



**University of
Reading**

**Autism and the Experience of Transition from
Childhood to Adulthood**

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Declaration

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.’

This thesis has not been previously submitted for another Ph.D. or comparable academic award.

Reem Balubaid

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This thesis would not have been possible without the blessings of Almighty Allah.

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Abstract

The research explores ways through which individuals with autism spectrum disorders (ASD) and families experience a range of transitions from childhood to adulthood. It contributes to a debate over the recent decade concerning how transitions affect the individual and families. The research emphasises the personal experiences, concerns, and successes faced by those with the condition, alongside some parental perspectives during these phases. The study is located within a wide body of literature on autism in general, although constrained by limited access to target respondents both in the UK and in Saudi Arabia (KSA). The research questions that underlie the study deal with the perspectives of some individuals with ASD in the UK and a comparable number of parents in the KSA. The study adopts a qualitative method that incorporates life history interviews with six adults with autism from the UK, along with semi-structured interviews with thirteen parents of individuals with ASD from the KSA. These interviews were analysed by means of thematic analysis. The findings from the two groups are categorised in seven main themes: experiences with diagnosis, childhood experiences, school experiences, adolescence and puberty, employment, adulthood and relationships, including the availability of support across each transition. For each of these themes there are sub-themes the purpose of which is to allow for a more coherent analysis. This study fills a gap in current research in this area, by offering a unique insight into the lived experiences of those with ASD and parents from two different cultures. As such, it offers an improved understanding of the ways through which people with ASD and parents need an enhanced support during transitions. The findings are that there is a general need for an increased awareness by both parents and primary care providers of the nature of autism to ensure an early specialist diagnosis, and offer support. Such awareness is effective when made throughout communities and public services. The research recommends that KSA policy makers should consider the notion of inclusion into mainstream education, and special schools comparable to that in the UK. Both countries should re-appraise the role of employment and voluntary work in raising the self-esteem of young adults with ASD and the enhancement of their social skills.

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Chapter 1 Introduction

1.1 Research Background:

This thesis focuses on the challenges and successes related to transitions for children and young adults with Autism Spectrum Disorders (ASD). It does this by listening to the voice of young adults, along with parents (mothers) of individuals with ASD, using qualitative social research methods in both the United Kingdom (UK) and the Kingdom of Saudi Arabia (KSA). For the purposes of this thesis, autism or ASD are mainly used interchangeably to refer to Autism Spectrum Disorders (ASD).

Autism is a condition that impairs the individual's ability to communicate efficiently either with spoken language or nonverbal type of communication, or to interact socially with his/her surroundings, and is characterized by persistent behaviours and significantly limited interests (American Psychiatric Association, 2013). In addition, individuals with autism typically follow certain routines and exhibit sensory sensitivities (American Psychiatric Association, 2013). Therefore, it is very crucial to continue to recognize their needs and support these individuals with ASD when they step into their adult years (Rydzewska, 2012).

Research shows that one of the developmental areas in which individuals with autism tend to struggle is the management of transitions in their lives (Griffin, Taylor, Urbano, & Hodapp, 2014; Rydzewska, 2012). Individuals with autism typically follow set routines (Realmuto, 2015). Consequently, it is important to look at the times of the individual's life where routines are changed, to consider how they adjust. For the purposes of this thesis the researcher defined this as a 'transition'. Transitions refer to any period or situation in which the individual needs to significantly adjust his or her living or social circumstances (Kralik, Visentin, & Van Loon, 2006). Examples of these periods include transitioning from the home to the school environment, puberty, starting a new job, or graduating from one academic environment to the next, and integrating with society (Griffin et al., 2014; Hendricks & Wehman, 2009). Given the difficulties that individuals with ASD encounter during these varied transitions it is, therefore, important to seek the views of the individuals and families affected by this change and also to explore specifically the level of support that they need (Parr & Hunter, 2014).

Despite such recent research, there are still a number of gaps in the literature on the management of the different types of transitions among children and young adults with ASD.

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First, relatively little is known about the experiences, difficulties, and concerns associated with transitions of various types (Roberts, 2010; Taylor & Seltzer, 2011). Additionally, the point of view of the individuals with ASD regarding the different transitions in their lives is also limited.

In addition to the gap in literature regarding the voice of individuals at this time, it is also important to note that this issue is increasing, as has a wide impact. According to Duncan and Bishop (2015), since there is an increase in the number of individuals with autism transitioning into adulthood, it is very important to support and recognize the aspects that contributes to a better outcome in adulthood. Key players in this are educational institutions and schools, but they are not the only ones; educational institutions need to include parents and students to recognize their desired goals and reach the appropriate services, along with the necessary collaboration between schools and employment organizations (Friedman, Warfield, & Parish, 2013). Even so, practice is less clear and research in this area has recommended that all individuals with autism should have robust transition plans, in order to have a better quality of life (Stodden & Mruzek, 2010). Since one area of support is a transition plan: it should take into consideration individual needs, in order to develop a suitably adjusted approach (Szidon, Ruppard, & Smith, 2015). Additionally, in their examination of the transition process in adolescents with ASD, Lounds, Seltzer, Greenberg, and Shattuck (2007) found that the quality of the mother-child relationship played a crucial role in regulating the effects of the transition phase for individuals of this age. This finding is noteworthy, because it was one of the first studies to consider family members' understanding of the transition process.

In addition, greater insight is needed into how the transitions across all ages, from childhood to adulthood affects the individuals with ASD and their families, and what factors contribute to the challenges and successes. This information has the potential to support and assist practitioners to plan and develop suitable strategies to reduce stress, as well as facilitating additional positive interventions and a better adult quality of life (Griffin et al., 2014; Taylor & Seltzer, 2011). What this section has shown is the clear need for better information about the life transitions for individuals with autism.

1.2 The aims of the research

The aim of this research is to elicit the views of the individuals and families about the process of transition, given that transition has the potential to be a difficult time for children with

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ASD. This thesis aims to address a gap in the literature by exploring the actual views of the individuals with autism. Despite recent research on ASD and transitions, this continues to be an under-researched area, even though the topic has a significant impact on individuals with autism.

This qualitative study will contribute to the literature by providing an in depth understanding of the lived experiences of six adults with autism in the UK from their own point of view, and by exploring the experiences of thirteen mothers in the Kingdom of Saudi Arabia (KSA). Details of how these two groups were selected are described in Section 4.11. The term ‘parent’ and ‘mother’ have been used interchangeably throughout the research, and both of them refer to the mothers who took part in the current research.

A series of semi-structured life history interviews explored the individuals’ views of needs and strengths, and how these can be affected during this transition period from childhood to adulthood. This thesis will emphasise the personal experiences, difficulties, concerns, and successes faced by these individuals with ASD (in the UK) and families of people with ASD (in the KSA) during this phase of life. Moreover, the information gained from this study will provide insights and potentially useful strategies, which could be employed by individuals with ASD to help them cope more effectively during this period of transition.

The field of autism studies in Saudi Arabia is still emerging, and there is limited research in the KSA relating to the perspectives of parents of children with ASD on their children’s transitions from childhood to adulthood. This research will also make a distinct contribution to the field of autism studies in the UK, since it will use a life history method to focus on the perspectives and experiences of individuals with ASD in the UK. Such an approach has been used by other researchers (Atkinson, 2004; Goodley, 1996; Haglund, 2004), and still remains an innovative tool for autism research.

The research findings might also be helpful for others with autism and their parents, who are experiencing the various types of transitions that the individuals go through during their lives. It may also be helpful for teachers, and other professionals in the field of autism, in order to understand, plan and provide better support and services.

1.3 Research questions

The main research question is:

- How do individuals with autism and families experience transition from childhood to adulthood?

Related to this, further sub-questions are:

- What are the factors that hinder or help individuals with autism as they experience transitions?
- What are the mothers' perceptions of these transitions for their children with autism?

1.4 Research methodology

A qualitative research design is appropriate for this study, in order to gain insight and give a voice to the individuals with autism and their families. Life history interviews were conducted with an opportunity sample of six adults with ASD in the UK. Face-to-face semi-structured interviews were also conducted with thirteen mothers of individuals with ASD in the KSA, in order to ascertain how the needs and strengths of individuals with autism are affected by the transitional period from childhood to adulthood. This process is described in detail in the Methods Chapter 4.

1.5 Research rationale and motivation: a personal statement

My main motivation for choosing this topic is personal interest; I have both a brother and a cousin with ASD. Having these two individuals with ASD in my life taught me a lot, which I found both a blessing and a challenge. In particular, I have observed from first-hand experience their struggles during the transitions from childhood to adolescence and the efforts required to find appropriate support and services for them. My research design was based on my belief that a significant consideration in this research should be to give individuals with ASD a voice and an opportunity to contribute their own experiences, concerns, and achievements to a better understanding of this process. It is also important to add the views of parents and their experiences of raising individuals with ASD and undergoing these transitions.

There is strong evidence of a global rise in the prevalence of people being diagnosed with ASD (Blumberg et al., 2013; Neggers, 2014). This recognition of ASD needs to be

accompanied by an increasing recognition that individuals with ASD need appropriate services and support to help them throughout the transitions, from the initial diagnosis, starting school, forming relationships, getting a job and, overall, to living with the greatest possible independence. This research, therefore, aims to contribute to an understanding of these needs for all concerned.

1.6 Structure of the thesis

This chapter is an introduction to the research project. Chapter 2 provides an overview of the background of the Kingdom of Saudi Arabia and the UK, followed by Chapter 3 that examines the literature on ASD, with particular emphasis on the issue of transitions for individuals with ASD and the families' perspectives and experiences. This chapter initially provides a commentary on the diagnostic criteria and definitions of ASD, and at the emerging record of the prevalence of ASD around the world, in addition to the voices of individuals with ASD. The main focus of it is on the existing research related to the various educational transitions and challenges, transitions in adolescence such as puberty and sexual awareness, transitions into adulthood including employment and college, and developing meaningful relationships. The chapter concludes with a discussion of the perceptions of parents of individuals with ASD.

Chapter 4 details the methodological underpinnings and focuses on qualitative methodology used in this research, which adopts a life-history method for respondents with ASD in the UK. Alongside this are semi-structured one-to-one interviews with parents of individuals with ASD in the KSA. In addition, the selection of the sample (and justification for the two samples), data analysis, and ethical considerations of the research are described in this chapter. The choice of research methods is also made in this chapter, in addition to the pilot study. In Chapter 5 the outcomes of the first study are presented– that is, the life history interviews with the adults who have ASD in the UK – and an analysis of the themes of these results is made. An analysis of the outcomes of the second study is presented in Chapter 6. This concerns the semi-structured interviews with parents of individuals with ASD from the KSA. Then Chapter 7 provides a comparative discussion of the results of the two studies and focuses on the implications of these findings. Finally, Chapter 8 presents the research contribution to knowledge, conclusions, and limitations along with recommendations for future research.

1.7 Conclusion

In summary, each transition phase is typically challenging for individuals with ASD, where they need support to help them cope and manage during these different periods in their lives (Rydzewska, 2012). This study aims to explore ways through which people with autism and their families experience transition from childhood to adulthood in order to make recommendations that may help others. Research in this area is limited, especially in the KSA for which reason this chapter has outlined the purpose of the research, its background, the research questions, rationale, and structure of the thesis.

Chapter 2 Overview of Saudi Arabia and the United Kingdom

2.1 Introduction

This chapter introduces an important aspect of the research: that is, the culture and society of the Kingdom of Saudi Arabia (KSA) (Saudi Arabia and KSA will be used interchangeably throughout this thesis). A brief introduction to the KSA is given, outlining its history and social context, and this is followed by discussion of issues related to special educational needs in Saudi, and in particular autism spectrum disorders. This will help to contextualise the research conducted for this thesis in the KSA among mothers on the experiences of transitions from childhood to adulthood of their children with ASD. In this respect, it is particularly important to understand the distinct cultural and Islamic influences in the Kingdom. The chapter then discusses some relevant background issues relating to the United Kingdom (UK). While the research does not seek to provide a comparison between the countries, it will help to contextualise the research conducted with the UK.

2.2 Brief Overview of the Kingdom of Saudi Arabia

The modern Kingdom of Saudi Arabia (KSA) was established in 1932, when Ibn Saud, the leader of the House of Saud tribe, amalgamated his control of a large area of the Arabian Peninsula into a single country (Central Intelligence Agency, 2014). This was the culmination of several decades of military expansion by Ibn Saud through the peninsula (Central Intelligence Agency, 2014). As highlighted by Wynbrandt (2010, p.1), ‘the Kingdom of Saudi Arabia is a monarchy, headed by the Al Saud royal family, with a Council of Ministers’. Although the newly-founded state of the KSA was built on tribal alliances, continuing internal grievances between areas, tribes, and factions remained, and thus there was considerable potential for further conflict within the country. Therefore, it was critical for Ibn Saud to establish common allegiances among his subjects for this unification of the state to succeed (Wynbrandt, 2010). Since the eighteenth century, the people of the country that is now the KSA have been strongly united by a solid root of religion and tribal histories (Baki, 2004).

The kingdom forms a large part of the southwest of the Arabian Peninsula, comprising of two million square kilometres. It borders with Iraq, Jordan, and Kuwait to the north; Yemen and Oman to the south; Qatar, Bahrain, and the United Arab Emirates to the east; and most of its

western border is the Red Sea (Alquraini, 2010). Saudi has a total resident population of over 27 million people (Central Intelligence Agency, 2014).

Madi (2014) has pointed out that in recent decades, Saudi Arabia has been going through an unprecedented level of social and cultural changes, in particular due to oil prosperity and the government's determination to modernise the country. For example, considerable efforts and money have been invested by the KSA government during the past few decades into the economic system and the social structure, including education, communications, medical care, and transportation (Alnemary, Aldhalaan, Simon-Cereijido, & Alnemary, 2016; Madi, 2014). The result of this has been remarkable improvements in the overall quality of life for its citizens. In the midst of these changes, the government has made significant efforts to ensure the protection and maintenance of Saudi culture and traditions (Madi, 2014). As such, the KSA can be seen as a relatively young country that is in a state of transition, deeply rooted in its history and determined to provide its citizens with the best of the modern world.

2.3 The Social and Cultural Context of the KSA

An understanding of the second group of participants in this study in Saudi requires some knowledge of their cultural values. The culture of the KSA is defined by Islam, which has a very profound role in influencing and determining the community norms, rules, rights, responsibilities, and routines of the society (Al-Saggaf, 2004). Therefore, the social environment of Saudi Arabia is shaped by the major social and traditional beliefs of the Qur'an and the Sharia (legal-based) regulations of Islam (Alquraini, 2010; Wynbrandt, 2010). This is important for this research, since the parents of individuals with autism view and experience disability and special educational needs through this frame of reference.

A broad example of this is that gender roles and responsibilities are defined by Islam and Saudi traditions (Vidyasagar & Rea, 2004). Consequently, the definition of what could be appropriate and suitable within a society has long been determined by religious beliefs, and indeed within Islamic cultures social and religious values are not usually considered to be distinct (Rice & Al-Mossawi, 2002). In this respect, a combination of Islamic and cultural traditions is what has shaped and still continues to shape the society of Saudi Arabia (Al-Saggaf, 2004).

As an example, the particular customs of Bedouin tribes, which historically have played an important role in traditional Saudi Arabia, have produced a strict patriarchal family system in

contemporary the KSA society (Robertson, Al-Khatib, Al-Habib, & Lanoue, 2001). As the literature points out, these values and traditions that are in line with Islam are also considered to be more strict in the KSA than in other Arab countries (Ezzi, Teal, & Izzo, 2014; Robertson et al., 2001).

The KSA is also a place for the most holy sacred sites in the Muslim world, in particular in the cities of Makkah and Al-Madinah, which are associated with the Prophet Muhammad his Hadith (his life and teachings), and the revelation of the Qur'an. Being the location of these holy sites, therefore, has a very considerable influence on the self-perceptions of Saudi culture and identity, which strongly align themselves with the requirement to maintain a society based on the Islamic teachings of the Qur'an and the Prophet's Hadith (Baki, 2004).

Within this religious and cultural perspective among the people of the KSA, the Prophet Muhammad is not only 'the conduit for God's revelation' (Bazna & Hatab, 2005, p.8), but is also considered to be a living manifestation of a lifestyle which could be described as ideal, exemplary and something that Muslim people need to aspire to (Bazna & Hatab, 2005). Therefore, a person's values on health and welfare, religiousness, living within an equilibrium, together with socio-economic justice for everyone, are all generally considered to use this ideal Islamic framework, which sees Islam as a way of life (Chapra, 1992; Ezzi et al., 2014).

For example, Chapra (1992) has pointed out that Muslims are required to have faith in socio-economic justice for everyone, understanding that life requires a stable balance between religious beliefs and the material requirements of human beings. Therefore, the Qur'an is more than just a religious written text: it is a means of living and an approach to one's everyday life. Thus, at the core of Saudi Arabian society is an emphasis on family-based values and responsibilities, along with an understanding of what it means to be genuinely a good Muslim (Ezzi et al., 2014). This is important for all aspects of life, and includes issues related to disability.

In Saudi Arabia, the responsibility for looking after a relative with a disability lies primarily with family members rather than an institution (Madi, 2014). Such, meaningful relationships within the family are considered a priority within Saudi Arabia and Islamic society (Al-Saggaf, 2004). Maintaining contact with family members is expected from a Muslim, particularly with people related through blood ties, such as aunts, uncles, and grandparents.

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Such contact is maintained by regular visits, along with offering them emotional or material support if needed, as well as the demonstration of appropriate respect (Al-Saggaf, 2004). In the kingdom, family members count on one another and embrace fidelity and familial responsibilities (Madi, 2014). In the context of this study, this is a very important factor to note given the influence that religious and cultural values have on the Saudi participants, as well as the process of gaining information from them in the course of the research.

Furthermore, Saudi females are viewed as having a very distinctive traditional role within the community, which is highly restricted. In the KSA, Islam very strongly defines gender roles, and these are taken very seriously (Vidyasagar & Rea, 2004). Segregation of the sexes, for example, is a regulation that is part of Saudi everyday life, such as having separate schools, banks, waiting areas and sections in public places such as restaurants, hospitals, and shopping centres (Madi, 2014). For example, Alqahtani (2012) observed the problems he faced while conducting interviews with the parents (particularly the mothers) of children with autism. He found the major issue for him was the social prohibition within the research context in Saudi for males to interview women one-to-one in a closed room, due to cultural and Islamic requirements. Thus, a female interviewee could not be alone with a man, and vice versa: an interview could only be carried out if a male relative of the woman was present (Alqahtani, 2012). This is an important point for this research as it draws on and adds to the findings of Alqahtani's study of autism in the KSA. Mohammed Alqahtani is a consultant in clinical psychology at the National Neuroscience Institute, King Fahad Medical City (KFMC) Saudi Arabia.

The first part of the present research included conducting life history interviews with individuals in the UK with ASD. Since the researcher is a female, and most of the ASD individuals were males, it would not have been feasible to conduct this part of the research in Saudi, because of the culture and traditions of the society highlighted in this chapter. In contrast, interviews with males with ASD were conducted in an open public place in the UK, which was convenient for those being interviewed. Additionally, for the second part of this study, which involved interviewing parents of individuals with autism in the KSA, only the mothers could be interviewed. While Islam does not alter the symptoms ASD it does affect the societal context within which ASD individuals experience their disability. The next section will discuss some of the issues affecting individuals with special needs and ASD that are particular to Saudi Arabia.

2.4 Individuals with Special Needs in the Saudi context

Given that the population in Saudi Arabia is more than 28 million (Central Intelligence Agency, 2014), and the number of individuals with disabilities in the KSA is around one million (Waldman, Al-Nowaiser, Hamed, & Perlman, 2010), they make around 3.57 % of the whole population. However, there are several possible reasons for this. Generally, the unique background of the Saudi community can have significant implications for people with disabilities in Saudi Arabia. For instance, there is a high occurrence of inbreeding that is due to in-family marriages (for example, between cousins) (Al Essa, Ozand, & Al-Gain, 1997; Al-Gain & Al-Abdulwahab, 2002), which can lead to health risks or disabilities for the children of these unions (Hussain, 2002).

Despite this, disability research in Saudi Arabia has to date been very limited, and there is a pressing need for more research in this area to better address the needs of individuals (Al-Jadid, 2013; Alnema et al., 2016; Elsheikh & Alqurashi, 2013). One potential reason for this phenomenon could be due to the lack of professionals in this field in the kingdom of Saudi Arabia (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009; Almasoud, 2010b; Alquraini, 2010). The current research is an attempt to help address this need, particularly with respect to research on those with ASD in the KSA.

Al-Aoufi, Al-Zyoud, and Shahminan (2012) have discussed how disability has often been understood in Muslim societies with relation to moral and spiritual values either as a curse or as a gift, which may be another reason for the lack of research. This is despite the fact that in the Qur'an, physical disabilities are regarded as a natural part of a person's condition, and most importantly are not considered as a curse (Bazna & Hatab, 2005; Waldman et al., 2010). For instance, within some Islamic societies disabilities are referred to as 'an example of the need to be 'fatalistic', 'in the acceptance of difficulties in life; Islam requires submission to the will of Allah' (Al-Aoufi et al., 2012, p. 214). However, Waldman et al. (2010) observed that there is also a view among some people in the Saudi community that individuals with disabilities can be, 'helpless, dependent, home-bound and lack productivity' (p. 57).

As such, it may be that religious speculation on the causes of autism has served to indirectly deter rigorous investigation into its aetiology and consequences, as people simply accept the disability as another phenomenon of the natural world. It may also be that Saudi families have viewed the care of individuals with disabilities as merely another aspect of their familial

duties and have, therefore, been less sensitive to the disruption caused. As Waldman et al. (2010) states, “caring for a family member with a disability is viewed as being highly rewarding” (p.57). What follows is an account of the rights and legislations for individuals with special needs in the KSA.

Moreover, in a summary of a number of surveys and reports, Elsheikh and Alqurashi (2013) made an estimate of the number of disabled people or those with special needs as somewhere between 4% and 8% of the total Saudi population. Similarly, these authors reported that around 180,000 individuals with disabilities were estimated to be waiting to gain a work position in the KSA. Nonetheless, the Saudi Arabian authorities have helped to make significant social improvements in the country, to ensure that people with special needs and disabilities have both educational opportunities and civil rights (Alquraini, 2010; Elsheikh & Alqurashi, 2013). In particular, the Saudi government passed the Legislation of Disability Act in 1987, which was the first legislation to address the rights of this part of the population (Al-Jadid, 2013; Alquraini, 2010). This set out the fundamental principle that individuals with disabilities have the right to be treated equally as others within the community (Alquraini, 2010). The legislation also outlined a range of various disabilities, established appropriate programmes and services for the support and treatment of those with disabilities, and introduced standard methods of assessment for disabled people’s needs (Ministry of Social Affairs, 2015). In addition to this, the government passed the Disability Code in 2000 that guaranteed that public organizations would offer suitable and free educational, social, psychological, and medical assistance and care for individuals with special needs and disabilities. The Code also set out a guaranteed financial award for such individuals to support with training and searching for jobs (Ministry of Social Affairs, 2015).

Furthermore, since 1958 the government has offered educational services in special ‘scientific institutes’ for people with certain disabilities (Al-Jadid, 2013). The range of programmes for individuals with various types of disabilities has been considerably improved in the past ten years (Alnahdi, 2013). For example, the Ministry of Education have recently begun to offer educational services within different educational organizations, which are considered as scientific institutes, ‘such as the Noor Institute for the Blind, Amal Institute for the Deaf and the Institute for the Mentally Retarded [sic]’ (Al-Jadid, 2013, p.458). Additionally, the Ministry of Labour and Social Affairs runs programmes for educating and supporting the parents of individuals with disabilities, most of which are offered through charitable organizations (Al-Jadid, 2013), however these are not specifically for parents of children with

ASD.

Al-Jadid (2013) stated that despite the efforts of the government in this respect (such as the requirement of equal rights for individuals with disabilities, together with the Disability Code's pledge to provide free suitable education in the KSA), the unfortunate reality has been that "these laws were passed a decade ago and not practised well in the KSA. In fact, the lack of the effective implementation has created a gap between the framework of these laws and the provision of services, resulting in a lack of special education services for persons with disabilities" (Al-Jadid, 2013, p. 458). In addition, there are other challenges that ASD individuals face. Services and institutions for individuals with disabilities are generally based in cities rather than in rural regions, which therefore raise issues of accessibility and uneven provision, particularly for those living outside of cities (Alnemary et al., 2016; Elsheikh & Alqurashi, 2013). Recent literature also found that children with ASD in Saudi still experienced having inadequate accessibility to services (Alnemary et al., 2016).

2.5 Autism in Saudi Arabia

There is, in general, a poor awareness of the condition of autism in Saudi Arabia at present (Al-Salehi et al., 2009). In fact, attitudes towards autism in the Kingdom tend to follow the same general pattern of attitudes towards disability. That is, there is a tendency to avoid social contact with individuals with ASD, along with a sense of shame about the issue, and inadequate information regarding the condition (Al-Jadid, 2013). Views that disability may be a punishment for bad behaviour can also increase social isolation and negative responses; some Saudis are likely to ignore disabled people in public or prevent them from exercising their rights (Alquraini, 2010). Al-Ahmadi (2008) found that attitudes of teachers towards ASD students vary: male teachers were more likely to support the integration of students with disabilities than female, and a higher level of teacher qualification also predicted more positive attitudes.

Children with autism in Saudi are generally classified amongst other individuals with severe disabilities and, therefore, they usually attend specialised institutions (Al-Jadid, 2013; Almasoud, 2010a, 2010b). This could be because the individual would need to be quite severely affected with autism, thus are likely to be in specialised settings, as Almasoud (2010a) cited that "students with high functioning autism or Asperger syndrome often remain undiagnosed because teachers are unable to recognise the symptoms of autism" (p.3). Moreover, Almasoud (2010b) states that schools in the KSA were found to be generally

unsuitable for the inclusion of children with ASD, and therefore special educational facilities and institutions were adopted by the policy makers as a substitute to offer services for individuals with autism. It was found that regular schools in Saudi were unable to include children with ASD because of lack of information, poor understanding among teachers the social isolation of such children, as referred to earlier and the general lack of facilities and research on the issue. Thus, schools were either unable or unwilling to develop effective means and strategies to support of children with ASD (Almasoud, 2010a; Alquraini, 2012). Similarly, in a study conducted by Haimour and Obaidat (2013) it was found that school teachers only had a limited understanding regarding autism, while a decent level of understanding was found among special education teachers. In fact, their study showed that this might be due to the poor preparation of and limited availability of inclusion training courses for school teachers.

Moreover, a qualitative study was conducted by Alqahtani (2012) in the KSA to assess parents' views and understanding of the causes of autism. In the interviews he reported a relatively high non-response rate, with only 47 Saudi parents of children with ASD participating, out of a sample of 85. He attributed this to the fact that the community can often feel uncomfortable discussing the issue or can tend to avoid it altogether, which has implications for the ability of research to accurately assess the scope of the problem in Saudi. It is worth noting that none of the participants had a child identified as having Asperger's syndrome, a phenomenon also found by a previous study carried out in the KSA. This could possibly be due to the fact that professionals have insufficient knowledge regarding the two similar conditions (Al-Salehi et al., 2009; Alqahtani, 2012).

The parents of individuals with autism were, perhaps unsurprisingly, the most aware and knowledgeable about the condition (Alqahtani, 2012). He also found that many of the parents blame themselves for the overall condition of their children. This appears to derive from the historical understanding of autism: for example, Kanner's (1967) theory that autism is developed as a result of 'cold' parents who do not provide sufficient warmth for their children. Alqahtani (2012) also reported in his study additional explanations for autism, which were largely associated with the social and cultural context of the KSA.

As highlighted above, the social and cultural values of people in Saudi and in particular their religious beliefs, play an important role in the understanding of their lifestyle and disorders, such as ASD. A number of the mysterious disorders in the KSA are commonly explained with

reference to Saudis' religious and cultural beliefs regarding this matter (Alqahtani & Salmon, 2008). In particular, the belief in the 'evil eye' is commonly given as a reason or a factor for having autism (Alqahtani, 2012).

There is a limited belief by some members who interpret that based on traditional beliefs of some Muslims. Alqahtani and Salmon (2008) explain this as the evil eye "is emanating from another person, or rather from the bad soul, which inhabits that person" (p. 311). It is actually believed that the evil eye might impact on adults, youngsters, animals, and individuals' belongings (Madi, 2014), and the perception that the disabled child is therefore some indication of family shame only goes to worsen the public reception they receive. Religious explanations may be exacerbated by the unusual outward manifestations common in other mental health disturbances such as schizophrenia, where patients can report the hearing of voices, which is inexplicable to medical science and therefore considered to be some kind of spiritual activity (Mohr & Huguelet, 2004). As a psychological disorder with atypical outward behaviours, autism too has often been regarded as the consequence of demonic interference, operating in accordance with some Islamic beliefs. However, given mounting research on the genetic as well as environmental aetiologies, the findings of Alqahtani (2012) study indicate a relatively poor understanding of the causes of ASD within the Saudi community and that the local culture has a strong influence on these attitudes.

In summary, a brief synopsis of the KSA has been given, along to an overview of the society and beliefs of disability and autism within the Saudi community. The extent to which there is a clearer understanding of ASD in the UK is discussed in the following section.

2.6 Brief Overview of the United Kingdom

The present study has also gathered data on the experience of adults with autism within the United Kingdom (UK) and this chapter will consider the social context of ASD within the country. The UK is a nation formed out of successive European invasions and monarchial alliances (Jones, 2012; William, 2010). The term 'United Kingdom' is an abbreviation for the 'United Kingdom of Great Britain and Northern Ireland' and denotes the political union of the latter with England, Scotland, and Wales (Britain); a process of unification that began with the Laws in Wales Acts 1535 and 1542 (Welsh, 2002). While the Channel Islands and the Isle of Man are not part of the UK, they are included within the definition of the 'British Isles'. Despite the political union, each country retains its distinct cultural heritage and there remain minorities that still speak the traditional languages of Gaelic and Welsh (Wallenfeldt, 2013;

Welsh, 2002). Conflicts over whether Northern Ireland should remain part of the United Kingdom have marred much of the 20th century (Wallenfeldt, 2013).

Considered a parliamentary democracy (Jones, 2012), the Monarch sits as head of state and the Prime Minister as the head of government, with a separation of powers between Parliament, the Government and the judiciary. While it does not have a written constitution like the United States, its rich legal and political fabric consists of judicial case law, parliamentary statutes and international treaties, with a number of royal prerogatives remaining in force to this day. In 1972, the UK acceded to the then European Economic Community (EEC) (now known as the European Union (EU)) and this has had a considerable impact on the UK in terms of directly applicable legislation (Garnett & Lynch, 2014). However, due to recent events ‘Brexit’ was voted in favour for the UK to leave the EU in June 2016, which may result in significant impacts on the legislation for the future between the UK and European Union (Menon, Minto, & Wincott, 2016).

The United Kingdom has a legacy of colonialism and imperialism; in 1922 it possessed some form of control over approximately one-fifth of the global population and English is currently the premier international language of the world (Jackson, 2006; William, 2010). Its culture and international power was significantly influenced by the two World Wars, which left a victorious nation less capable of maintaining its imperialist scope. However, its supervisory role over the Commonwealth nations remains in force and it continues to seek a leading role in the United Nations and NATO (Garnett & Lynch, 2014; Lloyd, 2002). London is currently one of the greatest financial centres of the modern world (William, 2010). The primary culture is the British white culture (William, 2010), although various immigrant groups have generated a diverse English culture (Wallenfeldt, 2013). The present discussion is not intended to form a comparison, it is anticipated that the provisions for autism as a disability in the UK will have insightful relevance for the development of services within KSA.

2.7 The Social and Cultural Context of the United Kingdom

The UK is characterised by a number of pro-social, tolerant and libertarian values; it sees itself as a liberal democracy with fair, free, and competitive elections, the freedom to express dissenting opinions and equality for all citizens under law (Garnett & Lynch, 2014; William, 2010). Within this libertarian model, the UK is essentially capitalistic and people are generally free to do what they please, within the constraints of the law. Two of its greatest

achievements have been the National Health Service and the Welfare State and it is these that most of the services for individuals with autism are distributed (Lloyd, 2002; Webster, 2002).

The faith of the UK's society has also changed over time. Attendance in church is declining and the number of people identifying as Christian is also falling; as described by the study, *Religion in Great Britain* (Hawkins, 2012) there was a decrease in the Christian community from 78.0 per cent to 69.4 per cent between 2004 and 2010, yet at the same time the number of individuals identifying as having no religious beliefs rose from 15.7 to 22.4 per cent. Regardless of considerable levels of Christian immigration, some commentators have proposed that currently the UK is better referred to as a post-Christian or multi-faith society (Christopher, 2015; Lynas, 2001). Even so, the right to freedom of religion is enshrined in the UK by the European Convention on Human Rights (ECHR) (Lloyd, 2002).

Within UK society, a number of transitions have affected the provision of familial care for older relatives (Hoff, 2015). While the carer role has traditionally been undertaken by women (Hoff, 2015; Hutton & Hirst, 2001), the UK's move towards equality in the workplace has seen a growth in the numbers of females employed in the elsewhere (currently standing at two-thirds of British women) (Office for National Statistics, 2013). The UK, as well as Western society on the whole, is marked by nuclear rather than extended family structures and single-parent families are also on the rise (Walsh, Stephens, & Moore, 2000). These developments have implications for the care of relatives with autism and while UK families (like those in the KSA) are often left with unavoidable family duties as well as their work elsewhere. The term 'carer' became prevalent during the 1980's and brought attention to the unpaid contribution made by the families of the individuals with disabilities (Kirton, 2008; Lloyd & Heller, 2011).

Unfortunately, as in Saudi Arabia, individuals with autism and their families commonly receive disapproval from wider society, as many people are still not used to or aware of the unusual behaviours that autism can cause (Gray, 2002; Werner & Shulman, 2015). As such, some families may prefer to stay indoors, increasing their social isolation and dependence on national services (Gray, 2002; Werner & Shulman, 2015). Given some similarity between these experiences and those of the families in the KSA, it is valuable for the current study to reflect on how the UK has attempted to improve these challenges by using certain policy measures.

2.8 Individuals with Special Needs in England

England has a reputable history of confronting the inequalities encountered by individuals with learning disabilities and there have been a range of reports in this respect (National Development Team for Inclusion, 2012). Among these reports was ‘*Equal Treatment - Closing the Gap*’ by the Disability Rights Commission in 2006, which investigated the inequality that individuals with disabilities experience in primary care. Another report, the ‘*Independent Inquiry into Access to Healthcare for People with Learning Disabilities*’ (2008), examined the disparities that individuals with learning disabilities experience in relation to access to assessment and treatment. ‘*Valuing People Now*’ (2009) presented an evaluation of practice guidance on improving the lives of individuals with disabilities. In addition, the *Equality Act* (2010) obliges public bodies to make ‘reasonable adjustments’ to ensure their services are accessible and effective for disabled people. Similar duties also flow from revision of the *Disability Discrimination Act* 1995, which was revised in 2004 to include the obligation to make adjustments to physical premises as well as services (*Disability Discrimination Act* 1995, Part III s. 21). These legal duties place active responsibilities on departments to consider the needs of individuals with disabilities and remove physical and infrastructural obstacles to access, be it through policy adjustment or staff training. Further measures discussed by Pellicano, Dinsmore, and Charman (2013) to ensure equality include the recent guidelines from the National Institute for Health and Care Excellence (NICE): these include diagnosing, identifying, dealing with and handling individuals with autism. Finally, the recent *Autism Act* 2009, was the first piece of legislation to focus exclusively on the needs of ASD individuals and which places a duty on Government to produce a strategy for adults with autism in England and Wales (p. 9).

The UK Government provides a range of community care services for ASD individuals. In England for example, and it is emphasised that different services are available in each of the countries within the UK (National Audit Office, 2012). The *Carers and Disabled Children Act* 2000, sets out the duty of local authorities to assess the needs of children and their carers and offer appropriate services (for instance, s. 4). In England, the duty to carry out an assessment with a view to providing adult social care enshrined in the *Care Act* 2014 (s. 9). The aim of these provisions is to help vulnerable adult members of society, “live as independently as possible for as long as possible” (Prime Minister’s Strategy Unit, 2005). Needs are assessed on a personal basis and may include respite care to give regular carers a break or behaviour management advice to help them cope, as well as adaptations to the home,

communication technology, home help and after-school activities. The local authority in England then administers services according to the resulting ‘care plan’ (*Care Act 2014*, s. 25). While people are expected to pay for these services, they are ‘means tested’ (introduced in the *Care Act 2014*, s. 15 by a cap on costs), meaning contribution is dependent on ability to pay.

The Government supplements the provision of services with a range of supporting financial benefits (The National Autistic Society, 2016c). In England, Universal Credit is available for those with an income under £16,000 and this includes carers (Universal Credit, 2016). There is also a range of benefits available to families of children with disabilities under the age of 16 in England, including the Disability Living Allowance, Carers Allowance, Child Tax Credit and Working Tax Credit, Housing Benefit and Income Support (Bolger & Hothersall, 2016; Universal Credit, 2016). As mentioned, recent budget cuts in this field (in particular, regarding the Personal Independence Payment and Employment and Support Allowance) have led to significant criticism, as well as some cases of suicide (O'Hara, 2015; Universal Credit, 2016). Therefore, the system of services provided for individuals with ASD within England may be viewed as reasonably professional, regardless of the seeming bureaucracy that might threaten its success. This context is important for the present research as it provides a legislative background, which demonstrates the best of intentions for special needs provision in England, despite the complexities it entails.

2.9 Autism in England

The National Autistic Society (2016a) estimates that at present 700,000 individuals have autism in the UK, which is nearly 1.1% of the population. When their family members are included, autism is believed to impact around two and a half millions of people (Baird et al., 2006). While the economic impact of autism in Saudi Arabia remains unknown, the costs associated with addressing the needs of a person with autism in the UK has been estimated to be £1.5 million pounds (Buescher, Cidav, Knapp, & Mandell, 2014).

The aforementioned review of provision suggests autism is recognised by the public sector and increasingly so, even if there is still some progress to be made in terms of awareness among members of the public. Nevertheless, spending on autism remains significantly lower than in the US, where the “average research spend per autistic individual being 18 times higher” (Pellicano et al., 2013, p. 4). Another aspect related to autism in the UK is the reception that students receive in the educational system. Therefore, legislation has been

introduced in England to ensure schools develop cultures, policies and practices that promote inclusive learning (Department for Education and Skills (DfES), 2001) and various Acts of Parliament are in place, such as the *Disability Discrimination Act* 1995, as amended by the *Special Educational Needs and Disability Act* 2001 (Part IV). Additional help at school is also guaranteed under the *Children and Families Act* 2014 Part 3 of which sets out requirements concerning children with special educational needs, such as the duty to promote integration (s. 25) and keep their education and care under review (s. 27). The Government's report, *Removing Barriers to Achievement* (Department for Education and Skills (DfES), 2004) (DfES, 2004), published in 2004 sought to encourage teacher training and funding in the key areas of early intervention, removing barriers to learning, raising expectations and achievement. These measures have been supplemented by the Inclusion Development Programme (IDP), aimed at improving the ability of academic professionals to deal with students with special educational needs (SEN) (Garner, 2009). One such measure has been the introduction of the Assessment for Learning strategy (AfL), which involves the collection of data about pupils' ongoing performance to help teachers meet the particular needs of pupils (Department for Education and Skills, 2007) (DfES, 2007). The National Autistic Society has established a number of specialist schools that currently provide services for children with ASD across the UK (The National Autistic Society, 2016b). However, there are some difficulties concerning the inclusion of children with ASD in mainstream schools in spite of the legislation (Symes & Humphrey, 2011). The suitable support for children with ASD in some of the mainstream schools is missing, which impacts the future of children with ASD leading to inadequate education, and being out of school from an early age, as this could affect adulthood (The National Autistic Society, 2011). Previous literature has pointed out that ASD pupils are twenty times more prone to not being included in school compared to their peers who are typically developing (Humphrey, 2008; Symes & Humphrey, 2011). It is worth noting that "27% of children with autism have been excluded from school" (The National Autistic Society, 2011, p. 1). The (Department for Education and Skills (DfES)) in 2016 noted that, students with SEN assistance form the highest percentage of those receiving a long-term exclusion from schools, and are more prone to get a long-term exclusion in comparison to students without SEN.

2.10 Conclusion

This chapter has discussed the main characteristics of the background of Saudi Arabia, in

order to provide a cultural, social and religious context for the research conducted in the second part of this study. This has included a brief overview of the context of the KSA, the cultural and social aspects of the Kingdom and, in particular, the issues relevant to an understanding of individuals with special needs and autism in Saudi. The chapter then provided a similar overview of the political and social context of the ASD service provision within England. The literature has highlighted in particular that there is insufficient knowledge of ASD (and other areas of disability) in the KSA, and that the educational system continues to exclude children with ASD from regular schools, largely due to the schools and teachers being unable to integrate such children within their classes. As suggested, the research covering England's position has demonstrated it currently operates a comprehensive system of care, although there is still a long way to go in terms of public awareness and the funding of services. The current study considers the different transitions and services that have helped adults with ASD in the UK. These key elements are important in this research to gain a clearer understanding of Saudi society and the individuals with special needs and their families who live in the KSA. There is a need for more research and better education in Saudi on the needs of children with ASD. The present research will make a contribution to this: in particular, through the data and analysis of the interviews of parents of children with ASD in the KSA, which forms the second part of this study.

Chapter 3 Literature review

3.1 Introduction

The first two chapters set the context for this research: they established the situation related to the support mechanisms for those families and individuals who experience autism, with particular reference to England and the KSA. In the nature of things, the UK has more facilities to provide professional support for those children and adults who have ASD, so there is much to understand from this. Equally, the context of Saudi Arabia can illuminate such an understanding, particularly, as in the case of this research, from the perspective of parents. It is within this context that the research questions are framed. However, there is limited substantive prior academic research on parental views particularly in the KSA concerning the varied transitions or, indeed, the views of those who directly experience ASD.

The aim of this chapter is to provide an overview of current research on autism and transitions, as background to the empirical research that is presented later in this thesis. In order to explore the issues of transitions, the first part of this chapter gives an overview of the definition and diagnosis of ASD together with some discussion of the increasing prevalence of diagnosis of the condition. The second and main part of this chapter explores the most significant transitions that individuals with ASD encounter, in particular within the educational context and the transition from childhood to adulthood. These relate to the main themes of the present research.

Individuals will normally go through a number of different transitions during their lifetime. Often, these transitions are usually straightforward and follow processes which are broadly similar across different individuals – involving in particular the person's development and maturation, for example from childhood into adulthood. However, such transitions can prove to be particularly challenging for individuals with autism (Kapp, Gantman, & Laugeson, 2011). For example, the experience of maturing as a child will lead at some stage to an educational transition within school, between classes and grade levels. Another fundamental challenge that occurs in young adulthood is the transition from being at school and living at home to being in the work place and, to some extent, being independent. This applies also to puberty and sexuality. These transitions into adulthood can be difficult for young adults with ASD, since they may not have developed the social and emotional skills needed to effectively

deal with them.

A narrative review was undertaken for this chapter, which starts with an introductory exploration of literature on the selected topic (Green, Johnson, & Adams, 2006). According to Green et al. (2006), "...the intention of a narrative review is to describe and synthesize the available literature on a topic, providing a conclusion from this evidence"(p.106). Therefore, the literature review search is considered one of the primary features to be able to generate a thorough context for the study (Knopf, 2006; Mertens, 2014). Mertens (2014) argues that, this supports the description of the researched subject matter and developing a rationale, along with the importance of more research. Another important aspect of undertaking a literature review is that it identifies the gaps in the current literature (Knopf, 2006).

Searching the digital databases is regarded as the most beneficial method for exploring the literature, which is essential and influenced by the subject matter and objectives (Green et al., 2006). Therefore, the literature review search was guided by the research question (see section 1.3), and the literature included was selected following a review of research papers and books, identified through using search engines and electronic databases such as EBSCO, JSTOR, Educomplete, ERIC and others, in addition to using the University of Reading Library website to locate different journal articles and books. The previously mentioned databases were searched from January 2015 to April 2015 using the primary key terms such as 'ASD Parents', 'Autism Transitions', 'Autism Saudi Arabia', 'Autism Education', 'Autism Employment', 'ASD relationships', 'ASD puberty'. Literature was also sourced from the reference list of the papers that the researcher read. However, it is worth noting that the literature review was an interactive process, which developed exponentially and it was also revised and updated until December 2016. This is based on the interests and focus of the current research, and with respect to the themes that this literature review is organised around. Additionally, papers older than fifteen years were excluded with the exception of seminal papers. As Green et al. (2006) describe, this approach is typical of reviews that seek a narrative overview, as opposed to a systematic mapping of the area.

This chapter explores the literature related to different transitions in detail, specifically relating the discussion to individuals with autism. In particular, it starts with a definition of autism, the individuals perspectives and then discusses a range of other aspects related to transitions: education; employment; vocational training; further education; puberty and sexual awareness; relationships; and parental perceptions.

3.1.1 Definition and diagnosis of autism

The recent fifth edition of the Diagnostic and Statistical Manual of Mental Disorders in 2013 (DSM-5) (American Psychiatric Association, 2013) recommends the use of the term Autism Spectrum Disorder (ASD) to describe a broad classification of autism that is presented in individuals as mild, moderate, or severe types. It is this DSM-5 understanding of ASD that is used in this thesis.

ASD is a neuro-developmental condition that is generally regarded as a lifelong disorder, which is clinically apparent from the first childhood years (Baxter et al., 2015). The DSM-5 diagnostic criteria for ASD consider that it is a condition that impairs the individual's ability to communicate efficiently, either with spoken language or a non-verbal type of communication. It also impairs social development, and is characterized by repetitive behaviours and significantly limited interests. In addition, individuals with autism follow certain routines and exhibit sensory sensitivities (American Psychiatric Association, 2013).

A significant innovation in the 2013 DSM-5 diagnostic criteria was the re-classification of Asperger's syndrome (AS), and Pervasive developmental disorder not otherwise specified (PDD-NOS). Whereas in the previous DSM-IV criteria AS and PDD-NOS were classified separately to ASD, they are now (under DSM-5) classified as part of the Autism Spectrum Disorder (ASD) (American Psychiatric Association, 2013). This was largely due to the difficulties in making a clear distinction between a diagnosis of Asperger's syndrome and ASD. Both are described in terms of the exhibition of notable deficiencies in mutual social communication, problems with communication, and repeated behaviours (American Psychiatric Association, 2000). The three of these together are usually regarded as a 'triad of impairment' (Wing, Gould, & Gillberg, 2011), and the presence of this triad could indicate a diagnosis of either Asperger's syndrome or ASD, or both. The main way of distinguishing these disorders was largely related to the level of intellectual and language capabilities, both of which were often perceived as decreased in individuals with autism (Lotspeich et al., 2004). This relates to some of the issues raised in the present research, as all of the UK participants were diagnosed with Asperger's syndrome using the old diagnostic system, which was before the DSM 5.

Some recent research conducted in 2009 in Saudi Arabia is worth noting in this respect. Al-Salehi et al. (2009) found that none of the 49 participants in their study who had been

diagnosed with ASD had been diagnosed with Asperger's syndrome (AS). They argued that the missing data was likely a result of the difficulty in accessing it, insufficient knowledge about the condition, as well as limited suitable education and training programmes among specialists (Al-Salehi et al., 2009). The recent reclassification in DSM-5 of AS as part of ASD may be helpful in this respect and relevant to this study in terms of sample selection.

In this thesis, the current DSM-5 approach will be followed, that is to classify AS as a form of ASD. Thus, individuals diagnosed with mild forms of ASD may be generally referred to as having AS and/or High Functioning Autism (HFA). Moreover, getting a diagnosis is considered one of the first transitional steps that a person with ASD goes through. It is considered an important factor in transitioning, because it can lead to finding appropriate interventions and support, which also consists of preparing for the transitions that follow (Jones, Goddard, Hill, Henry, & Crane, 2014).

Therefore, it is important to note that one of the first challenges for the child and their family is often obtaining a recognition that their child's challenges align with autism as they secure an initial diagnosis of autism (Poslawsky, Naber, Van Daalen, & Van Engeland, 2014). The way in which the family and the child respond to the diagnosis usually has a significant influence on the child's education and development. It is important that all involved find suitable ways of coping with the initial news of this diagnosis, and that once the diagnosis is made families and authorities ensure that the child is placed in a suitable school and receiving a suitable level of education and support (Holtz, Owings, & Ziegert, 2006), which will be discussed in further details in Section 3.3.1.

3.1.2 Autism prevalence

A significant issue related to the diagnosis of autism spectrum disorder is the recent global rise in the number of individuals who are diagnosed with autism (Blumberg et al., 2013; Matson & Alison, 2011; Tsai, 2014). As highlighted below, in recent years estimations of the occurrence of ASD have risen by as much as 78% (Neggert, 2014). This means that any attempts to estimate figures for ASD on a global level pose a number of considerable difficulties, such as the lack of available diagnostic and support services, which can impact an individual's access to a diagnosis and therefore inadvertently reduce recognised numbers in some countries. This is an area where there needs to be much more research and more consistent awareness, diagnosis, data gathering, and reporting at all levels as different

countries have differing prevalence rates. Despite this, it is useful to report Baxter et al.'s (2015) estimate that across the world in 2010 there were 52 million individuals with ASD. This gives a mean occurrence of 7.6 per thousand, or possibly a single ASD case in 132 individuals.

Blumberg et al. (2013) have given an approximate occurrence statistic in the USA of 1 in 50 individual is identified as having ASD, which is around 20 per thousand. There has not been any recent public health report in the UK which provides a specified number of individuals diagnosed with ASD (Russell, Rodgers, Ukoumunne, & Ford, 2014). However, previous literature indicates that the prevalence in UK in 2006 is around 116 children diagnosed with ASD in 10,000 (Baird et al., 2006), that is 11.6 per thousand. Additionally, Russell et al., (2014) estimated the occurrence of ASD through parent reports to be around 1.7% in the UK.

The prevalence of ASD among Arab countries is more difficult to determine, as there is at present much more limited research in this area (Al-Salehi et al., 2009; Taha & Hussein, 2014). This as such should be considered a significant gap in the literature of the Arab world. The research that has been conducted in Arab contexts indicates there is not any precise statistical information regarding the prevalence of autism. For example, in Saudi Arabia in 2002 there were approximately 42,500 individuals identified as having ASD (representing approximately 2 per thousand), but in addition to this it is likely that there are a large number of further individuals who had still not been diagnosed. Because there are still no confirmed data about the precise number of ASD individuals in the KSA (Alnemary et al., 2016).

In research carried out in the neighbouring United Arab Emirates (UAE) (using a robust randomly selected sample consisting of 649 youngsters that were examined in the group by applying a two-stage research method and after using an autism-screening questionnaire in the initial stage), approximately 58 per ten thousands youngsters were identified as having ASD. This gives a projected average of 5.8 per thousand for the UAE. In a following stage, an interview was used and anticipated the occurrence of PDD-NOS to be around thirty in each ten thousands for a diagnosis according to the DSM 4 (Eapen, Mabrouk, Zoubeidi, & Yunis, 2007). As noted above, such a diagnosis would now be considered as ASD under DSM-5, which takes the overall projected rate for the UAE to 8.7 per thousand. Although this does not apply directly to Saudi, it gives a good indication of the prevalence rates in similar countries.

Autism and the Experience of Transition from Childhood to Adulthood

There are a number of factors behind the low prevalence rates of ASD in the Arab world in comparison with the UK and USA. One of the factors is the lack of access to the appropriate diagnosis centres or services, which is due to the fact that in the Middle East there are limited psychologists who specialize in children's developmental conditions (Mostafa, 2011).

Another factor is the limited knowledge and understanding of ASD amongst parents, which could lead to an inability to identify the signs and symptoms, and there is less likelihood of them looking for the appropriate treatment and diagnosis (Al-Farsi et al., 2011; Mostafa, 2011). One of the consequences of this is the potential to have large numbers of undiagnosed individuals with ASD in the KSA.

A clear awareness of the number of children diagnosed with this condition is essential for the development and planning of appropriate services and support (Russell et al., 2014; Taha & Hussein, 2014). However, the international literature indicates that there has been a rise in awareness in ASD in recent years. Statistics indicate that reporting the occurrence of ASD has significantly increased in the past decade and there are many more individuals now being diagnosed with ASD in comparison with even a short time ago (Blumberg et al., 2013; Neggers, 2014; Newschaffer et al., 2007; Ouellette-Kuntz et al., 2007).

One of the reasons behind the rising prevalence of ASD worldwide is because of the changes in the criteria of the diagnosis (Baird et al., 2006; Neggers, 2014; Newschaffer et al., 2007). In spite of this, there is not at present sufficient research to confirm whether this rising trend is due to this alone, or whether there are any other causal factors involved (Newschaffer et al., 2007). Neggers (2014) has suggested some further reasons behind the increase in prevalence of ASD. These are: the inaccurate identification and diagnosis of some individuals; the growth in awareness of the condition; the variations of research methods that give us the prevalence rate; and developments in primary health care of significantly low weight and premature new-borns that have led to increased survival rates of these premature infants. Blumberg et al. (2013) have argued that increases in the diagnosis of ASD during adolescence may also be another reason behind the rise of the prevalence of this condition. This could be a result of the recent increase in the identification of the symptoms of ASD (particularly those that are relatively mild) by clinical psychologists and physicians as well as others.

In summary, it is only in recent decades that the prevalence of ASD has begun to be recognised across the globe, and in many countries there is still further work to be done to get an accurate picture. The development of the diagnostic criteria for ASD has made an

important contribution to this. There are noticeably lower prevalence rates of diagnosis of ASD in developing countries compared to those found in the UK and USA, which is a matter that requires further research. It is most likely that the actual prevalence of ASD is no higher in the UK and USA than developing countries, and that the differences in the statistics are possibly due to lower levels of training, education, and clinical support related to ASD in developing countries. Despite this, diagnostic rates for ASD are generally increasing, even in developing countries, and in the Arab world in particular, as medical education and awareness of ASD improves. The importance of this increased awareness cannot be over-estimated, nor can the opinions of those most directly affected by the condition. At this point, therefore, the voices of individuals with ASD as reflected in earlier research are considered.

3.2 The voices of individuals with ASD

This section focuses on the voices and participation of the individuals with autism themselves in research. Taking the perspectives of individuals with autism into account is a significant feature of this study and is intended to be helpful in the belief that gaining insight and knowledge from these individuals themselves is the best way to understand the phenomenon. Therefore, life-history interviews with adults with ASD in the current research study provide a better insight into their experiences of transition from childhood to adulthood. Jones, Huws, and Beck (2013) have argued that gaining an insight from an insider – that is, the individual with autism himself/herself – is an important aspect of research into autism.

There are many reasons to explore the views of those affected by autism to gain their insights. In a study on the views of young adults with ASD and their parents related to their quality of life, Sheldrick, Neger, Shipman, and Perrin (2012) found that young adults' views were opposed to those of their parents, therefore, it was important to include them in the research. The researchers also found that the views of the parents tended to change, particularly when they were encouraged to view the issue of quality of life from their children's standpoint. In such cases, the parents' responses to the questionnaire tended to shift more towards agreement with their children's (Sheldrick et al., 2012). This indicated the importance of parents seeing issues or matters from their children's point of view as opposed to their own personal one.

Previous literature found that individuals with ASD were keen to talk about matters associated with autism, and they wished to be viewed as experts in the area of autism (Hurlbutt & Chalmers, 2002). Although the sample in their study was small, it is worth noting that the participants were generally confident and proud of having autism; they did not

desire to be typically-developing individuals, and they constructed their own views and knowledge on many different matters regarding autism over time (Hurlbutt & Chalmers, 2002). Nowadays, the voices of individuals with ASD (that were once missing or minimal within research on autism) have begun to increase within the literature. There is clearly a movement which aims to acquire the individuals' own perspectives on their experiences and points of views (Hannah & Topping, 2013; Jones et al., 2013; Kirby, Dickie, & Baranek, 2014).

A comparative research project by Browning, Osborne, and Reed (2009) based on interviews with ten individuals identified as having ASD and seven neuro-typical individuals explored their ways of perceiving stress and managing strategies at the transition point of leaving secondary school. The study showed that the individuals with ASD had concerns about social relationships, as well as acknowledging that they were not very effective at handling stressors. In comparison, typically developing individuals showed more worries regarding their future education and they had different approaches to deal with stressors. A later study set out to determine the views and experiences of individuals with autism regarding their participation in leisure activities (Brewster & Coleyshaw, 2011). Youngsters with ASD found it challenging to participate in leisure activities, whereas older individuals preferred to remain at home and use the Internet. Both studies show, either explicitly or, in the latter case implicitly, the different perspective that ASD individuals have, which signifies the importance of including them in this research.

Furthermore, considering the fact that individuals with ASD have some of the related ASD characteristics, which make transition more challenging for them, such as social difficulties, routine, limited interests, sensory difficulties, and communication challenges (Giarelli & Fisher, 2013). Certain transitions are likely to be difficult, because of the challenges that ASD individuals face when changing their routine (Tso & Strnadová, 2016). The next section will explore one of the important transitions that children go through, which are the educational transitions.

3.3 Educational transitions

Education provides for a number of what are described as sub-transitions: transition from early years at home to being part of the school environment; and grade transitions. These sub-transitions lead into a major transition from junior to senior school (Hannah & Topping, 2013). School transitions occur at multiple points – once the child starts school challenges

become more apparent and this is usually demonstrated through behavioural incidents. These transitions may either be major changes (such as starting school or changing a different class, teacher, subject, or a new school or making friends) or they may be more routine changes that occur within the school day (Section 3.3.2). For the purposes of this thesis, these will all be considered educational transitions.

The literature shows that the transition from kindergarten to elementary school is one the most significant transitions that a child and his/her family go through (Li, Chan, Mak, & Lam, 2013; Quintero & McIntyre, 2011). It is the first school transition that a child has to go through, and it is therefore a time when the child has the first opportunity to learn how to manage transitions in a social context away from the family home. Parents and teachers very often work together to develop an effective transition for children with autism in kindergarten as a first stage of their education (Quintero & McIntyre, 2011).

This transition in particular is a very significant phase of a child's schooling, and it can be highly stressful for these children as well as for their families (Ashburner, Ziviani, & Rodger, 2010; Li et al., 2013; Quintero & McIntyre, 2011). Moreover, the following section will discuss the varied educational provisions that children with ASD attend, such as to be included in mainstream schools or specialized schools/centres.

3.3.1 Educational provisions

Children with ASD typically attend mainstream schools or specialized centres, which is dependent on their intellectual capabilities and the severity of their ASD symptoms (Al-Zoubi & Abdel-Rahman, 2016; Lynch & Irvine, 2009; Rattaz et al., 2014; Waddington & Reed, 2016). The idea of inclusion reflects the increasing school of thought that students with disabilities would be best placed in regular environmental settings in schools, as opposed to special schools or centres, to ensure that all students are adequately involved in the school society (Lynch & Irvine, 2009). Scholars have agreed that this development in education has come from UNESCO's Salamanca Statement (United Nations Educational Scientific and Cultural Organisation (UNESCO), 1994), which emphasised the significance of education for all including on-going planning for children with disabilities to get into the broader society (Holt, Lea, & Bowlby, 2012). Since this statement, the amount of included children with disabilities in the typical classrooms in mainstream has been growing. Scholars have generally recognised this switch, which reflects the philosophical shift from integration to

inclusion, which means that the child can take part in all of school life. Roberts and Simpson (2016) note that the UNESCO Salamanca statement ruled that children with disabilities, must be entitled to be included in the community and not labelled.

However, it is essential to evaluate the particular advantages of mainstream education for students with ASD. A study by Ashburner et al. (2010), examined teacher's views on the comparative academic performance, the psychological emotions, and behaviour of typically developing students and ASD students. Their study showed that around half of ASD students were considered under-performers as opposed to 8% of their peers. This perspective provides one explanation for the conclusion that children with ASD would be best educated within segregated settings; this is a conclusion reached by some disability activists and some parents (Holt et al., 2012). Therefore, recent thinking has gone beyond thinking about the rights of students with ASD to considering their needs instead (Roberts & Simpson, 2016). This viewpoint expresses the significance of first determining, then catering for the child's specific disability, which has persuaded some scholars to advocate particular academic settings for students with ASD, including individual provisions for some of them (Ravet, 2011). It is this shift in the direction of considering the needs of individuals with disabilities approach, which has guided the authorities in Britain to change the assumed position of inclusive schooling and persisting with special schools (Holt et al., 2012). For instance, a research conducted in the UK by Waddington and Reed (2016) noted that "children in mainstream are not more academically successful than those in specialist placements, but, instead, a range of alternative factors are involved in promoting success" (p.8). Their research assessed educational accomplishment as outlined by the National Criteria (Waddington & Reed, 2016); however, it did not assess the interpersonal and psychological advantages that could develop from the interaction with typical developing peers. Therefore, this raises concerns about the wide range of needs, along with rights, that ASD students possess and the best way these can be accommodated.

Nations across the world have adopted varied approaches to the concept of inclusive education (Alkhateeb, Hadidi, & Alkhateeb, 2016; Holt et al., 2012). It is suggested in the literature that Arab nations have just begun to regard the significance of inclusive schooling (Alkhateeb et al., 2016). Nonetheless, the range of specialized and mainstream schools that offers inclusive education in this part of the world is growing (Alanazi, 2012; Dare, Nowicki, & Felimban, 2016). In an analysis of research from several Arabic nations by Alkhateeb et al. (2016), found few studies that looked at the case of the KSA in particular, regarding

including children with disabilities in schools. However, their review noted that PhD students had carried out numerous studies. It is noted by Al-Zoubi and Abdel-Rahman (2016) that, some students with learning disabilities, are taught in special resource rooms, within the mainstream school. It is acknowledged in their study that these resource rooms in Saudi are facing some difficulties, such as the qualifications of the resource room teacher, collaboration between the school staff and the parents, in addition to a lack of materials and resources (Al-Zoubi & Abdel-Rahman, 2016).

In addition to the research cited above, most of the research conducted in the KSA assessed the views of the teachers concerning the inclusion of children with learning disabilities in mainstream schools (Abu-Shaira, 2013; Alanazi, 2012; Alkhateeb et al., 2016; Alquraini, 2012). As an example, Alanazi (2012) looked into inclusive education at a primary school for young girls, and concluded that although school-teachers were positive about inclusive education, their views did not bring about the implementation of inclusion. This suggests that the practicalities of inclusive education are not always direct, despite the presence of the approach to include children with disabilities. Alanazi (2012) encountered difficulties in conducting research with males in Saudi, due to the separation of genders, given that ASD is more common in males as opposed to females (Head, McGillivray, & Stokes, 2014). Her speculation was that school teachers might find teaching young boys with ASD in mainstream schools even more challenging.

Research conducted by Alshahrani (2014) on beliefs concerning deaf children revealed that teachers have positive mind sets when it comes to children who are hard of hearing but less so for children who are severely deaf. This suggests the extent of the disability are likely to be crucial when considering a mainstream school teacher's capacity to respond to students with disabilities needs. Given the long lasting and persistent intellectual restrictions caused by ASD, this type of research shows that ASD children might gain more from being educated in locations that are suited to their own personal intellectual and learning requirements. These findings are confirmed by research in the UK Waddington and Reed, (2016), which found that students who had profound ASD along with less interpersonal abilities are usually placed in special schools as opposed to the mainstream, which implies that children are placed in educational provisions according to their particular needs and ASD severeness.

Further research by Alkhateeb et al. (2016) identified one study of the perceptions of parents along and their children concerning resource rooms in schools (Somaily, Al-Zoubi, & Abdel-

Rahman, 2012). This research discussed students with disabilities generally, and it pointed out that parents might not have a full understanding of the practicalities of the teaching in a classroom as teachers do. Most of the researches carried out in the Saudi concerned other disabilities for instance, hearing impairments (Abu-Shaira, 2013). It is discussed that not any of the studies assessed on the KSA experience by Alkhateeb et al. (2016) taken into consideration the accessibility and utility of specialized centres for ASD children, and the study itself recognised it may not have found all the appropriate studies carried out within this field. It is helpful to take into consideration the positive aspects that come from specialized centres along with mainstream schools, so that the advantages of each placement could be compared with each other, to understand whether positive attitudes towards inclusion in principle may be equivalent with the practicalities of teaching in the classroom. However, the challenges faced by children with ASD and their families in these varied educational provisions are particularly difficult and explored in the next section.

3.3.2 Challenges in the educational setting

A number of studies of young people with ASD have emphasized that they tend to find transitions during their education more difficult and challenging in comparison with their typically developing peers, due to the ASD symptoms that these children show (Adreon & Durocher, 2007; Colver et al., 2013; Friedman et al., 2013; Hannah & Topping, 2013; Hume, Sreckovic, Snyder, & Carnahan, 2014; Quintero & McIntyre, 2011). Indeed, most children with ASD and their families face numerous challenges throughout the child's school years.

The typical mainstream classroom setting can also be a significant challenge for children with ASD, as it is often very busy and noisy. The environment can discourage comprehension and may be a barrier to the child effectively communicating their needs to the classroom teacher and peers (Lindsay, Proulx, Scott, & Thomson, 2014). Their research showed that children with ASD usually have difficulties comprehending the social community and this may restrict their growth and the development of meaningful relationships with classmates. Moreover, the school offers a useful environment from which to examine the issues and factors that influence the process of transition for young people with autism. Adreon and Durchor (2007) point out that the various transitions young people with autism go through during their time at school present numerous complexities, which depend on the child's organizational abilities, friendships, and social and learning skills, as well as the school's educational materials along with their management of time and resources.

Often the consequence of these difficulties is that the child may present negative behaviour: throwing tantrums, noncompliance, or aggression toward adults, carers, or fellow pupils, and demonstrating stereotypical behaviours, in order to prevent and stay away from the challenging task or situation (Adreon & Durocher, 2007). This behaviour occurs mostly because the child is unsettled, when the task is not planned or clear, or because there is a change in their routine (Sterling-Turner & Jordan, 2007). Additionally, one particular problem is that children on the ASD spectrum may often exhibit difficulties and challenges for the classroom teacher or other students when they face a transition, and the management of this by the teacher reduces teaching time in the classroom (Sterling-Turner & Jordan, 2007). A further problem is that students with ASD tend to be underachieving in relation to their capabilities and potential, as they are often unable to retain their concentration and manage their thoughts and attitudes in the classroom (Ashburner et al., 2010).

It is important, therefore, for teachers in such contexts to be aware of helpful methods and techniques to efficiently involve these learners with autism within the mainstream classroom context and how they can manage transitions (Lindsay et al., 2014), as is discussed in the next section. However, whilst research does document well the issues and challenges the school environment can pose for children with ASD, there is little research that explores this specifically from the viewpoints of the young people themselves (Hannah & Topping, 2013), which is why the present research makes an important contribution to knowledge since it not only addresses their expressed concerns but also raises the issues of appropriate education and the arguments for inclusion and exclusion in schooling.

3.3.3 Managing educational transitions among children with ASD

One of the approaches for the management of young people with autism is that described by Adreon & Durocher (2007), who argued that there should be individualized strategies in place. Such strategies should take account of the particular levels of characteristics of autism (which can of course vary considerably), along with the child's interpersonal skills and intellectual performance. Alongside this, however, on-going classroom planning and preparation for the involvement of young people with autism also needs to recognise the particular issues in the child's experiences of transitions (Adreaon & Durocher, 2007).

In exploring such issues, Sterling-Turner and Jordan (2007) examined interventions made relating to the assessment and management of challenging behaviour of children with autism

who were going through transitional phases within the educational environment, such as transitioning between classes and activities. They found that although the interventions they examined lacked individualisation and depth, there was a clear need for functional evaluations of the students' personal needs and an assessment of their personal transitional difficulties.

Despite this limitation, there have been a number of techniques and strategies used as supports for transition, which have been developed and explored with children with autism to help them overcome the difficulties and challenges associated with transitions. Other studies have identified useful steps for conducting support for individuals with ASD in classrooms to help them to manage significant transitions more smoothly. One of these steps that were noted in previous research are: (1) to determine the type of transition; (2) to choose the suitable transition support tool and strategy; (3) to carry out the transition support strategy; and (4) to gather information and evaluate the effectiveness of the transition support strategy (Hume et al., 2014).

In addition to this, however, a review of the literature indicates that the successful management of transitions within the school environment also requires the building of good rapport and communication between schools, teachers and the parents (Hannah & Topping, 2013). It is also necessary for peers to have a good understanding and acceptance of autism and how the disorder manifests. Two previous studies illustrate these points and have explored these issues from different perspectives. One looked at the parents of individuals with autism and the other looked at the teachers' perspective (Dillon & Underwood, 2012; Lindsay et al., 2014).

In the first of these, Dillon and Underwood (2012) found that increased communication and discussion between parents and their child's educational institution at the time of transition from primary to secondary school could be one strategy to lower the parents' degree of anxiety during the pre-transition phase. They also found that parents mentioned that some of the main requirements for an effective transition were the development of groups of friends, the acceptance of their peers, and also a good knowledge about autism in the educational environment (Dillon & Underwood, 2012). The main critique of their study is the small number of participants, as their sample included only 15 parents of children diagnosed with ASD. The findings from this cannot be easily generalized to all the population of students with ASD. In addition, the research indicated the views of others (that is, parents in this case) and not the children themselves.

In the second study, Lindsay et al. (2014) noted that in many countries there are increasing numbers of learners with autism in mainstream classrooms. Therefore, schools often require teachers to effectively manage classes for the benefit of both the children with ASD and also the other learners. Lindsay et al. (2014) examined the advice given to elementary school teachers in such contexts in thirteen schools in Ontario, Canada, along with the strategies they adopted for including individuals with autism effectively in the mainstream class. This also confirms the results of Dillon and Underwood's (2012) study mentioned above.

Families face a key transition at the point of their child's entry to school. In addition, there are a number of challenges within the education process as the child goes through the school system, which are related to their studies, peers, teachers, education, and support services. Therefore, a child with ASD must be supported during such educational transitions in his/her life (Hannah & Topping, 2013). In this respect, parents and teachers must collaborate to ensure that the child is supported effectively within the school context. This will help the child not only to manage these transitions more effectively, but will also help them to learn how to manage later transitions in their life and to achieve a better overall quality of life. This is an area that requires further research, to which this present study is a contribution, with its particular emphasis on the role of parents in the process. Another transition that has not been fully researched is the transitions in adolescence, which includes puberty and sexuality.

3.4 Transitions in adolescence for individuals with autism

Adolescence can be a difficult time for many people, including those who are typically developing and for a number of reasons, as it can create particular challenges for young people with ASD. Indeed, it has been observed that adolescence is often the most challenging time in the life of a person with ASD (Tantam, 2003). Much of the research in this thesis will be looking at the particular transitions associated with the changes that occur with puberty for people with ASD during this time.

In general, adolescence is quite often an important planning phase for adulthood, due to the fact that, in this particular period it is a time when adolescents have to learn to manage and deal with a number of changes. These include changes in their bodies and their growing sexuality, gaining knowledge and suitable training to obtain employment, and acquiring the appropriate social skills so they can develop meaningful relationships in adulthood (Crockett & Crouter, 2014).

In addition to this, adolescents with ASD often face further challenges during this time due to their particular symptoms (Tantam, 2003). They need to acquire the appropriate information and knowledge about the transition to adolescence, in particular issues such as puberty, sexuality, and relationships (Volkmar & Wiesner, 2009). Similarly, they may only have limited appropriate information about sexuality and relationships, which can leave them vulnerable (Brown-Lavoie, Vecili, & Weiss, 2014). This section reviews how adolescents with autism navigate through the transitions into puberty and adolescence, and face the challenges of the development of their adult sexuality.

3.4.1 Puberty

Puberty is considered one of the major milestones in the transition phase from childhood to adulthood for individuals with autism, and therefore an important aspect of this thesis. The development of puberty in young people usually occurs around the ages of 8.5 to 13 years in girls, and for boys it is usually between 9 to 14 years (Murphy & Elias, 2006). Puberty is related to the changes of the physical features associated with the reproductive ability of women and men (Hénault, 2005). The changes of puberty are recognised as being among the major transitional milestones in sexual development, and these changes are compounded with other developmental adjustments including psychological, hormonal, interpersonal, and physical changes.

In a review of the existing research several decades ago on the effects of puberty on the development of individuals with autism, Gillberg (1984) looked at different facets of development, relating these in particular to the range of psychiatric problems that appear in adolescence during puberty among children with ASD. These included irregular sexual activity, inactivity, and depression. He also found that one-third of the children with ASD in his study suffered from regression during puberty. He found that puberty was generally uncomplicated, with children accepting the physical changes, although some did not know how to react socially to these changes. At that time Gillberg recognised the need for more research in this area, although very little has taken place since.

Gabriels and Van Bourgondien (2007) confirmed this earlier study, and observed that there is no significant difference between the physiological maturation of individuals with autism and the development of all children. However, the degree of autism tends to be reflected in sexual development and functionality in various ways: for example, the main impairments of autism

(social impairment and behaviour) can influence the development of essential social understanding (Beddows & Brooks, 2016; Gabriels & Van Bourgondien, 2007). Therefore, it is essential to teach individuals with autism suitable social skills in order to develop the ability to make appropriate social decisions and judgments, such as to help them make friends or get married. This also means being able to identify the difference between behaviour and activities that is private, as opposed to public.

Behavioural problems tend to start around the onset of puberty (Volkmar & Wiesner, 2009) among young people with autism, when the physical growth and hormonal changes begin: for example, there is often an increase in irritability, hyperactivity, inattentiveness, and stereotypicality. These problems may be alleviated when the child reaches puberty (Volkmar & Wiesner, 2009). It is important to note that sexuality is different between males and females with ASD, due to their different biology (Fernandes et al., 2016). Given that, it is noted in previous literature that girls with autism need more help to cope with menstruation and premenstrual symptoms, which may exacerbate irritability, anxiousness, inability to concentrate, and unsociability (Volkmar & Wiesner, 2009). The kind of help that these girls with autism require is a suitable sexual education and assistance, which should start in their childhood years (Cridland, Jones, Caputi, & Magee, 2014).

Cridland et al. (2014) also noted that mothers of girls with autism expressed a number of concerns related to their daughters' menstruation (ranging from its onset to its continual management), and this was considered a particularly strong puberty-related concern. Regardless of these concerns, it was found that girls with ASD were commonly able to manage this part of puberty well (Cridland et al., 2014; Koller, 2000). The most common changes related to puberty for boys with ASD included increased hair, voice changes, general growth, and genital development (Volkmar & Wiesner, 2009).

There is a common association between adolescence, puberty, and the increase in romantic and intimate relationships. It was reported in literature that adolescents with ASD are more likely to demonstrate unacceptable 'courting' behaviour compared to their non-ASD peers (Chen, Grandjean, & Richard, 2016; Fernandes et al., 2016; Stokes, Newton, & Kaur, 2007). This was thought to be the result of the lack of reliance on social peers for information on what is considered acceptable. It is concluded in the literature that this is largely related to a lack of intrapersonal and communication skills in individuals with ASD, which then leads to developmental challenges that hinder them in forming significant relationships with others

(Chen et al., 2016; Fernandes et al., 2016; Locke, Ishijima, Kasari, & London, 2010). The lack of social skills and communication, as well as the kind of help that these individuals with ASD need during the puberty phase requires further research. This particular research addresses the views and experiences of individuals with ASD and parents in relation to this transition phase.

In this respect, it is important for parents to carefully guide their children so that they can have a better understanding of their sexuality, such as what is to be kept private. Social skills groups can also be of great help in this area (Volkmar & Wiesner, 2009). An important risk for children with ASD is that they need to be instructed on boundaries so that they are not abused, whilst they also need to learn that in some instances being touched can be appropriate, such as by doctors or in the context of an intimate relationship (Holmes et al., 2014; Volkmar & Wiesner, 2009).

Unfortunately, there is at present a significant lack of research that explores whether there is any significant change in the degree of autism during puberty. It is crucial that such research necessary so that parents, teachers, social workers, and doctors have more information on how to manage and support individuals at this stage in their development, so that he or she can reach their highest potential.

3.4.2 Sexual Awareness

Sexual awareness is a very important aspect of growth for all individuals. Murphy and Elias (2006) noted that sexual growth is a process that all individuals go through during adolescence. It is associated with physiological changes, the fundamental natural desires of human beings for being loved and approved of, showing and getting passion, feeling desirable and valuable, as well as the exchange of feelings, values and views. Adolescence is the time when individuals begin to understand their sexuality and construct their beliefs and values connected to these areas (Dewinter, Van Parys, Vermeiren, & van Nieuwenhuizen, 2017; Murphy & Elias, 2006).

There is only limited research on sexuality and sexual functioning in individuals with autism (Dewinter et al., 2017; Dewinter, Vermeiren, Vanwesenbeeck, Lobbestael, & Van Nieuwenhuizen, 2014; Gabriels & Van Bourgondien, 2007) largely as a result of the sensitivity of the subject and the potential ethical problems associated with its investigation. The characteristics of ASD play a major role in the growth and sexual development of such

children and their transition into adulthood. Recent literature (Chen et al., 2016; Dewinter et al., 2014; Gabriels & Van Bourgondien, 2007) has pointed out that ASD characteristics such as sensory issues, communication, and preoccupation in individuals with autism might affect their sexual knowledge and attitudes. These characteristics impact on adolescents with ASD in various ways. In particular, the characteristics of ASD often limit the growth and development of relationships and friendships and decrease the possibility of them gaining knowledge about sexuality from friends. Autism can also affect the person's thinking with the result that they are unable to express their sexuality in a socially appropriate manner, and they may also be unable to understand other people's sexual motives. Additionally, the social skills and communication impairments in youngsters with ASD reflect in their capability to become engaged with someone sexually, which might add to the possibility of the development of unacceptable sexual behaviour (Hénault, 2005). However, in a recent study conducted by Dewinter et al. (2017) notes that ASD males understood sexuality by browsing the internet, and from watching friends. The boys with ASD in their study also said that they felt uneasy about discussing the matter of sexuality with their parents.

In a study carried out in Turkey by Isler, Tas, Beytut, and Conk (2009) explored the growth and development of understanding, thoughts, and behaviour related to sexuality among young individuals with mental disabilities. Their study sample included questionnaire responses from sixty young adults, aged between 15 and 20 years, with mild to moderate mental disabilities. The results of this study indicated that these young people with mental disabilities had limited levels of appropriate knowledge and understanding about sex and of the growth and development associated with adolescence. Almost half of their participants had not received proper education about sexuality, and 46% of these rarely discussed sex with their mothers and fathers (Isler et al., 2009). This was also found in the Dewinter et al. (2017) study, which suggested that this was because some individuals viewed the matter of sexuality as a taboo, and it was not commonly talked about with their parents. However, a more comprehensive study would examine the knowledge and understanding of sexuality in individuals with mental disabilities from different countries, as these specific results may be due to particular culture influences on the participants.

3.4.3 Sex education

An important element of the growth of sexual awareness among adolescents is the formal and informal sex education that they receive. It is, of course, very important to teach sex education

to all adolescents, and especially to adolescents with disabilities. There is some literature that has addressed the importance of sexual education for youngsters with ASD (Koller, 2000; Murphy & Elias, 2006; Sullivan & Caterino, 2008; Tissot, 2009), and these have argued that such education will enable the development of better sexual identity and relationships in adult life. Previous literature (Beddows & Brooks, 2016; Gougeon, 2010; Murphy & Elias, 2006) has recommended that sex education needs to be adapted to the developmental level of the child, and that parents should be the main medium for approaching the sex education of children with ASD. Gougeon (2010) found in his research that a number of both parents and specialists believed that children with ASD lacked any interest in sexual relationships, and because of such assumptions, issues of sexuality and sexual growth in such young people are often overlooked.

Chan and John (2012) found that the majority of the adolescents are able to figure out how to manage the changes in their physique and their growing sexuality through interaction within their everyday surroundings. They noted in their research that, these adolescents do this through exposure to a number of resources from which they are able to gather the required information and understanding of suitable attitudes. These resources include mothers and fathers, instructors, and friends, as well as television and social media (Chan & John, 2012). One question that needs to be asked, however, is whether individuals with autism learn and manage this development in their bodies in the same ways as typically developing children. It is also important to find out if adolescents with ASD use the same sources, and if so how do these sources affect their knowledge about the topic. Furthermore, there is a significant gap in the literature related to the views of those adults who have made the transition about the sources of information they used and the support they had, along with what support would have been valuable, in retrospect. This current research makes a significant contribution to knowledge in this regard.

It is useful to note here that Isler et al. (2009) found that around 47% of young people with autism hardly ever communicate with their family members regarding sexuality. Instead they acquired their information and understanding from peers, the worldwide web, and the media (Isler et al., 2009; Tissot, 2009). Conversely, relying on such resources leaves them vulnerable to a barrage of false information on issues related to sexuality that is available through such sources (Isler et al., 2009). Volkmar and Wiesner (2009) cited that one of the major resources of information available for typically developing children are friendships, and these might be not accessible to the children with ASD; because of the difficulties they

have with socialization and communication. Brown-Lavoie et al. (2014) confirmed this, finding in their research that adolescents with ASD were less likely to seek or acquire information on sexuality from their friends, mothers and fathers, or school-teachers. Instead, these youngsters gained their understanding and information from impersonal, non-social resources, such as the Internet and television.

We can conclude then that the inadequate knowledge and understanding of both puberty and sexuality in people with ASD is associated with the limited number of sources of information which they tend to rely on (Brown-Lavoie et al., 2014). In spite of this, it is also worth noting Chan and John (2012) important point that adolescents with ASD are in need of additional consideration and proper care throughout the transition of puberty. This is particularly so with regards to their growing sexuality and sexual health, which is among one of the crucial elements of the transition of puberty. The consequent section will explore the next transitions that individuals with ASD go through during their adult years, such as employment.

3.5 Transitions into adulthood

The transitions that occur at the completion of formal schooling years can also cause very significant challenges and difficulties for those with ASD, particularly with respect to the transition from school into some form of employment and/or vocational training, as well as changes in residence; if and when, this situation occurs. The transitions that occur at this stage of their life will be largely dependent on where the individual is placed on the autism spectrum and their functionality, as well as the facilities and opportunities available to them to make the transition effectively. In the following sections explores the transitions in to employment in more detail below.

3.5.1 Transitions into employment

A successful transition into employment is one of the most important outcomes to be attained in adulthood for most people (Cimera, Burgess, & Wiley, 2013). For people with autism, particularly those with high functionality, the transition into sustainable long-term employment will play a very significant role in them successfully achieving some form of independent living (Lee & Carter, 2012; Williamson, Robertson, & Casey, 2010).

If an individual with autism is able to find work this will enable them to be financially self-supporting, and so they will be able to fulfil their basic needs, such as purchasing groceries, meals, apparel, and affording an independent residence. In addition to this, being in work also

permits individuals to develop their self-worth, creates a sense of having a goal, and it enables them to build up friendships with others with similar interests (Jacob, Scott, Falkmer, & Falkmer, 2015). Therefore, employment is without a doubt an ideal outcome in early adulthood for most individuals, and is in many respects a necessity for an independent life (Cimera et al., 2013). Having a successful adult life is usually associated with having the capability of gaining an income, the sort of job that they perform, the job situation, and the on-going employment capabilities (Schall, Wehman, & McDonough, 2012).

Individuals with autism often need to deal with persistent issues and challenges within their work environment, which leads to behaviour that requires additional understanding and insight on the part of their managers and co-workers. One of the challenges that may result from this is related to the individual's level of social impairment, and in particular any communication difficulties they may have (Parr & Hunter, 2014).

A report by the National Autistic Society in Britain has shown that in 2009 only 15% of individuals with autism were employed full time (Redman, Downie, Rennison, & Batten, 2009). This indicates that there is a high rate of unemployment among individuals with autism, and that a high proportion of people with autism may need additional help to find and remain in employment. Previous studies have indicated that most of the job positions that adults with autism held were not well paid and required low qualifications, and this is often compounded for individuals with lower levels of functionality (Howlin, Moss, Savage, & Rutter, 2013; Taylor & Seltzer, 2011).

As Cimera et al. (2013) have noted, many individuals with autism require greater support throughout their school years to guide them in successfully navigating the transition process into employment. This is possible, as shown by another study by (Williamson et al., 2010), which found that six months after completing secondary school almost three quarters of the participants (147 individuals) with disabilities in their study were able to attain some kind of post-secondary work or education. The reasons given for their success were that these participants were had good self-care skills and independent living abilities, which were associated with obtaining some kind of a job (Williamson et al., 2010).

Hodges, Luken, and Hubbard (2004) noted that transitions related to employment are often overlooked by researchers, largely as a result of the reduced lifespan and employment capability of people with autism. There have been a number of studies made in the past

decade that address this oversight, particularly with regard to the transition into the adult years of people with autism (Hendricks, 2010; Holwerda, van der Klink, de Boer, Groothoff, & Brouwer, 2013; Holwerda, van der Klink, Groothoff, & Brouwer, 2012; Kinoshita et al., 2013), but there are still a number of gaps in the literature.

For example, Taylor and Seltzer (2011) have argued that insufficient interventions are made to find ways to support adults with autism in the management of the transition into the work environment. Research has indicated that this transition is associated with numerous obstacles, such as facing challenges with interacting socially and communicating with individuals from the opposite gender, co-workers and managers in the work place, and getting used to the new work routine (Hendricks, 2010; Sperry & Mesibov, 2005). The obstacles that individuals with autism face in their work environment is mainly associated to the degree of severity of the symptoms of the condition, their cognitive abilities, and comorbid conditions such as depression and anxiety (Holwerda et al., 2012).

There is a need for further research on how adults with ASD can be assisted with the challenges they face in making the transition into employment. In particular, there is a need to determine the most effective forms of support system and also to develop approaches that give most support to the experiences and functionality of individuals making this transition. Understanding how to help individuals with autism gain employment, as well as the individualization of transition programmes based on the particular needs of individuals would be useful in finding the best ways of helping adults with autism to start earning money to assist themselves, to be more independent, and to have a better quality of life (Hendricks, 2010; Järbrink & Knapp, 2001).

It is worth noting here Taylor and Seltzer's (2011) study of 66 young people with ASD in the UK and their post-secondary transition to work. Only a quarter of the young adults with autism in their sample who did not have an intellectual disability or other reason to impair their transition to work had found either work or further education, and only 18% were in employment. Of those that had a job, their work tended to be in lower skilled positions. This indicates that the present support and service systems do not suit the needs of adolescents with autism who do not have an intellectual disability. In addition, not enough is done to ensure that they make a successful transition to adult employment, or to address the low rates of adults successfully making the transition from secondary school into employment (Taylor & Seltzer, 2011).

There is a need for effective transition services to help enable individuals with autism to become employed, particularly those who are high functioning. Yet understanding this from the experiences of the adults themselves is important and forms part of the focus of this research. If this transition is not managed and supported effectively, then the individual may not be able to achieve an independent lifestyle. As noted in the previous section, in many respects the individual's education at school could be aimed at helping them to prepare to make this transition successfully.

This thesis addresses a particular gap in the literature by engaging adults with ASD in conversations about their employment status and experiences. The findings from this will provide a better understanding of their perspectives and employment experiences. One of the means by which the transition may be assisted is through supported employment programmes, which can help individuals with ASD to find and keep appropriate jobs after they have left school. Such programmes are discussed in the next section, together with the successful use of post-secondary and vocational programmes (including voluntary work).

3.5.2 Supported employment

The transition from school to employment can be facilitated and supported by structured supported employment programmes. There are a number of supported employment programmes to help individuals with disabilities and mental illnesses to find and maintain work. Most often these programmes aim to find the appropriate type of employment for each individual according to his/her abilities, choice, and work expertise. Most programmes also offer job coaching and guidance, as well as follow-up assistance (Bond et al., 2001; Kinoshita et al., 2013; Mavranouzouli et al., 2013; Wehman et al., 2016).

A successful supported jobs programme helps to guide individuals with disabilities to locate and maintain work. Such a programme also enables them to maximize their autonomy together with enhancing their confidence, in particular by providing social skills training and job coaching to help improve their quality of life (Vogeley, Kirchner, Gawronski, van Elst, & Dziobek, 2013).

Supported employment programmes seek to include the individual in effective jobs as opposed to sheltered work, and the localization of work are personalized according to the individual's choices, knowledge of the job, and their personal qualities and skills (Mavranouzouli et al., 2013). The achievement of these goals through such a programme gives

adult people with ASD significant advantages over other life and career options, such as sheltered programmes, since it provides them with considerably greater independence and a range of personal choices. In addition, García-Villamizar and Hughes (2007) noted that adults with autism who were in the supported job programmes showed enhanced cognitive functioning abilities.

There are a number of recent examples of successful supported employment programmes. One example in the UK is the 'Prospects' occupational service programme, run by the National Autistic Society (NAS), for individuals with autism who are high functioning, as described in the study by Howlin, Alcock, and Burkin (2005). The Prospects scheme offers job training, job localization and assistance with work, together with recruitment guidance, instruction, and preparation. It also offers support for organizations and companies in the management of employees with autism.

In many respects, therefore, the transition from education to employment can be more successfully managed by supported employment schemes, such as the Prospects scheme. Again, it is also worth noting that such support should not only occur at the time of the transition, but should also be built into the school-based education of individuals with ASD, to help them prepare for this very important transition.

3.5.3 College, voluntary work and vocational programmes

Another means of managing a successful transition from school to employment is the use of college (post-secondary) and vocational programmes, which can provide qualifications and skills that may help individuals enter full-time employment or unpaid voluntary work (Foley, Dyke, Girdler, Bourke, & Leonard, 2012).

3.5.3.1 Voluntary work

As a precursor to employment, voluntary work may be viewed as a positive step in ensuring the success of this transition. Taking part in voluntary work is considered very humanitarian, as volunteer work varies from participating in local communities and neighbourhood activities, to working with charitable organizations regularly and supporting individuals in need, which may provide the individual with a better quality of life (Taghian, D'Souza, & Polonsky, 2012). However, research on individuals with autism who are participating in voluntary work is very limited.

One advantage of voluntary work is the neighbourhood orientation in assisting other people, their understanding about volunteering, and the need to feel valuable and important (Shye, 2010). Another advantage is it is not likely to create as strong a pressure on an individual since there is not the concern about earning a living. Usually the work requirements are more flexible, and this can help an individual who is functioning, but not able to take on the responsibility of full-time employment. More research is needed in this area, particularly on volunteers with autism and how this improves their quality of life and their employment skills, which could be a process of making the transition to employment for individuals with autism.

3.5.3.2 Vocational programmes

The importance of vocational training and employment for individuals with ASD is that it can provide something of more significant meaning and value than a simple job. Vocational training, and any related employment opportunity, will have an additional positive impact on that person's life. Such a vocation will not only help them to organize their daytime activities and improve their prosperity and wellness. It will also contribute to their intellectual and interpersonal inspiration, their personal growth as an adult, and will in general positively improve their functionality and their quality of life (Taylor, Smith, & Mailick, 2014).

Some researchers have noted that there is generally a lack of vocational programmes for individuals with autism, and the programmes that are available usually do not match their abilities and interests (Davis, 2009; Nicholas, Attridge, Zwaigenbaum, & Clarke, 2014). Despite this, Hendricks and Wehman (2009) have noted that there is an increasing availability of college-based programmes in the US for individuals with autism, even though such learners often face difficulties and challenges with the academic and learning systems. This is an important aspect of this particular research study, as participants were asked about their jobs if they had any, and about the qualifications or trainings they had in order to get a job.

3.5.3.3 College

In research conducted by Zager and Alpern (2010), they noted that there were limited services and support for individuals with autism in the transition phase from school to adulthood. In their study of a college-based inclusion programme in the US, they found that most individuals with autism left school unqualified for post-secondary education. This was the case even with the high functioning individuals who had the capability to attend college.

Individuals with ASD who had limited functioning abilities and did not have the capability to go to college tended to stay in secondary school until the age of 20, which meant that their last three years in school were usually spent with younger students, and not in their peer group with more severe disabilities (Zager & Alpern, 2010).

This again underlines the need for the child's school education to be structured more effectively to prepare individuals with autism to make the transition to adulthood, which may include both employment and post-secondary adult education. Moreover, the experience of college life and post-secondary education will usually provide greater advantages for typically developing students in comparison with individuals with ASD related disabilities. Some of these advantages are improvements of the individual's educational skills, confidence, advocacy, and having better employment outcomes. All these skills are learned during college life, which can help the individual to achieve a more functional and independent lifestyle during adulthood (Hart, Grigal, & Weir, 2010).

However, the research on the post-secondary transition for individuals with ASD still considerably lacks the voices of individuals with autism themselves. As will be shown in my research, we can achieve a better understanding of the management of this transition if we listen more to the individuals themselves about their experiences with employment and adulthood. Furthermore, The perceptions of the parents concerning raising a child with ASD along with their experiences of their children's varied transitions, is going to be explored in the next section.

3.6 Perceptions of Parents of Children with Autistic Spectrum Disorder (ASD)

The following section will consider the perspectives of parents of children with autism in the transitional phases of their lives and the parents' experiences of raising a child with ASD. To be able to establish ways to help parents and children together, it is essential to take the parents of individuals with ASD into consideration. By seeking the opinions and perspectives of such parents, we will acquire a better and more profound knowledge of the dynamics of the families of children with ASD (Ozturk, Riccadonna, & Venuti, 2014).

There is already a considerable amount of literature concerned with parents' experiences of raising a child with ASD (Henninger & Taylor, 2014; Hetherington et al., 2010; Langan, 2011; Ozturk et al., 2014; Rattaz et al., 2014; Selimoglu, Ozdemir, Toret, & Ozkubat, 2013; Stoner, Angell, House, & Bock, 2007). For example, Dabrowska and Pisula (2010) compared

the levels of stress coupled with the types of managing stress in both parents of preschool youngsters with ASD and Down syndrome in Poland. It was found in their study, that mothers were more stressed than fathers and the study acknowledged some of the factors that were causing stress to the parents (Dąbrowska & Pisula, 2010). However, the study failed to consider the differing behavioural problems of youngsters with ASD that triggered the parents' stress.

Research has highlighted that numerous children with ASD may exhibit difficult and disturbing behaviour throughout situations of change and transitions in childhood (Schreibman, Whalen, & Stahmer, 2000). The contribution made by this study, which might be helpful for other individuals that are going through school transitions, is the recommendation that children and young people with ASD might be primed in advance regarding different transitions, such as changing or leaving school.

Transitioning is a challenging time for individuals with ASD, and the perspective of their parents is very important for a successful transition plan, and finding the appropriate education of their children (Stoner et al., 2007; Tissot, 2011). Stoner et al. (2007) noted in their study that parents of children with ASD stated that the effective transition support approaches were the ones that targeted the particular child, and that communication between parents and schools were also very crucial.

Throughout their lives, most individuals with ASD continue to be notably impaired by their condition, and they are usually dependent on the guidance and support of caregivers, parents, and other family members (Shattuck et al., 2007). Previous literature has noted that parents of individuals with ASD experience elevated stress as opposed to other parents of youngsters with different disorders or even typically developing youngsters (Freedman, Kalb, Zablotzky, & Stuart, 2012). The symptoms of autism – such as social and communication impairments – can lead to an increased influence upon an individual's capability to behave within their surroundings, creating confusion between individuals, caregivers, and their parents (Koller, 2000). When these individuals grow older, parents have found that they have obstacles with the capability to look after as well as to ensure their participation in significant activities and programmes for their youngsters with a disability (Foley et al., 2012). Therefore, raising and looking after children with ASD is a demanding and challenging task for the parents, since the parents usually have the essential role as the main caregivers for those children. In most

cases, having such a role involves considerable energy, time, and finances for the family (Kuhlthau et al., 2014).

Hetherington et al. (2010) mentioned in a study of parental experiences of transition planning for individuals with disabilities, that parents usually were the individuals' primary guides in the transition phase, finding the appropriate adult services, and transition plans. Several parents encountered issues and challenges in obtaining suitable care for their children, due mainly to the multi-dimensional experience of transition and gaps of support and systems (Hetherington et al., 2010). The duties and routines of the family members of individuals with disabilities become complicated due to the complexities associated with the different transition processes that an individual goes through in the course of his or her life, particularly after completing school (Cheak-Zamora, Teti, & First, 2015; Davies & Beamish, 2009). The involvement of parents in the transition process is considered an essential factor.

There has been considerable discussion in the research literature of how the parent's roles and perspectives are important (Henninger & Taylor, 2014; Hetherington et al., 2010; Langan, 2011; Ozturk et al., 2014; Rattaz et al., 2014; Selimoglu et al., 2013; Stoner et al., 2007). This research aims to explore this further in order to help provide a deeper understanding of the needs of individuals with ASD in the context of their surroundings and their family lives. Relationships with parents are particularly important, as are relationships beyond the immediate family. These are discussed in the following section, since they can be problematic for those with ASD.

3.7 Relationships

Positive relationships are important in the lives of individuals with ASD, as they can serve as a means of support through some of the transitions. Social relationships tend to considerably influence the emotional and even wellbeing of people with ASD (Cheak-Zamora et al., 2015; Kelly, Garnett, Attwood, & Peterson, 2008; O'Hagan & Hebron, 2016). Previous literature has mentioned the importance of close family and peer relationships as an important feature against depression and anxiety (Bollmer, Milich, Harris, & Maras, 2005; Kelly et al., 2008). However, impaired interpersonal behaviours skills are a well-recognised characteristic of ASD, and individuals with ASD usually manifest challenges with the essential skills needed for social interaction (Scheeren, Koot, & Begeer, 2012; Sedgewick, Hill, Yates, Pickering, & Pellicano, 2016).

It had been noted that children with ASD experience difficulties with socio-emotional capabilities, such as expressing and comprehending emotion, along with possessing a limited range of communication skills, which are essential to initiate dialogue, engage in mutual relations and respond appropriately to others (American Psychiatric Association, 2013; Brownlow, Bertilsdotter Rosqvist, & O'Dell, 2015; Goldstein, Schneider, & Thiemann, 2007). Therefore, children with ASD are more likely to experience some barriers when trying to get involved in supportive and rewarding relationships with peers and family, and they might show a minimal capability to effectively cope with negative events within these relationships (Kelly et al., 2008).

Research has found that ASD children show a decreased need for interpersonal closeness (Berthoz & Hill, 2005; Dunn, Myles, & Orr, 2002; Gabrielsen & Young, 2016; Harrison & Hare, 2004). Consequently, having a low motivation for socializing with others along with limited interpersonal understanding, and social knowledge influences the capability individual's with ASD have to involve themselves in meaningful relationships with others potentially (Gabrielsen & Young, 2016). However, a previous study conducted by Cheak-Zamora et al. (2015) showed that individuals with ASD highlighted the importance of relationships in their lives, which they found were supportive. Although, studies within this area has provided contradictory outcomes along with few other researchers that have noted that people with ASD do want to have meaningful relationships, despite their limited perceptions of the complexities of relationships (Stokes et al., 2007).

3.7.1 Blood Relatives and Next of Kin

The main relationship that parents of children with ASD have with their children is nurturing them in their early years, since most individuals with ASD continue to live at home with their parents (Orsmond, Krauss, & Seltzer, 2004). Some parents engage more with their children's activities and services. For example, Orsmond et al. (2004) found that some of the children with ASD participated more in social activities with others, when their mothers were involved with them. This is an important finding as it shows the significance of the mother's relationships with their children and how it can positively affect them.

Moreover, previous research suggests that families of children with ASD encounter a general lower functioning and quality of life as compared to families where they do not have a disabled member in the family (Khanna et al., 2011). It is well-recognised in literature that the difficulties related to raising a child with ASD may substantially lead to increased degrees of

stress for members of the family (Sikora et al., 2013), along with depressive disorders (Benson, 2006, 2010), along with the family interpersonal interactions, that may be equally impacted and be affected by ASD characteristics (Benson, 2010; Kelly et al., 2008). The child's difficulties associated with ASD symptoms, such as psychological and behavioural problems may cause a greater deal of stress on the parents (Herring et al., 2006). Previous research found that behavioural problems that children with ASD present, were often a critical factor in this respect (Hastings et al., 2005).

Therefore, the relationships of these problem behaviours of individuals with ASD and the functions of the family, are significant matter to be better understood, to help with developing effective interventions (Sikora et al., 2013). Members of the family often reorganising their lives to meet their children's additional needs (Sikora et al., 2013). Therefore, it is understandable that the quality of life of children with ASD appears to have been associated with the psychological, financial and interpersonal resources of their surrounding family (Davis & Gavidia-Payne, 2009).

Further relationships that children with ASD may have are relationships with their siblings. Previous research suggests that sibling's relationships are important for the individuals with ASD, as it can be a way of support, and they can also learn from them (Diener, Anderson, Wright, & Dunn, 2015; Kaminsky & Dewey, 2001). In a research conducted with individuals with ASD, Petalas, Hastings, Nash, and Duff (2015), found that these individuals viewed their typical devolving siblings as a way of assistance and getting information. Nevertheless, the relationships of these siblings may be complicated because of the sibling's ASD symptoms, which are mainly the communication and social impairments that can impact this relationship (Diener et al., 2015). However, it was noted in literature that some of the siblings of individuals with ASD experienced feelings ashamed of their brother/sister with autism (Mascha & Boucher, 2006).

It is clear that this present research has important implications for the immediate families of children with ASD. It aims to understand the experience that parents have and the pressures placed upon them through their imperfect knowledge about the condition of their children, and how to respond to it. In addition, it seeks for solutions and recommendations that will not only improve the situation of parents, but also guide the decisions of policy makers in this area.

3.7.2 Other Relationships

Outside the family system, research have suggested that people with ASD do have relationships with other people, such as friendships and colleagues although they may seem to appear not to be mutual or complicated (Locke et al., 2010). Previous literature found that people with autism encounter challenges with forming friendships, and only have a limited number of friends (Bauminger, Shulman, & Agam, 2003; Koning & Magill-Evans, 2001; Locke et al., 2010).

It has been speculated that children with ASD may have an inadequate ability to recognise the meaning of friendship and these difficulties increase as the child reaches adolescence, as children with autism may find they are less accepted by their non-disabled peers and marginalised (Locke et al., 2010). It was found in previous literature that children with ASD experienced increased feelings of loneliness than other children (Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Storch et al., 2012).

Rejection in peer relationships could be acknowledged as a critical psychological challenge for ASD individuals who would like to interact other people, as it was found in literature that ASD children are more inclined to experience bullying (Carrington & Graham, 2001; Little, 2002; Weiss, Cappadocia, Tint, & Pepler, 2015), and that generally associated with the child's particular psychological health issues, communication challenges along with the amount of school peers they have (Cappadocia, Weiss, & Pepler, 2012). The value of friendship has been found to be a protective element against bullies, and helps to minimize anxious and depressive feelings in people with ASD (Bollmer et al., 2005; Hay, Payne, & Chadwick, 2004).

In addition to friendships, some adults with ASD make efforts to form romantic relationships and some of them do get married (Farley et al., 2009; Howlin, Goode, Hutton, & Rutter, 2004). People with ASD as they grow-up, the start developing the desire for more social intimacy (Howard, Cohn, & Orsmond, 2006), despite the fact that they notice that a marriage relationship is usually more difficult in comparison to regular friendships (Sperry & Mesibov, 2005). A study conducted by Chamberlain, Kasari, and Rotheram-Fuller (2007) found that the challenge that individuals with ASD face, is that their relationships are not reciprocal with others. Conversely, people with ASD are less likely to be married or in committed relationships compared to their non-disabled peers (Gotham et al., 2015), even

while compared to other people with other intellectual disabilities (Barneveld, Swaab, Fagel, van Engeland, & de Sonnevill, 2014). Moreover, previous literature found that this was a significant concern by parents as well (Cheak-Zamora et al., 2015; Holmes, Himle, & Strassberg, 2016).

Despite the inherent difficulty in helping individuals with ASD to form friendships or intimate adult relationships, it is important to develop approaches that will help them to satisfy their needs either with others who have the condition or with those who do not, during the different transitions in their lives.

3.8 Chapter summary

Although there is some sound and informative literature about all aspects of transition, significant gaps exist. In particular, despite some current studies, a greater emphasis on the feelings and perspectives of those parents and individuals, both in the UK and the KSA, is missing. In addition, despite some research on the various transitions, there is a need for further research: for example, special schooling, puberty and sexuality, voluntary work.

Several themes have emerged in this chapter. A predominant theme centres on the complexity of the disorder and the consequent challenges of diagnosis. This is compounded further by some of the challenges faced by a child with ASD at the several transition points. For young people who do not have ASD the transition to school and to adolescence can be troublesome, and it is all the more so for those who experience various degrees of impairment. Added to this are the difficulties faced by parents, professionals and policy makers to determine appropriate courses of action: in education, for example, specialist centres may be appropriate; for others mainstream schooling may provide a solution. Although there is no easy solution, this chapter considers what guidance is available in the literature which could offer effective support to provide a secure basis for the transition to employment: one example of which is the suggestion of voluntary work which might enhance confidence and build relationships as a preparation for paid employment. Since the views of parents and those with ASD is seen as central to the care and support of children with ASD and adults in this research, the following chapter explains the methodological approach.

Chapter 4 Methodology

4.1 Introduction

The aim of this study is to discover how individuals with autism and families experience the varied transitions from childhood to adulthood, as well as how they cope through this critical period. A qualitative research design is chosen for this study, in order to gain insight. One of the gaps lies in the absence of a body of research in the KSA into transitions, support, and services for individuals with ASD and their families. Another gap is the limited research on the varied transitions that people with ASD make from childhood to adulthood. In addition, there is a lack of studies based on life history interviews with people with ASD. This chapter outlines the methodology that is adopted to address the research questions, including the research paradigm, methodological approach, research instrument, sample, design and procedure, data analysis, reliability and validity, the pilot study, and the ethical considerations.

4.2 Purpose of project and its academic rationale

This study will explore and describe ways through which people with autism and families experience the transition phase from childhood to adulthood, and explore ways in which the participants feel they could be helped to cope through this period. The research literature identified gaps, which can affect the transition period of their lives, emphasizing the personal experiences, childhood and school, work and income, relationships, and concerns faced by individuals with autism during this phase of their lives and the perspectives of families and their experiences of this transition phase. This research project aims to understand how these factors impact upon the transition experience. The findings of the study contributes new knowledge to provide an insight into the experiences of individuals and families, and to identify the difficulties they face, which may be used to maximize the developmental potential of the individual, and to make suggestions for services and support for individuals with autism and families.

4.3 Research questions

- How do individuals with autism and families experience transition from childhood to adulthood?

Sub questions:

- What are the factors that hinder or help individuals with autism as they go through the transition?
- What are the mother's perceptions regarding this transition period for their children with autism?

4.4 Ontological and Epistemological position:

Every research study conforms to an identifiable paradigm. The research paradigm is informed by the researcher's views, knowledge and beliefs of the world, which will consequently inspire the research methods that are going to be used in the study (Creswell, 2009). As all research is conducted using different concepts and beliefs, which directs the way the research is organized and interpreted. These views, knowledge and beliefs can be considered as reflecting ontological and epistemological viewpoints; where ontology means "the nature of reality" (Creswell, 2012, p.20), and epistemology the ways in which we believe we can acquire insight and information and defend and support the knowledge gained (Creswell, 2012). Therefore, it is very crucial for the researcher to choose an epistemological position, which will influence his/her study (Carter & Little, 2007). Some researchers argue that a particular ontological position determines the path of a specific type of methods and methodology. While other researchers view that certain epistemological and ontological positions should be used if they are suitable for the research study (Wagner & Okeke, 2009).

Carter and Little (2007) discuss how epistemological position impacts on several factors in a research study, such as the way of collecting data from the participant and how the researcher interprets the information provided, the suitability of the data collection method, the approach to the analysis, and the way of presenting the data. For instance, if a certain ontological position was adopted by the researcher, a specific epistemology, methods and analysis is going to be followed for the research study, and if the researcher chose a different ontological position, then the subsequent research epistemology and methods is going to change accordingly (Scott & Morrison, 2005).

4.5 Constructivist and Interpretivist paradigm:

There are two different epistemological positions in research, which are positivist and interpretivist. Interpretivism is an epistemological philosophical position, which aims to examine and understand the ways that people perceive their social world, and about the

individual's own views and experiences (Smith & Osborn, 2003). As such, interpretivism's position is subjective and interactive, and it proposes to understand people and their experiences by using qualitative methods (Avramidis & Smith, 1999). The interpretivist approach has been widely used in educational research for the past three decades (Scott & Morrison, 2005).

Interpretivism is associated within a constructivist paradigm, which is an approach that is about acquiring meaning from the world around us, by relying on the participant's own views and experiences (Creswell, 2009). Savin-Baden and Major (2013) asserts that constructivism is based on the participant's own experiences, and that the participant is the person who has the most knowledge about a certain subject matter.

4.6 Objectivistic and Positivist paradigm:

The objectivistic paradigm uses a positivist research epistemology. The positivist paradigm suggests the truth is there in our world to understand and study it in an objective way (Hatch, 2002). The epistemology of researchers who adopts the positivists approach is objectivist, and their ontology is realist-external (Avramidis & Smith, 1999). Mackenzie and Knipe (2006) stated that the main aim of choosing a certain paradigm is to choose the right methodology, which, will lead to a specific type of methods. Therefore, researchers who adopt a positivist approach to research will use quantitative research methods (Hatch, 2002). As Sale, Lohfeld, and Brazil (2002) observed that positivism is the ground for the quantitative approach. The positivists approach asserts on applying concrete knowledge established on evidence and truth (Tuedor, 2006).

4.7 Psycho-medical paradigm

When investigating special educational needs both paradigms have merit, but historically, the frequently implemented paradigm for investigating special educational needs has been the psycho medical paradigm (Kivirauma, 2004). The psycho medical paradigm proposes that the existence of a "special educational need", such as autism, is because of the occurrence of a collection of some evident recognizable traits that are found in the neurology of the individual because of a certain disorder (Avramidis & Smith, 1999). This would fit within an objectivist ontological position and a positivistic epistemological framework. Although this is one position, it is not the only position. Alternatively, a social model or an interpretivist paradigm implies that special educational needs is a relative concept that is socially constructed, as opposed to being originated from the individual himself (Avramidis & Smith, 1999).

Therefore, the environment has an important role to play when investigating issues and phenomena in this area. In this research the researcher explores the phenomena from the individuals with autism themselves and from the parents of individuals with autism. The next section will provide additional details as it relates to this research study.

4.8 The research paradigm of the study:

Given the aims and objectives of this study, an interpretivist epistemological position and a constructivist approach to the research methods is adopted. This is because this study is interested in exploring the personal views and experiences of individuals with autism and families. The researcher's main intention is to give to the individuals with autism and parents of individuals with autism a voice and make their experiences, views, concerns, and success heard. The researcher believes that the participants are the most knowledgeable about the topic: their personal views and experiences are valued about autism and how it impacts on their lives; these experiences can only be understood through individuals, their thoughts, values and the context in which they currently exist. Therefore, a constructivist approach is most suitable for this specific research topic.

4.9 Methodological Approach

The method that will be employed in the current study is a qualitative approach to explore the experiences of individuals with autism and mothers of adolescents with autism in the transition phase from childhood to adulthood. Specifically, a series of semi-structured face-to-face interviews were conducted with mothers of individuals who have been impacted by autism during the transition from childhood to adulthood, in addition to life history interviews were carried out with adults with autism.

Qualitative research is a method of study that attempts to achieve a thorough understanding of human nature, as well as the causes of certain forms of human behaviours (Howitt, 2010; Silverman, 2011). Therefore, most qualitative researchers work with fewer participants to be able to obtain in depth information (Maxwell, 2013; Wagner & Okeke, 2009). Unlike quantitative research, which is concerned with direct and measurable phenomena by using statistics, as quantitative researchers convert the information gathered from a certain research study into numbers, qualitative research aims to discover how and why these phenomena exist the way they do (Tracy, 2013). Similarly, qualitative research is predominantly focused on the process in which human behaviours occur, and the environment's impact on the participant's behaviours, rather than solely the outcomes of behaviours and actions (Maxwell, 2013).

Qualitative research is largely designed to identify the meanings people attribute to their lived experiences (Tracy, 2013).

However, there can be considerable challenges in conducting research that involves individuals with ASD. One particular issue may be gaining consent to conduct such research. Also, it may prove challenging to find ways in which individuals with ASD can be successfully involved in the research. This is mainly because of the nature of their disability, in particular the variation of the individuals' abilities to communicate and socialize with others (Brewster & Coleyshaw, 2011; Loyd, 2013b). The main symptoms of ASD tend to make the conduct of interviews with these individuals challenging, and this is probably the main reason behind the lack of research on the perspectives of individuals with autism themselves regarding their experiences. Largely because of this, a considerable amount of research on autism has been conducted on the viewpoints of parents, caregivers, teachers, and health care practitioners, rather than on the individuals themselves (Kirby, Dickie, & Baranek, 2014).

Therefore, for this study a qualitative approach was used to explore the subjective reality of individuals with autism and families during the transition from childhood to adulthood, as it was considered the most effective way to answer the research questions. In qualitative research procedure, the researcher allows a closer focus on the individual's voice and recognize the participants own lived experience and sense of a certain issue (Creswell, 2009). In this approach, the experience of transition from childhood to adulthood in individuals with autism was selected, and data is then collected to create an understanding of the nature of that experience, and the crucial aim is to show what was experienced and how (Creswell, 2009).

Qualitative research methods are associated with both strengths and weaknesses. A key strength of this approach is its tendency to produce a far richer explanation and analysis of a certain human behaviour or experience that cannot be caught as a whole by other types of quantitative approaches (Al-Busaidi, 2008; Castro, Kellison, Boyd, & Kopak, 2010). Neergaard, Olesen, Andersen, and Sondergaard (2009) noted that using a qualitative approach would be valuable when the researcher sometimes encounters a restricted time-frame, not to mention limited research materials. Conversely, qualitative research has been criticised for its lack of generalizability to larger population groups, as well as its dependence on the measurement skills of the researcher (Bryman, 2012; Neergaard et al., 2009). Quantitative, and some forms of qualitative, research attempt to remove the researcher from the

measurement process as much as possible. However, qualitative research necessitates that the investigator becomes the primary measuring tool, as this minimises problems concerning the validity, reliability, and causality when interpreting qualitative research (Neergaard et al., 2009).

Despite the potential limitations of the methodological approach utilised in this study, it should be noted that multiple previous studies (Hoogsteen & Woodgate, 2013; Hurlbutt & Chalmers, 2002; Jones et al., 2013; Woodgate, Ateah, & Secco, 2008) have used similar approaches to address the topic at hand. Hurlbutt and Chalmers (2002) and Jones et al. (2013) conducted a qualitative study with individuals with autism in order to find out about their lifetime thoughts, feelings and experiences. While other researchers explored the everyday life of families with individuals with autism by using semi-structured interviews (Hoogsteen & Woodgate, 2013; Woodgate et al., 2008).

Additionally, this approach was chosen largely due to the exploratory nature of the current research questions. Quantitative research is more effective when large sets of data are available to researchers and objective conclusions can be drawn about their relationships (Neergaard et al., 2009), and larger numbers of participants are included in quantitative research (Castro et al., 2010). Qualitative research is more appropriate when in-depth information is needed regarding a relatively novel topic, such as the experience of transition from childhood to adulthood in individuals with autism and families (Hoogsteen & Woodgate, 2013). Where the current methodological approach is limited, it is suggested that future research could expand on the current study by employing more objective methods of data analysis.

4.10 Methods of data Collection

4.10.1 Interviews

Semi-structured in depth interviews were used in this qualitative study to collect data from the participants. DiCicco-Bloom and Crabtree (2006) indicated that by using interviews the researcher could collect comprehensive data regarding a certain issue from the participant's views and experiences, which is commonly used in qualitative approach. This instrument consists of a series of open-ended questions concerning the experiences and feelings regarding the transition phase from childhood to adulthood that individuals with autism and families go through. Hermanowicz (2002) points out that a good interviewer should be able to attend carefully to what the participant is saying, and to look at the participant's body

language and expression, in order to have a valuable understanding and finds the significance of the topic being discussed with the interviewee.

This semi-structured interview guide will allow the primary investigator to follow a consistent interview structure, while also promoting the free conversational flow needed to conduct qualitative research effectively (Bryman, 2012). The researcher substantially chooses the structure and content of the interview questions, and the way of asking questions. The aim of the qualitative research is to gather, as much data regarding a particular human experience as possible, the open-ended nature of the interview guide will encourage participants to fully elaborate on the question being asked (Bryman, 2012). Additionally, qualitative research answers questions regarding the individual's thoughts and feelings about a certain topic rather than just finding the correlation between things or the amount of a certain element (Harper & Thompson, 2011). However, the structure of the guide will ensure that all participants received the same opportunity to respond to each question in the same order, thereby eliminating ordering biases or extraneous environmental variables (Bryman, 2012).

All interviews conducted with the participants were recorded on a handheld recording device for further analysis. Prior to engaging in the interview, each participant was informed of the recording process and asked to provide consent in order to continue with the study (for additional information on ethical considerations see Section 4.16). The recording session began just prior to the commencement of the interview session. Consequently, using a recorder is very helpful and beneficial in order not to lose the information that was gathered from the interview (Hermanowicz, 2002). The recorded interviews were later transcribed, in order to analyse them.

4.10.2 Life history

The method that was used to gather information from the adults with autism is the life history method. The life history method is a qualitative method used to document information and gain insight concerning health, behaviour patterns, and the lives of individuals in order to explore their personal experiences within the social world (Cole & Knowles, 2001). The data collection method that is commonly used in life histories is interviews. Interviews used should be flexible and open in nature, as this will be usually noted in research studies that are conducted by researchers who are holding an interpretivist epistemological position towards

their research, since the interviews are meant to construct knowledge, and the researcher therefore should be reflective in the analysis (Plummer, 2001).

The life history method explores a person's beliefs, experiences and values (Haglund, 2004). The life history model is rooted in Erikson's (1963) developmental theory of psychosocial stages that supports that the "ego identity" is shaped at the end of the individual's adolescent years, to the start of the adulthood years (cited in McAdams, 2001). It is during this period that individuals begin to construct their life stories to discover their identities (McAdams, 2001). As this is the stage of focus for this research, it seems suitable that the method is rooted in theory relating to late adolescence.

This method is very flexible and can be used with a variety of interview formats. A semi-structured format will be used in order to keep the interviews focused on the transition from childhood to adulthood, while allowing the participant to express his or her experiences in the context of a comfortable dialogue (Appendix 4). The interview will assist to produce a narrative from which themes will be subsequently derived. Using the life history interviews will support the researcher in gaining thorough understanding of the participant's life, and how does the participant interacts with the environment and the social world, which will help in explaining and figuring out the human being in the environment (Cole & Knowles, 2001). Moreover, the kind of story this study is interested in is the solicited story of individuals with autism about their experiences of the transition from childhood to adulthood. The researcher specifically gathers these stories with a specific topic and social goal in mind; therefore the researcher plays a major role in collecting the right information and asking the proper questions in order to have a significant life story (Plummer, 2001).

4.10.2.1 Strengths and Limitations

This method is cooperative and person-focused, with the importance of seeing the individual as a full human being in the environment, which will help in acknowledging life situations and experiences to be perceived within a broader perspective of life (Adriansen, 2012). It is a significant research tool that can produce rich data, noteworthy and unexpected perceptions from the participant's own perspective on a certain topic, it also provides information about their own social world (Goodley, 1996). In this research, the researcher is interested in knowing, and gaining insight about the individuals behind the diagnosis of autism, which is strength to give them a voice and let them be heard, so people would benefit from their

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experiences and help other individuals on the spectrum and their families. One of the major strengths that could be experienced by the participants is that they find telling their own life stories and experiences empowering (Atkinson, 2004; Goodley, 1996).

Some of its strengths can also be seen as limitations. The small number of interviewees could be seen as a limitation, but also as a strength since it helps the researcher to get more profound information (Cole & Knowles, 2001). The biggest criticism of the life history method is that life events are not likely to be remembered accurately. In a study conducted using life history method with adolescents by Haglund (2004), the researcher noted that one major limitation that was encountered in the study is related to the poor memory of adolescents about recalling their old previous childhood years, events and situations. While, Haglund (2004) also stated that the participants remembered better and shared more details about their current and more recent life situations and experiences. In the current study, the researcher used semi-structured interviews as a prompt, in order to help the interviewees recall certain events. Most of the questions that were asked were concerning the transition phase from childhood to adulthood, and the researcher did not ask specific questions about the very early childhood years of the participant that required recalling very old memories.

The reflective aspect of the life history timeline approach, or any other retrospective approach, involves the writer in constructing his own history (Plummer, 2001). It is simply a personal detailed perception on the world that is subjective, and must be examined as one view of the truth rather than an objective truth (Plummer, 2001). Reflective type of methods, such as the life history method is more prone to be inaccurate and biased by memory (Parry, Thompson, & Fowkes, 1999). However, providing dates and significant lifetime transitions can be crucial to helping participants recall more precise information (Parry et al., 1999). In this particular study, the participants were prompted to talk about the important transitions of their lifetime, such as their transition from childhood to adulthood, that includes things like school, and employment.

Finally, this method requires a lot of time and effort (Adriansen, 2012). Therefore, the small number of participants allowed for this project to be feasible and for analysis to be simpler. Furthermore, the participants are likely going to value the insight gained from the construction of their life history, and it helps to understand the individuals regardless of their diagnosis (Goodley, 1996).

4.11 Sample

To gather information about the transition period from childhood to adulthood in individuals with autism and families, two groups of participants were chosen. Coyne (1997) cited that selecting the appropriate sample for a certain research project is very crucial, as it effects on the value and quality of the research. The first group consisted of six adults with autism who were diagnosed with a form of Autism Spectrum Disorder, mainly Asperger's syndrome or High Functioning Autism. These individuals with autism were interviewed in person, in order to get their life history experience from childhood to adulthood.

The sampling method that was used in this study is a non-probability sampling approach, which incorporates purposive and snowball sampling. Initially, the researcher purposefully collected the sample to serve the need of a particular research, and therefore this sample is selected particularly to help enrich and gain more in depth information about certain phenomena (Coyne, 1997; Patton, 2002). Personal contacts were used to locate the sample in this study that were from England, in addition to asking few of them to recommend other potential participants, who might be able to take part in the study. Also, 20 GBP was given to each of the UK participants as an appreciation for their time spent in taking part in the study. Therefore, snowball sampling was also used, which consists of knowing a suitable participant for the specific research study, that helps the researcher with referring other suitable participants that shares the same condition or interest (Biernacki & Waldorf, 1981).

The second group was a sample recruited from the west of Saudi Arabia, an example of which is provided in appendix 7. It consisted of 13 mothers of adolescents or adults diagnosed with ASD. After obtaining ethical consent, the mothers were recruited from a support group from Jeddah, and from a specialized centre for children with ASD (appendix 7). The purpose of collecting this sample was to gain insight of a mother's perception, experiences, and views on raising a child with autism through adolescence. Furthermore, the researcher informed the participants that the purpose of the study is to obtain information about their own life history experience, or about their child pertinent to their transition from childhood to adulthood. Written and verbal informal consent were obtained from the participants at the commencement of the study and prior to each interview session (see section 4.16 for additional details about ethical procedures for this study).

A limited number of participants were selected because of the nature of the specific criteria of participants needed for this particular study (Castro et al., 2010). Additionally, in most

qualitative research the number of participant's recruited is usually small, whereas in quantitative research studies the number of participants is bigger (Patton, 2002). Both qualitative and quantitative studies have different reasons behind choosing the appropriate sample, therefore in quantitative research the reason is generality, while in qualitative research is gaining insight and in depth information (Merriam, 2009; Patton, 2002).

In this study, the initial part of the research was carrying out life history interviews with adults with ASD from England. For the reason that I am a woman, while the majority of individuals diagnosed with ASD are males, made it impossible to carry out this part of the study with ASD adults from the KSA, for traditional and cultural reasons (see Chapter 2 for additional details). Therefore, considering the researcher's cultural values, the life history interviews were conducted with ASD adults from the UK in an open public place in England, such as a park, or a quiet coffee shop, which accorded with the preference of the interviewees who preferred a less confined setting. Only one elected to be interviewed in a room at the University of Reading. By this process each of the respondents was made to feel comfortable before the interviews began. This is because of the difficulty that faces the interviewer in Saudi is social prohibition, which is for a female or a male interviewer to interview one-to-one a person from the opposite gender, which is mainly due to Islamic and traditional values (Alqahtani, 2012). Therefore, it is not possible for a female to be with a male alone in a room, and the interview could only be possible if one of the close female's relative is present at that time (Alqahtani, 2012). Another reason was that adults with Asperger's syndrome or High Functioning autism were very hard to find in Saudi. Considering that, it was pointed out in a previous research conducted in the KSA, that not any of the participants of Al-Salehi et al. (2009) had a diagnoses of Asperger's syndrome. Moreover, for the second part of the research that involved conducting interviews with parents of individuals with ASD in Saudi, only the mothers were interviewed. The research conducted the interviews with the mothers in a comfortable location for them such as, at their homes, or at a quiet coffee shop in Jeddah.

This research was not intended to be a comparison, as one of its main aims is to give a voice for these individuals with ASD and for the parents. Therefore, the two groups are viewed for the purpose of contrasting rather than comparing. They were chosen in order to contextualize the research carried out with individuals with ASD from the UK along with offering a justification for one of the aims of the particular research, which includes information about the UK system, which offers vital understanding for the growth and development of ASD services in the KSA.

4.12 Design and Procedure

Once the sample was obtained, a series of qualitative interviews took place with the two groups of participants in this study. Each interview was conducted independently with the individual with autism, and other interviews with the mothers of individuals with autism, in a setting that is convenient to the participant. Prior to engaging in the interview, each participant was given an information sheet regarding the nature and procedures of the study. The primary investigator described the interview guide and content of the study, as well as addressing any questions from the participants. Participants were also instructed of their rights as human subjects, including their right to withdraw from the study at any time or choose not to respond to a particular question. Following this, participants were required to sign an informed consent form in order to continue with the study.

Once informed consent has been obtained, the interview session commenced. With the first group of participants, who were individuals with ASD. Three interview sessions were conducted, each lasting about 30 to 60 minutes, were used to obtain information about the participants' life experience in regard to childhood and schooling, work and income, relationships, and any other areas of concern in relation to the transition from childhood to adulthood (see appendix 4) for more details about the interview questions. Three interviews leaves enough time for stories to emerge without exhausting the participant (Adriansen, 2012). In addition to getting written and verbal consent prior to interviewing, permissions were obtained to tape record the interview, to allow the researcher to focus on dialoguing with the participant and recording main events on the life history (Parry et al., 1999). Furthermore, the adult participants from the UK, were given 20GBP each, as a way of thanking them for their time spent in taking part in the study.

With the second group of participants', who were mothers of individuals with autism. Each mother was interviewed in person. Each question on the semi-structured interview guide (see appendix 6) was read, and participants were encouraged to provide as much detail about the question as they can. Once the participant has finished responding, follow-up questions were asked to ensure he or she does not have more information to add. Once all the questions have been read, responses were recited back to the participant to ensure they have been recorded accurately. During this time, participants were provided the opportunity to clarify responses where necessary, as well as provide more information about a particular question.

Following the interviews with all the participants, they were told how to contact the primary investigator should they have further questions about the study. Additionally, participants were informed about where they can receive copies of their transcribed interviews following the data analytic process, if they wanted. All datasets will be stored securely (Richards, 2009).

4.13 Data Analysis

The data gathered of this study from the interviews were recorded, and later transcribed. Transcription is a procedure that converts audio recordings into written scripts, and it is the first step towards the analysis process (Howitt, 2010). It is a process that helps the researcher to immerse and familiarize himself /herself with the data collected, which consequently guides the researcher towards the analysis process (Braun & Clarke, 2006; Howitt, 2010). All interviews in this study are interpreted and analysed using a thematic analysis approach. This method of data analysis involves identifying patterns in data based on similar themes and frequencies in which these themes appeared within the data gathered from interviews (Buetow, 2010). Furthermore, Boyatzis (1998. p.4) stated, “ Thematic analysis is a process for encoding qualitative information”. Identifying these patterns is critical to understanding the research question, and the emerging themes ultimately serve as classifications for more objective methods of data analysis (Buetow, 2010). During this analytic process, several phases of coding and interpreting responses are performed. A familiarisation phase took place first, in which all responses are read a couple of times by the researcher from immersing himself/herslef in the data. This phase enables the researcher to gain perspective on the dataset and gain knowledge as to sense the themes that may exist (Boyatzis, 1998). An initial coding process took place then, in which responses from the participants of this specific study are reduced into overarching categories and themes. These codes are identified based on similarities across the dataset, as well as the frequency in which they appear, in accordance with recommendations by Clarke and Braun (2013). An attempt to identify major themes will then be performed based on the degree to which the researcher believes these codes to appropriately fit into a cohesive main theme.

Themes will then be reviewed depending on their ability to support and explain the data provided in the transcript, as well as answering the specific research question. Therefore, the themes will be given labels and sufficiently described based on their relevance to the research question, using an approach similar to that of Clarke and Braun (2013). Finally, the identified themes will be placed into a set of coherent tables and reviewed based on their meaning, and

in order to classify valuable themes, the researcher should spend a good amount of time immersing himself in the data which will eventually lead to better themes in quality (Howitt, 2010). During this process, the primary investigator will enlist a colleague to verify the validity and reliability of the coding and interpretation of these themes, in addition to reviewing them with the researcher's supervisors. This process of checking strengthens the scientific rigour of the study and allows for any inaccuracies to be identified (Krefting, 1991; Lincoln & Guba, 1985). Further details regarding the reliability and validity of the current study will be discussed in the following section 4.14.

As with all forms of qualitative research, thematic analysis is associated with advantages and disadvantages. One of the advantages of using thematic analysis, is that it can be used as a method for analysing semi structured interviews, when the researcher needs to obtain insight about the participant's beliefs, thoughts, and experiences regarding a certain topic (Joffe, 2011). Another key advantage of this method is its adaptableness along with applicability to several potential theories (Joffe, 2011). In a novel research topic, such as that of the current study, the potential relevance to multiple theories of autism may help facilitate a greater amount of future research. Additionally, this process permits the researcher to effectively analyse the participants' lived experience of autism (Healy, Msetfi, & Gallagher, 2013). In addition to solely relying on the data, the researcher can further provide his or her own insight based on research and experience when identifying themes and patterns (Boyatzis, 1998). Finally, the thematic analysis process is systematic and encourages a reasonable amount of objectivity, in comparison to alternative qualitative approaches for analysing the data gathered in a certain study (Joffe, 2011).

Conversely, this approach lends itself to research biases related to interpretation of themes and drawing conclusions (Braun & Clarke, 2006). For example, personal theoretical biases may influence the researcher during the analytic process, causing him or her to view the data differently than other researchers (Castro et al., 2010). Therefore, checking the codes and interpretations with others was used as a strategy to alleviate this source of potential bias (Clarke & Braun, 2013), by using a second researcher to identify codes and themes, and then comparing the similarities and differences of both codes and themes provided by both researchers in order to check for reliability (Joffe, 2011).

4.14 Reliability and validity

Reliability and validity are crucial features of quality research (Kline, 2008), and it helps to ensure that a study can be regarded as meaningful and effective for scholarly understanding. The current study collected subjective qualitative data (as described in the current Chapter 4), to explore the lived transition experiences of two groups. Moreover, “reliability is concerned with the consistency, stability and repeatability of the informant’s accounts as well as the investigators’ ability to collect and record information accurately” (Selltiz, Wrightsman, & Cook, 1976, p. 182). The researcher developed interview schedules that were used with both groups of participants (appendix 4 and appendix 6), which is considered crucial in order to have data that is reliable and consistent (Kline, 2008).

The challenges that occur from interpreting qualitative records adequately have contributed to the arguments concerning the principles of validity and reliability, which are theoretically inconsistent with the basic concepts of qualitative research (Lincoln & Guba, 1985). It is suggested that qualitative data reflects the subjective thoughts and opinions of individuals, given its uniqueness that depends on each participant individual experience (Johnson & Waterfield, 2004; Lincoln & Guba, 1985). Therefore, it is difficult to measure ‘reliability’, which makes it challenging to be repeated, as the researcher should interpret the data gathered as opposed to measuring it (Johnson & Waterfield, 2004; Lincoln & Guba, 1985). Previous literature has suggested that this subjective nature of the qualitative research makes it unsuitable for statistical and empirical analysis and instead of reliability and validity, qualitative researchers should seek to ensure their findings are truthful (Brink, 1993).

It is important to acknowledge the researchers’ bias in order to obtain reliability for the research. As mentioned in (section 1.5), the researcher has a brother and a cousin with ASD, in addition to her previous experience with working with children with autism during volunteer work and her one-year internship at an Applied Behaviour Analysis (ABA) clinic. The researcher also acknowledged the different cultural background of both groups of participants from the UK and the KSA. The researcher acknowledges that her personal and practical experiences are related to the current research and can personally affect the research.

Furthermore, thematic analysis was used to evaluate the results (section 4.13). Considering the presence of these subjective aspects throughout the research design, the researcher was conscious of the need to maintain this study sufficiently rigorous through the research process, which was by implementing some kind of verification techniques (Rolfe, 2006).

Therefore, the interviews with the participants were recorded and later transcribed. The analysis of the raw data started with a focus on the first three transcripts from each of the two groups. These provided some initial themes that emerged from examples in the raw data. Over a period of time these were refined through co-validation with the researcher's supervisors.

Additionally, the researcher's supervisors then reviewed the themes that were generated in order for it to strengthen the validation. Three transcripts were also co-validated with the researcher's supervisors for the life-history interview of one UK participant. In addition to all translated documents to English, three interviews with KSA mothers were offered for similar co-validation. It is important for a researcher to identify the sections of text that support the themes and agree on the themes with another party (Alhojailan, 2012; Joffe, 2011). The current study used tape-recorded interviews in order to make certain that the records collected were precise, and that the written transcripts could in fact be validated. As it was stated by Markle, West, and Rich (2011, p. 3) "It was not until the 1970s, when portable audio recording could be taken directly into the field, that transcription became a viable method and researchers could analyse, interpret, and report participants' own words". This is significant because it enables the researcher to hear the recording many times in order to make sense of the data, and to recall important information, which could have been missed if the researcher just took notes at the time of the interview (Rapley, 2008).

Lincoln and Guba (1985) for example, developed the concept of 'trustworthiness' in qualitative research and divided this concept into sub-categories of: "credibility; transferability; dependability and confirmability" (p.43). These concepts were put forward as theoretical alternatives respectively to: "internal validity; external validity; reliability and objectivity" (Lincoln & Guba, 1985, p. 218). A research is recognized to have internal validity where its findings are generally regarded as a true reflection of the wider reality (Brink, 1993), and this concept has been further discussed with regards to credibility and 'truth value'; where a researcher has demonstrated adequate assurance in the truthfulness of their findings based on their participants, research setting and design (Krefting, 1991). External validity demonstrates the extent to which a research's findings are generally transferred or employed on the wider context (Johnson & Waterfield, 2004). This is important where thematic analysis is concerned because the themes and codes that are recognised reflect the personal perception of the researcher, which makes it crucial that the themes accurately reflect the entirety of the transcript (Alhojailan, 2012). The considerations cited in the current section were important in the present study, both during the collection of data as well as the

thematic analysis. The following section will discuss the translation process of the Arabic interviews that were conducted with the participants from the KSA.

4.14.1 Parallel translation

When a study involves more than one language, validity is a key factor, both with regards to the data collected and to the translation (Sutrisno, Nguyen, & Tangen, 2014). In qualitative studies, researchers must explain the translation process implemented, minimise issues within the translation, and include the opinions of a couple of translators, which will help to guarantee trustworthiness (Sutrisno et al., 2014). One of the critical factors in translation is to ensure that it captures the actual meanings provided by the participants (Wong-Anuchit et al., 2016). This is generally not a straightforward procedure, given the similar accurate sentence or word might not possibly happen to be in the alternative language (Regmi, Naidoo, & Pilkington, 2010). On account of this, qualitative studies generally rely upon a couple of translators who speaks both languages (Sutrisno et al., 2014). A further method to ensure the accuracy of translation is ‘Parallel translation’ (Sutrisno et al., 2014).

Parallel translations consists of various independent translators convert from the original language to the second required language separately, then to compare both versions to compose a final agreed one (Mayer, 1978; Usunier, Lee, & Lee, 2005). After that, an additional translator evaluates and checks the translated versions to reduce issues in the translation and to guarantee agreement (Douglas & Craig, 2007; Golafshani, 2003; Sutrisno et al., 2014).

In the present study, the semi-structured interviews were carried out with parents of individuals with ASD from KSA in Arabic (see appendix 6). The present researcher translated the interviews gathered. After that ‘Parallel translation’ technique was adopted with a PhD student colleague who conducted a translation for one of the interviews. Subsequently, a third bilingual PhD student was asked to read and compare both translated transcripts to ensure agreement, and this is to ensure that the translation from Arabic into English is accurate. All three interpreters, which are the researcher and her colleagues are native speakers of Arabic and are fluent in English. Neither is a certified translator. Similar approaches to translation have been adopted by other studies (Sutrisno et al., 2014).

4.15 Pilot study:

A pilot study using semi-structured interviews (appendix 2) was carried out with three mothers of adolescents with ASD from the UK, and two mothers of adolescents with ASD from Saudi. The researcher obtained ethical approval to carry out the research in general, along with getting the participants consent to take part in the pilot research (appendix 1). The pilot aimed at exploring the experiences of mothers of individuals with ASD from childhood to their adulthood, in order to gain an understanding of the varied transitional experiences of the parents from the UK along with the KSA, and to make adjustments to the approach where appropriate. Five key themes emerged from the piloted study. The first theme was maturity, which included physical and sexual maturation. The second theme was lack of services and support. School transition and school problems were the third theme brought up by the parents, and the final two themes related to challenging problems and comorbid conditions. .

These interim findings were in agreement with previous literature on autism, which shows that higher levels of anxiety and tension are present in parents of children with ASD compared to those with typical-developing children (Giovagnoli et al., 2015; Harrop, McBee, & Boyd, 2016; Hastings et al., 2005). In addition, the lack of support and services for children with ASD alluded to by parents is also highlighted in past research (Ludlow, Skelly, & Rohleder, 2011; Woodgate et al., 2008). Challenges with the transitions in schools were mentioned by all of the parents in the pilot study. However, one of the unexpected findings of the pilot was that the results showed that there was no major difference between the mothers interviewed from the KSA and those from the UK regarding the services and support. These themes and insights served to provide a framework for the study that followed.

Additionally, the pilot research influenced the main study of the thesis, and the interview questions. From the results of this, the researcher decided to explore the transition from childhood to adulthood from the viewpoint of individuals with ASD themselves. And to get a better insight into what have helped them or hindered them into these phases in their lives. It also shaped the interviews with participants from the KSA, in view of the lack of literature in Saudi, and lack of support and services, which might help service providers in the future for developing appropriate support and services for children with ASD and their families.

4.16 Ethical Considerations

This section presents ethical factors that were taken into consideration in the current study. Certainly research in the field of education carries ethical issues, because it includes gathering

information either from individuals or about them (Punch & Oancea, 2009). Research ethical issues of the current study are presented; also as information disclosed in this study may be personal, issues related to sensitivity are discussed as well. "This project has been reviewed following the procedures of the University Research Ethics Committee and has been given a favourable ethical opinion for conduct" and "The University has the appropriate insurances in place. Full details are available on request".

4.16.1 Consent

All participants in the current study provided informal oral consent prior to engaging in the research. This is then followed by a more formal consent process in which participants were given an information sheet as to the details and nature of the study and their rights as participants. During this consent process, participants were informed of their basic rights to confidentiality, privacy, reciprocity and equitability (Hammersley & Traianou, 2012). Special precautionary measures were considered to ensure that each participant is treated equitably and that their privacy and autonomy is respected throughout the course of the study. Each participant undertook the same procedures and was granted the same rights as the rest. The individuals with autism, who took part in the study, were adults or young adults with High Functioning Autism or Asperger's syndrome, which had the legal age and mental capacity to consent for themselves.

Before conducting the interview, an information sheet was provided to the interviewee explaining the objectives of the study. Additionally, interviewees were notified that they have the right to withdraw from the research study at any given time with no cost or penalty to them, As Cohen, Manion, and Morrison (2013) mentioned that the investigator has to respect the participant's right of self-determination. All interviewees then signed an informed consent form prior to engaging in this study. The definition of informed consent as stated by Diener and Crandall (1978) is informing individuals about the process of study that they will take part in, and providing them with significant information and facts about the study that would possibly influence their choices in whether to take part in the current study or not.

It should be noted that because of the nature of the topic in this study, some parents might find some elements in the interview upsetting. As parents of children with autism will to be asked to recall some memories and experiences of their child with autism, these participants may experience some level of psychological discomfort in response to this study (Pellicano & Stears, 2011). In the event that happens, the interviewer will give the option to the participant

if they wish to take a break, or to end the interview. The researcher will respect the parent's requests and follow them in all cases. The interviewer will also provide a debrief form that includes a list of recommended readings, support groups, and the contact information of the National Autistic Society that might be helpful to the participant.

4.16.2 Confidentiality

Thorough efforts were made to protect participants' identity throughout the course of this study. Confidentiality is an essential right of all human subjects, and the researcher insured that all information was stored securely and that no personal identifications were used for any participant in this study (Wertz et al., 2011). No names were used in the collection or analysis of data; each of the UK participants was assigned a pseudonym, and each of the KSA participants was assigned a number. The researcher protected the participants' confidentiality and privacy. For example, parents were informed that they have the right to decline comment for any questions asked during the qualitative interview process. However, given the nature of this qualitative, study participants were interviewed face to face or by phone. Consequently, the participants could not expect anonymity from the interviewer but confidentiality, which means that while the researcher recognizes the participant who provided the information, the association would not be made to the public by the researcher (Cohen et al., 2013).

During this study, every participant was given a number to guarantee confidentiality and anonymity throughout the data analysis process and for the data representation. The data collected from the interview such as the transcripts and the data analysis were retained confidential and saved in password-protected computer and a locked cabinet.

In the event if child protection was raised, the researcher followed the ethical procedures of the University of Reading and the British Educational Research Association (British Educational Research Association, 2004) and contact the appropriate authorities, which was in case if this happened.

4.16.3 Sensitivity

The current study asked that participants disclose personally sensitive information to the researcher. Therefore, stringent efforts were made to maintain a high degree of ethical responsibility and that the potential for harm was minimised. This study was given approval by the ethics board, and aimed to address each of the British Educational Research Association ethical considerations (British Educational Research Association, 2004) in order

to reduce such risk. Sensitivity was maintained and the potential for harm was minimised by allowing participants to take breaks from the interview when necessary or stop a particular line of questioning.

According to Gholami and Tirri (2012), empathy and compassion are critical ethical considerations that must be made in qualitative interview studies. Therefore, efforts were made to prevent social and personal biases that may confound data collection, and the primary researcher attempted to display a high level of empathy for participants' case scenarios. Furthermore, ethical sensitivity was also maintained during the data analysis process. No attempts were made to manipulate responses or to pressure the participants to answer questions they were not comfortable with. Cohen et al. (2013) stated that “most institutions of higher education have their own ethics committees, and these usually have their own codes of ethics against which they evaluate research proposals” (p. 99). The researcher complied with the university's ethics policy and code of practice for research with human participants in the current study.

4.17 Summary

In conclusion, the main aim of this study was to explore and determine how do individuals with autism and parents experience transition from childhood to adulthood. This chapter summarizes the ontology and epistemology of this current research, and it gave an overview of the methods of data collection, sample, the research design and procedure, ethical procedures for this particular study, in addition to a summary about the pilot study.

Chapter 5 The experiences of adults with ASD in the UK: Results

This chapter will present the qualitative results of the life history interviews see section (4.10.2), which was conducted with the sample of adults with ASD. As noted in the methodology chapter, the sample was made up of six adults with Asperger's syndrome from the UK, four men and two women. All of the individuals being introduced have been educated in the UK, and they are ranging in age from 18 to 51 years. This was an opportunity sample through referrals and personal contact. The analysis used was thematic analysis see section (4.13) in the Methodology Chapter for further details.

The interviewees' responses in the interviews are clustered into a number of themes, largely following through their typical life histories, beginning with issues of diagnosis of ASD, through their childhood, schooling and the transitions they experience, and concluding in the transitions from school to adult life, such as, employment, relationships, and leisure.

Table 5.1: Details of the six UK interviewees

Participant / pseudonym	Age	Gender	Diagnosis	Marital status	Employed
David	29	Male	Asperger's syndrome	Single	No
Michael	18	Male	Asperger's syndrome	Single	No
Charles	45	Male	Asperger's syndrome	Single	No
Daisy	24	Female	Asperger's syndrome	Single	No
Jasmine	25	Female	Asperger's syndrome	Single	No
Edward	51	Male	Asperger's syndrome	Married	No

5.1 Childhood and education

5.1.1 Diagnosis

In this first section, the researcher discusses the interviewees' perspectives on their diagnosis as having ASD, with particular note of their age at the time of the diagnosis, and the consequences of the diagnosis. Although not all of the interviewees were diagnosed with ASD at an early age (such as pre- or early school), this is a useful place to start in the discussion of the analysis about the various themes of the interviews. The issue of when and how their diagnosis was made had – in all cases – a significant impact on their childhood and education, either positively or negatively.

5.1.1.1 Diagnosis experience

The experience of the diagnosis of ASD was quite different for each of the individuals who were interviewed. Some individuals were diagnosed at an early age or at school, while others were not diagnosed until a later time, either in their teens or as an adult. All of these diagnoses (and the timing of the diagnosis) had a significant impact on the individual and the different transitions in his/her life, as those individuals who were diagnosed early had support for their special needs from an early age, because their needs were recognized at an early stage of their lives. In contrast, those who were diagnosed later in their childhood, or in adulthood, tended to feel much more 'lost' as children, particularly since neither they nor their parents and teachers knew the reason behind their behaviour and their specific needs.

Two of the participants stated that they had been diagnosed at an early age:

'I was about 5 years old when I had the diagnosis.' (Daisy)

'I was five years old.' (Jasmine)

One of the benefits of receiving a diagnosis at an early age is the opportunity for the child's parents (and other adults) to recognise the child's difficulties in order to help him/her to improve and to provide them with better support and services. For example, one the participants who was diagnosed at an early age had the opportunity to attend a special school. She said:

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'I went to mainstream at first until they recognized my difficulties; they sent me to a special school.' (Daisy)

One informant reported that he was diagnosed when he was an adolescent, and he talked about his experience with the diagnosis saying:

'Later on they diagnosed me with autism, but that was when I was already a teenager, young adult sort of thing...' (David)

'When I was about thirteen or fourteen.' (David)

There was a distinct contrast with the older participants in this group, who revealed that they had no relevant diagnosis during their childhood, and were only diagnosed with Asperger's syndrome when they were adults. Thus, they cited:

'I was about thirty-one.' (Edward)

'When I was twenty-seven.' (Charles)

Charles also talked about how his childhood experience had been affected by this lack of diagnosis, and how lack of knowledge of his disorder had made him feel. He said:

'I didn't fit in. I had known from a very young age that there was something different about me. The reason for why was unknown at that point because I hadn't been diagnosed.' (Charles)

Edward mentioned that during his childhood his disability was unknown and that in the absence of any further knowledge of his condition, the only term that was used about him when he was a child was simply that he was 'disabled'.

'Like when you are disabled, you can have Asperger's Syndrome you can have Down syndrome, things like that. But in those days, it was just you were disabled!' (Edward)

From these examples, it is clear that children who were diagnosed with ASD at an early age felt that they had an advantage during their childhood, since the diagnosis enabled them to have adequate care and support as possible. The fact that the older age range of interviewees were not diagnosed until well into their adult lives, indicates in particular the relatively recent developing awareness of ASD and the increasingly common prevalence of diagnosis during

childhood. The absence of diagnosis for these interviewees created some anxiety around ‘feeling different’ for which, in retrospect, an earlier diagnosis would have helped.

5.1.2 Childhood experiences

It was clear from the results that there were considerable variations in the experiences of being a child. Some individuals said that they had experienced a positive childhood, while the experiences of others during childhood were described as challenging.

5.1.2.1 Typical childhood experiences

Approximately half of the participants (3 adults) expressed the view that most of their childhood memories and experiences were pleasant and typical. For example, some of the comments made by participants about their childhoods were as follows:

‘It was always better back then. I don’t think I had an extraordinarily different childhood because Asperger’s Syndrome was just something that was in the background; I never thought it as being anything significant, but my childhood was very good.’ (Michael)

‘I was more nervous as a child but I didn’t have a bad childhood. It was quite a normal childhood.’ (Daisy)

‘I had a pretty simple childhood. I enjoyed my time at the infants’ school, it was really nice. I think I got along pretty well, except I kept chasing, no running away from the boys. And I don’t know, I just – it might’ve been difficult here and there and stuff, but not entirely difficult. I was pretty content.’ (Jasmine)

When asked ‘How would you describe your experience of being a child?’, one of the participants described how she felt her childhood was fun and happy:

‘I seemed content and I made the most out of the littlest things. My mum told me never to leave the street, so I would make the most of playing in my street. I was on my bike, I was climbing trees and I don’t know, would dance in my back garden. I would play with my Barbie dolls and put concerts on or pretend my bunk bed was a magic bus, or you know, just these things. Or make up dance routines in the kitchen, yeah. So yeah, I had a pretty content childhood, simple.’ (Jasmine)

The childhood experiences that individuals go through left them feeling content and happy about their childhood, which was expressed by three of the participants in this study. In the subsequent section, the researcher will discuss the cases of individuals who faced challenging

childhood experiences. It could be inferred from such differences that individuals' childhood experiences might influence their subsequent transitions to adulthood, whether positively or negatively.

5.1.2.2 Difficult/challenging childhood experiences

Three out of the six participants mentioned that they had experienced a challenging childhood. One of the individuals felt that the reason for his difficult childhood was because he had remained undiagnosed and this had a significant effect on his childhood, starting at the time when he first transitioned to school. He described it as follows:

'Tough. I didn't fit in... The reason for why was unknown at that point because I hadn't been diagnosed. So the problems I had with socialising with people – I was getting the blame, saying: "That's your fault; you're just not good enough at socializing." And so that was a large amount of the reason why at the age of twelve my mind collapsed and I ended up in mental hospital for a year.' (Charles)

One of the challenges that Charles also faced was the disruption caused by family problems during his childhood. He said:

'So at the age of four you're already abandoned by your parents, then fostered by a family.' (Charles)

Another participant stated that he had a difficult childhood because help and support were not available for him back then. He stated:

'Total horror! Because people didn't understand, wasn't aware ... And there was no help full stop.' (Edward)

The participant also stated how difficult his childhood experiences had been, by saying:

'Total upset, because I had a lot of different things to me, like happened to me, like I was bullied often and then I was abused.' 1 (Edward)

¹ In such cases, when the participant was upset, support was offered by the researcher when it was thought such support might be helpful. However, in this case the participant did not appear to be upset about discussing his challenging childhood, presumably because it was in the past, and therefore it was not felt necessary to offer any support in this particular instance.

One of the interviewees did not want to disclose information about their childhood and instead preferred to move on. He said:

'I had an okay upbringing. There were problems and that. Some of it I wouldn't want to discuss.' (David)

It is interesting to see how those individuals who expressed contented and happy childhood memories did not mention ASD or its effect on their childhood memories. In contrast, those individuals who experienced a difficult childhood made connections with ASD, This was not so much in terms of them blaming themselves for having ASD, but rather that they talked about the challenges they faced as being linked to their disability. The impact of getting a diagnosis with ASD on the individual and his/her family experiences has also been discussed by others (Crane, Chester, Goddard, Henry, & Hill, 2015; Jones et al., 2014; Punshon, Skirrow, & Murphy, 2009).

This section was about the challenging childhood experiences that individuals with ASD faced; the following section will discuss the broad stage of their childhoods, that is, their different school experiences.

5.1.3 School experiences

Of course, a major part of the participants' childhood experiences was their transition into and experiences of school. Important factors in this respect were whether they were educated in a mainstream or special school. Also of particular significance were their experiences of transitions within the school, whether these were experienced negatively or positively, and also any help they were given to manage such transitions effectively.

5.1.3.1 Mainstream school

Going to school is one of the first major transitions in every child's life. Mainstream school is a typical school that is not a specialist school. All of the individuals in this study stated that they had attended mainstream school at some time in their school experience, mostly during primary school. In 1978, the Warnock report was established to include children with special needs in schools (Warnock, 1978).

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The experiences of these adults with ASD in mainstream school varied considerably. Half of the participants had a positive experience in primary school. For example, those who had a positive experience said:

'In primary school I never really thought of it as being anything significant; I just had Asperger's Syndrome and that was on the sideline...' (Michael)

'Well the others in primary and infant school were pretty nice. I liked being in those classes. It was just so much easier.' (Jasmine)

These individuals who talked about having a good experience noted that one of reasons for their positive experience might have been because the primary school was easy and the people were nice. Also, they had some support in their schools.

One of the interviewees stated that in mainstream school they recognized his difficulties and he got a diagnosis with Asperger's when he was in school. He said:

'I remember I was at school there, and I was actually walked in by one of the teachers' assistants into a small room, maybe a third of the size of this room that we're in, and she came down to my level and she said, "You have Asperger's Syndrome".' (Michael)

Two of the interviewees elaborated on going to mainstream school and having support during primary school

'I went to mainstream school ... And in primary school I guess it was a little bit more difficult, but I had pretty good times there to. I didn't really have friends, but I was pretty much happy... I always had someone, a teacher near me, in the playground at primary school...' (Jasmine)

'I had mainstream primary school and then had support there I did because they recognized that an early age that I had problems... In primary school I had a very good experience.' (David)

In contrast to this, two of the participants stated that they had a difficult experience in primary mainstream school. They said:

'When I left primary school they said: "Charles will never get any school qualifications – he's that bad."' (Charles)

'I went to mainstream at first until they recognised my difficulties; they sent me to a special school... Mainstream was quite difficult in that the learning was quite hard and I just got really more nervous there.' (Daisy)

These two individuals' challenging experiences were because of their difficulties with mainstream primary school, which were mainly as a result of their ASD.

On the other hand, only two participants continued their schooling in mainstream school. Michael stated that generally it was a positive experience for him. He said:

'Well, I'm not amazingly affected by Asperger's Syndrome... it has been a good experience going to school, I cannot deny that. It's something I will cherish for the rest of my life but, at the same time, I nowhere near had the same experience as everyone else. I thought a lot more consciously about what I do, where I go, how I do things, as it were, and yes... but it was good.' (Michael)

While Edward mentioned having a challenging experience in mainstream school, because of the lack of awareness, which was long time ago for him because he is in his 50's now, and he got diagnosed when he was an adult. As he cited that education became better now. He quoted:

'These days I would have liked school a lot more. Because, you've got the help, the understanding and awareness there.' (Edward)

In summary, it is interesting to see that all of the participants at the beginning of their school life experience attended mainstream primary school, few of them continued in mainstream school while others moved to special schools, depending on their abilities, needs, and diagnoses that were made (or not made) at that time. The next section will discuss issues related to the interviewees who transitioned to special schools and their experiences with it.

5.1.3.2 Special school

Some individuals with ASD had the opportunity to transition into and attend a special school depending on their needs. From the sample, four of the participants went to a special school, and they talked about their experiences there.

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Going to a special school could be beneficial, in particular because they felt that the special schools had more of a focus on the child and his/her learning needs. One of the participants talked about the help that he had in special school regarding his learning abilities. He said:

'My boarding school was a specialist school for dyslexia originally and then they moved on to ASD conditions because they wanted to basically help everybody.'
(David)

He also talked about the different activities that this special school provided and of the beneficial impact of the school on him as a person. He said:

'I loved my boarding school because we did activities every day, which I thought was good because it helped me to grow as a person.' (David)

One of the benefits of going to a special school they felt was the help that was provided to these individuals to enable them to improve and prosper. Two of the participants described how going to a special school helped them develop more effectively:

'This one was a special school for people ... who had problems with learning or behavioural problems. So because this was actually a special school, I improved dramatically on learning.' (Charles)

Another respondent commented on how people were more understanding in the special school, which helped her improve:

'was better for me, my special school.... Well the learning was easier in the special school and I got on with people better so I was around people who understood me better...' (Daisy)

'In general it was really good because I was really comfortable in the school I was in, and I made friends that I have known over the years.' (Daisy)

Some of these individuals left mainstream school to attend a special school to better accommodate their special needs, and to have the appropriate support in a more understanding environment. These comments, therefore, indicate that special schools can be beneficial for the children with ASD. In the next section the researcher explores the next sub-theme, which is of the transition to secondary school.

5.1.3.3 Secondary school

Transitioning to secondary school is a very important step in any child's life. Children grow up and they become adolescents, which are considered to be a challenging time (Humphrey & Lewis, 2008) Two of the individuals spoke about this important transition in their life and how it affected them.

Michael mentioned that transitioning to secondary school was also related to him reaching puberty around the same time. He found this overwhelming because of the physiological and psychological changes that he had gone through. He had felt confused, and at this time he had become more aware of his Asperger's syndrome.

Talking about this matter, Michael said:

'When I went into [mainstream] secondary school it might be that my mindset changed, or that I just had a different outlook or something, but Asperger's Syndrome became a larger part, as it were. I think, as I became more mature and I went through puberty.... because the brain changes around puberty but my brain was already changed. It was everything that was in one place then goes to another place and then goes to another place, so nothing was entirely connected. I remember there being a lot of confusion when I was starting and had started secondary school. But yes, I think that's about it.' (Michael)

Jasmine also found transitioning to secondary school hard. She said that it was a confusing time for her, and the schoolwork was more difficult and she needed more help during that time. She said:

'But I don't know, somehow with [special] secondary school it was just a lot harder for me. So no, I just felt like I was just swimming in the shallow end and someone picked me up and popped me straight into the deep end and I just couldn't understand really what was going on. My brain was always somewhere else when they were explaining all these things that I guess were important...' (Jasmine)

'At secondary... I still had difficulties and I just couldn't concentrate. I just wanted to do other stuff. I kept digressing and I even had one-to-ones as well and it just didn't really work very well. I didn't do well in my exams.' (Jasmine)

In this section, both participants expressed how challenging the transition to secondary school was for them, particularly as this critical stage was also related to there reaching the age of

puberty, which most children find is a hard and confusing time of their life, although one of them was in mainstream school and the other one was in a special school.

5.2 Section Summary

In summary, this section has detailed the analysis of the results of the first set of interviews regarding the various transitions during childhood. The interviews have highlighted the individuals' varying experiences of diagnosis, emphasising in particular the distinction between those who had their diagnosis at a young age and those who were diagnosed later in their life.

The description then explored the transitions and experiences that the individuals faced during their childhood, if they experienced a typical childhood or a challenging childhood, along with their transitions in school. An important distinction was between those individuals who remained in mainstream school, in contrast to others who transferred to a special school. The different experiences related to their transitions to secondary school were also discussed.

5.3 Employment

The subsequent sets of interviews related to the life histories of these individuals with autism were focused on their experiences of employment and their income source(s). As has been noted already in Chapter Three the successful transition into employment is regarded as essential in any adult's life, and to do so effectively has considerable significance in particular for individuals of ASD (Cimera et al., 2013).

The first question in the second interview was 'are you employed?' Interestingly, all of the six individuals who took part in this study said that they were not employed. The next section provides further details behind this answer. The discussion of this examines the reasons they gave for their lack of employment, the jobs they would prefer, any previous jobs they have had, their particular difficulties with jobs, and their sources on income.

5.3.1 Reasons for not having a job

All of the participants at the time of the interview stated that they were unemployed. This is consistent with the literature. For example, in 2009, a study by the National Autistic Society in the UK revealed that only around 15% of individuals with ASD were in full time employment, while the rest remained unemployed (Redman et al., 2009). Moreover, the reasons behind not having a job varied between these individuals.

Two of the interviewees stated that they were still in the process of looking for a job. They said:

'I am seeking employment. I just haven't currently got one.' (David)

'I've only just left school so I'm still looking for a job, or training.' (Michael)

Another interviewee was unemployed because he had a health condition, which impaired him from working. He stated:

'No, I can't work because I've got... umm... have you heard of MA? It's a sort of another name! People more call it Chronic Fatigue. Yah, it's more like that.'
(Edward)

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Jasmine on the other hand talked about her struggle with getting a job, the stress of job interviews, along with her lack of qualifications, which had always ended up with her being rejected. She said:

'After school by myself I sent out several CVs to people with plenty of rejection letters that followed. I went to a few interviews but they always made me nervous. I really don't like interviews. There's a lot of pressure. I felt like again that I had to please them, that I had to be a bit impressive but I knew I had to be truthful at the same time, so when I was in an interview I was trying to be both impressive and truthful at the same time but you can't hold on to both without ending up reverting to your truthfulness. Because no one can live without being truthful, if you lie about who you are then you just don't get the job you want. I mean you don't feel like you deserve the job. But yes, I was always scared of not being up to scratch because of my lack of qualifications in school.' (Jasmine)

Charles revealed that he does not have a full-time paid job, but he had an unpaid job in order to gain experience:

'No, but I have formal work experience of up to fifteen hours a week.' (Charles)

Charles continued by explaining that he felt the primary reason for his unemployment was due to having a number of characteristics that employers would not be keen about. This made it very difficult for him to find a suitable job:

'it's just trying to find something where one... they're willing to accept somebody who can be critical; somebody who has problems with moving their hands for the very fine delicate movements; has problems with maths; a one finger typist because I can't control ten fingers to type... because that's as good as my manual dexterity is. If you can't count; you're a one finger typist; you're critical, you're sort of running out of job options.' (Charles)

All of these individuals were still looking for paid jobs: one of them had a health condition which made finding a job difficult for him, while another was involved in unpaid work experience to prepare him for a job. Others were having difficulties in finding the right job according to their unique characteristics. The next section will be about the previous jobs that some of these individuals had.

5.3.2 Previous work

Four of the participants have worked previously. The jobs that they have had before varied but they were mostly low paid jobs, or jobs that were based around their interests. For example, two of the individuals listed their former work:

'I've had cleaner, cook, sales assistant. I'm just trying to think what else, warehouse assistant. I've worked in an office briefly. I've done like mail clerk sort of things as well in another office. Yeah, I think that's about it really, I've also had work experience like as well.' (David)

'I have worked in Tesco's, on the tills, and I have worked as a trainee chef in a hotel... I enjoyed both of them, they were very helpful.' (Edward)

Jasmine explained her job role at Dimensions, which is a support network for people with autism and learning disabilities in the UK (Dimensions, 2015). Jasmine worked part time, doing a simple and straightforward job, which could be because they were aware of her ASD characteristics, and her strengths and weaknesses. She said:

'Well, Dimensions had me work for them only two hours a week at their office. What I did was, I was an office assistant and they do reviews annually with their support clients, and it was my job to type them up but also to add individuals, you know decorate them the way the person who had the review would like it. Let's say they interviewed someone named Gary, and Gary said to me that he would like it to be decorated with footballs or something, I would give it a real football theme. That's the sort of things that I would do and type it up and make it look nice for him and I would either laminate it or put a cover on it, and it was just nice for him. But yes, that was my job.' (Jasmine)

Nevertheless, Charles was in a training scheme that assisted him with preparation for employment. Such a scheme can often be an important means of helping people with ASD make a better transition to the work environment. Following that, he worked for seven years in a gardening position, growing plants, which was related to his personal interests. He explained:

'The first one was a training scheme for two years, which I was actually paid, where I was learning general skills for work: painting and decorating; carpentry; gardening; how to use a computer, all these different things.' (Charles)

'Then for the second year of the training... I was given a year training... working as a gardener, both growing plants to be sold and maintaining gardens, something like this... And that then... when the training scheme finished the employer said, "Well, as

you haven't found somewhere else to work you can stay with me." So I was there for another seven and a half years.' (Charles)

Some of the participants in this study had been previously employed in some capacity, but they were currently unemployed. They had held various jobs, and in some cases for a number of years. In the next subsection we will look at the various challenges and difficulties that they had with their previous jobs.

5.3.2.1 Previous work challenges

Some of the individuals talked about the challenges and difficulties they experienced with their previous work. Each participant had his/her own distinctive experience and particular issues, some of which might still cause difficulties in any future employment, and for which they could need suitable support to enable them to make an effective transition back into employment.

Michael described his previous work experience as being uncomfortable, and in particular his difficulties with focusing on a certain job:

'It had a good feeling to it, but I can't say that I was enjoying it when I was doing it. It was... this is going to sound cold now, but it was... sorry... how would I put it? It was uncomfortable. It wasn't the kind of thing that I would be able to manoeuvre myself socially in, and so I felt uncomfortable with it, because one wrong step... When I'm talking to a friend I can automatically resolve it, but one wrong step when I'm in a business world, as it were, doing those jobs, and it's virtually... that's it: just go and do something else, and I don't really like putting down a job and moving onto something else.' (Michael)

Edward expressed his difficulty with working overtime and how distressing it was for him. This might have been because of his tolerance level or because it was a change in his routine. He said:

'It has nearly pushed me to a couple of melt downs!' (Edward)

Two of the participants talked about feeling discouraged, since having the right support and motivation was very important to them in their work. For example, one of the challenges faced by one of the participants was feeling hopeless in doing the work, as she lacked the support and motivation needed to keep her going, along with feeling timid. She said:

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'I tried to take on other things as well like the newsletter, but I only managed to print one newsletter... I would want someone, whether it's a support worker or someone being supported, to just send their story on how they enjoyed the day and all the fun things that they did to add to the newsletter, but I couldn't get people to do that for me. I guess I should have been more pushy, but I guess I was a little bit shy at being pushy. Other people were so busy you just felt discouraged.' (Jasmine)

For most adults it is very important to feel that they have been able to transition effectively into work and the work environment, and it is also important to be able to remain in employment. The second participant also felt discouraged by the negative comments that were said to him by his employer, and because of his slow work productivity, which may have been due to the meticulous focus he gave to his work because of his ASD. He explained:

'the employer kept turning round to me and said, "You're lucky you're working for me because I'm a family friend and I'm a member of your church, because if you were working anywhere else you would have lost your work because you're not good enough for the work." Because the thing was, we were growing each year over a million plants to sell... so planting a million plants you needed to plant the plants quick and I was too slow. And there were other things as well, where he was saying I was costing him money; it was costing him more in wages than what I was getting... the worth of my wages. So he said, "Anywhere else you would be sacked," and he said, "As far as I am concerned you're unemployable."' (Charles)

Charles also talked about his experience in a previous work context, and the difficulty that he faced was because of his ASD. Individuals with ASD tend to follow instructions and routines closely, and so when he found that something was wrong he reported it, which got him to be fired and unemployed.

'I got a job working at... Dog Rescue, looking after homeless dogs, and I really liked the work. I didn't get on well with the staff though: got into a bit of trouble and then got forced out of that work because my boss was allowing the local builders to dump asbestos on the grounds illegally, and asbestos causes cancer which is fatal, and I reported it, and when he found out he threatened to beat me up. So I lost my work there because I'd reported my boss for breaking the law... sounds like "typical Asperger's": you know somebody's broken the law, you mention, so, then being unemployed pretty well since... for over ten years.' (Charles)

Four of the individuals in this study spoke about their previous work experience and the difficulties they faced with this transition in their lives, which varied from one individual to the other. The next section will discuss the jobs that these participants indicated they would prefer to have.

5.3.3 Preferred jobs

When asked about the type of job that they would prefer to have, all of the participants in this study mentioned simple jobs or jobs that were related to their areas of interest. Such preferences should be noted as an important element of the support that could be provided to help individuals with ASD to make the transition into employment.

Two of the participants revealed that they would like to have an easy straightforward job. One of them suggested that she would like someone to explain in detail and to simplify the job for her. Their comments were:

'I like to find a job that's simple and part time really... I would like to have a job in the supermarket to begin with, you know, just like stocking shelves really.' (Daisy)

'Something straightforward that I could keep my head down and do... Just something that I know that I can do, but If I'm going to be taking any job I would need someone to actually ease me in. They can't... expect me to get on with it. I need to know exactly what I'm doing. Once I do it's a breeze. It can honestly be a breeze for me. It depends on how they want to take their time on me.' (Jasmine)

The other half of the individuals (3 people) in this study, said that they would have a preference for a career that interests them. In this respect, one of them indicated that they liked computers, another one said they would like to be an electrician, and the third indicated a preference for either ecological or autism related jobs. They said:

'Something with computers, or maybe something sciency.' (David)

'I would love to be an electrician... I'm not really motivated by money, so any high paid job or high stressed job really wouldn't suit me, and I'm not really motivated by material possessions either... I think just something that would make me happy. So yes, an electrician, or something.' (Michael)

'Well the one I've got at the moment is ideal because I'm counting butterflies on nature reserves. Ideal work, because I can recognise butterflies and I can count... well, that way, at least, I can. So ideal job... When I then go for an ecological job in the future' (Charles)

'I would be happy to have a full-time job doing autism awareness training, travelling around explaining what it is and how I think people with autism should be handled' (Charles)

Michael continued by stating the type of work that he would also like to have that suited the characteristics of his ASD. Thus, he outlined his preference as follows:

'So, a job that I keep on doing the same thing every day is nice because it provides a pattern and I really like patterns. I think that's also a nature of autism, as well, that you tend to like patterns and rhythm and everything fitting together quite nicely and looking good. So that's what I want to do; I want to do something that everything can look quite nice and so... yes, everything will fit together nicely.' (Michael)

Therefore, there was a general preference for ideal types of work that were both 'simple' and straightforward or with a clear structure and routine. For some of the individuals in this study, there was also a preference for work that was closely related to their personal interests. The next subsection will explore some of the voluntary work that these individuals had previously been involved in.

5.3.4 Voluntary work

Four of the participants had taken part in voluntary work, which has the potential to be a practical step that can help to prepare them for the transition to full-time employment. Some of the people considered doing voluntary work to keep themselves busy, or to feel valuable in the community, and also for the sake of gaining some work experience.

Michael stated that he had volunteered a couple of times before. This was either to keep himself occupied and to make better use of his spare time, or to get some experience that would be good for him to add onto his CV. Such experience would also be helpful for him to make a future transition, at some point, to a full time job. He said:

'Yes, a couple of volunteer work, a couple of times a friend dropped out: "Can you help?" and sometimes, "Can I work here so that I can put it on my CV?" that kind of thing... Well, it's just time that if I don't use it there I'll be using somewhere else, so I may as well use it there.' (Michael)

When asked about voluntary work, one of the participants talked about his volunteer work and his role on several autism-related boards. This made him very aware of his ASD, and had encouraged a desire to help others affected by the same condition and to spread awareness and make their voices heard.

'I'm on the Autism Partnership Board for [town name], which is a partnership board set up by the council with various different trusts such as BAS and NAS, you know, like National Autistic Society and Berkshire Autistic Society. And they've got the heads of the various different departments. I'm also on the Safeguarding Forum Board or panel, whatever you want to call it... I'm also on the Health Watch Board

for [town name]. And I'm also on the Advocacy Group for Autism, which Just Advocacy does.' (David)

Another two of the individuals talked about their experience with voluntary work, which they liked and which they found kept them busy. They said:

'I had a gardening job, a gardening voluntary job. And I also worked in a couple of preschools, to assist the kids, and also I've done like a joint voluntary job with another student, and this teaching system which take us to counsellor's office in which we'll help out doing things in the office, like dealing with envelopes and all that... I am going to be doing dog walking soon with my support worker.' (Daisy)

'I volunteer at this community... this gardening project, but you see the problem is only the transportation... I'm going to look into whenever I can, so hopefully I'll get up there whenever I can because I'd like to do it a bit more regularly and try to go out the house and give mum her space from time to time.' (Jasmine)

In this subsection, the participants talked about their varied experiences with voluntary work. Such voluntary work can be a useful step towards the transition into their adult life and employment. It is interesting to note that most of the (albeit small) sample had some experience of voluntary work. In the next subsection, the analysis will explore the individuals' sources of income.

5.3.5 Sources of income

All adults need a source of income to transition to adulthood and to live an independent life. All of the participants in this study were in receipt of benefits as their source of income since they were all unemployed. They stated:

'None really, like I don't get any money off family. The only money I have coming in is benefits, like I get a little bit of DLA and I get a bit of Jobseekers'... Jobseekers' Allowance and Disability Living Allowance.' (David)

'Benefits, yes, I'm on loads. Disability living allowance; Low Care Component; Employment Support Allowance, which is basically unemployment benefit with extra because you're disabled; Housing Benefit; Council Tax Benefit. I've also got funding for personalisation from social services, which pays for trips to nature reserves and things and pays for my travel costs to church, etc., on the idea that if I'm doing things with my specialist interest I might actually be speaking to people and I might actually be socialising.' (Charles)

'I think, it's ESA actually, which is, ESA, Employment Support Allowance, so that's just employment money I get until I get a job... I'm currently living with my mum.' (Daisy)

'Well, I'm not in employment and I've never done a paid job, so I am living off the 'bank of mum and dad' ... I get DWP... Disability Working Pensions, I think it is but, in other words, the government will pay me because I have autism, and therefore because it is difficult for me to get a job or because it is difficult for me to interact with other people, the government is there to support me.' (Michael)

As is clear from this, these individuals received different types of benefits to give them financial support as unemployed people who were in the transition to adulthood. Some had housing benefits or employment support allowances and so on. In some cases these benefits were primarily related to being out of work, whilst others (disability allowances and pensions) were also related to the difficulties they faced in going into employment. One of the individuals also reported that he received financial assistance from his parents.

5.4 Section summary

In this section, the analysis of the results of the second sets of interviews, which were focused on issues relating to employment and income for those people with ASD, was described. The results showed that none of the participants in this study were presently in full-time employment. The reasons behind being unemployed were either because they were still looking for a job, lack of qualifications and support, or because of a health condition. The previous jobs that some of these individuals have had before were discussed, along with the difficulties and challenges that they faced. Additionally, the participants talked about their preferred jobs, their experiences with voluntary work, and their current sources of income (largely state benefits).

5.5 Adulthood and Relationships

The third set of interviews on the life histories of these individuals with ASD focused in particular on their experiences of transitioning into adolescence, adulthood, relationships and friendship; a very significant initial step into adolescence is puberty. Puberty (and more generally adolescence) is also usually regarded as the preparation stage for adulthood, in which the person will have to cope with and handle several changes that usually occur in his/her physique, some of which are directly related to his/her sexuality. During this time, they need to learn about and develop acceptable social abilities to help them develop significant relationships and friendships in adulthood, and employment (Crockett & Crouter, 2014).

5.5.1 Transitioning to Puberty

Reaching puberty and being an adolescent is often a challenging time for all individuals. However, as discussed in chapter 3 (section 3.4), the transitions of puberty and adolescence are very often particularly challenging for individuals with ASD (Tantam, 2003).

5.5.1.1 Puberty experiences

Each of the individuals interviewed had their own distinct experiences of reaching puberty. For example, Michael stated that he had found adolescence a difficult transition, but as it was for everyone else. He said:

'I believe it was like everyone else's. I do not believe the process was any different with me... I believe it was a hard transition but I don't think it is an easy transition for anyone.' (Michael)

Nevertheless, Michael continued by stating that he had suicidal thoughts during his transition to puberty, which he thought was normal and referred to it as just being 'temporary'. He stated:

'Going away from, in fact, maybe staying with. Most people, when they go through puberty have thoughts of suicide. I was one of those people as well... Most of the time at puberty when the world is going to end, as it were, it's really just a temporary thing...' (Michael)

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Two of the participants mentioned their difficulties with managing the transition to puberty and how things changed, along with feelings of anxiety, pain, and the different transitions that followed during adulthood, which made them worry:

'when things changed for me, like not just physically but mentally and I just felt myself completely changing and even changing my mind about certain things like, than I felt before' (Daisy)

'It wasn't bad, although I just get a bit anxious because, again, it's change, and when I had my first pains I didn't really handle it – I was kind of all over the place.' (Daisy)

'Puberty was when I was 13 and... in Year 10, that was when the anxiety disorders happened. I just don't know what ticked off in my head, maybe it was the sudden feel of changes, you know, when you are young, when you're a young child, you don't have to worry about many changes, you just let people take care of you, but then it starts to dawn on you, I think it must have started to dawn on me, that things were going to be changing in the future... Maybe a lot of scenarios came up in my head, marriage and things, excitement about being liked and I think, unconsciously I thought of the events that could follow... dating, marriage, sex, living together and I think it must have scared me very deeply and now every time I see something different or overwhelming or scary, I just, I get really scared. It gets scary for me and makes me shake.' (Jasmine)

The topic of puberty, and particularly the changes related to sexuality that are associated with puberty, might be considered as a taboo in some families, or some cultures. Thus, another participant brought up how difficult this transition can be for some people, particularly in cases where it may not be addressed. He related this to the frequent lack of support and guidance that is necessary in this area, to help such individuals to make the transition to adolescence. Edward said:

'Puberty is absolute hell ... When the problem is, it's not talked about. And still there are children aged 11 years old and that, and they are finding it absolute hell, and where to get help.' (Edward)

All of the participants talked about how challenging they found the transitions associated with puberty. During puberty individuals go through psychological and emotional changes (Hénault, 2005), which some of the participants found difficult, confusing, and made them feel more anxious.

In this section, some of the issues that the individuals faced in their transition to puberty are explored, and the following section will explore the support that some of them have received during this phase in their life.

5.5.1.2 Help during transition to puberty/ sexuality

It is very important for all children, and especially those with ASD, to receive help during this particular transitional phase of their lives. Some of the individuals were able to find some support during their transitions to puberty, in particular in learning about their sexuality, whilst others did not.

Two of the interviewees talked about the help that they had during transition. One of them mentioned the help he was given at school, in teaching him how to become independent. For example, learning self-help skills that are needed during puberty, instead of having someone who would help you do these things. Another participant mentioned the help provided at her school during puberty, through sex education classes. They said:

'I went to a really good (school name) [special school]. They helped me... Taught me to be independent really.' (David)

'I had sex education in year six, but I've also had it again, so I've basically had a recap on it.' (Daisy)

Edward on the other hand learned about sexuality visually, mostly through observing and trying to understand the changes that were happening to his naked body. He felt that he would have found any other explanations of the changes (such as through classes or books) too abstract and difficult. He stated:

'I think that where professionals are going wrong these days, is that... umm we don't learn by looking at papers, magazines, books... it helps us a little bit. But we learn, we understand by seeing things that are right in front of us, like my son is learning, and I have learned how puberty is and how we grow up and that, by being naked and being nude, because it is right in front of us.' (Edward)

'One of the ways that have helped us is actually, we understand and learn by books and that, but that is not possible with us with Asperger's or autism. We see what is right in front of us, and this is how we learn and become aware is right in front of us, face to face. Whether it is a person's body or picking up a fork it has to be face to face.' (Edward)

On the other hand, Charles discussed how his family helped by being open about the topic of sexuality, and reading a useful book about transitioning to adulthood, which is the opposite from what Edward had stated was useful. He said:

'Physical changes I was already aware of, because I was already keen on biology etc., and my foster parents weren't embarrassed once it came to me wanting information on sexuality etc. So, I've still actually got at least one of the books they bought me which was everything a teenage boy should know, which explains what the transition into adulthood was like, and what affect it's going to have on relationships; how your body is going to change.' (Charles)

In this section, four of the participants shared what helped them with the transition to puberty and understating sexuality. Some of them mentioned sex education in schools, talks with their family members regarding this matter, and learning from books. This illustrates the highly individualised nature of support needs, where 'one size does not fit all'.

The following section will now go on to discuss the significance of the relationships that the individuals establish, in particular with family and friends, and the importance of these relationships in a person's life during the different transitions from childhood to adulthood.

5.5.2 Relationships

Arguably, the most important types of relationships that people have are family relationships and friendships. These relationships are essential in everyone's life, and in particular they can be very helpful during the different transitions that a person goes through in his/her life. Most people need someone to help them go through such transitions, and being part of a supportive network, whether it is family or friends, is a very important part of their management. Human beings need company and usually prefer to be with a group. That is, human beings are designed to be with others. For people with ASD, such social interaction can be more difficult and they can have an even greater need for someone to help them to navigate their relationships and the changes in their lives, and to help them to understand social rules. This includes the successful management of transitions, the management of school, and having someone to support and steer the individual in the right directions.

Interestingly, when the interview participants were asked about their relationship status, only one of the six participants in this study was married, while the remainder were single. Because it can be noted that in previous literature, meaningful relationships such as marriage, are desired by some individuals with ASD, however, these types of relationships have been found to be more challenging to develop and manage compared to friendships (Sperry & Mesibov, 2005). Some of the individuals in this study talked about the difficulties of having these relationships, but one of them managed to find a wife and get married.

In this section, the different experiences of the family relationships and friendships of the participants will be discussed.

5.5.2.1 Family

Important relationships that a person might have are his/her relationships with family members, such as parents, siblings, grandparents, or even uncles/aunties and cousins. Half of the participants (3 adults) in this study talked about their close relationships with their family, how important their families were to them, and how they offered them significant long-term support.

Michael detailed his close family members, and described how they were fun, and good listeners when he needed to talk to them. He stated:

'I guess close people in my family: I have to start with mum, dad, sister, my granddad and grandmother... I think one of my uncles... I think those are the people who are close to me personally... I have one, my sister, who's at University... Yes, too close... She is very strong-minded, as it were. She's unique... it's fun.' (Michael)

'They were great walls. When I say 'wall' I don't mean protective. I mean I would be able to talk to them about what I felt and they wouldn't so much provide me with ideas... The best ideas that I get come from me. I get ideas from outside but, yeah, they've been very good sounding boards.' (Michael)

Daisy also listed her close members of the family, and she talked about how her family were supportive, encouraging and trying to help her to be more independent, which is a very important step towards transitioning in adulthood.

'I've got my mum and my sister to start with – I live with them so I'm quite close with them; and my grandmother – I visit her quite a bit and she comes over; and I also have cousins around here as well that I see quite often.' (Daisy)

'They always encouraged me by talking to me or showing me what to do or how to do something – they'll do it in a way to encourage me. Recently me and [sister's name] and my mum talked – Mum put in the idea about me and [sister's name] moving out so we would have a bit more independence, and me and [sister's name] quite liked that idea... They're quite important to me, yeah, because me and my sister and mum have always been getting along with each other, because we've always lived together and my grandmother as well – we all get along very well and we do a lot of things together.' (Daisy)

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On the other hand, half of the participants (3 adults) did not have close relationships with their parents. One of the participants, when asked about his close family members, and if they were helpful, he just said:

'Nope... not really' (David)

Edward revealed that he was not close with his parents and that he managed to cope on his own during the different transitions in his life, without the support of his family. He said:

'Not really, my own parents are about 200 miles away... Well, I rarely saw them, my parents! Because my dad was in the army and it was in different countries, so you know, so I just coped on my own and it was rarely talked about.' (Edward)

Edward was the only married participant in this study. He was not close with his parents, however he had a closer relationship with his own immediate family such as his wife and children. He disclosed that his wife was supportive and accepting. He stated:

'Both me and my wife wanted to have children. So we've got 2 boys and 1 girl, and we both wanted to get away from our parents and have a life of our own, and it's having my wife there, the understanding that I have never had from anybody else at all.' (Edward)

Another participant, who was fostered by a family from a young age, talked about his experience with the family, and how their relationship was broken. He stated:

'It's got to the stage now where my foster dad is all but refusing to speak to me, and on the rare occasions when my foster mum phones me... And it can sometimes even be nine months since either of them have seen me or spoken to me... It's a case of – I had made the relationship that bad that they don't actually want to end up making the time to come and visit me.' (Charles)

Some of the participants in this study talked about having close relationships with their parents and other members of their family, such as grandparents, siblings, and uncles. They said they found these relationships helpful, since they considered these family members supportive. However, half of the participants did not have close relationships with their family and they managed their own way through the different transitions of their lives. For some, a lack of positive family relationships were seen as their fault, either because, as with Edward, his family lived far away from his home, and he seemed busy with his own wife and children.

Charles however, felt that this was his fault because of the way he was in relation to his ASD and this explained why they no longer visited him.

The next sub-theme will examine the participants' friendships and the difficulties that they face in order to make friends, and sustain these relationships.

5.5.2.2 Friends

Previous literature indicates that individuals with ASD have difficulties making and sustaining friendship (Mazurek, 2014; Petrina, Carter, & Stephenson, 2015). Only two of the participants spoke about their friends, and their ability to sustain these friendships. They said:

'Yes but I have still got childhood friends as well... I have also expanded my repertoire.' (David)

'Yeah, we have quite a few friends who are on a similar spectrum to us, so me and [name] fit in with people more since we found people who are similar to us... Sometimes we invite them around our house for a movie night, or we will go out bowling, or to the cinema, or out for a meal.' (Daisy)

Thus, Daisy stated having friends who also had ASD, with whom she spent time by doing various social activities. This potentially reflected their need to have friends who could relate to them and be more understanding, because they shared the same condition.

A further two of the individuals in this study talked about not having close friends, although they said they had friends or acquaintances for a specific reason or interest, for example to play sports with or to attend purposeful meetings.

'I have acquaintances who interact with me for a particular purpose, like, for instance, church, natural history study and my Autism Awareness thing. I have more people who I interact with for a particular function; I wouldn't actually really say I have any real close friends.' (Charles)

'The only time I'm not that alone is on Fridays and Wednesdays when I play sport and there's a good fifty or sixty or so people I play with, who I'm friends with. I never want to do anything unless I feel it is necessary for me to do it. Therefore, I never really meet friends unless I need to.' (Michael)

Nevertheless, Jasmine expressed her difficulties with making friends, and she stated that she would like to at least have one friend, and that she had been working on making friends and organizing meet ups. However, so far she had been unsuccessful with this, since the people

she invited were unable to attend, and thus she felt she would have to be more understanding. She said:

'It would be nice to have at least one close friend but it is – that is another thing everyone else has their own schedule too and people do not have a lot of time to spend with each other.' (Jasmine)

'I really have been trying to make friends. I have been arranging for group get togethers and for people to come out but they cannot do it all the time because they have to spend money. And they tend to have lots of things that they have got going on anyway. And so I have to try to be understanding of that.' (Jasmine)

Moreover, Jasmine spoke about her worries of what others may think of her because of her autism, reporting a sense of 'difference' in her, and how it is difficult for her to make and sustain friends. This might infer a level of fear, and anxiety, which also might result in isolation. She revealed:

'I do worry about what other people feel and think. And I just don't know, I feel as I get older this autism sets me even more apart and makes me worry even more about other people, and whether they actually do understand me. So I do not make friends very easily because I am like this... because I am dealing with so many emotions and because I worry too much and I have to and I am trying to get, I am trying to and I have to deal with my autistic melt downs.' (Jasmine)

Additionally, Edward declared that he had no friends. He said that he would like to have friends but he found it difficult, which could be because he did not know how to make friends, and due to his social impairments that were related to ASD. This was demonstrated in Edward's self-awareness of his condition, when he stated that because of his ASD characteristics people were not friendly to him, as he was also bullied in school; largely as a result of a lack of awareness and help in the past. He stated:

'Yes, anybody does, but with Asperger's syndrome it's, you know, very difficult. People are often saying things that you haven't said and, you know, turned against you, so it is difficult... I was just mostly being bullied and that, because people weren't aware then...' (Edward)

'I didn't have like real friends, I think that was a very big setback as well' (Edward)

Only a few of the participants spoke about the importance of these friends in their lives. The others largely spoke about the difficulties they faced with making and sustaining friendship. Two of the participants mentioned not having any friends. This shows how challenging this

area is for these individuals despite how important they feel relationships are in their life. Participants consider relationships as key; yet consider themselves to have social impairments that make it much harder for them. Some anxiety and stress in this area was apparent, and it highlights how very crucial it is to help people with ASD to develop and sustain significant relationships in their lives. Moreover, the next sub-theme focuses on the individuals who expressed that they would prefer to spend their time alone.

5.5.2.3 Being alone

Half of the individuals (3 adults) indicated that sometimes they prefer to spend their time alone.

'Yes, I like to have company but I am not really fussed. I guess I just get on with it if I have not.' (David)

For example, two of the individuals stated that they would choose to spend their time solely or when they feel overwhelmed. However, other times they do not mind spending time with friends, which is sometimes needed to communicate with others and makes them feel more confident. They said:

'This is a double sided answer because both. I would primarily prefer to be on my own but I would not be able to survive on my own. I need to talk to people. I need to be there. I prefer being with people but I'm an introvert so after about four hours with a person, I usually can't stand them anymore, which I know, sounds bad but I'm just not that kind of person. At that point I'd really want to be on my own. There's only so much conversation I can take.' (Michael)

'Sometimes, but if I feel overwhelmed I like to have a bit of alone time. I used to be more nervous around people when I was younger, but over the years I've learnt to talk to people with more confidence.' (Daisy)

Three of the adults in the study spoke about their preference of having some time alone for themselves whenever they needed it.

5.5.2.4 The importance of friendship

Friendships are important and considered valuable in everybody's life. The ways in which these individuals with ASD talked about the importance of the friendships in their lives gave very interesting insights into how they managed the various transitions in their lives.

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All of the participants in this study talked about the importance of their social relationships. Michael mentioned the value that these friendships brought to his life during the various transitions he went through, since a friend could often be a good role model, or someone that you could learn from. He said:

'How important they are? They're invaluable... Oh my. They're good guidance because when you have people who are your age and you're adapting, as it were, it's useful to have a template for what you should be or where you should be at. So that's what you have your friends for. They're useful for keeping you as you are. At the same time it's useful to have people who are older than you so you can see what you want to do, where the future should be going and what changes you should do about it because, in the end, it's all about perception. If you can understand how other people see the world then, if you can mould your own view to see that then you should be able to change yourself to be something like them. In the end, now, not everyone would agree with being normal. Lots of people like being extra special with stars. Being normal is a gift that not many have or not many have the gift of having.' (Michael)

Michael continued by giving an example of how one of his friends had helped him to improve his gait:

'Apparently I used to walk funny and one of my friends pointed it out to me. Apparently my arms used to sway left and right. My friend said: don't do that because it makes you look weird. So I stopped doing it.' (David)

Jasmine stated that these friendships are very crucial; therefore she would like to make friends and sustain these friendships since she tended to feel lonely sometimes. However, she found it difficult due to her problems with socialization and the lack of opportunity. She also talked about her fear of losing confidence in people and also the particular importance of the potential for developing these relationships further, since they might lead to finding a husband. She stated:

'They are important to me because I do get to feel a little out of place and lonely. People spend more time communicating by technology and I don't feel like I get enough face-to-face time. If I don't get enough face-to-face I'll lose confidence in myself and people and faith in them too. My friendships aren't great at the moment because I don't get to see them often enough, which is sad for me, I need to make friends, especially when I'm looking to date, I need to have a friendship first but I'm lacking in social opportunities a little badly at the moment.' (Jasmine)

On the other hand, David stated that these friendships were important and helpful in a way in his life, although he had difficulties explaining the value of friendship. In fact, he made some

contradictory statements, since he said that sometimes he liked to be with friends and sometimes he did not like to be with others. He said:

'I do not know really. I guess they just help me be me I guess. I don't know I cannot really pin it into words as such. I don't know... I guess the relationships are important but it is from a different perspective maybe like a different viewpoint to what you have got. It is hard to explain it. I guess I do miss people sometimes but I do not always like really connecting with people.' (David)

Moreover, Charles talked about the possible effects that the lack of these important relationships could have on a person, since these different relationships and friendships could help people to navigate through the transitions in life. He felt that one of these relationships could lead to marriage, although in his case it had not worked out and he had been devastated by this. He said:

'It's been very important because when I've been suffering from the severe depression has been where a fairly good relationship of some sort or other has collapsed. I ended up in a mental hospital because of breakdown of relationships: I was being bullied etc., then ended up losing the gardening job because of the problems I had. The first person that I had ever fallen in love with, so she wasn't willing for anything more than good friends when I'd fallen in love with her. So, yes relationships have played really crucial points because they've been the bits which have quite often led onto very significant changes in my life, like, I actually now know what love is, for the first one... that was the lady... Yes, very important, when I get them, but few and far between.' (Charles)

Four of the individuals in the current study talked about the value of these relationships in their lives during the different transitions. The next theme is about the transition to adulthood regarding some of the challenges that these individuals might go through, and their feelings concerning becoming an adult.

5.5.3 Transition to adulthood

Transitioning to adulthood can often be a challenging time for individuals with ASD. And this was reflected in the interviews, since three of the participants mentioned that transitioning from childhood to adulthood had been challenging for them.

For example, Michael said that this transition was an essential process that everyone goes through, but it was a challenging one. He said:

'So the transition is definitely a scary and uncomfortable process, but it's necessary.'
(Michael)

David found the transition especially challenging because of his condition, which became more apparent when he reached his adolescence years. He said:

'Very hard, I thought... I didn't really need any help with my autism until I was older, with the transition from adulthood – well young adult.' (David)

David continued by stating that individuals with ASD need more guidance and support, because of the sense of helplessness and feeling lost without help during the transition to the adult years. He explained:

'There's not enough done to help us, I find. I'm not just the only adult. A lot of us we don't know where to go or what we're meant to be doing. We're just like lost sheep I guess you could say or we're lost in the dark. We've got skills and talents some of us have to give to the world but we don't know how to go on to do the next stage or progress our career or start the right tracks on our careers. I've noticed a lot of us – that's how I feel as well.' (David)

Daisy was feeling anxious about her transition from being a child to an adult, since she felt it was something unknown for her. These anxieties could have been because she was not adequately prepared for that transition in her life, and that had made her feel worried and confused. She said:

'It's quite difficult, it was quite difficult... because when I am going from childhood to adulthood, change to an adult is something I am not familiar with so I just felt quite, I got a bit nervous about it because my life is moving on and I'm at that stage where I am changing and I'm quite confused.' (Daisy)

5.5.4 Feelings about being an adult

The transition to adulthood involves the individual in taking on different responsibilities in life, which can be particularly challenging for individuals with ASD. All of the interviewees in the present study were adults, and their ages ranged from 18 to 51.

One of the interview questions that was asked was: *'How do you feel about being an adult now?'* Two of the participants declared that on reaching the age of 18 years they felt they were becoming adults, but sometimes they feel confused, scared, and they had mixed feelings towards this transition to adulthood. Charles said:

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'Maybe it was pretty easy because I knew in Britain, from the age of eighteen, you're deemed to be an adult, I knew that by law you're allowed to leave school at the age of sixteen, so it was fairly easy.' (Charles)

Charles, a 45 years old male continued by speaking about his worries after leaving school and transitioning to the adulthood, such as the transition to work and having different relationships with people. All of these different upcoming transitions to adulthood left Charles wondering about his future and feeling afraid of the new life and routines. He said:

'Looking forward to it, frightened, because being at school I was used to the environment, I knew how I was supposed to behave – coming out into somewhere else where I was going to have to learn a new routine, meet new people, learn new things – am I going to fit in? Am I going to find somebody who actually likes me, for once? It was a mixture of one: fright, fear – looking forward to a new change – thinking: "I might actually be able to earn some money – I'm going to actually spend my own money, rather than having to wait for other people to give me money," et cetera – so very mixed.' (Charles)

Daisy also knew that she became an adult when she reached 18 years of age. She stated that she was afraid of that transition to adulthood. She said:

'How did I know I became an adult? When I was about 18 and, no when things changed for me, like not just physically but mentally and I just felt myself completely changing and even changing my mind about certain things like than I felt before... It's kind of scary but that's quite normal for everyone, but it is quite a big change but I'm, it's, I'm happy at the same time, because I'm a full on adult now.' (Daisy)

However, half of the interviewees (3 adults) cited that they still felt that they were not adults yet. Some of them said they felt like children, while others just still felt confused. They were also asked, "if they reached the acceptance of being adults?" and this half of the participants spoke about their difficulties of accepting themselves as adults now. For example one of the participants stated his confusion and his difficulties with accepting that he was now an adult, along with having the sense of still being a child rather than a grownup. He said:

'I still don't know [laughter]. Even now I just have to look in the mirror sometimes, and I still don't really accept it. I still feel like a kid.' (David)

David explained that his feeling of still being a child was because he still wanted to have fun and enjoy his time, instead of being an adult, which he found boring probably because of the responsibilities that comes with reaching adulthood, such as being employed. He said:

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'Well I seem to have the way the world should work, the value system of an adult – I've always had that – but I just seem to want to have fun and things like that, whereas adults seem to be always boring and work really hard. Don't get me wrong, I can work hard but I want to play as well. Maybe it's me and people outgrow it as they get older or they forget that it's important to have fun as well as work hard.' (David)

Michael was also confused about whether he felt like an adult yet. He said:

'Considering my maturity, I'm probably not an adult [laughter], but I seem old and I give good advice. I don't think I'm an adult yet, I'm not sure.' (Michael)

Additionally, Jasmine expressed her feelings of not being an adult. She felt that mentally she had not reached adulthood even though she physically looked like an adult. She explained:

'I don't think I'm an adult yet. I don't know, in my mind I don't think I am. I mean I appear to be, but when I was in my teenage years – I mean I've heard this sort of theory where I think meant – I may have grown physically, but I think I grow slowly mentally I think. Because for a while I've been treated like a child and I would act like a child. I was always goofing off and being silly and people just looked at me like I was a child.' (Jasmine)

When Jasmine was asked about her acceptance of being an adult, she admitted that she actually felt like an adolescent even though she was 25 years old. Jasmine also stated how people would expect things from her because she is an adult, like finding a job or driving, which made her feel pressured and anxious. We might infer from this that Jasmine expressed feelings about her lack of power and barriers to identity. She said:

'No I don't think I have, no, no. I would say I was a teenager really, to be honest, yeah.' (Jasmine)

'I don't know. As I've already said, I don't feel like mentally I am an adult. Because when I want to go for something, like if I want to go for a driving test, because there are people around me now, they look at me, they see me physically as an adult, but I have this weird – you see, because I'm a people pleaser I get myself upset because I'm not what people want me to be and then I pressure myself in trying to do things like learn to drive or get a job. But my mum and someone else close to us stops me and says to me that you don't have to do these things just to make yourself a more appealing person, to make yourself look like an adult.' (Jasmine)

Furthermore, Jasmine expressed low self-esteem believing that she cannot achieve other people's expectations of her, she is also afraid of failure and letting people down. She also continued by expressing her concerns about what others might think of her because she did not see herself acting like an adult, which creates worry because of the expectations and

perceptions of others in the community. Another concern was that she still did not feel ready for adulthood because she was not prepared for it. She said:

'I don't know, I'm worried that people will look at me as an adult and see who I am and think that I'm not acting, that even though I'm an adult I don't act like an adult. They'll wonder what is wrong with me. They'll think I'm rather strange. So yeah, I've just been getting upset with people expecting more of me than I was really equipped for. I don't feel equipped for adulthood really yet. I'm just trying to do my everyday routines, just try to keep busy, try to keep going.' (Jasmine)

The individuals in this section talked about their worries and concerns of transitioning to adulthood, and how some of them felt they had not been accepted as adults and they still felt like adolescents or children. In particular, they mentioned that it would be helpful to be given more effective preparation for adulthood. This matter will be discussed in further details in the Discussion Chapter 7.

5.5.5 Transition support

Individuals with ASD go through different types of transitions in their lives, and they need support and guidance throughout these various transitions. The participants in the current research spoke about some of the available support that they had during some of these transitions, while lacking other kinds of support during other transitions.

5.5.5.1 Good support

All of the individuals in this study pointed out some of the support that they had during some of the transitions in their lives. Some of the support that was available for these participants was help from school, family, friends, and the government.

Three of the participants talked about good support and help that they had in school, which had been very useful for them making their transitions. For example, David mentioned the help that he had in his special school that helped him with the transition to college, along with the support workers. Although, he did complain that the support was only with this certain transition to college and it stopped, while he struggled and needed more support after that. He said:

'Like at my [school name/special school] they helped us to get to and from the College. Basically they had a site for us to live on but they let us go to mainstream College with a support worker and that and they had close connections with the

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College tutors and that really helped, and they helped us for the most part with the transition. They just obviously could only do so much and people never picked up where they left off really with me, so I sort of had to muddle my own way through life and existence sort of thing.’ (David)

Charles also talked about the help that he had from his special school, and the support that helped him with the transition to college.

‘the special school, that one helped a lot on the academic side, because they had the knowledge, experience and techniques to help somebody.’ (Charles)

‘My school helped, because they sent me off to college to learn a trade... “Well, I’ve actually got this”, and I learnt, basically, what college was like before I’d left school, because I’d already been attending college one day a week, so when I then was going to college after school, I already knew what college was like, which helped.’ (Charles)

Additionally, three of the participants also talked about their family support, which was very crucial to them. Charles talked about all the different support that he had during his transitions in life, one of them was the support from his family, with teaching him daily life skills that helped him when he lived on his own and in his everyday life. He said:

‘my foster family, because they were still willing to help me try to learn skills – for instance they tried to teach me to cook, failed miserably, but they tried – they taught me house-cleaning, et cetera; they also helped me understand budgeting, et cetera.’ (Charles)

Having someone who would accept you as you are could be considered as a form of support, as Edward spoke about the understanding and support that he had from his wife. He said:

‘That would have been my wife. Who sees who I am and not what other people mostly see me for, just a disabled person! Both me and my wife wanted to have children. So we’ve got 2 boys and 1 girl, and we both wanted to get away from our parents and have a life of our own, and it’s having my wife there, the understanding that I have never had from anybody else at all.’ (Edward)

All the participants brought up some of the organizations, support groups, and social services that helped them in some way with the different transitions in their life. Jasmine talked about the guidance she had from support workers and Dimensions (Dimensions are an organization that supports people with varied disabilities in the UK):

‘Oh yes the support workers, because I was with Dimensions for a while and they did help me with some of the cooking and things. Dimensions, they’re a support company

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that support people with certain types of autism or mental or physical disabilities.’
(Jasmine)

Charles also spoke of the organizations that helped him and taught him about his rights (for example, help with accommodation, and social services in relation to benefits, and welfare rights). He stated:

‘Also having the acceptance, to large extent, was Be Heard – the local self-advocacy group for people with learning difficulties and autism – they provided a lot of the training for what are your rights, what are you entitled to? So I learnt a lot there, and they were pushing a lot for people to stand up and say: “Well this is how I want my life to be, I should have say.” So because of that pushing and training I’ve had from Be Heard, now the university lecturer at two universities on autism, it was as a result of what I had been doing with Be Heard... I had lots of individuals, institutions, et cetera, who did their best to steer me in the right way, so I’ve had lots of influences.’
(Charles)

In addition, Charles continued stating the help he had from social services, and he interestingly highlighted that some of the support he received during transitions in his life was because he was adopted and not because he had autism.

‘also social services – because I was a foster child – they were saying for about two years beforehand – before I left school – “What do we do with [Charles]? Does he stay with his foster family? Do we help him to do education? Do we help him to get a job?” ...So yeah, I had been living on my own with very limited support at that point, so social services found me the training scheme when I left school, et cetera, and they made sure that local government were made aware that I was in care, so should be allowed council accommodation earlier... The support I had, basically it wasn’t because of my autism, it was because I was a foster child and social services were saying: “We’ve got to make sure that once he comes out of care, he can live.” So that was basically the only help I had in transition – it was because I was in care, not because I was autistic.’ (Charles)

Furthermore, Daisy expressed the help and guidance that she had from social services and an autism related organization, which she felt had helped her become the person she had become and with some of the transitions that she faced, along with teaching her everyday life skills. She said:

‘I’ve had support workers come in and support me so they’ve helped me and they’ve helped me to come out of my shell more, given me more confidence and helping me to have a bit more sense of responsibility... I’ve also joined this group called the Transition Challenge, which they do for people with disabilities, so I’ve learnt a lot of transition skills, so that’s helped me quite a lot. We did things like domestic skills,

house cleaning or, we also did learn a bit more about shopping and more cooking and I think we've learnt about budgeting as well so if we are buying things, we need to learn to keep things under the budget and we just did things like visiting places and going on trips and learning more about responsibilities.' (Daisy)

The participants mentioned a variety of helpful agencies for support, such as school, social services, or other organizations. However, they also noted there was a lack of support in some respects, which is discussed in the next subsection.

5.5.5.2 Lack of support

Several participants also talked about some of the support that had been missing during their transition from childhood to adulthood.

David talked about how he had struggled with explaining his rights to the social services, in an effort to obtain help that he needed. He also stated that an organized structured support system for individuals with ASD would be very helpful. He said:

'Maybe social services, like adult social services, they could get off their backsides and help people more they could because they only do what they're told to do, and the best of times you have to struggle and argue with them and you even have to quote the laws to them. People with ASD and that, they shouldn't be having to learn the law in order to tell a social worker this is what you should be doing for me. They should just be doing it because they're told to do it, or they should be going beyond what they're told to do because it's obvious that that's what needs to be done.' (David)

'Just they need the right support structure and they need people prompting them and telling them what they've got to do in order to get it done.' (David)

He also stated that medical doctors should be more aware, and as well as giving the diagnosis of ASD, doctors should be expected to provide support for individuals with autism, because some people feel lost after the diagnosis. He said:

'Oh, and doctors could probably help more as well I think. They don't do enough. There isn't really anything within the NHS where they help people with ASD. All they do is get you a diagnosis and then they don't do anything after that and that's even if you get it through the medical profession' (David)

Edward stated that people who live in big cities have better support services in comparison with the support and services that are available for people who live in small towns. He said:

'It depends on which area you are living, this is just a small town, and this is a very low area for support and that. You have to go to really big cities and towns to get a lot better.' (Edward)

In summary, this section has examined the available support for the transition to adulthood for individuals with ASD. This support was particularly from family, support groups, friends, or social workers. In contrast, the interviewees highlighted the support they found was lacking, which was the lack of awareness among doctors or social services, and the lack of the appropriate support in small towns.

The next section will discuss the suggested advice that people with ASD gave to help others who are going through transitions in their lives.

5.5.6 Reflections from the inside

The participants in the present study were asked about the advice that they would give to others who are going through the different transitions from childhood to adulthood. The advice that the individuals gave was quite varied, reflecting on their own experiences, which could be very helpful to different people going through the transitions in their lives.

One of the first steps that are helpful for any individual with ASD during the different transitions is having a diagnosis, in order to get the suitable support available. Alongside this diagnosis, though, there was also the suggestion that the person should have an individualized plan, as Charles declared:

'One, make sure somebody's got a diagnosis, because the help I got with the transition suffered a lot because I wasn't diagnosed. They were looking at the symptoms, and there was a lot of help which I could have had, which I wasn't entitled to ... apparently wasn't entitled to because I hadn't been diagnosed. So, diagnosis beforehand. Make sure that help is appropriate to the person; everybody's individual.' (Charles)

Charles continued with further advice, which was to make use of the benefit of advocacy groups that help individuals with disabilities know their rights, and who generally spread awareness of ASD.

'So, there's support which is appropriate, and get them to... get somebody who's going into transition, I would say, fit them into an advocacy group because advocacy groups, if they're working properly, know what support's available. They help to train

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a person what's their rights, what they're entitled to... Everybody needs the full autism awareness training, ideally before they're dealing with the person.' (Charles)

The advice that David suggested is important, which is not giving up, and to try to be a valuable member in the community. He also suggested that people with ASD usually have an interest that they are good at, which could later develop into their profession, and this interest might be helpful for them when they get employed. He said:

'Do not give up. Try and get yourself in a productive environment where you can become a valued member of society because it can be done... Try and find something that you are good at. Something that you are better at than pretty much everybody else and stick at it if that is what you enjoy. But that is one of the most important things... Because then it will not be like work and you will not feel like you are working because that is probably a problem for people with autism and Asperger's that suffer from.' (David)

Daisy recommended that if a person is struggling with the different transitions that a person could face, he/she can seek help from a psychologist, support workers, or autism groups. She stated:

'I would advise – if they're really struggling – maybe to see some therapists. I also forgot to mention that I've seen psychologists and done talking therapies as well, which is quite good. If they suffer from specific anxieties or if they really need to, have support workers help them out, if transition's quite difficult; or join certain autism groups'. (Daisy)

Another important point was brought up by Jasmine, which is to make sure that individuals with ASD are prepared in advance for the next transitions that they will face in life. This would involve them being provided with sufficient information, along with acknowledging their own lives and emotions. She stated:

'Try to take more notice as to what is going on in your life, what's going on with you. Try to take notice of your emotions. Try to understand yourself better because it could only get much worse if, it can't be very good if you try to shelter yourself, it can't be very good when you don't understand and if you can get as much information as you can possible, possibly beforehand, as to the events that come later on in your life whether you're in your late teens to adulthood, that would be very great if you can do that, if you can be more prepared, but no one is ever prepared, no one is ever understanding, no one.' (Jasmine)

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Jasmine continued her advice by suggesting different ways to create information for individuals with ASD during their transitions, such as websites, or booklets. She asserted that it is all right if the person cried, because it might be overwhelming. She also advised individuals to seek information and help from others.

'Sometimes it just creeps up on you. How can we prepare them? You see, if people like you are taking information like this, that would be great if they could, if there was a website about it, or a pamphlet or a book that talks about the transitions and it's good to read up and have a bite-sized understanding of it, but people should not, it shouldn't be the kind of information that should make you worry. No one should ever be afraid, no one should be afraid about what they are about to go through, but don't be afraid to cry if it every does get, if any horrible thoughts or any, or the information that you researched gets overwhelming or too much for you. Just don't be afraid to cry and don't be afraid to keep talking it out to someone you feel very comfortable with and yes, there is nothing wrong with that. You see crying is acceptance, crying helps you to accept what is going on and you can only cry so much before the emotion gets fed up and goes away from you.' (Jasmine)

Edward spoke about the importance of awareness and research, and he advised people to take part in order to help with spreading knowledge, so the community can have greater understanding and awareness of ASD. He said:

'Asperger's and autism is affecting in different ways, and if you don't take part, then how can you expect people to understand, to be aware, and to help... It's something that professionals are missing out. It's same like the subject of sex. I have taken part in 2 researches on autism Asperger's on the subject of sex, and yet there is nothing in this country. It was from Canada and Australia. And I have got the results as well.' (Edward)

In this section, the participants recommended some valuable advice for people going through any transition in their lives. This advice included getting a diagnosis as early as possible, creating accessible information, taking part in research, seeking help from others, joining different autism groups or advocacy groups, and going to therapy.

5.6 Section Summary

This section has discussed the analysis of the third set of interviews regarding relationships and adulthood. The results showed the experiences of these individuals when reaching puberty; along with the challenges, and help they had during this transition period. The interview outcomes outlined the different important relationships that these individuals have,

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which includes friendships, and family relationships, in conjunction with the difficulties they face with making or sustaining them, together with the importance of these relationships.

The participant's feelings and thoughts with regards to reaching adulthood and their acceptance were also pointed out, in addition to the available and unavailable support has also been mentioned. As a final point, the individuals provided some valuable reflections that have been highlighted.

Chapter 6 The perspective of KSA mothers of children with ASD: Results

The current chapter highlights results from the interviews of the second group of participants, which were conducted with mothers of individuals with ASD, and their children's age ranged from 13 to 33 years. The sample was made up of 13 mothers from the KSA, and this was an opportunity sample compiled through referrals and personal contact. See section (4.11) for more information about the selection of the sample. Moreover, thematic analysis was employed for the analyses of the transcripts see section (4.13) as described in the Methodology Chapter.

This research has adapted a constructivist approach with the aim of responding to the voices and perceptions of the parents of children with ASD as they move through the different transitions in their lives. By adopting a constructivist approach it allows the voice of the families to be heard and it enables them to construct the reality of their situation in their own voice, manners and words. This is consistent with the data collection methods, which are semi-structured interviews that focus on the themes and key transitions that are highlighted in the literature. This also answers the research question regarding the mother's perceptions about their children's transitions from childhood to adulthood. The responses of the interviewees start from their experiences with the diagnosis of their child (Theme1), their experience with education, whether with specialized centres or schools, and inclusion (Theme 2). These themes are followed by their experiences during childhood, adolescence and puberty (Theme 3). Finally, themes are devoted to support, services, and awareness (Theme4), along with the parent's future concerns (Theme 5). These themes are organised in a way that expresses the voices and experiences of the parents of individuals with ASD from the KSA [see table on the next page].

Table 6.1: Details of the 13 parent’s children interviewed in the KSA

Mother* ¹	Child Gender	Child age	Diagnosis age	Education
1	Male	14	3	Centre
2	Female	17	3	Home schooled
3	Male	13	3	Centre
4* ²	Female	18 (Daughter)	1 and 4 months	Centre Centre
	male	24 (Son)	3 (Son)	
5	Male	14	4	School
6	Male	13	3	Centre then School
7	Male	14	3	Centre
8	Male	13	3	Centre
9	Male	16	2 and 10 months	Centre /school
10* ²	Male	33	8	Centre Centre
	Male	20	1 years old	
11	Female	16	3	Centre
12	Male	15	4	Centre / school
13	Female	15	13	School

6.1 Theme 1: Diagnosis experience

Having a diagnosis is considered the first important step, because it leads to an improved plan for the different transitions that the child with ASD encounters.

In this section, the mother’s experiences with the diagnosis of their children with ASD are discussed, whether they diagnosed their child abroad or if he/she was misdiagnosed.

¹ * All of the mothers in this study are given a number and named (Parent *)

² * Parent of two children with ASD

6.1.1 Diagnosis

The experience of diagnosis is varied between the parents. However, all of the parents in the study had a common comment, which was that they were the first to notice that their child was different and, accordingly, they proceeded to get a diagnosis. For example, one of the mothers noticed that her son tiptoed (Parent 12), which she found to be odd and different from his siblings, while other mothers noticed after their children stopped talking or showed other developmental signs of being atypical children. They said:

'by the age of 2 my son stopped talking after he developed speech...he also refused eating and only started to eat one type of food... I felt that there was something wrong with my son!' (Parent 3)

'I personally diagnosed him of being an atypical child when he was about 7 months old' (Parent 4)

'He wasn't like his siblings, because he was behind. He had delays with sitting, walking, talking, and even when I started breastfeeding him it wasn't right or normal. So I felt that there was something wrong with my son...' (Parent 7)

Two of the mothers had two children with autism, and they both declared that the diagnostic experience was easier and faster with the second child, as they became more knowledgeable about the condition:

'My daughter came after 7 years of (Son's name). I had some background knowledge by then, which made it easier for me. So when she was about 4 months old, she started behaving the same way as her brother, which made me notice that there was something wrong with her, like her older brother' (Parent 4)

'When it came to (Son's name 2) we knew straight away that it was autism, we have been through the experience of having (son's name 1) and we became more aware about autism.' (Parent 10)

The mothers felt that their children were different and wanted to help them by seeking a diagnosis first. Most parents did not refer to how they felt about the diagnosis: they simply wanted to find out answers why their children were different. One answer could be because of the lack of clinicians in the KSA and the limited services. Additionally, having a previous experience of the condition, made the diagnosis quicker with the parents who had two children with autism. However, diagnosis was not always straightforward.

6.1.1.1 Misdiagnosis

The results showed that for almost half of children's the participants (7 participants) had obtained the diagnosis by the age of three years. Of these four claimed an initial misdiagnosis. Having the right diagnosis from an early age helps the individual with autism, because it enables plans and support during the different transitions:

'We sought medical advice, and actually one of the Doctor's told us that he have hearing problems after testing him... he was misdiagnosed and that his hearing was actually very good. After going to several doctors and performing endless tests on him we found out that he had Autism when he was 3 years old' (Parent 3)

Two of the mothers, who had older children with ASD, referred to previous diagnosis experiences when they had a lack of awareness of autism, and a lack of diagnosticians. These parents experienced a misdiagnosis of their first children, while they had a faster more accurate diagnosis with their second children, (see section 6.1.1). One of the mothers stated:

'Back then, there wasn't much available and even doctors were confused. They weren't sure if he had just a delay or a mental retardation...' (Parent 10)

Another mother spoke about her experience with the misdiagnosis of her daughter, as the Doctor did not even provide her with a name for her daughter's condition, which made her feel frustrated and lost. This affected the mother by forcing her to seek different clinicians to get the appropriate diagnosis for her daughter, and it also impacted on her child because she was not receiving the help that she needed because of her unknown condition at that time:

'They actually misdiagnosed her when she was 3 years old. I took her to a clinical psychologist and they told me that she will never be able to learn or go to school... the Doctor actually refused to give me a report, and he didn't give me a name for her condition... She didn't tell me any name for her condition, neither learning disability or mental retardation, nothing!' (Parent 13)

Having a child misdiagnosed at first reveals the lack of awareness of the condition in the KSA, along with the lack of proper clinicians (Al-Farsi et al., 2011). This affects the families by leaving them feeling helpless, and not allowing them to move forward to the next transition. Such as education, which is finding the appropriate school or specialized centre for

their child, depending on his/her abilities and their ASD severity. The consequence of this has led some of the parents to seek a diagnosis abroad.

6.1.1.2 Diagnosed abroad

Awareness of autism is more advanced and people are more aware in other developed countries, where some of the parents took their children. After travelling abroad one of the mothers was able to get a quick diagnosis for her daughter after a week, which helped her to take the next step to finding suitable provision for her daughter:

'We took her to USA.... so they were several doctors and each of them saw her separately, the paediatrician, the clinician, the OT, speech therapist, so several of them...After a week they gave us a report stating that she has mild autism' (Parent 2)

Another parent lived in a small city in the KSA, where there were few specialists, so she took her child to get a diagnosis abroad. However, after receiving the diagnosis the doctor advised the mother to move to another country where she would be provided with better support and provision for her child, which made her feel frustrated because of the disruption it would cause her life and family in Saudi. Similarly, following the misdiagnosis of their children, two other parents took their children to get a better diagnosis abroad:

'We travelled to the UK and the Doctor confirmed that he had autism' (Parent 7)

'I took her to a lot of specialists in Saudi and in Egypt, they never told me that she had autism, until I brought her to the UK 2 years ago, when she was 13 years old they diagnosed her with autism' (Parent 13)

Getting the appropriate diagnosis for a child is crucial as this is a stressful phase for the parents, along with their experience of the diagnosis process (Crane et al., 2015). Diagnosis is clearly not a straightforward process; especially when some parents have to travel abroad to get it. This has important implications for those parents who are unable to take such journeys, because they have to search for knowledgeable clinicians to get the right diagnosis for their children.

6.2 Theme2: Education

Education and going to a school or a centre is the first transition that a child goes through. Some of the children go to mainstream schools, while others go to specialized centres in Saudi, according to their developmental and speech abilities. It is important in this study to explore their different transitions to these specialized centres or mainstream schools, along with the different transitions that they face within them.

6.2.1 Specialized centres

Almost half of the participant's children (8) go to specialized centres. Most of these centres mentioned by the parents were available in Saudi, while a few parents also talked about their experience with centres abroad. Such experiences vary along with the different transitions that their children had within a specialized centre.

6.2.1.1 Positive experience with specialized centres

All of the parents who had children in the specialized centres had some positive experiences that they shared. These experiences influence the child's transition to the centres whether positively or not, along with the different transitions that a child may go through within them. The common positive theme that these parents expressed was the centres' cooperation with the parents and understanding of their child's condition. Having a positive communication between the centres and the parents makes them feel connected and informed about their children's progress and less worried:

'They are cooperative, friendly, and professional...' (Parent 1)

'The centre that he is at now are cooperative, they invite the parents from time to time to come and watch your son for a day in school, they assess them and send us his progress report, we also have a notebook where the teacher writes his comments or questions about son's behaviour or progress, and we as parents comment back or ask questions on the same notebook' (Parent 3)

The centre's cooperation with the parents was described in terms of their responsiveness, providing support on matters those parents or children needs and by keeping them updated with their child's progress. Another mother's positive experience with the centre concerned its reliability and the services that they provide, such as outings for the children. One mother mentioned that the centre helped her by guiding her and explaining her child's plan, which

included educational, social, and self-help skills. This made her feel better when she previously had been feeling overwhelmed and helpless. She said:

'It was a very good centre, and they helped me. I went there crying, and I was devastated, my son drove me crazy... So we started by making him a plan ... and what were the activities and things that they will work with him' (parent 7)

The improvement of child behaviours, skills and learning was also considered as a positive experience that three of the parents had with the centres, along with the different services or activities that they provide:

'there were some things that our son learned quite quickly, such as computer and art' (parent 10)

'They have worked really hard with her on behaviour management, concentration, focusing and paying attention, speech and everything including art. I can see the difference in her...she is much better now except for the speech' (Parent 11)

The cooperation of the specialized centres and their teachers with the parents are very important for the parental satisfaction with their child's education (Rattaz et al., 2014). These mothers spoke about the positive experience with the centres: their comments emphasised the importance of the cooperation of the centres with the parents, along with providing them with information, appropriate services and resources for their children. If a parent was not satisfied with the centre they could transfer the child to another centre. Unfortunately, this entails yet another transition that the child has to go through. Therefore, having a good centre that provides positive experiences will lead to a satisfied child and a parent.

6.2.1.2 Limited experience with the specialized centres

Some of the mothers spoke of the mixed experiences that they faced with their children's specialized centres. One of the mothers mentioned that she had a problem with one of the teachers, when her child transitioned to a new class:

'I never had any problem with them, except once when they transferred him to a class with a Teacher called (Teacher B). I had a problem with that teacher and his assistant' (Parent 1)

However, she did not elaborate on what were her specific concerns, but the reason this was raised was that the centre and the teacher were not listening and engaging with the parent's

views and concerns. Finding a suitable specialized centre is vital, as two of the parents spoke about their distressing experience in not finding one that had professional and knowledgeable staff that could benefit their child's learning:

'I found out that they used to put the children in a room and open the TV on a kids music channel for the whole day. I was surprised to know that the first centre didn't use to teach him anything beneficial... they told me you could design a program for your child. But I don't know! ' (Parent 8)

'... I don't think that they had well trained specialist or teachers who were qualified; I think the teachers there didn't even held a degree in education. They used to implement some of the basic simple programs and behaviour management; they also lacked teaching the children some of the academic skills... They didn't know how to work with our son' (Parent 10)

The mother continued by stating that the challenging experience was also with the teachers, one of whom was not professional in the way of talking with them, while another one used to pinch the child:

'what was annoying him in the previous centre were some of the teachers. Some of the teachers in the previous centre used to pinch children very harshly, we once complained....and they actually took the teacher's side and not ours...then one of teachers actually told us: this is the way to control the child. Another teacher just said that your child is spoiled, which is not appropriate to say' (Parent 10)

All of these challenging experiences affected the parents and the children, by hampering their progress and transition. These experiences varied from changing the teacher, lack of cooperation, lack of qualified centres and teachers, to unethical teachers. Moving children to male's only centres or sections presents another challenge.

6.2.1.3 Male sections/centres

When boys begin to show signs of puberty, which is at approximately 10 years of age, they are transferred to the male sections within specialized centres or to another centre that has all male staff. This affects those children with ASD, since Saudi Arabia is a gender-segregated society (Madi, 2014). Four of the parents spoke about the transition of their children to be taught only by males and how it was for them. One of them spoke about the rules for transferring boys to male only classes and the difficulties that her son had coping with this new transition:

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'There was a new rule that after the age of 12 children cannot stay in regular centres, and they have to be moved.... In addition, all the teachers have to be male teachers for male students' (parent 8)

'At the beginning it was difficult for him to accept and adjust with the new specialized centre, because he stayed in the previous one for about 7 years, especially that the staff are all males. Accordingly, we started for one month with a daily session that lasted only two hours, until he began to take it slowly eventually with acceptance.' (Parent 8)

Another mother had two children with autism, the youngest a girl and the eldest a man who was 24 years old. They both used to go to the same centre and were in the same class. The mother said that her son's transition to a males only centre was the father's idea, for the reason that he believed that the child needed to learn and model masculine behaviours:

'Both of my children used to go to the same centre, and his father was refusing that he stays under the care of women, he said that he won't be a man...He used to tell me that it is better if he stays with men, especially when he started the transition to the puberty phase... so he can start learning from them.' (Parent 4)

Some parents can struggle with the transition of their sons to a new centre, because they feel a rapport with the staff and are comfortable with the previous one. As mothers are the ones who are mostly dealing with their child's education, when the child moves to a male section or centre the staff are going to be all males. This makes it harder for the mother to directly communicate with them due to the culture in the KSA:

'They don't accept older children, after the age of 11. So they told me that I have to move him to the male centre because he grew up. I moved him while I was crying feeling sorry that I had to take him out from there...The previous centre had all female staff, so it was easier for me to deal with. The principal of the centre was a psychologist, and he used to be cooperative and understanding. He told me that... he might suffer, but he will eventually get used to us and he will settle down. The period when the child transitions from one centre to the other is a challenging phase, that we suffer as parents as well. Because his teacher changed, the person who used to understand him, the way they used to deal with him is different. Some people used to be calm and kind, and some are strict. It made him more tense....' (Parent 7)

Three of the parents said that their children found it hard to accept this change of transitioning to a male centre or section, and they expressed this by refusing to go and showing unacceptable behaviour, such as having a tantrum, showing aggressiveness, and refusing to go to the centre:

'...he was refusing to leave the house and go to the centre and threw himself on the floor. And he also used to refuse to enter the centre when he gets there....' (Parent 4)

'...At first he struggled and he used to cry refusing to wake up, get dressed, and go to the centre' (Parent 3)

Culture impacts on the experiences and their quality in a way that sometimes conflicts with the child's specific need. Since most of the available centres in Saudi are run by female staff, and it affects male children by having to move them to a male only sections or centre. Such a move entails a new transition that could be challenging and difficult for the child and the family. Hence, some parents make the difficult decision of sending their child abroad.

6.2.1.4 Centres abroad

Two parents spoke about their experience of sending their children to a specialized centre overseas, because of the lack of suitable centres for their children at that time, along with the lack of significant services for individuals with ASD in the country. One of the mothers who had two children with autism spoke of her experience of not finding an appropriate centre for her son because of the lack of centres and services at that time, especially since he is 24 years old. The son was sent to a residential centre in Jordan for about a year and few months, while she was working with her daughter. He stayed there until she settled down and the mother noticed an improvement in her son, who she then brought back to Saudi:

'He became very challenging, and the centre told me ... you need to find another place. So back then we didn't have enough centres or available services that would suite my son. Therefore... I had to take my son to Jordan, which was because I was only able to be there for one of them.' (Parent 4)

Fortunately, her two other children helped and supported her and their siblings by keeping her other two children with ASD in Saudi. Another parent of two sons with autism had different experiences with residential centres. Their first son is now 33 years old, and goes to a residential centre in Jordan because of the lack of centres and services in Saudi in the past, and because they faced difficulties with managing their child's behaviour at that time. This parent revealed some positive and challenging experiences with the residential centre in Jordan, where initially their son's behaviour improved. However, the parent had an unpleasant experience when she found out that the centre gave some medicines to calm her

son down without making them aware of it, which left her feeling devastated. Even so, the last time the mother visited the centre she had a positive experience because it had changed all the staff and recruited better ones:

'They used to complain about his behaviours, and they used to give him some injections and medications [without my consent]. He used to sleep most of the time, and when I asked them: why is he sleeping most of the time? It is obvious that he is taking something that would make him sleep all day; we really suffered with (son's name1) in Jordan a lot. I used to come back home psychologically sick from this matter. Though, when I went there last time he was really doing well, thanks to Allah' (Parent 10)

The parents wanted to bring their son back to the KSA after going through these mixed experiences, but they had no choice because only centres abroad provide a range of facilities and services, which are not available in the KSA. This made the parent's feel powerless having to leave their child abroad, in order to get better provision:

'We were thinking of bringing him back and providing all of the facilities for him at home, but I told my family that we can't do that. because... they have a lot of facilities and services there. And they have a lot of specialists... we don't have all this? They have different specialists form different majors, like a speech therapist, a psychologist and many more who work with the children.' (Parent 10)

The second son is twenty years old and the parent took him to a residential centre in UAE for two years, and they brought him back after their experiences there, because they felt that their son did not improve. The parent also said that transitioning from one country to the other was a pressure on their second son and on them as a family, because he had a new place to eat and sleep, which was not like his home:

'The transition from one country to the other is difficult, because (son's name2) got psychologically sick when he went to UAE. It was a new place for him, new environment, different food, and everything was new and different to him' (Parent 10)

Another mother had a different experience with a centre abroad, since she brought a private teacher from there and she started home schooling her daughter, with the supervision and plans from a centre in South Africa:

'So we were going to South Africa for our summer holiday.... we found out about a special teacher from a centre, where you can have a teacher with a special program that she can teach her at home. So I started the journey since then with home schooling.' (Parent 2)

'... they developed an IEP [individualized educational plan] for her... they send a program every month, they send books, social stories, and anything useful.' (Parent 2)

The mother continued talking about her positive experience with the centre from abroad, which she found very helpful and cooperative, because they were providing them with beneficial materials and resources. The services that the parent received was more suited to her child:

'For example, once I told them that I am travelling, and I need a social story. They told me to send them all of the pictures of our next trip and we will make it for you. This is very helpful, and we don't find this with centres here in the KSA, you just request something and you get it.' (Parent 2)

The parents in this section spoke about their different experiences with the centres abroad, which were residential specialised centers or centres that provide teachers. The lack of appropriate specialized centres and services in Saudi Arabia were the primary reasons why parents chose to take and look for services abroad. These parents were proactive parents who were looking for better provisions for their children from abroad.

6.2.1.5 Lack of centres

A number of parents (6 participants) have spoken about the need of having more suitable specialized centres that provides adequate services and support for their children, which were lacking or very limited in the kingdom. They reported:

'... there was no place for her to go to, and there wasn't any special centre that my husband and I liked for our daughter.' (Parent 2)

Three parents specifically expressed that the lack of appropriate centres was more challenging in the past because they had older children with autism:

'This was 10 years ago or more, we didn't use to have a lot of specialized centres' and things like that. (Parent 8)

Another major concern that two of the interviewees talked about was the lack of centres for children after the age of 16, as they are regarded as graduates from the specialized centres at that age. It also leaves the parents wondering and worrying about what to do with their children after that age:

'I wish if they would develop a place for teenagers after they consider them graduates... because we do not want our kids to be sitting at home after they graduate from the centres... There are ones who graduated and got employed and others who graduated and are staying at home.' (Parent 11)

'... he will only be at the centre until the age of 16 when they supposedly graduate from it! I still don't know where I am going to take him after that?' (Parent 3)

The lack of centres was an issue that the respondents spoke about, and their wish for more specialized centres that could provide suitable services for their children, which would help them during the different transitions in their lives.

6.2.2 Mainstream school

Some of the children with autism manage to attend mainstream school, and these children had different experiences there. Five of the parents in the study reported that their children went to mainstream school, some of whom moved from centres where they encountered mixed experiences from positive to challenging.

6.2.2.1 Transitions from centres to schools

Four of the interviewees' children went to specialized centres before transitioning to a mainstream school. One of the mothers said that she took her son to a specialized centre at first, where they taught him self-help skills, which are very useful before going to school. After that centre, the mother moved her son to a kindergarten for him to be socially included and learn the prerequisite skills to enter a school.

She spoke of her struggle of finding a mainstream school that offered inclusion and had special education teachers for these children, which she did not find at the beginning and had to move her son to a specialized centre again to prepare him to be included in a school:

'Afterwards, I did not find a school that had inclusion for these children, so I took him back to a centre, because when I looked for mainstream schools I also couldn't find something that suits our budget, and they did not accept him anyway. I also found a school only for English speakers and they told me I had to make him learn English for 2 years... So I took him to a centre that had teachers and it was for both genders. And thank god he started to talk. He took 1st, 2nd, 3rd grade at this centre and they had a resource room. Although at his second year a governmental decision was made that they have prohibited boys and girls to be merged at the same classroom, so they have separated them and we started looking for a new school.' (Parent 9)

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The child managed to be transitioned to a mainstream school that offered inclusion after preparing him in the specialized centre, which unfortunately closed, and the child had to transition to another school that did not offer inclusion.

Transitioning to a new school is difficult for these children and their families, because the parents are used to dealing with the school and staff, which leads to leaving them feeling worried and helpless. The mother (Parent 9) spoke about the struggle that her child went through because of the transition from one school to the other and how it impacted them and her child. Moreover, this child moved and had to transition five times in his life between specialized centres and schools, which made it difficult for him and his parents.

Another mother also shared her experience with preparing her son first at a specialized centre in order to transition him after that to a mainstream school. She started by enrolling him at a kindergarten after the centre to familiarise him with the school and to be socially included with other typically developing children:

'When he first got the diagnosis with Autism ... I started taking him to special autism centre, until when he was about 8 years ... he was being prepared in these special centres thank god, and he was getting ready to go to inclusion in mainstream school... so, he studied 1st year primary school in 2 years in the last special centre, but I went back and put him in a normal kindergarten just for him to be included with other children' (Parent 6)

The mother also said that she and her son found the transition to the mainstream school challenging, and that it was difficult for the new teachers and the school to get used to the child and accept him. It was also a new environment for him, with new teachers and more students in class, which proved stressful, and made him ask his mother to take him back to the centre instead of the school:

'It was really hard for me, and he used to keep saying to me: 'I want autism centres' ... And he is not really convinced of attending this school. And there are a lot of boys with him in the school and in class... there are like 12 boys in class at the school, and this is too much for him... Difficulties for (Son's name) to accept his new school, and difficulties with the people there and with the teachers to accept him.' (Parent 6)

One of the mother's (Parent 13) was feeling lost and helpless at the beginning of her child's transition into education, as she did not know if her daughter would go to a mainstream

school or to a specialized centre. Because she struggled between both schools and centres, they both refused to take her, which made it an unpleasant experience for the family.

A description of a series of transitions were explained by a parent, where her son started by going to a centre, a kindergarten at a school, then to a centre for children with autism. The mother said that her main aim was for her son to be socially included with other children, while he had extra help from a speech specialist and an autism specialist at home, in order to better prepare him to be included in school:

'I registered him in a centre for speech and hearing ... I said that he will socialize with other children, which can help improve his language. He stayed there for 2 years. Later, I registered him in a private school for kindergarten where he stayed for a year, and my aim from this was for him to be integrated with other kids rather than learning. And we were having the help of a special teacher who specialized in speech and used to work in a centre for children with special needs. Also we had the help of an autism specialist who worked on behaviour management... In this period he built a good base for reading and writing... After that I registered him at an autism centre.'
(Parent 12)

Then, the child moved to a school that offered inclusion for children with autism, where he remained for two years until they stopped the inclusion and moved all the children with autism there to a specialised centre. Consequently, the child found the transition very difficult, which made him feel frustrated leading to his refusal to go to the centre. Subsequently, the mother (Parent 12) moved her son back to the autism centre for two years, until she moved him again to a school that offered inclusion for children with autism. The child experienced seven educational transitions in his life between centres and schools, which was at the very least challenging for the parent and the child.

The children of some of the mothers transitioned between centres and schools, and some of these transitions were because the child was being prepared in the centres to be included in a mainstream school. Some of the parents expressed their worries and the challenges they faced with their children during these transitions.

6.2.2.2 Positive and challenging school experience

The parents faced some positive and some challenging experiences with their children's schools. Some of the positive points were that the school cooperated with the parent, had a resource room and was knowledgeable about dealing with children with special needs. Another mother revealed that the school's attitude towards her son's education was one of the

positive points, along with the fact that the school had an electronic education system, which she believed helped children with autism. On the other hand, the mother also said that some of the problematic points, which were that the teachers were not knowledgeable about her son's condition, and they complained about him. This school was a school that did not offer inclusion, resource rooms or special education teachers:

'They don't have special teachers, therefore, I face problems with the teachers, because they don't understand my son's condition, and they do not know how to deal with him... They do complain a lot about him, mostly from his behaviours in school.' (Parent 5)

She added that she joined her son's class in order to show the teacher how to teach and deal with these children. This mother expressed the difficulties she faced with her son's education, which can make parents feel overwhelmed:

'We actually suffered during that experience, it wasn't easy at all... I am suffering since kindergarten, because there is no acceptance of children with autism in the community. Their knowledge is very limited, and they are not aware about autism, or how to deal with those children.' (Parent 5)

The child's experiences in school affects his transition there. The school's cooperation, understanding, knowledgeable staff, and electronic education system were mentioned as positive points that led to a positive experience with the school. On the other hand, lack of understanding, knowledge and acceptance in some of the schools were considered as a challenging experience.

6.2.2.3 Problems with Inclusion

Mainstream schools that offer appropriate inclusion and have resource rooms for children with special needs are very limited in Saudi Arabia. Five of the parents in this study talked about their struggle to find suitable schools that offers these services for their children. A mother was able to find a school that offered inclusion for children with special needs until 3rd grade, but there was no resource room after that. However her daughter still goes to the same school now, because she had established a rapport with them:

'...they accepted her in a school that had inclusion, so they used to include her sometimes in the classroom with other children and after that they take her to the resource room ... They used to have a resource room in 1st, 2nd, and 3rd grade but not anymore.' (Parent 13)

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The mother felt that her daughter was doing well at school because she had a private teacher at home, who had the knowledge of dealing and teaching children with special needs. This shows that the child was only included in school socially, and that her education and learning took place at home with the private teacher. She said:

'She was doing well at school because she has a private teacher at home who is specialized with dealing with children who have learning disabilities' (Parent 13)

One of the mothers shared the same experience as the previous parent, by stating that her son's education was taking place at home, and that he was only socially included in school:

'The school did not have inclusion or a resource room, so it was a normal school. So it was only social inclusion, during breaks, morning lines, and this like that. But all the learning and teaching was taking place at home... we didn't really benefit from the school learning wise. Because the teacher used to talk with the whole class, which wasn't beneficial for him...' (Parent 6)

Because of the lack of mainstream schools that offered inclusion for children with autism, another mother (Parent 9) had to put her child in a regular school that did not offer inclusion. A parent found difficulties with finding a mainstream school that offered inclusion for children with autism, after her son's previous school closed and moved him to a specialized centre. Therefore, the mother pursued the Ministry of Education who then directed her to an available public school that offered inclusion for children with ASD:

'So one of the teachers I know told me that I should seek mainstream schools with inclusion classes, and I went to the Ministry of Education and they guided me to one of the schools who had inclusion' (Parent 12)

Another participant suggested that even some of the schools that offered inclusion, were not including the children properly, and that might be because they did not have knowledgeable teachers and staff. She also mentioned that her son's school that provided inclusion had an increased number of children with special needs than typically developing children:

'Mainstream schools here that have inclusion, they do not include the children in an appropriate way. So after that I moved him to a school that has inclusion, but their performance wasn't up to the required level. They used to include the children in a right way, but in the last few years the number of children with special needs started to increase in the school than the typical developing children, so it started to be more

like a specialized centre rather than a mainstream school with inclusion. So, actually this school was closed down,' (Parent 5)

After the school closed down the mother moved her son to a school that had no inclusion, which is considered an additional transition for the child, with new environment, teachers, and new classmates. And two of the mothers after their children transitioned to new schools, noted that their children had some behaviour problems at school that could be some of the ASD symptoms. This made it difficult for them to be included in a school that was not aware and did not have knowledge about the condition. Transition to a new school was difficult for these children, which could lead to the child refusing to go to school, and leaving their parents frustrated. They commented:

'So he starts behaving, which annoys the school. Because he doesn't follow the school rules, he doesn't sit still in class, or he doesn't sit properly on the chair, he leaves the class. Sometimes he shows some behaviour that other children in class don't do. For example, he gets very nervous, and he acts out like some of the cartoon characters that he sees on TV. Which all of this makes it difficult to be included in a school, or even with the community! He starts to get psychologically sick and he refuses the school as well...' (Parent 5)

'... at first he was not able to sit still ... which was a problem, because his school teachers were not really accepting these types of behaviours... and they are not willing to have a child with special needs in their classes. This is a problem that we face until today...Although I told his school that he have autism, because I did not want them to treat him harshly or to punish him for his behaviour, they have to understand his needs... so he moved on with the transition but we had some challenges during it.' (Parent 6)

The parent has to keep reminding the school and teacher about the child's condition and his needs, especially if the school was not a mainstream school that offered inclusion, because the staff are mostly not knowledgeable about the child's condition. This could leave the parent feeling overwhelmed and worried about their child's education, and that teachers still do not fully understand their child's situation:

'Every semester I have to do a meeting with the teachers, and I have to remind them about his needs, and I have all their phone numbers, and I call them all the time to check on him, and ask about his homework, I have to continue all these things and follow up with them.' (Parent 6)

Schools that offer support and inclusion for children with ASD are very limited in Saudi, which obliges the parents to enrol their children in normal mainstream schools. Two of the mothers said that some of the teachers in schools advised them not to say that their child had autism or to include the child's reports in his/her school file, if they want their child to have more options with schools:

'... his old school wrote in his certificate that he was normal, and they told me its better, because he improved and so he can have better options. But the school knows that he has Autism they have 6 cases who transferred from the previous school to this one, and his teacher have informed them with his case.' (Parent 9)

'After I got her the diagnosis when she was 13 years old that summer, I took her report to the school, and the teacher told me not to show it to anyone, because if they knew that she had autism they will ask me to move her to another school or a centre, because they do not have teachers or a specialist that can deal with her. The school only knew that she have some learning difficulties because they used to take her to the resource room, which they stopped after 3rd grade.' (Parent 13)

In summary, it was noted by the parents that schools that offer inclusion for children with ASD are limited, and two of the mothers stated that their child's actual learning was taking place at home with the help of a private teacher. However, these educational transitions that the child goes through impact the parents as well, leaving them feeling worried.

6.3 Theme 3: Childhood and adolescence experiences

Individuals go through different experiences during their childhood and their adolescence. Some of the experiences and challenges that the parents of these children with ASD went through with their children's transitions were in their childhood, puberty, and adolescence. These are discussed along with some of the helpful strategies that were used with their children.

6.3.1 Childhood experiences

This theme explores the childhood experiences from the perception of the parents. As, the experiences that an individual with ASD and his/her family go through during childhood might influence their next transitions in life. More than half of the parents (8) mentioned that their child's childhood was challenging. Some of the mothers stated that the difficulties they faced were because of their child's challenging behaviours or ASD symptoms, which some of them were not aware of. Additionally, the lack of awareness and services in the KSA has

made the childhood experience difficult. Consequently, this makes parents feel helpless and confused, especially during the childhood years, because autism was something new for them at that time, and they did not know how to deal with their children:

'In general, it was very hard, and even now I keep thinking how was I able to adapt and to think of this or to find a solution for this and that? Maybe because in the past we didn't have someone to teach us...His behaviours and everything was typical autism.' (Parent 6)

'Honestly, the first 10 years of her life were challenging, because there was no awareness, or good autism centres. Actually her life was normal in the beginning, she crawled and walked normally... She never had any delays; her childhood and infant years were very normal. Of course with varied ASD symptoms.' (Parent 2)

One of the mothers (Parent 4), who had two children with autism, said that both their childhoods were difficult. Her son had difficulties with talking, walking, eating, and some behaviour problems, which made his childhood very challenging, and left the mother feeling overwhelmed. Since her son is now 24 years old and this referred to the past when there was limited autism awareness and services in Saudi. The mother also said that her daughter's childhood was challenging, especially because she exhibited some self-injurious behaviour. However, she said that she had learned from her previous experience about ASD symptoms and behaviours from her older son, which made it less overwhelming.

Another mother recalled that one of the main challenges that she faced with her son, was when he started showing the signs of autism, and because he was a nonverbal it made it more difficult, since they did not know what was wrong with him when he cried. So they used to take him to the hospital and check on his health, and that made the parents feel helpless and worried about their child:

'...He did not used to like to get out, did not like anyone to touch him or get near him, did not like anyone to talk with him. He used to get annoyed from the noises... He started showing the autism symptoms, the tantrums, and started losing eye contact ...His childhood was very hard, especially because when he did not know how to express his needs. The only way was that, he would grab someone's hands and pull them strongly for his necessities. But when he starts crying, especially when it increases his father carries him and immediately we take him to the hospital, because we didn't use to know what is wrong with him?... And that was the most difficult part of it.' (Parent 8)

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Problems with toilet training children with ASD were also brought up by four of the parents. Since toilet training is an important skill in any child's life it would affect his next transition, such as school:

'... he started to be fully toilet trained until recently like 2 or 1 year ago or when he was about 11 years old. Until last year we used to help him to get to the toilet.'
(Parent 6)

Almost half of the parents talked about another difficulty that they faced with their children during their childhood, which was following a strict routine. As some of the children had a routine with eating certain type of foods at certain times, or changing clothes, bed sheets and so on. Some of these routines affect the individual's life, leaving the child and the parent feeling anxious and frustrated:

'He used to follow his routine strictly in all ways.' (Parent 4)

A mother talked about how she used to work and tried to change her daughter's routine to make her more flexible, because she was worried that it might affect her transitions later in life:

'Yes, it was difficult. Especially her routine, and I was trying my best to break her routine...She used to have a schedule in her room that she follows, and every day I change it, even going to the toilet and brushing her teeth, I used to switch it up for her now and then, just to make her flexible. And to make her less strictly attached to her routines, because it will cause problems.' (Parent 2)

Three of the mothers disclosed that their children had a typical early childhood and infant years, until they regressed and started developing ASD symptoms after the age of 2 or 9 months. This had affected the child and the family, because it impacted on the subsequent transitions.

In this sub-theme, the participants spoke about the experiences of their children during childhood, and the challenges that they faced during this period, such as with the ASD symptoms, toilet training, and routines. Some of these challenges were because of the lack of awareness, services and support for these children with autism, which therefore impacted their lives whether positively or negatively. The following sub-theme will explore the views of the parents and their experience with the next transition of their child, which is to puberty.

6.3.2 Puberty

The perceptions of the parents regarding the transition to puberty of their children with ASD were analysed. Families spoke about their concerns, difficulties with preparing their children, and some of the behaviours they encountered.

Some of mothers of daughters with ASD said that they felt anxious and concerned about what would happen to their daughters when they reach puberty, which was a burden on them, because of the lack of knowledge, and good specialized centres that might help their child during this phase. The parents also expressed their concerns about how to teach their children and better prepare them for this phase:

'When she was young and I knew she had autism I started asking around about how should I deal with her? and that was even before she was in the centre, and I did not have any knowledge and autism was not that well known' (Parent 11)

'I was worried about what to do and what to say when she reaches puberty? Who will help me? It was really a burden.' (Parent 13)

'... when she reached 12 years old, and I started feeling that she will reach puberty, I was confused about what should I do and how can I deal with the situation?' (Parent 4)

'So far we are in this transition period, and some things are already starting to show on him... and honestly I am very scared and worried abnormally from this phase. I don't know how to deal with it?... because after puberty it comes more problems. Even with puberty how can I teach him about it? or how to clean himself?' (Parent 6)

One of mothers talked about how other people's difficult experiences with their children's puberty made her feel helpless, more worried and stressed, which also made her wonder about what to do and how to help her daughter when she transitions to puberty?

Almost half of the participants mentioned that their children noticed the physical changes in their bodies, and that made them curious about their body parts. Some of these behaviours could be problematic, especially if a child started touching body parts in public or at the centre. This can make the parents worry about ways of helping their child in this certain phase. They said:

'He started discovering his body parts, and sometimes he touches his private parts, also his voice started to change so he started to sing a rhyme of noises,

which might be because he noticed the change that is happening to him.’ (Parent 3)

‘I immediately went to his doctor, and she helped me a lot. He started touching his private parts. She told me: ‘this is normal and he wants to discover himself and his body, so don’t give it too much attention and try to ignore it, I tried that, and it decreased a little bit but it didn’t go away, it is still there.... Even the centre contacted me and told me that he started mimicking sexual behaviour but it is not a lot, he does it sometimes’ (Parent 7)

‘We also started noticing that sometimes he starts touching his private parts from time to time, but we’re watching him and trying to manage it, by telling him that this is wrong, and you shouldn’t do this. He started to know when I overlook and I notice there’s something wrong, he starts saying: ‘this is wrong’ and he tries to approach me, kiss me and say: ‘I won’t do it again’’. (Parent 8)

‘She reached puberty at the age of nine, and the first physical thing that showed on her were her breasts, which got her feeling confused...she used to stand in front of the mirror and lift her shirt and look surprised at what she thought was something growing in her body, and I talked to her teachers in the centre regarding this behaviour, and I asked them to help her stop it because it was embarrassing.’ (Parent 11)

Another mother expressed her feelings of helplessness and worry, having to pay more attention to the child with ASD going through the transition to puberty, which the mother feels a challenging phase:

‘It has been difficult to keep an eye on him the whole time, and I have to check on him every five minutes... now I have to be careful, and to watch all his moves myself. Because now he’s able to discover new habits and I’m afraid and worried it could lead to a problematic cause. Also when I have guests I’m anxious that he might act in an inappropriate manner in front of them, you know people have no understanding. For this reason, I have to pay more attention, I have to make more effort and I have to concentrate on him more.’ (Parent 8)

A further participant stated that the puberty phase was difficult on her, and that she noticed behaviour that she did not understand at first, such as rubbing himself on the floor. Because her child was non-verbal, which made it very difficult to communicate with him and understand his needs in order to better help and prepare him for this transition. Another parent stated that she noticed difficulties with her daughter in expressing herself and her needs because she was non-verbal. This had made the parents feel confused, helpless, and anxious:

'It was very hard. Especially when we used to see him trying to isolate himself, sit alone, and rubs himself on the floor. I didn't use to understand what was his problem? Or what was he doing? So it is very difficult and hard on you to understand what is wrong with your child? especially if he cannot talk...how can he communicate with you? What hurts him, or what annoys him? He used to cry for no reason as well, I didn't use to know why was he crying or what made him sad?' (Parent 1)

Two of the mothers of girls with autism said that after their daughters reached the puberty phase it was a smooth transition and not worrying as previously. The first mother said that what made the transition easy on her child was the guidance of the centre from abroad, which helped her in preparing her child for this transition. The second parent mentioned that her daughter's interest in reading and reading books about the transition to puberty is what helped her in making it easy and understandable:

'they really made the transition to puberty easy ...I found it smooth, with the presence of [centre's name], since I was worried before' (Parent 2)

'The transition to puberty went well after all, and her love for reading made things smoother, and this is what helped her understand it better' (Parent 13)

The mothers in this section spoke about their varied experiences with their children as they transitioned through puberty. Such varied experiences also occurred during adolescences.

6.3.3 Experiences in Adolescence

Parents of children with ASD have varied experiences and views regarding the transition to adolescence. Some of them expressed their worries about this transition. Some said:

'I am actually worried from his transition from childhood to adolescence. I don't know what to do?' (Parent 5)

'The centre sometimes worry us even more, and they used to always remind us about the adolescence and how hard it can be' (Parent 8)

Nevertheless, three parents in the study experienced a smooth and easy transition with their children with ASD. One of the mothers indicated that her son's transition to adolescence was easier on her than his other typically developing siblings:

'Considering him and his sisters he was much easier for me, the only thing that was different it was his anger.' (Parent 12)

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A smooth transition to adolescence was experienced by a mother, because of the help of the centre from abroad, which provided her with guidance in order to help her daughter, which was by teaching her to request and express her needs during this phase. On the other hand, another parent reported that her daughter experienced a typical transition to adolescence, and that she became curious about life around her by asking questions and wanting to know more. Nevertheless, her daughter still prefers to act like a child. As she preferred to play with children's things as a way of avoidance, since she probably knew about the responsibilities of adolescence and the following transitions, such as graduation from school, going to a university, and finding a job:

'It was a normal adolescence. She accepted it and she is doing well with it, but sometimes she says: 'I hate puberty', I still feel that sometimes she prefers to be a child. She changed, she grew up, and she started understanding things more. She didn't use to know a lot of things about life in general when she was a child... she grew up and she reads a lot. She asks a lot of questions, why is this and why is that?'
(Parent 13)

Five of the participants declared that their children actually improved when they transitioned to adolescence. As one of the parents expressed that she was worried about the adolescence phase of her child, which left her thinking about her child's plans and how to prepare him for this following transition. However, this transition went smooth with her child, as she noticed that her son actually started improving regarding his self-help skills and became friendlier with others, which left the mother feeling relieved:

'At first I was really worried ... which leaves me wondering about the next step that I will take with my son... (Son's name) progressed a lot, he started going to the bathroom by himself, washes his hands, brushes his hair, brushes his teeth, loves to shower, and applies perfume. He started changing his routine such as if he saw a stranger he doesn't mind it, he can shake hands with people, he can also hug if someone asked. As a mother I am content with his transition so far.' (Parent 3)

The next mother also noticed that both of her children with ASD started improving regarding their behaviours, they became more flexible with their routines, and started having better sleep patterns. This made the mother feeling relieved, and less stressed, with the help of specialists. She said:

'I feel that they changed inside out... Their looks and behaviours started to become closer to normal. Their eating habits were stricter before, but now they started eating 3 normal meals like any other human being. (Son's name) sleeping habit improved....'

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I started feeling less pressured as they started to grow older. Everything is going on a particular system, and organized from them now. Each one of them now has their own specialists that help them with everything they need. This helped them and it is a relief for me as well... all their things now are organized and better.’ (Parent 4)

The child’s improvement was also related to the fact that the mother started understanding and knowing how to deal with her child after a period of time.

Conversely, a challenging transition to adolescences was also stated by six of the mothers. Along with mentioning that their children started showing some changes in their moods, which affected them. As one of the participants pointed out that she noticed a general change in her son’s temperament considering that he became irritated and anxious, with demonstrating an increase in his stereotypical movements in this particular period. She said:

‘Psychologically, I noticed that he started becoming very nervous and angry. For example, if you didn’t give him what he wants, he starts hitting walls, or doing some of the stereotypical movements like flapping his hands, which really increased during this period.’ (Parent 7)

A second mother expressed her feelings of worry and helplessness, because the adolescence phase was the transition that worries her the most, and that she does not know how to deal with it, which might be more challenging on her son because of his condition. The mother also mentioned noticing a sudden change in her son’s temperament:

‘When I read your research topic I was very interested, because this is our problem now and it even causes me insomnia. He gets angry a lot and he have these behaviours....Suddenly, he started to get angry and scream! I didn’t understand why at that time, and then I noticed that he is going to reach puberty, and changes in hormones and a new situation that is against his will. And I noticed this and started to try to understand and to try to make this phase go through without any problems... So as being autistic, it is difficult.’ (Parent 6)

Four of the mothers noted the change in temperament of their children, or becoming stubborn, which they considered challenging, was mainly because few of them stated that their child with ASD does not know how to express his/her feelings and needs, especially if the child had limited verbal abilities. They stated:

‘I just noticed that (Son’s name 2) gets angry and feels annoyed sometimes, but he doesn’t know how to express himself because he is nonverbal.’ (Parent 10)

'She becomes angry, and I feel that she hates herself ... she suddenly come towards wanting to bite me, and I feel it is because of the physiological changes that happens to her and the pain that she cannot verbally express' (Parent 11)

In this theme, the mothers expressed their experiences that they had with their children going through adolescence, which varied from challenging to smooth transitions. Nevertheless, a number of the parents spoke about some of the strategies they used to help their child during this phase, which is going to be discussed in the following sub-theme.

6.3.3.1 Strategies that helped during the transition to puberty

Almost half of the parents revealed the strategies that they used to help their children with ASD during the transitions to puberty. Reading books about the transition to puberty, and what to expect during that phase was a helpful method for one of the interviewee's daughter:

'Because she reads a lot of books.... I brought her books to read ... I found a book about puberty for girls, it had information about the physical changes such as hair growth and things like that, and it talked about periods as well. I also explained that to her...' (Parent 13)

A further mother's strategy was to read books and educate herself more about the transition phase to puberty, in order to help her son go through this period smoothly. She also advised that the carers should keep trying different strategies with their children:

'I used to read about adolescences and the puberty stages. For example, when the child is on this phase of transitioning to puberty, you do not introduce new things to him ... We also tried taking him out more as a change, so he will feel less annoyed. There is nothing specific that is useful in this transition phase; you just have to keep trying different things...' (Parent 1)

Another mother used various strategies with the help and guidance from the centre from abroad, which provided her with a private teacher at home, since her daughter was home-schooled. These strategies included, social stories, the use of pictures, and modelling, which all were used in order to prepare her daughter with autism for the transition to puberty.

A mother of two individuals with ASD used varied approaches, since she had a male and a female child with ASD. For the boy when he reached puberty, she made him wear tight underwear, which she believed that it prevents chafing. For her daughter, she used to

calculate her period, gave her painkillers, a hot drink, and applied hot water bottles, which was to help her with the cramps she goes through during that time.

Some parents face difficulties with teaching their children about hygiene and preparing them for the transition to puberty. Two of the parents spoke about their children's experience with shaving; since hair growth is considered one of the physical signs of transitioning to puberty. One of the boys learned how to shave his beard by the modelling method, of imitating his father's behaviour. The other child, his mother used a gradual teaching method overtime, until the son learned how to shave.

The specialized centre helped the daughter of one of the parents, by preparing her for the puberty phase and teaching her hands on steps of what to do exactly when she gets her period as a strategy, which she was able to do independently:

'The centre did work on teaching her ...about her period and what to do when she have her period... they used a social story, in addition to hands on practice where they would bring a pantie and pad and she would do the whole process and they found out that she knew the steps. When she got her period, she used to go on her own to the bathroom, clean, and change.' (Parent 11)

Two of the mothers of girls with autism shared that after their daughters reached the puberty phase; it was a smooth transition not as much as they were worried before. The first mother said that what made the transition easy on her child, is the presence of the guidance of the centre from abroad, which helped her in preparing her child for this transition. The second parent mentioned that her daughter's interest in reading and reading books about transition to puberty is what helped her in making it an easy transition.

Parents of children with autism used varied strategies with their children depending on their abilities and needs, because the parents want them to learn and be more independent during the puberty phase. Some of the strategies used were books, modelling, hands on approach, and social stories. Further strategies that were used by the parents with their children during the different transitions are discussed in the next theme.

6.3.4 Strategies

There are different strategies that the mothers stated, which have helped them with their children in general. Some of the parents brought up that they have learned some of the strategies that they were implementing through a support group of mothers who have children

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with autism, which was through the various experiences that these mothers went through. A mother has additionally stated that this support group has created a group on Whatsapp, where they are able to share their experiences and make inquiries to get information from other parents in the group, so they can learn from each other. Having a support group and sharing their own experiences make the mothers feel less anxious, knowing that they are not alone in this, and that some of them share the same concerns. They noted:

'I learned different strategies from the support group...whenever something goes wrong I ask them, and we learn from our experiences. We now have 'Whatsapp groups' on our mobiles, and any mother in the group can ask any question and we can answer her and provide help or strategies that were successful with us.' (Parent 3)

'I gathered with parents who had older children, and some of them had successful stories. You do benefit from these parents, you ask them about their experiences with their children when they reached puberty, how did they calm their child down? What was useful for them?' (Parent 1)

Having private teachers or specialists were considered as a strategy for the mothers, which maybe because their child benefited from the extra help that he/she have been given from the private teacher or specialist. In addition, the mothers felt more relieved for getting additional help from someone who is a specialist, easing the burden from the mother:

'I brought him a private special education teacher at home an hour or 2 every day. He really improved.' (Parent 7)

'I got her a shadow teacher, I used to bring her 3 to 4 private specialists every day when we were in Egypt for the summer holidays. One of them was a speech therapist, a reading and writing teacher, an occupational therapist for the sensory integration ... and another one just to do some activities with her.' (Parent 13)

Another participant replicated a strategy that she saw the centre utilizing with the children, which was creating some label cards that stated that the child has autism whenever they go to field trips. The parent stated that this approach made her feel relieved and less worried just in case anytime her daughter goes out, although she will not allow her to go alone. She stated:

'I am forced to make my daughter wear a label card that says she has autism... once they forgot my daughter's label card with her...I liked it so I made her a similar one to wear whenever we go out...The idea of a label card really relieved me' (Parent 11)

Moreover, one of the mothers used different methods with her daughter. For example, the use of ‘Epsom Salt’ in baths that her daughter takes was one of the methods, which she claimed had an impact on her daughter’s behaviour and made her calmer. Another method was trying to keep her daughter busy by taking her out and including her in some activities, such as horseback riding, and clay making. Her daughter enjoyed these activities, although the downside of this, as the mother explained, was that these activities were solitary, and she could do these activities on her own, which she did not prefer because she wanted her daughter to be engaged in activities with others. The respondent said:

‘We started to make her a take a bath in (Epsom Salt) every single day... But when we suddenly stop it... We notice some behaviours that starts to show up ...We also take her horse back riding, and she really enjoys it. I also took her to a place to make clay, and she made clay plates and things like that. We try to include her but unfortunately theses things are just things that you do individually’ (Parent 2)

Various strategies were learned and used by the mothers. As some of them revealed how they benefited and learned from the support group, or the centre that their child goes to. In addition, getting additional help, such as private teachers or specialists were also a relief for some of the parents. Using label cards, or taking the child to do some activities, along with the use of baths with ‘Epsom salt’ were mentioned by other mothers. The next theme is going to discuss the varied available support and the needed support that the mothers cited.

6.4 Theme 4: Support

Having support is a very important factor that helps the parents through the different transitions that their children go through. However, the lack of support could hinder some of the families while their children are going through various transitions.

6.4.1 Available support

Almost all of the parents in the study spoke about the available support that they have. More than half of the participants talked about how having supportive family members, such as siblings, husband, parents, and in-laws were very helpful in their lives. The understanding and acceptance of the family was considered as an important support factor:

‘I found supportive people around me, like my family, sisters, in-laws, husband, and friends, they were very kind and understanding of my son’s case.’ (Parent 7)

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One of the mothers talked about the support she had from her other son, where he used to look after his brother with autism and follow up with him in school, he also used to tell his mother if he noticed anything with his brother. This was a relief for the mother to have his brother's support and follow up in school, since he attended a male's school only and it was difficult for the mother to do that. She said:

'His younger brother... is with him in the same school, and he used to follow up on his brother more... So until now he keeps telling me: ' Mum look (Brother's name) did that and things like that' (Parent 5)

An additional mother (Parent 4) mentioned that her son with autism used to go to a residential specialized centre abroad, and when he came on holiday his siblings promised their mother that they would help her with looking after him if she did not send him back to the residential school. So she decided to bring him back, and her children were very supportive and helped with their brother with ASD.

The mother continued and spoke of the support of her husband, which was giving up his own rights and allowing the mother extra time to look after her son and daughter with ASD. The help and support of her in-laws were essential as well, given that they were accepting and they helped her with looking after them. Having these supportive family members made the mother feel more at ease and less pressured about raising her two children with ASD.

The spouse support plays a vital role especially because it is a segregated community. Since one of the participants stated that her son is 13 years old and he was moved to a male only centre, the father is the one responsible to follow up with the centre. This is because the mother cannot go there and communicate with them herself; however she is able to send her queries regarding her son's education through her husband. He also looks after the son and takes him out sometimes:

'My husband is very understanding, and he helps me a lot, which I consider him to be my biggest supporter, he is there in every step with us...He is the one who's taking care of (Son's name), he takes him out and things. Nowadays, with his centre especially that now they're all men, he takes him there and ask about his performance, and if I have some comments and things I write it on paper for him, and he gives it to them or tells them about it' (Parent 8)

An additional main support that one of the mothers received was from her daughters. She stated that one of her daughters used to help her with looking after her son with autism, by taking him to extra classes and various appointments. This made the mother feel supported by sharing her son's responsibilities with her daughters taking some of the pressure from her shoulders.

Support groups for parents of individuals with autism are found to be important, since the parents support each other by sharing their knowledge and guidance to the rest of the group. Support groups help create a community for these parents that share a similar situation and transitions, which makes the mothers feel more relieved. In these support groups they provide lectures and workshops of how to deal and help their children with ASD. They also created a group chat on Whatsapp so parents can ask questions and communicate easily with each other. These support groups opened a door for other mothers to receive help by being a part of these support groups. They said:

'For myself the support group are helping me psychologically.' (Parent 3)

'We have a support group that we created as mothers. You know in our support group "Mommy cares" we were able to spread our own personal knowledge to each other, and we were able to bring specialist and teachers to teach all the mothers how to deal with their children in different situations.' (Parent 6)

'We have groups for families of children with autism; we call it 'The autism families forum', which includes mothers, fathers, teachers, and specialists. These are voluntary groups for any mother who faces problems, she can share her problem, and we can provide her with solutions on Whatsapp ...we really felt relieved after this, because these things were not available long time ago. The new mothers nowadays are benefiting from us ... and they benefit from the specialists. And we do provide a lecture every week for the mothers.' (Parent 7)

The financial support of the government was mentioned as being helpful by one of the parents. As the government started paying her son's tuition fees, which made the parent feel less financially burdened.

Another mother considered the help of the specialized centre in guiding her daughter with learning and implementing a skill as very crucial and beneficial for her daughter. They helped her with learning some handcrafts and she also improved. The centre also provided her with the needed materials at home, which is the kind of support that the mother needed from the centre.

Most of the parents spoke about the support that they have received from their families, and how their understanding and acceptance of their children was meaningful to them. Also some parents mentioned the support they have got from their children's centres and from support groups of parents of children with ASD. The following sub-theme is going to discuss the missing support and services that the parents mentioned.

6.4.2 Lack of support and services

Families of children with ASD lack some support that might be helpful for them during the different transitions that their children go through. Providing emotional and psychological support was lacking, as it is important for the parents in order to keep them going with helping and supporting their children in the different transitions in life. Two of the mothers observed:

'A mother also needs someone to listen to her. The child is not the only one who needs a psychologist in this phase.' (Parent 7)

'Especially when you have a huge responsibility and the support that you need is very limited, especially emotional support so you have to continue this difficult path.' (Parent 1)

On the other hand, a parent (Parent 4) mentioned that she would like to learn more about ASD, and how she could help her two children during the different transitions. This could be by taking some extra workshops from qualified institutes or individuals, which she found was very limited in the KSA.

Parents may feel lost and helpless, not knowing the best way to deal or educate their children. As two of the parents pointed out that they needed support and guidance in methods to handle their youngsters, and where to take them for diagnosis and schooling. They said:

'What is missing is the support that can show you how to deal and help with behaviour management of your child. We don't have any technical support. I read some books about autism, and the implementation of these things aren't available... there is no technical support to train families, or give consultations, and intervene when the child has a very difficult behaviour that the family can't deal with' (Parent 10)

It is very crucial for the parents to be able to find the appropriate therapies that would help the child improve and progress. As two of the mothers pointed out the lack of therapies for the

children with ASD, such as speech therapy and occupational therapy, which made one of the parents take her daughter abroad to benefit from these therapies that lacked in the kingdom.

The mothers said:

'We also need therapies such as, OT , Speech therapy. These kinds of therapies are very limited, and the centres that have those kinds of therapies, which were considered to be the best, really failed in it. So we just don't have anything actually!' (Parent 2)

'I didn't find good therapists for my daughter here, and it was very beneficial when I took her to Egypt and worked hard with her. She wouldn't have been like this now if I didn't take her there, so she can benefit from the specialists like the sensory integration therapist, the OT, and the speech therapists' (Parent 13)

The participants in this section discussed the limited psychological support, information and knowledge that they needed about ASD, and how to handle their children, along with the lack of therapies available in Saudi, in order to help their children achieve their best potential.

6.4.3 Lack of awareness

Some of the mothers spoke about the inadequate information and awareness for themselves regarding particular transitions that their children experience, in addition to the lack of awareness in the community.

As one of the mothers said that she needed awareness about the transition to puberty in individuals with ASD before her son reaches it. This could be better for the parents so they can start preparing for a plan to work and help their child undergo this phase smoothly, which some of the parents consider to be a challenging phase. The parent said:

'I would have wished if they made us more aware about the transition to adolescence and puberty before the age of 9.' (Parent 1)

More awareness is needed in the community and in schools, so these children can feel accepted around their peers. The rejection, misunderstanding and avoidance of these children in the society, makes the parents feel stressed and worried about their children. They expressed:

'Unfortunately, schools or even students are still not very aware, and they need some work on getting them to accept others with ASD. What surprises me is when we go anywhere, I see some children avoiding these other children with autism, which really

shocks me! ... They are just trying to play with you, even if she is making some involuntary noises!' (Parent 2)

6.4.4 Lack of services/ sport clubs and activities

More than half of the parents in the study spoke about the lack of leisure parks, clubs and extra activities for their children with ASD in the kingdom. These clubs or activities might be helpful. For example, by socializing with others, putting their energy in it, and keeping them occupied during the various transitions. They stated:

'We need special clubs for children with Autism' (Parent 3)

'They don't have activities, like sports in the centre.' (Parent 8)

'I wish we had centres, institutes, gyms and clubs, or afternoon activities where children can play Taekwondo, Yoga, swimming, basketball. A place where our children are allowed to join. We would love to have somewhere where our children can go and do any of the leisure activities like playing, colouring, or anything.' (Parent 2)

'If only the government would provide a park for individuals with special needs and their families' (Parent 11)

Some of the mothers' pointed out the lack of places where children with autism would go play and relief, a place for them to be entertained, as these could benefit the child by keeping him busy and relief some of the stress. One of the concerns stated by a mother was that when her son goes to a public park, they get annoyed from the starrng of others, and this is one of the reasons why they need something special for the special needs children. Considering that this made the mothers feel frustrated, not knowing where to take their children out? Or how to keep them busy by joining some clubs or extra activities? Also feeling that their children are experiencing stress having no place to go to feel less pressured. They explained:

'Children with autism have no place for entertainment, where they can be themselves freely. Or leisure parks only for children with autism.' (Parent 10)

'I wished if he would go to a sport club. These sport activities can be helpful, but the ones in the public parks don't do any help, we need something for teenagers more for older age group ... They're supposed to make some gyms with free subscription for teenagers for every neighbourhood. My wish is to have these sport machines that would be available in every neighbourhood park.' (Parent 9)

One of the struggles that confronted a couple of the parents arose from the fact that ‘Saudi Arabia is a gender-segregated community’ (Madi, 2014). The special needs sports clubs are very limited and are male only clubs. Therefore, the mothers are not allowed to go with their sons there, so the son needs to go with a male figure, such as a father or a brother. Another challenge that the mothers highlighted was considering that females are not allowed to drive in the KSA; they were unable to take their son to the club because they did not have drivers. This made the mothers feel helpless and frustrated. They expressed:

‘The specialized sports clubs here are limited, because I need to take him for a specialized sport club for special needs... The one available is very far from where I live, and transportation is difficult, also his father comes late from work. . Therefore, I can’t always take him there, and transportation costs a lot’ (Parent 8)

‘There is only one club in (City name) that only have swimming classes for children with special needs, and I cannot take my son there, because I am a female and I can’t send him with the driver, he doesn’t have brothers, also because his father is very busy and mostly at work.’ (Parent 3)

‘There is nothing that you can do in this country were you can leave your child without having someone sent from home with him. Because I am a female, I can’t drive and I don’t even have a driver so this is a struggle for me.’ (Parent 1)

6.4.5 Lack of qualifications and centres

There are limited specialized centres for individuals with ASD in Saudi Arabia (Al-Jadid, 2013; Elsheikh & Alqurashi, 2013). Several parents spoke about the lack of qualified centres, materials, along with the lack of specialists, and the lack of centres for older individuals with ASD.

Having qualified teachers and specialists is very crucial, because it will allow better education for the children and more opportunities for them to progress and grow.

Two of the mothers talked about the challenges that the parents faced were because the centres required having resources and materials, in addition to developing good educational plans for children including improving all of the important domains that a child with autism would have. Also the unqualified centres that had unqualified staff, along with the need of hiring qualified teachers and specialists, who would know how to deal and teach children with

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ASD. The parents were left feeling concerned about their children, and helpless about where to take them? The respondents stated:

'We should have autism specialists that have good knowledge, and who can deal with these children... Other specialists are not working in the right way with these children... Specialised centres here, lacks a lot of things. The help where they show you what to do is very limited.... No one used to just volunteer to provide you with information... I also wish if these specialized centres focus more on improving the children's speech and communication abilities' (Parent 5)

'The specialized centres were bad; there wasn't any special education teachers, so if you didn't work with your child as a mother, your child will not learn much... The centres are lacking specialists, and qualified teachers... I noticed that most of the teachers here only had workshops for few months and things like that, which is considered a problem. The centres are ineligible; there are a lot of missing things in those centres.' (Parent 7)

One of the mothers highlighted the lack of materials and resources for children with ASD in Arabic, as most of these are available in English. As this mother used to buy these materials for her daughter in English, while her daughter needed to learn Arabic, which she found challenging:

'All the materials around us, and all the things we buy were in English. But they want her to learn Arabic!' (Parent 2)

The lack of centres in the past put the parents in front of a difficult choice, which was either keeping the child uneducated or sending him/her abroad and away from their families, which made the parent under a lot of pressure feeling helpless. Two of the mothers that had older children with autism aged 24 and 33 experienced the pressure of finding the right specialized centre for their child, and these were not available in Saudi back then, leading them to send their children to residential centres abroad. They said:

'I wish if we had better specialized centres than the ones that we have now... (Son's name), became very challenging, and the centre told me that the early intervention period has finished and you need to find another place. So back then we didn't have enough specialized centres or available services that would suite my son. So we decided to send him to a more specialized centre in Jordan' (Parent 4)

'We need a specialized centre for the older children here, so that families won't need to send their children abroad, and not to make children and families suffer... I really suffered that I had to leave my son there, and I see him suffering there as well, and I am unable to help him. I can't bring him back here, because there is nothing that I can

do for him, I really can't. He grew up, and we don't have specialized centres so I feel helpless.' (Parent 10)

Furthermore, the child is considered a graduate after the age of 16 from the specialized centre, and there are almost no centres that would take him/her. This is not what parents would aim for their children, which led to an increase in the parent's worries and burden when their children reached this age, leaving the parents wondering what to do with their children? How can they train them? The interviewee said:

'I wish if they would develop a place for teenagers after they consider them graduates, which we talked to the centre to open a section for teenagers about because we do not want our kids to be sitting at home after they graduate from the centre... 16 years old, which is the last year for my daughter. There are ones who graduated and got employed and others who graduated and are staying at home.' (Parent 11)

The parents spoke about the pressure they go through with finding the right educational setting for their children, and the shortage in the KSA, which made them feel more frustrated and helpless.

6.4.6 Lack of schools with inclusion services

Finding the suitable mainstream school with inclusion is very important for the parents of individuals who are high functioning with autism. Three of the parents in the study spoke about their struggle of finding inclusive schools that has resource rooms and special education teachers, in order to better help their children progress in schools. These schools are very limited in Saudi Arabia, which leaves the parents feeling stressed trying to look for these schools, and they feel frustrated when schools refuse to take their children with autism, which makes it a challenging transition with finding schools, and moving from one grade to the other. The respondents said:

'Mainstream schools that provide inclusion are very limited or just unavailable. The stage when I moved my son in 6th grade, you can't believe how much I suffered! I searched all the schools in (City name). They didn't want to accept him at all. When he just sits with them, and he shows some of the behaviours, or no eye contact, because he still have weakness with eye-contact. They immediately say: ' sorry we can't accept him in our school' (Parent 5)

'I wish if we had a mainstream school, which had real inclusion for these children. These children need to be included in schools that have proper resource rooms, and shadow teachers. Schools needs support to be able to do all that, for example, shadow

teachers costs a lot, and we are supposed to have some of them in classes supporting these children, which we don't have here in Saudi.' (Parent 13)

Schools that offer inclusion services for individuals with ASD are needed in the KSA, and the parents spoke about their own personal experiences with finding these schools, and how these schools are very limited.

6.4.7 Limited governmental support

Few parents spoke about the limited support from the government for their children with ASD. Even though the government stated that school should be able to provide inclusion and support to those with disabilities, however the implementation of these rules has been very poorly taken into action (Almasoud, 2010b; Alquraini, 2010; Zeina, Al-Ayadhi, & Bashir, 2014). In addition, individuals with ASD, who are not severely effected by it, do not benefit from the governmental support, such as paying the fees of the private schools, or providing shadow teachers, offering more available public schools with inclusion, and vocational training along with work opportunities for them. As this might affect the progress of the individual and subsequently his/her transition to the next educational grade and graduation, which leaves the parents feeling lost, pressured, and helpless trying to fight for their children's right and finding the appropriate schools. Three of the parents cited:

'Their rights are not considered, and I am not the only one. For example, their education rights, the right for inclusion, support for them during the inclusion' (Parent 5)

'We would like governmental support although it does not exist. Although the things that exists, they only exist by name but we are not using it and we all know that. For example, in the case of my son, he needs someone who is a specialist in special needs area who would know how to communicate with him and help him understand things and details that I don't know how to make him understands it!' (Parent 6)

'The government should have this in mind as well, to provide them with work opportunities, certificates that they can gain, vocational training, workshops, and to see what are the abilities of each child, in order to help that child accordingly, offer him a job, or a salary, just to make the person feel as a responsible person in the community. Not as a burden on anyone.' (Parent 7)

The parents needed governmental support, and the rights of their children to be implemented, which would be a relief for them and benefit their children in the future. The following theme is going to discuss the future worries of families of individuals with ASD.

6.5 Theme 5: Parental concerns

A number of the parents pointed out some of their concerns about the future of their children with ASD in their upcoming transitions in life. One of the main worries was whether their child is going to be independent in the future? For example, concerns about getting qualifications, being able to find a job and become financially stable. Another concern was about, who will look after those individuals with autism that are dependent on their parents in case they passed away. All of these concerns leave the parents feeling worried, stressed, and helpless. They revealed:

'There is a problem, which is that the mother worries about her son's future. I keep wondering about my son's future. He didn't learn any vocational skills, he doesn't have any qualifications or a degree! What if my husband and I died? His brothers are going to look after him, but he will be a burden on them, a burden on the community. But if there was a way where he can learn something, or have vocational training. So he can work in the future, and be financially independent. This is a huge problem that the mother and child face' (Parent 7)

'Except that the only fact that's worrying his father and I, is concerning his future if anything happened to us. We don't know what might happen to him? What might his future be like?' (Parent 8)

'I would like to know his capabilities and what he can do, can he work? Because at the moment, his time is managed and organized by school but later on it won't be the same and this is what I wish for him. Is he going to be accepted in universities and jobs?' (Parent 12)

'I am actually worried from his transition from childhood to adolescence. I don't know what to do? ... I have a hope that I wish to get him married one day, and find him a good wife. But I still have a lot of question marks around that, and I don't know what will happen in the future?... I am hoping that one day with the help of Allah he will be independent, work, and be a valued member in the community.... I think I will even face difficulties regarding finding him a job, if I ever found one.' (Parent 5)

These parents talked about their wishes for their children to become independent members in the community, and they also expressed some of their worries regarding this matter.

6.6 Chapter Summary

The results of the interviews with parents from the KSA are expressed in five themes. The first theme focused on the participants' varied experiences with diagnosis. The second theme concerned the experience with educational provision, such as inclusion or specialized centres, and some of the positive and challenging experiences in these settings. Theme three

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addressed childhood and adolescence experiences, which included puberty and strategies used in this particular transition, as highlighted by the parents. Finally, available and missing supports, along with parental worries were the last two themes explored in the study. In Chapter 7 there is further discussion of these themes and outcomes.

Chapter 7 Discussion

The present chapter discusses the findings from the study concerning how individuals with autism and families experience transition from childhood to adulthood. As previously discussed, the study applied the life history method to collect the data from the first group of participants. There are limited researches that have used this method with Adults with ASD from the UK, to explore the different transitions in their lives. The raw data revealed some significant qualitative findings, enabling the present study to contribute to current awareness of the unique experiences of people with autism during their lives. Additionally, this is the first study to explore these transitions through the perspectives of mothers in the KSA, by using semi-structured interviews. The results are evaluated using thematic analysis. The following chapter is organised using these themes: diagnosis experience; childhood experience; educational provisions; the transition to puberty and adolescence; employment experiences; in addition to the varied support and their relationships experiences.

7.1 Theme 1: Diagnosis experience

The first theme explored describes the varied diagnosis experiences of the participants in this study. Since getting a diagnosis with ASD is considered one of the first transitions an individual with ASD and families go through, it is an important place to start. Although the sample from the UK were in a different age range to the KSA sample overall, it enables this study to offer insightful comments from both groups about the importance of a diagnosis.

At first glance, there are differences between the diagnostic practices experienced by each sample. Practice in the UK twenty years ago was not as robust as it is now. This means that possibly there were not enough services and professionals to support these individuals in the UK (Howlin & Moore, 1997), as they are now. This is because the age of the participants from the UK varied between 18 to 51 years old as was remarked by Charles and Edward, (the older participants in the group). This is similar to the present situation in the KSA, which was commented on by the mothers of individuals with ASD. In addition, the sample from the UK were diagnosed at a different point in time to the Saudi sample, which was at a time when services were less developed in the UK than they are today. Different time periods would also mean that prevailing diagnostic criteria were different. The reason for this finding could be related to the fact that the participants were diagnosed using the old versions of the diagnostic

manual, consistent with their age and the tools that were used at that time. At that time all the participants in the UK were diagnosed as having Asperger's syndrome. Indeed, the revision of diagnostic criteria is a significant matter in the development of autism services in general, (Worley & Matson, 2012). The literature demonstrates that appropriate intervention can lead to a significant development in the quality of life for individuals with ASD and their families (Karst & Van Hecke, 2012). The data shows that the participants felt that getting a proper diagnosis was a major milestone in their lives.

Although many studies in the KSA literature have mentioned autism service provision, there are less particular details of the application and operation of these services. The present study seeks to contribute to the understanding of the different transitions along with the available services in the KSA. This is because the literature in this field is limited. As Al-Ahmadi and Roland (2005) point out, "like other countries, Saudi Arabia is facing challenges due to growing demand on health services, rising costs, and public pressure for better services" (p.331). In the current study, some of the participants from Saudi were ultimately diagnosed abroad, such as in the UK. One of the issues that emerge from these findings is that it indicates that services in the KSA remain scarce. Therefore, the present findings can support movements towards additional and more effective services and diagnosis in Saudi Arabia. Hence, these results are in accord with recent studies indicating that services are limited in major cities in the KSA (Almasoud, 2010b; Babatin, Alzahrani, Jan, Alkarimi, & Jan, 2016). Even these limited services have been established only recently, which means that younger children with ASD will benefit more than the older individuals with ASD. The results show that the mothers of the children who had an early diagnosis were able to find suitable specialized centres for their children and to access support.

In summary, this study contributes to the issues surrounding the diagnosis of autism by considering the views of those most affected by either an early or a belated assessment. The next section will consider early diagnosis.

7.1.1 Factors that Help Individuals with ASD: Early Diagnosis

During the data collection various sub-themes were explored, including those factors that either hinder or help with autism transition, from the perspective of the participants. In this respect, the stage and quality of diagnosis is crucial to transitioning considering that it puts

the individual on a course of intervention and improvement, which includes preparing them for the next transition (Jones et al., 2014).

In the UK sample, positive experiences were recounted by Daisy and Jasmine, who indicated they had been diagnosed at an early age and felt this had helped them. They stated this enabled them to access appropriate care, and be educated in a special school where they felt more understood. This is an interesting finding, since both participants were females, which could be due to the fact that school staffs were aware of their condition, because they recognized their difficulties in school. Interestingly, they were the only females who took part in the study and the only ones who reported an early diagnosis. This needs further follow-up to ascertain why only females made this point.

A diagnostic experience can affect how families respond to and cope with intervention plans for their children (Hasnat & Graves, 2000). Clinical understanding implies that relevant intervention methods are connected with significant development in functioning, which means early and appropriate diagnosis could have a significant long-term impact on outcomes (Hedley, Young, Angelica, Gallegos, & Marcin Salazar, 2010; Leyfer et al., 2006). The current study found that most of the Saudi parent's children were diagnosed when they were 3 years old. After that, the parents sought appropriate education for their children. In addition, two of the Saudi mothers who had two children with ASD in their family (Parent 4 and Parent 10) were able to get an earlier diagnosis for their second child compared to their first child. These mothers stated it was because of their previous experience with the first child, which led them to intervene early and seek the appropriate support for their children. It might be argued that the mothers in the study felt that they got a direction to get a better provision for their children, even if it is not perfect but they started the journey. The stage at which an individual with autism is correctly diagnosed is, therefore, important, since it enables the child to get the suitable care and help needed as soon as possible (Wing et al., 2011). This appears to suggest that, early diagnosis can help individuals with autism and families decide what the next suitable transition for the individual.

Early diagnosis has different valuable implications to the individuals with ASD's lives, which are very important. This is because it affects the individual's different transitions in life, along with finding the appropriate support for the individuals and families. Therefore, diagnosis is the key to access the appropriate available support in both sets of samples. This is because the data from both samples showed that individuals who were diagnosed early were able to access

support in a more timely manner. The following subtheme will discuss an opposing matter, which is late diagnosis.

7.1.2 Factors that Hinder Individuals with ASD:

7.1.2.1 Late Diagnosis

Some of the participants from the UK experienced a late diagnosis. For example, Charles felt socially isolated when he was a child, which he feels was because he was undiagnosed. Interestingly, he claims he had been aware there was '*something different*' about him, which may have made him feel excluded. This result may be explained because Charles received a late diagnosis when he was 27 years old. The implication for this was that Charles faced difficulties in his school because educational professionals were not aware of his condition, and how it had an impact on his transitions in school. The difference that this might have had if he had an early diagnosis, will be finding Charles the appropriate education that suits his needs. In addition to having teachers and staff that are more aware and understanding of the condition, might have made the following transitions smoother in his life.

The problems that late diagnosis can cause were also reflected in the experiences of Parent 13 in the Saudi sample. The mother spoke of her frustrations during her challenging diagnosis experience, where her daughter eventually was appropriately diagnosed when she was 13 years old, in the UK. Without a diagnosis, parents may not fully understand why their children act differently as a consequence they may become anxious when they are confronted with the symptoms of ASD. Not only is this challenging for them but it may also influence the adjustments of the rest of the family (Rao & Beidel, 2009). Parents within the sample often had to visit numerous professionals, which may have been a challenging process in itself and also added to the postponement in getting the diagnosis, which is consistent with experiences in the UK (Howlin & Moore, 1997). Delays in diagnosis might usually lead to delays in transition (Hedley et al., 2010), and research has indicated that adequate information and direction is related with parental satisfaction of care (Hasnat & Graves, 2000). What the majority of the two samples had in common was a struggle to get a diagnosis and then to benefit from that.

7.1.2.2 Misdiagnosis

Another factor that might affect and hinder children with ASD is being misdiagnosed. Because a misdiagnosis could be misleading, which will make the parents and individuals with ASD look in the wrong direction for support and services. Therefore, it affects the following transitions in their lives. From the data, Parent 3 said her doctor had thought there was something wrong with her child's hearing, which was not the case for her son. This is often a first check, which is done in both countries to eliminate hearing loss as a cause for the child's difficulties. This is an interesting finding, since it is also known that people with autism may be unusually sensitive to stimulus, including noise and also that studies have found a mild connection between autism and deafness (Rosenhall, Nordin, Sandström, Ahlsén, & Gillberg, 1999). However, an explanation to this could be because children with ASD lack eye contact, and some of them have difficulties responding to their names. This might appear to suggest that this makes the diagnosis challenging to the clinicians leading them to wrong conclusions regarding the diagnosis. Or some general practitioners might be encountered with cases of autism for the first time in their practice. It could alternatively show drawing of improper conclusions from unclear data. For example, if the child was not paying attention or responding, due to a lack of awareness in social interaction (McConnell, 2002), which the doctor could incorrectly assume that it was due to their auditory capacity. Alternatively, doctors may have had training or access to manuals such as the DSM or ICD, but did not accurately apply them or did not associate the criteria with the child's behaviour. The actual reasons why the misdiagnosis occurred in each case are important. Because this could be either that doctors did not apply their knowledge and expertise of diagnosing individuals with ASD adequately, or because of some issues in the actual diagnostic criteria themselves (Wing et al., 2011). These problems that arise with diagnosis are the ones that should be reflected in measures to improve public services.

However, these findings do not necessarily indicate any particular deficiencies with medical practice in Saudi Arabia as compared to that in the UK. This is since misdiagnosis is a relatively common experience reported by families of children with ASD (Al-Ahmadi & Roland, 2005; Takara, Kondo, & Kuba, 2015). The literature has shown that parents of children with ASD in the UK often encounter limited understanding in the medical profession and an increased awareness amongst healthcare professionals has been known by the UK Government as an essential first step in improving health care for people with ASD (Department of Health, 2010; Jones et al., 2014). In the current study, the actual reasons why

the doctors did not make a correct diagnosis are not the focus of this study. However, some of the reasons that might be behind the misdiagnosis in the KSA as reported by the mothers and previous literature, were because of the lack of clinicians in the field and lack of awareness (Al-Farsi et al., 2011). Additionally, the misdiagnosis encountered by the UK sample, is probably because the participants that experienced a misdiagnosis were Charles and Edward. As they were the older participants, since Charles is 45 and Edward is 51 years old. This might appear to suggest that the reason behind this finding could be because of the lack of appropriate diagnosis and awareness about the condition in the past in the UK. Autism may be particularly difficult to diagnose, because it involve behaviours that are difficult to distinguish from other disorders, for example, Takara et al. (2015) noted “poor social communication skills, unique thinking and bizarre behaviours of ASD resemble negative symptoms and disorganized thoughts/behaviours of schizophrenia” (p.74). This finding has important implications for developing better awareness, more professionals in the field, and services such as the path taken by the UK or USA, which made them more advanced in the field.

This raises questions about differences in awareness and readiness amongst general practitioners within primary care, as opposed to specialists with specific training in child disability. Consequently, the ability of primary care specialists to detect the condition is essential because primary care is usually the first step for parents (Robins, 2008). Primary care practitioners play an important part raising awareness of ASD especially in the referral process. Parent 13 in the Saudi sample stated a psychologist saw their child and she felt that services were poor, even with specialist training. She also stated her concern at what she considered to be a lack of efficiency, as the doctor had not provided her with a report about her child’s condition, which left the parent feeling lost and worried about her daughter. Some of the factors that hinders individuals with ASD and families relates to experiencing a late diagnosis or a misdiagnosis. However, this impacts the varied next transitions that the person with ASD and families experience. The next subtheme is going to explore parental awareness regarding the diagnosis of their children.

7.1.3 Parental awareness

Typically, children spend most of their infant and early childhood years at home with their parents, and therefore, parents tend to know their children best. It follows then that it will often be the parents who first recognise there are problems and that their child is different to

others. This was the case with all the children in the KSA sample, although the experience of children in the UK varied, with some children only being identified by their school. For example, it was only when Daisy and Michael had gone to mainstream school that their teachers recognised their condition. This finding is interesting, given that neither sets of parents would be expected to have any required technical knowledge. It may also reflect a simple lack of knowledge on the part of the UK sample of their parents' views. In addition, the symptoms of Asperger's syndrome are less obvious in the UK sample, whereas parents in KSA are more likely to encounter severe symptoms at an early stage, even without a diagnosis. It is also the case that in the UK, there is a greater awareness of special educational needs, as it is more embedded into the school curriculum, and into the education school system. It is unsurprising that many of the young people were their challenges where picked up by the school when they were young. So schools and families were working together but mostly the referral was coming from the school. This result was in contradiction to the mother's experience in Saudi, where none of their children was identified in school, and the parent had to push to seek the appropriate diagnosis for their children. This could be explained by the fact as mentioned in the review of the KSA chapter 2 (section 2.5) regarding provision for special educational needs for children in Saudi, where it is limited.

It is also interesting to note from the results that Parent 1 in the Saudi sample appeared to have some awareness of conditions such as ADHD. This result indicates the importance of public awareness of developmental disorders in general. Parental awareness may also be quicker where the parent has more than one child with ASD, enabling them to compare development between children. This highlights the importance of knowledge and awareness not only of the conditions themselves but also the process. This section explored the parents' awareness and identification of their children. The next theme is concerned with the transition, which focuses on the childhood experience of individuals with ASD.

7.2 Theme 2: Transitioning to childhood

As infants grow into children, they are involved in a much wider range of behaviours and interactions. However, ASD might impact their capabilities throughout the varied transitions in life (Wehman et al., 2014) and this can have a significant influence on their childhood experience overall.

7.2.1 Factors that hinders individuals with ASD: challenging childhood

Some children with ASD may show challenging and distressing behaviour during circumstances of change and transitions in their childhood (Bull, Oliver, & Woodcock, 2017; Schreibman et al., 2000). In the current study, experiences of challenges during childhood were reported by half of the mothers from the KSA, along with half of the UK participants. One of the most frequent comments made reflected on ASD related symptoms and characteristics that children with ASD exhibit, such as social and communication impairments. For example, Parent 8 struggled with her son because she was having difficulties communicating with him during his childhood *'He didn't know how to express his needs'*. Also, other mothers reported that their children had not developed basic abilities expected of children at their age, such as talking or eating (Parent 4). This suggests that difficulties that children with ASD encounter during their childhood, impacts on their subsequent transitions, such as school. Therefore, early and targeted intervention could provide children with life-long learning abilities, which could result in recognisable improvements in intellectual, behavioural and language abilities (Rogers & Vismara, 2008).

Similarly, from the UK sample Charles expressed that he experienced a challenging childhood due to having family problems, challenges in school, and difficulties making friends. He stated that by the age of 12 he was admitted to a mental healthcare facility, which had a significant effect on him and his self-perceptions during his childhood years. Furthermore, Charles said his parents *'abandoned'* him and then he was fostered. It seems reasonable to conclude that his family's behaviour was a result of their not being aware of his condition, rather than being neglectful of him. This is a significant insight for this study, because it points to the anxiety that a lack of understanding or ignorance of autism, both from parents and individuals alike, can cause. This may be considered self evident, but it offers a powerful example of the reality.

The second challenge pointed out by the sample parents was some of the monotonous and restricted behaviour their children or the individual displayed. From the results, almost half of the mothers found challenges during their children's childhood with their attachments to routine or a certain type of food, or clothes. Also, Parent 10 noted the difficulties they faced with her daughter, were because she displayed self-harming behaviour *'biting her fingers'*. All of these behaviours are considered "Restricted and repetitive behaviours" that some individuals with ASD exhibit, which are considered challenging for the parents, and causing

them stress (Harrop et al., 2016, p. 1773). All of these challenges could hinder the child's socialization with others around him/her, or learning and attending school particularly during childhood, which will consequently affect the following transitions in adulthood.

The third finding that the mothers in the present research reported was the difficulties with toilet training, which they faced during their children's childhood years. This finding is consistent with previous literature that found that children with ASD face difficulties with toilet-training (Dalrymple & Ruble, 1992; Drysdale, Lee, Anderson, & Moore, 2015; McLay, Carnett, van der Meer, & Lang, 2015; Richardson, 2016). The data gathered in Saudi Arabia showed that this factor could hinder some of the individuals with ASD. This could be because some schools or special centers do not accept children who are not toilet-trained. However, the adults with ASD did not mention this difficulty during their childhood. A possible explanation for this could be because they were not directly asked about it, since it is not the focus of this study. Also, perhaps they felt embarrassed discussing it or could not recall it.

Another challenge stated in both of the samples was the lack of awareness in the community and lack of services, which the individuals and families encountered. From the findings, a number of participants indicated considerable disappointment with the capability of services in their country to assist their transition throughout childhood. For instance, Edward stated that there had not been given enough information or knowledge concerning his condition when he was growing up, given that he is 51 years old. This appears to show the lack of services in the past, which also made him feel that he was not offered appropriate services that were suitable for his developmental needs. However, he suggested school experience is likely to be better at the present time due to improved '*understanding*'.

Edward's experience is familiar to people living in the KSA, where the country undergoes a lack of service provision in general (Al-Salehi et al., 2009). Moreover, Edward associated this lack of provision with his unpleasant social experiences during his childhood years. He claimed he was '*bullied...and abused*' by people as well, and that his childhood years were '*total horror*'. The result may be explained by that fact that services in the past were not well established, and the community lacked general awareness about the condition. The current study therefore contributes to an understanding of the experiences that individuals with autism go through, which implies the need for improved provision at this transition stage.

Transitions are a critical matter for families with a child with ASD (Lounds et al., 2007), and parents take the responsibility for guiding their children throughout their life when services and support services are lacking. For instance, a number of the parents knew their children and their particular behavioural tendencies, more than anybody. Parents in many cases are the first point of contact as they are the most familiar with their child's condition. (Dymond, Gilson, & Myran, 2007). The results also show that these challenging childhood experiences that children with ASD go through affect parents as well, making them feel stressed and overwhelmed (Harrop, Gulsrud, Shih, Hovsepyan, & Kasari, 2015; Harrop et al., 2016; Hastings, 2003; Henninger & Taylor, 2014; Ozturk et al., 2014). There is already a considerable amount of literature concerned with parents' experiences of raising a child with ASD (Henninger & Taylor, 2014; Hetherington et al., 2010; Langan, 2011; Ozturk et al., 2014; Rattaz et al., 2014; Selimoglu et al., 2013; Stoner et al., 2007). However, the development of suitable strategies and services for transition is what most parents need help with. These findings might help us understand the varied challenges that individuals with ASD and families encounter since childhood. This is important to understand, in order to help them during this childhood phase, which might impact their next transitions.

7.2.2 Unexpected points

Regardless of these challenging experiences, an unanticipated point was that half of the UK sample reported a positive childhood experience. For example, Daisy, Michael and Jasmine stated that their childhood had been '*content*' and '*simple childhood*'. They all suggested that they had noticed there was something different about them; still, they felt that it did not significantly impact negatively on their childhood years. Daisy found she enjoyed her experience at the special school where the people understood her and spoke of her potential to experience lifelong friendships with the people she met there. Another factor underlying her positive feelings was Daisy's strong relationship with her close family members. This point consequently serves to demonstrate that significant relationships and understanding of others around, and produce positive childhood experiences in the subsequent transitions. Yet, another explanation to this finding could be because the participants were young children mostly playing and not focused on the implications of having ASD in their following transitions in life. It also shows that sometimes a positive childhood experience does not necessarily impact the following transitions in adolescence or adulthood, since some of these individuals experienced challenges in the following transitions after childhood (see Chapter 5). Nevertheless, this needs to be further investigated with a wider sample. It is also

interesting to note that in the Saudi sample, positive experience was generally acknowledged by the parents in terms of their satisfaction with the services (for instance, Parent 2 and Parent 9), as well as the noticeable improvements in their children's skills. What is clear is that where support services are provided parents must be positively engaged with them from the outset so that they, in turn, can encourage their children to feel equally positive. It also behoves providers to adopt an invitational approach when interacting with these parents and their children.

This theme encompasses the varied childhood experiences that individuals with ASD and parents encounter with their children, from obvious factors that hinder their childhood development, to some unexpected outcomes, such as where the child reported no challenging factors during childhood.

7.3 Theme 3: Educational provision

All of the participants in the UK sample began their education at mainstream primary schools, before having to continue or make the switch to special schools at a later stage. Children in the Saudi sample have been to both mainstream and special centers. All of the participants had varying experiences. This raises questions concerning the participant's views on the positive aspects and disadvantages of mainstream and special centers along with the appropriate place whereby a child with autism could be taught.

7.3.1 Factors that hinders individuals with ASD and families: educational challenges

Some of the children with ASD face certain difficulties when they first transition to school, which hinder their learning. Therefore, in most cases, additional support is needed for children with disabilities while they transition to nursery school mainly because of their special needs (Quintero & McIntyre, 2011). The results are in line with those of previous studies that mentioned, children with ASD face some difficulties when they first transition to school, due to their ASD characteristics, (Hume et al., 2014; Quintero & McIntyre, 2011) as in the case of two of the UK participants, Charles and Daisy. In the case of the KSA, some of the mothers found this transition to be challenging, because they were not able to find suitable schools/ specialized centers that were willing to accept their children. However, the findings also showed that three of the participants (Michael, Jasmine, David) had a positive school experience when they first joined school. For instance, Jasmine said: '*It was just so much easier.*' This result may be explained by the fact that nursery and primary school had a simple

and easy curriculum, and the fact that the sample from the UK consisted of adults with Asperger's, which made this first school transition smooth.

Another factor that hinders children with ASD is the shortage of available services, teachers, and suitable schools. This implies that some students with disabilities in the KSA are not getting the support they need (Alquraini, 2010). Moreover, Aldabas (2015) points to the Rules and Regulations of Special Education Programs (RRSEP), which was in 2001 and recognized "the right of students with disabilities to have access to special education programs" (p.1161). He notes that its practical application happens to be limited by insufficient expert staff needed to carry out diagnostic assessments, along with a shortage of evaluation tools to identify the suitable learning setting for such individuals with disabilities. Lack of training may account for why mainstream and specialised schools refused to take Parent 13's child, in circumstances where both thought the child's needs were more appropriate to the other type of school, which left the parent feeling lost and helpless.

The sample parents reported that the KSA currently lacks services for children with more severe needs and funding remains insufficient to meet the costs of private institutions (Almasoud, 2010b; Alquraini, 2010, 2013; Kelly et al., 2016). However, the results showed that Parent 3 was the only mother who reported she had support from the government by paying for her child's education at a private specialized center in Saudi. This result may be explained by the fact that Parent 3 son's ASD characteristics were severe, which necessitated that he attend specialized centres. On the other hand, the only option that is provided by the government for children who were not severely affected with ASD, is to attend a public mainstream school that offers inclusion specifically for children with autism, of which there are very few in the KSA.

One interesting finding is that one of the hardest transitions that four of the mothers noted was the transition of their sons to a boys' school or centre. This may be explained by the fact that Saudi Arabia is a gender-segregated community (Madi, 2014) [see Chapter 2 for additional detail on the education system in the KSA]. It shows how culture can impact the child's transition between schools. Since the mothers in the study stated that this specific transition to a male centre proved very challenging to the child and to the family.

7.3.2 Mainstream schools and inclusion

Mainstream schools effectively mirror the real world; the place where individuals with autism could be prepared to come across a majority population of typically developing individuals, in a modern and mainstream setting. Through these situations, mainstream schools can offer academic education but importantly the chance for students with disabilities to be familiar with intrapersonal abilities needed to be successful in the broader community as well.

Training in social skills is particularly critical for children with ASD, considering their typical disinterest in social interaction along with poorer basic social skills and communication in general (Lal, 2005). The need to provide both students with disabilities and typically developing students with opportunities to interact with each other has influenced the steady development of inclusive philosophies, steering the trend towards the deeper integration of disabled students into mainstream education.

Integration and inclusion allow able and disabled students to interact with each other and provide the student with ASD with a more realistic social education. Mainstream schools are perhaps unique in their ability to provide such an experience, in comparison with special schools. Interestingly, the findings showed that three of the parents from the KSA enrolled their children in schools mainly for social inclusion, while they were specifically trained for autism. For example, parent 12 said: *‘...my aim from this was for him to be integrated with other kids rather than learning’*. Sample parents felt that this was an important aspect of education.

Knowledge of disability along with ways to communicate with children with disabilities is important, so inclusion helps ensure an essential exchange of information and understanding between both sets of students. Lal (2005) argues that integration could possibly develop the beliefs and communication of typically developing students regarding their peers with disabilities and promote more well-adjusted societies in adulthood. There is a need for more teachers who understand autism in mainstream schools, as the participants in both samples felt that it was lacking. Consequently, half of the UK participants had to move to special schools, rather than be included in mainstream schools. Primarily because they struggle with managing their feelings and learning, for which reason they transfer to special schools where they feel accepted and supported. Mothers from the KSA also struggled with finding the appropriate provision for their children. The more pressing issue was the availability and accessibility of specialist autism services. Most of the discussions with Saudi families

revealed they had been struggling to find schools that could support their children. Some mothers reported that their children ended up attending mainstream schools where no process of inclusion was provided. These findings suggest that the KSA is arguably a few stages behind the UK in terms of service provision but it is likely that similar concerns about the efficiency of services will arise, as in the UK, when availability increases.

Legislation for promoting inclusive learning for individuals with disabilities started in the early 2000's (Department for Education and Skills (DfES), 2001). This might have been the case in the past 15 years in England, as the experience of the older UK participants (Charles and Edward). Since, the first legislation in England focusing on individuals with ASD was the '*Autism Act 2009*' (Pellicano et al., 2013).

From the results, a number of the parents pointed out their struggle with finding suitable mainstream schools that offers inclusion for children with ASD. However, the findings show that individuals in the UK are better able to access supportive schools in comparison to Saudi. Three of the mothers brought up the lack of specialized centres after their child got past the age of 16, which left the parents feeling worried about the next transition for their child. Three of the mothers discussed other failings with governmental support, such as providing inclusive schools, and support teachers for individuals with ASD. The ability of the school to offer inclusion and support to those with disabilities appear to have been expected by the KSA government, but the implementation of these particular guidelines is limited, as previous literature has indicated (Almasoud, 2010b; Alquraini, 2010; Zeina et al., 2014).

In contrast to many other sample parents, Parent 12 was eventually able to find a mainstream school with inclusion, but this was only after she had contacted the Ministry of Education directly, despite the fact that legislation for individuals with disabilities in the KSA has been available for over a decade (Alquraini, 2010, 2013). Although, these findings suggest it is important for parents in Saudi to be informed about the services available, even though the sample parents reported a gap between the KSA's stated policies and service provision in practice. These results are in agreement with previous literature regarding the disparity between legislation and implementation in Saudi Arabia (Alquraini, 2010, 2013; Zeina et al., 2014). A possible explanation for this, is the lack of specialists in the field, and the lack of awareness among parents regarding their children's rights (Aldabas, 2015; Alquraini, 2013). Another finding was also similar to these previous literature, which revealed that two of the mothers (Parent 5 and 13), spoke about the lack of specialists who can deal with their children

in school: Parent 13 said: *'because they do not have teachers or a specialist that can deal with her'*.

The findings of this study showed that inclusion is paradoxical. Since the parents from Saudi Arabia wanted an inclusion of their children in mainstream that is exclusive sometimes. Inclusion for the Saudi parents is for children to be included in the class for certain subjects, and excluded from class for other subjects, then they are taught in a separate room called a 'resource room'. As Parent 13 noted, her daughter used to be excluded from certain subjects to be taught in the resource room: *'They used to have a resource room in 1st, 2nd, and 3rd grade but not anymore'*. This is something that most of the mothers from the KSA wanted for their children in mainstream schools. The parents wanted their children to access the curriculum but also to be exclusive, so that it is tailored for their needs. Therefore, this is inclusion that is exclusive, which is paradoxical.

However, this contrasts with the experience in the UK, because students have TAs (teaching assistants) with them in class who keep them on task and this is seen as an inclusive provision. The adults in the UK all stated that they went to mainstream schools at the beginning, which is inclusive because they were not taken out from their class at any time. However, some of them did not feel part of the system; they felt misunderstood and unsupported. Therefore, they were transferred to special schools where they felt accepted and understood. For example, Daisy said: *'I went to mainstream at first until they recognised my difficulties; they sent me to a special school'*.

The findings from this research show that inclusion means different things in different contexts. It is considered paradoxical because inclusion by its nature is exclusion, since it was not providing individuals with what they needed. Children in Saudi did not get what they required from their parents perspective, and the adults in the UK felt very overwhelmed by an educational system that was not meeting their needs. These results are in line with previous literature that discussed the nature of inclusive or exclusive education for children with ASD (Ravet, 2011). Additionally, only two of the UK participants spoke about their experience in secondary school. For example, Jasmine pointed out her difficulties with understanding the material, which made it hard to pass the exams. This result, is consistent with those of Hannah and Topping (2013), which found that individuals with ASD face some difficulties regarding their studies and the curriculum in secondary school.

The varied educational provisions that the participants and families went through during this transition were discussed in this theme. Furthermore, the next theme will explore the puberty and adolescence transitions of the participants in the current study.

7.4 Theme 4: Adolescence and Puberty Experiences

As opposed to transitions to new educational settings, which can be social and intellectual transitions in general, whereas transitions into puberty and adolescence are biological and physiological (Dewinter et al., 2014; Hénault, 2005). Puberty happens gradually over time, usually without distinct indicators to either the parents or child that this process is happening at any specific moment. Previous literature have shown that there has been limited research concerning issues of sexuality in individuals with autism (Dewinter et al., 2014; Sullivan & Caterino, 2008), so the current study is able to contribute to an understanding of the experiences of people with autism and families throughout these transitions. The following section begins by discussing the results from the research regarding the experiences associated with adolescence, puberty, along with the unexpected findings that had been noted from the study.

7.4.1 Experiences during Adolescence

Previous literature has found that adolescence could be a challenging transition in the life of people with ASD, considering that it is the time when the individuals with ASD and their families need planning for the upcoming transitions to the adult years (Seltzer et al., 2003). Some of the mothers from the KSA noted mixed experiences during the adolescence phase of their children, three of them talked about their increased concerns regarding their children reaching adolescence, while other mothers noted a positive experience.

The Saudi parents talked about the psychological changes that their youngsters experienced when reaching adolescence. For instance, four of the mothers noticed that their children started exhibiting changes in their behaviours and temperament such as stubbornness, which could be due to their limited verbal abilities of expressing themselves. This result is in agreement with O'Brien (2016) findings, which showed that the parents in the research noted difficulties regarding the behaviours that their adolescents exhibit. This might indicate the enhanced interest of the child when growing up in self-determination. These findings are in agreement with Crockett and Crouter (2014) regarding the adolescent phase of individuals.

From the raw data, adults from the UK such as Daisy pointed out experiencing confusion when going through adolescence, yet eventually felt happy when she became more mature. However, mixed feelings were experienced by Charles, who stated feeling scared regarding the following transitions but also being curious and looking forward to new choices in his life, such as earning his own money. Alongside these challenging experiences that were also found in previous literature (O'Brien, 2016; Seltzer et al., 2003). Some points were also made by the participants, which consequently offer a further aspect to the perception of adolescence and puberty transitions among individuals with ASD. The next section will focus on discussing the results associated with the parents' perception regarding their experiences with the puberty phase of their children.

7.4.2 Puberty: Parental Perceptions

The parent's perception of the transition to puberty of their children with ASD was explored in this study. The results of the study are in agreement with those obtained by (Gillberg, 1984; Seltzer et al., 2003), as data from the KSA sample showed that the parents were particularly concerned about their children's transition during puberty. Four of the mothers were worried and had concerns about what they are supposed to do or say at the time when puberty occurs, and how to deal with their child. Another concern noted by Parent 2 and Parent 5 was how to react to changes in their child's behaviour, for example, their child's interest in their changing physiologies, hair growth, and developing body parts (Parent 3 and Parent 7).

It is found in previous literature that adolescents with ASD may often engage in inappropriate sexual behaviour publically (Cridland, Caputi, Jones, & Magee, 2015; Dewinter et al., 2014) and the parents find this particularly problematic (Dewinter et al., 2014). As, Parent 8 talked about her understanding that her son may possibly develop other different challenging behaviours, which she might need to address, along with the challenging behaviours displayed previously (Seltzer et al., 2003). However, two of the mothers noted experiencing increased challenges because their children were non-verbal, which has implications for developing special transition plans for children with ASD, who are non-verbal.

Another finding was the menstruation pain that was experienced by the females in the study, such as pointed out by Parent 4, Parent 11 and Daisy from the UK sample. The mothers noticed some behavioural changes in their daughters during that time. This may be specifically worrisome at the time, even for typically developing individuals (Rawat, Sagar, &

Khakha, 2015). It has been shown in the literature that menstruation can be a major difficulty for girls with ASD (Skinner, Ng, McDonald, & Walters, 2005). However, this is certainly a gender-specific transition, in situations whereas numerous studies have tended to give attention to males with ASD as opposed to females (Cridland et al., 2014). This finding has implications for developing further research, which is needed to understand the puberty process in girls with autism.

7.4.3 Puberty: Perceptions of individuals with ASD

The current study aims to clarify the perceptions of people with ASD regarding their transition experiences during puberty. The adults from the UK sample provided a slightly different perception of their experiences during puberty, as opposed to the perceptions of the mothers from the KSA. For instance, Michael considered that his transition to puberty was not more challenging for him compared to typically developing children. This could suggest that parents are particularly more concerned about the puberty phase of their children with ASD and may possibly indicate a significantly broader variety of differences, such as the severity of disability between individuals, cultural differences, or the accessibility to support.

Jasmine and Daisy talked about being anxious through the transition to puberty period. In addition, to Parent 13 who revealed that her daughter has cited, "*I hate puberty*". A probable explanation to this could be because her daughter found this phase challenging and this is why she hated it, with all the responsibilities that she will have after this phase. Therefore, the data from the UK sample complements the results from mothers in the KSA. Due to the fact that the UK participants felt able to talk about their own subjective, psychological experiences and views, while the parents were able to recognise further objective, physiological and behavioural changes in their children.

Another key finding, was that Michael shared that when he was younger; he started to think of suicide, even though in his opinion that it was a passing phase, as he thought that he was not the only one. He thought that even typical developing children generally encounter such similar suicidal thoughts. There is anecdotal information about suicidal thoughts reported, which are considered to be prevalent in individuals with ASD, particularly adolescents (Cassidy et al., 2014). However, specific research into suicidal thinking among individuals with ASD is relatively limited. It is pointed in previous research that suicidal thoughts are more common in individuals with ASD compared to typical developing individuals in the

UK, which is in contrast to what Michael have suggested to be common between adolescents (Cassidy et al., 2014; Raja, Azzoni, & Frustaci, 2011). This finding, was only brought up by one of the participants, however it offers significant implications for conducting more research into individuals with ASD and their suicidal thoughts, in order to develop suitable services for them as they go through puberty. The present research has provided an insight into some of the challenges that individuals with ASD encounter. The subsequent section is going to discuss some of the aspects that helped them and families throughout this transition.

7.4.4 Factors that helped individuals with ASD and families

There are different features and strategies that helped people with ASD and parents throughout the transition to puberty. From the results, Parent 2 pointed out the professional guidance given by the special centre from abroad, expressing that her daughter had benefited from the use of modelling and social stories, which were about the puberty phase of a girl and using menstrual pads.

Another helpful strategy that individuals from the UK found beneficial, that Daisy has pointed out was getting sex education classes at school. Also David talked about the help he got in school by teaching him how to be independent. On the other hand, sex education is not widely offered within the educational facilities in the KSA, which is often for the reason that these particular matters are viewed as a taboo traditionally (Alquaiz, Almuneef, & Minhas, 2012; AlQuaiz, Kazi, & Al Muneef, 2013). Sex education programs need to be developed and implemented in Saudi Arabia, which should be intended to be appropriate culturally (AlQuaiz et al., 2013). Previous research has found that a lack of sexual awareness among individuals with ASD might lead to be at heightened threat of victimisation sexually (Brown-Lavoie et al., 2014). It is interesting that none of the Saudi mothers has mentioned the absence of sex education in specific. A possible explanation for this could be, because they were not directly asked about sex education, or because the parents were not aware about the importance of it, along with regarding the topic as a taboo culturally. This could likely be a major obstacle during the adolescence together with the puberty transitions that children with ASD go through, as opposed to the positive aspects that sex awareness provided in schools offer for children in the UK.

Reading books was an additional strategy that was common between both groups. As Charles and Parent 13 stated that they benefited from the information included in books regarding the

transition to adolescence and puberty. Alternatively, Edward had another perception, given that he viewed books to be challenging, in order to fully understand from. He also considered them as not useful for individuals with ASD. However, the useful strategy that he found was visually through observing others and modelling them. This rather contradictory result is very important. Since this may be due to the fact that each individual with ASD has a different way of learning, processing information, and of what might be helpful to each person.

Furthermore, this also shows that strategies such as modelling could be a helpful method for other individuals with ASD to learn from, which is to physically show and model new behaviours, seeing that modelling was also one of the strategies implemented with few of the parents. This suggests similar finding to previous literature, which pointed out that people with autism are visual learners, where video-modelling method was proven to be effective (Schaeffer, Hamilton, & Bauman Johnson, 2016; Schatz, Peterson, & Bellini, 2016).

The findings of this study also found that several mothers from the KSA reported increased stress and worries regarding this specific transition of their child. Therefore, Parent 1 mentioned that she required more information and understanding about the transition of her son to puberty in advance. This is an important finding, due to the fact that all youngsters will undergo through puberty at a certain point, and thus parents are supposed to be familiar with some of these concerns that might occur at some time. Therefore, the experience of some of the parents shows that transitions could be notably difficult for the parents. The findings of this study highlight the challenges that parents of youngsters with ASD in Saudi encounter, and recommend the importance of further intensive training concerning puberty in the KSA.

This section included a discussion on the strategies that participants have used to assist them with transitions during puberty, which included reading books, additional guidance from educational facilities, as well as methods like modelling. The following section is going to mention two of the unexpected results. First, that smooth transitions were encountered by some of the participants, and second that a number of the participants were unable to feel that they fully matured and became adults, regardless of going through these transitions.

7.4.5 Unexpected Points

A significant minority of the participants reported an unexpected smooth transition through adolescence. It is interesting because there is an overall negative perception of adolescence and autism, which emphasises the challenges encountered (O'Brien, 2016; Rawat et al., 2015;

Seltzer et al., 2003). Unusually, therefore, this study focuses on a positive approach to the views and perceptions of the parents and individuals with ASD as they move through this phase.

One unanticipated finding was that two of the mothers from the KSA reported going through smoother transitions compared to the rest of the participants in the study. It is notable that both of these mothers had daughters with ASD, and a probable explanation for this could be, as it is noted in previous literature, that females with ASD exhibit less problematic behaviours in general (Cridland et al., 2014). Conversely, other positive experience during the transition to adolescence was brought up by some of the parents who had boys with ASD. For example, two of the parents stated that they saw some improvements in their son's personal self-help skills. These improvements noted by the parents were considered a relief for them, making them less worried about their children. These results are also in line with the limited previous literature that suggested that some of the individuals with ASD could show some improvement in their abilities when they grow up (Cridland et al., 2015; Gillberg, 1984).

A further interesting finding was that Parent 12 indicated that her child's transition was easier as opposed to her other typically developing children. This may show that parents with more than one child could probably be better prepared, because of their previous experiences with their other children in handling issues when they arise throughout their child's growth. This suggests that there is value in the experiences of these parents with ASD children, which could be shared with others and may also help in better understanding of how to support them.

Another unexpected point, which was reported in the results, was that some of the adult participants felt like children. This was common between Parent 13 and three of the UK adults. A possible explanation for this could be that the individual with ASD wanted to avoid the adulthood responsibilities, or perhaps they were still attached to their childhood. For instance, Jasmine shared the same feeling, regardless of being 25. Personal feelings regarding maturation are an under-explored aspect in individuals with ASD. Therefore, the current study might be able to offer a unique insight into the experiences and views of these individuals.

In summary, the perspectives of transition to adolescence and puberty from the parents and individuals' viewpoint, along with the unexpected findings of this particular transition were

explored. Moreover, the next theme will explore the different kind of supports that helped or hindered the individuals with ASD and parents.

7.5 Theme 5: Support

This research has shown that the individuals from both countries depend on a variety of types of support. Determining the type of suitable support that individuals with ASD require will provide significant developments in their lives, along with identifying the appropriate approach to implement it effectively, as this can result in significant benefits in their quality of life.

The current research will also contribute to the understanding of the approaches and support that will help individuals with ASD and their families. The present discussion describes the results of the research regarding the different available supports, particularly the support for seeking accurate diagnosis, family support, wider support groups, specialised service providers, together with the particular strategies employed by autistic families. As well as the aspects that hinder ASD families, particularly when support systems are lacking.

7.5.1 Factors that helped individuals with ASD and families

The results of the present study highlight two of the aspects that helped individuals with ASD: diagnosis and support orientation. For example, Charles pointed out the importance of getting an accurate diagnosis, given that he suggested that without the diagnosis, people with ASD might be unable to orientate independently or reach out to suitable support services. This result seems to be consistent with Begeer et al. (2013), who also suggested that early diagnosis of ASD is important for the individual, in order to get appropriate services and support. It is also found in previous literature that Asperger's syndrome is diagnosed in individuals at a later age in general, around the age of 8 years (Begeer et al., 2013).

The personal experience of individuals with ASD is essential for focusing the attention of other people in their environment, who are willing to support them and their families. Therefore, when the disability is identified, people with ASD and their families reach for further options of support, which will be discussed in the next three sections.

7.5.1.1 Family support

As noted earlier, families are one of the important sources of support for parents of children with ASD (Gupta & Singhal, 2005; Guralnick, 2008; Hartley & Schultz, 2015; Zaidman-Zait et al., 2016). More than half of the mothers from the KSA indicated that various members of the family were helpful. A number of the sample parents highlighted that their family were '*understanding*', which they found helpful. Three of the mothers pointed out the valuable support and relationships between the children with ASD and their typically developing siblings.

Additionally, mothers spoke about the support they had from their husbands. This result was in accordance to previous literature, which mentioned that some of the mothers tend to seek support from their husbands (Boyd, 2002). It was also found in literature that the support of the spouse is considered one of the most valuable assistance to the parent of a child with ASD (Searing, Graham, & Grainger, 2015). For example, Parent 8 mentioned that the valuable support that she had from her husband was that he dealt with her son's school. This is very important to the Saudi mothers because of the gender-segregation in schools (Baki, 2004). The effect of this is that it limits the mother's communication with her son's school and teachers (Aldosari & Pufpaff, 2014). Given that, mothers are considered the primary caregivers of their children with ASD (Aldosari & Pufpaff, 2014; Benson, 2010; Boyd, 2002; Hartley & Schultz, 2015; Zaidman-Zait et al., 2016), mothers require the assistance of a male relative, such as a father or a brother, particularly when they have a male with ASD (Aldosari & Pufpaff, 2014; Baki, 2004).

Individuals from the UK sample also spoke of the assistance they had from their families. For example, Michael regarded them as '*great walls*', because they were understanding and supportive. Edward indicated the best support he got was the emotional support from his spouse. This implies that social skill training is essential for individuals with ASD, in order to help them build their own supportive relationships later in life. Beyond these informal support networks individuals with ASD and parents also access formal professional support, which is going to be discussed in the next subtheme.

7.5.1.2 Professional Support

Searing et al. (2015) indicated that "formal support refers to support provided by an agency or organisation and may be privately or publicly funded but in either case the support-giver has a

formal role and is usually paid for their assistance. Formal supports include family doctors, early intervention programmes and respite care providers.” (p. 3693). Specialists in the field are expected to play a major part in guiding parents of children with autism, and in finding the appropriate services and interventions that will benefit the individual (Lord & Bishop, 2010). From the results, private teachers were employed by a number of the parents as a support strategy in helping them with their children. For instance, Parent 13 employed a different specialist for a variety of skills to teach and train her daughter. In addition, some of the skills or information learnt from the various professionals and private teachers could be shared between parents in their personal support groups. As was found in the KSA sample, where they had a 'Whatsapp group' that included, '*mothers, fathers, teachers, and specialists*' (Parent 7). Lack of the varied support for children with ASD and families in Saudi was also found in previous literature (Babatin et al., 2016). According to these data, it can be inferred that having support for the parents of individuals with ASD is helpful in guiding them through the different transitions in life.

From the UK results, the majority of the participants explained the assistance they received from the government, as well as from different non-profit organisations. Daisy and Jasmine declared that non-profit organisations assisted them with learning a variety of skills. Support workers were mentioned as very helpful to almost all of the UK participants, as they assisted them during some of the different transitions. These findings may help us to understand the value of professional support received by the state for these individuals.

One finding emerged from Charles, is that some of the support he had from the state throughout the transitions in his life, both in his education and employment, was more based on the fact that he was a foster child and less so because he had ASD. This raises the question whether fostered children with ASD have more support and better access to services than others. If so, the implication for this is that individuals with ASD must have access to services and support from the state, regardless whether they were fostered or not.

Charles also talked about an advocacy group that he joined, which assisted him in gaining an awareness of his entitlements, and training him regarding his rights as an Individual with ASD, along with encouraging him to assert them. In his view, this is essential for all the individuals in the spectrum, because it offers information about the available support. Furthermore, Daisy spoke about the support and training she received from the '*Transition Challenge group*', which helped her to learn a variety of skills such as cooking, cleaning, and

budgeting. All of these non-profit organizational supports were found helpful and beneficial for individuals with ASD, which are lacking in the KSA. This has clear implications for developing such services and support for people with ASD in Saudi.

Knowing about the rights for individuals with ASD and families is essential because it enables the person to know the available range of rights and services, including financial assistance (Derguy, Michel, M'Bailara, Roux, & Bouvard, 2015; Siklos & Kerns, 2006). From the Saudi sample, only Parent 3 noted that the state funded her son's private special centre's tuition fees, which was because of the lack of public specialised centres for males in the Kingdom. An explanation for this could be because of the severity of ASD that her child had, or because the parent's knew their child's rights and asked for it. It is found in literature that parents experience some challenges with getting the formal assistance needed (Searing et al., 2015). From these results, the participants spoke of importance and benefits of these organisations. Therefore, it is essential for the individuals to join such organizations, which will offer them support and guidance, along with the varied support that the parents of children with ASD had. The present section has discussed the various forms of formal and informal support that people rely on, and the subsequent section will discuss some of the wider support groups that were mentioned by the participants in this study.

7.5.1.3 Wider Support Groups

Another approach relied upon by parents from the KSA, is through the common support networks of other parents with ASD children, (Clifford & Minnes, 2013; Elfert & Mirenda, 2015; Zaidman-Zait et al., 2016). These kinds of support groups offered parents with some of the methods, mentioned by Parent1 and Parent 3, which have been tried and found useful with their own children. The parents were able to share their experiences, ideas and ask questions easily, utilizing modern technology such as '*Whatsapp groups*'. The mothers revealed that their support groups offered them an approach to obtaining psychological support, along with a place on which they can depend on when things went '*wrong*' (Parent 3).

The current research confirms the effectiveness of support groups for people who share similar experience, even while it has been found that time is often essential for the group participants to develop trust (Shu & Lung, 2005). It can therefore be assumed that support groups were beneficial for the parents where they shared knowledge and understanding for

each other. The following section is going to go over some of the support-related aspects that impede individuals with ASD.

7.5.2 Factors that Hinder Individuals with ASD: Lack of Support

The research gathered data concerning aspects that hinder individuals with ASD and families, which also answers one of the research sub-questions. As it is an essential aspect of this study and it is recognised in the literature (Al-Ahmadi & Roland, 2005; Zeina et al., 2014). There are challenges regarding insufficient support services in the KSA that individuals and families with ASD face, and the current study contributes to the development of sufficient services and support in the country. From the results, it is noted that individuals did not feel that services were sufficient in the UK either, as shown in the results: the proper care and continuing development of people with ASD necessitates valuable cooperation between the individuals, families, formalised assistant networks and the state (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Dunn, Constable, Martins, & Cammuso, 2016).

One of the mothers indicated that her experience of support had been specifically poor, which was in contrast to most of the sample parents in the study. As the parents themselves needed emotional support, they found it essential, as indicated by Parent1, Parent7 and Parent 8. This contrasted with most of the parents in the study who valued the family support that they had. Three of the parents mentioned that they wanted to learn more about the condition to be able to understand and help their children, along with learning ways of how to manage some of their behaviours. Understandably insufficient practical support can add to the emotional challenges parents go through as well (Boyd, 2002).

Participants described numerous support systems that they lacked. Two of the mothers reported the shortage of suitable therapies that are helpful and necessary for their children, such as the lack of speech therapists and occupational therapists. Parent 1 pointed out that she needed information and preparation for her in advance of the transition of her son into puberty. The parents also recommended more awareness in the community and in schools in order for their children to feel more accepted. Further, parents spoken of insufficient clubs and activities in the country for their children.

Furthermore, gender-segregation served as an added difficulty for individuals in the KSA, which is a matter that impacts schools, specialised centres and sports clubs (Baki, 2004; Madi, 2014). For example, three of the mothers explained they were not allowed to undertake things

they would have liked to have accomplished, such as accompanying their son's to sports clubs or driving them to there (Parent 1, 3 and 8). The downside of this is that not having a male relative to help the mothers is a factor that hinders the families and the person with ASD.

Nevertheless, David from the UK participants also felt that social services were not taking enough of their own initiative, which meant he needed to proactively get to know the system that was supposed to be assisting him as a disabled individual. These types of experience provide crucial data for the current study to collect, because feelings of anger and aggravation might be experienced by the individuals as a consequence of poor interaction with the support organisations (Boyd, 2002). It is very important to engage the individual with ASD along with the parents and prepare them to become valuable partners with the different service providers as they grow up (Blue-Banning et al., 2004; Dunn et al., 2016).

Some mothers reported the shortage of appropriate centres, which led to the need to travel to another country, and this in fact is a significant action for a family. In addition, David in the UK pointed out that doctors need to be more helpful for individuals with ASD and families. Another common problem that was raised by Edward and Parent 1 was that less support was provided in small towns in comparison to big cities. This finding has significant implication for developing more accessible ASD services and support in small towns for individuals with ASD and families.

This theme explored the varied available and missing support that helped or hindered the parents of individuals with ASD and the individuals themselves. The following theme with explores the experiences of individuals with ASD regarding the transition to employment.

7.6 Theme 6: Employment

Since autism is a lifelong condition (Hendricks, 2010), individuals with disabilities and their parents can expect further challenges as children transition into adulthood and seek employment. Employment can provide a meaningful way to spend everyday life, allow people to make a contribution to society, and also provide a social circle of support (Chen, Leader, Sung, & Leahy, 2015). Employment can also be seen as a transition for people with ASD (McDonough & Revell, 2010) as they become accustomed to new routines, behaviours and requirements.

In keeping with the research questions, the present study gathered data as to how people with ASD experience this transition phase. The study collected data from adults with ASD who

could provide information from experience, as well as from parents who had concerns about their child's future well-being. It had been noted in previous literature that only a small number of adults with ASD obtain long-term, paid employment (Boeltzig, Timmons, & Butterworth, 2008). The following discussion explores employment experiences: the employment process; qualifications; job interviews; and voluntary and previous work placements.

7.6.1 Qualifications

Qualifications are a standard measure of competence used by employers, and therefore facilitate a better chance of getting employment. Intelligence has also been found in literature as a major predictor for getting work (Holwerda et al., 2012). Therefore, previous literatures has noted that in order to transition to work successfully and get into full-time job or voluntary work, the individual might obtain skills as well as qualifications by obtaining a college (post-secondary) education, in addition to vocational courses (Foley et al., 2012). From the Saudi sample, Parent 12 expressed her concerns regarding the acceptance of her child in higher educational institutes. Also, Parent 7 was particularly concerned since her child does not have any qualifications at all. This could be because her son goes to a specialized centre. Carter, Austin, and Trainor (2012) found that “young people with severe disabilities often leave high school without the skills, supports, and connections that lead to meaningful employment” (P. 58). From the UK sample, Jasmine said that her lack of qualifications was the reason why she was unable to find a job and that this was as a source of anxiety to her. An implication for this is to better help the individuals in getting qualifications, which will help with finding jobs.

Parent 7 said that governmental support was necessary to ensure that students with ASD obtained sufficient vocational training and support to help them obtain employment. This result supports previous research that suggests developing vocational preparation programs for individuals with disabilities in general, in order to help them find suitable employment (Issa, 2013). Therefore, this is an important point raised by the study, since it suggests long-term career support and guidance will be necessary for people with ASD to ensure that a lack of qualifications does not act as a barrier for them at the employment stage. This study did not focus on the aspect of employment of the individuals with ASD. However, few of the parents brought up their concerns regarding this specific transition of their children. Interestingly, there is no research regarding employment and autism in specific in the KSA.

Qualifications are important for ensuring a candidate secures a job interview, and the present discussion has revealed this was particularly problematic for the sample. The following section will discuss the individual's experience of job interviews, which is the next stage of the employment process.

7.6.2 Job Interviews

Job interviews are recognised as particularly challenging for people with ASD due to their social and communication deficits, that also impacts on their work prospects (Hendricks, 2010; Parr & Hunter, 2014). The only participant to discuss their experience of job interviews was Jasmine. She stated she felt the job interview process was a significant pressure, mentioning she had found it difficult to strike a balance between impressing her employees and telling the truth. The unique qualitative data of this study provides an insight into the types of considerations that people with ASD make. It suggests that people with autism will need particular assistance in terms of vocational support, which could support and guide them to find suitable jobs (Hillier et al., 2007; Kinoshita et al., 2013; Mavranouzouli et al., 2013; Vogeley et al., 2013). Previous literature has discussed a wide variety of vocational support programmes and techniques that can help individuals with ASD who are looking for work, selecting suitable employment, along with writing CV's and job interviews (Allen, Burke, Howard, Wallace, & Bowen, 2012; Hendricks, 2010; Hillier et al., 2007; Kinoshita et al., 2013; Mavranouzouli et al., 2013; Vogeley et al., 2013).

Job interviews are a crucial step for the individual with ASD to get a suitable job, although only one participant pointed out this matter. However, Jasmine's data shows this may serve as a particular barrier for people on the spectrum. The next sections will discuss the challenges people with ASD face if they finally obtain voluntary work, along with their previous experiences with work placements.

7.6.3 Voluntary Work

The results show that four of the UK participants had taken part in voluntary work. Obtaining voluntary positions is in contrast to the literature, which shows that individuals with ASD face challenges in keeping their full time paid jobs (Chen et al., 2015). Jasmine had some part time unpaid work with a charity that was supporting her at the time, and the other individuals also had placements with dedicated organisations for people with ASD. It was found in previous literature that some individuals with ASD had voluntary work (Eaves & Ho, 2008). From the

UK results, some of the participants considered voluntary work kept them busy, and feeling valued. From the Saudi sample, Parent 5 said she hoped her child would become, '*a valued member in the community*'. Voluntary work is also important since it can serve as a practical step in the transition towards paid employment, and is considered more flexible. This could be a possible explanation for having more than half of the UK adults volunteering in the community. Generally, work has been found to improve the quality of life of those with ASD and encourages their self-confidence (Hendricks, 2010).

The findings suggest that voluntary work, even if it is with supporting organisations, can serve as a factor that helps individuals with ASD. Therefore, it is important to provide voluntary work opportunities, which will help the individuals in the future with feeling valued in the community and finding work. The following section will discuss the data regarding the previous employment opportunities that the sample experienced.

7.6.4 Previous Employment and challenges

Paid employment is a factor that helps individuals with ASD in a number of respects. Unlike voluntary work, the transition to ordinary employment leads to a financial income, which can lead to less reliance on governments as well as a contribution to taxes in order to have a successful independent life (Järbrink, McCrone, Fombonne, Zandén, & Knapp, 2007; Lee & Carter, 2012; Williamson et al., 2010). It also provides an opportunity for social integration and worker satisfaction (Chen et al., 2015). From the Saudi sample, Parent 7 considered financial independence to be particularly important and expressed concerns about what would happen if one of the parents were to pass away unexpectedly. A few of the mothers brought up their future concerns regarding what would happen to their child if someone else had to take over the responsibility of caring for them, since they may not be working. Therefore, paid employment is considered a significant concern for ASD individuals and families, both in terms of present income but also in terms of collecting a pension in the future, which may be particularly important as the individual ages and needs financial assistance later in life.

Previous literature shows that some ASD individuals can be successful in employment (Hillier et al., 2007; Howlin et al., 2005). However, the impression gained from this study indicates that employment is problematic for the participants on the spectrum, which is also in accordance with previous studies (Burke, Andersen, Bowen, Howard, & Allen, 2010; Hedley et al., 2016; McDonough & Revell, 2010; Parr & Hunter, 2014). Minimal rates of

employment were also reported in previous research (Redman et al., 2009; Taylor & Seltzer, 2011). The current study found that none of the UK participants were in full-time work at all. This confirms the fears of the parents in the Saudi sample. It shows that the parents are concerned about their child's future development through this transition a concern regarding future expectations amongst parents is in line with the previous literature (Heiman, 2002).

From the responses, it is apparent that various participants had different reasons for not being employed full-time. For example, Edward reported he had chronic fatigue, which served as an additional barrier, which is consistent with previous work that on comorbidity that can add to the challenges that individuals with ASD encounter while trying to find a suitable job (Hendricks, 2010). Charles indicated he had been lucky since he had been given the opportunity to continue working with his training position when it ended, as he had not found alternative employment. However, he added that this benefit did not '*come free*' as he was constantly reminded that he was being helped and also that he was not good enough at what he was doing, as they told him '*you're not good enough for the work*'. This is unfortunate since the literatures suggest employment might be a factor in strengthening the mental health of employees with disabilities (Burke et al., 2010).

Although David was 29, he was also unemployed but had various work experience in the past, stating he had been a cleaner, cook, sales assistant, warehouse assistant, office worker as well as mail clerk. Edward said he had been a supermarket cashier and a chef as well. These findings are in line with previous research, which found that individuals with ASD had work placements that were low paid jobs and did not require high qualifications (Howlin et al., 2013; Taylor & Seltzer, 2011).

The current study was able to identify factors that might possibly help people with ASD find and maintain suitable employment, bearing in mind their perceptions about the process. When the participants were asked '*What sort of job do you like?*' three of the UK participants mentioned they would prefer work in areas they enjoyed, and a job that was suited to their specific interest. As the literature has found, individuals with ASD often desire certain types of jobs which reflect their limited ranges of interests and preoccupation with non-functional routines (Burke et al., 2010). Therefore, the research suggests that ensuring ASD individuals are matched to appropriate jobs is an essential for an effective transition. Charles spoke of employers needing to be '*willing to accept*' employees who may present challenges. In addition, Jasmine talked about the special help she would need from an employer to help

understand what is needed from her. This suggests that adults with ASD need particular guidance, and detailed information regarding what is needed from them in their work placement. Charles also indicated that various duties would be more difficult, such as typing on a computer, due to the need to possess refined motor skills. Given the widespread use of computers in the modern workplace, this could serve to exclude him from a significant number of jobs he might otherwise enjoy. On the other hand, Jasmine had mentioned typing on a keyboard had been part of her duties at her voluntary placement, with which she had no difficulties. Edward, however, spoke of the difficulties that change in routine had for him when he was asked to work overtime. Acclimatising to new routines and modifications in the work environment can be particularly problematic for employees with ASD (Hendricks, 2010).

Jasmine and Charles noted another factor that hinders adults with autism in work. They pointed out the difficulties in engaging with other work colleagues, because they appeared not to respond to their requests for information. This is another example of the need to spread awareness of autism in the work place. Such awareness could help them making friendship in the work place.

The factors identified by the participants serve as indications of what is needed to provide people with ASD appropriate support while trying to enter the workplace, and therefore should be taken into account by employers (Hagner & Cooney, 2005; Howlin et al., 2005). This raises questions regarding the various approaches that could be adopted and in this respect, such as providing autism awareness training to current staff (Bolman, 2008). Similarly, various support programs for employees with ASD, which reflects a more detailed approach to hiring and retaining employees are recommended by various writers (Allen et al., 2012; García-Villamizar & Hughes, 2007; Hedley et al., 2016; Hillier et al., 2007; Howlin et al., 2005; Kinoshita et al., 2013; Mavranouzouli et al., 2013). Furthermore, participants from the UK reported that they were in receipt of various types of benefits from the Government, both for being out of work and due to their disability as their source of income.

In this section, all of the individuals with ASD were unemployed. However, their experiences with work qualifications, job interviews, along with previous work experiences and challenges were discussed. Moreover, the different relationships that individuals with ASD have with others such as family and friends are going to be explored in the next theme.

7.7 Theme 7: Relationships

Individuals with ASD tend to face challenges with relationships considering the common deficits in social interaction (Kelly et al., 2008; Orsmond et al., 2004; Sedgewick et al., 2016). Nevertheless, there is currently little information concerning the outcomes and effects of relationships for individuals with ASD in general (Kelly et al., 2008). Therefore, the current research provides a contribution to the existing understanding regarding this particular matter.

The present discussion examines the relationships experienced by the adults with ASD from the UK sample, and it offers an insight into how individuals with autism experience this aspect of life. The results suggest that relationships can be a positive source of social support for people with ASD. Not only can relationships be enjoyable but they can also ensure assistance is provided where necessary. The following discussion concentrates on the relationships experiences that individuals with ASD from the UK have such both in family and friend-based relationships. The experience of the children with ASD from the KSA regarding relationships was hard to gather, because the individuals interviewed were their parents, and many of their children were severely affected by ASD, some being non-verbal, so they would have experienced significant barriers to forming relationships. The mothers stated that all of their children were single and lived with them, except for one who was living at a residential specialized centre away from home. As most of the parents stated, their children did not have any friends.

7.7.1 Blood Relatives and Next of Kin

Having close relatives was declared by half of the UK participants. For example, Michael sensed they were there for him and served as '*sounding boards*'. This means that having supportive family members is helpful for the well being of the individual with ASD. Additionally, Daisy said that she had a close relationship with her direct family members, and that her mother had suggested that she live with her sister when she became older. This is consistent with the literature, which indicates many people with autism continue to live with their families as they grow up and also that mothers perform a critical role in orchestrating the interpersonal lives of individuals with ASD (Orsmond et al., 2004). This is common practice with the parents from Saudi, as their children with ASD still live with them at home. Since it is difficult for them to live independently because they still need continuous care from their parents, along with the cultural and religious beliefs of the Saudi participants.

Sibling relationships were emphasised by a number of the parents from the KSA, and they mentioned it as a way of support: how the siblings help parents to care for the one with ASD. However, no details were given regarding the type of relationships between the siblings and how they felt about it. However, since individuals with ASD have communication and social impairments, it can lead to some difficulties in forming relationships with their own siblings.(Diener et al., 2015). For example, Parent 4 spoke about the support she had from her other children with helping her taking care for their two siblings with ASD and their insistence that they are not be sent to a residential centre abroad. This presents an example of positive support that siblings can provide for each other.

From the UK results, Michael described a particular relationship with his sister, saying that he felt the relationship was '*too close*' and '*fun*'. This finding resonates with a recent study based on qualitative interviews with adolescents with ASD about their sibling relationships. It concluded that the participants indicated feelings of appreciation and love towards their typically developing siblings, as they thought of them as a source support and information, along with referring to the fun time shared with them (Petalas et al., 2015). Sibling relationships play a vital role for various reasons: they provide a means for social support in addition to an approach for children with autism to learn and develop skills (Diener et al., 2015; Kaminsky & Dewey, 2001). Nevertheless, previous literature stated that the experience of individuals with ASD regarding their relationships with their siblings was also lacking in some respects (Petalas et al., 2015). Therefore, the present research will add to the gap in understanding this matter by offering an insight into the individuals' experiences with their siblings.

On the other hand, half of the adults from the UK sample stated that they did not have strong relationships with their family members. For instance, Edward mentioned that he lived away from his direct family. It is clear from this that distance played a major aspect behind the reason for Edward not having a close relationship with his family members. However, as the only married individual from the UK participants, he said that he had a closer relationship with his immediate relatives - his wife and children. Edward talked about the support and understanding that he had received from his wife. It demonstrates that having a strong marital relationship is helpful for the individual with ASD.

Charles spoke of the problematic relationship he has with his foster family. He also stated that the relationship with both foster parents broke down. It appears to suggest that Charles

blamed himself for having such a broken relationship with his family. Although, it was not clear why the relationship broke down and whether it was related to his autism symptoms, such as communication and intrapersonal difficulties. Biological parents of children with ASD who care for their children demonstrate a great deal of concern about the caring process. This suggests that some foster parents may need specific training when it comes to adopting children with autism, as it is clear that poor family relationships can lead to the development of maladaptive behaviours (Kelly et al., 2008) and children with poor relationships maybe more vulnerable to developing depression (Rice, Harold, Shelton, & Thapar, 2006).

This study reveals varied experiences of positive and useful family relationships for ASD individuals. While family relationships are generally established from birth, the following section will explore friendships as a particular interpersonal process. It is interesting to study this phenomenon from the viewpoint of the individuals with autism, who offers a unique range of perceptions with regards to social interaction.

7.7.2 Other relationships

Many of the UK respondents pointed out the importance that friendships had in their lives. Nevertheless, the study shows that only two participants had friends. This suggests that individuals with ASD face some difficulties in establishing peer relationships and rarely have more than a few friends (Bauminger et al., 2003; Koning & Magill-Evans, 2001; Locke et al., 2010). The current study is able to contribute to this by focusing on the views of the individuals themselves, which is an under-researched area, given the widely-held belief that people with autism are simply not able to form friendships (Locke et al., 2010). Some friends can also be supportive for their friends with ASD, as in the case of Michael he felt that he was able to use them as a way to gauge the status of his own personal development. These findings are perhaps in contrast to literature that suggests people with ASD sense a reduced need for relationships, do not seek assistance from others, and do not see others as a prospective way out to their difficulties (Berthoz & Hill, 2005; Dunn et al., 2002; Harrison & Hare, 2004).

Developing friendship happens during childhood as well as during adulthood; it also occurs when the individual finds employment. David said he is still in contact with friends he had during childhood but also that he has, '*expanded [his] repertoire*'. It is actually unclear from the data precisely what this means, as it may suggest that he has been capable of developing

further friendships all through his life or that he has established additional skills needed for social interaction in general. Similarly, Daisy explained she had friends and pointed out that they were on ‘*a similar spectrum*’ to her. She stated that she carried out regular sociable activities with them. This suggests that it has been helpful to find friends who have the same condition at roughly the same level of severity. A probable explanation for this is that it is easier to have friends who share the same experience, because a person can relate more to the other person when they have things in common, and could be more understanding of each other. In this respect, Daisy’s comments shows how having friends who can relate to them and be understanding can be a factor that helps individuals with ASD. According to Locke et al. (2010), “it is not just whether children have friendships that are important but rather the quality of these friendships that makes a difference in terms of the function of that friendship” (p. 75). It seems reasonable to conclude that it is important to seek ways that people with ASD can find friends who sufficiently match their personalities and capabilities.

Two of the adults from the UK pointed out the significance of these friendships along with the help and guidance that they had from them. For instance, Michael mentioned that his typical developing friends provided him with a different perception and he considered that, by imitating them as he managed to become more of what a ‘*normal*’ person should be like. Charles declared he had friends who interacted with him in particular settings, such as when he was working for his Autism Awareness organisation. According to Orsmond et al. (2004) “Community-based services ... provide opportunities for peer relationships and social activities” (p. 247). Michael on the other hand, also suggested he had a reduced interest in social interaction generally. This accords with the Sedgewick et al. (2016) finding, that decreased degrees of interpersonal motivation were considerably found in males with ASD, together with experiencing a varied quality of friendships compared to others.

Developing peer relationships are essential for children with ASD, although they tend to be more lonely than their peers (Wainscot, Naylor, Sutcliffe, Tantam, & Williams, 2008), which is a factor that could impact on their mental health and self-confidence. From the UK sample, Jasmine said she would have liked to have more friends, but found it challenging to sustain relationships due to busy schedules, as she had been particularly proactive in this respect. However, this contrasts with the literature, which suggests that people with autism are generally less eager to seek out friendships and thereby making fewer initiations (Orsmond et al., 2004). Jasmine also felt her autism may have been impairing her ability to maintain friendships. She experienced some anxiety from the process, and felt this was crucial in terms

of preparing herself for finding a partner later in life. It is significant to see that Jasmine, as a female with ASD, is interested in developing more interaction that is social and friendships with other people, which might help us to understand if there is a gender difference with socialization in people with ASD. Females with ASD experience a reduced amount of interpersonal challenges in comparison to males with ASD (Sedgewick et al., 2016).

As individuals with ASD mature, they begin to develop a need for interpersonal intimacy (Howard et al., 2006), although they find that marriage relationships are typically more challenging than for example ordinary friendships (Sperry & Mesibov, 2005). Charles said he had fallen in love with someone who did not love him back and seemed to feel some despair. It is argued by some that relationships with people with ASD might not continuously be reciprocated (Chamberlain et al., 2007). Therefore, it is common to find single adults with ASD. However, in the study Edward was the only participant to be married. Given the satisfaction that marriage has brought him, understanding the dynamics of successful relationships is a key factor in improving the quality of life for people with ASD.

Edward considered he had no friends at all. In fact, Edward and Charles expressed that they have been bullied at times in the past. These findings are consistent with data obtained from previous literature that shows ASD individuals are at a higher risk of being bullied (Carrington & Graham, 2001; Weiss et al., 2015). A possible explanation for this could be because individuals with ASD understand language literally, thereby making it challenging to enable them to comprehend the different social rules along with the intentions of other youngsters in terms of jokes, thus causing them to be a fairly easy target for mockery (Rowley et al., 2012). Charles also revealed that not having friends was problematic, stating that the breaking up of relationships often had a damaging effect on his mental state, and had made him be admitted to a mental hospital, and thus lose his gardening job. This is consistent with literature that suggests quality relationships can reduce feelings of depression and anxiety (Bollmer et al., 2005; Hay et al., 2004).

The current study reveals that half of the participants suggest they liked spending time alone, with David indicating he was not '*really fussed*' either way. Michael and Daisy said that they would have liked to be on their own sometimes, when they feel overwhelmed, even though both of them felt that they needed social interaction at times. A possible explanation for this could be that social interaction is a skill learned over time. This suggests that while people with ASD can often experience higher levels of loneliness, there is also evidence to suggest

that they actively seek isolation (Locke et al., 2010). In summary, this section explored the different relationships that individuals with ASD have either with family or friends.

7.8 Conclusion

The discussion chapter has outlined how the research questions had been answered. It has addressed a range of topics, which are classified into themes. It is clear that different individuals have varied experiences according to each theme. In line with the literature, the research finds that only some individuals with ASD attained an accurate diagnosis early in life (Hedley et al., 2010; Leyfer et al., 2006). Therefore, early diagnosis emerges as a factor that helps people with ASD, and late diagnosis, along with misdiagnosis, causes unnecessary challenges to individuals. Varied childhood experiences were reported by both groups of the participants, and the main challenges were related to the characteristics of ASD. Moreover, attending mainstream school is generally dependent on the severity of the autism, in addition to accessibility to specialist support, particularly within the sample from the KSA (Alquraini, 2010). This suggests that people with autism in the KSA encounter significant challenges as they transition to adulthood.

Moreover, most of the participants from both countries discussed experiencing some challenges with transitions throughout puberty and adolescence. The study notes that further means of support for individuals with autism depends on in other contexts: for example, families of children with ASD often rely on support from within the family and from friends, in addition to official government services. This has been helpful for the current research in identifying strategies that provide families with practical support. Furthermore, all of the UK participants were unemployed which reveals the challenges they faced with work. Finally, the different relationships that the participants had from both groups are discussed. All of the participants from both groups were single, except for one adult from the UK, who was married and had children. The importance of family relationships and friendships are noted, along with the preference that these individuals have for having some alone time. These results suggest the need for social skills programmes in order to help individuals with ASD to form effective relationships throughout their lives.

Chapter 8 Conclusion

8.1 Introduction

The study has focused on the key research question, which is how those with autism experience the transition from childhood to their adult years. A significant feature of their experience is the involvement of families, particularly in respect of the KSA. Additional sub-questions are posed: these are related to features that impede or benefit individuals as they undergo the varied life transitions; further, and importantly, the views of mothers are sought. The purpose of this research is to contribute to an improved understanding of the direct experience of ASD, together with an understanding of the transition processes from the perspectives of those directly involved.

In this study, the research collected data from adult ASD individuals from the UK as well as mothers of children with autism in the KSA, and employed a qualitative approach. The method of life history interviews was used with the adults from the UK to provide insightful, qualitative data. In addition to these interviews, semi-structured interviews were employed with the parents from Saudi. This approach was considered useful, particularly because it provided an insight into the parents' views and experiences, and also because research in this field is limited in the KSA (Alnema et al., 2016). This is the first time that research has been carried out with mothers regarding the varied transitions for children with ASD in Saudi Arabia from childhood to adulthood and thus it is hoped that it will add significantly to the understanding in this area.

By gathering data from both countries together with collecting the views and experience of people with ASD and parents, the research gathered an overall perspective, although limited, of how individuals experience transitions in their lives. Despite the limitation in focusing on two seemingly different groups, some similarities do appear: for example, the restricted access to services for both groups is similar. The data from each of those sets of participants is compared and synthesised to offer a greater understanding of the factors that impact on individuals during each transition, from the perspectives of two interrelated groups. This study provided a greater understanding of the ways through which individuals with ASD need improved support during the changing periods in their lives.

8.2 Contribution to knowledge

It is acknowledged that previous studies have explored certain transition phases that people with ASD and families go through such as transition to school, work, adolescence, and adulthood (Chen et al., 2015; Mandy et al., 2015; Rawat et al., 2015; Wehman et al., 2014). However, there is limited research that considers different types of transitions comparatively. The present research therefore broadens and deepens the understanding by all those directly involved in these different transitions that individuals with ASD experience in their lives, that is: those with autism, their families, those who are responsible for diagnosis and academics who engage in relevant research in this area. By a process of enhancement this research makes all concerned, particularly those in the KSA, to be more informed about the condition. It should facilitate more effective planning and preparation in order to achieve a better quality of life, not just for those with ASD but for their families too. Not only does this research project contribute to the literature, particularly as they pertain to Saudi Arabia, it opens up a discussion of the support role of parents and families. The study of parental perceptions of autism, as it applies to their children during their transitions, provides an original perspective that can serve to guide future policy and action, both in Saudi Arabia and the UK. More broadly, it argues the case for a greater understanding of the role that parents and families have, and how this can be enhanced by improved knowledge and guidance from professionals in the field. Finally, it gives voice to parents: voices that have been less audible in the context of the KSA.

In addition, the importance of perceptions of those adults with ASD provides meaningful insights into the problems they encounter as they move through the various transitions, such as puberty, where there is limited substantive research to date. This research not only highlights this from the perspective of those going through the transitions but it also illustrates the importance of understanding those subjective perspectives, in this case possible through in-depth interviews which allows for much deeper understanding than is possible through other methods. Such an approach is therefore also original as, although there is some reference in previous research to transitions in the life of individuals with ASD, none of it is based on the life history method despite there being more interest in this method in recent times in an effort to give voice to individuals with ASD and families (Griffith, Totsika, Nash, & Hastings, 2011; Harrington, Foster, Rodger, & Ashburner, 2014; Hurlbutt & Chalmers, 2002; Huws & Jones, 2008; Jones et al., 2013; Loyd, 2013a; Parsons, 2014; Potter, 2014; Ruef & Turnbull, 2002).

In summary, this research explored the perspective of mothers of individuals with autism from the KSA, where evidence from the literature is limited and sought to integrate their perspectives with that of the adult individuals with ASD from the UK in order to understand what it is that affects people during each transition period from two different contexts. By gathering information from these seemingly distinct groups the research is able to recommend what support or intervention may be helpful. In this respect, the results of this study are important for service providers, schools, communities and families. It is particularly important for the continued development of an inclusive society in both countries. In addition, it adds to our understanding of the universality of the challenges that parents and adults of ASD experience. Thus it makes an important and an original contribution to knowledge, which is valuable in this area.

8.3 Summary of key findings

8.3.1.1 Diagnosis

The study raises several points concerning individuals with ASD. First, an early and accurate diagnosis is identified as an important initial step in the process of transition for children with ASD. Also, a delayed diagnosis is viewed as a significant barrier by a number of the participants, as expressed by the adults from the UK. This point was made forcefully by Edward, who had passed the whole of his childhood and part of his adult life before he was diagnosed. Clearly, any lack of diagnosis or misdiagnosis of the condition has consequences for the participants over the long-term. Therefore, awareness of the condition and having appropriate services and specialities in the field play a major role in the lives of people with ASD and their families.

8.3.1.2 Childhood experiences

The findings of the study show that the participants from both countries have different childhood experiences. Some of the UK participants refer to positive experiences during their childhood. While a number of the KSA mothers and UK adults experienced some challenges during the childhood years, which were mainly because of some of the ASD characteristics, such as social and communication difficulties. In addition, problems with routine and toilet training are mentioned by some of the parents from the KSA, as a challenge they faced with their children during their childhood. This shows the importance of professional services and early support for individuals with ASD and families.

8.3.1.3 Educational Provisions

The data suggests a range of appropriate educational settings is desirable for different individuals, based on their unique circumstances. Therefore, it is difficult for the study to draw a general conclusion regarding the appropriateness of either mainstream or specialized schooling for individuals with ASD. From the current findings, it is clear that the quality of teaching along with the availability of specialists in the field, at either type of institution is very important. It is also noted that children with autism may struggle with mainstream curricula in inclusive schools and experience some challenges there, which is in accordance to some previous findings (Hume et al., 2014; Quintero & McIntyre, 2011). As discussed, some with ASD report a more positive experience when their education is personalised. The study shows that there is a clear and pressing need for the provision of more specialist services in the KSA, and these findings accord with the literature (Almasoud, 2010b; Alquraini, 2010, 2013; Kelly et al., 2016; Zeina et al., 2014).

Moreover, the study between the KSA and the UK is revealing, given that the UK is generally considered to be a country with an increased standard of social service provisions. As the data indicates, service provision has not been totally successful within the UK for the adult participants either; however, the significantly larger number of services provided by the UK are recognized by most of the participants.

Taken together, these results highlight a crucial deficit currently existing within Saudi. Children with autism are often left without specialist care and some have to travel overseas to obtain services. This can potentially cause considerable disruption to families along with the burden of financial expenses. The research shows that, when approached, the Ministry of Education is willing to provide limited assistance, such as subsidising the expenses of private specialized centres. Nevertheless, these supports are limited because of the general lack of inclusive schools, specialized centres, and specialists in the field. This does not include supporting individuals who are less severely affected by autism, such as higher functioning individuals with ASD.

The findings of this study show that inclusion is paradoxical: it means different things to different people (as described at length in section 7.3.2). From the results, these findings show that generally children in Saudi do not receive the help they need from school, in addition to the adults in the UK feel that the learning system is not meeting their needs.

8.3.1.4 Adolescence and Puberty

The findings of this study suggest that children with ASD and parents need specific assistance with the transition throughout the phase of puberty and adolescence. As the results reveal, this is especially difficult when children are non-verbal and their parents say that they had faced some challenges during this particular transition. In this respect, the research is able to identify various strategies that will assist individuals with ASD, and this is in keeping with the research questions. Many of the ideas and techniques that are used by the individuals with ASD, and the parents, are based on their own experiences through trial and error.

Some culturally specific matters were also raised in the sample from the KSA about this transition. This relates to the traditional gender segregation matter in Muslim countries (Alkhateeb et al., 2016; Vidyasagar & Rea, 2004). The study shows that mothers of male children with ASD often find themselves with many new challenges as their sons come of age and often have to rely on male relatives, along with changing their son's educational institutions to male-only schools or centres. This is very challenging for mothers who do not have many close male relatives, who are able to take the time necessary because they have work commitments.

8.3.1.5 Support

Another theme that emerges from the study is the sources of support that are available to the participants. In accordance with the literature (Ekas, Lickenbrock, & Whitman, 2010) social support is identified as a factor that significantly supports individuals with ASD. Chapter 7 (section 7.5) breaks this issue down into various sub-categories: specifically, support from family members, wider support groups such as parental networks, and professional support from social services. As the study finds, most of the parents of individuals with ASD in Saudi noted the significance of the assistance provided by their families, while only some participants from the UK reported any experience with their immediate family members.

Parent-based support groups are a particular source of assistance for parents. Within these groups, parents are able to share techniques and experience. Therefore, this study successfully achieves its objective in answering one of the research questions about how people with ASD and families can be assisted as they transition. Moreover, official support services are found to be very important, particularly where familial support is lacking, as the study shows a greater number and variety of services that currently exists in the UK. The study also shows

that individuals with ASD often rely on non-governmental organisations as well, such as advocacy groups, which provide them with employment as well as social opportunities.

8.3.1.6 Employment

The research shows that finding a suitable job is challenging for the UK participants. In addition, it helps individuals with ASD to seek qualifications and prepares them for job interviews. Moreover, voluntary work is seen as an essential step in helping individuals with ASD feel valued members in the community and prepares them for their next full-time work. These results highlight the preferred jobs for people with ASD, which are related to their specific interest, and are uncomplicated.

8.3.1.7 Relationships

Relationships are important in the lives of people with ASD. However, the results are in agreement with the previous literature that referred to ASD individuals who face some difficulties with forming and keeping relationships (Kelly et al., 2008; Orsmond et al., 2004; Sedgewick et al., 2016). This study discusses the varied experiences of positive and challenging relationships with family members for individuals with ASD. It shows that having close relationships with members of the family are beneficial for them. Moreover, the study notes that half of the participants prefer to spend their time alone, while the others have friends, or want to make friends but struggle with that.

8.3.2 Limitations

There are several limitations to the current study. Firstly, it was difficult to locate adults with ASD from the KSA to take part in the study [section 4.11]. This meant the study was broadened to depend on the statements of the mothers of the children with autism, which generated some challenges regarding the consequent data. For the same reasons it was difficult for the researcher to interview fathers of children with ASD from Saudi, so only mothers participated.

An additional limitation was having two groups from different countries, which made some of the findings interesting to compare, because of cultural and traditional influences. As the sample size was small and there are no implications for wider generalisation, this limitation is kept in context. The limited number of the parents included mothers from Saudi, and they were from one city only and it did not include other mothers from elsewhere in the Kingdom.

Also, the small number of the UK participants was due to the difficulty in finding volunteers bearing in mind that the research design used life history interviews, which entailed multiple interviews with each participant.

It is well-known that the school system in the KSA is based on gender-segregation (Alhazmi & Nyland, 2010). Therefore, a further limitation is that the transition in a specialized centre to a gender segregated centre is based on the maturity of the child (pubertal stage), as opposed to the UK education system, which is age based (primary-secondary).

In addition, the UK participants and the mothers' children had both different abilities and levels of ASD severity; adults from the UK had Asperger's syndrome as opposed to the children of the mothers from KSA, where their children had more severe ASD symptoms and more limited abilities. The effect of this may have influenced the results because their needs and transitions might differ according to their abilities. For example, the UK adults were concerned about the transition to employment that all of the participants discussed, but only a few mothers from the KSA mentioned.

8.3.3 Recommendations

The results of the current research have a number of critical implications for future practice.

- Primary care service providers should be aware of the nature of autism, when a patient seeks assessment, in order to ensure that an appropriate assessment is made at an early stage.
- Parents must also be educated on the warning signs of autism because it may be easy to mistake the unusual symptoms. Awareness and appropriate information must also be spread and offered throughout communities via public services.
- In order to make an informed diagnosis, specialists must be made available.
- The following four aspects should be considered:
 - For the KSA, a policy of inclusion into mainstream education, comparable to that in the UK;
 - The role of employment and voluntary work;
 - Social skills training programmes to enhance social inclusion.
 - Sex education programmes that are culturally appropriate and particularly designed for children in the KSA.

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Areas for further research:

- To consider further the experience of adults with ASD in KSA;
- To conduct a qualitative and quantitative research methods to further explore the varied transitions in depth
- To explore whether there is any major change in the severity of autism during puberty.
- To replicate the present study and include individuals with ASD and their immediate parents, with a larger sample.
- To further research the pros and cons of special needs inclusion and specialized centres in the KSA, with special reference to ASD.
- To further investigate the value of voluntary employment for those with ASD.

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Appendices

Appendix 1: Pilot study information sheet and consent form



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Information sheet

Research Project: How do individuals with autism and families experience the transition from childhood to adulthood?

What is the study?

The study is being conducted as a pilot for part of my PhD research at the University of Reading. The purpose of this pilot study is to explore your experiences about your own child as they grow up. I'm particularly interested in the ways in which you have helped your child cope through this period and the successes and concerns faced by families during the transition phase from childhood to adulthood of their child's life.

Why have I been chosen to take part?

You have been asked to participate in the pilot study as a parent of a child with autism. Six parents of individuals with autism have been asked to participate in this pilot study.

Do I have to take part?

It is entirely up to you whether you would like to participate or not. You may also withdraw your consent for participation at any time during the study, without any repercussions to you, by contacting the researcher Reem Balubaid, Tel:+44 (0) 7527647953, email: r.a.a.balubaid@pgr.reading.ac.uk , or the supervisors, Dr. Catherine Tissot, University of Reading; Tel: +44 (0) 118 378 2674 , email:c.tissot@reading.ac.uk , and Dr. Carol Fuller, University of Reading; Tel: +44 (0) 118 378 2662, email: c.l.fuller@reading.ac.uk

What will happen if I take part?

You will be interviewed for about 30 to 40 minutes, using open-ended questions, and the interview will be recorded after gaining your consent. The indicative questions will be made available in advance if you wish, and they will be about the experiences, strategies and concerns that you have had as a parent of an individual with autism in the transition phase from childhood to adulthood.

Autism and the Experience of Transition from Childhood to Adulthood

After that, the data gathered from the interview will be transcribed and later analysed by the student researcher. The findings of this study will be used for research purposes and will help me to conduct my actual study. Your thoughts and experiences will be a crucial input to informing the project.

What are the risks and benefits of taking part?

The information you give will remain confidential and will only be seen by the researcher and supervisors listed. You will not be identifiable in any published report resulting from the pilot study. This study is interested in your views and experience, therefore some of the questions, although not intended, may be considered to be too personal. If you feel this is the case, please stop the interview or ask the interviewer to move on to the next question, or you can always decline to answer the question.

Participants in similar studies have found it interesting to reflect on the changes in their children and share these successes and challenges. This is an under researched area and one where families often wish there was additional support. I anticipate that the findings of the study will be useful for other parents going through this stage in their own child's development. An electronic copy of a summary of the published findings of the study can be made available to you by contacting the researcher through the details at the top of this page.

What will happen to the data?

Any data collected will be strictly confidential, and no real names will be used in this study or in any subsequent publications. The records of this study will be kept private. No identifiers linking you or your child will be included in any sort of report that might be published. You will be assigned an identification number (ID) in order to distinguish your responses from those of the other participants. I will transcribe the recordings from the interview before analysing the results. Research records will be stored securely in a locked filing cabinet and on a password-protected computer, and only the researcher Reem Balubaid, and supervisors Dr Catherine Tissot and Dr Carol Fuller will have access to the records. The data will be securely destroyed after five years once the findings of the study are written up. The results of the study will be presented at national and international conferences and in written reports and articles. The researcher can also send a summary of the results of this research to you electronically if you wish to have them.

Who has reviewed the study?

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

What happens if I change my mind?

You can change your mind at any time without any repercussions; your decision to participate is entirely voluntary and very much appreciated. During the research, you can stop the interview at any time. If you change your mind after data collection has ended, we will discard your data. Also, you are free to withdraw your consent at any time and without giving any reason by contacting either the researcher or the supervisors Dr. Tissot and Dr. Fuller.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you can contact the researcher, Reem Balubaid, or the supervisors, Dr. Catherine Tissot, and Dr. Carol Fuller, at the details listed at the top of this document.

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Where can I get more information?

If you would like more information, please contact Reem Balubaid:

Tel: +44 (0)7527647953, email: r.a.a.balubaid@pgr.reading.ac.uk

We do hope that you will agree to participate in the study. If you do, please complete the attached consent form and return it. Thank you for your time.

Consent Form

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

I understand that I will be interviewed and that the interview will be recorded and transcribed with your consent.

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

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

Please tick as appropriate:

I consent to being interviewed: yes no

I consent to this interview being recorded: yes no

Name:

Signed:

Date:

Appendix 2: Pilot study Interview schedule

1. How old is your son/ daughter with autism? Do you have other children? If so, how old are they?
2. How would you describe your experiences of having a child with autism? How have you found parenting a child with autism?
3. Tell me about your child's transition from childhood to adulthood?
4. Were there any changes that were made to support your child? Adolescence can be a difficult time, how was this time for your son/daughter?
5. If you have other children? Was the transition to adulthood different between your children? How was this different to your other children?
6. Where there services and support available for yourself and your child to help in this period? If yes, what were these; were they helpful and in what way?
7. Did you use any strategies with your son/daughter to help him/her through adolescence? How did you find out about these?
8. Is there any help you would have found useful if it were available? Is there any advice you would give to other parents going through this period?

Appendix 3: UK adults information sheet and consent



Researcher:

Reem Balubaid

Phone: +44 (0) 7527647953
2662

Email: r.a.a.balubaid@pgr.reading.ac.uk

Supervisors:

Dr. Catherine Tissot / Dr. Carol Fuller

Phone: +44 (0) 118 378 2674 / +44 (0) 118 378
2662

Email: c.tissot@reading.ac.uk /

c.l.fuller@reading.ac.uk

Information sheet

Research Project: How do individuals with autism and families experience the transition from childhood to adulthood?

What is the study?

The study is being conducted as a part of my PhD research at the University of Reading. The purpose of this study is to explore your own personal experience as you grew up. I'm particularly interested in the ways in which you have coped through this period and the successes and concerns that you faced during the transition phase from childhood to adulthood in your life.

Why have I been chosen to take part?

You have been asked to participate in this study as an individual with high functioning autism or Asperger's. Six individuals with autism have been asked to participate in this study.

Do I have to take part?

It is entirely up to you whether you would like to participate or not. You may also withdraw your consent for participation at any time during the study, without any repercussions to you, by contacting the researcher Reem Balubaid, Tel:+44 (0) 7527647953, email: r.a.a.balubaid@pgr.reading.ac.uk, or the supervisors, Dr. Catherine Tissot, University of Reading; Tel: +44 (0) 118 378 2674, email: c.tissot@reading.ac.uk, and Dr. Carol Fuller, University of Reading; Tel: +44 (0) 118 378 2662, email: c.l.fuller@reading.ac.uk

What will happen if I take part?

You will be asked to be interviewed for a series of three interviews, which will be about 30 to 40 minutes, using open-ended questions, and the interview will be recorded after gaining your consent. The indicative questions will be made available in advance if you wish, and they will be about the experiences, strategies and concerns that you have had as an individual with autism in the transition phase from childhood to adulthood.

Autism and the Experience of Transition from Childhood to Adulthood

In this study £20 will be given after the third interview. This can be offered as either cash payment or a cheque/gift card can be posted. This token payment is in recognition of the time you have given to participate in the research and to cover any expenses.

After that, the data gathered from the interview will be transcribed and later analysed by the student researcher. The findings of this study will be used for research purposes and your thoughts and experiences will be a crucial input to informing the project.

What are the risks and benefits of taking part?

The information you give will remain confidential and will only be seen by the researcher and supervisors listed. You will not be identifiable in any published report resulting from the study. This study is interested in your own personal experience, therefore some of the questions, although not intended, may be considered to be too personal. If you feel this is the case, please stop the interview or ask the interviewer to move on to the next question, or you can always decline to answer the question.

Participants in similar studies have found it interesting to make their voices heard and share their successes and challenges. This is an under researched area and one where individuals and families often wish there was additional support. I anticipate that the findings of the study will be useful for other individuals and families going through this stage in their own life or of their child's development. An electronic copy of a summary of the published findings of the study can be made available to you by contacting the researcher through the details available at the end of next page.

What will happen to the data?

Any data collected will be strictly confidential, and no real names will be used in this study or in any subsequent publications. The records of this study will be kept private. No identifiers linking you will be included in any sort of report that might be published. You will be assigned an identification number (ID) in order to distinguish your responses from those of the other participants. Interviews will be transcribed and anonymised before data are analysed. Research records will be stored securely in a locked filing cabinet and on a password-protected computer, and only the researcher Reem Balubaid, and supervisors Dr Catherine Tissot and Dr Carol Fuller will have access to the records. The data will be securely destroyed after five years once the findings of the study are written up. The results of the study will be presented at national and international conferences and in written reports and articles. The researcher can also send a summary of the results of this research to you electronically if you wish to have them.

Who has reviewed the study?

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

What happens if I change my mind?

You can change your mind at any time without any repercussions; your decision to participate is entirely voluntary and very much appreciated. During the research, you can stop the interview at any time. If you change your mind after data collection has ended, we will discard your data. Also, you are free to withdraw your consent at any time and without giving any reason by contacting either the researcher or the supervisors Dr. Tissot and Dr. Fuller.

Autism and the Experience of Transition from Childhood to Adulthood

What happens if something goes wrong?

In the unlikely case of concern or complaint, you can contact the researcher, Reem Balubaid, or the supervisors, Dr. Catherine Tissot, and Dr. Carol Fuller, at the details listed at the end of this document.

Where can I get more information?

If you would like more information, please contact Reem Balubaid:

Tel: +44 (0) 7527647953, email: r.a.a.balubaid@pgr.reading.ac.uk

We do hope that you will agree to participate in the study. If you do, please complete the attached consent form and return it. Thank you for your time.

Researcher:

Reem Balubaid

Phone: +44 (0) 7527647953

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Email: r.a.a.balubaid@pgr.reading.ac.uk

Supervisors:

Dr. Catherine Tissot / Dr. Carol Fuller

Phone: +44 (0) 118 378 2674 / +44

(0) 118 378 2662

Email: c.tissot@reading.ac.uk /

c.l.fuller@reading.ac.uk

Consent Form

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

I understand that I will be interviewed and that the interview will be recorded and transcribed with my consent.

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

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

Please tick as appropriate:

I consent to being interviewed: yes no

I consent to this interview being recorded: yes no

Name:

Signed:

Date:

Appendix 4: UK adults interview questions

Interview 1 (childhood and schooling)

- 1- Can you tell me how old are you?
- 2- When did you first get the diagnosis with autism?
- 3- What was the name of the diagnosis?
- 4- Did you go to school?
- 5- Describe your experience in school?
- 6- What type of schooling did you have (mainstream or special school)?
- 7- What is your level of education?
- 8- If you went to university, how was your transition from high school to university?
- 9- As a person with Autism/Asperger's what are your strengths and weaknesses?
- 10- How would you describe your experience of being a child?
- 11- How was your childhood?
- 12- Tell me something when you were in school? How was it for you?
- 13- How did you know that you became an adult?
- 14- How did you feel about becoming an adult/ or being (age) now?
- 15- How did you reach acceptance about being an adult?
- 16- Tell me about your transition from childhood to adulthood?
- 17- What helped you cope in your transition phase from childhood to adulthood?
- 18- Is there any experiences or things that helped you in your childhood to become a better adult?
- 19- What helped you become the person you are today?

Interview 2 (work and income)

- 1- Are you employed?
- 2- If No, why you don't have a job?
- 3- If yes, what type of job do you have, can you describe it?
- 4- Is it a full time job or a part time job?
- 5- What are your work hours per week?
- 6- How did you find this job?
- 7- Have you ever worked overtime?
- 8- What sort of job do you like?
- 9- How many jobs did you had in the past, and what were they?
- 10- When did you last have a holiday?
- 11- Do you take your yearly holiday break? How do you spend it?
- 12- What do you like most about this job?
- 13- What do you not like about this job?
- 14- What other sources of income do you have?
- 15- Do you have a pension of any sort, such as a child benefit, or a housing benefit?

Interview 3 (relationships)

- 1- Can you tell me about your marital status?
- 2- Have you ever been in a relationship before? For how long?
- 3- Do you have children?
- 4- How do you spend your time with them?
- 5- Who do you spend your time with?
- 6- What do you do in your free time? or what do you enjoy doing in your free time?
- 7- Do you have a hobby or an interest?
- 8- Do you prefer to be with yourself or around someone specific?
- 9- Do you have close family members? Who are they?
- 10- How do you spend your time with your family members?
- 11- How did your family members help you cope in your transition from childhood to adulthood?
- 12- Do you have friends?
- 13- Any reason for not having friends?
- 14- Do you tend to communicate with people online? And how?
- 15- How do you spend your time with friends?
- 16- Are you friends with your co-workers?
- 17- How do you spend your time with them?
- 18- Can you describe how important are these relationships in your life from childhood to adulthood?
- 19- Did any of your friend's help you cope in the transition period from childhood to adulthood?
- 20- Can you describe how did your friend help you?
- 21- Did your childhood friends change when you became an adult?

Appendix 5: KSA participants Arabic information sheet and consent



المشرفون:

المشرفون:

ريم بالبيد

د. كاترين تيسوت / د. كارول فولر

الهاتف: +44 (0) 7527647953

الهاتف: +44 (0) 118 378 2674

: الإللكتروني البريد

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لائحة المعلومات

مشروع البحث: كيف يواجه المصابون بالتوحد وعائلاتهم المرحلة الانتقالية من مرحلة الطفولة إلى البلوغ؟

ما هي الدراسة ؟

تتم الدراسة بصفتها جزء من بحث شهادة الدكتوراة في جامعة ريدينج. الغرض من هذه الدراسة هو البحث في مجال التجارب التي يواجهها ذوو الأطفال المصابون بالتوحد أثناء نمو أطفالهم. وأنا مهتمة بصفة خاصة في التعرف على تجربتكم

الخاصة والطرق التي تمكنتم بواسطتها من مساعدة أبنائكم على التكيف خلال هذه المرحلة الحرجة من مراحل نموه، والتجارب الناجحة والتحديات التي تواجهها الأسر في المراحل المختلفة من تطور نمو الأطفال المعنيين.

لم تم اختياري للمشاركة ؟

لقد طُلبت منك المشاركة في هذه الدراسة بصفتك ولي أمر طفل مصاب بالتوحد. وقد طلبت مشاركة نحو خمسة عشر من ذوي الأطفال المصابون بالتوحد في هذه الدراسة.

هل يتحتم علي المشاركة ؟

الأمر يعود لك بالموافقة على المشاركة. كما يمكنك الانسحاب من المشاركة في أي وقت حتى بعد الالتزام والبدء في الدراسة، دون تحمل أي عواقب من جانبك، وذلك من خلال الاتصال بالباحثة ريم بالبيد، هاتف (0)44+ :7527647953 وبريد إلكتروني: r.a.a.balubaid@pgr.reading.ac.uk; أو الاتصال بالمشرفين د. كاترين

تيسو، بجامعة ريدينج. هاتف: +44 (0) 118 378 2674 ، بريد إلكتروني: c.tissot@reading.ac.uk ، ود .
كارول فولر، جامعة ريدينج؛ هاتف: +44 (0) 118 378 2662 ، بريد إلكتروني: c.l.fuller@reading.ac.uk

ما الذي سوف يحدث في حال مشاركتي؟

سوف تجري مقابلة شخصية لمدة ٥٤ إلى ٠٦ دقيقة، من خلال أسئلة ذات إجابات مفتوحة دون تحديد، وسوف يتم تسجيل المقابلة عقب الحصول على الموافقة . سوف تتوفر للأهل أسئلة ذات دلالات قبل المقابلة، وسوف تكون حول تجاربهم، واستراتيجياتهم واهتماماتهم حول نمو أطفالهم المصابون بالتوحد ومرورهم بالمراحل الانتقالية في حياتهم.

بعد ذلك، تدون المعلومات التي تم تجميعها وتحليلها من قبل الباحث . جميع نتائج المعلومات سوف تستخدم لأغراض كما أن أفكاركم وتجاربكم تعد ذات قيمة كبيرة على المشروع.

ما هي المخاطر والمزايا للمشاركة في الدراسة؟

سوف تحفظ جميع المعلومات التي تدلي بها بسرية تامة من قبل الباحثة والمشرفين . ولن يكشف بأي حال من الأحوال عن شخصيتك ولن تذكر في أي تقرير يتم التوصل إليه بعد الانتهاء من هذه الدراسة . تهتم الدراسة في الأساس بأفكارك وتجاربك لذلك فإن بعض الأسئلة، قد تبدو شخصية إلى حد بعيد على الرغم من عدم القصد . في حال شعرت بعدم الارتياح من الأسئلة فضلاً عن توقف عن إجراء المقابلة أو أطلب دون تردد ممن يجربها أن ينتقل إلى السؤال التالي . بعض المشاركين في الدراسة اهتموا كثيرًا بالإشارة إلى التغييرات التي ظهرت على أطفالهم واهتموا بمشاركتنا ما مروا به من تحديات ونجاحات. يعد هذا الجانب الأقل اكتشافاً وهو من أكثر الجوانب التي تحتاج فيها الأسر للمساعدة. وتوقعي أن ما تتوصل إليه هذه الدراسة سوف يكون مفيداً جداً بالنسبة لباقي الأسر الذين يعانون من نفس المواقف خلال هذه المرحلة الحرجة في عمر أطفالهم. وسوف تتوفر كذلك نسخة إلكترونية تحتوي على نتائج هذا البحث والتي يمكنك الحصول عليها من الباحث والذي تتوفر تفاصيل الاتصال به في أعلى الصفحة.

ما الذي سيحدث لتلك المعلومات؟

سوف تحفظ أي معلومات تجمع بسرية تامة ولن تذكر أي أسماء شاركت في الدراسة أو في أي إصدارات أخرى. سوف تحفظ كافة سجلات الدراسة خاصة وسرية. كما أنه لن تذكر أي معلومات تشير إلى المشارك أو إلى الطفل ولن تذكر أسمائهم في أي تقرير قد يصدر في أي وقت. سوف يمنح المشارك رقمًا شخصيًا كي يتم تمييز إجابة كل مشارك على حده. وسوف أفرغ كتابي جميع المعلومات قبل تحليل النتائج. سوف يحصل والدي كل طفل على رقم وهو الرقم الذي سوف يشير إلى كل تسجيل صوتي. كما ستحفظ تسجيلات الباحث مع المشاركين بسرية تامة في ملف خاص بالملفات ويرقم سري محمي في جهاز الحاسوب الذي لن تصل إليه سوى الباحثة ريم بالبيد والمشرفين د. كاترين تيسوت ود. كارول فولر. كما أن جميع المعلومات سوف يتم إتلافها متى ما انتهت كتابتها، أي بعد مرور خمس سنوات. سوف تستخدم الدراسة في المؤتمرات الدولية والمحلية، وفي التقارير المكتوبة والمقالات. كما يمكن للباحثة أن تبعث بملخص نتائج البحث إليكم إلكترونياً في حال رغبتكم في ذلك.

من الذي قام بمراجعة الدراسة؟

تم مراجعة هذا المشروع وفق الإجراءات اللجنة الأخلاقية الخاصة بالبحث في الجامعة، وقد أعطيت إذنًا بصلاحيته من الناحية الأخلاقية حيث أن الجامعة لديها جميع التأمينات المناسبة. تتوفر كافة التفاصيل عند الطلب.

ما الذي يمكن حدوثه في حال غيرت رأيك؟

يمكنك تغيير رأيك في أي وقت دون أي عواقب؛ حيث أن مشاركتك تعد عملاً اختياريًا. أثناء البحث، يمكنك التوقف عن إجراء المقابلة في أي وقت في حال غيرت رأيك بعد الانتهاء من جمع المعلومات، وسوف نتلف جميع تلك المعلومات . كما أن لديك كامل الحرية في الانسحاب من هذه الموافقة في أي وقت، دون إبداء أي أسباب وذلك من خلال الاتصال بالباحثة، ريم بالبيد أو أي من المشرفين د. تيسوت ود. فولر.

ما الذي يمكن أن يحدث في حال حدوث أي خلل؟

في حال الحاجة إلى التقدم بأي شكوى أو استفسار، يمكنك الاتصال بالباحثة ريم بالبيد على الهاتف: +44 (0) 7527647953

Autism and the Experience of Transition from Childhood to Adulthood

كما يمكنك التواصل على البريد الإلكتروني r.a.a.balubaid@pgr.reading.ac ؛ أو الاتصال على المشرفين د. كاثرين تيسوت، بجامعة ريدينج؛ هاتف: +44 (0) 118 378 2674 ؛ أو على البريد الإلكتروني: c.tissot@reading.ac.uk ود. كارول فوللر، بجامعة ريدينج؛ هاتف: +44 (0) 118 378 2662 ، أو على البريد الإلكتروني c.l.fuller@reading.ac.uk

كيف يمكنني الحصول على المزيد من المعلومات؟

إذا رغبت في الحصول على المزيد من المعلومات، فضلا ا اتصل بريم بالبيد على الهاتف: +44 (0) 7527647953 أو على البريد الإلكتروني r.a.a.balubaid@pgr.reading.ac.uk

نأمل مشاركتكم في هذه الدراسة ، في حال رغبتكم فضلا ا أكملوا استمارة الموافقة المرفقة وإعادتها إلي مع جزيل الشكر..

استمارة الموافقة:

لقد حصلت على الشرح الوافي الخاص بالمشروع والمطلوب مني، وقد حصلت على كافة الإجابات حول الأسئلة التي طرحتها أوافق على الترتيبات التي تم سردها في لائحة المعلومات المفصلة حول كل ما يتعلق بمشاركتي.

أنا على علم كذلك بأنه سوف تجرى معي مقابلة وسوف يتم تسجيلها وتدوينها.

كما أنني على علم بأن مشاركتي اختيارية بحتة وأنه لدي كامل الحق في الانسحاب من المشروع في أي وقت رغبت؛ دون تحملي لأي عواقب.

وقد حصلت على نسخة من استمارة الموافقة مرفقة بلائحة المعلومات.

فضلا ا ضع علامة في المكان المرغوب:

أوافق على إجراء المقابلة:

نعم _____ لا _____

أوافق على تسجيل المقابلة:

نعم _____ لا _____

الاسم:

التوقيع

Appendix 6: Interview Schedules for KSA participants (English/ Arabic)

1. How old is your son/ daughter with autism? Do you have other children? If so, how old are they?
2. Does your child go to a school or to a special center? And in which year is he/her?
3. For how long did your child go to this school/center? And what were the help provided from this school/center?
4. How is it like to have a child with autism? How have you found parenting a child with autism?
5. What are the strengths and weaknesses of your child? And what is his interest?
6. Does your son/daughter have any friends?
7. Tell me about your child's transition from being a child to an adolescent?
8. How was the experience of reaching puberty for your child?
9. Were there any changes that were made to support your child? Adolescence can be a difficult time, how is this time for your son/daughter?
10. If you have other children? Was the transition to adolescence different between your children? How was this different to your other children?
11. Is there any services and support available for yourself and your child to help in this period? If yes, what are these; are they helpful and in what way?
12. Do you use any strategies with your son/daughter to help him/her through adolescence? How did you find out about these?
13. How are you coping with this phase in your child's life?
14. Do you have any support for yourself as a parent of a child with autism? And which kinds of support have you found useful, and why?

Autism and the Experience of Transition from Childhood to Adulthood

15. Do you have any future plans for your child when he reaches adulthood? Do you have a pension of any sort, such as a child benefit, or a housing benefit?
16. Is there any help you would have found useful if it were available? Is there any advice you would give to other parents going through this period?

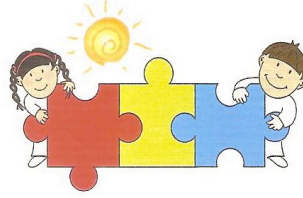
١. ماهو عمر طفلك المصاب بالتوحد؟ هل لديك اطفال اخرون؟ وما اعمارهم؟
٢. أخبريني كيف كان تشخيص طفلك ، و كم كان عمره عندما شخص؟
٣. هل يرتاد طفلك الي مدرسة او مركز متخصص؟ اخبريني عن تجربتك معهم؟
٤. كيف تصفي تجربتك كأم طفل مصاب بالتوحد؟
٥. هل تستطيعي اخباري عن تجربتك لتربية وتعليم طفلك المصاب بالتوحد؟
٦. كيف كانت مرحلة الطفولة لدى طفلك؟
٧. هل كانت كانت مرحلة الطفولة لدى طفلك المصاب بالتوحد صعبة؟ من حيث السلوكيات، الروتين، طريقة اللعب و التعامل؟
٨. اخبريني عن انتقال طفلك من مرحلة الطفولة الي مرحلة البلوغ، من حيث التغيرات الجسدية و النفسية؟ و كيف كان تأثير هذه المرحلة عليك و على طفلك المصاب بالتوحد؟
٩. المراهقة ممكن ان تكون مرحلة صعبه، من حيث تكوين الصداقات ، التعليم .. كيف كانت هذه المرحلة لابنك / ابنتك المصاب بالتوحد؟
١٠. هل لاحظتي أي تغييرات في طفلك بعد مرحلة الطفولة؟ وماهي؟
١١. هل كانت هناك اي تغييرات في المحيط تم اجراؤها لدعم طفلك في هذه الفترة؟
١٢. اذا كان لديك اطفال اخرون، هل كانت مرحلة الانتقال من الطفولة الي مرحلة المراهقه تختلف بين اطفالك؟ وكيف كان هذا الاختلاف؟
١٣. هل هناك خدمات ودعم لنفسك ولطفلك للمساعدة في هذه الفترة؟ اذا كانت الاجابة بنعم، فما هي هذه الخدمات، وهل كانت مفيدة وبأي طريقة؟
١٤. هل استعلمت اي استراتيجيات مع ابنك / ابنتك لمساعدته في فترة المراهقة؟ وكيف عرفتي عن هذه الاستراتيجيات؟
١٥. هل هناك اي مساعدة مفيدة كنت تتمنين وجودها؟ وماهي؟
١٦. هل هناك اي نصيحة توجيهيها الي الاءاء والامهات الاخرين الذين يمرون بهذه الفترة؟

Appendix 7: Jeddah Autism Centre Letter

AL FAISALYA WOMEN WELFARE SOCIETY
Registered in The Ministry of Social Affairs No.19

الجمعية الفيصلية الخيرية النسوية
مسجلة بوزارة الشؤون الاجتماعية برقم ١٩

Jeddah Autism Center
Your Way to Our World



مركز جدة للتوحد
طريقكم إلى عالمنا

الرقم: ٢٠١٤ / ٢٠١٤
التاريخ: ٢٠١٤ / ٢٠١٤
الموضوع:

الملحقية الثقافية بلندن

حفظه الله

سعادة الملحق الثقافي الدكتور/ فيصل بن محمد ابا الخيل

السلام عليكم ورحمة الله وبركاته ...

خية طيبة وبعد ...

لا يخفى على سعادتكم أن مركز جدة للتوحد هو الأول من نوعه في المملكة العربية السعودية ويعتبر المركز من أهم المؤسسات الرائدة التي تقدم أفضل البرامج التربوية و الدعم الأسري للأطفال التوحديين كما يمثل أحد أهم المشاريع التي قامت بتنفيذها الجمعية الفيصلية الخيرية النسوية منذ عام ١٩٩٣م - ١٤١٤هـ لدعم وتنمية القدرات الذاتية لدى الأطفال التوحديين لتمكينهم من خدمة أنفسهم واستقلالهم الذاتي وتيسير سبل تعاملهم مع وسطهم الخارجي وذلك بإيجاد البيئة و الوسائل التعليمية الملائمة لهذه الحالات و إعداد الكوادر التعليمية و التربوية المتخصصة في مجالات التوحد .

وانطلاقاً من مبدأ التعاون ما بين المركز وبين الكفاءات العلمية وامتداداً لجسور التبادل العلمي للاستفادة من الخبرات والكفاءات العلمية وذلك في سبيل تثقيف الكوادر العلمية والطامحين إليها .

عليه نفيدكم بأنه لا مانع من تطبيق الطالبة ريم عبدالله بالبيد من جامعة Reading في بريطانيا بحثها بعنوان " كيف تكون تجربة الأفراد المصابين بالتوحد و أسرهم في مرحلة الانتقال من الطفولة الى مرحلة الرشد؟" في مركز جدة للتوحد .

نحن على ثقة من تعاونكم وجاهابكم معنا سائلين المولى القدير أن يديمكم ويسدد على الخير خطاكم

ودمتم في حفظ الله ورعابته ...

رئيسة الجمعية

فهد بن سعود بن عبد العزيز آل سعود

