

**Autism Spectrum Disorder  
(Inclusion of Children on the Spectrum)**

**BY**

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## **ABSTRACT**

This study explored the parental perspectives regarding the inclusion of young children diagnosed with autism spectrum disorder in mainstream kindergartens in Kuwait. To undertake the study, twenty seven parents of young children with autism were interviewed to explore their perspectives on the inclusion of their autistic children. Additionally, two owners and two administrators of private and public kindergartens were interviewed individually to substantiate whether early childhood inclusive education policies had been implemented in Kuwait. As an essential element of the study, eleven mothers of normally developing children at the kindergarten stage were individually interviewed verify whether the Kuwait cultural traditions had an impact on the implementation of inclusive education for autistic children. In the quest to answer the research question, the researcher employed a qualitative holistic single case study approach while constructing the study from within Bronfenbrenner's Bio-ecological Systems Theory (1998). From within the theoretical framework of this study, the researcher approached parents' perspectives on early childhood inclusive education for children with autism as being embedded in a series of contexts. The contexts explored extended from the autistic children's characteristics (Person) through the early childhood inclusive education policy (Exo-system) to the broad society (Macro-system) in order to explore the contexts that might have the potential to form parents' viewpoints towards the inclusion of autistic children. The conceptual framework of this study facilitated the presentation of a holistic picture of the study results demonstrating the interconnected nature of the contexts surrounding the

inclusion of young children with autism spectrum disorder from the parental perspectives and how these contexts operate to influence parental viewpoints and consequently came to constitute one of the barriers to the inclusion of young children with autism spectrum disorder. Furthermore, the employment of the qualitative single, case study method enabled the researcher to deeply understand the multiple factors that influenced the study participants' perspectives from within their cultural context.

The findings of this study reveal the influence of traditional Kuwaiti societal norms and the characteristics unique to autism spectrum disorder on the negative parental view of the inclusion of young children with autism spectrum disorder. The negative social attitudes of Kuwaiti society towards children with autism spectrum disorder have led to the dominance of the medical model of understanding disability and subsequently, to the barriers to the implementation of inclusive education for young children with autism spectrum disorder. The parental views aligned with a medical model of disability, therefore, these parents favoured segregated settings for children with autism spectrum disorder and identified barriers as within-child factors. However, given that autism spectrum disorder is a diverse and complex developmental disorder broadly characterised by impaired communication skills and social interaction, as well as limited interests and repetitive behaviours, the appropriateness of inclusion for students with autism spectrum disorder remains a controversial topic. Many authors claim that the inclusion of young children with autism spectrum disorder in general education settings is the best approach to support educational and overall progress in children with autism spectrum disorder. Others, however, harbour concerns about whether the inclusion program can meet the social and educational needs of children with autism spectrum disorder. Given the issues raised in this study regarding the relationships between early childhood inclusive

education for children with autism spectrum disorder and its multidimensional contexts, the study findings suggest that the deeply-rooted traditional norms in Kuwait do not accommodate the inclusive education model for young children with autism spectrum disorder in Kuwait. Although the results of the present research indicate that the characteristics unique to autism spectrum disorder constitute one of the barriers to the inclusion of young children on the spectrum, these challenges that arise from autistic children's neurodevelopmental disabilities cannot be addressed without recognising the traditional cultural norms that stigmatise these children.

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# CHAPTER ONE: INTRODUCTION

## 1.1 Introduction

In this introductory chapter the rationale for this study is explained and an overview of the thesis is provided. The chapter begins by providing preliminary background information and presenting the context within which this study is conducted as well as its focus. In this chapter the specific research aims and objectives guiding the study are detailed. The theoretical framework utilised to structure this study and an overview of the research method are briefly outlined. Finally, an overview of the significance of the study is provided.

## 1.2 Context of the Study

The concept of inclusive education gained momentum following the Salamanca Statement and Framework of Action on Special Needs Education (UNESCO, 1994) and the Convention on the Rights of Persons with Disabilities (CRPD) (2006). Article 3 of the Salamanca Framework for Action explicitly stated that "Schools should accommodate all children regardless of their physical, intellectual, emotional, social, linguistic or other conditions". That is to say that education policy makers are required to adopt the inclusive education movement by making schools capable of serving all children including children with disabilities. These policy documents stressed the principles of human rights, social justice, equality of opportunity and the right to a basic education for all (Charema, 2010). The inclusion debate has essentially developed along ethical and moral positions, with the right of entry to regular schools seen as a basic right for all students. Several researchers including Charema, (2010); Dixon and Verenikina (2007) and Fitch (2009) endorsed the view that in contrast to the moral and principled nature of

inclusive education, separation of any group is in breach of civil rights and against the doctrine of equality and therefore discriminatory. Thus, teaching children on a separate basis can engender negative views of children with disabilities in society and can cause irreparable damage to the children themselves. The above mentioned authors noted the relationship between civil rights and inclusion and acknowledged the civil rights grounding of inclusive education thereby, stressing the moral and ethical obligations of inclusive education.

As stated earlier, since the Salamanca Statement the movement for inclusion has gathered momentum evidently seeking to bridge the gap between general and special education and to eliminate marginalisation of those with special needs. Although, the range of definitions and lack of a common vision of inclusive education, unclear policies, poor implementation of inclusive practices and negative perceptions towards disability and inclusion have generated widespread controversial opinions (Mittler, 2014; Peters, 2007; Artiles and Dyson 2005; and Slee, 2001), the majority of the authors took the view that inclusive education means the education of all students in their local schools without any discrimination against students with disabilities (Kuyini, A. et al, 2015; Ainscow, 2005; and Mitchell, 2006). According to Ainscow (2005), the concept of inclusive education is that students with special needs can and should be educated in the same settings as their normally developing peers with appropriate support services, rather than being placed in special education classrooms or schools. It is undeniable that there have been significant advances in respect of inclusive education following on from the Salamanca Statement of 1994 the Convention on the Rights of Persons with Disabilities (DeVore and Russell, 2007; Brown, 2006). The reforms in education policies over the past decades have affected

the education of children with disabilities including young children with autism spectrum disorder (De Boer and Simpson, 2009; Loreman, 2007; Lindsay, 2003).

Early childhood inclusive education typically reflects the Salamanca Statement (Bruder, 2010; Guralnick, 2001). It is a field characterised by a philosophy and practice that encourages the participation of children with disabilities in everyday school activities with their normally developing peers (Odom, 2002). Inclusion for early childhood programs supports the right of all children, regardless of abilities, to socialise and play with children who are developing typically (DeVore and Bowers, 2006). The inclusion of children with disabilities from birth to the age of six in preschool settings and kindergartens is a legal mandate and civil right under the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA). Early childhood inclusion requires the removal of barriers in existing programs; and providing auxiliary aids and services such as special equipment and individualised supports (Shipley, 2002 and Soodak, et al, 2002). Similarly, the full participation of children with autism spectrum disorder with their normally developing peers and early interventions can have a positive impact on autistic children's cognitive and social development (Bitterman, et al, 2008). Therefore, the inclusion of young children with autism spectrum disorder can be broadly defined as the process of identifying and removing the barriers to participation and belonging of these children (Mackenzie and Cologon, 2016). Autism spectrum disorder is a diverse and complex developmental disorder broadly characterised by impaired communication skills and social interaction, as well as limited interests and repetitive behaviours (Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The social deficits associated with autism spectrum disorder including the incapacity to imitate normally developing peers and the inability to communicate and play with other children make it difficult

for autistic children to interact with and learn from their peers (De Boer and Simpson, 2009; Behrmann, et al. 2006). Therefore, the appropriateness of inclusive education for students with autism spectrum disorders continues to be a controversial topic (Simpson, 2005 and Lord et al 2000). These behavioural challenges have been found to contribute to the autistic child's emotional susceptibility, stress, frustration and depression (Müller et al., 2008). This wide range of autistic student behaviours can pose significant teaching challenges to educators. Every autistic child is unique and their needs will be reflected differently and it is challenging for a teacher to create an inclusive environment within their classroom that can meet autistic children's needs effectively. Whitaker (2007) and Jordan (2008) also argued that the inability of children with autism spectrum disorder to think and act flexibly, as well as the effects of their social and communication limitations present considerable challenges for teachers and the other students in the general classroom. Therefore, several researchers including Lindsay (2014) and Odom (2000) recommended that teachers need more resources, training and support to enhance the education and inclusion of children with autism.

Autism spectrum disorder has become the fastest growing disability (Centres for Disease Control and Prevention, 2012). A greater number of young children with autism spectrum disorder now participate fully in general early childhood education settings (Falkmer, 2015 and Guralnick et al., 2008). The increase in the number of students identified with autism spectrum disorder has significant implications for schools. Several researchers including Odom et al. (2011); and Ainscow et.al. (2006) stated that the benefits of an inclusive classroom for young children with disabilities reach beyond academics. Inclusion goes beyond education to comprise the total experiences of the children with autism spectrum disorder and their families (Starr

and Foy, 2012; Lynch and Irvine, 2009; and Starr and Foy, 2001). Young children with disabilities develop better communication and social skills in an inclusive environment that encourages young children's social and emotional development and learn best when they feel safe and secure in their classrooms (Matson and Kozlowski (2011). However, the inclusion of students with autism spectrum disorder remains a highly contested concern (Bitterman et al, 2008; Kuoch and Mirenda, 2003). For example, whilst some researchers such as Simpson (2003) and Lynch and Irvine, (2009), claimed that the inclusion of young children with autism spectrum disorder in general education settings is the best approach to support educational and overall progress in children with autism spectrum disorder, other researchers, such as Falkmer, et al. (2015); Ravet (2011); Ingersoll (2008); Landrum, et al (2003) and Harrower and Dunlap (2001), voiced concerns about whether the inclusive education model can meet the social and educational needs of children with autism spectrum disorder. Hebron and Humphrey (2014) and Carter and Spencer (2006) also argued that given that students with autism are increasingly being taught in inclusive settings, autistic children might be at an increased risk of victimisation and marginalisation. As such, autistic children can be more at risk of being bullied than their normally developing peers because of their difficulties with verbal and nonverbal communication (Schroeder et al, 2014, Hansen et al, 20114). Forms of bullying include name-calling, teasing, taking belongings, imitating, and making fun of the students with disabilities (Hebron and Humphrey, 2014). Similarly, Alsaker (2004, pp. 289) stated that “the extent to which victimisation occurs in the early childhood years is comparable with that in grade school”. The controversy that surrounds the inclusion of students with autism spectrum disorder was the impetus behind this study. In addition to the researcher’s interest in autism spectrum disorder, the search

for literature proved telling as it revealed the absence of studies relating to the educational and social inclusion of children with autism spectrum disorder in Kuwait. From the review of the articles in peer-reviewed journals and data-based chapters published between 2000 and 2016, to the best of the researcher's knowledge, the originality of this study stems from its being the first to explore the inclusion of children with autism spectrum disorder at kindergarten stage from parental viewpoints. Therefore, this study is an attempt to bridge the knowledge gap in the field of early childhood inclusive education for autistic children in Kuwait from parental viewpoint.

### **1.3 Focus of the Study**

A parent's role in the education of a child with a disability is unique. Dunst and Dempsey (2007, p. 305) proposed that "the role of parents with a child with a disability shows a level of complexity and intensity not generally found in the general population". This study focuses on the parental perspectives towards the inclusion of young children with autism spectrum disorder and explores the role parents play as social actors with unique perspectives and insights into their own experiences in the decision-making processes relating to the inclusion of their autistic children. The involvement of the parents in their children's education is vital because parents know their children best of all. Parents need to be fully involved in decisions that affect their children (Dunst and Dempsey, 2007). Parents might also have a role in developing the legislative context of inclusive education (Tisdall and Riddell, 2006). Similarly, the UK Special Educational Needs and Disability Code of Practice (2015) emphasised the importance of the involvement of parents in the decision-making of their children's education. According to Wright and Taylor (2012, pp. 1) "Advocacy on behalf of children with disabilities starts early and is important from birth to age 6". That is to

say that parental involvement in their children's education is important at all stages of schooling and particularly at kindergarten levels. The decisions taken by parents on behalf of their children with autism spectrum disorder are particularly important when the children are in early years settings because parents have unique knowledge of their autistic child's needs . Parents also have the right to be involved in decisions that identify and evaluate the development and educational placement of their disabled children (The Individuals with Disabilities Education Improvement Act (IDEA), 2004). One of the laws governing the education of students with disabilities in the USA specifies the right of parents to participate in the educational decision-making process (IDEA, 2004). This federal guarantee strengthens the role of parents in the education process of children with disabilities and emphasises the notion that the education of children with disabilities is made more effective when parents are involved in the decision-making process (Wright and Taylor, 2012). The educational placement decisions taken by parents on behalf of their children can be particularly important when the young children have autism spectrum disorder (Christie, et al., 2009). Furthermore, a number of authors including de Boer (2015); Carrington and Robinson (2006); and McCarron and Inkelas (2006) argued that a critical aspect of the success of inclusive education is parental involvement and support for the current inclusive educational movement. Parents of children with disabilities have been described as one of the main forces behind the drive towards inclusive education (Ainscow, 2002).

Similarly, parents of children with autism have played a major role in controversies surrounding autism spectrum disorder (Hrdlicka and Dudova, 2013). Parental opinions were critical in challenging the “refrigerator mother” hypothesis of autism in the 1950s and 1960s that blamed autism on a maternal lack of warmth and

affection (Mesibov, et al, 2000). In addition, parents of autistic children rejected the more recent claims that autism may be caused by childhood vaccinations. Therefore, the influence of parental activities in relation to their children with autism has been the subject of significant academic attention. It is then not surprising that several studies investigated the attitudes held by parents of children with and without disabilities towards inclusive education such as the studies conducted by de Boer (2015); Afolabi (2014); Brookman et al (2004) and Gill (2004), and Farrell (2000), who were of the view that parents should be crucial members of the educational decision- making team because they have unique knowledge of their child's strengths and needs. Consequently, the expectation of the parents of children with disabilities is that they should be advocates to preserve their children's rights to inclusive education. From this standpoint, the researcher focused on Kuwaiti parental perspectives toward the inclusion of young autistic children.

This study also focuses on the inclusion of children with autism spectrum disorder at the kindergarten stage. The kindergarten educational stages in Kuwaiti government and private schools consist of two stages: KG1 for children between 3 ½ - 4 ½ years old and KG2 for children between the ages of 4 ½ - 5 ½ years. Education is free for Kuwaiti nationals (Kuwait Ministry of Education, 2016). Early childhood education is essential for all children to develop their potential that will ensure their successful participation in school and adult life (Bartolo et al, 2016). Similarly, inclusive early childhood education for children with disabilities provides important opportunities for disabled children, including autistic children, to receive the specialist support and services they need to meet their rights and needs (WHO, 2012). Without the appropriate early interventions, support and protection, impairments in children with autism spectrum disorder could become more severe or complex, potentially

leading to long-term negative consequences (The European Agency for Special Needs and Inclusive Education, 2015). There is a general consensus amongst professionals in the field of autism and developmental disabilities that the early childhood years are a vital period during which early intervention programs can have the greatest impact on learning and development (Corsello, 2005; Simpson et al, 2003; Koegel, 2001).

This study focuses on young children with autism spectrum disorder at the kindergarten educational stage because early childhood is a crucial phase of growth and development and the experiences during early childhood can influence outcomes across the entire course of the child's life. For children with autism spectrum disorder, the early childhood stage is a time to ensure access to interventions which can help them reach their full potential. Furthermore, the inclusion of young children with autism spectrum disorder allows for an opportunity to learn social and developmental skills through modelling normally developing peers at the same time providing an opportunity for normally developing young children to acquire sensitivity to individual differences and be more accepting of others. In addition to my personal and professional interest in autism spectrum disorder (explained in section 3.14), this study is motivated by the lack of research on early childhood inclusive education for children with autism spectrum disorder in Kuwait.

#### **1.4 Research Aims and Objectives**

As stated above, the purpose of this study is to explore the perspectives of parents towards the inclusion of young students with autism spectrum disorder in public and private kindergartens in Kuwait. Although the reports from the Kuwaiti Ministry of Education (2011 and 2008) stated that the movement towards including children with disabilities in general education schools has commenced, numerous researchers including Alkhateeb, et al (2016); Al-Nakib, (2015); Al-Hilawani, Y.

(2011); and Al-Kandari and Salih, (2008) argued otherwise. These authors were of the view that special schools and centres are still the only option for the education of all children with disabilities in Kuwait. However, given that all children with disabilities including children with autism spectrum disorder have the right to inclusive education at every level of education (Convention on the Rights of the Child, 1989), this study aims to explore parental perspectives towards the inclusion of autistic children with a view to understanding these opinions and the factors that shaped them and then to report the findings of the study in a holistic descriptive manner. In accordance with the above outlined purposes, the objectives of this study were:

- To explore the knowledge and understanding of the concept of inclusive education;
- To identify the factors that shaped positive or negative perceptions towards inclusion;
- To examine the application of current discourse in early childhood inclusive education for young children with autism spectrum disorder in Kuwait;
- To explore the role played by parents as advocates for the right of their autistic children to inclusive education.

### **1.5 Overview of the Research Method**

In order to answer the research questions and to capture real-life experiences of the study participants, which may vary significantly from one study participant to the next, the researcher employed a qualitative case study approach to conduct this study. According to a number of authors including Creswell, (2013); Yin (2009); and Denzin, and Lincoln (2000), a qualitative approach is employed when the researcher seeks to understand a given topic from the perspectives of the local population it

involves and is especially effective in obtaining culturally specific information about the opinions and social contexts of particular populations.

The study had two stages: the first involved exploratory focus-group interviews with a total of 27 parents of young children with autism spectrum disorder; and, stage two was based upon individual interviews with owners and administrators of 7 private and public kindergartens. Rationales from international and national reports and literature were also consulted to seek evidence of the administration of inclusive education in Kuwait. Through the focus groups and the individual face-to-face interviews, the researcher developed a deep understanding of the multiple factors including the social meanings that shaped the parental perspectives on the inclusion of young children with autism spectrum disorder.

### **1.6 Theoretical Framework**

The multiple interpretations of the concept of inclusion, cultural differences, diverse perceptions of disability, characteristics unique to autism spectrum disorder and disparities between theory and practice at the local level all influence the research on inclusive education for children with autism. In order to be able to place limits on the scope of the study and increase the feasibility of completing the project, the researcher structured the study from within Bronfenbrenner's Bioecological Systems theory (1998). The theory suggests the interactions between the individual and their environment, categorised into various systems, shape the individual's development over time (Bronfenbrenner and Morris, 2007).

### **1.8 Significance of the Study**

The focus of this study as previously stated is on Kuwaiti parental perspectives towards the inclusion of young children with autism spectrum disorder. The search for

literature revealed that parental perspectives on early childhood inclusive education is an area completely ignored in research studies in Kuwait. The review of literature also showed the absence of studies on early childhood inclusive education for children with autism spectrum disorder in Kuwait. In addition, autism spectrum disorder generally remains an under-researched subject in Kuwait. The descriptive case study approach of this study through which the researcher attempted to fully describe the distinct characteristics of the current provision of early childhood inclusive education for children with autism in Kuwait, will furnish future researchers with the foundational knowledge to be utilised in the decision-making process in terms of areas of study and possible changes to be implemented in their studies.

Additionally, this study's significance is reflected in its aim to prepare the ground and initiate a dialogue for further research on early childhood inclusive education for children with autism in Kuwait. Furthermore, given that the focus of this research is on the education of young children with autism spectrum disorder, this study could also be linked to studies on early intervention methods for children with autism spectrum disorder in Kuwait.

## **1.9 Conclusion**

The term 'inclusive education' is nowadays broadly conceptualised to include students from different backgrounds and with different languages as well as students with disabilities (Ashman, 2002). However, for the purposes of this study, the term inclusion is defined as the inclusion of young children with autism in regular classrooms along with normally developing children at kindergarten stage (Ainscow, 2005; Odom, 2000). This study aimed to explore Kuwaiti parental perspectives towards the inclusion of young children with autism spectrum disorder and to identify

the factors that shaped the parental perspectives towards the inclusion of these young children. Other objectives of this study include examining whether inclusive education for young children with autism spectrum disorder has been successfully implemented at the kindergarten stage as well as ascertaining the role parents play as advocates for the right of children with autism spectrum disorder to inclusive education. The study explored the topic through focus groups and individual interviews with parents of young autistic children and kindergarten administrators. This study is an attempt to provide real and important guidance for future research on the inclusion of children with autism spectrum disorder. While several lines, already established in this research, should be maintained and will likely offer more knowledge and practical guidance for future studies, other lines of research should be developed to further expand our understanding of the inclusion of children with autism spectrum disorder.

### **1.10 Thesis structure**

This study consists of six chapters. The first chapter is the introduction chapter which provides a brief discussion of the research aims, objectives, methodology, the rationale for conducting the study and the significance of the study. Chapter Two reviews the literature on five key topics: inclusive education; early childhood inclusion; autism spectrum disorder; the educational context in Kuwait; and parents' role as advocate for the rights of their autistic children to inclusive education. Chapter Three outlines the research methodology and discusses the underpinning philosophical considerations adopted by the researcher. The chapter includes the conceptual framework of the study, the rationale for adopting the qualitative approach, the research design, the method of data collection, the researcher's positionality and the ethical considerations in qualitative research. Chapter Four

presents the findings of the study in the light of the research questions. Chapter Five synthesises the overall findings of the study, analysis the findings thematically and discusses the findings of the study in relevance to previous literature. Finally, Chapter six presents the discussion and the conclusion of the study. This chapter draws conclusions from the results of the study, states the contribution of the study, discusses the limitations of the study and provides recommendations and suggestions for future research.

## CHAPTER TWO: LITERATURE REVIEW

### 2.1 Introduction

This study focuses on parents' perspectives on the early childhood inclusive education of children with autism spectrum disorder in the State of Kuwait (Kuwait). Questions about the inclusion of students with disabilities are not new. However, despite decades of research, inclusive education continues to be debated among researchers. There has been, since the Salamanca Statement (1994) and the Convention on the Rights of Persons with Disabilities (CRPD) (2006), a steady push towards more inclusion of students with disabilities in many developed countries. Yet, according to a number of researchers including Messiou (2017); Haug (2016); Rieser (2014); D'Alessio (2009); and Brown (2006) there are regions that are still far from effectively implementing the concept of inclusive education and transforming the education system at large. A number of countries are still focusing on either special needs schools or other marginalised educational centres. Kuwait is one of these developing countries that according to several authors including Al-Nakib (2015); Aldaihani (2011); and Al-Thani (2006) is far from effectively implementing the concept of inclusive education.

The aim of this study was to explore the application of current discourse in early childhood inclusive education for young autistic children in the State of Kuwait from the parents' perspectives. The objective of this study was to explore the factors that shaped the Kuwaiti parents viewpoints towards the inclusion of young children with autism, with special focus on the social and cultural factors. Inclusive education in Kuwait has been briefly addressed in the literature. Some researchers such as Alshemari (2016) and Aldaihani (2011) argued that the inclusive education is a new

concept in Kuwait and therefore it has not received much attention from researchers. As far as the researcher knows, no previous research has explored parents' perspectives towards the inclusion of autistic children in Kuwait or the impact of the social and cultural factors on shaping parents opinions these children's inclusion..

The general approach to completing this review of literature involved: conducting a thematic review of literature; gathering pertinent information; summarizing and synthesising the key themes relevant to this study. Sources covered in the review included scholarly journal articles, books, PhD theses and national and international official published reports on inclusive education in Kuwait in both English and Arabic languages between the years 2000 and 2016. Considerable library references and electronic databases were utilised in searching for the required literature including: EBSCOhost, ERIC, PsychINFO, University of Lincoln Library Catalogue, PubMed, United Nations Educational, Scientific and Cultural Organization's (UNESCO) reports, World Bank reports concerning Kuwait, United Nations Development Programme (UNDP) reports and the Kuwaiti Ministry of Education published information. The researcher also used the reference lists from previously completed literature reviews. To trace the academic progression of the field, including key discussions, to locate this study within the context of existing literature, to identify where gaps exist and to gain a greater insight into the issue of early childhood inclusive education of children with autism spectrum disorder in Kuwait, it was essential to examine the existing literature and studies already undertaken on the subject.

## **2.2 The structure of the literature review**

This literature review was guided by Bronfenbrenner's Bio-ecological Theory (1998) which is referred to as the "Person-Process- Context-Time model" (PPCT), (Bronfenbrenner and Morris, 1998, p. 996). According to the PPCT model, Person refers to the genetic and biological traits which the person brings with him into the social situation; Process is the reciprocal interaction between the individual and his immediate environment such as young children playing together, group games and children learning skills; Context involves four interconnected systems: The Microsystem such as home and school; the Mesosystem consists of the interactions between the different parts of a person's microsystem such as family and school relationships; the Exosystem refers to external influence that does not involve individuals as active participants but still affects them, such as policies; and the Macrosystem context such as the social and cultural structures. The final element of the Bio-ecological model is Time which has a crucial role in the process of human development. This literature review included each of the elements of the Bio-ecological theory except for the Time element of the PPCT, which is not within the scope of this research.

The researcher sought to refine the literature review by focusing on perceptions, interpretations and conclusions specifically on the following key areas of the research question and within the theoretical framework of the Bio-ecological System theory: autistic children (ASD), (i.e. Person); early childhood inclusion of autistic children in Kuwait (i.e. Person and Process); Kuwaiti education system and the inclusive education policy and its implementation (i.e. Context/Mesosystem and Exosystem); Kuwaiti culture with reference to perceptions towards autism spectrum disorder (i.e. Context/ Macrosystem) ; and the roles of parents' as advocates of inclusive education with particular reference to Kuwaiti parents in deciding their

autistic young children's educational best interest (i.e. Process and Mircosystem and Exosystem) . However, the review was by no means exhaustive. This review drew from current research, defined as published works in scholarly journal articles, books and policy reports published between 2000 and 2016. This review was also limited to researches on early childhood inclusive education of children with autism. In the Kuwaitis context early childhood education is provided by kindergarten schools. The entry age is usually 3 ½ years and the duration of the programme is two years (Kuwait Ministry of Education, 2017).

Reviewing this vast literature was restricted by the thesis word limit, time frame and the need to focus on specific issues related to research question. The scope of this review encompassed the following key areas for this research questions:

- a) The concept of inclusive education;
- b) The research context i.e. the State of Kuwait;
- c) Autism spectrum disorder;
- d) Early childhood inclusive education for autistic children
- e) Parents role as advocates for the rights for their autistic young children to inclusive education in Kuwait.

## **2.3 Section one: Understanding the concept of inclusion**

### **2.3.1 A historical overview of the social and educational exclusion**

A first step towards the understanding and clarification of inclusive education for young children with autism in Kuwait might be to note when, how and under what conditions inclusive education came to be on the global agenda as a principle for

societal reform in order to provide quality early childhood education for children with autism.

The philosophy of inclusive education is based on the right of all individuals to a quality education with equality of opportunity (Ainscow, 2012). This concept, originating in Western nations, such as the United States of America and the United Kingdom, reflects changing attitudes and signifies a radical shift in societal norms (Mitchell, 2006). Although the origins of inclusion were rooted in the need for societal change the initial focus was not on people with disabilities nor solely on the issue of education. The concept of inclusion emerged from a growing awareness of widespread discrimination in society and out of pressure applied by other marginalised groups such as the African American population of the United States of America (Fremon, 2014); women in their struggle for liberation and gender equality (Chaney, 2016); and the right to provide students with disabilities the same opportunity for education as those students who do not have a disability (UK Special Education Needs and Disability Act 2001 and US Individuals with Disabilities Education Act 1990).

### **2.3.2 Exclusion based on disability: historical overview**

In previous centuries disability was viewed negatively whilst perceptions of disabled people were generally unfavourable. Through the 1600s and the 1800s disability was regarded as being of divine origins, a punishment from god or as a sign of possession of the soul which was to be feared (Gelb, 2003). In Britain, having a disabled child or family member was generally considered a great disgrace which led to the disabled including children being hidden from society. The belief that people with disabilities should be removed from their localities led to the rise of the 18th

century private home which usually housed disabled people from wealthier backgrounds and were often under the charge of people without medical credentials (Emery, 2003). The opinions of those affected by such difficulties subsequently altered somewhat and were regarded as being insane or as suffering from a loss of reason which could be treatable and as being deserving of charity (Barnes, 2014). Charity however, was often in short supply and the responsibility to support and care for the disabled did not necessarily lie with the state. Disabled people could support themselves through physical labour if able or would have to rely on the support of family or charitable donations. Stigmatisation meant that disabled adults and children were often faced with abandonment by family and with rejection by wider society (Burdett, 2014; Gelb, 2003). Apart from the lucky few, disabled people, irrespective of social class, could generally face a demeaning existence devoid of acceptance in society). It was not until the Regulation of Madhouses Act of 1774 that there was any form of certification of such premises. The industrialisation of the 19th century, the British government playing a greater role in the affairs of disabled people and the growing concern toward the disabled, led to the rise of state run asylums and of the workhouse ( Burdett, 2014; Jarrett, 2012). An institution was now seen as being the best solution to the ‘problem’ and the 1834 Poor Law Act proposed the establishment of hundreds of workhouses (Burdett, 2014).

By 1900 the populations of these types of institutions had risen from a few hundred disabled people in a handful of small institutions to thousands living in over a hundred asylums (Burdett, 2014; Jarrett, 2012; Humphries, 2012). Whilst the phenomenon of the institution continued to grow, many disabled people remained with family in their own local areas or lived as vagrants since begging was seen as preferable to confinement and the severe methods implemented in such

establishments (Gooding, 2014). The workhouse was a hostile, forbidding place which enforced strict gender segregation, harsh punishment, hard labour and the separation of families (Emery, 2003). Poverty was viewed as being tantamount to a crime. Further, visits from outsiders for the undeserving poor were opposed and seldom happened and the inmates were cut off from the outside world in the most dismal of circumstances (Emery, 2003). As the most able would avoid the workhouse if possible, it was largely the mentally and physically disabled that found themselves imprisoned there. Any initial charitable thoughts of providing restorative treatment soon disappeared and these were places of lifetime confinement built on the outskirts of towns so as not to cause offence to citizens (Jarrett, 2012).

### **2.3.3 Social inclusion of people with disabilities**

In the 19th and early 20th centuries many prominent figures including scientists and politicians, such as Winston Churchill, subscribed to the theory of eugenics (Barrett and Kurzman, 2004). The Eugenics' objective was to improve and perfect society by improving the genetic composition of the human race through segregation, experimentation, sterilisation and the denial of the medical and social services to people with disabilities. People with learning disabilities and mental health issues were classified as 'idiots', 'imbeciles', 'feeble-minded' or 'moral defectives' under the 1913 Mental Deficiency Act (NHS, 2013; Barrett and Kurzman, 2004).

Given the tone of this legislation and other legal rulings in respect of disability it is therefore unsurprising that disabled people were considered to be a burden on society. The Eugenics Education Society had already been established in 1907 (Barrett and Kurzman, 2004). The eugenics movement had gained ground in many countries and the belief was that the disabled were 'defective' and would infect

society leading to its degeneration (Burdett, 2014; Barrett and Kurzman, 2004). The disabled men, women and children incarcerated in institutions suffered the horrors of being used as the subjects of eugenic based experiments as their lives were deemed to be worthless (Barrett and Kurzman, 2004).

There were certain accomplished figures who held the opposite view, believing that people with disabilities were people of value, that they should be supported to live in wider society and not have to suffer the fate of confinement in a workhouse or asylum. Those who were more kindly disposed towards disability assisted in the campaign for education and better treatment for disabled people. One such campaigner was Thomas Braidwood who established academies in Scotland and England. In his London academy founded in 1783, Braidwood implemented the 'combined' or 'Braidwoodian system' of communication which subsequently developed into British Sign Language (Jarrett, 2012). Although those with physical and mental disabilities were generally rejected by society, there were several issues that helped to change the situation of treatment they received and to encourage more positive attitudes towards disability. Details of widespread abuses of people in workhouses, hospitals and asylums became public and gave rise to changing sentiments towards the plight of the poor and the disabled (Barrett and Kurzman, 2004). A wave of philanthropic interest during the Victorian period had seen the establishment of charitable groups and organisations concerned with the situation of disabled people and offering, education, medical treatment and employment such as the Liverpool Workshops and Home Teaching Society for the Blind (Jarret, 2012).

The outbreak of the First World War in 1914 saw the conscription of able bodied men to fight in the conflict which led to a manpower shortage at home (Cohen, 2001). Many of the disabled people formerly viewed as a burden on society were

needed to work in support of the war effort. The significant contribution of those with special needs meant that they could no longer just be dismissed as worthless (Gelb, 2003). Similarly the high human cost of the war meant that a large number of disabled soldiers returned to Britain. The corresponding physical, psychological and financial needs of the ex-servicemen not only led to advances in social care and therapeutic services but also reinforced the fact that attitudes to disability had to change given that these were the heroic defenders of the nation (Cohen, 2001). The advent of the Second World War once again compelled the British government to recruit labour from amongst the disabled population. The formerly deemed 'unemployables' were brought into the workforce (Gelb 2003). The essential participation of disabled people in the labour market and their readiness to serve demonstrated their worth and that segregation in an institution should not necessarily be their designated path (Withers, 2016).

In the Arab Gulf States in general and in Kuwait in particular, disabled people were unable to benefit from their basic human rights in comparison with those without disabilities (Brown, 2006). A disabled person was deemed completely incapable and therefore unable to perform any task that a non-disabled person could perform. Therefore, individuals with disabilities were considered shameful on the family and burdensome on the family and the society. Disparaging and depreciatory terms such as 'incapable' and 'invalid' were used to refer to disabled persons (Raman, et al, 2010). There was no adequate education for disabled persons and they were not considered to be part of the community. According to Al-Hilawani et al., (2008) hiding disabled individuals from the rest of society was a very normal practice in the Arab Gulf countries. This approach was due to poor social reactions and negative consequences from a society not yet ready to accept disabled people as a useful part

of the community. In Kuwait, having a disabled member in a family had a defaming effect on both the immediate and extended family; therefore families were inclined to keep their disabled members, especially the ones with developmental and intellectual disabilities hidden (Al-Kandari, 2014). In the Kuwaiti culture there was also a traditional belief that having a child with disabilities is either God's way of testing the parents' patience or punishing parents (Alshaemari, 2016). With the passage of time, however, the way that disabled people and disability were viewed has evolved. The common assumption now is that people with any kind of disability have varying levels of ability measured according to a multidimensional continuum (WHO, Kuwait health profile, 2015). Disability researchers such as Burns, (2017); Emerson, (2013); and Morgan, (2012) argued that although there is a medical aspect to any kind of disability, far more important is the significant role played by the society in the creation of the hindrances that people with disabilities experience. That is to say that disability is a social construct and the limitations which the disabled people face are the products of social perception of stereotypical images and not the products of the disabled people's medical condition. The move away from the medical model of disability to a model based on social justice meant that the segregation of disabled people was in breach of ethical principles and basic civil rights (Quinn and Degener, 2002).

#### **2.3.4 Special Education for Students with Disabilities**

From a historical perspective, for centuries, education had not been considered to be the right of the many but rather the preserve of the few (Phillips and Harvey, 2008). The Elementary Education Act of 1870 was the first act of parliament to create compulsory education in England and Wales for children with the school

leaving age being raised to 12 by 1899 (Gillard, 2011). For the disabled amongst the poorer classes, there was little opportunity for education nor were those with disabilities deemed to have the capacity to be truly educated until 1819. The importance of the 1918 Education Act was that everyone now had the right to education as school attendance was made compulsory for all disabled children (Gillard, 2011). The recognition that all were deserving of education was a progressive development. From the societal changes brought about by positive changes in attitude, greater educational opportunities and personal contributions during the wars, a greater sense of self-worth developed amongst people with disabilities. In 1946 the National Association for Mental Health was created, later to become MIND (Crossley, 2001). In the same year the National Association of Parents of Backward Children was founded, subsequently being known as Mencap (Ralph and Corbett, 1994) and successive years saw the establishment of a multitude of organisations seeking justice and equality for those with disabilities. Many of the new campaign groups were led by parents and families. People with disabilities were not passive bystanders and were at the forefront of the struggle for their human and civil rights (Gillard, 2011). Throughout the 20th century there were mass protests by disabled ex-servicemen, blind workers, parents of disabled children and campaigners demonstrating against the lack of opportunities, inadequate education, poor employment prospects and overall inequality (Anderson and Carden-Coyne, 2007).

Against this backdrop of civil unrest came legislation critical to improving conditions for disabled people. The 1944 Disability Employment Act gave greater access to employment and implemented quotas of disabled people to be hired (Gillard, 2011). There were new programmes in respect of skills training for all those with disabilities not just for those discharged from the armed forces. Key medical

services required by disabled people were brought under the umbrella of the newly established National Health Service (The NHS from 1948 to 1959). The rise in advocacy in respect of disabled people has been considerable so the previously common terms such as 'mentally defective' are now seen as pejorative and have been replaced. To establish and protect human rights for individuals with disabilities was now at the heart of global discourse. Amongst the core principals now considered of vital importance were the rights of disabled citizens and central to this was the question of education. The Universal Declaration of Human Rights, (1948, article 26. 2) stated that education is a fundamental right of every human being. The right to education was embraced by all countries including Kuwait as it opened the gates for employment opportunities; enhanced the quality of life; gave empowerment to the individual; and promoted equity in society (Peters, 2007).

In Kuwait, on the other hand, in 1965, Law no. 11 ensured the education of children with auditory, visual, mental and physical handicaps in the schools of Special Education "as long as they are capable of studying there" (Kuwait Ministry of Education, 1986, p.10). In Kuwait, Special education began in 1955 under the sponsorships of the Kuwait Ministry of Education with Al-Nour Institute for the Blind. The Ministry of Education delivered special training schools with the aims of connecting the child with both his "family and society without keeping him away from getting in touch with other normal children" (Ministry of Education, 1988, p.31). Schools for children with Mental Handicap were divided into schools for the mentally impaired and schools for 'trainables' (Weber, 2012). Special schools for those with mobility impairments came later around the turn of the 20th century (Gaad, 2011). These beginnings of special education provision in Kuwait were driven by

professionals who developed interventions focused on particular types of impairments.

Kuwait followed the example of the USA for special education. When the landmark United States Education for All Handicapped Children Act in 1975 passed, this act mandated access to education for students with all types and degrees of disability. Kuwait education system espoused the same strategy to ensure equal access to education by introducing the special education needs provision in the public and private schools (Gaad, 2011). Special Education as a separate system of education for disabled children outside the mainstream education continued evolving throughout the 1980s to this day in Kuwait (Abdulgafoor, 2004). It was based on the assumption that children with disability had special needs that could not be met in mainstream schools therefore, they need to study in a separate school with other children having similar needs. The Ministry of Education in Kuwait provided special education programs and services to students with intellectual disabilities in centre-based educational programs, while students with visual, hearing and physical disabilities received their education in special schools named 'Schools for Special Needs Education' (Al-Nakib, 2015).

The historical conviction that disabled people should be shunned and removed from society has now shifted towards social and educational inclusion. The medical model of understanding disability as a biological impairment have also given way to the social model of understanding disability which recognises that people are disabled by environmental factors (Davis, 2013). The social model approach mandates barrier removal which are caused by the social organisation (Shakespeare, 2013). In most western countries many changes have taken place in attitudes towards persons with disabilities (Haegele and Hodge, 2016). The change of negative responses to disability were prompted mostly by "the self-organization of people with disabilities

and by the growing tendency to see disability as a human rights issue” (WHO, 2011, pp. 3) and due to parents advocacy (Causton and Bronson, 2015).

### **2.3.5 Inclusive education for students with disabilities**

The rise in advocacy in respect of disabled people has been considerable. Key legislation such as the Salamanca Statement (1994) has reinforced the principles of inclusive education and set the objective of eradicating marginalisation firmly on the world stage. Concepts of being truly valued, acceptance, social equality, empowerment and independence have come to the fore. The idea is that there should be no part of society which is out of bounds for those with disabilities and this is for the betterment of all (Peters, 2007). The aspiration is for an inclusive community consciously evolving to address and respond to the changing needs of its members. The philosophy of inclusion is underpinned by human rights principles and ethical values which aim to create a better world for all citizens (Lynch and Baker, 2005).

The Declaration of Salamanca in 1994 which was acknowledged as setting the global agenda on inclusive education given the number of signatories; 92 nations and 25 international agencies and was a milestone and veritable landmark of the rights discourse on students’ educational needs. Fundamental to the principals of inclusion is the need to address the historically entrenched educational, cultural and societal inequities of nation states in relation to schooling. This vital element has been widely acknowledged by education policy makers and gave rise to the extensive and comprehensive aims of inclusive education to adopt a more democratic and just approach to education and thereby redress the balance (The Salamanca Statement and Framework for Action on Special Needs Education, 1994).

The international initiatives and UN agencies such as the International Disability Alliance assisted people with disabilities had focused on improving the rights

for individuals with disabilities around the globe. The work of these initiatives culminated in 2006 with the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The international human rights treaty of the United Nations (CRPD) in its Article 24-(a) and (b) stated that States Parties shall take all essential procedures to ensure that:

“a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability”;

“b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live”.

Article 24 of CRPD treaty was intended for disabled students and explained how education providers had to make adjustments to ensure the full enjoyment by children with disabilities of all human rights on an equal basis with normally developing children. Adopted by the United Nations General Assembly in 2006, the CRPD treaty became the first comprehensive human rights treaty of the 21st century and set disability firmly within the framework of human rights. The treaty being comprehensive in nature included areas such as education for individuals with disability. These global declarations of a broader view of inclusive education began to find their way to more countries in the world.

Educational policies and practice in the UK, the USA and most of the western countries stipulated that inclusive education should be an option available to all students with a disability (Mitchell, 2006). Although education policies in most countries began adopting policies and guidelines for implementing inclusive education however, there are a number of countries that are still far from effectively

implementing the concept of inclusive education and are still focusing on either special needs schools or education community centres for marginalised groups (Messiou, 2017). In Kuwait for example, several researchers including Weber (2012), Gaad (2011) and Nadra (2009) believed that inclusive education is still very new to Kuwait. The authors were of the opinion that it cannot be said with any certainty that inclusion policies will be put into practice successfully. Hence, this present study sought to explore how the concept of inclusion has been perceived by the parents of autistic children in Kuwait, the challenges encountered and to what extent inclusive education has been implemented in the domestic arena.

### **2.3.6 The scope of inclusive education in literature**

Since the Salamanca Statement (1994), the notion of inclusion has pushed the debate regarding the education of students with disabilities further (Konza, 2008). The mere existence of the Salamanca Statement however, did not ensure the successful implementation of inclusive education as it failed to provide a clear definition of inclusive education to which the participating nations were required to adhere (The Guidelines for Inclusion, UNESCO 2005, pp. 13). Consequently the absence of a single common definition has led to the presence of multiple interpretations of inclusive education amongst nations, academics and educationalists alike. .

In response to both research findings about the effectiveness of inclusive education settings, and a shift in attitudes in the Western world towards the right of people with disabilities to a learning environment as close to normal as possible, a large number of researchers wrote extensively on inclusive education. Some writers highlighted the right of people with disabilities to have the right to educational inclusion on the basis of civil rights principles. For example, the focus of Claude (2005) was on the civil rights principle of inclusion and the author took the position

that the legal aspect is paramount and outweighs any scholastic or philosophical concerns. Florina (2008) raised the point, that in contrast to the moral and principled nature of inclusive education, separation of any group is in breach of civil rights and against the doctrine of equality. Both writers felt this argument to be convincing as teaching children on a separate basis can engender negative views of children with disabilities in society and can cause irreparable damage to the children themselves.

Other researchers including Shyman (2015) and Peters (2007) argued that the philosophy of inclusion represents a commitment to creating schools and classrooms in which all children, without regard to individual needs or disabilities, are educated together. For Shyman and Peters, there was to be no partial inclusion of students with disabilities or individuals with exceptionalities. The predominant approach towards inclusive education in literature is the commitment to creating schools and classrooms in which all children, without regard to individual needs or disabilities, are educated together. From the inconsistency between inclusion theory and the practical concerns of inclusive education emerged the dimensions of national and international implementation concerns. For example, Loreman, (2007) argued that there are scenarios in which the influence of the Salamanca Statement is not sufficient to ensure effective implementation. For instance, where local inclusion policy is at odds with international standards. Similarly, at the local level, there is often an unwillingness to reconcile the principles of inclusion with set practice. Where local educators are not well disposed to give their support, access to inclusive education is often impeded.

Given the prevailing situation and the distinct perceptions and complex attitudes UNESCO realised the need to provide a more precise definition of inclusive

education. In 2005, UNESCO published The Guidelines for Inclusion Report. The report stated that:

“Inclusion is seen as a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the regular system to educate all children” (The Guidelines for Inclusion, UNESCO 2005, pp.13).

The Guidelines for Inclusion report used a number of elements to conceptualize inclusive education. As such, the UNESCO report summed up inclusive education concept by stating that inclusive education is about equal opportunities for all students who have been traditionally excluded, including students with disabilities.

Dissenting perspectives to inclusion however came not only from education professionals and academics but also from other sources. An indication of the apprehensions to inclusive education was given by a number of researcher including Leysera and Kirk (2004) and Elkins, et al. (2003). For example, Leysera and Kirk surveyed 437 parents’ viewpoints on inclusive education for their children with special needs in the USA. The children’s type of disability included ADHD and learning disabilities. Although the response rate of the survey did not reach 50%, the authors reported that their study results revealed that parents expressed a number of doubts and concerns about their child's progress under inclusion such as the quality of teaching, social isolation, support from teachers and teacher training and skills. However, the major concerns that parents expressed were about teachers’ skills and the child's social attitudes.

The expectation was that discussions in respect of whether or not inclusive practices should be implemented in regular schools would have ceased by this stage

however this was not the case and such concerns continued to persist. At the 48th session of the International Conference on Education (ICE), 2008, on the theme “Inclusive Education: The Way of the Future” it was stated that there are numerous viewpoints and disagreements, much indecision and widespread controversy in respect of inclusive education. Inclusive education is viewed as the principal question to be addressed by educational systems the world over, irrespective of a nation’s level of development. The above statement recognised the myriad of diverse perceptions and wide ranging attitudes on the subject of inclusive education. The International Conference of Education in 2008 articulated its aim of eradicating all types of exclusion in the sphere of education. Several commentators took a similarly principled view of inclusive education. The majority of scholars and professionals from Ainscow, Booth, and Dyson (2006) who maintained that values and ethics form the basis of inclusion and are the platform upon which educational practices should be established and asserted that inclusive education legislation renders segregation illegal to Messiou (2017) who contended that inclusion is arguably the most vigorously debated issue in education adding that inclusive education has been strongly disputed since the very introduction of the term, concurred on the positive effects of the UNESCO’s Guidelines for Inclusion Report and the 48th session of the International Conference on Education Report. It has become more difficult to justify segregated education, given the ethical and social justice considerations and particularly since any advantages of segregation are not reflected in research material.

From the literature review conducted by the researcher between the years 2000- 2016 regarding inclusive education in Kuwait only a few studies were found. For example, Al-Shammari, (2006) PhD thesis on “Special education teachers' attitudes towards disabled students in Kuwait”; Aldaihani (2011) PhD thesis on a

“Comparative study of inclusive education in Kuwait and England”; Almotari’s (2013) PhD thesis on “Kuwaiti teachers and head teacher’s attitude towards inclusion”; Al-Kandari et al’s (2017) a “Brief report on the social support for children with disabilities in Kuwait”; Al Tahni, (2006), an article on “Disability in the Arab region”; and few other studies on disabled people in Kuwait. However, no research has been conducted as far as this researcher’s knowledge, on early childhood inclusive education in Kuwait nor on the inclusion of young children with autism specifically, or on parents’ perspectives towards inclusive education in Kuwait. Some of the themes that were included in the above mentioned studies and in the literature on the Arab Gulf region that were of relevance to this research included: the lack of commonly accepted definition of what constitutes inclusion; confusion over the semantics of inclusive education; the lack of conceptual clarity of the very notion of inclusive education; lack of skills among teachers; and lack of adequate preparation of schools. However, barriers to inclusive education for children with disabilities arising from societal values and beliefs were hardly mentioned expect for Brown (2006) and Al-Thani (2006). For example, Al- Thani who was selected to be the UN’s Rapporteur on disabilities in the Arab region, conducted a survey to explore attitudes as they affect women with disabilities. The author shed some light on the cultural diversity of the region. However, the focus of Al-Thani’s study was on the positive effect that the drafting of the International Convention on the Rights of Persons with Disabilities had on disability efforts in the Arab region and disability prevention. Concerning cultural issues in the Arab region in general, the writer touched on the societal perspectives towards people with disabilities as being a source of shame or as being a curse on their families. The author further noted that people with disabilities are stigmatised although this approach is not particular to the Arab region alone. A

number of authors who wrote on the Arab region including Al-Thani acknowledge in their works the economic, social and political diversity of the twenty two countries in the region in spite of the common language. **2.3.7 Conclusion**

The search for literature on inclusive education including its key concepts, its definitions, its principles and practice proved telling as it revealed the several perspectives towards the concept of inclusive education and many multifaceted challenges. According to the Salamanca Statement (1994, p. ix), inclusive schools are “the most effective means of combating discriminatory attitudes, building an inclusive society and achieving education for all” (UNESCO, 1994, p. ix). However, Salamanca’s Framework for Action did not provide clear definition of the concept and did not fully explain how inclusion should be implemented (Allan and Slee, 2008). The definitions of inclusive education that exist are culturally driven interpretations and there is no internationally agreed definition of inclusive education (Schwab et al., 2015). Subsequently, the inconsistency between inclusion definitions and the practical concerns of inclusive education resulted in various practices and definitions of inclusive education (Kiuppis, 2014) and from which have emerged problems in implementation.

It can be argued that special education grew out of the failure of the general education system to be responsive to the needs of disabled students. Since the Salamanca Statement, the movement for inclusion has gathered momentum evidently seeking to bridge the gap between general and special education and to eliminate marginalisation of those with special needs. However, according to Ganapathi (2014, pp.3) inclusion appears to be a “grand and elusive concept” and a distinct definition of inclusive education is still indefinable. There are multiple perspectives in the field of inclusion and many complex challenges and tensions involved. A number of

researchers including Slee (2001), Shyman (2015) and Farrell and Ainscow (2002) argued that inclusive education is a controversial concept because it relates to educational and social values and because the definition of inclusive education and describing best practice is still a contested issue. Furthermore, “while there were many definitions of inclusion put forward in multiple contexts, no single definition had been universally accepted” (Winter and O’Raw, 2010, pp.3). The variety of definitions and lack of a common vision of inclusive education, unclear policies and poor implementation of inclusive practices might reflect the complex nature of inclusion. Inclusive education has progressively become a focus of discussions about the development of educational policy globally (Farrell and Ainscow, 2002) and the dissatisfaction with progress towards inclusion drove demands for more fundamental changes in many countries (Slee, 2001). However, the lack of a single definition of inclusive education and the means by which inclusive education is to be achieved resulted in considerable debate and generated the widespread controversial opinions worldwide which have yet to be appropriately countered.

## **2.4 Section Two: Research Context; Kuwait**

### **2.4.1 Introduction**

The multiple interpretations of the concept of inclusion, the cultural differences, the diverse perceptions of disability and the national and international disparities all influence the implementation of inclusive education. This section sheds some light on the geographical context of this study.

### **2.4.2 The State of Kuwait**

The State of Kuwait is a sovereign emirate which was a British protectorate from 1899 until 1961. Kuwait is a small desert country located in the Middle East on the Arab/Persian Gulf, bordered by Saudi Arabia in the south and Iraq in the north and

west. The native and official language is Arabic. Kuwaiti culture is a conservative culture with social traditions and values (Al Junahi, 2005, Arabic). Kuwait has a population of 4.2 million people; 1.3 million are Kuwaitis and 2.9 million are expatriates (Kuwait Central Statistical Bureau, 2017). Expatriates account for 70% of the population. Kuwaitis constitute a minority in their own country due to large numbers of immigrants seeking employment in the light of ambitious economic development (Al Junahi, 2005).

The massive growth of the oil industry has transformed Kuwait into one of the richest countries in the world and has contributed to significant improvements in human development, including increases in school enrolment rates for boys and girls (UNECEP, 2014). The government invests heavily in the social sector and the data shows that Kuwait has the highest Human Development Index in the Arab world; ranking 33rd out of 177 countries in terms of improvement of living standards and human development (World Bank, 2005).

#### **2.4.3 The provision of Early Childhood Education in Kuwait**

The focus of this study as stated earlier is on the educational inclusion of young children with autism. The underlying principle being that kindergarten is the stage in which children receive their first formal education and exposure to knowledge, whilst transitioning from the home environment to school or kindergarten. It also helps in creating students soft skills and gives insight about academic potentialities (UNICEF, 2001). Several researchers including Odom et al. (2011) and Ainscow et.al. (2006) stated that the benefits of an inclusive classroom for young children with disabilities reach beyond academics. That is to say that young children with disabilities develop better communication and social skills in an environment

that encourages young children's social and emotional development and learn best when they feel safe and secure in their classrooms.

Education in Kuwait is divided into kindergarten, elementary, intermediate, and secondary for both public and private schools in Kuwait. All schools are subject to regulations by Ministry of Education. The government sector is restricted to Kuwaiti children (State of Kuwait, Ministry of Education: National Report on the Development of Education 2004-2008). The country reports a high gross rate of pre-school enrolment at 90 per cent (UNICEF, 2009). According to the World Economic Forum Report (2016), amongst Gulf Cooperation Council (GCC) Kuwait is considered a regional leader in preschool registration. The report states expenditure on education and other social issues, including projects for the disabled, accounts for 20 per cent of the total government budget. For children with special education needs, children are issued with a disability certificate following a formal diagnosis. Depending on the severity of the disability, parents have the option to enrol their child either to a special school or to join special classes in mainstream schools (Al daihani, 2010).

According to the Kuwait Ministry of Education (2016) kindergartens in Kuwait strive to provide a safe environment for the development of the child mentally, socially and physically, in accordance with the child's needs and to encourage children to discover their environment and provide them with social and moral guidance. The curriculum for the KG stages is focused largely on children's play and follows principally Froebel's theory (Al Shatti, 2011). Froebel was a German educator who invented the kindergarten-. Froebel believed that play is the highest expression of human development in childhood for it alone is the free expression of what is in the child's soul (Provenzo, 2009). Private KGs on the other hand, have their own structure and curriculum and they do not follow the Kuwaiti government KGs

educational system and curriculum (Management of private education in the Kuwaiti Ministry of Education, 1989).

In 2008 the United Nations Development Programme (UNDP) organised their first workshop to address early learning and associated challenges in Kuwait (ELC). As a result, toolkits were provided for teachers and parents of disabled children. The aim of the UNDP programme was to assist the Kuwaiti education policy makers to take positive stance towards the inclusion of young students with disabilities. According to Almoosa et al (2012) and Weber (2012) recently, the Ministry of Education in Kuwait succeeded in integrating children with Downs syndrome into a limited number of selected public kindergarten, no other effort has been made to integrate other children with other types of disabilities into inclusive educational settings.

#### **2.4.4 Disability-related issues in the Kuwaiti context**

In the past, disabled people were considered burdensome and shameful in the Arab Societies including Kuwait, rendering disabled individuals unable to benefit from their basic human rights in comparison with those without disabilities (Al Lawati, 2011). A disabled person was deemed completely incapable and therefore unable to perform any task that a non-disabled person could perform. Disparaging and depreciatory terms such as ‘incapable’ and ‘invalid’ were used to refer to disabled persons (Al Lawati, 2011). There was no adequate education for disabled persons and they were not considered to be part of the community in Kuwait and the rest of the Gulf Cooperation Council (GCC). According to Al-Hilawani et al. (2008) and Al-Thani (2006) hiding disabled individuals from the rest of society was a very normal practice in the GCC countries. This societal attitude was due to poor social reactions

and negative consequences from a society not yet ready to accept disabled people as a useful part of the community (Al- Hilawani et al, 2008).

With the passage of time, however, the way that disabled people and disability were viewed has evolved. According to the Equality Act, UK (2010), disability is defined as “if you have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to undertake normal daily activities”. The status of people with disabilities and the attitudes towards those with physical impediments and learning difficulties with the passage of time has changed dramatically in the United Kingdom, the United States and to some extent in Kuwait (Brown, 2006).

The Disability Law of 1996 in Kuwait article 13, emphasized the rights of individuals with disabilities to be integrated in the society. The “Disability Law” was officially passed which cemented the way for the formation of The Higher Council for the Disabled Affairs (HCDA). The policy was updated later in 2005 by The Law on the Integration of People with Disability. Articles 2 and 4 of the new policy stated that the purpose of this Law shall be to provide guaranties for equality for the people with disabilities and social integration and shall be implemented through education. The United Nations Development Programme (UNDP) (2008, pp. 1) reported that “Kuwait plays a significant and leading role amongst Arab States in terms of awareness, advocacy and recognition of disabilities and inclusion”. According to official statistics, more than 43,955 disabled persons were registered in Kuwait by the end of 2017, their registration provides them with a wide range of benefits including inclusive education and constructive contribution to society (Kuwait Public Authority for the Disabled, 2017).

A search in the literature reveals that studies on disability related issues in Kuwait are scarce. Most of the disability research are medically focused (Alenaizi, 2017). However, there are some studies that might be classified as having social and psychological orientation towards disability. For example, a study conducted by Al-Kandari (2014) on professionals' perceptions of the services provided to children with disabilities in special education schools. The objective of the study was to help social service providers and professionals in Kuwait to identify laws that meet the needs of those disabled children. In a study by Alkandari (2006) on parenting stressors of mothers of children with and without disabilities, the researcher investigated factors that may affect the families of disabled children. The study investigated the differences in stressors experienced by mothers in parenting a child with and without disabilities at the elementary level of the Special Education Schools in Kuwait. The finding indicated that Kuwaiti mothers of children with disability perceived themselves as subjected to severe stressors related to 'acceptability'. This stressor of negative and non-acceptance is a direct result of stigmatization and negative attitudes held by non-disabled people towards disabled people in Kuwait. Another study conducted by Salih et al. (2008) found that teachers have negative attitudes towards students with learning disability. The authors concluded that disability is socially stigmatised and that this prevailing attitude causes families to exclude their disabled children and hide them from sight. Such studies are valuable on the social and cultural level and relevant to this research as they allow one to identify the cultural perspective towards disabled people. However, to the best of the researcher's knowledge, none of the studies on disabilities and disorders in Kuwait addressed autism spectrum disorder in terms of their educational and social inclusion nor the perspectives of parents

towards inclusive education of young children with autism which is the focus of this study.

#### **2.4.5 Inclusive Education in Kuwait**

Amongst other world nations, Kuwait has become one of the foremost countries to recognise the human and constitutional rights of disabled students (Aldaihani, 2010). The Higher Council for Disability Affairs was established with representation from both government agencies and those advocating on behalf of disabled citizens. The legal framework and policy for the education of disabled students was adopted from older models of the special education for disabled students in the United States and the United Kingdom (Almoosa, 2012). The older models of both these countries were based on separate education for disabled students. In Kuwait, education for disabled students has been achieved by establishing special institutes each allocated to a particular disability (Weber, 2012).

The search for Kuwaiti educational policy documentations, both in Arabic and English, regarding inclusive education proved telling as it revealed the non-existence of inclusive education policy documents in Kuwait. Similar observations were reported by a number of researchers including Al-Kandari and Salih's, (2008), Hadidi and Al Khateeb (2015); Weber (2012); Al-Hilawani (2011); and Gaad (2011) Alkhateeb et al. (2016). The confusion over the terms of reference was also noted in an official public report by the Kuwaiti Ministry of Education (2008). Reading through the Ministry of Education report (2008) on Kuwaiti's educational vision 2005-2025, the report used the terms 'inclusion' and 'integration' interchangeably. This confusion over the semantics of inclusive education and integration indicates the

lack of clarity between what constitutes inclusive education and what constitutes integration (Alkhateeb et al. 2016; Hadidi and Al Khateeb, 2015).

As stated earlier, The United Nations Development Programme (2015) reported that that a number of strategies have been adopted in Kuwait's educational system to move from separate schools to inclusive schooling, however, the policy of inclusive education has not yet been implemented as an educational policy of schooling in the country. Similarly, the World Bank (2013) reported that what has been accomplished so far regarding inclusive education in Kuwait is more theoretical than practical. Other researchers including (Alkhateeb et al. (2016) and Al-Nakib, (2015) argued that the lack of Kuwaiti published policy reports on inclusive education is because inclusive education is a new concept in Kuwait.

The United Nations Development Programme (UNDP, 2011-2013) in Kuwait aimed to work on issues related to inclusive education and to remove any obstacles in the way of achieving programme objectives. However, The United Nations Development Programme report of (2015) indicates that inclusive education is still in its infancy in terms of strategic planning and has not yet been implemented as an educational policy of schooling in the country.

Several researchers including Weber (2012), Gaad (2011) and Nadra (2009) believed that inclusive education is still very new to Kuwait. The authors were of the opinion that it cannot be said with any certainty that inclusion policies will be put into practice successfully. The authors argued that apart from theoretical government support for an inclusive model, issues such as establishing special education facilities, education officials' lack of interest in inclusion and resistance from teachers and also from students without disabilities are the main obstacles to implementing

comprehensive plans for inclusion in Kuwait. A common strategy has yet to be established to deal with of students with special needs. For successful inclusive education in Kuwait, legal and policy frameworks have yet to be established (Almoosa, 2012). Therefore, it can be said with certainty that this practice requires proper planning and a measured and constructive process for successful implementation. Evidence of lack of policy framework form inclusive education can be clearly seen in constitutional and communal talks (Emam, 2016). A paradigm shift in the overall education system of Kuwait is required to implement the concept of inclusion (Gaad, 2011). Inclusion needs the establishment of basic principles such as professional conduct, work ethics, teacher training programs, accountability and collective team efforts and activities. Along with the requisite paradigm shift in the education system, is the need for a national and social consensus about inclusion in Kuwait. Greater implementation cannot be achieved without the help of the community (UNESCO, 2004). It is critical that the community acknowledges the principle of equal learning prospects for all youngsters, adolescents and adults in integrated environments (Brown, 2006). According to Alkandari (2013) at present it seems inappropriate to implement inclusive education in Kuwait for a number of reasons. Students with disabilities require qualified teachers who can manage their needs. The lack of skilled and trained staff in conjunction with the absence of preparatory programmes for the required staff signifies the predominant issue. Similarly, issues associated with local communities are also major concerns to be addressed (Al-Hilawani, 2011, Salih and Al-Kandari, 2007, Brown, 2006). Furthermore, Al-Hilawani (2011) and Hadidi and Al Khateeb (2015) said that complete inclusion is not considered as a possibility for the near future in Kuwait until

broad-based capacities and school systems and teachers attitudes toward accommodating children with disabilities into regular classrooms setting is adequate.

When discussing the numerous issues placing obstacles in the way of implementing inclusion, Al Hilawani (2011) mentioned the shortage of qualified and skilled specialists and raised questions about the suitability of the existing teacher training programs in Kuwait and the rest of the Gulf region. Hadidi and Al khateeb (2015) endorsed this view point and mentioned the persistence of these problems and failings in the services department. Along with the aforementioned issues, another key impediment to the development of special education in Kuwait is the presence of incomplete or misleading data. Accurate statistics or data is very important for making policy and setting precedence. Unreliable data leads to considerable difficulties in defining policy relating to disabilities and disabled people. Insufficient data, improper documentation and poor management of existing data are a few of the key issues in Arab countries including Kuwait (WHO, 2012; Al-Thani, 2006). According to Hadidi and Al khateeb (2015), an example of this absence of accurate data can be seen when comparing the report from the World Health Organisation with other published national surveys. As stated by the WHO report (2012) the prevalence rate of disability in Arab countries is almost 15 percent of the total population. Whilst national surveys show that it is nearly 1 percent of the total population. This disparity clearly demonstrates the inaccuracy of the data. In the same way, the literature available in Kuwait pertaining to disability is equally unreliable. Where the definition of disability is examined, the existing multiple definitions proved to be no more than translated versions of foreign references (Hadidi and Al Khateeb, 2015). In addition, the absence of skilled and qualified trainers; the fact that there are no or very limited opportunities for personnel development or training and the lack of social and

constitutional support represent significant challenges towards the implementation of inclusive education in Kuwait (Hadidi and Al Khateeb, 2015, Al Hilawani, 2011). Subsequently, several authors including Weber (2012); Aldaihani, (2010); and Brown (2006) stated that although Kuwait signed the Salamanca Statement in 1994, Kuwait does not yet have a clear strategy for the implementation of inclusive education and students with disabilities in Kuwait remain disadvantaged.

#### **2.4.6 Conclusion**

A thematic review of the national surveys and reports published by the government of Kuwait was also conducted by the researcher. A comparison was made between the Kuwaiti national reports and international development reports published by organisations such as UNESCO, WHO, the World Bank and the UNDP. The purpose of this comparison was to explore inclusive education in Kuwait against the background of international educational organizations reports. It could be argued that in Kuwait, sincere efforts are being made to provide programmes and to serve children with special needs. However, statistics and facts related to performance indicators, quality of service and beneficiaries of the programme and services are not available. This may be due to a lack of updated government figures about inclusive education or inappropriate representation and description of planned initiatives on government websites or perhaps poor information and other issues including data accumulation systems and different information linkages. However, the advancement of better factual data will clearly be a long-term project, involving specialists with various foundations and a number of researchers with different backgrounds (Hadidi and Al Khateeb, 2015). Another issue that limits the extent of information of relevance to this study about inclusive education in the Arab countries is that a great part of the research in the existing literature most frequently address teachers'

attitudes towards inclusive. For example, Alshemari (2016) thesis on “Inclusive education and students with disabilities in Kuwait; Anati (2012) thesis on “Including students with disabilities in UAE schools”; Amr (2011) study on “Teacher education for inclusive education in the Arab world: The case of Jordan”; and Emam and Mohamed (2011) study on “Preschool and primary school teachers’ attitudes toward inclusive education in Egypt”. Studies concerning the attitudes displayed demonstrate that teachers are divided on the subject of inclusion and that the challenges they face are many. However, to the best of the researcher’s knowledge, there are no studies on parent’s perspectives on inclusive education and similarly with studies on the inclusion of young children with autism spectrum disorder. There is a gap in literature for studies on early childhood inclusion for children with autism in Kuwait.

Therefore, exploring parents perspectives on inclusive education of young children with autism in Kuwait would be of great value to lay the grounds for further studies in this field. The work in this thesis as stated earlier focused specifically on the inclusion of children with autism spectrum disorders. In the next section the prominent literature in the area of autism will be reviewed including: the characteristics of autistic children and the intervention methods that assist the education of the autistic children.

## **2.5 Section three: Autism Spectrum Disorder**

### **2.5.1 Introduction**

Autism is a complex, pervasive, and multifactorial neurodevelopmental condition (Diagnostic and Statistical Manual of Mental Disorders (DSM-5), 2013). The major features of autism according to the DSM-5 include: peculiar behaviour; impaired social interaction; inability to initiate and sustain appropriate conversation;

communication problems; delayed language development; eye-contact avoidance; difficulty making friends; and repetitive behaviours. Autism is a spectrum condition. All autistic people share certain difficulties but autistic people are different and the autism spectrum will affect them in different ways (Jordan, 2003). The disorder is now widely accepted as a complex and heterogeneous condition with comorbid psychiatric and medical morbidities including intellectual disability, epilepsy, and social anxiety disorder (Masi et al., 2017).

### **2.5.2 A Brief History of Autism**

Kanner's study "Autistic disturbances of affective contact" published in 1943 featured case studies of a total of eleven children, eight boys and three girls, who had attended his clinics from the ages of 2 years and 4 months up to 11 years. Kanner watched the children and found them unable to form connections with others, an issue that had affected them apparently since earliest childhood. Besides their solitary nature Kanner also noted an atypical pattern of speech development as the children had the capacity to learn nouns and nursery rhymes but had not learnt the type of speech necessary for effective communication. Similarly the children exhibited a propensity for repetition and literal interpretation whilst at the same time displaying sensory sensitivities and repetitive behaviours (Kanner, 1943). Children for whom non-verbal communication and corresponding social skills were the principal problem were featured in the 1944 paper on "autistic psychopathy" published in German by Hans Asperger. Readership was low due to the language of publication and as it was published during the Second World War. For these reasons English speaking medical specialists could not access the document until the 1970s (Wing, 1981). In her 1981 account of the syndrome as suggested by Asperger, Wing remarked upon the parallel factors in Kanner and Asperger studies observing that it was as yet unclear whether

these were different manifestations of one primary abnormality. Wing, drew attention to the extremely broad autism spectrum varying between the lesser performing Kanner's autism to Asperger's syndrome to those developing in a more standard way but exhibiting aspects of Asperger's syndrome. In the estimation of Firth (1991) Asperger's work on the concept of autism would become as significant as Kanner's given that they have both identified the same main indicators albeit that Asperger's work deals with higher-functioning individuals. Individuals with higher functioning autism "fail to translate their cognitive potential into real-life adaptation, and the severity of their symptoms is considerable despite their intellectual ability" (Saulnier and Klin, 2007, pp.1).

Since Leo Kanner's original depiction of the syndrome in 1943 the way that autism is viewed and interpreted has undergone several changes in line with the concurrent direction of scientific advances including genetic advances, aspects of the condition such as anxiety, environment studies, technological progress and psychological treatments. Aitken (2012) also highlighted the significant role of parents in shaping both research and service developments of the autism disorder. In the mid-twentieth century parents' relationships and their parental styles with their children were thought of as being the reasons for autism. The concept of parents who were unengaged emotionally with their children, the "refrigerator mother theory, which was developed by the child psychologist Bettelheim's in 1967 and published in his book "The Empty Fortress" was considered the main cause for autism (Rutter, 2005). The theory that autism was a reaction to bad parenting remained prevalent until 1964 when the "Infantile Autism" book was published by Bernard Rimland asserting that autism was a biological condition which could be improved by educational and behavioural interventions (Aitken, 2012). The late twentieth century

marked a new understanding of autism as a developmental disorder and the ability of children with autism to learn and to develop through educational and behavioural early interventions such as Lovaas's Applied Behaviour Analysis (ABA) method which validated that the behaviours of children with autism could be improved (Anderson, 2007). Verhoeff, (2013) and Wing and Potter (2002) asserted that expounding theories, interventions, greater knowledge of the general public and designated services have evidently all advanced with the passage of time. Wing and Potter contend that the reasons for a constant expansion of the concept of autism are usually given in the justifications for the dramatically increased number of people identified as being on the autism spectrum. These changes in the particular symptoms and impairments is reflected in the expansion of indicative factors for autistic disorder recorded in editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM), the World Health Organisation's International Classification of Diseases (ICD) and the continual refinement from the DSM-III, 1980 with 'Infantile Autism' to the current Diagnostic and Statistical Manual of Mental Disorders, DSM-V diagnosis, 2013 (Masi et al., 2017; Kawa and Giordano, 2012). Kanner's original publication precedes the inclusion of 'autism' as an infantile disorder in the international classification systems by some decades (Kawa and Giordano, 2012; Wing and Potter, 2002). It was initially categorised as one of the schizophrenia groups in ICD-8 (World Health Organisation, 1967) and a significant revision of the concept of childhood autism from a psychiatric to a developmental disorder was apparent in DSM-III (American Psychiatric Association, 1980).

The 1980 Diagnostic and Statistical Manual of Mental Disorders, third edition (DSM-III) first showed childhood autism as a legitimate medical diagnosis and defined a subcategory of persistent developmental conditions (PDD), (American

Psychiatric Association, 1980). The indicators described for Infantile Autism were: appearance of symptoms before 30 months old, lack of responsiveness to others, major deficiencies in language development, and extraordinary responses to environmental stimuli (DSM-III, 1980). More comprehensive criteria were added in the DSM-IV (American Psychiatric Association, 1994) in recognition of the prevalent nature of the disorder with the idea of a spectrum emerging in the revised version of DSM-III, referred to as DSM-IV. The DSM-IV retained the categorisation of pervasive developmental disorder with no other classification (PDD-NOS), but the subgroups were labelled autistic disorder. The descriptions of the subgroups varied from those in DSM-III and were prescribed as official diagnostic criteria comprising an array of pertinent aspects of behaviour (Wing and Potter, 2002). Nor was it restricted to the very young, as the criteria for Infantile Autism omitted a subgroup of those who were higher-functioning but for whom there was no diagnosis due to a lack of evidence of having exhibited the behaviours in early childhood (Masi et al., 2017; Fombonne et al., 2014; and Kawa and Giordano, 2012). The reformation of Infantile Autism to Autistic Disorder in the DSM acknowledged the wider continuum of behavioural indicators needed for diagnosis and the age at which symptoms would emerge was stated as either during the initial stage of life or early childhood, (Masi et al., 2017). The 10th revision of the International Classification of Diseases, ICD-10, had analogous sub-groups and research factors (Wing and Potter, 2002; World Health Organisation, 1993). These criteria permitted possible diagnosis of less-affected individuals (Wing and Potter, 2002). The DSM-IV presented an official set of criteria for Asperger's Syndrome utilising some of the factors explained by Wing in 1981 translation of Asperger's work (Wing and Potter, 2002). The criteria for Asperger's Syndrome defined a disorder with deficiencies in social contact, communication, and

imagination, akin to that of the Autistic Disorder criteria, but without the impairments in language or perception (DSM-IV, 1994) and both DSM-IV and ICD-10 criteria are essentially the same (Wing and Potter, 2002).

The two foremost diagnostic classification systems in psychiatry are the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013) and the International Classification of Diseases (ICD-10, World Health Organization, 1993). Globally ICD is the most consistently applied system for clinical diagnosis and training and is the most generally utilised diagnostic manual in Britain, whereas DSM is the method ordinarily used for research (Sorensen et al., 2005). In terms of structure and proposed use to a certain degree the two approved models differ, however, the introduction of standardised processes to the diagnosis of autism will assist both research and clinical services (Volkmar, 1998). The ICD-10 demarcates autism profiles, such as: infantile autism, i.e. a disorder appearing in children before the age of two and a half; uncharacteristic autism, i.e. pervasive developmental disorder with no other classification; and Asperger syndrome. These profiles are incorporated into the Pervasive Developmental Disorders section, described as a "abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests" (ICD-10, F84). Alternatively the DSM-5 categorises autism spectrum disorder (ASD) by deficiencies in social communication in conjunction with repetitive, limited forms of behaviour exhibited in formative years (American Psychiatric Association, 2013). The diagnosis for Asperger is removed from DSM-5 and it has been folded into one category of autism spectrum disorder while ICD-10 lists Asperger's Disorder as a separate diagnosis.

Less restrictive autism related indicators and a wider definition indicated the change to the DSM-5 in 2013 (Diagnostic and Statistical Manual of Mental Disorders Fifth Edition, 2013) and announced considerable alterations to the diagnostic criteria. Diagnoses of Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder— Not Otherwise Specified (PDD-NOS), were eliminated as diagnostic categories and merged into two diagnoses, Autism Spectrum Disorder and Social Communication Disorder (DSM-5, 2013). At the time of this most recent adjustment, proof that the Asperger's diagnosis was being used interchangeably with Autistic Disorder exposed fears surrounding the soundness of the Asperger's diagnosis (Verhoeff, 2013, Masi et al. 2017). Those who would previously have been said to have Asperger's Syndrome were assumed to receive a diagnosis of Autism Spectrum Disorder without speech or perceptible impairment (DSM-5, 2013; Happé, 2011). A large number of researchers in Autism such as Verhoeff (2013), Happé (2011) and Sanders (2009) argued that the basic rationale for forming one ASD category was that there is little to substantiate the present diagnostic variation between Asperger disorder and high-functioning autism. Further the authors stated that comparative studies of clinical and demographic features, neuropsychological profiles, comorbidity and predictions between autism and Asperger's disorder principally did not endorse a diagnostic distinction between the two diagnostic classifications of Asperger and high-functioning autism. Lord and Jones (2012) added that DSM-IV criteria are hard to apply because firstly, the term Asperger is used inconsistently. Secondly, different specialists use the term Asperger differently to the extent that the best predictor of whether individuals receive the diagnosis of autism or Asperger depends on which clinic individuals go to rather than the traits of the individuals themselves. However, The DSM-V has attracted some criticism. For example, Young

(2016) argued that DSM-V sets too low standards and renders vulnerable and normal individuals to the risks of being over diagnosed. The elimination of subcategories was also criticized on the basis that DSM-5 affects access to services to those with high-functioning autism and those diagnosed with pervasive developmental disorder. Rutter (2013) for example, stated that DSM-V has completely ignored the broader spectrum of autism and the individuals who have cognitive features similar to autism. Never the less, in the context of the diagnosing ASD in the DSM-V, there is a wide agreement among researchers in ASD that Asperger syndrome is part of the autism spectrum. Masi et al. (2017), Verhoeff (2013) and Lord and Jones (2012) said that the DSM-5 provide a clear and simple diagnostic structure for people with autism and that the DSM-5 diagnosis ensures that individuals are classified in terms of their precise characteristics and needs. Similarly, Fombonne et al., (2014) and Verhoeff, (2013) argued that in the DSM-5, Social Communication Disorder (SCD) was brought in on the assumption that for those individuals who had received a diagnosis as PDD-NOS, without issues relating to restricted, repetitive behaviour and do not fit the DSM-5 Autism Spectrum Disorder criteria, would be more likely to be diagnosed with SCD.

Diagnosis of autism spectrum disorder is still founded upon observation of unusual behaviours, with indicators of continual deficiencies in social communication and interaction, limited and repetitive patterns of behaviour, interests, or activities (Strauss et al., 2015). Fombonne (2003) and Strauss (2015) proposed that autism conditions are amongst the most common childhood neurodevelopmental disorders, with an increased likelihood of heritability (Rutter, 2000) and so represent a major public health issue (Isaksen et al., 2013). Masi et al. (2017) and Geschwind (2004) also contended that commonly identified psychiatric and cognitive comorbidities with

ASD include social anxiety disorder, attention-deficit, hyperactivity disorder (ADHD), and intellectual disability. There is now a more comprehensive acknowledgement of complex symptomatology including medical and mental health comorbidities, due to the recent detection of correlations between comorbidities and the severity of autism related symptoms (Masi et al., 2017). Furthermore, Strauss et al. (2015) confirmed that the implementation of contemporary neuroimaging methods have allowed for the identification of particular medical and genetic syndromes linked to autism in approximately 20% of the patients. The causes of ASD remains unknown in 80% of cases and that presently evidence strongly supports the interplay of genetic sources and environmental exposure leading to changes in brain networks (Strauss et al., 2015). Kutscher (2005) affirmed that disorders on the spectrum often present with other mental health or developmental incapacities. For example, it is not unusual for a child with autism to also experience learning disabilities, mental retardation, obsessive compulsive disorders, attention deficits, sensory integration problems, bipolar disorder or any variety of conditions.

### **2.5.3 Methods of Interventions for Autistic Children**

The Centres for Disease Control (CDC), (2012) confirmed autism as coming second only to mental retardation as the most common serious developmental disability. The CDC stressed the importance of public awareness of the growing rates of autism and indicated the earliest possible intervention for children on the spectrum as studies show that if intervention occurs at young age for children with autism stand a better chance of making sufficient progress for inclusion in regular education classes. There is a substantial published research on methods of intervention for autism. The methods of intervention range from those based on behaviour and development to those based on medicine. Examples of researches on medical

intervention methods for autism include, Siegel and Beaulieu's (2012) study in which the authors carried out a systematic review, rating and synthesis of the empirical evidence for the use of psychotropic medications in children with autism spectrum disorders (ASD). The study showed that although medical interventions are frequent for children with ASDs, there is little evidence verifying the benefit of most treatments and the impact on the core features of autism was very limited.

Other researchers took the alternative view that intensively delivered behavioural interventions early in life are considered the optimal treatment for ASD related behavioural symptoms. Chasson et al. (2007), for example, stressed the behavioural basis of all evidence-based interventions in autism and contend that all interventions stated to be effective in the treatment of autism are centred on the implementation of Applied Behaviour Analysis (ABA) particularly in the early years. Applied Behaviour Analysis (ABA) is based on learning theory, which comes from the field of behavioural psychology. The first study that looked at the use of ABA techniques with young children with autism was published by Dr Lovaas in 1987 (Cooper et al., 2007). The Lovaas ABA method focuses on dividing complex tasks into smaller steps and as children learn each step, the children get rewards while challenging behaviour is ignored when it happens.

Other types of interventions have been implemented for children on the spectrum with the focus being placed on adaptation of the setting to accommodate the child such as Treatment and Education of Autistic and Communication related handicapped children (TEACCH). This skills programme uses structured teaching to train children in social and communication skills and relies heavily on cooperation between teachers and parents (Bolagh et al., 2013). Similarly, the Developmentally Appropriate Treatment for Autism (DATA) which gives prominence to building the

child's repertoire thereby enabling him or her to successfully participate in environments alongside typically developing peers (Schwartz et al., 2004). Conclusions drawn from existing literature show that interventions based on behavioural and developmental principles to be the most effective methods for ASD in improving autistic symptoms and developmental outcome relating to cognitive functioning, language skills and adaptive and aberrant behaviours. These programs span from one-to-one, to interventions delivered in regular educational settings such as child care and schools.

The report from The Centres for Disease Control and several researchers including Stahmer et al (2014) and Corsello (2005) emphasised that there is empirical evidence that autistic children who enter inclusive education settings at young ages gain significant improvement in developmental level, adaptive behaviour and communication. The CDC reports (2012) and the above mentioned studies substantiate the rationale of this study's focus on early childhood inclusion of children with autism spectrum disorder in regular education classes. The early childhood stage is the most rapid period of development of a human being's cognitive, emotional and physical development and growth (UNICEF, 2000). The same is true for children on the autism spectrum. Most of the educational and behavioural intervention methods for children with autism focused on children of preschool age and have shown a considerable impact and significant improvements.

#### **2.5.4 Global Prevalence of Autism**

The sustained growth of diagnoses of Autism reflects the fact that it is the most common of all widespread development disorders (Landa et al., 2011). The predominance of boys with autism spectrum disorder, four times as many as girls, is

also noted by Landa et al. Alternatively, Baron-Cohen et al., (2005) contend that this ratio may be altered by other considerations such as intellectual functioning and genetic variance between genders. Proposed explanations of the gender disparity include the “extreme male brain” theory founded on the belief that a standard male cognitive profile is comprised of those more adept at systemising than empathising and autism is an extreme of that profile. A possible channel for this theory is raised male sex steroids, as recent report findings indicate that males subsequently diagnosed with ASD had previously shown elevated amniotic fluid steroid hormones (Baron-Cohen et al., 2015). Of late a ‘female protective model’ has been suggested by researchers conducting studies in DNA and genetics such as Frazier et al., (2014); Bergmann et al., (2014); Dworzynski et al., (2012);; Szatmari et al. (2012); and Mandy et al., (2012), the researchers maintained that girls’ superior ability to withstand genetic assaults means girls have greater neurodevelopmentally related genetic mutations than boys with similar indicators. Possible gender unfairness in diagnostic factors and the underrepresentation of females is raised by Werling (2016). In addition, Masi (2017) and Werling (2016) referred to the results of an extensive study indicating that females display greater impairments such as social communication and interaction problems, lower cognitive and language abilities and heightened externalising behaviour and irritability. The implication being that girls must exhibit a higher number of severe symptoms for a diagnosis of ASD to be made.

Wing and Potter, (2002) took the view that a true increase in numbers is conceivable however, there are other causes influencing the growth of stated incidents of ASD. Alterations in diagnostic criteria, evolution of the concept of the broad autistic spectrum, distinct methodology utilised for studies, increased awareness and knowledge of parents and professional workers and the expansion of specialist

services are all contributory elements. Environmental factors have also been proposed, including the MMR vaccine to protect against measles, mumps and rubella however, such suggestions remain unsubstantiated by independent scientific study, whilst the evidence verifying the considerable influence of complex genetic factors on etiology is compelling (Goldstein et al., 2009). Insel (2012) also believed the higher number of autism cases may be attributed to diverse factors such as the modern method of screening, more access to diagnostic services and the governmental assistance specific to children with autism. In charting the rise of the once rare ASD, the US Centre for Disease Control and Prevention's (CDC) (2010) estimate of the prevalence of autism was 1 in 68 children, about twice as high as their 2000 estimate (CDC, 2010). These figures were based on data gathered through the Autism and Developmental Disabilities Monitoring (ADDM) network from health and special education records of children in 11 areas in the United States in 2010 (CDC 2014). The prevalence of autism in adults in England was estimated to be around 0.8% ( UK governmental statistical service, 2014) and the World Health Organization report (2017) estimated 1 in 160 children has an autism spectrum disorder (ASD) around the world.

Wing and Potter (2002) scrutinised 39 European, North American and Japanese studies but were of the opinion that these countries did not present evidence of any possible national, regional or local variation in prevalence rates. Also the reasons for some studies showing trends of higher rates could be owing to the case finding methods employed such as the use of medical and educational agencies closely linked to the routine developmental checks for preschool children. Fombonne et al., (2001) additionally indicated that studies in which regional prevalence disparities are shown may use different means of case identification and draw from

target populations differing in both size and type. In other words, ethnic and national differences in prevalence of autism may be attributable to diagnostic patterns and access to health care. Although ASD occurs worldwide, studies on autism and prevalence researches have mainly been conducted in developed countries and there is limited information on ASD in developing countries (Samadi, 2011). Thus, differences exist in the reported prevalence rates of ASD as much higher in developed countries than the prevalence rates from developing countries. Other reason might be attributed to the awareness and the better detection in developed countries, cultural differences, behaviours related to ASD may be considered as ordinary childhood behaviours in some cultures in developing world (Abubakar, 2016). Al-Farsi et al. (2011) added that the limited availability of diagnostic tool in the developing countries has resulted in scarcity of reliable data for the prevalence rates of autism. Consequently, low reported rates of prevalence in comparison with the developed countries rates do not represent the true representation in developing countries.

### **2.5.5 Autism and autism prevalence in the State of Kuwait**

As a reflection of growing awareness of autism spectrum disorder in Kuwait, in 1995 the Kuwaiti government, the Directorate General of Religious Affairs, the Ministry of Education and private sponsors established the first Kuwait Centre for Autism and the first funded institution in the country to deal exclusively with autism. The establishment of the centre represents governmental acknowledgement of the inconsistency in special needs provision (Al-Hilawani et al. 2008) Ashkanani, (2000) in his research on disabled children in Kuwait claimed that the establishment of the Kuwait Centre for Autism also served to highlight the pressure being exerted from families with autistic members, for whom suitable provision has hitherto been

unavailable. Al-Shammari's, (2006) case study investigated Kuwaiti special education teachers' attitudes toward autistic children by featuring two special education teachers from the Autism School of Kuwait. Teachers' responses exposed the pressing need for special education programs, particularly at the Autism School in Kuwait. Consequently Al-Shammari recommended that the Ministry of Education should deliver educational programs for teachers in Kuwait to ensure teachers are well trained and equipped to develop and coordinate support services which address the needs of students with autism.

Despite increased awareness in developing nations over the past decades and Autism being a global disorder, most of the published studies originate from the West (Elsabbagh, 2012). As such there is little data published regarding autism occurrence and prevalence in developing countries. Al-Salehi and Ghaziuddin, (2009) stated that what is known about the etiology and outcome of autism, may not be applicable to cases from developing countries such as the Middle East, due to the rarity of studies on autism spectrum disorder. Affifi, (2005) sought to identify mental health publications in the Arab world named in the US National Library of Medicine National Institutes of Health (PubMed) database by means of a geographical analysis of publications produced in 22 Arab countries from 1987 to 2002. The results revealed that in Arab nations over the preceding 15 years there had been 338 mental health research citations published, 1.2% of the total citations related to biomedical research; 17% were on child and adolescent mental health. In terms of mental health research most attention was focused on anxiety, mood disorders and substance abuse. However, Arab researchers have not conceded significant importance to child psychiatry and conditions like autism. Affifi concluded that the lack of researchers' interest and of studies on child autism by researchers, health policy-makers and

clinicians is undermining diagnosis and treatment for ASD in Arab Gulf countries and therefore needs to change. Affifi's research has certain limitations which the author acknowledges in the study itself and may not present a true picture of the total number of medical articles if these articles were only published in local journals and not on PubMed. Nonetheless, this research suggests that the issue of child autism needs to be thoroughly addressed in the Arab Gulf countries, specifically in Kuwait and followed-up by well-designed studies.

Similarly, Salhia et al. (2014) used the PubMed and Science Direct databases to identify English language studies on the epidemiology of autism undertaken in any Arab Gulf countries by 2013. The authors discovered that only a few studies looked into the epidemiology of autism in the Arab Gulf countries and none considered the burden the disorder placed on the child, family, or society. Salhia et al, also suggested that the existence of a prevalence rate of autism in the Gulf countries ranging from 1.4 to 29 per 10,000 individuals. Ouhtit et al. (2015) took a different view that the epidemiology of ASD in developing countries suggested a lower prevalence when compared to western nations and the semblance of a low ASD rate is partially due to the lack of reliable biological markers for diagnosis and the lack of health services for children with ASD, thereby limiting the number of participants in epidemiological surveys. Further examination of the literature on autism in the Arab Gulf regions shows that most of the Arab mental health research used hospital or primary care as study settings rather than being community based.

Those researching autism in the Arab world including Kelly et al., (2016), Nahad, (2015), Taha and Hussein (2014) and Salhia et al., (2014) contended that studies on autism in the Middle East are rare particularly from the Gulf countries; namely, Bahrain, Kuwait, Oman, Qatar, Saudi Arabia and the United Arab Emirates.

The writers argued that the reasons for the limited number of studies on autism in the Gulf region are because firstly, most studies on autism and intervention methods have been created in the Western countries for a primarily Western nations and may not be relevant to the Arab nations. Secondly, the Gulf region needs to bring proper psychology education into medical studies curricula. Thirdly, the limited information and underdeveloped services for children with special needs in the Gulf region gives the false impression that autism is rare in non-Western cultures. In other words, it will take a concerted social effort to address autism in the Arab Gulf countries and to continue raising awareness, provide more easily accessible information about autism for the public.

#### **2.5.6 Conclusion**

The research review so far explored autism through the presentation of the professionals' points of view on autism, autism prevalence in the developed countries and autism within the Kuwaiti context as well. The review reveals that there has been a progress in the scientific research on autism spectrum disorder in the Western literature albeit, causes of autism, prevention measures and cure for this neurodevelopmental disorder remains elusive. This literature review proved telling that there is a scarcity of studies on both autism and the prevalence of autism in Kuwait.

### **2.6 Section four: Inclusive Education for Young Children with Autism Spectrum Disorder**

#### **2.6.1 Introduction**

This section explores the application of current discourse in early childhood inclusive education for children with autism spectrum disorder. In recent years, the

issue of inclusive education has been placed on the forefront of nearly all scholastic policies around the world. Inclusive education is one of the most dominant and controversial issues confronting educational policy makers and professionals around the world today (UNESCO, 2010). The explanation for the controversy surrounding inclusive education lies in the different interpretations of inclusive education which led to conceptual confusion surrounding inclusion (Ainscow et al., 2006). Regarding children with autism, Crosland and Dunlap's (2012) noted that the examination of methods of promoting inclusive practices suggested that despite extensive research related to educational interventions for children with autism the absence of best practice guidelines means there is no widespread agreement on the proper educational practice for students with autism. Despite controversy, the prominent view based on existing literature is that autistic children in inclusive classes consistently perform better than their peers in segregated settings (Mittler, 2014; UN, 2013 and Ainscow, 2006).

### **2.6.2 Inclusion of autistic young children**

The characteristics of students with autism often present challenges to educators. The common characteristics of students on the spectrum include withdrawal from social contact, sensory sensitivities, the lack of ability to establish relationships, and understanding and managing behaviour (Obrusnikova and Dillon, 2011). These behavioural challenges have been found to contribute to the autistic child's emotional susceptibility, stress, frustration and depression (Müller et al., 2008). This wide repertoire of autistic student behaviours can pose significant teaching challenges to educators. Every autistic child is unique and their needs will be reflected differently and it is challenging for teacher to create an inclusive environment within their classroom that can meet autistic children's needs effectively.

Whitaker (2007), Jordan (2008) also argued that the inability of children with autism spectrum disorder to think and act flexibly, as well as the effects of their social and communication limitations present considerable challenges for teachers and the other students in the general classroom. Therefore, several researchers including Lindsay (2014) and Odom (2000) recommended that teachers need more resources, training and support to enhance the education and inclusion of children with autism.

The degree to which a student with autism requires support will vary widely given the highly heterogeneous nature of the disability in relation to level of functioning and the precise manner in which the student functions (Lord, 2012). For example, atypical behaviours, such as compulsive responding, increasingly exhibited by highly functioning individuals present considerable challenges for educators. Whereas an individual with severe intellectual and behavioural issues may require a great deal of attention and partial participation in the inclusive setting (Boyd, 2012). Although, the general consensus amongst professionals in the field of autism is that the preschool years are a vital period during which early intervention programs can have the greatest impact on learning and development (Corsello, 2005). Despite this widespread agreement, further investigation is required into which programs would be the most beneficial for children with autism spectrum disorder and the likely effect on their cognitive, developmental, social and emotional skills (Martínez-Pedraza and Carter, 2009).

The importance of early intervention has been highlighted by several researchers including Dawson et al (2009), Hume et al (2005) and Smith et al (2000). Early intervention for young children with autism significantly improve autism symptoms, increases communication skills and develop abilities and daily living skills (Paynter et al, 2012). However, effective strategies are needed to provide experts in

autism in inclusive settings and to ensure that teachers are well equipped and supported to avoid them becoming overly fatigued and disenchanted (Wahn and Mutius 2001). According to The National Association for the Education of Young Children (NAEYC), (2017) preschool teachers should be ready to utilise classroom strategies suitable for the inclusion of children with autism in the general education setting in order to respond to the growth of autism diagnoses. Any strategy employed must take into account developmentally appropriate practice, best practices, and differences in learning styles of each individual student. Therefore to include a child with autism in the classroom, the teacher must also be aware of learning styles and challenges typical of children on the autism spectrum. Hooper and Umansky, (2004), argued that outside of private preschool programs which adhere to government regulations, such as teacher/child ratios, general education preschool teachers have little experience of teaching children with varying disabilities. Similarly, Purcell et al (2007) shared this opinion and maintained that the lack of public preschool educational settings for typically developing children leaves children with autism to be educated at home in many localities or to be placed in a self-contained, public special education preschool classroom alongside other children with disabilities rather than being included with typically developing peers.

Machalicek et al., (2007), conducted a comprehensive review of challenging behaviour intervention researches conducted in school settings for students with ASD, aged between 3 and 21 years. The authors examination of twenty-six studies published between 1995 and 2005 made interesting findings. Firstly, challenging behaviours tend to persist in people with ASD where no appropriate intervention was made. Secondly, behavioural issues can jeopardise a student's future educational opportunities and consequently their development. Thirdly, teachers develop negative

attitudes towards inclusion and suffer increased levels of mental and emotional exhaustion following exposure to challenging behaviour with which they are not equipped to deal. For many students with ASD the school is often the primary or sole source of intervention for challenging behaviour. In their evaluation of the research Machalicek et al., found teachers often intervene when challenging behaviour is displayed but do not have the required skills, resources, or time to create and utilise a behavioural intervention plan. To reduce challenging behaviour the design of any such intervention must be appropriate to the classroom routines and expectations and methods of intervention must overcome common classroom distractions not present in the experimental setting. Machalicek et al's study indicated some success in decreasing a range of challenging behaviours through intervention methods over the years. Machalicek et al., concluded that the interventions used in the 26 studies were effective in reducing some challenging behaviours, but in respect of the permanency of any treatment gains they could only draw limited conclusions. Furthermore, the findings of the studies reviewed often lacked clarity, offered contradictory results or were not supported with unequivocal data (Machalicek et al., 2007).

The education of children, parents and teachers is the principal treatment in autism (Steiner et al., 2012) and the term 'education' comprises knowledge and skills obtained from schools in both the public and private sectors (Goin-Kochel et al., 2007). The increased likelihood of children with autism having other impairments signifies that educational planning must incorporate the needs characteristic of autistic spectrum disorders as well as those corresponding to accompanying disabilities in a manner in which, substantial research claims, has not been managed as yet (Rumsey et al., 2000). Similarly, Crosland and Dunlap's (2012) examination of methods of promoting inclusive practices suggested that despite extensive research related to

educational and early behavioural interventions for children with ASD the absence of best practice guidelines means there is no widespread agreement on the proper educational practice for students with autism and that schools are placed in a difficult position in relation to program selection and implementation.

Despite some progress made in educating children with developmental disabilities in recent years in Kuwait, like most developing nations Arab states are still facing challenges in reforming their educational systems and transforming them into inclusive systems (World Health Organisation, 2011). Indicative of this consideration is the argument put forward by some authors such as; Anati (2012), Weber (2012), and Emam and Mohamed (2011) that inclusive education as perceived and practiced in Arab countries may not necessarily have the same meanings and contexts as inclusive education described in the international literature and whether inclusion concept used in western countries can be adopted by Arab countries without adaptation or considerations of cultural impact. Almoosa, (2012) noted that while Kuwait's rhetoric suggests an increasing appreciation of the importance of creating an inclusive environment in schools as evidenced in teacher preparation programs, the reality is that this is not observable in the classroom or in current education policy.

There is no consistent research evidence to suggest any short- and long-term benefits of segregated education over inclusive education (Jackson, 2008). Research has also shown that early childhood inclusion benefits children with and without disabilities (Odom, 2011). Furthermore, it has become more difficult to justify segregated education, given the social justice and the rights for disabled people considerations. However, it is quite evident that the field of inclusive education is not without uncertainties, disputes and contradictions (Acedo et al., 2009). Inclusive education is one of the greatest challenges facing educational systems throughout the

world today, whether we are referring to developing or developed countries (International Conference of Education, 2008). Exclusion from education exists in every country, in different forms and to varying degrees. In spite of substantial progress and landmark legislations, inclusive education in schools remains elusive and the whole inclusion in the school context is neither uniformly understood, readily accepted, nor willingly acted upon (Fitch, 2009).

The search for literature proved telling as it revealed that Kuwait is lagging behind in keeping abreast with the changes in special education. Several researcher including Weber (2012), Almoosa, (2012) and Nadra, (2009) argued that factors that obstruct progress in implementing Inclusive Education in Kuwait include: the absence of enabling policies, limited teachers training programs, lack of adequate resources, local teachers in most of the schools in Kuwait lack training in special needs education and lack of informative research on inclusive education. Mitchell (2006) on the other hand, believed that the main factors that hinder progress in implementing inclusive education in the Arab countries in general are the confusion over the meaning of inclusion and that inclusive education is a western idea that would not work in developing countries and does not necessarily suit every country's circumstances.

### **2.6.3 Conclusion**

Be it in the general classroom or the special educational environment autism spectrum disorders raise challenges for teacher and student alike. Simpson (2003), in his works on autism believed that changes in public policy and greater awareness of appropriate education of individuals with ASD, is driving educators and parents in the quest to discover the most effective way to educate these students. Disagreements

arise between researchers, practitioners and parents in relation to the criteria for the most beneficial setting, however, due to inclusive education concept and corresponding legislation, the education of students with ASD is the area most frequently contested (Ivanonne et al. 2003). The following section will review the works related to the roles parents play in advancing the rights of their autistic children to inclusive education.

## **2.7 Section Five: Parents Role as Advocates for the Rights of Autistic Children to Inclusion**

### **2.7.1 Introduction**

This section explores the role parents play as social actors with unique perspectives and insights into their own experiences in the decision-making processes concerning the inclusion of their autistic children.

### **2.7.2 A Brief History**

The early 1960s saw the growth of voluntary associations in the USA and the UK, such as the National Autistic Society. The abovementioned alliances were initially made up of parents who were subsequently joined by interested professionals. The associations' purpose was to promote research and to advocate for educational and treatment services for the autistic children. The years to follow saw the emergence of associations in other countries across the globe such as The World Autism Organisation (WAO) in Luxembourg and Autism-Europe (aisbl). These organisations were most vigorous in gaining publicity regarding the needs of autistic people through all media outlets (Bertelli et al, 2015). The 2012 World Health Organisation (WHO) report confirmed the status of parents of autistic children as key partners in the early intervention assessment and planning process, and subject to

assessment, may require counselling and support on how to address the needs of their child. The report stated that inclusion begins at home in the formative years and later extends to school and community settings. Families should be given the knowledge, skills and support to respond to, and advocate for the needs and rights of their autistic child in all settings. Close collaboration is required between service providers and families to create and carry out culturally appropriate interventions that meet autistic persons' needs. Information should be imparted in ways that educates parents and encourages constructive dialogue within the family and wider community (WHO, 2012).

In the West, the assessment of family needs is conventionally undertaken by psychologists, family therapists, and social workers (Kilpatrick and Holland 2008). The growing interest in such family assessment is reflected in the implementation of early intervention programs, public laws, health policy measures and research. The family's responsibility is to share information with professionals to determine service requirement whilst, on the other hand, the professionals' task is to solicit this information and be attentive at the time of presentation (Mandell and Novak, 2005). This two way communication would provide a learning experience for professionals to establish the efficacy of planned programming and is crucial to parental empowerment—that is, helping parents to help their children (Henderson and Mapp, 2002). The Individual with Disabilities Education Act of 2004 (IDEA) for example gives parents of children with disabilities the right to participate in the educational decision-making process. This legislation empowers parents of children with disabilities as it grants them the right to request services suited to their needs (Haren and Fiedler, 2008).

Parents have become the focus of clinical and research interest given the difficulties faced as primary care-givers (Reinhard, 2008). Current literature highlights parents' right to play an active role in deciding what should be done with their child. Itzhaky and Schwartz (2000) maintained that the role of parents in decision-making has grown both personally, in respect of their own child, and publicly in their efforts to advocate for the welfare of all disabled people. The problems encountered by parents and their demand for involvement emphasises the need to strengthen and empower this group. In recent years, social workers have increasingly sought to empower parents, by equipping them with the tools and furnishing them with the requisite skills to campaign for legislation, help fulfil their rights and develop much needed services (Green et al., 2007).

A parent's role in the education of a child with a disability is unique. In fact, Dunst and Dempsey (2007, p. 305) proposed that "the role of parents with a child with a disability shows a level of complexity and intensity not generally found in the general population". In light of the multifaceted nature of the role played by parents raising a child with a disability, educators should work to empower parents in these efforts (Green et al., 2007; Dunst and Dempsey, 2007). To define the construct of parental empowerment, it is essential to give consideration to the characteristics that make up this term. These multidisciplinary factors comprise playing an active role in the education and decision-making process; obtaining access to resources; effecting change in one's life and community; feeling part of a group and being respected (Murray et al., 2007; Summers et al., 2005; Dunst, 2002).

From the perspective of inclusive education, the involvement of the parents in their children's education is vital because parents know their children best of all. Parents need to be fully involved in decisions that affect their children. Parents' might

also have a role in developing legislative context of inclusive education (Tisdall and Riddell, 2006). Similarly, the UK Special Educational Needs and Disability Code of Practice (2015) emphasises the importance of the involvement of parents in the decision-making of their children's education. "Advocacy on behalf of children with disabilities starts early and is important from birth to age 6" (Wright and Taylor, 2012, pp. 1). The decisions taken by parents on behalf of their disabled children are particularly important when the children are in early years settings.

This section presented a review of literature on the parents' involvement in the planning of the implementation of Inclusive Education. One of the objectives of this study was to explore the role parents of young autistic children play in advocating for their autistic children's rights in inclusive education in the kindergarten stages. At all stages of school education parents' involvement in their children education is important. This is particularly the case at kindergarten levels because parents have unique knowledge of their autistic child's needs. Parents also have the right to be involved in decisions that identify and evaluate the development and educational placement of their disabled children (The Individuals with Disabilities Education Improvement Act (IDEA), 2004). One of the laws governing the education of students with disabilities in the USA specifies the right of parents to participate in the educational decision-making process (IDEA, 2004). This federal guarantee strengthens the role of parents in the education process of children with disabilities and emphasises the notion that the education of children with disabilities is made more effective when parents are involved in the decision-making process.

### **2.7.3 The Role Kuwaiti Parents Play as Advocates to Inclusive Education**

The important role played by parents in advocating for the right of their young autistic child to inclusive education has been evident as illustrated in this review of the literature. However, this is not the case in Kuwait where the voice of parents of children with autism is still missing (Kandari, 2001). Of particular concern in this study was the lack of literature on the role parents play in the decision making process of their autistic children in Kuwait. As far as the researcher knows, no study to date has examined the role of parents in advocating for their autistic children's rights to inclusive education in Kuwait. The question that then naturally arises is: Are Kuwaiti parents active advocates for their young autistic children's rights to inclusive education? To fill this literature gap, one of the objectives of this study was to identify the answer to this question.

## **CHAPTER THREE: METHODOLOGY**

### **Study Design and Methods**

#### **3.1 Purpose of Research**

The aim of this study was to explore parents' perspectives on early childhood inclusive education for children with autism spectrum disorder. This study was conducted within the State of Kuwait. The research question was explored through the administration of focus groups with parents of young autistic children. In addition, individual interviews with administrators and owners of kindergartens were administered to verify whether the policy of inclusive education for young autistic children has been implemented in Kuwait.

#### **3.2 Overview of the chapter organisation**

To fully comprehend the significance of this study it is essential to recognise the research paradigm, its underlying ontological and epistemological philosophical assumptions and how these suppositions illustrated the chosen methodology and methods in connection to the findings of the research question on Kuwaiti parents' perspectives on early childhood inclusion of their autistic children. This section presents the study's design, the rationale for adopting the qualitative research approach and the rationale for employing a qualitative case study method as well as the procedures used in conducting this study.

The research was conducted from within a subjectivist epistemology, a relativist ontological stance, whilst adopting a qualitative case study research design based on a qualitative research approach. The research involved a comprehensive

description of the case within its context as the researcher undertook a field a study to gather the information needed for this research. Bronfenbrenner's Bio-ecological Theory (1998) provided the theoretical framework for this study. A purposive sampling strategy was adopted and individual interviews and focus group discussions were conducted in Arabic and then translated to English followed by theoretical thematic analysis.

This section begins with the philosophical underpinning of the research paradigm, the rational for adopting constructivism paradigm and description of the paradigm components: ontology, epistemology, methodology. Followed by a discussion on the rational for adopting a qualitative approach and employing a case study strategy. The discussion then moves towards data collection strategies including design and administration of instruments (individual interviews, focus group discussions and documentary data) and the theoretical basis of the data collection methods. Lastly, the chapter addresses the sampling scope and context, strategies for analysing and synthesising the data, ethical considerations, trustworthiness, the finding and their interpretations and the limitations of the study.

### **3.3 The approaches to conducting research**

Research can be based on either quantitative or qualitative approaches, or on a combination of both. Creswell (2003), distinguished between these approaches by stating that the method to gathering information in the qualitative study focuses on describing a phenomenon in a comprehensive manner and is often used for to explore. The qualitative approach assists researchers to gain an understanding of the underlying of perspectives and reasons. Data is usually collected in the familiar settings of the research participants. The aforementioned data collection is normally

through the use of interviews, observation, diary studies or focus groups. Interviews can be structured and guided by open-ended questions, either semi-structured or unstructured. Generally, a small number of interviewees participate in this type of research, as the qualitative approach requires multiple resources and considerable time. Consequently, findings from qualitative research cannot be generalised to the whole population. However, such an approach provides a deep understanding of the phenomena and can serve to inform theories. Alternatively; the quantitative approach is used to both quantify the problem by examining the relationship between variables and to produce numerical data that can be converted into tangible statistics (Creswell, 2003 and Yilmaz, 2013). This approach relies on the methods of natural sciences. The quantitative study uses a large population sample and quantifiable data to formulate facts, therefore, the findings can be generalised. Data collection methods in quantitative research include structured surveys and questionnaires and systematic observations. The findings of the quantitative study can provide guidelines and substantial evidence for policy formulation (Almeida, 2006). The mixed methods approach on the other hand, involves comprises both quantitative and qualitative techniques of data collection. The advantage of combining both the qualitative and the quantitative approaches in the inquiry is that a more comprehensive understanding of the phenomena is achieved than would be gained from utilising a sole approach (Creswell, 2003).

The overall orientation of this study, the research design and the research question are all connected and these elements determined the appropriateness of employing a qualitative research approach over any other. The justification for adopting a qualitative research approach for this study and the constructivism

philosophical paradigm, including the ontological, epistemological philosophical assumptions and the methodology will now be explained in depth:

### **3.4 The underpinning philosophy**

A research philosophy is the conceptual root upon which the quest for knowledge is firmly based (Ponterotto, 2005). Ponterotto stated that incorporated within this philosophy are: the assumptions regarding ontology which relates to the nature of being and reality and its characteristics; and epistemology which relates to the study of knowledge and its attainment including the relationship between the study participants and the researcher and methodology which relates to the procedures of research. The underpinning philosophy of this study's assumptions of ontology, epistemology and methodology are discussed from the constructivism paradigm stand point of this research.

### **3.5 Research paradigms**

The term 'paradigm' has been defined by a number of researchers, including Bryman (2016) and Guba and Lincoln (1994) an indication of which is now given. Paradigm according to Bryman (2016, pp. 637) is a cluster of beliefs that influence the researchers choice of "what should be studied, how research should be done and how results should be interpreted". That is to say, that the ontological and epistemological stances and the choice of methods to conduct the study form a worldview that guides the researcher. Thus, the choice of paradigm influences the researcher's undertaking of the study in accordance with a set of rules, concepts and procedures.

Lincoln et al (2011) have provided the assumptions of a number of paradigms in social science research including: a) positivism, b) critical theory and c) constructivism:

a) Positivism paradigm: Bryman (2015, pp. 24) defined positivism as “an epistemological position that advocates the application of the methods of natural science to the study of social reality”. The positivist paradigm takes realism as its ontological position, supposing that reality exists and is determined by natural laws (Guba and Lincoln, 1994). For a positivist, reality exists in the world independent of the researcher and this reality is discovered by scientific methodologies whilst the researcher is detached from the objective reality (Gray, 2014). Positivism is regarded as a scientific method that generally considers only knowledge confirmed by the senses to be warranted as knowledge (Guba and Lincoln, 1994). The positivist researcher’s position is that the world is identifiable and it can be explored through quantitative methodologies.

b) Critical theory paradigm: The critical theory is “a realist epistemology that asserts that the study of the social world should be concerned with the identification of the structures that generate that world” (Bryman, 2015, pp. 25). That is to say that the critical theory paradigm tries to liberate people by changing their social and cultural settings and it considers the researcher to be a transformative intellectual who frees people from their social conditions (Guba and Lincoln, 1994). The researcher and the issue examined are interactively linked however, the values and beliefs of the researcher inevitably influence the inquiry of the study. Research in this paradigm advocates changes in social structures and aims at pragmatism. Moreover, it vouches for collective freedom and social transformation (Gray, 2014). Historical realism is the ontological position of the critical theorists who view reality as tangible and

historically placed in social structures (Guba and Lincoln, 1994). Reality is shaped by social, political and cultural values. Critical researchers implement dialogic and transformative methodologies. “The transactional nature of inquiry” involves the researchers and the subjects in logical dialogues to “transform ignorance and misapprehension” (Guba and Lincoln, 1994, pp.110). Critical researchers may employ qualitative, quantitative or mixed methods to structure their research with the purpose of critically examining the realities from the standpoint of political attitudes, cultural and historical perspectives to set out to change the situation being researched and improve the standard of practice in different contexts.

c) Constructivism paradigm: Honebein (1996) defined the constructivism paradigm as an approach that asserts that people construct their own understanding and form their knowledge of the world through their experiences. Constructivists hold that reality is constructed in the mind of the individual, rather than it being an outward object (Hansen, 2004). The constructivist position maintains that meaning is hidden and must be brought to the surface through deep reflection which can be encouraged by a shared dialogue between the researcher and the participants in the study (Ponterotto, 2005). Accordingly, a unique characteristic of the constructivism paradigm is the importance of the communication between the researcher and the research participants because through this communication more profound meanings can be uncovered. The expressions constructivism and interpretivism appear together or interchangeably in the vocabulary of social science methodologists. That is to say that interpretivism and constructivism are correlated approaches to research that are characteristic of a particular philosophical world view that directs researchers towards a specific perspective.

### **3.6 Rational for adopting a constructivism paradigm**

Based on the constructivism paradigm, this study examines parental perspectives on early childhood inclusive education for children with autism. Several parents with young children on the spectrum were interviewed to gather their viewpoints and experiences regarding the inclusion of their autistic children. The parents' perspectives as reflected in the study were appreciated as being objective and as a valid reality, the constructivism paradigm stance being that one cannot separate reality from those who are experiencing that reality. For Guba and Lincoln (1994) the constructivist approach meant that the social world and its categories are not external to us, but are established in and through interaction. The aim of this research was to explore the impact of social and cultural factors on the concept of early childhood inclusive education for autistic children from the perspective of the parents' lived experiences. Having a constructivist approach, the study adopted the stance of multiple realities by interviewing several parents of young autistic children to conduct a qualitative research in order to report these realities from the viewpoints of the parents themselves. As stated earlier, a paradigm contains ontology, epistemology, methodology and methods. Each component is explained, and then their implications on this research are discussed:

### **3.6.1 Ontology**

The ontological assumption of the constructivism paradigm of philosophy is relativist (Creswell, 2013). According to Guba (1993) and Creswell (2013) ontology concerns the nature of reality and being. Similarly, Bryman (2015, pp. 28) defines ontology as "concerned with the nature of social entities". Ontology is about the nature of reality, how things are and how they work. Thus, ontological assumption for constructivists is about how one understands the social world. Crotty (1998, pp. 64) also defined ontology as a study of what is being and what the nature of existence is

and stated that relativism is “what is said to be ‘the way things are is really just the sense we make out of them”.

In other words ontology provides a certain way of understanding the world and the structure of reality. This study, being based on a relativist ontological assumption, embraced the idea of multiple realities and explored several forms of evidence of the perspectives and experiences of a number of parents of autistic children regarding the concept of early childhood inclusive education in Kuwait. The variances in parental perspectives were due to: the nature of the parents’ experiences of the inclusion of their autistic children; the parents’ understanding of the concept of inclusion; and the impact of the cultural and social lived realities. Therefore, the interpretations of the parents’ perspectives on early childhood inclusion for children with autism and the patterns that emerged through the individual and focus group interviews, were reported on the basis of the ontological assumption of the constructivism paradigm adopted in this study.

### **3.6.2 Epistemology**

The epistemology of the constructivism paradigm is subjectivist (Guba and Lincoln, 1994). Creswell (2013) described the epistemological assumption of constructivism as how do researchers know what they know. That is to say that knowledge is the clear and coherent information acquired through the process of reason applied to reality. Epistemology is about questions having to do with the conception of knowledge in specific areas of inquiry (Carswell, 2012). “Truth, or, meaning, comes into existence in and out of our engagement with the realities in our world” and that meaning is “not discovered but constructed” (Crotty, 1998, pp. 8). Furthermore, the researcher and the participants of the study are supposed to be linked

so that the outcomes are literally created. Therefore, in correspondence with the above definitions of the subjectivist epistemology of the constructivism paradigm, firstly, the researcher conducted the research in Kuwait. Secondly, the researcher worked also on developing a close relationship with the parents who participated in the interviews in order to grasp the meanings ascribed by the parents themselves to the concept of inclusion of young children with autism. Thirdly, the communication with parents lead to several perspectives and meanings of the inclusion of young children with autism. These findings were interpreted and presented from a subjectivist stance.

### **3.6.3 Methodology**

Research methodology refers to the process and procedures which the researcher uses in order to solve the research problem (Creswell, 2007). That is, the strategy lying behind the choice of using particular method. Research methodology has been defined by a number of writers. For example, Bryman (2015) said that methodology is the design of the research and the specific research methods used are determined by the methodological orientation of the study. Similarly, Creswell (2007) argued that methodology is a comprehensive approach to the study, identifying how research questions should be answered. That is to say that, the research methodology informs the researcher which method has to be used out of the various existing methods and the justification for the type of data collected as well as the rationale for employing a particular technique of analysis of data used. Research methodology is informed by the philosophical stance and the theoretical perspective of the study (Crotty (1998), thus, grounding the logic behind the choice of certain method out of the other various existing methods to answer the research question.

The orientation of the methodology of this study was grounded on the constructivism paradigm and the philosophical assumption of this paradigm. The connections between the assumptions of this study about reality, determined the process of finding the answers to the issue that warranted this research. Therefore, it can be said that methodology have several dimensions and its scope is wider than that of research methods because research methodology includes the many steps that are adopted in the study along with the logic behind these procedures and research methods are only a part of the research methodology. In order to explore the multiple constructs of evidence from several parents' perspectives and the cultural logic behind these perspectives on the inclusion of autistic children, the research was conducted in the social context of the study participants.

### **3.7 The qualitative research**

The constructivist philosophical paradigm provided the primary foundation for the qualitative approach for this study. Qualitative Research is primarily an exploratory research (Carswel, 2003). Researchers conduct qualitative studies to gain an understanding of and insights into the underlying reasons and opinions of a phenomena (Denzin and Lincoln, 2005). Qualitative research is also a type of research investigation that examines a contemporary phenomenon (Yin, 2009). Furthermore, Denzin and Lincoln (2000, pp. 8) noted that: "Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry". Similarly, according to Denzin and Lincoln (2003) the goal of the qualitative researcher is to understand the meaning of a social phenomenon from the experiences of the participants in the research participants' social and cultural settings. The above mentioned authors' definitions illustrated the main characteristics of the qualitative

research highlighting that qualitative studies emphasises on the qualities of the issue under study and on processes and meanings that are not experimentally measured in terms of quantity. In accordance with the above mentioned definitions and explanations of the qualitative study, this study was conducted in line with these detentions, namely; the study was conducted from within constructivism paradigm, it is an exploratory study; the study was undertaken in the cultural context of the participants; the research concerned a new phenomenon in Kuwait, i.e., inclusion of autistic children; and the goal of the study was to explore the cultural impact on parental perspectives.

Qualitative research, however, has been subject to criticism in respect of the issues of the lack of: a) generalisability, b) subjectivity, c) failure to adhere to principles of credibility and reliability and d) biases in data collection procedures such as focus group interviews (Yin, 2009; Holliday, 2007).

a) Regarding generalisability, according to several researchers including, Choy (2014); Yilmaz (2013); and Holliday (2007) the quantitative study uses a large population sample and quantifiable data to formulate facts, therefore, the findings can be generalised. The qualitative methods, on the other hand, tend to generate large amounts of detailed information about a small number of settings. Consequently, it is impossible "to imagine that all human activity is completely determined by one universal set of relationships" (Guba and Lincoln 1989, pp.94). (See 3.3) for a comparison between quantitative and qualitative approaches. The researcher recognises that a study of a relatively small size does not yield information that could be generalised beyond the scope of this study. The researcher also recognises that the relevant reality of the study participants' experiences took place in their subjective experiences and within their social context, hence, it is difficult to generalise the

findings to the larger population. Therefore, the researcher identified throughout the study that the study findings are of non-representative nature in relation to the broader population. The significance and value of this study stems not from its being an attempt to produce numbers and generalisable outcomes to all populations, but from its being an attempt to bridge the knowledge gap in the field of early childhood inclusive education for autistic children in Kuwait.

b) On the subject of subjectivity, qualitative methodology recognises that the subjectivity of the researcher is intimately involved in academic research. A number of authors including; Cohen et al., (2007); and Holliday, (2007) suggested that the subjective nature of qualitative research may make it difficult for the researcher to be detached completely from the data to maintain objectivity. Therefore, it is important for the qualitative researcher to acknowledge that subjectivity is an invariable element of their study than it is for them to assert that their ideal is to achieve objectivity (Holliday, 2007). The philosophical stance of this study; the researcher's concern with the interpretation of the subjective opinions of the participants; and the researcher's positionality (see 3.14), are factors that might lead to the researcher's subjectivity being called into question. This is usually tied to a broader critique of qualitative research methods as a whole because these approaches are less formalised than the quantitative method (Verschuren, 2003). Therefore, it is important that qualitative researchers explicitly-acknowledge interpretive basis for meanings, reasons, and understandings. However, there are, several researcher such as Flyvbjerg (2006, p. 237) who suggest that the case study contains no greater bias on verification than other methods of inquiry, and that "on the contrary, experience indicates that the case study contains a greater bias toward falsification of preconceived notions than toward verification". In this study the researcher acknowledges her subjectivity and that this

is an unavoidably, given that she has both an insider and an outsider status (see 3.14). In fact, for the researcher, recognising her subjectivity enabled her objective comprehension in the sense that she became more conscious of her own views towards the inclusion of autistic children and consequently approached the mothers interviewed from a standpoint of genuinely wanting to learn about their unique experiences. Furthermore, recognising her subjectivity enabled the researcher to gain the trust of the research participants; made having access and establishing rapport relatively easy; and helped her to reach a balance between building the rapport and trust with the mothers interviewed whilst maintaining the appropriate distance as a researcher. As researchers, we are ethically bound to acknowledge our prejudices, preferences, and points of viewing. In qualitative approaches acknowledging subjectivity would not necessarily be a weakness (Crotty, 2003) and it aligns well with the epistemological and ontological underpinnings of this study.

Throughout the process of collecting the information from the study participants and interpreting the findings the researcher was extremely cautious about her own beliefs and perspectives. The researcher's stance as an advocate for the inclusion of autistic children and her strong belief in social justice for these children gave rise to inner concerns regarding her opinions and the participants' opinions. To manage any conflict between the researcher's opinions and those of the participants, the research kept a personal study journal for her subjective and reflexive feelings which she used during and after the interviews. A number of authors including Bryman (2016), Yin (2009), Holliday (2007) Stake (2005) and Lincoln and Guba (1985) argued that it is not possible to eliminate bias but a reflexive process ensured transparency. The researcher documented the procedures for checking the data throughout the research and used the reflexivity technique by keeping a journal to

document any accounts of her individual subjectivity, opinions and biases towards parents' perspectives. Prior to every interview and interpretation of the findings. The researcher wrote notes serving as reminders that her research is an explorative case study that entails providing an impartial interpretation of the participants' perspectives. This technique assisted in committing the researcher's feelings and thoughts to paper rather than verbalising them during the interviews or imposing them on the final descriptive report.

c) In terms of adherence to principles of credibility and trustworthiness these elements have been detailed throughout sections (3.25 to 3.25.5).

d) Regarding ethical implications relating to the methods employed in this study, the researcher is aware of the ethical issues that might be derived from her interactions with study participants in both focus group and individual interviews. This awareness meant that consideration was given to ethical issues throughout all stages of this study to maintain the balance between the potential risks of the methods employed and the likely benefits of the research. Although the Ethical Review Board of the University of Lincoln scrutinised the research proposals, and the study was in adherence to the University of Lincoln ethics policy (2004) and the British Educational Research Association (BERA) (2004) guidelines, the researcher recognises that she is ultimately responsible for protecting her study participants. According to Sanjari et al (2014) qualitative researchers face ethical challenges in all stages of the study. These challenges include anonymity, confidentiality, informed consent, and researchers' impact on the participants. To provide a trustworthy outcomes, the researcher employed the following procedures including the ethical principles of anonymity, confidentiality, informed consent, risk of harm, and the researcher's potential impact on the participants:

a) during recruitment, the researcher clearly explained the project to potential study participants. For recruitment procedures and the relationship between the researcher and the participants see section (3.22)

b) the researcher prepared an information sheet (Appendix 4) and translated it into Arabic. The information sheet was handed out to each parent and the researcher went through all the items on the form prior to the interview. Parents were encouraged to ask questions on any issue unclear to them. The main aim of providing an information sheet to each participant before any interview session commenced was to ensure that all parents clearly understood: the research purpose; the nature of the research; the importance of the parents' participation in the study; how the study would be used; to whom the study would be reported; that parents' viewpoints would not be used for any purpose other than the study itself; that the parents' participation in the interviews was completely voluntary; that parents had the right to withdraw from the interviews or to refuse to answer any questions with which they were uncomfortable. For further details see (sections: 3.19.2 and 3.20).

c) the researcher assured the mothers interviewed that their names were anonymised and remained confidential; that all the information collected was secured in the researcher's computer to protect the parents' confidentiality. The procedures the researcher used to maintain anonymity and confidentiality included the identification details from the interviews being changed in the transcribing process and kept in a separate location. In Kuwaiti culture the mother and the father have nicknames. "Um" means "Mother or Mum," and "Abu" means "Father or Dad." So, the researcher used this Kuwaiti custom when quoting what the mothers said. The researcher also changed the names of the children and instead used a nickname. For example, if the mother was called "Um Abdallah," it would be changed to "Um Abadi."

d) The researcher gave an overview of the questions she would be asking and informed the participants that if at any point during the discussion an issue brought up unpleasant memories the discussion would be stopped. “Stopping the interview and searching for possible solutions for the participants’ distress” (Orb, et al, 2000, p.93) indicates that the researcher is aware of the participants rights. In such a situation the researcher is to refer the participant to counselling or ensure that they have regained control of the situation by talking. The researcher ensured that no participating parent was placed in a situation in which they might be harmed physically or psychologically as a result of their participation in the interviews. The researcher was mindful of the cultural sensitivity of the parents and their values as well as of the researcher’s own values and culture.

e) the researcher ensured that the participants were fully aware of what was involved so that they could give informed consent. Prior to each interview, whether focus group or individual interview, the researcher obtained informed consent from each participant to ensure that the interviewees understood what it meant to participate in this study so they could appropriately decide whether they wished to participate. The researcher took the proper steps to adhere to the ethical guidelines in order to uphold the participants’ anonymity, confidentiality and rights and to achieve the reliability of the data collected and of the data analysis. In accordance with the ethics principles, the researcher distributed a consent form (Appendix 5) to each parent, translated into Arabic, to obtain their informed consent in writing. For additional information on the above stated issues see sections (3.20, 3.19.2 and 3.22).

Beyond the issues discussed above, the issue of the role of the researcher as a data collection instrument also presents unique ethical considerations in qualitative research (Lincoln and Cannella, 2007). The researcher recognises her role as a data

collection instrument given her role as a partner and co-producer of the knowledge. This role entails having a responsibility to interpret the data and present evidence in a manner that is true to the participants' experiences and ultimately, the credibility of the research. The researcher considered all the data obtained and analysed it with a clear and unbiased mind. The impressions and responses were continually re-evaluated, and the researcher ensured that any personal pre-existing assumptions were documented in a separate personal study journal. In addition, the researcher described the methods of data collection, and described the way in which the data was integrated to arrive at the results of the study. The strength of this consistent method of data collection is that it affords the opportunity to triangulate the data through member checking and ultimately acts as a safeguard against researcher bias.

In terms of power relation, the constructivism paradigm “proposes to reduce power differences and encourages disclosure and authenticity between researchers and participants” (Orit et al, 2009, p. 279). Creswell (1998) and Gergen and Gergen, (2000) argued that the case study approach responds to this call based on its epistemological grounds and consequently minimises the distance and separateness of researcher–participant relationships. Therefore, the researcher recognises that this study is a researcher–participant coproduction of knowledge acquired in the study and that they had both a co-producer role as well as a role in discussing outcomes. That is to say whilst the mothers interviewed contributed their perspectives, the researcher contributed her understanding and interpretation of these perspectives. The researcher is aware that the primary ethical consideration is for the participants and their welfare, and then to present the study report in a trustworthy manner, which can be achieved only through non-judgmental interpretations and writing. For further discussion regarding the researcher-participant relationship (see 3.14 and 3.20; and 3.22)

Furthermore, Creswell (2007); Trimble and Fisher, (2006); and Haverkamp, (2005) noted a number of factors that present ethical challenges for the qualitative research methods. These authors argued that vigilant ethical practice is more a function of the researcher's own self-awareness and multicultural competence, than it is a function of design characteristics (see the section on insider subjectivity and outsider status). Haverkamp also emphasised that the overriding ethical mandate of the researcher is competence. This researcher's competence is discussed under (section 3.14: the researcher's positionality). Fendler (2016) noted other ethical issues facing qualitative researchers in relation to data handling. These issues include stereotyping, dehumanisation and determinism. However, according to Fendler, these issues can be avoided in qualitative researches by the credibility and trustworthiness of the study (see section: 3.25- 25.5). It should be stressed that given that this study is a holistic, exploratory single case study, stereotyping, generalising and determinism are not applicable to either the research question or to the philosophical stance of the study. Furthermore, Creswell (2007); Trimble and Fisher, (2006); and Haverkamp, (2005) noted a number of factors that present ethical challenges for the qualitative research methods. These authors argued that vigilant ethical practice is more a function of the researcher's own self-awareness and multicultural competence, than it is a function of design characteristics (see the section on subjectivity insider and an outsider status). The purpose of this study, however, was to produce findings true to the participants' experiences and subsequently, the credibility of the research. The process of data collection was not an end in itself. The challenge was to make sense of substantial amounts of information, identify significant themes and construct a framework for presenting the essence of what the data revealed.

### **3.8 Rationale for a qualitative approach**

There is consistent evidence that inclusive educational settings can confer substantial benefits for autistic students (UNESCO, 2009; UNICEF, 2003). Inclusive education policies have featured in international declarations, national laws, and education policies but have not formed part of Kuwaiti educational policies. Kuwait, although being a signatory to UN agreements on the inclusive education of students with disabilities, maintains a segregated approach to education for disabled students (Hadidi and Al Khateeb, 2016; WHO, 2011).

In addition, Kuwait is an oil rich country, with the financial resources to implement inclusive education without placing a burden on its economy. All of these issues roused the researcher's interest in exploring, through parental perspectives, whether the Kuwaiti culture was one of the factors hindering the implementation of inclusive education for autistic children. For a number of reasons, such as the researcher not knowing what the parental perspectives would be on the inclusion of autistic children or whether culture played a significant role in impeding the implementation of inclusive education, to conduct this study the researcher used an exploratory qualitative approach. The researcher having no prior indication of such issues is due to the lack of studies in Kuwait in this field. Furthermore, the researcher had to rely on the study participants' perspectives towards the inclusion of autistic children. Consequently, the researcher needed to interact with the participants in their context to understand the Kuwaiti cultural setting and societal norms to explore whether cultural norms had an impact on the inclusion of autistic children.

With regard to the rationale for employing a qualitative approach, the choice of this method was directed by the research question. In order to understand and

develop comprehensive answers to the research questions the researcher needed to conduct her study from within the cultural context of the participants. The qualitative approach also facilitates the induction of rich data and offers opportunities for exploring all possible social and cultural variables that might have influenced parents' viewpoints through individual interviews and focus group discussions. These tools led to a more informed exploration and enabled this researcher to build a holistic picture of the research participants' viewpoints, to explore the multiple meanings parents attributed to the concept of inclusive education, and the impact of cultural norms on the implementation of inclusive education for autistic children.

The contextual conditions surrounding the concept of inclusive education as portrayed by the parents' perspectives produced a wide range of issues which came from multiple sources of evidence. Each research participant had their own perspective on the inclusion of young children with autism and the focus of this researcher was on the identification of contextualised meaning of these multiple perspectives with the goal of generating a combined reconstruction from the multiple realities that were presented. These multiple perspectives in turn provided the opportunity for this researcher to develop a deep holistic understanding of the concerns surrounding the concept of inclusive education of young autistic children in Kuwait from the parents' viewpoints and to identify the many factors that formed and reinforced the parents' perspectives.

By adopting a qualitative approach; namely; a qualitative case study approach, the researcher was able to focus on the role of the social contextual issues that shaped the research participants' perspectives.

### **3.9 Rationale for employing a qualitative case study method**

Qualitative approaches are all broadly consistent with the emphasis of qualitative research on understanding meanings and interpretations. Research methodology is informed by the philosophical position of the study, consequently, grounding the logic behind the choice of one method out of the other methods to answer the research question (Creswell, 2007). One of the key factors in conducting research is the selection of the methodology and methods appropriate for the type of research question that is posed (Creswell, 2013; Flick, 2002). A general categorisation separates qualitative methods and research design into five groups: ethnography; narrative; grounded theory; phenomenology; and case study. (Creswell, 2007). However, each method has a distinctive emphasis (Denzin and Lincoln, 2005). The three most common qualitative methods of inquiry, are participant observation, interviews, and focus groups. Each method is particularly suited for obtaining a specific type of data and each approach will be more useful in some research projects and less relevant to others. The approach employed in this study was the case study approach and the data collection methods used were focus groups and interviews (3.19). This study is an exploratory case study. Although case study and other methods of qualitative inquiries may have some similarities, there are, however, some principal differences between the case study, the ethnographical approach, the grounded theory and the narrative method. The difference between the case study and the other qualitative approaches lies in their intent, focus and data collection strategies. Some of the more prominent methods of conducting a qualitative research and the rationale for choosing a case study method over the other methods is described here:

- 1) Ethnography

Ethnography has its roots in cultural anthropology where researchers immerse themselves within a particular culture for a considerable amount of time (Hammersley, 2006; Denzin, 2003). According to (Zaharlick, 1992, pp.119) “A year is ordinarily considered a minimum, because a year usually allows people to go through their regular routine, patterns of work and play and special activities”. The researcher is immersed in living life just like the people being studied and observing intently to note down nuanced descriptions of the context under study (Luders, 2004; Flick, 2002). Participant observation and interviews are two of the main data collection methods in this these types of studies, however, ethnographic research mainly involves field observations (Zaharlick, 1992). In addition, there is a debate regarding whether ethnographic research should be restricted to observational data collected in naturally occurring settings, ruling out the use of interviews completely (Hammersley, 2006). An ethnographic analysis draws on a range of data including fieldwork experience notes, interview transcripts and documents, to define issues, and group behaviours that have developed in the setting over time. Whilst the ethnographic design incorporates extended periods of observation by the researcher (Creswell, 2013; Flick, 2002), time constraints and the costs likely to be incurred for a lengthy stay in Kuwait meant that ethnographic design was not suitable and so the researcher opted for a case study design. Furthermore, given that the aim of this research was not to study the Kuwaiti culture as a whole but the impact that Kuwaiti culture might have on the inclusive education program, the researcher deemed the case study approach to be more appropriate for the purposes of the study. In the opinion of Creswell (2007) “to study cultural behaviour, language, or artefacts, then the study of a system might be undertaken as an ethnography” whilst “a smaller "bounded" system, such as an event, a program, or an activity, may be studied as a

case study (p.30). Yin, (2003) stated that case study is a research design that focuses on a bounded case rather than a population sample. While ethnography observes cultural phenomenon, this case study was bound by the geographical location, the ages of the autistic children, the type of disability, the parents' nationality, time and the three layers of Bronfenbrenner's Bio-Ecological System Theory in its design. That is to say that the case study approach for this research has as its central purpose to study a bounded system, to provide an in-depth understanding of the case under study. In addition, in the ethnographic approach the researcher needs to live in a specific community for an extended period of time. Ethnographic research involves a detailed description of the whole of a culture using a cultural lens for the study of people's lives within their communities (Hammersley and Atkinson, 2007). In this case study approach the researcher used a cultural lens in an attempt to explore, through parental perspectives, whether the cultural aspect had an impact on the inclusion of autistic children. This case study is about an exploration of a single case in order to unearth the complex issue of the cultural traditions (Creswell, 2007). An ethnography on the other hand is a detailed and systematic study of people and cultures. In this case study research, the researcher focused on exploring, from the parental perspective, whether Kuwaiti cultural tradition had an impact on the implementation of inclusive education of autistic children. An ethnographic study results in rich cultural description as it involves extensive fieldwork that may be pursued in a variety of social settings that allow for direct observation of the activities of the group being studied. According to Sanjari et al, (2014 p. 3) "ethnographic investigators need to be immersed in the culture and to live among the study population". In comparison with the case study approach "ethnography has singular characteristics. When a researcher aims to study the culture of certain people, living amongst them is inevitable. (Sanjari et al, 2014, p.4).

This case study on the other hand, aimed to provide an in depth description of the factors that shaped parental opinions towards the inclusion of autistic children. The brief trip that the researcher took to Kuwait was not for observation purposes. The reason for the trip was that the researcher takes the view that that the lack of discussion between the study participants cannot be captured via telephone and this would result in loss of contextual data. There are also differences between case study and ethnography methods in terms of data collection. According to (Hammersley, 2006) exclusive reliance on interview data cannot be ethnographic, even if the interviews are relatively open-ended ones. (Luders, 2004; Flick, 2002) affirm that interview is an additional technique the ethnographer may utilise to provide a comprehensive representation of the participant's perspectives. In this study, to present the findings, the researcher relied exclusively on data gathered from focus group and individual interviews. Whereas ethnographic studies aim to describe the nature of the phenomena through detailed investigations of individual cases (Creswell, 2007), in this case study the researcher sought to uncover the tacit knowledge of the culture of the participants that might have influenced their perspectives towards the inclusion of autistic children.

## 2) Narrative methodology

The central purpose of the narrative methodology is to study the experience of one or a number of people and weave together a sequence of events to form a cohesive story (Creswell, 2007). A narrative inquiry draws on a range of data, including conversation and interview transcripts, field notes, documents and photographs. Often this method is longitudinal but the final narrative does not need to be in chronological order. The final report can be presented as a story with themes (Andrews, et al., 2013). The researcher chose the case study method over the narrative method because in the

narrative research method, the researcher focuses on the stories told by one person or more. In this case study research, on the other hand, the researcher selected to illustrate a current phenomena through parental perspectives rather than to focus on the lives of the participants as told through their own stories.

### 3) Grounded theory

The central purpose of this research methodology is to develop a theory grounded in the data gathered from the experiences of the participants. Data is usually gathered from a variety of sources, including interviews and field observations. Once the data is gathered, the researchers analyse the information using three major strategies of data coding, memo writing, and theoretical sampling procedures. A set of interpretative procedures are then used to assist in the construction of a theory that emerges from, and is grounded in, the data (Creswell, 2013; Hancock, 1998). According to Charmaz (2001) and Strauss (1987), grounded theory is introduced as an inductive, comparative methodology that provides systematic guidelines for gathering, synthesising, analysing, and conceptualising qualitative data for the purpose of theory construction. With regard to the difference between the case study and the grounded theory method, both the case study and the grounded theory methods use interviews to collect information. However, the purpose of gathering data differs in each method. In the grounded theory design the aim is to generate a theory grounded in data from the field (Creswell, 2013; Hancock, 1998). Alternatively, in this exploratory case study the purpose for collecting data was to provide an in-depth picture of the case under study and not to conceptualise a theory or to discover a research question for testing.

#### 4) Phenomenology

The focus of this approach is “to understand the essence of the experience [and] to describe the essence of a lived phenomenon” (Creswell 2007, p. 78). Thus, phenomenology provides information about unique individual experiences, offering a rich and complete description of human experiences and meaning. A phenomenological analysis draws primarily on interview data. According to Moustakas, 1994, the interviews in this approach attempt to answer broad questions: What have you experienced in terms of the phenomenon? Thus, phenomenology provides information about individual experiences, offering a rich and complete description of human experiences and meanings. A researcher applying phenomenology is concerned with the lived experiences of the people involved, or who were involved, with the issue that is being researched (Greene, 1997; Holloway, 1997). In this case study the researcher did not know whether inclusive education for autistic children was implemented due to the lack of research in this field in Kuwait. Therefore, the researcher focused on developing an in-depth description of a cause and effect that is grounded in an interactive relationship between the participants and their context to explore the case.

#### 5) Case study

A case study is an empirical inquiry that “Investigates a contemporary phenomenon within its real life context, especially when the boundaries between phenomenon and context are not clearly evident” (Yin; 1994, p.13). A case study is an in-depth study of a particular research problem. It is often used to narrow down a broad field of research into one or a few easily researchable examples especially when not much is known about a phenomenon (Creswell, 2007). This method of research produces

descriptive data that the researchers must then interpret using rigorous methods of transcribing, coding, and analysis of themes to report their findings.

In addition to the rationale for employing a case study method as stated above, the use of the case study was an appropriate choice given that, to the best of the researcher's knowledge, literature investigating the cultural influence on the inclusion of autistic children in Kuwait, does not exist. Consequently, the lack of studies that help predict an outcome or that establish a clear understanding about how best to proceed in addressing the research question made an exploratory case study an appropriate approach (Seawright and Gerring, 2008). Furthermore, the researcher wanted to gain concrete, contextual, in-depth knowledge about the impact of the culture on shaping parental perspectives, the exploratory case study method allowed the researcher to explore the key characteristics, meanings, and cultural implications of the inclusion for autistic children. The case study method enabled the researcher to present a platform to produce considerable insights into the cultural impact on the inclusion for young autistic children in Kuwait. The employment of a case study approach kept the project focused and manageable especially that the researcher did not have the resources to undertake large-scale research. The importance of this study, as stated in its contribution section, is that it reveals new directions for future research since the study expressly focused on a neglected aspect of the inclusion of autistic children in Kuwait. The case in this study provides an important insight into the barriers to the inclusion of autistic children by drawing attention to an issue ignored by previous studies. Therefore, the researcher maintains that this study is an exploratory case study and the researcher favoured this approach over the rest of the qualitative methods to answer the research question.

However, the limitations of the case study approach is usually tied to a broader critique of qualitative research methods as a whole (Yin (2009), such as criticism of generalizability, subjectivity, and trustworthiness. The issues are discussed in this thesis under section (3.7).

### **Conclusion:**

In the case study approach, the researcher undertakes an investigation into a phenomenon in its context in order to better understand the phenomenon (Yen, 1994). In this study, the researcher selected a case study design. The factors that determined this to be the most appropriate approach were: the study question, the study philosophical stance, the degree of focus on contemporary as opposed to historical events, the accessibility of the cultural context and the researcher's familiarity with the case study approach gained in her previous studies and work experience. Evidently the philosophical perspective of the study and the guiding questions are important, however the methods employed for answering the research question are similarly significant (Creswell, 2007).

According to Yin (2003) "You would use the case study method because you deliberately wanted to cover contextual conditions-believing that they might be highly pertinent to your phenomenon of study" (p. 13). Therefore a qualitative case study method was essential in order to explore whether culture had an impact on the implementation of inclusive education. Yin emphasised the case under study to be a contemporary phenomenon in nature. A number of researchers including Alkhateeb, et al. (2016); Mittler (2014); and Brown (2006) argued that inclusive education is a new phenomenon in Kuwait. The researcher conducted both focus group and individual interviews to ensure that the case study is not explored through one lens

(Yin, 2009), thus, allowing for multi-faceted perspectives to be revealed and understood.

Merriam (2009, pp. 40) defined case study as “an in depth description and analysis of a bounded system. The implications of Merriam’s definitions of the qualitative case study are aligned with this study. The case in this study, was bounded by its focus on autism; its location, i.e. Kuwait; the segment, i.e. the parents and the scholastic age; i.e. kindergarten. The multiple perspectives on early childhood inclusion for children with autism in Kuwait ascertained from the interviewees were shaped by the context and the information disclosed provided the researcher with a profound understanding of the case and facilitated the gathering of comprehensive data. The analysis and interpretation of the data gathered were subsequently reported in a descriptive format.

According to Lincoln and Guba (1985, pp. 37) qualitative research produces “multiple constructed realities that can be studied holistically”. Each research participant had their own perspective on the inclusion of autistic children which assisted the researcher in the identification of contextualised meaning of these multiple perspectives with the goal of generating a combined reconstruction from the multiple realities that were presented. These multiple perspectives in turn provided the chance for this researcher to develop a deep holistic understanding of the concerns surrounding the concept of inclusive education of young autistic children in Kuwait from the parents’ viewpoints and to identify the key factors that formed and embedded the parents’ perspectives.

However, case study has been devalued by comparisons with quantitative approaches (Creswell, 2013 and Holliday, 2007). Case study method has been criticised for its inability to generalise its findings, the scepticism towards the grounds

for establishing validity and credibility, the research workings lack of rigour, and the uncertainty surrounding the researcher's bias in interpreting the data (yin, 2009 and Holiday, 2007). In response to this criticism, writers such as Holliday (2007) argued that case study is not a comparative approach to quantitative research. The aim of the case study is not to produce numbers and generalisable outcomes to all populations and the comparisons between qualitative case study and quantitative study fails to recognise the case study's inherent significance and value. Authors such as Creswell (2013), Holliday (2007) and Yin (2003, 2006) claimed that qualitative research methods are increasing in use in a wide range of academic areas and researchers continue to deploy the case study method particularly in studies of real-life situations governing social issues. Holiday (2007) argued that to understand human affairs it is insufficient to rely on quantitative survey and numbers, it is necessary instead to delve deep into the subjective qualities that govern behaviour. So despite criticism, case studies from various disciplines are widely reported in the literature. However, authors such as Yin, Creswell and Holliday stressed that in order to make a valued contribution to the field of qualitative case study inquiry, researchers are required to demonstrate rigour through adequate descriptions of methodological foundations and issues regarding the credibility of the study must be considered. Therefore, this qualitative case study research was conducted within a theoretical framework, namely; Bronfenbrenner's Ecological System Theory (1998) to add precision to the interpretations of the research findings and from within the constructivist theoretical perspective to avoid validity and reliability challenges. The researcher followed Yin's (2009) approach to case study by developing clear case study procedures with careful consideration of validity and potential bias and ensured that all elements of the case were adequately described. For further details on this issue see (3.7; and 3.22).

### **3.10 Holistic single case study design**

In describing the types of case studies Yin (2003) noted three distinct types. Firstly, the exploratory case study, in which the researcher conducts a study to explore a case by asking general questions to introduce the case for further examination. Secondly, the explanatory case study in which the researcher undertakes the study to scrutinise the data carefully with the intention of forming a theory and sets out to test this theory. Lastly, the descriptive case study where the researcher sets out to describe the case and to describe the facts as they happened. The descriptive case study is the option selected for the present study in order to examine the depth and scope of parental perspectives on early childhood inclusive education for children with autism in Kuwait and to describe the data as it was obtained.

Yin (2003) also identified the designs of the case study. Namely, the embedded case study: a case study comprising more than one sub-unit of analysis; the multiple case study design used when the study contains more than a single case; and the holistic single case design, which is the design employed in this research. The descriptive holistic case design of this study focused on the inclusive education movement which is a contemporary phenomenon. The study relied on multiple sources of evidence while taking into consideration the real-life context of the participants. The researcher interviewed several parents to find out their viewpoints on the inclusion of young children with autism in their natural setting. The multiple sources of evidence obtained from the interview provided a deeper understanding of the issue and enabled the researcher to gather ample data. Furthermore, through individual interviews, focus group discussion and triangulation, the study affirmed the validity of the research (Yin, 2003). Due to the employment of the holistic single case design, detailed qualitative accounts were drawn from the interviews with the parents

which not only provided an accurate reflection of the parents' perspectives towards the inclusion of autistic children, but also assisted in expressing the complexities of the cultural and societal real-life situations of these parents and their young autistic children.

### **3. 11 Theoretical Perspective: Constructivism**

The constructivism theoretical perspective informed the methodology, the method and the research design of this study. Completion of this study was in line with the worldview embodied in the constructivism theoretical perspective. Following the constructivism paradigm of this study, i.e., the "basic set of beliefs that guide action" (Guba, 1990, pp.17) the researcher carried out the study in the natural settings of the research participants, because the perceptions of the research participants are shaped by the interactions with their society and culture (Denzin and Lincoln, 2000). This study sought to understand parents' perspectives on early childhood inclusive education of children with autism through the variety of constructions that parents had within their social setting. Through a constructivist lens, parents' perspectives were considered as being shaped by their context. Furthermore, from the subjectivist epistemology, i.e., that people build meanings about their reality through meaningful interaction with others including the researcher (Guba and Lincoln, 1985) and the relativist ontology, i.e., that there are socially constructed multiple realities (Guba and Lincoln, 1985) the researcher included in the study's findings all the parents' different viewpoints on the inclusion of children with autism. The parents interviewed had diverse understandings of the inclusion of children with autism. These differences were based on the parents' experiences, values and societal structure. Crotty (1998) argued that social reality exists according to an individual's experience of it and as it

has meaning for them. It follows that this researcher included all the interviewed parents' understandings of the inclusion of young children with autism and the context in which their experiences occurred. By means of incorporating all the perspectives that emerged during the interviews, including the conflicting viewpoints, this research achieved the holistic procedure of this single case study as noted by (Denzin and Lincoln, 2000).

The implications of the constructivist theoretical perspective on this descriptive holistic case study signified that: there were multiple perspectives as a result of the data from the interviews with the parents of autistic children; parents' perceptions depended on their understanding and experiences; parents were the data collection instrument; interviews with the parents of autistic children were conducted in their cultural setting; the researcher identified and contextualised the meaning that parents ascribed to inclusive education; the enquiry that underpinned the approach was thematic moving from fragmentary details to a connected view of the situation (Crotty, 1998); and parents had both a co-producers role in the study and a role in discussing outcomes (Denzin and Lincoln, 2000 and Crotty, 1998).

### **3.12 Theoretical Framework**

The purpose for examining parental perspectives on early childhood inclusive education for children with autism was to discover whether culture plays a key role in shaping parents' views of the inclusion of children with autism in regular kindergarten settings. Dahl (2004), defined culture as a connection of ideas and feelings accepted by the majority of people in a society. Similarly, Mahadi and Jafari (2012, pp. 233) argued that culture is described as "a socially acquired knowledge, to be precise, as the knowledge that someone has by virtue of his being a member of a particular

society”. This study embraced Matsumoto’s (1996, pp.16) definition of culture “... the set of attitudes, values, beliefs, and behaviours shared by a group of people, but different for each individual, communicated from one generation to the next”. That is to say, that culture refers to the norms and values of a society and for a meaning or a belief to be considered cultural, it must be shared by a social group or society. Therefore, culture can be considered as a lens through which individuals experience the world and develop shared meaning. Other objectives of this study included: determining whether the approach of the medical and social models towards children with autism had an impact on shaping parents’ perspectives on the inclusive education of autistic children; examining whether national educational policy factors impact on the implementation of inclusive education in general and ascertaining parents understanding of the concept of inclusive education and parents roles as advocates for inclusive education. To guide this study in exploring, describing and interpreting parents’ perspectives on early childhood inclusion of children with autism and to structure the study, the researcher used Bronfenbrenner’s Bio-ecological Theory (1998) as a theoretical framework. A theoretical framework is the application of a set of concepts drawn from the same theory, to offer an explanation of a particular phenomenon or research problem. (Lederman and Lederman, 2015). Similarly, Maxwell (2005, pp. 48) stated that theory means “a set of concepts and ideas and the proposed relationships among these”.

### **3.13 The rationale for using Bronfenbrenner’s Theory**

The Bio-ecological model is a theory of educational psychology that studies human development (Bronfenbrenner, 1994). Bronfenbrenner’s Bio-ecological theory of development enabled the researcher to organise the complex relationships between personal, social and cultural factor of the study. The model suggests that the

interactions between each child's unique biology and the environments in which the child grows up, categorised into various systems, shape the child's development. Bronfenbrenner suggested that children's development and learning can be understood and explained by thinking in terms of a number of the layers that encompass children as they grow and develop (Bronfenbrenner and Morris, 2006). That is to say that Bronfenbrenner's theory provides a broad focus on environmental influences that impact directly and indirectly on the lives of children. Although this theory has received criticism on the basis that it does not pay enough attention to the individual development of the child (Caswell, 1988) and that the theory is, on Bronfenbrenner's own admission, a difficult theory to corroborate by research, because of its complexity (Mol and Spaargaren, 2000). Nevertheless, Bronfenbrenner's theory brought together ideas from psychology and sociology and offered a valuable method of thinking about how wider aspects of society in which the child grows up that influence the child's development and learning. In addition, several researchers employed the Bio-ecological Theory in their educational studies. For example, Taylor and Gebre (2016) used Bronfenbrenner's theory as a conceptual framework to study teacher–student relationships and personalized learning. Similarly, Leonard, (2011), employed Bronfenbrenner's theory to understand community partnerships with high schools.

The rationale for using Bronfenbrenner's Bio-ecological Theory (1998) in this study was that inclusive education is a social concept, dependent on relationships between people and social structures to facilitate its implementation (Slee, 2001). According to Mitchell (2006) inclusive education is the process whereby individuals with disabilities are included into a socially constructed environment. Therefore, this study on early childhood inclusion of children with autism aimed to explore the

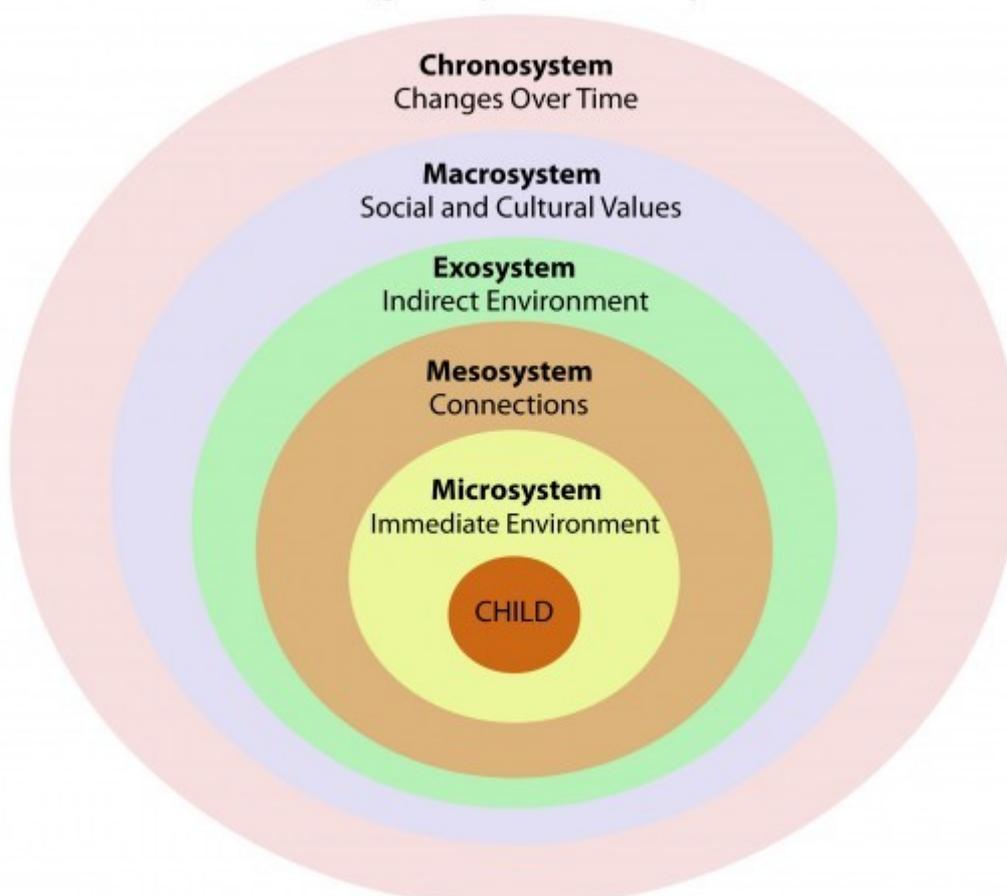
relationships between young autistic children and the social structure in Kuwait from their parents' perspective. Bronfenbrenner's Bio-Ecological Theory has provided a structure to identify and organise the influencing factors shaping parents' perspectives towards the inclusion of autistic children and to understand the interconnectivity between these factors on the implementation of early childhood inclusive education in Kuwait. According to Odom (2000) the characteristics of the learner should not influence the inclusion of the individual. It is, however, the environments and factors set within the context that influence the success (or lack of success) of inclusive education. Here Odom differentiates between the social model and the medical model of approaching disability. Bronfenbrenner's Bio-Ecological Theory offered a significant framework for this study to identify the cultural factors and comprehend their influences on forming parents' viewpoints whilst placing the autistic child at the centre and identifying each cultural influential factor in relation to the autistic child's educational ecosystem (Bronfenbrenner and Morris, 1998).

Bronfenbrenner's Bio-ecological Theory (1998) is referred to as the "Person-Process-Context-Time model" (PPCT), (Bronfenbrenner and Morris, 1998, pp. 996). According to the PPCT model, Person refers to the genetic and biological traits which the person brings with him into the social situation; Process is the reciprocal interaction between the individual and his immediate environment such as young children playing together, group games and children learning skills; Context involves four interconnected systems: a) The Microsystem such as home and school; b) the Mesosystem consists of the interactions between the different parts of a person's microsystem such as family and school relationships; c) the Exosystem refers to external influence that does not involve individuals as active participants but still affects them, such as educational policies; and d) the Macrosystem context such as the

social and cultural structures. The final element of the Bio-ecological model is Time which has a crucial role in the process of human development.

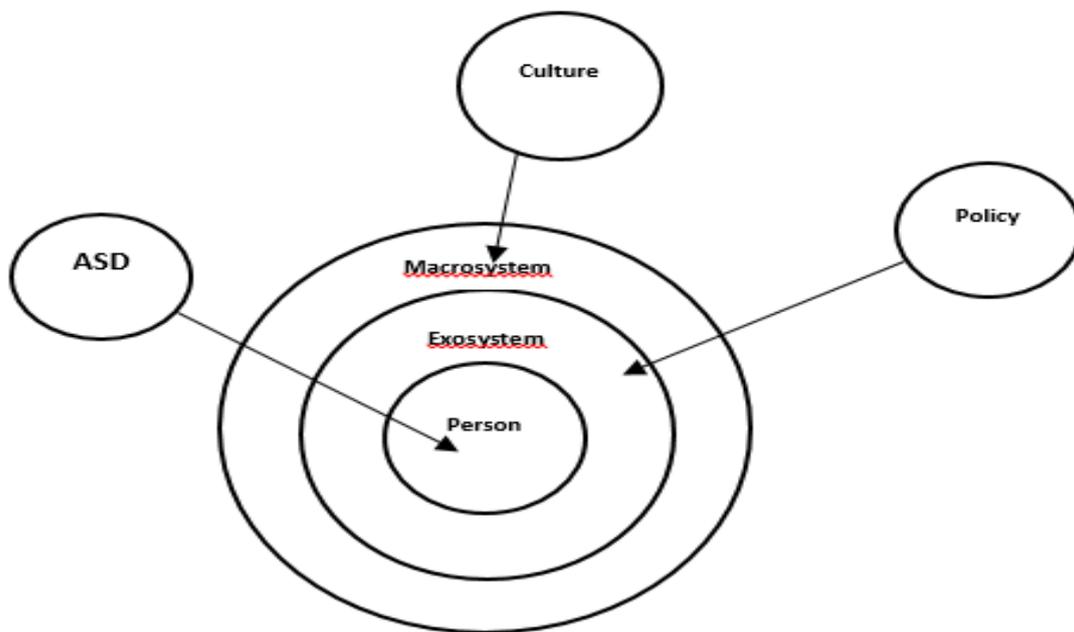
The researcher sought to refine the workings of the study by focusing on perceptions, interpretations and conclusions from within two levels of the theoretical framework of the Bio-ecological System theory; namely; the Person level and the two sub-levels of the Context level: the Macrosystem and the Exosystem. As such, the aim and the objectives of the study were framed as follows: autistic children's characteristics in relevance to inclusive education (Person); Kuwaiti education system and the inclusive education policy and its implementation (Macrosystem and Exosystem) ; Kuwaiti culture with reference to its impact on parents' viewpoints towards the inclusion of children with autism spectrum disorder (Macrosystem); the roles of parents' as advocates of inclusive education with particular reference to Kuwaiti parents in deciding their young autistic children's educational best interest (i.e. Macrosystem and Exosystem and Person) and the medical and social model approaches towards children with autism (Person and Macrosystem)

### **Bronfenbrenner's Ecological Systems Theory**



**Figure 1:** DEVELOPMENTAL PSYCHOLOGY / PSYCHOLOGY NOTES, 2018.

[www.psychologynoteshq.com/bronfenbrenner-ecological-theory/](http://www.psychologynoteshq.com/bronfenbrenner-ecological-theory/)



**Figure 2:** Modification of the illustration of Bronfenbrenner's Bio-ecological Theory (1998) based on the layers employed in this study.

### 3.14 Researcher Positionality

Following her graduation as an instructor of Therapeutic Riding, the researcher established a therapeutic riding program. This program ran for two consecutive years, 2007 and 2008, at her private stables in Al-Abdaali farms in Kuwait. Al-Abdali is a rural area close to the Kuwaiti/Iraqi border with a population of less than 5,000 people (Kuwaiti Central statistical Bureau 2016). At her stables the researcher trained 5 autistic children, aged between 7 and 11 years, on horsemanship. This experience was an impetus behind the researcher's interest in pursuing her studies in the education of autistic children and their inclusion.

The researcher had previously lived in Al-Abdali in Kuwait where she established a therapeutic riding programme designed for children with disabilities. There were five autistic children attending the programme which was in operation in 2007 and 2008. The researcher did return to Kuwait to undertake the present study on the inclusive education of children with autism in Kuwait city.

The discussions with parents during the time the researcher was in Al Abdali, provided the motivation for the present study. Conversations were held with several parents, almost all of whom expressed their concerns regarding the lack of adequate educational facilities and the lack of social activities for children with autism. Although the researcher did speak with parents, the conversations tended to be brief since the objective of the program was horsemanship and their remarks were not central to that purpose. The children were progressing steadily on the therapeutic riding program and this was reflected in their learning the basic techniques of riding and acquiring a significant number of new words thereby extending their vocabulary. The therapeutic riding program allowed the researcher to observe that children with autism were more able to retain information when it was constant and repetitive. The benefits gained from group sessions were limited as the children did not imitate each other nor did they display any sense of rivalry or feeling of being in competition with each other. More importantly, the children on the spectrum did not develop any friendships with their peers, although they did form attachments with their instructors and the horses. The above mentioned observations provided the impetus for the researcher to question whether an inclusive educational setting would be the best approach to resolve parents' concerns regarding the educational and social inclusion of young children with autism.

Regarding the interviewing skills, it should be mentioned that the researcher was the publisher of a magazine for 4 years and her job entailed interviewing people from diverse backgrounds. Furthermore, during her previous studies at PhD level the researcher interviewed several Chechen refugees using the Chechen language and adhered to their unique cultural norms during the interviews conducted for the purposes of her study. Therefore, the researcher can argue that she is multicultural, competent, experienced in interviewing strategies and aware of her role as a researcher and of the ethical implications in her research.

In addition, although the researcher is from a similar background as the study participants, however, conducting this study made that researcher appreciate that factors such as having been away from my original culture for more than 30 years; having been raised by a western mother; and the impact of my values shaped by social justice and human rights concerns on issues such as inclusive education, might all have created cultural differences between the participants and myself. In this study the researcher acknowledges her subjectivity given that she has both an insider and an outsider status. The insider status stems from the researcher being a Saudi national whilst the outsider status stems from the researcher having spent almost all her life in Russia, in a Russian cultural context. The researcher describes negotiating her insider and outsider status throughout the study methods, shifting from trying to maintain objectivity to embracing the fluidity of her own identity.

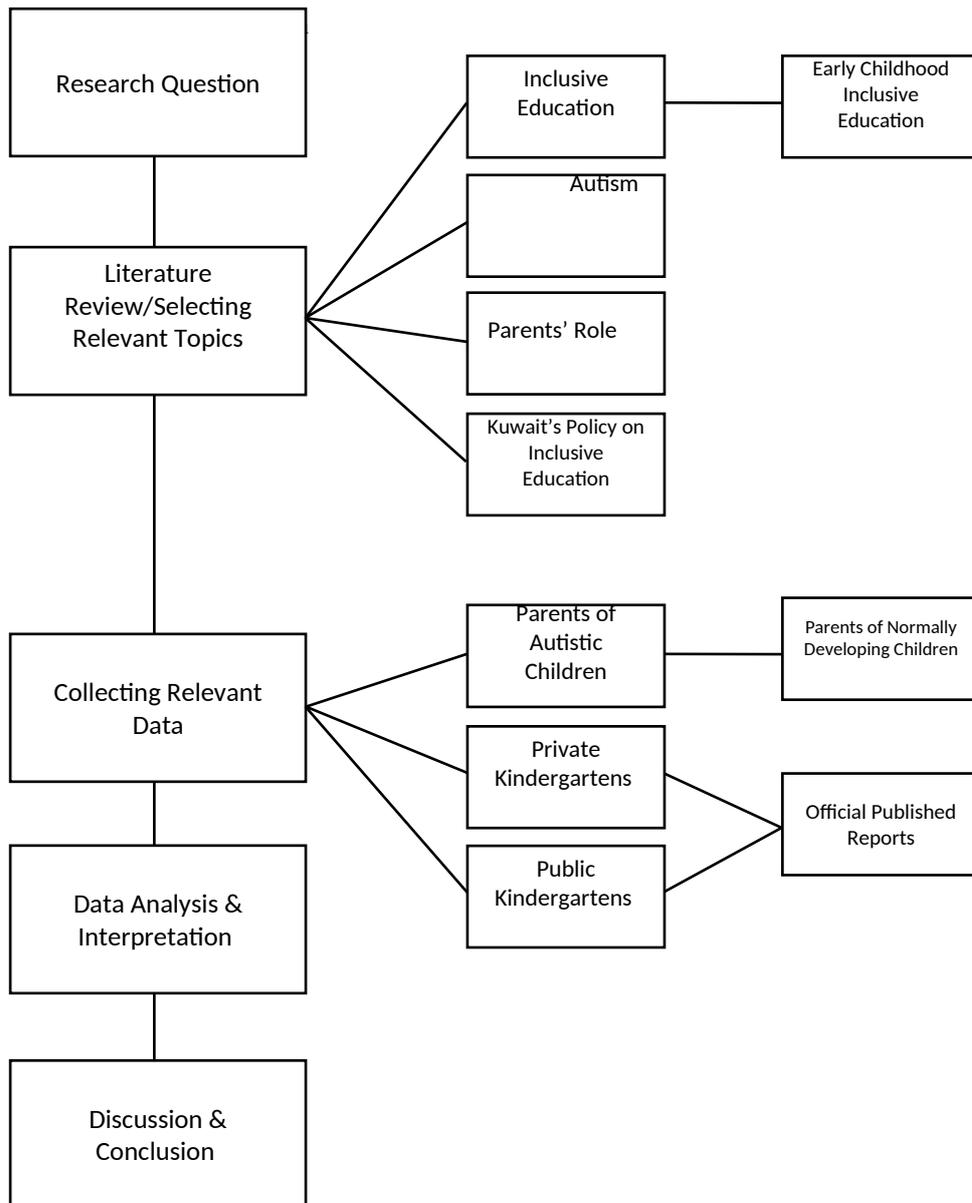
### **3.15. Research Design Overview**

The research question that directed this study was: What are parents' perspectives on early childhood inclusive education for children with autism. The qualitative case study design met the aim of providing a description of this

contemporary educational movement in Kuwait. The procedures for conducting this study included the use of robust data collection methods, the documentation of the research stages and the data analysis procedures. A rigorous case study requires a logical and coherent argument that defines the selection of study methods (Denzin and Lincoln, 2011). In line with the case study method the purposive sampling and thematic data analysis strategy were chosen.

The data collection methods that were employed in this study were: a pilot study; semi-structured focus group interviews; individual face-to-face interviews and Kuwaiti official documents. Data collection stages occurred in a sequential manner and from within the case study method framework. The data collection methods were conducted from within the social context of the research participants as the researcher wanted to explore the contextual conditions. The context is an integral aspect of the phenomenon under study (Yin, 2009, Stake, 2006). According to several authors including Yin (2009), Merriam (2009), Denzin and Lincoln (2011) and Creswell (2013) the fundamental objective of case study research is to conduct an in-depth analysis of phenomena, within its context in order to understand the issue from the perspective of participants. Hence, the qualitative methodology of this study and the case study design enabled the researcher to explore, understand and present the participants' perspectives from within their natural setting (Creswell, 2013). This approach provided an in-depth understanding and a holistic picture of the parents' perspectives towards early childhood inclusive education for children with autism. The research design can therefore be seen as a plan for the conditions of the data collection and analysis (Creswell, 2013). The following sections present the methods used in the collection of data within the case study framework.

**Figure 3.** Research Design



### 3.16 Data Collecting Instruments

The instrumentation usually administered in the constructivism paradigm and the qualitative research method is through interview, observation and document review (Adom et al, 2016). According to Yin (2003, pp 89) “one of the most important sources of case study information is the interview”. Accordingly, the researcher used focus group discussions with parents of autistic children and individual interview with private kindergartens owners and public kindergartens administrators to obtain a clearer picture of the early childhood inclusive education policy in Kuwait. The researcher utilised an interview guide with a set of questions that was used in the focus group sessions with parents of autistic children (Appendix 1). The interview guide was informed by the information gained from the literature review on barriers and facilitators of inclusive education in Kuwait and from the pilot study. For individual interviews with parents of normally developing young children who were registered in kindergartens, the researcher asked one open-ended question, namely: *Do you support including young children with autism in a regular classroom setting? Give reasons for your answer?* (Appendix 2) and another one open-ended questions for the owners of the private Kindergartens and the administrators of the public kindergartens, namely: *Have you received any policy guidelines from the Ministry of Education regarding early childhood inclusive education and if so what were they?* (Appendix 3). Furthermore, the researcher conducted an exploratory focus-group interview with five Kuwaiti citizens before travelling to Kuwait for piloting the interview questions. Only one couple met the criteria of the purposive sampling, the other couple had two older children on the spectrum and one participant was a postgraduate student who had worked previously as a teacher in an elementary school in Kuwait. The pilot study stage is discussed further in the next section.

The researcher was the moderator of each focus group session and steered the discussion towards the topics that were listed in the interview guides. All questions in the interview guides were asked using similar wording from parent to parent and from focus group session to focus group session. The open-ended questions allowed for information to flow naturally from the participants and encouraged the participants to engage freely in discussions. No changes were made to the questions in the interview guide in the consecutive interview sessions as the questions were informed by the literature review and the pilot study. The questions were comprehensive and designed to elicit the relevant information for the study as such it was not necessary to revise the questions.

Through conducting interviews with parents, careful documentation and thoughtful descriptions of parental perspectives on early childhood inclusive education for children with autism was established. However, methods of collecting data for case study approaches such as interviews, have been subject to criticism. According to a number of writers of qualitative case study research including Bryman (2016), Yin (2009) and Stake (2005) and Lincoln and Guba (1985) collecting case study evidence through interviews has its strengths and weaknesses. The strength and weaknesses of interviews were summarised by Yin (2009, pp. 102) as follows: “Strengths: targeted, focuses directly on case study topics, insightful, and provides perceived casual inferences and explanations” and “Weakness: bias due to poorly articulated question, response bias and inaccuracies due to poor recall and reflexivity-interviewee gives what interviewer wants to hear”. Managing the ‘weakness’ in Yin’s quote above was discussed in detail in the trustworthiness section and throughout the interview procedures.

### **3.17 sample size**

Regarding the Sample Size. According to Bryman (2016) there is a range of opinions regarding the appropriate sample sizes for qualitative research. Bryman quotes a number of writers including Warren (2002) who said that in order for qualitative interview research to be published, the study should consist of at least 20 interviews. Gerson and Horowitz (2002) argued that less than 60 interviews cannot support substantial inferences whilst Alder and Alder (2012) recommended a range of 12 to 60 interviews in order for an interview based research study to be both credible and persuasive. Couch and McKenzie (2006), on the other hand, remarked that samples of less than 20 enhance the researcher's chances of becoming closely involved with the interview participants and generate more detailed data for the study. On the other hand, Patton (1990, pp. 185) argued that "validity and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected "...than with sample size". In other words, Patton suggested that sampling procedures, depth of interview data and the quality of the data are of greater significance than sample size. As noted above, there is substantial variation amongst writers in relation to sample size as the criterion for a qualitative interview study. The researcher interviewed thirty one individuals in total. The purposive sample size was not fixed prior to data collection but because the researcher was reviewing the data in conjunction with data collection, consequently, the size of the sample was determined on the basis of theoretical saturation, i.e. the point in data collection when new information no longer brought new insights to the research questions.

### **3.18 Sample Design**

The aims of the study defined the criteria for those participating in it. The sampling framework was set according to the age of the autistic children, that is;

children (boys and girls) registered at the kindergarten level for ages 3 ½ - 5 ½ years. The parents (mothers and fathers) were Kuwaiti nationals of any age or level of education. However, in the demographic section of the interview guide, the researcher included the level of education of the parents to explore whether the level of education was relevant to the parents' awareness of the inclusive education concept.

Autism comprises multiple degrees of functional difficulty such as; mild, moderate or severe, with mild being the most common (Weitlauf et al., 2014 and Schepis et al., 2003). Some children with severe autism may never progress past the sensory-motor play stage and their teaching practices require direct input from specialists using specific interventions efficiently and effectively (Plauché et al., 2007; Schepis et al., 2003; and Lovaas, 1981). The efforts required for the successful inclusion of children with severe autism and severe challenges are usually extensive and require well-trained professionals. Therefore, in the sample design this research included parents of children diagnosed with moderate and mild autism but not the children with severe disorders.

In terms of sampling approach, the researcher used purposive sampling and snow ball sampling methods in order to gather as much information as possible. The rationale for using a purposive sampling approach was that the question of this research was bound by a number of factors including: time; place; research objectives and context (Yin, 2003). These boundaries; specifically, geographical setting in Kuwait; participation of parents of young children with autism; and early childhood inclusive education for children with autism as the area of focus, ensured that the research remained within scope. In addition, the researcher used snowball sampling through participants, with whom contact had already been made, to refer the researcher to other parents for their contribution to the study. The information

produced by both the purposeful sampling and snow ball sampling techniques allowed the researcher to settle on a set of participants who met the established boundaries for inclusion in the study.

The purposive sample size was not fixed prior to data collection but as the researcher was reviewing the data in conjunction with data collection, consequently, the size of the sample was determined on the basis of theoretical saturation.

### **3.19 Stages of data collection methods**

In qualitative research, the interview is “a basic mode of inquiry. Recounting narratives of experience” and interview “has been the major way throughout recorded history that humans have made sense of their experience” (Seidman, 2013 pp.8). Seidman (pp.7) added “I interview because I am interested in other people’s stories “. For qualitative researchers, the most widely used tool for collecting data is interview (Seidman, 2012 and (Bryman, 2016). The data needed to provide holistic answers to the research question determined that interviews were the most convenient form of data information gathering to be employed especially since, in this case study, the social context is an integral part of the inquiry. In this study, the researcher began with a pilot study followed by semi-structured focus group interviews. Furthermore, interviews were conducted with the owners of private kindergartens and public kindergarten administrators as the educational system employed in the kindergartens would be a reflection of the general educational policy in Kuwait with reference to kindergartens. Yin (2003) stated that if the researcher collected from multiple sources and aimed at corroborating the same phenomenon, then the researcher would have actually triangulated the data.

#### **3.19.1 Stage One: Pilot Study**

As stated earlier, a number of researchers including Yin (2011) and Denzin and Lincoln (1994) highlighted the importance of piloting specific aspects of research design for qualitative research. For example, Yin (2011, pp. 37) stated that pilot studies “help test and refine one or more aspects of a final study”. Similarly, Denzin and Lincoln (1994, pp. 201) stated that the pilot study is an essential aspect of the research process and serves as a “warm-up exercise” in preparation for a full-scale study. According to Teijlingen and Hundley (2001) one of the advantages of piloting is that it might caution the researcher regarding where the main research project could possibly fail or whether the proposed methods are inappropriate.

Prior to travelling to Kuwait, the researcher conducted a pilot focus group session before the actual investigation to inform a main study and all participants were Kuwaiti nationals. Two sets of parents had registered their autistic children in a special school for autism in the UK. One participant was a postgraduate student who worked as a teacher in Kuwait. Only one set of parents met the criteria of the purposive sample of this study in that they had an autistic child aged five years. The other parents had two autistic children aged seven and eleven years. The fifth participant had previously worked as an elementary stage teacher in Kuwait. The researcher conducted the pilot study to test the interview guide and to have a general idea of how the focus group interviews would work with the study sample in Kuwait. The pilot study involved using in-depth interviews to gain a deeper understanding of the cultural context of this research. By conducting the pilot study, the researcher aimed to test the adequacy of the research guide and to collect preliminary data. By conducting this small-scale pilot study the researcher practiced the interviewing techniques, measured the approximate time needed to cover all the questions in the

research guide and identified any potential problems with the definition of inclusive education.

The researcher found that most of the study aspects including the methodology and the study design can be conducted in the way that has been planned. In addition, there were no problems with collecting all the data needed for future analysis. However, some of the procedural components of the study required adaptation. These procedures included: the timing for the field visit and the time needed for focus group sessions and the number of participants in each session. Firstly, with regards to the timing of the trip to Kuwait, the pilot study participants drew the researcher's attention to the fact that her proposed time to travel to Kuwait was not appropriate as it would coincide with the National Day celebrations and Kuwaitis would have made holiday plans.

Secondly, although the number of participants in the focus group would vary, to accommodate the open ended questions the researcher realised that the average time to be allocated for these sessions would require extension. Similarly, the number of participants would need to be limited to not more than seven per session. Such measures would give all the participants' sufficient time to answer the research questions and to engage in conversations amongst themselves.

Thirdly, as some of the pilot study participants were unaware of the concept of inclusive education, the researcher was conscious of the need to explain this concept and clarify the difference between inclusion and integration when discussing inclusive education with them. To emphasise this vital distinction the researcher used Ashman and Elkins' (2005) definition of integration, i.e., as the process of moving students from special education settings into regular classrooms where they undertake some of their schooling, and Ainscow's (2005), definition of the concept of inclusive

education, i.e., that students with special needs can and should be educated in the same settings as their normally developing peers with appropriate support services, rather than being placed in special education classrooms or schools.

### **3.19.2 Stage Two: The Focus Groups**

Interviewing and document analysis, is one of the major ways qualitative researchers generate and collect data for their research studies ((Yin, 2003). Researchers who conduct exploration oriented inquiries, similar in nature to this study, usually create specific questions for their interviews instead of employing pre-established questionnaires or survey instrument (Yin, 2003). In this case study the researcher formulated open-ended question to provide openings through which the participants can contribute their perspectives with little limitations imposed by more closed-ended questions. In such a manner the researcher is the primary instrument for data collection and analysis as data are mediated through the researcher, rather than through inventories or questionnaires (Sanjari et al, 2014). In this qualitative case study the researcher was an integral part of the process of conducting this researcher and was involved in all the stages including the design, interviews, analysis and reporting the themes. However, the researcher as instrument raises concerns regarding trustworthiness and bias (Poggenpoel and Myburgh, 2003). In addition, the researcher-participant relationship in qualitative researches can also raise a range of ethical concerns such as the anonymity and confidentiality of the participants (Arifin, 2018; Orb et al, 2000). These issues are discussed further in the following section and in section (3.7 and 3.25).

Focus groups are considered to be a useful method for exploring cultural values and tenets (Seidman, 2013). This means that instead of the researcher asking each interviewee to answer each question in turn, participants are encouraged to talk to one another and comment on the respective points of view. This approach is useful for exploring participants' experiences and to examine how participants think and why they think in that way. What is important about a focus group is the group dynamic (Farnsworth and Boon, 2010). That is, the way in which participants of the focus group engage in discussion with one another will determine the success of the focus group approach.

The researcher conducted five focus group sessions for twenty seven mothers of children with autism to discuss their views and experiences of early childhood inclusive education for their children. Fathers did not participate in the focus group sessions only mothers of autistic children. Three quarters of the participants explained that it was not appropriate for the fathers to attend meetings along with women to discuss the issues of young children. The rest of the mothers were either divorced or they apologised on the behalf of their husbands for being busy with other engagements. However, all the mothers agreed that their husbands are hardly involved in their autistic children's affairs. All the interviews were conducted in the meeting room of the hotel where the researcher was staying. The meeting room was equipped with stationery and a snack bar with soft drinks. Seven mothers took part in the first session, five in the second session and four in the third. In the fourth and fifth sessions participation in the interviews came from eight and three mothers respectively. By the end of the fifth session data saturation was achieved. According to Guest et al. (2006, pp.59) the size of the sample "...relies on the concept of saturation". The duration of the sessions varied between 60 and 90 minutes. At each session some participants did

not consent to having their conversations recorded, therefore, the researcher used the journal note-taking technique to document the participants' responses and discussions.

The focus group method used in the study elicited in-depth data as the researcher captured the parents' perspectives and beliefs revealed through the social interaction between these parents. Furthermore, the discussions between the parents allowed the researcher to explore the degree of consensus on a given issue which in turn helped the researcher to identify the main themes. This approach for collecting data provided the study with several perspectives about early childhood inclusion of autistic children in Kuwait. Although the focus group sessions were moderated successfully, it was difficult at certain points to identify the individual perspective from the group viewpoints. Nonetheless, the identification of individual participants' viewpoints was resolved through the member checking procedure. The advantages of focus group sessions included gaining insight into the parents shared understanding of everyday concerns regarding their autistic children and the ways in which the societal structure and culture influenced the parents' perspectives.

However, the focus group approach has its limitations in terms of the method's inability to generalise findings to a whole population because of the small number of people participating (see generalizability section 3.7). The focus group depends on assisted discussion to produce results; therefore, the facilitation of the discussion is very important (Mansell, 2004). Additionally the possibility of outspoken individuals dominating the discussion (Leung, and Savithiri, 2009). These issues are discussed further in the following section. Furthermore, focus group method generates distinct ethical challenges that do not correspond fully to those raised by one-to-one interviews. The following section addresses in both conceptual

and practical terms, the key issues: consent; confidentiality and anonymity; and risk of harm. These issues are further addressed in section (3.7).

### **3.20 Procedures for Conducting the Focus Group interviews**

Several researchers including Sanjari, et al. (2014); Yin (2009); Holliday (2007); Creswell (2007) argued that qualitative research methods including case studies have some ethical challenges given that such methods are frequently conducted in settings involving people. Therefore researchers are responsible for ensuring that participants are not harmed, privacy is maintained, and the participants have provided informed consent. These issues are addressed in (section 3.7).

The interview guide directed the data collection and discussion and each proposition determined the direction and the scope of the study. Collectively, these propositions were structured within the Bronfenbrenner's Bioecological Systems theory and formed the conceptual framework of this study. Through structuring the study within the various layers of this theory, the researcher organised the different contexts that might have shaped the parental perspectives towards the inclusion of autistic children and the factors that might have influenced the implementation of early childhood inclusive education for autistic children in Kuwait. In line with the case study method the purposive sampling and thematic data analysis strategy were chosen.

As neither the researcher nor the participants in the focus group sessions had met before or had previous knowledge of each other prior to the interviews (see 3.14) and the researcher did not question the mothers regarding the reasons for their willingness to participate, one can assume that these mothers wanted their voices to be heard, or they were interested in the study topic or their willingness to help the

researcher. However, the researcher was at an advantage given that she spoke the same language and was capable of employing culturally distinctive approaches and terminologies. The researcher recognises that development of personal relationships with participants may be inevitable while collecting data (Hennink, M. et al., 2012; Sanjari et al, 2014). Therefore, the researcher defined and explained her insider and outsider status in sections (3.22 and 6.9). Although “personal interaction between researchers and participants is crucial in data gathering” (Orb et al, 2000, p.95), the researcher kept in mind the study focus and her role as a researcher to maintain a balanced research relationship with the participants.

At the beginning of each focus group session, the researcher confirmed that the participants met the criteria to participate in the study and introduced herself and asked the participants to introduce themselves to the group. Before the questions were administered, the parents were verbally given additional information concerning the purpose of the questions and the importance of honesty and accuracy in their responses. The confidentiality and anonymity of their responses were also emphasised, along with the important contribution that their responses would provide. The difficulties inherent in qualitative research can be alleviated by awareness and use of well-established ethical principles, including autonomy, confidentiality and informed consent (Arifin, 2018; Hennink, M. et al., 2012). Therefore, in order to foster the mothers’ trust in the researcher and increase the likelihood of open, interactive dialogue, the researcher assured the participants that: their identities would be anonymised; judgement would not be passed on the mothers’ perspectives either by the researcher or anyone else; the sole purpose of the interviews was to gather

information; and participants could refuse to answer questions with which they were not comfortable or could withdraw from the study at any time should they so wish.

Given that participants need to be sufficiently informed about the study, understand the information and have a freedom of choice to decide whether to participate or decline (Arifin, 2018), participants consent forms to participation in this study were obtained only after a thorough explanation of the research process. Mothers were encouraged to ask for further clarification should any issue be unclear. Similarly, copies of the interview guide were distributed and mothers were asked to read through the questions before signing the consent forms. Once it was felt that the mothers were comfortable and ready to begin, the researcher asked for permission to switch on the recorder and commence the interview. During the sessions it became apparent that some mothers were not comfortable with their discussions being recorded. Consequently the researcher ceased tape recording the interviews and instead utilised the journal note-taking technique. The anonymity and confidentiality of the participants was preserved by not revealing their names and identity in the data collection, analysis and dissemination of the findings. In presenting the findings of the study, the participants were referred to by their pseudonym names in the verbatim quotes. According to Aluwihare, (2012, p. 69) “to facilitate participants’ full understanding, the study information sheet must be written in a manner to meet the reading levels of the participants”, therefore, the study information sheet was translated into Arabic.

All of the focus group sessions flowed naturally. Seidman (2013) and Robson (2001) suggested that the interviewer should listen more than speak to obtain in-depth data. Any interruptions by the researcher were kept to a minimum and only occurred when the discussion deviated away from the target topics or when the researcher did

not understand certain phrases and words that were Kuwaiti specific colloquial terms. For example, a recurrent topic raised during parental interaction was the comparison between and evaluation of the different centres for autism. At such points it was necessary for the researcher to steer the conversation back to the target topics. Another example of terms and phrases unfamiliar to the researcher arose from the colloquial Kuwaiti dialect where one finds that the letter 'k' is pronounced as 'ch', the letter 'q' is pronounced as 'g' and the letter 'j' as 'y' as well as the presence of Persian and Urdu words (AL Rasheed, 2010, in Arabic). Consequently, the researcher had to interrupt the discussion to have these phrases explained in classical Arabic. The researcher also avoided giving personal opinions so as not to influence participants towards any particular opinion (Breen, 2006). The researcher initially requested that the mothers to complete the simple demographic questions (the parent's name, the parent's level of education, the child's age and gender, the child's functional level of autism and the scholastic setting attended by the child). These questions provided background information and initiated the involvement of all the mothers. The interview guide included four key open-ended questions:

- 1- If your child is attending an inclusive education setting in a kindergarten, explain what is meant by "inclusive" in your opinion.
- 2- Would you support young children with autism being included in regular classroom settings with their normally developing peers with appropriate support services? Give reasons for your answer?
- 3- In your opinion are children with autism socially stigmatised? If yes, describe how from your own experience?

4- Have you actively participated in decision making regarding the policies relating to the education of children with autism?

The question on the child's functional level of autism was proposed to substantiate the impact of the stance of both the medical and social models understanding to autism on shaping the perspective of the parents towards the inclusion of their autistic children. This question being a scale question allowed the conversation to flow naturally when followed by the open ended questions. The rest of the open-ended questions were content questions and were left broad and supplemented with prompts and probes to obtain more comprehensive information in the response (Appendix 1).

Question (1) was informed by the literature review and the pilot study. Questions (2) and (3) were posed to obtain insight into the cultural and social issues which formed the parents' perspectives. These questions elicited information contextually meaningful to the aim of this research and assisted in unravelling the complexity of the parents' real life experiences. Question (4) addressed the second objective of the study, i.e. parents' role in the policy and implementation of early childhood inclusive education for children with autism. This question brought into focus whether parents actually had a role, which roles were considered particularly important and satisfying for them; the reasons for not playing any role, if that was the case and which roles would they like to perform in their children's education. All the questions posed helped the researcher to holistically capture the realities and meanings of early childhood inclusive education for children with autism from the parents' perspectives.

The interview guide was translated into Arabic. However, Kuwait is a diglossic speech community in which people speak one language and write in another.

What is more, Kuwaitis have greater regional lexical variations than the rest of the Arab regions. Consequently, the questions were posed verbally in classical Arabic and the answers were transcribed during the interviews using the terms as stated by the parents in their distinctive dialect. The parents' answers were then translated into English by the researcher with the help of two colleagues. A number of qualitative authors including Seidman (2012); Robson (2011); Breen, (2006) and Cassell (2005) agreed that interviews take too much time, as the researcher needs to undergo a long process, starting from establishing access to making contact with participants, conducting the interviews followed by transcribing the data in order to achieve the purpose of the research. However, the researcher's relationship with the case, i.e. the researcher's interest in autism and the inclusion of autistic children as a field of study as well as the friendly relationship that developed between the researcher and participants helped the researcher to enjoy the research process and the time spent conducting the interviews. At the end of each session the researcher expressed appreciation for the mothers' involvement in the study. The participants were cooperative and willing to help in any further procedures needed to accomplish the study. The researcher arranged with the participants to be contacted again for the purposes of member checking.

### **3.21 Stage Three: Individual Interviews**

#### **3.21.1 Interview with Kindergarten Owners and Administrators**

A face-to-face interview was conducted with two partners of a chain of five private kindergartens in Kuwait and two separate interviews with two administrators of public kindergartens. The rationale for conducting these interviews was to explore the educational policy for early childhood inclusive education in Kuwait. The

kindergarten policies and the operation of the education system in Kuwait, whether in the private or the public sector, are governed by laws and rules of the Kuwaiti Ministry of Education (Kuwaiti Ministry of Education, 2012).

The literature review and the review of the Kuwaiti official reports regarding inclusive education provided some theoretical information on Kuwait's participation in UNESCO's conferences concerning inclusive education and the projects of the United Nation Development Program (2008) for inclusion of disabled people in Kuwait. However, from the initial analysis of the data collected from the parents through the interviews there were disparities between policy rhetoric and practice relating to inclusive education for children with disabilities in general. Moreover, there was not a single official report on inclusive education for young children with autism

Therefore, in order to obtain actual information directly from those who were personally involved in the policies of education and early childhood inclusive education, the researcher interviewed owners of private kindergartens and administrators of public kindergartens. These interviews represented one of the three levels of the Bronfenbrenner's Bio-ecological Theory (1998) which provided the theoretical framework for this study, namely; the Exosystem level as reflected by the educational policy for children with autism. Therefore, to better understand the concept and the policy of early childhood inclusive education in Kuwait, the researcher addressed these individual interviews from within the Exosystem layer of the theoretical frame of this study. The owners and the administrators were given copies of the information sheet and the consent forms to sign. The researcher posed one open-ended question:

1) Have you received any policy guidelines from the Ministry of Education regarding early childhood inclusive education and if so what were they?

The interview with the private kindergarten owners was held in their offices for 40 minutes. The interviews with the public kindergarten administrators were held individually at the hotel where the researcher was staying and each interview lasted for 40 minutes.

### **3.21.2 Parents of Normally Developing Young Children**

#### **1) Rationale for conducting individual interviews with mothers of typically developing young children:**

Given the volume of international research on the impact of autism characteristics on the inclusion of autistic children, the member checking method and the relevance of this issue to existing literature would have established both the credibility and the validity of these findings (see section 4.2 Findings in relevance to the study questions and literature: the focus groups interviews). However, to the best of the researcher's knowledge, literature investigating the cultural influence on the inclusion of autistic children in Kuwait, does not exist and this is a subject that has been completely ignored in previous research. The researcher used the member checking method to validate the findings which clearly indicated the influence of cultural traditions on parental perspectives and therefore on the implementation of inclusive education in Kuwait.

The researcher conducted her study through the lens of culture. The strikingly unanimous perspective in relation to cultural traditions was the rejection of the inclusive education concept based on the importance given to the opinions of parents of normally developing children. All the mothers in the focus groups stated that the

families of typically developing children would not accept their children being exposed on a daily basis to the behaviour of autistic children. The general feeling was that their children would imitate the behaviour of the autistic children and consequently in public encounters would mistakenly be viewed as autistic. This disclosure clearly indicates the social stigmatisation of autistic children, and that being labelled as autistic is a source of disappointment, annoyance, and shame in Kuwait. The researcher chose to conduct an exploratory case study and as stated in the purposes for employing a case study method, one of the aims of this method was for the researcher to develop a deep understanding of the cultural aspect of the inclusive education concept. Therefore, the researcher conducted individual interviews of mothers of young typically developing children.

To explore the research question the researcher opted for the use of focus group interviews as being best suited for data collection. The researcher purposely decided to interview mothers of normally developing children. She was aware of the limitations of this approach due to the size of the sample and that only one question was posed when interviewing the mothers of normally developing children. However, these interviews were not for the purposes of triangulating the information gathered from the focus groups. The objective was for the researcher to increase her own understanding of the Kuwaiti cultural characteristics relevant to the inclusion of autistic children. In this sense, the researcher followed the arguments of a number of writers who stated that rather than seeing triangulation as a method for verification, qualitative researchers generally use this technique to ensure that an account is comprehensive (Honorene, 2017, Carter et al., 2014). Lambert and Loiselle, 2008, Patton, 2001). The individual interviews with the mothers of typically developing children provided a deeper insight into Kuwaiti cultural attitudes relevant to the

inclusion of autistic children. All of these mothers expressed negative views on the inclusion of autistic children.

Those mothers stated clearly, that in Kuwait having a child with disability is considered shameful and autism is accompanied by strong perceptions of stigmatisation. The mothers explained that having an autistic child poses risks to family status and honour. Some of these mothers noted that they are from tribal communities therefore, if a family has an autistic child, the family will hide the child to protect the family from the external judgment of inadequacy. The findings from these individual interviews clearly suggested that having an autistic child poses risks to the family's status and honour. These interviews enabled the researcher to develop a more in depth understanding of the impact of Kuwaiti cultural traditions on the inclusion of autistic children. As a result of conducting these individual interviews the researcher was confident enough to argue that within the context of this study Kuwaiti culture did in fact shape the perspectives of the mothers interviewed about the inclusion of autistic children. The researcher is of the view that, given her moral and ethical obligation as a researcher, within the context of her study it would have been unethical to write the final study report without being able to firmly establish whether cultural traditions were one of the factors hindering the implementation of the inclusion of autistic children.

The main purpose of the individual interviews was to acquire a deeper level of understanding of the influence of Kuwaiti cultural traditions on the inclusion of autistic children from different perspectives. This should not necessarily mean cross-checking data from two sources or methods and either confirming or disproving its correctness. It is more to increase the level of knowledge of the cultural attitudes towards inclusive education for autistic children and to strengthen the researcher's

position from various aspects particularly when following the theoretical framework of the study, interpreting the data and writing the final report. The researcher has a genuine interest in the issue of inclusive education for autistic children in Kuwait and wished to learn more about the cultural influences which proved problematic given the lack of available resources. Amongst the researcher's recommendations is for further research on inclusive education in Kuwait to consider a comparative study of the perspectives of both groups of mothers, those with children with autism and those with normally developing children. A principal objective of this study is to initiate a discussion in the field centred on the impact of culture on inclusive education in Kuwait.

Conducting individual interviews with nine mothers of normally developing young children registered at kindergartens allowed the researcher to develop a deeper insight into the influences of culture on the inclusion of autistic children to reinforce interpretations. Ritchi and Lewis (2003, pp. 36) argued that individual interviews are well appropriate to studies that "require an understanding of delicate phenomena" as well as studies that require answers to multifaceted experiences "because of the depth of focus and the opportunity they offer for clarification and detailed understanding". The researcher posed one topic question in these individual interviews, namely: 'Would you object to having autistic children included with your child in the same kindergarten classroom? Why?'

The researcher chose the face-to-face individual approach as group interviews or focus group interviews might discourage some parents from expressing their viewpoints towards the early childhood inclusion of children with autism. Wilson et al. (1998, pp. 315) noted that individual "face-to-face interviews are particularly prone to the problems of reactivity", that is "respondents may express socially

acceptable, rather than authentic, attitudes". Mothers of normally developing children might not feel comfortable to reveal some sensitive information regarding their genuine perspectives out of ethical correctness. Ritchi and Lewis (2003, pp. 58) stated that when it comes to "topics which people are likely to see as confidential" and when the researcher is "concerned to get beyond what may be seen as socially acceptable" then a "more private setting of an individual interview is useful here". Therefore, the researcher opted for the one-to-one interviews with the mothers of normally developing children to further establish whether stigmatisation and cultural traditions constituted one of the barriers to the inclusion of autistic children. In the face-to-face interviews, the researcher was not concerned with the non-verbal data therefore these aspects of the individual interviews were not acknowledged. The face-to-face interview is consistent with the aims and objectives of the study and enabled the researcher to delve deeper into the cultural issues concerning the inclusion of autistic children. The individual interviews were conducted informally for 40 minutes in a quiet area of the lounge of the hotel in which the researcher was staying. For details on the procedures of conducting these individual interviews see the following section (3.22 Ethical Considerations).

### **3.22 Ethical Considerations**

This study employed a qualitative exploratory scientific method that involves a description of issues related to the research question and the meanings and interpretations which the parents perceived about the concept of the inclusion of autistic children. The approaches to conducting this research included interviews and focus group discussions. Although academic research needs to be handled objectively, the subjective nature of qualitative research may make it difficult for the researcher to

be detached completely from the data, which in other words means that it is difficult to maintain objectivity and avoid bias (Holliday, 2007).

As a result, qualitative research is often criticized for lacking transparency and scientific rigour. It is criticised for being a compilation of impressions that are subjected to researcher bias and that may not necessarily be reproducible. The literature review showed that there are different types of biases that might face the qualitative researchers including social desirability bias; researcher bias, leading questions and wording bias, habituation bias; question-order bias; sponsor bias; and acquiescence bias (Holliday, 2007; Creswell, 2003). These authors also said that most biases can be avoided by framing the questions and structuring the interview skilfully.

Other researchers such as Velardo and Elliot, (2018), Esposito et al (2017), and Gregory (2003) said that qualitative research also poses ethical challenges including the need to obtain ethical approval and consideration of issues around informed consent, recruiting participants, risk of harm, confidentiality, and accountability in terms of the accuracy of reporting. These authors suggested that the researcher needs to carefully incorporate these ethics whilst also ensuring the quality of the research results. These issues are detailed under section (3.7). Whilst several methods were reported in the literature to address the issue of biases in academic researches the majority of authors including those mentioned above recognised that once the researcher understands and identifies the different types of biases, it will become easier to take measures to avoid them.

Given that bias exists in all research and it can occur at each stage of the research process, the researcher employed several means that can aid in taking appropriate preventive measures. For examples, to minimise the study design bias, the

researcher structured the study design from within the later adapted model of Bronfenbrenner's bioecological theory which includes Process — Person — Context — Time (PPCT) (See 1.6 and 3.13). Using Bronfenbrenner's theory provided a theoretical framework for the study that established a congruence between the research question and the methods employed to answer the question. Employing the Bioecological theory framework limited the study design bias in mapping out of the contextual and individual factors contributing to the outcomes of the study as well as limiting the bias that might have impacted the interpretation of the influences that might have shaped the mothers perspectives. Other types of bias and the way to avoid them are further discussed under (section 3.19.2 and 3.20). Whilst research that is completely unbiased is ideal, it may not always be possible. Therefore, the researcher attempted to outline potential sources of bias to facilitate for greater critical evaluation of the research findings and conclusions.

As stated earlier (see. 3.14) the researcher had previously lived in Kuwait where she established a therapeutic riding programme designed for children with disabilities. There were five autistic children attending the programme which was in operation in 2007 and 2008. The researcher did return to Kuwait to undertake the present study on the inclusive education of children with autism. As the researcher had already worked in the country with children with disabilities it could be suggested that the study participants might have felt pressured in some way into taking part in the study due to previous interaction with the researcher. Such an assumption in relation to this study would be incorrect for several reasons. As the researcher had already worked in the country with children with disabilities it could be suggested that the study participants might have felt pressured in some way into taking part in the study due to previous interaction with the researcher. Such an assumption in relation

to this study would be incorrect for several reasons: The rural district of Al-Abdali had been the setting for the therapeutic riding programme. This agricultural region of Kuwait is close to the border with Iraq and at a great distance from the City of Kuwait where this study was conducted. Not only was a different location used for this study but the parents of the autistic children who formed the group of participants were distinct from those that had taken their children to attend the therapeutic riding programme several years before. The researcher had not previously acted as a consultant for, or provided any services to, either the parents participating in the study or to their autistic children, so the assumption of any sense of parental indebtedness due to earlier assistance or benefits provided to the study participants by the researcher is not applicable in this case.

The mothers of the normally developing children were selected from and through the researcher's social network of contacts that she established after arriving in Kuwait. The rationale for selecting to meet individually was because the researcher considered that the mothers in a group interview might feel embarrassed addressing sensitive topics in focus groups sessions. The mothers might also feel pressure to conform to social expectations and might under-report certain viewpoints (Ritchi and Lewis (2003)). These mothers were introduced to the researcher through people who the researcher met during the social activities (golf, swimming, gym and friendships with hotel staff) in the hotel where the researcher stayed following her arrival in Kuwait. The friendly relationship between the researcher and the interviewees and the informal setting eliminated the possible emergence of any power imbalance between the researcher and the mothers. By the end of each session, the researcher assured the mothers of the confidentiality and anonymity of their perspectives and that data would be stored on a password-protected computer.

In fact, to the best of the researcher's knowledge she had no previous relationship with any of the study participants. Similarly regarding the mothers who were interviewed on one-to-one basis. These mothers the researcher met after she arrived in Kuwait and during her stay at the hotel. Therefore, there were no previous connections with the researcher influencing the parents' decision to take part in the research and there were no issues of prior acquaintance impacting on their subsequent participation. No payment was offered by the researcher to those participating in this study. As residents of a wealthy nation no such incentive would have been required however, and more importantly, to introduce financial incentives could influence participation and adversely affect the research. Nor was there the suggestion on the part of the researcher of any potential personal benefit for the study participants as a result of having taken part in the study. Any such enticements would not have been appropriate for the purposes of the study and all the parents taking part did so purely on a voluntary basis without payment or inducement of any kind. Although the researcher did not specifically question the mothers regarding their reasons for wishing to volunteer, one might assume that their willingness to participate stemmed from their view of the study presenting a forum in which to express their opinions and in which their voices could be heard. Additionally, the participants might have considered the focus group sessions to be an opportunity to meet other mothers of autistic children sharing similar concerns. Furthermore, the researcher being from the Middle East could have given the participants a greater inclination to take part in this research. The researcher speaks the language spoken by the participants and was familiar with the type of approach, specific to the Gulf region, to use to invite the mothers to take part in the study.

Given that the focus of the study is on autistic children at a kindergarten level and the study was conducted in the city of Kuwait, the researcher did not have prospective participants. Therefore, prior to travelling to Kuwait the researcher contacted 2 of the mothers of the autistic children she previously trained in Al-Abdali to find out if they knew mothers of young autistic children living in the city of Kuwait. One of the mothers suggested contacting the owner of an Instagram account who seems to have an interest in autism. The researcher contacted the owner of the account who happened to be the mother of young autistic children willing to participate in the study. In addition, she gave the researcher contacts of two other mothers of autistic children. Consequently, the snowball method provided the researcher with 27 participants who met the study criteria. As neither the researcher nor the participants had met before or had previous knowledge of each other prior to the interviews, and the researcher did not question the mothers regarding the reasons for their willingness to participate, one can assume that these mothers wanted their voices to be heard. In addition, the researcher was at an advantage given that she spoke the same language and was capable of employing culturally distinctive approaches and terminologies.

It could be argued that for those from a similar background, sharing fundamental cultural values potentially provides a source of support especially in respect of women supporting each other for cultural or religious motives or for reasons of female empowerment. To illustrate this point, the researcher's position is that should she receive a request to take part in a study being conducted by a woman in the Gulf region, she would be well disposed to participate and to support the research should she meet the research criteria. A further motivation for their participation could have come from the parents' educational background. Eighteen of

the mothers interviewed were MA and PhD graduates from both national and international universities. As such, they were conscious of the importance of interviewing as a tool in qualitative research and were willing to offer their assistance and be interviewed for the study.

Regarding the issue of social desirability bias in the method of data collection used, the researcher is aware that she has an ethical duty to account for potential sources of bias and the strategies she used in an attempt to minimise these biases. The most commonly recognised source of bias in interviews is social desirability bias (Krumpal, 2013; Grimm, 2010). When this case study research was conducted, the researcher wanted ascertain the views of the parents of autistic children on the inclusion of their children. The researcher wanted to learn their real thoughts and feelings, to understand whether cultural traditions had an impact on the implementation of inclusive education in Kuwait. In an ideal world, all participants would provide honest and clear answers about their innermost thoughts, but the researcher is aware that this is not always the case. Participants will sometimes change their answers in different ways, depending on the environment. Given that self-reporting in the interviews has been used to gain insights, participant bias can have an impact on research findings. Regarding the researcher's subjectivity and bias, this issue as well as the researcher-participants power relationships are discussed under section (3.7).

In the context of conducting her study, the researcher was aware that social desirability bias might stem from a number of factors including a) that the study involves socially sensitive issues for Kuwaitis such as autism and stigmatisation; b) that Kuwait is a highly collectivist society, so its citizens might tend to reinforce conformity to established cultural norms (Ali et al, 1997). According to Johnson and

Van de Vijver, (2002), social desirability bias has been found to manifest in different forms depending on the cultural values of the community. Consequently, there might be a tendency for some study participants to present themselves in positive light to for the approval of others rather than to give truthful answers. According to several researchers including Smith and Noble, (2014); Krumpal, (2013); and Chenail (2011), the wording of bias questions is the key to minimising responses influenced by social desirability bias. Hence, the researcher formulated the questions in a non-leading way so as not to influence the information elicited; the questions were in a format that requires descriptions, explanations, and the rationale behind the answers of the mothers interviewed; and the questions were open-ended to prevent the participant from simply agreeing or disagreeing, and to guide the mothers interviewed to provide a truthful and honest answer.

In the focus group interviews, the researcher employed a number of strategies to detect and limit social desirability bias. For example, the researcher followed each open ended question with a phrase like” “give reasons for your answer” and “describe how from your own experience” (appendix 2). Such requests minimised the social desirability bias in the sense that the participants in the focus groups needed to verify their answers from their own personal experiences and give reasons to justify their replies. Consequently, this limited the participants’ inclinations to provide answers similar to those provided by preceding mothers in the group. Similarly, if one of the participants listed some reasons the same as the mother who proceeded her, the researcher listened as the participant expressed these ideas, and then proceeded to ask questions about the participant’s own experiences, perspectives, and asked whether the participant had any additional comments, or whether she could recall other reasons from her own experience. The researcher also translated the questions into

Arabic in a simple, clear, and concrete manner to reduce any misunderstandings. In addition, the researcher phrased the questions in a manner that allowed the mothers to feel irrespective of their answers. For example, the researcher followed the question with “in your opinion “and “from your own point of view”. The researcher also frequently reminded the mothers that their opinions were not being judged. Thus, encouraging these mothers to give their true opinions and speak freely. The researcher avoided using questions that were likely to receive a closed “yes” or “no” response to gain insight into the participants’ experiences. The researcher also maintained a neutral stance throughout the interview sessions and avoided implying that there was a right answer so as not to influence the participants’ responses. Neither approval nor disapproval of the parents’ responses was conveyed through the researcher’s facial expressions or nonverbal behaviour. Careful contemplation was given to controlling any possible bias on the part of the researcher to ensure the integrity of the study and to guard against influencing the participants in any way. Since the researcher holds different views from the mothers interviewed regarding the inclusion of autistic children, namely, being in favour of inclusion and supportive of social justice for autistic children, it was important that a neutral stance was adopted by the researcher during the interviews.

Furthermore, to mitigate social desirability tendencies the researcher checked the surnames of the mothers with one of the hotel managers prior to each session to verify whether any of the mothers participating or any of her close relatives held a position of power in Kuwait. In tribal cultures, social desirability bias often occurs when someone in a position of power is present in the setting. Given that the researcher is aware of the Arab culture, whilst conducting the focus group discussions, the researcher used the Gulf regions distinctive approaches to establish

rapport with participants, including the use of humour and displayed hospitality and respect. These strategies helped to put participants at ease and make them feel comfortable. Although building rapport is important, the researcher made sure to keep steering the conversation directly back to the questions asked. The researcher also thoroughly explained the confidentiality, anonymity procedures at the beginning of each focus group discussion (see sections 3.7; 3.19.2, and 3.20) and then offered reminders throughout the sessions, especially before raising sensitive issues. By ensuring that the participants know that their data is truly confidential, they will be more likely to reveal the truth (Joinson, 1999). Similarly, assuring the mothers interviewed that their anonymity is maintained also minimises social bias. According to (Joinson, 1999, p.433) “It was found that people reported lower social desirability when they were anonymous than when they were non-anonymous”.

Regarding, the face to face interviews with private kindergarten owners, the interviews were held at the offices of the schools owners. The interviews with kindergarten administrators on the other hand were held at the hotel where the researcher was staying (see 3.21 and 4.3). The questions which the researcher posed in these interviews were socially neutral questions. Thus, the participants were not likely to engage in impression management and social desirability bias issues as their responses did not require them to make social judgments or provide their perspectives. However, the owners of the kindergarten volunteered their opinions about the inclusion of autistic children (see 4.3). These perspectives the researcher documented as they reflect the cultural traditional norms in Kuwait and stigmatisation of autistic children based on their challenges.

The individual interviews with the mothers of typically developing children were largely dependent on building good interpersonal relations between researcher

and participant. When setting up these interviews the researcher ensured that the location was private and not within the hearing range of others. Ritchi and Lewis (2003, pp. 58) stated that when it comes to “topics which people are likely to see as confidential [and] when the researcher is concerned to get beyond what may be seen as socially acceptable” then a private setting of an individual interview is useful. This strategy helped in avoiding social desirability bias and provided the mothers with a sense of safety conducive to revealing particularly sensitive information. Individual interviewing elicits less social desirability bias than focus group interviews (Gaskell, 2000) and participants are less likely to distort the truth to be perceived positively by the researcher. The researcher explained to the mothers interviewed the purpose of the research and how their confidentiality would be protected. The researcher assured the mothers interviewed that their anonymity was guaranteed, and their viewpoints not being judged. As such, they would be more likely to reveal the truth, even if they did not believe it to be social desirable. Although the setting was flexible, the researcher was aware of her body language, vocal inflections, gestures, and facial expressions as these elements might influence how a question is asked and subsequently answered. The researcher also assured the mothers that the objective of the interviews was to understand their viewpoints and, not whether their position would be considered correct or incorrect. Although establishing rapport between the researcher and the participants was important to generate rich data, the researcher made sure that respect was maintained between the participant and herself.

The researcher acknowledges that the development of personal relationships with the study participants was inevitable whilst collecting data. However, building trust and confidentiality with the mothers interviewed, being or becoming familiar with the local culture to understand its traditional values, and being aware of her own

biases are all important elements in collecting valid and reliable data. Whilst the personal relationship with the mothers interviewed encouraged disclosure and trust, it enabled the researcher to understand the cultural context as an insider and to interpret the finding as an outsider and from an impartial perspective. The researcher also acknowledges the possibility of social desirability bias as a limitation in her study method. Whilst the findings of this study are not an attempt to measure social desirability bias per se, the researcher attempted to provide an account of how the implications of social desirability bias in this study might be better understood and addressed.

The researchers recognises that she brought to her study her experiences, ideas, and personal philosophies. Hence, the researcher addressed these factors to enhance the transparency of possible research bias in section (3.7). The University of Lincoln Ethics Committees, the researcher's supervisors had also an important role in considering whether the research design and methodological approaches were biased and provided valuable practical guidance in developing the trustworthiness for this research.

### **3.23 Data Analysis: Thematic Analysis**

The data analysis approach in this study was thematic, moving from fragmentary details to a connected view of the research question. The theoretical thematic analysis procedures for this study involved thorough examination of the transcripts and data revision, comparing the transcripts in order to identify themes and sub-themes and finally, transforming data into research results to make possible the interpretation of the findings. In the process of the thematic data analysis the researcher moved beyond counting explicit phrases and focused on identifying and describing both implicit and explicit ideas. The goal of the researcher was not only to

identify the themes and summarise the information, but also to interpret the data and to construct a complete portrait of early childhood inclusive education for children with autism from the perspectives of Kuwaiti parents. Although the thematic analysis approach is generally considered fundamental in data analysis, this did not signify that this approach produced simple and low quality findings (Braun and Clarke, 2006). Hence, the researcher frequently reviewed the data from the parents' different perspectives searching for the underlying themes which might not have been immediately apparent. In order to allow the study participants to respond freely and to provide rich information to the inquiry, the researcher asked the interviewees open ended questions such as: their understanding of inclusive education; whether they support the concept of inclusive education for children with autism and the reasons for their support; and whether their autistic children were socially stigmatised citing examples from their own experiences. According to Geer (1988, pp.1), the results obtained from open ended questions "should increase our confidence in the work of scholars who have relied on these kinds of questions for their analyses". Mertens et al. (2005) argued that in studies that aimed at providing in-depth description of a phenomenon, qualitative methods are mostly used. Following Mertens' argument, the objective of this study was to comprehend the interviewees' viewpoints and describe in-depth the participants' experiences in their own words. Furthermore, given this research's philosophical assumptions and paradigm, i.e.; relativist ontology, the subjectivist epistemology and the constructivism paradigm, provided the anchor for this study to adopt a qualitative approach.

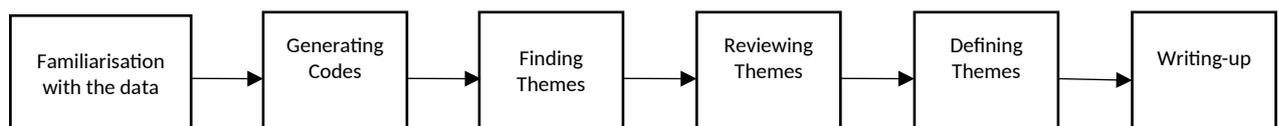
Bogdan and Biklen (1982, pp. 145) defined qualitative data analysis as "working with data, organising it, breaking it into manageable units, synthesising it, searching for patterns" in order to address the initial propositions of a study. Stake

(2005) also argued that the main types of analysis are categorical aggregation and direct interpretation. Based on the above mentioned definitions there are several steps to follow in the thematic data analysis including coding data, managing information, developing themes, describing the findings and interpreting results. In this study, the researcher employed a thematic analysis approach. The researcher followed Braun and Clarke's (2006) thematic analysis framework to identifying themes within the interview transcripts. Braun and Clarke's thematic analysis framework provided the researcher with a clear set of stages to follow in conducting the thematic analysis approach and because it "provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data" (Braun and Clarke's, 2006, pp.5). The thematic analysis in this study was conducted from within the constructivist paradigm i.e., where themes are "identified as socially produced, but no discursive analysis is conducted" (Braun and Clarke, 2006, pp.8) and from within the theoretical framework of the study. Consequently, this study having a constructivism stance sought to identify the themes relevant to the cultural contexts and the social structural conditions through the parents' perspectives towards early childhood inclusion of children with autism. Therefore, the researcher was concerned with addressing specific questions and did not code the interview transcripts line-by-line. By using a theoretical thematic analysis, but not pre-set codes, the researcher coded each and every piece of information relevant to the research questions whilst working through the coding process.

The theoretical thematic analysis procedures for this study involved thorough examination of the transcripts and revising data, comparing the transcripts in order to identify themes and sub-themes and finally, transforming data into research results to make possible the interpretation of the findings. Namey et al. (2008, pp. 138) stated

that “Thematic moves beyond counting explicit words or phrases and focuses on identifying and describing both implicit and explicit ideas”. Thus, by conducting a thematic analysis, the goal of the researcher was not only to identify the themes and summarise the information, but also to interpret the data and to construct a complete portrait of early childhood inclusive education for children with autism from the perspectives of Kuwaiti parents. Although the thematic analysis approach is generally considered fundamental in data analysis, this did not signify that this approach produced simple and low quality findings (Braun and Clarke, 2006). Hence, the researcher frequently reviewed the data from parents’ different perspectives searching for the underlying themes which might not have been immediately apparent.

Braun and Clarke (2006) suggested a guided of six steps as a frame work for thematic analysis:



**Figure 4.** Six Steps of Thematic Analysis

### **3.23.1 Familiarisation with the Data**

Following each interview session the researcher filed all interview notes in order of date of creation. The data was re-transcribed verbatim and placed into separate files according to necessity and relevance, given the research questions and initial analysis. The researcher reviewed the research questions and compared them against the data collected to determine whether the information actually answered the research questions. The analysis of the data was driven by the study questions and the

thematic analysis of this study was theoretical thematic analysis. The files created depended completely on what was reasonable and necessary, given the research questions. Braun and Clarke (2006) distinguished between a theoretical thematic analysis, driven by the researcher's focus and the specific research questions and the inductive analysis driven by the data itself. Bogdan and Biklen (1982) and Yin (2009) argued that in a case study, data collection and analysis often go hand in hand whereby the results of the analysis will help guide the succeeding collection of data. That is to say that, data collection and data analysis inform each other to synthesise the information induced from the interviews. Therefore, the researcher examined and re-examined the raw data after each interview and categorised the information in the form of headings that described the parents' responses and the information that the researcher considered important.

### **3.23.2 Generating Codes**

The process of data coding or data reduction was described by Bryman (2016, pp. 689) as “the process whereby data are broken down into component parts, which are given names”. The researcher repeatedly read through interview notes to identify items relevant to the research questions. Data coding these items involved the systematic processes of looking for frequency, and declaration, i.e. issues, the existence of which were identified to the researcher by the parents such as certain matters of a traditional nature. The researcher coded and sub-coded the data by using a short phrase that descriptively captured the core components of the data transcripts. The codes were cut and pasted on a poster board while other pieces of information from the raw data were written down in a journal to be used later in the final analytical process stages. The coding process was based on organising the information relevant to the conceptual frame and the objectives of this study. By

coding the data the researcher reduced the volume of information collected in order to manage the information and to map the relevant information into key themes. The main purpose of coding in this thematic analysis approach was to make connections between different sections of the data (Braun and Clarke, 2006). Thus, the identification of key themes depended on the data coding process in which the various codes were classified and partitioned into larger themes and sub-themes (Gibbs, 2007). Subsequently, these themes were analysed, interpreted and conceptualised in relation to the research questions.

### **3.23.3 Finding Themes**

Themes were characterised by their significance (Braun and Clarke, 2006). Following the coding of each transcript by chunking the data into their component parts, these parts of data were given descriptive phrases and organised into headings and subheadings. This stage was followed by the search for reoccurrences of these sequences of coded texts within and across parents' responses and also for the links between the different codes (Guest et al. 2012). Codes that fitted together were connected and then categorised into themes and the items that were identified as the constituent parts of the themes were classified into sub-themes. Themes that captured significance about the research questions were organised in terms of meanings and perspectives which the interviewed parents described with reference to each question of the interview guide. For example, the transcripts had several codes that related to parents' understanding of the concept of inclusive education. These meanings were collected into one initial theme and given the phrase 'meaning of IE' (inclusive education). The few codes that were relevant to two themes were initially classified under miscellaneous theme to be managed at a later stage. To avoid contradictions between the themes the research constantly compared the descriptions, and the

supporting data of each theme (Braun and Clarke, 2006). The themes were assembled in ways that established a coherent description of parents' viewpoints and the regularity of the patterns within the Kuwaiti cultural context.

#### **3.23.4 Reviewing the Themes**

Borkan (1999) argued that the process of going through data thoroughly is known as 'immersion'. In scrutinising the data, the researcher employed the two processes which Borkan referred to as 'immersion' and 'crystallisation'. Crystallisation according to Borkan is the process of temporarily suspending immersion in order to identify and substantiate the themes. Hence, the researcher used the individual interviews with parents of normally developing young children to ensure the appropriateness of data, the reliability of interpretation and the triangulation of data (Braun and Clarke, 2006). The researcher re-examined the descriptions and meanings of the themes to ensure that all sets of items served to answer the research questions and that these themes were triangulated.

#### **3.23.5 Defining the Themes**

Regarding the manner or the level in which themes were identified, Boyatzis (1998) claimed that themes should be identified either at an explicit level or at an interpretative level. Conversely, Braun and Clarke (2006) stated that thematic analysis incorporates both explicit and interpretative aspects and that the analysis of interpretive content of data is an inseparable part of the explicit analysis approach. Following Braun and Clarke, the researcher employed an analytical process which involved progression from description, where the data was organised to show patterns from the explicit content to identifying the underlying ideas, assumptions, and ideologies that might have shaped the explicit content of the data. The combination of

both the explicit and interpretive manner of identifying themes was compatible with this studies constructivism paradigm, namely; by attempting to understand the complex world of lived experience from the point of view of the parents toward early childhood inclusion for children with autism (Schwandt, 2000). In the final stage the researcher assigned the final title to each theme, wrote its description and clarified each theme with excerpts from the transcript to support the qualitative data and finally reported each theme. The translated themes and excerpts from the transcript were compared to the original meaning unit to ensure that the essence of the original meaning was preserved. Relationships of the themes with one another were re-examined and, finally, integrated into a coherent concepts and assembled into structures that taken together, built an overall description of parents perspectives towards the inclusion of young children with autism. It is worth mentioning here that the researcher used manual analysis because the data contained direct quotations regarding the participants' perspectives and meanings. Furthermore, all the data was collected in Arabic using the journal note- taking method.

### **223.6 Writing-Up**

The themes in this study were drawn from the data collected in order to construct a holistic picture of the concept of early childhood inclusive education in Kuwait for children with autism from the parents' perspectives. In this final stage of the thematic data analysis, the researcher refined the themes by checking whether the sub-themes related to the key themes and whether the themes logically interconnected to maintain a chain of evidence and to present a holistic picture of parental perspectives on the early childhood inclusive education of children with autism in Kuwait. In order to bring to closure the series of steps of the findings of this case study, the researcher produced a comprehensive descriptive report of the analysis.

According to Yin (2003), case study is a process of inquiry and the product of that inquiry is the report. Therefore the researcher submitted a rich descriptive report of each theme which emerged from the data, quoting evidence from the parents' perspectives whilst relating these themes to the literature written on each specific topic. The themes and their interpretations that provided answers to the research question were presented in separate sections and within the conceptual and theoretical frameworks of this holistic single case study.

### **3.24 Rationale for Thematic Analysis**

The rationale for using thematic analysis was that this approach can be based on constructivism paradigms (Braun and Clarke, 2006). Sandelowski, (2003) also noted that researchers employ thematic analysis when they want to find out about the actual viewpoints of the people being studied. From a constructivist point of view, the researcher believed that the parents' interpretations of their realities as conveyed through their perspectives were factual and truthful indexes of their reality. The thematic analysis approach was chosen because: it was the appropriate approach to answer the study question; it enabled the researcher to conduct a methodologically robust study of a novel phenomenon in Kuwait; the thematic approach provided the researcher with a framework of analysis within which the Kuwaiti cultural context of data was evident; the thematic analysis approach also enabled the researcher to combine analysis of data meanings within their particular context, and this approach "can be applied across a range of theoretical and epistemological approaches" (Braun and Clarke, 2006, pp.4).

However, thematic analysis has been criticised as being a flexible method and 'anything goes' (Braun and Clarke, 2006, pp. 27). Braun and Clarke argued that

criticism of thematic analysis is similar to the criticism of the qualitative research approach in general, i.e. the lack of scientific rigour and credibility associated with traditionally accepted quantitative methods. Hence, Braun and Clarke advised the researchers who employ thematic analysis in their studies to be explicit about the procedures of conducting the analysis and to apply the methods rigorously. “Rigour lies in devising a systematic method whose assumptions are congruent with the way one conceptualises the subject matter” (Braun and Clarke, 2006, pp. 27). Lincoln and Guba (1985) argued that credibility, dependability, confirmability and transferability are the most common measures to achieve rigour in qualitative studies including the case study method. These measures are discussed in the next section.

### **3.25 Issues of Trustworthiness**

According to Creswell (2007), trustworthiness and validation provide a qualitative research with distinct strength in that the account made through extensive time spent with the participants, the detailed description, and the closeness of the researcher to participants in the study all add to the value or accuracy of a study. On the other hand, Lincoln and Guba (1985, pp. 18) stated that:

Instead of using quantitative terms such as "internal validity," "external validity," "generalizability," and "objectivity," the qualitative researcher writing a case study may employ terms such as "credibility," "transferability," "dependability," and "confirmability".

To this end, Guba and Lincoln were of the opinion that trustworthiness involves establishing a number of strategies in order to demonstrate the trustworthiness of the findings of a qualitative study. These strategies included: 1) credibility, in order to establish credence in the truth of the study findings; 2) transferability, to indicate that the findings are applicable in other situations; 3) dependability, to show that the

findings are consistent and 4) confirmability, to demonstrate that the findings of the research are unbiased. Informed by the literature on the strategies that ensure the trustworthiness and the authenticity of the qualitative case study, the researcher employed the following strategies:

### **3.25.1 Credibility**

Guba and Lincoln (1994) claimed that credibility is one of most important measures in establishing the trustworthiness of the findings of a qualitative study and emphasised that credibility can be established through triangulation. Yin (2003) and (Patton, 1999) stated that triangulation refers to the use of multiple data sources in qualitative research to develop a comprehensive understanding of phenomena. The authors identified four types of triangulation: (a) method triangulation (b) investigator triangulation, (c) theory triangulation, and (d) data source triangulation. According to several researchers including Meijer et al (2002); Denzin and Lincoln, (2000) and Patton, (1999); Morgan, (1996) the type of triangulation chosen depends on the nature of the research question and should complement the methodological paradigm that informs the question. (Creswell, 2007).

The researcher used the data source triangulation method to test the credibility of the findings within the focus groups. This method involved the member checking strategy of the multiple perspectives about the same phenomenon collected from twenty seven mothers of autistic children who were interviewed over five focus group sessions. The researcher employed the data source triangulation method by accommodating the viewpoints and experiences of all interviewed parents and comparing the accounts of the parents' responses in the same context as well as

member checking. In the context of all of the issues within the focus groups the member checking strategy for triangulation purposes was established.

Given the lack of literature regarding inclusive education for autistic children in Kuwait, the researcher employed data source triangulation to validate data from the focus groups. To triangulate the mothers' replies regarding the concept and the implantation of inclusive education for autistic children, the researcher interviewed owners and administrators of public and private schools (see. 3.21.1). These interviews enabled the researcher to obtain actual information directly from those who were personally involved in the policies of education and early childhood inclusive education. The findings of these interviews corresponded to those obtained from the focus group sessions. Inclusive education has not been implemented in Kuwait and integration and inclusive education are used interchangeably in Arabic whether as concepts or terms of reference. Despite policy makers' reports that suggest that inclusive education is in the process of being implemented, the findings of the study demonstrate that the absence of direction in inclusive education for children with autism is evident in Kuwait.

The researcher used the member checking method to triangulate the study findings regarding the lack of advocacy and support for inclusive education for autistic children based on: concerns for the well-being of both normally developing autistic children in an inclusive setting; concerns regarding bullying; apathy towards the benefits of inclusive education in developing autistic children's social skills; rejection of inclusive education in favour of self-contained special education; concerns and considerations for normally developing children's parents; and stigmatisation of autistic children as well as the non-existence of parental role in participating in decision making regarding the policies relating to the education of

autistic children. In addition, the researcher tested the validity through the convergence of information from the literature review (see 4.2.2 Section two). All but two of the findings were not identified in the literature review, i.e., apathy towards the benefits of inclusive education in developing autistic children's social skills; and concerns and considerations for normally developing children's parents. However, these two factors are culture specific. Regarding the first factor, Kuwait's tribal settings offer a large family size with siblings close in age (Ibrahim, 2012). Therefore, autistic children are usually surrounded by typically developing children including their siblings and cousins. As such, this advantage was not much of significance to the study participants. As for the second factor, the negative attitudes of the society, based on stereotype, stigmatisation, and associating autism with shame, is also specific to the Kuwaiti traditional norms.

To decrease the incidence of incorrect data and the incorrect interpretation of data, with the overall goal of providing findings that are authentic and original (Creswell, 2007; the researcher used the member checking strategy. Following each interview the researcher: examined the transcripts; initially identified the relative information to the study questions; each mother's answers to the interview's questions were organised; and the core information were categorised and tentatively analysed. The researcher outlined each mothers' viewpoints and contacted each mother to schedule to meet again or to review her perspectives by phone. Thirteen mothers were met for a second time face-to face and fourteen mothers were consulted by telephone. The initial impressions of the findings from each mother's viewpoint were discussed with the individual mothers and the relevant modifications or additions were made. By comparing information from different mothers on diverse issues and confirming the information of the participants at different stages of the study, as well as

examining the participant's responses to the questions versus in contrast with what she said during the discussion with the rest of the group, if consistent; such triangulation contributed to knowledge production and synthesis.

In this manner, the co-created conclusion of the study was established and the researcher ensured that the data was true to the participants' experiences and subsequently, the credibility of the research. Albeit that the agreement of the parents' perspectives was an added value since the purpose of this study was to identify parental perspectives towards the inclusion of young children with autism, additionally, member checking, contributed significantly both to the construction of a case and to its validity. However, the convergence of the parents' viewpoints is not a representation of the whole population but to the study participants and the scope of the study. The limitation of member checking, however, is that it depend on the perception that there is a fixed reality that can be accounted for by a researcher and can be confirmed by a respondent, which may not be true (Lincoln and Guba, 1985).

### **3.25.2 Transferability**

Guba and Lincoln (1994) suggested that the strategy that can be used to facilitate transferability is a thick description of the study. Schwandt, (2001, pp. 255) defined thick description by stating that "It is this interpretive characteristic of description rather than detail per se that makes it thick". Similarly, Ponterotto (2006, pp. 543 ) summarised the definition of several authors including Ryle (1971), Geertz (1973), Denzin (1989), Holloway's (1997) and Schwandt, (2001) and concluded that thick description describes observed social actions and assigns purpose to these actions, "by way of the researcher's understanding and clear description of the context under which the social actions took place". Therefore the researcher described

thoroughly not only of parents' perspectives on inclusive education for children with autism but also of the contexts in which parents' experiences occurred. The research also interpreted the findings in terms of the implications of the social, religious and cultural dimensions of the environment of the parents as well as the impact of the social context on shaping parents' perspectives.

### **3.25.3 Confirmability and Auditability**

Lincoln and Guba (1994) argued that auditing establishes the dependability and the confirmability of the study. Auditability and confirmability refer to the arrangements that would enable one researcher to follow the analysis pattern of another and arrive at similar findings by using the same documents and transcripts. Therefore, the researcher laid down the audit trail by describing all the stages of the study and included all the tools used in the study in the appendixes section. This procedure ensured the reliability and reproducibility of the data and the stability of the workings of the study. Moreover, the researcher archived collected data in an organised form in order to make it available for other researchers or should the findings of the study be challenged.

### **3.25.4 Reflexivity**

A number of authors including Bryman (2016), Yin (2009), Holliday (2007) Stake (2005) and Lincoln and Guba (1985) argued that it is not possible to eliminate bias but a reflexive process ensured transparency. The researcher documented the procedures for checking the data throughout the research and used the reflexivity technique by keeping a journal to document any accounts of the researcher's individual subjectivity, opinions and biases towards parents' perspectives on early childhood inclusive education for children with autism. The research journal included

the researcher's reflections from the data collecting phases and some assumptions that have been made.

### **3.25.5 Rigour**

Tobin and Begley (2004, pp. 390) defined rigour as the way by which “we demonstrate integrity and competence, a way of demonstrating the legitimacy of the research process”. Similarly, Holliday (2007, pp. 58) argued that in order to establish validity and rigour “researchers need to show their workings in their writing as explicitly as possible”. Accordingly, the researcher detailed the description of the procedures of the study including the management of subjectivity and bias. In this qualitative case study the overall reliability of the research was demonstrated by the various strategies adopted from within the constructivist paradigm and the qualitative methodology. The several steps inherent in qualitative case study method were applied throughout the study to demonstrate the study's credibility and rigour.

## **CHAPTER FOUR: STUDY FINDINGS**

### **4.1 Introduction**

The aim of this holistic, single case study research was to present an accurate account of the parents' perspectives on early childhood inclusive education for children with autism in Kuwait. Most importantly to represent in a straightforward manner, the factors that shaped the parents' perspectives including the cultural aspects; educational policies regarding early childhood inclusive education in Kuwait; and the parents' stances towards autism, namely, whether parents' approached autism disorder from a medical model, that is if parents perceived autism disorder as a medical condition and it is the autistic person's brain that needs to be fixed (Davis, 2013) or from a social model that perceives the problem of the disorder as a problem with the society and not as a problem within the autistic person (Haegele and Hodge,

2016). Furthermore, the study explored parents' roles as partners in the educational decision making process for their autistic children and as advocates for their autistic children's rights to educational inclusion. To undertake the study, twenty seven parents of young children with autism were interviewed to explore their perspectives on the inclusion of their autistic children. Additionally, two owners and two administrators of private and public kindergartens were interviewed individually to substantiate whether early childhood inclusive education policies had been implemented in Kuwait. This section on the description of the findings in relevance to the study questions and literature will be followed by a section on the analysis and the interpretations of the findings from within the theoretical frame work, namely; the Bio-ecological Systems Theory (Bronfenbrenner and Morris 2007).

## **4.2 Findings in relevance to the study questions and literature: the focus groups Interviews**

### **4.2.1 Section1: Parents' understanding/lack of understanding of early childhood inclusive education for autistic children**

Question (1) was regarding parents understanding of the concept of inclusive education for young children with autism. This question was informed by the pilot study and the literature review. For example, several researchers including Weber (2012), Gaad (2011) and Nadra (2009), believed that inclusive education is still very new to Kuwait and it might not be implemented successfully in the near future. None of the mothers interviewed were familiar with the concept of inclusive education which was defined by a number of authors including Falkmer et al., (2015); Peters (2007); and Ainscow et al. (2005) as an education movement that secures

opportunities for students with special needs to learn alongside their normally developing peers in general education classrooms rather than being placed in special education settings. In answering the first question: If your child is attending an inclusive education setting in a kindergarten, explain what does 'inclusive' mean in your opinion? None of the mothers interviewed differentiated between integration and inclusive education. The mothers interviewed provided different interpretations of inclusive education based on their children's scholastic settings. For example: Um Jojo noted: *"my daughter attends a private inclusive kindergarten which has a section for autistic children. She joins her non-disabled peers at lunch time"*. Similarly, Um Abadi said *"the kindergarten which my son attends is a public kindergarten, all the kindergartens are the same whether public or private. They lack specialised teachers"*. On the other hand, a different interpretation of inclusive setting was given by Um Ros who stated that: *"the kindergarten which my son attends does not have a special section for autistic children. All children with different disabilities study together in the same classroom"*. Likewise Um Aziz noted *"there are some inclusive kindergartens here where children with different disabilities are all educated in the same classrooms"*. Um Wahabi noted *"my son is a genius in maths. The teacher pulls him out from his class to attend math classes with his normal peers, but I always receive complaints about his behaviour"*. Equally, all the mothers interviewed gave similar descriptions to their children's educational settings and regarded all the settings as being inclusive.

Mothers with kindergarten-age autistic children considered integration and inclusion to be synonyms. However, the difference between inclusion and integration according to Falkmer et al., (2015) is that integration assumes that children have a special education setting from which they might be placed periodically into a regular

setting when educators think that these children will be successful there, while inclusion assumes that the regular setting is, not a placement to be earned. From the perspectives of all the parents interviewed, early childhood inclusive education meant that autistic children in the kindergarten setting join their normally developing peers in some play sessions and at lunch time or all children with different types of disabilities are taught in the same classrooms. All the research participants agreed that inclusive kindergartens offering provision for autistic children fall into two settings models: one setting is where autistic children are grouped with other children with different types of disabilities in the same classrooms; and the other setting model is where autistic children have their own classes in regular schools but they are sometimes integrated with normally developing children in the playgrounds during break times. The study participants' responses regarding the inclusive educational settings for autistic children in kindergartens demonstrated that there was a confusion over the semantics of inclusive education and integration as well as the lack of conceptual clarity of the very notion of inclusive education. The implications of these findings in relation to the educational developments at policy level in Kuwait are discussed in the data analysis section of this study.

#### **4.2.2 Section two: Lack of advocacy and support for early childhood inclusive education for children with autism.**

Young children with autism need comprehensive intervention methods focusing on improving socialisation and communication (Koegel, et al., 2012). Despite the unique challenges that children with autism present to the school system, children with autism are increasingly enrolled in general education classrooms (Centre for Disease Control, 2010). In response to the second question of the study: whether the mothers interviewed would support inclusive education of their autistic

children with appropriate support services? Almost all of the mothers interviewed opposed the idea of having their autistic children pursuing all of their education within an ordinary kindergarten setting with their normally developing peers. Only two of the mothers interviewed were of the opinion that inclusive education might be a good setting for their high functioning children. These two mothers stated that once their children's challenging behaviours were managed and there were schools that have teachers specialised in autism the idea of inclusive education might be feasible. However, these two mothers added that "*inclusive education for autistic children will not happen in our life time*". All of the mothers interviewed were supportive of partial inclusion only for high functioning autistic children provided that there was appropriate support such as the presence of special education teachers with the child during inclusive sessions to manage the child's behaviours.

According to O'Gorman and Drudy (2010), the scholastic settings available for students with special needs include: full inclusion, i.e. the placement of a special needs student into the general education setting full time with support provided in accordance with each student's specific needs; or partial inclusion namely, special needs students being included in the general education classroom only for particular subjects such as mathematics whilst the remainder of the day is spent in a special education classroom or resource room; or a self-contained setting, i.e. students with special needs are placed in separate classes with specialised instruction but may still join their general education peers at recess and lunch. All of the mothers interviewed were of the opinion that self-contained settings are the best educational setting for autistic children whereas the partial inclusive settings might be a suitable settings for high functioning autistic children with support provided by a special education teacher. The participants unanimously expressed disapproval of the concept of

inclusive education for autistic children. The study participants' disapproval of inclusive education was based on 6 areas of concern:

- Firstly, concerns for the well-being of normally developing children in an inclusive setting. Mothers were concerned that autistic children's self-injurious behaviours might cause fear in other normally developing children. For example, Um Kimo was of the opinion that: *"my son's frequent tantrums and self-harm might scare other normally developing children in an inclusive setting"*. Similarly, Um Koko said: *"my son hits himself with his fists and bangs his head. Such behaviours will distract his normal peers and will negatively affect the quality of their education"*. Some mothers were concerned that normally developing children would learn to imitate the self-stimulatory behaviours relevant to autism such as hand flapping, spinning, or repetition of words. For example, Um Dan noted that:

My normal twins who are younger than my autistic child started imitating their brother. They bite themselves and flap their hands. Children imitate each other. When autistic children are with non-autistic children in the same classroom every day, normal children will imitate autistic children but autistic children will not imitate normal children because they do not pay attention to people around them.

Ingersoll (2008) argued that children copy what they hear and see other people say and do. Children pay attention to one another and influence each other's behaviour. One of the ways by which children influence one another is through imitation of each other's actions. Imitation is a powerful form of learning and children commonly use imitation to foster a sense of social connection with their peers (Bandura, 1977). Autistic children on the other hand, have deficits in imitation skills. This deficit is predominantly pronounced when the purpose of imitation is social.

Typically developing children learn to imitate without being taught but children with autism on average fail to use imitation in the absence of direct instruction (Ingersoll, 2008). Correspondingly, in describing this type of behaviour in her own child Um Kadi said *“my child does not even look any one in the eye, how is he going to learn from other children”*. Similarly, Um Hamani noted *“my child probably knows what is going around him but he does not show any reaction”*.

- Secondly, concerns regarding autistic children in an inclusive setting. For example, Um Nafnaf said that: *“My daughter is intolerant of loud noises. She cannot be among normal children, noises cause her extreme responses”*.

Equally, Um Fodi stated that *“my child screams when he is touched”* and Um kadi noted *“my son can be hurt or injured by accident, but he would not know how to relate his pain in words”*. Most of the mothers had concerns regarding the sensory sensitivity of their autistic children such as light and noise.

Children with autism have impairments in sensory processing (Brown and Dunn, 2010). A high percentage of children with autism show unusual responses to sensory experiences compared to the responses of typically developing children with the same chronological age (Wiggins, et al 2009).

The inclusion of sensory difficulties in the DSM-5 criteria (American Psychiatric Association, 2013) indicated that the sensory dysfunctions affect the entire spectrum. However, the greater the severity of autism the greater the sensory dysfunction. Environmental aspects of the classroom context, such as stimulation overload produced by noise, light and physical contact when working cooperatively with peers can affect not only the children's personal functioning, but also their classrooms daily routines (Wiggins, et al 2009 and Ashburner et al., 2008). This pervasive feature of autism spectrum disorder

may contribute to inappropriate behaviour and can keep children from engaging in scholastic daily activities and performing positive adaptive responses to classroom demands.

- Thirdly, concerns regarding bullying were expressed by the mothers regarding their autistic children being educated in an inclusive setting. For example, Um Kadi said that *“in an inclusive setting my son will be bullied by normally developing children the way he is bullied by his cousins”*. Um Al also noted that *“my normal son attends the same school as my autistic son but in general education. He tells me that children in special education classes are bullied constantly”*. Um Jojo noted *“my daughter might not recognise that she is being bullied but I will never put her in the same classroom with children who will bully her”*. Autistic children can be more at risk of being bullied than their normally developing peers because of their difficulties with verbal and nonverbal communication (Schroeder et al, 2014). Alsaker (2004, pp. 289) stated that *“the extent to which victimisation occurs in the early childhood years is comparable with that in grade school”*. Bullying has a stressful effect on young children with autism and may influence the autistic child to display a wide range of challenging behaviours including spinning and arm flapping in the classroom (Schroeder et al, 2014). Similarly, Mishna (2003) in a literature review on the factors and the characteristics that make children with disabilities vulnerable to bullying argued that many children with disabilities bear a stigma related to their disabilities which poses a risk for their social, emotional, and behavioural problems.
- Fourthly, apathy towards the benefits of inclusive education in developing autistic children’s social skills was reported. The researcher prompted the

participants to discuss the socialising benefits of inclusive education for autistic children. Several authors including Hansen, et al. (2014) and Willis (2006) argued that in an inclusive setting playing with peers such as sharing, taking turns and forming friendships provides natural opportunities for children with autism to learn to play. Similarly, Odom and Bailey (2001) cited a body of research that has shown that children with autism participate in more advanced forms of play with normal children than when joining in play with other children with disabilities. Strain et al. (2012) also stated that young children with autism are more likely to generalise their learnt social skills while in inclusive settings particularly with peer support. The above mentioned authors were in agreement that regular and continual interaction in inclusive classrooms offers children with autism opportunities to develop and generalise their social skills. However, the study participants showed a lack of interest in the benefits of inclusive education in developing the social skills of their children. According to the mothers interviewed, their autistic children are always surrounded by normally developing children including their siblings and cousins. For example, Um Kadi said:

Families in western countries normally have one child or two therefore they encourage inclusive classrooms in order for their autistic children to play with other normal children. For us in Kuwait each house has dozens of children in the family. I have 5 children and my sisters and sisters-in-law have large number of children. We live in the same building and all the children play together all the time, but my son refuses to join them.

The apathy of almost all the mothers interviewed towards the socialisation benefit of their autistic children in an inclusive setting was based on multiple factors such as: having a relatively large number of siblings with whom the autistic child can socialise; being part of an extended family living all together as is the case in tribal

societies; the mothers' concerns in respect of the difficulties their autistic children might face such as bullying and harassment by their normally developing peers in inclusive classroom settings; the belief that autistic children do not try to get close to other children; and that autistic children do not have play skills. Furthermore, some of the mothers interviewed argued that their children were incapable of social interaction because their children were nonverbal, they lacked awareness of their surroundings and they lacked the social and emotional reciprocity. According to Neitola and Laine (2003) during early childhood, at the kindergarten stage, autistic children have many kinds of peer related problems including rejection, harassment, withdrawal, and loneliness. A number of researchers on autism also noted that children with autism lack the ability to relate to others in a reciprocal fashion. For example, Kanner (1943, pp.247) stated that the autistic child "when with other children, he does not play with them. He plays alone while they are around, maintaining no bodily, physiognomic, or verbal contact with them". The National Association for the Education of Young Children (2007) held the opposite view to the perspectives expressed by the interviewed mothers of young children with autism towards their inclusion in terms of benefits of socialising and playing. The Association reported that through play, preschool children develop social and communication skills and become better prepared for future school years. The report highlighted the importance of social reciprocity as a major educational goal for all preschool children. However, social reciprocity is a challenging deficit for the children with autism and they lack the skills to develop peer relationships (Chang et al, 2015). Therefore a number of researchers including Warner et al (2007), Speer et al. (2007) and Howley and Arnold (2005) maintained that children with autism require specific direct instruction on how to play with peers to develop their playing

skills when they are placed in an inclusive environment. The educational inclusion of children with autism, continues to be a topic of controversy (Harrower and Dunlap, 2001). However, without effective planning and systematic intervention, children with autism may be at increased risk for social isolation (Hansen et al., 2014). As noted above the opinions of the mothers interviewed were more of concern and apprehension towards the inclusionary play method and the acclaimed benefits of socialising for autistic children in inclusive classrooms.

- Fifthly, the mothers rejected inclusive education in favour of self-contained special education for autistic children. Several scholars contended that students with disabilities benefit socially and academically from inclusive education (Ainscow et al, 2011; Mitchell, 2006; Odom et al, 2004). Conversely, the study participants strongly believed that self-contained settings are the best education settings for autistic children. All the mothers interviewed stated that their autistic children are either non-verbal or having challenging behaviours or sensory processing challenges therefore, the mothers maintained that their children cannot participate in general education programs. For example, Um Adi said “*my son is non-verbal and he needs one-on-one attention and behavioural support. In general education his needs can never be met*”. Um Kimo also stated “*my son needs routine. General classrooms will be overwhelming for him. A self-contained classroom is the best setting*” Um Saud added “*even the teachers complain about the autistic children behaviour, they say children with Down syndrome are much easier to manage*”. The mothers interviewed unanimously agreed that small group classrooms where teachers who are specialised in ABA (applied behaviour analysis) would be the best setting for their children. However, the mothers

voiced their concerns regarding the lack of professionals in ABA in Kuwait.

Um Hamani stated “*we don’t have teachers who are qualified to teach children with autism. Special education teachers are not trained to work with autistic students*”. Similarly, Um Ros said “*We need ABA qualified educators. The most important issue for us is the behaviour of our children not the academic subjects*”. Um Saud added:

My son is in KG2. He still has major social and behavioural problems. It is impossible for him to study in a general education school. I don’t blame the teachers because they are not specialised in behaviour techniques and management. It is the policy makers fault. They should provide studies in intervention methods at university level.

Kauffman, et al (2005) backed the study participants’ viewpoints regarding self-contained educational settings being the best option for students with cognitive or behavioural disabilities. Kauffman, et al (pp. 2) stated that: “Some children with disabilities can be and are taught very well in general education classrooms. We do not believe that all of them are or can be”. The authors argued that students with autism need to be educated in separate environments and that general education settings may be incapable of accommodating students’ diversities. Correspondingly, Landrum et al (2003) stated that self-contained classrooms for small groups of children with behaviour difficulties can provide more individualised highly structured environments. Kauffman, et al and Landrum et al backed their arguments by claiming that the goal of inclusive education is that all children with and without disabilities are all well educated at the same time and in the same classroom. However, the authors added, there is no empirical evidence that all teachers can teach all students including students with diverse disabilities within a general education setting. The authors’ arguments were aligned with the perspectives of the parents interviewed that, general

education cannot meet their autistic children's needs and that self-contained education classroom settings provide better support and structure for autistic children.

Nonetheless, the mothers unanimously emphasised that even in a self-contained classroom, unless there are specialised teachers in autism and ABA, their children can never improve. All of the mothers interviewed blamed the Ministry of Education in Kuwait for not arranging with universities to establish courses in autism and methods of early interventions. Um Adi for example, argued that "*some families invite specialists in autism from abroad on their own expense for their own autistic members of the family. Not every family can do that*". Um Kadi also argued that: "*our children's behaviours are challenging and the prevalence of autism is high. We don't have specialists and policy makers do nothing*". The participants voiced their frustration regarding: the lack of early intervention specialists, the high prevalence of autism with no cure in sight, the passivity of the policy makers towards establishing facilities and support services for autistic children in Kuwait, and the social stigmatisation towards their children. However, none of the mothers interviewed expressed concerns towards the right of their autistic children to inclusive early childhood education. The mothers interviewed rejected the concept of inclusive education for autistic children in favour of the special education setting. The study participants were of the view that inclusive education settings do not meet the needs of autistic children. It was obvious from the study participants' viewpoints that the characteristic of autism was an important aspect influencing the inclusion of autistic children. Autism characteristics, such as the lack of social skills and social interest; being unable to concentrate and understand instructions; and the lack of adaptive responses to situational demands were perceived by the interviewed mothers as barriers to their autistic children's inclusion.

- Sixthly, concerns and considerations for normally developing children's parents were highlighted in responses. All of the mothers interviewed showed great consideration for the attitudes of parents of normally developing children in an inclusive setting with autistic children. The mothers interviewed extended their concern not only to the normal children but to their parents as well. For example, Um Jojo said "*parents of normally developing children will never accept having autistic children educated alongside their children*". Similarly, a number of mothers including Um Aloush, Um Fodi and Um Susu stated "*I myself would not accept that my normal child be taught in the same classroom with disabled children. This will affect his education*" or "*other families would not want their children acquiring negative behaviours from autistic children and acting these behaviours in public and be labelled*". Some of the mothers interviewed also stated that parents of normally developing children would not want their normal children affiliated with autistic children in order not to be mistaken for being autistic. A few of the mothers interviewed who had high functioning autistic children described the strengths their children have and the unique ways their children demonstrated their talents in maths, memorising or drawing, these mothers argued that because their children are diagnosed with autism and because at times they behave inappropriately, the kindergartens would not accept them in regular classroom. Um Sami for example pointed out "*people do not understand that Albert Einstein was autistic, but in our society brilliant autistic children are not appreciated because of their abnormal behaviours*". However, even these few mothers were content with having their high functioning children in special education sections because of these children's autistic behaviours.

#### **4.2.3 Section three: Children with autism are socially stigmatised in Kuwait**

The third question in the interview guide focused on whether autistic children were socially stigmatised. The rationale for this question was to draw out the implications of stigmatisation on the implementation of early educational inclusion of children with autism in Kuwait. Furthermore, this question was posed to explore the impact of culture on shaping parents' perspectives towards the inclusion of autistic children. In this study culture refers to the shared beliefs, norms, values, traditions and religious orientation that the study participants had in common (APA, 2003). The objective of the study was to explore the cultural implications on parents' perspectives as they relate to the stigmatisation of autistic children. Stigma on the other hand, according to Hinshaw (2007) is the devaluation of certain people on the basis of some characteristic they possess and therefore these individuals are disgraced by the general society. That is to say that, for this study, stigma refers to the social judgment of autistic children due to being labelled as having a disorder.

When questioning the mothers about the labelling of their children, the responses from mothers of children with moderate autism were often accompanied by strong views on social stigmatisation within the family members as well as in public encounters. Mothers of high functioning autistic children argued that their children are less stigmatised in the outside world, but their children still generated conflicts based on stereotyping among family members. For example, Um Aloush said:

People pull away their children as if my child has some contagious disease. I don't go out or socialise to avoid rejection due to my son's autism. People in shopping malls or restaurants and even my friends do not accept my child's behaviour.

Similarly, Um Jo said:

A couple of weeks ago I took my son with me to the supermarket. Two children kept following us, watching my son flapping his arms, spinning and screaming. The children's father approached me and when he saw my son he told me: if your son is crazy, why don't you keep him at home instead of creating a scene and scaring other children.

All of the participants shared the same viewpoints. Their autistic children were stigmatised and their children's autism characteristics had negatively impacted their family lives and their social lives. For example, Um Fodi stated that "*My husband recently married another woman. We have two autistic children and he blames that on my genetic heritage*". On the other hand Um Sous who has a high functioning autistic daughter said:

I don't have problems when I take my daughter out because she is pretty and looks normal. However, I don't introduce her to people because my older daughters will never have the chance to marry into other families. It's God's will.

In terms of stigmatisation in inclusive settings, the study participants unanimously agreed that the parents of normally developing children would oppose the concept of inclusive education. The mothers interviewed stated that they themselves would not accept their non- autistic child being in the same classroom with a number of autistic children through the entire day. The mothers provided a number of reasons for their opinions. For example, Um Nana said "*I would not want my normal daughter to be labelled. Parents who visit the kindergarten might think she is not normal*". Um Kimo also noted that "*parents of normally developing children will not accept having autistic children in the same classroom because this will negatively impact the quality of the education*". Several mothers stated that children with autism are the most stigmatised disabled group compared with other

forms of childhood disability such as Down's syndrome. For example, Um Aloush said:

In a few kindergartens children with Down's syndrome attend classes with normal children but that is not the case with autistic children. This is due to the disruptive nature of autistic children's behaviour such as tantrums and self-harm.

Stigmatisation has direct consequences not only for the children but for their mothers. The perception of stigma and its negative impact on the families' lives was shared by all the parents interviewed. For example, Um K said that *"I do not have a social life. I cannot take my child out in public and I cannot leave him alone"*; Um Kimo stated *"when my daughters have friends over we hide Kimo in his room because they don't want their friends to know of him" [and] "no one will accept to marry my daughters"*. Other mothers shared the same view, for example Um Sal said: *"I have four daughters and my youngest son has severe autism. I had to send him to a centre abroad"*. Similarly, Um Naf said *"my elder son has severe autism and he is now in a private centre abroad, it is hard to manage autistic children when they grow older"*. The more severe the autistic characteristics the more labelling affects the parents. For mothers the risks of having a disabled child is high. Some of the mothers interviewed stated that having autistic children threatened the security of their marriages. For example Um Sous said *"my husband is constantly threatening polygamy because I have two disabled children"*. Um Kadi also said *"my in-laws always talk my husband about taking a second wife"*. All the study participants agreed that they experienced discrimination towards them from within the immediate family and the community for having disabled children and that stigmatisation against autism was widespread in the society.

The social stigmatisation of children with autism affected the various aspects of the lives of both the autistic children and their families, as indicated by the mothers' viewpoints. The negative social image of the family was manifested in the mothers' worries about their other children's prospects for marriage and the unwillingness of other families to marry into their family because of their autistic child or children. Some of the married mothers feared their husbands divorcing them or taking a second wife to produce normally developing children. Such situations had arisen for a number of the mothers interviewed, while some others expressed that they are under constant threat by either their husbands or their in-laws. Most of the mothers interviewed also reported feeling that socially their images as good mothers were doubted as their children threw tantrums or destroyed property in public. This is even more pronounced when their children's disorders are not visibly apparent and they are normal looking children. Therefore, when the children engaged in autistic behaviours in public places people thought that the children were just badly behaved and that their mothers were unfit and did not know how to raise them properly. A number of mothers interviewed stated that people cannot determine whether their children are autistic by looking at them. It is the way that the autistic children behave that leads to stigma. Many of the symptoms of autism include bizarre behaviour, tantrums and language, and talking to self, these acts which are manifest indicators of autism that cause stereotyping. According to Corrigan and Watson (2002) research has shown that autistic symptoms like these noted above tend to produce more stigmatising reactions than those associated with labels alone. This stigma reaction was revealed by some of the mothers interviewed who had teenage children. The autistic child's siblings did not want their friends to know that they have an autistic sister or brother as this might encourage their friends to bully them. Similarly, some mothers

interviewed stated that their close family members always advised them not to take their autistic children out in public or even send them to school. All the mothers in the focus group sessions said that people with autism are viewed as a disgrace by the general society. Brown (2006, pp. 270) noted that in the Arab countries “the acknowledgment of a disabling condition in a child risks triggering the same response for the entire family”. Brown added that it is hard for people raised in the Western culture to understand the depth of the shame reaction in Arab culture when family honour is damaged. Amongst tribal communities the shame response “is more protracted and complicated by the need to protect the family from the external judgment of inadequacy associated with the child’s disabling condition” (Brown (2006, pp. 270). That is to say that in the tribal traditions people with disability are stigmatised because their disability makes them burdensome and prevents them from contributing to the traditional social responsibilities assigned for non-disabled people. Therefore, in the group discussions the interviewees were exchanging information regarding some families they knew who sent their autistic children abroad to boarding schools and other families who kept their autistic children at home excluding them from social interaction. Families’ fear of stigmatisation resulted in them hiding their circumstances from their community.

Furthermore, the mothers interviewed stated that their social activities were limited because they neither could leave their autistic children at home on their own nor could they handle their autistic children’s behaviours in social settings such as children’s birthdays, shopping places or restaurants. The damage to property, the tantrums and inappropriate toileting incidents cause severe embarrassment for the parents in public places. Social humiliation and unwarranted expressions of sympathy towards their autistic children’s behaviours forced the mothers to withdraw their

children socially to avoid rejection due to stigmatisation. The lack of opportunities for families with children with autism coupled with the social stigma led to mothers feeling disabled by association. Al- Kandari and Salih, (2008) stated that in Kuwaiti culture, disability has a stigmatising effect on members of both the immediate and the extended family. Therefore, families tend to hide their disabled children from other members of the public. In Kuwait “the acknowledgment of disabling condition in a child risks triggering the shame response for the entire family” (Brown, 2006, pp.270). Therefore, families tend to hide their disabled children or deny having a disabled child in order to protect the family’s status from external judgment of inadequacy.

#### **4.2.4 Section four: Parents never actively participated in decision making regarding the policies relating to the education of children with autism.**

The fourth question in the interview guide concerned the role the interviewed parents play in the education decision making processes of their autistic children. The rationale for posing this question is that a parent’s role in the education of a child with a disability is unique. In fact, Dunst and Dempsey (2007, p. 305) proposed that “the role of parents with a child with a disability shows a level of complexity and intensity not generally found in the general population”. To achieve the goals of inclusive education recognition must be given to the vital role played by parents as teachers, decision makers and advocates on behalf of their children (Murray et al. 2013; Summers et al., 2005). Current literature highlighted parents’ right to play an active role in deciding what should be done with their child’s education. Itzhaky and Schwartz (2000) maintained that the role of parents in decision-making has grown both personally, in respect of their own child, and publicly in their efforts to advocate for the welfare of all disabled people. Perceptions of parents towards inclusive

education is one of the important factors to make inclusive education successful as they have unique knowledge about their child's needs (Malakar and Saikia, 2017). Subsequently, the mothers interviewed were asked about their participation in the educational decision-making process for young autistic students.

The interviewed mothers unanimously confirmed that they do not have the power to influence decisions about their autistic children's educational policies. Um Ren said "*we have no voice. Policy makers impose their decisions on us. We know about these decisions from the newspapers or the schools*". Um Jem also stated that "*we formed a group and arranged to meet with officials at the Ministry of Education for better services for our autistic children, but to no avail*". All of the mothers agreed that there is no policy for educating children with autism specifically. The mothers interviewed argued that the only decision they are entitled to make regarding their autistic children's education is to choose between the available educational settings. These settings include specialised centres for autism and special education sections in some private and public kindergartens. The interviewed mothers' replies to the study question regarding the role they play in the decision-making process of the education of their autistic children aligned with the viewpoints of Hadidi and Al Khateeb (2015). The authors claimed that families of children with disabilities in Kuwait are not active supporters and promoters of the rights of their children as they have minimal information about their rights. Education policy makers in Kuwait legislate education policies for children with disabilities on behalf of the students and their families.

#### **4.3 Findings in relevance to the study questions and literature: Individual Interviews.**

#### **4.3.1 Inclusive early childhood education policy has not been adopted by Kuwait**

As an essential background to this study, the researcher familiarised herself with the relevant policy documents through the literature review. These documents included those from Kuwaiti education departments and international literature such as The United Nations Development Programme (UNDP) and UNESCO reports on Kuwait in order to frame the study. However, due to the lack of information and scarcity of research on early childhood inclusive education for children with autism in Kuwait, the researcher sought to explore whether inclusive education policy has been implemented in both public and private kindergartens. Therefore, the researcher interviewed those involved in the educational setting namely; two owners of a chain of five private kindergartens and two public kindergarten administrators, to explore the policies and practices of the inclusion of young pupils with autism.

In responding to the question: Have you received any policy guidelines from the Ministry of Education regarding early childhood inclusive education, and if so what were they? The kindergarten owners were not familiar with the concept of inclusion and they stated that:

Do you mean disabled and non-disabled children to study together in the same classroom? No, we did not receive any information or instructions regarding inclusive education. We don't have such a system in Kuwait. It will not be good for anybody anyway, not for the teachers nor for the children whether normal or disabled.

The kindergarten owners further stated that:

Logically speaking, children with disabilities are different from normal children. God created them different. Normal children you teach them in normal ways and in normal schools and disabled children should be taught differently in special education schools.

The interviewed kindergarten owners were not supportive of the concept of inclusive education. The owners also confirmed that early childhood inclusive education for children with autism was not implemented in Kuwait. The kindergarten owners further argued that the concept of inclusive education will not be implemented in the near future because the implementation of inclusive education will require a massive programme of change including: teacher training; creating teachers training institutions; changes in curriculum, changes in cultural attitudes towards children with disabilities; convincing parents of normally developing children. One of the kindergarten owners further added that:

Students with autism are educated in special schools and special education classrooms in some public and private schools. Students with disabilities normally remain in the special education units until their education comes to an end.

Similarly, two public kindergarten administrators were separately asked the same question as the owners of the kindergartens: Have you received any policy guidelines from the Ministry of Education regarding early childhood inclusive education, and if so what were they? Both administrators were also not aware of the concept of inclusive education. One of the administrators (Admin 1) stated that “*we have a special unit for children with disabilities but the unit is not specifically for autistic children*”. (Admin 1) added “*in the special unit we have young children with different types of intellectual disabilities but not physical disabilities*”. The kindergarten administrators interviewed confirmed that they did not receive any instruction regarding any changes in the current policies of educating children with disabilities. Similarly, the second kindergarten administrators claimed that in the kindergarten where she works there is a special unit for children with ADHD, Down syndrome and autism and these children learn in the same classroom. The second administrators (Admin 2) said:

We have received some information from the Ministry of Education that some extra classes will be added to public kindergartens for children with disabilities next year. I know this will not be for physically disabled children because these children have their own special schools. I think it will be for autistic children and children with learning difficulties and other mental disabilities. They will be separated in special education classrooms and they will have their own teachers and their own administrators.

Both of the interviewed kindergartens administrators confirmed that early childhood inclusive education for autistic children was not implemented in the kindergartens in Kuwait. Furthermore, dissenting attitudes to the inclusion of children with autism were evident in the kindergarten owners and administrators' responses.

In the next section the interviewed mothers' perspectives towards the inclusion of autistic children will be thematically interpreted from within the Bio-ecological systems and organised according to the emerged themes.

## **CHAPTER FIVE: THEMATIC DATA ANALYSIS**

### **5.1 Introduction**

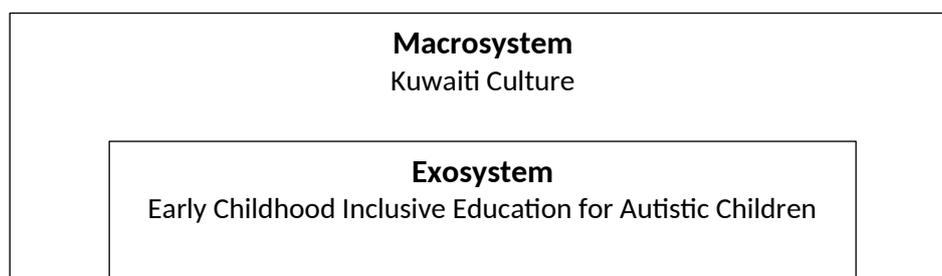
In this section all the data that were gathered holistically were rearranged under the themes which emerged from the discussions with the study participants. The development of the themes and the organisation of the data were interconnected and structured within the theoretical framework of the study in order to develop a coherent argument. The study findings were classified under two main themes and two sub-themes and were arranged into four sections in this data analysis chapter. This organisation facilitated for the researcher the writing of a detailed description on the parental perspectives towards the inclusion of young autistic children. Following the data collection, the themes that emerged were interpreted, analysed, organised and presented in a descriptive manner. Data analysis was done thematically from the information gathered through the in-depth exploratory interviews with the study participants.

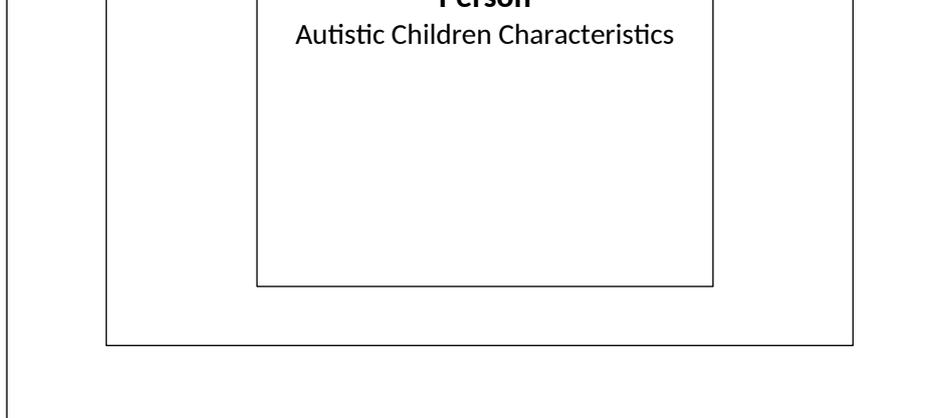
Keeping with the descriptive case study method and protocol, the researcher described the different aspects of the study participants' perspectives in their contexts and ensured that the relevant information was collected. The interviews with the parents of autistic children, kindergarten owners and administrators provided a large amount of information which was linked to the proposition of the study. The study participants' responses were noted down in detail, coded into themes and then thematically analysed. The measures adopted for interpreting the findings included relevant literature and opposing explanations to the findings. Given that this research is a qualitative case study research with a constructivism stance, the researcher interpreted and contextualised the information obtained from the study participants' beliefs and practices. The study sought to identify the themes that were relevant to the social reality of the participants from within their cultural contexts and to interpret these findings from within the social structural conditions of the study participants.

## **5.2 Thematic Analysis**

In the previous section the researcher relayed the data by means of the research questions. This section analyses the data thematically in order to explain the findings from within the theoretical framework of the study and interprets the interrelated factors that have shaped the interviewed parents' perspectives toward early childhood inclusion of children with autism.

### **5.2.1 Rationale for Employing Bronfenbrenner's Theory in the Process of Data Analysis**





**Figure 5:** Data analysis from within the Bio-ecological System Theory

The researcher employed Bronfenbrenner's Bio-ecological Systems theory (1998) as a conceptual framework for this study (see section 3.13).

The Bio-ecological theory of human development explains how the interaction between the inherent qualities of children and their environment can influence the way children will grow and develop. The influences of the different layers of the environment are reciprocal, (Bronfenbrenner, 2007). Similarly, one of the objectives of early childhood inclusive education concerns the social growth and development of disabled children (Lal, 2005). According to Mitchell (2006), inclusive education is embedded in a series of contexts and the child's environment affects how the child grows and develops socially and educationally. Correspondingly, Bronfenbrenner's theory stressed the importance of the interaction between the child's characteristics and his multiple contexts to understand how the child will develop and grow as well as the impact of the various contexts on the development of the child. The employment of the Bioecological system theory helped the researcher in structuring the study in a way that enabled the researcher to explore the multidimensional

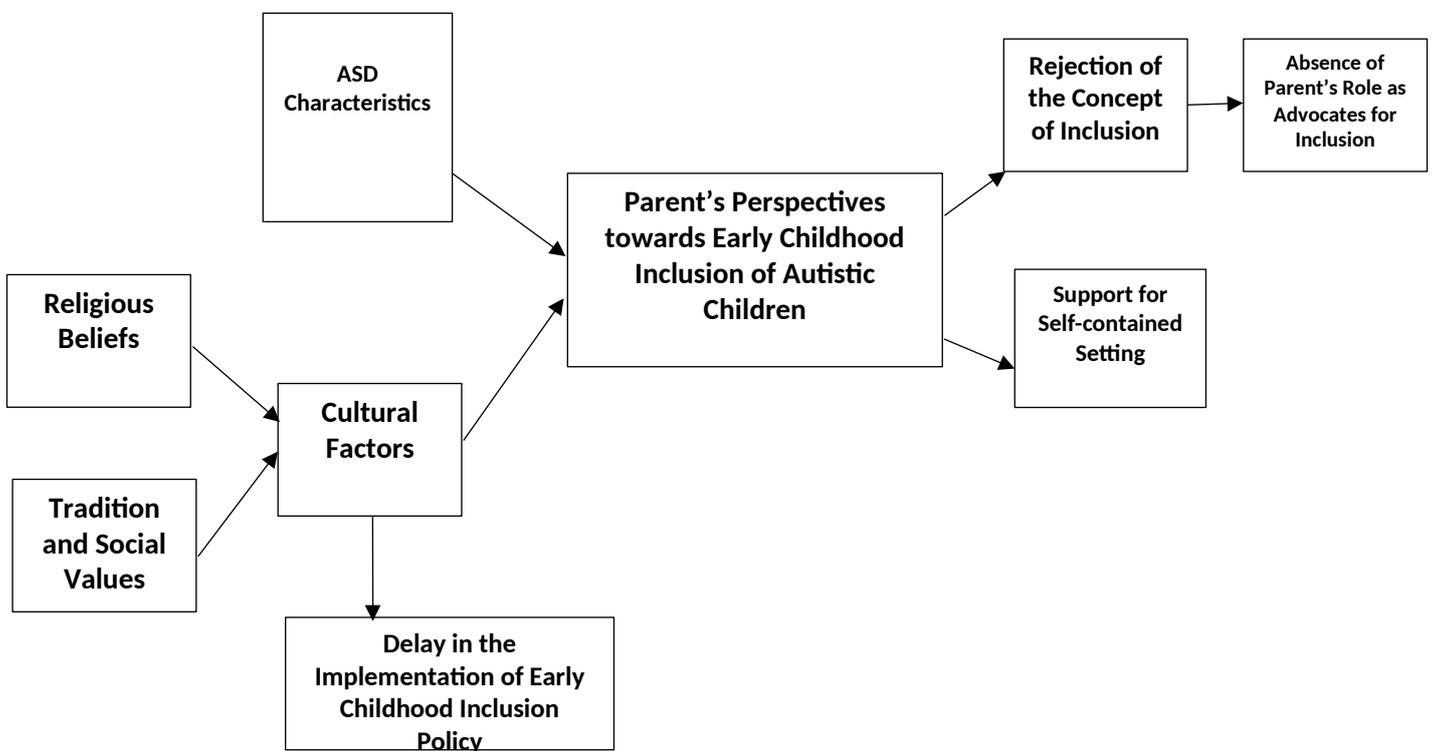
contexts that may have shaped the parents' viewpoints towards the inclusion of children with autism. Yet, the three layers of Bronfenbrenner's theory employed in structuring the analyses of the findings are not by any means static therefore, in the process of interpreting the findings contexts correlated and sometimes overlapped.

### **5.3 Factors that Shaped the Perspectives of the Parents Interviewed**

In the process of analysing the interviews data, some unexpected findings emerged. Firstly, the lack of the study participants knowledge of the concept of early childhood inclusive education including the owners kindergarten administrators; secondly, the participant's unanimous disapproval of the concept of inclusive education of autistic children in favour of self-contained special education settings. In addition, the findings suggested the non-existence of early childhood inclusive education for children with autism in Kuwait. Furthermore, the parents interviewed did not have a say in the education decision- making process of their autistic children.

From the analysis of the findings, the researcher came to the recognition that the main factors influencing the parental perspectives towards the inclusion of autistic children can be placed under two main categories: the first being the overarching theme of Kuwaiti national culture and the second concerns the characteristics of autism. The cultural theme produced a sub-theme relating to the non-existence of the inclusive education policy for young children with autism. A second sub-theme emerged from the analysis relating to autism characteristics which demonstrates the absence of a parental role in the decision making process of the inclusion of autistic children. This study being a qualitative case study closely considered the interpretations of the parents' responses within the cultural context that informed their perspectives towards the inclusion of autistic children.

The organisational flow of the different sections of this chapter are illustrated in Figure 3. The chart has been provided to make it easier for the reader to follow the progress of the discussion.



**Figure 6:** A representation of the different sections of this chapter, illustrating the structure of the discussion

### 5.3.1 The Impact of Autism Characteristics on Parents' perspectives

Students with autism have difficulties with behaviour, social interaction and developing meaningful social relationships with other people (Diagnostic and Statistical Manual of Mental Disorders, DSM-5, 2013). Furthermore, some autistic children are non-verbal, have sensory sensitivities and engage in aggressive behaviours such as self-injury, tantrums and property destruction. However, a number of authors including Strain and Bovey, (2011) and Odom and Bailey (2001) stressed that the benefits of inclusive education include increased social communication, more learning, and behavioural modelling of normally developing peers and less stigma for autistic children. Although the concept of inclusive education has an appeal for parents concerned about their children's right to inclusive education, there was hardly any support for this educational approach from the perspectives of the study participants. The parents of autistic children viewed the self-contained educational setting as the best setting for their children because of their children's autistic characteristics. The study participants did not appreciate the value of inclusion and rejected the concept of inclusive education for autistic children in favour of the special education setting. However, the participants were in favour of the integration of high functioning autistic children with the assumption that these children have a special educational setting from which they might be placed at times into the regular setting with appropriate support services. It was evident that the interviewees' unanimous non-acceptance of the concept of early childhood inclusion of children with autism pertained to the characteristics of autistic children. All of the mothers interviewed had concerns regarding the intensification of the characteristics of their autistic children including the unusual sensory processing to light, touch and noise and the resistance to change in an inclusive setting. Furthermore, the participants had concerns regarding the adverse impact of these traits on the educational performance

of the normally developing children in inclusive settings. The unique behavioural and intellectual developmental challenges of autistic children clearly had a strong impact on forming the perspectives of the mothers interviewed on the inclusion of autistic children.

The review of literature in this study showed that there is a continuous debate regarding the inclusion of children with autism. For example, Whitaker (2007) in his quantitative research on the views of parents and carer of the inclusion of children with autism living within one English county, argued that autistic children have communication impairments and unique cognitive style in thinking and learning which can be particularly challenging for educators and peers in an inclusive school classroom. On the other hand, Frederickson et al (2007) reported that the results of their study of 14 Key Stage 2 autistic pupils who moved from full-time special school placements to full-time inclusive school placements showed that the inclusive setting facilitated the social development of the children with autism which presented major developmental milestone. While there is an increasing number of students with autism now attending general education (Harrower and Dunlap, 2001), the review of literature in this study showed mixed results and indecisiveness about the appropriateness of inclusive education for autistic children and what makes inclusion successful for these children. The mothers interviewed; nevertheless perceived that autistic children do not advance academically unless their challenging behaviours are reduced and the only way for autistic children to develop adaptive skills is through behaviour management techniques and individualised attention within a self-contained setting. The participants also stressed that one of their chief concerns is the lack of adequately trained teachers who are sufficiently knowledgeable about early methods of intervention in order to provide appropriate services to their children.

Some of the mothers interviewed who were graduates of the educational studies departments in Kuwait universities confirmed that teachers get no training on including children with disabilities. The training the teachers get is based on a special education needs model, where the focus is on separating the child from their peers to segregated classes. One can claim that the perspectives of the study participants towards the inclusion of autistic children were influenced by the characteristics that typify autism. The implication of this claim is that it sheds a light on what might be one of the barriers to the implementation of early childhood inclusive education of autistic children in Kuwait.

The following section will describe the most dominant models of understanding autism spectrum disorder and the inclusion of autistic children that shaped the perspectives of the study participants. A number of researchers including Retief and Letšosa (2018) and Henderson and Bryan (2011) pointed out that models of understanding disability serve a number of important purposes including shaping the perceptions of people with disabilities and guiding the formulation and implementation of policies such as the early childhood inclusive education of autistic children. The study findings suggest that the dominant models of understanding autism amongst the study participants were the religious model and the medical model of understanding autism (Miles, 2010). The following section will describe the study participants' understanding of autism from the approaches of both the religious and the medical models

### **5.3.2 The religious model of understanding autism spectrum disorder**

Kuwait is an Islamic country and Islam is the religion of almost 99% of Kuwaitis (Bazna and Reid, 2009). Most people in Islamic countries are religious and share the same beliefs and principles (Al-Aoufi et al., 2012). These religious values

were also evident in the findings of this study. The religious context of many characteristics of the social life and the ways in which the study participants lived clearly influenced the way the participants perceived autism and the inclusion in their children.

The stances the study participants adopted towards autism were shaped by their faith as was demonstrated in the constant repetition of maxims outlined in the primary sources of Islamic religious texts, i.e., Qur'an and Hadith (the record of the sayings and actions of the Prophet Muhammad) in their reactions and discussions during the focus group sessions. Although according to several researchers including Amr et al. (2009); and Ghaly, (2006), the term 'disability' was not documented in the religious texts however, the concept of disability and the ways in which people with disabilities interacted in the society can be found throughout the history of Islam. Islamic philosophy has a positive attitude towards disabled people and the Qur'an declared the existence of disabilities as a natural part of human nature (Al-Aoufi et al., 2012; Amr et al., 2009; and Ghaly, 2006). Amr et al. (2009, pp. 169) stated that Islam views disability as "a normal and morally neutral aspect of the human condition". The authors further added that in Islam "not only is disability not an abnormality among humans, it is also not a sign of evilness or impurity". That is to say that disability from an Islamic perspective is merely an inevitable element of human well-being and that difference in people's conditions is a normal fact of life.

All of the mothers interviewed had an Islamic view of their children's disorder and the participant's discussions frequently emphasised the importance of religious beliefs and piety in aiding them to accept and appreciate their children's autism. The responses and the discussions of the research participants were repetitively illustrated by either Quranic verses or Prophet Mohammed's sayings such

as ‘What God wants, He gives’; ‘‘glory to God’’, and ‘‘I ask God for forgiveness’’. Despite the parents interviewed rejecting of the concept of inclusive education for their autistic children due to the autism characteristic, the acceptance of autism in children was viewed by the mothers interviewed as integral to their religious beliefs. The parents interviewed showed acceptance and even gratitude for having autistic children. For example Um Kadi said that ‘‘*since I had my son my life prospered, he is a blessings upon our lives*’’. Similarly, almost all the mothers interviewed believed that God provided their families with an autistic child for a positive divine plan. As an example Um K said ‘‘*Having an autistic child is a blessing from God and He would not have given me (K) unless it was good for me*’’. Similar phrases were repeated by all of the study participants although often in different words such as ‘‘*everything was created and occurs to satisfy a particular purpose which only God knows*’’ or ‘‘*God does things according to His sovereign will, not always according to what we want*’’. Almost all the mothers interviewed considered having an autistic child as a gift from God. Only a few mothers had an opposite interpretation of having an autistic child and considered it as a punishment from God. The two mothers who viewed having autistic children as a punishment from God were admonished by the rest of the participants in the focus group sessions. Some authors such as Henderson and Bryan, (2011) and Swinton (2011) argued that in a number of societies in which the religious and moral models of disability are still adopted, disability is considered to be a punishment from God for certain sins. However, the admonishment of the two mothers who expressed negative interpretation of having autistic children revealed that these two mothers were deemed to offend the standard religious culture of the rest of the study participants. In rebuking the mothers who said that having an autistic child is a punishment in their opinion, the responses of the other participants included

rebuking phrases such as “*don’t you fear God?*” and “*you and your child have been selected by God for a special calling, you should be grateful*”. Adherence to the religious system and the impact of the religious beliefs on the study participants was obvious in their pious stance of appreciating their children’s disorder as being a blessing from God. This idea has a religious basis, as Islam holds that all things, whether good or bad, are in the interest of the believer. Therefore, any opinion that did not uphold the religious standards and possessed negative views of disability as a reflection of punishment was considered as showing less intensity of personal faith and was met with rebuke and objection.

On the other hand, the mothers interviewed were critical of people who approached their children as if their disorder merited pity. Um Fodi for example, noted that “*I feel very offended when people express pity toward my son*”. Similarly, many of the study participants expressed their discomfort when people look at their children with pity or have pity in their voices. The mothers highlighted their feelings of distress towards people expressing pity towards their children and considered them ignorant for not knowing that autistic children are blessing of God. The mothers interviewed cited religious statements such as “*If God intends good for someone, then he afflicts him*” and “*when God loves a person he will test him*” and “*whoever is pleased will be satisfied*” to confirm that they were blessed for having an autistic child. The mothers interviewed strongly believed that disabled people and those who take care of them will be rewarded in this life and the hereafter and that their children’s autism is essentially a test of faith. This moral and religious model of disability was prominent in the discussions with the study participants. Swinton (2011) described the conception of disability as a test of faith, whereby people are specially selected by God to have a disability and are given the chance to redeem

themselves through their endurance and piety. Therefore, the mothers interviewed disapproved of the charity model approach towards their autistic children because this model contrasts with the religious model of understanding autism. According to the charity model, people with disabilities “are victims of circumstance who should be pitied” (Retief and Letšosa, 2018, pp.7). That is to say that, in the charity model of understanding disability, people with disabilities are victims of their conditions and their situation is tragic because they are dependent on other people for care and protection.

One can argue that the study participants’ perceptions of autism from a religious model of understanding has effectively increased the sense of alienation and difference between autistic children and normally developing children. This distancing, that was reflected in the parental perspectives toward the inclusion of autistic children, clearly contributed to the medical model of understanding of the disorder (Miles, 2010) by way of rejecting the idea of inclusive education. The mothers interviewed stressed that autistic children are not comparable to normally developing children and their inclusion in the same educational settings with normal children will not meet the needs of either group. The study participants’ belief that early childhood inclusive education was not appropriate for autistic children was indicative of the influence of both the religious model and the medical model of disability as well as of the societal attitudes towards autism.

### **5.3.3 The medical model of understanding the inclusion of autistic children**

Perspectives from which autism in inclusive early childhood education can be approached from a number of models including the medical model of disability and the social model of disability (Mackenzie et al, 2016). The study participants’ lack of

support for early childhood inclusive education for children with autism was interlinked with the parents' religious model view of understanding autism; the medical model approach to autism; and the Kuwaiti cultural norms and traditions. The medical model of disability emerged from the mid-1800s onwards as a result of significant advances in the field of medical science (Retief and Letšosa, 2018). In this model disability is seen as a medical problem and a defect inherent in the individual (Smith, 2008). Smith noted that under the medical model of disability the impairments of disabled individuals should be treated medically or by other means so that the disabled person can be fit to have an inclusive way of living. The basic characteristics of the medical model of disability is that disabled people are expected to avail themselves of the services accessible to them and to spend time in the role of learner being helped by trained professionals to cure to the greatest extent possible (Retief and Letšosa, 2018). The medical model of disability defines disability in a fundamentally negative way (Hughes and Paterson, 2010) and a pitiable condition for both the disabled people and their families. Although the study participants did not define autism in a negative way, their perspectives towards the inclusive education of autistic children however, clearly reflected the characteristics of the medical model approach that encourages continual search for finding a way to prevent or cure autism. Several of the mothers interviewed stated that their autistic children need to be cured before they can join their normally developing children in an inclusive setting. Phrases like *"I pray day and night that God will cure my son"* or *"I hope I will live until my child recovers"* were frequently repeated by the study participants. The Parents interviewed subscribed to the medical model that tends to consider disability as a problem to be solved. Similarly, the study participants posed a number of rhetorical questions regarding early childhood inclusive education. For example, Um

D asked “*how can autistic children study with normally developing children in the same classroom all day?*” and “*how can teachers control the behaviours of autistic children and teach normal children at the same time?*” Um Naf also asked “*what quality of education would normal children receive when they are with autistic children?*” Other opinions presented by the mothers interviewed included: “*normal children follow classroom instructions, but autistic children cannot, they need years to be trained*” and “*normal children are smart and they learn fast, autistic children are neither smart nor fast learners*” and “*it is impossible to provide instruction to normally developing students and autistic students within the same setting*”. The mothers interviewed argued that self-contained settings offer a controlled and structured environment that autistic children require and individualised instruction cannot be provided in a general education classroom. Moreover, the study participants were of the view that self-contained settings provide distraction-free environments and focus on behaviour issues. However, the mothers interviewed unanimously agreed that the current situation in relation to the scholastic provision for autistic children in Kuwait needs restructuring. The study participants were in favour of self-contained placements for children with autism but they wanted special educators who had specific training in early intervention methods for autism and were adequately resourced as well as small class sizes to provide more individualised instruction for the children.

The study participants’ approach to autism from the religious model reinforced the notion that autistic children are not comparable with their normal peers. Similarly, the medical model of interpretation of disability tends to categorise normal people as somehow superior to disabled people (Retief and Letšosa, 2018). Furthermore, the study participants highlighted the limitations associated with their children’s autism

and questioned the benefits of inclusive settings for autistic children who cannot explore and learn from their physical and social environment. All of the mother's interviewed were of the opinion that the behaviours of their autistic children are difficult to manage and these challenging behaviours would distract the normally developing children in an inclusive setting. For example, some mothers interviewed including Um Abadi, Um Adi and Um Al said "*it is not the fault of the teachers, our children's behaviours are hard to manage*". Similarly, Um Abi said "*I don't blame parents of normally developing children for not accepting my son to study in the same classroom as their children*". Um Kadi said "*why should the normally developing children tolerate my child's behaviours*". Um Ren noted "*my child needs the right intervention methods in order to become better, inclusive education does not meet her needs*". The parents interviewed adhered to the medical model by continuing to search for within child based interventions to alleviate the impact of autism. In addition, the mothers interviewed also asserted that parents of normal children would not subscribe to the inclusion of autistic children in the same classroom as their children. This lack of support for the concept of inclusion of autistic children was also evident from the data gathered from the nine mothers of normally developing young children.

The findings from this study revealed that the participants' viewpoints towards the inclusion of autistic children were aligned with the medical model of understanding autism. The above extracts from the opinions expressed by the parents interviewed affirmed the opposition to inclusive education as voiced by parents of children with autism. It can be argued that the medical model stance adopted by the study participants was one of the factors forming the negative viewpoints towards early childhood inclusion of children with autism. The study participants considered

autism as a disease, i.e. they were looking for a therapy that would heal the condition to make the autistic child more normal. Parents interviewed were also of the view that their autistic children pose a burden on educators because they require the use of distinct, appropriate teaching approaches for which even special education teachers are not qualified. The mothers interviewed were apprehensive about the move to inclusive education and of the negative effect it will have both on their children and on the normally developing children. Um K for example said that “*normal children will be scared when they see my son throwing tantrums and hitting his head against the wall and bleeding*”. Um Hammani added “*autistic children are different from normal children and we have to accept this reality, it is God’s will*”. Furthermore, the mothers of autistic children were convinced that the best means of teaching their children is through specialised intervention such as ABA (Applied Behaviour Analysis), in a self-contained education setting or on an individual basis. As such, the ultimate goal of the study participants was that autistic children will be cured. As stated earlier, the mothers interviewed clearly adopted the medical model stance of autism and viewed autism disorder as a medical condition. The mothers did not consider the problem within their autistic children to be a problem with the society as the social model of disability suggests. Under the social model of disability, disabled people can be independent and equal in society. The approach of the social model is that disability is not caused by the individual’s disability but by the way society is organised (Davis, 2013). Similarly, Oliver, 2013, pp. 2024) stated that “we were not disabled by our impairments but by the disabling barriers we faced in society”. That is to say that, the society plays a major role in disabling people, therefore, it is the society that has to remove the barriers that restrict the life of the disabled person. The study participants’ approach to autism did not acknowledge any social relational

components of autism such as changing the environment to include the autistic children, but rather conceptualised autism as an impairment in their children. The enduring prevalence of the medical model of understanding autism has resulted in less attention being paid to the social model of disability. The study participants did not subscribe to the social model of disability although the social model aligns with the study participants religious beliefs in terms of the social responsibility towards people with disabilities. In Islamic teachings the society is responsible for taking care of disabled individuals and is responsible for improving their conditions (Ghaly, 2016; Al-Aoufi et al, 2012; Bazna and Hatab, 2008). Correspondingly, fundamental to the social model of disability is the belief that disability is a socially constructed phenomenon therefore, it is the environment that must change to suit the disabled person, not the disabled person that must change to suit the environment (Retief and Letšosa , 2018). One can argue that the mothers' interviewed acceptance of the medical model of understanding autism despite its contradiction to the study participants' religious value system was mainly due to the strong influence of the local cultural values.

#### **5.4 The impact of culture on the parental perspectives on the inclusion of autistic children**

Cultural influence on the parents' perspectives towards the inclusion of their autistic children was evident in the mothers' discussions during the focus group sessions and from the participants' responses to the study questions. Culture as noted earlier refers to the common values and beliefs to which members of a society conform (Weisner, 2002). Kumar (2000) for example, argued that the local culture refers to the

knowledge and values that an individual requires to function within a society in a manner acceptable to the systems and norms of that society. Similarly, Hofstede (2001, pp.9 and 2011, pp.3) defined the local culture as the "collective programming of the mind that distinguishes the members of one group or category of people from another". Hofstede (2011) argued that the term culture is used in different disciplines including political science, sociology and management, however, most commonly the term culture is used anthropologically to refer to ethnic groups and tribes. The societal culture which is reflected in the pattern of ideas, beliefs, values and behaviours is generally acquired by children from their earliest youth onwards (Hofstede, 2011). Therefore, societal culture is deeply rooted in its members' minds and it is shared by all the society's members. Cultural influence on the other hand, according to Lindsey et al. (2003) refers to the social factors that influence the beliefs and perspectives of members of a society including approaches to disability. According to a number of researchers including Weber (2012); Banza and Ried (2009), Brown (2006) the national culture of Kuwait is characterised by conservative social traditions and values. Kuwaiti local culture "includes (a) values and ethics rooted in Kuwait's traditional Arab and tribal heritage and (b) beliefs and values stemming from the principles of Islam" (Banza and Ried, 2009, pp. 148). It is worth noting that despite Kuwait's rapid economic development and the socio-economic transformations which took place over the years as a result of economic growth (Al-Jassar, 2009), Kuwaitis traditional cultural practices remained unchanged. Tribalism as a cultural pattern in Kuwait is still prevalent (Brown, 2006). The cultural values and the religious outlook with regards to the inclusion of autistic children were manifested in the parents interviewed deep concern towards normally developing children in an inclusive setting. The parents interviewed asserted that an inclusive education setting would

neither be beneficial for autistic children nor for normally developing children. The mothers' expressed concerns about the negative impact of autistic children's behaviours on normally developing children in an inclusive setting (Um Abi) said "*I will feel sorry for normal children if they started imitating my child's self-injurious behaviour, why should I expose other children to this*". Similarly (Um Sous) noted that "*the normal children will be punished by their parents if they copy my child's tantrums, why should other parents suffer like we do*". There was a unanimous agreement of the mothers interviewed on the negative impact of their autistic children's behaviour on normal children. (Um Saud) for example noted "*normal children will not be able to focus on their tasks with autistic children distracting them*". Similarly, (Um K) said "*the teachers will be torn between autistic children and normal children and the session time will be wasted*". Conversely, several researchers including Odom, et al (2011) and Lindsay (2007) claimed that inclusive education benefits children who do and do not experience disability. Odom, et al (2011, pp. 349) stated that "participation in inclusive programs may positively affect typically developing children's knowledge and attitude about disabilities". It is suggested that inclusive education settings provide an opportunity for normally developing children to develop sensitivity to individual differences and an overall acceptance of others' diversity. Similarly, Brennan (2015, pp.12) stated that "it has been observed in research of pre-existing preschool inclusion programs that there are many long-term positive social behaviours that have roots in an early childhood inclusive experience". Correspondingly, the study produced by Peck, et al (2004) was based on information from 389 parents who gave their perceptions of the effects of their normally developing children's participation in classrooms in which children with disabilities were enrolled full time. The authors argued that the study survey

responses indicated that the parents generally perceived their normally developing children to have benefited from the experience. This study's participants did however, unanimously agree that the inclusion of autistic children will have a negative impact on normally developing children as well as on autistic children.

It was evident that the concern of the study participants towards the normally developing children in an inclusive setting was shaped by the interviewed mothers' personal faith and the cultural norms surrounding autistic children in the community. For example, when mothers expressed their concern for nondisabled children in an inclusive setting, the mothers followed their opinions with the prophet Mohammed's quotations such as: "Love for your brother in humanity what you love for yourself" or "None of you will believe until you love for your brother what you love for yourself" or "do unto others as you would want done unto you". The mothers interviewed believed that it would not be fair for the normally developing children to have autistic children in the same setting as such a situation would consume the class session time and nondisabled children would be deprived of appropriate education. Although the study participants' apprehension towards the disadvantages for normally developing children in an inclusive setting stemmed from their religious beliefs, the tribal traditions also had an impact on the study participants' concerns. As noted earlier the Kuwaiti culture embraces values imbedded in Kuwaiti tribal heritage and beliefs stemming from Islam. In the traditional Arab societies, members of the society "must take care of and protect the individuals within it" (Ibrahim, 2012, pp.74). Subsequently, Kuwaitis sustained collective orientations in their society especially in the light of the existing close and tight family and intra- family connections. Therefore, the deep concern of the mothers interviewed towards the wellbeing of other people's normally developing children in an inclusive setting was also

influenced by the cultural norms. Moreover, the mothers interviewed gave careful consideration for the attitudes and opinions of the families of the normally developing children towards the unfavourable effects that the autistic children's behaviours might have on their classroom peers. Kuwait is a tribal culture that highly values group identity and is built on strong community relationships (Al Thani, 2006). Unity is an essential characteristic of the tribe and the society members usually look after the wellbeing of the members (Krenawi and Graham, 2000).

The traditional characteristic rooted in the tribal Arab culture and the traditions and practices that are generally adhered to in Kuwait evidently had an impact on the study participants' perspectives towards the early childhood inclusive education of children with autism. However, according to Ramadan (2010) religion and culture are intertwined and have always existed in a close relation. Therefore, one can argue that the study participants' identification with religious cultural ties and the deeply rooted cultural harmonies with regard to religious beliefs influenced the interviewees' apprehension towards the normally developing children in an inclusive setting and was also behind their total agreement on the diverse issues concerning early childhood inclusion of autistic children.

However, when the participants were asked about the stigmatisation of autistic children, all of the participants acknowledged that the problems with having an autistic child are intensified by the society. The study participants did show resentment towards general social stigmatisation of their children and felt that there is little acceptance of autistic children. According to Papadopoulos (2014) empirical evidence shows that communities with higher levels of religious faith are more likely to stigmatise. This may sometimes be due to poor cultural awareness. The stigma surrounding individuals with disabilities was defined by Abdullah and Brown (2011)

as the devaluing and disgracing of individuals with disorders by the general public. Similarly, The World Health Organisation (WHO) report (2001, chapter 4, pp.1) stated that stigma and discrimination towards individuals with mental and behavioural disorders “is the single most important barrier to overcome in the community”. Papadopoulos (2014) also affirmed that disability is a notion tied to culture, and consequently, the stigmatisation of disability is likely to vary across cultures.

The findings from the parents’ responses suggested that autism in Kuwait is accompanied by strong perceptions of stigmatisation. It is conceivable that stigmatisation would be magnified in a cultural context, such as Arab societies, where disability poses risks to family status and honour (Crabtree, 2007). The general view according to the participants was that autistic people should be kept hidden away from the world with no participation in the wider society. For example, Um Saud describing their experiences said that “*I was very hurt when a man told me not to take my crazy child outside the house because he scares other children*”. Um Sam also noted “*people do not accept autistic children in any social activity. People look at me as if it is my fault that my son does not behave well*”. Similarly, Um Al said “*people pull away their children from us when my daughter starts flapping her arms and spinning*”. The mothers interviewed were of the opinion that stigmatisation was a result of ignorance and to some extent the lack of general religiousness. For example Um Abadi said “*if people adhered to Islamic values they would have a tolerance of autism or any other disability*”. Similarly, Um Fodi said “*pious people do not discriminate against disabled people*” also Um Jojo noted “*My daughter’s autism is from God, if people were sincere believers, they should not reject my daughters*”. The responses of the study participants revealed that stigmatisation of autistic children is a product of the local societal structure only and not a product of religion. According to

Crabtree et al., (2010); Bywaters et al., (2002) discrimination towards people with disabilities is not tolerated by Islam; instead Muslims are urged to extend care to vulnerable individuals. Therefore, if the cause of derogatory attitudes cannot be found in religion, it is likely that the source lies instead in cultural beliefs. Similarly, Bhatti et al. (2009, pp.170) stated that stigmatisation “attitude toward disability is heavily steeped in culture but over time has mistakenly justified itself in religious terms”. One interpretation is that despite the Islamic concern for the moral neutrality and equal rights of disability the traditional tribal practices have more clearly shaped the Kuwaiti cultural attitudes towards disability. As such, the social pressure on the mothers of autistic children extended from their immediate family context to the larger social environment. This is heightened by the ‘associative stigma’, that is the extension of stigma to the autistic child’s family which is culturally determined (Cathoor et al 2015). The associative stigma is highly common in Kuwait (Al-Kandari and Salih, 2008). Therefore, the behaviours of people with autism disorder considered abnormal bring social shame not only upon the autistic individuals but also upon their families. Some of the mothers interviewed such as Um Ren stated that “*in order for the society to accept our children we need to change the whole society*”. Um Koko also noted “*people’s attitudes towards autism will not change in our life time*”. These remarks of the mothers interviewed were reactions to the way autistic people and their families were negatively viewed from within their society.

The mothers interviewed stated that both their immediate families and the public reactions to their autistic children are stereotypical and negative, and this in turn limited the interviewed mothers’ social activities and threatened their marriage security. Most stigma studies have considered stigmatisation of individuals with disorders to be a universal occurrence, but with different manifestations in diverse

contexts (Thornicroft, 2007). Stigma appears to be a universal phenomenon and stigma and discrimination exist in every culture where people with disabilities do not receive the same social acceptance as individuals who do not have disorders. Al-Kandari and Salih (2008) noted that Kuwait's legacy of cultural beliefs considers disability to be a shameful matter. Therefore, one can argue that the negative attitudes of the mothers interviewed toward the inclusion of autistic children were not only based on autism characteristics but also are a reflection of the society's perspective on people with disabilities and the common notion in Kuwait that autistic children are associated with the attribution of shame.

Given that the Kuwaiti culture is a tribal culture that places importance on shared community values, researchers such as Papadopoulos et al, (2013) and Ibrahim (2012) argued that collectivist cultures are more likely than individualist cultures which place priority on personal independence, to stigmatise people with disabilities. This is partly because such people are more "visible to the community due to higher surveillance levels". As a consequence, families are more likely to try to hide the existence of a member who has a disability (Papadopoulos et al, 2013, pp.9). Those who are identified as deviating from group accord are vulnerable to being rejected and stigmatised. The social stigmatisation of people with disability and the study participants understanding of autism through the medical model are in reality problems of culture, traditions and tribal codes and not religion. Islam's value system as noted earlier does not condone such social practices (Al-Aoufi et al., 2012). Ramadan, (2004) argued that for many Muslims, as with people of other faiths, their cultures have a strong impact on their lives however, there is a distinction between culture and religion. That is to say that certain practices such as stigmatisation and victimisation of people with disabilities are not part of the religious values even when

such practices appear to observers to be clearly associated. Ramadan explained that the reason for some practices still being a mixture of tribal values and Islamic beliefs in Arabic cultures is that Islam happened to emerge in that region.

Furthermore, the medical model approach to disability also reinforces the stigma attached to disability (Scully, 2012). As noted above, the perspectives towards autism shown by the mothers interviewed were based on the medical model. The study participants confirmed that stigma surrounding autistic children is widely endorsed by the general public although these views have no basis in religion. Therefore, it would be fair to say that in Kuwait the society's perspective on disability has been influenced by the cultural context, rather than a reflection of the religious values. It would also be fair to say that the influence of cultural factors fundamental to societal attitudes played a major role in forming the mothers' medical model approach to autism and subsequently the rejection of the concept of early childhood inclusive education of children with autism disorder. One can argue that the unanimous agreement of the study participants regarding the disadvantages of the inclusive setting for autistic children and normally developing children suggests that the parental viewpoints were not only a consequence of autism characteristics but of the local culture and the societal conditioning as well. Therefore, understanding national cultural values and norms is important in gaining an understanding of the awareness of and attitudes towards the inclusion of children with autism.

### **5.5 Parents' role as advocates for their autistic children's educational inclusion in kindergartens**

Evidence from existing research demonstrates the vital role played by parents as teachers, decision makers and advocates on behalf of their autistic children to be

placed at the heart of the school community. Parents also have the responsibility to ensure that they are contributing partners with the teachers and the school as a system as this collaboration will influence their child's future (de Boer, 2015). Perceptions of parents is one of the important factors to make inclusive education successful as they have unique knowledge about their child's needs (de Boer, 2015 and Langan, 2011). From the literature on the history of autism such as the writings of Frith (2005), Wolf (2004) and Wing (1996) parents of children with autism have played a prominent role in controversies surrounding autism spectrum disorder. For example parental critical voices in challenging the 'refrigerator mother' theory and the claims that autism may be caused by childhood vaccinations (Gerber and Offit, 2009). Through the study of parental accounts on autism such as the Langan (2011) and Ward (2014) studies that reported on how parental voices have contributed to the evolving official discourse around autism as well as to public awareness of the condition. It can be said that parents' attitudes can effectually change the perspective of inclusive education. Similarly, Dunst and Dempsey (2007) argued that parents play a vital role in the education of their children including their participation in the educational decision-making process as their child progresses through educational systems and in the educational placement of their children. Parents also have the responsibility to ensure that they are a contributing partner with professionals who will influence their child's future. Similarly, section 1400 (c) (5: B) of The Individuals with Disabilities Education Act (IDEA), (2004) which is a law that makes available a free appropriate public education to children with disabilities throughout the USA, stated that following decades of research and experience the education of children with disabilities can be made more effective by "strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities

to participate in the education of their children”. Parents can offer insight into the best educational instruction and strategies that can help their children learn. Parents also can provide suggestions or be partners in the decision making process regarding their disabled children’s education. There is no one as interested in and motivated to see his/her child succeed and thrive than her own parents, and this alone places the parent in a crucial role on the child education team. Parental participation in the special education decision-making process is vitally important.

One of the objectives of this study was to explore parents’ role as advocates for their autistic children’s educational inclusion in kindergartens. The rationale for the researchers’ interest in exploring the parents’ role in the decision making process of the education of their autistic children was based on a number of reasons including: parents know their children better than anyone else and have the most complete understanding of a child's social and developmental history; parents are vital to the inclusive education team process; parents can provide information on the child's strengths and weaknesses, background information and information on any family factors that may affect the child's learning; and parents’ attitudes can effectually change the perspective towards the inclusive education movement (Xu and Filler, 2008). As noted earlier, the development of inclusive education has partly been enhanced through the advocacy work of many parents of children with disabilities. However, given the mothers’ negative view of early childhood inclusion, it was obvious that the mothers would not play any role in advocating for an educational movement of which they are not in favour. The findings of this study revealed that mothers feel powerless in decision-making processes even in terms of demanding professional teachers skilled in intervention methods for autism. The mothers’ emphasis on exclusion as the best educational option for autistic children also

removed the need to reflect on practices and pursue ways to better support the young autistic children in their inclusive education setting. It can be said that the corresponding elimination of the role of parents as advocates for early childhood inclusive education for autistic children in Kuwait served to deprive autistic children of the opportunity to fully participate in kindergartens in the same way as normally developing children.

### **5.6 The policy of early childhood inclusion in Kuwait**

The findings in this study clearly reflect the study participants' lack of awareness of the global definition of the concept of early childhood inclusive education. The international principles of inclusive education were defined in the Salamanca Statement and Framework for Action (UNESCO, 1994). These principles included that all children regardless of their special needs should learn together within inclusive settings wherever possible, in order to enable disabled children to have a sense of belonging and to facilitate their social interaction and academic achievements (Odom et al., 2011). Even though the Salamanca Framework for Action provided the principles of inclusive education, the understanding of the term inclusive education varied and according to Hunt et al., (2004) and Guralnick, (2001), there is no standard international definition of inclusive education. However, the majority of authors such as Messiou (2017; Jackson (2008); and Ainscow et al. (2006); took the view that inclusive education is defined as education for all children, regardless of their disabilities, in the same classrooms alongside their normally developing peers.

Conversely, the parents interviewed defined early childhood inclusive education for children with autism as the integration of high functioning autistic children in certain regular classrooms based on the autistic child's capability; or having children with moderate autistic characteristics in a classroom setting along

with other children with different disabilities; or having a segregated unit within the regular school premises where children with autism are integrated with normally developing children during break times. However, none of the interviewees described inclusive education according to the most commonly accepted definition in the literature on inclusive education. It can be argued that the lack of understanding of the global definition of inclusive education cannot be attributed to the mothers' level of education as the vast majority of the mothers interviewed were graduates and post graduates in different fields of study, from numerous universities, both national and international. According to the World Bank Group Report (2016) and Kuwaiti Central Statistical Bureau (2015) women in Kuwait are among the most emancipated women in the Middle East region and Kuwaiti women outnumber men in the workforce. Similarly, UNESCO Institute for Statistics (2015) reported that female literacy rate in Kuwait is 99.4 per cent. Therefore, the characteristics of the sample interviewed represented the normal characteristics of the female population in Kuwait.

It can be said from within the Exosystem layer of the theoretical frame of the study, that the mothers interviewed defined inclusion in accordance with the locally available educational settings for children with autism. The lack of awareness of the concept of inclusion among the study participants might in turn demonstrate that the Kuwaiti educational policy has not yet introduced early childhood inclusive education in to the national education system. The non-existence of inclusive education policy was also confirmed by the interviewed kindergarten owners and administrators as well as in the writings of a number of authors such as Al Nakib (2015) and Al-Thani (2006) who argued that Kuwait is far from effectively implementing the concept of inclusive education. The non-existence of an inclusion policy highlights the non-fulfilment of the Kuwaiti educational authorities' commitment to the right of young

children with autism to an inclusive education as stipulated in the Salamanca Framework of Action (1994) despite Kuwait being a signatory to this convention. So, from the viewpoint of parents interviewed special education units within kindergartens were considered inclusive because these units share the same location within the regular kindergarten. Moreover, having all children with different disabilities in one classroom setting was also referred to by parents interviewed as inclusive education.

The intention was that in the process of developing special needs education the concept of inclusive education would replace integration and mainstreaming terminology and the education of children with disability would take place in regular classrooms (Odom et al, 2011). However, according to Weber (2012) and Brown (2006) in the Arab region there is a lack of a national definition of the term inclusion. Terms such as 'integration', 'mainstreaming' and 'inclusion' remain in common usage and are still used interchangeably in relation to inclusive education. Therefore, in the interviews, the researcher used the term full inclusion reinforcing it further by stating: 'whereby autistic children are to join their typically developing peers in every classroom for the entire school day'. The argument of Brown and Weber regarding the interchangeable use of terms referring to inclusive education has been supported by the findings of this study as well. However, it could be claimed that the absence of a specific term for inclusive education might be an indication that there is no need to have a reference for a concept that does not exist or an idea that has not been put into any form of practice as yet. Language is a dynamic phenomenon (Charema, 2010), that is to say that there are many different ways in which a language can add new meanings by utilising or compounding words. Accordingly, if an idea becomes a permanent feature of society then a term of reference will be designated to represent

this idea even if it was not originally found in the language itself. For example, in Arabic, the term (Damj) refers to integration, if a second term was added to it, a compound term would emerge which eventually could be a sensible representation of inclusive education.

Furthermore, as per the study findings, there is a theory-practice disparity in the context of inclusive education in Kuwait. A report published in 2015 by the Ministry of Education of Kuwait and a report published by the United Nations Development Programme in 2015, stated that considerable objectives have been accomplished since 2010 regarding the inclusive educational school projects in Kuwait. During this period some reports by the Kuwaiti Ministry of Education have also been published concerning disabled persons and their inclusion. Amongst these reports was a study on establishing a curriculum for slow learners at different school levels, a study on establishing a disability information centre by the Ministry of Education, and a Kuwaiti national prize for the best teachers in special education. However, the review of literature in this study has shown that most of the research conducted on inclusive education in the Arab Gulf region including Kuwait has been more focused on the theoretical aspects than on the actual implementation. Hadidi and Al Khateeb (2015) who conducted a literature review to analyse studies published from 1990 to 2014 on inclusion of children with developmental disabilities in Arab countries, argued that apart from theoretical government support for an inclusive model, education officials lack interest in implementing inclusive education. The disparity between the theory of inclusion and practice and the scarcity of research in the field of inclusive education in the Arab region was also noted by a number of researchers including Hadidi and Al Khateeb (2015), Hamaidi et al., (2012) and Amr (2011). Hadidi and Al Khateeb further argued that resistance from teachers and also

from students without disabilities are the main obstacles to implementing comprehensive plans for inclusive education in Kuwait. As the scope of this study does not include teachers' attitudes nor the viewpoints of normally developing students, the findings of this study, though not generally applicable, indicated that parents of autistic children are also not supportive of early childhood inclusive education for children with autism. Therefore, and from within the Macrosystem layer one can claim that the argument of Hadidi and Al Khateeb regarding the resistance of the teachers and normally developing students to inclusive education as well as the argument of this study concerning the absence of parental support for early childhood inclusive education for children with autism suggest that one of the main obstacles to implementing early childhood inclusive education is embedded in the Kuwaiti social context itself. Similarly, Brown (2005, p.253) in his report on inclusive education in the Gulf States including Kuwait noted that "the effort to translate rhetoric into action involves confrontation with the bedrock values and beliefs of the region". This study's findings aligned with Brown's above claim that the main reason that Kuwaiti educational policy has not translated inclusive education rhetoric into action for young children with autism as yet, is the influence of the Kuwaiti notational culture.

The lack of societal support for early childhood inclusive education has been also demonstrated by the persistence of the parallel provision of segregated educational settings for the early childhood education of children with autism. The information from parents revealed that, when an autistic child's educational ability is assessed as not meeting the standardised criteria for normally developing children, as a consequence, exclusion of the autistic child is considered a legitimate response. The interviews with the kindergartens owners and the administrators confirmed that the segregated system is still in operation in Kuwait, despite the intended plans relating to

inclusive education for children with disabilities in the official published reports. However, none of these reports addressed issues with specific relevance to autistic children. The preservation of the segregated education system for children with autism seems to have reinforced rather than reduced segregated education. The information gathered in this study indicated clearly that Kuwait does not yet have a clear strategy for implementing early childhood inclusive education for children with autism. Subsequently one might argue that the lack of urgency of the Kuwaiti educational authorities to implement inclusive education for children with autism might have led to the interviewees' lack of awareness of the international understanding of the early childhood inclusive education model.

## **5.7 Conclusion**

The two main factors that shaped the perspectives of the mothers interviewed towards inclusive education were: the characteristics of autism and the national culture. These two factors have influenced the absence of the role of parents as advocates for the rights of their autistic children to inclusive education. The mothers interviewed rejection of the inclusive education settings for autistic children was based on a number of reasons including: autism characteristics; concerns for autistic children being bullied and concerns for normally developing children and their families. The study participants' viewpoint of autism as a disorder were influenced by the religious model while the perspectives of the mothers interviewed towards inclusive education was in congruence with the medical model. However, in the processes of interpreting the data, it became evident that the cultural influence was the underlying reason behind the study participants' adoption of the medical model and

subsequently on their perspectives towards the concept of the inclusion of autistic children. This influence of the tribal traditions became more evident through the discussions regarding the stigmatisation of autistic children.

The interviews manifested the strong influence of the tribal culture as revealed by the study participants' perspectives. Despite the lack of professionals in intervention methods for children with autism in Kuwait being one of the issues emerging from the findings, this issue was not featured in the study as the participants' concern for this shortage of professionals was addressed in terms of segregated settings for autistic children, which defies the purpose of this study. The perspectives prevalent in the Kuwaiti cultural context and raised in the interviews conducted with the mothers of autistic children reflected the social perspectives on disability in general and autism in particular and the impact of these factors on forming the study participants' perspectives towards the early childhood inclusive education of autistic children. Based on the above arguments, it could well be that the negative attitudes toward autism represent one of the potential barriers for the inclusion of autistic children. It can also be suggested that the ministry of education assessed the societal attitudes towards students with autism and subsequently decided not to implement the inclusion policy for autistic children in the kindergartens.

This study gives an accurate portrayal of early childhood inclusive education for autistic children and it reports the viewpoints of the parents on the behalf of their young autistic children who might not be able to speak. With respect to interpretation of the data, the researcher selected the genuinely relevant themes to the study. The findings apply to this case and not for the purposes of generalisation. The interpretations made were specific to the context and the researcher. The following

chapter presents a discussion of the interpretation of the study's findings in relation to both the research questions and existing knowledge.

## **CHAPTER SIX: DISCUSSION**

### **6.1 Introduction**

This section concludes the study by reflecting on what the study sought to explore. The purpose of this study was to explore Kuwaiti parental perspectives on early childhood inclusive education for children with autism spectrum disorder. The objectives of the study included: exploring the factors that shaped parental perspectives; describing the implications of the parental perspectives on the early

childhood inclusive policy for children with autism spectrum disorder; and exploring the role parents play as advocates for the rights of their autistic children to inclusive education. The findings of this study demonstrate that the non-acceptance of the concept of inclusive education for children with autism is based on autism characteristics and the impact of traditional cultural factors. These factors that shaped the negative parental perspective towards the inclusion of autistic children encouraged the medical model of thinking of autism spectrum disorder and the preservation of segregated educational settings for children with autism spectrum disorder in Kuwait. Although some research on inclusive education in Kuwait has provided valuable insights into the barriers to the implementation of inclusive education such as negative attitudes held by teachers and staff in schools; resourcing difficulties; and lack of adequate teacher training, the results of this study suggest that the main barrier to the implementation of early childhood inclusive education for autistic children lies within the Kuwaiti traditional culture itself and the characteristics of autism.

## **6.2 Summary of the Study and the Main Findings**

In this section the researcher will firstly, highlight a number of findings that reinforce what is already known about inclusive education in Kuwait and relate this knowledge to the inclusion of young autistic children from the parental perspectives. Secondly; the researcher will outline the factors that shaped the parental perspectives towards the inclusion of young autistic children. Finally; the research will discuss the implications of these findings on the policy of inclusive education for young children with autism spectrum disorder in Kuwait. The originality of this study stems from the issues this study addresses that have not been addressed in previous studies in Kuwait. These topics include: the inclusion of children with autism spectrum disorder; reviewing inclusive education from parental perspectives; and the inclusion of autistic

children at the kindergarten educational stage. The search for literature proved telling as it revealed the absence of studies relating to the inclusive education for children with autism spectrum disorder and the lack of studies on parental perspectives on inclusive education in Kuwait. From the review of the articles in peer-reviewed journals and data-based chapters published between 2000 and 2016, to the best of the researcher's knowledge, this study is the first to explore the inclusion of autistic children at kindergarten stage from the parental perspectives. The researcher limited the review to this time period due to the lack of research on inclusive education in Kuwait prior to this period. Examples of the published studies found on inclusive education for individuals with disabilities are listed in the table below:

Al-Kandari et al's (2017)	brief report on the social support for children with disabilities in Kuwait
Al-Shammari and Evans (2017)	Conference report: The Kuwait Inclusive Education: Initiation and Development
Almotari's (2013)	PhD thesis on Kuwaiti teachers and head teacher's attitude towards inclusion
Aldaihani (2010)	PhD thesis on a comparative study of inclusive education in Kuwait and England
Bazna and Reid (2009)	Would rethinking learning disabilities benefit Kuwait?
Almuhareb, (2007)	PhD thesis Cross-cultural comparison of special education practices in Kuwait
Al-Shammari, (2006)	PhD thesis on Special Education Teachers' Attitudes Toward Autistic Students in the Autism Centre in Kuwait
Al Kandari, (2006)	PhD thesis on how the mothers of adult autistic children managed their lives around their children's needs.

#### Sample of published studies on inclusive education in Kuwait

Few other studies were conducted on people with different types of disabilities from within the medical and the psychological fields such as Al-Kandari and Salih's, (2008) study on Adapting Antonak and Harth's Mental Retardation Attitude Inventory for Kuwait. Other authors such Hadidi and Al Khateeb (2015); Weber (2012); Al-Hilawani (2011); and Gaad (2011) also published articles on inclusive education in the Arab region in general. These authors noted the scarcity of research in the field of inclusive education in the Arab region. The lack of studies on inclusive education according to Alkhateeb et al. (2016) and Gaad (2010) is because Arab countries have only recently joined the global movement towards inclusive education for children with disabilities. Overall, the findings reported by the above mentioned authors regarding the inclusive education policies in the Arab region are in accordance with the findings of this study. These findings include: the lack of a commonly accepted definition of what constitutes inclusive education for students with disabilities; the confusion over the semantics of inclusive education; and the lack of conceptual clarity of the very notion of inclusive education. Furthermore, the above mentioned authors highlighted a number of factors as being the barriers to the inclusive education in the Arab region. These barriers included teachers' attitudes toward the inclusion of students with disabilities; teachers having inadequate training in inclusive practises; limited support for children with disabilities; and the lack of appropriate facilities in schools. The above mentioned factors can be understood to have an impact on inclusive education policy, however, these issues are not within the scope of this study. Barriers to the inclusive education for children with disabilities in the Arab countries arising from the societal values and beliefs were observed by Weber (2012) and Brown (2006) and briefly touched upon by a few other writers. However, as none

of the studies in Kuwait were on the inclusion of autistic children, this study's argument regarding the impact of parental resistance to the inclusion of autistic children can also be understood to be one of the factors that has an impact on the inclusive educational policy for children with autism in Kuwait. Although one cannot conclude which barriers are perceived as most problematic by policy makers involved in planning or implementing inclusive education, it is evident from the results of this study that the lack of parental support to the inclusion of children with autism and the negative societal attitudes towards the autistic children may be amongst the main reasons for the delay in implementing inclusive education for young autistic children in Kuwait. Despite policy makers' reports that suggest that inclusive education is in the process of being implemented, the findings of the study demonstrate that the absence of direction in inclusive education for children with autism is evident in Kuwait. Therefore, the researcher is of the view that the importance of this study stems from its attempt to extend the knowledge of the current situation regarding parental perspectives on inclusive education for autistic children at the kindergarten stage and to fill this knowledge gap. It is worth mentioning that the age range in Kuwaiti kindergartens is between 3 ½ and 5 ½ years. Following the kindergarten stages children with disabilities enter the traditional elementary school system.

The significance of the kindergarten stage formed the rationale for this study's focus on children in their early years. The underlying principle being that kindergarten is the stage in which children receive their first formal education and exposure to knowledge, whilst transitioning from the home environment to kindergarten. The early childhood stage is the most rapid period of development of a human being's cognitive, emotional and physical development and growth (UNICEF, 2000). The same is true for children on the autism spectrum. Most of the educational

and behavioural intervention methods for children with autism focused on children of preschool age (generally ages 3-6) and have shown a considerable impact and significant improvements (Centre for Disease Control (CDC), 2012). In addition, the researcher focused on the inclusion of autistic children at the kindergarten stage because social relationships with peers are less firmly fixed for young students than older students (Odom et al, 2004) and because the nature of the curriculum in early childhood education focuses on developmental domains such as social skills and cognitive skills (Kuwait Ministry of Education, 2008). The assumption was that these factors will facilitate the inclusion of young students with autism spectrum disorder.

To date, parental perspectives toward the inclusion of autistic children remain unknown in Kuwait. The researcher speculates that this lack of knowledge might be due to the scarcity of research on inclusive education in Kuwait in general and as Gaad (2011) noted that the concept of inclusive education is new in the Arab region. A number of authors including de Boer (2015); Carrington and Robinson (2006); and McCarron and Inkelas (2006) argued that a critical aspect of the success of inclusive education is the parental involvement and support for the current inclusive educational movement. The educational placement decisions taken by parents on behalf of their children can be particularly important when the young children have disabilities. Similarly, parents of children with autism have played a major role in controversies surrounding autism spectrum disorder. Parental opinions were critical in challenging the “refrigerator mother” hypothesis of autism in the 1950’s and 1960’s that blamed autism on a maternal lack of warmth and affection (Mesibov, et al, 2000). In addition, parents of autistic children rejected the more recent claims that autism may be caused by childhood vaccinations. Therefore, the influence of parental activities in relation to their children with autism has been the subject of significant

academic attention. The role parents' play in relation to the inclusion of autistic children has also been studied by several researchers such as Brookman-Frazee and Koegel (2004) and Gill (2004). de Boer (2015); Afolabi (2014); and Farrell (2000), who were of the view that parents should be crucial members of the educational decision- making team because they have unique knowledge of their child's strengths and needs. Subsequently, the expectation of the parents of children with disabilities is that they should be advocates to preserve their children's rights to inclusive education. From this standpoint, the researcher focused on Kuwaiti parental perspectives toward the inclusion of young autistic children. However, from the results of the study, it is evident that there is hardly any support from the mothers of autistic children in Kuwait for the inclusion of autistic children model. Therefore, given the negative parental view of early childhood inclusion for autistic children, it was obvious that the mothers would not play any role in advocating for an educational movement of which they are not in favour.

Another critical factor to be contemplated is that in mid 1980s affluent Kuwaiti parents invited US experts to establish a special educational centre for children with disabilities. The special education centre had "almost all classroom teachers, language and physical therapists and school psychologists are North American or English speaking European, as are most administrators" (Bazna and Reid, 2009, pp.147). This suggests that, being an affluent nation, Kuwait could have also invited experts in inclusive education methods to the country in order to establish the inclusive education model and train Kuwaiti teachers in the various approaches that would ensure the successful implementation of inclusive education. This argument raises the issue of the medical model of educational setting being widely accepted in Kuwait until today/until the present. While the financial considerations

relating to education such as resources, teacher training and services for disabled children hinder most of the developing countries from implementing inclusive education, such issues will not pose a financial burden on the budget of this oil rich country. The findings of the study demonstrate that Kuwait maintains special education settings for children with disabilities including children with autism spectrum disorder. According to the World Bank Report (2015), Kuwait apportions about 15 % of its total budget to education. However, the research found that while this small oil rich country has achieved a considerable extent of development and growth in the last decades, the education of children with autism spectrum disorder remains delivered in segregated settings and children with autism spectrum disorder are legally banned from admission to regular schools. This study shows that both the parents and the educational decision-makers believe that the best educational setting for autistic children is either self-contained settings or specialised centres.

Given issues explored in this study regarding the relationships between inclusive education of autistic children and its multi –dimensional contexts, the parental resistance to the inclusion of autistic children suggests that one of the barriers to early childhood inclusion for children with autism is due to the alignment of traditional cultural norms with the medical model understanding of autism. These findings tie in well with what was stated in the United Nations Children’s Fund (UNICEF) (2014) report that early childhood inclusive education can be fostered when parents and policy makers recognise and remove barriers and perceive inclusive education as ordinary practice. The findings of this study suggest that unless social beliefs and practices align with a social model of understanding autism spectrum disorders, it will not be possible to accommodate the inclusion of young autistic

children in Kuwait. This argument will be discussed further later in this chapter when discussing the tribal traditional norms of the Kuwaiti society.

In the quest to answer the research question, the researcher employed a qualitative holistic single case study approach while constructing the study from within Bronfenbrenner's Bio-ecological Systems Theory (1998). The study was concerned with the interpretation of the subjective perspectives of the study participants. The employment of the qualitative single, case study method enabled the researcher to deeply understand the multiple factors that influenced the study participants' perspectives from within their cultural context. The interview method with the parents and the further discussions with key people served to refine of the issues of relevance and assisted in fine tuning the development of the research process in order to build up a meaningful picture. By adopting a theoretical thematic analysis the researcher was able to organise and simplify the complexity of the data into meaningful and manageable themes while providing a thorough description of the context which is an integral part of this case study. The literature review and the formal and informal feedback about the findings as they developed helped with keeping the study factual and on the right track. From the subjectivist position, the researcher constructed an impression of what the parents believed about the concept of early childhood inclusive education for autistic children in their cultural context. The perspectives of the parents interviewed were explored through focus group interviews of 27 parents, whilst the policy of inclusive education for young autistic children was explored through individual interviews with the owners and the administrators of 7 kindergartens as well as the rationales from the international and national reports and literature. The trustworthiness of the study was established through member-checking Furthermore, the official published reports were

triangulated during the individual interviews with the kindergarten owners and the kindergarten administrators as well as during the individual interviews with the participants in the focus group sessions. In order to ensure the authenticity of the findings the researcher was very attentive to the study participants' accounts of their personal experiences and to the discussions between the mothers interviewed in the focus groups sessions. Furthermore, the researcher used prompts and probes to encourage the interviewees to explain and clarify their responses and viewpoints in order to ensure the accuracy of this study.

As noted above, the study was organised around an ecological system conceptual framework proposed originally by Bronfenbrenner (1979) and extended by Bronfenbrenner and Morris (1998). Bronfenbrenner's theory holds that people come upon different contexts throughout their lifespan that may impact upon their development and their behaviour. The three layers employed in this study are the Bio-system layer that represents the characteristics of autistic children, the Exo-system layer that represents the policy of inclusive education for children with autism spectrum disorder and the Macro-system layer that represents the Kuwaiti national cultural values. The nested layers of Bronfenbrenner's theory correspond to the concept of inclusive education. Inclusive education is also embedded in a sequence of contexts (Mitchell, 2006). These contexts extend from the society through the local community, the family and to the school. The employment of these three levels enabled the researcher to explore the factors that shaped the study participants' perspectives, to examine the associations between the variables surrounding the concept of the inclusion of young children with autism spectrum disorder from the parental viewpoint and to explore the impact across the contexts on the implementation of early childhood inclusive education for children with autism

spectrum disorder in Kuwait. The early childhood inclusive education for children with autism spectrum disorder was explored through the study participants' perspectives by means of the three layers of the Bio-ecological Systems Theory. For the researcher, the conceptual framework of this study facilitated the presentation of a holistic picture of the study results demonstrating the interconnected nature of the contexts surrounding the inclusion of young children with autism spectrum disorder from the parental perspectives and how these contexts operate to influence parental viewpoints and consequently came to constitute one of the barriers to the inclusion of young children with autism spectrum disorder. The interaction between the various contexts relating to the inclusion of children with autism spectrum disorder is reflected in the ways in which the study findings at times overlapped or even changed order in some circumstances whilst defining the parental perspectives on the inclusion of young children with autism spectrum disorder.

The findings of the study show that the mothers interviewed unanimously: a) were apprehensive about the move to the inclusive education model for children with autism spectrum disorder; b) believed that the inclusive setting will have a negative effect not only on the children with autism spectrum disorder but also on their normally developing peers; c) were of the opinion that the best educational environment that would facilitate the learning for children with autism spectrum disorder is through specialised interventions on an individual or small group basis in a highly structured setting. Although the mothers interviewed had not actually experienced including their children with autism spectrum disorder in general education classrooms, however, these mothers firmly rejected the concept of inclusive education in favour of self-contained special education settings for the children with autism. From the results of the study, it is evident that the mothers interviewed are

struggling to find teachers with expertise in appropriate intervention methods that respond to their autistic children's needs, but are not fighting for their autistic children's rights to inclusive education.

It is evident from the study results that the study participants were perplexed by the concept of inclusive education. All of the study participants including those working in the education field were unaware of the current inclusive educational movement. Subsequently, the concept of inclusive education was translated by the study participants in varied and distinct ways. These descriptions and explanations of the practices of inclusive education for children with autism spectrum disorder did not correspond to the definitions of inclusive education reported in the Salamanca Statement (1994) and the Convention on the Rights of Persons with Disabilities (2006). These conventions stated that all students whoever they are and whatever their abilities or requirements should learn together in the same setting and no-one should be excluded. Every child has a right to inclusive education regardless of any disability or other social or cultural difference. The lack of knowledge of the concept of inclusive education among the study participants might be due to a number of reasons such as the lack of relevant research and literature on inclusive education in Arabic; or as some researchers including Weber (2012) and Brown (2006), argued there is a difficulty in defining the concept of inclusive education in the Arab region due to the fact that in these countries not only is there no national definition of the term inclusive education but terms such as 'inclusion' and 'integration' remain in common usage and are still used interchangeably; or as Al-Hilawani (2011) noted inclusive education is a new concept in the Arab region. The confusion over the terms of reference was also noted in the findings of this study. Reading through the Ministry of Education report (2008) on Kuwaiti's educational vision 2005-2025, the report used the terms

‘inclusion’ and ‘integration’ interchangeably indicating the lack of clarity between what constitutes inclusive education and what constitutes integration. Gaad (2011) also noted that there is a lack of awareness of inclusive education and limited awareness of disability among teachers and school staff in the Arab region. It also can be argued that the study participants’ understanding of inclusive education for children with autism spectrum disorder was based on the models available in their local context which were provided by the centralised policy of education decision-making.

As stated earlier in the previous chapter, the parents have no role in the educational decision-making process for their children with autism spectrum disorder and the policy-makers take the decisions concerning the education of autistic children on the parents’ behalf. The elimination of the parents from being part of the decision making team and the absence of the legislation that obliges the schools to adopt the inclusive model might have also led to the study participants’ lack of knowledge of the globally accepted concept of what constitutes inclusive education. Another factor behind this lack of awareness of the concept of inclusive education might be relevant to Charema’s (2010) observation that in developing countries educational institutions are still working on improving the policy of integration and these countries did not catch up with the new wave of change towards inclusive education. In line with Charema’s remark, the findings of the study also demonstrate that the mothers interviewed were more occupied with issues regarding the behaviours of the children with autism and their battle was for providing experts in the field of behavioural management methods for autistic children. This might have driven the parenteral focus away from the educational settings for autistic children, as some of the mothers interviewed stated “our problem with our autistic children is their behaviour and not

their education or where they are educated, once their behaviour is managed then we will think about their education”. The study results demonstrate that the study participants prefer to maintain the special education settings for children with autism spectrum disorder even if such a segregation might lead to labelling these children. Nonetheless, the varied interpretations of inclusive education as presented by the study participants mark the disparity between the concept of inclusion as stated by the Salamanca Statement and Framework for Action on Special Needs Education and the local interpretations of the concept.

The recent developments in inclusive education policy including the Salamanca Statement (1994) and the Convention on the Rights of Persons with a Disability (2006) regarding inclusive education have led to the increase in the numbers of student with autism in general education classrooms (Yell, 2003). The core principle of early childhood inclusion as stated earlier, is that all students with disabilities have a right to be educated and engaged in activities with their normally developing peers in the same educational setting (Lord et al, 2003). This view relates to the commitment to educate each child, to the maximum extent appropriate, in the classroom the students would otherwise attend. The Salamanca Statement also placed the onus on governments to eradicate barriers and negative attitudes to inclusive education and stressed the role of governments to impart quality general education in a mainstream environment that is responsive to the needs of all students from the early years stage through to adult and vocational education (The Salamanca Statement and Framework for Action on Special Needs Education, 1994). Given that Kuwait was one of the countries that signed both the Salamanca Statement and the Convention on the Rights of Persons with Disabilities, indicates that Kuwait will implement the inclusive education policy. However, from the findings of this study

and the literature on inclusive education in the Arab region it is evident that the mere existence of the Salamanca Statement did not ensure the successful implementation of inclusive education in Kuwait. In addition, because governments are not bound legally to the United Nations' educational declarations and statements, this encouraged the governments to interpret international initiatives in accordance with their social, cultural and political structures (Fletcher, 2006). Consequently, despite the current shift of the international educational movement from segregated settings to a more inclusive model of education for students with disabilities, Kuwait continues to preserve the provision of special education settings for students with disabilities which were introduced in Kuwait in the 1970s for blind and deaf people and later in the 1980s for people with other types of disabilities (Almosa, 2012). However, as has been previously reported in the literature, inclusive education has not been implemented worldwide. For instance, Opertti et al. (2009) highlighted that the actual inclusion of disabled students into general schools has not taken place. Any efforts made have generally put special needs students into a regular classroom setting with little meaningful modifications in terms of the teaching, curriculum and school culture. The researchers added that there is also the danger of inclusion remaining an intellectual theory which fails to be translated into a reality as there has been little concession to the vital alterations in curricula and pedagogy critical to meeting the children's learning needs. Similarly, Bouck (2009) in an analysis of the articles concerning the policies affecting the education of students with disabilities presented in the two federal education legislations: No Child Left Behind (2002) and the Individuals with Disabilities Education Act (IDEA, 2004), Bouck argued that actual inclusion in the classroom for some disabled students has been only partial at best. That is to say that inclusive education remains a principal objective yet to be achieved

not only in Kuwait but also in other parts of the world. The myriad of diverse perceptions and wide ranging attitudes on the subject of inclusive education and discrepancy between the concept of inclusive education and the practical concerns of the implementation of inclusive education were acknowledged by several researchers including Messiou (2017); Operti et al. (2009); and Slee (2001) as well as in the report of the International Conference on Education (ICE), (2008), which stated that there are numerous viewpoints and disagreements, much indecision and widespread controversy and inconsistency between the rhetoric of inclusion and the practices of inclusive education which should be addressed by educational systems, irrespective of the nation's level of development. This report implies that the Salamanca Statement was not sufficient to ensure an effective implementation of inclusive education in every country including the signatory countries of the Salamanca statement as is the case with Kuwait.

In relation to the inconsistency between the rhetoric of inclusive education and the practices in Kuwait, the results of this study suggest that one of the reasons for these discrepancies is associated with the national cultural dimension and the societal unwillingness to accept the principles of inclusive education for children with autism spectrum disorder. The results of this study demonstrate that the principles of inclusive education for autistic children are at odds with the local traditional norms. The influence of the traditional values and norms is apparent from the parental perspectives toward the inclusion of the young children with autism spectrum disorder. This impact is reflected in the parental adoption of the medical model of viewing autism spectrum disorder and in the parental preference for the special needs segregated setting for students with autism spectrum disorder.

As stated earlier, the results of the study demonstrate that the two main factors that shaped the parental perspectives towards the inclusion of autistic children are the characteristics of the children with autism spectrum disorder and the local traditional beliefs and norms. While the autism characteristic factor was discussed with the study participants, the local traditional norms factor was established by the researcher through the logical connection between a number of variables that were elicited from the discussions between the study participants and from their responses when the mothers interviewed were prompted to explain their experiences further regarding the stigmatisation of children with autism spectrum disorder. The researcher will further describe the two main factors that shaped the parental perspectives towards the inclusion of autistic children in two separate sections, whilst at the same time highlighting the interconnectedness of these two factors throughout the discussions. In order to keep within the conceptual framework for this study, the researcher will first discuss the results associated with autistic child characteristics (Biosystem level), followed by the results related to traditional cultural and societal values (Macrosystem level) that influenced the parental anti-inclusion perspectives for children with autism spectrum disorder. At the Exosystem level the researcher will describe the influences that stemmed from the Biosystem and the Macrosystem layers on the policy of early childhood inclusive education for children with autism in Kuwait:

### **6.3 Autism characteristics factor (the Biosystem layer)**

The characteristics of children with autism spectrum disorder reflect the Biosystem proposed by Bronfenbrenner as the centre of the Bioecological Systems Theory. Researchers such as Allen and Cowdery (2009) and Fuchs (2003) emphasised the importance of child characteristics in research on early childhood inclusive education. Inclusion for young children with autism spectrum disorder is controversial

(Koegel et al, 2001) because of the unique characteristics of autism and because children with autism spectrum disorder need specialised intervention methods to manage their behaviours and to increase their social interactions with their normally developing peers in inclusive settings. Autism spectrum disorders is a complex, pervasive, multifactorial neurodevelopmental condition with an estimated prevalence of 1 in 160 children around the world and a 1 to 4 female to male ratio regardless of ethnicity and socioeconomic background (World Health Organization, 2017). Some features of autism spectrum disorder include impaired social interaction, deficiency in communication skills, delayed language development and restricted and repetitive behaviours (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), 2013). In addition, autism spectrum disorder is a heterogeneous condition with psychiatric and medical morbidities including intellectual disability, attention deficits and social anxiety disorder (Maski, 2011) . The substantial direct and indirect effects of autism spectrum disorder extend across many different sectors including the education sector presenting considerable challenges to special educators assigned to provide suitable services (Birchler, 2016 and Masino, 2016). Connected to these multiple and consequential factors, there is little argument that students with autism spectrum disorder present significant educational challenges. Consequently, educating students with autism spectrum disorder requires an understanding of the unique cognitive, social, sensory, and behavioural deficits that characterises this disorder. This description of the characteristics unique to autism spectrum disorder does not mean that students with autism spectrum disorder are incapable of learning, it does mean however, that most children with autism spectrum disorder require specialised instructional techniques (Lord et al, 2003). Although a key element of the early childhood inclusive education model is the inclusion of children with autism spectrum

disorders in general education classrooms, the challenges of including students with autism are many because of the nature and severity of their disability (IDEA, 2004). Since the studies of Kanner (1943) and Asperger (1944) who in detail depicted the characteristics of children with autism spectrum disorder and described the disorder as puzzling and enigmatic, decades later, this enigmatic legacy has continued. Accordingly, it is not surprising that otherwise competent teachers frequently report that they consider themselves to be less than fully capable of meeting the needs of students with autism spectrum disorder (Scheuermann and Webber, 2002 and Simpson, 2001).

Educational placement of children with autism has been a topic of debate for a long time (Kauffman, 2005 and Landrum, 2003). Advocates of placement in a general classroom believe that the benefits for autistic students in inclusive settings include: increased social communication, improvement of behavioural modelling of normally developing peers; less stigma for the autistic children; and more acceptance of the autistic child by her/his normally developing peers (Peters and Forlin, 2011; Operti et al, 2009). Contrary to the arguments of the advocates of inclusive education, the findings of this study did not find any support for the inclusion of children with autism. The analysis of the study shows that the study participants unanimously rejected the inclusion of children with autism spectrum disorder in favour of the self-contained educational settings which represents the model that was adopted since the 1950s in Kuwait (Barr 1983). Although the literature on inclusive education maintains that inclusive education does not mean placing children with disabilities in regular schooling settings in an arbitrary manner or with no accommodation for their needs (Michailakisa and Reich, 2009), nonetheless, the results of this study show that there

is an apprehension towards the concept of inclusive education for children with autism spectrum disorder.

The general view from the findings of this study is that including children with autism spectrum disorder in general classrooms will cause regression to these children and will not meet their needs. In a study of a review of literature conducted by de Boer et al. (2010) about parents' attitudes towards inclusive education, the authors reported that a large number of studies showed that the majority of parents of typically developing children held positive or neutral attitudes while parents of children with disabilities reported various concerns. However, The authors concluded by stating that for both groups of parents a number of variables had an impact on parents' attitudes towards inclusive education including: the type and the severity of the disability of the child, resources and aide support, teachers' attitudes, teachers competence and professional development, class sizes and parents' level of education. On the other hand, the findings of this study indicate that in relation to the inclusion of autistic children, none of the variables that were noted in de Boer et al report constituted a concern for the parents of autistic children in this study. However, the findings of this study demonstrate that the competence of the teachers is of paramount importance but not in relation to the instruction being delivered in an inclusive setting; rather in a self-contained setting. The study participants were convinced that the characteristics of autistic children cannot be managed except in highly structured special education units.

The findings demonstrate that the main concerns regarding the inclusion of autistic children and subsequent lack of support for the concept of inclusive education for children with autism spectrum disorder were based on the characteristics of autism spectrum disorder. The two main factors for the lack of support for the inclusion of

autistic children in relation to autism spectrum disorder characteristics are the negative impact of the inclusive education setting on the children with autism spectrum disorder and the negative impact of inclusive education setting on normally developing children. Regarding the factors that might have a negative impact on autistic children in inclusive settings, the study results show that bullying, is one of these factors. Olweus, (2013, pp. 756) defined bullying as a “behaviour intended to inflict injury or discomfort upon another individual”. Olweus argued that being bullied means that the person is being exposed to negative actions and behaviours repeatedly and over time intentionally. The purpose of bullying is to inflict discomfort on the bullied person. Disabled students are targets of victimisation more often than their normally developing peers (Chad et al, 2010). Similarly, in a study conducted by Kirves and Sajaniemi (2012) on children in kindergarten aged three to six years in kindergarten stage, the authors argued that these children were involved in bullying and that the most common form of bullying at kindergarten stage was the exclusion from peer relationships. As students with autism are increasingly being taught in inclusive settings, autistic children might be at an increased risk of victimisation and marginalisation. Forms of bullying according to Carter and Spencer (2006) included name-calling, teasing, taking belongings, imitating, and making fun of the students with disabilities. The issue of bullying and victimisation of young children with autism was acknowledged in previous studies. As such, the study findings regarding the parental concerns about the bullying of autistic children in an inclusive setting were consistent with the results of the past studies.

The second factor regarding the negative impact of inclusive settings on children with autism spectrum disorder from the parental perspective has to do with the autistic children’s unusual sensory processing. In a general classroom setting

autistic children will experience sensory-perceptual difficulties which will lead to their distress, agitation and aggressive outburst. Behrmann et al (2006, pp. 260) stated that “Strong affinities and aversions for various tactile sensations, smells, flavours and sounds are often reported by individuals with ASD or by their parents”. Researchers including Behrmann, et al. (2006) Jones, et al. (2003), and Morris (2003) also argued that many children with autism experience auditory sensitivity, a condition that can cause irritation, pain, and, in some cases, profound fear. Sensory processing disorder is a symptom of autism (DSM-5, 2013). Processing lights, sound and chaos, which are inevitable in general kindergartens environment can be challenging and overwhelming for children with autism spectrum disorder. Autistic children’s intolerance to certain noises or loud noises in a regular classroom environment can evoke irregular responses. Similarly, children with autism spectrum disorder have difficulty with change or transitions. Children with autism spectrum disorder can have real problems with switching from one activity to another or changing classrooms. Any disruption to routine and order or any affront to the autistic children’s sensitivities can result in sometimes violent, outbursts with aggression, being self-inflicted or inflicted upon others or objects in their immediate setting, or can cause meltdowns or total withdrawal.

Furthermore, although children with autism share many characteristics, autistic children differ greatly from one another. For example, McPartland et al. (2012) argued that autistic children’s IQ ranges from severely mentally retarded to gifted, from passive to hyperactive and from gentle to explosive. Therefore autistic children require many adaptations in inclusive settings to meet their individual needs. Given the autistic children’s diversity, it is inconceivable that a general classroom setting could meet the individualised need of all students with autism spectrum

disorder (Kauffman, 2005). Similarly, the study findings show that most children with autism spectrum disorder have fundamental deficit in the area of language, therefore, verbal explanations in general classroom settings are among the least productive ways of conveying information to these children.

The findings of the study also show that the mothers interviewed have concerns regarding the negative impact on normally developing children of a setting that includes children with autism spectrum disorder. Proponents of early childhood inclusion such as Odom et al (2011) and Guralnick (2001), argued that some of the benefits that parents of normally developing children perceived of early childhood inclusive placements for their children included more awareness of other children's needs, more helpfulness to the needs of their peers with disabilities and more acceptance of others with disabilities. On the other hand, the study participants were of the view that there are several disadvantages for normally developing children in inclusive classrooms that include children with autism spectrum disorder. The study findings show that the parents think that the frequently inappropriate social behaviours, self- injurious actions, screaming, and self-stimulatory behaviour will cause fear and discomfort to the normally developing children in the same classroom. Furthermore, in an inclusive setting where normally developing children will be exposed to autism challenging behaviours all day and every day, there is a high risk that normally developing peers will imitate autistic children's challenging behaviours. Advocates of autistic children placement in general classroom settings such as Opertti et al, (2009) argued that the benefits for students with autism spectrum disorder in inclusive settings include improvement of behavioural modelling of normally developing peers. Children use imitation to have social exchanges and they interact by copying each other's actions. This kind of imitation increases throughout early

childhood. However, Ingersoll, (2008) and Nadel, (2004) argued that empirical researches had shown that children with autism have poor imitation skills and often have great difficulty with imitation. Autistic children's inability to imitate gestures and body movement is related to developmental issues including the inability to maintain joint attention and share focus with another person. Given that autistic children have relatively poor imitation skills, the inclusive settings as means of encouraging autistic children to model the behaviour of normally developing students might be ineffective.

The results of the study also show that the presence of autistic children in inclusive settings will have a negative impact on the quality of the education for the normally developing children. Parental support as noted above is regarded as being very important in facilitating inclusive education. However, based on the findings of this study, it seems reasonable to argue that when both groups of parents, those of children with autism spectrum disorder and those of children without disabilities have negative opinions towards inclusive education for children with autism spectrum disorder, it will be more difficult to realise the implementation of inclusive education in Kuwait.

Parents who advocated for the right of their disabled children to inclusive education expected that inclusive settings would lead to their children participating socially with normally developing peers. Similarly, many writers such as Operti et al. (2009) who were in favour of inclusive education highlighted the importance of the social participation and communication dimension benefit for disabled children in inclusive educational settings. However, children with autism have difficulty in participating socially in any type of setting and the type of setting has no differential impact on children with autism spectrum disorder. Kanner (1943, pp.247) stated that

the autistic child “when with other children, he does not play with them. He plays alone while they are around, maintaining no bodily, physiognomic, or verbal contact with them”. Other researchers including Knox and Ramsden (2010); Pijl et al, (2010); and Carter and Spencer (2006) also argued that even though children with autism may be physically included in inclusive settings, their social inclusion is not guaranteed. It would be reasonable to argue that even if children with autism spectrum disorder are unable to understand the level of peer rejection, victimisation or experience negative feelings linked to their isolation or loneliness, the emotional well-being of autistic children is of utmost concern to their families.

Furthermore, Kuwait is a tribal culture and tribal settings offer a large family size with siblings close in age (Ibrahim, 2012). Therefore, children with autism spectrum disorder are usually surrounded by normally developing children including their siblings and cousins. As such, the advantage of inclusive settings possibly encouraging greater social participation for children with autism spectrum disorder with their normally developing peers, was not determined in the study findings as a factor of much significance to the study participants. The study results also show that almost all of the benefits which the advocates of inclusive education highlighted in their writings were negated by this study’s participants. The study participants maintained that highly structured self-contained settings are the best form of setting that will meet the needs of children with autism spectrum disorder.

Although early childhood inclusive education program is advocated as the best practice from the experts in early childhood education and early childhood special education fields (Division for Early Childhood and the National Association for the Education of Young Children (NAEYC- DEC, 2009), the findings of this study are in line with some previous studies such as Hilbert’s, (2014) study on the perceptions of

parents of young children with and without disabilities attending inclusive preschool programs as it was argued that the parents of children with autism spectrum disorder were less likely to favour the inclusive program.

The general view amongst the study participants was that autistic children need special instruction, with a specific intervention method; namely, Applied Behaviour Analysis, delivered in self-contained settings as being the best approach to present information in ways autistic children comprehend. Parents' main concern was having the professional staff complete with the requisite skills to manage the behaviour and learning of autistic children according to their diverse needs. The study participants stated that the graduates from university teacher preparation programs have minimal skills in the early intervention methods that are based on the principles of Applied Behaviour Analysis for children with autism. Therefore, these teachers continue to face challenges in managing the behaviours of children with autism. In the process of analysing the data, the researcher noted that Applied Behaviour Analysis was mentioned more than twenty times during the interviews. As this method seemed to be of great interest to the study participants, the researcher reviewed some literature on this method and some other methods of intervention for autistic children. The researcher wanted to explore whether any of these methods could be employed in an inclusive setting. The literature proved telling as it revealed that Lovaas, (1960) stressed the remarkable results gained from the use of Applied Behaviour Analysis (ABA) practices as early intervention for young children with autism spectrum disorder. According to a number of researchers including Klin (2013); Ospina et al. (2008); and Eldevik et al (2007) Applied Behaviour Analysis is one of the advanced interventions utilised as awareness of autism has grown. The intensively delivered behavioural interventions early in life are considered the optimal treatment for autism

related behavioural symptoms. The authors argued that it is widely held that early intervention using Applied Behaviour Analysis is vital to the development of children on the autism spectrum. Similarly, Chasson et al. (2007), stressed that Applied Behaviour Analysis is the basis of all evidence-based interventions in autism. The authors also contended that all interventions stated to be effective in the treatment of autism are centred on the implementation of Applied Behaviour Analysis particularly in the early years. Therefore it can be said that the regular delivery of methodical educational and behavioural techniques is one of the key elements of the early intervention approach to the behavioural management and education of children with autism. However, the Applied Behaviour Analysis programme uses structured teaching to train children in social and communication skills and relies heavily on one-to-one or small group settings and not on inclusive settings. It then comes as no surprise that the study participants held this method of intervention in high regard and emphasised delivering the Applied Behavioural Analysis method in the self-contained setting to ensure its effectiveness.

The analysis of the findings on the parental approach to the characteristics of autistic children in respect of their inclusion, demonstrates that autism spectrum disorder is reduced to an issue of a medical problem and a medical cure. The general opinion was that autistic children's performance is related to a medical condition and the recovery from autism symptoms was a prerequisite for inclusion. As such, normality is the anticipated state of being especially when the disorder is constructed as residing within the children as a result of their impairments. This viewpoint deems autistic children as having a problem that needs to be adapted to inclusive settings. The study participants did not acknowledge any environmental factors such as the social or the educational policy components that require change to include the child

with autism spectrum disorder. Consequently, the ultimate goal is to cure the autistic child. These results align with the medical model of understanding disability. The medical model conceptualises autism from individual or tragedy perspectives (Connors and Stalker, 2007) which contrasts with the social model that emphasises changing the environment to include the child (Armstrong et al, 2011). The mere acceptance of the medical model is disabling in itself as the emphasis is on the impairments in autistic children but not on any of the strengths these children might have. Some of these strengths include the ability to look at parts of a whole and focus on small details and patterns (Mortton, 2011).

In addition, the results show that none of the advantages of inclusive education neither for the normally developing children nor for the children with autism were noted by the study participants. The complete lack of acknowledgement of any benefits of inclusive education and the rejection of the concept of inclusive education in favour of segregated settings demonstrate the dominance of the medical model approach to disability. The medical model of viewing autism placed the emphasis on the differences between the children with autism spectrum disorder and the normally developing children by underlining the limitations and characteristics of autism. This medical model approach to autism spectrum disorder also contradicts the social model approach upon which the inclusive education principals are based (Lindsay, 2003). In light of the comprehensive description of autism characteristics from the study findings and the considerable body of literature, this study's findings demonstrate that one of the main factors influencing the negative parental perspectives towards early childhood inclusive education for children with autism spectrum disorder is the characteristics that are unique to the autism spectrum disorder.

#### **6.4 The national traditional values factor (The Macrosystem layer in Bronfenbrenner's theory)**

As discussed above, the results demonstrate as discussed above that one of the factors that influenced parental non-acceptance of the concept of inclusion of autistic children arises from the non-normative behaviours of the children with autism spectrum disorder. This section will describe this study's results concerning the second factor that shaped the parental perspectives towards the inclusion of young children with autism in general kindergartens, that is, the Kuwaiti tribal traditional norms factor embodied in the negative societal attitudes towards children with autism spectrum disorder. According to Odom et al, (2004) the research literature has been surprisingly sparse regarding the influence of cultural variables on the inclusion process. Odom et al's statement also applies to the research conducted in Kuwait. The search for literature proved telling as it revealed that there is a dearth of studies relating to the influence of culture on the process of early childhood inclusive education for children with autism spectrum disorder in Kuwait.

The results of this study show that the negative societal attitudes and the social stigmatisation of people with autism spectrum disorder, significantly play a major role in forming the parental medical model approach to autism and subsequently, led to the absence of support for the inclusion of autistic young children with autism spectrum disorder. The findings of the study show that there are consistent indications of the challenge of traditions to accommodate for the concept of inclusive education for children with autism spectrum disorder. The negative attitudes of the society, based on stereotype and stigmatisation, clearly prevented autistic children from having equal opportunities for education and social inclusion. While almost all Kuwaitis are Muslims (Kuwait International Religious Freedom, 2017), and the Islamic value

system views disability as part of the human condition (Ghaly, 2016), the results show that the dominant tribal cultural norms have strongly influenced the societal attitudes towards disability. The results derived from the discussions with the mothers interviewed on the stigmatisation of autistic children, provided evidence to the extent to which the traditional norms including the element of associating disability with shame, have led to the parental adoption of the medical model and the resistance to the concept of inclusive education for young children with autism spectrum disorder.

Given that this study is a holistic case study and the local context is an integral part of the research approach, the researcher aimed to explore the relationship that existed between Kuwaiti cultural contexts and the concept of early childhood inclusive education for children with autism through the parents' perspectives. In order to tap into the local traditional norms that might have influenced the parental perspectives towards the inclusion of children with autism spectrum disorder, the researcher took an insider position. The researcher reflected on her own cultural knowledge which is similar to the Kuwaiti culture in order to probe into a deeper level of discussion. Asking questions on the social stigmatisation of autistic children is a sensitive area especially in the Arab region that associates disability with shame as disability contradicts the powerful cultural image of wholeness in the Arab tribal traditions (Hamid and Furnham, 2012). This is also heightened by the fact that 'associative stigma', i.e., the extension of stigma to family members (Cathoor et al, 2015) is highly common in Kuwait. Therefore, the behaviour considered abnormal brings social shame not only upon the child with autism spectrum disorder but also upon her/his family. However, as the researcher shares a similar cultural background with the study participants, speaks the same language and has lived in Kuwait for several years, these factors enabled the researcher to overcome the sensitivity issue

barrier while closely considering the ethical dimension of the research. It would have been difficult to understand the parental perspectives towards the inclusion of young autistic children without exploring the tenets of Kuwait traditional culture and the societal attitudes toward the children with autism spectrum disorder. It is only through such reflection that one can understand the factors that led to the dominance of the medical model approach towards autism even though the medical model opposes the religious values to which the study participants adhere. The study participants' observance for their religion was evident from their continuous use of Quranic verses and religious sayings. Although the religious model of disability is no longer as prevalent as it was in the past (Retief and Letšosa, 2018), in the Kuwaiti culture the religious model of disability is still a common approach towards having a child with a disability or a child with autism spectrum disorder. The results demonstrate that the intrinsic personal religious orientation positively impacted the mothers' psychological adjustment for having autistic children and enhanced the mother's resilience and well-being despite the fact that parenting a child with autism can be bleak and stressful.

The results also show that autism is regarded as a stigmatising condition and as a source of shame for the families. Although all children with different types of disabilities are stigmatised in Kuwait, because of the characteristics of autism, children with autism spectrum disorder are more isolated and they experience greater stigmatisation and rejection than other children with other types of disabilities. Children with autism spectrum disorder are viewed as a source of disappointment, annoyance and shame. The negative impact of having an autistic child is experienced by the family of the autistic children in public encounters and within the family, especially by the mothers. It is conceivable that the negative reactions and their

impact on the family would be magnified in the Kuwaiti cultural context, where disability poses risks to the family's status and honour (Crabtree, 2007).

The findings show that because children with autism usually do not have identifiable physical features, nor do they use devices such as wheelchairs to make others aware of the presence of a disability, their unusual behaviours such as screaming, spinning or making noises may be mistaken for the child's lack of discipline and very bad parenting. These behaviours then place the mothers on the receiving end of disapproving stares, hostility or blame for subjecting other normally developing children to such antisocial behaviours. The results of the study show that tantrums and problems in shopping areas and restaurants were common and particularly difficult experiences because of the stereotypical and negative reactions of the people towards the behaviours of autistic children. Several sources of evidence suggest that strong genetic components are involved in susceptibility to Autism. For example, Vander-Weele et al, (2004, pp. 379) stated that "Autism is one of the most heritable complex disorders, with compelling evidence for genetic factors and little or no support for environmental influence". As such, having an autistic child in the family threatens the marriage prospects of the unaffected siblings; threatens the stability of the marriage and the family discord; strains familial relationships; and causes general social rejection. Stigmatisation also led some families either to hide their autistic children out of the public eye or deliberately to avoid diagnosing their children in order not to expose the child and the family to social stigma. Most stigma studies have considered stigmatisation of individuals with disabilities to be a universal occurrence, but with different manifestations in different cultures (Thorncroft, 2006). Yang et al. (2007, pp. 1528) for example, noted that "stigma appears to be a universal phenomenon, a shared existential experience". That is to say that stigma and

discrimination exist in every culture where people with disabilities do not receive the same social acceptance as non-disabled individuals. Similarly, the study findings show that negative social perceptions prevented autistic children from being socially accepted and led to the lack of support for the inclusion of these children.

The results of the study demonstrate that the pattern of stigma and associative stigma in Kuwait reflect conventions of conformity to the tribal traditions norms. As noted earlier, neither stigmatisation of children with autism, nor the medical model of disability or the discrimination towards people with disabilities are tolerated under Islam. While the religious model of thinking that stemmed from the personal religious beliefs of the study participants has led to their resilience in the face of the negative societal approach towards them and their children, the medical model approach to autism and the non-acceptance of the inclusion of autistic children rose from the local traditional norms and values. Although religion plays a central role in the lives of Kuwaiti people, traditions seem to have to some extent a stronger impact on people's lives. Islamic teachings confirm that: disability is a natural part of being a human; humans are created different; and disability is neither a blessing nor a punishment (Ghaly; 2016). Although Islamic teachings acknowledge disability, Islam also acknowledges the strengths in disabled people (Bano, 2013; Hasnain et al. 2008). Similarly, Baron-Cohen et al (2009, pp.500) also acknowledged the strengths in autistic people and replaced autism spectrum disorder with autism spectrum condition as the term condition "is less stigmatising, and it reflects that these individuals have not only disabilities which require a medical diagnosis, but also areas of cognitive strength". Similar to the Islamic teachings, Baron-Cohen et al did not view people with autism as distinctly different from others, but rather limited in certain abilities. Islam removes any stigma and barrier to the full inclusion of people with disabilities.

In addition, Islam recognises that the disadvantages that people with disabilities may experience are created by the society and places the responsibility of removing these barriers on the shoulder of the society (Ghaly; 2016; Hasnain et al. 2008). Similarly, Bazna and. Hatab (2005, pp.25) stated that “Islam proclaims the right of the disadvantaged to full inclusion and full support; and affirms the responsibility and duty of society towards its disadvantaged members”. As such, Islamic teachings encompass the principles of the social model of disability and stress the principle of social justice and the rights of people with disabilities to full inclusion. Similarly, in the social model of disability, being disabled is perceived as part of the normal spectrum of human life and people are disabled not by their impairments but by the society’s failure to include these people. Therefore, both Islamic values and the social model of thinking are critical of the medical model which is prevalent in Kuwaiti society. The acceptance of the medical model and the stigma towards children with autism spectrum disorder demonstrates the society’s unwillingness to accept its responsibility towards the marginalisation of children with autism spectrum disorder.

The dominant tribal traditional norms of stigmatisation against those members of the society who cannot meet the challenges of life and who pose a burden on their families and the society, encouraged the negative approaches to autism. Similar observations were noted by Brown (2006, pp. 253) who stated that in the Arab region “while many of the basic cultural values and sentiments toward the disabled provide a wellspring of potential support for inclusive thinking, deeply rooted cultural beliefs and traditions pose obstacles that are difficult to overcome”. Even though the study findings are in accordance with findings reported by Brown, the researcher exercised caution in using the term ‘culture’ and employed the term ‘traditions’, i.e., the transmission of customs or beliefs from generation to generation (Oxford dictionary).

Several researchers including Croucher et al (2017); Beyers (2017) Ramadan (2010) have asserted that religion is an essential part of culture. Given that the findings of the study show that the social stigmatisation and the medical model approach to autism by the study participants are a product of the tribal traditional norms and not the religious beliefs, employing the term ‘culture’ may suggest that both the tradition and the religion elements of culture are denoted. In support of this argument, the researcher found a number of reliable sources including the religious texts, i.e. Qur’an and Hadith as well as the documentations of several researchers such as Beyers (2017) and Ramadan (2010) who maintained that the essence of Islam is religious and religion is a segment of culture therefore, Islam must not be viewed as a culture. Equally, Beyers (2017, pp.3) stated that “Even when religion is part of culture, it is possible to differentiate religion from a worldview governing a cultural community”. That is to say that, even if religion is a segment of culture, it still remains identifiable what constitutes religion and what constitutes culture still remains identifiable even if some elements of culture and religion are connected. Given that Kuwaiti culture is a tribal traditional culture (see chapter 5), the tribal culture is an all-encompassing reality that characterises the customs and habitual behaviours of the way of life of people in Kuwait. Therefore, the study participants’ perspectives towards the inclusion of autistic children; the adoption of the medical model of disability; the social stigmatisation of autistic children; and the encouragement of the separation of children with autism and their exclusion from participating in society, all these factors are a result of people becoming alienated from the religious beliefs and practices and turning to cultural identities or traditional culture, which does not necessarily include religious beliefs.

According to articles arising from international conventions concerning the inclusion of children with disabilities such as the Salamanca Statement and the Framework of Action on Special Needs Education (1994); Education For All, The Dakar Framework (2000); and the UN Convention on the Rights of Persons with Disabilities 2006, it is evident that these conventions emphasised the following: intrinsic to the definition of inclusive education is the notion that it is the environment that must change to suit the disabled individual and not the individual with disability that must change to suit the environment; unless society moves towards the social model of disability and looks at ways of removing traditional and societal barriers rather than focusing on peoples' disabilities, individuals with disabilities or developmental disorders such as autistic children will remain excluded; and inclusive education can only be achieved when policies and practices are consistent with a social model understanding of disability. However, the results of this study demonstrate that the current situation in Kuwait regarding the inclusion of young children with autism spectrum disorder negates the principles of inclusive education as articulated in the above mentioned international conventions. Neither the philosophical approach nor the political will that is reflected by the Kuwaiti government being a signatory to the international conventions, provided the necessary grounding for the inclusion of young children with autism spectrum disorder. The findings of this study show that unless the society re-structures some of its tribal values, for instance, through the adoption of the Islamic teachings of social justice and human rights which correspond to the social model of disability, the current medical model of viewing autism spectrum disorder will continue to prevail. However, shifts in societal attitudes are difficult to make and take time. According to Hofstede (2003), changes in societal attitudes are difficult given that values and attitudes are embedded

and programmed within individual minds and are passed on from one generation to another. Given that the Kuwaiti society is a conservative society and its members show respect to their tribal heritage, it is inconceivable that the social model of disability will entirely replace the dominant medical model of thinking. Progression from a medical to a social model of disability will take time and effort. The findings of this study demonstrate that the parental non-acceptance of the concept of inclusive education for children with autism is based on autism characteristics and the impact of traditional cultural factors. These factors that shaped the negative parental perspective towards the inclusion of children with autism spectrum disorder encouraged the medical model of thinking and the preservation of the segregated educational settings for children with autism spectrum disorder. Although it has become more difficult to justify segregated education, particularly since any advantages of segregation were not reflected in the previous literature given the ethical and social justice considerations, in Kuwait, learning for children with autism spectrum disorder at kindergarten stage still take place in special education settings.

#### **6.5 The implication of parental perspectives on the policy of inclusive education for autistic children (The Exosystem layer in Bronfenbrenner's theory)**

Inclusive early childhood education programming is advocated as a best practice from the experts in early childhood education and early childhood special education fields (Division for Early Childhood and the National Association for the Education of Young Children, 2009). The ethical rationale for placing children with disabilities in inclusive classrooms emphasises that children with disabilities should experience a preschool classroom program of the same quality as normally developing children. The early childhood inclusive education model enables children with disabilities to become participants of the classroom community through involvement in class

activities and also helps children with special needs to develop positive social relationships with their normally developing peers. However, the report from the Department for International Development (DFID), (2010) stated that there are a numbers of factors that have a significant impact on implementing inclusive inclusion and that the greatest barriers to the inclusive education process are caused by society not by medical impairments. The results of this study demonstrate that the parents of young children with autism spectrum disorder are not supportive of the early childhood inclusive education movement for children with autism spectrum disorder in Kuwait. The perceived risks of an inclusive sitting for children with autism spectrum disorder; the characteristics unique to autism spectrum disorder; the unaccommodating societal attitudes; and the socially imposed restrictions and the stigma of children with autism spectrum disorder, are all factors that negatively influenced the parental perspectives. The study's findings also show that Kuwait has no substantive policy on the provision of early childhood inclusive education for children with autism spectrum disorder. The current situation highlights the failure of the education system to meet the rights of children with autism spectrum disorder to an inclusive education program as stipulated in the Salamanca Statement (1994) and the UN Convention on the Rights of Persons with Disabilities (2006).

Parents' perceptions are vital for the success of the inclusion philosophy (Hilbert, 2014). By acknowledging the perspectives of the parents, policy makers can decide upon the strategies that help implement the early childhood inclusive education program. The findings of the study show that Kuwait has a centralised education system and there is no direct collaboration and communication between the policy-makers and the parents of the students. The policy of centralisation does not allow for such direct collaboration and consequently, it is the policy makers therefore that make

educational decisions on behalf of the students and their families. However, it can be argued that the absence of educational legislation supporting inclusive education for young children with autism spectrum disorder is due to the conformity of the educational policy with the national traditional values that encourage segregated settings for autistic children. When the obstacles associated with adopting a new educational movement stem from within the national cultural traditions, it comes as no surprise that the policy makers maintain a cautious approach mapping out the strategies to develop policies in support of the development and implementation of inclusive education for children with autism. Given that the parents of children with autism spectrum disorder are members of the society, the parental perspectives will have an impact, albeit indirect, on the policy makers' decisions regarding the implementation of early childhood inclusive education for children with autism spectrum disorder.

The Kuwaiti educational system persists with the parallel provision of segregated educational settings and practices for children with autism spectrum disorder which contradicts its commitment to inclusive education and ratification of the Salamanca Statement. However, the gap between educational policy and prevailing attitudes, that in reality have been adhered to for decades, will not easily be bridged nor will such attitudes be easily abandoned in response to legislative mandates. Changing society's attitudes towards autistic children is not an easy matter and requires time and effort. Including children with autism spectrum disorder in the general education setting requires many of the parents of both groups, the parents of children with autism spectrum disorder and the parents of normally developing children, to recognise the inadequacy of segregated settings for children with autism spectrum disorder. The review of literature revealed that the shift from special education to inclusive

education demands reforms in education from the very core of the whole learning approach (Kuyini, et al, 2015) and a change of the educational environment of all children, with or without disability (Kavale and Forness, 2000). According to Meyer (2004), no society can claim a good record for solving this problem. The findings of this study show that the move towards the inclusive education program for children with autism spectrum disorder is not an easy matter especially since the educational policy in Kuwait is driven by regimented traditional norms and practices.

However, most developing countries get their education literature and resources from developed countries (Charema, 2010). Therefore, educational development and transformation such as the early childhood inclusive education program that occurs in developed countries will have direct influence on Kuwaiti educational policy.

Developing countries “cannot afford to develop far behind because most of their personnel are educated and trained in developed countries” (Charema, 2010, pp. 78).

While Kuwait can learn from developed countries’ experiences regarding the inclusion of children with autism spectrum disorder, it seems inconceivable that education policy-makers will not give due consideration to the deeply- rooted local traditional norms and social attitudes towards children with autism in the process of implementing inclusive education programs. Therefore, although Kuwait’s rhetoric suggests that there is an increasing appreciation of the importance of creating an inclusive environment in Kuwaiti schools, this study’s results show that currently Kuwait is still far from effectively implementing the inclusive education program for children with autism spectrum disorder. The disparity between rhetoric and reality in implementing public policy on inclusive education programs may suggest that unless the national context is prepared to adopt the new initiative of the inclusion of children

with autism spectrum disorder into the mainstream society, the inclusion of children with autism spectrum disorder remains a principal objective yet to be achieved.

Exploring the parental perspectives of the inclusive educational model for young children with autism spectrum disorder and the impact that an inclusive setting may have on their children proved to be vital in understanding the overall benefits and disadvantages of the inclusive education model on children with autism spectrum disorder. The study findings show that the study participants believe that students with autism spectrum disorder are better served outside the mainstream classroom setting. Indeed, the parental lack of support for the inclusive education program does not mean that children with autism spectrum do not have access to other provisions of education. The mothers interviewed believed that children with autism spectrum disorder have educational needs that differ from those of normally developing children and that the educational needs of autistic children can be better met through special education programs and specialised centres depending on the severity of the autistic characteristics. The results of the study demonstrate that by providing different mechanisms, such as special education units within mainstream schools or in special education kindergartens or specialised autism centres, Kuwait maintained its commitment to the Education For All concept, whereas in terms of the rights to inclusive education which is based on equity in education for children with autism spectrum disorder and the shift in focus from differences among students to learning for all in the same educational settings, this concept has not yet been in Kuwait.

## **6.6 Conclusion**

As the number of children with autism spectrum disorder continue to rise, it is vital to provide effective educational opportunities for these children. The findings of

this study demonstrate that the study participants are not supportive of the early childhood inclusive education model for children with autism spectrum disorder. The parental negative perspectives towards the inclusion of young children with autism spectrum disorder are influenced by the characteristics unique to autism spectrum disorder and by the social negative attitudes towards children with autism. These factors that shaped the parental perspectives encouraged the resistance to the inclusive setting in favour of the self-contained segregated educational setting and indorsed the medical model of thinking of autism spectrum disorder. The findings of this study also show that the policy for an inclusive education program for children with autism spectrum has not been established in Kuwait yet. In the process of discussing the results, the researcher provided an overview of the perspectives from which the study participants approached autism spectrum disorder, namely; the religious model, the medical model and the social model of thinking. The findings show that parental perspectives aligned with a medical model of understanding autism spectrum disorder, and as such the study participants rejected the concept of the inclusion for children with autism spectrum disorder in favour of the self-contained highly structured settings.

The study findings demonstrate that Kuwait is still far from effectively implementing the concept of early childhood inclusive education for children with autism spectrum disorder. The discrepancy between the rhetoric and the current practice on inclusive education, shows that early childhood inclusive education for children with autism remains an objective yet to be achieved. The education system in Kuwait still focuses on the special needs model to meet the educational demands of young children with autism spectrum disorder. Based on the study results, the reality of the situation in Kuwait is that the concept of inclusive education for children with

autism spectrum disorder is at odds with the dominating traditional norms. Therefore, the main implication of this study is that in order to develop the concept of early childhood inclusive education for children with autism spectrum disorder, a change is required in the overall societal mind-set with a focus on rethinking the underlying traditional norms that continue to permit the stigmatisation and exclusion of children with autism spectrum disorder. Without negating the importance of the concept of early childhood inclusive education for children with autism spectrum disorder, the Kuwaiti educational policy corresponds to the parental perspectives in this study and the general traditional cultural norms and attitudes towards children with autism spectrum disorder. Consequently, the Kuwaiti educational system seems to be lagging behind in the process of implementing early childhood inclusive education programs for children with autism spectrum disorder.

### **6.7 Recommendations**

As the number of children with autism spectrum disorder continues to rise, it is vital to provide effective educational opportunities for these children. The findings of this study demonstrate that the study participants are not supportive of the early childhood inclusive education model for children with autism spectrum disorder. The negative parental perspectives towards the inclusion of young children with autism spectrum disorder were influenced by the characteristics unique to autism spectrum disorder and by the negative social attitudes towards children with autism. These factors that shaped the parental perspectives encouraged their resistance to the inclusive setting in favour of the segregated, self-contained educational setting and endorsed the medical model perception of autism spectrum disorder. The findings of this study also show that the policy for an inclusive education program for children with autism spectrum has yet to be established in Kuwait. The results of the current

study call for greater importance to be conceded to the inclusion of autistic children at the social, cultural and policy levels respectively. The recommendations here will be presented based on the factors that were explored in the study. It is proposed that these recommendations would help to overcome the barriers that were identified in this study.

### **1) Recommendations at the social and cultural level**

This study suggests that public awareness of autism needs improvement. Considerable misconceptions and misinformation were identified during the course of the study. The evidence showed that such limited awareness and understanding about autism was found not only amongst the public but also amongst the mothers of autistic children. These included a lack of knowledge of the various intervention methods, the feeling that these children should not attend regular schools, and the belief that such a disorder can be a blessing or a punishment from God.

The research suggests that the lack of awareness about autism can be targeted by focused media campaigns. For example, using the various media outlets to show support for autistic children by promoting the Autism Awareness Puzzle Ribbon which is the most recognised global symbol of the autism community. This symbol can be worn as a pin on school uniforms, displayed as a magnet on motor cars, or as a Facebook profile picture. The film industry and production companies are other possible mediums by which to encourage support for autistic children. Films similar to *“Rain Man”*, *“The United States of Autism”*, *“Sounding the Alarm,”* could be produced in Arabic to disseminate beneficial information to affected families (and the general public). Similarly, the production of animated films in the Arabic language

could be a means of educating typically developing children on the potential of autistic children.

Initiatives such as focused educational campaigns should facilitate the development of systematic and sustainable solutions to enhance autism awareness amongst health care professionals, teachers, and students at all educational levels. Furthermore, well-researched Arabic language programs are needed to validate/demonstrate the potential advantages of the early childhood inclusive education program for children with autism spectrum disorder. The review of literature revealed that there is a lack of Arabic resources that provide information for the parents of children on autism spectrum disorder and a lack of information on the rights of autistic children to inclusive education. Therefore, it is essential for parents to organise themselves to challenge exclusionary practices in the current educational system. They can do this through obtaining information and support from national and international nongovernmental organisations to learn further about the rights of their children to inclusive education.

Furthermore, in order to encourage the social model of disability and to diminish the negative attitudes towards children with autism spectrum disorder, it would perhaps behoove Kuwaiti religious scholars place greater emphasis on the Islamic values system to which the Kuwaiti society adheres. In their speeches, Islamic clerics could underline the religious values that are in line with the social model of disability and the duty of Muslims to include people with disabilities in everyday activities could form part of the Friday religious sermons at the mosques. Given that Kuwait is an Islamic country and Islam is the religion of almost 99% of Kuwaitis (Bazna and Reid, 2009), the onus is on Islamic scholars to influence society's attitudes and the policy of adopting human-right and social justice based approaches

to challenge the stigma and discriminatory practices that so often impede the inclusion of autistic children.

The review of literature for this study proved significant as it revealed that there is a scarcity of research in Arabic on autism and the inclusion of autistic individuals. Therefore, the researcher recommends that researchers who conduct their studies on these subjects, should consider translating their research into the Arabic language and make them available throughout the community for the general public to benefit from the knowledge and information these studies provide.

## **2) Recommendations at the educational level**

Implementing inclusive education is one of the major challenges facing the Kuwaiti educational system. The implementation of inclusive education for Kuwaiti autistic children may require many steps to translate this concept into a reality. The following recommendations are based on the study findings.

One of the main difficulties in implementing inclusive education is that general education teachers do not receive sufficient training to work in complex teaching contexts and to respond to the unique needs of autistic pupils in their classroom. The findings indicate a lack of appropriate teacher training, that is, training not in a parallel, divisive system as at present, but training that reflects autistic children's educational needs. The Kuwaiti Ministry of Education might consider collaborating with professionals from Western countries in the training of Kindergarten level teachers and to provide assistance in establishing inclusive classrooms that accommodate the needs of autistic children. This might ensure a positive attitude towards autistic children and protect their rights to inclusive education.

Resources, including human resources, educational resources and well-equipped classrooms would enable teachers and staff to support autistic students within regular educational settings. There is a need for co-authored research between international educational agencies and local researchers to develop local capacity without neglecting the local cultural norms.

The Kuwaiti Ministry of Education should also consider giving opportunities to Kuwaiti teachers by sending them as delegates to attend and participate in global initiatives conferences on inclusive education to improve teachers' knowledge of the inclusive education movement. Such participation will motivate the teachers and might support them in finding the appropriate and practical measures that would facilitate the implementation of inclusive education.

There is an urgent need for the policy-makers to work on introducing models of inclusive educational settings for autistic children at the kindergarten stage. Providing early childhood inclusive settings programs for children with autism spectrum disorder may enable the parents to voluntarily choose between the special needs settings and the inclusive settings based on their children's needs and the severity of their children's conditions.

In addition, universities and colleges also need to prepare educators to teach children with autism spectrum disorder in inclusive classrooms. These educational institutions should offer specialised programs on the various intervention methods for educating and managing the behaviours of children with autism spectrum disorder such as the Applied Behaviour Analysis methods or the skills programme that uses structured teaching to train children in social communication skills (TEACCH) or Learning Experiences and Alternative Program for Pre-schoolers (LEAP) or the

Developmentally Appropriate Treatment for Autism (DATA) that gives prominence to building the child's repertoire thereby enabling her or him to successfully participate in environments alongside typically developing peers or any of the other types of intervention that have been recognised to facilitate the inclusion of children with autism spectrum disorder in general education settings.

Along with the aforementioned issues, another key impediment to the development of inclusive education in Kuwait is the presence of incomplete or misleading data (WHO, 2012; Al-Thani, 2006). Accurate statistics or data is very important for making policy and setting precedence. Unreliable data leads to considerable difficulties in defining educational policy relating to autism and autistic students. Insufficient data, improper documentation and poor management of existing data are a few of the key issues in Kuwait. Therefore, the policy makers should consider the updating of the statistics relating to educational issues and autism disorder prevalence of paramount importance. Accurate statistics facilitate for the researchers to present practical recommendations and methods in the field of inclusive education for autistic children that might support the inclusion of these children.

### **6.8 Contribution of the study**

The study provided the researcher with an insightful appreciation of the contemporary issues within the current inclusive education movement and the factors that might either contribute to the successful implementation of inclusive education or that might constitute a barrier to the implementation of this current educational movement. The importance of this study is that it draws the attention of researchers, interested in working on inclusive education for students with autism, to the role of the traditional cultural understanding in forming perspectives on the inclusion of these

children, with particular reference to the social attitudes and traditional beliefs. The results of the study show that the multiple interpretations of the concept of inclusion, the cultural differences, the diverse perceptions of disability and the national disparities all influence the implementation of inclusive education at the local level.

In addition, given the lack of literature on studies of early childhood inclusion for children with autism spectrum disorder in Kuwait, the study's contribution is reflected in its aim to prepare the ground and initiate a dialogue for further research on early childhood inclusive education for children with autism in the Arab region. This study will initiate an area of research on the importance of parental perspectives in deciding the best educational approach for their autistic children based on their children's needs. Furthermore, the focus of this research, being on young children with autism spectrum disorder and their characteristics including the significant deficits in basic areas of the functioning of autism such as, social interaction, communication, learning and behaviours which contribute to the challenges of teachers and related service professionals effectively serving these children, could also be linked to the studies on early intervention methods for children with autism spectrum disorder in Kuwait. Given that there has been a sustained increase in the number of children diagnosed with autism spectrum disorder and this prevalence of the disorder has become a widespread concern globally (Individuals with Disabilities Education Act (IDEA0, 2004), the importance of early intervention methods is paramount in facilitating the participation and acceptance of children with autism in mainstream settings.

In view of the findings and conclusions derived from this study, it can be said that this research has made a valid contribution to knowledge which features some factors that have shaped the parental perspectives towards the inclusion of young

autistic children and the models of disabilities that not only have formed the parental perspective but also have shaped the early childhood education policy and practice offered for autistic children in Kuwait. The results of this study demonstrate that the adoption of the international concept and practice of inclusive education without careful scrutiny of the local cultural traditions and the societal factors is not likely to bring about the expected effects.

The methodological contribution of the study became evident in the process of the thematic analysis of the data. The qualitative holistic single case study approach made it possible to explore in-depth the complexities of inclusive education for young autistic children in Kuwait and has established a platform for other researchers in Kuwait to consider utilising similar methodology in conducting research on a contemporary phenomenon within its cultural context. Through employing a qualitative approach, the study provides a rich and detailed holistic picture of the parental perspectives towards early childhood inclusive education for children with autism that to the best of the researcher's knowledge has not been explored previously in the Kuwaiti context. Additionally, the descriptive case study approach of this study through which the researcher attempted to fully describe the distinct characteristics of the current provision of early childhood inclusive education for children with autism in Kuwait, will provide the foundational knowledge for future researchers before these researchers can make useful judgments about what they ought to study and what changes their studies may make.

The novelty in using the Bio-ecological Systems Theory proposed by Bronfenbrenner as a conceptual framework to explore early childhood inclusive education for children with autism spectrum disorder in Kuwait from the parental perspective, marks also another contribution of this study. The study explored the

autistic children's characteristics (biosystem), parental perspectives (mesosystem), education policy (exosystem) and cultural factors that shaped the parental perspectives (macrosystem). The study demonstrates the effectiveness of employing Bronfenbrenner's Bio-ecological Systems Theory as a theoretical framework for research on early childhood inclusive education. Through structuring the study within the various layers of this theory, the researcher can organise the different contexts that may influence the implementation of early childhood inclusive education and show the interconnectedness of these contexts in order to present a coherent report. Although, Bronfenbrenner's Bioecology Systems Theory has served as a conceptual framework for organising this study, however, to use all the layers of the Bioecology Systems Theory as a theoretical framework and the associations of variables and impacts across levels of the contexts will be a challenge for research on early childhood inclusive education.

The study of parental perspectives on early childhood inclusive education has been a neglected area of research in Kuwait. This study highlights the significant role the parents play in the development of effective early childhood inclusion programs. The information of this study can add to professionals' knowledge of effective culturally sensitive inclusive practices. The researcher hopes that this study will draw international awareness to the role of cultural understanding, specifically the traditional values and beliefs, in forming fixed ideas, towards autism and the inclusion of children with autism spectrum disorder.

## **6.9 Reflexive Notes**

All researchers are positioned by a number of factors including their cultural backgrounds, personal circumstances, or interest. However, the extent to which such

influences are manifested or concealed when reporting data is bound by the philosophical stance and the methodology employed in the study (Suryani, 2013 and Reeves, et al, 2013). This study, as stated throughout this thesis is an exploratory case study and not an ethnography (see 3.9: Rationale for employing a qualitative case study method). In the section which I referred to above, I discussed my reasons for choosing a case study method over an ethnographic method in order to conduct this study and I drew a comparison between these two methods to justify the appropriateness of the case study approach over the ethnographic approach in answering the research question. However, it is worth mentioning here that in ethnography, a major goal of the research process is self-reflexivity, (Suryani, 2013; Byrne, 2001; and Lambert et al., 2011). In addition, according to Chiseri-Strater, (2017, p.116) “for ethnographers, writing about how we are positioned is part of the data [and] the ethnographers detail how their stance-position location affects the entire ethnographic process: from data collection, theory construction, and methodological understanding, through the creation of the narrative voice and overall writing of the ethnography”. In the case study method on the other hand, the researcher's perceptions and interpretations become part of the research and consequently, a subjective and interpretive orientation flows throughout the study (Harisson, 2017; Yin, 2014; Creswell, 2014). Subjectivity is openly acknowledged in the case study and to manage this, the researcher embraces a reflexive stance within the study” (Harisson, 2017; Denzin and Lincoln, 2011; Miles et al., 2014, Stake, 2006; Yin, 2014).

However, I am aware that all researchers are positioned whether they write about it explicitly, separately, or not at all (Reeves, et al, 2013; Lambert et al, 2011). Therefore, in the thesis I reflected on some issues that might have influenced my

position including: my own perceptions of where I stand in relation to the participants (see sections 3:14; 3.22); my insider/outsider status (see 3.7 and 3:14), my cultural background (see sections 3.7; 3:14; 3.22); biases (section 3.7; 3:22); and the rationale for focusing on autistic children (section 3:14). Similarly, in choosing my case study methodological position, I considered the different qualitative research methods to determine the design that best addresses the aim of my study in section (3.7; 3:9), and that aligns with my constructivism philosophical position (see section 3.6). Acknowledging the factors that influenced my position in my research helped increase my capacity to understand the significance of the knowledge that I brought into the field of the cultural impact on the inclusion of autistic children in Kuwait.

During my research I kept a journal which contained the steps that I should take to gather my information, including meetings with the mothers of autistic children, kindergarten owners and administrators; as well as mothers of typically developing children. I recorded contact details of participants including their full names, date of the interview, email address, telephone number in case they wished to withdraw their data from the interview. I also included sketches of the seating arrangements in every meeting and some description of each participant for the purpose of identifying individuals and the comments they made and I included a large amount of vocabulary unique to the Kuwaiti dialect. I also wrote down similar information in the study journal for individual interviews including descriptions of the settings in which we met. I updated these journal entries after each interview.

In this journal I also included my thoughts, ideas, concerns and emotions. I carried this journal with me all the time to write down ideas or issues I needed to become familiar with or read more about. During the interviews I kept the journal with me as I stated on page 87: “*The researcher wrote notes serving as reminders*

*that her research is an explorative case study that entails providing an impartial interpretation of the participants' perspectives. This technique assisted in committing the researcher's feelings and thoughts to paper rather than verbalising them during the interviews or imposing them on the final descriptive report".* My study journal also included issues concerning my reflections, assumptions, concerns and beliefs that not only influenced my position but also made me recognise my position as a researcher. I believe this is one of the areas of this research that has had a positive impact on me.

Prior to conducting the interviews, one of my main concerns was how to establish my outsider status as a researcher. I knew that my insider status would follow naturally, given that I have a similar cultural background and I speak the same language as the participants. This dilemma of how to establish my outsider status was mainly manifested principally during the stage of initial contact with the mothers prior to the interviews due to the similarities of our cultural background. In my attempts to find ways of how to position myself as an outsider I used my journal to determine the strategies I should employ. For example, I decided not to reveal any intimate details of my life; to stay focused on the participants' responses and record them accurately; to keep reminding myself of what I had to accomplish. I struggled with this issue until I conducted the first explorative focus group session. During the short break in the first interview, I noted a number of thoughts and ideas in my journal. For example, translation of a few of these thoughts are *"I empathise with them, but I don't agree with their opinions. They rejected inclusive education as soon as I explained its concept. How do they know if it's not good for their children and for typically developing children? They all stated with an assertive tone that the families of typically developing children will not accept such an educational model ..... they*

*passed a judgment on something before experiencing it, I think this is an indicator of the cultural impact on the concept itself” and “They keep repeating Quranic verses, but none of them noted the Islamic teaching regarding the inclusion of people with disability, I should write about the difference between the Islamic social model and the medical model”; and “why do they keep saying to me INDAKUM , “ (a phrase used in Arabic when talking to a stranger or someone who is not part of the group), it seems to me that the majority of them consider me an outsider.*

In the second interview and the interviews thereafter, phrases such as “*in your country; your culture*” that mothers used to justify or compare their viewpoints, substantiated my initial thought that the majority of the participants in some instances considered me an outsider. This was a breakthrough for me. My own perceptions of being an insider in terms of my relationship with the mothers interviewed, was not in many instances similar to the mothers’ view of me as an outsider. Therefore, although I felt considerable empathy with the mothers interviewed, my increasing understanding of my differing perspectives at various stages of the research enabled me to step inside and outside of the perceptions of the study participants. Consequently, elements of “insiderness” on some dimensions of my research and the elements of “outsiderness” on other dimensions enabled me to balance my insider-outsider position. Although there are many advantages of the insider position (see 3.7 and 3.14), the outsider status gave me a certain kind of objectivity not usually afforded to the insider. Shifting positions on the insider-outsider continuum was of considerable value in relation to my analysis and interpretations of the research findings.

However, looking back at the various strategies I employed to manage my subjectivity, bias and outsider-insider status and to my deliberate self-scrutiny in

relation to my research, I realised that these factors were not the goal of this study. The aim of this research was to provide an authentic, honest, and holistic picture of the study results and to reveal a new understanding of the impact of culture on inclusive education in Kuwait, and, in so doing, to contribute new knowledge to this subject previously unresearched.

#### **6.10 Limitations of the study**

It is essential to recognise certain limitations of this study and to take them into account when considering the results. Firstly, given that this is a qualitative case study, the case under study needed to be contextually bound. The study was bound by its geographical location; i.e., Kuwait, and by the criteria of the study sample. The criteria for the study participants were limited to the mothers whose children are at kindergarten stage; i.e. 3 ½-5 ½ years old and their autism is between moderate to mild on the autism spectrum scale. In addition the study is on kindergarten-based inclusive settings and not on community integration through social or sports activities, although the study did include some information on societal attitudes.

The study only focused on Kuwaiti mothers, therefore, the sample in this study did not include mothers of other nationalities living in Kuwait. Thus, the results from this study may only be applicable to Kuwaiti mothers of children with autism. Secondly, the expectation was that both parents of the autistic children would participate in the study and consequently, the study sample would have been larger than the (31) participants, however, none of the autistic children's father participated, only the mothers did. The fathers were described by the wives as busy with employed work. It is very likely, however, that, due to some strict gender norms operating in Kuwait, it was considered inappropriate for the men to meet with a group of women.

Given that parental perspectives are a very important component in the field of early childhood inclusion as parents play a very important part because they are viewed as partners of the team in the educational decision making-process, a larger number of participants was required to expand on certain issues including the training and services needed to meet the diverse needs of young children with autism spectrum disorder. This study is of a relatively small size, which makes it difficult to generalise the findings to the larger population of parents of young children with autism spectrum disorder. To expand our knowledge of parental perspectives on early childhood inclusion for children with autism, future research is needed to address these limitations. Thirdly, the review of literature was limited to the years 2000-2016, and mainly on studies conducted in English. Therefore, the review may not have covered all the research conducted on inclusive education and autism spectrum disorder in Kuwait. Fourthly, the time factor. The researcher spent almost three weeks in Kuwait. In scheduling the interviews, the researcher had to schedule most of the focus group sessions over the week-ends as almost all of the mothers interviewed were working mothers. The individual face to face interviews however, took place during the week days. Finally, along with the aforementioned issues, the official public reports on inclusive education in Kuwait were misleading in terms of issues concerning inclusive education and its practices as well as the inconsistency of the usage of the terms inclusive education, integration and mainstreaming. Therefore, the researcher triangulated the data gathered from the kindergarten owners and kindergarten administrators through member-checking whilst triangulating the published reports during both the focus groups and the individual interviews.

This study focused only on the parents of children with autism. As such, the results of this study may not be applicable to parental perspectives of children with

other types of disabilities. Notwithstanding the limitations which surround the study, of particular concern in this study was the dearth of research on inclusive education; the lack of research on early childhood inclusion; the scarcity of studies on autism spectrum disorder in the State of Kuwait; and the lack of research on parental perspectives and experiences. Given that this study is a qualitative case study, the results of this study may not be generalised to the country as a whole. However, despite the interesting findings of the study regarding the complexity of inclusive education for young autistic children, generalisation of the results was not the main aim of this study. This study is an attempt to bridge the knowledge gap in the field of early childhood inclusive education for autistic children in Kuwait. As far as to the researcher's knowledge, this study is the first of its kind to explore the inclusion of young autistic children from the parental perspective in Kuwait. Therefore, the aim of this study is not to generalise the results; rather to pave the way for further research in this field.

### **6.11 Directions for Further Research**

This study identified potential areas for future research based on the study results, further research is needed in the area of parental perspectives towards the inclusion of students with autism spectrum disorder. There is a lack of research in Kuwait on the parental perspectives towards the inclusion of autistic children for both groups of parents, the parents of children with autism spectrum disorder and the parents of normally developing children. Acknowledging the parental perspectives and the concerns parents have, is essential to understanding the advantages and the disadvantages of any new educational initiative as parents are best at knowing their children's idiosyncratic needs. Therefore, a replication of this study using a

quantitative or a mixed methods approach will be essential for further exploration of the concerns cited by this study's participant regarding the inclusion of children with autism spectrum disorder.

Further research is also needed on the impact of the cultural traditional values and beliefs on shaping parental perspectives towards the inclusion of young children with autism spectrum disorder. Developing an understanding of the cultural norms that are predominant in the society, which in turn influences the attitudes of its members, is very important in planning for a shift from the predominant medical model of thinking of autism spectrum disorder to a social model of understanding of the disorder. Therefore, further research is needed in the types of measures that need to be taken and the effectiveness of these measures in the process of changing social attitudes towards the inclusion of children with autism spectrum disorder. Researchers can further evaluate the changes in social attitudes toward the children with autism spectrum disorder and identify any serious impediments to the progress of these children's inclusion in the general educational settings. Future research should further investigate the social interaction between the young children with autism spectrum disorder and normally developing children in a general kindergarten setting. The findings of this study also recommend future research to be empirically conducted on autism spectrum disorder and the various methods of early intervention techniques that can be employed to manage the characteristics of autism spectrum disorder in inclusive classrooms. Future research needs to focus on the social aspects of autism spectrum disorder, especially how the social environment imposes limitations upon children with autism spectrum disorder.

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## Appendix One

### Interview guide for focus group interviews

- 1-Name of interviewee -----
- 2-Place of interview -----
- 3-Date of interview -----
- 4- Parent's level of education
- 5- Is your child medically diagnosed as having:

Low-functioning autism	mild autism	high functioning autism
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#### **a) Research questions for parents in the focus group interviews:**

- 1- If your child is attending an inclusive education setting in a kindergarten, explain what is meant by "inclusive" in your opinion?
- 2- Would you support young children with autism being included in regular classroom settings with their normally developing peers with appropriate support services? Give reasons for your answer.
- 3- In your opinion are children with autism socially stigmatised? If yes, describe how from your own experience.
- 4- Have you actively participated in decision making process regarding the policies relating to the education of young children with autism?

## **Appendix 2**

### **Research question for mothers of normally developing children at kindergarten stage**

1) Do you support including young children with autism in a regular classroom setting? Give reasons for your answer?

### **Appendix 3**

#### **Research question for kindergarten owners and administrators in individual interviews:**

- 1) Have you received any policy guidelines from the Ministry of Education regarding early childhood inclusive education and if so what were they?

## **Appendix Four**

### **Research Information Sheet**

#### **Parental perspectives on inclusive education for young children with autism spectrum disorder in Kuwait**

#### **University of Lincoln**

The researcher would like to invite you to take part in an interview for a research study. Before you decide, the researcher would like you to understand the reasons for conducting the research and what it would involve for you. Please take time to read the following information carefully.

#### **Study title**

This study is on parents' perspectives on inclusive education for young children (3 ½ -5 ½ years old) with autism spectrum disorder in Kuwait.

#### **Purpose of the study**

The purpose of the interview is to discuss your views, experiences and concerns about the inclusion of your children in a regular kindergarten setting. We will focus on the effectiveness of inclusive education and whether inclusion meets the needs of your children as well your expectations. Further, we will talk about your role as parents in the decision making of your children's inclusion.

#### **Participation in the interview**

Taking part in the study is entirely voluntary. Should you not feel comfortable to take part in this study after having read this information sheet, then you are free to withdraw without giving a reason. However, if you decide to take part in the interviews you will be asked to sign a consent form to confirm that you have agreed to participate. If you wish to withdraw after signing the consent form, please inform the researcher. You can withdraw completely from the interview at any time or not answer questions as you deem appropriate.

Any data collected up to the point of your withdrawal will be retained and anonymised for use in the final study analysis unless you specifically ask for it to be

withdrawn. You have the right to request all your responses to be withdrawn from the study, up until the point of submission of the findings to the University of Lincoln.

### **The interview**

The interview will be for 60-90 minutes. The time and location will be agreed upon according to the convenience of the majority of participants. However, should you wish to participate but are unable to attend any suggested times for group sessions, you can inform the researcher of your preferred times and we will discuss the possibility of alternative arrangements. The interview will be held once with each group, however, any participant who wishes to participate in further sessions in order to add or clarify certain issues of relevance, will be welcome to attend. The interview is a discussion session during which you may speak as freely as you wish. There are no right or wrong answers.

### **Benefits of participating**

I cannot promise that the research will directly benefit you or your children but the information I gather from you will help to increase awareness of the importance of utilising the most effective methods in educational settings for children with autism that will enable them to reach their potential on educational, social and behavioural levels. In addition, your participation will highlight the important role you play in your children's education and will add weight to your voice concerning the implementation of current educational policies of inclusive education for children with autism.

### **Disadvantages and risks**

Taking part in this research should not bring any risk or cause you any inconvenience. You will not be asked to answer any questions that you believe to be inappropriate or make you feel uncomfortable. In the event of any complaint being raised during the interview or of any possible distress occurring then this would be addressed either prior to or during the session.

### **Confidentiality**

All research conducted at the University of Lincoln follows ethical practice and all information about you will be treated confidentially. All data files including audio recordings, personally identifiable material, participant names and interview transcripts will be stored securely at the University of Lincoln in a separate location to the data according to the University of Lincoln's policy. Any information about you will be anonymised so that you cannot be recognised. Only the researcher involved in this study will have access to identifiable data. The data from this study will be retained for approximately 8 years. After this time, it will be disposed of securely.

### **Research results**

Results from the study may be published within scientific journals. A written summary of research findings will be provided to all participants, upon request. All data will be anonymous so that you will not be identified in any report or publication. There will be no exact quotations from interview material as all your answers will be

translated into English and all names and identifiable material will be removed so that you cannot be recognised.

### **Method of data recording**

The interview responses will be either digitally recorded or transcribed as is convenient for you. If you permit digital recording, please rest assured that your discussion will be recorded for transcribing purposes only. Only the researcher will ever hear the tape, and no names will feature in the transcript.

Within two weeks of the of data analysis completion, you will be sent a copy of your interview so that you can review it and edit it for accuracy. You will be asked if the interview transcript accurately reflects the comments you made during the interview. You will then have the opportunity to revise and confirm whether the interpretation of the findings is consistent with your responses.

## Appendix Five

### Consent Form

**Title of the research: Parents' perspectives on inclusive education for preschool children with autism spectrum disorder in Kuwait**

- I have read and understood the Research Information Sheet dated -----
- I confirm that I have been given the opportunity to ask questions about the Research and have had these answered satisfactorily.
- I agree to take part in the interview. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
- I understand that taking part in the research will include being interviewed and will only be audio recorded with my authorisation.
- I understand that my personal details such as my name, my phone number and my email will not be revealed to anyone outside of the research.
- I agree to take part in the above study

Name of Participant ----- Date-----

Signature of Researcher ----- Date -----