

**Family Quality of Life for Families of Children with
Intellectual Disability in Saudi Arabia**

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Declaration

This work contains no material which has been accepted for the award of another degree or diploma in any university or other tertiary institution, and to the best of my knowledge and belief, contains no material previously published or written by another person except where due reference is made in the text.

Khalid Alshamri

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Abstract

This thesis was primarily concerned with the quality of life of Saudi Arabian families who are caring for children of primary school age with intellectual disability. The four research aims were as follows. (1) Construct and verify the validity of the Beach Center Family Quality of Life Scale, augmented to include variables assumed to be relevant to Saudi Arabian families of children with intellectual disability, including the new measures of religiosity and other religio-cultural factors related to caring for a child with an intellectual disability. (2) Examine whether the identified factors of the Saudi Arabian Family Quality of Life questionnaire, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with intellectual disability are reliable. (3) Determine whether caring for children with intellectual disability, compared to caring for children without intellectual disability, is associated with family quality of life among Saudi Arabian families. And whether demographic factors, religiosity, and other religio-cultural factors were associated with family quality of life for Saudi Arabian families were the same for families with and without children with intellectual disability. (4) To explore the possible phenomenological reasons behind the observed quantitative results for examining family quality of life of Saudi Arabian families, and to discern what kinds of support parents feel they need.

In order to achieve these aims, quantitative and qualitative data were collected about family quality of life of Saudi Arabian families with and without children with intellectual disability. A questionnaire based on the Beach Center Family Quality of Life Scale, modified for Saudi Arabia, was administered to 201 families, and interviews were conducted with eight Saudi families. Of the 201 participant families, 82 per cent of the respondents/participants were male and 28 per cent of them were

the primary carer; 88 per cent had at least a college level of education and 41 per cent were engaged in further study, with 28 per cent being unemployed; 93 per cent of them were married; 58 percent lived in a city; 36 per cent earned less than SAR60,000 p.a. while 54 per cent earned between SAR60,000 and SAR120,000 p.a. All families had at least one child (between 2-17 years of age), and 86 families (43% of the sample) had one child with intellectual disability. Of them, 52 children had a mild intellectual disability and 31 had a moderate intellectual disability.

The major findings of the current study were as follows. First, the Family Quality of Life scale developed for the current study was found to be valid and reliable for Saudi Arabian families. Second, it was found that families who were caring for a child with an intellectual disability reported a significantly lower quality of life than those who did not. Third, it was found that socio-economic status and marital status were the major factors impacting on family quality of life for families with and without children with intellectual disability; and further, that higher socio-economic status and being married (as opposed to divorced) mitigated the negative impact on family quality of life of caring for a child with an intellectual disability. Fourth, the qualitative results of interviews with selected families largely cohered with the quantitative results of the questionnaire. However, although the quantitative analysis showed that the subscales of family religiosity and social and religious perspectives on intellectual disability were not reliable, the interviews revealed that the functional role of religion varied and played important, albeit different roles, in how families dealt with the fact that they had children with intellectual disability. Finally, the request for special assistance on the part of families of children with intellectual disability was largely dependent on their socio-economic status.

The main research implication of this thesis is that the augmented Saudi Arabian Family Quality of Life can be used in future family quality of life studies for the Saudi Arabian population, and may be extended to other Gulf countries to see whether the scale has validity in culturally similar societies beyond Saudi Arabia. The current study also found that social acceptance/stigmatisation of children with intellectual disability had an impact on family quality of life, but the precise sources of social stigmatisation were not explored. This could be an important area for future research. Another important implication of the current study is that attempting to capture the impact of religion on family quality of life requires qualitative analysis in the form of interviews because subjective interpretations of the role of religion in people's lives are sometimes only revealed via discussion (as opposed to questionnaires).

Another finding with important practical/policy implications is that families who have a relatively lower family quality of life are also those who have low incomes, meaning that they are already vulnerable and potentially 'marginalized' groups. Government programs providing real income and employment support is a possible albeit partial solution in such cases. Furthermore, there are other forms of support, not currently available in Saudi Arabia, that can also be provided to families of children with intellectual disability. These include (1) assistance with parenting skills, (2) better tailored education services for children, (3) assistance with marital stability, and (4) combating stigmatisation.

Chapter 1 : Introduction

This chapter provides a brief overview of the general field of interest to this thesis, coupled with a justification of the thesis' worth, and then provides an outline of the thesis' structure (namely, its chapters and their content).

1.1 Overview and Justification

Like all countries, the Kingdom of Saudi Arabia has children with intellectual disability. In 1987 the Saudi Arabian state introduced legislation specifying the rights of people with disabilities (Alquraini, 2011). In 2000 it introduced the Disability Code to ensure that people with disabilities could access various kinds of support services through public agencies (Prince Salman Center for Disability Research, 2004). However, it was not until 2001 that the state explicitly acknowledged that children with intellectual disability required special assistance, when it introduced the Regulations of Special Education Programs and Institutes (AlBuhairan et al., 2015; Al-Jadid, 2013; Al-Khateeb & Al-Khateeb, 2014). When it comes to families of children with intellectual disability, legislation is insufficient; knowledge of families' actual experiences is also important. This thesis is interested in the quality of life of families who care for children with intellectual disability.

Conceptualising *quality of life* is a difficult task, because it involves a complex weaving together of multiple dimensions: it combines numerous material and social circumstances with subjective experiences and evaluations of those circumstances. Although there is not universal agreement on what constitutes quality of life (for the individual), there is a broad consensus on some of the basic or essential dimensions.

The Quality of Life Special Interest Research Group, for example, has recognised that quality of life is multidimensional – it includes not just ‘external’ requirements such as material standard of living, housing and health factors, but also social integration and inclusion as well as personal subjective factors such as self-determination and self-esteem (Brown, Brown, et.al. 2000; Schalock, 2004). The World Health Organisation has identified similar domains including physical, psychological, independence, social relationships, environments and spiritual/personal beliefs (Schalock, et.al. 2002). Rillotta (2010), drawing on the work of Schalock (2004) and others, argues that there is now something of a consensus about the ‘core’ domains of quality of life: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights.

The concept quality of life has been extended to the family unit to give us the concept of *family quality of life*, and thence to families of children with intellectual disability (among other variations, such as physical disabilities). The attention shifts here from the individual to the collective needs and preferences of the family as a unit, acknowledging and incorporating the quality of life of individual family members in interacting with each other. This of course presupposes that the term ‘family’ has a determinate meaning. Unfortunately, there is no universally agreed upon definition, and what is agreed upon is vague and question-begging: namely, more than one person who believes they are a member of a family (Bailey, et.al., 1998; Poston, et.al., 2003). For the purposes of the current study, ‘family’ will refer to a ‘household’ social group consisting of at least one parent and one child. This, of course, is not the only legitimate meaning of the term, but for the current study, since

it is interested in comparison of the quality of life of social units which includes at least one child with or without an intellectual disability, other definitions of ‘family’ are simply not relevant.

One commonly used definition of family quality of life is that of Park et al. (2003) and Turner et al. (2004) which, in summary, stipulates that a satisfactory quality of life is where the family’s needs are met, family members enjoy their life together as a family, and they have the chance to do things which are important to them. There is still debate over the ‘correct’ framework for understanding family quality of life, and thus there are different specifications of what dimensions ‘count’ as making up family quality of life (Zuna, et.al. 2011). However, there is general consensus about at least the basic nature of family quality of life in much of the literature. Most literature of family quality of life acknowledges Brown and Brown’s (2004) three framework components: (1) Attainment: attaining a standard of living comparable to other families, and attaining what the family deems to be important to it; (2) Satisfaction: being satisfied with what the family has attained; and (3) Empowerment: being empowered to live according to the family’s preferences, and being able to meet challenges and act on the opportunities that are afforded to the family (cf. Schalock, 2004; Turnbull, Brown & Turnbull, 2004; Zuna, et.al. 2011). In this framework, there are both subjective and objective aspects, which is why there is general consensus among researchers that a combination of qualitative and quantitative methods is appropriate for the study of family quality of life (cf. Schalock, 2004; Turnbull, Brown & Turnbull, 2004; Brown & Brown, 2005; Verdugo, Schalock, et.al., 2005). The subjective aspects relate to perceptions of psychological wellbeing, satisfaction with circumstances and choices, and happiness

on the part of family members, as well as belief in empowerment (capacity to deal effectively with challenges and take advantage of opportunities). The objective aspects relate to standard of living, including income, employment, housing, health and support services. Because there is a subjective side to family quality of life, as will be discussed later, there is room for variation on the relevant dimensions that arise due to differences in the cultural contexts of different populations. Thus the augmentation of some dimensions of family quality of life for Saudi Arabian culture is a key concern of this thesis.

Families of children with intellectual disability constitute a distinctive cohort because they face unique challenges since, in most cases, such children have various kinds of communication and cognitive deficits, which are often accompanied by behavioural problems (Perkins & Hale, 2010). The study of the relationship between family quality of life and caring for children with intellectual disability began in the 1980s with the work of researchers such as Turnbull et al. (1984). Since then, research in this area has expanded considerably and has been substantially enhanced by the development of instruments designed to provide a way of statistically measuring family quality of life for families with children with intellectual disability (e.g. Isaacs et al., 2007; Poston et al., 2003; Summers et al., 2005). The most notable of these instruments is the Beach Center Family Quality of Life Scale which has spurred considerable empirical work around the world (Hoffman et al., 2006). The Beach Center Family Quality of Life Scale, which is drawn upon in this thesis, identifies family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support as key dimensions of family quality of life (Hoffman et al., 2006). At present, existing research from numerous countries

suggests that caring for a child with an intellectual disability substantially affects a family's quality of life, and that a family requires ongoing financial, medical and educational support in order for their material, emotional and social needs to be met (e.g. Samuel et al., 2012; Turnbull, Brown & Turnbull, 2004; Turnbull et al., 2011).

Despite the substantial amount of empirical research conducted in this field, almost no work has been conducted on family quality of life in the particular case of Saudi Arabian families of children with intellectual disability. First, it has not yet been well-established that existing family quality of life scales, such as the Beach Center Family Quality of Life Scale, are reliable and valid in a Saudi cultural environment. Concomitantly, there is little empirical knowledge of the extent to which family quality of life is affected by having a child with intellectual disability; and therefore, there is no solid informational foundation for government programs which can target the specific needs of such families. This is the motivating challenge of this thesis.

Thus, this thesis is concerned with achieving five cascading research aims. The first aim is to develop a valid family quality of life scale suitable to Saudi Arabian families, given the culturally specific nature of Saudi Arabian society. This involves a confirmatory factor analysis of an augmented version of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006), and the use of exploratory factor analysis for newly introduced measures. The second aim is to test the reliability of the measures of family quality of life, religiosity, and other religio-cultural factors relevant to caring for a child with intellectual disability. The third aim is to determine whether demographic factors, religiosity, and other religio-cultural factors related to caring for a child with intellectual disability impact on family quality of life for

Saudi Arabian families. The fourth aim is to determine whether caring for children with intellectual disability, compared to caring for children without intellectual disability, is associated with higher or lower family quality of life among Saudi Arabian families. The fifth and final aim is to explore the possible phenomenological reasons behind the observed quantitative data for family quality of life of Saudi Arabian families, and to gather personal perspectives on whether special assistance is needed for families of children with intellectual disability.

From an academic perspective, the current study is significant in terms of broadening the applicability of family quality of life for a new societal context. Given that there are significant cultural differences between Saudi Arabia and the Western cultures for which ‘standard’ measures of family quality of life have been developed, it cannot be assumed that these measures, such as the Beach Center Family Quality of Life Scale, can be uncritically applied to Saudi families. It is important to examine the validity of a ‘standard’ scale and, if deemed necessary, to adjust the instrument in order to ensure its reliability and validity. This is an important endeavour in itself, and will be of value to future researchers in the field. Thus, the current study has the potential to encourage further research into family quality of life within the Saudi Arabian context, and to make fruitful inter-cultural comparisons.

From an advocacy perspective, the current study is also important for the Saudi Arabian government. As noted above, the Kingdom of Saudi Arabia has made a number of legislative interventions in order to improve the lives of children with intellectual disability and their families. This is in accord with the government’s stated mission of protecting and promoting the socioeconomic wellbeing of all of its

citizens, in particular its most vulnerable citizens (Albatel, 2003; Aydin, 2014; Information Office of the Royal Embassy of Saudi Arabia, 2013a; Information Office of the Royal Embassy of Saudi Arabia, 2013b). However, since there is very little systematic empirical research on the quality of life of Saudi families, it is exceedingly difficult for the Ministries of Health and Education in Saudi Arabia to determine the best strategies to employ in order to efficiently and effectively support families of children with intellectual disability, so as to meaningfully improve their lives. This thesis aims to help close the knowledge-gap faced by the government in order to help improve the quality of life of families who have unique needs and vulnerabilities. By examining the quality of life of families with and without children with intellectual disability, and then analysing the reasons behind any significant differences found, the current study can assist government ministries in better targeting their resources to improving the quality of life of Saudi Arabian families, and thus serve the state's professed social welfare objectives.

1.2 Outline of Thesis Structure

This section provides synopses of the content of the nine chapters of the thesis.

Chapters 2 and 3 of this thesis review the literature on intellectual disability and family quality of life. In Chapter 2, the literature on intellectual disability in general, and for Saudi Arabia in particular, is reviewed. Chapter 3 reviews the development of 'family quality of life' as a construct and considers the applicability of an existing family quality of life questionnaire to the Saudi Arabian cultural context.

Chapter 4 formulates the motivation and the five aims and research questions of this thesis. The study then moves on to detail the methodology utilised in the current study to achieve the above stated research aims. As such, Chapter 5 details the steps taken to develop a conception of family quality of life appropriate to Saudi Arabian families, the empirical questionnaire used to generate data, and the methods used to analyse those data.

Chapter 6 presents the results from testing the validity and reliability of the Saudi Family Quality of Life questionnaire developed for the current study.

Chapter 7 tests the major empirical hypotheses of the current study. It reports on whether caring for a child with intellectual disability is associated with Saudi family quality of life, as well as identifying and exploring the factors which may impact on family quality of life in Saudi Arabia.

Chapter 8 reports on the perceptions and possible reasons behind the observed differences in family quality of life between various Saudi Arabian families, as gleaned from a thematic analysis of semi-structured, open ended interviews with eight volunteers who had also completed the questionnaire.

Finally, in Chapter 9, the results of the study are drawn together and discussed, along with an observation of the strengths and limitations of the current study, and recommendations for future research.

Chapter 2 : Intellectual Disability and Saudi Arabia

2.1 Introduction

This chapter reviews the literature on intellectual disability, and examines the construct of disability in general, and especially of intellectual disability in the context of Saudi Arabia. The chapter commences with an exploration of the definition and characteristics of intellectual disability based on the most recent publication from the American Psychiatric Association (2013). This is followed by an assessment and discussion of the causes and prevalence of intellectual disability as reported in different studies. The chapter then shifts its focus to the context of Saudi Arabia. The historical perception of Saudi Arabians towards people with disabilities is discussed and an analysis is conducted regarding the steps the government has taken in order to advocate for the rights of people with disabilities, particularly those with intellectual disability.

2.1.1 Systematic Review

The goal of the present systematic review is to examine the literature and identify the changing definitions of intellectual disability and its aetiology, the development of legislation in the field, the social construction of intellectual disability, and to identify the existing gaps in the literature in order to suggest areas for future research. Consequently, the literature review moves from the general to the specific by assessing the factors that are instrumental in determining the social construct of intellectual disability in Saudi Arabia. The review of the literature identifies the views on the historical development of social responses to intellectual

disability and the changing definitions of intellectual disability. The literature review also considers the cultural and religious norms and practices involved and how they influence social construction in Saudi Arabia. Discrepancies are identified and the possible causes for these discrepancies are explored.

2.1.1.1 Method

2.1.1.1.1 Searching for relevant publications

A comprehensive search strategy was used in order to identify the studies and reports related to intellectual disability. For this purpose, the following key words were used: ‘intellectual disability’ and ‘mental retardation’ were used synonymously; they were coupled with ‘children’ in most instances because minors were the focus of the study. These words were then coupled with each of the following words independently: ‘Saudi Arabia’, ‘definition’, ‘history’, ‘aetiology’, ‘social construction’, ‘stigma’, ‘prevalence’, and ‘legislation’. This search pattern was applied to the electronic databases of: Psychinfo, Medline, SocIndex, Cinahl and ERIC. These searches were limited to abstracts of peer reviewed material in the English language for the period 1970 to 2016, and were sorted by relevance. Experimentation with a relaxation of these search parameters resulted in findings exploding into the tens of thousands, which was deemed to be unmanageable. The reference lists of many relevant papers were also subsequently considered for finding the potentially relevant studies.

2.1.1.1.2 Selection of publications

The abstracts and title of the publications were reviewed in order to analyse whether each article fitted within the criteria of the study, or if it fell in the exclusion

criteria of the study. Google Scholar and library catalogues were used to search for books and further articles. All studies which were related to intellectual disability, its aetiology and prevalence, and intellectual disability as a social construct, were included. This was done in order to capture articles that provided a perspective on the history of approaches and attitudes towards intellectual disability.

Articles which were focused on preventive measures and the management of the disabilities were not included. A formal meta-analysis was not conducted because of the heterogeneity of identified articles and outcome measures used. Results have therefore been synthesized narratively.

2.1.1.1.3 Results

The initial search of the literature identified 871 potential studies. On the basis of a general inspection of the titles and abstracts of the studies, 474 papers were excluded, as these studies were more related to management, medication and prevention of the disability. Of the remaining 397 studies, 315 were subsequently excluded because on a detailed examination of their texts, they did not meet the inclusion criteria. For example, the abstracts of some articles mention prevalence of intellectual disability, but the article itself was about something different. The abstracts of some articles referred to the causes of intellectual disability, but the articles focused on the elderly (dementia, Parkinson's disease, etc.). The abstracts of some articles purported to discuss the social construction of intellectual disability, but focused on highly philosophical debates regarding social constructivism that did not relate to actual cases. Therefore, 82 full papers survived the selection process and were subjected to further review.

Of the 82 selected, 21 studies were conducted in Saudi Arabia and 9 were conducted in other Muslim countries. Fifty two of the included studies were based on people in non-Muslim countries. These studies included correlational studies, prevalence studies, longitudinal studies, comparative studies, reports, and meta-analyses. These studies were utilized in the literature review that follows.

2.2 Origins, Definition, and Diagnosis of Intellectual Disability

The term ‘intellectual disability’ is a relatively new construct and differs considerably from the terminology used in previous editions of the Diagnostic and Statistical Manual of Mental Disorders where this disorder was referred to as ‘mental retardation’ (Greenspan & Switzky, 2006). The use of the term ‘mental retardation’ was discontinued in 2013 (Harris, 2013). Intellectual disability is now seen as having both a clinical and a social perspective (Boat & Wu, 2015). For example, Wilmshurst (2012) has defined intellectual disability as a generalized neuro-developmental disorder that is evidenced by low intellectual capacity. The Intellectual Disability Rights Service (2016) defines intellectual disability in terms of the person’s intellectual quotient, and in terms of the support needs of the individual and the environment in which the individual lives. Similarly, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) characterises a person who has intellectual disability as one who possesses an intellectual quotient less than 70 and has deficits in at least two adaptive behaviours in relation to everyday, general living. This new definition of intellectual disability moves away from the formerly purely cognitive characterisation of an intellectual quotient, and considers the importance of examining a person’s

functioning in order to classify him or her as having an intellectual disability. This involves the assessment of an individual according to three dimensions.

Thus, apart from the measurement of one's intellectual quotient, assessment for intellectual disability necessitates an examination of the individual's personal functioning across three domains, which are the conceptual domain, the social domain, and the practical domain (American Psychiatric Association, 2013). The conceptual domain covers general mental abilities that are relevant to everyday functioning, such as language, mathematics, reasoning, and memory (American Psychiatric Association, 2013). The social domain covers the person's ability to function effectively in social situations, and includes their ability for empathy, social judgment, and interpersonal skills (American Psychiatric Association, 2013). Finally, the practical domain covers self-management and includes the person's ability to perform personal care activities such as bathing or feeding him/herself, as well as more complicated tasks such as holding a job or school responsibilities and engaging in recreational activities (American Psychiatric Association, 2013). This new definition is aligned with the World Health Organization's International Classification of Diseases (World Health Organisation, 2016) as well as the definition of other professional organizations such as the American Association on Intellectual and Developmental Disabilities (2013).

In order to be classified as having an intellectual disability, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) mandates the use of clinical assessments and standardized intelligence testing (American Psychiatric Association, 2013). The severity of the disability is gauged not by the intellectual quotient, but by the number of adaptive functioning impairments identified. A 'mild intellectual

disability' is diagnosed when the individual has only 1 to 2 deficits across at most two domains, while a 'moderate disability' is diagnosed when the individual has deficits across all domains (American Psychiatric Association, 2013). A 'severe intellectual disability' is determined when the individual has more than 2 deficits across all domains (American Psychiatric Association, 2013).

A person with a moderate intellectual disability can participate in a range of activities, is able to make their own choices as to what they can eat and drink, and can understand schedules, although they may need assistance in planning a schedule (Tracy, 2009). Individuals with a severe or profound intellectual disability can recognise familiar faces but have little or no speech and require lifelong support (Tracy, 2009). As such, a person who has an intellectual quotient lower than 70, but is capable of functioning across all three domains, is not considered to have an intellectual disability (American Psychiatric Association, 2013). This method of assessment de-emphasizes IQ tests as the defining element of intellectual disability. In addition to this, the emphasis on personal functioning in determining the severity of intellectual disability is considered to assist clinicians to develop customized management or treatment plans for individuals, focusing on the specific functioning of the individual rather than an intellectual quotient.

Intellectual disability must also be differentiated from acquired brain injury, mainly through consideration of the age of onset. By definition, intellectual disability is diagnosed for individuals aged 18 and below who have no history of brain trauma (Wilmshurst, 2012). A clear definition of what constitutes an intellectual disability has therefore been provided, which has been essential in the pursuit of the current study. The information gathered from the above sources defines critical parameters

for the study, particularly in terms of the age at which the family members who have an intellectual disability were identified, in order for the family to be included in the sample.

2.3 Aetiology and Prevalence of Intellectual Disability

There are many possible causes of intellectual disability (Daily, Ardinger & Holmes, 2000). First, genetics has been found to play an important role. A person diagnosed with an intellectual disability is more likely to have a family member who also has an intellectual disability than a person without an intellectual disability. For example, Siderius et al. (2000) identified the PHF8 gene as being commonly shared by people with intellectual disability. However, genetics is far from being the only cause. Daily et al. (2000) also identified problems during pregnancy and during labour as potential causes of intellectual disability. In addition, incidents that may occur in early childhood, such as exposure to toxins, were also often found to affect the development of the child and lead to the onset of intellectual disability (Daily et al., 2000). Finally, malnutrition and certain diseases, such as whooping cough, meningitis, and measles have also been linked to the development of intellectual disability (Daily et al., 2000). In the present study, no families were excluded from examination because of the aetiology, nature or severity of their child's intellectual disability. The cause of an intellectual disability is not deemed to be of interest in itself for the current study. It is relevant only insofar as it is associated with family quality of life.

It is critical to know how widespread the cases of intellectual disability are as part of gauging the relevance of the current study. In line with this, various studies

have examined the epidemiology of intellectual disability. According to Vos et al. (2015), who conducted an epidemiological study of 301 diseases and injuries (including intellectual disability) across 188 countries (including the Middle East and North Africa), intellectual disability occurs in less than 3% of the general population. Of those affected, about 80% are classified as having mild intellectual disability, while about 50% of cases were found to have genetic origins; several people in the family genealogy having been previously diagnosed with intellectual disability (Vos et al., 2015). Maulik et al. (2011) focused specifically on determining the prevalence rate of intellectual disability and determined it to be 1.04%, much lower than the estimate of Vos et al. (2015). The study of Maulik et al. (2011) relied on compiling results from previous studies through meta-analysis, whereas Vos et al. (2015) gathered primary data across multiple countries through various research collaborators in each country. Meta-analysis is considered to be a more accurate methodology than single empirical studies, so the findings of Maulik et al. (2011) are likely to be more accurate. This is evidenced by the estimate of Maulik et al. (2011) being closer to the estimate of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which was found to be 1.41% (American Psychiatric Association, 2013). As such, the prevalence rate determined by Maulik et al. (2011) may reflect reality more accurately.

Maulik et al. (2011) also found that the highest rates of intellectual disability were in low and middle-income countries. This may be due to deficiencies in accessible pre- and post-natal care (Daily et al., 2000). It was also found that the prevalence of intellectual disability was higher in studies concerning children and

adolescents than those concerning adults (Maulik et al., 2011). This may be because of the confounding of intellectual disability and brain injury.

Meanwhile Lapid (2009) reported that adults with lower Intelligence Quotients tend to have a shorter lifespan than those with average or above average Intelligence Quotients, and that the level of care provided by parents to their children affected the lifespan of the children as they grew to adulthood. This leads to the concern of the current study on the nature of the care that families provide for children who have intellectual disability, as the quality of care provided can impact on the individual's lifespan, which in turn can impact on a family's quality of life.

2.4 History of United States and international legislation regarding individuals with disabilities

Across history, there have been numerous changes in the way that societies perceive people with disabilities. These changes have affected the nature of legislation that has been passed in order to protect and support people with intellectual disability. Before the 20th century, people with intellectual disability were considered as defective individuals (Goodey, 2015; Mutua et al., 2011). During this time, the field of medicine was dominant in determining how people with intellectual disability were perceived (Mutua et al., 2011). The clinical focus tended to be on the weaknesses and limitations of the individual (Mutua et al., 2011). Dr. Benjamin Rush, one of the 'founding fathers' of the United States (US) and of American psychiatry, published the first modern medical explanation for mental disorders in 1805, but it was not until the 1900s that a classification of people based on their intellectual capacity was proposed (Mutua et al., 2011).

This lack of understanding about intellectual disability resulted in various misconceptions and stereotyping of people with all kinds of disabilities (Mutua et al., 2011). Historical records reveal that in Europe right up to the 20th century, people with disabilities were widely seen as individuals to be objects of pity, mockery and bigotry (Neuhaus et al., 2014). These attitudes were transported to colonies such as the Americas, so that extremely negative perceptions and treatment of all people with disabilities was common to most parts of the Western world (Neuhaus et al., 2014). For example, people with mental illnesses were locked away in asylums for the insane where they were sometimes chained to cell walls and endured experimentation. People with physical disabilities were often compelled to work as sideshow attractions in fairs and carnivals as ‘freaks of nature’ in order to survive. Meanwhile, people with intellectual disability – usually classified as ‘idiots’ or the ‘feble-minded’ – were commonly institutionalised in almshouses, workhouses and asylums to live out their lives away from family and the public view (Neuhaus et al., 2014). Thus the stigmatisation of intellectual disability (along with all other disabilities) was a social phenomenon that was ingrained in many Western cultures for a considerable period of time.

Coupled with the ill-treatment of the disabled by society generally, there was a lack of government support for the welfare of people with disabilities of all kinds (Neuhaus et al., 2014). Even when a modicum of government support was supposed to be offered, this was rarely honoured in practice. For example, in colonial America during the 18th century, laws were enacted by the British government to hold colonial governments responsible for the minimum welfare of people with disabilities, particularly those who were incapable of surviving on their own (Lawson et al.,

2008). Colonial governments resorted to various means to escape their stipulated responsibility to people with severe intellectual disability who lived in their territory. This involved, for example, moving them out of their territory at night and dropping them off in another colony (Lawson et al., 2008). By the late 19th century, matters were made worse as governments increasingly turned from relative neglect of those with disabilities to outright abuse. This was because of the rise of the eugenics movement in the United Kingdom (UK) and the US, which perceived people with intellectual disability to be inferior and defective and who, if allowed to procreate, would ‘weaken’ the species (Davis, 2006). By the 1890s, half the states in the US had nullified marriages between people deemed mentally ‘unfit’, and by the 1930s 28 states in the US had enacted sterilisation laws (Neuhaus et al., 2014).

Thus it is evident that the stigmatisation of and discrimination against those with disabilities, abetted by governments, persisted into the 20th century. That said, progress was slowly being made in changing attitudes. This is reflected in some legislative changes in the US. For example, in 1935 President Roosevelt signed the Social Security Act (US Congress, 1935), which secured the availability of financial assistance for adults with disabilities (Lawson et al., 2008). Interestingly, similar laws were enacted in a few other countries. For example, in 1944 the UK enacted the Disabled Persons (Employment) Act (HM Government, 1944) which required large employers to have at least 3% of their employees with a disability (Thornton & Lunt, 1995). In Japan, the passing of the School Education Law in 1947 mandated that the government provide special education for children with disabilities (Ministry of Education, Culture, Sports, Science & Technology, 2009). These laws show how governments in developed countries began to recognize their role in supporting

people with disabilities and combating the prejudice that is imposed upon them by society.

Despite this progress, the dominant practice in the mid-19th century regarding people with disabilities was still their separation and exclusion from mainstream society. Children who were blind were considered to be best served in schools for the blind. This exclusion of children with disabilities from mainstream schooling was extended to children with intellectual disability. It was not until a century later that the rights of children with disabilities to inclusive education were recognised, due in part to advocacy by grassroots organisations such as Inclusion International, which was established in the 1960s to fight for the human rights of people with intellectual disability (Inclusion International, 2016). Significant changes thus began to occur in the 1960s in the US. For example in the US, a court in Utah determined in 1969 that the exclusion of children from public education due to their intellectual disability was unconstitutional (Neuhaus & Smith, 2014). Three years later, the US Federal Court established the need for school districts to adapt to meet the needs of children with disabilities. The Education for All Handicapped Children Act (US Congress, 1975) that embodied this perspective was passed in the US in 1975 (Neuhaus & Smith, 2014). This began a revolution in the field of education in the US that focused on introducing diverse learning stimuli in order to appeal to diverse students, including those with intellectual disability.

The most significant sign of international changes in attitudes towards people with disabilities came when the United Nations declared 1981 to be the International Year of Disabled Persons. The declaration enjoined member countries to address issues concerning people with disabilities by enacting laws and establishing

organisations to recognise the rights of those with disabilities to fully participate in society (United Nations General Assembly, 1976). The declaration subsequently led to various new laws across different countries that sought to prevent discrimination against people with disabilities in employment, education, and access to public establishments. For example, in 1981, the UK passed their Education Act that included provisions for the inclusion of children with intellectual disability (HM Government, 1981).

In summary, slow progress has been made towards addressing the needs and recognising the rights of people with disabilities. Nonetheless, the perspectives that societies held towards people with disabilities have undergone a transformation: from people who are merely burdens on society and threats to the gene pool, to people who have needs, rights, and potential just like other people. There was a shift from exclusion to inclusion across different countries, supported by the enactment of laws and the establishment of organisations tasked with looking after the best interests of people with disabilities.

2.5 The Social Construction of Disability

In the previous section, it was established that perspectives about disability in different parts of the world have changed across history. It is also important to understand the social construction of disability. Freidson (1970) first published the idea that disability was socially constructed. According to this theory, disability is fundamentally a difference of a subpopulation from the norm, where the perception of people with disabilities is dependent on localised expectations and ideals (Freidson, 1970). For example, in the Middle Ages, disability was constructed as a

moral consequence: people who had disabilities were seen as being punished by some divine power for sins committed by that person or by their kin (Shakespeare, 2006). When disability was considered as a consequence of human fallibility, society saw no need to be responsible for those who had disabilities. People with disabilities were considered to be the responsibility of their relatives, since it was their relatives who were considered to be somehow implicated in the imagined sin. As the success of scientific endeavours grew and religious explanations lost their plausibility in the 19th and 20th centuries, there was a shift of social construction to a biomedical perspective, where disability was considered as a biological consequence of heredity or prenatal activity. When disability was constructed biomedically, scientists and policy-makers became interested in studying the causes of different disabilities in order to prevent them from occurring in the future (Hubbard, 2006; Kevles, 1985).

The social construction of disability affects various operative components of society, including technology, education, and public policy (Davis, 2006). In today's era where disability in many countries is seen as something that should be adapted to, technological devices are developed in order to help people with disabilities to function effectively in society despite their disabilities. In many cultures at present, there is the dominance of the idea of disability as something that should be accepted and even celebrated (Linton, 2006). One example of the presence of this idea is among people who are deaf. Rather than considering deafness medically as a loss of one's hearing, the social construction of many deaf communities views deafness as merely a difference in human experience (Lane, 2006). People who are deaf experience the world differently from people who are not, with there being no necessary difference in their ability to function effectively in society (Ladd, 2003).

Thus it can be seen that the social construction of disability provides an important theoretical component in examining how intellectual disability is treated in a particular geographical context such as Saudi Arabia.

In this regard, the way in which intellectual disability is socially constructed in Saudi Arabia has an important impact on how children with intellectual disability and by extension, their families, are perceived and then treated by others. It can affect the way children and their family members are treated in civil society spaces by public officials, religious advisors, teachers, other parents, and even by distant relatives. How families and family members are treated by others on a regular basis – whether they are celebrated, accepted, ignored, or discriminated against – can have a significant impact on the quality of life of a family. For example, if a child with an intellectual disability is continuously shunned by people in public out of fear, the child's family is less likely to be able to freely engage in normal, happy social interactions with others, and thus is less likely to experience as high a quality of life as mainstream families. Thus, understanding how family quality of life is associated with having a child with an intellectual disability should help in understanding the social constructions that are evident in Saudi Arabian society.

2.6 Disability and Intellectual Disability in Saudi Arabia

2.6.1 Prevalence of Disabilities and Intellectual Disability in Saudi Arabia

There is a lack of data on the prevalence of disabilities in Saudi Arabia. As Al-Jadid (2013) has reported, there is no central government body in Saudi Arabia which collects data on the prevalence of intellectual disability on a regular basis. Also, there have been very few independent studies conducted on the disability

patterns in the country, and there is no uniform set of definitions or methods to be used when seeking to establish the prevalence of intellectual disability in Saudi Arabia (Al-Jadid, 2013). As a result, a range of prevalence rates of unknown veracity have been reported. A 2014 report by the Economic and Social Commission of Western Asia and the League of Arab States (2014) collected officially available data from countries in the Arab region. Fifteen of these countries reported disability prevalences of less than 3% (see Figure 2.1). The reported percentage for Saudi Arabia was a mere 0.8%, based on 2004 data collected by the Kingdom of Saudi Arabia Central Department of Statistics and Information (see Figure 2.1).

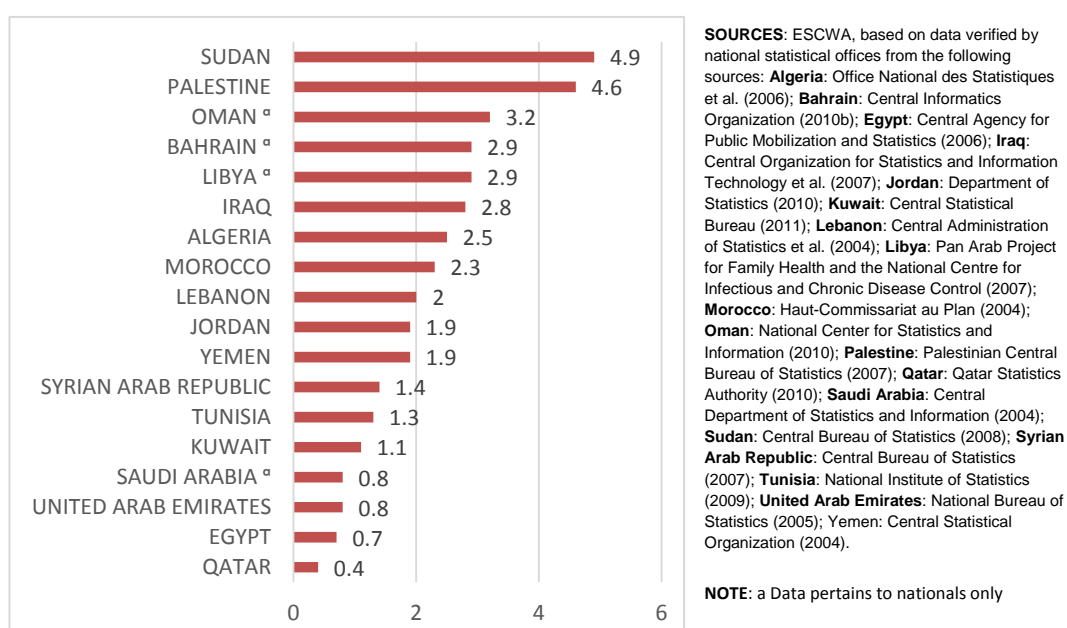


Figure 2.1: Prevalence of disability in countries in the Arab region (% of total population). (Source: Economic and Social Commission of Western Asia and the League of Arab States, 2014)

The report points out that such percentages are remarkably low when compared to global averages; for example, the World Bank (2005) estimated that approximately 15% of the world’s population lives with a disability. The report casts further suspicion on the accuracy of the low prevalence rates by commenting that:

disability prevalence in Arab countries is remarkably low given the widespread occurrence of risk factors and disability causes in the region, including consanguinity, communicable and chronic diseases, road traffic accidents and armed conflict. Thus, existing disability prevalence rates in Arab countries must be taken with a grain of salt. (Economic & Social Commission of Western Asia & the League of Arab States, 2014, p.9).

Al Thani (2007), who investigated the situation of women with disabilities in the Middle East was similarly suspicious:

It is perhaps telling that there is a direct and positive correlation between the level of development of a country and the reported percentages of disability. While Europeans place the percentage of persons with disabilities in their countries in the double digits, the Arab countries invariably report that figure at under 5%. Considering all the factors that cause disability in the region.... such percentages are certainly unrealistic and do not reflect the true situation (Al Thani, 2007, p.6).

It is not entirely clear why the officially reported prevalence rates are sometimes so low for Saudi Arabia, but a number of explanations have been offered. One is that the official survey of disability is incorporated into a more general census survey and thus does not provide sufficient scope to accurately detail the levels of disability actually experienced (Economic & Social Commission of Western Asia & the League of Arab States, 2014). Another explanation is that because Saudi Arabia is a highly patriarchal society, women with disabilities tend to be highly marginalised to the extent that they become 'invisible' to the data collection agencies (Al Thani,

2007). Yet another explanation is that there is an under-reporting of the prevalence of disabilities in Saudi Arabia because of the social stigma associated with disabilities (Ciftci, Jones & Corrigan, 2012).

The most recent survey of the incidence of disabilities in Saudi Arabia was commissioned by the Saudi Arabian Ministry of Health in 2007 in conjunction with the World Health Organisation. This was the first national attempt to systematically measure the prevalence of disability in Saudi Arabia (Almubarak, 2008). Participants were asked to rate themselves with respect to mobility, self-care, pain and discomfort, cognition, interpersonal activities, vision, sleep and energy, and affect. The prevalence rates of ‘extreme’ and ‘severe’ disabilities, as subjectively self-assessed by participants, are presented in Figure 2.2.

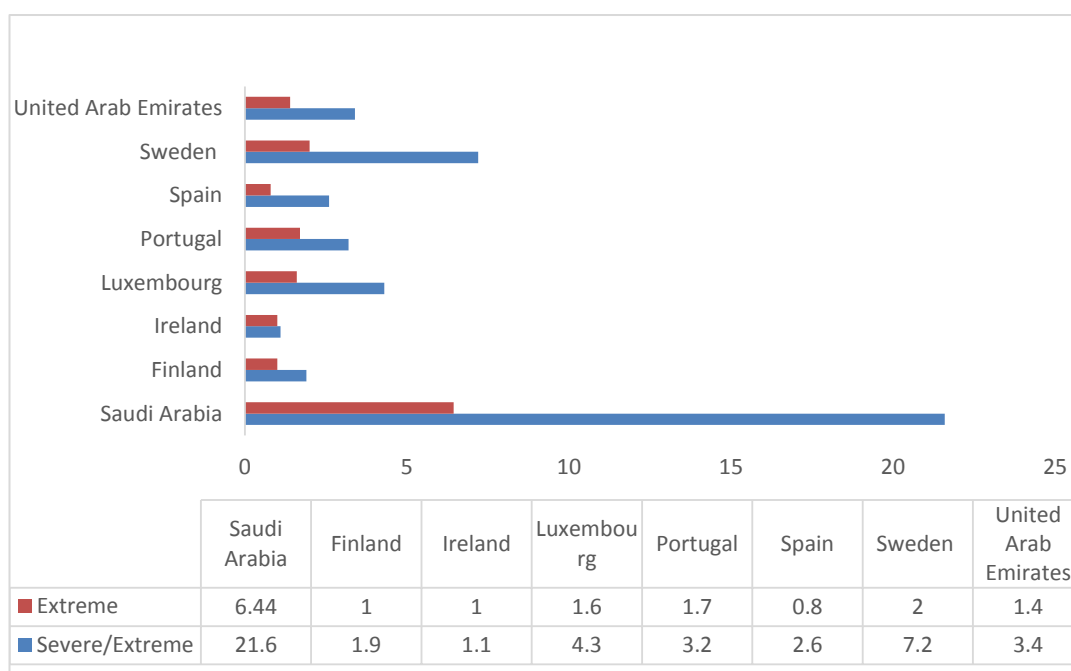


Figure 2.2: Prevalence of severe and extreme disability in Saudi Arabia compared to other countries. (Source: Almubarak, 2008).

Figure 2.2 indicates that the percentage of people in Saudi Arabia with severe and extreme disabilities may be as high as 21.6% of all disabilities. This is considerably higher than the rate for other comparative countries, but is more in line with the World Bank's (2005) world estimate (which includes all the OECD countries) of 15% of all disabilities. The research of the World Health Organisation study reported by Almubarak (2008) also identified that the patterns of disability differ between men and women as shown in Table 2.1.

Table 2-1 :Prevalence of severe/extreme disability amongst men and women in Saudi Arabia

	Men (n=2852; Weighted n=6,810,881.8) or % (SE)	Women (n=2947; Weighted n=7,086,101.6) % (SE)
Severe Disability	16.21(0.86)	26.78 (1.07)
Extreme Disability	5.08(0.49)	7.76 (0.58)

(Source: Almubarak, 2008).

From Table 2.1 it can be seen that the prevalence of severe disabilities is higher amongst women than men in Saudi Arabia ('severe' indicates incapacity with respect to mobility, communication, self-care, self-direction, interpersonal skills; 'extreme' indicates multiple severe disabilities). The study, which included age related disabilities, also revealed that women aged between 50 to 69 years old have twice the prevalence of extreme disability of men (Almubarak, 2008). Given the results of the current study, one must indeed be sceptical of claims that the prevalence rate in Saudi Arabia (and other Middle Eastern countries) is considerably lower than that in the US (Boyle et al., 2011) and in Australia (Australian Institute of Health & Welfare, 2008).

There have been no other studies within the past five years on the prevalence rate of disabilities in Saudi Arabia. As discussed by Elsheikh and Alqurashi (2013), there is a lack of political will to map the prevalence of different disabilities. Given the results of the 2007 World Health Organisation study (Almubarak, 2008), the statistics from Al-Jadid (2013) need to be viewed with caution. The problem of accurately identifying the prevalence of disabilities is not specific to Saudi Arabia. Other countries, such as the US and Australia, are also faced with challenges concerning the accuracy of prevalence rates of disabilities from their census data (Australian Institute of Health & Welfare. 2008; Boyle et al., 2011).

For intellectual disability specifically, if one uses the officially collected data from the Kingdom of Saudi Arabia Central Department of Statistics and Information, as reported by the Economic and Social Commission of Western Asia and the League of Arab States (2014), the prevalence of intellectual disability is 19.8% of all people with disability, which works out to be 0.15% of the population. When that figure is broken down by age, only 0.08% of children aged 0-14 years would be living with an intellectual disability. Again, this is considerably lower than that reported by the few studies which have independently measured intellectual disability prevalence among Saudi Arabian children. Alsekait (1993) reported that in Qaseem, the incidence of intellectual disability among children was 1.4%. The current study was for a limited geographical area. A more recent and broader study by El-Hazmi et al. (2003) examined a nationwide survey that was conducted between 1996 and 1999, which found that intellectual disability (still labelled as mental retardation at the time of that study) affected about 0.89% of children aged 0 to 18 years. Again, the work of El-Hazmi et al. (2003) was conducted over a decade ago

and may not provide an accurate depiction of the current prevalence rates. A report by the General Directorate for Educational Research in the Saudi Arabian Ministry of Education (2000) found that 0.9% of all Saudi children (under 15 years of age) had been diagnosed with an intellectual disability. Of these, the report stated that 29% had a 'simple mental disability', 35% had a 'mild mental disability', and 36% had a 'severe mental disability'. These terms were said to be based on IQ scores, but the ranges were not identified in the report, nor were the terms defined; also the methodology used was not specified. Suffice to say that there is still little broad-based standardised research on the prevalence of intellectual disability in Saudi Arabia, let alone for children with intellectual disability.

2.6.2 Stigma towards Disabilities in Saudi Arabia

According to Abu-ras, Gheith and Cournos (2008) Muslims tend to view intellectual disability as being a hardship or punishment imposed on an individual and their family by God. In contrast, Rassool (2000) claims that it is more commonly held by the wider Muslim society that intellectual disability are seen as being an illness. Rather than seek assistance from medical practitioners, cultural factors influence individuals to seek advice from members of the extended family and from religious leaders (Aloud & Rathur, 2009). The strong belief in destiny in Muslim culture results in a fatalistic attitude towards intellectual disability (Nabolsi & Carson, 2011). Social stigma towards people with intellectual disability is therefore very strong. Families with individuals with intellectual disability often feel ashamed (Aloud & Rathur, 2009). Because of the stereotypical perceptions held about intellectual disability, it is sometimes difficult for parents of children with

intellectual disability to believe that their children could themselves get married and start a family. In most cases, such views arise from a limited understanding that parenting is not entirely dependent on an individual parent since other parents, relatives from the extended family, community members, teachers, institutions, and other public personnel can make an important contribution to child rearing (Llewellyn et al., 2003). This social stigma, and the cultural characteristic of Saudi Arabian society as having high uncertainty avoidance and a low sense of the importance of individuality, may lead family members interviewed in the census to be less likely to give negative information about the family, such as having a member with a disability.

2.6.3 Cultural Perceptions about Disabilities and Intellectual Disability in Saudi Arabia

Despite the caution that needs to be exercised towards relying on the statistical findings of the prevalence of intellectual disability, the study by Al-Jadid (2013) is a significant milestone in the research on intellectual disability in Saudi Arabia. Al-Jadid (2013) conducted a study on the social construct of disability in Saudi Arabia and the implications of this for disability research in general. Al-Jadid (2013) was able to make a number of inferences that were critical to the development of the present study. He argued that the cultural traditions of extended family has resulted in families relying on relatives and hired household help (rather than, for example, ‘external’ support from the state or medical practitioners) in caring for family members with disabilities. Further, some families feel there is stigmatisation and embarrassment associated with caring for a disabled child. A concomitant side-

effect for research is, according to Al-Jadid (2013), that people are often reluctant to talk about the disability of family members, and thus tend to either decline from participating in research or supply inaccurate data (understating the nature of disabilities).

Parallels to the situation in Saudi Arabia can be drawn from many other studies on disability in other countries in the Middle East (Alkhateeb et al., 2016; Eapen et al., 2006; Miller et al., 2016). As explained by Alkhateeb et al. (2016) there are strong persisting negative cultural beliefs in Middle Eastern countries in general about having a child with a disability. Al-Dawood and Albar (1994) found that parents typically felt guilty about having children with intellectual disability, and were ashamed about sharing their situation with others. In a study that involved Muslim students of medicine, El-Gilany et al. (2010) found that there persisted a perception held by students that patients who have developed both mental and intellectual disability were being punished for religious transgressions, and that children with intellectual disability were born to parents who have likewise committed religious transgressions. El-Islam (2008) and Al-Adawi et al. (2002) further assert that for some Muslims, intellectual disability and mental illness are often conceived of as being evidence of malevolent spirits inhabiting the person, which then leads to the stigmatisation and avoidance of such persons and their families for fear of being similarly afflicted.

Whilst there is no debate in the literature about the prevalence of stigmatisation of adults and children who possess intellectual disability, there is significant disagreement about the extent to which this stigmatisation can be attributed to the religion of Islam. Some researchers claim that Islamic beliefs are

directly responsible for stigmatisation because there are Islamic teachings that treat children with disability as in some way defective, or as being punished for future sins, or as being instruments of punishment for their parents (Abu-ras, Gheith & Cournos, 2008; Aloud & Rathur, 2009; Nabolsi & Carson, 2011). This view is bolstered by the fact that Islam is the pervasive state ideology in Saudi Arabia (Al-Rasheed, 2010). On the other hand, other researchers assert that this claim lacks nuance (Al-Jadid, 2013; Al-Aoufi et al., 2012; Ansari, 2007; Bazna & Hatab, 2005). They argue that if one examines the teachings and *fatawa* (religious rulings) of the scholarly class who professionally study the religion, one finds that the religion prohibits discrimination against people with disabilities, and by extension, people with intellectual disability; that it grants the same rights to people with disabilities as those without; and that it imposes obligations on the community to assist people with intellectual disability in living their lives in accordance with their rights. In short, the normative teachings of the religion *oppose* stigmatisation, rather than reinforce it. They explain stigmatisation as being due to deeply rooted, Arab cultural perceptions about disability that pre-date Islam, but which have been woven into ‘folk’ understandings of the religion, thereby making them resilient enough to remain among even educated members of the population to the present day.

While it is not possible to resolve the theological question of the status of children with intellectual disability in Islam, one can seek to determine the role that stigmatisation plays in affecting families of children with intellectual disability. One may ask to what extent a family’s quality of life is affected by stigmatisation, including whether the families themselves internalise such stigmatisation as being justified.

2.6.4 Legislation and Support Services for Disabilities and Intellectual

Disability in Saudi Arabia

Legislation on disabilities passed in Saudi Arabia refers to disabilities in general terms; it does not make special or specific provisions for intellectual disability (AlBuhairan et al., 2015; Al-Khateeb & Al-Khateeb, 2014; Elsheikh & Alqurashi, 2013). The earliest law passed was identified as the Legislation of Disability of 1987 that made provisions for the rights of persons with disabilities being equal to those of persons without disabilities (Alquraini, 2011). The Legislation was mainly to prevent discrimination against persons with disabilities in matters of education and work, which is consistent with Islamic grounding discussed by Al-Jadid (2013). As dictated in Islamic law, people with disabilities have the right to live with dignity and the benefit of welfare (Al-Aoufi et al., 2012). However, the Legislation of 1987 did not include provisions for government support for people with disabilities. This came only in 2000 with the introduction of the Disability Code (Prince Salman Center for Disability Research, 2004), which pledged free medical, social, and educational services for people with disabilities (AlBuhairan et al., 2015; Al-Jadid, 2013; Al-Khateeb & Al-Khateeb, 2014).

In 2001, the government passed the Regulations of Special Education Programs and Institutes (RSEPI), which led to the establishment of several special education institutions in the country (Alquraini, 2011). However, Alquraini (2011) argued that despite the decade-long existence of these regulations, their implementation has not been progressing in the country. On the contrary, there persists a gap between the mandate of the RSPEI and the actual accessibility and quality of educational services that are made available for people with intellectual

disability. Support services for people with intellectual disability in Saudi Arabia have also been found to be more accessible to people in the urban areas than in the rural areas (El-Gilany et al., 2010). According to Al-Jadid (2013), many persons with disabilities in Saudi Arabia are marginalized because of the lack of information about the support services that they can avail themselves of. Despite this, the Saudi Arabian government provides considerable healthcare funding for the support of people with disabilities in the country (Al-Jadid, 2013; El-Gilany et al., 2010).

At the same time, it was found that the lack of research into specific areas of disability in the country severely limited the ability of government agencies to accurately respond to the needs of people with disabilities, as well as the needs of the families of those people in relation to caring for them (Al-Jadid, 2013). As such, this further establishes the need to examine the current impact on the quality of life of Saudi Arabian families of having children with an intellectual disability. If, as found in the studies of Al-Jadid (2013) and El-Gilany et al. (2010), there are not sufficient healthcare and educational provisions for children with intellectual disability in the country, then the hypothesis that the families taking care of these children are under higher levels of stress than families who do not have children with intellectual disability may be supported. In relation to this, the outcomes from studies on the actual impact measured quantitatively through validated questionnaires can lead to realizations on the need to further drive sufficient support services for these families.

2.6.5 Educational Policy and Practice for Students with Disabilities in Saudi Arabia

Saudi Arabia was the first Arab country to trial the mainstreaming of students with disabilities. In 1984, mainstreaming was trialled and then implemented on a small scale in schools in 1990 (Al-Mousa, 2010). As noted above, the government passed the Provision Code for Persons with Disabilities (Prince Salman Center for Disability Research, 2004) that gave people with disabilities the right to free public education (Al-Mousa, 2010). In 2001, the government passed the Rules and Regulations of Special Education Programs that gave students with disabilities the right to special education (Aldabas, 2015). In 2009, Saudi Arabia became a signatory to the Convention on the Rights of Persons with Disabilities that requires the government under Article 24 to provide an inclusive education system (Al-Mousa, 2010). Two delivery approaches were implemented. One was partial mainstreaming, that involved establishing self-contained classes within the public school setting with students integrated into some curricula and non-curricula activities (Al-Mousa, 2010). The other approach is full mainstreaming, that provides full support programs in schools for students with disabilities placed in the mainstream classroom (Al-Mousa, 2010). Students with mild and moderate intellectual disability are integrated into the general education classroom while those students with severe or profound disabilities are located in special day schools (Aldabas, 2015).

The major driving force for the increase in the inclusion of people with disabilities in the mainstream schools has been the passage of legislation. Universally, the passage of legislation by governments is the primary driver for educational change and increased inclusion of children with disabilities in

mainstream schooling (Cushing, Clark, Carter & Kennedy, 2005). Although laws ensure that students with disabilities have a right to an education, there exists only a policy framework requiring parents to bring it to the attention of the school if their child exhibits signs of having a disability (Proctor & Niemeier, 2001). This often means that students with disabilities are not provided with the services and support that they need at an early age in order to promote their development (Proctor & Niemeier, 2001). Greater efforts are needed to ensure that there is parental involvement, a greater use of assistive technologies and the integration of health services with educational services (Cushing et al., 2005). Greater teacher awareness and training is also needed as there is still resistance from many teachers to have students with disabilities in their classes (Al-Ahmadi, 2009).

2.7 Saudi Arabian Culture: Hofstede's Analysis

One of the important aspects of the local setting that should be considered in the current study is Saudi Arabian culture. The culture of a country dictates how people live their lives in that country (Hofstede, 2011). In the context of the current study, culture is hypothesized to be a critical factor to consider when investigating how families perceive intellectual disability among their children, and the nature of the quality of life that is experienced by the child and his or her family. In line with this, the work of Hofstede (2011) has focused on characterizing the cultures of different countries in the world. According to Hofstede (2011), while culture is a highly complex concept, it can be understood based on a set number of dimensions. Hofstede (2011) identified these dimensions as power distance, individuality, masculinity, uncertainty avoidance, and long-term orientation. The Hofstede Center for Culture, Strategy, and Change has put considerable effort into the profiling of

individual countries according to these dimensions, yielding a compilation of such information. This information is available on the website of the Hofstede Center for Culture, Strategy, and Change (2015). The website enables an analysis to be provided of the culture of a specific country.

The Hofstede Center (2015) provides scores for each of Hofstede’s cultural dimensions on a 100-point scale. The score reflects the relative ranking of Saudi Arabia in relation to other countries. The cultural dimensions of Saudi Arabia are presented in Figure 2.3 below.

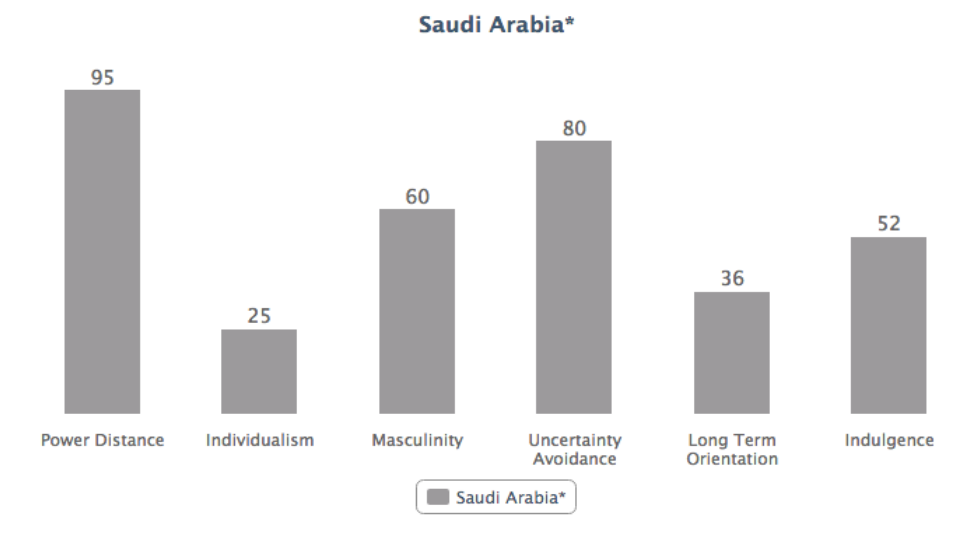


Figure 2.3 :Hofstede’s cultural profile of Saudi Arabia. (Source: Hofstede, 2015).

A score of 95 implies that the country is among the highest 5% of countries in that dimension. Saudi Arabia reported a very high power-distance score of 95 out of 100 (Figure 2.3). Power-distance is the cultural dimension that deals with the individual attitude towards authority and the presence of social inequality. It is the extent to which people who have a lower level of power in a society accept the idea that power is not distributed equally. As such, Saudi Arabia’s score of 95 implies that

the people in this country are very accepting of the existence of a hierarchical order of society in which people who are at the bottom of the order must respect and follow those at the higher levels.

This is consistent with the findings in such studies conducted by Havril (2015) and Yavas (1994), which established that women in the country accept the authority of males in their families, particularly that of their husbands. Yavas (1994) found clear gender roles between males and females in Saudi Arabian households, with females being expected to stay home and care for children while males go out to work. At the same time, the authority of females in making household decisions is limited, with males in the household still making decisions in relation to making large, important purchases. More recently, as found by Havril (2015), while females in the country have begun to become more progressive in terms of aspiring to higher education, they nonetheless retain the culture-grounded perspective of males as the 'natural' leaders of a society. Thus, it is expected that males are more likely to participate in social activities, including participation in social research, than females. Therefore, studies that require making contact with families in Saudi Arabia must account for this cultural characteristic. Studies may account for this by ensuring that the gender of participants is included in data collection, so that appropriate statistical procedures such as analysis of covariance may be used in considering the extent of the impact of gender on data for other variables of interest that are collected in the study.

It has also been suggested by some researchers (e.g. Aloud & Rathur, 2009; Alquraini, 2011) that Saudi Arabians are likely to discriminate against people with disabilities of all kinds due to a 'folk' understanding of the Islamic tenet of *qadar*,

which is ‘the belief in preordination (fate or destiny), which supports the idea that what is meant to be, will be, and what is not meant to happen, can never occur’ (Hasnain et al., 2008). Thus, without knowledge of Islamic stipulations about the rights of and responsibilities towards people with disabilities (Al-Aoufi et al., 2012), it is arguable that less educated people would treat disadvantages such as intellectual disability as being part of a natural and justified hierarchy. This ideological framework tends to facilitate the acceptance of a hierarchy of inequality of opportunity and outcomes in terms of physical and mental disabilities.

The individualism dimension of Hofstede (2011) refers to the level of interdependence of people in the society with other members. Countries that have high levels of individualism typically have people who are independent; they tend to leave their parents upon adulthood and start a new life on their own (Hofstede, 2011). On the other hand, a low score for a society indicates a strong belief in the need to stay together as a family and help one another. Saudi Arabia was found to have a low score of 25 in individualism (Figure 2.3), meaning that its level of individualism is lower than that of 75% of all other countries in the world. This indicates that the Saudi Arabian society has a collectivist nature. People tend to live with extended families and relationships, and loyalty towards one’s family is highly valued (Al-Jadid, 2013). As such, it is unlikely that individuals within a family would talk negatively about the family or about other members of the family. This is especially true when considering the high power-distance dimension of Saudi Arabian culture, and further solidifies the expectation that male members of the household, acting as heads of their respective households, are more likely to be called upon by other members to participate in social research studies concerning the

family. Families with a child with an intellectual disability are likely to be expected to provide long-term care and support for the child. Another implication of this dimension is that in the event of family breakdown (divorce), family quality of life may be expected to suffer considerably because of the social undesirability of divorce (Shehan, 2013) and the subsequent fracturing of the collectivist nature of the family support structure. It should be noted, however, that at present there is no research on the impact of marital status on family quality of life for families of children with intellectual disability.

The masculinity dimension refers to the extent to which a society is characterized by masculine values over feminine values. According to Hofstede (2010), the masculine values are competition, achievement, and material success, while feminine values are co-operation, care, and nurturing. In this dimension, Saudi Arabia scored 60 (Figure 2.3), which is a moderately high score. This means that the country has both masculine and feminine values, but is more inclined towards the former. The dominance of the masculine perspective may mean that the focus is less on care and nurturing of the child with a disability, and more on seeing that the individual is provided with the opportunity for self-development and achievement. This dimension may have some impact on the way in which family members conceive of family quality of life, such as the degree to which they emphasise emotional wellbeing versus material wellbeing. To date, there is no research on Saudi Arabian families which investigates this dimension.

The next dimension is uncertainty avoidance, in which Saudi Arabia was found to have a high score of 80 (Figure 2.3). According to Hofstede (2011), this dimension deals with the extent to which people in the society consider the

uncertainty of their future and take steps to control it, such as by planning their finances, or working hard in order to establish security in their job. With a high score, this implies that people in Saudi Arabia dislike uncertainties in their life. There is a strong grounding in proven values and practices, and a conservative approach towards interaction with external entities and individuals. This has some implications regarding challenges that a family may encounter, such as having a child with an intellectual disability. Given the high uncertainty avoidance of Saudi Arabian culture, it is likely that the family would seek sufficient support in order to know exactly how to deal with having a child with an intellectual disability. A lack of support may thus translate into negatively affecting the quality of life experienced by the family.

The dimension of long-term orientation refers to the extent to which a society maintains its links to its past while being responsive to the challenges of the present. Those that have a low score in this dimension, such as Saudi Arabia which only scored 36 (Figure 2.3) prefer to maintain their cultural traditions over embracing new ideals and innovations. This may make it difficult to introduce institutional changes in order to improve the care and support available for people with intellectual disability. This cultural characteristic is grounded in the country's strong religiosity. Islam is considered an essential pillar of society on which not just traditions and cultural practices, but everyday life is based (Hammoudeh, 2012). In relation to the current study, this cultural characteristic suggests that Saudi Arabians may refer to religious beliefs in approaching the situation of having a child with intellectual disability in their family. As noted already, it will be necessary in the current study to

understand the religious belief systems that underpin the attitudes that are held towards people with intellectual disability.

From Figure 2.3 it can be seen that Saudi Arabian society is a male orientated society that is very conservative, with a strong dependence on religious values. The influence of the family and the tribal nature of society is very strong. Change is difficult to engineer due to the high level of risk aversion. The hierarchical nature of society is reflected in a strong hierarchical structure in the family, that places males in the family as the key decision makers and women as the carers and nurturers. Unfortunately, very little and sporadic research has been conducted concerning how these cultural dimensions play into the conception of, and the effect of, having children with intellectual disability. Without further research, the impact of these cultural dimensions on family quality of life for families caring for children with disabilities will remain the subject of anecdotal and intuitive speculation only.

2.8 Conclusion

This chapter has reviewed literature relating to the historical emergence of a definition of intellectual disability; the aetiology and prevalence of intellectual disability; international legislation; and the notion of the social construction of disability. It has also surveyed the literature relating to the prevalence of intellectual disability in Saudi Arabia; the social construction of disability in Saudi Arabia and the associated problem of stigmatization; Saudi Arabian legislation intended to protect and support people with disability; and educational policy for students with disabilities in Saudi Arabia.

Most important to the current study is the finding that relatively little empirical work has been conducted on intellectual disability of children in Saudi Arabia. A number of key areas are especially relevant to the current study. First, there is almost no accurate and reliable up-to-date data on the prevalence and types of disabilities in Saudi Arabia, let alone for children with intellectual disability. It is beyond the scope and resources of the present study to fill this knowledge-gap, but it can at least be inferred that the prevalence rate is likely to be greater than the officially reported rate of 0.08% of the population (Economic & Social Commission of Western Asia & the League of Arab States, 2014). The current study can, however, indirectly address one of the potential causes of the low reported prevalence rates – namely, social stigmatization of intellectual disability.

Although it is agreed that stigmatization exists, there is virtually no empirical research for Saudi Arabia on the extent to which it impacts on the lives of families of children with intellectual disability. The extent to which families experience stigmatization, whether they have internalized that stigmatization themselves, and the extent (if any) to which this affects their quality of life, is unknown. This is an important gap in our knowledge, and is worthy of further exploration given that such stigmatization is said to be pervasive in Saudi Arabia (Aloud & Rathur, 2009).

Another area in which little empirical research has been conducted relates to the impact of cultural factors vis-à-vis intellectual disability. Hofstede's (1984; 1993; 2011; 2015) work on the impact of cultural differences between peoples is widely recognized, but it has not been investigated as to whether the various cultural dimensions of Saudi Arabia, such as the acceptance of hierarchy, masculinity (material outcome focus), collectivism (extended family solidity), or attachment to

tradition, have any impact on the ways in which families deal with caring for children with intellectual disability. Such cultural factors may have a significant impact (positive or negative) on the quality of life experienced by families of children with intellectual disability, but empirical investigation, rather than just intuitive inference, is required in order to determine this.

Finally, although social and educational support services have been legislated to help children with intellectual disability in Saudi Arabia, as Al-Jadid (2013) and El-Gilany et al. (2010) have found, in practice, to-date they have not been well-targeted. The unanswered empirical question is whether the families taking care of these children are thus under higher levels of stress despite the existence of such services. The current study can thus contribute to filling this knowledge-gap too, which may contribute to the drive for better targeted support services for these families.

Chapter 3 : Family Quality of Life and the Factors

Associated With It

3.1 Introduction

This chapter details the development of family quality of life as a construct and considers the applicability of an existing family quality of life questionnaire to the context of Saudi Arabia.

The chapter first examines the concept “family quality of life” in general. It recounts the historical emergence of the concept, and then puts forward a specific definition of the term based on the current literature. It then reviews the literature on the impact that disabilities have on family quality of life. Second, the chapter goes on to examine the process of developing a questionnaire for measuring family quality of life. It is argued that the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) developed by the Beach Center of Kansas University, is the most appropriate questionnaire for the current study. To date this Scale is the most widely used one in current research on family quality of life across different contexts (Van Beurden, 2011). The chapter then examines the extent to which the Beach Center Family Quality of Life Scale, which was initially developed for a Western population, can be used in Saudi Arabia. In relation to this, it is argued that additional variables not included in the original questionnaire are likely to be important in the context of Saudi Arabian culture. Certain cultural perceptions about intellectual disability are identified, examined, and considered for inclusion in the current study. Finally, the chapter turns to the literature on various mediating factors that may impact on family quality of life – specifically, demographic factors and some family-specific factors

for families of children with intellectual disability – that have been identified as worthy of incorporation into the empirical component of the thesis.

3.1.1 Systematic Review

The primary goal of the systematic review is to examine the literature related to family quality of life and associated factors, in order to explore how family quality of life is related to the presence of an individual with an intellectual disability in the family. The systematic review also seeks to critique the validity and reliability of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) which, as noted in Chapter 1, is the most common measure used in research on family quality of life.

3.1.1.1 Method

3.1.1.1.1 Searching

In the current study a comprehensive search strategy was used in order to identify the studies and reports related to family quality of life and associated. The search procedure and databases used were essentially the same as for the literature search in Chapter 2. The following words were searched for independently: ‘family quality of life’ and ‘Beach Center’. Because ‘family quality of life’ narrowed the search results considerably, the broader term ‘quality of life’ was then coupled with either ‘Islam’ (and its synonym, ‘Muslims’) or with ‘religion’ if the former yielded no results. Finally, ‘quality of life’ was coupled with ‘intellectual disability’ (and the synonymously used ‘mental retardation’), and then combined with each of the following independent terms: ‘stigma’, ‘support services’ and ‘severity’. As before, the databases searched were: Psychinfo, Medline, SocIndex, Cinahl, and ERIC. These searches were limited to abstracts of peer reviewed material in the English

language for the period 1970 to 2016 and were sorted by relevance. The reference lists of many papers subsequently found to be relevant were also considered for their potential as relevant studies.

3.1.1.1.2 Selection of relevant studies

The abstracts and titles were reviewed in order to analyse whether each article found matched the inclusion criteria or fell outside it. All studies related to the family quality of life and having a family member with disability were included. This was done in order to capture articles that provided a perspective on the factors associated with the quality of family life due to the intellectual disability in the family. Articles concerning other acute diseases, and their impacts on the quality of life of families, were excluded from the study. A formal meta-analysis was not conducted because of the heterogeneity of identified articles. Results have, therefore, been synthesized narratively.

3.1.1.1.3 Results

An initial search of the literature identified 980 potential studies. On the basis of a general inspection of the titles and abstracts, 598 were excluded because they did not match the inclusion criteria, and the remaining 382 papers were retained for closer inspection. Of these, 265 were eventually ruled out because on closer inspection they did not match the inclusion criteria – they mostly related to management and counselling. Thus, 117 full papers were finally deemed relevant for the further review, of which 14 focused on Saudi Arabia. These studies included correlational studies, prevalence studies, clinical reports, and meta-analyses. These remaining studies were utilized in the literature review that follows. In broad terms, these studies were categorized and used to: (1) review the construct of family quality

of life in general terms and its relation to disabilities; (2) examine the Beach Center Family Quality of Life Scale; and (3) explore the factors that might be involved in customising the Beach Center Family Quality of Life Scale for the Saudi Arabian context.

3.2 Quality of Life and Family Quality of Life

3.2.1 The Emergence and History of Quality of Life and Family Quality of Life

The concept of quality of life has been an important part of philosophical reflection since the time of Aristotle (Rosser, 1993; Smith, 2000). In the 1930s researchers sought to empirically measure and define quality of life (Massam, 2002). This proved to be difficult because of its inherently subjective nature (Massam, 2002). Nonetheless, the term became increasingly prevalent in the fields of health and economics (Massam, 2002) and in the 1960s and 1970s the term was used as a means to assist clinicians in making decisions on the treatment of their patients (Pennacchini, Bertolaso, Elvira & de Marinis, 2011). The focus was on the development of questionnaires that could effectively measure quality of life. There was a shift from the focus on the individual's quality of life to a consideration of quality of life in the family context (Gardiner & Iarocci, 2012). The theories of Bowlby (1969), Bronfenbrenner (1979) and Turnbull, Summers and Brotherson (1984) were catalysts for exploring quality of life in the family context. With the rise of increased participation in the community, and a drive to support people to remain at home in the family context, increased attention was given to understanding family quality of life (Samuel, Rillotta & Brown, 2012). The need for research into this area

was accelerated by the de-institutionalisation of the disability field in the 1960s (Gardiner & Iarocci, 2012). Like quality of life, the focus of studies into family quality of life has been on identifying the significant variables and the development of reliable questionnaires that can be used to measure the construct.

The term “family quality of life” does not appear in the relevant literature until the work of Poston et al. (2003). The need to develop a questionnaire of family quality of life for families with children who have intellectual disability was first conceptualized by the Beach Center at the University of Kansas in 2003 (Poston et al., 2003). Prior to the development of the questionnaire, quality of life was only measured using individual quality of life scales. However, according to Turnbull et al. (2007), individual quality of life measures are not sufficient for the examination of phenomena experienced by children with intellectual disability, since these phenomena are typically experienced within the context of such individuals’ families. Thus, the concern must not be on the individual child alone, but on the entire family. This is reflective of a shift towards a family-centred approach to supporting not only the person with the disability, but also to supporting the members of the family.

Prior to the development of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006), studies that sought to compare the quality of life of families with children who have disabilities in general, with those who did not, relied on outcome measures such as stress or depression levels of individual family members, particularly of the parents. Turnbull et al. (2007) discussed a wide range of these measures, and argued that these measures were problematic primarily because they were not able to provide a balanced view of the experiences that families have in

raising children with disabilities. That is, these measures automatically consider the presence of disability in the family as having an adverse effect on family quality of life, and therefore correlate increases in the stress levels of parents in such settings as being derived from having to care for children with intellectual disability.

3.2.2 Definition and Construct of Quality of Life and Family Quality of Life

The discussion of the key ideas and research study outcomes included in this literature review is framed around the concept of family quality of life. For the purposes of this review, *quality of life* is to be understood as “having a life that is good and meaningful for every individual” (Moyson & Roeyers, 2012, p. 87).

According to Wu (2015), quality of life is a gauge of the overall health and wellbeing of the individual, as reflected by the individual’s physiological, psychosocial, and socioeconomic experiences. As explained by Moyson and Roeyers (2012), quality of life is a highly complex construct that needs to be examined based on the different factors that affect it. While the objective of measurement is to consolidate these factors into a single, meaningful score, identifying the appropriate factors that should contribute to this score is critical (Turnbull, Summers & Brotherson, 1984). This is because of the highly subjective nature of the individual’s perception of what is good and meaningful in their life, which may differ across cultural contexts (Wu, 2015). From these definitions, the current study adopts the perspective of Wu (2015) and considers quality of life as a multi-dimensional measure of wellbeing.

As found in other quality of life studies, factors that contribute to quality of life differ not just across cultural contexts, but also within specific subpopulations within such contexts (Salomé et al., 2015; Siu et al., 2015). For example, quality of

life aspects that were identified among people with schizophrenia by Siu et al. (2015) differed from those identified among patients with intestinal stoma by Salomé et al. (2015). In both cases, the studies examined the extent to which patients experienced different symptoms of their respective diseases, and measured their quality of life based on the gravity and impact of those symptoms. However, schizophrenia is a psychological disease with symptoms that are completely different from intestinal stoma, which is a gastrointestinal disease, and so the same questionnaire for measuring quality of life in one cannot be used for the other. Since schizophrenia and intestinal stoma have very different symptoms that can affect the quality of life of patients, questionnaires used to measure quality of life for such patients must be constructed differently (Salomé et al., 2015). Thus, when it comes to intellectual disability, and more specifically, children with intellectual disability, it must be considered that the impact on quality of life is going to be different in nature from other kinds of disabilities. As such, generalisations about the effect of disabilities in the abstract are likely to be inaccurate; a specific focus on children with intellectual disability is necessary if one is to gain an accurate picture of quality of life for this sub-group.

While quality of life is focused on the measurement of individual wellbeing, *family* quality of life is a construct that strives to capture the wellbeing of an entire family, typically based on the perspective of one of its members (Marlow et al., 2015; Walkner et al., 2015). As such, the construct and measurement of family quality of life is considered as being even more complex than individual quality of life, owing to the need for an individual to gauge not just his or her internal subjective perspective about the quality of his or her life, but more importantly,

consider the overall quality of life of the people around him or her (Walkner et al., 2015). As in the case for quality of life, family quality of life has been found in the literature to be composed of various sub-constructs, which also change based on the specifics of the participants of interest (Marlow et al., 2015). Hence it is multi-dimensional. It is critical therefore for studies that seek to measure family quality of life to clearly define and examine the specific context in which the construct is measured.

Following from the multi-dimensional concept of quality of life adopted by Wu (2015), the definition of family quality of life that is adopted in the current study is that which was constructed by the Beach Center on Disability (2016). According to the Beach Center on Disability (2016), family quality of life is “the extent to which families’ needs are met, family members enjoy their life together, and family members have a chance to do the things that are important to them.” This definition is consistent with Wu’s (2015) in terms of its treatment of family quality of life as multi-dimensional. In the subsequent development of the Beach Center Family Quality of Life Scale, as will be examined below, family quality of life was captured in five dimensions: family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support.

3.2.3 Relationships between Disabilities and (Family) Quality of Life

Since the de-institutionalisation of people with disabilities and the increased pressure on families to provide the necessary care and support for people with disabilities, there has been an increase in research into family quality of life (Samuel, Rillotta & Brown, 2012). This research adopts a holistic and unitary approach that

considers the impact of the home environment on the quality of life for the person with the disability and for their family members. The research covers a wide range of disabilities in a wide range of countries (Gardiner & Iarocci, 2012). Hu, Wang and Fei (2012) researched family quality of life for 442 families with children with intellectual disability in a Chinese context. Boehm, Carter, and Taylor (2015) investigated family quality of life for parents in American families with a young adult with an intellectual disability and/or autism.

Intellectual disability have long been demonstrated to have a significant negative impact on the quality of life experienced by the individual (Katschnig, 2006; Seltzer & Krauss, 2001; Turnbull, Turnbull, et al., 2004). Family quality of life emerged out of the work on personal quality of life studies with a focus on the family as a distinct collective unit. It focused on quality of life for the family-group as a whole as opposed to the family members as individuals (Schalock, 2004).

Interestingly, Turnbull et al. (2007) found that family quality of life of families with children who have disabilities may not always be negatively affected by such circumstances. This perspective is supported from the outcomes of some studies, such as Hebbeler et al. (2007) in the United States, which found that some families with children who have disabilities have actually adapted positively and have been able to develop well as a family. Similar outcomes were found in the works of Thompson et al. (2014) and Al Samadi et al. (2014). As discussed by Al Samadi et al. (2014) in a study of the wellbeing of Iranian parents who have children with disabilities, parents who were able to derive satisfaction from the caring role that they played in their children's lives were able to experience better emotional health and lower stress levels. Thus, the presence of a child with a disability in the

family should not be summarily considered as a negative element; there may be positive contributions of this situation to the family's well-being. The current study therefore needs to take account of this possibility in the context of Saudi Arabian families. Despite these interesting findings, the greater majority of studies found that having a child with an intellectual disability in the family was associated with a lower family quality of life (Juhásová, 2015; Marlow et al., 2015; Michalik, 2015; Rillotta, 2010). However, the majority of studies in this area have been conducted in a Western context (Seltzer & Krauss, 2001; Walton-Moss et al., 2005).

The exploration of the impact of intellectual disability on family quality of life has been the subject of more recent research (Boehm, Carter & Taylor, 2015; Hu, Wang & Fei, 2012; Rillotta, 2010). In Rillotta (2010), 42 individuals in Australia who cared for family members who had developmental or intellectual disability were interviewed. In the interviews, they were assessed for family quality of life based on the health of their family, their financial wellbeing, their relationships within the family, the support that they receive from external sources, and their values, careers, and leisure activities. Results of the study found no indication that having to care for children with disabilities negatively impacted upon the family quality of life of the participants (Rillotta, 2010). Instead, it was found that the participants were all generally satisfied with each of the family quality of life domains considered (Rillotta, 2010). While each of the domains considered was found to be important from the perspective of the participants regarding their family quality of life, there was a need to distinguish between the emotional and practical support that the family received from external sources, since it was found that the former was considered slightly more important than the latter (Rillotta, 2010). The current study conducted

by Rillotta (2010) followed all the generally acceptable protocols in conducting interview studies. The outcomes of Rillotta's study (2010) seem to be directly and genuinely derived from participants' inputs, therefore indicating that at least in some cultures, having children with disabilities is not considered as a burden that affects family quality of life negatively.

In another study, Juhásová (2015) compared the quality of life of families who had children with disabilities, with that of families who only had children without disabilities, as rated by the mothers and fathers of those families. The study was conducted in Slovakia, and involved 100 participants (Juhásová, 2015). Unlike the study by Rillotta (2010), Juhásová (2015) considered all disabilities, not just intellectual disability. Also, Juhásová (2015) measured family quality of life quantitatively through an adaptation of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006). Contrary to the findings of Rillotta (2010), Juhásová (2015) found that there was a significant difference in the family quality of life experienced by families who had children with disabilities compared to families who did not. Specifically, it was found that families with children who had disabilities rated their quality of life lower than those who only had children without disabilities. There were significant differences found across each of the dimensions of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006). Juhásová (2015) discussed this as being consistent with the expectations of the study, since participants considered the presence of disability as taking both material and emotional tolls on the family, thereby creating a negative impact on family quality of life. Since each of the dimensions of family quality of life was found to differ between families who had children with disabilities, and families who only had

children without disabilities, Juhásová (2015) concluded that the effect of having to care for children with disabilities on family quality of life was overarching.

In another study, Marlow et al. (2015) found that for families who had children with a disability, this negatively impacted on the quality of life experienced by the family for many years. Specifically, Marlow et al. (2015) found that disability among children in the family decreased the capacity of parents to work, thereby leading to impairment in the ability of the family to provide sufficient resources for its sustenance. Michalik (2015) examined the quality of life specifically of parental caregivers of children with disabilities. As with Marlow et al. (2015), results indicated that parents who cared for children with disabilities reported a lower standard of individual quality of life compared to people who only cared for children without disabilities. Similar results were found in the study by Schertz et al. (2016) on family quality of life of families with children who had severe neurodevelopmental disability, as well as in the works of Riley and Rubarth (2015) and Chambers and Chambers (2015), which examined the general impacts of having children with disabilities on family functioning and quality of life. As discussed in the earlier works of Simeonsson and McDevitt (1999) and Simeonsson et al. (1992), raising children with disabilities greatly affects families at both emotional and practical levels. Thus, it is critical for social service units to address the particular needs of parents who are caring for children who have disabilities (Simeonsson et al., 1992).

The contrast between the findings of Rillotta (2010) and of Juhásová (2015), Marlow et al. (2015), Michalik (2015), Schertz et al. (2016), Riley and Rubarth (2015), and Chambers and Chambers (2015) show that the relationship between

family quality of life and the disabilities of children may not be constant across all contexts. There is a tendency amongst both families and professionals to underestimate the impact that cultural variables and the degree of disability has on the quality of life (Crocker, Smith & Skevington, 2015). However, the variables within a family with a child with an intellectual disability can indeed impact upon quality of life (Francis, Blue-Banning & Turnbull, 2014). There are also variations due to culture, religion, social support structures, the legislative regime and social attitudes towards people with an intellectual disability. As such, there is a need to examine this relationship in the context of Saudi Arabian families. Furthermore, it is important to identify how different factors, such as religiosity or cultural perspectives about disability, are associated with family quality of life for families that have children with intellectual disability.

3.3 Measures of Family Quality of Life

3.3.1 Identification of the Need for a Psychometrically Strong Measure of Family Quality of Life

As the trend to greater inclusion of children with disabilities in wider society emerged, so too did the need for a robust family quality of life questionnaire in order to determine whether families caring for children with disabilities are experiencing a more positive or negative family quality of life.

On finding that families with children who have disabilities may not always be negatively affected by such circumstances, Turnbull et al. (2007) argued that family quality of life cannot be reasonably contained under just a few, negatively-aligned constructs, but must incorporate a wide range of physical, emotional, and

economic dimensions. As such, there is movement in the literature towards the use of multi-dimensional measures in evaluating family quality of life (Brown et al., 2006; Hoffman et al., 2006; Saito & Turnbull, 2007; Samuel, 2010). Therefore, in measuring family quality of life, there is a need to identify the different variables that are associated with family quality of life for a given population due to the inherent differences in culture and social constructs.

A comprehensive search of the questionnaires available for the measurement of family quality of life was conducted by Hu, Summers, Turnbull and Zuna (2011). Sixteen questionnaires were identified that measured family quality of life (Hu, Summers, Turnbull and Zuna, 2011). Of these sixteen questionnaires, Samuel, Rillotta, and Brown (2012) found that there were two dominant measures: the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) and the Family Quality of Life Survey (Isaacs et al., 2007). Both scales were identified as valid and reliable (Samuel, Rillotta & Brown, 2012). However, in terms of administering the questionnaire, Rillotta (2010) found that the Beach Center instrument was superior because of its user-friendly terminology. She found that participants seemed not to encounter any problems understanding the questions from the Beach Center instrument, which is crucial for ensuring reliable and valid measurement scales. For this thesis, it is suggested by way of analogy that first, the Beach Center Family Quality of Life Scale would also be easier to translate because of its more straightforward language and concepts; and second, it would therefore be more 'user-friendly' for Arabic participants as well. In short, in order to maximise the chance of accurately judging the reliability and validity of a family quality of life scale for the Saudi Arabian context, the Beach Center Family Quality of Life Scale would be the

best because it minimises the chance of misinterpretation and miscommunication, both in translation and in administration of the questionnaire.

3.3.2 Origins, Development, and Application of the Beach Center Family Quality of Life Scale

In line with the need to develop a quality of life measure that considered the position of the entire family rather than just the individual, Poston et al. (2003) conducted a qualitative inquiry about family quality of life which provided the basis for the development of a validated family quality of life measure –now known as the Beach Center Family Quality of Life Scale (Hoffman et al., 2006). According to Poston et al. (2003), family quality of life as a construct has been recognized by previous studies (Dean, 1999; Katz, 2002; Stewart et al., 1999; Tennvall & Apelqvist, 2000) as an important measure particularly in the context of families who have members who have disabilities, but the conceptualization of that measure has been considerably limited. In their study, which gathered data from focus groups of professionals who work with families who have members with disabilities, and interviews with parents of children who have disabilities, Poston et al. (2003) discovered ten potential domains for the measurement of quality of life in the family. These domains included: Advocacy, Health, Productivity, Emotional Well-Being, Social Well-Being, Physical Environment, Daily Family Life, Family Interaction, Financial Well-Being, and Parenting. These domains served as the bases for the construction of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006), which was developed in succeeding studies (e.g. Brown et al., 2006; Hoffman et al., 2006; Saito & Turnbull, 2007; Samuel, 2010; Turnbull et al., 2007). The ten

domains were further reduced in the work of Turnbull et al. (2007) to five, which were identified as Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-related support. Family interaction refers to the extent of communication that occurs within the family (Turnbull et al., 2007). Parenting refers to the extent to which the parents in the family are able to undertake their parental duties (Turnbull et al., 2007). Emotional well-being refers to the quality of emotional states of people within the family and the extent to which members of the family felt happy or satisfied, while physical well-being refers to the extent to which the family is able to satisfy its physiological and material needs (Turnbull et al., 2007). Disability-related support refers to the extent to which the family receives support to help them in taking care of their child who has a disability. Importantly, each of these sub-constructs was found to be independent of the others, thus demonstrating the multi-dimensional nature of family quality of life (Turnbull et al., 2007).

While initially used to measure family quality of life in families with children who have intellectual disability, the scale was later tested on families who only had children with no intellectual disability (Zuna et al., 2009). Despite the removal of the domain addressing disability-related supports, Zuna et al. (2009) found that the scale remained reliable and valid for this new population, with a Cronbach alpha of 0.90. This is similar to the original reliability coefficient computed by Turnbull et al. (2007) for the questionnaire, which was at 0.92. At the same time, confirmatory factor analysis conducted by Zuna et al. (2009) was able to identify the five domains that were found by Turnbull et al. (2007). As such, the questionnaire was found to be applicable for comparing the family quality of life experienced by families who have

children with intellectual disability, with families who did not have children with intellectual disability. This was an important addition to the research agenda, as it would allow researchers and practitioners to make direct comparisons of the family quality of life reported by families who have children with disabilities, with those who do not.

While the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) has been extensively used across different studies on family quality of life (Eskow et al., 2011; Summers et al., 2007), the applications of the measure have mostly been in Western cultural contexts. This presents some problems given the wide differences between the values held by countries in the West and those in the Middle East. Nonetheless, there have been some studies that examined family quality of life in non-Western contexts using the Beach Center Family Quality of Life Scale (Hoffman et al., 2006). Clark et al. (2012) conducted an initial study of family quality of life of Malaysian families who had children with disabilities using the family quality of life questionnaire developed by Brown et al. (2006), which was found to be an earlier version of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) used in the current study. While Clark et al. (2012) did not collect data on the religion of the participants, Malaysia is known to have a large Muslim population, and so the questionnaire may have already been applied in a context that shared the same religion as Saudi Arabians. Nine out of the ten domains initially identified by Poston et al. (2003) were used, whereas the work of Turnbull et al. (2007) had already further reduced the number of subscales necessary to five. Administering the questionnaire to 52 families, Clark et al. (2012) suggested that each of the domains was important to the population as aspects of their quality of life. Clark et al. (2012)

did not collect extensive demographic data from the participants, and relied mainly on qualitative inputs with regard to the importance of each domain. They also acknowledged that their sample size needed to be broader, and should have included a comparison with families of children without intellectual disability. Nonetheless, their research is at least suggestive that the questionnaire is also applicable to non-Western populations, which is an important concern in the present study since it is focused on Saudi Arabian families.

Another study that made use of the questionnaire developed by Brown et al. (2006) was conducted with participants from Slovenia (Cargan et al., 2011). Comparing the outcomes from different domains, Cargan et al. (2011) found that families who had children with intellectual or developmental disabilities found family relations to be the most important concern. This shows that families who have children with intellectual disability may have differing perspectives from those who do not have children with intellectual disability where family quality of life is concerned, which is one of the focal points of interest in the present study.

One important study that made use of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) was conducted in Turkey which, like Saudi Arabia, has a Middle Eastern culture. Meral and Cavkaytar (2013) examined the validity of the scale for the Turkish population. After administering the scale to over 300 families, results showed a highly acceptable Cronbach alpha of 0.92, and subsequent confirmatory factor analysis was able to identify all five domains as relevant to the family quality of life construct. Using split-half reliability testing, it was also found that the scale produced consistent outcomes. Thus, it was concluded that the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) is valid for measuring

family quality of life in the Turkish population. Given the close similarity between the Turkish and Saudi Arabian cultural contexts, it was considered that this version of family quality of life measure was more applicable than that developed by Brown et al. (2006) and would be used in the present study.

3.3.3 Customization of the Beach Center Family Quality of Life Scale for Saudi Arabia

Despite the fact that the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) was found to be valid in the Turkish context, it was still important to examine the applicability of the measure in the particular context of Saudi Arabia. At present, there have been no studies that have attempted to validate the use of the Beach Center Family Quality of Life Scale for Saudi Arabian families with children with intellectual disability. This represents a substantial gap in our knowledge. Thus it would be a major step forward if it could be established that the Beach Center Family Quality of Life Scale was a valid and reliable measure of family quality of life in the context of Saudi Arabia.

There are a number of specific factors that need to be considered carefully when thinking about the application of the Beach Center Family Quality of Life Scale in the context of Saudi Arabia. The following section thus examines the different factors that were also considered for measurement, due to their hypothesized relevance to family quality of life and their potential mediating effects on the family quality of life of families with children who have intellectual disability, and those without. These factors are: religion, the perception of stigma attached to having a child with an intellectual disability, and support services.

3.3.3.1 Religion

A major driving factor behind the differences between Western and Middle Eastern cultures is Islam, which is the dominant religion in the Middle East, particularly in Saudi Arabia and is a strong guiding force in determining what people in Saudi Arabia consider to be a good quality life (Hammoudeh, 2012). From Hammoudeh (2012), it can be seen that the Saudi Arabian perspective of quality of life is highly spiritual, and that family quality of life has not been explored, if at all, in this cultural context. According to Hammoudeh (2012), Saudi Arabians perceive quality of life significantly as the quality of their direct relationship with God, and are less likely to consider material or tangible aspects of quality of life over spiritual aspects. This is corroborated in other studies about Saudi Arabian culture across several decades (Abdel-Khalek, 2009; Al-Khalifah, 1994; Longa & Elghanemib, 1987). As explained by Al-Khalifah (1994), Saudi Arabia's religious culture serves as a protective mechanism against crime. Fear of God is so embedded in people's everyday life that going against the law is unthinkable for many (Al-Khalifah, 1994). This reflects the importance of religion in Saudi Arabian culture.

On the other hand, prior to the development of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006), Poston and Turnbull (2004) conducted a qualitative study that examined the role of spirituality and religion in the quality of life of families who have children with disabilities. This was a study on religiosity in general, but was mainly focused on the Western context and Christian religion (as it was conducted in the USA), rather than on Islam, which is the religion of interest in the current study. In the work of Poston and Turnbull (2004) found that families turned to religion and prayer to help them deal with the hardships of raising a child

with intellectual disability. They sought positive meaning from religion in order to help them make sense of why they have been ‘given’ a child with a disability. However, these factors were ultimately not included in the measure of family quality of life because this factor was not found to be statistically significant ($p>0.20$) (Turnbull et al., 2007).

However, the case may be different in the context of Saudi Arabia, as quality of life may be considered to be closely tied towards abiding by the laws of Islam (Hammoudeh, 2012). As discussed by Hammoudeh (2012), the perspective of Muslims about quality of life is more focused on what they do rather than what they have. Translated to the context of family quality of life, a sub-construct for family quality of life in Saudi Arabian families should include the extent to which the family is able to accomplish its religious duties, which may be associated with having additional responsibilities in caring for children with intellectual disability. The Beach Center Family Quality of Life Scale (Hoffman et al., 2006) is focused more on the experiences of the families, rather than their actions in relation to such experiences, which may be of greater importance to the Saudi Arabian context, as suggested by Hammoudeh (2012). This establishes the need to measure religiosity in the Islamic context as a potential mitigating factor on the relationship between family quality of life and having a child with an intellectual disability. As such, religiosity was included as one of the possible factors associated with family quality of life in the current study, and items were constructed in order to measure it for the Saudi Arabian population.

3.3.3.2 Perception of stigma attached to having a child with an intellectual disability

The association of stigma with intellectual disability is described as focusing on the extent to which the intellectual disability diminishes or reduces the bearer from being a whole person to a diminished person (Werner, Corrigan, Ditchman & Sokol, 2012). On the basis of this principle of human diminishment, it is worthwhile to also consider whether the stigma associated with intellectual disability also “diminishes” the quality of life of family members of a person with an intellectual disability. In their study of this issue for families from Italy, Bertelli et al. (2011) found that families reported a low quality of life in the dimension of ‘Support from Others’. The authors argued that this would most likely be due to the prevalence of stigmatisation surrounding intellectual disability that leads many Italian families to “hide their relatives with intellectual disability and makes them reluctant to ask for help” (Bertelli et al., 2011, p 1147). This finding can make it difficult for studies on disability to be able to identify families who have children with disabilities to contribute information to the study. This is due to the tendency of parents with children who have intellectual disability to withdraw from situations where their having a child with a disability may be exposed. This has some implications for the present study. For example, it may be difficult to recruit participants from families who have children with intellectual disability because of their reservations about exposing themselves and their family to public scrutiny. Another issue is that participants from such families may not be sufficiently motivated to answer questions regarding the challenges of raising a child with an intellectual disability honestly, for fear of how their answers might reflect upon them and their family.

However, this perspective is in strong contrast with those found among families in other studies, such as the study by Poston and Turnbull (2004), who did not view the disability as a diminishment of a family member but as a source of inspiration and strength for the family. Nonetheless, the idea of diminishment clearly has implications for perceived family quality of life. In the current study, this can be related back to the Saudi Arabian perspective about disability which was examined in the previous chapter. As shown from the works of Al-Dawood and Albar (1994) and El-Gilany et al. (2010), there persisted a sense of the stigmatization of people with disabilities in Saudi Arabia, as well as negative connotations about the families who those people belong to. Thus, it is very important to consider the measurement of people's perspectives about disability, in examining family quality of life of families in Saudi Arabia who have children with intellectual disability.

While some elements of this dimension are already present in the Beach Center family quality of life questionnaire developed by the Beach Center, it may have been necessary to add more items that more directly address this dimension as a family quality of life sub-construct. However, after considering the impacts that adding such items may have on the known reliability and validity of the questionnaire, it was decided to not include any further items under this dimension.

3.3.3.3 Support services

Another factor which may have an effect on the quality of life of families of children with intellectual disability is the extent to which various kinds of support services are available to these families. Support can take many forms, ranging from help with caring and household duties, to help with education of children with

special needs, to emotional support for carers and siblings, to financial support with the extra costs of caring for children with intellectual disability (Meral et al., 2013).

At the intra-family level, Nolan et al.'s (1990) large study of 726 US families found that poor relationships with, and little support from, extended family members contribute to the experience of increased stress for parents of children with disabilities: in addition to subjective feelings of a lack of control and possible guilt at not fulfilling their obligations, "Carer malaise is also more likely when there is a lack of family support and adverse financial burdens imposed by caring and when the carer perceives these as stressful" (Nolan et al., 1990, p. 552). Being part of a cohesive, co-operative and flexible family with open communication has been found to enable parents to better cope with caring for a child with intellectual disability (Olson, 1997; Grant & Whittell, 2000).

With respect to parents' perceptions of the availability of the necessary professional supports (such as medical, nursing, educational & psychological), Llewellyn et al.'s (2004) analysis of interviews with 64 carers of adult children with intellectual disability found that increased parental stress and lower quality of life satisfaction was associated with decreased levels of such professional support. A similar result was found by Minnes and Woodford (2005) in a study of the mismatch between needs and support services for 80 ageing Canadian parents of adult children with developmental disabilities. They found that the availability of a range of professional services for children (such as social and recreational activities, respite care, supported employment, day programs, residential placements, in home support, counselling and behaviour management services) functioned as a psychologically protective barrier against parental stress.

This finding was supported with respect to families caring for young children (aged 0-5 years) with intellectual disability. Summers et al. (2007) surveyed 180 families of young children being served in early childhood special education programmes in one Midwestern U.S. state in order to examine: (1) whether family quality of life was affected by service adequacy ratings of disability-related support, and (2) whether the effect on family quality of life of caring for children with disabilities was mediated by family satisfaction with professional partnerships. They found that both service adequacy ratings and family satisfaction with professional partnerships were indeed significant positive predictors of family quality of life.

Caples and Sweeney (2011) examined the family quality of life issues linked to family members' needs for respite care when caring for a child with an intellectual disability in Ireland. What is identified by the authors as a key concern for parents is the quality of life implications of being able to reconcile their desire to care for their child with intellectual disability, with their need to secure access to respite services when necessary. Access to respite services is positively associated by parents with a sense of relief from "parental burdens" (Caples & Sweeney, 2011, p. 64). However, Caples and Sweeney (2011) also presented findings to show that the impact on family quality of life of accessing respite support services is both positive and negative. According to reports from family members who access the services, the primary difficulty is in fact reconciling personal, family and professional issues when attempting to negotiate the complex barriers to accessing respite support services (Caples & Sweeney, 2011). As such, there is evidence to show that when barriers to accessing support services present challenges to parents' abilities to support the

health and well-being of their child and themselves, then there is a significant adverse impact on their perceptions of quality of life (Caples & Sweeney, 2011).

Davis and Gavidia-Payne (2009) examined the effect of support characteristics on the quality of life in 64 Australian families of children aged between 3 and 5 years with a developmental delay or disability. They found that parental perceptions and experiences of family-centred professional support was one of the strongest positive predictors of family quality of life, and that support from extended family members also accounted for a substantial proportion of variance in predicting quality of family life. Similarly, Rillotta (2010) found, through the use of a quantitative survey of 53 Australian families, that the quality of life of families living with members who had intellectual disability was significantly affected by having such members. These families reported various challenges, such as finding appropriate healthcare services for their members with intellectual disability, which placed significant burdens on their quality of life.

Meral et al. (2013) examined the validity of the Beach Center Family Quality of Life Scale for over 300 Turkish families to examine family quality of life of families caring for children with autism. The current study also found that family social support, specifically emotional support, was the most significant predictor of overall family quality of life perception. The authors deemed their evidence to be so strong that it warranted direct policy application: in addition to “parent-to-parent” support networks, “to improve FQOL and family social support, the Ministry of Family and Social Policies of Turkey and the Ministry of National Education of Turkey should take measures to increase the provision of social support” (Meral et al., 2013, p 242). Meral et al. (2013) also argued that because poverty was also a

significant contributor to low quality of life for Turkish families caring for children with autism, greater financial support from the government to assist with the additional costs of educating and caring for autistic children would contribute to improvements in family quality of life. This is a confirmation of the more general findings of previous studies. For example, Herman (1991) found that greater financial support from government was associated with lower stress in the families of children with a disability. Caldwell and Heller (2003) found that direct financial payments to families caring for adult children with intellectual disability, in some cases, resulted in an overall improvement in family satisfaction and greater community integration for the adult child.

It seems to be fairly clear that various support services (emotional, familial, educational and financial) play an integral part in determining – even characterising – family quality of life. The Beach Center Family Quality of Life Scale (Hoffman et al., 2006) incorporates ‘support’ items for a family member with a disability (questions 22 to 25), but because in the current study it is intended that there be an explicit *comparison* between families with and without *children with intellectual disability*, it makes sense to alter these questions to allow families without children with intellectual disability to respond to them.

3.4 Factors Impacting on Family Quality of Life

The current study does not simply attempt to measure the impact on family quality of life of having children with intellectual disability. It also examines the impact of mediating factors on family quality of life for families with and without children with intellectual disability. A review of the literature on these potential

mediating factors reveals that a number of causal variables appear to be important, while for others there are conflicting findings.

3.4.1 The Impact of Demographic Factors on Family Quality of Life

Studies that examined family quality of life across different contexts have included the measurement of a number of demographic variables in order to determine their impact on family quality of life. Among the variables commonly measured in these studies are: socioeconomic status of the family, family size, the gender and the age of the primary carer of the child with an intellectual disability, and the marital status of the parents in the family. These variables have been considered as relevant because they may have impacts on the quality of life of families of children with intellectual disability although the evidence for the effect of each often varies from study to study (Barnett & Hunter, 2012; Chen & Zheng, 2014; Emerson et al., 2006; Esdaile & Greenwood, 2003; Floyd & Zmich, 1991; Ganesha & Venatesan, 2012; Graham et al., 2008; Grant & Whittell, 2000; Hastings, 2003; Kersh et al., 2006; Kilmer et al., 2008; Krau, 1985; Lawson & Mace, 2010; Liu et al., 2007; Llewellyn, Thompson et al., 2003; Maurya, Parasar & Sharma, 2015; McDermott et al., 1996; Meral et al., 2013; Minnes & Woodford, 2005; Mulroy et al., 2008; Musselwhite & Haddad, 2010; Norizan & Shamsuddin, 2010; Norlin & Broberg, 2013; Olsson & Hwang, 2001; Rillotta et al. 2012; Roberto, 1995; Zabriskie & McCormick, 2003). The findings of these studies are outlined below. As will be indicated, the findings of these past studies are not entirely consistent, which provides grounds for further research to be conducted in the current study. Furthermore, no rigorous studies on such demographic factors vis-à-vis family

quality of life for children with intellectual disability have been conducted for Saudi Arabian families. This provides further justification for the current study's investigation of those factors.

3.4.1.1 Socio-economic status

Having low socioeconomic status can have a significant effect on the quality of life experienced by the family as this means that the family is not able to afford various necessities that may be enjoyed by other families. As such, a family who has a child with a disability may have a higher quality of life experience than a family who does not have a child with a disability, but is at a much lower level on the socioeconomic stratum. This is well supported in the literature. For example, various studies across the past 30 years have found a strong correlation between socioeconomic wellbeing and experienced quality of life (e.g. Chen & Zheng, 2014; Graham et al., 2008; Krau, 1985; Musselwhite & Haddad, 2010). This makes it essential to include these variables as part of the analysis in the current study.

In their study of family quality of life for Australian families with a child with an intellectual disability, Rillotta et al. (2012) examined (among other domains) the issue of financial well-being affecting family members' perceptions of quality of life. According to the authors, Australian families regard the issue of financial well-being as one of the more important impact domains compared, for example, to "practical and emotional support from others" (Rillotta et al. 2012, p. 71). The importance placed on this impact domain by family members coheres well with the recognition from family members that the social expectation placed upon parents to nurture and financially support their children is very real. As such, this expectation can become a real source of pressure for families with a child with an intellectual

disability, as they attempt to meet the challenges to the family's financial resources presented by the intellectual disability (Rillotta et al. 2012).

It is interesting to note, however, that the results from the Rillotta et al. (2012) study showed that most families reported that they were “neither satisfied or dissatisfied with financial well-being” (p. 78). This result may be compared to the domain ‘practical and emotional support from others’ for example, to reveal the family members indicated higher levels of dissatisfaction. Moreover, most family members were of the view that financial well-being was likely to “stay about the same” or even “decline”, compared to most other domains which were expected to “*stay about the same or improve* in the near future” (p. 79). In turn, the conclusion that may be drawn from the Rillotta et al. (2012) study on financial well-being and quality of life is that family members are highly aware of money matters as an aspect of their quality of life in caring for a child with an intellectual disability, but it is not a significant factor in their overall perceptions of quality of life. Nevertheless, the inclusion of socioeconomic status as reflected by the income of the family, and the current employment status of the head of the household, are clearly important factors to consider.

3.4.1.2 Family size

The research on the impact of family size on family quality of life is limited and mixed. There appear to be no robust studies that focus specifically on how this factor affects the quality of life of families of children with intellectual disability. There are a few studies which could be treated as somewhat analogous. Kilmer et al. (2008) studied the psychological difficulties and well-being experienced by siblings of children with mental illnesses. They found that the size of the family was not

related to sibling psychological functioning, and thus would not in itself significantly affect family quality of life. Mulroy et al. (2008) also examined the wellbeing effects on siblings of children with intellectual disability (particularly Down syndrome and Rett syndrome). They too found that family size was not a significant predictor of sibling wellbeing. Drawing an analogy between mental illness and intellectual disability, these studies may suggest that, similarly, family size would not have a major impact on family quality of life, at least in terms of any effect on siblings' psychological wellbeing.

By contrast, Lawson and Mace (2010) found a positive relationship between larger family size and 'externalising disorders' of children, such as rule-breaking, aggressive behaviour and attention problems. However, conversely, Barnett and Hunter (2012), who studied the psychological difficulties and quality of life of siblings of children with mental health problems, did not find this effect to hold. They did find, however, that smaller family size was a predictor of 'internalising disorders' such as anxiety and depression in the sibling, which then impacted on the sibling's quality of life. This may suggest that a smaller family size may then negatively impact on family quality of life.

Given the limited number and the contradictory findings of the above studies, the possible impact of family size on family quality of life is deserving of further investigation. It is thus worthy of inclusion in the current study.

3.4.1.3 Gender of Carers

Traditionally, since mothers are deemed to be the primary carers of children in Arab culture (Ali et al. 2008), the question of whether the gender of the primary

carer is a relevant factor in affecting family quality of life is an important one. Again, the results are mixed, but there are grounds for suggesting that mothers, more so than fathers, tend to experience a lower quality of life than men when caring for a child with an intellectual disability.

Interestingly, Zabriskie and McCormick (2003) found no relationship between parental gender and participants' reported family quality of life. Wang et al. (2006) also reported no differences in perceptions of satisfaction between mothers and fathers. However, the authors acknowledged that the parents may have completed the survey together, which may have interfered with the veracity of the report of there being 'no gender differences'.

By contrast, Esdaile and Greenwood (2003) found that both mothers and fathers of children with disabilities experience higher levels of child-related parenting stress than parents of children who have no disability. They also asserted that mothers' stress tended to be more sensitive (i.e. more prone to increase) than fathers' stress. This may be suggestive of the possibility that caring for a child with an intellectual disability would increase stress levels and thus lower family quality of life. However, Esdaile and Greenwood's finding is empirically weak because of the small sample size and the relative lack of response from fathers to the investigators.

A similar finding was made by Hastings (2003) who found that the mothers of autistic children reported greater anxiety than did their fathers. Further, mothers' stress levels were found to correlate with both their child's behavioural problems and their male partner's mental health, but that this correlation did not hold for the fathers' stress levels, which suggests that their stress was due to other factors. Again,

although the current study's findings are suggestive of the possibility that family quality of life could be negatively affected by caring for a child with an intellectual disability, the results were not robust because they were based on a very small sample of only 18 couples.

Emerson et al. (2006) conducted a large study of the socio-economic position and well-being of mothers of children with and without intellectual disability in Britain. The researchers used a very large sample (6,954 British mothers with dependent children under the age of 17 years, with 514 of them caring for a child with an intellectual disability). They found that mothers caring for children with an intellectual disability were unambiguously more likely to report lower levels of well-being than mothers of children without intellectual disability. Further, a statistically significant proportion of the increased risk of poorer well-being among mothers of children with an intellectual disability could be attributed to their increased risk of socio-economic disadvantage. This empirically powerful study clearly suggests that the quality of life experienced by mothers caring for children with an intellectual disability is elevated by both the stresses and responsibilities of their caring duties, as well as their often more difficult economic circumstances. This again may be suggestive that caring for a child with an intellectual disability negatively impacts on family quality of life. However, the study does not establish whether this is different or the same for fathers of such children, because it focused entirely on mothers to the exclusion of fathers.

Olsson and Hwang (2001) found that there were indeed differential effects that the presence in the family of a child with an intellectual disability seems to have on men and women. Mothers were more likely to experience higher levels of

depression than fathers; mothers of children with intellectual disability experience higher rates of depression than ‘control’ mothers, but fathers have depression levels comparable to ‘control’ fathers. This finding was supported by a more recent study by Norlin and Broberg (2013) that found that parents of children with intellectual disability not only reported lower well-being than control parents, but that the fathers reported higher well-being than the mothers. Olsson and Hwang (2001) attributed their findings to the fact that men and women are socialised into different family roles, where the woman assumes a larger share of the responsibility for caregiving. Needless to say, depression is a condition that is detrimental not only to the individual but also to family quality of life.

In a qualitative (interview-based) study, Grant and Whittell (2000) found that fathers tended to play a secondary role to mothers in terms of day-to-day practical and personal caring, and were thus better able to maintain greater emotional distance as a way of raising a child with an intellectual disability. This reflected the fathers’ stereotypical status as ‘secondary’ carers where they either deferred to the experience and expertise of their female spouses or partners, or merely opted out (Grant & Whittell, 2000). This coheres with research into the negotiation of fatherhood in families in general, which has indicated that the competence of fathers in relation to their knowledge and ability regarding child-rearing is perceived to be inferior to that of mothers (Backett, 1987).

In a similarly themed study, Norlin and Broberg (2013) found that the extent to which co-parenting (collaboration and sharing of parenting responsibilities and tasks between mothers and fathers) occurs for children with intellectual disability had a marked positive impact on the reported prospective well-being of parents.

However, the impact on mothers was far greater than that on fathers. This confirms the findings of Hughes et al. (2004) who found a stronger association between co-parenting and well-being in mothers than in fathers. Hughes et al. (2004) argued that lack of support from the father is more deleterious to the mother, as the mother often carries the greater parenting burden. Norlin and Broberg (2013) added that this coheres with the near-universal stereotypical expectation that women are more relationship orientated than men.

So the results of the research into the effect on the wellbeing of the different parents who serve as primary carer-givers for children with an intellectual disability are mixed, if only because a number of studies finding a gender difference have been characterised by small samples. Nonetheless, overall it seems plausible that the gender of the primary caregiver is important and warrants inclusion in the current study.

3.4.1.4 Age of the Carers

Two opposing views can be inferred from the literature relating to whether the age of primary carers (especially parents) is positively or negatively correlated with individual and/or family wellbeing. The ‘wear and tear’ view suggests that over time parents become ‘worn down’ by the constant demands of caregiving, resulting in diminution of both physical and psychological wellbeing (Cuskelly, 2006). The implication of this view is that older parents would tend to experience a lower quality of life than younger parents. This view was originally developed in Johnson and Catalano’s (1983) longitudinal study about caring for the elderly, so it is not necessarily a good indicator for considering the effect of caring for children with an intellectual disability. Nonetheless, the analogy is suggestive. It is a position that is

broadly supported by Roberto's (1995) review of literature which suggests that as caregivers age, their declining health and psychological resilience contributes to their increasing parental stress and declining wellbeing as their children get older.

The second and opposing view is that older parents have more life experience and have thus tended to develop strategies for dealing with difficult circumstances, such as caring for a child with an intellectual disability (Olson et al., 1983). There would appear to be more support for this latter view. For example, McDermott et al. (1996) found that in the case of parents caring for an adult child with an intellectual disability, there was no difference in parental wellbeing between those parents over 60 and those under 60 years old. This finding was supported by Minnes and Woodford (2005) who examined 80 ageing Canadian parents (aged 50 to 80) of adults with developmental disabilities. They found that parents over 65 years of age did not report parental stress levels any different to parents aged 50 to 65 years. It is arguable that for these age ranges one is likely to be looking at parents who have well-established patterns of coping, so it is unclear whether this result would also hold for much younger parents of children with an intellectual disability. Other studies have examined precisely this question, however. For example, Grant and Whittell (2000) found that older parents, more so than younger parents, tended to effectively use cognitive coping strategies in dealing with children with an intellectual disability. They concluded that:

There is little support for the 'wear and tear' hypothesis, which suggests that, as people age, their resourcefulness declines. The situation appears to be rather more complex than this. If anything, there is more evidence from the present work and other studies (Dyson, 1993) to support the adaptation

hypothesis which suggests that people continue to learn and adapt as they grow older, and as a result, their coping repertoires expand and change in ways which are functional (Grant & Whittell, 2000, p. 272).

Subsequent empirical studies of families of children with an intellectual disability have backed the view that the age of parents does not seem to be a relevant factor affecting individual or family quality of life. In a longitudinal study of over 8,000 Wisconsin high school graduates from 1957 to 1992, Seltzer et al. (2001) found that the physical health and psychological well-being of parents of a child with a developmental disability did not diminish with age relative to parents without such children. Llewellyn, Thompson et al. (2003), who investigated family well-being among 81 Australian families with children with disabilities and high support needs aged 6-13 years, found no association between family well-being and parental age. Liu et al. (2007) who surveyed 97 mainland Chinese parents with a child with a mental illness, found no significant difference in parental caregiver burden among parents of different ages. Norizan and Shamsuddin (2010), who examined the level of parenting stress experienced by 147 Malaysian mothers of children with Down syndrome, found that the age of the mothers was not a significant predictor of parenting stress. Finally, Meral et al. (2013) found that in their survey of 3,147 Turkish mothers who cared for children with intellectual disability, their age (ranging from 18 to 65+) was not an important predictor of family quality of life.

The weight of the evidence to date suggests that the age of parents is not relevant to the quality of life for families of children with intellectual disability. Nonetheless, the results are not unambiguous. There is still no research on this factor

for Saudi Arabian families (children with or without intellectual disability). It is thus a factor which is worthy of inclusion in the present study.

3.4.1.5 Marital status of the parents

Although some studies have examined the effect that raising a child with intellectual disability has on marital stability and status (e.g. Risdal & Singer, 2004), the question of the impact on family quality of life of the marital status of the parents of children with intellectual disability, has been less well studied. This latter is a potentially controversial relationship because it sometimes becomes a magnet for conservative moralising (Wilcox, 2012).

It is arguable that the marital status of carers is less relevant than the *quality* of parental relationships. That is, it is conceivable that married parents who have a dysfunctional relationship contribute to a lowering of the family quality of life, compared to the quality of life they might experience if they separated (Musick & Meier, 2010). This is indirectly suggested by some researchers who found that there was a lower quality of marriage for parents of children with intellectual disability (Floyd & Zmich, 1991; Kersh et al., 2006). This suggestion is, however, somewhat speculative, and in any case, Norlin and Broberg (2013) found that on average, parents with children with intellectual disability reported the same levels of marital quality as control parents. In fact, there are no robust empirical studies which have specifically focused on the question of the effect on family quality of life for dual versus single parent structures (where children with intellectual disability are involved). It is nonetheless plausible to say that single-parent families face difficulties and stressors that two-parent families do not. For example, single-parent families often experience both lower income, higher childcare expenses, and limited

quality-time with children due to additional work and home duties (Dunifon et al., 2005). This was certainly a finding of Grant and Whittell's (2000) qualitative study, in which parents from a variety of family structures were interviewed. Grant and Whittell (2000, p 271) state:

As the main or sole providers of support for their children, lone carers found meeting all their commitments very demanding. This was exacerbated when respite and home care support services were lacking or perceived to be inflexible in responding to their expressed needs.

Some quantitative studies also back this qualitative finding. Brandon and Hogan (2004), for example, using data from a 48-month longitudinal, nationally representative, stratified random sample of the US population for the period 1996–1999, found that sole parents caring for a child with a disability were far less likely to escape welfare dependency than other groups. They also found that having a child with a disability had almost the same impact on welfare dependency as the mother having a disability herself. This was because caring for a child with a disability entails high levels of specialised care that is unaffordable to sole parents, which prevented them from escaping welfare dependence. Lukemeyer et al. (2000) reported similar findings for sole parents of children with disabilities. They found that sole parents were less likely to be employed and experienced more financial difficulties, compared not just to dual parent families, but to sole parent families who were not caring for a child with disabilities. Intuitively, this would suggest that married-parent families would tend to have a better quality of life than single-parent families. Norizan and Shamsuddin (2010, p 997), who examined Malaysian families caring for children with Down syndrome, similarly found that “parenting stress was higher

among mothers who were divorced or widowed compared to married mothers.

Although significant, there were very few ($N = 8$) mothers who were either divorced or widowed in the current study.”

Ganesha and Venatesan (2012) found that children from dual-parent families had significantly fewer behavioural problems (such as aggression and rule-breaking) than single-parent families. These findings were supported by Maurya, Parasar and Sharma’s (2015) study which also found that children (aged 6-18 years) from ‘not-intact’ families experienced significantly greater emotional problems (such as anxiety and depression) and behavioural problems than those from ‘intact’ families. This would suggest that a single-parent status of carers would seem to have a negative impact on family quality of life. It is reasonable to believe that this would also hold true – and if anything would be more pronounced – in the case of families caring for a child with intellectual disability.

By contrast, Barnett and Hunter (2012), who studied the psychological difficulties experienced by siblings of children with mental health problems, which was found to negatively impact on (individual) quality of life, found that family structure (be it dual biological or non-biological parents, sole parent, or foster carer families) was not a significant factor in affecting the psychological wellbeing of the siblings. Rather, they found that the style of family functioning and family communication, irrespective of family structure, was the most relevant predictor of the quality of life of siblings. It is possible that studies examining family structure alone are in fact picking up the negative effect of family dys-function on quality of life that can emerge due to the pressures of certain kinds of family structure (such as

sole parent families), rather than a negative effect that is due to the marital status of parents per se.

So although the marital status of parents of children with disabilities has been little studied, there are studies of family structure and children's wellbeing which are suggestive of the possibility that a dual-parent family would have a higher quality of life than a single-parent family. That said, the evidence is by no means conclusive. Further research is warranted, especially when it comes to families of children with intellectual disability. This is especially so in the case of Saudi Arabia where there are no studies examining this factor for such families.

3.4.2 Family-specific Factors for Families of Children with Intellectual disability

3.4.2.1 Severity of intellectual disability

People who care for relatives with profound and multiple learning disabilities must undertake a wide range of physical tasks, which can take up almost all of their waking hours (Mencap, 2001). Unsurprisingly, the parents of children with such disabilities have reported high levels of stress and a poor quality of life (Walden et al., 2000). For example, Wang et al. (2004) found that the severity of the intellectual disability of their child (along with family income) was a good (inverse) predictor of both mothers' and fathers' satisfaction with their family quality of life during the early years of a child's life: the more severe the disability, the lower the parental satisfaction. This result was confirmed by Hu, Wang and Fei (2012). There are, however, methodological concerns about objectively determining 'severity' of disability.

Walton-Moss et al. (2005), for example, made no attempt to homogenise the sample of families with members who have disabilities. At the same time, the type of disability was not considered as a factor in quantitatively analysing the quality of life of the sample families. This may be due to the limited sample size of the study, which only consisted of 17 families. This may also be because of the very wide range of intellectual disability that can affect a child. With such a small sample size, it would not have been possible to consider such factors. The study by Walton-Moss et al. (2005) also did not control for these factors, which may have had significant impacts on the results. Walton-Moss et al. (2005) found that families experienced difficulty from having a member who has an intellectual disability, regardless of what that disability was. However, the study did not describe the different disabilities that members of the different families in the sample experienced. As a methodological point, Rillotta (2010) emphasised the need to include the type and level of disability experienced by a family member as a factor when analysing quality of life quantitatively. Ensuring the homogeneity of samples where the level of intellectual disability is concerned may not be possible, but ensuring that the impact of these differences is accounted for is of the utmost importance.

Brown et al. (2006) compared the family quality of life of three groups: families with a child with Down syndrome, those with a child with autism, and those with children without any intellectual disability. They found that families with children with autism reported overall lower family quality of life than those with Down syndrome. An interesting explanatory possibility that arose out of these findings was that children with autism were reported as having greater severity in their condition (35%) than children with Down syndrome (11%). This may suggest

that the greater severity of the intellectual disability is an underlying cause of lower family quality of life scores, rather than the type of intellectual disability itself.

Hu et al. (2012) confirmed the above results for families in China. They too found that the severity of the child's intellectual disability significantly (negatively) predicted the family's perceived satisfaction with family quality of life. The authors argued that this may be in large part because of the limited support provided to such families:

The more severe the disability of a child has (*sic*), the more challenges the family of that child is likely to have. In China, when the resources of supports and services for children with disabilities are still very limited, families who have children with severe disabilities are likely to perceive a less satisfactory FQOL because of all the challenges they face (Hu et al. 2012, p. 40).

Meral et al. (2013) found a significant variation in the reported family quality of life between families of children with intellectual disability in general, compared to families of children with autism in particular; namely, the former was higher than the latter. Since autism is commonly associated with general intellectual disability (approximately 75% of people with autism have a non-verbal Intelligence Quotient below 70) (Howlin, 2015) and is generally regarded as a very demanding disability (Brown, et al. 2006), this suggests that the severity of the disability has a discernible impact on family quality of life. It is worth noting, however, that in a study by Barnett and Hunter (2012), who studied the psychological difficulties experienced by siblings of children with mental health problems, it was found that the severity of a child's mental health problems had no significant impact on their siblings' own

psychological wellbeing or quality of life. While the type of disability may be an important consideration, as reiterated by Rillota (2010), limitations on how to properly determine the type of intellectual disability experienced by children leads the current study to limit its examination to intellectual disability in general, and no longer consider the subtype of intellectual disability in its investigation. However, the current study must at least identify the level of intellectual disability that is experienced by the child in the family, which can be ascertained based on the intellectual disability scale from the American Psychiatric Association (2015) that was presented in the preceding chapter.

3.4.2.2 Multiple children with disabilities

No studies were found that focused specifically on the impact on family quality of life of having multiple children with an intellectual disability. In fact, very few studies examine this factor even incidentally. This may be because having multiple children with intellectual disability is relatively rare, so statistical inferences cannot be drawn about it as an independent variable. One study by Orsmond et al. (2007) did examine the personal well-being and family functioning of 325 mothers of adolescents and adults with autism, compared to 59 mothers who had an additional child with a medical condition, learning disability or psychiatric disorder. It was found that caring for multiple children with disabilities was associated with lower personal well-being and family functioning compared to caring for only one child with a disability.

As an incidental finding, Rogers' (2007) qualitative study of 24 families raising children with learning disabilities – which examined the negative effect of internalised norms and societal expectations about raising a 'perfect' child – found

that when a second child in the family began exhibiting disabilities similar to those of their first child, the mothers were severely psychologically affected with strong feelings of disappointment and sadness. This would seem to suggest that although parents may be better ‘technically’ equipped to deal with a second child with an intellectual disability due to having learnt from the first, they are phenomenologically harmed because they often pin their hopes on having a second child without a disability.

On the other hand, McStay et al. (2014), who sought to determine the effect of child age (3 to 16 years) on maternal stress and family quality of life in 140 mothers caring for autistic children, made a contrary incidental finding. Not only did they find no significant age effects, they also found that the mothers caring for more than one child with autism (27% of the sample) did not have significantly different maternal stress or family quality of life scores from the others.

Again, the fact that there are so few and only contradictory findings about the effect on family quality of life of the number of children with intellectual disability within one family, suggests that this is a factor that requires further investigation, and should be included in the current study.

3.5 Conclusion

This chapter has examined the definition and historical development of family quality of life as a construct, and has explored the literature on the impact of disability on family quality of life. The most common finding of numerous studies is that family quality of life is significantly and negatively associated with caring for children with intellectual disability. This chapter has reviewed the literature on the

various demographic factors that may impact on the quality of life of families of children with intellectual disability, including socio-economic status, family size, the gender of carers, and the marital status of parents. Furthermore, the literature on certain family-specific factors (such as the severity of intellectual disability) that may be associated with the quality of life of families of children with intellectual disability has been scrutinised. The empirical findings for all these factors, when combined, are in some cases ambiguous or contradictory. This is due, it would seem, to the field being marred by many studies of varying quality in terms of sample size and statistical power. Further empirical investigation of these factors is warranted in the present study.

Importantly, with respect to Saudi Arabia in particular, very little is known about family quality of life vis-à-vis children with intellectual disability. The literature search reveals that there are no empirical studies of this particular topic. Concomitantly, there are thus no studies of the various demographic factors or family-specific factors which may impact upon family quality of life for families of children with intellectual disability. In fact, there are not even good records of the prevalence of intellectual disability in Saudi Arabia. As such, the knowledge-gap in this field with respect to Saudi Arabia is almost entirely unfilled. This alone justifies investigating the matter.

The question of how to measure family quality of life in Saudi Arabia can be answered by the use of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) developed by the Beach Center of Kansas University. This chapter has reviewed the development and application of the Beach Center Family Quality of Life Scale and found it to be a suitable instrument. This measure is selected because

of its dominance in the field, because it has been found to be reliable and valid in many studies (Van Beurden, 2011), and because it has been found to be more ‘user-friendly’ (Rillotta, 2010) and thus easier to translate than other scales.

It has also been suggested in this chapter that there are some culturally and religiously specific features of Saudi Arabian society that deserve special attention. With respect to the measurement of family quality of life using the Beach Center Family Quality of Life Scale, one approach to dealing with these country-specific features is to treat them as independent variables that are associated (positively or negatively) with family quality of life. By this approach, family quality of life would be treated as a universal, culturally non-specific, ahistorical construct. An alternative approach is to be open to the possibility that family quality of life can differ *in its nature* across different societies, depending on salient features of their unique cultures (Brown & Brown, 2005; Verdugo, Schalock et.al., 2005; Verdugo & Schalock, 2009). Such an approach would entail a modification of the Beach Center Family Quality of Life Scale – which was originally developed with ‘Western’ cultural norms built in to its various dimensions – so as to incorporate within it those salient features of Saudi Arabian society not present in the original Scale.

The current study posits that this latter context-specific approach is a reasonable one to explore: that the Beach Center Family Quality of Life Scale be modified to account for religious and cultural dimensions that are specific to Saudi Arabia. It has been pointed out that Saudi Arabian culture and family life is heavily influenced by the religion of Islam, and so the nominated scale should be modified to take this into account. Further, the literature reveals that Saudi Arabian civil society has embedded within it a tendency to stigmatise intellectual disability.

Stigmatisation, it is posited, may play a significant role in determining or even characterising family quality of life for families of children with intellectual disability, and that religious and cultural perspectives on intellectual disability should be incorporated into the Beach Center Family Quality of Life Scale for Saudi Arabia. These augmentations of the scale, informed by the literature, constitute an important and interesting innovation in the application of the Beach Center Family Quality of Life Scale to a new religious and cultural context.

Chapter 4 : Research Aims, Questions and Hypotheses

4.1 Introduction

This chapter defines and details the problem that the current study seeks to address. First, the statement of the problem is formulated and supported based on the current literature. Following this, the specific aims are derived in order to provide sufficient direction for the conduct of the study. Finally, the chapter elaborates upon the significance of the study to different stakeholders. The chapter will demonstrate that the pursuit of the empirical study recognises the current state of the research field and its shortcomings, and addresses key research questions that are pertinent to advancing our knowledge of family quality of life in Saudi Arabia.

4.2 Statement of the Problem

The population of the Kingdom of Saudi Arabia enjoys a relatively high standard of living, and the government identifies one of its central goals as ensuring the welfare of its citizens. However, it is also known that some marginalised groups exist that require greater attention and assistance from the government in order to share equitably in the fruits of economic development. One group that has received very little attention from either the government or researchers is families with children who have intellectual disability. The experience of intellectual disability among children is an important issue for the children themselves, their parents and other members of their families (i.e. their siblings, grandparents, etc.). If families caring for children with an intellectual disability experience a significantly lower quality of life than other families, then this would also constitute an issue of social inequality that would and should be of considerable concern to the government, as

part of its duty is to protect the welfare of all of its citizens, especially children (Information Office of the Royal Embassy of Saudi Arabia, 2013b).

From both a research and a governmental perspective, the most immediate problem in seeking to address this potential concern is one of a lack of information: exactly what family quality of life is like in Saudi Arabia is simply unknown, let alone the family quality of life for families of children with intellectual disability. Without such information, it is not possible to know whether, and to what extent, there is inequity in the experiences of family quality of life between these two groups. It is not evident which of the particular factors making up family quality of life are most important to families of children with intellectual disability, versus those without. Thus, a primary aim of this body of research is to address these shortcomings and advance our understanding of the experience of Saudi Arabian families. This will provide a strong foundation for future research into the experiences of Saudi families of children with intellectual disability, by not only producing substantive findings about the levels of family quality of life and the factors influencing it, but also by establishing a robust measure to be used by others in the future. It will also provide valuable information to the Saudi government about whether there is a matter of social inequity that needs to be addressed, and which factors in particular (if any) need to be targeted in order to ensure that families of children with intellectual disability can enjoy the same quality of life as those children without intellectual disability.

Given the importance to the current study of understanding family quality of life, the measurement of family quality of life needs to be sensitive to the cultural characteristics of the population of interest. This is because the perception of family

quality of life is expected to be different from one culture to the next. An examination of the relevant literature has revealed that most of the studies on measures of family quality of life have been conducted in Western contexts (Hoffman et al., 2006; Rillotta, 2010; Walton-Moss et al., 2005). Thus, a critical aspect of the research problem in the current study is to identify and verify a measure for family quality of life that is applicable to the Saudi Arabian context.

Another part of the research problem is the determination of the different factors that are associated with family quality of life among Saudi Arabian families. While the measurement of family quality of life and the variables associated with it, such as socioeconomic status and culture, have been widely researched in extant literature (Eskow et al., 2011; Hammoudeh, 2012 Hammoudeh, 2012; Hebbeler et al. 2007; Summers et al., 2007; Zuna et al., 2009), its examination in the context of Saudi Arabia was found to be relatively uncharted. Thus, it is important in the current study to quantitatively determine whether factors that were found to impact family quality of life in other socio-cultural contexts also impact the variables among Saudi Arabian families.

Finally, the last goal of this research is to examine any observed differences in family quality of life among families with and without children with intellectual disability in Saudi Arabia, and to attempt to explain the reasons behind such differences so that future policy and practice may better support vulnerable families. Some factors found from the literature that may possibly explain differences in family quality of life relevant to Saudi Arabian families include religiosity, cultural attitudes towards disability, socioeconomic status, and the availability of support for

people with intellectual disability (Caples & Sweeney, 2011; Rillotta et al. 2012; Walton-Moss et al., 2005).

4.3 Research Aims, Questions and Hypotheses

Based on the above statement of the problem – the lack of knowledge by researchers and the government about Saudi Arabian family quality of life, and in particular that of families of children with intellectual disability – five research aims were formulated for the current study. These aims and their associated hypotheses or research questions, as applicable, are presented below.

4.3.1 Research Aims

Because the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) was constructed for use in Western societies, it has not been validated or modified for nations such as Saudi Arabia. Western populations differ considerably from Middle Eastern populations in terms of various cultural and socioeconomic characteristics (Hofstede, 2015). Therefore, the standard family quality of life measure cannot be applied to Saudi Arabian families without a determination of its validity. So in order for the current study to proceed, the first step must be to construct an augmented version of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) tailored to the Saudi Arabian population, henceforth referred to as the Saudi Arabia Family Quality of Life Scale. In particular, because of the centrality and pervasiveness of religiously informed beliefs in Saudi culture, the augmentation of the scale will require the addition of questions that directly address concepts of perceived religiously-based social acceptance and support for a family

with a child with a disability, as well as the perceived role of religious faith in raising a child with an intellectual disability.

The principal preliminary issue of concern for the current study is therefore to establish whether the measures of augmented family quality of life, religiosity, and other religio-cultural factors related to caring for a child with an intellectual disability are valid and reliable. Thus, the first two research aims of the current study are the following:

Research Aim 1: Construct and verify the validity of the Beach Center Family Quality of Life Scale, augmented to include variables assumed to be relevant to Saudi Arabian families of children with intellectual disability, including the new measures of religiosity and other religio-cultural factors related to caring for a child with an intellectual disability.

Research Aim 2: Examine whether the identified factors of the Saudi Arabian Family Quality of Life questionnaire, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with intellectual disability are reliable.

The literature review identified a number of factors that were potentially associated with, and perhaps affecting, family quality of life. The factors associated with family quality of life identified in the literature were as follows:

(a) Various demographic variables: marital status, family size, parental education level, employment and socioeconomic status.

(b) Family-specific factors for those families of children with intellectual disability: the number of children in the family with intellectual disability, and the severity of the intellectual disability.

It has been suggested that these additional factors can mitigate or exacerbate potentially negative effects on the family quality of life of families with children with intellectual disability (Al-Dawood & Albar, 1994; Caples & Sweeney, 2011; Rillotta et al. 2012; Walton-Moss et al., 2005; Werner, et al., 2012).

In addition to these above factors, the literature suggests that religiosity may be a relevant factor associated with family quality of life because Saudi Arabian society is so imbued with Islam as the dominant ideological framework of the country (Al-Rasheed, 2010). Also, the extant literature suggests that there is a significant stigma in Saudi Arabia attached to intellectual disability which exists at the level of civil society, but may also be internalised by a family (Al-Dawood & Albar, 1994). Such religio-cultural acceptance (or stigmatisation) of intellectual disability could also have a powerful impact on family quality of life for families of children with intellectual disability. Thus the present study is also interested in the possible positive or negative impact of (1) Religiosity (that is, the extent of Islamic religious belief & practice), and (2) other religio-cultural factors related to caring for a child with an intellectual disability. Thus the third aim of the current study is:

Research Aim 3: To determine whether demographic factors, religiosity, and other religio-cultural factors related to caring for a child with an intellectual disability, impact on family quality of life for Saudi Arabian families.

The primary empirical issue the current study is interested in is the impact that having a child with an intellectual disability has on a family's quality of life in Saudi Arabia. This is the primary focus of the current study, which examines the literature that suggests that having a child with an intellectual disability can impose a wide range of challenges on a family which can significantly impact its family quality of life, compared to families who are only raising children who do not have intellectual disability (Rillotta et al. 2012; Werner, et al., 2012). However, there were also studies found in the literature that indicated that having children with intellectual disability did not affect the quality of life of carers negatively, and even contributed to carers having a positive perspective regarding their quality of life (Green et al., 2013; Poston & Turnbull, 2004). As such, the current study considered it critical to examine this variable in the context of Saudi Arabia, giving rise to the fourth research aim:

Research Aim 4: Determine whether caring for children with intellectual disability, compared to caring for children without intellectual disability, is associated with family quality of life among Saudi Arabian families.

Finally, the fifth aim of the current study is to gain a greater phenomenological understanding of the findings from the quantitative analysis by utilizing qualitative data gathered by interviewing some of the participant-parents directly. The research question associated with this aim thus relates to families' own reflections on their situations and experiences of raising children with intellectual disability. This aim also seeks to connect the current study to the context of special education services. Special education services in Saudi Arabia receive considerable financial support from the government, but remain relatively underdeveloped

because of the current lack of detailed knowledge of the needs and challenges faced by different families who have children with intellectual disability. The outcomes of data-gathering and analysis in the current study are thus focused towards formulating recommendations that can be useful for special education services in the country.

Research Aim 5: To explore the possible phenomenological reasons behind the observed quantitative results for examining family quality of life of Saudi Arabian families, and to discern what kinds of support they feel they need.

4.3.2 Research Questions and Hypotheses

Corresponding to the above research aims, the current study seeks to answer the following research questions:

Research Question 1: Are the Saudi Family Quality of Life Scale, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with an intellectual disability, valid with respect to Saudi Arabian families?

Hypothesis 1a: The proposed Saudi Family Quality of Life Scale, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with an intellectual disability will receive face validation by a panel of experts.

Hypothesis 1b: The religiosity factors (Part 2 of the questionnaire) will be validated by an exploratory factor analysis.

Hypothesis 1c: The other religio-cultural factors related to caring for a child with intellectual disability (Part 4 of the questionnaire) will be validated by an exploratory factor analysis.

Hypothesis 1d: The new items added to the Beach Center Family Quality of Life Scale (items 26-31 in Part 3 of the questionnaire) will be validated by an exploratory factor analysis.

Hypothesis 1e: The validity of the factor structure of the original Beach Center Family Quality of Life Scale will be confirmed by a confirmatory factor analysis.

Research Question 2: Are the identified factors of the Saudi Family Quality of Life Scale, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with an intellectual disability, reliable with respect to Saudi Arabian families? Further, are there inter-correlations between the factors?

Hypothesis 2a: The identified factors of the religiosity measure (from Part 2 of the questionnaire) are internally consistent for Saudi Arabian families.

Hypothesis 2b: The identified factors of the other religio-cultural factors related to caring for a child with an intellectual disability (from Part 4 of the questionnaire) are internally consistent for Saudi Arabian families.

Hypothesis 2c: The identified factors of the Saudi Family Quality of Life Scale (from Part 3 of the questionnaire) are internally consistent for Saudi Arabian families.

Hypothesis 2d: The identified factors of the original Beach Center Family Quality of Life Scale will be positively inter-correlated.

Hypothesis 2e: The identified factors of the Saudi Family Quality of Life Scale will be positively correlated with the validated factors of the religiosity construct and the other religio-cultural factors related to caring for a child with an intellectual disability measure.

Hypothesis 2f: The identified factors of the religiosity construct will be positively correlated with the identified factors of the other religio-cultural factors related to caring for a child with an intellectual disability measure.

Research Question 3: Do Saudi families who care for children with intellectual disability experience a significantly different quality of life compared to those families who do not, and are the factors associated with both groups the same?

Hypothesis 3a: For all dimensions of the Beach Center Family Quality of Life Scale, quality of life for families with children who have intellectual disability will be lower than that for families of children without intellectual disability.

Hypothesis 3b: Religiosity factors will be more positively correlated with the dimensions of family quality of life for families of children with intellectual disability than for families of children without intellectual disability.

Hypothesis 3c: Demographic factors associated with Saudi family quality of life (income of participant-parent, employment status of participant-parent, gender of participant-parent, marital status of parents, age of participant-

parent, and family size) will be the related in the same ways for families of children both with and without intellectual disability.

Hypothesis 3d: Religio-cultural factors associated with Saudi family quality of life (love for children with intellectual disability, family acceptance of children with intellectual disability, and social acceptance of children with intellectual disability) will be the related in the same ways for families of children both with and without intellectual disability.

Research question 4: Based on the personal opinions of participant-parents, are there discernible patterns in families' interpretations of what is most important to family quality of life, in their perceptions of the challenges of raising children with intellectual disability, and in the kinds of special assistance families feel they require due to having to care for children with intellectual disability?

4.4 Significance of the Research

There are various stakeholders who are expected to benefit from the current study. First, from an academic perspective, the current study is significant in terms of broadening the applicability of family quality of life and the other aforementioned measures for different social cultural contexts. As explained by Turnbull et al. (2007), family quality of life is a highly complex construct since it deals with the perception of individuals regarding the quality of the life of their family. The measure goes beyond objective considerations in determining the wellbeing of a family, such as having sufficient income or an independent dwelling. The standard measure utilised in developed Western countries cannot be immediately automatically applied to all cultures. Rather, it is important to examine the validity of

the measure in each cultural context and adjust, if needed, the items in the questionnaire according to the uniqueness of contexts. While doing so may affect the comparability of outcomes between questionnaires, what is more important is to ensure that the questionnaire used for Saudi Arabian families is applicable to these families, in order for the study to be able to formulate practical recommendations that can benefit the government of Saudi Arabia and its constituents. This is an important scholarly endeavour that is part of the protocols that are conducted in the current study.

The improvement in the measurement of family quality of life is considered as a key contribution to both the current study and future studies of the numerous factors that impact on families in Saudi Arabia. Indeed, it is hoped that the current study may serve as a catalyst for the further expansion of research on family quality of life measures in other social contexts. Taking their cue from the methodology and findings of the current study, other studies may conduct superior family quality of life research on families with children who have, or do not have, intellectual disability in other Middle East countries. Such studies may further validate the applicability of the Saudi Arabian Family Quality of Life questionnaire, and may determine the consistency of the outcomes of the current study for other cultures. As such, the current study has the potential to encourage further research into family quality of life within the Saudi Arabian context which will not only further the rigor of methodology, but enhance our understanding of this phenomenon in Saudi Arabia in the future.

From the perspective of Saudi Arabian society in particular, the current study is also expected to provide a number of benefits. The Kingdom of Saudi Arabia is

considered one of the more affluent nations in the world (Global Finance Magazine, 2015). Commensurate with its financial capacities, the Saudi Arabian state has long regarded itself as one that is focused on protecting and promoting the socioeconomic wellbeing of all of its citizens (Albatel, 2003; Aydin, 2014). In line with this obligation, the government is concerned with identifying and assisting those subsets of its population which face special, as yet unaddressed difficulties (Albatel, 2003). Addressing the needs of such groups is consistent with the mandate of the Ministry of Health to provide accessible quality care to all Saudi Arabian citizens (Information Office of the Royal Embassy of Saudi Arabia, 2013a), and more specifically, to address the special needs of those who have physical and intellectual disability (Information Office of the Royal Embassy of Saudi Arabia, 2013b). In as much as the Ministry seeks to do this, limited existing research on quality of life in Saudi Arabian families makes it difficult for the Ministry to identify particular foci that it can work on with its available resources. The same is true with respect to the Ministry of Education, which is also tasked to look after the educational needs of all school-aged citizens in Saudi Arabia, especially marginalized groups such as children with intellectual disability.

In the current study, the examination of family quality of life is expected to furnish the government with essential information that will help it to better evaluate the extent to which it is meeting its stated obligation of ensuring an acceptable quality of life for all of its families.

In particular, the current study seeks to aid the government in determining whether there are challenges being faced by families with children who have intellectual disability that significantly differ from families who only have children

without intellectual disability. By examining the family quality of life of these two groups, and then moving further into an analysis of the reasons behind any significant differences found, the current study intends to discover areas where different government agencies can help in improving the quality of life of Saudi Arabian families.

4.5 Conclusion

In very general terms, the current study aims to fill a gap that exists in our knowledge about the family quality of life experienced by families who care for children with intellectual disability. The study is motivated by the concern that the Saudi Arabian state should seek to fulfil its social welfare obligations with respect to such families. With knowledge of whether families of children with intellectual disability experience the same or a lower quality of life as other families, and if so, determining why, it is then possible to, if need be, formulate appropriately targeted programs to satisfy unmet needs.

The particular aims and associated research questions of this body of research are thus as follows. The first two research aims centre on establishing that the Beach Center Family Quality of Life Scale, augmented for the specific context of Saudi Arabia, can be used to measure family quality of life for Saudi Arabian families, including families of children with intellectual disability. The next two research aims relate to substantive empirical questions about Saudi family quality of life, especially with respect to families of children with intellectual disability. The final research aim of the study seeks to ‘get behind’ the quantitative analysis of Saudi family quality of

life to explore the possible reasons that some Saudi Arabian family members might offer which might explain some of the quantitative findings.

This will be the first attempt in the academic research literature to develop and validate a family quality of life construct, and then to measure quality of life for families of children with intellectual disability in the context of Saudi Arabia. It will thus also be the first attempt in the context of Saudi Arabia to ascertain whether family quality of life is significantly different between families who do, and do not have children with intellectual disability. Furthermore, the current study will also be the first to attempt to discern various demographic, religious and cultural factors that may impact on family quality of life in Saudi Arabia, particularly for families of children with intellectual disability. Thus it is anticipated that by satisfying these aims and answering these research questions, a substantial new contribution will be made to the knowledge about the quality of life of families of children with intellectual disability.

Chapter 5 : Methodology

5.1 Introduction

This chapter details the steps taken in order to develop a conception of family quality of life appropriate to Saudi Arabian families, the empirical questionnaires used to generate data, and the methods used to analyse those data. The structure of the chapter is as follows. First, a justification is provided for the mixed methods approach (quantitative and qualitative analysis) that is subsequently employed in the current study. Next, an account is given of the Delphi Technique used to develop a conception of Saudi Arabian family quality of life, which can then be used for questionnaire construction. Third, there is a detailed description of the application of the new Saudi Arabian Family Quality of Life Scale. Phases 1, 2 and 3 are presented. Detail is provided regarding the selection of participants; the two data collection methods employed (that is, a questionnaire and semi-structured interviews); the procedures followed in gathering the data; ethical concerns; and finally, the methods of data-analysis.

5.2 Research Design

The current study will employ a sequential mixed methods approach (Onwuegbuzie & Teddlie, 2003) to the investigation of the family quality of life of Saudi Arabian families with and without children with intellectual disability. Mixed methods research can be characterised in various ways, but in essence it amounts to the investigation of one phenomenon or problem by means of a number of different methods (Creswell, 2013). Typically, it involves the combination of a quantitative

technique and a qualitative technique in a manner that is complementary. A more formal definition is provided by Johnson, Onwuegbuzie, and Turner (2007, p. 19):

Mixed research is formally defined here as the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language in a single study or set of related studies. This type of research should be used when the contingencies suggest that it is likely to provide superior answers to a research question or set of research questions.

The mixed methods approach may be judged to be innovative or problematic, depending on one's philosophical preconceptions. In the social sciences, a bifurcation of methods emerged in the 20th century (Kincaid, 2002). A quantitative approach to empirical studies has traditionally been associated with a positivist philosophy which stresses the importance of objective, observable, measurable data as essential to an understanding of 'reality' (Michell, 2003). By contrast, subjectivist, constructivist and hermeneutic philosophical approaches to human-social phenomena stress the importance of 'meaning' and 'reflexivity' (Creswell, 2013; Gergen & Gergen, 2000; Margolis et al., 1986). Although a mixed methods approach has existed since the beginning of the 20th century, it is only until relatively recently that it has become a 'mainstream' approach to empirical research deemed to provide greater insight into problems and phenomena of interest, rather than single-method approaches provide (Creswell & Plano-Clark, 2010; Nastasi & Hitchcock, 2015; Teddlie & Tashakkori, 2008). There are a number of reasons for this development. Most notably, the collapse of the positivist hegemony in the philosophy of science opened a space for more liberal and pluralist thinking on methodology (Longino,

2002). Thus, it became methodologically acceptable to explore the possibility of combining methods that were previously deemed to be incompatible on the grounds that it may simply prove 'workable' in practice. In this respect, mixed methods approaches may be said to either explicitly or implicitly rely upon a pragmatist philosophical framework (Johnson & Onwuegbuzie, 2004; Heyvaert et al. 2013). Another reason for the rise of mixed methods approaches is advances in the capacity to statistically analyse qualitative data in new ways, and new more rigorous protocols for collecting and interpreting qualitative data from interviews (Nastasi & Hitchcock, 2015). Perhaps more importantly, however, it is the manifest advantages that have emerged in practice that led to mixed methods approaches becoming acceptable.

Greene et al. (1989) have summarised the chief advantages of a mixed methods approach. They identify five reasons or useful functions. First, the use of multiple methods in the one study better enables the answering of research questions by tackling a problem from different directions (also known as 'triangulation'). Second, different methods, which furnish different kinds of data, facilitate a better overall understanding of the phenomenon of interest (also known as 'complementarity'). Third, similarly, different methods can yield a better understanding of the nature of the research problem because one method may shed light on how the other method can be improved (also known as 'development'). Fourth, when multiple methods are used, the likelihood increases of discovering something problematic about the theories or models being used or tested (also known as 'initiation'). Finally, a mixed methods approach, by expanding the range of exploratory and testing techniques utilised, tends to generate more new theories,

models and research projects than single-method approaches (also known as ‘expansion’).

These are all compelling reasons for employing a mixed methods approach rather than a narrower single-method approach, however, it should be said that for the purposes of the current study, it is the advantages of ‘triangulation’ and ‘complementarity’ that are the most compelling reasons. At a general methodological level, it is for these reasons that it was decided that this thesis should utilise a number of different methods sequentially in seeking to satisfy its aims and answer its research questions. Also, a mixed methods approach to the study of families of children with intellectual disability was appropriate because families in such situations have personal experiences which often cannot be captured by just a quantitative analysis of their objective characteristics, while at the same time it is undeniable that there is much to be gained from a statistical examination of their circumstances.

The particular mixed methods approach adopted in the current study is best described as a *sequential quantitative-qualitative follow-up analysis* (Onwuegbuzie & Teddlie, 2003). An initial item development phase (known as the Delphi Technique) was used to develop a questionnaire to measure components of Saudi Arabian family quality of life. Then after administering the questionnaire, the quantitative analysis would serve to establish the psychometric robustness of the questionnaire for Saudi Arabian families, and investigate the existence of hypothesized relationships between family quality of life and different variables, such as religiosity and other religio-cultural factors related to caring for a child with an intellectual disability. Next, semi-structured interviews would be conducted that

reflexively referred to the questionnaire; the subsequent qualitative analysis would then serve to help explain the reasons behind the relationships found from the quantitative analysis. The quantitative analysis is thus complemented by the qualitative analysis: the latter enables exploration of the subjective significance of factors associated with family quality of life of those caring for children with an intellectual disability, and the former assists in identifying the objective context of the subjective concerns of families.

As explained by Creswell (2013), the value of a sequential approach is that it enables the study to go deeper into understanding a phenomenon by using the outcomes from one method as a basis for the conduct of the second method. In the current study, the quantitative method will be used first in order to measure family quality of life among families in Saudi Arabia. Based on this, it will then be possible to identify families who have different characteristics and family quality of life experiences considered to be ideal for the succeeding part of the study, which intends to understand families' experiences better through qualitative data-gathering and analysis. The sequencing of the quantitative-then-qualitative phases is also essential because the interview phase requires that participants have first completed the questionnaire in order to reflect on their answers to it. (For example, one of the interview questions asks: "Based on the questionnaire that you completed, the quality of life of your family is (describe result). Do you agree with this evaluation? Why/why not?") Also, as a practical matter, the quantitative-then-qualitative sequence is necessary because the participants in the qualitative phase (interviews) will be selected based on their responses to the quantitative phase (questionnaire). Finally, the use of a sequential mixed methods research design is consistent with

other studies that have similarly examined family quality of life but in different, Western contexts, such as in Steel et al. (2011) and in Michalik (2015), thereby demonstrating the contemporary adoption of this design in the field of quality of life research.

It should be noted that a mixed methods approach is not accepted as being legitimate by all researchers. At a general philosophical level, some have argued that the supposed clear distinction between quantitative and qualitative data and methods makes a mixed methods approach problematic. Giddings (2006, p.195), for example, claims that “the use of the terms ‘qualitative’ and ‘quantitative’ as normative descriptors reinforces their binary positioning, effectively marginalising the methodological diversity within them”. Hammersley (2008) argues that by reinforcing the dichotomy, the conception of mixed methods actually inhibits methodological innovation which would transcend the schism. Bergman (2008) strongly contends that the quantitative-qualitative division is artificially maintained to protect established researchers’ self-identities and interests. Others, by contrast, have been critical of researchers using mixed methods approaches because they have failed to recognise that there is a fundamental ‘formal’ (logical) difference between qualitative and quantitative properties of phenomena (Michell, 2011). While it is acknowledged that mixed methods approaches can be misused or used in confused ways, it does not follow that they are always inferior to a single-method approach, or that the empirical insights they can yield are illusions (Teddle & Tashakkori, 2003). It is for these reasons that a mixed methods approach was seen as most appropriate for the current study.

5.2.1 The Sequential Quantitative-Qualitative Analysis and Research Aims

Turning now to the details of the mixed methods approach to be used in the current study, it can be seen that the sequential quantitative-qualitative follow-up analysis is highly suitable, given the research questions that are posed, because they will require both quantitative and qualitative data in order for them to be answered comprehensively.

The first research aim of the study is to construct and verify the validity of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) augmented to include variables assumed to be relevant to Saudi Arabian families of children with intellectual disability. This will require the adaption and evaluation of an existing questionnaire for measuring family quality of life in Saudi Arabian families. First, the current study will employ the Delphi Technique in order to establish the face validity of the proposed questionnaire. The Delphi Technique is a qualitative method of marshalling the knowledge and advice of experts without interpersonal biases (Linstone & Turoff, 1975). In the current study, that expert knowledge and advice is used to augment a conceptual construct (referred to as the *Saudi Arabian Family Quality of Life*) in order to then develop a questionnaire to generate data. Following the face validity test, and the collection of data from the administration of the questionnaire, the study will conduct an exploratory factor analysis of the newly added measures of religiosity, other religio-cultural factors related to caring for a child with an intellectual disability, and the augmented factors of the Beach Center Family Quality of Life Scale. Confirmatory factor analysis of the original Beach Center Family Quality of Life Scale will be conducted. These analyses will serve to quantitatively validate the factors in the questionnaire.

After conducting this validity test, the second research aim can then be dealt with, namely, to test the reliability of identified factors (if any) in the Saudi Arabian Family Quality of Life questionnaire, including any possibly identified factors of the proposed measures of religiosity (Part 2 of the questionnaire) and other religio-cultural factors related to caring for a child with an intellectual disability (Part 4 of the questionnaire).

The third research aim is to determine the factors that could impact upon family quality of life among Saudi Arabian families, including for families caring for children with an intellectual disability. The factors will include the gender of participants, family size, marital status of parents, socioeconomic and employment status, religiosity and other religio-cultural factors related to caring for a child with an intellectual disability. Examination of how these factors associated with family quality of life also entails the use of specific statistical techniques, such as analysis of covariance.

The fourth research aim is to determine whether caring for children with intellectual disability is associated with family quality of life among Saudi Arabian families (positively or negatively) relative to those families caring for children without intellectual disability. This will entail a comparison of the measured family quality of life of families with children who have intellectual disability, with families who have children with no intellectual disability. This is best achieved quantitatively, and requires an approach that is similar to that used by Rillotta (2010), requiring a sufficiently large sample of the target population. As such, the quantitative part of the study can be best described as a cross-sectional, comparative design (Blair & Blair, 2011).

The fifth research aim is to explore the possible phenomenological reasons behind the observed quantitative results for examining family quality of life of Saudi Arabian families; as well as to gather the perspectives of families on what kinds of special assistance the families of children with intellectual disability feel they require due to having to care for a child with an intellectual disability. These aims involve finding out how individual families interpret 'quality of life' for themselves and the extent to which they regard raising children with intellectual disability as burdensome or a challenge. It also involves exploring how they believe their particular needs would best be met. The answers to such questions are bound to be inherently subjective and personal, and are best elicited by allowing participants to develop extended answers which enable them to fully express their beliefs and experiences. Thus, to achieve this fifth research aim, a different kind of data collection strategy will be required that goes beyond the information that could be transmitted via a closed-response questionnaire. Because the subjective lived experiences of participants cannot be easily captured by a closed-response questionnaire (Brown, 2009), a qualitative type of instrument will be necessary: namely, semi-structured interviews with open-ended questions that will allow participants to answer in any way they want, and thereby better capture the responses needed to address the research aims. This is consistent with the description of a phenomenological qualitative research design (Creswell, 2013; Merriam, 2009). As explained by Merriam (2009), in order to be able to understand the phenomenon of interest sufficiently, those who experience the phenomenon need to be interviewed in detail. The phenomenon itself cannot be studied in a vacuum; it must be studied based on how other people perceive it.

5.2.2 Overview of Sequential Phases of Investigation

As already stated, the current study required both qualitative and quantitative components in order to establish a comprehensive understanding of family quality of life for Saudi Arabian families. The phases and steps of the study are set out in the diagram below (Figure 5.1).

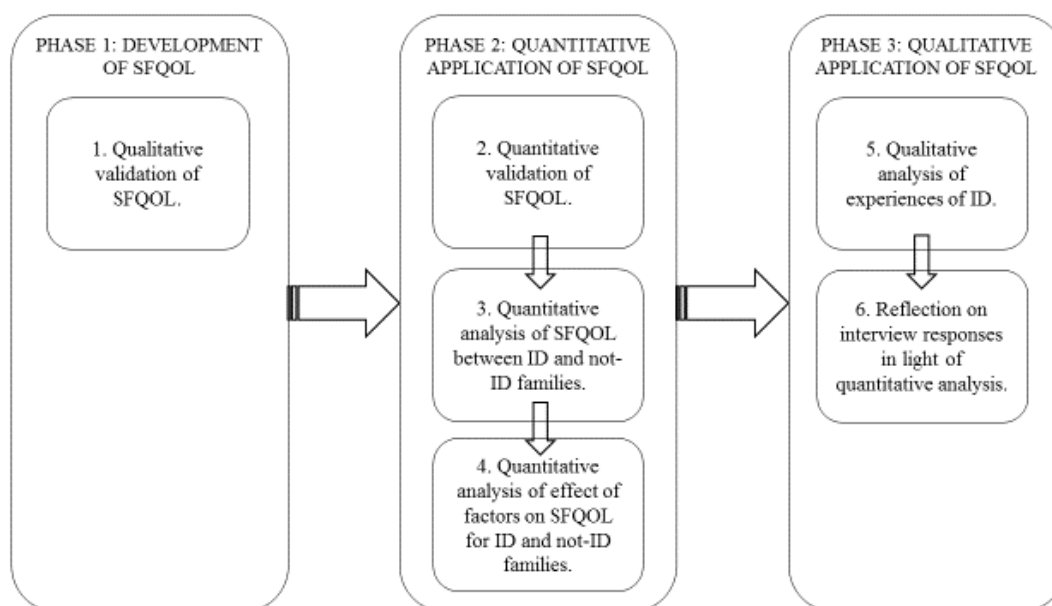


Figure 5.1: Sequence of Phases of Study

Note: SFQOL = Saudi Arabian Family Quality of Life Questionnaire; ID = children with intellectual disability

Phase 1 is devoted to the initial development and face validation of the entire Saudi Arabian Family Quality of Life Questionnaire. It involves the use of the (qualitative) Delphi Technique to augment the existing Beach Center Family Quality of Life Scale (Hoffman et al., 2006).

Phase 2 is devoted to the implementation and quantitative analysis of the Saudi Arabian Family Quality of Life Questionnaire. This will involve three steps. First, a factor analysis will be conducted on responses by a (non-random) sample of Saudi Arabian families to the Saudi Arabian Family Quality of Life Questionnaire

for validation and reliability (step 2). This will be conducted in order to ensure the suitability of the questions and format for the given population of interest, as well as to establish the validity and reliability of additional constructs vital to address the research aims. Thereafter, in step 3, there will be a statistical examination of whether there are differences between the family quality of life experienced by Saudi Arabian families with children who have intellectual disability, and Saudi Arabian families who only have children without intellectual disability. Following this, in step 4, covariance analysis will be conducted to examine the association with other factors, such as demographic variables, religiosity, and other religio-cultural factors related to caring for a child with an intellectual disability, on family quality of life.

Finally, *Phase 3* is devoted to a qualitative examination of Saudi Arabian family quality of life. It involves semi-structured, open-ended question interviews with participants to ascertain their personal experiences and subjective beliefs about caring for a child with an intellectual disability, and how that affects their perception of family quality of life, as well as their views on whether they have unmet needs that should be addressed (step 5). After this step, there will be a synthesis of all these results, which reflects on the quantitative results in the light of the interview responses, in order to gain some insight into both the quantitative and the qualitative findings (step 6). These three Phases are explained in detail in the following sections.

5.3 Phase 1: Development and Face Validation of the Saudi Arabian Quality of Life Questionnaire

The Beach Center in the United States of America developed a questionnaire for measuring family quality of life, known as the Beach Center Family Quality of

Life Scale (Hoffman et al., 2006), and established the validity of this questionnaire for Western populations. However, this questionnaire had not yet been validated for use in Saudi Arabia. Considering the substantial differences between Saudi Arabian and Western culture, such validation is necessary before the construct can be administered or interpreted with confidence in Saudi Arabia. In addition to this, the extant literature identifies different variables that were found to be associated with family quality of life (Hoffman et al., 2006; Poston et al., 2003; Saito & Turnbull, 2007; Tay & Diener, 2011). These variables include demographic variables (age, gender, marital status, socioeconomic status, educational attainment, family size), religiosity, and other religio-cultural factors related to caring for a child with an intellectual disability. However, validated questionnaires for the measurement of religiosity, and other religio-cultural factors related to caring for a child with an intellectual disability were not found, so items needed to be constructed for this purpose and included in the questionnaire.

Before administering the questionnaire, it is first important to establish the suitability of the item content and format – that is, to qualitatively validate the questionnaire. Thus the Delphi Technique will be utilised to assess the face validity of the Beach Center Family Quality of Life Scale, and to potentially validate augmentations to it based on advice from a panel of experts. This is intended to partially satisfy Research Aim 1 of the current study – namely, to construct and verify the validity of the Beach Center Family Quality of Life Scale – and to address Hypothesis 1a, which states: The proposed Saudi Arabian Family Quality of Life Scale, the measure of religiosity, and the measure of other religio-cultural factors

related to caring for a child with intellectual disability will receive face validation by a panel of experts. (Complete validation testing would then be completed in Phase 2).

Ethics approval to conduct Delphi Technique interviews was obtained from the Western Sydney University Human Research Ethics Committee. The ethics approval code that was issued to the study is H10980. See Appendix D.

5.3.1 Participants

In order to employ the Delphi Technique, a purposeful sample of 10 expert participants will be invited from among Saudi Arabian education professionals – specifically academics in the education field – who have worked within or who have studied special education programs in Saudi Arabia. Further, the 10 participants, being Saudi Arabian citizens who have lived most of their lives in Saudi Arabia, could be considered as experts in relation to questions that are related to quality of life, religiosity, and perspectives about intellectual disability held by fellow Saudi Arabians.

A purposeful sample is appropriate for this Delphi Technique since the objective is not to actually derive data about the population, but to examine the appropriateness of a construct of Saudi Arabian Family Quality of Life for the Saudi Arabian population, with a view to constructing a data-generating questionnaire. As explained by Green et al. (2007), this is best determined through a discussion with a panel of experts. As such, in the context of developing the questionnaire as in the case of the current study, the technique serves as a means of establishing the face validity of the measure.

The members of the sample will be invited personally, by email or telephone, to participate in the study as resource persons for the Delphi Technique. They will consist of academic colleagues of the researcher who have demonstrated an intellectual interest in children with disabilities. The researcher is connected to these experts through the academic program with the government of Saudi Arabia in which the researcher is engaged. The participants range from 32 to 55 years old, and each has had at least 3 years' experience teaching or managing educational programs in Saudi Arabia. Furthermore, they have different specializations; three of them are academicians in the social sciences while the other seven are academicians in the natural sciences. Seven participants are married and have children, but three of the participants do not have children of their own. None of the participants was considered as an expert on the measurement of family quality of life. However, what is important is that they be able to understand each item and relate its relevance to their socio-cultural perspective as Saudi Arabians. All of the participants are male, but they come from different universities in Saudi Arabia. It is important to note that some female experts were informally asked, but were not willing or able to participate for various reasons.

5.3.2 Procedure

To begin with, a copy of the original questionnaire formulated by The Beach Center (Hoffman et al., 2006), along with a list of suggested augmentations to the original questionnaire (based on extant published research) will be sent to each of the experts individually via email. The suggested augmentations will include adding questions about family religiosity, as well as other religio-cultural factors related to

caring for a child with an intellectual disability. Also, other items (questions) will be suggested for addition to the questionnaire that may be relevant in determining the factors which impact on Saudi Arabian Family Quality of Life. These include: asking about marital status, family size, parental education level, employment and socioeconomic status (income), the number of children in the family with intellectual disability, secondary disabilities (such as physical disabilities) of the children with intellectual disability, and the severity of the intellectual disability.

The experts will be asked to read the questionnaire, examine the items in the questionnaire, including the suggested additions, and reflect on whether or not each item included is important for assessing family quality of life from their perspective. In addition to this, they will be asked to provide reasons for considering an item to be important or unimportant. The experts' answers will be used as the basis for revising the questionnaire.

Upon revision, the revised questionnaire, as well as the answers provided in the previous round, will be de-identified and sent back to the participating experts. Each participant will be asked to review the comments from all other participants and then, if necessary, make revisions to his earlier comments based on any changes in his perspective coming from having read the positions of other participants. They will also be asked to provide comments on the inputs of the other participants where they felt this was appropriate. The resulting comments will then be collected again and copies will be provided to the participants for further review. The process will be repeated three times.

All communication will be conducted anonymously via email; that is, none of the experts will have any knowledge of the identity of the other participants. All direct email communication will be with the researcher of the current study. Communication between the experts will be conducted through the researcher who will de-identify each expert's comments before making them accessible to others. They will be rendered anonymous because it is important for the experts to be able to evaluate their peers' perspectives objectively without reference to the identity, status or reputation of the peer.

5.3.2.1 Translation

The original Beach Center Family Quality of Life Scale was written in English. In order to ensure that the experts will be able to accurately understand and freely reflect on the subsequently developed questionnaire for the Saudi Arabian Family Quality of Life Scale, the original questionnaire needs to be translated into Arabic. The translation will be first performed by the researcher, who will then subsequently employ the services of a professional English-Arabic translator to verify the researcher's translation. After the questionnaire has been finally developed in Arabic via the Delphi Technique, the questionnaire will be ready to be administered to Saudi Arabian families. For the publication and examination of this thesis, the augmentations to the original questionnaire will be translated back from Arabic into English for English speakers. Again, the researcher will perform the first 'draft' translation, which will then be verified by the professional English-Arabic translator. The use of a professional translator ensures that semantic fidelity will be maintained in shifting back and forth between the two languages.

5.3.3 Results

In the first round of evaluation, some of the participants pointed out that the questions about family religiosity in the second part of the questionnaire were not needed because all Muslims were likely to answer “yes” to each of the questions. For example, “There is only one God” is definitional to the identity of Saudi Arabian citizens; “I pray to God five times a day” is legally mandated behaviour in Saudi Arabia that is virtually guaranteed by belief, by the state, and by social expectations. Another matter that the participants pointed out was that there was some confusion as to what “family” referred to in the third part of the questionnaire (The Beach Center Family Quality of Life Scale; Hoffman et al., 2006). There was also some confusion among the participants as to how to answer the items about children when the participant did not have a child. The three participants who did not have children refrained from commenting about items that they felt they did not have sufficient experience with or could not relate to. For example, they refrained from commenting on the item “My child with an intellectual disability has support to accomplish goals at home” because they were unsure as to what a child “accomplishing goals at home” would involve. However, concerning other items referring to children, they felt more confident about commenting, such as “People in my religious and/or cultural community do not reject my child with/WITHOUT an intellectual disability” because of their experience observing how others in public and family settings reacted to children with intellectual disability.

In the second round of the evaluation, one of the participants rejected the concern that one would not expect any variance in the answers to questions about religiosity. He argued that just as in any society, there were some Saudi Arabians

who may be considered as highly religious and others who could not be considered as such. Another participant added that while it was likely that many Saudi Arabians would answer positively to the items, there would still be some variability if the choices for answering were scaled, such as from “highly disagree” to “highly agree”, instead of binary responses (yes/no). Furthermore, another participant suggested that additional items be added to the religiosity part of the questionnaire (such as “I am content with the extent to which religious and/or cultural values contribute to my family's quality of life”) to try to make the measure of religiosity more sensitive.

With regard to the matter on the definition of “family”, one of the participants observed that there should be a clear definition of what should be included as part of the family on the first page of the questionnaire. He suggested that it may be difficult for participants to remember this when they arrived at Part 3 of the document, and recommended moving the description of “family” closer to that part of the questionnaire. Two of the participants claimed that the questions about family quality of life which explicitly mentioned children could be confusing to participants who did not have children. However, at this point, the researcher intervened and explained to these participants that the questionnaire will be administered only to families who have children.

During the third round of evaluation, there were no new inputs collected. The participants agreed to keep the questions in Part 2, as well as add the new questions suggested in the previous round. They also agreed to move the description of family closer to Part 3 of the questionnaire. These changes were then implemented before the questionnaire was administered to the target sample.

This questionnaire, entitled the Saudi Arabian Family Quality of Life, included The Beach Center Family Quality of Life Scale (Hoffman et al., 2006), additional items added to the original scale about social support and faith-based support, a measure of religiosity, and other religio-cultural factors related to caring for a child with an intellectual disability, and other sections on various demographic variables and family-specific factors for those families with children with intellectual disability. The final copy of this questionnaire, as distributed after the pilot study, can be found in Appendix A while a copy of the original Beach Center Family Quality of Life Scale can be found in Appendix B.

In summary, the Delphi Technique was adopted to yield a questionnaire that was supported by each of the 10 professionals who had expertise in the area of education and Saudi Arabia. As such, this questionnaire can be considered to have face validity. It can thus be concluded that Hypothesis 1a – that the proposed Saudi Arabian Family Quality of Life Scale, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with an intellectual disability will receive face validation by a panel of experts – was confirmed. It remained critical, however, to employ quantitative means to determine whether the questionnaire could be considered as both externally reliable and valid. For this purpose, reliability and validity testing of the questionnaire was conducted using the sample data in the first step of Phase 2 of the current study (See Figure 5.1 above).

5.4 Phase 2: Quantitative Validation and Implementation of the Saudi Arabian Family Quality of Life Questionnaire

The central purpose of Phase 2 is to address the quantitative aspects of Research Aims 1, 2, 3 and 4 of this body of research. Aim 1 focuses on quantitative validation of the Saudi Arabian Family Quality of Life Questionnaire by examining the statistical relations between family quality of life and the additional dimensions added due to the recommendations of experts via the Delphi Technique. Ethics approval for the administration of the questionnaire and use of the collected data was obtained from the Western Sydney University Human Research Ethics Committee. The ethics approval code that was issued to the study is H10980. The researcher also obtained approval from the Ministry of Education in Aljouf, Saudi Arabia under Approval# 36611389. These two approval letters can be found in Appendix D.

Aim 2 is to examine whether the identified factors of the Saudi Arabian Family Quality of Life Scale, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with an intellectual disability are reliable. Aim 3 is to determine whether demographic factors, religiosity, and other religio-cultural factors related to caring for a child with an intellectual disability impact on family quality of life for Saudi Arabian families. Aim 4 is to determine whether caring for children with intellectual disability, compared to caring for children without intellectual disability, is associated with family quality of life among Saudi Arabian families (positive or negative).

5.4.1 Procedure for Recruitment of Participants

As explained by Blair and Blair (2011) and Argyrous (2013), samples are selected from populations of interest. In the current study, the populations of interest are Saudi Arabian families who have school age children with intellectual disability, and Saudi Arabian families who only have school age children without intellectual disability.

Recruitment of the sample was facilitated by the Ministry of Education in Saudi Arabia. From the Ministry of Education, the researcher was able to identify schools which were attended by students with, and without, intellectual disability. All children with intellectual disability came either from special education schools or schools which specially catered for students with intellectual disability (with separate classes and teachers). The researcher requested that the Ministry of Education identify a sufficient number of schools such that 150 families of children with intellectual disability, and 150 families without intellectual disability, could eventually be invited to participate in the study. Thus a projected sample of 300 Saudi Arabian families was identified. This sample size was considered appropriately large by conventional statistical standards (Blair & Blair, 2013; Stevens, 1996; Teddlie & Tashakkori, 2008), and similar to those used in other studies that examined family quality of life (Michalik, 2015; Steel et al., 2011). It should be noted, however, that the researcher was not privy to the means by which the Ministry of Education selected the schools which it made available to the researcher. It is thus unknown whether the selection of the schools was by random selection or not, and if not, what selection rule was applied.

The Ministry of Education provided the researcher with the contact details of the Principals of these schools. The researcher contacted these Principals, explained the purpose of the study, and requested that they contact families who had children either with or without intellectual disability in their schools. No Principals who were contacted by the researcher refused the request. The researcher supplied the Principals with copies of the study's questionnaire and a cover letter explaining the study to potential participants, and the extent of his or her prospective participation should he or she choose to become a participant. The Principal of each school contacted parents via the telephone and asked if they were willing to participate in the study.

From the pool of 150 families contacted who had children with intellectual disability, 110 (73%) agreed to participate. Among the 150 families contacted who only had children without intellectual disability, 139 (93%) agreed to participate. (Note that this is the number who agreed to complete the questionnaire, not the number who actually *did* complete the questionnaire). Although the response rate may be regarded as somewhat high, it may be accounted for by the fact that parents were contacted directly by their school Principal, rather than merely by an impersonal letter. Certainly, Schilpzand et al. (2015) found that taking a more personal approach markedly increased questionnaire response rates from parents. With respect to Saudi Arabia in particular, traditional methods of administering questionnaires (such as by telephone) have been found to have very high rates of compliance (response) rates (Al-Subaihi, 2008).

After recruiting the sample, the questionnaire, along with information about participants' rights and protections, was distributed by the school Principal to one of the parents of each child either by email, by hand, or via the child.

5.4.2 Participants

Of the 110 people who agreed to participate and who had children in special education, only 86 (78%) actually completed the questionnaire. On the other hand, 115 (82%) out of 139 of the participants who had children without intellectual disability and who attended a mainstream public school completed the questionnaire. This led to a total sample size of 201, which was lower than the target of 300 (67%). Nonetheless, this can still be considered a sufficiently large sample and is comparable to those found in studies by Michalik (2015) and Steel et al. (2011). The responses on each questionnaire were encoded in an electronic database for analysis.

5.4.2.1 Characteristics of Participants

The following table summarises the characteristics of the participants in Phase 2.

Table 5-1: Characteristics of Phase 2 Participants

	Frequency	%
Gender		
Mother	36	17.9
Father	165	82.1
Marital status		
Divorced	14	7
Married	187	93
Location		
City	117	58.2
Town	77	38.3
Village	7	3.5
Carer status		
Not primary carer	145	72.1
Primary carer	56	27.9
Highest Education Qualification		
Under High School	10	5
High School	13	6.5
College	92	45.8
Post Graduate	86	42.8
Employment status		
Employed	62	30.8
Student	83	41.3
None	56	27.9
Annual income		
Less than 60k	73	36.3
60k-120k	109	54.2
Over 120k	19	9.5

Of the 201 participants, the majority were male (82.1%). This was expected, given it is atypical for females in Saudi Arabia to interact with people they do not know. At the same time, there is the issue of males being the dominant personality in the household, and so are in greater authority on matters concerning the family (Moghadam, 2004). It is therefore typical for the participants of questionnaires conducted in Saudi Arabia to be predominantly male.

The overwhelming majority of participants were married (93%), with the remainder being divorced (7%). The percentage of divorced participants was higher than an estimated average for the population. The average percentage of divorced

Saudi men (excluding single men) in 2007 was only 1.3%, although for men aged under 45, the percentage was slightly higher (United Nations, 2009). It should be noted, however, that the percentage of divorced people in Saudi Arabia has been trending upwards since the 1990s, so a projection to approximately 2015, based on a 20 year trend up to 2007, would generate an estimated percentage of divorces in the population of between 2% and 4.5%. This is at least approaching the observed divorce percentage for the current study's sample. There were no unmarried participants, which is unsurprising given that having children out of wedlock is effectively illegal in Saudi Arabia.

A majority of the participants lived in the city (58.2%), while 38.3% lived in towns. The remainder lived in rural areas. Thus 96.5% of the sample was located in urban areas (i.e. a city or town). This is a higher level of urbanised living than for the population as a whole, of whom 83.1% lived in urban locations in 2015 (Central Intelligence Agency, 2016). This discrepancy may be explained by the source of the sample, which was taken from the records of families in the public school system. Public schools are unlikely to be located in rural villages, so there will be fewer available records of families in those locations. One may also surmise, however, that families of children with intellectual disability are likely to gravitate to urban areas where there is more social and governmental support than in isolated villages.

A majority of the participants did not claim to be the primary carer of their children (72.1%). This is expected since most of the participants were males, and are more likely to be in employment fulltime rather than being the primary carers of their children. One implication of this characteristic of the sample is that most of the participants were not the people who were primarily responsible for taking care of

children in the family. This could have affected the responses provided on the family quality of life questionnaire, since it is recommended that a family quality of life scale be administered to the primary carer of the family (Hoffman et al., 2006). This characteristic of the sample, however, could not be avoided as it is part of the cultural characteristics of Saudi Arabia to limit the exposure of women to strangers. In order to address the possible bias from this situation, it was considered whether the gender of the participant had any effect on the responses to the questionnaire. “Gender” was included as an item in the questionnaire, and was treated as a potential factor affecting the responses to the Saudi Arabian Family Quality of Life Scale.

A surprising feature of the data was the high percentage of participants with tertiary qualifications. Of all participants, 45% reported having a college (undergraduate) education and a very high 42% reported having post-graduate qualifications. The college percentage can be explained by the fact that gross tertiary enrolments in Saudi Arabia have risen rapidly over the last decade, with a 61% gross enrolment rate in 2015 (percentage of the total population of the five-year age group following on from leaving secondary school) (World Bank, 2016). It is more difficult to account for the high percentage of post-graduate participants in the sample. Some could be explained by the high enrolment in tertiary education just mentioned, but not all. It is possible that the high percentage is due to some mis-reporting by participants. That is, it may be the case that some of them are still in the process of completing their post-graduate qualifications. Thus, the relatively high proportion of adult students was not regarded as being a problematic characteristic compared to the average Saudi Arabian family.

In the light of the above observations, 41.3% of the participants listed their occupation as being students, while 30.8% listed themselves as being employed. The fact that a larger percentage of participants reported being students (rather than being employed) does not seem to have resulted in a socioeconomic discrepancy (in terms of income) between the sample and the Saudi Arabian population in general. A majority of the participants (54.2%) reported earning between SAR60,000 to SAR120,000 a year, while 36.3% reported earning less than SAR60,000. These findings are similar to the average salary in Saudi Arabia of SAR 85,230 (OECD, 2014), which suggests that student-status did not have an obvious skewing effect on the socioeconomic status of those participants in Phase 2.

From this demographic information collected from the questionnaire, it can be inferred that the sample that was collected in the current study exhibited substantial similarities to the Saudi Arabian population. Of course, there is some skewness to be expected in any sampling protocol, but the current study was able to exercise all means available in order to gather as representative a sample of the target population as possible.

5.4.2.2 Characteristics of Participants' Children

There were also more focused demographic data collected about the participants' children. These data are shown in Table 5.2.

Table 5-2: Characteristics of Questionnaire Participants' Children

	Frequency	%
Intellectual Disability status		
Without Intellectual Disability	115	57.2
With Intellectual Disability	86	42.8
Degree of Intellectual Disability		
Mild Intellectual Disability	52	25.9
Moderate Intellectual Disability	31	15.4
Severe Intellectual Disability	3	1.5
Secondary disability		
No	85	42.3
Yes	1	0.5

As previously mentioned, 86 of the participants had at least one child with an intellectual disability and 115 had children without an intellectual disability. Of those children with an intellectual disability, 57 (66%) were male and 29 (34%) were female. Of those without an intellectual disability, 62 (54%) were male and 53 (46%) were female.

With regard to the severity of the intellectual disability of the children, a majority of families with children who have intellectual disability reported their children as having only mild intellectual disability (60%), with 36% reporting having children with moderate intellectual disability and 4% with severe intellectual disability. In this regard, it was assumed that the participants were knowledgeable enough to identify the severity of the intellectual disability of their children. They could have gained this knowledge from having their children diagnosed with intellectual disability by a professional, or they could have gauged this based on their experiences in raising their child. Of course, one weakness of the data gathering procedure used is that the accuracy of the participants' responses cannot be verified.

There may have been underlying cultural issues that could have led some participants to misrepresent the severity of their child's intellectual disability, but there was no way for the study to efficiently determine if this was the case. This is an issue that needs to be considered when interpreting the data.

Only one of the participants who listed their child as having an intellectual disability stated that the child had a secondary disability. The impact of secondary disability cannot therefore be considered as a factor for quantitative analysis in the current study. As in the case of reporting on the severity of intellectual disability, the veracity of this finding about the characteristics of the sample also cannot be verified, and there may be underlying socio-cultural reasons why participants may not want to disclose the presence of a second disability for their child with an intellectual disability. This will be considered in a later section of this research.

5.4.3 Data Collection Instrument: Saudi Arabian Family Quality of Life Questionnaire

As already indicated, the questionnaire used was adapted from the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) but with additional elements found from the literature on religiosity, and based on other religio-cultural factors related to caring for a child with an intellectual disability that were considered relevant to establishing family quality of life for the Saudi Arabian context. In addition, some demographic characteristics that were considered relevant as factors associated with family quality of life, such as the number of children and marital status of the parents, were also gathered. A copy of the original questionnaire from the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) is attached as

Appendix B, while a copy of the final questionnaire that was used in the study is attached as Appendix A. As shown in Appendix A, the questionnaire designed for the current study consisted of five sections. The questionnaire was accompanied by a cover letter (Appendix C) which detailed the purpose of the questionnaire and assured the participants that their responses would be kept confidential and that no identifying information about them would be collected.

5.4.3.1 Part 1 – Demographic details

Part 1 of the questionnaire asked a series of demographic questions which were considered as significant in characterizing the different families included in the sample for the purposes of factor analysis, as identified in the literature review (Brown et al., 2006; Hoffman et al., 2006; Marlow et al., 2015 Turnbull et al., 2007; Saito & Turnbull, 2007; Samuel, 2010; Walkner et al., 2015). These included:

- a) Gender (male or female) and age of the participant.
- b) Marital status (married, single or divorced).
- c) Family size (number of family members, adults and children).
- d) Geographical location (city, town, village).
- e) Socioeconomic status as measured by their income bracket (less than 60,000 SAR to over 120,001 SAR).
- f) Highest educational qualification (no schooling, under high school, high school, bachelor, postgraduate, other).
- g) Current employment status (none, working, student, other).

In addition to this, Part 1 also collected data that determined whether or not participants' families had children with intellectual disability, as well as other details in relation to this such as the severity of the intellectual disability, the number of children with intellectual disability, and the presence of any secondary disability.

5.4.3.2 Part 2 – Religiosity.

Part 2 of the questionnaire sought to measure the religiosity of the participants, and consisted of 12 items that participants could answer by indicating the extent to which they agreed or disagreed with the statement on a five point Likert scale (1 = strongly disagree, 2 = disagree, 3 = neither, 4 = agree, and 5 = strongly agree). The items in this part of the questionnaire were constructed by the researcher for the current study and supported through the Delphi Technique described above, and informed by findings in the review of the literature about the relevance of religiosity in measuring the family quality of life of families who have children with disabilities in Arab cultures (Abdel-Khalek, 2009; Al-Khalifah, 1994; Hammoudeh, 2012; Longa & Elghanemib, 1987). Some items pertained to the participants' submission to particular tenets of the Islamic religion such as "I pray to God five times a day," and "I fast during Ramadan." There were also items that sought to draw more general data about the individual's religiosity, such as "I believe in the wisdom of my religion's laws," and "I believe the stories of the past taught in my religion." Higher scores indicated stronger religious beliefs.

5.4.3.3 Part 3 – Family Quality of Life.

The third part of the questionnaire consists of 31 items that were adapted from the Beach Center Family Quality of Life Scale (Hoffman et al., 2006). These

items asked about the participants' satisfaction across a wide range of elements in relation to the participants' family, and were responded to on a 5 point Likert scale (1 = very dissatisfied, 2 = dissatisfied, 3 = neither, 4 = satisfied, and 5 = very satisfied). Higher scores indicated higher family quality of life.

The Beach Center Family Quality of Life Scale (Hoffman et al., 2006) measures five domains of family quality of life deriving from 25 items. The first domain is family interaction, which is focused on measuring the extent to which members of the family communicate with one another and do activities with each other (questions 1-6). The second domain is parenting, which examines how parental figures nurture and guide the children in the family (questions 7-12). The third domain has items that seek to measure the emotional well-being of the members of the family (questions 13-16) while the fourth domain focuses on the physical as well as the material well-being of the family members (questions 17-21). Finally, the last domain in the original questionnaire considers disability-related support (questions 22-25).

For the current study, the first 21 questions were taken directly from the Beach Center Family Quality of Life Scale (Hoffman et al., 2006). They were accepted unchanged because they were all reflective of very general, unremarkable and readily identifiable characteristics of family life in Saudi Arabian culture. This was supported by the Delphi Technique, where none of the participating experts deemed any of these items to be inappropriate or abnormal vis-à-vis the average Saudi Arabian family. The next four items (questions 22-25) were modified based on the present study's desire to compare families who have children with intellectual disability, with families who do not have children with intellectual disability. For

example, in the Beach Center Family Quality of Life Scale, item 24 states: “*My family member with a disability has support to make friends*”, whereas the current study’s modified item 24 was: “*My child with an intellectual disability has support to make friends. (if you do not have a child with an intellectual disability answer this question for your children)*”.

Finally, the last six items (questions 26-31) were newly constructed by the researcher in order to capture a culturally specific aspect of Saudi Arabian Family Quality of Life relating to religious support. Three of the items (26-28) focus on social acceptance and support from the religious community of which the family is a member (by virtue of religious affiliation). The other three items (29-31) focus on the support that religion provides from within the family itself. As discussed above, these were developed by an examination of the extant literature (Al-Jadid, 2013; Alkhateeb et al., 2016; Eapen et al., 2006; Miller et al., 2016) and via consultation with experts using the Delphi Technique. Three of these new items focused on behavioural characteristics of the religious community in which the participant’s family was embedded. They are:

26. People in my religious and/or cultural community do not reject my child with/WITHOUT an intellectual disability.

27. People in my religious and/or cultural community provide practical assistance to my family because we have intellectual disability-related needs. (If you do not have a child with an intellectual disability, answer this question for your children).

28. People in my religious and/or cultural community provide emotional support to my family because we have intellectual disability-related needs. (If you do not have a child with an intellectual disability, answer this question for your children).

The other three new items focused on the religious characteristics internal to the family itself. They are:

29. My family's religion gives us strength and enables us to make sense of life.

30. My family relies on God and turns to God for aid.

31. My family's faith enables us to make sense of having a child with/WITHOUT an intellectual disability.

5.4.3.4 Part 4 - Families with Children with Intellectual disability.

The fourth part of the questionnaire was only for the families who had children with intellectual disability. An instruction was included at the beginning of Part 4 which instructed participants who did not have a child with an intellectual disability to skip Part 4 and proceed to Part 5. This part included 10 items that sought to measure different concerns that were found from the literature to be relevant in measuring family quality of life of families who have children with intellectual disability (Juhásová, 2015; Katschnig, 2006; Marlow et al., 2015; Michalik, 2015; Seltzer & Krauss, 2001). Some of these factors included the participants' perspective on whether there was a spiritual rationale behind being given a child with an intellectual disability, as well as other religio-cultural factors related to caring for a

child with an intellectual disability. As in Part 2, the participants for this part provided responses on a 5-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = neither, 4 = agree, and 5 = strongly agree). However, unlike in Part 2, the items in Part 4 were not designed to measure a single construct, but rather distinct, albeit related perspectives which parents may have about raising children with intellectual disability.

Three of the items in Part 4 were reverse scored after considering the direction of responses for such items in relation to the other items. The items that were reverse scored were “Having a child with an intellectual disability is a punishment from God for sinful behaviour,” “I am embarrassed by my child who has an intellectual disability,” and “I would prefer that non-family members not know that my child has an intellectual disability.” The reverse scoring was necessary for these items because, in contrast to the other items in Part 4, these items were ‘negatively’ framed statements. Since high Likert rankings were intended to indicate a ‘positive’ outlook about children with intellectual disability (e.g. “I love my child who has an intellectual disability” would score highly for a participant with a positive perspective), reverse scoring was necessary for items 2, 3, and 4 to ensure consistency (e.g. a high score indicating a positive outlook in response to “I am embarrassed by my child who has an intellectual disability” required that its scoring be reversed).

As a point of clarification, it should be noted that although there are nominal similarities between the ‘religious’ items in Parts 3 and 4, they are intended to explore different issues. The ‘religious’ items in Part 3 relate specifically to perceived *support for a family of a child with intellectual disability* – either

community support of a religiously-identifying group or religiously-informed support internal to a family. By contrast, the ‘religious’ items in Part 4 relate specifically to the religiously-informed *particular personal beliefs and attitudes* of the respondents *towards* a child with intellectual disability. In short, the Part 3 items relate to *perceptions about others* with respect to a family, whereas Part 4 items relate to *particular beliefs/attitudes of a respondent* with respect to having a child with intellectual disability.

5.4.3.5 Part 5 – Willingness to be Interviewed.

The last part of the questionnaire inquired about the participant’s willingness to participate in an interview and to provide their contact details if they were interested in doing this. It thus allowed recruitment of participants for the qualitative part of the study, Phase 3.

5.4.4 Data Analysis.

In line with Research Question 1 (see Chapter 4) on the validation of a questionnaire for measuring family quality of life among Saudi Arabian families, confirmatory factor analysis was used to determine the factor structure of the original Beach Center Family Quality of Life Scale – items 1 to 25 in Part 3 of the questionnaire – since these items were taken from the Beach Center Family Quality of Life Scale (Hoffman et al., 2006), with the minor adaptations noted above.

Exploratory factor analysis was conducted and reliability coefficients were calculated in order to determine whether the following factors were all applicable to

the population of interest, since they were new measures and because the Part 4 items were not intended to measure a single construct (Weisberg & Krosnick, 1996):

(a) Religiosity – Part 2 of the questionnaire.

(b) Other religio-cultural factors related to caring for a child with an intellectual disability – Part 4 of the questionnaire.

(c) The augmented and added factors to the Beach Center Family Quality of Life Scale – items 26 to 31 in Part 3 of the questionnaire.

Through the use of exploratory factor analysis, it could be determined whether or not grouping items in this part effectively measured those factors deemed in the literature to be important to family quality of life.

As per Research Question 2, reliability analyses of the identified factors from the above parts of the questionnaire were then conducted. As explained by Weisberg and Krosnick (1996), the internal reliability of a questionnaire is measured through the use of Cronbach alpha, which is a statistical measure of the extent to which the different items in the questionnaire seem to measure a single construct. Thus Cronbach alpha was used in order to determine whether the questionnaire had an acceptable level of internal reliability. A Cronbach alpha of at least 0.70 is considered to be acceptable for reliability (Weisberg & Krosnick, 1996). Then Pearson correlation coefficients for each of the factors remaining from the exploratory, confirmatory and reliability analyses were derived. Specifically, correlation coefficients for the factors making up the original Beach Center Family Quality of Life Scale were derived; cross-correlation coefficients for Part 3 with

Parts 2 and 4 of the questionnaire were derived; and cross-correlation coefficients for Parts 2 and 4 were derived.

Research Questions 3 and 4 were addressed with an analysis of covariance, to explore the extent to which different factors were associated with family quality of life in the study. Analysis of Covariance (ANCOVA) is a method which combines one-way ANOVA (Analysis of Variance) with linear regression, and which can deal with both categorical and continuous variables. Its central purpose is to determine the extent of the variance of one variable due to the variability of other variables. In the current study, these 'other variables' referred to the items in Part 1 (gender, marital status, family size, socioeconomic status, employment status), Part 2 (religiosity), and Part 4 (other religio-cultural factors related to caring for a child with an intellectual disability) of the questionnaire.

5.5 Phase 3: Qualitative Examination of Saudi Arabian Family Quality of Life.

The central purpose of Phase 3 of the current study is to address Research Aim 5 of this thesis, namely, to explore the possible reasons behind the observed differences in family quality of life between Saudi Arabian families, and to gather the perspectives of families on the kinds of special assistance they feel they require due to having to care for a child with an intellectual disability.

5.5.1 Participant Recruitment and Characteristics.

For the qualitative phase of the study, Phase 3, purposive sampling was used. As explained by Seidman (2012), purposive sampling is the selection of a sample

based on a set of criteria. Purposive sampling is preferred for qualitative studies in order to be able to get the full breadth of the diversity of participants in the population. In the study, the sample for the interviews was selected from the previous sample of families in Phase 2. The criteria applied were based on the outcomes of the questionnaire distributed in the quantitative Phase 2, with the purpose of ensuring that families with different family quality of life and different situations in terms of having children with intellectual disability, or having only children without intellectual disability, were included. These criteria were:

(1) Families with high scores on the Saudi Arabian Family Quality of Life Scale (a) with and (b) without children with intellectual disability.

(2) Families with low scores on the Saudi Arabian Family Quality of Life Scale (a) with and (b) without children with intellectual disability.

Following the conduct of the quantitative Phase 2, participants who met the criteria and who had indicated their willingness to undertake an interview in the questionnaire were contacted ($N = 27$).

The 27 participants who agreed to be interviewed were contacted by phone (having provided their contact details in the questionnaire) and asked if they were willing to participate in a one-on-one interview as a follow-up for the questionnaire they had completed. Out of the 27 people contacted, eight agreed to be interviewed for the study. All of the participants were male, which is reflective of Saudi Arabian culture where females are less likely to participate in private communication with a stranger (Moghadam, 2004). Table 5.3 provides demographic information about the interviewees.

Table 5-3: Characteristics of Interview Participants

Marital Status	Age	Location	Family size	Number of Children	Primary Carer	Employment status	Level of education	Household Income	Child with Intellectual Disability	Saudi Family Quality of Life
Married	53	City	7	4	Yes	None	Postgrad	> 120k	Yes	3.96
Married	45	Town	6	3	No	Working	Bachelor	> 120k	No	4.8
Divorced	33	Town	7	4	No	Working	Bachelor	< 60k	No	2.93
Divorced	50	City	6	3	No	Student	Secondary	< 60k	No	2
Married	45	City	7	4	No	Working	Post grad	> 120k	Yes	3.93
Divorced	34	Town	8	4	No	Working	Post grad	< 60k	Yes	1
Divorced	43	City	6	3	No	Student	Secondary	< 60k	Yes	1
Married	49	City	7	4	No	Student	Secondary	> 120k	No	4.7

Of the eight participants, four of them had family quality of life scores that were high (mean of at least 3.93 out of 5) while the other four had family quality of life scores that were moderate to low (mean of at most 2.93 out of 5). Among each of these groups, two participants had a child with an intellectual disability while the other two only had children without intellectual disability. Participants were recruited to represent each subgroup of interest:

- (a) Relatively higher family quality of life and a child with an intellectual disability.
- (b) Relatively higher family quality of life and no child with an intellectual disability.
- (c) Relatively lower family quality of life and a child with an intellectual disability.
- (d) Relatively lower family quality of life and no child with an intellectual disability.

5.5.2 Data Collection Instrument: Semi-Structured Interviews

For the qualitative phase of the study, a semi-structured interview was designed. In designing semi-structured interviews, it is important to formulate core questions that relate to each of the research questions relevant for this Phase 3 (Brinkmann & Kvale, 2014; DiCicco-Bloom & Crabtree, 2006; Gubrium & Holstein, 2002). In addition, the interviewer may proceed to ask follow up questions based on the participants' initial answer. These follow up questions can seek to clarify, explore, and expound upon the participants' perspectives in relation to the core question. Each interview is concluded after each of the core questions has been asked and explored sufficiently through follow-up questions (Brinkmann & Kvale, 2014; DiCicco-Bloom & Crabtree, 2006; Gubrium & Holstein, 2002).

For Phase 3, five sets of core questions were formulated. These core questions were:

1. What would you say are the most important things to consider in measuring the quality of life in a family? Why are these elements important?
2. Based on the questionnaire that you completed, the quality of life of your family is (describe result). Do you agree with this evaluation? Why/why not?
3. What are the major challenges that you face in your everyday life as a family? Can you describe these challenges? What makes them challenging? How do they affect your lives?
4. How would you describe your relationship with your children? What principles of parenting do you live by? Are you happy with how they are growing up? Why/why not?

5. What is your opinion about intellectual disability? How should people/do you cope with having a family member with intellectual disability? What are the major challenges? Do you think this affects the quality of life of your family? In what ways can special education services serve you best?

The first core question sought to establish the perspective of the participant in terms of considering what aspects of family life were considered as important in measuring its quality. The second core question sought to establish confirmation regarding whether or not the participant agreed with the family quality of life evaluation that he received for his family, based on the outcomes from the questionnaire that he had completed. This question sought to examine the internal validity of the questionnaire based on the individual perspectives of the participants, which was important in moving on with the succeeding questions in the interview. The third question then considered the challenges that the family experienced in its daily existence. These challenges were presumed to impact upon the family quality of life of these participants' families, and so examining these challenges was considered as a means of finding out why their family quality of life was observed to be high or low. The next core question sought to examine how important the children were to the challenges that affected the family's quality of life and, particularly for families with children who have intellectual disability, whether there were any additional challenges associated with raising a child who has an intellectual disability. Finally, the last core question focused on the participants' perception of intellectual disability, regardless of whether or not the family had a child who had an intellectual disability, as well as the role of special education in helping children with intellectual disability. This question sought to examine the participants' approach to

raising children with intellectual disability, or to consider the impact that raising such children could have on their current lifestyle.

5.5.3 Procedure

The eight participants who agreed to be interviewed were scheduled for interview according to their preferences. Two of the participants wished to hold their interviews in their work offices; two preferred being interviewed at an outdoor café; and four consented to conducting their interviews at their homes. The interview time was provisionally set by the researcher for approximately one hour, with participants being aware that they could cease the interview at any time. In the event, all of the interviews lasted between 30 and 90 minutes, with an average duration of approximately 40 minutes. Each participant was provided the option of having the interview audio recorded and all of them consented to this. The recordings were then typed-up in a Microsoft Word document, encoded and stored securely electronically.

5.5.3.1 Translation

The interview questions were originally written in English. The questions were then translated into Arabic for the interviews in Saudi Arabia. The interviews were conducted in Arabic and the transcriptions of the participants' answers were originally written-up in Arabic. Since Arabic was the researcher's native language, and the researcher had to conduct the selective coding, which is an inherently reflective exercise, the original coding was conducted in Arabic. Subsequently, the transcripts and all the coding were translated into English. The translations were first conducted by the researcher, and then were verified by a professional English-Arabic translator for accuracy.

5.5.4 Data Analysis

Qualitative data analysis was conducted using multi-level coding. Multi-level coding is defined by Merriam (2009) as a type of qualitative analysis that seeks to develop an understanding of traditionally qualitative data, such as interview transcripts, in an organised and systematic manner. According to Seidman (2012), this method of analysis is appropriate for interview data in that its iterative nature provides the means for the researcher to review the data multiple times and refine the outcomes derived from the data each time. Procedures similar to those discussed by Merriam (2009) were found in the works of Bazeley (2013), Miles et al. (2013) and Saldaña (2012), indicating that this method is acceptable in the field of qualitative research. Based on these sources, the procedure consists of three to four stages. For the current study, three stages, open coding, axial coding, and selective coding (Merriam, 2009; Miles et al., 2013) were used.

In the first stage of analysis, each interview transcript was reviewed and broken down into codes. A code is defined by Merriam (2009) as a group of words that express a single thought. This can be a sentence, or a sentence fragment, and it is critical for the researcher to be able to recognize when one code ends and another begins (Miles et al., 2013). In particular, what is important is that a code is identified as something that can be potentially useful to the study (Bazeley, 2013). In breaking down a transcript into codes, it is important to be able to keep track of the interviewee to which each coded text belongs (Miles et al., 2013; Saldaña, 2012). Once all of the transcripts were broken down into their respective codes, the analysis proceeded to the second stage, which required the axial categorization of the codes that were collected (Merriam, 2009).

Axial coding entailed examining the different research questions which were of interest to the study, and then categorizing each code as belonging under at least one of those research questions (Miles et al., 2013; Saldaña, 2012). At this stage, it was important to create sub-categories under each of the research questions within which the codes could be accurately categorized. It was also important to be thorough in determining to which category each code belonged, as a code could belong to more than one axis (Miles et al., 2013; Saldaña, 2012). After all of the codes were categorized, the analysis procedure moved to the next stage, which was selective coding.

In selective coding, the codes under each axis constructed in the previous stage were examined in order to draw out themes (Merriam, 2009). A theme refers to a common perspective held by the different participants in the study within one of the axial categories considered (Bazeley, 2013; Merriam 2009; Miles et al., 2013). Drawing out themes is the heart of qualitative data analysis, and requires the researcher to take on the role of the data analysis 'instrument' (Bazeley, 2013). That is, the identification of themes required both analytical and reflective thinking on the part of the researcher, as it was the researcher who needed to make sense of the codes within each axis and understand what the participants were commonly saying based on those codes. No inter-rater reliability test was conducted since the researcher was the only person who examined the transcripts. This was because the interviews were conducted in Arabic and the researcher was the only Arabic speaker involved in the project. There were no other Arabic speakers familiar with the content and the methodological issues who were available or willing to conduct reliability testing.

5.6 Ethical Concerns

There were a number of ethical issues in conducting the current study that were identified and addressed. First, it was essential for the study to be able to protect the identity of its participants. As explained by Comstock (2013), anonymity is the obscuring of any personal information that can lead to the identification of a research participant. This is an important concern, since the revelation of the identity of a participant can have various unknown but potentially harmful repercussions on the life of the participant or the participants' loved ones (Comstock, 2013). From case studies by Flynn and Goldsmith (2012), it was found that even if personal information was not intended to be gathered from the participants, it can be accidentally collected by both questionnaire and interview instruments. Flynn and Goldsmith (2012) advised that it was necessary for researchers to review all data gathered before including them in the published output of their study.

In relation to this, sensitive information was gathered in the current study through both the questionnaire and the semi-structured interviews. Thus, it was paramount that individuals' responses about their families should not lead to their being identifiable. Therefore, the questionnaires used for data gathering were checked in order to ensure that they did not contain any items that could lead to the identification of specific participants. Only those participants who indicated that they would be willing to be interviewed by the researcher wrote their contact details (name, cell phone number, and email or land phone number) at the bottom of the questionnaire. Since the questionnaires were sealed in envelopes, only the researcher was able to access this information in order to contact a selection of these willing participants. Likewise, the interview transcripts were reviewed for any personal

information such as names of people in the family, and such information was removed.

Second, it was also important to be able to obtain the informed consent of all of the participants in the study (Commonwealth of Australia, 2015). As discussed by Comstock (2013), acquiring consent includes approval from institutions that would be involved in the conduct of the study, and considering the social norms and cultural sensitivities of the population of interest. In Saudi Arabia, there is a strong cultural norm of adherence to authority, such that people are easily persuaded to agree when it is shown that the individual asking them to do something is in authority (Hofstede, 2015). Knowing this, it was important for this research to not take advantage of the participants by telling them that their participation was required by the Ministry of Education. Instead, they needed to be sufficiently informed about the study and the voluntary nature of their participation. As such, a cover letter was constructed to provide information to the participant about the study, and the extent of his or her prospective participation should he or she choose to become a participant. These are to be found in Appendix C. In addition to this, in answering the questionnaire or the interview questions, the participants were reminded that participation in the study was completely voluntary, and that they reserved the right to refuse to answer any item in the questionnaire or any question in the interview that they did not feel comfortable answering.

Furthermore, for the interviews, each of the participants was consulted for the best time, place, and medium to conduct the interview. This was then coordinated with the availability of the researcher's time and resources. It was an important ethical concern of the current study to ensure that participants were not placed at risk

through their participation in the study. During the interview, the welfare of the interviewees was carefully considered, and if an interviewee expressed discomfort in answering any of the questions, the interviewer proceeded to the next question.

Addressing these concerns, ethics approval for the study was obtained from the Western Sydney University Human Research Ethics Committee prior to the commencement of the study. The ethics approval code that was issued to the study is H10980. The researcher also obtained approval from the Ministry of Education in Aljouf, Saudi Arabia under Approval# 36611389. These two approval letters can be found in Appendix D.

5.7 Conclusion

This chapter has provided a comprehensive picture of the research methodology used to address the research aims and questions of the current study of the impact of children with intellectual disability on family quality of life in Saudi Arabia. The current study has used a mixed methods approach in order to counter the limitations of either a quantitative approach alone or a qualitative approach alone. The use of both quantitative and qualitative methods and a sequential design offers a better rounded understanding of family quality of life for Saudi Arabian families of children with intellectual disability.

The chapter has detailed how the Delphi Technique was used to develop and initially provide face validity to the questionnaire, including the Saudi Arabian Family Quality of Life Scale for Saudi Arabian families, which was then administered with anonymity to a large sample of Saudi Arabian families. Quantitative methods of exploratory factor analysis, confirmatory factor analysis,

calculation of Cronbach alpha, and correlational analysis were used in order to determine the validity and the reliability of the questionnaire for family quality of life and other related constructs for families in Saudi Arabia. Research Questions 1 and 2 were answered in this way. Quantitative methods were subsequently used to answer Research Questions 3 and 4 relating to whether there were substantive differences in quality of life between Saudi Arabian families with and without children with intellectual disability, as well as to discern what demographic, family-specific and religio-cultural factors may impact on Saudi Arabian families' quality of life.

Based on the findings from the quantitative part of the study, a small number of participants for the qualitative part of the study were recruited. These participants were interviewed in order to examine the reasons behind their reported family quality of life, given a wide range of their family's experiences. A thematic analysis of the interview transcripts was used to discern patterns in families' interpretations of what is most important to family quality of life; their perceptions of the challenges of raising children with intellectual disability; and to ascertain what kinds of special assistance participants felt they required due to having to care for children with intellectual disability.

The following Chapter 6 presents the findings from the Delphi Technique and an analysis of the quantitative data to establish whether the measures in Parts 2, 3 and 4 of the developed questionnaire are valid and reliable for Saudi Arabian families. Chapter 7 presents analyses of the quantitative data to show whether there are differences in family quality of life, and considers which factors may be influencing family quality of life for Saudi Arabian families. Chapter 8 will present the evaluation of the thematic analysis of the interviews with selected Saudi Arabian families who either do, or do not care for children with intellectual disability.

Chapter 6 : Testing the Validity and Reliability of the Saudi Arabian Family Quality of Life Questionnaire

6.1 Introduction

This chapter addresses the first two research questions of the current study. Research Question 1 was: are the Saudi Arabian Family Quality of Life Scale, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with an intellectual disability, valid with respect to Saudi Arabian families? Research Question 2 was: are the identified factors of the Saudi Arabian Family Quality of Life Scale, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with an intellectual disability, reliable with respect to Saudi Arabian families? Are there inter-correlations between the factors? This chapter presents the results from the development of the constructs, and the results from testing for the validity and reliability of the questionnaire used for examining the quality of life of the Saudi Arabian families in Phase 2 of the study.

It will be recalled that of the 300 families invited to participate in the study, 201 family members (each from different families) completed the questionnaire. Eighty six of the participants (42.8%) had at least one child with an intellectual disability and 115 of the participants (57.2%) had only children without intellectual disability. This was the final sample size of the study.

To recap the structure of the questionnaire: Part 2 consisted of 12 items asking about the religiosity of the participants. For Part 3, the first 25 items were essentially the same as for the original Beach Center Family Quality of Life Scale

(with very slight modifications to the wording of items 21 to 25 so that it referred to children with intellectual disability). The last six items in Part 3 (items 26 to 31) were new additions to the original Beach Center Family Quality of Life Scale, designed to capture a culturally specific aspect of Saudi Arabian family quality of life relating to the support provided by religion (either social support by the religious community or religious support within the family itself). Part 4 included 10 items that sought to measure a variety of different concerns relevant to quality of life of families who specifically have children with intellectual disability. It was not envisioned that these 10 items measured a single construct. The items included: religiously informed views on intellectual disability, feelings of stigmatism, love of child, government support, and overall satisfaction.

First, an exploratory factor analysis was conducted on Part 2 in order to determine whether the 12 newly developed items could identify a construct around religiosity. Second, an exploratory factor analysis was conducted on Part 4 in order to determine whether these ‘other religio-cultural factors’ had validity, since they were not intended to measure a single construct. Thirdly, an exploratory factor analysis was conducted on the last six items of Part 3 in order to determine whether these newly added items identified one or more new factors for family quality of life. Finally, a confirmatory factor analysis was conducted on the factor structure of the original Beach Center Family Quality of Life Scale with its five factors – that is, items 1 to 25 in Part 3 of the questionnaire – to confirm its validity for the Saudi Arabian context.

As per Research Question 2, following the exploratory and confirmatory factor analyses, reliability tests of the identified factors from the above parts of the

questionnaire were then conducted using Cronbach alpha set at 0.70 as the criterion to establish internal consistency (Weisberg & Krosnick, 1996). Finally, Pearson correlation coefficients were derived for each of the factors. Specifically, correlation coefficients were derived for the factors making up the original Beach Center Family Quality of Life Scale; cross-correlation coefficients for Part 3 with extracted factors from Parts 2 and 4 of the questionnaire; and cross-correlation coefficients for extracted factors from Parts 2 and 4.

6.2 Testing for Validity using Exploratory and Confirmatory Factor Analyses

The following three subsections (6.2.1 - 6.2.3) sought to address that part of Research Question 1 dealing with religiosity (Part 2), other religio-cultural factors related to caring for a child with an intellectual disability (Part 4), and new items 26 - 31 added to the Beach Center Quality of Life Scale (Part 3). Exploratory factor analyses were used.

6.2.1 Exploratory Factor Analysis of Religiosity (Part 2)

In this subsection, Hypothesis 1b is tested. This hypothesis states: the religiosity factors (Part 2 of the questionnaire) will be validated by an exploratory factor analysis.

Table 6.1 below shows the summary of variance explained by the components of the religiosity measure, using a principal component analysis. As shown from Table 6.1, a total of six components were extracted, which collectively explain approximately 66% of the variability in the data.

Table 6-1: Variance Explained for Religiosity Items (Part 2)

Factors	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1. Prayer	1.688	14.068	14.068	1.688	14.068	14.068	1.438	11.986	11.986
2. Religious Belief	1.522	12.686	26.755	1.522	12.686	26.755	1.364	11.369	23.355
3. Minimum Obedience	1.374	11.447	38.202	1.374	11.447	38.202	1.314	10.952	34.308
4. Faith	1.257	10.474	48.676	1.257	10.474	48.676	1.281	10.678	44.986
5. Maximum Obedience	1.066	8.880	57.556	1.066	8.880	57.556	1.275	10.622	55.608
6. Family Religiosity	1.005	8.375	65.932	1.005	8.375	65.932	1.239	10.324	65.932

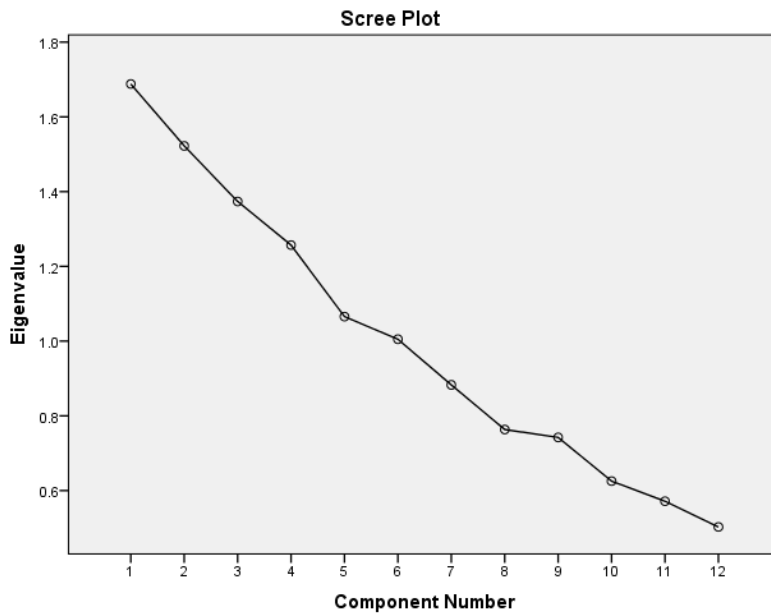


Figure 6.1: Variance Explained for Religiosity Items (Part 2)

As shown from Table 6.1 and Figure 6.1 above, assuming the criterion of factors selected for eigenvalues > 1 gives 6 religiosity factors that cumulatively explain approximately 66% of the total variance in the data.

Table 6.2 below shows the goodness-of-fit measures that were investigated on the exploratory factor analysis, as run through the AMOS program. The chi-square statistic was significant, and the χ^2/df statistic was considered significant based on the cut-off of between 2 and 5 set by Hooper, Coughlan, and Mullen (2008), indicating a good fit. The Kaiser-Meyer-Olkin (KMO) test result, however, was less than 0.6 but greater than 0.5, indicating partial correlations compared to the sum of correlations. An index number of $0.60 > \text{KMO} > 0.50$, although ultimately a matter of subjective evaluation, is generally deemed to minimally acceptable (Kaiser, 1974; Hutcheson & Sofroniou, 1999).

Table 6-2: Goodness-of-Fit Indicators

N = 201				
Model	χ^2	df	χ^2/df	KMO
Default	165.993***	66	2.515	0.502

*** $p < 0.001$

Rotated component loadings using Varimax are shown in Table 6.3 below. In this table, the first factor was found to include items 9 and 10 of the questionnaire, which are “I communicate and access my faith with God by praying,” and “I think that the values taught by my religion and/or culture contribute to the family's quality of life,” which may be labelled as the “prayer” domain of religiosity.

Factor 2 combines items 1 and 2, “I am a religious person,” and “There is only one God,” which can be labelled as “Religious Belief.”

Factor 3 combines items 3 and 4 which are “I pray to God five times a day,” and “I give at least 2.5% of what I earn to the poor and needy,” which pertain to obedience to two of the behavioural pillars of Islam. They can be labelled under the domain of “Minimum Obedience” because they are minimum unconditional legal demands on all Muslims (Nawawi & Keller, 2003).

Factor 4 combines items 7 and 8, which are “I believe in the wisdom of my religion’s laws” and “I believe the stories of the past taught in my religion” which can be considered as falling under the domain of “Faith.”

Factor 5 also combines items 5 and 6 which are “I fast during Ramadan,” and “I have visited Mecca”. These are two of the behavioural five pillars of Islam. They can be considered as falling under a “Maximum Obedience” domain because they are conditional legal requirements of all Muslims, which is to say that there are circumstances under which a Muslim need not fulfil them. So if they are fulfilled, this would suggest a high level of conformity to the essential behavioural pillars of the religion (Nawawi & Keller, 2003).

Finally, Factor 6 can be defined under the “Family Religiosity” domain as it includes items 11 and 12, which relate to the extension of religiosity from the individual to the family: “My family members strive to uphold religious and/or cultural values that contribute to the family's quality of life” and “I am content with the extent to which religious and/or cultural values contribute to my family's quality of life.”

Table 6-3 Component Loadings of Religiosity (Part 2) (for loadings > 0.3)

Items	Components					
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>
1. I am a religious person.		.780				
2. There is only one God.		.779				
3. I pray to God five times a day.			.517			
4. I give at least 2.5% of what I earn to the poor and needy.			.759			
5. I fast during Ramadan.					.625	
6. I have visited Mecca.					.864	
7. I believe in the wisdom of my religion's laws.					.699	
8. I believe the stories of the past taught in my religion.					.830	
9. I communicate and access my faith with God by praying.	.698					
10. I think that the values taught by my religion and/or culture contribute to the family's quality of life.	.725					
11. My family members strive to uphold religious and/or cultural values that contribute to the family's quality of life.						.617
12. I am content with the extent to which religious and/or cultural values contribute to my family's quality of life.						.828

The results in this section show that the questionnaire is capable of measuring different aspects of respondents' religiosity related to Islam. These components were

thus considered as potentially significant variables in examining family quality of life, and so Hypothesis 1b is deemed to be satisfied.

6.2.2 Exploratory Factor Analysis of other Religio-cultural Factors related to Having Children with Intellectual disability (Part 4)

In this subsection, Hypothesis 1c is tested. This hypothesis states: the other religio-cultural factors related to caring for a child with an intellectual disability (Part 4 of the questionnaire) will be validated by an exploratory factor analysis.

Table 6.4 below shows the results of a principal component analysis summarising the variance explained by the various items under Part 4 of the questionnaire relating to various ‘other’ religio-cultural factors related to having children with intellectual disability.

Table 6-4: Variance Explained for ‘Other’ Religio-cultural Factors (in Part 4)

Factors	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1. Love for Children	1.833	18.331	18.331	1.833	18.331	18.331	1.637	16.369	16.369
2. Religious Acceptance	1.498	14.983	33.314	1.498	14.983	33.314	1.428	14.276	30.645
3. Social Acceptance	1.361	13.610	46.924	1.361	13.610	46.924	1.343	13.434	44.079

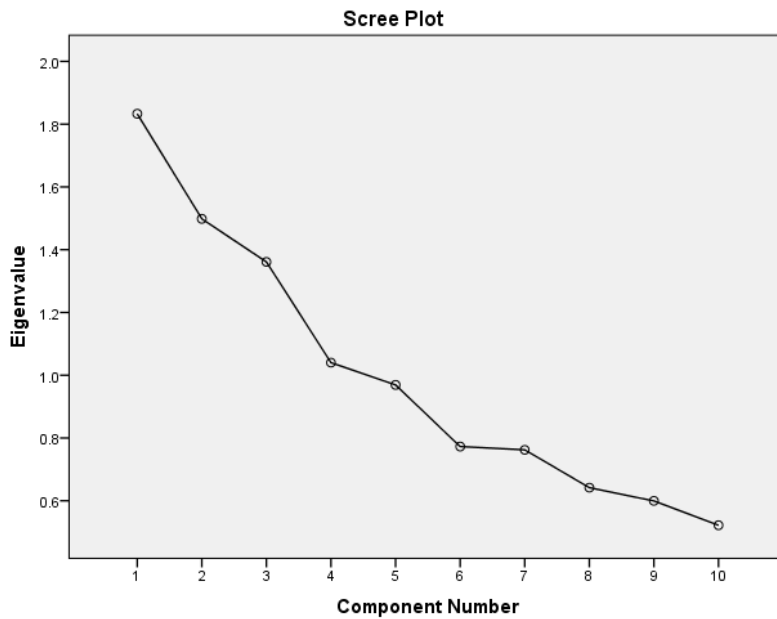


Figure 6.2: Variance Explained for 'Other' Religio-cultural Factors (in Part 4)

Table 6.4 and Figure 6.2, assuming the criterion of factors selected for eigenvalues > 1 , shows that there were 3 factors extracted, which cumulatively explain approximately 47% of the variability in the data.

Table 6.5 below shows the goodness-of-fit measures that were investigated on the exploratory factor analysis, as run through the AMOS program. Although the chi-square statistic was significant (for $p < 0.05$), and the χ^2/df statistic was not considered significant based on the cut-off of between 2 and 5 set by Hooper, Coughlan, and Mullen (2008), indicating a good fit. Also, the Kaiser-Meyer-Olkin (KMO) test result was less than 0.60, indicating partial correlations compared to the sum of correlations, although greater than 0.50, which is widely regarded as being minimally acceptable (Kaiser, 1974; Hutcheson & Sofroniou, 1999).

Table 6-5: Goodness-of-Fit Indicators

N = 86				
Model	χ^2	df	χ^2 / df	KMO
Default	65.301*	45	1.451	0.569

* $p < 0.05$

Table 6.6 below shows rotated factor loadings of the items under Varimax rotation, which is useful for discerning and interpreting the extracted component factors.

Table 6-6: Component Loadings: 'Other' Religio-cultural Factors (in Part 4) (for loadings > 0.3)

Items	Factors		
	1	2	3
	Love for Children	Religious Acceptance	Social Acceptance
1. Having a child with an intellectual disability is a blessing from God or a test of our faith.		.789	
2. Having a child with an intellectual disability is a punishment from God for sinful behaviour.		.417	
3. I am embarrassed by my child who has an intellectual disability.			.725
4. I would prefer that non-family members not know that my child has an intellectual disability.			.535
5. My child who has an intellectual disability gets along well with my other child/children who does/do not have intellectual disability.			.715
6. I love my child who has an intellectual disability.	.671		
7. I love my child who has an intellectual disability as much as I do my other children.	.804		
8. I love my child who has an intellectual disability more than I do my other children.	.582		
9. The government helps me in raising my child who has an intellectual disability.		.615	
10. I am satisfied with my family's quality of life.			.402

With respect to Table 6.6 above, the first component includes items 6, 7 and 8, “I love my child who has an intellectual disability,” “I love my child who has an intellectual disability as much as I do my other children,” and “I love my child who has an intellectual disability more than I do my other children”. Based on this, the factor can be defined as “Love for Children.” The factor loading for item 8 is a

negative correlation, indicating that respondents do not deem preferential love for their child with a disability to characterise their Love for Children.

Factor 2 combines items 1, 2 and 9, “Having a child with an intellectual disability is a blessing from God or a test of our faith,” “Having a child with an intellectual disability is a punishment from God for sinful behaviour,” and “The government helps me in raising my child who has an intellectual disability.” Items 1 and 2 describe the participants’ perspectives regarding the religious meaning of having a child with an intellectual disability, but item 9 considers the extent to which parents believe the government bears some responsibility in helping them to raise a child with an intellectual disability. Considering that Saudi Arabian socio-political culture is highly religious and the government is regarded as an extension of religious authority (Al Turaiqi, 2008), these loadings can be conceived as a domain for “Religious Acceptance [of having a child with an intellectual disability]”. Since item 9 is unequivocally about religiously-based (governmental) *help* for a family of a child with an intellectual disability, and since it is grouped with item 1 which is equivocal about whether God is testing or blessing such a family, it is possible that participants interpreted item 1 in a normatively similar manner to the way they interpreted item 9; that is, they may interpret item 1 as expressing God *helping* them in some way. It should be noted, however, that the factor loading for item 1 about God’s providence is greater than that for item 9 about governmental support, so it cannot be said that they are expressing perfectly identical notions (Note that item 2 was reverse scored).

Factor 3 combines items 3, 4, 5 and 10 – “I am embarrassed by my child who has an intellectual disability,” “I would prefer that non-family members not know

that my child has an intellectual disability,” “My child who has an intellectual disability gets along well with my other child/children who does/do not have an intellectual disability,” and “I am satisfied with my family's quality of life” – which appear to relate to “Social Acceptance [of having a child with an intellectual disability]”. (Note that items 3 and 4 were reverse scored). Item 5, which is about acceptance of a child with an intellectual disability by siblings, was most strongly positively correlated with this component.

In summary, as in the case of the religiosity part of the questionnaire (Part 2), the exploratory factor analysis for Part 4 reveals that the items in this part produced three different meaningful factors: “Love for Children,” “Religious Acceptance of having children with intellectual disability,” and “Social Acceptance of having children with intellectual disability” which can be used in the subsequent modelling of family quality of life on the variables observed among Saudi Arabian families. It is thus concluded that Hypothesis 1c was confirmed.

6.2.3 Exploratory Factor Analysis of Religious Support (last six items in Part 3)

In this subsection, Hypothesis 1d is tested. This hypothesis states: the factors added to the Beach Center Family Quality of Life Scale (items 26 - 31 in Part 3 of the questionnaire) will be validated by an exploratory factor analysis.

The last six items in Part 3 of the questionnaire focused on support from the religious community of which the family is a member, as well as the support that religion provides from within the family itself. These items sought to capture an aspect of family quality of life that is culturally specific to Saudi Arabian families –

namely, the support that religion provides both socially and within the family itself. Because these were new items purporting to be measuring family quality of life, an exploratory factor analysis was conducted on these items. Table 6.7 below shows results of the exploratory factor analysis in order to check the validity of the six items.

Table 6-7: EFA Validity of Six Items concerning 'Religious Support' (item 26-31) in Part 3

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	
Religious Support	5.803	96.708	96.708	5.803	96.708	

As shown from Table 6.7 above, the principal component analysis demonstrates that approximately 97% of the total variance is explained in the data. This confirms that it is valid to use this subscale in the Saudi Arabian context for family quality of life. Therefore it can be concluded that Hypothesis 1d is confirmed, because what is common to the items in the subscale is that they all relate to support provided by religion (either socially or within the family): the factor identified by this analysis will be labelled 'Religious Support'.

6.2.4 Confirmatory Factor Analysis of the Saudi Arabian Family Quality of Life Scale (Part 3)

A confirmatory factor analysis using the principal components method was conducted on the first 25 items of the Beach Center Family Quality of Life Scale, to

examine whether the factor structure found in previous studies conducted in Western contexts (Hoffman et al., 2006; Zuna et al., 2009) occurred when the questionnaire was given to Saudi Arabian families. (It should be recalled that items 22 to 25 of the original scale were slightly altered so as to include a reference to a child with an intellectual disability, as discussed in 5.4.2.3 of Chapter 5.) This subsection tested the final hypothesis arising out of the first research question of the current study, namely Hypothesis 1e, which states: the validity of the factor structure of the original Beach Center Family Quality of Life Scale will be tested through a confirmatory factor analysis.

Table 6.8 below shows the initial eigenvalues, the amount of variance explained by the principal components analysis, and the extraction sums of squared loadings.

Table 6-8: Variance explained for Family Quality of Life Items

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	30.006	96.794	96.794	30.006	96.794	96.794

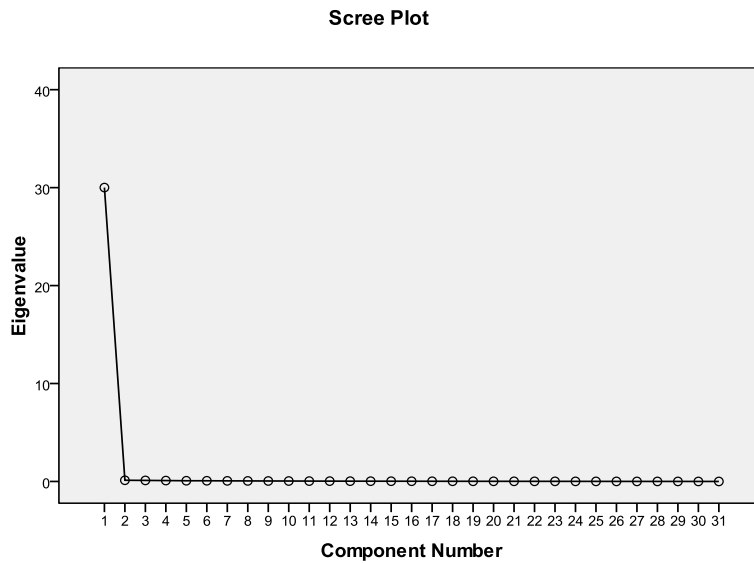


Figure 6.3: Variance Explained for Family Quality of Life Items

As shown from Table 6.8 and Figure 6.3 above, the principal component analysis produced an Eigen value of 30 and was able to explain approximately 97% of the total variance in the data. It was therefore concluded that it is valid to use the Beach Center Family Quality of Life Scale for Saudi Arabian families.

Table 6.9 below shows the goodness-of-fit measures that were investigated on the confirmatory factor analysis, as run through the AMOS program. Although the chi-square statistic was significant, the χ^2/df statistic was not considered significant based on the cut-off of between 2 and 5 set by Hooper, Coughlan, and Mullen (2008), indicating a poor fit. The root mean square error of approximation (RMSEA) also showed poor fit for the model, which was inconsistent with the results reported by Zuna, Selig, Summers, and Turnbull (2009).

Table 6-9: Goodness-of-Fit Indicators for Family Quality of Life Model

<i>N</i> = 201					
Model	χ^2	df	χ^2 / df	CFI	RMSEA
Default	1776.38***	265	6.703	0.915	0.169

*** $p < 0.001$

The level of covariance between factors displayed in the current study (ranging from 0.65 to 0.69) were lower than those displayed in the original studies by Turnbull, Summers, and Brotherson (1984) and Hoffman et al. (2006), but still fell below 0.80, indicating discriminant validity between the factors.

The confirmatory factor analyses were conducted on the different expected factors of the family quality of life items. Results of these analyses are show in Table 6.10 below. As demonstrated in Table 6.8, it was found that the items for each factor, when analysed apart from the other factors, were consistent in measuring each of the respective factors as expected. The five factors that were extracted were emotional well-being (EWB), physical and material well-being (PMWB), disability-related support (DRS), family interaction (FI) and parenting (PAR). This suggests the validity of this part of the questionnaire, as each of the sets of items for specific factors was found to have data that were consistent with one another. Thus it can be concluded that Hypothesis 1e is supported by this analysis.

Table 6-10: Confirmatory Factor Analysis per Dimension using AMOS Program for Part 3

		<i>N</i> = 201			
Question	Dimension	Estimate	S.E.	C.R.	P
Q13	<--- Emotional Well Being	1.000			
Q9	<--- Emotional Well Being	1.050	0.018	57.231	.001
Q4	<--- Emotional Well Being	1.018	0.019	53.096	.001
Q3	<--- Emotional Well Being	1.025	0.020	52.338	.001
Q21	<--- Physical and Material Well-being	1.000			.001
Q20	<--- Physical and Material Well-being	1.020	0.016	65.130	.001
Q16	<--- Physical and Material Well-being	1.004	0.018	54.580	.001
Q15	<--- Physical and Material Well-being	1.008	0.018	57.178	.001
Q6	<--- Physical and Material Well-being	1.013	0.018	54.796	.001
Q22	<--- Disability-Related Support	1.000			.001
Q23	<--- Disability-Related Support	1.016	0.021	48.544	.001
Q24	<--- Disability-Related Support	0.959	0.024	39.791	.001
Q25	<--- Disability-Related Support	1.005	0.022	46.070	.001
Q18	<--- Family Interaction	1.000			.001
Q12	<--- Family Interaction	1.006	0.020	49.223	.001
Q11	<--- Family Interaction	0.988	0.019	51.667	.001
Q10	<--- Family Interaction	1.018	0.019	54.793	.001
Q7	<--- Family Interaction	1.014	0.019	53.050	.001
Q1	<--- Family Interaction	0.981	0.021	45.726	.001
Q2	<--- Parenting	1.000			.001
Q5	<--- Parenting	0.986	0.015	65.829	.001
Q8	<--- Parenting	0.940	0.016	58.922	.001
Q14	<--- Parenting	1.000	0.013	78.913	.001
Q17	<--- Parenting	0.994	0.012	82.251	.001
Q19	<--- Parenting	0.979	0.015	63.548	.001

A visual representation of the outcomes of confirmatory factor analyses conducted is presented in Figure 6.4 below. As shown from Figure 6.4, each of the

factors were found to be closely correlated with the other factors, which is why the initial results, when analysing the items altogether, explained a large amount of the total variance. This means that strong relationships exist across different factors of family quality of life for the Saudi Arabian families. Thus, the factors were extracted by conducting the confirmatory factor analysis only on those items, and by checking to see whether the consistency of the responses remained.

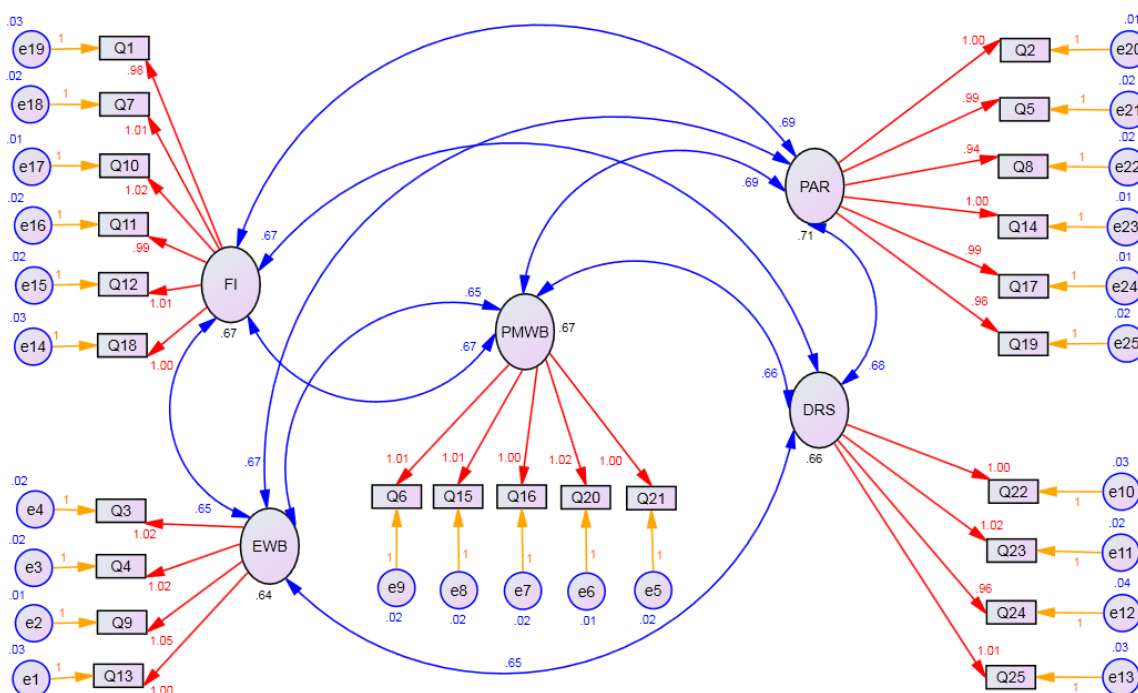


Figure 6.4: Confirmatory Factor Analysis Factors Cross-correlation

Note: FI = family interaction; PAR = parenting; EWB = emotional well-being; PMWB = physical/material well-being; DRS = disability related support; Q = question; e = endogenous.

Table 6.11 below shows the factor loadings for family quality of life factors of the different items and reveals that each item loads almost perfectly. These results are inconsistent with what was expected from the design of the Beach Center Family Quality of Life Scale, which was found to have five factors (Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-

Related Support) (Hoffman et al., 2006). One possible reason for this inconsistency is the cultural difference between the target population of the study and the population that Hoffman et al. (2006) worked with in developing the Beach Center Family Quality of Life Scale. The Western population that was used in validating the scale may have been more diverse in terms of its perspectives and experiences in relation to the items of the Beach Center Family Quality of Life Scale.

On the other hand, the Saudi Arabian population from which the sample for the current study was drawn may be more homogeneous in their perspectives and experiences, leading the five factors to become so closely correlated to one another as to merge into just one factor. That is, in Saudi Arabia, people who had high scores for one factor of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) also tended to have high scores on the other factors of the measure, leading to very high cross-correlations among the different items and therefore resulting in the identification of only a single factor with an eigenvalue greater than one.

Table 6-11: Factor Loadings for all Family Quality of Life Items in Part 3

Items	N = 201 Component
	<u>1</u>
1. My family enjoys spending time together.	0.979
2. My family members help the children learn to be independent.	0.992
3. My family has the support we need to relieve stress.	0.985
4. My family members have friends or others who provide support.	0.985
5. My family members help the children with schoolwork and activities.	0.988
6. My family members have transportation to get to the places they need to be.	0.984
7. My family members talk openly with each other.	0.990
8. My family members teach the children how to get along with others.	0.980
9. My family members have some time to pursue their own interests.	0.989
10. Our family solves problems together.	0.991
11. My family members support each other to accomplish goals.	0.987
12. My family members show that they love and care for each other.	0.984
13. My family has outside help available to us to take care of special needs of all family members.	0.981
14. Adults in our family teach the children to make good decisions.	0.993
15. My family gets medical care when needed.	0.983
16. My family has a way to take care of our expenses.	0.980
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	0.994
18. My family is able to handle life's ups and downs.	0.979
19. Adults in my family have time to take care of the individual needs of every child.	0.984
20. My family gets dental care when needed.	0.991
21. My family feels safe at home, work, school, and in our neighbourhood.	0.984
22. My child with/without an intellectual disability has support to accomplish goals at school or at the workplace	0.977
23. My child with/without an intellectual disability has support to accomplish goals at home.	0.985
24. My child with/without an intellectual disability has support to make friends.	0.969
25. My family has good relationships with the service providers who provide services and support to our child with/without an intellectual disability.	0.981
26. People in my religious and/or cultural community do not reject my child with/WITHOUT an intellectual disability.	0.985
27. People in my religious and/or cultural community provide practical assistance to my family because we have intellectual disability-related needs (If you do not have a child with an intellectual disability, answer this question for your children).	0.979
28. People in my religious and/or cultural community provide emotional support to my family because we have intellectual disability-related needs. (If you do not have a child with an intellectual disability, answer this question for your children).	0.993
29. My family's religion gives us strength and enables us to make sense of life.	0.970
30. My family relies on God and turns to God for aid.	0.971
31. My family's faith enables us to make sense of having a child with/WITHOUT an intellectual disability.	0.987

6.3 Reliability Analysis

Since the Saudi Arabian Family Quality of Life Scale was adapted from the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) for use in the

Saudi Arabian context, it was necessary to examine the reliability of the questionnaire to measure the extent to which religiosity (Part 2), family quality of life (Part 3), and other religio-cultural factors related to caring for a child with an intellectual disability (part 4) produced internally consistent results. These three parts are the parts deemed pertinent to assess the family quality of life of the Saudi Arabian families. Thus this subsection is addressed to Research Question 2: are the identified factors of the Saudi Arabian Family Quality of Life Scale, the measure of religiosity, and the measure of other religio-cultural factors related to caring for a child with an intellectual disability, reliable with respect to Saudi Arabian families? Are there inter-correlations between the factors? From this Research Question, six hypotheses emanate, which will be tested below.

As explained by Weisberg and Krosnick (1996), Cronbach alpha is a measure of the reliability of a questionnaire or subscale for measuring a general construct that may or may not be multi-dimensional. Therefore, even if the construct was multi-dimensional, the value of the Cronbach alpha shows the consistency among the various items and explains the extent to which they measure the same aspects they were intended to measure. The alpha criterion for internal consistency in the current study is set at 0.7.

6.3.1 Reliability Analysis of Religiosity (Part 2)

In this subsection, Hypothesis 2a is tested. This hypothesis states: the identified factors of the religiosity measure (from Part 2 of the questionnaire) are internally consistent for Saudi Arabian families.

As can be seen in Table 6.12, for the six factors identified by the exploratory analysis of Part 2 of the questionnaire which sought to measure Religiosity – namely, Prayer, Religious Belief, Minimum Obedience, Faith, Maximum Obedience, and Family Religiosity – the Cronbach alphas ranged from 0.275 to 0.480. Thus each religiosity factor was lower than the minimum value of the coefficient ($\alpha > 0.7$) required to conclude that the items are consistently measuring identified factors. Given the poor reliability coefficient found for each of the religiosity factors identified by exploratory analysis, it may be considered that this attempt to measure the religiosity construct is not able to exhibit internal consistency for the population under consideration (Saudi Arabian families). As such, care needs to be taken in interpreting the inferences that may relate to religiosity.

Table 6-12: Reliability Analysis of Religiosity Items (Part 2)

<i>N</i> = 201	
Factors	Cronbach Alpha
1- Prayer	0.368
2- Religious Belief	0.480
3- Minimum Obedience	0.275
4- Faith	0.428
5- Maximum Obedience	0.377
6- Family Religiosity	0.303

It must thus be concluded that Part 2 is not capturing a single religiosity construct; nor has it identified reliable factor components of the said construct. Hypothesis 2a has therefore not been confirmed.

At the very least, this finding requires further examination. On reviewing the data from Part 2, it was observed that there was limited variance in participant responses in this part of the questionnaire – the participants mostly answered “agree” or “strongly agree” to each of the items. The items under this part of the questionnaire are measured on a five-point Likert scale where the participants’ opinions are scored based on the level of agreement to each question, and since the Likert scale assumes that the strength or intensity of level of agreement is linear, the absence of satisfaction of this constraint in the data gathered may account for the insufficient variability to support the measurement of a ‘level’ of ‘degree’ of religiosity. This is the most likely explanation for the low Cronbach alphas computed. Interestingly, this discovery is consistent with the expectations of one of the expert participants from the Delphi Technique, who warned that Saudi Arabians were likely to respond in precisely the uniform manner found such that Part 2 would be undermined as a means of measuring religiosity. As contended by this expert, it is possible that most, if not all Saudi Arabians can be considered as highly religious. Further, it is a powerful taboo in Saudi society, both in law and by custom, to be even privately irreligious. Thus, it is also at least possible that even those participants who were not ‘subjectively’ religious would respond to the items in Part 2 in a manner that conformed with high religiosity.

6.3.2 Reliability Analysis of other Religio-cultural Factors related to Caring for a Child with an Intellectual Disability (Part 4)

In this subsection, Hypothesis 2b is tested. This hypothesis states: The identified factors of the other religio-cultural factors related to caring for a child with

an intellectual disability measure (from Part 4 of the questionnaire) are internally consistent for Saudi Arabian families.

For Part 4 of the questionnaire, which was only for the 86 families of children with intellectual disability who participated, three factors were identified by exploratory factor analysis: Love for Children [with intellectual disability], Religious Acceptance [of children with intellectual disability], and Social Acceptance [of children with intellectual disability]. For each of these factors, as shown in Table 6.13, the Cronbach alphas were found to be 0.022, 0.337 and 0.317 respectively. These very low coefficients fell below the minimum coefficient value ($\alpha > 0.7$) required to claim internal consistency of these identified factors. It must thus be concluded that Hypothesis 2b has not been confirmed. As with the reliability finding for Part 2, this may be due to the uniformity of responses by participants. In the case of Love for Children, this is perhaps unsurprising as it is hardly remarkable that parents would tend to uniformly say they love their children with disabilities as much as their other children. As for the Religious Acceptance and Social Acceptance factors, it may be that families gave uniform responses perhaps due to uniform experiences, although this is speculative.

Table 6-13: Reliability Analysis of other Religio-cultural Factors related to Caring for a Child with an Intellectual Disability (Part 4)

N = 86	
Factors	Cronbach Alpha
1- Love for Children	0.022
2- Religious Acceptance	0.337
3- Social Acceptance	0.317

6.3.3 Reliability Analysis of Saudi Arabian Family Quality of Life Scale (Part 3)

In this section, the reliability of the factors identified in Part 3 of the questionnaire is examined. This addresses Hypothesis 2c: The identified factors of the Saudi Arabian Family Quality of Life Scale construct are internally consistent for Saudi Arabian families. As per above, items 1 to 25 relate to the original Beach Center Family Quality of Life Scale as augmented for families with or without children with an intellectual disability. Confirmatory factor analysis established the five factors of the original Beach Center Family Quality of Life Scale – namely, Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability Related-Support. The newly added items 26 to 31 were found by exploratory factor analysis to identify the new factor of Religious Support for Saudi Arabian families.

Table 6.14 below reports the reliability coefficient (the Cronbach alpha) for each of the six factors making up the Saudi Arabian Family Quality of Life Scale for families both with, and without, children with an intellectual disability. For families of children with an intellectual disability, the Cronbach alpha for the six factors ranged from 0.995 to 0.999. For families of children without an intellectual disability, the Cronbach alpha for the six factors similarly ranged from 0.964 to 0.988. These results clearly exceed the commonly accepted minimum requirement of $\alpha > 0.70$. These findings are quite similar to those of Zuna et al. (2009) for whom the Cronbach alpha for their Beach Center Family Quality of Life Scale was 0.92. This in turn was similar to Hoffman et al.'s (2006) Cronbach alpha of 0.88 for the Beach

Center Family Quality of Life Scale, which was administered to a disability-only sample.

Each of the factors identified in the current study, including the newly added factor of Religious Support, can be deemed internally consistent and thus reliable for both groups of families. Therefore, it can be concluded that the Saudi Arabian Family Quality of Life Scale developed for the current study should be considered valid for Saudi Arabian families, whether they do or do not have children with intellectual disability. Thus it can be concluded that Hypothesis 2c was confirmed.

Table 6-14: Reliability Analysis of Family Quality of Life Measure in Part 3

For Families of Children with an Intellectual Disability, N=86	
Factors	Cronbach Alpha
1- Family Interaction	0.997
2- Parenting	0.998
3- Emotional Well-being	0.999
4- Physical / Material Well-being	0.998
5- Disability Related-Support	0.995
6- Religious Support	0.995
For Families of Children without an Intellectual Disability, N=115	
Factors	Cronbach Alpha
1- Family Interaction	0.985
2- Parenting	0.988
3- Emotional Well-being	0.975
4- Physical / Material Well-being	0.983
5- Disability Related-Support	0.964
6- Religious Support	0.982

It should be noted, however, that all these alpha values are above the upper limit recommended by some statisticians, who suggest that an alpha value greater than 0.95 may indicate unnecessary item ‘overlapping’ thereby resulting in ‘inflated’ internal consistency (e.g. Bland & Altman, 1997; Streiner, 2003). That said, it does not follow that the Saudi Arabian Family Quality of Life Scale fails the test of reliability per se. Rather, it may suggest that in the case of the cohort under investigation, the questionnaire could possibly be rendered more parsimonious without substantially harming its reliability. This possibility, however, is not explored here.

6.4 Correlation Analysis

Having sought to identify component factors in Parts 2, 3 and 4 by exploratory and confirmatory factor analysis, this section moves towards examining the inter-correlations which may exist among these different component factors. This addresses Hypotheses 2d, 2e and 2f. The results from this analysis will reveal the extent of association or agreement among the various factors obtained above. The results reported in the tables below present the correlations of each of the factors that were established from the exploratory, confirmatory and reliability analyses conducted in the previous sections. (Again, the sample size of 201 pertained to all members of the original sample size examined, while the sample size of 86 indicated just the families of those 201 who had children with intellectual disability.

First, Hypothesis 2d was addressed. This hypothesis states: the identified factors of the Saudi Arabian Family Quality of Life Scale construct will be positively inter-correlated. Table 6.15 below shows the correlations of the identified Saudi Arabian Family Quality of Life factors – namely Family Interaction, Parenting,

Emotional Well-being, Physical/Material Well-being, Disability Related-Support, and Religious Support. (Recall that the first five are the same as for the original Beach Center Family Quality of Life Scale (Hoffman et al. 2006), and the last factor is the newly added factor deemed to be relevant to Saudi Arabian families.) As expected, each of the factors was found to be very strongly positively correlated with each other, with all Pearson correlation coefficients being greater than 0.9. Further, all the coefficients were significant ($p < 0.01$). Thus Hypothesis 2d was well-confirmed.

Table 6-15: Correlations within Original Family Quality of Life Factors (items 1-25 in Part 3)

		EWB	PMWB	DRS	FI	PAR	RS
Emotional Well Being	Pearson Correlation	1	0.962	0.952	0.962	0.921	0.992
	P-value	0.001	0.001	0.001	0.001	0.001	0.001
	N	201	201	201	201	201	201
Physical and Material Well-being	Pearson Correlation	0.962	1	0.961	0.942	0.932	0.993
	P-value	0.001	0.001	0.001	0.001	0.001	0.001
	N	201	201	201	201	201	201
Disability-Related Support	Pearson Correlation	0.952	0.961	1	0.942	0.987	0.991
	P-value	0.001	0.001	0.001	0.001	0.001	0.001
	N	201	201	201	201	201	201
Family Interaction	Pearson Correlation	0.962	0.942	0.942	1	0.969	0.994
	P-value	0.001	0.001	0.001	0.001	0.001	0.001
	N	201	201	201	201	201	201
Parenting	Pearson Correlation	0.921	0.932	0.986	0.969	1	0.994
	P-value	0.001	0.001	0.001	0.001	0.001	0.001
	N	201	201	201	201	201	201
Religious Support	Person						
	Correlation	0.992	0.993	0.991	0.994	0.994	1
	P-value	0.001	0.001	0.001	0.001	0.001	0.001
	N	201	201	201	201	201	201

Note: FI = family interaction; PAR = parenting; EWB = emotional well-being; PMWB = physical/material well-being; DRS = disability related support; Religious Support = RS. The P values have been rounded.

The next hypothesis to be examined is 2e. It states: the identified factors of the Saudi Arabian Family Quality of Life Scale (from Part 3 of the questionnaire) will be positively correlated with the identified factors of the religiosity construct

(from Part 2 of the questionnaire) and the other religio-cultural factors related to caring for a child with an intellectual disability measure (from Part 4 of the questionnaire). As shown in Table 6.16 below, it was found that all factors extracted from Part 3 of the study were significantly positively correlated with Social Acceptance of children with intellectual disability, with positive correlation coefficients of approximately 0.54 ($p < 0.05$), indicating that the correlation strength was 'moderate' (Cohen, 1988). These results were found to be consistent across all the different factors of family quality of life. This means that parents who are comfortable with having other people know that they have a child with an intellectual disability, and who feel that their children with intellectual disability are able to get along well with their other children, reported an overall higher family quality of life. Although causality is not established by the finding, it is plausible to suggest that the positive perceived social acceptance of children with intellectual disability contributes to improving the quality of life for Saudi Arabian families with such children.

All of the religiosity factors (Part 2) and the remaining other religio-cultural factors related to caring for a child with an intellectual disability (Part 4) were found to not be statistically significantly correlated with the Saudi Arabian Family Quality of Life Scale or any of its six factors.

In summary, Hypothesis 2e was not well-supported. However, one factor from Part 4 – Social Acceptance of children with intellectual disability – was significantly positively correlated with all the factors of the Saudi Arabian Family Quality of Life Scale.

Table 6-16: Correlation between Factors Extracted from Family Quality of Life Factors (Part 3) and Factors Extracted from Religiosity (Part 2) and other Religio-cultural Factors related to Caring for a Child with an Intellectual Disability (Part 4).

		Prayer	Religious Belief	Minimum Obedience	Faith	Maximum Obedience	Family Religiosity	Love for Children	Religious Acceptance	Social Acceptance
Family quality of life	Pearson Correlation	0.120	0.031	0.021	0.089	0.014	0.019	0.028	0.139	0.537
	P-value	0.089	0.660	0.771	0.209	0.848	0.789	0.796	0.201	0.001
	N	201	201	201	201	201	201	86	86	86
Emotional Well Being	Pearson Correlation	0.12	0.043	0.021	0.089	0.013	0.019	0.028	0.139	0.538
	P-value	0.089	0.543	0.772	0.21	0.856	0.789	0.797	0.201	0.001
	N	201	201	201	201	201	201	86	86	86
Physical and Material Well-being	Pearson Correlation	0.119	0.027	0.02	0.089	0.022	0.018	0.028	0.139	0.537
	P-value	0.089	0.708	0.772	0.21	0.752	0.789	0.797	0.202	0.001
	N	201	201	201	201	201	201	86	86	86
Disability-Related Support	Pearson Correlation	0.12	0.018	0.021	0.088	0.018	0.019	0.029	0.14	0.537
	P-value	0.089	0.803	0.772	0.21	0.801	0.789	0.797	0.201	0.001
	N	201	201	201	201	201	201	86	86	86
Family Interaction	Pearson Correlation	0.119	0.028	0.020	0.089	0.005	0.018	0.029	0.14	0.538
	P-value	0.089	0.696	0.772	0.21	0.940	0.79	0.797	0.202	0.001
	N	201	201	201	201	201	201	86	86	86
Parenting	Pearson Correlation	0.12	0.038	0.021	0.089	0.005	0.019	0.028	0.139	0.537
	P-value	0.089	0.594	0.772	0.209	0.946	0.789	0.797	0.201	0.001
	N	201	201	201	201	201	201	86	86	86
Religious Support	Pearson Correlation	0.126	0.032	0.024	0.081	0.021	0.026	0.030	0.147	0.537
	P-value	0.076	0.657	0.730	0.252	0.768	0.711	0.785	0.178	0.001
	N	201	201	201	201	201	201	86	86	86

Finally, Hypothesis 2f was addressed. This hypothesis states: the identified factors of the religiosity construct will be positively correlated with the identified factors of the other religio-cultural factors related to caring for a child with an intellectual disability measure.

Table 6.17 below shows cross-correlations of the six factors extracted from the religiosity items in Part 2, and from the three factors extracted from the items in Part 4 of the questionnaire. As can be seen, there were no significant correlations between pairs of factors from the two parts of the questionnaire. The cross-correlation of Social Acceptance of children with intellectual disability and prayer was slightly negative (approximately 0.2), but did not achieve statistical significance ($p < 0.07$) for the cut-off of $p < 0.05$. Thus Hypothesis 2f was not well-supported. Given the above correlation results in Table 6.14, this was not entirely unexpected.

Table 6-17: Correlations between Religiosity (Part 2) and other Religio-cultural Factors related to Caring for a Child with an Intellectual Disability (Part 4)

		Prayer	Religious Belief	Minimum Obedience	Faith	Maximum Obedience	Family Religiosity
Love for Children	Pearson Correlation	0.054	0.104	0.125	0.043	0.097	0.097
	Sig. (2-tailed)	0.624	0.343	0.250	0.694	0.375	0.376
	N	86	86	86	86	86	86
Religious acceptance	Pearson Correlation	0.044	0.090	0.036	0.130	0.049	0.018
	Sig. (2-tailed)	0.068	0.410	0.739	0.232	0.652	0.870
	N	86	86	86	86	86	86
Social acceptance	Pearson Correlation	0.198	0.133	0.096	0.016	0.068	0.127
	Sig. (2-tailed)	0.068	0.223	0.379	0.882	0.536	0.242
	N	86	86	86	86	86	86

In summary, Hypothesis 2d was confirmed: the factors of the original Beach Center Family Quality of Life Scale were found to be significantly and strongly positively correlated with each other. Hypothesis 2e was not well-confirmed. The factors of the original Beach Center Family Quality of Life Scale were not found to be significantly correlated with the factors extracted from religiosity (Part 2). Nor were they significantly correlated with the other religio-cultural factors related to caring for a child with an intellectual disability (Part 4) *except* for the factor of Social Acceptance of a child with an intellectual disability, where there was a weak-to-moderate significant positive correlation. Hypothesis 2f was not well-confirmed.

6.5 Conclusion

This chapter has sought to satisfy Research Aims 1 and 2 and concomitantly, has sought to answer Research Questions 1 and 2. The most important positive finding of this chapter was that the Saudi Arabian Family Quality of Life Scale was found to be valid and reliable. Confirmatory factor analysis was able to extract the five factors of family quality of life identified from the original Beach Center Family Quality of Life Scale, and exploratory factor analysis was able to extract a single new culturally specific factor, Religious Support. The reliability analysis showed that the Cronbach alpha was well beyond the minimum required value for internal consistency for all six of the factors identified for Saudi Arabian family quality of life (for families both with and without children with intellectual disability). Thus this new Saudi Arabian Family Quality of Life Scale can serve as a robust method of measuring family quality of life for Saudi Arabian families.

Further, these identified factors were found to be significantly correlated with one another, which supported the conclusion that, for the Saudi Arabian population, measurement of family quality of life was collinear across factors.

With respect to Parts 2 and 4 of the questionnaire, which sought to capture ‘religiosity’ and ‘other religio-cultural factors relating to caring for children with intellectual disability’ respectively, the findings were mixed and far less positive. Exploratory factor analysis was able to identify six factors making up ‘religiosity’: Prayer, Religious Belief, Minimum Obedience, Faith, Maximum Obedience, and Family Religiosity. However, reliability could not be established for these factors. Exploratory factor analysis was also able to identify three factors making up ‘other religio-cultural factors related to caring for a child with an intellectual disability’,

namely: Love for Children with intellectual disability, Religious Acceptance of children with intellectual disability, and Social Acceptance of children with intellectual disability. However, reliability analysis was not able to establish internal consistency for any of these factors either. Finally, there was no significant cross-correlation between the factors of Parts 2 and 3, nor between the factors of Parts 3 and 4, although the factor of Social Acceptance of children with intellectual disability (from Part 4) was significantly and moderately positively correlated with all the factors of family quality of life in Part 3.

Chapter 7 : Modelling of Saudi Arabian Family Quality of Life and Analysis of Differences Related to Having Children with Intellectual disability

7.1 Introduction

Having demonstrated the reliability and validity of the questionnaire used for the current study in the previous chapter, this chapter deals with the testing of the substantive hypotheses arising from the third and fourth research aims. Research Aim 3 seeks to determine whether demographic factors, religiosity, and other religio-cultural factors related to caring for a child with an intellectual disability impact on family quality of life for Saudi Arabian families. Research Aim 4 is to determine whether caring for children with intellectual disability, compared to caring for children without intellectual disability, was associated with family quality of life among Saudi Arabian families. The concomitant Research Questions that this chapter seeks to answer are the following. Research Question 3: Do Saudi Arabian families who care for children with intellectual disability experience a significantly different quality of life compared to those families who do not?

The results of independent t-tests and the analysis of covariance (ANCOVA) are presented in order to establish whether there are any differences in family quality of life both in general, and in its different factors, (including demographic factors and religiosity) between families who have children with intellectual disability and families who only have children without intellectual disability, as well as examining the potential relevance of other religio-cultural factors related to caring for a child with an intellectual disability,

7.2 The Impact of Having a Child with an Intellectual Disability on Family Quality of Life

Each hypothesis will be addressed in turn, starting with Hypothesis 3a. As shown from the previous section, it was found that having a child with a severe intellectual disability was negatively associated with family quality of life. Participants reported lower scores compared to those caring for children who had a mild level of intellectual disability.

As shown in Table 7.1 below, families who had children without intellectual disability reported higher family quality of life scores than families who had children with intellectual disability. Specifically, families with a child with an intellectual disability recorded a mean family quality of life score of 2.62 out of 5, while families with children who did not have an intellectual disability recorded a mean family quality of life score of 3.63 out of 5 – a difference in means of 1.01 (Significance of results are reported below).

Because family quality of life is a multi-dimensional construct, one can also examine the differences between families who do and do not care for a child with an intellectual disability, in terms of the individual factors. Table 7.1 shows comparisons of means of families with children who have intellectual disability, and families who have children without intellectual disability, across all five factors of family quality of life (in Part 3). As can be seen, for each of the five factors of family quality of life, the mean values for those with children with an intellectual disability is lower than for those without. The greatest difference is on the dimension of Family Interaction, where the gap in the means is 1.13. The next largest difference in means

is 1.09 for Physical and Material Well-being, which is very close to the difference of 1.07 for Disability-related Support. Finally, Parenting and Emotional Well-being also share very similar differences in mean values of 0.77 and 0.73 respectively.

Table 7-1: Mean Family Quality of Life Comparison: With/Without Children with Intellectual Disability

	Child with Intellectual Disability	N	Mean	Std. Deviation	Std. Error Mean
Family Quality of Life	Yes	86	2.625	0.726	0.078
	No	115	3.638	0.588	0.055
Emotional Well-being	Yes	86	3.055	0.764	0.082
	No	115	3.789	0.674	0.063
Physical and Material Well-being	Yes	86	2.812	0.735	0.0792
	No	115	3.903	0.682	0.064
Disability-Related Support	Yes	86	2.758	0.816	0.088
	No	115	3.825	0.686	0.064
Family Interaction	Yes	86	2.659	0.846	0.091
	No	115	3.792	0.687	0.064
Parenting	Yes	86	2.902	0.848	0.091
	No	115	3.658	0.675	0.063

In order to establish whether these differences in family quality of life scores were statistically significant, independent t-tests were conducted. They are reported in Table 7.2 below. This serves to test Hypothesis 3a, that the family quality of life of Saudi Arabian families with children who have intellectual disability is significantly lower than those families without children with intellectual disability. Based on Levene's test of homogeneity of variance for the two groups presented in Table 7.2 below, the variance between the two groups was found to be statistically significant ($p < 0.01$).

Following this result, Hypothesis 3a – that there are significant differences between the family quality of life scores of families with children who have

intellectual disability, and families who only have children without intellectual disability – was accepted (since $t = 10.915$, $p < 0.01$). Thus, it can be inferred that participants from families who had children with intellectual disability reported significantly lower family quality of life scores than participants from families who only had children without intellectual disability. Specifically, family quality of life scores of participants who only had children without intellectual disability were found to be from 0.83 to 1.2 points (17% to 24%) higher than those with children who did have intellectual disability (This answers Research Question 4).

As seen in Table 7.2 below, the results of Levene's test for equality of variances for each of the five factors follow the same trajectory as that for the general family quality of life variable. As such the adjusted t value was used for hypothesis testing for the factors. Results of independent t -tests conducted found that as in the overall family quality of life score, the mean scores for each of the factors of family quality of life differ significantly ($p < 0.01$) between families with children who have intellectual disability (who have lower scores) and families who only have children without intellectual disability (who have higher scores). This provides further support for the implicit implications of Hypothesis 3a. As was noted with the differences in the mean scores of the factors for Table 7.1, the gap between Family Interaction scores for families of children with intellectual disability compared to those without was the largest (from 0.92 to 1.35 points lower for families with a child with an intellectual disability). The gap was only slightly smaller for Physical and Material Well-being (from 0.89 to 1.29 points lower for families with children with an intellectual disability) and for Disability-related Support (from 0.86 to 1.28 points lower for families with a child with an intellectual disability). The gap between

Parenting scores for families of children with intellectual disability compared to those without, and for Emotional Well-being scores, were the smallest; for the former, from 0.55 to 0.97 points lower for families with a child with an intellectual disability, and for the latter, from 0.53 to 0.93 points lower for families with a child with an intellectual disability. This is suggestive of the possibility that the first three factors mentioned are most strongly associated with having a child with an intellectual disability.

Table 7-2: Independent t-test Family Quality of Life between Families With and Without Children with Intellectual disability

		N = 201							95% Confidence Interval of the Difference	
		Levene's Test for Equality of Variances		t-test for Equality of Means					Lower	Upper
		F	Sig.	t	df	p-value	Mean Difference	Std. Error Difference		
Family quality of life	Equal variances assumed	7.052	0.009	10.915	199	.000	1.013	0.093	1.20	0.83
Emotional Well-being	Equal variances-assumed	7.63	0.006	7.184	199	.000	0.733	0.102	0.93	0.53
Physical and Material Well-being	Equal variances assumed	6.502	0.011	10.832	199	.000	1.092	0.101	1.29	0.89
Disability-Related Support	Equal variances assumed	7.46	0.006	10.025	199	.000	1.067	0.106	1.28	0.86
Family Interaction	Equal variances assumed	8.56	0.004	10.448	199	.000	1.133	0.108	1.35	0.92
Parenting	Equal variances assumed	6.98	0.009	7.016	199	.000	0.756	0.108	0.97	0.55

It is also worth examining correlations across some of the culturally specific variables identified in the exploratory analyses in Chapter 6 to see whether there are any interesting differences in correlations for families that do, and do not care for children with intellectual disability. Hypothesis 3b posits that the religiosity factors (extracted from exploratory analysis in Chapter 6) will be more positively correlated with the factors of family quality of life for families with children with intellectual disability than for families without.

The data comparison is set out below in Table 7.3. With respect to both families with and without children with intellectual disability, most of the factors of family quality of life were negatively correlated with most of the religiosity factors. Thus, the presumption in Hypothesis 3b of positive correlations already renders it not confirmed. Also, it should be noted that all of the correlation coefficients were very small, with some approaching zero.

As for family quality of life overall, two negative comments can be made. First, it can be seen that just in terms of the direction of the correlations for the four extracted religiosity factors, Hypothesis 3b is not well-supported: two of the religiosity factors – Faith and Prayer – were clearly negatively correlated with Saudi Arabian family quality of life. Second, for those religiosity factors which had technically positive correlations, their values were in fact approaching zero for both groups. For families of children without intellectual disability, the near-uncorrelated factor (with family quality of life) was Family Religiosity. For families of children with intellectual disability, both Family Religiosity and Minimum [ritual] Obedience were near-uncorrelated with family quality of life. In summary, Hypothesis 3b is not well-supported by the correlation coefficients. In any case, the p-values for all the

coefficients were far greater than 0.05, so none of the coefficients were statistically significant anyway. Thus nothing informative can really be concluded based on a comparison of the correlations, and Hypothesis 3b must be rejected.

Table 7-3: Correlations of Extracted Religiosity Factors (from Part 2) with Family Quality of Life (Part 3) for Families of Children With/Without Intellectual disability

		Family of child with Intellectual disability				Family of child without Intellectual disability			
		Prayer	Minimum Obedience	Faith	Family Religiosity	Prayer	Minimum Obedience	Faith	Family Religiosity
Family Quality of Life	Pearson Correlation	0.106	0.018	0.077	0.001	0.155	0.047	0.063	0.014
	P-value	0.33	0.87	0.48	0.99	0.098	0.62	0.50	0.88
	N	86	86	86	86	115	115	115	115
Emotional Well-being	Pearson Correlation	0.111	0.022	0.04	0.006	0.111	0.042	0.071	0.018
	P-value	0.31	0.84	0.72	0.96	0.24	0.66	0.45	0.85
	N	86	86	86	86	115	115	115	115
Physical and Material Well-being	Pearson Correlation	0.102	0.02	0.12	0.004	0.078	0.056	0.111	0.063
	P-value	0.35	0.90	0.27	0.97	0.41	0.55	0.24	0.50
	N	86	86	86	86	115	115	115	115
Disability-Related Support	Pearson Correlation	0.121	0.022	0.073	0.006	0.117	0.003	0.048	0.025
	P-value	0.27	0.84	0.50	0.96	0.21	0.98	0.61	0.79
	N	86	86	86	86	115	115	115	115
Family Interaction	Pearson Correlation	0.169	0.02	0.1	0.042	0.14	0.046	0.074	0.064
	P-value	0.12	0.86	0.36	0.70	0.14	0.63	0.43	0.50
	N	86	86	86	86	115	115	115	115
Parenting	Pearson Correlation	0.144	0.038	0.1	0.032	0.119	0.043	0.041	0.012
	P-value	0.19	0.73	0.36	0.77	0.21	0.65	0.66	0.90
	N	86	86	86	86	115	115	115	115

7.3 Differences between Families with respect to Demographic Factors

All the possible explanatory factors that survived reliability testing are now examined to determine which of them significantly are associated with family quality of life scores for families with children with intellectual disability ($N = 86$), compared to all participants ($N = 201$). This analysis was intended to address Hypothesis 3c, which states that the posited demographic associated with Saudi Arabian family quality of life will be the same for families of children both with, and without intellectual disability. To address this hypothesis, an Analysis of Covariance (ANCOVA) was conducted.

Table 7.4 below shows the ANCOVA results for families who have children with intellectual disability. It was found that marital status (divorced vs married, $B = 1.01$, $p < 0.001$) and income (low vs high, $B = 1.87$, $p < 0.001$; and medium vs high, $B = 0.88$, $p < 0.001$) were significant demographic factors associated with family quality of life, because the p-values of both variables are significant. Thus lower income had a negative impact on family quality of life, as did being divorced. Further, the impact on family quality of life was found to be dependent on the severity of the intellectual disability (mild vs severe disability, $B = 0.16$, $p < 0.001$; and moderate vs severe disability, $B = 0.15$, $p < 0.001$). It was also found that family size has an impact on family quality of life ($B = 0.013$, $p < 0.02$), with larger families having a higher quality of life than smaller families.

Table 7-4: ANCOVA Results for Families of Children with Intellectual disability

<i>N</i> = 86				
Parameter	B	Std. Error	t	Sig.
Intercept	3.647	.048	76.111	.000
Gender (Female)	.002	.024	.091	.928
Gender (Male)	0 ^a	.	.	.
Income (Low)	1.874	.020	93.391	.000
Income (Mid)	.882	.019	46.322	.000
Income (High)	0 ^a	.	.	.
Employment (yes)	.000	.023	.012	.991
Employment (Student)	.027	.022	1.235	.221
Employment (No)	0 ^a	.	.	.
Marital (Divorced)	1.018	.022	45.300	.000
Marital (Married)	0 ^a	.	.	.
Age	.001	.001	.798	.428
Family size	.013	.005	2.491	.015
Severity of ID (Mild)	.163	.031	5.190	.000
Severity of ID (Moderate)	.148	.032	4.615	.000

By way of comparison, Table 7.5 below shows the results for all 201 participants with and without children with intellectual disability in the current study. Here we find that having a child with an intellectual disability is significantly associated with family quality of life (without ID vs with ID, $B = 0.97$, $p < 0.001$), with those families with a child with an intellectual disability having a lower quality of life on average. It will be noted that two of the variables relevant to families with a

child with an intellectual disability also appear to be relevant to families generally. Namely, for all families, lower income has a significant negative impact on family quality of life (low vs high, $B = 1.79$, $p < 0.001$; medium vs high, $B = 0.81$, $p < 0.001$), as does marital status (divorced vs married, $B = 1.03$, $p < 0.001$). However, compared to families caring for a child with an intellectual disability, family size was not significant at the level of all families, which suggests that this variable is uniquely important to families of children with intellectual disability. Also, age was significant and positive for all families ($B = 0.001$, $p < 0.01$), but was not relevant to the quality of life for families of children with intellectual disability. Overall, Hypothesis 3c was rejected since there was only partial overlap of the remaining explanatory factors associated with family quality of life between the two groups of families.

Table 7-5: ANCOVA Results for all Participants (With/Without an Intellectual Disability)

N = 201

Parameter	B	Std. Error	t	Sig.
Intercept	3.748	.027	139.565	.000
Gender (Female)	.002	.014	.135	.892
Gender (Male)	0 ^a	.	.	.
Income (Low)	1.791	.013	137.663	.000
Income (Mid)	.811	.012	65.053	.000
Income (High)	0 ^a	.	.	.
Employment (Yes)	.005	.013	.403	.688
Employment (Student)	.020	.013	1.637	.103
Employment (No)	0 ^a	.	.	.
Marital (Divorced)	1.033	.014	74.252	.000
Marital (Married)	0 ^a	.	.	.
Age	.001	.000	2.599	.010
Family size	.005	.003	1.932	.055
Child with ID (No)	.965	.008	128.337	.000
Child with ID (Yes)	0 ^a	.	.	.

7.4 Conclusion

This chapter sought to answer Research Question 3, which asked the ‘core’ question of the current study: do Saudi families of children with intellectual disability experience a significantly different quality of life compared to those families who do not, and are the factors associated with both groups the same? This question was accompanied by three hypotheses. Hypothesis 3a was tested by mean comparison; Hypothesis 3b was tested by correlation analysis; and Hypothesis 3c was tested by ANCOVA. Hypothesis 3a was confirmed. Hypothesis 3b was rejected. Hypothesis 3c was not well-confirmed overall, nor was Hypothesis 3d.

In summary, in answer to Research Question 4, it is the case that Saudi Arabian families of children with intellectual disability experience a significantly lower family quality of life compared to those families who do not have a child with an intellectual disability. Further, Saudi Arabian family quality of life overall is predictively related to the demographic factors of family income, marital status of parents, and family size. There is some overlap in the factors associated with both groups – namely family income and marital status – but that overlap is not pronounced. Further, religiosity factors and other religio-cultural factors related to views on intellectual disability are not apparently relevant because they did not survive tests of reliability.

Chapter 8 : Qualitative Analysis: Themes from the Interviews

8.1 Introduction

This chapter was primarily motivated by Research Aim 5, namely, to explore the possible phenomenological reasons behind the observed quantitative results for examining family quality of life of Saudi Arabian families (as detailed in the previous chapter). The concomitant Research Question was; based on the personal opinions of participant-parents, are there discernible patterns in families' interpretations of what is most important to family quality of life, in their perceptions of the challenges of raising children with intellectual disability, and in the kinds of special assistance families feel they require due to having to care for children with intellectual disability? (It should be recalled that these are the opinions and perceptions of participant-parents both with, and without, children with intellectual disability.) Because the answers to these questions tend to be subjective and personal, answers are best elicited by allowing participants to develop extended answers which enable them to fully express their beliefs and experiences. Thus, individual interviews were used as per a standard phenomenological qualitative research design (Creswell, 2013; Merriam, 2009).

Thus, this chapter presents the findings of the qualitative, and final, phase of the study which collected data through semi-structured interviews with open-ended questions. The eight interviewees were categorised according to the axes of interest. The two axes were (A1) *Relatively Higher-Lower* family quality of life and (A2) *With/Without* children with intellectual disability (ID). Following this, the chapter

proceeds to a discussion of the themes that were identified in relation to the challenges that the families of the participants faced. The chapter then moves on to themes related to the participants' relationships with their children, followed by their perspectives on intellectual disability and recommendations as to how special education services can help families who have children with intellectual disability.

Procedurally, it will be recalled from Chapter 5 that after the selection of eight interviewees, one hour interviews were scheduled in locations agreeable to them, and were recorded lasted between 30 and 90 minutes. The recordings were then transcribed and encoded. As previously indicated, qualitative data analysis was conducted using multi-level coding (Merriam, 2009; Miles et al., 2013).

8.2 Key Comparisons along Axes: Families with Relatively Higher/Lower Quality of Life and with/without Children with Intellectual disability

In this section, comparisons are made among participants based on the two major variables of the current study, which are family quality of life and having a child with an intellectual disability. The following table shows the grouping of the participants under each categorization.

As can be seen from Table 8.1 below, there were four participants interviewed who had a relatively higher family quality of life, which was stipulated as a mean score of > 3 out of 5 for global family quality of life. Their experiences are compared against the four participants who reported a relatively lower family quality of life (stipulated as a mean score of < 3 out of 5 for global family quality of life). Whilst admittedly, the selection of a dividing score is somewhat arbitrary, the score of 3 was chosen as the dividing score between relatively higher and relatively lower

family quality of life because a score of less than 3 implies more ‘dissatisfied’ responses, whilst a score of more than 3 implies more ‘satisfied’ responses, on the Saudi Arabian Family Quality of Life Scale.

Table 8-1: Axes of Interview Participants

	Child without intellectual disability		Child with intellectual disability	
Relatively Higher Family Quality of Life	Participant 120	FQOL=4.8	Participant 56	FQOL=3.96
	Participant 97	FQOL=4.7	Participant 16	FQOL=3.93
Relatively Lower Family Quality of Life	Participant 183	FQOL=2	Participant 75	FQOL=1
	Participant 136	FQOL=2.93	Participant 32	FQOL=1

The goal of the comparison is to determine the reasons why the members of one group reported a relatively higher family quality of life while the members of the other group reported a relatively lower family quality of life. This chapter now makes a comparison between participants who had children with intellectual disability and those who only had children without intellectual disability. The goal of this second comparison is to identify the experiences of each group, and determine the main focal points that can explain why some of the participants who had children with intellectual disability still reported having a relatively higher family quality of life, while others who only had children without intellectual disability reported having a relatively lower family quality of life. As such, through these two comparisons, a nuanced understanding of the factors associated with family quality of life for families who have children with intellectual disability, and of the factors

associated with families who only have children without intellectual disability, can be reached.

8.2.1 Thematic Comparisons between Families along Axis 1: Relatively Higher/Lower Family Quality of Life

8.2.1.1 Participants with Relatively Higher Family Quality of Life Scores

The first set of questions that was asked of each interviewee inquired about what they considered as the qualities of a good family life. These questions sought to frame the perspective in which each interviewee saw the value of different aspects of family life. When asked what was most important to their families, participants with high scores on the Saudi Family Arabian Family Quality of Life Scale responded with a combination of material and ‘divine’ items: “food, clothes, everyday needs.education.... faith” (Participant 56 with child with an intellectual disability); “God, our health, and our children’s education” (Participant 120); “I would say God and each other” (Participant 97); “That we are able to provide for our children and raise them well, according to the tenets of Islam.” (Participant 16 with child with an intellectual disability).

For high scoring participants, their personal conception of a good quality family life corresponded closely with the Saudi Arabian Family Quality of Life construct. Thus, for the next set of questions, which inquired about whether or not the participants agreed with the assessment of their family quality of life based on the questionnaire, unsurprisingly all of the high scoring participants agreed with the outcomes of the questionnaire (that is, they regarded the Saudi Arabian Family Quality of Life construct as accurately measuring their own family quality of life).

In their responses to why they experienced a relatively higher family quality of life, a number of common themes emerged from all four interviewees: (1) successful provision for emotional and material family needs; (2) the wellbeing and behaviour of children; and (3) providential belief.

(1) *Satisfying emotional and material needs*: Consistent with the findings from the previous phase of investigation, three of the four participants who had a relatively higher family quality of life considered themselves as being able to *provide for the emotional and material needs* of their wives and children well:

I have a good business that pays for our needs (Participant 56 with a child with an intellectual disability).

...we are healthy and my children are going to school and are doing well in school so I am happy, my wife is happy. Our children are happy too. So I think that yes, we are a happy family (Participant 120).

We have each other, our family is whole and we are able to be together and love one another ... [I] work at a prestigious company so that I can take home enough money for my family. ... My children ... are able to go to a good school so that they can learn to be productive and moral adults who follow God's will (Participant 97).

(2) *Wellbeing of children*: Related to satisfying the needs of the family was a particular emphasis on the *wellbeing and behaviour of children* as being intimately bound up in the family's quality of life: "Everything that I do, I do for my children" (Participant 97), "That we are able to provide for our children and raise them well,"

(Participant 16 with a child with an intellectual disability). For three of the participants, evidence of the wellbeing of their children seemed to be their children's educational success, obedience or both:

I have ... kind, obedient children (Participant 56 with a child with an intellectual disability).

My children are going to school and are doing well in school so I am happy (Participant 120).

My children obey their mother and me, and they are good children who are able to go to a good school so that they can learn to be productive and moral adults who follow God's will (Participant 97).

(3) *Divine providence*: Perhaps the most dominant theme, however, was that of *providential belief* (that is, the belief that God was in some sense responsible for their relatively higher family quality of life). This theme came through strongly in all participants' answers to the question of why their family quality of life was high. For example, Participant 56 immediately prefaced his answer with, "I have a good business ... a nice wife and kind, obedient children" by saying "Because we are blessed by our God", as if the latter determined the former. Although Participant 120 does not make an explicit causal link between his family's wellbeing and divine will, he did state that one of the reasons for the family being "happy" was that "We have faith" (Participant 120). On the other hand, both Participant 97 and Participant 16 were explicitly providential in their accounts of their family wellbeing, as demonstrated below.

We have each other, our family is whole and we are able to be together and love one another under God's grace. God provides the rest. He gives me opportunity to work at a prestigious company.... He guides my wife in taking care of our children at home, and in managing our household (Participant 97).

The quality of our life is a gift as well from God. He blesses us for our good work and we reap the rewards. Yes, I think that we have a good quality of life but I do not say this like we are solely responsible for it. We have a happy life as a family because we do our best to stand by our faith in everything that we do (Participant 16 child with intellectual disability).

Concomitantly, all of the participants identified having strong faith as critical to the family's quality of life: "Ah, God, of course. That is number one. Faith" (Participant 56 with child with an intellectual disability), "God, our health, and our children's education" (Participant 120), "God is most important for us" (Participant 97). Even when Participant 16 identified the children as the most important aspect of quality of life in their family, the reason behind this included their responsibility towards God: "God gave them to us for us to love and take care of them" (Participant 16 with a child with an intellectual disability).

This suggests that families reporting or experiencing a high quality of life seem to regard faith as being an important factor in explaining their situation, although objectively speaking it is difficult to establish the direction in which causality runs. It is possible that it is other factors contributing to relatively higher family quality of life, such as income and/or marital stability, which provides the

foundation for attributing importance to faith and providence. This is a possibility raised in the next sub-section.

8.2.1.2 Participants with Relatively lower family Quality of Life Scores

Turning now to participants with low scores on the Saudi Arabian Family Quality of Life Questionnaire, only one of them cited a ‘divine’ interpretation of what constituted ‘family quality of life’: “The most important is that we live by the laws of God.... It is important for my family to take care of each other” (Participant 32 with a child with an intellectual disability). For the other three interviewees however, the provision of material needs was deemed to be most important. Participant 163 stated simply that what was most important was “That we are all safe, healthy, and together.” Participant 183 was clearest in his emphasis on material concerns, seemingly suggesting that ‘otherworldly’ matters lay in the background; “I am a practical man. For me, what is important is having enough money. Being able to take care of the children.” Participant 75 was similarly focused, but added a familial inter-generational aspiration to his material priorities:

It is important to have food on the table, a roof over our heads. It is important for my children to go to school, to learn and grow up so they can be responsible and have good jobs and do better for their children than their father did for them (Participant 75 with a child with an intellectual disability).

It was thus unsurprising that three of the four participants stated that their Saudi Arabian Family Quality of Life score accurately reflected their experiences of their family’s quality of life. The lone dissenter, Participant 32 (with a child with an intellectual disability), deflated material concerns relative to divine ones: “No, I do

not [agree that the quality of life of my family is low]. The quality of our life is good for so long as we hold on to our faith.” For them, their faith seemed to function as a consolation in the face of a lack of material goods.

Again unsurprisingly, in their responses to *why* they experienced a relatively lower family quality of life (in accordance with their recorded score), the three who agreed with the measure identified (1) difficulty in meeting material needs as a central theme, and the related theme was (2) concern over the wellbeing of children.

1. Difficulty in satisfying material needs

The three participants with relatively lower family quality of life scores tended to focus on the theme of *difficulty in meeting material needs*. Importantly, the participants did not see their circumstances as a matter of personal choice which could be easily changed. As Participant 136 stoically said, “Life is not always wonderful, but we get by. There are problems every now and then but we are able to handle it as a family.” Participant 183, however, while apparently seeing his situation as inescapable, was clearly more open in expressing his frustration; “I wish I can do more for my family but I cannot. The work I do is the only work I know. I want to do more but I cannot and it is very frustrating.” His difficulties were clearly linked to his occupational circumstances; “I only work a simple job, the pay is not much” and to his additional burdens; “I do not have a wife. But I have three children and an old mother to take care of”. His frustration was obviously exacerbated by his dependence on what he saw as meagre government support and the government’s apparent lack of concern about his circumstances:

I am the eldest in the family, we live almost entirely from what I make and what we get from the government. You know, they say that in this country, nobody is poor. That is not true really. There are many poor, but government does not want other countries to see.

Participant 75 (with a child with an intellectual disability) was similarly frustrated with his family's material circumstances. He saw his lack of income and additional burdens as something imposed upon him in a manner beyond his control:

I came from a rich family; I was used to luxury. So things for me were easy, I got married, arranged by my family and we had children. But then unfortunate events happened and our family lost our fortune. I was left to fend for myself and my family. I was not able to do that well, which is why my wife left. ... After my father died and our livelihood was taken from us, my mother fell sick and now I nurse her at home. We cannot afford a nanny, but my sisters help out.

Participant 75 also expressed frustration at having to sometimes rely on extended family to cover expenses: "I make enough money to maintain our small household, but sometimes, it is not enough and I need to borrow from some relatives, which is embarrassing but I have no choice." The exception to these accounts of difficulty in meeting material needs was the responses of Participant 32, who had a child with an intellectual disability. He perceived his family's quality of life to be similar to those who scored high on the Saudi Arabian Family Quality of Life Questionnaire. Participant 32 explicitly attributed this to the centrality of *providence*

and faith. As noted above, religious perceptions seem to function as a consolation that resulted in a downgrading of the importance of material concerns:

The quality of our life is good for so long as we hold on to our faith. We may not have many material things, that is true, but we get by. We are able to do so with the help of God. ... God is the centre of one's life. What good are all of the riches in the world for a man who has no God?

(2) *Concern over wellbeing of children*

Related to the financial burden for three of the participants with relatively lower family quality of life, the theme of the *importance of children's material wellbeing* is also evident among these participants, and it can be seen that the reason why they consider material things as important is because these are needed for their children's wellbeing:

Everything that I do, I do for my children. As a single father, my children mean more to me than anything else in the world (Participant 136).

If you do not make enough money, then you will not be able to provide for your family. How will they get by? If you do not work enough, then how can you make sure that your children have the things that they need in everyday life?" (Participant 183).

I can eat anything, but my children, I try my best to make sure that they eat healthy food so that they will have proper nutrition (Participant 75 with a child with an intellectual disability).

Participant 75, who as revealed above, originally came from a wealthy family which had fallen on hard times, also expressed not only a concern for his children's present material wellbeing, but was also looking to their future: "So, I am doing my best now to make sure that what happened to me will not happen to my children. I want them to grow up and become better persons so that they can be happy in their lives."

8.2.1.3 Comparison of Participants with Relatively Lower and Higher Family Quality of Life Scores

(1) *Wellbeing of children:* The thematic commonality between families with low and high Saudi Arabian Family Quality of Life scores was their concern for the wellbeing of their children. Both considered being able to take care of their children as an essential element of their family's quality of life. Interestingly, at this level of comparison, the fact that some of the participants had children with intellectual disability and others only had children without intellectual disability did *not* emerge as a thematic focus. That is, none of the participants with relatively lower family quality of life who had children with intellectual disability brought up having a child with intellectual disability as a reason why their family experienced relatively lower family quality of life. Thus, a more nuanced comparison between families who have children with intellectual disability and those who do not is needed, and is provided in the succeeding section.

(2) *Meeting needs:* Despite the commonality of concern for children's wellbeing, it is arguable that there was a subtle difference in the nature of the participants' focus of concern when conceptualising their children's wellbeing. This is brought out in the theme of *family needs*. For those with relatively lower family quality of life scores, there was an almost exclusive focus on meeting (or struggling

to meet) the *material* needs of the family (which obviously includes children), whereas for high scoring families, this concern tends to have a greater focus on *emotional* wellbeing. For example, compare the following low and then high quality of life scoring responses. Note that the latter mentions happiness or love of children to a greater extent than the former:

Low scoring participants:

That we are all safe, healthy, and together (Participant 163).

What is important is having enough money. Being able to take care of the children (Participant 183).

So, I am doing my best now to make sure that what happened to me will not happen to my children (Participant 75 with a child with an intellectual disability).

High scoring participants:

We have a happy life as a family because we do our best to stand by our faith in everything that we do (Participant 16 with a child with an intellectual disability).

Our children are happy too. So I think that yes, we are a happy family (Participant 120).

We have each other, our family is whole and we are able to be together and love one another (Participant 97).

(3) *Providence*: The most marked difference in themes between low and high scoring families was on the role of perceived providence in participants' lives. For participants with relatively higher family quality of life, there was a marked emphasis on the importance of God and their faith. They did not attribute their high quality of life to choices they had made or to good fortune. Rather, God ultimately explained their circumstances. This is clearly expressed in Participant 97's comment: "...we are able to be together and love one another under God's grace. God provides the rest" – the "rest" here was their material circumstances. At least one of the participants suggested there was a degree of personal agency involved in their family's good fortune: that their faithfulness explained God's bestowal of a high quality of life: "God ... blesses us for our good work and we reap the rewards. ... We have a happy life as a family because we do our best to stand by our faith in everything that we do" (Participant 16 with a child with an intellectual disability).

In stark contrast, for three of the four participants scoring low on the family quality of life questionnaire, God and faith played no such explanatory role. These participants seemed to attribute their lower quality of life simply to either accidental or structural circumstances beyond their control. For example, "After my father died and our livelihood was taken from us" (Participant 75 with a child with an intellectual disability) and "The work I do is the only work I know. I want to do more but I cannot" (Participant 183). No additional divine explanations were offered. One participant did apportion some 'blame' to the government – "There are many poor [in Saudi Arabia], but government does not want other countries to see" (Participant 183) – but did not extend this ultimately to God. As noted previously, only one participant with a measured relatively lower family quality of life explicitly

referenced God, but in a positive way. Rather than not mentioning God, Participant 32 (with a child with an intellectual disability) interpreted his family's circumstances counter-factually. They are able to survive despite their difficult circumstances because of God: "We may not have many material things, that is true, but we get by. We are able to do so with the help of God." In the case of this participant, God was not conceptualised as punitive or wrathful, but as merciful and compassionate, which is widely regarded as a dominant attribute of God in Islam (Nawawi & Keller, 2003).

8.2.2 Thematic Comparisons between Families along Axis 2: With/Without Children with Intellectual disability

In this section, the relevant themes that emerged in comparing the experiences of participants who had children with intellectual disability and participants who only had children without intellectual disability are made. It is important to consider that among the participants who had children with intellectual disability, all of them reported the level of intellectual disability of their child to be mild. While attempts were made to contact those with children who had moderate or severe intellectual disability to be interviewed, none such participants from the questionnaire agreed to be interviewed.

8.2.2.1 Families with Children with Intellectual disability

A major thematic finding at this level of comparison was the presence of *mitigating factors* that appear to diminish the perception of negative impacts of having a child with intellectual disability on the family quality of life. One mitigating factor was the capacity to (1) *provide special services* for their children with

intellectual disability, and the other was a (2) *normative parental focus* away from intellectual disability per se.

(1) *Mitigation: provision of special services*: When Participant 16 (who has a child with an intellectual disability) was asked the question, he explained that family quality of life was affected by the circumstances of his children, but it was found that he was actually referring to the illness of his child without an intellectual disability, who suffered from severe chest pains: “Just looking at my children, my youngest, when he is suffering from pain, he clutches his chest. ... It is very painful for a man to see his child in pain like that but I try my best to be strong for them.” While Participant 16 later admitted that his child with intellectual disability also had special needs, he explained that this had far less impact on their quality of life than the challenges faced by his other child who has ill health, describing how his child with intellectual disability even “takes care of his younger brother.” In addition to this, it is noticeable that Participant 16 mentioned the different services that his family are able to afford which helps them deal with having a child with an intellectual disability: “with the right teachers and the right training for us as parents, we were able to help him become better. I think that this is a very big blessing from God, that we are able to do this.” As such, these affordances seem to minimise any possible negative impact that having a child with intellectual disability may have on the family quality of life of Participant 16’s family.

However, in contrast to the above experiences, Participant 75 who also has a child with intellectual disability expressed how the intellectual disability of his child had a negative impact on their family quality of life. Asked if their situation would not have been as bad if his child did not have this intellectual disability, Participant

75 answered “yes”. While he loved his child, he admitted that the child’s intellectual disability “takes such a toll on the family.” It is important to contrast this with the experience of Participant 16, particularly since Participant 75 claimed that he:

cannot afford to provide him with the special private schooling that he needs.

So we send him to government school but I do not know if this is working for him. He has not changed much in his abilities.

As such, it can be derived from this comparison that since Participant 16 has the means to address the special needs of his child with intellectual disability, the impact of having a child with intellectual disability on family quality of life is mitigated relative to the case of Participant 75.

(2) *Mitigation: normative parental focus*: Another mitigating factor could be the normative focus of the parent’s attention. For example, when asked about whether having a child with intellectual disability made his family’s quality of life higher or lower, Participant 56 answered that it was not really relevant: “I do not think it matters. My child is my child. He has a disability, but all children have good and bad characteristics. I do not think it should affect the quality of life. A child is a child.” Rather, he reasoned that it is parents who have children that are disobedient or disrespectful (independent of disability) who are “unfortunate,” but his “children are obedient and respectful. All of them are, so (he is) blessed.” This is not to say that Participant 56 did not think that life was more challenging for his *child* with intellectual disability, but somewhat curiously, Participant 56 did not see this challenge ‘spilling over’ into challenges for the *family*: “I think that the family, we ourselves do not face difficult challenges. The one who does is our child. Our child is

the one who must overcome many challenges in life”. Because Participant 56 places such a heavy emphasis on the importance of children being “obedient and respectful”, this characteristic of his child with an intellectual disability completely overshadows any perception of family disadvantage arising out of intellectual disability.

8.2.2.2 *Families without Children with Intellectual disability*

The above responses can be fruitfully compared with the opinions of interviewees who did *not* have children with intellectual disability. The views of these participants were not informed by direct experience of caring for a child with intellectual disability, and so would have had to be hypothetical projections from their own lives. For these interviewees, they imagined that having to care for a child with an intellectual disability would have an unambiguously negative impact on family quality of life. As explained by Participant 120 who does not have a child with intellectual disability:

It is very challenging to raise a child with any disability. I think it would be very hard because of all of the special needs of that child and the child’s inability to understand things even when he becomes older.

This same perspective was shared by Participant 136, another participant who did *not* have a child with intellectual disability: “I think first, it is hard because the parents would need more effort, more money too. Their child would need to go to a special school.” The response of Participant 136 further emphasizes the theme of underlying factors which mitigate the impact of having a child with intellectual disability on the family’s quality of life. As discussed by Participant 136, the parents of a child with

intellectual disability need more resources in order to deal with the challenges of raising their child, and the unavailability of such resources can then take a difficult toll on the family. This is reiterated by Participant 183, who stated that while having a child with intellectual disability may be a difficult situation, it depends on the circumstances of the family:

If the person has enough money, he can get the things that are needed in order to take care of such a child properly. I know there are schools and carers that can be hired who specialize in those children. So I think that it would be ok. The problem is if the money is not there, then it would be so very difficult (Participant 183).

Both Participant 136 and Participant 183, however, also maintained that there are other problems that they believed families with children who have intellectual disability faced which can also impact upon family quality of life: one being the inability to communicate effectively with their child, and the other having to live with the fact that their child may be bullied:

The parent would still have to think about how to provide for someone who may not be able to understand many things on his own. I think that is a very big problem (Participant 183).

It is hard because parents do not want to see their children suffering, having a hard time, and this is what will happen to a child with that disability. Maybe the child will even be taunted by other children. It is heartbreaking for a parent to see that and to consider that their child will have to live with that for the rest of his life (Participant 136).

Thus, this also further establishes the second theme about the perception of people without children with intellectual disability of there being a negative impact on family quality of life of having a child with an intellectual disability.

8.2.2.3 Summary of Comparison of Families with and without Children with Intellectual disability

In summary, it is clear that the primary reason why participants believe that families with children who have intellectual disability will have a more difficult time is because of the added financial burdens carried by these families and the inadequacies of the resources available to them. This is consistent with a theme that was drawn from among those participants who actually had a child with an intellectual disability.

According to most of these participants, there is *an extra challenge* that comes with having a child with an intellectual disability. This was confirmed by those who had children with intellectual disability: “His disability is also a challenge for us” (Participant 16 with a child with an intellectual disability), “He needed much more care and effort than our other two” (Participant 75 with a child with an intellectual disability), “The challenge comes from needing to understand the child and his needs” (Participant 32 with a child with an intellectual disability). However, a dissenting perspective was presented by Participant 56, who had a child with an intellectual disability but did not consider this to be the source of any challenge for the family. However, as noted above, Participant 56 did admit that his child’s intellectual disability caused challenges for *the child* although not for the family in general:

I think that the family, we ourselves do not face difficult challenges.

The one who does is our child. Our child is the one who must overcome many challenges in life; we must do our best to prepare him for this.... He does not understand things at the same pace as other children.

That said, it seems clear that Participant 56's testimony revealed, even though he himself did not admit it, that he was negatively emotionally affected in a way that would not be the case if his child did not have an intellectual disability:

Sometimes, people see him and they have this look in them, like he is not a person. I hate that look because it is not true, he is still my son. He is still a person. But he must do harder to be accepted by society (Participant 56 with a child with an intellectual disability).

These results show that participants do acknowledge (or at least subconsciously feel) the challenge presented by raising a child with an intellectual disability. However, at the same time, these challenges were found to be closely related to the capacity of participants to provide for the special needs of their children who have intellectual disability. This can explain why participants such as Participant 56, who has a child with intellectual disability but is also gainfully employed, do not consider having a child with an intellectual disability as a burden at all. Participant 75 on the other hand, who also has a child with an intellectual disability but is struggling financially, considers the intellectual disability of his child as a burden to the family.

8.3 Perspectives about Intellectual Disability

When asked about what comes to their mind when talking about intellectual disability, the dominant theme that was drawn was that intellectual disability are *a challenge*, which was evident from both parents who had children with intellectual disability as well as parents who did not have children with intellectual disability:

I think what comes to mind is it is a challenge. When you have intellectual disability, the things you do are harder for you than for other people, so you need to work harder, it's a challenge (Participant 56 with a child with an intellectual disability).

I think intellectual disability is a difficult challenge (Participant 120).

Their parents need to put in more effort, I think that is what comes to mind (Participant 136).

I am aware that this can be very challenging for both them and their parents (Participant 97).

That this was drawn from both parents who had children with intellectual disability and parents who did not, shows that even parents who did not have children with intellectual disability acknowledged the difficulty of raising them. This theme was also found to be consistent among those with a relatively higher family quality of life and those with a relatively lower family quality of life, thus showing that all of the participants believed that having intellectual disability is a challenge for the family of the child with an intellectual disability.

There was nonetheless a dividing line between the sub-groups. Participants *without* children with intellectual disability concurred with *relatively lower family* quality of life participants *with* children with intellectual disability. These two sub-groups considered that having to care for children with intellectual disability was a considerable challenge that definitely impacts upon family quality of life:

Definitely. I really think [it affects family quality of life]. It is very challenging to raise a child with any disability. I think it would be very hard because of all of the special needs of that child and the child's inability to understand things even when he becomes older (Participant 120).

Yes, of course. I love my child, but I have to admit that his condition takes such a toll on the family. I cannot afford to provide him with the special private schooling that he needs (Participant 75 with a child with an intellectual disability).

It seems clear that families of children with intellectual disability who are relatively poor, or who face illness in their family, or have only one parent, face a serious burden in terms of caring for their children, which in turn affects their perspective of their family quality of life. For those who do not have the experience of raising children with intellectual disability, they imagine (without direct experience) that looking after a child with an intellectual disability is sufficiently daunting to think that it must negatively affect a family's quality of life. These responses contrasted sharply with the two participants who reported a *relatively higher family* quality of life *and had* children with intellectual disability. These two participants, with

sufficient material resources at their disposal, stated that their family quality of life was not detrimentally affected by having children with intellectual disability.

As to *how* life would be made more challenging by raising a child with an intellectual disability, as previously noted, a dominant theme was that it would be a *financial challenge*: “I mean, if the person has enough money, he can get the things that are needed in order to take care of such a child properly” (Participant 183). “I think first, it is hard because the parents would need more effort, more money too. Their child would need to go to a special school” (Participant 136). Arguably, this could relate to social acceptability of families with children with intellectual disability because it would appear that all interviewees, whatever their circumstances, recognised that financial challenges would be significant, whilst implicitly recognising also that these challenges may be quite difficult to meet for some families. This is perhaps more likely to be the case in a highly religious country like Saudi Arabia because, as all those participants with high scores on family quality of life stated (as already noted in a previous section), they did not claim that they personally were responsible for their good fortune. As such, it is possible that they would not ‘blame’ people facing greater financial challenges for their circumstances; they may instead sympathise with them, rather than chastising or socially isolating them. For example, as Participant 97 (who does *not* have a child with an intellectual disability) stated when asked what immediately comes to mind when hearing about a child’s intellectual disability:

I think the first thing that comes to my mind is sadness. I feel sad for people, especially children who suffer from this condition. I am aware that this can be

very challenging for both them and their parents, I think that the parents should take care of their children well.

On the other hand, at least two interviewees acknowledged (if somewhat unconsciously) that there is likely to be a significant *emotional challenge* raising a child with an intellectual disability because of a perceived lack of social acceptance of their children in the broader community. Participant 136 who did *not* have a child with an intellectual disability expressed the fear that: “Maybe the child will even be taunted by other children. It is heartbreaking for a parent to see that and to consider that their child will have to live with that for the rest of his life.” Participant 56, who was raising a child with a disability, spoke from bitter first-hand experience: “Sometimes, people see him and they have this look in them, like he is not a person. I hate that look because it is not true, he is still my son” (Participant 56 with a child with an intellectual disability). Participant 56 went on to suggest that this kind of negative social perspective was likely to have unfortunate implications for his son in the future: “Like if you are getting a job, if you have this disability, you might not get the job, someone else might get it. It is more difficult; you understand? So some people think you cannot work, but you can.” Although other interviewees did not comment directly on the issue of the social acceptability of intellectual disability (despite all of them feeling it was an undesirable fate), the frank responses of the above two interviewees would seem to suggest that society has not yet reached the highest level of acceptance that is needed in order for their children to be able to participate fully in society.

8.4 Role of Special Education

One of the aims of the current study – Research Aim 5 – was to explore possible recommendations by families as to how special education services in Saudi Arabia can address the needs of families with children who have intellectual disability. Recommendations were therefore drawn from the participants during the interviews and the outcomes of these are presented below. Further recommendations based on the overall outcomes of the study will be presented in the discussion chapter.

After comparing the responses of parents with children who had intellectual disability, with parents who did not have children with intellectual disability, both groups were found to make suggestions on the actions that special education can take to improve the quality of life of families who have children with intellectual disability. However, the suggestions of interviewees who did not have children with intellectual disability tended not to be as urgently expressed as those who did have children with intellectual disability. This is to be expected, since those with children who had intellectual disability were able to apply their own experiences in making recommendations. For example, Participant 75 related his recommendation on the challenges that his family faced in taking care of their child with intellectual disability at home. According to Participant 75, having special education services teach them about different ways to deal with the challenges that their child encounters on a normal basis at home, can be a great way of alleviating some of the burden that they experience in raising a child with intellectual disability. Similarly, the recommendation of Participant 32 was focused on his experiences about the inaccessibility of special education facilities.

The interviews revealed five themes relating to the recommendations. They were: (1) ignorance of what was needed; (2) advocacy of special education facilities; (3) the provision of parental guidance; (4) the existence of economic constraints; and (5) the need for further research.

(1) *Ignorance of what was needed*: With regard to how special education can help families with children who have intellectual disability, one dominant theme that emerged from the interviews was *an ignorance of what was needed*. This theme was unambiguously expressed by four of the interviewees. Three of those participants did not have children with intellectual disability. ‘Ignorance’ here does not mean participants were ill-informed or misinformed, and so offered unhelpful or unrealistic suggestions. Rather, it means that the participants self-consciously believed that they were not really qualified to identify recommendations that can actually be of benefit to families with children who have intellectual disability: “I am not sure about that” (Participant 120), “I honestly have no idea about that [i.e. special education]” (Participant 183), and “I do not know. I have never had that experience. I think that the experience is unique, such that it is difficult for one who is not in that position to say anything about how such parents cope” (Participant 97). This suggests that although families without children with intellectual disability are capable of imagining that life would be difficult, their lack of any first-hand experience of such a situation meant that they were not willing to offer what could be erroneous suggestions. As such, most suggestions about what could be done in practical terms had to come from those families which had direct, lived experience of caring for children with intellectual disability. Interestingly however, one of the participants who expressed their ignorance of what should or could be done, Participant 56, who

said “I do not know. I do not think so because I am not a teacher, I do not know those things”, was in fact caring for a child with intellectual disability. This suggests that merely living with and attempting to deal with a child with an intellectual disability is no guarantee that one will be an ‘expert’ or have definite views on the matter.

(2) *Special education facilities*: Although as noted immediately above, half the participants claimed they did not know what to do to support children with intellectual disability and their families, six participants expressed positive explicit or implicit views on the need for special education for children with intellectual disability. Each endorsed the notion of special education schools or facilities either from the perspective of the children or their parents. For example:

I think that with their [i.e. special education schools] help, the burden of the parents will become lighter (Participant 97).

I know there are schools and carers that can be hired who specialize in those children. So I think that it would be ok (Participant 183).

I think ...it is hard because the parents would need more effort... Their child would need to go to special school (Participant 136).

I think that each school should have facilities for children with such disabilities (Participant 32 with a child with an intellectual disability).

Participant 56 was the only participant caring for a child with intellectual disability who had been able to enrol his child in a special education school, so he was the only interviewee with direct experience of the institution called for by the others. His response was a strong endorsement of the provision of such facilities:

I think that special education is doing very good for our child. He goes regularly, and is able to interact with other people who also have a disability.

I think that the school is good in helping him become better, more independent (Participant 56 with a child with an intellectual disability).

(3) *Parental guidance*: A theme that emerged out of the previous theme (about the advocacy of special education) is the need for parental guidance from special needs educators about how to best deal with children with intellectual disability. This suggestion was made by one participant who did not have children with intellectual disability, and seemed to be somewhat paternalistic, but well intentioned:

I think that these schools know more about children with these disabilities and that they should be the ones to orient family members, parents on how to take care of their children. I think that with their help, the burden of the parents will become lighter. They will have more knowledge on how to handle things in raising their child (Participant 97).

This theme was also expressed, however, by a participant who was caring for a child with an intellectual disability. Participant 75 (with a child with an intellectual disability) admitted that he was “no expert” when it came to raising children with intellectual disability, and believed that since he was not able to afford to hire help, educators should consider providing guidance on how best to deal with children in the home:

I think that they should also look into how they can help us parents care for our child at home. I think that there needs to be a partnership, between us and

them [i.e. educators], because I myself am no expert in this matter, I do not know what to do in order to make my child learn best. I cannot afford to hire someone to do it for me. I have to rely on the school; I think that this is one thing that they can do which can matter a great deal (Participant 75 with a child with an intellectual disability).

(4) *Economic constraints on accessing special education services:* Two of the parents caring for children with intellectual disability, although endorsing the need for special education for their children, did not themselves have access to such facilities. They lamented this fact and pointed out that this was because they were not able to afford such facilities for their child (or were not able to move to where those facilities existed):

I cannot afford to provide him with the special private schooling that he needs. So we send him to government school but I do not know if this is working for him. ... I cannot afford to hire someone to do it [i.e. teach] for me. I have to rely on the school (Participant 75 with a child with an intellectual disability).

We do not have access to those special schools here. I tried to sometime ago but the facility is too far away. We have to include him in regular school (Participant 32 with a child with an intellectual disability).

Perhaps unsurprisingly, the burden of higher educational costs was clearly on the minds of the two participants with lower material standards of living, who did not have children with intellectual disability. Participant 136 mentions this in passing: “I think first, it is hard because the parents would need more effort, more money too.”

In response to a question about how families deal with children with intellectual disability, Participant 183 was more explicit:

I think that is a difficult situation. I think it depends though on the person. I mean, if the person has enough money, he can get the things that are needed in order to take care of such a child properly. ... The problem is if the money is not there [for special education support], then it would be so very difficult (Participant 183).

On the other hand, interviewees who had high scores on their family quality of life, and so had relatively comfortable material lives, did not seem to contemplate the possibility of a family facing economic constraints on their capacity to deal with a child with an intellectual disability.

(5) *Further research*: Finally, a theme related to the above theme of ignorance is the need for *further research* into what kind of environment and schooling would be best (or better) for children with intellectual disability. This was a view expressed by two of the participants, both of whom did not have children with intellectual disability. Participant 136 suggested that special education institutions conduct more research into helping children with intellectual disability based on techniques that have been tested in other countries:

Maybe what they can do is do more research into the needs of special education? I think we have some special education schools here but in other countries, they are better. I think ours should learn from those countries maybe so that they can teach special children here better (Participant 136).

Participant 120 similarly suggested that special education institutions should play a larger role than just looking after and teaching children with intellectual disability. Rather, they should be actively exploring the best ways of teaching:

I think special education can look into how the child is able to learn compared to other children, maybe they can find a way to teach things in ways that a child with disability would be able to understand easily (Participant 120).

8.5 Summary of Interview Findings

Based on the themes which were drawn from the interviews, the following summary of findings can be offered. First, participants with relatively higher family quality of life had different perspectives about quality of life than participants with relatively lower family quality of life. In particular, participants with relatively lower family quality of life tended to focus on material aspects as important in measuring quality of life, while those with relatively higher family quality of life tended to focus on familial and transcendental aspects. In addition to this, it was found that participants with relatively higher family quality of life who also had children with intellectual disability tended to dismiss the impact of having a child with intellectual disability on the quality of life experienced by their family. On the other hand, participants with relatively lower family quality of life who also had children with intellectual disability reported that the intellectual disability experienced by their child had a negative impact on their family quality of life (bar one). As such, the difference between family quality of life of families who had children with

intellectual disability and families who did not, seems to have been mitigated by other factors, such as the economic stability of the family.

In line with this, economic stability was found to play a critical role in family quality of life. Those with relatively higher family quality of life regarded being blessed with material resources as an important element in considering themselves to be enjoying a good quality of life. Consistent with this, those who have relatively lower family quality of life considered being poor as one of the strongest reasons for their relatively lower family quality of life. In both cases, material wealth was not considered as an end unto itself, but as a means to provide for the needs of the family, especially the children. In general, participants considered it critical for them to be able to sustain the needs of their children, and considered the inability to do so as having a grave impact on family quality of life. The impact of financial stability was evident across other themes that were identified, such as the challenges faced by the family both in general and in raising children with intellectual disability. Participants noted that the complex needs of children with intellectual disability meant that the need to supply sufficient financial resources was even more pressing for the family. In addition to this, having a child with intellectual disability was generally found to add an extra challenge to the lives of both the individual with intellectual disability, and their family. As for the children, it was found that those with intellectual disability required more care and attention than other children.

Participants generally reported having positive relationships with their children, and that they fostered principles of discipline, respect, and religiosity in raising their children. This was argued to be consistent with what can be expected

from people in Saudi Arabia given the strong collectivist and religious culture of its society.

Intellectual disability was considered as a challenge by all of the interviewees. While some may have considered the impact of having a child with an intellectual disability on family quality of life as minimal, they nonetheless acknowledged that their child with an intellectual disability needs to face many challenges that children without intellectual disability do not. This shows that while having a child with an intellectual disability is a challenge, families are very capable of experiencing relatively higher family quality of life despite having a child with intellectual disability. Families with relatively higher family quality of life who have children with intellectual disability consider their children as blessings despite having disabilities. They believe that through proper care and support, their children will still be able to grow up as productive members of society.

Overall, the results of the Phase 3 qualitative analysis establish that the effect of having a child with an intellectual disability on the family quality of life of Saudi Arabian families is not straightforward. It has a complex structure that can be better understood in the context of extant literature. This is addressed in the succeeding chapter.

8.6 Conclusion

This chapter has reported the results of the qualitative empirical component of the study of the effect on Saudi Arabian Family Quality of Life associated with caring for children with intellectual disability. It has sought to tackle this thesis' fifth Research Aim, namely, to explore the possible phenomenological reasons behind the

observed quantitative results for family quality of life of Saudi Arabian families. The accompanying Research Question asked whether there were discernible patterns in families' interpretations of what is most important to family quality of life, in their perceptions of the challenges of raising children with intellectual disability, and in the kinds of special assistance families feel they require due to having to care for children with intellectual disability.

In summary, thematic analysis of the interviews revealed that interviewees with high vs low Saudi Arabian Family Quality of Life scores conceptualised 'quality of life' differently. Although both groups on this axis regarded their children's wellbeing as central, low scoring participants emphasised material over emotional wellbeing compared to high scoring participants. Also high scoring participants heavily emphasised the role of divine providence in explaining their high quality of life, whereas low scoring participants did not. It was also found that all participants perceived raising a child with intellectual disability to be challenging, however, participants actually caring for a child with intellectual disability were far more reticent about saying that their child harmed their family's quality of life. Participants who did not have a child with an intellectual disability seemed to feel no such compunction.

As to the matter of recommendations about special education for children with an intellectual disability, the interview results found that interviewees were generally in favour of the provision of special education services or schools, not just to teach students with intellectual disability, but also to provide parenting guidance to families about how to best meet the needs of their children with intellectual

disability. It was also revealed, however, that economic constraints currently curtail such support.

In the next chapter, there will be a discussion of all the results – both quantitative and qualitative.

Chapter 9 : Discussion of Findings, Recommendations and Conclusions

9.1 Introduction

In this chapter, the results of the study are discussed with respect to the aims and research questions. The discussion covers the following topics. First, the construction and evaluation of the questionnaire used in the current study is briefly recounted and re-examined. This is followed by an examination of the correlational relationships found among the different constructs posited in the questionnaire. In this regard, the invariance of religiosity is commented on as a precursor to a subsequent discussion of the possible role of religion in Saudi Arabian families' lives. The discussion then proceeds to examine the factors that were found to be associated with the family quality of life of Saudi Arabian families, including the comparison of families who do and do not care for children with intellectual disability. In this regard, the dominance of socio-economic status is commented on, and the puzzle of the apparent explanatory irrelevance of religiosity is explored. Finally, this chapter discusses the strengths and limitations of the study, and provides some recommendations for policy and further research that can be pursued in future studies. In all, this chapter highlights the significant contribution that the study has made to our substantive and methodological understanding of family quality of life in Saudi Arabia, and its potential role as a driver of future research and best practice.

9.2 Discussion of Findings

9.2.1 Construction and Evaluation of the Saudi Arabian Family Quality of Life construct

As discussed in Chapters 3 and 5, in order to measure the family quality of life of families in Saudi Arabia, the current study adapted the Beach Center Family Quality of Life Scale (Hoffman et al., 2006). The Beach Center Family Quality of Life Scale has been validated and applied in various contexts (Eskow et al., 2011; Summers et al., 2007; Turnbull et al., 2007; Zuna et al., 2009), but not in a Middle Eastern setting. Since there were a considerable number of contrasting differences between Saudi Arabian and Western cultures based on Hofstede's cultural dimensions (Hofstede, 2010), validation and modification of the questionnaire were deemed necessary. The first two research questions of the current study were centred on whether this could be done successfully (that is, could the Beach Center Family Quality of Life Scale be augmented and still be found to be reliable and valid for the new target population). The Beach Center Family Quality of Life Scale was thus modified into the Saudi Arabian Family Quality of Life Scale, which apart from the original factors measured in the Beach Center Family Quality of Life Scale (Hoffman et al., 2006), included items designed to capture a religious factor to Saudi Arabian family quality of life. This was Part 3 of the questionnaire. The questionnaire that was developed for the current study also sought to measure the constructs of 'religiosity' (Part 2) and 'other religio-cultural factors related to caring for a child with an intellectual disability' (Part 4). These elements were included based on initial findings from the literature on the importance of such values as religiosity and religio-cultural perspectives on intellectual disability in Saudi Arabia

(Al-Dawood & Albar, 1994; El-Gilany et al., 2010; Hammoudeh, 2012) and the importance of a number of demographic variables in the measurement of family quality of life (Cagran et al., 2011; Eskow et al., 2011; Meral & Cavkaytar, 2013; Summers et al., 2007). In addition to this, the questionnaire also included a section for gathering demographic data, particularly the participant's gender, marital status, socioeconomic status, level of education, and employment status. This was Part 1 of the questionnaire.

Development of the content and format of the questionnaire was assisted by consultation with a panel of experts using the Delphi Technique. Some issues that were raised during this process included: the relevance of measuring religiosity as a construct for the Saudi Family Quality of Life and the need to be specific about the context of quality of life that was being measured by the questionnaire. These issues were resolved during the process, and the final version of the questionnaire was modified according to the inputs of the experts. There was general agreement about the need for culturally specific items in the questionnaire, and there was some debate among the experts over the usefulness of attempting to measure 'religiosity' (Part 2 of the questionnaire), but ultimately all new aspects that related to the role of religion were retained. In particular, Part 3 of the questionnaire, which was based on the original Beach Center Family Quality of Life Scale, was augmented (a) to allow answers from families both with and without children with intellectual disability, and (b) to include six new culturally specific items that were intended to be about how, in various ways, religion was able to support families, thereby making up a factor of their family quality of life.

Confirmatory factor analysis was able to establish the existence of the five factors of family quality of life in accord with the original Beach Center Family Quality of Life Scale, namely, Emotional Well-being, Physical and Material Well-being, Disability-Related Support, Family Interaction and Parenting (Hoffman et al., 2006). This result was expected as the original Beach Center Family Quality of Life Scale had been validated in numerous other contexts, including, by Meral and Cavkaytar (2013) who established this in an extensive study of families in the majority-Muslim country of Turkey. As an aside, Meral and Cavkaytar (2013) speculated that Islam may be playing some role in accounting for their results (that religious belief may be mitigating the negative impact of low socioeconomic status on family quality of life), but they did not explore this possibility. The current study has followed up on this possibility with an exploratory factor analysis on the six new items added to Part 3 of the questionnaire, which was indeed able to capture a single new factor of family quality of life (in the Saudi Arabian context), which was labelled 'Religious Support'. Given the fact that Meral and Cavkaytar (2013) singled out religion as being a possible factor for Turkish families, despite there being a great deal of variability in the extent to which Islam plays a role in Turkish families lives (WIN-Gallup International, 2012), it was unsurprising that the addition of Religious Support' turned out to be a relevant (validated) factor of family quality of life for a more conspicuously religious country such as Saudi Arabia.

Results of reliability testing conducted showed that all the factors identified in Part 3 of the questionnaire, including the new factor of 'Religious Support', were highly reliable with Cronbach alpha values greater than 0.95 for each factor. This is an important finding in itself because it shows that an adaptation of the Beach Center

Quality of Life Scale, designed to include families with and without intellectual disability and also augmented for the religious nature of the Saudi Arabian population, is a valid and reliable measure of family quality of life. As such, it can be said that a new instrument of investigation of family quality of life for Saudi Arabia has been developed. It may well be the case that this instrument can also be used in similar societies in the region, especially in neighbouring countries such as the United Arab Emirates, Oman, Kuwait and Qatar, where there are strong cultural similarities and sensitivities to Saudi Arabia when it comes to matters of religion.

It must be said, however, that when it came to the reliability coefficients for both the 'religiosity' construct (Part 2 of the questionnaire) and 'other religio-cultural factors relating to caring for children with an intellectual disability' (Part 4 of the questionnaire), they were lower than the required standard of a Cronbach alpha value of at least 0.70 (Streiner, 2003; Weisberg & Krosnick, 1996). As to 'other religio-cultural factors relating to caring for children with intellectual disability' (Part 4), this outcome was not entirely surprising, given that Part 4 was not really attempting to present a single construct, but rather sought to identify a variety of different items about participants' perceptions of children with intellectual disability. In the case of 'religiosity' (Part 2), it was noted that the variance of responses of the participants to the questions was quite low; participants tended to rate all of the items under the construct highly, leaving little room for variation. This is the most likely explanation for the low Cronbach alpha result for this part of the questionnaire. Indeed, this is what was predicted by one of the experts consulted by the Delphi Technique when constructing this part of the questionnaire. He argued that although the items were *prima facie* internally consistent, this consistency would not be exhibited *statistically*

in Saudi Arabia because of the religious homogeneity of the population, and because participants would be unlikely to answer negatively in a questionnaire that measures their religiosity. As the reliability result suggests, this qualm turned out to be correct: the participants gave highly uniform ‘positive’ responses to all the items in Part 2.

This preliminary finding in the validation phases of the Saudi Arabian Family Quality of Life Questionnaire was interesting in two respects. First, with respect to the original Beach Center Family Quality of Life Scale, although it was developed in North America and may initially be presumed to be reflective of a ‘Western’ conception of family quality of life, since it turned out to be well-validated, it would seem to suggest that it in fact captures aspects of family quality of life that transcend any particular cultural formation. This would seem to undermine a line of ethnographic-political discourse in the West, which goes back to 19th century Orientalism (Said, 1978) and which has re-emerged with Samuel Huntington’s ‘clash of civilisations’ thesis (Huntington, 1996). There is also a parallel line of thought that developed among some Muslim intellectuals as well, which similarly posited a whole ‘Islamic way of life’ that was essentially incompatible with Western ideas (Akhavi, 1994; Nasr, 1996). These parallel lines of discourse posit that there are irreconcilable cultural differences between Western and Muslim societies that run so deep that their value systems and modes of conceptualising all aspects of life – including norms of family relationships – are fundamentally incompatible. An implication of the initial findings of the current study, however, strongly suggest that there are deep commonalities in perceptions and experiences of what constitutes family quality of life in both Western and Arab-Muslim families. So in this respect at least, the

Orientalist / Islamicist notion of fundamental incommensurability is both crude and flawed.

This is not to say, however, that there are no religio-cultural differences between different cultures, or that those differences are irrelevant. Indeed, the second point of interest arising out of the preliminary validation finding for the Saudi Arabian Family Quality of Life Questionnaire is that a widely believed presupposition about Saudi culture – that religious thinking and practice permeates all aspects of Saudi life (Al-Rasheed, 2010) – is manifested in the validation tests. Secularisation of beliefs and practices is a rising trend in Western societies (WIN-Gallup International, 2012). Because of the greater variability in religious attitudes and practices between families in Western societies, one might suspect it to be manifested in different experiences of life and family. But in the case of Saudi Arabia, there is really only one religious framework (Islam) that is sanctioned and enforced by the state (Al-Rasheed, 2010). Islamic teachings are mandated and dominate the primary and secondary school syllabuses for Saudi students (Ministry of Education, 2008), so that when combined with traditional family dynamics (where basic religious practices, such as prayer, are taught), it ensures that certain common religious beliefs are reproduced inter-generationally in a fairly uniform fashion across the population.

That said, it is reasonable to speculate that there would be *some* variability between individual participants with respect to at least some *aspects* of religiosity, if only because different individual life experiences ‘beyond the reach’ of the state and education, can modify a person’s way of interpreting the importance or relevance of certain aspects of religious belief and practice in his or her life. Indeed, this is what

was found following an exploratory factor analysis of responses to the ‘religiosity’ construct and the ‘other religio-cultural factors related to caring for a child with an intellectual disability’ construct in the questionnaire. It was discovered that certain *factors* of these parts of the questionnaire were potentially relevant to the study. For the religiosity part of the questionnaire (Part 2), the factors identified by exploratory factor analysis were “Prayer,” “Religious Belief” “Minimum Obedience,” “Faith,” “Maximum Obedience” and “Family Religiosity.” For the other religio-cultural factors related to caring for a child with an intellectual disability (Part 4), the factors found were “Love for Children,” “Religious acceptance of having children with intellectual disability,” and “Social acceptance of children with intellectual disability.” As already noted above, reliability analysis was not able to establish internal consistency for Part 4. It is arguable that this is not a serious concern because each of the items in this part of the questionnaire was not really envisioned to represent a single underlying construct. None the less, for future research, these factors should probably not be grouped together to avoid the impression that they form a single construct. As for the fact that the Cronbach alpha was low for religiosity (Part 2), it should be noted that all of the experts consulted (using the Delphi Technique) believed that all of the items in Part 2 were undoubtedly aspects of a single underlying construct of (Muslim) religiosity, because each item was in fact a well-known legal tenet of Islamic faith. So from the point of view of the expert panel, there was no question as to whether this part of the questionnaire was internally consistent. That said, the opinion of the panel was not borne out statistically suggesting either a fundamental misconception on the part of the panel or a lack of subtlety in the stated factors for religiosity in the questionnaire for a Saudi Arabian population. If the questionnaire were to be applied to a larger, more diverse

Muslim population, it is possible that different results would be obtained given the greater variation in religiosity across Muslim-majority countries (WIN-Gallup International, 2012). Alternatively, this part of the questionnaire should be revised, perhaps based on more detailed phenomenological field-work interviews, to better capture whatever variations in religiosity t may exist within Saudi Arabian society.

In summary, it was demonstrated that the Saudi Arabian Family Quality of Life Scale, based on the original Beach Center Family Quality of Life Scale, has been successfully developed and sufficiently validated for use for Saudi Arabian families. This is an important finding in itself because such a task had not been attempted before now, especially as it relates to families of children with intellectual disability. Perhaps the most important general lesson to be drawn from the validation stage of the current study is that it is definitely worth incorporating what are widely perceived to be culturally specific features of family life into any measure of family quality of life – in the case of Saudi Arabia, religious beliefs and attitudes. *However*, one must be mindful of the fact that a culturally specific feature may have a range of factors, some of which will be better markers of individual differences than others. This is in line with the literature advocating close attention to subjective aspects of family quality of life (Shek, Chan & Lee, 2005). A construct such as ‘religiosity’ may have numerous aspects that are subtly different between different people. A sophisticated and highly nuanced set of items on a family quality of life questionnaire may be required in order to ‘capture’ those aspects of individual participants’ lives that constitute their actual family quality of life. As noted, the questionnaire developed for the current study did survive the tests of validity, but it

was also clear that it only imperfectly captured the subtle nature of religiously informed perceptions affecting family quality of life. Further research is therefore needed to address this issue.

9.2.2 Factors Impacting on and Relationships among the Constructs of Saudi Arabian Family Quality of Life

The third research question of the current study was about whether Saudi Arabian family quality of life was significantly impacted by various demographic factors and religiosity; and whether family quality of life for those Saudi families of children with intellectual disability significantly impacted by other religio-cultural factors related to caring for a child with an intellectual disability. The empirical findings in this regard were mixed.

Hypothesis 3c – which posited that income of participant-parents, employment status of participant-parents, gender of participant-parents, marital status of parents, age of participant-parents, and family size will all be positive predictors of all valid factors of Saudi Arabian family quality of life – was largely, though not fully confirmed. Most of these variables were found to be relevant, but the gender and the age of the parental participants was not. This result conformed to the majority of findings in the extant literature, especially related to income and employment (e.g. Chen & Zheng, 2014; Graham et al., 2008; Krau, 1985; Musselwhite & Haddad, 2010) and the marital status of parents (e.g. Floyd & Zmich, 1991; Grant & Whittell, 2000; Kersh et al., 2006; Norizan & Shamsuddin, 2010). The results also support the suggestion in a few studies that family size is positively related to family quality of life (e.g. Lawson & Mace, 2010). Further, the results add

weight to those studies which have found that the age of the parent is not a significant factor in determining family quality of life (e.g. Grant & Whittell, 2000; Llewellyn, Thompson et al., 2003; Liu et al., 2007; McDermott et al., 1996; Meral et al., 2013; Minnes & Woodford, 2005; Norizan & Shamsuddin, 2010; Olson et al., 1983; Seltzer et al., 2001). It also supports those studies which found no relationship between parent gender and participants' reported family quality of life (e.g. Wang et al., 2006; Zabriskie & McCormick, 2003). The current study's result is curious, given the patriarchal nature of Saudi Arabian society. On the other hand, this result may simply be a function of the relatively small percentage of female participants in the study, despite the fact that mothers are traditionally deemed to be the primary carers of children in Arab culture (Ali et al. 2008).

Hypothesis 3a – which implied that the number of children with disabilities, and the severity of those disabilities, will be negative predictors of Saudi Arabian family quality of life – was partially confirmed. As to the severity of intellectual disability, it was found that having a child with a severe intellectual disability significantly impacted on family quality of life. The impact of this was negative, with participants from families who had a child with a severe intellectual disability reporting 0.168 points less for family quality of life on average. This finding was expected as it coheres with most of the extant literature (e.g. Boehm, Carter & Taylor, 2015; Hu, Wang & Fei, 2012; Juhásová, 2015; Marlow et al., 2015; Michalik, 2015; Rillotta, 2010).

An important particular concern of the current study has been to examine the role played by religious issues in family quality of life in Saudi Arabian families. In the literature review, it was found that both religiosity (Part 2 of the questionnaire)

and some other religio-cultural factors related to caring for a child with an intellectual disability were related to family quality of life (Part 4 of the questionnaire) (Krauss & Seltzer, 2001; Walton-Moss et al., 2005). Importantly for the current study, none of the six religiosity factors identified by exploratory factor analysis (prayer, religious belief, minimum obedience, faith, maximum obedience, and family religiosity) were not found to be relevant explanatory variables in the model. Thus, Hypothesis 3b, which implied that the religiosity of participant-parents will be a positive predictor of Saudi Arabian family quality of life, was rejected outright. In the case of the religio-cultural factors identified in the exploratory analysis in the previous chapter (Love for Children with intellectual disability, Religious Acceptance of children with intellectual disability, and Social Acceptance of children with intellectual disability), none achieved statistical significance. Thus Hypothesis 3d, which implied that all of the identified factors making up religio-cultural factors related to caring for a child with an intellectual disability would be positive predictors of Saudi Arabian family quality of life, was also disconfirmed. These findings are particularly deserving of further discussion.

With respect to Part 4 of the questionnaire, results showed that the family quality of life measure was positively correlated with *one* of the factors dealing with religio-cultural perspectives on children with intellectual disability – namely, social acceptance of children with intellectual disability. That is, parents who are comfortable with having other people know that they have a child with an intellectual disability, and who feel that their children with intellectual disability are able to get along well with their other children, reported higher family quality of life scores. This result was found to be consistent across all family quality of life domains. This

is an interesting result in terms of the existing literature. It will be recalled that according to Al-Jadid (2013), people were ashamed to talk about the disabilities of their relatives. Al-Dawood and Albar (1994) similarly found that parents typically felt guilty over having children with intellectual disability, and were ashamed about sharing their situation with others. Alkhateeb et al. (2016) claimed that this was due to strong persisting negative cultural beliefs in Middle Eastern countries in general about having a child with a disability. This paralleled findings in a number of other countries in the Middle East (Alkhateeb et al., 2016; Bertelli et al., 2011; Eapen et al., 2006; Miller et al., 2016). The fact that the current study found the opposite result is a curious one. It may be claimed that this unusual finding is the result of an unwillingness to admit that having a child with an intellectual disability brings shame or embarrassment on the family, thereby resulting in false reporting. But if social stigmatisation were as strong in Saudi Arabia as is suggested by these previous studies, then one would have expected participants to point this out. To suggest otherwise would imply that there is stigmatisation about admitting there is stigmatisation, which seems both overly convoluted and implausibly ad hoc. A more plausible explanation is that attitudinal changes are starting to occur in Saudi Arabia, perhaps in part due to relatively recent official state pronouncements and laws about the positive rights of those with disabilities (Prince Salman Center for Disability Research, 2004). So, although social stigmatisation might still exist, the new more positive perspective on disability may be slowly but surely being internalised, at least by family members and friends of families with children with intellectual disability.

When it comes to ‘religiosity’ (Part 2 of the questionnaire) and its possible correlation with family quality of life, it was expected there would be a strong

positive relationship between the two. This is because the existing literature is unified on such a hypothesis. Hammoudeh (2012) argued forcefully that Islam in Saudi Arabia was a powerful guiding ideology in determining what would be considered a good quality life. This presupposition was corroborated in studies about Saudi Arabian culture across several decades (Abdel-Khaleka, 2009; Al-Khalifah, 1994; Longa & Elghanemib, 1987). But surprisingly, and contrary to what was expected, no correlation was found between religiosity and family quality of life. It is by no means obvious that this finding really contradicts the conclusions of previous work. Paradoxically, it may cohere with it perfectly well. Once again, the lack of a correlation may be due to the relatively low variance of religiosity scores found in the study. Since nearly all of the participants reported being very religious, it was difficult to examine correlations between religiosity and other variables, even domains of religiosity that were extracted using exploratory factor analysis. Furthermore, no significant correlations were flagged between the religiosity factors and ‘other religio-cultural factors relating to caring for a child with an intellectual disability’. This finding shows that these two additional constructs are statistically independent of each other, which indicates that they are indeed measuring distinct and different variables. This is curious because one might expect there to be high covariance between these constructs: it is not unreasonable to speculate that, say, a person’s religiosity would inform their religious perspectives on all sorts of aspects of life, including their views on children with intellectual disability. The finding here, however, suggests that this is not true. Religiosity in itself seems to be a poor indicator of the religious perspective on children with intellectual disability. This result is, however, not surprising when it is realised there can be quite different, even opposing, religious interpretations within Islam of what having a child with an

intellectual disability ‘means’, theologically speaking; there may even be different Islamically appropriate reactions as to how to relate to children with intellectual disability. For example, having a child with an intellectual disability could be interpreted as a test of faith and a temporary hardship which will be compensated for in the hereafter (Al-Mousa, 1999). By contrast, it can also be conceptualised as a divine punishment for secret sins of family members (Abu-ras, Gheith & Cournos, 2008). As to how a child with an intellectual disability should be treated by others (whether they are family members or not), one view is that discriminatory behaviour is discouraged, if not prohibited (Al-Jadid, 2013); but another view is that hiding or even shunning a child with an intellectual disability is permissible because of the associated shame of having such a child (Aloud, & Rathur, 2009). So even if two people are equally religiously pious in terms of core beliefs and ritualistic practices, they can still hold diametrically opposed religiously-informed views about children with intellectual disability. Thus, the finding that ‘religiosity’ and ‘other religio-cultural factors related to caring for a child with an intellectual disability’ were not closely correlated implicitly, suggests that religiously-informed views about children with intellectual disability are not homogenous in Saudi Arabia. This directly contradicts the generalisation made by Abu-ras, Gheith and Cournos (2008) that Muslims (via Muslim clerics) hold a uniformly negative perception of intellectual disability (This is an issue which is further discussed below in subsection 9.2.3.1.3.).

Importantly, in terms of the subsequent quantitative analysis of the factors that impact on Saudi Arabian Family Quality of Life, because these results establish that these constructs are independent of each other, they can therefore be used as

potential factors in modelling family quality of life. Results of such modelling are discussed in the succeeding subsection.

9.2.3 Comparisons between Families with / without Children with Intellectual disability

A core question for this thesis – Research Question 4 – was (a) whether Saudi Arabian families who care for children with intellectual disability experienced a significantly different quality of life compared to those who do not, and if so, (b) what measurable factors could account for that possible difference?

With respect to the impact on family quality of life of having a child with an intellectual disability (versus not having such a child), it will be recalled that a substantial amount of empirical work has now been conducted. The results are somewhat mixed. On the one hand, work by Turnbull et al. (2007), for example, found that family quality of life of families with children who have disabilities may not always be negatively associated with such circumstances. This finding has been supported by Hebbeler et al. (2007), Thompson et al. (2014) and Al Samadi et al. (2014). However, the majority of studies have found that having a child with an intellectual disability in the family impacts upon family quality of life negatively (Boehm, Carter & Taylor, 2015; Gardiner & Iarocci, 2012; Hu, Wang & Fei, 2012; Juhásová, 2015; Marlow et al., 2015; Michalik, 2015; Rillotta, 2010; Seltzer & Krauss, 2001; Walton-Moss et al., 2005). Given that this negative finding has been replicated in various cultural contexts (as indicated in the references above), it was to be expected that the same negative impact would be found for Saudi Arabian

families of children with intellectual disability compared to those without such children.

The quantitative results are indeed definitive with respect to part (a) of this question. Caring for children with intellectual disability has an unambiguously significant negative impact on Saudi Arabian Family Quality of Life scores. From results of t-tests, it was found that families who only had children without intellectual disability reported family quality of life scores that were 0.83 to 1.2 (out of a 5-point scale) points higher on average than those reported by families who did have children with intellectual disability. Corresponding to the 5-point scale used to measure family quality of life in the study; this translates to a 17% to 24% difference in family quality of life between the two groups, which was found to be statistically significant at a 95% confidence level. Further testing found that this result is consistent across all five factors of family quality of life, which means that families who only had children without intellectual disability reported higher scores than families who did have children with intellectual disability, in the areas of emotional well-being, physical and material well-being, disability-related support, family interaction, and parenting.

These results are consistent with and corroborate the findings from most of the extant literature on the effect of having a child with an intellectual disability on a family's quality of life. The results of this current study thus add to the growing body of studies to show that the experiences of Saudi Arabian families of children with intellectual disability are similarly negative vis-à-vis quality of life. It strengthens the supposition that this general finding may be common across a wide range of geographically, culturally, economically and religiously distinct populations. It

severely undermines any suggestion, were it to be made, that there are perhaps some cultural or social formations that are somehow ‘special’ in not experiencing an inequality in family quality of life between those families with, and those without children with intellectual disability. The problem, although perhaps differing in its severity between countries (Meral et al. 2013), cannot be reasonably presumed to not exist *at all* in some country or other not yet studied.

Furthermore, the finding that Saudi Arabian families who care for children with intellectual disability experience a significantly lower family quality of life implies that this is an issue that must be acknowledged and addressed by the Saudi Arabian government. Despite the introduction of valuable legislation in 2000 and 2001 intended to help address hardships associated with raising and educating children with intellectual disability, these findings suggest that the legislation has failed to eliminate the differences in family quality of life associated with caring for children with intellectual disability. Al-Jadid (2013) has argued that it is the lack of knowledge of (research into) families of children with intellectual disability that has severely limited the ability of government agencies to accurately respond to the needs of families. This thesis is helping to close that knowledge-gap by demonstrating that there is a genuine ‘problem’ that the government, according to its own statement about social welfare (Information Office of the Royal Embassy of Saudi Arabia, 2013b), needs to address.

Given the undeniable existence of the difference in family quality of life between Saudi Arabian families with and without children with intellectual disability, the concomitant research question (b) that needed to be answered was, what possible factors could help account for the difference? This is discussed below.

9.2.3.1 Factors that Impact Family Quality of Life among Saudi Arabian Families

9.2.3.1.1 Material Needs and Marital Status

By far the most significant factors associated with Saudi Family Quality of Life across the families surveyed were material standard of living and family support for the participants. Participants who were employed, earned high incomes and were members of large intact families, garnered higher Saudi Arabian Family Quality of Life scores than others. Families of children with intellectual disability who enjoyed the benefits of these factors reported experiencing a higher Saudi Arabian Family Quality of Life than those who were less fortunate in these respects. This result accords with both common-sense and numerous previous studies from other countries.

The ANCOVA revealed two demographic factors which stood out strongest were socioeconomic status (based on income) and marital status, so these will be focused on here.

With regard to socioeconomic status (based on income), most studies over the last 30 years have found a strong correlation between socioeconomic wellbeing and experienced quality of life (e.g. Chen & Zheng, 2014; Graham et al., 2008; Krau, 1985; Musselwhite & Haddad, 2010; Rillotta et al., 2012). Such a finding is in some sense intuitively obvious: higher family income and wealth enables a family to better financially deal with the special needs of a child with intellectual disability by being able to afford tailored education, household and parenting support, and respite time, all of which can contribute to a better family quality of life. The present study

similarly found that participants who had a higher family income tended to have significantly higher family quality of life than participants with low reported family income. Correspondingly, participants who were not employed (and thus struggled financially) were found to have a lower family quality of life than participants who were employed or were running their own business. Given the predominance of this finding in the extant literature, this result was thus quite unsurprising. As to the factor of marital status, the literature was somewhat mixed. Norlin and Broberg (2013), for example, found that on average, parents with children with intellectual disability reported the same levels of marital quality as control parents. However, most studies found the opposite correlation: dual-parent families as opposed to single-parent families were more likely to experience a higher quality of life (e.g. Brandon & Hogan, 2001; Grant & Whittell, 2000; Lukemeyer et al., 2000; Norizan & Shamsuddin, 2010). Given this predominant finding in the literature one might be inclined to expect the same for Saudi Arabia. Indeed, it was found that participants who were married reported a higher family quality of life than participants who were divorced.

In terms of a theory of psychological wellbeing, this first set of findings conforms relatively well with Maslow's (1943; 1970) hierarchy of needs. Maslow's theory proposed that the needs of individual human beings were tiered according to a set hierarchy, with material needs (basic physiological and then safety needs) at the bottom followed by social-emotional needs of love and belonging, then self-esteem and self-respect, and finally self-actualization needs. Maslow revised the theory slightly over time, but the essentials of the hierarchy of needs remained intact (Maslow, 1970; Tay & Diener, 2011). The findings indicate that family quality of

life is associated first and foremost with typical, every day, material needs, and then, or additionally, by the social needs of family companionship suggested by an intact family. The ‘higher up’ the hierarchy a participant reported being, the higher the Saudi Arabian Family Quality of Life tended to be. That is, when the basic needs (according to Maslow’s hierarchy) were able to be met, then families were able to enjoy a higher family quality of life.

Importantly, the results also suggest that these factors of income and non-separation of parents may be having a powerful mitigating effect on the challenges faced by caring for children with intellectual disability. This in turn suggests that having a child with intellectual disability may not *in and of itself* be an overwhelmingly dominant factor in determining a family’s quality of life: economic and family *context* into which that child is born may have a powerful ramifying effect. This accords with Maslow’s (1970) theory which says that the satisfaction of basic material needs is a precondition of the satisfaction of the other ‘higher’ needs of self-esteem and self-actualisation, although it should be noted that the results of the current study do not establish a *causal* direction from material and marital circumstances to family quality of life. It is of course possible that there could be a two-way causal relationship or a feedback loop causal relation.

The study employed a mixed methods design, and thus was able to gather interview data to corroborate and deepen our understanding of this phenomenon. When participants were asked about what aspects of their life mattered most to their family’s quality of life, just as with Maslow’s (1970) theory, material considerations were central. It should be noted that Maslow’s theory is really one of *individual* wellbeing, not *family* wellbeing, but nonetheless the answers of the participants

translated from one domain to the other easily. Thus all participants emphasised meeting the material needs of the family as a whole as being important, and allied to this, ensuring the wellbeing of children. However, interestingly – and in line with Maslow’s theory – the *emphasis* varied according to the socio-economic status of the participants, which suggests that the ability (or failure) to satisfy needs on Maslow’s hierarchy affected the decision as to which needs they focused their attention on. For those with relatively lower family quality of life scores, participants were preoccupied with struggling to meet the material needs of the family, whereas high scoring families, having presumably taken care of material needs, concerned themselves to a greater extent with the emotional wellbeing of their families (a higher tier in Maslow’s hierarchy). But when it came to concern over the wellbeing of their children, families with high and low scores did *not* make the intellectual disability (or otherwise) of their children a focus of attention.

This particular finding from the interviews coheres with the quantitative finding, but also reveals something not evident in the questionnaire data. The participants with low Saudi Arabian Family Quality of Life scores who were caring for children with intellectual disability did *not* offer their child as a reason for their relatively lower family quality of life. In other words, they did not seem to *conceptualise* their own children *per se* as being *determinants* of family quality of life; their level of material economic and family-support were the key ‘inputs’ into family quality of life, and their children were instead recipients of those inputs. Interviewee Participant 56 was clearest in this regard:

I do not think it matters [that my son has an intellectual disability]. My child is my child. He has a disability, but all children have good and bad

characteristics. I do not think it should affect the quality of life. A child is a child.

Interviewee Participant 16 said his child with an intellectual disability was less of a ‘challenge’ than his other son who had a heart condition. He went on to point out – in line with the quantitative finding that meeting material needs dominated the Saudi Arabian Family Quality of Life score – that because of his family’s high socio-economic status they are able to access numerous support services: “with the right teachers and the right training for us as parents, we were able to help him become better. I think that this is a very big blessing from God, that we are able to do this.” Meanwhile interviewee Participant 75 who also cared for a child with an intellectual disability, did say that his child “takes such a toll on the family.” But in line with the above findings, again, the economic capacity to meet the family’s material needs turned out to be the decisive factor for him: “I cannot afford to provide him with the special private schooling that he needs.”

The interviews also supported Maslow’s idea that satisfying a sense of belonging that tends to come with family solidarity is essential to quality of life for family members. According to Maslow, people need to be able to satisfy lower order needs first before proceeding to recognize higher order needs (Maslow, 1970; Tay & Diener, 2011).

For those participants who were caring for a child with an intellectual disability, being divorced was clearly not perceived to be ideal for them, whereas those who were married clearly drew strength from their marital stability (where parents have not separated). It will be recalled, for example, that Participant 56 who

was married presented a very rosy, happy picture: “we are blessed by our God. I have a good business that pays for our needs. I have a nice wife and kind, obedient children”, whereas Participant 57 who was divorced presented a manifestly unhappy situation:

... unfortunate events happened and our family lost our fortune. I was left to fend for myself and my family. I was not able to do that well, which is why my wife left. So, I am doing my best now to make sure that what happened to me will not happen to my children.

The importance of maintaining a dual-parent family on family quality of life is reinforced by recalling that on the individualism dimension of Hofstede’s (2011) cultural analysis of Saudi Arabia, the society is ranked high on collectivism (low on individualism). This sense of importance of being part of a collective entity – chiefly a family, including an extended family by marriage – could play an important subjective role in participants’ conceptualisation of family quality of life (Al-Jadid, 2013). Thus it is not unreasonable to infer that family breakdown (divorce), and the subsequent fracturing of the collectivist nature of the family support structure, would be likely to have a substantial negative impact on family quality of life because of its social undesirability (Shehan, 2013).

Despite what has been suggested above, it may be thought that the dominance of economic and family contexts, where children with disabilities are concerned, in affecting Saudi Family Quality of Life is somewhat implausible: for example, it will be recalled that in the current study’s interviews, participants *with no* experience of raising children with intellectual disability believed it would be highly challenging

(irrespective of socio-economic status). However, this first set of findings actually corroborates the findings of a number of previous studies. For example, as found in Cagran et al. (2011) and Park et al. (2002), economic status is an important mitigating element in the quality of life of families who have children with intellectual disability. This is chiefly because raising children with intellectual disability requires considerable support and resources, and if present social welfare programs are insufficient in providing for the needs of families with children who have intellectual disability, the quality of life of these families is expected to be low.

The only existing studies which diverge somewhat from the above results are those of the Turkish Statistical Institute (2009) and Meral et al. (2013), both of which claim that socio-economic status is only a weak predictor of family quality of life for Turkish families of children with intellectual disability. Meral et al. (2013) further found that family social support, specifically emotional support, was a far more significant predictor of overall family quality of life perception. Since the current study found that socio-economic status and being married (not divorced) tended to occur together, it is possible that at least in the case of Saudi Arabian families, these factors may reinforce each other – that is, it is possible that having satisfactory financial resources reinforces social (family) stability and support, and vice versa – and that thus *both* of them together have a powerful effect on Saudi Arabian Family Quality of Life for families with, and without, children with intellectual disability. Furthermore, a number of other studies, such as Davis and Gavidia-Payne (2009), Md-Sidin et al. (2010), Mannan et al. (2006) and Summers et al. (2007), also found that the presence of internal family support (evidenced among other aspects by an intact marriage), is important to maintaining quality of life in a family that is caring

for a child with an intellectual disability. This is because the challenges of caring for a child with substantially greater needs than other children can be shared between family members, and with emotional support from others, primary care-givers are better able to deal with the associated psychological stresses (Brown et al. 2010; Steel et al, 2011).

These findings are to a large extent in accord with another conceptual framework that focuses on ‘ecocultural niches’ (Gallimore, Bernheimer & Weisner, 1999; Gallimore, et.al., 1989; Nihira, Weisner, & Bernheimer, 1994). Ecocultural niches are comprised of the material ecology which create objective constraints on families (such as income, employment, housing, etc.), and the cultural aspects of families’ lives which give meaning, understanding and organisational norms for their daily lives (including goals, moral values and cultural norms). These forces are manifest in the daily routines and ordinary activities of family life (preparing meals, engaging in entertainment, etc.). To this Gallimore, et.al. (1989, p.218) add a ‘family accommodation process’, which they define as ‘the proactive, social construction actions of the family to adapt, exploit, counterbalance, and react to many competing, and sometimes contradictory, forces.’ They argue that families consciously or unconsciously construct ‘activity settings’ informed by their cultural and personal goals and values that influence the broader ecological niche of family life, such as children’s interactions, meeting material needs, and shaping children’s development given the socioeconomic constraints that the family faces. It is certainly true that Saudi Arabian families seek to find ‘accommodating’ strategies in the context of the socioeconomic constraints they face in dealing with children with intellectual disability – and that this is influenced heavily by the cultural values and norms

associated with religion. It is also true that each family in the study has developed its own ecocultural niche strategies, often of a psychological nature (rather than material actions) to incorporate the fact that they have a child with an intellectual disability. Often this entails simply treating the child as ‘just another member of the family’, thereby being integrated into daily routines within the household – rather than being treated as ‘exceptional’ or a ‘burden’ or ‘hardship’. Where household activities revolve around routines of meals, prayer and entertainment, there was no suggestion on the part of any interviewees that their children with intellectual disability were excluded or treated differently in these respects. Often this form of accommodation was backed by a religious interpretation. On the one hand, communal family prayer, communal meals and interactions between parents and children, are often highly structured by well-established traditions, which thereby makes it a taboo to exclude a family member (whatever their physical or intellectual capacity) from them. On the other hand, it is worth noting, as found in the interviews, that the religious interpretation of the *ease* of accommodation materially varied depending on the socioeconomic status of the family. Wealthier families treat their circumstances as a ‘blessing’, whereas less fortunate families tend to take their circumstances to be a trial or test of their steadfastness. As such, one can say that the cultural resources of an ecocultural niche, whilst apparently the same for all families in the study (all coming from a Saudi Arabian collectivist, patriarchal environment, and all adhering to Islamic tenets and norms), nonetheless adapt those resources in particular ways depending on the objective socioeconomic context of the family.

9.2.3.1.2 Severity of Intellectual Disability

The other factor that the analysis found to have a significant and negative impact on Saudi Arabian Family Quality of Life was having a child with a *severe* intellectual disability. This factor seems to have resulted in a considerable reduction in the family quality of life score of the family. This finding is of interest, mainly because out of 86 families in the sample that reported having a child with an intellectual disability, only 3 reported having a child with a severe intellectual disability. The rest of the participants reported having a child with a mild or moderate degree of intellectual disability only. Yet these three participants elicited an extremely powerful impact on the results.

It could be argued that this result should be discarded because the number of families reporting a severe intellectual disability was so small. However, some justification for these results can be drawn from extant literature. Numerous other studies – such as Wang et al. (2004), Wilmshurst (2012), Schertz et al. (2016), Riley and Rubarth (2015) and Chambers and Chambers (2015) – also point out that it is not just having a child with an intellectual disability that impacts upon the quality of life of carers, but the severity of the child’s intellectual disability. Indeed, the result is unsurprising given the definition of ‘severe intellectual disability’. As previously defined by the American Psychiatric Association (2013), severe intellectual disability is considered when the individual has multiple deficits across the conceptual, social and practical domains. Further, as described by Sturmey and Didden (2014), such an individual would have difficulty in interacting with other people, and in doing everyday tasks to take care of him or herself. Given such a description, it becomes clear why having a child with a severe intellectual disability can take a considerable

toll on the quality of life experienced by the family. There are various practical and psychological strains that taking care of such a child can have on members of the family which, in turn, negatively impact their perception about the quality of their family life. Because this factor was overwhelming, it was able to ‘swamp’ even the positive effects of socio-economic status and marital status of parents on the Saudi Arabian Family Quality of Life Scale. This would suggest that for families caring for children with severe intellectual disability, private financial and family support on their own would not be sufficient to substantially alter Saudi Arabian Family Quality of Life in a positive direction. It is likely that more extensive parent-to-parent networks, professional assistance, and institutional support would be required in order to improve the quality of life for families in such circumstances (Meral et al. 2013; Wang & Brown, 2009).

9.2.3.1.3 The Puzzle of Religiosity

Obviously socio-economic status has proved to be very important to an understanding of the Saudi Arabian Family Quality of Life scores for families of children with intellectual disability. But what of the mysterious statistical irrelevance of religiosity? It is worth following up on the issue of religiosity for two reasons. First, it was initially believed by the researcher that religious belief would play a significant role in understanding the results of Saudi Arabian family quality of life analysis for families with and without children with intellectual disability, if only because Saudi Arabia is a self-identified ‘highly religious’ country. (In a 2009 Gallup Poll, 93% of Saudis said ‘yes’ to the question, ‘Is religion an important part of your daily life?’ (Crabtree, 2010). Second, numerous studies have found that there is a

positive correlation between quality of life (both subjective and objective) and holding religious beliefs.

In an extensive review of the existing literature up to 2000, Koenig et al. (2000) found that despite research from the mid-20th century finding no positive effect of religion on psychological wellbeing, from the 1980s onwards such conclusions were reversed. They attributed the switch to improved methodology. Today, religiosity is widely regarded as being associated with greater life satisfaction, optimism, and hope for the future. Similarly, Ellison and Levin's (1998) review of the literature also found that religious involvement had a positive impact on well-being, depression, and stress. In the most recent meta-analysis of quantitative data, Sawatzky et al. (2005) also found a moderate correlation between spirituality and quality of life. This result has been found to hold true for Muslims too. For example, using an Islamic Religiosity Scale, Tiliouine et al. (2009) found a positive correlation between adherence to religious practice and personal wellbeing for Muslims from Algeria. Abdel-Khalek (2010) also found a significant positive correlation between religiosity and quality of life, and between religiosity and subjective wellbeing in US Muslim university students.

In the current study, however, when it came to the quantitative analysis of the questionnaire results, no significant link was found between the levels of religiosity of families whether they did or did not have children with intellectual disability. In short, religiosity did not play a statistically significant role in accounting for any of the variables in the quantitative phase of the current study. This was not because Saudis were found to be irreligious, but rather that they tended to exhibit a fairly uniform (invariant) degree of religiosity in their answers to the questionnaire items

about religious belief and practice. This may be because the Saudi state has strict control over the officially sanctioned beliefs, practices and education as drawn from its founding fathers, which arguably produces a uniform, if distinctively Saudi, Islamic orthopraxis (Al-Rasheed, 2010). Alternatively, it may be that there is some degree of variety in thinking about how religion plays a role in different people's lives depending on whether they are well-off or not, and whether they care for children with intellectual disability or not. Certainly religious views and religious interpretations of one's life are bound to be complex and subtly context-dependent, in ways that are unlikely to be captured by closed-questions on a questionnaire. It is for this reason that if there are any insights to be gleaned that may be more revealing than the quantitative analysis, we need to turn to the interviews.

It will be recalled that a major finding from the interviews was that divine providence (*qadar*) was a strongly evident theme in the explanations that high Saudi Arabian Family Quality of Life families gave for their favourable socio-economic circumstances, but that such discourse was absent from those participants with low Saudi Arabian Family Quality of Life scores, who apparently faced more difficult lives. This result indicates that at least in the case of these Saudi participants, there is context-dependence in the different individuals' conceptualisations of religiosity. Some international studies have suggested that religiosity is inversely related to economic standard of living: as a population becomes wealthier, religiosity declines. As WIN-Gallup International (2012) reveals, globally, the lowest income groups are 17% more religious than the highest income groups. But by contrast, the interview results of the current study found that it was the *most* well-off participants who were more inclined to say that God was ultimately responsible for their fortunate

circumstances; as Participant 16 neatly put it: “God ... blesses us for our good work and we reap the rewards. ... We have a happy life as a family because we do our best to stand by our faith in everything that we do.” By contrast, for three of the four less well-off participants, God was conspicuously absent from their explanations of their circumstances. Instead they referred only to either accidental or structural material circumstances beyond their control (such as a death in the family, or having little education).

This result may seem odd, because belief in divine providence (*qadar*) is a fundamental tenet of Islamic faith on a par with the tenet of monotheism. One must be careful with interpreting these responses, however. We cannot conclude that participants scoring low on the Saudi Arabian Family Quality of Life Questionnaire were somehow impious or lacking in faith. This is for two reasons. First, their religiosity scores on the questionnaire were not statistically significantly different from high scoring families. Second, it is possible that these low-Saudi Arabian Family Quality of Life interviewees were following another Islamic principle which is complementary to *qadar*, namely, not ‘blaming’ God for their less fortunate circumstances. To openly say that God was responsible for their difficult socio-economic difficulties could be easily construed as *criticising* God, which would be a grave violation of a theological tenet of the religion (Nawawi & Keller, 2003). Ironically, it may be that their piety led them to be silent about divine providence.

Given that one must be mindful of the context-dependent discursive manifestation of religiosity in interviews, what can be said about how interviewees caring for children with intellectual disability *in particular* conceptualise their circumstances vis-à-vis their religiosity? The first thing to say is that for all of them,

their faith clearly lay at the centre of their family lives. The functions that religion served were all well within acknowledged understandings of Islam (as construed by both the Saudi state and elsewhere in the world – that is, the functions were not particular to Saudi Arabia). Interestingly and importantly, these traditional understandings were *almost entirely positive*, which is in stark contrast to several widely reported interpretations: that Islam (allegedly) teaches that having a child with an intellectual disability is a punishment for parental sins (Abu-Ras, Gheith and Cournos, 2008) or the result of being plagued by malevolent spirits (Al-Adawi et al., 2002; El-Islam, 2008), which then contributes to stigmatisation of such children and their families by Muslim societies (Aloud and Rathur, 2009). However, the traditional Islamic injunctions drawn upon by the parents of children with intellectual disability were not uniform. They varied across the interviewees and across the Saudi Arabian Family Quality of Life scores. They appeared to be specific to each participant (with some overlapping), which suggests that each was drawing on different yet interrelated aspects of the religion in seeking to understand and deal with their circumstances.

For example, two interviewees (one with a high Saudi Arabian Family Quality of Life score and the other with a low score) took their children with intellectual disability to be part of a *test* from God. As Participant 32 put it: “We treat it as a test from God. God has given this child to us for us to care for, and we do so with all of our wills. It may not be easy, but it is a challenge that we accept every day.” Participant 16 felt that in his test his family was being assisted by God: “I think that this is a very big blessing from God, that we are able to do this.” This is a very traditional – indeed an ‘orthodox’ – theological wisdom (*hikmah*) provided to parents

who have children with any kind of disability. The test is intimately associated with just rewards on the day of judgement for having responded positively to a divinely imposed challenge (Al-Aoufi, Al-Zyoud and Shahminan, 2012; Morad, Nasri and Merrick, 2001). As such it may be thought of as a kind of consolation in the face of difficulty which has been successfully internalised by these interviewees. Indeed, two other interviewees took this concept to its limit by interpreting their children and their family life as *blessings (barakat)*, rather than tests: “we are blessed by our God” (Participant 57) and “The quality of our life is a gift as well from God. He blesses us for our good work and we reap the rewards” (Participant 16). This reaction, however, may be evidence of an overall evaluation of their lives because these two participants both enjoyed high material standards of living. It is perhaps worth noting that this ‘blessing interpretation’ is not an entirely orthodox one, and is more likely to be found among Islamic religious advisors from wealthy countries such as the USA (e.g. Ansari, 2007).

On the other hand, two interviewees with low Saudi Arabian Family Quality of Life scores and a lower economic status, took their consolation from a belief or hope that God would *assist them in their difficulties*: “I look at him and I think ‘God, please let my child survive in this world despite his disability, please guide him so that he will still be able to become a good person’” (Participant 75); “We are able to do ... [get by] with the help of God” (Participant 32). This too is a traditional response within Islam: imploring God for assistance in times of struggle is deemed a virtuous act of worship that is even mandated by religious law (Nawawi and Keller, 2003).

Finally, another traditional resource that can be drawn upon – and is explicitly mentioned by one interviewee – is a purely *juridical* one of parental obligation: “our children are our responsibility. God gave them to us for us to love and take care of them. ... I think that as a parent, the important principles are to make sure that children grow up responsible and good people who follow God.” (Participant 16). In Bazna and Hatab’s (2005) account, in terms of jurisprudential interpretation (*fiqh*), a disability is not a blessing nor a curse; it is simply a fact with certain legal ramifications: a child with a disability has all the rights (*haq*) of a child without a disability under Islamic law, and is bound by no legal obligations except those she or he can fully understand and fulfil. Further, parents have the legal obligation (*fardh*) to care for children with disabilities in the same way that they would care for any other child, subject to the exception that the child may have additional needs above others, which must also be met by the parent. Thus the child is not to be legally discriminated against by either parents or others, and must have his or her additional needs met by the parents (*fardh al-ayn*) or the society as a whole (*fardh al-kifayah*) (Al-Aoufi, Al-Zyoud and Shahminan, 2012; Guvercin, 2008).

In summary, the puzzle of the apparent statistical irrelevance of religiosity to the quality of life of Saudi Arabian families who care for children with intellectual disability is not really a puzzle at all. In terms of simple closed-questions in the questionnaire, there is no significant difference in terms of religiosity between the participants. But when it comes to exploring the role of religion more closely in interviews, one finds that it is both *essential and variable* between different participants. For some, religion gives succour and functions as a powerful consolation, which enables a positive interpretation to be given to their family’s

situation; and for others it seems to provide a framework of obligations and rights which provides a moral justificatory backing to their children in the face of potential discrimination. So, far from religion being a basis for stigmatisation, for these participants, it served the opposite purpose.

9.3 Strengths of the Current Study

The current study is the first of its kind to attempt to measure the quality of life of families in Saudi Arabia, and compare the experiences of families who have children with intellectual disability against those who only have children without intellectual disability. The sample size used for the current study was relatively large – 201 families participated, 43% of whom had children with intellectual disability – which allowed for meaningful statistical analyses to be conducted on the data collected. Hopefully, this kind of sample size will set a minimum standard for future studies that then conduct comparably robust statistical analyses.

The Beach Center Family Quality of Life Scale is a high quality questionnaire that has been tested and used across various contexts in different studies, and is recommended by various studies for use in examining quality of life among families who have children with disabilities (Eskow et al., 2011; Summers et al., 2007; Turnbull et al., 2007; Zuna et al., 2009). In selecting and augmenting the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) and validating it for the Saudi Arabian population, the current study was able to ensure the formal validity of the questionnaire that it used in order to measure family quality of life as supported in extant literature. The Beach Center Family Quality of Life Scale was a good choice for the current study because it provided a strong, valid foundation for

the subsequently developed Saudi Arabian Family Quality of Life questionnaire in this thesis.

Another strength of the study is its use of the Delphi technique and preliminary statistical tools for validating the questionnaire used for the Saudi Arabian population. These procedures provided meaningful insights as to how the study should proceed with data collection, and the exploratory factor analysis conducted helped the study shape the new items added to the original Beach Center Family Quality of Life Scale (giving the 'Religious Support' factor), as well as the factors extracted from the newly posited constructs of 'religiosity' and 'other religio-cultural factors related to caring for children with intellectual disability'. Also, these new constructs were based on findings from an extensive review of the factors which can be expected to be associated with family quality of life, both in general and particularly for the Saudi Arabian population. Thus, the study has a very strong grounding in the literature in its construction of the Saudi Arabian Family Quality of Life Scale in particular, and of the questionnaire overall.

Furthermore, the statistical validation of a questionnaire for measuring family quality of life among Saudi Arabian Families was rigorously conducted. Factor analyses and reliability analyses were conducted in order to determine whether each of the Parts (particularly Parts 2, 3 and 4) of the questionnaire were applicable to the population of interest. A confirmatory factor analysis was used for the original Beach Center component of the questionnaire (items 1-25 in Part 3), and exploratory factor analysis was used for the augmentation (items 26-31 in Part 3) – as well as the newly posited constructs of 'religiosity' (Part 2) and 'other religio-cultural factors related to caring for children with intellectual disability' (Part 4). Cronbach alpha was used in

order to determine whether the factors identified by confirmatory and exploratory factor analyses had acceptable levels of internal reliability.

Another major strength of the current study is the scale at which sampling has been conducted. Using a wide sampling frame provided by the Ministry of Education in Saudi Arabia, the study was able to gather a large sample of families to represent families both with, and without, children with intellectual disability. This strengthened the extent to which the sample gathered in the study can be considered to adequately represent the Saudi Arabian population of families both with, and without, children with intellectual disability. It must be acknowledged that the sampling was not strictly random, because the pool of schools from which participating families were drawn was selected by the Ministry; it is unknown how that selection process was conducted. However, the sample was larger than any other study in Saudi Arabia to date.

Finally, the current study's use of a sequential quantitative-qualitative follow-up method (Onwuegbuzie & Teddlie, 2003) enabled triangulation of results from quantitative and qualitative perspectives. This sequential approach proved to be extremely valuable, because it facilitated a deeper understanding of the factors associated with the Saudi Arabian Family Quality of Life for families both with, and without, children with intellectual disability. The quantitative analysis served to examine whether relationships existed between Saudi Arabian Family Quality of Life and 'religiosity' factors and 'other religio-cultural factors related to caring for a child with an intellectual disability'. It enabled the drawing out of statistical differences between families with and without children with intellectual disability that would otherwise not be directly observable. The semi-structured interviews which followed

reflexively referred to the questionnaire and gave the researcher the opportunity to explore the reasons behind relationships found from quantitative analysis. The qualitative analysis thus complemented the quantitative analysis: the former helped explore the subjective significance of factors associated with the family quality of life of those caring for children with intellectual disability, and the latter assisted in identifying the objective context of the subjective concerns of families. Each by themselves would have been poorer. Their sequential combination in the current study enhanced the findings of both by reflection on them together.

9.4 Limitations of the Current Study

Despite the strengths identified in the previous section, the study still faced a number of limitations. One of these limitations related to the new subscales in the questionnaire. The other limitations relate to the sample for the study.

The new questionnaire subscales designed for the Saudi Arabian Family Quality of Life Questionnaire were found to not be ideal. As previously discussed, although exploratory factor analysis was able to draw out usable factors from the data for the 'religiosity' construct and the 'other religio-cultural factors related to caring for children with intellectual disability' construct, the low Cronbach alphas they elicited meant that these subscales could be improved. In the case of the 'religiosity' construct for example, the items used may have been insufficiently sensitive, such that they were unable to distinguish actually existing different levels of religiosity among participants. Alternately, it may be that Saudi Arabian participants are actually just so uniformly religious that any attempt to measure differences in religiosity as a predictive variable will always be invalid. In any case,

it is a matter for future empirical study as to whether a superior subscale for a 'religiosity' construct can be developed.

The remaining limitations all revolve around the sample that was ultimately used to generate results in the current study. While the study was able to gather a large sample of Saudi Arabian families, one important assumption of the statistical analyses that were conducted in the current study is that samples were sufficiently randomly selected. However, in the study, it was left to the Ministry of Education to provide the sample of families based on the records that they have. Reliance on this procedure meant that the study had no real way of determining the extent to which the participants were randomly selected. However, this was the only way for the study to be able to identify families who had children with intellectual disability. There was no possibility of the researcher dictating to the Ministry how it selected the schools that it made available for the current study. As such, this limitation could not be avoided. It should be noted that such purposeful sampling is actually a common and widely accepted form of sampling for 'information-rich' phenomena, including those involving children with intellectual disability and special education (Brotherson & Goldstein, 1992; Onwuegbuzie & Leech, 2007; Palinkas et al. 2015). Nonetheless, the choice of the Ministry of Education as the sampling frame for the current study also subjects it to some level of bias. The samples of families selected in the current study are all families who have children studying in the country's school system, whether in special education, or regular classes. Thus, whereas the intended population of the study is Saudi Arabian families with children, only Saudi Arabian families who have children enrolled in the Ministry of Education's school system were ultimately sampled. The effects of these limitations are difficult to

gauge. Ultimately, they are conceded in the current study as weaknesses that may be addressed through future research.

Furthermore, there is the issue of the choice of sampling only families with school aged children. The choice to narrow the age range of children with intellectual disability to school age (6-18 years old) was made largely for reasons of tractability of the study. It should be recognised that longitudinal studies show that as children develop – especially when transitioning into adulthood – the stresses and demands on family members change qualitatively (Glidden & Jobe, 2007; Nuehring & Sitlington, 2003). However, it should also be noted that Janus et al. (2008) found that family stress levels diminished and stabilised once children started attending school, and other past studies have *not* found the age of the child to have a significant impact on family stress (Bruce & Schultz, 1994; Floyd & Gallagher, 1997). Nonetheless, it is by no means clear that the findings from the current study can be confidently extended beyond the scope of families with school age children. In this sense, the narrowing of the scope of the sample is a limitation of the study.

An associated limitation of the study was the lack of sufficient diversity in its selection of participants for the qualitative analysis. Initially, it was considered that it was enough to select participants who have different levels of family quality of life and who either have children with intellectual disability, or only have children without intellectual disability. This was successfully done in the study, and many important insights were drawn from the interviews conducted with such participants. However, the quantitative and qualitative results gave rise to the very real possibility that the level of *severity* of a child's intellectual disability was a very important variable. Thus, in qualitative analysis, it became apparent that the study needed to

include families with children who have mild, moderate, and severe intellectual disability. All of the participants who were interviewed who belonged to the group who had children with intellectual disability only had children with mild intellectual disability. When efforts were conducted to invite additional interviewees who had children with severe or moderate intellectual disability, none of the candidates that were asked agreed to participate in the interview. As such, this is a perspective that was not captured in the research, which may have contributed more factors in the understanding of how intellectual disability is associated with the quality of life of Saudi Arabian families.

Similarly, although there were some women who responded to the questionnaire (albeit only 18%), all of the participants in the interviews were male (and of them only one was a primary carer). This was because no female participants in the survey agreed to be interviewed. The study acknowledges that the findings drawn from interview data were limited to Saudi Arabian male perspectives. This experience was not found to be unusual. Rather, various studies established that females in Saudi Arabia are unlikely to interact with people that they do not know (Havril, 2015; Yavas, 1994). The reason behind this phenomenon was traced to be due to cultural norms; females in the country tend to be precluded by their families from outsiders, especially male outsiders (Havril, 2015; Yavas, 1994). Female members of the population may have had more insights, different from those of males, which could have contributed to a deeper understanding of important issues, such as the impacts of raising children with intellectual disability on family quality of life. However, there was no way for the research to include such participants in the interviews without their consent.

With respect to the sample *size* for the interviews, only members from eight families were willing to be interviewed. There is still much debate over the number of interviews needed to reach data saturation. Recommended numbers vary widely from as low as six to as high as sixty (Hagaman & Wutich, 2017). However, there is general consensus that the more interviewees there are, the better – and the smaller the number, the more problematic the findings could be. With a small number of interviewees, such as in the present study, it is possible that some themes did not emerge that would have if the sample were larger. There also seems to be a consensus, however, that the data saturation threshold is highly study-specific – for some studies it can be lower than for others (Baker & Edwards, 2012). In the present study, it is possible that saturation was achieved even with only eight interviewees because of the particular mixed method used – namely, the interviews were constructed to elucidate themes that had already been identified from the survey results. That said, there is no certainty in this regard. An improvement to the study would be to increase the number of interviewees beyond eight. Unfortunately, this was not possible in the present study due to the unwillingness of the vast majority of the participants to be interviewed in this instance. Perhaps a further study could consider the possibility of providing some kind of nominal incentive to be interviewed (such as monetary compensation for time spent).

Finally, it will be recalled that with respect to qualitative data analysis, there was no inter-rater reliability testing for the identification of themes from the coding of the interviews. It was the researcher alone who examined, coded and then interpreted the coding outcomes from the transcripts. This was because the interviews were conducted in Arabic and there were no other Arabic speakers

familiar with the content and the methodological issues who were available or willing to conduct reliability testing. This practical problem renders the qualitative analysis of the interviews – and in particular the thematic analysis – less than certain. It is possible that the themes identified and discussed in the current study would have been modified, or additional themes may have been identified if inter-rater reliability testing had been conducted, although it should be noted (as mentioned above) that the interviews were constructed to elucidate themes that had already been identified from the survey results. Nonetheless, any future study should seek to conduct inter-rater reliability testing in order to remove any doubt about the qualitative findings from interviews.

9.5 Implications for Further Research

A number of directions for further research were opened by the findings of the current study. One of the most important findings of the current study is that the augmented Saudi Arabian Family Quality of Life measure was validated for Saudi Arabian families. This suggests that this measure can be used in future family quality of life studies for the Saudi Arabian population. This is an important result because relatively little research has been done in this area. It also provides impetus for improving upon and refining the Saudi Arabian Family Quality of Life measure developed here. In relation to the measure, it is interesting to note that the two additions to the original family quality of life construct – ‘religiosity’, and ‘other religio-cultural factors related to caring for a child with an intellectual disability’ – were found to be statistically independent of each other, which indicates that they are indeed measuring distinct and different variables. Future studies should thus seek to retain these elements as separate variables.

It is also worth recalling that the religiosity measure was found to be largely invariant for Saudi participants, which contrasts with some studies of Muslims in other places (e.g. Abdel-Khalek, 2010; Crabtree, 2010; WIN-Gallup International, 2012). However, the interviews conducted for the current study did find considerable variation in the *subjective functions* that religion played, particularly for families of children with intellectual disability. This suggests that the religiosity measure used in the current study may have been insufficiently sensitive to the way religiosity manifests itself and the role it plays in the lives of Saudi families. This is an issue that deserves further exploration by future researchers, which may contribute to a more sophisticated and statistically relevant measure of religiosity.

As for the measure of social acceptance of children with intellectual disability, it was found that parents who are comfortable with having other people know that they have a child with an intellectual disability, *and* who feel that their child with an intellectual disability is able to get along well with their other children, reported higher Saudi Arabian Family Quality of Life scores. This result is also an important finding which perhaps can be further explored in future studies. The measure used in the current study focused on the views of parents, but did not explore the precise sources of potential social stigmatisation. Future studies could explore the weighting that parents and other family members give to different groups who may accept or reject children with intellectual disability. Such groups may include extended family members, friends of the family, neighbours, teachers, parents from local schools, public figures of note, and family religious advisors (local *imams*). It may be that some of these groups have a greater impact on parents' subjective beliefs about the social acceptability of children with disabilities, which

may in turn have a salient effect on their Saudi Arabian Family Quality of Life scores.

Another possible line of future research is the development of program prototypes that can be of use to governments in addressing the challenges faced by families who have children with intellectual disability. Clearly, from the results of the study, these families who have a relatively lower family quality of life are also those who have low incomes, meaning that they are already considered as ‘marginalized’ groups that need government attention. The study has brought open the need of such families to be able to properly care for and nourish the development of their child with an intellectual disability. Research can be conducted on possible ways to do so, such as educational programs geared towards providing parents with greater knowledge about intellectual disability and how to care for someone with an intellectual disability. A pilot of such a program, involving at least some of the participants of the current study, may be carried out in order to determine the program’s effectiveness.

Another direction for future research may focus on better understanding the differences in the experiences of families who have children with different levels of intellectual disability. As found in the current study, the American Psychiatric Association (2013) has clearly developed metrics for differentiating among the various levels of intellectual disability, and the American Psychiatric Association (2013) emphasized the importance of being able to determine the level of intellectual disability that a child is experiencing in relation to determining the proper courses of action for the care of the child. In the current study, the quantitative analysis found that severity of intellectual disability is an important factor that is negatively

associated with family quality of life, but qualitative analysis failed to include representatives of families with children who had moderate or severe intellectual disability. Thus, in a future study, a qualitative analysis may be conducted, recruiting families in Saudi Arabia who have children with severe intellectual disability. While the current study had difficulty in recruiting such families, a more intensive search for potential participants may be conducted in order to find those who are willing to participate. At the same time, a study may also be focused on differences in the experiences of families who have children with different types of intellectual disability. In the current study, the type of intellectual disability was excluded from data gathering, mainly since it was assumed that since the parents are not experts in intellectual disability, they may not know the exact intellectual disability that their child has.

Ideally, a multiple perspectives approach should be taken with respect to the evaluation of family quality of life (Werner et al. 2009). This is because, to a large extent, the experience of family quality of life is subjective, such that people with different roles in the family will have different experiences and perspectives on the quality of life experienced by the family. To gain a well-rounded account, not just mothers and fathers should be asked for their evaluations, but so should the children and members of the extended family who play significant parts in the family's life. Additionally, the current study did not seek to take into account individual-specific factors such as psychological well-being, a sense of coherence, a capacity for coping, and so forth that are characteristic of studies of individual quality of life. These factors could have a bearing or influence on the overall *family* quality of life, especially as it relates to how parents develop different strategies to care for children

with intellectual disability. Thus a future line of research could seek to not only measure family quality of life, but also individual parental quality of life and look for potentially causal linkages between them.

For the current study, however, there was a still more basic limitation which needs to be overcome in any future study; namely, the gender imbalance of participants. The primary carer in Saudi Arabian families is still the mother, so female participants to questionnaires and interviews are very likely to yield valuable insights into family quality of life, and may also supply quite a different perspective on family life, especially the potential impacts of raising children with intellectual disability, compared to male participants. When it comes to participants to the questionnaire, it appears that in most cases fathers (82% of participants) decided to answer it on behalf of the family, perhaps seeing it as their responsibility as the 'head' of the household. So perhaps in future research, half the questionnaires could be addressed to mothers and the other half to fathers, and then have them randomly distributed among participating households. Another alternative is that two questionnaires could be supplied to each household: one for the mother and the other for the father. When it comes to the interviews, as noted in the above section on limitations of the study, the major methodological difficulty here is that there is a strong taboo on females interacting with unknown males (or males who are not family members). For future research, a solution to this problem could be that male potential participants could be interviewed by a male, and female potential participants could be explicitly ensured that they would be only interviewed by a female interviewer. By applying this methodological rule, for both male and female

researchers, it is more likely that female participants would be more willing to be interviewed.

The next direction for future research that may be taken is to focus on correlating cultural factors with the effects of intellectual disability on family quality of life. In the current study, culture was an important consideration, since the Beach Center (Hoffman et al., 2006) scale was mainly validated for western cultures, which are very different from Middle Eastern cultures. While the current study found that the effect of having a child with an intellectual disability on the family quality of life of Saudi Arabian Families is similar to those effects found in other studies concerning Western families, a wider study needs to be conducted, involving other countries in the Middle East, in order to more generally capture the impact of having a child with an intellectual disability on family quality of life on families in this region. An overarching study may then be conducted, considering whether or not different dimensions of culture have some mitigating effects on the relationship between family quality of life and having a child with an intellectual disability. Such a study would need to consolidate data from different studies into a meta-analysis, including the results that were found in the current study.

9.6 Recommendations for Government Support and Education

As has previously been discussed, although legislation on disabilities in Saudi Arabia was passed in 1987 and the Disability Code was introduced in 2000, to ensure that people with disabilities could access various kinds of support services through public agencies (Prince Salman Center for Disability Research, 2004), it was only in 2001 that the Regulations of Special Education Programs and Institutes were introduced. These were the first regulations for students with disabilities in Saudi

Arabia. These entitled children to individual special education programs and early intervention programs in schools. Children with mild intellectual disability attend special education classes within regular schools, while children with severe intellectual disability are supposed to attend separate special education institutes. In practice, however, the legislation has not been implemented in a widespread and equitable manner. In regular schools, teachers often do not have appropriate training, attitudes or resources. Meanwhile special institutes are often located long distances from children's homes, sometimes making them inaccessible. As Alquraini (2011, p. 151) laments, "In fact, the lack of the effective implementation has created a gap between the framework of these laws and the provision of services, resulting in a lack of special education services for some students with disabilities."

This in itself is a serious failing that requires a solution. The findings of the current study provide further impetus for improvement, because it has been shown that caring for a child with intellectual disability is not just challenging for the child, but has a significant effect on an entire family's quality of life. Importantly, this negative impact is more likely to be felt by families that are already having other difficulties, due to the lower socioeconomic status of the family's adults or due to marital breakdown. It was found in the study that such families who already face the above difficulties tend to feel the burden of having to care for a child with an intellectual disability more than families who have no socioeconomic problems. Although this is only a correlational finding, it suggests the possibility that having a child with an intellectual disability is an especially important concern for families that are already in vulnerable positions. The Saudi Arabian government must recognize this possibility, and seek to establish whether this is merely a correlation or

a causal relationship. If it is the latter, it should focus on helping families in the lower socioeconomic brackets deal with having to raise children with intellectual disability, by providing them with the support necessary for them to address the challenges that they and their children face in their everyday lives.

The most obvious difficulty that the government needs to face in seeking to improve the quality of life of all families, but especially those caring for children with intellectual disability, is to ensure that adult family members are employed and able to earn a decent income to support their families. This involves making difficult politico-economic decisions, such as considering the redistribution of the unequal distribution of income and wealth in Saudi Arabia through a more generous welfare system, especially in terms of unemployment benefits (which can be below a relative poverty line of 50% of average income) and child disability payments (which are currently extremely small). It also entails consideration of jobs programs that can be targeted at those families who have particularly serious and permanent needs, such as those with children with intellectual disability. It seems likely that greater financial assistance to families of children with intellectual disability would improve the quality of life of those families because it would enable them, especially mothers, to hire additional in-house assistance with daily household activities, and enable families to afford private psychological and educational support for their children if needed. This is especially important in those cases where families do not just have a lower than average income, but who are living in poverty. As has been argued by Enwefa, Enwefa and Jennings (2006), poverty contributes to a wide variety of additional problems, such as child abuse and neglect, low educational attainment, and long-term health problems. It also increases the rate of family conflict and

divorce, which as the current study found were also contributors on their own to a lower family quality of life.

There are other forms of support, not currently available in Saudi Arabia, that can also be provided to families of children with intellectual disability. These include (1) assistance with parenting skills, (2) better tailored education services for children, (3) assistance with marital stability, and (4) combating stigmatisation.

9.6.1 Assistance with Parenting Skills

Alquraini (2011) argues that the official assessment of whether or not a child has an intellectual disability does not occur until the child goes to school. Parents are thus very often left without any kind of official support, or even proper knowledge of their child's condition, until six years of age. If there were instead early intervention programs for children with intellectual disability and their families, provided for example by the Ministry of Health, then this would considerably decrease uncertainty, anxiety and hardship on the part of parents in the crucial early stages of parenting. Allied with this, guidance and training programs dedicated to how to provide the best form of parenting for children with intellectual disability, would also serve to relieve the distress associated with trying to figure out how to raise children with intellectual disability. Such parenting courses could be provided by a combination of the Ministries of Health and Education. In addition to this, parents should be made aware of their children's rights under the law, and be apprised of the support services available in their community, of which they may not be fully aware.

9.6.2 Better Tailored Education Services for Children

When it comes to schools themselves, teachers should be fully educated about the rights and requirements of children with intellectual disability, and should be continually updated with the latest international and national research on best-practice in special education. Al-Herz (2008) has pointed out that although special education teachers are relatively well-trained, teachers themselves felt that they required additional training and support, and that schools lacked multidisciplinary teams (including the special education teacher, the child's previous teachers, the parents of the child) to decide on the educational needs of each individual child. The inclusion of parents in the educational decision-making process was deemed to be something that would be very beneficial to the child. By extension, if a child were receiving the best tailored education for their needs, this would be likely to contribute to a less challenging environment for the family in general.

9.6.3 Assistance with Marital Stability

Maintaining marital stability (avoiding parental separation), which requires providing better 'internal' family support when facing the challenges of caring for a child with intellectual disability, is a difficult problem for the state to tackle. Nonetheless, it is a problem that needs to be addressed because, as the current study found, this is one of the important factors that is associated with family quality of life. Several proposals are available, but would need to be handled in a sensitive fashion. One is that dedicated marriage support and counselling services may prove to also be a useful way to maintain marital stability in the long-term. Currently, there is little by way of such public services available in Saudi Arabia, leaving such

matters to be dealt with privately by a family which may not have the expertise to deal with such marital stresses (Al-Bahadel, 2009).

Another suggestion is the development of family-to-family support networks for parents of children with intellectual disability, so that parents can interact with each other, share their experiences and knowledge and offer camaraderie. The alleviation of social isolation may help to avoid marital breakdown and improve family quality of life. As Meral et al. (2013, p.242) have pointed out, “Parents who have used Parent-to-Parent services have reported that they view their circumstances in a more positive light, have made progress on goals important to them, and have dealt more positively with their child and family situation.”

9.6.4 Combating stigmatisation

Finally, in order to combat the social stigmatisation of children with intellectual disability, the government should consider a continuous, comprehensive public education strategy to alter community attitudes towards intellectual disability. This can include national media campaigns designed to dispel folk-myths about intellectual disability, drawing upon religious legal authority about the rights of people with intellectual disability, and encouraging social inclusion in employment and in civil society more generally. At the grass-roots level, schools can hold information sessions and workshops for all parents about intellectual disability and the need to educate their children about respectfulness and compassion for children who are not as advantaged as themselves. Also, within schools themselves, anti-bullying programs, education of the student population, and inclusion and integration of children with intellectual disability into school-wide activities is also likely to

have long term beneficial effects on the attitudes of the general population as those children enter adulthood themselves.

9.7 Thesis Conclusion

In conclusion, this thesis has made a number of contributions. First, it has been demonstrated that the Saudi Arabian Family Quality of Life Scale developed in this thesis provides a valid and reliable indicator of quality of life for Saudi Arabian families, in particular for Saudi Arabian families of children with intellectual disability. Such research is in its infancy in Saudi Arabia, so this is a particularly important result because it means that this scale, along with the sequential mixed methods approach employed in this thesis, can be used in future research to further investigate family quality of life in the country. The availability and use of such a scale is important in normative terms as well: the government and community organisations should look beyond financial expenditure on people's disabilities to the actual quality of life experienced by their family members, in order to better meet its stated objectives of equitable wellbeing for all of its citizens, and especially its most vulnerable citizens. This new scale now enables investigation of quality of life of Saudi Arabian families in many contexts to be conducted with greater confidence than before.

Second, the thesis has demonstrated that families of children with intellectual disability in Saudi Arabia have a measurably lower quality of life than those families without children with intellectual disability. Further, this family quality of life gap can be, and is, reduced when the socio-economic standing of the family improves, and when marital stability is maintained (that is, when marriages do not break down). In short, aside from the programs and legislative support that already exist in the

country, the most significant ways in which family quality of life can be better equalised is if greater financial support is provided to families of children with intellectual disability, and if various kinds of social support can be offered to such families to assist them in maintaining intra-family harmony.

Third, the augmentation of the original Beach Center Family Quality of Life Scale was found to be appropriately modified for Saudi Arabia. However, an important ‘negative’ finding of the thesis was that the ‘religiosity’ measure did not yield any significant correlational results in terms of family quality of life. This would appear to be because among Saudi Arabians, religiosity measures are high and at a general level of questioning, relatively invariant. The subsequent interviews, however, suggested that participants interpreted and used religion in a number of different ways in living their lives. This suggests that religiosity is playing a significant role in the lives of families of children with intellectual disability, but it will require a more nuanced and complex construct if it is to be shown to have an effect on family quality of life in any future iteration of the Saudi Arabian Family Quality of Life Questionnaire used in this thesis.

Finally, although in general terms financial assistance and support for marital stability have been identified as key means of closing the family quality of life gap between Saudi Arabian families of children with intellectual disability compared to those who do not, this thesis has also suggested a number particular strategies which would serve to close the gap. These include: early intervention programs to identify intellectual disability in children; guidance and training programs for parents; provision of information for parents about their children’s rights; better training and support for teachers and multidisciplinary teams to assess children with intellectual

disability; and a multi-pronged attack on social stigmatisation of children with intellectual disability at the national and grassroots levels. If all these findings and recommendations are taken seriously, it is contended that the quality of life of Saudi Arabian families of children with intellectual disability will be substantially improved, and the Saudi state will be able to better claim that it is meeting the needs of its most vulnerable citizens.

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Appendix A: Saudi Family Quality of Life Questionnaire

School of Education

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k.alshamri@uws.edu.au



Quality of life for families of children with intellectual disability in Saudi Arabia

Dear Participant,

First, I would like to thank you for your interest in participating in the current study. Participation in the current study simply entails completing the survey that is attached to this letter. Your completing the survey is taken as consent to participate.

Participation is completely voluntary, and you may choose not to answer any item in the survey that you do not feel comfortable answering. Also, you may withdraw from the study at any time prior to submitting the attached survey form. Your identity as a respondent in the current study will be kept confidential at all times, and no identifying information about you will be collected. This survey is part of my PhD research at University of Western Sydney, Australia and, as noted, in the Information Sheet has been approved by the University of Western Sydney Human Ethics Committee (Approval number H10980). The survey will be collected in 1 week from the box in the school office. If you have any further questions before or after submitting this form, you may contact me at 0451389699.

Sincerely,

Khalid Alshamri

Part 1: Respond to each question by either selecting the best answer, or placing the answer as a number in the box.

1. Are you the father or mother in the family? Father Mother
2. What is your marital status? Married Divorced
3. How old are you? (Please write the number in the box)
4. Do you live in? City Town Village
5. How many people do you have in your family including adults and children?
6. How many children (less than 18 years old) do you have in the family?
7. Are you the person that is the primary carer – home all the time with the children?
 Yes No
8. What is your employment status?
 Working Student Not Employed, for example (Stay home, retired).
9. What is the highest level of education that you have completed?
 No schooling completed Under high school High school
 Bachelor Postgraduate or above Other (Please indicate)

10. What is your yearly total household income from all sources?
 Less than 60,000 SA Between 60,001-120,000 SA Over 120,001 SA
11. Do you have a child/children who has/have been diagnosed with an intellectual disability? No Yes. If yes, how many _____
12. Do you have a child/children whom you believe has/have intellectual disability but has/have not yet been diagnosed? No Yes. If yes, how many _____
13. Who looks after/cares for your children when you are not at home?
 Spouse Sibling Other Family Member Friend Other (maid etc.)
14. For your children WITHOUT an intellectual disability, how many are female and how many are male? Male female
15. How old are they? (Please indicate) _____
 - **If your answer was NO in question 11&12, please move on to Part 2.**
16. For your children WITH an intellectual disability, how many are female and how many are male? Male female
17. How old are they? (Please indicate) _____
18. For your children with an intellectual disability, how many have the following level of disability? Mild Moderate Severe
19. How many of your children with an intellectual disability have a secondary disability?

Part 2: Respond to each item by checking how much you agree with the statement provided. (Check ✓one)

	Strongly Agree	Agree	Neither	Disagree	Strongly disagree
1. I am a religious person.					
2. There is only one God.					
3. I pray to God five times a day.					
4. I give at least 2.5% of what I earn to the poor and needy.					
5. I fast during Ramadan.					
6. I have visited Mecca.					
7. I believe in the wisdom of my religion's laws.					
8. I believe the stories of the past taught in my religion.					
9. I communicate and access my faith with God by praying.					
10. I think that the values taught by my religion and/or culture contribute to the family's quality of life.					
11. My family members strive to uphold religious and/or cultural values that contribute to the family's quality of life.					
12. I am contented with the extent to which religious and/or cultural values contribute to my family's quality of life.					

Part 3: Turnbull's Family Quality of Life Scale. Respond to each item by checking how satisfied you are about each matter concerning your family. (Check ✓one)

How satisfied am I that...	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1. My family enjoys spending time together.					
2. My family members help the children learn to be independent.					
3. My family has the support we need to relieve stress.					

4. My family members have friends or others who provide support.					
5. My family members help the children with schoolwork and activities.					
6. My family members have transportation to get to the places they need to be.					
7. My family members talk openly with each other.					
8. My family members teach the children how to get along with others.					
9. My family members have some time to pursue our own interests.					
10. Our family solves problems together.					
11. My family members support each other to accomplish goals.					
12. My family members show that they love and care for each other.					
13. My family has outside help available to us to take care of special needs of all family members.					
14. Adults in our family teach the children to make good decisions.					
15. My family gets medical care when needed.					
16. My family has a way to take care of our expenses.					
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).					
18. My family is able to handle life's ups and downs.					
19. Adults in my family have time to take care of the individual needs of					

every child.					
20. My family gets dental care when needed.					
21. My family feels safe at home, work, school, and in our neighbourhood.					
22. My child with an intellectual disability has support to accomplish goals at school or at the workplace (if you do not have a child with an intellectual disability answer this question for your children).					
23. My child with an intellectual disability has support to accomplish goals at home (if you do not have a child with an intellectual disability answer this question for your children).					
24. My child with an intellectual disability has support to make friends (if you do not have a child with an intellectual disability answer this question for your children)					
25. My family has good relationships with the service providers who provide services and support to our child with an intellectual disability (if you do not have a child with an intellectual disability answer this question for your children)					
26. People in my religious and/or cultural community do not reject my child with/WITHOUT an intellectual disability.					
27. People in my religious and/or cultural community provide practical assistance					

to my family because we have intellectual disability-related needs (If you do not have a child with an intellectual disability, answer this question for your children).					
28. People in my religious and/or cultural community provide emotional support to my family because we have intellectual disability-related needs (If you do not have a child with an intellectual disability, answer this question for your children).					
29. My family's religion gives us strength and enables us to make sense of life.					
30. My family relies on God and turns to God for aid.					
31. My family's faith enables us to make sense of having a child with/WITHOUT an intellectual disability.					

- **If you do NOT have child/children with a disability, please move on to Part 5.**

Part 4: Respond to each item by checking how much you agree with the statement provided.

(Check ✓one)

	Strongly Agree	Agree	Neither	Disagree	Strongly disagree
1. Having a child with an intellectual disability is a blessing from God or a test of our faith.					
2. Having a child with an intellectual disability is a punishment from God for sinful					

behaviour.					
3. I am embarrassed by my child who has an intellectual disability.					
4. I would prefer that non-family members not know that my child has an intellectual disability.					
5. My child who has an intellectual disability gets along well with my other child/children who does/do not have intellectual disability.					
6. I love my child who has an intellectual disability.					
7. I love my child who has an intellectual disability as much as I do my other children.					
8. I love my child who has an intellectual disability more than I do my other children.					
9. The government helps me in raising my child who has an intellectual disability.					
10. I am satisfied with my family's quality of life.					

Part 5: Please indicate if you are willing to participate in an interview. This interview will be face to face and will last about 30 minutes to 1 hour and will be scheduled at a time and place that is convenient for you. The interview will be related to your answers in this survey.

Yes

No

If yes, please give your contact details (Name, Cell phone, and email or land phone number)

Name: -----

Contact: -----

Thank you for completing this survey. Please place it into the envelope provided and drop it at the school office.

Khalid

Arabic Version of Saudi Family Quality of Life Survey

عزيزي المشارك،

أولاً، أود أن أشكركم على اهتمامكم في المشاركة في هذه الدراسة. المشاركة في هذه الدراسة تنطوي ببساطة على تعبئة الاستبيان لأغراض هذه الدراسة. يرجى النظر الى افراد عائلتك الذين تعيش معهم ، وأولئك الذين تدعمهم وغيرهم من الناس في منزلك. يرجى التفكير في حياتك العائلية على مدى الأشهر الـ 12 الماضية.

يرجى العلم أن المشاركة اختيارية تماماً، وإذا كنت غير راضياً على أي بند يمكنك عدم الاجابة عليه وايضا يمكنك الانسحاب كلياً. هويتك في هذا الاستبيان ستكون سرية تماماً. إذا كان لديك أي أسئلة أخرى قبل أو بعد تقديم هذا النموذج اتصل بي مباشرة على الرقم التالي : 61451389699.

مع خالص التقدير والشكر،

خالد حبيب الشمري

الجزء الاول / ضع إشارة في الفراغ المناسب :

- 1- هل انت الأب ام الأم؟ الأب أم
- 2- ماهي حالتك الاجتماعية؟ متزوج طلق
- 3- كم عمرك؟ اكتب الرقم بالمربع
- 4- هل تعيش في؟ منطقة محافظة
- 5- كم عدد عائلتك اطفال وبالغين؟
- 6- كم عدد الاطفال في عائلتك (اقل من 18 عاماً)؟
- 7- هل انت الشخص الذي يرعى اولاده ويبقى معهم طول اليوم؟ نعم لا
- 8- ماهي حالتك الوظيفية؟ اعمل طالب عمل ، مثلاً متسبب او متقاعد
- 9- ماهي الدرجة التعليمية التي حصلت عليها؟ بدون شهادة من الثانوية العامة ا اية العامة
بكالوريوس اساتذ عليا ذلك (اكتب هنا) _____
- 10- ماهو مستوى دخلك السنوي من جميع المصادر؟
اقل من 60.000 ريال 60.001-120.000 ريال من 60.001 ريال
- 11- هل عندك طفل/ اطفال تم تشخيصهم كمعاقين ذهنياً؟ نعم لا اذا ، كم عددهم _____
- 12- هل عندك طفل/ اطفال ولم يتم تشخيصهم ولكن انك تعتقد انهم معاقين ذهنياً؟ نعم لا كم عددهم _____
- 13- من الذي يعتني بأطفالك اذا كنت بخارج المنزل؟ الزوج لاشقاء احد افراد العائلة
مثل الاب او الام صديق غير مثل العام منزلية

14- لأطفالك الغير معاقين ذهنيا ، كم عدد الذكور؟ كم عدد الاناث؟

15- كم اعمارهم ؟ _____

اذا كانت اجابتك بلا على الاسئلة 11 و 12 ، اذهب مباشرة الى الجزء الثاني :

16- لأطفالك المعاقين عقليا كم عدد الذكور وكم عدد الاناث ؟ ذكر أنثى

17- كم اعمارهم ؟ _____

18- ما هو مستوى اعاقه طفلك ؟ بسيطة متوسطة

19- كم عدد الاطفال الذي يعانون من اعاقه مزدوجة ؟

الجزء الثاني / الرد من خلال الاجابة ب موافق بشدة او موافق او ولا واحد او غير موافق او غير موافق بشدة .. تستطيع تجنب اجابة أي سؤال لا تريد الاجابة عليه :

موافق بشدة	موافق	ولا واحد	غير موافق	غير موافق بشدة
				1- انا شخص متدين
				2- يوجد فقط رب واحد
				3- اصلي خمس فروض باليوم
				4- ادفع نسبة الزكاة 2.5% كل عام للفقراء
				5- اصوم رمضان كاملا
				6- ازور مكة
				7- اصدق احكام وقوانين الدين
				8- اصدق بالقصص القديمة والاحاديث
				9- اتواصل مع الله بالصلاة والدعاء
				10- اعتقد ان القيم التي نتعلمها من ديننا تساهم في جودة حياتنا
				11- يحافظ افراد عائلتي على /او تعزيز القيم الثقافية والدينية التي تساهم في جودة حياتنا
				12- أنا راضي على مساهمة القيم الدينية والثقافية على جودة حياة عائلتي

الجزء الثالث / عن طريق التأشير على احد هذه البنود مما ترى انه يناسبك وعائلتك .. تستطيع تجنب اجابة أي من هذه البنود :

السؤال : ما مدى رضاك عن ..	غير راضي بقوة	غير راضي	لا	راضي	راضي بقوة
1- تتمتع عائلتي بقضاء اوقاتنا مع بعضها					
2- افراد عائلتي يُعلمون اشقائهم العيش باستقلالية					
3- عائلتي لديها الدعم المناسب الذي نحتاجه لتخفيف الضغط عنا					
4- لدى افراد عائلتي اصدقاء وآخرون يقدمون المساعدة					
5- افراد عائلتي يساعدون الاطفال بالأنشطة والواجبات المدرسية					
6- افراد عائلتي لديهم وسيلة نقل للوصول للاماكن التي يريدون الوصول لها					

					7-الاشقاء يتكلمون مع بعض بصراحة
					8-الاشقاء يعلمون اشقائهم عن كيفية التواصل مع الآخرين
					9-الاشقاء لديهم وقت للقيام بأمر اشقائهم الآخرين الخاصة
					10-كعائلة نحل مشاكلنا مع بعضنا البعض
					11-يدعم الاشقاء كل منهم الآخر لتحقيق الاهداف
					12-يظهر او يكشف الاشقاء عن حبهم ورعايتهم لبعض لبعض
					13-عائلي لديها مساعدات خارجية متاحة لنا للعناية بكل ذوي الاحتياجات الخاصة
					14-البالغين بالأسرة يدرسون اشقائهم على اتخاذ القرارات السليمة
					15-عائلي تحصل على الرعاية الطبية اللازمة فورا عند الحاجة
					16-عائلي لديها وسائل لرعاية نفقاتنا المالية
					17-البالغين بعائلي يعرفون اصدقاء اشقائهم ومعلميهم وغيرهم
					18-عائلي قادرة على التعامل مع متغيرات الحياة صعودا ونزولا
					19-البالغين في عائلي لديهم الوقت لرعاية كل احتياجات اشقائهم الفردية
					20-اطفالي يستطيعون مراجعة عيادات الاسنان فورا عن الحاجة
					21-تشعر عائلي بالأمان في البيت ، العمل ، المدرسة ، الجيران
					22-طفلي المعاق ذهنيا لديه دعم لتحقيق اهدافه اما من المدرسة او العمل (اذا لم يكن لديك طفل معاك أجب على السؤال عن اطفالك الغير معاقين)
					23-طفلي المعاق لديه دعم لتحقيق اهدافه بالمنزل (اذا لم يكن لديك طفل معاك أجب على السؤال عن اطفالك الغير معاقين)
					24-طفلي المعاق ذهنيا لديه القدرة والدعم لتكوين صداقات خارج المنزل (اذا لم يكن لديك طفل معاك أجب على السؤال عن اطفالك الغير معاقين)
					25-لدينا علاقات جيدة مع مقدمي الدعم والخدمات للأطفال المعاقين مثل بعض الادارات التي تقدم الخدمات للمعاقين (اذا لم يكن لديك طفل معاك أجب على السؤال عن اطفالك الغير معاقين)
					26-الناس في مجتمعي يتقبلون طفلي المعاق (اذا لم يكن لديك طفل معاك أجب على السؤال عن اطفالك الغير معاقين)
					27-الناس في مجتمعي يساعدون طفلي عمليا باحتياجاته المرتبطة بالإعاقة (اذا لم يكن لديك طفل معاك أجب على السؤال عن اطفالك الغير معاقين)
					28-الناس في مجتمعي يساعدون طفلي عاطفيا لتلبية احتياجاته المرتبطة بالإعاقة (اذا لم يكن لديك طفل معاك أجب على السؤال عن اطفالك الغير معاقين)

					29- ايمان الاسرة يعطينا القوة ويساعدنا لنجد معنى لحياتنا
					30- يقود ايمان الاسرة على الاعتماد المباشر على الله
					31- الايمان يساعد شعورنا بوجود طفل معاق ويجعله ذو معنى (اذا لم يكن لديك طفل معاك أجب على السؤال عن اطفالك الغير معاقين)

• اذا لم يكن لديك طفل/اطفال معاقين اذهب مباشرة للجزء الخامس

الجزء الرابع : الرد من خلال الاجابة بـ موافق بشدة او موافق او ولا واحد او غير موافق او غير موافق بشدة .. تستطيع تجنب اجابة أي سؤال لا تريد الاجابة عليه :

غير موافق بشدة	غير موافق	ولا واحد	موافق	موافق بشدة	
					1- وجود اطفال معاقين هو نعمة من الله او اختبار من الله
					2- وجود اطفال معاقين هو بسبب اخطاء قمت بعملها وهو عقاب من الله
					3- اشعر بالخجل من بسبب ان طفلي معاق
					4- لا أريد ان يعرف الناس الاخرين بوجود طفل معاق بالعائلة
					5- طفلي المعاق علاقته جيدة مع شقيقه / اشقائه المعاقين او الغير معاقين
					6- أنا احب طفلي المعاق
					7- أنا احب طفلي المعاق مثله مثل اشقائه الآخرين
					8- أنا احب طفلي المعاق اكثر من اشقائه الآخرين
					9- الحكومة تساعدني كثيرا في رفع مستوى حياة الاطفال المعاقين من علاج وخدمات مقدمة
					10- انا راضي على جودة حياة عائلتي

الجزء الخامس : إذا كنت توافق ان اقوم بأجراء مقابلة شخصية معك حول حياة طفلك ومتطلباتها .. ارجوا الاجابة بنعم ؟

نعم لا

• إذا كانت الإجابة نعم، يرجى إعطاء التفاصيل الخاصة بك للاتصال (الهاتف الجوال، البريد الإلكتروني أو الهاتف الارضي)

الاسم / ----- التلفون الجوال / -----

شكرا لك لتعبنتك للاستمارة . الرجاء ارسالها بمغلف الى مدير المدرسة .

الباحث / خالد الشمري

Appendix B: The Original Beach Center FQOL Scale

How satisfied am I that...	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1. My family enjoys spending time together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My family members help the children learn to be independent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My family has the support we need to relieve stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My family members have friends or others who provide support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My family members help the children with schoolwork and activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My family members have transportation to get to the places they need to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My family members talk openly with each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My family members teach the children how to get along with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. My family members have some time to pursue our own interests.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Our family solves problems together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My family members support each other to accomplish goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My family members show that they love and care for each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. My family has outside help available to us to take care of special needs of all family members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Adults in our family teach the children to make good decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How satisfied am I that...	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
15. My family gets medical care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. My family has a way to take care of our expenses.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. My family is able to handle life's ups and downs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Adults in my family have time to take care of the individual needs of every child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. My family gets dental care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. My family feels safe at home, work, school, and in our neighborhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. My family member with a disability has support to accomplish goals at school or at workplace.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. My family member with a disability has support to accomplish goals at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. My family member with a disability has support to make friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix C: Consent Form



Human Research Ethics Committee

Office of Research Services

Participant Consent Form

This is a project specific consent form. It restricts the use of the data collected to the named project by the named investigators.

Project Title: Quality of life for families of children with intellectual disability in Saudi Arabia

I,----- consent to participate in the research project titled: Quality of life for families of children with intellectual disability in Saudi Arabia.

I acknowledge that:

I have read the participant information sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher.

The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

I consent to participate in the current study.

I understand that my involvement is confidential and that the information gained during the study may be published but no information about me will be used in any way that reveals my identity.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher now or in the future.

Signed:-----

Name:-----

Date:---/---/---

Return Address: 3904 Alsahhar St, Almorj 75911, Aljouf, Saudi Arabia.

The current study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is: [H10980]

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229

Fax +61 2 4736 0013 or email humanethics@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Human Research Ethics Committee

Appendix D: Ethical Approval

Locked Bag 1797
Penrith NSW 2751 Australia
Office of Research Services

ORS Reference: H10980



HUMAN RESEARCH ETHICS COMMITTEE

7 April 2015

Associate Professor Christine Johnston
School of Education

Dear Christine,

I wish to formally advise you that the Human Research Ethics Committee has approved your research proposal H10980 "Quality of life for families of children with intellectual disabilities in Saudi Arabia", until 1 March 2017 with the provision of a progress report annually if over 12 months and a final report on completion.

Conditions of Approval

1. A progress report will be due annually on the anniversary of the approval date.
2. A final report will be due at the expiration of the approval period.
3. Any amendments to the project must be approved by the Human Research Ethics Committee prior to being implemented. Amendments must be requested using the HREC Amendment Request Form: http://www.uws.edu.au/data/assets/pdf_file/0018/491130/HREC_Amendment_Request_Form.pdf
4. Any serious or unexpected adverse events on participants must be reported to the Human Ethics Committee via the Human Ethics Officer as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the Committee as a matter of priority
6. Consent forms are to be retained within the archives of the School or Research Institute and made available to the Committee upon request.

Please quote the registration number and title as indicated above in the subject line on all future correspondence related to this project. All correspondence should be sent to the email address humanethics@uws.edu.au.

This protocol covers the following researchers:

Christine Johnston, Danielle Tracey, Khalid Alshamri

Yours sincerely

A handwritten signature in black ink, appearing to read "E. Deane".

Professor Elizabeth Deane
Presiding Member,
Human Researcher Ethics Committee

Saudi Ministry of Education Ethics Approval

المملكة العربية السعودية
وزارة التربية والتعليم
إدارة التربية والتعليم بمحافظة الفيحاء
الشؤون التعليمية
التربية الخاصة

الرقم: ٣٢٢١١٣٨٩
التاريخ: ١٦ / ٣ / ١٤٤٤ هـ
المشرفات:

سعادة المحقق الثقافي السعودي في سفارة خادم الحرمين الشريفين في استراليا سلمه الله
السلام عليكم ورحمة الله وبركاته وبعد :-
بشأن حاجة المبتعث / خالد بن حبيب مفلح الشمري رقم الهوية (١٠٣٢٩٩٧٦٩٢) للقيام برحلة جمع
معلومات متعلقة برسالته للدكتوراة ، عليه نفيد سعادتكم بأنه لامانع لدينا من الاشراف على تطبيق أداة
الدراسة على العينة المطلوبة للطالب المذكور.

هذا والله يحفظكم ويرعاكم

مدبر التربية والتعليم بمحافظة الفيحاء
محمد بن عبدالله الشبيبي

سكترال الإدارة ٠٤٦٤٣٣٠٢٤ تحويله ٣٣٣