findings can be supported by the data obtained. So, from the perspective of a PhD researcher undertaking research using a quantitative methodology precision, reliability and validity are of real importance to the researcher.

However, within the context of research that adopts a qualitative methodology, concepts such as reliability and validity to a certain extent lose their established meanings (Golafshani, 2003; Leung, 2015; Noble and Smith, 2015). For example, how can a PhD researcher prove the reliability of their interview method, or how can a PhD researcher prove the validity of the interview data that was found (Roberts and Priest, 2006)? Furthermore, within such a context the researcher might then ask if the concept of reliability is really a necessary measure in qualitative research (Brink, 1993)? How can a PhD researcher prove consistency and repeatability of the measures that were carried out? For example, the time of day could be a factor that changes the nature of the interview.

A future research participant might be feeling ill and the nature of the interview would be different, they might be feeling hungry or the interview is undertaken close to lunch time and so responses that are offered are quick and not the same as the previous

interview undertaken. The circumstances of a future research participant might have changed, or the month may be different, the interview may be undertaken in summer when it is too hot, and the research participants are not as responsive as last time. Some research participants may have moved on or the research participant may now be feeling better because he or she is receiving financial subsidies or is receiving physiotherapy. There may have been a change in staff and the nature of the services provided may be different in the future. A future researcher may adopt a different interview style and may not obtain the same rich and deep type of data that was obtained for this research study.

So as a PhD researcher I can contemplate the theory behind reliability but when applied within the context of qualitative research it is difficult to reconcile the theory with the practice (Golafshani, 2003; Roberts and Priest, 2006). As a researcher I ask myself, should I put in place reliability measures in order to tick all the right research boxes but knowing that in reality they may not make a difference? At the same time as a researcher I have learnt of the importance of adopting a neutral and as objective an approach to a research study as possible, in order to eliminate bias, and also in order to ensure that the data that is obtained is as accurate as possible (Jones 2001; Mehra, 2002). Now, that is the theory that emanates from the literature covering research design and research methodology.

However, I ask myself is that really absolutely essential in every situation? As a PhD researcher I am seeking to identify the truth, the truth relating to a person and the truth relating to a situation. However, to the extent that it is possible to understand the truth, it is about establishing subjective perspectives of the situation, especially when dealing with human perspectives, emotions, and beliefs. This is what I believe is the ultimate objective of PhD research. Yet, if I adopt a neutral and objective approach to the research study, I run the risk of failing to achieve that objective. If I adopt a neutral and objective approach to the interviews, I run the risk that I will not be able to sufficiently empathise with the research participants and I will not be able to obtain the information that I really need in order to establish the truth.

There is a clash between neutrality and objectivity and the truth. If the goal of qualitative research is to understand behaviour in a natural setting, then the importance of reliability within the context of semi-structured interviews can be questioned. Furthermore, I ask myself is the ultimate goal of a PhD researcher to remain neutral and unattached? When I am faced with highly troubling stories that are being recalled

by a person with disabilities that is sitting across the table from me, I ask myself what should I do? I am human, I have emotions and feelings too and these emotions and feelings make me sympathise for this individual, I can feel their pain and suffering too, I do not want them to be feeling depressed, or lonely, or sad, or anxious.

Is it my goal as a PhD researcher to switch my feelings off, or should I accept these feelings and help to comfort and understand the research participants in greater depth? These are questions that they do not teach you the answers to in social studies books or the literature. Consequently, when faced with these kinds of issues relating to barriers and social disability when undertaking social research, I believe it is also important to address what the role of the researcher may be in 'righting' any wrongs that they may encounter in research. We may ask does the researcher have a responsibility towards the research participants that extends beyond the collection of data? The feminist researcher Shulamit Reinharz has made some particularly interesting commentary in this area.

Reinharz (1992) notes that in addition to the connection with theory, much feminist research is connected with social change and social policy questions, i.e. explicit policy recommendations are typical in feminist research. Reinharz (1992) adds that the international feminist community believes social research can contribute both to the welfare of women and to knowledge. This is referred to as a 'dual vision' or 'dual responsibility' that many feminist researchers see as part of their responsibilities – part of the general burden that women must satisfy multiple constituencies (Reinharz, 1992).

Interestingly Reinharz (1992) notes that personal experience is typically irrelevant in mainstream research, or it is seen as contaminating a project's objectivity. However, in feminist research personal experience is relevant and repairs the project's 'pseudo-objectivity' (Reinharz, 1992). Reinharz (1992, p.259) argues that feminists reintroduce passion, and that "It requires courage to violate the norms of dispassionate research." Reinharz (1992, p.259) provides a practical example:

> Joyce Leland is one of many feminists who includes a discussion of her motives as part of her research text. She writes that her motive for studying the masculinity of gay men stems from her being the mother of one such young man as well as the mother of a straight son. She identifies with both of her sons and is angered by homophobia. As a sociologist she is trying to

convert her anger into research that might show that gay men are ordinary members of society.

In addition to this passionate discourse, Reinharz (1992) believes that feminist observational or interview-based studies often include a connection between the researcher and the subject that develops during the course of the study and lasts beyond it. This leads to a blurring of the role of the researcher and the subject, often because many feminist researchers give direct assistance to the women they study, or because they are carrying out action research (Reinharz, 1992). Reinharz (1992, p.263) comments:

> In these studies, the relationship leaves the realm of research and enters the personal lives of the individuals involved. This blurring of the distinction between formal and personal relations, just as the removal of the distinction in the previous section between the research project and the researcher's life, is a char-acteristic [*sic*] of much, though not all, feminist research.

When viewed in this way a feminist perspective on qualitative research can be viewed favourably. A feminist perspective is more passionate about the research topic, there is a personal motivation of the feminist researcher to analyse the subject in depth. There is also a greater desire from the feminist perspective to bond with the research participants, and to emphasise more with their personal experiences. Moreover, in feminist action research the researcher does not simply study the research participants with the context of the research study, but thereafter starts to participate in the context of the research participants with a view to enacting some type of change.

Taylor (1998) notes that feminist conventions are almost the reverse of textbook models of scientific inquiry, referred to as a one-way process in which the researcher seeks and receive data. Taylor (1998, p.370) states:

> Feminists advocate research techniques designed to break down the false separation and hierarchy between the researcher and the researched. This includes not only participating in the activist community being studied but empowering the community by en-couraging [*sic*] their involvement in the research process.

Within the context of the current research study I found it difficult to adopt a neutral and unbiased approach to the research process overall. It was difficult to listen to the

problems and challenges that the research participants faced in their daily lives and were still facing. There is certainly an argument to be made that if the findings of the research study are published then the stories of the research participants will be heard. But at the same time it might be asked 'how will this help AAFIA and the current problems she is encountering in terms of receiving her financial support'? On reflection it might be said that given the nature of the findings in this study, changing the basis of the study to an action research type study might have been more beneficial for the research participants involved.

When I started out this study I had a general belief that I would find the research study difficult to carry out, but that it was vital that I carry out the project to find out the real truth about what the lives of people with disabilities living in Jeddah were really like. In light of my past experience, I had a general belief that I would find that the research participants would face problems. But I had no idea that I would find that the research participants still continued to face such a range of difficult and challenging problems. I found it very difficult at times not to feel so sorry for the circumstances that they disclosed to me during the interviews. Indeed, I found many of the interviews difficult to carry out because they made me very emotional.

It was very difficult to remain unmoved when people disclose such a range of problems to you, such suffering that they had previously suffered or continued to suffer. For example, I could see how sad and scared a research participant was about the problems she was having with her financial subsidies that she was meant to receive but that were not being passed on to her. She asked me for help as she was at a loss for what to do. Similarly, I could see how sad and upset one of the research participants was at the lack of mobility he experienced and I imagined what his life consisted of every day, repeating the same thing, without really being able to move around or finding it very difficult each day to try to visit common areas.

I could see how disability had impacted some of the research participants, how it was a heavy burden that they carried and faced each day. I could see that they needed support, I could feel that they needed support and that in many ways they felt isolated from society. I could feel the emotion in their voices as they recalled their past experiences, experiences which hurt them and which left painful scars. Experiences such as not being taken to family outings, being regularly refused by taxi drivers and finding transportation difficult. Experiences such as being perceived as a beggar by others and then understanding that that is the way that you are seen by others, that is

how others view you, not as a real person, but as someone who is in need and is to be pitied.

This research study has really opened up my eyes to the challenges and problems that people with disabilities in the KSA face. From my perspective they need as much help as possible. They should be made to feel like society welcomes them rather than oppressing them. Undertaking this research study has allowed me to develop the skills that I need as a researcher undertaking research at PhD level. I feel that it has also done much more than that. It has allowed me to develop skills that I can apply in the future to help others, especially people with disabilities in the KSA if I so choose. I believe I have developed good writing skills that I could apply in practice if I wanted to. I could write news stories to newspapers in the KSA to be printed in print or online.

I could send a letter to the King summarising my research findings and I could include a copy of my PhD thesis. I could write letters to Government Ministries in the KSA, to explain my research study and my research findings. I could write articles and submit them to journals in order to try to get them published so others can read about my study and research findings and could better understand the situation that people with disabilities face in the KSA. I could aim to set up an institution or a support network for people with disabilities in the KSA. An institution or support network that aims to empower people with disabilities, and to help them to obtain financial subsidies or other support that they lack. I believe the research study has helped me to find a voice, to tell the stories of others who need their story to be told.

CONTEXTUALISATION OF THE RECOMMENDATIONS FOR PRACTICE

In order to contextualise the recommendations for practice, it is helpful to set out findings identified by the World Health Organization (**WHO**). It was observed that in reality, people with disabilities still face social, economic, and cultural difficulties in relation to social inclusion (WHO, 2011a; 2011b). Applied within the specific context of the KSA, this is clearly still the case. The findings show that many of the research participants face a broad range of social, economic and cultural difficulties in relation to social inclusion. Social difficulties include that many of the research participants could not draw upon a range of social support services, many did not have any family and friends which could support them, and they encountered mobility issues which negatively impacted their social lives. Economic issues included a lack of significant

financial assistance and cultural difficulties were evidenced by the research participants noting that they had often been seen as beggars when out in Jeddah.

People with disabilities also still experience difficulties with mobility on the streets as well as accessibility problems when in buildings (WHO, 2011a; 2011b). Because of the difficulty of travelling and access to rehabilitation services, people with disabilities lead a restricted social life, with little opportunity for social inclusion, thereby leading to social isolation (WHO, 2011; 2011b). Exclusion is multi-dimensional as it includes deprivations of economic, social, gender, cultural, and political rights (UNICEF, 2006). When applied within the specific context of the research participants, the restricted social life that the research participants are leading would tend to support the contention by the WHO that their current situation is likely to lead to them developing feelings of social isolation.

One of the social workers had noted that the research participants are sometimes taken on trips and this is definitely encouraging as this would benefit them in terms of social inclusion. However, it was also worrying that the other social worker noted that some of the research participants were not allowed to travel on these trips because of the length of time they had spent in the institution. Essentially the approach that they had adopted was that, although the institution was there to provide rehabilitation services and to try to provide the research participants with opportunities for social inclusion, some research participants were 'punished' if they had stayed at the institution too long.

There were very little focus on a social model of disability that could be identified in the White Hospital. If there are few or no recreational activities, or opportunities to interact socially, then such a situation is likely to lead to increased feelings of social isolation and in turn sadness and depression. This is what seemed to be happing to some research participants at the institution. Unfortunately, it seemed to be the case that because some of the research participants had spent a while at the institution, they seemed to be treated with a lower quality of healthcare and attention than might be given to a new in-patient. These research participants that had to live and cope with a disability every single day of their lives needed more attention than others because of their impairment, and yet in practice it seemed to be the case that they were given less attention.

An analysis of the *World Health Survey* data for fifteen developing countries suggests that households that have disabled members spend relatively more on healthcare than those households without disabled members (WHO, 2011a; 2011b). An analysis of fourteen household surveys in thirteen developing countries found that adults with disabilities as a group were poorer than average households (WHO, 2011a; 2011b). It was also identified that a study undertaken in Sierra Leone found that households with persons with disabilities (severe or very severe) spend on average 1.3 times more on healthcare than non-disabled respondents (WHO, 2011a; 2011b). Overall, many studies have shown that households with disabled members generally held fewer assets and encountered worse living conditions when compared with households without a disabled member (WHO, 2011a; 2011b).

It is has been proposed that state funding of responsive formal support services is an important aspect of policies that enable full participation of persons with disabilities in social and economic life (WHO, 2011a; 2011b). It has also been stated that it is governments that play an important role in setting standards, as well as regulating and providing services (WHO, 2011a; 2011b). It has been observed that social safety net programmes in developing countries typically total between 1-2% of gross domestic product (WHO, 2011a; 2011b). Furthermore, in many developing countries a large share of safety net resources are often allocated to cash programmes aimed at poor and vulnerable households (WHO, 2011a; 2011b).

This means that only a fraction of safety net resources is used for the provision of social welfare services to vulnerable groups, including individuals with disabilities or their families (WHO, 2011a; 2011b). The conclusion that is reached is that in low-income settings, social welfare services are often the only safety net that is available, however spending on them is low, programmes are fragmented, are of a small scale, and they often only reach a fraction of the needy population (WHO, 2011a; 2011b). These findings by the WHO highlight the real and significant need for social support programmes and frameworks for people with disabilities.

However, because of the medical model of disability in place at the institution it would seem to be the case that this aspect of rehabilitation was being overlooked. This aspect of social work and the role of the social worker in the rehabilitation process could be seriously called into question at the institution. My reasons for arguing this are set out below. Firstly, many of the research participants noted that they had not been informed about social services they could avail themselves of. Many of them had not known

about financial support services they could avail themselves of and some of the research participants had not been informed of the availability of these types of services.

Now I believe the role of a social worker is to help a person with disabilities to the best of his or her ability. At the very least it would include the social worker sitting down with the person for at least one hour upon admission to the hospital in order to better understand his or her background and social situation. This would include informing the person about financial subsidies that may be available, and the availability of medical support services and equipment such as wheelchairs. It would also include informing the person about other services that might be available from charities and whether they might be interested in availing themselves of those services. If the preferred social model of disability is used, then rehabilitation services should incorporate not only medical rehabilitation services, but also social rehabilitation services.

The rehabilitation services provided by the social worker should include discussing the person's social situation and identifying what social support services and network they may have in place following a discharge from the rehabilitation centre. Otherwise purely medical rehabilitation services are essentially failing the individual, as the individual has not learnt how to cope on the outside, and may therefore be more likely to fall victim to social isolation. Many of those people calling out for, or supporting, social assistance stress its role in facilitating the independence of people with disabilities, as well as adopting an empowering approach (Marriott and Gooding, 2007).

Social assistance can enable independence because it allows individuals with disabilities to meet extra costs associated with disability, such as extra transport fares or the need to pay for an assistant (Marriott and Gooding, 2007). By meeting these costs, social assistance enables access to education, employment, and other opportunities (Marriott and Gooding, 2007). In this way, social assistance is about enabling independence, not charity and dependence (Marriott and Gooding, 2007). From what I saw in the institution, this absolutely necessary and vital social assistance that could help the research participants to better cope and to move towards independence was clearly lacking or even missing. This is therefore clearly an area that needs to be directly addressed.

RECOMMENDATIONS

Ensuring rehabilitation staff are regularly rotated

It is recommended that staff that are working at the institution with the research participants be regularly rotated so that they will be less likely to feel job stress and more likely to be attentive. By requiring staff to be more attentive when supporting people with disabilities, this may in turn lead to increased job stress and increased burnout. The duration and intensity of emotional labour may lead to negative consequences for employees (Wilding *et al.*, 2014). This would seem to reflect one of the comments made by the research participants, that at the beginning the staff helped him but that now they did so only with a sense of resentment about doing it. It is understandable that staff that have to carry out high attentiveness roles day in day out, and they may find themselves feeling increased levels of job stress and lower levels of job satisfaction. This may also in turn negatively affect the people with disabilities. Therefore, the institution should aim to regularly rotate staff in order to ensure people with disabilities undergoing rehabilitation are provided with good quality medical services throughout their period of stay at the institution.

Monthly group rehabilitation and gender discussion and counselling sessions

It is recommended that the rehabilitation hospital could establish monthly group rehabilitation sessions that would help the research participants to talk freely and openly about their problems and the challenges that they face. These sessions would allow the research participants to support each other and would allow them to discuss what progress they were making, or if they felt that they were not progressing in terms of their rehabilitation. The counselling sessions could provide them with group support that might help to fight off feelings of loneliness and depression.

This requires moving beyond the medical model of disability. At present the research participants are attending the rehabilitation hospital in order to obtain rehabilitation services that will help them to better cope with their medical impairment. The problem with this approach is that it overlooks other aspects of rehabilitation which are crucial to the rehabilitation of the research participants. Focusing on aspects including mental and social rehabilitation of the research participants would help the research

participants to cope mentally and learn to accept and deal with their disability, as well as helping the research participants to adjust socially in order to fully participate in society.

The research participants could openly discuss challenges that they might face once rehabilitated and discuss potential ways to overcome such challenges. As a group and guided by a social worker, they might be able to talk about potential sources of financial and social support that they could access in the future, and how they might go about doing that. They could also potentially discuss what types of help they might receive from charities and how they could contact such charities. Gender and disability are other areas that could be incorporated into the group discussion and counselling sessions. By discussing the issues and challenges that the research participants have faced, or will potentially face in the future openly in the group, such discussions might help to better equip the research participants to handle gender-based issues and challenges that might arise in the future.

For example, if a female with disabilities is feeling lonely or isolated, and might continue to feel in such way in the future once rehabilitated, the group might discuss ways of supporting her. This might be ways to set up public disability support groups for females with disabilities, where she could meet with others females with disabilities to discuss issues they might be facing and also to provide emotional and behavioural support for each other. It might also include discussions about how to set up public disability support groups for females with disabilities online, using social media tools such as Facebook.

Developing a social rehabilitation, training, and integration programme

It is recommended that the rehabilitation hospital develops a social rehabilitation, training, and integration programme, which would be significantly beneficial to the research participants. At present the rehabilitation hospital has put in place a medical rehabilitation programme for people with disabilities attending the hospital. However, the research study has identified a number of problem areas that the current rehabilitation programme does not cover. Some of the research participants simply stay in bed and watch television all day long. Some of the research participants have

been attending the rehabilitation hospital for years. There would seem to be a lack of motivation to exit the rehabilitation hospital exhibited by some research participants.

A social rehabilitation, training, and integration programme would help to better rehabilitate the research participants. This type of programme would require the rehabilitation hospital to work more closely with the research participants in order to build up a social rehabilitation, training, and integration programme for each of the research participants. For example, instead of simply providing the research participant with physiotherapy, the rehabilitation hospital could work a research participant to identify what kind of social support network the individual has, and who he or she can rely on or turn to for support. It could identify the interests of the research participants and help the research participants to develop better social integration skills. Just imagine if all that time that the research participants are spending staying in bed and watching television or playing games was spent on a productive activity that could help improve their job prospects (e.g. learning a language, learning to touch type, or learning computer skills).

Strengthen the provision of financial assistance to people with disabilities

It is recommended that the Saudi government increase the current level of financial support provided to people with disabilities, and also that it increases awareness of financial support through public and other media channels. Both the literature review and the findings showed that there is a clear link between disability and poverty. The findings also demonstrated that the majority of the research participants noted that they received insufficient, or no, financial assistance from the Saudi government. This is an area that clearly needs to be addressed because this is one of the most important factors that people with disabilities rely on, the ability to obtain sufficient money to care for themselves and to allow them to cope with their disability in their daily lives.

AlMubrak (2014) notes that the KSA has 13 provinces, with 150 cities, and more than 2000 villages, and with vast distances between cities. It is also noted that statistics from 2012 indicate that approximately 143,000 people above the age of 15 were out of work owing to disability, and that approximately 400,000 people with disabilities had registered as beneficiaries for financial support from the government. Given the huge number of villages across the KSA it is likely that there are still people with disabilities

in the KSA who do not have access to financial assistance at present, either because they do not know about such financial assistance available, or they are not able to access it because of distances between villages and cities.

The research participants showed that the amount of financial assistance they received was small, and in practice unlikely to be sufficient to support their actual needs. If in principle the Saudi government has committed itself to upholding the rights of people with disabilities across the KSA, and has committed itself to helping to effectively support people with disabilities, then the amount of financial assistance they receive should be increased. The existing system needs to be reviewed and updated to better reflect modern living costs for people with disabilities, and also potentially with a view to implementing a system which better reflects means-tested financial support.

In addition to this, the Saudi government should implement an awareness campaign that will provide regular updates across the KSA about financial assistance available to people with disabilities. This should be carried out by regularly broadcasting radio and television commercials that explain these rights and provide information about how to obtain this financial support and where people need to go.

Creating national disability statistics

It is recommended that the Saudi government creates a central national disability registry. Currently there is no single source of national data for disability in the KSA (AlMubarak, 2014)). It is also observed that no formal data collection approach is in place for the country; that there are very limited publications that have addressed the prevalence of disability in the KSA; and that the only disability figures available date back to 2007 when the Saudi Ministry of Health (**MoH**) commissioned the national world health survey (AlMubarak, 2014). The prevalence of disability was reported to be considerably higher than other high income countries (AlMubarak, 2014).

With such a high prevalence of disability reported it is submitted that it is absolutely crucial for the Saudi government to be able to understand what support people with disabilities require across the KSA. However, this is only possible if there are accurate and recent statistics showing the levels of disability present in the KSA. However, currently no such statistics exist and therefore creating such statistics is a top priority for the Saudi government. The creation of a national disability registry would: provide

vital information to the organisations catering to people with disabilities; help in the provision of necessary services; and allow information on people with disabilities to be registered or to add information about people with disabilities (AlMubarak, 2014).

Such a registry would not only provide up-to-date statistics on people with disabilities, but it would provide reliable data for planning purposes; it could facilitate universal access to services; it would provide ease of access to benefits; it would provide internationally-comparable data; it would provide a platform for information dissemination; and it would provide a platform to facilitate awareness of legislation, rights of people with disabilities, and existing programmes for people with disabilities (AlMubarak, 2014). As noted previously, approximately 400,000 people with disabilities have registered as beneficiaries for financial support from the government. This could form the basis for the start of a new 'disability registry'.

Full control of finances for people with disabilities

It is recommended that the Saudi government put in place measures to ensure that people with disabilities have full control of the finances they are receiving. This includes the provision of planned financial support packages as well as safeguards to ensure minimal financial risk. The literature has shown that people with learning disabilities in the United Kingdom (**UK**) had little control of their own resources, and most were given 'pocket money' which they spent on small non-essential items (Williams *et al.* 2007). In addition, it was seen that people had few opportunities to improve their financial knowledge, and that the low income received by people with learning disabilities led in some cases to a potential 'benefit trap' (i.e. where taking paid work might jeopardize the benefits the family depended on) (Williams *et al.*, 2007).

The findings showed that control of finances was a problem for some people with disabilities. It has been seen that the current financial assistance services that are provided to people with disabilities in the KSA are open to abuse by families and/or carers of people with disabilities. Consequently, it is recommended that the Saudi government review the system in order to put in place safeguards to guard against such abuse. This should be done in order to ensure that people with disabilities are the ones that actually receive the financial support they receive from the Saudi government. The Saudi government should also provide planned support packages for

people with disabilities that take into account the circumstances of people with disabilities, and can help them fully control their financial affairs as well as planning for daily living expenses, and budgeting for accommodation, food, travel, and bills.

Central disability support service

It is recommended that the Saudi government put in place a centralised disability support service. The centralised disability support service would provide a very broad range of support services to people with disabilities across the KSA. The disability support service could help people with disabilities to find any information that might be relevant to them. For example, the support service could be accessed by telephone, email, or at locations throughout the KSA. It could help people with disabilities identify the social support services that they could access or benefit from. It could also help to put them in touch with charities or other institutions that might be in a position to help them. This type of centralised disability support service would be extremely beneficial to people with disabilities across the KSA as they would be able to use the service to find out all types of information that they might not currently be able to access.

The support service could inform them about hospitals and rehabilitation centres in the KSA, it could inform them about financial assistance, mobility assistance, and other social support services they could access. It could also send out further information to people with disabilities, either by email or by mail. This type of centralised support service could bring together a range of disability stakeholders in the KSA and would act to provide a centralised gateway that is well known and recognised by all people with disabilities across the KSA.

Mobility initiatives for people with disabilities

It is recommended that the Saudi government review existing mobility initiatives with a view to improving them and potentially increasing the number of mobility initiatives rolled out across the KSA. The findings show that the research participants still faced many problems with mobility in their daily lives. One of the main difficulties stems from the fact that there is no public transport available in Jeddah that is readily accessible by people with disabilities. Therefore, in practice people with disabilities have to rely

on family and friends for transport, or they must rely on private taxi drivers that often do not want to take people with disabilities as passengers.

In addition to this, although the Saudi government has announced in practice that it plans to provide all people with disabilities specially adapted cars, the existing system is limited and slow. This is because the system is highly bureaucratic, and applications take a long time to process because of the large amount of paperwork that needs to be completed. In practice there are fewer applications processed each month. Overall this means that people with disabilities may be left waiting years to secure a specially adapted car or may never receive one. It is therefore recommended that the Saudi government review existing mobility initiatives within each province and to identify to what extent they have been successful or not. This thesis has highlighted a broad range of mobility challenges that the research participants face, and it is likely the case that they mobility challenges still exist for other people with disabilities across the KSA. If these mobility challenges are not effectively addressed, then people with disabilities will fail to achieve the social inclusion to which they have rights under existing disability convention laws.

Centralised review of implementation of disability law and policies

Although the Saudi government has committed itself to implementing the Disability Convention in the KSA, the findings from the research study have highlighted that there is much work that still needs to be done in order to fully implement the true objectives of the Disability Convention into practice throughout the KSA. In reality, the study has identified that there exist a broad range of legislation and policies governing disability in the KSA. Many of these pieces of legislation, as well as policies, are old and the entire disability framework in the KSA is highly fractured. People with disabilities in the KSA really need laws and policies that are clear for them to understand and that help to support people with disabilities. At present, that would not seem to be the case.

It is recommended that as part of the implementation of the Disability Convention in the KSA, a government committee could be put into place in order to review how disability laws and policies in the KSA have been implemented, and whether or not the existing system can be improved, and if so, in what way. The research study has identified that there still exists a deficiency in the way that disability laws and policies

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have been implemented, as the research participants identified that they did not know of their disability rights and entitlements in the KSA. A centralised review of the implementation of disability law and policies throughout the KSA would be a highly effective way of reviewing the existing system in order to identify problems, deficiencies, and practical challenges that may continue to negatively impact the lives of people with disabilities throughout the KSA.

RESEARCH LIMITATIONS

Despite the opportunities that this study has opened up, there are a number of limitations that can be identified. First, it may be said that because the research study was based on a qualitative methodology that used a relatively small number of research participants, the findings are not statistically generalizable to a larger target population. This is true, but it was not my main aim to obtain findings that were generalizable. Rather, I wanted to investigate the situation of a small group of people with disabilities, to obtain a better understanding of the barriers to social inclusion and the impact of social exclusion. Therefore, taken together with my personal experiences of people with disabilities in the KSA, I do feel that they represent realistic viewpoints of what people with disabilities may experience in the KSA.

Another limitation to this research study is that the research study was not longitudinal in nature. If the research study had been longitudinal, I would have been able to identify whether the situation of research participants persisted, whether it improved, or whether it deteriorated. This may have provided the research study with added value. However, it should also be noted that the research participants did not report large changes in their lives in the two or three years prior to the interviews and so the utility of such an approach should not go unquestioned. Moreover, single interviews were effective in addressing the research questions at hand.

The study did incorporate interviews with two social workers. However, another limitation of the research study was that I was not able to interview a wider range of relevant stakeholders. For example, other stakeholders that might have been included were other nurses, doctors, physiotherapists, family members, and friends. This would have potentially allowed me to obtain a more comprehensive collection of viewpoints relating to the research participants. As such, my post-doctoral work could focus on

other relevant stakeholders and perhaps even carers and relatives of people with disabilities to obtain a richer and deeper insight into their lives.

Another limitation of the research study was that it was based on people with disabilities at one institution. It could be argued that obtaining the viewpoints of research participants from a number of different institutions in the KSA would have strengthened the study. However, this would have presented considerable challenges in terms of obtaining consent from the relevant government authorities. I feel that on balance, despite these limitations, the study throws important light on the experience and social situation of people with disabilities in the KSA, which can be built upon in the future. It may open the door to wider ranging and important research in the future.

SUGGESTIONS FOR FUTURE RESEARCH

There are a number of suggestions for future research that can be identified and that would clearly add to the literature on disability in the KSA. For instance, a quantitative research study might help to identify the extent of problems that people with disabilities face in the KSA. For example, there would be value in an ambitious quantitative study which included in its sample people from different parts of the KSA in order to make the findings generalizable to the broader population of people with disabilities. Such a study could use structured questionnaires, developed from the findings in this study or the international literature in order to identify distinct trends.

One type of research study that is clearly needed is research that focuses on generating or identifying disability statistics. There are no public statistics relating to the prevalence of disability in the KSA and this is an area that could prove to be very helpful in terms of identifying levels of disability in the KSA. Research that focused on building disability statistics in the KSA could help to contextualise the social and financial needs of people with disabilities.

A mixed methods research study would also have advantages if it were able to obtain rich and deep data from research participants via interviews or focus groups, whilst also obtaining data from a broad range of research participants. This type of study would allow the results from each research method to be triangulated to see if they support each other or not. Another type of research study might use multiple cases to identify the extent to which the medical model or social model of disability exists in the

KSA. This type of research might identify different institutions in different cities and towns in the KSA in order to research where the medical or the social model of disability seemed to be practiced or present in each particular institution.

Another type of research study that might prove to be particularly helpful would be an action research study. This type of research study might focus on identifying people with disabilities in a particular institution, area, city, or town. It could identify what problems or challenges they face in practice and could seek to involve the researcher by allowing the researcher to become involved in the lives of the research participants and helping the research participants in some way. This type of research study might prove to be really helpful as it could potentially benefit the research participants as well as helping society in general.

RESEARCH DISSEMINATION PLAN

I will distribute copies of this thesis to the research participants; to the institution; to the University; to news and media outlets; to charities for people with disabilities in the KSA; and to Saudi government agencies and other relevant institutions. I feel as though this might help people in the KSA to better understand the situation the research participants find themselves in, and also to better understand disability in general within the context of the KSA.

I aim to draw on this study to submit at least three articles to different journals. The first article will use the literature review as the basis of the article. The second article will use the overall PhD research study and summarise the research methodology, the findings, the interpretation and conclusion. The third article will seek to discuss the research study within the context of disability in the KSA and the problems and challenges highlighted by the research study.

There are a number of international journals to which I could submit articles, such as the Journal of Literary & Cultural Disability Studies, Disability and Rehabilitation, Disability & Society, and the American Journal of Physical Medicine & Rehabilitation. However, I would like to submit one article to a journal that is focused on the Middle East. So, this will include either the Middle Eastern Journal of Disability Studies or the Saudi Medical Journal. The other articles may be submitted to one of four journals: (1) the Journal of Social Work in Disability & Rehabilitation; (2) Disability and

Rehabilitation; (3) Disability Studies Quarterly; and (4) Disability and Health Journal. In the process of developing my work for journal submission, I will present papers at academic conferences in order to disseminate my ideas, raise awareness of my work and get feedback from a range of experts. I plan to present my work at select disability events in 2019.

FINAL COMMENTS

This research study has been a long journey that I believe has resulted in the identification of highly significant information. The review of the literature has identified a wide range of barriers to social inclusion that people with disabilities face all around the world. The interviews with the research participants have identified that they also face a wide range of barriers to social inclusion in their lives today. The impact of the resultant social exclusion on the research participants was significant. These barriers influenced their mobility in general, whether trying to go to restaurants, shopping malls, or trying to travel in taxis. These barriers influenced their financial needs, since many of the research participants found that the financial assistance they received was insufficient to fully support their needs.

These barriers were cultural and attitudinal, as the research participants were viewed with pity, with hostility, and sometimes were looked down upon as beggars. These barriers were social, as many of the research participants found that they lacked social support, or had difficulties accessing social support services. If these barriers exist for this particular group of research participants, then I also believe that they may exist for people with disabilities across all of the KSA. In fact, it may be the case that these barriers are greater in number and more significant for people with disabilities in small towns and villages and rural areas where they may find it even more difficult to obtain the right medical and social care and support services they need.

In practice the Saudi government has publicly committed itself to improving the lives of people with disabilities all across the KSA. Indeed, the government has put in place a legal framework to implement the Convention on the Rights of Persons with Disabilities. However, as this research study has demonstrated, there would still seem to be a large gap between what the Saudi government has promised and what people with disabilities in the KSA actually receive. The research study has proposed a number of new strategies for achieving better social inclusion of people with disabilities

in the KSA. These include new ways to undertake future research that could help in achieving social inclusion of people with disabilities. They also include ways in which the findings in the research study can be disseminated in order to make people aware of the challenges and difficulties that people with disabilities still face in the KSA. They also include recommendations that could help the research participants and potentially other people with disabilities feel more socially included, or help them to be better prepared to integrate with society.

I believe this research study has given the research participants a voice. Their voices are crying out for help, from the Saudi government and from society in general. I believe all people with disabilities in the KSA should have a voice, a voice that is heard. Through this research study I am hoping that other people with disabilities in the KSA and society in general will join that voice in crying out for change in the KSA. People with disabilities need more support from others and from the Saudi government. The Saudi government has promised to support the rights of people with disabilities in the KSA. I believe it is our role as Saudi citizens and people living in the KSA to join our voices together in order to help people with disabilities throughout the KSA.

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APPENDIXES

APPENDIX 1: Disability Prevalence Rates for Thresholds 40 and 50 derived from multidomain functioning levels in 59 countries, by country income level, sex, age, place of residence, and wealth

Population Subgroup	Threshold of 40			Threshold of 50		
	High Income countries (standard error)	Lower Income countries (standard error)	All countries (standard error)	Higher Income countries (standard error)	Lower Income countries (standard error)	All countries (standard error)
Sex						
Male	9.1 (0.32)	13.8 (0.22)	12.0 (0.18)	1.0 (0.09)	1.7 (0.07)	1.4 (0.06)
Female	14.4 (0.32)	22.1 (0.24)	19.2 (0.19)	1.8 (0.10)	3.3 (0.10)	2.7 (0.07)
Age group						
18-49	6.4 (0.27)	10.4 (0.20)	8.9 (0.16)	0.5 (0.06)	0.8 (0.04)	0.7 (0.03)
50-59	15.9 (0.63)	23.4 (0.48)	20.6 (0.38)	1.7 (0.23)	2.7 (0.19)	2.4 (0.14)
60 and over	29.5 (0.66)	43.4 (0.47)	38.1 (0.38)	4.4 (0.25)	9.1 (0.27)	7.4 (0.19)
Place of residence						
Urban	11.3 (0.29)	16.5 (0.25)	14.6 (0.19)	1.2 (0.08)	2.2 (0.09)	2.0 (0.07)
Rural	12.3 (0.34)	18.6 (0.24)	16.4 (0.19)	1.7 (0.13)	2.6 (0.08)	2.3 (0.07)
Wealth quintile						
Q1 (poorest)	17.6 (0.58)	22.4 (0.36)	20.7 (0.31)	2.4 (0.22)	3.6 (0.13)	3.2 (0.11)
Q2	13.2 (0.46)	19.7 (0.31)	17.4 (0.25)	1.8 (0.19)	2.5 (0.11)	2.3 (0.10)
Q3	11.6 (0.44)	18.3 (0.30)	15.9 (0.25)	1.1 (0.14)	2.1 (0.11)	1.8 (0.09)
Q4	8.8 (0.36)	16.2 (0.27)	13.6 (0.22)	0.8 (0.08)	2.3 (0.11)	1.7 (0.08)
Q5 (richest)	6.5 (0.35)	13.3 (0.25)	11.0 (0.20)	0.5 (0.07)	1.6 (0.09)	1.2 (0.07)
Total	11.8 (0.24)	18.0 (0.19)	15.6 (0.15)	2.0 (0.13)	2.3 (0.09)	2.2 (0.07)

Note: Prevalence rates are standardized for age and sex. Countries are divided between low-income and high-income according to their 2004 gross national income (GNI) per capita. The dividing point is a GNI of US$ 3255.

Source: Adapted from WHO (2011a; 2011b)

APPENDIX 2: Estimated Prevalence of Moderate and Severe Disability, by Region, Sex, and Age, Global Burden of Disease Estimates for 2004

Sex/age group	Percent							
	World	High-Income countries	Low-Income and middle-Income countries, WHO region					
			African	Americas	South-East Asia	European	Eastern Mediterranean	Western Pacific
Severe disability								
Males								
0-14 years	0.7	0.4	1.2	0.7	0.7	0.9	0.9	0.5
15-59 years	2.6	2.2	3.3	2.6	2.7	2.8	2.9	2.4
≥ 60 years	9.8	7.9	15.7	9.2	11.9	7.3	11.8	9.8
Females								
0-14 years	0.7	0.4	1.2	0.6	0.7	0.8	0.8	0.5
15-59 years	2.8	2.5	3.3	2.6	3.1	2.7	3.0	2.4
≥ 60 years	10.5	9.0	17.9	9.2	13.2	7.2	13.0	10.3
All people								
0-14 years	0.7	0.4	1.2	0.6	0.7	0.8	0.9	0.5
15-59 years	2.7	2.3	3.3	2.6	2.9	2.7	3.0	2.4
≥ 60 years	10.2	8.5	16.9	9.2	12.6	7.2	12.4	10.0
≥ 15 years	3.8	3.8	4.5	3.4	4.0	3.6	3.9	3.4
All ages	2.9	3.2	3.1	2.6	2.9	3.0	2.8	2.7
Moderate and severe disability								
Males								
0-14 years	5.2	2.9	6.4	4.6	5.3	4.4	5.3	5.4
15-59 years	14.2	12.3	16.4	14.3	14.8	14.9	13.7	14.0
≥ 60 years	45.9	36.1	52.1	45.1	57.5	41.9	53.1	46.4
Females								
0-14 years	5.0	2.8	6.5	4.3	5.2	4.0	5.2	5.2
15-59 years	15.7	12.6	21.6	14.9	18.0	13.7	17.3	13.3
≥ 60 years	46.3	37.4	54.3	43.6	60.1	41.1	54.4	47.0
All people								
0-14 years	5.1	2.8	6.4	4.5	5.2	4.2	5.2	5.3
15-59 years	14.9	12.4	19.1	14.6	16.3	14.3	15.5	13.7
≥ 60 years	46.1	36.8	53.3	44.3	58.8	41.4	53.7	46.7
≥ 15 years	19.4	18.3	22.0	18.3	21.1	19.5	19.1	18.1
All ages	15.3	15.4	15.3	14.1	16.0	16.4	14.0	15.0

Note: High-income countries are those with a 2004 gross national income (GNI) per capita of US$ 10 066 or more in 2004, as estimated by the World Bank. Low-Income and middle-Income countries are grouped according to WHO region and are those with a 2004 GNI per capita of less than US$ 10 066 in 2004, as estimated by the World Bank. Severe disability comprises classes VI and VII, moderate and severe disability, classes III and above.

Source: Adapted from WHO (2011a; 2011b)

APPENDIX 3: British Association of Social Workers Professional Capabilities Framework for Social Work in England

1.   PROFESSIONALISM

Identify and behave as a professional social worker, committed to professional development

Social workers are members of an internationally recognised profession. Our title is protected in UK law. We demonstrate professional commitment by taking responsibility for our conduct, practice, self-care and development. We seek and use supervision and other professional support. We promote excellent practice, and challenge circumstances that compromise this. As representatives of the profession, we safeguard its reputation. We are accountable to people using services, the public, employers and the regulator. We take ethical decisions in the context of multiple accountabilities.

2.   VALUES AND ETHICS

Apply social work ethical principles and values to guide professional practices. Social workers have an obligation to conduct themselves and make decisions in accordance with our Code of Ethics. This includes working in partnership with people who use our services. We promote human rights and social justice. We develop and maintain our understanding of the value base of our profession throughout our career, its ethical standards and relevant law.

3.   DIVERSITY AND EQUALITY

Recognise diversity and apply anti-discriminatory and anti-oppressive principles in practice. Social workers understand that diversity characterises and shapes human experience and is critical to the formation of identity. Diversity is multi-dimensional and includes race, disability, class, economic status, age, sexuality, gender (including transgender), faith and belief, and the intersection of these and other characteristics. We understand that because of difference, and perception of

difference, a person's life experience may include oppression, marginalisation and alienation as well as privilege, power and acclaim. We identify this and promote equality.

4.   RIGHTS, JUSTICE AND ECONOMIC WELLBEING

Advance human rights and promote social justice and economic wellbeing. Social workers recognise and promote the fundamental principles of human rights, social justice and economic wellbeing enshrined in national and international laws, conventions and policies. These principles underpin our practice and we use statutory and case law effectively in our work. We understand and address the effects of oppression, discrimination and poverty. Wherever possible, we work in partnership with people using services, their carers and families, to challenge inequality and injustice, and promote strengths, agency, hope and self- determination.

5.   KNOWLEDGE

Develop and apply relevant knowledge from social work practice and research, social sciences, law, other professional and relevant fields, and from the experience of people who use services

We develop our professional knowledge throughout our careers and sustain our curiosity. As a unified profession, we develop core knowledge that relates to our purpose, values and ethics. We also develop specific knowledge needed for fields of practice and roles. Our knowledge comes from social work practice, theory, law, research, expertise by experience, and from other relevant fields and disciplines. All social workers contribute to creating as well as using professional knowledge. We understand our distinctive knowledge complements that of other disciplines to provide effective services.

6.   CRITICAL REFLECTION AND ANALYSIS

Apply critical reflection and analysis to inform and provide a rationale for professional decision-making. Social workers critically reflect on their practice, use analysis, apply professional judgement and reasoned discernment. We identify, evaluate and integrate multiple sources of knowledge and evidence. We continuously evaluate our impact and benefit to service users. We use supervision and other support to reflect on our work and sustain our practice and wellbeing. We apply our critical reflective skills to the context and conditions under which we practise. Our reflection enables us to challenge ourselves and others, and maintain our professional curiosity, creativity and self- awareness.

7.   INTERVENTION AND SKILLS

Use judgement, knowledge and authority to intervene with individuals, families and communities to promote independence, provide support, prevent harm and enable progress. Social workers engage with individuals, families, and communities, working alongside people to determine their needs and wishes, and what action may be helpful. We build productive working relationships and communicate effectively. Using our professional judgement, we employ appropriate interventions, promoting self-determination, support, protection and positive change. We develop and maintain skills relevant to our roles. We understand and take account of power differentials and use our authority appropriately. We evaluate our own practice and its impact, and how we improve outcomes for those we work with.

8.   CONTEXTS AND ORGANISATIONS

Engage with, inform, and adapt to changing organisational contexts, and the social and policy environments that shape practice. Operate effectively within and contribute to the development of organisations and services, including multi-agency and inter-professional settings.

Social workers are informed about and pro-actively respond to the challenges and opportunities that come from changing social, policy and work contexts. We fulfil this responsibility in accordance with our professional values and ethics, as individual and collective professionals and as members of the organisations in which we work. We collaborate, inform and are informed by our work with other social workers, other professions, individuals and communities.

9.   PROFESSIONAL LEADERSHIP

Promote the profession and good social work practice. Take responsibility for the professional learning and development of others. Develop personal influence and be part of the collective leadership and impact of the profession.

We develop and show our leadership, individually and collectively, through promoting social work's purpose, practices and impact. We achieve this through diverse activities which may include: advancing practice; supervising; educating others; research; evaluation; using innovation and creativity; writing; using social media positively; being active in professional networks and bodies; contributing to policy; taking formal leadership/ management roles. We promote organisational contexts conducive to good

practice and learning. We work in partnership with people who use services and stakeholders in developing our leadership and aims for the profession.

APPENDIX 4: Direct and Indirect Costs of Disability

Direct Costs		Indirect Costs
Additional costs incurred by people with disabilities (and their families incurred in achieving a reasonable standard of living.	**Disability benefits in cash and in kind paid for by governments and delivered through various programmes.**	**Indirect economic and non-economic costs**
• Health care services. • Assistive devices. • Costlier transportation options. • Heating. • Laundry services. • Special diets. • Personal assistance.	• Health and rehabilitation services. • Labour market programmes. • Vocational education and training. • Disability social insurance (contributory) benefits. • Social assistance (non-contributory) disability benefits in cash. • Provision of assistive devices. • Subsidised access to transport. • Subsidised utilities. • Various support services including personal assistants and sign language interpreters. • Administrative overheads.	**Economic Costs** • Loss of productivity from insufficient investment in educating children with disabilities. • Exits from work or reduced work related to the onset of disability. • Loss of taxes related to the onset of disability. • Loss of taxes related to the loss of productivity. **Non-Economic Costs** • Social isolation. • Stress.

Source: Adapted from (WHO, 2011a; 2011b)

APPENDIX 5: Outline of the International Covenant on Civil and Political Rights

Part 1 (Articles 1-3) of the ICCPR expressly acknowledges the right of all peoples to have self-determination, in order that they may freely determine their political status, and are free to pursue their own economic, social and cultural development.

Part 2 (Articles 2-5) of the ICCPR set out the progressive realisation of these rights, and to ensure that these rights are respected absolutely without distinction of any kind, such as race, colour, sex, religion, language, social origin, political or other opinion, social origin, or other status.

Part 3 (Articles 6-27) of the ICCPR lists the rights themselves, which include rights to physical integrity, liberty and security of the person, procedural fairness in law, individual liberty, prohibition of propaganda for war, political participation (including the right to vote), and non-discrimination and minority rights.

Part 4 (Articles 28-45) of the ICCPR covers the establishment and operation of the Human Rights Committee, which has oversight on the reporting and monitoring of the ICCPR and is considered competent to resolve disputes.

Part 5 (Articles 46-47) provides clarification that the ICCPR is not interpreted as interfering with the operations of the United Nations.

Part 6 (Articles 48-53) is concerned with ratification and amendment of the ICCPR. The core provisions of the ICCPR are: rights to physical integrity; liberty and security of person; procedural fairness and rights of the accused; individual liberties; and political rights.

APPENDIX 6: Outline of the International Covenant on Economic, Social, and Cultural Rights

Part 1 (Article 1) of the ICESCR recognises the right of all peoples to self-determination, which includes the right to "freely determine their political status", pursue their economic, social and cultural goals, and also to manage and dispose of their own resources. Additionally, it also recognises a negative right of a people not to be deprived of its means of subsistence. The ICESCR also imposes an obligation on those parties still responsible for non-self governing and trust territories, to actively encourage and respect their self-determination.

Part 2 (Articles 2–5) of the ICESCR establishes the principle of "progressive realisation". It requires the rights to be recognised "without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status". It acknowledges that the rights can only be limited by law, and in a manner compatible with the nature of the rights, and in this way only for the purpose of "promoting the general welfare in a democratic society".

Part 3 (Articles 6–15) of the ICESR lists the actual rights themselves, which include the right to work under "just and favourable conditions", with the right to form and join trade unions; social security, including social insurance; family life, including paid parental leave and the protection of children; an adequate standard of living, including adequate food, clothing and housing, and the "continuous improvement of living conditions"; health, specifically "the highest attainable standard of physical and mental health"; and education (which also includes free universal primary education, generally available secondary education and equally accessible higher education). It acknowledges that this should be directed to "the full development of the human personality and the sense of its dignity", and works to enable all persons to participate effectively in society; and also participation in cultural life. Several of the tights within the ICESCR include specific actions, which must be undertaken to realise the rights themselves.

Part 4 (Articles 16–25) of the ICESCR is concerned with the area that governs the actual reporting and monitoring of the Covenant itself, and the steps taken by all the parties to implement it. Additionally, it also allows the monitoring body, which is now

the Committee on Economic, Social and Cultural Rights (originally the United Nations Economic and Social Council), empowerment to make general recommendations to the UN General Assembly on appropriate measures to realise the rights of the ICESCR.

Part 5 (Articles 26–31) of the ICESCR governs ratification, the entry into force, and also covers amendment of the Covenant.

APPENDIX 7: A Brief History of the Convention on the Rights of People with Disabilities

The Convention on the Rights of Persons with Disabilities (**CRPD**) is an international treaty that has 160 signatories and came into force on 3 May 2008. It aims to set out in detail and protect the rights and dignity of persons with disabilities. Article 1 CRPD sets out its purpose:

> The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

The definition of a person with disability adopted under the CRPD is "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (CRPD, Article 1). This definition clearly seeks to set out a psychosocial view of disability which identifies the fact that barriers in society may hinder the full and effective participation of people with disabilities in society on an equal basis. Article 3 specifies the general principles under the Convention and Article 4 specifies the general obligations. Article 5 recognises that persons with disabilities should enjoy the right of equality and non-discrimination. It is noted:

> **1.   State Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.**
>
> **2.   State Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.**

The right of equality and non-discrimination requires States Parties to prohibit all discrimination on the basis of disability, and to guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds. This right also requires States Parties to take all appropriate steps to ensure that reasonable

accommodation is provided. The CRPD recognises that women and girls with disabilities may be subject to multiple discrimination and it requires that States Parties take appropriate measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms (CRPD, Article 6). Article 6(1) goes further and seeks to empower women or girls with disabilities:

> States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

The CRPD also mandates that States Parties must take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children (CRPD, Article 7(1)). Under Article 8 States Parties are also required to undertake to adopt, immediate, effective and appropriate measures to raise awareness of issues relating to people with disabilities, including combating stereotypes and prejudices, and helping to promote awareness and capabilities of persons with disabilities.

APPENDIX 8: The Convention on the Rights of Persons with Disabilities General Principles and General Obligations

Table 9: CRPD Article 3 (General Principles) and Article 4 (General Obligations)

General Principle 1	Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
General Principle 2	Non-discrimination.
General Principle 3	Full and effective participation and inclusion in society.
General Principle 4	Respect for the difference and acceptance of persons with disabilities as part of human diversity and humanity.
General Principle 5	Equality of opportunity.
General Principle 6	Accessibility.
General Principle 7	Equality between men and women.
General Principle 8	Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.
General Obligation 1	To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the Convention.
General Obligation 2	To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities.
General Obligation 3	To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes.
General Obligation 4	To refrain from engaging in any act or practice that is inconsistent with the Convention and to ensure that public authorities and institutions act in conformity with the Convention.
General Obligation 5	To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation, or private enterprise.
General Obligation 6	To undertake or promote research and development of universally designed goods, services, equipment and facilities[1] which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines.

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[1] "Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed **[CRPD, Article 2]**.

General Obligation 7	To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost.
General Obligation 8	To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities.
General Obligation 9	To promote the training of professionals and staff working with persons with disabilities in the rights recognised by the Convention, so as to better provide the assistance and services guaranteed by those rights.

APPENDIX 9: The Convention on the Rights of Persons with Disabilities Awareness Raising Measures (Primary Measures and Practical Measures)

Table 10: A Summary of CRPD Article 8 (Awareness-raising) Measures

Primary Measure 1	Primary Measure 2	Primary Measure 3
To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities.	To combat stereotypes, prejudices and harmful practices relating to people with disabilities, including those based on sex and age, in all areas of life.	To promote awareness of the capabilities and contributions of persons with disabilities.
Practical Measure 1		
Initiating and maintaining effective public awareness campaigns designed:		
To nurture receptiveness to the rights of persons with disabilities.	To promote positive perceptions and greater social awareness towards persons with disabilities	To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market.
Practical Measure 2		
Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities.		
Practical Measure 3		
Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the Convention.		
Practical Measure 4		
Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.		

APPENDIX 10: Summary of Laws and Regulations on Disability

Title	Year Legislated	Description
Basic System, Issue No. A/90, Article 27	1992 (1412H)	The government guarantees the rights of citizens in cases of emergency, sickness, disability, or old age by providing social security and encouraging agencies and individuals to participate in charitable activities.
The Labor Code (Royal Decree No. M/21)	1969 (1389H)	Emphasises labour rights and details vocational rehabilitation for persons with disabilities.
Council of Ministers Resolution No. 407	1973 (1393H)	Provides for allocation of monthly allowances to persons with disabilities who participate at Disabled Training Centres.
Council of Ministers Resolution No. 715	1974 (1394H)	Provides rehabilitation for paraplegics, epilepsy patients and those who require medical care under the Supervision of the Ministry of Health. Also establishes mother and childcare centres affiliated with the MoH, in order to take care of pregnant women and children.
Regulation for Rehabilitation Program No. 1355		Establishes a career rehabilitation department at the MoLSA with regards to: (1) following up and implementing career rehabilitation programmes, drawing up general policies, and carrying out research on the development of programmes; (2) suggesting means of rehabilitation and services for people with disabilities; (3) preparing persons with disabilities for employment; and (4) recording the types of services provided to persons with disabilities.
Decree No. 129	1976 (1394H)	Policy of the General Department of Rehabilitation, which includes the creation of special programmes for those people with disabilities who can be vocationally trained. It also sets out programmes for those who are not fit to work by giving them special medical and psychological rehabilitation.
Council of Ministers Resolution No. 219	1980 (1400H)	The General Department of Rehabilitation under the MoLSA offers an annual donation of Saudi Riyal 30,000 to persons with disabilities projects that are initiated by persons with disabilities (individuals or groups).
Council of Ministers Resolution No. 7	1999 (1420H)	Grants approval to raise donations of up to Saudi Riyal 50,000 for rehabilitation projects developed by people with disabilities (individuals or groups) that are intended to achieve training goals for persons with disabilities.
Council of Ministers Resolution No. 187	1981 (1401H)	Persons with disabilities and their companions will receive 50% discounts on all government owned transportation, including ships, airplanes, trains, and buses.
Council of Ministers Resolution No. 85	1997 (1418H)	Establishes the Persons with Disabilities Services Coordination Committee with a member from the King Saud University and Presidency of Girls' Education.

Title	Year Legislated	Description
		Donates to the families of persons with disabilities and prepares publicity plans for raising awareness and finding means of prevention.
Labor and Workman Law	1969 (1389H)	Aims to provide vocational rehabilitation of persons with disabilities by establishing and organising institutions necessary to provide vocational training services, and by promoting the employment of persons with disabilities.

(Source: Adapted from: JICAPED, 2002)

APPENDIX 11: The Saudi Disability Code

ARTICLE 1

The following words and expressions, used in this code, have the following meanings:

Persons with disabilities

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.

For the purpose of this code, "persons with disabilities" shall refer to individuals who have one or more of the following disabilities: visual disability, hearing disability, cognitive disability, motor disability, learning disabilities, speech and language impairments, behavioral problems, pervasive developmental delay, multi-disabilities, and other disabilities which require special care.

Prevention

The set of medical, psychological, social, educational, informational and regulatory procedures, which aim at preventing or limiting the effect of disabilities and at pre-empting and easing the consequences thereof.

Welfare

To provide care services to persons with disabilities dependent upon the degree of their disability, as well as their medical and social situation.

Habilitation

A coordinated process to utilize medical, social, psychological, educational and professional services to enable the disabled to achieve the maximum feasible degree of functional efficiency; to enable persons with disabilities to adapt to the needs and requirements of their natural and social environment, as well as developing their capabilities to attain independence and be productive members of society to the extent possible.

The Supreme Council
The Supreme Council for the Affairs of Persons with Disabilities.

ARTICLE 2

The Government shall guarantee the prevention, welfare and habilitation services to persons with disabilities and their families, and will encourage institutions and individuals to contribute to charitable activities within the field of disability. The Government shall guarantee to provide services to persons with disabilities in the following areas:

1. Health
This includes:

- providing medical, preventive and habilitation services, including genetic counseling, laboratory testing and analyses for the early detection of disease and necessary intervention,

- registering children who are at risk or born with a disability, and conducting follow-up monitoring of their condition(s), and communicating relevant information to the appropriate authorities,

- enriching the health care of the disabled and taking the necessary steps to achieve this,

- training health care providers and paramedics in appropriate procedures for the safe handling of injured persons on site to prevent further complications during transit, and

- training families of the disabled on handling and care.

2. Education

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.

3. Training and habilitation

This includes the provision of training and habilitation services as required by the labor market, in order to be competitively employable. This also includes the provision of vocational and social habilitation centers and adequate training aids.

4. Work

This includes recruiting and employing persons with disabilities to give them the opportunity to discover their personal capabilities and potential and enabling them to earn and generate an income like other members of the community. This also includes enhancing the performance of employed persons with disabilities by providing further ongoing training.

5. Social

This includes programs which contribute to developing the capabilities of persons with disabilities to enable them to integrate naturally into various facets of public life without hindrance from the nature of their disability.

6. Culture and sports

This includes utilization of cultural and sporting facilities, and the adaptation of such facilities to enable persons with disabilities to participate therein, indoors and outdoors, in a manner suitable to their abilities.

7. Information

This includes the role the mass media plays in enlightening and educating the community by:

- defining the types and causes of disabilities, and the importance of the processes of early diagnosis and prevention,

- educating the public in the role of persons with disabilities in society, by identifying their rights, needs, abilities and their contribution to the services available; as well as educating persons with disabilities regarding their duties towards themselves and their role in society,

- producing special programs for persons with disabilities that will assist them in their integration into society, and

- encouraging individuals and institutions to provide financial and moral support to the disabled and encouraging volunteer work in the community to serve persons with disabilities.

8. Complementary services

This includes:

- facilitating a method of public transport to securely and safely transport the disabled and their caretakers, at reduced cost (depending on the condition of the disability),

- providing day-care centers and/or home help to assist persons with disabilities, and

- providing technical aids.

ARTICLE 3
The Supreme Council shall coordinate with authorities to abide by the regulations for architectural specifications required to provide access and accommodate persons with disabilities in all centers for habilitation, training, education, medical, welfare and public places, as well as all other areas, to enable persons with disabilities easy access of movement and transportation. All authorities shall abide by the said regulation.

ARTICLE 4
The Supreme Council will coordinate with authorities to provide manpower to be educated and trained nationally and internationally in the field of disability, and to promote the exchange of experience with other countries.

ARTICLE 5
The Government shall award loans for persons with disabilities to establish occupational or commercial employment that is suited to their abilities in their capacity as individuals or as a group.

ARTICLE 6
Technical aids and devices used by persons with disabilities shall be exempt from customs duties. These will be specified in a list approved by the Ministry of Finance and National Economy.

ARTICLE 7
A trust fund shall be established, under the control of the Supreme Council, for depositing all endowments, donations and revenues from fines, and which will be used for providing care for persons with disabilities.

ARTICLE 8
A Supreme Council for the Affairs of Persons with Disabilities will be

established. The Council shall be associated with the Prime Minister and shall be constituted as follows:

a Chairman, to be appointed by Royal Order, and members -

" A Secretary General for the Supreme Council
" The Minister of Labor and Social Affairs
" The Minister of Health
" The Minister of Higher Education
" The Minister of Education
" The Minister of Finance and National Economy
" The Minister of Municipal and Rural Affairs
" The General President of Girls Education
" Two persons with disabilities
" Two businessmen interested in the affairs of persons with disabilities
" Two specialists in the field of disability.

The latter six members are appointed by the Prime Minister based on recommendations of the Chairman of the Supreme Council and their appointments are for renewable terms of four years.
The Chairman of the Supreme Council may appoint any member of the Council to act on his behalf in the event of his absence.

ARTICLE 9
The Supreme Council will be authorized in the organization of the affairs of persons with disabilities in the following:

- issue policies and procedures and decisions required to implement this code,

- propose modifications of regulations pertaining to the affairs of persons with disabilities in different areas, propose basic standards to what is offered to them or to whoever takes care of them, i.e. financial benefits,

- ensure implementation of this code and its regulations, including other policies and procedures relating to the affairs of persons with disabilities,

- coordination between the Government and private sectors in relation to services provided to persons with disabilities.

ARTICLE 10

An annual report will be submitted to the prime minister regarding the achievements of the Supreme experienced, and means of support services provided to persons with disabilities

ARTICLE 11
a)   The Chairman or his Acting will call upon the Supreme Council for a twice annual meeting.
b)   The Supreme Council shall convene upon the presence of a majority of its members, including the Chairman or his Acting, and shall take its decisions by the majority of the votes of the attendees. In the case of a tie, Chairman shall have the deciding vote.

ARTICLE 12

The Supreme Council shall a General Secretariat and shall appoint a Secretary General and necessary staff, in accordance with the regulations of the civil service. The Secretary General will be responsible for the following;

a) Administer to the General Secretariat,
b) Assume responsibility for convening meetings, taking minutes, informing the concerned parties of decisions taken in the meetings,
c) Prepare executive policies for this code,
d) Prepare technical reviews on the work of the Supreme Council,
e) Format policies and procedures relating to the affairs of persons with disabilities, in coordination with the concerned parties,
f) Represent the Supreme Council to governmental departments, institutions and other related organizations,
g) Form committees consisting of members specialized and experienced in reviewing the issues related to the disabled,
h) Prepare an annual report on the work of the Supreme Council, and
i) Perform other duties allocated to him by the Supreme Council.

ARTICLE 13

The Supreme Council shall form a working group from amongst its members or otherwise. The Council shall determine and specify the Group's expertise and work methodology.

ARTICLE 14

The Supreme Council shall have a budget which shall be subject to the general rules and provisions of the Kingdom's budget.

ARTICLE 15

All pre-existing codes, policies, procedures, decisions and instructions relating to persons with disabilities shall be modified according to this code within three years of the date of its publication.

ARTICLE 16

This code will be published in the official book of law shall be valid and the effect after 180 days from the date of publication.

APPENDIX 12: Draft Guidelines for Periodic Reporting to the Committee on the Rights of Persons with Disabilities (2016 Guidelines)

Table 11: 2016 Guidelines Articles

Article	Area	Paragraph
Article 5	Equality and non-discrimination.	Measures to ensure that persons with disabilities are entitled to protection under the law on an equal basis with others. **[Article 5, Paragraph 1, 29(S)]** Measures to ensure appropriate dissemination and awareness raising about anti-discrimination frameworks, particularly among persons with disabilities and their representative organizations. **[Article 5, Paragraph 2, 34(P)]** Statistics on the number and percentage of claims of discrimination on the basis of disability, disaggregated by sex, age, and type of impairment and the sector in which discrimination occurred, and information on the number and percentage of cases that resulted in sanctions. **[Article 5, Paragraph 2, 38(P)]** Policies and programmes, including affirmative action measures, are allocated the sufficient financial and human resources, to achieve the de facto equality of persons with disabilities, taking into account their diversity. **[Article 5, Paragraph 4, 42(P)]**
Article 6	Women with disabilities.	Measures adopted to ensure that gender and disability perspectives are included in all legislative, administrative and policies in all areas of life and in all spheres, and that they effectively address specific risk and marginalization factors. **[Article 6, Paragraph 1, 43(S/P)]** Statistics and data collected in all areas of the Convention are appropriately disaggregated by sex and are publicly available. **[Article 6, Paragraph 1, 47(P)]**
Article 7	Children with disabilities.	What concrete legislative and administrative measures have been taken to prevent the abandonment, neglect and institutionalization of children with disabilities? **[Article 7, Paragraph 1, 52(S)]** Efforts to carry out de-institutionalization and initiatives to monitor the process and ensure they are appropriate and effective. **[Article 7, Paragraph 1, 53(P)]** Initiatives to raise awareness of the rights of children with disabilities through public campaigns targeted to the community at large. **[Article 7, Paragraph 1, 52(S)]** The resources, including budgetary resources, allocated to implement a broad policy on inclusion of children with disabilities in all areas of life, including family life and community life, with community-based rehabilitation programmes for children with disabilities. **[Article 7, Paragraph 1, 59(P)]**
Article 8	Awareness-raising.	Strategies, including campaigns, to systematically and continuously raise awareness throughout society regarding persons with disabilities, and to foster respect for their rights and dignity according to the human rights model of disability. **[Article 8, Paragraph 1, 70(P)]**

Article	Area	Paragraph
		Measures targeted at public and private actors undertaken to combat stigma, stereotypes, prejudices, harmful practices, deep-rooted cultural beliefs, negative attitudes, bullying, hate crimes, and discriminatory language against persons with disabilities, including those based on gender and age, in all areas of life. **[Article 7, Paragraph 1, 73(P)]**
Article 12	Equal recognition before the law.	Measures taken to raise awareness and carry out education campaigns in relation to the equal recognition of all persons with disabilities before the law. **[Article 12, Paragraph 2, 117(S)]** Measures taken by the State party to ensure that all persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life, in particular, measures to ensure the equal right of persons with disabilities to maintain their physical and mental integrity, the right to fully participation as citizens, to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit and banking procedures, in both the public and private sectors, , and the right not to be arbitrarily deprived of their property. **[Article12, Paragraph 2, 118(P)]**
Article 31	Statistics and data collection	Steps taken to develop statistics and data collection in accordance with the human rights-based model of disability focusing on the disabling barriers experienced by persons living with an impairment, by way of example, in line with the scope defined by The Washington Group on Statistics or the World Health Organization. **[Article 31, Paragraph 1, 353(P)]** Steps taken to develop a national system for the systematic collection of updated statistical and research data indicators, disaggregated by age, sex, type of impairment, and other relevant factors, which reflects the situation of persons with disabilities for the purpose of formulating and implementing policies to give effect to the Convention. **[Article 31, Paragraph 2, 360(P)]**

APPENDIX 13: Project Information Sheet

Research study title

Towards the Social Inclusion of Physically Disabled People in the Kingdom of Saudi Arabia: An Investigation of Barriers to Social Inclusion in Higher Education.

Background to the research study

I am currently completing a research study for my PhD at University of Salford. I would like to invite you to take part in this research study. Ethical approval has been obtained from the University of Salford and it is important that you understand both the purpose of the research and your role as a participant. Please ask any questions if any part of the information is unclear to you. Finally, it is your decision whether or not to be part of the study and you may withdraw from this research study at any time and for any reason.

What is the purpose of the study?

This research study seeks to identify and characterise the barriers to social inclusion in higher education, and to provide initial evidence for future social polices targeted at physically disabled young people accessing tertiary education in Saudi Arabia.

Why have I been invited to participate in the study?

You have been invited to participate in this research study because your experience and knowledge will help me to gain more information about social barriers that you may face, or you may have faced, as a physically disabled person in accessing higher education.

Do I have to take part in this research study?

It is completely your choice as to whether you wish to participate in this study or not. This information sheet will provide further details to help you make an informed decision about your participation. You can also contact me if you have any question about the about the research study. If you agree to take part in the research study, you will be asked to sign an informed consent form. You are free to withdraw from the research study at any point while taking part in the research study, and for any reason.

What will I be required to do in the research study?

If you choose to take part in the research study your participation will involve the following:

1. You will be asked to sign an informed consent form to document that you have willingly given your informed consent to participate in the research study.

2. You will be asked to sign an informed consent form to attend a face-to-face tape recorded interview.

3. The length of the interview will differ depending on the details you would like to offer in response to the questions asked. However, it is expected that the interview will take approximately 30-60 minutes.

4. The interview will be held in a quiet and private place, during normal working hours.

5. The interview will be confidential and the recorded interview will be stored securely and safely. The study will have two forms of data, a hard copy, and a soft copy. Hard copy data will be kept in a locked locker and no one will be authorized to use it except the researcher. The soft copy data will be secured in a password protected external hard disk and will be connected only to the researcher's private laptop. Only the researcher can access the saved study data. Your identity will be kept secure by the researcher.

What if I become distressed during the interview?

Throughout the interview the researcher will try to ensure that you feel comfortable and not emotionally distressed. However, if at any time before, during, or after the interview you feel distress arising, or you feel distressed, you can ask the researcher to immediately stop the interview. At the point the researcher will immediately stop the interview. You may then choose to take a break and return to the interview later, or you may stop the interview proceeding completely. Should you wish to speak to a counsellor or other suitably qualified health professional, one will be made available to you at your request.

Does the research study cover expenses and payments?

No expenses or payments will be made for this research study.

Are there any potential risks associated with participating in this research study?

There are no personal risks associated with participating in the research study.

Will I benefit by participating in this research study?

I cannot promise the research study will directly benefit you. However the information I obtain from the research study is intended to help me to developing recommendations for future social policies, as well as the nurturing of social inclusion for young physically disabled people within the KSA higher education system based on the research findings.

How can I make a complaint about this research study?

If you would like to complain about any aspect of the research study, please contact the first supervisor, Dr Mark Wilding. Contact details are provided below.

Dr Mark Wilding
School of Health & Society
Mary Seacole Building
University of Salford
Frederick Road Campus
Salford M6 6PU
United Kingdom

TEL: +44 (0)161 295 2500 or 295 2978
EMAIL: M.A.WILDING@SALFORD.AC.UK

If you are dissatisfied with the way your complaint is being handled, then you may escalate your complaint by contacting Mr Anish Kurien. Contact details are provided below.

Mr Anish Kurien, Research Centres Manager
The University of Salford
Joule House
Salford M6 6PU

United Kingdom

TEL: +44 (0)161 295 522280
EMAIL: <u>a.kurien@salford.ac.uk</u>

Will my taking part in the study be kept confidential?

The information that you provide will be confidential. No names will appear in the study. Your identity and personal contact details will be known only to the researcher, the research assistants, and the research supervisors at the University of Salford. The researcher will not use your name or any information that could reveal their identity in this or any future research study, publication, conference presentation or teaching session. Storage and destruction of data will conform to the Data Protection Act (1998).

What will happen if I do not carry on with the study?

You have the right to withdraw from the study at any point without prejudice and this will not affect your care in any way. If you withdraw from the study all the information and data collected from you will be destroyed and your name removed from all the study files.

What will happen to the results of the research study?

The results will be published in a PhD thesis and parts of the study may be published in health care journals and/or presented at conferences. You have the right to ask for the results if needed and the choice of seeing the completed transcript following interview.

Who is organising or sponsoring the research?

The University of Salford and the Saudi Ministry of Education**.**

Thank you for taking the time to read this information sheet.

Regards
Researcher's Name: Reemah Yousef

PhD candidate
School of School of Health & Society

University of Salford
Salford
Manchester
M6 6PU
United Kingdom

If there are any further questions regarding this study, you can contact me (by phone or email) or my supervisors (by email) as follows. If you prefer, we can arrange to discuss this invitation, face to face, at a mutually convenient place and time.

Contact Details

Researcher's Name Reemah Yousef

TEL: 00966505662627

EMAIL: R.yousef@edu.salford.ac.uk

Supervisors

Dr Mark Wilding

TEL: +44 (0)161 295 2500 or 295 2978
EMAIL: M.A.WILDING@SALFORD.AC.UK

Martin Johnson

TEL: +44 (0)161 295 2733

EMAIL: m.johnson2@salford.ac.uk

APPENDIX 14: Informed Consent Form

Research Participant Consent Form for decision maker

Title of Project: Towards the Social Inclusion of Physically Disabled People in the Kingdom of Saudi Arabia: An Investigation of Barriers to Social Inclusion in Higher Education.

Ethics Reference No:

Name of Researcher:

➢ I confirm that I have read and understood the information sheet for the above study and what my contribution will be.	**Yes**	**No**

➢ I have been given the opportunity to ask questions through the use of an interview guide.	**Yes**	**No**

➢ I voluntarily agree to take part in the interview.	**Yes**	**No**

➢ I voluntarily agree to the interview being tape recorded.	**Yes**	**No**

➢ I understand that my participation is voluntary and that I can withdraw from the research at any time without giving any reason.	**Yes**	**No**

➢ I understand how the researcher will use my responses, who will see them and how the data will be stored.	**Yes**	**No**

➢ I agree to take part in the above study.	**Yes**	**No**

Name of participant (print)

………………………………………………………………………

………………………………………………………………………

Signature

Date   ……………………………….

APPENDIX 15: Approval Letter from the Saudi Ministry of Health

RISK ASSESSMENT FOR RESEARCH AND PROJECTS

COVER SHEET.

Student's surname	Yousef
Student's forenames	Reemah
Section of School	School of Health & Society
Degree	Research PhD
Title of Project	Towards the Social Inclusion of Physically Disabled People in the Kingdom of Saudi Arabia: An Investigation of Barriers to Social Inclusion in Higher Education
Brief description of the project	The number of disabled people continues to grow in the Kingdom of Saudi Arabia (KSA), with the current estimate of around 4% of the total population. Over the past two decades, the Saudi government has implemented little disability legislation and proposed few legal, social, and economic initiatives in order to help and support disabled people in the KSA, which increases the need for improvements in special disability education services in the KSA. Access to higher education by young people in KSA is recognised as an area that needs improvement. The identification of the difficulties faced by young disabled people when accessing higher education within KSA might help in the development of better social policies and support services to improve the social inclusion of young disabled people into mainstream higher education. The study is aimed at identifying and characterising the barriers to social inclusion in higher education and providing initial evidence for future educational polices targeted at disabled people

	and non-disabled people alike, within mainstream higher education.
Supervisor's name	Dr. Mark Wilding
Reserve supervisor in case of absence.	Professor Martin Johnson
Locations where work will be carried out	Jeddah, The Kingdom of Saudi Arabia

It is the responsibility of the PI / Supervisor to ensure the risk assessment is suitable and sufficient and that risk assessments are reviewed should any significant changes to the project / research be made.

Risk assessment (RA) tracking;				
Hazard	**RA required**	**RA complete**	**Risk level as identified in RA**	**Authorised as suitable and sufficient by supervisor**
Initial Risk Assessment.	✔			
Physical / mechanical / electrical / animal				
Biological – microorganisms				
Chemical				
Radiation				

Travel / Fieldwork	✔			
Host Organisation				

I shall be working in the establishment named below (where applicable):
Name; Specialist Hospital & Research Centre, Jeddah Address;Zahrawi Street, Al Maather, Jeddah 12713, Saudi Arabia Tel; + 966 11 464 7272

Emergency Contact Details.		
Role	**Name**	**Telephone & email**
Student	Reemah Yousef	[●]
Academic Supervisor	Dr. Mark Wilding	TEL: +44 (0)161 295 2500 or 295 2978 EMAIL:
Host organisation Supervisor (where applicable)		

Please complete the following risk assessment forms as dictated by the proposed project.

Guidance on how to complete the assessments can be found in the Project RA handbook.

To save paper please delete the sections that are irrelevant to your project.

Initial Risk Assessment.

Location: Jeddah, Saudi Arabia	Task/Activity/Environment: Public Hospital	Date of Assessment: 12th May 2016	
Identify Hazards which could cause harm:	Identify risks = what could go wrong if hazards cause harm:		
No.	*Hazard*	No.	**Risk**
	Physical / ~~mechanical / electrical / animal~~		Harmed by participants.
	~~Biological~~		
	~~Chemical~~		
	~~Radiation / Lasers~~		
	Lone working		Fall ill.
	Travel / Fieldwork		Plane crash (Manchester to Saudi Arabia). Participants become emotional (e.g. stressed, anxious, agitated, or upset).
	~~Disposal of waste material~~		
List groups of people who could be affected:		What numbers of people are involved?	27-32 people

| Young physically disabled people based in public hospital.

Director of the Saudi Ministry of Health

Director of the Saudi Ministry of Education			
What existing precautions are in place to reduce risks?		Risk level with existing precautions	
Harmed by participants	I will be speaking with the participants before the interviews take place in order to reassure the participants about their involvement, if they experience any stress or anxiety, or if they wish to stop the interview. Hospital staff members will be on hand to supervise the interviews and will be made available if required.	Very Low	
Fall ill	I will have access to medications whilst working in Jeddah, and I will also be working in a Hospital with a doctor's clinic available onsite.	Very Low	
Plane Crash	Saudia airlines has a 7/7 airline safety rating	Very Low	
Participants become emotional	I will be speaking with hospital staff in order to ensure that the participants have access to a counsellor or other suitably qualified professional should they wish to do so. I will inform participants that we can stop the interview immediately if they become emotional in any way.	Low	

What additional actions are required to ensure precautions are implemented/effective or to reduce the risk further?		Risk level with additional precautions
Is health surveillance required? YES/NO	**If YES, please detail:**	
Who will be responsible for implementing the precautions: I will be responsible for contacting hospital staff members in order to put in place the required precautions.		By When: Before the interviews are commenced.

Completed by: Signed:

REEMAH YOUSEF   ....

Record of annual
review:

....

Risk Rating: **2**

	Risk levels
5 10 15 20 25 4 8 12 16 20 3 6 9 12 15 2 4 6 8 10 1 2 3 4 5 Increasing Likelihood	**17-25** **Unacceptable** – Stop activity and make immediate improvements/seek further advice
	10-16 **Tolerable** – look to improve within specified timescale
	5-9 **Adequate** – Look to improve at next review
	1-4 **Acceptable** - No further action, but ensure controls are maintained

Guide to using the risk rating table:

Consequences	Likelihood
1 Insignificant – no injury	**1 Very unlikely** – 1 in a million chance of it happening
2 Minor – minor injuries	**2 Unlikely** – 1 in 100,000 chance of it happening
3 Moderate – up to three days absence	**3 Fairly likely** – 1 in 10,000 chance of it happening
4 Major – more than three days absence	**4 Likely** – 1 in 1,000 chance of it happening
5 Catastrophic – death or disabling	**5 Very likely** – 1 in 100 chance of it happening

Travel / Fieldwork Risk Assessment

This form should be completed in conjunction with the University Travel and Fieldwork Policy and Code of Practice.

Destination(s)	**Jeddah, Saudi Arabia**
Date of trip	**From:** _ _ : _ _ hrs on 12 / 07 / 2016 **To:** _ _ : _ _ hrs on 12 / 09 / 2016
Number of participants	**1**
First Aider **(where required)**	
Emergency Contact in School	Dr. Mark Wilding M.A.WILDING@SALFORD.AC.UK **Or Maxwell Control (Security) +44 (0)161 29 5 33 33 out of hours.**

Potential Hazard	Existing Controls	Risk Level	Additional Controls (if existing risk level is med or above)	Risk Level
Weather conditions	Travel to and from hospital in a car.	1		

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Terrain	Travel to and from hospital in a car.	1		
Water (tides / deep water / currentsetc)				
Harmful substances (Chem or bio)				
Animals				
Danger from traffic / site vehicles	Travel to and from hospital in a car.	1		
Industrial processes / plant etc				
Transport to and from site				
Transport on site				

Crime				
Other **(please state)**				

For destinations with medium (or above) risk ratings from Control Risks website (http://www.hr.salford.ac.uk/safety/controlrisk/index**) please attach a copy of their advice and complete the additional assessment as per the Travel and Fireldwork Policy / Code of Practice.**

Completed by: Signed:

REEMAH YOUSEF

Record of annual review:

Risk Rating: **1**

5	10	15	20	25
4	8	12	16	20
3	6	9	12	15
2	4	6	8	10
1	2	3	4	5

Increasing Consequence

Increasing Likelihood

17-25 Unacceptable – Stop activity and make immediate improvements/seek further advice

10-16 Tolerable – look to improve within specified timescale

5-9 Adequate – Look to improve at next review

1-4 Acceptable - No further action, but ensure controls are maintained

Guide to using the risk rating table:

Consequences	Likelihood
1 Insignificant – no injury	**1 Very unlikely** – 1 in a million chance of it happening
2 Minor – minor injuries	**2 Unlikely** – 1 in 100,000 chance of it happening
3 Moderate – up to three days absence	**3 Fairly likely** – 1 in 10,000 chance of it happening

4 Major – more than three days absence	**4 Likely** – 1 in 1,000 chance of it happening
5 Catastrophic – death or disabling	**5 Very likely** – 1 in 100 chance of it happening

APPENDIX 17: Research Ethics Approval Letter

University of
Salford
MANCHESTER

24 May 2016

Dear Reemah,

RE: ETHICS APPLICATION HSCR 16-20– Towards the Social Inclusion of Physically Disabled People in the Kingdom of Saudi Arabia: An Investigation of Barriers to Social Inclusion in Higher Education

Based on the information you provided, I am pleased to inform you that application HSCR16-20 has been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

Sue McAndrew
Chair of the Research Ethics Panel