

# Health Related Quality of Life Screening for Children and Adolescents in Saudi Arabia

# PhD in Education

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**Abstract** 

In recent years, there has been a growing interest in the welfare of children,

whether they have special needs or health conditions such as ASD, or not (Al-Fayez

& Ohaeri, 2011). It is also important to acknowledge that children with Autistic

Spectrum Disorders (ASD) and neurotypical children in schools may be affected by

low self-esteem, poor physical health, or psychological distress, and this could in turn

influence their QoL. For these reasons, it is essential that children's QoL is measured

and understood, as this may give better insights into how their lives can be improved.

Therefore, this study aims to evaluate the QoL for both schoolchildren with

ASD and neurotypical schoolchildren within the KSA school system. This study also

aims to increase the validity for a standardised QoL instrument in Arabic for

schoolchildren with ASD. Finally, it aims to compare QoL in KSA schoolchildren

with ASD with those from Republic of Ireland. In order to achieve the pervious aims,

quantitative approach has been employed. The quantitative component consists of the

instrument translation and standardised assessment of QoL in KSA schoolchildren.

This method is selected due to the need to empirically and objectively evaluate QoL

in KSA schoolchildren as well as compare this dataset with pre-existing samples, such

as that of the Kidscreen data collected amongst Irish schoolchildren.

In KSA, while neurotypical schoolchildren rated their quality of life higher

than schoolchildren with ASD, overall the findings of this study suggest that most

Saudi Arabian schoolchildren with ASD enjoy a high health-related quality of life.

Findings in this study will be of interest to the education sector and to people working

with and on behalf of schoolchildren and young people.

Keywords: Kidscreen 52, OoL, Autism, KSA, neurotypical, Republic of Ireland

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# **Declaration**

# I hereby declare that:

- I assume full responsibility for this research and its findings and conclusions
- This study has been written, in its existing form, by me
- All the sources and verbatim extracts contained in this research has been distinguished and due credit has been given to the other researchers for their works.

## 1. Chapter One: Introduction

#### 1.1.Introduction

The current study seeks to explore the quality of life (QoL) in (Kingdom of Saudi Arabia specifically Makkah, Jeddah and Riyadh) KSA schoolchildren with Autistic Spectrum Disorders (ASD) and neurotypical schoolchildren. I chose this topic due to the fact that, I am employed with my university in KSA, and the department in which I am employed recently opened a new department for special education needs. As there is no enough staff specialist, the department provided me with a scholarship to study ASD. I find autism to be an interesting condition, and I have chosen to conduct my doctoral dissertation on the subject because I want to understand these children's QoL and experiences. I found receiving the scholarship to be a tremendous honour, and I believe that my research helps to provide insight into ASD in Eastern nations.

This is important because in recent years there has been a growing interest in the welfare of children, whether they have special needs or health conditions such as ASD, or not (Al-Fayez & Ohaeri, 2011). It is also important to acknowledge that children with Autistic Spectrum Disorders (ASD) and neurotypical children in schools may be affected by low self-esteem, poor physical health, or psychological distress, and this could in turn influence their QoL. For these reasons, it is essential that children's QoL is measured and understood, as this may give better insights into how their lives can be improved. According to UNICEF (1989), the 1989 Convention on the Rights of Children emphasized on the need to ensure that every child is able to develop physically, socially and mentally so that they can achieve a good QoL (Al-Fayez & Ohaeri, 2011). Unfortunately, this is might be not the case for some children

with disabilities. Children with ASD are more likely to struggle in school (Ashburner, Ziviani and Rodger, 2010), in comparison with neurotypical children. Therefore, under these circumstances one could argue that understanding their QoL is essential to understanding children's wellbeing. The QoL of children in schools can therefore be used as a measure to explore children's wellbeing and in establishing if their rights are enacted.

Numerous scholars in Western societies have sought to measure the QoL of school children for various reasons (Felder-Puig et al., 2008; Gkoltsiou et al., 2008; Simon, Chan & Forrest, 2008). However, a few studies have been carried out in an Arab setting (e.g., Al-Fayez & Ohaeri, 2011; Matza et al., 2004). Matza et al., (2004) focused on the QoL for students and the relationship with intensity of religiosity (Al-Fayez & Ohaeri, 2011). Another study, conducted by Al-Fayez and Ohaeri (2011) had three key objectives: firstly, to determine the level of satisfaction with life circumstances among high school students in Kuwait (Al-Fayez & Ohaeri, 2011); secondly, to assess the prevalence of at risk status for impaired QoL and establish the QoL domain normative values (Al-Fayez & Ohaeri, 2011); and lastly, to examine the relationship of QoL with personal, parental, and socio-environmental factors (Al-Fayez & Ohaeri, 2011). None of these studies sought to understand the QoL of both schoolchildren with ASD and neurotypical schoolchildren in Saudi Arabia. Therefore, this research intends to fill this existing gap in literature by investigating and evaluating the QoL of both schoolchildren with ASD and neurotypical schoolchildren in the Kingdom of Saudi Arabia. Furthermore, this is the first time that a screening instrument to test the QoL of school children is used in the KSA. To do so, with the consent of the authors, the HRQoL measures is translated in Arabic, so that it may further benefit others should they wish to use this in the future.

In addition, this study is carried out in the KSA school system, which has a number of unique features (Kanalan & Celep, 2011). According to Aljughaiman and Grigorenko (2013: 308) "the modern system is characterized by a strong orientation toward Islamic roots and societal values, with learning and teaching based on the requisite that, no matter the academic subject, the Islamic faith is developed and maintained, and that the students are furnished with Muslim ideals and equipped with skills and knowledge that will guarantee KSA society's economic, social, and cultural prosperity." The research is conducted after having taken into account all of these interrelated notions, which are based on both the traditions and new ideas that have come together to form modern KSA society this research are commenced.

There are many factors that affect QoL including education. Neurotypical children's access to education may be affected by their socio-economic status, class, and gender (Escarce, 2003). Simultaneously, these factors may all affect a child's educational experiences and QoL. Considerations here are on how gender based segregation can be implemented (Almutairi, 2008; Al Rawaf & Simmons, 1991; Baki, 2004) and how all students, including those with disabilities, were provided with the education that they need (Aljughaiman, Majiney and Barakat, 2012). These factors are now considered starting with a discussion regarding gender in the Kingdom's school system.

The culture in Saudi Arabia is derived from the ideals associated with Islam, which, based on much of the educational curriculum centering on Islam religious teachings with Islamic studies. The education system has been devised in accordance with these traditional values (Al-Sadan, 2000). Therefore, the school system has been designed with these Islamic traditions in mind and those, which are applied in modern society. One of the features of the school system is that students are segregated

according to their gender. The educational policy is instigated for "the purpose of educating a girl is to bring her up in a proper Islamic way so as to perform her duty in life, be an ideal and successful housewife and a good mother, ready to do things which suit her nature such as teaching, nursing and medical treatment" (Al-Salloom, 1995: 19-20). Although, females are educated to fulfil this role, it is also acknowledged that, "it is a women's right to obtain suitable education on equal footing with men in light of Islamic laws" (Al-Salloom, 1995: 19-20). In this way, females are expected to fulfill their societal roles and the educational system reinforces this (Baki, 2004). Boys are educated to fulfill different roles so that they are able to work and provide for their families more than girls.

Further to this, The Ministry of Education is responsible for diagnosing, assessing and ensuring that children with disabilities (such as, ASD) receive an education that meets their needs and that the services they access enable these students to be able to live in society independently (Al-Mousa *et al.*, 2006; Ministry of Education, 2008).

Children with disabilities also have a number of legal rights. In 1987, the Legislation of Disability was instigated and thus making a provision for all people with disabilities to be treated equally in society. It stipulates that, "all public bodies must provide rehabilitation services and training programs that support independent living" (Al\_Quraini, 2011: online: 150). There is also a disability code 2000, which supports this law which states that disabled individuals must have free access to all medical, educational and other services that they require (Prince Salman Center for Disability Research, 2004). Depending on the severity of their disability, those children who have been diagnosed with ASD are educated in classrooms with special education services and in severe cases, they are taught in separate institutions.

According to Al-Quraini, (2011) 'students with disabilities in these institutes receive Individual Education Program (IEP) that are modified from a special education curriculum and designed by the Ministry of Education for these students. The IEPs often do not meet their unique and individual needs; instead these students should receive IEPs based upon the general curriculum'. This is why it is so essential to assess their QoL in order to ensure that their educational needs and legal rights are being met.

This thesis is based very much on Saudi Arabia as a research context. Education in Saudi Arabia is different compared to Western countries in some aspects. For example, my experience in Saudi Arabia has demonstrated that there is segregation amongst students of various demographic groups within this nation. Examples of this segregation include gender, socioeconomic status, and class. Accordingly, I have found that schoolchildren with special needs may benefit from some special attention within the KSA's special education system. Additionally, some boys and girls with ASD within the KSA's special education system traditionally attend special schools until they reach nine and ten years old because of their condition in understanding gender and their personal needs as well, at which point they enter gender-matched academic settings. Therefore, children in KSA school system, receive education in line with Islamic values from an early age. Boys and girls within the KSA education system normally enter gender-mixed academic settings in a kindergarten environment from about three to five years of age. They are believed to understand gender and be able to move to gender-matched academic settings and enter the primary school environment at approximately the age of six. Female education in Saudi Arabia differs from that of males from an early age based on many of these traditional and societal underpinnings. The teaching staff within the KSA school system are also gender-matched (with male teachers teaching male students and female teachers teaching female students). Based on some of these traditions within the KSA school system, I believe that special needs students could benefit from current research as their needs and legal rights must be met. This can be achieved by increasing the research in this area.

Understanding how to improve QoL in such schoolchildren remains critical for ensuring children with ASD receive the same level of education as their peers. The current study utilizes a multi-part, quantitative design to explore the impact of QoL for children with ASD and neurotypical children in Saudi Arabia. This study also seeks to provide further empirical support for a previously validated QoL instrument for KSA schoolchildren. Finally, this study also compares the QoL of schoolchildren with ASD in KAS with those from Republic of Ireland. The Irish study took place as part of the KIDSCREEN project, which was conducted over 3 years (2001-2004) and the Irish data adopted from the standardized data sets. This section describes the research design and theoretical framework used to guide this study.

#### 1.2.Quality of Life

Quality of Life (QoL) refers to the general health and well-being of an individual or group of individuals (Fairclough, 2012). While previous conceptions of QoL emphasised strictly physical factors contributing to this construct, researchers now recognise the psychological and social dimensions of QoL as well. QoL has become an increasingly important outcome variable in public health and medical interventions due to its relationship with physical health (Fairclough, 2012). An abundance of empirical research (e.g., Winters et al., 2010; Pucci et al., 2012) have demonstrated the relationship between psychological, social, and physical outcomes.

Winters et al. (2010) recently reviewed the relationship between QoL and long-term health outcomes. Based on a systematic review of studies examining the relationship between QoL and long-term mortality rates, these researchers found that, while ailments resulted in reduced QoL, improved QoL was associated with improved mortality rates associated even with ailments.

According to Schalock, Keith, Verdugo, and Gomez (2011), QoL is difficult to assess due to its subjective qualities. For example, while one individual may consider physical health to be important for QoL, another may not highly value this factor. Varying definitions of QoL produces inconsistencies amongst the body of research designed to describe this experience, and potentially limits its generalizability and validity (Schalock et al., 2011). For the purposes of the current study, the World Health Organization's (WHO, 1997) classic definition is used because of its universality and applicability to multiple fields of study. According to the WHO (1997: online: 1), QoL refers to, "an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" It was felt that this definition provided the most broad and holistic conception of QoL available, and highlights the subjectivity and individuality of the QoL experience.

Additionally, the WHO's definition of health is used within the current study in order to describe this multi-faceted state. According to the WHO (1997: 1), health refers to, "a state of complete physical, mental, and social well-being not merely the absence of ailment." It was also felt that this definition highlighted both the objective and subjective elements of health, as well as the multiple related factors that combine to create physical health. This section discussed background information related to QoL. Definitions and conceptualisations of this construct were presented, as well as

research regarding its measurement. The next section discusses the interaction between Qol, HRQoL, and ASD in Saudi Arabia.

### 1.3.QoL, HRQoL and Autism in Saudi Arabia

Unfortunately, there are limited studies (e.g., Al-Qahtani, 2012; Pani al., 2013) which have empirically evaluated the QoL on children with ASD in Saudi Arabia. Pani and colleagues (2013) examined oral health-related quality of life in KSA children with ASD, while Algahtani (2012) qualitatively examined quality of life factors in both adults and children with ASD in Saudi Arabia. These studies offer some insight into the impact of ASD in KSA children's quality of life, although there remains a lack of empirical evidence regarding this topic. Pani's (2013) study focused on oral and dental health, while Algahtani's (2012) study was quite generic in focus and investigated global factors. The Algahtani (2012) study was about parents and children with ASD in Saudi Arabia. This study has some similarities to the one I am conducting, although my goal is to utilise the Kidscreen questionnaire to empirically examine specific QoL variables in these children. However, the Algahtani (2012) study was strictly qualitative in nature, explored the cultural context of ASD in Saudi Arabia, and did not utilise the Kidscreen instrument to evaluate QoL. The Algahtani (2012) study was also qualitative in nature. However, my study focuses on KSA parents of children with ASD. A quantitative approach was applied in this research to evaluate the QoL of schoolchildren with ASD and neurotypical schoolchildren in Saudi Arabia. Therefore, this research helps to enhance the stock of the phenomena under investigation and therefore makes an original contribution to knowledge.

While this lack of evidence may be due to the low reported incidence of ASD in Middle Eastern nations, more research is needed to understand the specific determinants and effects of QoL in children with ASD in this population (Algahtani,

2012). Obtaining accurate prevalence statistics has been difficult due to a lack of knowledge or empirical research on this topic in Saudi Arabia. Estimates suggest the prevalence of ASD in Saudi Arabia is 0.0018% although information on the prevalence on KSA schoolchildren is lacking (Al-Salehi et al., 2009). Therefore, this study serves to address Qol in Saudi Arabia in more details (specifically related to health issues) and fills a significant gap in the literature.

ASD remains an enigmatic subject within the Middle East due to the documented low incidence rates (Crabtree, 2007). Rates of ASD in the Middle East may be lower due to several reasons. One possibility is that knowledge and awareness of ASD is limited in this region, as research and study of the subject has been sparse throughout the region's history (Crabtree, 2007). Additionally, conceptions of mental illness also differ in this region compared to the UK (Abdullah & Brown, 2011). Although ASD is a widely recognised and documented disability worldwide, diagnostic and treatment methods for the condition have been inconsistent through different regions of the world (Abdullah & Brown, 2011).

As research has begun to develop regarding ASD in Saudi Arabia, holistic impacts of the ailment have been explored, such as the relationship between ASD and QoL in these individuals. According to Alqahtani (2012), symptom management strategies for autism and treatments are still contradictory within Saudi Arabia, and this misinformation may result in reduced QoL for patients and their support groups. This differs from Western research, which has generally found reduced QoL as a result of communication difficulties and increased stress associated with caring for the patient (Abdullah & Brown, 2011). However, Alqahtani (2012) suggests that improved education is needed amongst KSA citizens regarding the causes and physiological underpinnings of the mental disorder in order to promote the most

efficacious intervention strategies. Therefore, the current study intends to obtain insight into the factors that may improve these educational results in schoolchildren with ASD in Saudi Arabia.

#### 1.4.Kidscreen-52 instrument

Health-related quality of life (QoL) instruments are increasingly used as outcome measures in a variety of settings, including clinical research, population health surveys, and clinical practice, and in both adult and pediatric populations. Therefore, the number of instruments available has also increased; a 2008 review identified 30 generic and 64 ailment-specific instruments available for use in children and adolescents. Despite recent developments, instruments used to assess QoL in children and adolescents still show problems relating to international comparability and may not take into account different cultural perspectives during their construction (Kidscreen, 2011). However, the current study adopts the Kidscreen-52 instrument that is a generic nature, applicable in different national and cultural contexts, complies with quality standards in instrument development and is practical, short and easy to use. The instrument results in a profile describing health-related quality of life and a better understanding of perceived health in children and adolescents in Europe and thus to contribute to planning, implementing and evaluating innovations in the healthcare field (Keenaghan and Kilroe, 2008).

The Kidscreen-52 instrument was developed by a collaborative effort of European pediatric researchers to measure quality of life and well-being in children. the Kidscreen-52 has been shown to have superior reliability across differing demographic groups, and has already been adapted in more than 10 different languages with sufficient validity and reliability scores in each one (Kidscreen, 2011).

Therefore, the current study contributes to a growing body of evidence

regarding the Kidscreen-52 QoL instrument and its usefulness across cultures and settings. This is the first time that this instrument is translated into Arabic. The Kidscreen-52 contains 10 dimensions, including: physical well-being, psychological well-being, mood and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance (bullying), and financial resources (Kidscreen, 2011). The 52-item version was developed and evaluated with a sample of over 3,000 European schoolchildren, showing strong psychometric properties. These findings lend strength to the usefulness of the Kidscreen-52 within the current study, and its adaptability to different cultures and languages.

#### 1.5.Gaps in Research

Difficulties in communicating with children with ASD have also led to the delay of research evaluating QoL in this demographic group in Saudi Arabia (Alqahtani, 2012). No known studies have specifically examined HRQoL in schoolchildren in Saudi Arabia. Additionally, the majority of studies evaluating QoL or HRQoL in Saudi Arabia have been conducted with family members or caregivers. Finally, results regarding the sources of reduced QoL in children and their families differ than that of Western research in some aspects (e.g., Baxter et al., 2014). Therefore, more work is needed within this topic in Saudi Arabia and the Middle East in general.

However, research from Western cultures has demonstrated some important relationships between autism and QoL. Interestingly, a substantial portion of the research regarding this topic has been conducted with parents and family members of children with ASD (van Heijst & Geurts, 2014). Research (e.g., Shipman, Sheldrick & Perrin, 2011) demonstrates that family and friends do have reduced QoL when tasked

to care for a family member with autism. Reductions in social life, constraints on personal time and stresses associated with communication with the child with autism all contribute to this reduction in QoL (van Heijst & Geurts, 2014). Studies examining QoL in children with ASD are less abundant, as obtaining accurate and reliable self-report data from children with ASD can present logistical and methodological challenges to researchers (Shipman et al., 2011). Interestingly, some recent research that has been able to gather data on this topic has shown that children with ASD do not always experience reduced QoL (van Heijst & Geurts, 2014). Children with ASD often demonstrate similar levels of QoL as peers without disabilities, illustrating the subjective nature of this construct (Baxter et al., 2014). However, the increased social and physiological challenges that occur with autism do have the potential to impact QoL, and assessing this construct in children with ASD offers a potentially useful means by which to evaluate intervention effectiveness (Baxter et al., 2014).

#### **1.6.** Aims

The aim of this study is to obtain a better understanding of QoL of schoolchildren with ASD and neurotypical schoolchildren in Saudi Arabia. Additionally, this study aims to increase the validity for a standardised QoL instrument in Arabic for schoolchildren with ASD. Finally, this study aims to compare QoL in KSA schoolchildren with ASD with those from Republic of Ireland.

### 1.7. Objectives

The objectives of this study are threefold. First, this study translates a screening tool and uses it with KSA schoolchildren with ASD, while also comparing the instrument to mainstream children in KSA. Second, this study uses this data to seek to obtain a better understanding of QoL for children with ASD by measuring QoL is a sample of KSA children on the autism spectrum. Comparisons are made

with neurotypical children in KSA. This means that results from children with ASD and neurotypical children- are analysed based on their similarities and differences and then compared with schoolchildren from Republic of Ireland. Third, the evidence obtained from the current study can be used as a basis for informing future related studies that are interested in understanding of the effects of autism on the QoL of children. In other words, this study could act as a case example for such studies.

#### 1.8. Research Questions

This study has one main research question and two sub-questions as following:

"Are there differences in health-related QoL between school children with ASD and neurotypical children in Saudi Arabia?"

The first sub-question is "Does an Arabic-translated version of a widely used QoL instrument achieve sufficient psychometric properties?"

The second sub-question is "do KSA with ASD possess similar QoL ratings as those from Republic of Ireland?"

#### 1.9. Conclusion

The current study seeks to evaluate QoL in children with ASD and neurotypical children within the KSA school system. This study was chosen because of my employment within the special education department of a KSA university. Therefore, I received a grant to conduct a project on autism.

The KSA school system offers an interesting view of varying perspectives on autism within the public education system. The KSA school system is often segregated based on gender, with gender-matched teachers, from an early age, and much of the curriculum is based on religious traditions. Some of these differences in educational philosophy can result in differing understandings of both autism and QoL.

Unfortunately, a lack of research exists regarding autism and QoL in the KSA school system. Therefore, this study is among the first to explore these topics and provide empirical evidence of QoL variables within schoolchildren with autism and neurotypical children. Results from this study are hoped to improve understanding of autism in its relationship to QoL with schoolchildren in Saudi Arabia.

It is important to undertake a research study of this nature because autism has a significant effect on the quality of life (QoL) of the children affected. Evidently, children with ASD also have a right to receive quality education in the same way that their neurotypical peers do. Therefore, by assessing their QoL, it would be important to also determine if their legal rights and educational needs are also being met. By carrying out this study, the researcher hopes to make an original contribution to enable a better understand of autism within the educational system in Saudi Arabia.

It is hoped that an assessment of the factors related to autism in the population under investigation also shed light on the factors that impact on the QoL of children with ASD. On this, the study hopes to answer three research questions: whether an Arabic-translated version of the widely used QoL instrument can attain sufficient psychometric characteristics; whether children with ASD differ in their health-related QoL in comparison with their neurotypical peers; and if there is variation in terms of QoL scores among school children with ASD in Saudi Arabia relative to those from Republic of Ireland. Only a few studies have thus far endeavored to assess the effects of QoL on children with ASD in Saudi Arabia, pointing at an existing gap in literature that the current study seeks to fill.

While similar studies have also been conducted (e.g., Alqahtani 2012); this one was qualitative in design, whereas the current study is quantitative in design. The choice of a quantitative design enables the researcher to undertake a more focused

description of the study, in addition to conducting a more conclusive research. Moreover, unlike the qualitative study by Alqahtani (2012) that has a subjective approach on account of its qualitative nature, the current research affords objectivity to the researcher. This can ensure separation of the researcher form the subject matter, in effect minimizing researcher bias.

## 2. Chapter Two: A Review of the Literature

#### 2.1. Introduction

This literature review sets out a discussion of the debate for the screening of Quality of Life (QoL) in Saudi Arabia, including the theoretical incongruity and inconsistencies with the field of education. It then discusses both the definitions and theoretical notions of QoL, moving on to discuss the literature on QoL in relation to youth populations, and in children and adolescents with autism. This is followed by an account of health related screening for children and adolescents, and QoL in KSA youth. The review ends with a statement based on the evidence set out in this review, which supports this thesis' view that QoL screening would be important for KSA children and adolescents.

Assessing quality of life (QoL) has become an increasing concern within KSA schools, as researchers (e.g., Al-Jadid, Al-Asmari & Al-Moutarey, 2004; Robaee, 2007) have become more aware of the impact of this concept on numerous psychological and social outcomes. For example, QoL has been linked to successful identification of risk factors such as depression (Lancaster et al., 2010) and cognitive decline (Plassman, Williams, Burke, Holsinger, & Benjamin, 2010), as well as healthy growth patterns (Sabbah, Stewart & Owusu-Agyakwa, 2003) leading researchers and educators to consider implementing a regular screening for this construct for Saudi Arabia's youth. Unfortunately, some debate has persisted regarding the implementation of such programmes, as the measurement of QoL is still rife with inconsistencies and theoretical incongruence within the education field (Shye, 2010). For example, QoL is a highly subjective construct, and some have criticised the validity of such a measure for youth populations (Fairclough, 2010).

Additionally, measures of QoL that have been translated into Arabic may yield different results due to language differences (Al-Jadid, Al-Asmari, & Al-Moutarey, 2004). This research is the first research to use a standardised screening instrument to measure QoL in a sample of children and adolescents in Saudi Arabia. The 'Kidscreen' screening instrument (See Section 1.4) is translated into Arabic and administered and tested on children in schools in Saudi Arabia, with ASD and neurotypical schoolchildren. It discussed below the research supporting the view that children with ASD have an impaired QoL, for example, they are less likely to participate in social activities and more likely to miss school. If teachers are provided with the results of the QoL it may make teachers more aware of what the quality of life is like for children with ASD. With this increased level of awareness about children with ASD, teachers may be able to enhance children's QoL and improve children's educational achievements, and their general quality of life.

#### 2.2.Defining QoL

Definitions of QoL have varied greatly depending on the particular field and theoretical underpinnings of the construct. For example, researchers from the social sciences have posited that QoL consists on an individual's subjective evaluation of happiness based on five dimensions, including: "physical wellbeing, material wellbeing, social wellbeing, emotional wellbeing, and development and activity" (Felce & Perry, 1995, p. 51). This study adopted the definition of The World Health Organization (WHO) of QoL (as discussed in Chapter One), the WHO (1997) agrees that QoL is a broad ranging concept that is determined by many factors beyond just physical and psychological health. However, the vagueness of these definitions illustrates some of the difficulties researchers have faced empirically assessing this construct. Finally, research in the education field (i.e., Young, 2008) has suggested

that QoL consists of learning and education status, as well as the material comforts, psychological, physical and social health suggested by previous authors.

Such a wide range of definitions has meant that the generation of a universal and widely agreed upon definition of QoL has remained elusive, despite significant advancements in the measurement of this construct in recent years. The factors that constitute QoL are highly dependent on the field of study, as well as the demographic group of interest. Young (2008) estimates that there are currently more than 200 indicators used to evaluate QoL within different instruments and fields of study. Unfortunately, the inconsistencies existing regarding definitions of QoL have the potential to not only impact future interventions aimed at improving QoL in these fields, but also national policy designed to fund programmes that screen for this construct (Young, 2008). Further complicating existing definitions of QoL is the subjective and objective nature of this construct, which makes obtaining valid and reliable QoL measurements particularly difficult (Reininghaus et al., , 2012).

Educational researchers (e.g., Ross & Willigen, 1997; Young, 2008) have agreed that QoL has the ability to predict numerous educational outcomes, such as dropout rates and test scores. Furthermore, higher levels of education have been linked to increase QoL (Lachapelle et al., 2005). Therefore, it is clear that QoL bears several psychological and social implications for young students, and assessing this construct is of critical importance in the field of education. However, the indicators and determinants of QoL still remain somewhat inconsistent. Halpern (1993) explored QoL as a theoretical framework for exploring educational transitions, noting that QoL could potentially serve as a moderator for successful or unsuccessful transitioning between academic grade levels. However, no empirical data was collected using this model, and subsequent researchers have neglected to further pursue Halpern's (1993)

recommendations. Much of the education research (e.g., Wehmeyer & Schalock, 2001) that has drawn on QoL assessments has relied on definitions from the health and social sciences. However, educational researchers have also sought to combine QoL frameworks with self-determination theory to explain determinants of this construct on school-aged children. For example, Wehmeyer and Schalock (2001) and McDougall, Evans and Baldwin (2010) both suggested that self-determination in these populations was a key determinant of QoL, and these researchers concluded that professionals in the education field should seek to promote an atmosphere that fosters intrinsic motivation and autonomy in order to improve educational QoL. Therefore, there are a wide variety of definitions exist which include many diverse elements.

For the purpose of this thesis, the definition of quality of life that is used is a multidimensional concept that encompasses core elements that vary among individuals. In line with earlier work on QoL and self-determination, QoL will be taken to be eight dimensions, as follows: 'emotional wellbeing; interpersonal relations; material well-being; personal development; physical well-being; self-determination; social inclusion, and rights' (Wehmeyer & Schalock, 2001). However, this research uses the ten dimensions of Sieberer et al., (2006) which are considered the essential components of QoL because they are applicable in different national and cultural contexts.

## 2.3. Theoretical Contributions to QoL

The prevalence of multiple definitions of QoL stems from the varying theoretical underpinnings of this construct. Concepts of life satisfaction and happiness relate to many fields, and each one has adopted multiple theories and sub-theories to explain the determinants and consequences of QoL. One historical theory that has had

a strong influence on modern perspectives of QoL is Maslow's (1943) developmental perspective. Maslow's original hierarchy of needs, which outlines the progressive fashion in which human needs must be met in order to achieve psychosocial well-being, has helped modern researchers explain why some individuals possess a higher QoL than others, despite the absence of several seemingly important determinants. Maslow's model suggests that basic biological needs (e.g., food, shelter, safety) must be met before higher needs (e.g., love, understanding, self-actualisation) can be achieved (1943). Sirgy (1986) proposed a classic model of QoL derived from Maslow's theory, suggesting that "life satisfaction" fits within the realm of higher-order needs, and these satisfaction needs are strongly influenced by societal institutions that also exist within a hierarchical fashion. Sirgy's (1986) model has helped subsequent researchers consider the relative role physical, social, emotional and psychological health all play in determining QoL.

Ventegodt, Merrick and Andersen (2003) attempted to integrate the increasingly divergent QoL theories that existed within education, psychology and health sciences. As research expanded throughout the 1980s and 1990s, and valid instruments began to emerge assessing QoL, these researchers were able to incorporate several diverse perspectives of this construct into one integrative theory, which they termed the "global quality of life" concept (p. 1030). Although QoL differs based on a number of demographic variables, Ventegodt, and colleagues (2003) asserted that certain universal factors exist that dictate life satisfaction, largely reflecting Maslow's hierarchy of needs. Ventegodt and colleagues (2003) were also among the first to consider the difference between the subjective, objective and existential components of QoL. According to these researchers, universal subjective components of QoL include well-being, satisfaction, happiness and meaning.

Conversely, universal objective components include adherence to cultural norms, fulfilment of biological needs and realisation of one's potential. These two QoL elements then combine to determine one's existential QoL, or his or her overall happiness with life (Ventegodt and colleagues, 2003).

While Ventegodt and colleagues' (2003) integrative theory has helped researchers expand their conceptions of QoL and explore the subjective and objective elements of this construct, the model does not lend itself well to empirical research. Its lack of testable hypotheses and perhaps overly ambitious attempt to integrate perspectives from a diverse range of disciplines has led subsequent researchers to expand on Ventegodt and colleagues' (2003) model. For example, Cummins (2005) proposed a conceptual model of QoL aimed at highlighting the specific causal and indicator variables that determine this construct. According to this model, QoL is dependent upon maintaining a sense of homeostasis within one's subjective and objective QoL needs (Cummins, 2005). Imbalances result in reduced QoL, while achieving an optimal balance is likely to improve QoL and lead to higher levels of satisfaction and happiness (Cummins, 2005).

Bakas and colleagues (2012) conducted a recent systematic review of existing QoL models, seeking to identify the most frequently cited in empirical research, as well as to critically analyse their efficacy. Based on 100 studies that met inclusion criteria, it was determined that Ferrans and Power's (1992) individual and environmental health-related QoL model was the most holistic and valid framework for conceptualising this construct. Though not as frequently cited as other models, Bakas and colleagues (2012) found that Ferrans and Power's (1992) model was superior because of its ability to depict causal associations between QoL variables, more effectively lending itself to intervention designs. As designing effective QoL

interventions is a critical next step in QoL research, Bakas and colleagues (2012) suggested that such a model would yield the most promising results in future research. Thus, it seems that an intervention could help improve QoL and lead to higher levels of satisfaction and happiness.

QoL has not been studied as extensively in education as it has in health or other social sciences, thus, the context-specific theories of QoL in this field are lacking. However, based on the assumptions of Maslow's (1943) and Sirgy's (1986) models, it is evident that learning has a key influence of QoL. According to Maslow (1943), the need to understand one's environment and surroundings is a higher-order need that is only fully achieved by a small percentage of the population. Furthermore, Sirgy (1986) views education as a social institution that helps fulfil a key subjective QoL need. The role of education in social and economic advancement is clear, and the opportunity to adapt existing theories, or develop new ones, specifically within the field of education is abundant (Paro et al., 2010). Nevertheless, little is known about QoL in education or the social, emotional and psychological determinants of this construct for school-aged populations. This doctoral research attempts to bridge the gap in education by providing the first translation of Kidscreen in the Arabic language, for assessing of school age children and adolescents in Saudi Arabia. The lack of research in education has detracted contemporary educators from designing efficacious QoL screening methods and interventions in schools. Therefore, this research assesses the QoL of both children school with ASD and neurotypical children school in KSA. The next section discusses the QoL for both children with ASD and neurotypical children.

#### 2.4. QoL in Children and Adolescents, Including those with Disability

Recent efforts to assess QoL in children have proven relatively fruitful, with a plethora of empirical studies (e.g., Tsiros et al., 2009; McDougall et al., 2010; Ravens-Sieberer et al., 2010) emerging within the past decade pertaining to this demographic. For example, McDougall and colleagues, (2010) examined QoL in a group of 34 school-aged children, specifically seeking to evaluate the role of self-determination in moderating long-term life satisfaction. Results from this study demonstrated that those with higher levels of self-determination experienced higher perceptions of life satisfaction, personal development and personal fulfilment over a one-year period. Furthermore, Griffiths et al. (2010) demonstrated that higher levels of QoL predicted increased self-esteem, psychological coping skills and social functioning in school-aged children. Results from this study led these researchers to advocate for school-based assessment and intervention aimed at improving QoL (Griffiths et al., 2010).

While these researchers have advocated for QoL-based screenings and interventions, empirical studies assessing the impact of these objectives are less abundant. The majority of studies (e.g., Tsiros et al., 2009; Ravens-Sieberer et al., 2010) examining QoL in children and adolescents have explored physical health outcomes, while generally omitting the role of this construct in education. Those studies that have examined QoL in education have generally focused on schoolchildren with specific learning disabilities or cognitive disorders. For example, Hintermair (2011) examined health-related QoL in deaf students, and how this disability impacted these students' social functioning in the classroom. As can be expected, deaf children were shown to exhibit reduced QoL. However, this study also revealed that participation in social activities was a significant buffer to this reduction

in QoL, leading Hintermair (2011) to recommend a socially based QoL intervention for students with learning disabilities. Danckaerts and colleagues (2010) also explored QoL in students with attention deficit/hyperactivity disorder. Drawing on a systematic review of 36 QoL studies that met inclusion criteria, these researchers concluded that this learning disability severely hindered QoL in these students, which subsequently had a negative impact on learning outcomes. Therefore, it appears that learning disabilities themselves may only be partially responsible for negative academic performance, as reductions in psychological and social QoL factors contribute as well (Danckaerts et al., 2010). To the best of my knowledge, very little research has been done investigating whether and to what extent low QoL influence learning results of children with ASD. Many of the studies below have also neglected the role of the construct in education in improving QoL or determining QoL in children or adolescents.

The implications of these recent studies on youth are fairly intuitive. As numerous studies have demonstrated the positive health and educational impacts of QoL (Mcdougall et al., 2010; Hintermair, 2011) as well as the negative consequences of low QoL (Lancaster et al., 2010; Danckaerts et al., 2010), it appears worthwhile to intervene in the public education system in an effort to assess and improve this construct. However, a number of gaps in the literature still remain regarding the assessment of QoL in children. In addition to the inconsistencies regarding definitions and dimensions of QoL described above, there is also a high degree of variability regarding the instruments used to measure QoL in children (Griffiths, Parsons, & Hill, 2010). Many of the leading QoL instruments, such as the MacNew Health-Related QoL Instrument (Lim, Hofer, Guyatt, & Oldridge, 2004) and the Minneapolis-Manchester Quality of Life Instrument (Bhatia et al., 2004), have yet to be adapted to

youth populations, or suffer reduced psychometric strength when they have been adapted, leading to some speculation about the validity of school-based QoL studies. The benefits of evaluating this construct are clear, but understanding the specific factors that determine QoL in youth, as well as the most effective strategies for improving this construct in school-aged populations, such as those in Saudi Arabia remain unknown, therefore making this research an important contribution to knowledge. The following section discussed QoL in individuals with disabilities.

### 2.5. QoL in individuals with disabilities

QoL has also been shown to be an important predictor of improved outcomes in individuals with psychological or behavioural disorders. For example, Danckaerts et al. (2010) reviewed studies examining QoL outcomes in children with attentiondeficit hyperactivity disorder (ADHD). This is a key study, which is based on a review of 37 independent studies utilising QoL as an outcome variable, results showed that QoL has a strong positive relationship with ADHD demonstrating that ADHD reduced QoL, while improving QoL dimensions resulted in improved ADHD variables. This appears to indicate that either a uni-directional or a bi-directional relationship exists between these variables, although this study fails to provide causal evidence. Similar results were found when researchers explored the relationship between obesity and QoL. Perceptions of reduced physical competency and reduced self-esteem associated with obesity were associated with significantly reduced QoL (Griffiths, Parsons & Hill, 2010). Conversely, improvements in competency resulted from emphasising QoL variables in weight-loss efforts for obese children (Griffiths et al., 2010). These results show that QoL plays a key role in the psychological, social and physiological well-being of individuals both with and without physical or psychological disorders. The next section discusses a specific type of QoL that has received attention in recent empirical research.

## 2.6. Health-Related QoL

Health-related QoL (HRQoL) is an individual component of QoL that is oriented specifically toward those physiological aspects of well-being, such as being free of ailment and illness (McDougall et al., 2013). HRQoL is also a multidimensional construct that is used to track public health data (McDougall et al., 2013). HRQoL is associated with unique determinants that make this concept more targeted than general QoL (McDougall et al., 2013). On the individual level, correlates of HRQoL include health risks and conditions, physical functionality, level of social support and socioeconomic status (Centers for Ailment Control and Prevention, CDC, 2014). HRQoL has been an important concept to understand for public health researchers, as tracking this data allows for broad trends in ailment; mortality and morbidity can be predicted based on the prevalence of this concept of well-being (CDC, 2014).

Based on this evidence, there appears to be a bidirectional relationship between measures of QoL. The presence of QoL appears to be associated with improved health outcomes, while improved health outcomes are associated with higher levels of QoL. While HRQoL is clearly linked to the physiological aspect of well-being, this construct is also correlated with social and psychological well-being (Pucci et al., 2012). Researchers have also demonstrated that improvements in HRQoL were associated with significantly higher psychological and social well-being (McDougall et al., 2013). Therefore, targeting HRQoL appears to offer significant advantages beyond just physical well-being (McDougall et al., 2013). While all aspects of QoL are subjective due to personal standards of what constitutes well-being, these individual concepts of well-being and QoL are critical outcome variables

for interventions due to their effect on multiple dimensions of health. Therefore, it is important to recognise that although, health related QoL has been shown to be relevant to individuals with disabilities in the general sense and next section will look at this specifically to individuals with autism.

#### 2.7. HRQoL and Autism

HRQoL may also offer an efficacious means by which to explore the views of individuals with autism about the quality of their own lives. In order to do so, it is important to define what is meant by autism spectrum condition. There is no specific definition for autism, as this condition existing on a spectrum, with various levels of severity representing differing symptoms (American Psychiatric Association, 2014). According to the National Institute of Neurological Disorders and Stroke (2014), autism spectrum disorder is a range of complex neurodevelopment disorders, characterised by impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior (NINDS). Autism and related autism spectrum disorders are complex and enigmatic conditions that are characterised by impairments in social interactions, communication and regular daily functioning (Allik, Larsson & Smedje, 2006). Autism is also associated with repetitive behaviours or thoughts that can often lead to exceptional ability at one or a few tasks (Allik et al., 2006). However, the intense engagement in repetition typically prevents individuals with autism from functioning socially (Lee et al., 2008). For children with ASD or autism spectrum disorders, this lack of social functioning can be particularly debilitating as the socialisation process is a critical component of psychosocial development (Lee et al., 2008). Instead, children with ASD are often isolated from their peers and depend on family members for social support (Lee et al., 2008). Therefore, these inherent difficulties with the condition of autism can have a significant impact on an

individual's quality of life. HRQoL has been shown to be lower in individuals with autism and similar conditions (Sauerwein, 2001). The impaired social functioning may serve as the biggest detractor from HRQoL in these individuals, although physical and psychological well-being may be affected by the condition (Sauerwein, 2001). QoL is important assessment for individuals with disabilities and in particular in those with autism. However, the sparse research literature that has been done on this topic to date has mainly focused in the western world. There is very little that is looking at this in the Middle Eastern Nations which is an important gap in the research literature and the focus of the next section.

#### 2.8. QoL and HRQoL in Middle Eastern Cultures

Measuring QoL has increased in importance within Middle Eastern nations as researchers have recognised the impact this state has on student's psychological and social well-being (e.g., Al-Jadid, Al-Asmari & Al-Moutarey, 2004; Robaee, 2007). Additionally, QoL appears to have a direct impact on positive educational outcomes in young students (Sabbah, Steward, & Owusu-Agyakwa, 2003; Plassman, Williams, Burke, Holsinder, & Benjamin, 2010). In Western research, QoL has been identified as a significant predictor of positive educational outcomes in children with ASD as well (Billstedt, Gilber, & Gilberg, 2011). Definitions of QoL vary widely between studies, although this construct has been shown to predict positive educational outcomes (Samadi, 2011). Although the constituents of QoL differ between researchers and disciplines, the concept that psychological, social and physical well-being result in improved academic performance has been well documented (Johnson, Beitchman & Brownlie, 2010; Samadi, 2011). The underpinnings of this relationship are not entirely clear, although there may be both physical and emotional links between QoL and educational performance. For example, positive social relationships

may improve confidence, affect, and relieve stress (Samadi, 2011). There is also evidence that such social support and general positive affect throughout life facilitates improved cognitive aptitude (Johnson et al., 2010). In other words, receiving support from family and friends can result in greater happiness and improved academic performance. The following section will discuss the assessment of QoL in children and adolescents with autism.

## 2.9. QoL in Children and Adolescents with Autism

Assessing QoL in children with ASD has become a topic of interest in recent years. This dissertation is specifically interested in assessing the QoL in children and adolescents with autism in Saudi Arabia. The research discussed below indicates that children with ASD experience poor QoL in various dimensions of their lives, including in their education. This research aims to make the finding of the assessment of QoL in children and adolescents with autism in Saudi Arabia available to teachers to enable them to intervene in their pupils lives to help to develop and enhance the children's quality of life in Saudi Arabia. Previous studies (e.g., Lee et al., 2008) have demonstrated that both children with ASD and their families experience impaired QoL in several traditional domains. Within the educational realm, Lee and colleagues (2008) showed that children with ASD were much more likely to miss school, and were less likely to participate in social activities than counterparts without autism. Furthermore, parents of children with ASD often have some aspect of emotional stress and impaired coping abilities, compared to parents of neurotypical children (Lee et al., 2008). Therefore, it is clear that assessing QoL is important to understanding this issue in order to develop strategies for improving children's with autism psychosocial well-being, as well as their academic performance.

Kuhlthau and colleagues (2010) examined data from 286 children with ASD, collected by the Autism Treatment Network, to evaluate the role of QoL in this disorder. Results showed that those children with ASD experienced significantly reduced QoL scores than neurotypical children. Furthermore, children with ASD boasted lower QoL scores than children with other chronic conditions. Interestingly, these results remained consistent across psychosocial, emotional and social components of QoL, but did not impact school functioning. Based on these results, Kuhlthau and colleagues (2010) speculated that behavioural patterns associated with autism that disrupted typical social and emotional interactions may not necessarily disrupt academic outcomes. Smith, Greenberg and Mailick (2014) achieved similar results in a study of the family context of autism and QoL. According to these researchers, psychological and emotional stress served as a significant moderator of QoL in children with ASD, in which case the family environment plays an important role in the social and cognitive functioning of these individuals.

QoL in children and adolescents with autism may be influenced by whether or not participants complete the self-report by themselves, or with the help of a parent or guardian. In a study of 30 high-functioning children with ASD and 30 healthy peers, Potvin, Snider, Prelock, Wood-Dauphinee, and Kehayia (2013) found that health-related QoL in school-aged children with high-functioning autism was generally poorer than counterparts without autism. However, QoL was significantly higher in high-functioning children with ASD when completing the instrument with a parent report than when completing the instrument as a self-report. These findings are revealing of the inability for current instruments to validly capture the subjective nature of QoL in youth with autism, as well as the potential limitations of previous studies utilising parental reports (Potvin et al., 2013). The reasons QoL impacted

when children completed the report by themselves was not immediate clear to these researchers, but may indicate the significance of the role of family members in buffering some of the psychosocial challenges associated with autism or a potential difficulty in understanding the questions posed.

Though recent research regarding QoL in children with ASD is promising, numerous gaps remain in this line of inquiry as well. The novelty of assessing QoL in children with ASD has prevented the ability to draw any strong conclusions about this construct's role in improving educational outcomes, or how to most effectively intervene with children with ASD in the academic environment. Furthermore, the subjective nature of QoL presents further problems in measuring this construct in children with ASD, who face severe deficiencies with respect to expressing themselves emotionally and subjectively evaluating their emotional experiences (Legisa, Messinger, Kermol, & Marlier, 2013). More efforts are needed to understand the QoL experience in youth with autism, how to validly assess this construct in populations with autism and how to most effectively intervene to improve educational functioning in children with ASD. This research explores the efficacy of a screening instrument that may be used as a guide for improving educational outcomes for children and adolescents with autism, since it fills the gap in the literature by measuring this construct in children with ASD in Saudi Arabia. The QoL screening instrument has also been used for other health conditions in addition to autism.

## 2.10. Health-Related QoL Screenings for Children and Adolescents

In addition to children with ASD, screening has been used for a number of other conditions. A number of studies have attempted to conduct health-related QoL screenings for children and adolescents with various conditions. For example, Varni and colleagues (2005) conducted a QoL intervention to determine the degree to which

youth populations with cerebral palsy could validly self-report their psychosocial well-being using a widely used QoL inventory. Results from this study demonstrated that just 47% of the 148 participant's sampled reported valid and reliable QoL scores in re-tests. This study confirms the findings of previous researchers (e.g., Griffiths et al., 2010) regarding the challenges of screening for QoL in youth populations, particularly when faced with a chronic health condition. Those participants with cerebral palsy who could self-report demonstrated generally lower health-related QoL than their healthy counterparts, which illustrates the increased need, particularly in Saudi Arabia where such screening has been neglected for adapting instruments that specifically identify QoL determinants for relevant health outcomes.

Solans and colleagues (2008) performed a systematic review of health-related QoL measurements in children and adolescents up to 19 years of age. Locating 51 studies that met inclusion criteria, authors of this study discovered several common flaws existing within frequently used instruments. For example, less than 50% of the health-related QoL instruments used in mainstream research had conducted sufficient test-retest stability analyses, while just 67% empirically tested the instrument's internal consistency. Furthermore, just five of the 51 studies evaluated the instrument's criterion validity; 15 assessed structural validity; and 14 tested change-sensitivity. Only 26% of the health-related QoL instruments were needs-based and adapted to the specific health condition of the population being tested. On a more positive note, the majority of instruments had been subjected to construct validity tests, suggesting that the instruments did capture the QoL experience of the sample populations (Solans et al., 2008). However, the lack of health-condition-specific measures and the failure to include adequate validity and reliability testing is alarming and illustrates a critical need for future research in this area. Very few studies have

explored health-related QoL in children with ASD, as noted above and the difficulty associated with assessing the subjective components of this construct is potentially exacerbated by the inadequate instruments available (Griffiths et al., 2010). Instead of adapting versions of instruments designed for adults, it is critical to incorporate children and adolescents from the beginning of the assessment process (Solans et al., 2008).

Shipman, Sheldrick and Perrin (2011) conducted a recent study seeking to examine the reliability and validity of self-report QoL screenings in adolescents with autism and autism spectrum disorders. Drawing on the same instrument as Solans and colleagues (2008), the Pediatric Quality of Life Inventory (PQLI), these researchers screened 30 adolescents with autism and autism spectrum disorders, as well as their parents. As expected, adolescents with autism and autism spectrum disorders, as well as their parents, reported reduced QoL across all domains of the instrument, illustrating the need for health-related QoL interventions. Interestingly, these researchers also achieved slightly better validity scores than Solans and colleagues (2008). While this evidence appears to indicate that adolescents with autism are able to validly report subjective QoL scores, the small sample and poor psychometric properties of the PQLI, warrant future empirical study. Hence, the current research assesses and helps to increase validity 'Kidscreen-52' instrument with its 10 dimensions in Saudi setting, especially, unlike the PQLI assessment questionnaire which only assessed 4 dimensions of QoL, consisting of physical, emotional, social and school functioning. It is expected that this research provides more comprehensive and informative data to analyse as a result. The 10 items are discussed in full in Chapter 3, the Methodology for the research. Arguably, the QoL cannot be adequately measured by the use of 4 dimensions, since this can restrict the scores on a QoL screening test.

## 2.11. QoL Screenings in Saudi Arabia

The assessment instrument to be used in this research is an instrument called Kidscreen. This is the first time that this instrument has been translated into Arabic and used to assess children with ASD in Saudi Arabia.

Based on the promising research related to the economic and health-related implications of QoL, KSA researchers have begun to explore this construct in greater depth. Studies have emerged assessing the role of QoL among adolescents with sickle cell ailment (Amr, Amin & Al-Omair, 2011), vitiligo and psoriasis patients (Al-Mubarak, Al-Mohanna, Al-Issa, Jabak, & Mulekar (2011), haemodialysis patients (Al-Jumaih, Onazi, Binsalih, Hejaili, & Al-Sayyari, 2011) and a range of other health conditions. While the majority of research on QoL in Saudi Arabia has related to medical and health issues, a handful of studies (e.g., Al-Dabal, Houra & Makki, 2010; Kheir et al., 2012) have also emerged regarding QoL in education. However, no known studies have specifically examined the impact of screening for QoL in schoolaged children, nor have any examined the impact of QoL on KSA youth with ASD. Thus, this research makes a significant contribution to educational research in KSA specifically in relation to the impact of assessment of QoL and the impact of QoL in children and adolescents with autism. This research fills the gap in the since it is a new instrument for assessing KSA children and adolescents and it adds to the literature in this field. Furthermore, as previous research (i.e., Herman, Hopman & Craig, 2010) has suggested that QoL possesses a strong sociocultural component, and understanding the unique social and cultural makeup of KSA youth has the potential to greatly expand current knowledge on QoL.

Al-Mubarak and colleagues (2011) confirm that the cultural traditions of Saudi society are different than the Western world in some aspects, and the determinants and impacts of QoL are likely to be different as well. Evidence exists to suggest that familial and social status, as well as socioeconomic status, play a more significant role on QoL than individual psychological and emotional factors within Saudi society (Al-Kandari & Gaither, 2011). Attempts to adapt existing instruments (e.g., McGrath, Alhhatib, Al-Munif, Bedi, & Zaki, 2003; Brown & Al-Khayal, 2006) to Arabic have proven somewhat successful and have generated promising external validity and reliability scores. However, these studies are also not without their faults. For example, McGrath and colleagues (2003) attempted to translate and validate an Arabic version of the UK oral health-related QoL measure (OHRQol). While the adapted version demonstrated sufficient construct and criterion validity, as well as internal consistency, this study failed to account for change-sensitivity, which is a strong indicator of the instrument's ability to effectively capture the same meanings from one language to the next (Fairclough, 2010). Brown and Al-Khayal (2006) similarly attempted to translate the child oral-health-related QoL instrument (CPQ 11-14) from English to Arabic. Results demonstrated sufficient construct validity and internal consistency, but all other measures of validity were omitted, providing little indication of the adapted instrument's applicability to the Saudi population.

Finally, there remains limited data on QoL in Saudi Arabia's youth populations, and little is known about how QoL is perceived differently within the KSA education system. This lack of research especially holds true for youth with autism in Saudi Arabia, in which there are no known peer-reviewed studies existing related to this topic. Mostafa (2011) estimates that autism exists in about 1.4 cases per 10,000 children in the Arab world, although no known statistics could be located

specifically for Saudi Arabia. Considerably lower than the 1.1% autism rate in the UK (The National Autistic Society, 2013), it is evident that this disorder still afflicts thousands of Saudi children. The perceptions of the causes and consequences of autism in Saudi Arabia may be different than those in the UK, and context-specific QoL instruments are needed to explore how to improve the psychosocial well-being and educational performance of these individuals (Mostafa, 2011). The lower incidence of autism and autism spectrum disorders in the Arab world may also contribute to reduced awareness of these conditions, thus, exacerbating the impaired QoL these children have (Mostafa, 2011). Future efforts are also clearly needed to explore the determinants of QoL in KSA youth, as well as to develop interventions specifically designed to target this construct in KSA schoolchildren with ASD.

#### 2.12. Discussion

QoL has become an important construct within the health and social sciences within recent years due to the associated physical, psychological, social and cultural advantages of improving its associated determinants (Danckaerts et al., 2010). While research has grown substantially with respect to health-related QoL, education has lagged in its assessment of QoL determinants, its design of context-specific instruments to evaluate QoL variables in youth and its efforts to design interventions to increase QoL in student populations. While there has been some research (e.g., Ross & Willigen, 1997 Wehmeyer. & Schalock, 2001) to suggest that enhancing QoL can improve educational outcomes, little empirical data exists to support this assumption. Higher levels of education are associated with improved QoL, providing some promising preliminary data to support the role of QoL screenings in schools (Ross & Willigen, 1997).

As a result of the contributions health sciences have made to current understandings of health-related QoL, KSAresearchers have begun to consider the impact of such screenings within the education system. While no known empirical data could be located to determine the efficacy of such attempts, recent translations of health-related QoL instruments into Arabic have proven relatively successful (Sayah, Ishaque, Lau, & Johnson, 2013). Considerably more work needs to be done to adapt these instruments to youth populations, as well as to ensure that such instruments maintain the same validity and reliability ratings as their English versions (Danial-Saad, Weiss & Schreuer, 2012).

Furthermore, the cultural and social differences that exist between the UK and Saudi Arabia, particularly within the education system, likely warrant the design of novel instruments specifically aimed at Saudi school populations (Sayah et al., 2013). Existing health-related QoL instruments have been criticised for their lack of several forms of validity, which are exacerbated when translated to alternative languages (Griffiths et al., 2010). Similarly, several of the leading child-based health-related QoL instruments have been adapted from adult versions, leading Griffiths et al. (2010) and Fairclough (2010), to criticise their efficacy in assessing QoL determinants in youth. Prior to screening for health-related QoL in KSA children and adolescents, researchers must be sure that their instruments truly capture the construct attempting to be measured.

Finally, many of the problems that exist with current health-related QoL instruments may be further compounded when screening for this construct in children with ASD (Kuhlthau et al., 2010). Research (e.g., Lee et al., 2008; Kuhlthau et al., 2010) is equivocal regarding the ability of children with ASD to validly and reliably report subjective aspects of QoL, and further research efforts are needed before

educational professionals can confidently screen for these outcomes in schools. Assessing QoL in children and adolescents with autism is a complicated matter that appears to be impacted by a variety of individual and familial factors. The suggestion that self-report ratings of health-related QoL change when completing the form in the presence of a parent- or guardian-proxy versus individually suggest that existing instruments may be insufficient (Potvin et al., 2013). It is widely understood that children and adolescents with autism, as well as their families, are shown to have a reduced QoL (Lee et al., 2008; Potvin et al., 2013). However, the degree to which this construct can be improved is of critical importance to educational professionals, thus, efficacious instruments for screening for this variable is essential (Potvin et al., 2013). With the low documented prevalence of autism and autism spectrum disorders in the Arab world, there is some degree of ambiguity surrounding these conditions within public schools (Mostafa, 2011). The design of valid instruments targeted specifically for children and adolescents with autism may help shed light on how to best intervene for those affected by autism in the Arab education system.

Based on the evidence presented in this review, it appears that screening for health-related QoL is a worthwhile pursuit for KSA educators. However, much work needs to be done before these professionals can confidently identify the determinants and consequences of health-related QoL in school populations. This need is even greater with children and adolescents with autism. The lack of context- and demographic-specific instruments, potential language and cultural barriers when using adapted instruments and problems with children with ASD reliably completing subjective QoL self-reports are some of the key areas in which future research is needed.

#### 2.13. Conclusion

The purpose of this review of literature was to critically analyse existing research related to QoL, particularly emphasising the potential role of QoL to be used as an assessment method in Saudi Arabia. Definitions of QoL were first presented, followed by a discussion of the theoretical contributions to current conceptions of QoL variables. Contemporary research related to QoL in children and adolescents was then reviewed, as well as children and adolescents with autism. Consideration was then given to health-related QoL screenings and the efficacy of existing programmes seeking to achieve this goal. While little research exists regarding QoL in KSAchildren and adolescents, a handful of authors have begun to explore this outcome in more depth. This research was reviewed, as well as the potential efficacy of assessing QoL in Saudi children and adolescents with autism. Discussion then focused on the merit of conducting a health-related QoL screening for children and adolescents in Saudi Arabia.

While the potential value of conducting such screenings is without question, much work needs to be done before researchers can confidently and validly assess health-related QoL in youth populations. Existing QoL instruments possess a number of psychometric problems, which are potentially exacerbated when utilising adapted versions for youth and populations with autism. Future research is needed to establish new context- and demographic-specific instruments that reliably and validly capture health-related QoL in these respective sample groups. Furthermore, QoL instruments that are adapted from English to Arabic may also have reduced psychometric properties, and research is needed to develop original Arabic instruments that do not risk omitting subtle linguistic and cultural idiosyncrasies. The establishment of such instruments will assist future researchers in effectively conducting health-related QoL

screenings, leading to the development of evidence-based interventions for improving this construct in youth populations both with and without autism.

# 3. Chapter Three: Overview of the Kingdom of Saudi Arabia

## 3.1. Introduction

This chapter provides an overview of the essential background knowledge relating to the Saudi Arabian context. It starts with shedding light on general information about Saudi Arabia and an historical perspective on the education system. The discussion then becomes more focused on the area of development of special education in Saudi Arabia. After that the chapter discusses the special educational needs policies across the KSA. Finally, the chapter concludes with discussing the current provision for children with autism in Saudi Arabia.

# 3.2. Overview of the Kingdom of Saudi Arabia

The Kingdom of Saudi Arabia (KSA) was established in the 1932, when Ibn Saud conquered the majority of the Arabian Peninsula after a bloody war that lasted three decades (World Factbook, 2010). It is located in the southwest of the Arabian Peninsula and is bordered on the west is the Red Sea and on the north by Kuwait, Iraq, and Jordan and on the east by United Arab Emirates, Bahrain, the Arabian Gulf Sea and Qatar,. On the south are Yemen and Oman and. KSA dominates the Arabian Peninsula in terms of land area, having over two million square kilometers of land. According to a census conducted in 2004, there is more than 22 million people live in Saudi Arabia, The geography of Saudi Arabia ranges includes desert, plains and mountains, plains. The temperature varies from over one hundred degrees Fahrenheit

in daytime to well below 30 degrees on a cold desert night. Riyadh is Saudi Arabia's capital (Royal Embassy of Saudi Arabia, 2010).

The KSA economy is driven by oil. The country has more oil than any other nation; some experts estimate that KSA has one fourth of the world's total reserves. Most of its economy is based on the collection and refining of oil products like kerosene or gasoline. In addition to oil resources, the KSA starts to look to other natural resources to boost its income, such as natural gas, minerals, and precious metals (Royal Embassy of Saudi Arabia, 2010).

The Kingdom of Saudi Arabia is a theocratic monarchy. It is ruled over by a royal family, which rules according to the Quran's teachings of Sharia based on Islamic religious law. By far the dominant religion in KSA is Islam. Under Sharia law, certain rights are applied to all people, such as life, dignity, and education (World Factbook, 2010).

# 3.3. The Saudi Education System

The education system of Saudi Arabia has been founded 78 years ago and has witnessed a dramatic evolve (Royal Embassy of Saudi Arabia, 2010). In the beginning, education was the privilege mainly for children of wealthy families and elite. Currently, the education system in KSA has a boom in education facility construction, with more than twenty-five thousand schools built. Now, education is available to all children and tiers of society.

The curricula are a mix of traditional Islamic religious education and lessons in many other fields, usually based on the curricula of schools in the United Kingdom or the United States of America. The schedule of these schools is usually modelled on the American system, with nine to 10 months of schooling broken by summer breaks and occasional time off for religious holidays (World Factbook, 2010).

MoE is responsible for providing an appropriate and free education for all children, including children with ASD. The Ministry of Education is also the main responsible for maintaining old schools and establishing new schools. It also provides and develops curricula, establish training programs to in-service teachers, and offers adult education literacy (Ministry of Education, 2008). This ministry also is responsible for special education services to schoolchildren with disabilities. There is where eligibilities for these services are established and special education services are provided in order to help schoolchildren with disabilities be able to live independently and safely (Al-Mousa, Al-Sartawi, Al-Adbuljbbar, Al-Btal, & Al-Husain, 2006).

# 3.3. Regulations of Special Education Programs and Institutes (RSEPI)

It is beneficial to mention that Saudi Arabia signed the United Nations' Convention for children with special needs. The United Nations' recognised the importance of the rights of children with special needs and its Convention states these rights in several articles in the International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.

Recently, KSA has witnessed a huge improvement in special education services, which lead to establishing regulations that guarantee rights for people with disabilities, increasing the quality of special education services, and educating professionals who are qualified to provide these services. Furthermore, a Ministry of Education reviewed the United States' special education policies, including the Education for all Handicapped Children Act (EHA) in 1975 and Individual with Disabilities Education Act (IDEA) in 1990. The Regulations of Special Education

Programs and Institutes (RSEPI) were modelled after those U.S. policies and introduced in 2001. The first regulations for schoolchildren with disabilities in Saudi Arabia, RESPI outlines rights and regulations for schoolchildren having disabilities in the Saudi Arabia and requiring special education services. The RSEPI defines the main categories of schoolchildren with disabilities; mental retardation, learning disability, deafness, blindness, and multiple disabilities, as well as tasks for professionals who work with these schoolchildren. It also describes an individual education program (IEP), elements of an IEP, and individuals who should participate in planning and providing an IEP. The RSEPI includes procedures of assessment and evaluation for schoolchildren to determine if they are eligible for special education services. Under the RSEPI, all children with disabilities are entitled to a free and appropriate education, individual education programs, early intervention programs, related services, and transition services. The RESPI also specifies how schools must provide these services to schoolchildren with disabilities. Thus, RSEPI supports the quality of the special education services in Saudi Arabia.

In summary, these policies support the equal rights of individuals with disabilities in obtaining free and appropriate education. They are applied in the main cities mainly like Makah and Riyadh. In fact, the lack of the effective implementation has created in a gap between the framework of these laws and the provision of services, resulting in a lack of special education services for some children with disabilities in small cities (Al-Quraini, 2010).

# 3.4. The Beneficiaries from Special Education Services

The General Secretariat of Special Education Needs recognised the beneficiaries of the special education program policy as being students with autism, learning difficulties, mental disability, deafness, blindness and mixed disabilities (Al-Mousa, 1999). Moreover, the Secretariat also included students who were talented and gifted as beneficiaries of the program of policies. Al-khashrmi (2000) confirmed that: 'All students with special education need to have the right to be learning at general schools with their peers... learning for those students who are gifted and talented and those who have disability forms an integral part of Saudi policy in various types of inclusive education.... there is recognition that Students with special needs constitute at least 20% of the school population. The mainstream schools are the natural place for learning students with special education needs '(p.152).

As stated above the children within these types are entitled to appropriate services and programs specifically designed to meet the special needs of students in mainstream schools, and this includes teaching methods, tools and equipment, as well as support services and specialists (Ministry of Education, 2001; section 76).

# 3.5. Current provision for children with autism in Saudi Arabia

In terms of the educational placements that are available in public schools, children with autism are being referred to centres for those with severe learning difficulties, regardless of their intellectual ability or their different needs. In terms of the private sector, there are a few centres that specialise in autism in the major cities, and they seem capable of meeting the special needs of these students. They have specialists and experts in the field who are able to work effectively with children, and their parents, from an early age through adulthood. They adopt many approaches and

interventions and mainly use the Treatment and Education of Autistic and related Communication handicapped Children (Division TEACCH) as the foundation for their educational programmes.

With regard to the educational approaches used in schools and units, schools adopt a number of interventions and approaches (e.g. daily life therapy, music therapy and diet). These approaches are influenced by the experience and expertise of the staff in the school and the visits of professionals such as physiotherapists, occupational therapists and speech and language therapists. Finally, all schools, mainstream schools and special schools, follow the national curriculum (Jordan, 1998). However, Al-masoud (2010) confirmed that there is an extra need for increased training of teachers in Saudi Arabia, along with the need for increasing government initiatives. In addition, enhancing diagnosing services is strongly required, especially to identify students who have high functioning autism in order to provide them with the correct support. It is also necessary to provide appropriate educational placements depending on the severity of the condition and to adopt the best possible interventions and educational approaches in order to meet the special needs of these students and to provide an inclusive educational environment for them.

Currently, the vision of the Ministry of Education in KSA in including and supporting Saudi schoolchildren with autism is to provide services, educational programmes and excellent provision. These educational programmes can help in meeting the unique needs of children with autism. The Ministry of Education has a strategic plan (2012-2016) that aims to provide high standards in teachers' performance, admission, diagnosis, management, appropriate education environments and services and mutual support with other partners globally (Al-masoud, 2010). The plan also includes development according to Islamic values and principles, for

example professionalism, teamwork, equality, high performance and solidarity. The Ministry aims to accomplish high standards globally in autism programmes and achieve a satisfactory performance in terms of the rights of schoolchildren with autism to provide high-quality education by the end of 2016 (Al-masoud, 2013).

## 3.6. Conclusion

This chapter has examined key aspects of the context in which the present study was carried out, attention given to the general information about Saudi Arabia and education of children with special needs and more particularly to autism education in the country. Also, this chapter has discussed the special school settings and the inclusive education movement in Saudi Arabia. In addition, the initiatives mentioned show the government's seriousness and effort in developing special education for children with autism in Saudi Arabia, nonetheless, even with all these initiatives and attention, more is needed.

# 4. Chapter Four: The Methodology

## 4.1. Introduction

The research question directs this study to measure Quality of Life (QoL) in schoolchildren with ASD and neurotypical schoolchildren in Saudi Arabia. This chapter explores the theoretical underpinning, research methodology and research methods. It also describes the sample and investigates validity and reliability. Finally, a throrough investigation of research ethics and ethical consideration is explored. This study employs a quantitative approach. The quantitative component consists of the instrument translation and standardised assessment of QoL in KSA schoolchildren. This method is selected due to the need to empirically and objectively evaluate QoL in KSA schoolchildren as well as compare this dataset with pre-existing samples, such as that of the Kidscreen data collected amongst European schoolchildren. The purpose of this study is to observe and compare trends across a large sample of individuals. The rationale and approach taken in this study is presented in detail below.

## 4.2. Theoretical Framework

Once again, the research questions in this study include one main question and two sub-questions. This study mainly aims to inquire if there are differences in health-related QoL between schoolchildren with ASD and neurotypical schoolchildren in Saudi Arabia. This study also seeks to ask the following two sub-questions; first, "Does an Arabic-translated version of a widely used QoL instrument achieve sufficient psychometric properties?". Second, "Do KSA schoolchildren with ASD show similar QoL scores as schoolchildren from Republic of Ireland?"

This study employs a quantitative approach, characterised by an objective and subjective ontological perspective. The main research question is quantitative because

the aim is to quantify the QoL differences between KSA schoolchildren with ASD and neurotypical children. The first sub - research question is quantitative because the aim is to quantify the psychometric properties of the newly translated QoL instrument. The second sub- question also aims to quaintly the factors that determine QoL in KSA schoolchildren with ASD comparing with those from other countries and Republic of Ireland. Based on the nature of these research questions, a quantitative approach is selected.

This ontological perspective posits that knowledge can be shared amongst individuals, and that an objective reality exists that can be defined and measured (Creswell, 2013; Jones et al., 2013). Quantitative studies generally have a clear idea as to what it is that is being measured or defined prior to the conduction of the research and the research process is then used to gather and analyse objective facts about these phenomena (Tuli, 2011; Polgar & Thomas, 2013). Such an approach was felt necessary in the current study due to the desire to compare the objective experiences of QoL in KSA schoolchildren. Specifically, this study statistically compares datasets between the samples. Therefore, a quantitative approach was essential for this study. Due to the lack of information available regarding autism and QoL in Saudi Arabia, this study seeks to gather such data and compares this evidence with other geographic regions. This analysis offers statistical evidence of the factors that determine QoL in these schoolchildren. This empirical evidence can be useful for future researchers and practitioners seeking to employ preventative or intervention strategies for schoolchildren to improve their QoL.

Similarly, this study adopts an epistemological perspective that knowledge differs from opinion, and that such knowledge can be supported by objective facts and data. Epistemology is concerned with the understanding of knowledge and how this

knowledge can be expressed or transferred within a population (Wisdom, Cavaleri, Onwuegbuzie, & Green, 2012). The current study adopts a perspective that assumes that personal experiences can be quantified and expressed in a way that objectively and accurately reflects reality. This research adopts the quantitative research, which begins with a specific hypothesis and aims to test that hypothesis. However, qualitative research is exploratory and has no hypotheses (Bernard & Bernard, 2013). Instead, such research in flexible, dynamic and aims to subjectively describe the existence of phenomena, rather than present objective data that explains its occurrence (Creswell et al., 2011; Jones et al., 2013). While such research is beneficial when relatively little is known about a particular topic, the desire to present normative data and draw comparisons between the study sample and the wide population warranted the ontological and epistemological positions taken within this research.

Additionally, while qualitative research is effective for providing a rich source of data regarding the subjective experience of QoL, this approach does not allow for objective analysis of trends related to QoL (Tuli, 2011; Flick, 2014). Additionally, such research also limits the ability to systematically compare data from previously published studies. The current design seeks to provide quantifiable evidence of the QoL experience in schoolchildren with ASD and neurotypical schoolchildren, as well as empirical support for the effectiveness of a QoL intervention for both KSA neurotypical schoolchildren and schoolchildren with ASD. Finally, this study seeks to obtain objective evidence of the properties of a widely used QoL instrument translated into Arabic (Cresswell, 2013). The purpose of the current study is to objectively compare QoL in KSA schoolchildren with ASD with other geographic regions, as well as to enhance the validity of a KSA version of the Kidscreen-52 QoL instrument and understand the factors that determine QoL in these individuals. Therefore, a

quantitative approach was essential for addressing these research questions. This quantitative data regarding QoL variables may be useful for future researchers and practitioners seeking to employ qualitative case studies oriented toward specific dimensions of QoL.

## 4.3. Research Design

A quantitative design is used to explore QoL variables in KSA schoolchildren, for those with ASD and neurotypical schoolchildren. A quantitative approach is deemed beneficial for the purpose of this study due to the need to compare data from KSA schoolchildren with those of Republic of Ireland, as well as to provide empirical evidence as to the efficacy of the Kidscreen-52 instrument within the KSA population. Though useful, qualitative data does not provide the ability to standardise a novel instrument or objectively compare one sample to another (Cresswell, 2013). The primary focus of this study is to gather data regarding the Kidscreen-52 instrument and QoL of KSA schoolchildren with ASD and neurotypical schoolchildren.

Four convenience samples are collected for the purpose of this study (see section 4.7 for more details). The first sample takes KSA 51 schoolchildren with ASD as participants and second participants 51 parents of schoolchildren with ASD. The third sample employs the KSA 340 schoolchildren who are neurotypical and last one 300 parents of neurotypical schoolchildren, and differences in QoL are evaluated according to a standardised QoL assessment tool. Generally, the children with ASD were attending diagnostic centres in Saudi Arabia. These specialist centres help to diagnose the type and the extent of the disability for children. In addition, these specialist centres have an extensive collaboration with both private and public schools

in Saudi Arabian. The research has targeted the diagnostic centres as a first step to identify and collect the data from schoolchildren with ASD and their parents.

This is done by adhering to the recommendations of the Kidscreen manual (Kidscreen, 2011), selecting 341 neurotypical schoolchildren and 300 of their parents, as well as 51 schoolchildren with ASD and 51 of their parents. This study employs a positivist research philosophy, which assumes that an objective reality exists that can be measured and validated amongst multiple researchers (Tuli, 2011). Within such research, data is limited to that which can be systematically measured, and reliability and validity can be established through relevant statistical tests (Tuli, 2011). Reliability refers to the ability to produce consistent results between multiple researchers or tests, while validity refers to the degree to which a particular test measures what it intends to measure (Tuli, 2011). These two principles form the basis of positivist, quantitative research.

This approach is in contrast to antipositivism, or interpretivism, which suggests that reality is experienced independently and subjectively (Jones, Torres, & Arminio, 2013). A positivist approach was selected due to the need to empirically assess the experience of QoL of schoolchildren with ASD and neurotypical schoolchildren. Such information is needed to help establish standards related to QoL in these populations, as well as to systematically compare findings with normative data within Saudi Arabia, and throughout the world. The ability to analyse results of this study and compare them with standardised data can provide guidance regarding how to most effectively intervene for schoolchildren with ASD to improve their QoL. It was felt that a positivist approach would provide the richest and most meaningful source of data in this respect.

Saudi Arabia was selected for the purposes of this study, as little is known

about either autism or QoL in this country. Saudi Arabia experiences one of the lowest rates of autism in the world (Al-Salehi et al., 2009). As the causes of autism and its effect on QoL are not completely understood, the reasons for this could be due to a general lack of awareness and access to diagnostic services mainly available in large cities in Saudi Arabia. However, it is also clear that research is somewhat lacking with respect to autism in Saudi Arabia (Al-Salehi et al., 2009). Understanding of clinical diagnosis, causes, and symptoms of autism is scarce due to the lack of context-specific research in Saudi Arabia (Al-Salehi et al., 2009). Therefore, this study is among the first to compare data regarding QoL and autism with mainstream schoolchildren within this region. As data is somewhat limited with respect to autism in Saudi Arabia, it was felt that the utilisation of a validated instrument would be helpful as an indicator of QoL for this sample population.

## 4.4. Instrumentation

The current study utilises the Kidscreen-52 (Kidscreen, 2011). Although alternative QoL instruments exist (e.g., Kolotkin et al., 2006; Upton, Lawford & Eiser, 2008), the Kidscreen-52 has been shown to have superior reliability across differing demographic groups, and has already been adapted in more than 10 different languages with sufficient validity and reliability scores in each one (Kidscreen, 2011). The availability of data related to Kidscreen-52 variables far exceeds that of alternative instruments. Therefore, the current study contributes to a growing body of evidence regarding the Kidscreen-52 QoL instrument and its usefulness across cultures and settings.

The current study utilises the Kidscreen-52 QoL instrument to assess QoL in KSA schoolchildren with ASD and neurotypical schoolchildren. Kidscreen (Kidscreen, 2011) is an international organisation that has contributed extensive

research regarding QoL, and this data has proven valuable in the design of QoL interventions (Ravens-Sieberer et al., 2005). The 'Kidscreen' is a standardised tool designed to assess children's subjective health and well-being. Containing 52 items, the instrument has been validated for use between the ages of 8 and 18. Additionally, this instrument has been adapted for specific countries including: Austria, Czech Republic, France, German, Greece, Hungary, Ireland, Poland, Spain, Sweden, Switzerland, the Netherlands and the United Kingdom (Kidscreen, 2011). This instrument has not yet been adapted to Arabic, and the current study helps to increase the validity of this instrument for Arabic population.

The Kidscreen-52 contains 10 dimensions, including: physical well-being, psychological well-being, mood and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance (bullying), and financial resources (Kidscreen, 2011). The 52-item version was developed and evaluated with a sample of over 3,000 European schoolchildren, showing strong psychometric properties. This is impactful for the current study because it demonstrates that this instrument has been used efficaciously in a large sample of students from a novel environment. This large sample size provides strong statistical support for the instrument, and the current study seeks to determine its validity for a novel population. Convergent and discriminant validity tests demonstrated high correlations between items on the assessment and physical health (Kidscreen, 2011). All countries in which the instrument has been adapted have subsequently demonstrated satisfactory discriminant and convergent validity (Kidscreen, 2011). These findings lend strength to the usefulness of the Kidscreen-52 within the current study, and its adaptability to different cultures and languages.

## 4.5. Data Collection

Data collection consists of the implementation of questionnaires to the school children selected in this study (see section 4.7 for Sampling and Participant Recruitment). The primary investigator contacts KSA schools selected using a convenience sample from an education database in Ministry of Education. Within these selected schools, families were contacted to locate 51 schoolchildren with ASD, 51 parents of schoolchildren with ASD, 341 neurotypical schoolchildren and 300 of their parents. In addition to a convenience sample of these schoolchildren were included within the initial data collection phase. All surveys were taken via Survey Monkey. Instructions for the surveys were provided to the respondents so that the instrument is completed correctly. All participants described above were taking the survey. To target appropriate functioning levels of schoolchildren who have been diagnosed with ASD in KSA and following ethical protocols, I have received recommendations from the schools and special care centres to contact those families who, their children identified as having autism spectrum disorder to gain this information. A link to the instrument was provided to the participants. Following the survey, data was transferred from Survey Monkey to the Statistical Package for the Social Sciences (SPSS) for analysis.

# 4.6. Procedures

This study employed a convenience sample based on geographic location, which further elicits the chance for bias. This study started with translation of the Kidscreen-52 instrument from English to Arabic. This step has been done by a native Arabic speaker who is also fluent in English. Dr. Zikrah Alkhayal who, working in the Research Centre at King Faisal Specialist Hospital as Paediatric Dentist Consultant Joint Appointee/Scientist. The most interesting publication for the purpose

of the current study is The Validity and Reliability the Arabic Translation of the Child Oral Health-Related Quality of Life Questionnaire in Saudi. Dr. AlKhayal has collaborated and done the second translation into Arabic language (See Appendixes C & D).

This step followed the WHO's (2014) recommended four-step process, consisting of: forward translation, expert panel back-translation, pre-testing and cognitive interviewing, and final version. The forward translation was conducted by the primary investigator, whereby all sentences and phrases from the Kidscreen-52 were converted into their Arabic conceptual equivalents. The expert panel consisted of two additional Arabic/English speakers working in the education field. All translations were then translated back from Arabic into English to ensure they have retained their same meanings. The backward translation has been conducted by Ms Johnson who is multilingual (English, Arabic and French). The expert panel has approved final version. Finally, pre-testing was then conducted with a small sample of schoolchildren to increase the validity and reliability of the instrument, which was as a pilot step.

The assessment phase of this study was conducted with a sample of KSA schoolchildren within the public education system (see section 4.7 for additional details). A convenience sample has been utilised to recruit approximately 341 neurotypical scoolchildren with 300 of their parents and 51 schoolchildren with ASD with 51 of their parents, between the ages of 8 and 18. While this sampling method is not ideal for generating external validity and generalizability of the findings, the necessity to obtain participants that met the specific inclusion criteria (i.e., schoolchildren with ASD and neurotypical schoolchildren the ages of 8 and 18)

warranted the use of this alternative sampling method. Schoolchildren with ASD are recruited by contacting agencies and special education programmes within the district that specialise in working with these special needs groups. As all participants in this study are below the age of 18, parents or guardians of these schoolchildren were contacted and asked to provide consent prior to engaging in the study. All participants with consent were administered the Arabic Kidscreen-52, which they complete online via Survey Monkey. All data was then transferred to SPSS. Data was collected by the primary investigator using the Kidscreen QoL instrument. This was completed electronically on the Survey Monkey site, whereby Kidscreen items were entered into an online survey that is available for participants to take when they have time. The link to this questionnaire has sent to families of the 51 schoolchildren with ASD and 51 of their parents and 341 neurotypical schoolchildren and 300 of their parents in KSA.

All data were then transferred to SPSS using the Survey Monkey data transfer feature and/or the SPSS import function. The primary investigator then analysed data from the 51 schoolchildren with ASD and 51 of their parents, and the 341 neurotypical schoolchildren and 300 of their parents using the SPSS software. Dimensions of the Kidscreen instrument were scored according to guidelines and recommendations listed within the Kidscreen scoring manual. The first step in analysing this data was to score the self-report items from all participants. To score self-report instruments utilising SPSS, response choices were first coded and given item names. Negatively formulated items (i.e., those in which disagreeing with an item would indicate a positive response) were then recoded in reverse to allow for a consistent dataset. All items of each respective scale were then summed. Any missing values were substituted with parameter estimates made by previous research. This

parameter estimates with then be transformed into z-scores, and subsequently 'T-values' based on internationally standardised results from 12 countries using the Kidscreen instrument. These steps allow comparisons to be made for individuals within the study, between groups within the study and between the current sample and the population at large.

Following the coding and recoding of variables, interpretations of the variables were made. Kidscreen scores can be interpreted in three different ways, depending on the results of the analysis and the makeup of the sample. These methods of interpretation include comparing between group scores and the reference population, interpreting individual parameter estimates (i.e., the Rasch model method) and interpreting individual Kidscreen profiles. Each is used in this study, depending on the results output and nature of the sample. The first method involves making interpretations for each raw scale score. These interpretations were made based on percentage ranks derived from the tables listed within the manual. For example, the population norm for each scale has been weighted as a mean of 50, with percentage ranks higher or lower indicating where a particular individual or sample fits compared to the broader population. For example, scored below 50 on the autonomy and parent relation subscale will indicate feelings of restriction or being overlooked, while higher scores will indicate feeling positive about one's relationship with parents and possessing a sufficient degree of personal independence.

In cases in which data are inconsistent with other research, a second method of interpreting scores was utilised. Specifically, parameter estimates were made, and comparisons of well-being were conducted based on international "T-values", or standardised thresholds for each dimension of the Kidscreen instrument. A third way of analysing Kidscreen scores may also be used where necessary, in which

interpretations of responders' scores were made across all participants and a summary of both individual and group health-related QoL can be made. Individual profiles were calculated based on the T-values and parameter estimates of the previous two methods, while group profiles can be estimated for both schoolchildren with ASD, the parents of schoolchildren with ASD, neurotypical schoolchildren and the parents of neurotypical schoolchildren living within Saudi Arabia. This also allows for comparisons with previously established data sets, as well as known personality types derived through previous research. In such cases, a cluster analysis can be conducted for data derived from the current study. Additional comparisons may be conducted based as directed by the findings.

## 4.7. Sampling and Participant Recruitment

The actual collection of the data took place through contacting schools. Though not a sampling issue, this may also induce the possibility of bias or research error.

• Participants from this study were recruited from the KSA school system. This was done by selecting schools listed in an education database of KSA schools based on their location (Jeddah, Riyadh and Makkah). This was done by adhering to the procedures in the Kidscreen book (See Appendix E), as well as establishing contacts with KSA school administrators to access schoolchildren. approval was granted from the Ministry of Education (See Appendix F) to contact these schoolchildren. For the initial standardisation phase of this study, schoolchildren and parents were recruited from multiple schools, as well as a special care centre located within the community that specialises in working with schoolchildren with ASD and their parents. In terms of Neurotypical schoolchildren, the sample is a

convenience sample, resulting in restrictions related to sample size and representativeness. With a large population in KSA, the majority of Saudi Arabian residents live in the urbanized cities. Just 17% of the population lives in the country's rural areas, while the remaining 83% live in the larger cities (World Population Review, 2017). Therefore, it can mention here that this can make the sample representative of the population. Additionally, this study adopted 52-kidscreen instrument, which has been shown to have superior reliability and has already been adapted in more than 10 different languages with sufficient reliability and validity scores in each one (Kidscreen, 2011). Therefore, it can be mentioned here that this study overcomes on the limitation related with sample size and representativeness. Wellington (2000, p. 58) confirms that "we can never be sure that our sample is fully representative of the whole population, wherever we draw the line. Sampling always involves a compromise".

Neurotypical schoolchildren and their respective parents and legal guardians were contacted for completion of this study. Following the selection of schools, a convenience sample of households within the local community were utilised and contacted. Participants received the questionnaires and given two to five days to reply. Within the questionnaires were also the parental information form, consent form, and information about the study for the participants (see section 4.9 for more information on research ethics). Cooperation rates and response rates were factored into the final analysis and compared with normative Kidscreen-52 data for purposes of standardisation of the current results. The number of 341 neurotypical schoolchildren

and 300 of their parents was selected based on the recommendations documented within the Kidscreen-52 (2011) manual.

While this sample does not draw on true randomisation procedures, the selective inclusion and exclusion criteria for this particular demographic group warranted the use of the current sampling method. For example, the necessity to recruit 51 KSA schoolchildren with ASD and 51 of their parents necessitated establishing contacts with administrators and educators who have experience working with such groups of schoolchildren. It is hoped that future studies will utilise true random sampling to improve the external validity and generalizability of the results (Creswell, 2013). For schoolchildren with ASD, participants are recruited based on contacting the school's administrators for potentially eligible candidates. Approximately 51 of these schoolchildren and 51 of their parents were selected by the schools and specialist centres and contacted and recruited for study purposes. The main reason why the current sample is small since it was impossible to investigate too many cases and the agreement of particular schoolchildren and their parents to participate. The results of these samples were then compared with normative Kidscreen data from the 37 countries that have established data related to QoL in these population groups. These statistics were utilised to increase the validity of the current instrument as well as determine the representativeness of the current study with national and international results.

# 4.8. Validity and Reliability of Measurement

The validity of the first question was established by undergoing the extensive following a rigorous translation process. As detailed above, The World Health Organisation's (2014) recommended translation and adaptation process is used to

establish validity and reliability of this instrument.

The validity of the second question was established by employing the statistical procedures described above. Specifically, QoL results were analysed for statistical differences across the multiple Kidscreen dimensions.

As already discussed, the Kidscreen instrument has previously been validated with a sample of more than 3,000 European schoolchildren, demonstrating sufficient psychometric properties across this sample. The Kidscreen (2011) manual also includes statistics on its psychometric properties for its initial validation process. Like previous assessments, Cronbach's alpha ranged from 0.77 to 0.89, with test-retest reliability ranging from 0.56 to 0.77 for the long and condensed versions.

Efforts to standardise this instrument across multiple populations have also demonstrated sufficient external validity. In addition to the initial validation process described above, Erhart and colleagues (2009) also conducted a standardisation of this instrument with 15 different European countries with schoolchildren aged 11 to 15. Cronbach's alpha for this study was 0.81, with a Rash infit mean square residual of 0.7 to 1.3.

#### 4.9. Ethical Considerations

This project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct. This approval was obtained from the ethics committee, documenting all procedures, materials, and data analytical methods. Additionally, the Consent form provided a detailed explanation of the current study's attention to human and participant rights issues throughout the course of the study. Due to the potentially sensitive nature of the study material, as well as the necessity to obtain underage participants, some ethical concerns may be

evident within this study. For example, assessing QoL requires participants to reflect on potentially personal issues, such as family and social concerns (Oliver, 2010). This reflection may elicit exposure to some degree of psychological distress. As a result, all participants were instructed of their rights to omit any of the questions, as well as the right to stop at any time. Second, the utilisation of participants under the age of 18 requires parental or guardian consent prior to conducting the study (Oliver, 2010). Therefore, such consent was obtained from one or both of the participants' legal guardians. No coercion or incentives were used at any phase of this study.

All participants were provided with a contact number in order to receive more information about the nature and content of the study. This study strived to maximise participant and guardian confidentiality during all phases of the study. No identifying information were used during the data collection, analysis or reporting of results. Participants were provided with an identification code for the purposes of data analysis, and no personally identifying information was attached to the participants' actual names. Upon completion of the study, all data was locked in a file cabinet in the primary investigator's office to prevent any tampering or modification of the data. The electronic data was secured by password protected computer. The data will be destroyed after a period of seven years. As all instrumentation took place via Survey Monkey, participants have not had the opportunity to ask questions or clarify items with the primary investigator during the survey. However, all participants were provided with the primary investigator's contact information, and instructed to withhold from taking the survey until they have had a chance to speak with the primary investigator.

Children with ASD were considered a vulnerable population group, and warrant special consideration when attempting to include as participants within a

study (Creswell, 2013). Therefore, stringent efforts were made to protect the rights and human dignity of these participants. Throughout the course of the study, children with ASD were allowed to complete any self-report items with the help of an advocate or specialist who is familiar with his or her condition. Participants, guardians and/or advocates were instructed of their rights as human participants during all phases of the study, as well as their rights to omit any components of the procedures and withdraw from the study at any point in time.

#### 4.10. Conclusion

Results from this study are beneficial in understanding QoL experiences in KSA schoolchildren with ASD and neurotypical schoolchildren, as well as the dimensions of QoL within these schoolchildren. Results from this study may be useful in identifying how to improve QoL amongst KSA schoolchildren. Through working with parents regarding QoL, the KSA education system will ideally experience improved performance, as well as improved social outcomes on behalf of the schoolchildren. Furthermore, validating a QoL instrument for KSA schoolchildren is a critical step in designing more effective interventions for this population group. Similarly, little is known about autism in Saudi Arabia, and the adaptation of an instrument specifically for this population group is long overdue. Therefore, this study helps to further the understanding of QoL in schoolchildren with ASD and neurotipcal schoolchildren in Saudi Arabia, as well as to draw comparison with other cultures. Finally, this study provides evidence of the effectiveness of an intervention designed to improve QoL in schoolchildren with ASD. This information might be beneficial for KSA educators working with these special needs group.

Determining QoL has increased in significance within the Middle Eastern region of the world as practitioners have acknowledged the impact this state has on

student's general health, well-being, and educational outcomes. Additionally, QoL seems to have a substantial impact on inducing beneficial academic outcomes in students. However, few empirical studies have systematically evaluated the impact of QoL on schoolchildren with ASD in Saudi Arabia. Therefore, the purpose of this study is to gain a better understanding of QoL in schoolchildren with ASD and neurotypical children in Saudi Arabia. Furthermore, this study intends to enhance the validation for a standardised QoL instrument in Arabic for schoolchildren with ASD and neurotypical schoolchildren.

A quantitative approach was utilised to evaluate QoL variables in KSA schoolchildren with ASD and neurotypical schoolchildren. A sample of KSA community schoolchildren with ASD, their parents, neurotypical schoolchildren and their parents were selected for participation in this study, and discrepancies in QoL were evaluated according to a standardised QoL assessment tool. This study consists of two phases, including: instrument translation and QoL assessment. First, the Kidscreen-52 was translated from English to Arabic as a first translation and the second translation by a native Arabic speaker who is also fluent in English. The assessment phase of this study was performed with a sample of KSA community schoolchildren and their parents within the public education system, and this phase was utilised to determine validity and reliability of the new instrument.

## 5. Chapter Five: Data Analysis

#### 5.1. Introduction

This chapter explores the data gathered using the Kidscreen instrument to measure Quality of Life in the Kingdom of Saudi Arabia. The raw data used to analyse the quality of life characteristics in the samples are analysed using SPSS software. More specifically, Principal Component Analysis was employed to analyse the collected data. This analysis was applied to four groups: KSA schoolchildren with ASD, the parents of KSA schoolchildren with ASD, the neurotypical schoolchildren and the parents of the neurotypical schoolchildren. The chapter starts with the evaluation of the background information of research participants. After this, the principal component analysis was conducted to single out the key factors of quality of life among four groups. Finally, the results were tested for reliability and frequency tables are provided.

In responses, the values such as 'never', 'seldom', 'quite often', 'very often' and 'always' are given values from 1 to 5 respectively. In the same way, the values such as 'not at all', 'slightly', 'moderately', 'very' and 'extremely' are valued from 1 to 5 where 1 indicates the least values whereas 5 indicates the highest or extreme values.

Principal Component Analysis (PCA) is applied to the data collected by structured questionnaires based on (Raven-Sieberer, 2006) and distributed among Saudi schoolchildren and their parents. Ravens-Sieberer (2006) suggests that the quality of life can be assessed based on ten categories, namely: Physical Well-being, Psychological Well-being, Moods and Emotions, Self-Perception, Autonomy, Parent Relationships & Home Life, Financial Resources, Social Support and Peers, School

Environment and Social Acceptance. Principal Component Analysis demonstrates how well the data collected using the structured questionnaires fit into these ten categories. The first part of the chapter deals with the analysis of the survey of schoolchildren with ASD whereas the second part of the chapter provides an analysis of the survey of parents of schoolchildren with ASD. The third part concentrates on the neurotypical schoolchildren whereas the last part deals with the parents of the neurotypical schoolchildren.

#### 5.2. Analysis of Schoolchildren's Responses (Schoolchildren with ASD)

The first step of the analysis is the assessment of the sample and respondents' profile. This includes such background information as the type of school the schoolchildren attend, income of their family, city from which responses were obtained and gender of the schoolchildren. The summary information for this background data is reported in the following frequency table.

**Table 5.1 Frequency Table of Schoolchildren Background Information** 

		Frequency	Percent	Valid Percent	<b>Cumulative Percent</b>
	Primary School 5-11 years	26	51.0	51.0	51.0
School	Secondary School 12-18 years	25	49.0	49.0	100.0
	Total	51	100.0	100.0	
	Low	2	3.9	3.9	3.9
Income	Medium	35	68.6	68.6	72.5
Income	High	14	27.5	27.5	100.0
	Total	51	100.0	100.0	
	Al-Riyadh	12	23.5	23.5	23.5
City	Jeddah	15	29.4	29.4	52.9
City	Makkah	24	47.1	47.1	100.0
	Total	51	100.0	100.0	
	Boy	31	60.8	60.8	60.8
Gender	Girl	20	39.2	39.2	100.0
	Total	51	100.0	100.0	

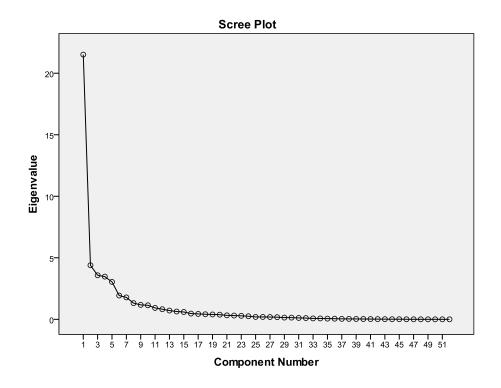
There are 51 respondents among the schoolchildren with ASD in the sample.

The sample is nearly equally distributed between primary school and secondary

school. The former constitute 51% of the respondents whereas the latter constitute 49%. In terms of income, the questionnaire is included three categories for income; low, medium and high. This classification is defined according to the participants. In other words, the participants classify themselves into one of these groups according to their personal view. As the participant self declares if he/she has low, medium or high income, the families of the schoolchildren with ASD that participated in the survey are predominantly from middle class and only fewer than 4% of respondents considered themselves of low income. High income respondents constitute 27.5% of the sample. The majority of the schoolchildren were surveyed in Makkah because the researcher is from this city and starts collecting from Makkah first. This city accounts for more than 47% of the total sample whereas schoolchildren from Al-Riyadh and Jeddah constitute 23.5% and 29.4% of the sample respectively. Finally, the sample of respondents is skewed towards boys. There are 60.8% of boys among respondents and only 39.2% of girls. This result can be contributed to the reason that boys had a higher probability to have autism than girls, and this result empirically is tested by Dworzynski (2012).

There are 52 questions in the Kidscreen questionnaire related to the quality of life of schoolchildren with ASD and neurotypical schoolchildren. Principal Components Analysis was used to estimate the number of factors into which these 52 questions fall. The number of eigenvalues (Heck, Thomas, & Tabata, 2012) was based on the correlations between the responses for the questions. The following scree plot (Field, 2013) has been constructed based on the estimates.

Figure 5.1 Scree Plot



The Scree test (see Figure 5.1) consists of eigenvalues and factors (Cattell, 1978). The number of factors to be retained is the data points that are above the break (i.e., point of inflexion). To determine the 'break', the researcher drew a horizontal line and a vertical line starting from each end of the curve (Costello & Osborne, 2005). By applying the previous rule of thumb in the current study, the scree plot illustrates that there are exactly ten factors with eigenvalues above one, which is consistent with the classification of Raven-Sieberer (2006). However, among these ten factors, the highest weight belongs to only one factor, which accounts for 21.5% of total variance in the sample (Table 5.2).

**Table 5.2 Total Variance Explained** 

		Initial Eigenval	ues	Extraction Sums of Squared Loadings			
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	
1	21.515	41.374	41.374	21.515	41.374	41.374	
2	4.394	8.449	49.823	4.394	8.449	49.823	
3	3.580	6.885	56.709	3.580	6.885	56.709	
4	3.471	6.675	63.383	3.471	6.675	63.383	
5	3.043	5.852	69.235	3.043	5.852	69.235	
6	1.933	3.716	72.951	1.933	3.716	72.951	
7	1.782	3.427	76.378	1.782	3.427	76.378	
8	1.317	2.532	78.911	1.317	2.532	78.911	
9	1.175	2.260	81.171	1.175	2.260	81.171	
10	1.140	2.193	83.364	1.140	2.193	83.364	

All ten factors together explain more than 83% of total variance in responses of the schoolchildren with ASD. However, the explanatory power of the last five factors is rather weak compared to the dominant factor. In order to test which questions fall into which factors, factor loadings were calculated based on the rotated pattern matrix (Muijs, 2011). Rotation was performed using the Direct Oblimin method in SPSS. This type of rotation is also applied by Raven-Sieberer (2006) because it allows for an assumption that factors could correlate (Davies, Hughes, & Hughes, 2014). This assumption had to be accounted for because it was expected that emotions and mood of respondents would be linked to psychological and physical wellbeing. Other rotation methods such as Varimax do not allow for such an assumption (Burns & Burns, 2008). The output provided both structured and pattern matrix of factors. However, the latter was analysed because it demonstrated unique contributions of each factor whereas the structured matrix demonstrated cumulative contributions, which would be meaningful only under an assumption that the factors are uncorrelated, which has not been proven (Bryman & Cramer, 2009). The pattern matrix is reported in Appendix A. The only group of questions that could not be fit into the principal components is the one referred to as "Parent Relationships and Home Life" by Raven-Sieberer (2006). This is evidenced in Appendix A. The

loadings are too small for this factor in the pattern matrix. In order to test interrelations between the ten measures of quality of life of schoolchildren with ASD, the following correlation coefficients between factors were estimated.

**Table 5.3 Correlations between Components** 

Component	Autono my	Psychologi cal Wellbeing	Mood and Emotio ns	Physical Wellbei ng	Social Acceptan ce	Social Suppo rt and Peers	Parent Relationshi ps and Home Life	Financia 1 Resourc es	Self- Perceptio	School Environme nt
Autonomy	1.000									
Psychologic al Wellbeing	.336	1.000								
Mood and Emotions	.514	.388	1.000							
Physical Wellbeing	.483	.323	.446	1.000						
Social Acceptance	.209	252	.309	.429	1.000					
Social Support and Peers	.449	294	.527	.367	.382	1.000				
Parent Relationship s and Home Life	.267	.336	.242	.458	.335	267	1.000			
Financial Resources	.519	285	.338	.301	.326	.237	268	1.000		
Self- Perception	.368	.264	.444	.399	.310	.368	.279	238	1.000	
School Environment	124	.352	.350	173	.324	216	.376	.311	127	1.000

The table 5.3 report statistically significant correlation coefficients. The results indicate that the highest correlation exists between Mood & Emotions and Social Support & Peers. This finding can suggest that as schoolchildren with ASD in KSA spend more time with their peers and have social support from them, their mood and positive emotions increase. Interestingly, the findings also report a high correlation between the degree of autonomy of schoolchildren with ASD and their mood and emotions. Hence, the more free time they have and the more they are allowed to be by themselves, the better they feel. The most negative correlation was found between the degree of autonomy given to the schoolchildren with ASD and the quality of their school environment. The more freedom these schoolchildren were given to be by themselves and do what they like, the less happy they felt at school and the less attention they could pay at classes. It could be interpreted that in order to enjoy school

and improve relationships with teachers, the schoolchildren with ASD should be restricted from excessive freedom and put in a more constrained social environment, but further analysis is needed to draw this conclusion.

The next section of the analysis tests each category from Raven-Sieberer (2006) for internal consistency using the Cronbach's alpha (Wagner, 2015) and frequency of responses of schoolchildren with ASD.

### **5.2.1.** Physical Activities and Health (Physical Well-being)

The reliability statistics used in this research to test internal consistency of responses were also employed in the Kidscreen surveys conducted in Germany. The results from the surveys published by Kidscreen indicated that the Cronbach's alpha ranged from 0.77 to 0.9. With some minor exceptions, this research also provides a similar range of reliability statistics. Physical well-being of schoolchildren with ASD was assessed based on responses to the questions related to their health, physical activity and running. The results were internally consistent as the Cranbach's alpha is higher than 0.7 (Table 5.4).

**Table 5.4 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.824	4			

The findings from the assessment of responses in regards to the physical well-being demonstrate that more than a half of the schoolchildren with ASD gave positive evaluations of their health (Table 5.5).

**Table 5.5 Frequency Tables** 

	In	general, how wor	ıld vou sav vour	health is?	
		<b>g</b> ,			Cumulative
		Frequency	Percent	Valid Percent	Percent
	Poor (1)	2	3.9	3.9	3.9
	Fair (2)	2	3.9	3.9	7.8
	Good (3)	14	27.5	27.5	35.3
	Very Good				
	(4)	17	33.3	33.3	68.6
	Excellent				
Valid	(5)	16	31.4	31.4	100.0
	Thinkin	g about the last v	veek, Have you f	felt fit and well?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all	1 ,			
	(1)	1	2.0	2.0	2.0
	Moderately				
	(3)	19	37.3	37.3	39.2
	Very (4)	13	25.5	25.5	64.7
	Extremely				
Valid	(5)	18	35.3	35.3	100.0
	Have you be	en physically act	ive (e.g. running	g, climbing, biking)	?
		1 0	, J		Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all	•			
	(1)	5	9.8	9.8	9.8
	Slightly (2)	8	15.7	15.7	25.5
	Moderately				
	(3)	16	31.4	31.4	56.9
	Very (4)	7	13.7	13.7	70.6
	Extremely				
Valid	(5)	15	29.4	29.4	100.0
		Have you be	en able to run w	ell?	
		•			Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all	•			
	(1)	1	2.0	2.0	2.0
	Slightly (2)	9	17.6	17.6	19.6
	Moderately				
	(3)	15	29.4	29.4	49.0
	Very (4)	8	15.7	15.7	64.7
	Extremely				

This finding indicates that the schoolchildren with ASD do not consider themselves to be deprived of physical activities and consider themselves mostly healthy.

# **5.2.2.** Feelings (Psychological Well-being)

Psychological well-being of schoolchildren with ASD was assessed based on responses to the questions related to their energy, enjoyment of life and satisfaction with life. The results were internally consistent based on the Cranbach's alpha which is higher than 0.7 (Table 5.6).

**Table 5.6 Reliability Test** 

Reliability Statistics						
Cronbach's Alpha	N of Items					
.792	4					

The schoolchildren with ASD also demonstrated mostly positive attitudes to their satisfaction with life and healthy psychological wellbeing (Table 5.7).

**Table 5.7 Frequency Tables** 

	Thinking	about the last we	ek, Have you fe	lt full of energy?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	7	13.7	13.7	17.6
	Quite Often				
	(3)	11	21.6	21.6	39.2
	Very Often				
	(4)	18	35.3	35.3	74.5
Valid	Always (5)	13	25.5	25.5	100.0
		about the last we	ek. Has vour life	e been eniovable?	
	Î		,	J.,	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all	<u>, · · · · · · · · · · · · · · · · · · ·</u>			
	(1)	2	3.9	3.9	3.9
	Slightly (2)	3	5.9	5.9	9.8
	Moderately	<del>-</del>			
	(3)	26	51.0	51.0	60.8
	Very (4)	6	11.8	11.8	72.5
	Extremely				
Valid	(5)	14	27.5	27.5	100.0
		Have you felt plea	ased that you ar	e alive?	
			•		Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all				
	(1)	1	2.0	2.0	2.0
	Slightly (2)	3	5.9	5.9	7.8
	Moderately				
	(3)	17	33.3	33.3	41.2
	Very (4)	4	7.8	7.8	49.0
	Extremely				
Valid	(5)	26	51.0	51.0	100.0
		Have you felt sa	tisfied with you	r life?	
			-		Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all	<del>-</del> <del>-</del>			
	(1)	2	3.9	3.9	3.9
	Slightly (2)	4	7.8	7.8	11.8
	Moderately				
	(3)	24	47.1	47.1	58.8
	Very (4)	3	5.9	5.9	64.7
	Extremely				
Valid	(5)	18	35.3	35.3	100.0

Schoolchildren with ASD show a tendency to enjoy life and be satisfied with their life, and this state in which they are found is reflected in their physical and psychological well-being.

#### **5.2.3.** General Moods (Moods and Emotions)

Mood and emotions of schoolchildren with ASD were evaluated based on responses to the questions whether they felt sad, fun, cheerful, frustrated or apathetic. The results were internally consistent because the Cranbach's alpha reports the value above 0.7 (Table 5.8).

**Table 5.8 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.739	10			

The positive attitude of schoolchildren with ASD in KSA is also reflected in their mood and emotions. The most common responses from them are that they quite often and very often find themselves in a good mood (Table 5.9).

**Table 5.9 Frequency Tables** 

	Thinking o	hout the lest week	Hove you bee	n in a good mood?	
	Tilliking a	bout the last week	k, nave you bee	in in a good mood:	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Seldom (2)	5	9.8	9.8	9.8
	Quite Often	3	7.0	7.0	7.0
	(3)	17	33.3	33.3	43.1
		17	33.3	33.3	43.1
	Very Often	17	22.2	22.2	765
	(4)	17	33.3	33.3	76.5
Valid	Always (5)	12	23.5	23.5	100.0
		Have you	felt cheerful?		
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Seldom (2)	10	19.6	19.6	19.6
	Quite Often				
	(3)	11	21.6	21.6	41.2
	Very Often		21.0	21.0	
	(4)	20	39.2	39.2	80.4
Valid	Always (5)	10	19.6	19.6	100.0
vanu	Always (3)			19.0	100.0
		Have y	ou had fun?		G 1.1
			ъ	V 11 1 5	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	10	19.6	19.6	21.6
	Quite Often				
	(3)	14	27.5	27.5	49.0
	Very Often				
	(4)	15	29.4	29.4	78.4
Valid	Always (5)	11	21.6	21.6	100.0
				ou do everything b	
	Timiking about t	ne last week, Hav	e you lest that y		Cumulative
		Eraguanav	Percent	Valid Percent	Percent
	NI (1)	Frequency			
	Never (1)	10	19.6	19.6	19.6
	Seldom (2)	24	47.1	47.1	66.7
	Quite Often	_			
	(3)	8	15.7	15.7	82.4
	Very Often				
	(4)	6	11.8	11.8	94.1
Valid	Always (5)	3	5.9	5.9	100.0
	•	Have v	ou felt sad?	•	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	13	25.5	25.5	25.5
	Seldom (2)	20	39.2	39.2	64.7
	Quite Often	20	37.4	37.2	U <del>1</del> ./
	-	10	22 5	23.5	00.2
	(3)	12	23.5	23.3	88.2
	Very Often	_	6.3		60.0
	(4)	5	9.8	9.8	98.0
Valid	Always (5)	1	2.0	2.0	100.0
	Have you	felt so bad that y	ou did not wan	t to do anything?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	13	25.5	25.5	25.5
	Seldom (2)	21	41.2	41.2	66.7
		<b>∠</b> 1	11.2	11.2	50.7
	Quite Often		17.6	17.6	012
Valid		9	17.6 11.8	17.6 11.8	84.3 96.1

	(4)				
	Always (5)	2	3.9	3.9	100.0
	Have y	ou felt that every	thing in your lif	fe goes wrong?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	19	37.3	37.3	37.3
	Seldom (2)	20	39.2	39.2	76.5
	Quite Often				
	(3)	7	13.7	13.7	90.2
	Very Often				
	(4)	2	3.9	3.9	94.1
Valid	Always (5)	3	5.9	5.9	100.0
		Have yo	u felt fed up?		
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	10	19.6	19.6	19.6
	Seldom (2)	25	49.0	49.0	68.6
	Quite Often				
	(3)	8	15.7	15.7	84.3
	Very Often				
	(4)	4	7.8	7.8	92.2
Valid	Always (5)	4	7.8	7.8	100.0
		Have yo	u felt lonely?		
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	20	39.2	39.2	39.2
	Seldom (2)	12	23.5	23.5	62.7
	Quite Often				
	(3)	12	23.5	23.5	86.3
	Very Often				
	(4)	3	5.9	5.9	92.2
Valid	Always (5)	4	7.8	7.8	100.0
		Have you fel	t under pressur	e?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	15	29.4	29.4	29.4
	Seldom (2)	17	33.3	33.3	62.7
	Quite Often				
	(3)	10	19.6	19.6	82.4
	Very Often				
	(4)	7	13.7	13.7	96.1
Valid	Always (5)	2	3.9	3.9	100.0

They also state that more often than not, they feel cheerful and are having fun. When negative questions were asked such if they felt sad and fed up, the schoolchildren with ASD predominantly reported that this occurred rather seldom or not quite often. This finding is consistent with their responses on physical wellbeing and psychological wellbeing.

# **5.2.4.** About Your-self (Self-Perception)

The responses on self-perception also demonstrated high internal consistency as evidenced from the Cronbach's alpha test (Table 5.10).

**Table 5.1 Reliability Test** 

Reliability Statistics for Positive Questions						
Cronbach's Alpha N of Items						
.778	3					
Reliability Statist	ics for Negative Questions					
Cronbach's Alpha	N of Items					
.901	2					

The responses summarised in the frequency table illustrate that the schoolchildren with ASD tend to be confident in how they look and what they wear (Table 5.11).

**Table 5.2 Frequency Tables** 

	H	ave you been hap	py with the way	you are?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	5	9.8	9.8	11.8
	Quite Often				
	(3)	18	35.3	35.3	47.1
	Very Often				
	(4)	12	23.5	23.5	70.6
Valid	Always (5)	15	29.4	29.4	100.0
		Have you been ha	ppy with your	clothes?	
		J	117		Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	7	13.7	13.7	15.7
	Quite Often	•		-5	10.,
	(3)	16	31.4	31.4	47.1
	Very Often	10	51.1	51.1	1/.1
	(4)	7	13.7	13.7	60.8
Valid	Always (5)	20	39.2	39.2	100.0
v una		e you been worri			100.0
	IIav	c you been worrn	ed about the wa	you look.	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	32	62.7	62.7	62.7
	Seldom (2)	11	21.6	21.6	84.3
	Quite Often	11	21.0	21.0	04.3
	(3)	3	5.9	5.9	90.2
	Very Often	J	3.9	3.9	90.2
		1	2.0	2.0	92.2
Valid	(4) Always (5)	<u>1</u> Δ	7.8	7.8	100.0
vanu		felt jealous of the			100.0
	nave you	Ten jeanous of the	e way other giri	s and boys look:	Cumulative
		Fragueray	Percent	Valid Percent	Percent
	N (1)	Frequency			
	Never (1)	32	62.7	62.7	62.7
	Seldom (2)	11	21.6	21.6	84.3
	Quite Often	4	7.0	7.0	02.2
	(3)	4	7.8	7.8	92.2
X7.1' 1	Very Often	4	7.0	7.0	100.0
Valid	(4)	4	7.8	7.8	100.0
	Would	you like to chang	e something abo	out your body?	
			ъ .	W 1: 1 B	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	38	74.5	74.5	74.5
	Seldom (2)	6	11.8	11.8	86.3
	Quite Often				
	(3)	4	7.8	7.8	94.1
	Very Often				
	(4)	1	2.0	2.0	96.1
Valid	Always (5)	2	3.9	3.9	100.0

When the schoolchildren were asked if they felt jealous of the way others look, predominantly negative responses were received which proved their confidence in their looks and clothes. More than 70% of schoolchildren also stated that they do

not want to change anything about their body. This also speaks of a confident attitude and high self-perception.

## **5.2.5. Free Time (Autonomy)**

The questions that disclose autonomy are concerned with the free time of schoolchildren with ASD. The responses to these questions reveal internal consistency based on the findings from the Cronbach's alpha (Table 5.12).

**Table 5.3 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.846	5			

Most of the respondents agree that they are able to do things that they want indicating that they are given freedom to be by themselves. However, responses to some of the questions such is if they had enough time to themselves and whether they had enough time to meet friends are rather mixed and without a particular tendency (Table 5.13).

**Table 5.4 Frequency Tables** 

		Have you had end	ough time for yo	ourself?	
			•		Cumulative
		Frequency	Percent	Valid Percent	Percent
	Seldom (2)	8	15.7	15.7	15.7
	Quite Often				
	(3)	14	27.5	27.5	43.1
	Very Often				
	(4)	16	31.4	31.4	74.5
Valid	Always (5)	13	25.5	25.5	100.0
, and		u been able to do			100.0
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	4	7.8	7.8	7.8
	Seldom (2)	4	7.8	7.8	15.7
	Quite Often	т	7.0	7.0	13.7
	(3)	12	23.5	23.5	39.2
	Very Often	12	43.3	23.3	37.4
	(4)	17	33.3	33.3	72.5
<b>37.1: J</b>	` '	14	27.5	27.5	
Valid	Always (5)				100.0
	Have	e you had enough	opportunity to	be outside?	G 1 .:
		-		******	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	4	7.8	7.8	7.8
	Seldom (2)	10	19.6	19.6	27.5
	Quite Often				
	(3)	18	35.3	35.3	62.7
	Very Often				
	(4)	11	21.6	21.6	84.3
Valid	Always (5)	8	15.7	15.7	100.0
	Н	ave you had enou	gh time to meet	t friends?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	5	9.8	9.8	9.8
	Seldom (2)	15	29.4	29.4	39.2
	Quite Often				
	(3)	17	33.3	33.3	72.5
	Very Often		22.2	23.0	,
	(4)	9	17.6	17.6	90.2
Valid	Always (5)	9 5	9.8	9.8	100.0
7 4114		been able to choo			100.0
	Have you	been able to choc	oc what to uo h	i your free time:	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	5	9.8	9.8	13.7
	Quite Often	4.5	22.2	20.0	
	(3)	17	33.3	33.3	47.1
	Very Often				_
	(4)	14	27.5	27.5	74.5
Valid	Always (5)	13	25.5	25.5	100.0

The schoolchildren with ASD that took part in the survey were also rather unsure whether they had enough time to be outside but they predominantly agreed

that they were able to choose what to do in free time. This analysis demonstrates high quality of life for schoolchildren with ASD.

#### **5.2.6.** Family and Home Life (Parent Relationships & Home Life)

It was hypothesised that schoolchildren with ASD could have misunderstandings with their parents and this aspect of their life was tested using the quality of life questionnaire. The responses of schoolchildren with ASD demonstrated internal consistency (Table 5.14).

**Table 5.5 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.914	6			

It is revealed schoolchildren with ASD and their parents share high mutual understanding and schoolchildren feel love according to their responses (Table 5.15).

**Table 5.6 Frequency Tables** 

	Thinking a	bout the last week,	Have your parent	(s) understood you?	•
	J	Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	1	2.0	2.0	2.0
	Slightly (2)	4	7.8	7.8	9.8
	Moderately				
	(3)	8	15.7	15.7	25.5
	Very (4)	20	39.2	39.2	64.7
	Extremely				
Valid	(5)	18	35.3	35.3	100.0
			ved by your parer	nt(s)?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Slightly (2)	3	5.9	5.9	5.9
	Moderately				
	(3)	7	13.7	13.7	19.6
	Very (4)	17	33.3	33.3	52.9
	Extremely				
Valid	(5)	24	47.1	47.1	100.0
	Thinkin	g about the last wee	k, Have you been	happy at home?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	3	5.9	5.9	5.9
	Seldom (2)	4	7.8	7.8	13.7
	Quite Often				
	(3)	13	25.5	25.5	39.2
	Very Often				
	(4)	11	21.6	21.6	60.8
Valid	Always (5)	20	39.2	39.2	100.0
		Have your parent(s)			
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	4	7.8	7.8	7.8
	Seldom (2)	3	5.9	5.9	13.7
	Quite Often	-			
	(3)	15	29.4	29.4	43.1
	Very Often				
	(4)	11	21.6	21.6	64.7
Valid	Always (5)	18	35.3	35.3	100.0
	1 (- )	Have your parer	it(s) treated you fa		
		Frequency	Percent	Valid Percent	Cumulative Percent
	Seldom (2)	5	9.8	9.8	9.8
	Quite Often	-			
	(3)	12	23.5	23.5	33.3
	Very Often				
	(4)	19	37.3	37.3	70.6
Valid	Always (5)	15	29.4	29.4	100.0
	Have you	u been able talk to y		* '	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	2	3.9	3.9	7.8
	Quite Often				
	(3)	17	33.3	33.3	41.2
	Very Often	·			
	(4)	11	21.6	21.6	62.7
Valid	Always (5)	19	37.3	37.3	100.0
		-/	27.00	1 27.0	

More than a half of the respondents state that they are happy at home and that parents treat them fairly. It is also found that schoolchildren with ASD are mostly able

to talk to their parents when they want, which also indicates a positive area in the quality of their life.

#### **5.2.7.** Money Matters (Financial Resources)

Financial resources are also an important aspect of quality of life and responses of schoolchildren with ASD in this respect demonstrate internal consistency (Table 5.16).

**Table 5.7 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.858	3			

While the majority of schoolchildren who took part in the survey stated that they had enough money for their expenses, the responses were rather mixed in regards to the question whether they had enough money to do the same thing as their friends (Table 5.17).

**Table 5.8 Frequency Tables** 

	Have yo	u had enough mor	ney to do things	as your friends?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	6	11.8	11.8	11.8
	Seldom (2)	10	19.6	19.6	31.4
	Quite Often				
	(3)	16	31.4	31.4	62.7
	Very Often				
	(4)	13	25.5	25.5	88.2
Valid	Always (5)	6	11.8	11.8	100.0
	Hav	ve you had enough	money for you	r expenses?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	3	5.9	5.9	5.9
	Seldom (2)	5	9.8	9.8	15.7
	Quite Often				
	(3)	12	23.5	23.5	39.2
	Very Often				
	(4)	12	23.5	23.5	62.7
Valid	Always (5)	19	37.3	37.3	100.0
	Do you h	ave enough mone	y to do things w	ith your friends?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all				
	(1)	3	5.9	5.9	5.9
	Slightly (2)	8	15.7	15.7	21.6
	Moderately				
	(3)	35	68.6	68.6	90.2
	Extremely				
Valid	(5)	5	9.8	9.8	100.0

Thus, the peer pressure and comparison to others play a significant role in the perception of the financial position of schoolchildren with ASD.

# **5.2.8. Friends (Social Support and Peers)**

The answers of schoolchildren with ASD in relation to the perception of their social support and peers show internal consistency indicated by high Cranbach's alpha (Table 5.18).

**Table 5.9 Reliability Test** 

Reliability Statistics		
Cronbach's Alpha	N of Items	
.953	6	

The schoolchildren with ASD find it very difficult to rely on their friends according to their responses (Table 5.19).

**Table 5.10 Frequency Tables** 

		Have you spent t	ime with your f	riends?	
		•	•		Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	15	29.4	29.4	33.3
	Quite Often				
	(3)	19	37.3	37.3	70.6
	Very Often				
	(4)	8	15.7	15.7	86.3
Valid	Always (5)	7	13.7	13.7	100.0
		e you done things			
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	4	7.8	7.8	7.8
	Seldom (2)	14	27.5	27.5	35.3
	Quite Often				
	(3)	20	39.2	39.2	74.5
	Very Often	v	27.2	37.2	, 1.5
	(4)	8	15.7	15.7	90.2
Valid	Always (5)	5	9.8	9.8	100.0
v and	mways (5)	Have you had fo			100.0
		Have you hau h	un with your m	lenus.	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	18	35.3	35.3	39.2
	Quite Often	10	33.3	33.3	39.2
	(3)	18	35.3	35.3	74.5
	Very Often	10	33.3	33.3	14.3
		6	11.8	11.8	86.3
Valid	(4) Always (5)	7	13.7	13.7	100.0
vanu		ve you and your f			100.0
	па	ve you and your i	Tienus neipeu e	acii other:	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)		11.8	11.8	11.8
	Seldom (2)	6 15	29.4	29.4	41.2
	Quite Often	13	∠ <b>7.</b> 4	27.4	41.2
	~	14	27.5	27.5	68.6
	(3)	14	27.5	27.5	08.0
	Very Often	0	17.6	17.6	96.2
X7.11.1	(4)	9 7	17.6 13.7	17.6	86.3
Valid	Always (5)	·		13.7	100.0
	Have you b	een adie to taik al	oout everytning	with your friends?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	N (1)				
	Never (1)	10	19.6	19.6	19.6
	Seldom (2)	14	27.5	27.5	47.1
	Quite Often	1.5	20.4	20.4	76.5
	(3)	15	29.4	29.4	76.5
	Very Often		110	11.0	00.2
	(4)	6	11.8	11.8	88.2
Valid	Always (5)	6	11.8	11.8	100.0
	H	ave you been ablo			
		Frequency	Percent	Valid Percent	Cumulative

					Percent
	Never (1)	11	21.6	21.6	21.6
	Seldom (2)	17	33.3	33.3	54.9
	Quite Often				
	(3)	12	23.5	23.5	78.4
	Very Often				
	(4)	6	11.8	11.8	90.2
Valid	Always (5)	5	9.8	9.8	100.0

Even though the majority of respondents state that they spend time with their friends quite often and did things with other girls and boys, when it comes to trust and mutual help, more negative responses are received. This finding indicates that even though schoolchildren with ASD can engage, to some extent, in social contact with their peers, the relationships are still far from being open and trusting.

## **5.2.9.** School and Learning (School Environment)

Difficulties in socialisation of the schoolchildren with ASD were expected to have an effect on the perception of their school environment. The schoolchildren with ASD responded to a set of six questions relating to this field and their responses were internally consistent (Table 5.20).

**Table 5.11 Reliability Test** 

Reliability Statistics			
Cronbach's Alpha	N of Items		
.960	6		

Predominantly, the schoolchildren with ASD demonstrate that they often feel happy at school and got on well (Table 5.21).

**Table 5.12 Frequency Tables** 

	Thinkin	g about the last wee	k, Have you been	happy at school?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	4	7.8	7.8	7.8
	Slightly (2)	4	7.8	7.8	15.7
	Moderately				
	(3)	27	52.9	52.9	68.6
	Very (4)	2	3.9	3.9	72.5
	Extremely				
Valid	(5)	14	27.5	27.5	100.0
		Have you go	t on well at schoo	1?	•
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	5	9.8	9.8	9.8
	Slightly (2)	5	9.8	9.8	19.6
	Moderately				
	(3)	27	52.9	52.9	72.5
	Very (4)	3	5.9	5.9	78.4
	Extremely		3.7	3.9	70.1
Valid	(5)	11	21.6	21.6	100.0
vand	(3)	Have you been sati			100.0
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	5	9.8	9.8	9.8
	Slightly (2)	2	3.9	3.9	13.7
	Moderately		3.9	3.9	13.7
		20	540	540	(0.6
	(3)	28	54.9	54.9	68.6
	Very (4)	3	5.9	5.9	74.5
37 11 1	Extremely	10	25.5	25.5	100.0
Valid	(5)	13	25.5	25.5	100.0
	Thinking a	,		ole to pay attention?	
	1	Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	12	23.5	23.5	25.5
	Quite Often				
	(3)	10	19.6	19.6	45.1
	Very Often				
	(4)	13	25.5	25.5	70.6
Valid	Always (5)	15	29.4	29.4	100.0
			yed going to scho	ool?	
	_	Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	13	25.5	25.5	29.4
	Quite Often				
	(3)	14	27.5	27.5	56.9
	Very Often				
	(4)	11	21.6	21.6	78.4
Valid	Always (5)	11	21.6	21.6	100.0
		Have you got along			•
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	4	7.8	7.8	7.8
	Seldom (2)	9	17.6	17.6	25.5
	Quite Often		17.0	27.0	20.0
	(3)	14	27.5	27.5	52.9
	Very Often	17	21.3	27.3	32.7
	(4)	11	21.6	21.6	74.5
Valid	Always (5)	13	25.5	25.5	100.0
v allu	raiways (3)	13	۷۵.۵	23.3	100.0

They also expressed satisfaction with their teachers and ability to pay attention during classes. Their responses also show that they were mostly able to get along well

with the teachers. Thus, in this respect the schoolchildren demonstrate a rather positive aspect in the quality of life.

#### **5.2.10.** Bullying (Social Acceptance)

The last area that was considered in the questionnaire is social acceptance of schoolchildren with ASD. The responses in this block of questions demonstrate internal consistency based on the Cranbach's alpha (Table 5.22).

**Table 5.13 Reliability Test** 

Reliability Statistics			
Cronbach's Alpha	N of Items		
.773	3		

Even though it was expected that abnormal behaviour of schoolchildren with ASD could alienate other schoolchildren and even cause bullying, these expectations were not confirmed based on the responses of schoolchildren with ASD (Table 5.23).

**Table 5.14 Frequency Tables** 

	H	ave you been afrai	d of other girls a	and boys?	
		•			Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	25	49.0	49.0	49.0
	Seldom (2)	16	31.4	31.4	80.4
	Quite Often				
	(3)	4	7.8	7.8	88.2
	Very Often				
	(4)	5	9.8	9.8	98.0
Valid	Always (5)	1	2.0	2.0	100.0
	H	Have other girls an	d boys made fui	n of you?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	30	58.8	58.8	58.8
	Seldom (2)	14	27.5	27.5	86.3
	Quite Often				
	(3)	3	5.9	5.9	92.2
	Very Often				
	(4)	3	5.9	5.9	98.0
Valid	Always (5)	1	2.0	2.0	100.0
		Have other girls	and boys bullied	d you?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	29	56.9	56.9	56.9
	Seldom (2)	13	25.5	25.5	82.4
	Quite Often				
	(3)	3	5.9	5.9	88.2
	Very Often				
	(4)	4	7.8	7.8	96.1
Valid	Always (5)	2	3.9	3.9	100.0

More than 80% of respondents expressed that they never or seldom feared other girls and boys. Quite similar results were achieved in regards to whether other boys and girls made fun of them and bullied them. Most of the schoolchildren with ASD reported that this occurred never or very seldom.

Analysis of the data of schoolchildren with ASD shows that the quality of life of the schoolchildren with ASD can be assessed based on ten categories, namely: Physical Well-being, Psychological Well-being, Moods and Emotions, Self-Perception, Autonomy, Parent Relationships & Home Life, Financial Resources, Social Support and Peers, School Environment and Social Acceptance. However, parent relationships and home life is the dominant factor in explaining the quality of the life of the schoolchildren with ASD whereas the explanatory power of the

following five factors; bullying, mood and emotions, self-perception, autonomy and social support and peers is weak comparing with parent relationships and home life. The following part will explore the data of the parents of the schoolchildren with ASD. This point will be explored further in the discussion chapter.

#### 5.3. Analysis of Parents' Data (the parents of schoolchildren with ASD)

The survey used the same questions and the same categories of answers provided to the parents. The main background information on parents and their schoolchildren who participated in the survey is provided in Table 5.24.

**Table 5.15 Background Information: Frequencies Table** 

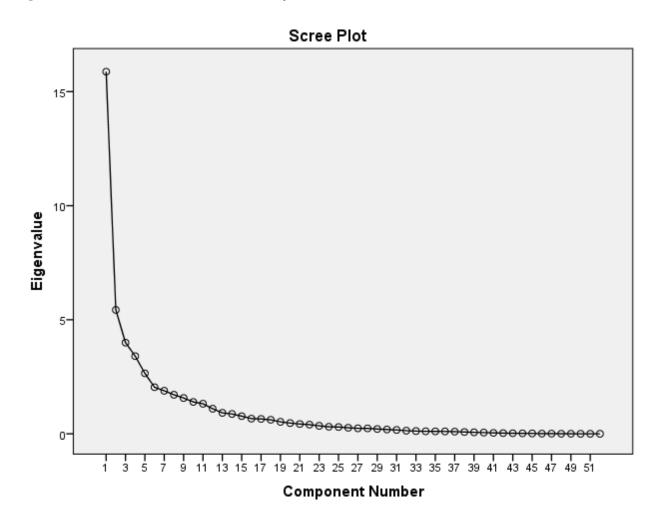
		Frequency	Percent	Valid Percent	Cumulative Percent
	Father	15	29.4	29.4	29.4
Parent	Mother	36	70.6	70.6	100.0
	Total	51	100.0	100.0	
	Low	5	9.8	9.8	9.8
Income	Medium	34	66.7	66.7	76.5
Hicome	High	12	23.5	23.5	100.0
	Total	51	100.0	100.0	
	Al-Riyadh	12	23.5	23.5	23.5
City	Jeddah	12	23.5	23.5	47.1
City	Makkah	27	52.9	52.9	100.0
	Total	51	100.0	100.0	
	Boy	30	58.8	58.8	58.8
Gender	Girl	21	41.2	41.2	100.0
	Total	51	100.0	100.0	

It can be seen that more than 70% of parents who participated in the survey are mothers. Fathers comprised only less than 30% of the sample. This can be explained by that women have a higher desire to participate than men and in addition to that typically mothers do complete surveys such as these and with the culture in KSA typically the mother would be responsible for this type of thing.

. The majority of respondents, namely 67% are from the middle income category. This is consistent with the results from the survey of schoolchildren. More than a half of respondents are from Makkah, and boys constitute the majority of the surveyed schoolchildren with ASD. This can be explained by the fact that boys had a higher probability to have autism than girls and sampling issues as it was impossible to generate a large enough sample to achieve an equal number of respondents. As in

the case with the schoolchildren survey, the principal component analysis was applied to the primary data based on the parents' survey. The following scree plot illustrates that similarity with the results from the schoolchildren's with ASD survey, there could be up to 10 significant factors.

Figure 5.1 Scree Plot for Parent's survey



However, the strongest factors are only the first five. Table 5.25 illustrates how much variance is explained by each of the factors. The components with less than one initial eigenvalues were not considered as significant.

**Table 5.16 Total Variance Explained** 

Component	Initial Eigenvalues			<b>Extraction Sums of Squared Loadings</b>			
	Total	% of Variance	<b>Cumulative %</b>	Total	% of Variance	Cumulative %	
1	15.889	29.979	29.979	15.889	29.979	29.979	
2	5.882	11.098	41.077	5.882	11.098	41.077	
3	4.049	7.639	48.716	4.049	7.639	48.716	
4	3.435	6.481	55.197	3.435	6.481	55.197	
5	2.655	5.009	60.206	2.655	5.009	60.206	
6	2.037	3.843	64.049	2.037	3.843	64.049	
7	1.966	3.710	67.759	1.966	3.710	67.759	
8	1.710	3.225	70.985	1.710	3.225	70.985	
9	1.641	3.096	74.080	1.641	3.096	74.080	
10	1.416	2.673	76.753	1.416	2.673	76.753	

It is observed that the first component explains more than 29.979% of total variance. Thus, it has the highest weight. Altogether, the first ten components explain 76.753% of total variance. At the same time, the survey of schoolchildren with ASD showed that 83% of variance could be explained by the first ten factors.

The main purpose of the principal component analysis is to distribute all responses by factors and for this reason factor loadings were calculated using the rotated pattern matrix. To be consistent with the case of the schoolchildren's survey, the rotation was conducted by employing the direct Oblimin technique in SPSS. Thus, an assumption was made that factors could be correlated.

The SPSS output produced several matrices including the pattern matrix and structured matrix. As in the case of the schoolchildren's survey, the pattern matrix was preferred because of the assumption of correlation between factors. This matrix demonstrated unique contributions of each factor in contrast to cumulative contributions evidenced by the structured matrix. Appendix B provides an output of the pattern matrix for the sample of parents' responses.

It can be clearly noticeable that the factors under investigation in the parent's survey are also correlated compared to the results of the principal component analysis in the schoolchildren's survey. However, the differences in the correlation results can be contributed to the differences in the perceptions of both the schoolchildren and their parents. The following table reports the correlations between components.

**Table 5.17 Correlations between Components** 

	Autonomy	Psychological Wellbeing	Mood and	Physical Wellbeing	Bullying	Social	Parent	Financial Resources	Self-	School Environment
Component		wendenig	Emotions	wendenig	Acceptance	Support and	Relationships and Home	Resources	Perception	Environment
Autonomy	1.000									
Psychologically	204	1.000								
Mood and emotions	.268	.303	1.000							
Physical well being	.303	.212	.336	1.000						
Bullying	.355	.236	238	.359	1.000					
Social peers	.314	.380	.273	.260	.239	1.000				
Parent relationships	.305	.479	.520	.357	297	.296	1.000			
financial resources	.374	.363	.489	.226	.284	.250	283	1.000		
self-perception	.332	.461	.205	.306	.257	.264	.435	167	1.000	
School environment	.379	203	.474	.314	.350	.208	.301	.182	216	1.000

It can be seen that, most of factors are correlated, which similar to the findings from the schoolchildren's survey. Noticeably, the highest correlation is between parent relationship and mood and emotions. Ten major factors are produced by the analysis. This indicates that this sample is more consistent with the theoretical factors. The rest of the chapter provides an in-depth analysis and comparison of each factor based on the two surveys.

#### **5.3.1.** Physical Activities and Health (Physical Well-being)

Physical well-being based on the responses of parents of schoolchildren with ASD was estimated and evaluated using the questions on health and physical activity of the parents' schoolchildren with ASD. Cronbach alpha was also used for testing internal consistency of response and this test was passed according to Table 5.27.

**Table 5.18 Reliability Test** 

Reliability Statistics						
Cronbach's Alpha	N of Items					
.758	4					

The results of testing of physical well-being are quite consistent with the schoolchildren's survey, which showed that more than fifty percent of the schoolchildren with ASD positively evaluated their health. The parents' survey demonstrated that only less than 8% of parents considered the physical well-being of their schoolchildren as fair and only two percent of respondents indicate that their schoolchildren were not physically active (Table 5.28).

**Table 5.19 Frequency Tables** 

In general, how would your child say his/her health?							
					Cumulative		
		Frequency	Percent	Valid Percent	Percent		
	Fair (2)	4	7.8	7.8	7.8		
	Good (3)	17	33.3	33.3	41.2		
Valid	Very Good (4)	25	49.0	49.0	90.2		
	Excellent (5)	5	9.8	9.8	100.0		
	Thinking a	bout the last weel	k, Has your chil	d felt fit and well?			
		Frequency	Percent	Valid Percent	Cumulative Percent		
	Not at all (1)	3	5.9	5.9	5.9		
	Moderately (2)	25	49.0	49.0	54.9		
	Very (3)	17	33.3	33.3	88.2		
Valid	Extremely (4)	6	11.8	11.8	100.0		
	Has your child	been physically a	ctive (e.g. runni	ng, climbing, bikir	ng)?		
		Frequency	Percent	Valid Percent	Cumulative Percent		
	Not at all (1)	1	2.0	2.0	2.0		
	Slightly (2)	17	33.3	33.3	35.3		
	Moderately (3)	22	43.1	43.1	78.4		
	Very (4)	3	5.9	5.9	84.3		
Valid	Extremely (5)	8	15.7	15.7	100.0		
		Has your child l	peen able to run	well?			
		Frequency	Percent	Valid Percent	Cumulative Percent		
	Slightly (2)	7	13.7	13.7	13.7		
Valid	Moderately (3)	27	52.9	52.9	66.7		
v and	Very (4)	8	15.7	15.7	82.4		
	Extremely (5)	9	17.6	17.6	100.0		

This proves that parents of schoolchildren with ASD feel that their children are rather healthy and lead a normal physical life as neurotypical schoolchildren. This is consistent with both the schoolchildren with ASD and their parents survey.

#### **5.3.2.** Feelings (Psychological Well-being)

Psychological well-being is as important as physical well-being. The former was assessed using responses of the parents of schoolchildren with ASD to the questions the schoolchildren's energy, enjoyment of life and satisfaction with life. According to the Cronbach's alpha test, these answers are internally consistent as evidenced from Table 5.29.

**Table 5.20 Reliability Test** 

Reliability Statistics						
Cronbach's Alpha	N of Items					
.703	4					

The original survey conducted among schoolchildren with ASD showed mostly positive attitudes to life and psychological well-being of schoolchildren. In contrast to this, parents predominantly chose a moderate answer indicating that they are not very certain about the psychological well-being of their schoolchildren (Table 5.30). This could be contributed that the parents might be more aware to the type of the disability and its impact of the quality of life than their schoolchildren with ASD might.

**Table 5.21 Frequency Tables** 

	Thinking al	out the last week	, Has your child	felt full of energy	?
		,	-		Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	9	17.6	17.6	19.6
	Quite Often (3)	22	43.1	43.1	62.7
	Very Often (4)	12	23.5	23.5	86.3
Valid	Always (5)	7	13.7	13.7	100.0
	Thinking about	the last week, Has	your child felt	that life was enjoy	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	2	3.9	3.9	3.9
	Slightly (2)	4	7.8	7.8	11.8
	Moderately (3)	37	72.5	72.5	84.3
	Very (4)	4	7.8	7.8	92.2
Valid	Extremely (5)	4	7.8	7.8	100.0
	Ha	s your child felt p	leased that he/sl	he is alive?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	3	5.9	5.9	5.9
	Slightly (2)	3	5.9	5.9	11.8
	Moderately (3)	30	58.8	58.8	70.6
	Very (4)	8	15.7	15.7	86.3
Valid	Extremely (5)	7	13.7	13.7	100.0
	•	Has your felt sati	sfied with his/h	er life?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	3	5.9	5.9	5.9
	Slightly (2)	4	7.8	7.8	13.7
	Moderately (3)	34	66.7	66.7	80.4
	Very (4)	5	9.8	9.8	90.2
Valid	Extremely (5)	5	9.8	9.8	100.0

Even though schoolchildren with ASD could demonstrate a tendency to enjoy life, they are not very open about this in front of their parents, which may explain why parents did not provide a strong answer to these questions.

# **5.3.3.** General Moods (Moods and Emotions)

Mood and emotions are measured by using 7 items. It is clear from the table 5.31, which represents the Cronbach's alpha test for reliability, that measurement is internally consistent because the value of Cronbach's alpha is 0.784.

**Table 5.22 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha N of Items				
.784	7			

However, in regards to mood and emotions, there appears to be more consistency in responses of schoolchildren and parents as evidenced from Table 5.32.

**Table 5.23 Frequency Tables** 

1	ninking about the			/she does everythin	
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	6	11.8	11.8	11.8
	Seldom (2)	32	62.7	62.7	74.5
	Quite Often (3)	11	21.6	21.6	96.1
Valid	Very Often (4)	2	3.9	3.9	100.0
, 4110	1 ('/	Has your	r child felt sad?		<u> </u>
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	5	9.8	9.8	9.8
	Seldom (2)	32	62.7	62.7	72.5
	Quite Often				
	(3)	12	23.5	23.5	96.1
Valid	Very Often (4)	2	3.9	3.9	100.0
	Has your cl	hild felt so bad that	he/she did not w	ant to do anything?	
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	11	21.6	21.6	21.6
	Seldom (2)	29	56.9	56.9	78.4
	Quite Often	10			
	(3)	10	19.6	19.6	98.0
	Very Often		2.0	2.0	4000
Valid	(4)	1	2.0	2.0	100.0
	· /	r child felt that ever	rything in his her	life goes wrong?	-1
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	14	27.5	27.5	27.5
	Seldom (2)	30	58.8	58.8	86.3
	Quite Often	6	11.8	11.8	98.0
T7 1' 1	Very Often	1	2.0	2.0	100.0
Valid	(4)	TT	1716461		
	1		child felt fed up?	7/ 1' 1 D	G 14: D
	1 27 (4)	Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	5	9.8	9.8	9.8
	Seldom (2)	35	68.6	68.6	78.4
	Quite Often (3)	10	19.6	19.6	98.0
Valid	Very Often (4)	1	2.0	2.0	100.0
	. ,	Has your	child felt lonely?	- I	
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	15	29.4	29.4	29.4
	Seldom (2)	29	56.9	56.9	86.3
	Quite Often				
	(3)	5	9.8	9.8	96.1
	Very Often				
Valid	(4)	2	3.9	3.9	100.0
	1		felt under pressu		0 1 2 5
	1 22	Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	10	19.6	19.6	19.6
	Seldom (2)	31	60.8	60.8	80.4
	Quite Often		17.6	17.6	98.0
	(3)	9	17.0	17.0	76.0

The majority of parents agree that their schoolchildren with ASD quite often had fun, felt cheerful and were in a good mood. At the same time, they state that their

schoolchildren seldom felt sad, were under pressure and felt lonely and fed.

Approximately, the same answers were received from schoolchildren themselves,
which makes this area of study rather consistent.

# **5.3.4.** About Your-self (Self-Perception)

There are also three questions that help describe self-perception of schoolchildren with ASD. Reliability test reported that answers to questions were internally consistent (See Table 5.33).

**Table 5.24 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha N of Items				
.908	3			

Both parents and schoolchildren provided rather close responses indicating that the schoolchildren with ASD are mostly confident about the way they look, what they wear, and feel happy with the way they are (Table 5.34).

**Table 5.25 Frequency Tables** 

	Has yo	ur child been worr	ried about the wa	y he/she look?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	40	78.4	78.4	78.4
	Seldom (2)	8	15.7	15.7	94.1
	Quite Often (3)	1	2.0	2.0	96.1
Valid	Very Often (4)	2	3.9	3.9	100.0
	Has your c	rls and boys look	?		
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	37	72.5	72.5	72.5
	Seldom (2)	11	21.6	21.6	94.1
	Quite Often (3)	2	3.9	3.9	98.0
Valid	Always (5)	1	2.0	2.0	100.0
	Has your		ge something abo	out his/her body?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	41	80.4	80.4	80.4
	Seldom (2)	8	15.7	15.7	96.1
	Quite Often (3)	1	2.0	2.0	98.0
Valid	Very Often (4)	1	2.0	2.0	100.0

The schoolchildren's survey reported that about 70% of respondents did not want to change anything in their body whereas more than 80% of parents stated that their schoolchildren did not want to change anything in their body. This slight discrepancy in results indicates that in some cases, parents tend to be more optimistic about their schoolchildren. However, the trends remain the same and consistent indicating that schoolchildren with ASD have rather high self-perception.

# 5.3.5. Free Time (Autonomy)

If schoolchildren are given enough autonomy, they will have more freedom and this was confirmed in the survey of the schoolchildren with ASD. The same questions were asked among parents. Just as in the schoolchildren's survey, the responses of parents were internally consistent following the results of the Cronbach's alpha statistic illustrated in Table 5.35.

**Table 5.26 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.801	5			

Most of the schoolchildren with ASD in the previous survey agreed that they were able to do things they wanted and had freedom. These responses found support in the parents' survey as parents also predominantly reported that their schoolchildren quite often could have time for themselves and were able to do what they wanted (Table 5.36).

**Table 5.27 Frequency Tables** 

	Has	your child had er	nough time for h	nim/his self?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	4	7.8	7.8	9.8
	Quite Often (3)	26	51.0	51.0	60.8
	Very Often (4)	16	31.4	31.4	92.2
Valid	Always (5)	4	7.8	7.8	100.0
			the things that	he/she wants to do	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	6	11.8	11.8	13.7
	Quite Often				
	(3)	21	41.2	41.2	54.9
	Very Often (4)	20	39.2	39.2	94.1
Valid	Always (5)	3	5.9	5.9	100.0
	Has yo	ur child had enou	igh opportunity	to be outside?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	9	17.6	17.6	21.6
	Quite Often (3)	29	56.9	56.9	78.4
	Very Often (4)	9	17.6	17.6	96.1
Valid	Always (5)	2	3.9	3.9	100.0
		your child had er	nough time to m		
					Cumulative
	NT (1)	Frequency	Percent	Valid Percent	Percent
	Never (1)	4	7.8	7.8	7.8
	Seldom (2)	21	41.2	41.2	49.0
	Quite Often (3)	23	45.1	45.1	94.1
	Very Often (4)	2	3.9	3.9	98.0
Valid	Always (5)	1	2.0	2.0	100.0
		ld been able to ch	oose what to do	in his/her free tim	e?
	j				Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	13	25.5	25.5	29.4
	Quite Often (3)	26	51.0	51.0	80.4
	Very Often	8	15.7	15.7	96.1
Vol: 1	(4)	2	2.0	2.0	100.0
Valid	Always (5)	2	3.9	3.9	100.0

However, in regards to the question whether their schoolchildren had enough time to meet friends provided rather mixed and even negative results stressing their

inability to find a quick social contact with their peers. In this respect, there is not much divergence between the responses of parents and schoolchildren. Both schoolchildren with ASD and parents predominantly stated that the schoolchildren could spend time outside quite often.

# 5.3.6. Family and Home Life (Parent Relationships & Home Life)

The little discrepancies in responses of schoolchildren with ASD and their parents, however, the responses of both schoolchildren and parents to these questions were mostly internally consistent (Table 5.37). The parent relationships and home life were assessed using six questions.

**Table 5.28 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha N of Items				
.867	6			

The survey of schoolchildren with ASD revealed that they had a good understanding with their parents and felt loved. These responses were confirmed by the survey of parents as shown in Table 5.38.

**Table 5.29 Frequency Tables** 

Thin	king about the	last week, Has you	r child felt unde	erstood by his/her	
		F	Danasant	Walid Dansont	Cumulative
	Moderately	Frequency	Percent	Valid Percent	Percent
	(3)	21	41.2	41.2	41.2
Valid	Very (4)	21	41.2	41.2	82.4
	Extremely (5)	9	17.6	17.6	100.0
		as your child felt le	oved by his/her	parent(s)?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Moderately (3)	18	35.3	35.3	35.3
Valid	Very (4)	21	41.2	41.2	76.5
	Extremely (5)	12	23.5	23.5	100.0
		out the last week,	Has your child l	peen happy at hom	ne?
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Seldom (2)	3	5.9	5.9	5.9
Valid	Quite Often (3)	27	52.9	52.9	58.8
vanu	Very Often (4)	12	23.5	23.5	82.4
	Always (5)	9	17.6	17.6	100.0
	Has your child	l felt that his/her p	arent(s) had en	ough time for his/l	
		_	_		Cumulative
	1 37 (4)	Frequency	Percent	Valid Percent	Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	4	7.8	7.8	9.8
	Quite Often (3)	24	47.1	47.1	56.9
	Very Often (4)	14	27.5	27.5	84.3
Valid	Always (5)	8	15.7	15.7	100.0
	Has your c	hild felt that his/h	er parent(s) trea	ated him/his fairly	
			ъ.	W P D	Cumulative
	Navan (1)	Frequency	Percent	Valid Percent	Percent
	Never (1) Quite Often	22	3.9 43.1	3.9	3.9 47.1
	(3) Very Often (4)	17	33.3	33.3	80.4
	(4)			1	
Valid		10	19.6	19.6	100.0
Valid	Always (5)	10 been able talk to be	19.6 er/his parent(s)	19.6 when he/she want	100.0 ed to?
	Always (5)	10 been able talk to h			
	Always (5)				ed to?
	Always (5)	been able talk to h	er/his parent(s)	when he/she want	ed to? Cumulative
	Always (5)  Has your child	been able talk to he Frequency	er/his parent(s) Percent	When he/she want	ed to?  Cumulative  Percent
	Always (5) Has your child Never (1)	Frequency	Percent 2.0	When he/she want Valid Percent 2.0	Cumulative Percent 2.0
	Always (5) Has your child  Never (1) Seldom (2) Quite Often	Frequency 1 6	Percent 2.0 11.8	Valid Percent 2.0 11.8	Cumulative Percent 2.0 13.7

More than 50% of schoolchildren with ASD indicated that they felt happy and treated at home. More than 75% of parents of schoolchildren with ASD agreed that their children quite often or very often felt happy at home. The responses also confirmed the statement of the schoolchildren with ASD that they could talk to their parents any time they wanted. The majority of parents indicated that their children quite often had this opportunity.

#### **5.3.7.** Money Matters (Financial Resources)

The survey also assess such an aspect of the schoolchildren's quality of life as availability of financial resources, and the answers to these questions among parents demonstrated high internal consistency proven by the high Cronbach's alpha statistic.

**Table 5.30 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha N of Items				
.802	3			

The schoolchildren's survey demonstrated that financial resources were sufficient for most schoolchildren with ASD but some respondents considered they could still do less than their friends with the money available. The parents' survey confirms that most parents state that their schoolchildren with ASD always or often have enough money for their expenses whereas only approximately 5% of respondents had problems with financial resources (Table 5.40).

**Table 5.31 Frequency Tables** 

	Has your ch	ild had enough mo	oney to do things	as his/her friend	s?
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	12	23.5	23.5	27.5
	Quite Often (3)	27	52.9	52.9	80.4
	Very Often (4)	7	13.7	13.7	94.1
Valid	Always (5)	3	5.9	5.9	100.0
		hild felt that had e	nough money for	r his/her expenses	?
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	1	2.0	2.0	5.9
	Quite Often (3)	15	29.4	29.4	35.3
	Very Often (4)	11	21.6	21.6	56.9
Valid	Always (5)	22	43.1	43.1	100.0
Does	your child felt t	hat he/she has eno	ugh money to do	things with his/h	er friends?
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all (1)	2	3.9	3.9	3.9
	Slightly (2)	22	43.1	43.1	47.1
	Moderately (3)	20	39.2	39.2	86.3
	Very (4)	5	9.8	9.8	96.1
Valid	Extremely (5)	2	3.9	3.9	100.0

However, the parents also demonstrated consistent results with their schoolchildren showing that even though in absolute terms financial resources are sufficient, they are not enough to do all things with their schoolchildren's friends.

# **5.3.8. Friends (Social Support and Peers)**

Both schoolchildren with ASD and their parents were asked about the social support and relationships with peers. This area was disclosed using six questions, and the parents' surveyed demonstrated rather high internal consistency of the answers indicated by the Cronbach's alpha reaching almost 0.9 (Table 5.41).

**Table 5.32 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.882	6			

The results of the survey conducted among schoolchildren with ASD reported difficulties associated with reliance of such schoolchildren on their friends. The same point of view is supported by the responses of parents as evidenced from Table 5.42.

**Table 5.33 Frequency Tables** 

		Has your child spent	t time with his/her	r friends?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	2	3.9	3.9	3.9
	Seldom (2)	21	41.2	41.2	45.1
	Quite Often (3)	24	47.1	47.1	92.2
	Very Often (4)	3	5.9	5.9	98.0
Valid	Always (5)	1	2.0	2.0	100.0
	Has	s your child done thi	ngs with other gir		
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	21	41.2	41.2	43.1
	Quite Often (3)	22	43.1	43.1	86.3
	Very Often (4)	6	11.8	11.8	98.0
Valid	Always (5)	1	2.0	2.0	100.0
, und	Titways (5)	Has your child had			100.0
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	1	2.0	2.0	2.0
	Seldom (2)	24	47.1	47.1	49.0
	Quite Often				
	(3)	22	43.1	43.1	92.2
	Very Often (4)	3	5.9	5.9	98.0
Valid	Always (5)	1	2.0	2.0	100.0
		ve you child and his/			
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	7	13.7	13.7	13.7
	Seldom (2)	35	68.6	68.6	82.4
	Quite Often (3)	6	11.8	11.8	94.1
	Very Often (4)	1	2.0	2.0	96.1
Valid	Always (5)	2	3.9	3.9	100.0
	Has your ch	ild been able to talk	about everything	with his/her friend	s?
	·	Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	14	27.5	27.5	27.5
	Seldom (2)	29	56.9	56.9	84.3
	Quite Often (3)	5	9.8	9.8	94.1
	Very Often (4)	1	2.0	2.0	96.1
Valid	Always (5)	2	3.9	3.9	100.0
			ole to rely on his/h	ner friends?	
	Ha	as your chiid been ai			
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)			Valid Percent 31.4	Cumulative Percent 31.4
		Frequency	Percent		
	Never (1)	Frequency 16	Percent 31.4	31.4	31.4
	Never (1) Seldom (2) Quite Often	Frequency 16 28	Percent 31.4 54.9	31.4 54.9	31.4 86.3

Only less than 8% of parents stated that their schoolchildren with ASD spent time with their friends very often or always. The majority indicated that such meetings were either rare or quite often. The same trend was observed in the

responses of the parents in relation to the activities of their schoolchildren with other boys and girls. Fewer than 6% of parents believed that friends of their schoolchildren provided any help constantly. Moreover, only less than 8% of respondents agreed that their schoolchildren with ASD had fun with their friends very often or always. Approximately 85% of parents state that their schoolchildren with ASD can seldom or never rely on friends and approximately 84% of parents state that their schoolchildren can seldom or never talk to their friends about anything. This supports the evidence from the schoolchildren's survey that even though schoolchildren with ASD get involved in social interactions, they find it difficult to develop open and trusting relationships.

#### **5.3.9.** School and Learning (School Environment)

The findings from the schoolchildren's with ASD survey demonstrated positive answers in the school environment. These answers are compared to the views provided by the parents. The following table reports that the responses provided by parents in regards to the questions that describe school environment are internally consistent according to the Cronbach's alpha statistic.

**Table 5.34 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.771	6			

Even though, most of the surveyed schoolchildren were rather happy at school, their parents predominantly state only moderate happiness of their schoolchildren with school (Table 5.44).

**Table 5.35 Frequency Tables** 

Frequency   Percent   Valid Percent   Cumulative Percent   (3)   28   54.9   54.9   68.6		Thinking a	bout the last week, l			
Moderately (3)			Frequency	Percent	Valid Percent	Cumulative Percent
(3)   28   54.9   54.9   54.9   56.0			7	13.7	13.7	13.7
Extremely (5)   8		· · · · · · · · · · · · · · · · · · ·	28	54.9	54.9	68.6
Extremely (5)   8		Very (4)	8	15.7	15.7	84.3
Has your child got on well at school?		Extremely	8	15.7	15.7	100.0
Not at all (1)   1   2.0   2.0   2.0			Has vour child	got on well at sch	ool?	
Not at all (1)						Cumulative Percent
Moderately (3)   25   49.0   49.0   64.7		Not at all (1)	1	2.0	2.0	2.0
Valid   Vali		Slightly (2)	7	13.7	13.7	15.7
Very (4)			25	49.0	49.0	64.7
Valid   Extremely (5)   4   7.8   7.8   100.0			14	27.5	27.5	92.2
Has your child been satisfied with her/his teachers?	Valid	Extremely	4			100.0
Not at all (1)			s vour child been sa	tisfied with her/h	is teachers?	
Not at all (1)						Cumulative Percent
Slightly (2)   10   19.6   19.6   21.6     Moderately (3)   22   43.1   43.1   64.7     Very (4)   12   23.5   23.5   88.2     Extremely (5)   6   11.8   11.8   100.0     Thinking about the last week, Has your child been able to pay attention?		Not at all (1)				
Moderately (3)   22   43.1   43.1   64.7			10		19.6	21.6
Valid   Valid   Extremely   6		Moderately	22	43.1	43.1	64.7
Extremely (5)   6			12	23.5	23.5	88.2
Thinking about the last week, Has your child been able to pay attention?	Valid	Extremely	6			
Never (1)			out the last week. Ha	s vour child been	able to pay attentio	n?
Never (1)   1   2.0   2.0   2.0   2.0   Seldom (2)   16   31.4   31.4   33.3   33.3   Quite Often (3)   20   39.2   39.2   72.5   72.5						
Seldom (2)   16   31.4   31.4   33.3		Never (1)				
Valid   Valid   Always (5)   3   5.9   5.9   100.0			16	31.4	31.4	33.3
Valid         Very Often (4)         11         21.6         21.6         94.1           Has your child enjoyed going to school?           Has your child enjoyed going to school?           Frequency         Percent         Valid Percent         Cumulative Percent           Seldom (2)         9         17.6         17.6         17.6           Quite Often (3)         24         47.1         47.1         64.7           Very Often (4)         10         19.6         19.6         84.3           Always (5)         8         15.7         15.7         100.0           Has your child got along well with his/her teachers?           Frequency         Percent         Valid Percent         Cumulative Percent           Seldom (2)         13         25.5         25.5         25.5           Quite Often (3)         17         33.3         33.3         58.8           Very Often         14         27.5         27.5         86.3		-	20	39.2	39.2	72.5
Has your child enjoyed going to school?   Frequency			11	21.6	21.6	94.1
Frequency   Percent   Valid Percent   Cumulative Percent     Seldom (2)   9   17.6   17.6   17.6     Quite Often (3)   24   47.1   47.1   64.7     Very Often (4)   10   19.6   19.6   84.3     Always (5)   8   15.7   15.7   100.0     Has your child got along well with his/her teachers?     Frequency   Percent   Valid Percent   Cumulative Percent     Seldom (2)   13   25.5   25.5   25.5     Quite Often (3)   17   33.3   33.3   58.8     Very Often   14   27.5   27.5   86.3	Valid	Always (5)				100.0
Seldom (2)         9         17.6         17.6         17.6           Quite Often (3)         24         47.1         47.1         64.7           Very Often (4)         10         19.6         19.6         84.3           Always (5)         8         15.7         15.7         100.0           Has your child got along well with his/her teachers?           Frequency         Percent         Valid Percent         Cumulative Percent           Seldom (2)         13         25.5         25.5         25.5           Quite Often (3)         17         33.3         33.3         58.8           Very Often         14         27.5         27.5         86.3			Has your child e	njoyed going to so		
Quite Often (3)         24         47.1         47.1         64.7           Very Often (4)         10         19.6         19.6         84.3           Always (5)         8         15.7         15.7         100.0           Has your child got along well with his/her teachers?           Frequency         Percent         Valid Percent         Cumulative Percent           Seldom (2)         13         25.5         25.5         25.5           Quite Often (3)         17         33.3         33.3         58.8           Very Often         14         27.5         27.5         86.3			Frequency			
Carro Often			9	17.6	17.6	17.6
(4)         10         19.6         19.6         84.3           Always (5)         8         15.7         15.7         100.0           Has your child got along well with his/her teachers?           Frequency         Percent         Valid Percent         Cumulative Percent           Seldom (2)         13         25.5         25.5         25.5           Quite Often (3)         17         33.3         33.3         58.8           Very Often         14         27.5         27.5         86.3		(3)	24	47.1	47.1	64.7
Always (5)   8   15.7   15.7   100.0		7.43	10	19.6	19.6	84.3
Has your child got along well with his/her teachers?           Frequency         Percent         Valid Percent         Cumulative Percent           Seldom (2)         13         25.5         25.5         25.5           Quite Often (3)         17         33.3         33.3         58.8           Very Often         14         27.5         27.5         86.3		Always (5)				100.0
Seldom (2)     13     25.5     25.5     25.5       Quite Often (3)     17     33.3     33.3     58.8       Very Often (4)     27.5     27.5     86.3		Ha	s your child got alor	ng well with his/ho	er teachers?	
Quite Often (3)     17     33.3     33.3     58.8       Very Often (14)     27.5     27.5     86.3			Frequency			Cumulative Percent
(3) 1/ 33.3 33.3 58.8 Very Often 14 27.5 27.5 86.3			13	25.5	25.5	25.5
		(3)	17	33.3	33.3	58.8
			14	27.5	27.5	86.3
Always (5) 7 13.7 13.7 100.0		Always (5)	7	13.7	13.7	100.0

The surveyed schoolchildren with ASD expressed satisfaction with their teachers but the majority of parents still provide moderate answers. Moreover, approximately a quarter of the surveyed parents reported that their schoolchildren

seldom got along well with teachers. It is also interesting to note that while the majority of schoolchildren reported that they were able to pay attention during classes, about a third of the parents stated that this occurred seldom. It can be concluded that schoolchildren provided more positive responses in relation to their school environment than parents who have been more critical about this element of quality of life. This result might partly be justified to that the parents have a higher level of expectation from school that schoolchildren especially that MOE (Ministry of Education) in KSA provide a lot of funds for both mainstream school and private school to accept more schoolchildren with disabilities.

#### **5.3.10** Bullying (Social Acceptance)

Social acceptance of schoolchildren with ASD was studied using three questions related to bullying. The parents responses indicate internal consistency (Table 5.45).

Table 5.36 Reliability Test

Reliability Statistics					
Cronbach's Alpha	N of Items				
.707	3				

The survey of schoolchildren with ASD did not confirm that such schoolchildren were subject to abnormal bullying and fears of other girls and boys. These responses were predominantly confirmed by parents as reported in Table 5.46.

**Table 5.37 Frequency Tables** 

	Has your child been afraid of other girls and boys?							
		Frequency	Percent	Valid Percent	Cumulative Percent			
	Never (1)	24	47.1	47.1	47.1			
	Seldom (2)	22	43.1	43.1	90.2			
	Quite Often (3)	4	7.8	7.8	98.0			
Valid	Very Often (4)	1	2.0	2.0	100.0			
	Hav	e other girls and b	oys made fun of	your child?				
					Cumulative			
		Frequency	Percent	Valid Percent	Percent			
	Never (1)	30	58.8	58.8	58.8			
	Seldom (2)	17	33.3	33.3	92.2			
Valid	Quite Often (3)	4	7.8	7.8	100.0			
	Н	ave other girls and	l boys bullied yo	ur child?				
		Frequency	Percent	Valid Percent	Cumulative Percent			
	Never (1)	36	70.6	70.6	70.6			
	Seldom (2)	13	25.5	25.5	96.1			
Valid	Quite Often (3)	2	3.9	3.9	100.0			

More than 70% of schoolchildren stated that they never or seldom were afraid of other boys and girls whereas more than 80% of parents held this position. The majority of parents also stated that their schoolchildren were never made fun of by other boys and girls and were never bullied. The next section will deal with data of the neurotypical schoolchildren.

#### 5.4. Analysis of Neurotypical Schoolchildren's Responses

The first step of the analysis is the assessment of the sample and respondents' profile. This includes such background information as the type of school the schoolchildren attend, income of their family, city from which responses were obtained and gender of the schoolchildren. The summary information for this background data is reported in the following frequency table.

**Table 5.47 Frequency Table of Schoolchildren Background Information** 

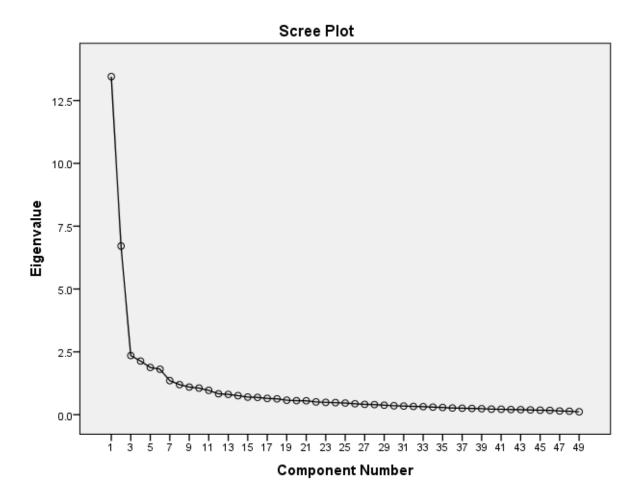
		Frequency	Percent	Valid Percent	Cumulative Percent
	Primary School 5-11 years	193	56.6	56.6	56.6
School	Secondary School 12-18	148	43.4	43.4	100.0
School	years				
	Total	341	100.0	100.0	
	Low	42	12.3	12.3	12.3
Income	Medium	15	4.4	4.4	16.7
income	High	284	83.3	83.3	100.0
	Total	341	100.0	100.0	
	Al-Riyadh	52	15.2	15.2	15.2
City	Jeddah	264	77.4	77.4	92.7
City	Makkah	25	7.3	7.3	100.0
	Total	341	100.0	100.0	
	Boy	99	29.0	29.0	29.0
Gender	Girl	242	71.0	71.0	100.0
	Total	341	100.0	100.0	

The sample size of the neurotypical schoolchildren is 341; the number of children in the primary school is slightly more than the number of children in the secondary school. The former constitute 56.6% of the respondents whereas the latter constitute 43.4. Concerning the income, the families of the neurotypical schoolchildren that participated in the survey are mainly from high class and only less than 4.4% of respondents considered themselves of middle income. Low-income participants constitute around 12.3% of the sample. The majority of the neurotypical schoolchildren were participated in the survey from Jeddah. This city accounts for more than 77.4% of the total sample whereas schoolchildren from Al-Riyadh and Makkah constitute 15.2% and 7.3% of the sample respectively. Finally, the sample of

respondents is skewed towards girls. The number of the girls in the sample is 242 respondents whereas the boys are only 99 respondents. This result can be contributed for two reasons, the first reason that empirical studies show the gender imbalance between the sexes (Dworzynski, 2012). This study is consistent with typical rates across the two sexes. The second reason that the Researcher has access to the girls' schools more than boys' schools for cultural limitations in Saudi Arabia. Therefore, it was impossible to increase the sample size to achieve the balance in the sample.

The questionnaire includes 52 questions in related to the quality of life of neurotypical schoolchildren. The estimation of the number of factors was achieved by applying Principal Components Analysis by using the 52 questions. This estimation was accomplished by identified the number of eigenvalues (Heck, Thomas, & Tabata, 2012) based on the correlations between the participants' answers in the questionnaire. The following scree plot has been constructed based on the estimates (Field, 2013).

Figure 5.3 Scree Plot



It can be seen from the scree plot above that there are only ten components with eigenvalues above one, which is consistent with the classification of Raven-Sieberer (2006). However, among these ten components, the highest weight belongs to the first component, which accounts for 13.452 % of total variance in the sample (Table 5.48).

**Table 5.48 Total Variance Explained** 

		Initial Eigenval	ues	<b>Extraction Sums of Squared Loadings</b>			
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	
1	13.452	27.454	27.454	13.452	27.454	27.454	
2	6.709	13.692	41.146	6.709	13.692	41.146	
3	2.351	4.798	45.943	2.351	4.798	45.943	
4	2.131	4.348	50.292	2.131	4.348	50.292	
5	1.877	3.830	54.122	1.877	3.830	54.122	
6	1.808	3.689	57.811	1.808	3.689	57.811	
7	1.354	2.764	60.575	1.354	2.764	60.575	
8	1.195	2.440	63.015	1.195	2.440	63.015	
9	1.099	2.243	65.258	1.099	2.243	65.258	
10	1.058	2.160	67.418	1.058	2.160	67.418	

The components together clarify around 67.418% of total variance in responses of the neurotypical schoolchildren. However, the explanatory power of the last five components such as school environment, self-perception, financial resources, parent relationships and home life and social support and peers is rather weak compared to the dominant factor, namely Physical activities and health. In order to test which questions fall into which factors, factor loadings were calculated based on the rotated pattern matrix (Muijs, 2011). Rotation was performed using the Direct Oblimin method in SPSS V 21 because it allows for an assumption that factors could be correlate (Davies, Hughes, & Hughes, 2014). This assumption had to be accounted for because it was expected that emotions and mood of respondents would be linked to psychological and physical wellbeing. Other rotation methods such as Varimax do not allow for such an assumption (Burns & Burns, 2008). The output provided both structured and pattern matrix of factors. However, the latter was analysed because it demonstrated unique contributions of each factor whereas the structured matrix demonstrated cumulative contributions, which would be meaningful only under an assumption that the factors are uncorrelated, which has not been proven (Bryman & Cramer, 2009).

In order to test interrelations between the ten measures of quality of life of neurotypical schoolchildren, the following correlation coefficients between components were estimated.

Table 5.49 Correlations between Components

Component	Physical Activities and Health	Feelings	General Mood	About yourself	Free time	Family and Home life	Money Matters	Friends	School and Learning	Bullying
Physical Activities and Health	1									
Feelings	.648	1								
General Mood	158	179	1							
About yourself	.153	.247	.482	1						
Free time	.453	.530	034	.377	1					
Family and Home life	.472	.593	274	.167	.505	1				
Money Matters	.319	.414	074	.212	.513	.519	1			
Friends	.404	.485	061	.229	.565	.405	.485	1		
School and Learning	.405	.490	204	.151	.419	.516	.466	.469	1	
Bullying	.058	.077	.483	.514	.264	.055	.096	.204	.156	1

The results indicate that the highest correlation exists between physical activities & health and feelings. This result can propose that the neurotypical schoolchildren the more they have a better health, the better they feel. The findings also show that a high correlation between the degree of self-perception of the neurotypical schoolchildren and their moods. In addition, the more free time the neurotypical schoolchildren have the more they feel better. This finding has a serious implication. In order to enjoy school and improve relationships with teachers, their parents at home should treat the neurotypical schoolchildren fairly.

The next section of the analysis tests each category from Raven-Sieberer (2006) for internal consistency using the Cranbach's alpha (Wagner, 2015) and frequency of responses of the neurotypical schoolchildren.

#### **5.4.1.** Physical activities and health (Physical Well-being)

Physical activities and health based on the responses of neurotypical schoolchildren were assessed by using the questions on health and physical activity of the neurotypical schoolchildren. The scale which has been used to measure the health and physical activity includes five questions. However, The Cronbach alpha was used for testing internal consistency of responses. This test indicates that internal consistently does not match the rule of thumb when the five items have been used. As a result, one item has been removed in order to meet the rule of thumb of reliability. After deleting the item, the Cronbach alpha test was passed according to table 5.50.

Table 5.50 Reliability Test

Reliability Statistics				
Cronbach's Alpha	N of Items			
.823	4			

The findings from the assessment of responses in regards to the physical activity, energy and fitness show that the majority of the neurotypical schoolchildren confirm positive assessments of their well-being. So the level of physical activity of the neurotypical schoolchildren is seen high with reference to the schoolchildren' ability to get around the home, to play and do physical activities such as sports (Table 5.51).

**Table 5.381 Frequency Tables** 

	Thinkin	g about the last w	eek. Have vou	felt fit and well?	
		B			Cumulative
		Frequency	Percent	Valid Percent	Percent
	Poor (1)	4	1.2	1.2	1.2
	Fair (2)	13	3.8	3.8	5.0
	Good (3)	62	18.2	18.2	23.2
	Very Good	73	21.4	21.4	44.6
	(4)				
	Excellent	189	55.4	55.4	100.0
Valid	(5)				
	Have you be	en physically acti	ve (e.g. running	g, climbing, biking)	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all	24	7.0	7.0	7.0
	(1)				
	Slightly (2)	18	5.3	5.3	12.3
	Moderately	62	18.2	18.2	30.5
	(3)				
	Very (4)	70	20.5	20.5	51.0
	Extremely	167	49.0	49.0	100.0
Valid	(5)				
		Have you bee	n able to run w	ell?	
		_	_		Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all	10	2.9	2.9	2.9
	(1)	17	<b>5</b> 0	7.0	7.0
	Slightly (2)	17 51	5.0 15.0	5.0	7.9 22.9
	Moderately (3)	51	15.0	15.0	22.9
	Very (4)	79	23.2	23.2	46.0
	Extremely	184	54.0	54.0	100.0
Valid	(5)				
		Have you fo	elt full of energy	y?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Poor (1)	6	1.8	1.8	1.8
	Fair (2)	21	6.2	6.2	7.9
	Good (3)	60	17.6	17.6	25.5
	Very Good (4)	125	36.7	36.7	62.2
	Excellent	129	37.8	37.8	100.0
Valid	(5)				

# **5.4.2.** Feelings (Psychological Well-being)

Psychological well-being of the neurotypical schoolchildren was assessed based on answers to six questions related to their emotions and satisfaction with life.

The results were internally consistent based on the Cranbach's alpha which is higher than 0.8 (Table 5.52).

**Table 5.52 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.827	6			

The view of neurotypical schoolchildren also demonstrate a tendency to be satisfied with their life so far, have generally positive emotions and enjoy life. In addition, the neurotypical schoolchildren experience positive feelings such as joy, happiness and cheerfulness (Table 5.53).

**Table 5.53 Frequency Tables** 

	Thinkin	g about the last we	ek, Has your life	been enjoyable?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	12	3.5	3.5	3.5
	Slightly (2)	13	3.8	3.8	7.3
	Moderately	152	44.6	44.6	51.9
	(3)				
	Very (4)	164	48.1	48.1	100.0
	Extremely	12	3.5	3.5	3.5
Valid	(5)				
		Have you felt ple			
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	8	2.3	2.3	2.3
	Slightly (2)	5	1.5	1.5	3.8
	Moderately	78	22.9	22.9	26.7
	(3)				
	Very (4)	250	73.3	73.3	100.0
** 11.1	Extremely	8	2.3	2.3	2.3
Valid	(5)	II fold as	latisfied with your	126.9	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	9	2.6	2.6	2.6
	Slightly (2)	<del>9</del>	2.0	2.0	4.7
	Moderately	113	33.1	33.1	37.8
	(3)	113	33.1	33.1	37.0
	Very (4)	212	62.2	62.2	100.0
	Extremely	9	2.6	2.6	2.6
Valid	(5)	,	2.0	2.0	2.0
, ,,,,,,,,,		about the last wee	k, Have you been	in a good mood?	<u> </u>
		Frequency	Percent	Valid Percent	Cumulative Percent
	Seldom (2)	9	2.6	2.6	2.6
	Quite Often	21	6.2	6.2	8.8
	(3)				
	Very Often	64	18.8	18.8	27.6
	(4)				
Valid	Always (5)	111	32.6	32.6	60.1
			u felt cheerful?	T	T =
	1 7 11 (2)	Frequency	Percent	Valid Percent	Cumulative Percent
	Seldom (2)	7	2.1	2.1	2.1
	Quite Often	25	7.3	7.3	9.4
	(3)	55	16.1	16.1	25.5
	Very Often (4)	33	10.1	10.1	25.5
Valid	Always (5)	113	33.1	33.1	58.7
v anu	Aiways (3)		you had fun?	33.1	30.1
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	4	1.2	1.2	1.2
	Seldom (2)	28	8.2	8.2	9.4
	Quite Often	67	19.6	19.6	29.0
	(3)	<del>-</del> *		-2.0	
	Very Often	92	27.0	27.0	56.0
	(4)				
	( ')				

# **5.4. 3. General Moods ( Moods and Emotions )**

Mood and emotions of the neurotypical schoolchildren were evaluated based on responses to the questions whether they felt depressed, unhappy, or in a bad mood. The results were internally consistent because the Cranbach's alpha reports the value above 0.9 (Table 5.54).

**Table 5.54 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.931	7			

The positive attitude of the neurotypical schoolchildren demonstrates a tendency to be in good mood. Mostly, they do not experience depressive moods, emotions and stressful feelings. The negative emotions are rare. The most common responses from them are that they quite often and very often find themselves in a good mood (Table 5.55).

**Table 5.55 Frequency Tables** 

	Thinking abou	t the last week Ha	vo vou folt that vo	u do everything bac	41 <sub>12</sub> 9
	i miiking abou	Frequency	Percent	Valid Percent	Cumulative Percent
	37 (1)				
	Never (1)	132	38.7	38.7	38.7
	Seldom (2)	117	34.3	34.3	73.0
	Quite Often (3)	34	10.0	10.0	83.0
	Very Often (4)	24	7.0	7.0	90.0
Valid	Always (5)	34	10.0	10.0	100.0
			you felt sad?		
		Frequency	Percent	Valid Percent	Cumulative Percen
	Never (1)	90	26.4	26.4	26.4
	Seldom (2)	136	39.9	39.9	66.3
	Quite Often (3)	47	13.8	13.8	80.1
	Very Often (4)	34	10.0	10.0	90.0
Valid	Always (5)	34	10.0	10.0	100.0
	Have y	you felt so bad that	you didn't want t		
		Frequency	Percent	Valid Percent	Cumulative Percer
	Never (1)	156	45.7	45.7	45.7
	Seldom (2)	78	22.9	22.9	68.6
	Quite Often	40	11.7	11.7	80.4
	(3)				
	Very Often (4)	32	9.4	9.4	89.7
Valid	Always (5)	35	10.3	10.3	100.0
	Hav	e you felt that every			
		Frequency	Percent	Valid Percent	Cumulative Percer
	Never (1)	194	56.9	56.9	56.9
	Seldom (2)	65	19.1	19.1	76.0
	Quite Often (3)	28	8.2	8.2	84.2
	Very Often (4)	23	6.7	6.7	90.9
Valid	Always (5)	31	9.1	9.1	100.0
		Have v	ou felt fed up?		· L
		Frequency	Percent	Valid Percent	Cumulative Percer
	Never (1)	123	36.1	36.1	36.1
	Seldom (2)	105	30.8	30.8	66.9
	Quite Often (3)	43	12.6	12.6	79.5
	Very Often (4)	34	10.0	10.0	89.4
Valid	Always (5)	36	10.6	10.6	100.0
· · · · · · · · · · · · · · · · · · ·		Have v	ou felt lonely?		
		Frequency	Percent	Valid Percent	Cumulative Percer
	Never (1)	172	50.4	50.4	50.4
	Seldom (2)	70	20.5	20.5	71.0
	Quite Often	33	9.7	9.7	80.6
	(3) Very Often (4)	31	9.1	9.1	89.7
Valid	Always (5)	35	10.3	10.3	100.0
*			elt under pressure		
		Frequency	Percent	Valid Percent	Cumulative Percer
	Nov (1)				
	Never (1)	152	44.6	44.6	44.6
	Seldom (2) Quite Often	69 40	20.2 11.7	20.2	64.8 76.5
	(3) Very Often	37	10.9	10.9	87.4
Valid	(4)				

A.1 (F)	10	10.6	10.6	100.0	í
Always (5)	43	12.6	12.6	100.0	i
			12.0		

When negative questions were asked such if they felt under pressure, 12.6 % of the neurotypical schoolchildren state that always, they feel under pressure.

# **5.4.4.** About Your-self (Self-perception)

The responses on self-perception also demonstrated high internal consistency as evidenced from the Cronbach's alpha test. The Cranbach's alpha reports the value above 0.7 (Table 5.56).

**Table 5.56 Reliability Test** 

Reliability Statistics for Negative Questions				
Cronbach's Alpha N of Items				
.871	3			
Reliability Statistics for Positive Questions				
Cronbach's Alpha	N of Items			
.711	2			

The responses summarised in the frequency table illustrate that the neurotypical schoolchildren tend to be comfortable with her/his appearance, self-confident and have a positive body image (Table 5.57).

**Table 5.57 Frequency Tables** 

	H	ave you been hap	py with the way	you are?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	6	1.8	1.8	1.8
	Seldom (2)	14	4.1	4.1	5.9
	Quite Often	46	13.5	13.5	19.4
	(3)				
	Very Often (4)	82	24.0	24.0	43.4
Valid	Always (5)	193	56.6	56.6	100.0
		Have you been ha	ppy with your	clothes?	
		J. S.	PPJ		Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	6	1.8	1.8	1.8
	Seldom (2)	12	3.5	3.5	5.3
	Quite Often	55	16.1	16.1	21.4
	(3)				
	Very Often (4)	61	17.9	17.9	39.3
Valid	Always (5)	207	60.7	60.7	100.0
		e you been worrie	ed about the wa	v vou look?	
		,			Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	159	46.6	46.6	46.6
	Seldom (2)	57	16.7	16.7	63.3
	Quite Often	26	7.6	7.6	71.0
	(3)				
	Very Often (4)	39	11.4	11.4	82.4
Valid	Always (5)	60	17.6	17.6	100.0
, 4110		felt jealous of the			100.0
	Trave you	reit jealous of the	c way other girl	and boys rook.	Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	179	52.5	52.5	52.5
	Seldom (2)	64	18.8	18.8	71.3
	Quite Often	32	9.4	9.4	80.6
	(3)	32	9.4	9.4	80.0
	Very Often	28	8.2	8.2	88.9
Valid	(4)				
	Would	you like to change	e something abo	out your body?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	208	61.0	61.0	61.0
	Seldom (2)	37	10.9	10.9	71.8
	Quite Often	16	4.7	4.7	76.5
	(3)	•			
	Very Often	23	6.7	6.7	83.3
	(4)				
Valid	Always (5)	57	16.7	16.7	100.0

When the neurotypical schoolchildren were asked if they felt jealous of the way others look, predominantly negative responses were received which proved their

confidence in their looks and clothes. Surprisingly, only 61.0% of schoolchildren confirmed that they do not want to change anything in their body. However, more than 70% of schoolchildren with ASD stated that they do not want to change anything about their body. This results show that the schoolchildren with ASD have higher self-perception than the neurotypical schoolchildren.

#### **5.4.5. Free Time (Autonomy)**

Five questions related with the level of the autonomy were employed in order to test internal consistency. The results from the surveys published by Kidscreen indicated that the Cronbach's alpha ranged from 0.77 to 0.9. With some minor exceptions, this research also provides a similar range of reliability statistics. The responses to these questions reveal internal consistency based on the findings from the Cranbach's alpha (Table 5.58).

**Table 5.58 Reliability Test** 

Reliability Statistics					
Cronbach's Alpha	N of Items				
.843	5				

Around 40% of the neurotypical schoolchildren agree that they are able to do things that they want showing that they are given freedom to be by themselves. However, responses to some of the questions such is if they had enough time to themselves and whether they had enough time to meet friends are rather mixed and without a particular tendency. These results are consistent with the results of the schoolchildren with ASD. They also do not have a specific tendency (Table 5.59).

**Table 5.59 Frequency Tables** 

		Have you had end	ough time for yo	ourself?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	13	3.8	3.8	3.8
	Seldom (2)	40	11.7	11.7	15.5
	Quite Often	61	17.9	17.9	33.4
	(3)				
	Very Often	86	25.2	25.2	58.7
	(4)				
Valid	Always (5)	13	3.8	3.8	3.8
	Have yo	u been able to do	the things that	you want to do?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	17	5.0	5.0	5.0
	Seldom (2)	35	10.3	10.3	15.2
	Quite Often	71	20.8	20.8	36.1
	(3)				
	Very Often	78	22.9	22.9	58.9
	(4)				
Valid	Always (5)	140	41.1	41.1	100.0
	Hav	e you had enough	opportunity to	be outside?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	43	12.6	12.6	12.6
	Seldom (2)	60	17.6	17.6	30.2
	Quite Often	62	18.2	18.2	48.4
	(3)				
	Very Often	82	24.0	24.0	72.4
	(4)				
Valid	Always (5)	94	27.6	27.6	100.0
	Н	ave you had enou	gh time to meet	t friends?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	33	9.7	9.7	9.7
	Seldom (2)	58	17.0	17.0	26.7
	Quite Often	71	20.8	20.8	47.5
	(3)				
	Very Often	66	19.4	19.4	66.9
** ** *	(4)		22 :		105 -
Valid	Always (5)	113	33.1	33.1	100.0
	Have you	been able to choo	ose what to do i	n your free time?	G 1.3
			ъ.	W II I D	Cumulative
	NT (4)	Frequency	Percent	Valid Percent	Percent
	Never (1)	8	2.3	2.3	2.3
	Seldom (2)	39	11.4	11.4	13.8
	Quite Often	65	19.1	19.1	32.8
	(3)		_		
	Very Often	89	26.1	26.1	58.9
	(4)				
Valid	Always (5)	140	41.1	41.1	100.0

The neurotypical schoolchildren who participated in the survey were unsure if they had enough time to be outside. This result is predominantly consistent with the

result of the schoolchildren with ASD who were hesitant whether they had enough time to be outside as well. This analysis demonstrates mostly high quality of life for both the neurotypical schoolchildren and schoolchildren with ASD.

# 5.4.6. Family and Home Life (Parents Relationships and Home Life)

Parents' relationship and home life is an important dimension of the quality of life. Six questions were applied to measure the quality of the interaction between the neurotypical schoolchildren and their parents or carer, and their feelings towards parents or carer. The responses of the neurotypical schoolchildren demonstrated internal consistency (Table 5.60).

**Table 5.60 Reliability Test** 

Reliability Statistics					
Cronbach's Alpha	N of Items				
.859	6				

It can be seen from the results that 68.0% of the neurotypical schoolchildren feel loved and supported by their families, 55.4% of them confirmed that the atmosphere at home is comfortable and their parents treat them fairly. These findings are steady with schoolchildren with ASD and their parents who share high mutual understanding and schoolchildren with ASD feel love according to their responses (Table 5.61).

**Table 5.61 Frequency Tables** 

	Thinking abou	ıt the last week, H	Iave your pare	nt(s) understood yo	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all (1)	11	3.2	3.2	3.2
	Slightly (2)	18	5.3	5.3	8.5
	Moderately (3)	64	18.8	18.8	27.3
	Very (4)	71	20.8	20.8	48.1
	Extremely	177	51.9	51.9	100.0
Valid	(5)				
		Have you felt lov	ed by your par	ent(s)?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	8	2.3	2.3	2.3
	Slightly (2)	8	2.3	2.3	4.7
	Moderately (3)	27	7.9	7.9	12.6
	Very (4)	66	19.4	19.4	32.0
Valid	Extremely (5)	232	68.0	68.0	100.0
		bout the last weel	k, Have you bee	en happy at home?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	6	1.8	1.8	1.8
	Seldom (2)	32	9.4	9.4	11.1
	Quite Often (3)	52	15.2	15.2	26.4
	Very Often (4)	76	22.3	22.3	48.7
Valid	Always (5)	175	51.3	51.3	100.0
	Hav	ve your parent(s)	had enough tin	ne for you?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	16	4.7	4.7	4.7
	Seldom (2)	35	10.3	10.3	15.0
	Quite Often (3)	60	17.6	17.6	32.6
	Very Often (4)	89	26.1	26.1	58.7
Valid	Always (5)	141	41.3	41.3	100.0
	,	Have your paren	t(s) treated you	fairly?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	9	2.6	2.6	2.6
	Seldom (2)	18	5.3	5.3	7.9
	Quite Often (3)	45	13.2	13.2	21.1
	Very Often (4)	80	23.5	23.5	44.6
Valid	Always (5)	189	55.4	55.4	100.0
	Have you be	een able talk to yo	our parent(s) w	hen you wanted to?	
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never (1)	9	2.6	2.6	2.6

Seldom (2)	17	5.0	5.0	7.6
Quite Often	36	10.6	10.6	18.2
(3)				
Very Often	85	24.9	24.9	43.1
(4)				
Always (5)	194	56.9	56.9	100.0

It is also found that both the neurotypical schoolchildren and schoolchildren with ASD are mostly able to talk to their parents when they want, more than half of them. Both indicate a positive area in the quality of their life.

# **5.4.7.** Money Matters (Financial Resources)

Financial resources are also another essential aspect of quality of life and answers of the neurotypical schoolchildren in this respect confirm internal consistency. Cronbach's Alpha meets the rule of thumb and falls in the acceptable range (Table 5.62).

**Table 5.62 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.876	3			

More than half of the neurotypical schoolchildren who participated in the survey confirmed that they feel satisfied and enjoy with financial resources. They have enough financial resources to cover their expenses. However, the neurotypical schoolchildren are unsure if they had enough money to do the same thing as their peers. The answers were mixed in terms of the question whether they had enough money to do things as their friends (Table 5.63).

**Table 5.63 Frequency Tables** 

	Have you	ı had enough mon	ey to do things	as your friends?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	15	4.4	4.4	4.4
	Seldom (2)	49	14.4	14.4	18.8
	Quite Often (3)	57	16.7	16.7	35.5
	Very Often (4)	90	26.4	26.4	61.9
Valid	Always (5)	130	38.1	38.1	100.0
	Hav	e you had enough	money for you	r expenses?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Never (1)	17	5.0	5.0	5.0
	Seldom (2)	28	8.2	8.2	13.2
	Quite Often (3)	50	14.7	14.7	27.9
	Very Often (4)	78	22.9	22.9	50.7
Valid	Always (5)	168	49.3	49.3	100.0
		ave enough money	y to do things w	ith your friends?	
					Cumulative
		Frequency	Percent	Valid Percent	Percent
	Not at all (1)	17	5.0	5.0	5.0
	Slightly (2)	25	7.3	7.3	12.3
	Moderately (3)	163	47.8	47.8	60.1
	Very (4)	136	39.9	39.9	100.0
Valid	Extremely (5)	17	5.0	5.0	5.0

This result is consistent with the schoolchildren with ASD who are unsure they had enough money to do things as their friends. Therefore, the peer pressure and comparison to others play a significant role in the perception of the financial position of both the neurotypical schoolchildren and the schoolchildren with ASD.

# **5.4.8. Friends (Social Support and Peers)**

This dimension investigates the nature of the neurotypical schoolchildren's relationships with other peers. The scale employed to measure the social support and peers includes a set of six questions. The responses of the neurotypical schoolchildren show internal consistency indicated by high Cranbach's alpha (Table 5.64).

**Table 5.64 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.864	6			

28.7% of the neurotypical schoolchildren show that it is hard to talk about everything with their friends according to their responses. Even 30.8% of the neurotypical schoolchildren find it is very difficult to rely on their friends. Similar results were achieved in regards to schoolchildren with ASD.

**Table 5.65 Frequency Tables** 

		Have you spent t	ime with your fri	ends?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	21	6.2	6.2	6.2
	Seldom (2)	31	9.1	9.1	15.2
	Quite Often (3)	65	19.1	19.1	34.3
	Very Often (4)	93	27.3	27.3	61.6
Valid	Always (5)	131	38.4	38.4	100.0
		lave you done thing		and boys?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	27	7.9	7.9	7.9
	Seldom (2)	44	12.9	12.9	20.8
	Quite Often	64	18.8	18.8	39.6
	(3)				
	Very Often (4)	91	26.7	26.7	66.3
Valid	Always (5)	115	33.7	33.7	100.0
Vulla	Tilways (5)		un with your frie		100.0
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	17	5.0	5.0	5.0
	Seldom (2)	18	5.3	5.3	10.3
	Quite Often	46	13.5	13.5	23.8
	(3)	40	13.3	15.5	23.0
	Very Often (4)	79	23.2	23.2	46.9
Valid	Always (5)	181	53.1	53.1	100.0
, ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		Have you and your			
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	10	2.9	2.9	2.9
	Seldom (2)	28	8.2	8.2	11.1
	Quite Often (3)	61	17.9	17.9	29.0
	Very Often (4)	86	25.2	25.2	54.3
Valid	Always (5)	156	45.7	45.7	100.0
	Have you	been able to talk a	bout everything v	vith your friends?	
	·	Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	21	6.2	6.2	6.2
	Seldom (2)	54	15.8	15.8	22.0
	Quite Often (3)	71	20.8	20.8	42.8
	Very Often (4)	97	28.4	28.4	71.3
Valid	Always (5)	98	28.7	28.7	100.0
**		Have you been able			
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	23	6.7	6.7	6.7
	Seldom (2)	47	13.8	13.8	20.5
	Quite Often (3)	82	24.0	24.0	44.6
	Very Often (4)	84	24.6	24.6	69.2
	(41)				

In addition, 38.4% of the neurotypical schoolchildren state that they spend time with their friends always and they experience positive group feelings. This finding indicates that the neurotypical schoolchildren easily engage in social contact

with their peers and friends. However, the schoolchildren with ASD had difficulties in socialisation.

## **5.4.9.** School and Learning (School Environment)

This filed explores the neurotypical schoolchildren's perceptions of their learning, concertation and feelings about the school. To what extent the neurotypical schoolchildren are satisfied with their ability and performance at school. The neurotypical schoolchildren responded to a set of six questions in terms of this dimension and their answers were internally consistent (Table 5.66).

**Table 5.66 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.858	6			

Predominantly, the neurotypical schoolchildren confirm that they are quote often feel happy at school and got on well (Table 5.67).

**Table 5.67 Frequency Tables** 

	Thinking	about the last wee	k, Have you been	happy at school?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	10	2.9	2.9	2.9
	Slightly (2)	21	6.2	6.2	9.1
	Moderately (3)	129	37.8	37.8	46.9
	Very (4)	181	53.1	53.1	100.0
	Extremely	10	2.9	2.9	2.9
Valid	(5)	10	2.7	2.9	2.7
		Have you go	t on well at schoo		ı
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	12	3.5	3.5	3.5
	Slightly (2)	16	4.7	4.7	8.2
	Moderately (3)	146	42.8	42.8	51.0
	Very (4)	167	49.0	49.0	100.0
Valid	Extremely (5)	12	3.5	3.5	3.5
v anu		Have you been sati	 sfied with your te	eachers?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	17	5.0	5.0	5.0
	Slightly (2)	26	7.6	7.6	12.6
				41.3	
	Moderately	141	41.3	41.3	54.0
	(3)	157	46.0	46.0	100.0
	Very (4)	157	46.0	46.0	100.0
Valid	Extremely (5)	17	5.0	5.0	5.0
	Thinking al	bout the last week,	Have you been ab	ole to pay attention?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	6	1.8	1.8	1.8
	Seldom (2)	23	6.7	6.7	8.5
	Quite Often (3)	46	13.5	13.5	22.0
	Very Often (4)	104	30.5	30.5	52.5
Valid	Always (5)	161	47.2	47.2	99.7
	, , , , , , , , , , , , , , , , , , ,	Have you enjo	yed going to scho	ool?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	9	2.6	2.6	2.6
	Seldom (2)	29	8.5	8.5	11.1
	Quite Often (3)	59	17.3	17.3	28.4
	Very Often (4)	71	20.8	20.8	49.3
Valid	Always (5)	173	50.7	50.7	100.0
, una		Have you got along			100.0
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	12	3.5	3.5	3.5
	Seldom (2)	32	9.4	9.4	12.9
	` ' '	84	24.6	24.6	37.5
	Ouite Often		∠4.0	∠4.0	31.3
	Quite Often (3)				
	-	78	22.9	22.9	60.4

They also expressed satisfaction with their teachers and ability to pay attention during classes. Their responses also show that they were mostly able to get along well

with the teachers. Thus, in this respect the schoolchildren demonstrate a rather positive aspect in the quality of life.

## **5.4.10.** Bulling (Social Acceptance)

The last dimension that was considered in the questionnaire is bullying of the neurotypical schoolchildren. This area covers the aspect of feeling rejected by friends and peers in schools. The responses in this block of questions demonstrate high internal consistency based on the Cranbach's alpha (Table 5.68).

**Table 5.68 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha N of Items				
.865	3			

Around 61 % of the neurotypical schoolchildren confirmed that other boys and girls in school are never bullying them and never made fun on them (Table 5.69).

**Table 5.69 Frequency Tables** 

	Ha	ive you been afrai	d of other girls a	and boys?	
		Frequency	Percent	Valid Percent	Cumulative
	Never (1)	211	61.9	61.9	61.9
	Seldom (2)	50	14.7	14.7	76.5
	Quite Often	12	3.5	3.5	80.1
	Very Often	25	7.3	7.3	87.4
Valid	Always (5)	43	12.6	12.6	100.0
	Н	lave other girls an	d boys made fui	n of you?	
		Frequency	Percent	Valid Percent	Cumulative
	Never (1)	210	61.6	61.6	61.6
	Seldom (2)	55	16.1	16.1	77.7
	Quite Often	22	6.5	6.5	84.2
	Very Often	24	7.0	7.0	91.2
Valid	Always (5)	30	8.8	8.8	100.0
		Have other girls	and boys bullied	l you?	
		Frequency	Percent	Valid Percent	Cumulative
	Never (1)	208	61.0	61.0	61.0
	Seldom (2)	53	15.5	15.5	76.5
	Quite Often	22	6.5	6.5	83.0
	Very Often	25	7.3	7.3	90.3
Valid	Always (5)	33	9.7	9.7	100.0

The neurotypical schoolchildren who participated in the survey also demonstrated that their peers and friends never fared them. This dimension shows a good score in quality of life because the negative feelings are rare.

# 5.5. Analysis of Parents' Data (The parents of the neurotypical schoolchildren)

The parent's survey used identical questions and the same categories of answers provided to the schoolchildren. The main background information on the parents of neurotypical schoolchildren who participated in the survey is provided in Table 5.70. The main background information on the parents of neurotypical schoolchildren who participated in the survey is provided in Table 5.70.

**Table 5.70 Background Information: Frequencies Table** 

		Frequency	Percent	Valid Percent	Cumulative Percent
	Father	48	16.0	16.0	16.0
Parent	Mother	252	84.0	84.0	100.0
	Total	300	100.0	100.0	
	Low	42	14.0	14.0	14.0
Income	Medium	12	4.0	4.0	18.0
income	High	246	82.0	82.0	100.0
	Total	300	100.0	100.0	
	Al-Riyadh	29	9.7	9.7	9.7
City	Jeddah	255	85.0	85.0	94.7
City	Makkah	16	5.3	5.3	100.0
	Total	300	100.0	100.0	
	Boy	103	34.3	34.3	34.3
Gender	Girl	197	65.7	65.7	100.0
	Total	300	100.0	100.0	

It can be seen that the majority of parents who participated in the survey are mothers. Fathers comprised only less than 16.0% of the sample. This can be explained by a higher responsiveness of females and their desire to share. This result is consistent with many previous studies, which show that women are more likely to participate than men (Moore & Tarnai, 2002). In terms of income, it can be seen that a large proportion of sample is high income earners, namely 82.0% of respondents are from the high income category. This is consistent with the results from the survey of schoolchildren. This is expected result because the average Saudi per capita annual income of SR 93,472 (\$ 24,925) is one of the highest in the Middle East and North

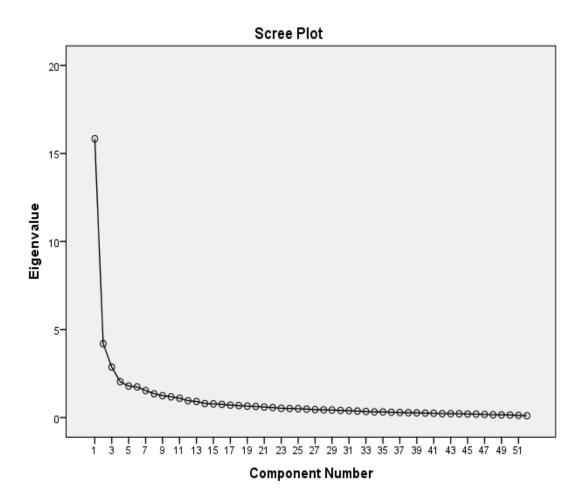
Africa region. Saudi economy depends on oil and is considered stable because there are no economic shocks that are affecting other countries, especially in Europe, and there are limited economic risks facing the Kingdom (Haddad, 2013).

More than a half of respondents are from Jeddah; this can be contributed to that Jeddah as Saudi Arabia's second largest city has many centres and schools for Autism. As a result, the large proportion of the data has been collected from this city. In addition to Makkah and Al-Riyadh have a few centers for autism, which have been used to collect the rest of the data in order to meet the target sample. Because of that the data for autism schoolchildren has been collected from three main cities in Saudi so the data for neurotypical schoolchildren also has been collected from the same three main cities in order to avoid the bias in the sample.

In addition, it can be clear from the table 5.70 that girls constitute the majority of the surveyed neurotypical schoolchildren. This can be explained by many reasons: first, for cultural reasons the researcher has easier access to girls' schools than boys' schools; second, the fact that it was impossible to generate a large enough sample to achieve an equal number of respondents; finally, this result is consistent with many previous studies. For example, Wolthers (2006) aimed to assess socio-demographic characteristics in healthy schoolchildren and adolescents and showed that girls are more likely to participate than boys.

As in the case with the schoolchildren survey, the principal component analysis was applied to the primary data based on the parents' survey. The following scree plot illustrates that in similarity to the results from the schoolchildren's survey, there could be up to 10 significant factors. There is similarity in the results of parents and schoolchildren.

Figure 5.4 Scree Plot



However, the strongest factors are only the first four. Table 5.71 illustrates how much variance is explained by each of the factors. The components with less than one initial eigenvalues were not considered as significant.

**Table 5.71 Total Variance Explained** 

	Total Variance Explained							
C	Initi	al Eigenvalues		Extracti	on Sums of Square	ed Loadings		
Component	Total	% of Variance	Cumulative	Total	% of Variance	Cumulative %		
1	15.834	30.450	30.450	15.834	30.450	30.450		
2	4.190	8.057	38.507	4.190	8.057	38.507		
3	2.870	5.519	44.027	2.870	5.519	44.027		
4	2.043	3.928	47.955	2.043	3.928	47.955		
5	1.790	3.442	51.397	1.790	3.442	51.397		
6	1.744	3.355	54.752	1.744	3.355	54.752		
7	1.534	2.950	57.702	1.534	2.950	57.702		
8	1.352	2.601	60.302	1.352	2.601	60.302		
9	1.241	2.386	62.688	1.241	2.386	62.688		
10	1.175	2.259	64.947	1.175	2.259	64.947		
Extra	ction Method: Pr	incipal Compo	nent Analysi	is.				

It is observed that the first component explains more than 30.45% of total variance. Thus, it has the highest weight. Altogether, the first ten components explain 64.947% of total variance. At the same time, the survey of neurotypical schoolchildren showed that 83% of variance could be explained by the first ten factors.

The main purpose of the principal component analysis is to distribute all responses by factors and for this reason factor loadings were calculated using the rotated pattern matrix. To be consistent with the case of the neurotypical schoolchildren's survey, the rotation was conducted by employing the direct oblimin technique in SPSS Version 21. Thus, an assumption was made that factors could be correlated.

The SPSS output produced several matrices including the pattern matrix and structured matrix. As in the case of the neurotypical schoolchildren's survey, the pattern matrix was preferred because of the assumption of correlation between factors.

This matrix demonstrated unique contributions of each factor in contrast to cumulative contributions evidenced by the structured matrix. Appendix B provides an output of the pattern matrix for the sample of parents' of neurotypial schoolchildren responses.

It is beneficial to notice that the results of the parents' of neurotypical schoolchildren survey is that the estimated factors are correlated in the same degree compared to the results of the principal component analysis based on the neurotypical schoolchildren's survey. This can be explained by similar views of neurotypical schoolchildren and their parents. The following table reports the correlations between components.

**Table 5.72 Correlations between Components** 

Component	Physical activities and health	Feelings	General Mood	Yourself	Free time	Family and free home life	Money	Friends	School and learning	Bullying
Physical activities and health	1.000									
Feelings	235	1.000								
General Mood	.413	334	1.000							
Yourself	.483	311	.326	1.000						
Free time	.009	132	.109	.029	1.000					
Family and free home life	.449	260	.437	.389	182	1.000				
Money	.267	336	.242	.058	035	.267	1.000			
Friends	.519	285	.338	.301	.126	.237	.268	1.000		
School and learning	.435	264	.465	.399	.010	.356	079	.238	1.000	
Bullying	345	.246	350	156	126	216	299	358	127	1.000

The positive correlation in the table 5.72 indicates that there is a positive relationship between the variables; as one variable increases or decreases, the other tends to increase or decrease with it. For example, when the Physical activities and

health increase the general mood of neurotypical schoolchildren increase as well. In the same way, when the general mood increase so the family and free home life will increase with it. Whereas, the negative correlation refers to that one of the variables increases, the other tends to decrease. For example, the physical activities and health of neurotypical schoolchildren increase the positive feelings and satisfaction with the life decrease.

#### **5.5.1.** Physical Activities and Health (Physical Well-being)

Physical activities and health based on the responses of parents of neurotypical schoolchildren was estimated and evaluated using the questions on health and physical activity of the parents' neurotypical schoolchildren. The scale which has been used to measure the health and physical activity includes five items. However, The Cronbach alpha was used for testing internal consistency of responses. This test indicates that internal consistency is under the acceptable range when the five items have been used. As a result, two items have been removed in order to meet the rule of thumb of reliability. After deleting the two items, the Cronbach alpha test was passed according to table 5.73.

**Table 5.73 Reliability Test** 

Reliability Statistics					
Cronbach's Alpha	N of Items				
0.732	3				

The results of testing of physical activities and health are quite consistent with the neurotypical schoolchildren's survey, which showed that the majority of the schoolchildren who are neurotypical positively evaluated their health. The parents' of the neurotypical schoolchildren survey demonstrated that more than 80% of parents considered the physical activities and health of their schoolchildren as very good (Table 5.74).

**Table 5.74 Frequency Tables** 

	Thinking about the last week Has your child felt fit and well?								
		Frequency	Percent	Valid Percent	Cumulative				
	Not at all	1	.3	.3	.3				
	Slightly (2)	8	2.7	2.7	3.0				
Valid	Moderately	40	13.3	13.3	16.3				
	Very (4)	58	19.3	19.3	35.7				
	Extremely	193	64.3	64.3	100.0				
	Have you been physically active (e.g. running, climbing, biking)?								
		Frequency	Percent	Valid Percent	Cumulative				
	Not at all	6	2.0	2.0	2.0				
	Slightly (2)	23	7.7	7.7	9.7				
Valid	Moderately	67	22.3	22.3	32.0				
	Very (4)	66	22.0	22.0	54.0				
	Extremely	138	46.0	46.0	100.0				
	Thinking ab	out the last week .	Has your child	l felt full of energ	y?				
		Frequency	Percent	Valid Percent	Cumulative				
	Never (1)	4	1.3	1.3	1.3				
	Seldom (2)	20	6.7	6.7	8.0				
Valid	Quite often	53	17.7	17.7	25.7				
	Very often	108	36.0	36.0	61.7				
	always (5)	115	38.3	38.3	100.0				

# **5.5.2.** Feelings (Psychological Well-being)

Feelings are measured by using 6 items. It is clear from the table 5.75, which represents the Cronbach's alpha test for reliability, that measurement is internally consistent because the value of Cronbach's alpha is 0.862

**Table 5.75 Reliability Test** 

Reliability Statistics					
Cronbach's Alpha	N of Items				
0.862	6				

Table 5.76 Frequency Tables

		1. Has your child fe	elt that life was enjo	yable?	
		Frequency	Percent	Valid Percent	Cumulative Perce
	Not at all (1)	1	.3	.3	.3
Valid	Slightly (2)	11	3.7	3.7	4.0
vana	moderately	138	46.0	46.0	50.0
	Extremely (5)	150	50.0	50.0	100.0
		Frequency	Percent	Valid Percent	Cumulative Perce
	Not at all (1)	3	1.0	1.0	1.0
	Slightly (2)	4	1.3	1.3	2.3
Valid	moderately	84	28.0	28.0	30.3
	Extremely (5)	209	69.7	69.7	100.0
	Extremely (3)	Has your child felt	l .		100.0
		Frequency	Percent	Valid Percent	Cumulative Perce
	Not at all (1)	2	.7	.7	.7
	Slightly (2)	12	4.0	4.0	4.7
Valid	moderately	113	37.7	37.7	42.3
	Extremely (5)	173	57.7	57.7	100.0
		bout the last week	. Has your child be	en in a good mood?	I
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	4	1.3	1.3	1.3
	Seldom (2)	15	5.0	5.0	6.3
Valid	Quite Often	51	17.0	17.0	23.3
	Very Often	120	40.0	40.0	63.3
	Always (5)	110	36.7	36.7	100.0
	• ` ` ` `	Has your c	hild felt cheerful?	1	II.
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	1	.3	.3	.3
	Seldom (2)	19	6.3	6.3	6.7
Valid	Quite Often	59	19.7	19.7	26.3
	Very Often	113	37.7	37.7	64.0
	Always (5)	108	36.0	36.0	100.0
		Has you	r child had fun?		
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	18	6.0	6.0	6.0
	Seldom (2)	58	19.3	19.3	25.3
Valid	Quite Often	110	36.7	36.7	62.0
	Very Often	114	38.0	38.0	100.0
	Always (5)	18	6.0	6.0	6.0

The majority of parents agree that their neurotypical schoolchildren quite often had satisfaction and positive feelings with life such as happiness, cheerfulness and joy. At the same time, they state that their schoolchildren seldom felt sad and they showed satisfaction with the life so far.

#### **5.5.3.** General Moods (Moods and Emotions)

General Mood is measured by using 7 items. It is clear from Table 5.77, which represents the Cronbach's alpha test for reliability, that measurement is internally consistent because the value of Cronbach's alpha is 0.875.

**Table 5.77 Reliability Test** 

Reliability Statistics					
Cronbach's Alpha	N of Items				
.875	7				

More than 80% of parents agree that their neurotypical schoolchildren quite often had fun, felt cheerful and were in a good mood. At the same time, they state that their schoolchildren seldom felt sad, were under pressure and felt lonely and fed. Approximately, the same answers were received from neurotypical schoolchildren themselves, which makes this area of study rather consistent as clear in the first part of this chapter.

**Table 5.78 Frequency Tables** 

	King about the las			he/she does everyth	
	1 //	Frequency	Percent	Valid Percent	Cumulative
	Never (1)	134	44.7	44.7	44.7
	Seldom (2)	111	37.0	37.0	81.7
Valid	Quite Often	27	9.0	9.0	90.7
	Very Often	23	7.7	7.7	98.3
	Always (5)	5	1.7	1.7	100.0
			child felt sad?	1 1	
		Frequency	Percent	Valid Percent	Cumulative
	Never (1)	107	35.7	35.7	35.7
	Seldom (2)	140	46.7	46.7	82.3
Valid	Quite Often	21	7.0	7.0	89.3
	Very Often	27	9.0	9.0	98.3
	Always (5)	5	1.7	1.7	100.0
	Has your chi	ld felt so bad that	he/she didn't v	vant to do anything	
		Frequency	Percent	Valid Percent	Cumulative
	Never (1)	154	51.3	51.3	51.3
	Seldom (2)	96	32.0	32.0	83.3
Valid	Quite Often	21	7.0	7.0	90.3
	Very Often	27	9.0	9.0	99.3
	Always (5)	2	.7	.7	100.0
	Has your c	hild felt that ever	ything in his he	er life goes wrong?	
	•	Frequency	Percent	Valid Percent	Cumulative
	Never (1)	202	67.3	67.3	67.3
	Seldom (2)	69	23.0	23.0	90.3
Valid	Quite Often	12	4.0	4.0	94.3
	Very Often	16	5.3	5.3	99.7
	Always (5)	1	.3	.3	100.0
		Has your c	hild felt fed up		
		Frequency	Percent	Valid Percent	Cumulative
	Never (1)	111	37.0	37.0	37.0
	Seldom (2)	116	38.7	38.7	75.7
Valid	Quite Often	36	12.0	12.0	87.7
	Very Often	31	10.3	10.3	98.0
	Always (5)	6	2.0	2.0	100.0
	1) = (= )		hild felt lonely		
		Frequency	Percent	Valid Percent	Cumulative
	Never (1)	197	65.7	65.7	65.7
	Seldom (2)	58	19.3	19.3	85.0
Valid	Quite Often	16	5.3	5.3	90.3
	Very Often	20	6.7	6.7	97.0
	Always (5)	9	3.0	3.0	100.0
	111111111111111111111111111111111111111	Has your child			100.0
		Frequency	Percent	Valid Percent	Cumulative
	Never (1)	178	59.3	59.3	59.3
	Seldom (2)	79	26.3	26.3	85.7
Volid	Quite Often	17	5.7	5.7	91.3
Valid			.)./		71)
Valid	Very Often	20	6.7	6.7	98.0

## **5.5.4.** About Your-self (Self-Perception)

There are originally five questions that help to describe about yourself factor of parents of neurotypical schoolchildren. However, Reliability test reported that answers to questions were not internally consistent. The reliability is 0.460 which is under the rule of thumb (0.7). As a result, two questions have been removed in order to meet the acceptable level of reliability. There are only three questions that help describe about yourself factor of parents of neurotypical schoolchildren. Reliability test reported that answers to questions were internally consistent See (Table 5.79).

**Table 5.79 Reliability Test** 

Reliability Statistics					
Cronbach's Alpha N of Items					
.801	3				

**Table 5.80 Frequency Table** 

	Has	your child been wor	ried about the way	he/she look?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	177	59.0	59.0	59.0
	Seldom (2)	54	18.0	18.0	77.0
Valid	Quite Often	24	8.0	8.0	85.0
	Very Often (4)	25	8.3	8.3	93.3
	Always (5)	20	6.7	6.7	100.0
	Has you	ır child felt jealous o	f the way other girls	s and boys look?	1
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	178	59.3	59.3	59.3
	Seldom (2)	71	23.7	23.7	83.0
Valid	Quite Often	17	5.7	5.7	88.7
	Very Often (4)	18	6.0	6.0	94.7
	Always (5)	16	5.3	5.3	100.0
	Would	your child like to cha	nge something abou	ut his/her body?	•
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	192	64.0	64.0	64.0
	Seldom (2)	62	20.7	20.7	84.7
Valid	Quite Often	15	5.0	5.0	89.7
	Very Often (4)	18	6.0	6.0	95.7
	Always (5)	13	4.3	4.3	100.0

More than 64 % of the parents of neurotypical schoolchildren stated that their schoolchildren did not want to change anything in their body whereas the neurotypical schoolchildren's survey reported that majority of respondents around 90% did not want to change anything in their body. This slight discrepancy in results indicates that in some cases, parents tend to be more optimistic about their schoolchildren. However, the trends remain the same and consistent indicating that neurotypical schoolchildren have rather high self-esteem.

## 5.5.5. Free Time (Autonomy)

If schoolchildren are given enough free time, they will have the opportunity to make choice and this was confirmed in the survey of the neurotypical schoolchildren. The same questions were asked among their parents. Just as in the neurotypical schoolchildren's survey, the responses of parents were internally consistent following the results of the Cronbach's alpha statistic illustrated in Table 5.81.

Table 5.81 Reliability Test

Reliability Statistics				
Cronbach's Alpha N of Items				
.805	5			

Most of the neurotypical schoolchildren in the main survey agreed that they were able to do things they wanted when they have a free time. These responses found support in the parents' survey as parents also predominantly reported that their schoolchildren quite often could have time for themselves and were able to do what they wanted (Table 5.82).

**Table 5.82 Frequency Tables** 

		Has your child had e	enough time for his/	herself?	
		Frequency	Percent	Valid Percent	Cumulative Percen
	Never (1)	2	.7	.7	.7
	Seldom (2)	32	10.7	10.7	11.3
	Quite Often (3)	56	18.7	18.7	30.0
Valid	Very Often (4)	72	24.0	24.0	54.0
	Always (5)	138	46.0	46.0	100.0
	Has you	r child been able to d	lo the things that he	e/she want to do?	П
		Frequency	Percent	Valid Percent	Cumulative Percen
	Never (1)	2	.7	.7	.7
	Seldom (2)	18	6.0	6.0	6.7
Valid	Quite Often (3)	59	19.7	19.7	26.3
	Very Often (4)	87	29.0	29.0	55.3
	Always (5)	134	44.7	44.7	100.0
	На	s your child had eno	ugh opportunity to	be outside?	I
		Frequency	Percent	Valid Percent	Cumulative Percen
	Never (1)	45	15.0	15.0	15.0
	Seldom (2)	52	17.3	17.3	32.3
Valid	Quite Often (3)	69	23.0	23.0	55.3
	Very Often (4)	86	28.7	28.7	84.0
	Always (5)	48	16.0	16.0	100.0
	I I	Has your child had e	nough time to meet	friends?	ı
		Frequency	Percent	Valid Percent	Cumulative Percer
	Never (1)	28	9.3	9.3	9.3
	Seldom (2)	70	23.3	23.3	32.7
Valid	Quite Often (3)	62	20.7	20.7	53.3
	Very Often (4)	82	27.3	27.3	80.7
	Always (5)	58	19.3	19.3	100.0
		child been able to ch	noose what to do in	his/her free time?	I
		Frequency	Percent	Valid Percent	Cumulative Percen
	Never (1)	6	2.0	2.0	2.0
	Seldom (2)	20	6.7	6.7	8.7
Valid	Quite Often (3)	64	21.3	21.3	30.0
	Very Often (4)	96	32.0	32.0	62.0
	Always (5)	114	38.0	38.0	100.0

Approximately 90% of parents of neurotypical schoolchildren state that their children are able to choose what to do in their free time. However, in regards to the question whether their schoolchildren had enough time to meet friends provided

positive results stressing their ability to find a quick social interaction with their friends. In this respect, there is not much divergence between the responses of parents and schoolchildren. Both schoolchildren and parents predominantly stated that the schoolchildren could spend time outside quite often.

## 5.5.6. Family and Home Life (Parents Relationship and Home Life)

The family relationships and home life were assessed using six questions. The responses of both neurotypical schoolchildren and their parents to these questions were mostly internally consistent (Table 5.83).

**Table 5.83 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.857	6			

The main survey of neurotypical schoolchildren revealed that they had a good understanding with their parents and felt loved. These responses were confirmed by the survey of parents as shown in Table 5.84.

**Table 5.84 Frequency Tables** 

	Thinking about	t the last week, Has	your child felt t	understood by his/her p	parent(s)?
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	7	2.3	2.3	2.3
	Seldom (2)	11	3.7	3.7	6.0
Valid	Moderately (3)	58	19.3	19.3	25.3
	Very (4)	86	28.7	28.7	54.0
	Extremely (5)	138	46.0	46.0	100.0
		Has your child f	elt loved by his/	her parent(s)?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	4	1.3	1.3	1.3
	Seldom (2)	3	1.0	1.0	2.3
Valid	Moderately (3)	28	9.3	9.3	11.7
_	Very (4)	66	22.0	22.0	33.7
	Extremely (5)	199	66.3	66.3	100.0
I	Thinkir	ng about the last we	ek, Has your ch	ild been happy at home	e?
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	3	1.0	1.0	1.0
_	Seldom (2)	13	4.3	4.3	5.3
Valid	Quite Often (3)	44	14.7	14.7	20.0
_	Very Often (4)	98	32.7	32.7	52.7
	Always (5)	142	47.3	47.3	100.0
<u> </u>	Has your	child felt that his/l	ner parent(s) ha	d enough time for his/h	er?
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	5	1.7	1.7	1.7
	Seldom (2)	27	9.0	9.0	10.7
Valid	Quite Often (3)	62	20.7	20.7	31.3
	Very Often (4)	93	31.0	31.0	62.3
-	Always (5)	113	37.7	37.7	100.0
<u> </u>	Has y	our child felt that h	is/her parent(s)	treated him/his fairly?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	4	1.3	1.3	1.3
-	Seldom (2)	17	5.7	5.7	7.0
Valid	Quite Often (3)	58	19.3	19.3	26.3
-	Very Often (4)	90	30.0	30.0	56.3
-	Always (5)	131	43.7	43.7	100.0
		hild been able talk	to her/his paren	nt(s) when he/she wante	d to?
	•	Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	2	.7	.7	.7
-	Seldom (2)	10	3.3	3.3	4.0
Valid	Quite Often (3)	36	12.0	12.0	16.0
-	Very Often (4)	74	24.7	24.7	40.7
-	Always (5)	178	59.3	59.3	100.0

The majority of the sample of neurotypical schoolchildren indicated that they felt happy and treated at home. More than 79% of their parents agreed that their children always or very often felt happy at home. The parents of neurotypical schoolchildren also confirmed the statement of their children that they could talk to their parents any time they wanted. The majority of parents indicated that their children quite often had this opportunity.

#### **5.5.7.** Money Matters (Financial Resources)

The survey also assesses such an aspect of the neurotypical schoolchildren's quality of life as availability of financial resources, and the answers to these questions among their parents demonstrated high internal consistency proven by the high Cronbach's alpha statistic.

**Table 5.85 Reliability Test** 

Reliability Statistics					
Cronbach's Alpha	N of Items				
.825	3				

On the one hand, the answers of neurotypical schoolchildren demonstrated that financial resources were sufficient for neurotypical schoolchildren. However, some respondents considered they could still do less than their friends with the money available. On the other hand, 77% of the parents' survey confirms that most parents state that their children always or often have enough money for their expenses whereas only nearly 0.7% of respondents had problems with financial resources (Table 5.86).

**Table 5.86 Frequency Tables** 

	Has your	child had enough m	oney to do things	as his/her friends?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	14	4.7	4.7	4.7
	Seldom (2)	30	10.0	10.0	14.7
Valid	Quite Often	69	23.0	23.0	37.7
	Very Often	88	29.3	29.3	67.0
	Always (5)	99	33.0	33.0	100.0
	Has y	your child had enoug	gh money for his/l	her expenses?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	2	.7	.7	.7
	Seldom (2)	18	6.0	6.0	6.7
Valid	Quite Often	49	16.3	16.3	23.0
	Very Often	75	25.0	25.0	48.0
	Always (5)	156	52.0	52.0	100.0
	Does your cl	hild have enough me	oney to do things	with his/her friends	?
		Frequency	Percent	Valid Percent	Cumulative Percent
	Not at all (1)	11	3.7	3.7	3.7
	Slightly (2)	17	5.7	5.7	9.3
Valid	Moderately	169	56.3	56.3	65.7
	Very (4)	103	34.3	34.3	100.0
	Extremely	11	3.7	3.7	3.7

However, the parents of neurotypical schoolchildren confirmed consistent results with their neurotypical schoolchildren showing that even though in absolute terms money is sufficient, it is enough to allow schoolchildren to live a lifestyle which is comparable to other schoolchildren and provides the opportunity to do things together with peers and friends.

## **5.5.8. Friends (Social Support and Peers)**

Both neurotypical schoolchildren and their parents were asked about their friends. This area was disclosed using six questions, and the parents' surveyed demonstrated rather high internal consistency of the answers indicated by the Cronbach's alpha reaching almost 0.874 (Table 5.87).

**Table 5.87 Reliability Test** 

Reliability Statistics				
Cronbach's Alpha	N of Items			
.874	6			

The findings of the main survey conducted among neurotypical schoolchildren reported difficulties related to reliance of such schoolchildren on their friends. The same point of view is supported by the responses of parents as evidenced from Table 5.88.

**Table 5.88 Frequency Tables** 

		Has your child spen	ı	1	1
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	16	5.3	5.3	5.3
	Seldom (2)	48	16.0	16.0	21.3
Valid	Quite Often	69	23.0	23.0	44.3
	Very Often (4)	86	28.7	28.7	73.0
	Always (5)	81	27.0	27.0	100.0
	Ha	s your child done thi	ings with other girls	and boys?	
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	11	3.7	3.7	3.7
	Seldom (2)	37	12.3	12.3	16.0
Valid	Quite Often	80	26.7	26.7	42.7
	Very Often (4)	92	30.7	30.7	73.3
	Always (5)	80	26.7	26.7	100.0
		Has your child had	l fun with his/her fr	iends?	•
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	8	2.7	2.7	2.7
	Seldom (2)	29	9.7	9.7	12.3
Valid	Quite Often	61	20.3	20.3	32.7
	Very Often (4)	85	28.3	28.3	61.0
	Always (5)	117	39.0	39.0	100.0
	Ha	s your child and his/	her friends helped e	each other?	1
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	12	4.0	4.0	4.0
	Seldom (2)	23	7.7	7.7	11.7
Valid	Quite Often	69	23.0	23.0	34.7
	Very Often (4)	89	29.7	29.7	64.3
	Always (5)	107	35.7	35.7	100.0
	Has your cl	aild been able to talk	about everything w	vith his/her friends?	L
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	16	5.3	5.3	5.3
	Seldom (2)	51	17.0	17.0	22.3
Valid	Quite Often	87	29.0	29.0	51.3
	Very Often (4)	77	25.7	25.7	77.0
	Always (5)	69	23.0	23.0	100.0
	•	as your child been a	ble to rely on his/he	er friends?	ı
		Frequency	Percent	Valid Percent	Cumulative Perce
	Never (1)	28	9.3	9.3	9.3
	Seldom (2)	78	26.0	26.0	35.3
Valid	Quite Often	64	21.3	21.3	56.7
7 unu	Very Often (4)	71	23.7	23.7	80.3
	vory Officia (4)				

More than 51.7 % of parents of neurotypical schoolchildren stated that their children spent time with their friends very or quite often whereas around 27.0% of the parents of neurotypical schoolchildren indicated that such meetings were always. Totally, 78.7% of neurotypical schoolchildren spent time with their friends according to their parents. Similar findings were observed in the responses of the neurotypical schoolchildren in relation to their activities with other boys and girls. Approximately 88% of parents believed that their children and their friends helped each other so children have the ability to form and maintain friendships. Moreover, over 39.0% of respondents agreed that their children had fun with their friends always. Roughly, 19.7% of parents state that their children can always rely on friends and approximately 77.7% of parents state that their children can talk to their friends about anything. This supports the evidence from the neurotypical schoolchildren's survey that even though neurotypical schoolchildren get involved in social interactions. To conclude the neurotypical schoolchildren experience positive group feelings and feel part of a group and respected by peers and friends.

#### **5.5.9.** School and learning (School Environment)

The findings from the parents of neurotypical schoolchildren's survey demonstrated very positive answers in terms of engaging in school environment. The following table reports that the responses provided by parents of neurotypical schoolchildren in regards to the questions that describe school environment are internally consistent according to the Cronbach's alpha statistic.

**Table 5.89 Reliability Test** 

Reliability Statistics			
Cronbach's Alpha	N of Items		
.891	6		

Even though, most of the surveyed neurotypical schoolchildren were rather happy at school, their parents mainly state the same results in terms of the happiness of their schoolchildren with school (Table 5.90).

**Table 5.90 Frequency Tables** 

	Thinking	about the last week,	Has your child beer	happy at school?	
		Frequency	Percent	Valid Percent	Cumulative Percen
	Not at all (1)	2	.7	.7	.7
	Slightly (2)	12	4.0	4.0	4.7
Valid	Moderately	42	14.0	14.0	18.7
	Very (4)	83	27.7	27.7	46.3
	Extremely (5)	161	53.7	53.7	100.0
		Has your child	got on well at school	ol?	•
		Frequency	Percent	Valid Percent	Cumulative Percen
	Not at all (1)	1	.3	.3	.3
	Slightly (2)	8	2.7	2.7	3.0
Valid	Moderately	41	13.7	13.7	16.7
	Very (4)	88	29.3	29.3	46.0
	Extremely (5)	162	54.0	54.0	100.0
	H	las your child been sa	tisfied with his/her	teachers?	
		Frequency	Percent	Valid Percent	Cumulative Percen
	Not at all (1)	5	1.7	1.7	1.7
	Slightly (2)	12	4.0	4.0	5.7
Valid	Moderately	44	14.7	14.7	20.3
	Very (4)	103	34.3	34.3	54.7
	Extremely (5)	136	45.3	45.3	100.0
	Thinking ab	out the last week, Ha	s your child been a	ble to pay attention?	
		Frequency	Percent	Valid Percent	Cumulative Percen
	Never (1)	2	.7	.7	.7
	Seldom (2)	17	5.7	5.7	6.3
Valid	Quite Often	33	11.0	11.0	17.3
	Very Often (4)	107	35.7	35.7	53.0
	Always (5)	141	47.0	47.0	100.0
		Has your child e	njoyed going to sch	ool?	
		F			G 1 .: B
		Frequency	Percent	Valid Percent	Cumulative Percer
	Never (1)	5	Percent 1.7	Valid Percent	1.7
	Never (1) Seldom (2)				
Valid		5	1.7	1.7	1.7
Valid	Seldom (2)	5 16	1.7 5.3	5.3	1.7 7.0
Valid	Seldom (2)  Quite Often	5 16 54	1.7 5.3 18.0	1.7 5.3 18.0	1.7 7.0 25.0
Valid	Seldom (2) Quite Often (2) Very Often (4)	5 16 54 68	1.7 5.3 18.0 22.7 52.3	1.7 5.3 18.0 22.7 52.3	1.7 7.0 25.0 47.7
Valid	Seldom (2) Quite Often (2) Very Often (4)	5 16 54 68 157	1.7 5.3 18.0 22.7 52.3	1.7 5.3 18.0 22.7 52.3	1.7 7.0 25.0 47.7 100.0
Valid	Seldom (2) Quite Often (2) Very Often (4)	5 16 54 68 157 Has you got along v	1.7 5.3 18.0 22.7 52.3 well with his/her tea	1.7 5.3 18.0 22.7 52.3 chers?	1.7 7.0 25.0 47.7 100.0
	Seldom (2) Quite Often Very Often (4) Always (5)	5 16 54 68 157 Has you got along v	1.7 5.3 18.0 22.7 52.3 well with his/her tea	1.7 5.3 18.0 22.7 52.3 chers? Valid Percent	1.7 7.0 25.0 47.7 100.0  Cumulative Percen
Valid Valid	Seldom (2) Quite Often (2) Very Often (4) Always (5)  Never (1)	5 16 54 68 157 Has you got along v Frequency 4	1.7 5.3 18.0 22.7 52.3  vell with his/her tea  Percent 1.3	1.7 5.3 18.0 22.7 52.3 chers? Valid Percent 1.3	7.0 25.0 47.7 100.0 Cumulative Percen

j i	ì	i	i .	i
Always (5)	129	43.0	43.0	100.0

The neurotypical schoolchildren in the main survey are happy and satisfied with their teachers. However, the majority of parents still give moderate answers. In addition, more than 75.3% of the parents of neurotypical schoolchildren reported that their schoolchildren got along well with teachers very often or always. It is also beneficial to mention that while the majority of neurotypical schoolchildren reported that they were able to pay attention during classes, about 82.7% of the parents confirmed that their schoolchildren were able to pay enough attention in the class. It can be concluded that schoolchildren provided more positive responses in relation to their school environment than parents who have been more critical about this element of quality of life.

## **5.5.10. Bullying (Social Acceptance)**

Bullying of neurotypical schoolchildren was studied using three questions. The parent's responses indicate internal consistency (Table 5.91).

**Table 5.91 Reliability Test** 

Reliability Statistics			
Cronbach's Alpha	N of Items		
.845	3		

The main survey of neurotypical schoolchildren did not confirm that they were subject to abnormal bullying and fears of other girls and boys. These participants were mainly confirmed by parents as reported in Table 5.92.

**Table 5.92 Frequency Tables** 

		Has your child been a	afraid of other girls a	and boys?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	184	61.3	61.3	61.3
	Seldom (2)	67	22.3	22.3	83.7
Valid	Quite Often (3)	20	6.7	6.7	90.3
	Very Often (4)	23	7.7	7.7	98.0
	Always (5)	6	2.0	2.0	100.0
		Has other girls and	boys made fun of you	ır child?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	208	69.3	69.3	69.3
	Seldom (2)	55	18.3	18.3	87.7
Valid	Quite Often (3)	16	5.3	5.3	93.0
	Very Often (4)	13	4.3	4.3	97.3
	Always (5)	8	2.7	2.7	100.0
		Has other girls an	d boys bullied your	child?	
		Frequency	Percent	Valid Percent	Cumulative Percent
	Never (1)	195	65.0	65.0	65.0
	Seldom (2)	68	22.7	22.7	87.7
Valid	Quite Often (3)	17	5.7	5.7	93.3
	Very Often (4)	14	4.7	4.7	98.0
	Always (5)	6	2.0	2.0	100.0

## 5.6. Conclusion

This chapter has provided an analysis of four surveys conducted among schoolchildren with ASD, the parents of schoolchildren with ASD, the neurotypical schoolchildren, the parents of the neurotypical schoolchildren. This has been done by employing the principal component analysis framework, frequency tables and reliability tests. The next chapter will explore the comparison between two countries; Republic of Ireland and Saudi Arab.

## 6. Chapter Six: Discussion

#### **6.1 Introduction**

The well-being of humans and societies is considered the Quality of Life for that person or society. It further outlines the positive and less positive aspects of life. It incorporates the observation of satisfaction levels of humans with life, and thus accounts for their health status, education attainment, family life, employment status, earnings, finances, religion and the overall environment a person dwells in. Therefore, Quality of Life, (QoL) is a concept with very broad perspective. It can be regarded as a multidimensional ideal that generally depends upon the inclusion of subjective assessment of both negative and positive features of life. It is considered as a really dynamic and responsive theory that immediately reacts to various happening of life like illness or recovery from one, taking a job or losing it, and such other variations of health, money, employment, etc. that can considerably alter an individual's description for OoL (Ferrans, 1990).

Health-related Quality of Life (HRQOL) is important, since the fundamental measure of life is health. It includes concerns associated with both physical and mental health and their impact on life. Whatever the aspects of life that affect the individual's health either physically or mentally are all encompassed in Health-Related Quality of Life. Both mental and physical health is affected by many factors that are not related to medical aspects in any way, like health risks arising from individual's financial conditions, economic status and social support, etc.. For example, getting fired from job as the employer decides to downsize the business, can have a severe effect on an individual's health who needs to support his family

financially. Many studies have shown that a loss of job creates high probability of heart attacks, anxiety, depression, stress, tension, etc. for the individual who will be affected either physically or mentally (Burgard, Brand and House, 2007).

This chapter presents a discussion of the main findings and relates these findings back to the main research question and sub-questions, especially in relation to theoretical considerations and the literature. It will also include an in-depth discussion on whether there are differences in health-related QoL between schoolchildren with ASD and neurotypical schoolchildren in Saudi Arabia. Then, this chapter shows that an Arabic-translated version of a widely used QoL instrument achieved sufficient psychometric properties. Particular attention is drawn to the differences between KSA schoolchildren with ASD and schoolchildren with ASD from other countries in terms of QoL scores. Finally, this chapter includes by comparing QoL ratings between KSA neurotypical and ASD schoolchildren and those in Republic of Ireland. Consequently, this chapter not only highlights the QoL but further provides a number of focused, practical implications to these findings, offering suggestions for ways in which these obstacles may be overcome in the educational system.

Republic of Ireland has been selected as a basis for comparison due to the fact that it also has a historically strong faith culture which is similar to KSA. The influence of the Catholic Church in areas of education and health is still significant (Vasquez del Aguila and Cantillon, 2012). The actual sample size is 1265 participants, aged 8-17 years, from 39 randomly selected schools throughout Republic of Ireland. The Irish data is available from the Kidscreen data sets. The study involved two short

self-completion questionnaires, the first designed for schoolchildren aged 8-11 and the second for adolescents aged 12-17. 90% of Irish schoolchildren in the sample did not have a long-term disability, illness or medical condition. However, 10% of the sample did have, such as dyslexia. The study confirmed that Irish schoolchildren evaluate their perceptions of their well- being and health across 10 dimensions of health.

In terms of the Republic of Ireland, the results demonstrate that a majority of Irish schoolchildren enjoy a high quality of life. Parent relations and home life, was a dimension that most schoolchildren rated highly. This dimension relates to respondents feeling that their parents understood them, that their parents treated them fairly and that they had the ability to talk to their parents when they wanted to. Social acceptance (bullying) is the dimension in which respondents rated their perceptions of being afraid of neurotypical schoolchildren, who bullying them, further discussion for this point will be presented later. The majority of respondents rated the quality of their financial resources highly. The most negative dimension for all groups was school environment. However, over half of Irish schoolchildren reported being happy at school (52%) (Keenaghan and Kilroe, 2008). The Irish study took place as part of the KIDSCREEN project, which was conducted over 3 years (2001-2004). This was one of the reasons why Republic of Ireland was chosen for comparison as it was a few years ago when their religious culture was stronger.

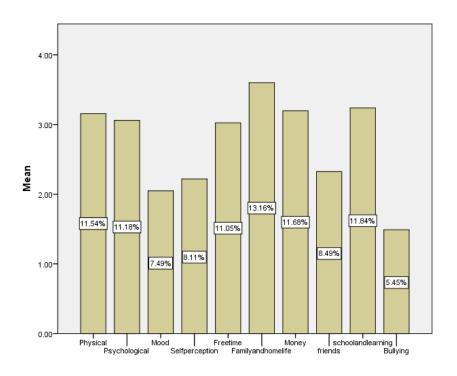
#### 6.2. KIDSCREEN instrument and QoL in KSA

Halwani (2008) in his research on KSA schoolchildren described autism as a complex developmental disability that typically appears during the first three years of life. He added, "The result of a neurological disorder that affects the functioning of the brain, autism and its associated behaviours has been estimated to occur in as many as 6 to 32 in 1,000 SA individuals" (p.23). Al-Wazna (2008) reveals that there are around 100,000 autistic schoolchildren in KSA and the ratio is 6:1000 who are at school age (Al-Wazna, 2008). This is somewhat at odds with the rest of the developed world, so it is important to look at this group in KSA to find out more about how they perceive their QoL. This will hopefully give researchers and educators the tools needed to support this group further.

This study is first of its kind, assessing the schoolchildren feeling and attitudes about their perceived health-related quality of life by applying the KIDSCREEN instrument. Therefore, this study enables better understanding of the perceived health in schoolchildren and can help to identify if the population is at risk. The information generated from the survey is an important source of evidence for health service provision, policy and practice for schoolchildren, both nationally and internationally.

In KSA, while neurotypical schoolchildren rated their quality of life higher than schoolchildren with ASD, overall the findings presented in the previous chapter suggest that most Saudi Arabian schoolchildren with ASD enjoy a high health-related quality of life. Kuhlthau and colleagues (2010) examined data from 286 schoolchildren with ASD, collected by the Autism Treatment Network across the United States and Canada, to evaluate the role of QoL in this disorder. Results showed that those schoolchildren with ASD experienced significantly reduced QoL scores

than neurotypical schoolchildren. Measuring quality of life is a complex task because a number of relevant dimensions is needed for this purpose. Therefore, Reven-Sieberer (2006) suggests that QoLcan be assessed based on ten categories, namely: Parent Relationships & Home Life, School Environment, Financial Resources, Physical Well-being, Psychological Well-being, Autonomy, Social Support and Peers, Self-Perception, Moods and Emotions, and bullying. According to the findings of this study, these ten dimensions contributed significantly in health-related quality of life for both the neurotypical schoolchildren and schoolchildren with ASD in KSA. The following figure illustrates the ten categories according to its significance in the quality of life of schoolchildren with ASD including: parents relationship and home life (13.16), school environment (11.84), financial resources (11.68), physical well-being (11.54), physiological well-being (11.18), autonomy (11.05), self-perception (8.11), friend and peers (8.49), mood and emotions (7.49) and bullying (5.45) (See Figure 6.1). The next sections will discuss the most significant results of these then dimensions comparing with Republic of Ireland.



#### **6.2.1.** Self-perception

The first dimension discussed is Self-perception, which evaluates the schoolchildren's perception of themselves. It includes whether the sample view their body appearance as positive or negative. The data of this study showed schoolchildren with ASD ranked self-perception as their second lowest rated dimension. Figure 6.1 illustrates that the self-perception contributes only 8.11% of quality of life. This is an unexpected finding because the data from Europe and the rest of the world shows this dimension to be strong, as it is rated as second highest (10.18%) in terms of its contribution to quality of life in Europe (Reven-Sieberer, 2006). Therefore, it is important to look deeper in to see if there is any reason beyond that difference in results. That is where the importance of comparison with Republic of Ireland has emerged and is discussed in detail.

The results indicate that almost 90% of Irish schoolchildren confirmed that they have been happy with the way they are and happy with their clothes (86%). Overall, 3% of them stated they have 'never' been happy with the way they are. 81% of Irish schoolchildren reported that they would not like to change something about their body (See table 4 in Appendix I). It can be surprisingly noticeable by comparing the results in both countries that the schoolchildren with autism in KSA have significantly lower self-perception than the Irish schoolchildren. However, Al-Mubarak and colleagues (2011) confirm that the cultural traditions of Saudi society are different than the Western world, and the determinants and impacts of QoL are likely to be different as well. Evidence exists to suggest that familial and social status,

as well as socioeconomic status, play a more significant role on QoL than individual psychological and emotional factors within Saudi society (Al-Kandari & Gaither, 2011).

Another interesting finding related to self-perception dimension is that the self-perception of schoolchildren with ASD is higher than the self-perception of neurotypical schoolchildren in KSA. Although low in both groups, this unexpected result from the data might be justified by positive attitudes towards persons with disabilities in KSA, which might increase the self-perception of schoolchildren with disabilities. In KSA, many studies (e.g. Al Rubiyea, 2010) reported that Saudi people exhibit positive attitudes toward persons with disabilities. KSA has a strong culture based on faith which may be one reason for this finding.

Moreover, a third point considered in this area is that a majority of the participants stated that they have never worried about their looks. They were not willing to change any part of their bodies even if given the chance. These responses affirm that the sample of schoolchildren affected by ASD in KSA were comfortable with what they looked like, and they did not possess any kind of inferiority complex. This is not consistent with the literature and is quite the opposite. Vickerstaff, (2006) found that schoolchildren with ASD had lower levels of self-perception, social competence and higher levels of depressive symptomatology. Furthermore, an analysis of the literature by Samadi et al., (2013) explained that quality of life must be allied with not only medical variables, but also lifestyle actions. Such association would put forward an opportunity for extensive understandings of the role of quality of life, which would be of immense value to strategy designers. In this regard, Al-Wazna (2008) added that self-acceptance for an individual can be demonstrated by having positive feelings for one's own self, accepting and acknowledging one's own

multiple aspects of personality, either good or bad, and keeps their thoughts positive about the past and future. The finding on dimension relating to self-perception will be useful in furthering understanding on issues of mental health eating disorders and obesity.

#### 6.2.2 Parent Relations and Home Life

The second theme explored looks at parent relations and home life. This is an important aspect in schoolchildren's life, for all schoolchildren including those without such disorders. Spending time with parents is important for schoolchildren, and this tends to improve the quality of life of schoolchildren significantly. In today's competitive world, both parents are often busy working outside the home and many feel that they do not find enough time for their schoolchildren (Cohn, 2006).

The data of this study showed schoolchildren with ASD ranked parent relations as their highest rated dimension, with school environment coming second for them. This is a totally unexpected finding because the data from Europe and rest of the world shows this dimension to be strong but not at the level that it is for this research. This positive result of parent relationships in KSA can possibly be contributed to the wider faith values regarding the Saudi family that may have helped promote the value of family life. Even people who are not involved in faith practice are still involved in faith-based ceremonies and society in general. These values can affect the attitude, behaviors and interaction with others in society (Al Rubiyea, 2010). They provide guidance and instruction for the family and the relationships between the members. The values also emphasise the role, importance and responsibilities of parents towards their schoolchildren. For example, upon birth, the parents are expected to provide all their rights; health care, clothing, feeding and

showing them love. Thus, these values stress the parent's role and help prepare their children so they can fulfill their duties towards their schoolchildren, in turn, which reflect positively on the child/parents relationship. It is essential to mention here that Republic of Ireland has strong faith values like KSA, however, the parent relationships results are not strong as much as KSA. This result needs further research to investigate the potential factors beyond this which may lower the result of parent relations comparison with KSA.

In terms of disability, it has been seem to have a moral significance, in some Islamic cultures, such as KSA. The presence of schoolchildren with disabilities is seen to be a test of faith and is viewed as a blessing by some (Bazna & Hatab, 2005). This understanding of disability and its causes within the context of faith-based values, can lead to positive perspectives about having schoolchildren with disabilities in the family, consequently, this positive view of disability can be seen to improve the parent/child with disability relationships (Al-Aoufi et al., 2012).

The majority of the sample stated that they felt they were understood by their parents, they felt love from their parents, they felt happy being home, their parents had time for them, they were fairly treated at home, and their parents always talked to them whenever they needed. A significant majority of the respondents (n= 44, 86%) stated that they are happy at home and that their parents treat them fairly. There is some literature, which confirms this finding. For example, Pozo et al. (2013) confirmed that schoolchildren with ASD are mostly able to talk to their parents when they want, which also indicates a positive area in the quality of their life. However, this is not consistent across the literature. Behavioural problems were found to affect negatively on family life. Schoolchildren need a great deal of time with parents, and parents need to realize the importance of a strong relationship with schoolchildren. In

the early stages, some schoolchildren are very shy to talk to strangers or make new friends.

Although this pattern in the results is inconsistent with Europe, however, it is consistent with the results of Irish schoolchildren, who ranked this dimension the highest as well (Keenaghan and Kilroe, 2005). The results of Irish schoolchildren indicate that 64% of them agree with statement that their parents understand them. In the same sense, the majority of the Irish schoolchildren (85%) reported that they are loved by their parents. In addition, three quarter of Irish schoolchildren confirmed that their parents treated them fairly and had enough time for them (72%). At the other end of the scale, 14% of Irish schoolchildren stated that their parents have understood them, while 12% perceived that they have been able to talk to their parents when they wanted to (See table 6 in Appendix I). This is an interesting finding and consistent with the results between Republic of Ireland and KSA in terms of parent relationship and parents might be partly contributed to the similarities between two countries, as both are strong- faith based.

#### 6.2.3. School Environment

The third factor explored is the school environment as this can be a significant matter for schoolchildren with ASD. This daily environment should be very friendly, in which they can adjust easily and feel comfortable in their surroundings. The third interesting result from the raw data relates to school and learning in KSA, which also indicates a positive area in the quality of their life. However, this finding is very inconsistent to that of all total KIDSCREEN Europe study population. Lee and colleagues (2008) showed that schoolchildren with ASD were much more likely to

miss school, and were less likely to participate in social activities than neurotypical schoolchildren. Moreover, previous studies show that schoolchildren with ASD find it difficult to make friendships and get along with teachers at school (Kasari, Locke, Gulsrud & Rotheram-Fuller, 2010). Further, teachers sometimes show a less than positive attitude towards teaching students with ASD, which can leave a negative impact on these schoolchildren. This is similar to the views of fellow students of their classmates with ASD. Difficulties in socialisation of the schoolchildren with ASD is expected to have an effect on the perception of their peers.

Speculatively, the positive result of school environment in KSA can be partly due to the recent improvement in the education system in KSA. For example, the Ministry of Education (MOE) provides an individual educational program (IEP) for each student with a disability (Al-Quraini, 2010). This results in a personalized programme of support for these students. In addition, the KSA education system provides a number of appropriate services and programs specifically designed to meet the schoolchildren with autism in mainstream schools, and this includes teaching methods, facilities, tools and equipment, as well as support services and specialists. Moreover, the MOE has expanded its activities, working to establish legislative protections and guarantees for individuals with disabilities, ensuring equal educational access and rights for all Saudi school aged schoolchildren (Al-Quraini, 2010).

In addition, the positive result from this research can possibly be justified by teacher attitudes towards schoolchildren with disabilities. For example, Al-Faiz (2006) investigated the attitudes of primary school teachers toward inclusive education for schoolchildren with ASD. Al-Faiz (2006) confirmed that most Saudi teachers have positive attitudes toward inclusive education for schoolchildren with ASD. Jones (2009) stated that the value of interaction between adult and child comes

directly from the adult, proving that opinion, ideas and experiences of adults (teachers) promotes schoolchildren with special needs being accepted and served in regular classrooms with their peers. Findings in this dimension will be of interest to the education sector and to people working with and on behalf of schoolchildren and young people.

In terms of comparing between KSA and Republic of Ireland, more than half of all Irish respondents reported that they have been happy at school. 63% of Irish respondents confirmed that they have got on well at school, while 46% of them indicated that they have been satisfied with their teachers. Over half of Irish respondents (n= 54) confirmed the statement that they have been able to pay attention to their teachers and got along well with their teachers (55%). On the other hand, 30% of the Irish respondents indicated that they have never enjoyed going to school and not at all satisfied with their teachers at school (24%) (See table 8 in Appendix I). Thus, there is a clear difference between KSA and Republic of Ireland in terms of significance of the school environment in quality of life. The Irish respondents rated the school environment the second lowest whereas it was rated the third highest by Saudi participants. Findings in this dimension will be of interest to the education sector and to people working with and on behalf of schoolchildren.

#### **6.2.4. Financial Resources**

The fourth area of quality of life is financial resources. The majority of the KSA sample stated that they have money to finance their expenses comparing with their friends. It is important to remember that the sample for this study was largely self-defined as middle or upper class. The region in KSA where the sample was taken from is considered economically strong. Conversely, Sharp & Baker (2007), US study

based, found that families of schoolchildren with autism lost future financial security and even went bankrupt, where schoolchildren could not have enough money to live a life like other schoolchildren. Financial support does matter a lot in today's world. One needs money to fulfil their desires and acquire the necessities. Schoolchildren can be considered as inexperienced youth why may not realize the importance of money for their future, and can be insistent on everything of the best quality without any compromises (Gyourko & Tracy, 1991). Parents of a child with ASD often have different pressures in terms of time and money than they would for neurotypical schoolchildren. For example, specialized childcare can be costly and often such care must be purchased for a longer period than neurtypical schoolchildren would need. In the US, Sharpe and Baker (2007) gave the example that mainstream schools can offer language and speech therapy, however, families cannot afford to pay the high cost of behavioral intervention for each child with ASD diagnosis and, even if they could, they might not be able to hire the necessary personnel.

Montes and Halterman, (2008) showed that parents of schoolchildren with ASD have a lower income because they have to spend a greater part of their income on their schoolchildren Moreover, many parents have to stop or reduce the number of work hours to look after their schoolchildren with ASD (Kogan et al., 2006). Furthermore, some parents cannot participate in psycho-educational early intervention program for many reasons such as a long waiting time (Birkin et al., 2008). The parents of schoolchildren with ASD need to spend around 100 hours for supporting and carrying their schoolchildren (Kogan et al., 2006). Therefore, the families of schoolchildren with ASD face financial problems, which can place additional

pressures on them (Kogan et al., 2006). But this does not seem to be the case in the KSA sample.

The results of this study reveal that the sample of parents in KSA do not have many concerns about financial issues. As mentioned, this could be due to the self-declared financial status or region the sample was drawn from, however, the result is very different in Republic of Ireland. Financial resources do not contribute equally in the quality of the life in both countries. The schoolchildren with ASD in KSA ranked the financial resources the third highest (See Figure 6.1), whereas this dimension is rated third lowest in Republic of Ireland (See table 10 in Appendix I).

This result might be an indication of the sample itself or it might indicate that there is a large number of services available to people with disabilities in KSA (Al Rubiyea, 2010). These services are provided through non-profit organisations or associations and several Ministries. For example, Ministry of Social Welfare offers to people with disabilities in KSA many welfare rights. These rights include free medical services including free medicine, 50% discount for all public transport, a monthly remuneration, full accommodation for people with special needs who live far away from the special needs centres, financial support for undergraduate and postgraduate study, free entertainment and meals (Ministry of Social Welfare, 2016). These welfare rights aim to provide services to people with special needs in order to support and to interact with the society. Therefore, speculatively, the parents of schoolchildren with disabilities might not have of the same pressure in terms of financial issues in KSA that they do in other countries.

#### **6.2.5.** Issues arising on friends

The penultimate section explores friendship issues and presents interesting results in terms of social acceptance, autonomy, friend relationships and peers in KSA. When schoolchildren with ASD asked if they spend time with their friends, some reported low scales. Schoolchildren with ASD in KSA have rated the social acceptance by (5.45) in terms of its contribution to quality of life (See Figure 6.1). It is evident that the schoolchildren who have ASD, may not socialize with their friends and peers to the same extent as their neurotypical peers. This result is consistent with Buminger and Kasari (2000) who had observed that schoolchildren with ASD felt lonelier. The schoolchildren in their study reported to have a friend at least but the friendship was not strong enough. The schoolchildren with ASD are often isolated from their peers and depend on family members for social support (Lee et al., 2008). Hinckson et al., (2013) does also validate with the result of this study and reciprocated that these schoolchildren and young people often have difficulty making friends and integrate into groups of their age; are often linked to at-risk groups which contributes to aggravate their problems. Schoolchildren have the best moments with their friends, making memories all the way long, and have a lot of learning opportunities from their peers (Helgeson, 2003).

Despite the predominance of inclusivists, there is the concern of how much full inclusion can become reality, because even though students are enrolled in regular integrated social groups, this fact, by itself, does not alter the quality of their schooling.

Rowley et al., (2012) found that schoolchildren with ASD were more likely to be victimized by other schoolchildren with bullying. Additional evidence suggests that schoolchildren with ASD can experience rejection and bullying in mainstream schools (Ainscow et al., 2006). Bandini et al., (2013) explained that bullying studies

in-depth analysis of the relationship between bullying and ASD schoolchildren. In a study by Cappadocia et al., (2012), the vast majority of focus group participants with ASD, report having physical violence practiced by peers at school. The study also highlights the actions of friends, as important help to avoid or stop these and other aggressions. In these initiatives the cohesion, in general, refers to the groups in the classroom. Playgrounds are complex experience for those who do not belong to some group.

In KSA, it is officially documented, as Al-Mousa (1999) states, that Special Education in the KSA follows the Sharia Law that constantly commands people to take responsibility for each other. Therefore, the MOE in the KSA have attempted to develop and spread education to give all citizens the opportunity to receive education. This projects the idea that schoolchildren with ASD are similar to their typically developing peers, and that they are part of the society they live in. Moreover, the Saudi educational system has designed a programme for schoolchildren with ASD in mainstream schools enable both academic and social inclusion.

In terms of Republic of Ireland, the majority of Irish schoolchildren, around 90%, confirmed that they have not been afraid of other girls and boys. In addition, the same percentage stated that other schoolchildren never bullied them. At the other end of the scale, only 8% of all Irish schoolchildren revealed that other schoolchildren have made fun of them (See table 9 in Appendix I). By comparing the results in KSA and Republic of Irish, it can be noticed that there are significant differences in the results in terms of whether other schoolchildren made fun of schoolchildren and bullied them. The level of bullying in KSA is higher than Irish schools. This might be contributed that there is no consistent check on the implementation of special education needs policy in KSA. Therefore, results in this dimension will be of precise

use and interest to those working in communities and schools that deal with the issue of bullying.

In terms of autonomy, Lickenbrock et al., (2011) declared, from a philosophical perspective, that the concepts of relational autonomy and coping and how they contribute to quality of life and how they can be applied in daily care practice. The findings in dimension relating to the autonomy illustrates significantly that this dimension contributes by 11.05% to quality of life for schoolchildren with ASD. Most of the respondents agree that they are able to do things that they indicate that they want free time to work by themselves. Conversely, Burrows et al., (2016) stated that families of schoolchildren with ASD provide very limited autonomy to avoid bad experiences with every day activities. Samadi et al., (2013) explained that for schoolchildren with special needs, autonomy is essentially important. Normally, schoolchildren do not like to be given instruction at each and every step, but mainstream schoolchildren usually cope with this attitude from parents or guardians. Leaving schoolchildren with ASD for what they do can help them with their psychological issues and they can grow up stronger.

The results also showed that the schoolchildren frequently get enough time to meet friends. Majority of them were also free to choose what they need to do in their free time. Hence, Perkins (2012) believed that the quality of life is a relatively modern concept that is essential for people with chronic (psychiatric) condition. Quality of life and of the care relationship between patient and professional get progressively more attention. The authors explained that within the care for schoolchildren with autism have defined and conceptualize the concept of quality of life, however, still relatively little attention have been paid in this context. Abu-Elmagd et al., (2012) implicated that if parents observe a bad habit developing in the child, they must help him learn

with love, peace and harmony. Creation of a sense of autonomy not only helps schoolchildren gain independent skills, but helps them learn from their mistakes as well.

However, in Republic of Ireland, the results indicate that over half of Irish schoolchildren in the sample (59%) confirmed that they have had enough time for themselves. 65% of the Irish sample confirmed that they have had enough time to meet friends, while 18% revealed that they have not had such time (See table 5 in Appendix I). It can be spotted by comparing the findings in both countries that the neurotypical schoolchildren and the schoolchildren with ASD in KSA do not have a specific tendency in their responses in terms of they had enough time to meet friends and to themselves. The results of Irish schoolchildren are consistent with the results of schoolchildren in Saudi; also, the results of Irish schoolchildren are rather mixed in terms of if they have enough time to meet their friends and enough time for themselves. Findings on autonomy are important in considering schoolchildren opportunities to participate in social activities and will be particularly useful in informing the implementation of the national policies on play and recreation.

#### 6.2. 6. Issues of interest for schoolchildren well-being

The final important area of quality of life is psychological well-being, which suggests that there is limited stress, depression, anxiety, or other negative emotions of schoolchildren with autism. Psychological well-being measures general views about the lives of the young people in the sample. It represents the combination of functioning effectively and feeling good (Huppert, 2009). It has six dimensions, i.e. self-acceptance, positive relations with others, free time, environmental mastery, purpose in life and personal growth. While most schoolchildren with ASD in KSA

rated psychological well-being highly, there are other areas where this is not the case. This dimension contributes by 11.18% of quality of life for schoolchildren with ASD (See Figure 6.1). However, Irish respondents rated the psychological well-being lowest in their quality of life (See Table 2 in Appendix I). It can be seen clearly by comparing the results in Republic of Ireland and KSA that there are significant differences in the results across the psychological well-being dimension in both countries. Schoolchildren in KSA experience a variety of positive feelings such as cheerfulness, happiness and joy which is not the same as the Irish sample.

In this sense, Samadi et al., (2013) suggested that schoolchildren with ASD have gaps in psychological well-being, which can be fulfilled by directing intervention to deficit skills and acting in accordance with these positive expectations thus, impairing the performance of schoolchildren. Malkoc (2011) explained that people need satisfying, warm and trusting relationships with others in order to develop a healthy and pro-active mental well-being. They are usually concerned about welfare of other, and capable of strong empathy, affection and intimacy. They ably understand the give and take nature of relationships in humans.

Nearly 88% of the schoolchildren with ASD respondents from KSA have the tendency to be satisfied with their life. The majority of them have been feeling full of energy and moderately satisfied with their lives. These results accentuate that regardless of the disabilities, the schoolchildren can still feel good and contented.

Samadi et al., (2013) reciprocates that the inclusion process requires the school to teaching and learning resources, conceived from a change of attitudes in teachers and the institution itself, reducing all the conservatism of their practices towards an education truly interested in meeting the needs of needs of all ASD schoolchildren in KSA. The findings in dimension relating to moods and emotions are

particularly interesting in KSA. These results showed that this dimension contributes only 7.49% to quality of life for schoolchildren with ASD (See figure 6.1) and rated the second lowest in both KSA and Republic of Ireland. Thus, the findings on this dimension indicate that the general moods and emotions dimension contributes equally to quality of life in both countries.

The schoolchildren with ASD have been feeling cheerful, and most of them have been having fun. They have not felt disappointed with self, but majority of them feel that they have seldom done anything badly. Majority of them are of the opinion that they have seldom felt sad. Hinckson et al., (2013) argued that behaviour problems can arise at any age and often start early in life, further, oppositional and defiant behaviours, for example, are frequent in the large proportions (big tantrums, hitting, biting, kicks, breaking objects). Pozo et al., (2013) confirmed that behavioural problems affected negatively on psychological well-being. The majority of the respondents revealed that rarely does anything in their lives go wrong or only very seldom do they feel fed up or tired. Also, according to the results, 87% have never felt lonely; very few of them do. Most of the KSA samples have seldom felt pressure. This inference has been supported by Diener & Lucas, (2000), who depicted that feelings are more "cognitively saturated" as the emotions are processed in the brains & bodies and are often fuelled by a mix of emotions, and last for longer than emotions.

When negative questions were asked, such if they felt sad and fed up, the schoolchildren with ASD predominantly reported that this occurred rather seldom or not often. This finding is consistent with their responses on physical wellbeing and psychological wellbeing. Hinckson's et al., (2013) findings do not agree with the results of this study and stated that these schoolchildren and young people often have

difficulty making friends and becoming part of peer groups; are often linked to at-risk groups which contributes to aggravate their problems. The authors further argued that although they normally have an age appropriate intellectual level, their income, schooling tends to be weak, and there is a high risk of school failure and drop out. There is often also a feeling of intense devaluation, of which they defend themselves by blaming others for their problems. -Additionally, Kim et al., (2000) also demonstrated that schoolchildren with ASD experienced a greater rate of anxiety and depression problems.

The findings in the dimensions relating to psychological well-being and moods and emotions are particularly useful in understanding the mental health and well-being of schoolchildren. This information can be used as reference data for people working in the area of mental health services and mental health promotion.

In terms of physical well-being, which assumes individuals' satisfaction from physical health (Glajchen, 2012). In this regard, out of the ten categories contributing to quality of life, physical well-being contributes 11.54% to quality of life in the sample. Malkoc (2011) investigated if quality of life and its four dimension, i.e. psychological health, physical health; environment and social relationships can significantly predict the subjective well-being. In this respect, our results are not consistent with the study by Malkoc (2011).

Quality of life was significantly different with respect to an individual's socioeconomic level. The ability to function in routine activities like eating, dressing, bathing, and moving and interacting in social gathering can be termed as physical well-being. Hence, according to our results, 60% of schoolchildren with ASD feel that they are physically well, which enable them to interact and participate with their social environment., Hinckson et al., (2013) proclaimed similar results by stating that physical well-being is about physical health of an individual who is safe and sound by all external appearances and is utmost essential to ensure QoL. Hence, quality of life depends upon physical well-being to a good extent. Therefore, a person is fine and doing well, the probability for better quality of life increases.

With a person not feeling good, or if they have some kind of ailment where they cannot experience a good quality of life, he/she will not be feeling content with their own self and dissatisfaction in life leads to poor quality of life. The results to the questions about health in the questionnaire show that the majority of the schoolchildren with ASD considered that their health was quite good. They thought that they have been physically active and could take part in all activities like running, climbing, biking, etc. To the final question about physical well-being, the majority thought they were fully capable of being physically active. Hinckson et al., (2013) believed that schoolchildren with ASD do not feel any less than neurotypical schoolchildren, hence their spirits are high which is usually enough to cope with any problem.

In terms of Republic of Ireland, overall, 95% of Irish schoolchildren felt that they are physically well. (See table 1 in Appendix I). By comparing the results across this dimension in Republic of Ireland and KSA, it is clear from the findings that schoolchildren in both countries state that they have a high level of physical activities. Consequently, physical well-being dimension contributes significantly in quality of life and there is no significant difference across this dimension in both countries, Republic of Ireland and KSA. The results in this dimension will be of interest to people attempting to plan and provide child- centred health services.

#### 6.3. Conclusion

This chapter presented a discussion of the main findings and relates these findings back to the main research question and sub-questions. It also included an indepth discussion on the differences in health-related QoL between schoolchildren with ASD and neurotypical schoolchildren in Saudi Arabia. Then, this chapter showed that an Arabic-translated version of a widely used QoL instrument achieved sufficient psychometric properties. Finally, this chapter included by comparing QoL ratings between KSA neurotypical and ASD schoolchildren and those in Republic of Ireland. The next chapter will not only highlight the QoL but further provide a number of focused, practical implications to these findings, offering suggestions for ways in which these obstacles may be overcome in the educational system.

#### 7. Chapter Seven Conclusion

#### 7.1. Introduction

This is the final chapter of the thesis which reviews the research questions, identifies the unique contribution to knowledge and recognizes the limitations of this study. Finally, this chapter reviews recommendations for further studies.

#### 7.2. Research Questions and Novelty

This study has one main research question and two sub-questions as following:

"Are there differences in health-related QoL between school children with ASD and neurotypical children in Saudi Arabia?"

The first sub-question is "Does an Arabic-translated version of a widely used QoL instrument achieve sufficient psychometric properties?"

The second sub-question is "do KSA with ASD possess similar QoL ratings as those from Republic of Ireland?"

In terms of the main research question, the results of this study show that neurotypical schoolchildren rated their quality of life higher than schoolchildren with ASD; however, most Saudi Arabian schoolchildren with ASD enjoy a high health-related quality of life. In addition, the ten dimensions, suggested by Reven-Sieberer (2006) to assess QoL, contributed significantly in health-related quality of life for both the neurotypical schoolchildren and schoolchildren with ASD in KSA (See Section 6.2 for more details).

Concerning the first research sub-question, the results of this study confirms that Arabic-translated version of a widely used QoL instrument has sufficient psychometric properties.

Regarding the second research sub-question, the study confirmed that both schoolchildren in KSA and Irish schoolchildren evaluate their perceptions of their well- being and health across 10 dimensions of health, and the majority of Irish schoolchildren enjoy a high quality of life. However, the Irish schoolchildren rated the ten dimensions of quality of life differently from the schoolchildren in KSA (See Section 6.1 for more details).

This study contributes to the knowledge by evaluating QoL for both schoolchildren with ASD and neurotypical schoolchildren within the KSA school system. There is lack of a research on schoolchildren with autism and QoL in KSA. Also, this is the first study that translates a screening tool into Arabic and uses it with KSA schoolchildren with ASD and neurotypical schoolchildren. Therefore, this study helps to increases the validity and reliability for a standardised QoL instrument in Arabic for schoolchildren with ASD. This translated tool can be used by health centres to measure QoL for their patients in all domains. Another contribution is that results from children with ASD and neurotypical children- are analysed based on their similarities and differences and then compared with schoolchildren from Republic of Ireland. Moreover, the findings of this study can be used as a basis for informing future related studies that are interested in understanding of the effects of autism on the QoL of schoolchildren. In other words, this study could act as a case example for such studies.

#### 7.3. Research limitations

As with all studies, there are various limitations to this research:

- One major limitation of this study is associated with the sample size. This study has employed non-probability sampling; convenience sampling for both schoolchildren with ASD and neurotypical schoolchildren, resulting in restrictions related to this technique. Additionally, the two samples have been collected from a particular area, city environment, which might be different from other geographic areas such as aural areas. The results of this study are narrow to a single segment, which relates to a particular geographical region in KSA. This particular region, where the sample has self-identified as middle and high earners and this study used this factor to set some findings. This group has the enough financial resources to meet their wants and needs whereas this might not the case for schoolchildren in the rural regions. Therefore, the results of this study might not be generalisable to the wider population because the sample of schoolchildren with ASD in this study in Saudi Arabia is limited to those who are from city environment. Thus, it is suggested that future research may wish toexplore a wider geographical range.
- The second limitation in this study is related to the representativness of the sample, as the schoolchildren with ASD in this study can read and write. This is not presented as a representative sampel of all children with ASD as not all the schoolchildren with ASD can read and write. Therefore, this sample is a subset sample which represents the schoolchildren with ASD who meet the criteria: ability to read and write. This research offers the opportunity to explore if there are any similarities or differences in the

results between schoolchildren with ASD who are able to read and write to give them a chance to express their views by themselves as often when researchers want to find the views of children with ASD they go to parents and teachers due to general communication limitations.

- One further limitation is the lack of data from teachers. It would have been beneficial to conduct qualitative methods such as interviews with the teachers of schoolchildren with ASD in order to get in-depth personal voice of the teachers. This could potentially add some interesting data because their views about the aspects of quality of life might be different from schoolchildren with ASD and their parents. Particularly, there is a strong literature base shows that a positive attitude of those working with children with disabilities can lead to a successful environment of inclusion. Therefore, there is an opportunity for future research to discover if this group have consistent views with schoolchildren with ASD and their parents.
- Another limitation has been raised from the use of mixed samples, which have been collected from both mainstream and special schools. The study was designed to explore the views of school children and to see if there were difference between these groups. Both samples are opportunity samples so generalisations are somewhat limited, but it is interesting to note that the results are consistent across the both settings in this study.
- The final limitation is that the two samples of Kidscreen data are from two different countries. Because the focus of this study is the schoolchildren with ASD who are able to read and write in KSA and there is

no similar sample group in the Kidscreen dataset with any other comparable data, there is no directly comparable data generated from other countries of children with ASD. Therefore, it is difficult to compare the data of this study with dataset of other countries, however, it was beneficial to take a wide perspective. These samples are from different times and we are making assumptions about the faith base society of Republic of Ireland that existed at the time these results were generated. This study recognises that this is an assumption and not something that there is empirical evidence to support. Despite these limitations, it is useful to look at these two data sets because they provide an opportunity to look at similarities and difference, despite not being directly comparable.

#### 7.4. Research Recommendations

This study generates many interesting findings, which may have relevance to key stakeholders including: Ministry of Education in KSA, parents of schoolchildren with ASD, teachers and decision maker in KSA. Therefore, this research offers, based on its findings and limitations, recommendations for future research:

• The findings of this study show that schoolchildren with ASD experience rejection and bullying in both special and mainstream schools. Therefore, the Ministry of Education in KSA should consider creating a national programme to increase the awareness of both parents and society about different types of disability especially ASD. This programme might provide information about ASD, , and the implications for quality of life for each child with ASD.

- According to the finding of this research, the schoolchildren with ASD ranked the school environment as their second highest rated dimension. Therefore, the Ministry of Education should consider increasing the number of inclusive mainstream schools and possibly establish a curriculum and special education programs in all universities in KSA. This recommendation can contribute to improved teacher abilities to support schoolchildren with ASD, in the long run, and increase the academic and social achievements of schoolchildren with ASD.
- The importance of collaboration between staff and parents of schoolchildren with ASD should be taken into consideration as an essential factor to facilitate the social and academic achievement of schoolchildren with ASD. This collaboration can be achieved through a regular meeting to discuss whether the schoolchildren with ASD are meeting their targets for achievement. One possibility is to consider the discussion of innovative ways to involve both parents by using technology.
- The study shows a positive result for the school environment, as this is considered a significant matter for schoolchildren with ASD. The positive result of the school environment in KSA may be partly due to the recent improvement in the education system in KSA. Therefore, the MOE should build on this improvement by providing the opportunities for career development for future special education need (SEN) teachers. This could be accomplished through a variety of services, such as internships, job placements and workshops focusing on specific issues. This kind of addition to the current educational system would lead to a sharing of best practice and would be likely to help to develop the skills of other teachers. This would help with more awareness and wider knowledge, as well as the particular skills needed to excel

in their roles. This would in turn improve the quality of education for schoolchildren with disabilities in the KSA.

- There are a lot of policies which support the equal rights of individuals with disabilities in obtaining free and appropriate education in KSA. These are more evident in the main cities mainly like Makah and Riyadh. In fact, the lack of effective policy implementation across the whole of KSA 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 children with disabilities in small cities (Al-Quraini, 2010). However, this research focused on the large cities in KSA; Makah, Jeddah and Riyadh. There might some differences in social and medical services between the big cities and rural regions Therefore, additional research needed that focuses on schoolchildren with ASD in small cities and rural areas in order to find out if there are any differences in the findings.
- The quantitative self- questionnaire was employed in this research to assess QoL of schoolchildren with ASD. Therefore, it is beneficial for further research to apply a qualitative approach in addition to quantitative approach in order to gain a richer insight to the QoL of schoolchildren and their parents about ASD. There is a clear need for more in-depth qualitative studies, including for example observations, as so far the majority of the research conducted in the KSA has been of a quantitative nature (e.g., Alkhshrami, 2003; Samadi, and Marwa, 1991).
- According to the findings of this study, ten dimensions contributed significantly to the health-related quality of life for both the neurotypical schoolchildren and schoolchildren with ASD in KSA. However, there is a lack of longitudinal research, which would be greatly beneficial in order to chart the development of schoolchildren with ASD. This approach might provide a deeper

understanding of dimensions related to ASD. Finally, the translated Kidscreen tool will be available online for all researchers on health and condition not only for Saudi Researcher but also for the entire researcher from the Arab countries in the Middle East.

#### 7.5. Conclusion

This research has produced some important information about autism and its significant effect on the quality of life (QoL) of the schoolchildren affected. Both schoolchildren with ASD and their neurotypical peers have a right to receive quality education. Therefore, by assessing their QoL, it would be important to determine if their legal rights and educational needs are also being met. This research makes an original contribution by providing a better understand of autism within the educational system in Saudi Arabia. The findings of this research reveal that ten dimensions contribute significantly to OoL of schoolchildren with ASD.

The results of the current study show that both schoolchildren with ASD and neurotypical schoolchildren have a high QOL, however, these results might be inconsistent with the result from other countries. The unexpected results of the current study might partly contribute to the strong faith culture in KSA. This result is consistent with Alshowkan's et al., (2015) who confirmed that people with mental illness in Saudi Arabia believe that mental illness is caused by the will of God. Health and sickness are perceived as caused by God, and it is believed that health is distributed through his heavenly decisions and power. Therefore, people in Saudi Arabia tend to accept the will of God and face the illness with a strong faith and

patience. This foundation may have a strong impact on the way society perceives disability and therefore created a more positive environment for this group of children. This specific aspect was not the focus of this study so is an area worth further exploration.

The data of this study provides robust evidence of the value the children place in the various areas that have been discussed and it provides quiet strong evidence of the quality of life as defined by the Kidscreen instrument that children in Saudi Arabia feel, exists. Measuring quality of life using the Kidscreen tool has a huge impact on society because it's a robust measure to look at the various areas that children and young people find important. This particular tool is very well established and a reliable survey available to use in numerous countries around the world.

Also, it provides evidence of the quality of provision that's already on offer in this region of Saudi Arabia and that this study recognises that this is strong evidence of the impact of scholarly programme but you also have to recognise that the demand for this type of educational provision far out strips the availability of places, so therefore the implications of this is that there needs to be an increased provision for these groups of young people. Quality of life is an important indicator about what individuals feel about their life experience and the implications that may have on human rights. Therefore, by using the Kidscreen instrument, researchers are able to take a snapshot of what people felt like on that day and time. This allows researchers to compare the raw data to what other children think about their lives all across the world. This presents the opportunity for researchers to monitor areas that impact the experience of young people related to what they think about their lives. It also

enables a comparison to young people in other countries. This tool could be useful in looking further at possible areas of injustice as we identify gaps between countries.

## **Appendices**

# Appendix A: Pattern Matrix from Principal Component Analysis Applied to Schoolchildren's Data

					Comr	onent				1
	1	2	3	4	5	6	7	8	9	10
In general, how would you say your health is?	083	294	.366	.188	177	.145	418	.192	033	.087
Thinking about the last week, Have you felt fit and well?	.144	.085	.173	.306	.006	.101	666	.021	.031	.007
Have you been physically active (e.g. running, climbing, biking)?	124	.271	.320	.605	100	.016	242	045	146	.326
Have you been able to run well?	.054	065	.128	.856	.127	.034	038	.072	.167	.111
Thinking about the last week, Have you felt full of energy?	.140	.038	.145	.617	002	.097	212	.016	135	.145
Thinking about the last week, Has your life been enjoyable?	.118	149	025	.061	.003	.199	625	.094	138	.128
Have you felt pleased that you are alive?	.050	117	.722	.245	.162	074	195	178	010	062
Have you felt satisfied with your life?	.071	183	.710	.253	.056	.181	.017	050	079	293
Thinking about the last week, Have you	.406	076	.656	.073	131	.106	.066	054	068	012
been in a good mood?										
Have you felt cheerful? Have you had fun?	.284	350 135	.508	.127 092	310 213	.056	070 231	.260	.040	.022
Thinking about the last week, Have you										
felt that you do everything badly?	137	.740	029	104	.017	135	.140	024	.130	.079
Have you felt sad?	.145	.636	104	.014	157	233	.030	.051	.097	148
Have you felt so bad that you didn't want to do anything?	.101	.636	124	.108	286	134	.000	013	.121	104
Have you felt that everything in your life goes wrong?	008	.591	053	.039	.104	068	.128	042	.457	060
Have you felt fed up?	.333	.496	278	.077	094	.042	055	284	.333	159
Have you felt lonely?	083	.432	084	.121	231	182	.142	.004	.224	145
Have you felt under pressure?	150	.600	.074	043	133	.030	.173	157	.175	163
Thinking about the last week, Have you	153	.012	.507	.043	.146	003	308	.403	071	.128
been happy with the way you are?  Have you been happy with your clothes?	.090	.234	.564	.006	.268	030	030	.373	116	.122
Have you been worried about the way you look?	019	.061	.040	.078	.047	.017	012	002	.894	.081
Have you felt jealous of the way other girls and boys look?	.040	.341	.002	170	177	136	018	.118	.625	.078
Would you like to change something about your body?	021	.054	.042	038	369	.040	201	076	.496	351
Thinking about the last week, Have you had enough time for yourself?	.621	.034	.077	.213	016	.182	037	.129	058	.135
Have you been able to do the things that you want to do in your free time?	.590	.060	.131	.125	.060	.171	042	.082	167	.168
Have you had enough opportunity to be outside?	.434	064	.169	355	.130	.206	406	.007	.096	.151
Have you had enough time to meet friends?	.034	.072	.369	477	068	.368	166	.216	088	.071
Have you been able to choose what to do in your free time?	.456	064	.006	.135	.357	.380	.294	.111	.151	.001
Thinking about the last week, Have your parent(s) understood you?	.228	.111	.471	045	.375	030	.145	.091	160	.265
Have you felt loved by your parent(s)?	.304	077	.249	034	.376	051	056	051	276	.226
Thinking about the last week, Have you been happy at home?	.048	291	.452	270	.159	.015	.001	.316	.112	.261
Have your parent(s) had enough time for you?	.482	.115	.097	190	.123	009	187	.129	410	.216
Have your parent(s) treated you fairly?	.367	156	.124	.114	.158	181	.187	.287	260	.312
Have you been able talk to your parent(s) when you wanted to?	.324	086	.031	025	.319	.077	.152	.347	.066	.288
Thinking about the last week, Have you had enough money to do the same things as your friends?	.015	027	090	.065	048	.143	.035	.973	045	233
Have you had enough money for your expenses?	.147	230	253	.026	.121	140	121	.814	.048	.149
Thinking about the last week, Do you have enough money to do things with your	026	.266	.191	199	.081	.215	084	.688	008	008

friends?										
Thinking about the last week, Have you spent time with your friends?	.113	.097	203	.036	042	.705	237	.205	202	.097
Have you done things with other girls and boys?	268	.048	.289	055	050	.698	.061	.353	.006	.156
Have you had fun with your friends?	.184	.114	163	.136	.117	.777	051	.072	157	.053
Have you and your friends helped each other?	.044	204	.107	034	.078	.816	.038	.037	.124	.053
Have you been able to talk about everything with your friends?	001	086	.032	063	006	.841	091	138	.033	.145
Have you been able to rely on your friends?	.060	222	088	.068	066	.784	.009	.017	.001	.168
Thinking about the last week, Have you been happy at school?	035	.040	.021	.074	.014	.253	.089	047	200	.740
Have you got on well at school?	.061	146	065	.176	.034	.108	.138	.020	073	.786
Have you been satisfied with your teachers?	.152	.030	002	.079	.083	.090	.177	135	087	.810
Thinking about the last week, Have you been able to pay attention?	.032	081	.005	112	044	.175	153	080	.185	.824
Have you enjoyed going to school?	.032	052	084	.107	144	.048	114	.059	.025	.898
Have you got along well with your teachers?	012	.017	064	.003	047	.014	110	.029	.025	.960
Thinking about the last week, Have you been afraid of other girls and boys?	.186	.299	.155	004	354	009	.662	068	118	.073
Have other girls and boys made fun of you?	073	026	.050	019	854	046	.271	.010	.063	.020
Have other girls and boys bullied you?	.045	.129	072	074	820	.002	051	077	.027	.178

Appendix B: Pattern Matrix from Principal Component Analysis Applied to Parents' Data

						Comp	onent					
	1	2	3	4	5	6	7	8	9	10	11	12
In general, how would you say your health is?	100	033	.003	078	141	136	.122	121	.068	.207	793	.230
Thinking about the last week, Have you felt fit and well?	.142	.352	.164	075	.116	051	081	184	.002	294	606	.072
Have you been physically active (e.g. running, climbing, biking)?	.105	.764	060	046	037	044	118	105	045	.158	136	004
Have you been able to run well?	.151	.886	.106	.045	.093	.041	.068	024	006	.089	.082	081
Thinking about the last week, Have you felt full of energy?	.070	.760	147	068	177	.030	.058	154	.054	131	133	.166
Thinking about the last week, Has your life been enjoyable?	133	.063	.588	.021	.028	101	131	177	.046	.401	037	019
Have you felt pleased that you are alive?	089	015	.816	071	.043	.019	122	219	.028	024	088	.092
Have you felt satisfied with your life?	117	006	.863	.033	175	067	044	043	.000	008	098	021
Thinking about the last week, Have you been in a good mood?	120	044	.293	.028	003	.068	.133	893	051	.081	.056	.079
Have you felt cheerful?	.062	.071	028	014	001	.027	060	870	.016	001	012	095
Have you had fun?	.122	.074	172	.060	048	173	052	728	.076	008	168	188
Thinking about the last week, Have you felt that you do everything badly?	040	005	.062	.150	.293	.103	.129	.142	047	240	248	.498
Have you felt sad?	323	.038	581	.373	.121	056	063	069	151	021	358	.078
Have you felt so bad that you didn't want to do anything?	027	048	204	.050	.530	.201	.002	.077	.154	.109	.004	.368
Have you felt that everything in your life goes wrong?	112	034	.011	.112	.079	112	070	.114	113	.042	041	.792
Have you felt fed up?	196	.295	410	.178	338	062	261	.143	075	209	.193	.262
Have you felt lonely?	414	.546	108	.285	.155	.115	.067	.096	.097	.056	.128	.076
Have you felt under pressure? Thinking about the last week, Have	401	.288	.093	.044	.296	.015	086	.018	311	.028	.269	.110
you been happy with the way you are?	079	121	.071	147	797	021	010	042	.067	.148	023	072
Have you been happy with your clothes?	.065	.151	067	.036	672	.041	230	160	206	.167	053	.033
Have you been worried about the way you look?	.175	049	160	.844	057	051	.008	094	.016	014	044	.276
Have you felt jealous of the way other girls and boys look?	.086	.035	.031	.870	.103	.170	107	.109	.009	.090	.065	046
Would you like to change something about your body?	.031	.048	.102	.864	.028	.242	033	006	.041	.019	.010	.124
Thinking about the last week, Have you had enough time for yourself?	.057	093	206	460	.044	069	525	147	.237	.292	.044	.140
Have you been able to do the things that you want to do in your free time?	.302	.068	.208	623	106	.187	064	.076	.176	.067	094	.272
Have you had enough opportunity to be outside?	.237	.098	.256	285	.121	210	204	144	.144	.006	204	.221
Have you had enough time to meet friends?	.001	095	098	181	045	158	.009	176	.174	.674	.051	159
Have you been able to choose what to do in your free time?	.569	276	.144	009	.136	005	002	014	.056	.273	285	007
Thinking about the last week, Have your parent(s) understood you?	.011	.361	.179	217	275	.064	199	.020	062	070	387	149
Have you felt loved by your parent(s)?	.214	.436	.258	.147	133	118	340	029	035	121	192	022
Thinking about the last week, Have you been happy at home?	.177	.176	.183	192	208	.084	304	184	.176	161	194	.318
Have your parent(s) had enough time for you?	.162	065	.129	.022	090	167	712	.112	.142	.117	.020	.138
Have your parent(s) treated you fairly?	.038	.036	.158	.231	225	017	642	216	.198	065	.061	093
Have you been able talk to your parent(s) when you wanted to?	.054	053	.141	.186	038	.231	454	.113	.288	.146	488	212
Thinking about the last week, Have you had enough money to do the same things as your friends?	087	.105	031	140	.105	.094	204	220	.826	.052	.055	.043
Have you had enough money for your expenses?	.049	327	.190	.142	131	233	085	104	.655	251	030	085
Thinking about the last week, Do you have enough money to do things with your friends?	.013	.040	.049	017	.088	318	081	.199	.690	.151	164	105
Thinking about the last week, Have you spent time with your friends?	.096	.112	.244	.025	042	022	.081	.055	.373	.602	.155	.078
Have you done things with other girls and boys?	.064	.224	.301	.217	162	221	.374	009	.304	.406	086	.178

Have you had fun with your friends?	.174	.075	.215	.117	245	176	.059	.076	.187	.529	014	.232
Have you and your friends helped each other?	.146	078	.105	.196	388	.150	.051	142	.092	.575	063	.190
Have you been able to talk about everything with your friends?	.115	025	.061	.040	214	.048	172	190	056	.685	017	.072
Have you been able to rely on your friends?	099	.296	.051	.023	.015	.033	173	057	224	.688	315	050
Thinking about the last week, Have you been happy at school?	.582	.369	077	.017	184	.169	.072	064	.270	024	132	093
Have you got on well at school?	.594	.054	.023	021	128	.087	.028	104	.356	.041	006	126
Have you been satisfied with your teachers?	.817	.162	037	030	.024	142	090	158	013	026	.172	113
Thinking about the last week, Have you been able to pay attention?	.628	114	.187	001	.120	224	225	045	148	.335	.018	022
Have you enjoyed going to school?	.741	.240	003	.118	021	107	241	085	078	019	073	.037
Have you got along well with your teachers?	.849	.153	092	.068	106	092	098	008	022	003	053	007
Thinking about the last week, Have you been afraid of other girls and boys?	566	029	.179	033	.098	.210	098	.234	232	.013	348	031
Have other girls and boys made fun of you?	196	.020	069	.123	.023	.773	.018	.029	021	076	.061	101
Have other girls and boys bullied you?	.070	.001	.031	.066	011	.904	.013	021	029	.063	003	.005

#### **Appendix C: Students - Questionnaire (Arabic Version)**

## استبيان الطلاب بسم الله الرحمن الرحيم عزيزي المشارك /المشاركة:

السلام عليكم ورحمة الله وبركاته.

يسرني أن أضع بين أيديكم استبانه در اسة علمية بعنوان " قياس جودة حياة الأطفال والمراهقين باستخدام مقياس كيدسكرين"

الذي هو مفيد جدا للدراسة ونشكركم سلفا على المساهمة و في حال الرغبة في الحصول على النتائج يمكنكم التواصل عبر البريد الالكتروني amor\_amor\_uk@hotmail.com

#### الأهداف:

- 1- تقييم المسائل المتعلقة بنوعية الحياة فإن الباحثة تحاول المساهمة في النقاش حول سبل زيادة الوعي لدى المعلمين اللذين يعملون مع الأطفال والشباب لتوفير التدخل المناسب لتحسين جودة الحياة.
- 2- قياس وتقييم الحالة الصحية المتعلقة بجودة حياة الأطفال والشياب وإتاحة الفرصة لهم للمشاركة في تشكيل حياتهم الخاصة بهم مما له الأثر الكبير على الناحية النفسية وبالتالي على مخرجات التعليم من خلال مدى شعور هم بالرضا والسعادة عن حياتهم.

### الرجاء تعبئة البيانات بوضع أشارة ( [] ) في الحقل المناسب:

)	8() 9() 10()	11 ( ) 12 ( ) 13 ( )	14() 15() 16()	17() 18()
)	( ) حکومیة ( ) مطورة ( ) أهلیة			
)	( ) ابتدائي ( ) متوسط ( ) ثانوي			
الصف الدراسي {ابتدائي}	( )الصف الثالث	( )الصف الرابع	( )الصف الخامس	( )الصف السادس
, , ,	<ul><li>( ) الصف الأول</li><li>( ) الصف الأول</li></ul>	() الصف الثاني () الصف الثاني	() الصف الثالث	

ر ) عالي ر ) متوسط ر ) منخفض	المستوى المعيشي
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#### مرحيا

كيف حالك و كيف تشعر ؟ هذا ما نريد أن تخبرنا به. نتمنى أن تقرأ كل سؤال بتركيز وتختار الإجابة التي تخطر في ذهنك أولا. و لكن تذكر هذا ليس اختبارا فلا توجد إجابات خاطئة .و من المهم أيضا أن تجيب على كل الأسئلة حتى نتمكن من تحديد الدرجة بدقة. و لكن عندما تجيب ضع في ذهنك الأسبوع الأخير. لا داع لعرض إجاباتك للأخرين كما أنه لن يعرف أي شخص بإجاباتك حالما تنتهي منها.

				<u> </u>	استبيان جودة حياة الأطفال والشب	
					١- الصحة والأنشطة الجسدية	
سيئة	لا بأس بها	جداً جيدة	جيدة	ممتازة	<u> </u>	
					بشكل عام. كيف تقيم /تقيمي صحتك؟	1
إلى أقصى حد	جدا	إلى حد ما	قليلا	مطلقا	ِ الأسبوع الماضي	تذكر
					هل شعرت بالنشاط والحيوية ؟	2
					هل تمارس /تمارسي النشاط الجسدي (الجري التسلق- ركوب الدراجة) ؟	3
					هل تستطيع /تستطيعي الجري؟	4
					هل كنت بكامل نشاطك و حيويتك؟	5
					٢ ـ المشاعر	
					ِ الأسبوع الماضي	تذكر
					هل كانت حياتك ممتعة؟	1
					هل أنت سعيد /سعيدة لأنك على قيد الحياة؟	2
					هل أنت راض / راضية عن حياتك؟	3
دائماً	في أغلب الأحيان	أحياناً	نادراً	أبدأ	ِ الأسبوع الماضي	تذكر
					هل كنت في مزاج جيد؟	4
					هل شعرت بالمرح؟	5
					هل استمتعت بوقتك؟	6
					٣- الحالة المزاجية العامة	
					ِ الأسبوع الماضي	تذكر
					هل شعرت أنك تفعل كل شي بشكل سيء؟	1
					هل شعرت بالحزن؟	2
					هل شعرت بالحزن لدرجة أنك لا تريد أن تفعل /لا تريدي أن تفعلي أي شئ؟	3
					هل شعرت أن كل ما في حياتك يسير بشكل خاطئ؟	4
					هل شعرت بالضجر؟	5
					هل شعرت بالوحدة؟	6
					هل شعرت أنك تحت ضغط؟	7
					<u>٤ - عنك أنت</u>	
					ِ الأسبوع الماضي	تذكر
					هل أنت سعيد و راض / سعيدة وراضية عن نفسك؟	1
					هل أنت سعيد و راض / سعيدة وراضية عن ملابسك؟	2
					هل أنت قلق /قلقة بشأن المظهر الذي أنت عليه؟	3

					هل شعرت بالغيرة تجاه المظهر يبدو به الأخرين من الفتيان و الفتيات؟	4
					هل ترغب / ترغبي في تغيير شي من مظهرك؟	5
					٥- وقت الفراغ	3
					الأسبوع الماضي	تذكر
					هل كان لديك الوقت الكافي لنفسك؟	1
					هل أنت قادر على فعل الأُشياء التي تريد أن تفعلها في وقت فراغك /قادرة على فعل الأشياء	1
					التي تريدين أن تفعلينها في وقت فراغك؟	2
					هل كان لديك الفرصة للخروج من المنزل؟	3
					هل كان لديك الوقت الكافي للالتقاء بأصدقائك /بصديقاتك؟ هل أنت قادر على اختيار ما تريد أن تفعله في وقت فراغك / قادرة على اختيار ما تريدين أن	4
					هن الله قادر على احتيار ما تريد أن تفعله في وقت قراعك / قادره على احتيار ما تريدين أن تقعلينه في وقت فراغك؟	5
					٦- العائلة والحياة المنزلية	
إلى أقصى حد	جدا	إلى حد ما	قليلا	مطلقا	ِ الأسبوع الماضي	تذكر
					هل و الديك متفهمانك؟	1
					هل تشعر أنك محبوب من قبل والديك /تشعري أنك محبوبة من قبل والديك؟	2
دائماً	في أغلب الأحيان	أحياناً	نادرأ	أبدأ	ِ الأسبوع الماضي	تذكر
					هل أنت سعيد / سعيدة في منزلك؟	3
					هل والديك لديهم الوقت الكافي لك؟	4
					هل يعاملك والداك /والديك بإنصاف ؟	5
					هل أنت قادر على التحدث مع والديك كلما أردت؟	6
					٧- الأمور المالية	
					ِ الأسبوع الماضي	تذكر
					هل كان لديك ما يكفي من المال لتفعل مثل الأشياء التي يفعلها أصدقاؤك /لتفعلي مثل الأشياء التي تفعلها صديقاتك؟	1
					هل كان لديك المال الكافي لنفقاتك الخاصة؟	2
إلى أقصى حد	جدا	إلى حد ما	قليلا	مطلقا	ِ الأسبوع الماضي	تذكر
					هل تملك المال الكافي لتستمتع بوقتك مع أصدقائك /تملكي المال الكافي لتستمتعي بوقتك مع صديقاتك؟	3
					٨- الأصدقاء	
دائماً	في أغلب الأحيان	أحياناً	نادراً	أبدأ	ِ الأسبوع الماضي	تذكر
					هل أمضيت وقتا مع أصدقائك /صديقاتك؟	1
					هل فعلت أي نشاط مع الآخرين من أصدقائك /صديقاتك؟	2
					هل استمتعت بوقتك مع أصدقائك /صديقاتك؟	3
					هل أنت وأصدقاؤك /صديقاتك تساعدون بعضكم البعض؟	4
					هل أنت قادر على التحدث عن كل أمورك مع أصدقائك /قادرة على التحدث عن كل أمورك مع صديقاتك؟	5
					صديعات: هل أنت قادر على الاعتماد على أصدقائك /قادرة على الاعتماد على صديقاتك؟	5 6
					س الله والرابطي المحدود على المحدود المحدود المحدود على المحدود المحد	_ 0
إلى أقصى	جدا	إلى حد ما	قليلا	مطلقا	الأسبوع الماضي	تذكر
					هل أنت سعيد / سعيدة في المدرسة؟	1
					هل أمورك على ما يرام في المدرسة؟	2
	1	<u> </u>	j .		هل المورث على مد يرام في المدرسة.	

					3 هل أنت راض بمعلميك /راضية بمعلماتك؟
دائماً	في أغلب الأحيان	أحياناً	نادراً	أبدأ	تذكر الأسبوع الماضي
					4 هل أنت قادر /قادرة على الانتباه؟
					5 هل استمتعت بالذهاب إلى المدرسة؟
					6 هل أنت متفق مع معلميك /متفقة مع معلماتك؟
					١٠- السخرية
					تذكر الأسبوع الماضي
					1 هل تخاف/تخافي من الفتيان والفتيات الأخرين؟
					2 هل يجعل الأخرين منك أضحوكة ؟
					3 هل يسخر بك الأخرون؟

#### **Appendix D: Parents – Questionnaire (Arabic Version)**

## استبيان الوالدين بسم الله الرحمن الرحيم

## عزيزي المشارك /المشاركة:

السلام عليكم ورحمة الله وبركاته,

يسرني أن أضع بين أيديكم استبانه دراسة علمية بعنوان " قياس جودة حياة الأطفال والمراهقين باستخدام مقياس كيدسكرين"

الذي هو مفيد جدا للدراسة ونشكركم سلفا على المساهمة و في حال الرغبة في الحصول على amor\_amor\_uk@hotmail.com

### الأهداف:

- 1- تقييم المسائل المتعلقة بنوعية الحياة فإن الباحثة تحاول المساهمة في النقاش حول سبل زيادة الوعي لدى المعلمين اللذين يعملون مع الأطفال والشباب لتوفير التدخل المناسب لتحسين جودة الحياة.
- 2- قياس وتقييم الحالة الصحية المتعلقة بجودة حياة الأطفال والشباب وإتاحة الفرصة لهم للمشاركة في تشكيل حياتهم الخاصة بهم مما له الأثر الكبير على الناحية النفسية وبالتالي على مخرجات التعليم من خلال مدى شعور هم بالرضا والسعادة عن حياتهم.

## الرجاء تعبئة البيانات بوضع أشارة ( 🖸 ) في الحقل المناسب:

17() 18()	14() 15() 16()	11() 12() 13()	8() 9() 10()	العمر
			( ) حكومية ( ) مطورة ( ) أهلية	المدرسة
			( ) ابتدائي ( ) متوسط ( ) ثانوي	المرحلة الدراسية
( )الصف السادس	() الصف الثالث	( )الصف الرابع ( ) الصف الثاني	( )الصف الثالث ( ) الصف الأول	الصف الدراسي {ابتدائي}

( ) الصف الثالث	( ) الصف الثاني	( ) الصف الأول	الصف الدراسي (ثانوي)
		( ) عالي ( ) متوسط ( ) منخفض	المستوى المعيشي

عزيزي الأب عزيزتي الأم:

كيف حال ابنك/ابنتك؟ كيف هو شعوره/شعورها ؟ وهذا ما نحن نريدك أن تخبرنا به.

نرجو الإجابة على الأسئلة التالية بأفضل ما تعرف من خلال التأكد أن الإجابات تعكس منظور ابنك/ابنتك.

رجاءً تذكر خبرات ابنك/ابنتك خلال الأسبوع الماضي...

					رجو سر جرب بعد المارة ا
	1 .				استبيان جودة حياة الأطفال والشباب
ضعيفة	لا بأس بها	جداً جيدة	جيدة	ممتازة	١ ـ الصحة والأنشطة الجسدية
					مكيف يقيم ابنك صحته /تقيم ابنتك صحتها؟
إلى أقصى حد	جدا	إلى حد ما	قليلا	مطلقا	الماضي
					ابنك /شعرت ابنتك بصحة ونشاط؟
					ر ابنك /تمارس ابنتك نشاط جسدي ( مثال، جري ، تسلق ، دراجة)؟
					قادر البنتك قادرة على الجري بنشاط؟
_					بنك بكامل نشاطه وحيويته /كانت ابنتك بكامل نشاطها وحيويتها ؟
_					٢_ المشاعر
					بوع الماضي
_					حياة ابنك /ابنتك ممتعة؟
					سعيد انه /ابنتك سعيدة أنها على قيد الحياة ؟
					ابنك بالرضا عن حياته /شعرت ابنتك بالرضا عن حياتها؟
دائماً	في أغلب الأحيان	أحياناً	نادرأ	أبدأ	الماضي
					بنك /كانت ابنتك في مز اج جيد؟
					ابنك/شعرت ابنتك بالمرح ؟
					ع ابنك بوقته/استمتعت ابنتك بوقتها؟
					٣- الحالة المزاجية العامة
					الماضي
					ابنك انه يفعل كل شيء بشكل سيئ/شعرت ابنتك أنها تفعل كل شيء بشكل سيئ؟
					ابنك /شعرت ابنتك بالحزن؟
					ابنك بالحزن لدرجة انه لا يريد أن يفعل أي شيء/شعرت ابنتك بالحزن لدرجة أنها لا تريد أن ا
					ئىيء؟ ابنك أن كل ما في حياته يسير بشكل خاطئ /شعرت ابنتك أن كل ما في حياتها تسير بشكل
					ابنك بالضجر/شعرت ابنتك بالضجر؟
					ابنك /شعرت ابنتك بالوحدة؟
					ابنك انه تحت ضغط /شعرت ابنتك أنها تحت ضغط؟
					٤ ـ عن ابنك /ابنتك
					الماضي
					ي سعيد وراض عن نفسه /ابنتك سعيدة وراضية عن نفسها؟
					سعيد بملابسه /ابنتك سعيدة بملابسها؟
					قلق بشان المظهر الذي هو عليه /ابنتك قلقة بشأن المظهر الذي هي عليه؟

					ابنك /شعرت ابنتك بالغيرة تجاه المظهر الذي يبدو به الأخرين من الفتيان والفتيات ؟
					ا بنك في تغيير شيء من مظهره /تر غب ابنتك في تغيير شيء من مظهر ها؟
					٥- وقت الفراغ
					لماضى
					ي دى ابنك الوقت كافي لنفسه/ابنتك الوقت كافي لنفسها؟
					نك قادر على فعل الأشياء التي يريد أن يفعلها في وقت فراغه /ابنتك قادرة على فعل الأشياء
					أن تفعلها في وقت فراغها؟ أ
					دى ابنك /ابنتك الفرصة الكافية للخروج من المنزل ؟
					دى ابنك/ابنتك الوقت الكافي للالتقاء بأصدقائه/صديقاتها؟
					قادر على اختيار ما يريد أنَّ يفعله في وقت فراغه/ابنتك قادرة على اختيار ما تريد أن تفعله في غها؟
					٦_ العائلة والحياة المنزلية
إلى أقصى حد	جدا	إلى حد ما	قليلا	مطلقا	الماضي
					ابنك أن والديه متفهمانه /تشعر ابنتك أن والداها متفهمانها؟
					ابنك انه محبوب من قبل والديه/تشعر ابنتك أنها محبوبة من قبل والديها؟
دائماً	في أغلب الأحيان	أحياناً	نادراً	أبدأ	الماضي
					سعيد في المنزل/ابنتك سعيدة في المنزل؟
					ابنك أن والديه لديهم الوقت الكافي له/تشعر ابنتك أن والداها لديهم الوقت الكافي لها؟
					بشعر أن والديه يعاملانه بإنصاف/ابنتك تشعر أن والداها يعاملانها بإنصاف؟
					قادر على التحدث إلى والديه كل ما أر اد/ابنتك قادرة على التحدث إلى والداها كل ما أر ادت ؟
					٧- الأمور المالية
					الماضي
					دى ابنك ما يكفي من المال ليفعل مثل الأشياء التي يفعلها أصدقاؤه /ابنتك لتفعل مثل الأشياء با صديقاتها؟
					دى ابنك المال الكافي لنفقاته الخاصة /ابنتك المال الكافي لنفقاتها الخاصة؟
إلى أقصى حد	جدا	إلى حد ما	قليلا	مطلقا	الماضي
					بملك المال الكافي ليستمتع بوقته مع أصدقائه/ابنتك تملك المال لتستمتع بوقتها مع صديقاتها؟
					٨ - الأصدقاء
دائماً	في أغلب الأحيان	أحياناً	نادراً	أبدأ	الماضي
					ل ابنك وقتا مع أصدقائه/أمضت ابنتك وقتاً مع صديقاتها؟
					بنك أي نشاط مع الأخرين من أصدقائه /ابنتك أي نشاط مع الأخرين من صديقاتها؟
					ع ابنك بوقته مع أصدقائه/تستمع ابنتك بوقتها مع صديقاتها؟
					رأصدقاؤه /ابنتك وصديقاتها يساعدون بعضهم البعض؟ قادر على التحدث عن كل أموره مع أصدقائه/ابنتك قادرة على التحدث عن كل أمورها مع ؟
					فادر على الاعتماد على أصدقائه/ابنتك قادرة على الاعتماد على صديقاتها؟
					٩ ـ المدرسة والتعلم
إلى أقصى حد	جدا	إلى حد ما	قليلا	مطلقا	الماضي
					سعيد/ابنتك سعيدة في المدر سة؟
					ابنتك على ما يرام في المدرسة؟

ض بمعلميه/ابنتك راضية بمعلماتها؟					
على بمعلمية البنتك والصيبة بمعلماتها:					
اضي	أبدأ	نادرأ	أحياناً	في أغلب الأحيان	دائماً
ر/ابنتك قادرة على الانتباه؟					
تمتع/ابنتك استمتعت بالذهاب إلى المدرسة؟					
ى مع معلميه/ابنتك متفقة مع معلماتها؟					
١٠ - السخرية					
اضي					
اف /ابنتك تخاف من الفتيان والفتيات الأخرين؟					
الفتيات الأخرين يجعلون من ابنك/ابنتك أضحوكة؟					
الفتيات الأخرين يسخرون من ابنك /ابنتك؟					

## **Appendix E: KIDSCREEN Collaboration – Form**



Collaboration Form between the KIDSCREEN Group and

« Person, University, Company» referred hereinafter as « User »

# **Co-ordinator and Contact Person of the KIDSCREEN Group is**

Prof. Dr. Ulrike Ravens-Sieberer M.P.H.

## **Contact Address:**

Prof. Dr. Ulrike Ravens-Sieberer MPH
Head of Research - Professor for Child Public Health
University Medical Center Hamburg-Eppendorf
Department of Child and Adolescent Psychiatry, Psychotherapy and Psychosomatics
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D - 20246 Hamburg

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 Fax:
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 Ravens-Sieberer@uke.de

 Website:
 www.kidscreen.org

## I. COLLABORATION between the KIDSCREEN Group and Name (Title): Budor Saigh (miss) Institution: Reading university Dept: School of Education Street Address: London Road campus 18 4 Red ands Road City: Reading State: Zip (Postal) Code: RCT15EX Country UK Phone Number: (0044) 1742620377 Fax:\_ E-mail: b.h.a.saigh @pgr.reading.ac.uk SUMMARY of the STUDY Title of the study: Health Related Quality of Life Screening for children and Adolescents in Type of Research: Saudi Arabia. PhD Objectives/ Design: Translating KIDSCREEN instrument into Arabic - Validate the KIDSCREEN instrument in Saudi Arabia schools. - Ascertaining whether children with Autism have different quality of life from those without Autism. Study population: (including the number of cases, age, illnesses/diseases) 300 and children and adolescents aged 8-18 with their parents. 50 children and adolescents with autism with their parents. Measurement points: Quality of Life issues. Other Instruments: -Name of funder: Timeframe: Beginning of Study: 10/2013 Expected end of Study: 10/2016 Questionnaire Version(s) planned to be included: ☐ KIDSCREEN-52 parent version ☐ KIDSCREEN-27 parent version ☐ KIDSCREEN-27 child & adolescent version ☐ KIDSCREEN-10 index child & adolescent version ☐ KIDSCREEN-10 index parent version Language Version(s) planned to be included:

#### KIDSCREEN USER AGREEMENT

IMPORTANT REMARK: THE KIDSCREEN INSTRUMENTS MAY BE USED IN THE ABOVE MENTIONED INVESTIGATIONS WHEN THE FOLLOWING AGREEMENT IS COMPLETED AND SIGNED BY "USER".

The KIDSCREEN Group distributes the KIDSCREEN instruments and translations which are so far available for example for Argentina, Austria, Belgium, Brazil, Chile, Croatia, Czech Republic, Denmark, Dholuo, Finland, France, Germany, Greek, Hungary, Iceland, Iran, Ireland, Italy, Korea, Mexico, The Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, Sweden, Switzerland, Uganda, United Kingdom, USA.

The User (Include name) <u>Budor</u> wishes to use the KIDSCREEN instruments

Therefore, User and KIDSCREEN group agree as follows:

#### 1. KIDSCREEN obligations

The KIDSCREEN Group shall deliver the original KIDSCREEN instruments and/or the translations requested by "User" subject to the following conditions:

The translations requested are available; the present agreement is duly completed and signed by "User".

#### 2. "User"'s obligations

#### 2.1 No modification

"User" shall not modify, abridge, condense, adapt, recast or transform the KIDSCREEN instruments in any manner or form, including but not limited to any minor or significant change in wordings or organisation in KIDSCREEN, without the prior written agreement of KIDSCREEN Group

2.2 No translation
"User" shall not translate KIDSCREEN, without the prior written agreement of the KIDSCREEN Group.

#### 2.3 No reproduction

"User" shall not reproduce the KIDSCREEN instruments except for the limited purpose of generating sufficient copies for use in investigations stated hereunder and shall in no event distribute copies of the KIDSCREEN instruments to third parties by sale, rental, lease, lending, or any others means.

#### 2.4. Publication

- In case of publication of study results, "User" shall cite
  (1) Ravens-Sieberer, U., Gosch, A., Rajmil, L., Erhart, M., Bruil, J., Duer, W., Auquier, P.,
  Power, M., Abel, T., Czemy, L., Mazur, J., Czimbalmos, A., Tountas, Y., Hagquist, C.,
  Kilroe, J. and the European KIDSCREEN Group. (2005). KIDSCREEN-52 quality-of-life measure for children and adolescents. Expert Review of Pharmacoeconomics & Outcomes Research, 5 (3), 353-364,
  The KIDSCREEN Group Europe. (2006). The KIDSCREEN Questionnaires — Quality of life questionnaires for children and adolescents. Handbook. Lengerich: Pabst Science
- Publishers.

in reference section of the publication. (New publications may be added and older ones deleted).

#### 2.5 Provision of data

All data, results and reports obtained by, or prepared in connection with the KIDSCREEN instruments shall remain the User's property. However, KIDSCREEN Group may request the User to share data, results and reports obtained through the use of the KIDSCREEN.

It is agreed that KIDSCREEN Group shall not disclose, whether by the public press or otherwise, the name of "User' or institution", to any third party to this agreement except to the copyright holder(s) of the KIDSCREEN instruments.

#### 6. Liability

#### 6.1 In case of breach of contract

In the event of total or partial breach by KIDSCREEN Group of any of its obligations hereunder, the KIDSCREEN Group's liability shall be limited to the direct loss or damage (excluding loss of profit and operating losses) suffered by "User" as a result of such breach and shall not include any other damages and particular consequential damages.

#### 6.2 In the scope of the use of the "Questionnaire"

Under no circumstances may the KIDSCREEN Group be held liable for direct or consequential damage resulting from the use of the KIDSCREEN.

#### 6.3 In the event of non-renewal of this Agreement

In the event of non-renewal of this Agreement by KIDSCREEN Group for any cause or failure by KIDSCREEN Group to conclude a new agreement with "User" upon the expiry of this Agreement, KIDSCREEN Group will have no liability for payment of any damages and/or indemnity to "User".

#### 7. Term and termination

This agreement shall be effective as the date of its signature by "User" and shall at least or until the term of the study above mentioned in SUMMARY OF THE STUDY.

Either party may terminate this Agreement immediately upon providing written notice to the other party in the event of: (a) the other party's unexcused failure to fulfil any of its material obligations under this Agreement or (b) upon the insolvency or bankruptcy of, or the filing of a petition in bankruptcy or similar arrangement by the other party. Upon expiration or termination of this Agreement KIDSCREEN Group may retain in its possession confidential information it acquired from KIDSCREEN instruments while under contract. The obligations which by their terms survive provisions of this Agreement, shall survive termination.

#### 8. Assignment

This Agreement and any of the rights and obligations of "User" are personal to the "User" and cannot be assigned or transferred by "User" to any third party or by operation of law, except with the written consent of KIDSCREEN Group notified to "User".

#### 9. Separate Agreement

This Agreement holds for the above mentioned study only. The use of the KIDSCREEN instruments in any additional study of the "User" will require a separate agreement without additional fees, unless significant updates have been added to the user manual (new edition, etc.).

#### 10. Entire Agreement, Modification, Enforceability

The entire agreement hereto is contained herein and this Agreement cancels and supersedes all prior agreements, oral or written, between the parties hereto with the respect to the subject matter hereto.

This Agreement or any of its terms may not be changed or amended except by written document and the failure by either party hereto to enforce any or all of the provision(s) of this Agreement shall not be deemed a waiver or an amendment of the same and shall not prevent future enforcement thereof.

If any one or more of the provisions or clauses of this Agreement are adjudged by a court to be invalid or unenforceable, this shall in no way prejudice or affect the binding nature of this

Agreement as a whole, or the validity or enforceability of each/and every other provision of this Agreement.

#### 11. Governing law

This Agreement shall be governed by and construed in accordance with the laws of the European Union.

#### 12. The KIDSCREEN Manual

User/University/Company:

The <u>KIDSCREEN Manual\*</u> can be directly ordered at the publishing company "<u>Pabst-Science-Publishers</u>" (here you can search for *KIDSCREEN*). The manual describes all relevant user information necessary for applying the KIDSCREEN questionnaires, e.g. psychometrics, norm data for group and individual comparisons, and instructions on how to score the instrument.

\*http://pabst-science-publishers.com/index.php?30&backPID=30&swords=kidscreen&tt\_products=100

IN WITNESS WHEREOF, the parties hereto have caused this agreement to be executed by their duly authorized representatives as of the date first above written.

Name: Budor Saigh				
Title: University of Realing				
Signature:				
Date: 06/05/2014				
If <u>not used for academic research</u> , please complete the following: BILLING ADDRESS:				
Institution:Dept:				
Street Address:				
City:State:Zip (Postal) Code:				
Country				

## **Appendix F: Approval from the Ministry of Education**



ROYAL EMBASSY OF SAUDI ARABIA CULTURAL BUREAU LONDON





التاريخ ٢١/٥/٥٣٤ هـ

إفادة

رقم الملف U526

تفيد الملحقية الثقافية بسفارة المملكة العربية السعودية في لندن بأن الطالبة/ بدور حامد احمد صانغ سجل مدني (١٠١٢٨١٦٥٥٧) والمبتعثة من قبل جامعة أم القرى لدراسة الدكتوراه بجامعة Reading في مجال التعليم قد التحق ت بالبعثة بتاريخ ١٤٣٤/١١٢٥هـ ومن المتوقع أن تنتهي بعثتها بتاريخ ١٤٣٧/١٢/٢٩هـ. ترغب بجمع بيانات تساعدها في بحثها لمرحلة الدكتوراه

وقد اعطيت لها هذه الإفادة بناء على طلبها لتقديمها الى وزارة التربية والتعليم السم التخطيط التربوي لمساعدتها في تسهيل مهمتها.

وتقبلوا فانق التحيات،،،

مساعد الملحق الشوون التعليمية والأكاديمية د محمد بن سعيد الأحمدي

> >. ج الرقم: .....

المرفقات: ..

الموافق: ...

التاريخ:.

630 Chiswick High Road, London W4 5RY Tel: +44 (0) 20 3249 7000 Fax: +44 (0) 20 3249 7001 E-mail: sacbuk@uksacb.org www.uksacb.org

## **Appendix G: Students - Questionnaire (English - Version)**

### Hello,

How are you? How do you feel? This is what we would like you to tell us. Please read every question carefully. What answer comes to your mind first? Choose the box that fits your answer best and cross it. Remember this is not a test so there are no wrong answers. It is important that you answer all the questions and also that we can see your marks clearly. When you think of your answer please try to remember the last W ows yo

## $\mathbf{T}$

		your answers to a ire once you have t	•	nobody who kn
1- Physical Activ	EN Health Relation in the EN Health IN THE EN HE EN HEALTH IN THE EN HEALT	ited Quality of Lif		e
_	out the last week felt fit and well slightly()		very()	extremely()
3- Have you not at all ()		active (e.g. running moderately()	-	ing)? extremely()
4- Have you not at all ()	been able to run slightly()		very()	extremely()
5- Have you	out the last week felt full of ener seldom()		very often()	always()
	out the last week r life been enjoy slightly()	able?	very()	extremely()
2- Have you not at all ()	felt pleased tha slightly()	t you are alive? moderately()	very()	extremely()
3- Have you not at all ()	felt satisfied wi slightly()	th your life? moderately()	very()	extremely()
Thinking abo	out the last week	-		

I hinking about the last week...

	4- Have you never ()	been in a good seldom()	mood? quite often()	very often()	always()
	5- Have you never ()	felt cheerful? seldom()	quite often()	very often()	always()
	6- Have you never ()		quite often()	very often()	always()
3- (	General Mood	l			
	Thinking abo	out the last week	•••		
	•	•	everything badly?		
	never ()	seldom()	quite often()	very often()	always()
	2- Have you	felt sad?			
	never ()		quite often()	very often()	always()
	<b>~</b>	<b>~</b>	1 ~	•	<i>y</i> • • • • • • • • • • • • • • • • • • •
	•		you didn't want to		
	never ()	seldom()	1 ~	very often()	always()
			in your life goes wr	_	alwaya()
	never ()	seldom()	quite often()	very often()	always()
	5- Have you	felt fed up?			
	never ()	-	quite often()	very often()	always()
				•	
	6- Have you	•			
	never ()	seldom()	quite often()	very often()	always()
	7- Have you	felt under press	ure?		
	never ()	seldom()	quite often()	very often()	always()
	never ()	seldom()	quite often()	very often()	ui ways()
4- 4	About Yourse				
	-	out the last week			
	•	* * *	h the way you are?	<b>C</b> . ()	1 0
	never ()	seldom()	quite often()	very often()	always()
	2- Have you	been happy wit	h vour clothes?		
	never ()	seldom()	quite often()	very often()	always()
	V	~	1 ~	<b>3</b>	<b>3</b> V
			oout the way you lo	ok?	
	never ()	seldom()	quite often()	very often()	always()
	A₋ Have you	felt jealous of th	he way other girls a	nd hove look?	
	never ()	seldom()	quite often()	very often()	always()
	110,01	soldoni()	quite often()	in the second	ai ways()
	5- Would yo	u like to change	something about y	our body?	
	never ()	seldom()	quite often()	very often()	always()

## 5- Free Time

Thinking about the last week...

	1- Have you never ()	had enough tim seldom()	e for yourself? quite often()	very often()	always()
	2- Have beer never ()		things that you want quite often()		
	never ()	scidoiii()	quite orten()	very often()	aiways()
	3- Have you never ()		portunity to be outsi quite often()	de? very often()	always()
	4- Have you never ()	_	ne to meet friends? quite often()	very often()	always()
	5- Have you never ()	been able to che seldom()	oose what to do in y quite often()		always()
6- F	1- Have you	me Life out the last wee ur parent(s) und () slightly()	erstood you?	very()	extremely()
	2- Have you not at all	u felt loved by y () slightly()	your parent(s)? moderately()	very()	extremely()
Thi	nking about th 3- Have voi	e last week I been happy at	home?		
	never ()		quite often()	very often()	always()
	4- Have you never ()	-	enough time for yo quite often()		always()
	5- Have you never ()	ur parent(s) trea seldom()	ted you fairly? quite often()	very often()	always()
	6- Have you never ()	a been able talk seldom()	to your parent(s) war	-	o? always()
7- N	_	out last week a had enough m	oney to do the same quite often()	e things as your fr very often()	iends? always()
	2- Have you never ()	ı had enough m seldom()	oney for your exper quite often()		always()
			k oney to do things wi moderately()		extremely()

8- Friends

	_	ut the last week spend time with seldom()		very often()	always()
	2- Have you on never ()	lone things with seldom()	n other girls and boy quite often()	ys? very often()	always()
	3- Have you haver ()	nad fun with yo seldom()	ur friends? quite often()	very often()	always()
	4- Have you a never ()	and your friends seldom()	s helped each other quite often()	very often()	always()
	5- Have you be never ()	peen able to talk seldom()	about everything v quite often()	with your friends? very often()	always()
	6- Have you never ()	been able to rel seldom()	y on your friends? quite often()	very often()	always()
9- Sc	_	out the last weel			
	not at all ()	been happy at s slightly()	moderately()	very()	extremely()
	2- Have you not at all ()	got on well at s slightly()	chool? moderately()	very()	extremely()
	3- Have you not at all ()		with your teachers? moderately()	very()	extremely()
Т	_	t the last week. been able to pageseldom()		very often()	always()
	5- Have you never ()	enjoying going seldom()	to school? quite often()	very often()	always()
	6- Have you never ()	got along well v seldom()	with your teachers? quite often()	very often()	always()
	Sullying	t the last week.			
	_		 other girls and boys quite often()	? very often()	always()
	,	V	made fun of you?	very orien()	arways()
	never ()	seldom()	quite often()	very often()	always()
	3- Have other never ()	r girls and boys seldom()	bullied you? quite often()	very often()	always()

## **Appendix H: Parents - Questionnaire (English - Version)**

### Dear Parents,

How is your child? How does he/she feel? This is what we would like to know from you. Please answer the following questions to the best of your knowledge, ensuring that the answers you give reflect the perspective of your child. Please try to remember your child's experience over the last week.

#### Th

your	cilia s expe	richee over the	last week		
1- Ph 1- () () () ()	ysical Activ	ities and Healtl	ated Quality of Lift h ar child rate his/her		e
	_	ut the last week child felt fit and			
_	•	slightly()		very()	extremely()
3	3- Has your o not at all ()		sically active (e.g. r moderately()	•	-
4	•	child been able slightly()	to run well? moderately()	very()	extremely()
	_	ut the last week child felt full of seldom()		very often()	always()
T 1	_		fe was enjoyable? moderately()	very()	extremely()
2	2- Has your on not at all ()	-	ed that he/she is aliv moderately()	ve?	extremely()
3	3- Has your o not at all ()	child felt satisfi slightly()	ed with her/his life moderately()	? very()	extremely()
	_	ut the last week child been in a seldom()		very often()	always()
5	5- Has your onever ()	child felt cheer seldom()	ful? quite often()	very often()	always()

	6- Has your c	hild had fun?			
	never ()		quite often()	very often()	always()
3- (	General Mood				
	Thinking abou	it the last week	•••		
	1- Has your c	hild felt that he	she does everythin	ng badly?	
	never ()	seldom()	quite often()	very often()	always()
	2 11	1 1 1 6 1 10			
	2- Has your c		anita aftan()	······································	almana()
	never ()	seldom()	quite often()	very often()	always()
	3- Has your c	hild felt so bad	that he/she didn't v	want to do anything	?
	never ()	seldom()	quite often()		always()
	· · · · · · · · · · · · · · · · · · ·		verything in his/her		<b>3</b>
	never ()		quite often()		always()
	•	hild felt fed up			
	never ()	seldom()	quite often()	very often()	always()
	( II	1. 11 1 C 14 1 1	n		
	•	hild felt lonely seldom()		vomv often()	alwaya()
	never ()	seidom()	quite often()	very often()	always()
	7- Has your c	hild felt under	nressure?		
	never ()		quite often()	very often()	always()
	ne ver ()	seraom()	quite orten()	very orden()	ar ways()
<b>1</b> - <i>1</i>	About Your Ch	ild			
	Thinking abou	it the last week	•••		
	•		y with the way he/s		
	never ()	seldom()	quite often()	very often()	always()
	2 11	1 '1 1 1 1		0	
	•		y with his/her cloth quite often()		olwowa()
	never ()	seldom()	quite orien()	very often()	always()
	3- Has your c	hild been worri	ied about the way h	e/she looks?	
	never ()	seldom()	quite often()	very often()	always()
	()	2 - 2 - 2 - 2 - 2 - 2 - 2	4	5	
	4- Has your c	hild felt jealous	s of the way other g	girls and boys look?	
	never ()	seldom()	quite often()	very often()	always()
	•		-	about his/her body?	
	never ()	seldom()	quite often()	very often()	always()
<b>5</b> 1	Free Time				
ן - כ		ut the last week	r		
	•		gh time for him/hers	self?	
	never ()	seldom()	quite often()	very often()	always()
	(	<del></del> ()	1	, J ()	
	2- Has your	child been abl	e to do the things	that he/she wants to	o do in his/hei
free	e time?		_		
	never ()	seldom()	quite often()	very often()	always()

	never ()	seldom()	quite often()	very often()	always()
	4- Has your cl never ()	hild had enough seldom()	n time to meet frien quite often()	ds? very often()	always()
	5- Has your cl never ()	hild been able t seldom()	o choose what to do quite often()	o in his/her free to very often()	ime? always()
6- Fa		out the last week child felt under	c stood by his/her pa moderately()	rents(s)? very()	extremely()
	2- Has your ont at all ()		by his/her parent(s moderately()	)? very()	extremely()
Thinl	king about the 3- Has your never ()	e last week child been happ seldom()	by at home? quite often()	very often()	always()
	4- Has your never ()	child felt that h seldom()	is/her parent(s) had quite often()	enough time for very often()	him/her? always()
	5- Has your never ()	child felt that h seldom()	is/her parent(s) trea quite often()		y? always()
	6- Has your never ()	child been able seldom()	talk to his/her pare quite often()	* *	e wanted to? always()
7- M	1- Has your never ()	seldom()	gh money to do the quite often()	very often()	always()
	2- Has your never ()	seldom()	e/she had enough n quite often()	very often()	expenses? always()
friend	3- Does you	out the last week r child feel that	c he/she has enough	n money to do thi	ings with his/her
1116110	not at all ()	slightly()	moderately()	very()	extremely()
8- F1	_	out the last week		1.0	
	never ()	seldom()	e with his/her friend quite often()	very often()	always()

•	seldom()	s with other girls ar quite often()	very often()	always()
•	ild had fun wi seldom()	th his/her friends? quite often()	very often()	always()
<u>▼</u>	nild and his/her seldom()	friends helped eac quite often()	h other? very often()	always()
	ild been able t seldom()	to talk about everytl quite often()	hing with his/he very often()	r friends? always()
6- Has your cl never ()	hild been able seldom()	to rely on his/her fr quite often()	riends? very often()	always()
1- Has your cl	ing at the last weel hild been happ slightly()	y at school?	very()	extremely()
2- Has your cl not at all ()	hild got on we slightly()	ll at school? moderately()	very()	extremely()
3- Has your cl not at all ()		fied with his/her tea moderately()	nchers? very()	extremely()
Thinking about 4- Has your cl never ()	hild been able	to pay attention? quite often()	very often()	always()
5- Has your cl never ()	hild enjoyed go seldom()	oing to school? quite often()	very often()	always()
6- Has your cl never ()	hild got along seldom()	well with his/her te quite often()	achers? very often()	always()
10- Bullying Thinking about 1- Has your cl never ()		d of other girls and quite often()	boys? very often()	always()
V	v	made fun of your ch quite often()	•	always()
3- Has other g never ()	girls and boys to seldom()	oullied your child? quite often()	very often()	always()

## **Appendix I: Irish Respondents**

**Table 1: Physical Well-being of Irish respondents** 

	Not at all	Slightly	Moderately	Very	Extremely
In general, how would you say your health is?*	1%	4%	29%	43%	23%
Have you felt fit and well?	2%	9%	27%	43%	19%
Have you been physically active (e.g. running, climbing, biking)?	4%	9%	22%	34%	31%
Have you been able to run well?	3%	8%	22%	39%	26%
Have you felt full of energy?**	1%	12%	32%	35%	20%

Table 2: Psychological well-being of all respondents in Ireland

	Never	Seldom	Quite often	Very often	Always
Has your life been enjoyable?*	1%	6%	17%	41%	34%
Have you felt pleased that you are alive?*	1%	4%	9%	27%	59%
Have you felt satisfied with your life?*	3%	5%	17%	38%	36%
Have you been in a good mood?	1%	7%	30%	45%	17%
Have you felt cheerful?	1%	8%	25%	46%	20%
Have you had fun?	1%	5%	16%	39%	39%

Table3: Moods and emotions of Irish respondents

	Never	Seldom	Quite often	Very often	Always
Have you felt that you do everything badly?	25%	53%	14%	5%	2%
Have you felt sad?	21%	55%	16%	6%	1%
Have you felt so bad that you didn't want to do anything?	55%	29%	10%	4%	2%
Have you felt that everything in your life goes wrong?	49%	34%	10%	4%	3%
Have you felt fed up?	21%	49%	19%	8%	3%
Have you felt lonely?	53%	28%	11%	5%	3%
Have you felt under pressure?	31%	32%	20%	11%	6%

**Table 4: Self-perceptions of Irish respondents** 

	Never	Seldom	Quite often	Very often	Always
Have you been happy with the way you are?	3%	9%	23%	32%	33%
Have you been happy with your clothes?	2%	8%	17%	30%	43%
Have you been worried about the way you look?	27%	30%	18%	14%	10%
Have you felt jealous of the way other girls and boys look?	43%	27%	12%	11%	7%
Would you like to change something about your body?	37%	24%	12%	10%	17%

**Table 5: Autonomy of Irish respondents** 

	Never	Seldom	Quite often	Very often	Always
Have you had enough time for yourself?	3%	13%	25%	29%	30%
Have you been able to do the things that you want to do in your free time?	3%	15%	26%	28%	28%
Have you had enough opportunity to be outside?	4%	11%	17%	26%	42%
Have you had enough time to meet friends?	4%	14%	21%	29%	31%
Have you been able to choose what to do in your free time?	2%	10%	22%	31%	34%

**Table 6: Parents relations for Irish respondents** 

	Never	Seldom	Quite often	Very often	Always
Have your parent(s) understood you?*	4%	10%	22%	36%	28%
Have you felt loved by your parent(s)?*	1%	3%	10%	26%	59%
Have you been happy at home?	1%	6%	18%	32%	43%
Have your parent(s) had enough time for you?	2%	7%	18%	26%	46%
Have your parent(s) treated you fairly?	3%	7%	15%	27%	48%
Have you been able to talk to your parent(s) when you wanted to?	3%	9%	18%	23%	46%

**Table 7: Social support of Irish respondents** 

	Never	Seldom	Quite often	Very often	Always
Have you spent time with your friends?	1%	4%	16%	39%	40%
Have you done things with other girls and boys?	4%	9%	21%	34%	31%
Have you had fun with your friends?	1%	2%	10%	27%	59%
Have you had fun with your friends?	2%	6%	23%	31%	38%
Have you been able to talk about everything with your friends?	4%	13%	23%	25%	35%
Have you been able to rely on your friends?	3%	7%	18%	28%	44%

**Table 8: School Environment of Irish respondents** 

	Never	Seldom	Quite often	Very	Always
				often	
Have you been happy at school?*	7%	12%	29%	35%	17%
Have you got on well at school?*	4%	8%	24%	40%	23%
Have you been satisfied with your teachers?*	10%	14%	29%	28%	18%
Have you been able to pay attention?	3%	11%	31%	35%	19%
Have you enjoyed going to school?	11%	19%	27%	26%	16%
Have you got along well with your teachers?	4%	13%	28%	33%	22%

**Table 9: Bullying of Irish respondents** 

	Never	Seldom	Quite often	Very often	Always
Have you had enough money to do the same things as your friends?	65%	25%	5%	3%	2%
Have you had enough money for your expenses?	49%	34%	9%	4%	4%
Do you have enough money to do things with your friends?*	70%	20%	5%	2%	3%

**Table 10: Financial resources of Irish respondents** 

	Never	Seldom	Quite often	Very often	Always
Have you had enough money to do the same things as your friends?	4%	10%	17%	27%	43%
Have you had enough money for your expenses?	3%	9%	19%	25%	43%
Do you have enough money to do things with your friends?*	2%	7%	20%	34%	37%

## **Appendix J: Ethical documentations**



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Supervisor: Dr. Catherine Tissot

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#### **Head teacher permission information**

Invitation For Your Teachers and Students with Autism to Join The Study

For Project On: The KIDSCREEN Health Related Quality of Life Questionnaires For Children and Adolescents In SAUDI ARABIA.

#### Dear Head teacher,

I am contacting you to invite your teachers and your students with autism to take part in a study to explore quality of life for young children and adolescents and their state of health in Saudi Arabia.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read this Information and ask the researcher if there is anything that is not clear, or if you would like more information. This research is being supported by the Saudi Ministry of Higher Education and has permission from the Ministry of Education to proceed.

#### What is the study?

The study is a part of PhD project that I am undertaking at the Institute of Education, University of Reading in the UK. Its aim is to assess generic health-related quality of life (HRQoL) for both children and adolescents with autism. By assessing quality of life issues, the researcher will attempt to contribute to the discussion on ways to increase awareness of teachers who work with children with autism and their health related to quality of life.

### Why has my school been chosen to take part?

It has been chosen to take part because your school is a special needs school (with children with autism) in Jeddah and has been suggested by the Ministry of Education.

### What happen if the school take part?

If you agree and permit your school to take part, there are two methods of research will be done:

- 1- The researcher will ask the students (with permission from their parents) to complete a questionnaire about the following ten dimensions: Physical and Psychological Well being; Moods and Emotions; Self-Perception; Autonomy; Parents Relation & Home Life; Financial Resources; Social Support & Peers; Social Environment; Social Acceptance (Bullying).
- 2- After obtaining consent, some of your teachers for Year Fifteen will take part in an interview to highlight their aims and their goals in addressing quality of life issues related to teaching students with autism and supporting them. With their permission, this interview will be recorded and transcribed.

#### Do the participants have to take part?

No, participation is voluntary. They may also withdraw at any time during the project, without any repercussion to them, by contacting the researcher using the details above.

#### Who has reviewed the study?

This study has been reviewed following the procedures of the University Research Ethics Committee and has been given a favourable ethical opinion for conduct. The university has the appropriate insurance in place. Full details are available on request.

#### What are the risks and the benefits of taking part?

All information that is collected about the participants during the research will be kept strictly confidential. All interview recordings will be destroyed after five years after the end of the research. Names or any contact details will not be recorded on the questionnaire or interviews transcripts. My academic supervisors will have access to the transcripts, but I will be the only person to have access to the original recordings. All identifying details will be changed in any publication resulting from this research. Concerning confidentiality, all questionnaires will be identified by a number, which will be kept separate from the personal identification of participants. The number corresponding to each participant will only be available to the investigators in the study while the study is in progress. Afterwards, the number will be eliminated.

I anticipate that the findings of this study will be used to help to support teachers and educators as well as to enable students with autism to shape their own life with a better quality of life, and identify areas of greatest need for development as well as spread good practice.

I know how busy you are, but I highly value the information which only your school can provide regarding the realities of special needs education, and I hope that you will be able

and willing to contribute to this research project by giving the permission. If you do, **please complete the attached consent form.** A summary of the results can be sent upon sending an email to the address above.



Researcher: Budor Saigh

E-mail: b.h.a.saigh@pgr.reading.ac.uk

Supervisor: Dr. Catherine Tissot

E-mail: c.tissot@reading.ac.uk

#### **Head teacher Consent Form**

Project Title: The KIDSCREEN Health Related Quality of Life Questionnaires For Children and Adolescents In SAUDI ARABIA.

I have read the information sheet and the researcher explained it to me.

I have had explained to me the purpose of the project and what will be required of me, and any questions have been answered to my satisfaction. I agree to the arrangements described in the information Sheet in so far as they relate to the teachers and students with autism participation.

I understand that they will be completed the questionnaires and interviewed and that the interview will be recorded and transcribed.

I understand that their participations are entirely voluntary and that I have the right to withdraw them from the project any time, without giving a reason and without repercussions by sending an email to the addresses above.

I have received a copy of this Consent Form and of the accompanying Information Sheet.

Please tick as appropriate:	
I consent to this research to take place in my school	
Name:	
Signed:	



Date:

Researcher: Budor Saigh

E-mail: b.h.a.saigh@pgr.reading.ac.uk

Supervisor: Dr. Catherine Tissot

E-mail: c.tissot@reading.ac.uk

#### Participant information sheet

#### Invitation to join the study

For Project On: The KIDSCREEN Health Related Quality of Life Questionnaires For Children and Adolescents In SAUDI ARABIA.

Dear Teacher,

You are being invited to take part in my study to explore quality of life for young children and adolescents and their state of health.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully. Ask the researcher if there is anything that is not clear or if you would like more information. This research is being supported by the Saudi Ministry of Higher Education and has permission from the Ministry of Education to proceed.

The rest of this sheet explains the study in more detail, and describes what being in the study would mean for you.

#### What is the study?

The study is a part of PhD project that I am undertaking at the Institute of Education, University of Reading in the UK. Its aim is to assess generic health-related quality of life (HRQoL) in Children with disabilities and adolescents. I hope it will shed light about the general curriculum and how children with autism have adapted in special education needs. By assessing quality of life issues, the researcher will attempt to contribute to the discussion on ways to increase the awareness of teachers who work with children with autism related to quality of life.

#### Why have I been chosen to take part?

You have been invited to take part, as you are a teacher of some students who are diagnosed with autism in your class, and your opinion will be helpful in this project.

#### Do I have to take part?

No, your participant is voluntary. You may also withdraw at any time during the project, without any repercussion to you, by contacting the researcher using the details above.

#### What happens if I take part?

If you agree to take part, you will take part in:

- 1- Help with fieldwork: to be present when the researcher administers the questionnaire (or only at the beginning of the activity).
- 2- An interview of about 40 minutes, to highlight your aims and your goals in assessing quality of life issues related to teaching students with autism and supporting them. With your permission, this interview will be recorded and transcribed.

#### Who has reviewed the study?

This study has been reviewed following the procedures of the University Research Ethics Committee and has been given a favourable ethical opinion for conduct. The university has the appropriate insurance in place. Full details are available on request.

#### What are the risks and the benefits of taking part?

All information that is collected about you during the research will be kept strictly confidential. All interview recordings will be destroyed at the end of the research. Your name or any contact details will not be recorded on the interview transcripts. My academic supervisors will have access to the transcripts of your interview, but I will be the only person to have access to the original recordings of the interview.

I anticipate that the findings of this study will be used to help to support teachers and educators as well as to enable students with autism to shape their own life with a better

quality of life, and identify areas of greatest need for development as well as spread good practice.

I know how busy you are, but I highly value the information which only you can provide regarding the realities of special needs education, and we hope that you will be able and willing to contribute to this research project. If you do, please complete the attached consent form. A summary of the results can be sent upon sending an email to the address above.



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E-mail: b.h.a.saigh@pgr.reading.ac.uk

Supervisor: Dr. Catherine Tissot

E-mail: c.tissot@reading.ac.uk

#### **Teacher Consent Form**

Project Title: The KIDSCREEN Health Related Quality of Life Questionnaires For Children and Adolescents In SAUDI ARABIA.

I have read the information sheet and the researcher explained it to me.

I have had explained to me the purpose of the project and what will be required of me, and any questions have been answered to my satisfaction. I agree to the arrangements described in the information Sheet in so far as they relate to my participation.

I understand that I will collaborate in the field work and participate in an interview and that the interview will be recorded and transcribed.

I understand that my participation is entirely voluntary and that I have the right to withdraw from the project any time, without giving a reason and without repercussions by sending an email to the addresses above.

I have received a copy of this Consent Form and of the accompanying Information Sheet.

Please tick as appropriate:	
I consent to being interviewed	
I consent to this interview being recorded:	
Name:	
Signed:	



Date:

Researcher: Budor Saigh

E-mail: b.h.a.saigh@pgr.reading.ac.uk

Supervisor: Dr. Catherine Tissot

E-mail: c.tissot@reading.ac.uk

#### **Parental Permission Information**

#### Invitation for your daughter/son to join the study

For Project On: The KIDSCREEN Health Related Quality of Life Questionnaires For Children and Adolescents In SAUDI ARABIA.

Dear parent of a student with autism,

Your daughter/son is being invited to take part in this study to explore quality of life for young children and adolescents and their state of health. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read this Parental Permission Information carefully. Ask the researcher if there is anything that is not clear or if you would like more information. This research is being supported by the Saudi Ministry of Higher Education and has permission from the Ministry of Education to proceed.

#### What is the study?

The study is a part of PhD project that I am undertaking at the Institute of Education, University of Reading in the UK. It's aim is to assess generic health-related quality of life (HRQoL) in children with disabilities and adolescents. It will shed light also in the general curriculums and how children with autism have adapted in special education needs. By assessing quality of life issues, the researcher will attempt to contribute to the discussion on

ways to increase awareness of teachers who work with children with autism and their health related to quality of life.

#### Why has my daughter/son been invited to participate in this study?

Your child has been invited to participate in this study because her/his school has identified her/him as a student with autism.

#### What if I don't want my child to do this?

You are free to decline permission for your child to take part in this study as your child's participation in this study is voluntary. Refusal to allow your daughter/son to participate in the study will not affect your child's current or future education in any way. You may also withdraw your permission for your child to participate at any time during the project, by contacting the researcher using the details above.

#### What happen if I my child take part?

If you agree for your child to participate, your daughter/son will complete the questionnaire about the following ten dimensions: Physical and Psychological Well being; Moods and Emotions; Self-Perception; Autonomy; Parents Relation & Home Life; Financial Resources; Social Support & Peers; Social Environment; Social Acceptance (Bullying). The questionnaire should be administered in the class time with collaboration between the teacher and the researcher; the time required for the questionnaire to be completed is approx. 15-20 minutes. We are interested in the opinion of your daughter/son regarding her/his state of health. The summary of the results will be sent upon request by sending an email to the address above.

#### Who has reviewed the study?

This study has been reviewed following the procedures of the University Research Ethics Committee and has been given a favourable ethical opinion for conduct. The university has the appropriate insurance in place. Full details are available on request.

#### What are the risks and the benefits of taking part?

All information that is collected about you child during the research will be kept strictly confidential. Your child's name or any contact details will not be recorded on the transcripts, or in any publication. My academic supervisors will have access to the transcripts, but I will be the only person to have access to the original recording. Concerning confidentiality, all

questionnaires will be identified by a number, which will be kept separate from the personal identification of participants. The number corresponding to each participant will only be available to the responsible investigators in the study while the study is in progress. Afterwards, the number will be eliminated.

I anticipate that the findings of this study will be used to help to support teachers and educators as well as to enable students with autism to shape their own life with better quality of life, and identify areas of greatest need for development as well as spread good practice.

I highly value the information, which only your child can provide regarding the realities of special needs education, and I hope that you will be able and willing to give your child permission to contribute to this research project. If you do, please complete the attached consent form.



Researcher: Budor Saigh

E-mail: b.h.a.saigh@pgr.reading.ac.uk

Supervisor: Dr. Catherine Tissot

E-mail: c.tissot@reading.ac.uk

#### **Parent Consent Form**

Project Title: The KIDSCREEN Health Related Quality of Life Questionnaires For Children and Adolescents In SAUDI ARABIA.

I have read the information sheet and the researcher explained it to me.

I have had explained to me the purpose of the project and what will be required of me, and any questions have been answered to my satisfaction. I agree to the arrangements described in the information Sheet in so far as they relate to my participation.

I understand that my daughter/son will complete the questionnaire.

I understand that my daughter's/son's participation is entirely voluntary and that I have the right to withdraw her/him from the project any time, without giving a reason and without repercussions by sending an email to the addresses above.

I have received a copy of this Consent Form and of the accompanying Information Sheet.

#### Please tick as appropriate:

I consent to my daughter/son to participate	
Name:	
Signed:	
Date:	



Researcher: Budor Saigh

E-mail: b.h.a.saigh@pgr.reading.ac.uk

Supervisor: Dr. Catherine Tissot E-mail: c.tissot@reading.ac.uk

#### **Student Consent Form**

## Project Title: The KIDSCREEN Health Related Quality of Life Questionnaires For Children and Adolescents In SAUDI ARABIA.

(This would be read to individuals if they are not able to read themselves and it could be read by either researcher or teacher).

I have read the information sheet and the researcher explained it to me.

I understand what the study is about.

I understand that I am required to complete questionnaire and I understand that this study has ethics approval and is safe to do.

I understand that I don't have to take part and can drop out of the study at any time, without giving a reason just ask your teacher or your parents to tell us if you want to stop.

I have received a copy of this Consent Form and Information Sheet.

Please tick as appropriate:		
I agree to take part in this study:	YSE	NO
Name:		Signed:
Date:		

(This would be read to individuals if they are not able to read themselves and it could be read by either researcher or teacher).

#### Dear student,

You are being invited to take part in my study to help me to understand your opinion of your quality of life and your state of health.

The results from this project will be part of my PhD study at the University of Reading.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please ask if there is anything you don't understand. This research is being supported by the Saudi Ministry of Higher Education and has permission from the Ministry of education to proceed.

## Why have I been invited to take part?

You have been invited to take part because you go to special needs school. So, your opinion will be helpful in this project.

### What happens if I take part?

If you agree to take part, you will be asked to fill in a questionnaire in the classroom. This takes about 15 - 20 minutes. In general some of the

questions will be about yourself and home, and some will be about your school day.

## Do I have to take part?

No, it is up to you. You don't have to take part, but I hope you will.

### Will anyone know about my answers?

Only my supervisors and me will know about your answers. We won't tell your school how you answered, or your parents.

### Will I benefit by taking part?

We think you will find it exciting and fun to do the questionnaire. Your answers and thoughts will help us to understand your views so your teachers, with your parents help, will support you to have a good quality of life and learn better.

### Who has reviewed the study?

This study has been reviewed following the procedures of the University Research Ethics Committee and has been given a favourable ethical opinion for conduct. The university has the appropriate insurance in place. Full details are available on request.

#### When I will take part?

Your parents have been sent a letter about the project and the questionnaire. If they agree for you to be part of the research, you will be given a time and more details to complete questionnaire.

I am happy to provide any further information about it, which you may need in greater details. My e-mail address is:

b.h.a.saigh@pgr.reading.ac.uk

My supervisor: Dr. Catherine Tissot

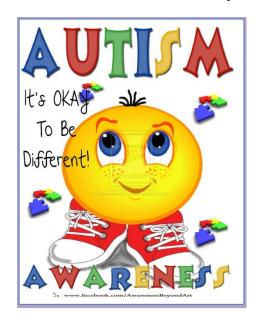
E-mail: c.tissot@reading.ac.uk



Student information sheet

Invitation to join the study

For Project on:





The KIDSCREEN Health Related Quality of Life Questionnaires For Children and Adolescents in Saudi Arabia

With

Budor Saigh



## University of Reading

## Institute of Education

## **Ethical Approval Form A (version September 2013)**

	Tick one:
	Staff project: PhD
	Name of applicant (s):Budor Saigh
Chi	Title of project: The KIDSCREEN Health Related Quality of Life Questionnaires For ildren and Adolescents In SAUDI ARABIA
	Name of supervisor (for student projects): Dr. Catherine Tissot

Please complete the form below including relevant sections overleaf.

	YES	NO
Have you prepared an Information Sheet for participants and/or their parents/carers that:	Х	
a) explains the purpose(s) of the project	Х	
b) explains how they have been selected as potential participants	Х	
c) gives a full, fair and clear account of what will be asked of them and how the information that they provide will be used	Х	
d) makes clear that participation in the project is voluntary	Х	
e) explains the arrangements to allow participants to withdraw at any stage if they wish	Х	
f) explains the arrangements to ensure the confidentiality of any material collected during the project, including secure arrangements for its storage, retention and disposal	Х	
g) explains the arrangements for publishing the research results and, if confidentiality might	Х	

he affected for obtaining written concent for this		
be affected, for obtaining written consent for this		
h) explains the arrangements for providing participants with the research results if they wish	Х	
to have them		
i) gives the name and designation of the member of staff with responsibility for the project	Х	
together with contact details, including email . If any of the project investigators are students	^	
at the IoE, then this information must be included and their name provided		
at the fore, then this information must be included and then hame provided		
k) explains, where applicable, the arrangements for expenses and other payments to be made to the	n/a	
participants		
j) includes a standard statement indicating the process of ethical review at the University	Х	
undergone by the project, as follows:		
'This project has been reviewed following the procedures of the University Research Ethics		
Committee and has been given a favourable ethical opinion for conduct'.		
·		
k)includes a standard statement regarding insurance:	Х	
"The University has the appropriate insurances in place. Full details are available on request".		
Please answer the following questions		
1) Will you provide participants involved in your research with all the information necessary	Х	
to ensure that they are fully informed and not in any way deceived or misled as to the		
purpose(s) and nature of the research? (Please use the subheadings used in the example		
information sheets on blackboard to ensure this).		
2) Will you seek written or other formal consent from all participants, if they are able to	Х	
provide it, in addition to (1)?		
3) Is there any risk that participants may experience physical or psychological distress in		X
taking part in your research?		
4) Have you taken the online training modules in data protection and information security		
(which can be found here: http://www.reading.ac.uk/internal/imps/Staffpages/imps-		
training.aspx)?		
5) Does your research comply with the University's Code of Good Practice in Research?	Х	
	YES	NO
	163	INO
6) If your research is taking place in a school, have you prepared an information sheet and	Х	
consent form to gain the permission in writing of the head teacher or other relevant		
supervisory professional?		
7) Harda data allo tara data da distributa de RDC d		
7) Has the data collector obtained satisfactory DBS clearance?		
8) If your research involves working with children under the age of 16 (or those whose	Х	
special educational needs mean they are unable to give informed consent), have you prepared		
an information sheet and consent form for parents/carers to seek permission in writing, or to		
give parents/carers the opportunity to decline consent?		

9) If your research involves processing sensitive personal data <sup>1</sup> , or if it involves audio/video recordings, have you obtained the explicit consent of participants/parents?		
10) If you are using a data processor to subcontract any part of your research, have you got a written contract with that contractor which (a) specifies that the contractor is required to act only on your instructions, and (b) provides for appropriate technical and organisational security measures to protect the data?		
11a) Does your research involve data collection outside the UK?	Х	
11b) If the answer to question 11a is "yes", does your research comply with the legal and ethical requirements for doing research in that country?	Х	
12a. Does the proposed research involve children under the age of 5?		Х
12b. If the answer to question 12a is "yes":  My Head of School (or authorised Head of Department) has given details of the proposed research to the University's insurance officer, and the research will not proceed until I have confirmation that insurance cover is in place.		
If you have answered YES to Question 3, please complete Section B below		

## PLEASE COMPLETE **EITHER SECTION A OR B** AND PROVIDE THE DETAILS REQUIRED IN

SUPPORT OF YOUR APPLICATION, THEN SIGN THE FORM (SECTION C)

**A:** My research goes beyond the 'accepted custom and practice of teaching' but I consider that this project has **no** significant ethical implications.

Give a brief description of the aims and the methods (participants, instruments and procedures) of the project in up to 200 words. Attach any consent form, information sheet and research instruments to be used in the project (e.g. tests, questionnaires, interview schedules).

Please state how many participants will be involved in the project:

This form and any attachments should now be submitted to the Institute's Ethics Committee for consideration. Any missing information will result in the form being returned to you.

<sup>&</sup>lt;sup>1</sup> Sensitive personal data consists of information relating to the racial or ethnic origin of a data subject, their political opinions, religious beliefs, trade union membership, sexual life, physical or mental health or condition, or criminal offences or record.

This research will explore quality of life issues in individuals with disabilities in Saudi Arabia. It will assess generic health-related quality of life in children with disabilities and adolescents who are identified, as students with autism in special need school in Saudi Arabia. Qualitative and Quantitative data will be together gathered through the use of two methods: The KIDSCREEN Health Related Quality of life questionnaires for children/adolescents and interviews for the teachers. The KIDSCREEN instruments were developed to gain information about children's and adolescents' well-being and health-related quality of life. The questionnaire about the following ten dimensions: Physical and Psychological Well being; Moods and Emotions; Self-Perception; Autonomy; Parents Relation & Home Life; Financial Resources; Social Support & Peers; Social Environment; Social Acceptance (Bullying).

The study should be a cross-sectional study including 300-400 children and adolescents aged about 13 in schools or health care centres. The study can take place in schools or health care centres with a range of socio-economic characteristics. Although convenience sampling can be used (i.e. the sample does not necessarily nationally representative), it is important to ensure a good spread of respondent characteristics in the sample. The sample should consist of children and adolescents aged about 13 of both genders. Within each group, children from higher and lower socio-economic background/areas should be included. An exclusion criterion is when parents and/or children and adolescents refuse consent to participate in the study.

**B:** I consider that this project **may** have ethical implications that should be brought before the Institute's Ethics Committee.

## Please provide all the further information listed below in a separate attachment.

- 1. title of project
- 2. purpose of project and its academic rationale
- 3. brief description of methods and measurements
- 4. participants: recruitment methods, number, age, gender, exclusion/inclusion criteria
- 5. consent and participant information arrangements, debriefing (attach forms where necessary)
- 6. a clear and concise statement of the ethical considerations raised by the project and how you intend to deal with then.
- 7. estimated start date and duration of project

This form and any attachments should now be submitted to the Institute's Ethics Committee for consideration. Any missing information will result in the form being returned to you.

## **C: SIGNATURE OF APPLICANT:**

I have declared all relevant information regarding my proposed project and confirm that ethical good practice will be followed within the project.						
Signed:						
STATEMENT OF ETHICAL APPROVAL FOR PROPOSALS SUBMITTED TO THE INSTITUTE ETHICS COMMITTEE						
This project has been considered using agreed Institute procedures and is now approved.						
Signed: Print NameDaisy Powell Date24/2/14  (IoE Research Ethics Committee representative)*						
* A decision to allow a project to proceed is not an expert assessment of its content or of the possible risks involved in the investigation, nor does it detract in any way from the ultimate responsibility which students/investigators must themselves have for these matters. Approval is granted on the basis of the information declared by the applicant.						
The KIDSCREEN Health Related Quality of Life Questionnaire						
1- Physical Activities and Health 1- In general how would you say your health is? () Excellent () Very good () Good () Fair () Poor						
Thinking about the last week 2- Have you felt fit and well? not at all () slightly() moderately() very() extremely()						

3- Have you been physically active (e.g. running, climbing, biking)?

n	ot at all ()	slightly()	moderately()	very()	extremely()	
	Have you be ot at all ()	en able to rur slightly()	n well? moderately()	very()	extremely()	
5-	inking about Have you fel ever () so			very often()	always()	
2- Feelings Thinking about the last week 1- Have your life been enjoyable?						
n	ot at all ()	slightly()	moderately()	very()	extremely()	
	Have you fel ot at all ()	t pleased that slightly()	t you are alive? moderately()	very()	extremely()	
	Have you fel ot at all ()	t satisfied wi slightly()	•	very()	extremely()	
Thi	inking about	the last week				
	Have you be ever () so	en in a good eldom()	mood? quite often()	very often()	always()	
	Have you fel ever () so		quite often()	very often()	always()	
	Have you have you have () see	d fun? eldom()	quite often()	very often()	always()	
	eral Mood					
Thinking about the last week  1- Have you felt that you do everything badly?						
	•	seldom()	quite often()	very often()	always()	
	Have you fel never () s	t sad? seldom()	quite often()	very often()	always()	
3-	Have you fel	t so bad that	you didn't want to	do anything?		
r	never () s	seldom()	quite often()	very often()	always()	
		it everything is seldom()	in your life goes war quite often()	rong'? very often()	always()	
	Have you fel	•	•	•	•	
	•	seldom()	quite often()	very often()	always()	
	Have you fel never () s	t lonely? seldom()	quite often()	very often()	always()	
	Have you fel never () s	t under press seldom()	ure? quite often()	very often()	always()	
4- Abo	ut Yourself					

## 4- About Yourself

Thinking about the last week...
1- Have you been happy with the way you are?

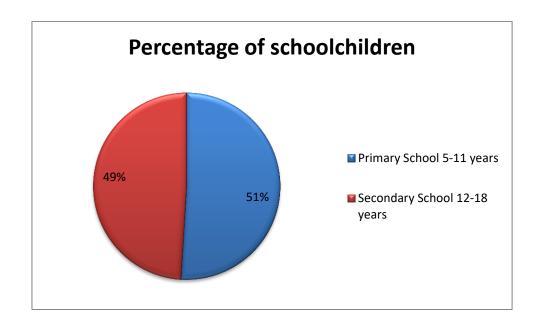
	never ()	seldom()	quite often()	very often()	always()			
	2- Have you to never ()	peen happy with seldom()	your clothes? quite often()	very often()	always()			
	3- Have you been worried about the way you look? never () seldom() quite often() very often() always()							
	4- Have you f never ()	Felt jealous of the seldom()	ne way other girls an quite often()	nd boys look? very often()	always()			
	5- Would you never ()	like to change seldom()	something about yo quite often()	our body? very often()	always()			
5- I	5- Free Time Thinking about the last week 1- Have you had enough time for yourself? never () seldom() quite often() very often() always()							
	2- Have been never ()	able to do the seldom()	things that you wan quite often()	t to do in your free very often()	time? always()			
	3- Have you never ()	had enough opp seldom()	portunity to be outsi quite often()	ide? very often()	always()			
	4- Have you never ()	had enough tim seldom()	ne to meet friends? quite often()	very often()	always()			
	5- Have you never ()	been able to che seldom()	oose what to do in y quite often()	your free time? very often()	always()			
6- Family and Home Life Thinking about the last week 1- Have your parent(s) understood you? not at all () slightly() moderately() very() extremely()								
	2- Have you not at all (	ı felt loved by y () slightly()	* · ·	very()	extremely()			
Thinking about the last week  3- Have you been happy at home? never () seldom() quite often() very often() always()								
	4- Have you never ()	or parent(s) had seldom()	enough time for you	ou? very often()	always()			
	5- Have you never ()	ur parent(s) trea seldom()	ted you fairly? quite often()	very often()	always()			
	6- Have you never ()	been able talk seldom()	to your parent(s) w quite often()	then you wanted to very often()	? always()			
7- Money Matters Thinking about last week								

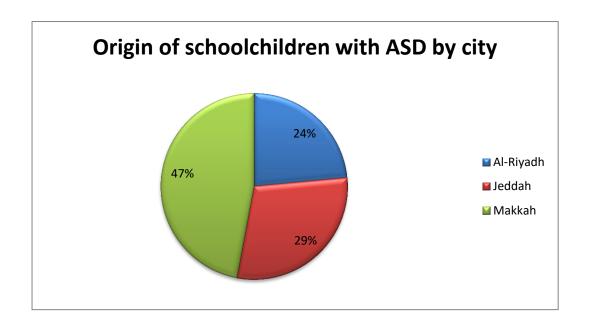
1- Have yo never ()	•	oney to do the same quite often()	things as your frie very often()	ends? always()
2- Have yo never ()	u had enough mo seldom()	oney for your expen quite often()	nses? very often()	always()
•	_	x ney to do things wit moderately()	h your friends? very()	extremely()
8- Friends	1			
	oout the last weel spend time with seldom()		very often()	always()
2- Have you never ()	done things wit seldom()	th other girls and bo quite often()	ys? very often()	always()
3- Have you never ()	had fun with yo seldom()		very often()	always()
4- Have you never ()	and your friend seldom()	s helped each other quite often()	? very often()	always()
5- Have you never ()	been able to tal seldom()	k about everything quite often()	with your friends? very often()	always()
6- Have yo never ()	u been able to re seldom()	ly on your friends? quite often()	very often()	always()
9- School and Lea				
	bout the last wee u been happy at			
not at all		moderately()	very()	extremely()
2- Have yo not at all	u got on well at a () slightly()	school? moderately()	very()	extremely()
3- Have yo not at all		with your teachers? moderately()	very()	extremely()
	out the last week.			
4- Have yo never ()	u been able to pa seldom()	y attention? quite often()	very often()	always()
5- Have yo never ()	u enjoying going seldom()	g to school? quite often()	very often()	always()
6- Have yo never ()	u got along well seldom()	with your teachers? quite often()	very often()	always()
_	out the last week. u been afraid of seldom()	 other girls and boys quite often()	very often()	always()

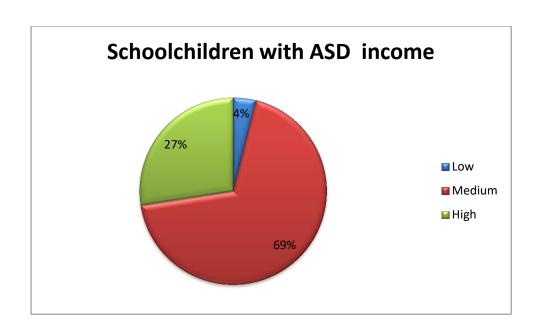
2- Have other girls and boys made fun of you?
never () seldom() quite often() very often() always()

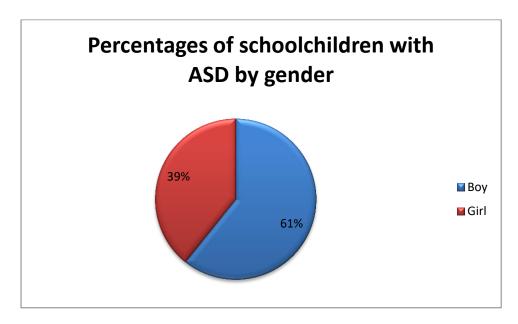
3- Have other girls and boys bullied you?
never () seldom() quite often() very often() always()

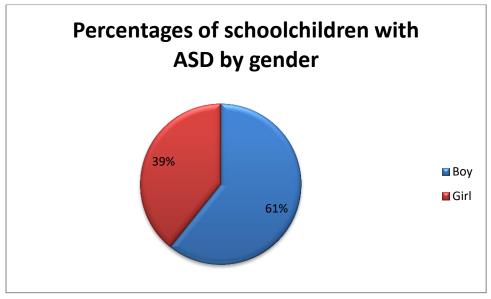
Appendix K: The demographic profile of schoolchildren with autism











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